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PATIENT EXPERIENCE EXPECTATIONS KNOWLEDGE

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Rheumatoid Arthritis Australian Study

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The Centre for Community-Driven Research team for this study included:

Catherine Holliday
Anne Holliday
Josephine Byrne
Vanessa Brunelli
Katriona Christiansen
Jenny Gleeson
Calum Smith
Heather Still
Jill Wilson

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Summary of results

Executive summary

The participants in this PEEK study population experienced a diagnosis characterised by symptoms including joint pain, swelling and general pain. Those with a complex diagnosis reported that this was due to health care professional's uncertainty of rheumatoid arthritis or due to having other conditions, which often led to the symptoms of rheumatoid arthritis being seen as symptoms of these other, long-standing conditions.

The condition was most commonly diagnosed by a rheumatologist or a general practitioner and this patient population had between one and six diagnostic tests, with two thirds having three or more diagnostic tests. Almost all the participants recalled having had blood tests and a physical examination, with very few participants recalling having any discussions in relation to biomarker or genetic tests.

This patient population was also characterised by comorbidities with almost all of the participants describing at least one other condition in addition to rheumatoid arthritis including anxiety, depression, chronic pain, sleep problems, and asthma.

The participants in this cohort experienced a range of treatment with approximately one quarter having one or more surgeries and the most common treatments being disease-modifying rheumatic drugs, paracetamol, nonsteroidal anti-inflammatory drugs. Almost half the participants had physiotherapy with only a small proportion had occupational therapy. Complementary therapy use was largely vitamins and supplements, and close to a quarter of this population reported that they did not use complementary therapies at all.

Very few participants in this study population reported having discussions about clinical trials with their clinician and only five participants had taken part in a clinical trial, while close to three quarters would like to participate if there was a suitable trial for them.

This is a population that explained that in order for them to feel like treatment is working for them, they needed to experience a difference in pain levels, as well as an increase in day-to-day functioning, and quality of life/ wellbeing.

In relation to quality of life, this cohort described one or more negative aspects on their quality of life as a result of rheumatoid arthritis, and over a third of these participants noted an impact on their physical limitations.

This is a patient population where almost half of the participants described having an overall positive communication experience, with the main reason being that their healthcare professional(s) was/were caring, supportive and understanding.

To help maintain or manage mental and emotional health, approximately one fifth of this patient population reported visiting a mental health professional such as psychiatrists, psychologists, or counsellors

This is a patient population that is grateful for the Australian health system and turning to the future, they are looking for more affordable treatments, for health professionals to be more forthcoming with information and to communicate with more compassion/empathy, and a general improvement in the understanding of rheumatoid arthritis within care and support systems.

Summary of results

Section 1: Introduction and methodology

Summary

Rheumatoid arthritis is a chronic inflammatory disease., it is an auto-immune disease that targets the lining of joints. It is characterized by swelling, pain and damage to joints, usually affecting smaller joints such as those in the hands and feet but can also affect larger joints such as hips and knees. Over time, inflammation spreads to the organs and leads to comorbidities such as cardiovascular disease and lung disease.

In 2015, approximately 2% of the Australian population reported having rheumatoid arthritis amounting to around 407,900 people in total. Three quarters of those diagnosed are female.

Early diagnosis and treatment of rheumatoid arthritis is important to prevent and minimize joint damage, to minimise loss of function, to relieve pain and improve quality of life.

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

In this PEEK study, 100 people with rheumatoid arthritis throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in Rheumatoid arthritis is the largest mixed methodology study in Australia in the past five years. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2: Demographics and study population characteristics

Participants

- One hundred participants with rheumatoid arthritis were recruited into the study, 88 females (88.00%) and 12 males (12.00%), aged mostly between 35 and 64 (n=70, 70.00), and most participants identified as Caucasian/white (75.00%).
- The majority of participants were from New South Wales (n=27, 27.00%), Queensland (n=27, 27.00%), and Victoria (n=21, 21.00%), and most live in major cities (n=56, 56.00%), they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), half the participants lived in an area with a high SEIFA score of 7 to 10 (more advantage), and half lived in an area of mid to low SEIFA scores of 1 to 6 (less advantaged).
- The majority of participants had completed some university (n=67, 67.00%), and most were employed either full time (n=39, 39.00%) or part time (n=25, 25.00%). Under half of the participants were carers to either family members or spouses (n=42, 42.00%)

Arthritis Impact Measure Scale

- The Arthritis Impact Measure Scale 2 short form (AIMS2 SF) is a 26 item questionnaire with five scales; Physical, Symptoms, Affect, Social, and Work. Each scale has a possible score of between 0 (best health status) and 10 (worst health status).
- The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities: “All days”, “Most days”, “Some days”, “Few days” or “No days”. In this cohort, the majority scored less than 4, which is in the able to perform physical activities in the all to most days range (n=63, 63.00%).

- The symptoms scale is comprised of 3 questions about frequency of pain and stiffness: "All days", "Most days", "Some days", "Few days" or "No days". Just over half of the participants in this study scored more than 6 for symptoms, which relates to pain and stiffness on most to all days (N=53, 53.00%).
- The affect scale is comprised of 5 questions about experience of anxiety, depression and burden: "Always", "Very often", "Some times", "Almost never" or "Never". Most participants scored in the middle of this scale, indicating that they are affected sometimes (n=42, 42.00%). Thirty-nine participants (39.00%) never or almost never were affected.
- The social scale is comprised of 4 questions about frequency of social interactions: "All days", "Most days", "Some days", "Few days" or "No days". Most participants scored in the middle of this scale, indicating that they have social interactions some days (n=36, 36.00%). Forty-four participants (39.00%) had few to no days with social interactions.
- The work scale is completed by those that are employed and includes two questions about reduced hours or days absent from work: "Always", "Very often", "Some times", "Almost never" or "Never. Almost half of the participants reduced their work few to no days (n=47, 62.67%).

Disease description

- Participants described their disease by severity, location of disease, frequency of flare-ups and biomarkers. The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). Twenty-three (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission.
- Participants described the affected areas, with the majority having four or more affected areas (n=61, 61.00%). The most common sites affected were hands/wrists/fingers (n=93, 93.00%) and feet/ankles/toes (n=82, 82.00%).
- Participants most commonly reported that they had flare-ups once a week (n=26, 26.00%), more than half had flare-ups once a month or more frequently (n=68, 68.00%). Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (n=47, 47.00%).
- The most common biomarker was C-Reactive protein (n=34, 34.00%), followed by Rheumatoid factor (n=33, 33.00%).

Baseline health

- The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.
- The overall scores for the cohort were in the second highest quintile for "**SF36 Emotional well-being"** (Mean = 63.04, SD = 20.40) indicating good emotional well-being.
- The overall scores for **"SF36 Physical functioning"** (Mean = 48.90, SD = 26.29), **"SF36 Social functioning"** (Mean = 49.88, SD =25.41**), "SF36 Pain"** (Mean = 41.25, SD = 21.76) and **"SF36 Health change"** (Median = 50.00, IQR = 50.00) were in the middle of the scale, indicating moderate health or function.
- The overall scores for **"SF36 Role functioning/emotional"** (Median = 33.33, IQR = 100.00), **"SF36 Energy/Fatigue"** (Mean = 27.35, SD = 18.37) and "**SF36 General health"** (Mean = 33.05, SD = 20.44) were in the second lowest quintile, indicating poor health or function.
- The overall score for the "**SF36 Role functioning/physical"** was in the lowest quintile (Median = 0.00, IQR = 25.00) indicating very poor health limitations due to physical function.

Section 3: Experience of symptoms and diagnosis

Other health conditions

- Participants described other conditions that they had in addition to rheumatoid arthritis. There were 87 (87.00%) participants had at least one other condition.
- There were 37 participants (37.00%) described having anxiety, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=13, 13.00%); and 31 participants (31.00%) described having depression, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=7, 7.00%).
- Other common co-morbidities were chronic pain (n=42, 42.00%), sleep problems (n=32, 32.00%), and asthma (n=24, 24.00%). There were 13 participants had no other conditions (13.00%).

Experience of symptoms before diagnosis

- Participants were asked on the questionnaire which symptoms they had before diagnosis. The most common symptoms were joint pain (n=93, 93.00%), joint stiffness (n=90, 90.00%) and fatigue/loss of energy (n=84, 84.00%).
- Participants had between zero and ten symptoms, most commonly four symptoms (N=18, 18.00%) or five symptoms (n=20, 20.00%).
- The median quality of life was in the “Life was distressing” range for fatigue/loss of energy.
- The median quality of life was in the “Life was a little distressing” range for joint pain, joint stiffness, warm, swollen or tender joints, sweating more than usual, fever, loss of appetite, chest pain, and weight loss.
- The median quality of life was in the “Life was average” range for dry eyes.

Symptoms leading to diagnosis

- In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was pain. Overall there were 73 participants (73.00%) that noted this, of which 67 described general pain or joint pain and five described an aching pain. There were 18 participants (18.00%) that experienced swelling in their joints leading to diagnosis. The next most frequent themes were swelling that was often described as being sprain-like (n=14, 14.00%), followed by severe fatigue (n=13, 13.00%) and having flu-like symptoms (n=10, 10.00%).

Diagnostic tests

- Participants were asked on the online questionnaire what tests that they had received leading up to their diagnosis with Rheumatoid arthritis. Almost all the participants had blood tests (n=96, 96.00%), and the majority had a physical examination (n=87, 87.00%).
- Participants had between one and six diagnostic tests, two thirds (n=66, 66.00%) had three or more diagnostic tests.

Time from diagnostic tests to diagnosis

- Participants were asked on the online questionnaire about the amount of time from diagnostic test until they received a diagnosis. The time ranged from less than one week to 4 months. The most common response was four weeks or more (n=35, 35.00%), and more than half of the participants waited less than three weeks (n=63, 63.00%).

Diagnosis provider

- Participants were asked who gave them their diagnosis and where the diagnosis was given. The majority were diagnosed by a rheumatologist (n=51, 51.00%), or by a general practitioner (n= 46, 46.00%).

Diagnosis location

- Most participants received their diagnosis at a specialist clinic (n=47, 48.45%), followed by at the general practice (n=41, 42.27%).

Emotional support at diagnosis

- Participants were asked whether they felt supported at the time of diagnosis. There were 61 participants (61.00%) that indicated that they had no support at diagnosis, while 18 participants (18.00%) noted that they had enough support. An additional 21 participants (21.00%) indicated that they had some support but that it was not enough.

Information given at diagnosis

- Participants were asked whether they felt they were given enough information at diagnosis. There were 17 participants (17.00%) that indicated that they were given no information at diagnosis, while 26 participants (26.00%) noted that they were given enough information. The majority of participants (N=57, 57.00%) indicated that they were given some information but that it was not enough.

Costs at diagnosis

- Participants estimated the amount of out of pocket expenses they had for diagnostic tests and medical consultations. There were 24 participants (24.00%) had no out of pocket expenses, 18 participants (14.00%) spent between $100 and $500, 12 participants (12.00%) between $500 and $1000, and four participants (4.00%) spent more than $1000. The remaining 42 participants were unable to recall how much they spent (42.00%).

Burden of costs at diagnosis

- Participants described if the costs at diagnosis were a burden. For six participants (n= 6, 7.89%), it was no burden at all, 31 participants (40.79%) found it extremely or moderately significant burden, and 39 participants (51.31%) found it a somewhat or slightly significant burden.

Discussions about genetic tests and biomarkers

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. There were three participants (3.00%) that indicated that they had brought up the topic for discussion with their doctor and 8 participants (8.00%) that reported that their doctor had brought up the topic for discussion. There were also 89 participants (89.00%) that indicated that no one had ever spoken to them about this.

Experience of genetic tests

- Participants were asked what their experience of, or interest in genetic and biomarker tests. The majority of the participants did not have these tests but would like to (n=82, 82.00%), and a total of ten participants (10.00%) had these tests either by paying for the tests themselves (n=3, 3.00%) or having no out of pocket costs (n=7, 7.00%). There were 8 participants (n=8, 8.00%) were not interested in having these tests.

Diagnosis

- The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). There were 23 (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission.
- Participants described the affected areas, with the majority having four or more affected areas (n=61, 61.00%). The most common sites affected were hands/wrists/fingers (n=93, 93.00%) and feet/ankles/toes (n=82, 82.00%).
- Participants most commonly reported that they had flare-ups once a week (n=26, 26.00%), more than half had flare-ups once a month or more frequently (n=68, 68.00%).
- Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (N=47, 47.00%). The most common biomarker was C-Reactive protein (n=34, 34.00%), followed by Rheumatoid factor (n=33, 33.00%).

Understanding of disease at diagnosis

- Participants were asked how much they knew about rheumatoid arthritis at diagnosis. There were 53 participants (53.00%) reported having no knowledge. Other reported themes included knowing few details (n=16, 16.00%), having a professional background that meant that participants had some knowledge of the condition (n=10, 10.00%), having had a family member with rheumatoid arthritis that helped them understand the condition (n=9, 9.00%) and participants knowing about Rheumatoid arthritis through their own research before the diagnosis (n=8, 8.00%).

Understanding of prognosis

- Participants were asked in the structured interview to describe their understanding of their prognosis. The most common theme (n=19, 19.00%) was that participants describes not being sure of their prognosis as they had not had a proper conversation about this with their clinician. This was followed by the description of prognosis in the context of it being managed with medication (n=13, 13.00%), prognosis being described as currently having stable disease (n=9, 9.00%) and prognosis being described as a good prognosis and being positive (n=9, 9.00%).

Section 4: Experience of health professional communication

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common treatment option described was only one treatment option presented with participants having no say over this choice. This option was described by 39 participants (n=39.00). The next most common theme was all options presented, and felt able to talk about them with clinician (n=33, 33.00%), followed by being presented with one treatment option and being content with clinician's advice (n=15, 15.00%); only presented with one option but would appreciate more discussion about treatment (n=12, 12.00%) and participants describing the treatment of biologics as the treatment conversations (n=9, 9.00%).

Decision-making

Participants were asked to describe the most important factors they took into consideration whilst making decisions about their treatment. The highest reported theme was considering the side effects only (n=26, 26.00%) when making decisions about treatment, followed by side effects & or QOL (n=24, 24.00%), Quality of life only (n=22, 22.00%), always follows medical advice when making treatment decisions (n=17, 17.00%) and how much the medication costs (n=15, 15.00%).

Changes in decision making

Participants were asked to consider whether they believed their decision making towards treatment had changed over time. There were 67 participants (67.00%) that felt the way they made decisions about treatment had changed over time, and 11 participants (11.00%) that described decision making not changing. This was primarily because they had felt that they have always been assertive towards their decision making.

Of those participants that felt as though the way they made decisions had changed, 31 participants (31.00%) attributed this change to becoming more informed or assertive, 20 participants believed they are more accepting of treatment, though not through their own choice (20.00%), whilst 16 considered how RA has impacted on their life, and this has changed their decision making (16.00%). There were 8 participants who did not respond directly to the question or elaborate to why they had/had not changed, primarily due to their diagnosis being quite recent, therefore enough time had not passed to consider change in decision making.

Section 5: Experience of treatment

Main provider of treatment

- Participants answered questions about access to health services in the online questionnaire. The main physician treating participants for rheumatoid arthritis was a rheumatologist (n=79, 80.61%), others were treated mainly their general practitioner (n=16, 16.33%).

Access to health professionals

- Participants had access to a general practitioner (n=99, 99.00%), a rheumatologist (n=98, 98.00%), a pharmacist (n=62, 62.00%), and a physiotherapist (n=56, 56.00%), for the treatment of their rheumatoid arthritis.

Treated with respect during treatment

- Half of the participants indicated that they had been treated with respect throughout their treatment (n=50, 50.00%), 39 (39.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 11 (11.00%) participants felt they had not been treated with respect throughout their treatment.

Health care system

- The majority of participants were asked if they had private health insurance (n=86, 86.00%), and 38 (38.00%) participants were asked if they wanted to be treated as a public or private patient. The majority of patients had private healthcare insurance (n=67, 67.00%), and almost half were treated as private patients (n=47, 47.00%), and almost half were treated in a public hospital (n=47, 47.00%).

Affordability of healthcare

- Participants were asked about costs/affordability issues associated with rheumatoid arthritis. Over half of the participants have never or rarely missed medical appointments due to cost (n=58, 58.00%), 27 participants (27.00%) sometimes missed appointments due to cost, and 15 participants (15.00%) often or very often missed appointments due to costs.
- Over half the participants never did not fill prescriptions due to cost (n=57, 57.00%), 17 (17.00%) rarely couldn’t fill their prescriptions, 22 (22.00%) sometimes could not fill prescriptions and 4 (4.00%) often could not fill prescriptions due to costs.
- Almost half of the participants had never had difficulty paying for basic necessities such as housing, food and electricity (n=48, 48.00%). Twenty participants (20.00%) rarely had difficulty, and additional 20 participants (20.00%) sometimes had difficulty, and 12 participants (12.00%) often or very often had difficulty paying for basic necessities.
- The majority of participants did not need to pay for additional carers for either themselves or their family members due to rheumatoid arthritis (n=82, 82.00%).

Reduced income due to rheumatoid arthritis

- Forty-two participants (42.00%) reported that their income or family income had been reduced due to rheumatoid arthritis. The amount of lost monthly income was reported to be between $150 and $10 000 AUD a month, the most common response was between $1001 and $2000 AUD a month (n=10, 23.81). For those that had a reduced income, for more than half (n=24, 57.14%) this was moderately or extremely significant.

Cost of rheumatoid arthritis

- In the online questionnaire, the participants indicated described the amount spent per month on rheumatoid arthritis. Almost all participants had some costs associated with rheumatoid arthritis with only a single participant (1.00%) having no cost at all. The most common amount spent was between $101 and $250 a month (N=31, 31.00%). There were 9 participants (9.00%) who spent more than $500 a month.
- Participants were asked if the amount spent was a burden, for 18 participants (18.00%) this was an extremely significant burden, for 21 participants (21.00%) this was a moderately significant burden and for 22 participants (22.00%) this was a somewhat significant burden.

Changes to employment status

- Participants described changes in work status due to rheumatoid arthritis. More than half of the participants described changes that reduced income through quitting their job, reduced number of hours they worked or by taking leave without pay (N=58, 58.00%).

Changes to partner/main carer work status

- Participants noted in the online questionnaire the changes to their partner’s or main carer’s work status. Twelve participants (12.00%) noted that their partner of main carer made changes to employment that resulted in a loss of income (due to quitting work, reduced hours of work or leave without pay).

Surgery

- Twenty-three participants (23.00%) had one or more surgeries for their rheumatoid arthritis, fifteen of these had a single surgery (65.22%). The most common type of surgery reported per participant was arthroscopy (n=12, 52.17%), and the most common joint operated on was the knee (n=14, 60.87%). Other surgeries included synovectomies, tenolysis, carpel tunnel surgery, laser eye surgery, spinal fusion and Anterior cervical discectomy and fusion.

Disease-modifying antirheumatic drugs (DMARDs)

- Participants described their experience of DMARDs. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while taking DMARDs (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).
- The most common DMARD taken was methotrexate (n=86, 86.00%), the median quality of life was 4, in the "Life was average" range, and the effectiveness was rated as 3, in the moderately effective range. The most common side effect reported was feeling sick or nausea (n=45, 52.33). The next most frequently used DMARD was hydroxychloroquine (n=50, 50.00%). The median quality of life while on this treatment was 4, in the "Life was average" range, and the median effectiveness was 2.5, in the somewhat effective range. The most common side effect reported from taking hydroxychloroquine was feeling sick or nauseous (n=15, 31.25%). Thirty-four participants (34.00%) took lefluomide, the median quality of life was 3, in the "Life was a little distressing range", and the median effectiveness was rated as 2, in the somewhat effective range. Thirty-three participants (33.00%), took sulfasalazine, the median quality of life as 3, in the "Life was a little distressing" range, and the median effectiveness was 1, in the ineffective range.

Biological DMARDs

- Adalimumab was the most common biological DMARD used by participants in this study (n=24, 24.00%). The median quality of life was 5, in the "life was good" range, and the median effectiveness was rated as 3.5, in the moderately effective range. Half of participants that used adalimumab had no side effects (n=12, 50,00%) and the most common side effect was a skin reaction at the site of injection (n=8, 33.33%). Twenty- two participants (22.00%) took etanercept, the median quality of life was 4.5, in the "Life was average", and the median effectiveness was 3, in the moderately effective range. Nineteen participants (19.00%) took tofacitinib, the median quality of life was 4, in the "Life was average" range, and the median effectiveness was 2, in the somewhat effective range.

Pain killers and anti-inflammatories

- The majority of participants (n=84, 84.00%) had used paracetamol for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 2, in the somewhat effective range. Very few participants (n=4, 4.76%) reported side effects from paracetamol. More than half of the participants had taken codeine, the median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 3, in the moderately effective range. The most commonly reported side effects from codeine were feeling sleepy (n=16, 21.92%) and constipation (n=12, 17.81%).
- The majority of participants (n=73, 73.00%) had used NSAIDs for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 3, in the moderately effective range. More than half of the participants that used NSAIDs had no side effects (n=42, 57.53%), the most common side effect was stomach aches (n=18, 24.66%). Seventy-four participants (74.00%) had taken corticosteroids, the median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 4, in the effective range. The most commonly reported side effects from corticosteroids were trouble sleeping (n=38, 51.35%%) and bloating of the face and swelling of the abdomen (n=36, 48.65%).

Supportive care

- Almost half of the participants had physiotherapy (n=49, 49.00%), the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=7, 14.15%). Fifteen participants (15.00%) had occupational therapy, the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=1, 6.67%). Thirty-three participants (33.00%) had seen a podiatrist, the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 4 (in the effective range), and 23 participants (23.00%) had had counselling or seen a phycologist, the median quality of life was 3 (in the “Life was a little distressing” range) and the median effectiveness was 4 (in the effective range).

Complementary therapies

- Participants described their experience of relaxation techniques, massage therapy, and acupuncture. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being ‘Life was very distressing and 7 being ‘Life was great’). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.
- Participants described their experience of relaxation techniques, massage therapy, and acupuncture. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being ‘Life was very distressing and 7 being ‘Life was great’). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

Discussions about clinical trials

- In this PEEK study, 85.00% of all participants (n=85) describe not being spoken to about clinical trials, 7 participants (7.00%) brought up the topic with their doctor, and the doctors of 8 participants (8.00%) brought up the topic of clinical trials.

Participation in clinical trials

- Five (5.00%) participants have taken part in a clinical trial, and 70 (70.00%) participants have not taken part in a clinical trial but would like if one was suitable for them. Twenty-five (25.00%) participants have not taken part and do not want to.

Mild side effects

- In the structured interview, participants were asked how they would describe the term ‘Mild side effects’. The most common description of mild side effects came in the form of participants providing examples of specific side effects (n=49, 49%). Of these, the most commonly described side effects were vomiting/nausea (n=26, 26%), headaches (n=13, 13%), stomach upset (n=10, 10%), and lethargy/fatigue (n=9, 9%). Other descriptions provided included participants describing mild side effects as those that do not impact ability to carry out everyday tasks (n=27, 27%), do not require medical attention (n=9, 9%) and do not last (n=9, 9%).

Severe side effects

- In the structured interview, participants were asked how they would describe the term ‘Severe side effects’. The most common description of severe side effects was that they impact day to day functioning (n=37, 37%). Other descriptions of severe side effects included nausea (n=16, 16%), causing permanent damage (n=13, 13%), having a psychological effect (n=13, 13%), and being long-lasting (n=12, 12%). 13 participants provided specific examples of times when they experienced severe side effects, rather than providing a description (13%). Gastro-intestinal issues were provided as an example of severe side effects by 9 participants (9%).

Adherence to treatment

- Participants were asked what influences their decision to continue with a treatment regime. The most common theme described was adhering to treatment for a specific amount of time (n=41, 41%). Participants also reported following specialists' advice (n=30, 30%), adhering to a treatment regime as long as side effects were tolerable (n=24, 24%), and adhering to treatment as long as they thought it was effective (n=9, 9%). Nine of participants reported willingness to adhere to treatment regimens regardless of efficacy (n=9, 9%).

What needs to change to feel like treatment is effective

- Participants were asked to describe what needs to change to feel like treatment is effective. 60% of participants reported that for a treatment to be effective they had to experience a difference in pain (n=60). Increase in day-to-day functioning (n=28, 28%) and QOL/wellbeing (n=26, 26%) were the also described, as were reductions in specific symptoms associated with RA, such as swelling (n=19, 19%), fatigue (n=18, 18%), and mobility (n=12, 12%). 10 participants reported that for a treatment to be effective there had to be either no disease or a stable disease (10%).

Section 6: Information and communication

Access to information

- Participants were asked what information they had been able to access. The most common responses were accessing information from internet search engines, primarily Google, which was occasionally nicknamed "Dr Google" by some participants, (n=51, 51.00%). Australian charities were also mentioned (n=45, 45.00%), as was information from specialists (n=33, 33.00%). Online forums and social media (n=23, 23.00%), medical journals and articles (n=17, 17.00%) and books (n=10, 10.00%) were also reported.

Information that has been helpful

- The information that participants found most helpful was medical journals/articles (n=15, 15.00%). Other helpful information included unspecified online examples (n=13, 13.00%), information from a doctor or specialist (n=11, 11.00%), online support groups (n=10, 10.00%), other people's stories (n=10, 10.00%), unspecified online information (n=10, 10.00%), information from charities (n=9, 9.00%), information provided by drug companies on medication packaging (n=9, 9.00%), and support groups (n=8, 8.00%). There were 9% of participants that reported that no information they had received had been helpful.

Information that has not been helpful

- Participants were asked if there was any information that they found to be unhelpful. The most common theme described by 34 participants as unhelpful were other people's opinions (34.00%). This was followed by no unhelpful information found (n=28, 28.00%), online sources (n=23, 23.00%), participants deciding for themselves what was relevant to themselves (n=12, 12.00%), healthcare professionals (n=11, 11.00%), online support groups (n=9, 9.00%) and being told about disease progression (n=8, 8.00%).

Information preferences

- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common theme overall was a preference for talking to someone (n=45, 45.00%). This included a preference for talking to someone (in general (n=19, 19.00%), talking to someone as well as online information (n=15, 15.00%) and talking to a specialist nurse (n=11, 11.00%). The next most common theme overall was accessing online information (n=38, 30.80%) and this was due to its accessibility. There were also 17 participants (17.00%) that described a preference for booklets and nine participants (9.00%) that had a preference for apps.

Timing of Information

- The most common time that participants described being receptive to receiving information was being receptive since diagnosis (27.00%). This is followed by: Receptive after initial shock (24.00%), receptive after months (20.00%), slowly receptive to new information (17.00%) and not receptive for years (16.00%).

Healthcare professional communication

- Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described was having an overall positive experience as their healthcare professional was caring, supportive and understanding (21.00%). Where participants described a positive experience, this related to their healthcare professional being supportive and understanding (21.00%), taking the time to answer participant questions and provide information (18.00%), and reporting having a positive experience but not elaborating (15.00%). When participants described a negative experience, this related to healthcare professionals being dismissive and/or participants feeling ignored (17.00%), and participants reported not being given enough time or support to ask questions (14.00%). Some participants (13.00%) reported having neither a positive or negative experience.

Knowledge and confidence

- The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and management of symptoms, and adherence to treatment. A higher score denotes a better understanding and knowledge of disease.

Partners in health – overall score

- Overall, the participants scored in the top quintile for **"Partners in health: adherence to treatment"** (median =14.00, IQR = 4.00), indicating very good adherence to treatment. **"Partners in health: knowledge"** (median = 25.00, IQR = 8.00), **"Partners in health: recognition and management of symptoms"** (median = 18.00, IQR = 5.00), and "**Partners in health: total score"** (mean = 69.47, SD = 13.06) scored in the second highest quintile indicating good health outcomes. Participants scored in the middle of the scale for **"Partners in health: coping"** (mean = 13.72, SD = 5.37), indicating moderate scores.

Information given by healthcare professionals and searched for independently.

- Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=73, 73.00%), disease management (n=54, 54.00%), and disease management (n=48, 48.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (n=3, 3.00%), psychological/social support (n=8, 8.00%) and hereditary considerations genes or genomic biomarker information (n=8, 8.00%).

Information searched for independently

- Participants were asked about what type of information they searched for after receiving information from healthcare professionals. Information about disease cause (72.00%) was most often searched for, followed by treatment options (65.00%), complementary therapies (63.00%) and disease management (63.00%). The least searched for topic was hereditary considerations genes or genomic biomarker information (22.50%).

Information gaps

- The largest gaps in information, where information was neither given to patients nor searched for independently clinical trials (n=74, 74.00%), hereditary, genes or genomic biomarkers (n=69, 69.00%), and psychological/social support (n=62, 62.00%) (Figure 6.72). Participants were given most information either from healthcare professionals or independently for treatment options (n=95, 95.00%), disease cause (n=88, 88.00%) and disease management (n=86, 86.00%). Complementary therapies (n= 54, 54.00%), how to interpret test results (n=53, 53.00%) and Dietary information (n=51, 51.00%) were the topics that was most searched for independently following no information from health professionals

Most trusted information sources

- Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Figure 6.73. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from non-profit or charities or patient organisations were most trusted, followed by information from the government. Information from pharmaceutical companies and from medical journals were least trusted.

Accessed "My Health Record"

- My Health Record is an online summary of key health information, an initiative of the Australian Government. Thirty-eight (38.00%) had accessed "My Health Record", 59 (59.00%) had not, and three (3.00%) were no sure. Of those that had accessed "My Health Record", four participants (10.81%) found it good or very good., 11 (29.73%) found it acceptable, and 22 (59.46%) found it poor or very poor).

Section 7: Experience of care and support

Care coordination

The Care Coordination questionnaire comprises a total score, 2 scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

- Overall the entire cohort had a median score of 7.0 for "**Care coordination: quality of care global measure"** (IQR = 2.00), which is in the second highest quintile, indicating good care received.
- The mean scores for "**Care coordination: navigation"** (Mean = 26.20, SD=4.46), and (**"Care coordination: total score** (Mean = 65.70, SD = 11.80), and the median score for "**Care coordination: care coordination global measure"** (Median = 7.00, IQR = 2.00) were in the middle of the scale, indicating moderate scores.
- The mean score for "**Care coordination: communication"** (Mean = 33.46, SD = 10.18) was in the second lowest quintile, indicating poor communication.

Ability to take medicine and stick to it (adherence)

- Participants were asked about their ability to take medicine and stick to that regimen. More than half responded that they could take medicine and stick to it "All the time" (N=55, 55.00%), 40 participants (40.00%) responded "Most of the time", very few answered "Sometimes" (N=4, 4.00%) or "Rarely" (N=1, 1.00%).

Experience of care and support

- The most common description of care and support was from participant's GP/specialist (n=33, 33.00%), followed by friends (n=28, 28%), family (n=21, 21.00%), support group (n=18, 18.00%), complimentary therapy and allied health (n=15, 15.00%), received no help (n= 14, 14.00%), online peer support (n=14, 14.00%), partner support (n=14, 14%), parental/sibling support (n=13, 13%), support from charities (n=12, 12.00%) and domestic support (n=8, 8.00%).

Section 8: Experience of quality of life

Impact on quality of life

- Overall, there were 78 participants that described at least one negative impact on quality of life and 14 that described no impact or a positive impact on quality of life, with a further two participants who described an overall positive impact of quality of life. There were six participants who described both positive and negative impacts of quality of life in equal measure. The most common themes in relation to having a negative impact on quality of life included impact on physical activity (37.00%), impact on children (26.00%), impact on their partner (25.00%), impact on fatigue levels (23,00%), reduced social life (19.00%), inability to work (14.00%) and impact on immediate family including parents/siblings (12.00%).

Regular activities to maintain mental health

- The most common way that participants reported managing their mental and emotional health was by visiting a mental health professional, usually a psychiatrist, psychologist, or counsellor (20.00%). Other activities that participants reported practicing regularly in order to maintain their mental health were receiving emotional support from family and friends (18.00%), practicing mindfulness meditation (13.00%), remaining physically active (11.00%), ensuring they retained a positive outlook (10%), and using antidepressants (8.00%). There were 10.00% of participants who reported that they struggled with mental health issues but did not practice any regular activities to maintain their mental health, and 10.00% of participants reported that they did not have to practice any activities as their mental health was good.

Regular activities to maintain physical health

- The most common theme described by participants as a regularly performed activity to maintain health was listening to their body and resting (29.00%). Other reported activities included ensuring they were compliant to treatment regimens (27.00%), keeping up physical activities (19.00%), getting enough sleep (14.00%), pacing their activities and/or accepting help when required (11.00%), practicing meditation or mindfulness (9.00%) and modifying their diet (9.00%).

Impact on relationships

- The most common theme described by participants was a loss of friendship (34.00%). This was followed by no impact on family/friends (30%), not being able to attend social events (16.00%), stress on their partner (16.00%), relationship becoming more complicated (15.00%), and low awareness of rheumatoid arthritis which had an impact on relationships (15.00%).

Burden on family

- Participants were also asked if their condition caused any additional burden on their family. The most common theme was that the family takes on extra duties (41.00%). This was followed by worrying about the future burden that may result from their rheumatoid arthritis (19.00%), the mental/emotional burden on their family (18.00%), no burden as they require little assistance (12.00%) and family taking up extra driving duties for the participant (8.00%).

Cost considerations

- There were 39% of participants who mentioned that treatment costs were a significant burden of having rheumatoid arthritis. Other costs included having to take time off work (37.00%), spending money on specialists (36.00%), day to day costs associated with the condition (10.00%), costs of complementary therapies (10.00%) and costs at diagnosis (8.00%). There were also 9.00% of participants that described not struggling financially as their insurance covered their treatment.

Anxiety and fear of progression

- The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Overall the entire cohort had a mean total score of 38.67 (SD = 8.88), which is a score in the middle of the scale, indicating a moderate anxiety about their health.

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

- In the structured interview, participants were asked what they expected from future treatments. The most common theme was less treatment expense (n=43, 43.00%). This was followed by less side effects (n=34, 34.00%), more oral treatments (n=18, 18.00%), more varied and/or accessible treatments (n=13, 13.00%) and more holistic care (n=12, 12.00%).

Expectations of future information

- In the structured interview, participants were asked what they wanted from information in the future. The most common theme was wanting their healthcare professionals to be more forthcoming with information (n=18, 18.00%). This was followed by participants being satisfied with current information (n=13, 13.00%), changing the format of the current information (n=11, 11.00%), more lifestyle information (n=10, 10.00%), more awareness about rheumatoid arthritis (n=10, 10.00%), holistic options (n=10, 10.00%), more information about patient experiences (n=9, 9.00%), more information about specific symptoms (n=9, 9.00%) and new treatments/clinical trials (n=8, 8.00%).

Expectations of future healthcare professional communication

- In the structured interview, participants were asked what they wanted from healthcare professional communication in the future. The most common themes were that participants wanted health professionals to communicate with more compassion/empathy and establish a connection with patients (n=25, 25.00%). Other themes included having experienced good communication and not having any recommendations (n=22, 22.00%), wanting to have more time to communicate with health professionals (n=21, 21.00%), that health professionals communicate more holistically; that is, talk more holistically about treatment options or participants' experiences (n=18, 18.00%), and that clinicians explain diagnosis/test results/prognosis/treatment more clearly (n=9, 9.00%).

Expectations of future care and support

- In the structured interview, participants were asked what they expected of care and support in the future. The most common reported expectation of future care and support was that there was an increased understanding of rheumatoid arthritis within care and support systems, as well as within the general population (n=22, 22.00%). Other reported themes included a desire for more affordable complementary therapies (n=17, 17.00%), increased access to or improvement of support groups/charity support (n=16, 16.00%), more access to domestic support (n=15, 15.00%) and psychological support (n=15, 15.00%), more opportunity to connect with other patients (n=14, 14.00%), more transport support (n=10, 10.00%), increased funding into RA research and support services, and easier access to services (n=8, 8.00%) for those that either live regionally or work full-time. Twelve participants (12.00%) reported that they had no recommendations for improvement.

Aspects of the Australian health system patients are grateful for

- In the structured interview, participants were asked what aspects of the Australian health system they were most grateful for. The most common theme was being grateful for the Australian health system being low cost/free (n=40, 40.00%). Other commonly reported themes included gratitude for being able to access treatment through Medicare (n=39, 39.00%), for healthcare professionals (n=27, 27.00%) access to a rheumatologist (19.00%), access to diagnostic tests (n=13, 13.00%), and for the entire health system (n=11, 11.00%). In addition, 29 participants (29.00%), when asked what aspects of the health system they were grateful, expressed a degree of gratitude but also said that there were significant improvements that needed to be made.

Symptoms and aspects of quality of life important for treatment considerations

- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 9 is the least important. The most important aspects reported were pain, physical function, and level of independence; the least important was redness.

Length of time to take a treatment for good quality of life

- In response to "For you to feel that a treatment was worthwhile, how many months or years would you consider taking it, provided it gave you a good quality of life, even if it didn't offer a cure?", the majority of participants would take the treatment for more than 10 years (n=71, 71.00%).

Values that are important to patients when making decisions

- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "The ability to include my family in making treatment decisions", and "My ability to follow and stick to a treatment regime".

Values that are important to patients when others are making decisions on their behalf

- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were "quality of life for patients", and "access for all patients to all treatments and services"; the least important was "economic value to government".

Message to decision makers

- The most common message participants wanted to tell decision makers was that there should be more awareness of and research into rheumatoid arthritis (23.00%). Other common messages included that treatment should be affordable (19.00%), there should be better access to different medicines through the PBS (19.00%), there should be a reduction of stigma surrounding RA (17.00%), there needs to be more efficient hospital processes (14.00%), that complementary therapies needed to be more affordable (10.00%), and that there needs to be a change to the referral process surrounding biologics (8.00%).

Section 10: Advice to other patients and families

- The most common advice to other patients and families was to become more informed about your rheumatoid arthritis (25%) and this was followed by being more assertive, mainly towards healthcare professionals in regard to their treatment options (23%). There were 16 participants (16%) whose advice was to kinder towards yourself and acknowledge and/or accept your limitations, 15 participants (15%) whose advice was to remain positive, 14 participants (14%) advised to be mindful of emotional wellbeing and to seek mental health help or counselling support, a further 14 participants (14%) who advised talking to other patients with rheumatoid arthritis, 10 participants (10%) advised practical support such as health diet and exercise, and a further 10 participants (10%) advised participating more in complimentary therapy to help ease symptoms, particularly hydrotherapy.

Section 1 Introduction and methods

Section 1: Introduction and methodology

Summary

Rheumatoid arthritis is a chronic inflammatory disease., it is an auto-immune disease that targets the lining of joints. It is characterized by swelling, pain and damage to joints, usually affecting smaller joints such as those in the hands and feet but can also affect larger joints such as hips and knees. Over time, inflammation spreads to the organs and leads to comorbidities such as cardiovascular disease and lung disease.

In 2015, approximately 2% of the Australian population reported having rheumatoid arthritis amounting to around 407,900 people in total. Three quarters of those diagnosed are female.

Early diagnosis and treatment of rheumatoid arthritis is important to prevent and minimize joint damage, to minimise loss of function, to relieve pain and improve quality of life.

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

In this PEEK study, 100 people with rheumatoid arthritis throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in Rheumatoid arthritis is the largest mixed methodology study in Australia in the past five years. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Rheumatoid arthritis is a an auto-immune disease that targets the lining of joints[1]. It is characterized by swelling, pain and damage of joints, usually affecting smaller joints such as those in the hands and feet but can also affect larger joints such as hips and knees[1-3]. Over time inflammation spreads to the organs and leads to comorbidities such as cardiovascular disease and lung disease[4]. Inflammation can also affect the blood vessels, in particular the eyes, and this can lead to dry eyes[5]. Comorbidities are common, mainly osteoporosis, heart disease, anaemia and infections such as chest infection and sepsis[4]. Depression and anxiety are common in this population[6].

Genetic factors are important in the development of rheumatoid arthritis, however the underlying causes are not well described[1]. Smoking increases risk of rheumatoid arthritis, most often in women and in those over the age of 30[1].

The global prevalence of rheumatoid arthritis is estimated to be between 0.3% and 1% of the global population, and is thought to be more common in women and in developed countries[7]. In 2015, approximately 2% of the Australian population reported having rheumatoid arthritis amounting to around 407,900 people in total. Three quarters of those diagnosed are female[8]. The average age of onset is between 35-64, often during working age[8]. Within two years of diagnosis, around one third of those with RA stop work due to the rheumatoid arthritis[4].

There were 13,188 hospitalisations during 2014 with the principal reason for admission relating to rheumatoid arthritis, with those aged between 60-64 most likely to be hospitalised[9]. This amounts to 55 hospitalisations per 100,000 of the Australian population[9]. The number of hospital admissions for rheumatoid arthritis increased by 72% between 2005 and 2015[9].

Early diagnosis and treatment of rheumatoid arthritis is important to prevent and minimize joint damage, to minimise loss of function, to relieve pain and improve quality of life[3].

Patient Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Methodology

Participants

To be eligible for the study, participants needed to have been diagnosed with rheumatoid arthritis, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced on 2 October 2018 and the study closed for recruitment on 23 January 2019. Participants were recruited via email and social media through CCDR and study partners Young Women's Arthritis Support Group, Arthritis Australia, Arthritis & Osteoporosis NSW.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey from October 2018 to January 2019.

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from October 2018 to January 2019.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[10], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ) (Young et al 2011)[11], the Short Fear of Progression Questionnaire (FOP12) (Hinz et al)[12], and the Partners in Health version 2 (PIH) (Petov 2010)[13]. In addition investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by a registered nurse or researcher with a background in psychology, who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

The next set of questions allowed patients to reflect on what they would like to see in the future in relation to treatment and care and asked them what their messages to decision-makers would be about the care and treatment patients with their condition receive. The interview also asks patients about the advice they would give to others recently diagnosed with their condition or disease. All interviews were recorded and transcribed verbatim.

Questionnaire analysis

Statistical analysis was conducted using R included in the package's "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). Global scales and sub scales were calculated according to reported instructions[10-13].(1,3,4) The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by subgroups.

The Arthritis Impact Measurement Scale 2 Short-form **(AIMS2 SF)** is a health-related quality of life assessment specific to arthritis, subscales were calculated according to reported instructions[14]. The subgroups used in this study are based on differences in participants in the following categories: **AIMS2 SF physical scale**, **AIMS2 SF Symptoms Scale**, **AIMS2 SF Affect scale**, **AIMS2 SF Social scale**, **Flare-up frequency**, **Age**, **Location**, **Education**, and Socio-economic Indexes for Areas (**SEIFA**)

For comparisons by **AIMS2 SF) physical scale**, **AIMS2 SF Symptoms Scale**, **AIMS2 SF Affect scale**, **AIMS2 SF Social scale**, and **Age**, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kuskal-Wallis rank sum test on care was conducted with post hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used.

Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in MaxQDA. The minimum coded unit was a sentence however there were also paragraphs and phrases that were coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 8 times it was not included in the study results.

Data analysis and final reporting was completed in April 2019.

Position of this study

A search was conducted in Pubmed to identify rheumatoid arthritis studies that included quality of life or patient experience components, that had been conducted in the past ten years in solely in Australia.

Sixteen studies were identified of between 42 and 2375 participants (Table 1.1). Two studies were mixed methods, one study included a total of 27 participants that focused on the knowledge and information needs of women with children[15], the second study included 29 participants and was focused on foot care[16].

A single qualitative study of 154 participants used written narratives to discuss motherhood decision making for women with rheumatoid arthritis[17].

Thirteen quantitative studies were identified. Of these, six studies were focused on drug therapy, collected data from between 149 and 2375 participants[18-23] and reported on health status[18,19,21-23], HRQOL[18,19,21-23], symptoms[21-23], treatment satisfaction[20,21], treatment side effects[20-22], and health literacy/treatment adherence[20]. Two studies focused on pain[24,25], both collected information on symptoms, one study also reported health status, and HRQOL data[25]. A study of 170 participants focused on patient reported HRQOL collected patient reported data for health status, symptoms, economic impact, and health literacy/treatment adherence[26.] A self-management program was evaluated in 113 participants and collected patient reported information about health status, HRQOL symptoms, health literacy/self-management and depression and anxiety[27]. A study of 80 participants focused on ultrasound collected information about information and communication[28], one study compared osteoarthritis with rheumatoid arthritis and collected information about health status and symptoms[29]. A surgical study of 42 participants reported health status HRQOL, symptoms, and economic impact[30].

The 2019 Rheumatoid Arthritis Australian PEEK is a mixed methods study of 100 participants. The PEEK study covers the experience of people living with rheumatoid arthritis in the Australian health system from the time symptoms were first experienced through diagnosis, treatment and future expectations. The PEEK study collects participant reported information about health status, HRQOL, symptoms, decision making, treatment satisfaction, treatment side effects, economic impact of disease, information and communication experience and needs, health literacy and treatment adherence, anxiety, and future expectations. The Rheumatoid Arthritis 2019 Australian PEEK Study is the largest mixed methods study of Rheumatoid Arthritis in Australia, in addition, it is the most comprehensive study detailing the experience of people with Rheumatoid arthritis in the Australian health system.

Table 1.1: Position of this PEEK study

Author, Year	Study type	Number of participants	Study focus	Health status	HRQOL	Symptoms	Decision Making	Treatment satisfaction	Treatment side effects	Economic impact	Information and communication	Health Literacy /Treatment	Depression/Anxiety	Expectations
Hendry et al[16], 2013	Mixed methods	n=12 Interviews n=29 Quantitative	Foot care	x	x	x						x		
Ackerman et al[15], 2015	Mixed methods	n=15 Interviews n=12 Focus groups n=27 Quantitative	Knowledge information needs of women with children								x	x		
Meade et al[17], 2013	Qualitative	n=154 Written narratives	Motherhood decisions											
Chen et al[18], 2014	Quantitative	2375	Drug therapy	x	x									
Staples et al[19], 2011	Quantitative	1801	Drug therapy	x	x									
Nash et al[20], 2013	Quantitative	1313	Drug therapy					x	x			x		
Voight et al[21], 2012	Quantitative	351	Drug therapy	x	x	x		x	x					
Wechalekar et al[23], 2016	Quantitative	266	Drug therapy	x	x	x								
Wabe et al[22], 2016	Quantitative	149	Drug therapy	x	x	x			x					
de Luca et al[24], 2017	Quantitative	227	Pain			x								
Gist et al[25], 2018	Quantitative	117	Pain	x	x	x								
Standfield et al[26], 2010	Quantitative	170	HRQOL	x	x	x				x		x		
Vermaak et al[27], 2015	Quantitative	113	Self management program	x	x	x						x	x	
Joshua et al[28], 2017	Quantitative	80	Ultrasound								x			
El-Haddad et al[29], 2017	Quantitative	64	Osteo/rheumatoid arthritis comparison	x		x								
March et al[30], 2008	Quantitative	42	Surgery	x	x	x				x				

Common abbreviations

CCDR	Centre for Community-Driven Research
DF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
F	F-statistic. An **F statistic** is a value you get when you run an ANOVA test or a regression analysis to find out if the means between two populations are significantly different.
FOP	Fear of Progression. Tool to measure anxiety related to progression.
MS	Mean of Squares. Estimates of variance across groups
SD Standard Deviation.	A quantity expressing by how much the members of a group differ from the mean value for the group.
SF 36	Short Form Health Survey 36
SS or χ^2	Sum of the Squares. The sum of squares is used as a mathematical way to find the function which best fits (varies least) from the data.
t	t-Statistic. Size of the difference relative to the variation in your sample data.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
P	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
QoL	Quality of LIfe
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.

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Section 2 Demographics

Section 2 Demographics

Participants

- One hundred participants with rheumatoid arthritis were recruited into the study, 88 females (88.00%) and 12 males (12.00%), aged mostly between 35 and 64 (N=70, 70.00), and most participants identified as Caucasian/white (75.00%).
- The majority of participants were from New South Wales (N=27, 27.00%), Queensland (N=27, 27.00%), and Victoria (N=21, 21.00%), and most live in major cities (N=56, 56.00%), they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), half the participants lived in an area with a high SEIFA score of 7 to 10 (more advantage), and half lived in an area of mid to low SEIFA scores of 1 to 6 (less advantaged).
- The majority of participants had completed some university (N=67, 67.00%), and most were employed either full time (N=39, 39.00%) or part time (N=25, 25.00%). Under half of the participants were carers to either family members or spouses (N=42, 42.00%)

Arthritis Impact Measure Scale

- The Arthritis Impact Measure Scale 2 short form (AIMS2 SF) is a 26 item questionnaire with five scales; Physical, Symptoms, Affect, Social, and Work. Each scale has a possible score of between 0 (best health status) and 10 (worst health status).
- The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities: “All days”, “Most days”, “Some days”, “Few days” or “No days”. In this cohort, the majority scored less than 4, which is in the able to perform physical activities in the all to most days range (N=63, 63.00%).
- The symptoms scale is comprised of 3 questions about frequency of pain and stiffness: “All days”, “Most days”, “Some days”, “Few days” or “No days”. Just over half of the participants in this study scored more than 6 for symptoms, which relates to pain and stiffness on most to all days (N=53, 53.00%).
- The affect scale is comprised of 5 questions about experience of anxiety, depression and burden: “Always”, “Very often”, “Some times”, “Almost never” or “Never”. Most participants scored in the middle of this scale, indicating that they are affected sometimes (N=42, 42.00%). Thirty-nine participants (39.00%) never or almost never were affected.
- The social scale is comprised of 4 questions about frequency of social interactions: “All days”, “Most days”, “Some days”, “Few days” or “No days”. Most participants scored in the middle of this scale, indicating that they have social interactions some days (N=36, 36.00%). Forty-four participants (39.00%) had few to no days with social interactions.
- The work scale is completed by those that are employed and includes two questions about reduced hours or days absent from work: “Always”, “Very often”, “Some times”, “Almost never” or “Never. Almost half of the participants reduced their work few to no days (N=47, 62.67%).

Disease description

- Participants described their disease by severity, location of disease, frequency of flare-ups and biomarkers. The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). Twenty-three (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission.
- Participants described the affected areas, with the majority having four or more affected areas (N=61, 61.00%). The most common sites affected were hands/wrists/fingers (N=93, 93.00%) and feet/ankles/toes (N=82, 82.00%).
- Participants most commonly reported that they had flare-ups once a week (N=26, 26.00%), more than half had flare-ups once a month or more frequently (N=68, 68.00%). Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (N=47, 47.00%).
- The most common biomarker was C-Reactive protein (N=34, 34.00%), followed by Rheumatoid factor (N=33, 33.00%).

Baseline health

- The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.
- The **"SF36 Physical functioning"** measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities for participants in this study were moderately limited.
- The "**SF36 Role functioning/physical"** scale measures how physical health interferes with work or other activities. On average, physical health of the participants in this study extremely interfered with work or other activities.
- The **"SF36 Role functioning/emotional"** scale measures how emotional problems interfere with work or other activities. On average, any emotional problems of the participants in this study interfere quite a lot with work or other activities.
- The **"SF36 Emotional well-being"** scale which measures how a person feels, for example happy, calm, depressed or anxious, on average, the participants in this study felt happy and calm most of the time, and depressed and anxious a little of the time.
- The **"SF36 Social functioning"** scale measures the limitations on social activities due to physical or emotional problems. On average for the participants in this study, social activities are moderately limited.
- The **"SF36 Role Energy/Fatigue"** scale measures the amount of energy or fatigue. On average the participants in this study they felt tired most of the time and had energy a little of the time.
- The **"SF36 Pain"** scale measures the amount of pain, and how pain interferes with work and other activities. On average the participants in this study had moderate pain.
- The **"SF36 Health change"** scale measures health now compared to a year ago. On average, the participants in this study had about the same health now as they did a year ago.
- The **"SF36 General health"** scale measures general health, on average the participants in this study had poor health.

Demographics

One hundred participants with rheumatoid arthritis were recruited into the study, 88 females (88.00%) and 12 males (12.00%), aged mostly between 35 and 64 (N=70, 70.00), and most participants identified as Caucasian/white (N=75, 84.27%).

The majority of participants were from New South Wales (N=27, 27.00%), Queensland (N=27, 27.00%), and Victoria (N=21, 21.00%), and most live in major cities (N=56, 56.00%), they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), half the participants lived in an area with a high SEIFA score of 7 to 10 (more advantage), and half lived in an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

The majority of participants had completed some university (N=67, 67.00%), and most were employed either full time (N=39, 39.00%) or part time (N=25, 25.00%). Under half of the participants were carers to either family members or spouses (N=42, 42.00%). The demographics of participants are listed in Table 2.1.

Table 2.1: Demographics

Characteristic		Count (N=100)	Percent
Age	18-24	5	5.00
	25-34	13	13.00
	35-44	28	28.00
	45-54	23	23.00
	55-64	19	19.00
	65-74	9	9.00
	75-84	3	3.00
Gender	Female	88	88.00
	Male	12	12.00
State	New South Wales	27	27.00
	Queensland	27	27.00
	Victoria	21	21.00
	South Australia	8	8.00
	Tasmania	7	7.00
	Australian Capital Territory	5	5.00
	Western Australia	5	5.00
Location	Major city	56	56.00
	Inner regional	31	31.00
	Outer regional	12	12.00
	Remote	1	1.00
SEIFA	1	4	4.00
	2	9	9.00
	3	6	6.00
	4	11	11.00
	5	9	9.00
	6	11	11.00
	7	10	10.00
	8	11	11.00
	9	15	15.00
	10	14	14.00

Table 2.1: Demographics (continued)

Characteristic		Count (N=100)*	Percent
Race/ethnicity (N=89)	Caucasian/White	75	84.27
	Indigenous	5	5.62
	Asian	2	2.25
	Arab	1	1.12
	Australian	1	1.12
	Australian with mixed ethnic heritage	1	1.12
	Indian and Caucasian	1	1.12
	Mixed - Caucasian/Asian	1	1.12
	Pacific Islander	1	1.12
	Romany	1	1.12
Education	Associate degree	7	7.00
	Bachelor degree	27	27.00
	Graduate degree	33	33.00
	High school degree or equivalent	13	13.00
	Less than high school degree	3	3.00
	Some college but no degree	15	15.00
	Trade	2	2.00
Employment status	Employed, working full time (total = 39))	39	39.00
	Plus full/part time study (1)		
	Plus full/part time carer (1)		
	Employed, working part time (total =25)	25	25.00
	Plus currently receiving Centrelink support (3)		
	Plus full/part time study (3)		
	Full/part time carer (total =5)	5	5.00
	Plus not employed, looking for work, Disabled, not able to work (1)		
	Full/part time study (total =5)	5	5.00
	Plus currently receiving Centrelink support (1)		
	Plus not employed, looking for work (1)		
	Retired	14	14.00
	Disabled, not able to work	9	9.00
	Currently receiving Centrelink support	2	2.00
	Not employed, looking for work	1	1.00
Carer	Children	30	30.00
	Parents	3	3.00
	Spouse	3	3.00
	Grandchildren	2	2.00
	Children, Grandparents, Spouse	1	1.00
	Children, Parents	1	1.00
	Clients	1	1.00
	Grandparents	1	1.00
	Spouse, and adult son	1	1.00
	I am not a carer	57	57.00

*N=89 for Race/ethnicity

Arthritis Impact Measurement Score

The Arthritis Impact Measure Scale 2 short form (AIMS2 SF) is a 26-item questionnaire with five scales; Physical, Symptoms, Affect, Social, and Work. Each scale has a possible score of between 0 (best health status) and 10 (worst health status).

The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities "All days", "Most days", "Some days", "Few days" or "No days". In this cohort, the majority scored less than 4, which is in the able to perform physical activities in the all to most days range (N=63, 63.00%).

The symptoms scale is comprised of 3 questions about frequency of pain and stiffness "All days", "Most days", "Some days", "Few days" or "No days". Just over half of the participants in this study scored more than 6 for symptoms, which relates to pain and stiffness on most to all days (N=53, 53.00%).

The affect scale is comprised of 5 questions about experience of anxiety, depression and burden "Always", "Very often", "Sometimes", "Almost never" or "Never". Most participants scored in the middle of this scale, indicating that they are affected sometimes (N=42, 42.00%). Thirty-nine participants (39.00%) never or almost never were affected, a score less than 4.

The social scale is comprised of 4 questions about frequency of social interactions "All days", "Most days", "Some days", "Few days" or "No days". Most participants scored in the middle of this scale, indicating that they have social interactions some days (N=36, 36.00%). Forty-four participants (44.00%) had few to no days with social interactions, a score greater than 6.

The work scale is completed by those that are employed and includes two questions about reduced hours or days absent from work, "Always", "Very often", "Sometimes", "Almost never" or "Never". Almost half of the participants reduced their work few to no days (N=47, 62.67%), a score of less than 4.

Table 2.2: Arthritis Impact Measure Scale 2 short form

AIMS2 SF Scale	Score	N=100	Percent
Physical	0 to 2	19	19.00
	>2 to 4	44	44.00
	>4 to 6	29	29.00
	>6 to 8	8	8.00
	>8 to 10	0	0.00
Symptom	0 to 2	9	9.00
	>2 to 4	11	11.00
	>4 to 6	27	27.00
	>6 to 8	32	32.00
	>8 to 10	21	21.00
Affect	0 to 2	12	12.00
	>2 to 4	27	27.00
	>4 to 6	42	42.00
	>6 to 8	15	15.00
	>8 to 10	4	4.00
Social	0 to 2	1	1.00
	>2 to 4	19	19.00
	>4 to 6	36	36.00
	>6 to 8	32	32.00
	>8 to 10	12	12.00
Work (N=75)	0 to 2	23	30.67
	>2 to 4	24	32.00
	>4 to 6	10	13.33
	>6 to 8	15	20.00
	>8 to 10	3	4.00

Disease description

Participants described their disease by severity, location of disease, frequency of flare-ups and biomarkers. The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). Twenty-three (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission. Participants described the affected areas, with the majority having four or more affected areas (N=61, 61.00%). The most common sites affected were hands/wrists/fingers (N=93, 93.00%) and feet/ankles/toes (N=82, 82.00%). Participants most commonly reported that they had flare-ups once a week (N=26, 26.00%), more than half had flare-ups once a month or more frequently (N=68, 68.00%). Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (N=47, 47.00%). The most common biomarker was C-Reactive protein (N=34, 34.00%), followed by Rheumatoid factor (N=33, 33.00%).

Table 2.3: Disease description

Disease description		N=100	Percent
Participant description of disease	High Disease Activity	23	23.00
	Moderate to high	1	1.00
	Moderate Disease Activity	43	43.00
	Low to moderate	2	2.00
	Low Disease Activity	20	20.00
	Remission	4	4.00
	Difficult to describe	2	2.00
	Not sure	5	5.00
Number of areas affected	1	5	5.00
	2	10	10.00
	3	24	24.00
	4 or more	61	61.00
Main areas affected by rheumatoid arthritis	Hands/Wrists/Fingers	93	93.00
	Feet/Ankles/Toes	82	82.00
	Shoulders	53	53.00
	Knees	51	51.00
	Hips	36	36.00
	Spine	34	34.00
	Elbows	31	31.00
	Whole body	5	5.00
	Eyes	2	2.00
	Jaw	2	2.00
	Neck/base skull	3	3.00
	Ribs/Chest	2	2.00
Flare-up frequency	Once a day	18	18.00
	Once a week	26	26.00
	Once a month	24	24.00
	Once every two months	13	13.00
	Once every three months	8	8.00
	Once a year	4	4.00
	Twice a year	7	7.00
Biomarkers (Can report more than one biomarker)	Not sure	47	47.00
	C-Reactive protein	34	34.00
	Rheumatoid factor	33	33.00
	Anti-cyclic citrullinated protein antibodies (ACPA)	9	9.00
	I do not have any markers	4	4.00
	HLA-DRB1	3	3.00
	Coeliac	1	1.00
	CMV	1	1.00

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.3. The **AIMS2-SF Physical scale** is the Arthritis Impact Measure Scale short form physical scale. The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities “All days”, “Most days”, “Some days”, “Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Physical limitations: no days* (AIMS2-SF physical scale score between 0 and 2, N=19, 19.00%), *Physical limitations: few days* (AIMS2-SF physical scale score greater than 2 to 4, N=44, 44.00%), and *Physical limitations: some to most days* (AIMS2-SF physical scale score greater than 4 to 8, N=37, 37.00%).

The **AIMS2-SF Symptoms scale** is the Arthritis Impact Measure Scale short form symptoms scale. The symptoms scale is comprised of 3 questions about frequency of pain and stiffness “All days”, “Most days”, “Some days”, “Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Symptoms: no to few days* (AIMS2-SF symptoms scale score between 0 and 4, N=20, 20.00%), *Symptoms: some days* (AIMS2-SF symptoms scale score greater than 4 to 6, N=27, 27.00%), *Symptoms: most days* (AIMS2-SF symptoms scale score greater than 6 to 8, N=32, 32.00%), and Symptoms: all days (AIMS2-SF symptoms scale score greater than 8 to 10, N=21, 21.00%).

The **AIMS2-SF Affect scale** is the Arthritis Impact Measure Scale short form affect scale. The affect scale is comprised of 5 questions about experience of anxiety, depression and burden “Always”, “Very often”, “Sometimes”, “Almost never” or “Never”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Affect: never to almost never* (AIMS2-SF affect scale score between 0 and 4, N=33, 33.00%), *Affect: sometimes* (AIMS2-SF Affect scale score greater than 4 to 6, N=36, 36.00%), *Affect: very often to always* (AIMS2-SF affect scale score greater than 6 to 10, N=32, 32.00%), and *Symptoms: all days* (AIMS2-SF affect scale score greater than 8 to 10, N=31, 31.00%).

The **AIMS2-SF Social scale** is the Arthritis Impact Measure Scale short form social scale. The social scale is comprised of 4 questions about frequency of social interactions “All days”, “Most days”, “Some days”, “Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants with *Social: all to most days* (AIMS2-SF social scale score between 0 and 4, N=20, 20.00%), *Social; some days* (AIMS2-SF Social scale score greater than 4 to 6, N=36, 36.00%), and *Social; few to no days* (AIMS2-SF affect scale score greater than 6 to 10, N=32, 32.00%), and *Social: all days* (AIMS2-SF affect scale score greater than 8 to 10, N=31, 31.00%).

Comparisons were made by **Flare-up frequency**, between participants that had *Frequent flare-ups* (daily or weekly flare-ups, N=44, 44.00%)) and participants that had *Occasional flare-ups* (monthly flare-ups or less frequently, N=56, 56.00%). Comparisons were made by the **Age** of the participants, those that were *aged 55 or older* (N=31, 31.00%), aged 35 – 54 (N=51, 51.00%) and participants aged 18 – 34 (N=18, 18.00%).

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from DoctorConnect (doctorconnect.gov.au), those living in a major city, *metropolitan* (N=56, 56.00%) were compared to those living in regional/rural areas, *regional or remote* (N=44, 44.00%). Comparisons were made by **education** status, between those with a university qualification, *University* (N= 66, 66.00%), and those with trade or high school qualifications, *trade or high school* (N=33, 33.00%); and by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *High SEIFA* (N=50, 50.00%) compared to those with a mid to low SEIFA score of 1-6, *Mid-low SEIFA* (N=50, 50.00%).

Table 2.4: Subgroups

Formal name	Formal subgroup	N = 100	Percent
AIMS2-SF Physical scale	*Physical limitations: no days*	19	19.00
	Physical limitations: few days	44	44.00
	Physical limitations: some to most days	37	37.00
AIMS2-SF Symptoms scale	*Symptoms : no to few days*	20	20.00
	Symptoms: some days	27	27.00
	Symptoms: most days	32	32.00
	Symptoms: all days	21	21.00
AIMS2-SF Affect scale	*Affect: never to almost never*	33	33.00
	Affect : sometimes	36	36.00
	Affect: very often to always	31	31.00
AIMS2-SF Social scale	*Social : all to most days*	20	20.00
	Social: some days	36	36.00
	Social: no to few days	44	44.00
Flare- up frequency	*Occasional flare-ups*	56	56.00
	Frequent flare-ups	44	44.00
Age	*Aged 55 or older*	31	31.00
	Aged 35 - 54	51	51.00
	Aged 18 - 34	18	18.00
Location	*Metropolitan*	56	56.00
	Regional or remote	44	44.00
Education	*Trade or high school*	33	33.00
	University	67	67.00
Socio-Economic Indexes for Areas	*High SEIFA*	50	50.00
	Mid to Low SEIFA	50	50.00

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.5, where the scale has a normal distribution mean and SD are used as a central measure, otherwise the median and IQR are used.

The overall scores for the cohort were in the second highest quintile for **"SF36 Emotional well-being"** (Mean = 63.04, SD = 20.40) indicating good emotional well-being. The overall scores for **"SF36 Physical functioning"** (Mean = 48.90, SD = 26.29), **"SF36 Social functioning"** (Mean = 49.88, SD =25.41**), "SF36 Pain"** (Mean = 41.25, SD = 21.76) and **"SF36 Health change"** (Median = 50.00, IQR = 50.00) were in the middle of the scale, indicating moderate health or function.

The overall scores for **"SF36 Role functioning/emotional"** (Median = 33.33, IQR = 100.00), **"SF36 Energy/Fatigue"** (Mean = 27.35, SD = 18.37) and **"SF36 General health"** (Mean = 33.05, SD = 20.44) were in the second lowest quintile, indicating poor health or function. The overall score for the **"SF36 Role functioning/physical"** was in the lowest quintile (Median = 0.00, IQR = 25.00) indicating very poor health limitations due to physical function.

Comparisons of SF36 have been made based on **AIMS2-SF Physical scale** (Figures 2.1 to 2.9, Tables 2.6 to 2.12), **AIMS2-SF Symptoms scale** (Figures 2.10 to 2.18, Tables 2.13 to 2.19), **AIMS2-SF Affect scale** (Figures 2.19 to 2.27, Tables 2.20 to 2.26), **AIMS2-SF Social scale,** (Figures 2.28 to 2.36, Tables 2.27 to 2.32), **Flare-up frequency** (Figures 2.37 to 2.45, (Tables 2.33 to 2.34), **Age** (Figures 2.46 to 2.54, Tables 2.35 to 2.37), **Location** (Figures 2.55 to 2.63, Table 2.38), **Education** (Figures 2.64 to 2.72, Table 2.39), and **SEIFA** (Figures 2.73 to 2.81, Table 2.40).

Table 2.5: SF36 summary statistics

SF36 scale	Count N=100	Percent	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning*	100	100.00	48.90	26.29	47.50	37.50	0 to 100	3
Role functioning/physical	100	100.00	21.25	34.15	0.00	25.00	0 to 100	1
Role functioning/emotional	100	100.00	46.33	45.91	33.33	100.00	0 to 100	2
Energy/Fatigue*	100	100.00	27.35	18.37	25.00	30.00	0 to 100	2
Emotional well-being*	100	100.00	63.04	20.40	64.00	24.00	0 to 100	4
Social functioning*	100	100.00	49.88	25.41	50.00	50.00	0 to 100	3
Pain*	100	100.00	41.25	21.76	40.00	33.13	0 to 100	3
General health*	100	100.00	33.05	20.44	30.00	26.25	0 to 100	2
Health change	100	100.00	49.75	28.98	50.00	50.00	0 to 100	3

Comparisons of SF36 scales by AIMS2-SF Physical scale.

The **AIMS2-SF Physical scale** is the Arthritis Impact Measure Scale short form physical scale. The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities: "All days", "Most days", "Some days", "Few days" or "No days". A score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Physical limitations: no days* (AIMS2-SF physical scale score between 0 and 2, N=19, 19.00%), *Physical limitations: few days* (AIMS2-SF physical scale score greater than 2 to 4, N=44, 44.00%), and *Physical limitations: some to most days* (AIMS2-SF physical scale score greater than 4 to 8, N=37, 37.00%).

Boxplots of each SF36 scale by **AIMS2-SF Physical scale** are displayed in Figures 2.1-2.9, summary statistics are displayed in Table 2.6.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.7). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.8). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.9). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.10). When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances (Tables 2.11 to 2.12).

A one way ANOVA test indicated a statistically significant difference in the **"SF36 Social functioning"** scale between groups, F(2, 97) = 13.37 ,p <0.0001 (Table 2.7). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Physical limitations: no days* (mean = 67.11, SD = 20.92) was significantly higher than participants that scored *Physical limitations: some to most days* (mean = 35.81, SD = 21.28, p<0.0001); and that participants that had a mean score for *Physical limitations: few days* (mean = 54.26, SD = 24.55) was significantly higher than participants that scored *Physical limitations: some to most days* (mean = 35.81, SD = 21.28, p=0.0012).

A Kruskal-Wallis test indicated a statistically significant difference in the **"SF36 Physical functioning"** scale between groups, $\chi^2(2) = 18.05$, p = 0.0001 (Table 2.9). Wilcoxon rank sum tests between groups indicated that those that scored *Physical limitations: no days* (median = 80.00, IQR = 40.00) scored significantly higher than those that scored *Physical limitations: few days* (median = 50.00, IQR = 25.00, p=0.0068) and *Physical limitations: some to most days* (median = 30.00, IQR = 35.00, p=0.0006); participants that scored *Physical limitations: few days* (median = 50.00, IQR = 25.00) scored significantly higher than those that scored *Physical limitations: some to most days* (median = 30.00, IQR = 35.00, p=0.0110).

A Kruskal-Wallis test indicated a statistically significant difference in the **"SF36 Energy/fatigue"** scale between groups, $\chi^2(2) = 7.23$, p = 0.0210 (Table 2.9). Wilcoxon rank sum tests between groups indicated that those that scored *Physical limitations: no days* (median = 35.00, IQR = 30.00) scored significantly higher than those that scored *Physical limitations: some to most days* (median = 20.00, IQR = 25.00, p=0.0200).

A Kruskal-Wallis test indicated a statistically significant difference in the **"SF36 Pain"** scale between groups, $\chi^2(2) = 22.83$, p < 0.0001 (Table 2.9). Wilcoxon rank sum tests between groups indicated that participants that scored *Physical limitations: no days* (median = 57.5, IQR = 33.75) scored significantly higher than those that scored *Physical limitations: few days* (median = 45.00, IQR = 15.00, p=0.0038), and significantly higher than participants that scored *Physical limitations: some to most days* (median = 22.50, IQR = 12.50, p<0.0001). Participants that scored *Physical limitations: few days* (median = 45.00, IQR = 15.00) scored significantly higher than those that scored *Physical limitations: some to most days* (median = 22.50, IQR = 12.50, p=0.0039).

A Welch one-way test indicated indicated a statistically significant difference in the **"SF36 Role functioning/physical"** scale between groups F(2, 39.79) = 9.65, p<0.0001 (Table 2.11). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants that scored *Physical limitations: no days* (mean = 42.11, SD = 44.92) scored significantly higher than those that scored *Physical limitations: some to most days* (mean = 6.08, SD = 16.04, p=0.0043), and participants that scored *Physical limitations: few* (mean = 25.00, SD = 39.94) scored significantly higher than those that scored *Physical limitations: some to most days* (mean = 6.08, SD = 16.04, p=0.0043).

The **"SF36 Physical functioning"** mean scores for participants that scored *Physical limitations: no days* were significantly better than those that scored *Physical limitations: few days, and Physical limitations: some to most days;* and the scores for participants that scored *Physical limitations: few days* were significantly better than those that scored *Physical limitations: some to most days.* These scores correspond to physical functioning that is in the good range for participants that scored *Physical limitations: no days,* moderate physical functioning for participants that scored *Physical limitations: few days,* and poor physical functioning for participants that scored *Physical limitations: some to most days.*

The **"SF36 Role functioning/physical"** mean scores for participants that scored *Physical limitations: no days* were significantly better than those that scored *Physical limitations: some to most days,* and the scores for participants that scored *Physical limitations: few days* were significantly better than those that scored *Physical limitations: some to most days.* These scores correspond to role limitations due to physical functioning that is in the moderate range for participants that scored *Physical limitations: no days,* and poor role limitations due to physical functioning for participants that scored *Physical limitations: few days,* and very poor role limitations due to physical functioning for participants *that scored Physical limitations: some to most days.*

Key differences

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants that scored *Physical limitations: no days* felt tired most of the time and have energy a little of the time of the time compared to those that scored *Physical limitations: some to most days* who felt tired all of the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. Social activities are slightly limited for participants that scored *Physical limitations: no days,* and moderately limited for participants that scored *Physical limitations: few days* compared to limited quite a bit for those that scored *Physical limitations: some to most days.*

"SF36 Pain": measures the amount of pain, and how pain interferes with work and other activities. Participants that scored *Physical limitations: no days* had moderate pain, compared to those that scored *Physical limitations: few days,* who had a significantly lower score but still in the moderate pain range, *and Physical limitations: some to most days* who had severe pain. Participants that scored *Physical limitations: few days,* had a significantly higher score than participants that scored *Physical limitations: some to most days.*

Table 2.6: SF36 by AIMS2-SF Physical scale summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	*Physical limitations: no days*	19	19.00	69.47	27.58	80.00	40.00
	Physical limitations: few days	44	44.00	50.00	20.52	50.00	25.00
	Physical limitations: some to most days	37	37.00	37.03	25.45	30.00	35.00
Role functioning/physical	*Physical limitations: no days*	19	19.00	42.11	44.92	25.00	100.00
	Physical limitations: few days	44	44.00	25.00	34.94	0.00	50.00
	Physical limitations: some to most days	37	37.00	6.08	16.04	0.00	0.00
Role functioning/emotional	*Physical limitations: no days*	19	19.00	49.12	47.62	33.33	100.00
	Physical limitations: few days	44	44.00	52.27	46.25	66.67	100.00
	Physical limitations: some to most days	37	37.00	37.84	44.56	0.00	100.00
Energy/Fatigue	*Physical limitations: no days*	19	19.00	37.11	20.37	35.00	30.00
	Physical limitations: few days	44	44.00	27.73	16.86	25.00	25.00
	Physical limitations: some to most days	37	37.00	21.89	17.33	20.00	25.00
Emotional well-being	*Physical limitations: no days*	19	19.00	69.26	15.26	72.00	20.00
	Physical limitations: few days	44	44.00	64.91	19.38	68.00	20.00
	Physical limitations: some to most days	37	37.00	57.62	22.89	56.00	32.00
Social functioning	*Physical limitations: no days*	19	19.00	67.11	20.92	62.50	25.00
	Physical limitations: few days	44	44.00	54.26	24.55	50.00	37.50
	Physical limitations: some to most days	37	37.00	35.81	21.28	37.50	25.00
Pain	*Physical limitations: no days*	19	19.00	61.32	23.65	57.50	33.75
	Physical limitations: few days	44	44.00	41.36	17.58	45.00	15.00
	Physical limitations: some to most days	37	37.00	30.81	18.13	22.50	12.50
General health	*Physical limitations: no days*	19	19.00	44.74	24.69	45.00	37.50
	Physical limitations: few days	44	44.00	30.68	16.90	30.00	25.00
	Physical limitations: some to most days	37	37.00	29.86	20.33	25.00	20.00
Health change	*Physical limitations: no days*	19	19.00	56.58	26.14	50.00	37.50
	Physical limitations: few days	44	44.00	53.41	29.33	50.00	50.00
	Physical limitations: some to most days	37	37.00	41.89	28.90	50.00	50.00

Table 2.7: SF36 by AIMS2-SF Physical scale ANOVA table

SF36 Scale		Sum of squares	DF	Mean Square	F	p
Social functioning	Between groups	13806	2	6903	13.37	<0.0001*
	Within groups	50099	97	516		
	Total	63905	99			

*Statistically significant at P<0.05

Table 2.8: SF36 by AIMS2-SF Physical scale post hoc Tukey HSD test

SF36 Scale	AIMS2-SF Physical scale	Difference	Lower	Upper	P adjusted
Social functioning	*Few days - No days*	-12.84	-27.69	2.01	0.1040
	Some to most days -No days	-31.29	-46.56	-16.03	<0.0001*
	Some to most days – Few days	-18.45	-30.52	-6.38	0.0012*

*Statistically significant at P<0.05

Table 2.9: SF36 by AIMS2-SF Physical scale Kruskal-Wallis test

SF36 Scale	X^2	dF	p
Physical functioning	18.05	2	0.0001*
Role functioning/emotional	2.36	2	0.3078
Energy/Fatigue	7.73	2	0.0210*
Emotional well-being	4.22	2	0.1210
Pain	22.83	2	<0.0001*
General health	5.95	2	0.0511
Health Change	4.13	2	0.1267

*Statistically significant at P<0.05

Table 2.10: SF36 by AIMS2-SF Physical scale post hoc pairwise Wilcoxon rank sum test

SF36 Scale	Group	*No days*	*Few days*
Physical functioning	*Few days*	0.0068*	
	Some to most days	0.0006*	0.0110*
Energy/fatigue	*Few days*	0.1200	
	Some to most days	0.0200*	0.1200
Pain	*Few days*	0.0038*	
	Some to most days	<0.0001*	0.0039*

*Statistically significant at P<0.05

Table 2.11: SF36 by AIMS2-SF Physical scale Welch one-way test

SF36 Scale	F	dF1	dF2	p
Role functioning/physical	9.65	2.00	39.79	<0.0001*

*Statistically significant at P<0.05

Table 2.12: SF36 by AIMS2-SF Physical scale post hoc pairwise t-test

		No days	Few days
Role functioning/physical	Few days	0.1506	
	Some to most days	0.0043*	0.0043*

*Statistically significant at P<0.05

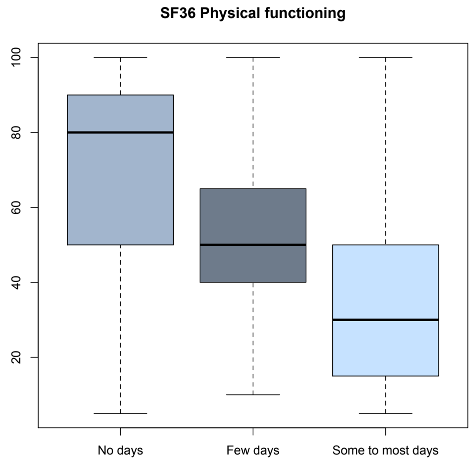

Figure 2.1: Boxplot of SF36 Physical functioning by AIMS2-SF Physical Scale

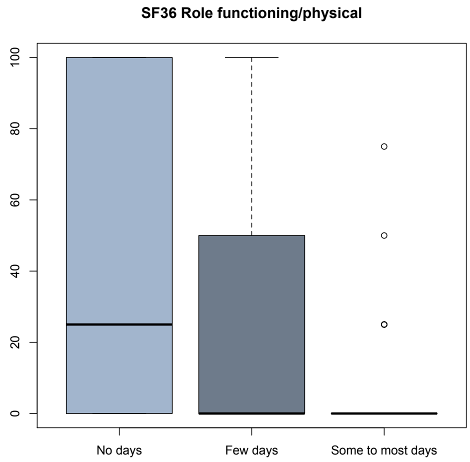

Figure 2.2: Boxplot of SF36 Role functioning/physical by AIMS2-SF Physical Scale

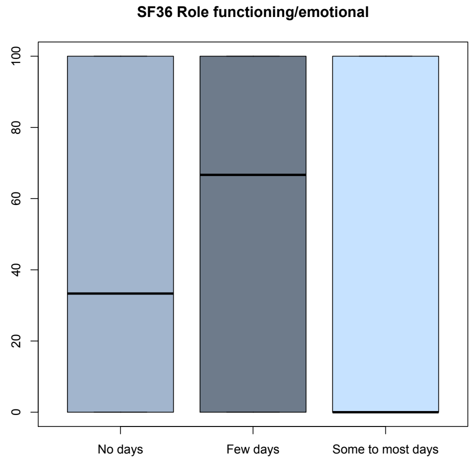

Figure 2.3: Boxplot of SF36 Role functioning/emotional by AIMS2-SF Physical Scale

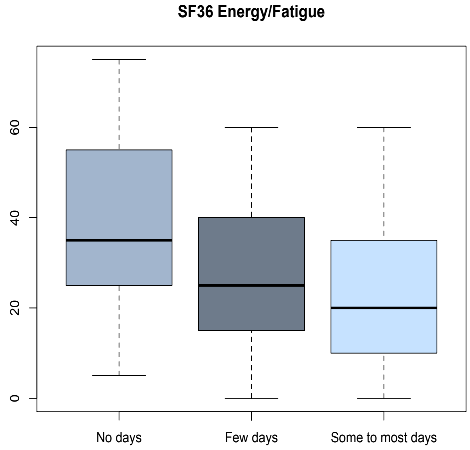

Figure 2.4: Boxplot of SF36 Energy/fatigue by AIMS2-SF Physical Scale

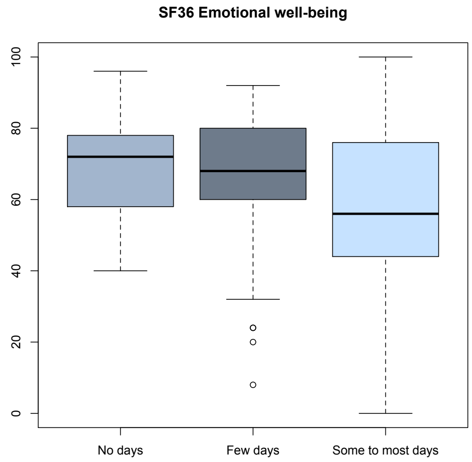

Figure 2.5: Boxplot of SF36 Emotional well-being by AIMS2-SF Physical Scale

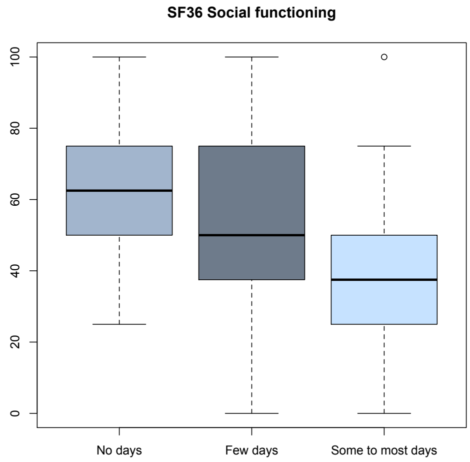

Figure 2.6: Boxplot of SF36 Social functioning by AIMS2-SF Physical Scale

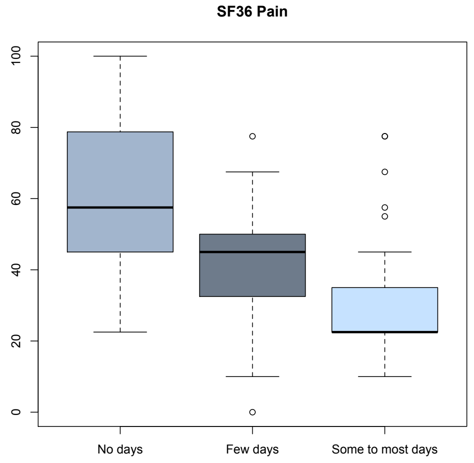

Figure 2.7: Boxplot of SF36 Pain by AIMS2-SF Physical Scale

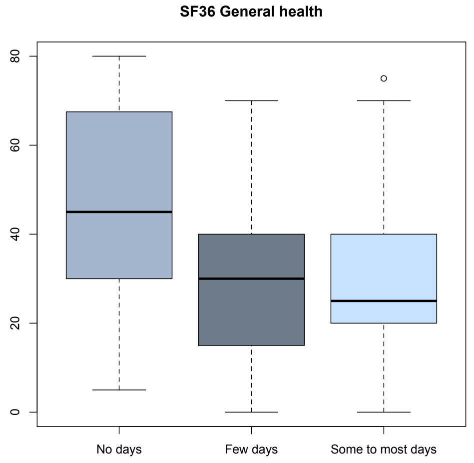

Figure 2.8: Boxplot of SF36 General health by AIMS2-SF Physical Scale

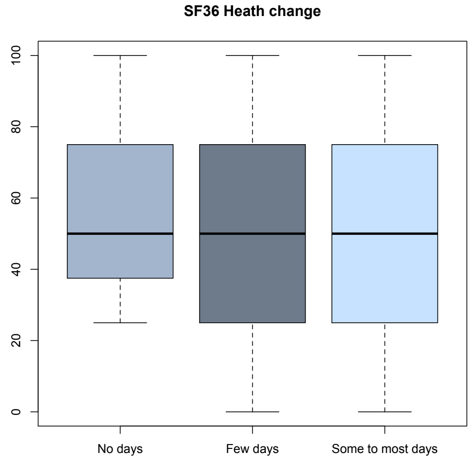

Figure 2.9: Boxplot of SF36 Health change by AIMS2-SF Physical Scale

Comparisons of SF36 scales by AIMS2-SF Symptoms scale

The **AIMS2-SF Symptoms scale** is the Arthritis Impact Measure Scale short form symptoms scale. The symptoms scale is comprised of 3 questions about frequency of pain and stiffness: “All days”, “Most days”, “Some days”, “Few days” or “No days”. A score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Symptoms: no to few days* (AIMS2-SF symptoms scale score between 0 and 4, N=20, 20.00%), *Symptoms: some days* (AIMS2-SF symptoms scale score greater than 4 to 6, N=27, 27.00%), *Symptoms: most days* (AIMS2-SF symptoms scale score greater than 6 to 8, N=32, 32.00%), and Symptoms: all days (AIMS2-SF symptoms scale score greater than 8 to 10, N=21, 21.00%).

Boxplots of each SF36 scale by **AIMS2-SF Symptoms scale** are displayed in Figures 2.10 - 2.18, summary statistics are displayed in Table 2.13

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.14). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.15). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.16). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.17). When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances (Tables 2.18 to 19).

A one way ANOVA test indicated a statistically significant difference in the **“SF36 Physical functioning”** scale between groups, F(3, 96) = 20.26 ,p <0.0001 (Table 2.14). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Symptoms: no to few days* (mean =78.50, SD = 15.31) was significantly higher than all other groups; *Symptoms: some days* (mean = 51.48, SD = 20.93, p=0.0002), *Symptoms: most days* (mean = 39.06, SD = 21.27, p< 0.0001), *Symptoms: all days* (mean = 32.38, SD = 24.53, p<0.0001): and the mean score for those that scored *Symptoms: some days* (mean = 51.48, SD = 20.93) was significantly higher than *Symptoms: all days* (mean = 32.38, SD = 24.53, p<0.0118).

A one way ANOVA test indicated a statistically significant difference in the **“SF36 Energy/fatigue”** scale between groups, F(3, 96) = 4.97 ,p = 0.0030 (Table 2.14). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Symptoms: no to few days* (mean =37.75, SD = 18.95) was significantly higher than participants that scored *Symptoms: most days* (mean = 22.81, SD = 14.97, p= 0.0169) and *Symptoms: all days* (mean = 19.52, SD = 18.23, p = 0.0061).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Social functioning”** scale between groups, $\chi^2(3)$ = 19.33, p = 0.0002 (Table 2.16). Wilcoxon rank sum tests between groups indicated that those that scored *Symptoms: no to few days* (median = 62.50, IQR = 28.13) scored significantly higher than those that scored *Symptoms: most days* (median = 37.50, IQR = 37.40, p=0.0021) and *Symptoms: all days* (median = 37.50, IQR = 37.40, p=0.0021). Participants that scored *Symptoms: some days* (median =62.50, IQR = 37.50) scored significantly higher than those that scored *Symptoms: most days* (median = 37.50, IQR = 37.50, p=0.0139) and *Symptoms: all days* (median = 37.50, IQR = 37.50, p=0.0139).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Pain”** scale between groups, $\chi^2(2)$ = 25.23, p < 0.0001 (Table 2.16). Wilcoxon rank sum tests between groups indicated that participants that scored *Symptoms: no to few days* (median = 57.50, IQR = 32.50) scored significantly higher than all other groups; *Symptoms: some days* (median = 45.00, IQR = 30.00, p = 0.0237), *Symptoms: most days* (median = 32.50, IQR = 22.50, p=0.0001), and *Symptoms: all days* (median = 22.50, IQR = 12.50, p=0.0001). Participants that scored *Symptoms: some days* (median = 45.00, IQR = 30.00) scored significantly higher than those that scored *Symptoms: all days* (median = 22.50, IQR = 12.50, p=0.0123).

A Welch one-way test indicated indicated a statistically significant difference in the **“SF36 Role functioning/physical”** scale between groups F(3, 48.74) = 5.08, p=0.0038 (Table 2.18). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants that scored *Symptoms: no to few days* (mean = 47.50, SD = 42.07) scored significantly higher than those that scored *Symptoms: most days* (mean = 10.94, SD = 26.13, p=0.0048), and *Symptoms: all days* (mean = 9.52, SD = 20.12, p= 0.048)

Key differences

"SF36 Physical functioning": measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities were slightly limited for participants that scored *Symptoms: no to few days* compared to moderately limited for those that scored *Symptoms: some days,* and limited quite a lot for participants that scored *Symptoms: most days,* and *Symptoms: all days.* Participants that scored *Symptoms: some days* score was significantly higher than those that scored *Symptoms: all days.*

"SF36 Role functioning/physical": measures how physical health interferes with work or other activities. Physical health moderately interfered with work or other activities for participants that scored *Symptoms: no to few days* compared to extremely interfered with work or other activities for than those that scored *Symptoms: most days* and *Symptoms: all days.*

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants with that scored *Symptoms: no to few days* felt tired most of the time and had energy a little of the time, the average score was higher compared to participants that scored *Symptoms: most days* that had energy/fatigue levels in the same range, and scored significantly higher compared to participants that scored *Symptoms: all days* who felt tired all of the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. Social activities are slightly limited for participants that scored *Symptoms: no to few days* and *Symptoms: some days* compared to quite a bit limited for participants with *Poorly controlled asthma.*

"SF36 Pain": measures the amount of pain, and how pain interferes with work and other activities.
Participants that scored *Symptoms: no days* had moderate pain and scored significantly higher than all the other groups. Participants that scored *Symptoms: some days* had moderate pain and participants that scored *Symptoms: all days* had severe pain. The average scores were significantly higher for *Symptoms: some days* compared to *Symptoms: all days*.

Table 2.13 SF36 by AIMS2-SF Symptoms scale summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	*Symptoms (no to few days)*	20.00	20.00	78.50	15.31	80.00	26.25
	Symptoms (some days)	27.00	27.00	51.48	20.93	50.00	27.50
	Symptoms (most days)	32.00	32.00	39.06	21.27	40.00	30.00
	Symptoms (all days)	21.00	21.00	32.38	24.53	25.00	35.00
Role functioning/physical	*Symptoms (no to few days)*	20.00	20.00	47.50	42.07	37.50	100.00
	Symptoms (some days)	27.00	27.00	23.15	35.30	0.00	37.50
	Symptoms (most days)	32.00	32.00	10.94	26.13	0.00	0.00
	Symptoms (all days)	21.00	21.00	9.52	20.12	0.00	0.00
Role functioning/emotional	*Symptoms (no to few days)*	20.00	20.00	55.00	48.70	83.33	100.00
	Symptoms (some days)	27.00	27.00	50.62	47.48	33.33	100.00
	Symptoms (most days)	32.00	32.00	43.75	44.35	50.00	100.00
	Symptoms (all days)	21.00	21.00	36.51	44.60	0.00	100.00
Energy/Fatigue*	*Symptoms (no to few days)*	20.00	20.00	37.75	18.95	37.50	26.25
	Symptoms (some days)	27.00	27.00	31.11	18.10	30.00	27.50
	Symptoms (most days)	32.00	32.00	22.81	14.97	22.50	25.00
	Symptoms (all days)	21.00	21.00	19.52	18.23	20.00	20.00
Emotional well-being	*Symptoms (no to few days)*	20.00	20.00	67.60	13.16	62.00	17.00
	Symptoms (some days)	27.00	27.00	63.85	23.10	64.00	26.00
	Symptoms (most days)	32.00	32.00	61.50	19.67	66.00	25.00
	Symptoms (all days)	21.00	21.00	60.00	23.80	64.00	36.00
Social functioning	*Symptoms (no to few days)*	20.00	20.00	66.25	19.91	62.50	28.13
	Symptoms (some days)	27.00	27.00	57.87	23.29	62.50	37.50
	Symptoms (most days)	32.00	32.00	40.23	25.35	37.50	37.50
	Symptoms (all days)	21.00	21.00	38.69	21.97	37.50	37.50
Pain	*Symptoms (no to few days)*	20.00	20.00	60.50	21.14	57.50	32.50
	Symptoms (some days)	27.00	27.00	44.91	20.36	45.00	30.00
	Symptoms (most days)	32.00	32.00	34.38	16.10	32.50	22.50
	Symptoms (all days)	21.00	21.00	28.69	18.67	22.50	12.50
General health	*Symptoms (no to few days)*	20.00	20.00	43.75	22.29	45.00	37.50
	Symptoms (some days)	27.00	27.00	34.81	20.36	30.00	32.50
	Symptoms (most days)	32.00	32.00	26.88	18.17	25.00	20.00
	Symptoms (all days)	21.00	21.00	30.00	18.84	25.00	20.00
Health change	*Symptoms (no to few days)*	20.00	20.00	51.25	26.25	50.00	31.25
	Symptoms (some days)	27.00	27.00	58.33	27.74	50.00	37.50
	Symptoms (most days)	32.00	32.00	49.22	28.74	50.00	50.00
	Symptoms (all days)	21.00	21.00	38.10	31.24	25.00	25.00

Table 2.14: SF36 by AIMS2-SF Symptoms scale ANOVA table

SF36 Scale		Sum of squares	dF	Mean Square	F	p
Physical functioning	Between groups	26530	3	8843.00	20.26	<0.0001*
	Within groups	42899	96	436.00		
	Total	69429	99			
Energy/fatigue	Between groups	4490	3	1496.70	4.97	0.0030*
	Within groups	28933	96	301.40		
	Total	33423	99			
Health change	Between groups	4896	3	1631.90	2.003	0.1190
	Within groups	78223	96	814.80		
	Total	83119	99			

*Statistically significant at P<0.05

Table 2.15: SF36 by AIMS2-SF Symptoms scale post hoc Tukey HSD test

SF36 Scale	AIMS2-SF Symptoms	Difference	Lower	Upper	P adjusted
Physical functioning	*Some days - No to few days*	-27.02	-43.13	-10.90	0.0002*
	Most days - No to few days	-39.44	-55.01	-23.87	<0.0001*
	All days - No to few days	-46.12	-63.19	-29.05	<0.0001*
	Most days-Some days	-12.42	-26.69	1.85	0.1112
	All days - Some days	-19.10	-34.99	-3.21	0.0118*
	All days – Most days	-6.68	-22.02	8.66	0.6665
Energy/fatigue	*Some days - No to few days*	-6.64	-20.03	6.75	0.5676
	Most days - No to few days	-14.94	-27.88	-2.00	0.0169*
	All days - No to few days	-18.23	-32.41	-4.04	0.0061*
	Most days-Some days	-8.30	-20.16	3.56	0.2661
	All days - Some days	-11.59	-24.79	1.62	0.1066
	All days – Most days	-3.29	-16.04	9.46	0.9065

*Statistically significant at P<0.05

Table 2.16: SF36 by AIMS2-SF Symptoms scale Kruskal-Wallis test

SF36 Scale	X^2	df	p
Role functioning/emotional	2.07	3	0.5582
Emotional well-being	0.89	3	0.8267
Social functioning	19.33	3	0.0002*
Pain	25.23	3	<0.0001*
General health	7.73	3	0.0520

*Statistically significant at P<0.05

Table 2.17: SF36 by AIMS2-SF Symptoms scale post hoc pairwise Wilcoxon rank sum test

SF36 Scale	AIMS2-SF Symptoms	*No to few days*	*Some days*	*Most days*
Social functioning	*Some days*	0.2743		
	Most days	0.0021*	0.0139*	
	All days	0.0021*	0.0139*	0.8752
Pain	*Some days*	0.0237*		
	Most days	0.0001*	0.0798	
	All days	0.0001*	0.0123*	0.1801

Table 2.18: SF36 by AIMS2-SF Symptoms scale Welch one-way test

SF36 Scale	F	dF1	dF2	p
Role functioning/physical	5.08	3.00	48.74	0.0038*

*Statistically significant at P<0.05

Table 2.19: SF36 by AIMS2-SF Symptoms scale post hoc pairwise t-test

SF36 scale	AIMS2-SF Symptoms	No to few days	Some days	Most days
Role functioning/physical	*Some days*	0.0856		
	Most days	0.0048*	0.1727	
	All days	0.0048*	0.1492	0.8254

*Statistically significant at P<0.05

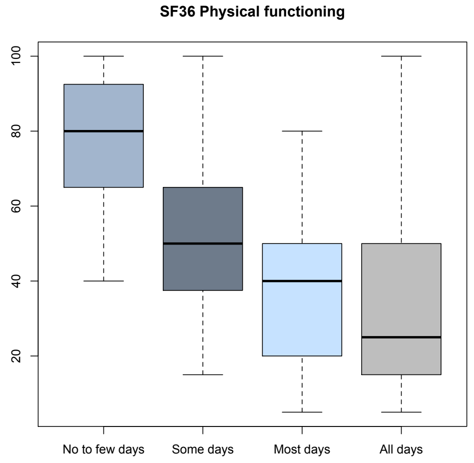

Figure 2.10: Boxplot of SF36 Physical functioning by AIMS2-SF Symptoms Scale

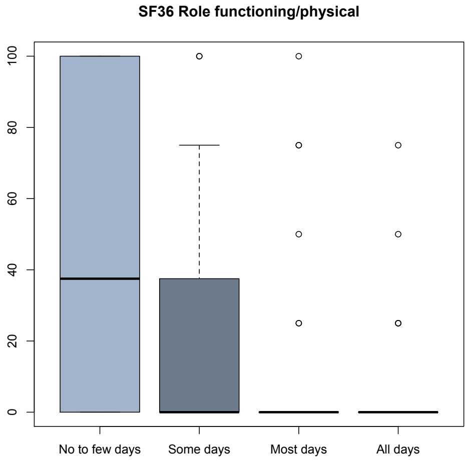

Figure 2.11: Boxplot of SF36 Role functioning/physical by AIMS2-SF Symptoms Scale

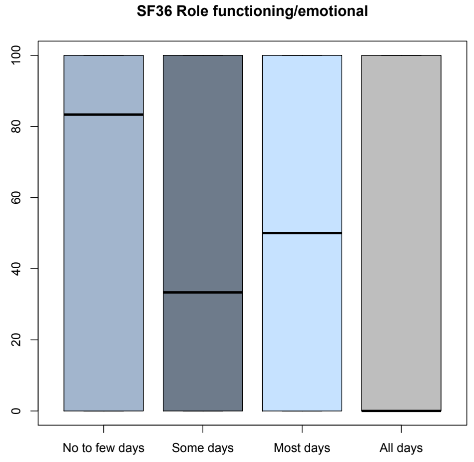

Figure 2.12: Boxplot of SF36 Role functioning/ emotional by AIMS2-SF Symptoms Scale

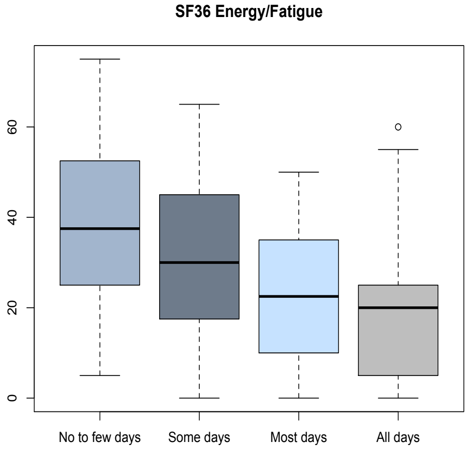

Figure 2.13: Boxplot of SF36 Energy/fatigue by AIMS2-SF Symptoms Scale

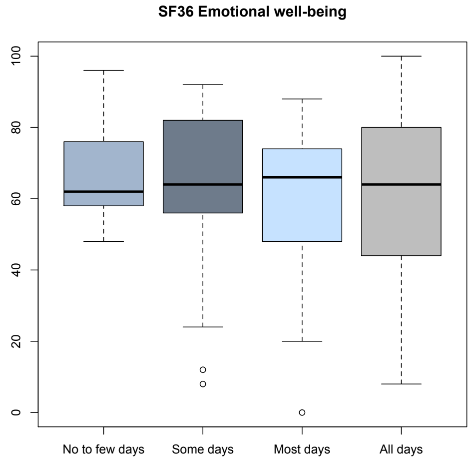

Figure 2.14: Boxplot of SF36 Emotional well-being by AIMS2-SF Symptoms Scale

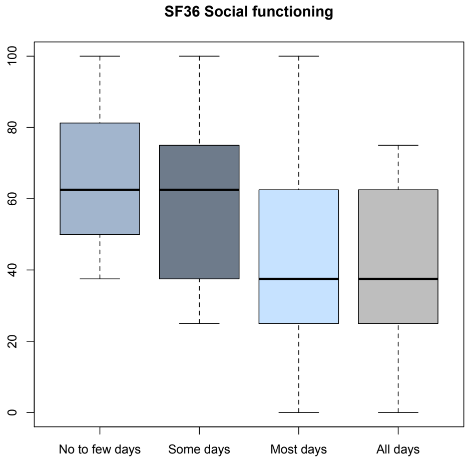

Figure 2.15: Boxplot of SF36 Social functioning by AIMS2-SF Symptoms Scale

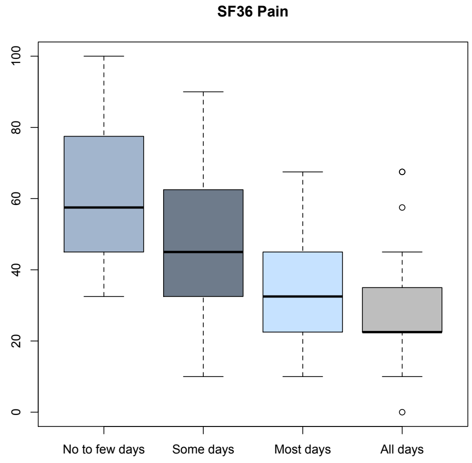

Figure 2.16: Boxplot of SF36 Pain by AIMS2-SF Symptoms Scale

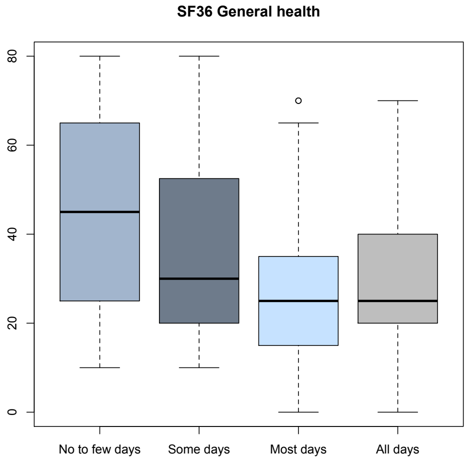

Figure 2.17: Boxplot of SF36 General health by AIMS2-SFSymptoms Scale

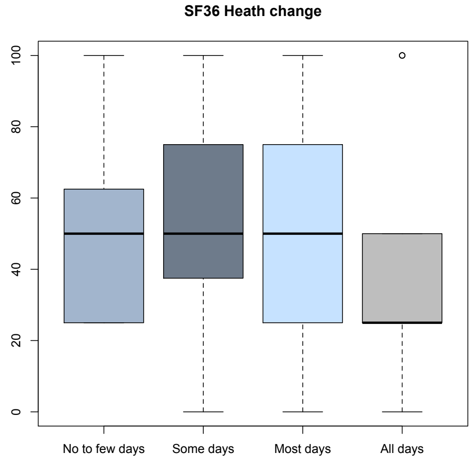

Figure 2.18: Boxplot of SF36 Health change by AIMS2-SF Symptoms Scale

Comparisons of SF36 scales by AIMS2-SF Affect scale

The **AIMS2-SF Affect scale** is the Arthritis Impact Measure Scale short form affect scale. The affect scale is comprised of 5 questions about experience of anxiety, depression and burden: “Always”, “Very often”, “Sometimes”, “Almost never” or “Never”. A score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Affect: never to almost never* (AIMS2-SF affect scale score between 0 and 4, N=33, 33.00%), *Affect: sometimes* (AIMS2-SF Affect scale score greater than 4 to 6, N=36, 36.00%), *Affect: very often to always* (AIMS2-SF affect scale score greater than 6 to 10, N=32, 32.00%), and Symptoms: all days (AIMS2-SF affect scale score greater than 8 to 10, N=31, 31.00%).

Boxplots of each SF36 scale by **AIMS2-SF Affect scale** are displayed in Figures 2.19-2.27, summary statistics are displayed in Table 2.20

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.21). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.22). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.23). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.24). When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances (Tables 2.25 to 2.26).

A one way ANOVA test indicated a statistically significant difference in the **“SF36 Energy/fatigue”** scale between groups, F(2, 97) = 8.95, p = 0.0003 (Table 2.21). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never to almost* (mean = 35.67, SD = 19.45) was significantly higher than participants that scored *Affect: very often to always* (mean = 17.74, SD = 13.77, p=0.0002). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: sometimes* (mean = 27.92, SD = 17.25) was significantly higher than participants that scored *Affect: very often to always* (mean = 17.74, SD = 13.77, p=0.0438).

A one way ANOVA test indicated a statistically significant difference in the **“SF36 Social functioning”** scale between groups, F(2, 97) = 7.85, p = 0.0007 (Table 2.21). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never almost never* (mean = 62.88, SD = 26.24) was significantly higher than participants that scored *Affect: sometimes* (mean = 46.18, SD = 21.30, p = 0.0124), and *Affect: very often to always* (mean = 40.32, SD = 23.87 p = 0.0008).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Role functioning/emotional”** scale between groups, $\chi^2(2) = 11.58$, p = 0.0031 (Table 2.23). Wilcoxon rank sum tests between groups indicated that those that scored *Affect: never to almost never* (median = 100.00, IQR = 66.67) scored significantly higher than those that scored *Affect: sometimes* (median = 0.00, IQR = 100.00, p=0.0238) and *Affect: very often to always* (median = 0.00, IQR = 66.67, p=0.0029).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Emotional well-being”** scale between groups, $\chi^2(2) = 26.88$, p < 0.0001 (Table 2.23). Wilcoxon rank sum tests between groups indicated that those that scored *Affect: never to almost never* (median = 76.00, IQR = 16.00) scored significantly higher than those that scored *Affect: sometimes* (median = 64.00, IQR = 17.00, p=0.0008) and *Affect: very often to always* (median = 52.00, IQR = 22.00, p<0.0001). Participants that scored *Affect: Affect: sometimes* (median = 64.00, IQR = 17.00) scored significantly higher compared to *Affect: very often to always* (median = 52.00, IQR = 22.00, p<0.0177).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Pain”** scale between groups, $\chi^2(2) = 10.52$, p = 0.0052 (Table 2.23). Wilcoxon rank sum tests between groups indicated that those that scored *Affect: never to almost never* (median = 45.00, IQR = 35.00) scored significantly higher than those that scored *Affect: sometimes* (median = 32.50, IQR = 22.50, p=0.0235) and *Affect: very often to always* (median =22.50, IQR = 22.50, p=0.0064).

A Welch one-way test indicated indicated a statistically significant difference in the **“SF36 Role functioning/physical”** scale between groups F(2, 61.02) = 3.88, p = 0.0259 (Table 2.25). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants that scored *Affect: never to almost never* (mean = 35.61, SD = 41.00) scored significantly higher than those that scored *Affect: sometimes* (mean = 12.50, SD = 25.70, p=0.0230), and *Affect: very often to always* (mean = 16.31, SD = 30.63, p=0.0520).

Key differences

"SF36 Role functioning/physical": measures how physical health interferes with work or other activities. Physical health interfered quite a bit with work or other activities for participants that scored *Affect: never to almost never* compared to extremely interfered with work or other activities for those that scored *Affect: sometimes* and *Affect: very often to always.*

"SF36 Role functioning/emotional" measures how much emotional problems interfered with work or other activities. Emotional problems interfered quite a bit with work or other activities for participants that scored *Affect: never to almost never* compared to extremely interfered with work or other activities for those that scored *Affect: sometimes* and *Affect: very often to always.*

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants with that scored *Affect: never to almost never* and *Affect: sometimes* felt tired most of the time and had energy a little of the time, compared to participants that scored *Affect: very often to always* who felt tired all of the time.

"SF36 Emotional well-being" measures how a person feels, for example happy, calm, depressed or anxious. Participants that scored *Affect: never to almost never* were significantly higher than those that scored *Affect: sometimes* and *Affect: very often to always:* and *Affect: sometimes* was significantly higher than *Affect: very often to always.* Participants who scored *Affect: never to almost never* and *Affect: sometimes* felt happy and calm most of the time, and anxious and depressed a little of the time, and participants that scored *Affect: very often to always* felt happy and calm some of the time, and depressed and anxious some of the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. Social activities are slightly limited for participants that scored *Affect: never to almost never* compared to moderately limited for participants that scored *Affect: sometimes* and *Affect: very often to always.*

"SF36 Pain": measures the amount of pain, and how pain interferes with work and other activities. Participants that scored *Affect: never to almost never* had moderate pain compared to severe pain for participants that scored *Affect: sometimes* and *Affect: very often to always.*

Table 2.20: SF36 by AIMS2-SF Affect scale summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	*Affect (never to almost never)*	33	33.00	58.18	27.15	60.00	40.00
	Affect (sometimes)	36	36.00	46.11	25.33	47.50	41.25
	Affect(very often to always)	31	31.00	42.26	24.42	45.00	35.00
Role functioning/physical	*Affect (never to almost never)*	33	33.00	35.61	41.00	25.00	75.00
	Affect (sometimes)	36	36.00	12.50	25.70	0.00	6.25
	Affect(very often to always)	31	31.00	16.13	30.65	0.00	25.00
Role functioning/emotional	*Affect (never to almost never)*	33	33.00	66.67	44.10	100.00	66.67
	Affect (sometimes)	36	36.00	40.74	46.54	0.00	100.00
	Affect(very often to always)	31	31.00	31.18	40.31	0.00	66.67
Energy/Fatigue*	*Affect (never to almost never)*	33	33.00	35.76	19.45	35.00	25.00
	Affect (sometimes)	36	36.00	27.92	17.25	27.50	25.00
	Affect(very often to always)	31	31.00	17.74	13.77	15.00	15.00
Emotional well-being	*Affect (never to almost never)*	33	33.00	76.24	12.20	76.00	16.00
	Affect (sometimes)	36	36.00	61.67	18.62	64.00	17.00
	Affect(very often to always)	31	31.00	50.58	21.33	52.00	22.00
Social functioning*	*Affect (never to almost never)*	33	33.00	62.88	26.24	75.00	25.00
	Affect (sometimes)	36	36.00	46.18	21.30	50.00	37.50
	Affect(very often to always)	31	31.00	40.32	23.87	37.50	37.50
Pain	*Affect (never to almost never)*	33	33.00	50.68	22.41	45.00	35.00
	Affect (sometimes)	36	36.00	37.99	19.84	32.50	22.50
	Affect(very often to always)	31	31.00	35.00	20.42	22.50	22.50
General health	*Affect (never to almost never)*	33	33.00	38.33	20.60	35.00	35.00
	Affect (sometimes)	36	36.00	31.94	22.91	25.00	30.00
	Affect(very often to always)	31	31.00	28.71	16.17	30.00	17.50
Health change	*Affect (never to almost never)*	33	33.00	53.03	27.78	50.00	50.00
	Affect (sometimes)	36	36.00	47.92	29.50	50.00	50.00
	Affect(very often to always)	31	31.00	48.39	30.23	50.00	50.00

Table 2.21: SF36 by AIMS2-SF Affect scale ANOVA table

SF36 Scale		Sum of squares	DF	Mean Square	F	p
Energy/fatigue	Between groups	5206	2	2603.00	8.95	0.0003*
	Within groups	28217	97	290.00		
	Total	33423	99			
Social functioning	Between groups	8900	2	4450.00	7.85	0.0007*
	Within groups	55004	97	567.00		
	Total	63904	99			

*Statistically significant at p<0.05

Table 2.22: SF36 by AIMS2-SF Affect scale post hoc Tukey HSD test

SF36 scale	AIMS2-SF Affect scale	Difference	Lower	Upper	P adjusted
SF36 Energy/fatigue	*Sometimes - Never to almost never*	-7.84	-17.62	1.94	0.1420
	Very often to always -Never to almost never	-18.02	-28.17	-7.86	0.0002*
	Very often to always - Sometimes	-10.17	-20.12	-0.23	0.0438*
SF36 Social functioning	*Sometimes - Never to almost never*	-16. 70	-30.36	-3.04	0.0124*
	Very often to always -Never to almost never	-22.56	-36.73	-8.38	0.0008*
	Very often to always - Sometimes	-5.86	-19.75	8.30	0.5761

*Statistically significant at p<0.05

Table 2.23: SF36 by AIMS2-SF Affect scale Kruskal-Wallis test

SF36 Scale	X^2	df	p
Physical functioning	5.41	2	0.0669
Role functioning/emotional	11.58	2	0.0031*
Emotional well-being	26.88	2	<0.0001*
Pain	10.52	2	0.0052*
General health	3.22	2	0.1999
Health change	0.49	2	0.7825

*Statistically significant at p<0.05

Table 2.24: SF36 by AIMS2-SF Affect scale post hoc pairwise Wilcoxon rank sum test

SF36 Scale	AIMS2-SF Affect scale	Never to almost never	Sometimes
Role functioning/emotional	*Sometimes*	0.0238 *	
	Very often to always	0.0029*	0.3910
Emotional well-being	*Sometimes*	0.0008*	
	Very often to always	<0.0001*	0.0177*
Pain	*Sometimes*	0.0235*	
	Very often to always	0.0064*	0.4458

*Statistically significant at p<0.05

Table 2.25: SF36 by AIMS2-SF Affect scale Welch one-way test

SF36 Scale	F	dF1	dF2	p
Role functioning/physical	3.88	2.00	61.02	0.0259*

*Statistically significant at p<0.05

Table 2.26: SF36 by AIMS2-SF Affect scale post hoc pairwise t-test

SF36 Scale	AIMS2-SF Affect scale	Never to almost never	Sometimes
Role functioning/physical	*Sometimes*	0.0230*	
	Very often to always	0.0520*	0.6050

*Statistically significant at p<0.05

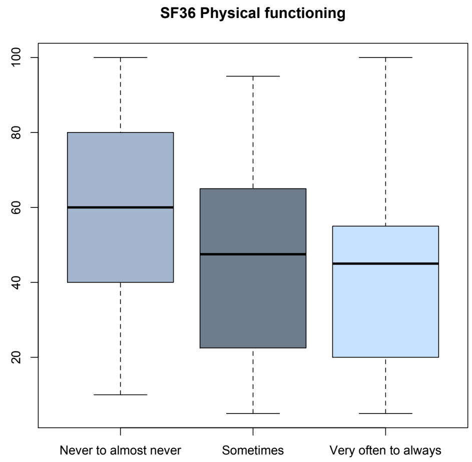

Figure 2.19: Boxplot of SF36 Physical functioning by AIMS2-SF Affect Scale

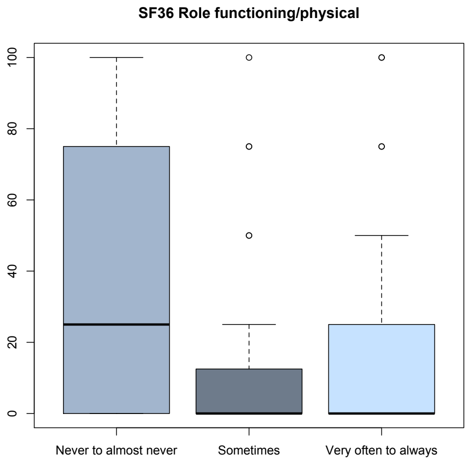

Figure 2.20: Boxplot of SF36 Role functioning/physical by AIMS2-SF Affect Scale

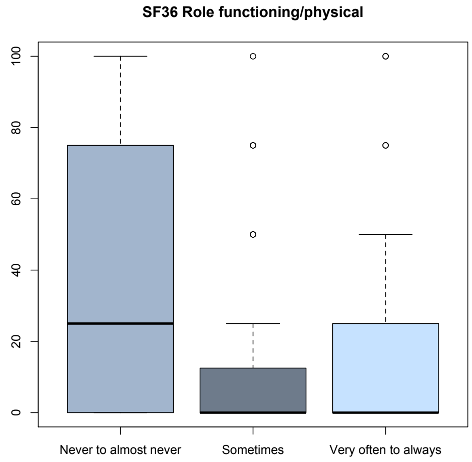

Figure 2.21: Boxplot of SF36 Role functioning/ emotional by AIMS2-SF Affect Scale

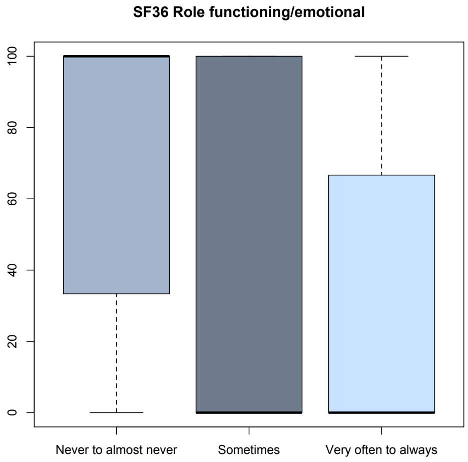

Figure 2.22: Boxplot of SF36 Energy/fatigue by AIMS2-SF Affect Scale

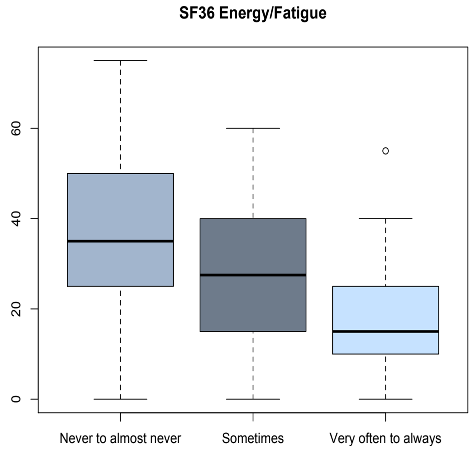

Figure 2.23: Boxplot of SF36 Emotional well-being by AIMS2-SF Affect Scale

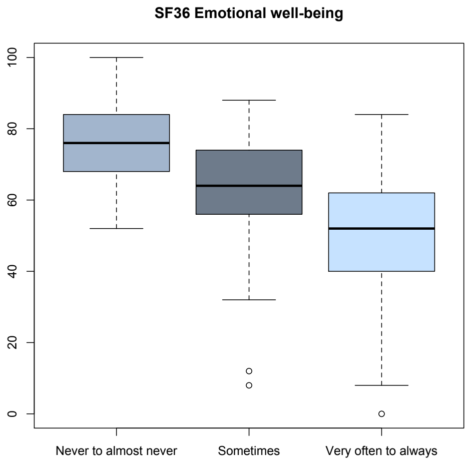

Figure 2.24: Boxplot of SF36 Social functioning by AIMS2-SF Affect Scale

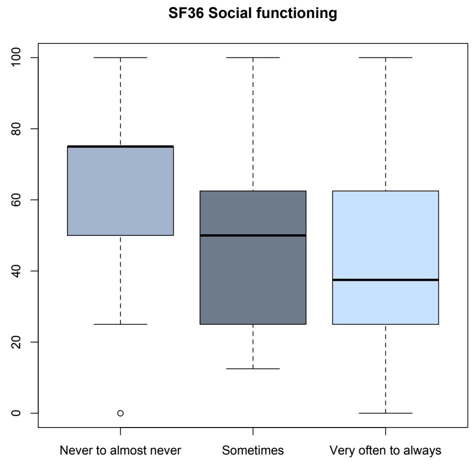

Figure 2.25: Boxplot of SF36 Pain by AIMS2-SF Affect Scale

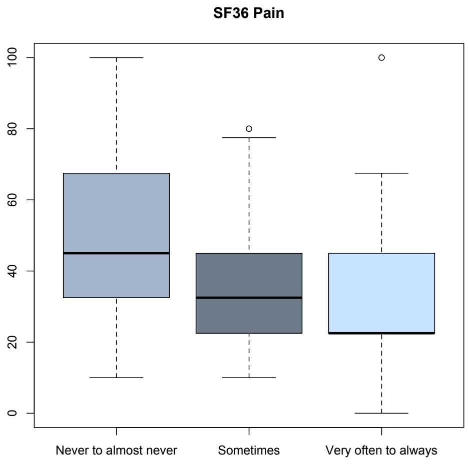

Figure 2.26: Boxplot of SF36 General health by AIMS2-SF Affect Scale

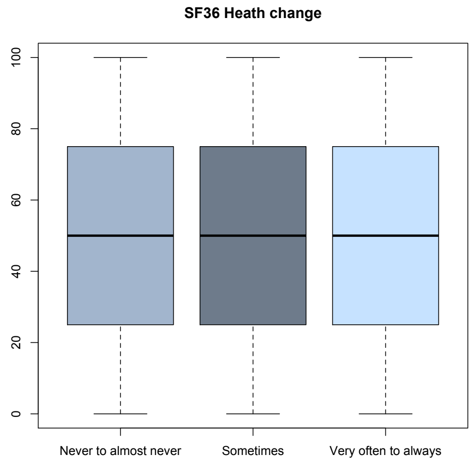

Figure 2.27: Boxplot of SF36 Health change by AIMS2-SF Affect Scale

Comparisons of SF36 scales by AIMS2-SF Social scale

The **AIMS2-SF Social scale** is the Arthritis Impact Measure Scale short form social scale. The social scale is comprised of 4 questions about frequency of social interactions: "All days", "Most days", "Some days", "Few days" or "No days". A score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Social: all to most days* (AIMS2-SF social scale score between 0 and 4, N=20, 20.00%), *Social: some days* (AIMS2-SF Social scale score greater than 4 to 6, N=36, 36.00%), and *Social; few to no days* (AIMS2-SF affect scale score greater than 6 to 10, N=32, 32.00%), and *Social: all days* (AIMS2-SF affect scale score greater than 8 to 10, N=31, 31.00%).

Boxplots of each SF36 scale by **AIMS2-SF Social scale** are displayed in Figures 2.28-2.36, summary statistics are displayed in Table 2.27

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.28). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.29). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.30). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.31). When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances (Table 2.32).

A one way ANOVA test indicated a statistically significant difference in the **"SF36 Social functioning"** scale between groups, F(2, 97) = 4.87, p = 0.0097 (Table 2.28). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 63.75, SD = 23.61) was significantly higher than participants that scored *Social: no to few days* (mean = 43.18, SD = 26.61, p=0.0067).

A Kruskal-Wallis test indicated a statistically significant difference in the **"SF36 Energy/fatigue"** scale between groups, $\chi^2(2)$ = 6.35, p = 0.0418 (Table 2.30). Wilcoxon rank sum tests between groups indicated that those that scored *Social: all to most days* (median = 40.00, IQR = 22.50) scored significantly higher than those that scored *Social: some days* (median = 20.00, IQR = 26.25, p=0.0480) and *Social: no to few days* (median =25.00, IQR = 26.25, p=0.0480).

