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**Asthma  
Australian Study**

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**Thank you to each and every person that participated in this PEEK study,  
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# Summary of results

## Executive summary

There were 100 participants in this study from across Australia, who lived in all levels of socio-economic advantage or disadvantage. Most participants were women, and most participants were aged between 35 and 64. Most participants had asthma that could be better controlled.

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

Before diagnosis, this is a patient population that commonly experienced breathing difficulties, however a number of participants were too young when they were diagnosed and could not remember symptoms. The condition was most commonly diagnosed by a general practitioner and this patient population had between one and seven diagnostic tests, with two thirds having three or more diagnostic tests. The most common diagnostic tests were physical examination and spirometry tests, with very few participants recalling having any discussions in relation to biomarker or genetic tests.

This is a patient population that had very little discussion about their treatment options and who considered cost, side effects, quality of life and efficacy when making treatment decisions. Participants changed the way they made treatment decisions over time as they became more informed, assertive and changed life stages (e.g. having children, retirement).

Almost all the participants in this study used a reliever puffer, and a preventer puffer. Very few participants used monoclonal antibodies. Physiotherapy was only used by about a fifth of the participants. Complementary therapy use was largely relaxation techniques, while close to half did not report using complementary therapies at all.

Very few participants in this study population reported having discussions about clinical trials with their clinician and only eight 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 patient population that defined 'mild side effects' as those that they can self-manage, and do not interfere with daily life and 'severe side effects' as those that impact everyday life of the ability to conduct activities of daily living.

This is a study cohort that needed to experience less asthma symptoms to know that the treatment was working, in particular less tightness in chest and increase in ability to breathe.

This is a study cohort that commonly knew (or their parents knew) nothing or very little at all about asthma when they were diagnosed. Within this patient population, there was an awareness that asthma is controlled, it is managed by medication. Participants in this PEEK study found most of their information about asthma on the internet, from Asthma Australia, or from health professionals. They found information about medication or treatments to be most helpful and appreciated any information but needed adequate time with healthcare professionals to get information. To get information, they had a preference for talking to a health professional but appreciated combining this with other forms of written information. The timing of information was important, for some as they became adults they became more receptive, others were more receptive after a flare-up.

This is a patient population that experienced a negative impact on their quality of life due to asthma. However, they had an overall positive experience communicating with their healthcare professionals, and they experienced care and support mostly from their family and friends.

This is a patient population that would like to see more affordable treatments, more detail about current and emerging treatments. They would like to have more options, and personalised, comprehensive asthma management plans

The participants in this study would like to send the message to the health minister that the cost of treatment is a burden.

Participants in this study were grateful for access to treatment through Medicare, the healthcare system and the healthcare staff they have encountered.

## Sub-group variations

Go to the appendix attached to this section to see a matrix of sub-group variations

**Table S.1: Sub-groups with the most to the least variations**

Sub-group variations – most common by sub-group		
Sub-group	n=	As a % of all sub-group variations (n=209)
Moderately controlled asthma	34	16.27
Infrequent flare ups	32	15.31
Controlled asthma	31	14.83
Aged 18-34	29	13.88
Severe asthma	22	10.53
Regional or remote	16	7.66
Infrequent sleep deprivation	11	5.26
Aged 55 or older	11	5.26
Moderate to well controlled asthma	7	3.35
Frequent flare ups	6	2.87
Mid to low SEIFA	6	2.87
Poorly controlled asthma	5	2.39
Aged 35-54	5	2.39
Trade or high school	5	2.39
Occasional flare ups	4	1.91
University	4	1.44
Frequent sleep deprivation	2	0.96
High SEIFA	2	0.96
Non-severe asthma	2	0.96
Metropolitan	0	0.00

Table S2: Sub-groups variations – themes with the most to the least variations

Sub-group variations – most common by theme				
Themes with most to least variations	Number of themes reported	Number of sub-group variations	Number of possible sub-group variations across 18 subgroups	Number of sub-group variations (%)
What patients are grateful for in the Australian health system	5	15	90	16.67
Burden on family	6	17	108	15.74
Conversations about treatment	3	8	54	14.81
Information accessed	4	9	72	12.50
Expectations of future treatment	4	9	72	12.50
Impact on mental health	6	13	108	12.04
Cost considerations	6	13	108	12.04
Understanding of prognosis	6	12	108	11.11
Activities to maintain mental health	6	11	108	10.19
Understanding of disease at diagnosis	6	10	108	9.26
Impact on relationships	3	5	54	9.26
Injection at home support	5	8	90	8.89
Description of severe side effects	7	11	126	8.73
Impact on quality of life	5	7	90	7.78
Regular activities to maintain health	3	4	54	7.41
Description of mild side effects	6	8	108	7.41
Does decision-making change over time	4	5	72	6.94
Injection current preference	5	6	90	6.67
Message to decision-makers	5	6	90	6.67
Timing of information	6	7	108	6.48
Health professional communication	4	4	72	5.56
Considerations when making decisions about treatment	6	6	108	5.56
What needs to change to feel like treatment is effective	7	6	126	4.76
Information that has not been helpful	5	4	90	4.44
Information preferences	4	3	72	4.17
Information that has been helpful	7	5	126	3.97
Care and support received	6	4	108	3.70
Adherence to treatment	8	5	144	3.47
Expectations of communication	5	3	90	3.33
Symptoms leading to diagnosis	5	3	90	3.33
Expectation of future information	5	3	90	3.33
Expectations of future care and support	4	2	72	2.78

# Summary of results

## Section 1: Introduction and methodology

- Asthma is a chronic lung condition in which inflammation causes widespread narrowing of the airways. It is characterised by episodes of breathlessness, wheezing, chest tightness and cough, often referred to as flare-ups.
- Flare-up triggers may differ between patients, they may include; viral respiratory infections, exercise, exposure to allergens, environmental irritants, dietary intake, medicines and occupational exposures.
- In 2014-2015, 1 in 9 Australians reported having asthma.
- In 2015, there were 421 deaths in Australia due to asthma.
- 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 diagnosed with asthma throughout Australia participated in the study that included a structured interview and quantitative questionnaire. The PEEK study covers the experience of people living with asthma 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 2019 Australian Asthma PEEK Study is the largest mixed methods study of Asthma in Australia, in addition, it is the most comprehensive study detailing the experience of people with Asthma in the Australian health system

## Section 2: Demographics and study population characteristics

### Participants

One hundred participants with asthma were recruited into the study; 84 females (84.00%) and 16 males (16.00%), aged mostly between 35 and 64 (N=65, 65.00%).

Participants were included from across Australia. The majority of participants were from New South Wales (N=34, 34.00%), Queensland (N=21, 21.00%), and Victoria (N=16, 16.00%), and most live in major cities (N=66, 66.00%). Participants lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) ([www.abs.gov.au](http://www.abs.gov.au)), and more than half lived in an area with a high SEIFA score of 7 to 10 (more advantage) (n=56, 56.00%).

The majority of participants identified as Caucasian/white (n=92, 92.00%). The majority of participants had completed some university (N=56, 56.00%). and most were employed either full time (N=47, 47.00%) or part time (N=20, 20.00%). Approximately a third of participants (n=33, 33.00%) were carers to family members or spouses.

### Disease description

The **Asthma control test** is a five-item questionnaire that helps determine level of control that a person with asthma has with their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. The majority of the participants scored between 5 and 19 (n=74, 74.00%), which indicated that their asthma may not have been controlled, 21 participants (21.00%) scored between 20 and 24, indicating that asthma is reasonably well controlled and 5 participants (5.00%) score 25 indicating asthma that is under control.

Participants indicated the frequency of flare-up or asthma attack, the most common responses were 21 participants described a flare-up once a month (21.00%), 18 participants described a flare-up once a week (18.00%), and 18 participants described a flare up once a day (18.00%).

### 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 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 do not at all interfere 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 some of the time, and depressed and anxious some of the time.

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 slightly 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 moderately interfered with work or other activities.

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 slightly limited

The **"SF36 Role Energy/Fatigue"** scale measures the amount of energy or fatigue. On average the participants in this study had moderate energy/fatigue, that is they felt tired some of the time and have energy some 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.

The overall scores for **"SF36 Pain"** were in the middle of the scale, this indicated a moderate amount of pain and a moderate effect of pain on daily activities.

The overall scores for **"SF36 Health change"** were in the middle of the scale, this correlates to no health change over the past year. The overall score for **"SF36 General health"** was in the second lowest quintile, indicating poor general health.

## Section 3: Symptoms and diagnosis

### Symptoms

The most common symptoms experienced were coughing or wheezing attacks worsened by a respiratory virus, such as a cold or the flu (n=91, 91.00%), trouble sleeping (caused by shortness of breath, coughing or wheezing) (n=87, 87.00%) and shortness of breath (n=85, 95.00%). Whistling or wheezing sound when exhaling (n=71) and chest tightness or pain (n=72) were experienced by most participants. The median quality of life while experiencing symptoms was in the "Life was distressing" range for all of these symptoms.

### Symptoms leading to diagnosis

The most common symptom leading to diagnosis was difficulty breathing (n=39, 39.00%). There were 27 participants (27.00%) who described having been too young to remember, and ten participants (10.00%) who described having bronchitis or a chest infection. Other symptoms leading to diagnosis included recalling hospitalisation but being too young to remember (n=8, 8.00%).

**Diagnostic tests**

Of the 92 participants who could recall the diagnostic tests, participants had between one and seven diagnostic tests, most commonly three tests (n=22, 23.91%) or five tests (n=21, 22.83%) (median = 3.00, IQR = 3.00). The most common diagnostic test was a physical examination (n=76, 82.61%), followed by spirometry tests (n=69, 75.00%).

**Time from diagnostic tests to diagnosis**

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis, 78 participants (78.00%) were able to recall the length of time, more than half of these were diagnosed immediately (n=50, 64.10%), however for 13 participants (16.67%) the result took 4 weeks or more.

**Diagnosis provider and location**

Of the 81 participants who could recall who gave the asthma diagnosis, the majority of participants were given their diagnosis by a general practitioner (n=69, 85.19%). Of the 93 participants who could recall where the diagnosis was given, most received their diagnosis at the General Practice (n=56, 60.22%).

**Understanding of disease at diagnosis**

Participants were asked in the structured interview how much they knew about their condition at diagnosis. There were 28 participants (28.00%) that described themselves or their parents knowing nothing about asthma upon diagnosis and this was the most common theme. There were 22 participants (22.00%) noting that themselves or their parents knew very little about asthma. There were 13 participants (13.00%) that described that they knew of asthma but not in great detail due to a family member or friend with asthma, and 9 participants (9.00%) that knew a good amount about asthma due to a family member or friend with asthma.

**Emotional support at diagnosis**

Participants were asked in the online questionnaire how much support that they/their family received between diagnostic testing and diagnosis. Approximately a third of participants had enough support (n=32, 32.00%), 44 participants (44.00%) had no support, and 24 participants (24.00%) had some support but it wasn't enough.

**Information given at diagnosis**

Participants were asked in the online questionnaire how much information they/their family receive at diagnosis. Approximately a third of participants had enough information (n=33, 33.00%), 44 participants (44.00%) had some information but not enough and 23 participants (23.00%) had no information.

**Costs at diagnosis**

Of the 32 participants who could recall out of pocket costs, the majority had no out of pocket costs at diagnosis (n=20, 62.50%), and 12 participants who paid between \$40 and \$1,200 in out of pocket expenses. In the follow-up question about the burden of costs at diagnosis, for 33 participants (41.25%) the cost was either slightly significant or not significant at all. For 23 participants (28.75%) the out of pocket expenses were moderately significant, and for 24 participants (30.00%), the burden of out of pocket expenses were moderately or extremely significant.

**Genetic tests and biomarkers**

Participants answered questions in the online questionnaire about biomarkers, genomic and gene testing. Almost all the participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=97, 97.00%). The majority of participants have not had any testing but would like to (n=83, 83.00%). The majority of participants were not sure if they had specific biomarkers (a total of 93, 93.00%), however while not sure of any specific biomarkers, 55 participants (55.00%) had a family history of asthma and/or allergies.

**Disease description**

The **Asthma control test** is a five-item questionnaire that helps determine level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. The most common response for each of the questions is as follows: asthma kept participants from getting work done some of the time (n=34, 34.00%); participants has shortness of breath 1-2 times a week (n=33, 33.00%); participants sleep was disturbed by asthma symptoms 2-3 nights a week (n=33, 33.00%); participants used reliever medication 1-2 times a day (n=30, 30.00%); and an equal number of participants rated their asthma control as somewhat controlled (n=37, 37.00%) or well controlled (n=37, 37.00%).

The **Asthma control test score** is a total of the responses from each question, it ranges from 5 (poorly controlled) to 25 (under control). The majority of the participants scored between 5 and 19 (n=74, 74.00%), which indicated that their asthma may not have been controlled, 21 participants (21.00%) scored between 20 and 24, indicating that asthma is reasonably well controlled and 5 participants (5.00%) score 25 indicating asthma that is under control.

**Frequency of flare-up or asthma attack**

Participants described the frequency of flare-up or asthma attack, the most common responses were 21 participants who described a flare-up once a month (21.00%), 18 participants who described a flare-up once a day (18.00%), and 18 participants who described a flare-up once a week (18.00%).

**Time with symptom before seeking medical attention**

Participants noted in the online questionnaire the symptoms the length of time they have waited to seek medical attention or schedule an appointment with GP due to a list of symptoms. "Severe shortness of breath, chest tightness or pain, and coughing or wheezing" was the symptom where most participants had sought medical attention (n=95, 95.00%), and "Low peak flow readings when using a peak flow meter" was the symptom were only half of the participants had sought medical attention (n=50, 50.00%).

The most common symptoms that participants sought medical attention quickly were "The inability to speak more than short phrases due to shortness of breath and "Symptoms that fail to respond to use of a quick-acting (rescue) inhaler". The symptoms where participants waited for two days or longer for medical attention were "Severe shortness of breath, chest tightness or pain, and coughing or wheezing" and "Symptoms that fail to respond to use of a quick-acting (rescue) inhaler".

**Common ways of dealing with a flare-up or asthma attack**

Participants noted in the online questionnaire the common ways that they deal with an asthma flare-up or attack. Almost all participants used a puffer (n=95, 95.00%), the next most common way to deal with an attack was to try to relax (n=43, 43.00%).

**Understanding of prognosis**

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common theme was that their condition is controlled and managed with medication (n=34, 34.00%). There were 15 participants (15.00%) that understood the relationship with allergies and triggers, and the need to manage those to maintain their health, and 14 participants (14.00%) that understood that asthma is a lifelong condition that will need to be managed. There were 8 participants (8.00%) that understood asthma as a serious, scary or possibly life-threatening condition, and 8 participants (8.00%) understood that asthma is not controlled and it is complex to manage.

#### Section 4: Experience of health professional communication

##### Discussions about treatment

The most common treatment discussion described was having had little discussion with only one option or approach presented and this was described by 65 participants (65.00%). This was followed by participants not being able to remember due to childhood diagnosis (n=19, 19.00%); and options being presented and being able to participate in decision making (n=16, 16.00%).

##### Decision-making

The most reported component of decision-making described was taking into account the side effects and this was described by 28 participants (28.00%). This was followed by a combination of cost, side effects or effectiveness (n=18, 18.00%); efficacy (n=17, 17.00%); following doctor's advice or does not make active decisions (n=13, 13.00%); quality of life only (n=9, 9.00%) and cost of treatment (n=8, 8.00%).

##### Changes in decision-making

Participants were asked if the way they made decisions had changed over time. There were 72 participants (72.00%) that felt the way they made decisions about treatment had changed over time, and 13 participants (13.00%) that described decision-making not changing. Where participants had changed the way they make decisions, this was primarily in relation to becoming more aware of their health (n=38, 38.00%); becoming more informed, assertive or considered (n=24, 24.00%); and taking into account the impact on their family (n=9, 9.00%).

#### Section 5: Experience of treatment

##### Main provider of treatment

The general practitioner was the main provider of asthma treatment for the majority of participants (n=74, 76.29%), followed by a respiratory specialist (n=20, 20.62%).

##### Access to health professionals

Almost all participants had access to a general practitioner (n=99, 99.00%), and more than half of the participants had access to a pharmacist (n=61, 61.00%), and a respiratory specialist (n=60, 60.00%), for the treatment of their asthma.

##### Respect shown

Half of the participants indicated that they had been treated with respect throughout their experience (n=51, 51.00%), 41 (41.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 8 (8.00%) participants felt they had not been treated with respect throughout their treatment.

##### Healthcare system

While two-thirds of the participants had private health insurance (n=67, 67.00%), only a third were asked if they want to be treated as a public or private patient (n=34, 34.00%), in addition, less than half were asked if they had private health insurance (n=45, 45.00%).

The majority of participants had been hospitalised for asthma (n=81, 81.00%), and were mostly treated as public patients (n=51, 62.96%), and most were treated in the public hospital system (n=60, 74.07%). Participants had been hospitalised most commonly two to five times through-out their life (n=35, 43.21%), and the most common length of admission was one day (n=23, 28.40%).

**Affordability of healthcare**

The majority of participants never or rarely canceled their appointments due to cost (n=64, 64.00%), while four (4.00%) participants had to cancel often or very often. The majority of participants (n=61, 61.00%) never or rarely could not fill prescriptions due to cost, while 13 (13.00%) often or very often had difficulty filling these prescriptions due to cost. Most participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=65, 65.00%). Ten participants (10.00%) had to pay for additional carers for self or family.

**Reduced income due to asthma**

A quarter of participants (25.00%) had a reduced family income due to asthma, for 15 of these participants (60.00%), the burden of this reduced income was extremely or moderately significant.

**Cost of asthma**

Participants estimated the amount they spend per month on asthma. The most common amount was less than \$50 (n=32, 32.00%), there were five participants who spent more than \$500 a month. The amount spent was a significant or moderately significant burden for 20 (20.00%) participants.

**Changes to employment status**

Two thirds (n=66, 66.00%) of the participants of this PEEK study have made changes to their employment that has resulted in a reduced income (taking leave without pay, reducing hours or quitting their job). There were 66 (66.00%) participants with a main partner or carer, of these, ten partners or main carers made changes to their employment that has resulted in a reduced income (15.16%) taking leave without pay, reducing hours or quitting their job).

**Treatment: medications**

Almost all participants used a reliever puffer like Airmol or Ventolin (n=98, 98.00%). The next most common treatment was a preventer puffer like Breo or Flutiform (n=91, 91.00%). Very few participants used monoclonal antibodies where five participants (5.00%) used Omalizumab and four (4.00%) used Mepolizumab.

Treatments were prescribed by general practitioners more often than by respiratory specialists for almost all of the treatments, only non-steroid preventer (Montelukast, Singulair), and long-acting reliever (Spiriva Respimat) were prescribed by a respiratory specialist more often.

The most commonly used medication, reliever puffer (e.g. Airmol, Ventolin) (n=98) were used for more than ten years by the majority of participants (n=78, 79.59%). Preventer puffer (e.g. Breo, Flutiform) was used by 90 participants, and was most commonly used for more than ten years (n=29, 32.22%).

Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Median quality of life scores ranged from 3.50 to 5.00, that is, all quality of life scores were within the 'Life was a little distressing' to 'Life was good' range. The treatment that scored the highest median quality of life was preventer puffer (Breo, Flutiform, Fluticasone/Salmeterol Cipla, Seretide or Symbicort) (median =5.00, IQR =1.50) which is in the "Life was good range". The treatment that scored the lowest median quality of life was medication for sudden or severe asthma flare-up (Panafcort, Panafcortelone, Solone, Redipred or Predmix) (median = 3.50, IQR = 1.25) this is in the "Life was a little distressing range. The most commonly used treatment, reliever puffer (Airmol, Asmol, Bricanyl or Ventolin) (n=98), the median quality of life was 4.50 in the life was average to life was good range.

Participants rated how effective they felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored a median score between 3.00 and 5.00, that is between moderately effective and very effective. The most commonly used treatments, reliever puffer (Airmol, Asmol, Bricanyl or Ventolin) (n=98) and preventer puffer (Breo, Flutiform, Fluticasone/Salmeterol Cipla, Seretide or Symbicort) (n=91) had a median effectiveness score of 4.00, in the "effective" range.

**Supportive care: Physiotherapy**

There were 17 (17.00%) participants who were prescribed physiotherapy. The majority were prescribed physiotherapy by their general practitioner (n=11, 64.71%). The median quality of life score was 3.00, in the 'Life was a little distressing' range. The median effectiveness score was 3.00, in the 'moderately effective' range.

**Treatment: complementary therapies**

Participants were asked in the online questionnaire about complementary therapies used (relaxation, massage and acupuncture). The most commonly used complementary therapy was relaxation techniques (n=44), the median quality of life (4.00) for this was in the 'life was average' range, and the median effectiveness (median =3.00) was rated as 'somewhat effective'. There were 11 participants that used massage therapy, the median quality of life (median =4.50) was in the 'life was average to good range', and the median effectiveness (median =4.00) was in the 'effective' range. There were eight participants who used acupuncture for asthma, the median quality of life was 4.00, in the 'life was average' range, and the median effectiveness (median =2.50) was rated in the 'somewhat to moderately effective' range. There were no side effects from any of the complementary therapies.

**Clinical trials**

There was a total of 15 participants (15.00%) that had discussions about clinical trials, either by bringing up the topic themselves (n=9, 9.00%) or their doctor bringing up the topic (n=6, 6.00%). There were eight participants (8.00%) who had taken part in a clinical trial, and 72 (72.00%) who would like to take part in a clinical trial if there was a suitable one.

**Description of mild side effects**

The most common description of 'mild side effects' was those that they can self-manage and do not interfere with daily life (n=42, 42.00%). Other descriptions of 'mild side effects' include shakiness or rapid heart rate associated with medication (n=22, 22.00%) and mild side effects such as headaches with or without nausea (n=11, 11.00%).

**Section 6: Information and communication****Access to information**

The most common place information was accessed was google or the internet in general (n=44, 44.00%), and this was followed by Australian charities such as Asthma Australia (40, 40.00%). There were 31 participants (31.00%) that described accessing information through interactions with their specialist general practitioner or other healthcare professional and 18 participants (18.00%) that described accessing information through pamphlets from their specialist general practitioner or other healthcare professional.

**Information that has been helpful**

The most common type of information found to be helpful by 25 participants (25.00%) was information about medication or treatment options, and this was followed by talking to a doctor or specialist (21, 21.00%). There were 11 participants (11.00%) that described information from Australian charities as being helpful, and there were 8 participants (8.00%) that described no particular information as being especially helpful. Other types of information described as being helpful included pamphlets, printed information and fact sheets (n=8, 8.00%), and information about triggers (n=8, 8.00%).

**Information that has not been helpful**

Participants were asked if there had been any information that they did not find to be helpful. The most common response was that they had not come across unhelpful information (39, 39.00%), and this was followed by information from healthcare professionals when they do not take time, do not know your case or do not know a lot about asthma (22, 22.00%). There were 15 participants (15.00%) that described other people giving their opinion as not being helpful, 12 participants (12.00%) that described misinformation about treatments and treatment indication as not being helpful, and 9 participants (9.00%) that described deciding for themselves what is not 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. Overall, the most common theme was talking to someone (n=45; 45.00%) which included participants that described talking to someone as first choice (n=32, 32.00%) and a preference for talking to someone plus online information (n=17, 17.00%). This was closely followed by 43 participants (43.00%) that described a preference for online information.

### Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was during adulthood, often when they were ready to take responsibility for their own health (n=27, 27.00%) and this was followed by participants describing being most receptive to information during a flare-up or exacerbation of their asthma (n=22, 22.00%). There were 16 participants (16.00%) that described being receptive to information during pre-teen or teenage years (16.00%). There were 8 participants (8.00%) that described being receptive from diagnosis so that they can manage and understand their condition, 8 participants (8.00%) who were receptive at all times, and 8 participants (8.00%) who were receptive when they are feeling well (when not having difficulties).

### 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 having an overall positive experience (n=43; 43.00%). There were 30 participants (30.00%) that described an overall negative experience, for 15 participants (15.00%) this was due to not having enough time or attention with healthcare professionals, and for 8 participants (8.00%) this was due to contradictory information from healthcare professionals. There were 13 participants (13.00%) that described both positive and negative experiences.

### Knowledge and confidence

#### Partners in health – overall score

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.

The overall scores for the **“Partners in health: knowledge”** (median =26.00, IQR = 7.00), **“Partners in health: adherence to treatment”**, and **“Partners in health: recognition and management of symptoms”** (median = 20.00, IQR = 5.00) were in the highest quintile, indicating very good knowledge, very good recognition and very good management of symptoms adherence to treatment (median =15.00, IQR =3.00). The median scores for the **“for Partners in health: coping”** (median = 16.50, IQR = 8.00), and **“Partners in health: total score”** (median = 76.00, IQR= 12.25) were in the second highest quintile indicating good coping, and good overall knowledge and confidence for managing their health.

#### Information given by healthcare professionals

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about treatment options (72.00%), disease management (55.00%) and information about allergies (32.00%) were most frequently given to participants by healthcare professionals, and information about hereditary considerations genes or genomic biomarker information (2.00%), clinical trials (3.00%) and complementary therapies (7.00%) were given least often.

#### Information searched for independently

Information about treatment options (53.00%), disease management (41.00%) and information about allergies (39.00) were most often searched for independently by participants. Psychological/social support (14.00%), hereditary considerations genes or genomic biomarker information (15.00%), and clinical trials (17.00%) were least searched for.

**Information gaps**

The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials (83.00%), hereditary considerations genes or genomic biomarker information (83.00%), and psychological/social support (78.00%). Participants were given most information either from healthcare professionals or independently for treatment options (87.00%). Disease cause was the topic that was most searched for independently following no information from health professionals (26.00%), followed by complementary therapies (n=25.00%).

**Most trusted information sources**

Participants were asked to rank which information source that they most trusted. Across all participants, information from the government were most trusted, followed by information from non-profit or charities or patient organisations. 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. There were 26 (26.00%) participants that had accessed "My Health Record", 66 (66.00%) had not, two participants did not know what it is (2.00%), and six (6.00%) were not sure. Of those that had accessed "My Health Record", five participants (19.23%) found it good or very good, seven (26.92%) found it acceptable, and 14 (53.85%) found it poor or very poor.

**Section 7: Experience of care and support****Care coordination**

A Care Coordination questionnaire within the online questionnaire was completed by participants. 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.

Overall, the participants in this PEEK study had a median score in the second highest quintile for "**Care coordination: Navigation**" (mean = 23.82, SD = 5.43), and a median score in the second highest quintile for "**Care coordination: Care coordination global measure**" (median = 7.00, IQR = 4.00), and "**Care coordination: Quality of care global measure**" (median = 7.00, IQR = 3.00), indicating good navigation of the healthcare system, overall care coordination and overall quality of care. The mean scores for "**Care coordination: Communication**" (mean = 37.06, SD = 10.85), and "**Care coordination: Total score**" (mean = 60.88, SD = 13.79) were in the middle of the scale indicating moderate communication and overall experience of care coordination.

**Experience of care and support**

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common description of care and support was support from family and friends (n=56, 56.00%). This was followed by receiving support from health professionals (general practitioner or specialist) (n=15, 15.00%), through charities (primarily Asthma Australia (n=10, 10.00%), and support from health professionals (nurses) (n=8, 8.00%). There were 9 participants (9.00%) who did not receive any care or support, and an additional 9 participants (9.00%) did not receive any additional support however they did not feel as though they needed any as they can manage on their own.

## Section 8: Experience of quality of life

### Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 78 participants (78.00%) that described a negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included reduced capacity for physical activity (n=27; 27.00%), emotional/psychological strain (n=25; 25.00%), not being able to participate in hobbies or social activities to avoid triggers or overexertion (n=21, 21.00%) and an overall negative impact on quality of life (n=21, 21.00%). There were 21 participants (21.00%) that reported minimal impact on quality of life.

### Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotion and mental health. There were 22 participants (22.00%) who described that their mental health was not affected. The most common way that participants reported managing their mental and emotional health was by consulting a mental health professional (n=19; 19.00%). There were 15 participants (15.00%) that described mindfulness, meditation or self-awareness. Other common themes included physical exercise to manage emotions (n=13; 13.00%), help from family and friends (n=13; 13.00%) and coping strategies such as remaining social, lifestyle changes and participating in hobbies (n=12; 12.00%).

### Regular activities to maintain health

In the structured interview, participants were asked what some of the things were they needed to do every day to maintain their health. The most common way that participants reported managing their health was by complying with treatment (n=60; 60.00%). There were 32 participants (32.00%) that described being aware of triggers and preventing the impact of triggers and 18 (18.00%) that described the benefits of being physically active.

### Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 46 participants (46.00%) that described a negative impact on relationships, 49 participants (49.00%) that reported no impact on relationships. The most common themes in relation to having a negative impact on relationships included change in dynamics of relationships due to anxiety in relation to exacerbations or physical limitations (n=22; 22.00%), and stress on relationship or inability to cope (n=12; 12.00%).

### Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 35 participants (35.00%) that felt there was an additional burden and 55 participants (55.00%) who felt there was no additional burden overall. Where participants described no additional burden, 33 participants (33.00%) that reported no additional burden but did not specify a reason, 11 participants (11.00%) felt like they had required little assistance and 10 participants (10.00%) that felt that their condition was not a burden at the moment but is likely to be in the future. Where participants described there was an additional burden, this was primarily due to extra duties or responsibilities for family (n=16; 16.00%), a burden on family in general (n=12, 12.00%), and due to mental or emotional strain (n=8; 8.00%).

### Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 53 participants (53.00%) that spoke about struggling with the costs of treatments, and 38 participants (38.00%) that reported needing to take time of work. Other costs described cost of general practitioner and specialist appointments (particularly repeat scripts, travel time/cost) (20.00%), indirect costs in relation to their ability to make life choices (12.00%), and family members needing to take time of work (10.00%). There were 12 participants (12.00%) who described that they were not struggling with costs.

**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. Summary statistics for the entire cohort are displayed in Table 8.2. Overall the entire cohort had a median total score of 31.00 (IQR = 14.00), which corresponds to low levels of anxiety.

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

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was participants expecting that treatments are more affordable, noting that cost is currently a burden (n=45, 45.00%), and this was followed by participants expecting that treatments are easier to administer with less disruption (for example injections or tablets) (n=39, 39.00%). There were 17 participants (17.00%) that recommended that treatments have less side effects, often in relation to long term side effects of steroids and 9 participants (9.00%) that called for more effective treatments, particularly in relation to immediate and longer-lasting relief.

**Expectations of future information**

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common themes were participants recommending more detailed information about current and emerging treatments (including research and clinical trials (n=18, 18.00%), and participants recommending more information to help the community understand the severity of asthma and common triggers (n=18, 18.00%). This was followed by participants recommending comprehensive information in a language that is easy to understand (without jargon or overly scientific language) (n=16, 16.00%). There were 14 participants (14.00%) that did not have any recommendations or were satisfied with information. There were 10 participants (10.00%) that recommended information or tools to help them manage and monitor their asthma and its side effects.

**Expectations of future communication with healthcare professionals**

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were participants experiencing good communication with health professionals (n=24, 24.00%), and participants recommending that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans (n=24, 24.00%). These were followed by participants recommending that health professionals have a better understanding of the severity of asthma, emergency care, and how to manage asthma (n=17, 17.00%). There were 14 participants (14.00%) that recommended health professionals listening to patients and not dismissing their concerns, or that they have expertise in their own. There were 14 participants (14.00%) that recommended that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis.

**Expectations of future care and support**

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was participants not having any suggestions, or reporting being content with the information received (n=15, 15.00%), followed by participants recommending more long-term asthma management and treatment plans and/or holistic care (n=12, 12.00%). There were nine participants (9.00%) that recommended more community-based support, specifically peer support including support groups and information sessions, or family peer support, and 8 participants (8.00%) that recommended more opportunities to access specialists in asthma for treatment, information and support.

**What participants are grateful for in the health system**

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for access to treatment through Medicare (n=24, 24.00%) This was followed by being grateful for the entire health system (n=19, 19.00%), being grateful for healthcare staff (n=18, 18.00%), being grateful that the health system is low cost or free (n=17, 17.00%) and being grateful for access to hospital care through Medicare (n= 8, 8.00%).

**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. The most important aspects reported were shortness of breath and coughing or wheezing attacks worsened by a respiratory virus. The least important was whistling or wheezing sound when exhaling.

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

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=66, 66.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

**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.

**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**

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was that the cost of treatment is a burden (n=35, 35.00%), followed by the message that there should be equitable funding, with specific focus on the need for long-term treatment options and cost-effective management (n=23, 23.00%). This was followed by the message that there needs to be more education within the general community so that the severity of the condition is understood (n=22, 22.00%). There were 17 participants (17.00%) described the message that there needs to be more education for medical professionals to know how to best treat asthma and empower patient awareness of treatment options or services available. The message that there should be specialist treatments or access to specialist help for management and care plan development was reported by 13 participants (13.00%).

**Section 10: Advice to other patients and families**

In the structured interview, participants were asked what advice they would give to other patients and families in the future. The most common advice was to be assertive and ask a lot of questions (n=22, 22.00%), followed by take medication (n=19, 19.00%). There were 12 participants (12.00%) who advised to get as much information as you can, and 9 participants (9.00%) advised to get as much information as possible and to understand triggers (9.00%).

# Sub-group variations: appendix





# Section 1 Introduction and methodology

## Section 1: Introduction and methodology

### Summary

- Asthma is a chronic lung condition in which inflammation causes widespread narrowing of the airways. It is characterised by episodes of breathlessness, wheezing, chest tightness and cough, often referred to as flare-ups.
- Flare-up triggers may differ between patients, they may include: viral respiratory infections, exercise, exposure to allergens, environmental irritants, dietary intake, medicines and occupational exposures.
- In 2014-2015, 1 in 9 Australians reported having asthma.
- In 2015, there were 421 deaths in Australia due to asthma.
- 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 diagnosed with asthma throughout Australia participated in the study that included a structured interview and quantitative questionnaire. The PEEK study covers the experience of people living with asthma 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 2019 Australian Asthma PEEK Study is the largest mixed methods study of asthma in Australia, in addition, it is the most comprehensive study detailing the experience of people with asthma in the Australian health system

**Introduction**

Asthma is a chronic lung condition in which inflammation causes widespread narrowing of the airways. It is characterised by episodes of breathlessness, wheezing, chest tightness and cough, often referred to as flare-ups<sup>1</sup>. The symptoms of asthma are variable in presence and severity. They may be experienced in a mild, intermittent form or be persistent and severe<sup>1</sup>. Symptoms are usually non-permanent and may be reversible with or without medication. A number of factors have been identified as triggers for asthma symptoms. While triggers may differ between patients, they may include: viral respiratory infections, exercise, exposure to allergens, environmental irritants, dietary intake, medicines and occupational exposures<sup>2</sup>.

The pathophysiology of asthma is complex and the role of genetic, environmental, and lifestyle factors is acknowledged but not well understood<sup>2</sup>. Common risk factors include a family history of asthma, smoking or exposure to cigarette smoke, overweight or obesity, sedentary lifestyle, and exposure to environmental hazards such as air pollutants<sup>2</sup>. In addition, asthma in adults is associated with comorbid conditions including obesity, mental illness, arthritis, and cardiovascular disease<sup>3,4</sup>. It is suggested that the occurrence of asthma with one or more additional chronic conditions increases with age<sup>5</sup>.

In 2014-2015, 1 in 9 Australians reported having asthma<sup>5</sup>. In children, aged 5 to 14 years, asthma is a leading cause of burden of disease and is more common in males<sup>6</sup>. Comparatively, in adults, asthma is more common in females<sup>5</sup>. In the female population, asthma is more prevalent in outer regional and remote areas and higher in those of a low socioeconomic status<sup>5</sup>. In the male population, there is insignificant variation by remoteness and socioeconomic status<sup>5</sup>.

A 2012 survey of 2,686 Australians living with asthma identified that 29% required urgent health care due to their asthma in the year prior<sup>7</sup>. Despite this, in 2014–15 only 28% of Australians living with asthma reported having an asthma action plan<sup>8</sup>. In the adult asthma population, those aged 25-34 were least likely to have a written action plan (16%) while children aged 0-14 were most likely (57%)<sup>8</sup>.

The rate of mortality due to asthma as of 2015 is 1.5 deaths per 100,000 people, that is 421 deaths. In the combined population, the rate of mortality is higher in females than males. In those aged 5-34 years, however, males have a higher rate of mortality<sup>9</sup>.

**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 asthma, 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 in January 2019 and the study closed for recruitment in April 2019. Participants were recruited via email and social media through CCDR and study partners, Asthma Australia.

**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](http://www.zoho.com/survey)). Participants completed the survey from January 2019 to May 2019.

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

Interview data was collected from January 2019 to May 2019.

**Online questionnaire (quantitative)**

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36)<sup>10</sup>, a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)<sup>11</sup>, the Short Fear of Progression Questionnaire (FOP12)<sup>12</sup>, and the Partners in Health version 2 (PIH)<sup>13</sup>. In addition, investigator derived questions about demographics, diagnosis, treatment received, and future treatment decision-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 asked 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<sup>10-12</sup>. The aim of the statistical analysis of

the SF36, CCCQ, FOP12, and PIH responses was to identify variations by subgroups.

The **Asthma Control Test** is a five-item questionnaire that helps determine level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma<sup>14</sup>. Sub-group analysis is included throughout the study; comparisons were made by **Asthma Control Test, Flare-up frequency, Severity, Sleep disruption, Age, Location Education**, and Socio-economic Indexes for Areas (SEIFA).

For comparisons by **Asthma Control Test** (comparing three levels of control), **Flare-ups** 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 comparisons by **Asthma Control Test** (comparing two levels of control), **Severity, Sleep disruption, Location, Education** and **SEIFA**, 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 October 2019.

### **Position of this study**

A search was conducted in Pubmed to identify asthma studies that included quality of life or patient experience components, that had been conducted in the past five years in Australia. The search was conducted 17 April 2019, studies of children were excluded, and studies of five or less participants were excluded.

Twenty-eight studies were identified of between 18 and 2686 Australian participants (Table 1.1). There were 19 quantitative studies, eight qualitative studies and one mixed method study. The largest study was a web-based survey investigating asthma control and healthcare use in 2686 Australian participants (an additional 537 participants from New Zealand were also included in this study)<sup>15</sup>.

There were five studies of pregnant women with asthma. These were all quantitative studies and included between 20 and 220 pregnant women with asthma. These studies collected data about symptoms<sup>16,17</sup>, treatment/healthcare services<sup>16,18</sup>, health self-management<sup>16,18</sup>, quality of life<sup>16,17,19,20</sup>, and anxiety and depression<sup>16,19</sup>.

There were three studies that focused on education and self-management; these were qualitative studies of between 18 and 27 participants. The studies reported about information and education<sup>21,22</sup>, health self-management<sup>21,22</sup>, care and support<sup>22,23</sup>, and quality of life<sup>23</sup>.

Three quantitative studies of between 65 and 403 Australian participants focused on asthma control/management. These studies collected data about symptoms<sup>24,25</sup>, diagnosis<sup>25</sup>, treatment/healthcare services<sup>24,26</sup>, information and education<sup>24</sup>, health self-management<sup>24,26</sup>, quality of life<sup>24</sup>, and anxiety and depression<sup>24,25</sup>.

Healthcare services were the main focus of two qualitative studies of between 25 and 37 participants. The topics reported included treatment/healthcare

services<sup>27,28</sup>, health self-management<sup>27</sup>, care and support<sup>27</sup>, quality of life<sup>28</sup>, and anxiety and depression<sup>28</sup>.

Four studies focused on medicines, these included between 177 and 420 participants, these studies all used quantitative methods to collect patient reported information. The topics reported include: symptom, treatment/healthcare services, health self-management<sup>29,30</sup>, and quality of life<sup>29-32</sup>.

Three qualitative studies of between 37 and 238 Australian participants, and a mixed methods study of 25 participants focused on inhaler technique. These studies covered: decision-making<sup>33</sup>, treatment/healthcare services<sup>33-35</sup>, information and education<sup>35</sup>, health self-management<sup>33-36</sup>, quality of life<sup>35</sup>, and expectations<sup>33</sup>.

Phone applications were explored in two qualitative studies, these reported on treatment/healthcare services, information and education, health self-management<sup>37,38</sup>, care and support, quality of life<sup>37</sup>, and expectations<sup>38</sup>.

A single study focused on multidisciplinary care. This was a qualitative study of 47 participants. The topics covered included: treatment/healthcare services, information and education, health self-management, and care and support<sup>39</sup>. A single study about diet and exercise reported on symptoms, health self-management and quality of life<sup>40</sup>. A quantitative study focused on comorbidities and reported in quality of life<sup>41</sup>, and a study of a medical procedure reported on symptoms and health self-management<sup>42</sup>.

The 2019 Australian Asthma PEEK study is a mixed methods study of 100 participants. The PEEK study covers the experience of people living with asthma 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 2019 Australian Asthma PEEK Study is the largest mixed methods study of Asthma in Australia, in addition, it is the most comprehensive study detailing the experience of people with Asthma in the Australian health system.

Table 1.1: Position of this PEEK study

First Author, year	Number of participants	Study type	Study focus	Health status	Symptoms	Diagnosis	Genetics/ biomarkers	Decision making	Treatment and	Information and	Health self-	Care and support	Quality of life	Anxiety and	Expectations
Schubert, 2017 <sup>19</sup>	355 (193 asthma)	Quantitative	Asthma during pregnancy										x	x	
Burgess, 2015 <sup>16</sup>	220	Quantitative	Asthma during pregnancy		x				x		x		x	x	
Zairina, 2016 <sup>20</sup>	72	Quantitative	Asthma during pregnancy										x		
Lim, 2014 <sup>18</sup>	60	Quantitative	Asthma during pregnancy						x		x				
Zairina, 2016 <sup>17</sup>	20	Quantitative	Asthma during pregnancy		x								x		
Taylor, 2014 <sup>21</sup>	27	Qualitative: interviews	Education/self-management/ knowledge							x	x				
Saba, 2014 <sup>22</sup>	24	Qualitative: interviews	Education/self-management /knowledge							x	x	x			
Cheung, 2018 <sup>23</sup>	18	Qualitative: interviews	Education/self-management/ knowledge									x	x		
Gold, 2014 <sup>24</sup>	3630* (403 Australia)	Quantitative	Asthma control/ management		x				x	x	x	x	x		
Cheung, 2014 <sup>26</sup>	77	Quantitative	Asthma control/management						x		x				
Tay, 2017 <sup>25</sup>	65	Quantitative	Asthma control/management		x	x							x		
Naik-Panvelkar, 2015 <sup>27</sup>	37 (n=16 interview and n=21 focus groups)	Qualitative: interview and focus groups	Healthcare services						x	x	x				
Reddel, 2017 <sup>15</sup>	3223* (2686 Australia)	Quantitative	Healthcare services		x				x		x				
Foster, 2017 <sup>28</sup>	25	Qualitative: interviews	Healthcare services						x		x	x	x		
Gibson, 2017 <sup>31</sup>	420	Quantitative	Medicines										x		
Gibson, 2016 <sup>30</sup>	192	Quantitative	Medicines		x				x		x		x		
Hew, 2016 <sup>29</sup>	179	Quantitative	Medicines		x				x		x		x		
Maltby, 2017 <sup>32</sup>	177	Quantitative	Medicines										x		
Westerik, 2016 <sup>34</sup>	623* (37 Australia)	Quantitative	Inhaler technique						x		x				
Azzi, 2017 <sup>35</sup>	238	Quantitative	Inhaler technique						x	x	x		x		

First Author, year	Number of participants	Study type	Study focus	Health status	Symptoms	Diagnosis	Genetics/ biomarkers	Decision making	Treatment and	Information and	Health self-	Care and support	Quality of life	Anxiety and	Expectations
Toumas-Shehata, 2014 <sup>36</sup>	101	Quantitative	Inhaler technique								x				
Jahedi, 2017 <sup>33</sup>	25	Mixed methods: interviews and questionnaires	Inhaler technique					x	x		x				x
Cheong, 2015 <sup>39</sup>	47	Qualitative: interviews	Multi-disciplinary care						x	x	x	x			
Scott, 2015 <sup>40</sup>	38	Quantitative	Diet and/or exercise		x						x		x		
Peters, 2017 <sup>37</sup>	20	Qualitative: workshop/workbook	App design						x	x	x	x	x	x	
Foster, 2017 <sup>37,38</sup>	18	Qualitative: interviews	App design						x	x	x	x			x
Tay, 2016 <sup>41</sup>	90	Quantitative	Comorbidities										x		
Langton, 2017 <sup>42</sup>	20	Quantitative	Medical procedure		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 <b>F statistic</b> 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 $\chi^2$	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 <i>p</i> -value (typically $\leq 0.05$ ) indicates strong. A large <i>p</i> -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 asthma were recruited into the study, 84 females (84.00%) and 16 males (16.00%), aged mostly between 35 and 64 (n=65, 65.00%).