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants with that scored *Social: all to most days* felt tired most of the time and had energy a little of the time, had significantly higher scores compared to participants that scored *Social: some days* who also felt tired most of the time and had energy a little of the time and *Social; few to no days* who were tired all the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. Social activities are not at all limited for participants that scored *Social: all to most days* compared to moderately limited for participants that scored *Social: no to few days*

Table 2.27: SF36 by AIMS2-SF Social scale summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	*Social (all to most days)*	20	20.00	56.00	29.41	57.50	43.75
	Social (some days)	36	36.00	45.97	22.83	47.50	36.25
	Social (no to few days)	44	44.00	48.07	27.45	45.00	41.25
Role functioning/physical	*Social (all to most days)*	20	20.00	36.25	41.73	25.00	75.00
	Social (some days)	36	36.00	18.75	31.83	0.00	31.25
	Social (no to few days)	44	44.00	16.48	30.95	0.00	25.00
Role functioning/emotional	*Social (all to most days)*	20	20.00	46.67	47.63	33.33	100.00
	Social (some days)	36	36.00	45.37	45.18	33.33	100.00
	Social (no to few days)	44	44.00	46.97	46.77	33.33	100.00
Energy/Fatigue*	*Social (all to most days)*	20	20.00	36.50	18.07	40.00	22.50
	Social (some days)	36	36.00	26.11	16.95	20.00	26.25
	Social (no to few days)	44	44.00	24.20	18.68	25.00	26.25
Emotional well-being	*Social (all to most days)*	20	20.00	71.20	17.49	76.00	18.00
	Social (some days)	36	36.00	63.56	16.75	64.00	21.00
	Social (no to few days)	44	44.00	58.91	23.36	60.00	25.00
Social functioning	*Social (all to most days)*	20	20.00	63.75	23.61	62.50	25.00
	Social (some days)	36	36.00	50.35	22.06	50.00	25.00
	Social (no to few days)	44	44.00	43.18	26.61	43.75	37.50
Pain	*Social (all to most days)*	20	20.00	51.38	26.48	50.00	28.13
	Social (some days)	36	36.00	37.71	20.24	32.50	22.50
	Social (no to few days)	44	44.00	39.55	19.64	35.00	25.00
General health	*Social (all to most days)*	20	20.00	35.00	19.80	37.50	25.00
	Social (some days)	36	36.00	31.81	19.05	27.50	26.25
	Social (no to few days)	44	44.00	33.18	22.13	25.00	26.25
Health change	*Social (all to most days)*	20	20.00	60.00	37.52	62.50	75.00
	Social (some days)	36	36.00	50.00	28.66	50.00	50.00
	Social (no to few days)	44	44.00	44.89	23.86	50.00	25.00

Table 2.28: SF36 by AIMS2-SF Social scale ANOVA table

SF36 Scale		Sum of squares	DF	Mean Square	F	p
	Between groups	1347	2	673.60	0.97	0.3810
	Within groups	67082	97	691.60		
	Total	68429	99			
Social functioning	Between groups	5829	2	2914.70	4.87	0.0097*
	Within groups	58075	97	598.7		
	Total	63904	99			

*Statistically significant at $p<0.05$

Table 2.29: SF36 by AIMS2-SF Social scale post hoc Tukey HSD test

	AIMS2-SF Social scale	Difference	Lower	Upper	P adjusted
SF36 Physical functioning	*Some days - All to most days*	-10.03	-27.48	7.43	0.3620
	No to few days - All to most days	-7.93	-24.81	8.95	0.5051
	No to few days – Some days	-2.10	-11.97	16.16	0.9331
SF36 Social functioning	*Some days - All to most days*	-13.40	-29.65	2.84	0.1367
	No to few days - All to most days	-20.57	-36.27	-4.86	0.0067*
	No to few days – Some days	-7.17	-20.25	5.92	0.3970

*Statistically significant at $p<0.05$

Table 2.30: SF36 by AIMS2-SF Social scale Kruskal-Wallis test

SF36 Scale	X^2	df	p
Role functional/physical	4.92	2	0.0853
Role functioning/emotional	0.04	2	0.9810
Energy/fatigue	6.35	2	0.0418*
Emotional well-being	4.98	2	0.0829
Pain	4.84	2	0.0891
General health	0.82	2	0.6632

*Statistically significant at $p<0.05$

Table 2.31: SF36 by AIMS2-SF Social scale post hoc pairwise Wilcoxon rank sum test

SF36 Scale	AIMS2-SF Social scale	All to most days	Some days
Role functioning/emotional	Some days	0.0480*	
	No to few days	0.0480*	0.6510

*Statistically significant at $p<0.05$

Table 2.25: SF36 by AIMS2-SF Social scale Welch one-way test

SF36 Scale	F	dF1	dF2	p
Health change	1.80	2.00	46.55	0.1764

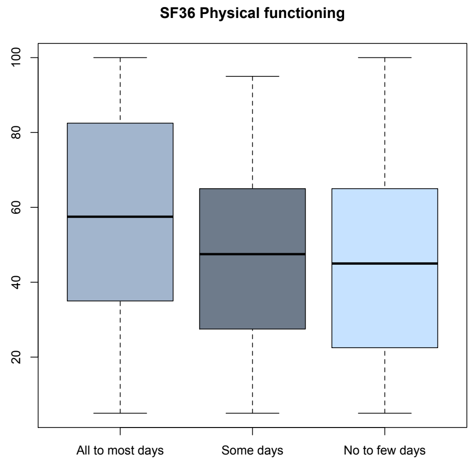

Figure 2.28: Boxplot of SF36 Physical functioning by AIMS2-SF Social Scale

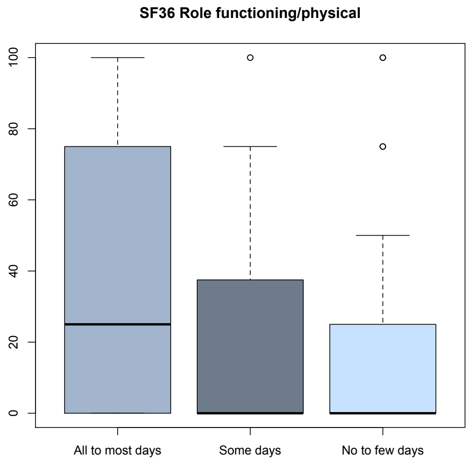

Figure 2.29: Boxplot of SF36 Role functioning/physical by AIMS2-SF Social Scale

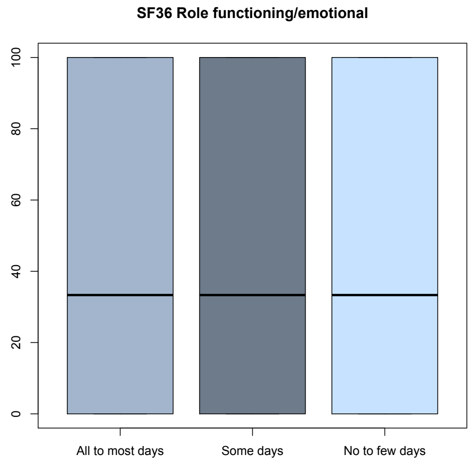

Figure 2.30: Boxplot of SF36 Role functioning/emotional by AIMS2-SF Social Scale

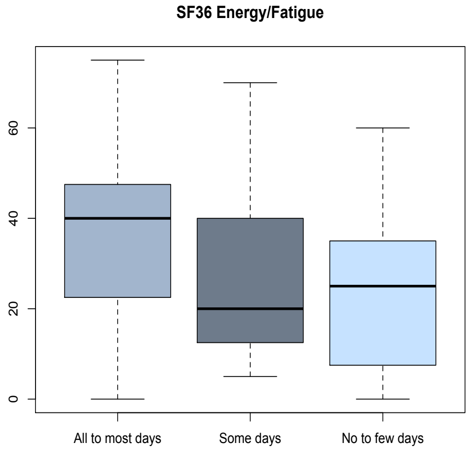

Figure 2.31: Boxplot of SF36 Energy/fatigue by AIMS2-SF Social Scale

Figure 2.32: Boxplot of SF36 Emotional well-being by AIMS2-SF Social Scale

Figure 2.33: Boxplot of SF36 Social functioning by AIMS2-SF Social Scale

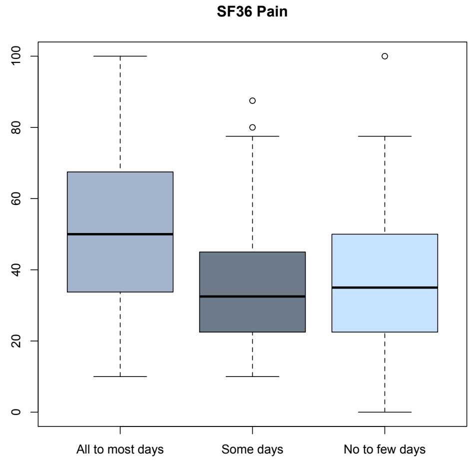

Figure 2.34: Boxplot of SF36 Pain by AIMS2-SF Social Scale

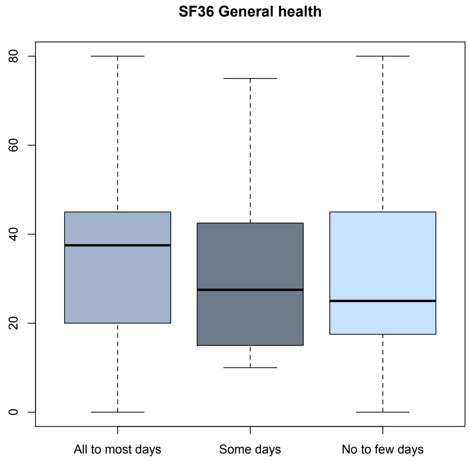

Figure 2.35: Boxplot of SF36 General health by AIMS2-SF Social Scale

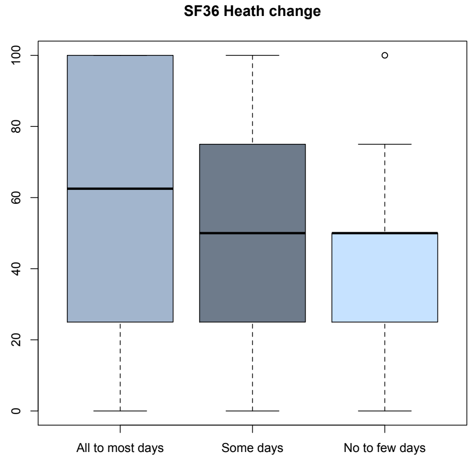

Figure 2.36: Boxplot of SF36 Health change by AIMS2-SF Social Scale

Comparisons of SF36 scales by Flare-up frequency

Comparisons were made by **Flare-up frequency**, between participants that had *frequent flare-ups* (daily or weekly flare-ups, N=44, 44.00%) and participants that had *occasional flare-ups* (monthly flare-ups or less frequently, N=56, 56.00%).

Boxplots of each SF36 scale by **Flare-up frequency** are displayed in Figures 2.37-2.45, summary statistics are displayed in Tables 2.33 – 2.34. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.33), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.34).

A two sample t-test indicated that the mean score for the **"SF36 Physical functioning**" [t(98) = 2.08, p=0.0404] was significantly better for those with *Occasion flare –ups* (Mean = 53.66, SD= 26.82) compared to those with *frequent flare-ups* (Mean = 42.66, SD = 26.82).

A two sample t-test indicated that the mean score for the **"SF36 Social functioning**" [t(98) = 2.39, p=0.0188] was significantly better for those with *Occasion flare –ups* (Mean = 55.13, SD= 25.09) compared to those with *frequent flare-ups* (Mean = 43.18, SD = 24.48).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Role functioning/physical"** [W=1614.50, p=0.0018] was significantly higher for those with *Occasional flare-ups* (Median = 0.00, IQR =56.25) compared to those with *frequent flare-ups* (Median =0.00, IQR = 0.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Role functioning/emotional"** [W=1571.50, p=0.0110] was significantly higher for those with *Occasional flare-ups* (Median = 66.67, IQR =100.00) compared to those with *frequent flare-ups* (Median =0.00, IQR = 75.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Energy/fatigue"** [W=1701.50, p=0.0011] was significantly higher for those with *Occasional flare-ups* (Median = 35.00, IQR =26.25) compared to those with *frequent flare-ups* (Median =20.00, IQR = 16.25).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Pain"** [W=1794.50, p<0.0001] was significantly higher for those with *Occasional flare-ups* (Median = 45.00, IQR =27.50) compared to those with *frequent flare-ups* (Median =22.50, IQR = 22.50).

Key differences

"SF36 Physical functioning": measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework Participants with *Occasional flare-ups* scored significantly higher than participants with *Frequent flare-ups*. However, the scores were in the physical activities are moderately limited for both groups.

"SF36 Role functioning/physical": measures how physical health interferes with work or other activities. Participants with *Occasional flare-ups* scored significantly higher than participants with *Frequent flare-ups*. However, the scores were in the physical health interferes quite a bit with work or other activities range for both groups.

"SF36 Role functioning/emotional" measures how emotional problems interfered with work or other activities. Emotional problems slightly interfered with work or other activities for participants with *Occasional flare-ups* compared to extremely interfered with work or other activities for those with *Frequent flare-ups.*

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants with *Occasional flare-ups* felt tired most of the time and had energy a little of the time, compared to participants that scored *Frequent flare-ups* who felt tired all of the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. Participants with *Occasional flare-ups* scored significantly higher than participants with *Frequent flare-ups*. However, the scores were in the social activities are moderately limited for both groups.

"SF36 Pain": measures the amount of pain, and how pain interferes with work and other activities. Participants with *Occasional flare-ups* had moderate pain compared to severe pain for participants with *Frequent flare-ups*.

Table 2.33: SF36 by Flare-up frequency two sample t-test

*Statistically significant at p<0.05

SF36 Scale	Group	Count	Percent	Mean	SD	t	dF	p
Physical functioning	Occasional flare up	56	56.00	53.66	26.82	2.08	98	0.0404*
	Frequent flare up	44	44.00	42.84	24.58			
Social functioning	Occasional flare up	56	56.00	55.13	25.09	2.39	98	0.0188*
	Frequent flare up	44	44.00	43.18	24.48			

*Statistically significant at p<0.05

Table 2.34: SF36 by Flare-up frequency Wilcoxon rank sum test

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Role functioning/physical	Occasional flare up	56	56.00	0.00	56.25	1614.50	0.0018*
	Frequent flare up	44	44.00	0.00	0.00		
Role functioning/emotional	Occasional flare up	56	56.00	66.67	100.00	1571.50	0.0110*
	Frequent flare up	44	44.00	0.00	75.00		
Energy/fatigue	Occasional flare up	56	56.00	35.00	26.25	1701.50	0.0011*
	Frequent flare up	44	44.00	20.00	16.25		
Emotional well-being	Occasional flare up	56	56.00	68.00	21.00	1446.00	0.1371
	Frequent flare up	44	44.00	62.00	33.00		
Pain	Occasional flare up	56	84.00	45.00	27.50	1794.00	<0.0001*
	Frequent flare up	44	44.00	22.50	22.50		
General health	Occasional flare up	56	56.00	35.00	31.25	1511.00	0.0522
	Frequent flare up	44	44.00	25.00	26.25		
Health change	Occasional flare up	56	56.00	50.00	50.00	1512.50	0.0449
	Frequent flare up	44	44.00	50.00	50.00		

*Statistically significant at p<0.05

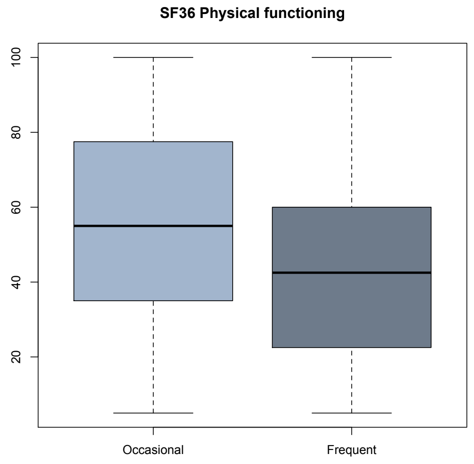

Figure 2.37: Boxplot of SF36 Physical functioning by Flare-up frequency

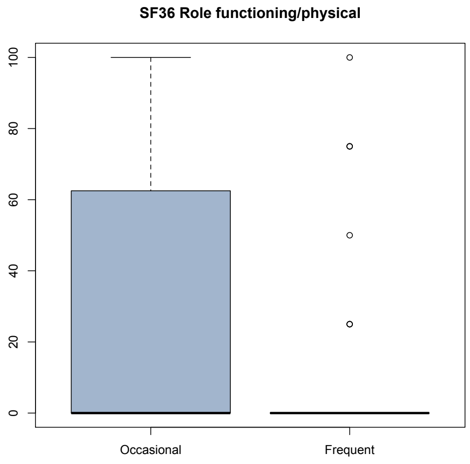

Figure 2.38: Boxplot of SF36 Role functioning/physical by Flare-up frequency

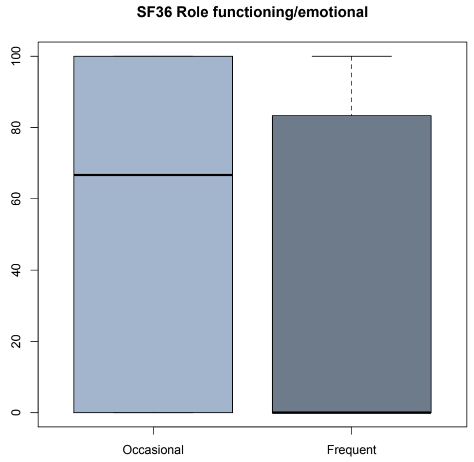

Figure 2.39: Boxplot of SF36 Role functioning/ emotional by Flare-up frequency

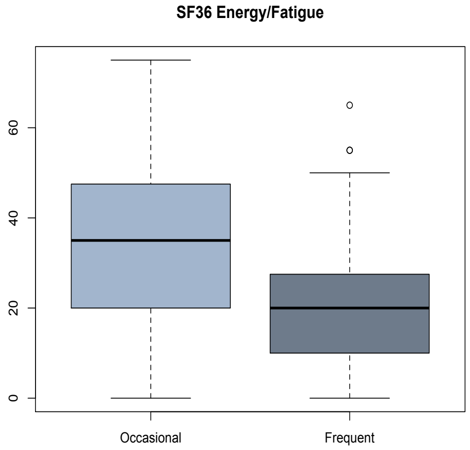

Figure 2.40: Boxplot of SF36 Energy/fatigue by Flare-up frequency

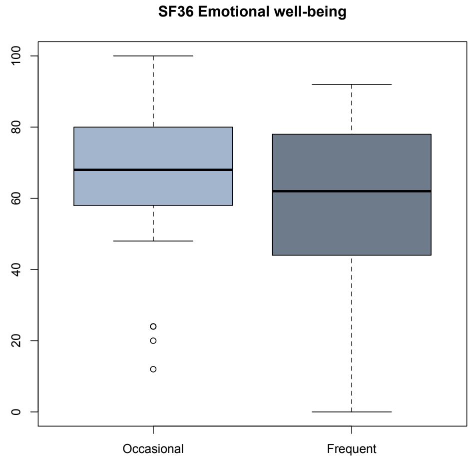

Figure 2.41: Boxplot of SF36 Emotional well-being by Flare-up frequency

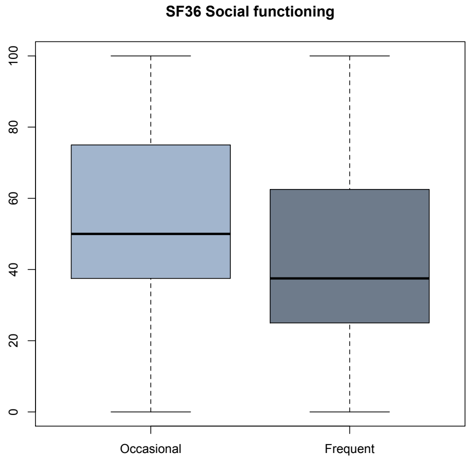

Figure 2.42: Boxplot of SF36 Social functioning by Flare-up frequency

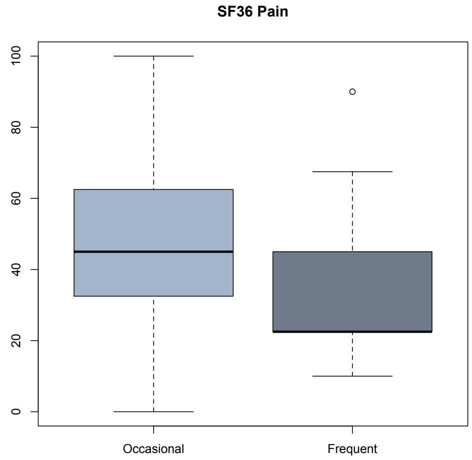

Figure 2.43: Boxplot of SF36 Pain by Flare-up frequency

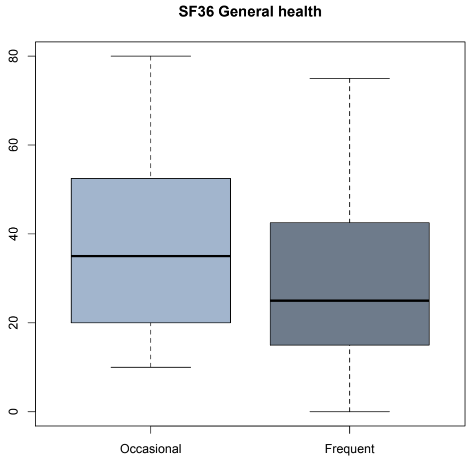

Figure 2.44: Boxplot of SF36 General health by Flare-up frequency

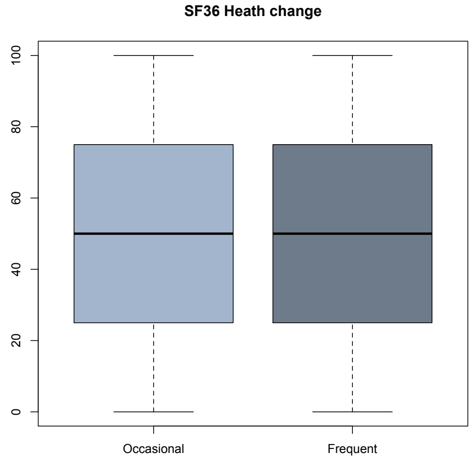

Figure 2.45: Boxplot of SF36 Health change by Flare-up frequency

Comparisons of SF36 scales by age

Comparisons were made by the **Age** of the participants, those that were *aged 55 or older* (N=31, 31.00%), aged 35 – 54 (N=51, 51.00%) and participants aged 18 – 34 (N=18, 18.00%).

Boxplots of each SF36 scale by **Age** are displayed in Figures 2.46-2.54, summary statistics are displayed in Table 2.35

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.36). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.37). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test.

No significant differences were observed between participants by **Age** any of the SF36 scales.

Table 2.35: SF36 by Age summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	*Aged 18 -34*	18	31.00	54.44	25.14	52.50	28.75
	Aged 35 - 44	51	51.00	51.18	25.68	50.00	35.00
	Aged 55 or older	31	18.00	41.94	27.32	35.00	45.00
Role functioning/physical	*Aged 18 -34*	18	31.00	27.78	43.63	0.00	62.50
	Aged 35 - 44	51	51.00	22.06	32.65	0.00	25.00
	Aged 55 or older	31	18.00	16.13	30.65	0.00	12.50
Role functioning/emotional	*Aged 18 -34*	18	31.00	46.30	48.69	33.33	100.00
	Aged 35 - 44	51	51.00	45.10	45.13	33.33	100.00
	Aged 55 or older	31	18.00	48.39	47.01	66.67	100.00
Energy/Fatigue*	*Aged 18 -34*	18	31.00	30.00	20.65	30.00	41.25
	Aged 35 - 44	51	51.00	27.45	16.89	25.00	20.00
	Aged 55 or older	31	18.00	25.65	19.74	25.00	32.50
Emotional well-being	*Aged 18 -34*	18	31.00	62.44	23.53	66.00	24.00
	Aged 35 - 44	51	51.00	64.31	17.81	64.00	20.00
	Aged 55 or older	31	18.00	61.29	22.89	64.00	32.00
Social functioning	*Aged 18 -34*	18	31.00	52.78	30.18	50.00	46.88
	Aged 35 - 44	51	51.00	51.23	24.27	50.00	37.50
	Aged 55 or older	31	18.00	45.97	24.66	37.50	37.50
Pain	*Aged 18 -34*	18	31.00	45.56	25.62	45.00	35.00
	Aged 35 - 44	51	51.00	41.72	22.04	45.00	35.00
	Aged 55 or older	31	18.00	37.98	18.95	32.50	22.50
General health	*Aged 18 -34*	18	31.00	30.83	22.25	30.00	30.00
	Aged 35 - 44	51	51.00	34.22	19.55	30.00	25.00
	Aged 55 or older	31	18.00	32.42	21.33	25.00	25.00
Health change	*Aged 18 -34*	18	31.00	59.72	25.92	50.00	25.00
	Aged 35 - 44	51	51.00	50.49	28.94	50.00	50.00
	Aged 55 or older	31	18.00	42.74	29.72	50.00	50.00

Table 2.36: SF36 by Age ANOVA table

SF36 Scale		Sum of squares	dF	Mean Square	F	p
Physical functioning	Between groups	2321	2	1160.60	1.70	0.1880
	Within groups	66108	97	681.50		
	Total	66340	99			
Social functioning	Between groups	718	2	359.00	0.55	0.5780
	Within groups	63187	97	651.40		
	Total	63905	99			

Table 2.37: SF36 by Age Kruskal-Wallis test

SF36 Scale	X^2	dF	p
Role functioning/physical	1.50	2	0.4717
Role functioning/emotional	0.043	2	0.9804
Energy/fatigue	0.60	2	0.7404
Emotional well-being	0.28	2	0.8703
Pain	0.89	2	0.6395
General health	0.69	2	0.7080
Health change	3.82	2	0.1482

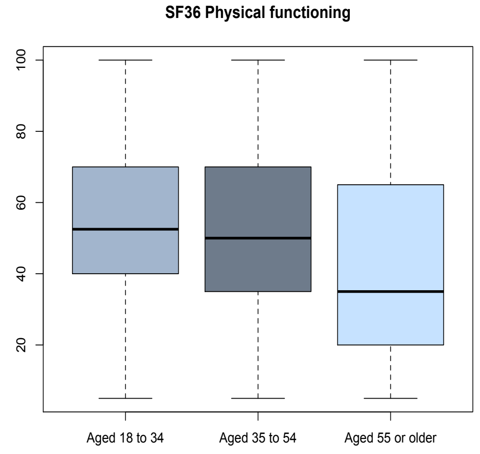

Figure 2.46: Boxplot of SF36 Physical functioning by Age

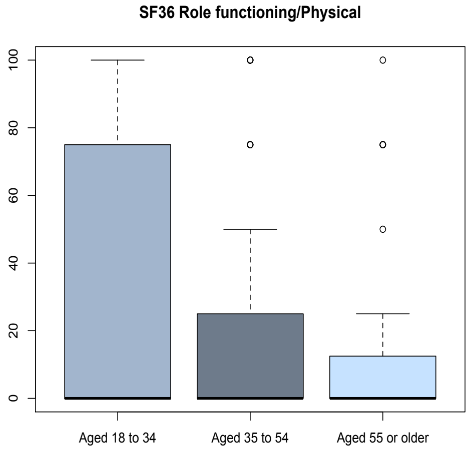

Figure 2.47: Boxplot of SF36 Role functioning/physical by Age

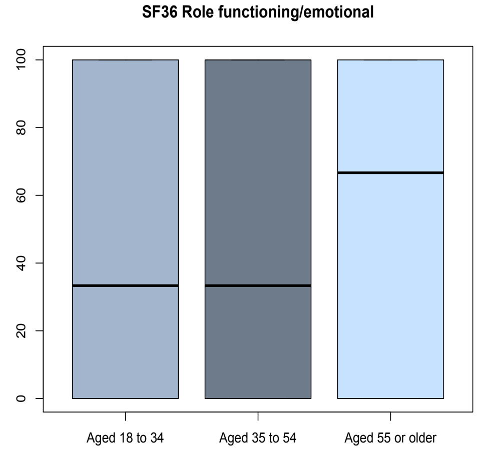

Figure 2.48: Boxplot of SF36 Role functioning/ emotional by Age

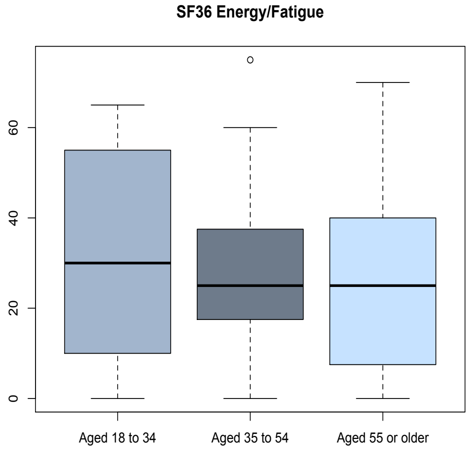

Figure 2.49: Boxplot of SF36 Energy/fatigue by Age

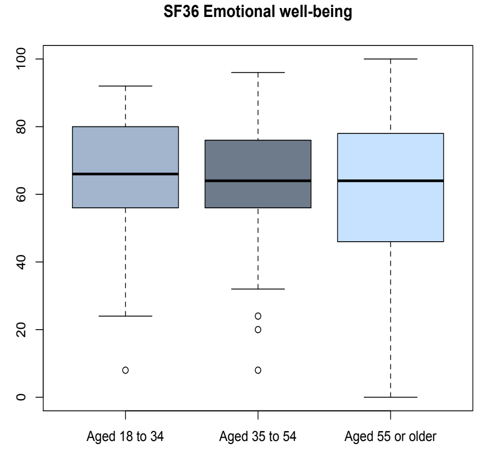

Figure 2.50: Boxplot of SF36 Emotional well-being by Age

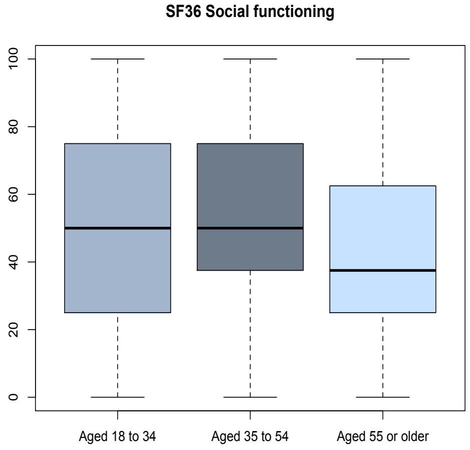

Figure 2.51: Boxplot of SF36 Social functioning by Age

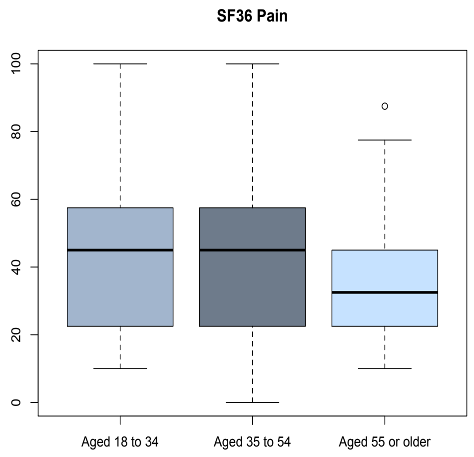

Figure 2.52: Boxplot of SF36 Pain by Age

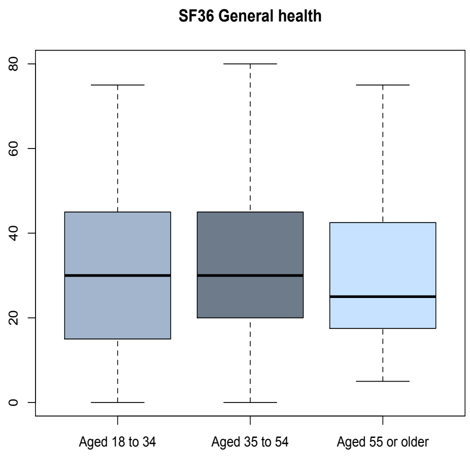

Figure 2.53: Boxplot of SF36 General health by Age

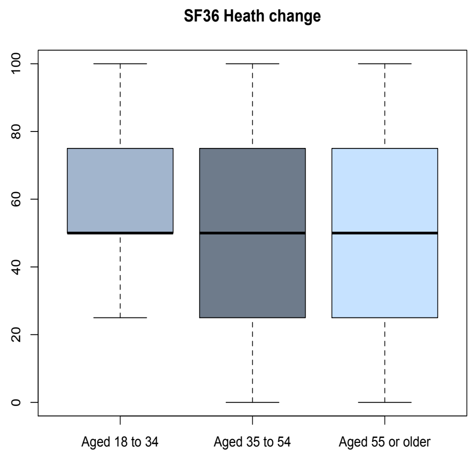

Figure 2.54: Boxplot of SF36 Health change by Age

Comparisons of SF36 scales by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from DoctorConnect (doctorconnect.gov.au), those living in a metropolitan area, *metropolitan* (N=56, 56.00%) were compared to those living in regional/rural areas, *regional or remote* (N=44, 44.00%).

Boxplots of each SF36 scale by **location** are displayed in Figures 2.55-2.63, summary statistics are displayed in Table 2.38 Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.38).

No significant differences were observed between participants that lived in *metropolitan* areas compared to those that lived in an *regional or remote* areas for any of the SF36 scales.

Table 2.38: SF36 by Location Wilcoxon rank sum test

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	Metropolitan	56	56.00	50.00	35.00	1392.00	0.2670
	Regional or remote	44	44.00	45.00	45.00		
Role functioning/physical	Metropolitan	56	56.00	0.00	50.00	1287.50	0.6531
	Regional or remote	44	44.00	0.00	25.00		
Role functioning/emotional	Metropolitan	56	56.00	50.00	100.00	1259.00	0.8424
	Regional or remote	44	44.00	33.33	100.00		
Energy/fatigue	Metropolitan	56	56.00	27.50	30.00	1287.00	0.7039
	Regional or remote	44	44.00	25.00	26.25		
Emotional well-being	Metropolitan	56	56.00	62.00	24.00	1235.00	0.9861
	Regional or remote	44	44.00	64.00	26.00		
Social functioning	Metropolitan	56	56.00	50.00	40.63	1277.00	0.7546
	Regional or remote	44	44.00	50.00	37.50		
Pain	Metropolitan	56	84.00	45.00	33.13	1282.50	0.7251
	Regional or remote	44	44.00	33.75	33.13		
General health	Metropolitan	56	56.00	30.00	25.00	1370.50	0.3361
	Regional or remote	44	44.00	25.00	26.25		
Health change	Metropolitan	56	56.00	50.00	50.00	1319.00	0.5354
	Regional or remote	44	44.00	50.00	31.25		

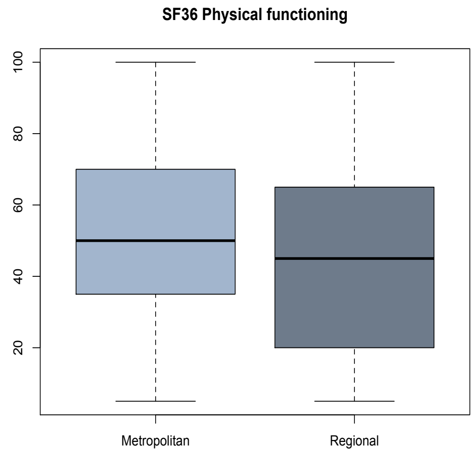

Figure 2.55: Boxplot of SF36 Physical functioning by Location

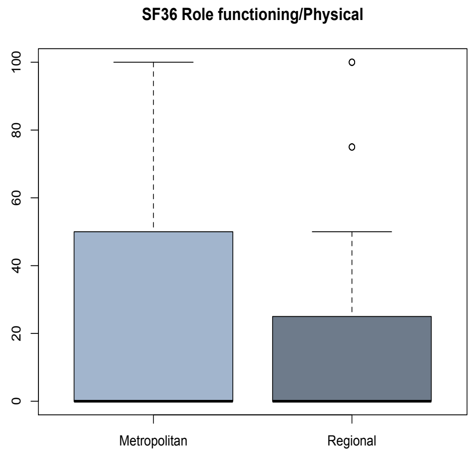

Figure 2.56: Boxplot of SF36 Role functioning/physical by Location

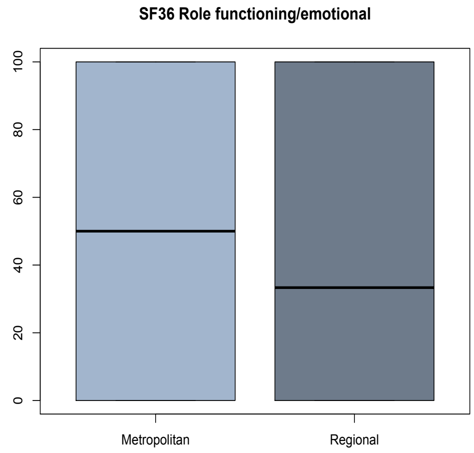

Figure 2.57: Boxplot of SF36 Role functioning/ emotional by Location

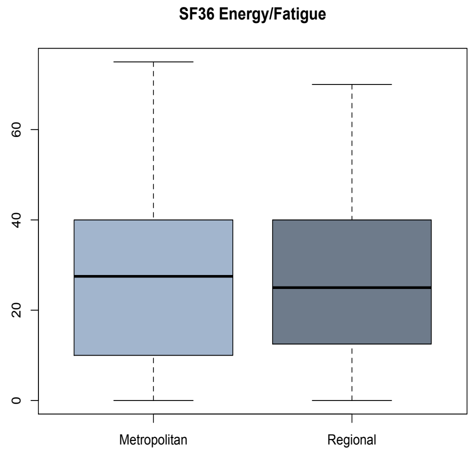

Figure 2.58: Boxplot of SF36 Energy/fatigue by Location

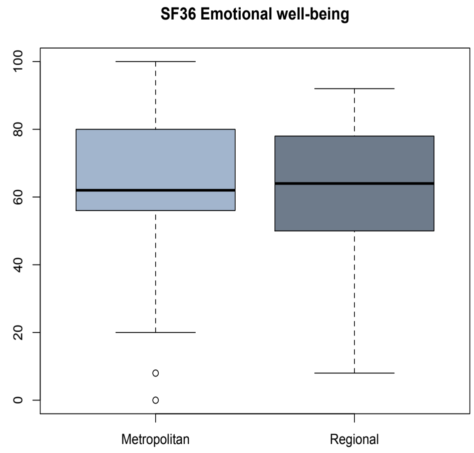

Figure 2.59: Boxplot of SF36 Emotional well-being by Location

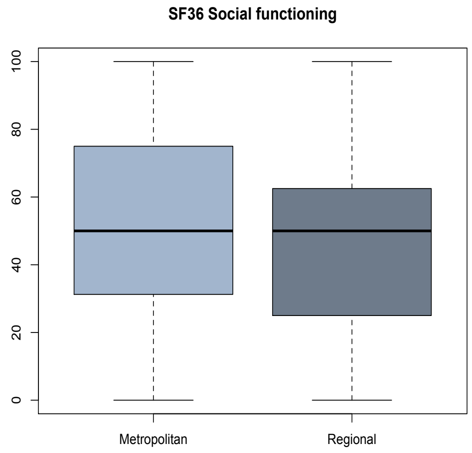

Figure 2.60: Boxplot of SF36 Social functioning by Location

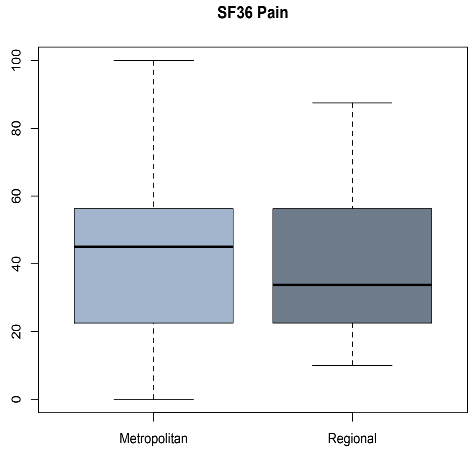

Figure 2.61: Boxplot of SF36 Pain by Location

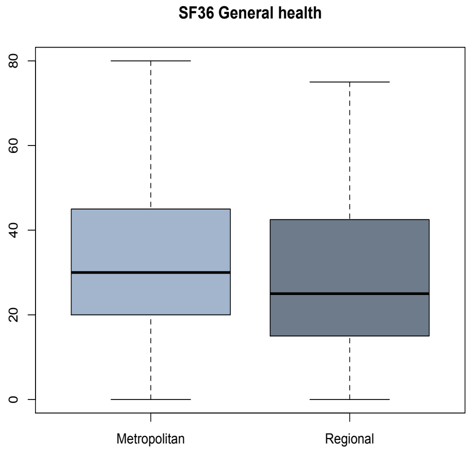

Figure 2.62: Boxplot of SF36 General health by Location

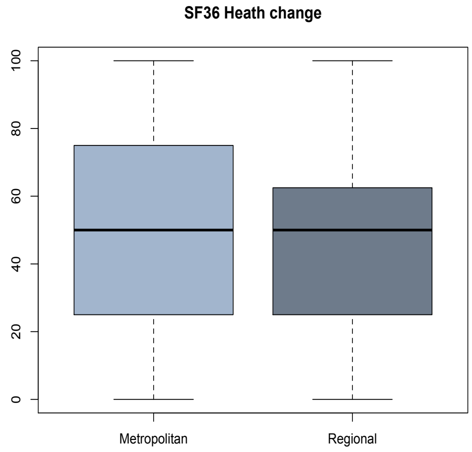

Figure 2.63: Boxplot of SF36 Health change by Location

Comparisons of SF36 scales by education

Comparisons were made by **Education** status, between those with a university degree, *university* (N= 66, 66.00%), and those with trade or high school qualifications, *trade or high school* (N=33, 33.00%).

Boxplots of each SF36 scale by **Education** are displayed in Figures 2.64-2.72, summary statistics are displayed in Table 2.39. Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.39).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 physical functioning"** [W = 764.50, p=0.0124] was significantly higher for those with *University* qualifications (Median = 50.00, IQR = 37.50) compared to those with *Trade or high school* qualifications (Median = 40.00, IQR = 40.00).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Role functioning/physical"** [W = 775.50, p=0.0047] was significantly higher for those with *University* qualifications (Median = 0.00, IQR = 50.00) compared to those with *Trade or high school* qualifications (Median = 0.00, IQR = 0.00).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Role functioning/emotional"** [W = 770.50, p=0.0081] was significantly higher for those with *University* qualifications (Median = 66.67, IQR = 100.00) compared to those with *Trade or high school* qualifications (Median = 0.00, IQR =66.67).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Energy/fatigue"** [W = 744.500, p=0.0080] was significantly higher for those with *University* qualifications (Median = 30.00, IQR = 20.00) compared to those with *Trade or high school* qualifications (Median = 15.00, IQR = 30.00).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Emotional well-being"** [W = 762.00, p=0.0117] was significantly higher for those with *University* qualifications (Median = 68.00, IQR = 22.00) compared to those with *Trade or high school* qualifications (Median =56.00, IQR = 28.00).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Social functioning"** [W = 694.50, p=0.0023] was significantly higher for those with *University* qualifications (Median = 50.00, IQR = 37.50) compared to those with *Trade or high school* qualifications (Median =37.50, IQR = 25.00).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 Pain"** [W = 640.50, p=0.0006] was significantly higher for those with *University* qualifications (Median = 45.00, IQR = 35.00) compared to those with *Trade or high school* qualifications (Median = 32.50, IQR = 22.50).

A Wilcoxon rank sum test with continuity correction indicated that the median score for the **"SF36 General health"** [W = 690.00, p=0.0023] was significantly higher for those with *University* qualifications (Median = 35.00, IQR = 30.00) compared to those with *Trade or high school* qualifications (Median = 20.00, IQR = 15.00).

Key differences

"SF36 Physical functioning": measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants with *University* qualifications compared to limited quite a bit for participants with *Trade or high school* qualifications.

"SF36 Role functioning/physical": measures how physical health interferes with work or other activities. Participants with *University* qualifications scored significantly higher than participants with *Trade or high school* qualifications. However, the scores were in the physical health extremely interferes with work or other activities range for both groups.

"SF36 Role functioning/emotional" measures how emotional problems interfered with work or other activities. Emotional problems slightly interfered with work or other activities for participants with *University* qualifications compared to extremely interfered with work or other activities for those with *Trade or high school* qualifications.

"SF36 Energy/fatigue": measures the amount of energy or fatigue. Participants with *University* qualifications felt tired most of the time and had energy a little of the time, compared to participants with *Trade or high school* qualifications who felt tired all of the time.

"SF36 Emotional well-being" measures how a person feels, for example happy, calm, depressed or anxious. Participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications. On average, participants with *University* qualifications felt happy and calm most of the time, and anxious and depressed a little of the time compared to participants with *Trade or high school* qualifications who felt happy and calm some of the time, and depressed and anxious some of the time.

"SF36 Social functioning": measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited for participants with *University* qualifications compared to limited quite a bit for participants with *Trade or high school* qualifications.

"SF36 Pain": measures the amount of pain, and how pain interferes with work and other activities. Participants *University* qualifications had severe pain compared to very severe pain for participants with *Trade or high school* qualifications.

Table 2.39: SF36 by Education Wilcoxon rank sum test

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	Trade or high school	33	33.00	40.00	40.00	764.50	0.0124*
	University	67	67.00	50.00	37.50		
Role functioning/physical	Trade or high school	33	33.00	0.00	0.00	777.50	0.0047*
	University	67	67.00	0.00	50.00		
Role functioning/emotional	Trade or high school	33	33.00	0.00	66.67	770.50	0.0081*
	University	67	67.00	66.67	100.00		
Energy/fatigue	Trade or high school	33	33.00	15.00	30.00	744.50	0.0080*
	University	67	67.00	30.00	20.00		
Emotional well-being	Trade or high school	33	33.00	56.00	28.00	762.00	0.0117*
	University	67	67.00	68.00	22.00		
Social functioning	Trade or high school	33	33.00	37.50	25.00	694.50	0.0023*
	University	67	67.00	50.00	37.50		
Pain	Trade or high school	33	84.00	32.50	22.50	640.50	0.0006*
	University	67	67.00	45.00	35.00		
General health	Trade or high school	33	33.00	20.00	15.00	690.00	0.0023*
	University	67	67.00	35.00	30.00		
Health change	Trade or high school	33	33.00	50.00	25.00	918.00	0.1573
	University	67	67.00	50.00	50.00		

*Statistically significant at p<0.05

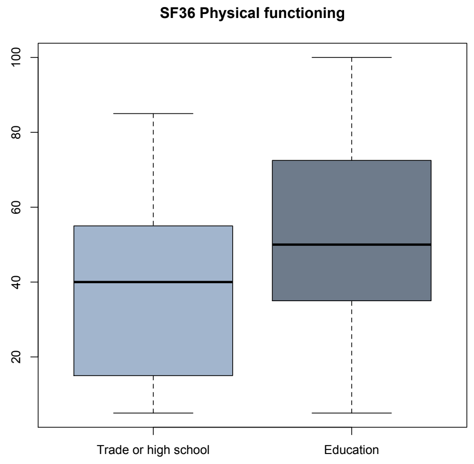

Figure 2.64: Boxplot of SF36 Physical functioning by Education

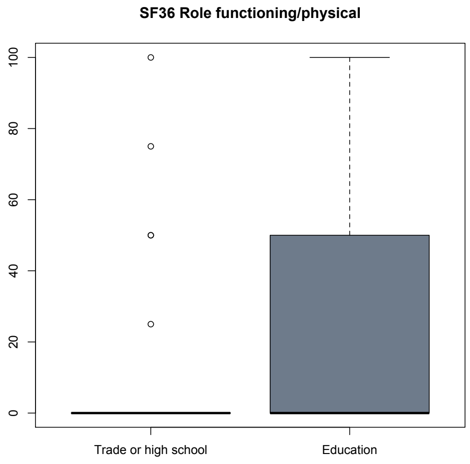

Figure 2.65: Boxplot of SF36 Role functioning/physical by Education

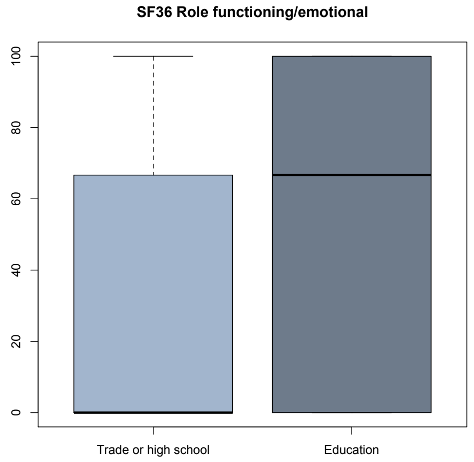

Figure 2.66: Boxplot of SF36 Role functioning/ emotional by Education

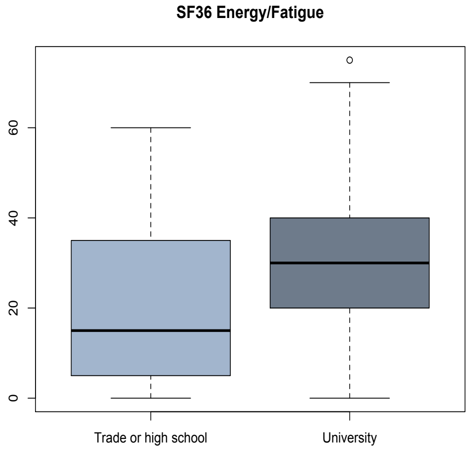

Figure 2.67: Boxplot of SF36 Energy/fatigue by Education

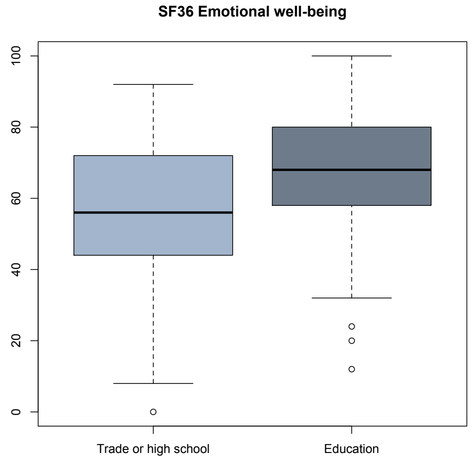

Figure 2.68: Boxplot of SF36 Emotional well-being by Education

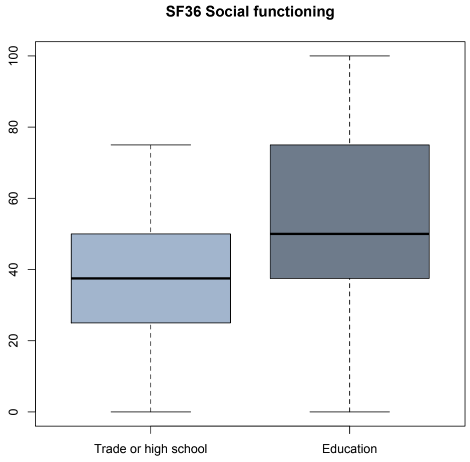

Figure 2.69: Boxplot of SF36 Social functioning by Education

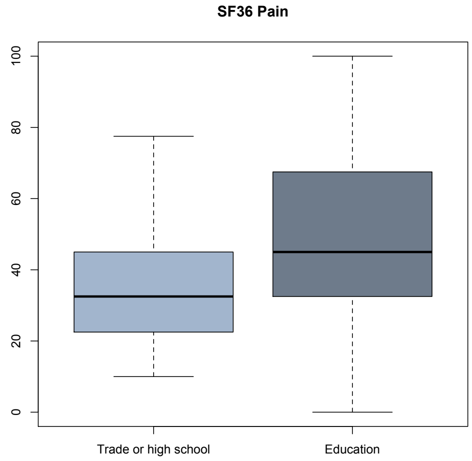

Figure 2.70: Boxplot of SF36 Pain by Education

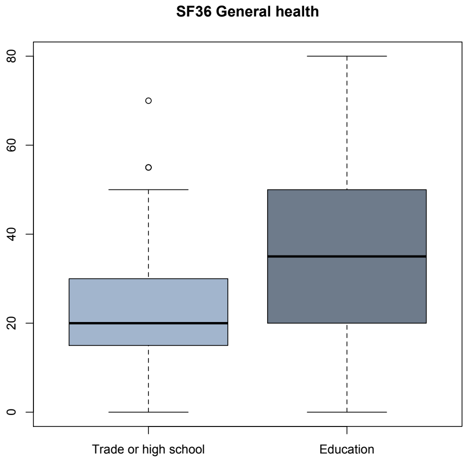

Figure 2.71: Boxplot of SF36 General health by Education

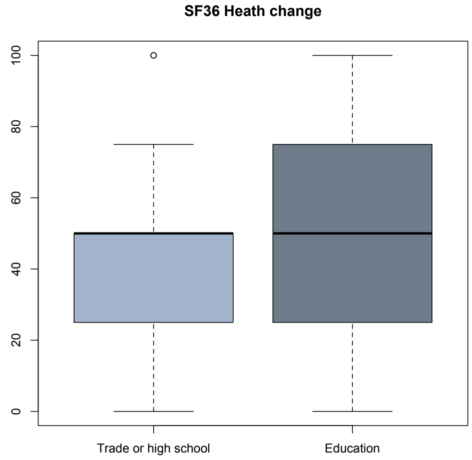

Figure 2.72: Boxplot of SF36 Health change by Education

Comparisons of SF36 scales by Socio-Economic Indexes For Areas (SEIFA)

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10 , *high SEIFA* (N=50, 50.00%) compared to those with a mid to low SEIFA score of 1-6, *mid-low SEIFA* (N=50, 50.00%).

Boxplots of each SF36 scale by **SEIFA** are displayed in Figures 2.73-2.81, summary statistics are displayed in Table 2.40 Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.40).

No significant differences were observed between participants that lived in areas with a *High SEIFA* compared to those that lived in an area with *a Mid to low SEIFA* areas for any of the SF36 scales.

Table 2.40: SF36 by SEIFA Wilcoxon rank sum test

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	High SEIFA	50	50.00	50.00	30.00	1317.00	0.6459
	Mid to low SEIFA	50	50.00	45.00	47.50		
Role functioning/physical	High SEIFA	50	50.00	0.00	43.75	1293.50	0.7272
	Mid to low SEIFA	50	50.00	0.00	25.00		
Role functioning/emotional	High SEIFA	50	50.00	33.33	100.00	1188.00	0.6469
	Mid to low SEIFA	50	50.00	50.00	100.00		
Energy/fatigue	High SEIFA	50	50.00	25.00	30.00	1120.50	0.3719
	Mid to low SEIFA	50	50.00	25.00	30.00		
Emotional well-being	High SEIFA	50	50.00	62.00	24.00	1132.00	0.4166
	Mid to low SEIFA	50	50.00	66.00	24.00		
Social functioning	High SEIFA	50	50.00	43.75	50.00	1142.50	0.4555
	Mid to low SEIFA	50	50.00	50.00	25.00		
Pain	High SEIFA	50	84.00	40.00	35.00	1232.00	0.9027
	Mid to low SEIFA	50	50.00	40.00	30.00		
General health	High SEIFA	50	50.00	25.00	30.00	1143.50	0.4632
	Mid to low SEIFA	50	50.00	30.00	25.00		
Health change	High SEIFA	50	50.00	50.00	50.00	1425.00	0.2146
	Mid to low SEIFA	50	50.00	50.00	43.75		

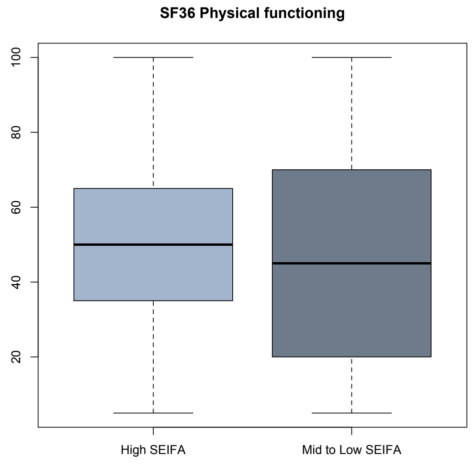

Figure 2.73: Boxplot of SF36 Physical functioning by SEIFA

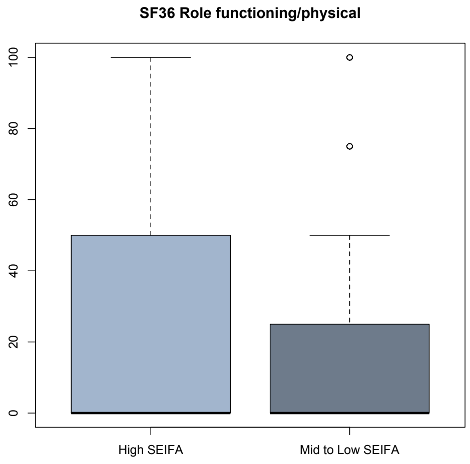

Figure 2.74: Boxplot of SF36 Role functioning/physical by SEIFA

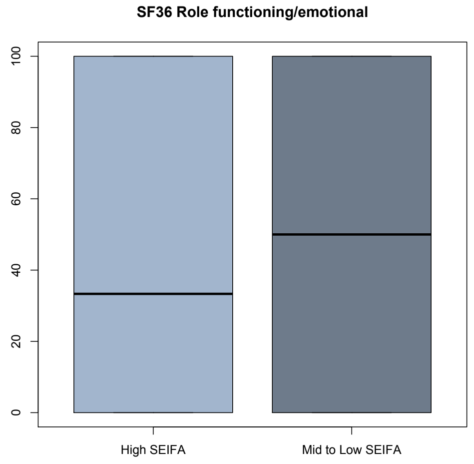

Figure 2.75: Boxplot of SF36 Role functioning/ emotional by SEIFA

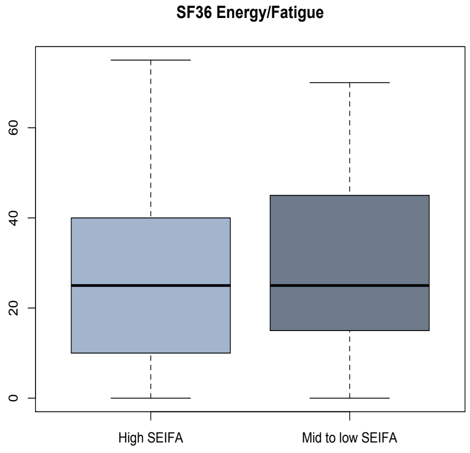

Figure 2.76: Boxplot of SF36 Energy/fatigue by SEIFA

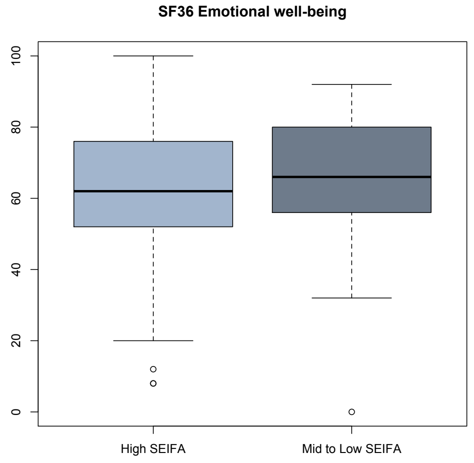

Figure 2.77: Boxplot of SF36 Emotional well-being by SEIFA

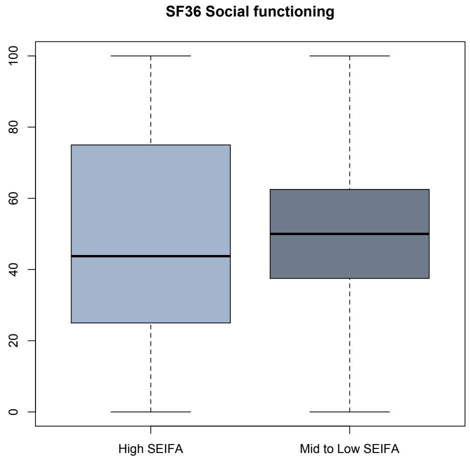

Figure 2.78: Boxplot of SF36 Social functioning by SEIFA

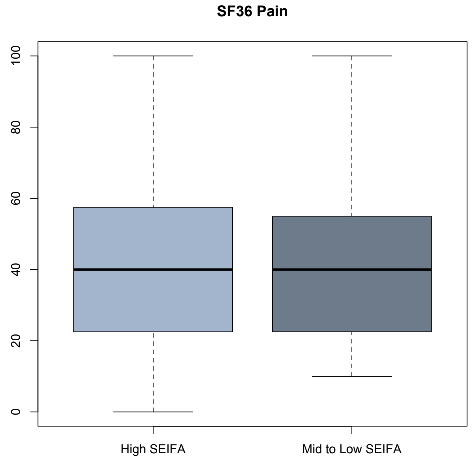

Figure 2.79: Boxplot of SF36 Pain by SEIFA

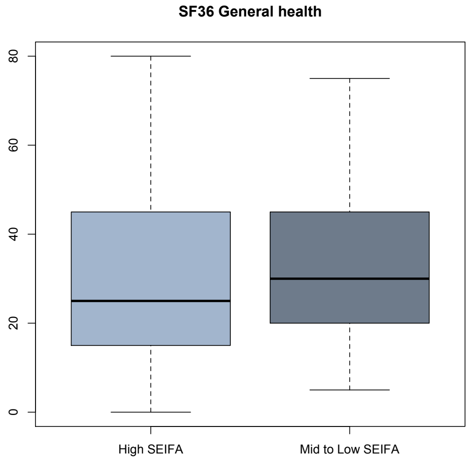

Figure 2.80: Boxplot of SF36 General health by SEIFA

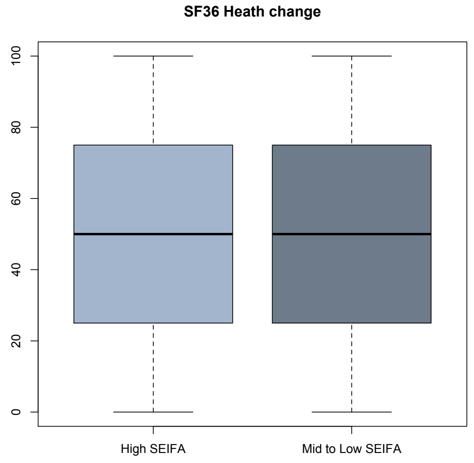

Figure 2.81: Boxplot of SF36 Health change by SEIFA

Section 3 Symptoms and diagnosis

Section 3: Experience of symptoms and diagnosis

Other health conditions

- Participants described other conditions that they had in addition to rheumatoid arthritis. There were 87 (87.00%) participants had at least one other condition.
- There were 37 participants (37.00%) described having anxiety, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=13, 13.00%); and 31 participants (31.00%) described having depression, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=7, 7.00%).
- Other common co-morbidities were chronic pain (n=42, 42.00%), sleep problems (n=32, 32.00%), and asthma (n=24, 24.00%). There were 13 participants had no other conditions (13.00%).

Experience of symptoms before diagnosis

- Participants were asked on the questionnaire which symptoms they had before diagnosis. The most common symptoms were joint pain (n=93, 93.00%), joint stiffness (n=90, 90.00%) and fatigue/loss of energy (n=84, 84.00%).
- Participants had between zero and ten symptoms, most commonly four symptoms (N=18, 18.00%) or five symptoms (n=20, 20.00%).
- The median quality of life was in the “Life was distressing” range for fatigue/loss of energy.
- The median quality of life was in the “Life was a little distressing” range for joint pain, joint stiffness, warm, swollen or tender joints, sweating more than usual, fever, loss of appetite, chest pain, and weight loss.
- The median quality of life was in the “Life was average” range for dry eyes.

Symptoms leading to diagnosis

- In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was pain. Overall there were 73 participants (73.00%) that noted this, of which 67 described general pain or joint pain and five described an aching pain. There were 18 participants (18.00%) that experienced swelling in their joints leading to diagnosis. The next most frequent themes were swelling that was often described as being sprain-like (n=14, 14.00%), followed by severe fatigue (n=13, 13.00%) and having flu-like symptoms (n=10, 10.00%).

Diagnostic tests

- Participants were asked on the online questionnaire what tests that they had received leading up to their diagnosis with Rheumatoid arthritis. Almost all the participants had blood tests (n=96, 96.00%), and the majority had a physical examination (n=87, 87.00%).
- Participants had between one and six diagnostic tests, two thirds (n=66, 66.00%) had three or more diagnostic tests.

Time from diagnostic tests to diagnosis

- Participants were asked on the online questionnaire about the amount of time from diagnostic test until they received a diagnosis. The time ranged from less than one week to 4 months. The most common response was four weeks or more (n=35, 35.00%), and more than half of the participants waited less than three weeks (n=63, 63.00%).

Diagnosis provider

- Participants were asked who gave them their diagnosis and where the diagnosis was given. The majority were diagnosed by a rheumatologist (n=51, 51.00%), or by a general practitioner (n= 46, 46.00%).

Diagnosis location

- Most participants received their diagnosis at a specialist clinic (n=47, 48.45%), followed by at the general practice (n=41, 42.27%).

Emotional support at diagnosis

- Participants were asked whether they felt supported at the time of diagnosis. There were 61 participants (61.00%) that indicated that they had no support at diagnosis, while 18 participants (18.00%) noted that they had enough support. An additional 21 participants (21.00%) indicated that they had some support but that it was not enough.

Information given at diagnosis

- Participants were asked whether they felt they were given enough information at diagnosis. There were 17 participants (17.00%) that indicated that they were given no information at diagnosis, while 26 participants (26.00%) noted that they were given enough information. The majority of participants (N=57, 57.00%) indicated that they were given some information but that it was not enough.

Costs at diagnosis

- Participants estimated the amount of out of pocket expenses they had for diagnostic tests and medical consultations. There were 24 participants (24.00%) had no out of pocket expenses, 18 participants (14.00%) spent between $100 and $500, 12 participants (12.00%) between $500 and $1000, and four participants (4.00%) spent more than $1000. The remaining 42 participants were unable to recall how much they spent (42.00%).

Burden of costs at diagnosis

- Participants described if the costs at diagnosis were a burden. For six participants (n= 6, 7.89%), it was no burden at all, 31 participants (40.79%) found it extremely or moderately significant burden, and 39 participants (51.31%) found it a somewhat or slightly significant burden.

Discussions about genetic tests and biomarkers

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. There were three participants (3.00%) that indicated that they had brought up the topic for discussion with their doctor and 8 participants (8.00%) that reported that their doctor had brought up the topic for discussion. There were also 89 participants (89.00%) that indicated that no one had ever spoken to them about this.

Experience of genetic tests

- Participants were asked what their experience of, or interest in genetic and biomarker tests. The majority of the participants did not have these tests but would like to (n=82, 82.00%), and a total of ten participants (10.00%) had these tests either by paying for the tests themselves (n=3, 3.00%) or having no out of pocket costs (n=7, 7.00%). There were 8 participants (n=8, 8.00%) were not interested in having these tests.

Diagnosis

- The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). There were 23 (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission.
- Participants described the affected areas, with the majority having four or more affected areas (n=61, 61.00%). The most common sites affected were hands/wrists/fingers (n=93, 93.00%) and feet/ankles/toes (n=82, 82.00%).
- Participants most commonly reported that they had flare-ups once a week (n=26, 26.00%), more than half had flare-ups once a month or more frequently (n=68, 68.00%).
- Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (N=47, 47.00%). The most common biomarker was C-Reactive protein (n=34, 34.00%), followed by rheumatoid factor (n=33, 33.00%).

Understanding of disease at diagnosis

- Participants were asked how much they knew about rheumatoid arthritis at diagnosis. There were 53 participants (53.00%) reported having no knowledge. Other reported themes included knowing few details (n=16, 16.00%), having a professional background that meant that participants had some knowledge of the condition (n=10, 10.00%), having had a family member with rheumatoid arthritis that helped them understand the condition (n=9, 9.00%) and participants knowing about rheumatoid arthritis through their own research before the diagnosis (n=8, 8.00%).

Understanding of prognosis

- Participants were asked in the structured interview to describe their understanding of their prognosis. The most common theme (n=19, 19.00%) was that participants describes not being sure of their prognosis as they had not had a proper conversation about this with their clinician. This was followed by the description of prognosis in the context of it being managed with medication (n=13, 13.00%), prognosis being described as currently having stable disease (n=9, 9.00%) and prognosis being described as a good prognosis and being positive (n=9, 9.00%).

Other health conditions

Participants described other conditions that had in addition to rheumatoid arthritis. There were 87 (87.00%) participants had at least one other condition (Table 3.1). There were 37 participants (37.00%) described having anxiety, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=13, 13.00%); and 31 participants (31.00%) described having depression, either diagnosed by a clinician (n=24, 24.00%) or self-diagnosed (n=7, 7.00%). Other common co-morbidities were chronic pain (n=42, 42.00%), sleep problems (n=32, 32.00%), and asthma (n=24, 24.00%). There were 13 participants had no other conditions (13.00%).

Table 3.1: Other conditions

Other conditions	N= 100	%
Chronic pain	42	42.00
Sleep problems or insomnia	32	32.00
Anxiety (Diagnosed by a clinician)	24	24.00
Asthma	24	24.00
Depression (Diagnosed by a clinician)	24	24.00
Hypertension	21	21.00
Anxiety (Self diagnosed)	13	13.00
Arrhythmias	8	8.00
COPD	8	8.00
Depression (Self diagnosed)	7	7.00
Diabetes	5	5.00
No other conditions	13	13.00
Specify other		
Other arthritis	14	
CNS problems	13	
Immune system problems	13	
Muscular/skeletal problems	8	
Reproductive system problems	7	
Skin problems	7	
Digestive system problems	7	
Endocrine system problems	6	
Respiratory problems	6	
Cardiovascular problems	3	
Liver problems	3	
Eye problems	2	
Bladder/urinary problems	1	
Dental problems	1	
Ear problems	1	
Mental health problems	1	

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis. Participants had between zero and ten symptoms, most commonly four symptoms (n=18, 18.00%) or five symptoms (n=20, 20.00%) (Table 3.2). The most common symptoms were joint pain (n=93, 93.00%), joint stiffness (n=90, 90.00%) and fatigue/loss of energy (n=84, 84.00%) (Table 3.3).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great” (Table 3.4, Figures 3.1 to 3.10). The median quality of life was in the “Life was distressing” range for fatigue/loss of energy (n=84, median = 2.00). The median quality of life was in the, “Life was a little distressing” range for joint pain (n= 93, median = 3), joint stiffness (n=90, median = 3), warm, swollen or tender joints (n=83, median = 3), sweating more than usual (n=40, median = 3), fever (n=31, median = 3), loss of appetite (n= 26, median = 3), chest pain (n=17, median = 3), and weight loss (n=24, median = 3.5). The median quality of life was in the “Life was average” range for dry eyes (n=43, median = 4).

Table 3.2: Number of symptoms

Number of symptoms	N=100	Percent
0	1	1.00
1	4	4.00
2	11	11.00
3	12	12.00
4	18	18.00
5	20	20.00
6	11	11.00
7	9	9.00
8	7	7.00
9	3	3.00
10	4	4.00

Table 3.3: Symptoms experienced before diagnosis.

Other conditions	N=100	Percent
Chronic pain	42	42.00
Sleep problems or insomnia	32	32.00
Anxiety (Diagnosed by a clinician)	24	24.00
Asthma	24	24.00
Depression (Diagnosed by a clinician)	24	24.00
Hypertension	21	21.00
Anxiety (Self diagnosed)	13	13.00
Arrhythmias	8	8.00
COPD	8	8.00
Depression (Self diagnosed)	7	7.00
Diabetes	5	5.00
No other conditions	13	13.00
Specify other		
Other arthritis	14	
CNS problems	13	
Immune system problems	13	
Muscular/skeletal problems	8	
Reproductive system problems	7	
Skin problems	7	
Digestive system problems	7	
Endocrine system problems	6	
Respiratory problems	6	
Cardiovascular problems	3	
Liver problems	3	
Eye problems	2	
Bladder/urinary problems	1	
Dental problems	1	
Ear problems	1	
Mental health problems	1	

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Table 3.4: Symptoms and quality of life

Symptom	Joint pain N=93		Joint stiffness N=90		Warm, swollen or tender joints N=83		Fatigue/loss of energy N=84		Fever N=31	
Quality of life rating	N	%	N	%	N	%	N	%	N	%
1 Life was very distressing	18	19.35	12	13.33	16	19.28	25	29.76	7	22.58
2 Life was distressing	25	26.88	24	26.67	25	30.12	30	35.71	4	12.90
3 Life was a little distressing	33	35.48	33	36.67	31	37.35	18	21.43	8	25.81
4 Life was average	9	9.68	14	15.56	6	7.23	8	9.52	11	35.48
5 Life was good	3	3.23	5	5.56	2	2.41	1	1.19	0	0
6 Life was very good	3	3.23	2	2.22	1	1.20	1	1.19	0	0
7 Life was great	2	2.15	0	0	2	2.41	1	1.19	1	3.23
Mean QOL		2.69		2.08		2.57		2.25		2.91
Median QOL		3.00		3.00		3.00		2.00		3.00

Symptom	Sweat N=40		Loss of appetite N=26		Weight loss N=24		Dry eyes N=43		Chest pain N=17	
Quality of life rating	N	%	N	%	N	%	N	%	N	%
1 Life was very distressing	7	17.50	2	7.69	3	12.5	3	6.98	3	17.65
2 Life was distressing	9	22.50	6	23.08	3	12.5	8	18.60	5	29.41
3 Life was a little distressing	15	37.50	8	30.77	6	25	10	23.26	8	47.06
4 Life was average	7	17.50	8	30.77	9	37.5	17	39.53	1	5.88
5 Life was good	0	0	1	3.85	1	4.17	5	11.63	0	0
6 Life was very good	1	2.50	0	0	1	4.17	0	0	0	0
7 Life was great	1	2.50	1	3.85	1	4.17	0	0	0	0
Mean QOL		2.78		3.15		3.38		3.30		2.41
Median QOL		3.00		3.00		3.50		4.00		3.00

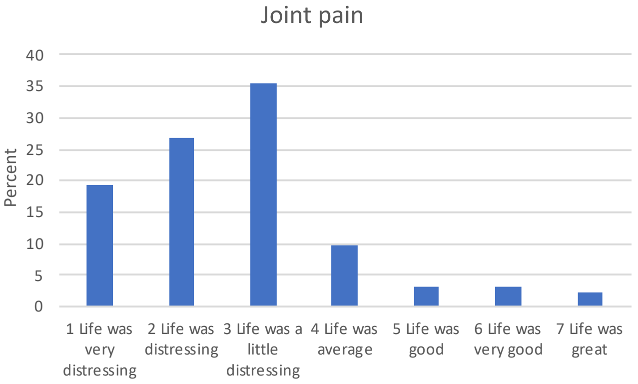


Figure 3.1: Quality of life from joint pain

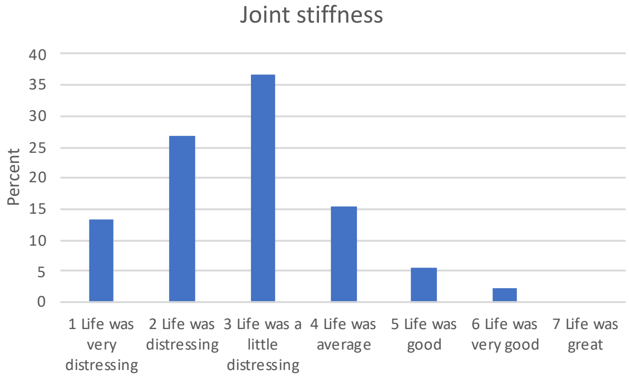


Figure 3.2: Quality of life from joint stiffness

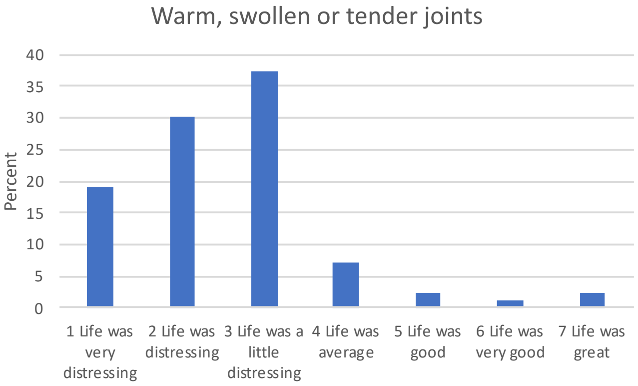


Figure 3.3: Quality of life from warm swollen or tender joints

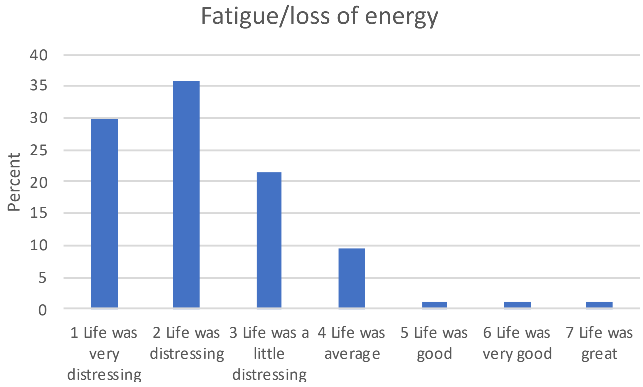


Figure 3.4: Quality of life from fatigue/loss of energy

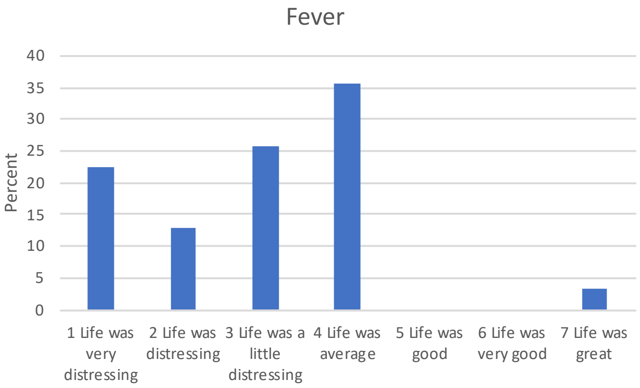


Figure 3.5: Quality of life from fever

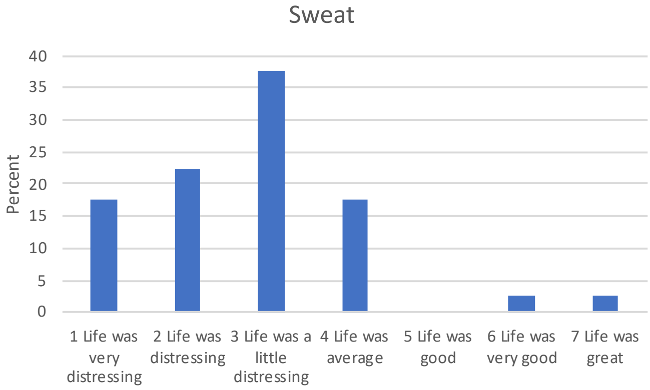


Figure 3.6: Quality of life from sweat

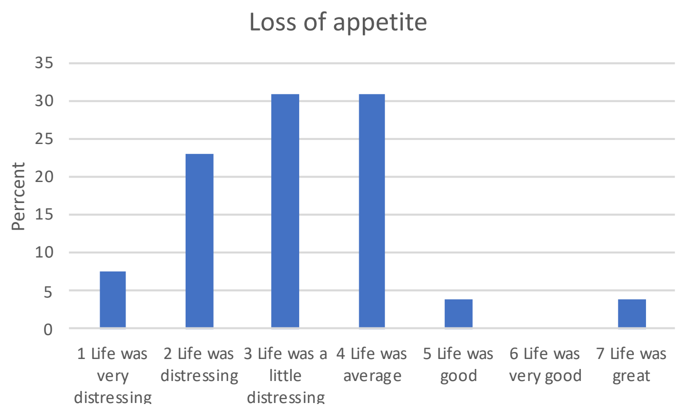


Figure 3.7: Quality of life from loss of appetite

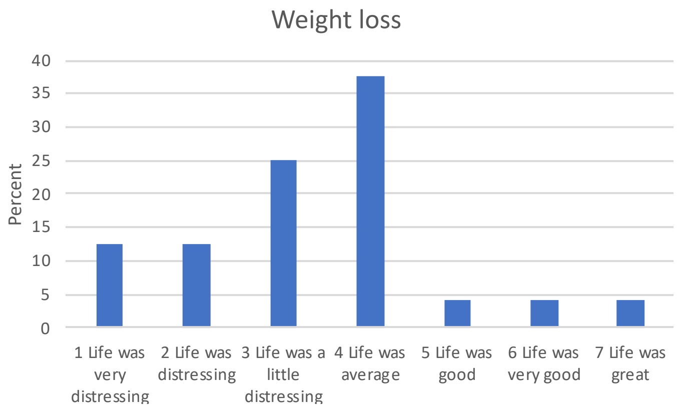


Figure 3.8: Quality of life from weight loss

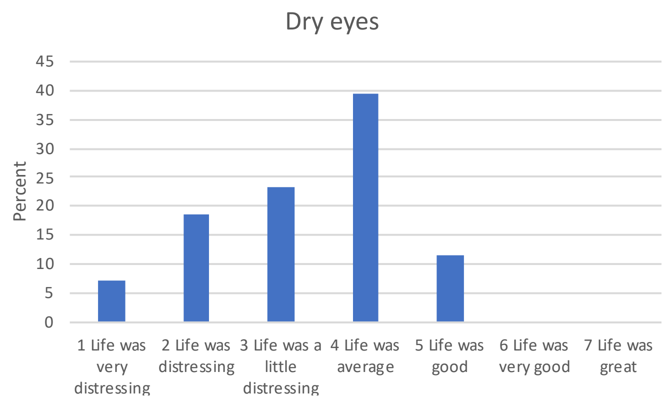


Figure 3.9: Quality of life from dry eyes

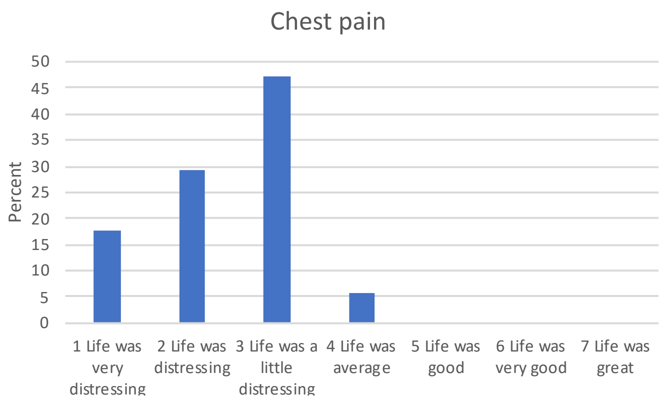


Figure 3.10: Quality of life from chest pain

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was pain. Overall there were 73 participants (73.00%) that noted this, of which 67 described general pain or joint pain and five described an aching pain. There were 18 participants (18.00%) that experienced swelling in their joints leading to diagnosis. The next most frequent themes were swelling that was often described as being sprain-like (n=14, 14.00%), followed by severe fatigue (n=13, 13.00%) and having flu-like symptoms (n=10, 10.00%).

In relation to sub-group variations, participants in the sub-group *Symptoms: most days* (56.25%%), described experiencing pain more frequently than the general population (73.00%), while those in the *Symptoms: no to few days* subgroup described this more frequently (85.00%).

Participants in the subgroups *Physical limitations: some to most days* (32.43%), *Symptoms: all days* (33.33%), *Affect: very often to always* (25.81%), *Social: no to few days* (25.00%), those aged *55 or older* (25.81%), those from *Regional or Remote areas* (31.82%) and those with a *Trade or high school education* (27.27%), described experiencing swelling (sprain-line or reduced flexibility), more frequently than the general population (14.00%), while there were no participants in the *Physical limitations: no days* subgroup that described this.

Participants in the *Physical limitations: no days* (36.84%) and *Symptoms: no to few days* (35.00%) sub-groups described experiencing severe fatigue more frequently than the general population (13.00%), while those in the *Physical limitations: some to most days* sub-group described this less frequently (2.70%).

Participants in the *Symptoms: most days* (21.88%) sub-group described having flu-like symptoms more frequently than the general population (10.00%).

Participants in the sub-groups *Symptoms: all days* (4.76%), Affect: sometimes (5.56%), *Affect: very often to always* (3.23%), *Social: no to few days* (6.82%), *Frequent flare ups* (2.27%), Aged 35 – 54 (7.84%), *Metropolitan* (3.57%), *High SEIFA* (6.00%) and *Mid to low SEIFA* (6.00%), all reported experiencing swelling (at joints), less frequently than the general population

(18.00%). There were no participants in the following groups that reported this: *Physical limitations: some to most days*, *Symptoms: most days, Social: some days, Aged 55 or older,* and *Trade or high school.*

Participant describes pain

For a couple of nights going to bed I was in pain all over, so, um, it felt like whole body pain and um, and then I pretty quickly went to the doctor because I thought, well this is pretty weird. Participant 3

The pain in my left foot just got worse and worse, and my right knee was getting worse as well. I'd been working for about six months and ended up finally going to the doctor and he took one look at the, sort of looked at my feet and turned around and said to me, this is the status, it's arthritis. Participant 30

I went to the rheumatologist for the very first time and he actually said to me, why didn't you come earlier? And I said to him, well, I had a pain in my wrist, you know you don't go to the doctor for a pain in your wrist. I had a sore heel and I thought I bought incorrect shoes, things like that. Participant 52

I noticed a couple of days when I got up, my feet were really sore. I thought "I don't think I can manage this". I didn't really think much of it, to be perfectly honest. After a little while, because I used to walk to the station – walking was my biggest joy. Now, all of a sudden, I couldn't do it very well, or as well anyhow. I was limping. It wasn't like it was a bit of morning stiffness and I could just walk it out. It stayed throughout the day. Participant 68

Participant describes swelling

Um, on my left hand, my ring finger was really swollen one morning when I wake up and, um, sore and I thought that I'd somehow broken it or something. So I went to the doctors and he sent me for some blood tests and an x-ray and he said that he thought that it could be maybe rheumatoid arthritis, but also maybe gout, that I was still a little bit convinced that it would be something like I've sprained my finger. Participant 7

I was called a hypochondriac, um, that they could not see anything wrong. Um, and left, told me to go. Within a month, um, my body blew up like a balloon. Participant 98

So that was over a period of about a month and then the fingers were really swelling badly, and I tore my shoulder, I did something and I hit my shoulder. So, I had to go to the doctor because of that. And there was no connection between that at the time. But I said to her, can you look at these fingers? You know, they're really swollen. And luckily her mum had it and she said she thought that's what it was. Participant 94

In addition to the specific symptoms experienced, below are some examples of comments made indicating that some participants had a difficult or complex diagnostic pathway:

And I said I want a referral to a rheumatologist. And he agreed to give me one, but he also said, you know, they might not find anything wrong with you and you shouldn't, you know, you should just get on with life. You shouldn't dwell on these little aches and pains. Participant 4

And it just, it just over the years kept getting more and more symptoms. Like my wrist started aching. Um, I noticed it in my shoulders and my back and my doctors kept saying, oh you must still have growing pains. Participant 5

When I went to the GP and they didn't want to do a blood test and he kept telling me I just wanted anti-inflammatories, the pain's in my head, there was nothing wrong and all this stuff. Participant 38

I just went from being physically fit, but having been pregnant for nine months, but apart from the last six weeks I was fine. I was active except for when I got really big and I went from being physically fit to not being able to move. And all these doctors basically just kept saying, well, you had a baby. It takes a while to recover and wouldn't listen to what I was telling them was my pain. Participant 72

In the end, he just tried to tell me it was all in my head and I was just depressed. Because I'm one of those very stubborn people, I just pretty much stamped my foot and said "No, I'm not". Participant 93

Table 3.5: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes having pain leading up to diagnosis (All descriptions of pain)	73	73.00	15	78.95	33	75.00	25	67.57	**17**	**85.00**	22	81.48	18	56.25	16	76.19
Participant describes having pain leading up to diagnosis	67	67.00	13	68.42	29	65.91	25	67.57	15	75.00	19	70.37	18	56.25	15	71.43
Participant describes having pain - described as aching pain - leading up to diagnosis	6	6.00	4	21.05	2	4.55	1	2.70	4	20.00	2	7.41	1	3.13	0	0.00
Participant describes experiencing swelling (at joints) leading up to diagnosis	18	18.00	2	10.53	4	9.09	0	0.00	2	10.00	3	11.11	0	0.00	1	4.76
Participant describes experiencing swelling (Sprain-like or reduced flexibility), leading up to diagnosis	14	14.00	0	0.00	6	13.64	**12**	**32.43**	1	5.00	3	11.11	7	21.88	**7**	**33.33**
Participant describes experiencing severe fatigue leading up to diagnosis	13	13.00	7	36.84	6	13.64	1	2.70	7	35.00	4	14.81	2	6.25	1	4.76
Participant describes having flu-like symptoms (including body aches, fever, general malaise and fatigue), leading up to diagnosis	10	10.00	3	15.79	4	9.09	6	16.22	1	5.00	4	14.81	7	21.88	1	4.76
Participant describes noticing spurs or nodules or cyst leading up to diagnosis	7	7.00	1	5.26	5	11.36	4	10.81	2	10.00	1	3.70	4	12.50	3	14.29
Participant describes having sudden onset loss of mobility leading to diagnosis	6	6.00	0	0.00	2	4.55	4	10.81	0	0.00	1	3.70	3	9.38	2	9.52

Symptoms leading to diagnosis	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes having pain leading up to diagnosis (All descriptions of pain)	73	73.00	26	78.79	23	63.89	24	77.42	15	75.00	24	66.67	34	77.27
Participant describes having pain leading up to diagnosis	67	67.00	23	69.70	21	58.33	23	74.19	12	60.00	24	66.67	31	70.45
Participant describes having pain - described as aching pain - leading up to diagnosis	6	6.00	2	6.06	4	11.11	1	3.23	3	15.00	3	8.33	1	2.27
Participant describes experiencing swelling (at joints) leading up to diagnosis	18	18.00	3	9.09	2	5.56	1	3.23	3	15.00	0	0.00	3	6.82
Participant describes experiencing swelling (Sprain-like or reduced flexibility), leading up to diagnosis	14	14.00	3	9.09	7	19.44	8	25.81	3	15.00	4	11.11	11	25.00
Participant describes experiencing severe fatigue leading up to diagnosis	13	13.00	7	21.21	6	16.67	1	3.23	4	20.00	6	16.67	4	9.09
Participant describes having flu-like symptoms (including body aches, fever, general malaise and fatigue), leading up to diagnosis	10	10.00	2	6.06	5	13.89	6	19.35	1	5.00	7	19.44	5	11.36
Participant describes noticing spurs or nodules or cyst leading up to diagnosis	7	7.00	1	3.03	5	13.89	4	12.90	1	5.00	3	8.33	6	13.64
Participant describes having sudden onset loss of mobility leading to diagnosis	6	6.00	1	3.03	2	5.56	3	9.68	1	5.00	5	13.89	0	0.00

Symptoms leading to diagnosis	All participants		Occasional flare ups		Frequent flare ups		Aged 55 or older		Aged 35 - 54		Aged 18 – 34	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes having pain leading up to diagnosis (All descriptions of pain)	73	73.00	41	73.21	32	72.73	22	70.97	38	74.51	13	72.22
Participant describes having pain leading up to diagnosis	67	67.00	36	64.29	31	70.45	22	70.97	34	66.67	11	61.11
Participant describes having pain - described as aching pain - leading up to diagnosis	6	6.00	4	7.14	3	6.82	1	3.23	3	5.88	3	16.67
Participant describes experiencing swelling (at joints) leading up to diagnosis	18	18.00	5	8.93	1	2.27	0	0.00	4	7.84	2	11.11
Participant describes experiencing swelling (Sprain-like or reduced flexibility), leading up to diagnosis	14	14.00	8	14.29	10	22.73	8	25.81	7	13.73	3	16.67
Participant describes experiencing severe fatigue leading up to diagnosis	13	13.00	10	17.86	4	9.09	3	9.68	9	17.65	2	11.11
Participant describes having flu-like symptoms (including body aches, fever, general malaise and fatigue), leading up to diagnosis	10	10.00	6	10.71	7	15.91	4	12.90	8	15.69	1	5.56
Participant describes noticing spurs or nodules or cyst leading up to diagnosis	7	7.00	4	7.14	6	13.64	3	9.68	4	7.84	3	16.67
Participant describes having sudden onset loss of mobility leading to diagnosis	6	6.00	4	7.14	2	4.55	3	9.68	2	3.92	1	5.56

Symptoms leading to diagnosis	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes having pain leading up to diagnosis (All descriptions of pain)	73	73.00	45	80.36	28	63.64	22	66.67	51	76.12	37	74.00	36	72.00
Participant describes having pain leading up to diagnosis	67	67.00	43	76.79	24	54.55	22	66.67	45	67.16	34	68.00	33	66.00
Participant describes having pain - described as aching pain - leading up to diagnosis	6	6.00	6	10.71	1	2.27	3	9.09	4	5.97	6	12.00	1	2.00
Participant describes experiencing swelling (at joints) leading up to diagnosis	18	18.00	2	3.57	4	9.09	0	0.00	6	8.96	3	6.00	3	6.00
Participant describes experiencing swelling (Sprain-like or reduced flexibility), leading up to diagnosis	14	14.00	4	7.14	14	31.82	9	27.27	9	13.43	7	14.00	11	22.00
Participant describes experiencing severe fatigue leading up to diagnosis	13	13.00	10	17.86	4	9.09	5	15.15	9	13.43	10	20.00	4	8.00
Participant describes having flu-like symptoms (including body aches, fever, general malaise and fatigue), leading up to diagnosis	10	10.00	7	12.50	6	13.64	3	9.09	10	14.93	8	16.00	5	10.00
Participant describes noticing spurs or nodules or cyst leading up to diagnosis	7	7.00	6	10.71	4	9.09	4	12.12	6	8.96	4	8.00	6	12.00
Participant describes having sudden onset loss of mobility leading to diagnosis	6	6.00	2	3.57	4	9.09	2	6.06	4	5.97	3	6.00	3	6.00

Table 3.5: Symptoms leading to diagnosis (Cont.)

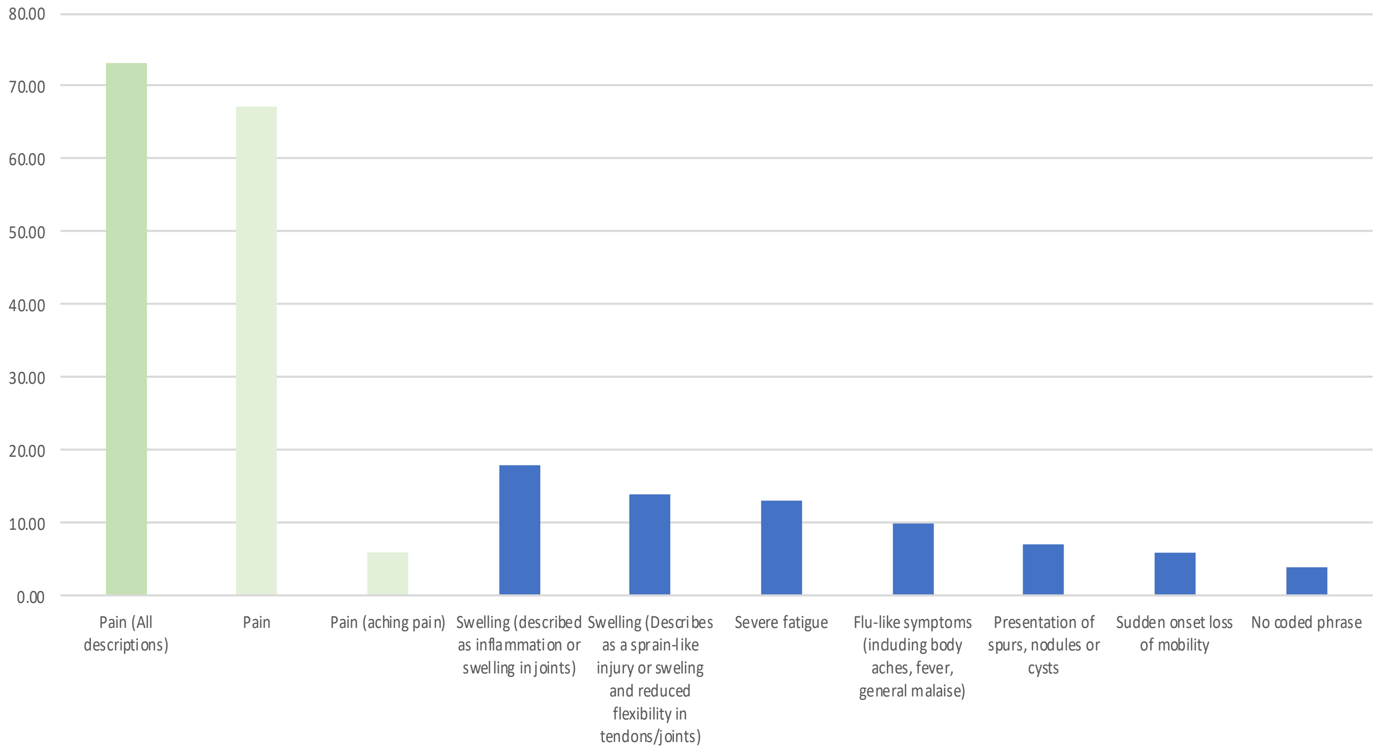


Figure 3.11: Symptoms leading to diagnosis

Diagnostic pathway

Participants were asked on the online questionnaire what tests they had received leading up to their diagnosis with rheumatoid arthritis. Almost all the participants had blood tests (n=96, 96.00%), and the majority had a physical examination (n=87, 87.00%) (Table 3.6). Participants had between one and six diagnostic tests, two thirds (n=66, 66.00%) had three or more diagnostic tests (Table 3.7).

Table 3.6: Diagnostic tests

Diagnostic test	N=100	Percent
Blood tests	96	96.00
Physical examination	87	87.00
X-Ray	62	62.00
MRI	28	28.00
None	1	1.00
Other		
Bone scan	7	
Ultrasound	6	
CT scan	3	
Hospital stay	2	
Biopsy	1	
Eye test	1	
Food sensitivity	1	
Gallium scan	1	
Medical history	1	
Sestamibi scan	1	

Table 3.7: Number of diagnostic tests

Number of Diagnostic Tests	N=100	Percent
0	1	1.00
1	9	9.00
2	24	24.00
3	33	33.00
4 or more	33	33.00

Time from diagnostic tests to diagnosis

Participants were asked on the online questionnaire about the amount of time from diagnostic test until they received a diagnosis. The time ranged from less than one week to 4 months. The most common response was 4 weeks or more (n=35, 35.00%), and more than half of the participants waited less than 3 weeks (n=63, 63.00%) (Table 3.8, Figure 3.12).

Table 3.8: Time from diagnostic test to diagnosis

Time from diagnostic test to diagnosis	N=100	Percent
Less than 1 week	23	23.00
Between 1 and 2 weeks	25	25.00
Between 2 and 3 weeks	15	15.00
4 weeks or more	35	35.00
Don't know	2	2.00

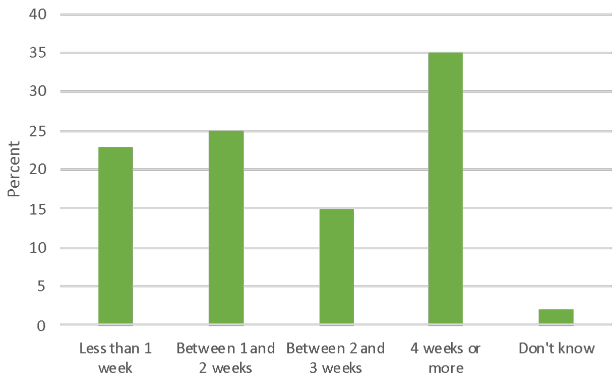


Figure 3.12: Time from diagnostic test to diagnosis

Diagnosis provider

Participants were asked who gave them their diagnosis and where the diagnosis was given. The majority were diagnosed by a rheumatologist (n=51, 51.00%), followed by a general practitioner (n= 46, 46.00%) (Table 3.9).

Table 3.9: Diagnosis provider

Number of Diagnostic Tests	N=100	Percent
0	1	1.00
1	9	9.00
2	24	24.00
3	33	33.00
4 or more	33	33.00

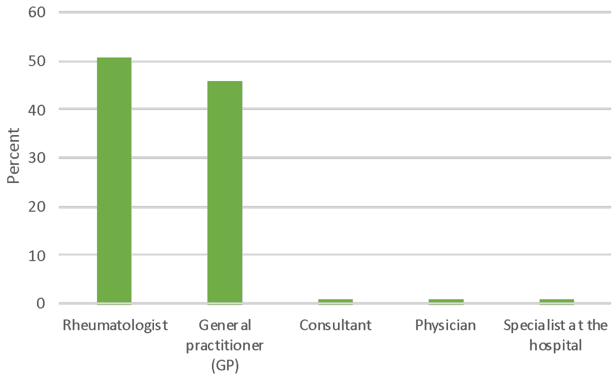


Figure 3.13: Diagnosis provider

Diagnosis location

Most participants received their diagnosis at a specialist clinic (n=47, 48.45%), followed by at the general practice (n=41, 42.27%) (Table 3.10).

Table 3.10: Diagnosis location

Place of diagnosis	N=97	Percent
Specialist clinic	47	48.45
General practice (GP)	41	42.27
Hospital	8	8.25
By phone	1	1.03

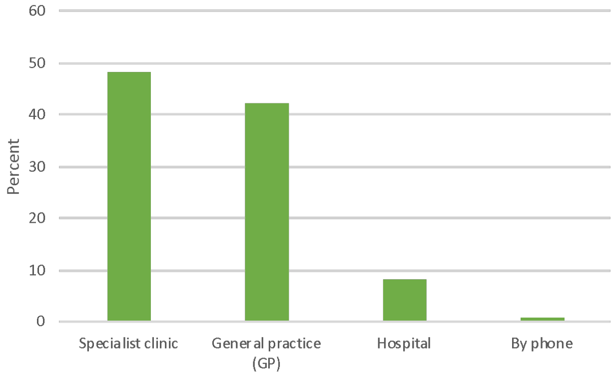


Figure 3.14 Diagnosis location

Emotional support at diagnosis

In the questionnaire, participants were asked whether they felt supported at the time of diagnosis. There were 61 participants (61.0%) that indicated that they had no support at diagnosis, while 18 participants (18.00%) noted that they had enough support. An additional 21 participants (21.00%) indicated that they had some support but that it was not enough (Table 3.11, Figure 3.15).

Table 3.11: Emotional support at diagnosis

Emotional support from healthcare professionals between testing and diagnosis	N=100	Percent
I/we had enough support	18	18.00
I/we had no support	61	61.00
I/we had some support but it wasn't enough	21	21.00

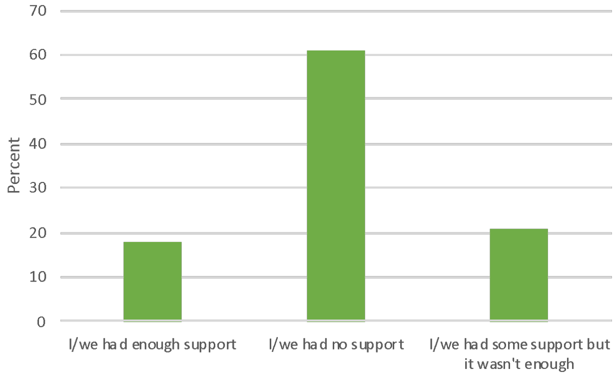


Figure 3.15: Emotional support at diagnosis

In relation to sub-group variations, subgroups that had "Enough support" more often than the general population (n=18, 18.00%) were participants in the sub-groups *Symptoms: no to few days* (n=6, 30.00%), *Affect: never to almost never* (N=10, 30.30%), and *Social: all to most* (n=6, 30.00%). Subgroups that had "Enough support" less often than the general population were participants in the sub-group *Affect: very often to always* (n= 2, 6.45%) (Table 3.12).

Participants that had "No support" more often than the general population (n=61, 61.00%) were the sub-groups *Physical: no days* (n=15, 78.95%), *Social: no to few days* (n=33, 75.00%), participants *Aged 18 to 34* (n=14, 77.78%), participants that lived in *Metropolitan* areas (n=41, 73.21%) and those that had *Trade or high school qualifications* (n=24, 72.73). Participants that had "No support" less often than the general population included the subgroups *Physical: few days* (n=22, 50.00%), *Social: sometimes* (n=16, 44.00%), and participants that lived in *Regional or remote* areas (n=20, 45.45%).

Participants that had "Some support, but not enough" more often than the general population (n=21, 21.00%) included the subgroups *Symptoms: most days (*n=10, 31.25%), *Social: sometimes* (n=14, 38.89%), and those that lived in *Regional or remote* areas (n=16, 36.36%). Participants that had "Some support, but not enough" less often than the general population included the sub-groups *Physical: no days* (n=1, 5.26%), *Symptoms: no to few days* (n=0, 0.00%), *Social: all to most* (n=2, 10.00%), participants *Aged 18 to 24* (n=1, 5.56%), and participants that lived in *Metropolitan* areas (n=5, 8.93%).

Table 3.12: Support at diagnosis by subgroups

Support at diagnosis	All participants		AIMS2-SF Physical Limitations scale						AIMS2-SF Symptoms scale							
			No days		Few days		Some to most days		No to few days		Some days		Most days		All days	
	N= 100	%	N=19	%	N=44	%	N=37	%	N=20	%	N=27	%	N=32	%	N=21	%
Enough Support	18	18.00	3	15.79	9	20.45	6	16.22	**6**	**30.00**	4	14.81	5	15.63	3	14.29
No support	61	61.00	**15**	**78.95**	**22**	**50.00**	24	64.86	14	70.00	17	62.96	17	53.13	13	61.90
Some support, but not enough	21	21.00	**1**	**5.26**	13	29.55	7	18.92	**0**	**0.00**	6	22.22	**10**	**31.25**	5	23.81

Support at diagnosis	All participants		AIMS2-SF Affect scale						AIMS2-SF Social scale					
			Never to almost never		Sometimes		Very often to always		All to most		Sometimes		No to few days	
	N= 100	%	N=33	%	N=36	%	N=31	%	N=20	%	N=36	%	N=44	%
Enough Support	18	18.00	**10**	**30.30**	6	16.67	**2**	**6.45**	**6**	**30.00**	6	16.67	6	13.64
No support	61	61.00	19	57.58	20	55.56	22	70.97	12	60.00	**16**	**44.44**	**33**	**75.00**
Some support, but not enough	21	21.00	4	12.12	10	27.78	7	22.58	**2**	**10.00**	**14**	**38.89**	5	11.36

Information given at diagnosis

In the questionnaire, participants were asked whether they felt they were given enough information at diagnosis. There were 17 participants (17.00%) that indicated that they were given no information at diagnosis, while 26 participants (26.00%) noted that they were given enough information. The majority of participants (n=57, 57.00%) indicated that they were given some information but that it was not enough (Table 3.13, Figure 3.16).

Table 3.13: Information at diagnosis

Information received at diagnosis	N=100	Percent
I/we had enough information	26	26.00
I/we had no information	17	17.00
I/we had some information but it wasn't enough	57	57.00

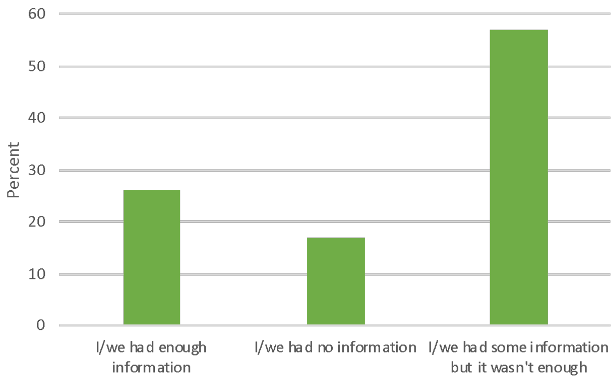


Figure 3.16: Information at diagnosis

In relation to sub-group variations, participants that had “Enough information” more often than the general population (n=26, 26.00%) were the sub-groups *Affect: never to almost never* (n=14, 42.42%), and *Social: all to most* (n=8, 40.00%). Participants that had “Enough information” less often than the general population were the sub-groups *Social: no to few days* (n= 7, 15.91%) (Table 3.14).

Participants that had “Some information, but not enough” less often than the general population (n=57, 57.00%) were in the sub-group *Affect: all to most* (n=9, 45.00%).

Table 3.14 Information given at diagnosis by subgroups

Information at diagnosis	All participants		AIMS2-SF Physical limitations						AIMS2-SF Symptoms							
			No days		Few days		Some to most days		No to few days		Some days		Most days		All days	
	N=100	%	N=19	%	N=44	%	N=37	%	N=20	%	N=27	%	N=32	%	N=21	%
Enough information	26	26.00	6	31.58	13	29.55	7	18.92	7	35.00	8	29.63	6	18.75	5	23.81
No information	17	17.00	3	15.79	4	9.09	10	27.03	3	15.00	3	11.11	7	21.88	4	19.05
Some information, but not enough	57	57.00	10	52.63	27	61.36	20	54.05	10	50.00	16	59.26	19	59.38	12	57.14

	All participants		AIMS2-SF Affect						AIMS2-SF Social					
			Never to almost never		Sometimes		Very often to always		All to most		Sometimes		No to few days	
	N=100	%	N=33	%	N=36	%	N=31	%	N=20	%	N=36	%	N=44	%
Enough information	26	26.00	14	42.42	7	19.44	5	16.13	8	40.00	11	30.56	7	15.91
No information	17	17.00	4	12.12	6	16.67	7	22.58	3	15.00	4	11.11	10	22.73
Some information, but not enough	57	57.00	15	45.45	23	63.89	19	61.29	9	45.00	21	58.33	27	61.36

Table 3.14 Information given at diagnosis by subgroups (Cont.)

	All participants						Age					
			Occasional		Frequent		Aged 18 to 34		Aged 35 to 44		Aged 55 or older	
	N=100	%	N=56	%	N=44	%	N=31	%	N=51	%	N=18	%
Enough information	26	26.00	18	32.14	8	18.18	3	16.67	15	29.41	8	25.81
No information	17	17.00	9	16.07	8	18.18	4	22.22	7	13.73	6	19.35
Some information, but not enough	57	57.00	29	51.79	28	63.64	11	61.11	29	56.86	17	54.84

	All participants		Location				Education				SEIFA			
			Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	N=100	%	N=56	%	N=44	%	N=33	%	N=67	%	N=50	%	N=50	%
Enough information	26	26.00	15	26.79	11	25.00	6	18.18	20	29.85	13	26.00	13	26.00
No information	17	17.00	7	12.50	10	22.73	5	15.15	12	17.91	10	20.00	7	14.00
Some information, but not enough	57	57.00	34	60.71	23	52.27	22	66.67	35	52.24	27	54.00	30	60.00

Costs at diagnosis

In the questionnaire, participants were asked to estimate the amount of out of pocket expenses they had for diagnostic tests and medical consultations. Twenty-four participants (24.00%) had no out of pocket expenses, 18 participants (18.00%) spent between $100 and $500, 12 participants (12.00%) between $500 and $1000, and four participants (4.00%) spent more than $1000. The remaining 42 participants were unable to recall how much they spent (42.00%) (Table 3.15).

Table 3.15: Out of pocket costs at diagnosis

Amount spent put of pocket for diagnosis ($AUD)	N=100	Percent
I didn't pay anything out of pocket	24	24.00
100 to under 250	4	4.00
250 to under 500	14	14.00
500 to under 750	9	9.00
750 to under 1000	3	3.00
more than 1000	4	4.00
Not sure	42	42.00

Burden of costs at diagnosis

The participants were then asked on the online questionnaire if the amount they spent was a burden, for six participants (N= 6, 7.89%), it was no burden at all, 31 participants (40.79%) found it extremely or moderately significant burden, and 39 participants (51.31%) found it a somewhat or slightly significant burden (Table 3.16).

Table 3:16: Burden of diagnostic costs

Costs a significant burden	N=76	Percent
Not at all significant	6	7.89
Slightly significant	16	21.05
Somewhat significant	23	30.26
Moderately significant	16	21.05
Extremely significant	15	19.74

Discussions about genetic tests and biomarkers

Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment (Table 3.17, Figure 3.17). There were three participants (3.00%) that indicated that they had brought up the topic for discussion with their doctor and 8 participants (8.00%) that reported that their doctor had brought up the topic for discussion. There were also 89 participants (89.00%) that indicated that no one had ever spoken to them about this.

Table 3.17: Discussions about biomarkers

Discussions about biomarkers	N=100	Percent
I brought up the topic with my doctor for discussion	3	3.00
My doctor brought up the topic with me for discussion	8	8.00
No one has ever spoken to me about this type of test	89	89.00

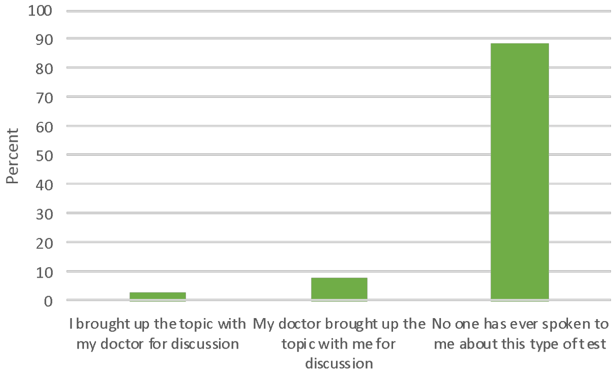


Figure 3.17: Discussions about biomarkers

Experience of genetic tests and biomarkers

Participants were asked about their experience of, or interest in genetic and biomarker tests (Table 3.18, Figure 3.18). The majority of the participants did not have these tests but would like to (n=82, 82.00%), and a total of ten participants (10.00%) had these tests either by paying for the tests themselves (n=3, 3.00%) or having no out of pocket costs (n=7, 7.00%). Eight participants (n=8, 8.00%) were not interested in having these tests.

Table 3.18: Experience of biomarker tests

Experience with biomarker/genomic/gene tests	N=100	percent
I have had this test and did not have to pay out of pocket for it	7	7.00
I have had this type of test and paid for it myself	3	3.00
I have not had this test and am not interested in it	8	8.00
I have not had this test but would like to	82	82.00

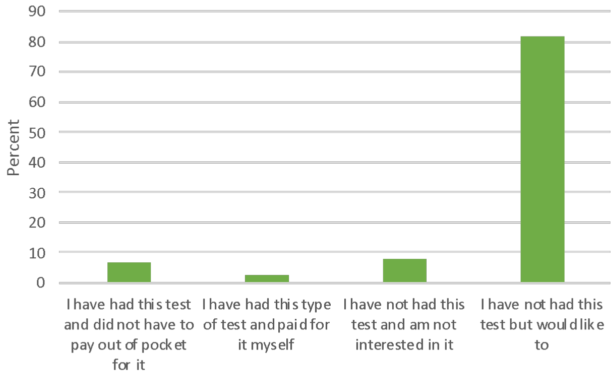


Figure 3.18: Experience of biomarker tests

Diagnosis

Participants described their disease by severity, location of disease, frequency of flare-ups and biomarkers. The majority of participants were able to describe their disease activity, with seven participants either not sure or who found it difficult to describe (7.00%). There were 23 (23.00%) participants had high activity, 43 (43.00%) had moderate activity, 20 (20.00%) had low activity and four (4.00%) were in remission. Participants described the affected areas, with the majority having four or more affected areas (n=61, 61.00%). The most common sites affected were hands/wrists/fingers (n=93, 93.00%) and feet/ankles/toes (n=82, 82.00%). Participants most commonly reported that they had flare-ups once a week (n=26, 26.00%), more than half had flare-ups once a month or more frequently (n=68, 68.00%). Almost half the participants were not sure if they had any biomarkers for rheumatoid arthritis (n=47, 47.00%). The most common biomarker was C-Reactive protein (n=34, 34.00%), followed by rheumatoid factor (n=33, 33.00%).

Table 3.19: Disease description

Disease description		N=100	Percent
Participant description of disease	High Disease Activity	23	23.00
	Moderate to high	1	1.00
	Moderate Disease Activity	43	43.00
	Low to moderate	2	2.00
	Low Disease Activity	20	20.00
	Remission	4	4.00
	Difficult to describe	2	2.00
	Not sure	5	5.00
Number of areas affected	1	5	5.00
	2	10	10.00
	3	24	24.00
	4 or more	61	61.00
Main areas affected by rheumatoid arthritis	Hands/Wrists/Fingers	93	93.00
	Feet/Ankles/Toes	82	82.00
	Shoulders	53	53.00
	Knees	51	51.00
	Hips	36	36.00
	Spine	34	34.00
	Elbows	31	31.00
	Whole body	5	5.00
	Eyes	2	2.00
	Jaw	2	2.00
	Neck/base skull	3	3.00
	Ribs/Chest	2	2.00
Flare-up frequency	Once a day	18	18.00
	Once a week	26	26.00
	Once a month	24	24.00
	Once every two months	13	13.00
	Once every three months	8	8.00
	Once a year	4	4.00
	Twice a year	7	7.00
Biomarkers (Can report more than one biomarker)	Not sure	47	47.00
	C-Reactive protein	34	34.00
	Rheumatoid factor	33	33.00
	Anti-cyclic citrullinated protein antibodies (ACPA)	9	9.00
	I do not have any markers	4	4.00
	HLA-DRB1	3	3.00
	Coeliac	1	1.00
	CMV	1	1.00

Understanding of disease at diagnosis

In the structured interview, participants were asked how much they knew about rheumatoid arthritis at diagnosis. There were 53 participants (53.00%) who reported having no knowledge. Other reported themes included knowing few details (n=16, 16.00%), having a professional background that had led the participant to having some knowledge about the condition (n=10, 10.00%), having a family with rheumatoid arthritis that helped them understand the condition (n=9, 9.00%) and participants knowing about rheumatoid arthritis through their own research (N=8, 8.00%).

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (42.11%), *Symptoms: some days* (40.74%), and *Affect: never to almost never* (39.39%) had no knowledge of rheumatoid arthritis before diagnosis less often than the general population (53.00%), while those in the sub-groups *Affect: very often to always* (67.74%), *and Trade or high school (63.63%)* had no knowledge of rheumatoid arthritis more often.

Participants in the subgroup *Symptoms: all days* (4.76%) knew a few details about rheumatoid arthritis less frequently than the general population (16.00%), and those in the sub-group *Symptoms: some days* (29.63%) reported knowing a few details about rheumatoid arthritis more often.

No participants with *Trade or high school* qualifications reported knowing about rheumatoid arthritis from their professional background compared to 10.00% in the general population.

No participants in the sub-group *Physical limitations: no days* knew about rheumatoid arthritis from having friends or family with the condition, while participants in the sub-group *Symptoms: all days (*19.05%) knew about it from family and friends more often than the general population (9.00%).

Participants in the subgroups *Symptoms: some days* (22.22%) and *Affect: never to almost never* (18.18%) did their own research about rheumatoid arthritis more frequently than the general population (8.00%).

Participant describes knowing nothing at all about their condition

I didn't understand it at all, even having read a million things I think because I'd never heard of it, but I didn't know what it was. I didn't know what it meant and I certainly had no idea what it was like. I think at that point I was so desperate for someone to just tell me what was wrong so I could fix it, that I just wanted it to be that, but I certainly had no comprehension at all of what it meant or what it would be for the future. Like I knew nothing. I had no idea. Participant 24

I had honestly never heard of it before. Participant 39

Not a lot initially. The rheumatologist I went to was very-- he's excellent and he was very good at keeping a lid on things. He said to me immediately after the diagnosis, "You are probably now imagining people you've seen with clawed hands, all that sort of stuff," and he said "Look, years ago that was the result of us just treating the symptoms." He said, "The view today is, we go straight in with heavy duty drugs which actually try and fight the disease, so you know the prognosis is so much better. Our goal is that that does not happen, that you don't get the deformities, blah blah blah." He was very good from that point of view. Participant 22

Participant describes knowing of the condition, but does not know any or knew few details about the condition

Um, I knew a little bit about it, but I knew it in the context of just arthritis. Um, yeah, I didn't necessarily understand that it is an autoimmune disorder necessarily. Um, I just kind of grouped it with like osteoarthritis and other arthritis, and I just knew that it was a joint disorder pretty much. Participant 15

Very little. I knew about arthritis from the point of view of osteoarthritis 'cause I had a grandparent and a mother with it. So all I knew about arthritis was that. And I considered it what I called an old person's disease. So that's what I knew when I was diagnosed. I had heard of rheumatoid, but I didn't know anything about it. Participant 92

Stiffness in the joints and blah blah blah. But yeah, very vague, very vague understanding really. Um, yeah. Participant 14

Participant describes knowing about the condition as they have a medical/scientific/relevant professional background

Um, so I'm fortunate to be a HEALTHCARE PROFESSIONAL, so I have like a big understanding of both the physiological processes of the disease and what potentially can happen symptomatically. Participant 82

I knew a little bit because I'm a HEALTHCARE PROFESSIONAL, so I'd sort of, I've looked after patients, um, with this, um with rheumatoid arthritis. So I think that um, certainly I have to go investigate a bit more just to, yes, talking to you about the basics of it, I just don't want it. Participant 67

Um, well I, um, I'm a HEALTHCARE PROFESSIONAL. So from having looked after people with RA more than probably I wanted to. Yes, yes, yes. Fortunately for me, I was diagnosed quickly and early and it's not a severe case. Participant 10

Participant describes knowing about the condition as a family member/friend/acquaintance has/had the condition also

I knew my mother had it and a few. My auntie on my mother's side had suffered from it. I now know much more about it than I did then. Participant 73
Well I knew a little bit because my sister has it, but I never really paid much attention. I knew that it was awful. Participant 99

I'd say, um, I have a family history with RA so I knew a bit about it, I've got other, you know, sort of relatives in the family on my mother's side that have been very badly affected by it. Participant 87

Participant describes knowing about the condition through their own research

By the time I went to the rheumatologist, I had done some research online, um, you know…that's how I sort of approached it so that I had a little bit of knowledge when I went into the rheumatologist. Participant 29

When it was suspected, I did start doing my own research because I like to know what's, what's going on. So a lot of the information I figured out myself what other symptoms could relate to the disease rather than just sore and stiff joints. Participant 43

Um, I'd read a little bit beforehand. I, I kind of had a sense before I went to the rheumatologist that that was probably what the outcome was going to be. So I know, I think I talked to somebody in town who has the same condition and did a little bit of reading, um prior to going in. Participant 45

Table 3.20: Understanding of disease at diagnosis

Understanding of disease at diagnosis	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes having no knowledge of disease at diagnosis	53	53.00	8	42.11	24	54.55	21	56.76	11	55.00	11	40.74	18	56.25	13	61.90
Participant describes knowing only few details about the disease at diagnosis	16	16.00	4	21.05	6	13.64	6	16.22	3	15.00	8	29.63	4	12.50	1	4.76
Participant describes having a professional background and knowing about the condition	10	10.00	2	10.53	6	13.64	2	5.41	2	10.00	1	3.70	6	18.75	1	4.76
Participant describes having a family member with the condition and therefore knowing about it	9	9.00	0	0.00	2	4.55	7	18.92	1	5.00	2	7.41	2	6.25	4	19.05
Participant describes conducting their own research	8	8.00	1	5.26	5	11.36	2	5.41	1	5.00	6	22.22	1	3.13	0	0.00

Understanding of disease at diagnosis	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes having no knowledge of disease at diagnosis	53	53.00	8	42.11	24	54.55	21	56.76	11	55.00	11	40.74	18	56.25	13	61.90
Participant describes knowing only few details about the disease at diagnosis	16	16.00	4	21.05	6	13.64	6	16.22	3	15.00	8	29.63	4	12.50	1	4.76
Participant describes having a professional background and knowing about the condition	10	10.00	2	10.53	6	13.64	2	5.41	2	10.00	1	3.70	6	18.75	1	4.76
Participant describes having a family member with the condition and therefore knowing about it	9	9.00	0	0.00	2	4.55	7	18.92	1	5.00	2	7.41	2	6.25	4	19.05
Participant describes conducting their own research	8	8.00	1	5.26	5	11.36	2	5.41	1	5.00	6	22.22	1	3.13	0	0.00

Understanding of disease at diagnosis	***All participants***		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes having no knowledge of disease at diagnosis	53	53.00	27	48.21	26	59.09	16	51.61	27	52.94	10	55.56
Participant describes knowing only few details about the disease at diagnosis	16	16.00	10	17.86	6	13.64	7	22.58	5	9.80	4	22.22
Participant describes having a professional background and knowing about the condition	10	10.00	6	10.71	4	9.09	1	3.23	6	11.76	3	16.67
Participant describes having a family member with the condition and therefore knowing about it	9	9.00	2	3.57	7	15.91	5	16.13	2	3.92	2	11.11
Participant describes conducting their own research	8	8.00	6	10.71	2	4.55	1	3.23	6	11.76	1	5.56

Understanding of disease at diagnosis	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes having no knowledge of disease at diagnosis	53	53.00	31	55.36	22	50.00	21	63.64	32	47.76	28	56.00	25	50.00
Participant describes knowing only few details about the disease at diagnosis	16	16.00	10	17.86	6	13.64	2	6.06	14	20.90	8	16.00	8	16.00
Participant describes having a professional background and knowing about the condition	10	10.00	7	12.50	3	6.82	0	0.00	10	14.93	3	6.00	7	14.00
Participant describes having a family member with the condition and therefore knowing about it	9	9.00	6	10.71	3	6.82	3	9.09	6	8.96	5	10.00	4	8.00
Participant describes conducting their own research	8	8.00	4	7.14	4	9.09	2	6.06	6	8.96	3	6.00	5	10.00

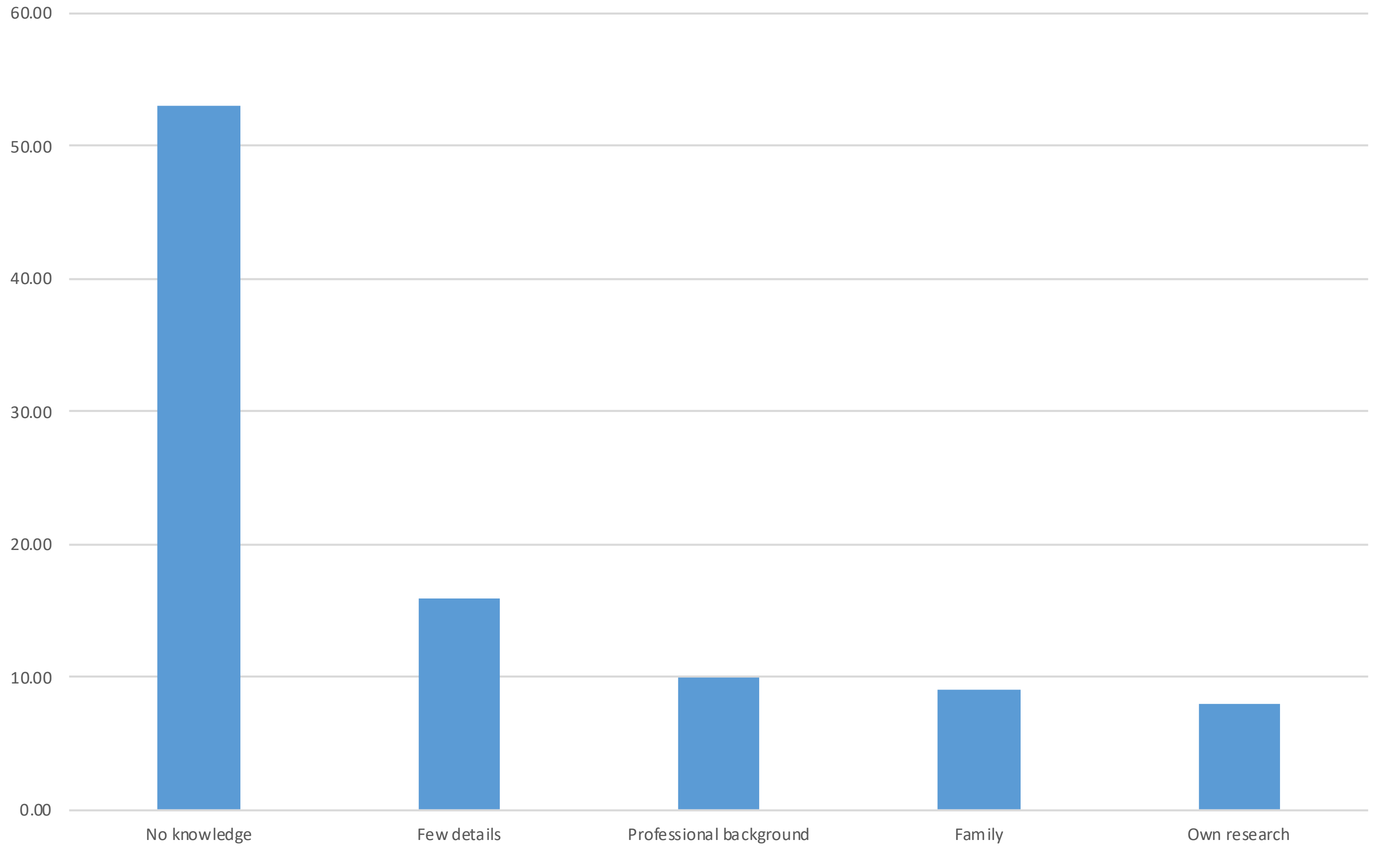


Figure 3.19: Understanding of disease at diagnosis

Understanding of prognosis

Participants were asked in the structured interview to describe their understanding of their prognosis. The most common theme (n=19, 19.00%) was that participants describes not being sure of their prognosis as they had not had a proper conversation about this with their clinician. This was followed by the description of prognosis in the context of it being managed with medication (n=13, 13.00%), prognosis being described as currently having stable disease (n=9, 9.00%) and prognosis being described as a good prognosis and being positive (n=9, 9.00%).

In relation to sub-group variations, participants in the sub-group *Affect: very often to always* (29.03%) described not being sure of their prognosis, more frequently than the general population (19.00%), while those in the sub-group *Symptoms: some days* (7.41%), reported this less frequently.

Participants in the *Social: all to most days* (20.00%) reported prognosis as being currently stable, more frequently than the general population (9.00%).

Participants in the sub-groups *Physical limitations: no days* (21.05%) and the *Symptoms: no to few days* (20.00%) described having a good prognosis and being positive, more frequently than the general population (9.00%).

There were no participants in the *Symptoms: all days* sub-group that described prognosis in the context of it being stable long-term. There were also no participants in the *Symptoms: all days* and *Physical limitations: no days* that described prognosis in the context of expecting that their condition will worsen.

Table 3.21: Understanding of prognosis

Understanding of prognosis	All participants		Physical limitations: no days		Physical limitations: few days		Physical limitations: some to most days		Symptoms: no to few days		Symptoms: some days		Symptoms: most days		Symptoms: all days	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes not being sure of their prognosis as they have not had a proper conversation about this with their clinician	19	19.00	3	15.79	7	15.91	9	24.32	5	25.00	2	7.41	7	21.88	5	23.81
Participant describes prognosis in the context of it being managed with medication	13	13.00	2	10.53	7	15.91	4	10.81	4	20.00	5	18.52	3	9.38	1	4.76
Participant describes prognosis as being currently stable	9	9.00	3	15.79	4	9.09	2	5.41	3	15.00	2	7.41	2	6.25	2	9.52
Participant describes having a good prognosis and being positive	9	9.00	4	21.05	4	9.09	1	2.70	4	20.00	3	11.11	1	3.13	1	4.76
Participant describes prognosis in the context of it being stable long-term	7	7.00	3	15.79	2	4.55	2	5.41	2	10.00	3	11.11	2	6.25	0	0.00
Participant describes prognosis in the context of expecting that their condition will worsen	6	6.00	0	0.00	3	6.82	3	8.11	1	5.00	2	7.41	3	9.38	0	0.00

Understanding of prognosis	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes not being sure of their prognosis as they have not had a proper conversation about this with their clinician	19	19.00	4	12.12	6	16.67	9	29.03	4	20.00	6	16.67	9	20.45
Participant describes prognosis in the context of it being managed with medication	13	13.00	7	21.21	4	11.11	2	6.45	2	10.00	5	13.89	6	13.64
Participant describes prognosis as being currently stable	9	9.00	3	9.09	4	11.11	2	6.45	4	20.00	2	5.56	3	6.82
Participant describes having a good prognosis and being positive	9	9.00	5	15.15	3	8.33	1	3.23	2	10.00	5	13.89	2	4.55
Participant describes prognosis in the context of it being stable long-term	7	7.00	3	9.09	3	8.33	1	3.23	3	15.00	1	2.78	3	6.82
Participant describes prognosis in the context of expecting that their condition will worsen	6	6.00	1	3.03	3	8.33	2	6.45	1	5.00	2	5.56	3	6.82

Understanding of prognosis	All participants		Occasional flare ups		Frequent flare ups		Aged 55 or older		Aged 35 - 54		Aged 18 – 34	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes not being sure of their prognosis as they have not had a proper conversation about this with their clinician	19	19.00	10	17.86	9	20.45	7	22.58	9	17.65	3	16.67
Participant describes prognosis in the context of it being managed with medication	13	13.00	7	12.50	6	13.64	3	9.68	9	17.65	1	5.56
Participant describes prognosis as being currently stable	9	9.00	5	8.93	4	9.09	3	9.68	4	7.84	2	11.11
Participant describes having a good prognosis and being positive	9	9.00	6	10.71	3	6.82	2	6.45	6	11.76	1	5.56
Participant describes prognosis in the context of it being stable long-term	7	7.00	6	10.71	1	2.27	1	3.23	4	7.84	2	11.11
Participant describes prognosis in the context of expecting that their condition will worsen	6	6.00	4	7.14	2	4.55	4	12.90	1	1.96	1	5.56

Table 3.21: Understanding of prognosis (Cont.)

Understanding of prognosis	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes not being sure of their prognosis as they have not had a proper conversation about this with their clinician	19	19.00	10	17.86	9	20.45	5	15.15	14	20.90	7	14.00	12	24.00
Participant describes prognosis in the context of it being managed with medication	13	13.00	9	16.07	4	9.09	4	12.12	9	13.43	8	16.00	5	10.00
Participant describes prognosis as being currently stable	9	9.00	2	3.57	7	15.91	2	6.06	7	10.45	2	4.00	7	14.00
Participant describes having a good prognosis and being positive	9	9.00	4	7.14	5	11.36	2	6.06	7	10.45	4	8.00	5	10.00
Participant describes prognosis in the context of it being stable long-term	7	7.00	4	7.14	3	6.82	2	6.06	5	7.46	2	4.00	5	10.00
Participant describes prognosis in the context of expecting that their condition will worsen	6	6.00	4	7.14	2	4.55	2	6.06	4	5.97	6	12.00	0	0.00

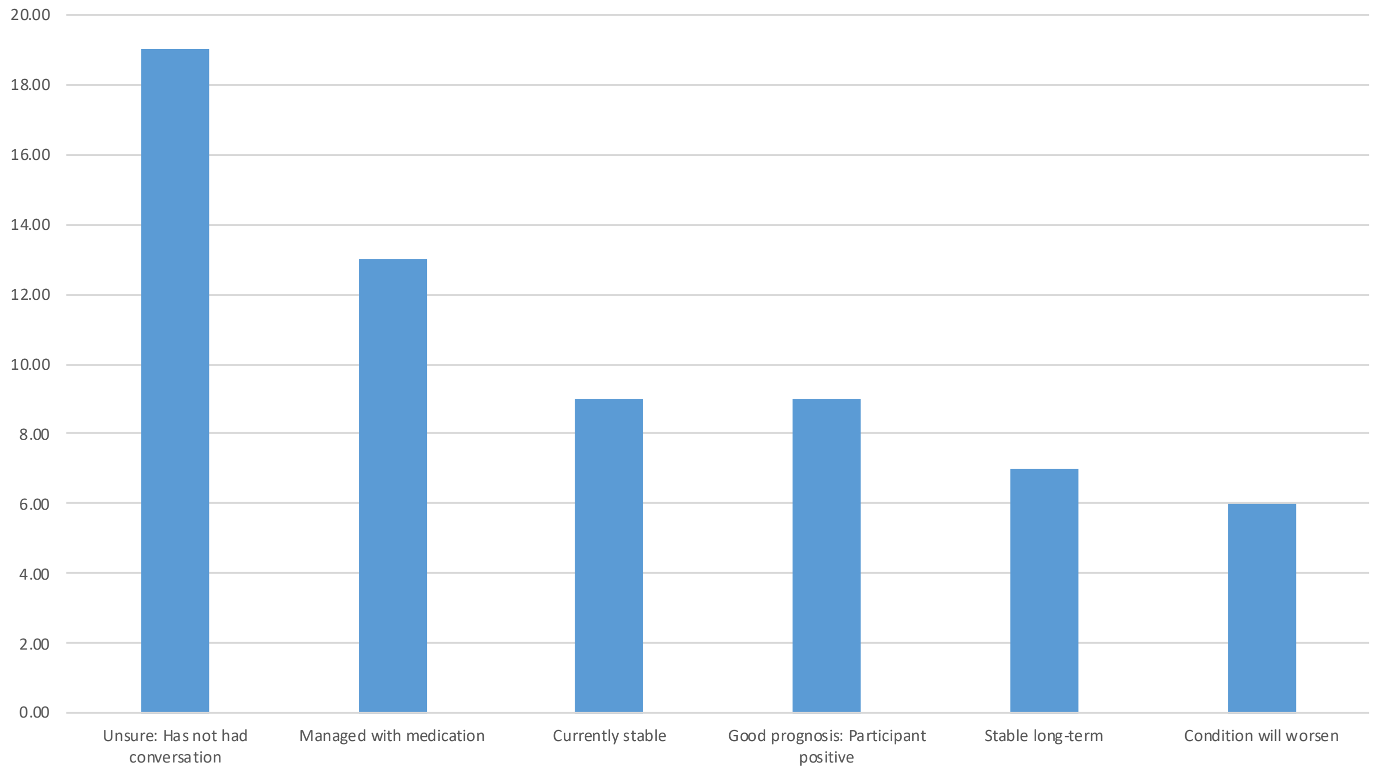


Figure 3.20: Understanding of prognosis (Cont.)

Section 4 Decision-making

Section 4: Experience of health professional communication

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common treatment option described was only one treatment option presented with participants having no say over this choice. This was described by 39 participants (n=39.00). The next most common theme was that all options presented, and participants felt as that they were able to talk with their clinician (n=33, 33.00%). This was followed by being presented with one treatment option and being content with clinician's advice (n= 15, 15.00%); only presented with one option but would appreciate more discussion about treatment (n=12, 12.00%) and participants describing the treatment of biologics as the treatment conversations (n=9, 9.00%).

Decision-making

Participants were asked to describe the most important factors they took into consideration when making decisions about their treatment. The highest reported theme was considering the side effects only (n=26, 26.00%) when making decisions about treatment, followed by side effects & or quality of life (n=24, 24.00%), quality of life only (n=22, 22.00%), always following medical advice when making treatment decisions (n=17, 17.00%), and how much the medication costs (n=15, 15.00%).

Changes in decision making

Participants were asked to consider whether they believed their decision making in relation to treatment had changed over time. There were 67 participants (67.00%) that felt the way they made decisions about treatment had changed over time, and 11 participants (11.00%) that described decision making not changing. This was primarily because they had felt that they have always been assertive towards their decision making.

Of those participants that felt as though the way they made decisions had changed, 31 participants (31.00%) attributed this change to becoming more informed or assertive, 20 participants believed they are more accepting of treatment, though not through their own choice (20.00%), while 16 considered how rheumatoid arthritis has impacted on their life, and this has changed their decision making (16.00%). There were 8 participants who did not respond directly to the question or elaborate to why they had/had not changed, primarily due to their diagnosis being quite recent, therefore enough time had not passed to consider change in decision making.

Discussions about treatment

Participants were asked to recall what treatment options they were presented with at diagnosis. The most common treatment option described was having only one treatment option presented and this was described by 39 participants (39.00%). This was followed by having all treatment options presented and being able to talk about options with clinician (33.00%); being presented with one treatment option and being content with clinician's advice (15.00%); only being presented with one option and would appreciate more discussion about treatment (12.00%) and participants describing discussions about the treatment of biologics (9.00%).

In relation to sub group variations, participants in the sub-groups *Physical limitations: some to most days* (24.32%), *Symptoms: most days* (25.00%), *Affect: very often to always* (25.81%), *Social: some days* (27.78%), and *Aged 18 – 34* (27.78%), reported that they had no choice in treatment given less frequently than the general population (39.00%); and the sub-groups *Symptoms: no to few days* (50.00%), *Symptoms: some days* (51.85%), *Affect: never to almost never* (51.52%), and *Social: no to few days* (50.00%) reported they had no choice in treatment more often than the general population.

Participants in the sub-groups *Symptoms: no to few days* (5.00%), *Symptoms: some days (3.70),* and *Affect: never to almost never* (3.03%), reported that one option presented, happy to follow clinician's option less often than the general population (15.00%). Participants in the sub-groups *Symptoms: most days* (28.13%), *Affect: very often to always* (25.81%), *Social: some days* (25.00%), *Aged 18 – 34* (33.33%) reported more frequently that they had one option presented, happy to follow clinician's option compared to the general population.

No participants in the sub-groups *Physical limitations: no days , Symptoms: no to few days , Affect: never to almost never ,*and *Social: all to most days* reported that one option was presented, yet they wanted more discussion, whereas participants in the sub-group *Physical limitations: some to most days* (21.62%), reported this more frequently than the general population (12.00%).

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days , Symptoms: some days, and Aged 18 – 34* reported that they discussed biologics, while participants in the sub-groups *Aged 55 or older* (19.35%), *Symptoms: all days* (19.05%), *Social: some days* (27.78%), *Social: no to few days* (50.00%) discussed biologics more often than the general population (9.00%).

Participant describes being told one treatment plan with little discussion

They didn't really tell me a great deal. The rheumatologist said, look, you've got inflammatory arthritis and you have to take drugs. I said oh okay. And he said, you'll probably have to take them for the rest of your life. And I thought, what? And that was about it. He didn't really explain things really well. I didn't find a great deal of help from the doctor. Participant 99.

I don't think there was much discussion about options. It was, we can put you, we'll put you on Plaquenil we'll put you on this. Participant 23.

I've been concerned the entire time about having kids and um, because I think she, she, um, wanted to start me initially on methotrexate and she sort of told me that that would need to be out of my system for so long before that could be an option which upset me quite a bit at the time. Um, yeah. Um, my, my rheumatologist feels quite strongly, I think that methotrexate is sort of the gold standard. Um, and um, after I suppose, um, we didn't really talk that much about other drugs at the time. It was just, you know, we'll, we'll start with this and go from there. Participant 40.

There was little information or discussion about, this is what I'm going to do and these are the possible side effects. Yes, this is quite common or this is quite rare, but no, I just didn't think there was enough discussion. Participant 21.

Nothing. Nobody told me anything. was never told of any side effects of medication. I was never told, um, you know, anything at all. I was just told this as this is what we're going to try now. There should help you. And it was just basically assessing how I was according to what medicine that we're going to give me now, whether we're going to continue giving me [inaudible], you know, whatever. But nobody really spoke about long term damage or what I could do. Participant 34.

Participant describes options being presented and being able to discuss them with their clinician to inform their decision

He's been really, really open and honest. I'm trying different things. So I've now moved onto my third biologic with him. I've had president all sorts of stuff mixed in. Every time I've brought up the possibility of changing has been really, really honest and open about what we need to do, why things can't change or why things could change and even down to changing the methotrexate and whatnot to try and see if that will help. Participants 82.

Basically what was the best thing to be on. Will it, it won't stop the disease, it won't stop the rheumatoid, it'll just keep things from getting any worse. We discussed that quite a bit and to have blood tests and that will show the medication and keeping an eye just on your kidney and liver functions. We discussed that a bit, just the general thing. Participant 16.

Everything I've asked, um, when I've gone in and seen him the three times, any questions that he said, even if I've got a question like that comes up and I still don't see him for a few months, I can either the call the surgery or send him an email and he's happy to answer any questions, any concerns I have about anything. Um, he's, he's been really open and like he always says he's always available to talk either through email or on the phone to answer some questions or, or whatever. Participant 38.

Participant describes only one option being presented but ultimately taking the advice of their clinician.

I think that the initial option was a conservative treatment to see if that will help out first off. And then we've moved on to a less conservative treatments as I've needed to, as I've progressed with the different diagnoses and the crossover diagnosis through time. Participant 97.

We talked about the possible side effects, and it's not right for everybody, but it was a start point. We started with that, and I tolerated it that. Participant 60.

So I mean, it doesn't really affect me much, but um, at least the rest of my fingers are still workable. I remember being on a variety of medications, most prevalent in my memory was Naprosyn and as an adult now I take a box of camp, so I'm just a variety of nonsteroidal or steroidal anti inflammatory. Um, but aside from the surgeries, the physio therapy and the medication, there wasn't any further discussion of other kinds of treatment options. Participant 41.

Yeah. She's, she's the one is really managing it. Participant 89.

Participant describes only one option or approach being presented and that they would have liked more of a discussion

He wasn't bad as far as controlling your symptoms and doing that, but he had no, I guess the old-fashioned word is bedside manner. I just couldn't talk to him after a while. but he'd sort of tell you, "This will do this and this works at a higher level," but that's about it. He didn't ask you. He didn't say, "What do you think about that?" give you the information and say, "What do you think about that?" He'd just say, "We'll try this and blah blah blah". Participant 46.

I don't remember doctors ever been very, very um, like giving me any, in depth information about how the medications work, what part of the, what part they targeted or anything like that. I basically did all that myself to get all that information myself. Participant 64.

Not really, no. I have to say like again, the face to face discussions and I'll come in there for five minutes and I just, I can't get very much out of him at all. Participant 51.

Participant describes discussing biologics

She was very scary, I got very scared of this woman, and I didn't trust her or believe her because she was... and I just was like, no, I'm not buying this and I would go off and do my own research and I would literally cry every time I saw her as soon as she said look, you know, it's not responding as well as we'd like, you need to take methotrexate. As soon as she said that, I just started crying. and for the last seven, seven or eight years been since she's been trying to get me on this methotrexate I just cried. Like, I don't want to do it. And then, um, then, you know, I finally about three years ago did take methotrexate and she's very very good. Like she has explained things. Um, and, but, you know, I just didn't want to take it. I just thought there must be another way to deal with the fact that I even had it. Participant 95.

She made a suggestion to start with, um, methotrexate, and I thought about it for a bit because I can have lots of side effects. Um, but you know, I've thought about it and said, you know,
I think that's fine. I will try it. And I was fine on it. Participant 55.

Yeah, we did, took some prednisolone as a short term fix to put out the immediate fire. Um, then started on methotrexate and he's like, look, read the side effects, but take them with a grain of salt because you're in a really low dose. Um, and he's like, but I like I want to get you on biologic straightaway. So yeah, we're going to do these first, but I'm going to push you straight on the biologics if I can. Okay. So pred worked amazingly. I went from not being able to wash up a cup, to sewing a button on a jacket in three days and I could to literally see my hand just shrinking back to normal size, I had energy. Participant 71.

Table 4.1: Conversations about treatment

Conversations about treatment	*All participants*		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes being told one treatment plan with little discussion	39	39.00	9	47.37	21	47.73	9	24.32	10	50.00	14	51.85	8	25.00	7	33.33
Participant describes options being presented and being able to discuss them with their clinician to inform their decision	33	33.00	7	36.84	13	29.55	13	35.14	7	35.00	9	33.33	12	37.50	5	23.81
Participant describes only one option being presented but ultimately taking the advice of their clinician	15	15.00	2	10.53	5	11.36	8	21.62	1	5.00	1	3.70	9	28.13	4	19.05
Participant describes only one option or approach being presented and that they would have liked more of a discussion	12	12.00	0	0.00	4	9.09	8	21.62	0	0.00	3	11.11	7	21.88	2	9.52
Participant describes discussing biologics	9	9.00	0	0.00	4	9.09	5	13.51	0	0.00	0	0.00	5	15.63	4	19.05

Conversations about treatment	**All participants**		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes being told one treatment plan with little discussion	39	39.00	17	51.52	14	38.89	8	25.81	7	35.00	10	27.78	22	50.00
Participant describes options being presented and being able to discuss them with their clinician to inform their decision	33	33.00	10	30.30	13	36.11	10	32.26	5	25.00	14	38.89	14	31.82
Participant describes only one option being presented but ultimately taking the advice of their clinician	15	15.00	1	3.03	7	19.44	7	22.58	2	10.00	9	25.00	4	9.09
Participant describes only one option or approach being presented and that they would have liked more of a discussion	12	12.00	0	0.00	4	11.11	8	25.81	0	0.00	6	16.67	6	13.64
Participant describes discussing biologics	9	9.00	3	9.09	3	8.33	3	9.68	2	10.00	10	27.78	22	50.00

Conversations about treatment	**All participants**		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes being told one treatment plan with little discussion	39	39.00	26	46.43	13	29.55	15	48.39	19	37.25	5	27.78
Participant describes options being presented and being able to discuss them with their clinician to inform their decision	33	33.00	15	26.79	18	40.91	11	35.48	16	31.37	6	33.33
Participant describes only one option being presented but ultimately taking the advice of their clinician	15	15.00	8	14.29	7	15.91	2	6.45	7	13.73	6	33.33
Participant describes only one option or approach being presented and that they would have liked more of a discussion	12	12.00	4	7.14	8	18.18	4	12.90	5	9.80	3	16.67
Participant describes discussing biologics	9	9.00	5	8.93	4	9.09	6	19.35	3	5.88	0	0.00

Conversations about treatment	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes being told one treatment plan with little discussion	39	39.00	22	39.29	17	38.64	16	48.48	23	34.33	19	38.00	20	40.00
Participant describes options being presented and being able to discuss them with their clinician to inform their decision	33	33.00	19	33.93	14	31.82	10	30.30	23	34.33	18	36.00	15	30.00
Participant describes only one option being presented but ultimately taking the advice of their clinician	15	15.00	7	12.50	8	18.18	5	15.15	10	14.93	6	12.00	9	18.00
Participant describes only one option or approach being presented and that they would have liked more of a discussion	12	12.00	7	12.50	5	11.36	4	12.12	8	11.94	6	12.00	6	12.00
Participant describes discussing biologics	9	9.00	5	8.93	4	9.09	4	12.12	5	7.46	4	8.00	5	10.00

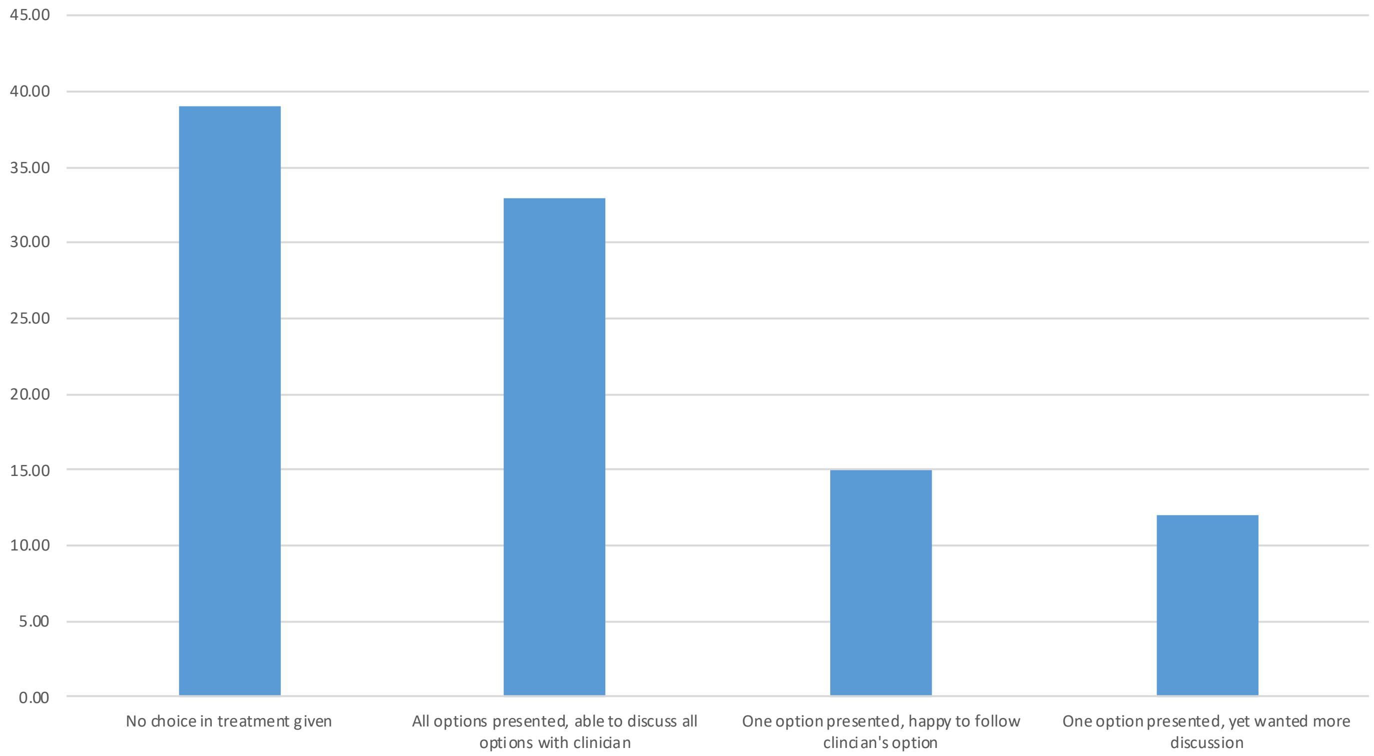


Figure 4.1: Conversations about treatment

Decision-making

Participants were asked to describe the most important factors they took into consideration when making decisions about their treatment. The most frequently reported theme was considering the side effects only (n=26, 26.00%) when making decisions about treatment, followed by side effects & or quality of life (n=24, 24.00%), quality of life only (n=22, 22.00%), always following medical advice when making treatment decisions (n=17, 17.00%), and how much the medication costs (n=15, 15.00%).

In relation to sub-group variations, participants who were in the sub-group *Physical limitations: no days* (15.79%) described considering side effects less frequently than the general population (26.00%), and participants in the sub-group *Symptoms: all days* (47.62%) described considering side effects less often than the general population.

Participants who were in the sub-groups *Physical limitations: no days* (10.53%), *Physical limitations: few days* (34.09%), *Affect: sometimes* (13.89%), *Regional or remote* (11.36), *Trade or high school* (12.12%)

described considering side effects and quality of life less frequently than the general population (24.00%). No participants in the sub-group *Symptoms: all days* described considering quality of life only, while participants in the sub-group *Symptoms: some days* (33.33%) considered quality of life more often than the general population (22.00%).

Participants *Aged 18 – 34* (5.56%) described always following medical advice less often than the general population (15.00%) and participants in the sub-group *Social: all to most days* (30.00%) described following medical advice more frequently than the general population.

Participants in the sub-group *Symptoms: most days* (25.00%) described cost considerations more frequently than the general population (15.00%).

Participant describes taking into account side effects only

Actually, look up the medications and I realized that with that, with the treatments that are available now, the side effects are worse I think than the disease itself. You know, like some of the, some of the medication can give you a lymphoma and brain tumours. Participant 8.

Delve into the side effects because as I mentioned, I've got a lot of allergies and yeah, I just want to be careful before them I'm putting into the body because sometimes I feel like that the rheumatologist is so focused on the rheumatoid that the presence of problems in lung problems, which I had previous to that I'm not taking too much into consideration and I don't know if there's ever a conflict of the effects the drug had on the body. Participant 74.

Yes, that's still quite important and probably the side effects is being another huge factor because I've had huge issues with side effects and the other factor was the likelihood of getting cancer down the track. Participant 90

Participant describes taking into account the side effects of treatment and/or impact on quality of life (Combination)

The big thing at the moment was the ability to have children safely while I'm taking that meditation. Side effects, overall side effects. I was taking methotrexate and my hair was falling out. I wasn't feeling. Like prednisone was making me put on weight. Comfortable relief but initially came with having to go. The side effects was a big thing. Lifestyle. Things like, I travelled to Europe last year with injections that I needed to keep refrigerated under eight degrees. I had five needles with me. Participant 6.

I looked into what are these things going to do to my cognitive awareness? For me, that was more important than physical. Is that stage been in any stage of my life? Obviously, I want my brain working more than anything. I really looked into that and just quality of life in terms of what kind of life do I want to live, and what do these drugs do to that, and what are the potential side effects? It's a balancing act. Am I willing to take the risk of the joint damage and all the other things that are going to happen if I leave this technically untreated versus some of the really, really crappy side effects that are almost certain? That's what I weighed on. Participant 46.

They're probably still the two things. Definitely that, "Don't kill my liver anymore, because it can't take it, and don't make me so sick that I can't get up and go to work, because I will, I'll stop taking it." Participant 96.

Participant describes taking into account quality of life only

You know, you still need to live. So then you like a glass of wine, who doesn't say that's a great, realistic and practical consideration. Participant 11.

If it's going to improve me, my quality of life because I'm a very, a strong advocate for quality and not quantity, at least the life I've got I want to be able to, you know, enjoy it as best I can. Participant 47.

PARTICIPANT: The quality of life, is very important.
INTERVIEWER: Do you think--
PARTICIPANT: Or I'm just paying to give up a few years of my life to have a quality of life.
INTERVIEWER: The quality over the quantity?
PARTICIPANT: Absolutely. Participant 80.

Obviously not taking any time off work, no surgery or anything like that where, you know, it doesn't impact on my ability to, to live, to earn money to live. Participant 27

Well, think in the course of my treatment I haven't felt like I've had a lot of choice because I thought like I can't live like this like this I need these drugs has changed my life. Like, I mean I would've killed myself if I just could not live in a body that is like so broken. I think the drugs, drugs make me able to have a full life. Participant 12.

Participant describes following the specialist's advice

Um, I trust my doctor. So, if he says, I think we should try this, I say okay. It. Because I've had him for over 20 years. Participant 2.

To be honest, I don't really feel like I've had decisions to make. I've been prescribed things by the rheumatologist then I've really just done what he did. Participant 39.
I don't make the decisions. He makes the decision. So I don't make the decisions. I just go along like a sheep. Participant 81.

Participant describes taking into account the cost of treatment only

Of course, money was a big thing because you know, there's no way we could consider trying the injection before they went on PBS. Participant 14.

I guess the first step from our perspective is cost. Um, cause I'm on a pension. It needs to be bulk bills. Um, you know, I had some suggestions go off and do specialized physio for him at all. There's a few in LOCATION that they're $170 a session, which is there, you're limited on a pension, so it's not realistic. Um, there's lots of stuff and they go, well, if you can't afford it, here's the, here's the sheet of exercises that you're going to have to learn to try and do. Participant 86.

Cost as well. I've actually quit my job in October. I can't go to work, I can't do it. I just physically can't do my job at the moment. I've quit my job and I'm self-funded sit-at-home person. Participant 75.

Table 4.2: Considerations when making decisions

Considerations when making decisions about treatment	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes considering side effects only	26	26.00	3	15.79	12	27.27	11	29.73	5	25.00	5	18.52	6	18.75	10	47.62
Participant describes side effects & QOL	24	24.00	2	10.53	15	34.09	7	18.92	3	15.00	6	22.22	8	25.00	7	33.33
Participant describes Quality of life only	22	22.00	4	21.05	8	18.18	10	27.03	3	15.00	9	33.33	10	31.25	0	0.00
Participant describes always following medical advice	17	17.00	4	21.05	10	22.73	3	8.11	3	15.00	7	25.93	4	12.50	3	14.29
Participant describes cost considerations	15	15.00	2	10.53	8	18.18	5	13.51	2	10.00	3	11.11	8	25.00	2	9.52

Considerations when making decisions about treatment	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes considering side effects only	26	26.00	8	24.24	11	30.56	7	22.58	4	20.00	9	25.00	13	29.55
Participant describes side effects & QOL	24	24.00	10	30.30	5	13.89	9	29.03	5	25.00	9	25.00	10	22.73
Participant describes Quality of life only	22	22.00	6	18.18	9	25.00	7	22.58	5	25.00	11	30.56	6	13.64
Participant describes always following medical advice	17	17.00	6	18.18	5	13.89	6	19.35	6	30.00	3	8.33	8	18.18
Participant describes cost considerations	15	15.00	5	15.15	5	13.89	5	16.13	2	10.00	6	16.67	7	15.91

Considerations when making decisions about treatment	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes taking into account the side effects of treatment only	26	26.00	14	25.00	12	27.27	10	32.26	11	21.57	5	27.78
Participant describes taking into account side effects of treatment and impact on quality of life (Combination)	24	24.00	12	21.43	12	27.27	6	19.35	15	29.41	3	16.67
Participant describes taking into account quality of life only	22	22.00	15	26.79	7	15.91	8	25.81	9	17.65	5	27.78
Participant describes taking into account always following specialist advice	17	17.00	12	21.43	5	11.36	5	16.13	11	21.57	1	5.56
Participant describes taking into account side effects of treatment & efficacy (Combination)	15	15.00	9	16.07	6	13.64	6	19.35	6	11.76	3	16.67

Considerations when making decisions about treatment	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes considering side effects only	26	26.00	12	21.43	14	31.82	11	33.33	15	22.39	11	22.00	15	30.00
Participant describes side effects & QOL	24	24.00	19	33.93	5	11.36	4	12.12	20	29.85	15	30.00	9	18.00
Participant describes Quality of life only	22	22.00	10	17.86	12	27.27	8	24.24	14	20.90	13	26.00	9	18.00
Participant describes always following medical advice	17	17.00	6	10.71	11	25.00	6	18.18	11	16.42	5	10.00	12	24.00
Participant describes cost considerations	15	15.00	11	19.64	4	9.09	5	15.15	10	14.93	8	16.00	7	14.00

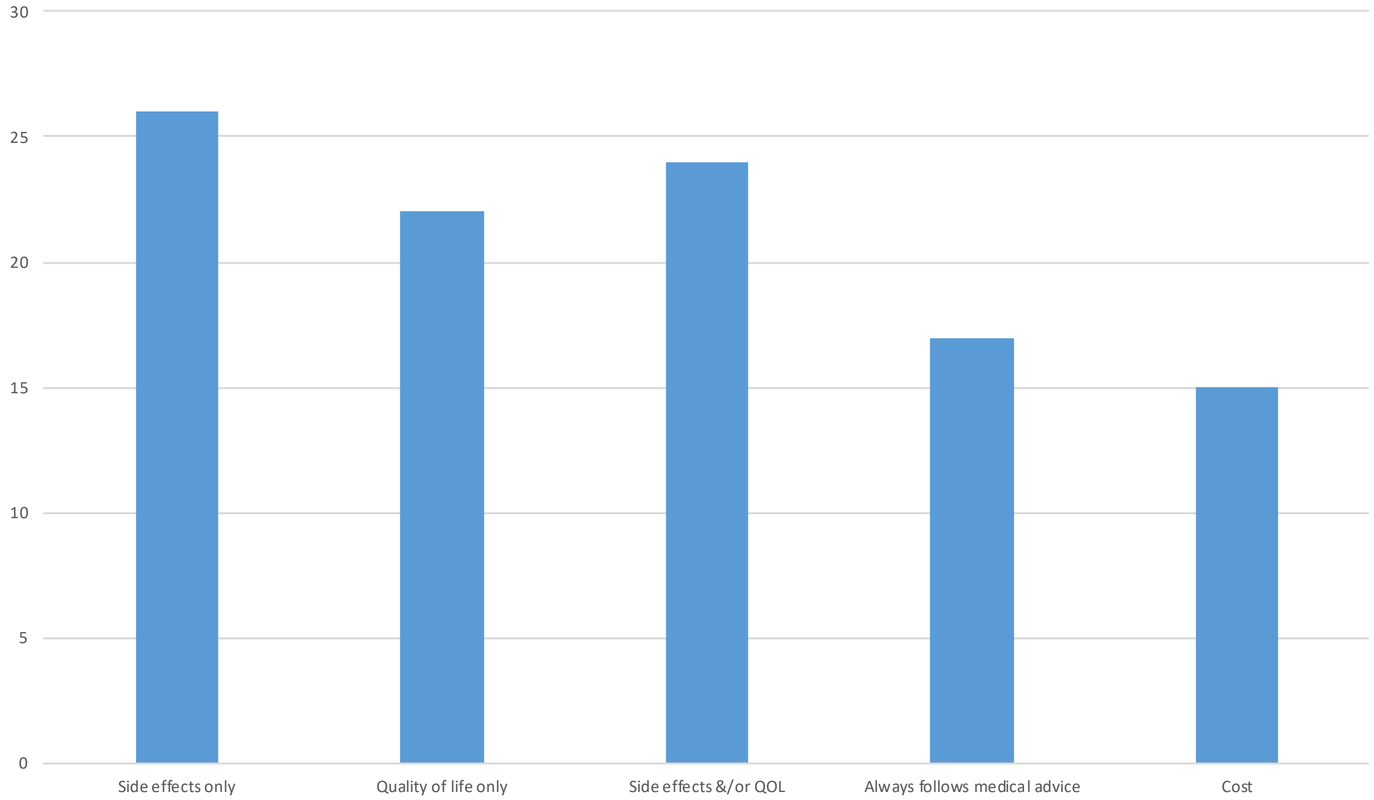


Figure 4.2: Considerations when making decisions

Decision-making over time

Participants were asked to consider whether they believed their decision making in relation to treatment had changed over time. There were 67 participants (67.00%) that felt the way they made decisions about treatment had changed over time, and 11 participants (11.00%) that described decision making not changing. This was primarily because they had felt that they have always been assertive towards their decision making.

Of those participants that felt as though the way they made decisions had changed, 31 participants (31.00%) attributed this change to becoming more informed or assertive, 20 participants believed they are more accepting of treatment, though not through their own choice (20.00%), while 16 considered how rheumatoid arthritis has impacted on their life, and this has changed their decision making (16.00%). There were 8 participants who did not respond directly to the question or elaborate to why they had/had not changed, primarily due to their diagnosis being quite recent, therefore enough time had not passed to consider change in decision making.

In relation to sub-group variations, compared to the general population (31.00%), participants in the sub-group *Symptoms: no to few days* (10.00%), reported less frequently that they were more informed or assertive; and the participants in the subgroups *Symptoms: some days* (44.44%), *Social: some days* (44.44%), and *Social: some days* (44.44%) reported this more frequently.

Participants in the sub-group *Affect: never to almost never (9.09%)* reported that they were more accepting of treatment less frequently than the general population (20.00%).

Participants *Aged 18 – 34* (27.78%) considered the impact on life more frequently than the general population (16.00%).

Participants in the sub-group *Social: all to most days* (25.00%) reported they had always been assertive more often than the general population (11.00%).

No participants *Aged 18 – 34* did not respond directly to the question or elaborate to why they had/had not changed, while participants in the sub-group *Affect: never to almost never* (18.18%) did not respond more frequently than the general population (8.00%).

Participant describes change by becoming more informed/ assertive

I'm much more aware that doctors are all guessing and all they can do is give you an educated guess and you need to trust yourself own. And if I had not backed myself and advocated for myself, I wouldn't be here holding my own with doctors and making my own decisions and pushing them to explain in detail or explain what other options are there. Participant 71.

I've become, I've become more confident in understanding how my body works. Um and I think because of that I've been asking more questions. And, ensuring that I'm more a part of the process of having the discussions about, about the different options. Whereas to start with it was like I had no idea about the disease and it was like, okay, if you say I've got to take this for the rest of my life, I'll just do it, because it was better than the pain I was in. Participant 37.

I'm a little bit more, a little bit more aware now that there are other options. And I think in retrospect I should've demanded more back in those early years. Mm hmm. But that's something you can't change. Participant 57.

Participant describes change, by being more accepting but not through choice.

No, I've changed. I do much more what I'm told now than before. I think it's, I don't know why maybe they've ground me down, I've just given in. Um, drugs, um, again, I'd love to take a natural path, but I think you need, we're lucky to live in the 21st century. There are drugs available. Um, and you just got to do it. You just got to suck it up because this is an evil thing that I need drugs to get rid of it. That's awful. Isn't that horrible? Participant 99.

Yeah. Um, I think they have changed to be honest because you kind of get into a state of being desperate to do something to work and obviously you just willing to try anything basically. I've been trying every single thing like I've been going to physio Pilates, massage therapist, which didn't work at all or that was all the and diet changes, you know, I've, I've been, you know, so I think there's an element of desperation in decision making. Participant 89

I've had to become more relaxed about taking drugs. Sorry, I, I'm a person that would have taken. Maybe I would take less than one Panadol year. Yeah, the only drugs that I've taken long term is antidepressants a, they've just doubled my dosage for that and now I have to say, and I think it's six pills a day Yeah. But I mean before I've tried to go off the steroids and really ended up quite bad and I'm going to see my GP and I said, you know, I don't like taking the steroids and he's like… take the drugs. I've had to just go. Okay. I'm, I'm, I have to take these because I honestly, I do not like taking medicines. I made my husband get a vasectomy, so I didn't have to take the pill. I hate it, but what can you do? Participant 4.

Yeah, it probably had more I feel like I'm grasping at straws more now trying to get it controlled. Try anything that control management. Participant 88.

A lot has changed because I realized that I don't really get much of a say anymore. I have to do what I'm being told basically because I'm aware that my body is crumbling. I feel I have less of a say. So, yes. Participant 75.

Participant describes change, considering how rheumatoid arthritis impacts life

Oh God, no. I am so different about now because I'm, I'm 59 to and there's, there's a big difference I'd have to say between 19 and 50 with your mental state when it comes to these things. And I mean I had to deal with. I was very depressed when I first got diagnosed, as you can imagine, 19 years old and everybody else is running around doing stuff and suddenly you can't do what you said. Participant 36.

The ability to have kids when I'm ready has been a big thing for me. Um, yeah. And, and um, I sort of put my foot down a bit recently with the methotrexate, so, um, yeah, which, um, I'm not sure it's necessarily the best decision for my treatment, but um, yeah, I, for me it's important not to have big life choices taken away from me. Participant 40.

When I do that will I injure myself doing that? Can I do it. Yes, I suppose I do look at it differently. There's things that I know that I can't do any more, and I've got to accept that. As much as I don't want to, I've got to accept it. My decision is based on whether or not I'm going to be sore for the next day or whether or not I can do something because my fingers and my feet are really sore. It just depends. Participant 16.

Participant describes no change as they have always been assertive.

The same way. I'm a very pragmatic person. Participant 59.

I’m much the same even since my first diagnosis when I was a teenager because I, I've always had a health background, um, and mum's a nurse, so I guess in some ways she guided me just think more about the full picture of the drug rather than dwelling on what the side effects might be. Participant 82.

Well, I'm very similar I would have thought. I've dealt with, I had childhood asthma and a few other things. I've always sort of dealt with the medical community throughout my life so it's always been similar process. I guess the difference this time was that I didn't go to my GP, well I did, but I didn't get any answers from the GP and the diagnosis was basically self-run if you like. Participant 18.

Table 4.3: Changes in Decision Making

Does decision-making change over time?	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes change by becoming more informed/ assertive	31	31.00	4	21.05	16	36.36	11	29.73	2	10.00	12	44.44	12	37.50	5	23.81
Participant describes change, by being more accepting of treatment but not through choice	20	20.00	2	10.53	10	22.73	8	21.62	3	15.00	4	14.81	2	6.25	11	52.38
Participant describes change, considering how rheumatoid arthritis impacts life	16	16.00	3	15.79	6	13.64	7	18.92	4	20.00	2	7.41	9	28.13	1	4.76
Participant describes no change as they have always been assertive	11	11.00	2	10.53	3	6.82	6	16.22	3	15.00	2	7.41	4	12.50	2	9.52
No confirmative response	8	8.00	2	10.53	4	9.09	2	5.41	2	10.00	2	7.41	3	9.38	1	4.76

Does decision-making change over time?	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes change by becoming more informed/ assertive	31	31.00	11	33.33	9	25.00	11	35.48	5	25.00	16	44.44	10	22.73
Participant describes change, by being more accepting of treatment but not through choice	20	20.00	3	9.09	10	27.78	7	22.58	4	20.00	7	19.44	9	20.45
Participant describes change, considering how rheumatoid arthritis impacts life	16	16.00	2	6.06	6	16.67	8	25.81	2	10.00	6	16.67	8	18.18
Participant describes no change as they have always been assertive	11	11.00	6	18.18	4	11.11	1	3.23	5	25.00	2	5.56	4	9.09
No confirmative response	8	8.00	6	18.18	1	2.78	1	3.23	2	10.00	1	2.78	5	11.36

Table 4.3: Changes in Decision Making (cont.)

Does decision-making change over time?	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes change by becoming more informed/ assertive	31	31.00	17	30.36	14	31.82	8	25.81	19	37.25	4	22.22
Participant describes change, by being more accepting of treatment but not through choice	20	20.00	7	12.50	13	29.55	5	16.13	10	19.61	5	27.78
Participant describes change, considering how rheumatoid arthritis impacts life	16	16.00	10	17.86	6	13.64	4	12.90	7	13.73	5	27.78
Participant describes no change as they have always been assertive	11	11.00	9	16.07	2	4.55	6	19.35	3	5.88	2	11.11
No confirmative response	8	8.00	7	12.50	1	2.27	3	9.68	5	9.80	0	0.00

Does decision-making change over time?	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes change by becoming more informed/ assertive	31	31.00	18	32.14	13	29.55	13	39.39	18	26.87	17	34.00	14	28.00
Participant describes change, by being more accepting of treatment but not through choice	20	20.00	11	19.64	9	20.45	7	21.21	13	19.40	11	22.00	9	18.00
Participant describes change, considering how rheumatoid arthritis impacts life	16	16.00	11	19.64	5	11.36	4	12.12	12	17.91	8	16.00	8	16.00
Participant describes no change as they have always been assertive	11	11.00	6	10.71	5	11.36	1	3.03	10	14.93	6	12.00	5	10.00
No confirmative response	8	8.00	4	7.14	4	9.09	4	12.12	4	5.97	3	6.00	5	10.00

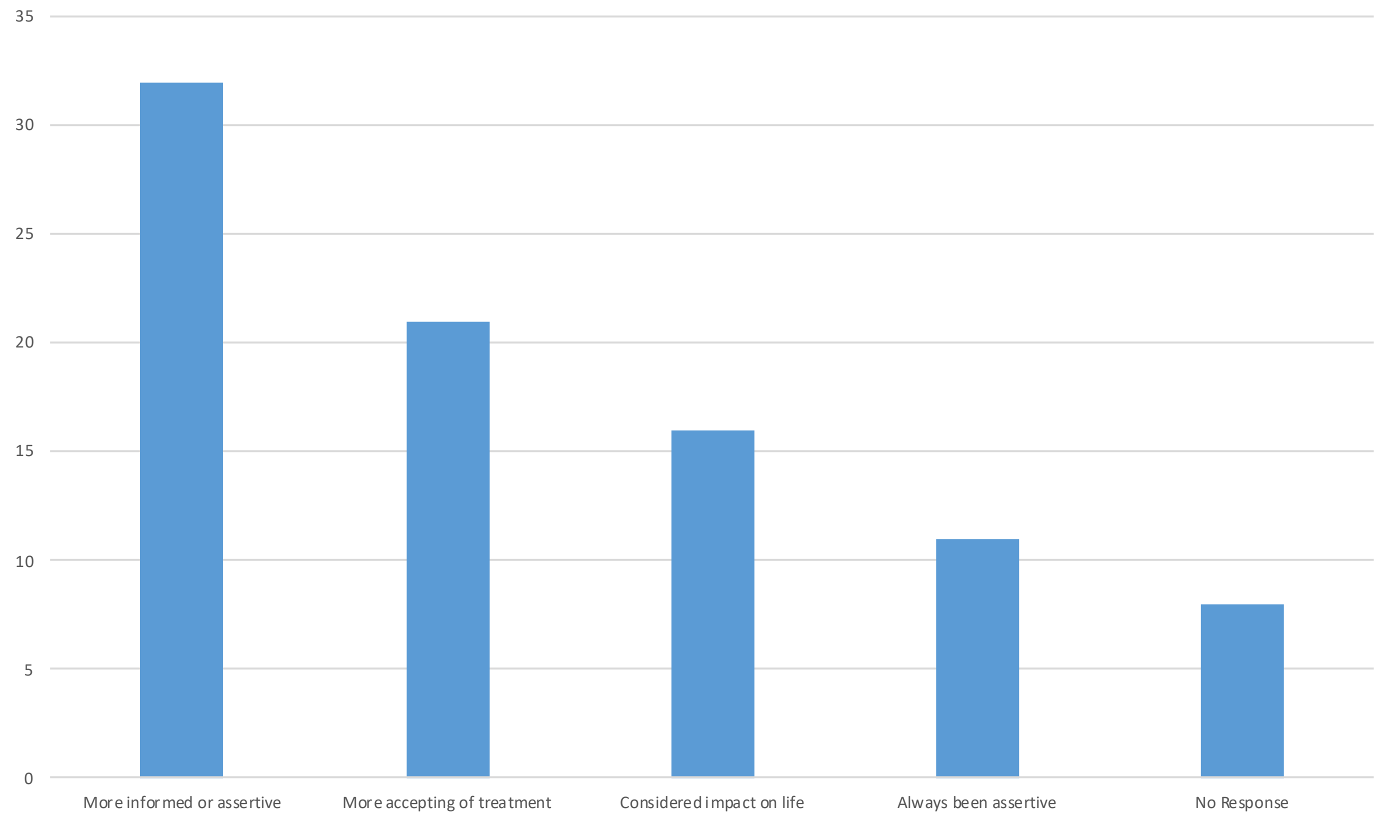


Table 4.3: Changes in Decision Making

Section 5 Treatment and health service provision

Section 5: Experience of treatment

Main provider of treatment

- Participants answered questions about access to health services in the online questionnaire. The main physician treating participants for rheumatoid arthritis was a rheumatologist (n=79, 80.61%), others were treated mainly their general practitioner (n=16, 16.33%).

Access to health professionals

- Participants had access to a general practitioner (n=99, 99.00%), a rheumatologist (n=98, 98.00%), a pharmacist (n=62, 62.00%), and a physiotherapist (n=56, 56.00%), for the treatment of their rheumatoid arthritis.

Treated with respect during treatment

- Half of the participants indicated that they had been treated with respect throughout their treatment (n=50, 50.00%), 39 (39.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 11 (11.00%) participants felt they had not been treated with respect throughout their treatment.

Health care system

- The majority of participants were asked if they had private health insurance (n=86, 86.00%), and 38 (38.00%) participants were asked if they wanted to be treated as a public or private patient. The majority of patients had private healthcare insurance (n=67, 67.00%), and almost half were treated as private patients (n=47, 47.00%), and almost half were treated in a public hospital (n=47, 47.00%).

Affordability of healthcare

- Participants were asked about costs/affordability issues associated with rheumatoid arthritis. Over half of the participants have never or rarely missed medical appointments due to cost (n=58, 58.00%), 27 participants (27.00%) sometimes missed appointments due to cost, and 15 participants (15.00%) often or very often missed appointments due to costs.
- Over half the participants never did not fill prescriptions due to cost (n=57, 57.00%), 17 (17.00%) rarely couldn’t fill their prescriptions, 22 (22.00%) sometimes could not fill prescriptions and 4 (4.00%) often could not fill prescriptions due to costs.
- Almost half of the participants had never had difficulty paying for basic necessities such as housing, food and electricity (n=48, 48.00%). Twenty participants (20.00%) rarely had difficulty, and additional 20 participants (20.00%) sometimes had difficulty, and 12 participants (12.00%) often or very often had difficulty paying for basic necessities.
- The majority of participants did not need to pay for additional carers for either themselves or their family members due to rheumatoid arthritis (n=82, 82.00%).

Reduced income due to rheumatoid arthritis.

- Forty-two participants (42.00%) reported that their income or family income had been reduced due to rheumatoid arthritis. The amount of lost monthly income was reported to be between $150 and $10 000 AUD a month, the most common response was between $1001 and $2000 AUD a month (n=10, 23.81). For those that had a reduced income, for more than half (n=24, 57.14%) this was moderately or extremely significant.

Cost of rheumatoid arthritis

- In the online questionnaire, the participants indicated described the amount spent per month on rheumatoid arthritis. Almost all participants had some costs associated with rheumatoid arthritis with only a single participant (1.00%) having no cost at all. The most common amount spent was between $101 and $250 a month (N=31, 31.00%). There were 9 participants (9.00%) who spent more than $500 a month.
- Participants were asked if the amount spent was a burden, for 18 participants (18.00%) this was an extremely significant burden, for 21 participants (21.00%) this was a moderately significant burden and for 22 participants (22.00%) this was a somewhat significant burden.

Changes to employment status

- Participants described changes in work status due to rheumatoid arthritis. More than half of the participants described changes that reduced income through quitting their job, reduced number of hours they worked or by taking leave without pay (n=58, 58.00%).

Changes to partner/main carer work status

- Participants noted in the online questionnaire the changes to their partner's or main carer's work status. Twelve participants (12.00%) noted that their partner of main carer made changes to employment that resulted in a loss of income (due to quitting work, reduced hours of work or leave without pay).

Surgery

- Twenty-three participants (23.00%) had one or more surgeries for their rheumatoid arthritis, fifteen of these had a single surgery (65.22%). The most common type of surgery reported per participant was arthroscopy (n=12, 52.17%), and the most common joint operated on was the knee (n=14, 60.87%). Other surgeries included synovectomies, tenolysis, carpel tunnel surgery, laser eye surgery, spinal fusion and Anterior cervical discectomy and fusion.

Disease-modifying antirheumatic drugs (DMARDs)

- Participants described their experience of DMARDs. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while taking DMARDs (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).
- The most common DMARD taken was methotrexate (n=86, 86.00%), the median quality of life was 4, in the "Life was average" range, and the effectiveness was rated as 3, in the moderately effective range. The most common side effect reported was feeling sick or nausea (n=45, 52.33). The next most frequently used DMARD was hydroxychloroquine (n=50, 50.00%). The median quality of life while on this treatment was 4, in the "Life was average" range, and the median effectiveness was 2.5, in the somewhat effective range. The most common side effect reported from taking hydroxychloroquine was feeling sick or nauseous (n=15, 31.25%). Thirty-four participants (34.00%) took lefluomide, the median quality of life was 3, in the "Life was a little distressing range", and the median effectiveness was rated as 2, in the somewhat effective range. Thirty-three participants (33.00%), took sulfasalazine, the median quality of life as 3, in the "Life was a little distressing" range, and the median effectiveness was 1, in the ineffective range.

Biological DMARDs

- Adalimumab was the most common biological DMARD used by participants in this study (n=24, 24.00%). The median quality of life was 5, in the "life was good" range, and the median effectiveness was rated as 3.5, in the moderately effective range. Half of participants that used adalimumab had no side effects (n=12, 50,00%) and the most common side effect was a skin reaction at the site of injection (n=8, 33.33%). Twenty-two participants (22.00%) took etanercept, the median quality of life was 4.5, in the "Life was average", and the median effectiveness was 3, in the moderately effective range. Nineteen participants (19.00%) took tofacitinib, the median quality of life was 4, in the "Life was average" range, and the median effectiveness was 2, in the somewhat effective range.

Pain killers and anti-inflammatories

- The majority of participants (n=84, 84.00%) had used paracetamol for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 2, in the somewhat effective range. Very few participants (n=4, 4.76%) reported side effects from paracetamol. More than half of the participants had taken codeine, the median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 3, in the moderately effective range. The most commonly reported side effects from codeine were feeling sleepy (n=16, 21.92%) and constipation (n=12, 17.81%).
- The majority of participants (n=73, 73.00%) had used NSAIDs for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 3, in the moderately effective range. More than half of the participants that used NSAIDs had no side effects (n=42, 57.53%), the most common side effect was stomach aches (n=18, 24.66%). Seventy-four participants (74.00%) had taken corticosteroids, the median quality of life was reported as 4, in the "Life was average" range, and the median effectiveness was rated as 4, in the effective range. The most commonly reported side effects from corticosteroids were trouble sleeping (n=38, 51.35%%) and bloating of the face and swelling of the abdomen (n=36, 48.65%).

Supportive care

- Almost half of the participants had physiotherapy (n=49, 49.00%), the median quality of life was 4 (in the "Life was average" range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=7, 14.15%). Fifteen participants (15.00%) had occupational therapy, the median quality of life was 4 (in the "Life was average" range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=1, 6.67%). Thirty-three participants (33.00%) had seen a podiatrist, the median quality of life was 4 (in the "Life was average" range) and the median effectiveness was 4 (in the effective range), and 23 participants (23.00%) had had counselling or seen a phycologist, the median quality of life was 3 (in the "Life was a little distressing" range) and the median effectiveness was 4 (in the effective range).

Complementary therapies.

- Participants described their experience of relaxation techniques, massage therapy, and acupuncture. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.
- Participants described their experience of relaxation techniques, massage therapy, and acupuncture. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

Discussions about clinical trials

- In this PEEK study, 85.00% of all participants (n=85) describe not being spoken to about clinical trials, 7 participants (7.00%) brought up the topic with their doctor, and the doctors of 8 participants (8.00%) brought up the topic of clinical trials.

Participation in clinical trials

- Five (5.00%) participants have taken part in a clinical trial, and 70 (70.00%) participants have not taken part in a clinical trial but would like if one was suitable for them. Twenty-five (25.00%) participants have not taken part and do not want to.

Mild side effects

- In the structured interview, participants were asked how they would describe the term 'Mild side effects'. The most common description of mild side effects came in the form of participants providing examples of specific side effects (n=49, 49.00%). Of these, the most commonly described side effects were vomiting/nausea (n=26, 26.00%), headaches (n=13, 13.00%), stomach upset (n=10, 10.00%), and lethargy/fatigue (n=9, 9.00%). Other descriptions provided included participants describing mild side effects as those that do not impact ability to carry out everyday tasks (n=27, 27.00%), those that do not require medical attention (n=9, 9.00%) and do not last a long time (n=9, 9.00%).

Severe side effects

- In the structured interview, participants were asked how they would describe the term 'Severe side effects'. The most common description of severe side effects were those that impact everyday life/ability to conduct activities of daily living (n=48, 48.00%). The next most common themes were side effects that result in long-term damage or risk of other disease (n=20, 20.00%) and those that result in hospitalization or are life threatening (n=13, 13.00%). Some participants chose to describe specific side effects (n=62, 62.00%) that they considered severe and these included nausea and vomiting including dizziness (n=16, 16.00%), gastrointestinal distress (n=14, 14.00%) and impact on mental health (n=14, 14.00%).

Adherence to treatment

- Participants were asked what influences their decision to continue with a treatment regime. The most common theme described was adhering to treatment for a specific amount of time (n=41, 41%). Participants also reported following specialists' advice (n=30, 30%), adhering to a treatment regime as long as side effects were tolerable (n=24, 24%), and adhering to treatment as long as they thought it was effective (n=9, 9%). Nine of participants reported willingness to adhere to treatment regimens regardless of efficacy (n=9, 9%).

What needs to change to feel like treatment is effective

- Participants were asked to describe what needs to change to feel like treatment is effective. 60% of participants reported that for a treatment to be effective they had to experience a difference in pain (n=60). Increase in day-to-day functioning (n=28, 28%) and QOL/wellbeing (n=26, 26%) were the also described, as were reductions in specific symptoms associated with RA, such as swelling (n=19, 19%), fatigue (n=18, 18%), and mobility (n=12, 12%). 10 participants reported that for a treatment to be effective there had to be either no disease or a stable disease (10%).

Main provider of treatment

Participants answered questions about access to health services in the online questionnaire. The main physician treating participants for rheumatoid arthritis was a rheumatologist (n=79, 80.61%), others were treated mainly their general practitioner (n=16, 16.33%).

Table 5.1: Main provider of treatment

Main Provider of treatment	N=98	Percent
Rheumatologist	79	80.61
General practitioner (GP)	16	16.33
Rhuematologist and GP equally	2	2.04
Naturopath	1	1.02

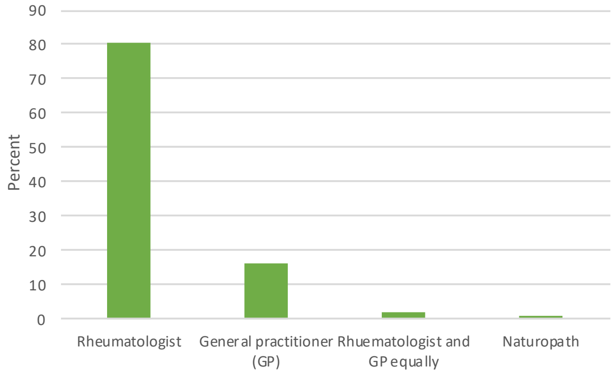


Figure 5.1: Main provider of treatment

Access to health professionals

Participants had access to a general practitioner (n=99, 99.00%), a rheumatologist (n=98, 98.00%), a pharmacist (n=62, 62.00%), and a physiotherapist (n=56, 56.00%), for the treatment of their rheumatoid arthritis.

Table 5.2: Access to health professionals

Health professional	N=100	Percent
General Practitioner	99	99.00
Rheumatologist	98	98.00
Pharmacist	62	62.00
Physiotherapist	56	56.00
Counsellor or psychologist	27	27.00
Dietician	21	21.00
Orthopaedic (Bone) surgeon	17	17.00
Rheumatology nurse	17	17.00
Complementary therapist	16	16.00
Occupational therapist	15	15.00
Exercise physiologist	14	14.00
Weight loss specialist	6	6.00
Chiropractor	3	3.00
Specify other		
Osteopath	3	3.00
Podiatrist	3	3.00
Gynaecologist	2	2.00
Community social worker	1	1.00
Dentist	1	1.00
Endocrinologist	1	1.00
Hand Therapist	1	1.00
Immunologist	1	1.00
Massage therapist	1	1.00
Myotherapist	1	1.00
Neurologist	1	1.00
Oncology Nurse for arthritis treatment at hospital	1	1.00
Paediatrician	1	1.00
Respiratory specialist	1	1.00

Respect shown

Half of the participants indicated that they had been treated with respect throughout their experience (n=50, 50.00%), 39 (39.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 11 (11.00%) participants felt they had not been treated with respect throughout their treatment.

Table 5.3: Treated with respect

Treated respectfully throughout your experience	N=100	Percer
No	11	11.0
Yes	50	50.0
Yes, with the exception of one or two occasions	39	39.0

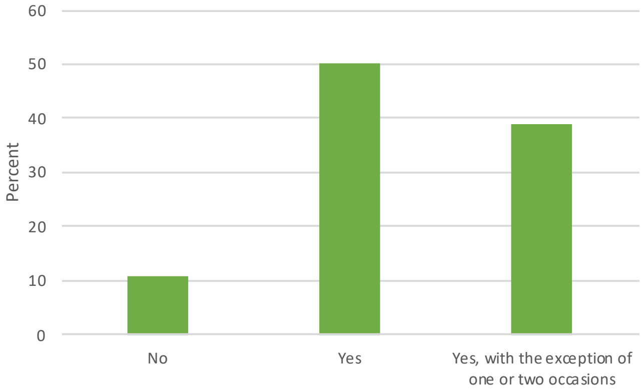


Figure 5.2: Treated with respect

Health care system

The majority of participants were asked if they had private health insurance (n=86, 86.00%), and 38 (38.00%) participants were asked if they wanted to be treated as a public or private patient. The majority of patients had private healthcare insurance (n=67, 67.00%), and almost half were treated as private patients (n=47, 47.00%), in a public hospital (n=47, 47.00%).

Table 5.4: Public/private healthcare

Health system	N=100	Percent
Private health insurance		
No	33	33.00
Yes	67	67.00
Asked if wanted to be treated as a public or private patient		
No	62	62.00
Yes	38	38.00
Asked if had private health insurance		
No	14	14.00
Yes	86	86.00
Treated mostly as a public or a private patient		
Equally as a public and private patient	20	20.00
I'm not sure	4	4.00
Private patient	47	47.00
Public patient	29	29.00
Hospital system primarily been treated in		
Both public and private	22	22.00
Private	31	31.00
Public	47	47.00

Affordability of healthcare

Participants were asked about costs/affordability issues associated with rheumatoid arthritis. Over half of the participants have never or rarely missed medical appointments due to cost (n=58, 58.00%), 27 participants (27.00%) sometimes missed appointments due to cost, and 15 participants (15.00%) often or very often missed appointments due to costs.

Over half the participants never did not fill prescriptions due to cost (n=57, 57.00%), 17 (17.00%) rarely couldn't fill their prescriptions, 22 (22.00%) sometimes could not fill prescriptions and 4 (4.00%) often could not fill prescriptions due to costs.

Almost half of the participants had never had difficulty paying for basic necessities such as housing, food and electricity (n=48, 48.00%). There were 20 participants (20.00%) that rarely had difficulty, and additional 20 participants (20.00%) sometimes had difficulty, and 12 participants (12.00%) often or very often had difficulty paying for basic necessities.

The majority of participants did not need to pay for additional carers for either themselves or their family members due to rheumatoid arthritis (n=82, 82.00%).

Table 5.5: Affordability of healthcare

Affordability	N=100	Percent
Delay or cancel healthcare appointments due to affordability		
Never	44	44.00
Rarely	14	14.00
Sometimes	27	27.00
Often	12	12.00
Very often	3	3.00
Did not fill prescriptions for essential medicines because of costs		
Never	57	57.00
Rarely	17	17.00
Sometimes	22	22.00
Often	4	4.00
Very often	0	0
Due to rheumatoid arthritis, difficult to pay for basic necessities such as housing, food, electricity		
Never	48	48.00
Rarely	20	20.00
Sometimes	20	20.00
Often	4	4.00
Very often	8	8.00
Due to rheumatoid arthritis, had to pay for additional carers for self or family		
No	82	82.00
Yes	18	18.00

Reduced income due to rheumatoid arthritis

There were 42 participants (42.00%) that reported their income or family income had been reduced due to rheumatoid arthritis. The amount of lost monthly income was reported to be between $150 and $10 000 AUD a month, the most common response was between $1001 and $2000 AUD a month (n=10, 23.81%). For those that had a reduced income, for more than half (n=24, 57.14%) this was moderately or extremely significant.

Table 5.6: Reduced family income

Reduced income or family income due to rheumatoid arthritis	N=100	Percent
No	58	58.00
Yes	42	42.00

Table 5.7: Burden of reduced family income

Burden of reduced income	N=42	Percent
Not at all significant	0	0.00
Slightly significant	6	14.29
Somewhat significant	12	28.57
Moderately significant	11	26.19
Extremely significant	13	30.95

Table 5.8: Estimate of reduced monthly income

Estimated reduced income ($AUD)	N=42	Percent
1 to 500	5	11.90
501 to 1000	7	16.67
1001 to 2000	10	23.81
2001 to 4000	9	21.43
more than 4000	3	7.14
Don't know	6	14.29
Reduced or lost income	2	4.76

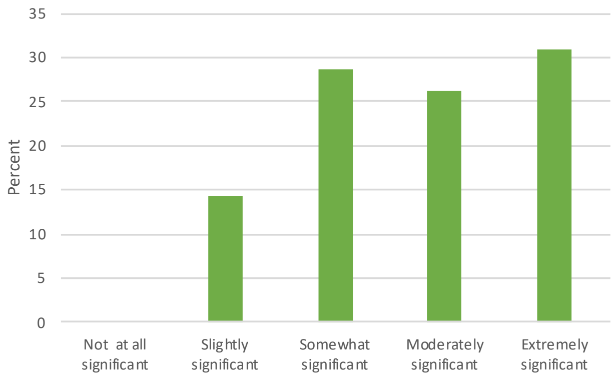


Figure 5.3: Burden of reduced family income

Cost of rheumatoid arthritis

In the online questionnaire, the participants indicated the amount spent per month on rheumatoid arthritis. Almost all participants had some costs associated with rheumatoid arthritis with only a single participant (1.00%) having no cost at all. The most common amount spent was between $101 and $250 a month (N=31, 31.00%). There were 9 participants (9.00%) who spent more than $500 a month.

Participants were asked if the amount spent was a burden, for 18 participants (18.00%) this was an extremely significant burden, for 21 participants (21.00%) this was a moderately significant burden and for 22 participants (22.00%) this was a somewhat significant burden.

Table 5.9: Estimated monthly expenses for rheumatoid arthritis

Estimated monthly expenses for rheumatoid arthritis ($AUD)	N=100	Percent
0	1	1.00
1 to 50	7	7.00
51 to 100	17	17.00
101 to 250	31	31.00
251 to 500	25	25.00
501 to 1000	6	6.00
More than 1000	3	3.00
Don't know	10	10.00

Table 5.10: Burden of monthly expenses for rheumatoid arthritis

Burden of monthly expenses for rheumatoid arthritis	N=100	Percent
Not at all significant	15	15.00
Slightly significant	24	24.00
Somewhat significant	22	22.00
Moderately significant	21	21.00
Extremely significant	18	18.00

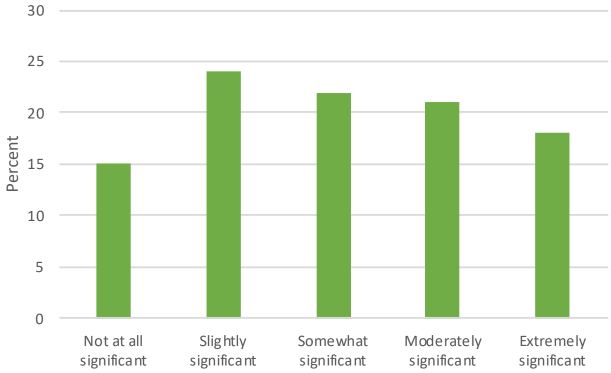


Figure 5.4: Burden of monthly expenses for rheumatoid arthritis

Changes to employment status

Participants described changes in work status due to rheumatoid arthritis. More than half of the participants described changes that reduced income through quitting their job, reduced number of hours they worked or by taking leave without pay (n=58, 58.00%). Thirty-four (34.00%) reduced the number of hours worked, in addition to reducing their hours. Of these 34 participants, two took leave from work with pay and four took leave from work without pay. Twenty-two participants (22.00%) quit their job due to rheumatoid arthritis: of these 22 participants, in addition to quitting their job, two participants accessed early superannuation; one reduced the number of hours of work and took leave with pay; four reduced hours of work and took leave without pay; and two reduced the number of hours worked, took leave with and without pay and accessed superannuation early.

Table 5.11: Changes to employment status

Changes to employment status	N=100	Percent
Quit job	22	22.00
plus accessed superannuation early (N=2)		
plus reduced hours of work (N=1)		
plus have reduced hours of work, and leave from work with pay (N=1)		
plus reduced hours of work, leave from work with pay, and leave from work without pay (N= 4)		
plus reduced hours of work, leave from work with pay, leave from work without pay, accessed superannuation early (N=2)		
I have reduced the number of hours that I work	34	34.00
plus leave from work with pay (N=2)		
plus leave from work with pay, and leave from work without pay (N=8)		
plus leave from work without pay (N=4)		
I have taken leave from work without pay	2	2.00
plus leave with pay (N=1)		
I have taken leave from work with pay	5	5.00
I was retired or did not have a job when I was diagnosed	10	10.00
My work status has not changed since I was diagnosed	27	27.00

Changes to partner/main carer work status

Participants noted in the online questionnaire the changes to their partner's or main carer's work status. Twelve participants (12.00%) noted that their partner of main carer made changes to employment that resulted in a loss of income (due to quitting work, reduced hours of work or leave without pay). Half of the participants (n=50, 50.00%) partner/carers were either retired or have had no changes to employment status, and 36 participants (36.00%) have no partner or main carer.

Table 5.12: Changes to partner/main carer work status

Changes to partner/main carer work status	N=100	Percent
My partner/main carer quit job	3	3.00
My partner/main carer reduced hours of work	4	4.00
plus leave without pay (N=1)		
My partner/main carer took leave from work without pay	5	5.00
My partner/main carer took leave from work with pay	2	2.00
My partner/main carer was retired or did not have a job when I was diagnosed	5	5.00
Employment status of my partner/main carer status has not changed since diagnosis	45	45.00
I do not have a partner/main carer	36	36.00

Changes to work

Of those that described changes to work, participants described that they had changed the type of work that they did (n=11), that they worked from home (n=4), had flexible working arrangements (n=2) or did freelance work (n=1). Participants described limited career or promotion opportunities due to rheumatoid arthritis or effective demotion (n=1).

Table 5.13: Other changes to work for participant or partner/main carer

Other changes to work	N=21	%
Changed type of work	11	52.38
Work from home	4	19.05
Flexible working arrangements	2	9.52
Limited career or promotion opportunities	2	9.52
Demotion	1	4.76
Freelance work	1	4.76

Surgery

Twenty-three participants (23.00%) had one or more surgeries for their rheumatoid arthritis, fifteen of these had a single surgery (65.22%). The most common type of surgery reported per participant was arthroscopy (n=12, 52.17%), and the most common joint operated on was the knee (n=14, 60.87%). Other surgeries included synovectomies, tenolysis, carpel tunnel surgery, laser eye surgery, spinal fusion and Anterior cervical discectomy and fusion.

Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, following their operation (with 1 being 'Life was very distressing and 7 being 'Life was great'). Quality of life scores ranges from 1 to 6, with a median score of 3, that is, in the 'Life was a little distressing' range. A second follow-up question was asked in relation to how effective the participant felt the procedure was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). Effectiveness scores ranged from 1 to 5, with a median score of 4, in the 'Effective' range.

Table 5.14: Summary of surgery

Surgery	Number of participants N=23	Percent
Number of surgeries per patient		
1	15	65.22
2	2	8.70
3	2	13.04
4 or more	4	13.04
Operation type		
Arthrodesis (bone fusion)	4	17.39
Arthroscopy	12	52.17
Osteotomy (cutting and repositioning a bone)	1	4.35
Resection (removal of part or all of a bone or an entire joint)	4	17.39
Joint replacement	7	30.43
Other	10	
QOL		
Range	1 to 6	
Mean	2.75	Life was distressing range
Median	3	Life was a little distressing range
Effective	1 to 5	
Mean	3.71	Moderate range
Median	4	Effective range
Joint (per patient)		
Knee	14	60.87
Hand/Wrist/Fingers	9	39.13
Foot/Ankle/Toes	3	13.04
Hips	3	13.04
Elbow	2	8.70
spine	2	8.70
Shoulders	1	4.35
Eye	1	4.35
Jaw	1	4.35

By procedure type, 12 participants had an arthroscopy, the reported median quality of life was 3, in the "Life was a little distressing" range, and the median effectiveness score was rated as 3, in the moderately effective range. Seven participants had a joint replacement, the median quality of life was reported as 2, in the "Life was distressing" range, and the median effectiveness was 4, in the effective range.

Table 5.15: Details of surgery

Operation type	Arthrodesis N=4	Arthroscopy N=12	Osteotomy N=1	Resection N=4	Joint replacement N=7
Number last five years	3	5	0	2	6
Method					
Open	3	0	1	4	
Keyhole	1	12			7
QOL					
Range	1 to 4	1 to 6	3	1 to 4	1 to 3
Mean	3	3.25	3	2	2
Median	3.5	3	3	1.5	2
Effective					
Range	4 to 5	1 to 5	4	4 to 5	2 to 5
Mean	4.75	2.92	4	4.5	4
Median	5	3	4	4.5	4
Joint (per patient)					
Knee		9			5
Hand/Wrist/Fingers	3	1	1	3	3
Foot/Ankle/Toes	2	1			
Hips		1			2
Elbow		2			1
spine					
Shoulders				1	
Eye					
Jaw					
Side effects per participant					
Pain	2	11	1	4	2
Fatigue	2	4	1	3	1

Disease-modifying antirheumatic drugs (DMARDs)

Participants described their experience of DMARDs. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while taking DMARDs (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

The most common DMARD taken was methotrexate (N=86, 86.00%), the median quality of life was 4, in the "Life was average" range, and the effectiveness was rated as 3, in the moderately effective range. The most common side effect reported was feeling sick or nauseous (n=45, 52.33). The next most frequently used DMARD was hydroxychloroquine (n=50, 50.00%). The median quality of life while on this treatment was 4, in the "Life was average" range, and the median effectiveness was 2.5, in the somewhat effective range. The most common side effect reported from taking hydroxychloroquine was feeling sick or nauseous (n=15, 31.25%). Thirty-four participants (34.00%) took lefluomide, the median quality of life was 3, in the "Life was a little distressing range", and the median effectiveness was rated as 2, in the somewhat effective range. Thirty-three participants (33.00%), took sulfasalazine, the median quality of life as 3, in the "Life was a little distressing" range, and the median effectiveness was 1, in the ineffective range.

Table 5.16: Disease-modifying antirheumatic drugs (DMARDs)

DMARD	Methotrexate N=86		Leflunomide N=34		Hydroxychoroquine N=50		Sulfasalazine N=33	
QOL								
Range	1 to 7		1 to 6		1 to 7		1 to 6	
Mean	3.67	Life was a little distressing	3.29	Life was a little distressing	4.47	Life was average	3.09	Life was a little distressing
Median	4	Life was average	3	Life was a little distressing	4	Life was average	3	Life was a little distressing
Effectiveness								
Range	1 to 5		1 to 5		1 to 5		1 to 4	
Mean	3.19	Moderately effective	2.24	Somewhat effective	2.63	Somewhat effective	1.88	Ineffective
Median	3	Moderately effective	2	Somewhat effective	2.5	Somewhat effective	1	Ineffective
Side effects								
No side effects	16	18.60	3	8.82	19	39.58	14	42.42
Feeling sick/nausea	45	52.33	9	16.47	15	31.25	13	39.39
Loss of appetite	16	18.60	4	11.76	3	6.25	4	12.12
A sore mouth	27	31.40	3	8.82	4	8.33	0	0.00
Diarrhoea	20	23.26	17	50.00	12	25.00	4	12.12
Headaches	21	24.42	4	11.76	8	16.67	5	15.15
Hair loss	22	25.58	6	17.65	2	4.17	1	3.03
Rash	8	9.30	2	5.88	4	8.33	2	6.06
Dizziness	12	13.95	2	5.88	2	4.17	4	12.12
Specify other side effects								
Allergic reaction	0		0		0		3	
Concentration problems	4		0		0		1	
Ear problems	1		0		1		0	
Eye problems	1		0		5		0	
Fatigue	7		0		1		0	
Gastrointestinal	1		1		1		1	
Hand and nail problems	0		1		0		0	
Heart palpitations	1		0		0		0	
Liver problems	4		1		0		1	
Migraines	0		0		0		1	
Miscarriage	1		0		0		0	
Mood and personality changes	3		0		1		0	
Neuropathy	0		1		0		0	
Short of breath	1		0		0		0	
Skin changes	1		0		0		0	
Sun sensitivity	0		0		2		0	
Swelling	1		1		0		0	
Taste changes	1		0		0		0	
Tingling	0		1		0		0	
Unable to take due to size and smell of tablet	0		0		0		1	

Biological DMARDs

Participants described their experience of biological DMARDs. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while taking biological DMARDs (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.

Adalimumab was the most common biological DMARD used by participants in this study (n=24, 24.00%). The median quality of life was 5, in the "life was good" range, and the median effectiveness was rated as 3.5, in the moderately effective range. Half of participants that used adalimumab had no side effects (n=12, 50,00%) and the most common side effect was a skin reaction at the site of injection (n=8, 33.33%). Twenty-two participants (22.00%) took etanercept, the median quality of life was 4.5, in the "Life was average" range, and the median effectiveness was 3, in the moderately effective range. Nineteen participants (19.00%) took tofacitinib, the median quality of life was 4, in the "Life was average" range, and the median effectiveness was 2, in the somewhat effective range.

Few participants took abatacept (n=13), tocilizumab (n=11), Golimumab (n=9), Certolizumab (n=8), Infliximab (n=5), Rituximab (n=1), and Anakinra (n=1). The median quality of life was 4 (in the "Life was average" range) for abatacept and infliximab, and the median quality of life was 5 (in the "Life was good" range) for Tocilizumab, Golimumab and Certolizumab. The median effectiveness was 4 (in the effective range) for Tocilizumab and infliximab, and the median effectiveness was 5 (in the very effective range) for Golimumab and Certolizumab.

Participants noted other treatments not listed in the questionnaire, one participant used Brenzys, an Etanercept biosimilar, and two participants used Olumiant.

Table 5.17: Biological Disease-modifying antirheumatic drugs (DMARDs)

Biological DMARD	Adalimumab N=24		Etanercept N=22		Tofacitinib N=19		Abatacept N=13		Tocilizumab N=11	
QOL										
Range	1 to 7		2 to 7		2 to 6		2 to 7		2 to 7	
Mean	4.5		4.18		3.89		4.54		4.82	
Median	5		4.5		4		4		5	
Effectiveness										
Range	1 to 5		1 to 5		1 to 5		1 to 5		2 to 5	
Mean	3.33		2.91		2.68		3.08		3.91	
Median	3.5		3		2		3		4	
Side effects										
No side effects	12	50.00	9	40.91	3	15.79	6	46.15	6	54.55
Skin reaction	8	33.33	9	40.91	2	10.53	3	23.08	3	27.27
Infection	3	12.50	4	18.18	4	21.05	3	23.08	1	9.09
Feeling sick	1	4.17	0	0	6	31.58	1	7.69	1	9.09
Fever	2	8.33	0	0	2	10.53	0	0	2	18.18
Headaches	2	8.33	2	9.09	4	21.05	0	0	2	18.18
Specify other side effects										
Gastrointestinal	0		0		0		1		0	
Pins and needles/nerve pain	1		0		0		0		0	
Skin problems	1		1		1		0		1	
Cardiovascular problems	3		1		0		0		0	
Allergic reaction	1		1		0		0		0	
Multiple organ failure	1		0		0		0		0	
Sun sensitivity	0		0		0		0		0	
Itch	0		0		0		0		0	
Fatigue	0		1		0		0		0	
Too soon to comment	0		1		1		0		0	
Cognitive problems	0		1		0		0		0	
Loss of appetite	0		0		0		0		1	
Hair loss	0		0		1		0		0	
Dizziness and vertigo	0		0		1		0		0	
Mouth ulcer	0		0		1		0		0	

Table 5.17 (Cont.): Biological Disease-modifying antirheumatic drugs (DMARDs)

Biological DMARD	Adalimumab N=24		Etanercept N=22		Tofacitinib N=19		Abatacept N=13		Tocilizumab N=11	
QOL										
Range	1 to 7		2 to 7		2 to 6		2 to 7		2 to 7	
Mean	4.5		4.18		3.89		4.54		4.82	
Median	5		4.5		4		4		5	
Effectiveness										
Range	1 to 5		1 to 5		1 to 5		1 to 5		2 to 5	
Mean	3.33		2.91		2.68		3.08		3.91	
Median	3.5		3		2		3		4	
Side effects										
No side effects	12	50.00	9	40.91	3	15.79	6	46.15	6	54.55
Skin reaction	8	33.33	9	40.91	2	10.53	3	23.08	3	27.27
Infection	3	12.50	4	18.18	4	21.05	3	23.08	1	9.09
Feeling sick	1	4.17	0	0	6	31.58	1	7.69	1	9.09
Fever	2	8.33	0	0	2	10.53	0	0	2	18.18
Headaches	2	8.33	2	9.09	4	21.05	0	0	2	18.18
Specify other side effects										
Gastrointestinal	0		0		0		1		0	
Pins and needles/nerve pain	1		0		0		0		0	
Skin problems	1		1		1		0		1	
Cardiovascular problems	3		1		0		0		0	
Allergic reaction	1		1		0		0		0	
Multiple organ failure	1		0		0		0		0	
Sun sensitivity	0		0		0		0		0	
Itch	0		0		0		0		0	
Fatigue	0		1		0		0		0	
Too soon to comment	0		1		1		0		0	
Cognitive problems	0		1		0		0		0	
Loss of appetite	0		0		0		0		1	
Hair loss	0		0		1		0		0	
Dizziness and vertigo	0		0		1		0		0	
Mouth ulcer	0		0		1		0		0	

Pain killers and anti-inflammatories

Participants described their experience of paracetamol, codeine, NSAIDs and corticosteroids. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being ‘Life was very distressing and 7 being ‘Life was great’). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.

The majority of participants (n=84, 84.00%) had used paracetamol for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average” range, and the median effectiveness was rated as 2, in the somewhat effective range. Very few participants (n=4, 4.76%) reported side effects from paracetamol. More than half of the participants had taken codeine, the median quality of life was reported was 4, in the "Life was average” range, and the median effectiveness was rated as 3, in the moderately effective range. The most commonly reported side effects from codeine were feeling sleepy (n=16, 21.92%) and constipation (n=12, 17.81%).

The majority of participants (n=73, 73.00%) had used NSAIDs for their rheumatoid arthritis. The median quality of life was reported as 4, in the "Life was average” range, and the median effectiveness was rated as 3, in the moderately effective range. More than half of the participants that used NSAIDs had no side effects (n=42, 57.53%), the most common side effect was stomach aches (n=18, 24.66%). Seventy-four participants (74.00%) had taken corticosteroids, the median quality of life was reported as 4, in the "Life was average” range, and the median effectiveness was rated as 4, in the effective range. The most commonly reported side effects from corticosteroids were trouble sleeping (n=38, 51.35%%) and bloating of the face and swelling of the abdomen (n=36, 48.65%).

Table 5.18: Pain killers and anti-inflammatories

Pain relief/anti-infalmmatory	Paracetamol N=84			Codeine N=47		
		N=84	Percent		N=47	Percent
QOL						
Range	1 to 6			1 to 6		
Mean	3.68			3.45		
Median	4			4		
Effectiveness						
Range	1 to 5			1 to 5		
Mean	2.3			2.89		
Median	2			3		
Side effects	No side effects	80	95.24	No side effects	21	28.77
				Constipation	13	17.81
				Feeling sick or vomiting	6	8.22
				Feeling sleepy	16	21.92
				Dizziness/vertigo	3	4.11
				Dry mouth	6	8.22
				Confusion	2	2.74
				Headaches	2	2.74
Specify other side effects	Gastrointestinal	2		Allergic reaction	1	
	Fatigue	1		Hives/Itchy Skin	2	
	Concentration problems	1				

Table 5.18 (cont.): Pain killers and anti-inflammatories

Pain relief/anti-infalmmatory	NSAIDs N=73			Corticosteroids N=74		
		N=73	Percent		N=74	Percent
QOL						
range	1 to 7			1 to 7		
mean	3.66			3.85		
median	4			4		
Effectiveness						
Range	1 to 5			1 to 5		
mean	2.99			3.81		
median	3			4		
Side effects	No side effects	42	57.53	No side effects	11	14.86
	Indigestion	15	20.55	Fluid retention, which can lead to heart problems	21	28.38
	Stomach aches	18	24.66	Trouble sleeping	38	51.35
	Feeling sick	12	16.44	Bloating of the face and swelling of the abdomen	36	48.65
	Diarrhoea	8	10.96	Weight gain	44	59.46
	Headaches	4	5.48	Muscle cramps	13	17.57
	Drowsiness	5	6.85	Thin skin with easy bruising and acne	28	37.84
	Dizziness	3	4.11			
	Flu-like symptoms	4	5.48			
Specify other symptoms	Esophagitis	1		Cushingoid's syndrome	1	
	Pain	1		Osteoporosis	3	
	Allergic reaction	1		Concentration problems	1	
	Stomach ulcers	1		Type 2 diabetes/high blood sugar	3	
				Cataracts	1	
				Cardiovascular problems	2	
				Increased appetite	1	
				Nervous symptoms	1	
				Nausea	1	
				Sweating more	1	
				Changes to mood	1	

Supportive care

Participants described their experience of physiotherapy, occupational therapy, podiatry and counselling. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being ‘Life was very distressing and 7 being ‘Life was great’). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.

Almost half of the participants had physiotherapy (n=49, 49.00%), the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=7, 14.15%). Fifteen participants (15.00%) had occupational therapy, the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 3 (in the moderately effective range), very few participants reported side effects (n=1, 6.67%). Thirty-three participants (33.00%) had seen a podiatrist, the median quality of life was 4 (in the “Life was average” range) and the median effectiveness was 4 (in the effective range), and 23 participants (23.00%) had counselling or had seen a phycologist, the median quality of life was 3 (in the “Life was a little distressing” range) and the median effectiveness was 4 (in the effective range).

Participants noted other supportive care not listed in the questionnaire, three participants saw an osteopath, and one participant used invasive laser treatment with their physiotherapist.

Table 5.19: Supportive care

Supportive care	Physiotherapy N=49		Occupational therapy N=15	
QOL				
Range		2 to 6		1 to 6
Mean		3.96		3.67
Median		4		4
Effectiveness				
Range		1 to 5		1 to 5
Mean		2.92		3.13
Median		3		3
No Side effects		41 (85.45%)		14(93.33%)
Specify other side effects	Pain	2	Financially unrealistic recommendations	1
	Too strenuous	1		
	Fatigue	2		
	Flare up	2		
	Swelling	1		

Table 5.19 (cont.): Supportive care

Supportive care	Podiatrist N=33			Counsellor/phycologist N=23
QOL				
Range		1 to 6		1 to 6
Mean		3.59		3.22
Median		4		3
Effectiveness				
Range		1 to 5		1 to 5
Mean		3.28		3.61
Median		4		4
No Side effects		28(87.50%)		21(91.30%)
Specify other side effects	Humiliating shoe choice for young person	1	Did not understand illness	1
	Pain	1	Made it worse	1
	Frustration	1		
	Orthotics/shoes did not help	1		

Complementary therapies

Participants described their experience of relaxation techniques, massage therapy, and acupuncture. Participants were asked (within the questionnaire), to rate their quality of life on a scale of 1 to 7, while using these treatments (with 1 being 'Life was very distressing and 7 being 'Life was great'). A second follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective.

Forty-four participants (n=44, 44.00%) had relaxation techniques, 36 participants (36.00%) had massage therapy and 17 participants (17.00%) had acupuncture. The median quality of life was 4 (in the "Life was average" range) and the median effectiveness was 3 (in the moderately effective range) for all of these complementary therapies.

Participants noted other therapies they used that were not listed in the questionnaire, 12 participants used a form of exercise, six used diet or dietary supplements, two mediated, two used hydrotherapy, two saw a naturopath, and others used Reiki/energy healing, hypnosis, myofascial dry needling, gong bath, hand therapy, hot wax hand bath, gold injection, and saw a herbalist.

Table 5.20: Complementary therapies

Complementary therapies	Relaxation techniques N=44		Massage therapy N=36		Acupuncture N=17	
QOL						
Range	2 to 7		1 to 7		1 to 7	
Mean	4.18		4.09		4.32	
Median	4		4		4	
Effectiveness						
Range	1 to 5		1 to 5		1 to 5	
Mean	3.11		2.94		3	
Median	3		3		3	
No Side effects	43 (97.72%)		28 (80.00%)		16 (94.12%)	
Specify other side effects	Aggravated wrists	1	Pain	5	Bleeding	1
			Bruising	1		
			Inflammation	3		

In the structured interview, participants were asked to then describe any complementary therapies that they had used. The most commonly reported complementary therapy was the use of vitamins and supplements (n=37, 37.00%). Other reported complementary therapies used included massage (n=30, 30.00%), physiotherapist (n=19, 19%), acupuncture (n=16, 16.00%), hydrotherapy (n=14, 14%), naturopathy (n=13, 13.00%), eating healthily and remaining active (n=11, 11.00%), seeing an osteopath or undergoing chiropractic treatment (n=10, 10.00%), yoga (n=9, 9.00%), and adopting a gluten free diet (n=8, 8%). In addition to reporting on the types of complementary therapies used, twelve participants (12.00%) reported that they did not use complementary therapies, and eleven participants (11.00%) explained that they would like to use complementary therapies but were unable to for financial reasons.

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (26.32%), *Affect: never to almost never* (21.21%), and, *Social: all to most days* (15.00%) described using vitamins and supplements less often than the *General population* (37.00%); while those in the sub-groups *Physical limitations: some to most days* (48.65%), *Affect: very often to always* (51.61%), and those *Aged 18 to 34* (50.00%) described using these more often.

Participants in the sub-groups *Symptoms: all days* (19.05%), and those with *Trade or high school* qualifications (18.18%) reported using massage less often than the general population (30.00%); while those *Aged 18 to 34* (44.44%) reported using massage more often.

Compared to the general population (19.00%), participants in the subgroup *Physical limitations: no days* (5.26%), reported having ever seen a physiotherapist less often compared to the general population (32.26%), while participants in the subgroup *Affect: very often to always* (32.26%) reported having ever seen a physiotherapist more frequently.

Participants in the subgroup *Symptoms: no to few days* (5.00%) reported ever having had Acupuncture less frequently than the general population (16.00%).
No participants in the sub-groups *Physical limitations: some to most days*, Affect: very often to always, and *Aged 18 to 34*, reported that they do not use complementary therapies, compared with the 12.00% of the general population who did, while participants in the sub-group *Affect: never to almost never* (27.27%) reported this less often.

No participants Aged 18 to 34 reported that they were unable to use complementary therapies due to financial reasons, compared to 11.00% in the in the general population, while those with *Trade or high school qualifications* (24.24%) reported this more often.

No participants in the sub-group *Symptoms: all days* reported doing yoga, compared to 9.00% in general population, and no participants in the sub-group *Physical limitations: no days* reported using a gluten free diet compared to 8.00% in the general population.

Participant describes using vitamins and supplements

I've tried vitamins, people have suggested tablets, I don't know, fish oil, all that sort of stuff. I've tried a different variety of those, but I think when you're flaring up nothing really helps anyway. Participant 35

I'm taking, um, aloe vera oil, aloe vera juice, so I had it, the natural stuff….When I was pregnant years ago I used to get really bad pelvic pain when I was pregnant and I tell you what, it really, um, really, really helped ease the pain and then I've, I've been taking it for a few months now. I have it every day and I find if I have the flare now, the flare's there, but there's no pain. It's there, but it's not excruciating pain. Participant 8

Um, I tried everything from taking 7.000 supplements like bromelain and turmeric and in fact, I still take turmeric and magnesium. Participant 24

But then as I mentioned earlier, complementary therapies, complementary therapies. Really all I could afford was the vitamin stuff. I've tried the um, fish oil. Participant 86

Participant describes using massage

Oh yeah, oh yeah. I have all sorts of stuff. Um, I guess the main complementary therapy that I like to use is massage, and I find that incredibly helpful. Participant 12

I have used massage therapy and I continue to use that because what I've found is that when joints flare, it's not just the joints that flare, but the muscles around the joints tend to tighten as well. Massage often actually deals with the RA in the joint, but it actually, if you can relax the muscles around that joint, it has actually helped with mobility and, over time, can actually help lessen the pain a little bit. Participant 22

Um, look, I have remedial massage, I have that just to try to assist, I have that tomorrow and I go there about once a week, but now I haven't, I haven't even really had it recommended to be to be honest. But then rheumatologists don't know how much things like that would help. Participant 51

I've been a massive fan of just purely therapeutic massage because I feel like for a very long time, I've been well aware that stress can make it so much worse. I have been getting massages my whole life… I have always gone into those 20-minute, $20 massage places a couple of times a week. Participant 62

Participant describes using physiotherapy

Yep. Massage, physio, chiropractor, all of those. Participant 83

One lady was saying, oh, her physio gave me exercises and if you do the exercises in the morning, it actually helps for the lower backache. And I thought well instead of going to a chiropractor and just alleviating the painful for the next couple of months she might actually might be worth paying the extra money and maybe she can give me something more that will alleviate the pain more long term, if you know what I mean. Participant 34

Um, and then so I ended up, um, going back to my dad's physio. Um, it's lovely and she, um, gave me lots of tips to cope with the stiffness. That really, like, helped more so than the medication. Participant 89

Participant describes using acupuncture

I've also used acupuncture at times, not regularly. I tend to keep it for when I was in acute flares. I found that it never took the pain away completely, but it would bring the level of the pain down a couple of notches. If I was in a really, really bad flare, and pain relief just wasn't touching it, acupuncture would just lessen it slightly. Participant 22

I did try some acupuncture back in the nineties, but it was kind of expensive, so I gave up. At the time I didn't have great health insurance. I haven't really gone back to it. Participant 36

I have had acupuncture, um, which was, uh, which I used before I started taking any medication before I realized it was arthritis. Um, and that certainly did make a difference to a certain extent. Um, and I still use acupuncture now, uh, but more, not so much for, for pain relief, but more just for stress relief. Participant 52

Participant describes using hydrotherapy

Hydrotherapy is fantastic for rheumatoid arthritis, things like that. Participant 31

It was a physio that put me onto it, aqua aerobics, because at the time when my feet were just so painful, I'm walking in and I was really keen to shift the weight that I had put on with the prednisone. And so she was the one who put me on that. So doing that three times a week, that shifted the weight and it was a great way to get fit with water resistance, which was a pain free way to exercise. Participant 44

Yes. The hydrotherapy was working better than absolutely anything, so we had a hydrotherapy pool put in at the house, so I have one here. I don't know, I'm spoiled. Participant 48

*I saw an OT, um, uh, went to hydrotherapy. Yeah. And so, they kind of just showed me, you know, different techniques in the water and *inaudible* because I didn't realize that the water, like warm water, would give me more mobility around my joints. Um, yeah. So, like different techniques that I could just go to my local pool and use as well. Participant 15*

Participant describes using naturopathy

Uh, I have been to naturopaths in the past, it's quite difficult to find naturopath that is quite respectful. like, I'm quite an alternative person, but I'm very much with the understanding that this disease, I think they will potentially find it as they use to secure a cure in my lifetime. Participant 12

But I find that with some alternative health, particularly naturopathy or like some other ones, there's this idea that if there's a lot of a shame, it's your fault. You didn't eat right. Think they can cure you just, you know, distilled water and cucumber juice and like either you have like… oh yeah, I just feel like there's a lot of fear mongering and shame and there's not a lot of like, you know, the understanding that you get when you come to a health professional. Participant 12

Um, I did go to a naturopath about dietary things, um, taking what might flare up your arthritis or might not and I felt it, but that again relies on money, whether you can afford these types of things as well. Participant 98

Participant describes not using complementary therapies

No, because I'm not a believer in them at all. I've never seen decent results or decent trials. No. Never taken complementary. Participant 1

My rheumatologist is very anti. Anything he doesn't know about and I mean as far as um, things live as you're saying things like um, you can no longer take things like Nurofen for pain, you can only take Panadol. So he's very, very specific on a few things and he said I really don't want you on any sort of chemist sport treatments like multivitamins or supplements or anything like that. So I have to run it past him. Participant 17

No. No, I, um, my rheumatologist is against them pretty much. He said, look, you know, none of these things actually work. My cousin has tried all of them and none of them have worked with her. Participant 33

Participant would like to use complementary therapies but is unable to afford them

Others use osteopath, naturopath, herbalists, which is terrific if you've got private health insurance or a lot of money. Participant 85

Mm-Hmm, wouldn't it be lovely if you could afford it? Participant 87

I am on a disability pension, I'm struggling to pay my bills and my medical bill, let alone for any extras. Participant 87

I can't afford physio so I don't use. But I have thought about it. Yes. And I'd think about massage, you know, lymphatic drain. I don't know if that would work or acupuncture or I'd do anything like that. I don't do any of it because it's a money thing. Participant 27

Well, I used to usually go to a chiropractor, but admittedly I can't afford to. I normally wait until, um, I am screaming in pain. Participant 34

I did a fair bit of Reiki on myself and that was amazing but then that got too stressful and I gave up on it. I find personally therapies that go along with it are too expensive to be able to use. Participant 62

Participant describes eating healthy and remaining active

I probably haven't explored that too much, besides probably eating habits I've explored a bit, but I would like to. I haven't really found there to be much information about that out there. Participant 90

I have just been kind of in desperation, just been trying to do whatever we can to just be healthier basically just to give my body the best fighting chance it's got kind of thing. So trying to eat less processed, more fresh food basically and limit my carb in terms of bread and all of that stuff I think actually has helped. Participant 89

I'm a great believer that eating just whole foods, changing your diet, eating a healthy diet, which I always have done. Participant 73

Participant describes seeing an osteopath or chiropractor

I go to osteo still to maintain my posture and iron out any issues. Participant 18

Osteopath, I'm actually going tomorrow. They do massage and they do a bit of stretching and stuff. I've read that I shouldn't ever have chiropractic treatment. It's not good for people with Rheumatoid to have their bones cracked and stuff. Participant 75

Um, I did see a chiropractor as well. Um, my rheumatologist, when and I told him I was going to see a chiropractor. He said, don't get your bones cracked. Participant 14

I have been over the years, that's nothing to do with arthritis, but I have been to chiropractors, I've always gone to chiropractors over the years since I was a teenager. Participant 35

Participant describes practicing yoga

On and off I've done yoga which I love. I noticed in the years that I didn't do yoga at this point because I stopped for various personal reasons. I didn't realize how much of a difference it was making until I stopped it for a few years. Then when I came back to it, I realized it was just helping everything. It just helps your overall health. It helps your joint support, your muscles, keeps them supple, that thing. It works on your adrenaline. It helps you with your energy. It helps with the mental health side of things as well which is a whole other aspect. Participant 26

I'm trying to manage stress by doing like a very light yoga or body balance. I try to go once a week. Participant 50

I do think that yoga helps a lot getting some movement into joints. Yeah, that's really as far as I've experimented. Participant 91

Table 5.21: Complementary therapies used

Use of complementary therapy	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes using vitamins and supplements	37	37.00	5	26.32	14	31.82	18	48.65	7	35.00	9	33.33	13	40.63	8	38.10
Participant describes using massage	30	30.00	4	21.05	13	29.55	13	35.14	5	25.00	9	33.33	12	37.50	4	19.05
Participant describes accessing a physiotherapist	19	19.00	1	5.26	9	20.45	9	24.32	3	15.00	5	18.52	7	21.88	4	19.05
Participant describes using acupuncture	16	16.00	2	10.53	5	11.36	9	24.32	1	5.00	5	18.52	5	15.63	5	23.81
Participant describes accessing hydrotherapy	14	14.00	1	5.26	5	11.36	8	21.62	2	10.00	6	22.22	2	6.25	4	19.05
Participant describes accessing naturopathy	13	13.00	2	10.53	6	13.64	5	13.51	3	15.00	4	14.81	2	6.25	4	19.05
Participant describes not using complementary therapies	12	12.00	4	21.05	8	18.18	0	0.00	4	20.00	4	14.81	3	9.38	1	4.76
Participant describes not being able to use complementary therapies due to cost	11	11.00	1	5.26	3	6.82	7	18.92	1	5.00	4	14.81	3	9.38	3	14.29
Participant describes eating healthy and remaining active	11	11.00	1	5.26	6	13.64	4	10.81	2	10.00	2	7.41	6	18.75	1	4.76
Participant describes accessing an osetopath or chiropractor	10	10.00	1	5.26	5	11.36	4	10.81	2	10.00	3	11.11	3	9.38	2	9.52
Participant describes doing yoga	9	9.00	2	10.53	5	11.36	2	5.41	2	10.00	2	7.41	5	15.63	0	0.00
Participant describes taking up a gluten free diet	8	8.00	0	0.00	4	9.09	4	10.81	1	5.00	3	11.11	3	9.38	1	4.76

Table 5.21: Complementary therapies used (Cont.)

Use of complementary therapy	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes using vitamins and supplements	37	37.00	7	21.21	14	38.89	16	51.61	3	15.00	16	44.44	18	40.91
Participant describes using massage	30	30.00	7	21.21	12	33.33	11	35.48	6	30.00	12	33.33	12	27.27
Participant describes accessing a physiotherapist	19	19.00	4	12.12	5	13.89	10	32.26	3	15.00	5	13.89	11	25.00
Participant describes using acupuncture	16	16.00	4	12.12	4	11.11	8	25.81	3	15.00	9	25.00	4	9.09
Participant describes accessing hydrotherapy	14	14.00	4	12.12	4	11.11	6	19.35	4	20.00	4	11.11	6	13.64
Participant describes accessing naturopathy	13	13.00	1	3.03	7	19.44	5	16.13	2	10.00	4	11.11	7	15.91
Participant describes not using complementary therapies	12	12.00	9	27.27	3	8.33	0	0.00	1	5.00	4	11.11	7	15.91
Participant describes not being able to use complementary therapies due to cost	11	11.00	3	9.09	3	8.33	5	16.13	1	5.00	4	11.11	6	13.64
Participant describes eating healthy and remaining active	11	11.00	3	9.09	5	13.89	3	9.68	1	5.00	4	11.11	6	13.64
Participant describes accessing an osetopath or chiropractor	10	10.00	5	15.15	2	5.56	3	9.68	1	5.00	4	11.11	5	11.36
Participant describes doing yoga	9	9.00	2	6.06	3	8.33	4	12.90	1	5.00	5	13.89	3	6.82
Participant describes taking up a gluten free diet	8	8.00	1	3.03	4	11.11	3	9.68	1	5.00	5	13.89	2	4.55

Use of complementary therapy	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 to 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes using vitamins and supplements	37	37.00	22	39.29	15	34.09	13	41.94	15	29.41	9	50.00
Participant describes using massage	30	30.00	17	30.36	13	29.55	9	29.03	13	25.49	8	44.44
Participant describes accessing a physiotherapist	19	19.00	11	19.64	8	18.18	8	25.81	7	13.73	4	22.22
Participant describes using acupuncture	16	16.00	7	12.50	9	20.45	3	9.68	11	21.57	2	11.11
Participant describes accessing hydrotherapy	14	14.00	6	10.71	8	18.18	4	12.90	7	13.73	3	16.67
Participant describes accessing naturopathy	13	13.00	4	7.14	9	20.45	1	3.23	9	17.65	3	16.67
Participant describes not using complementary therapies	12	12.00	11	19.64	1	2.27	4	12.90	8	15.69	0	0.00
Participant describes not being able to use complementary therapies due to cost	11	11.00	6	10.71	5	11.36	3	9.68	8	15.69	0	0.00
Participant describes eating healthy and remaining active	11	11.00	5	8.93	6	13.64	3	9.68	7	13.73	1	5.56
Participant describes accessing an osetopath or chiropractor	10	10.00	8	14.29	2	4.55	3	9.68	6	11.76	1	5.56
Participant describes doing yoga	9	9.00	3	5.36	6	13.64	3	9.68	3	5.88	3	16.67
Participant describes taking up a gluten free diet	8	8.00	4	7.14	4	9.09	3	9.68	3	5.88	2	11.11

Table 5.21: Complementary therapies used (Cont.)

Use of complementary therapy	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes using vitamins and supplements	37	37.00	21	37.50	16	36.36	15	45.45	22	32.84	15	30.00	22	44.00
Participant describes using massage	30	30.00	17	30.36	13	29.55	6	18.18	24	35.82	16	32.00	14	28.00
Participant describes accessing a physiotherapist	19	19.00	11	19.64	8	18.18	8	24.24	11	16.42	7	14.00	12	24.00
Participant describes using acupuncture	16	16.00	11	19.64	5	11.36	4	12.12	12	17.91	11	22.00	5	10.00
Participant describes accessing hydrotherapy	14	14.00	8	14.29	6	13.64	4	12.12	10	14.93	5	10.00	9	18.00
Participant describes accessing naturopathy	13	13.00	8	14.29	5	11.36	3	9.09	10	14.93	7	14.00	6	12.00
Participant describes not using complementary therapies	12	12.00	6	10.71	6	13.64	6	18.18	6	8.96	7	14.00	5	10.00
Participant describes not being able to use complementary therapies due to cost	11	11.00	7	12.50	4	9.09	8	**24.24**	3	4.48	6	12.00	5	10.00
Participant describes eating healthy and remaining active	11	11.00	4	7.14	7	15.91	3	9.09	8	11.94	7	14.00	4	8.00
Participant describes accessing an osetopath or chiropractor	10	10.00	6	10.71	4	9.09	4	12.12	6	8.96	5	10.00	5	10.00
Participant describes doing yoga	9	9.00	7	12.50	2	4.55	1	3.03	8	11.94	5	10.00	4	8.00
Participant describes taking up a gluten free diet	8	8.00	6	10.71	2	4.55	2	6.06	6	8.96	5	10.00	3	6.00

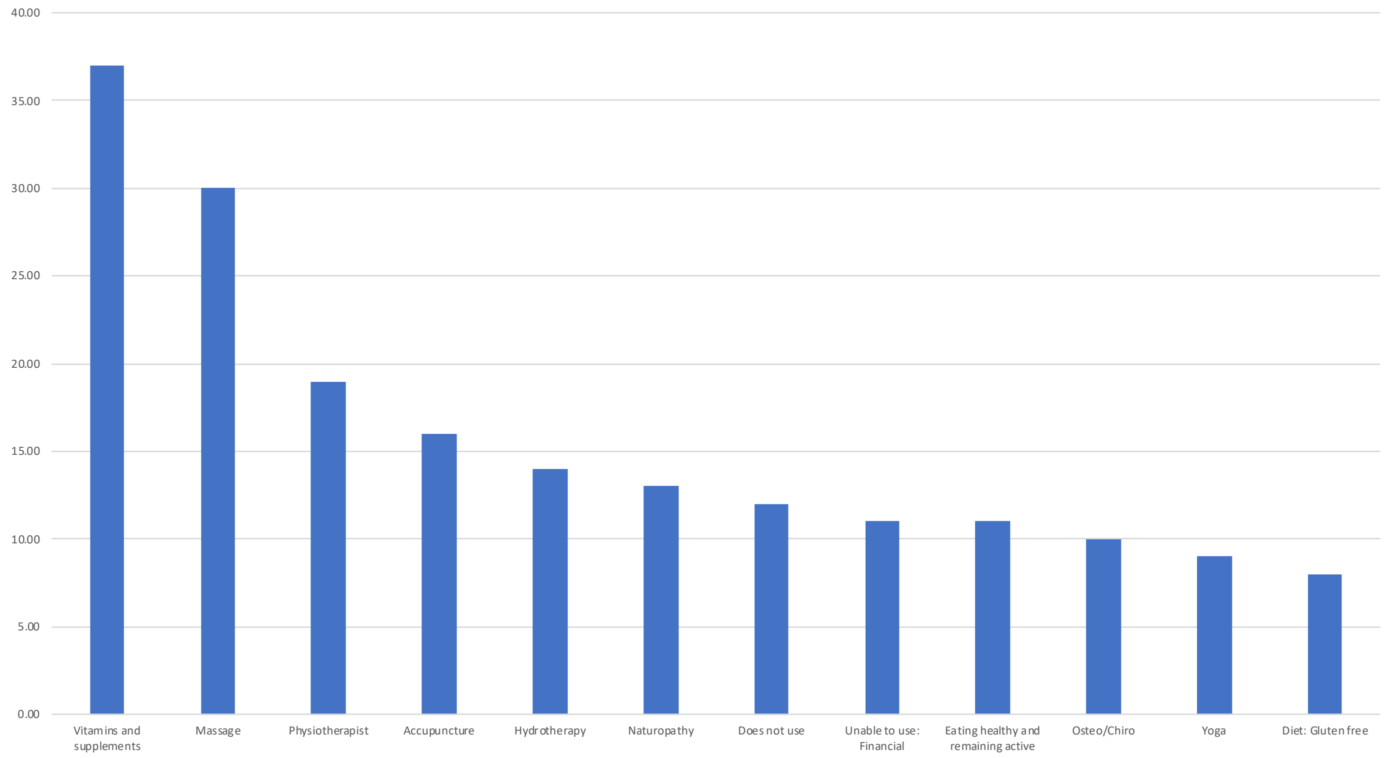


Figure 5.5: Complementary therapies used

Discussions about clinical trials

In this PEEK study, 85.00% of all participants (n=85) describe not being spoken to about clinical trials, 7 participants (7.00%) brought up the topic with their doctor, and the doctors of 8 participants (8.00%) brought up the topic of clinical trials.

Table 5.22: Discussions about clinical trials

Discussions about clinical trials	N=100	Percent
I brought up the topic of clinical trials with my doctor for discussion	7	7.00
My doctor brought up the topic of clinical trials for discussion	8	8.00
No one has ever spoken to me about clinical trials	85	85.00

Participation in clinical trials

Five (5.00%) participants have taken part in a clinical trial, and 70 (70.00%) participants have not taken part in a clinical trial but would like if one was suitable for them. Twenty-five (25.00%) participants have not taken part and do not want to. Five participants took part in clinical trials, the details are listed in Table 5.24.

Table 5.23: Experience of clinical trials

Participation in clinical trials	N=100	Percent
I have not participated in a clinical trial and do not want to	25	25.00
I have not participated in a clinical trial but would like to if there is one for me	70	70.00
I have participated in a clinical trial	5	5.00

Table 5.24: Participation in clinical trials

Clinical trial	N=5
Clinical trial taken part in	
Double blind trial for abatacept and methotrexate	1
Enbrel (etanercept)	1
Family Genetics	1
Heart study	1
Simponi auto injector	1
QOL on clinical trial	
3 Life is/was a little distressing	1
4 Life is/was average	2
5 Life is/was good	2
Side effects	
None	5
Completed clinical trial	
Completed the clinical trial as planned	4
Stopped the clinical trial because it wasn't working	1
How effective was the treatment used in clinical trial	
Effective	1
Very effective	4

Mild side effects

In the structured interview, participants were asked how they would describe the term ‘Mild side effects’. The most common description of mild side effects came in the form of participants providing examples of specific side effects (n=49, 49.00%). Of these, the most commonly described side effects were vomiting/nausea (n=26, 26.00%), headaches (n=13, 13.00%), stomach upset (n=10, 10.00%), and lethargy/fatigue (n=9, 9.00%). Other descriptions provided included participants describing mild side effects as those that do not impact ability to carry out everyday tasks (n=27, 27.00%), those that do not require medical attention (n=9, 9.00%) and do not last a long time (n=9, 9.00%).

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (21.05%), *Symptoms: no to few days* (30.00%), *Symptoms: some days* (37.04%), and *Affect: very often to always* (64.52%) described a specific side effect as an example less frequently than the general population (49.00%). Participants in the sub-groups *Physical limitations: some to most days* (64.86%), *Symptoms: most days* (62.50%), *Symptoms: all days* (61.90%) and *Trade or high school* (60.61%) specific side effect as an example more frequently than the general population (49.00%).

Participants in the sub-groups *Symptoms: no to few days* (15.00%), *Symptoms: some days* (14.81%), and *Aged 55 or older* (16.13%) described mild side effects as those that don't impact ability to do everyday things less often than the general population (27.00%); participants in the sub-group *Symptoms: most days* (43.75%) described this more often then the general population.

Participants in the sub-groups *Physical limitations: no days* (5.26%) and *Symptoms: no to few days* (5.00%) described vomiting/nausea less frequently than the general population (26.00%) and participants in the sub-groups *Symptoms: all days* (38.10%), and *Trade or high school* (36.36%) reported this more often than the general population.

No participants in the sub-groups *Physical limitations: no days* , *Symptoms: no to few days* and *Aged 18-34* described stomach upset as a mild side effect, while participants in the sub-group *Physical limitations: some to most days* (21.62%) reported this less often than the general population (10.00%), and participants in the sub-group *Social: all to most days* (20.00%) reported this more frequently.

No participants in the sub-groups *Affect: very often to always,* and *Aged 18 – 34 described* mild side effects as those that do not need medical attention or they can handle on their own, while participants in the sub-group *Symptoms: no to few days* (20.00%) described this more frequently than the general population (9.00%).

No participants in the sub-groups *Symptoms: most days,* and *Trade or high school* described mild side effects as those that do not last own, while participants in the sub-group, while *Symptoms: no to few days* (25.00%) described this more frequently than the general population (9.00%).

No participants in the *Symptoms: no to few days* described lethargy/Fatigue as a mild side effect, compared to 9.00% of the general population.

Participant defines mild side effects by providing an example

It's the things that you can cope with, so like, I mean I would really call the hair loss a mild side effect. Like it doesn't, you know, obviously it was distressing, but it was more distressing to find out how vain I was about my hair with me where I am. Participant 9

You might feel a little bit of nausea or you might get a redness at your injection site or it's just sort of not feeling right, maybe it's a slight headache. Participant 20

That would be the odd headache, the little aches and pains. If the pain's not like, when people think of pain they think of falling over hurting your knee, breaking a leg, that sort of pain but it's not that sort of pain. It's more of an achy pain. Participant 96

Participant describes mild side effects as those that do not impact ability to do everyday things

Mild side effects would be, I can still get up and go to work without feeling like a dead person. I could not go to work if I felt that bad. That, to me, would be mild side effects. Participant 93

Um, I guess for me, mild side effects, anything that I can still go on with my daily life with that are annoying and a pain, but I can still function with them. Participant 64

Something that is not going to generally interfere too much with my functioning day to day, you know? Yeah. Nice and easy. Participant 71

Vomiting/Nausea

Okay. So, I would say, um, nausea is a really common one. Participant 42

Yeah, I cope with that. You know, the nausea yeah. Yeah. You cope with those and they weren't, they weren't severe. Participant 57

I don't mind feeling a little bit under the weather like maybe the day after, uh, um, a medication. Um, I don't, um, feeling slightly nauseated. I have a number of medications that sort of make me feel that way and it's doable. Yeah, I guess probably those, those I'm willing to put up with. That's all. Participant 40

Headaches

Mild side effects to me means you might have a, might, from the medication, might be a bit of a headache, nothing too drastic. Participant 47

A bit of a headache could be a mild side effect, I think, considering what you're combating. Participant 62

Gastrointestinal distress

Nothing too drastic. You might, your stomach might feel a bit churney. Yeah, you can live with it. Participant 47

Um, mild side effects might be, um, you know, like a little bit of like the burping or gastric reflux and that's not a major one. Participant 98

Um, if it's something that's irritating, or it only impacts like part of my day. Um, so for example, it upsets my stomach just in the morning or just in the evening. I can probably deal with that. I would class that as a mild side effect. Participant 97

Participant describes mild side effects as those that do not need medical attention or that they can manage on their own

Mild is when you can basically either go to a chemist and go, you know, work it out yourself and go, okay, we'll talk to a chemist or something that can give you something over the counter. Participant 73

Mild side effects for me would be things that are manageable. So don't um, get you that you can't work and you can still do everything you need to do, but you might be maybe having to push past some tiredness or some feelings of sickness or maybe lack of appetite or something like that. Participant 94

A mild side effect would be something that I can possibly ignore and continue on with my day, whether that be I'm feeling stiff in the morning, but knowing that it's not severe and I can get out of bed. Participant 41

Participant describes mild side effects as those that do not last a long time

Um, mild side effects would be, um, temporary, temporary, temporary, short-term and liveable or cope-able. Participant 77

I would think of things like, um, I might have some nausea that would be temporary. I might, um, I might feel sore, I might feel a bit tired. Um, I would think of symptoms that didn't persist, you know, came on for a couple of hours and then were resolved. Participant 11

I would imagine, you know I'd be hopeful that if they were mild side effects that they might go away anyway, you know, after that sort of, um, you know, transitional period So it wouldn't really worry me. Participant 14

Lethargy/fatigue

If you're talking only mild versus severe, I would say my nausea and fatigue for methotrexate is mild because I still can function, not 100%, but I can still function. Participant 29

I just want to lie down a lot of the time. I don't want to sleep necessarily. I just want to get off my feet. I just feel lethargic. It's not debilitating. It's just, it's just something that I'd like to be doing more than the severe side effects. Participant 72

Probably be something that makes you drowsy or um, maybe give you a bit of little headache, something like that. Participant 95

Table 5.25: Mild side effects

Description of mild side effects	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes mild side effect by giving an example of a specific side effect	49	49.00	4	21.05	21	47.73	24	64.86	6	30.00	10	37.04	20	62.50	13	61.90
Participant describes vomiting /nausea as a mild side effect	26	26.00	1	5.26	14	31.82	11	29.73	1	5.00	6	22.22	11	34.38	8	38.10
Participant describes headaches as a mild side effect	13	13.00	1	5.26	7	15.91	5	13.51	2	10.00	3	11.11	7	21.88	1	4.76
Participant describes stomach upset as a mild side effect	10	10.00	0	0.00	2	4.55	8	21.62	0	0.00	3	11.11	4	12.50	3	14.29
Participant describes mild side effects as those that don't impact ability to do everyday things	27	27.00	5	26.32	12	27.27	10	27.03	3	15.00	4	14.81	14	43.75	6	28.57
Participant describes mild side effects as those that do not need medical attention or they can manage on their own	9	9.00	3	15.79	3	6.82	3	8.11	4	20.00	3	11.11	1	3.13	1	4.76
Participant describes mild side effects as those that do not last	9	9.00	3	15.79	3	6.82	3	8.11	5	25.00	2	7.41	0	0.00	2	9.52
Participant describes lethargy /fatigue as a mild side effect	9	9.00	1	5.26	3	6.82	5	13.51	0	0.00	3	11.11	3	9.38	3	14.29

Table 5.25: Mild side effects (Cont.)