Participants were included from across Australia. The majority of participants were from New South Wales (n=34, 34.00%), Queensland (n=21, 21.00%), and Victoria (n=16, 16.00%), and most live in major cities (n=66, 66.00%). Participants lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) ([www.abs.gov.au](http://www.abs.gov.au)), and more than half lived in an area with a high SEIFA score of 7 to 10 (more advantage) (n=56, 56.00%).

The majority of participants identified as Caucasian/white (n=92, 92.00%). The majority of participants had completed some university (N=56, 56.00%), and most were employed either full time (n=47, 47.00%) or part time (n=20, 20.00%). Approximately a third of participants (n=33, 33.00%) were carers to family members or spouses.

### Disease description

The **Asthma control test** is a five-item questionnaire that helps determine level of control that a person with asthma has with their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. The majority of the participants scored between 5 and 19 (n=74, 74.00%), which indicated that their asthma may not have been controlled. 21 participants (21.00%) scored between 20 and 24, indicating that asthma was reasonably well controlled and 5 participants (5.00%) scored 25, indicating asthma that was under control.

Participants also indicated the frequency of flare-up or asthma attack. The most common responses were as follows: 21 participants described a flare-up once a month (21.00%), 18 participants described a flare-up once a week (18.00%), and 18 participants described a flare-up once a day (18.00%).

### 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, where a higher score denotes better health or function.

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 do not at all interfere with work or other activities. The **“SF36 Emotional well-being”** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, the participants in this study felt happy and calm some of the time, and depressed and anxious some of the time.

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 slightly 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 moderately interfered with work or other activities.

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 were slightly limited.

The **“SF36 Role Energy/Fatigue”** scale measures the amount of energy or fatigue. On average the participants in this study had moderate energy/fatigue, that is, they felt tired some of the time and had energy some 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. The overall scores for “**SF36 Pain**” were in the middle of the scale, this indicated a moderate amount of pain and a moderate effect of pain on daily activities.

The overall scores for “**SF36 Health change**” were in the middle of the scale, this correlates to no health change over the past year. The overall score for “**SF36 General health**” was in the second lowest quintile, indicating poor general health.

## Demographics

One hundred participants with asthma were recruited into the study; 84 females (84.00%) and 16 males (16.00%), aged mostly between 35 and 64 (n=65, 65.00%).

Participants were included from across Australia. The majority of participants were from New South Wales (n=34, 34.00%), Queensland (n=21, 21.00%), and Victoria (n=16, 16.00%). Most lived in major cities (n=66, 66.00%), and lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) ([www.abs.gov.au](http://www.abs.gov.au)), more than half the participants

lived in an area with a high SEIFA score of 7 to 10 (more advantage) (n=56, 56.00%).

The majority of participants identified as Caucasian/white (n=92, 92.00%). The majority of participants had completed some university (n=56, 56.00%), and most were employed either full time (n=47, 47.00%) or part time (n=20, 20.00%). Approximately a third of participants (n=33, 33.00%) were carers to family members or spouses. The demographics of participants are listed in Table 2.1.

**Table 2.1: Demographics**

Characteristic		Count (n=100)	Percent
Gender	Female	84	84.00
	Male	16	16.00
Age	18 – 24	7	7.00
	25 – 34	16	16.00
	35 – 44	22	22.00
	45 – 54	20	20.00
	55 – 64	23	23.00
	65 – 74	10	10.00
	75+	2	2.00
Race/ethnicity	Caucasian/White	92	92.00
	Asian	2	2.00
	Indigenous	2	2.00
	African	1	1.00
	Indian	1	1.00
	Indian and Sri Lankan	1	1.00
	Torres Strait Islander	1	1.00
State	NSW	34	34.00
	QLD	21	21.00
	VIC	16	16.00
	WA	12	12.00
	ACT	8	8.00
	SA	6	6.00
	TAS	2	2.00
	NT	1	1.00
SEIFA	1	2	2.00
	2	6	6.00
	3	9	9.00
	4	6	6.00
	5	4	4.00
	6	17	17.00
	7	12	12.00
	8	15	15.00
	9	13	13.00
	10	16	16.00
Location	Major city	66	66.00
	Inner regional	18	18.00
	Outer regional	15	15.00
	Remote	1	1.00
Education	Less than high school degree	1	1.00
	High school degree or equivalent	18	18.00
	Some college but no degree	15	15.00
	Trade	10	10.00
	Associate degree	11	11.00
	Bachelor degree	22	22.00
Graduate degree	23	23.00	

Table 2.1: Demographics (Cont.)

Topic		Count (n=100, more than once response can apply per Topic)	Percent of participants	
Employment status (More than one can apply)	Employed, working full time	47	47.00	
	Employed, working part time 3: with Full/part time study 1: with Full/part time study and Centrelink support 3: Centrelink support	20	20.00	
	Retired	16	16.00	
	Full/part time study 3: with Part time work 1: with Part time work and Centrelink support	8	8.00	
	Currently receiving Centrelink support 3: with part time work 1: plus Full/part time carer 1: plus part time work and Full/part time study	7	7.00	
	Disabled, not able to work	5	5.00	
	Not employed, looking for work	3	3.00	
	Full/part time carer 1: plus Full/part time carer	1	1.00	
	Carer status (more than one can apply)	I am not a carer	67	67.00
		Children 2: plus parents 2: plus children	25	25.00
Parents 1: plus grandchildren		6	6.00	
Grandchildren 1: plus parents		3	3.00	
Siblings		1	1.00	
Spouse		1	1.00	

## Asthma Control Tests

The **Asthma control test** is a five-item questionnaire that helps determine the level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control, and the highest score is 25, indicating controlled asthma. The five questions and responses are listed in Table 2.2. The most common response for each of the questions is as follows: asthma kept participants from getting

work done some of the time (n=34, 34.00%); participants has shortness of breath 1-2 times a week (n=33, 33.00%); participants sleep was disturbed by asthma symptoms 2-3 nights a week (n=33, 33.00%); participants used reliever medication 1-2 times a day (n=30, 30.00%); and an equal number of participants rated their asthma control as somewhat controlled (n=37, 37.00%) or well controlled (n=37, 37.00%).

**Table 2.2: Asthma control test**

Asthma control test question	Response	Count (n=100)	Percent
In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or home?	All of the time	3	3.00
	Most of the time	16	16.00
	Some of the time	34	34.00
	A little of the time	28	28.00
	None of the time	19	19.00
During the past 4 weeks, how often have you had shortness of breath?	More than once a day	27	27.00
	Once a day	14	14.00
	3-6 times a week	17	17.00
	1-2 times a week	33	33.00
	Not at all	9	9.00
During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?	4 or more times a week	11	11.00
	2-3 nights a week	33	33.00
	Once a week	15	15.00
	Once or twice	16	16.00
	Not at all	25	25.00
During the past 4 weeks, how often have you used your blue puffer or reliever medication (such as Ventolin, Asmol, Airomir, Apo-Salbutamol or Bricanyl)?	1-2 times a day	30	30.00
	2-3 times a week	20	20.00
	Once a week or less	18	18.00
	Not at all	10	10.00
How would you rate your asthma control during the past 4 weeks?	Not controlled	4	4.00
	Poorly controlled	13	13.00
	Somewhat controlled	37	37.00
	Well controlled	37	37.00
	Completely controlled	9	9.00

The Asthma control score is a total of the responses from each question, it ranges from 5 (poorly controlled) to 25 (under control). The majority of the participants scored between 5 and 19 (n=74, 74.00%), which indicated that their asthma may not have been controlled. 21 participants (21.00%) scored between 20 and 24, indicating that asthma is reasonably well controlled, and 5 participants (5.00%) scored 25 indicating asthma that is under control (Table 2.3).

Participants indicated the frequency of flare-up or asthma attack. The most common responses were: 21 participants described a flare-up once a month (21.00%), 18 participants described a flare-up once a week (18.00%), and 18 participants described a flare-up once a day (18.00%) (Table 2.4)

**Table 2.3: Asthma control test score**

Asthma control score	Count (n=100)	Percent
May not have been controlled (5 to 19)	74	74.00
Reasonably well controlled (20 to 24)	21	21.00
Under control (25)	5	5.00

**Table 2.4: Frequency of flare-up or asthma attack**

Frequency of flare-up or asthma attack	Count (n=100)	Percent
Once a day	18	18.00
Once a week	18	18.00
Once a month	21	21.00
Once every two months	7	7.00
Once every three months	13	13.00
Twice a year	16	16.00
Once a year	7	7.00

### Sub-group analysis

Sub-group analysis are included throughout the study and the sub-groups are listed in Table 2.5. The **Asthma control test** is a five-item questionnaire that helps determine level of asthma control. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between participants that scored 20 or more *Controlled asthma* (n=26, 26.00%), between 16 and 19 *Moderately controlled asthma* (n=22, 22.00%), and those who scored 15 or less *Poorly controlled asthma* (n=52, 52.00%). Separate comparisons were also made between those who scored between 16 and 25 *Moderate to well controlled asthma* (n=48, 48.00%), and those who score 15 or less *Poorly controlled asthma* (n=52, 52.00%).

Comparisons were made by **Flare-ups**, between participants that reported having a flare-up or asthma

attacks once a month or more frequently, *Frequent flare-ups* (n=36, 36.00%), those that had a flare-up once a month to once every three months, *Occasional flare-ups* (n=41, 41.00%), and those that had a flare-up once or twice a year, *Infrequent flare-ups* (n=23, 23.00%).

Comparisons were made by **Severity**, between participants that reported having *Severe asthma* (n=29, 29.00%), and those that had *Non-severe asthma* (n=79, 79.00%). Participants in the Severe asthma sub-group included those who confirmed that they had been diagnosed with severe asthma in the semi-structured interview (this was then cross-checked with the treatments they are taking for verification), and those that were taking regular treatments beyond preventer and reliever medication including monoclonal antibodies, daily/very frequent oral corticosteroid use, long acting muscarinic antagonists, leukotriene receptor antagonists, or a high dose of regular treatment (such as high dose Seretide).

Comparisons were made by the frequency of **Sleep disruption**, those who noted in the Asthma control test the frequency that they had sleep disruptions due to asthma. Those that had sleep disruptions once a week or more frequently *Frequent sleep disruption* (n=59, 59.00%) were compared to those who responded that they had sleep disruptions once a month or not at all *Infrequent sleep disruption* (n=41, 41.00%).

Comparisons were made by the **Age** of the participants, those that were *Aged 18 – 34* (n=23, 23.00%), *Aged 35 – 54* (n=42, 42.00%) and participants *Aged 55 or older* (n=35, 35.00%)

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=66, 66.00%) were compared to those living in regional/rural areas, *Regional or remote* (n=34, 34.00%). Comparisons were made by **Education** status, between those with a university qualification, *University* (n=56, 56.00%), and those with trade or high school qualifications, *Trade or high school* (n=44, 44.00%).

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=56 56.00%) compared to those with a mid to low SEIFA score of 1-6, *Mid-low SEIFA* (n=44, 44.00%).

Table 2.5: Sub-group descriptions

Group	Definition	Subgroup	Count (n=100)	Percent
<b>Asthma Control Test</b>	Total score of 20 or more	<i>Controlled Asthma</i>	26	26.00
	Total score of 16-19	<i>Moderately controlled Asthma</i>	22	22.00
	Total score of 15 or less	<i>Poorly controlled Asthma</i>	52	52.00
<b>Asthma Control Test 2</b>	Total score of 16 to 25	<i>Moderate to well controlled Asthma</i>	48	48.00
	Total score of 15 or less	<i>Poorly controlled Asthma</i>	52	52.00
<b>Flare-ups</b>	Once a week or more frequently	<i>Frequent flare-ups</i>	36	36.00
	Once a month to once every 3 months	<i>Occasional flare-ups</i>	41	41.00
	Once or twice a year	<i>Infrequent flare-ups</i>	23	23.00
<b>Sleep disruption</b>	ACT sleep question: Sleep problems once a week or more frequently	<i>Frequent sleep disruption</i>	59	59.00
	ACT sleep question: Sleep problems once a month or not at all	<i>Infrequent sleep disruption</i>	41	41.00
<b>Age</b>	Aged 18 to 34	<i>Aged 18 to 34</i>	23	23.00
	Aged 35 to 44	<i>Aged 35 to 54</i>	42	42.00
	Aged 55 or older	<i>Aged 55 or older</i>	35	35.00
<b>Location</b>	Major city by AGSG Remoteness 2016	<i>Metropolitan</i>	66	66.00
	Inner/outer regional by AGSG	<i>Regional or remote</i>	34	34.00
<b>Education</b>	Did not graduate from university	<i>Trade or high school</i>	44	44.00
	Anyone that graduated	<i>University</i>	56	56.00
<b>Socio-Economic Indexes for Areas (SEIFA)</b>	SEIFA decile 7-10	<i>High SEIFA</i>	56	56.00
	SEIFA decile 1-6	<i>Mid to Low SEIFA</i>	44	44.00

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## Other health conditions

Table 2.6 displays the responses to other conditions that were listed in the online questionnaire. Participants noted between one and 13 other health conditions, with a median of three health conditions (Table 2.7). The most commonly reported conditions were sleep problems or insomnia (n=56, 56.00%), and depression and anxiety. A total of 40 participants had depression (40.00%), [36 of these were diagnosed by a

doctor, 26 self-diagnosed and diagnosed by a doctor], a total of 51 participants had anxiety, [37 of these were diagnosed by a doctor, 28 self-diagnosed and diagnosed by a doctor].

Participants listed other conditions they had. The most common were various auto-immune disorders or diseases (n=24, 24.00%), followed by any form of arthritis (n=16, 16.00) (Table 2.8).

**Table 2.6: Other health conditions**

Condition		Count (n=100)	Percent	Hospitalised for condition		How often hospitalised		Average length of stay in hospital	
Nasal polyps	Yes	9	9	Yes	6	One time only	3	1 day	2
	No	91	91	No	3	Not in last five years	3	2 days	3
								3 days	1
Sleep problems or insomnia	Yes	56	56	Yes	13	One time only	4	1 day	6
	No	44	44	No	43	Two times	1	4 days	2
						Three times	2	5 days	2
						Four times	2	6 days	1
						Five times or more	1	7 days or more	2
						Not in last five years	3		
COPD	Yes	8	8	Yes	6	Two times	1	3 days	2
	No	92	92	No	3	Three times	2	4 days	1
						Five times or more	3	5 days	1
								7 days or more	2
Depression (Self diagnosed)	Yes	30	30	Yes	2	Not in last five years	1	1 day	1
	No	70	70	No	28	Not stated		3 days	1
Depression (Diagnosed by a doctor)	Yes	36	36	Yes	3	Three times	1	1 day	1
	No	64	64	No	33	Not in last five years	2	2 days	1
								7 days or more	1
Anxiety (self diagnosed)	Yes	42	42	Yes	1	Five times or more	1	7 days or more	1
	No	58	58	No	41				
Anxiety (diagnosed by a doctor)	Yes	37	37	Yes	4	Two times	1	1 day	2
	No	63	63	No	33	Five times or more	1	2 days	1
						Not in last five years	1	7 days or more	1
						Not stated	1		
Hypertension?	Yes	15	15	No	15	NA		NA	
	No	85	85						
Diabetes	Yes	10	10	No	10	NA		NA	
	No	90	90						
Arrhythmias	Yes	11	11	Yes	5	One time only	1	1 day	2
	No	89	89	No	6	Two times	3	3 days	2
						Not stated	1	7 days or more	1
Chronic pain	Yes	32	32	Yes	6	Two times	1	1 day	1
	No	68	68	No	26	Four times	1	2 days	1
						Five times or more	3	4 days	1
						Not stated	1	6 days	1
								7 days or more	2
Chronic heart failure	Yes	3	3	Yes	3	Two times	2	3 days	2
	No	97	97	No	0	Not stated	1	7 days or more	1
Angina	Yes	3	3	Yes	2	Two times	2	3 days	2
	No	97	97	No	1				

Table 2.7: Number of other conditions

Number of other conditions	Count (n=100)	Percent
0	6	6
1	15	15
2	17	17
3	14	14
4	9	9
5	10	10
6 or more	10	29
Summary statistics		
Median	3.00	
IQR	4.00	
Mean	4.06	
SD	2.98	

Table 2.8: Specified other conditions

Other conditions	Count (n=100)	Percent
Auto immune disorder/disease	24	24.00
Arthritis	16	16.00
Musculoskeletal disorder/disease	13	13.00
Gastrointestinal disorder/disease	10	10.00
Hormone disorder/disease	7	7.00
Mental health problems	6	6.00
Cardiovascular disorder/disease	6	6.00
Migraine	5	5.00
Sinus disorder/disease	5	5.00
Skin disorder/disease	6	6.00
Blood disorder/disease	3	3.00
Ear/hearing problems	3	3.00
Chronic fatigue syndrome	2	2.00
Liver disorder/disease	2	2.00
Central nervous system disease/disorder	2	2.00
Lung disease/disorder	2	2.00

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## 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 2.9, 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 highest quintile for **“SF36 Role functioning/emotional”** (Median = 100.00, SD = 100.00) indicating very good role functioning. The overall scores for **“SF36 Physical functioning”** (Median = 65.00, IQR = 45.00), and **“SF36 Social functioning”** (Median = 68.75, IQR = 37.50), were in the second highest quintile, indicating good social and physical functioning.

The overall scores for **“SF36 Role functioning/physical”** (Median = 50.00, IQR = 100.00), **“SF36 Role Energy/Fatigue”** (Mean = 41.30, SD = 20.38), **“SF36 Emotional well-being”** (Median = 68.00, IQR = 28.00), **“SF36 Pain”** (Median = 57.50, IQR = 35.00) and, **“SF36 Health change”** (Median = 50.00, IQR = 25.00) were in the middle of the scale, indicating moderate function, energy/fatigue, emotional well-being, pain and health change.

The overall score for **“SF36 General health”** (Median = 35.00, IQR = 40.00) was in the second lowest quintile, indicating poor general health.

Comparisons of SF36 have been made based on **Asthma control test** (Figures 2.1 to 2.9, Tables 2.10 to 2.16), **Asthma control test** (Figures 2.10 to 2.18, Tables 2.17 to 2.18), **Flare-ups**, (Figures 2.19 to 2.27, Tables 2.19 to 2.23), **Severity** (Figures 2.28 to 2.36, Tables 2.24 to 2.25), **Sleep disruption** (Figures 2.37 to 2.45, Tables 2.26 to 2.27), **Age** (Figures 2.38 to 2.54, Tables 2.28 to 2.31), **Location** (Figures 2.55 to 2.63, Tables 2.32 to 2.33), **Education** (Figures 2.64 to 2.72, Tables 2.34 to 2.35), and **SEIFA** (Figures 2.73 to 2.81, Table 2.36)

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 do not at all interfere 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 some of the time, and depressed and anxious some of the time.

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 slightly 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 moderately interfered with work or other activities.

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 slightly limited

The **“SF36 Role Energy/Fatigue”** scale measures the amount of energy or fatigue. On average the participants in this study had moderate energy/fatigue, that is they felt tired some of the time and have energy some 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.

Table 2.9: SF36 scores, all participants

SF36 scale	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	65.05	25.88	65.00	45.00	0 to 100	4
Role functioning/physical	43.00	42.21	50.00	100.00	0 to 100	3
Role functioning/emotional	62.67	42.98	100.00	100.00	0 to 100	5
Energy/Fatigue*	41.30	20.38	40.00	31.25	0 to 100	2
Emotional well-being	67.28	18.50	68.00	28.00	0 to 100	3
Social functioning	63.00	28.53	68.75	37.50	0 to 100	4
Pain	61.15	25.55	57.50	35.00	0 to 100	3
General health	42.05	23.40	35.00	40.00	0 to 100	2
Health change	55.25	29.58	50.00	25.00	0 to 100	3

\*Normal distribution, use mean and SD as central measure.

### SF36 by Asthma control test (three groups)

The **Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between participants that scored 20 or more *Controlled asthma* (n=26, 26.00%), between 16 and 19 *Moderately controlled asthma* (n=22, 22.00%), and those who scored 15 or less *Poorly controlled asthma* (n=52, 52.00%).

Boxplots of each SF36 scale by the **Asthma control test** are displayed in Figures 2.1-2.9, summary statistics are displayed in Table 2.10.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.11). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.12). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.13). 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 2.14). 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 (Tables 2.15 to 2.16).

A one way ANOVA test indicated a statistically significant difference in the “**SF36 Energy/Fatigue**” scale between groups,  $F(2, 97) = 7.71, p = 0.0008$  (Table 2.11). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants with *Controlled asthma* (mean = 52.50, SD = 16.81) was

significantly higher compared to participants with *Poorly controlled asthma* (mean = 34.71, SD = 19.76  $p=0.0006$ ).

A one-way ANOVA test indicated a statistically significant difference in the “**SF36 Pain**” scale between groups,  $F(2, 97) = 6.10, p = 0.0032$  (Table 2.11). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants with *Controlled asthma* (mean = 73.27, SD = 26.56,  $p=0.0029$ ) was significantly higher compared to participants with *Poorly controlled asthma* (mean = 53.46, SD = 25.60).

A one way ANOVA test indicated a statistically significant difference in the “**SF36 General health**” scale between groups,  $F(2, 97) = 8.20, p = 0.0005$  (Table 2.11). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants with *Controlled asthma* (mean = 54.04, SD = 23.41,  $p=0.0006$ ), and participants with *Moderately controlled asthma* (mean = 47.27, SD = 24.63,  $p=0.0460$ ), was significantly higher compared to participants with *Poorly controlled asthma* (mean = 33.85, SD = 19.77).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Physical functioning**” scale between groups,  $\chi^2(2) = 13.90, p = 0.0010$  (Table 2.13). Wilcoxon rank sum tests between groups indicated that those with *Controlled asthma* (median = 90.00, IQR = 31.25,  $p=0.0012$ ) scored significantly higher than participants with *Poorly controlled asthma* (median = 55.00, IQR = 41.25).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Role functioning/physical”** scale between groups,  $\chi^2(2) = 16.13$ ,  $p = 0.0003$  (Table 2.13). Wilcoxon rank sum tests between groups indicated that those with *Controlled asthma* (median = 100.00, IQR = 68.75,  $p=0.0003$ ) scored significantly higher than participants with *Poorly controlled asthma* (median = 0.00, IQR = 50.00).

A Kruskal-Wallis test indicated a statistically significant difference in the **“SF36 Social functioning”** scale between groups,  $\chi^2(2) = 16.13$ ,  $p = 0.0018$  (Table 2.13). Wilcoxon rank sum tests between groups indicated that those with *Controlled asthma* (median = 81.25, IQR = 37.50,  $p=0.0019$ ) scored significantly higher than participants with *Poorly controlled asthma* (median = 50.00, IQR = 40.63).

A Welch one-way test indicated a statistically significant difference in the **“SF36 Role functioning/emotional”** scale between groups  $F(2, 52.00) = 4.55$ ,  $p=0.0151$  (Table 2.15). Post hoc pairwise t-tests with no assumption of equal variances indicated that participants with *Controlled asthma* (mean = 82.05, SD = 35.57) scored significantly higher than those with *Moderately controlled asthma* (mean = 57.58, SD = 38.74,  $p=0.0043$ ), and significantly higher than those with *Poorly controlled asthma* (mean = 55.13, SD = 45.68,  $p=0.0170$ ).

Welch one-way test indicated a statistically significant difference in the **“SF36 Emotional well-being”** scale between groups  $F(2, 46.23) = 3.75$ ,  $p=0.0310$  (Table 2.15). Post hoc pairwise t-tests with no assumption of equal variances indicated that participants with *Controlled asthma* (mean = 76.46, SD = 13.95) significantly higher than those with *Poorly controlled asthma* (mean = 65.00, SD = 17.21,  $p=0.0350$ ).

#### Key differences

**“SF36 Physical functioning”** measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities were not limited at all for *Controlled asthma* compared to moderately limited for *Poorly controlled asthma*.

**“SF36 Role functioning/physical”** measures how physical health interferes with work or other activities. Physical health did not interfere at all with work or other activities for *Controlled asthma* compared to extremely interfered with work or other activities for *Poorly controlled asthma*.

The **“SF36 Role functioning/emotional”** scale measures how emotional problems interfere with work or other activities. Emotional problems did not at all interfere with work or other activities for participants with *Controlled asthma* compared to moderately interfered for participants with *Moderately controlled asthma* and *Poorly controlled asthma*.

The **“SF36 Energy/fatigue”** measures the amount of energy or fatigue. Participants with *Controlled asthma* felt tired some of the time and have energy some of the time compared to *Poorly controlled asthma* participants who felt tired most of the time and had energy a little of the time.

The **“SF36 Emotional well-being”** scale measures how a person feels, for example happy, calm, depressed or anxious. Participants with *Controlled asthma* were significantly higher than those with *Poorly controlled asthma*, however, the scores for both groups were in the “felt happy and calm most of the time, and anxious and depressed a little of the time” range.

**“SF36 Social functioning”** measures limitations on social activities due to physical or emotional problems. Social activities are not at all limited for participants with *Controlled asthma* compared to moderately limited for participants with *Poorly controlled asthma*.

**“SF36 Pain”** measures the amount of pain, and how pain interferes with work and other activities. Participants with *Controlled asthma* had mild pain compared to severe pain for participants with *Poorly controlled asthma*.

**“SF36 General health”** measures general health. Participants with *Controlled asthma* and participants with *Moderately controlled asthma* had moderate general health compared to and poor general health for participants with *Poorly controlled asthma*.

Table 2.10: SF36 by Asthma control test summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	<i>Controlled asthma</i>	26	26.00	78.08	23.96	90.00	31.25
	<i>Moderately controlled asthma</i>	22	22.00	68.86	20.29	67.50	28.75
	<i>Poorly controlled asthma</i>	52	52.00	56.92	26.26	55.00	41.25
Role functioning/physical	<i>Controlled asthma</i>	26	26.00	69.23	41.42	100.00	68.75
	<i>Moderately controlled asthma</i>	22	22.00	45.45	39.82	50.00	75.00
	<i>Poorly controlled asthma</i>	52	52.00	28.85	37.50	0.00	50.00
Role functioning/emotional	<i>Controlled asthma</i>	26	26.00	82.05	35.57	100.00	0.00
	<i>Moderately controlled asthma</i>	22	22.00	57.58	38.74	66.67	66.67
	<i>Poorly controlled asthma</i>	52	52.00	55.13	45.68	66.67	100.00
Energy/Fatigue*	<i>Controlled asthma</i>	26	26.00	52.50	16.81	55.00	18.75
	<i>Moderately controlled asthma</i>	22	22.00	43.64	20.13	40.00	31.25
	<i>Poorly controlled asthma</i>	52	52.00	34.71	19.76	32.50	26.25
Emotional well-being	<i>Controlled asthma</i>	26	26.00	74.46	13.95	80.00	16.00
	<i>Moderately controlled asthma</i>	22	22.00	64.18	24.02	70.00	43.00
	<i>Poorly controlled asthma</i>	52	52.00	65.00	17.21	68.00	25.00
Social functioning	<i>Controlled asthma</i>	26	26.00	78.37	23.86	81.25	37.50
	<i>Moderately controlled asthma</i>	22	22.00	66.48	22.95	75.00	21.88
	<i>Poorly controlled asthma</i>	52	52.00	53.85	29.55	50.00	40.63
Pain	<i>Controlled asthma</i>	26	26.00	73.27	26.56	80.00	39.38
	<i>Moderately controlled asthma</i>	22	22.00	65.00	17.37	67.50	20.00
	<i>Poorly controlled asthma</i>	52	52.00	53.46	25.60	56.25	33.13
General health	<i>Controlled asthma</i>	26	26.00	54.04	23.41	57.50	35.00
	<i>Moderately controlled asthma</i>	22	22.00	47.27	24.63	45.00	33.75
	<i>Poorly controlled asthma</i>	52	52.00	33.85	19.77	30.00	25.00
Health change	<i>Controlled asthma</i>	26	26.00	63.46	22.62	50.00	25.00
	<i>Moderately controlled asthma</i>	22	22.00	63.64	24.06	50.00	25.00
	<i>Poorly controlled asthma</i>	52	52.00	47.60	32.94	50.00	50.00

Table 2.11: SF36 by Asthma Control Test one-way ANOVA

SF36 Scale		Sum of squares	dF	Mean Square	F	p
Energy/fatigue	Between groups	5381.00	2	2819.40	7.71	0.0008*
	Within groups	720.00	97	365.90		
	Total	6101.00	99			
Pain	Between groups	7219.00	2	3609.00	6.10	0.0032*
	Within groups	57399.00	97	592.00		
	Total	64618.00	99			
General health	Between groups	7837.00	2	3918.00	8.20	0.0005*
	Within groups	46368.00	97	478.00		
	Total	54205.00	99			

\*Statistically significant at P<0.05

Table 2.12: SF36 by Asthma Control Test post-hoc Tukey HSD test

SF36 Scale	Asthma control test	Difference	Lower	Upper	P adjusted
Energy/fatigue	<i>Moderately controlled asthma-Controlled asthma</i>	-8.86	-22.05	4.33	0.2507
	<i>Poorly controlled asthma-Controlled asthma</i>	-17.79	-28.72	-6.85	0.0006*
	<i>Poorly controlled asthma-Moderately controlled asthma</i>	-8.92	-20.50	2.65	0.1638
Pain	<i>Moderately controlled asthma-Controlled asthma</i>	-8.27	-25.04	8.50	0.4718
	<i>Poorly controlled asthma-Controlled asthma</i>	-19.81	-33.71	-5.90	0.0029*
	<i>Poorly controlled asthma-Moderately controlled asthma</i>	-11.54	-26.26	3.19	0.1544
General health	<i>Moderately controlled asthma-Controlled asthma</i>	-6.77	-21.84	8.31	0.5360
	<i>Poorly controlled asthma-Controlled asthma</i>	-20.19	-32.69	-7.69	0.0006*
	<i>Poorly controlled asthma-Moderately controlled asthma</i>	-13.43	-26.66	-0.19	0.0460*

\*Statistically significant at P<0.05

Table 2.13: SF36 by Asthma Control Test Kruskal -Wallis test

SF36 Scale	X <sup>2</sup>	df	p
Physical functioning	13.90	2	0.0010*
Role functioning/physical	16.13	2	0.0003*
Social functioning	12.67	2	0.0018*
Health change	5.93	2	0.0515

\*Statistically significant at P<0.05

Table 2.14: SF36 by Asthma Control Test post hoc pairwise comparisons using Wilcoxon rank sum test

SF36 Scale	Asthma control test	<i>Controlled asthma</i>	<i>Moderately controlled asthma</i>
Physical functioning	<i>Moderately controlled asthma</i>	0.0770	
	<i>Poorly controlled asthma</i>	0.0012*	0.0770
Role functioning/physical	<i>Moderately controlled asthma</i>	0.0517	
	<i>Poorly controlled asthma</i>	0.0003*	0.0884
Social functioning	<i>Moderately controlled asthma</i>	0.0953	
	<i>Poorly controlled asthma</i>	0.0019*	0.0953

\*Statistically significant at P<0.05

Table 2.15: SF36 by Asthma Control Test Welch one-way test

SF36 Scale	F	df1	df2	p
Role functioning/emotional	4.55	2.00	52.00	0.0151*
Emotional well-being	3.75	2.00	46.23	0.0310*

\*Statistically significant at P<0.05

Table 2.16: SF36 by Asthma Control Test post hoc pairwise t-tests with no assumption of equal variances

SF36 scale	Asthma control test	<i>Controlled asthma</i>	<i>Moderately controlled asthma</i>
Role functioning/emotional	<i>Moderately controlled asthma</i>	0.0430*	
	<i>Poorly controlled asthma</i>	0.0170*	0.8150
Emotional well-being	<i>Moderately controlled asthma</i>	0.1290	
	<i>Poorly controlled asthma</i>	0.0350*	0.8860

\*Statistically significant at P<0.05

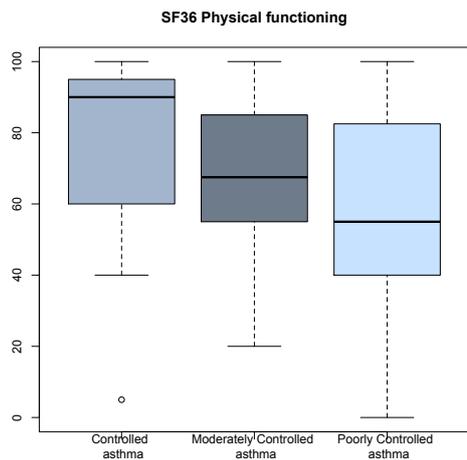


Figure 2.1: Boxplot of SF36 Physical functioning by Asthma Control Test

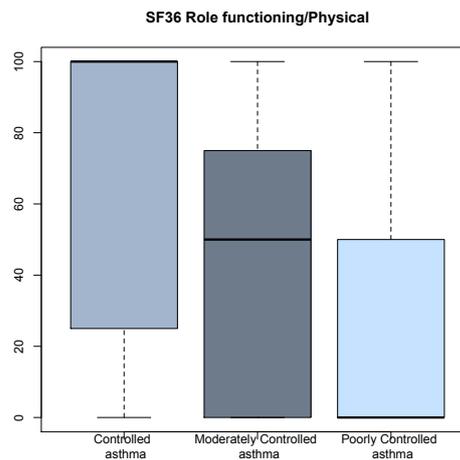


Figure 2.2: Boxplot of SF36 Role functioning/physical by Asthma Control Test

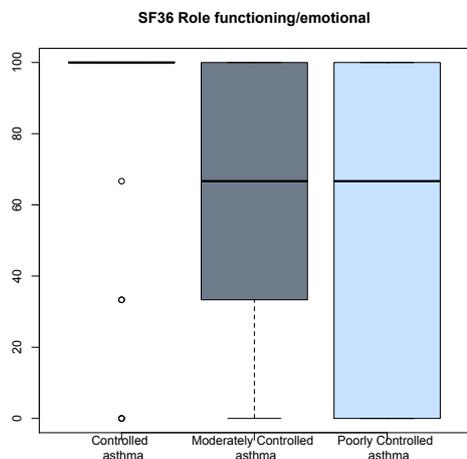


Figure 2.3: Boxplot of SF36 Role functioning/emotional by Asthma Control Test

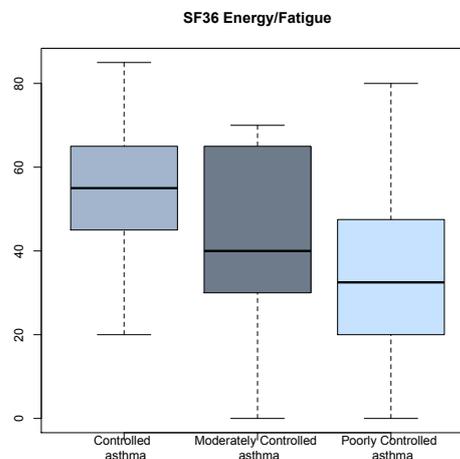


Figure 2.4: Boxplot of SF36 Energy/fatigue by Asthma Control Test

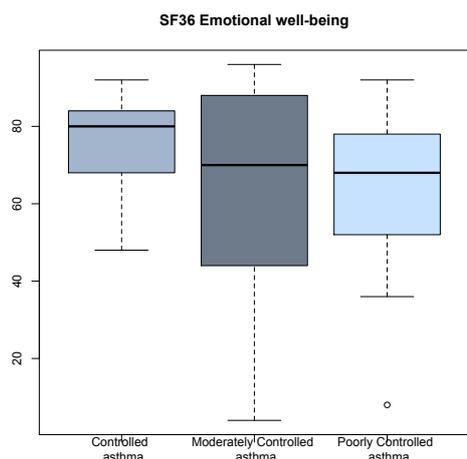


Figure 2.5: Boxplot of SF36 Emotional well-being by Asthma Control Test

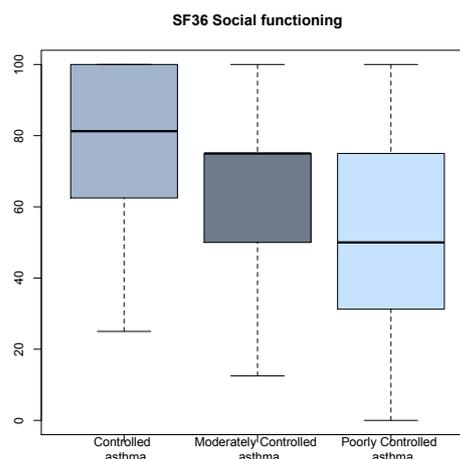


Figure 2.6: Boxplot of SF36 Social functioning by Asthma Control Test

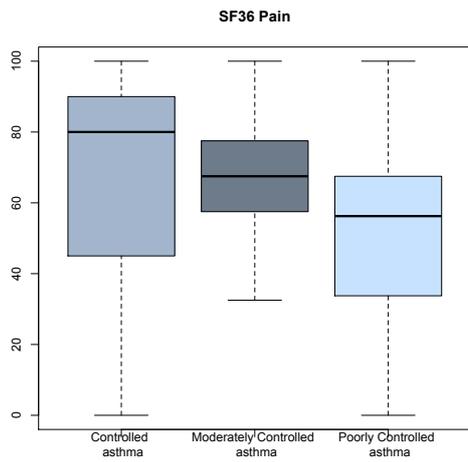


Figure 2.7: Boxplot of SF36 Pain by Asthma Control Test

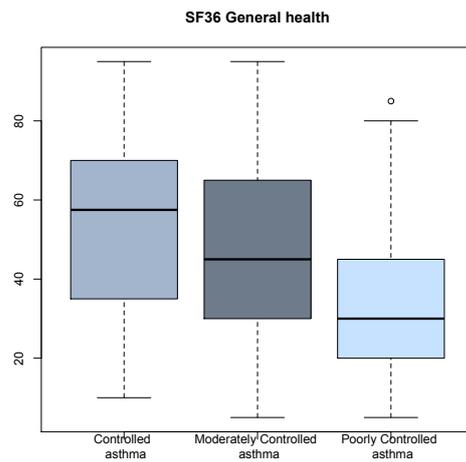


Figure 2.8: Boxplot of SF36 General health by Asthma Control Test

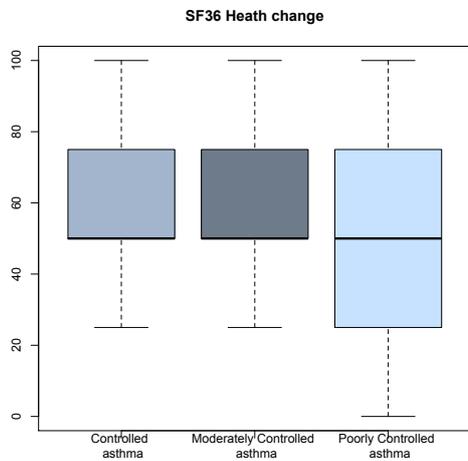


Figure 2.9: Boxplot of SF36 Health change by Asthma Control Test

**SF36 by Asthma control test (two groups)**

The **Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between those who scored between 16 and 25 “Moderate to well controlled asthma” (n=48, 48.00%), and those who score 15 or less “Poorly controlled asthma” (n=52, 52.00%).

Boxplots of each SF36 scale by **Asthma control test** are displayed in Figures 2.10-2.18, summary statistics are displayed in Tables 2.17 – 2.18. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.18).

A two sample t-test indicated that the mean score for the “**SF36 Energy/fatigue**” [t(98) = 3.56, p=0.0006] was significantly higher for those with *Moderate to well controlled asthma* (Mean = 48.44, SD= 18.74) compared to those with *Poorly controlled asthma* (Mean = 34.71, SD = 19.76).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Physical functioning**” [W=1740.50, p=0.0007] was significantly higher for those with *Moderate to well controlled asthma* (Median = 77.50, IQR =36.25) compared to those with *Poorly controlled asthma* (Median =55.00, IQR = 41.25).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Role functioning/physical**” [W=1728.50, p=0.0005] was significantly higher for those with *Moderate to well controlled asthma* (Median = 62.50, IQR =100.00) compared to those with *Poorly controlled asthma* (Median =0.00, IQR = 50.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Social functioning**” [W=1709.00, p=0.0013] was significantly higher for those with *Moderate to well controlled asthma* (Median = 75.00, IQR = 40.63) compared to those with *Poorly controlled asthma* (Median =50.00, IQR = 40.63).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Pain**” [W=1711.00, p=0.0013] was significantly higher for those with *Moderate to well controlled asthma* (Median = 72.50, IQR = 35.63) compared to those with *Poorly controlled asthma* (Median =56.25, IQR = 33.13).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 General health**” [W=1763.00, p = 0.0004] was significantly higher for those with *Moderate to well controlled asthma* (Median = 50.00, IQR = 35.00) compared to those with *Poorly controlled asthma* (Median = 30.00, IQR = 25.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Health change**” [W=1588.00, p=0.0150] was significantly higher for those with *Moderate to well controlled asthma* (Median = 50.00, IQR =25.00) compared to those with *Poorly controlled asthma* (Median =50.00, IQR = 50.00).

### 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 *Moderately to well controlled asthma* compared to moderately limited for *Poorly controlled asthma*

“**SF36 Role functioning/physical**” measures how physical health interferes with work or other activities. Physical health slightly interfered with work or other activities for *Moderately to well controlled asthma* compared to extremely interfered with work or other activities for *Poorly controlled asthma*.

“**SF36 Energy/fatigue**” measures the amount of energy or fatigue. Participants with *Moderately to well controlled asthma* felt tired some of the time and have energy some of the time compared to *Poorly controlled asthma* participants who felt tired most of the time or had energy a little of the time.

“**SF36 Social functioning**” measures limitations on social activities due to physical or emotional problems. Social activities are slightly limited for participants with *Moderately to well controlled asthma* compared to moderately limited for participants with *Poorly controlled asthma*.

“**SF36 Pain**” measures the amount of pain, and how pain interferes with work and other activities. Participants with *Moderately to well controlled asthma* had mild pain compared to severe pain for participants with *Poorly controlled asthma*

“**SF36 General health**” measures general health. Participants with *Moderately to well controlled asthma* had moderate general health compared to poor general health for participants with *Poorly controlled asthma*.

**Table 2.17: SF36 by Asthma Control Test two-sample t-test**

SF36 Scale	Group	Count	Percent	Mean	SD	t	dF	p
Energy/fatigue	<i>Moderately to well controlled asthma</i>	48	48.00	48.44	18.74	3.56	98	0.0006*
	<i>Poorly controlled asthma</i>	52	52.00	34.71	19.76			

\*Statistically significant at P<0.05

**Table 2.18: SF36 by Asthma Control Test Wilcoxon rank sum test with continuity correction**

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	<i>Moderate to well controlled asthma</i>	48	48.00	77.50	36.25	1740.50	0.0007*
	<i>Poorly controlled asthma</i>	52	52.00	55.00	41.25		
Role functioning/physical	<i>Moderate to well controlled asthma</i>	48	48.00	62.50	100.00	1728.50	0.0005*
	<i>Poorly controlled asthma</i>	52	52.00	0.00	50.00		
Role functioning/emotional	<i>Moderate to well controlled asthma</i>	48	48.00	100.00	66.67	1492.00	0.0679
	<i>Poorly controlled asthma</i>	52	52.00	66.67	100.00		
Emotional well-being	<i>Moderate to well controlled asthma</i>	48	48.00	74.00	30.00	1490.50	0.0938
	<i>Poorly controlled asthma</i>	52	52.00	68.00	25.00		
Social functioning	<i>Moderate to well controlled asthma</i>	48	48.00	75.00	40.63	1709.00	0.0013*
	<i>Poorly controlled asthma</i>	52	52.00	50.00	40.63		
Pain	<i>Moderate to well controlled asthma</i>	48	48.00	72.50	35.63	1711.00	0.0013*
	<i>Poorly controlled asthma</i>	52	52.00	56.25	33.13		
General health	<i>Moderate to well controlled asthma</i>	48	48.00	50.00	35.00	1763.00	0.0004*
	<i>Poorly controlled asthma</i>	52	52.00	30.00	25.00		
Health change	<i>Moderate to well controlled asthma</i>	48	48.00	50.00	25.00	1588.00	0.0150*
	<i>Poorly controlled asthma</i>	52	52.00	50.00	50.00		

\*Statistically significant at P<0.0

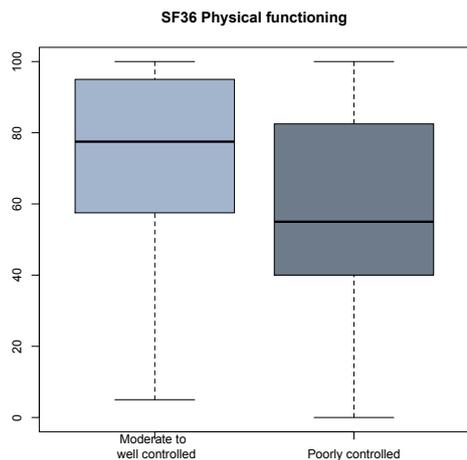


Figure 2.10: Boxplot of SF36 Physical functioning by Asthma Control Test

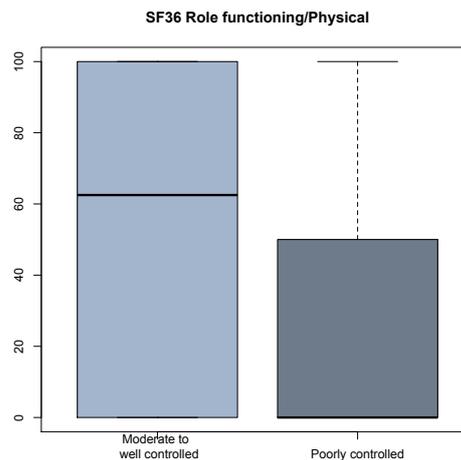


Figure 2.11: Boxplot of SF36 Role functioning/physical by Asthma Control Test

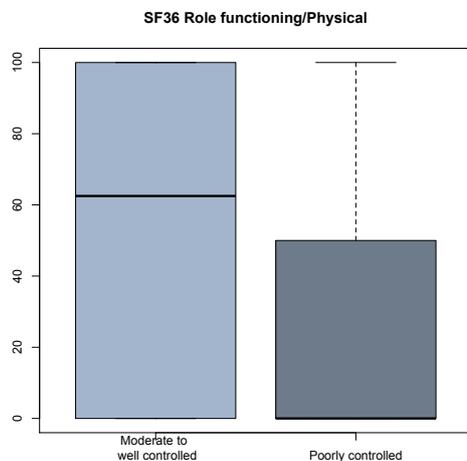


Figure 2.12: Boxplot of SF36 Role functioning/emotional by Asthma Control Test

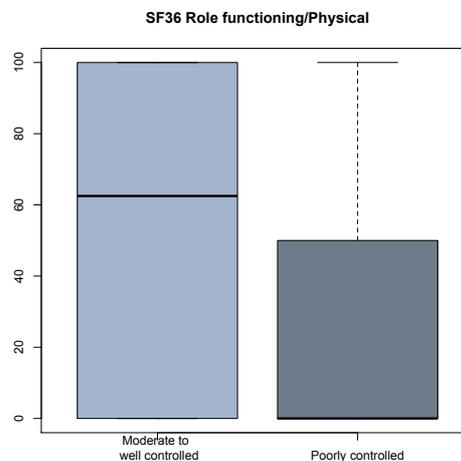


Figure 2.13: Boxplot of SF36 Energy/fatigue by Asthma Control Test

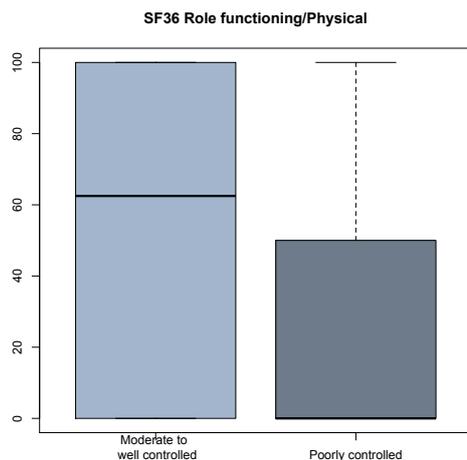


Figure 2.14: Boxplot of SF36 Emotional well-being by Asthma Control Test

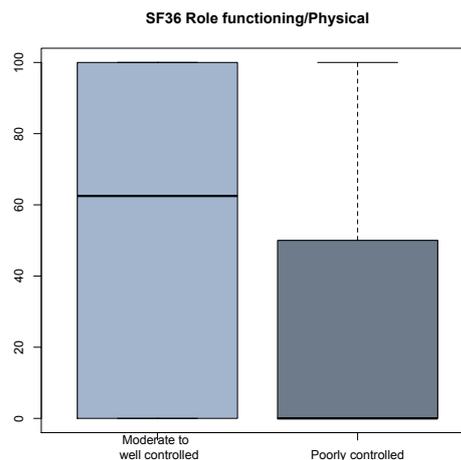


Figure 2.15: Boxplot of SF36 Social functioning by Asthma Control Test

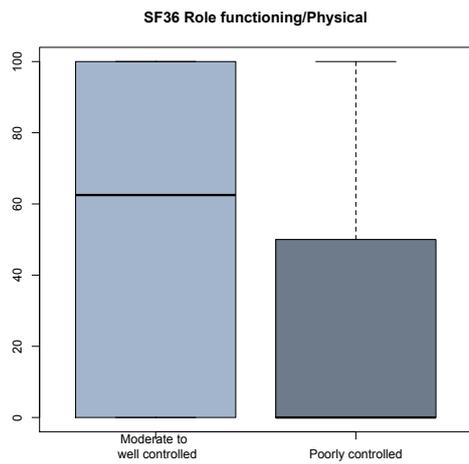


Figure 2.16: Boxplot of SF36 Pain by Asthma Control Test

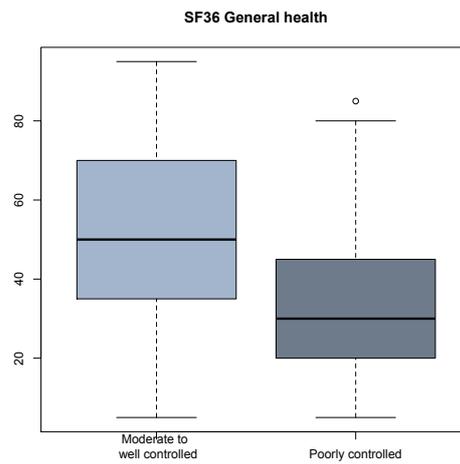


Figure 2.17: Boxplot of SF36 General health by Asthma Control Test

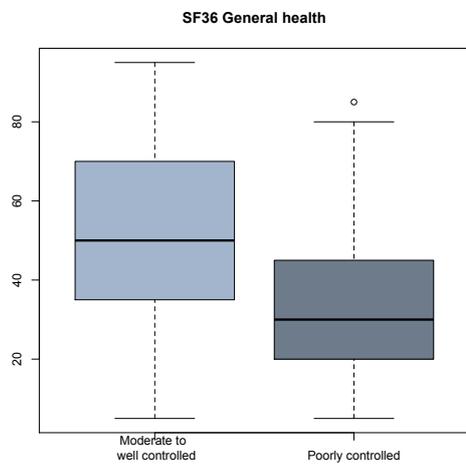


Figure 2.18: Boxplot of SF36 Health change by Asthma Control Test

### SF36 by Flare-ups

Comparisons were made by **Flare-ups**, between participants that reported having a flare-up or asthma attacks once a month or more frequently, “Frequent flare-ups” (n=36, 36.00%), those that had a flare-up once a month to once every three months, “Occasional flare-ups” (n=41, 41.00%), and those that had a flare-up once or twice a year, “Infrequent flare-ups” (n=23, 23.00%).

Boxplots of each SF36 scale by the **Flare-ups** are displayed in Figures 2.19-2.27, summary statistics are displayed in Table 2.19.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.20). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.21). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.22). 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 2.23).

A one-way ANOVA test indicated a statistically significant difference in the “**SF36 Energy/Fatigue**” scale between groups,  $F(2, 97) = 6.16, p = 0.0030$  (Table 2.20). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants with *Infrequent flare-ups* (mean = 52.61, SD = 17.57) was significantly higher compared to participants with *Frequent flare-ups* (34.44, SD = 21.74,  $p = 0.0020$ ).

A one way ANOVA test indicated a statistically significant difference in the “**SF36 Pain**” scale between groups,  $F(2, 97) = 6.42, p = 0.0024$  (Table 2.20). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants with *Infrequent flare-ups* (mean = 76.63, SD = 22.44) was significantly higher compared to participants with *Occasional flare-ups* (mean = 58.66, SD = 26.32,  $p = 0.0149$ ), and participants with *Frequent flare-ups* (mean = 54.10, SD = 22.85,  $p = 0.0022$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Physical functioning**” scale

between groups,  $\chi^2(2) = 13.37, p = 0.0013$  (Table 2.22). Wilcoxon rank sum tests between groups indicated that those with *Infrequent flare-ups* (median = 90.00, IQR = 30.00) scored significantly higher than participants with *Occasional flare-ups* (median = 70.00, IQR = 40.00,  $p = 0.0264$ ), and higher than participants with *Frequent flare-ups* (median = 55.00, IQR = 40.00,  $p = 0.0011$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Role functioning/physical**” scale between groups,  $\chi^2(2) = 18.74, p < 0.0001$  (Table 2.22). Wilcoxon rank sum tests between groups indicated that those with *Infrequent flare-ups* (median = 100.00, IQR = 50.00) scored significantly higher than participants with *Occasional flare-ups* (median = 25.00, IQR = 75.00,  $p = 0.0022$ ), and higher than participants with *Frequent flare-ups* (median = 0.00, IQR = 50.00,  $p < 0.0001$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Role functioning/emotional**” scale between groups,  $\chi^2(2) = 6.43, p = 0.0401$  (Table 2.22). Wilcoxon rank sum tests between groups indicated that those with *Infrequent flare-ups* (median = 100.00, IQR = 33.33) scored significantly higher than participants with *Frequent flare-ups* (median = 66.67, IQR = 100.00,  $p = 0.0430$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Social functioning**” scale between groups,  $\chi^2(2) = 12.55, p = 0.0019$  (Table 2.22). Wilcoxon rank sum tests between groups indicated that those with *Infrequent flare-ups* (median = 75.00, IQR = 31.25) scored significantly higher than participants with *Occasional flare-ups* (median = 62.50, IQR = 25.00,  $p = 0.0297$ ), and higher than participants with *Frequent flare-ups* (median = 50.00, IQR = 40.63,  $p = 0.0017$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 General health**” scale between groups,  $\chi^2(2) = 12.08, p = 0.0024$  (Table 2.22). Wilcoxon rank sum tests between groups indicated that those with *Infrequent flare-ups* (median = 55.00, IQR = 35.00) scored significantly higher than participants with *Frequent flare-ups* (median = 27.50, IQR = 25.00,  $p = 0.0013$ ).

**Key differences**

“**SF36 Physical functioning**” measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities not limited at all for *Infrequent flare-ups* compared to moderately limited for *Frequent flare-ups*.

“**SF36 Role functioning/physical**” measures how physical health interferes with work or other activities. Physical health extremely interfered with work or other activities for participants with *Frequent flare-ups* compared to did not interfere at all with work or other activities for participants with *Infrequent flare-ups* and physical health interfered quite a bit with work or other activities for participants with *Occasional flare-ups*.

The “**SF36 Role functioning/emotional**” scale measures how emotional problems interfere with work or other activities. Emotional problems did not at all interfere with work or other activities for participants with *Infrequent flare-ups* compared to slightly interfered for participants with *Frequent flare-ups*.

“**SF36 Energy/fatigue**” measures the amount of energy or fatigue. Participants with *Infrequent flare-ups* felt tired some of the time and have energy some of the time compared to participants with *Frequent flare-ups* who felt tired most of the time and had energy a little of the time.

“**SF36 Social functioning**” measures limitations on social activities due to physical or emotional problems. Social activities were limited a little bit for participants with *Infrequent flares ups* and participants with *Occasional flare-ups* compared to moderately limited for participants with *Frequent flare ups*.

“**SF36 Pain**” measures the amount of pain, and how pain interferes with work and other activities. Participants with *Infrequent flare-ups* had little pain compared to moderate pain for participants with *Frequent flare-ups* .

“**SF36 General health**” measures general health. Participants with *Infrequent flare-ups* and had moderate general health compared to poor general health for participants with *Frequent flare-ups*.

Table 2.19: SF36 by Flare-ups summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	<i>Frequent flare-ups</i>	36	36.00	56.53	23.36	55.00	40.00
	<i>Occasional flare-ups</i>	41	41.00	65.00	25.71	70.00	40.00
	<i>Infrequent flare-ups</i>	23	23.00	78.48	25.25	90.00	30.00
Role functioning/physical	<i>Frequent flare-ups</i>	36	36.00	27.08	35.04	0.00	50.00
	<i>Occasional flare-ups</i>	41	41.00	39.02	41.85	25.00	75.00
	<i>Infrequent flare-ups</i>	23	23.00	75.00	36.93	100.00	50.00
Role functioning/emotional	<i>Frequent flare-ups</i>	36	36.00	50.00	46.12	66.67	100.00
	<i>Occasional flare-ups</i>	41	41.00	64.23	42.42	100.00	66.67
	<i>Infrequent flare-ups</i>	23	23.00	79.71	32.94	100.00	33.33
Energy/Fatigue*	<i>Frequent flare-ups</i>	36	36.00	34.44	21.74	30.00	35.00
	<i>Occasional flare-ups</i>	41	41.00	40.98	18.14	40.00	25.00
	<i>Infrequent flare-ups</i>	23	23.00	52.61	17.57	60.00	25.00
Emotional well-being	<i>Frequent flare-ups</i>	36	36.00	62.67	21.25	64.00	28.00
	<i>Occasional flare-ups</i>	41	41.00	69.37	17.38	72.00	32.00
	<i>Infrequent flare-ups</i>	23	23.00	70.78	14.74	72.00	12.00
Social functioning	<i>Frequent flare-ups</i>	36	36.00	52.78	28.68	50.00	40.63
	<i>Occasional flare-ups</i>	41	41.00	62.80	28.16	62.50	25.00
	<i>Infrequent flare-ups</i>	23	23.00	79.35	21.52	75.00	31.25
Pain	<i>Frequent flare-ups</i>	36	36.00	54.10	22.85	56.25	32.50
	<i>Occasional flare-ups</i>	41	41.00	58.66	26.32	57.50	32.50
	<i>Infrequent flare-ups</i>	23	23.00	76.63	22.44	80.00	22.50
General health	<i>Frequent flare-ups</i>	36	36.00	33.47	20.21	27.50	25.00
	<i>Occasional flare-ups</i>	41	41.00	42.32	24.52	35.00	40.00
	<i>Infrequent flare-ups</i>	23	23.00	55.00	20.62	55.00	35.00
Health change	<i>Frequent flare-ups</i>	36	36.00	47.22	33.15	50.00	50.00
	<i>Occasional flare-ups</i>	41	41.00	60.98	26.25	50.00	25.00
	<i>Infrequent flare-ups</i>	23	23.00	57.61	27.63	50.00	37.50

Table 2.20: SF36 by Flare-ups ANOVA table

SF36 Scale		Sum of squares	dF	Mean Square	F	p
Energy/fatigue	Between groups	4638.00	2	2318.80	6.16	0.0030*
	Within groups	36493.00	97	376.20		
	Total	41131.00	99			
Pain	Between groups	7557.00	2	3779.00	6.42	0.0024*
	Within groups	57061.00	97	588.00		
	Total	64618.00	99			

\*Statistically significant at  $P < 0.05$

Table 2.21: SF36 by Flare-ups post hoc Tukey HSD test

SF36 Scale	Flare-ups	Difference	Lower	Upper	P adjusted
Energy/fatigue	<i>Occasional flare-ups-Frequent flare-ups</i>	6.53	-4.01	17.08	0.3077
	<i>Infrequent flare-ups-Frequent flare-ups</i>	18.16	5.84	30.49	0.0020*
	<i>Infrequent flare-ups-Occasional flare-ups</i>	11.63	-0.39	23.66	0.0602
Pain	<i>Occasional flare-ups-Frequent flare-ups</i>	4.56	-8.62	17.75	0.6895
	<i>Infrequent flare-ups-Frequent flare-ups</i>	22.53	7.12	37.94	0.0022*
	<i>Infrequent flare-ups-Occasional flare-ups</i>	17.97	2.93	33.01	0.0149*

\*Statistically significant at  $P < 0.05$

Table 2.22: SF36 by Flare-ups Kruskal-Wallis test

SF36 Scale	X <sup>2</sup>	df	p
Physical functioning	13.37	2	0.0013*
Role functioning/physical	18.74	2	<0.0001*
Role functioning/emotional	6.43	2	0.0401*
Emotional well-being	2.51	2	0.2846
Social functioning	12.55	2	0.0019*
General health	12.08	2	0.0024*
Health change	3.25	2	0.1971

\*Statistically significant at P<0.05

Table 2.23: SF36 by Flare-ups post hoc pairwise Wilcoxon rank sum test

SF36 Scale	Flare-ups	Frequent flare-ups	Occasional flare-ups
Physical functioning	Occasional flare-ups	0.0922	
	Infrequent flare-ups	0.0011*	0.0264*
Role functioning/physical	Occasional flare-ups	0.2013	
	Infrequent flare-ups	<0.0001*	0.0022*
Role functioning/emotional	Occasional flare-ups	0.1970	
	Infrequent flare-ups	0.0430*	0.1990
Social functioning	Occasional flare-ups	0.1114	
	Infrequent flare-ups	0.0017*	0.0297*
General health	Occasional flare-ups	0.1266	
	Infrequent flare-ups	0.0013*	0.0533

\*Statistically significant at P<0.05

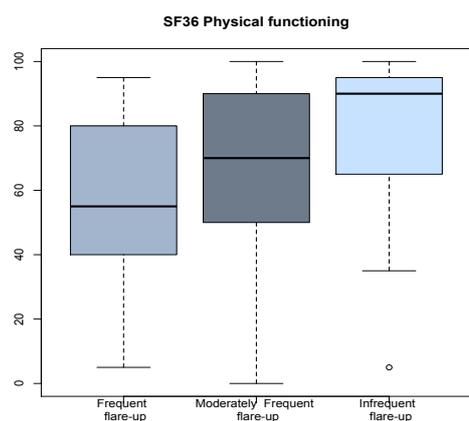


Figure 2.19: Boxplot of SF36 Physical functioning by Flare-ups

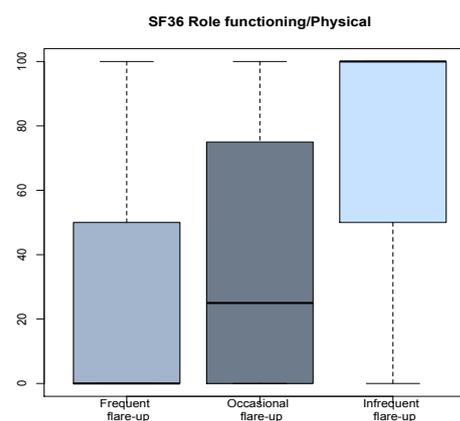


Figure 2.20: Boxplot of SF36 Role functioning/physical by Flare-ups

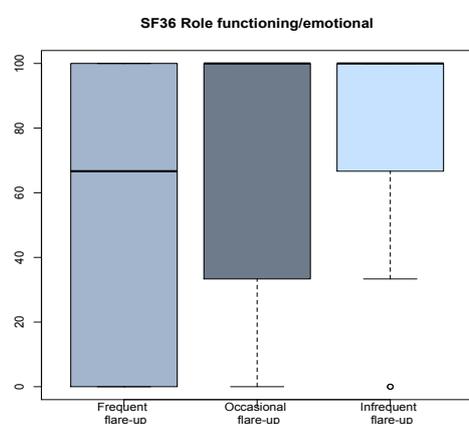


Figure 2.21: Boxplot of SF36 Role functioning/emotional by Flare-ups

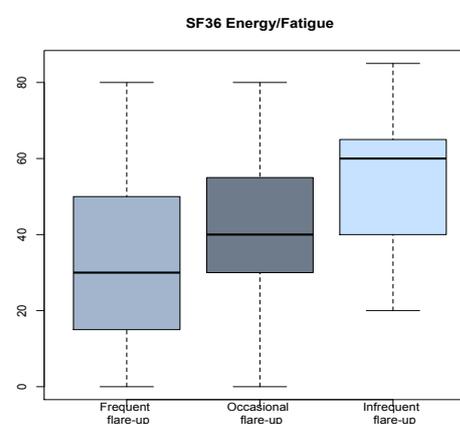


Figure 2.22: Boxplot of SF36 Energy/fatigue by Flare-ups

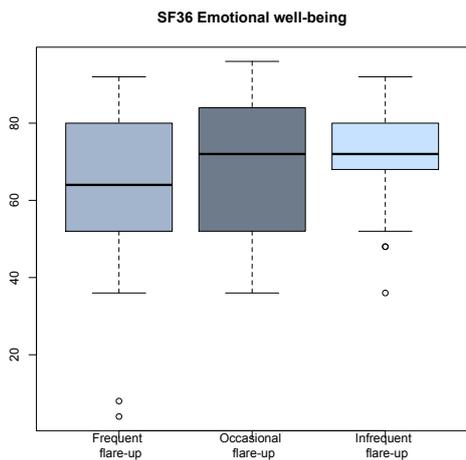


Figure 2.23: Boxplot of SF36 Emotional well-being by Flare-ups

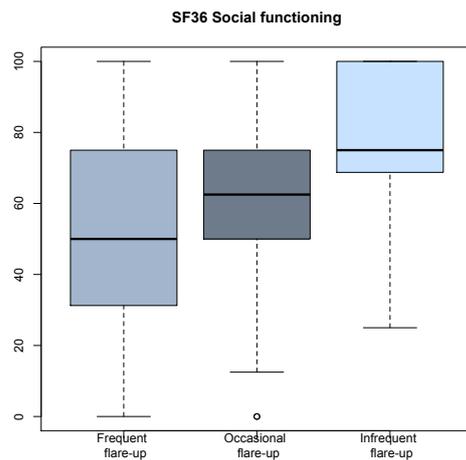


Figure 2.24: Boxplot of SF36 Social functioning by Flare-ups

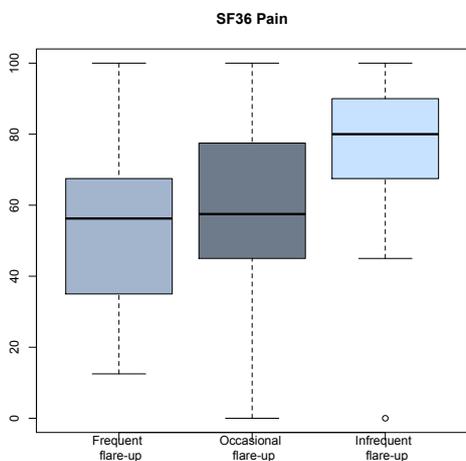


Figure 2.25: Boxplot of SF36 Pain by Flare-ups

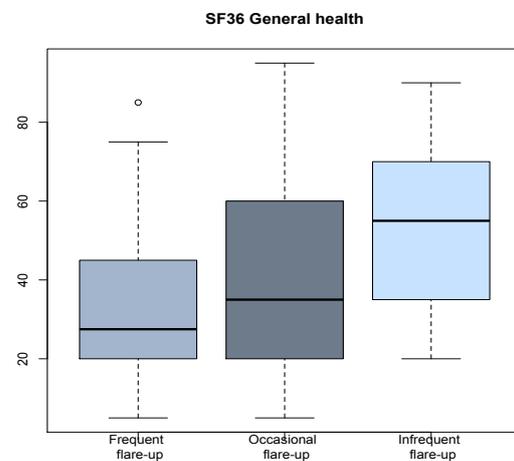


Figure 2.26: Boxplot of SF36 General health by Flare-ups

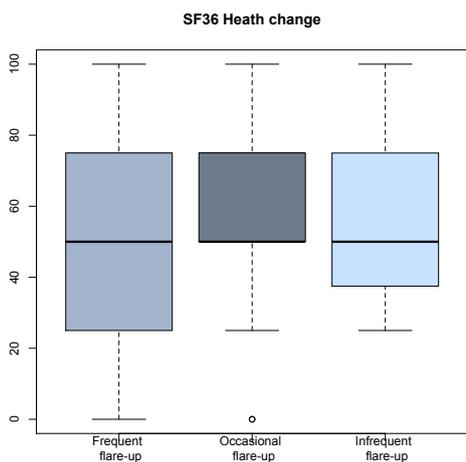


Figure 2.27: Boxplot of SF36 Health change by Flare-ups

### SF36 by Severity

Comparisons were made by **Severity**, between participants that reported having *Severe asthma* (n=29, 29.00%), and those that had *Non-severe asthma* (n=79, 79.00%). Participants in the *Severe asthma* sub-group included those who confirmed that they had been diagnosed with severe asthma in the semi-structured interview (this was then cross-checked with the treatments they are taking for verification), and those that were taking regular treatments beyond preventer and reliever medication including monoclonal antibodies, daily/very frequent oral corticosteroid use, long acting muscarinic antagonists, leukotriene receptor antagonists, or a high dose of regular treatment (such as high dose Seretide).

Boxplots of each SF36 scale by **Severity** are displayed in Figures 2.28 - 2.36, summary statistics are displayed in Tables 2.24 – 2.25. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.25).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“SF36 Role functioning/physical”** [W=697.00, p=0.0076] was significantly higher for those with *Non-severe asthma* (Median = 50.00, IQR = 100.00) compared to those with *Severe asthma* (Median = 0.00, IQR = 50.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“SF36 Social**

**functioning”** [W=744.50, p=0.0283] was significantly higher for those with *Non-severe asthma* (Median = 75.00, IQR = 50.00) compared to those with *Severe asthma* (Median = 50.00, IQR = 37.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“SF36 General health”** [W=717.50, p=0.0004] was significantly higher for those with *Non-severe asthma* (Median = 45.00, IQR = 37.50) compared to those with *Severe asthma* (Median = 30.00, IQR = 25.00).

#### Key differences

**“SF36 Role functioning/physical”** measures how physical health interferes with work or other activities. Physical health moderately interfered with work or other activities for *Non-severe asthma* compared to extremely interfered with work or other activities for *Severe asthma*.

**“SF36 Social functioning”** measures limitations on social activities due to physical or emotional problems. Social activities are slightly limited for participants with *Non-severe asthma* compared to moderately limited for participants with *Severe asthma*.

**“SF36 General health”** measures general health. Participants with *Non-severe asthma* had moderate general health compared to poor general health for participants with *Severe asthma*.

Table 2.24: SF36 by Severity two-sample t-test

SF36 Scale	Group	Count	Percent	Mean	SD	t	df	p
Energy/fatigue	<i>Severe asthma</i>	29	29.00	36.72	18.53	-1.44	98	0.1523
	<i>Non-severe asthma</i>	71	71.00	43.17	20.93			

Table 2.25: SF36 by Severity Wilcoxon rank sum test with continuity correction

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	<i>Severe asthma</i>	29	29.00	55.00	40.00	774.50	0.05254
	<i>Non-severe asthma</i>	71	71.00	70.00	37.50		
Role functioning/physical	<i>Severe asthma</i>	29	29.00	0.00	50.00	697.00	0.0076*
	<i>Non-severe asthma</i>	71	71.00	50.00	100.00		
Role functioning/emotional	<i>Severe asthma</i>	29	29.00	66.67	100.00	844.00	0.1267
	<i>Non-severe asthma</i>	71	71.00	100.00	83.33		
Emotional well-being	<i>Severe asthma</i>	29	29.00	64.00	28.00	887.50	0.2807
	<i>Non-severe asthma</i>	71	71.00	72.00	26.00		
Social functioning	<i>Severe asthma</i>	29	29.00	50.00	37.50	744.50	0.0283*
	<i>Non-severe asthma</i>	71	71.00	75.00	50.00		
Pain	<i>Severe asthma</i>	29	29.00	57.50	22.50	954.00	0.5662
	<i>Non-severe asthma</i>	71	71.00	57.50	40.00		
General health	<i>Severe asthma</i>	29	29.00	30.00	25.00	717.50	0.0175*
	<i>Non-severe asthma</i>	71	71.00	45.00	37.50		
Health change	<i>Severe asthma</i>	29	29.00	50.00	75.00	1092.00	0.6248
	<i>Non-severe asthma</i>	71	71.00	50.00	25.00		

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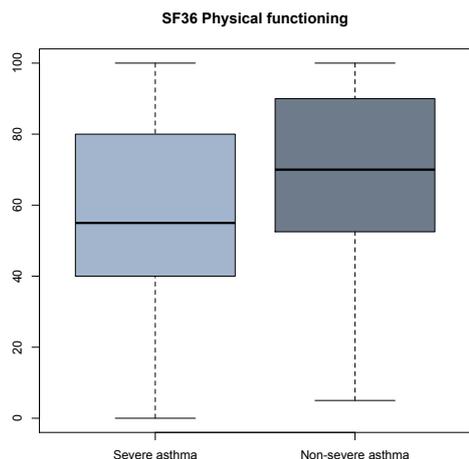


Figure 2.28: Boxplot of SF36 Physical functioning by Flare-ups

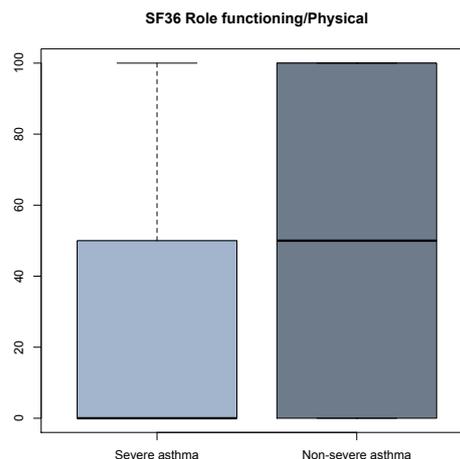


Figure 2.29: Boxplot of SF36 Role functioning/physical by Flare-ups

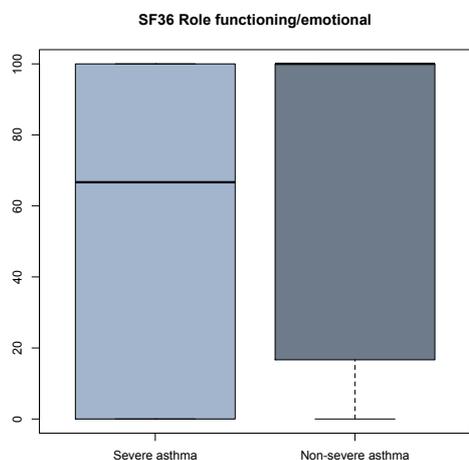


Figure 2.30: Boxplot of SF36 Role functioning/emotional by Flare-ups

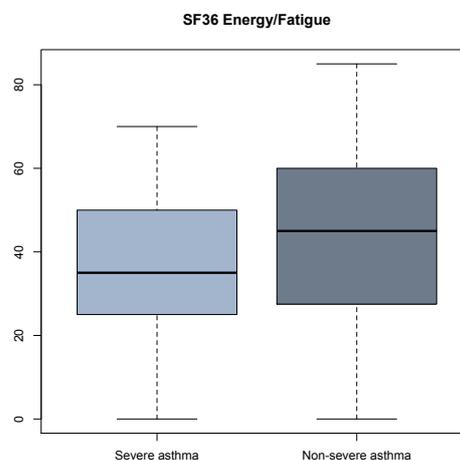


Figure 2.31: Boxplot of SF36 Energy/fatigue by Flare-ups

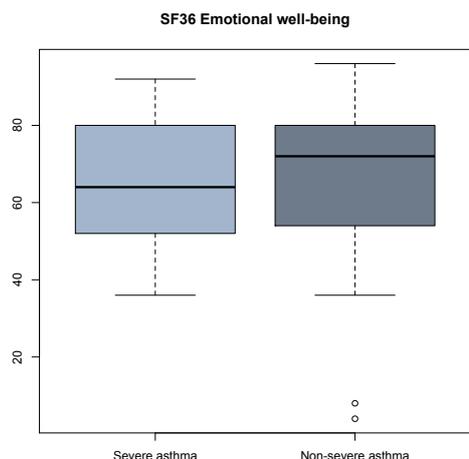


Figure 2.32: Boxplot of SF36 Emotional well-being by Flare-ups

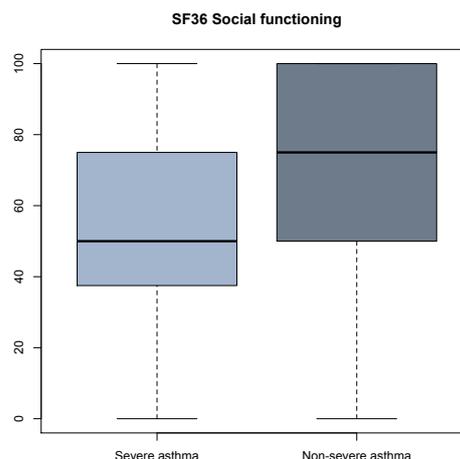


Figure 2.33: Boxplot of SF36 Social functioning by Flare-ups

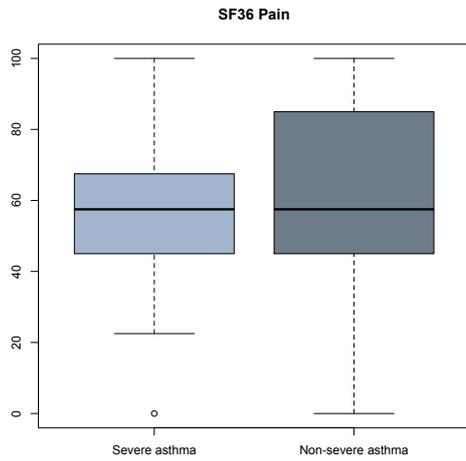


Figure 2.34: Boxplot of SF36 Pain by Flare-ups

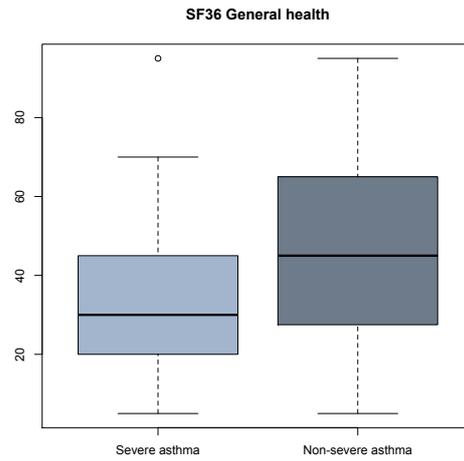


Figure 2.35: Boxplot of SF36 General health by Flare-ups

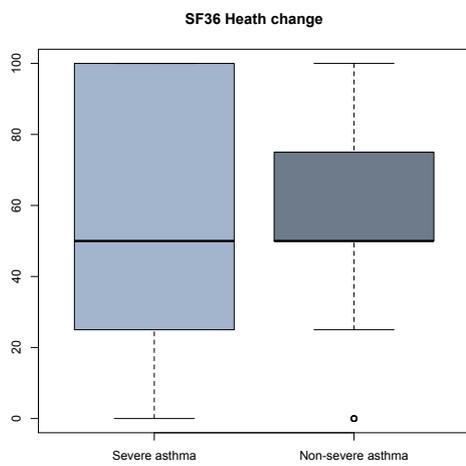


Figure 2.36: Boxplot of SF36 Health change by Flare-ups

### SF36 by Sleep disruption

Comparisons were made by the frequency of **Sleep disruption**, those who noted in the Asthma control test the frequency that they had sleep disruptions due to asthma. Those that had sleep disruptions once a week or more frequently “Frequent sleep disruption” (n=59, 59.00%) were compared to those who responded that they had sleep disruptions once a month or not at all “Infrequent sleep disruption” (n=41, 41.00%).

Boxplots of each SF36 scale by **Sleep disruption** are displayed in Figures 2.37-2.45, summary statistics are displayed in Tables 2.26 – 2.27. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.27).

A two sample t-test indicated that the mean score for the “**SF36 Energy/fatigue**” [t(98) = -2.42, p=0.0174] was significantly higher for those with *Infrequent sleep disruption* (Mean = 75.00, SD = 21.65 compared to those with *Frequent sleep disruption*) (Mean = 58.14, SD = 26.49).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Physical functioning**” [W=744.00, p=0.0011] was significantly higher for those with *Infrequent sleep disruption* (Median = 80.00, IQR = 35.00) compared to those with *Frequent sleep disruption* (Median = 55.00, IQR = 45.00)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Role functioning/physical**” [W=711.50, p=0.0002] was significantly higher for those with *Infrequent sleep disruption* (Median = 75.00, IQR = 75.00) compared to those with *Frequent sleep disruption* (Median = 0.00, IQR = 50.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Social functioning**” [W=877.00, p=0.0182] was significantly higher for those with *Infrequent sleep disruption* (Median = 75.00, IQR = 50.00) compared to those with *Frequent sleep disruption* (Median = 62.50, IQR = 31.25).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Pain**”

[W=689.00, p=0.0002] was significantly higher for those with *Infrequent sleep disruption* (Median = 77.50, IQR = 32.50) compared to those with *Frequent sleep disruption* (Median = 57.50, IQR = 27.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 General health**” [W=846.50, p<0.0108] was significantly higher for those with *Infrequent sleep disruption* (Median = 50.00, IQR = 35.00) compared to those with *Frequent sleep disruption* (Median = 35.00, IQR = 25.00).

#### Key differences

“**SF36 Physical functioning**” measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities were limited a little for participants with *Infrequent sleep disruption* compared to moderately limited for participants with *Frequent sleep disruption*.

“**SF36 Role functioning/physical**” measures how physical health interferes with work or other activities. Physical health interfered a little with work or other activities for participants with *Infrequent sleep disruption* compared to extremely interferes with work or other activities for participants with *Frequent sleep disruption*.

“**SF36 Energy/fatigue**” measures the amount of energy or fatigue. Participants with *Infrequent sleep disruption* felt tired a little of the time and had energy most of the time compared to participants with *Frequent sleep disruption* who felt tired some of the time and had energy some of the time.

“**SF36 Social functioning**” measures limitations on social activities due to physical or emotional problems. Participants with *Infrequent sleep disruption* scored significantly higher than those with *Frequent sleep disruption*. However, the scores indicated that social activities were limited a little bit for both groups.

“**SF36 Pain**” measures the amount of pain, and how pain interferes with work and other activities. Participants with *Infrequent sleep disruption* had little pain compared to moderate pain for participants with *Frequent sleep disruption*.

Table 2.26: SF36 by Sleep disruption two-sample t-test

SF36 Scale	Group	Count	Percent	Mean	SD	t	dF	p
Energy/fatigue	<i>Frequent sleep disruption</i>	59	59.00	58.14	26.49	-2.42	98	0.0174*
	<i>Infrequent sleep disruption</i>	41	41.00	75.00	21.65			

\*Statistically significant at  $P < 0.05$

Table 2.27: SF36 by Sleep disruption Wilcoxon rank sum test with continuity correction

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	<i>Frequent sleep disruption</i>	59	59.00	55.00	45.00	744.00	0.0011*
	<i>Infrequent sleep disruption</i>	41	41.00	80.00	35.00		
Role functioning/physical	<i>Frequent sleep disruption</i>	59	59.00	0.00	50.00	711.50	0.0002*
	<i>Infrequent sleep disruption</i>	41	41.00	75.00	75.00		
Role functioning/emotional	<i>Frequent sleep disruption</i>	59	59.00	66.67	100.00	1049.50	0.2245
	<i>Infrequent sleep disruption</i>	41	41.00	100.00	66.67		
Emotional well-being	<i>Frequent sleep disruption</i>	59	59.00	68.00	28.00	1063.00	0.3045
	<i>Infrequent sleep disruption</i>	41	41.00	72.00	24.00		
Social functioning	<i>Frequent sleep disruption</i>	59	59.00	62.50	31.25	877.00	0.0182*
	<i>Infrequent sleep disruption</i>	41	41.00	75.00	50.00		
Pain	<i>Frequent sleep disruption</i>	59	59.00	57.50	27.50	689.00	0.0002*
	<i>Infrequent sleep disruption</i>	41	41.00	77.50	32.50		
General health	<i>Frequent sleep disruption</i>	59	59.00	35.00	25.00	846.50	0.0108*
	<i>Infrequent sleep disruption</i>	41	41.00	50.00	35.00		
Health change	<i>Frequent sleep disruption</i>	59	59.00	50.00	50.00	1025.00	0.1805
	<i>Infrequent sleep disruption</i>	41	41.00	50.00	25.00		

\*Statistically significant at  $P < 0.05$

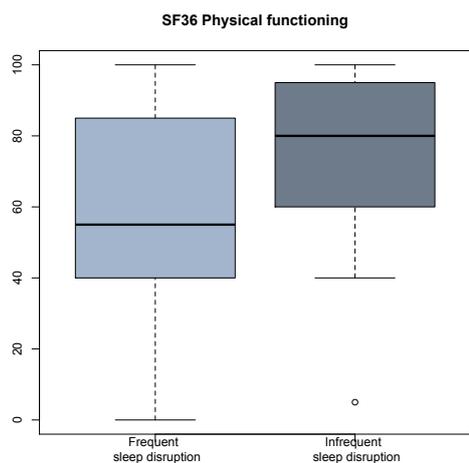


Figure 2.37: Boxplot of SF36 Physical functioning by Sleep disruption

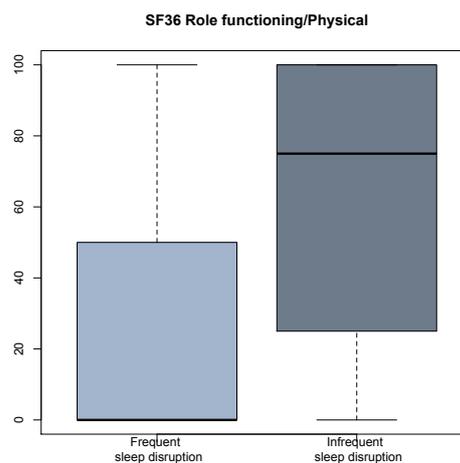


Figure 2.38: Boxplot of SF36 Role functioning/physical by Sleep disruption

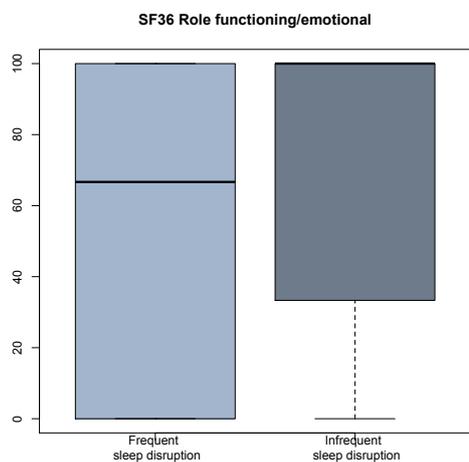


Figure 2.39: Boxplot of SF36 Role functioning/emotional by Sleep disruption

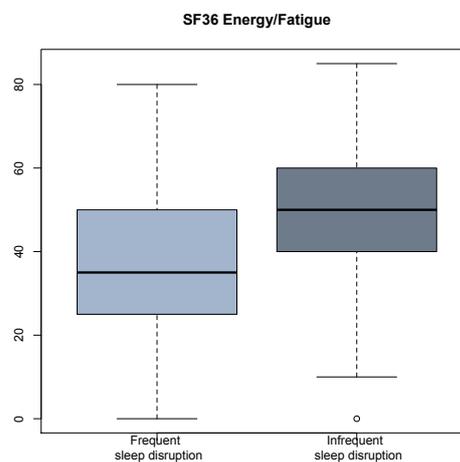


Figure 2.40: Boxplot of SF36 Energy/fatigue by Sleep disruption

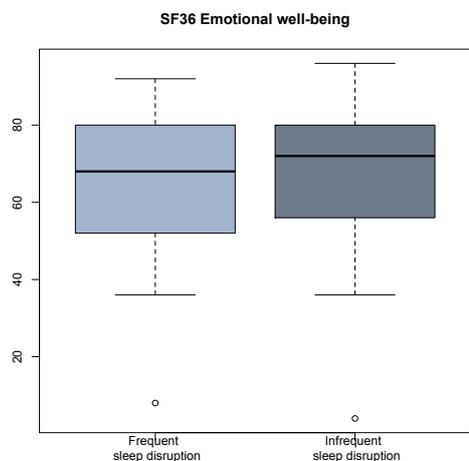


Figure 2.41: Boxplot of SF36 Emotional well-being by Sleep disruption

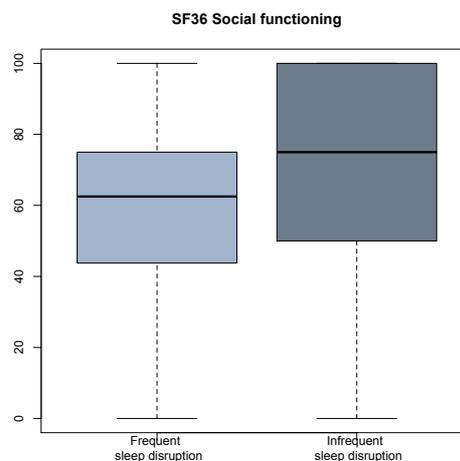


Figure 2.42: Boxplot of SF36 Social functioning by Sleep disruption

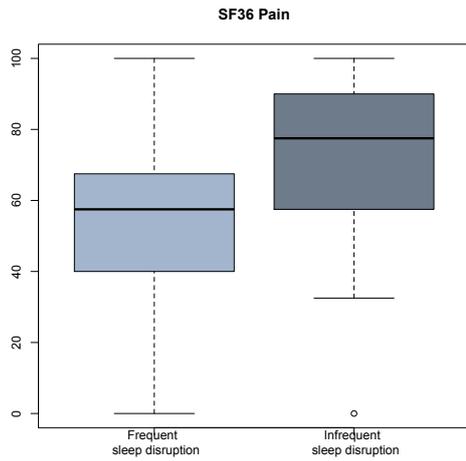


Figure 2.43: Boxplot of SF36 Pain by Sleep disruption

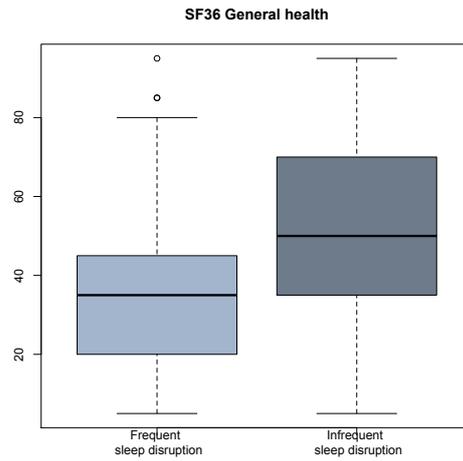


Figure 2.44: Boxplot of SF36 General health by Sleep disruption

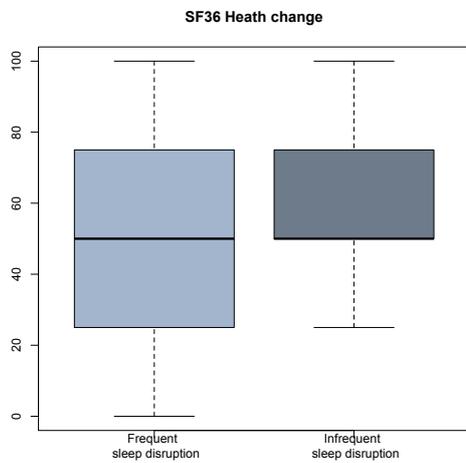


Figure 2.45: Boxplot of SF36 Health change by Sleep disruption

### SF36 by Age

Comparisons were made by the **Age** of the participants, those that were “aged 18 – 34” (n=23, 23.00%), “aged 35 – 54” (n=42, 42.00%) and participants “aged 55 or older” (n=35, 35.00%).