Description of mild side effects	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes mild side effect by giving an example of a specific side effect	49	49.00	14	42.42	15	41.67	20	64.52	11	55.00	17	47.22	21	47.73
Participant describes vomiting /nausea as a mild side effect	26	26.00	7	21.21	9	25.00	10	32.26	6	30.00	11	30.56	9	20.45
Participant describes headaches as a mild side effect	13	13.00	2	6.06	5	13.89	6	19.35	3	15.00	6	16.67	4	9.09
Participant describes stomach upset as a mild side effect	10	10.00	2	6.06	2	5.56	6	19.35	4	20.00	3	8.33	3	6.82
Participant describes mild side effects as those that don't impact ability to do everyday things	27	27.00	8	24.24	10	27.78	9	29.03	5	25.00	12	33.33	10	22.73
Participant describes mild side effects as those that do not need medical attention or they can manage on their own	9	9.00	3	9.09	6	16.67	0	0.00	1	5.00	1	2.78	7	15.91
Participant describes mild side effects as those that do not last	9	9.00	5	15.15	1	2.78	3	9.68	3	15.00	2	5.56	4	9.09
Participant describes lethargy /fatigue as a mild side effect	9	9.00	3	9.09	3	8.33	3	9.68	2	10.00	3	8.33	4	9.09

Description of mild side effects	All participants		Occasional flare ups		Frequent flare ups		Aged 55 or older		Aged 35 - 54		Aged 18 – 34	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes mild side effect by giving an example of a specific side effect	49	49.00	28	50.00	21	47.73	17	54.84	23	45.10	9	50.00
Participant describes vomiting /nausea as a mild side effect	26	26.00	14	25.00	12	27.27	8	25.81	13	25.49	5	27.78
Participant describes headaches as a mild side effect	13	13.00	8	14.29	5	11.36	4	12.90	7	13.73	2	11.11
Participant describes stomach upset as a mild side effect	10	10.00	6	10.71	4	9.09	5	16.13	5	9.80	0	0.00
Participant describes mild side effects as those that don't impact ability to do everyday things	27	27.00	12	21.43	15	34.09	5	16.13	18	35.29	4	22.22
Participant describes mild side effects as those that do not need medical attention or they can manage on their own	9	9.00	7	12.50	2	4.55	4	12.90	5	9.80	0	0.00
Participant describes mild side effects as those that do not last	9	9.00	5	8.93	4	9.09	3	9.68	5	9.80	1	5.56
Participant describes lethargy /fatigue as a mild side effect	9	9.00	2	3.57	7	15.91	1	3.23	5	9.80	3	16.67

Description of mild side effects	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes mild side effect by giving an example of a specific side effect	49	49.00	26	46.43	23	52.27	20	60.61	29	43.28	23	46.00	26	52.00
Participant describes vomiting /nausea as a mild side effect	26	26.00	16	28.57	10	22.73	12	36.36	14	20.90	17	34.00	9	18.00
Participant describes headaches as a mild side effect	13	13.00	5	8.93	8	18.18	4	12.12	9	13.43	3	6.00	10	20.00
Participant describes stomach upset as a mild side effect	10	10.00	2	3.57	8	18.18	5	15.15	5	7.46	1	2.00	9	18.00
Participant describes mild side effects as those that don't impact ability to do everyday things	27	27.00	12	21.43	15	34.09	11	33.33	16	23.88	15	30.00	12	24.00
Participant describes mild side effects as those that do not need medical attention or they can manage on their own	9	9.00	7	12.50	2	4.55	1	3.03	8	11.94	6	12.00	3	6.00
Participant describes mild side effects as those that do not last	9	9.00	5	8.93	4	9.09	0	0.00	9	13.43	6	12.00	3	6.00
Participant describes lethargy /fatigue as a mild side effect	9	9.00	7	12.50	2	4.55	2	6.06	7	10.45	7	14.00	2	4.00

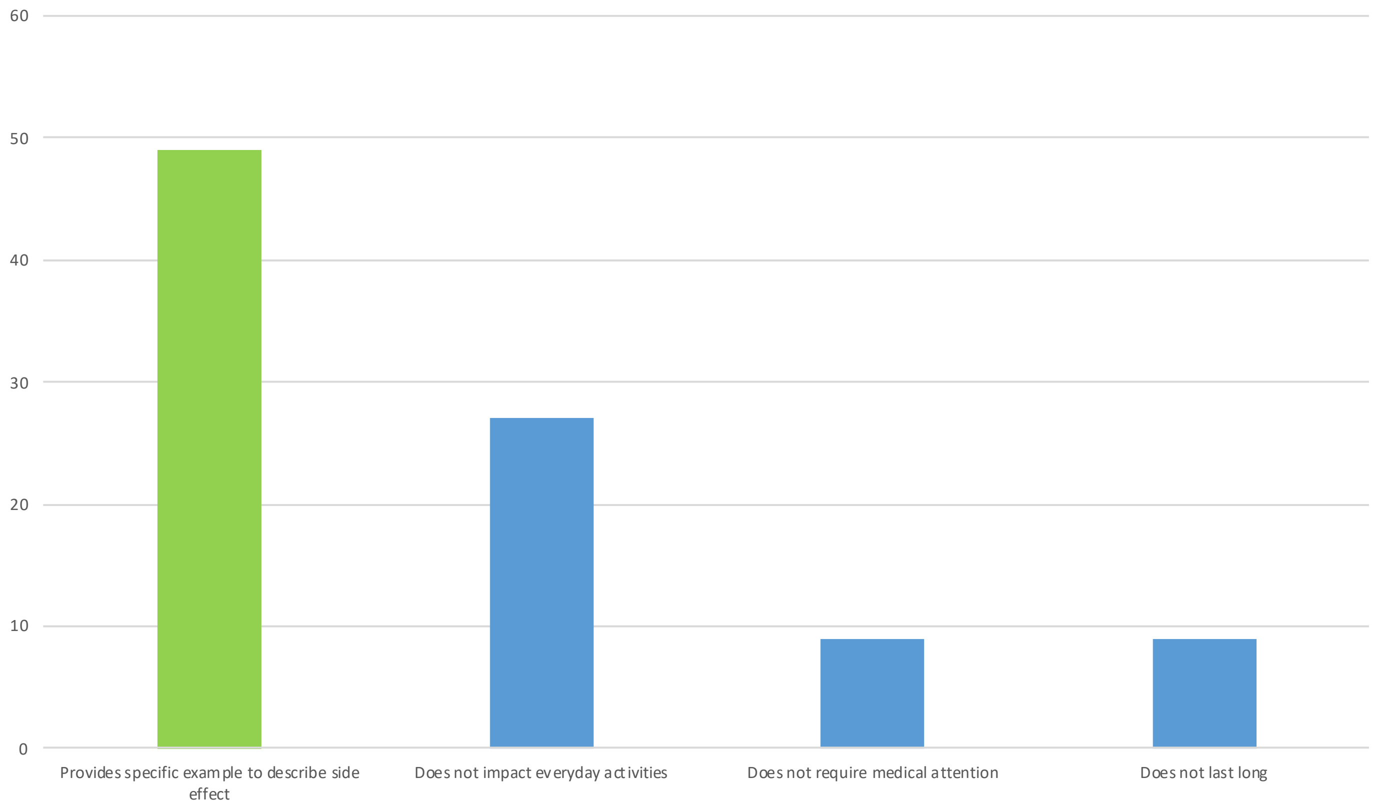


Figure 5.6: Mild side effects

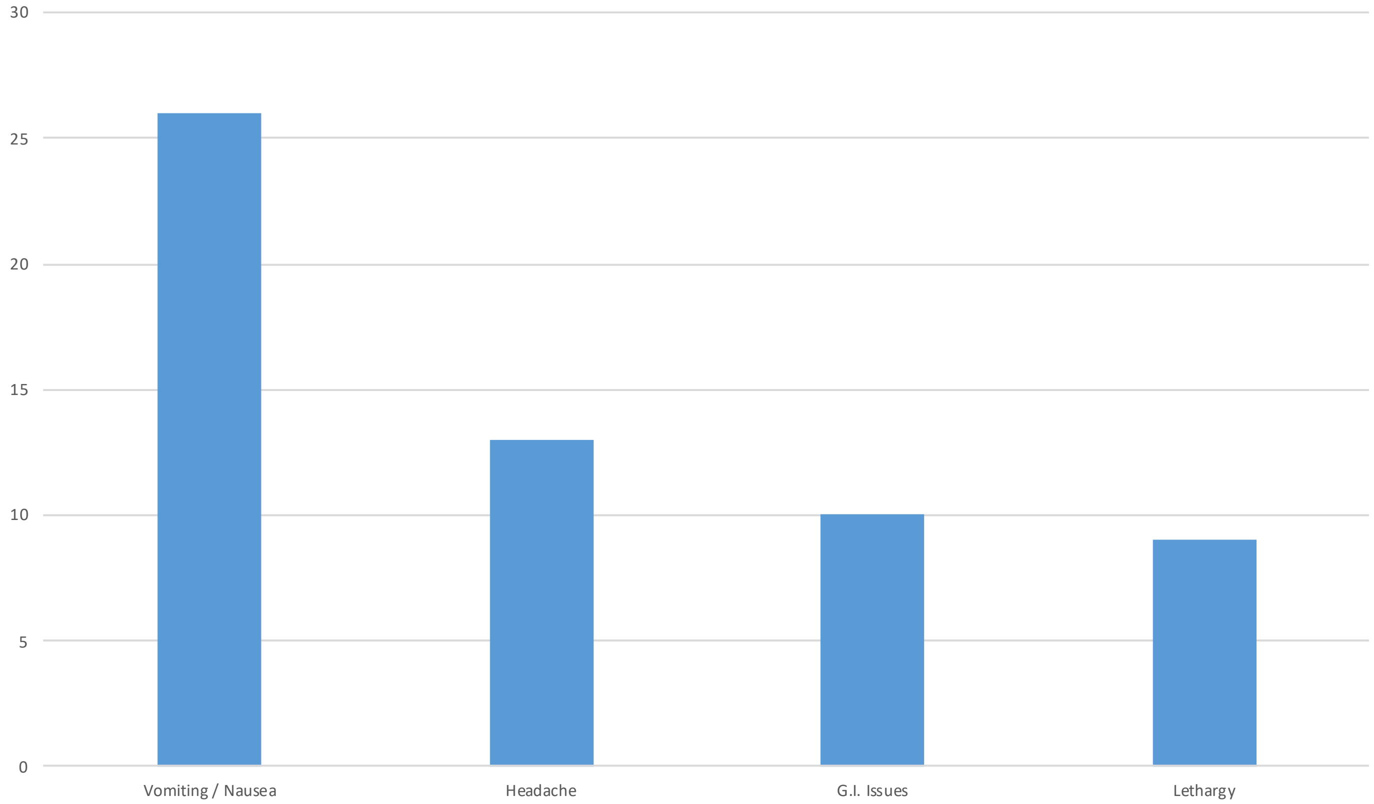


Figure 5.7: Specific mild side effects

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'Severe side effects'. The most common description of severe side effects were those that impact everyday life/ability to conduct activities of daily living (n=48, 48.00%). The next most common themes were side effects that result in long-term damage or risk of other disease (n=20, 20.00%) and those that result in hospitalization or are life threatening (n=13, 13.00%). Some participants chose to describe specific side effects (n=62, 62.00%) that they considered severe and these included nausea and vomiting including dizziness (n=16, 16.00%), gastrointestinal distress (n=14, 14.00%) and impact on mental health (n=14, 14.00%).

In relation to sub-group variations participants in the ***Affect: never to almost never*** (60.61%) and ***Frequent flare ups*** (59.09%), described side effects as those that impact everyday life/ability to conduct activities of daily living more frequently than the general population (48.00%).

Participants *aged Aged 55 or older (9.68%)* and those with a *trade or high school education (9.09%), described severe side effects as those that result in long-term damage or risk of other disease, less frequently than the general population (20.00%).*

Participants in the sub-groups *Physical limitations: no days* (26.32%), *Symptoms: no to few days* (25.00%), described severe side effects as those that result in hospitalisation or life threatening, more frequently than the general population (13.00%), while there were no participants *Aged 55 or older* that described this.

Participants in the sub-group *Symptoms: most days* (31.25%) described nausea and vomiting as a severe side effect, more frequently than the general population (62.00%). There were no participants in the *Physical limitations: no days* that described this.

Participants in the sub-group *Social: all to most days* (25.00%) and those aged *18 – 34* (27.78%) described gastrointestinal distress more frequently than the general population (14.00%).

Participant describes severe side effects as those that impact the ability to do everyday things

I really hate it and, um, and it means I don't drive so I don't work if I have to take morphine, like life just comes to a grinding halt. Participant 11

Probably at the point where my house feels like a prison and I can't go outside, I can't work because of side effects but I can't rely on my, my body to get me through the day at work. Participant 63

Severe is like the one where you go into free fall. Or they incapacitated me, so I couldn't get out of bed. Because, to me, that treatment's not worth it, if you can't even function. Participant 93

Nausea and vomiting

If you're actually really nauseous and vomiting all the time, bad headache that wouldn't go away. And just really struggling to get off the bed because you just felt awful. Participant 47

If I'm that nauseous, struggling to eat enough food to get my next lot of medications down that's not good because then I have other symptoms if I'm taking medication on an empty stomach. Participant 78

For me is the nausea. I can't stand feeling nauseous because you can't get on with your life. With a headache you can take a panadol. Yeah. You just, you can't get away from it. It's horrible. Um, I don't like it at all and I, it makes me feel unwell and I don't, I don't want to feel unwell even though sure of don't feel sick, you know, but sick and ill.. Participant 95

Long-term damage or risk of other disease

Side effect of the methotrexate I mentioned too, when I was reading methotrexate side effects…and it says, and NAME wasn't too aware of this, "Reduce your fertility." and I said, "Oh, okay." Again being open with you about it, that I had my fertility tested and sperm count was almost non-existent. Participant 01

That's the biggest one was a lot of the drugs that we take regardless of what it is that we take. That's why we're always doing all these blood tests, you know, they're, they're the major side effects is what effect it will have on say your liver function, kidney function, what it's doing to your immune system and all the rest of it. But they're the ones we need to worry about. Participant 31

Anything that would have a significant long-term effect that wasn't reversible if you stopped. Participant 55

Hospitalisation of life threatening

Well, severe side effects I would, I would assume would be potentially life threatening and you would have an impact on your quality of life? Participant 10

So these are um, I'd say that would make someone very, very sick, possibly hospitalized. Participant 33

Severe side effects, you're unable to do anything. You possibly need to go to the hospital, call an ambulance. You pretty much can't do what you need to do. Participant 53

Participant describes severe side effects as those that are long-lasting

A long term one. Diabetes and things like that. They don't happen if you're on the medication just for a few weeks, but if you're on them year after year, then they sort of build up in your system and then they can cause other issues. Participant 26

You'll be able to get through day-to-day, but it may upset your liver and you may eventually have liver failure. 68

Severe would be something that may subsequently deal with getting cancer or something horrible like that. Participant 90

Gastrointestinal distress

I lost eight kilos through diarrhea from taking the Plaquenil and Arava. I got to the stage where I wasn't eating because I would have bad diarrhea from those tablets. Participant 16

You can manage them, but severe side effects like the concept of nausea to their point of like I was eating Maxalon to try and make sure I eat food and quite significant diarrhea where you like you sort of add more to the point of like you feel like, legitimately feel sick because you can't even control the need to go to the toilet. So severe stuff. The stuff that's really intrusive, like you wouldn't be able to go to work and continue on with your day. Whereas the mild stuff you can manage. Participant 82

You know, like some people get severe diarrhea and you can't go outside. Like, that to me would be an unacceptable side effect. Participant 55

Table 5.26: Severe side effects

Description of severe side effects	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	48	48.00	10	52.63	22	50.00	16	43.24	9	45.00	14	51.85	17	53.13	8	38.10
Participant describes severe side effects as those that result in long-term damage or risk of other disease	20	20.00	5	26.32	7	15.91	8	21.62	2	10.00	8	29.63	5	15.63	5	23.81
Participant describes severe side effects as those that result in hospitalisation or life threatening	13	13.00	5	26.32	5	11.36	3	8.11	5	25.00	3	11.11	2	6.25	3	14.29
Participant describes severe side effects (Total)	62	62.00	7	36.84	31	70.45	24	64.86	12	60.00	12	44.44	26	81.25	12	57.14
Participant describes severe side effects as nausea and vomiting (including dizziness)	16	16.00	0	0.00	7	15.91	9	24.32	2	10.00	2	7.41	10	31.25	2	9.52
Participant describes severe side effects as gastrointestinal distress	14	14.00	3	15.79	7	15.91	4	10.81	3	15.00	3	11.11	5	15.63	3	14.29
Participant describes severe side effects as those that impact their mental health	8	8.00	1	5.26	5	11.36	2	5.41	1	5.00	2	7.41	2	6.25	3	14.29
Participant describes severe side effects as pain	6	6.00	0	0.00	2	4.55	4	10.81	0	0.00	2	7.41	1	3.13	3	14.29
Participant describes severe side effects as those that result in a decrease in cognitive ability	5	5.00	1	5.26	3	6.82	1	2.70	2	10.00	1	3.70	2	6.25	0	0.00
Participant describes severe side effects as those that severe fatigue	5	5.00	2	10.53	2	4.55	1	2.70	3	15.00	0	0.00	2	6.25	0	0.00
Participant describes severe side effects as severe itch/rash/skin irritation	4	4.00	0	0.00	2	4.55	2	5.41	0	0.00	1	3.70	3	9.38	0	0.00
Participant describes severe side effects as hair loss	3	3.00	0	0.00	2	4.55	1	2.70	1	5.00	1	3.70	1	3.13	0	0.00
Participant describes severe side effects as those that result in heart palpitations/shakes/artificial anxiety	1	1.00	0	0.00	1	2.27	0	0.00	0	0.00	0	0.00	0	0.00	1	4.76

Description of severe side effects	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	48	48.00	20	60.61	17	47.22	11	35.48	11	55.00	17	47.22	20	45.45
Participant describes severe side effects as those that result in long-term damage or risk of other disease	20	20.00	5	15.15	8	22.22	7	22.58	2	10.00	8	22.22	10	22.73
Participant describes severe side effects as those that result in hospitalisation or life threatening	13	13.00	5	15.15	5	13.89	3	9.68	3	15.00	4	11.11	6	13.64
Participant describes severe side effects (Total)	62	62.00	16	48.48	25	69.44	21	67.74	16	80.00	24	66.67	22	50.00
Participant describes severe side effects as nausea and vomiting (including dizziness)	16	16.00	3	9.09	8	22.22	5	16.13	2	10.00	9	25.00	5	11.36
Participant describes severe side effects as gastrointestinal distress	14	14.00	4	12.12	6	16.67	4	12.90	5	25.00	4	11.11	5	11.36
Participant describes severe side effects as those that impact their mental health	8	8.00	2	6.06	2	5.56	4	12.90	2	10.00	2	5.56	4	9.09
Participant describes severe side effects as pain	6	6.00	0	0.00	2	5.56	4	12.90	2	10.00	2	5.56	2	4.55
Participant describes severe side effects as those that result in a decrease in cognitive ability	5	5.00	2	6.06	3	8.33	0	0.00	2	10.00	1	2.78	2	4.55
Participant describes severe side effects as those that severe fatigue	5	5.00	1	3.03	3	8.33	1	3.23	2	10.00	2	5.56	1	2.27
Participant describes severe side effects as severe itch/rash/skin irritation	4	4.00	2	6.06	1	2.78	1	3.23	1	5.00	2	5.56	1	2.27
Participant describes severe side effects as hair loss	3	3.00	2	6.06	0	0.00	1	3.23	0	0.00	2	5.56	1	2.27
Participant describes severe side effects as those that result in heart palpitations/shakes/artificial anxiety	1	1.00	0	0.00	0	0.00	1	3.23	0	0.00	0	0.00	1	2.27

Table 5.26: Severe side effects (Cont.)

Description of severe side effects	All participants		Occasional flare ups		Frequent flare ups		Aged 55 or older		Aged 35 - 54		Aged 18 – 34	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	48	48.00	22	39.29	26	59.09	13	41.94	26	50.98	9	50.00
Participant describes severe side effects as those that result in long-term damage or risk of other disease	20	20.00	8	14.29	12	27.27	3	9.68	13	25.49	4	22.22
Participant describes severe side effects as those that result in hospitalisation or life threatening	13	13.00	10	17.86	3	6.82	0	0.00	11	21.57	2	11.11
Participant describes severe side effects (Total)	62	62.00	30	53.57	32	72.73	22	70.97	25	49.02	15	83.33
Participant describes severe side effects as nausea and vomiting (including dizziness)	16	16.00	5	8.93	11	25.00	5	16.13	6	11.76	5	27.78
Participant describes severe side effects as gastrointestinal distress	14	14.00	9	16.07	5	11.36	5	16.13	4	7.84	5	27.78
Participant describes severe side effects as those that impact their mental health	8	8.00	5	8.93	3	6.82	1	3.23	6	11.76	1	5.56
Participant describes severe side effects as pain	6	6.00	0	0.00	6	13.64	3	9.68	2	3.92	1	5.56
Participant describes severe side effects as those that result in a decrease in cognitive ability	5	5.00	2	3.57	3	6.82	1	3.23	4	7.84	0	0.00
Participant describes severe side effects as those that severe fatigue	5	5.00	2	3.57	3	6.82	1	3.23	1	1.96	3	16.67
Participant describes severe side effects as severe itch/rash/skin irritation	4	4.00	3	5.36	1	2.27	4	12.90	0	0.00	0	0.00
Participant describes severe side effects as hair loss	3	3.00	3	5.36	0	0.00	2	6.45	1	1.96	0	0.00
Participant describes severe side effects as those that result in heart palpitations/shakes/artificial anxiety	1	1.00	1	1.79	0	0.00	0	0.00	1	1.96	0	0.00

Description of severe side effects	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	48	48.00	25	44.64	23	52.27	17	51.52	31	46.27	23	46.00	25	50.00
Participant describes severe side effects as those that result in long-term damage or risk of other disease	20	20.00	14	25.00	6	13.64	3	9.09	17	25.37	9	18.00	11	22.00
Participant describes severe side effects as those that result in hospitalisation or life threatening	13	13.00	10	17.86	3	6.82	4	12.12	9	13.43	10	20.00	3	6.00
Participant describes severe side effects (Total)	62	62.00	34	60.71	28	63.64	19	57.58	43	64.18	34	68.00	28	56.00
Participant describes severe side effects as nausea and vomiting (including dizziness)	16	16.00	11	19.64	5	11.36	4	12.12	12	17.91	9	18.00	7	14.00
Participant describes severe side effects as gastrointestinal distress	14	14.00	8	14.29	6	13.64	5	15.15	9	13.43	9	18.00	5	10.00
Participant describes severe side effects as those that impact their mental health	8	8.00	4	7.14	4	9.09	2	6.06	6	8.96	4	8.00	4	8.00
Participant describes severe side effects as pain	6	6.00	3	5.36	3	6.82	5	15.15	1	1.49	4	8.00	2	4.00
Participant describes severe side effects as those that result in a decrease in cognitive ability	5	5.00	3	5.36	2	4.55	0	0.00	5	7.46	1	2.00	4	8.00
Participant describes severe side effects as those that severe fatigue	5	5.00	1	1.79	4	9.09	0	0.00	5	7.46	1	2.00	4	8.00
Participant describes severe side effects as severe itch/rash/skin irritation	4	4.00	2	3.57	2	4.55	2	6.06	2	2.99	3	6.00	1	2.00
Participant describes severe side effects as hair loss	3	3.00	1	1.79	2	4.55	1	3.03	2	2.99	2	4.00	1	2.00
Participant describes severe side effects as those that result in heart palpitations/shakes/artificial anxiety	1	1.00	1	1.79	0	0.00	0	0.00	1	1.49	1	2.00	0	0.00

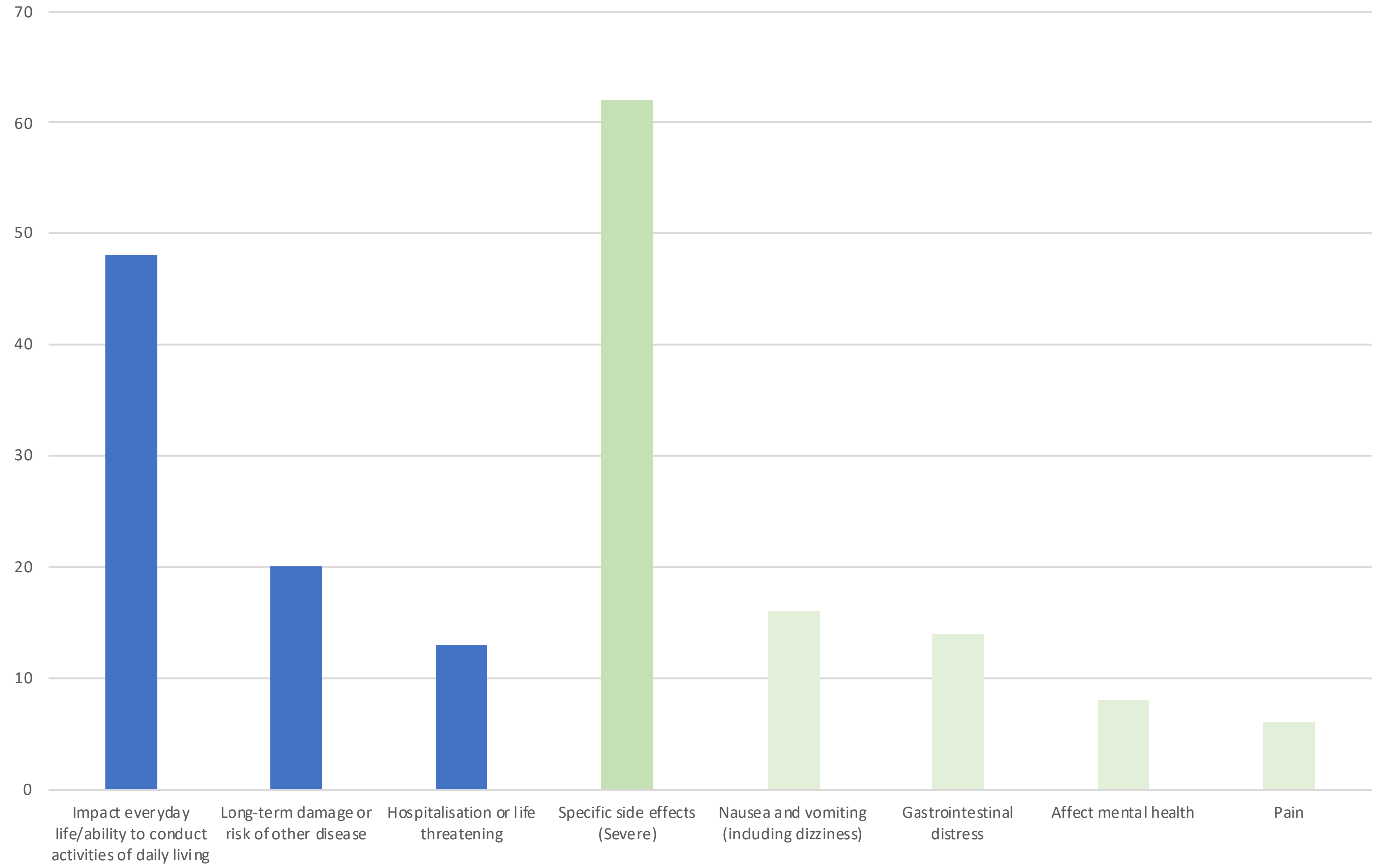


Figure 5.8: Severe side effects

Adherence to treatment

Participants were asked how long they adhere to treatment. The most common theme described was adhering to treatment for a specific amount of time (n=50, 50.00%). Participants also reported adhering to treatment as per the advice of their specialist/as long as prescribed (n=36, 36.00%), adhering to treatment as long as side effects are tolerable (n=23, 23.00%), and needing to see test results order to adhere to treatment (n=5, 5.00). Where participants noted a specific time that they adhered to treatment, the most common themes were adhering to treatment for 6 months (n=15, 15.00%), 3-4 months (n=13, 13.00%) or 2-3 months (n=12, 12.00%).

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (47.37%), *Affect: sometimes (50.00%) and Social: some days* (47.22%) reported adhering to treatment as per the advice of their specialist, more frequently than the general population (36.00%).

Participants in the sub-groups *Symptoms: no to few days* (35.00%) and *Symptoms: all days* (33.33%) reported adhering to treatment as long as side effects are tolerable, more frequently than the general population (n=23, 23.00%).

There were no participants in the sub-group *Physical limitations: no days* that reported needing to see test results order to adhere to treatment, and no participants aged 18 – 34 that reported adhering to treatment for a specific amount of time (2 - 3 months).

Participant reports adhering to treatment for a specific amount of time

They kind of know that if they're not working within 12 weeks they're not really going to work. That tends to be the marker for most of them. Some of them you can notice the difference within weeks for biologics, and sometimes even the first week. Participant 26

About six months, maybe six to eight months. Some things take six months just to kick in. It also depends. Obviously if it's an odd fact, it's going to take three to six months for your medicine to kick in well, you know, by eight months you would have a better idea. You know, just how the medicine works. Participant 34

Usually need to stick with it a good six months because some of them take a long time to really show a benefit, so. Yeah, the rule of thumb has been at least six months if I feel it's made a bit of a difference, I'll keep going for longer. Participant 37

Participant reports following specialist's advice

I'd probably try not to come off something without seeking right guidance from the GP or the Rheumatologist. Participant 25

Stick with it as long as the rheumatologist tells me to, because some of them take, you know, a long time to kick in. Yeah, yeah. I mean they're pretty accurate if I seem to be upfront and honest about it. Participant 4

Um, months, like a long time. Like it would be, um, whatever the, that would be in conjunction with a decision made with my doctor. Participant 59

Participant reports adhering to a treatment regime as long as side effects are tolerable

So, I'm happy to stick with that as long as it doesn't affect my eyes, which is one of the things that they were really concerned about. I had an eye test done and it looked all fine, so they just wanted me to check it again in five years. Participant 72

Um, depending on the severity of the side effects. One of them only lasted a week. Um, and other times I try to, I try to stay at least six weeks if the side effects are going to be severe than they happen really quickly and I can't probably give it enough time to see the side effects, cos for me if it means I'm too sick to be at work, then I can't work. Participant 69

With the methotrexate I didn't last very long at all because that was just, um, I just couldn't get through the day feeling like I was feeling. So I gave up on that pretty soon. Participant 65

Table 5.27: Adherence to treatment

Adherence to treatment	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	36	36.00	9	47.37	14	31.82	13	35.14	9	45.00	7	25.93	13	40.63	7	33.33
Participant describes adhering to treatment as long as side effects are tolerable	23	23.00	3	15.79	8	18.18	12	32.43	7	35.00	3	11.11	6	18.75	7	33.33
Partiicipant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	5	5.00	0	0.00	2	4.55	3	8.11	1	5.00	2	7.41	1	3.13	1	4.76
Participant describes adhering to treatment for a specific amount of time (Total)	50	50.00	9	47.37	22	50.00	19	51.35	8	40.00	15	55.56	15	46.88	12	57.14
Participant describes adhering to treatment for a specific amount of time (6 months)	15	15.00	2	10.53	5	11.36	8	21.62	2	10.00	4	14.81	3	9.38	6	28.57
Participant describes adhering to treatment for a specific amount of time (3 - 4 months)	13	13.00	2	10.53	9	20.45	2	5.41	2	10.00	5	18.52	3	9.38	3	14.29
Participant describes adhering to treatment for a specific amount of time (2 - 3 months)	12	12.00	2	10.53	6	13.64	4	10.81	2	10.00	4	14.81	5	15.63	1	4.76
Participant describes adhering to treatment for a specific amount of time (12 months or more)	4	4.00	0	0.00	0	0.00	4	10.81	0	0.00	0	0.00	2	6.25	2	9.52
Participant describes adhering to treatment for a specific amount of time (1 month)	3	3.00	3	15.79	0	0.00	0	0.00	1	5.00	1	3.70	1	3.13	0	0.00
Participant describes adhering to treatment for a specific amount of time (2 - 3 weeks)	2	2.00	0	0.00	1	2.27	1	2.70	1	5.00	0	0.00	1	3.13	0	0.00
Participant describes adhering to treatment for a specific amount of time (6-12 months)	1	1.00	0	0.00	1	2.27	0	0.00	0	0.00	1	3.70	0	0.00	0	0.00

Adherence to treatment	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	36	36.00	10	30.30	18	50.00	8	25.81	6	30.00	17	47.22	13	29.55
Participant describes adhering to treatment as long as side effects are tolerable	23	23.00	6	18.18	9	25.00	8	25.81	4	20.00	8	22.22	11	25.00
Partiicipant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	5	5.00	1	3.03	2	5.56	2	6.45	0	0.00	2	5.56	3	6.82
Participant describes adhering to treatment for a specific amount of time (Total)	50	50.00	19	57.58	16	44.44	15	48.39	12	60.00	14	38.89	24	54.55
Participant describes adhering to treatment for a specific amount of time (6 months)	15	15.00	7	21.21	3	8.33	5	16.13	4	20.00	4	11.11	7	15.91
Participant describes adhering to treatment for a specific amount of time (3 - 4 months)	13	13.00	4	12.12	3	8.33	6	19.35	5	25.00	4	11.11	4	9.09
Participant describes adhering to treatment for a specific amount of time (2 - 3 months)	12	12.00	5	15.15	5	13.89	2	6.45	0	0.00	3	8.33	9	20.45
Participant describes adhering to treatment for a specific amount of time (12 months or more)	4	4.00	0	0.00	2	5.56	2	6.45	1	5.00	1	2.78	2	4.55
Participant describes adhering to treatment for a specific amount of time (1 month)	3	3.00	1	3.03	2	5.56	0	0.00	2	10.00	0	0.00	1	2.27
Participant describes adhering to treatment for a specific amount of time (2 - 3 weeks)	2	2.00	1	3.03	1	2.78	0	0.00	0	0.00	1	2.78	1	2.27
Participant describes adhering to treatment for a specific amount of time (6-12 months)	1	1.00	1	3.03	0	0.00	0	0.00	0	0.00	1	2.78	0	0.00

Adherence to treatment	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	36	36.00	21	37.50	15	34.09	12	38.71	18	35.29	6	33.33
Participant describes adhering to treatment as long as side effects are tolerable	23	23.00	12	21.43	11	25.00	9	29.03	11	21.57	3	16.67
Partiicipant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	5	5.00	4	7.14	1	2.27	2	6.45	1	1.96	2	11.11
Participant describes adhering to treatment for a specific amount of time (Total)	50	50.00	28	50.00	22	50.00	15	48.39	27	52.94	8	44.44
Participant describes adhering to treatment for a specific amount of time (6 months)	15	15.00	8	14.29	7	15.91	5	16.13	7	13.73	3	16.67
Participant describes adhering to treatment for a specific amount of time (3 - 4 months)	13	13.00	5	8.93	8	18.18	3	9.68	6	11.76	4	22.22
Participant describes adhering to treatment for a specific amount of time (2 - 3 months)	12	12.00	8	14.29	4	9.09	3	9.68	9	17.65	0	0.00
Participant describes adhering to treatment for a specific amount of time (12 months or more)	4	4.00	3	5.36	1	2.27	2	6.45	2	3.92	0	0.00
Participant describes adhering to treatment for a specific amount of time (1 month)	3	3.00	2	3.57	1	2.27	0	0.00	2	3.92	1	5.56
Participant describes adhering to treatment for a specific amount of time (2 - 3 weeks)	2	2.00	1	1.79	1	2.27	1	3.23	1	1.96	0	0.00
Participant describes adhering to treatment for a specific amount of time (6-12 months)	1	1.00	1	1.79	0	0.00	1	3.23	0	0.00	0	0.00

Adherence to treatment	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	36	36.00	21	37.50	15	34.09	12	38.71	18	35.29	6	33.33
Participant describes adhering to treatment as long as side effects are tolerable	23	23.00	12	21.43	11	25.00	9	29.03	11	21.57	3	16.67
Partiicipant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	5	5.00	4	7.14	1	2.27	2	6.45	1	1.96	2	11.11
Participant describes adhering to treatment for a specific amount of time (Total)	50	50.00	28	50.00	22	50.00	15	48.39	27	52.94	8	44.44
Participant describes adhering to treatment for a specific amount of time (6 months)	15	15.00	8	14.29	7	15.91	5	16.13	7	13.73	3	16.67
Participant describes adhering to treatment for a specific amount of time (3 - 4 months)	13	13.00	5	8.93	8	18.18	3	9.68	6	11.76	4	22.22
Participant describes adhering to treatment for a specific amount of time (2 - 3 months)	12	12.00	8	14.29	4	9.09	3	9.68	9	17.65	0	0.00
Participant describes adhering to treatment for a specific amount of time (12 months or more)	4	4.00	3	5.36	1	2.27	2	6.45	2	3.92	0	0.00
Participant describes adhering to treatment for a specific amount of time (1 month)	3	3.00	2	3.57	1	2.27	0	0.00	2	3.92	1	5.56
Participant describes adhering to treatment for a specific amount of time (2 - 3 weeks)	2	2.00	1	1.79	1	2.27	1	3.23	1	1.96	0	0.00
Participant describes adhering to treatment for a specific amount of time (6-12 months)	1	1.00	1	1.79	0	0.00	1	3.23	0	0.00	0	0.00

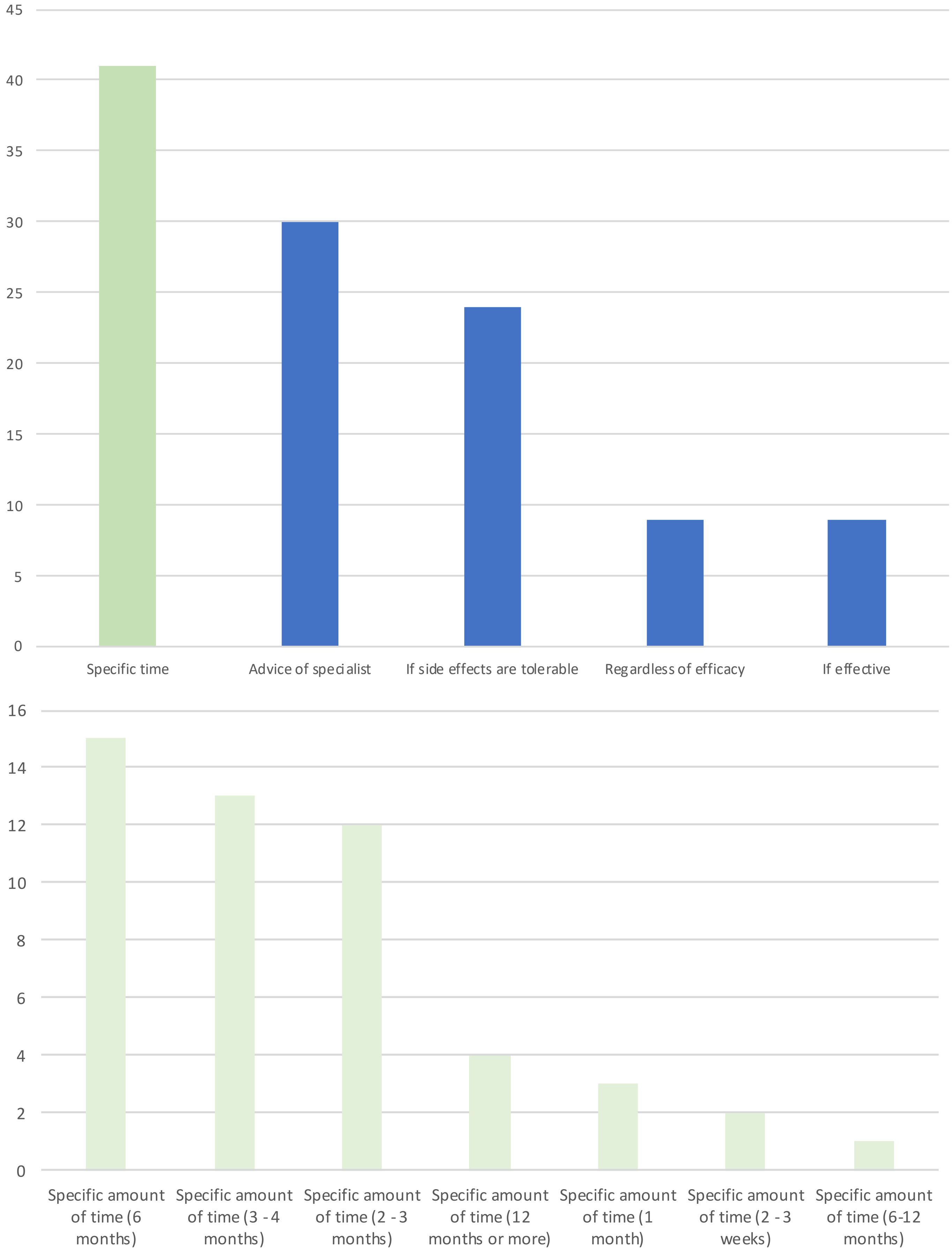


Figure 5.9: Adherence to treatment

What needs to change to feel like treatment is effective

Participants were asked to describe what needs to change to feel like treatment is effective. Sixty participants reported that for a treatment to be effective they had to experience a difference in pain (n=60). Increase in day-to-day functioning (n=28, 28.00%) and quality of life/ wellbeing (n=26, 26.00%) were the also described, as were reductions in specific symptoms associated with RA, such as swelling (n=19, 19.00%), fatigue (n=18, 18.00%), and mobility (n=12, 12.00%). 10 participants reported that for a treatment to be effective there had to be either no disease or a stable disease (n=10, 10.00%).

In relation to sub-group variations, participants *Aged 18 – 34* (50.00%) reported that for a treatment to be effective they had to experience a difference in pain less often than the general population (60.00%).

Participants in the sub-group *Symptoms: no to few days* (15.00%) reported that for a treatment to be effective they had to experience an increase day-to-day functioning less frequently than the general population (28.00%).

Participants in the sub-groups *Physical limitations: no days* (10.53%), *Symptoms: some days* (14.81%), *Affect: never to almost never* (9.09%) and *Social: all to most days* (15.00%) reported that for a treatment to be effective they had to experience a change in quality of life / Wellbeing less frequently than the general population (26.00%). Participants in the sub-groups *Physical limitations: no days* (10.53 *Symptoms: all days* (42.86%), *Affect: very often to always* (41.94%), and *Frequent flare ups* (38.64%) reported a change in quality of life/ Wellbeing more frequently.

Participants in the sub-groups *Affect: sometimes* (8.33%), and *Social: all to most days* (15.00%) reported that for a treatment to be effective they had to experience reduced swelling less frequently than the general population (19.00%). Participants in the sub-groups *Physical limitations: no days* (31.58%), *Symptoms: no to few days* (35.00%) and, *Affect: never to almost never* (30.30%) reported a change in reduced swelling more frequently.

Participants in the sub-group *Social: all to most days* (5.00%) reported that for a treatment to be effective they had to experience reduced fatigue less frequently than the general population (18.00%). Participants in the sub-groups *Physical limitations: some to most days* (29.73%), and *Symptoms: some days* (29.63%) reported a change in reduced fatigue more frequently.

No participants in the sub-groups *Physical limitations: no days,* and *Symptoms: no to few days* reported that for a treatment to be effective they had to experience increased mobility compared to 12.00% of the general population.

Participants reported needing to experience an improvement in pain levels

A difference in pain would be lovely. Participant 87.
Less pain, less dizziness and you know, you just know. You've got more energy to do things. It's just things we take for granted like lifting up a kettle that's maybe half full and I'll say to my husband, "Please don't fill it up so much", but you don't know till you actually go and lift it up. It's, "Oh can you undo this cap on a jar", a lid on a jar or something. Participant 21.

I think the biggest issue for me was receiving like spontaneous pain. Yeah. Like just out of all of a sudden like I just feel like a sharp pain in my wrist and so like if I can manage my day without that happening then I feel like the treatment is working. Participant 15.

Participants reported needing to experience an improvement in wellbeing and quality of life

Those things, and the overwhelming tiredness, just the feeling of not being able to function. If I feel because I'm getting back to sort of something like a normal life, even if it does mean that I'm still having to pace myself and watch things, I think that that's pretty successful. I don't expect perfection. I don't expect this to be cured, I don't expect history to be rolled back. Participant 70.

I'm like, I know that I need to feel like my house is not a prison because I have nowhere else to go. Participant 63.

Just maybe not having to worry about it every minute. Like if when you're in pain and it's right in the front of your face and everything has to get filtered through that, when that goes away a bit, it's like suddenly you can concentrate on all these other things and it's not so good, and bouncing out of bed I've noticed for myself the last week or two I've been able to get out of bed thinking how I'm going to put my feet down on the floor. Participant 95.

Participants reported needing to experience a return to day-to-day functionality

I could go, Ooh, I can pull up my own underwear in the morning, I can tie up my own shoe laces. So some ways it has just been watching for those small changes and going, oh actually I don't need help being pulled out of a chair at seven, eight at night any more. Participant 63.

I suppose, I mean to have more days when I function than not. I need to be able to walk and get around and do things. I don't mind being in, I guess a little bit of discomfort, but yeah, I just, I just need to be able to function. Participant 40.

I live rural, so I'm in the middle of nowhere, so I can't go anywhere. I can't do anything. Um, and it means that we might not be able to get groceries for a week because we have no other means of getting groceries here and my husband works away. Participant 97.

Participants reported needing to experience a reduction in swelling

Well just that I'm not having any swelling. That's pretty much in my hands. My hands are pretty, I can wear all my rings. But you know, for a was while I really thought that was never going to wear one again. You know. Participant 9.

For me it would be reduction of pain, reduction of inflammation, swelling, and if there's been any joint in impact, but any improvement in the impact upon the joints. Participant 29.

Well, I'm not sure exactly what it's supposed to do, except maybe reduce inflammation, so I assume, my own thinking, is that it might make it easier to do things. If you reduce the inflammation and maybe you reduce the pain, so maybe then you can do more. Participant 85.

Participants reported needing to experience a reduction in fatigue levels

The fatigue is the big thing for me. My fatigue levels are so bad, sometimes. I know when it's working because I feel better in myself, I'm more able to do things. For me, that's the indication that it's actually working. Participant 93.

I would also hope to have an improvement in fatigue. Not everything about the fatigue, but because that is such a, an intrusive symptom. Participant 82.

The incredible fatigue, incredible fatigue and I know I've got a pretty high pain threshold I always have considered, but that's fatigue just knocked me around something shocking. I just, you know, it's interesting because a lot of, I find a lot of specialists probably don't put a lot of emphasis on fatigue, as much as your joint symptoms. I personally think that the fatigue that I describe it, like how about you hit a brick wall and you just can't do a thing. Yeah. That definitely is an awful feeling. And when you've got that day in and day out, you just can't. You can see what you want to do. Participant 97.

Participants reported needing to experience a reduction in stiffness

Um, I guess the, the joint stiffness and the pain would be the first thing that I'd been noticing straightaway. Participant 56.

So to not get those reoccurring episodes as general stiffness in spots across my body. That would, that would tell me if that wasn't happening at all then yeah, that would tell me that something's. Something's better or working. Participant 23.

Obviously not so much the swelling, but the morning stiffness, that's quite a significant thing. Participant 89.

Participants reported needing to experience improved mobility

Ability to move my joints. Participant 65.

I guess increased mobility. Participant 91.

Um, my mobility and the pain has to be less so I need to get around more easily. Participant 54

Participants reported needing to experience evidence of stable disease/no disease progression

For me as the person with RA, I have to come to the conclusion I'm happy being on that even keel rather than maybe go up and feel terrific but it's also then going to start affecting kidneys, liver, et cetera, et cetera. To me, that's not worth it. Participant 80.

Because to me the inflammation means that the disease is active. So that is scary because I think, okay, I might not be in pain and I might not have a lot of swelling, but it's still really inflamed. So there's still something bad going on in there. Yeah. And you know, I mean for the medications to be actually doing what you wanted to do, it doesn't need to just mask all those things. It needs to stop the progression of the disease. Participant 94.

For me, it's to see my fingers stay normal instead of bones popping out the side of them and one finger's going one way and one finger's going another way. For me, being on the treatment, you would think that that wouldn't be still happening, and it wouldn't be infuriating, but it still is. They say it's just to help keep it at bay. I'd just like to see my fingers be normal for once, but it's not going to happen. Participant 16.

Table 5.28: What needs to change to feel like treatment is effective

What needs to change to feel like treatment is effective	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participants reported needing to experience an improvement in pain levels	60	60.00	12	63.16	28	63.64	20	54.05	12	60.00	16	59.26	19	59.38	13	61.90
Participants reported needing to experience a return to day-to-day functionality	28	28.00	4	21.05	14	31.82	10	27.03	3	15.00	9	33.33	10	31.25	6	28.57
Participants reported needing to experience an improvement in wellbeing and quality of life	26	26.00	2	10.53	11	25.00	13	35.14	4	20.00	4	14.81	9	28.13	9	42.86
Participants reported needing to experience a reduction in swelling	19	19.00	6	31.58	9	20.45	4	10.81	7	35.00	6	22.22	3	9.38	3	14.29
Participants reported needing to experience a reduction in fatigue levels	18	18.00	3	15.79	4	9.09	11	29.73	2	10.00	8	29.63	4	12.50	4	19.05
Participants reported needing to experience improved mobility	12	12.00	0	0.00	4	9.09	8	21.62	0	0.00	3	11.11	5	15.63	4	19.05
Participants reported needing to experience evidence of stable disease/no disease progression	10	10.00	1	5.26	3	6.82	6	16.22	2	10.00	2	7.41	3	9.38	3	14.29

What needs to change to feel like treatment is effective	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participants reported needing to experience an improvement in pain levels	60	60.00	21	63.64	21	58.33	18	58.06	13	65.00	19	52.78	28	63.64
Participants reported needing to experience a return to day-to-day functionality	28	28.00	8	24.24	10	27.78	10	32.26	3	15.00	12	33.33	13	29.55
Participants reported needing to experience an improvement in wellbeing and quality of life	26	26.00	3	9.09	10	27.78	13	41.94	3	15.00	9	25.00	14	31.82
Participants reported needing to experience a reduction in swelling	19	19.00	10	30.30	3	8.33	6	19.35	1	5.00	7	19.44	11	25.00
Participants reported needing to experience a reduction in fatigue levels	18	18.00	6	18.18	8	22.22	4	12.90	2	10.00	7	19.44	9	20.45
Participants reported needing to experience improved mobility	12	12.00	2	6.06	5	13.89	5	16.13	2	10.00	4	11.11	6	13.64
Participants reported needing to experience evidence of stable disease/no disease progression	10	10.00	2	6.06	3	8.33	5	16.13	2	10.00	3	8.33	5	11.36

What needs to change to feel like treatment is effective	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participants reported needing to experience an improvement in pain levels	60	60.00	34	60.71	26	59.09	18	58.06	33	64.71	9	50.00
Participants reported needing to experience a return to day-to-day functionality	28	28.00	13	23.21	15	34.09	7	22.58	16	31.37	5	27.78
Participants reported needing to experience an improvement in wellbeing and quality of life	26	26.00	9	16.07	17	38.64	5	16.13	16	31.37	5	27.78
Participants reported needing to experience a reduction in swelling	19	19.00	14	25.00	5	11.36	5	16.13	11	21.57	3	16.67
Participants reported needing to experience a reduction in fatigue levels	18	18.00	9	16.07	9	20.45	7	22.58	7	13.73	4	22.22
Participants reported needing to experience improved mobility	12	12.00	5	8.93	7	15.91	4	12.90	6	11.76	2	11.11
Participants reported needing to experience evidence of stable disease/no disease progression	10	10.00	8	14.29	2	4.55	5	16.13	4	7.84	1	5.56

Table 5.28: What needs to change to feel like treatment is effective (Cont.)

What needs to change to feel like treatment is effective	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participants reported needing to experience an improvement in pain levels	60	60.00	32	57.14	28	63.64	20	60.61	40	59.70	26	52.00	34	68.00
Participants reported needing to experience a return to day-to-day functionality	28	28.00	14	25.00	14	31.82	11	33.33	17	25.37	13	26.00	15	30.00
Participants reported needing to experience an improvement in wellbeing and quality of life	26	26.00	14	25.00	12	27.27	9	27.27	17	25.37	12	24.00	14	28.00
Participants reported needing to experience a reduction in swelling	19	19.00	11	19.64	8	18.18	7	21.21	12	17.91	7	14.00	12	24.00
Participants reported needing to experience a reduction in fatigue levels	18	18.00	11	19.64	7	15.91	5	15.15	13	19.40	12	24.00	6	12.00
Participants reported needing to experience improved mobility	12	12.00	5	8.93	7	15.91	4	12.12	8	11.94	2	4.00	10	20.00
Participants reported needing to experience evidence of stable disease/no disease progression	10	10.00	6	10.71	4	9.09	6	18.18	4	5.97	6	12.00	4	8.00

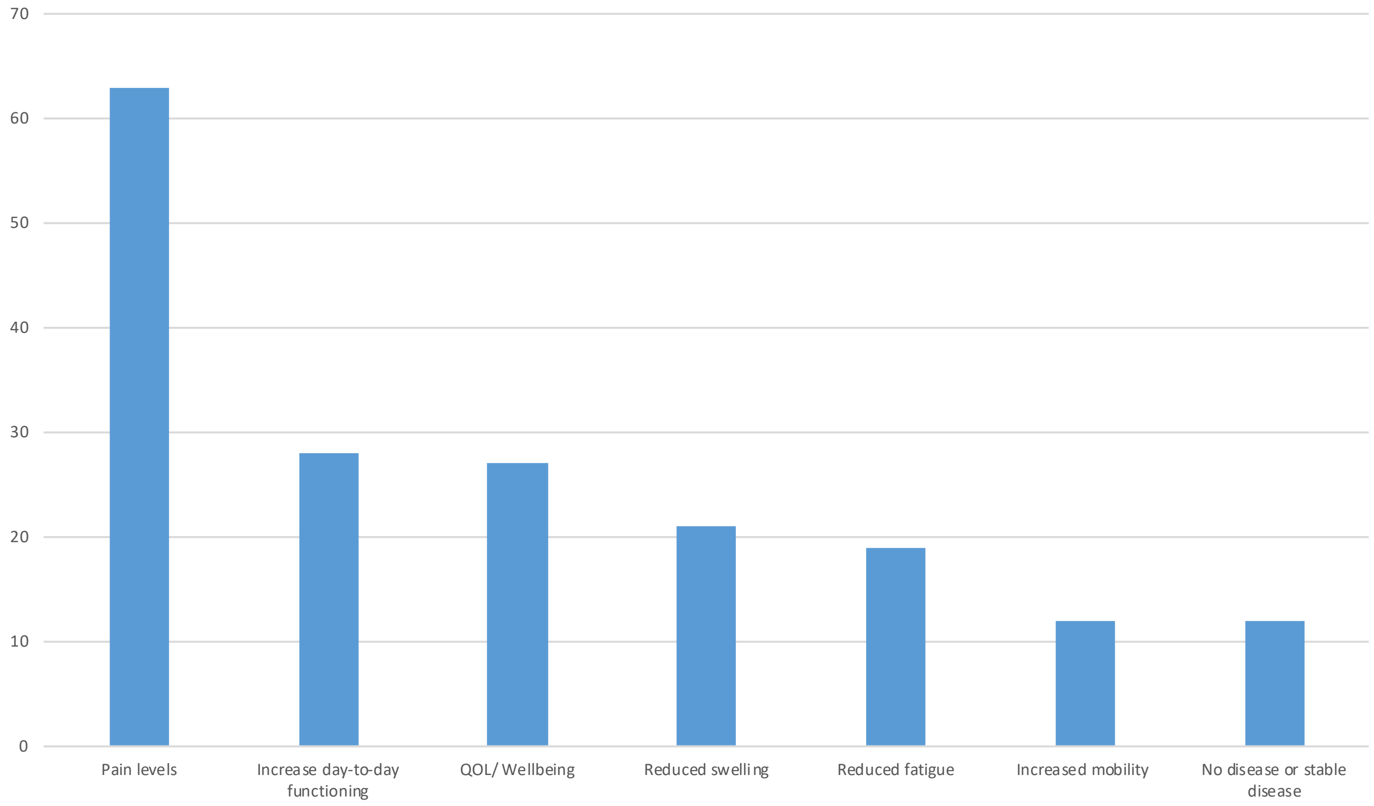


Figure 5.10: What needs to change to feel like treatment is effective

Section 6 Information and communication

Section 6: Information and communication

Access to information

- Participants were asked what information they had been able to access. The most common responses were accessing information from internet search engines, primarily Google, which was occasionally nicknamed “Dr Google” by some participants, (n=51, 51.00%). Australian charities were also mentioned (n=45, 45.00%), as was information from specialists (n=33, 33.00%). Online forums and social media (n=23, 23.00%), medical journals and articles (n=17, 17.00%) and books (n=10, 10.00%) were also reported.

Information that has been helpful

- The information that participants found most helpful was medical journals/articles (n=15, 15.00%). Other helpful information included unspecified online examples (n=13, 13.00%), information from a doctor or specialist (n=11, 11.00%), online support groups (n=10, 10.00%), other people’s stories (n=10, 10.00%), unspecified online information (n=10, 10.00%), information from charities (n=9, 9.00%), information provided by drug companies on medication packaging (n=9, 9.00%), and support groups (n=8, 8.00%). There were 9% of participants that reported that no information they had received had been helpful.

Information that has not been helpful

- Participants were asked if there was any information that they found to be unhelpful. The most common theme described by 34 participants as unhelpful were other people’s opinions (34.00%). This was followed by no unhelpful information found (n=28, 28.00%), online sources (n=23, 23.00%), participants deciding for themselves what was relevant to themselves (n=12, 12.00%), healthcare professionals (n=11, 11.00%), online support groups (n=9, 9.00%) and being told about disease progression (n=8, 8.00%).

Information preferences

- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common theme overall was a preference for talking to someone (n=45, 45.00%). This included a preference for talking to someone (in general (n=19, 19.00%), talking to someone as well as online information (n=15, 15.00%) and talking to a specialist nurse (n=11, 11.00%). The next most common theme overall was accessing online information (n=38, 30.80%) and this was due to its accessibility. There were also 17 participants (17.00%) that described a preference for booklets and nine participants (9.00%) that had a preference for apps.

Timing of Information

- The most common time that participants described being receptive to receiving information was being receptive since diagnosis (27.00%). This is followed by: Receptive after initial shock (24.00%), receptive after months (20.00%), slowly receptive to new information (17.00%) and not receptive for years (16.00%).

Healthcare professional communication

- Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described was having an overall positive experience as their healthcare professional was caring, supportive and understanding (21.00%). Where participants described a positive experience, this related to their healthcare professional being supportive and understanding (21.00%), taking the time to answer participant questions and provide information (18.00%), and reporting having a positive experience but not elaborating (15.00%). When participants described a negative experience, this related to healthcare professionals being dismissive and/or participants feeling ignored (17.00%), and participants reported not being given enough time or support to ask questions (14.00%). Some participants (13.00%) reported having neither a positive or negative experience.

Knowledge and confidence

- The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and management of symptoms, and adherence to treatment. A higher score denotes a better understanding and knowledge of disease.

Partners in health – overall score

- Overall, the participants scored in the top quintile for **"Partners in health: adherence to treatment"** (median =14.00, IQR = 4.00), indicating very good adherence to treatment. **"Partners in health: knowledge"** (median = 25.00, IQR = 8.00), **"Partners in health: recognition and management of symptoms"** (median = 18.00, IQR = 5.00), and "**Partners in health: total score"** (mean = 69.47, SD = 13.06) scored in the second highest quintile indicating good health outcomes. Participants scored in the middle of the scale for **"Partners in health: coping"** (mean = 13.72, SD = 5.37), indicating moderate scores.

Information given by healthcare professionals and searched for independently.

- Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=73, 73.00%), disease management (n=54, 54.00%), and disease management (n=48, 48.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (n=3, 3.00%), psychological/social support (n=8, 8.00%) and hereditary considerations genes or genomic biomarker information (n=8, 8.00%).

Information searched for independently

- Participants were asked about what type of information they searched for after receiving information from healthcare professionals. Information about disease cause (72.00%) was most often searched for, followed by treatment options (65.00%), complementary therapies (63.00%) and disease management (63.00%). The least searched for topic was hereditary considerations genes or genomic biomarker information (22.50%).

Information gaps

- The largest gaps in information, where information was neither given to patients nor searched for independently clinical trials (n=74, 74.00%), hereditary, genes or genomic biomarkers (n=69, 69.00%), and psychological/social support (n=62, 62.00%) (Figure 6.72). Participants were given most information either from healthcare professionals or independently for treatment options (n=95, 95.00%), disease cause (n=88, 88.00%) and disease management (n=86, 86.00%). Complementary therapies (n= 54, 54.00%), how to interpret test results (n=53, 53.00%) and Dietary information (n=51, 51.00%) were the topics that was most searched for independently following no information from health professionals

Most trusted information sources

- Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Figure 6.73. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from non-profit or charities or patient organisations were most trusted, followed by information from the government. Information from pharmaceutical companies and from medical journals were least trusted.

Accessed "My Health Record"

- My Health Record is an online summary of key health information, an initiative of the Australian Government. Thirty-eight (38.00%) had accessed "My Health Record", 59 (59.00%) had not, and three (3.00%) were no sure. Of those that had accessed "My Health Record", four participants (10.81%) found it good or very good., 11 (29.73%) found it acceptable, and 22 (59.46%) found it poor or very poor).

Access to information

Participants were asked what information they had been able to access. The most common responses were accessing information from internet search engines, primarily Google, which was occasionally nicknamed “Dr Google” by some participants, (n=51, 51.00%). Australian charities were also mentioned (n=45, 45.00%), as was information from specialists (n=33, 33.00%). Online forums and social media (n=23, 23.00%), medical journals and articles (n=17, 17.00%) and books (n=10, 10.00%) were also reported.

In relation to sub-group variations, participants in the sub-group *Symptoms: no to few days* (40.00%) accessed information from internet search engines/ Google less frequently compared to the general population (51.00%), and participants in the sub-groups *Symptoms: all days* (66.67%), and *Social: some days* (61.11%) accessed information from the internet more frequently.

Participants *Aged 18 – 34* (33.33%) reported accessing information from Australian charities less often compared with the general population (45.00%).

Participants in the sub-group *Symptoms: some days* (18.52%) accessed information from specialists less frequently compared to the general population (33.00%), and participants in the sub-group *Symptoms: most days* (50.00%) accessed information from specialists more frequently.

Participants in the sub-groups *Symptoms: most days (12.50%), Affect: very often to always* (35.48%) accessed information from online forums/ social media more frequently compared to the general population (23.00%).

No participants *Aged 18 – 34* reported accessing information from Medical journals/articles compared with 17.00% of the general population. Participants who lived in regional or remote areas (6.82%) reported accessing information from medical journals less frequently than the general population.

No participants *Aged 18 – 34* reported accessing information from books compared with 10.00% of the general population.

Participant describes accessing information from google (or generally internet)

I did print it off and tried to read to understand rheumatoid arthritis online. I did read up the guidelines or protocols for the professional- what do you call? Prescribing of biologics? It might be something like the Australia College of Rheumatologists. I went to somewhere authoritative. Participant 1.

So you really never know what the hell is going on and the doctors just ignore you or they just look at you like you're crazy or say, oh no, you won't experience any further things coming off it, which really isn't true because if you Google a medicine and you go on people’s reviews, some of the stuff that they, the last, the last trickling things that they come down was coming off. Participant 34.

Um, well, a lot on the internet. not always good, shouldn't really research too much on there. Participant 95.

Participant describes accessing information from Australian charities

Pretty much what I've sourced myself. I'm actually joined up with the Arthritis foundation and I received their, their newsletters. I'm on a regular basis, so I tend to read articles on them. Participant 10.

Initially I went to Arthritis Australia's website and just googled what I could google. That was probably the most reputable website I was able to find information on. Participant 90.

Um, I follow the arthritis foundation website and I, I find it really helpful when I read it. Peoples stories and stuff. Cause when you’ve got like people saying that, they don't understand and it frustrates you because people, um, I get frustrated, but it's good to hear other people's stories and how they feel and then I don't feel so bad or I don't feel, so, I think well like, I'm in better nick, so what have I got to complain about, it sort of gives me something to do. Participant 100.

Participant describes accessing information from their specialist

Um, my pharmacist has probably given me more information than anybody. He's brilliant. He gave me my, every time I change medications, he gives me an information sheet on that medication. Participant 13.

Information through GP, just through conversation, on the internet. My rheumatologists was good with information, and he also sent me some resources. He also gave me the option to email him, particularly early when I was diagnosed, if I had any questions, queries, concerns, whatever and we were emailing quite often in the beginning just when I was getting my head around it all. Participant 60.

My GP's Fantastic. Um, yeah, will let me know, positives and negatives if I go in there with questions, um, yeah, can offer some information as well. Rheumatologists, likewise, we'll talk about oh there's, um, this drug that if this one isn't as effective we can, there's this step we could look at and she's done that a couple of times. Participant 80.

Participant describes accessing information through online forums (including Facebook)

Personal blogs, like people who are both to experiencing chronic conditions and that doesn't necessarily mean I'm specifically but any sort of particularly auto immune based on it. Participant 12.

I'm on quite a few different support groups. It's all basically around Facebook where people have created groups where they can share their experiences with medications and natural therapies and changes in the food they're eating. I've never really understood the physicality of rheumatoid arthritis and I've never really understood an avenue that well either. I can't bend my mind around-- like there's a lot of people out there that they are changing their diet, watching symptoms, cutting out this, cutting out that, reintroducing. Participant 62.

I would say, let me think, probably that six months ago, then I started going on to social media onto Facebook support groups and everything but then I found some of those want people were just whinging and telling you the worst things possible. Participant 90.

Participant describes accessing information through books

Tried to read as much as I possibly can about rheumatoid arthritis, I bought some books on rheumatoid arthritis, living with rheumatoid arthritis, etc. and read them. So yeah. Participant 47.

I've accessed, um, an extensive number of books from the library because we have a very good library system. You just jump online and, you know, go through their catalogue. Um, so loads of books. Participant 79.

I've been to the library like when I was first diagnosed I got out lots of books. Participant 35.

Table 6.1 Access to information

Information accessed	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes accessing information from google (or generally internet)	51	51.00	10	52.63	19	43.18	22	59.46	8	40.00	14	51.85	15	46.88	14	66.67
Participant describes accessing information from Australian charities	45	45.00	9	47.37	20	45.45	16	43.24	8	40.00	14	51.85	14	43.75	9	42.86
Participant describes accessing information from their specialist	33	33.00	7	36.84	14	31.82	12	32.43	7	35.00	5	18.52	16	50.00	5	23.81
Participant describes accessing information through online forums (including Facebook)	23	23.00	4	21.05	8	18.18	11	29.73	5	25.00	8	29.63	4	12.50	6	28.57
Participant describes accessing information medical journals/articles	17	17.00	5	26.32	5	11.36	7	18.92	2	10.00	4	14.81	7	21.88	4	19.05
Participant describes accessing information through books	10	10.00	1	5.26	2	4.55	7	18.92	2	10.00	3	11.11	1	3.13	4	19.05

Information accessed	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes accessing information from google (or generally internet)	51	51.00	17	51.52	17	47.22	17	54.84	10	50.00	22	61.11	19	43.18
Participant describes accessing information from Australian charities	45	45.00	15	45.45	18	50.00	12	38.71	10	50.00	15	41.67	20	45.45
Participant describes accessing information from their specialist	33	33.00	11	33.33	14	38.89	8	25.81	7	35.00	13	36.11	13	29.55
Participant describes accessing information through online forums (including Facebook)	23	23.00	7	21.21	5	13.89	11	35.48	3	15.00	11	30.56	9	20.45
Participant describes accessing information medical journals/articles	17	17.00	6	18.18	7	19.44	4	12.90	3	15.00	4	11.11	10	22.73
Participant describes accessing information through books	10	10.00	6	18.18	2	5.56	2	6.45	2	10.00	3	8.33	5	11.36

Information accessed	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes accessing information from google (or generally internet)	51	51.00	26	46.43	25	56.82	18	58.06	25	49.02	8	44.44
Participant describes accessing information from Australian charities	45	45.00	28	50.00	17	38.64	13	41.94	26	50.98	6	33.33
Participant describes accessing information from their specialist	33	33.00	17	30.36	16	36.36	11	35.48	17	33.33	5	27.78
Participant describes accessing information through online forums (including Facebook)	23	23.00	11	19.64	12	27.27	5	16.13	13	25.49	5	27.78
Participant describes accessing information medical journals/articles	17	17.00	8	14.29	9	20.45	0	0.00	12	23.53	5	27.78
Participant describes accessing information through books	10	10.00	7	12.50	3	6.82	5	16.13	5	9.80	0	0.00

Table 6.1 Access to information (Cont.).

Information accessed	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes accessing information from google (or generally internet)	51	51.00	25	44.64	26	59.09	17	51.52	34	50.75	25	50.00	26	52.00
Participant describes accessing information from Australian charities	45	45.00	25	44.64	20	45.45	17	51.52	28	41.79	27	54.00	18	36.00
Participant describes accessing information from their specialist	33	33.00	17	30.36	16	36.36	8	24.24	25	37.31	15	30.00	18	36.00
Participant describes accessing information through online forums (including Facebook)	23	23.00	10	17.86	13	29.55	9	27.27	14	20.90	12	24.00	11	22.00
Participant describes accessing information medical journals/articles	17	17.00	14	25.00	3	6.82	5	15.15	12	17.91	12	24.00	5	10.00
Participant describes accessing information through books	10	10.00	2	3.57	8	18.18	4	12.12	6	8.96	3	6.00	7	14.00

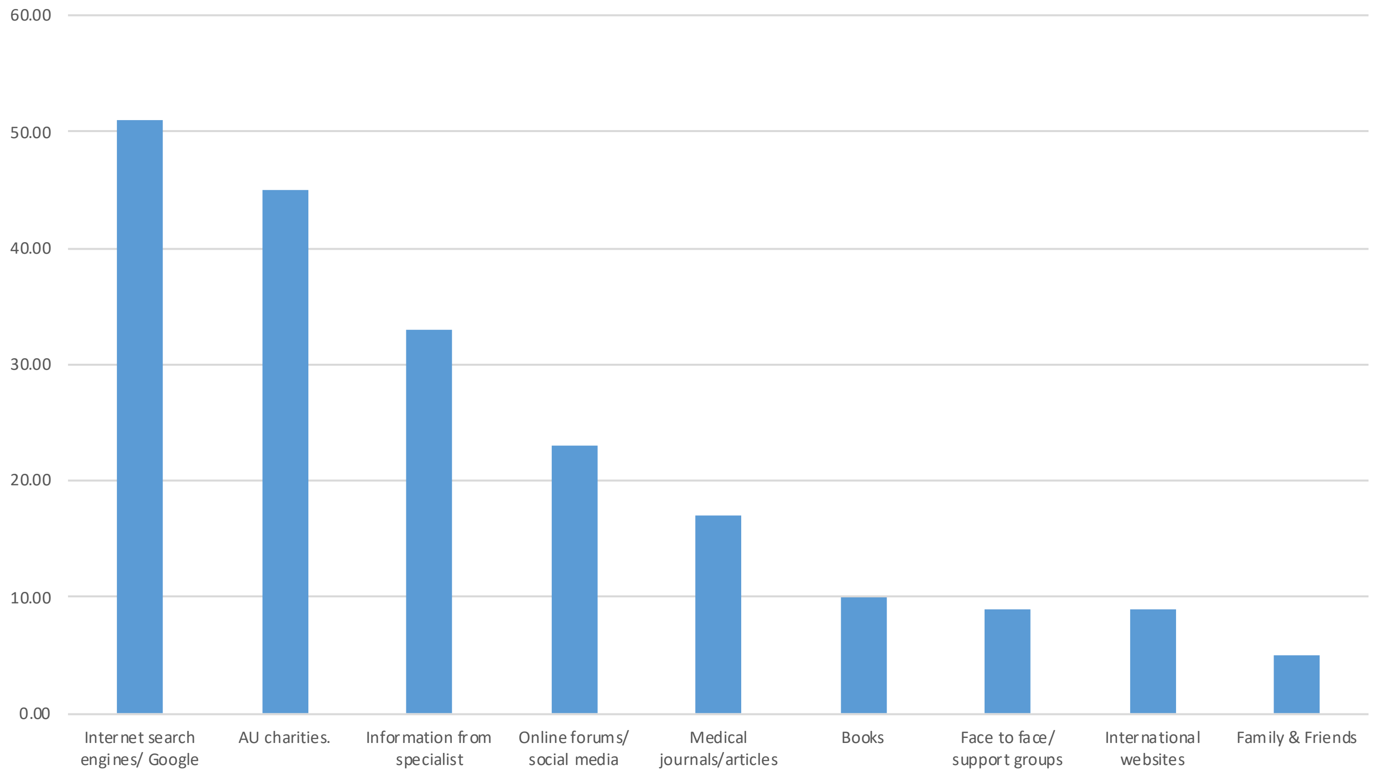


Figure 6.1 Access to information.

Information that has been helpful

The information that participants found most helpful was medical journals/articles (n=15, 15.00%). Other helpful information included unspecified online examples (n=13, 13.00%), information from a doctor or specialist (n=11, 11.00%), online support groups (n=10, 10.00%), other people's stories (n=10, 10.00%), unspecified online information (n=10, 10.00%), information from charities (n=9, 9.00%), information provided by drug companies on medication packaging (n=9, 9.00%), and support groups (n=8, 8.00%). There were 9% of participants that reported that no information they had received had been helpful.

In relation to the subgroup variations, participants in the sub-groups *Physical limitations: no days* (26.32%), and *Symptoms: no to few days* (25.00%) found that information from medical journals was helpful less often than the general population (15.00%).

No participants in the sub-groups *Physical limitations: no days,* and *Symptoms: no to few days reported unspecified online information* compared to 13.00% of the general population.

Participants in the sub-group *Affect: never to almost never* (21.21%) reported that information from doctor or specialist was helpful more often than the general population (11.00%).

No participants in the sub-group *Social: all to most days* reported information from online support groups was helpful compared to 10.00% of the general population. Participants in the sub-groups *Symptoms: no to few days* and (20.00%), *Social: some days* (22.22%) reported information from online support groups was helpful more often than the general population (10.00%).

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days* reported information from other people's stories was helpful compared to 10.00% of the general population. Participants in the sub-group *Physical limitations: some to most days* (21.62%) reported information from other people's stories was helpful more often than the general population.

No participants in the sub-group *Symptoms: some days* reported unspecified online information was helpful compared to 10.00% of the general population. Participants in the sub-group *Social: all to most days* (20.00%) reported information from unspecified online information more often than the general population.

No participants in the sub-group *Symptoms: all days* reported information from medication packaging was helpful compared to 9.00% of the general population. Participants *Aged 18 – 34* (22.22%) reported information from medication packaging more often than the general population.

No participants in the sub-group *Physical limitations: no days* reported that no information was helpful compared to 9.00% of the general population. Participants *in the Symptoms: all days* (23.81%) that no information was useful more often than the general population.

No participants Aged 18 to 34 reported that information from support groups was helpful compared to 8.00% of the general population.

Participant describes online medical journals as helpful

There's a couple of studies that the Australian government put out I think in 2015-- 2012 or 2015. It was the most recent one. It was just understanding the demographics of the people with that condition as well, and how to fit. It was just basically knowing I wasn't the only one. Participant 6

Oh, um, actually a long time ago, one of the most useful things I ever read was a book that unpacks the diagnostic criteria as an algorithm and it helps me to think really clearly about the diagnostic criteria. Um, so it was a little textbook written for, um, for medical professionals working in Rheumatology. Participant 11

There's not a lot of research on the way I'm trying to go about this, but it has been helpful just to read some of those journal articles enough to know the seriousness of what I'm dealing with as well. Participant 48

I probably I think the evidence-based information. So, papers that I've read them or um, discussions I've had with my rheumatologists probably. Yes. Okay. I find that the printed things are very over simplified, you know, they're, they're written at a level for anyone who may have whatever level of understanding they have. And so they tend to be very basic. Participant 55

Participant describes unspecified websites\Examples

The most helpful. Probably ways of helping, dealing with the pain and with the, with the emotional change that needed to happen because it's not just a disease, it changes your whole life. So helping, somebody there just to help go, Yep. Know what. That's like a process. It's helpful to have tips and hints to try and subtly change things in your life to be able to make it any easier. Participant 43

So more information about how, how it works, what things set it off. Certainly knowing about the foods, what not to eat and things like that. That's been quite good. Um, and understanding. I think the big thing was understanding the effect that stress has on it. Participant 61

What to expect from medication, solutions to problems, practical logistical problems at home or with the kids, lifestyle solutions. When I first had my girls I think there must be women out there that are having the same problems as me. A few people shared post about how to make life easier. Make sure you're getting the most lightweight manoeuvrable pram, histories of unknown because anything else is going to make you worse. Things are fabulous, they're really good looking and you look so comfortable but who's going to do it up behind your back when you have a baby by self. Participant 62

Participant describes talking to their doctor or specialist as helpful

Um, oh I think when my rheumatologist told me like what, what to expect and what some signs of improvement with that I go look for and also signs if it's getting worse, what to look for to make sure I go back to see him. Like before my next appointment. Participant 7

Um, well probably the rheumatologist's information has been most helpful because it's specific to my condition, whereas a lot of the other information around these generic rheumatoid arthritis stuff, it's not, I know mine's not that, so how much in that, what is in the document applies to me. Participant 18

My doctor will give me, you know, they answer my questions and yeah. And point me in the right, point me in the direction, like give me, you know, give me places to go. Participant 59

Participant describes online support groups (including Facebook) as helpful

I'm in a Facebook group for rheumatoid arthritis sufferers in Australia. That's quite helpful because you can kind of check in with people and say, hey, is anyone had these, how did it go? Well, what these I've had this happen. Should I be worried feedback? Um, so that is, that is helpful to just, to have that community. Participant 4

Um, yeah, just, that's really the main one and then my Facebook group is great for just like that general psychological support. Yeah. When I was needing that kind of support. Participant 9

For example, when I first got the side rash when I was using one of the in-built, I'd take a photo of it and put it up in some of the support groups online and say, "Does this look like what you guys get?" Other people would say, "Yes. That's it. That's right and this is what you can do to manage it. Use ice or whatever it is or try this product to manage it." That information about the day to day and managing of it is absolutely vital. It can really…from some other people who live through it. Participant 26

Participant describes other people's stories as having been helpful

I think what I find really the most helpful is um, information from other sufferers, other people and their experiences and what, how they deal with those experiences. Quite often pick up bits from other, other people in relation to, you know, especially things like, um, you know, comfortable shoes to wear and things like that. Yeah. Other people who have also suffered or who also got rheumatoid arthritis. Participant 47

I'm speaking to forums and places where I can actually go and ask real people real questions. Participant 71

When you do though, kind of thing with arthritis course for 20 other people that are you at the disease too, that did a lot for, I guess they causing myself amongst peers and different age groups and men, women, different conditions of the same range. That did a lot because it normalizes you within the, you're still human. You're not just a sick person talking to a doctor that doesn't have it because everyone else in the room goes. Yeah. Oh, I haven't gotten that bit, but that sounds right. Participant 86

Participant describes information on medication packaging as helpful

I would say the information leaflets that you get when you're trying a new drug and also what's available online for any drugs and also anything that- whenever there's a new breakthrough or something, I would read up about that online. Yes, stuff like that. Participant 20

Just the sheets, the sheets that come with the medications I find quite helpful. It's helpful. So I know what to look out for. Participant 33

Probably things about your side effects of medications and that kind of thing, what I can expect from different treatments from what I've received. Participant 39

Participant describes nothing being helpful

Oh, I don't know if any of it has been, it's just been informative more than helpful. It's just what the doctors told me to do it, that sort of thing. Participant 81

None of it's been overly helpful. Participant 82

Um, I don't know that anything's ever really made a difference. It's a bit hard to tell really if you would have made a choice without that information because it's pretty straightforward and logic. Participant 95

Participant describes face- to- face support groups as being helpful

I like to be a bit more positive and I've made great friends, from support groups and stuff. Participant 37

Um, well we just support groups is probably been the most help out of the things that I've come across. Information wise. Participant 38

Interestingly enough, I think what I find really the most helpful is um, information from other sufferers, other people and their experiences and what, how they deal with those experiences. Quite often pick up bits from other, other people in relation to, you know, especially things like, um, you know, comfortable shoes to wear and things like that. Yeah. Other people who have also suffered or who also got rheumatoid arthritis. Participant 47

Table 6.2 Information that has been helpful

Information that has been helpful	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes online medical journals as helpful	15	15.00	5	26.32	6	13.64	4	10.81	5	25.00	3	11.11	3	9.38	4	19.05
Participant describes unspecified websites\Examples	13	13.00	0	0.00	8	18.18	5	13.51	0	0.00	3	11.11	7	21.88	3	14.29
Participant describes talking to their doctor or specialist as helpful	11	11.00	3	15.79	6	13.64	2	5.41	3	15.00	3	11.11	3	9.38	2	9.52
Participant describes online support groups (including Facebook) as helpful	10	10.00	3	15.79	4	9.09	3	8.11	4	20.00	4	14.81	1	3.13	1	4.76
Participant describes other people's stories as having been helpful	10	10.00	0	0.00	2	4.55	8	21.62	0	0.00	2	7.41	4	12.50	4	19.05
Participant describes general online information as helpful	10	10.00	3	15.79	4	9.09	3	8.11	3	15.00	0	0.00	3	9.38	4	19.05
Participant describes information from charities as being helpful	9	9.00	2	10.53	3	6.82	4	10.81	1	5.00	5	18.52	1	3.13	2	9.52
Participant describes information on medication packaging as helpful	9	9.00	2	10.53	7	15.91	0	0.00	3	15.00	3	11.11	3	9.38	0	0.00
Participant describes nothing being helpful	9	9.00	0	0.00	3	6.82	6	16.22	0	0.00	1	3.70	3	9.38	5	23.81
Participant describes face- to- face support groups as being helpful	8	8.00	1	5.26	1	2.27	6	16.22	2	10.00	2	7.41	3	9.38	1	4.76

Information that has been helpful	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes online medical journals as helpful	15	15.00	8	24.24	4	11.11	3	9.68	3	15.00	5	13.89	7	15.91
Participant describes unspecified websites\Examples	13	13.00	4	12.12	2	5.56	7	22.58	3	15.00	7	19.44	3	6.82
Participant describes talking to their doctor or specialist as helpful	11	11.00	7	21.21	2	5.56	2	6.45	4	20.00	4	11.11	3	6.82
Participant describes online support groups (including Facebook) as helpful	10	10.00	2	6.06	6	16.67	2	6.45	0	0.00	8	22.22	2	4.55
Participant describes other people's stories as having been helpful	10	10.00	2	6.06	4	11.11	4	12.90	1	5.00	5	13.89	4	9.09
Participant describes general online information as helpful	10	10.00	2	6.06	5	13.89	3	9.68	4	20.00	3	8.33	3	6.82
Participant describes information from charities as being helpful	9	9.00	3	9.09	4	11.11	2	6.45	1	5.00	3	8.33	5	11.36
Participant describes information on medication packaging as helpful	9	9.00	2	6.06	5	13.89	2	6.45	2	10.00	2	5.56	5	11.36
Participant describes nothing being helpful	9	9.00	3	9.09	2	5.56	4	12.90	2	10.00	1	2.78	6	13.64
Participant describes face- to- face support groups as being helpful	8	8.00	2	6.06	3	8.33	3	9.68	1	5.00	3	8.33	4	9.09

Table 6.2 Information that has been helpful (Cont.)

Information that has been helpful	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes online medical journals as helpful	15	15.00	10	17.86	5	11.36	5	16.13	7	13.73	3	16.67
Participant describes unspecified websites\Examples	13	13.00	8	14.29	5	11.36	4	12.90	7	13.73	2	11.11
Participant describes talking to their doctor or specialist as helpful	11	11.00	7	12.50	4	9.09	2	6.45	7	13.73	2	11.11
Participant describes online support groups (including Facebook) as helpful	10	10.00	4	7.14	6	13.64	4	12.90	5	9.80	1	5.56
Participant describes other people's stories as having been helpful	10	10.00	4	7.14	6	13.64	3	9.68	4	7.84	3	16.67
Participant describes general online information as helpful	10	10.00	6	10.71	4	9.09	3	9.68	6	11.76	1	5.56
Participant describes information from charities as being helpful	9	9.00	5	8.93	4	9.09	2	6.45	5	9.80	2	11.11
Participant describes information on medication packaging as helpful	9	9.00	5	8.93	4	9.09	1	3.23	4	7.84	4	22.22
Participant describes nothing being helpful	9	9.00	3	5.36	6	13.64	4	12.90	4	7.84	1	5.56
Participant describes face- to- face support groups as being helpful	8	8.00	6	10.71	2	4.55	3	9.68	5	9.80	0	0.00

Information that has been helpful	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes online medical journals as helpful	15	15.00	11	19.64	4	9.09	2	6.06	13	19.40	11	22.00	4	8.00
Participant describes unspecified websites\Examples	13	13.00	7	12.50	6	13.64	3	9.09	10	14.93	8	16.00	5	10.00
Participant describes talking to their doctor or specialist as helpful	11	11.00	5	8.93	6	13.64	3	9.09	8	11.94	7	14.00	4	8.00
Participant describes online support groups (including Facebook) as helpful	10	10.00	5	8.93	5	11.36	5	15.15	5	7.46	3	6.00	7	14.00
Participant describes other people's stories as having been helpful	10	10.00	6	10.71	4	9.09	6	18.18	4	5.97	6	12.00	4	8.00
Participant describes general online information as helpful	10	10.00	3	5.36	7	15.91	2	6.06	8	11.94	4	8.00	6	12.00
Participant describes information from charities as being helpful	9	9.00	7	12.50	2	4.55	3	9.09	6	8.96	3	6.00	6	12.00
Participant describes information on medication packaging as helpful	9	9.00	7	12.50	2	4.55	2	6.06	7	10.45	5	10.00	4	8.00
Participant describes nothing being helpful	9	9.00	5	8.93	4	9.09	6	18.18	3	4.48	5	10.00	4	8.00
Participant describes face- to- face support groups as being helpful	8	8.00	4	7.14	4	9.09	3	9.09	5	7.46	3	6.00	5	10.00

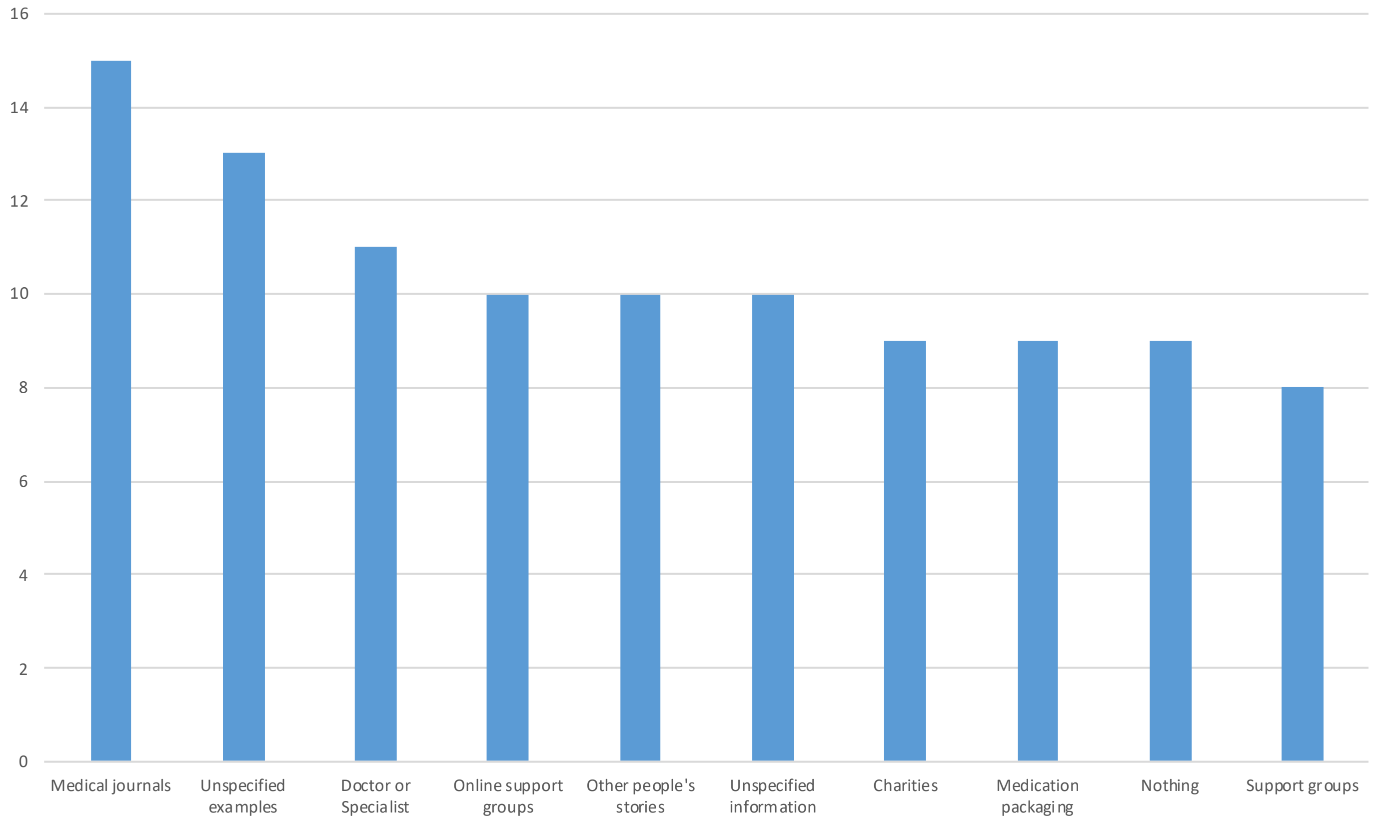


Figure 6.2 Information that has been helpful

Information that has not been helpful

Participants were asked if there was any information that they found to be unhelpful. The most common theme described by 34 participants as unhelpful were other people's opinions (34.00%). This was followed by no unhelpful information found (n=28, 28.00%), online sources (n=23, 23.00%), participants deciding for themselves what was relevant to themselves (n=12, 12.00%), healthcare professionals (n=11, 11.00%), online support groups (n=9, 9.00%) and being told about disease progression (n=8, 8.00%).

In regards to the subgroup variations, participants *Aged 18 – 34* (22.22%) found other people's opinion unhelpful less often than the general population (34.00%).

Participants that lived in an area with a *High SEIFA* (14.00%) found no unhelpful information less often than the general population (28.00%), while participants in the sub-groups *Symptoms: no to few days* (40.00%), *Symptoms: all days*
(38.10%), and *Mid to low SEIFA* (42.00%) found no unhelpful information more frequently.

Participants that in the sub-group *Symptoms: some days (7.41%)* online information unhelpful less often than the general population (23.00%), whereas participants in the sub-group *Symptoms: no to few days* (35.00%) found it unhelpful more frequently.

No participants in the sub-group *Symptoms: no to few days* reported that they decide for themselves what was relevant compared to 12.00% of the general population. Participants *Aged 18 to 34* reported this less frequently than the general population and participants in the sub-group *Symptoms: some days* (22.22%) reported this more frequently.

No participants in the sub-groups *Physical limitations: no days,* and *Symptoms: no to few days* found healthcare professional comments unhelpful. Participants in the *Symptoms: most days* (21.88%), and *Aged 18 – 34* (27.78%) reported they found healthcare professional comments unhelpful more frequently than the general population (11.00%).

No participants with *Trade or high school* qualifications reported that support groups were not helpful compared with 9.00% of the general population.

Participant describes other people giving their opinion as not being helpful

Um, and other people who talk about their grandparents and um, or um, also people who say, well, you need to lower stress in your life. You need to quit that job, you need to quit that. But honestly quitting my job is kind of open up a whole can of other worms… And then these people who are saying this, are they going to pay for my medical appointment? Are they going to pay for my daughter's education? Participant 50

Sometimes painted a pretty bleak outlook, but some people were obviously having bad days. They needed to vent and sometimes that's just the first thing you read and you see anything. Well, is that going to be me forever or. Yeah, so just some of those more like, I guess they call them blogs now, those blog type thing where people were just needing to vent that day. Participant 91

It's probably the people that want to give you the ten cents worth that RA is an old football injury and no. Yeah, I get arthritis every day. Yeah Bullshit, yeah, yeah. It's the, it's the people, the people out that don't understand that it's autoimmune, your cold is going to knocked me for two months. Yeah, yeah, yeah. It's the uninformed crap that's not helpful and it's tiring and it's frustrating. Participant 23

Participant describes they have not come across unhelpful information

No, look, I've got a great boss at work who's very supportive of me, my ever present GP, she's brilliant. My rheumatologist, my husband, my family. I've not really-- People look at you because it is an invisible disease sometimes, it is invisible. People look at you, but, look, I just get on with life. There's lots of others worse off when they-- I say it every day at work, so it's nothing. Participant 16

Um, probably not. Because I think you can glean something from almost anything. Participant 37

Hmm. No, I don't think so. I haven't really, probably should research it a bit more, but I get too exhausted to research it and I just, you, I just, I don't know. I just want to go to sleep. Participant 81

Participant describes 'Dr Google' or generally search for information on the internet as not being helpful

The Internet is um, of course, uh, well, well, well the risks, the risks are three-fold, things similar social media and that are brilliant, that for every good piece of information that's spread. Um, there's a lot of bullshit that's proliferated 10,000 fold, uh, so there's that, um, uh, there's a great deal of um, 'you can just solve everything with positive thinking', there's a lot of that, oh just rub some positive thinking on it, just think about this fairy dust it'll all be fine. Participant 87

Um, well there's a few of the websites that you go on and you know, they're talking about five great tips to get rid of your rheumatoid arthritis and really all they want to do and they usually American, they rave on and on and on, and then they want to sell you a pile of expensive medications. Participant 94

Well, I think as I said, you know, when I first looked it up and they're just pictures of deformed hands all over the Internet was really, really unhelpful or really just thought, oh my God, that's my future. Like, yeah, yeah, yeah. Participant 9

Participant describes deciding for themselves what is not helpful or dismissing irrelevant information or avoiding information that is not credible

Yup. You've got to be very careful to avoid all of that because you can get confused, depressed, and buying some rubbish that you really don't need, if you're not careful, which is why you've got to be very careful about your sources. Participant 87.

I think precisely that when people just putting up the, the PDF, how to take this drug information, I think that is not helpful. I think anyone who's actively seeking information is looking for so much more than than just how I take the medication, you know. Participant 24.

I mean some of the journals that I've read, I actually don't even understand. So if we were going to go down that academic side, I can't understand half of what they're saying. Participant 58.

Participant describes health professionals not being helpful

I expect other professionals to fully understand what this disease is, or to a limited extent or understand that I don't understand what this is, therefore you're going to have to guide me. If people aren't that way inclined, then I find that really unhelpful. Because sometimes they're a bit arrogant going, "You can just blah, blah," or, "Why can't you get up out of that chair that's opposite my desk? Because that's the only chair I've got in the room.". Participant 68

Um, I mean this with respect, but it's because mainly this category of the medical profession is a very busy environment and it's just your general GP, people, that's the first place people go when they've got rheumatoid an because it's a specialist disease, um, yes there's respect but the doctors are busy and you automatically a given quite often medication that's not necessarily right for you and even then some specialists are better than others. So I've signed what I'm hasn't worked. I'm trying to. It gets a bit political actually. I find it all to do with the dollar. Participant 73

Participant describes support groups as not helpful

But I, I just found that it wasn't particularly helpful to just just just vent about how deformed you were or you know, it just. There wasn't a nice vibe about the group in general. It seemed to be more people, people just trying to one up themselves with how badly affected by it. Participant 72.

The only thing I would say is their support group chat group. I find there's a lot of negativity and misinformation in those groups. I think negativity feeds negativity. I think sometimes people weren't always getting good advice through there or good support, so I think that wasn't very helpful. Not necessarily for me because I could see it and remove myself from that. I don't need that sort of thing, but I think for a lot of people that might have a negative impact on them and their experience. Participant 60.

I think a lot of it comes from online support groups. Everyone's experience is different. You don't want to roll things out. I see a lot of forums, I've joined a lot of support groups on Facebook and whatnot to see what people say and how people feel about what they've got. It got to a point where it was really depressing. Participant 6.

Participant describes advice on disease progression as not helpful

It was a south Australian arthritis website, rheumatoid arthritis website, arthritis Australia, I can't remember at the moment, but I just found it was really negative. It was just all about how to manage in your disease, say and how bad it would get and how you had to learn how to live with all this. And I thought, well, that's not helping me, I'm trying to get out of that situation and I didn't found, that very motivating at all. Participant 94.

Well, I think as I said, you know, when I first looked it up and they're just pictures of deformed hands all over the Internet was really, really unhelpful or really just thought, oh my God, that's my future. Participant 9.

Well, some of the stuff that tells you when a lot of websites talked about this figure of 50 percent within five years with another disability and that was just not helpful. Participant 44.

Table 6.3 Information that has not been helpful

Information that has not been helpful	All participants		Physical limitations: no days		Physical limitations: few days		Physical limitations: some to most days		Symptoms: no to few days		Symptoms: some days		Symptoms: most days		Symptoms: all days	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes other people giving their opinion as not being helpful	34	34.00	6	31.58	14	31.82	14	37.84	5	25.00	8	29.63	12	37.50	9	42.86
Participant describes they have not come across unhelpful information	28	28.00	7	36.84	13	29.55	8	21.62	8	40.00	8	29.63	4	12.50	8	38.10
Participant describes 'Dr Google' or generally search for information on the internet as not being helpful	23	23.00	4	21.05	9	20.45	10	27.03	7	35.00	2	7.41	8	25.00	6	28.57
Participant describes deciding for themselves what is not helpful or dismissing irrelevant information or avoiding information that is not credible	12	12.00	1	5.26	6	13.64	5	13.51	0	0.00	6	22.22	3	9.38	3	14.29
Participant describes health professionals not being helpful	11	11.00	0	0.00	7	15.91	4	10.81	0	0.00	3	11.11	7	21.88	1	4.76
Participant describes support groups as not helpful	9	9.00	2	10.53	5	11.36	2	5.41	3	15.00	1	3.70	4	12.50	1	4.76
Participant describes advice on disease progression as not helpful	8	8.00	3	15.79	2	4.55	3	8.11	3	15.00	3	11.11	1	3.13	1	4.76

Information that has not been helpful	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes other people giving their opinion as not being helpful	34	34.00	9	27.27	13	36.11	12	38.71	7	35.00	12	33.33	15	34.09
Participant describes they have not come across unhelpful information	28	28.00	8	24.24	11	30.56	9	29.03	6	30.00	10	27.78	12	27.27
Participant describes 'Dr Google' or generally search for information on the internet as not being helpful	23	23.00	10	30.30	6	16.67	7	22.58	4	20.00	7	19.44	12	27.27
Participant describes deciding for themselves what is not helpful or dismissing irrelevant information or avoiding information that is not credible	12	12.00	4	12.12	4	11.11	4	12.90	1	5.00	7	19.44	4	9.09
Participant describes health professionals not being helpful	11	11.00	4	12.12	4	11.11	3	9.68	2	10.00	4	11.11	5	11.36
Participant describes support groups as not helpful	9	9.00	4	12.12	3	8.33	2	6.45	3	15.00	5	13.89	1	2.27
Participant describes advice on disease progression as not helpful	8	8.00	5	15.15	2	5.56	1	3.23	2	10.00	1	2.78	5	11.36

Information that has not been helpful	All participants		Occasional flare ups		Frequent flare ups		Aged 55 or older		Aged 35 - 54		Aged 18 – 34	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes other people giving their opinion as not being helpful	34	34.00	18	32.14	16	36.36	8	25.81	22	43.14	4	22.22
Participant describes they have not come across unhelpful information	28	28.00	14	25.00	14	31.82	10	32.26	13	25.49	5	27.78
Participant describes 'Dr Google' or generally search for information on the internet as not being helpful	23	23.00	13	23.21	10	22.73	8	25.81	13	25.49	2	11.11
Participant describes deciding for themselves what is not helpful or dismissing irrelevant information or avoiding information that is not credible	12	12.00	4	7.14	8	18.18	2	6.45	5	9.80	5	27.78
Participant describes health professionals not being helpful	11	11.00	7	12.50	4	9.09	5	16.13	5	9.80	1	5.56
Participant describes support groups as not helpful	9	9.00	5	8.93	4	9.09	1	3.23	5	9.80	3	16.67
Participant describes advice on disease progression as not helpful	8	8.00	7	12.50	1	2.27	3	9.68	3	5.88	2	11.11

Table 6.3 Information that has not been helpful (Cont.)

Information that has not been helpful	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes other people giving their opinion as not being helpful	34	34.00	19	33.93	15	34.09	11	33.33	23	34.33	21	42.00	13	26.00
Participant describes they have not come across unhelpful information	28	28.00	12	21.43	16	36.36	9	27.27	19	28.36	7	14.00	21	42.00
Participant describes 'Dr Google' or generally search for information on the internet as not being helpful	23	23.00	11	19.64	12	27.27	7	21.21	16	23.88	11	22.00	12	24.00
Participant describes deciding for themselves what is not helpful or dismissing irrelevant information or avoiding information that is not credible	12	12.00	8	14.29	4	9.09	5	15.15	7	10.45	9	18.00	3	6.00
Participant describes health professionals not being helpful	11	11.00	7	12.50	4	9.09	5	15.15	6	8.96	9	18.00	2	4.00
Participant describes support groups as not helpful	9	9.00	6	10.71	3	6.82	0	0.00	9	13.43	6	12.00	3	6.00
Participant describes advice on disease progression as not helpful	8	8.00	2	3.57	6	13.64	3	9.09	5	7.46	2	4.00	6	12.00

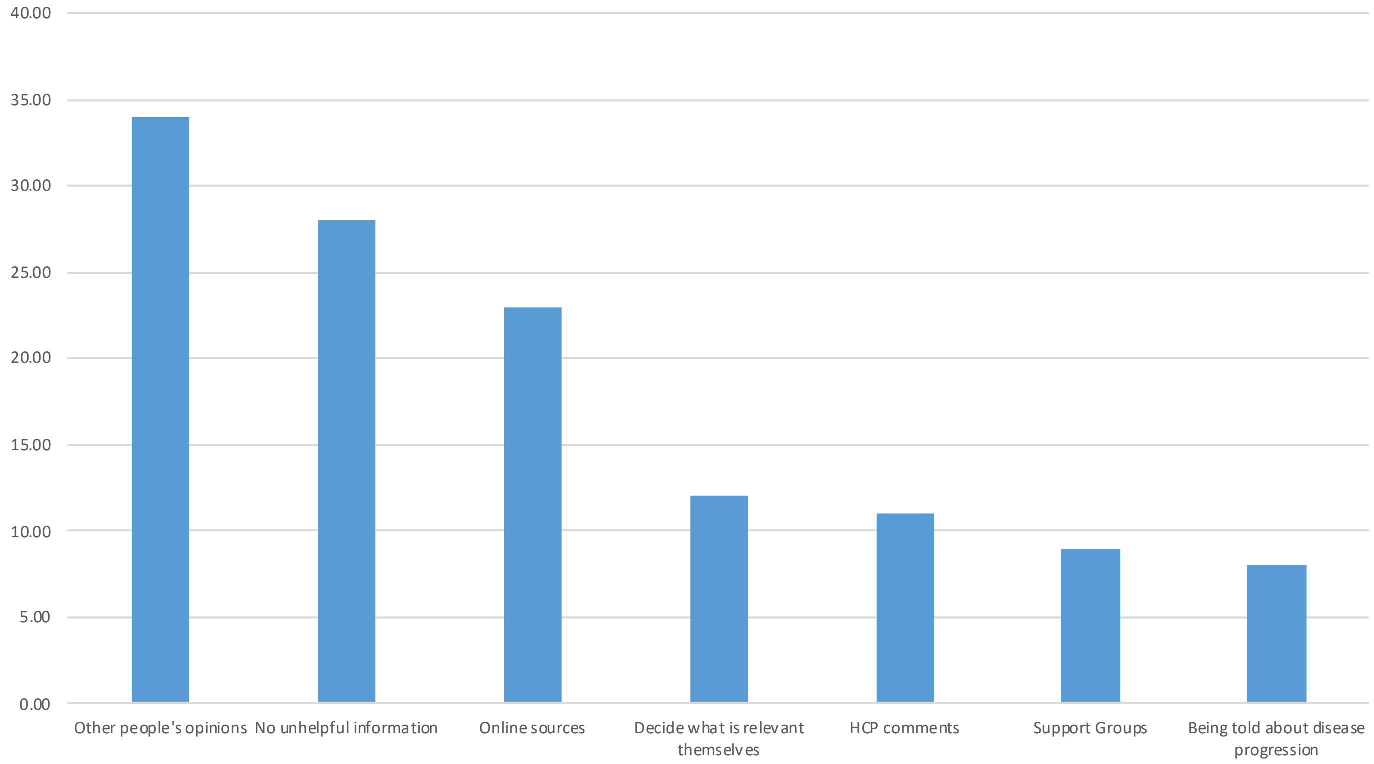


Figure 6.3 Information that has not been helpful

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common theme overall was a preference for talking to someone (n=45, 45.00%). This included a preference for talking to someone (in general (n=19, 19.00%), talking to someone as well as online information (n=15, 15.00%) and talking to a specialist nurse (n=11, 11.00%). The next most common theme overall was accessing online information (n=38, 30.80%) and this was due to its accessibility. There were also 17 participants (17.00%) that described a preference for booklets and nine participants (9.00%) that had a preference for apps.

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (26.32%), *Symptoms: no to few days* (25.00%) and *Social: no to few days* (27.27%) described a preference for talking to someone, less frequently than the general populaiton (45.00%), while participants in the sub-groups *Physical limitations: some to most days* (64.86%), *Symptoms: most days* (56.25%), *Social: some days* (66.67%), *Aged 55 or older* (64.52%), *Regional or remote* (56.82%), and those with a *trade or high school education (57.58%) described this more frequently.*

Participants in the *Social: all to most days* (25.00%) and those *Aged 55 or older (25.81%) reported a preference for online information, less frequently than the general population (38.00%), while those in the sub-group Affect: very often to always (48.39%) reported this more frequently.*

Participant describes a preference for online information due to its accessibility

Um, probably online. Basically because I'm so time poor. Yes. And yeah, I can read bits of it and then I can always go back to It. Participant 10

Online. Just, um, well, it's free and immediate as well. So you can find a lot of stuff at the touch of a button. Participant 12

I'm online, I think, and it's just a time thing that, you know, when I have time to look stuff up, it's easily, you know, quite late at night and yeah, just um, yeah. And I, I prefer online or so because it's um, you know, more available like at this booklets and leaflets and stuff, you're kind of limited information if they can't search for different aspects of things. Participant 19

Probably online, main reason is because of a location where I live in a very small community. There was no support groups anywhere near me. Participant 47

Participant describes a preference for talking to someone

Probably talking to someone because I find that online, I tend to skim unless something catches my eye and if I miss something, at least I've got the opportunity to, if I'm talking to someone, go, "Hang on. Go back. What do you mean by XYZ?" I appreciate hearing about people's experiences, "What did you do that helped? Who do you see that helps?" That would be probably my first preference. My second one is online, because it's easy, accessible and I can just read it when I want. Pamphlets. I'm hopeless with pieces of paper. I think giving me a pamphlet there's a nine out of 10 chance that I'll never see it again. Participant 68

I like talking to people as long as I can take notes and preferably get back to them when I've got home and something goes, oh, I forgot to ask that or was that about, yeah. Participant 79

I prefer talking because it's a more personal thing and you can explain it maybe a little bit better by actually talking to someone rather than trying to put it into words. Participant 80

Participant describes a preference for booklets

Um, I guess printed booklets or stuff online I think would be preferable for me to talking to somebody because then I've got it and I can read it and go back and read it again. And then if I'm don't understand something, I can look that up in my own time. I think sometimes when I'm talking it's a bit overwhelming and I don't take it all in. Participant 7

But I do like booklet because I can share it with my family and if there's something you can put on the fridge. Something basic that they can understand. It helps because it's really hard to. If I tell my husband on repeat he'll forget and not know what to do. So sometimes I have to create my own from things I've read and put it on the fridge. Participant 95

I much prefer the booklet information because I find that easier to read than online stuff. I just find having a book in your hand is a lot easier to read and also you can highlight stuff and take it along to your rheumatologist and ask her to explain why this and why that. Participant 16

Participant describes a preference for online information plus talking

Online information would be my first preference then I'd be speaking to somebody after that. Participant 56

I think I have, I have a preference for online but I like to discuss it. I like to be well informed before I go into a discussion with someone. Participant 57

I do like online, because I can research at my own pace. I can go back, and re-read if I didn't quite understand something. Or, I can research further if there's one point that I think I want to know more about. It gives me the opportunity to research further, and talking to other people who are experiencing similar things is also good. I was talking about the online support group. Participant 93

Participant would like having a specialist to talk to on the phone

I think just to get a lot of information that way the person you're talking to they really have to know what they're doing. I suppose there are clinical nurses who are trained in auto-immune disease area, or rheumatoid arthritis. I haven't come across any, but I'm sure they must exist from where probably in clinics and hospitals. Participant 21

Um, I think a phone, it would be brilliant. Um talking to somebody, but finding time in business hours to do that is pretty tricky for me. Participant 71

A clinician or someone that um, knows, what it's all about. Even your GP. It's because they are there and I'm in the country, you know, I'm in a rural area so you don't get um, you can't just ring up and say, I'd like to see the doctor this afternoon. Participant 81

Participant describes having a preference for apps

Um, I'm guess online and apps are useful because it's timely, you can just look up yourself and find it when you need it. So if it's, for example, the treatments or particular drugs and stuff you can find out side effects and that sort of thing. Participant 18

I probably say Internet and phone apps I would like more, because then with phone apps, it stays on your phone, so you got it on hands, then you can easily record your information or you can record the side effects that you had, and go to your rheumatologist so you can say "Look, I'm on this drug and I have this side effect during this week," or whatever. "What should I do or who should I speak to?" Then at least you've got it on hand to treat somebody, it's that kind of practicality I think I like. It's easily on hands. Participant 66

Um, probably online or an APP. The being remote, sometimes it's hard to get to places. So, um, so yeah. So online and phone apps and probably the big thing for me. Participant 88

Participant describes having a preference for online information but does not provide a reason

I'll probably go online and then if someone's telling me about it then I'll question them more. Um, yeah, I'll probably go online more than anything now. Participant 13

I think I have, I have a preference for online but I like to discuss it. I like to be well informed before I go into a discussion with someone. Participant 57

For General Research I would go online because I'm fairly comfortable in researching and selecting a legitimate source. Participant 4

Table 6.4 Information preferences

Information preferences	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes a preference for talking to someone (Total)	45	45.00	5	26.32	16	36.36	24	64.86	5	25.00	11	40.74	18	56.25	11	52.38
Participant describes a preference for talking to someone	19	19.00	0	0.00	7	15.91	12	32.43	2	10.00	5	18.52	8	25.00	4	19.05
Participant describes a preference for talking to someone, with online information available	15	15.00	3	15.79	5	11.36	7	18.92	3	15.00	2	7.41	6	18.75	4	19.05
Participant would like having a specialist or nurse to talk to on the phone	11	11.00	2	10.53	4	9.09	5	13.51	0	0.00	4	14.81	4	12.50	3	14.29
Participant describes a preference for online information (Total)	38	38.00	6	31.58	18	40.91	14	37.84	6	30.00	13	48.15	10	31.25	9	42.86
Participant describes a preference for online information due to its accessibility	30	30.00	4	21.05	15	34.09	11	29.73	4	20.00	11	40.74	8	25.00	7	33.33
Participant describes having a preference for online information but does not provide a reason	8	8.00	2	10.53	3	6.82	3	8.11	2	10.00	2	7.41	2	6.25	2	9.52
Participant describes a preference for booklets	17	17.00	6	31.58	4	9.09	7	18.92	5	25.00	4	14.81	5	15.63	3	14.29
Participant describes having a preference for apps	9	9.00	2	10.53	6	13.64	1	2.70	2	10.00	2	7.41	4	12.50	1	4.76

Information preferences	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes a preference for talking to someone (Total)	45	45.00	14	42.42	18	50.00	13	41.94	9	45.00	24	66.67	12	27.27
Participant describes a preference for talking to someone	19	19.00	7	21.21	7	19.44	5	16.13	6	30.00	8	22.22	5	11.36
Participant describes a preference for talking to someone, with online information available	15	15.00	4	12.12	8	22.22	3	9.68	1	5.00	11	30.56	3	6.82
Participant would like having a specialist or nurse to talk to on the phone	11	11.00	3	9.09	3	8.33	5	16.13	2	10.00	5	13.89	4	9.09
Participant describes a preference for online information (Total)	38	38.00	11	33.33	12	33.33	15	48.39	5	25.00	14	38.89	19	43.18
Participant describes a preference for online information due to its accessibility	30	30.00	8	24.24	10	27.78	12	38.71	3	15.00	13	36.11	14	31.82
Participant describes having a preference for online information but does not provide a reason	8	8.00	3	9.09	2	5.56	3	9.68	2	10.00	1	2.78	5	11.36
Participant describes a preference for booklets	17	17.00	8	24.24	5	13.89	4	12.90	5	25.00	5	13.89	7	15.91
Participant describes having a preference for apps	9	9.00	4	12.12	4	11.11	1	3.23	2	10.00	1	2.78	6	13.64

Information preferences	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes a preference for talking to someone (Total)	45	45.00	27	48.21	18	40.91	20	64.52	18	35.29	7	38.89
Participant describes a preference for talking to someone	19	19.00	14	25.00	5	11.36	11	35.48	6	11.76	2	11.11
Participant describes a preference for talking to someone, with online information available	15	15.00	8	14.29	7	15.91	5	16.13	8	15.69	2	11.11
Participant would like having a specialist or nurse to talk to on the phone	11	11.00	5	8.93	6	13.64	4	12.90	4	7.84	3	16.67
Participant describes a preference for online information (Total)	38	38.00	20	35.71	18	40.91	8	25.81	23	45.10	7	38.89
Participant describes a preference for online information due to its accessibility	30	30.00	16	28.57	14	31.82	8	25.81	16	31.37	6	33.33
Participant describes having a preference for online information but does not provide a reason	8	8.00	4	7.14	4	9.09	0	0.00	7	13.73	1	5.56
Participant describes a preference for booklets	17	17.00	10	17.86	7	15.91	5	16.13	9	17.65	3	16.67
Participant describes having a preference for apps	9	9.00	4	7.14	5	11.36	1	3.23	5	9.80	3	16.67

Information preferences	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes a preference for talking to someone (Total)	45	45.00	20	35.71	25	56.82	19	57.58	26	38.81	21	42.00	24	48.00
Participant describes a preference for talking to someone	19	19.00	8	14.29	11	25.00	9	27.27	10	14.93	9	18.00	10	20.00
Participant describes a preference for talking to someone, with online information available	15	15.00	5	8.93	10	22.73	4	12.12	11	16.42	7	14.00	8	16.00
Participant would like having a specialist or nurse to talk to on the phone	11	11.00	7	12.50	4	9.09	6	18.18	5	7.46	5	10.00	6	12.00
Participant describes a preference for online information (Total)	38	38.00	24	42.86	14	31.82	12	36.36	26	38.81	21	42.00	17	34.00
Participant describes a preference for online information due to its accessibility	30	30.00	20	35.71	10	22.73	9	27.27	21	31.34	18	36.00	12	24.00
Participant describes having a preference for online information but does not provide a reason	8	8.00	4	7.14	4	9.09	3	9.09	5	7.46	3	6.00	5	10.00
Participant describes a preference for booklets	17	17.00	10	17.86	7	15.91	6	18.18	11	16.42	9	18.00	8	16.00
Participant describes having a preference for apps	9	9.00	6	10.71	3	6.82	3	9.09	6	8.96	6	12.00	3	6.00

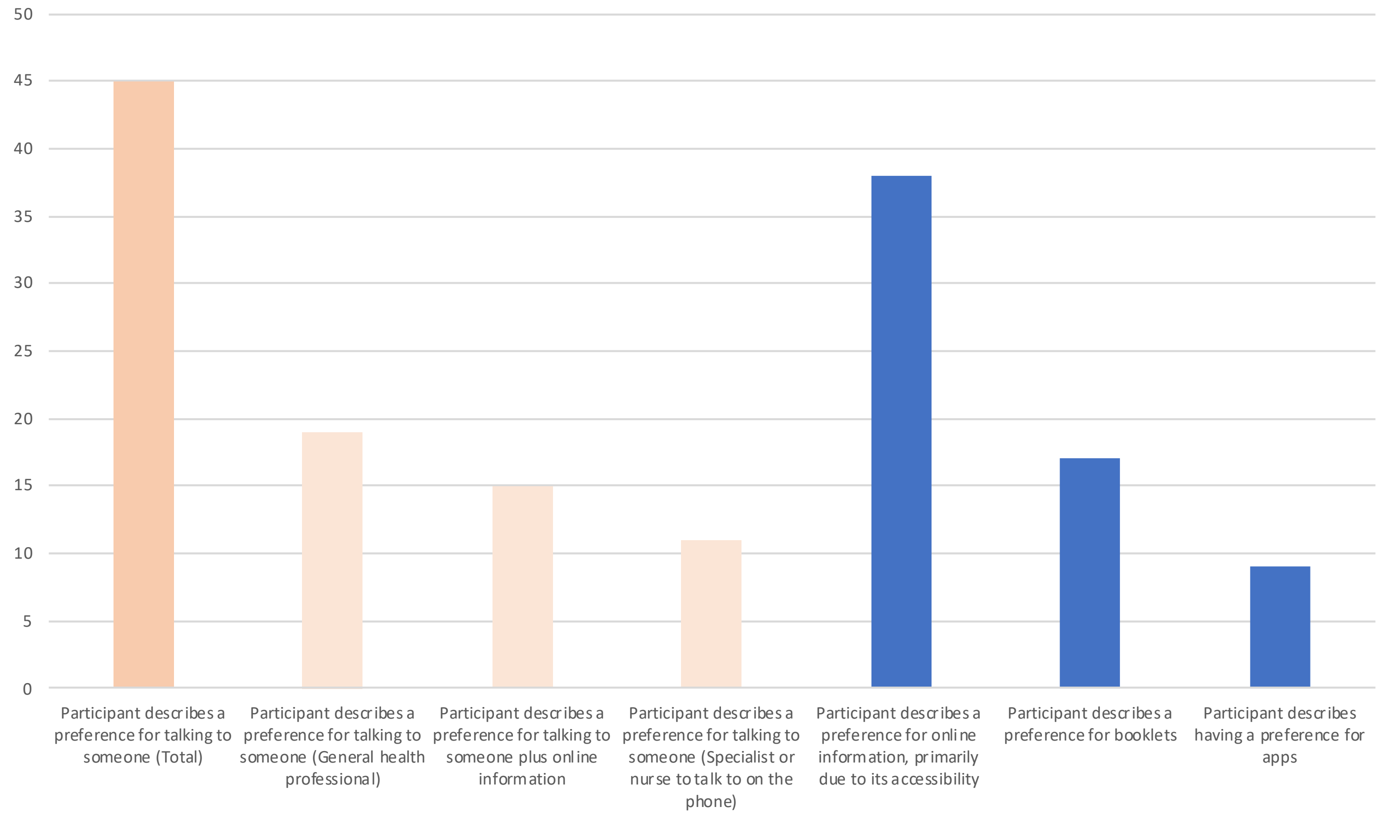


Figure 6.4 Information preferences

Timing of information

The most common time that participants described being receptive to receiving information was being receptive since diagnosis (27.00%). This is followed by: Receptive after initial shock (24.00%), receptive after months (n=20), slowly receptive to new information (17.00%) and not receptive for years (16.00%).

In relation to sub-group variations, participants in the sub-group Social: all to most days (15.00%) were receptive to information from diagnosis less often compared to the general population (27.00%).

Participants in the sub-group *Symptoms: some days* (40.74%) were receptive to information after the initial shock of the diagnosis more frequently compared to the general population (24.00%), and those with *Trade or high school* qualifications (12.12%) were less frequently receptive after the initial shock.

No Participants in the sub-group *Physical limitations: no days* were receptive to information after months. Participants in the sub-group *Symptoms: no to few days* (5.00%) were receptive to information after less frequently compared to the general population (20.00%), and those in the sub-groups *Symptoms: most days* (40.63%), *Affect: sometimes* (30.56%,), and *Social: all to most days (30.00%)* were receptive after months more frequently.

Participants in the sub-groups Affect: never to almost never (9.09%), Affect: very often to always (6.45%), Social: all to most days (5.00%), and *Aged 55 or older* (6.45%) were slowly receptive to new information less frequently compared to the general population (17.00%), and those in the sub-group *Physical limitations: no days* (31.58%) were slowly receptive to new information more frequently.

Participants in the sub-groups *Symptoms: no to few days* (5.00%), and *Aged 35 – 54* (9.80%) were not receptive for years less frequently compared to the general population (16.00%), and those in the sub-groups *Physical limitations: some to most days* (29.73%), Affect: never to almost never (30.30%), *Aged 18 – 34* (33.33%), and those with *Trade or high school* qualifications (27.27%) were not receptive to information more frequently.

Participant describes being receptive from the beginning (diagnosis)

So I need to find out what's going on. Okay. And I probably didn't take my head out of a book or the computer for the first three months trying to find out what on earth I could do about it. There's so much information out there, you know, it's hard to digest it all. Yeah. Participant 94

At the beginning, I was really desperate. [laughs] I was so desperate for information and understanding and knowledge about it. Participant 6

I think at the start I was very open to taking it in because I idea know what was happening and I was kind of at that crazy stage of wanting to know absolutely everything but because you don't have the understanding like you haven't lived through how it impacts your life, you haven't lived through the side effects or what it all means for you. You can take it in but you can only understand to a certain point Participant 24

Participant describes being receptive to information after the shock of diagnosis

I probably was more able to take it in once the initial reorganizing of everything was sort of there. Once I started to get a grip on the pain and get some sense of the initial issues in managing it. Then I was able to take a step back and say to myself, okay, this is permanent. What do I most need to do. Participant 70.

I think it was probably a couple months after my diagnosis, so right at the start I was kind of still reeling from it and trying to adjust to the idea that this wasn't going to go away. And for me it was career ending as well. Participant19.

The diagnosis was a shock though, especially when you read about all the negative aspects of the disease and the fact that it is a life sentence is for some people, et cetera, so I was probably receptive, but at the same time in a state of shock for a period of time and then you sort of overcome that and say, well, this is the new norm, let's go find information to help me with the new norm. Participant 29

Participant describes not being receptive for months post diagnosis

Because I think I just didn't believe it when I was first diagnosed that I actually had arthritis at such a young age. I was like, "Well, I seriously can't have arthritis at this age, it's not me." Then I got a health scare I think about eight months down the track after I was diagnosed. It just kind of really hit home the fact that well, yes, I'm on some serious medication. I definitely have arthritis. It's obviously, I have really have to take this diagnosis seriously, and maybe I really should be thinking about researching it and understanding it. Participant 66

Probably the first, cause I had to wait about three months to see to a rheumatologist. So I think when I first saw her, I waited a long time and I've got my head around having rheumatoid. So I was pretty receptive to the information then. Participant 42.