Boxplots of each SF36 scale by **age** are displayed in Figures 2.46-2.54, summary statistics are displayed in Table 2.28.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (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).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Physical functioning**” scale between groups [ $\chi^2(2) = 8.52, p=0.0141$ ]. Wilcoxon rank sum tests between groups indicated that those *Aged 18 to 34* (median = 75.00, IQR = 30.00,  $p=0.0210$ ), and participants *Aged 35 to 54* (median = 80.00, IQR = 40.00,  $p=0.0210$ ) scored significantly higher than participants *Aged 55 or older* (median = 55.00, IQR = 35.00).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Role functioning/physical**” scale between groups,  $\chi^2(2) = 6.43, p = 0.0402$ . Wilcoxon rank sum tests between groups indicated that those *Aged 18 to 34* (median = 75.00, IQR = 75.00) scored significantly higher than participants *Aged 55 or older* (median = 0.00, IQR = 50.00,  $p=0.0390$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the “**SF36 Emotional well-being**” scale between groups [ $\chi^2(2) = 7.27, p = 0.0264$ ]. Wilcoxon rank sum tests between groups indicated that those *Aged 35 to 54* (median = 76.00, IQR = 31.00,  $p=0.0240$ ), and participants *Aged 55 or older* (median = 68.00, IQR = 22.00,  $p=0.0240$ ),  $p =$ , scored significantly higher than participants *Aged 18 to 34* (median = 60.00, IQR = 26.00).

#### Key differences

“**SF36 Physical functioning**” measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities were limited a little for *Aged 18 to 34*, and *Aged 35 to 54* compared to moderately limited for participants *Aged 55 or older*.

“**SF36 Role functioning/physical**” measures how physical health interferes with work or other activities. Physical health interfered a little with work or other activities for participants *Aged 18 to 34* compared to extremely interferes with work or other activities for participants with *Aged 55 or older*.

The “**SF36 Emotional well-being**” scale which measures how a person feels, for example happy, calm, depressed or anxious. Participants *Aged 35 to 54* and participants *Aged 55 or older* felt happy and calm most of the time, and anxious and depressed a little of the time compared to participants *Aged 18 to 34* who felt happy and calm some of the time, and anxious and depressed some of the time.

Table 2.28: SF36 by Age summary statistics

SF36 Scale	Group	Count	Percent	Mean	SD	Median	IQR
Physical functioning	Aged 18 to 34	23	23.00	71.74	22.19	75.00	30.00
	Aged 35 to 44	42	42.00	69.40	26.44	80.00	40.00
	Aged 55 or older	35	35.00	55.43	25.30	55.00	35.00
Role functioning/physical	Aged 18 to 34	23	23.00	58.70	40.32	75.00	75.00
	Aged 35 to 44	42	42.00	45.24	42.85	50.00	100.00
	Aged 55 or older	35	35.00	30.00	39.67	0.00	50.00
Role functioning/emotional	Aged 18 to 34	23	23.00	49.28	40.04	66.67	83.33
	Aged 35 to 44	42	42.00	69.84	42.81	100.00	66.67
	Aged 55 or older	35	35.00	62.86	44.11	100.00	83.33
Energy/Fatigue*	Aged 18 to 34	23	23.00	35.65	19.03	35.00	20.00
	Aged 35 to 44	42	42.00	44.29	21.74	45.00	40.00
	Aged 55 or older	35	35.00	41.43	19.31	40.00	25.00
Emotional well-being	Aged 18 to 34	23	23.00	56.87	22.20	60.00	26.00
	Aged 35 to 44	42	42.00	70.10	17.81	76.00	31.00
	Aged 55 or older	35	35.00	70.74	14.15	68.00	22.00
Social functioning	Aged 18 to 34	23	23.00	58.15	30.99	50.00	31.25
	Aged 35 to 44	42	42.00	65.18	31.06	75.00	46.88
	Aged 55 or older	35	35.00	63.57	23.75	62.50	25.00
Pain	Aged 18 to 34	23	23.00	66.85	27.53	57.50	50.00
	Aged 35 to 44	42	42.00	60.71	29.13	67.50	35.00
	Aged 55 or older	35	35.00	57.93	18.81	57.50	22.50
General health	Aged 18 to 34	23	23.00	40.00	26.02	35.00	37.50
	Aged 35 to 44	42	42.00	44.76	23.89	45.00	45.00
	Aged 55 or older	35	35.00	40.14	21.26	35.00	27.50
Health change	Aged 18 to 34	23	23.00	56.52	29.40	50.00	25.00
	Aged 35 to 44	42	42.00	55.36	30.51	50.00	25.00
	Aged 55 or older	35	35.00	54.29	29.38	50.00	50.00

Table 2.29: SF36 by Age ANOVA table

SF36 Scale		Sum of squares	dF	Mean Square	F	p
Energy/fatigue	Between groups	1109.00	2	554.30	1.34	0.2660
	Within groups	40022.00	97	412.60		
	Total	41131.00	99			

Table 2.30: SF36 by Age Kruskal-Wallis test

SF36 Scale	$\chi^2$	df	p
Physical functioning	8.52	2	0.0141*
Role functioning/physical	6.43	2	0.0402*
Role functioning/emotional	4.56	2	0.1022
Emotional well-being	7.27	2	0.0264*
Social functioning	1.13	2	0.5672
Pain	1.73	2	0.4216
General health	0.94	2	0.6254
Health change	0.34	2	0.8416

\*Statistically significant at  $P < 0.05$

Table 2.31: SF36 by Age post hoc pairwise Wilcoxon rank sum test

SF36 Scale		Aged 18 -34	Aged 35 - 54
Physical functioning	Aged 35 to 54	0.8150	
	Aged 55 or older	0.0210*	0.0210*
Role functioning/physical	Aged 35 to 54	0.2470	
	Aged 55 or older	0.0390*	0.1680
Emotional well-being	Aged 35 to 54	0.0240*	
	Aged 55 or older	0.0240*	0.9300

\*Statistically significant at P<0.05

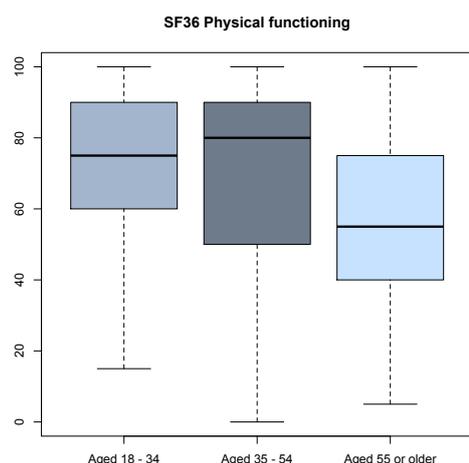


Figure 2.46: Boxplot of SF36 Physical functioning by Age

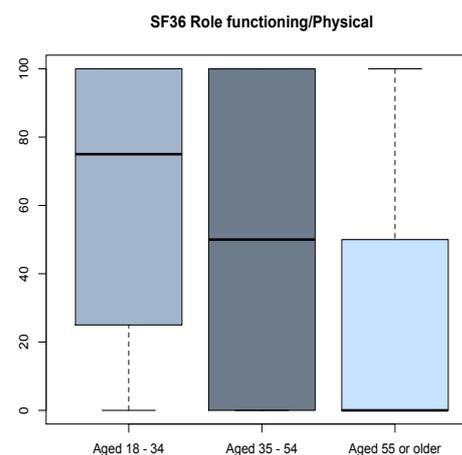


Figure 2.47: Boxplot of SF36 Role functioning/physical by Age

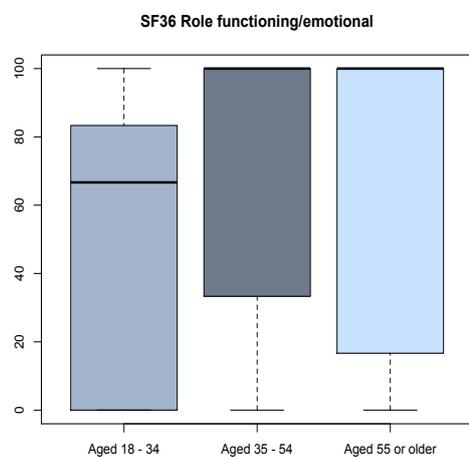


Figure 2.48: Boxplot of SF36 Role functioning/emotional by Age

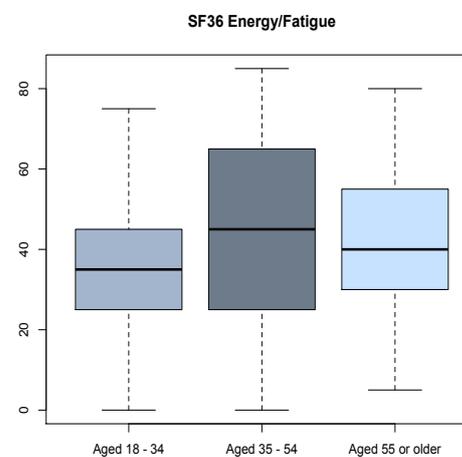


Figure 2.49: Boxplot of SF36 Energy/fatigue by Age

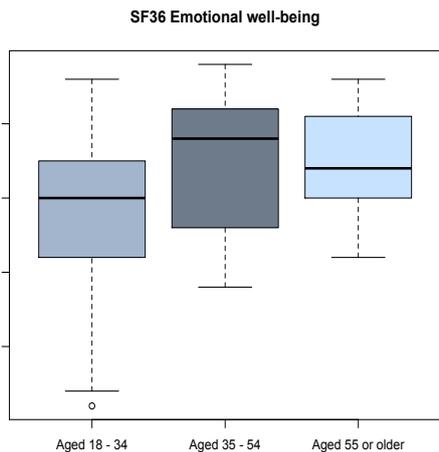


Figure 2.50: Boxplot of SF36 Emotional well-being by Age

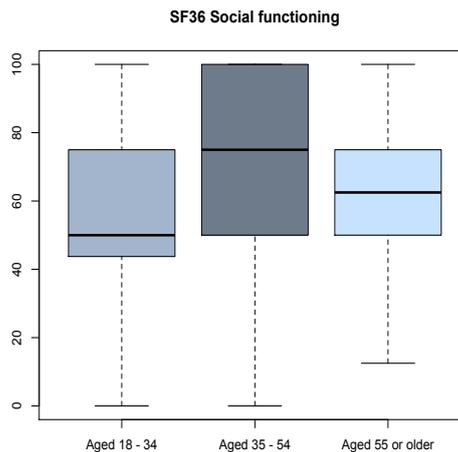


Figure 2.51: Boxplot of SF36 Social functioning by Age

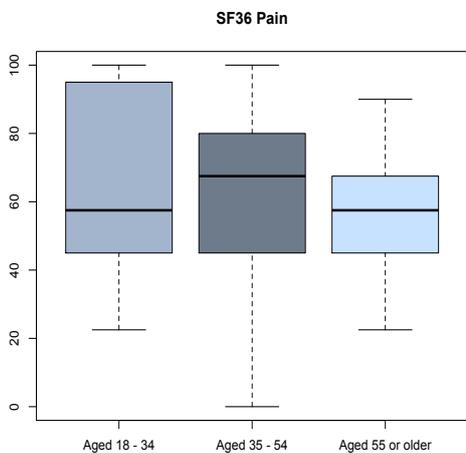


Figure 2.52: Boxplot of SF36 Pain by Age

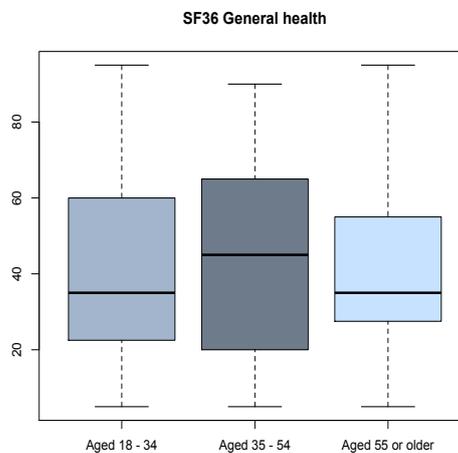


Figure 2.53: Boxplot of SF36 General health by Age

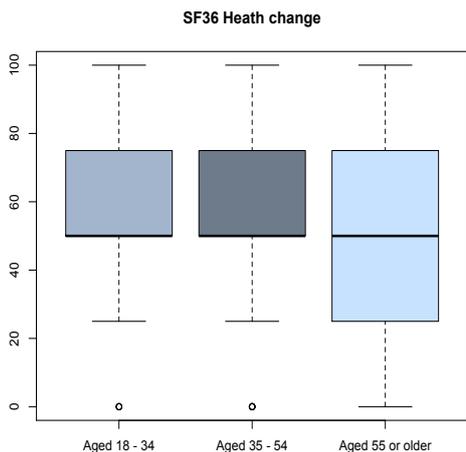


Figure 2.54: Boxplot of SF36 Health change by Age

## SF36 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 major city, “*metropolitan*” (n=66, 66.00%) were compared to those living in regional/rural areas, “*regional or remote*” (n=34, 34.00%).

Boxplots of each SF36 scale by **Location** are displayed in Figures 2.55 - 2.63, summary statistics are displayed in Tables 2.32 – 2.33. A two-sample t-test was used when assumptions for normality and variance were

met (Table 2.30), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.31). No significant differences were observed between participants by **Location** for any of the “**SF36**” scales.

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

**Table 2.32: SF36 by Location two-sample t-test**

SF36 Scale	Group	Count	Percent	Mean	SD	t	dF	p
Energy/fatigue	<i>Metropolitan</i>	66	66.00	42.80	19.22	1.03	98	0.3066
	<i>Regional or remote</i>	34	34.00	38.38	22.49			

**Table 2.33: SF36 by Location Wilcoxon rank sum test with continuity correction**

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	<i>Metropolitan</i>	66	66.00	72.50	40.00	1353.00	0.0926
	<i>Regional or remote</i>	34	34.00	55.00	35.00		
Role functioning/physical	<i>Metropolitan</i>	66	66.00	50.00	100.00	1346.00	0.0852
	<i>Regional or remote</i>	34	34.00	0.00	50.00		
Role functioning/emotional	<i>Metropolitan</i>	66	66.00	100.00	66.67	1336.50	0.0906
	<i>Regional or remote</i>	34	34.00	50.00	100.00		
Emotional well-being	<i>Metropolitan</i>	66	66.00	70.00	24.00	1163.50	0.7646
	<i>Regional or remote</i>	34	34.00	68.00	28.00		
Social functioning	<i>Metropolitan</i>	66	66.00	75.00	34.38	1211.50	0.5111
	<i>Regional or remote</i>	34	34.00	62.50	46.88		
Pain	<i>Metropolitan</i>	66	66.00	57.50	35.00	1242.00	0.3813
	<i>Regional or remote</i>	34	34.00	62.50	40.00		
General health	<i>Metropolitan</i>	66	66.00	40.00	35.00	1339.00	0.1138
	<i>Regional or remote</i>	34	34.00	35.00	37.50		
Health change	<i>Metropolitan</i>	66	66.00	50.00	25.00	1137.50	0.9098
	<i>Regional or remote</i>	34	34.00	50.00	25.00		

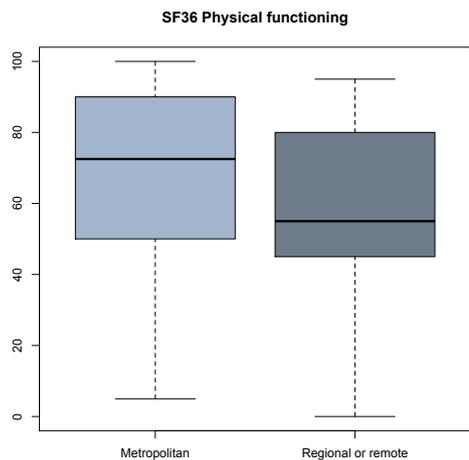


Figure 2.55: Boxplot of SF36 Physical functioning by Location

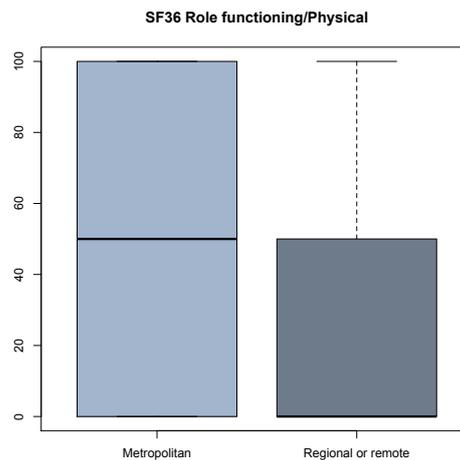


Figure 2.56: Boxplot of SF36 Role functioning/physical by Location

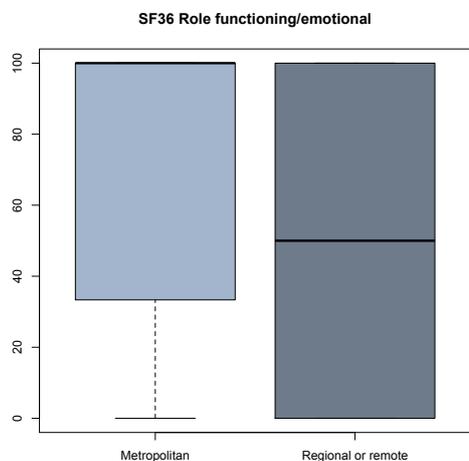


Figure 2.57: Boxplot of SF36 Role functioning/emotional by Location

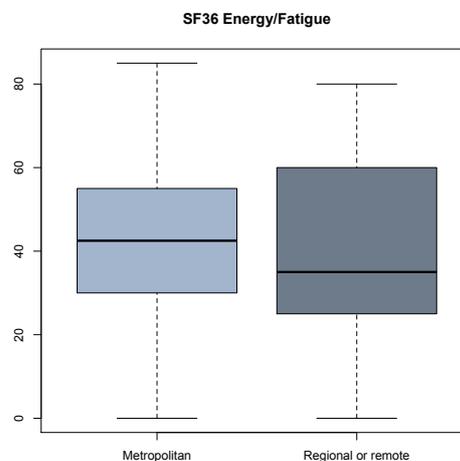


Figure 2.58: Boxplot of SF36 Energy/fatigue by Location

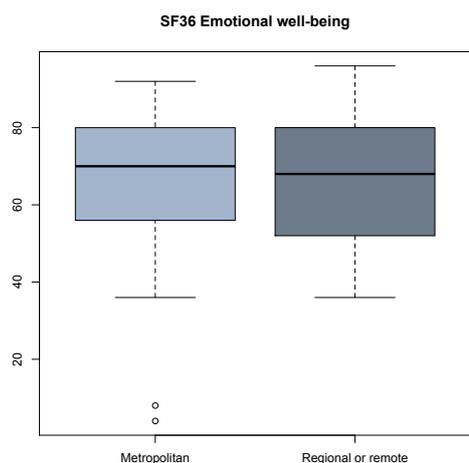


Figure 2.59: Boxplot of SF36 Emotional well-being by Location

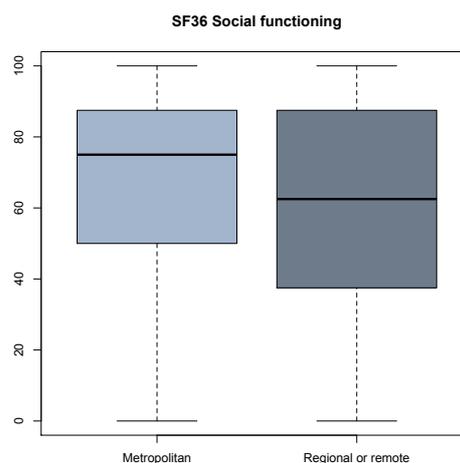


Figure 2.60: Boxplot of SF36 Social functioning by Location

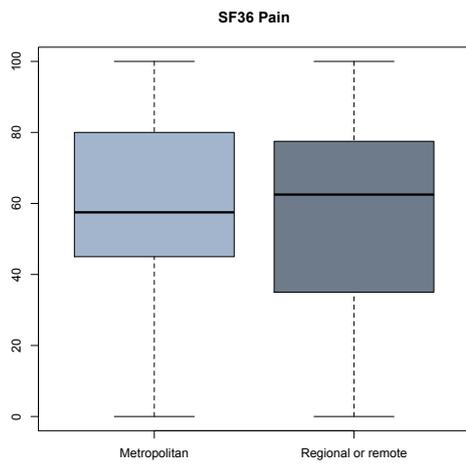


Figure 2.61: Boxplot of SF36 Pain by Location

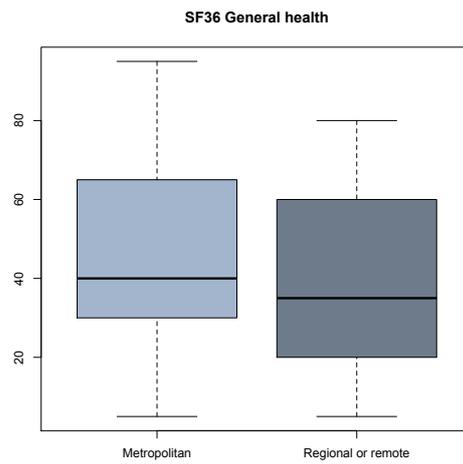


Figure 2.62: Boxplot of SF36 General health by Location

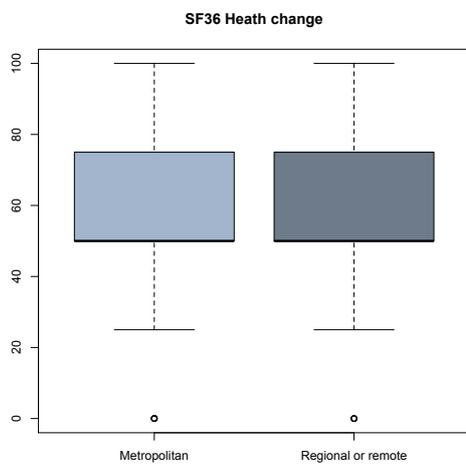


Figure 2.63: Boxplot of SF36 Health change by Location

### SF36 by Education

Comparisons were made by **Education** status, between those with a university qualification, “University” (n=56, 56.00%), and those with trade or high school qualifications, “trade or high school” (n=44, 44.00%).

Boxplots of each SF36 scale by **Education** are displayed in Figures 2.64 - 2.72, summary statistics are displayed in Tables 2.34 – 2.35. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.34), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.35).

A two sample t-test indicated that the mean score for the “**SF36 Energy/fatigue**” [t(98) = -2.08, p=0.0399] was significantly higher for those with *University* qualifications (Mean = 45.00, SD= 18.93) compared to those with *Trade or high school* qualifications (Mean = 36.59, SD = 21.40).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 Physical functioning**” [W=865.50, p=0.0108] was significantly higher for those with *University* qualifications (Median = 80.00, IQR =40.00) compared to those with *Trade or high school* qualifications (Median =60.00, IQR = 36.25).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the “**SF36 General**

**health**” [W=900.50, p=0.0211] was significantly higher for those with *University* qualifications (Median =45.00, IQR = 31.25) compared to those with *Trade or high school* qualifications (Median = 30.00, IQR =25.00).

#### Key differences

“**SF36 Physical functioning**” measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. Physical activities were limited a little for participants in the *University* sub-group, compared to moderately limited for participants in the *Trade or high school* sub-group.

“**SF36 Energy/fatigue**” measures the amount of energy or fatigue. Participants in the *University* sub-group felt tired some of the time and had energy some of the time compared to participants in the *Trade or high school* sub-group who felt tired most of the time and had energy a little of the time

“**SF36 General health**” measures general health. Participants in the *University* sub-group had moderate general health compared to poor general health for participants in the *Trade or high school* sub-group.

**Table 2.34: SF36 by Education two-sample t-test**

SF36 Scale	Group	Count	Percent	Mean	SD	t	dF	p
Energy/fatigue	<i>Trade or high school</i>	44	44.00	36.59	21.40	-2.08	98	0.0399*
	<i>University</i>	56	56.00	45.00	18.93			

\*Statistically significant at P<0.05

Table 2.35: SF36 by Education Wilcoxon rank sum test with continuity correction

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	Trade or high school	44	44.00	60.00	36.25	865.50	0.0108*
	University	56	56.00	80.00	40.00		
Role functioning/physical	Trade or high school	44	44.00	12.50	75.00	1042.50	0.1648
	University	56	56.00	50.00	100.00		
Role functioning/emotional	Trade or high school	44	44.00	66.67	100.00	1003.50	0.0853
	University	56	56.00	100.00	66.67		
Emotional well-being	Trade or high school	44	44.00	66.00	29.00	975.00	0.0739
	University	56	56.00	76.00	25.00		
Social functioning	Trade or high school	44	44.00	62.50	37.50	1024.00	0.1437
	University	56	56.00	75.00	37.50		
Pain	Trade or high school	44	44.00	57.50	35.63	990.50	0.0920
	University	56	56.00	67.50	35.00		
General health	Trade or high school	44	44.00	30.00	25.00	900.50	0.0211*
	University	56	56.00	45.00	31.25		
Health change	Trade or high school	44	44.00	50.00	25.00	1217.50	0.9196
	University	56	56.00	50.00	31.25		

\*Statistically significant at P<0.05

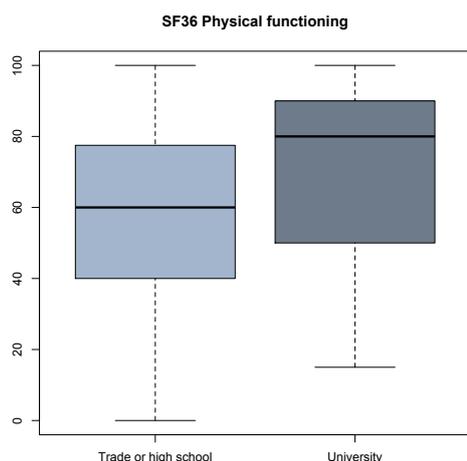


Figure 2.64: Boxplot of SF36 Physical functioning by Education

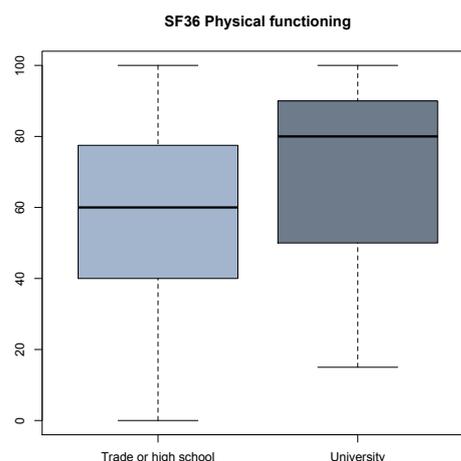


Figure 2.65: Boxplot of SF36 Role functioning/physical by Education

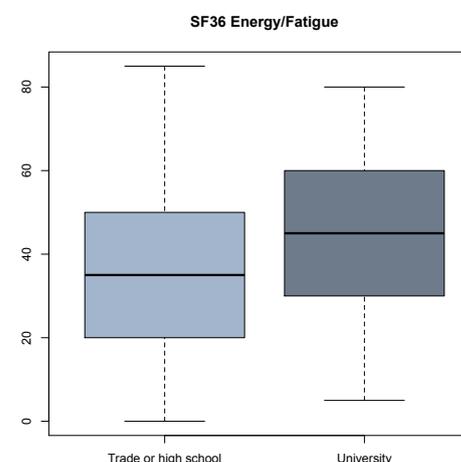
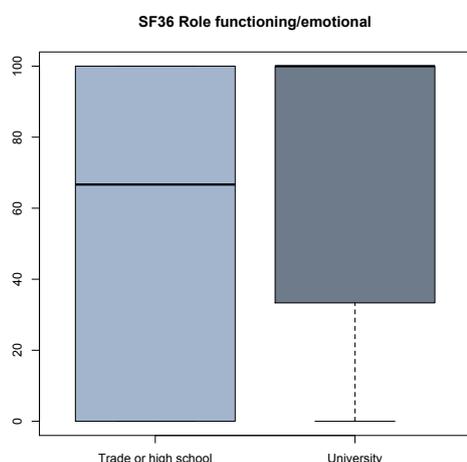


Figure 2.66: Boxplot of SF36 Role functioning/emotional by Education

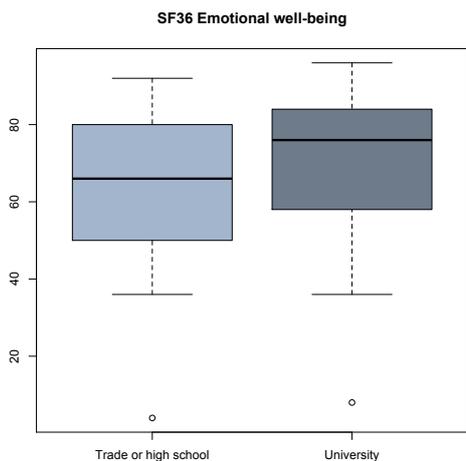


Figure 2.67: Boxplot of SF36 Energy/fatigue by Education

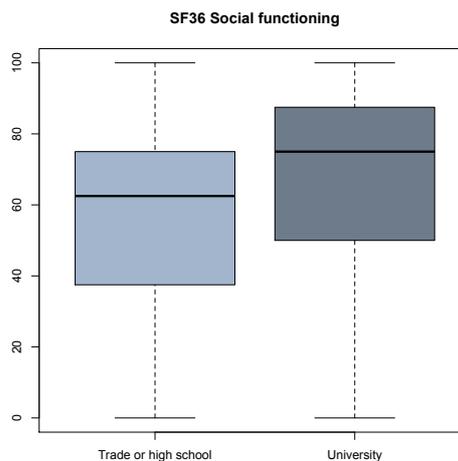


Figure 2.68: Boxplot of SF36 Emotional well-being by Education

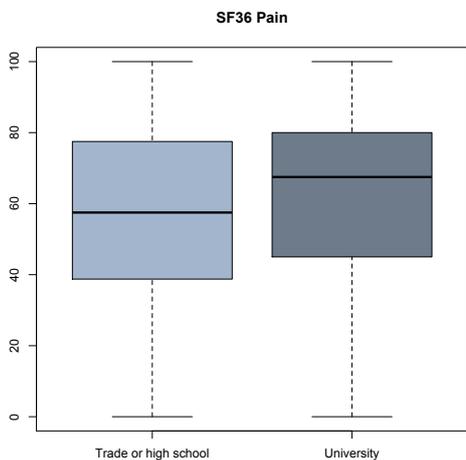


Figure 2.69: Boxplot of SF36 Social functioning by Education

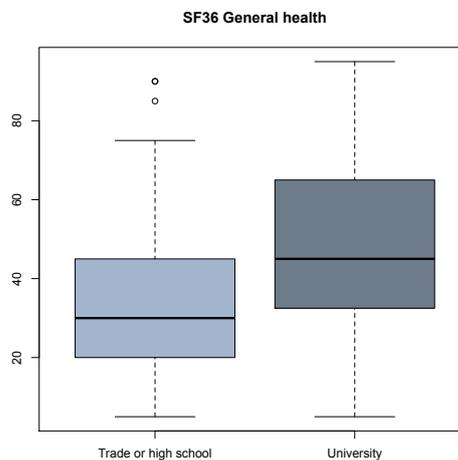


Figure 2.70: Boxplot of SF36 Pain by Education

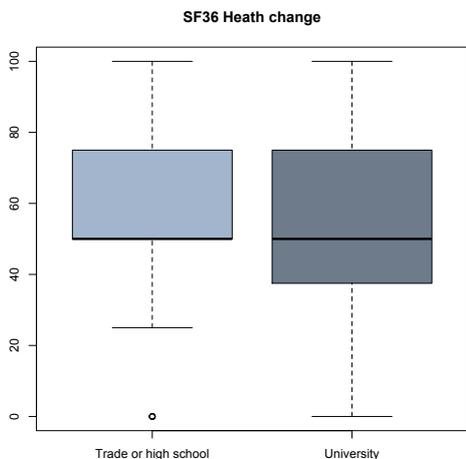


Figure 2.71: Boxplot of SF36 General health by Education

Figure 2.73: Boxplot of SF36 Health change by Education

### SF36 by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, where a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, "High SEIFA" (n=56, 56.00%) compared to those with a mid to low SEIFA score of 1-6, "Mid to low SEIFA" (n=44, 44.00%).

Boxplots of each SF36 scale by SEIFA are displayed in Figures 2.73-2.81, summary statistics are displayed in Table 2.36. 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 2.36).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the "SF36 Role

function/emotional" [W=1562.00, p=0.0129] was significantly higher for those who lived in an area with a *High SEIFA* (Median = 100.00, IQR =66.67) compared to those who lived in an area with a *Mid to low SEIFA* (Median =66.67, IQR = 100.00).

#### Key differences

The "SF36 Role functioning/emotional" scale measures how emotional problems interfere with work or other activities. Emotional problems did not at all interfere with work or other activities for participants in the *High SEIFA* sub-group compared to moderately interfered for participants with in the *Mid to low SEIFA* sub-group.

**Table 2.36: SF36 by SEIFA Wilcoxon rank sum test with continuity correction**

SF36 Scale	Group	Count	Percent	Median	IQR	W	p
Physical functioning	<i>High SEIFA</i>	56	56.00	75.00	40.00	1480.50	0.0842
	<i>Mid to low SEIFA</i>	44	44.00	60.00	45.00		
Role functioning/physical	<i>High SEIFA</i>	56	56.00	50.00	100.00	1377.50	0.2865
	<i>Mid to low SEIFA</i>	44	44.00	50.00	75.00		
Role functioning/emotional	<i>High SEIFA</i>	56	56.00	100.00	66.67	1562.00	0.0129*
	<i>Mid to low SEIFA</i>	44	44.00	66.67	100.00		
Energy/fatigue	<i>High SEIFA</i>	56	56.00	45.00	30.00	1480.50	0.0842
	<i>Mid to low SEIFA</i>	44	44.00	35.00	35.00		
Emotional well-being	<i>High SEIFA</i>	56	56.00	72.00	20.00	1346.50	0.4269
	<i>Mid to low SEIFA</i>	44	44.00	68.00	30.00		
Social functioning	<i>High SEIFA</i>	56	56.00	75.00	37.50	1417.00	0.1936
	<i>Mid to low SEIFA</i>	44	44.00	56.25	28.13		
Pain	<i>High SEIFA</i>	56	56.00	67.50	35.00	1465.00	0.1041
	<i>Mid to low SEIFA</i>	44	44.00	57.50	35.00		
General health	<i>High SEIFA</i>	56	56.00	40.00	35.00	1476.00	0.0897
	<i>Mid to low SEIFA</i>	44	44.00	35.00	31.25		
Health change	<i>High SEIFA</i>	56	56.00	50.00	25.00	1314.00	0.5567
	<i>Mid to low SEIFA</i>	44	44.00	50.00	50.00		

\*Statistically significant at P<0.05

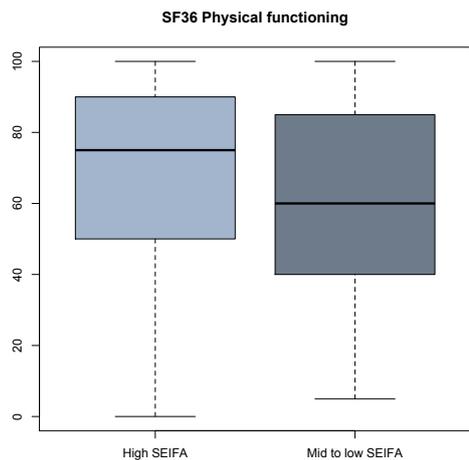


Figure 2.73: Boxplot of SF36 Physical functioning by SEIFA

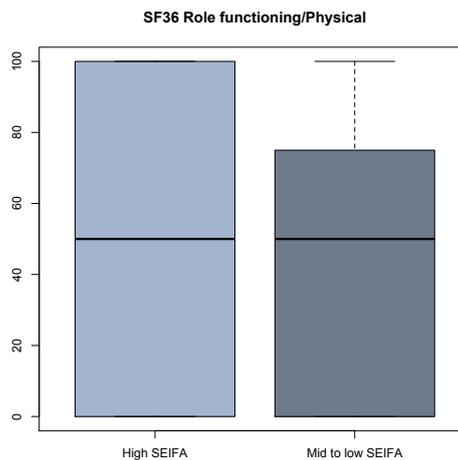


Figure 2.74: Boxplot of SF36 Role functioning/physical by SEIFA

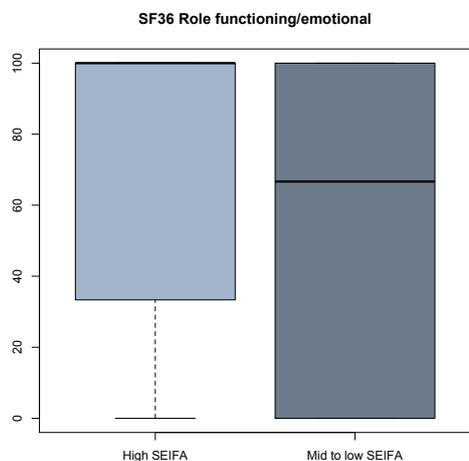


Figure 2.75: Boxplot of SF36 Role functioning/emotional by SEIFA

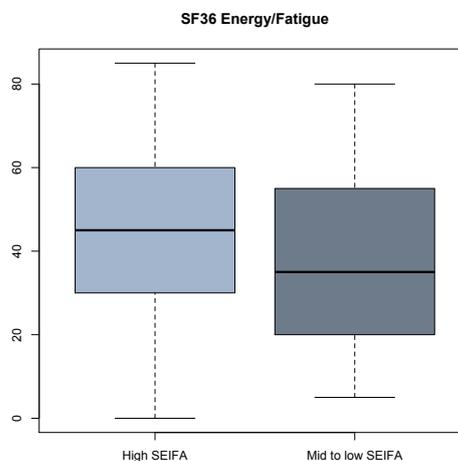


Figure 2.76: Boxplot of SF36 Energy/fatigue by SEIFA

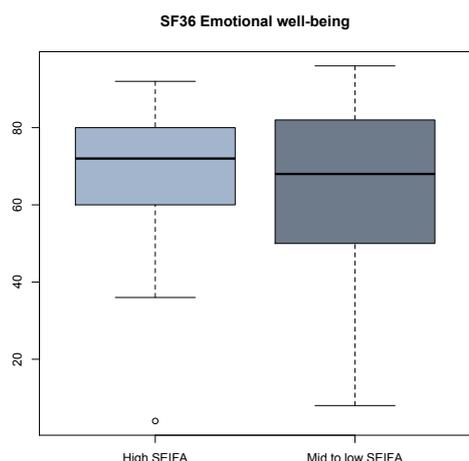


Figure 2.77: Boxplot of SF36 Emotional well-being by SEIFA

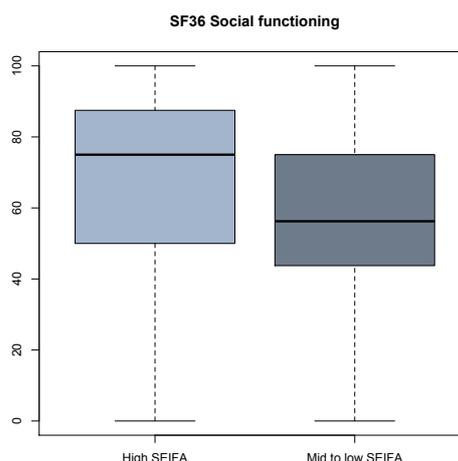


Figure 2.78: Boxplot of SF36 Social functioning by SEIFA

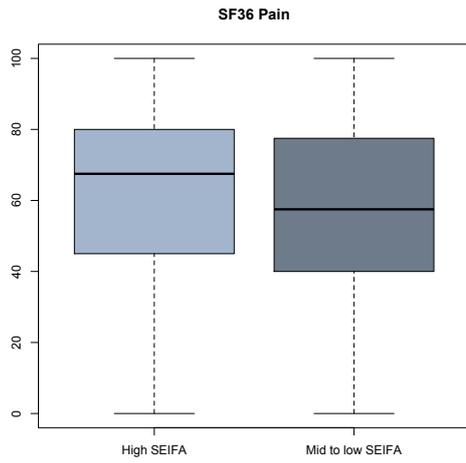


Figure 2.79: Boxplot of SF36 Pain by SEIFA

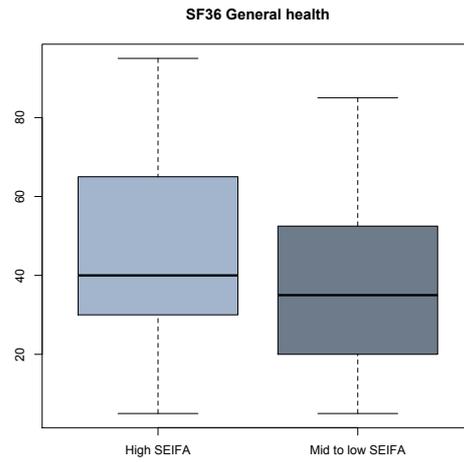


Figure 2.80: Boxplot of SF36 General health by SEIFA

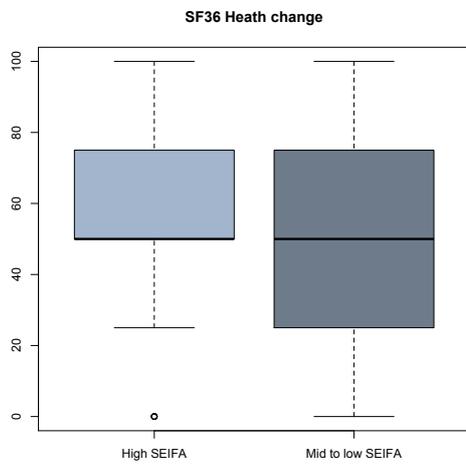


Figure 2.81: Boxplot of SF36 Health change by SEIFA

# Section 3 Symptoms and diagnosis

## Section 3: Symptoms and diagnosis

### Symptoms

The most common symptoms experienced were coughing or wheezing attacks worsened by a respiratory virus, such as a cold or the flu (n=91, 91.00%), trouble sleeping (caused by shortness of breath, coughing or wheezing) (n=87, 87.00%) and shortness of breath (n=85, 85.00%). Whistling or wheezing sound when exhaling (n=71, 71.00%) and chest tightness or pain (n=72, 72.00%) were experienced by most participants. The median quality of life while experiencing symptoms was in the “Life was distressing” range for all of these symptoms.

### Symptoms leading to diagnosis

The most common symptom leading to diagnosis was difficulty breathing (n=39, 39.00%). There were 27 participants (27.00%) who described having been too young to remember, and ten participants (10.00%) who described having bronchitis or a chest infection. Other symptoms leading to diagnosis included recalling hospitalisation but being too young to remember (n=8, 8.00%).

### Diagnostic tests

Of the 92 participants who could recall the diagnostic tests, participants had between one and seven diagnostic tests, most commonly three tests (n=22, 23.91%) or five tests (n=21, 22.83%) (median = 3.00, IQR = 3.00). The most common diagnostic test was a physical examination (n=76, 82.61%), followed by spirometry tests (n=69, 75.00%).

### Time from diagnostic tests to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis, 78 participants (78.00%) were able to recall the length of time, more than half of these were diagnosed immediately (n=50, 64.10%), however for 13 participants (16.67%) the result took 4 weeks or more.

### Diagnosis provider and location

Of the 81 participants who could recall who gave the asthma diagnosis, the majority of participants were given their diagnosis by a general practitioner (n=69, 85.19%). Of the 93 participants who could recall where the diagnosis was given, most received their diagnosis at the General Practice (n=56, 60.22%).

### Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. There were 28 participants (28.00%) that described themselves or their parents knowing nothing about asthma, and this was the most common theme. There were 22 participants (22.00%) noting that themselves or their parents knew very little about asthma. There were 13 participants (13.00%) that described that they knew of asthma but not in great detail due to a family member or friend with asthma, and 9 participants (9.00%) that knew a good amount about asthma due to a family member or friend with asthma.

### Emotional support at diagnosis

Participants were asked in the online questionnaire how much support they/their family received between diagnostic testing and diagnosis. Approximately a third of participants had enough support (n=32, 32.00%), 44 participants (44.00%) had no support, and 24 participants (24.00%) had some support but it wasn't enough.

### Information provided at diagnosis

Participants were asked in the online questionnaire how much information they/their family received at diagnosis. Approximately a third of participants had enough information (n=33, 33.00%), 44 participants (44.00%) had some information but not enough and 23 participants (23.00%) had no information.

### Costs at diagnosis

Of the 32 participants who could recall out of pocket costs, the majority had no out of pocket costs at diagnosis (n=20, 62.50%), and 12 participants paid between \$40 and \$1,200 in out of pocket expenses. A follow-up question about the burden of costs at diagnosis revealed that, for 33 participants (41.25%), the cost was either slightly significant or not significant at all. For 23 participants (28.75%) the out of pocket expenses were moderately significant, and for 24 participants (30.00%) the burden of out of pocket expenses were moderately or extremely significant.

### Genetic tests and biomarkers

Participants answered questions in the online questionnaire about biomarkers, genomic and gene testing. Almost all the participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=97, 97.00%). The majority of participants have not had any testing but would like to (n=83, 83.00%). The majority of participants were not sure if they had specific biomarkers (a total of 93, 93.00%), however while not sure of any specific biomarkers, 55 participants (55.00%) had a family history of asthma and/or allergies.

### Disease description

The **Asthma control test** is a five-item questionnaire that helps determine level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. The most common response for each of the questions is as follows: asthma kept participants from getting work done some of the time (n=34, 34.00%); participants has shortness of breath 1-2 times a week (n=33, 33.00%); participants sleep was disturbed by asthma symptoms 2-3 nights a week (n=33, 33.00%); participants used reliever medication 1-2 times a day (n=30, 30.00%); and an equal number of participants rated their asthma control as somewhat controlled (n=37, 37.00%) or well controlled (n=37, 37.00%).

The **Asthma control test score** is a total of the responses from each question, it ranges from 5 (poorly controlled) to 25 (under control). The majority of the participants scored between 5 and 19 (n=74, 74.00%), which indicated that their asthma may not have been controlled, 21 participants (21.00%) scored between 20 and 24, indicating that asthma was reasonably well controlled and 5 participants (5.00%) score 25 indicating asthma that was under control.

### Frequency of flare-up or asthma attack

Participants described the frequency of flare-up or asthma attack, the most common responses were 21 participants who described a flare-up once a month (21.00%), 18 participants who described a flare-up once a day (18.00%), and 18 participants who described a flare-up once a week (18.00%).

### Time with symptom before seeking medical attention

Participants noted in the online questionnaire the symptoms the length of time they have waited to seek medical attention or schedule an appointment with GP due to a list of symptoms. "Severe shortness of breath, chest tightness or pain, and coughing or wheezing" was the symptom where most participants had sought medical attention (n=95, 95.00%), and "Low peak flow readings when using a peak flow meter" was the symptom were only half of the participants had sought medical attention (n=50, 50.00%).

The most common symptoms that participants sought medical attention quickly were "The inability to speak more than short phrases due to shortness of breath and "Symptoms that fail to respond to use of a quick-acting (rescue) inhaler". The symptoms where participants waited for two days or longer for medical attention were "Severe shortness of breath, chest tightness or pain, and coughing or wheezing" and "Symptoms that fail to respond to use of a quick-acting (rescue) inhaler".

### Common ways of dealing with a flare-up or asthma attack

Participants noted in the online questionnaire the common ways that they deal with an asthma flare-up or attack. Almost all participants used a puffer (n=95, 95.00%), the next most common way to deal with an attack was to try to relax (n=43, 43.00%).

### Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common theme was that their condition is controlled and managed with medication (n=34, 34.00%). There were 15 participants (15.00%) that understood the relationship with allergies and triggers, and the need to manage those to maintain their health, and 14 participants (14.00%) that understood that asthma is a lifelong condition that will need to be managed. There were 8 participants (8.00%) that understood asthma as a serious, scary or possibly life-threatening condition, and 8 participants (8.00%) understood that their asthma is not controlled and it is complex to manage

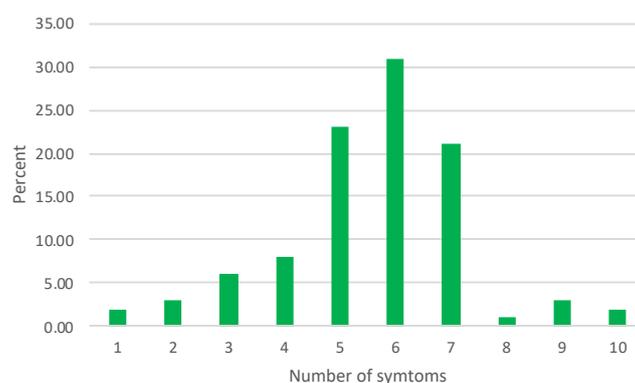
### Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis. Participants had between zero and nine symptoms (median = 5.00, IQR=2.00), most commonly five symptoms (n=31, 31.00%) (Table 3.1). The most common symptoms were coughing or wheezing attacks that were worsened by a respiratory virus, such as a cold or the flu (n=91, 91.00%), trouble sleeping caused by shortness of breath, coughing or wheezing (n=87, 87.00%) and shortness of breath (n=85, 95.00%) (Table 3.2). Whistling or wheezing sound when exhaling (n=71) and chest tightness or pain (n=72) were experienced by most participants. Other symptoms (noted by five or more participants) include exhaustion, fatigue, or lethargy (n=7), Infections (n=6) and allergies (n=5).

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 3.2, Figures 3.2 to 3.6). The median quality of life was in the “Life was distressing” range for all of the symptoms listed in the questionnaire.

**Table 3.1: Number of symptoms per participant**

Number of symptoms	Count	Percent
0	2	2.00
1	3	3.00
2	6	6.00
3	8	8.00
4	23	23.00
5	31	31.00
6	21	21.00
7	1	1.00
8	3	3.00
9	2	2.00
Summary statistics		
Mean	4.61	
SD	1.67	
Median	5.00	
IQR	2.00	



**Figure 3.1: Number of participants per participant**

**Table 3.2: Symptoms and quality of life**

Symptoms	Shortness of breath	Chest tightness or pain	Trouble sleeping caused by shortness of breath, coughing or wheezing	Whistling or wheezing sound when exhaling	Coughing or wheezing attacks that are worsened by a respiratory virus, such as a cold or the flu
Count	85	72	87	71	91
Percent	85	72.00	87.00	71.00	91.00
Average	2.71	2.71	2.53	2.86	2.21
SD	1.50	1.44	1.36	1.46	1.33
Median	2.00	2.00	2.00	2.00	2.00
IQR	2.00	1.25	1.00	2.00	2.00

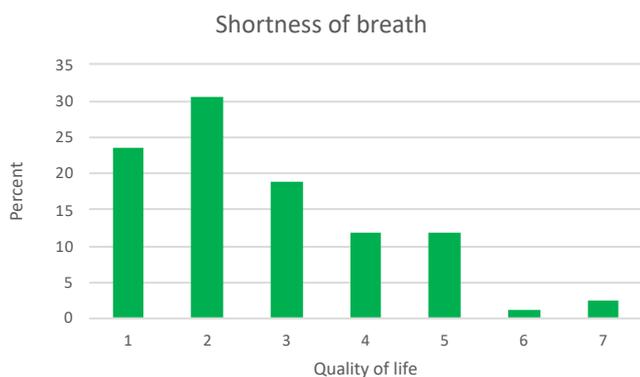


Figure 3.2: Quality of life from shortness of breath

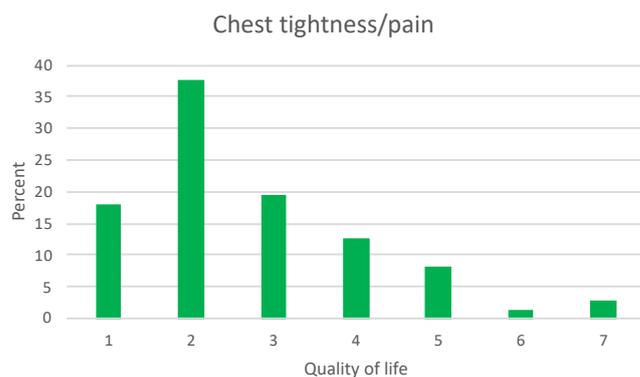


Figure 3.3: Quality of life from chest tightness/pain

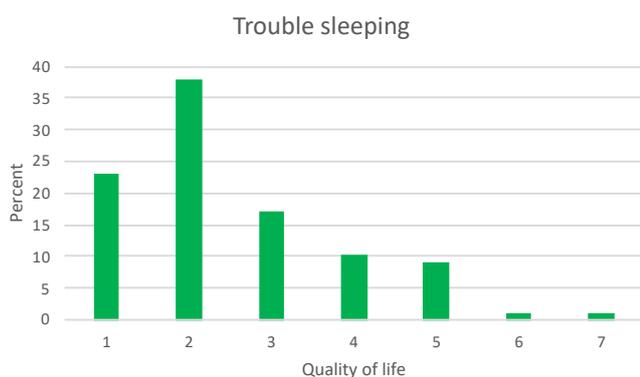


Figure 3.4: Quality of life from trouble sleeping

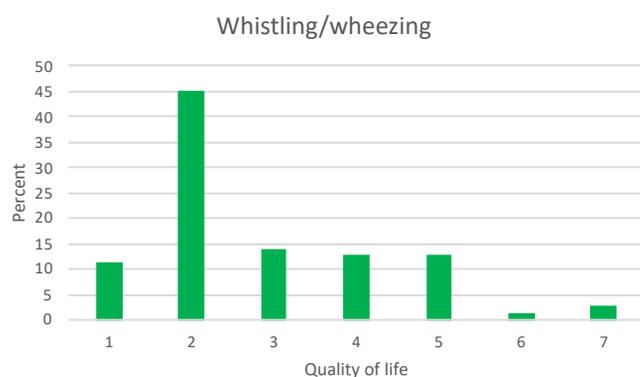


Figure 3.5: Quality of life from whistling/wheezing



Figure 3.6: Quality of life from cough wheeze/attack

### 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 difficulty breathing (n=39, 39.00%). There were 27 participants (27.00%) who described having been too young to remember, and 10 participants (10.00%) who described having bronchitis or a chest infection. Other symptoms leading to diagnosis included recalling hospitalisation but being too young to remember (n=8, 8.00%).

In relation to sub-group variations, participants in the *Moderately controlled asthma* sub-group (27.27%) and participants in the *Severe asthma* sub-group (27.59%) described difficulty breathing less frequently than the general population (39.00%). Participants in the *Controlled asthma* sub-group described recalling hospitalization but being too young to remember more frequently (19.23%) than the general population (8.00%).

### Participant describes experiencing difficulty breathing (including shortness of breath, wheezing, and cough not related to a cold/flu)

*I was in my very early childhood. I could have been maybe four, three or four when it first started becoming apparent. It was generally happening around night-time. When it got cold, I would get very short of breath and I guess this was like 25 years ago now. I was staying on my grandparent's property. This is my first known memory of it, I was staying on my grandparent's property and I couldn't breathe. Participant 93*

*It was on one of those, on a very smoky day in LOCATION, that I got extremely short of breath in a way that you would say, "Well, that's asthma or could potentially be asthma." I just went, "Oh, this is your classic--" what everyone thinks an asthma attack is, that sort of experience. I hobbled off to see my GP and said, "I think I've got asthma. Can you check me out?" He listened to my symptoms, listened to my top chest, whatever. He said, "I don't think you have. You need to go and see a specialist." I hobbled on to a specialist who checked me out and he said, "On the basis of that, I think you have, but I want you to go away, take this medication for a month. Go and do the respiratory blood thing and come back," which I did. He went, "No, you've got asthma". Participant 78*

*I was 25. I'd just moved to LOCATION. All of a sudden, I had trouble with shortness of breath and wheezing, which I thought was some high fever type allergy to maybe a new plant or something. I took myself off to the doctor and he said, "You have asthma." I had led an interesting time between 18 and 25, maybe, working and drinking too much. I hadn't looked after my health and hadn't been to the doctor. I just presumed I had an allergy. I would say it was a lot to do with when I was smoking and not looking at my health. Yes, he just said, "You have asthma. Here is a puffer." Participant 71*

### Participant describes being too young to remember symptoms leading to diagnosis

*To be honest, I can't really remember because I was diagnosed when I was three. I've not known anything else if you know what I mean? Participant 21*

*Yes. I was diagnosed with asthma pretty soon after I was born. I talked to my mum about it and she said it was pretty much something that was diagnosed like within a few weeks after I was born. I've had it my whole life so, it's kind of like a normal thing to me I guess. Yes. Participant 90*

*As far as I know, I've always had asthma. I remember having asthma as a child. My earliest memories of primary school would be taking a Ventolin to school, as young as I can remember, I had Ventolin in my bag and in my pocket. Participant 47*

Participant describes having bronchitis or chest infection leading to asthma diagnosis

*Yes. I had bronchitis as it turned out and I'd stayed home. I had an important meeting and my wife actually attended to on my behalf and after about 10 minutes, I felt so cross and found it very hard to breathe and at this stage, I hadn't-- I had had childhood asthma, but I hadn't had asthma for about 30 years. I wasn't thinking and didn't recognize asthma, except that I felt terrible, but I couldn't actually pick up the phone. Participant 18*

*I think I was about 20, 21 and I had been on a holiday. I had been on a cruise actually. I came back and I had a dreadful infection in my chest, and it seemed to go on. I went back to this doctor - the GP - and he gave me a lot of antibiotics and different process for the chest. I think it was just insulin and it really didn't improve. I think I was getting a bit anxious about it at that time too. I remember one day, I really just couldn't breathe, I was really breathless and distressed. Participant 97*

*I was diagnosed literally my final weeks of university, literally about two days before I finished. I got up for work to go for the oral assessment process we had to do in groups. I can remember getting up. I can remember picking myself up off the floor an hour later, went to a doctor and they said, "You've got a chest infection and by the way, you're an asthmatic." That was my diagnosis process. Participant 46*

Participant describes being too young to remember symptoms leading to diagnosis, but recalls being hospitalised

*Well, I was born with asthma. The earliest memory I have is being hospitalised as a young girl, about four, in NAME Hospital in the LOCATION, where I was in a bed with the tent around it, the see-through tent. Participant 98*

*...I certainly don't remember much, other than I was whipped off to hospital, because it was quite severe. Participant 29*

*My first recollections of being asthmatic were between four and five. By that point, rather than going into the hospital every time I had a flare-up, they'd actually given my parents a nebulizer so that I could be treated at home, and just spending all night on the nebulizer. Participant 8*

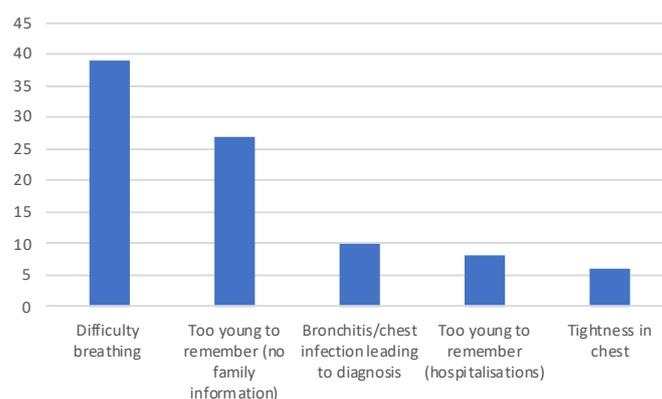


Figure 3.7: Symptoms leading to diagnosis

Table 3.3: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes experiencing difficulty breathing (including shortness of breath, wheezing, and cough not related to a cold/flu)	39	39.00	12	46.15	6	27.27	21	40.38	18	37.50	12	33.33	17	41.46	10	43.48
Participant describes being too young to remember symptoms leading to diagnosis	27	27.00	6	23.08	6	27.27	17	32.69	10	20.83	8	22.22	12	29.27	7	30.43
Participant describes having bronchitis or chest infection leading to asthma diagnosis	10	10.00	1	3.85	2	9.09	6	11.54	4	8.33	5	13.89	4	9.76	1	4.35
Participant describes being too young to remember symptoms leading to diagnosis, but recalls being hospitalised	8	8.00	5	19.23	2	9.09	1	1.92	7	14.58	4	11.11	2	4.88	2	8.70
Participant describes experiencing a tight chest	6	6.00	1	3.85	3	13.64	2	3.85	4	8.33	3	8.33	2	4.88	1	4.35

Symptoms leading to diagnosis	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes experiencing difficulty breathing (including shortness of breath, wheezing, and cough not related to a cold/flu)	39	39.00	8	27.59	31	43.66	18	43.90	21	35.59	9	39.13	18	42.86	12	34.29
Participant describes being too young to remember symptoms leading to diagnosis	27	27.00	8	27.59	19	26.76	11	26.83	16	27.12	6	26.09	11	26.19	10	28.57
Participant describes having bronchitis or chest infection leading to asthma diagnosis	10	10.00	3	10.34	7	9.86	2	4.88	8	13.56	3	13.04	5	11.90	2	5.71
Participant describes being too young to remember symptoms leading to diagnosis, but recalls being hospitalised	8	8.00	0	0.00	8	11.27	5	12.20	3	5.08	3	13.04	3	7.14	2	5.71
Participant describes experiencing a tight chest	6	6.00	1	3.45	5	7.04	3	7.32	3	5.08	1	4.35	3	7.14	2	5.71

Symptoms leading to diagnosis	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA		
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%	
Participant describes experiencing difficulty breathing (including shortness of breath, wheezing, and cough not related to a cold/flu)	39	39.00	26	39.39	13	38.24	17	38.64	22	39.29	22	39.29	17	38.64	39.00
Participant describes being too young to remember symptoms leading to diagnosis	27	27.00	16	24.24	11	32.35	12	27.27	15	26.79	15	26.79	12	27.27	27.00
Participant describes having bronchitis or chest infection leading to asthma diagnosis	10	10.00	9	13.64	1	2.94	5	11.36	5	8.93	4	7.14	6	13.64	10.00
Participant describes being too young to remember symptoms leading to diagnosis, but recalls being hospitalised	8	8.00	5	7.58	3	8.82	3	6.82	5	8.93	4	7.14	4	9.09	8.00
Participant describes experiencing a tight chest	6	6.00	5	7.58	1	2.94	2	4.55	4	7.14	4	7.14	2	4.55	6.00

### Diagnostic tests

The diagnostic tests reported by five or more participants are listed in Table 3.4. There were eight participants who were unable to recall which diagnostic tests they had to diagnose asthma due to tests being done in infancy or a long time ago. Of the remaining 92 participants who could recall the diagnostic tests, participants had between one and seven diagnostic tests, most commonly three tests (n=22, 23.91%) or five tests (n=21, 22.83%) (median = 3.00, IQR =3.00) (Table 3.5). The most common diagnostic test was a physical examination (n=76,

82.61%), followed by spirometry tests (n=69, 75.00%) (Table 3.4).

Table 3.4: Diagnostic tests

Diagnostic test	Count (n=92)	Percent
Physical examination	76	82.61
Spirometry tests	69	75.00
Family history review	59	64.13
Chest X-ray	53	57.61
Allergy testing	41	44.57

Table 3.5: Number of diagnostic tests

Number of diagnostic tests	Count (n=92)	Percent
1	13	14.13
2	13	14.13
3	22	23.91
4	18	19.57
5	21	22.83
6	4	4.35
7	1	1.09
Can't remember/Don't know	8	
<b>Summary statistics</b>		
Median	3.00	
IQR	3.00	
Mean	3.40	
SD	1.50	



Figure 3.8: Number of diagnostic tests

### Time from diagnostic tests to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis. 78 participants (78.00%) were able to recall the length of time, within which more than half of those were diagnosed immediately (n=50, 64.10%), however for 13 participants (16.67%), the result took 4 weeks or more (Table 3.6, Figure 3.9).

Table 3.6: Time from diagnostic test to diagnosis

Wait between tests and diagnosis	Count (n=78)	Percent
Diagnosed immediately at the consultation	50	64.10
Less than 1 week	13	16.67
Between 1 and 2 weeks	1	1.28
Between 2 and 3 weeks	1	1.28
4 weeks or more	13	16.67
Don't know	22	

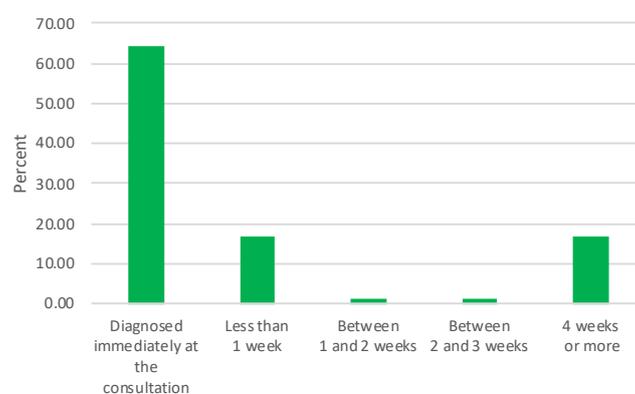


Figure 3.9: Time from diagnostic test to diagnosis

### Diagnosis provider and location

Of the 81 participants who could recall who gave the asthma diagnosis, the majority of participants were given their diagnosis by a general practitioner (n=69, 85.19%) (Table 3.7, Figure 3.10). Of the 93 participants who could recall where the diagnosis was given, most received their diagnosis at the General Practice (n=56, 60.22%) (Table 3.8, Figure 3.11).

Table 3.7: Diagnosis provider

Diagnosis given by	Count (n=81)	Percent
GP	69	85.19
Specialist	9	11.11
Paediatrician	7	8.64
Hospital/ED doctor	6	7.41
Don't know/can't remember	9	11.11

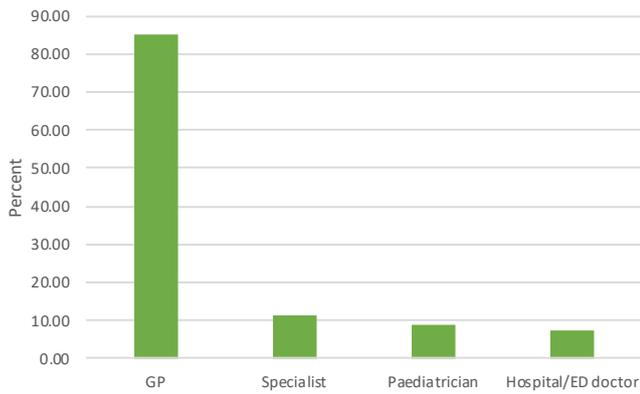


Figure 3.10: Diagnosis provider

Table 3.8: Diagnosis location

Where diagnosis was given	Count N=93	Percent
General practice (GP)	56	60.22
Hospital	26	27.96
Specialist clinic	10	10.75
After hours house call	1	1.08
Don't know/ can't remember	7	7.53

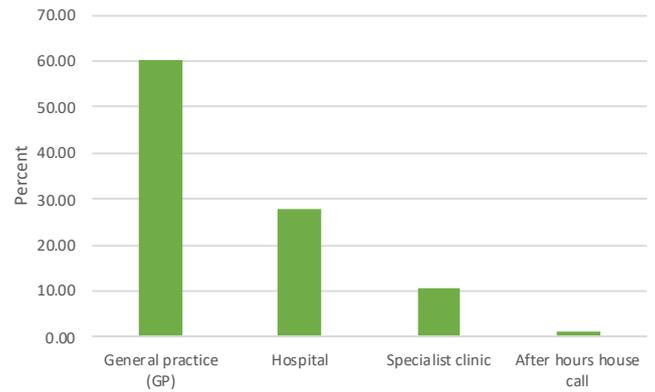


Figure 3.11 Diagnosis location

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### Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. There were 28 participants (28.00%) that described themselves or their parents knowing nothing about asthma, and this was the most common theme. There were 22 participants (22.00%) who reported that themselves or their parents knew very little about asthma. There were 13 participants (13.00%) that described knowing of asthma through a friend of family member's experience with it, but not in great detail, and 9 participants (9.00%) that knew a good amount about asthma due to a family member or friend with asthma.

In relation to sub-group variations, participants in the *Controlled asthma* sub-group (15.38%), described themselves or their parents knowing nothing at diagnosis less frequently than the general population (28.00%), while those in the *Moderately controlled* (40.91%), the *Occasional flare-ups* (39.02%) and the *Mid to low SEIFA* (38.64%) sub-groups described this more frequently. Participants *Age 55 or older* described that themselves or their parents knew very little about asthma less frequently (11.43%) than the general population (22.00%).

### Participant describes knowing either themselves or their parents knowing nothing about asthma

*I really didn't know anything. I don't think we'd really even thought about it. As I said, the fact we'd all been really healthy as kids, so perhaps in fact when I was year 7 and my sister was year 5, we both had about six months of ongoing infections. One of us would be home for the first few days of the week, and then mum would have the second one home, and then we'd both be healthy for the weekend and start all over again. Participant 46*

*Really, nothing. I have assumed all this time that it was smoking-related of course, because I smoked cigarettes until I was 45. That was 15 years ago. I have related it actually to giving up smoking, because I think smoking actually masked my asthma. If I was wheezing, shortness of breath, I actually put it down to smoking, not to anything else. For me, the challenge was to give up smoking, which I ultimately won that fight, and then I found out I had asthma. I also then realized that actually back on that life years ago, that's what happened to me then. I literally lived with asthma without even knowing about, because ...because I was smoking and not as fit as I should be. Participant 66*

*Very, very little. I knew that I was coughing and wheezing but I didn't know-- I honestly didn't even know what it was. Participant 41*

### Participant describes knowing either themselves or their parents knowing very little about asthma: basic symptoms and/or basic management

*To be honest, I didn't know that much. I thought I was just having a pretty bad cold. While growing up, I got to realize that it's not a cold that anyone just gets and - Whenever I had my brother getting a cold, he never had trouble breathing or making wheezing sounds while he was breathing. I realized a while after as I grew up into it Participant 68*

*Yes, well, as a child. I didn't know much about it. I knew what the symptoms were, and I think even sometimes when I was quite sick, I'd probably wasn't aware how sick I was. I just knew I didn't have much energy and found it difficult to run around and got tight in the chest and things, so not a lot. Participant 69*

*I was diagnosed asthma, my mum learnt it with me. I'm the oldest, so all my siblings have asthma, but I was the first diagnosis. She didn't know anything really about it other than it made it harder for you to breathe. Participant 85*

## Section 3

Participant describes knowing of the condition because of a family member or friend with asthma, but not in great detail

*I just had a vague idea of what would happen as an asthmatic because my aunt is an asthmatic patient, so I have seen her using a puffer. Other than that, I had no idea what would come off and what are the precautions I would have to take. I had no clue. Participant 5*

*I'd have to say absolutely nothing. I had a cousin who was also an asthmatic. Her mother used to take her to a different doctor in a different town. She'd turn up at our place and she this little vest on which was the view at the time that that would help asthmatics, so this is going back to the early '60s. In terms of how I didn't really, both of my parents were chain smokers. They didn't know there was a connection. It was that kind of generation. Participant 11*

*I knew a bit about it because my best friend had it too. Participant 036*

*I knew a little bit about it because I've got a friend who's asthmatic and I've got first aid training. I suppose that again, it's that thing where you're never really cured from asthma. Years, and years, and years ago, I did have a period I went through where a GP told me I was asthmatic. I was exercising just asthma. I wasn't really given any preventives or any management plan right then. I was sent to a specialist who was double-booked and was very cursory and told me I didn't have asthma. Participant 78*

Participant describes knowing a good/fair amount about the condition because of a family member or a friend with asthma

*A fair bit because my brother had already had asthma for so long. He took a steroid preventer every night and had to use Ventolin every once in a while. I already knew a fair bit about the treatment, I guess. Participant 67*

*At the time? I suppose if I was to say what my mum or family knew about it, they knew quite a lot because it was a family thing. Participant 80*

*As I said I grew up with a family of asthmatics, so it was just kind of part of growing up. I was aware of symptom. Participant 24*

*I knew my nana had it. She was often wheezing and couldn't do much at certain hours. I know the closing of the tubes and all that stuff. I didn't really-- As long as I could breathe all right. I was fine. [laughs] But when you can't breathe, you do get it. As I got older, certain things like wet paint. I ended up in the hospital because I was painting a house and we were using all those paints. It closed off my tubes. They had to put the injection. As I got older, it got worse. Participant 49*

Participant describes having good understanding through childhood experience (general)

*When I was young, a lot. I was in and out of hospital pretty much my whole life. I was educated quite a fair bit. Participant 3*

*I knew that it was-- I was brought up knowing that it could be serious real quick. I was very aware of my breathing like if anything would bother, whether I'd been out in the rain for too long or getting a cold and things like that. My mum was always on my back about it and also being around dusty environment, or cold environment and things like that. I was not brought up in a bubble, but I was more aware of my surroundings and things that could affect my breathing than, I suppose, most young people or children were, so I was a bit more cautious, I think. Participant 21*

*Yes, I do. Yes. My paediatrician was really great with educating me. I often see him really regularly about it. I was very lucky in that, my dad is a HEALTHCARE PROFESSIONAL, so he was able to get a lot of child-friendly information for me. I remember him sitting me down and showing me videos. I remember watching one, it was in like the late '80s, I think, early '90s, with some of the actor who was really big in the time and he did the video. That's one that really stands out to me. It was a really good discussion of the disease and how it manifests itself in the body, and what you have to do and things like that. Yes, I definitely had a lot at my fingertips, and I was definitely-- my family, and the people around me definitely took it very seriously. I was probably the one who didn't take it so seriously. I was really bad at always taking my medication and thinking I was being a hypochondriac, and all of that kind of stuff. I think that's where I felt down in my own response to it, but I definitely had a lot of education growing up, which was really good. Participant 20*

Participant describes having an understanding over time through childhood experience (understood how to manage exacerbations)

*Probably just being short of breath. When I was younger, I used to play a lot of sport even with asthma. It probably was drummed into me at an early age about taking my preventer. Even as a kid I can remember using the inhaler, putting a little capsule in the thing, and breathing it in twice a day. While I was taking the preventer when I was young it was probably fairly well controlled. I did play a lot of sport and doing quite well without getting too short of breath. Participant 8*

*I didn't really know too much. As I got a little bit older, especially going primary school and everything, we had the care plan in place. If the asthma gets too bad, I would go to the first aid office and take a Ventolin ... As long as I had a puffer with me at all times I was, I was pretty safe. If I extended myself too much and I started to feel it, I needed to let a teacher know straight away. Participant 48*

*I guess I just knew that I had bad lungs, and I just had to take medication and be careful really. I've had it for a while. Participant 26*

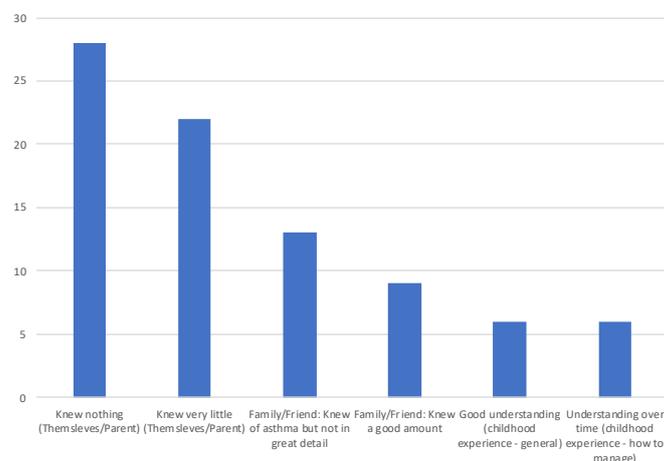


Figure 3.12 Understanding of disease at diagnosis

Table 3.9 Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes knowing either themselves or their parents knowing nothing about asthma	28	28.00	4	15.38	9	40.91	15	28.85	13	27.08	7	19.44	16	39.02	5	21.74
Participant describes knowing either themselves or their parents knowing very little about asthma: Basic symptoms and/or basic management	22	22.00	8	30.77	4	18.18	9	17.31	13	27.08	5	13.89	11	26.83	6	26.09
Participant describes knowing of the condition because of a family member or friend with asthma, but not in great detail	13	13.00	3	11.54	2	9.09	8	15.38	5	10.42	4	11.11	5	12.20	4	17.39
Participant describes knowing a good/fair amount about the condition because of a family member or friend with asthma	9	9.00	4	15.38	4	18.18	3	5.77	6	12.50	2	5.56	4	9.76	3	13.04
Participant describes having good understanding through childhood experience (General)	6	6.00	0	0.00	1	4.55	4	7.69	2	4.17	3	8.33	3	7.32	0	0.00
Participant describes having an understanding over time through childhood experience (Understood how to manage exacerbations)	6	6.00	2	7.69	0	0.00	4	7.69	2	4.17	5	13.89	0	0.00	1	4.35

Understanding of disease at diagnosis	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes knowing either themselves or their parents knowing nothing about asthma	28	28.00	8	27.59	20	28.17	11	26.83	17	28.81	6	26.09	10	23.81	12	34.29
Participant describes knowing either themselves or their parents knowing very little about asthma: Basic symptoms and/or basic management	22	22.00	6	20.69	16	22.54	11	26.83	11	18.64	5	21.74	13	30.95	4	11.43
Participant describes knowing of the condition because of a family member or friend with asthma, but not in great detail	13	13.00	3	10.34	10	14.08	4	9.76	9	15.25	1	4.35	6	14.29	6	17.14
Participant describes knowing a good/fair amount about the condition because of a family member or friend with asthma	9	9.00	2	6.90	7	9.86	5	12.20	4	6.78	2	8.70	3	7.14	4	11.43
Participant describes having good understanding through childhood experience (General)	6	6.00	3	10.34	3	4.23	0	0.00	6	10.17	1	4.35	4	9.52	1	2.86
Participant describes having an understanding over time through childhood experience (Understood how to manage exacerbations)	6	6.00	1	3.45	5	7.04	2	4.88	4	6.78	2	8.70	3	7.14	1	2.86

Table 3.9 Understanding of disease at diagnosis (Cont.)

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes knowing either themselves or their parents knowing nothing about asthma	28	28.00	16	24.24	12	35.29	14	31.82	14	25.00	11	19.64	17	38.64
Participant describes knowing either themselves or their parents knowing very little about asthma: Basic symptoms and/or basic management	22	22.00	15	22.73	7	20.59	10	22.73	12	21.43	14	25.00	8	18.18
Participant describes knowing of the condition because of a family member or friend with asthma, but not in great detail	13	13.00	8	12.12	5	14.71	6	13.64	7	12.50	9	16.07	4	9.09
Participant describes knowing a good/fair amount about the condition because of a family member or friend with asthma	9	9.00	5	7.58	4	11.76	4	9.09	5	8.93	5	8.93	4	9.09
Participant describes having good understanding through childhood experience (General)	6	6.00	6	9.09	0	0.00	1	2.27	5	8.93	3	5.36	3	6.82
Participant describes having an understanding over time through childhood experience (Understood how to manage exacerbations)	6	6.00	6	9.09	0	0.00	2	4.55	4	7.14	4	7.14	2	4.55

### Emotional support at diagnosis

Participants were asked in the online questionnaire how much support that they/their family received between diagnostic testing and diagnosis. Approximately a third of participants had enough support (n=32, 32.00%), 44 participants (44.00%) had no support, and 24 participants (24.00%) had some support but it wasn't enough (Table 3.10, Figure 3.13).

In relation to sub-group variations, participants *Aged 18 to 34* had enough support more frequently (n=14, 60.87%) than the general population (n=32, 32.00%), had some support less frequently (n=2, 8.70%) than the general population (n=24, 24.00%), and no support less frequently (n=7, 30.45%) less often than the general population (n=44, 44.00%). Participants *Aged 55 or older* had enough support (n=7, 20.00%) less often than the general population (n=32, 32.00%).

Participants who lived in a *Metropolitan* area had enough support (n=7, 20.59%) less often than the general population n=32, 32.00%).

Participants with *Trade or high school* qualifications had enough support (n=12, 21.43%) less often than the

general population (n=32, 32.00%); and participants with *University* qualifications had enough support (n=20, 45.45%) more often.

Participants who lived in an area with a *Mid to low SEIFA* had some support but not enough (n=15, 34.09%) more frequently than the general population (n=24, 24.00%).

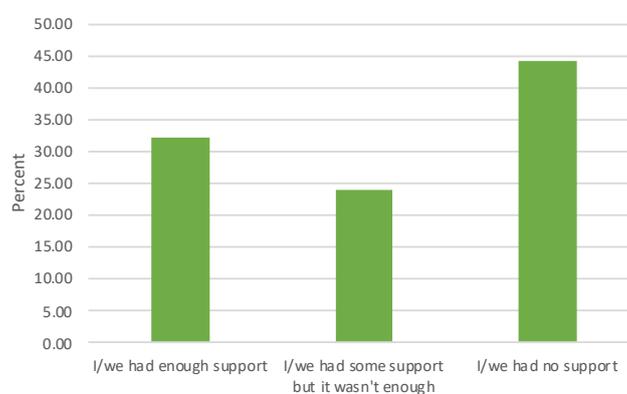


Figure 3.13: Emotional support at diagnosis

Table 3.10: Emotional support at diagnosis

Support at diagnosis	All participants		Asthma control test						Asthma control test			
	n=100	%	Controlled Asthma		Moderately controlled asthma		Poorly controlled asthma		Moderate to well controlled asthma		Poorly controlled asthma	
			n=26	%	n=22	%	n=52	%	n=48	%	n=52	%
I/we had enough support	32	32.00	8	30.77	8	36.36	16	30.77	16	33.33	16	30.77
I/we had some support but it wasn't enough	24	24.00	6	23.08	5	22.73	13	25.00	11	22.92	13	25.00
I/we had no support	44	44.00	12	46.15	9	40.91	23	44.23	21	43.75	23	44.23

Support at diagnosis	All participants		Flare-ups						Sleep disruption			
	All participants		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups		Frequent sleep disruption		Infrequent sleep disruption	
	n=100	Percent	n=36	%	n=41	%	n=23	%	n=59	%	n=41	%
I/we had enough support	32	32.00	10	27.78	15	36.59	7	30.43	19	32.20	13	31.71
I/we had some support but it wasn't enough	24	24.00	10	27.78	10	24.39	4	17.39	14	23.73	10	24.39
I/we had no support	44	44.00	16	44.44	16	39.02	12	52.17	26	44.07	18	43.90

Support at diagnosis	All participants		Age						Location			
	n=100	%	Aged 18 to 34		Aged 35 to 54		Aged 55 or older		Metropolitan		Regional or remote	
			n=23	%	n=42	%	n=35	%	n=66	%	n=34	%
I/we had enough support	32	32.00	14	60.87	11	26.19	7	20.00	25	37.88	7	20.59
I/we had some support but it wasn't enough	24	24.00	2	8.70	12	28.57	10	28.57	14	21.21	10	29.41
I/we had no support	44	44.00	7	30.43	19	45.24	18	51.43	27	40.91	17	50.00

Support at diagnosis	All participants		Education				SEIFA			
	n=100	%	Trade or high school		University		High SEIFA		Mid to low SEIFA	
			n=44	%	n=56	%	n=56	%	n=44	%
I/we had enough support	32	32.00	12	27.27	20	45.45	22	39.29	10	22.73
I/we had some support but it wasn't enough	24	24.00	15	62.50	9	37.50	9	37.50	15	62.50
I/we had no support	44	44.00	29	65.91	15	34.09	25	56.82	19	43.18

Information given at diagnosis

Participants were asked in the online questionnaire how much information they/their family receive at diagnosis. Approximately a third of participants had enough information (n=33, 33.00%), 44 participants (44.00%) had some information but not enough and 23 participants (23.00%) had no information (Table 3.11, Figure 3.14).

In relation to sub-group variations, participants with *Moderately controlled asthma* (n=12, 54.55%) had some information but not enough more often than the general population (n=44, 44.00%), and had enough information less often (n=5, 22.73%) than the general population (n=33, 33.00%).

Participants with *Infrequent sleep disruption* (n=9, 21.95%) had enough information less often than the general population (n=33, 33.00%). Participants *Aged 18 to 34* had enough information (n=11, 47.83%) more

often than the general population (n=33, 33.00%); and had some information but not enough (n=7, 30.43%) less frequently than the general population (n=44, 44.00%), while participants *Aged 35 to 54* had some information but not enough more frequently (n=22, 52.38%).