But when I was most receptive, probably not for a while, I was in such shock and denial and angry like, you know. Yeah. So probably a good three to six months, I think until the math checks out over three months. I would say within three to six months I'd probably most receptive. Participant 27.

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

He actually, and I recall you saying that you know, you just wanted to read as you want it to know exactly what was going on quite early in the piece will the first gp appointment where I kind of knew in the back of my head that I was going to be diagnosed with RA. I thought this is, the symptoms are so classic and I imagine that's what's happening. Participant 3

Because I'd passed the stage of being a stupid teenager and I can still conquer the world. This wasn't going to stop me from doing anything. Well, it does stop you from doing things and it wasn't until I thought I'd probably matured to the extent of, "Come on. Reality check here. You might be able to do it but you're not going to do it like you think you're going to do it." It makes your mind. It's like we get old, physically we get old, aging, what happens to our bodies and everything else but our brain doesn't. Participant 80

The most receptive I was to information was 18 years after my diagnosis and it was because I was desperate because I had to desperately make a change because I had a baby to look after. Participant 62.

Participant describes being receptive to information years after diagnosis

Actually, the last couple of years, I would probably take more information in. The first couple of years, it was a bit overwhelming that you have this disease. It was a bit of a shock to the system. You were just trying to find a treatment to get through it. Participant 46.

Um, it probably took me about three years because I just had such horrible side effects to everything with those first few treatments that I had and I suppose then I probably did get a bit depressed about it all. Participant 76.

PARTICIPANT: Probably in my 30s.
INTERVIEWER: Why is that?
PARTICIPANT: Because I'd passed the stage of being a stupid teenager and I can still conquer the world. This wasn't going to stop me from doing anything. Participant 80.

Table 6.5 Timing of information

Timing of information	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes being receptive from the beginning (diagnosis)	27	27.00	5	26.32	15	34.09	7	18.92	5	25.00	9	33.33	8	25.00	5	23.81
Participant describes being receptive to information after the shock of diagnosis	24	24.00	6	31.58	8	18.18	10	27.03	5	25.00	11	40.74	5	15.63	3	14.29
Participant describes not being receptive for months post diagnosis	20	20.00	0	0.00	10	22.73	10	27.03	1	5.00	3	11.11	13	40.63	3	14.29
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	17	17.00	6	31.58	7	15.91	4	10.81	5	25.00	5	18.52	3	9.38	4	19.05
Participant describes being receptive to information years after diagnosis	16	16.00	2	10.53	3	6.82	11	29.73	1	5.00	4	14.81	6	18.75	5	23.81

Timing of information	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes being receptive from the beginning (diagnosis)	27	27.00	7	21.21	11	30.56	9	29.03	3	15.00	9	25.00	15	34.09
Participant describes being receptive to information after the shock of diagnosis	24	24.00	9	27.27	8	22.22	7	22.58	4	20.00	6	16.67	14	31.82
Participant describes not being receptive for months post diagnosis	20	20.00	3	9.09	11	30.56	6	19.35	6	30.00	8	22.22	6	13.64
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	17	17.00	10	30.30	5	13.89	2	6.45	1	5.00	7	19.44	9	20.45
Participant describes being receptive to information years after diagnosis	16	16.00	3	9.09	6	16.67	7	22.58	3	15.00	8	22.22	5	11.36

Timing of information	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes being receptive from the beginning (diagnosis)	27	27.00	18	32.14	9	20.45	8	25.81	14	27.45	5	27.78
Participant describes being receptive to information after the shock of diagnosis	24	24.00	14	25.00	10	22.73	10	32.26	9	17.65	5	27.78
Participant describes not being receptive for months post diagnosis	20	20.00	8	14.29	12	27.27	8	25.81	10	19.61	2	11.11
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	17	17.00	10	17.86	7	15.91	2	6.45	13	25.49	2	11.11
Participant describes being receptive to information years after diagnosis	16	16.00	7	12.50	9	20.45	5	16.13	5	9.80	6	33.33

Timing of information	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes being receptive from the beginning (diagnosis)	27	27.00	15	26.79	12	27.27	11	33.33	16	23.88	13	26.00	14	28.00
Participant describes being receptive to information after the shock of diagnosis	24	24.00	16	28.57	8	18.18	4	12.12	20	29.85	13	26.00	11	22.00
Participant describes not being receptive for months post diagnosis	20	20.00	10	17.86	10	22.73	4	12.12	16	23.88	8	16.00	12	24.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	17	17.00	10	17.86	7	15.91	7	21.21	10	14.93	10	20.00	7	14.00
Participant describes being receptive to information years after diagnosis	16	16.00	8	14.29	8	18.18	9	27.27	7	10.45	9	18.00	7	14.00

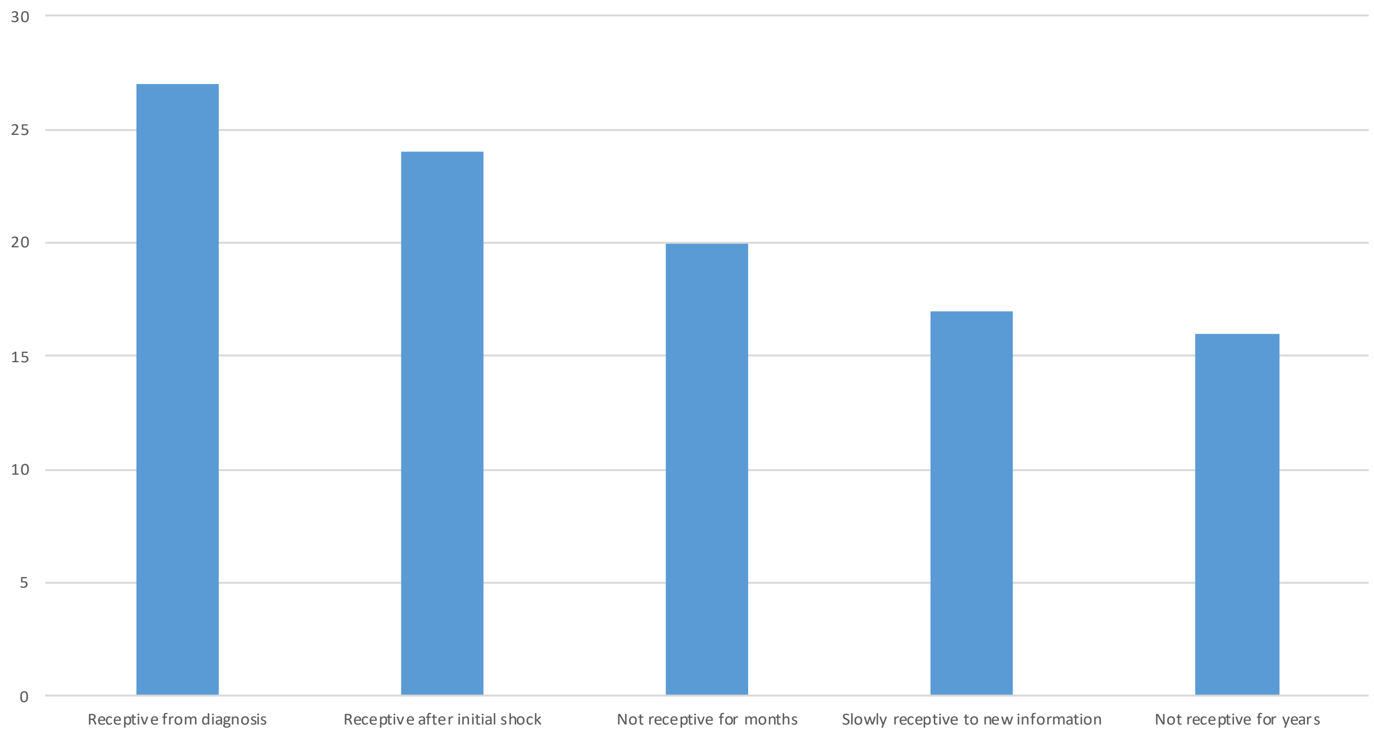


Figure 6.5 Timing of information

Communication with health professionals

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described was having an overall positive experience as their healthcare professional was caring, supportive and understanding (21.00%). Where participants described a positive experience, this related to their healthcare professional being supportive and understanding (21.00%), taking the time to answer participant questions and provide information (18.00%), and reporting having a positive experience but not elaborating (15.00%). Where participants described a negative experience, this related to healthcare professionals being dismissive and/or participants feeling ignored (17.00%), and participants reported not being given enough time or support to ask questions (14.00%). Some participants (13.00%) reported having neither a positive or negative experience.

In relation to sub-group variations, participants in the sub-group *Social: all to most days* (10.00%) reported positive communication that was supporting/understanding less frequently compared to the general population (21.00%), and participants *Aged 18 – 34* (5.56%) reported that more frequently.
Participants *Aged 18 – 34* (5.56%) reported positive communication that answered questions/provided information less frequently compared to the general population (18.00%), and participants in the sub-groups *Symptoms: all days* (28.57%) reported this more frequently.

Participants in the sub-groups *Symptoms: no to few days* (5.00%),and *Affect: never to almost never* (3.03%) reported negative communication that was dismissive/participant felt ignored less frequently compared to the general population (17.00%), and participants in the sub-groups *Symptoms: most days* (28.13%), and *Affect: very often to always* (29.03%) reported this more frequently.

Participants in the sub-groups *Symptoms: no to few days* (25.00%), *Social: all to most days* (30.00%), and *Aged 18 – 34* (27.78%) reported positive communication but did not elaborate more frequently compared to the general population (15.00%).

No participants in the sub-groups *Physical limitations: no days, Social: all to most days,* and *Aged 18 – 34* reported negative communication due to not enough time. Participants in the sub-group *Social: no to few days* (25.00%) reported negative communication due to not enough time more frequently than the general population (14.00%)

Positive: Supporting/understanding

They actually want to communicate with me, I don't know of any health professionals who go oh well, I actually don't care how well I communicate with my patients. Participant 11

My GP has been brilliant. He's a real lovely bedside manner and he's the one that, you know, when I'm in tears and stuff, we'll put his arm around me and hope we have and say it's all right, we'll work this out. Participant 17

And he's only a young doc too, so, um, he's, he's, he's always asking me how I'm going because I'll sort of get up and start walking in and he'll look at me and go, how's that going? So he's, he's very good. Participant 30

My rheumatologist is great. He's very smart and to the point, but he takes in everything that I've said and very quickly responds. I've found that people are giving it the time and consideration that it deserves now more than ever before. Participant 62

Positive: Answered questions/provided information

I understand that my rheumatologist has patients to get through everyday in some cases. He follows up quite well, say if I do get stuck on something and I call and leave a message with the receptionist, he will usually call me back later on to answer a question. Participant 6

Pretty good. Like, I feel like they're, they give me information that I need and it is straight forward. My rheumatologist, if I've not understood, she's been able to explain it in a different way to make sure I understood everything. Participant 7

With my rheumatologist and my GP. Yeah. I think it's been exceptional in both of those cases, both being very clear in what it is they're looking for a of the information they're telling me and the instruction if they giving me. Um, so, uh, yeah, I, I've very happy with the advice I've received from both of those. Participant 52

Negative: Dismissive/participant felt ignored

I take it for what it is. I know what he's going to say. I started to bring up in the beginning about diet and everything, and of course got shut down. I don't talk to him about that anymore. If I want to try different path, then I'll do that. I won't even bother to talk to him about it. Participant 20

Occasionally I'll show up if I've been complaining a little bit about the, the methotrexate and the side effects. And I feel like I'm a little bit spoiled now. I just want my regular life back. It's not about the choice anymore. The joints kind of all right. But it's all the other stuff that I want help with, but no one wants to help with that. So I feel a little bit ignored. Participant 24

I think that it's been a little bit lacking. Yeah. So I don't always find that the rheumatologists are very receptive to discussion or like I'll be in there for five minutes and three minutes of that is in writing more scripts. Participant 51

Positive: Does not elaborate

Quite all right. For my needs, yes. Participant 1

Oh, generally good. Participant 12

Um, it's been above average. Good. I say that. Yeah, it's, yeah, it's been above average. It hasn't been excellent, but it's been pretty good. And I suppose all I can say where that comes from is comparing it to other stories that I've heard. I feel supported in that respect. Participant 58

Negative: Not enough time

You're supposed to be checking to see how this is working, and whether it's working for me or not," and you can't even give me an appointment. Participant 35

The specialist I saw thought she knew everything and she didn't give me a choice or say, you know, we can try this, try this. She just said this is what you've got to take. She never gave me any, um, any. Um, what's the word I'm looking for? Any um, choice. Participant 8

They either, either just, yeah, there's not much information that anybody gives you when you got in here. Only have a short amount of time with your doctor. Participant 34

The GP is pretty useless to be honest. They do their six minute appointment and I need you to keep moving on. And that was very functional for someone with a chronic. Participant 61

Neither positive or negative

Overall, well, it's a mixed bag of fruit. It really is. Um, I've had people on opposite ends of the spectrum. Some people who have just been absolutely wonderful. There have been other people that have had so little understanding or, um, being very remote. Yeah. So it kind of balances out, I think. Participant 14.

Um, I've had a really mixed experience. I have done quite a bit of hands because my hands are pretty crappy, so I've had a really big mix of practitioners. Participant 82

Between one and 10? About four or five. Participant 83

Table 6.6 Healthcare professional communication

	All participants		Physical limitations: no days		Physical limitations: few days		Physical limitations: some to most days		Symptoms: no to few days		Symptoms: some days		Symptoms: most days		Symptoms: all days	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Positive: Supporting/understanding	21	21.00	5	26.32	8	18.18	8	21.62	6	30.00	7	25.93	4	12.50	4	19.05
Positive: Answered questions/provided information	18	18.00	3	15.79	9	20.45	6	16.22	5	25.00	3	11.11	4	12.50	6	28.57
Negative: Dismissive/participant felt ignored	17	17.00	3	15.79	8	18.18	6	16.22	1	5.00	4	14.81	9	28.13	3	14.29
Positive: Does not elaborate	15	15.00	4	21.05	6	13.64	5	13.51	5	25.00	3	11.11	5	15.63	2	9.52
Negative: Not enough time	14	14.00	0	0.00	8	18.18	6	16.22	1	5.00	3	11.11	5	15.63	5	23.81
Neither positive or negative	13	13.00	2	10.53	4	9.09	7	18.92	1	5.00	4	14.81	5	15.63	3	14.29

	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Positive: Supporting/understanding	21	21.00	10	30.30	7	19.44	4	12.90	2	10.00	8	22.22	11	25.00
Positive: Answered questions/provided information	18	18.00	8	24.24	5	13.89	5	16.13	5	25.00	6	16.67	7	15.91
Negative: Dismissive/participant felt ignored	17	17.00	1	3.03	7	19.44	9	29.03	3	15.00	9	25.00	5	11.36
Positive: Does not elaborate	15	15.00	6	18.18	7	19.44	2	6.45	6	30.00	4	11.11	5	11.36
Negative: Not enough time	14	14.00	6	18.18	2	5.56	6	19.35	0	0.00	3	8.33	11	25.00
Neither positive or negative	13	13.00	4	12.12	3	8.33	6	19.35	2	10.00	2	5.56	9	20.45

Table 6.6 Healthcare professional communication (Cont.)

	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Positive: Supporting/understanding	21	21.00	11	19.64	10	22.73	6	19.35	14	27.45	1	5.56
Positive: Answered questions/provided information	18	18.00	10	17.86	8	18.18	5	16.13	12	23.53	1	5.56
Negative: Dismissive/participant felt ignored	17	17.00	10	17.86	7	15.91	4	12.90	9	17.65	4	22.22
Positive: Does not elaborate	15	15.00	5	8.93	10	22.73	7	22.58	3	5.88	5	27.78
Negative: Not enough time	14	14.00	9	16.07	5	11.36	6	19.35	8	15.69	0	0.00
Neither positive or negative	13	13.00	11	19.64	2	4.55	3	9.68	6	11.76	4	22.22

	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Positive: Supporting/understanding	21	21.00	11	19.64	10	22.73	6	18.18	15	22.39	11	22.00	10	20.00
Positive: Answered questions/provided information	18	18.00	9	16.07	9	20.45	5	15.15	13	19.40	8	16.00	10	20.00
Negative: Dismissive/participant felt ignored	17	17.00	10	17.86	7	15.91	7	21.21	10	14.93	8	16.00	9	18.00
Positive: Does not elaborate	15	15.00	10	17.86	5	11.36	2	6.06	13	19.40	6	12.00	9	18.00
Negative: Not enough time	14	14.00	8	14.29	6	13.64	6	18.18	8	11.94	8	16.00	6	12.00
Neither positive or negative	13	13.00	8	14.29	5	11.36	6	18.18	7	10.45	8	16.00	5	10.00

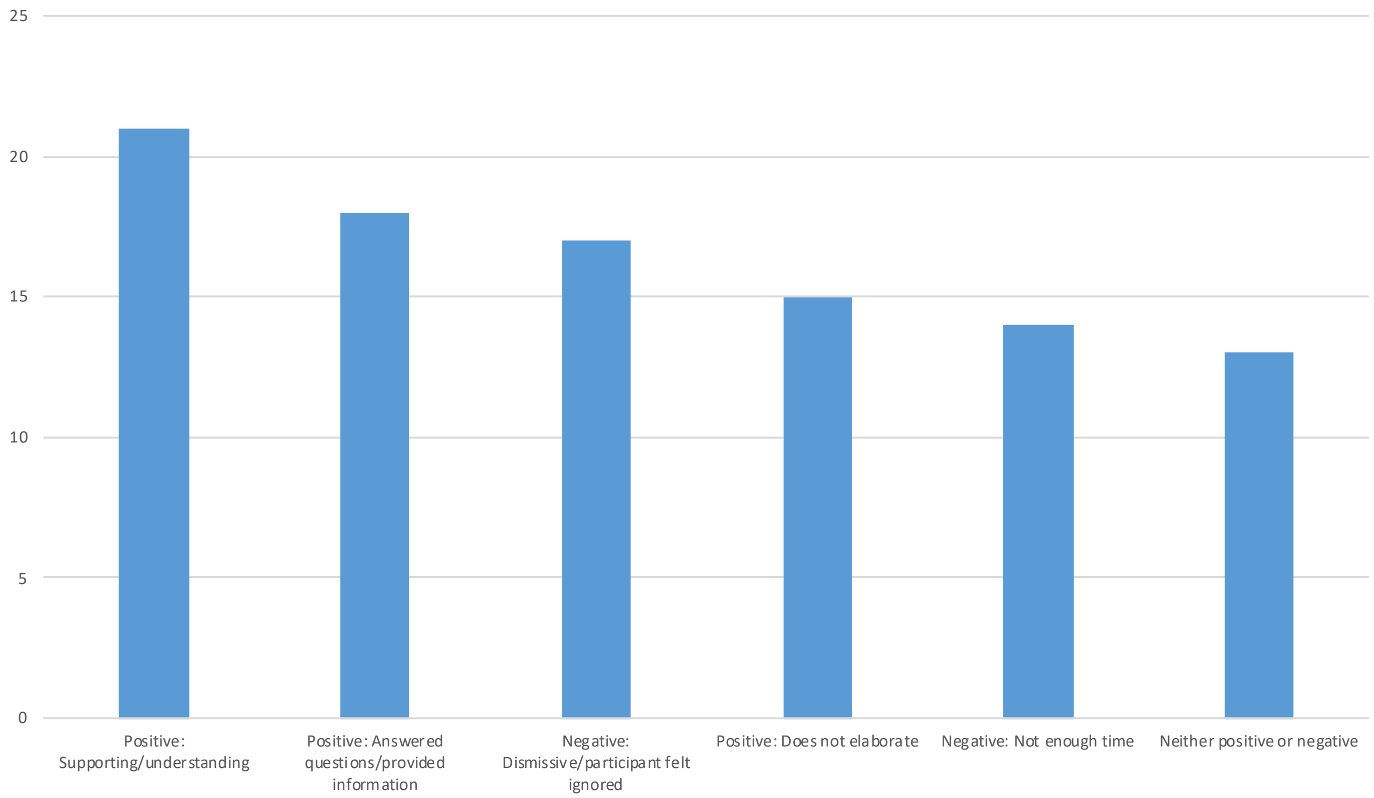


Figure 6.6 Healthcare professional communication

Knowledge and confidence

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.7. Overall, the participants scored in the top quintile for **"Partners in health: adherence to treatment"** (median =14.00, IQR = 4.00), indicating very good adherence to treatment. **"Partners in health: knowledge" (** median = 25.00, IQR = 8.00), **"Partners in health: recognition and management of symptoms"** (median = 18.00, IQR = 5.00), and "**Partners in health: total score"** (mean = 69.47, SD = 13.06) scored in the second highest quintile indicating good health outcomes. Participants scored in the middle of the scale for **"Partners in health: coping"** (mean = 13.72, SD = 5.37), indicating moderate scores.

Comparisons of Partners in health scales have been made based on **AIMS2-SF Physical scale** (Figures 6.7 to 6.11, Tables 6.8 to 6.10), **AIMS2-SF Symptoms scale** (Figures 6.12 to 2.16, Tables 6.11 to 6.15), **AIMS2-SF Affect scale** (Figures 6.17 to 6.21, Tables 6.16 to 6.20), **AIMS2-SF Social scale ,** (Figures 6.22 to 6.26, Tables 6.21 to 6.25), **Flare-up frequency** (Figures 6.27 to 6.31, (Tables 6.26 to 6.27), **Age** (Figures 6.32 to 6.36, Tables 6.28 to 6.31), **Location** (Figures 6.37 to 6.41, Tables 6.32 to 6.33), **Education** (Figures 6.42 to 6.46, Tables 6.34 to 6.35), and **SEIFA** (Figures 6.47 to 6.51, Tables 6.36 to 6.37).

Table 6.7: **"Partners in health"** summary statistics

Partners in health scale	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	24.06	5.60	25.00	8.00	0 to 32	4
Partners in health: coping*	13.72	5.37	14.00	8.00	0 to 24	3
Partners in health: recognition and management of symptoms	17.98	3.64	18.00	5.00	0 to 24	4
Partners in health: adherence to treatment	13.71	2.26	14.00	4.00	0 to 16	5
Partners in health: total score*	69.47	13.06	71.00	18.25	0 to 96	4

*** Normal distribution use Mean and SD**

Comparisons of PIH scales by AIMS2-SF Physical scale

The **AIMS2-SF Physical scale** is the Arthritis Impact Measure Scale short form physical scale. The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities ”All days”, “Most days”, “Some days”, ”Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Physical limitations: no days* (AIMS2-SF physical scale score between 0 and 2, n=19, 19.00%), *Physical limitations: few days* (AIMS2-SF physical scale score greater than 2 to 4, n=44, 44.00%), and *Physical limitations: some to most days* (AIMS2-SF physical scale score greater than 4 to 8, n=37, 37.00%).

Boxplots of each Partners in health scale by **AIMS2-SF Physical scale** are displayed in Figures 6.7 to 6.11, summary statistics are displayed in Table 6.8.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.9). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.10). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test.

No significant differences were observed between participants by **AIMS2-SF Physical scale** any of the Partners in health scales.

Table 6.8: **“Partners in health”** by **AIMS2-SF Physical** scale summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Physical limitations (no days)	19	19.00	24.00	5.16	25.00	6.50
	Physical limitations (few days)	44	44.00	23.95	6.15	24.50	8.00
	Physical limitations (some to most days)	37	37.00	24.22	5.26	25.00	7.00
Partners in health: coping	Physical limitations (no days)	19	19.00	16.21	6.00	17.00	9.00
	Physical limitations (few days)	44	44.00	13.34	5.45	13.00	8.50
	Physical limitations (some to most days)	37	37.00	12.89	4.67	13.00	6.00
Partners in health: recognition and management of symptoms	Physical limitations (no days)	19	19.00	18.79	4.12	19.00	6.50
	Physical limitations (few days)	44	44.00	17.89	3.67	18.00	5.00
	Physical limitations (some to most days)	37	37.00	17.68	3.37	18.00	4.00
Partners in health: adherence to treatment	Physical limitations (no days)	19	19.00	13.79	2.18	15.00	3.50
	Physical limitations (few days)	44	44.00	14.02	2.22	15.00	3.00
	Physical limitations (some to most days)	37	37.00	13.30	2.36	14.00	3.00
Partners in health: total score	Physical limitations (no days)	19	19.00	72.79	13.34	75.00	20.00
	Physical limitations (few days)	44	44.00	69.20	13.93	71.00	20.25
	Physical limitations (some to most days)	37	37.00	68.08	11.86	70.00	20.00

Table 6.9: **"Partners in health"** by **AIMS2-SF Physical** scale ANOVA

Partners in health scale		Sum of squares	dF	Mean Square	F	p
Coping	Between groups	149.50	2	74.77	2.68	0.0738
	Within groups	2708.60	97	27.92		
	Total	2858.10	99			
Total score	Between groups	284.00	2	141.9	0.83	0.4400
	Within groups	16611.00	97	171.2		
	Total	16895.00	99			

Table 6.10: **"Partners in health"** by **AIMS2-SF Physical** scale Kruskal-Wallis test

Partners in health scale	X^2	df	p
Knowledge	0.04	2	0.9808
Recognition and management of symptoms	1.10	2	0.5757
Adherence to treatment	2.36	2	0.3080

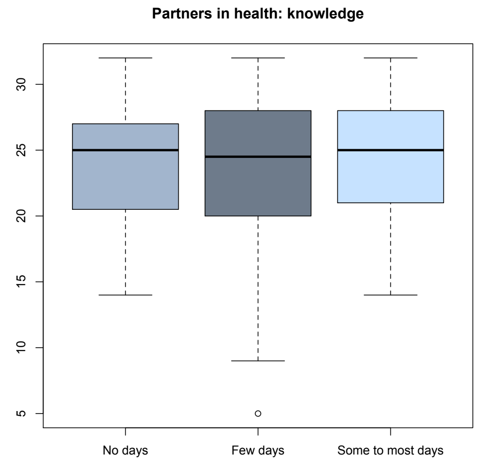


Figure 6.7: **"Partners in health: knowledge"** by **AIMS2-SF Physical**

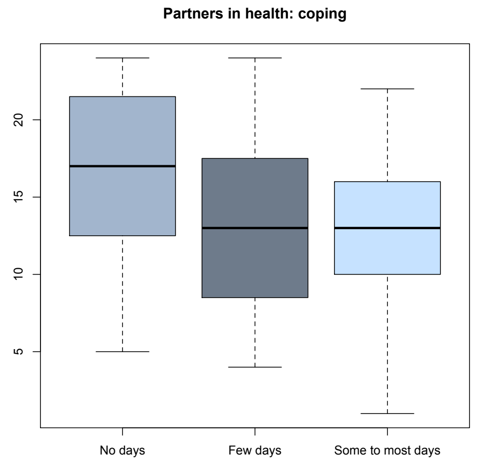


Figure 6.8: **"Partners in health: coping"** by **AIMS2-SF Physical**

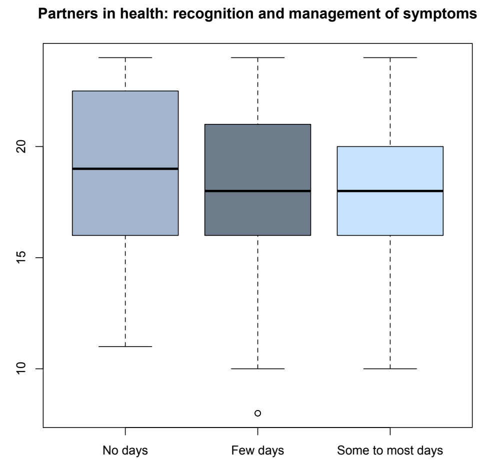


Figure 6.9: **"Partners in health: recognition and management of symptoms"** by **AIMS2-SF Physical**

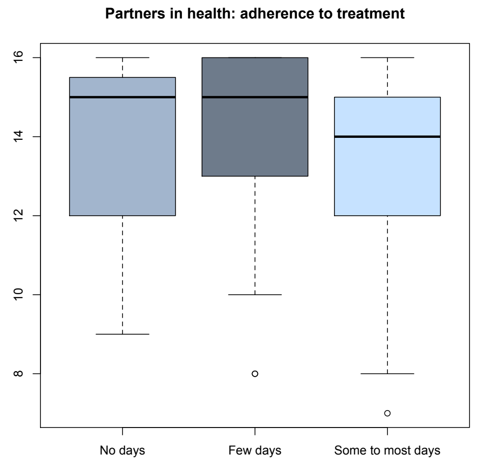


Figure 6.10: **"Partners in health: adherence to treatment"** by **AIMS2-SF Physical**

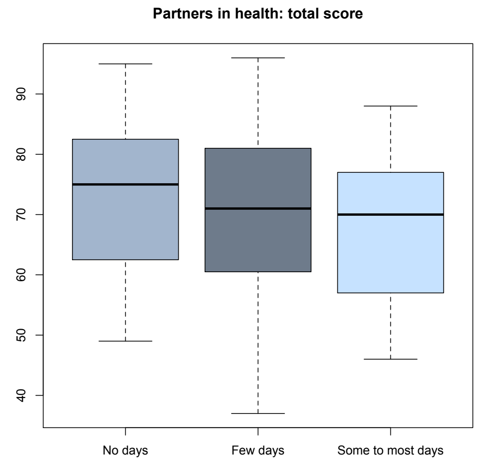


Figure 6.11: **"Partners in health: total score"** by **AIMS2-SF Physical**

Comparisons of PIH scales by AIMS2-SF Symptoms scale

The **AIMS2-SF Symptoms scale** is the Arthritis Impact Measure Scale short form symptoms scale. The symptoms scale is comprised of 3 questions about frequency of pain and stiffness "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Symptoms: no to few days* (AIMS2-SF symptoms scale score between 0 and 4, n=20, 20.00%), *Symptoms: some days* (AIMS2-SF symptoms scale score greater than 4 to 6, n=27, 27.00%), *Symptoms: most days* (AIMS2-SF symptoms scale score greater than 6 to 8, n=32, 32.00%), and Symptoms: all days (AIMS2-SF symptoms scale score greater than 8 to 10, n=21, 21.00%),

Boxplots of each Partners in health scale by **AIMS2-SF Symptoms scale** are displayed in Figures 6.12 - 2.16, summary statistics are displayed in Table 6.11.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.12). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 6.13). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.14). When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances (Table 6.15).

A one way ANOVA test indicated a statistically significant difference in the **"Partners in health: coping"** scale between groups, F(3, 96) = 3.21 ,p = 0.0230 (Table 6.12). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Symptoms: no to few days* (mean =16.30, SD = 5.41) was significantly higher than participants that scored *Symptoms: most days* (mean = 11.75, SD = 4.70, p=0.0144).

The **"Partners in health: coping"** median scores for participants that scored *Symptoms: no to few days* were significantly better than those that scored *Symptoms: most days* These scores correspond to role limitations due to physical functioning that is in the very good range for participants that scored *Symptoms: no to few days,* and moderate scores for participants that scored *Symptoms: most days.*

Table 6.11: **"Partners in health"** by **AIMS2-SF Symptoms** scale summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Symptoms (no to few days)	20.00	20.00	23.45	4.70	24.50	7.00
	Symptoms (some days)	27.00	27.00	24.96	6.27	26.00	9.00
	Symptoms (most days)	32.00	32.00	24.03	4.99	24.50	8.00
	Symptoms (all days)	21.00	21.00	23.52	6.53	24.00	4.00
Partners in health: coping	Symptoms (no to few days)	20.00	20.00	16.30	5.41	17.50	8.25
	Symptoms (some days)	27.00	27.00	14.33	5.36	15.00	8.50
	Symptoms (most days)	32.00	32.00	11.75	4.70	12.50	6.25
	Symptoms (all days)	21.00	21.00	13.48	5.49	14.00	5.00
Partners in health: recognition and management of symptoms	Symptoms (no to few days)	20.00	20.00	17.90	4.89	18.00	6.50
	Symptoms (some days)	27.00	27.00	18.67	3.54	19.00	5.00
	Symptoms (most days)	32.00	32.00	17.84	2.73	18.00	3.25
	Symptoms (all days)	21.00	21.00	17.38	3.73	18.00	5.00
Partners in health: adherence to treatment	Symptoms (no to few days)	20.00	20.00	13.90	2.34	15.00	4.00
	Symptoms (some days)	27.00	27.00	14.22	2.10	15.00	2.50
	Symptoms (most days)	32.00	32.00	13.09	2.44	13.00	4.00
	Symptoms (all days)	21.00	21.00	13.81	2.04	14.00	2.00
Partners in health: total score	Symptoms (no to few days)	20.00	20.00	71.55	12.87	73.50	16.75
	Symptoms (some days)	27.00	27.00	72.19	14.55	77.00	22.00
	Symptoms (most days)	32.00	32.00	66.72	11.07	66.50	14.25
	Symptoms (all days)	21.00	21.00	68.19	13.93	70.00	24.00

Table 6.12: **“Partners in health”** by **AIMS2-SF Symptoms** scale ANOVA

Partners in health scale		Sum of squares	dF	Mean Square	F	p
Coping	Between groups	268.70	3	89.57	3.32	0.0230*
	Within groups	2589.40	96	26.97		
	Total	2858.10	99			
Total score	Between groups	562.00	3	187.40	1.10	0.3520
	Within groups	16333.00	96	170.10		
	Total	16895.00	99			

*Statistically significant at p<0.05

Table 6.13: **“Partners in health” by AIMS2-SF Symptoms** scale Tukey HSD test

Partners in health scale	AIMS2-SF Symptoms	Difference	Lower	Upper	P adjusted
Coping	*Some days - No to few days*	-1.97	-5.97	2.04	0.5756
	Most days - No to few days	-4.55	-8.42	-0.68	0.0144*
	All days - No to few days	-2.82	-7.07	1.42	0.3088
	Most days-Some days	-2.58	-6.13	0.97	0.2334
	All days - Some days	-0.86	-4.81	3.09	0.9416
	All days – Most days	1.72	-2.09	5.54	0.6387

*Statistically significant at p<0.05

Table 6.14: **“Partners in health”** by **AIMS2-SF Symptoms** scale Kruskal-Wallis test

Partners in health	X^2	df	p
Knowledge	1.68	3	0.6419
Adherence to treatment	4.13	3	0.2479

Table 6.15: **“Partners in health”** by **AIMS2-SF Symptoms** scale Welch one-way test

Partners in health scale	F	dF1	dF2	p
Recognition and management of symptoms	0.53	3.00	46.37	0.6629

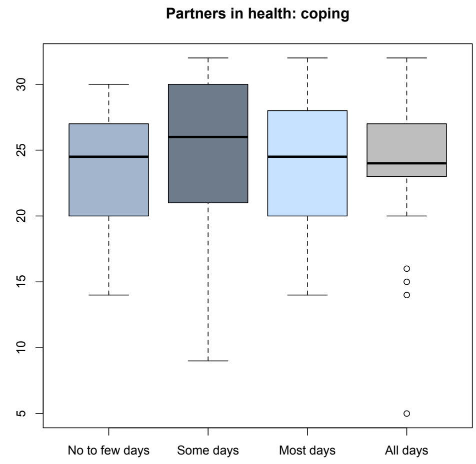


Figure 6.12: **"Partners in health: knowledge"** by **AIMS2-SF Symptoms**

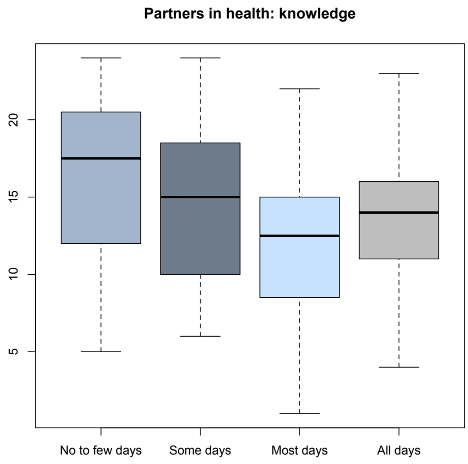


Figure 6.13: **"Partners in health: coping"** by **AIMS2-SF Symptoms**

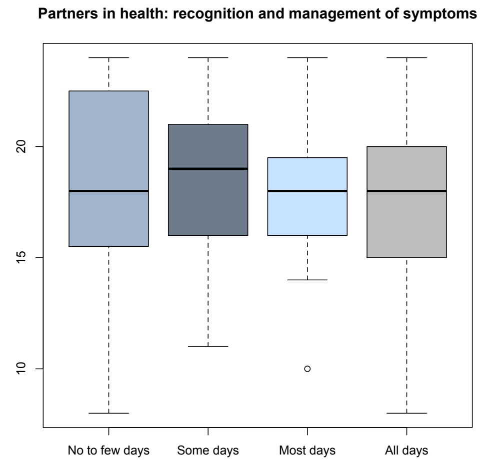


Figure 6.14: **"Partners in health: recognition and management of symptoms"** by **AIMS2-SF Symptoms**

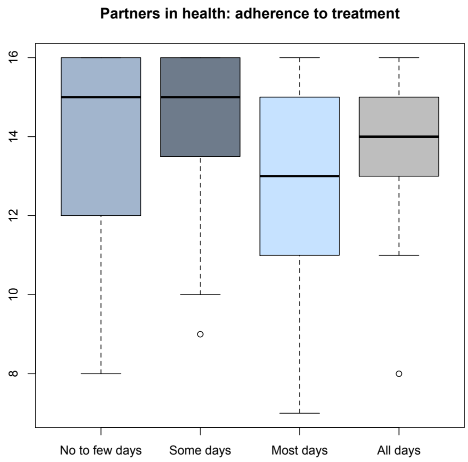


Figure 6.15: **"Partners in health: adherence to treatment"** by **AIMS2-SF Symptoms**

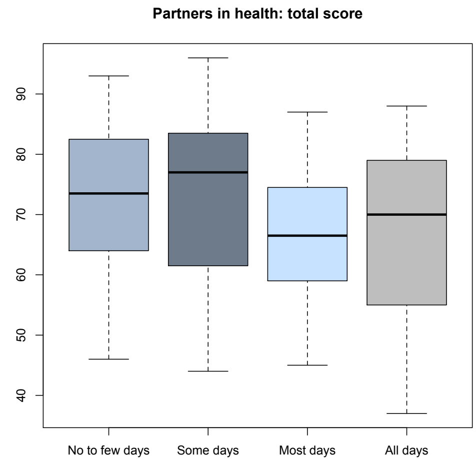


Figure 6.16: **"Partners in health: total score"** by **AIMS2-SF Symptoms**

Comparisons of PIH scales by AIMS2-SF Affect scale

The **AIMS2-SF Affect scale** is the Arthritis Impact Measure Scale short form affect scale. The affect scale is comprised of 5 questions about experience of anxiety, depression and burden “Always”, “Very often”, “Some times”, ”Almost never” or “Never”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Affect: never to almost never* (AIMS2-SF affect scale score between 0 and 4, n=33, 33.00%), *Affect: sometimes* (AIMS2-SF Affect scale score greater than 4 to 6, n=36, 36.00%), *Affect: very often to always* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and Symptoms: all days (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%).

Boxplots of each Partners in health scale by **AIMS2-SF Affect scale** are displayed in Figures 6.17-2.21, summary statistics are displayed in Table 6.16

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.17). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 6.18). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.19). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 6.20).

A one way ANOVA test indicated a statistically significant difference in the **“Partners in health: coping”** scale between groups, F(2, 97) = 4.34, p = 0.0157 (Table 6.17). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never to almost* (mean = 15.85, SD = 5.17) was significantly higher than participants that scored *Affect: very often to always* (mean = 12.23, SD = 5.74, p=0.0175).

A Kruskal-Wallis test indicated a statistically significant difference in the **“Partners in health: total score”** scale between groups, X^2 (2) = 7.25, P=0.0266 (Table 6.17). Post hoc comparisons using Wilcoxon rank sum test indicated that the median score for those that scored *Affect: never to almost* (mean = 75.00, IQR = 17.00) was significantly higher than participants that scored *Affect: very often to always* (median = 67.00, IQR = 21.00, p=0.0310).

The **“Partners in health: coping”** mean scores for participants that scored *Affect: very often to always* were significantly higher than those that scored *Affect: never to almost never.* These scores correspond to moderate pain for both groups of participants.

The **“Partners in health: total score”** median scores for participants that scored *Affect: very often to always* were significantly higher than those that scored *Affect: never to almost never.* These scores correspond to good knowledge and confidence for managing their own health, for both groups.

Table 6.16: **"Partners in health"** by **AIMS2-SF Affect** scale summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Affect: never to almost never	33	33.00	25.42	5.65	27.00	7.00
	Affect: sometimes	36	36.00	24.22	5.34	25.00	8.25
	Affect: very often to always	31	31.00	22.42	5.58	24.00	6.00
Partners in health: coping	Affect: never to almost never	33	33.00	15.85	5.17	16.00	7.00
	Affect: sometimes	36	36.00	13.06	4.71	13.00	6.00
	Affect: very often to always	31	31.00	12.23	5.74	12.00	9.00
Partners in health: recognition and management of symptoms	Affect: never to almost never	33	33.00	18.67	3.66	18.00	6.00
	Affect: sometimes	36	36.00	17.56	4.02	18.00	4.25
	Affect: very often to always	31	31.00	17.74	3.11	18.00	4.00
Partners in health: adherence to treatment	Affect: never to almost never	33	33.00	14.42	1.89	15.00	2.00
	Affect: sometimes	36	36.00	13.58	2.32	14.00	4.00
	Affect: very often to always	31	31.00	13.10	2.41	14.00	3.50
Partners in health: total score	Affect: never to almost never	33	33.00	74.36	12.72	75.00	17.00
	Affect: sometimes	36	36.00	68.42	12.18	68.50	19.00
	Affect: very often to always	31	31.00	65.48	13.17	67.00	21.00

Table 6.17: **"Partners in health"** by **AIMS2-SF Affect** scale ANOVA

Partners in health scale		Sum of squares	dF	Mean Square	F	p
Coping	Between groups	234.60	2	117.30	4.34	0.0157*
	Within groups	2623.60	97	27.05		
	Total	2858.20	99			

*Statistically significant at p<0.05

Table 6.18: **"Partners in health"** by **AIMS2-SF Affect** scale Tukey HSD test

Partners in health scale	AIMS2-SF Symptoms	Difference	Lower	Upper	P adjusted
Coping	*Sometimes - Never to almost never*	-2.79	-5.78	0.19	0.0715
	Very often to always -Never to almost never	-3.62	-6.72	-0.53	0.0175*
	Very often to always - Sometimes	-0.83	-3.86	2.20	0.7921

*Statistically significant at p<0.05

Table 6.19: **"Partners in health"** by **AIMS2-SF Affect** scale Kruskal-Wallis test

Partners in health scale	X^2	df	p
Knowledge	5.55	2	0.0624
Recognition and management of symptoms	1.30	2	0.5219
Adherence to treatment	5.78	2	0.0556
Total score	7.25	2	0.0266*

*Statistically significant at p<0.05

Table 6.20: **"Partners in health"** by **AIMS2-SF Affect** scale Wilcoxon rank sum test

Partners in health scale	AIMS2-SF Affect scale	Never to almost never	Sometimes
Total score	*Sometimes*	0.0900	
	Very often to always	0.0310*	0.3720

*Statistically significant at p<0.05

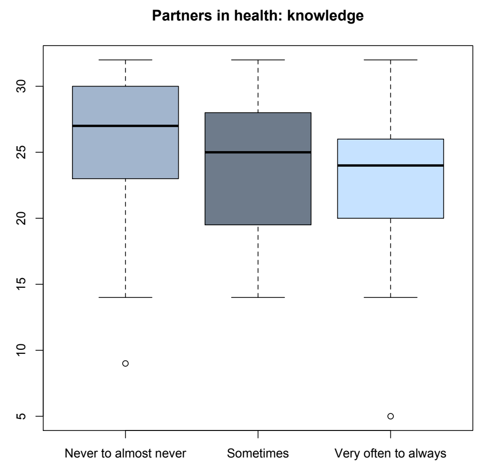


Figure 6.17: **"Partners in health: knowledge"** by **AIMS2-SF Affect**

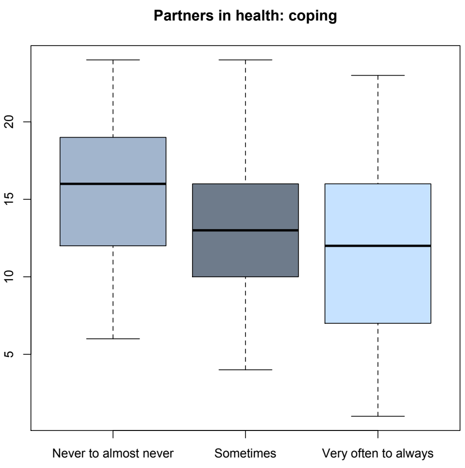


Figure 6.18: **"Partners in health: coping"** by **AIMS2-SF Affect**

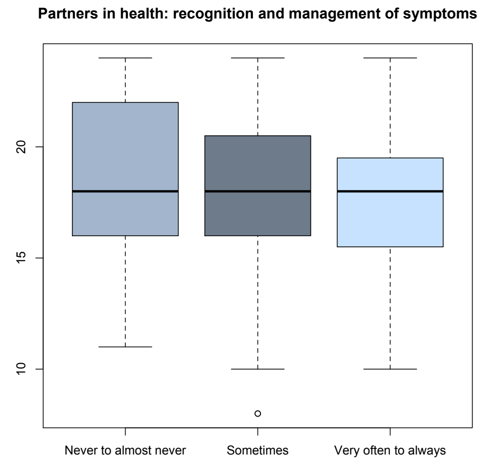


Figure 6.19: **"Partners in health: recognition and management of symptoms"** by **AIMS2-SF Affect**

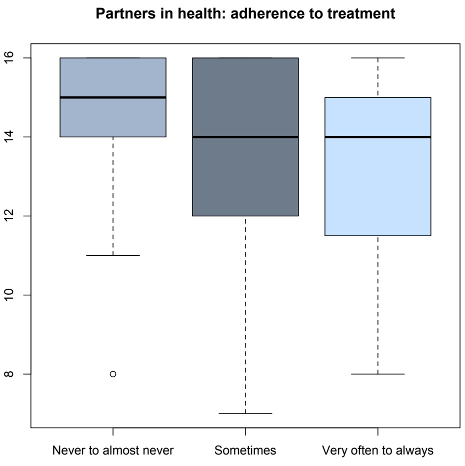


Figure 6.20**: "Partners in health: adherence to treatment"** by **AIMS2-SF Affect**

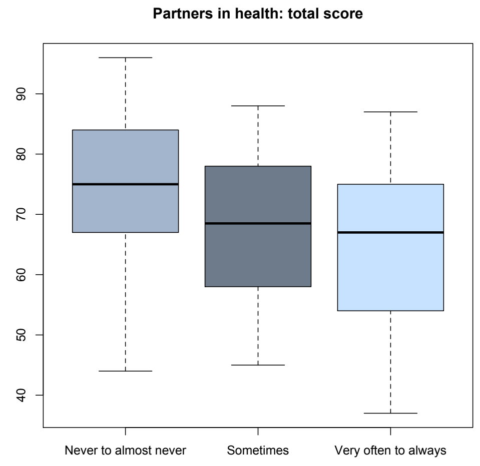


Figure 6.21**: "Partners in health: total score"** by **AIMS2-SF Affect**

Comparisons of PIH scales by AIMS2-SF Social scale

The **AIMS2-SF Social scale** is the Arthritis Impact Measure Scale short form social scale. The social scale is comprised of 4 questions about frequency of social interactions "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Social: all to most days* (AIMS2-SF social scale score between 0 and 4, n=20, 20.00%), *Social; some days* (AIMS2-SF Social scale score greater than 4 to 6, n=36, 36.00%), and *Social; few to no days* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and *Social: all days* (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%).

Boxplots of each Partners in health scale by **AIMS2-SF Social scale** are displayed in Figures 6.22 to 6.26, summary statistics are displayed in Table 6.21.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.22). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 6.23). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.24). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 6.50).
A one way ANOVA test indicated a statistically significant difference in the **"Partners in health: coping"** scale between groups, F(2, 97) = 4.16, p = 0.0185 (Table 6.22). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 16.40, SD = 5.99) was significantly higher than participants that scored *Social: no to few days* (mean = 12.36 , SD = 5.41, p=0.0137).

A one way ANOVA test indicated a statistically significant difference in the **"Partners in health: recognition and management of symptoms"** scale between groups, F(2, 97) = 6.28, p = 0.0027 (Table 6.22). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 20.00, SD = 3.03) was significantly higher than participants that scored *Social: no to few days* (mean = 16.77 , SD = 4.18, p=0.0023).

A one way ANOVA test indicated a statistically significant difference in the **"Partners in health: total score"** scale between groups, F(2, 97) = 7.90, p = 0.0007 (Table 6.22). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 77.30, SD = 13.28) was significantly higher than participants that scored *Social: no to few days* (mean = 64.59 , SD = 12.64, p=0.0006).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Partners in health: knowledge"** scale between groups, $\chi^2(2) = 12.73$, p = 0.0017 (Table 2.24). Wilcoxon rank sum tests between groups indicated that those that scored *Social: all to most days* (median = 27.00, IQR = 5.25) scored significantly higher than those that scored *Social: some days* (median = 25.50, IQR = 9.00, p=0.0333) and *Social: no to few days* (median =23.00, IQR = 7.25, p=0.0021).

The **"Partners in health: knowledge"** median scores for participants that scored *Social: all to most days* were significantly higher than those that scored *Social: some days* and *Social: no to few days.* These scores correspond to very good knowledge about their condition for participants that scored *Social: all to most days,* and good knowledge for participants that scored *Social: some days* and *Social: no to few days.*

The **"Partners in health: coping"** mean scores for participants that scored *Social: all to most days* were significantly higher than those that scored *Social: no to few days.* These scores correspond to good coping for participants that scored *Social: all to most days* and moderate coping for participants that scored *Social: no to few days*

The **"Partners in health: recognition and management of symptoms"** mean scores for participants that scored *Social: all to most days* were significantly higher than those that scored *Social: no to few days.* These scores correspond to very good recognition and management of symptoms for participants that scored *Social: all to most days* and good recognition and management of symptoms for participants that scored *Social: no to few days.*

The **"Partners in health: total score"** mean scores for participants that scored *Social: all to most days* were significantly lower than those that scored *Social: no to few days.* These scores correspond to very good knowledge and confidence for managing their own health for participants that scored *Social: all to most days* and good knowledge and confidence for managing their own health for participants that scored *Social: no to few days.*

Table 6.21: **"Partners in health"** by **AIMS2-SF Social** scale summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Social: all to most days	20	20.00	26.55	5.89	27.00	5.25
	Social: some days	36	36.00	24.86	5.49	25.50	9.00
	Social: no to few days	44	44.00	22.27	5.05	23.00	7.25
Partners in health: coping	Social: all to most days	20	20.00	16.40	5.99	16.50	10.00
	Social: some days	36	36.00	13.89	4.45	14.00	4.50
	Social: no to few days	44	44.00	12.36	5.41	13.00	8.50
Partners in health: recognition and management of symptoms	Social: all to most days	20	20.00	20.00	3.03	20.50	4.50
	Social: some days	36	36.00	18.33	2.59	18.00	5.00
	Social: no to few days	44	44.00	16.77	4.18	17.00	5.00
Partners in health: adherence to treatment	Social: all to most days	20	20.00	14.35	1.95	15.00	2.25
	Social: some days	36	36.00	14.00	2.15	14.00	3.00
	Social: no to few days	44	44.00	13.18	2.40	14.00	3.25
Partners in health: total score	Social: all to most days	20	20.00	77.30	13.28	80.00	15.00
	Social: some days	36	36.00	71.08	11.10	72.00	13.75
	Social: no to few days	44	44.00	64.59	12.64	63.50	21.50

Table 6.22: **"Partners in health"** by **AIMS2-SF Social** scale ANOVA

Partners in health scale11		Sum of squares	dF	Mean Square	F	p
Coping	Between groups	225.60	2	112.81	4.16	0.0185 *
	Within groups	2632.50	97	27.14		
	Total	2858.10	99			
Recognition and management of symptoms	Between groups	150.20	2	75.12	6.28	0.0027 *
	Within groups	1159.70	97	11.96		
	Total	1309.90	99			
Total score	Between groups	2367.00	2	1183.70	7.90	0.0007*
	Within groups	14528.00	97	149.8		
	Total	16895.00	99			

*Statistically significant at p<0.05

Table 6.23: **"Partners in health"** by **AIMS2-SF Social** scale Tukey HSD test

Partners in health scale	AIMS2-SF Symptoms	Difference	Lower	Upper	P adjusted
Coping	*Some days - All to most days*	-2.51	-5.97	0.95	0.1999
	No to few days - All to most days	-4.04	-7.38	-0.69	0.0137*
	No to few days – Some days	-1.53	-4.31	1.26	0.3971
Recognition and management of symptoms	*Some days - All to most days*	-1. 67	-3.96	0.63	0.1999
	No to few days - All to most days	-3.23	-5.45	-1.01	0.0023*
	No to few days – Some days	-1.56	-3.41	0.289	0.1156
Total score	*Some days - All to most days*	-6.22	-14.34	1.91	0.1680
	No to few days - All to most days	-12.71	-20.56	-4.85	0.0006*
	No to few days – Some days	-6.49	-13.04	0.05	0.0524

*Statistically significant at $p<0.05$

Table 6.24: **"Partners in health"** by **AIMS2-SF Social** scale Kruskal-Wallis test

Partners in health scale	X^2	df	p
Knowledge	12.73	2	0.0017*
Adherence to treatment	4.72	2	0.0946

*Statistically significant at $p<0.05$

Table 6.25: **"Partners in health"** by **AIMS2-SF Social** scale Wilcoxon rank sum test

Partners in health scale	AIMS2-SF Social scale	*All to most days*	*Some days*
Knowledge	*Some days*	0.1674	
	No to few days	0.0021*	0.0333*

*Statistically significant at $p<0.05$

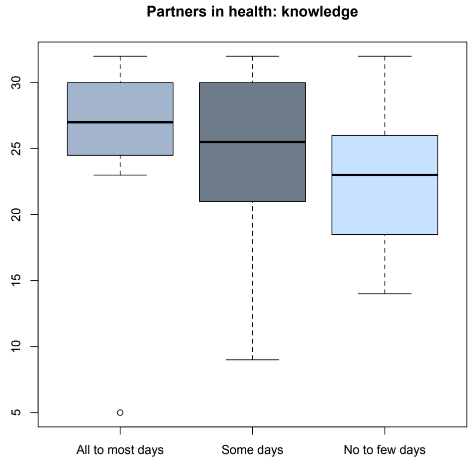


Figure 6.22: **"Partners in health: knowledge"** by **AIMS2-SF Social**

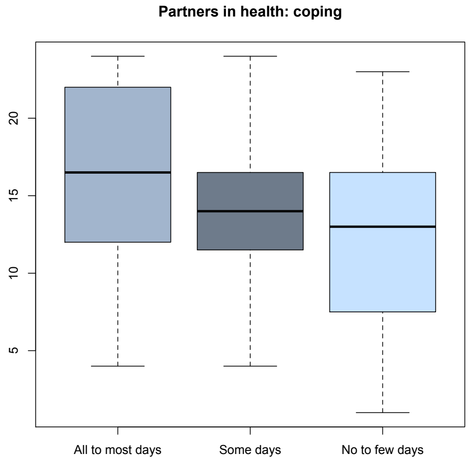


Figure 6.23**: "Partners in health: coping"** by **AIMS2-SF Social**

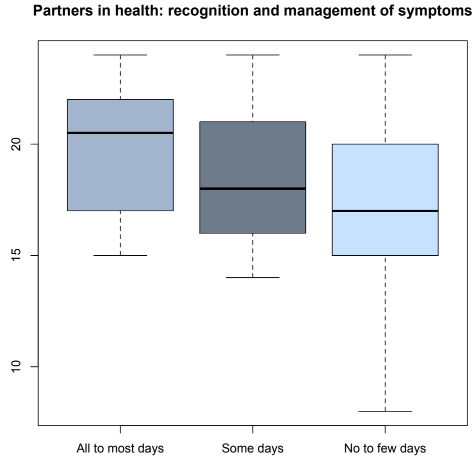


Figure 6.24: **"Partners in health: recognition and management of symptoms"** by **AIMS2-SF Social**

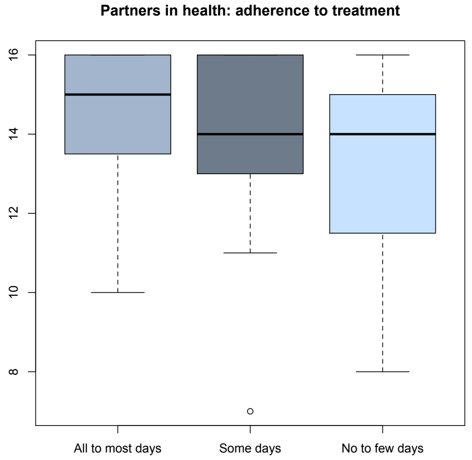


Figure 6.25: **"Partners in health: adherence to treatment"** by **AIMS2-SF Social**

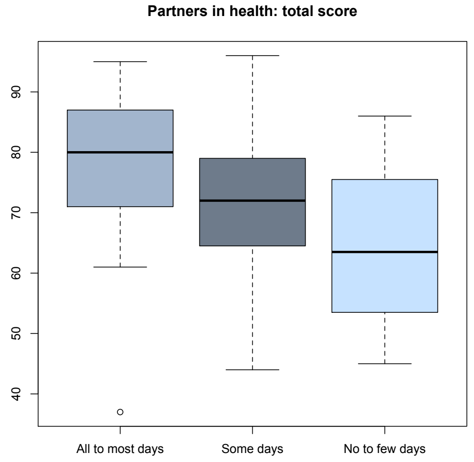


Figure 6.26: **"Partners in health: total score"** by **AIMS2-SF Social**

Comparisons of PIH scales by Flare-up frequency

Comparisons were made by **Flare-up frequency**, between participants that had *frequent flare-ups* (daily or weekly flare-ups, n=44, 44.00%) and participants that had *occasional flare-ups* (monthly flare-ups or less frequently, n=56, 56.00%).

Boxplots of each Partners in health scale by **Flare-up frequency** are displayed in Figures 6.27 to 6.31, summary statistics are displayed in Tables 6.27 to 6.28.

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.27), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.28).

No significant differences were observed between participants by **Flare-up frequency** any of the Partners in health scales.

Table 6.26: **"Partners in health"** by **Flare-up frequency** two sample t-test

Partners in health scale	Group	Count	Percent	Mean	SD	t	dF	p
Partners in health: total score	Occasional flare up	56	56.00	70.75	13.06	1.11	98	0.2712
	Frequent flare up	44	44.00	67.84	13.03			

Table 6.27: **"Partners in health"** by **Flare-up frequency** Wilcoxon rank sum test

Partners in health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	Occasional flare-up	56	56.00	25.50	7.25	1298.00	0.6485
	Frequent flare-up	44	44.00	24.50	8.00		
Partners in health: coping	Occasional flare-up	56	56.00	15.00	8.25	1352.50	0.4038
	Frequent flare-up	44	44.00	13.00	7.00		
Partners in health: recognition and management of symptoms	Occasional flare-up	56	56.00	18.00	5.00	1433.00	0.1616
	Frequent flare-up	44	44.00	17.50	4.00		
Partners in health: adherence to treatment	Occasional flare-up	56	56.00	14.00	4.00	1410.00	0.2089
	Frequent flare-up	44	44.00	15.00	4.00		

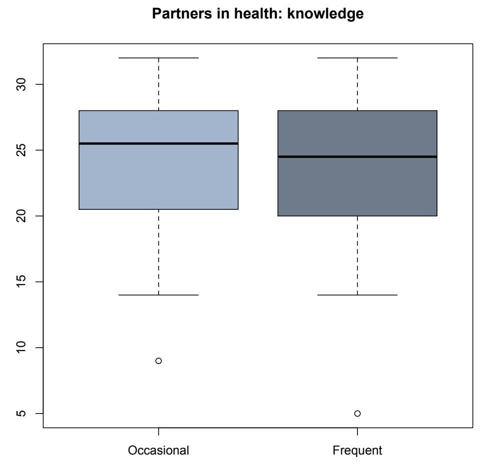


Figure 6.27: **"Partners in health: knowledge"** by **Flare-up frequency**

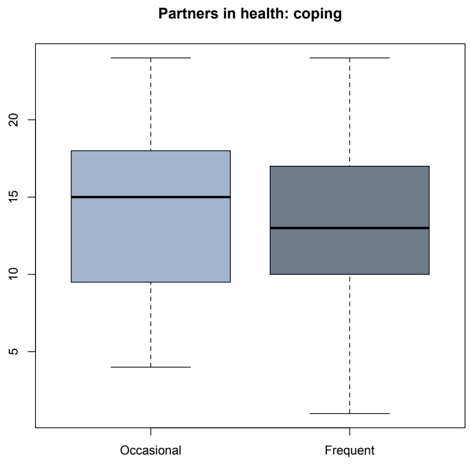


Figure 6.28: **"Partners in health: coping"** by **Flare-up frequency**

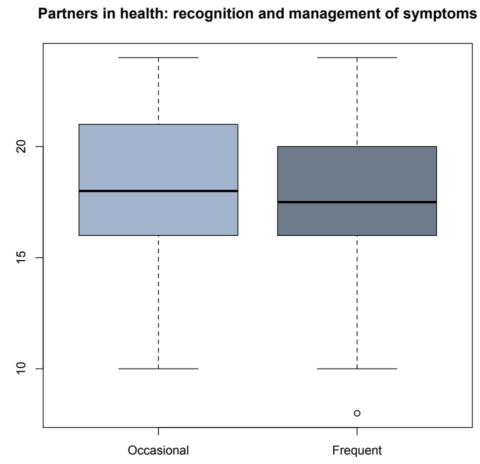


Figure 6.29**: "Partners in health: recognition and management"** of symptoms by **Flare-up frequency**

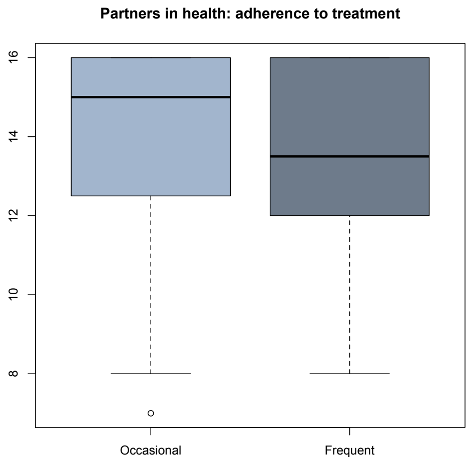


Figure 6.30: **"Partners in health: adherence"** to treatment by **Flare-up frequency**

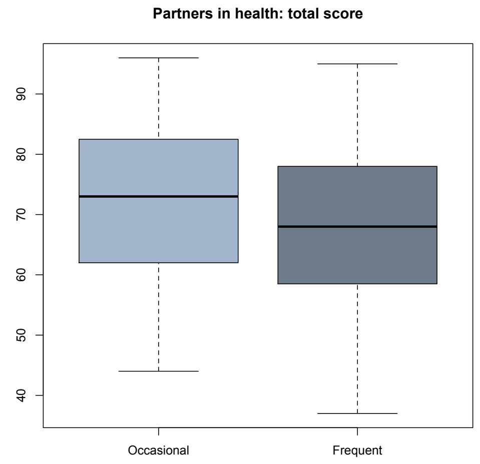


Figure 6.31: **"Partners in health: total score"** by **Flare-up frequency**

Comparisons of PIH scales by age

Comparisons were made by the **Age** of the participants, those that were *aged 55 or older* (n=31, 31.00%), aged 35 – 54 (n=51, 51.00%) and participants aged 18 – 34 (n=18, 18.00%) .

Boxplots of each SF36 scale by **Age** are displayed in Figures 6.32 to 6.36, summary statistics are displayed in Table 6.28

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.29). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.30). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 6.31).

A Kruskal-Wallis test indicated a statistically significant difference in the **“Partners in health: recognition and management of symptoms”** scale between groups, $\chi^2(2) = 6.01$, $p = 0.00494$ (Table 6.30). Post-hoc Wilcoxon rank sum tests between groups did not indicate any statistically significant differences between groups.

No significant differences were observed between participants by **Age** any of the Partners in health scales.

Table 6.28: **“Partners in health”** by **Age** summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Aged 18 -34	18	31.00	24.56	4.41	24.00	5.50
	Aged 35 - 44	51	51.00	23.37	5.44	24.00	8.00
	Aged 55 or older	31	18.00	24.90	6.42	26.00	7.50
Partners in health: coping	Aged 18 -34	18	31.00	15.39	6.78	17.00	10.75
	Aged 35 - 44	51	51.00	13.22	5.08	13.00	8.00
	Aged 55 or older	31	18.00	13.58	4.91	14.00	4.00
Partners in health: recognition and management of symptoms	Aged 18 -34	18	31.00	19.11	3.01	18.50	4.75
	Aged 35 - 44	51	51.00	17.20	3.66	17.00	5.00
	Aged 55 or older	31	18.00	18.61	3.75	18.00	4.00
Partners in health: adherence to treatment	Aged 18 -34	18	31.00	13.28	1.81	13.50	3.50
	Aged 35 - 44	51	51.00	13.55	2.36	14.00	3.50
	Aged 55 or older	31	18.00	14.23	2.31	16.00	3.00
Partners in health: total score	Aged 18 -34	18	31.00	72.33	12.45	74.50	20.50
	Aged 35 - 44	51	51.00	67.33	12.89	68.00	18.00
	Aged 55 or older	31	18.00	71.32	13.50	75.00	16.00

Table 6.29: **“Partners in health”** by **Age** ANOVA test

Partners in health		Sum of squares	dF	Mean Square	F	p
Coping	Between groups	63.70	2	31.85	1.106	0.3350
	Within groups	2794.50	97	28.81		
	Total	2858.20	99			
Total score	Between groups	487.00	2	243.40	1.44	0.2420
	Within groups	16408.00	97	169.20		
	Total	16895.00	99			

Table 6.30: **“Partners in health”** by **Age** Kruskal-Wallis test

Partners in health scale	X^2	dF	p
Knowledge	2.55	2	0.2797
Recognition and management of symptoms	6.01	2	0.0494*
Adherence to treatment	4.93	2	0.0851

*Statistically significant at p<0.05

Table 6.31: **“Partners in health”** by **Age** Wilcoxon rank sum test

Partners in health scale	AIMS2-SF Social scale	*Aged 18 to 34*	*Aged 35 to 54*
Recognition and management of symptoms	*Aged 35 to 54*	0.0800	
	Aged 55 and older	0.9900	0.0800

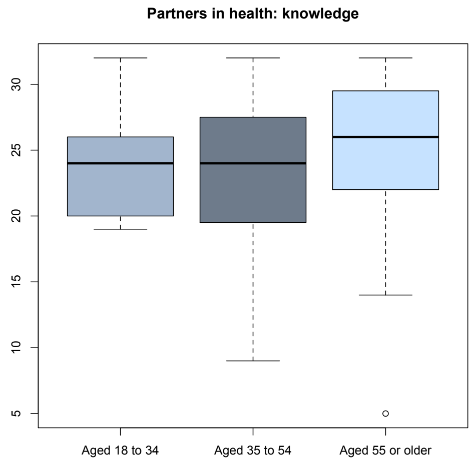


Figure 6.32: “**Partners in health: knowledge**” by **Age**

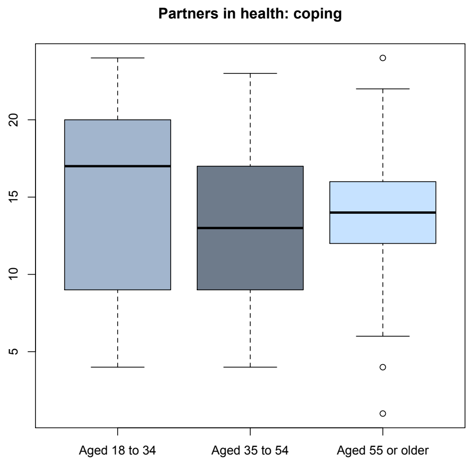


Figure 6.33: **“Partners in health: coping”** by **Age**

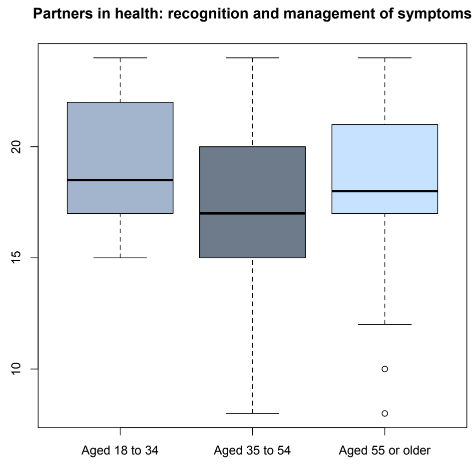


Figure 6.34: **“Partners in health: recognition and management” of symptoms”** by **Age**

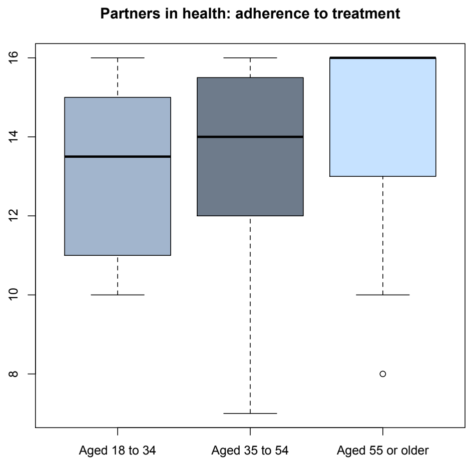


Figure 6.35: **“Partners in health: adherence” to treatment”** by **Age**

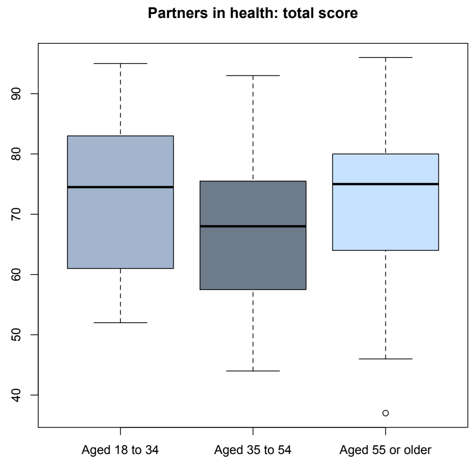


Figure 6.36: **“Partners in health: total score”** by **Age**

Comparisons of PIH scales by location

The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from DoctorConnect (doctorconnect.gov.au), those living in a metropolitan area, *metropolitan* (n=56, 56.00%) were compared to those living in regional/rural areas, *regional or remote* (n=44, 44.00%).

Boxplots of each Partners in health scale by **Location** are displayed in Figures 6.37-2.41, summary statistics are displayed in Tables 6.32 to 6.33 . A two-sample t-test was used when assumptions for normality and variance were met (Table 6.32), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.33).

No significant differences were observed between participants that lived in *metropolitan* areas compared to those that lived in an *regional or remote* areas for any of the Partners in health scales.

Table 6.32: **"Partners in health"** by **Location** two sample t-test

Partners in health scale	Group	Count	Percent	Mean	SD	t	dF	p
Partners in health: coping	Metropolitan	56	56.00	13.63	5.61	-0.20	98	0.8431
	Regional or remote	44	44.00	13.84	5.12			
Partners in health: total score	Metropolitan	56	56.00	69.96	13.21			
	Regional or remote	44	44.00	68.84	12.99	0.4251	98	0.6717

Table 6.33: **"Partners in health"** by **Location** Wilcoxon rank sum test

Partners in health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	Metropolitan	56	56.00	24.50	8.50	1327.00	0.5107
	Regional or remote	44	44.00	25.00	7.25		
Partners in health: recognition and management of symptoms	Metropolitan	56	56.00	18.00	5.00	1389.50	0.2731
	Regional or remote	44	44.00	18.00	4.00		
Partners in health: adherence to treatment	Metropolitan	56	56.00	14.00	4.00	1196.50	0.8043
	Regional or remote	44	44.00	14.00	3.25		

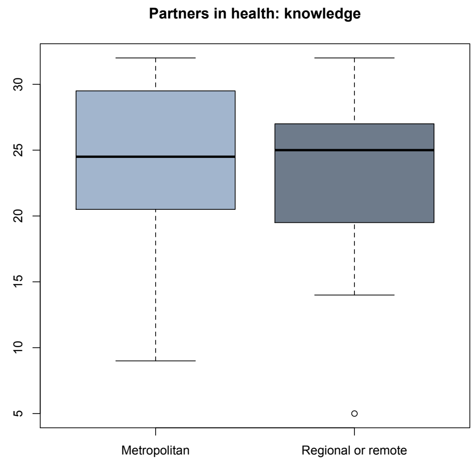


Figure 6.37: **“Partners in health: knowledge”** by **Location**

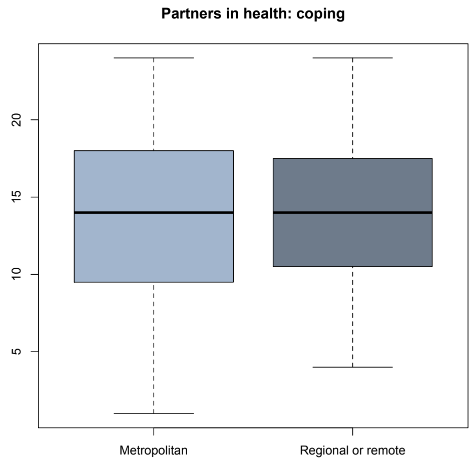


Figure 6.38: **“Partners in health: coping”** by **Location**

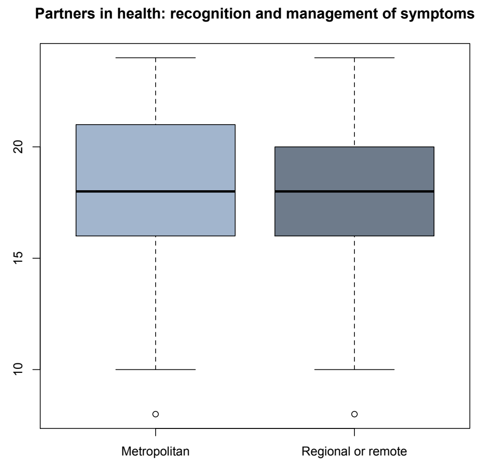


Figure 6.39: **“Partners in health: recognition and management of symptoms”** by **Location**

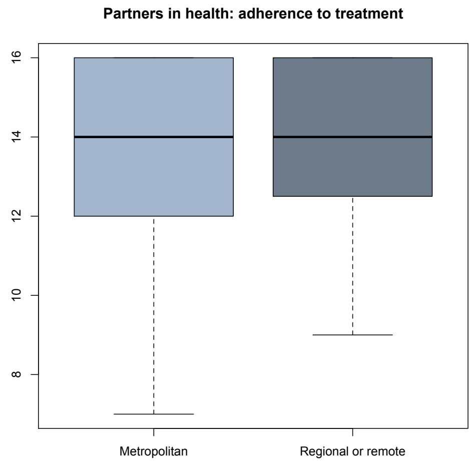


Figure 6.40: **“Partners in health: adherence to treatment”** by **Location**

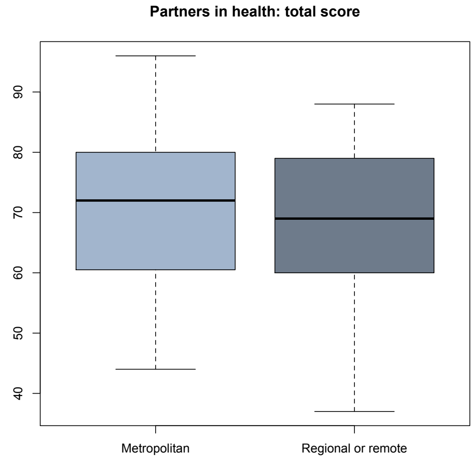


Figure 6.41: **“Partners in health: total score”** by **Location**

Comparisons of PIH scales by Education

Comparisons were made by **Education** status, between those with a university degree, *university* (n=66, 66.00%), and those with trade or high school qualifications, *trade or high school* (n=33, 33.00%);

Boxplots of each Partners in health scale by **Education** are displayed in Figures 6.42 to 6.46, summary statistics are displayed in Tables 6.34 to 6.35 . A two-sample t-test was used when assumptions for normality and variance were met (Table 6.34), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.35).

A two sample t-test indicated that the mean score for the **"Partners in health: coping"** scale [t(98) = -3.40, p=0.0022] (Table 6.34) was significantly higher for those with *University* qualifications (Mean = 14.94 SD= 5.30) compared to those with *Trade or high school* qualifications (Mean = 11.24, SD = 4.68).

A two sample t-test indicated that the mean score for the **"Partners in health: total score "** scale [t(98) = -2.46, p=0.0156] (Table 6.34) was significantly higher for those with *University* qualifications (Mean = 71.67 SD= 12.70) compared to those with *Trade or high school* qualifications (Mean = 65.00, SD = 12.83).

The **"Partners in health: coping"** mean scores for participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications. These scores correspond to good coping for participants with *University* qualifications and moderate coping for participants with *Trade or high school* qualifications.

The **"Partners in health: total"** mean scores for participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications. These scores correspond to good knowledge and confidence for managing their own health, for both groups.

Table 6.34: **"Partners in health"** by **Education** two sample t-test

Partners in health scale	Group	Count	Percent	Mean	SD	t	dF	p
Partners in health: coping	Trade or high school	33	33.00	11.24	4.68	-3.40	98	0.0010*
	University	67	67.00	14.94	5.30			
Partners in health: total score	Trade or high school	33	33.00	65.00	12.83	-2.46	98	0.0156*
	University	67	67.00	71.67	12.70			

*Statistically significant at p<0.05

Table 6.35: **"Partners in health"** by **Education** Wilcoxon rank sum test

Partners in health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	Trade or high school	33	33.00	25.00	7.00	1011.00	0.4898
	University	67	67.00	24.00	7.00		
Partners in health: recognition and management of symptoms	Trade or high school	33	33.00	17.00	2.00	906.00	0.1425
	University	67	67.00	18.00	5.00		
Partners in health: adherence to treatment	Trade or high school	33	33.00	13.00	4.00	853.50	0.0602
	University	67	67.00	15.00	3.00		

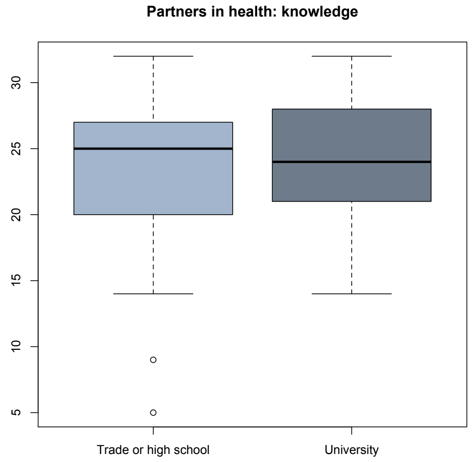


Figure 6.42: **“Partners in health: knowledge”** by **Education**

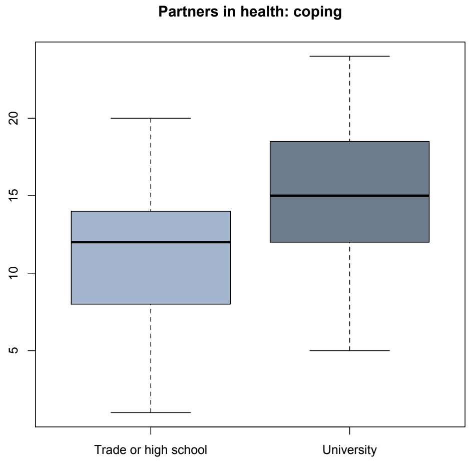


Figure 6.43: **“Partners in health: coping”** by **Education**

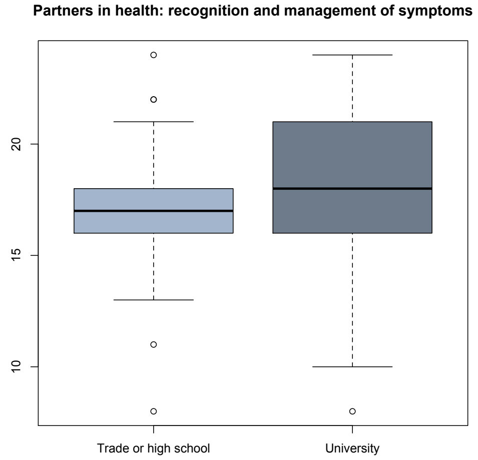


Figure 6.44: **“Partners in health: recognition and management of symptoms”** by **Education**

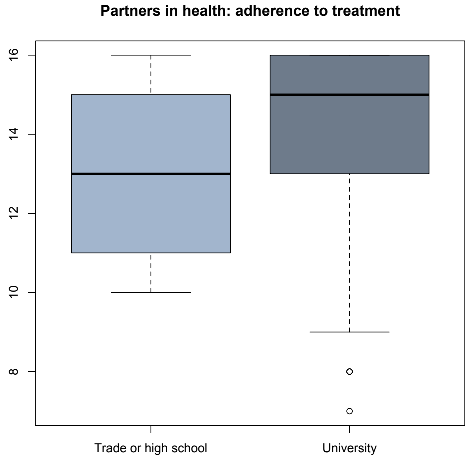


Figure 6.45: **“Partners in health: adherence to treatment”** by **Education**

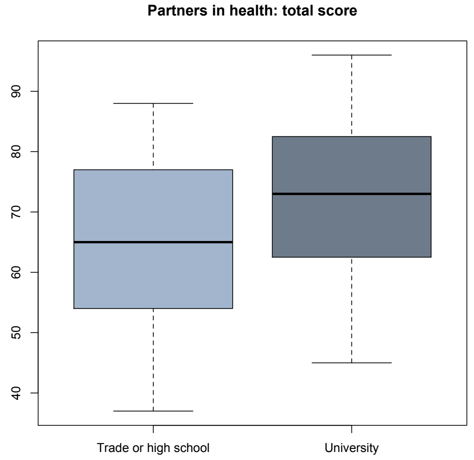


Figure 6.46: **“Partners in health: total score”** by **Education**

Comparisons of PIH scales by Socio-Economic Indexes For Areas (SEIFA)

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10 , *high SEIFA* (n=50, 50.00%) compared to those with a mid to low SEIFA score of 1-6, *mid-low SEIFA* (n=50, 50.00%).

Boxplots of each Partners in health scale by **SEIFA** are displayed in Figures 6.47-6.51, summary statistics are displayed in Tables 6.36 – 6.37 . A two-sample t-test was used when assumptions for normality and variance were met (Table 6.36), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 3.37).

No significant differences were observed between participants that lived in areas with a *High SEIFA* compared to those that lived in an area with *a Mid to low SEIFA* areas for any of the Partners in health scales.

Table 6.36: **"Partners in health"** by **SEIFA** two sample t-test

Partners in health scale	Group	Count	Percent	Mean	SD	t	dF	p
Partners in health: coping	High SEIFA	50	50.00	13.62	5.53	-0.19	98	0.8535
	Mid to low SEIFA	50	50.00	13.82	5.27			

Table 6.37: **"Partners in health"** by **SEIFA** Wilcoxon rank sum test

Partners in health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	High SEIFA	50	50.00	24.50	8.50	1285.5	0.8089
	Mid to low SEIFA	50	50.00	25.00	7.75		
Partners in health: recognition and management of symptoms	High SEIFA	50	50.00	18.00	4.75	1240	0.9475
	Mid to low SEIFA	50	50.00	18.00	5.00		
Partners in health: adherence to treatment	High SEIFA	50	50.00	14.00	4.00	1202	0.7385
	Mid to low SEIFA	50	50.00	14.00	3.75		
Partners in health: total score	High SEIFA	50	50.00	70.00	18.00	1220	0.8388
	Mid to low SEIFA	50	50.00	72.50	18.75		

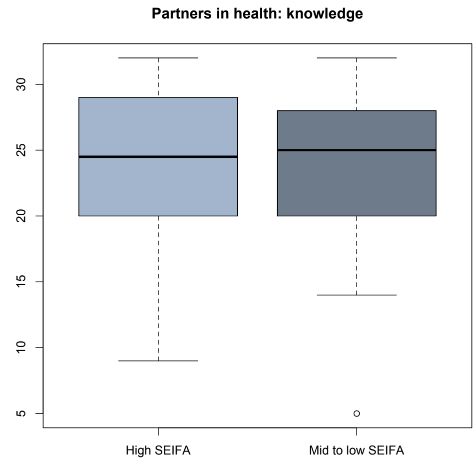


Figure 6.47: **"Partners in health: knowledge"** by **SEIFA**

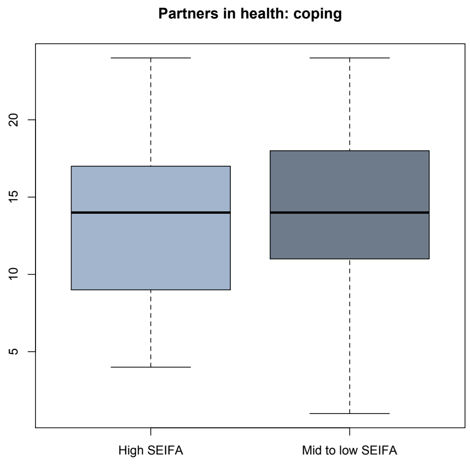


Figure 6.48: **"Partners in health: coping"** by **SEIFA**

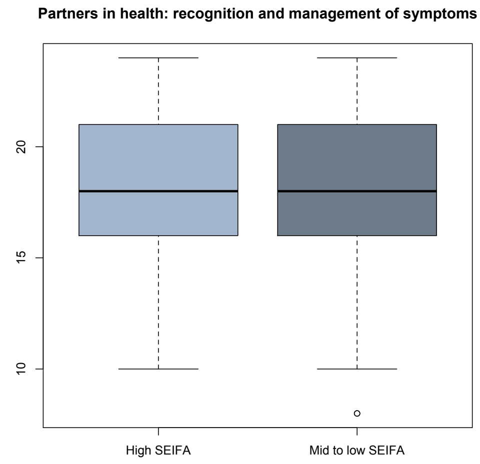


Figure 6.49: **"Partners in health: recognition and management of symptoms"** by **SEIFA**

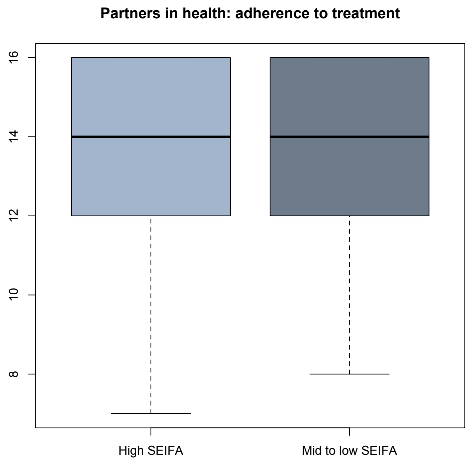


Figure 6.50: **"Partners in health: adherence to treatment"** by **SEIFA**

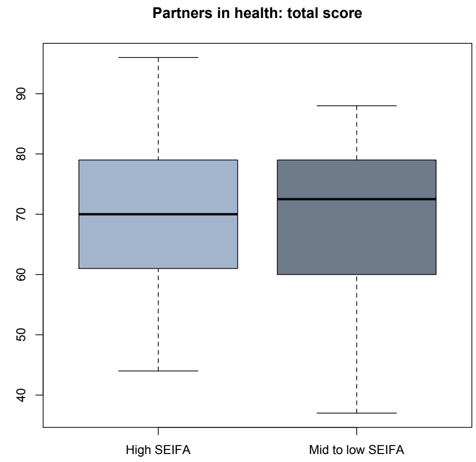


Figure 6.51: **"Partners in health: total score"** by **SEIFA**

Information given by healthcare professionals

Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=73, 73.00%), disease management (n=54, 54.00%), and disease management (n=48, 48.00%) were most frequently given to participants by healthcare professionals, and information about clinical trials (n=3, 3.00%), psychological/social support (n=8, 8.00%) and hereditary considerations genes or genomic biomarker information (n=8, 8.00%) (Figure 6.39).

Within subgroups, participants with *Physical limitations: some to most days* (37.84%) were given information about disease cause less often than the general population (48.00%) and participants with *Social: all to most days* (60.00%) with given information about disease cause more frequently.

Participants with *Symptoms: most days* (62.50%) were given information about Treatment options less often than the PEEK study population (73.00%) and participants with *Social: all to most days* (85.00%) received information more often.

Participants with *Social: no to few days* (38.64%) were given information about disease management less often than the PEEK study population (54.00%), and participants with *Symptoms: no to few days* (65.00%), *Social: all to most days* (75.00%), and *Aged 18 to 34* (66.67%) received information more often.

Participants with *Social: no to few days* (25.00%) were given information about physical activity less often than the PEEK study population (37.00%), and participants with *limitations: no days* (47.37%) and *Social: all to most days* (50.00%) received information more often.

Table 6.38: Information given by health professionals

Subgroups		Disease cause	Treatment options	Disease management	Complementary therapies	Clinical trials	Interpret test results	Dietary information	Physical activity	Psychological/ social support	Hereditary, genes or genomic biomarker information
All participants	All participants	**48.00**	**73.00**	**54.00**	**15.00**	**3.00**	**9.00**	**21.00**	**37.00**	**8.00**	**8.00**
Physical limitations	No days	52.63	73.68	57.89	21.05	5.26	10.53	31.58	47.37	10.53	15.79
	Few days	54.55	68.18	52.27	18.18	4.55	6.82	22.73	34.09	9.09	6.82
	Some to most days	37.84	78.38	54.05	8.11	0.00	10.81	13.51	35.14	5.41	5.41
Symptoms	No to few days	50.00	80.00	65.00	10.00	5.00	15.00	30.00	50.00	10.00	10.00
	Some days	44.44	77.78	48.15	29.63	7.41	14.81	22.22	29.63	3.70	18.52
	Most days	43.75	62.50	56.25	9.38	0.00	0.00	15.63	34.38	9.38	3.13
	All days	57.14	76.19	47.62	9.52	0.00	9.52	19.05	38.10	9.52	0.00
Affect	Never to almost never	48.48	81.82	57.58	33.33	9.09	18.18	30.30	42.42	6.06	15.15
	Sometimes	52.78	72.22	55.56	8.33	0.00	8.33	19.44	38.89	11.11	2.78
	Very often to always	41.94	64.52	48.39	3.23	0.00	0.00	12.90	29.03	6.45	6.45
Social	All to most days	60.00	85.00	75.00	25.00	0.00	20.00	30.00	50.00	25.00	5.00
	Some days	50.00	75.00	61.11	16.67	5.56	8.33	27.78	44.44	5.56	13.89
	No to few days	40.91	65.91	38.64	9.09	2.27	4.55	11.36	25.00	2.27	4.55
Flare ups	Occasional	44.64	73.21	53.57	19.64	5.36	12.50	26.79	39.29	8.93	8.93
	Frequent	52.27	72.73	54.55	9.09	0.00	4.55	13.64	34.09	6.82	6.82
Age	Aged 18 to 34	50.00	72.22	66.67	11.11	0.00	5.56	16.67	33.33	11.11	11.11
	Aged 35 to 54	49.02	76.47	52.94	17.65	3.92	5.88	21.57	39.22	7.84	7.84
	Aged 55 or older	45.16	67.74	48.39	12.90	3.23	16.13	22.58	35.48	6.45	6.45
Location	Metropolitan	46.43	67.86	55.36	17.86	5.36	8.93	21.43	39.29	7.14	12.50
	Regional or remote	50.00	79.55	52.27	11.36	0.00	9.09	20.45	34.09	9.09	2.27
Education	Trade or high school	42.42	69.70	48.48	9.09	3.03	9.09	15.15	27.27	9.09	6.06
	University	50.75	74.63	56.72	17.91	2.99	8.96	23.88	41.79	7.46	8.96
SEIFA	High SEIFA	44.00	68.00	54.00	18.00	6.00	14.00	22.00	36.00	8.00	8.00
	Mid to Low SEIFA	52.00	78.00	54.00	12.00	0.00	4.00	20.00	38.00	8.00	8.00

Information searched for independently

Participants were asked about what type of information they searched for after receiving information from healthcare professionals. Information about disease cause (72.00%) was most often searched for, followed by treatment options (65.00%), complementary therapies (63.00%) and disease management (63.00%). The least searched for topic was hereditary considerations genes or genomic biomarker information (22.50%) (Table 6.39).

In relation to subgroup variations, participants with *Symptoms: all days* (61.90%), *Affect: never to almost never* (60.61%), and *Social: all to most days* (55.00%),searched for information about disease cause less often than the general population (72.00%). Participants with *Symptoms: most days* (84.38%), and *Social: some days* (83.33%) searched for information about disease cause more often than the general population (72.00%).

Participants with *Symptoms: most days* (78.13%), and *Social: some days* (80.56%) searched for information about treatment options more often than the general population (65.00%). Participants with *Physical limitations: few days* (54.55%), *Symptoms: no to few days* (55.00%), *Symptoms: some days* (55.56%), and *Social: all to most days* (50.00%) less often than the general population (65.00%).

Participants with *Physical limitations: no days* (73.68%), *Symptoms: most days* (78.13%), and *Social: some days* (77.78%) searched for information about disease management more often than the general population (63.00%).Participants with *Physical limitations: few days* (52.27%), *Symptoms: no to few days* (40.00%), searched for information about disease management less often than the general population (63.00%).

Participants with *Physical limitations: no days* (52.63%), and *Affect: never to almost never* (51.52%), searched for information about complementary therapies less often than the general population (63.00%).

Participants with *Aged 18 to 34* (72.22%), searched for information about how to interpret test results more often than the general population (57.00%). Participants with *Aged 55 or older* (45.16%), searched for information about how to interpret test results less often than the general population (57.00%).

Participants with *Symptoms: most days* (84.38%), and *Affect: sometimes* (75.00%) searched for information about diet more often than the general population (63.00%). Participants with *Physical limitations: no days* (47.37%), (*Symptoms: no to few days* 40.00%), and *Affect: never to almost never* (48.48%) searched for information about diet less often than the general population (63.00%).

Participants with *Social: all to most days* (70.00%), and *Aged 18 to 34* (66.67%), searched for information about physical activity more often than the general population (56.00%). Participants with *Aged 55 or older* (45.16%), searched for information about physical activity less often than the general population (56.00%).

Participants with *Affect: very often to always* (45.16%), and *Aged 18 to 34* (55.56%) searched for information about psychological/social support more often than the general population (34.00%). Participants with *Aged 55 or older* (9.68%), searched for information about psychological/social support less often than the general population (34.00%).

Table 6.39: Information searched for independently

Group		Disease cause	Treatment options	Disease management	Complementary therapies	Clinical trials	How to interpret test results	Dietary information	Physical activity	Psychological/social support	Hereditary considerations genes or genomic biomarker information
All participants	All participants	72.00	65.00	63.00	63.00	23.00	57.00	63.00	56.00	34.00	27.00
Physical limitations	No days	73.68	73.68	**73.68**	**52.63**	21.05	57.89	**47.37**	57.89	42.11	**15.79**
	Few days	65.91	**54.55**	**52.27**	65.91	25.00	59.09	63.64	54.55	29.55	31.82
	Some to most days	78.38	72.97	70.27	64.86	21.62	54.05	70.27	56.76	35.14	27.03
Symptoms	No to few days	70.00	**55.00**	**40.00**	50.00	20.00	45.00	**40.00**	55.00	25.00	20.00
	Some days	66.67	**55.56**	62.96	59.26	14.81	62.96	59.26	51.85	37.04	25.93
	Most days	**84.38**	**78.13**	**78.13**	68.75	**37.50**	62.50	**84.38**	62.50	37.50	31.25
	All days	**61.90**	66.67	61.90	71.43	14.29	52.38	57.14	52.38	33.33	28.57
Affect	Never to almost never	**60.61**	60.61	54.55	**51.52**	**12.12**	51.52	**48.48**	57.58	24.24	24.24
	Sometimes	80.56	66.67	63.89	72.22	**36.11**	63.89	**75.00**	55.56	33.33	27.78
	Very often to always	74.19	67.74	70.97	64.52	19.35	54.84	64.52	54.84	**45.16**	29.03
Social	All to most days	**55.00**	**50.00**	55.00	65.00	30.00	65.00	70.00	**70.00**	35.00	30.00
	Some days	**83.33**	**80.56**	**77.78**	63.89	25.00	61.11	69.44	52.78	30.56	33.33
	No to few days	70.45	59.09	54.55	61.36	18.18	50.00	54.55	52.27	36.36	20.45
Flare ups	Occasional	71.43	64.29	57.14	55.36	17.86	51.79	57.14	50.00	28.57	26.79
	Frequent	72.73	65.91	70.45	72.73	29.55	63.64	70.45	63.64	40.91	27.27
Age	Aged 18 to 34	72.22	72.22	72.22	61.11	27.78	**72.22**	72.22	**66.67**	**55.56**	27.78
	Aged 35 to 54	76.47	58.82	60.78	68.63	25.49	58.82	62.75	58.82	41.18	33.33
	Aged 55 or older	64.52	70.97	61.29	54.84	16.13	**45.16**	58.06	**45.16**	**9.68**	**16.13**
Location	Metropolitan	73.21	66.07	64.29	64.29	21.43	62.50	66.07	57.14	32.14	26.79
	Regional or remote	70.45	63.64	61.36	61.36	25.00	50.00	59.09	54.55	36.36	27.27
Education	Trade or high school	69.70	63.64	57.58	60.61	21.21	57.58	60.61	57.58	33.33	24.24
	University	73.13	65.67	65.67	64.18	23.88	56.72	64.18	55.22	34.33	28.36
SEIFA	High SEIFA	74.00	68.00	72.00	70.00	24.00	60.00	68.00	60.00	32.00	28.00
	Mid to Low SEIFA	70.00	62.00	54.00	56.00	22.00	54.00	58.00	52.00	36.00	26.00

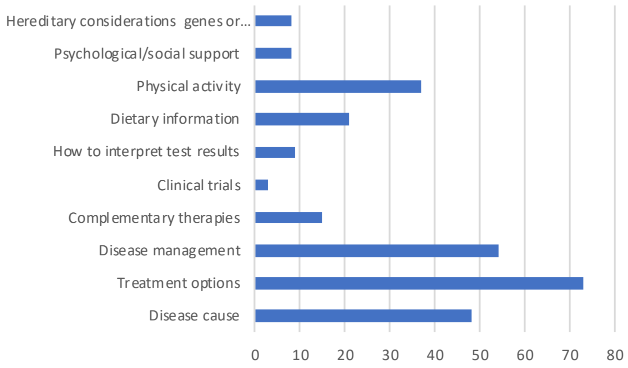


Figure 6.52: Information given

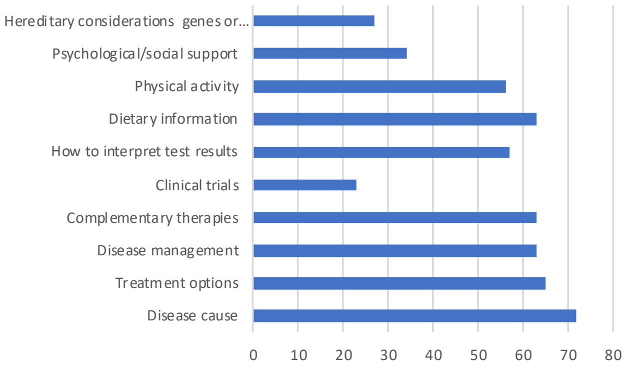


Figure 6.53: Information searched for

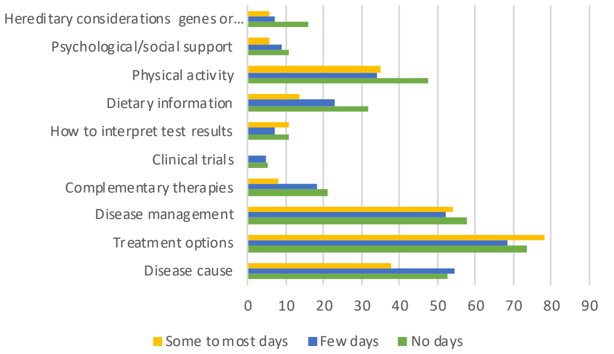


Figure 6.54: Information given by **AIMS2-SF Physical**

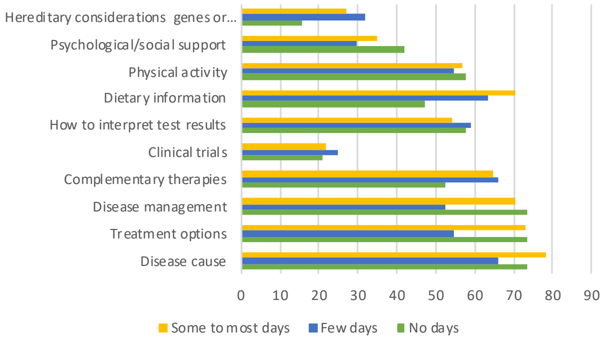


Figure 6.55: Information searched for by **AIMS2-SF Physical**

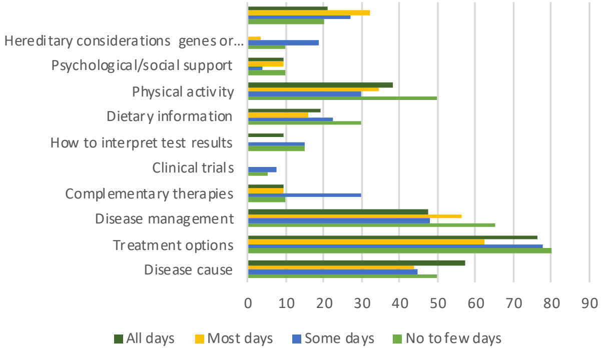


Figure 6.56: Information given by **AIMS2-SF Symptoms**

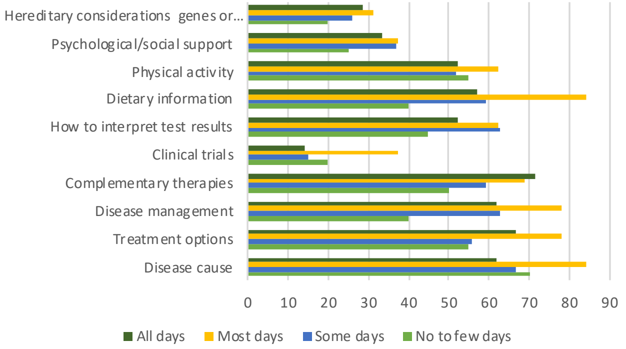


Figure 6.57: Information searched for by **AIMS2-SF Symptoms**

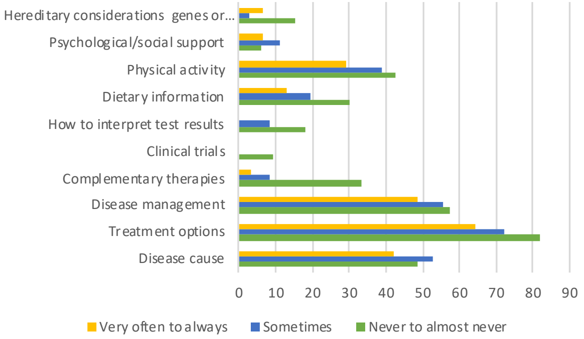


Figure 6.58: Information given by **AIMS2-SF Affect**

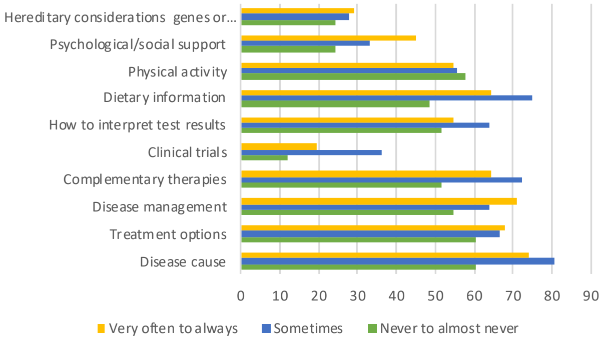


Figure 6.59: Information searched for by **AIMS2-SF Affect**

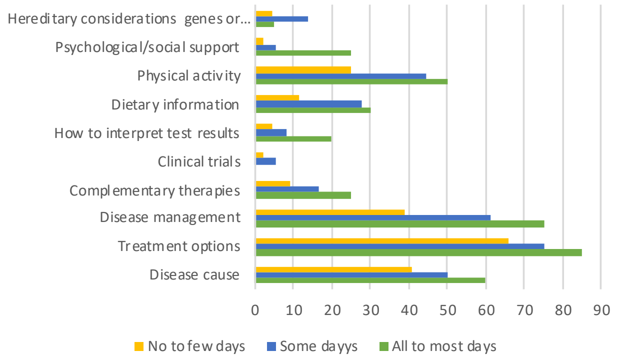


Figure 6.60: Information given by **AIMS2-SF Social**

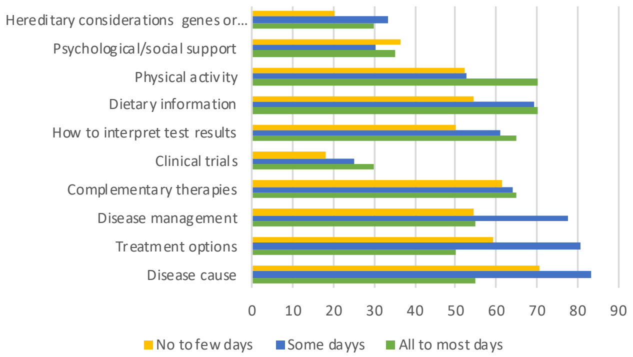


Figure 6.61: Information searched for by **AIMS2-SF Social**

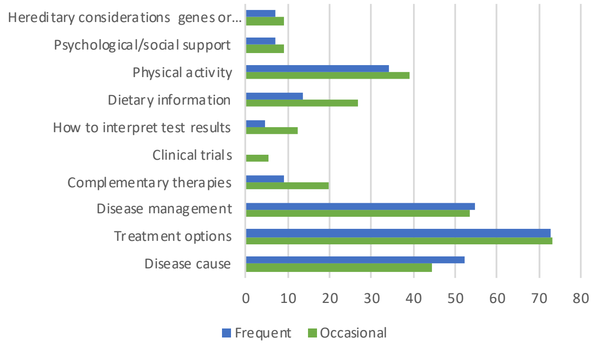


Figure 6.62: Information given by **Flare-up frequency**

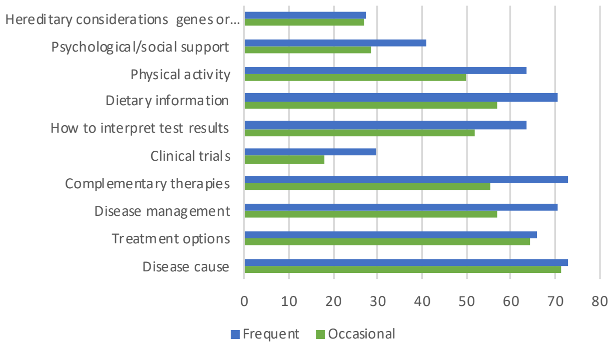


Figure 6.63: Information searched for by **Flare-up frequency**

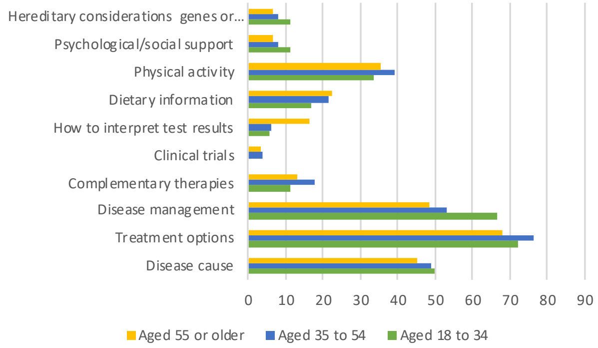


Figure 6.64: Information given by **Age**

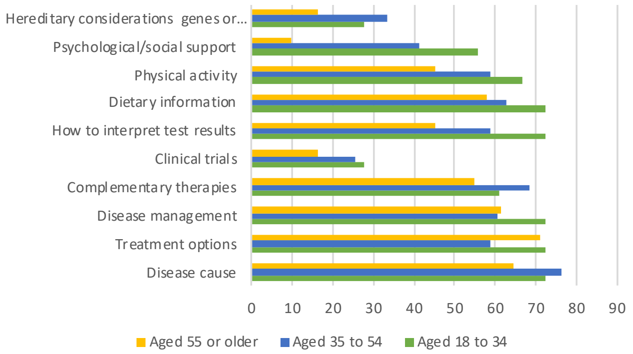


Figure 6.65: Information searched for by **Age**

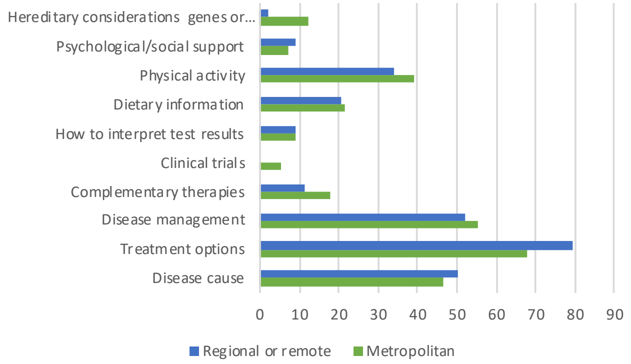


Figure 6.66: Information given by **Location**

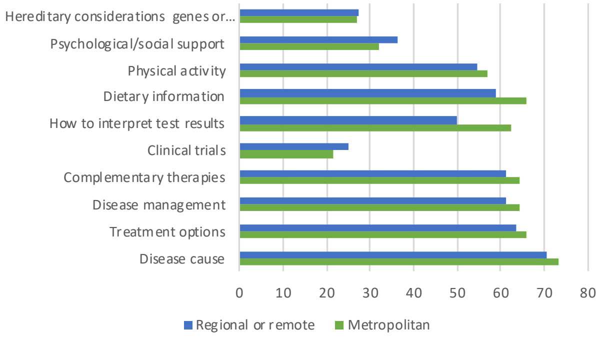


Figure 6.67: Information searched for by **Location**

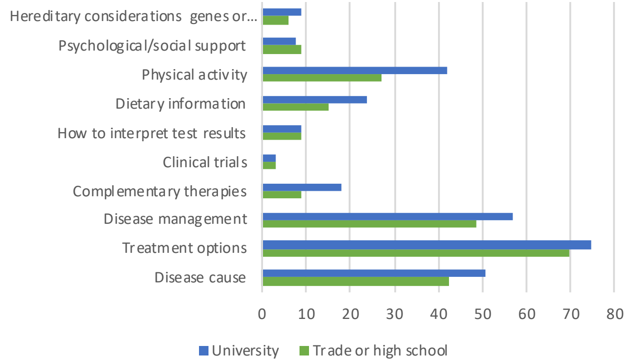


Figure 6.68: Information given by **Education**

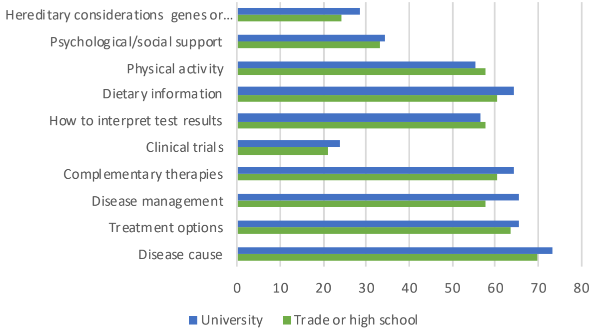


Figure 6.69: Information searched for by **Education**

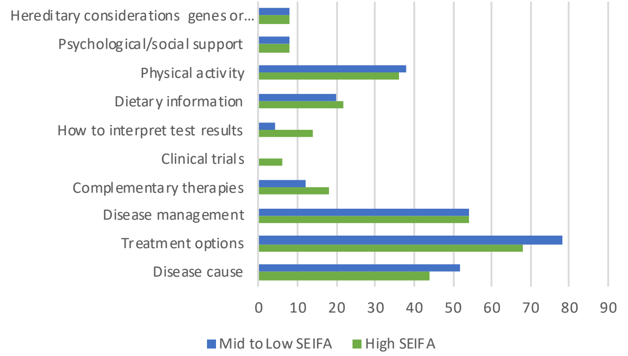


Figure 6.70: Information given by **SEIFA**

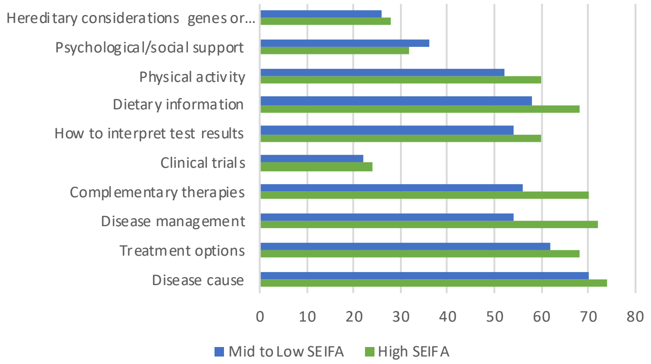


Figure 6.71: Information searched for by **SEIFA**

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently clinical trials (n=74, 74.00%), hereditary, genes or genomic biomarkers (n=69, 69.00%), and psychological/social support (n=62, 62.00%) (Figure 6.72). Participants were given most information either from healthcare professionals or independently for treatment options (N=95, 95.00%), disease cause (n=88, 88.00%) and disease management (n=86, 86.00%). Complementary therapies (n= 54, 54.00%), how to interpret test results (n=53, 53.00%) and Dietary information (n=51, 51.00%) were the topics that was most searched for independently following no information from health professionals.

Table 6.40: Information gaps

	Disease cause	Treatment options	Disease management	Complementary therapies	Clinical trials	How to interpret test results	Dietary information	Physical activity	Psychological/social support	Hereditary , genes or genomic biomarkers
Information given AND searched	32.00	43.00	31.00	9.00	0.00	4.00	12.00	19.00	4.00	4
Information given NOT searched	16.00	30.00	23.00	6.00	3.00	5.00	9.00	18.00	4.00	4
Information NOT given BUT searched	40.00	22.00	32.00	54.00	23.00	53.00	51.00	37.00	30.00	23
Information NOT given NOT searched	12.00	5.00	14.00	31.00	74.00	38.00	28.00	26.00	62.00	69

Figure 6.72: Information gaps

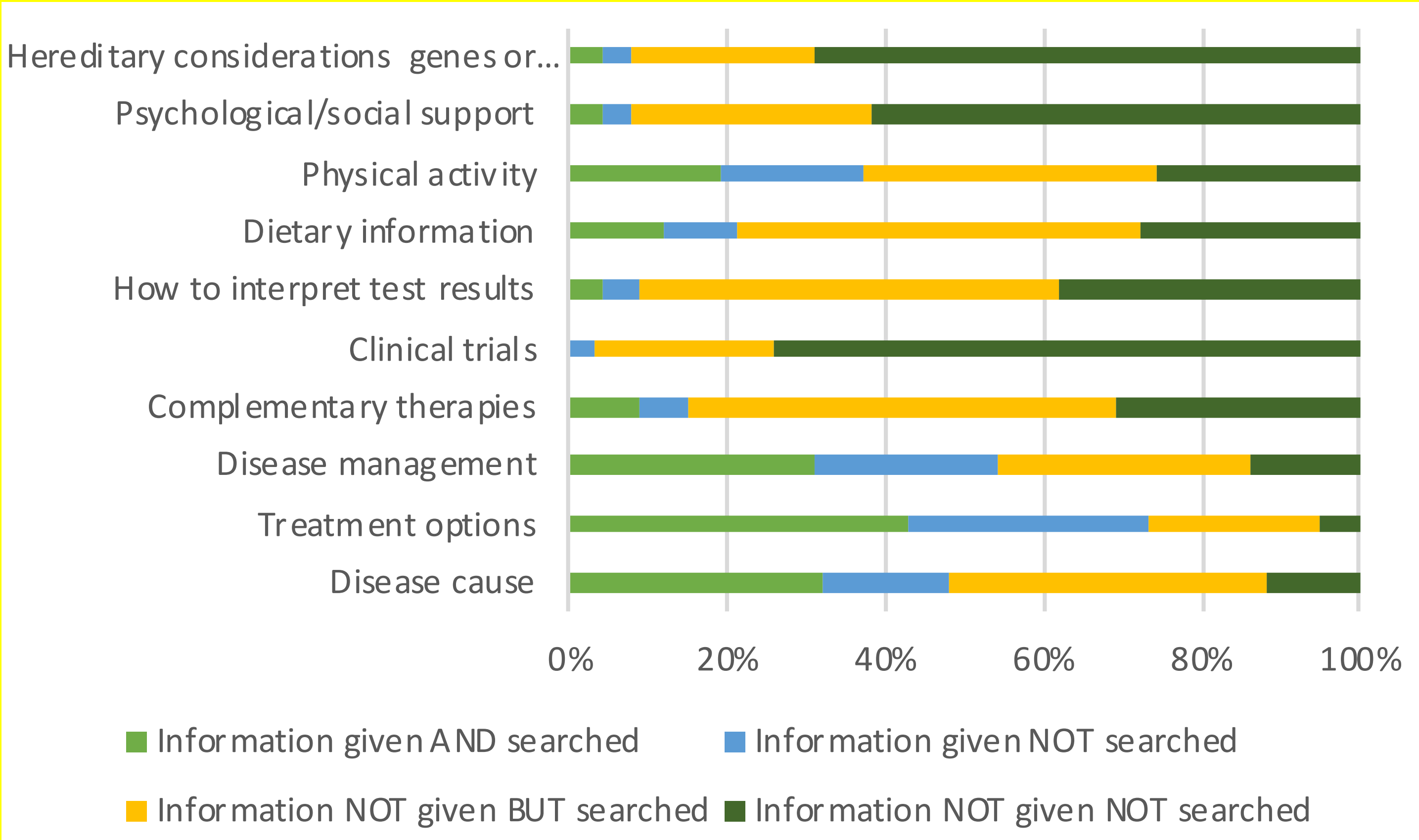


Figure 6.79: Proportion of information given by health care professionals and searched for independently.

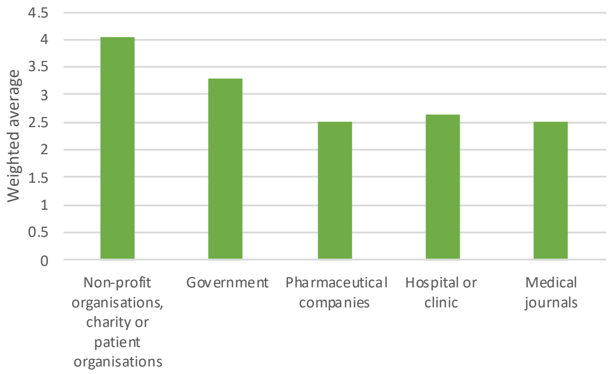
Most trusted information sources

Participants were asked to rank which information source that they most trusted, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Figure 6.73. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants, information from non-profit or charities or patient organisations were most trusted, followed by information from the government. Information from pharmaceutical companies and from medical journals were least trusted. (Figure 6.73).

Table 6.41: Trusted information source

Information source	Weighted average
Non-profit organisations, charity or patient organisations	4.05
Government	3.3
Pharmaceutical companies	2.51
Hospital or clinic	2.64
Medical journals	2.5

Figure 6.73: Trusted information source



Accessed "My Health Record"

My Health Record is an online summary of key health information, an initiative of the Australian Government. Thirty-eight (38.00%) had accessed "My Health Record", 59 (59.00%) had not, and three (3.00%) were no sure. Of those that had accessed "My Health Record", four participants (10.81%) found it good or very good., 11 (29.73%) found it acceptable, and 22 (59.46%) found it poor or very poor).

Table 6.42: My Health Record

Accessed "My Health Record"	N=100	Percent
Yes	38	38.00
No	59	59.00
I don't know what 'My Health Record' is	3	3.00

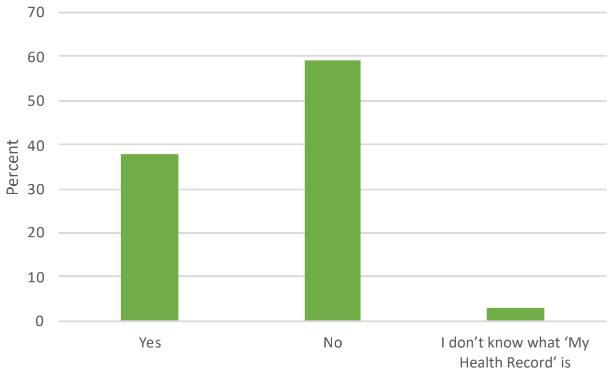


Figure 6.74: My Health Record

Table 6.43: How useful was "My Health Record"

How useful was 'My Health Record'	N=37	Percent
Very good	1	2.70
Good	3	8.11
Acceptable	11	29.73
Poor	12	32.43
Very poor	10	27.03

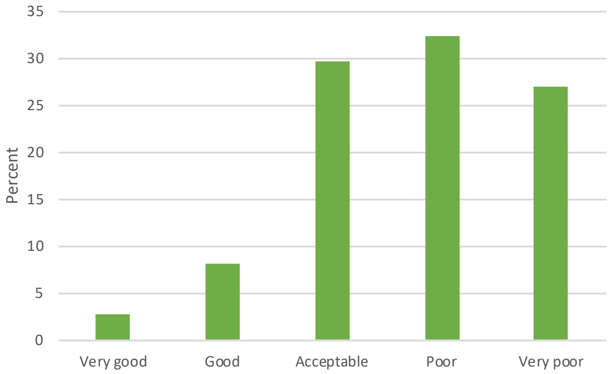


Figure 6.75: How useful was "My Health Record"

Section 7 Care and support

Section 7: Experience of care and support

Care coordination

The Care Coordination questionnaire comprises a total score, 2 scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

- Overall the entire cohort had a median score of 7.0 for "**Care coordination: quality of care global measure"** (IQR = 2.00), which is in the second highest quintile, indicating good care received.
- The mean scores for "**Care coordination: navigation"** (Mean = 26.20, SD=4.46), and (**"Care coordination: total score** (Mean = 65.70, SD = 11.80), and the median score for "**Care coordination: care coordination global measure"** (Median = 7.00, IQR = 2.00) were in the middle of the scale, indicating moderate scores.
- The mean score for "**Care coordination: communication"** (Mean = 33.46, SD = 10.18) was in the second lowest quintile, indicating poor communication.

Ability to adhere to treatment

- Participants were asked about their ability to take medicine and stick to that regimen. More than half responded that they could take medicine and stick to it "All the time" (n=55, 55.00%), 40 participants (40.00%) responded "Most of the time", very few answered "Sometimes" (n=4, 4.00%) or "Rarely" (n=1, 1.00%).

Experience of care and support

- The most common description of care and support was from participant's GP/specialist (n=33, 33.00%), followed by friends (n=28, 28%), family (n=21, 21.00%), support group (n=18, 18.00%), complimentary therapy and allied health (n=15, 15.00%), received no help (n= 14, 14.00%), online peer support (n=14, 14.00%), partner support (n=14, 14%), parental/sibling support (n=13, 13%), support from charities (n=12, 12.00%) and domestic support (n=8, 8.00%).

Experience of coordination of care

A Care Coordination questionnaire was completed by participants on the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

Overall the entire cohort had a median score of 7.0 for “**Care coordination: quality of care global measure”** (IQR = 2.00), which is in the second highest quintile, indicating good care received. The mean scores for “**Care coordination: navigation”** (Mean = 26.20, SD=4.46), and (**“Care coordination: total score** (Mean = 65.70, SD = 11.80), and the median score for “**Care coordination: care coordination global measure”** (Median = 7.00, IQR = 2.00) were in the middle of the scale, indicating moderate scores. The mean score for “**Care coordination: communication”** (Mean = 33.46, SD = 10.18) was in the second lowest quintile, indicating poor communication.

Comparisons of care coordination have been made based on **AIMS2-SF Physical scale** (Figures 7.1 to 7.5, Tables 7.2 to 7.4), **AIMS2-SF Symptoms scale**(Figures 7.6 to 7.10, Tables 7.5 to 7.7), **AIMS2-SF Affect scale** (Figures 7.11 to 7.15, Tables 7.8 to 7.12), **AIMS2-SF Social scale,** (Figures 7.16 to 7.20, Tables 7.13 to 7.16), **Flare-up frequency** (Figures 7.21 to 7.25, Tables 7.17 to 7.18), **Age** (Figures 7.26 to 7.30, Tables 7.19 to 7.21), **Location** (Figures 7.31 to 7.35, Tables 7.22 to 7.23), **Education** (Figures 7.36 to 7.40, Tables 7.24 to 7.25), and **SEIFA** (Figures 7.41 to 7.45, Tables 7.26 to 7.27).

Table 7.1: Summary statistics **“Care coordination”** scale

Care coordination scale	Mean	SD	Median	IQR	Possible range	Quintile
Care coordination: communication*	33.46	10.18	33.00	13.25	13 to 65	2
Care coordination: navigation*	22.23	5.37	21.50	8.00	7 to 35	3
Care coordination: total score*	55.69	13.73	55.00	17.50	20 to 100	3
Care coordination: care coordination global measure	5.58	2.49	6.00	4.00	1 to 10	3
Care coordination: quality of care global measure	6.85	1.98	7.00	2.00	1 to 10	4

*Normal distribution, use Mean and SD as central measure

Comparisons of Care Coordination scores by AIMS2-SF Physical scale

The **AIMS2-SF Physical scale** is the Arthritis Impact Measure Scale short form physical scale. The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities ”All days”, “Most days”, “Some days”, ”Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status.

Comparisons were made between participants that scored *Physical limitations: no days* (AIMS2-SF physical scale score between 0 and 2, n=19, 19.00%), *Physical limitations: few days* (AIMS2-SF physical scale score greater than 2 to 4, n=44, 44.00%), and *Physical limitations: some to most days* (AIMS2-SF physical scale score greater than 4 to 8, n=37, 37.00%).

Boxplots of each Care coordination scale by **AIMS2-SF Physical scale** are displayed in Figures 7.1 to 7.5, summary statistics are displayed in Table 7.2.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.3) When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.4).

No significant differences were observed between participants by **AIMS2-SF Physical scale** for any of the Care coordination scales.

Table 7.2: **“Care coordination”** by **AIMS2-SF Physical** scale summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Physical limitations: no days	19	19.00	36.16	10.29	35.00	15.00
	Physical limitations: few days	44	44.00	34.20	9.41	33.50	10.25
	Physical limitations: some to most days	37	37.00	31.19	10.79	33.00	17.00
Care coordination: navigation	Physical limitations: no days	19	19.00	23.79	5.73	24.00	7.00
	Physical limitations: few days	44	44.00	22.64	4.93	22.00	6.25
	Physical limitations: some to most days	37	37.00	20.95	5.54	21.00	9.00
Care coordination: total score	Physical limitations: no days	19	19.00	59.95	15.05	61.00	21.50
	Physical limitations: few days	44	44.00	56.84	13.05	56.00	14.00
	Physical limitations: some to most days	37	37.00	52.14	13.32	51.00	17.00
Care coordination: care coordination global measure	Physical limitations: no days	19	19.00	6.05	2.57	6.00	4.50
	Physical limitations: few days	44	44.00	5.64	2.35	6.00	4.00
	Physical limitations: some to most days	37	37.00	5.27	2.63	5.00	3.00
Care coordination: quality of care global measure	Physical limitations: no days	19	19.00	6.89	2.33	7.00	2.50
	Physical limitations: few days	44	44.00	6.95	1.83	7.00	2.00
	Physical limitations: some to most days	37	37.00	6.70	2.00	7.00	2.00

Table 7.3: **“Care coordination”** by **AIMS2-SF Physical** ANOVA table

Care coordination		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	353.00	2	176.70	1.73	0.1830
	Within groups	9903.00	97	102.10		
	Total	10256.00	99			
Care coordination: navigation	Between groups	114.50	2	57.24	2.03	0.1370
	Within groups	2741.20	97	28.26		
	Total	2855.70	99			
Care coordination: total score	Between groups	870.00	2	435.10	2.37	0.0986
	Within groups	17787.00	97	183.40		
	Total	18657.00	99			

Table 7.4: **“Care coordination”** by **AIMS2-SF Physical** Kruskal-Wallis test

Care coordination	X^2	df	p
Care coordination: care coordination global measure	1.14	2	0.5667
Care coordination: quality of care global measure	0.36	2	0.8360

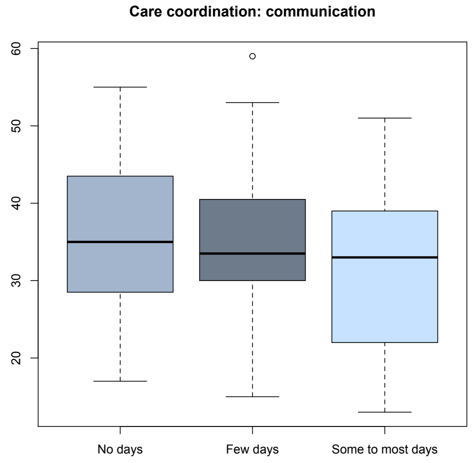


Figure 7.1: **"Care coordination: communication"** by **AIMS2-SF Physical**

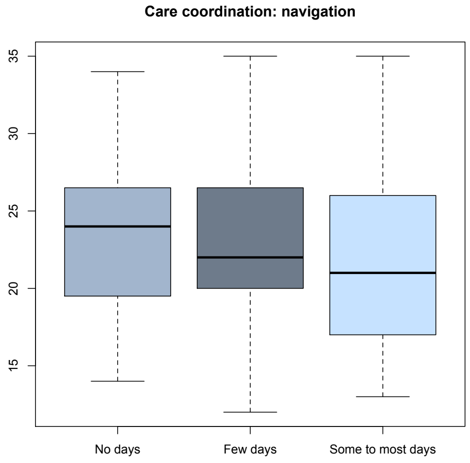


Figure 7.2: **"Care coordination: navigation"** by **AIMS2-SF Physical**

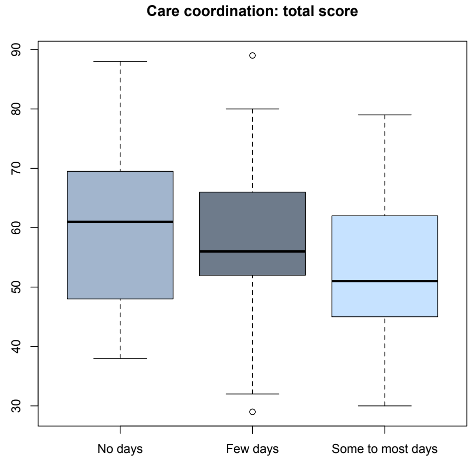


Figure 7.3: **"Care coordination: total score"** by **AIMS2-SF Physical**

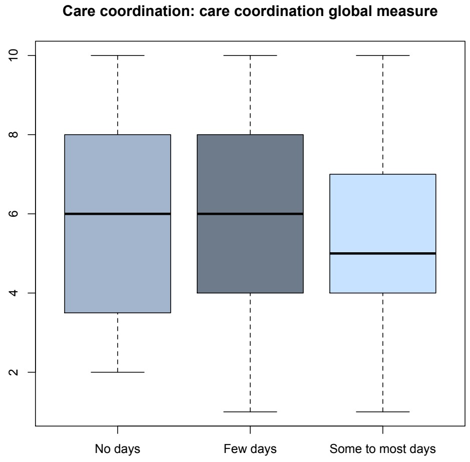


Figure 7.4: **"Care coordination: care coordination global measure"** by **AIMS2-SF Physical**

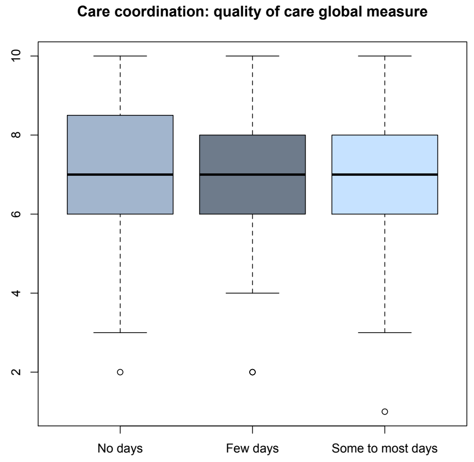


Figure 7.5: **"Care coordination: quality if care global measure"** by **AIMS2-SF Physical**

Comparisons of Care Coordination scores by AIMS2-SF Symptoms scale

The **AIMS2-SF Symptoms scale** is the Arthritis Impact Measure Scale short form symptoms scale. The symptoms scale is comprised of three questions about frequency of pain and stiffness "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Symptoms: no to few days* (AIMS2-SF symptoms scale score between 0 and 4, n=20, 20.00%), *Symptoms: some days* (AIMS2-SF symptoms scale score greater than 4 to 6, n=27, 27.00%), *Symptoms: most days* (AIMS2-SF symptoms scale score greater than 6 to 8, n=32, 32.00%), and Symptoms: all days (AIMS2-SF symptoms scale score greater than 8 to 10, n=21, 21.00%). Boxplots of each Care coordination scale by **AIMS2-SF Symptoms scale** are displayed in Figures 7.6 - 7.10, summary statistics are displayed in Table 7.5.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.6). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.7).

No significant differences were observed between participants by **AIMS2-SF Symptoms scale** for any of the Care coordination scales.

Table 7.5: **"Care coordination"** by **AIMS2-SF Symptoms** scale summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Symptoms: no to few days	20.00	20.00	36.65	9.56	33.50	13.25
	Symptoms: some days	27.00	27.00	33.59	10.65	32.00	16.50
	Symptoms: most days	32.00	32.00	32.00	9.28	33.00	11.50
	Symptoms: all days	21.00	21.00	32.48	11.42	34.00	15.00
Care coordination: navigation	Symptoms: no to few days	20.00	20.00	24.35	6.13	25.00	8.00
	Symptoms: some days	27.00	27.00	23.15	4.18	22.00	6.50
	Symptoms: most days	32.00	32.00	20.84	5.36	21.00	8.25
	Symptoms: all days	21.00	21.00	21.14	5.46	21.00	9.00
Care coordination: total score	Symptoms: no to few days	20.00	20.00	61.00	13.97	58.50	17.25
	Symptoms: some days	27.00	27.00	56.74	13.92	57.00	23.00
	Symptoms: most days	32.00	32.00	52.84	12.17	54.00	12.00
	Symptoms: all days	21.00	21.00	53.62	14.80	53.00	20.00
Care coordination: care coordination global measure	Symptoms: no to few days	20.00	20.00	6.50	2.72	7.00	2.50
	Symptoms: some days	27.00	27.00	5.48	2.47	6.00	4.00
	Symptoms: most days	32.00	32.00	5.03	2.39	5.00	3.00
	Symptoms: all days	21.00	21.00	5.67	2.35	6.00	3.00
Care coordination: quality of care global measure	Symptoms: no to few days	20.00	20.00	7.70	1.81	8.00	2.00
	Symptoms: some days	27.00	27.00	6.89	1.74	7.00	2.00
	Symptoms: most days	32.00	32.00	6.28	2.22	7.00	3.00
	Symptoms: all days	21.00	21.00	6.86	1.85	8.00	2.00

Table 7.6: **"Care coordination"** by **AIMS2-SF Symptoms** ANOVA table

Care coordination		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	293.00	3	97.51	0.94	0.4250
	Within groups	9964.00	96	103.79		
	Total	10257.00	99			
Care coordination: navigation	Between groups	199.00	3	66.32	2.40	0.0729
	Within groups	2657.00	96	27.67		
	Total	2856.00	99			
Care coordination: total score	Between groups	943.00	3	314.3	1.70	0.1710
	Within groups	17714.00	96	184.5		
	Total	18657.00	99			

Table 7.7: **"Care coordination"** by **AIMS2-SF Symptoms** Kruskal-Wallis test

Care coordination	X^2	dF	p
Care coordination: care coordination global measure	4.69	3	0.1964
Care coordination: quality of care global measure	6.47	3	0.0908

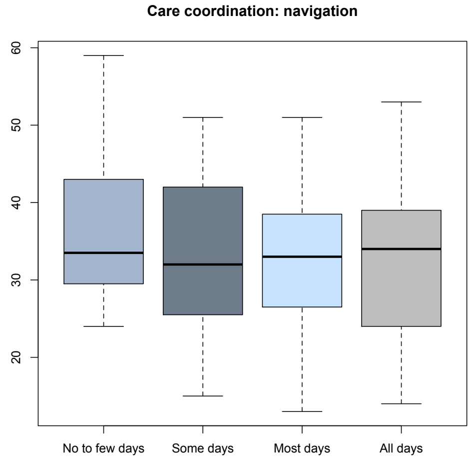


Figure 7.6: **"Care coordination: communication"** by **AIMS2-SF Symptoms**

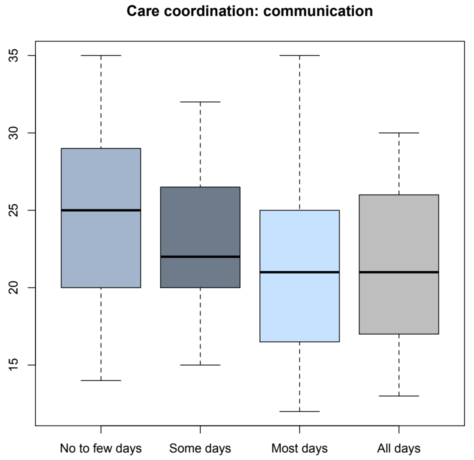


Figure 7.7: **"Care coordination: navigation"** by **AIMS2-SF Symptoms**

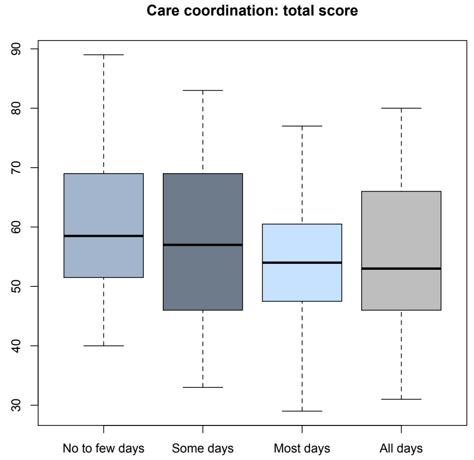


Figure 7.8: **"Care coordination: total score"** by **AIMS2-SF Symptoms**

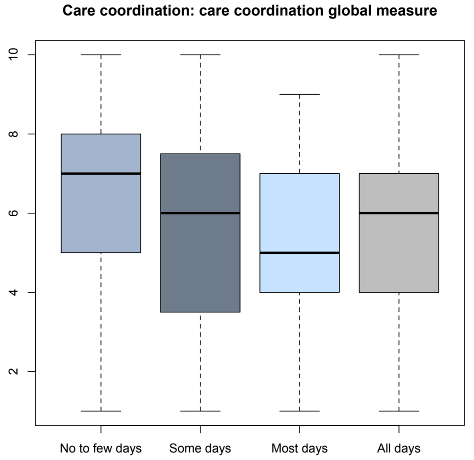


Figure 7.9: **"Care coordination: care coordination global measure"** by **AIMS2-SF Symptoms**

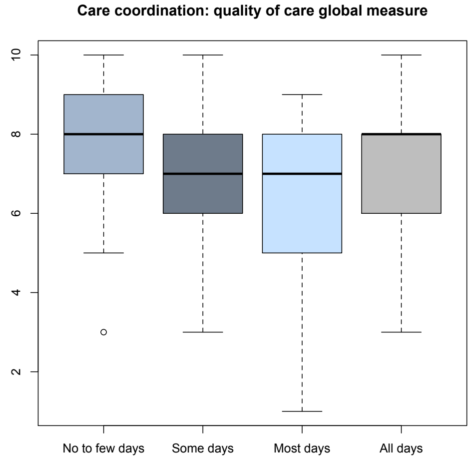


Figure 7.10: **"Care coordination: quality if care global measure"** by **AIMS2-SF Symptoms**

Comparisons of Care Coordination scores by AIMS2-SF Affect scale

The **AIMS2-SF Affect scale** is the Arthritis Impact Measure Scale short form affect scale. The affect scale is comprised of 5 questions about experience of anxiety, depression and burden "Always", "Very often", "Sometimes", "Almost never" or "Never", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Affect: never to almost never* (AIMS2-SF affect scale score between 0 and 4, n=33, 33.00%), *Affect: sometimes* (AIMS2-SF Affect scale score greater than 4 to 6, n=36, 36.00%), *Affect: very often to always* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and Symptoms: all days (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%),

Boxplots of each Care coordination scale by **AIMS2-SF Affect scale** are displayed in Figures 7.11 to 7.15, summary statistics are displayed in Table 7.8

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.9). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 7.10). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.11). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 7.12).

A one way ANOVA test indicated a statistically significant difference in the **"Care coordination: navigation"** scale between groups, F(2, 97) = 4.17, p = 0.0183 (Table 7.9). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never to almost never* (mean = 24.30, SD = 5.54) was significantly higher than participants that scored *Affect: very often to always* (mean = 20.71, SD = 4.85, p=0.0188).

A one way ANOVA test indicated a statistically significant difference in the **"Care coordination: total score"** scale between groups, F(2, 97) = 4.16, p = 0.0186 (Table 7.9). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never to almost* (mean = 60.27, SD = 13.96) was significantly higher than participants that scored *Affect: very often to always* (mean = 50.68, SD = 12.41, p=0.0134).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: care coordination global measure"** scale between groups, X^2 (2) = 6.27, P=0.0435 (Table 7.11). Post hoc comparisons using Wilcoxon rank sum test indicated that the median score for participants that scored *Affect: never to almost* (mean = 7.00, IQR = 3.00) was significantly higher than participants that scored *Affect: very often to always* (median = 5.00, IQR = 2.50, p=0.0310).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: quality of care global measure"** scale between groups, X^2 (2) = 8.13, P=0.0172 (Table 7.11). Post hoc comparisons using Wilcoxon rank sum test indicated that the median score for participants that scored *Affect: never to almost* (mean = 8.00, IQR = 1.00) was significantly higher than participants that scored *Affect: very often to always* (median = 7.00, IQR = 3.00, p=0.0140).

The mean scores of the **“Care coordination: navigation”** scores were significantly higher for participants that scored *Affect: never to almost never* compared to participants that scored *Affect: very often to always.* These scores correspond to good navigation of the healthcare system for participants that scored *Affect: never to almost never* and moderate navigation of the healthcare system for participants that scored *Affect: very often to always.*

The mean scores of the **“Care coordination: total score”** scores were significantly higher for participants that scored *Affect: never to almost never* compared to participants that scored *Affect: very often to always.* These scores correspond to moderate total care coordination (both communication and navigation) for participants that scored *Affect: never to almost never* and poor total care coordination (both communication and navigation) for participants that scored *Affect: very often to always.*

The median score for **“Care coordination: care coordination global measure”** was significantly higher for participants that scored *Affect: never to almost* compared to participants that scored *Affect: never to almost.* These scores correspond to a good rating of care coordination by participants that scored *Affect: never to almost* and a moderate rating of care coordination by participants that scored *Affect: very often to always.*

The median score for **“Care coordination: quality of care global measure”** was significantly higher for participants that scored *Affect: never to almost* compared to participants that scored *Affect: never to almost.* These scores correspond to a good rating of quality of care by both of these groups.

Table 7.8: **“Care coordination”** by **AIMS2-SF Affect** scale summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Affect: never to almost never	33	33.00	35.97	9.63	35.00	10.00
	Affect: sometimes	36	36.00	34.17	10.50	34.50	16.00
	Affect: very often to always	31	31.00	29.97	9.70	30.00	12.50
Care coordination: navigation	Affect: never to almost never	33	33.00	24.30	5.54	25.00	8.00
	Affect: sometimes	36	36.00	21.64	5.19	21.00	7.50
	Affect: very often to always	31	31.00	20.71	4.85	21.00	8.50
Care coordination: total score	Affect: never to almost never	33	33.00	60.27	13.96	58.00	16.00
	Affect: sometimes	36	36.00	55.81	13.45	55.50	16.25
	Affect: very often to always	31	31.00	50.68	12.41	52.00	14.50
Care coordination: care coordination global measure	Affect: never to almost never	33	33.00	6.36	2.47	7.00	3.00
	Affect: sometimes	36	36.00	5.33	2.73	5.00	4.25
	Affect: very often to always	31	31.00	5.03	2.06	5.00	2.50
Care coordination: quality of care global measure	Affect: never to almost never	33	33.00	7.61	1.58	8.00	1.00
	Affect: sometimes	36	36.00	6.67	2.12	7.00	2.50
	Affect: very often to always	31	31.00	6.26	1.98	7.00	3.00

Table 7.9: **“Care coordination”** by **AIMS2-SF Affect** ANOVA table

Care coordination scale		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	604.00	2	301.95	3.03	0.0527
	Within groups	9653.00	97	99.51		
	Total	10257.00	99			
Care coordination: navigation	Between groups	226.00	2	113.02	4.17	0.0183 *
	Within groups	2630.00	97	27.11		
	Total	2856.00	99			
Care coordination: total score	Between groups	1472.00	2	736.2	4.16	0.0186 *
	Within groups	17185.00	97	177.20		
	Total	18657.00	99			

*Statistically significant at $p<0.0005$

Table 7.10: **“Care coordination”** by **AIMS2-SF Affect** post-hoc Tukey HSD test

Care coordination scale	AIMS2-SF Affect scale	Difference	Lower	Upper	P adjusted
Care coordination: navigation	*Sometimes - Never to almost never*	-2.66	-5.65	0.32	0.0904
	Very often to always -Never to almost never	-3.59	-6.69	-0.49	0.0188*
	Very often to always - Sometimes	-0.93	-3.97	2.11	0.7473
Care coordination: total score	*Sometimes - Never to almost never*	-4.47	-12.10	3.17	0.3487
	Very often to always -Never to almost never	-9.60	-17.52	-1.67	0.0134*
	Very often to always - Sometimes	-5.13	-12.89	2.63	0.2625

*Statistically significant at $p<0.0005$

Table 7.11: **“Care coordination”** by **AIMS2-SF Affect** Kruskal-Wallis test

Care coordination scale	X^2	dF	p
Care coordination: care coordination global measure	6.27	2	0.0435*
Care coordination: quality of care global measure	8.13	2	0.0172*

Table 7.12: **“Care coordination”** by **AIMS2-SF Affect** post hoc Wilcoxon rank sum test

Care coordination scale	AIMS2-SF Affect scale	Never to almost never	Sometimes
Care coordination: care coordination global measure	*Sometimes*	0.1430	
	Very often to always	0.0310*	0.6300
Care coordination: quality of care global measure	*Sometimes*	0.0780	
	Very often to always	0.0140*	0.4450

* Statistically significant at $p<0.05$

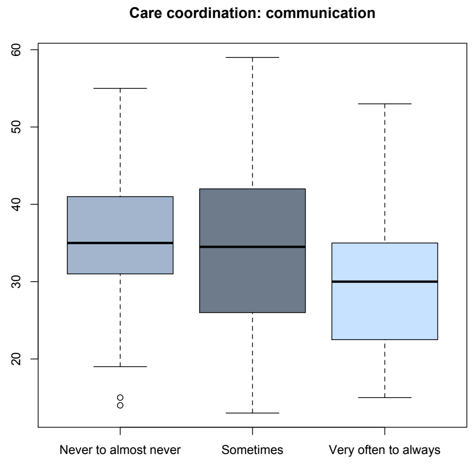


Figure 7.11: **"Care coordination: communication"** by **AIMS2-SF Affect**

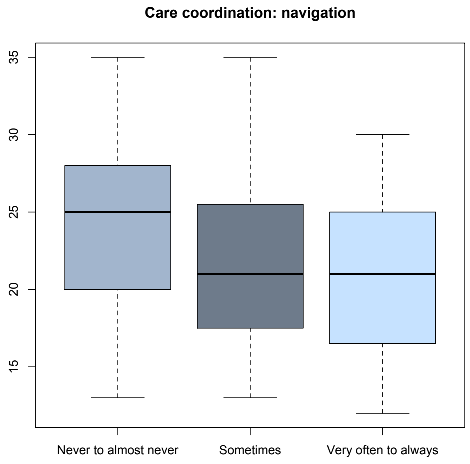


Figure 7.12: **"Care coordination: navigation"** by **AIMS2-SF Affect**

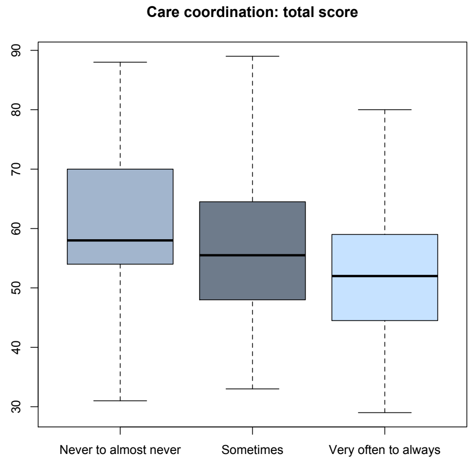


Figure 7.13: **"Care coordination: total score"** by **AIMS2-SF Affect**

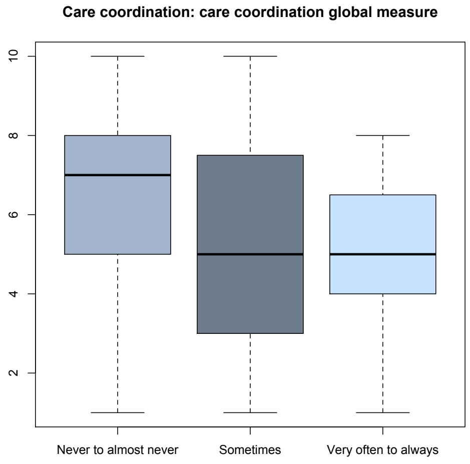


Figure 7.14: **"Care coordination: care coordination global measure"** by **AIMS2-SF Affect**

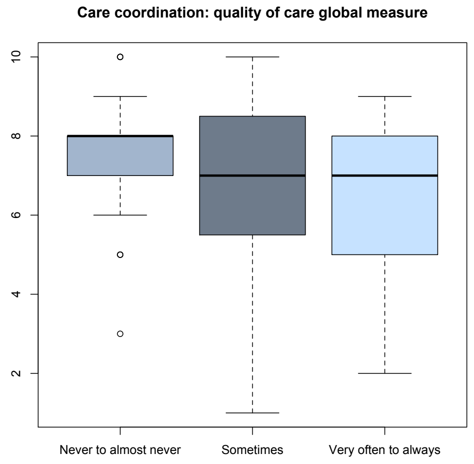


Figure 7.15: **"Care coordination: quality if care global measure"** by **AIMS2-SF Affect**

Comparisons of Care Coordination scores by Energy/Fatigue

The **AIMS2-SF Social scale** is the Arthritis Impact Measure Scale short form social scale. The social scale is comprised of 4 questions about frequency of social interactions "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Social: all to most days* (AIMS2-SF social scale score between 0 and 4, n=20, 20.00%), *Social; some days* (AIMS2-SF Social scale score greater than 4 to 6, n=36, 36.00%), and *Social; few to no days* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and *Social: all days* (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%),

Boxplots of each Care coordination scale by **AIMS2-SF Social scale** are displayed in Figures 7.16 to 7.20, summary statistics are displayed in Table 7.13.

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.14). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 7.15). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.16).

A one way ANOVA test indicated a statistically significant difference in the **"Care coordination: communication"** scale between groups, F(2, 97) = 7.93, p = 0.0006 (Table 7.14). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 39.30, SD = 9.73) was significantly higher than participants that scored *Social: some days* (mean = 35.00 , SD = 8.72, p=0.0007), and participants that scored *Social: no to few days* (mean = 29.55 , SD = 10.06, p=0.0331).

A one way ANOVA test indicated a statistically significant difference in the **"Care coordination: total score"** scale between groups, F(2, 97) = 6.86, p = 0.0016 (Table 7.14). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Social: all to most days* (mean = 63.25, SD = 14.71) was significantly higher than participants that scored *Social: no to few days* (mean = 50.80, SD = 13.26, p=0.0017).

The **"Care coordination: communication"** median scores for participants that scored *Social: all to most days* were significantly higher than those that scored *Social: some days* and *Social: no to few days.* These scores correspond to moderate healthcare communication for participants that scored *Social: all to most days,* and *Social: some days,* and poor healthcare communication for participants that scored *Social: no to few days.*

The **"Care coordination: total score"** median scores for participants that scored *Social: all to most days* were significantly higher than those that scored *Social: some days* and *Social: no to few days.* These scores correspond to moderate total care coordination (both communication and navigation) for participants that scored *Social: all to most days,* and poor total care coordination (both communication and navigation) for participants that scored *Social: no to few days.*

Table 7.13: **“Partners in health”** by **AIMS2-SF Social** scale summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Social: all to most days	20	20.00	39.30	9.73	40.50	9.75
	Social: some days	36	36.00	35.00	8.72	34.50	10.50
	Social: no to few days	44	44.00	29.55	10.06	30.50	14.00
Care coordination: navigation	Social: all to most days	20	20.00	23.95	5.75	25.00	8.75
	Social: some days	36	36.00	22.47	4.46	22.00	4.25
	Social: no to few days	44	44.00	21.25	5.76	20.00	8.25
Care coordination: total score	Social: all to most days	20	20.00	63.25	14.71	65.50	16.25
	Social: some days	36	36.00	57.47	11.56	56.50	12.25
	Social: no to few days	44	44.00	50.80	13.26	50.50	17.50
Care coordination: care coordination global measure	Social: all to most days	20	20.00	6.30	2.74	7.00	4.00
	Social: some days	36	36.00	5.75	2.27	6.00	4.00
	Social: no to few days	44	44.00	5.11	2.51	5.00	3.25
Care coordination: quality of care global measure	Social: all to most days	20	20.00	7.30	2.13	8.00	3.00
	Social: some days	36	36.00	7.06	1.80	7.00	2.00
	Social: no to few days	44	44.00	6.48	2.02	7.00	3.00

Table 7.14: **“Partners in health”** by **AIMS2-SF Social** ANOVA table

Care coordination scale		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	1442.00	2	720.90	7.93	0.0006*
	Within groups	8815.00	97	90.90		
	Total	10257.00	99			
Care coordination: navigation	Between groups	103.50	2	51.77	1.83	0.1670
	Within groups	2752.20	97	28.37		
	Total	2855.70	99			
Care coordination: total score	Between groups	2312.00	2	1155.80	6.86	0.0016*
	Within groups	16346.00	97	168.50		
	Total	18658.00	99			

* Statistically significant at $p<0.05$

Table 7.15: **“Partners in health”** by **AIMS2-SF Social** post hoc Tukey HSD test

Care coordination scale	AIMS2-SF Social scale	Difference	Lower	Upper	P adjusted
Care coordination: communication	*Some days - All to most days*	-4.30	-10.63	2.03	0.2432
	No to few days - All to most days	-9.75	-15.87	-3.64	0.0007*
	No to few days – Some days	-5.45	-10.55	-0.36	0.0331*
Care coordination: total score	*Some days - All to most days*	-5.78	-14.39	2.84	0.2523
	No to few days - All to most days	-12.45	-20.79	-4.12	0.0017*
	No to few days – Some days	-6.68	-13.62	0.27	0.0622

* Statistically significant at $p<0.05$

Table 7.16: **“Partners in health”** by **AIMS2-SF Social** Kruskal-Wallis test

Care coordination scale	X^2	df	p
Care coordination: care coordination global measure	3.33	2	0.1890
Care coordination: quality of care global measure	3.19	2	0.2029

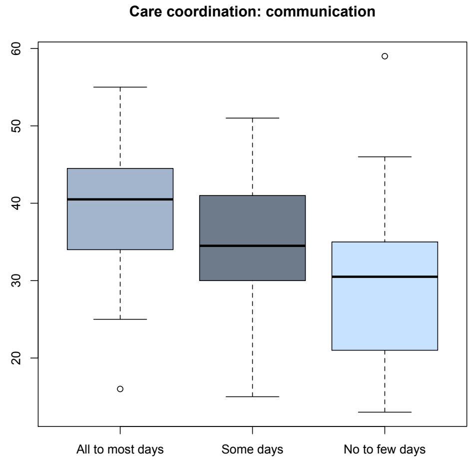


Figure 7.16: **"Care coordination: communication"** by **AIMS2-SF Social**

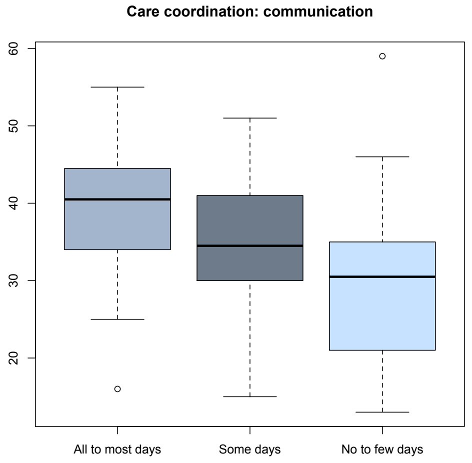


Figure 7.17: **"Care coordination: navigation"** by **AIMS2-SF Social**

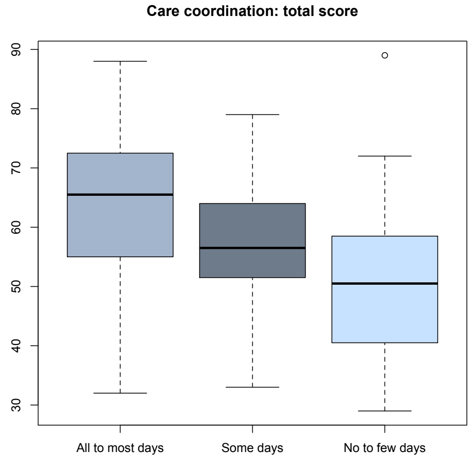


Figure 7.18: **"Care coordination: total score"** by **AIMS2-SF Social**

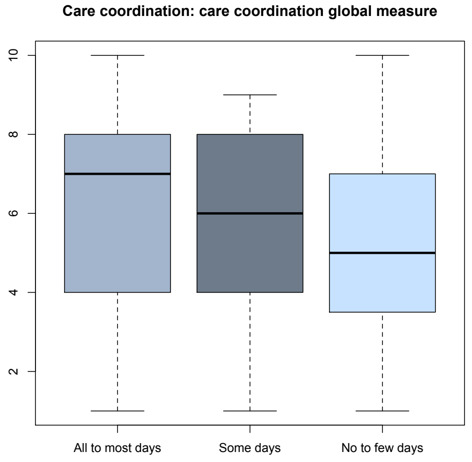


Figure 7.19: **"Care coordination: care coordination global measure"** by **AIMS2-SF Social**

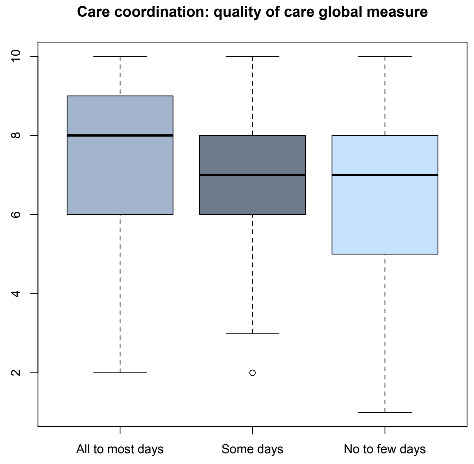


Figure 7.20: **"Care coordination: quality if care global measure"** by **AIMS2-SF Social**

Comparisons of Care Coordination scores by pain

Comparisons were made by **Flare-up frequency**, between participants that had *frequent flare-ups* (daily or weekly flare-ups, n=44, 44.00%) and participants that had *occasional flare-ups* (monthly flare-ups or less frequently, n=56, 56.00%).

Boxplots of each Partners in health scale by **Flare-up frequency** are displayed in Figures 7.21 to 7.25, summary statistics are displayed in Tables 7.17 to 7.18. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.18).

No significant differences were observed between participants by **Flare-up frequency** any of the Care coordination scales.

Table 7.17: **"Care coordination"** by **Flare-up frequency** two sample t-test

Care coordination	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: communication	Occasional flare-up	56	56.00	34.32	9.63	0.95	98	0.3423
	Frequent flare-up	44	44.00	32.36	10.85			
Care coordination: navigation	Occasional flare-up	56	56.00	22.63	5.07	0.83	98	0.4095
	Frequent flare-up	44	44.00	21.73	5.75			
Care coordination: total score	Occasional flare-up	56	56.00	56.95	13.38	1.03	98	0.3042
	Frequent flare-up	44	44.00	54.09	14.15			

Table 7.18: **"Care coordination"** by **Flare-up frequency** Wilcoxon rank sum test

Care coordination	Group	Count	Percent	Median	IQR	W	p
Care coordination: care coordination global measure	Occasional flare-up	56	56.00	7.00	4.00	1425.50	0.1763
	Frequent flare-up	44	44.00	5.00	3.00		
Care coordination: quality of care global measure	Occasional flare-up	56	56.00	7.00	2.00	1372.00	0.3258
	Frequent flare-up	44	44.00	7.00	3.00		

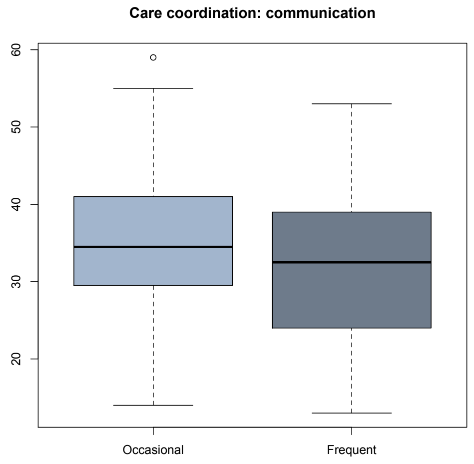


Figure 7.21: **“Care coordination: communication”** by **Flare-up frequency**

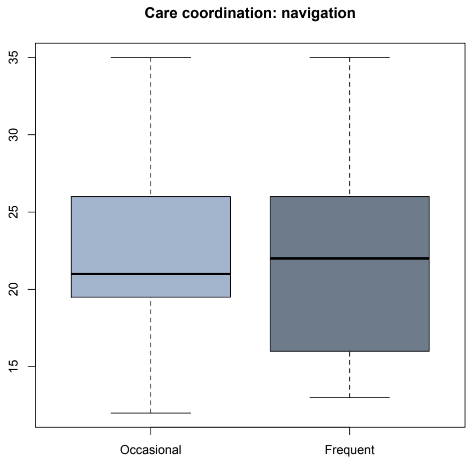


Figure 7.22: **“Care coordination: navigation”** by **Flare-up frequency**

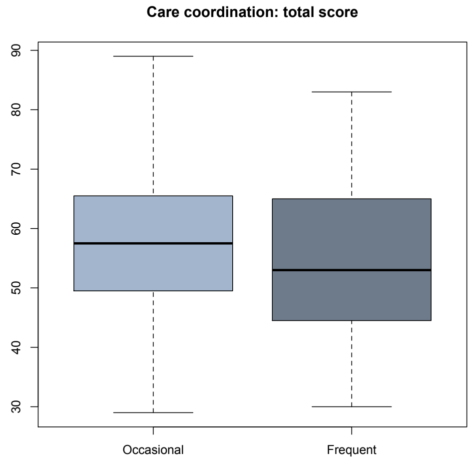


Figure 7.23: **“Care coordination: total score”** by **Flare-up frequency**

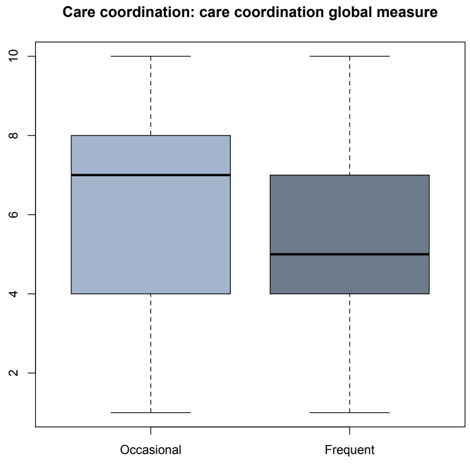


Figure 7.24: **“Care coordination: care coordination global measure”** by **Flare-up frequency**

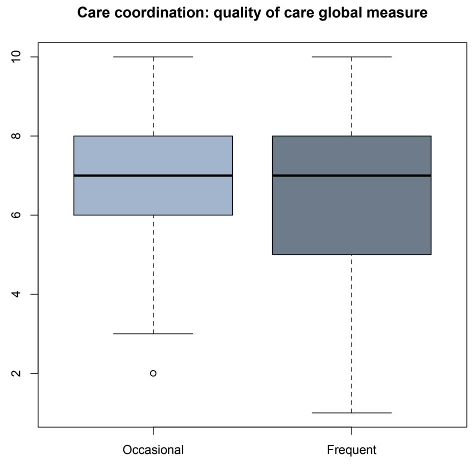


Figure 7.25: **“Care coordination: quality if care global measure”** by **Flare-up frequency**

Comparisons of Care Coordination scores by Age

Comparisons were made by the **Age** of the participants, those that were *aged 55 or older* (n=31, 31.00%), aged 35 – 54 (n=51, 51.00%) and participants aged 18 – 34 (n=18, 18.00%).

Boxplots of each Care coordination by **Age** are displayed in Figures 7.26 to 7.30, summary statistics are displayed in Table 7.19

A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.20). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.21).

No significant differences were observed between participants by **Age** any of the Care coordination scales.

Table 7.19: **"Partners in health"** by **Age** summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Aged 18 -34	18	31.00	33.28	10.32	33.50	17.50
	Aged 35 - 44	51	51.00	32.76	9.71	33.00	14.00
	Aged 55 or older	31	18.00	34.71	11.04	33.00	9.00
Care coordination: navigation	Aged 18 -34	18	31.00	22.56	5.12	23.00	5.50
	Aged 35 - 44	51	51.00	21.12	4.65	21.00	6.00
	Aged 55 or older	31	18.00	23.87	6.26	26.00	10.00
Care coordination: total score	Aged 18 -34	18	31.00	55.83	14.47	55.50	23.00
	Aged 35 - 44	51	51.00	53.88	12.77	54.00	15.50
	Aged 55 or older	31	18.00	58.58	14.74	59.00	17.50
Care coordination: care coordination global measure	Aged 18 -34	18	31.00	5.78	2.07	5.50	3.75
	Aged 35 - 44	51	51.00	5.43	2.39	6.00	3.00
	Aged 55 or older	31	18.00	5.71	2.90	7.00	4.00
Care coordination: quality of care global measure	Aged 18 -34	18	31.00	6.61	2.12	6.50	2.75
	Aged 35 - 44	51	51.00	6.88	1.68	7.00	2.00
	Aged 55 or older	31	18.00	6.94	2.37	8.00	3.50

Table 7.20: **"Partners in health"** by **Age** ANOVA table

Care coordination scale		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	74.00	2	36.83	0.35	0.7050
	Within groups	10183.00	97	104.98		
	Total	10257.00	2			
Care coordination: navigation	Between groups	148.50	97	74.24	2.66	0.0750
	Within groups	2707.20	2	27.91		
	Total	2855.70	97			
Care coordination: total score	Between groups	426.00	2	213.00	1.13	0.3260
	Within groups	18231.00	97	187.90		
	Total	18657.00	2			

Table 7.21: **"Partners in health"** by **Age** Kruskal-Wallis test

Care coordination scale	X^2	df	p
Care coordination: care coordination global measure	0.46	2	0.7933
Care coordination: quality of care global measure	0.72	2	0.6971

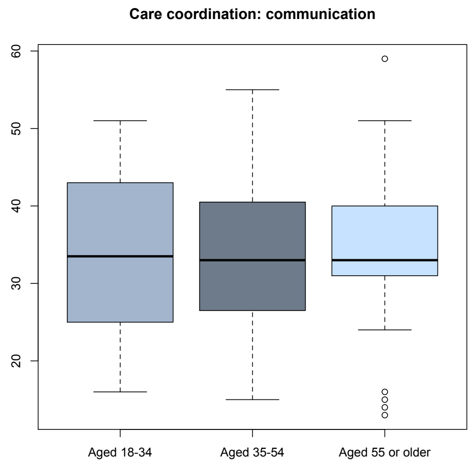


Figure 7.26: **"Care coordination: communication"** by **Age**

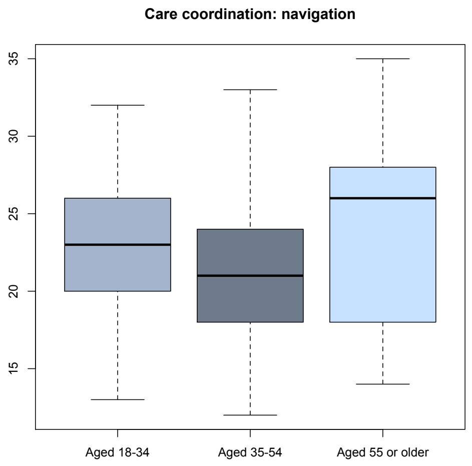


Figure 7.27: **"Care coordination: navigation"** by **Age**

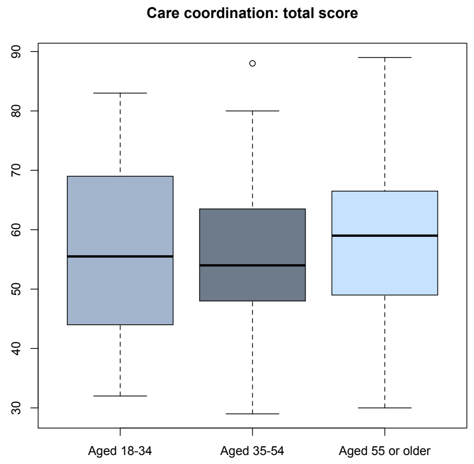


Figure 7.28: **"Care coordination: total score"** by **Age**

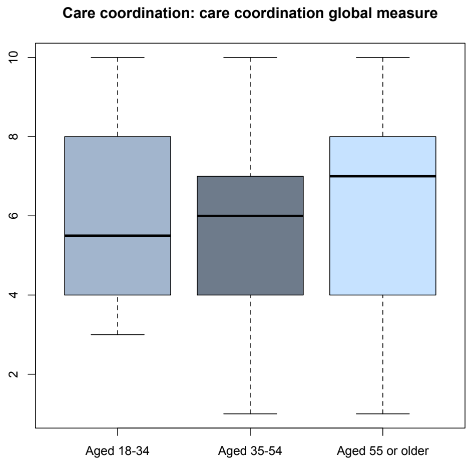


Figure 7.29: **"Care coordination: care coordination global measure"** by **Age**

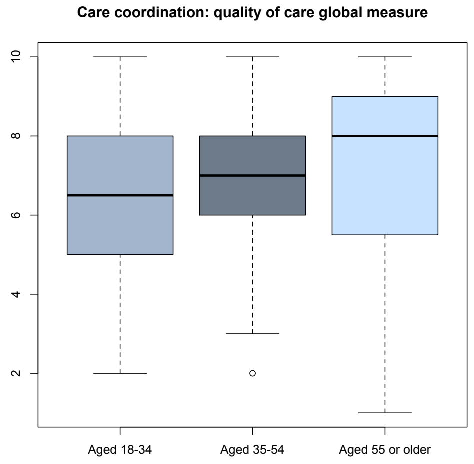


Figure 7.30: **"Care coordination: quality if care global measure"** by **Age**

Comparisons of Care Coordination scores by Location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from DoctorConnect (doctorconnect.gov.au), those living in a metropolitan area, *metropolitan* (n=56, 56.00%) were compared to those living in regional/rural areas, *regional or remote* (n=44, 44.00%).

Boxplots of each Care coordination by **Location** are displayed in Figures 7.31-7.35, summary statistics are displayed in Tables 7.22 to 7.23. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.23).

No significant differences were observed between participants that lived in *metropolitan* areas compared to those that lived in *regional or remote* areas for any of the Care coordination scales.

Table 7.22: **"Partners in health"** by **Location** two sample t-test

Care coordination	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: navigation	Metropolitan	56	56.00	22.84	5.75	1.28	98	0.2022
	Regional or remote	44	44.00	21.45	4.79			
Care coordination: total score	Metropolitan	56	56.00	55.73	15.34	0.03	98	0.9726
	Regional or remote	44	44.00	55.64	11.53			

Table 7.23: **"Partners in health"** by **Location** Wilcoxon rank sum test

Care coordination	Group	Count	Percent	Median	IQR	W	p
Care coordination: communication	Metropolitan	56	56.00	33.00	17.50	1134.00	0.4981
	Regional or remote	44	44.00	33.50	10.00		
Care coordination: care coordination global measure	Metropolitan	56	56.00	6.00	4.25	1165.50	0.6438
	Regional or remote	44	44.00	6.00	3.25		
Care coordination: quality of care global measure	Metropolitan	56	56.00	7.00	2.25	1181.50	0.7247
	Regional or remote	44	44.00	7.00	2.00		

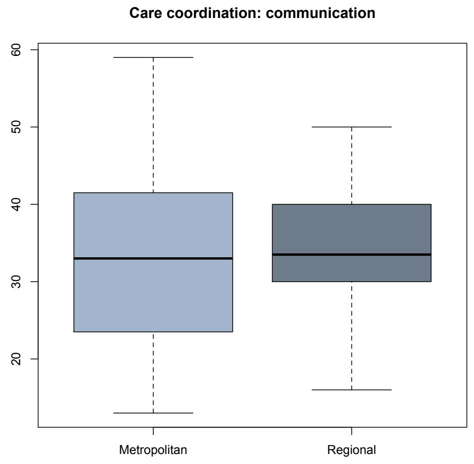


Figure 7.31: **“Care coordination: communication”** by **Location**

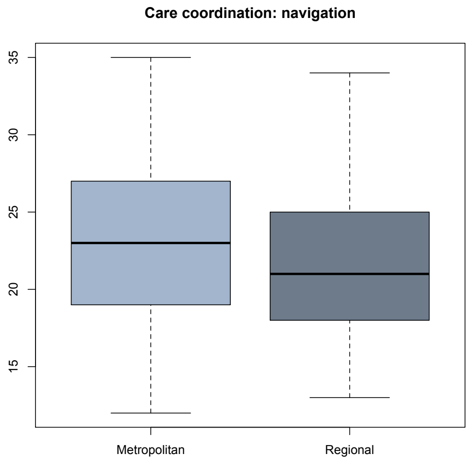


Figure 7.32: **“Care coordination: navigation”** by **Location**

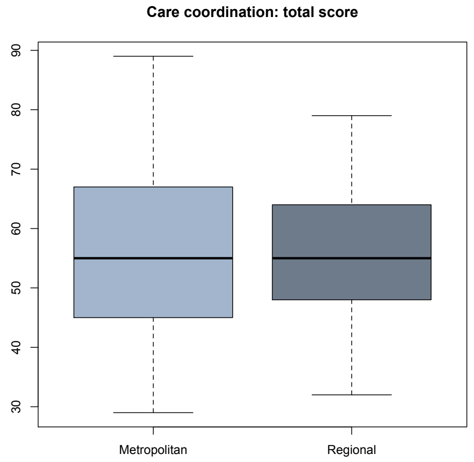


Figure 7.33: **“Care coordination: total score”** by **Location**

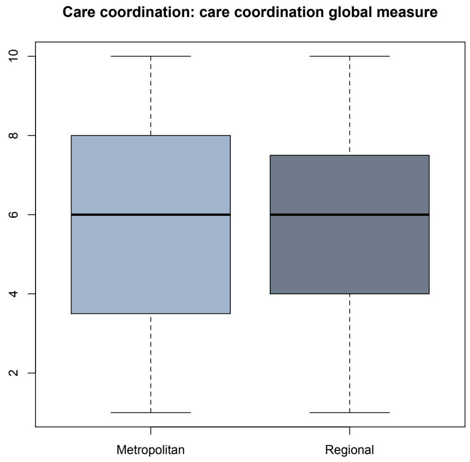


Figure 7.34: **“Care coordination: care coordination global measure”** by **Location**

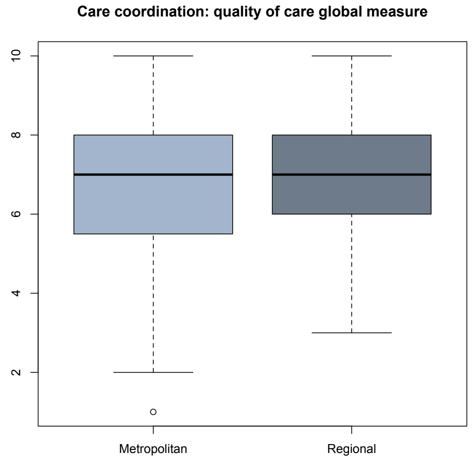


Figure 7.35: **“Care coordination: quality if care global measure”** by **Location**

Comparisons of Care Coordination scores by Education

Comparisons were made by **Education** status, between those with a university degree, *university* (n=66, 66.00%), and those with trade or high school qualifications, *trade or high school* (n=33, 33.00%); Boxplots of each Care coordination scale by **Education** are displayed in Figures 7.36 to 7.40, summary statistics are displayed in Tables 7.24 to 7.25. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.25).

A two sample t-test indicated that the mean score for the **"Care coordination: navigation"** scale [t(98) = -2.68, p=0.0087] (Table 7.24) was significantly higher for those with *University* qualifications (Mean = 23.21 SD= 5.43) compared to those with *Trade or high school* qualifications (Mean = 20.24, SD = 4.73).

A two sample t-test indicated that the mean score for the **"Care coordination: total score"** scale [t(98) = -2.14, p=0.0348] (Table 7.24) was significantly higher for those with *University* qualifications (Mean = 57.72 SD= 13.38) compared to those with *Trade or high school* qualifications (Mean = 51.58, SD = 13.70).

A Wilcoxon rank sum test indicated that the median score for the **"Care coordination: quality of care global measure"** [W=797.00, p=0.0220] (Table 7.25) was significantly higher for participants with *University* qualifications (Median =8.00, IQR = 3.00) compared to participants with *Trade or high school qualifications* (Median = 7.00, IQR = 3.00).

The **"Care coordination: navigation"** mean scores for participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications*.* These scores correspond to moderate navigation of the healthcare system for both groups.

The **"Care coordination: total score"** mean scores for participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications*.* These scores correspond to moderate total care coordination (both communication and navigation) for participants that with *University* qualifications*,* and poor total care coordination (both communication and navigation) for participants with *Trade or high school* qualifications.

The **"Care coordination: quality of care global measure"** median scores for participants with *University* qualifications were significantly higher than those with *Trade or high school* qualifications. These scores correspond to a good rating of quality of care by both of these groups.

Table 7.24: **"Partners in health"** by **Education** two sample t-test

Care coordination	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: communication	Trade or high school	33	33.00	31.33	10.36	-1.48	98	0.1434
	University	66	66.00	34.51	10.00			
Care coordination: navigation	Trade or high school	33	33.00	20.24	4.73	-2.68	98	0.0087*
	University	66	66.00	23.21	5.43			
Care coordination: total score	Trade or high school	33	33.00	51.58	13.70	-2.14	98	0.0348*
	University	66	66.00	57.72	13.38			

Table 7.25: **"Partners in health"** by **Education** Wilcoxon rank sum test

Care coordination	Group	Count	Percent	Median	IQR	W	p
Care coordination: care coordination global measure	Trade or high school	33	33.00	5.00	3.00	884.00	0.1021
	University	66	66.00	6.00	4.00		
Care coordination: quality of care global measure	Trade or high school	33	33.00	7.00	3.00	797.00	0.0220*
	University	66	66.00	8.00	3.00		

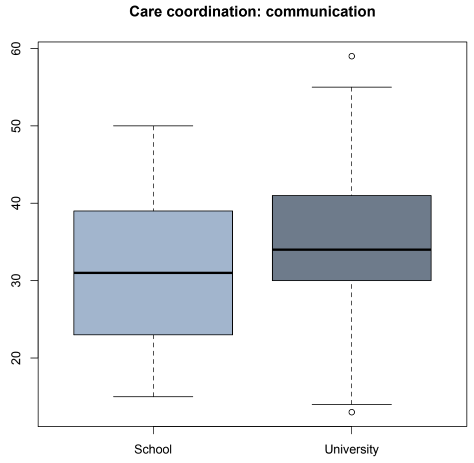


Figure 7.36: **"Care coordination: communication"** by **Education**

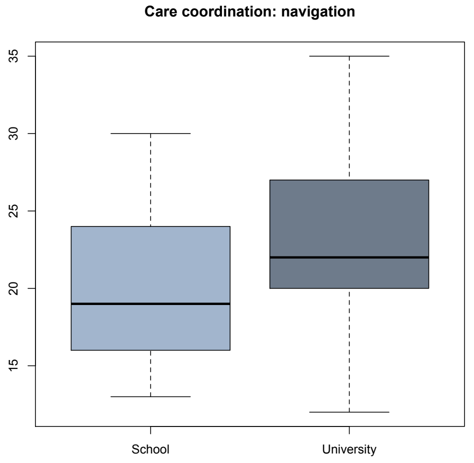


Figure 7.37: **"Care coordination: navigation"** by **Education**

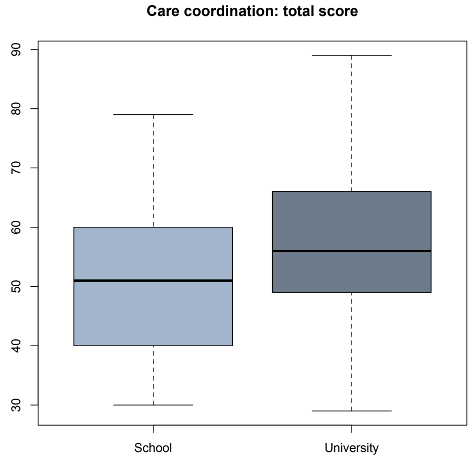


Figure 7.38: **"Care coordination: total score"** by **Education**

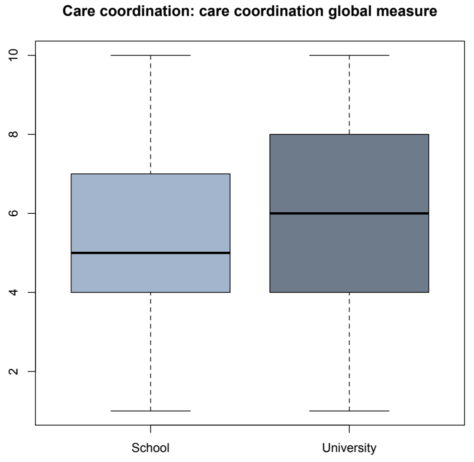


Figure 7.39: **"Care coordination: care coordination global measure"** by **Education**

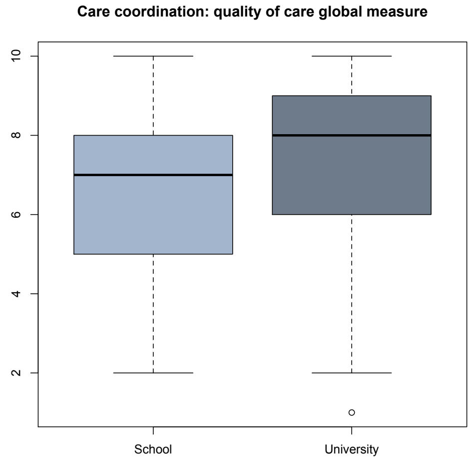


Figure 7.40: **"Care coordination: quality if care global measure"** by **Education**

Comparisons of Care Coordination scores by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10 , *high SEIFA* (n=50, 50.00%) compared to those with a mid to low SEIFA score of 1-6, *mid-low SEIFA* (n=50, 50.00%).

Boxplots of each Care coordination scale by **SEIFA** are displayed in Figures 7.41 to 7.45, summary statistics are displayed in Tables 7.26 – 7.27. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.27).

No significant differences were observed between participants that lived in areas with a *High SEIFA* compared to those that lived in an area with *a Mid to low SEIFA* areas for any of the Care coordination scales.

Table 7.26: **"Partners in health"** by **SEIFA** two sample t-test

Care coordination	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: navigation	High SEIFA	0.00	0.00	22.40	5.78	0.32	98	0.7534
	Mid to low SEIFA	0.00	0.00	22.06	4.98			

Table 7.27: **"Partners in health"** by **SEIFA** Wilcoxon rank sum test

Care coordination	Group	Count	Percent	Median	IQR	W	p
Care coordination: communication	High SEIFA	0.00	0.00	34.50	16.50	1302.00	0.7224
	Mid to low SEIFA	0.00	0.00	33.00	9.75		
Care coordination: total score	High SEIFA	0.00	0.00	55.50	19.50	1297.50	0.7458
	Mid to low SEIFA	0.00	0.00	54.50	16.00		
Care coordination: care coordination global measure	High SEIFA	0.00	0.00	6.00	4.00	1302.50	0.7176
	Mid to low SEIFA	0.00	0.00	6.00	3.00		
Care coordination: quality of care global measure	High SEIFA	0.00	0.00	7.00	2.00	1230.00	0.8915
	Mid to low SEIFA	0.00	0.00	7.00	2.00		

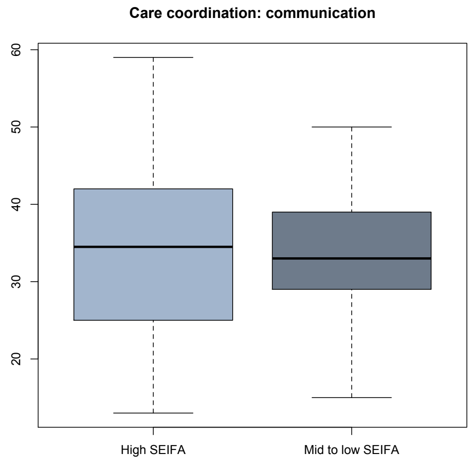


Figure 7.41: **“Care coordination: communication”** by **SEIFA**

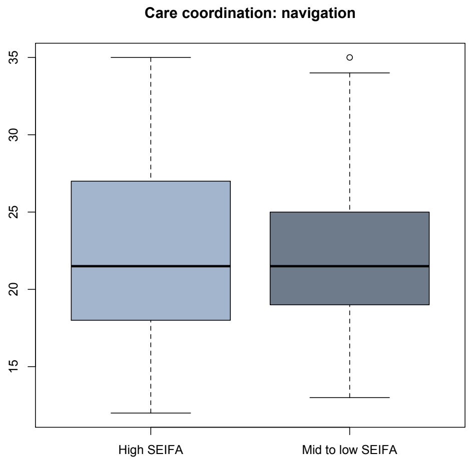


Figure 7.42: **“Care coordination: navigation”** by **SEIFA**

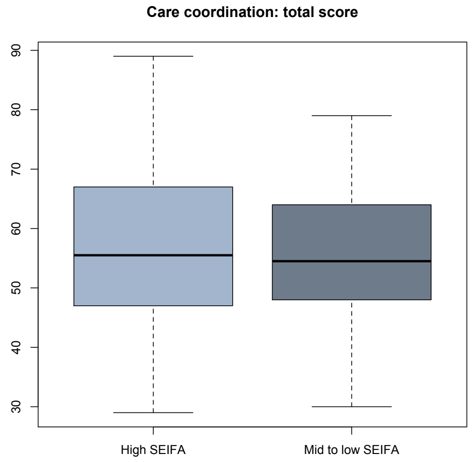


Figure 7.43: **“Care coordination: total score”** by **SEIFA**

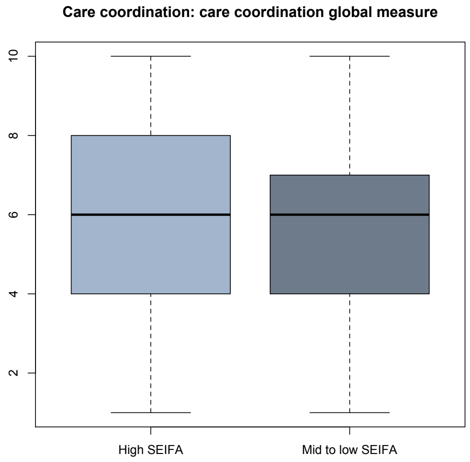


Figure 7.44: **“Care coordination: care coordination global measure”** by **SEIFA**

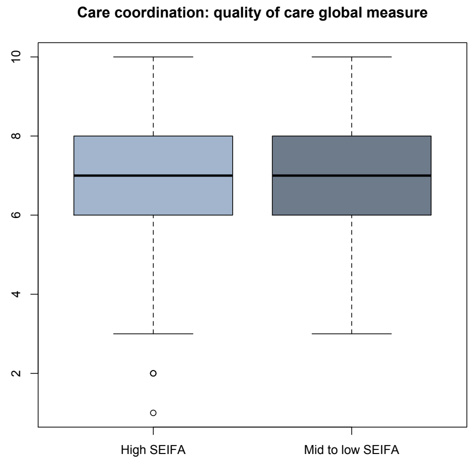


Figure 7.45: **“Care coordination: quality if care global measure”** by **SEIFA**

Adherence to treatment

Participants were asked about their ability to take medicine and stick to that regimen. More than half responded that they could take medicine and stick to it ”All the time” (n=55, 55.00%), 40 participants (40.00%) responded “Most of the time”, very few answered “Sometimes” (n=4, 4.00%) or “Rarely” (n=1, 1.00%).

Table 7.28: Ability to take medicine

Ability to take medicine and stick to it	N=100	Percent
Never	0	0.00
Rarely	1	1.00
Sometimes	4	4.00
Most of the time	40	40.00
All of the time	55	55.00

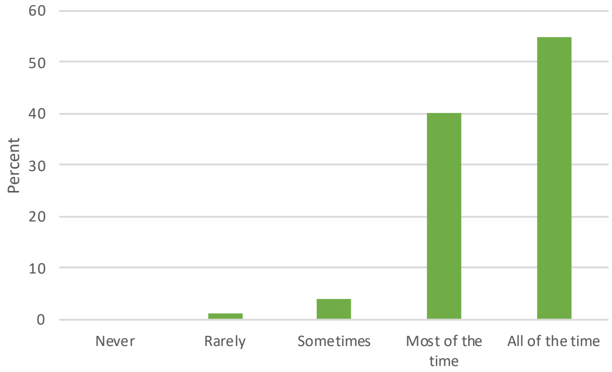


Figure 7. 46: Ability to take medicine

Experience of care and support

The most common source of care and support reported by participants was from participant's GP/specialist (n=33, 33.00%), followed by friends (n=28, 28.00%), family (n=21, 21.00%), support group (n=18, 18.00%), complimentary therapy and allied health (n=15, 15.00%), received no help (n= 14, 14.00%), online peer support (n=14, 14.00%), partner support (n=14, 14.00%), parental/sibling support (n=13, 13.00%), support from charities (n=12, 12.00%) and domestic support (n=8, 8.00%).

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (21.05%) , *Physical limitations: some to most days* (18.92%), *Symptoms: no to few days* (20.00%), *Affect: very often to always* (19.35), and *Aged 18 – 34* (22.22%) reported the care and support from GP/specialist less often than the general cohort (33.00%), and those in the sub-group *Physical limitations: few days* (50.00%) reported this more frequently.

Participants *Aged 55 or older* (41.94%) reported that the most common source of care and support was from friends more frequently than the general cohort (28.00%).

Participants in the sub-group *Physical limitations: no days* (10.53%) reported that the most common source of care and support was from family less frequently than the general cohort (21.00%), while participants *Aged 55 or older* (32.26%), reported this more frequently.

Participants in the sub-group *Social: all to most days* (30.00%) reported that the most common source of care and support was from support groups more frequently than the general cohort (18.00%).

Participants in the sub-group *Social: all to most days* (30.00%) reported that the most common source of care and support was from complementary therapies more frequently than the general cohort (15.00%).

Participants *Aged 55 or older* (3.23%) reported that the most common source of care and support was from online peer support less frequently than the general cohort (14.00%), while participants in the sub-group *Physical limitations: no days* (31.58%), reported this more frequently.

Participants *Aged 55 or older* ((25.81%) reported that the most common source of care and support was from their partner more frequently than the general cohort (14.00%).

No participants in the sub-group *Social: all to most days* reported that the most common source of care and support was from a charity, compared to 12.00% of the general population.

No participants in the sub-group *Physical limitations: no days,* reported that the most common source of care and support was from a domestic support, compared to 8.00% of the general population. Participants in the sub-groups. *some to most days* (18.92%), *Aged 55 or older* (19.35%) reported domestic support more frequently than the general population.

Participants describes receiving support from GP/Specialist

Excellent is all I can say, that the doctors and medical staff, the hospitals, they've all been wonderful, they're all compassionate. Participant 96.

I called the house doctor out and the house doctor was magnificent. He, he was just really lovely and he's sort of in a way sort of put my husband in his place. Just explained the severity of the situation how lightly he was taking it and almost being accusatory towards me as you know, blowing it out of proportion or whatever else. Participant 31.

GP has been good. Although there has been times I've taken him to task. Um, I think, well I've been going to him for over 20 years, so I'm really honest with him. Participant 10.

Participant describes support from friends

I'm assured definitely by NAME. She's like my best friend, my biggest support and she's very helpful because she's not, she should get it in a way that other people don't. Um, because she's been dealing with it to whole career…so, you know, she's been a big support. Participant 36.

I have friends who come around to do something instead of going out to strenuous mini golfing or something, we might just come around and watch movies at my house. Participant 91.

I have had friends like within the church or whatever that have bought me a hot meal for NAME and I can say it's particularly bad time, but I do just try not to sort of say too much and I do just try to keep going. Participant 61

Participant describes support from family

Well, I guess your family gives you moral support. They can't really do much else. Participant 20.

My grandparents have been supportive as well, you know, like just things like my nanny was, gives me a call every now and then just see how I'm going, which is made a difference at the time, which is nice. Participant 89.

Family, some are good, some are not, but the ones that are important are there for me. It's like, "You're not feeling good, so you have a lie down. I'll get you a cup of tea." or, "Do you want something to eat". Participant 96.

Participant describes support from face-to-face support groups

I found a sort of support group through friends that are exclusive to rheumatoid, you know, a specific place where you can exchange experiences. Participant 63.

Um, I've had a couple of colleagues that have introduced me to somebody else who they know who or somebody local who they know, who has had rheumatoid arthritis or who has rheumatoid arthritis and that's been useful to be able to just talk to somebody else who's been through the same thing. Participant 39.

I think just the support group would really be the main one that I have ran to now. I know we've got quite a lot of people in our area that have autoimmune diseases. So that's actually been scary because there's so many, but, um, it's been good because we've been able to link up with each other and support each other. Participant 97.

Participant describes support from complementary therapy practitioners

Probably the biggest support I've had is my meditation teacher. I go there quite regularly, not all the time. And I have periods where I don't go that she holds a really good space to just be able to talk and express yourself, what's going on and also just really tapping into gratitude and see yourself as, you know, a divine creature. You, you, you see the illness. Like I feel like really like when I, when I go there really recharges me totally, the best place that I go for support. Participant 99.

Uh, well, I've had physio and occupational therapy at times. Um, but that's, you know, that's expensive too so that isn't always freely available. Participant 54.

No, as I said before, we don't. Apart from having the occupational therapist come and assess the house and give useful advice about assistive technology and then the chaps from the planned modifications came and sorted out to the smaller issues, minor modifications with them. Participant 70.

Participant describes support from online rheumatoid arthritis groups

Just the online groups. That's pretty much it. I think it's good to be in a safe place to talk to other people about similar issues. It's like people with cancer who like to talk to other people with cancer because they truly understand what you're going through. I think there's that sense of sameness. We're standing outside everybody else, all the ones who keep saying, "My grandmother's got osteoarthritis." Participant 93.

I also actually joined an online, um, young adults who support group. I've now moved into an admin role, so I do more admin stuff than the support itself. Um, but that was quite good for a while as well because we had face to face meetups as well as online. Participant 82.

I did find a group on Facebook people the same or similar conditions are just leaving their example. So finding out What's normal? It's normal for them. It's been very interesting. Participant 5.

Participant describes support from partner

Support wise, mostly I think my wife, she's been very good with it all. Um, so that's been very helpful in terms of when I saw my diagnosis gets though, all the different testing, the medication, she was supportive in that process to the point where she covered all questions type of stuff, even when I'm not thinking that. Participant 18.

Yeah, he's amazing. He's, he'll help me dress, he'll help me the days I can't tie my shoe laces, he'll tie them for me like that. And then as the day goes on, I can get better. I know I'm increasingly having difficulty with my hands. And that's going to be, and my feet but that's normal. Participant 57.

And at the moment my partner does pretty much, he does a lot as well. Yeah. He'll brush my hair and, help me dress or help me with the toilet if I've got to be off the toilet. Participant 100.

Participant describes support from charities

Going back to talking about the arthritis organizations. Through the organizations that I'm working with-- The Young Women's Arthritis Support Group is the name of the support group that I help to run. We have had a relationship with what used to be known as Arthritis Victoria. They've gone through several name changes. They're now Musculoskeletal Australia. Participant 26.

I guess support, knowing there is an organization that focuses on the illness is great, but I'd like, I sign up, I've subscribed to my CHARITY, the newsletters and stuff, but RA wasn't always an article on RA in the newsletter. Sometimes it's on osteo, um, which is fine, but it's like, okay, it happened to me on that one, you know, so, it's interesting but it's not all relevant to me, if, you know what I mean. So I'm, I skim through looking for something that resonates with me and there hasn't been a lot in the ones that have already been signed up for six months or something. Participant 17.

Now I have through CHARITY, I have a woman come once a fortnight and vacuum the floors, anything and I pay a young fellow to come and help me in the garden. Participant 83.

Participant describes support from parents/siblings

I guess the main two would be from, directly from my family, my parents and my brother and his girlfriend. Um, and maybe the because they're around me most of the time. Um, one or two other friends have been really good. Participant 72.

Mostly it's family, yeah. Like I can't do up buttons, so I don't buy anything that has buttons. I struggle with shoe laces someday for most of my shoes are ones I can slip on or manage in other ways. If I can't do it, I can't find a gadget or a device that helps me do it. I have to cheat and get something different in place, but I can still do a lot of things. So funny. My mum's always going to be my mum. I think if she was 100 and she's still alive. She'll still cook extra meals for me and for the nieces and nephews so that you know, she'd. Yeah, there's some food so anytime we're going back to the country, they're coming home with fridges and freezers full of this stack of stuff so that when I'm having a bad day just there and it's easy to. Easy to manage, be just a planned thing. Participant 91.

I've always had, um, my mother or Father there, If not my sister. Yeah. My older sister. Yup. Yup. Other than that um, as my Daughter got older, she, um, did a lot for me as well. So, my younger sister also lived with me and she helped out with whatever she could do. So, I've just, I've always, I've never really looked for help beyond just always been one of my family members have always been there. Participant 100.

Table 7.29: Experience of care and support received

Care and support received	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes receiving care and support from their general practitioner or specialist	33	33.00	4	21.05	22	50.00	7	18.92	4	20.00	9	33.33	13	40.63	7	33.33
Participant describes receiving care and support from family and friends (Friends)	28	28.00	4	21.05	14	31.82	10	27.03	5	25.00	9	33.33	10	31.25	4	19.05
Participant describes receiving care and support from family and friends (General)	21	21.00	2	10.53	10	22.73	9	24.32	5	25.00	5	18.52	7	21.88	4	19.05
Participant describes receiving care and support from peer support (Support groups)	18	18.00	4	21.05	7	15.91	7	18.92	2	10.00	5	18.52	8	25.00	3	14.29
Participant describes receiving care and support from complementary therapists and allied health (All)	15	15.00	4	21.05	5	11.36	6	16.22	3	15.00	2	7.41	6	18.75	4	19.05
Participant describes receiving care and support from complementary therapists and allied health (Complementary therapists)	5	5.00	1	5.26	2	4.55	2	5.41	1	5.00	1	3.70	1	3.13	2	9.52
Participant describes receiving care and support from complementary therapists and allied health (Allied health)	10	10.00	3	15.79	3	6.82	4	10.81	2	10.00	1	3.70	5	15.63	2	9.52
Participant describes receiving no care and support (or felt alone)	14	14.00	3	15.79	6	13.64	5	13.51	2	10.00	6	22.22	4	12.50	2	9.52
Participant describes receiving care and support from peer support (Online including Facebook)	14	14.00	6	31.58	4	9.09	4	10.81	4	20.00	4	14.81	3	9.38	3	14.29
Participant describes receiving care and support from family and friends (Partner)	14	14.00	2	10.53	6	13.64	6	16.22	4	20.00	2	7.41	5	15.63	3	14.29
Participant describes receiving care and support from charities	12	12.00	4	21.05	2	4.55	6	16.22	3	15.00	3	11.11	4	12.50	2	9.52
Participant describes receiving care and support from family and friends (Immediate family specified)	13	13.00	3	15.79	4	9.09	6	16.22	2	10.00	4	14.81	4	12.50	3	14.29
Participant describes receiving care and support from domestic Support	8	8.00	0	0.00	1	2.27	7	18.92	0	0.00	1	3.70	5	15.63	2	9.52

Care and support received	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes receiving care and support from their general practitioner or specialist	33	33.00	13	39.39	14	38.89	6	19.35	7	35.00	14	38.89	12	27.27
Participant describes receiving care and support from family and friends (Friends)	28	28.00	8	24.24	10	27.78	10	32.26	5	25.00	13	36.11	10	22.73
Participant describes receiving care and support from family and friends (General)	21	21.00	6	18.18	10	27.78	5	16.13	6	30.00	7	19.44	8	18.18
Participant describes receiving care and support from peer support (Support groups)	18	18.00	4	12.12	7	19.44	7	22.58	6	30.00	5	13.89	7	15.91
Participant describes receiving care and support from complementary therapists and allied health (All)	15	15.00	5	15.15	6	16.67	4	12.90	5	25.00	4	11.11	6	13.64
Participant describes receiving care and support from complementary therapists and allied health (Complementary therapists)	5	5.00	1	3.03	3	8.33	1	3.23	3	15.00	1	2.78	1	2.27
Participant describes receiving care and support from complementary therapists and allied health (Allied health)	10	10.00	4	12.12	3	8.33	3	9.68	2	10.00	3	8.33	5	11.36
Participant describes receiving no care and support (or felt alone)	14	14.00	5	15.15	5	13.89	4	12.90	1	5.00	5	13.89	8	18.18
Participant describes receiving care and support from peer support (Online including Facebook)	14	14.00	4	12.12	5	13.89	5	16.13	1	5.00	3	8.33	10	22.73
Participant describes receiving care and support from family and friends (Partner)	14	14.00	3	9.09	6	16.67	5	16.13	1	5.00	6	16.67	7	15.91
Participant describes receiving care and support from charities	12	12.00	2	6.06	6	16.67	4	12.90	2	10.00	4	11.11	6	13.64
Participant describes receiving care and support from family and friends (Immediate family specified)	13	13.00	4	12.12	3	8.33	6	19.35	0	0.00	7	19.44	6	13.64
Participant describes receiving care and support from domestic Support	8	8.00	1	3.03	5	13.89	2	6.45	3	15.00	3	8.33	2	4.55

Care and support received	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 45***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes receiving care and support from their general practitioner or specialist	33	33.00	18	32.14	15	34.09	9	29.03	20	39.22	4	22.22
Participant describes receiving care and support from family and friends (Friends)	28	28.00	18	32.14	10	22.73	13	41.94	10	19.61	5	27.78
Participant describes receiving care and support from family and friends (General)	21	21.00	13	23.21	8	18.18	10	32.26	7	13.73	4	22.22
Participant describes receiving care and support from peer support (Support groups)	18	18.00	9	16.07	9	20.45	3	9.68	9	17.65	6	33.33
Participant describes receiving care and support from complementary therapists and allied health (All)	15	15.00	5	8.93	10	22.73	3	9.68	8	15.69	4	22.22
Participant describes receiving care and support from complementary therapists and allied health (Complementary therapists)	5	5.00	1	1.79	4	9.09	1	3.23	2	3.92	2	11.11
Participant describes receiving care and support from complementary therapists and allied health (Allied health)	10	10.00	4	7.14	6	13.64	2	6.45	6	11.76	2	11.11
Participant describes receiving no care and support (or felt alone)	14	14.00	8	14.29	6	13.64	4	12.90	8	15.69	2	11.11
Participant describes receiving care and support from peer support (Online including Facebook)	14	14.00	10	17.86	4	9.09	1	3.23	9	17.65	4	22.22
Participant describes receiving care and support from family and friends (Partner)	14	14.00	10	17.86	4	9.09	8	25.81	3	5.88	3	16.67
Participant describes receiving care and support from charities	12	12.00	7	12.50	5	11.36	4	12.90	7	13.73	1	5.56
Participant describes receiving care and support from family and friends (Immediate family specified)	13	13.00	6	10.71	7	15.91	2	6.45	9	17.65	2	11.11
Participant describes receiving care and support from domestic Support	8	8.00	6	10.71	2	4.55	6	19.35	2	3.92	0	0.00

Care and support received	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes receiving care and support from their general practitioner or specialist	33	33.00	21	37.50	12	27.27	12	36.36	21	31.34	18	36.00	15	30.00
Participant describes receiving care and support from family and friends (Friends)	28	28.00	14	25.00	14	31.82	8	24.24	20	29.85	15	30.00	13	26.00
Participant describes receiving care and support from family and friends (General)	21	21.00	9	16.07	12	27.27	7	21.21	14	20.90	10	20.00	11	22.00
Participant describes receiving care and support from peer support (Support groups)	18	18.00	11	19.64	7	15.91	8	24.24	10	14.93	9	18.00	9	18.00
Participant describes receiving care and support from complementary therapists and allied health (All)	15	15.00	7	12.50	8	18.18	5	15.15	10	14.93	9	18.00	6	12.00
Participant describes receiving care and support from complementary therapists and allied health (Complementary therapists)	5	5.00	3	5.36	2	4.55	2	6.06	3	4.48	2	4.00	3	6.00
Participant describes receiving care and support from complementary therapists and allied health (Allied health)	10	10.00	4	7.14	6	13.64	3	9.09	7	10.45	7	14.00	3	6.00
Participant describes receiving no care and support (or felt alone)	14	14.00	10	17.86	4	9.09	4	12.12	10	14.93	8	16.00	6	12.00
Participant describes receiving care and support from peer support (Online including Facebook)	14	14.00	7	12.50	7	15.91	3	9.09	11	16.42	5	10.00	9	18.00
Participant describes receiving care and support from family and friends (Partner)	14	14.00	7	12.50	7	15.91	3	9.09	11	16.42	8	16.00	6	12.00
Participant describes receiving care and support from charities	12	12.00	5	8.93	7	15.91	4	12.12	8	11.94	5	10.00	7	14.00
Participant describes receiving care and support from family and friends (Immediate family specified)	13	13.00	9	16.07	4	9.09	5	15.15	8	11.94	9	18.00	4	8.00
Participant describes receiving care and support from domestic Support	8	8.00	1	1.79	7	15.91	4	12.12	4	5.97	4	8.00	4	8.00

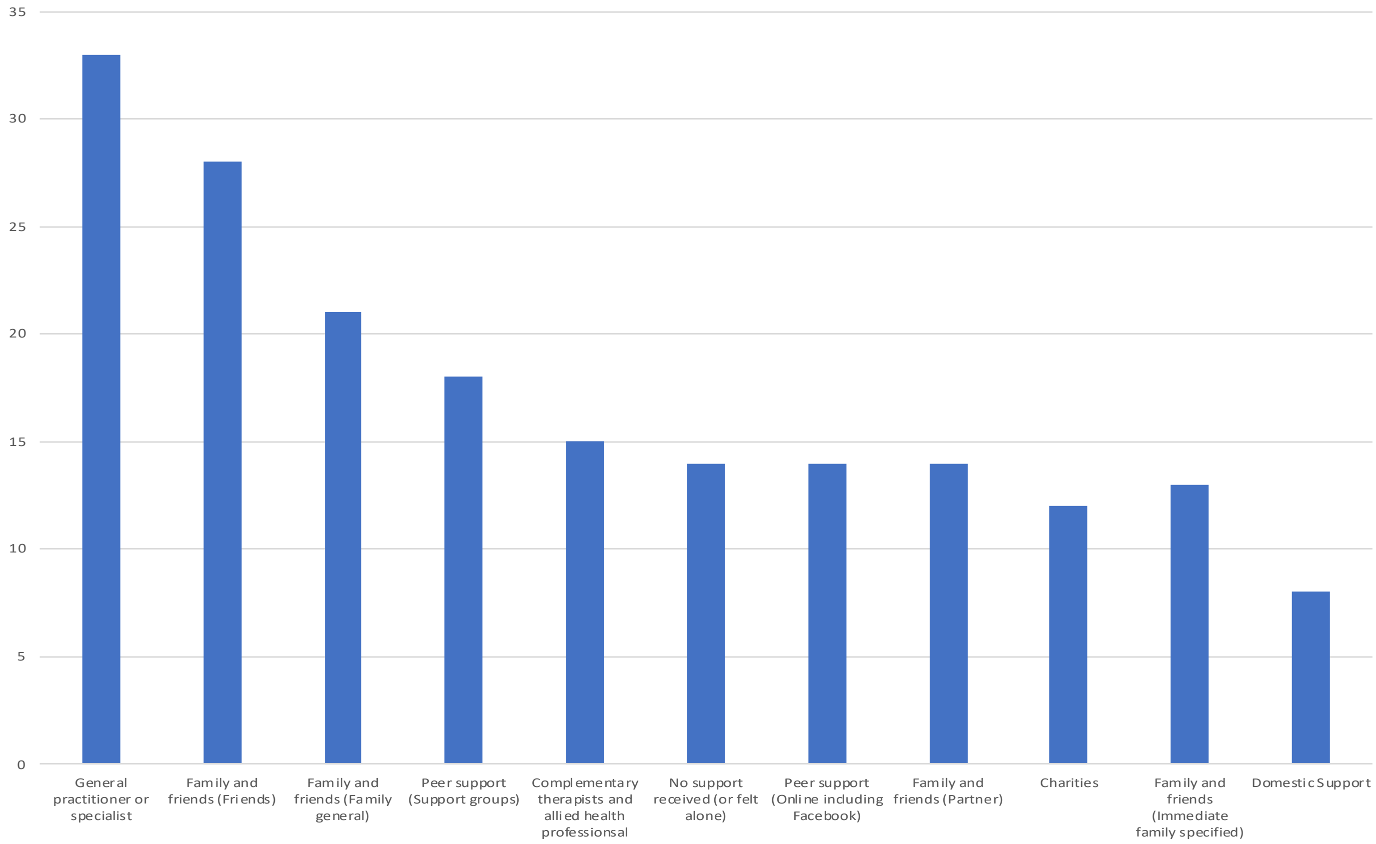


Figure 7.47: Experience of care and support received

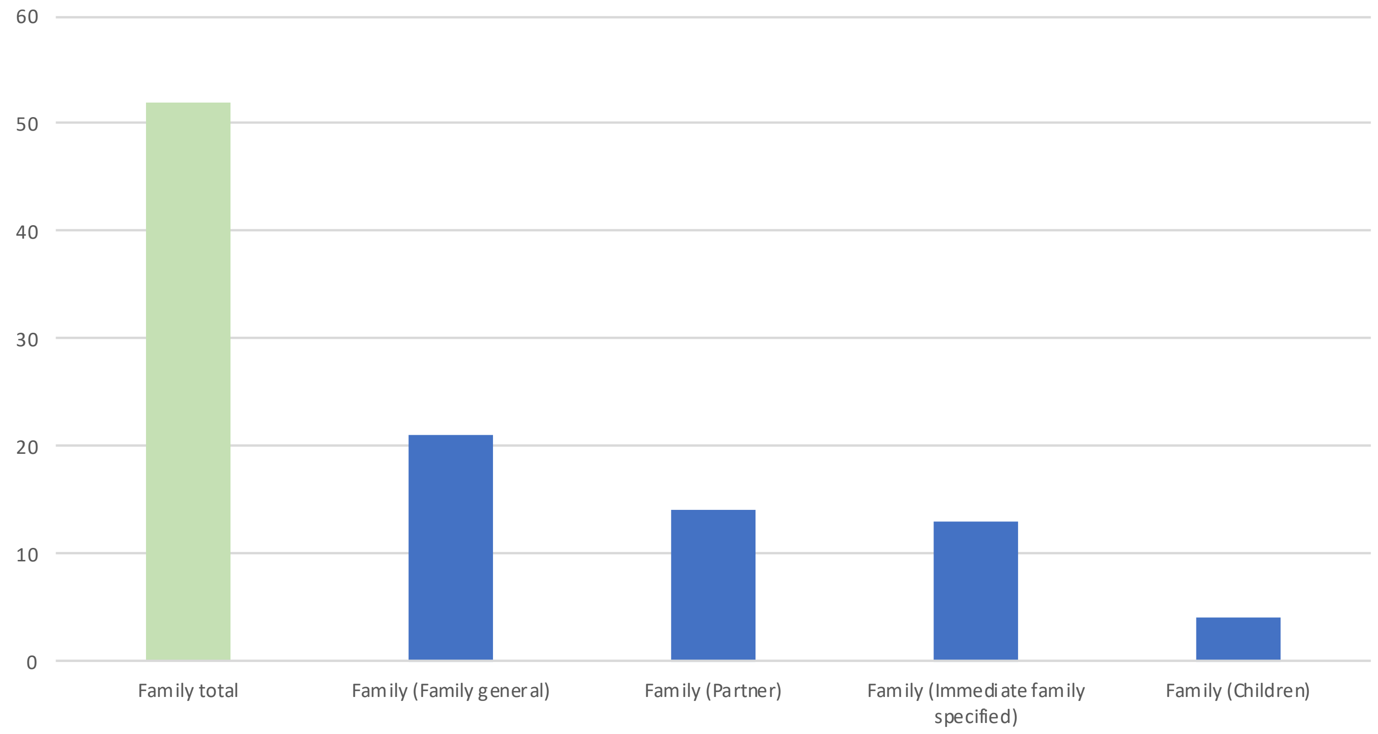


Figure 7.48: Experience of care and support received (Family support)

Section 8 Quality of life

Section 8: Experience of quality of life

Impact on quality of life

Overall, there were 78 participants that described at least one negative impact on quality of life and 14 that described no impact or a positive impact on quality of life, with a further two participants who described an overall positive impact of quality of life. There were six participants who described both positive and negative impacts of quality of life in equal measure. The most common themes in relation to having a negative impact on quality of life included impact on physical activity (37.00%), impact on children (26.00%), impact on their partner (25.00%), impact on fatigue levels (23,00%), reduced social life (19.00%), inability to work (14.00%) and impact on immediate family including parents/siblings (12.00%).

Regular activities to maintain mental health

The most common way that participants reported managing their mental and emotional health was by visiting a mental health professional, usually a psychiatrist, psychologist, or counsellor (20.00%). Other activities that participants reported practicing regularly in order to maintain their mental health were receiving emotional support from family and friends (18.00%), practicing mindfulness meditation (13.00%), remaining physically active (11.00%), ensuring they retained a positive outlook (10%), and using antidepressants (8.00%). There were 10.00% of participants who reported that they struggled with mental health issues but did not practice any regular activities to maintain their mental health, and 10.00% of participants reported that they did not have to practice any activities as their mental health was good.

Regular activities to maintain physical health

The most common theme described by participants as a regularly performed activity to maintain health was listening to their body and resting (29.00%). Other reported activities included ensuring they were compliant to treatment regimens (27.00%), keeping up physical activities (19.00%), getting enough sleep (14.00%), pacing their activities and/or accepting help when required (11.00%), practicing meditation or mindfulness (9.00%) and modifying their diet (9.00%).

Impact on relationships

The most common theme described by participants was a loss of friendship (34.00%). This was followed by no impact on family/friends (30%), not being able to attend social events (16.00%), stress on their partner (16.00%), relationship becoming more complicated (15.00%), and low awareness of rheumatoid arthritis which had an impact on relationships (15.00%).

Burden on family

Participants were also asked if their condition caused any additional burden on their family. The most common theme was that the family takes on extra duties (41.00%). This was followed by worrying about the future burden that may result from their rheumatoid arthritis (19.00%), the mental/emotional burden on their family (18.00%), no burden as they require little assistance (12.00%) and family taking up extra driving duties for the participant (8.00%).

Cost considerations

There were 39% of participants who mentioned that treatment costs were a significant burden of having rheumatoid arthritis. Other costs included having to take time off work (37.00%), spending money on specialists (36.00%), day to day costs associated with the condition (10.00%), costs of complementary therapies (10.00%) and costs at diagnosis (8.00%). There were also 9.00% of participants that described not struggling financially as their insurance covered their treatment.

Anxiety and fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Overall the entire cohort had a mean total score of 38.67 (SD = 8.88), which is a score in the middle of the scale, indicating a moderate anxiety about their health.

Experience of quality of life

Overall, there were 78 participants that described at least one negative impact on quality of life and 14 that described no impact or a positive impact on quality of life, with a further two participants who described an overall positive impact of quality of life. There were six participants who described both positive and negative impacts of quality of life in equal measure. The most common themes in relation to having a negative impact on quality of life included impact on physical activity (37.00%), impact on children (26.00%), impact on their partner (25.00%), impact on fatigue levels (23,00%), reduced social life (19.00%), inability to work (14.00%) and impact on immediate family including parents/siblings (12.00%).

In relation to sub-group variations, participants *Aged 55 or older* (48.39%) reported negative quality of life due to impact of physical activity more often than the general population (37.00%).

Participants in the sub-groups *Physical limitations: no days* (10.53%), *Symptoms: no to few days* (10.00%), *Affect: never to almost never* (9.90%),and *Social: all to most days* (10.00%) reported negative quality of life due to impact on children or grandchildren, less frequently than the general population (37.00%). Participants in the sub-groups *Physical limitations: some to most days (37.84%), Symptoms: most days,* (37.50%), *Affect: very often to always* (45.16%), and *Trade or high school* (39.39%) reported the impact on children more often than the general population.

Participants in the sub-groups *Symptoms: no to few days* (10.00%), *Symptoms: some days* (14.81%), and *Aged 18 – 34* (5.56%) reported negative quality of life due to impact on partner less frequently than the general population (25.00%). Participants in the sub-group *Symptoms: all days* (47.62%) reported the impact on partners more often than the general population.

No participants in the sub-group *Social: no to few days* (34.09%) reported that fatigue had a negative impact on quality of life. Participants in the sub-groups *Symptoms: most days* (9.38%), *Affect: very often to always* (12.90%), *Aged 55 or older* (9.68%), and *Aged 18 – 34* (11.11%) reported negative quality of life due to impact of fatigue less frequently than the general population (23.00%). Participants in the sub-groups *Physical limitations: no days (36.84%), Symptoms: no to few days (45.00%),* and *Aged 35 – 54 (35.29%)* reported the impact of fatigue more often than the general population.

No participants in the sub-group *Symptoms: no to few days* reported that reduced social life had a negative impact on quality of life. Participants in the sub-groups *Physical limitations: no days (5.36%),* and *Aged 18 – 34* (5.56%) reported negative quality of life due to impact of reduced social life less frequently than the general population (19.00%). Participants in the sub-groups *Physical limitations: some to most days (32.43%), Symptoms: all days* (33.33%), and *Aged 35 – 54* (29.41%) reported the impact of reduced social life more often than the general population.

No participants in the sub-group *Symptoms: all days* reported that reported a minimal impact. Participants in the sub-group *Affect: very often to always* (3.23%), minimal impact less frequently than the general population (14.00%). Participants in the sub-group *Affect: never to almost never* (24.24%) reported minimal more often than the general population.

No participants in the sub-group *Physical limitations: no days* reported that an inability to work had a negative impact on quality of life. Participants *Aged 18 – 34* (27.78%) reported negative quality of life due to inability to work less frequently than the general population (14.00%). Participants in the sub-group *Physical limitations: some to most days* (24.32%) reported the impact of the inability to work more often than the general population.

Participant describes negative impact on QOL due to reduced capacity for physical activity

I was physically incapable of doing a lot of things. So there was the stress associated with that and the what if this is the new norm. So they absolutely, it was a massive impact. Participant 60.

I returned to LOCATION REGIONAL a drug addicted cripple, it took everything. It took my whole quality of life. It was horrible, it still is, it just does. I mean, I walk a bit better now, but I can't begin to tell you, it just took everything. My mobility, everything. You can't go anywhere. You become depressed, you, but you can't, um, your life goes, you lose your life, basically. Awful. Terrible. Participant 99.

I've never, I don't have any days where I feel fine. I still have days where I don't feel quite so quite so sore, but I'm aware that every single morning from the minute that I wake up and try and move my legs and put my feet on the ground, I'm aware of it all day. So, it's never, it's never not there, it's just sometimes it's in all my joints and sometimes it's just in one or two, but there's never a day where I kind of wake up and forget that I have it. So it makes me on that level every day. Participant 72.

Participant describes negative impact on QOL due to impact on children

Over the years, quite a lot. I haven't been able to spend as much time with my grandchildren as I wanted to. I've got two that are teenagers, and I've only got one granddaughter. I've found that if I've had a flare, sometimes I will put off taking the medication so I've got money to spend on her when I have her, and that's caused a lot of rifts in the family because they don't know I've gone without to take her out. They don't understand. My son, one son and his family, they don't understand the disease. Participant 46.

I've got an 11 year-old and he would say, Oh, you're not any fun anymore if we never do anything fun. You just sleeping. Participant 39.

It's difficult because I've sort of taken on the role of looking after NAME and me and NAME is a very healthy, bubbly five-year-old and there is a lot of times where I can't keep up with her and I can't be the parent that I wanted to be. And so there's a lot of times where she is having to watch tv on a weekend because, you know, I'm going through flares and she's not able to do what normal little kid would be doing. Participant 50.

Participant describes negative impact on QOL due to fatigue.

I go, I go to ground sometimes and just have a couple of days where I just say, look, you know, would you want them out for coffee? I was like, I just really don't want to do anything today. I'm just going to have a down day. Um, and mum gets a bit peeved because I'm not taking her out and just like, I haven't got the energy mum. Participant 17.

My quality of life's changed a lot. I don't still have the energy or the physical ability any more to do a lot of the things I want to. Here's an example, I'm going to Sydney on Saturday because I've got 40% off tickets, but I said my daughter, "They've got buggies. Thank God. I can't walk at that pace any more. There's no way. I'll hire a buggy so that we can go up and down the hill". That really taxes me. It'll take me a couple of weeks do get over that. I'll come back on the Monday and probably just rest all Monday afternoon and evening. I'll get up and go to work on the Tuesday and it's going to take me that next two weeks to get my body rested again. It's had enough. It really does take it out of me now. Participant 93.

Yeah, pretty significantly. So I only have, I mean I'm fatigue is my main issue. The pain I can, it's there and it bothers me, but it's not, it's very rarely acute. It's more just a constant background noise. And so it makes me a little bit less enthusiastic about life. Sometimes I can be a bit grumpier but it's mainly fatigue. Um, and I basically just do what I have to. Participant 4.

Participant describes negative impact on QOL due to reduced social life.

I have no social life I literally go to work I do essential things like go to the doctor or go to get groceries. And even then I have to have someone with me because I can't walk around the shop on my own. Um, you know, I used to be able to go out with friends and go to the movies or something. Can't go to the movies because I fall asleep. Participant 97.

Friends can only ask you to come do things with them so often, but when friends want to go out and do something for a day, it's probably four legs of the day of the race. Whereas I can already see that first part which they want to do, walking from here to here is already going to be-- Going to this bar or this restaurant. If they don't have seating for us that is going to end the night. If we have to walk back somewhere for a taxi instead of standing still outside waiting for one, that's going to kill me. Participant 62.

I had to say no to going to a ends night earlier this year because they were going to walk around the city to a few different places and try different cocktails at different places. I just said walking, cocktails, sorry, can't do. I had to miss out on that social activity. Participant 26.

Participant describes minimal impact on the quality of life.

I think I've been pretty lucky that it's been so mild, so I haven't been to effective yet. Participant 7.

I feel like now like where I am right now, my quality of life is all right. I mean like I ain't complaining. How has affected my family? Um, I would say hasn't made any impact on my family to be honest. Yeah, I mean, I mean they're worried and stuff like that, that hasn't really changed our relationship in any way. Participant 15.

Um, I am going to probably say I'm probably one of the very lucky people that when I started realizing that RA was it, it kind of gave me a kick up the ass to go out there and do stuff that I've always wanted to do that I never did before. Um, I think because the idea settled into my head, I'm like, shit, if I don't do this now, I'm like, no joke, in a few year's time I might not be able to do. Participant 56.

Participant describes negative impact on QOL due to the emotional/psychological impact from the inability to work

I've had a few days off work because, you know, I didn't know at the time that when I hurt my knee that it was arthritis and stuff and when my hands hurt, steroids injections, one of my hands every few months when I've had that, when I find when I go through my body and it makes my body feel good. Participant 8.

I feel like there have been interviews where I've told people from the very beginning, and I've never got the job. Most of the interviews I've been at they've asked me; I haven't mentioned it. I think that's proof that that affects that aspect of life. Participant 62.

And I can't make a career move because I'm too scared I wouldn't be able to do the job properly. I'm so sick of my job and I'm bored. they're very supportive. I'm very lucky, but I can't make any changes. I can't seem to move forward anymore because I'm too scared of consequences, which sucks, you know, so um, and then it's overwhelming. It's overwhelming. Participant 95.

Participant describes negative impact on QOL due to impact on parents/siblings.

My parents blame themselves for this. It's not their fault, right? They just feel that this is something that might have happened. and might, of course, this to get triggered which I see what or how often they blame them. They just feel it is their responsibility. Participant 6.

My mum has refinance her mortgage that many times, but she can't even afford to move out of our house now because she has been paying for joint replacement surgeries. Participant 64.

My brother couldn't go to his soccer matches, it would all be down here in hospital with me. Um, yeah, like family holidays weren't always easy. Participant 91.

Table 8.1 Overall impact on Quality of life

Impact on quality of life	All participants		Physical limitations: no days		Physical limitations: few days		Physical limitations: some to most days		Symptoms: no to few days		Symptoms: some days		Symptoms: most days		Symptoms: all days	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	37	37.00	8	42.11	16	36.36	13	35.14	8	40.00	9	33.33	11	34.38	9	42.86
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	26	26.00	2	10.53	10	22.73	14	37.84	2	10.00	6	22.22	12	37.50	6	28.57
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	25	25.00	5	26.32	8	18.18	12	32.43	2	10.00	4	14.81	9	28.13	10	47.62
Participant describes negative impact on quality of life as a result of fatigue	23	23.00	7	36.84	11	25.00	5	13.51	9	45.00	6	22.22	3	9.38	5	23.81
Participant describes negative impact on quality of life due to reduced social interaction	19	19.00	1	5.26	6	13.64	12	32.43	0	0.00	6	22.22	6	18.75	7	33.33
Participant describes minimal impact on quality of life	14	14.00	3	15.79	9	20.45	2	5.41	3	15.00	4	14.81	7	21.88	0	0.00
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	14	14.00	0	0.00	5	11.36	9	24.32	1	5.00	4	14.81	6	18.75	3	14.29
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Immediate family - parents and /or siblings)	12	12.00	2	10.53	3	6.82	7	18.92	1	5.00	6	22.22	4	12.50	1	4.76

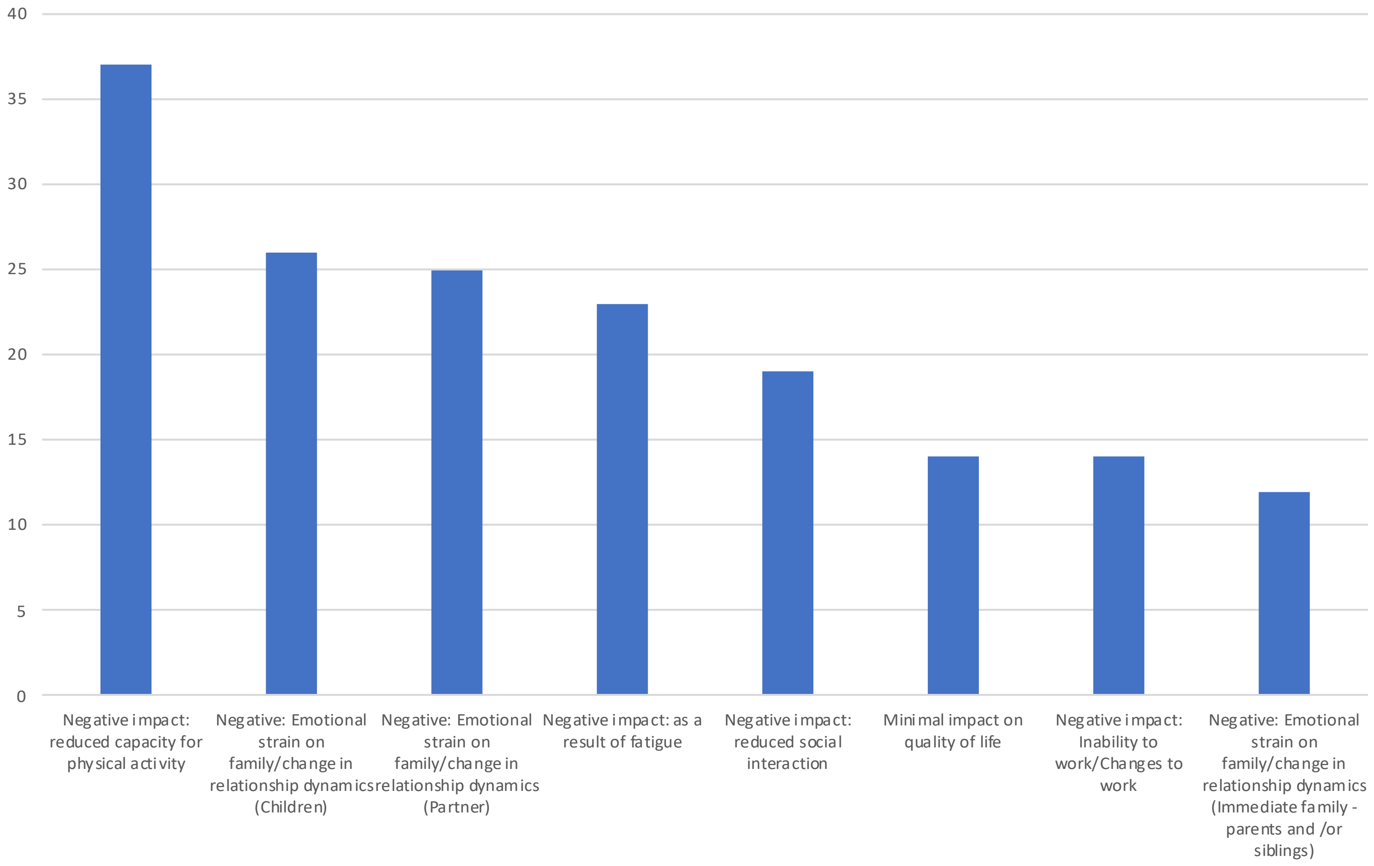
Impact on quality of life	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	37	37.00	9	27.27	16	44.44	12	38.71	6	30.00	13	36.11	18	40.91
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	26	26.00	3	9.09	9	25.00	14	45.16	2	10.00	11	30.56	13	29.55
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	25	25.00	7	21.21	9	25.00	9	29.03	4	20.00	10	27.78	11	25.00
Participant describes negative impact on quality of life as a result of fatigue	23	23.00	10	30.30	9	25.00	4	12.90	3	15.00	5	13.89	15	34.09
Participant describes negative impact on quality of life due to reduced social interaction	19	19.00	5	15.15	7	19.44	7	22.58	3	15.00	5	13.89	11	25.00
Participant describes minimal impact on quality of life	14	14.00	8	24.24	5	13.89	1	3.23	3	15.00	8	22.22	3	6.82
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	14	14.00	4	12.12	4	11.11	6	19.35	2	10.00	6	16.67	6	13.64
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Immediate family - parents and /or siblings)	12	12.00	4	12.12	3	8.33	5	16.13	1	5.00	7	19.44	4	9.09

Table 8.1 Overall impact on Quality of life (Cont.)

Impact on quality of life	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	37	37.00	19	33.93	18	40.91	15	48.39	17	33.33	5	27.78
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	26	26.00	13	23.21	13	29.55	6	19.35	17	33.33	3	16.67
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	25	25.00	12	21.43	13	29.55	9	29.03	15	29.41	1	5.56
Participant describes negative impact on quality of life as a result of fatigue	23	23.00	17	30.36	6	13.64	3	9.68	18	35.29	2	11.11
Participant describes negative impact on quality of life due to reduced social interaction	19	19.00	8	14.29	11	25.00	3	9.68	15	29.41	1	5.56
Participant describes minimal impact on quality of life	14	14.00	10	17.86	4	9.09	6	19.35	6	11.76	2	11.11
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	14	14.00	6	10.71	8	18.18	4	12.90	9	17.65	1	5.56
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Immediate family - parents and /or siblings)	12	12.00	4	7.14	8	18.18	2	6.45	5	9.80	5	27.78

Impact on quality of life	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	37	37.00	19	33.93	18	40.91	13	39.39	24	35.82	19	38.00	18	36.00
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	26	26.00	12	21.43	14	31.82	13	39.39	13	19.40	13	26.00	13	26.00
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	25	25.00	11	19.64	14	31.82	9	27.27	16	23.88	13	26.00	12	24.00
Participant describes negative impact on quality of life as a result of fatigue	23	23.00	15	26.79	8	18.18	8	24.24	15	22.39	13	26.00	10	20.00
Participant describes negative impact on quality of life due to reduced social interaction	19	19.00	7	12.50	12	27.27	7	21.21	12	17.91	11	22.00	8	16.00
Participant describes minimal impact on quality of life	14	14.00	7	12.50	7	15.91	3	9.09	11	16.42	7	14.00	7	14.00
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	14	14.00	9	16.07	5	11.36	4	12.12	10	14.93	6	12.00	8	16.00
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Immediate family - parents and /or siblings)	12	12.00	10	17.86	2	4.55	3	9.09	9	13.43	5	10.00	7	14.00

Figure 8.1 Overall impact on Quality of life



Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.4. Overall the entire cohort had a mean total score of 38.67 (SD = 8.88), which is a score in the middle of the scale.

The fear of progression questionnaire measures the level of anxiety people experience in relation to their conditions. The mean score for participants in this study was in the middle if the scale, indicating moderate anxiety about their rheumatoid arthritis.

Table 8.4: Fear of progression total score summary statistics

Subgroups	Group	Count	Percent	Mean	SD	Median	IQR
All participants	All participants	100.00	100.00	38.67	8.88	40.00	11.25
AIMS2-SF Physical scale	Physical limitations: no days	19.00	19.00	36.89	10.75	36.00	14.50
	Physical limitations: few days	44.00	44.00	38.82	7.19	39.00	8.25
	Physical limitations: some to most days	37.00	37.00	39.41	9.75	41.00	14.00
AIMS2-SF Symptoms scale	Symptoms: no to few days	20.00	20.00	32.95	9.28	34.50	8.25
	Symptoms: some days	27.00	27.00	39.00	8.80	40.00	10.00
	Symptoms: most days	32.00	32.00	40.50	7.45	40.50	9.00
	Symptoms: all days	21.00	21.00	40.90	8.86	42.00	12.00
AIMS2-SF Affect scale	Affect: never to almost never	33.00	33.00	33.94	8.09	35.00	11.00
	Affect: sometimes	36.00	36.00	39.14	7.79	40.50	10.25
	Affect: very often to always	31.00	31.00	43.16	8.61	43.00	11.50
AIMS2-SF Social scale	Social: all to most days	20.00	20.00	37.30	8.53	38.00	10.25
	Social: some days	36.00	36.00	39.44	9.00	40.00	8.50
	Social: no to few days	44.00	44.00	38.66	9.06	38.00	12.50
Flare - up frequency	Occasional flare up	56.00	56.00	36.66	9.17	36.00	11.25
	Frequent flare up	44.00	44.00	41.23	7.88	42.00	11.25
Age	Aged 18 -34	31.00	31.00	40.11	8.80	40.50	14.50
	Aged 35 - 44	51.00	51.00	41.20	7.43	42.00	10.00
	Aged 55 or older	18.00	18.00	33.68	9.30	34.00	13.00
Location	Metropolitan	56.00	56.00	39.00	8.55	39.50	10.50
	Regional or remote	44.00	44.00	38.25	9.38	40.00	11.50
Education	Trade or high school	66.00	66.00	41.06	8.52	40.00	12.00
	University	34.00	34.00	37.49	8.88	39.00	11.00
SEIFA	High SEIFA	50.00	50.00	40.24	8.02	41.00	9.25
	Mid to low SEIFA	50.00	50.00	37.10	9.49	35.50	12.50

The Fear of progression total score comparisons have been made by subgroups. A one-way ANOVA test was used with the assumptions for response variable residuals were normally distributed and variances of populations were equal for comparisons of **AIMS2-SF Physical**, **AIMS2-SF Symptoms**, **AIMS2-SF Affect**, **AIMS2-SF Social** and **Age** (Table 8.5). A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test (Table 8.6). Summary statistics are listed in Table 8.4**.**

No significant differences were observed between participants by **AIMS2-SF Physical scale** for the **"Fear of progression total score"**

The comparison of **"Fear of progression total score"** by **AIMS2-SF Symptoms** indicated that for participants that scored *Symptoms: no to few days* were significantly lower than those that scored *Symptoms: most days,* and *Symptoms: all days.* These scores correspond anxiety about their health condition that is in the moderate range for participants that scored *Symptoms: no to few days,* and *Symptoms: most days*; and low anxiety for participants that scored *Symptoms: all days.*

The comparison of **"Fear of progression total score"** by **AIMS2-SF Affect** indicated that for participants that scored *Affect: never to almost never* were significantly lower than those that scored *Affect: sometimes,* and *Affect: very often to always.* These scores correspond anxiety about their health condition that is in the moderate range for participants that scored *Affect: never to almost never,* and *Affect: sometimes*; and low anxiety for participants that scored *Affect: very often to always.*

No significant differences were observed between participants by **AIMS2-SF Social scale** for the **"Fear of progression total score"**

The comparison of **"Fear of progression total score"** by **Age** indicated that for participants *Aged 55 or older* was significantly lower than participants *Aged 18 to 34* and participants *Aged: 35 to 54 days.* These scores correspond anxiety about their health condition that is in the moderate range for participants *Aged: 55 or older,* and *Aged 18 to 34;* and low anxiety for participants that scored *Aged: 35 to 54.*

The **AIMS2-SF Physical scale** is the Arthritis Impact Measure Scale short form physical scale. The physical scale is comprised of 12 questions where participants responded to their ability to perform physical or dexterous activities "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Physical limitations: no days* (AIMS2-SF physical scale score between 0 and 2, n=19, 19.00%), *Physical limitations: few days* (AIMS2-SF physical scale score greater than 2 to 4, n=44, 44.00%), and *Physical limitations: some to most days* (AIMS2-SF physical scale score greater than 4 to 8, n=37, 37.00%).

No significant differences were observed between participants by **AIMS2-SF Physical scale** for the **"Fear of progression total score"**

The **AIMS2-SF Symptoms scale** is the Arthritis Impact Measure Scale short form symptoms scale. The symptoms scale is comprised of 3 questions about frequency of pain and stiffness "All days", "Most days", "Some days", "Few days" or "No days", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Symptoms: no to few days* (AIMS2-SF symptoms scale score between 0 and 4, n=20, 20.00%), *Symptoms: some days* (AIMS2-SF symptoms scale score greater than 4 to 6, n=27, 27.00%), *Symptoms: most days* (AIMS2-SF symptoms scale score greater than 6 to 8, N=32, 32.00%), and Symptoms: all days (AIMS2-SF symptoms scale score greater than 8 to 10, n=21, 21.00%).

A one way ANOVA test indicated a statistically significant difference in the **"Fear of progression total score"** between groups, F(3, 96) = 4.01 ,p = 0.0098 (Table 8.5). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Symptoms: no to few days* (mean =32.95, SD = 9.28) was significantly lower than participants that scored *Symptoms: most days* (mean = 40.50, SD = 4.45, p=0.0128) and participants that scored *Symptoms: all days* (mean = 40.90, SD = 8.86, p=0.0180).

The **AIMS2-SF Affect scale** is the Arthritis Impact Measure Scale short form affect scale. The affect scale is comprised of 5 questions about experience of anxiety, depression and burden "Always", "Very often", "Sometimes", "Almost never" or "Never", a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants that scored *Affect: never to almost never* (AIMS2-SF affect scale score between 0 and 4, n=33, 33.00%), *Affect: sometimes* (AIMS2-SF Affect scale score greater than 4 to 6, n=36, 36.00%), *Affect: very often to always* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and *Symptoms: all days* (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%).

A one way ANOVA test indicated a statistically significant difference in the **“Fear of progression total score”** between groups, F(2, 97) = 10.33, p = 0.0001 (Table 8.5). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those that scored *Affect: never to almost never* (mean = 33.94, SD = 8.09) was significantly lower than participants that scored *Affect: sometimes* (mean = 39.14, SD = 7.79, p=0.0254) and participants that scored *Affect: very often to always* (mean = 43.16, SD = 8.61, p<0.0001).

The **AIMS2-SF Social scale** is the Arthritis Impact Measure Scale short form social scale. The social scale is comprised of 4 questions about frequency of social interactions “All days”, “Most days”, “Some days”, ”Few days” or “No days”, a score of between 0 and 10 is generated, where 0 represents good health status and 10 represents poor health status. Comparisons were made between participants with *Social: all to most days* (AIMS2-SF social scale score between 0 and 4, n=20, 20.00%), *Social; some days* (AIMS2-SF Social scale score greater than 4 to 6, n=36, 36.00%), and *Social; few to no days* (AIMS2-SF affect scale score greater than 6 to 10, n=32, 32.00%), and *Social: all days* (AIMS2-SF affect scale score greater than 8 to 10, n=31, 31.00%).

No significant differences were observed between participants by **AIMS2-SF Social scale** for the **“Fear of progression total score”.**

Comparisons were made by the **Age** of the participants, those that were *aged 55 or older* (n=31, 31.00%), aged 35 – 54 (n=51, 51.00%) and participants aged 18 – 34 (n=18, 18.00%).

A one way ANOVA test indicated a statistically significant difference in the **“Fear of progression total score”** between groups, F(2, 97) = 8.25, p = 0.0005 (Table 8.5). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants *Aged: 55 or older* (mean = 33.68, SD = 9.30) was significantly lower than participants *Aged 18 to 34* (mean = 40.11, SD = 8.80, p=0.0275) and *Aged 35 to 54* (mean = 41.20, SD = 7.43, p=0.0004).

Table 8.5: Fear of Progression Total Score ANOVA Table

Subgroup		Sum of squares	dF	Mean Square	F	p
AIMS2-SF Physical	Between groups	81.00	2	40.43	0.51	0.604
	Within groups	7729.00	97	79.68		
	Total	7810.00	2			
AIMS2-SF Symptoms	Between groups	869.00	96	289.80	4.01	0.0098*
	Within groups	6941.00	3	72.30		
	Total	7810.00	97			
AIMS2-SF Affect	Between groups	1372.00	2	685.90	10.33	0.0001*
	Within groups	6438.00	97	66.40		
	Total	7810.00	2			
AIMS2-SF Social	Between groups	59.00	2	29.57	0.37	0.6920
	Within groups	7751.00	97	79.91		
	Total	7810.00	2			
Age	Between groups	1136.00	2	567.80	8.25	0.0005*
	Within groups	6675.00	97	68.80		
	Total	7811.00	2			

*Statistically significant at p=0.05

Table 8.6: Fear of Progression Total Score post hoc Tukey HSD test

Subgroup	AIMS2-SF Symptoms	Difference	Lower	Upper	P adjusted
AIMS2-SF Symptoms	*Some days - No to few days*	6.05	-0.51	12.61	0.0816
	Most days - No to few days	7.55	1.21	13.89	0.0128*
	All days - No to few days	7.95	1.01	14.90	0.0180*
	Most days-Some days	1.50	-4.31	7.31	0.9063
	All days - Some days	1.90	-4.56	8.37	0.8678
	All days – Most days	0.40	-5.84	6.65	0.9983
Affect	*Sometimes - Never to almost never*	5.20	0.53	9.87	0.0254*
	Very often to always -Never to almost never	9.22	4.37	14.07	<0.0001*
	Very often to always - Sometimes	4.02	-0.73	8.77	0.1140
Age	*Aged 35 to 54 - Aged 18 to 34*	1.08	-4.33	6.50	0.8823
	Aged 55 or older - Aged 18 to 34	-6.43	-12.28	-0.58	0.0275*
	Aged 55 or older - Aged 35 to 54	-7.52	-12.02	-3.02	0.0004*

*Statistically significant at p=0.05

The assumptions for normality and variance were met for **Flare-up frequency**, **Location**, **Education**, and **SEIFA**; comparisons were made by a two-sample t-test (Table 8.7).

Comparisons were made by **Flare-up frequency**, between participants that had *Frequent flare-ups* (daily or weekly flare-ups, n=44, 44.00%)) and participants that had *Occasional flare-ups* (monthly flare-ups or less frequently, n=56, 56.00%).

A two sample t-test indicated that the mean score for the **"Fear of progression total score**" [t(98) = -2.63, p=0.0100] was significantly lower for those with *Occasion flare –ups* (Mean = 36.66, SD= 9.17) compared to those with *frequent flare-ups* (Mean = 41.23, SD = 7.88).

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from DoctorConnect (doctorconnect.gov.au), those living in a major city, *metropolitan* (n=56, 56.00%) were compared to those living in regional/rural areas, *regional or remote* (n=44, 44.00%).

No significant differences were observed between participants by **Location** for the **"Fear of progression total score".**

Comparisons were made by **education** status, between those with a university qualification, *University* (n= 66, 66.00%), and those with trade or high school qualifications, *trade or high school* (n=33, 33.00%).
No significant differences were observed between participants by **Education** for the **"Fear of progression total score".**

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10 , *High SEIFA* (n=50, 50.00%) compared to those with a mid to low SEIFA score of 1-6, *Mid-low SEIFA* (n=50, 50.00%).