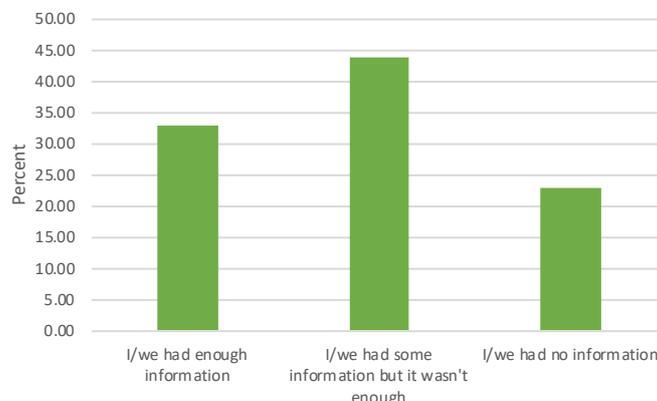


Figure 3.14: Information at diagnosis

Table 3.11: Information at diagnosis

Information received at diagnosis	All participants		Asthma control test						Asthma control test			
	n=100	%	Controlled Asthma		Moderately controlled asthma		Poorly controlled asthma		Moderate to well controlled asthma		Poorly controlled asthma	
			n=26	%	n=22	%	n=52	%	n=48	%	n=52	%
I/we had enough information	33	33.00	9	34.62	5	22.73	19	36.54	14	29.17	19	36.54
I/we had some information but it wasn't enough	44	44.00	10	38.46	12	54.55	22	42.31	22	45.83	22	42.31
I/we had no information	23	23.00	7	26.92	5	22.73	11	21.15	12	29.17	11	21.15

Information received at diagnosis	All participants		Flare-ups						Sleep disruption			
	n=100	Percent	Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups		Frequent sleep disruption		Infrequent sleep disruption	
			n=36	%	n=41	%	n=23	%	n=59	%	n=41	%
I/we had enough information	33	33.00	14	38.89	13	31.71	6	26.09	24	40.68	9	21.95
I/we had some information but it wasn't enough	44	44.00	14	38.89	18	43.90	12	52.17	24	40.68	20	48.78
I/we had no information	23	23.00	8	22.22	10	24.39	5	21.74	11	18.64	12	29.27

Information received at diagnosis	All participants		Age						Location			
	n=100	%	Aged 18 to 34		Aged 35 to 54		Aged 55 or older		Metropolitan		Regional or remote	
			n=23	%	n=42	%	n=35	%	n=66	%	n=34	%
I/we had enough information	33	33.00	11	47.83	12	28.57	10	28.57	23	34.85	10	29.41
I/we had some information but it wasn't enough	44	44.00	7	30.43	22	52.38	15	42.86	31	46.97	13	38.24
I/we had no information	23	23.00	5	21.74	8	19.05	10	28.57	12	18.18	11	32.35

Information received at diagnosis	All participants		Education				SEIFA			
	n=100	%	Trade or high school		University		High SEIFA		Mid to low SEIFA	
			n=44	%	n=56	%	n=56	%	n=44	%
I/we had enough information	33	33.00	17	38.64	16	28.57	19	33.93	14	31.82
I/we had some information but it wasn't enough	44	44.00	18	40.91	26	46.43	26	46.43	18	40.91
I/we had no information	23	23.00	9	20.45	14	25.00	11	19.64	12	27.27

**Costs at diagnosis**

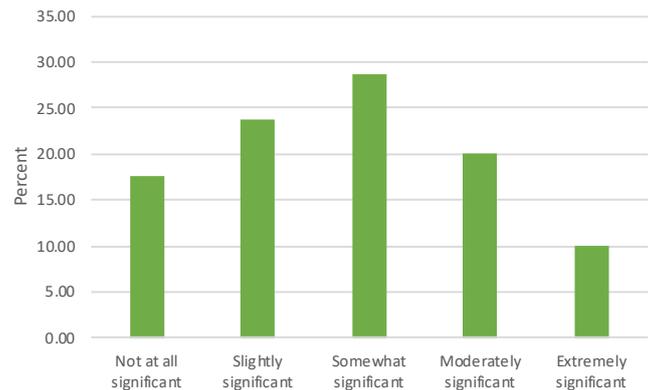
Participants noted in the online questionnaire the amount of out of pocket expenses they had at diagnosis. There were 32 participants who could recall the out of pocket expenses at diagnosis. Of the participants who could recall the out of pocket costs, the majority had no out of pocket costs at diagnosis (n=20, 62.50%), and 12 participants who paid between \$40 and \$1,200 in out of pocket expenses. In the follow-up question about the burden of costs at diagnosis, for 33 participants (41.25%) the cost was either slightly significant or not significant at all. For 23 participants (28.75%) the out of pocket expenses were moderately significant, and for 24 participants (30.00%), the burden of out of pocket expenses were moderately or extremely significant.

**Table 3.12: Out of pocket costs at diagnosis**

Out of pocket costs of diagnosis	Count (n=32)	Percent
\$40 - 50	3	9.38
\$51-100	3	9.38
\$200 - 500	3	9.38
\$600 - 1000	2	6.25
>\$1000	1	3.13
I didn't pay anything out of pocket	20	62.50
I'm not sure	68	N/A

**Table 3.13: Burden of diagnostic costs**

Burden of out of pocket expenses at diagnosis	Count (N=80)	Percent
Not at all significant	14	17.50
Slightly significant	19	23.75
Somewhat significant	23	28.75
Moderately significant	16	20.00
Extremely significant	8	10.00



**Figure 3.15: Burden of out of pocket expenses at diagnosis**

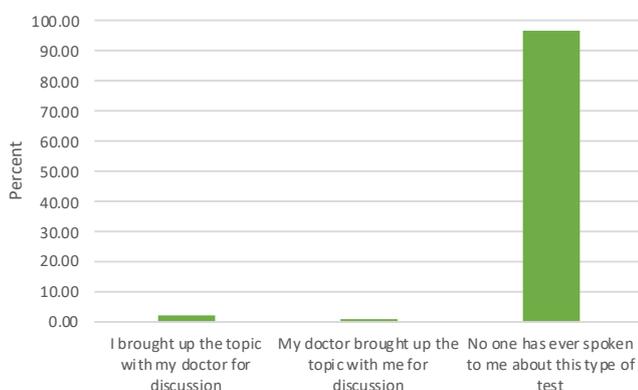
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**Genetic tests and biomarkers**

Participants answered questions in the online questionnaire about biomarkers, genomic and gene testing. Almost all the participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=97, 97.00%). The majority of participants have not had any testing but would like to (n=83, 83.00%). The majority of participants were not sure if they had specific biomarkers (a total of 93, 93.00%), however while not sure of any specific biomarkers, 55 participants (55.00%) had a family history of asthma and/or allergies.

**Table 3.14: Discussions about biomarkers**

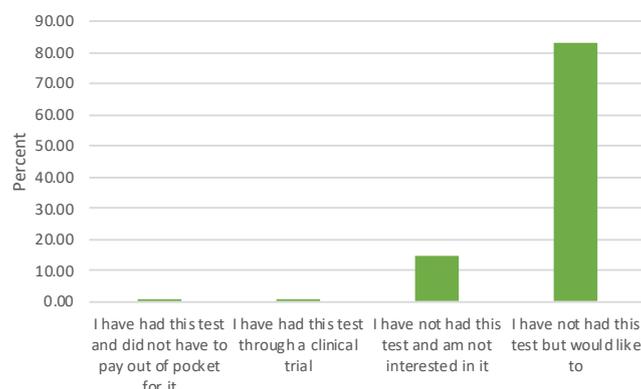
Conversations about biomarker/genomic/gene testing or to see if there are any markers that might be relevant to treatment	Count (n=100)	Percent
I brought up the topic with my doctor for discussion	2	2.00
My doctor brought up the topic with me for discussion	1	1.00
No one has ever spoken to me about this type of test	97	97.00



**Figure 3.16: Discussions about biomarkers**

**Table 3.15: Experience of genetic tests and biomarkers**

Conversations about biomarker/genomic/gene testing or to see if there are any markers that might be relevant to treatment	Count (n=100)	Percent
I brought up the topic with my doctor for discussion	2	2.00
My doctor brought up the topic with me for discussion	1	1.00
No one has ever spoken to me about this type of test	97	97.00



**Figure 3.17: Experience of genetic tests and biomarkers**

**Table 3.16: Specific biomarkers**

Specific biomarkers	Count (n=100)	Percent
Alpha Trypsin deficiency	1	1.00
I do not have any markers	6	6.00
Not sure but I do have a family history of asthma/allergies	55	55.00
Not sure	38	38.00

## Disease description

The **Asthma control test** is a five-item questionnaire that helps determine level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. The five questions and responses are listed in Table 2.17. The most common response for each of the questions is as

follows: asthma kept participants from getting work done some of the time (n=34, 34.00%); participants has shortness of breath 1-2 times a week (n=33, 33.00%); participants sleep was disturbed by asthma symptoms 2-3 nights a week (n=33, 33.00%); participants used reliever medication 1-2 times a day (n=30, 30.00%); and an equal number of participants rated their asthma control as somewhat controlled (n=37, 37.00%) or well controlled (n=37, 37.00%).

**Table 3.17: Asthma control test questions and responses**

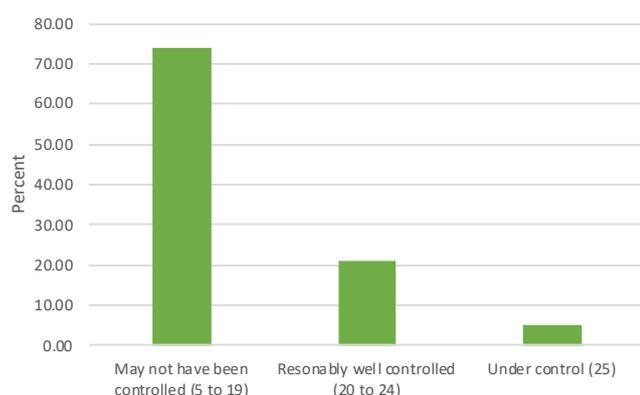
Asthma control test question	Response	Count (n=100)	Percent
In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or home?	All of the time	3	3.00
	Most of the time	16	16.00
	Some of the time	34	34.00
	A little of the time	28	28.00
	None of the time	19	19.00
During the past 4 weeks, how often have you had shortness of breath?	More than once a day	27	27.00
	Once a day	14	14.00
	3-6 times a week	17	17.00
	1-2 times a week	33	33.00
	Not at all	9	9.00
During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?	4 or more times a week	11	11.00
	2-3 nights a week	33	33.00
	Once a week	15	15.00
	Once or twice	16	16.00
	Not at all	25	25.00
During the past 4 weeks, how often have you used your blue puffer or reliever medication (such as Ventolin, Asmol, Airomir, Apo-Salbutamol or Bricanyl)?	3 or more times a day	22	22.00
	1-2 times a day	30	30.00
	2-3 times a week	20	20.00
	Once a week or less	18	18.00
	Not at all	10	10.00
How would you rate your asthma control during the past 4 weeks?	Not controlled	4	4.00
	Poorly controlled	13	13.00
	Somewhat controlled	37	37.00
	Well controlled	37	37.00
	Completely controlled	9	9.00

### Asthma control test score

The Asthma control test score is a total of the responses from each question, it ranges from 5 (poorly controlled) to 25 (under control). The majority of the participants scored between 5 and 19 ( $n=74$ , 74.00%), which indicated that their asthma may not have been controlled, 21 participants (21.00%) scored between 20 and 24, indicating that asthma is reasonably well controlled and 5 participants (5.00%) score 25 indicating asthma that is under control (Table 3.18, Figure 3.17).

**Table 3.18: Asthma control test score**

Asthma control score	Count (n=100)	Percent
May not have been controlled (5 to 19)	74	74.00
Reasonably well controlled (20 to 24)	21	21.00
Under control (25)	5	5.00



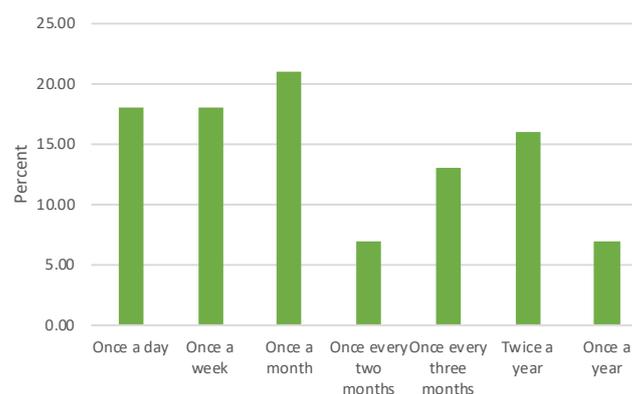
**Figure 3.18: Asthma control test score**

### Frequency of flare-up or asthma attack

Participants described the frequency of flare-ups or asthma attack, the most common responses were 21 participants described a flare-up once a month (21.00%), 18 participants described a flare-up once a day (18.00%), and 18 participants described a flare-up once a week (18.00%) (Table 3.19, Figure 3.19).

**Table 3.19: Frequency of flare-up or asthma attack**

Frequency of flare up or asthma attack	Count (n=100)	Percent
Once a day	18	18.00
Once a week	18	18.00
Once a month	21	21.00
Once every two months	7	7.00
Once every three months	13	13.00
Twice a year	16	16.00
Once a year	7	7.00



**Figure 3.19: Frequency of flare-up or asthma attack**

### Frequency of discussions about asthma with doctor

Participants were asked in the online questionnaire how frequently they have a discussion about their asthma with their doctor. The most common response was more than four times a year ( $n=35$ , 35.00%), however, there were 15 (15.00%) participants that had discussions less than once a year, and five (5.00%) that had not had a recent conversation (Table 3.20, Figure 3.20).

Table 3.20: Frequency of discussions about asthma with doctor

Frequency of discussions about asthma with doctor	Count (n=100)	%
Four times a year or more	35	35.00
Three times a year	10	10.00
Twice a year	16	16.00
Once a year	16	16.00
Less than once a year	15	15.00
No recent conversations	5	5.00
When required	3	3.00

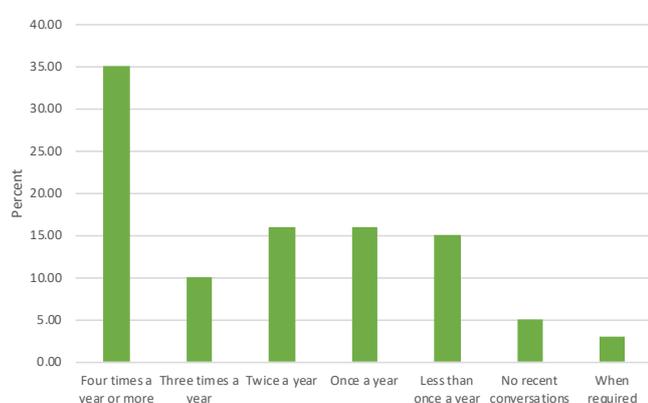


Figure 3.20: Frequency of discussions about asthma with doctor

## Time with symptom before seeking medical attention

Participants noted in the online questionnaire the symptoms the length of time they have waited to seek medical attention or schedule an appointment with GP due to a list of symptoms (Table 3.21). “Severe shortness of breath, chest tightness or pain, and coughing or wheezing” was the symptom where most participants had sought medical attention (n=95, 95.00%), and “Low peak flow readings when using a peak flow meter” was the symptom where only half of the participants had sought medical attention (n=50, 50.00%). The most common symptoms that participants sought medical attention quickly were “The inability to speak more than short phrases due to shortness of breath”, where 35 participants (35.00%) sought attention after experiencing the symptom for less than an hour, more than half of the participants (n=56, 56.00%) sought attention after experiencing this for a few hours to less than an hour. Almost half of the participants (n=46, 46.00%) sought medical attention for “Symptoms that fail to respond to use of a quick-acting (rescue) inhaler” after experiencing the symptom for a few hours to less than an hour. More participants waited for two days or more to seek medical attention for “Severe shortness of breath, chest tightness or pain, and coughing or wheezing” (n=40, 40.00%) than other symptoms, the next most common symptom to wait for two or more days was “Symptoms that fail to respond to use of a quick-acting (rescue) inhaler” (n=29, 29.00%).

Table 3.21: Time with symptom before seeking medical attention

Seeking medical attention after experiencing symptom	Severe shortness of breath, chest tightness or pain, and coughing or wheezing		Symptoms that fail to respond to use of a quick-acting (rescue) inhaler		The inability to speak more than short phrases due to shortness of breath		Having to strain chest muscles to breathe		Low peak flow readings when using a peak flow meter	
	Count (n=100)	%	Count (n=100)	%	Count (n=100)	%	Count (n=100)	%	Count (n=100)	%
I've never sought help because of this	5	5.00	12	12.00	18	18.00	19	19.00	50	50.00
For less than one hour	13	13.00	19	19.00	35	35.00	22	22.00	4	4.00
For a few hours	24	24.00	27	27.00	21	21.00	16	16.00	12	12.00
For one day	18	18.00	13	13.00	12	12.00	19	19.00	14	14.00
For two to three days	24	24.00	20	20.00	5	5.00	13	13.00	12	12.00
For more than three days	16	16.00	9	9.00	9	9.00	11	11.00	8	8.00

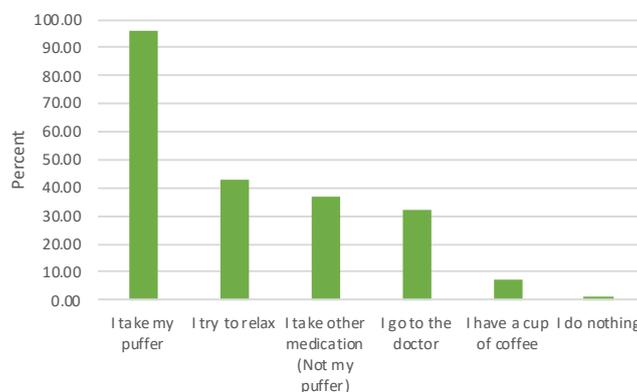
**Common ways of dealing with a flare-up or asthma attack**

Participants noted in the online questionnaire the common ways that they deal with an asthma flare-up

**Table 3.22: Common ways of dealing with a flare-up or asthma attack**

Common way of dealing with a flare-up or asthma attack	Count (n=100)	Percent
I take my puffer	96	96.00
I try to relax	43	43.00
I take other medication (Not my puffer)	37	37.00
I go to the doctor	32	32.00
I have a cup of coffee	7	7.00
I do nothing	1	1.00

or attack. Almost all participants used a puffer (n=95, 95.00%), the next most common way to deal with an attack was to try to relax (n=43, 43.00%) (Table 3.22, Figure 3.22).



**Figure 3.21: Common ways of dealing with a flare-up or asthma attack**

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### Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common theme was that their condition is controlled, that it is managed with medication (n=34, 34.00%). There were 15 participants (15.00%) that understood the relationship with allergies and triggers, and the need to manage those to maintain their health, and 14 participants (14.00%) that understood that asthma is a lifelong condition that will need to be managed. There were eight participants (8.00%) that understood asthma as a serious, scary or possibly life-threatening condition, and eight participants (8.00%) understood that asthma is not controlled and it is complex to manage.

In relation to sub-group variations, participants in the *Infrequent sleep disruptions* (48.78%) and *Controlled asthma* (46.15%) sub-groups described that their condition is controlled, that it is managed with medication, more frequently than the general population (34.00%) whilst participants in the *Frequent sleep disruption* sub-group describe this less frequently (23.73%). Participants in the *Moderately controlled asthma* sub-group described the relationship with allergies and triggers, and the need to manage those to maintain their health, more frequently (27.27%) than the general population (15.00%) whilst participants in the sub-group *Severe asthma* described this less frequently (3.45%).

#### Participant's understanding of prognosis is that their condition is controlled (managed with medication)

*Well, over the years, I've learnt a few very good ways of managing my asthma. One thing I tend to say is that at the moment, I'm managing pretty well. It's been two years since I had a hospital visit. I mean, not a hospital visit, but a hospital admission. This time if it gets hard to breathe, I use my puffer. I have some prednisone pills which I have on stand-by, just in case I feel like I'm about to get an asthma attack. Participant 68*

*For now, I manage it quite well. I'm on preventer so morning and night preventer. If I need the reliever, I take that as well. I know that there are certain times of the year that it's worse. It's worse now than what it was when I was younger, definitely. Participant 72*

*It's pretty good. At the moment I'm taking Flutiform. I've been taking that for five, six years maybe. That's twice a day and I don't get any symptoms of asthma while I'm taking that. Sometimes when I'm doing hard physical activity or I get cold and I'm not ready for it then I'll start getting a little bit tight, then I'll just take my Ventolin. It really doesn't bother me now. I was getting recurrent pneumonia from it when it was getting really cold. I have had three cases of pneumonia but that's it. I haven't had pneumonia for quite a long time. Participant 93*

*I feel like overall, the way that my asthma has progressed through my life is, I was very steady when I was small, and I spent a lot of time in hospital. I can remember being on nebulizer's and a lot of medication when I was up to the age of 10. Then, progressively, as I got older and I did sports and I did therapy sort of stuff. It got less severe and I'd say now, I take my preventers every day and night, it's well controlled. As in, I play sports, I can do most things normally, so it's not something that impedes me. Yes. I tell you overall, it's been very stable for a very long time and my medications are controlled. I take it every day. If I notice it getting worse, then I talk to GP, for a long time so we usually just up the medication. I know it gets worse when I get flu and stuff like that but that's the general outlook. Participant 90*

*It's under control. Flare-ups are managed. I have an additional preventer, Seretide, which I take especially during the cold season. It got to the stage where I am taking it as and where I am taking it permanently for the time being, so they can get it under control. During the last year or so, I've had a lot of the asthma flare-ups and colds and everything. We're trying to use it as a preventer to try and see if it helps picks up anything if I can manage my breathing a little bit better. Participant 48*

Participant's understanding of prognosis is in the context of the relationship with allergies and triggers, and the need to manage those to maintain their health (exacerbated with colds and flu)

*It's there all the time. I'm on everything I can be on preventative wise. For me winter, flus, colds, three grandchildren that I have regular contact with are the triggers for me when they bring whatever home from school, childcare or I get some sort of flu or virus. For me, that's a danger time. Participant 63*

*I'm pretty good at the moment, luckily. It comes and goes. If I get really stressed or anything like-- stress is a main factor of it. I can tell when I'm going to have an attack because I start getting really breathless and then I'd lose my voice altogether. I start talking like this, then it's time to grab the Ventolin. Participant 56*

*Mine is mostly self-monitored and self-managed. It tends to be seasonal for me, so it peaks around high fever season and when my other allergies flare up that seems to be a trigger. Usually about once a year, I go in and my GP and I discuss whether or not I'd like to change or continue my asthma management, which at the moment is generally the Asmol treatment inhaler and the Symbicort preventive puffer. I usually reassess whether or not I'm going to want that or change at the onset of allergy season around November every year. Participant 52*

Participant's understanding of prognosis is that it is a lifelong condition that they will need to manage

*It's a lifelong prognosis for me. Like it's never going to go away. I was born preemie and then when I got bronchitis, my brain system wasn't strong enough to be able to handle that and it just diminishes that just a little bit enough to make it a lifelong thing. Participant 15*

*It's from books that I've had with my GPs. It seems that I accept this to be lifelong, I don't expect asthma to go away. It's something that I've managed always so I assume that it will continue to get worse as I get older. I know that was a big problem for my Nana when she passed so I don't expect it to improve. I expect that I'll have to manage it really. Participant 47*

*I think I pretty much go to forever. It's gotten worse. I'm just resigned to the fact that I've got it. Participant 59*

*Obvious, I suppose. I know it's obviously something that I'm going to live with forever. A lifetime of it. I have learnt how to manage it and keep it under control. I suppose, I'm watching my mother go through the later stages of her life with asthma and she's developed severe lung conditions as a result. I suppose I'm looking towards that as, that's probably my future. Participant 80*

Participant describes their prognosis in relation to understanding the serious, scary and/or possibly life-threatening nature of asthma

*I don't know. It's a life-long condition and the young respiratory specialist that I see-- In fact, I'm seeing him again today has told me that I actually have some high risk of dying because of a number of factors, age, gender, number of hospital admissions, the length of time that I've had it and so on. I guess the prognosis is that it will continue, and it could kill me. Participant 7*

*Well, already this year I've had five days in the hospital. It's a week to week kind of thing. To be honest and not be dramatic, I think it's something that will take my life. I think it will contribute to my cause of death. I know that sounds dreadful, but I am realistic, and I think that's quite a strong likelihood. I've had several severe close calls and that's just the way it is. When it gets bad it's extremely bad. Participant 14*

*Currently, my immunologist that I went to and my GP, he said that my asthma is considered severe at the moment. At the moment I feel terrified but for myself I don't think it's getting any worse than what it was 8-12 months ago. Through changes and just the environment and stresses and things I do notice it a lot more than what I used to do when I was in my 20s. Does that make sense? Participant 77*

Participant's understanding of prognosis is that it is not controlled and complex to manage

*I'm a chronic severe asthmatic. It's uncontrollable. Therefore, my doctors consider it extreme asthma problems, obviously, which means, I can be set up from weather allergies, it can be down from just being simply sick. Again, basically, very, very tough to manage. Has been pretty much there the whole way through. Participant 3*

*At the moment, they've labelled me as a chronic asthmatic. I generally like over the last 20 years have been hospitalized at least once a year with it. I see an asthma specialist and I have done in the past as well. They just give me like an asthma plan and maybe change up my meds a little bit. Over the 20 years, I've had phenomenal amount of steroids. They have messed with my body big time. Participant 9*

*I think my doctor calls it "treatment resistant asthma". I have mild to moderate, but ongoing. It's not unusual to have months long flare-ups when it flares badly. It just won't come back under control. I've have had more than that. I've had six months at a time where it just would not get back into control, and then I'll have six really good months or two really good months or whatever else till a next thing causes a flare-up. Every now and then, they talk about it being severe asthma and without qualification, but treatment resistant is the one he uses most often. I don't get the real life threatening, but I feel pretty horrible all the same when it's going on. Participant 46*

Participant describes not having a clear understanding of prognosis (no conversation with clinician)

*Well, at the moment the doctors I've been with wouldn't have a clue. Participant 1*

*Doctors don't tell me anything, so I don't know. I just assume I've got it for the rest of my life. Participant 4*

*No and actually I feel that there's not enough conversation about that, because I've got no idea. We moved, we lived in LOCATION for the last five years, we moved around a lot. I'm 72 and two years ago, two years last March, we moved to LOCATION. Now, we moved here for a bit of climate, and the first 12 months I was here, I was so sick. I had already been in hospital for seven days with, I don't know, asthma. To me now it's different to when I was a child. I get a virus and it turns into something bad. I've been in hospital I think six or seven times with it over the years. Participant 19*

*Basically I treat it day by day as best I can. Like I said, I've seen multiple respiratory specialists, and they've just shrugged their shoulders, yelled at me or quoted the Bible at me. I haven't been back to them; they pay tends to handle it. Like I said, on a case by case thing, if I get sick, and we notice a wheeze, then we up and change medications and so forth. Other than that, I've got a management plan that I use, and that's the best I can do, but no prognosis. I don't even actually have a written asthma plan, which I know is really wrong but that's my GP for [laughs] We got one with myself at home, rush. Participant 10*

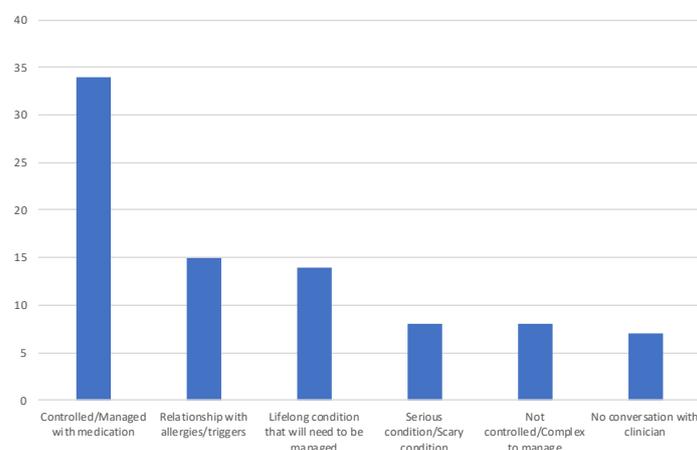


Figure 3.22: Understanding of prognosis

Table 3.23: Understanding of prognosis

Understanding of prognosis	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant's understanding of prognosis is that their condition is controlled (managed with medication)	34	34.00	12	46.15	8	36.36	14	26.92	20	41.67	10	27.78	18	43.90	6	26.09
Participant's understanding of prognosis is in the context of the relationship with allergies and triggers, and the need to manage those to maintain their health (Exacerbated with colds and flu)	15	15.00	4	15.38	6	27.27	5	9.62	10	20.83	7	19.44	6	14.63	2	8.70
Participant's understanding of prognosis is that it is a lifelong condition that they will need to manage	14	14.00	2	7.69	4	18.18	8	15.38	6	12.50	3	8.33	7	17.07	4	17.39
Participant describes their prognosis in relation to understanding the serious, scary and/or possibly life-threatening nature of asthma	8	8.00	3	11.54	1	4.55	4	7.69	4	8.33	2	5.56	4	9.76	2	8.70
Participant's understanding of prognosis is that it is not controlled and complex to manage	8	8.00	0	0.00	0	0.00	8	15.38	0	0.00	6	16.67	2	4.88	0	0.00
Participant describes not having a clear understanding of prognosis (No conversation with clinician)	7	7.00	0	0.00	0	0.00	7	13.46	0	0.00	5	13.89	1	2.44	1	4.35

Understanding of prognosis	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant's understanding of prognosis is that their condition is controlled (managed with medication)	34	34.00	7	24.14	27	38.03	20	48.78	14	23.73	10	43.48	14	33.33	10	28.57
Participant's understanding of prognosis is in the context of the relationship with allergies and triggers, and the need to manage those to maintain their health (Exacerbated with colds and flu)	15	15.00	1	3.45	14	19.72	7	17.07	8	13.56	3	13.04	5	11.90	7	20.00
Participant's understanding of prognosis is that it is a lifelong condition that they will need to manage	14	14.00	4	13.79	10	14.08	6	14.63	8	13.56	5	21.74	6	14.29	3	8.57
Participant describes their prognosis in relation to understanding the serious, scary and/or possibly life-threatening nature of asthma	8	8.00	4	13.79	4	5.63	3	7.32	5	8.47	2	8.70	4	9.52	2	5.71
Participant's understanding of prognosis is that it is not controlled and complex to manage	8	8.00	5	17.24	3	4.23	2	4.88	6	10.17	0	0.00	6	14.29	2	5.71
Participant describes not having a clear understanding of prognosis (No conversation with clinician)	7	7.00	1	3.45	6	8.45	0	0.00	7	11.86	1	4.35	3	7.14	3	8.57

Understanding of prognosis	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant's understanding of prognosis is that their condition is controlled (managed with medication)	34	34.00	20	30.30	14	41.18	14	31.82	20	35.71	16	28.57	18	40.91
Participant's understanding of prognosis is in the context of the relationship with allergies and triggers, and the need to manage those to maintain their health (Exacerbated with colds and flu)	15	15.00	11	16.67	4	11.76	6	13.64	9	16.07	9	16.07	6	13.64
Participant's understanding of prognosis is that it is a lifelong condition that they will need to manage	14	14.00	9	13.64	5	14.71	5	11.36	9	16.07	10	17.86	4	9.09
Participant describes their prognosis in relation to understanding the serious, scary and/or possibly life-threatening nature of asthma	8	8.00	6	9.09	2	5.88	3	6.82	5	8.93	6	10.71	2	4.55
Participant's understanding of prognosis is that it is not controlled and complex to manage	8	8.00	3	4.55	5	14.71	4	9.09	4	7.14	3	5.36	5	11.36
Participant describes not having a clear understanding of prognosis (No conversation with clinician)	7	7.00	4	6.06	3	8.82	3	6.82	4	7.14	3	5.36	4	9.09

# Section 4 Decision-making

**Section 4: Decision-making****Discussions about treatment**

The most common treatment discussion described was having had little discussion with only one option or approach presented and this was described by 65 participants (65.00%). This was followed by participants not being able to remember due to childhood diagnosis (n=19, 19.00%) and options being presented and being able to participate in decision making (n=16, 16.00%).

**Decision-making**

The most reported component of decision-making described was taking into account the side effects and this was described by 28 participants (28.00%). This was followed by a combination of cost, side effects or effectiveness (n=18, 18.00%); efficacy (n=17, 17.00%); following doctor's advice or does not make active decisions (n=13, 13.00%); quality of life only (n=9, 9.00%) and cost of treatment (n=8, 8.00%).

**Changes in decision making**

Participants were asked if the way they made decisions had changed over time. There were 72 participants (72.00%) that felt the way they made decisions about treatment had changed over time, and 13 participants (13.00%) that described decision making not changing. Where participants had changed the way they make decisions, this was primarily in relation to becoming more aware of their health (n=38, 38.00%); becoming more informed, assertive or considered (n=24, 24.00%); and taking into account the impact on their family (n=9, 9.00%).

### 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 theme was having had little discussion with only one option or approach presented and this was described by 65 participants (65.00%). This was followed by participants not being able to remember due to childhood diagnosis (n=19, 19.00%) and options being presented and being able to participate in decision-making (n=16, 16.00%).

In relation to sub-group variations, participants in the *Mid to low SEIFA* (54.44%), and *Age 18 to 34* (52.17%) sub-groups described little discussion less frequently than the general population (65.00%). Participants *Age 55 and older* described not remembering diagnosis due to being diagnosed as a child less frequently (5.71%) than the general population (19.00%) as did participants in the subgroup *Severe asthma* (3.45%), while those *Age 18 to 34* described this more frequently (30.43%). Participants in the *Moderately controlled asthma* sub-group described options being presented and being able to participate in decision making less frequently (4.55%) than the general population (16.00%) as did those in the sub-group *Infrequent sleep disruption* (4.88%), whilst participants in the sub-group *Severe asthma* described this more frequently (31.03%).

#### Participant describes little discussion – essentially one option or approach presented

*Nothing, none. He just said he would prescribe me the preventer, morning and evening one, and the other one for during the day, and that's it. He just told me when to take them and that was essentially it. Participant 4*

*Sometimes they told me very, very basic stuff that I've known forever, for years. The basic stuff - always carry your puffer. Other times nothing at all. Participant 36*

*I don't really think we had a conversation, well other than the GP said I should take this puffer medication and that was about it. Participant 37*

*I'm probably jumping forward given the three topic areas you spoke about. I don't think I've ever had too many things in terms of options or choices in terms of the treatments. Even down to consistencies, well, at one time a doctor will say, "Well, Pulmicort is the thing for you," Then you use that for a while and then someone will go, "Well, why are you using that? It should be this one." That's overall how I describe that treatment and has been explained. Participant 43.*

*Well, the options really were, "You need Ventolin, so here have some Ventolin. You need some " I think it was Seretide to start with. "To take Seretide every day and take the Ventolin as needed. Participant 55*

#### Participant cannot remember: childhood diagnosis

*When I was very young, and I didn't remember anything. It was like medications that were available then to what's now is quite different. Back then, I couldn't really remember. It wasn't until I got until 10 and over that I remember more about my treatment and whatnot. Participant 21*

*When I was first diagnosed? I don't know. I think the doctors just gave it to mum and said, "This is what she needs to take." Participant 70*

*I don't remember there were any. Mum was really dealing with it all back then, I think. Participant 72*

#### Participant describes options being presented and being able to participate in decision-making

*Many actually. I've tried, I'm still trying different drug regimes to try and get control. We've discussed a number of things actually. I don't qualify for biologic. I'm already taking biologic for another condition. Generally, we've just discussed trying different combinations of medication. Participant 7*

*My GP is a really, really good guy. He sort of went through various drug options. We tried a few of them to find the one that worked best for me. I didn't want anything that was going to be lifestyle limiting. He was very good about working around the fact that I travel a lot and I travel for work so I didn't want anything that was going to be bulky or limiting in any way so we can-- We tried a few different combinations of puffers and drugs to come up with the one that worked best for me. Participant 41*

*My GP has mentioned several different alternatives in terms of medications to try. In the past, I've trialed a few different types of medication. They're primarily oral inhalants style medications that I've tried. I tend to avoid anything like a tablet form of a steroid because I have gut issues that they trigger. With being sensitive of my other conditions in trying to manage my asthma. My GP has never really been over alarmed with my state of asthma. Participant 52*

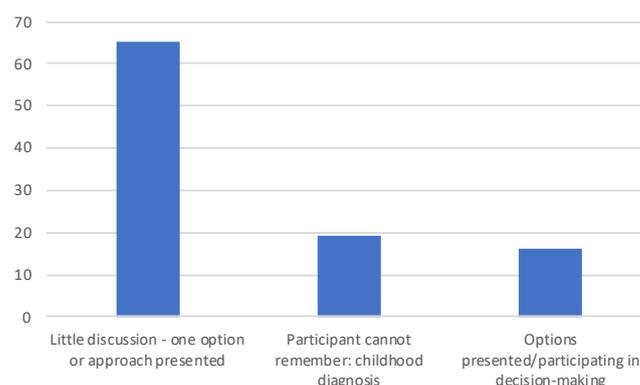


Figure 4.1: Conversations about treatment

Table 4.1: Conversations about treatment

Conversations about treatment	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes little discussion - essentially one option or approach presented	65	65.00	16	61.54	16	72.73	33	63.46	32	66.67	22	61.11	27	65.85	16	69.57
Participant cannot remember: childhood diagnosis	19	19.00	7	26.92	4	18.18	7	13.46	12	25.00	6	16.67	9	21.95	4	17.39
Participant describes options being presented and being able to participate in decision-making	16	16.00	2	7.69	1	4.55	13	25.00	3	6.25	7	19.44	7	17.07	2	8.70

Conversations about treatment	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes little discussion - essentially one option or approach presented	65	65.00	19	65.52	46	64.79	27	65.85	38	64.41	12	52.17	27	64.29	26	74.29
Participant cannot remember: childhood diagnosis	19	19.00	1	3.45	18	25.35	11	26.83	8	13.56	7	30.43	10	23.81	2	5.71
Participant describes options being presented and being able to participate in decision-making	16	16.00	9	31.03	7	9.86	2	4.88	14	23.73	5	21.74	5	11.90	6	17.14

Conversations about treatment	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes little discussion - essentially one option or approach presented	65	65.00	44	66.67	21	61.76	30	68.18	35	62.50	41	73.21	24	54.55
Participant cannot remember: childhood diagnosis	19	19.00	15	22.73	4	11.76	9	20.45	10	17.86	9	16.07	10	22.73
Participant describes options being presented and being able to participate in decision-making	16	16.00	8	12.12	8	23.53	5	11.36	11	19.64	7	12.50	9	20.45

### Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported was taking into account the side effects and this was described by 28 participants (28.00%). This was followed by a combination of cost, side effects or effectiveness (n=18, 18.00%); efficacy (n=17, 17.00%); following doctor's advice or does not make active decisions (n=13, 13.00%); quality of life only (n=9, 9.00%) and cost of treatment (n=8, 8.00%).

In relation to sub-group variations, participants in the *Frequent flare-ups* sub-group described taking efficacy into account less frequently (5.56%) than the general population (17.00%), while those in the *Regional or remote* sub-group described this more frequently (29.41%).

Participants in the *Moderately controlled asthma* sub-group described following doctor's advice or does not make active decisions more frequently (27.27%) than the general population (13.00%) whereas no participants in the sub-group *Severe asthma* described this (0.00%).