No significant differences were observed between participants by **SEIFA** for the **"Fear of progression total score".**

The comparison of **"Fear of progression total score"** by **Flare-up frequency** indicated that the scores for participants with *Occasional flare-ups* were significantly lower than with *Frequent flare-ups.* These scores correspond to anxiety about their health condition that is in the moderate range for participants with *Occasional flare-ups* and low anxiety for participants that with *Frequent flare-ups.*

No significant differences were observed between participants by **Location** for the **"Fear of progression total score"**

No significant differences were observed between participants by **Education** for the **"Fear of progression total score"**

No significant differences were observed between participants by **SEIFA** for the **"Fear of progression total score"**

Table 8.7: Fear of Progression Total Score two sample t-test

Group	Subgroup	Count	Percent	Mean	SD	t	dF	p
Flare-up frequency	Occasional flare-ups	56	56.00	36.66	9.17	-2.63	98	0.0100*
	Frequent flare-ups	44	44.00	41.23	7.88			
Location	Metropolitan	56	56.00	39.00	8.55	0.42	98	0.6773
	Regional or remote	44	44.00	38.25	9.38			
Education	Trade or high school	66	66.00	41.06	8.52	1.91	98	0.0585
	University	34	34.00	37.49	8.88			
SEIFA	High SEIFA	50	50.00	40.24	8.02	1.79	98	0.0770
	Mid to low SEIFA	50	50.00	37.10	9.49			

*Statistically significant at p=0.05

Regular activities to maintain mental health

The most common way that participants reported managing their mental and emotional health was by visiting a mental health professional, usually a psychiatrist, psychologist, or counsellor (20.00%). Other activities that participants reported practicing regularly in order to maintain their mental health were receiving emotional support from family and friends (18.00%), practicing mindfulness meditation (13.00%), remaining physically active (11.00%), ensuring they retained a positive outlook (10.00%), and using antidepressants (8.00%). There were 10.00% of participants who reported that they struggled with mental health issues but did not practice any regular activities to maintain their mental health, and 10.00% of participants reported that they did not have to practice any activities as their mental health was good.

In relation to sub-group variations, participants *Aged 55 or older* (3.23%) reported visiting a mental health professional less often than the general population (20.00%).

Participants in the sub-groups *Physical limitations: no days* (31.58%), *Social: all to most days* (30.00%) reported emotional support from family and friends more frequently than the general population (18.00%).

No participants with *Trade or high school* qualification reported remaining physically active compared with the 11.00% of the general population.

No participants in the sub-group *Symptoms: all days* reported that their mental health was ok compared to 10.00% of the general population. Participants in the sub-groups *Physical limitations: no days* (21.05%), and *Symptoms: no to few days* (20.00%) reported that their mental health was ok more frequently than the general population.

No participants in the sub-groups *Affect: never to almost never,* and *Social: all to most days* reported taking anti-depressants compared to 8.00% of the general population, while participants in the sub-group *Symptoms: no to few days* (20.00%) reported this more often.

Participant describes consulting a mental health professional to manage emotional impact (psychiatrist/psychologist/counsellor)

Much better since I did that COUNSELLING CHARITY you feel like. I think I'm. Yeah, well it's just a deep state of trauma. Essentially. You're in constant distress because I feel like people are confident in you because you've got this thing. It could fuck you up any minute or like I think also like you competence in yourself is really rocked because, especially around the brain fog, like part of your self confidence and self worth is bound to know your education or your ability to think and talk logically and do it eloquently. Participant 12

On and off, I've seen psychologists over the years. Um not specifically for rheumatoid arthritis, but that always kind of factors into it a little bit. Um, sometimes I, I get kind of frustrated that it's there and that, you know, like I just think it just wasn't there then I could do this or that does not, you know, obviously it's not going to go away. There's nothing I can do to make it disappear. Participant 19

So when I saw my gp the other day, I said I'm, I'm just not coping. And so she's actually written a script to have a chat to a psychologist because I said to her like, I'm, I'm like, I now, I now know I've sort of gone into a bit of a depression. Participant 77

Participant reports how their family or friends have helped them manage the emotional impact

I've met a lot of great people around and amazing friends. Just not being afraid to pick up a phone and call someone, and having such a good support network that consists of amazing people. Participant 6

Just friends again, that's what I've got amazing friends really amazing, some of whom like have counselling background, so that's really nice as well. Participant 9

Last year I joined a women's hiking group, which is not a serious hiking group. For example, the other day we went to the beach, played in the rock pools. Um, having the, having the ability to be with a, just a group of people, um, with no strings attached. Participant 52

It's just whining and bitching to my best friend. Twenty four seven. Participant 56

Participant describes using mindfulness or meditation to manage emotional impact

I've been doing headspace. I've got that APP on my phone, which I got the $20 one, which…were added onto my Telstra bill every month, and I do the…I'll do the sleep one, I do the pain management one and I've also done some of the eating ones on there, so that's really good. I found that really, really helpful in the last I've been using that. Participant 36

I've also done a mindfulness course which I do meditation, so all those things trying to help my brain cope. Um, but I think it's a really under downplayed underrecognized factor. Participant 55

The self-healing that I do, like just doing my contemplation reflection meditations, using those techniques.

What I've learned is they're really important as well. Participant 6

Participant describes using physical exercise to manage emotional impact

Exercise physical activity and I love gardening. Gardening is very therapeutic for me. Participant 14

I walk the dog every morning I have to or she bloody destroys the place, but it does me good because it makes, even if everything's a bit different because it makes me get moving and I'm better off if I force it, it just, it takes me a little bit. But once I get moving I'm better than if I was just gonna sit down and do nothing today. Participant 38

I think I'm normally a pretty positive person anyway, so I'm just going in the gym and swimming instead. So I probably do that to keep, keep myself sane. Participant 28

I'm really huge on sport. I think every doctor I've ever had told me not to, not the run lift weights. I do all of those things and I find that they're very, very helpful to me. In fact, like the only thing that saved me, there's something about the, I guess the endorphin release and the chemical balance in your body that can stop something like that. If I'm feeling really out of it and really sick, I can go and do some dancing or some exercise and it will actually bring me back. Participant 24

Participant describes how their positive outlook helps manage the emotional impact

It's just being able to recover from it, and also your approach to how you deal with it is just really important to how quickly or slowly you recover. I try and not dwell too much as well on things. Participant 6

I've never thought of counselling or professional help. I've just tried to be as positive and tried to keep going, tried to engage in things that bring me pleasure. Participant 22

I've never let the arthritis stop me from doing anything that I haven't wanted to try to do. Mentally, I'm on more on the positive side than the negative. Participant 80
Mentally I'm pretty good. I have a disgustingly positive attitude, unfortunately for most people. Participant 93

Participant reports practicing no activities but struggling with their mental health

Um, I think just the nature of RA and the fact that it is irreversible gives me anxiety and makes me almost like, a what'd you call a hypochondriac? Like you worry about your health all the time. Participant 15

And mentally it's just, that's the long-term fear. Particularly if you do have days where you wake up and you've got a bit of pain, like, oh god, is this just for today or is this for the next couple of weeks? Am I going back to the way I was that's more the annoyance than the the unknown. And also if I'm hurting now, I'm under 40. What's it going to be like when I'm 80? Kind of live in the moment, but you've got those fears. Participant 29

That part of my personality just sweep it under the carpet for pretend it's not there That's probably not the best. Participant 32

I don't think I do anything to look after. It definitely didn't practice. Probably noticed that more and more recently as well. I don't know you just feel it? Yeah. Constant. Yeah. just wish things were different. Participant 65

Participant describes their mental health being fine

As a family we try and be fairly stress free and actually have time away, both individually and as a group. I guess yes, but it's just how I live my life. Yeah. I guess it hasn't changed as a result of the diagnosis. Participant 18

There's nothing really that I do. I'm very accepting of it all. Like, you know, I'm having a bad day then I don't push it. I though I could do. And so I think, yeah. Yeah. Look, you know, once you get to that accepting stage you just, you have to just roll with it. Participant 33

Hey, I'm going along like at the moment everything's going along pretty smoothly. I have, you know, I guess some aches and pains and things in my fingers and hands, but when it's going along pretty smoothly like this, then I'm usually going okay as well. Participant 54

Participant describes taking antidepressants

I've long been prescribed antidepressants but like I said, the GP recently doubled my dosage and his reasoning for that was you've got a lot to deal with with the RA and I find it does help. I'm like, I have had chronic depression since I was a child and I was doing fine on a, you know, fairly basic dosage, but now just takes a bit extra to get through. It's just you wake up and you are sore and you're tired, you've got to get through and do all this stuff. Participant 4

I'm taking the antidepressants as a bit of a band-aid drug. Participant 50

That's kind of where I've had to put a lot of my effort because I have not been getting much joy elsewhere, so I've had to put the effort in. So what do I do for it? Well, I have in the past, seen a psychiatrist and taken antidepressants when I've had to, um, you know, no harm in that if you, if you have to, you have to. Participant 87

Table 8.2 Regular activities to maintain mental health.

Regular activities to maintain mental health	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes consulting a mental health professional	20	20.00	4	21.05	7	15.91	9	24.32	4	20.00	6	22.22	4	12.50	6	28.57
Participant describes family or friends support to maintain their mental health	18	18.00	6	31.58	6	13.64	6	16.22	5	25.00	2	7.41	8	25.00	3	14.29
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	13	13.00	2	10.53	6	13.64	5	13.51	3	15.00	1	3.70	6	18.75	3	14.29
Participant describes doing physical exercise to maintain their mental health	11	11.00	1	5.26	6	13.64	4	10.81	2	10.00	4	14.81	4	12.50	1	4.76
Participant describes having a positive outlook to maintain their mental health	10	10.00	3	15.79	3	6.82	4	10.81	2	10.00	3	11.11	3	9.38	2	9.52
Participant describes that they worry about long term impact/future impact of their condition	10	10.00	2	10.53	6	13.64	2	5.41	1	5.00	3	11.11	3	9.38	3	14.29
Participant describes that their mental health has not been affected	10	10.00	4	21.05	3	6.82	3	8.11	4	20.00	2	7.41	4	12.50	0	0.00
Participant describes taking medication to maintain their mental health	8	8.00	2	10.53	2	4.55	4	10.81	4	20.00	1	3.70	2	6.25	1	4.76

Regular activities to maintain mental health	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes consulting a mental health professional	20	20.00	4	12.12	7	19.44	9	29.03	3	15.00	8	22.22	9	20.45
Participant describes family or friends support to maintain their mental health	18	18.00	4	12.12	7	19.44	7	22.58	6	30.00	6	16.67	6	13.64
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	13	13.00	6	18.18	3	8.33	4	12.90	2	10.00	6	16.67	5	11.36
Participant describes doing physical exercise to maintain their mental health	11	11.00	4	12.12	3	8.33	4	12.90	4	20.00	3	8.33	4	9.09
Participant describes having a positive outlook to maintain their mental health	10	10.00	5	15.15	4	11.11	1	3.23	3	15.00	2	5.56	5	11.36
Participant describes that they worry about long term impact/future impact of their condition	10	10.00	3	9.09	4	11.11	3	9.68	1	5.00	3	8.33	6	13.64
Participant describes that their mental health has not been affected	10	10.00	4	12.12	4	11.11	2	6.45	2	10.00	5	13.89	3	6.82
Participant describes taking medication to maintain their mental health	8	8.00	0	0.00	4	11.11	4	12.90	0	0.00	2	5.56	6	13.64

Regular activities to maintain mental health	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 34 - 45***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes consulting a mental health professional	20	20.00	11	19.64	9	20.45	1	3.23	15	29.41	4	22.22
Participant describes family or friends support to maintain their mental health	18	18.00	8	14.29	10	22.73	6	19.35	7	13.73	5	27.78
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	13	13.00	6	10.71	7	15.91	4	12.90	8	15.69	1	5.56
Participant describes doing physical exercise to maintain their mental health	11	11.00	7	12.50	4	9.09	5	16.13	4	7.84	2	11.11
Participant describes having a positive outlook to maintain their mental health	10	10.00	6	10.71	4	9.09	4	12.90	4	7.84	2	11.11
Participant describes that they worry about long term impact/future impact of their condition	10	10.00	3	5.36	7	15.91	2	6.45	6	11.76	2	11.11
Participant describes that their mental health has not been affected	10	10.00	8	14.29	2	4.55	1	3.23	7	13.73	2	11.11
Participant describes taking medication to maintain their mental health	8	8.00	3	5.36	5	11.36	2	6.45	4	7.84	2	11.11

Table 8.2 Regular activities to maintain mental health (Cont.)

Regular activities to maintain mental health	***All participants***		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes consulting a mental health professional	20	20.00	12	21.43	8	18.18	8	24.24	12	17.91	9	18.00	11	22.00
Participant describes family or friends support to maintain their mental health	18	18.00	12	21.43	6	13.64	3	9.09	15	22.39	11	22.00	7	14.00
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	13	13.00	7	12.50	6	13.64	2	6.06	11	16.42	8	16.00	5	10.00
Participant describes doing physical exercise to maintain their mental health	11	11.00	6	10.71	5	11.36	0	0.00	11	16.42	3	6.00	8	16.00
Participant describes having a positive outlook to maintain their mental health	10	10.00	7	12.50	3	6.82	3	9.09	7	10.45	8	16.00	2	4.00
Participant describes that they worry about long term impact/future impact of their condition	10	10.00	6	10.71	4	9.09	5	15.15	5	7.46	6	12.00	4	8.00
Participant describes that their mental health has not been affected	10	10.00	4	7.14	6	13.64	2	6.06	8	11.94	2	4.00	8	16.00
Participant describes taking medication to maintain their mental health	8	8.00	6	10.71	2	4.55	5	15.15	3	4.48	2	4.00	6	12.00

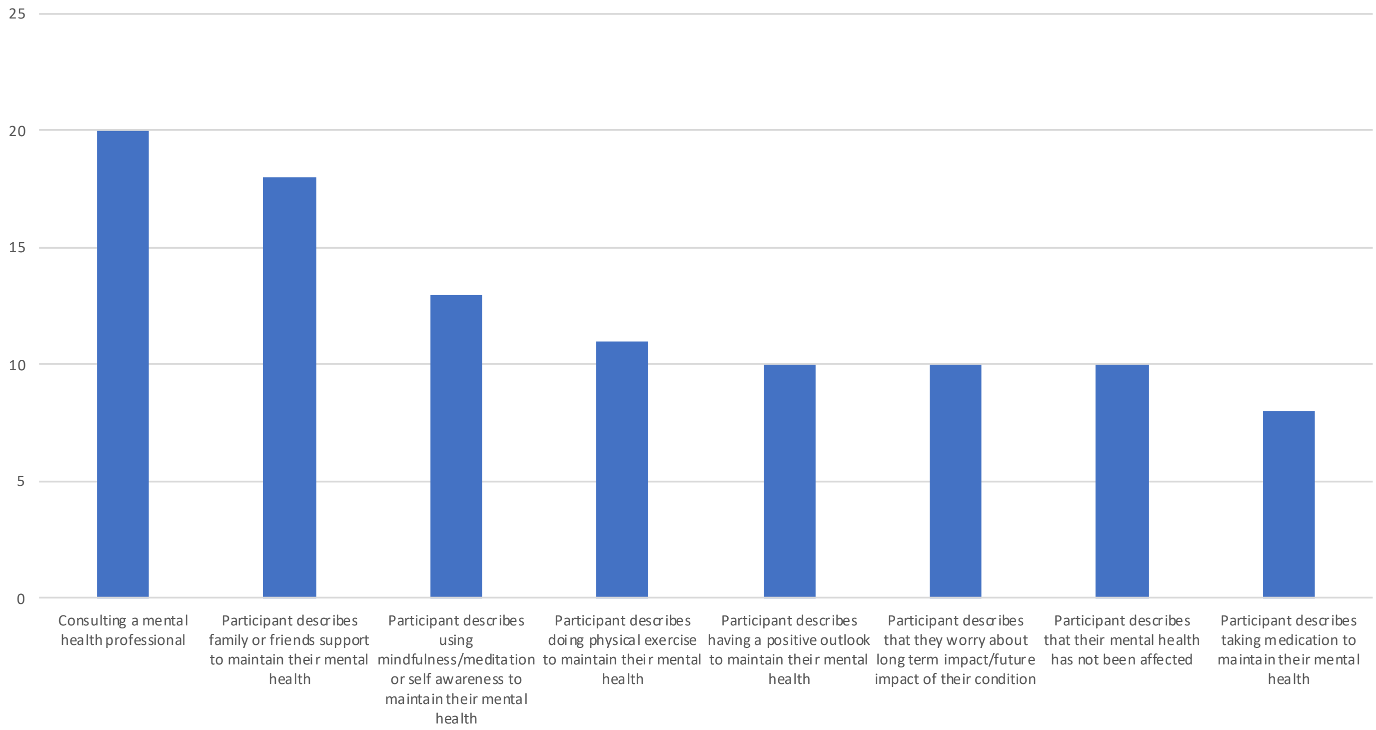


Figure 8.2 Regular activities to maintain mental health

Regular activities to maintain health

The most common theme described by participants as a regularly performed activity to maintain health was listening to their body and resting (29.00%). Other reported activities included ensuring they were compliant to treatment regimens (27.00%), keeping up physical activities (19.00%), getting enough sleep (14.00%), pacing their activities and/or accepting help when required (11.00%), practicing meditation or mindfulness (9.00%) and modifying their diet (9.00%).

In relation to sub-group variations, participants in the sub-groups *Symptoms: most days* (18.75%), and *Social: all to most days* (10.00%) reported listening to their body and resting less frequently than the general population (29.00%), while participants in the sub-groups *Symptoms: all days* (42.86%), and *Social: some days* (47.22%) reported this more frequently.

Participants in the sub-groups *Physical limitations: some to most days* (40.54%), *Symptoms: all days* (38.10%) reported treatment compliance more frequently compared to the general population (27.00%).

Participants in the sub-group *Symptoms: some days* (29.63%) reported physical activity more frequently than the general population (14.00%).

Participants in the sub-group *Physical limitations: no days* (26.32%) reported sleep more frequently compared to the general population (12.00%).

No participants in the sub-group *Physical limitations: no days* reported pacing activity and accepting health as a way of maintaining health compared to 11.00% of the general population.

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days, Aged 18 – 34* reported meditation as a way of maintaining health compared to 9.00% of the general population.

Participant reports benefits of listening to your body and resting when needed

You've got to kind of learn to watch your body signals and say, "This is what it's telling me right now". Then you've got to decide whether or not to listen to it or ignore it [laughs] because sometimes, particularly like if it's a party or something that you really want to be involved in, you might ignore it and just deal with the consequences later. You have to stop and think about it every single day. You have to stop and think, "What are my main things that I have to achieve today? How long is it going to take me? If I do too much what happens? Can I plan to rest time in-between?" Participant 26

I can go and do some dancing or some exercise and it will actually bring me back. Um, so I find that that is quite helpful, but it can have got to be careful because it also has this kind of chronic fatigue aspect that if you try to push physically, sometimes in that mindset you can set yourself back like three weeks of extreme fatigue. So it is a bit of a getting to know your body delicate balance that I get wrong quite frequently. I'm still learning. Participant 24

I used to push myself and still go out when I had promised somebody I was going to go somewhere, but I've now become more comfortable with saying to people, I'm sorry but I'm going to have to cancel. So I guess I've become more attuned to what I can and can't do. I still get frustrated at times, but um, I think everybody would. Participant 37

Participant reports importance of complying with their treatment regime

Stay on my medication every day. That's really the only thing that's in my control. Participant 31

What I have to do is obviously make sure I take my medications on time. I'm mindful. Um, I'll talk to the present now. Um, if I skip them or missed them, then within a few days I start to feel, you know, side effects that creeping and aches that craving back because I'm taking medication, you know, being strict with that. Participant 73

Well, I have to naturally have my drugs because I'm sure if I didn't have the drugs in my head, I would not be doing what I'm doing. Participant 80

Um, well you got to, you got to take pain medication for you. it's sort of about knowing what's going to happen, knowing your body and knowing what is possibly going to happen. Participant 95

Participant reports benefits of being physically active

Um, I need to keep moving. Yeah. And Yeah, if I get stuck and don't move around at my desk at work during the day, then I'm stuffed. Participant 23

I can go and do some dancing, or some exercise and it will actually bring me back. Um, so I find that that is quite helpful, but it can have got to be careful because it also has this kind of chronic fatigue aspect that if you try to push physically, sometimes in that mindset you can set yourself back like three weeks of extreme fatigue. Participant 24

I do need to exercise. I find exercise extremely difficult and that, but I realized that I need to try and exercise as much as I can. So again, so I'm trying to fit that in. Participant 47

Going to the gym now. I know that as much as I put it off and I still struggle with this. I put it off, and I put it off, but every single time I go, I feel like a million bucks the second I walk out. Participant 62

Participant reports benefits of sleep

Um, my biggest one is probably sleep. Um, I, I have to get eight hours sleep every day. So basically, I go to bed at 10, 10:30 in and I can't be working off either, have to have uninterrupted sleep. That's probably the biggest thing for me because otherwise I'm really tired and lethargic and I just don't cope with the day at all. Participant 2

I have to absolutely have to get enough sleep. Sleep is absolutely essential. If I don't get enough sleep, I'm sore. Um, and I have to get enough really deep body sleep. Um, so I track my sleep. I get, I, I try and make sure I get enough sleep, but I also track the type of sleep that I'm getting, and I get more deep body sleep. Participant 11

I find the routine that's working for me at the moment is um, generally the one day of the weekends. I've just got to do nothing. So, If I decide. Okay. It's say it's a Saturday. I'm not going anywhere. I'm not doing anything. If I want to sleep all day and Sunday, if I want to have a nap in the afternoon, I will be generally sleep. It's my main controlling and limiting the amount of time I'm out and about because it wares me out. Participant 25

Participant reports benefits of pacing their activity, and letting others help them

I suppose I have made sure that I am in a job that doesn't create too much stress and too much pressure. It doesn't tax me physically and that I only work in it part-time. I have always tended to stagger thing so, if I was going to do an activity, I would break it up into bits over a few days rather than all at once. Participant 22

Resting, I pace myself, I do a lot of stretching within my limits and walking and things like that. Because that also helps with the symptoms. I pace myself a lot more than I than I used to when I can. If I'm at home, I pace myself more with that, I don't push myself as much, and that helps me manage. Participant 60

Well, pacing yourself is an important one. It's one of those things that's taken me a while to figure out exactly how to make this work well. Things like breaking up the week so that I don't do things on consecutive days. Participant 70

Participant reports benefits of meditation/ mindfulness

The mindfulness, the head that that helps me. I'm getting exercise as I need to do in the morning to just get me up out of bed. Participant 36

I am on antidepressants and I have seen different counsellors over the years, that, I've not really found them to be very effective. Um, but I think my meditation and that helps me with that as well. Participant 37

Yes. So I'm just keeping like meditation and Yoga and stretching and things like that. It's sort of like, this is why I've taken the time off because it takes my whole day. Participant 77

Table 8.3. Regular activities to maintain physical health

Regular activities to maintain health	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes listening to their body and knowing limitations (Being proactive) to maintain their general health	29	29.00	4	21.05	11	25.00	14	37.84	4	20.00	10	37.04	6	18.75	9	42.86
Participant describes compliance with treatment to maintain general health	27	27.00	4	21.05	8	18.18	15	40.54	4	20.00	7	25.93	8	25.00	8	38.10
Participant describes needing to keep up with physical activity to maintain their general health	19	19.00	3	15.79	10	22.73	6	16.22	3	15.00	8	29.63	6	18.75	2	9.52
Participant describes needing to get enough sleep to maintain their general health	14	14.00	5	26.32	7	15.91	2	5.41	4	20.00	5	18.52	4	12.50	1	4.76
Participant describes needing to pace themselves to maintain their general health	11	11.00	0	0.00	7	15.91	4	10.81	1	5.00	5	18.52	3	9.38	2	9.52
Participant describes using meditation and mindfulness to maintain their general health	9	9.00	0	0.00	4	9.09	5	13.51	0	0.00	3	11.11	3	9.38	3	14.29
Participant describes changing their diet to maintain their general health	9	9.00	3	15.79	5	11.36	1	2.70	2	10.00	2	7.41	4	12.50	1	4.76

Regular activities to maintain health	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes listening to their body and knowing limitations (Being proactive) to maintain their general health	29	29.00	4	21.05	11	25.00	14	37.84	4	20.00	10	37.04	6	18.75	9	42.86
Participant describes compliance with treatment to maintain general health	27	27.00	4	21.05	8	18.18	15	40.54	4	20.00	7	25.93	8	25.00	8	38.10
Participant describes needing to keep up with physical activity to maintain their general health	19	19.00	3	15.79	10	22.73	6	16.22	3	15.00	8	29.63	6	18.75	2	9.52
Participant describes needing to get enough sleep to maintain their general health	14	14.00	5	26.32	7	15.91	2	5.41	4	20.00	5	18.52	4	12.50	1	4.76
Participant describes needing to pace themselves to maintain their general health	11	11.00	0	0.00	7	15.91	4	10.81	1	5.00	5	18.52	3	9.38	2	9.52
Participant describes using meditation and mindfulness to maintain their general health	9	9.00	0	0.00	4	9.09	5	13.51	0	0.00	3	11.11	3	9.38	3	14.29
Participant describes changing their diet to maintain their general health	9	9.00	3	15.79	5	11.36	1	2.70	2	10.00	2	7.41	4	12.50	1	4.76

Regular activities to maintain health	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 34 - 45***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes listening to their body and knowing limitations (Being proactive) to maintain their general health	29	29.00	14	25.00	15	34.09	8	25.81	15	29.41	6	33.33
Participant describes compliance with treatment to maintain general health	27	27.00	13	23.21	14	31.82	9	29.03	12	23.53	6	33.33
Participant describes needing to keep up with physical activity to maintain their general health	19	19.00	12	21.43	7	15.91	4	12.90	9	17.65	6	33.33
Participant describes needing to get enough sleep to maintain their general health	14	14.00	10	17.86	4	9.09	2	6.45	11	21.57	1	5.56
Participant describes needing to pace themselves to maintain their general health	11	11.00	8	14.29	3	6.82	5	16.13	4	7.84	2	11.11
Participant describes using meditation and mindfulness to maintain their general health	9	9.00	4	7.14	5	11.36	3	9.68	6	11.76	0	0.00
Participant describes changing their diet to maintain their general health	9	9.00	5	8.93	4	9.09	1	3.23	5	9.80	3	16.67

Table 8.3. Regular activities to maintain physical health (Cont.)

Regular activities to maintain health	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes listening to their body and knowing limitations (Being proactive) to maintain their general health	29	29.00	13	23.21	16	36.36	12	36.36	17	25.37	15	30.00	14	28.00
Participant describes compliance with treatment to maintain general health	27	27.00	12	21.43	15	34.09	14	42.42	13	19.40	14	28.00	13	26.00
Participant describes needing to keep up with physical activity to maintain their general health	19	19.00	15	26.79	4	9.09	6	18.18	13	19.40	7	14.00	12	24.00
Participant describes needing to get enough sleep to maintain their general health	14	14.00	9	16.07	5	11.36	1	3.03	13	19.40	9	18.00	5	10.00
Participant describes needing to pace themselves to maintain their general health	11	11.00	8	14.29	3	6.82	3	9.09	8	11.94	8	16.00	3	6.00
Participant describes using meditation and mindfulness to maintain their general health	9	9.00	5	8.93	4	9.09	4	12.12	5	7.46	3	6.00	6	12.00
Participant describes changing their diet to maintain their general health	9	9.00	6	10.71	3	6.82	2	6.06	7	10.45	6	12.00	3	6.00

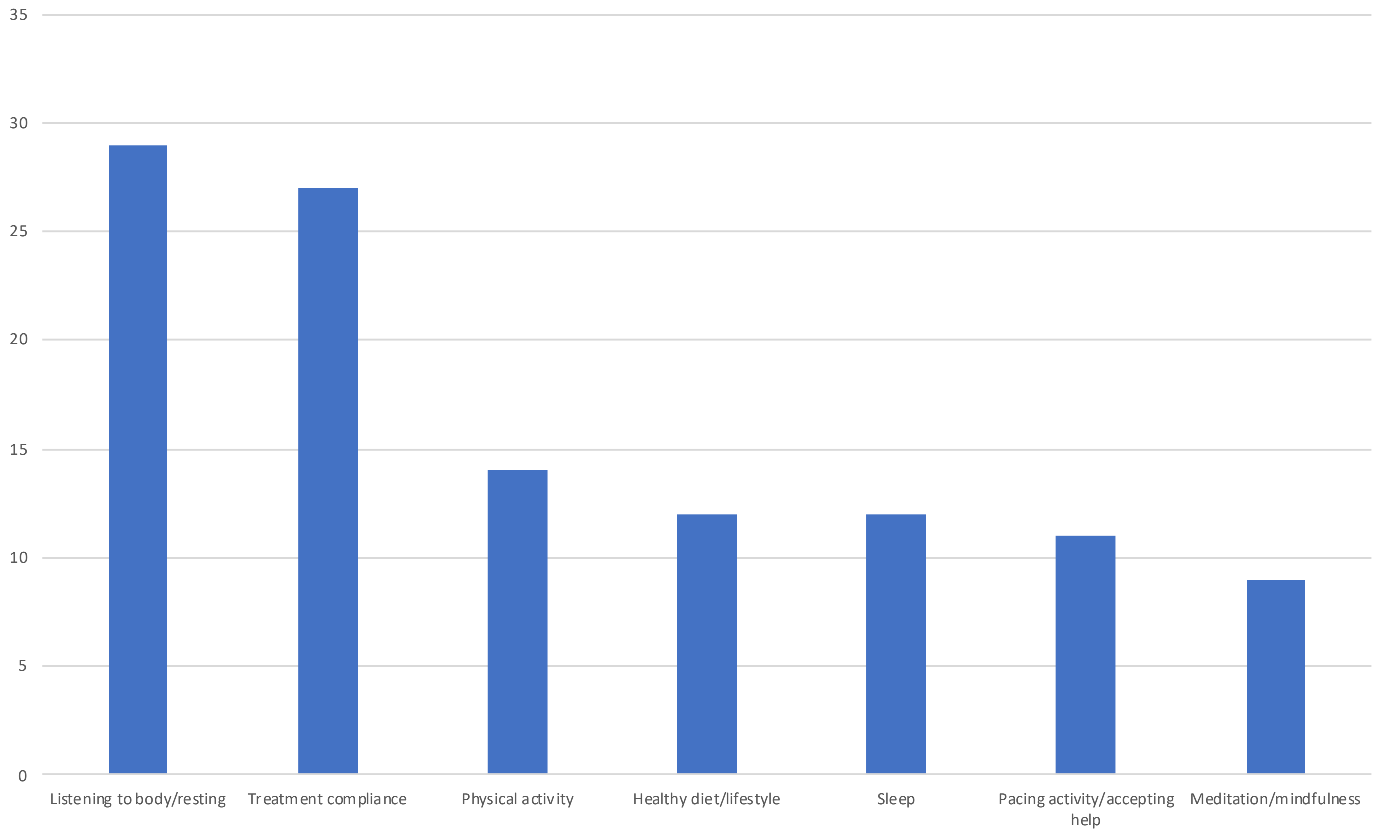


Figure 8.3. Regular activities to maintain physical health

Impact on relationships

The most common theme described by participants was a loss of friendship (34.00%). This was followed by no impact on family/friends (30%), not being able to attend social events (16.00%), stress on their partner (16.00%), relationship becoming more complicated (15.00%), and low awareness of rheumatoid arthritis which had an impact on relationships (15.00%).

In regard to subgroup variations, participants in the sub-groups *Physical limitations: few days* (22.73%), *Symptoms: no to few days* (20.00%), and *Social: all to most days* (15.00%) reported a loss of friendships less frequently than the general population (34.00%), compared with participants in the sub-groups *Physical limitations: some to most days* (45.95%), *Affect: very often to always* (45.16%), *Social: no to few days* (45.45%), and *Aged 18 – 34* (55.56%), who reported this more often than the general population.

Participants in the sub-groups *Physical limitations: some to most days* (10.81%), *Affect: never to almost never* (54.55%), *Affect: very often to always* (9.68%), and *Frequent flare ups* (18.18%) reported that rheumatoid arthritis had no impact on family and friends less frequently than the general population (30.00%), while participants in the sub-groups *Physical limitations: no days* (42.11%), *Physical limitations: few days* (40.91%), *Symptoms: no to few days* (45.00%), *Symptoms: some days* (40.74%), *Symptoms: all days* (9.52%), and *Social: all to most days* (40.00%) reported this more.

Participants in the sub-groups *Symptoms: no to few days* (5.00%), *Social: all to most days* (5.00%), and *Aged 18 – 34* (5.56%) reported stress on partner less frequently than the general population (16.00%).

Participants in the sub-group *Social: all to most days* (25.00%) reported that their relationship has become more complicated more frequently than the general population (15.00%).

Participants in the sub-group *Symptoms: most days* (3.13%)reported that a low awareness of rheumatoid arthritis in others having an impact on relationships less frequently than the general population (15.00%), while participants in the sub-groups *Physical limitations: no days* (31.58%), and *Symptoms: no to few days* (25.00%) reported this more often.

Participant describe a loss of friendships

A lot of them went ‘cause you haven't gotten any money anymore and you can't participate in a lot of the normal things. You're not forgotten. You're not really a runner anymore cause you just, you can't go on holidays. Participant 86.

You see less of people if you don't go out as much, you become isolated. You should really not become isolated. You've got to try not to be isolated or you'd be locked into you own little, you just become isolated at home. I talk, I do talk on the phone. I tried to keep in contact with people, but you don't go out like you used to do. You don't go out as movies or do things and meet people as much as you used to. Participant 99

To an extent, yeah. I just don't have the time to be able to spend, to maintain them as much as I used to visit them. Even with the help of social media, it's still having to think and function to be able to contact and being contact with people. Participant 43.

Participant describes no effect on relationships

Sometimes I can say it, straining them. Um, I'm very fortunate to have very supportive family and close friends, so I've been pretty good. Yeah. Participant 5.

I think us having to move around so my job's affected that more than the rheumatoid, so I would say no. Participant 23.

I, you know, those who are my friends and family really love me and they, no I don't, I mean I think, I think they feel really sorry for me but I don't go around like that so I don't want them to, but I know they do, but that's not projected on me in any shape or form. Participant 58.

Participant describes negative effect on partner as an impact on personal relationships

Well, I do have a partner. And um, most of the time, I don't think um I think he should Be with someone else because I can't do this and I can't do that where, I don't know, I've always been, well I have to look, I should be the one looking after the family, doing things you know like in the kitchen. I do do things in the kitchen, but I should be able to do other things like cook all the time. Sometimes I can't cook all the time because I'm standing for a long period or if I'm standing for a long period, my foot goes out or, and then it's like I'm on the side of my foot goes out and I'm in pain all night. And then sometimes I don't cook and then Um, because I think, you know, it's just maybe he's better off just having someone different that can do them sort of things. Participant 100.

Family and friends? Oh, absolutely. Without a doubt. I lost my first relationship over it and I'd been in for four years and he just probably a case of Shallow Hal. Anyway probably dodged a bullet. We know with all the steroids and um, you know, going from a size eight to a size 14, not being able to do all the exercise and what I was doing and just being so tired just said you're fat don't love you anymore. Participant 61.

My husband. I got to change the language, but he won't learn about it won't listen to me trying to talk about it He tries to talk about it probably feels like I'm whinging all the time. It has affected personal relationships with your weight, complete loss of interest in intimacy. Participant 32.

Participant describes others find it difficult to understand rheumatoid arthritis impacting personal relationships

So, I think sometimes people just get so sick of you not being able to come out with them, they stop inviting you. And that's pretty hard to have happened at my age and younger when it was first happening. But, um, yeah, I think a lot of it is just education. A lot of people don't understand. you can't do the things that people your own age to do and there's some people that will understand that, but there's other people, it just, it's too difficult for them to understand or it's too emotional for them to understand. And I understand that. I wouldn't want to be in this position neither if I had a choice. Participant 97.

People don't understand chronic illness unless they have it all, maybe they have it with someone they love and what have you. People just don't understand. Participant 21.

I saw a friend that I don't see very often, and I was limping. I had a sore knee and I was limping and she kind of said what's wrong with you. And I said, oh, just my, just my RA, you know, it'll be alright. And then saw her again three months later and I was actually limping again even though I'd been fine in those three months. And she went, oh my God, and like I really feel like people think we are faking symptoms. I really do believe that because it's not something I can literally be thinking walk, I can't walk and two days later I'll run up the street. Yeah. It's just people must look at that and think I'm faking for whatever reason. Participant 69.

Participant describes relationships have become more complex.

My eldest daughter who is sick now suffered from anxiety, um, and we, um, uh, like 90 percent sure that that is from the things that she has seen. So she's done things like that. She's gone to bed at night and woke up in the morning and not because I've been in the hospital overnight. Um, she's seen me crying and stuck in a wheelchair for four months. She seen me in pain. Um, I've had some injuries because we got to a stage where like I want stood up off the toilet and snapped my femur in half and so she wouldn't use the toilet at school. So like three whole terms of the public toilets. So, um, she was very concerned for a while there about me dying and she experienced a lot of separation anxiety from me and after all this sort of stuff happened, she was very worried about me dying and things like that. So I choose to deal. She's, she's been at school for a year, she's still will not go and line up in the canteen because she's worried that somebody will knock her over and because it's the one knocked me over, I can't do that and I could break a bone, you know, but if someone knocks her out but she doesn't realize she can just get the consequences we're getting her and things too. Participant 64.

Yes. Like I said before, I think my eldest son and his wife understand it because I got my daughter in law's mother's close friend has rheumatoid arthritis. They understand that a little bit more than what my youngest son does. His family are also a little bit on the selfish side because I'm not there all the time like I used to be so it just takes there. We're still close, but my daughter in law has moments where she doesn't talk to me. Yes, it has affected that. It's better with my husband than what it was, but it took him like eight out of the ten years I've been through with him. Participant 46.

…always outside the direct family I think I haven't got the energy or that's just gonna be too emotionally or mentally tough. I can't cope with it listening to somebody or or whatever. Participant 88.

Table 8.4 Impact on relationships

Impact on relationships	All participants		Physical limitations: no days		Physical limitations: few days		Physical limitations: some to most days		Symptoms: no to few days		Symptoms: some days		Symptoms: most days		Symptoms: all days	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant describes a negative impact in relation to losing friends or friends 'dropping away'	34	34.00	7	36.84	10	22.73	17	45.95	4	20.00	10	37.04	11	34.38	9	42.86
Participant describes having no significant impact on relationships with family or friends	30	30.00	8	42.11	18	40.91	4	10.81	9	45.00	11	40.74	8	25.00	2	9.52
Participant describes a negative impact in relation to a reduction in social interactions	16	16.00	3	15.79	5	11.36	8	21.62	2	10.00	4	14.81	6	18.75	4	19.05
Participant describes a negative impact in relation to their relationship with their partner (emotional strain)	16	16.00	3	15.79	6	13.64	7	18.92	1	5.00	5	18.52	6	18.75	4	19.05
Participant describes a negative impact as it is difficult for others to navigate a different type of relationship	15	15.00	3	15.79	8	18.18	4	10.81	4	20.00	3	11.11	5	15.63	3	14.29
Participant describes a negative impact as it is difficult for others to understand the complexity of rheumatoid arthritis	15	15.00	6	31.58	5	11.36	4	10.81	5	25.00	6	22.22	1	3.13	3	14.29

Regular activities to maintain health	All participants		Affect: never to almost never		Affect: sometimes		Affect: very often to always		Social: all to most days		Social: some days		Social: no to few days	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes a negative impact in relation to losing friends or friends 'dropping away'	34	34.00	9	27.27	11	30.56	14	45.16	3	15.00	11	30.56	20	45.45
Participant describes having no significant impact on relationships with family or friends	30	30.00	18	54.55	9	25.00	3	9.68	8	40.00	10	27.78	12	27.27
Participant describes a negative impact in relation to a reduction in social interactions	16	16.00	4	12.12	5	13.89	7	22.58	2	10.00	7	19.44	7	15.91
Participant describes a negative impact in relation to their relationship with their partner (emotional strain)	16	16.00	3	9.09	8	22.22	5	16.13	1	5.00	9	25.00	6	13.64
Participant describes a negative impact as it is difficult for others to navigate a different type of relationship	15	15.00	3	9.09	7	19.44	5	16.13	5	25.00	7	19.44	3	6.82
Participant describes a negative impact as it is difficult for others to understand the complexity of rheumatoid arthritis	15	15.00	6	18.18	4	11.11	5	16.13	4	20.00	3	8.33	8	18.18

Table 8.4 Impact on relationships (Cont.)

Impact on relationships	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 34 - 45***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes a negative impact in relation to losing friends or friends 'dropping away'	34	34.00	18	32.14	16	36.36	9	29.03	15	29.41	10	55.56
Participant describes having no significant impact on relationships with family or friends	30	30.00	22	39.29	8	18.18	9	29.03	15	29.41	6	33.33
Participant describes a negative impact in relation to a reduction in social interactions	16	16.00	9	16.07	7	15.91	5	16.13	7	13.73	4	22.22
Participant describes a negative impact in relation to their relationship with their partner (emotional strain)	16	16.00	9	16.07	7	15.91	4	12.90	11	21.57	1	5.56
Participant describes a negative impact as it is difficult for others to navigate a different type of relationship	15	15.00	10	17.86	5	11.36	2	6.45	10	19.61	3	16.67
Participant describes a negative impact as it is difficult for others to understand the complexity of rheumatoid arthritis	15	15.00	10	17.86	5	11.36	2	6.45	9	17.65	4	22.22

Impact on relationships	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes a negative impact in relation to losing friends or friends 'dropping away'	34	34.00	21	37.50	13	29.55	12	36.36	22	32.84	17	34.00	17	34.00
Participant describes having no significant impact on relationships with family or friends	30	30.00	17	30.36	13	29.55	8	24.24	22	32.84	16	32.00	14	28.00
Participant describes a negative impact in relation to a reduction in social interactions	16	16.00	10	17.86	6	13.64	6	18.18	10	14.93	6	12.00	10	20.00
Participant describes a negative impact in relation to their relationship with their partner (emotional strain)	16	16.00	7	12.50	9	20.45	5	15.15	11	16.42	6	12.00	10	20.00
Participant describes a negative impact as it is difficult for others to navigate a different type of relationship	15	15.00	6	10.71	9	20.45	5	15.15	10	14.93	6	12.00	9	18.00
Participant describes a negative impact as it is difficult for others to understand the complexity of rheumatoid arthritis	15	15.00	10	17.86	5	11.36	4	12.12	11	16.42	6	12.00	9	18.00

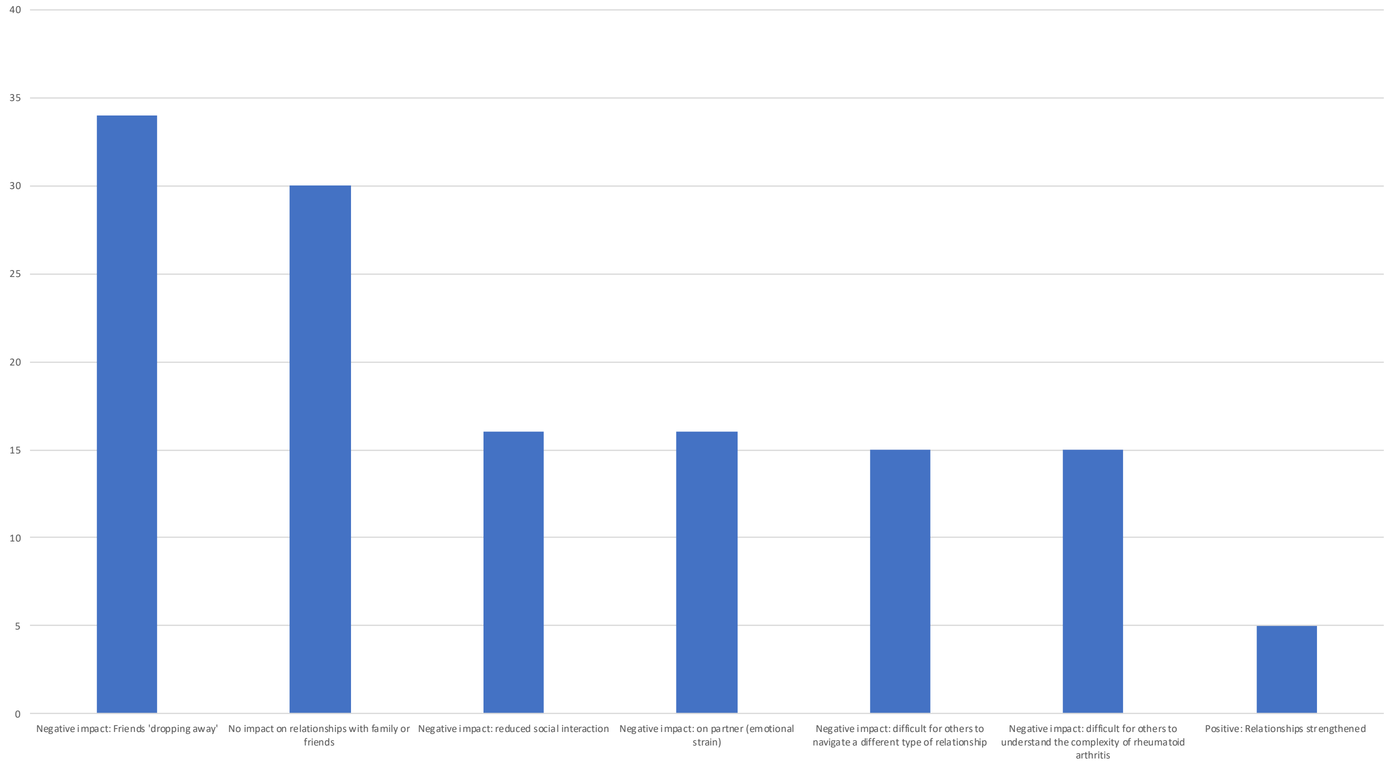


Figure 8.4 Impact on relationships

Burden on family

Participants were also asked if their condition caused any additional burden on their family. The most common theme was that the family takes on extra duties (41.00%). This was followed by worrying about the future burden that may result from their rheumatoid arthritis (19.00%), the mental/emotional burden on their family (18.00%), no burden as they require little assistance (12.00%) and family taking up extra driving duties for the participant (8.00%).

In relation to subgroup variations, participants in the sub-groups *Physical limitations: no days* (26.43%), *Symptoms: no to few days* (30.00%), *Affect: never to almost never* (30.30%), *Social: all to most days* (30.00%), *Aged 18 – 34* (27.78%), and *Trade or high school* (27.27%) reported that family takes on extra duties less frequently than the general population (41.00%), while participants in the sub-groups *Physical limitations: some to most days* (59.46%), *Affect: very often to always* (54.84%) reported this more often.

Participants in the sub-group *Physical limitations: some to most days* (8.11%) reported that they worried about future burden less frequently than the general population (19.00%), while participants in the sub-groups *Symptoms: some days* (29.63%) and *Affect: never to almost never* (33.33%) reported this more often.

Participants in the sub-group *Affect: never to almost never* (3.03%) reported that they worried mental/emotional burden less frequently than the general population (18.00%), while participants in the sub-groups *Symptoms: no to few days* (35.00%), *Affect: sometimes* (33.33%), and *Aged 18 – 34* (33.33%) reported this more often.

No participants in the sub-group *Physical limitations: no days* reported that family takes up extra driving compared to 8.00% of the general population.

Table 8.5 Burden on family

Burden on family	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes that their condition is a burden on their family due to the extra duties or responsibilities their family members have had to take on	41	41.00	5	26.32	14	31.82	22	59.46	6	30.00	11	40.74	15	46.88	9	42.86
Participant describes that their condition is not a burden on their family at this stage, but it is likely to be in the future	19	19.00	4	21.05	12	27.27	3	8.11	3	15.00	8	29.63	6	18.75	2	9.52
Participant describes that their condition is a burden on their family due to the mental or emotional strain it places on their family	18	18.00	5	26.32	7	15.91	6	16.22	7	35.00	3	11.11	5	15.63	3	14.29
Participant describes that their condition is not a burden on their family as they've required little assistance	12	12.00	3	15.79	5	11.36	4	10.81	3	15.00	1	3.70	4	12.50	4	19.05
Participant describes that their condition is a burden on their family due to the need to have others drive them around	8	8.00	0	0.00	4	9.09	4	10.81	1	5.00	3	11.11	2	6.25	2	9.52

Table 8.5 Impact on family (Cont.)

Burden on family	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant describes that their condition is a burden on their family due to the extra duties or responsibilities their family members have had to take on	41	41.00	10	30.30	14	38.89	17	54.84	6	30.00	15	41.67	20	45.45
Participant describes that their condition is not a burden on their family at this stage, but it is likely to be in the future	19	19.00	11	33.33	5	13.89	3	9.68	5	25.00	6	16.67	8	18.18
Participant describes that their condition is a burden on their family due to the mental or emotional strain it places on their family	18	18.00	1	3.03	12	33.33	5	16.13	4	20.00	8	22.22	6	13.64
Participant describes that their condition is not a burden on their family as they've required little assistance	12	12.00	5	15.15	3	8.33	4	12.90	2	10.00	6	16.67	4	9.09
Participant describes that their condition is a burden on their family due to the need to have others drive them around	8	8.00	3	9.09	3	8.33	2	6.45	3	15.00	1	2.78	4	9.09

Burden on family	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 34 - 45*		*Aged 18 – 34*	
	n=100	%	n=56	%	n=44	%	n=31	%	n=51	%	n=18	%
Participant describes that their condition is a burden on their family due to the extra duties or responsibilities their family members have had to take on	41	41.00	21	37.50	20	45.45	11	35.48	25	49.02	5	27.78
Participant describes that their condition is not a burden on their family at this stage, but it is likely to be in the future	19	19.00	12	21.43	7	15.91	8	25.81	8	15.69	3	16.67
Participant describes that their condition is a burden on their family due to the mental or emotional strain it places on their family	18	18.00	12	21.43	6	13.64	6	19.35	6	11.76	6	33.33
Participant describes that their condition is not a burden on their family as they've required little assistance	12	12.00	9	16.07	3	6.82	4	12.90	7	13.73	1	5.56
Participant describes that their condition is a burden on their family due to the need to have others drive them around	8	8.00	4	7.14	4	9.09	3	9.68	2	3.92	3	16.67

Burden on family	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	%	n=56	%	n=44	%	n=33	%	n=67	%	n=50	%	%	n=50
Participant describes that their condition is a burden on their family due to the extra duties or responsibilities their family members have had to take on	41	41.00	22	39.29	19	43.18	9	27.27	32	47.76	19	38.00	22	44.00
Participant describes that their condition is not a burden on their family at this stage, but it is likely to be in the future	19	19.00	12	21.43	7	15.91	8	24.24	11	16.42	9	18.00	10	20.00
Participant describes that their condition is a burden on their family due to the mental or emotional strain it places on their family	18	18.00	8	14.29	10	22.73	4	12.12	14	20.90	7	14.00	11	22.00
Participant describes that their condition is not a burden on their family as they've required little assistance	12	12.00	6	10.71	6	13.64	5	15.15	7	10.45	6	12.00	6	12.00
Participant describes that their condition is a burden on their family due to the need to have others drive them around	8	8.00	5	8.93	3	6.82	5	15.15	3	4.48	4	8.00	4	8.00

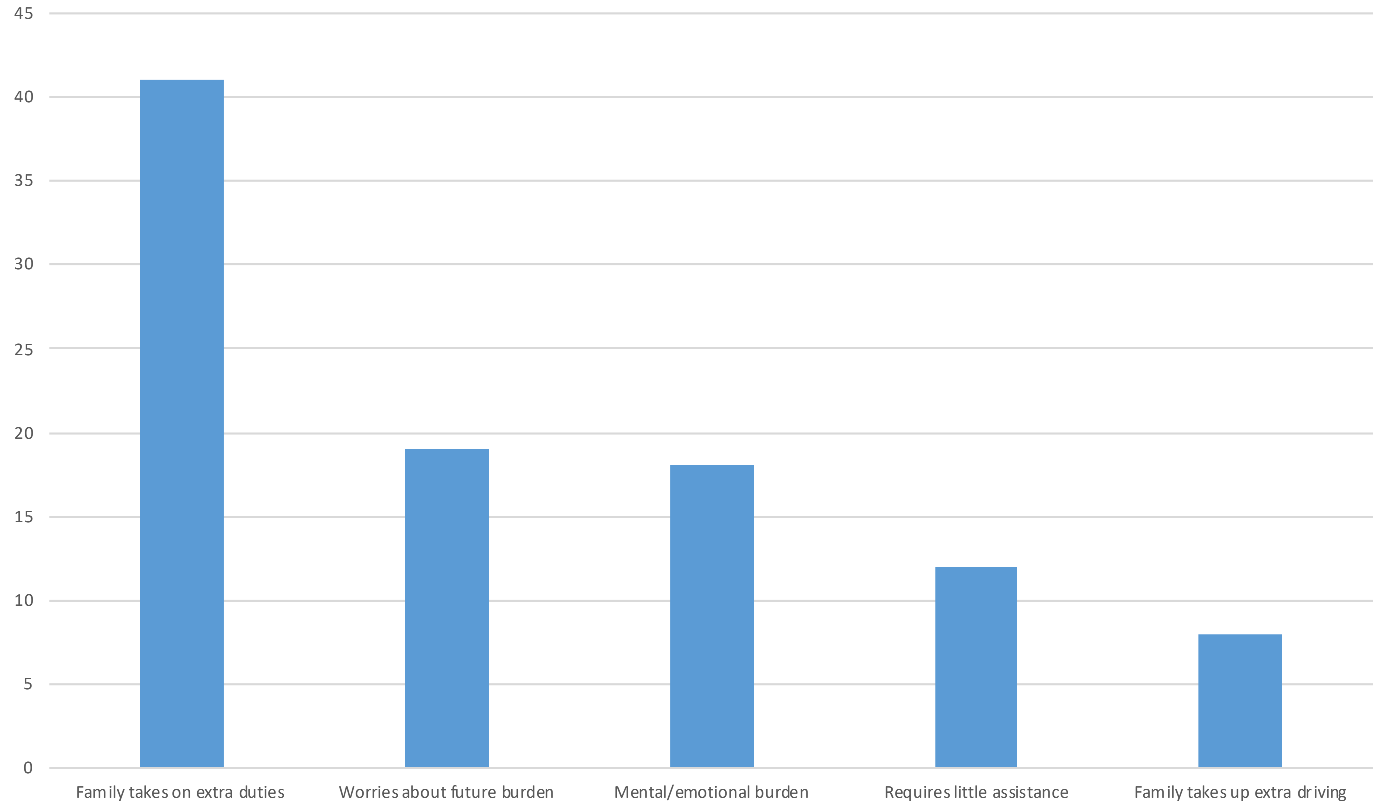


Figure 8.5 Burden on family

Cost considerations

Participants were also asked about costs associated with having rheumatoid arthritis. 39% of participants mentioned that treatment costs were a significant burden of having RA. Other costs included having to take time off work (37%), spending money on specialists (36%), day to day costs associated with the condition (10%), costs of complementary therapies (10%), not struggling financially as their insurance covers their treatment (9%), and costs at diagnosis (8%).

In relation to sub-group variations, participants in the sub-group *Physical limitations: some to most days* (27.03%) reported treatment costs less frequently than the general population (39.00%), while participants in the sub-group *Physical limitations: few days* (52.27%) reported this more often.

Participants in the sub-groups *Symptoms: no to few days* (25.00%), and *Social: all to most days (*15.00%) reported time-off work less often than the general population (37.00%), compared with participants in the sub-groups *Symptoms: some days* (51.85%), and *Social: some days* (47.22%) who reported this more frequently.

Participants in the sub-group *Social: all to most days (20.*00%) reported specialist costs less often than the general population (36.00%).

No participants in the sub-group *Physical limitations: no days* reported day to day costs, compared to 10.00% of the general population.

Participants in the sub-groups *Physical limitations: no days* (21.05%), and *Symptoms: no to few days* (20.00%) reported that they do struggle with cost due to insurance more often than the general population (9.00%).

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days, Symptoms: most days,* and *Social: all to most days* reported diagnostic, compared to 8.00% of the general population.

Participant describes struggling with the costs of treatment

I know while I was on the healthcare card for a time, which certainly helped. I don't know how it's going to work now because sometimes you see on the tablets and that's the full price which is like over a thousand dollars. It's like, "Do I have to pay that when my healthcare card expires?" which is six months I think, or next month. But I don't know. I'm pretty sure that it's covered under PBS but it does show like the full price here. Full cost $1,267. Participant 35

So um at the moment, I suppose the only cost is if you get medication, you know, and if you don't it's not very good. I think if you get diagnosed with something that you need medication every month, that's when you should get a healthcare card. So that's for that disease, you know what I mean? Participant 8

A non-prescription ones aren't on the PBS. So folic acid and fish oil and others are not on the PBS. Yes. Individually that don't cost much, but when you add everything up, it's nothing to walk into the pharmacy and spend $100 a month. Participant 10

Probably the cost of medications has been the biggest thing. I went from rarely having a Panadol to having huge amounts of medication. So at one stage it was costing me about $450 a month just on medications alone. Participant 37

Participant describes needing time of work

I haven't been able to work in a regular job. My body's just too unreliable. Participant 26

One of the problems with having a chronic illness like this can affect your ability to work and I've lost three jobs because of this, because of my sick leave and I was very broke for a very long time and I had massive debts. Participant 36

I found that it affected my work, so I had to give up working. I only work three days a week, but I couldn't even do that because some days you'd get up and you didn't know that you were going to be able to get out of bed. As far as that was, it cut down my income. Participant 46

I lost my job. Yeah. Other jobs because I couldn't be reliable. I lost my job. Participant 98

Participant describes costs of seeing a specialist

Like I said, rheumatologist appointment, medicare does cover that, but you've got to have, you know, the $200, whatever it is in the bank to pay for it. Participant 4

Um the specialist costs are significant. So he wants me to be going once every three months and every time I go cost me $300 and that's not something that, um, my health fund covers easily either. Participant 19

Every year, he puts his prices up, which I don't think is right. I haven't had a 50% pay increase in the last six years. Anyway, I think it's quite expensive for what it is. He has bulk-billed me once in the whole time I've been there. Participant 20

I mean the horrible old neurologist charged me $475, 15 minutes of his time. Participant 72

I have to fork out $400 for an appointment. My last appointment I had to cancel because I hadn't had the funds to do it. Participant 100

Struggles with costs\Day to day financial costs of RA

I've just had to go buy a new set of saucepans and pans today because I can't physically hold my old ones anymore. I can't cook. Participant 17

We have to get a cleaner in every week, so that's an extra $50 a week because I can't, I just, my hand won't let me clean and she's been here for two years now helping me out. Participant 31

My mother and my father, they divorced, but they have paid for me to have. There's been thousands and thousands, so they paid for my joint replacement surgeries. They paid, paid for my hospital admission. They have paid for. Um, my, like, yeah, all the different surgeries I've had. My mum still pays for my private health insurance now because I can't afford it and they pay for. They have brought me over the toilet seat, electric wheelchairs, manual, wheelchairs, crutches, lifted recliners. I'm a commode, chairs shower, my mum has paid. My Mum has given me a credit card that I can use now when I need to get scripts or creams or heat pack and all the things that aren't covered. Participant 64

It's just all that stuff and it's all the orthotic shoes at $300-and-odd a pop and all of that stuff. I'm finding now I'm becoming-- After seven years, I'm becoming less able to do stuff. It's trying to find aids and stuff and things that make life easier, I suppose, that also costs the money. It's pretty damn expensive. Most people have no idea. Participant 63

Struggles with costs\self-care/complementary therapy costs to help with symptoms

It's also things like, I don't know, like you sort of have to like things like, um, activities you need to do to make yourself feel better. Like you're going to massage or you're going the pool like that? All the money. Participant 12

Once you pay for all that sort of stuff, it adds up. And then, you know, the massage, which is not seen as therapy, but it actually works for me, so I'll keep doing it. You put all that together and it gets quite expensive. Participant 97

Then the hydrotherapy pool, again I know that's our choice, but it's ridiculously expensive. All the complementary therapies, all that stuff, I spent $100 a week on herbs. Now I'm never not going to do that, they are everything. They're keeping me going but it's expensive and you're on your own with it. It makes an impact but we've made the decision that we need to do it, we spend it. Participant 48

Does not struggle with costs/PBS/health-fund/bulk-billed/medicine

Not really, no stress because I pay, I think 125 to the rheumatologists and I get, I don't know, 60 something back. The medication hasn't cost me anything except what I've to normally pay but we reached the threshold anyway because the drugs my husband is on. I can't complain about that. No. I've got no complaints. Participant 21

I think um, and then I've been bulk billed ever since for my specialist. Yeah. And I don't know why they've just, they just have. Because I know that they charge, so I have no idea why, but they have anything at my gp has always been bulk billed in relation to rheumatoid. Participant 2

That's the other thing, those little things but mostly my health fund is pretty good with that. They'll pay for most of those visits to a hand therapist, I have to go quite regular after I had the finger joint replacement. I had to go quite regular to them and my health fund covered quite a bit. Participant 16

Does not struggle with costs (PBS/health-fund/bulkbilled/medicine)

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That's the other thing, those little things but mostly my health fund is pretty good with that. They'll pay for most of those visits to a hand therapist, I have to go quite regular after I had the finger joint replacement. I had to go quite regular to them and my health fund covered quite a bit. Participant 16

Participant describes struggling with the costs of diagnostic tests

I've had to have x-rays, ultrasounds, other things like that which has out me out of pocket. Participant 22

Very deeply paying out of pocket and then getting a full amount back in these specialist appointments and he has different scans and stuff like that that you have. Participant 65

I've had to have time off work for specialist appointments and then I think it is if you looked at it it would add up to thousands of dollars, uh, aside from the out of pocket specialist costs, the blood tests and things like that. Participant 71.

Table 8.6 Cost Considerations

Cost considerations	All participants		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes struggling with the costs of treatment	39	39.00	6	31.58	23	52.27	10	27.03	6	30.00	12	44.44	14	43.75	7	33.33
Participant describes needing time off work	37	37.00	7	36.84	17	38.64	13	35.14	5	25.00	14	51.85	12	37.50	6	28.57
Participant describes costs of seeing a specialist	36	36.00	6	31.58	17	38.64	13	35.14	8	40.00	9	33.33	12	37.50	7	33.33
Participant describes struggles with costs\day to day financial costs of RA	10	10.00	0	0.00	3	6.82	7	18.92	2	10.00	2	7.41	3	9.38	3	14.29
Participant describes struggling with costs\self-care/complementary therapy costs to help with symptoms	10	10.00	2	10.53	3	6.82	5	13.51	2	10.00	3	11.11	3	9.38	2	9.52
Participant does not struggle with costs as their costs are covered by insurance	9	9.00	4	21.05	4	9.09	1	2.70	4	20.00	3	11.11	0	0.00	2	9.52
Participant describes struggling with the costs of diagnostic tests	8	8.00	0	0.00	4	9.09	4	10.81	0	0.00	2	7.41	3	9.38	3	14.29

Cost considerations	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes struggling with the costs of treatment	39	39.00	14	42.42	15	41.67	10	32.26	8	40.00	14	38.89	17	38.64
Participant describes needing time off work	37	37.00	11	33.33	14	38.89	12	38.71	3	15.00	17	47.22	17	38.64
Participant describes costs of seeing a specialist	36	36.00	10	30.30	14	38.89	12	38.71	4	20.00	15	41.67	17	38.64
Participant describes struggles with costs\day to day financial costs of RA	10	10.00	3	9.09	3	8.33	4	12.90	1	5.00	2	5.56	7	15.91
Participant describes struggling with costs\self-care/complementary therapy costs to help with symptoms	10	10.00	5	15.15	3	8.33	2	6.45	2	10.00	4	11.11	4	9.09
Participant does not struggle with costs as their costs are covered by insurance	9	9.00	3	9.09	4	11.11	2	6.45	3	15.00	3	8.33	3	6.82
Participant describes struggling with the costs of diagnostic tests	8	8.00	2	6.06	2	5.56	4	12.90	0	0.00	4	11.11	4	9.09

Cost considerations	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35 - 54*		*Aged 18 – 34*	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes struggling with the cost of treatments	39	39.00	0	41.07	16	36.36	13	41.94	19	37.25	7	38.89
Participant describes needing to take time off work	37	37.00	21	37.50	16	36.36	7	22.58	22	43.14	8	44.44
Participant describes struggling with the cost of GP and specialist appointments (Particularly specialist fees)	36	36.00	22	39.29	14	31.82	8	25.81	23	45.10	5	27.78
Participant describes struggling with the cumulative costs (Everyday living costs)	10	10.00	3	5.36	7	15.91	3	9.68	5	9.80	2	11.11
Participant describes struggling with the cost of complementary therapies	10	10.00	6	10.71	4	9.09	4	12.90	4	7.84	2	11.11
Participant describes not struggling with costs due to their private health insurance	9	9.00	5	8.93	4	9.09	5	16.13	3	5.88	1	5.56
Participant describes struggling with cost of diagnostic tests	8	8.00	3	5.36	5	11.36	3	9.68	5	9.80	0	0.00

Table 8.6 Cost Considerations (Cont.)

Cost considerations	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes struggling with the costs of treatment	39	39.00	25	44.64	14	31.82	15	45.45	24	35.82	24	48.00	15	30.00
Participant describes needing time off work	37	37.00	24	42.86	13	29.55	10	30.30	27	40.30	24	48.00	13	26.00
Participant describes costs of seeing a specialist	36	36.00	17	30.36	19	43.18	15	45.45	21	31.34	19	38.00	17	34.00
Participant describes struggles with costs\day to day financial costs of RA	10	10.00	7	12.50	3	6.82	5	15.15	5	7.46	4	8.00	6	12.00
Participant describes struggling with costs\self-care/complementary therapy costs to help with symptoms	10	10.00	5	8.93	5	11.36	2	6.06	8	11.94	5	10.00	5	10.00
Participant does not struggle with costs as their costs are covered by insurance	9	9.00	4	7.14	5	11.36	2	6.06	7	10.45	5	10.00	4	8.00
Participant describes struggling with the costs of diagnostic tests	8	8.00	5	8.93	3	6.82	4	12.12	4	5.97	5	10.00	3	6.00

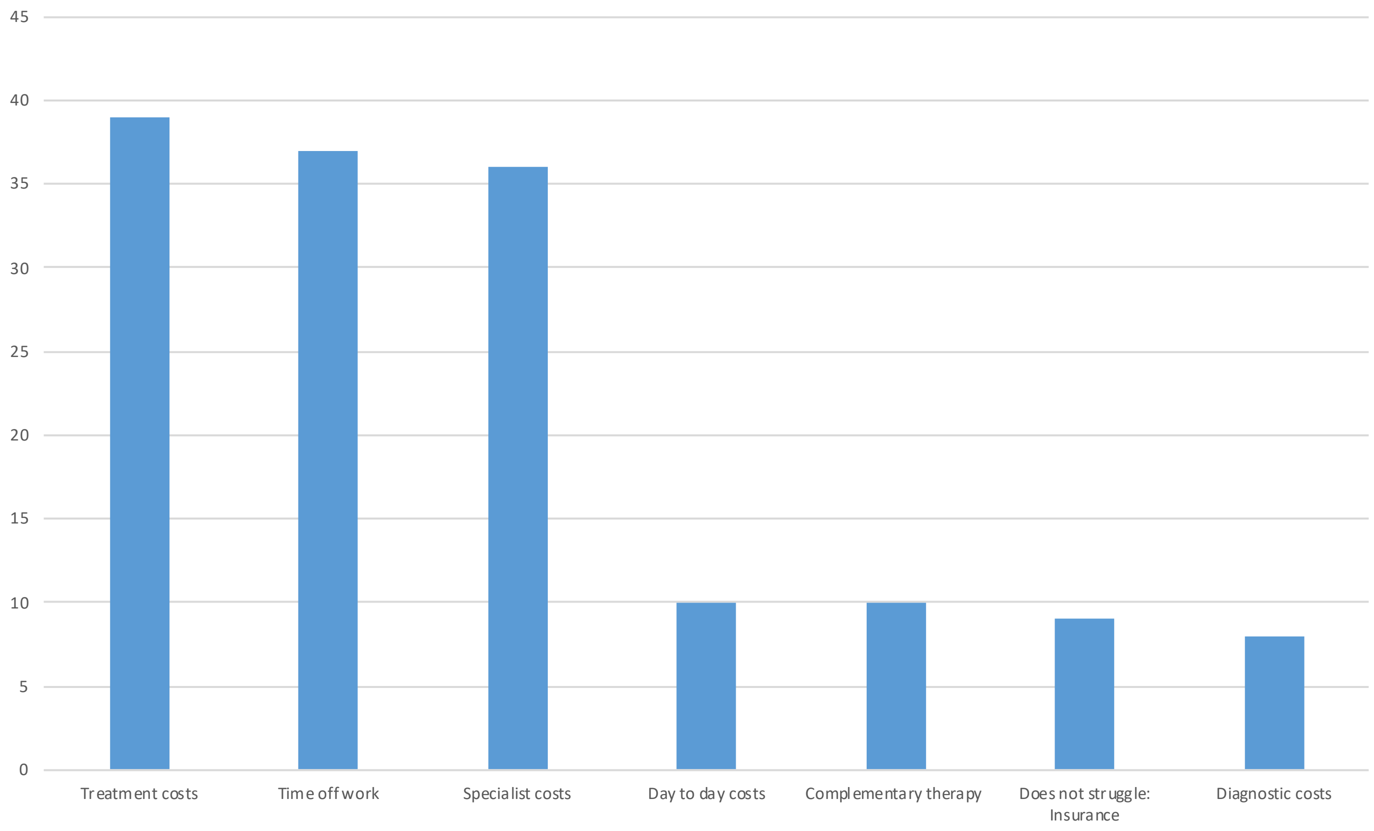


Figure 8.6 Cost Considerations

Section 9 Expectations and messages

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

In the structured interview, participants were asked what they expected from future treatments. The most common theme was less treatment expense (n=43, 43.00%). This was followed by less side effects (n=34, 34.00%), more oral treatments (n=18, 18.00%), more varied and/or accessible treatments (n=13, 13.00%) and more holistic care (n=12, 12.00%).

Expectations of future information

In the structured interview, participants were asked what they wanted from information in the future. The most common theme was wanting their healthcare professionals to be more forthcoming with information (n=18, 18.00%). This was followed by participants being satisfied with current information (n=13, 13.00%), changing the format of the current information (n=11, 11.00%), more lifestyle information (n=10, 10.00%), more awareness about rheumatoid arthritis (n=10, 10.00%), holistic options (n=10, 10.00%), more information about patient experiences (n=9, 9.00%), more information about specific symptoms (n=9, 9.00%) and new treatments/clinical trials (n=8, 8.00%).

Expectations of future healthcare professional communication

In the structured interview, participants were asked what they wanted from healthcare professional communication in the future. The most common themes were that participants wanted health professionals to communicate with more compassion/empathy and establish a connection with patients (n=25, 25.00%). Other themes included having experienced good communication and not having any recommendations (n=22, 22.00%), wanting to have more time to communicate with health professionals (n=21, 21.00%), that health professionals communicate more holistically; that is, talk more holistically about treatment options or participants' experiences (n=18, 18.00%), and that clinicians explain diagnosis/test results/prognosis/treatment more clearly (n=9, 9.00%).

Expectations of future care and support

In the structured interview, participants were asked what they expected of care and support in the future. The most common reported expectation of future care and support was that there was an increased understanding of rheumatoid arthritis within care and support systems, as well as within the general population (n=22, 22.00%). Other reported themes included a desire for more affordable complementary therapies (n=17, 17.00%), increased access to or improvement of support groups/charity support (n=16, 16.00%), more access to domestic support (n=15, 15.00%) and psychological support (n=15, 15.00%), more opportunity to connect with other patients (n=14, 14.00%), more transport support (n=10, 10.00%), increased funding into RA research and support services, and easier access to services (n=8, 8.00%) for those that either live regionally or work full-time. Twelve participants (12.00%) reported that they had no recommendations for improvement.

Aspects of the Australian health system patients are grateful for

In the structured interview, participants were asked what aspects of the Australian health system they were most grateful for. The most common theme was being grateful for the Australian health system being low cost/free (n=40, 40.00%). Other commonly reported themes included gratitude for being able to access treatment through Medicare (n=39, 39.00%), for healthcare professionals (n=27, 27.00%) access to a rheumatologist (19.00%), access to diagnostic tests (n=13, 13.00%), and for the entire health system (n=11, 11.00%). In addition, 29 participants (29.00%), when asked what aspects of the health system they were grateful, expressed a degree of gratitude but also said that there were significant improvements that needed to be made.

Symptoms and aspects of quality of life important for treatment considerations

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 9 is the least important. The most important aspects reported were pain, physical function, and level of independence; the least important was redness.

Length of time to take a treatment for good quality of life

In response to “For you to feel that a treatment was worthwhile, how many months or years would you consider taking it, provided it gave you a good quality of life, even if it didn’t offer a cure?”, the majority of participants would take the treatment for more than 10 years (n=71, 71.00%).

Values that are important to patients when making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important were “The ability to include my family in making treatment decisions”, and “My ability to follow and stick to a treatment regime”.

Values that are important to patients when others are making decisions on their behalf

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were “quality of life for patients”, and “access for all patients to all treatments and services”; the least important was “economic value to government”.

Message to decision makers

The most common message participants wanted to tell decision makers was that there should be more awareness of and research into rheumatoid arthritis (23.00%). Other common messages included that treatment should be affordable (19.00%), there should be better access to different medicines through the PBS (19.00%), there should be a reduction of stigma surrounding RA (17.00%), there needs to be more efficient hospital processes (14.00%), that complementary therapies needed to be more affordable (10.00%), and that there needs to be a change to the referral process surrounding biologics (8.00%).

Expectations of future treatment

In the structured interview, participants were asked what they expected from future treatments. The most common theme was less treatment expense (n=43, 43.00%). This was followed by less side effects (n=34, 34.00%), more oral treatments (n=18, 18.00%), more varied and/or accessible treatments (n=13, 13.00%) and more holistic care (n=12, 12.00%).

In relation to sub-group variations, participants in the sub-group *Symptoms: all days* (19.05%) wanted less treatment expense less frequently than the general population (43.00%), while participants in the sub-groups *Physical limitations: no days* (57.89%), and *Symptoms: no to few days* (65.00%), *Social: all to most days* (55.00%) wanted this more often. No participants in the sub-group *Symptoms: most days* (53.13%) reported wanting less treatment expense.

Participants in the sub-groups *Physical limitations: no days* (21.05%), and *Aged 18 – 34* (22.22%) wanted less side effects less frequently than the general population (34.00%), while participants in the sub-group *Social: some days* (44.44%) wanted this more often.

Participants in the sub-group *Symptoms: no to few days* (5.00%) wanted oral treatment less frequently than the general population (18.00%), while participants in the sub-group *Symptoms: all days* (33.33%) wanted this more often.

Participants in the sub-group *Social: some days* (2.78%) wanted more varied/accessible treatments less frequently than the general population (13.00%).

Participants in the sub-group *Symptoms: some days* (22.22%) wanted more holistic care less frequently than the general population (12.00%).

Participant notes the importance of affordability of treatment, particularly in relation to equitable access

Well a big issue is cost, and people shouldn't have to go without because they can't afford, um, treatments like that. The big one, um, or even surgeries. Um, I, yeah. Um, things, you know, there's been times where like I've got a friend, she's got RA and is a single mum with three kids as well, and her elbow was bone on bone, but she can't afford to get it replaced. Participants 64.

The cost of it, because they do get expensive. It's not cheap, especially if you're on multiple medications. And I was working part time. Participant 38.

Being on the pension most of mine are on the PBS list, which I get them a hell of a lot cheaper than what another person who's not on a pension would get. Some of the drugs are very expensive. If you're not on a pension and eligible for that, some of the drugs are very expensive. I think, maybe, that could be looked at. Participant 80.

Participant notes the importance of less side effects from their treatment

I don't know, something with no side effects, something safer. Yeah, something more natural, like it really scares me that everything is modifying your immune system. Participant 95.

It might be that your brain knows about pain, but it's not in your mind. It's a physical thing and it does pull together all sorts of other things like your dry eyes, like your dry mouth, like your irritable bowel, like all that other stuff. I think that's a bigger issue than just about anything else. Participant 70.

I'd really like something that's not so toxic and not so severe side effects. Participant 43.

Participant describes preferring oral treatment at home

I would probably like to see more drugs like xeljanz, so something that's taken orally rather than an injection or through an IV I guess. I think it's just a lifestyle thing, like for me at this point in time because I work full time and stuff like that, it's just easy to have medication for my breakfast and go do what I need to do rather than having a day off to go sit in hospital and, you know, get treatments done there. Participant 56.

The way they're administered is a good one to start with. Ideally, everything will be oral or patches and things like that. Participant 26.

I don't care if I take daily pills. If you said to me, I've got a one monthly tablet which gives you a lot of side effects and you can take a tablet every day which doesn't have side will I go for the everyday tablet or the five times a day tablet without the side effects because it doesn't worry me taking. I would hate to think that I have to take injections and do it myself. Participant 94.

Participant recommends more varied and accessible treatments

The variety in the drugs available to treat the various degrees of needs. Participant 6.

The hoops that you have to jump through to be able to access those more costly medication that are more effective and I understand some of the other treatments that might be more effective for most people, but it seems like a lot of people I've spoken to have said going through that process of taking the methotrexate, sulfasalazine or whatever, and then ended up on the biologics after a matter of time anyway, just sort of putting that off when it might be a more effective treatment. Participant 39.

Exploring non-invasive procedures, so decreasing surgeries because there's so many other side effects associated with that. Participant 41.

Participant recommends more holistic care in their treatment

Holistic approach. I guess a, let's see your bones, but let's really worry about your mental health and how it's impacting you. I would like to see some kind of, I don't know whether it includes support groups or other therapies or um, you know, even exercise groups or anything. I can't find any information on people's mental health while they're taking this stuff. Participant 24.

I think the holistic approach. That's what I'd like most to see. I'm taking things for RA, but now I have to go see a liver specialist because my liver is shot. Maybe they could not. The rheumatologist goes, "Liver is not my problem so I don't care." There's this real lack of, and I can't say break another part of your body. "That's not my area of the body, so." Participant 48.

Treatment, it should be, "Did you know that you're entitled to a discount home delivery from the chemist?" or "You're entitled to a mobility allowance." "Did you know that you can mail your application for a disability pension, instead of having to come to the office to do it?" That sort of stuff. That would be helpful because they know about that stuff that we don't. Participant 68.

Table 9.1: Expectations of future treatment

Expectations of future treatments	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant recommends that treatments are less expensive	43	43.00	11	57.89	19	43.18	13	35.14	13	65.00	9	33.33	17	53.13	4	19.05
Participant recommends that future treatments have less side effects	34	34.00	4	21.05	17	38.64	13	35.14	5	25.00	9	33.33	11	34.38	9	42.86
Participant recommends that more oral treatments become available	18	18.00	3	15.79	12	27.27	3	8.11	1	5.00	7	25.93	3	9.38	7	33.33
Participant recommends more varied and accessible treatments	13	13.00	3	15.79	5	11.36	5	13.51	3	15.00	4	14.81	4	12.50	2	9.52
Participant recommends that future treatment options are more holistic	12	12.00	3	15.79	6	13.64	3	8.11	3	15.00	6	22.22	2	6.25	1	4.76

Expectations of future treatments	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant recommends that treatments are less expensive	43	43.00	14	42.42	18	50.00	11	35.48	11	55.00	15	41.67	17	38.64
Participant recommends that future treatments have less side effects	34	34.00	12	36.36	10	27.78	12	38.71	5	25.00	16	44.44	13	29.55
Participant recommends that more oral treatments become available	18	18.00	8	24.24	6	16.67	4	12.90	4	20.00	7	19.44	7	15.91
Participant recommends more varied and accessible treatments	13	13.00	3	9.09	7	19.44	3	9.68	2	10.00	1	2.78	10	22.73
Participant recommends that future treatment options are more holistic	12	12.00	3	9.09	5	13.89	4	12.90	3	15.00	5	13.89	4	9.09

Expectations of future treatments	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends that treatments are less expensive	43	43.00	27	48.21	16	36.36	13	41.94	21	41.18	9	50.00
Participant recommends that future treatments have less side effects	34	34.00	19	33.93	15	34.09	11	35.48	19	37.25	4	22.22
Participant recommends that more oral treatments become available	18	18.00	9	16.07	9	20.45	3	9.68	12	23.53	3	16.67
Participant recommends more varied and accessible treatments	13	13.00	7	12.50	6	13.64	3	9.68	7	13.73	3	16.67
Participant recommends that future treatment options are more holistic	12	12.00	6	10.71	6	13.64	2	6.45	7	13.73	3	16.67

Table 9.1: Expectations of future treatment (Cont.)

Expectations of future treatments	***All participants***		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends that treatments are less expensive	43	43.00	23	41.07	20	45.45	12	36.36	31	46.27	20	40.00	23	46.00
Participant recommends that future treatments have less side effects	34	34.00	18	32.14	16	36.36	14	42.42	20	29.85	20	40.00	14	28.00
Participant recommends that more oral treatments become available	18	18.00	10	17.86	8	18.18	5	15.15	13	19.40	12	24.00	6	12.00
Participant recommends more varied and accessible treatments	13	13.00	9	16.07	3	6.82	2	6.06	10	14.93	7	14.00	5	10.00
Participant recommends that future treatment options are more holistic	12	12.00	9	16.07	4	9.09	5	15.15	8	11.94	7	14.00	6	12.00

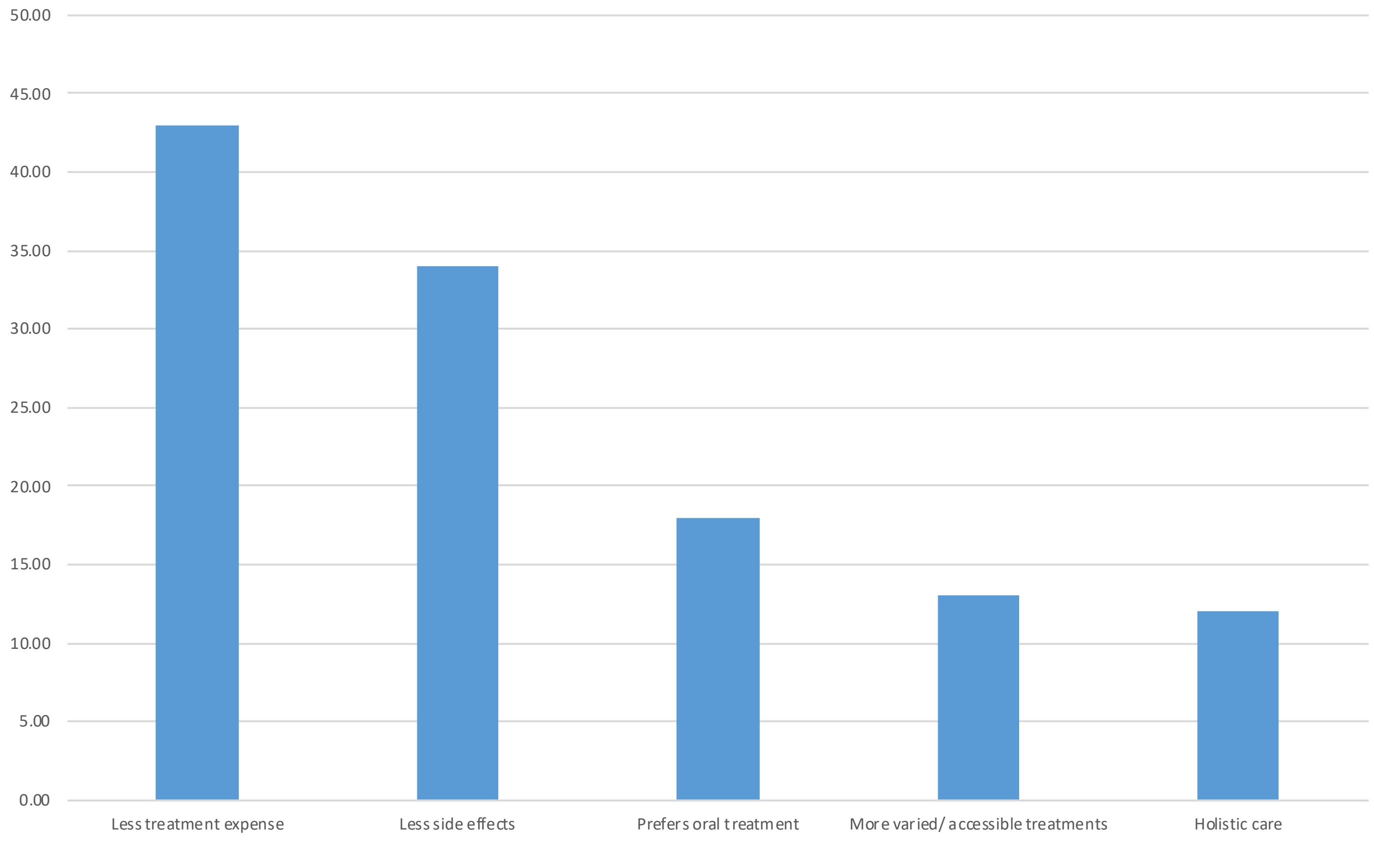


Figure 9.1: Expectations of future treatment

Expectations of future information

In the structured interview, participants were asked what they wanted from information in the future. The most common theme was wanting their healthcare professionals to be more forthcoming with information (n=18, 18.00%). This was followed by participants being satisfied with current information (n=13, 13.00%), changing the format of the current information (n=11, 11.00%), more lifestyle information (n=10, 10.00%), more awareness about rheumatoid arthritis (n=10, 10.00%), holistic options (n=10, 10.00%), more information about patient experiences (n=9, 9.00%), more information about specific symptoms (n=9, 9.00%) and new treatments/clinical trials (n=8, 8.00%).

In relation to sub-group variations, participants in the sub-group *Social: all to most days* (5.00%) wanted healthcare professionals to be more forthcoming with information less frequently compared with 18.00% of the general population.

No participants *Aged 18 – 34* wanted a change in format of information compared with 11.00% of the general population.

No participants in the sub-group *Physical limitations: no days* wanted more lifestyle information compared with 10.00% of the general population.
No participants in the sub-group *Symptoms: no to few days* wanted information about holistic options compared with 10.00% of the general population, while participants in the sub-groups *Social: all to most days* (20.00%) wanted this sort of information more frequently than the general population.

No participants in the sub-group *Symptoms: most days, Social: all to most days* wanted more information about patient experiences compared with 9.00% of the general population, while participants in the sub-groups *Symptoms: no to few days* (22.00%) wanted this sort of information more frequently than the general population.

No participants in the sub-groups *Physical limitations: no day, Symptoms: no to few days* wanted more information about specific symptoms compared with 9.00% of the general population.

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days* wanted more information about new treatments/clinical trials compared with 8.00% of the general population, while participants in the sub-group *Symptoms: some days* (18.52%) wanted this type of information more frequently than the general population.

Participant describes Health care professionals to be more forthcoming about information

If you're talking about people with a new diagnosis, they need to get information from whoever's just diagnosed them, the GP or the rheumatologist or whatever. It'd be good to have direct access to the people that are helping you online to ask questions rather than getting general information, but that seems to be a long way coming. Participant 26.

Yeah, actually it's funny that you say that because when I go to my specialist and my GP, none of them have any flyers or pamphlets on rheumatoid arthritis and like I've seen heaps on diabetes and you know, cancer treatments and um, uh, even just the cold and the flu like there's info on that, but I've never seen a, just a generic flyer been passed around about RA. Participant 56.

Rheumatologists don't touch on that {information}. They just basically give you drugs and that's it. And the GPs don't really know much about that either. So, then you've got to go to a naturopath or something and they're really, really expensive as you probably know. Participant 99.

Participant does not have any recommendations/ satisfied with information.

No, I think, well I've been quite satisfied with the information I've received. Participant 76.

Well I think because I've researched on my own information, I don't feel that I'm lacking in that area. Participant 42.

I was lucky that I was already going to Pilates and that I thought to mention to that, to my rheumatologist, he then suggested that I talk more in depth with my physio and that has been helpful. But if I, if I wasn't doing that, maybe nobody would have suggested that physio could be helpful. Like I wouldn't have thought of that. Participant 7.

Participant describes wanting more done to address stigma or educate.

I think the understanding about what RA is and how it impacts our lives needs to be improved because people just don't understand. Participant 2.

I'd like to see more out there and uh, very few people know what you're talking about and understand it. Say breast cancer and everybody jumps up and down and can't wait to help. When you say rheumatoid arthritis, they think of old people in a wheelchair. Participant 83.

I don't know whether there's any guides for families that are out there that can be given to family members but to-- That don't really understand because it's- I know there is people with it-- They can't- they don't understand. Even though they're explained to them and that there needs to be more communication with the families of the people with rheumatoid. It needs to explain more easily and easier that the people can read about it. Participant 16.

Participant describes wanting more information about patient experiences.

Probably what would be most useful is a collection of patient stories that cover the full spectrum of people that have mild symptoms that have lived a relatively good life. Of people that for each drug, people it worked for and people that it hasn't worked for, you know what I mean? Participant 4.

I'd like to see people's stories of treatment. If someone has had some kind of treatment and it's been a success, it'd be good to know those, and what else have they done to make it successful? Yeah. Yeah. I suppose just passing more information out on what could help. Yeah. Sharing it, sharing it. Yeah. Participant 100.

Yeah, just really basic understanding definition of rheumatoid arthritis, but not from a medical perspective, from an actual real-life person. Participant 27.

Participant describes wanting to know more lifestyle information

Information where you know, you can go and buy things that I like. I can't open jars, any more, so like information where you can buy jar openers or devices to help you put your socks on and devices to help with your um, you know, when you can't use your hands and stuff like that. Participant 8.

You know, changes you can make in your life. Um, you know, things about what you can do in your home to make things easier. Participant 52.

Meals, information and- Something to do with meals and for them being prepared and delivered at a discounted price or just a service that does that doesn't charge the earth. Participant 68.

Participant describes wanting to change the format of how information is presented.

Perhaps the format of how information is presented. Um, I mean like those youtube videos that, you know, people have some really good ones about explaining how it works and how it um, yeah, and how it impacts. Participant 9.

I suppose just making sure that there's information available in lots of different formats to suit lots of different people. No one thing is actually going to suit everybody. Participant 22.

Participant describes wanting more information on treatment/ clinical trials.

I guess what other, what other treatment options are. Participant 28.

I'd like to see more information regarding clinical trials in Australia. Participant 43.

What's the general progression of this thing? What options are out there? I will not let them operate. No way. Unless I get to a point where my fingers can't function anymore because I've just had too many disasters, operations gone wrong. Participant 85.

Participant describes wanting to know more information on specific symptoms/side effects

We know how it affects your joints, but not the fact that it can affect your heart and your lungs and your eyes and all the other things that are more down the line or things that it can affect, but I, I don't quite understand how it affects those things and I have the disease. Participant 72.

I didn't know the Methotrexate causes itchy scalp. All I knew was it was driving me crazy. I'm in my sleep scratching my head. It's just the little things, so if you had someone that you could, in the beginning, that would tell you that this is all normal and you could try in a gentle way, you could do this or do that, and it would alleviate. Try this everyday stuff that if someone could help you through that. Participant 46.

Side effects could be a little like you get the little thing in the chemist box and it says you may get all these but they don't kind of explain how you how much level you should be worried at, like for example, um, you know, they might say severe nausea, you know, 24 hours is that a problem or should I wait 48 hours? Participant 92.

Participant describes wanting more information about holistic care/options

I would like to see a full assistance booklet with every single bit of information from people with rheumatoid and healthcare professionals and family and friends of people with rheumatoid, full of practical, logistical lifestyle solutions, job suggestions. Participant 62.

On some of the more medical websites, an acknowledgement that there's more to treatment of this than just medicine. Participant 29.

I think initially on that, which is I guess where you're totally beneficial, statistics that 80 percent of people think what they said it was beneficial to try psychology or exercise physiology or here are some other, uh, things you can do alongside your medication. Participant 63.

Table 9.2: Expectations of future information

Expectations of future information	*All participants*		*Physical limitations: no days*		*Physical limitations: few days*		*Physical limitations: some to most days*		*Symptoms: no to few days*		*Symptoms: some days*		*Symptoms: most days*		*Symptoms: all days*	
	n=100	%	n=19	%	n=44	%	n=37	%	n=20	%	n=27	%	n=32	%	n=21	%
Participant recommends that healthcare professionals are more forthcoming with information	18	18.00	5	26.32	4	9.09	9	24.32	4	20.00	7	25.93	3	9.38	4	19.05
Participant describes being satisfied with current information and not having any recommendations	13	13.00	2	10.53	5	11.36	6	16.22	3	15.00	1	3.70	5	15.63	4	19.05
Participant recommends changing the format of information	11	11.00	2	10.53	6	13.64	3	8.11	1	5.00	5	18.52	3	9.38	2	9.52
Participant recommends that more lifestyle information is available	10	10.00	0	0.00	7	15.91	3	8.11	1	5.00	3	11.11	4	12.50	2	9.52
Participant recommends that there is more awareness about Rheumatoid arthritis amongst the general population	10	10.00	2	10.53	2	4.55	6	16.22	3	15.00	1	3.70	5	15.63	1	4.76
Participant recommends that more information on holistic options is available	10	10.00	1	5.26	3	6.82	6	16.22	0	0.00	4	14.81	4	12.50	2	9.52
Participant recommends that more information about other patients' experiences is available	9	9.00	2	10.53	4	9.09	3	8.11	4	20.00	2	7.41	0	0.00	3	14.29
Participant recommends that there is more information about specific symptoms/side effects available	9	9.00	0	0.00	3	6.82	6	16.22	0	0.00	2	7.41	4	12.50	3	14.29
Participant recommends that more information about new treatments/clinical trials is available	8	8.00	0	0.00	6	13.64	2	5.41	0	0.00	5	18.52	2	6.25	1	4.76

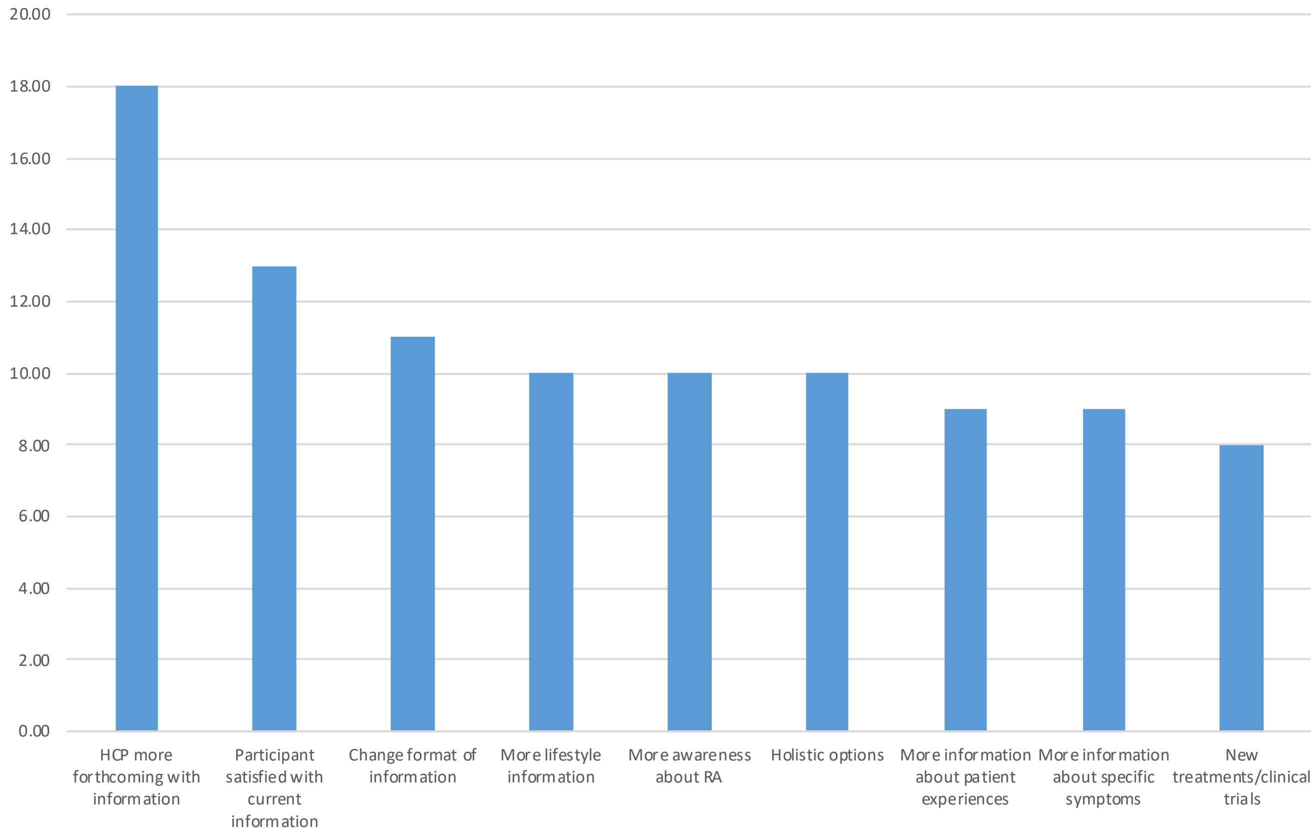
Expectations of future information	All participants		*Affect: never to almost never*		*Affect: sometimes*		*Affect: very often to always*		*Social: all to most days*		*Social: some days*		*Social: no to few days*	
	n=100	%	n=33	%	n=36	%	n=31	%	n=20	%	n=36	%	n=44	%
Participant recommends that healthcare professionals are more forthcoming with information	18	18.00	3	9.09	7	19.44	8	25.81	1	5.00	7	19.44	10	22.73
Participant describes being satisfied with current information and not having any recommendations	13	13.00	3	9.09	7	19.44	3	9.68	2	10.00	5	13.89	6	13.64
Participant recommends changing the format of information	11	11.00	6	18.18	3	8.33	2	6.45	2	10.00	4	11.11	5	11.36
Participant recommends that more lifestyle information is available	10	10.00	5	15.15	1	2.78	4	12.90	3	15.00	4	11.11	3	6.82
Participant recommends that there is more awareness about Rheumatoid arthritis amongst the general population	10	10.00	1	3.03	5	13.89	4	12.90	2	10.00	5	13.89	3	6.82
Participant recommends that more information on holistic options is available	10	10.00	4	12.12	3	8.33	3	9.68	4	20.00	4	11.11	2	4.55
Participant recommends that more information about other patients' experiences is available	9	9.00	4	12.12	2	5.56	3	9.68	0	0.00	5	13.89	4	9.09
Participant recommends that there is more information about specific symptoms/side effects available	9	9.00	1	3.03	3	8.33	5	16.13	2	10.00	4	11.11	3	6.82
Participant recommends that more information about new treatments/clinical trials is available	8	8.00	4	12.12	1	2.78	3	9.68	2	10.00	2	5.56	4	9.09

Table 9.2: Expectations of future information (Cont.)

Expectations of future information	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends that healthcare professionals are more forthcoming with information	18	18.00	8	14.29	10	22.73	7	22.58	7	13.73	4	22.22
Participant describes being satisfied with current information and not having any recommendations	13	13.00	5	8.93	8	18.18	5	16.13	6	11.76	2	11.11
Participant recommends changing the format of information	11	11.00	9	16.07	2	4.55	3	9.68	8	15.69	0	0.00
Participant recommends that more lifestyle information is available	10	10.00	5	8.93	5	11.36	2	6.45	7	13.73	1	5.56
Participant recommends that there is more awareness about Rheumatoid arthritis amongst the general population	10	10.00	5	8.93	5	11.36	4	12.90	5	9.80	1	5.56
Participant recommends that more information on holistic options is available	10	10.00	3	5.36	7	15.91	3	9.68	6	11.76	1	5.56
Participant recommends that more information about other patients' experiences is available	9	9.00	6	10.71	3	6.82	2	6.45	5	9.80	2	11.11
Participant recommends that there is more information about specific symptoms/side effects available	9	9.00	4	7.14	5	11.36	3	9.68	3	5.88	3	16.67
Participant recommends that more information about new treatments/clinical trials is available	8	8.00	6	10.71	2	4.55	3	9.68	3	5.88	2	11.11

Expectations of future information	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends that healthcare professionals are more forthcoming with information	18	18.00	11	19.64	7	15.91	6	18.18	12	17.91	9	18.00	9	18.00
Participant describes being satisfied with current information and not having any recommendations	13	13.00	6	10.71	7	15.91	4	12.12	9	13.43	3	6.00	10	20.00
Participant recommends changing the format of information	11	11.00	5	8.93	6	13.64	5	15.15	6	8.96	6	12.00	5	10.00
Participant recommends that more lifestyle information is available	10	10.00	8	14.29	2	4.55	1	3.03	9	13.43	7	14.00	3	6.00
Participant recommends that there is more awareness about Rheumatoid arthritis amongst the general population	10	10.00	5	8.93	5	11.36	2	6.06	8	11.94	5	10.00	5	10.00
Participant recommends that more information on holistic options is available	10	10.00	6	10.71	4	9.09	2	6.06	8	11.94	7	14.00	3	6.00
Participant recommends that more information about other patients' experiences is available	9	9.00	7	12.50	2	4.55	5	15.15	4	5.97	4	8.00	5	10.00
Participant recommends that there is more information about specific symptoms/side effects available	9	9.00	6	10.71	3	6.82	3	9.09	6	8.96	7	14.00	2	4.00
Participant recommends that more information about new treatments/clinical trials is available	8	8.00	4	7.14	4	9.09	5	15.15	3	4.48	4	8.00	4	8.00

Figure 9.2: Expectations of future information



Expectations of future healthcare professional communication

In the structured interview, participants were asked what they wanted from healthcare professional communication in the future. The most common themes were that participants wanted health professionals to communicate with more compassion/empathy and establish a connection with patients (n=25, 25.00%). Other themes included having experienced good communication and not having any recommendations (n=22, 22.00%), wanting to have more time to communicate with health professionals (n=21, 21.00%), that health professionals communicate more holistically; that is, talk more holistically about treatment options or participants' experiences (n=18, 18.00%), and that clinicians explain diagnosis/test results/prognosis/treatment more clearly (n=9, 9.00%).

In relation to sub-group variations, participants in the sub-groups *Symptoms: no to few days* (15.00%), and *Social: no to few days* (13.64%) wanted more compassion/empathy less frequently than the general population (25.00%), while participants in the sub-groups *Physical limitations: no days* (36.84%), *Symptoms: some days* (37.04%), and *Social: all to most days* (45.00%) wanted this more frequently.

Participants in the sub- *Social: some days* (33.33%), and *Aged 55 or older* (35.48%) had no recommendations more frequently than the general population (22.00%).

Participants in the sub-group *Symptoms: no to few days* (10.00%) wanted more time less frequently than the general population (21.00%), while participants in the sub-group *Symptoms: all days* (33.33%) wanted this more frequently.

No participants in the sub-group *Physical limitations: no days* reported wanting health professionals to communicate more holistically compared with 18.00% of the general population. Participants in the sub-group *Affect: very often to always* (29.03%) reported wanting health professionals to communicate more holistically more frequently than the general population.

No participants in the sub-groups *Physical limitations: no days, Symptoms: no to few days, Affect: never to almost never,* and *Aged 18 – 34* reported wanting clear explanations compared with 9.00% of the general population. Participants in the sub-group *Symptoms: all days* (19.05%) reported wanting clearer explanations more frequently than the general population.

Participant describes wanting clinicians to display more compassion/empathy or establish a connection with patients

I've always felt like I've been spoken to and not with. I would like a dialogue where I feel that I'm actually heard. Participant 24

Another area is where I've had the experience with doctors accusing me of doctor shopping and drug seeking and stuff. Um, so I think having more compassion for patients and for what they're going through, it's like they only think about the pain symptoms, the joint symptoms, they don't think about all of the other symptoms that go along with it Participant 37

I had a rheumatologist as well when I wanted to have children who was very, very unsupportive and said to me, yeah, you can come off your medication and try, but I don't think you're going to be successful. And I think that as soon as you get pregnant and that's even if you do get pregnant, you're just going to keep flaring up and having miscarriages. And that's what he told me as a 27-year-old woman who was desperate to have children. There was just no like care, it was just so cold. Participant 64

You need to remember that it's not just a patient sitting in front of you as a person, first and foremost the person, um, and the ones who are good up there, but I find a better at their job, surgeons or otherwise are the ones who talk to you as a human being. Participant 92

Participant describes experiencing good communication from health professional/no recommendations

To be honest, I don't really have too many complaints about what's going on with me and my treatment. As I said, I've been quite lucky because I proactively self-manage as well. I'm trying to think that the doctors know my rheumatologist- no he always gives me a full report of everything. No, I think I've been quite lucky in my treating physicians and stuff like that. Participant 29

Um, my, my GP and specialist, absolutely fantastic. So, it's been really open, and the lines of communication have really been brilliant. Participant 43

Well, I think I've been quite lucky because my health professionals have been very clear in what they've talked about and what they've talked about and how they've explained it all to me. Um, so I think, yeah, but I can't think of anything else, but it is just that clarity of explanation. Participant 53

I'm really quite fortunate at the children's hospital they were quite clear and even though I was young I was still present for those conversations and um, yeah, still felt very much included. It wasn't just a conversation with my parents that I wasn't a part of. Participant 78

Participant describes wanting health professionals to have more time to communicate/be easier to access

Um, I think it's just the appointments are always rushed, you know, I know they're specialists and that's how things roll that um, you know, so something that's really complex, um, it would have been nice to not have to rely on my own ability to find information. Participant 19

GPs seem to always be running late. They are always looking to catch up with their next appointment and every time I rock up, I feel like they aren't being as thorough as they could or they're not asking the right question. Um, and it's frustrating having to be the person to prompt tests or prompt some sort of examination or prompt a referral. Participant 41

You know, you sit there for half an hour waiting and then you go in and it's 10 minutes and they're out again. And it's very clinical. Not very informative. Participant 57

It'll be 12 months since like a literal 15-minute visit and that I'm supposed to tell him how I've been for a year. Participant 69

Participant describes wanting communication about themselves/their illness to be more holistic

I just think it would be helpful if they opened their mind and at least said, "Well, look, there's no evidence that- it's not going to hurt you, so go for it." Instead of just shutting you down and saying, "That's just quack medicine". Participant 20

I don't think it's a holistic approach at all. Um, I don't think in general, I just don't think, um, GPs and particularly specialists are looking at things holistically. Participant 25

I want to say inform people about what's available, out there. Support as well. I think sometimes GPs just look at treatment, but they don't always look around support over and above what they're able to offer, so what options are out there for- alternate, complementary. It's just looking at it holistically. Participant 60

Just because you're a doctor doesn't mean you can't discuss non-medical things. Participant 44

Participant describes wanting clinician to explain their diagnosis/prognosis/test results/treatment more clearly

They need to give you more everyday information, not just agree on what these drugs are and how they work. Part of it if you know what I mean. If they have to give you by law, that's about it. That's really what I would say. Participant 46

Even if they can't, in that 15-minute appointment, tell you about everything that they could possibly tell you, that might help you, at least give you some information or direction as to where to look afterwards. Participant 68

They explained it all to him, and he had a bit of an idea, but it was all big words in there. He points at me and he goes, "Tell me in words I'll understand." I looked at him and went, "You're fucked". And he goes to the doctor, "that's what I understand." Participant 96

Table 9.3: Expectations of future health professional communication

Expectations of future health professional communication	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant recommends that health professionals communicate with more compassion and empathy or establish a connection with patients	25	25.00	7	36.84	9	20.45	9	24.32	3	15.00	10	37.04	6	18.75	6	28.57
Participant describes not having any recommendations about health professional communication	22	22.00	3	15.79	9	20.45	10	27.03	4	20.00	6	22.22	8	25.00	4	19.05
Participant recommends that health professionals have more time to communicate with patients	21	21.00	4	21.05	9	20.45	8	21.62	2	10.00	4	14.81	8	25.00	7	33.33
Participant recommends that communication about themselves/their illness is more holistic	18	18.00	0	0.00	9	20.45	9	24.32	2	10.00	7	25.93	5	15.63	4	19.05
Participant recommends that health professionals explain diagnosis/prognosis/test results/treatment options more clearly	9	9.00	0	0.00	4	9.09	5	13.51	0	0.00	1	3.70	4	12.50	4	19.05

Expectations of future health professional communication	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant recommends that health professionals communicate with more compassion and empathy or establish a connection with patients	25	25.00	7	21.21	10	27.78	8	25.81	9	45.00	10	27.78	6	13.64
Participant describes not having any recommendations about health professional communication	22	22.00	10	30.30	8	22.22	4	12.90	4	20.00	12	33.33	6	13.64
Participant recommends that health professionals have more time to communicate with patients	21	21.00	8	24.24	6	16.67	7	22.58	4	20.00	6	16.67	11	25.00
Participant recommends that communication about themselves/their illness is more holistic	18	18.00	5	15.15	4	11.11	9	29.03	2	10.00	6	16.67	10	22.73
Participant recommends that health professionals explain diagnosis/prognosis/test results/treatment options more clearly	9	9.00	0	0.00	6	16.67	3	9.68	3	15.00	2	5.56	4	9.09

Expectations of future health professional communication	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends that health professionals communicate with more compassion and empathy or establish a connection with patients	25	25.00	12	21.43	13	29.55	8	25.81	11	21.57	6	33.33
Participant describes not having any recommendations about health professional communication	22	22.00	11	19.64	11	25.00	11	35.48	7	13.73	4	22.22
Participant recommends that health professionals have more time to communicate with patients	21	21.00	12	21.43	9	20.45	8	25.81	11	21.57	2	11.11
Participant recommends that communication about themselves/their illness is more holistic	18	18.00	10	17.86	8	18.18	3	9.68	12	23.53	3	16.67
Participant recommends that health professionals explain diagnosis/prognosis/test results/treatment options more clearly	9	9.00	3	5.36	6	13.64	5	16.13	4	7.84	0	0.00

Expectations of future health professional communication	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends that health professionals communicate with more compassion and empathy or establish a connection with patients	25	25.00	15	26.79	10	22.73	9	27.27	16	23.88	14	28.00	11	22.00
Participant describes not having any recommendations about health professional communication	22	22.00	12	21.43	10	22.73	5	15.15	17	25.37	12	24.00	10	20.00
Participant recommends that health professionals have more time to communicate with patients	21	21.00	9	16.07	12	27.27	8	24.24	13	19.40	11	22.00	10	20.00
Participant recommends that communication about themselves/their illness is more holistic	18	18.00	13	23.21	5	11.36	7	21.21	11	16.42	9	18.00	9	18.00
Participant recommends that health professionals explain diagnosis/prognosis/test results/treatment options more clearly	9	9.00	1	1.79	8	18.18	3	9.09	6	8.96	2	4.00	7	14.00

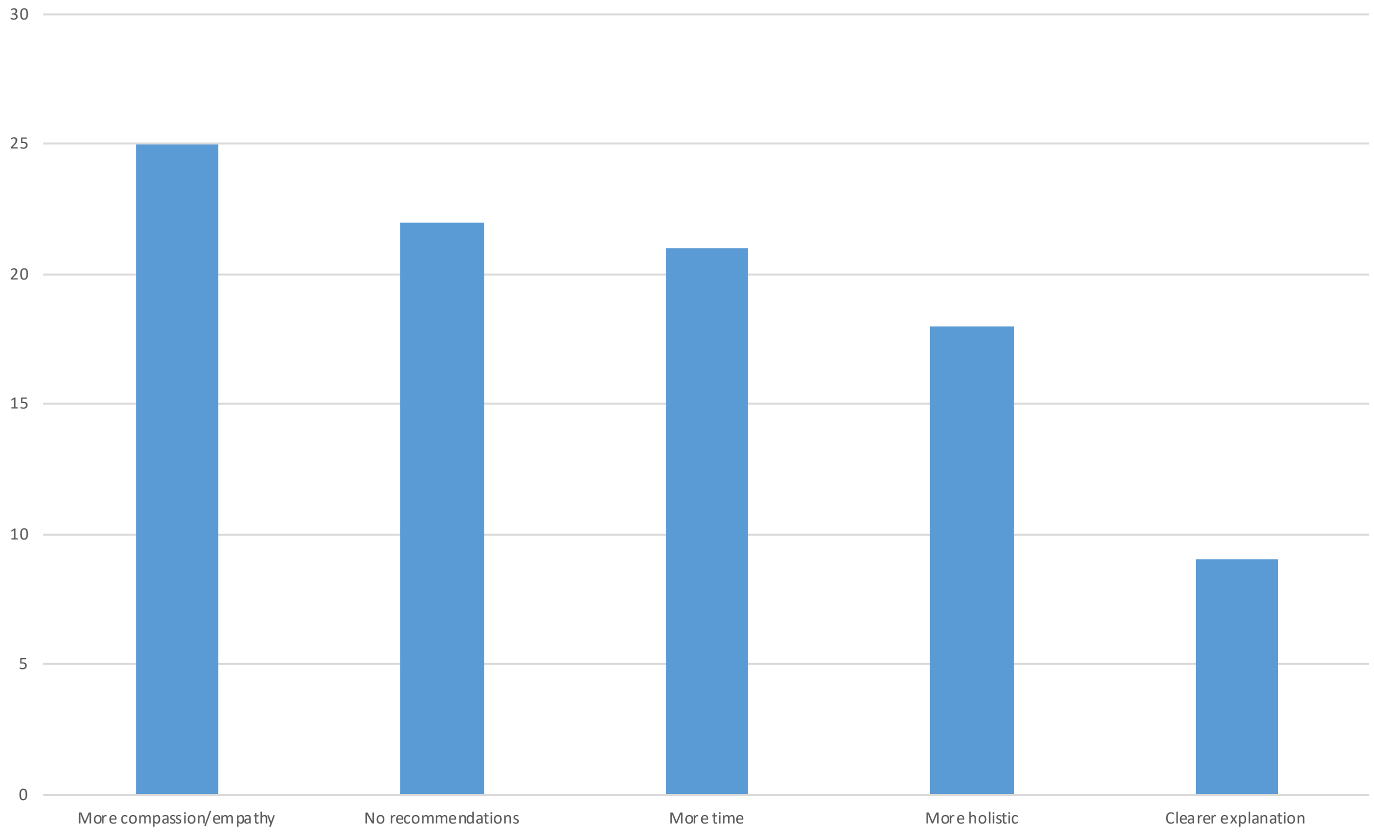


Figure 9.3: Expectations of future health professional communication

Expectations of future care and support

In the structured interview, participants were asked what they expected of care and support in the future. The most common reported expectation of future care and support was that there was an increased understanding of rheumatoid arthritis within care and support systems, as well as within the general population (n=22, 22.00%). Other reported themes included a desire for more affordable complementary therapies (n=17, 17.00%), increased access to or improvement of support groups/charity support (n=16, 16.00%), more access to domestic support (n=15, 15.00%) and psychological support (n=15, 15.00%), more opportunity to connect with other patients (n=14, 14.00%), more transport support (n=10, 10.00%), increased funding into RA research and support services, and easier access to services (n=8, 8.00%) for those that either live regionally or work full-time. Twelve participants (12.00%) reported that they had no recommendations for improvement.

In relation to sub-group variations, participants in the sub-group *Symptoms: all days* (9.52%) reported an expectation of increased understanding of RA less frequently than the general population (22.00%), while participants in the sub-group *Affect: very often to always* (35.48%) reported this more frequently.

Participants in the sub-groups *Affect: very often to always* (3.23%), and *Trade or high school* (6.06%) reported wanting affordable complementary therapies less frequently than the general population (17.00%), while participants in the sub-groups *Symptoms: no to few days* (30.00%), *Affect: never to almost never* (27.27%), and *Social: all to most days* (30.00%) reported this more frequently.

No participants *Aged 55 or older* reported wanting increased access or improvement of support groups/charity groups. Participants *Aged 18 – 34* (27.78%) reported wanting this more than the general population (16.00%).

Participants in the sub-group *Affect: never to almost never* (3.03%) reported wanting more access to domestic support less frequently compared to the general population (15.00%).

Participants in the sub-group *Affect: sometimes* (25.00%) reported wanting more psychological support more frequently compared to the general population (15.00%).

No participants *in the sub-groups Physical limitations: no days, Symptoms: no to few days, Affect: sometimes* reported wanting transport support. Participants in the sub-groups *Symptoms: all days* (23.81%) reported wanting this more than the general population (10.00%).

No participants in the sub-groups *Physical limitations: no days*, and *Trade or high school* reported wanting more funding in to RA research compared to 8.00% of the general population.

Aged 55 or older reported wanting increased access or improvement of support groups/charity groups. Participants *Aged 18 – 34* (27.78%) reported wanting this more than the general population (8.00%).

Participants in the sub-group *Social: all to most days* (20.00%) reported wanting easier access to services more frequently compared to the general population (8.00%).