### Participant describes taking into account the side effects of treatment

*Really, how it's going to affect me long term as well. I do worry about all the inhalers I take and what it's doing to my lungs. I worry that yes I can breathe, but what's it doing because-- I don't know. It can't be good having 30 years of puffing things. Yes, I'm just trying to stay as healthy as I can and avoid taking as much as I can which I guess it's possibly detrimental.*  
Participant 26

*I would really be thinking about what sort of long-term effects as well. I don't want to...If it's a new clinical thing, I'd be thinking, I don't want to grow another arm down the trachea or...[chuckles] I don't want to be a case study for a first-time experiment or whatever. I would just have to know a lot more about it. Then as well as time, like, I don't want to only be seeing results in another 18 months or so.*  
Participant 39

*Obviously side effects, because the side effects can be quite hardcore and they can have fairly serious lifestyle implications. Lifestyle factors. I don't want to have to carry a machine with me, or I don't want to*

*carry something that's illegal in certain countries. I tend to research those sorts of things because some of the actual drugs they use routinely here you can't take into America. Which means that you are either changing your medication before you go away, or you have to go through various channels to be able to take stuff with you, and it's just too hard. And I'm RELIGIOUS.* Participant 41

*I take into consideration the effects it will have on my day-to-day life as I suffer from depression and anxiety, and I'm on medication for that. Anything that would just stop me or affect those medications in a negative way, so like make them not usable, just like stuffing on my sleep or things like that. Just things that will affect my day-to-day life, I guess.*  
Participant 42

### Participant considers cost and side effects and/or effectiveness (combination)

*Probably the first one sadly is cost. I'm a single mother, my two children now are adults, but I'm still putting one through uni or helping put one through uni and the cost would be the first thing. After that, I don't know, I'd probably I'd look at if it's safe and the long-term impacts. I think that'd be the top three, yes.*  
Participant 14

*Cost is the first one, I guess. Then a lot of it is quality of life. It's because I have a young family and I'm married and have a mortgage and all that sort of stuff. Quality of life. I always look at the studies and the outcomes before I go on any new medication.*  
Participant 34

*Probably the cost and the effectiveness, and whether it's practical because I've recently retired and I'm working part-time. But when I was working full-time it was a real hassle to go, "Can't come in today, just a bit asthmatic." People don't really see it as an illness or an injury. They just don't go, "Oh yes, short of breath, no problems. Nothing big to be worried about." They don't understand what it's like unless you are having an asthma attack* Participant 55

*Currently, what is most effective, but certainly in the past, cost was a huge issue. Because some of the Preventers are like \$50, \$60 nearly \$100 because I don't have a healthcare card. Sometimes you'd have to go, "Okay, what? What do I have to choose between paying electricity bill or getting my asthma medication?" That's not so much the case now.*  
Participant 57

**Participant describes taking efficacy into account**

*For me, I just want the preventer to act, to work. I've gone through a few preventers. I'm on Seretide now and it seems to work the best, but I've been on some really crappy ones too, they just don't work. I want a good preventer, that's my thing. Participant 37*

*Just how effective I think it's going to be, really. That's my biggest fear. I hate the feeling of not being able to breathe. If that's going to fix it, I will do it. I don't care. Participant 32*

*I'll look at the research. I'm in the medical industry myself now anyway so I'm able to look at all the information that's handed out by the various companies and weigh up the benefits compared to what I'm on. A lot of the time I don't like starting a new medication if it means that I've got to go off an old one straight away. I prefer introducing one and then maybe weaning off the other ones I've got benefit of that changeover. The issue I'm having at the moment, a perfect example is there's two different medications that I'm on but I'm on a very rare medication that's an injection called NUCALA for my asthma. There's a new drug that's been introduced that's meant to be just as good if not better. However, just what's between the two if I go to that one and it doesn't work, then I've got to wait six months to get back on to the medication that works. I look at things like that. Participant 35.*

**Participant primarily follows doctor's advice or does not make active decisions**

*Okay. Pretty much the treatments been left with my doctors and I haven't really been consulted about that. Participant 9*

*Obviously, take the advice from the doctor, but nothing else has suggested besides preventatives and Ventolin and going to hospital and being on- I can't really remember what the other things are called. Tablets which I rarely take anyway, which I won't take because it's so strong. Is it prednisolone? Yes, I have to be desperate to take something like that. Participant 65*

*I don't really feel super-involved in the decision-making process. I feel the first preventer I ever got put on was just recommended by the doctor I was at at the time. It worked well for me so it's the same*

*preventer that I still use. I just take Ventolin as needed, the four puffs through a spacer.*

*Participant 67*

*I think I'm lucky enough that cost hasn't affected me or previously with my parents. They were supporting me on that front and recently the medication I've had to use hasn't been too expensive. Considerations, more so I think I guess when-- I haven't used anything other than-- I guess the types of medication I use, I use Flutiform and Ventolin as required. When deciding to use Flutiform, the reason I went with that was because my GP just told me it would be a good puffer to use consistently and if I can use it consistently then it should be well managed. I think just making sure that my medication provides some stability was the most important part. Participant 79*

**Participant describes taking into account quality of life only**

*Right now, we just try to deal with it the best way we can so I can manage to live my life, basically, so I can get to work, get home and have some quality of life. That's hard, but that's pretty much the action plan, which is not much of an action plan. Participant 3*

*Really, I'm at the point where I'll try anything because I had no quality of life. Like today I exactly in the hallway, and I had to have a nebulizer afterwards. I get so restless and because I've put on so much weight because of the Cushings, I think that makes it a lot worse as well. Some days it's worse than others, but because of the quality of life, which I know you're going to talk about later, but it's sort of I'm willing to give anything a go. You know how they got the chart with all the-- They used to have the chart with all the different puffers on there, the doctors. I literally had pretty much every single one throughout my life. Participant 2*

*My main thought- Yes. It would always be more quality of life things. I'm active and I keep active, but my chest is virtually always painful, and I've got to rest and whatever. Will it improve my comfort in terms of finding breathing painful and will it also enable me to physically do more? More activity, yes. Participant 18*

Participant considers cost of treatment

What we take into account is are we going to be out of pocket while we take a look at this. Is it going to have a serious effect on day to day life because with working full time and everything, I need to make sure that it wouldn't affect my job because I'm on contract. Participant 48

First of all is cost. Cost has actually plays a big role because sometimes being raised up in a middle class family, our problems generally revolves around cost of medication. Some cost can be covered by the insurer, but some can't, so I stay wary about that. I'll say coming from LOCATION access to some medication had been quite challenging. Participant 68

Cost and time. At the time I was... I'm retired now, I guess I still don't have a lot of time, but at work it was always difficult to just drop things and jump, go into. Do some of these sort of treatments or anything a bit different. Their cost is one and also the fact that the barrier of either waiting for someone to come across or having to go to LOCATION to get a treatment is another one. Accessibility and affordability I think are probably pretty key ones. Because my symptoms

aren't all that bad at the moment, I think if I was regularly going to the hospital because I couldn't control my asthma, so those things would be less important. Participant 69

Cost is the first one, I guess. Then a lot of it is quality of life. It's because I have a young family and I'm married and have a mortgage and all that sort of stuff. Quality of life. I always look at the studies and the outcomes before I go on any new medication. Participant 33

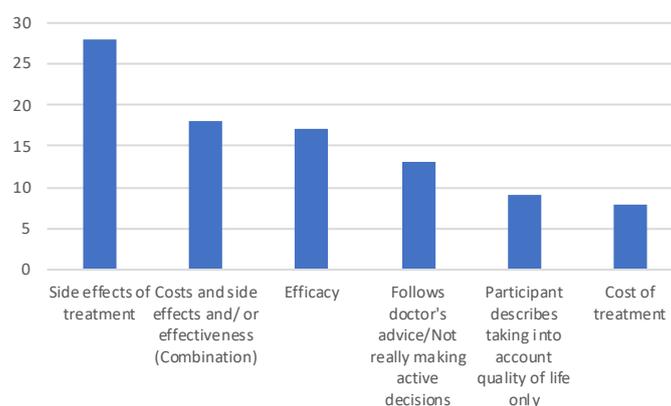


Figure 4.2: Considerations when making decisions

Table 4.2: Considerations when making decisions

Considerations when making decisions about treatment	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes taking into account the side effects of treatment	28	28.00	5	19.23	4	18.18	19	36.54	9	18.75	12	33.33	11	26.83	5	21.74
Participant considers cost and side effects and/or effectiveness (combination)	18	18.00	6	23.08	5	22.73	7	13.46	11	22.92	8	22.22	7	17.07	3	13.04
Participant describes taking efficacy into account	17	17.00	6	23.08	2	9.09	9	17.31	8	16.67	2	5.56	10	24.39	5	21.74
Participant primarily follows doctor's advice or does not make active decisions	13	13.00	4	15.38	6	27.27	3	5.77	10	20.83	6	16.67	3	7.32	4	17.39
Participant describes taking into account quality of life only	9	9.00	2	7.69	2	9.09	6	11.54	3	6.25	3	8.33	3	7.32	3	13.04
Participant considers cost of treatment	8	8.00	0	0.00	3	13.64	6	11.54	2	4.17	5	13.89	2	4.88	1	4.35

Considerations when making decisions about treatment	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes taking into account the side effects of treatment	28	28.00	8	27.59	20	28.17	10	24.39	18	30.51	8	34.78	10	23.81	10	28.57
Participant considers cost and side effects and/or effectiveness (combination)	18	18.00	6	20.69	12	16.90	8	19.51	10	16.95	5	21.74	8	19.05	5	14.29
Participant describes taking efficacy into account	17	17.00	6	20.69	11	15.49	7	17.07	10	16.95	3	13.04	9	21.43	5	14.29
Participant primarily follows doctor's advice or does not make active decisions	13	13.00	0	0.00	13	18.31	8	19.51	5	8.47	4	17.39	4	9.52	5	14.29
Participant describes taking into account quality of life only	9	9.00	5	17.24	4	5.63	2	4.88	7	11.86	0	0.00	6	14.29	3	8.57
Participant considers cost of treatment	8	8.00	2	6.90	6	8.45	3	7.32	5	8.47	2	8.70	2	4.76	4	11.43

Table 4.2: Considerations when making decisions (Cont)

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes taking into account the side effects of treatment	28	28.00	19	28.79	9	26.47	11	25.00	17	30.36	15	26.79	13	29.55
Participant considers cost and side effects and/or effectiveness (combination)	18	18.00	15	22.73	3	8.82	8	18.18	10	17.86	11	19.64	7	15.91
Participant describes taking efficacy into account	17	17.00	7	10.61	10	29.41	9	20.45	8	14.29	10	17.86	7	15.91
Participant primarily follows doctor's advice or does not make active decisions	13	13.00	8	12.12	5	14.71	5	11.36	8	14.29	8	14.29	5	11.36
Participant describes taking into account quality of life only	9	9.00	7	10.61	2	5.88	4	9.09	5	8.93	5	8.93	4	9.09
Participant considers cost of treatment	8	8.00	4	6.06	4	11.76	3	6.82	5	8.93	1	1.79	7	15.91

### Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 72 participants (72.00%) that felt the way they made decisions about treatment had changed over time, and 13 participants (13.00%) that described decision-making not changing. Where participants had changed the way they make decisions, this was primarily in relation to becoming more aware of their health (n=38, 38.00%); becoming more informed, assertive or considered (n=24, 24.00%); and taking into account the impact on their family (n=9, 9.00%).

In relation to sub-group variations, participants in the *Moderately controlled asthma* sub-group described changing their decision making over time primarily in relation to becoming more aware of their health more frequently (50.00%) than the general population (38.00%).

Participants in the *Controlled asthma* (11.54%), and *Infrequent flare-ups* (8.70%) sub-groups described changing decision making over time as they are more informed, assertive or considered less frequently than the general population (24.00%), while those in the *Occasional flare-ups* sub-group described this more frequently (36.59%) as did those in sub-group *Severe asthma* (34.48%).

### Participant describes decision-making changing over time as they have more awareness of their health, responsibility and/or own limitations

*Definitely, has changed as I have gotten older and realized just how serious it is. Just to put that into consideration. I've been [chuckles] clinically dead four times. Participant 3*

*It's definitely changed as I've gotten older. I've gotten more aware of my body I guess and long-term health Participant 26*

*No, totally changed. So initially I guess, my decisions were very selfish. My asthma was out of control nothing was working, and I just wanted to find something to help. Whereas now as much as probably say that's still a priority. I probably looked at it more as in "what is my participation going to do for medicine research?", "How's it going to improve people?", "If it doesn't help me, will it potentially help other people?". I have a much broader scope now and will engage if I can, for the benefit of all asthmatics, not just myself. I guess, it's gone from a very selfish to a more or less of that selfish element to a much more wider community effect, rather than just me. Participant 28*

*I think now that I'm a little bit older, I'm probably a bit more selfish. When you're young and you're trying to crawl your way up the career that you don't want to take time off, because people will think you're sick. Now that I'm retired I think stuff, "I don't feel well. I'm not going to do anything". Participant 55*

Participant describes decision-making changing over time as they are more informed or assertive - considered

*Yes. Now I know, I have an idea of what I need. I know when I go to the doctor, I know what to ask the doctor for rather than having to go over there and just surprise the doctor or me being surprised of what's happening with my body as well, because I've had-- Sometimes, I've coughed up blood or I've sneezed out blood or something and I'm not sure. I used to be a bit scared about it, but now I know that's something which I should be expecting at some point in time when my asthma goes really bad. Participant 5*

*No. I think I'm more proactive. Since I wasn't listened to, I want to make sure that I am now. I ask why that's been given to me and so on. I think I'm a little bit more proactive. I'm not quite so willing to just agree with what is being said to me. I think because I was told I had reflux at one point, and I almost passed out in the car park on the way out. I'm not quite so happy to take a diagnosis or take a suggestion without more questioning. Participant 32*

*It's vastly changed over time and I do think that's directly related to my education. Prior to my scientific education, I would go straight to my GP for anything and I would trust whatever they provided me, whatever they recommended. Participant 52*

Participant describes their decision-making not changing over time (no specific reason)

*No, nothing's really changed. I'm terribly ignorant about it. [laughs] I just do the laziest thing. I'm terrible. No, nothing's changed. I just got told to take medication, so I take it. Participant 71*

*I guess it's the same way because even like I was diagnosed with asthma very soon and then I just use medicine. Then I just follow that way using medicine. I didn't try any treatment, so it doesn't change. Participant 96*

Participant describes decision-making changing over time as decisions are more based on the impact of their family

*Yes. I think now I've got a family and a mortgage, it's definitely the cost thing. It definitely plays a lot more of a part, especially for some of the medication I'm on now. It's up to \$75,000 a year. That's luckily covered through PBS and the hospital. If that wasn't the case I definitely wouldn't be on that medication. Participant 33*

*That's a good question. I would say any change would have been determined by the age of my children. They are my absolute number one priority. When they were smaller, my decisions would have been based on, well, if I'm unwell who's there to care for them or if I have time off work, it would always have been, that's where my thoughts would go straight to. Now that they're older, obviously, that's not part of that thinking. I'd say that would be the difference. How it would impact on my children, depending on their age. Participant 14*

*Well, I suppose it has because at the time I was diagnosed, I had little babies. I was raising them and I was working and my focus was elsewhere. I'm retired and I suppose I have more time to think about, "You know, I should probably do something about that." It's a time thing. Participant 92*

*Yes. Since having a family I've become more serious about it. I really like I said before I just forgot about it. Now I do consider of what will happen if I didn't mismanage this and I was quite in a situation that I couldn't be treated. It's definitely-- I've respected it more over time. Participant 93*

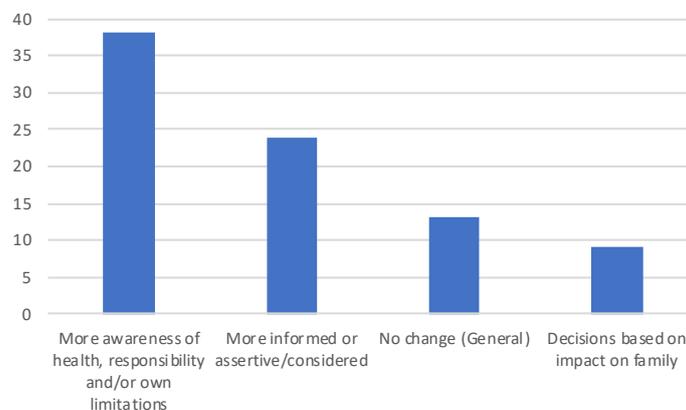


Figure 4.3: Decision-making over time – does it change?

Table 4.3: Decision-making over time – does it change and reasons for change

Does decision-making change over time?	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes decision-making changing over time as they have more awareness of their health, responsibility and/or own limitations	38	38.00	9	34.62	11	50.00	18	34.62	20	41.67	16	44.44	13	31.71	9	39.13
Participant describes decision-making changing over time as they are more informed or assertive/considered	24	24.00	3	11.54	4	18.18	17	32.69	7	14.58	7	19.44	15	36.59	2	8.70
Participant describes their decision-making not changing over time (No specific reason)	13	13.00	5	19.23	2	9.09	6	11.54	7	14.58	5	13.89	3	7.32	5	21.74
Participant describes decision-making changing over time as decisions are more based on the impact on their family	9	9.00	4	15.38	2	9.09	4	7.69	5	10.42	3	8.33	2	4.88	4	17.39

Does decision-making change over time?	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes decision-making changing over time as they have more awareness of their health, responsibility and/or own limitations	38	38.00	12	41.38	26	36.62	14	34.15	24	40.68	7	30.43	15	35.71	16	45.71
Participant describes decision-making changing over time as they are more informed or assertive/considered	24	24.00	10	34.48	14	19.72	9	21.95	15	25.42	5	21.74	12	28.57	7	20.00
Participant describes their decision-making not changing over time (No specific reason)	13	13.00	1	3.45	12	16.90	7	17.07	6	10.17	2	8.70	9	21.43	2	5.71
Participant describes decision-making changing over time as decisions are more based on the impact on their family	9	9.00	3	10.34	6	8.45	5	12.20	4	6.78	4	17.39	3	7.14	2	5.71

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes decision-making changing over time as they have more awareness of their health, responsibility and/or own limitations	38	38.00	28	42.42	10	29.41	17	38.64	21	37.50	21	37.50	17	38.64
Participant describes decision-making changing over time as they are more informed or assertive/considered	24	24.00	13	19.70	11	32.35	9	20.45	15	26.79	15	26.79	9	20.45
Participant describes their decision-making not changing over time (No specific reason)	13	13.00	7	10.61	6	17.65	3	6.82	10	17.86	6	10.71	7	15.91
Participant describes decision-making changing over time as decisions are more based on the impact on their family	9	9.00	7	10.61	2	5.88	7	15.91	2	3.57	6	10.71	3	6.82

# Section 5 Treatment and health service provision

**Section 5: Treatment and health service provision****Main provider of treatment**

The general practitioner was the main provider of asthma treatment for the majority of participants (n=74, 76.29%), followed by a respiratory specialist (n=20, 20.62%).

**Access to health professionals**

Almost all participants had access to a general practitioner (n=99, 99.00%), and more than half of the participants had access to a pharmacist (n=61, 61.00%), and a respiratory specialist (n=60, 60.00%), for the treatment of their asthma.

**Respect shown**

Half of the participants indicated that they had been treated with respect throughout their experience (n=51, 51.00%), 41 (41.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 8 (8.00%) participants felt they had not been treated with respect throughout their treatment.

**Health care system**

While two-thirds of the participants had private health insurance (n=67, 67.00%), only a third were asked if they want to be treated as a public or private patient (n=34, 34.00%), in addition, less than half were asked if they had private health insurance (n=45, 45.00%).

The majority of participants had been hospitalised for asthma (n=81, 81.00%), and of these most were treated as public patients (n=51, 62.96%) and treated in the public hospital system (n=60, 74.07%). Participants had been hospitalised most commonly two to five times throughout their life (n=35, 43.21%), and the most common length of admission was one day (n=23, 28.40%).

**Affordability of healthcare**

The majority of participants never or rarely canceled their appointments due to cost (n=64, 64.00%), while four (4.00%) participants had to cancel often or very often. The majority of participants (n=61, 61.00%) never or rarely could not fill prescriptions due to cost, while 13 (13.00%) often or very often had difficulty filling these prescriptions due to cost. Most participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=65, 65.00%). Ten participants (10.00%) had to pay for additional carers for self or family.

**Reduced income due to asthma**

A quarter of participants (25.00%) had a reduced family income due to asthma, for 15 of these participants (60.00%), the burden of this reduced income was extremely or moderately significant.

**Cost of asthma**

Participants estimated the amount they spend per month on asthma. The most common amount was less than \$50 (n=32, 32.00%), there were five participants who spent more than \$500 a month. The amount spent was a significant or moderately significant burden for 20 (20.00%) participants.

**Changes to employment status**

Two-thirds (n=66, 66.00%) of the participants of this PEEK study have made changes to their employment that has resulted in a reduced income (taking leave without pay, reducing hours or quitting their job). There were 66 (66.00%) participants with a main partner or carer, of these, ten partners or main carers made changes to their employment that has resulted in a reduced income (15.16%) taking leave without pay, reducing hours or quitting their job).

**Treatment: medications**

Almost all participants used a reliever puffer like Airmol or Ventolin (n=98, 98.00%). The next most common treatment was a preventer puffer like Breo or Flutiform (n=91, 91.00%). Very few participants used monoclonal antibodies where five participants (5.00%) used Omalizumab and four (4.00%) used Mepolizumab.

Treatments were prescribed by general practitioners more often than by respiratory specialists for almost all of the treatments, only non-steroid preventer (Montelukast, Singulair), and long-acting reliever (Spiriva Respimat) were prescribed by a respiratory specialist more often.

The most commonly used medications were reliever puffers (e.g. Airmol, Ventolin) (n=98). These were used for more than ten years by the majority of participants (n=78, 79.59%). Preventer puffers (e.g. Breo, Flutiform) were used by 90 participants, and were most commonly used for more than ten years (n=29, 32.22%). 73 participants reported oral corticosteroid usage. 20 participants skipped this question online. These were primarily people that had been prescribed OCS a long time ago or only once-off.

Participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Median quality of life scores ranged from 3.50 to 5.00, that is, all quality of life scores were within the 'Life was a little distressing' to 'Life was good' range. The treatment that scored the highest median quality of life was preventer puffer (Breo, Flutiform, Fluticasone/Salmeterol Cipla, Seretide or Symbicort) (median =5.00, IQR =1.50) which is in the "Life was good range". The treatment that scored the lowest median quality of life was oral corticosteroid medication (median =3.50, IQR =1.25) this is in the "Life was a little distressing range". The most commonly used treatment, reliever puffer (Airmol, Asmol, Bricanyl or Ventolin) (n=98), the median quality of life was 4.50 in the life was average to life was good range.

Participants rated how effective they felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective). All treatments scored a median score between 3.00 and 5.00, that is between moderately effective and very effective. The most commonly used treatments, reliever puffer (Airmol, Asmol, Bricanyl or Ventolin) (n=98) and preventer puffer (Breo, Flutiform, Fluticasone/Salmeterol Cipla, Seretide or Symbicort) (n=91), had a median effectiveness score of 4.00, in the "effective" range.

**Supportive care: Physiotherapy**

There were 17 (17.00%) participants who were prescribed physiotherapy. The majority were prescribed physiotherapy by their general practitioner (n=11, 64.71%). The median quality of life score was 3.00, in the 'Life was a little distressing' range. The median effectiveness score was 3.00, in the 'moderately effective' range.

**Treatment: complementary therapies**

Participants were asked in the online questionnaire about complementary therapies used (relaxation, massage and acupuncture). The most commonly used complementary therapy was relaxation techniques (n=44), the median quality of life (4.00) for this was in the 'life was average' range, and the median effectiveness (median =3.00) was rated as 'somewhat effective'. There were 11 participants that used massage therapy, the median quality of life (median =4.50) was in the 'life was average to good range', and the median effectiveness (median = 4.00) was in the 'effective' range. There were eight participants who used acupuncture for asthma, the median quality of life was 4.00, in the 'life was average' range, and the median effectiveness (median = 2.50) was rated in the 'somewhat to moderately effective' range. There were no side effects from any of the complementary therapies.

**Clinical trials**

There was a total of 15 participants (15.00%) that had discussions about clinical trials, wither by bringing up the topic themselves (n=9, 9.00%) or their doctor bringing up the topic (n=6, 6.00%). There were eight participants (8.00%) who had taken part in a clinical trial, and 72 (72.00%) who would like to take part in a clinical trial if there was a suitable one.

**Description of mild side effects**

The most common description of 'mild side effects' was those that they can self-manage and do not interfere with daily life (n=42, 42.00%). Other descriptions of 'mild side effects' include shakiness or rapid heart rate associated with medication (n=22, 22.00%) and mild side effects such as headaches with or without nausea (n=11, 11.00%).

**Description of severe side effects**

The most common description of 'severe side effects' was side effects that impact everyday life or the ability to conduct activities of daily living (n=35, 35.00%). Other descriptions of 'severe side effects' included those that are life threatening or result in hospitalisation (n=14, 14.00%), side effects that are long lasting and do not subside or exacerbate condition (n=11, 11.00%), and side effects such as heart palpitations, shakes and artificial anxiety (n=10, 10.00%). There were 8 participants (8.00%) that described 'severe side effects' as those that affect mental health, and there were 8 participants (8.00%) that had not experienced any severe side effects.

**Adherence to treatment: preventative medicine**

Participants were asked about their ability to take preventative asthma medicine every day or as prescribed and sticking to it. More than half responded that they took preventative medicine all the time (n=51, 53.13%), 32 (33.33%) took it most of the time, ten (10.42%) sometimes took preventative medicine and three participants (3.13%) rarely took preventative medicine as prescribed.

**Adherence to treatment: other asthma medications**

Participants were asked about their ability to take all other asthma medicine as prescribed and sticking to it. Almost half of the participants responded that they took other asthma medicine all the time (n=48, 48.00%), 35 (35.00%) took it most of the time, 13 (13.00%) sometimes took other asthma medicine and four participants (4.00%) rarely took other asthma medicine as prescribed.

**Adherence to treatment**

Participants were asked in the structured interview how long they stick to a treatment before they feel like it isn't working or they give up on it. The most common theme described was adhering to treatment for a specific amount of time (n=56, 56.00%). Where participants noted this, the lengths of time that they would adhere were two to three weeks (n=12, 12.00%), one month (n=10, 10.00%), two months (n=10, 10.00%) and 6 months (n=9, 9.00%). Participants also reported following specialists' advice (n=23, 23.00%), adhering to a treatment regime as long as side effects were tolerable (n=11, 11.00%), and making their own judgements on when to adhere to medication (n=10, 10.00%).

**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. The most common response from 27 participants (27.00%) was needing to experience a reduction in tightness in chest and increase in ability to breathe. There were 16 participants (16.00%) that reported needing to experience less wheezing and coughing (including nocturnal cough) and this was followed by needing to experience less sensitivity to triggers or less frequent attacks (n=13, 13.00%); Less shortness of breath, often in the context of being able to remain active and conduct activities of daily life (n=13, 13.00%); and experience a general reduction in symptoms (n=8, 8.00%).

### Main provider of treatment

The general practitioner was the main provider of asthma treatment for the majority of participants (n=74, 76.29%), followed by a respiratory specialist (n=20, 20.62%) (Table 5.1, Figure 5.1).

Table 5.1: Main provider of treatment

Main provider of asthma treatment	Count (n=100)	Percent (n=97)
General practitioner (GP)	74	76.29
Respiratory specialist	20	20.62
GP and chiropractor	1	1.03
GP and Respiratory Specialist	1	1.03
Myself	1	1.03
Not stated	3	

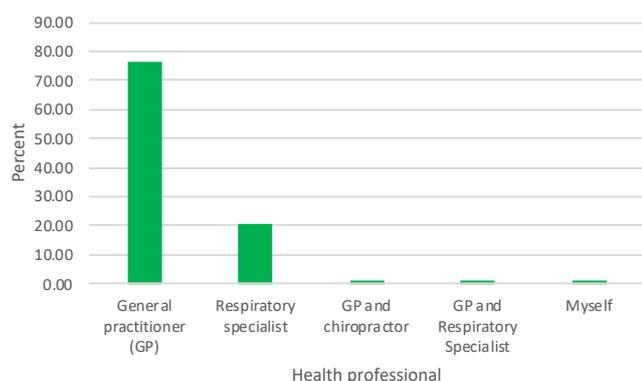


Figure 5.1: Main provider of treatment

### Access to health professionals

Almost all participants had access to a general practitioner (n=99, 99.00%), and more than half of the participants had access to a pharmacist (n=61, 61.00%), and a respiratory specialist (n=60, 60.00%), for the treatment of their asthma (Table 5.2).

Table 5.2: Access to health professionals

Health professional	Count (n=100)	Percent
General Practitioner	99	99.00
Pharmacist	61	61.00
Respiratory specialist	60	60.00
Physiotherapist	44	44.00
Allergy specialist	34	34.00
Counsellor or psychologist	28	28.00
Dietician	22	22.00
Respiratory nurse	22	22.00
Exercise physiologist	14	14.00
Complementary therapist or naturopath	11	11.00
Weight loss specialist	11	11.00
Occupational therapist	5	5.00

### Respect shown

Half of the participants indicated that they had been treated with respect throughout their experience (n=51, 51.00%), 41 (41.00%) participants felt they had been treated with respect with the exception of one or two occasions, and 8 (8.00%) participants felt they had not been treated with respect throughout their treatment.

Table 5.3: Treated with respect

Treated respectfully throughout treatment	Count (n=100)	Percent
Yes	51	51.00
Yes, with the exception of one or two occasions	41	41.00
No	8	8.00

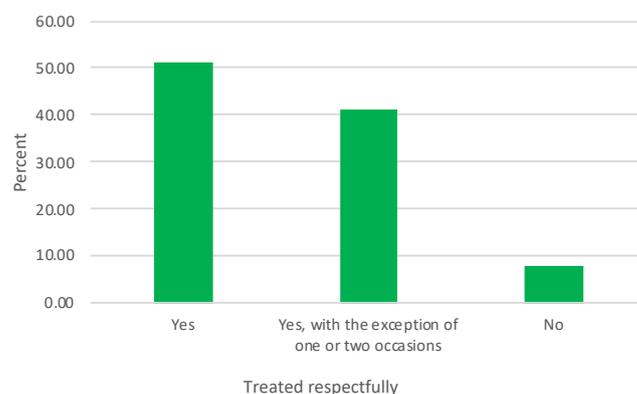


Figure 5.2: Treated with respect  
Health care system

While two-thirds of the participants had private health insurance (n=67, 67.00%), only a third were asked if they want to be treated as a public or private patient (n=34, 34.00%), in addition, less than half were asked if they had private health insurance (n=45, 45.00%).

The majority of participants had been hospitalised for asthma (n=81, 81.00%), and were mostly treated as

public patients (n=51, 62.96%), and most were treated in the public hospital system (n=60, 74.07%).

Participants had been hospitalised most commonly two to five times through-out their life (n=35, 43.21%), and the most common length of admission was one day (n=23, 28.40%).

Table 5.4: Health care system details

Health services and insurance	Response	Count (N=100)	Percent
Private Health Insurance	No	33	33.00
	Yes	67	67.00
Asked whether you wanted to be treated as a public or private patient	No	66	66.00
	Yes	34	34.00
Asked whether you had private health insurance	No	55	55.00
	Yes	45	45.00
Hospitalised as a result of your asthma	No	19	19.00
	Yes	81	81.00
Throughout your treatment in hospital, have you mostly been treated as a public or a private patient (n=81)	Equally as a public and private patient	12	14.81
	Private patient	10	12.35
	Public patient	51	62.96
	I'm not sure	8	9.88
Which hospital system have you primarily been treated in? (n=81)	Both public and private	13	16.05
	Private	8	9.88
	Public	60	74.07
Approximately how often have you had to be hospitalised for your asthma? (n=81)	More than three times a year	10	12.35
	Two to five times throughout my life	35	43.21
	Twice a year	8	9.88
	Once a year	9	11.11
	five to 10 times in my life	2	2.47
	One time only	8	9.88
	Frequent hospitalisations as a child. Very infrequent - not at all as an adult	9	11.11
When you have been hospitalised for asthma, how long on average do you stay in hospital for? (n=81)	1 day	23	28.40
	2 days	5	6.17
	3 days	11	13.58
	4 days	11	13.58
	5 days	9	11.11
	6 days	2	2.47
	A week or more	16	19.75
	not sure	4	4.94

## Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The majority of participants never or rarely cancelled their appointments due to cost (n=64, 64.00%), while four (4.00%) participants had to cancel often or very often. The majority of participants (n=61, 61.00%)

never or rarely could not fill prescriptions due to cost, while 13 (13.00%) often or very often had difficulty filling these prescriptions due to cost. Most participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=65, 65.00%). Ten participants (10.00%) had to pay for additional carers for self or family.

Table 5.5: Affordability of healthcare

Financial issues		Count (n=100)	Percent
Delay or cancel healthcare appointments due to affordability	Never	50	50.00
	Rarely	14	14.00
	Sometimes	32	32.00
	Often	3	3.00
	Very often	1	1.00
Did not fill my prescriptions for essential medicines because of costs	Never	45	45.00
	Rarely	16	16.00
	Sometimes	26	26.00
	Often	10	10.00
	Very often	3	3.00
As a result asthma, it is difficult to pay for basic necessities such as housing, food, electricity	Never	56	56.00
	Rarely	19	19.00
	Sometimes	20	20.00
	Often	2	2.00
	Very often	3	3.00
As a result asthma, had to pay for additional carers for self or family	No	90	90.00
	Yes	10	10.00

## Reduced income due to asthma

A quarter of participants (25.00%) had a reduced family income due to asthma. For 15 of these participants (60.00%), the burden of this reduced income was extremely or moderately significant. The most common amount of this reduced income was more than \$1000 (n=8, 33.33%).

Table 5.6: Reduced family income

Reduced income (self or family)	Count (n=100)	Percent
No	75	75.00
Yes	25	25.00

Table 5.7: Burden of reduced family income

Burden of reduced income	Count (n=25)	Percent
Extremely significant	6	24.00
Moderately significant	9	36.00
Somewhat significant	4	16.00
Slightly significant	4	16.00
Not at all significant	2	8.00

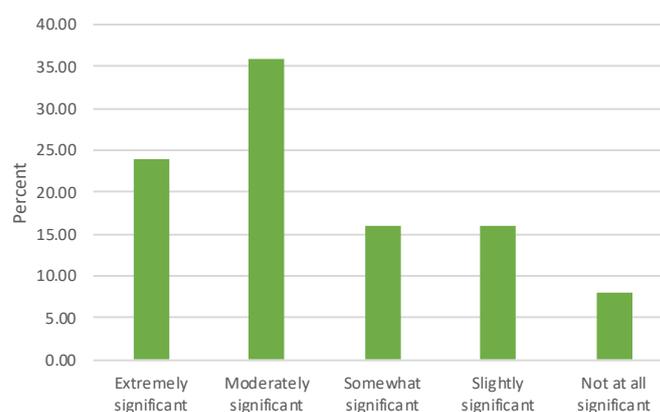


Figure 5.3: Burden of reduced family income

Figure 5.8: Estimate of reduced monthly income

Estimated monthly loss of income	Count (n=24)	Percent
<\$100	1	4.17
\$101 - 250	2	8.33
\$251-500	1	4.17
\$501-1000	3	12.50
>\$1000	8	33.33
Not sure/monthly income not specified	8	33.33

### Cost of asthma

Participants estimated the amount they spend per month on asthma. The most common amount was less than \$50 (n=32, 32.00%), there were five participants who spent more than \$500 a month. The amount spent was a significant or moderately significant burden for 20 (20.00%) participants.

Table 5.9: Estimated monthly expenses for asthma

Estimated monthly out of pocket expenses due to asthma	Count (n=100)	Percent
0	3	3.00
\$1 - 50	32	32.00
\$51-100	22	22.00
\$101-250	17	17.00
\$251-500	10	10.00
>\$501	5	5.00
Differs/don't know	11	11.00

Table 5.10: Burden of monthly expenses for asthma

Burden of monthly expenses	Count (n=100)	Percent
Extremely significant	9	9.00
Moderately significant	11	11.00
Somewhat significant	22	22.00
Slightly significant	29	29.00
Not at all significant	29	29.00

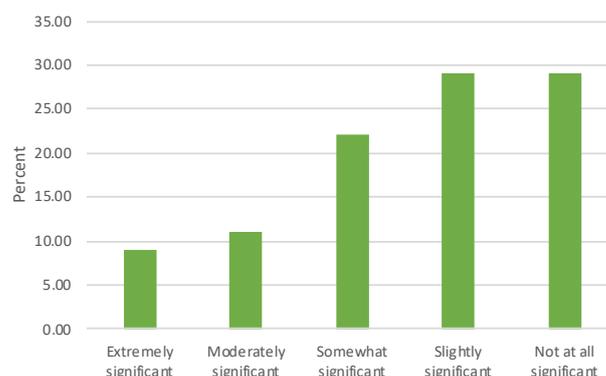


Figure 5.4: Burden of monthly expenses for asthma

### Changes to employment status

Two-thirds (n=66, 66.00%) of the participants of this PEEK study have made changes to their employment that has resulted in a reduced income (taking leave without pay, reducing hours or quitting their job). There were 66 (66.00%) participants with a main partner or carer, of these, ten partners or main carers made changes to their employment that has resulted in a reduced income (15.16% taking leave without pay, reducing hours or quitting their job).

Table 5.11: Changes to employment status

Changes to work status due to asthma	Count (n=100)	Percent
My work status has not changed since I was diagnosed	46	46.00
I have taken leave from work without pay	22	22.00
I have reduced the number of hours that I work	21	21.00
I have had to quit my job	13	13.00
I have accessed my Superannuation early due to my condition	4	4.00
I was retired or did not have a job when I was diagnosed	4	4.00

Table 5.12: Changes to partner/main carer work status

Changes to partner/main carer work status	Count (n=66)	Percent
The employment status has not changed	50	75.76
Took leave from work with pay	12	18.18
Took leave from work without pay	6	9.09
Reduced the number of hours of work	3	4.55
Retired or did not have a job when I was diagnosed	2	3.03
Had to quit their job	1	1.52
I do not have a partner/main carer	34	

## Treatment: medications

Almost all participants used a reliever puffer such as Airmol or Ventolin (n=98, 98.00%). The next most common treatment was a preventer puffer such as Breo or Flutiform (n=91, 91.00%). Overall, there were 73 participants that reported oral corticosteroid usage, noting that there were 20 participants skipped this question online. These were primarily people that had been prescribed OCS a long time ago or only once-off.

Some participants used monoclonal antibodies; five participants (5.00%) used Omalizumab and four (4.00%) used Mepolizumab. Participants answered follow-up questions about who prescribed the medication, how long they have taken it, quality of life, side effects and effectiveness. Table 5.13 is a summary of these follow-up questions with median or top responses given. More detailed information follows in the subsequent tables.

Table 5.13: Summary of medications

Treatment	Preventer puffer (corticosteroid)	Preventer puffer (e.g. Breo, Flutiform)	Non-steroid preventer (Montelukast, Singulair)	Non-steroid preventer inhaler (Intal, Tilade)	Reliever puffer called (e.g. Airmol, Ventolin)	Long-acting reliever (Spiriva, Respimat)	Oral corticosteroids (e.g. Prednisone)	Omalizumab (Xolair)	Mepolizumab (Nucala)
Number	70	91	23	14	98	19	53	5	4
Most commonly prescribed by:	GP	GP	Respiratory specialist	GP	GP	Respiratory specialist	GP	GP	GP
Most frequent length of time taken	More than 10 years	More than 10 years	6 months - 1 year	6 months or less	More than 10 years	6 months or less/2-3 years	More than 10 years	6 months to 1 year/2-3 years	6 months to 1 year/1 -2 years
Median Quality of Life	Life was average	Life was good	Life was average	Life was average to good	Life was average to good	Life was average	Life was a little distressing to average	Life was average	Life was good
Number of participants without side effects	26 (37.14%)	38 (41.76%)	15 (65.22%)	7 (50.00%)	39 (39.80%)	9 (34.62%)	12 (25.00%)	1 (20.00%)	2 (50.00%)
Most reported side effects	Throat infection	Hoarse voice	NA*	Unpleasant taste	Increased heart rate	Hoarse voice	Insomnia	NA*	NA*
	Horse voice	Sore throat or throat infection			Shaking hands		Increased heart rate		
Median Effectiveness	Effective	Effective	Effective	Moderately effective	Effective	Effective	Moderately effective	Very effective	Moderately effective

### Healthcare professional prescribed medication

Treatments were prescribed by general practitioners more often than by respiratory specialists for almost all

of the treatments, only non-steroid preventer (Montelukast, Singulair), and long-acting reliever (Spiriva Respimat) were prescribed by a respiratory specialist more often.

Table 5.14: Healthcare professional prescribed medication

Treatment	Count	General practitioner		Respiratory specialist		Emergency room doctor		other	
		n	%	n	%	n	%	n	%
Preventer puffer (corticosteroid)	68	48	70.59	20	29.41	1	1.47	1	1.47
Preventer puffer (e.g. Breo, Flutiform)	90	70	77.78	22	24.44	0	0	0	0
Non-steroid preventer (Montelukast, Singulair)	22	10	45.45	11	50.00	0	0	1	4.55
Non-steroid preventer inhaler (Intal, Tilade)	14	10	71.43	4	28.57	0	0	0	0
Reliever puffer called (e.g. Airmol, Ventolin)	96	85	88.54	7	7.29	2	2.08	2	2.08
Long-acting reliever (Spiriva Respimat)	19	8	42.11	11	57.89	0	0	0	0
Oral corticosteroids (e.g. Prednisone)	47	36	76.60	7	14.89	6	12.77	3	6.38
Omalizumab (Xolair)	5	1	20.00	4	80.00	0	0	0	0
Mepolizumab (Nucla)	3	2	66.67	0	0	0	0	1	33.33

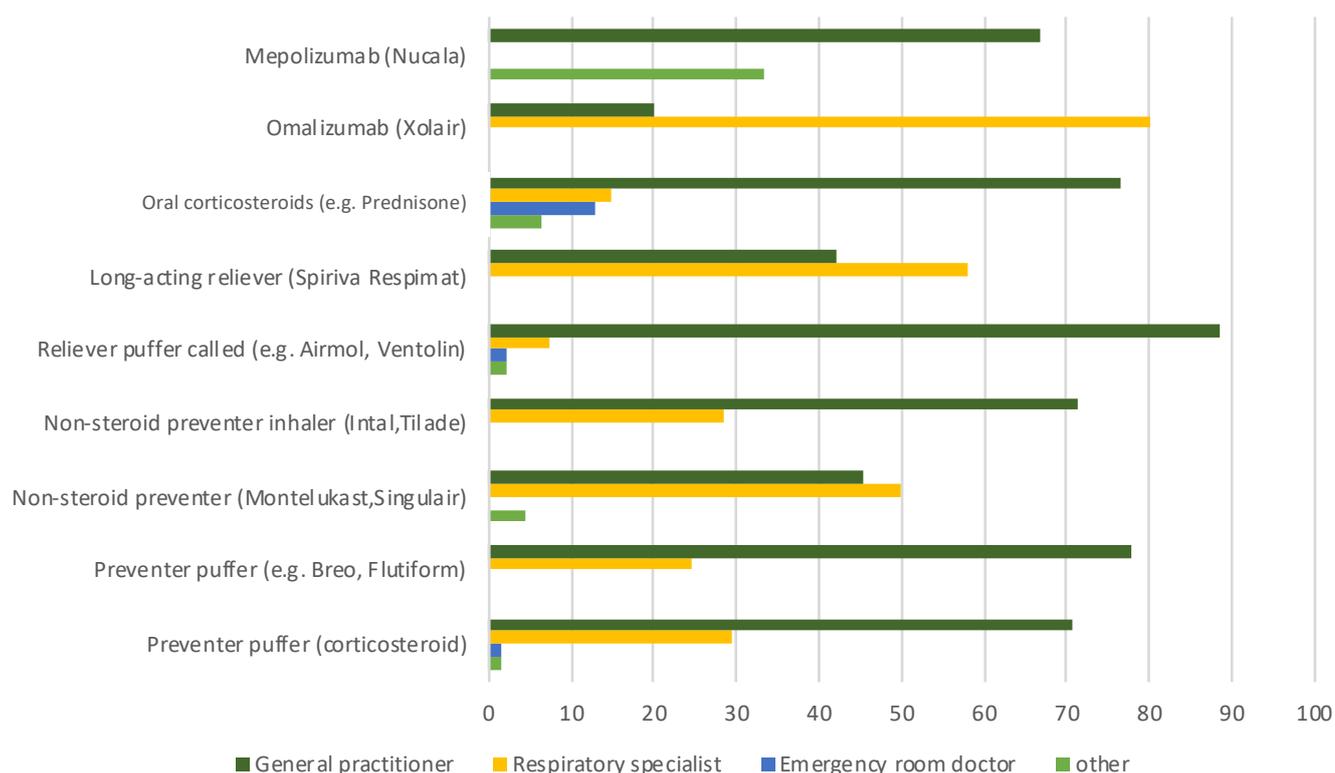


Figure 5.5: Healthcare professional prescribed medication

**Medication: length of time taken**

Participants noted in the online questionnaire the amount of time they had taken medications. The most commonly used medications were reliever puffers (e.g.

Airmol, Ventolin) (n=98) which were used for more than ten years by the majority of participants (n=78, 79.59%). Preventer puffers (e.g. Breo, Flutiform) were used by 90 participants, and was most commonly used for more than ten years (n=29, 32.22%).

Table 5.15: Length of time medication taken

Medication	Count	I only used it/had this a few times	6 month or less	6 months to 1 year	1 to 2 years	2 to 3 years	4 to 5 years	More than 5 years	More than 10 years	Other
Preventer puffer (corticosteroid)	n=67	2	4	6	5	5	8	6	30	1
	%	2.99	5.97	8.96	7.46	7.46	11.94	8.96	44.78	1.49
Preventer puffer (e.g. Breo, Flutiform)	n=90	1	3	7	10	13	10	14	29	3
	%	1.11	3.33	7.78	11.11	14.44	11.11	15.56	32.22	3.33
Non-steroid preventer (Montelukast,Singulair)	n=23	1	3	6	4	4	0	3	2	0
	%	4.35	13.04	26.09	17.39	17.39	0.00	13.04	8.70	0.00
Non-steroid preventer inhaler (Intal,Tilade)	n=14	1	4	1	1	3	1	2	1	0
	%	7.14	28.57	7.14	7.14	21.43	7.14	14.29	7.14	0.00
Reliever puffer called (e.g. Airmol, Ventolin)	n=98	0	1	5	1	2	4	6	78	1
	%	0.00	1.02	5.10	1.02	2.04	4.08	6.12	79.59	1.02
Long-acting reliever (Spiriva Respimat)	n=19	0	5	3	2	5	0	1	3	0
	%	0.00	26.32	15.79	10.53	26.32	0.00	5.26	15.79	0.00
Oral corticosteroids (e.g Prednisone)	n=46	10	6	1	0	2	1	4	16	6
	%	21.74	13.04	2.17	0	4.34	2.17	8.70	34.78	13.04
Omalizumab (Xolair)	n=5	0	0	2	1	2	0	0	0	0
	%	0.00	0.00	40	20	40.00	0.00	0.00	0.00	0.00
Mepolizumab (Nucala)	n=4	0	0	2	2	0	0	0	0	0
	%	0.00	0.00	50	50	0.00	0.00	0.00	0.00	0.00

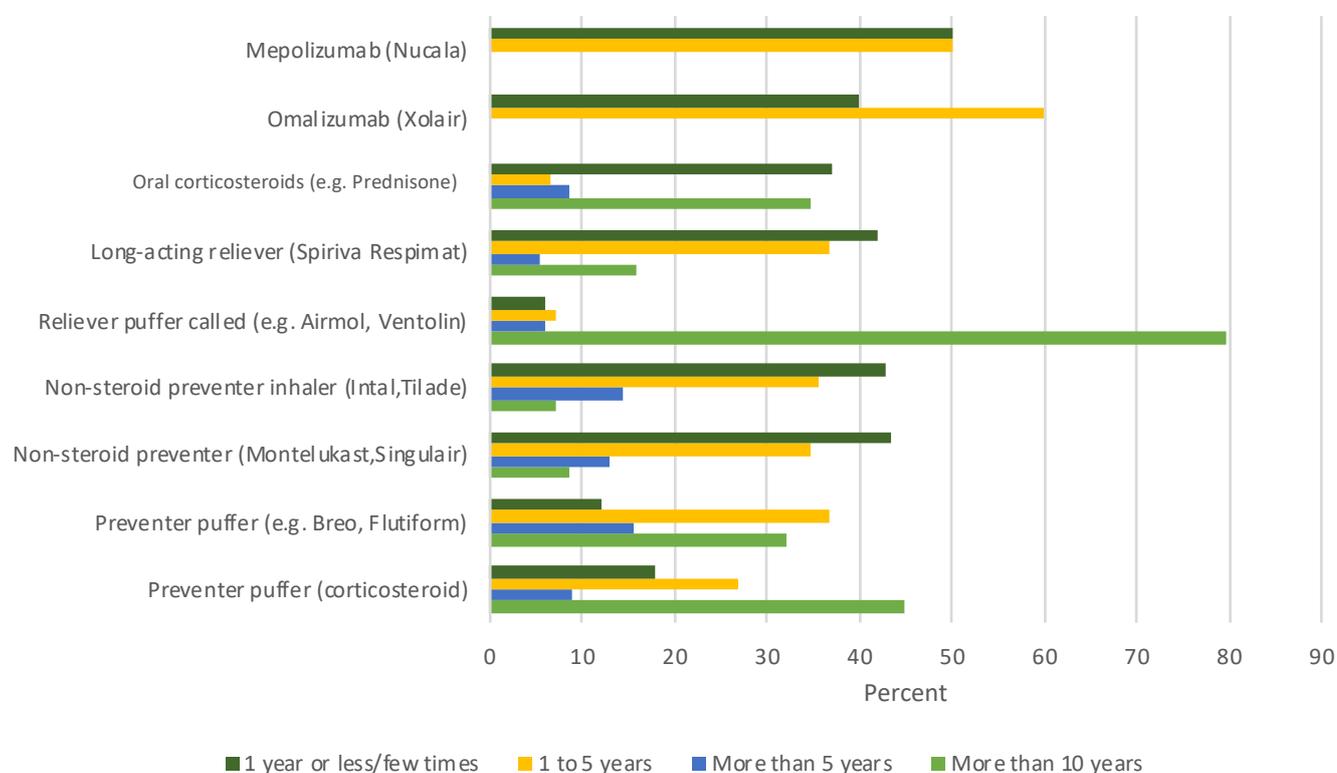


Figure 5.6: Length of time medication taken

### Quality of life while taking medication

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great'). Median quality of life scores ranged from 3.50 to 5.00, that is, all quality of life scores were within the 'Life was a little distressing' to 'Life was good' range. The treatment that scored the highest median

quality of life was preventer puffer (Breo, Flutiform, Fluticasone/Salmeterol Cipla, Seretide or Symbicort) (median =5.00, IQR =1.50) which is in the "Life was good range". The treatment that scored the lowest median quality of life was OCS medication (median =3.50, IQR =1.25) this is in the "Life was a little distressing range. The most commonly used treatment, reliever puffer called (Airmol, Asmol, Bricanyl or Ventolin) (n=98), the median quality of life was 4.50 in the life was average to life was good range.