Participant's recommendation is for increased understanding of and information about RA in general

Just things like, I'm not sure where coming to see a chiropractor or physio, or both yeah. A resource that might explain what we can do, what or which symptoms, et cetera. Um, just to make that a little less confusing. Participant 5

Yeah. Like maybe if there was, or even if there was a website you go to, if you were say you're looking for a rheumatologist and yes. And then you could bring up a list that had information about different ones and where they are and what they specialize. Participant 7

Um, I guess the biggest, biggest difficulties I had was understanding, understanding what the trajectory would be like nowadays with the medications we have now. When I was first diagnosed, um, I, when I looked up rheumatoid arthritis, it talked about people being in a wheelchair within 10 years and people being crippled and having to have joint replacements and all of this sort of stuff. And so, I was absolutely terrified. Participant 37

Participant's recommendation is for easier access to complementary therapies

Maybe even assistance for people to access things like hydrotherapy, etc. So very well for the doctor to say, oh no, you'd benefit from exercise. However, because of your joints you shouldn't walk up and down hills and yet I live on a hill, you know. Go running, um, that you'd benefit from hydrotherapy. Participant 10

I do know that there's special exercise programs around that deal with people with rheumatoid that can do gentle exercises and things like that. I think on the whole there is that out there it's just accessing them. Maybe more places could become available so it was easier for people to access it so they didn't have to travel great distances. Participant 16

Apart from the stuff I was saying originally about, access to complimentary therapies for people because it is expensive and they're not necessarily covered well by Medicare or by private health insurance and I think that there's a lot of benefits to a lot of people to even see an occupational therapist or an exercise physiologist or have access to hydrotherapy and a lot of people don't. Participant 29

Participant's recommendation is for more support groups/charity support

Help people with RA. Um, yeah. Yes. Charities are not that good because a lot of people who are on pensions, below the poverty line, who have chronic illnesses like RA can't get into these places to say I need help with food voucher this week or I need help with my hydro this week. I mean, I've had extraordinarily high hydro power bills because I can't take the cold. Uh, I, if I have to have my house heated, and we can afford to get what's needed to have your house fixed up to cope with the cold. Participant 98

I think along the way I would've liked some support, but I couldn't really find anything. I think that's why I looked at online forums and support groups. I was really excited when I went to the Arthritis Australia seminar because I thought they would have really good information and support and perhaps other alternatives that I didn't know about, but they didn't really. I was probably a bit disappointed with that I didn't come away if not a great deal from that. There's probably not a very specific support option out there or information for rheumatoid arthritis. Participant 60

Maybe if an organization like that could, could, you know, have more information sessions or seminars or workshops or whatever you know about things like diet and exercise that, that would be good because they already have like workshops about pain management and things like that. So obviously they take care of the, the medical side really well. But, um, yeah, I just wonder about, um, support in terms of what you can do physically. Participant 89

Participant's recommendation is for more domestic support

But um services, you know, people need help maybe and or services just for home help or I suppose, mind you I'm a carer myself, do you want me to care of myself? So, you know, it should be classed as a disability when the time comes and um, you know, so people can get home help and stuff. Participant 8

Is there somewhere I can get help to do housework or is there somewhere I can get help to do like school runs or something with the kids? Just the day to day tasks. Participant 38

Can you imagine? In the UK they do it with new mums. The service, the nurses would come to your home with the newborn and make sure that everything was going well. You could access a breastfeeding expert or a mental health expert or they could even get a cleaning service and they organize that for you. Participant 48

Participant's recommendation is for more psychological support, especially telephone-based

It would be great to have access to telephone counselling from people that understand the disease, or I mean my preference would be to have access to a clinical psychologist on your phone because I already have a mental health issue. Participant 4

Well, throughout my wonderful little journey not once, did anybody go, hey, you alright? Do you want some counselling for a bit? Okay. I think that that would have been probably thing to have pursued. Participant 71

Yeah. I, I don't know, maybe even. Okay. I think a phone thing would be good if someone, whether or not it was like RA patients that are willing to donate like two hours of their week or something and you know, people can have a talk that like people who are positive and, and doing well, you know, who can encourage. I've, I found my own friends who have Ra and we've become friends. We do reach out to each other and stuff like that. I think that happens organically. Participant 95

Participant's recommendation is for more opportunities to connect with other patients

So things like that would have been helpful, to talk to more people with arthritis. More groups that are... Because online is good, but you're just talking words. You're not meeting people. Participant 13

They could then provide a forum for people with life conditions to discuss with maybe some sort of, um, I guess um, mentor or convenor so that, as I mentioned with the Facebook groups like they just a bit of a site for anyone who's got that condition to have that kind of forum where people can talk and compare that with someone that actually has medical knowledge or can chime in and say, well, actually that's not right. If you're experiencing that, you should be seeing your doctor because that's not what you should see. Participant 18

Some actual place where you can come and people speak to you and you can talk to people and they're updating you on the latest of what's happening and just more of this dialogue that doesn't necessarily have to happen in a doctor's office that can happen somewhere with medical students or they can happen somewhere where you feel maybe more happier and it's an innovative space as opposed to just a desperate space that you could actually innovate and discuss ideas with people and come together and like of the industry of the entrepreneur and the start-up. Participant 24

Where are the conferences in the meetings for people who are suffering or have a family member. Like, you know, to go and hear what's happening and hear stories and develop something or you know, with a little bit more of a positive focus. Participant 24

Participant does not have any recommendations

Um, I don't think so, but again, just because I haven't been that severely impacted by it, I haven't really made it anything. Participant 19

No, I was quite satisfied. I knew places where I could go to get some services if I needed them. Access equipment if I needed that, all those sorts of things. Participant 22

I haven't, I haven't needed assistance with anything as yet, so I'm probably not really in a position to comment if, if, hopefully I won't. If I become more dependent, you know, I'd probably be more in a position to answer that. Participant 42

I know that you can go and you could get all these things, but I guess I've resisted even going there. I suppose if things got worse, I was reliant on um, you know, walking sticks and things like that, then yeah, I would be looking at different services, but at the moment I'm probably being. I'm determined that I'm going to get through this. Participant 94

Participant's recommendation is for more transport help

I don't know whether it is also then you know like similar with the ORGANIZATION where if you're in a car accident and you can't or if traffic accident you can't drive after the accident they, subsidize or pay for transport so people we've got more advanced symptoms than I do. They can't sometimes get to appointments or get to opportunities as well. So whether that's the ability to, to have subsidized access to some of that as well because then that's another cost prohibitive barrier. Participant 29

Then you start talking about transport. At the moment I don't qualify. I'm having to turn down medical appointments because I can't get there. What do I do? Risk driving and my feet and my hand cramping up and end up in a crash or do I catch public transport and ended up so crippled that I can't stand it? Participant 85

I mean I drive so I know people, couple of other people that don't, and they have trouble. I think half price taxis. Yeah. I don't know. Maybe more of a group thing where people get together. I think there's, yeah, I looked up groups and there's one or two around, but there's not a lot, but there's a lot of people with rheumatoid. Participant 99

Participant's recommendation is for more funding for RA

I just think that if you've got people with chronic disease, it eats so much of our financial resources, you know, people want to work, we should be trying to support them to do that. Participant 61

I've reduced my hours, my wage, if I was able to access some funding that might help and support me by doing some of the education or getting somebody to help with the kids [laughs] or whatever so I can go to medical appointments, that would be fantastic but that's a fairly big ask. Participant 90

Some sort of funding or relief for just general duties would be really helpful. Participant 72

Participant's recommendation is for easier access to services/support groups

Like you've got all day every day to be, oh, just go off and do pilates in pool in the middle of the day and then tomorrow I'll go off to my counselling group and I don't have to work to pay for all this shit that will all go to and then I'll sit my numerous appointments in, in the middle of the day or, or you know, like it's, it's, it's like you're not. Yeah. You're not part of a normal human race or a working person with a career and yeah, you can't be seen to be taking too much time off work these days. Know it feels a bit like they're all in La-la land to tell you the truth. Participant 23

Um, the reality is a lot of it's not available in country areas, so I think greater equity for rural and remote communities and mode, it's difficult because there's not the populations and all of those things. Yeah. But these things that are proven to help would be helpful to actually have the more widely available. Participant 45

I don't think so. I can't think of anything apart from the fact that because of the amount of isolation in, in rural areas, but that's not going to change. Participant 81

Table 9.4: Expectations of future care and support

Expectations of future care and support	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant recommends increased understanding of and information about rheumatoid arthritis in general to improve care and support	22	22.00	3	15.79	10	22.73	9	24.32	6	30.00	6	22.22	8	25.00	2	9.52
Participant recommends easier access to complementary therapies	17	17.00	5	26.32	8	18.18	4	10.81	6	30.00	6	22.22	3	9.38	2	9.52
Participant recommends that more support groups/charity support is available	16	16.00	2	10.53	8	18.18	6	16.22	2	10.00	3	11.11	7	21.88	4	19.05
Participant recommends that more domestic support is available	15	15.00	3	15.79	4	9.09	8	21.62	3	15.00	3	11.11	4	12.50	5	23.81
Participant recommends that more psychological support is available	15	15.00	3	15.79	3	6.82	9	24.32	4	20.00	3	11.11	6	18.75	2	9.52
Participant recommends that there are more opportunities to connect with other patients	14	14.00	2	10.53	8	18.18	4	10.81	3	15.00	4	14.81	5	15.63	2	9.52
Participant describes not having any recommendations	12	12.00	4	21.05	6	13.64	2	5.41	1	5.00	5	18.52	2	6.25	4	19.05
Participant recommends that more transport support is available	10	10.00	0	0.00	4	9.09	6	16.22	0	0.00	2	7.41	3	9.38	5	23.81
Participant recommends that there is more funding for rheumatoid arthritis	8	8.00	0	0.00	5	11.36	3	8.11	2	10.00	1	3.70	3	9.38	2	9.52
Participant recommends that there is easier access to services/support groups	8	8.00	1	5.26	3	6.82	4	10.81	1	5.00	2	7.41	3	9.38	2	9.52

Expectations of future care and support	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant recommends increased understanding of and information about rheumatoid arthritis in general to improve care and support	22	22.00	6	18.18	5	13.89	11	35.48	6	30.00	6	16.67	10	22.73
Participant recommends easier access to complementary therapies	17	17.00	9	27.27	7	19.44	1	3.23	6	30.00	5	13.89	6	13.64
Participant recommends that more support groups/charity support is available	16	16.00	3	9.09	5	13.89	8	25.81	3	15.00	5	13.89	8	18.18
Participant recommends that more domestic support is available	15	15.00	1	3.03	8	22.22	6	19.35	2	10.00	6	16.67	7	15.91
Participant recommends that more psychological support is available	15	15.00	4	12.12	9	25.00	2	6.45	4	20.00	6	16.67	5	11.36
Participant recommends that there are more opportunities to connect with other patients	14	14.00	6	18.18	5	13.89	3	9.68	3	15.00	7	19.44	4	9.09
Participant describes not having any recommendations	12	12.00	5	15.15	3	8.33	4	12.90	2	10.00	3	8.33	7	15.91
Participant recommends that more transport support is available	10	10.00	4	12.12	0	0.00	6	19.35	1	5.00	4	11.11	5	11.36
Participant recommends that there is more funding for rheumatoid arthritis	8	8.00	1	3.03	4	11.11	3	9.68	1	5.00	5	13.89	2	4.55
Participant recommends that there is easier access to services/support groups	8	8.00	4	12.12	1	2.78	3	9.68	4	20.00	1	2.78	3	6.82

Expectations of future care and support	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 34 - 45***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends increased understanding of and information about rheumatoid arthritis in general to improve care and support	22	22.00	15	26.79	7	15.91	4	12.90	15	29.41	3	16.67
Participant recommends easier access to complementary therapies	17	17.00	12	21.43	5	11.36	4	12.90	11	21.57	2	11.11
Participant recommends that more support groups/charity support is available	16	16.00	8	14.29	8	18.18	0	0.00	11	21.57	5	27.78
Participant recommends that more domestic support is available	15	15.00	6	10.71	9	20.45	5	16.13	7	13.73	3	16.67
Participant recommends that more psychological support is available	15	15.00	8	14.29	7	15.91	6	19.35	7	13.73	2	11.11
Participant recommends that there are more opportunities to connect with other patients	14	14.00	7	12.50	7	15.91	3	9.68	7	13.73	4	22.22
Participant describes not having any recommendations	12	12.00	8	14.29	4	9.09	4	12.90	5	9.80	3	16.67
Participant recommends that more transport support is available	10	10.00	4	7.14	6	13.64	3	9.68	6	11.76	1	5.56
Participant recommends that there is more funding for rheumatoid arthritis	8	8.00	2	3.57	6	13.64	1	3.23	6	11.76	1	5.56
Participant recommends that there is easier access to services/support groups	8	8.00	5	8.93	3	6.82	3	9.68	4	7.84	1	5.56

Expectations of future care and support	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends increased understanding of and information about rheumatoid arthritis in general to improve care and support	22	22.00	12	21.43	10	22.73	7	21.21	15	22.39	10	20.00	12	24.00
Participant recommends easier access to complementary therapies	17	17.00	10	17.86	7	15.91	2	6.06	15	22.39	11	22.00	6	12.00
Participant recommends that more support groups/charity support is available	16	16.00	8	14.29	8	18.18	7	21.21	9	13.43	8	16.00	8	16.00
Participant recommends that more domestic support is available	15	15.00	6	10.71	9	20.45	4	12.12	11	16.42	4	8.00	11	22.00
Participant recommends that more psychological support is available	15	15.00	11	19.64	4	9.09	4	12.12	11	16.42	10	20.00	5	10.00
Participant recommends that there are more opportunities to connect with other patients	14	14.00	8	14.29	6	13.64	4	12.12	10	14.93	7	14.00	7	14.00
Participant describes not having any recommendations	12	12.00	8	14.29	4	9.09	5	15.15	7	10.45	8	16.00	4	8.00
Participant recommends that more transport support is available	10	10.00	6	10.71	4	9.09	3	9.09	7	10.45	5	10.00	5	10.00
Participant recommends that there is more funding for rheumatoid arthritis	8	8.00	5	8.93	3	6.82	0	0.00	8	11.94	4	8.00	4	8.00
Participant recommends that there is easier access to services/support groups	8	8.00	4	7.14	4	9.09	4	12.12	4	5.97	4	8.00	4	8.00

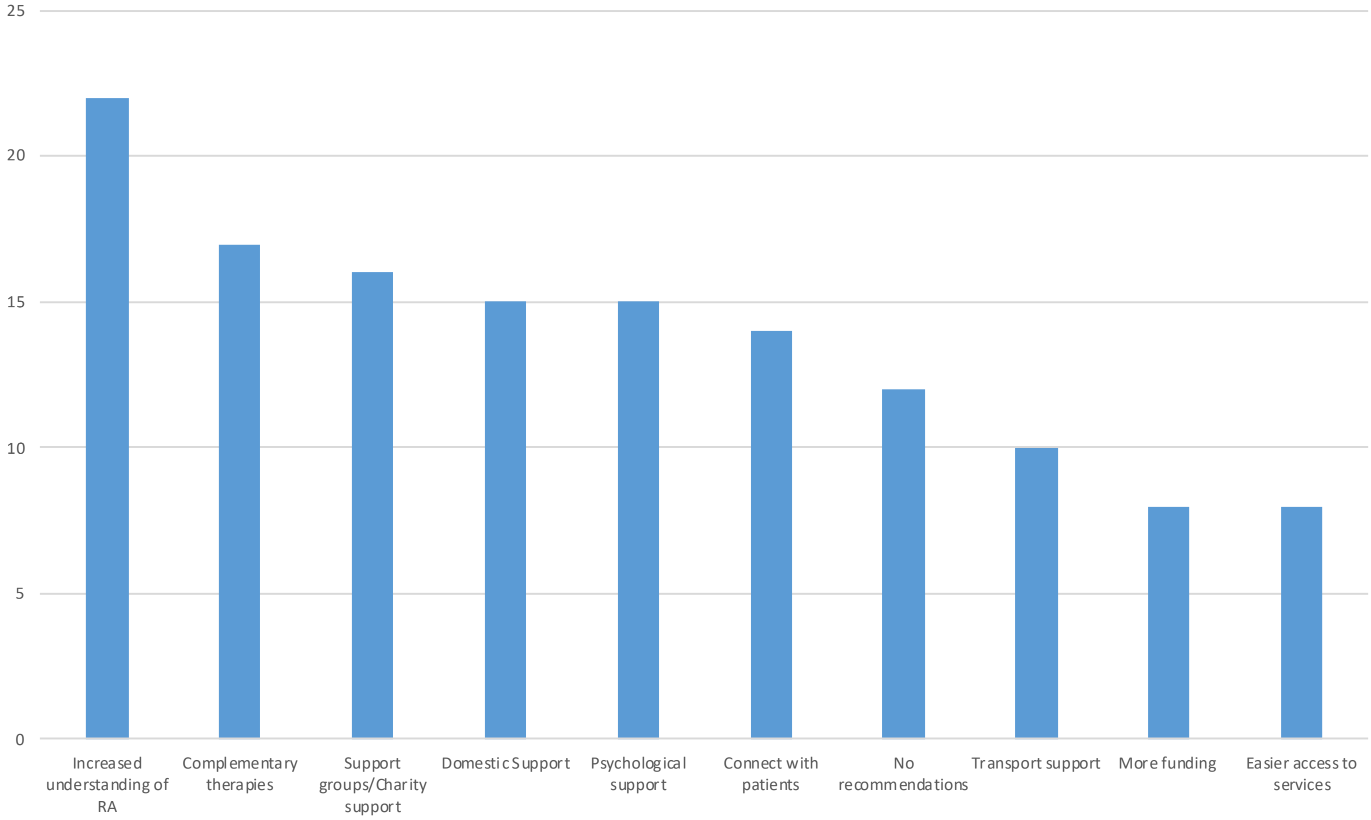


Figure 9.4: Expectations of future care and support

Aspects of the Australian health system that patients are grateful for.

In the structured interview, participants were asked what aspects of the Australian health system they were most grateful for. The most common theme was being grateful for the Australian health system being low cost/free (n=40, 40.00%). Other commonly reported themes included gratitude for being able to access treatment through Medicare (n=39, 39.00%), for healthcare professionals (n=27, 27.00%) access to a rheumatologist (19.00%), access to diagnostic tests (n=13, 13.00%), and for the entire health system (n=11, 11.00%). In addition, 29 participants (29.00%), when asked what aspects of the health system they were grateful, expressed a degree of gratitude but also said that there were significant improvements that needed to be made.

In relation to sub-group variations, participants in the sub-groups *Physical limitations: no days* (26.32%), *Physical limitations: few days* (29.55%), *Symptoms: no to few days* (25.00%), *Symptoms: some days* (18.52%), *Affect: never to almost never* (21.21%), and *Social: all to most days* (25.00%) reported being grateful for is the fact that the Australian health system was low cost/free less frequently compared to the general population (40.00%), while participants in the sub-groups *Physical limitations: some to most days* (59.46%), *Symptoms: most days* (65.63%), *Affect: sometimes* (50.00%), and *Aged 18 – 34* (50.00%) reported being grateful for this more frequently.

Participants in the sub-groups *Social: all to most days* (25.00%), and *Aged 18 – 34* (27.78%) reported being grateful for access to treatment through Medicare less frequently compared to the general population (39.00%), while participants in the sub-groups *Symptoms: some days* (51.85%), *Affect: never to almost never* (51.52%), and *Social: some days* (52.78%) reported being grateful for this more frequently.

Participants in the sub-groups *Physical limitations: no days* (15.79%), *Symptoms: no to few days* (15.00%), and *Aged 18 – 34* (11.11%) expressed a degree of gratitude but also said that there were significant improvements that needed to be made less frequently compared to the general population (29.00%), while participants in the sub-group *Social: all to most days* (40.00%) reported this more frequently than the general population.

Participants *Aged 18 – 34* (16.67%) responded that they were grateful for health professionals less often than the general population (27.00%).

Participants in the sub-group *Symptoms: all days* (4.76%) responded that there were grateful for access to a rheumatologist less frequently than the general population (19.00%), while participants in the subgroups *Physical limitations: no days* (31.58%), and *Symptoms: some days* (29.63%) responded gratitude for access to a rheumatologist more frequently.

No participants in the sub-group *Physical limitations: no days* responded that they were grateful for access to diagnostic tests compared with 13.00% of the general population.

Participants in the sub-group *Physical limitations: no days* (21.05%) responded that they were grateful for the entire health system more frequently than the general population (11.00%).

Participant describes being grateful for health system being low cost/free

The fact that we get everything always basically for free where in other countries it is not free at all and people just have to suffer. Participant 33

Oh, I'm so grateful for our Medicare and PBS and for all of those things that take away some of the burden. Like I said, I was once on a support group where there was a lot of people from America and it was horrifying. Like reading what they were going through. I had to get off it, I couldn't deal with these people I know that have to turn into a vegetable because they can't afford to get help, you know, so yeah. Participant 51

Um, look, I'm grateful every time I'm able to pop down and get an MRI not billed or CT scan not billed or a or a cortisone shot or an ultrasound not billed. I'm extremely grateful for that. I'm extremely grateful that I can pop off and get a, you know, blood test and stuff, not billed. I think we're extraordinarily lucky to be able to have access to all of that. Participant 87

Participant describes being grateful for access to treatment (through Medicare)

Um, they have worked together on the Humira. My rheumatologist says that that will cost Medicare $20,000 a year. So that is a, that's really humbling to me that the government will pay that. The bulk on my behalf like that is amazing. Participant 4

No, definitely no complaints about Medicare from me. I'm, the benefit I've got was with PBS, uh, their support in the xeljanz. So yeah, obviously without PBS approving that I would have been financially stuck if I really wanted to go into that specific medication. So yeah, so my specialist said that if PBS has an approver, you can get it privately, but it's going to cost you like $1,500 or $1,700 a month. Participant 56

I think the only positive thing I have been able to access is the subsidized drugs. Participant 82

Oh God, yes. I'm glad we do have Medicare system because I talked to people from America and if they don't have healthcare, they're screwed. They just live with it. They get no treatment. Yes, we are very lucky that we have the public health system, that we've got Medicare because we have no understanding of what it's like living in a country without it. You can't afford treatment. People who are saying, "No, I haven't got the $15,000 for the next three months to pay for the op, "I'm like, "Oh my God. How do you even do that?". Participant 93

Participant describes being grateful for health system but says that changes are necessary

The department of health, the federal department of health could probably improve a little bit sometimes the prescription that my doctor sends off for me, it, it can take, you know, four or five weeks to arrive. Um, it's always sort of a moment of sheer terror that it's not going to get there in time before my next injections are due. Um, so yeah, uh, I know it's a large and complex system, but I think that that could be improved. Participant 53

So like when I went on cinzia thought they'd sent the stuff through to Medicare and they hadn't. Six weeks later I'm still going. I haven't received anything from Medicare and it's sitting on the receptionist's desk. So just that whole process could be like the 21st century. Surely we don't have to send a hard copy in the mail to Medicare to go through like that process. Participant 65

I still think that there's ways we can improve it. Participant 71

We need more funding for all sorts of therapies and treatments, supplements, specialists. Just give me a blank check and I'll sort it out. Participant 85

Participant describes being grateful for healthcare professionals

The specialist, my GP, she's amazing. My GP and my specialists, everyone involved in my health support team like people who check my skin every year, gynaecologist, rheumatologist, GP, dietitian, my Pilates instructors. Participant 6

I'm fortunate that I have access to qualified people who are interested in my condition. Participant 12

We've got so many quality health care professionals here particularly in the cities, not so much in the regional areas, that it takes me-- I can go and see my rheumatologist who's 25 minutes away from my house. Participant 26

We have really well trained, knowledgeable, um, like the medical profession and the nursing profession that's always striving to improve, always looking. We've got a great research community. Generally, we're always looking to improve things. How can we do things better and more than anyone else. They're aware of, you know, the fiscal limitations I have and try and do more with less and they do a really good job of it. Participant 59

Participant describes being grateful for access to rheumatologist

I think main thing that I can't get over, and I know that I'm quite lucky about this, is that most of the time my rheumatologist has been pretty consistent. Participant 15

What I'm truly grateful for is the fact that rheumatologists will travel to a country town. Participant 32

I'm very grateful that at the moment that I've got a rheumatologist who's still trying, you know, still trying hard to help me and I have a good relationship with him. Participant 87

Participant describes being grateful for access to diagnostic tests

Um, one of the good things was that the MRIs and CTs and stuff that I did get done variously independently through different doctors, that were essentially accessible. Participant 18

I was lying there a couple of months ago having my feet and my wrists MRI and everything and I was looking at the equipment in this place and thinking I am very, very grateful for our healthcare system. Amazing. The sort of the level of testing that I've been through. Participant 77

We are very fortunate to have the diagnostic tools and things that we've got. Um, so I'm very grateful for that. Participant 87

Participant describes being grateful for entire health system

Oh yeah. I could tell you what, I could tell you all sorts of stories that outline why I think we have a fantastic public health system. But look, the, the short version is that I've worked in places that don't. Yeah. I've worked in places where I've seen people turned away in an emergency. Participant 11

Yes, all of it. The fact that we get always everything basically for free where in other countries it is not free at all and people just have to suffer. Participant 33

I'm certainly very thankful for our system of universal healthcare, which is not perfect, but it's far better than our friend across the pacific. Participant 44

Oh, all of it. I mean, I, we have, we're in the top four on the world. People don't realize it. It gets a lot of negative press. Participant 59

I'm just trying to think. Well, just everything really to be honest. Participant 89

Table 9.5: Aspects of the Australian health system patients are grateful for

Aspects of the Australian health system that patients are grateful for	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant describes being grateful that the Australian health system is low cost/free	40	40.00	5	26.32	13	29.55	22	59.46	5	25.00	5	18.52	21	65.63	9	42.86
Participant describes being grateful for being able to access treatment (through Medicare)	39	39.00	8	42.11	20	45.45	11	29.73	6	30.00	14	51.85	12	37.50	7	33.33
Participant describes being grateful for the Australian health system but says that changes are necessary	29	29.00	3	15.79	13	29.55	13	35.14	3	15.00	7	25.93	12	37.50	7	33.33
Participant describes being grateful for healthcare professionals	27	27.00	7	36.84	9	20.45	11	29.73	6	30.00	9	33.33	6	18.75	6	28.57
Participant describes being grateful for being able to access a rheumatologist	19	19.00	6	31.58	8	18.18	5	13.51	3	15.00	8	29.63	7	21.88	1	4.76
Participant describes being grateful for access to diagnostic tests	13	13.00	0	0.00	9	20.45	4	10.81	3	15.00	4	14.81	4	12.50	2	9.52
Participant describes being grateful for the entire health system	11	11.00	4	21.05	4	9.09	3	8.11	4	20.00	3	11.11	1	3.13	3	14.29

Aspects of the Australian health system that patients are grateful for	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant describes being grateful that the Australian health system is low cost/free	40	40.00	7	21.21	18	50.00	15	48.39	5	25.00	17	47.22	18	40.91
Participant describes being grateful for being able to access treatment (through Medicare)	39	39.00	17	51.52	13	36.11	9	29.03	5	25.00	19	52.78	15	34.09
Participant describes being grateful for the Australian health system but says that changes are necessary	29	29.00	7	21.21	12	33.33	10	32.26	8	40.00	8	22.22	13	29.55
Participant describes being grateful for healthcare professionals	27	27.00	8	24.24	12	33.33	7	22.58	6	30.00	8	22.22	13	29.55
Participant describes being grateful for being able to access a rheumatologist	19	19.00	4	12.12	8	22.22	7	22.58	3	15.00	6	16.67	10	22.73
Participant describes being grateful for access to diagnostic tests	13	13.00	7	21.21	3	8.33	3	9.68	2	10.00	4	11.11	7	15.91
Participant describes being grateful for the entire health system	11	11.00	5	15.15	5	13.89	1	3.23	2	10.00	3	8.33	6	13.64

Table 9.5: Aspects of the Australian health system patients are grateful for (Cont.)

Aspects of the Australian health system that patients are grateful for	All participants		*Occasional flare ups*		*Frequent flare ups*		*Aged 55 or older*		*Aged 35- 54*		*Aged 18 – 34*	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant describes being grateful that the Australian health system is low cost/free	40	40.00	19	33.93	21	47.73	13	41.94	18	35.29	9	50.00
Participant describes being grateful for being able to access treatment (through Medicare)	39	39.00	23	41.07	16	36.36	12	38.71	22	43.14	5	27.78
Participant describes being grateful for the Australian health system but says that changes are necessary	29	29.00	17	30.36	12	27.27	11	35.48	16	31.37	2	11.11
Participant describes being grateful for healthcare professionals	27	27.00	11	19.64	16	36.36	9	29.03	15	29.41	3	16.67
Participant describes being grateful for being able to access a rheumatologist	19	19.00	11	19.64	8	18.18	5	16.13	10	19.61	4	22.22
Participant describes being grateful for access to diagnostic tests	13	13.00	7	12.50	6	13.64	2	6.45	10	19.61	1	5.56
Participant describes being grateful for the entire health system	11	11.00	8	14.29	3	6.82	2	6.45	8	15.69	1	5.56

Aspects of the Australian health system that patients are grateful for	All participants		*Metropolitan*		*Regional or remote*		*Trade or high school*		*University*		*High SEIFA*		*Mid to low SEIFA*	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant describes being grateful that the Australian health system is low cost/free	40	40.00	23	41.07	17	38.64	13	39.39	27	40.30	23	46.00	17	34.00
Participant describes being grateful for being able to access treatment (through Medicare)	39	39.00	23	41.07	16	36.36	13	39.39	26	38.81	20	40.00	19	38.00
Participant describes being grateful for the Australian health system but says that changes are necessary	29	29.00	16	28.57	13	29.55	10	30.30	19	28.36	15	30.00	14	28.00
Participant describes being grateful for healthcare professionals	27	27.00	14	25.00	13	29.55	11	33.33	16	23.88	12	24.00	15	30.00
Participant describes being grateful for being able to access a rheumatologist	19	19.00	11	19.64	8	18.18	6	18.18	13	19.40	11	22.00	8	16.00
Participant describes being grateful for access to diagnostic tests	13	13.00	7	12.50	6	13.64	2	6.06	11	16.42	7	14.00	6	12.00
Participant describes being grateful for the entire health system	11	11.00	9	16.07	2	4.55	4	12.12	7	10.45	9	18.00	2	4.00

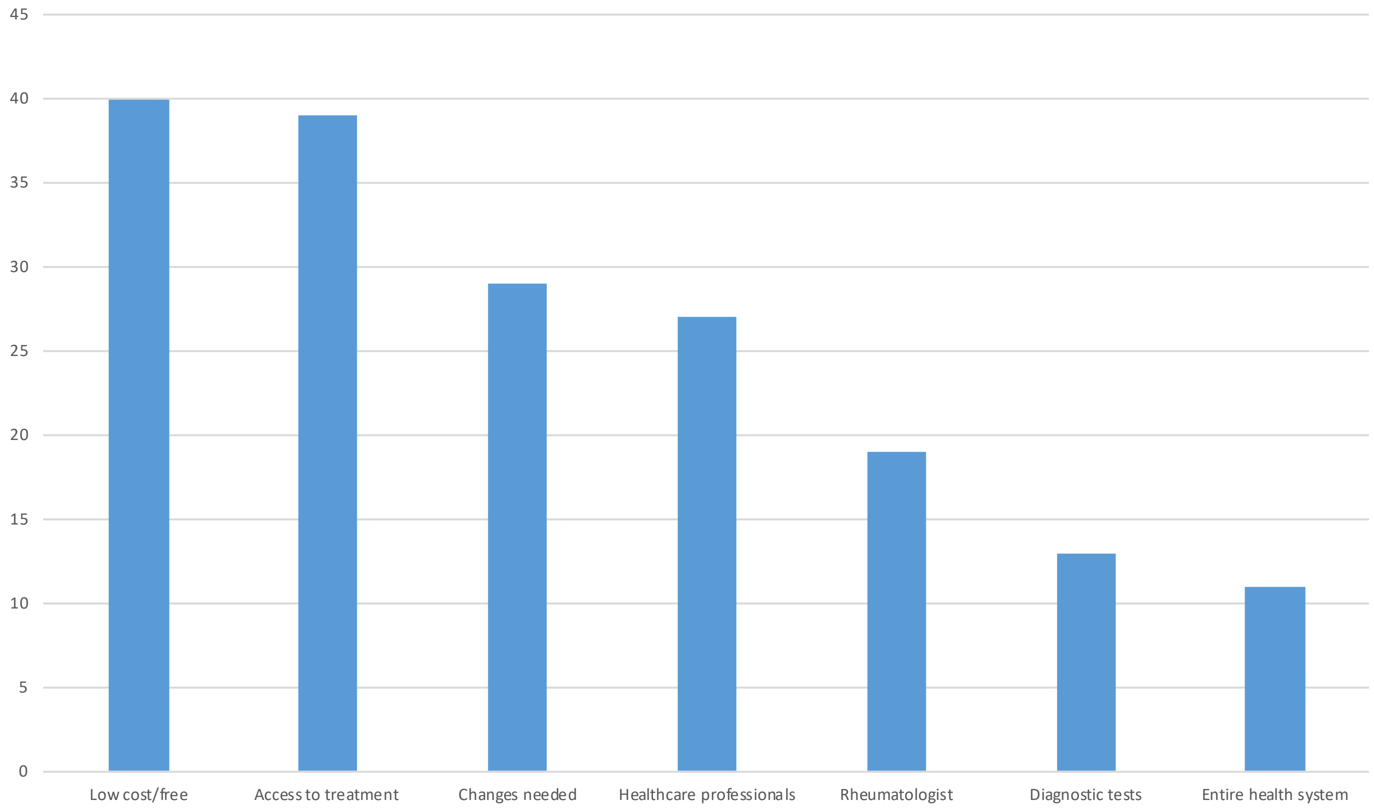


Figure 9.5: Aspects of the Australian health system patients are grateful for

Values when making decisions about treatment

Symptoms and aspects of quality of life important for treatment considerations

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 9 is the least important. A weighted average is presented in Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were pain, physical function, and level of independence; the least important was redness. Figures 9.7 to 9.15 show the weighted rank by subgroups. The ranking of symptoms are similar within sub groups and are similar to the overall cohort.

Table 9.6: Symptoms/aspects of quality of life important for treatment considerations

		Pain	Physical function	Level of independence	Psychological well-being	Swelling	Stiffness	Redness	Tenderness of joints	Deformities of joints
All Participants	All Participants	8.12	7.56	6.48	4.54	3.94	4.26	1.73	3.80	4.57
AIMS2-SF Physical	Physical limitations: no days	7.89	7.00	6.05	5.32	4.47	3.58	1.42	4.21	5.05
	Physical limitations: few days	8.30	7.70	6.30	4.23	3.80	4.30	1.77	3.95	4.66
	Physical limitations: some to most days	8.03	7.68	6.92	4.51	3.84	4.57	1.84	3.41	4.22
AIMS2-SF Physical	Symptoms: no to few days	7.75	7.30	6.75	4.75	4.35	3.70	1.55	3.85	5.00
	Symptoms: some days	8.15	7.52	5.96	5.04	4.11	4.19	1.74	4.00	4.30
	Symptoms: most days	8.28	7.41	7.00	4.09	3.50	4.34	1.75	3.81	4.81
	Symptoms: all days	8.19	8.10	6.10	4.38	4.00	4.76	1.86	3.48	4.14
AIMS2-SF Physical	Affect: never to almost never	8.15	7.39	6.24	4.39	4.36	4.55	1.76	3.67	4.48
	Affect: sometimes	8.14	7.72	6.53	4.39	3.78	4.17	1.78	4.31	4.19
	Affect: very often to always	8.06	7.55	6.68	4.87	3.68	4.06	1.65	3.35	5.10
AIMS2-SF Physical	Social: all to most days	8.15	7.45	6.75	4.90	3.75	4.15	1.80	3.90	4.15
	Social: some days	8.08	7.56	6.25	4.81	3.97	4.33	1.86	3.64	4.50
	Social: no to few days	8.14	7.61	6.55	4.16	4.00	4.25	1.59	3.89	4.82
Flare-up frequency	Occasional flare-ups	8.04	7.54	6.54	4.57	4.07	4.07	1.73	3.68	4.77
	Frequent flare-ups	8.23	7.59	6.41	4.50	3.77	4.50	1.73	3.95	4.32
Age	Aged 18 - 34	8.11	7.11	6.11	4.11	3.94	4.89	1.39	4.33	5.00
	Aged 35 - 54	8.14	7.78	6.37	4.57	3.92	4.06	1.76	3.63	4.76
	Aged 55 or older	8.10	7.45	6.87	4.74	3.97	4.23	1.87	3.77	4.00
Location	Metropolitan	8.11	7.43	6.27	4.61	4.07	4.34	1.73	3.75	4.70
	Regional or remote	8.14	7.73	6.75	4.45	3.77	4.16	1.73	3.86	4.41
Education	Trade or high school	8.27	7.52	6.55	4.61	3.76	4.15	1.73	3.73	4.70
	University	8.04	7.58	6.45	4.51	4.03	4.31	1.73	3.84	4.51
SEIFA	High SEIFA	8.08	7.48	6.30	4.40	4.00	4.48	1.74	3.70	4.82
	Mid to Low SEIFA	8.16	7.64	6.66	4.68	3.88	4.04	1.72	3.90	4.32

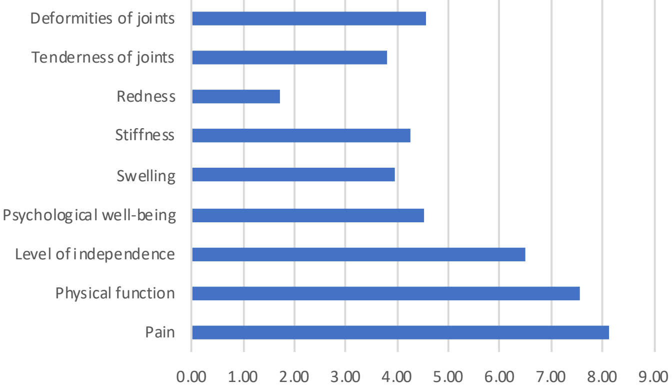


Figure 9.6: Symptoms/aspects of quality of life important for treatments all participants

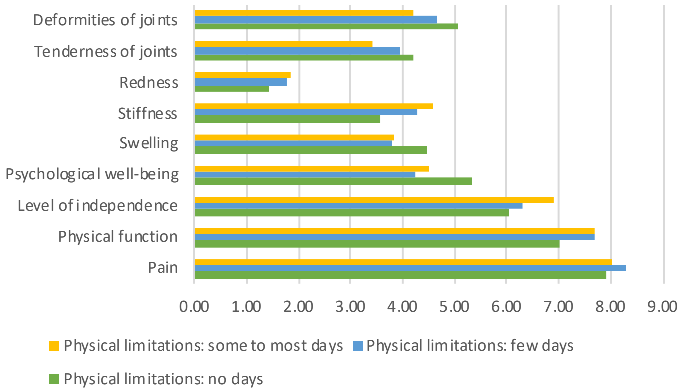
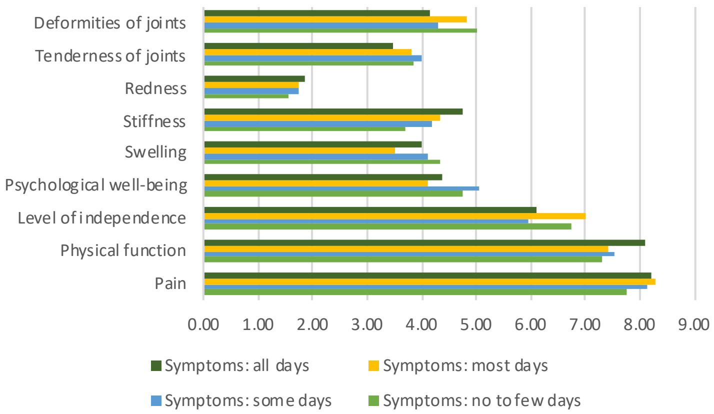


Figure 9.7: Symptoms/aspects of quality of life important for treatments by AIMS2-SF Physical



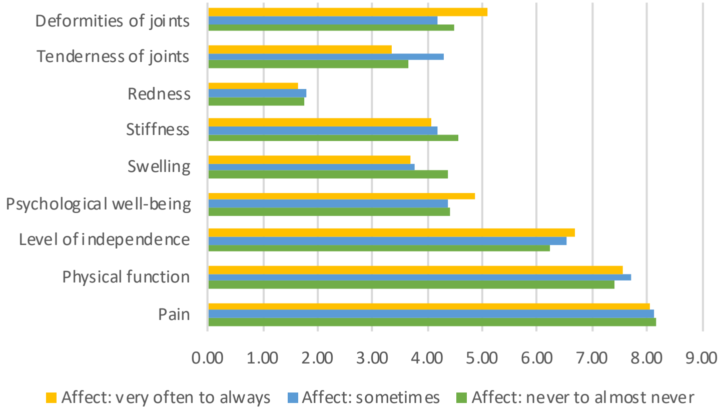
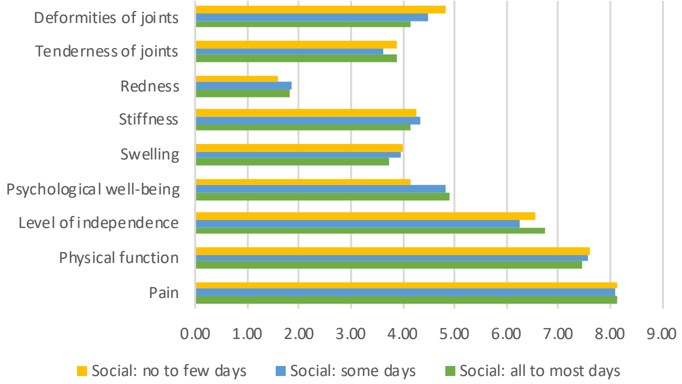


Figure 9.8: Symptoms/aspects of quality of life important for treatments by AIMS2-SF Symptoms

Figure 9.9: Symptoms/aspects of quality of life important for treatments by AIMS2-SF Affect



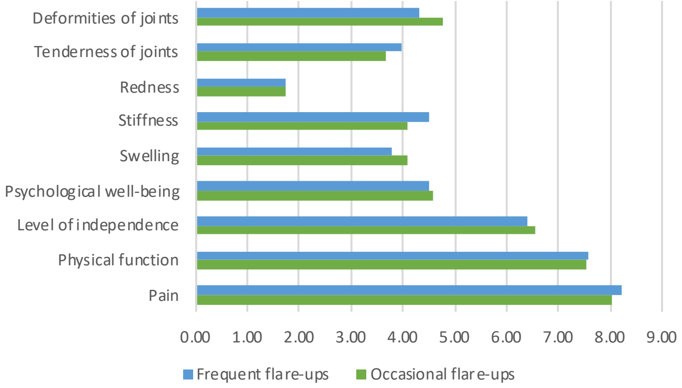


Figure 9.10: Symptoms/aspects of quality of life important for treatments by AIMS2-SF Social

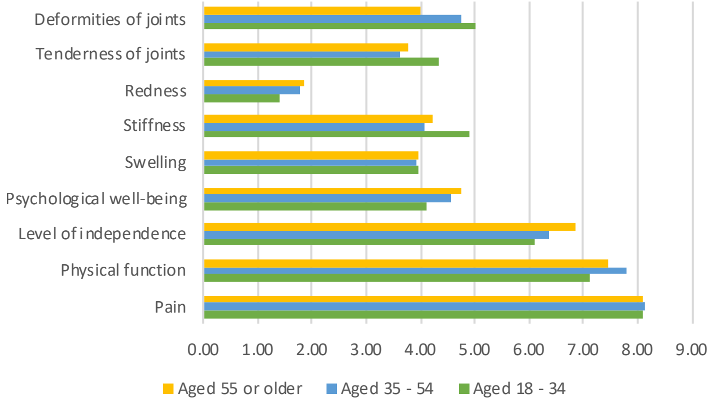


Figure 9.12: Symptoms/aspects of quality of life important for treatments by Age

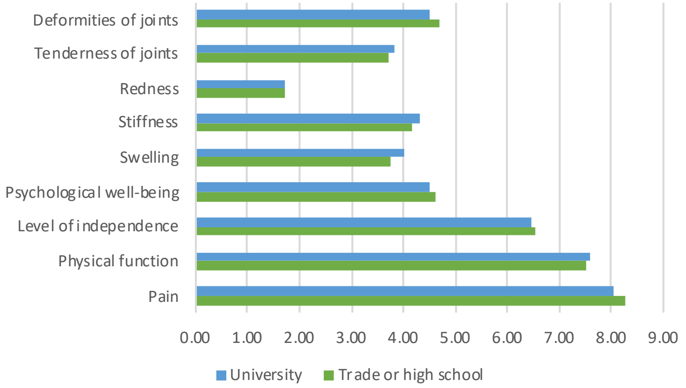


Figure 9.14: Symptoms/aspects of quality of life important for treatments by Education

Figure 9.11: Symptoms/aspects of quality of life important for treatments by Flare-up frequency

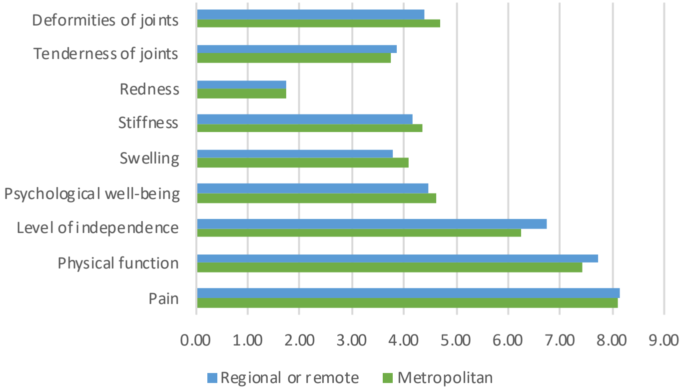


Figure 9.13: Symptoms/aspects of quality of life important for treatments by Location

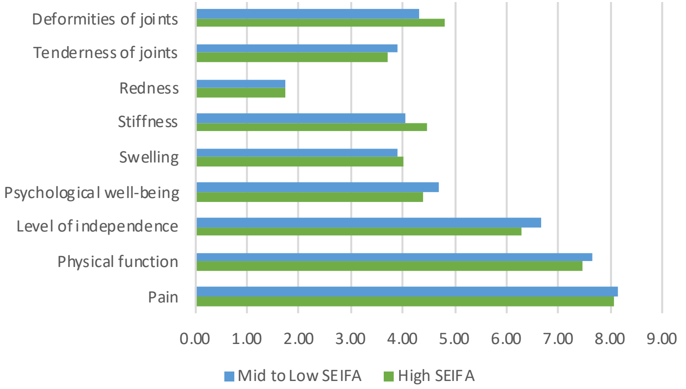


Figure 9.15: Symptoms/aspects of quality of life important for treatments by SEIFA

Length of time to take a treatment for good quality of life

Participants indicated in the online questionnaire “For you to feel that a treatment was worthwhile, how many months or years would you consider taking it, provided it gave you a good quality of life, even if it didn’t offer a cure?”. The majority of participants responded more than 10 years (N=71, 71.00%).

Table 9.7: Length of time to take a treatment for good quality of life

Time	N=100	Percent
3 to 6 months	6	6.00
1 to 2 years	12	12.00
3 to 5 years	7	7.00
8 to 10 years	4	4.00
10 years or more	71	71.00

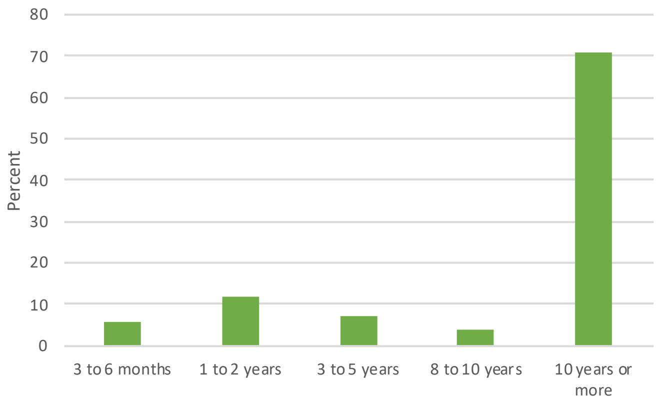


Figure 9.16: Length of time to take a treatment for good quality of life.

Values that are important to patients when making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.17. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "The ability to include my family in making treatment decisions", and "My ability to follow and stick to a treatment regime". Figures 9.18 to 9.26 show the weighted rank by all participants, and subgroups. The values for making are similar within sub groups and are similar to the overall cohort.

Table 9.8: Values that are important to patients when making decisions

Subgroup	Subgroup	How safe the medication is and weighing up the risks and benefits	The severity of the side effects	Time impact of the treatment on my quality of life	How the treatment is administered	How personalised the treatment is for me	The ability to include my family in making treatment decisions	My ability to follow and stick to a treatment regime	The financial costs to me and my family
All Participants	All Participants	7.26	6.79	5.53	3.51	3.81	1.89	2.94	4.27
AIMS2-SF Physical	Physical limitations: no days	7.53	6.68	5.68	3.11	3.58	1.84	3.11	4.47
	Physical limitations: few days	7.14	6.80	5.55	3.68	4.14	1.84	2.80	4.07
	Physical limitations: some to most days	7.27	6.84	5.43	3.51	3.54	1.97	3.03	4.41
AIMS2-SF Physical	Symptoms: no to few days	7.45	6.95	5.75	2.90	3.95	1.95	3.00	4.05
	Symptoms: some days	7.30	6.56	5.67	3.81	3.74	1.74	2.85	4.33
	Symptoms: most days	6.97	6.75	5.59	3.50	4.06	2.06	2.84	4.22
	Symptoms: all days	7.48	7.00	5.05	3.71	3.38	1.76	3.14	4.48
AIMS2-SF Physical	Affect: never to almost never	7.24	6.58	5.36	3.55	3.94	1.70	3.18	4.45
	Affect: sometimes	7.42	7.00	5.69	3.56	4.00	1.92	2.78	3.64
	Affect: very often to always	7.10	6.77	5.52	3.42	3.45	2.06	2.87	4.81
AIMS2-SF Physical	Social: all to most days	7.20	6.65	5.65	3.70	4.10	1.95	3.20	3.55
	Social: some days	7.28	6.94	5.53	3.47	4.08	1.78	3.03	3.89
	Social: no to few days	7.27	6.73	5.48	3.45	3.45	1.95	2.75	4.91
Flare-up frequency	Occasional flare-ups	7.14	6.68	5.79	3.38	3.96	1.82	3.07	4.16
	Frequent flare-ups	7.41	6.93	5.20	3.68	3.61	1.98	2.77	4.41
Age	Aged 18 - 34	7.44	6.50	5.78	3.33	3.56	2.11	2.39	4.89
	Aged 35 - 54	7.18	6.92	5.51	3.53	3.76	1.86	2.88	4.35
	Aged 55 or older	7.29	6.74	5.42	3.58	4.03	1.81	3.35	3.77
Location	Metropolitan	7.27	6.77	5.57	3.32	3.66	1.84	3.04	4.54
	Regional or remote	7.25	6.82	5.48	3.75	4.00	1.95	2.82	3.93
Education	Trade or high school	7.09	6.76	5.18	3.67	3.21	1.79	3.24	5.06
	University	7.34	6.81	5.70	3.43	4.10	1.94	2.79	3.88
SEIFA	High SEIFA	7.22	6.80	5.52	3.52	3.86	1.84	3.00	4.24
	Mid to Low SEIFA	7.30	6.78	5.54	3.50	3.76	1.94	2.88	4.30

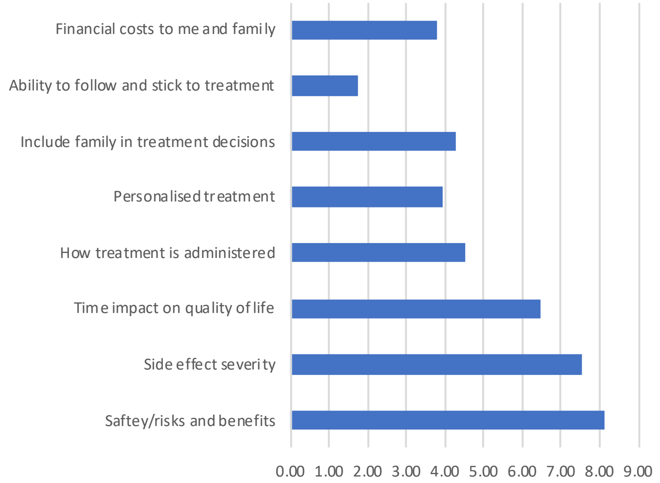


Figure 9.17: Decision making considerations

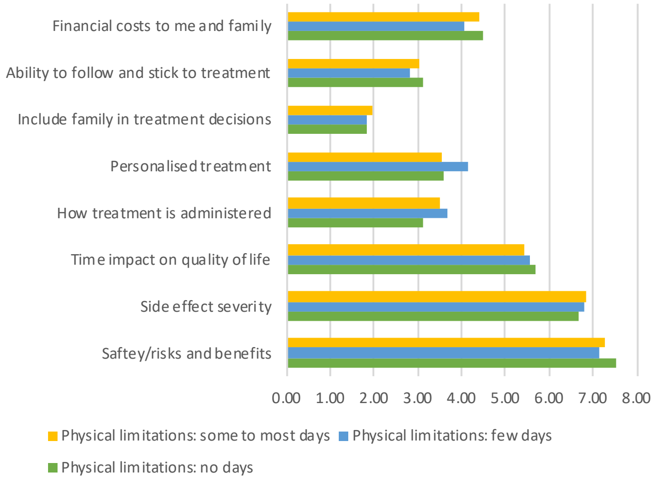


Figure 9.18: Decision making considerations by **AIMS2-SF Physical**

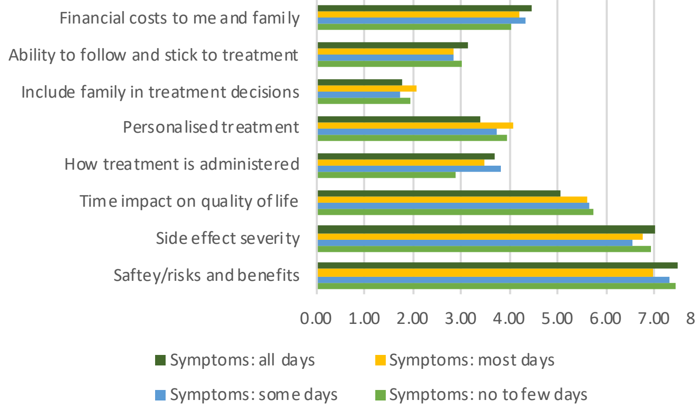


Figure 9.19: Decision making considerations by **AIMS2-SF Symptoms**

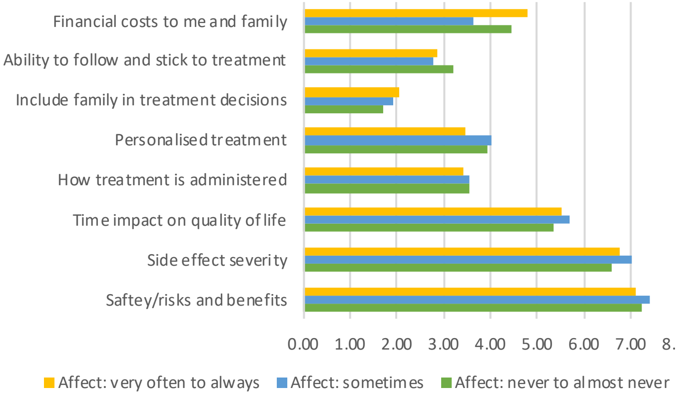


Figure 9.20: Decision making considerations by **AIMS2-SF Affect**

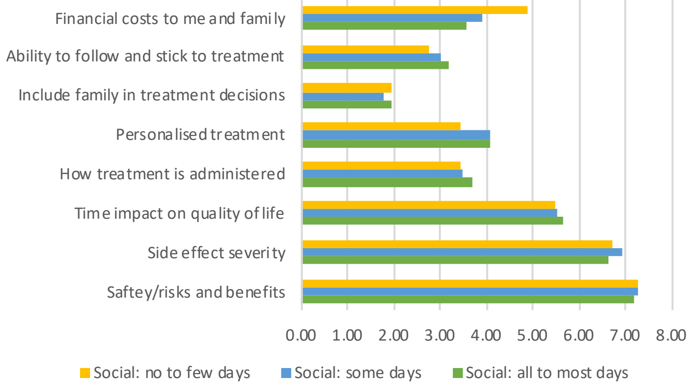


Figure 9.21: Decision making considerations by **AIMS2-SF Social**

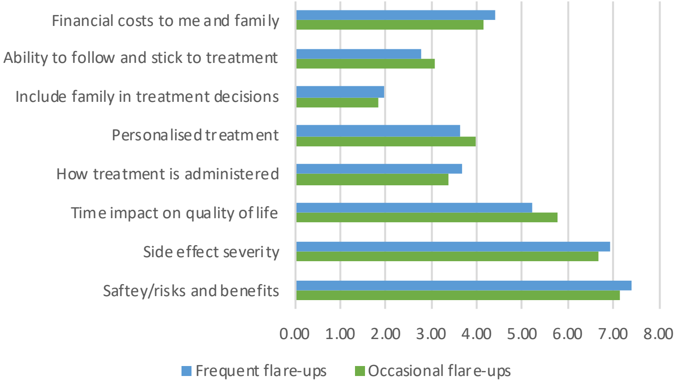


Figure 9.22: Decision making considerations by **Flare-up frequency**

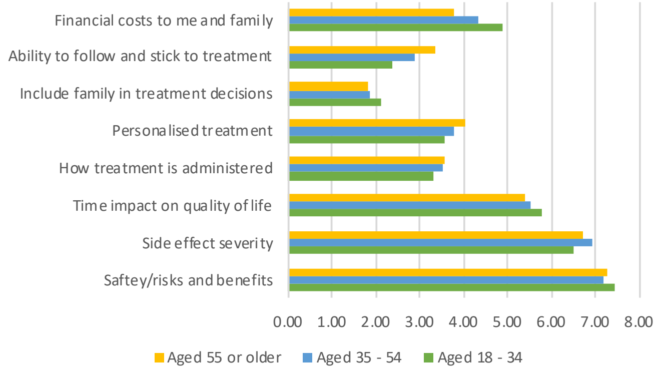


Figure 9.23: Decision making considerations by **Age**

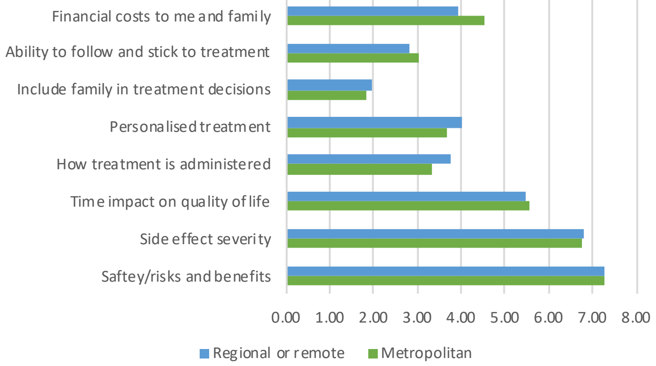


Figure 9.24: Decision making considerations by **Location**

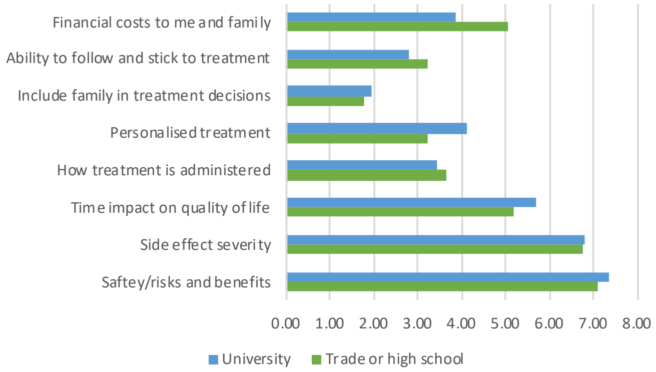


Figure 9.25: Decision making considerations by **Education**

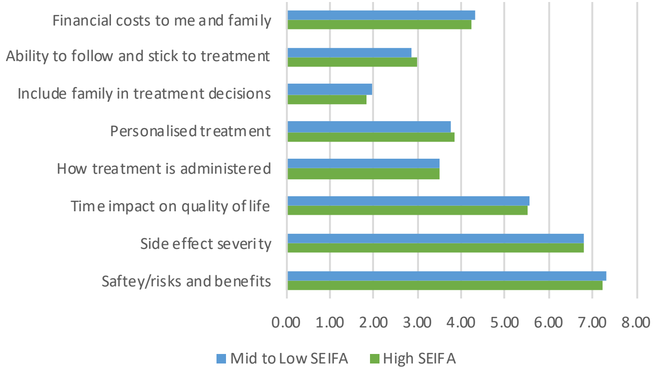


Figure 9.26: Decision making considerations by **SEIFA**

Values that are important to patients when others are making decisions on their behalf

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.27. With a weighted ranking, the higher the score, the greater value it is to participants. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government. Figures 9.28 to 9.36 show the weighted rank by all participants and by subgroups. The values for making decisions on their behalf are similar within sub groups and are similar to the overall cohort.

Table 9.9: Values that are important to patients when others are making decisions on their behalf

Subgroup	Subgroup	Economic value to government and tax payers	Economic value to patients and their families	Quality of life for patients	Compassion	All patients being able to access all available treatments and services
All Participants	All Participants	1.58	2.83	4.39	2.47	3.73
AIMS2-SF Physical	Physical limitations: no days	1.47	2.79	4.37	2.68	3.68
	Physical limitations: few days	1.50	2.82	4.55	2.41	3.73
	Physical limitations: some to most days	1.73	2.86	4.22	2.43	3.76
AIMS2-SF Physical	Symptoms: no to few days	1.60	2.60	4.35	2.70	3.75
	Symptoms: some days	1.44	3.00	4.56	2.41	3.59
	Symptoms: most days	1.81	2.78	4.34	2.38	3.69
	Symptoms: all days	1.38	2.90	4.29	2.48	3.95
AIMS2-SF Physical	Affect: never to almost never	1.48	2.82	4.67	2.39	3.64
	Affect: sometimes	1.53	2.75	4.39	2.42	3.92
	Affect: very often to always	1.74	2.94	4.10	2.61	3.61
AIMS2-SF Physical	Social: all to most days	1.60	2.60	4.35	2.65	3.80
	Social: some days	1.61	3.06	4.61	2.42	3.31
	Social: no to few days	1.55	2.75	4.23	2.43	4.05
Flare-up frequency	Occasional flare-ups	1.57	2.79	4.50	2.34	3.80
	Frequent flare-ups	1.59	2.89	4.25	2.64	3.64
Age	Aged 18 - 34	1.67	3.00	4.39	2.67	3.28
	Aged 35 - 54	1.53	2.90	4.43	2.33	3.80
	Aged 55 or older	1.61	2.61	4.32	2.58	3.87
Location	Metropolitan	1.43	2.71	4.48	2.59	3.79
	Regional or remote	1.77	2.98	4.27	2.32	3.66
Education	Trade or high school	1.67	2.91	4.27	2.42	3.73
	University	1.54	2.79	4.45	2.49	3.73
SEIFA	High SEIFA	1.32	2.58	4.56	2.56	3.98
	Mid to Low SEIFA	1.84	3.08	4.22	2.38	3.48

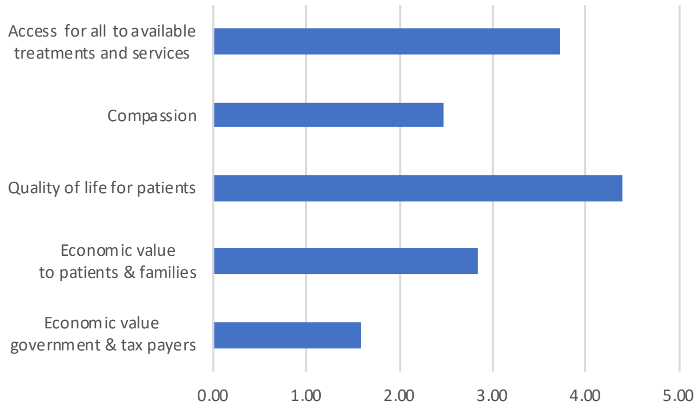


Figure 9.27: Decision making on patient behalf

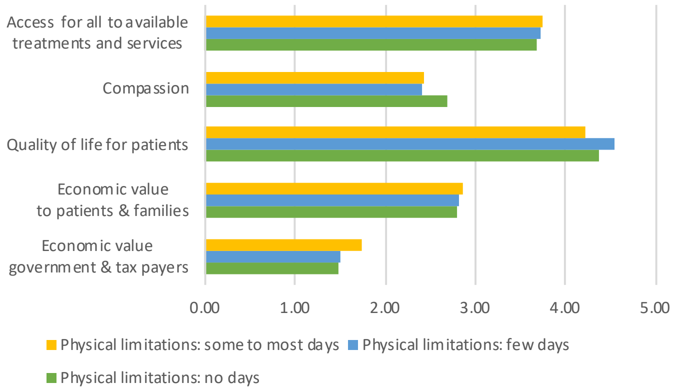


Figure 9.28: Decision making on patient behalf by **AIMS2-SF Physical**

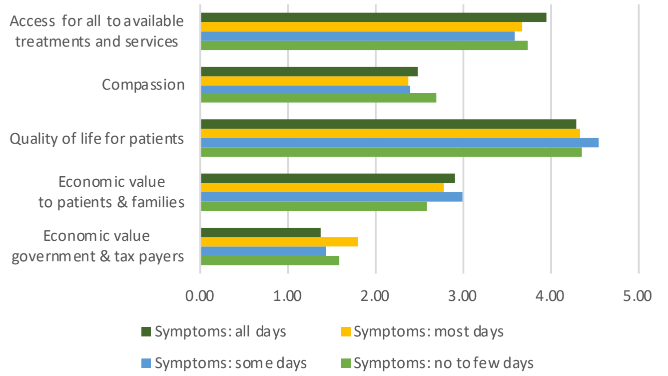


Figure 9.29: Decision making on patient behalf by **AIMS2-SF Symptoms**

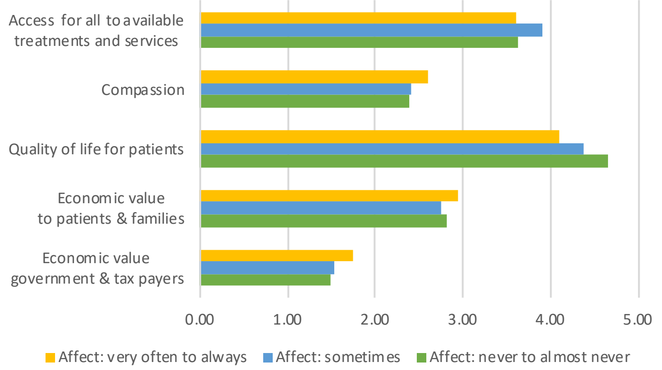


Figure 9.30: Decision making on patient behalf by **AIMS2-SF Affect**

Figure 9.31: Decision making on patient behalf by **AIMS2-SF Social**

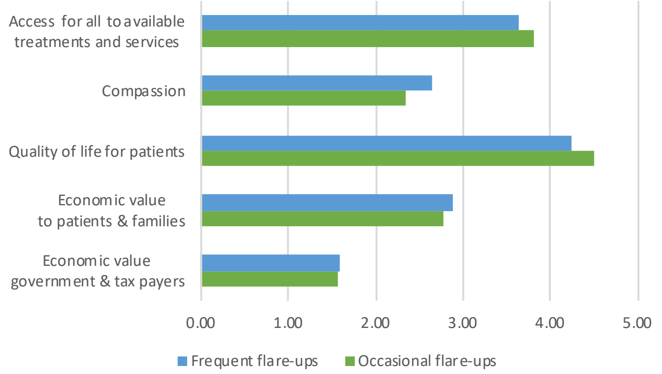


Figure 9.32: Decision making on patient behalf by **Flare-up frequency**

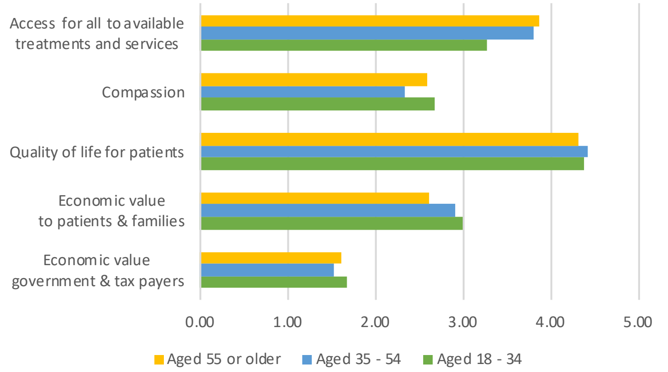


Figure 9.33: Decision making on patient behalf by **Age**

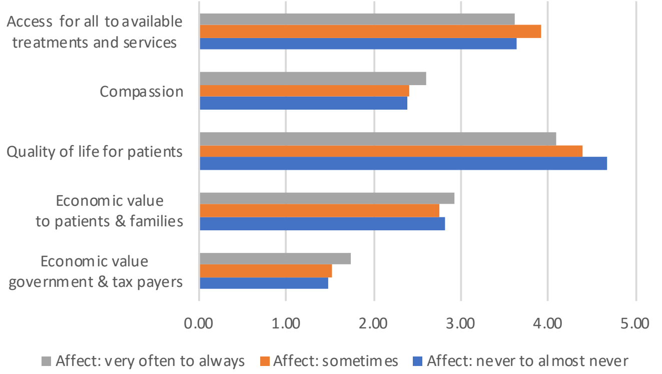


Figure 9.34: Decision making on patient behalf by **Location**

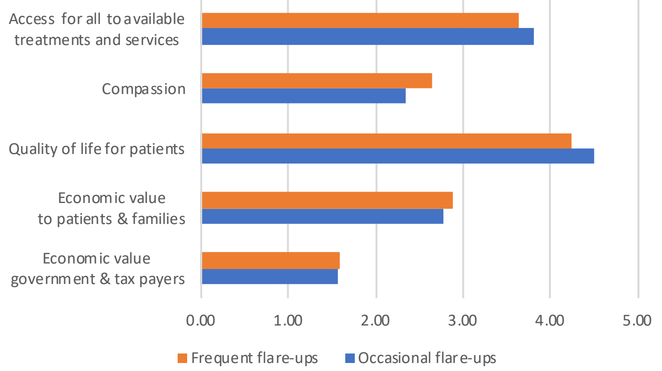


Figure 9.36: Decision making on patient behalf by **SEIFA**

Message to decision makers

Participants were asked what message they would like to say to decision makers. There were seven key themes and the most common message was that there should be more awareness of and research into rheumatoid arthritis (23%). Other common messages included that treatment should be affordable (19%), there should be better access to different medicines through the PBS (19%), there should be a reduction of stigma surrounding RA (17%), there needs to be more efficient hospital processes (14%), that complementary therapies needed to be more affordable (10%), and that there needs to be a change to the referral process surrounding biologics (8%).

In relation to sub-group variations, participants with *Trade or high school* qualification (12.12%) described a message of more awareness/research less frequently than the general population (23.00%), while participants in the sub-groups *Physical limitations: no days* (36.84%), *Symptoms: no to few days* (45.00%), and *Aged 18 – 34* (38.89%) described this more frequently than the general population.

Participants in the sub-groups *Physical limitations: no days* (5.26%), and *Symptoms: no to few days* (5.00%) described the message of affordability of treatment less frequently than the general population (19.00%).

Participants in the sub-group *Symptoms: no to few days* (5.00%) described wanting a reduction of stigma less frequently than the general population (17.00%).

No participants in the subgroup *Affect: very often to always* described wanting more efficient hospital processes. Participants in the sub-groups *Symptoms: most days* (3.13%), and *Affect: never to almost never* (24.24%) described wanting more efficient hospital processes less frequently than the general population (14.00%), while participants in the sub-group *Symptoms: some days* (33.33%) reported this more frequently.

Participants in the sub-group *Symptoms: all days* (19.05%) described wanting a change in biologics referral process more frequently than the general population (8.00%).

Participant's message is that there needs to be more awareness/research

If it's not a very sexy disease, there's not a great deal of awareness about it. And there's a whole bunch of people whose lives are messed up, who, you know, it'd be great to find more about it. Participant 4

I think we need a bit more research. Yeah. Not sure. Um, I think we had, in my case, it would be, I needed to know a diagnosis. I wouldn't be as bad as I am now. I'm not sure how this gets that, whether it's more awareness with of the community. Participant 5

It doesn't have the big exposure like it does with cancer or a heart condition, it gets downplayed a lot. The thing is that people actually get it especially when a majority of people get osteoporosis or osteoarthritis when they get older, then they realize, "Oh my gosh, it's really debilitating." Participant 6

Like when I got diagnosed, most of my family and friends said What, what's that? When I said I've got rheumatoid arthritis, they're like, never heard about it. To be honest, I hadn't either until I was told that's what I've got. Participant 38

Participant's message is that there is more affordable treatment

Make it cheaper. I'm not one of the people that struggles, but for a lot of elderly people that have this disease that have already got enough health issues and medication and, and financial troubles and you know, there, there are single parents and students and people that really already doing it tough, but I know though they'd probably have a healthcare card, Participant 31

Affordable medications and affordable access to services, um, in order to keep us functioning and be productive members of society. Participant 45

Yeah, I just think um probably more help to people that are still working and struggling because I know I used to pay about $700 a month, just the medications when I was working. So you were sort of working to pay for your medical treatment? Participant 76

Participant's message is that there is faster, better access through PBS

I hear that other people have a lot of trouble getting access. Like if you, you live in more remote areas or if they need a lot of assistance, it sounds like that it's not really covered if you can't afford to pay for it or completely be yourself. Right. It would be nice if people needed it if they had more help and better access in regional areas. Participant 7

Like with these biological or chemical, whatever, that's the enbrel that I'm on, like I don't, I guess they've got to try everything to see, you know, how I respond. But like I said, my friend who is on private health insurance within six months was on this medication. It took me three years, which really annoyed me. Participant 27

The public systems sucks, get your act together. With regards to getting, getting RA treatment and the biologics, um the whole approval system needs to be, um, I haven't gone through it as yet but from what I see, it's quite stringent. Um, and it, it needs to be looked at. Not Everything always works all the time. Participant 43

You need to lift your game in terms of offering more services and treatments old hun because it's costing the economy to have people out of action like this, um, it's not, it's not enough just to be showing in some cases just showing him that it means that people, and thinking this is putting people in wheelchairs. Participant 87

Participant's message is that there is a reduction of stigma and lack of understanding, and more compassion/empathy

Just because you don't look like you're sick, it doesn't mean you're not. Like diabetes and all that, isn't it? Unless you're in a wheelchair people don't believe you, you know, so I don't know. They're all a bunch of wankers anyway. Participant 8

It's a disability. Yeah. It's debilitating and people need help and support, but they need it officially recognized as a disability. Yeah. I'm not saying I want a hand out from the government, but it's not something you can have ignored. It does affect your day to day movements. Participant 32

I would say arthritis is just as real as every other illness and deserves the same amount of care and respect that you give to cancer research or that you'd give to aids research. Um, they are each so different, but arthritis deserves its time and its, it deserves its research funding. It deserves the acknowledgement because people are suffering and it's a lifelong illness and it doesn't get better, and we don't deserve to die. We deserve to be just as important as somebody else. We shouldn't just be pushed aside because it's invisible. Participant 41

I think they have to be a little bit more compassionate. I know they won't have a complete understanding of how you're feeling, and nobody will until you get it yourself. I'm not just a number. Sometimes you're just treated as if you're a number, "Okay, come. Oh, yes." They'll tell you that, give you that, and then out you go. Well, that's not good enough. Sometimes you just need time to just sit and talk to someone. Participant 80

Participant's message is that hospital processes should be more efficient

Like, I mean, so streamline that process. Yeah. And because I've been so long, so I'm not sure what it's like for a new person at the moment to be diagnosed and the diagnosis. A lot of people taking too long to be diagnosed and therefore not getting effective treatment soon enough. Participant 13

To try and streamline the process so that you're not relying on the post, on your scripts coming back through the mail, and that it's going to be sent away and sent back and that kind of stuff. Make the pharmacy stores have, not like your local chemist, but the companies have it readily available and have plenty of it in stock so they don't run out. Participant 46

They need to look at the cost it is to then produce these things, how easy it is to access it for people and how quickly they can access these things. Like, I mean, so streamline that process. Participant 2

Participant's message is that there is more affordable complementary therapies/mental health/ physiotherapy

As I said whatever that yearly cost, it might have been $400 or $500 but then that I could swim every day of the week rather than once a week. You make it worthwhile by doing it three or four times a week. Participant 1

I think I would say to him it needs to be more than clinical. Yeah. It needs to be because this disease affects your whole person and needs to be a whole person-centred approach to care. Yeah. So, it can't be just, it can't be just the drugs and the, you know, the x rays, it's gotta be, it's gotta be more of an emotional and psychological help as well. Participant 69

So I know that like they, he did give me a referral to a psychologist that I never went to see because it was $290 for the 50 minutes to go and see him and I just, I just can't afford that. Participant 69

So I think that should be brought into the health system and acknowledged and treated like the mainstream medical profession because they can be just as beneficial as the traditional medics. I don't think they're given, if you put it that way, do you know, the credibility that they deserve. Participant 73

Participant's message is that recommendations for biologics could change

I think one thing that's interesting with the department of health is that you have to try a drug for certain amounts of time. So even if your rheumatologist knows, if it's not working, you still have to persist with it. Participant 53

I would think first and foremost say please can we just get rid of that fail two drugs to get the good stuff because that's costing the economy for the people taking time off work for trial and error. Participant 63

I think that the people that don't tick all the boxes to be able to get through onto the biologics and have the costs by mostly covered and whatnot. I think it's pretty limited with what medication and treatments they can have and um, the costs involved in those seems to be quite high for them and considering it can be so debilitating. That's pretty sad. Participant 65

My big thing is the biologics. One, they should be made accessible right from the start at the doctor's discretion because I suffered two years of severe agony and crippling because my doctor could not prescribe me biologics until I'd failed every other drug that he had available. He knew they weren't going to work. He was so frustrated because he knew what I needed, and he couldn't give it to me. Participant 96

Table 9.10: Message to decision makers

Message to decision-makers	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant recommends more awareness of and research into rheumatoid arthritis	23	23.00	7	36.84	9	20.45	7	18.92	9	45.00	4	14.81	7	21.88	3	14.29
Participant recommends that treatment is more affordable	19	19.00	1	5.26	12	27.27	6	16.22	1	5.00	6	22.22	8	25.00	4	19.05
Participant recommends that there is faster, better access to treatments through the PBS	19	19.00	3	15.79	9	20.45	7	18.92	4	20.00	5	18.52	6	18.75	4	19.05
Participant describes the need for a reduction of stigma and lack of understanding	17	17.00	2	10.53	6	13.64	9	24.32	1	5.00	6	22.22	5	15.63	5	23.81
Participant recommends that hospital processes become more efficient	14	14.00	5	26.32	4	9.09	5	13.51	3	15.00	9	33.33	1	3.13	1	4.76
Participant recommends more affordable complementary therapies/mental health treatment/physiotherapy	10	10.00	2	10.53	4	9.09	4	10.81	2	10.00	2	7.41	5	15.63	1	4.76
Participant describes the need for a change to the process of getting biologics	8	8.00	0	0.00	4	9.09	4	10.81	0	0.00	0	0.00	4	12.50	4	19.05

Message to decision-makers	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant recommends more awareness of and research into rheumatoid arthritis	23	23.00	8	24.24	9	25.00	6	19.35	6	30.00	7	19.44	10	22.73
Participant recommends that treatment is more affordable	19	19.00	9	27.27	6	16.67	4	12.90	4	20.00	10	27.78	5	11.36
Participant recommends that there is faster, better access to treatments through the PBS	19	19.00	6	18.18	7	19.44	6	19.35	3	15.00	8	22.22	8	18.18
Participant describes the need for a reduction of stigma and lack of understanding	17	17.00	5	15.15	5	13.89	7	22.58	2	10.00	6	16.67	9	20.45
Participant recommends that hospital processes become more efficient	14	14.00	8	24.24	6	16.67	0	0.00	3	15.00	5	13.89	6	13.64
Participant recommends more affordable complementary therapies/mental health treatment/physiotherapy	10	10.00	2	6.06	5	13.89	3	9.68	1	5.00	5	13.89	4	9.09
Participant describes the need for a change to the process of getting biologics	8	8.00	0	0.00	5	13.89	3	9.68	2	10.00	4	11.11	2	4.55

Message to decision-makers	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends more awareness of and research into rheumatoid arthritis	23	23.00	15	26.79	8	18.18	7	22.58	9	17.65	7	38.89
Participant recommends that treatment is more affordable	19	19.00	11	19.64	8	18.18	6	19.35	10	19.61	3	16.67
Participant recommends that there is faster, better access to treatments through the PBS	19	19.00	12	21.43	7	15.91	3	9.68	13	25.49	3	16.67
Participant describes the need for a reduction of stigma and lack of understanding	17	17.00	8	14.29	9	20.45	5	16.13	8	15.69	4	22.22
Participant recommends that hospital processes become more efficient	14	14.00	11	19.64	3	6.82	4	12.90	7	13.73	3	16.67
Participant recommends more affordable complementary therapies/mental health treatment/physiotherapy	10	10.00	6	10.71	4	9.09	5	16.13	4	7.84	1	5.56
Participant describes the need for a change to the process of getting biologics	8	8.00	2	3.57	6	13.64	1	3.23	6	11.76	1	5.56

Table 9.10: Message to decision makers (Cont.)

Message to decision-makers	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends more awareness of and research into rheumatoid arthritis	23	23.00	10	17.86	13	29.55	4	12.12	19	28.36	8	16.00	15	30.00
Participant recommends that treatment is more affordable	19	19.00	8	14.29	11	25.00	8	24.24	11	16.42	7	14.00	12	24.00
Participant recommends that there is faster, better access to treatments through the PBS	19	19.00	11	19.64	8	18.18	4	12.12	15	22.39	13	26.00	6	12.00
Participant describes the need for a reduction of stigma and lack of understanding	17	17.00	11	19.64	6	13.64	5	15.15	12	17.91	8	16.00	9	18.00
Participant recommends that hospital processes become more efficient	14	14.00	10	17.86	4	9.09	2	6.06	12	17.91	7	14.00	7	14.00
Participant recommends more affordable complementary therapies/mental health treatment/physiotherapy	10	10.00	7	12.50	3	6.82	4	12.12	6	8.96	5	10.00	5	10.00
Participant describes the need for a change to the process of getting biologics	8	8.00	1	1.79	7	15.91	3	9.09	5	7.46	3	6.00	5	10.00

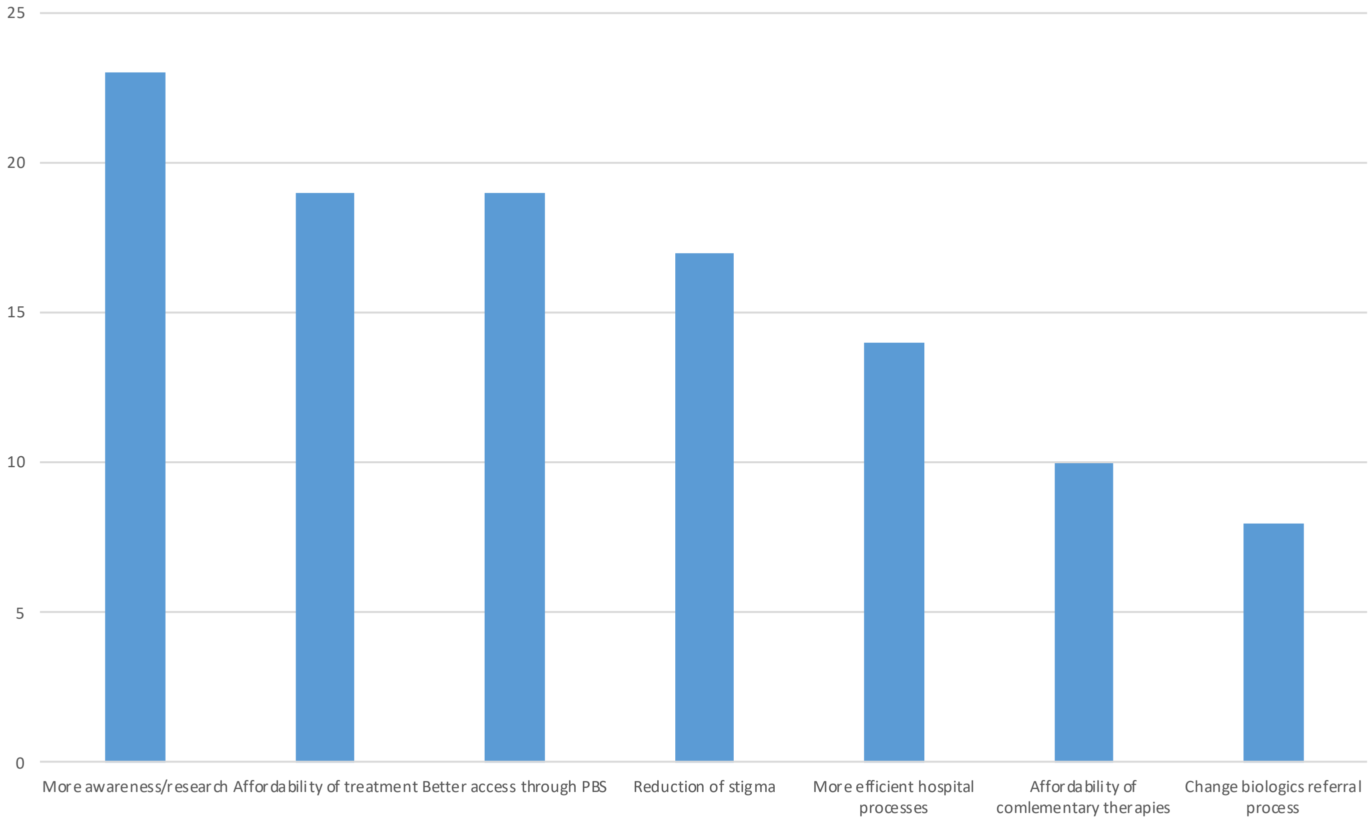


Figure 9.37: Message to decision-makers

Section 10 Advice to other patients and families

Section 10: Advice to other patients and families

The most common advice to other patients and families was to become more informed about your rheumatoid arthritis (25%) and this was followed by being more assertive, mainly towards healthcare professionals in regard to their treatment options (23%). There were 16 participants (16%) whose advice was to kinder towards yourself and acknowledge and/or accept your limitations, 15 participants (15%) whose advice was to remain positive, 14 participants (14%) advised to be mindful of emotional wellbeing and to seek mental health help or counselling support, a further 14 participants (14%) who advised talking to other patients with rheumatoid arthritis, 10 participants (10%) advised practical support such as health diet and exercise, and a further 10 participants (10%) advised participating more in complimentary therapy to help ease symptoms, particularly hydrotherapy.

Advice to patients in the future

The most common advice was to become more informed about your rheumatoid arthritis (n=25; 25.00%) and this was followed by being more assertive, mainly towards healthcare professionals in regard to their treatment options (n=23; 23.00%).

There were 16 participants (16.00%) whose advice was to be kinder towards yourself and acknowledge or accept your limitations, 15 participants (15.00%) whose advice was to remain positive, 14 participants (14.00%) whose advice was to be mindful of emotional wellbeing and to seek mental health help or counselling support. There were a further 14 participants (14.00%) who advised talking to other patients with rheumatoid arthritis, 10 participants (10.00%) who advised practical support such as health diet and exercise, and a further 10 participants (10.00%) who advised participating more in complimentary therapy to help ease symptoms, particularly hydrotherapy.

Participant's advice is to become informed about your rheumatoid arthritis.

Do as much reading as possible and learn as much about the disease and all the treatments as possible so that you know exactly the right question to ask. Um, and you have to be, you have to be proactive in your health care basically. Participant 3.

I would try and educate your family to do the same because sometimes families can be really resistant. Participant 97.

It might be just right from the very beginning that you're going to have to look up and find out as much as you can take and you know, um, you're to be asked to make decisions. So find out as much as you can. Okay. educate yourself. Participant 55.

Participant's advice is to become more assertive when talking to health professionals.

I'll say the same thing, I'll say it to lots of people, be your own best advocate. If you feel like something isn't right then it probably isn't, so fight back. Speak up, because people won't know unless you do. Definitely be your own best advocate and if you can't, take someone with you if you can. Lots of people aren't game. Participant 93.

Well… first be your own advocate. Don't take… from doctors and don't treat them like they're god, because they will expect you to and they are your employees. If you're dissatisfied, say so, and go somewhere else, you've got to advocate for yourself because nobody else is going to do, and it is exhausting when you're sick, and you shouldn't have to go in with that attitude, but you have to, um, you, you've got to be your own advocate. Participant 87.

If they are not happy with the diagnosis, get a second opinion. If they're not happy about going on the drugs, if they can, get a second opinion. Participant 21

Participant’s advice is to be kinder to your body and accept your limitations.

Well, I guess the biggest one is just, um, to learn how to pace yourself, and not burn yourself out. Um, like there's times when I've just cried in frustration because I can't do what I want to do. Um, and what have I tried that's been successful? Um, just listening to your body, having, having the nana naps, when you need them. Participant 37.

I guess my main advice would be just to, just to accept that you're going to have crappy days and to not beat yourself up about it. Participant 72.

Look after yourself. Look after yourself. Rest when you need to rest. Don't push Yourself. Participant 81.

Participant's advice is to remain positive and look for the good things in life.

You need to take it day by day, just because you're in the middle of a flare up doesn't mean that every day is going to be disastrous. Um, and you need to celebrate, um, what little milestones that you can, if that meant getting up, that's a milestone you need to celebrate, get a cake, have some chocolate and have a proper celebration because it can be incredibly demoralizing if you are a successful person or somebody contributing to society in some way and that's taken away from a little bit from you. Participant 41.

My greatest thing would be that you need to not see it as a life sentence, that you need to always look for the positive and that you actually need to keep yourself as active as possible and to some extent push through some of that pain. Because I still live with pain. I'm not without pain on any day. It's the level of pain. Like if you're able to put it to the back of your mind and concentrate on something else, then to me that's fine. That's life, that's a normal day. Participant 22.

Um, try to stay positive. I think that's one of the main things and talk to people when you need to look after yourself, eat properly, get plenty of rest and just always maintain that positive outlook. I think the best way to deal with it. Participant 76.

Participant's advice is to talk or connect to other patients.

Talk people who, who have, who are in that situation, you know, one of my very early in the piece when I was diagnosed and I was just trying to get my head around it and I had, I had a colleague who I worked with who always knew, but um, she was just more an acquaintance than a really good friend and I happened to run into her in a shopping centre when I was really struggling and she came over and said, I hear you've got it. She said, look, I've got it. I've had it for four years, ra ra, this is what's happening. Come and come and have a chat. And that was one of the best things that ever happened. And we've become very, very good friends and support each other. And so, um, yeah, so you're just encouraged people to do that and to research and read as much as they possibly can. Participant 47.

I'd say, reach out for other people. You really need support. I think that's the most important thing because if you become locked in your home in misery. Participant 99.

Join a support group, whether it be online or a meeting that you might go to, a coffee meeting or something so that you don't feel so isolated in your disease. Just try and get your family to understand what you're going through. It's not easy, but if you explain to them how you feel and be open about it without feeling yourself worth is gone if you know what I mean. If you're feeling that you're putting yourself down, if you can get them to understand. Just do anything you can that works for you. Participant 46.

Participants advised to be mindful of emotional wellbeing and to seek mental health help or counselling support

Deal with your emotional stuff. So there's a lot of grief involved when you have, um, a chronic illness, all the things that you can't do and you want it to do and impact on relationships and things. So actually deal with your emotional stuff, get some help around that or whatever that might look like for you. Participants 45.

The first thing I would start is emotionally, like if you're angry about being diagnosed with RA or then just be angry about it. Like, you know, I think the worst thing that I found that's the beginning was everyone will pat you on the shoulder and say it's going to be okay. It's going to be okay, but you know what? It's not okay now if I'm feeling upset and then I should be allowed to feel upset or you just need to let that. Participant 56.

I think some counselling or support for new patients in that aspect would be really helpful because if they're going to not be able to ride a bike one day suddenly, or suddenly not be able to walk. That can be very hard. I used to do all those things and I can't do anymore. Understand that the aid does define you, it simply helps you. Participant 68.

Participant's advice more practical support such as eat healthy/exercise more.

Immediately change your nutrition to whole foods and even organic. It sounds like it's not worth the money, but if anything is worth putting money into its avoiding toxins going into your body. I would say immediately switch to organic diet and whole foods. Just avoid all the processed frozen crap that people have become addicted to and organize the gym or the hydro pool immediately. Get into that. Make that commitment to start forming all the habits the food habits, the healthy eating, the fitness habits, habit. Participant 62.

I think that yeah, just like general fitness, I feel like that's really important when it comes to like RA. Participant 15.

Um, I'm not sure. Um, I mean, I suppose just not to maybe look too far into the side effects of the medications before you tried them. Um, so that you don't, um, look for things before they happen because some of the, um, side effects can sound really distressing but they may or may not actually happen. So, um, I guess my advice would be wait and see. Participant 40.

Participant's advice is to consider more complimentary therapy

Hydrotherapy, hydrotherapy, hydrotherapy. I think and water. Water is incredible what it does for your joints. Just floating in it, swimming in it, moving in it and doing physio in that water is really important. I think also just not letting it become your identity, don't obsess over it. Participant 98.

I think looking after yourself over and above the medication. Holistically, I think that really helped me. Like I said before about sleeping well, nutrition, hydration, and alternate therapies, and complementary therapies. All of those things really do help. Looking at diet side of things as well, I think there could be more around that. Participant 60.

Certain people do not close their minds to alternative therapy as well. There is definitely a place for the medicine and for complementary therapy. It all ended up verified to get a second opinion. Participant 6.

Figure 10.1: Advice to other patients

Advice to patients in the future	**All participants**		***Physical limitations: no days***		***Physical limitations: few days***		***Physical limitations: some to most days***		***Symptoms: no to few days***		***Symptoms: some days***		***Symptoms: most days***		***Symptoms: all days***	
	n=100	**%**	**n=19**	**%**	**n=44**	**%**	**n=37**	**%**	**n=20**	**%**	**n=27**	**%**	**n=32**	**%**	**n=21**	**%**
Participant recommends that future patients educate themselves about rheumatoid arthritis	25	25.00	6	31.58	13	29.55	6	16.22	6	30.00	6	22.22	8	25.00	5	23.81
Participant recommends that future patients are assertive and ask lots of questions when with their specialist	23	23.00	5	26.32	9	20.45	9	24.32	6	30.00	6	22.22	8	25.00	3	14.29
Participant recommends that future patients are gentle on themselves and go at their own pace	16	16.00	0	0.00	13	29.55	3	8.11	1	5.00	5	18.52	6	18.75	4	19.05
Participant recommends that future patients remain positive and not let rheumatoid arthritis control them	15	15.00	5	26.32	2	4.55	8	21.62	6	30.00	2	7.41	3	9.38	4	19.05
Participant recommends that future patients talk to and connect with other patients and families	14	14.00	3	15.79	5	11.36	6	16.22	3	15.00	5	18.52	1	3.13	5	23.81
Participant recommends that future patients seek mental health help/emotional support	14	14.00	3	15.79	7	15.91	4	10.81	3	15.00	3	11.11	6	18.75	2	9.52
Participant recommends that future patients eat healthily/exercise more	10	10.00	2	10.53	4	9.09	4	10.81	2	10.00	3	11.11	4	12.50	1	4.76
Participant recommends that future patients try complementary therapies	10	10.00	1	5.26	4	9.09	5	13.51	1	5.00	3	11.11	4	12.50	2	9.52

Advice to patients in the future	**All participants**		***Affect: never to almost never***		***Affect: sometimes***		***Affect: very often to always***		***Social: all to most days***		***Social: some days***		***Social: no to few days***	
	n=100	**%**	**n=33**	**%**	**n=36**	**%**	**n=31**	**%**	**n=20**	**%**	**n=36**	**%**	**n=44**	**%**
Participant recommends that future patients educate themselves about rheumatoid arthritis	25	25.00	8	24.24	10	27.78	7	22.58	3	15.00	12	33.33	10	22.73
Participant recommends that future patients are assertive and ask lots of questions when with their specialist	23	23.00	7	21.21	9	25.00	7	22.58	2	10.00	10	27.78	11	25.00
Participant recommends that future patients are gentle on themselves and go at their own pace	16	16.00	8	24.24	3	8.33	5	16.13	4	20.00	5	13.89	7	15.91
Participant recommends that future patients remain positive and not let rheumatoid arthritis control them	15	15.00	5	15.15	6	16.67	4	12.90	5	25.00	4	11.11	6	13.64
Participant recommends that future patients talk to and connect with other patients and families	14	14.00	4	12.12	5	13.89	5	16.13	2	10.00	8	22.22	4	9.09
Participant recommends that future patients seek mental health help/emotional support	14	14.00	4	12.12	6	16.67	4	12.90	4	20.00	6	16.67	4	9.09
Participant recommends that future patients eat healthily/exercise more	10	10.00	3	9.09	5	13.89	2	6.45	2	10.00	4	11.11	4	9.09
Participant recommends that future patients try complementary therapies	10	10.00	3	9.09	4	11.11	3	9.68	3	15.00	4	11.11	3	6.82

Figure 10.1: Advice to other patients (Cont.)

Advice to patients in the future	**All participants**		***Occasional flare ups***		***Frequent flare ups***		***Aged 55 or older***		***Aged 35 - 54***		***Aged 18 – 34***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=31**	**%**	**n=51**	**%**	**n=18**	**%**
Participant recommends that future patients educate themselves about rheumatoid arthritis	25	25.00	14	25.00	11	25.00	4	12.90	16	31.37	5	27.78
Participant recommends that future patients are assertive and ask lots of questions when with their specialist	23	23.00	12	21.43	11	25.00	7	22.58	11	21.57	5	27.78
Participant recommends that future patients are gentle on themselves and go at their own pace	16	16.00	9	16.07	7	15.91	3	9.68	11	21.57	2	11.11
Participant recommends that future patients remain positive and not let rheumatoid arthritis control them	15	15.00	9	16.07	6	13.64	4	12.90	9	17.65	2	11.11
Participant recommends that future patients talk to and connect with other patients and families	14	14.00	6	10.71	8	18.18	6	19.35	7	13.73	1	5.56
Participant recommends that future patients seek mental health help/emotional support	14	14.00	7	12.50	7	15.91	1	3.23	9	17.65	4	22.22
Participant recommends that future patients eat healthily/exercise more	10	10.00	4	7.14	6	13.64	5	16.13	3	5.88	2	11.11
Participant recommends that future patients try complementary therapies	10	10.00	6	10.71	4	9.09	3	9.68	6	11.76	1	5.56

Advice to patients in the future	**All participants**		***Metropolitan***		***Regional or remote***		***Trade or high school***		***University***		***High SEIFA***		***Mid to low SEIFA***	
	n=100	**%**	**n=56**	**%**	**n=44**	**%**	**n=33**	**%**	**n=67**	**%**	**n=50**	**%**	**%**	**n=50**
Participant recommends that future patients educate themselves about rheumatoid arthritis	25	25.00	18	32.14	7	15.91	7	21.21	18	26.87	13	26.00	12	24.00
Participant recommends that future patients are assertive and ask lots of questions when with their specialist	23	23.00	16	28.57	7	15.91	7	21.21	16	23.88	11	22.00	12	24.00
Participant recommends that future patients are gentle on themselves and go at their own pace	16	16.00	5	8.93	11	25.00	5	15.15	11	16.42	8	16.00	8	16.00
Participant recommends that future patients remain positive and not let rheumatoid arthritis control them	15	15.00	9	16.07	6	13.64	4	12.12	11	16.42	9	18.00	6	12.00
Participant recommends that future patients talk to and connect with other patients and families	14	14.00	8	14.29	6	13.64	4	12.12	10	14.93	7	14.00	7	14.00
Participant recommends that future patients seek mental health help/emotional support	14	14.00	9	16.07	5	11.36	3	9.09	11	16.42	6	12.00	8	16.00
Participant recommends that future patients eat healthily/exercise more	10	10.00	6	10.71	4	9.09	3	9.09	7	10.45	6	12.00	4	8.00
Participant recommends that future patients try complementary therapies	10	10.00	5	8.93	5	11.36	1	3.03	9	13.43	7	14.00	3	6.00

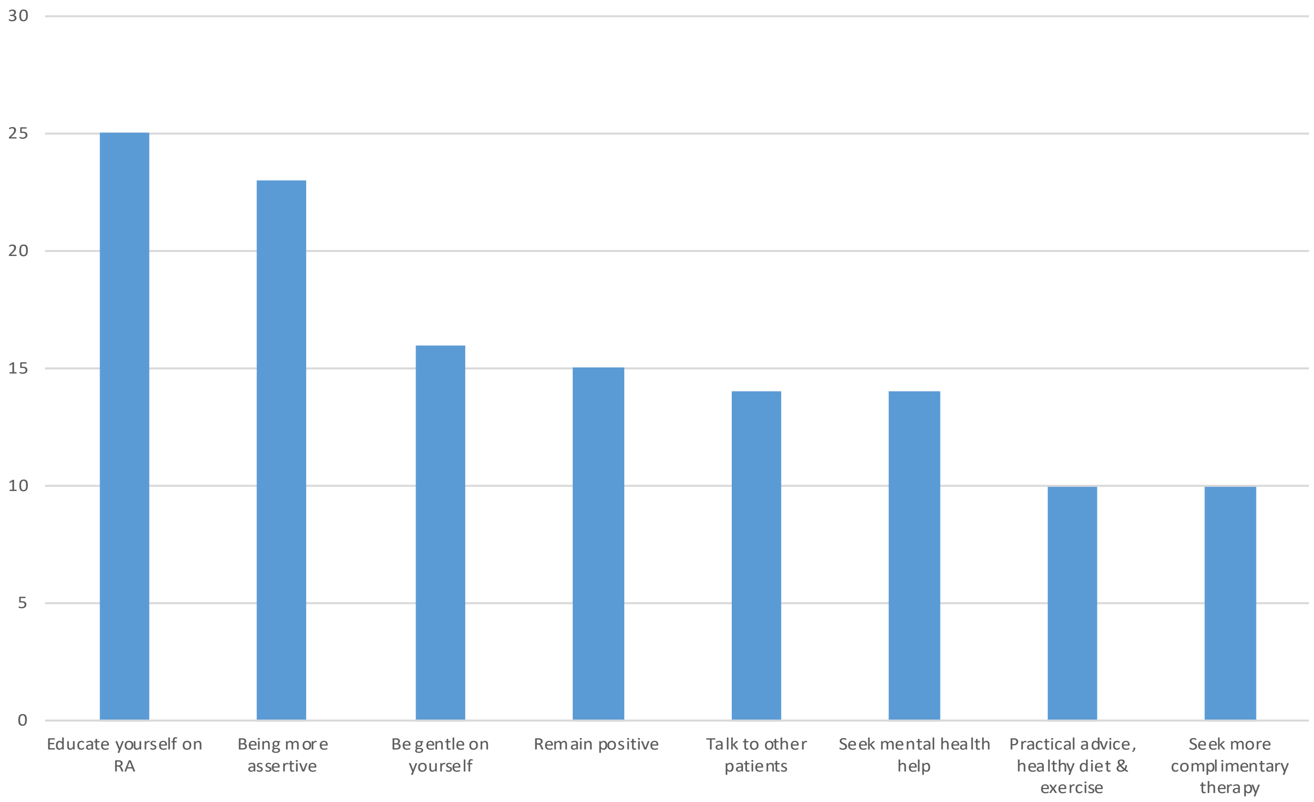


Figure 10.1: Advice to other patients

Section 11 Discussion

Background

The global prevalence of rheumatoid arthritis is estimated to be between 0.3% and 1% of the global population, it is thought to be more common in women and in developed countries[1].

In 2015, approximately 2% of the Australian population reported having rheumatoid arthritis amounting to around 407,900 people in total, with three quarters of those diagnosed being female[2]. The average age of onset is between 35-64, often during working age[2]. Within two years of diagnosis, around one third will stop work due to the rheumatoid arthritis[3].

In this PEEK study, the majority of participants were females (N=88, 88.00%), which is slightly higher than the proportion of women diagnosed in Australia. The majority of participants were aged between 35 and 64 (N=70, 70.00%), which is similar to the reported average age of onset.

There were 13,188 hospitalisations during 2014 due to rheumatoid arthritis, with those aged between 60-64 most likely to be hospitalised[4]. This amounts to 55 hospitalisations per 100,000 of the Australian population[4]. The number of hospital admissions for rheumatoid arthritis increased by 72% between 2005 and 2015[4].

Those with rheumatoid arthritis are at risk of developing further illnesses or conditions, known as comorbidities[3]. In Australia, 50% of this patient population also have coronary heart disease, compared to 18% of the Australian population who do not have rheumatoid arthritis[4]. Other health issues reported include back problems (32% in rheumatoid arthritis populations compared to 16% in the general population) and mental health problems (19% in rheumatoid arthritis populations compared to 11% in the general population)[4].

In this PEEK study the majority of participants described at least one other condition in addition to rheumatoid arthritis including anxiety, depression, chronic pain, sleep problems, and asthma.

A report by the Australian Institute of Health and Welfare reported quality of life measures indicating that despite higher rates of comorbidities, most people with rheumatoid arthritis reported that their health was either very good (29.4%) or good (29.2%), and 18.4% reported their health as poor. There were 52.3% of this population that reported only low levels of psychological distress, whilst 10.9% reported very high levels[5]. Most (32%) reported their pain levels as moderate or severe (28.1%), whilst 11.7% reported no pain[5].

The participants in this PEEK study reported overall poor general health on average (measured by SF36 General Health), and the pain levels were recorded as being moderate overall (measured by SF36 Pain).

Disease staging/disease types

According to the Australian Institute of Health and Welfare, there are three main clinical courses of rheumatoid arthritis[6]. Monocyclic effects one third of the rheumatoid arthritis population and is often characterised by a single episode or flare up and remission status reached within two years of onset[6]. Polycyclic is the most common type and effects 40% of the population[6]. This type is slow, progressive and marked by more frequent acute flare ups followed by periods of remission[6]. Over time, flare ups become more severe and longer lasting. Progressive rheumatoid arthritis accounts for 20% of cases is the most severe form. Symptoms are usually constant and cause quicker destruction to the body[6]. Out of all stages, progressive rheumatoid arthritis is the most likely to lead to a premature death, bone deformity and disfigurement[6]. Rheumatoid arthritis can also either be seropositive or seronegative[7]. This is when during the diagnosis phase the blood results show that someone is either positive or negative in antibodies thought to cause the symptoms of rheumatoid arthritis. Those with seropositive rheumatoid arthritis are more likely to go on to have worse symptoms and complications than someone with seronegative rheumatoid arthritis[7].

Participants in this PEEK study described their disease in terms of the severity disease with the majority describing moderate severity and the most common sites affected were hands/wrists/fingers and feet/ankles/toes. Participants most commonly reported that they had flare-ups once a month or more frequently .

Risk factors and symptoms

Rheumatoid arthritis is a long-term autoimmune disorder that affects the joints. Common symptoms of rheumatoid arthritis include swelling of the joints[4,8-10], as well as joint pain[8-13], which often happens early in the morning or after a period of inactivity[3]. Other common symptoms include fatigue[10,12], malaise, flu-like symptoms, and weight loss[14].

Over time, this inflammation spreads to the organs and leads to comorbidities such as cardiovascular disease and lung disease[3]. Inflammation can also affect the blood vessels, in particular the eyes, and this can lead to dry eyes[15]. Other comorbidities are common, mainly osteoporosis, heart disease, anaemia and infections such as chest infection and sepsis[3]. Depression and anxiety are also frequently reported in this population[16]. In this PEEK study, about a third of the participants described having anxiety or depression.

There is no known determinate cause of rheumatoid arthritis, it is best understood as a contribution of both biological and environmental factors[14]. Those with seropositive rheumatoid arthritis, where someone is tested positive for proteins in the rheumatoid factor blood test during the diagnosis phase, are shown to have a higher heritability risk than those with seronegative RA, with an average of 40% of heritability[17]. Studies involving identical twins show a 65% genetic component of rheumatoid arthritis, however combining all genetic factors only explain 16% of the total accountability for diagnosis, meaning there are other factors outside of heritability and genetics that may explain rheumatoid arthritis development[18]. For example, being female is shown to have a risk to developing rheumatoid arthritis, however heritability studies do not account for sex difference[17].

Environmental links to rheumatoid arthritis are somewhat limited, however there has been a link between smoking and rheumatoid arthritis, accounting for 20% of cases[18], not only has it been linked to an increased chance of developing rheumatoid arthritis, smoking may also decrease the effectiveness of arthritic medication[18]. Obesity is often linked to people with rheumatoid arthritis and is known to worsen inflammation and its associated pain, however it is not known whether obesity contributes towards the development of rheumatoid arthritis or that rheumatoid arthritis contributes towards obesity as an increase of sedentary behaviour caused by arthritic symptoms[19]. Outside of the individual, occupation is known is have an impact, with physical labour jobs contributing towards an increased chance of rheumatoid arthritis[20].

Studies by both Hulen et al[9] and Orbai and Bingham[13] identify the impact of the symptoms (specifically pain and fatigue) on the patient's functionality as the elements of RA that most concern patients.

The most common symptoms leading to diagnosis in this PEEK study was joint pain. Other reported symptoms included swelling, general pain, and having a flare-up. However, when asked about symptoms experienced before diagnosis about one fifth of participants reported that they had a complex diagnosis due to health care professional's uncertainty of rheumatoid arthritis, and another fifth of participants reported that their diagnosis was complex due to having other conditions, which often led to the symptoms of rheumatoid arthritis being seen as symptoms of these other, long-standing conditions.

Diagnostic pathway

The first point of call would usually be the general practitioner, who will assess any presenting symptoms, including examining the joints for warmth, tenderness and swelling, looking for rheumatoid nodules, and assessing whether the pain is symmetrical[3]. Further investigations are done at a hospital including X-rays of the affected area, MRI scans and blood tests to measure the rheumatoid factor antibody[3]. Diagnosis is primarily done by a rheumatology team and its consultants[3]. In this study, the majority were diagnosed by a rheumatologist followed by a general practitioner.

Tests include a full blood count, including testing for biomarkers, rheumatoid factor and anti-cyclic citrullinated[3]. Bloods will also indicate liver function. Hospital tests include X-rays of the affected area, usually the hands, wrists and feet[3]. A chest x-ray may be carried out if there are concerns about the heart function. A magnetic resonance imaging (MRI) test and/ or an ultrasound will be further carried out on the joints[3]. Assessing physical ability of day-to-day tasks may also be carried out according to severity or whether there is a social concern such as living alone or being socially isolated[15].

In relation to diagnostic tests for rheumatoid arthritis, participants in this PEEK study had between one and six diagnostic tests, two thirds had three or more diagnostic tests. Almost all the participants recalled having had blood tests (96.00%), and the majority recalled having a significant physical examination (87.00%). Almost two thirds had an x-ray and under a third had an MRI to diagnose rheumatoid arthritis.

Biomarkers

The most common diagnostic biomarkers are anti-cyclic citrullinated peptide and the rheumatoid factor[21]. These are found in blood tests during diagnosis. Rheumatoid factor is the oldest test, developed in the 1940[21]. Recently, anti-cyclic citrullinated peptide has become more popular due to its slightly stronger detectability of rheumatoid proteins[21]. These tests generally indicate whether the rheumatoid arthritis is seropositive or seronegative rheumatoid arthritis[21].

In a study by Matcham et al[22], many patients were said to value, and are more attentive to, health-related quality of life more than inflammatory biomarkers.

Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. Very few participants recalled having any discussions or having had any tests. Another question asked participants what biomarkers/genetic markers they had and almost half the participants in this study were not sure if they had any biomarkers for rheumatoid arthritis. The most commonly reported biomarker was C-Reactive protein followed by Rheumatoid factor.

Treatment

There is a "window of opportunity" during early diagnosis that can prevent rapid degeneration and help stabilise the condition. General assessment in the joints for swelling is recommended to be carried out three times a week[23]. Due to the high risk of developing cardiovascular disease, screening for this is recommended three times a year[23]. Toxicity of medications should be assessed every year, as well as general dosage monitoring[23].

Treatment for rheumatoid arthritis often involves a combination of drug therapy, biological treatments, pain relief and help to self-manage the condition[23]. Surgery is an option, but this is not common[23]**.** Surgery for rheumatoid arthritis usually falls into three categories: Arthroplasty (joint replacement), Osteotomy (removal of bone) and Arthrodesis (fusion of two bones). Arthroplasty usually occurs when there is extensive damage done to the cartilage and causes severe pain[24]. Side effects from performing arthroplasty include acute infection, chronic infection, joint dislocation, venous thromboembolism, soft tissue failure, and VTE prophylaxis[24]. Osteotomy (removal of bone) realigns the bones to reduce the pain caused by rheumatoid arthritis[25]. Side effects of this include: neurovascular injury, non-union, infection, loss of correction, and implant failure[25]. Arthrodesis (fusion of two bones) can be done when the damage of the tissue and cartilage between the two bones is too great[26]. Side effects from the surgery can include: failure of pain to resolve, failure for bones to heal, bones not healing in the correct position, infection, bleeding, blood clots, wound healing, nerve damage leading to numbness and protruding metalwork[26].

There were approximately one quarter of participants in this PEEK study that had one or more surgeries for their rheumatoid arthritis and most of these had a single surgery. The most common type of surgery reported per participant was arthroscopy, and the most common joint operated on was the knee.

Drug therapy is usually the first port of call[23]. Drugs usually prescribed for rheumatoid arthritis are a combination of anti-inflammatories, steroids, disease-modifying rheumatic drugs and pain relief[3]. Nonsteroidal anti-inflammatory drugs typically include naproxen or ibuprofen and these are meant to reduce inflammation. Common side effects include stomach upsets and ulcers with prolonged use[27]. Participants in this PEEK study described using paracetamol with few side effects but in general found it somewhat effective, codeine was used by half of the participants for pain relief, which was moderately effective with the most common side effects of sleepiness and constipation. The used of nonsteroidal anti-inflammatory drugs were moderately effective with stomach problems reported most frequently as a side effect.

Steroids or corticosteroids are prescribed to reduce swelling and pain[28]. Prednisolone is a common type of steroid prescribed for rheumatoid arthritis[28]. Common side effects include weight gain, hypertension, worsening of diabetes, reduced immunity, glaucoma and cataracts[28]. Three-quarters of the participants in this PEEK study had taken corticosteroids for rheumatoid arthritis, in general the participants scored their quality of life as "Life was average", and they found the treatment "effective".

The most commonly reported side effects in this group were trouble sleeping, bloating of the face and swelling of the abdomen.

Disease-modifying rheumatic drugs are often methotrexate, sulfasalazine, leflunomide or a combination of these[27]. These are strong medications and can cause liver, kidney and stomach problems[27]. Despite this, they can improve quality of life in people with rheumatoid arthritis[23]. In this PEEK study, the most common disease-modifying rheumatic drug taken was methotrexate and participants on average described their quality of life within the "Life was average" range, and the treatment moderately effective. The most common side effect reported from this treatment was feeling sick or nausea.

There are disease-modifying rheumatic drugs that are administered intravenously, through an artery, the spine or injected into the muscle or stomach, these are called biologic disease-modifying rheumatic drugs[27]. These are more potent, with the intention to slow the progression of inflammation. Common types of biologic disease-modifying rheumatic drugs are Abatacept**,** Anakinra, TNF inhibitors, and Tocilizumab[27]. Side effects of these are infection and skin reactions to the site entrance and abdominal pain[27]**.** Participants in this PEEK study most commonly reported taking adalimumab, etanercept, and tofacitinib. Infections and skin reactions at site of injections were the most frequently reported side effects.

Research has been conducted that focuses on the forms of treatment that patients prioritise, and the treatment regimens favoured by patients invariably aim to alleviate the symptoms that most impact the patients' functionality and quality of life. For example, Hulen et al[9] identify that patients prioritise physical therapy, social work, and mental health treatment. Similarly, a study conducted by Van Tuyl et al[29] suggested that treatment that targets patient-relevant outcomes, such as patients' perspectives on remission, would prove most agreeable to patients. The theme of patient-focused rheumatoid arthritis treatment can also be found in Voshaar et al[30], who found that involving patients in treatment decisions is positively correlated with medication adherence and treatment outcomes.

In this PEEK study, participants were asked to describe what needs to change in order for them to feel like their treatment has been effective. The most common theme was hat participants needed to experience a difference in pain levels. Also frequently reported was an increase in day-to-day functioning, and quality of life/ wellbeing. Some participants also specified that certain symptoms must reduce in order for a treatment to be effective. These symptoms most commonly included swelling and fatigue.

Asked whether their decision making has changed over time, participants in this PEEK study were most likely to describe that their decision making had changed, becoming more informed or assertive with their healthcare professional since diagnosis. This was followed by becoming more accepting of their treatment, but not through choice.

When asked what influences their decision to continue with a treatment regime, participants in this PEEK study most frequently reported that they normally continued with a treatment regime for a specific amount of time, with close to a third reporting that their treatment regime adherence was influenced by their specialist's advice, and a quarter of participants reporting that they adhered to a treatment regime as long as side effects were tolerable.

Allied health

Clinical guidelines recommend physiotherapy and occupational therapy for treating rheumatoid arthritis, alongside drug and biological treatments[3,23]. In this PEEK study, almost half the participants had physiotherapy and only a small proportion had occupational therapy. In general, participants found both of these interventions moderately effective.

Occupational therapy can be useful for assessing the risk of falls in people with rheumatoid arthritis who may live alone or may be otherwise living with frailty[15]. It may also help with joint protection and energy conservation[23]. Splints can be used by occupational therapists for the wrists and hands if the joints become swollen, although the effectiveness of this is debated[23].

Occupational therapy interventions that have strong evidence for rheumatoid arthritis symptom alleviation include aerobic exercise, resistive exercise, thermotherapy and aquatic therapy, and there is mixed evidence supporting the use of dynamic exercise, Tai Chi, and yoga[23,31-38].

Finally, foot care has been found to be effective in the later stages of the disease to prevent or reduce the severity of a flare up[23]. About a third of the participants in this study had seen a pordiatrist for rheumatoid arthritis, in general they found this treatment effective.

Complimentary therapies

In England[39] and Australia[6], prevalence of those with rheumatoid arthritis using complimentary therapies is approximately 38%. Comella et al[40] identifies that the global percentage of patients suffering from rheumatic diseases - such as rheumatoid arthritis - that use some form of complementary and/or alternative therapies is somewhere between 30% and 60%. Tamhane et al[41] estimate that worldwide, the prevalence of complementary and alternative therapy usage by rheumatoid arthritis sufferers is between 20% and 86%.

Patients who participate in complimentary therapy often do not communicate this with their medical professionals, and likewise, medical professionals do not usually speak about the use of complimentary therapy with their patients[39]. The relationship between complementary and alternative medicines and treatments prescribed by clinicians is often difficult. A study by Segan et al[42] points to the perceived need for community and alternative medicine and allied health approaches, but often adherence to complementary or alternative medicine treatment regimens are not disclosed by patients to their physician, which can hinder effective treatment as complementary and alternative therapy use can affect pharmacokinetics of conventional therapies[39].

There is evidence that evening primrose oil is being taken as a supplement for people with rheumatoid arthritis[43], however its side effects may interact with pain relief medication and may result in seizures, as well as allergy, hypersensitivity, occasional headaches, abdominal pain, nausea, loose stools[43].

Within this PEEK study, the most commonly-reported complementary therapy used was vitamins and supplements, the use of which was reported by over a third of the study population. Close to a quarter of participants reported that they did not use complementary therapies at all.

Clinical trials

A search of the Australia New Zealand Clinical Trials Registry was conducted 17 January 2019 (http://www.anzctr.org.au). The aim of the search was to give an over view of the clinical trials available to people in Australia with RA in the last five years. The search criteria used was: open to recruitment in the last 5 years (since 2014); disease investigated include “rheumatoid arthritis”; no healthy volunteers; recruitment status was recruiting, active not recruiting, completed, suspended stopped early; and countries of recruitment= Australia.

The search identified 23 studies of between 18 and 1822 participants. Fourteen of these studies included participants from other countries, these studies had between 124 and 1822 participants. There were nine studies that were conducted exclusively in Australia, these had between18 and 330 participants. Twenty studies were exclusive to rheumatoid arthritis, and three included rheumatoid arthritis among other diseases. There was one trial of 304 participants that was open to recruitment in all states and territories in Australia. By state or territory, there were 13 trials open in Queensland, 11 in New South Wales, 11 in South Australia, eight in Victoria, eight in Western Australia, four in Tasmania, two in the Australian Capital Territory, and one in the Northern Territory. Nineteen of the studies were drug clinical trials, two studies were observational, one study of surgery, one of complementary therapies and one of psychological aspects.

In this PEEK study there were very few participants that had discussions about clinical trials with their clinician and only five participants had taken part in a clinical trial, though close to three quarters would like to participate if there was a suitable trial for them.

Quality of life

There is a strong relationship between rheumatoid arthritis and negative experiences of mental health that impact on the quality of life of rheumatoid arthritis patients[16]. Psychiatric comorbidities such as depression and anxiety are prevalent in rheumatoid arthritis patients globally, with depression affecting up to 60% of rheumatoid arthritis patients, anxiety affecting up to 70% of rheumatoid arthritis patients, and almost 17% of rheumatoid arthritis patients experiencing major depressive episodes[44]. As well as affecting the patients' quality of life, psychiatric comorbidities such as depression can worsen treatment outcomes and drive discordance with healthcare professionals[12,45]. Psychosocial consequences of rheumatoid arthritis can include loss of self-identity, feeling negative emotions due disruption of social roles, and strain on time[46]. In this PEEK study, over a third of participants reported anxiety, and just under a third reported depression. Participants completed the Fear of Progression questionnaire, this measures the level of anxiety people experience in relation to their conditions, the average score was in the middle of the scale, indicating a moderate anxiety about their health.

The physical aspects of rheumatoid arthritis also influence quality of life, with social-financial life, work life, and sex life all affected by the effect that the physiological symptoms of rheumatoid arthritis have on functional capacity[8,9,47,48]. The financial burden imposed by rheumatoid arthritis medication can also affect quality of life [42].

The majority of participants in the PEEK study described one or more negative aspects on their quality of life as a result of rheumatoid arthritis, and over a third of these participants noted an impact on their physical limitations.

Costs associated with having rheumatoid arthritis were reported in this PEEK study. Close to half of the patient population reported that their income or family income had been reduced due to rheumatoid arthritis. More than half of the participants described changes that reduced income through quitting their job, reduced number of hours they worked or by taking leave without pay. For those that had a reduced income, for more than half this was moderately or extremely significant.

Participants in this PEEK study reported that relationships became more complex, and there was a stigma or a lack of understanding about their condition that negatively affected relationships. There was a loss of friendships, partly due to the inability to attend as many social events.

Matcham et al[22] identified lower health-related quality of life among rheumatoid arthritis patients than healthy populations, with rheumatoid arthritis having more impact on physical than mental health-related quality of life.

A study conducted by Hulen et al[9] identifies that the primary goal of patients' treatments was achieving normalcy and maintaining wellness; that is, treatment is effective insofar as it can improve quality of life through the restoration of functional capacity (stronger grip, increased muscle strength, restored arm function).

A study conducted by Gist et al[49] identifies a correlation between physical and mental stress and polysymptomatic distress levels in Australian patients with both RA and fibromyalgia. Patients with both rheumatoid arthritis and fibromyalgia recorded lower quality of life outcomes and higher medication use than patients with rheumatoid arthritis alone[49].

Health professional communication and multidisciplinary approaches

A study conducted by Sturgeon et al[45] identifies that trust and open, equal communication between patient and healthcare professional is integral to patients' decisions whether or not to take anti-rheumatic medication. According to a study by Segan[42], clear, empathetic communication (which involves adequate consultation length and continuity) and involvement in decision making is what is desired by rheumatoid arthritis patients of their interactions with healthcare professionals.

Successful health professional communication is perceived by patients as providing them with the necessary information that they need to take care into their own hands and become part of a multi-disciplinary care team [30].

Almost half of the participants in this PEEK study described having an overall positive communication experience, with the main reason being that their healthcare professional(s) was/were caring, supportive and understanding. When participants described other positive experiences, this related to their healthcare professional taking the time to answer participant questions and provide information. Where participants described a negative experience in regards to their healthcare professional communication, this related to healthcare professionals being dismissive and/or participants feeling ignored and participants reporting not being given enough time or support to ask questions.

Support/Psycho-social care

Patients with rheumatoid arthritis require support and psycho-social care that enables them to provide good self-management[30,50,51]. That is they require support so that they can support themselves.

Participants in this PEEK study reported ways of looking after themselves, both physically and mentally. To help manage or maintain their physical health, participants often spoke of listening to their body and resting as important to their quality of life.

A study by Dwarswaard et al[50] identifies three types of support that are essential foundations upon which the patient is able to support themselves: instrumental support (medical management of rheumatoid arthritis), psychosocial support (strengthen necessary emotional and psychological needs), and relational support (helpful interactions with others).

To help maintain or manage mental and emotional health, approximately one fifth of participants in this PEEK study reported visiting a mental health professional such as psychiatrists, psychologists, or counsellors. Other reported self-care activities involved receiving emotional support from family and friends, practicing mindfulness meditation, and remaining physically active.

When asked about expectations of future care and support, the most frequent response was that participants wanted increased understanding of rheumatoid arthritis within care and support systems, as well as within the general population, with other responses included a desire for more affordable complementary therapies, and increased access to or improvement of support groups/charity support.

Information and education

Among psychoeducational interventions for symptom alleviation, strong evidence supports the use of patient education and self-management, cognitive-behavioural approaches, multi-disciplinary approaches, and joint protection. Limited or mixed evidence supports the use of assistive technology and emotional disclosure[52-58].

A study by Segan et al[42] identifies experience-sharing with other rheumatoid arthritis patients as an important way that patients receive information about the disease.

In this PEEK study, close to half of the participants accessed information Australian rheumatoid arthritis charities. Participants in this PEEK study ranked most trusted information from non-profit or charities or patient organisations, followed by information from the government.

Information that healthcare professionals provide on how to explain symptoms, how rheumatoid arthritis will affect quality of life, cardiovascular risk, helpful physical exercises, and disease treatment options, is greatly valued by patients [50,51].

The majority of participants in this PEEK study were given information about treatment options, very few were given information about clinical trials, psychological/social support, and hereditary considerations genes or genomic biomarker information. The most common topics of information that was searched for independently was information about disease cause, treatment options, complementary therapies and disease management. The least searched for topic was hereditary considerations genes or genomic biomarker information. More than half of the participants searched for complementary therapies, how to interpret test results and dietary information following no information from health professionals.

A study by Barton et al[59] identifies bad communication between patients and healthcare professionals as the cause of potential mismatches between the goals of patients and the goals of their healthcare providers (e.g. the goal of healthcare providers may be to reduce inflammation and stall disease progression, without broader consideration of patient preferences).

Characterisation of this PEEK study patient population

The participants in this PEEK study population experienced a diagnosis characterised by symptoms including joint pain, swelling and general pain. Those with a complex diagnosis reported that this was due to health care professional's uncertainty of rheumatoid arthritis or due to having other conditions, which often led to the symptoms of rheumatoid arthritis being seen as symptoms of these other, long-standing conditions.

The condition was most commonly diagnosed by a rheumatologist or a general practitioner and this patient population had between one and six diagnostic tests, with two thirds having three or more diagnostic tests. Almost all the participants recalled having had blood tests and a physical examination, with very few participants recalling having any discussions in relation to biomarker or genetic tests.

This patient population was also characterised by comorbidities with almost all of the participants describing at least one other condition in addition to rheumatoid arthritis including anxiety, depression, chronic pain, sleep problems, and asthma.

The participants in this cohort experienced a range of treatment with approximately one quarter having one or more surgeries and the most common treatments being disease-modifying rheumatic drugs, paracetamol, nonsteroidal anti-inflammatory drugs. Almost half the participants had physiotherapy with only a small proportion had occupational therapy. Complementary therapy use was largely vitamins and supplements, and close to a quarter of this population reported that they did not use complementary therapies at all.

Very few participants in this study population reported having discussions about clinical trials with their clinician and only five participants had taken part in a clinical trial, while close to three quarters would like to participate if there was a suitable trial for them.

This is a population that explained that in order for them to feel like treatment is working for them, they needed to experience a difference in pain levels, as well as an increase in day-to-day functioning, and quality of life/ wellbeing.

In relation to quality of life, this cohort described one or more negative aspects on their quality of life as a result of rheumatoid arthritis, and over a third of these participants noted an impact on their physical limitations.

This is a patient population where almost half of the participants described having an overall positive communication experience, with the main reason being that their healthcare professional(s) was/were caring, supportive and understanding.

To help maintain or manage mental and emotional health, approximately one fifth of this patient population reported visiting a mental health professional such as psychiatrists, psychologists, or counsellors

This is a patient population that is grateful for the Australian health system and turning to the future, they are looking for more affordable treatments, for health professionals to be more forthcoming with information and to communicate with more compassion/empathy, and a general improvement in the understanding of rheumatoid arthritis within care and support systems.

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Section 12 Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas based on patient experience and feedback that, if improved, would increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to the rheumatoid arthritis community, these three areas are:

- Development of rheumatoid arthritis, health professional education with a specific focus on improving the time to diagnosis, and once diagnosed, to be able to be more forthcoming with information
- Development of rheumatoid arthritis-specific pain management information, support and care, so that pain is effectively managed through diagnosis, treatment and maintenance.
- Initiatives to increase awareness of the role of, and how to access allied health professionals to ensure patients have a holistic care plan

2019 Rheumatoid Arthritis metrics

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2019 rheumatoid arthritis metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1: Rheumatoid arthritis 2019 Metrics

Area of evaluation	2018 data	
Baseline health	**Mean**	**Median**
Physical functioning*	**48.90**	**47.50**
Role functioning/physical	21.25	0.00
Role functioning/emotional	**46.33**	**33.33**
Energy/fatigue*	27.35	25.00
Emotional well-being*	**63.04**	**64.00**
Social functioning*	49.88	50.00
Pain*	**41.25**	**40.00**
General health*	33.05	30.00
Health change	**49.75**	**50.00**
Percentage of participants that have accessed My Health Record	**38.00%**	
Percentage of participants that have a discussion about biomarkers/genetic tests	**11.00%**	
Knowledge of condition and treatments (Partners in Health)	**Mean**	**Median**
Knowledge	**24.06**	**25.00**
Coping*	13.72	14.00
Recognition and management of symptoms	**17.98**	**18.00**
Adherence to treatment	13.71	14.00
Total score*	**69.47**	**71.00**
Care Coordination and care received	**Mean**	**Median**
Communication*	**33.46**	**33.00**
Navigation*	22.23	21.50
Total Score*	**55.69**	**55.00**
Care coordination global measure	5.58	6.00
Quality of care global measure	**6.85**	**7.00**
Fear of progression	**Mean**	**Median**
Total Score*	**38.67**	**40.00**

*Normal distribution, use mean as measure of central tendency