Table 5.16: Quality of life while taking medication

Treatment	Count	Mean	SD	Median	IQR
Preventer puffer (corticosteroid)?	70	4.19	1.32	4.00	2.00
Preventer puffer (Breo, Flutiform, Fluticasone+Salmeterol Cipla, Seretide or Symbicort)	91	4.63	1.40	5.00	1.50
Non-steroid preventer (Montelukast or Singulair)	23	3.78	1.54	4.00	2.00
Non-steroid preventer inhaler (Intal or Tilade)?	14	4.07	1.38	4.50	1.75
Reliever puffer called (Airmol, Asmol, Bricanyl or Ventolin)	98	4.43	1.28	4.50	1.00
Long-acting reliever (Spiriva Respimat)	19	3.68	1.16	4.00	1.00
Oral corticosteroids (e.g Prednisone)	48	3.48	1.37	3.50	1.25
Omalizumab (Xolair)	5	4.60	1.52	4.00	1.00
Mepolizumab (Nucala)	4	4.75	0.50	5.00	0.25

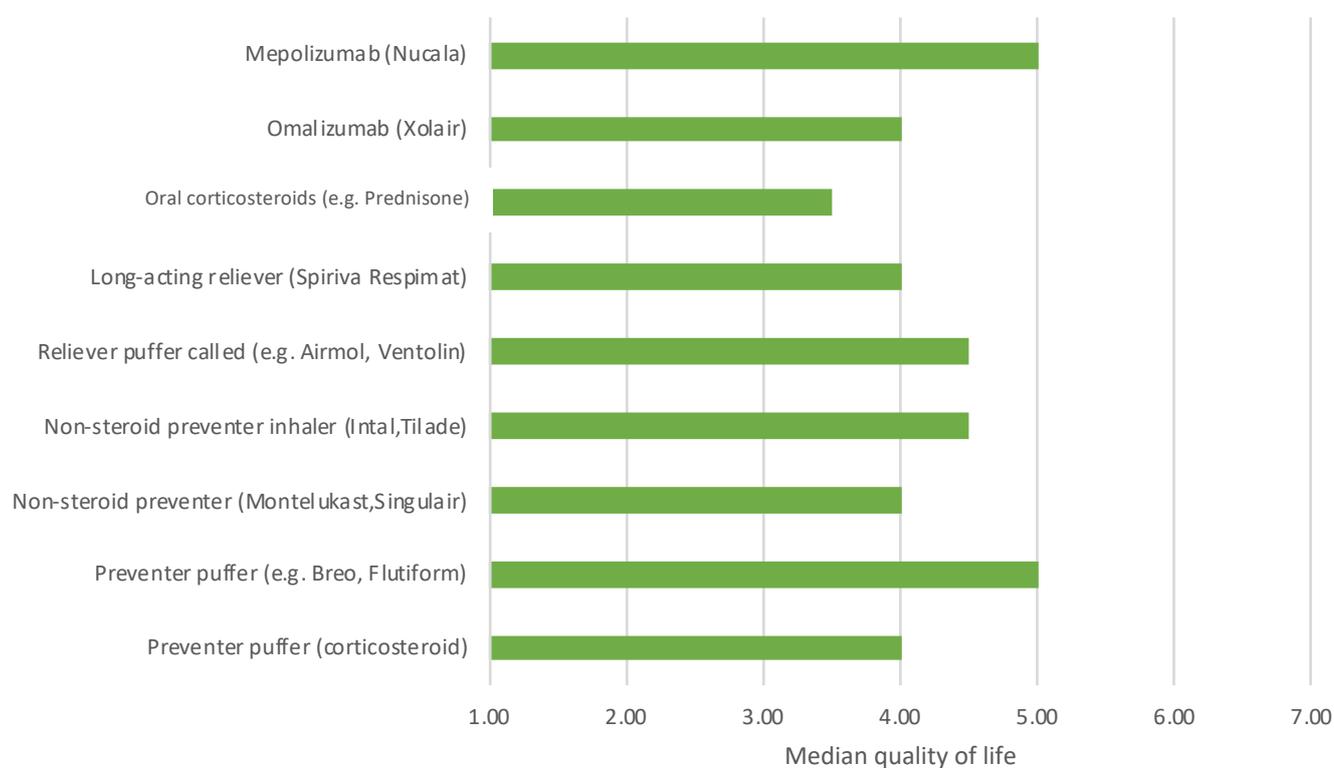


Figure 5.7: Quality of life while taking medication

### Oral corticosteroid use

Overall, there were 73 participants reported oral corticosteroid usage. This includes 20 participants that skipped this question online. These were primarily people that had been prescribed OCS a long time ago or only once-off

As oral corticosteroid use was associated with a significant impact on quality of life, additional information is provided here and is derived from the structured interview. Within the cohort, 49 of the 73 participants that reported oral corticosteroid use described a negative experience (67.12%), 2 of the 73 participants that reported oral corticosteroid described responding well in the absence of negative effects (2.74%). Those that had few comments or described no significant side effects used it once or very short term, did not adhere to treatment regime or it had not been prescribed recently.

In the structured interview, of the 49 participants that reported a negative impact in relation to oral corticosteroid use.

*I'm permanently on Prednisone which has had a lot of side effects. It's been weighing up the impact of those side effects with the fact of being able to breathe. That's probably the most dominant one I've had to think about. I've chosen to breathe. I'm taking- I'll start with the steroids because the steroids have the most impact. I've got osteoporosis from them. I've broken a few bones now. I have to have preventative for that. They also impact my sleep. I have to take a sleeper. It impacts my blood sugar. I've now got insulin-induced diabetes. My skin has got really thin. I'm constantly bruised between my arms and legs. I have blue-looking bruises that don't go away. The steroids have had the most impact on me...Participant 58*

*There's a lot of side effects from Prednisone that I did notice. The 25mg, I did notice that I'd get the jitters, I always put on weight. Take one tablet and I'm sure I'll put on a kilo. Sleep changes. I find that my whole body shakes on the inside, especially if I'm taking three of them in one day, like when I'm really sick and stuff. I feel like my whole body's trembling from the inside. What else? There are other side effects that I did notice on that one. I get really grumpy as well. I get really snappy at everyone and I know that just because it's a steroid, like a really high-dose steroid compared to what I usually take. Participant 70*

*The prednisolone, obviously, doesn't make you feel good at all. If you've ever tried that, so yes...I would imagine being on drugs, like speed or something. Participant 65*

*I mean the last time I had an awful lot of prednisolone I was thinking, "Oh I don't know if I want to go through that again.", because I was almost hyper. It was horrible. It was actually horrible. Participant 69*

*It's not anxiety. There's a very specific feeling after taking it after I've taken it. I'm sorry I don't know how to explain it. It's not jitteriness. I get that with Prednisone, but it's like a pre-jitteriness if that makes sense. Well, Prednisone makes me artificially awake. I'm still tired but it's like I'm incapable of sleeping. It adds to my insomnia. It makes me feel like I have a fever. I get sweaty. Participant 85*

### Side effects from medication

There were 70 participants that reported about side effects after taking a preventer puffer (corticosteroid), 26 (37.14%) had no side effects, and the most commonly reported side effects were sore throat or throat infection (n=16, 22.86%), and hoarse voice (n=16, 22.86%).

The side effects reported by the 91 participants that used a preventer puffer (e.g. Breo, Flutiform) included 38 (41.76%) with no side effects, and the most commonly reported side effects were hoarse voice (n=19, 20.88%) and sore throat or throat infection (n=18, 19.78%).

There were 23 participants that used a non-steroid preventer (Montelukast), 15 reported no side effects (65.22%), and there were no side effects that were reported in more than 10% of those who used it.

The most common side effect for those that used non-steroid preventer inhaler (n=14) was an unpleasant taste (n=4, 28.57%), 7 participants reported they had no side effects (50.00%).

Almost all the participants in this PEEK study used a reliever puffer (e.g. Airmol, Ventolin) (n=98), of which 39 reported no side effects (39.80%). The most commonly reported side effects were increased heart rate (n=35, 35.71%) and shaking hands (n=32, 32.65%). Of the 26 participants who took long-acting reliever (Spiriva Respimat), nine reported no side effects (34.62%), and the most commonly reported side effect was a hoarse voice (n=3, 11.54%).

There were 48 participants that reported on side effects from oral corticosteroids. Of these, 12 had no side effects (25.00%), and the most commonly reported side effects were insomnia (n=14, 29.17%) and increased heart rate (n=12, 25.00%). Very few participants took Mepolizumab or Omalizumab, the side effects are listed in Table 5.18.

Table 5.17: Side effects from medication

Side effects	Preventer puffer (corticosteroid)		Preventer puffer (e.g. Breo, Flutiform)		Non-steroid preventer (Montelukast)		Non-steroid preventer inhaler (Intal or Tilade)		Reliever puffer called (e.g. Airmol, Ventolin)		Long-acting reliever (Spiriva Respimat)		Oral corticosteroids (e.g Prednisone)	
	n=70	%	n=91	%	n=23	%	n=14	%	n=98	%	n=26	%	n=48	%
No side effects	26	37.14	38	41.76	15	65.22	7	50.00	39	39.80	9	34.62	12	25.00
Sore throat or throat irritation	16	22.86	18	19.78	1	4.35	0		4	4.08	2	7.69	1	2.08
Hoarse voice	16	22.86	19	20.88	1	4.35	1	7.14	10	10.2	3	11.54	3	6.25
Oral thrush	13	18.57	13	14.29	1	4.35	1	7.14	1	1.02	0		4	8.33
Shaking hands	13	18.57	1	1.1	2	8.7			32	32.65	2	7.69	11	22.92
Increased heart rate	12	17.14	15	16.48	1	4.35	1	7.14	35	35.71	1	3.85	12	25
Dry mouth	10	14.29	14	15.38	0		2	14.29	6	6.12	0		5	10.42
Unpleasant taste	9	12.86	16	17.58	1	4.35	4	28.57	6	6.12	1	3.85	7	14.58
Sore mouth or gums	7	10	10	10.99	0		0		2	2.04	2	7.69	1	2.08
Dry skin	7	10	7	7.69	0		0		0		0		3	6.25
Headache	5	7.14	8	8.79	2	8.7	0		8	8.16	1	3.85	10	20.83
Cough	5	7.14	7	7.69	0		0		9	9.18	1	3.85	3	6.25
Dizziness	4	5.71	4	4.4	2	8.7	2	14.29	10	10.2	0		4	8.33
Swollen tongue	2	2.86	4	4.4	1	4.35	0		0		0		1	2.08
Nose bleed	2	2.86	2	2.2	0		0		0		0		3	6.25
Nausea	1	1.43	3	3.3	1	4.35	0		4	4.08	0		8	16.67
Insomnia	0		0	0	0		0		0		0		14	29.17
Mood swings	0		0	0	2	8.7	0		0		0		5	10.42
Weight gain	0		1	1.1	0		0		0		1		5	10.42

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Table 5.18: Side effects from Mepolizumab and Omalizumab

Side effects	Mepolizumab (Nucala)	Omalizumab (Xolair)
	n=5	n=4
No side effects	1	2
Redness or pain at injection site	2	2
Tiredness	1	1
Hair loss	0	1
Joint pain	1	1
Increased exacerbation	1	1

### Effectiveness of medications

Another 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). All treatments scored a median score between 3.00 and 5.00, that is between moderately effective and very effective. The most commonly used treatments, reliever puffer (Airmol, Asmol, Bricanyl or Ventolin) (n=98) and preventer puffer (Breo, Flutiform, Fluticasone+Salmeterol Cipla, Seretide or Symbicort) (n=91) had a median effectiveness score of 4.00, in the “effective” range.

Table 5.19: Effectiveness of treatment

Treatment	Count	Mean	SD	Median	IQR
Preventer puffer (corticosteroid)?	70	3.43	1.26	4.00	1.00
Preventer puffer (Breo, Flutiform, Fluticasone+Salmeterol Cipla, Seretide or Symbicort)	91	3.84	1.14	4.00	2.00
Non-steroid preventer (Montelukast or Singulair)	23	3.26	1.25	4.00	1.50
Non-steroid preventer inhaler (Intal or Tilade)?	14	2.79	0.97	3.00	0.75
Reliever puffer called (Airmol, Asmol, Bricanyl or Ventolin)	98	3.76	1.05	4.00	1.00
Long-acting reliever (Spiriva Respimat)	19	4.15	0.92	4.00	1.00
Oral corticosteroids (e.g Prednisone)	48	3.00	2.00	3.00	4.00
Omalizumab (Xolair)	5	4.50	1.00	5.00	0.50
Mepolizumab (Nucala)	4	3.35	1.00	3.00	1.00

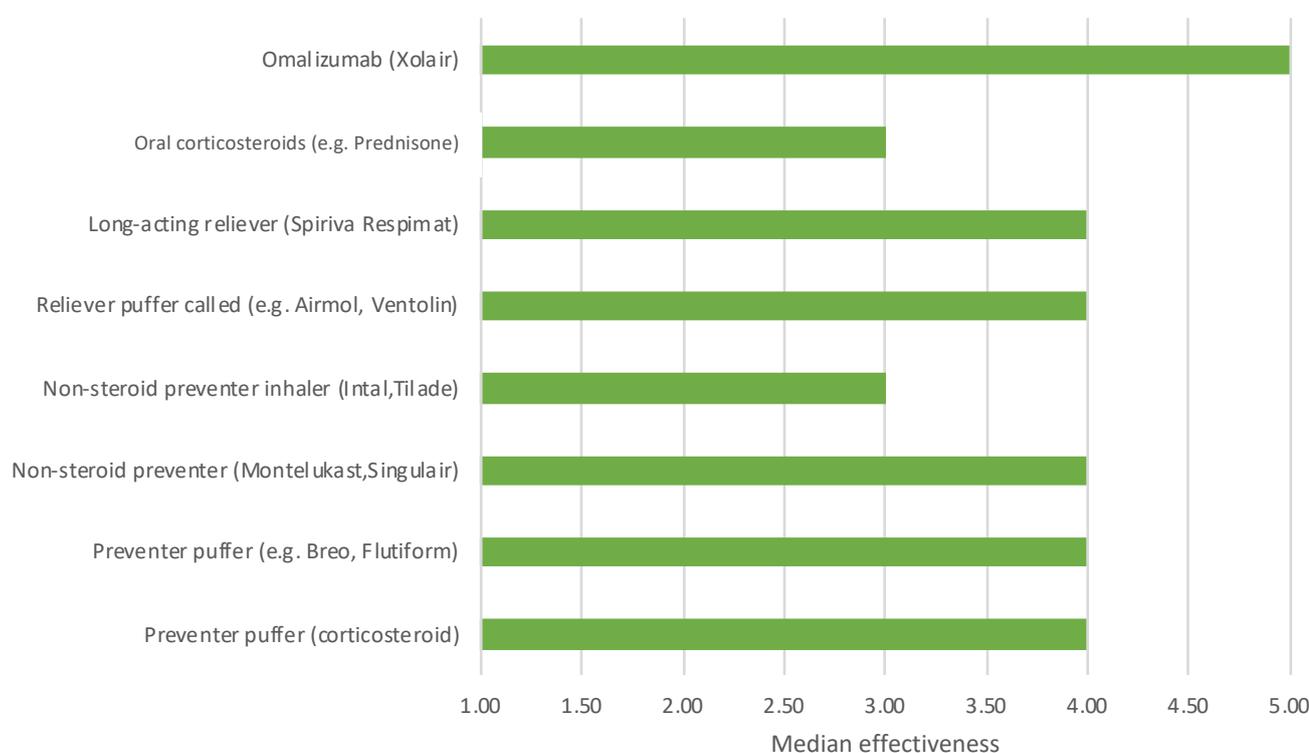


Figure 5.8: Effectiveness of treatment

### Supportive care: Physiotherapy

There were 17 (17.00%) participants who were prescribed physiotherapy. The majority were prescribed physiotherapy by their general practitioner (n=11, 64.71%). Most commonly, participants only used it once or a few times (n=7, 41.18%).

Participants were asked to rate their quality of life on a scale of 1 to 7, while using physiotherapy (with 1 being 'Life was very distressing and 7 being 'Life was great'). The median quality of life score was 3.00, in the 'Life was a little distressing' range. There were only two side effects reported from physiotherapy: headaches (n=1), and pain (n=1). A 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 median effectiveness score was 3.00, in the 'moderately effective' range.

Table 5.20: Physiotherapy

Physiotherapy	Count (N=17)	Percent
<b>Referred by</b>		
General practitioner	11	64.71
Emergency room doctor	3	17.65
Immunologist	1	5.88
<b>Time used</b>		
I only used it/had this a few times	7	41.18
Less than 6 months	3	17.65
6 months to 1 year	2	11.76
1 to 2 years	2	11.76
More than 5 years	2	11.76
More than 10 years	1	5.88
<b>Quality of life</b>		
Range	1 to 5	
mean	3.06	
median	3	
<b>Side effects</b>		
No side effects	15	
Headaches	1	
Pain	1	
<b>Effectiveness</b>		
Range	1 to 5	
mean	3.35	
median	3	

### Treatment: complementary therapies

Participants were asked in the online questionnaire about complementary therapies used (relaxation, massage and acupuncture). The most commonly used complementary therapy was relaxation techniques (n=44), the median quality of life (4.00) for this was in the 'life was average' range, and the median effectiveness (median =3.00) was rated as 'somewhat effective'. There were 11 participants that used

massage therapy, the median quality of life (median =4.50) was in the 'life was average to good range', and the median effectiveness (median =4.00) was in the 'effective' range. There were eight participants who used acupuncture for asthma, the median quality of life was 4.00, in the 'life was average' range, and the median effectiveness (median =2.50) was rated in the 'somewhat to moderately effective' range. There were no side effects from any of the complementary therapies.

Table 5.21: Complimentary therapies

Complementary therapies	Relaxation techniques	Massage	Acupuncture
	n=44	n=11	n=8
<b>Quality of life</b>			
Range	1 to 7	3 to 7	3 to 5
Mean	4.41	4.73	3.88
Median	4.00	4.50	4.00
<b>Side effects</b>			
No side effects	44	11	
<b>Effectiveness</b>			
Range	1 to 5	2 to 5	1 to 4
Mean	2.95	3.18	2.63
Median	3.00	4.00	2.50

### Clinical trials

There was a total of 15 participants (15.00%) that had discussions about clinical trials, either by bringing up the topic themselves (n=9, 9.00%) or their doctor bringing up the topic (n=6, 6.00%). There were eight participants (8.00%) who had taken part in a clinical trial, and 72 (72.00%) who would like to take part in a clinical trial if there was a suitable one.

Eight participants took part in clinical trials, the median quality of life (median =4.25) was rated in the 'life was average' range, and the effectiveness (median = 3.00) was rated in the 'moderately effective' range. Two participants reported having side effects.

Table 5.22: Discussions about clinical trials with doctor

Clinical trial discussion with doctor	Count n=100	Percent
I brought up the topic of clinical trials with my doctor for discussion	9	9.00
My doctor brought up the topic of clinical trials for discussion	6	6.00
No one has ever spoken to me about clinical trials	85	85.00

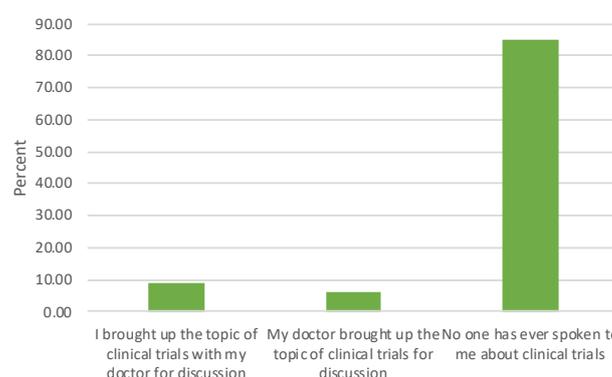


Figure 5.9: Discussions about clinical trials with doctor

Table 5.23: Participation in clinical trials

Clinical Trial participation	Count n=100	Percent
I have participated in a clinical trial	8	8.00
I have not participated in a clinical trial but would like to if there is one for me	72	72.00
I have not participated in a clinical trial and do not want to	20	20.00

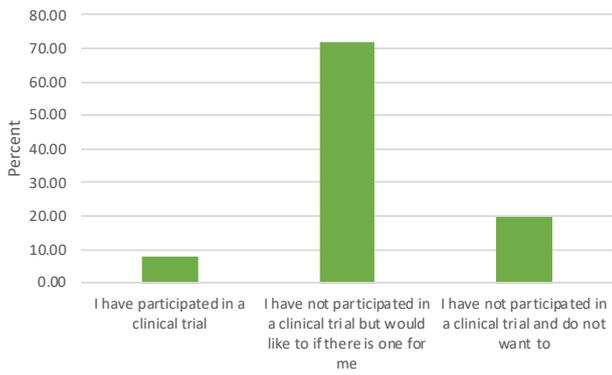


Figure 5.10: Participation in clinical trials

Table 5.24: Clinical trial details

Clinical trials	n=8
<b>Clinical trial quality of life</b>	
Range	1 to 6
Mean	4.5
Median	4.25
<b>Clinical trial side effects</b>	
Yes	2
No	6
<b>Effectiveness</b>	
Range	1 to 5
Mean	2.75
Median	3

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### Description of 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' was those that can be self-manage and do not interfere with daily life (n=42, 42.00%). Other descriptions of 'mild side effects' included shakiness or rapid heart rate associated with medication (n=22, 22.00%) and mild side effects such as headaches with or without nausea (n=11, 11.00%).

In relation to sub-group variations, participants *Aged 55 or older* described shakiness or rapid heart rate associated with medication less frequently (8.57%) than the general population (22.00%), while those *Aged 35 to 54* described this more frequently (33.33%). Participants in the sub-group *Severe asthma* (55.17%) described mild side effects as those that they can self-manage and do not interfere with daily life more frequently than the general population (42.00%).

No participants in the *Moderately controlled asthma* (0.00%) or the *Infrequent flare-up* sub-groups (0.00%) described mild side effects such as headaches with or without nausea compared to 11 participants (11.00%) in the general population.

### Participant describes mild side effects as those that they can self-manage and do not interfere with daily life

*I think mild side effect is something that I can manage myself. That doesn't impact on aspects of my life. Like, for instance, the mouth sensitivity. I think it seems more mindful of rinsing my mouth out properly and drinking lots water after taking the medication. This is more of learning how to take it better, rather than impacting on anything. Participant 57*

*Mild side effects was something you could just cope with I guess. It's like when I take antibiotics, some of the antibiotics churn the stomach up a lot. I wouldn't know what their side effects were, but I make sure I eat them with food and things like that. Participant 23*

*To me, a mild one is just something I've got to deal with today and take the Cortisone tablet in the morning. I'm not on that all the time but I would tweak that. Mild is manageable. Participant 27*

### Participant describes mild side effects as shakiness or rapid heart rate associated with medication

*Okay, mild I will just think that it was something like a little bit of shakiness that you got from all the-- because they're all kind of steroid based. Just mild shakiness or something like that. Participant 9*

*Mild? Maybe change in taste, or maybe a bit of change in skin color, or teeth colour, change in general colour or something like that. Maybe a bit of mild sweating, mild shaking, mild increase in heart rate, that sort of thing. Participant 75*

*I take it back. I said I've never had side effects with Ventolin. Actually, you get a faster heart rate, which can almost scare you, but that's I guess its purpose. I think I'd consider that a mild side effect that I have experienced sometimes, but not too often.*

*Participant 79*

### Participant describes mild side effects as headaches (with or without nausea)

*Exactly, that's the ones that you could live with where the benefits of the medication outweigh the annoyance of the side effects if that makes sense. For me, something like a headache, I'm more than happy to pop a couple of Panadol and just live with it if I can breathe. Participant 33*

*Mild side effects, for me, is something that would probably go away within half an hour to an hour or something that is not going to affect my day-to-day life or my quality of life and something that I can manage and put up with. That's mild to me, in my terminology. [laughs] It's something that's not interfering with my day-to-day life, I would say it's mild. It's like a headache, it will go away. It's just something you have to get through. Participant 3*

*Mild side effect would be a bit of nausea, or headaches, or maybe not working quite as instantly as you would've liked. It worked, but you could've been breathing for several minutes or something and you think, "Oh, it's not working-- Oh, yes, it is". Participant 94*

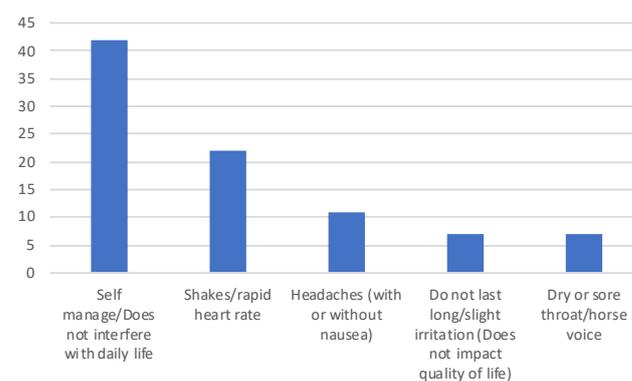


Figure 5.11: Description of mild side effects

Table 5.25: Description of mild side effects

Description of mild side effects	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes mild side effects as those that they can self-manage and do not interfere with daily life	42	42.00	12	46.15	11	50.00	19	36.54	23	47.92	13	36.11	18	43.90	11	47.83
Participant describes mild side effects as shakiness or rapid heart rate associated with medication	22	22.00	6	23.08	5	22.73	12	23.08	10	20.83	6	16.67	9	21.95	7	30.43
Participant describes mild side effects as headaches (with or without nausea)	11	11.00	2	7.69	0	0.00	9	17.31	2	4.17	7	19.44	4	9.76	0	0.00
Participant describes mild side effects as those that do not last long/slight irritation and do not impact quality of life	7	7.00	0	0.00	4	18.18	3	5.77	4	8.33	3	8.33	3	7.32	1	4.35
Participant describes mild side effects as a dry or sore throat/horse voice	7	7.00	3	11.54	1	4.55	3	5.77	4	8.33	1	2.78	6	14.63	0	0.00

Description of mild side effects	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes mild side effects as those that they can self-manage and do not interfere with daily life	42	42.00	16	55.17	26	36.62	18	43.90	24	40.68	10	43.48	16	38.10	16	45.71
Participant describes mild side effects as shakiness or rapid heart rate associated with medication	22	22.00	4	13.79	18	25.35	10	24.39	12	20.34	5	21.74	14	33.33	3	8.57
Participant describes mild side effects as headaches (with or without nausea)	11	11.00	4	13.79	7	9.86	2	4.88	9	15.25	2	8.70	5	11.90	4	11.43
Participant describes mild side effects as those that do not last long/slight irritation and do not impact quality of life	7	7.00	3	10.34	4	5.63	3	7.32	4	6.78	3	13.04	1	2.38	3	8.57
Participant describes mild side effects as a dry or sore throat/horse voice	7	7.00	1	3.45	6	8.45	4	9.76	3	5.08	2	8.70	2	4.76	3	8.57

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes mild side effects as those that they can self-manage and do not interfere with daily life	42	42.00	26	39.39	16	47.06	16	36.36	26	46.43	23	41.07	19	43.18
Participant describes mild side effects as shakiness or rapid heart rate associated with medication	22	22.00	16	24.24	6	17.65	11	25.00	11	19.64	11	19.64	11	25.00
Participant describes mild side effects as headaches (with or without nausea)	11	11.00	7	10.61	4	11.76	4	9.09	7	12.50	6	10.71	5	11.36
Participant describes mild side effects as those that do not last long/slight irritation and do not impact quality of life	7	7.00	5	7.58	2	5.88	3	6.82	4	7.14	4	7.14	3	6.82
Participant describes mild side effects as a dry or sore throat/horse voice	7	7.00	6	9.09	1	2.94	3	6.82	4	7.14	4	7.14	3	6.82

### 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' was side effects that impact everyday life or the ability to conduct activities of daily living (n=35, 35.00%). Other descriptions of 'severe side effects' included those that are life threatening or result in hospitalisation (n=14, 14.00%), side effects that are long lasting and do not subside or exacerbate condition (n=11, 11.00%), and side effects such as heart palpitations, shakes and artificial anxiety (n=10, 10.00%). There were 8 participants (8.00%) that described 'severe side effects' as those that affect mental health, and there were 8 participants (8.00%) that had not experienced any severe side effects.

In relation to sub-group variations, participants in the *Trade or high school* sub-group described severe side effects as those that impact everyday life, ability to conduct activities of daily living less frequently (25.00%) than the general population (35.00%), while those in the *Moderately controlled asthma* sub-group described this more frequently (50.00%).

Participants in the *Age 18 to 34* sub-group described long lasting and do not subside or exacerbate condition more frequently (26.09%) than the general population (11.00%). Participants in the sub-group *Severe asthma* described severe side effects as heart palpitations, shakes or artificial anxiety less frequently (0.00%) than the general population (10.00%).

Participants in the *Controlled asthma* (23.08%), and the *Infrequent flare-ups* (21.74%) sub-groups described not having experience any severe side effects more frequently than the general population (8.00%).

**Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living**

*Severe side effects how I describe that is it stops you from living your day-to-day life, like stops you from doing the activities you'd usually do, inhibits certain other aspects of your life. Participant 42*

*Severe. It would have affected my quality of life. If I couldn't participate everyday living, or playing sport, or walking the dogs, or I couldn't eat certain things. I'd say that was severe. Participant 49*

*I will describe a severe side effect is something that affects your everyday life or something that stops you from feeling safe. In that you know that you might have a heart attack you might-- Like you're actually losing vision or you're feeling dizzy or-- That can really affect your everyday life. Participant 57*

**Participant describes severe side effects as those that are life threatening or result in hospitalisation**

*I have anaphylaxis as well. If you're talking severe, then that would be severe reaction to me. Thank God I'm not allergic to any of the drugs. It's enough to stop breathing or inhibit the breathing so much that you potentially risk it getting worse, or just can't move. Can't get enough air in to move. Participant 45*

*I would say life-threatening. Can I say panic or anxiety because anything that affects your mental state is really scary. Participant 36*

*Then, it's an effect which is debilitating, which stops you from doing things, probably as bad as just sitting and actually not being able to get up and do anything or have a conversation with someone. I've certainly been in that situation, and I suppose could be life-threatening, or at least if you feel it's life-threatening. I would say it's severe. Participant 92*

Participant describes severe side effects as those that are long lasting and do not subside/exacerbate condition

*It'd depend too if the severe side effects, would dissipate once the body got used to the drug. If it's something that is like, "For a week, you're going to feel like crap and it's going to do this and it's going to do that, but then you should start to feel better and it will control you think them better and all the rest of it." I sort of sit there and go, "Okay, I'll suck it up for a week and try it.". It's sort of a fine balance with me, unfortunately. Participant 10*

*Anything where you're thinking, "Is this worth it or is asthma better?". Participant 82*

*Severe would probably be something like, is there risks associated with the medication in terms of long-term, I don't know, something like osteoporosis long-term. Something like that, you'd have to really look at what could happen if I was taking it frequently in the long-term, if there's any effects long-term, I suppose. As I said, probably if there were side effects that were - As I said, I'd probably look into taking something as an alternative measure rather than taking it just for the sake of short-term. It's a tough one. Participant 95*

Participant describes severe side effects (heart palpitations/shakes/artificial anxiety)

*I'd say, struggling to breathe or heart palpitations, or severe nausea, or in the case of that one that kicks in is that bloody suicidal thoughts. Participant 71*

*Severe side effects, got itchy skin as in like hives, or welts, or things like that that are unbearable. Having your femoral head collapse on you. Heart rate, or feeling too faint or dizzy, to the point where you're going to pass out or something like that, that could be kind of severe. Changes in vision, like blurry in the context. Participant 75*

*No, I wouldn't say that this is the- I'd say, if anything, the severe side effects would be the shakes from that other puffer that I had. They were pretty bad. Participant 34*

Participant describes severe side effects as those that affect mental health

*Severe side effects to me is definitely something that has an impact on either another part of my physical, mental, or emotional wellbeing. When I say that physically, not being able to exercise, that's a severe side effect. Not being able to sleep all the way through the night without having a good-quality sleep, that's a severe side effect. Not having a good quality life, that is a severe side effect. Severe, to me, is an impact that just cannot be overcome. Participant 3*

*The severe ones are ones where you struggle mentally and emotionally to deal with. Sometimes I guess you question whether or not you prefer the medication or not to be able to breathe or another medication altogether if possible. That would be a lot of negative thoughts and all that sort of stuff. Participant 33*

*I'd be thinking, because I know a lot of medications can affect your mental health and things like that, so I'd be wanting to know a little more about that as well just because in the past I have had problems with anxiety and I don't want to have it triggered by something like that as well. I'd be looking at those kinds of side effects as well. Participant 39*

Participant has not experienced any severe side effects

*I'm unsure because I've never come across and I think I've never had severe side effects from any of my medications. Participant 79*

*From the puffers, I wouldn't have a clue. I don't know what a severe side effect would be like. Participant 6*

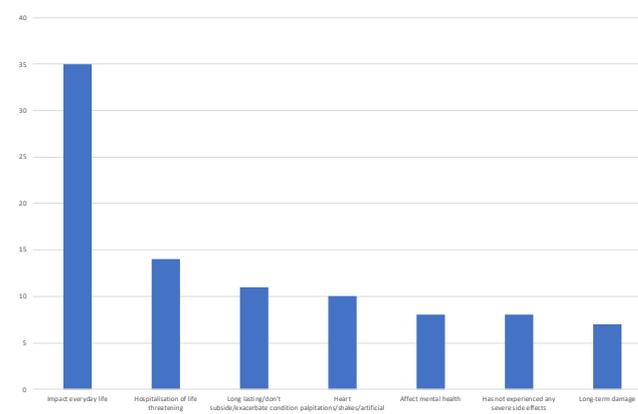


Figure 5.12: Description of severe side effects

Table 5.26: Description of severe side effects

Description of severe side effects	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	35	35.00	7	26.92	11	50.00	17	32.69	18	37.50	12	33.33	15	36.59	8	34.78
Participant describes severe side effects as those that are life threatening or result in hospitalisation	14	14.00	3	11.54	3	13.64	7	13.46	7	14.58	5	13.89	6	14.63	3	13.04
Participant describes severe side effects as those that are long lasting and don't subside/exacerbate condition	11	11.00	4	15.38	3	13.64	4	7.69	7	14.58	5	13.89	2	4.88	4	17.39
Participant describes severe side effects (Heart palpitations/shakes/artificial anxiety)	10	10.00	2	7.69	4	18.18	5	9.62	5	10.42	4	11.11	5	12.20	1	4.35
Participant describes severe side effects as those that affect mental health	8	8.00	0	0.00	0	0.00	8	15.38	0	0.00	5	13.89	3	7.32	0	0.00
Participant has not experienced any severe side effects	8	8.00	6	23.08	1	4.55	1	1.92	7	14.58	1	2.78	2	4.88	5	21.74
Participant describes severe side effects as those that cause long-term damage	7	7.00	2	7.69	0	0.00	5	9.62	2	4.17	1	2.78	5	12.20	1	4.35

Description of severe side effects	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	35	35.00	13	44.83	22	30.99	14	34.15	21	35.59	8	34.78	17	40.48	10	28.57
Participant describes severe side effects as those that are life threatening or result in hospitalisation	14	14.00	4	13.79	10	14.08	6	14.63	8	13.56	1	4.35	7	16.67	6	17.14
Participant describes severe side effects as those that are long lasting and don't subside/exacerbate condition	11	11.00	1	3.45	10	14.08	5	12.20	6	10.17	6	26.09	2	4.76	3	8.57
Participant describes severe side effects (Heart palpitations/shakes/artificial anxiety)	10	10.00	0	0.00	10	14.08	3	7.32	7	11.86	3	13.04	4	9.52	3	8.57
Participant describes severe side effects as those that affect mental health	8	8.00	4	13.79	4	5.63	1	2.44	7	11.86	2	8.70	5	11.90	1	2.86
Participant has not experienced any severe side effects	8	8.00	2	6.90	6	8.45	6	14.63	2	3.39	2	8.70	3	7.14	3	8.57
Participant describes severe side effects as those that cause long-term damage	7	7.00	2	6.90	5	7.04	2	4.88	5	8.47	0	0.00	2	4.76	5	14.29

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	35	35.00	24	36.36	11	32.35	11	25.00	24	42.86	20	35.71	15	34.09
Participant describes severe side effects as those that are life threatening or result in hospitalisation	14	14.00	6	9.09	8	23.53	8	18.18	6	10.71	6	10.71	8	18.18
Participant describes severe side effects as those that are long lasting and don't subside/exacerbate condition	11	11.00	10	15.15	1	2.94	6	13.64	5	8.93	5	8.93	6	13.64
Participant describes severe side effects (Heart palpitations/shakes/artificial anxiety)	10	10.00	7	10.61	3	8.82	5	11.36	5	8.93	3	5.36	7	15.91
Participant describes severe side effects as those that affect mental health	8	8.00	3	4.55	5	14.71	4	9.09	4	7.14	5	8.93	3	6.82
Participant has not experienced any severe side effects	8	8.00	7	10.61	1	2.94	0	0.00	8	14.29	7	12.50	1	2.27
Participant describes severe side effects as those that cause long-term damage	7	7.00	2	3.03	5	14.71	2	4.55	5	8.93	1	1.79	6	13.64

## Adherence to treatment

### Adherence to treatment: preventative medicine

In the online questionnaire, participants were asked about their ability to take preventative asthma medicine every day or as prescribed and sticking to it. More than half responded that they took preventative medicine all the time (n=51, 53.13%), 32 (33.33%) took it most of the time, ten (10.42%) sometimes took preventative medicine and three participants (3.13%) rarely took preventative medicine as prescribed.

Table 7.27: Ability to take preventative medicine

Ability to take preventative asthma medicine	Count (n=96)	Percent
All of the time	51	53.13
Most of the time	32	33.33
Sometimes	10	10.42
Rarely	3	3.13
I don't have preventer medicine/no response	4	

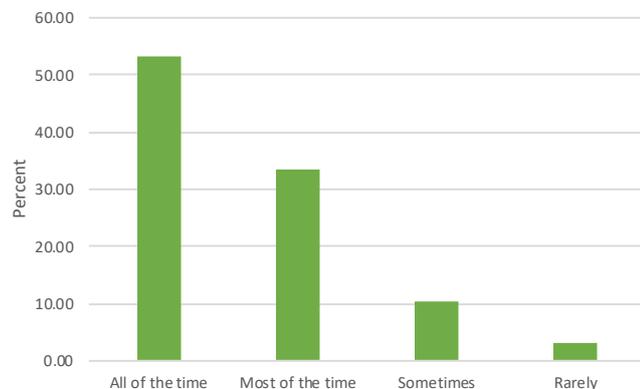


Figure 7. 13: Ability to take medicine

## Adherence to treatment

Participants were asked in the structured interview how long they stick to a treatment before they feel like it isn't working or they give up on it. The most common theme described was adhering to treatment for a specific amount of time (n=56, 56.00%). Where participants noted this, the lengths of time that they would adhere were two to three weeks (n=12, 12.00%), one month (n=10, 10.00%), two months (n=10, 10.00%) and 6 months (n=9, 9.00%). Participants also reported following specialists' advice (n=23, 23.00%), adhering to a treatment regime as long as side effects were tolerable (n=11, 11.00%), and making their own

### Adherence to treatment: other asthma medications

In the online questionnaire, participants were asked about their ability to take all other asthma medicine as prescribed and sticking to it. Almost half of the participants responded that they took other asthma medicine all the time (n=48, 48.00%), 35 (35.00%) took it most of the time, 13 (13.00%) sometimes took other asthma medicine and four participants (4.00%) rarely took other asthma medicine as prescribed.

Table 7.28: Ability to take other asthma medication

Ability to take all other asthma medicine as prescribed	Count (n=100)	Percent
All of the time	48	48.00
Most of the time	35	35.00
Sometimes	13	13.00
Rarely	4	4.00

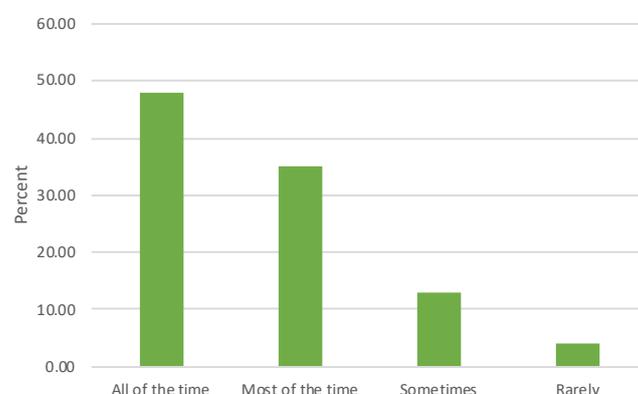


Figure 7. 14: Ability to take medicine

judgements on when to adhere to medication (n=10, 10.00%).

In relation to sub-group variations, participants *Age 55 or older* described adhering to a treatment as long as the side effects are tolerable more frequently (22.86%) than the general population (11.00%).

Participants *Age 55 or older* described using their own judgements on when to adhere to medication more frequently (20.00%) than the general population (10.0%).

## Section 5

Participant describes taking the advice of their specialist/adhering to treatment as long as it is prescribed

*I stick to it, unless I get any other allergic reaction, then I have it changed. Any medication they give me, I'll stick to it. They give you antibiotics, I take the full course. Participant 1*

*I stick with it until I've spoken to a doctor, to my doctor or my specialist who has put me on it and I'd have to say the specialist runs the rule over everything there. Participant 14*

*Well, if it's given to me by the doctor, I'll keep trying with it, and maybe if I didn't think it was working I would ring the surgery and say, "Listen, this isn't working for my asthma." Then they'd usually say, because it's always been a private doctor, they'll always say "Well, could you come in immediately?" That's what I would've done, I would say. Participant 94*

Participant describes a specific amount of time (2-3 weeks)

*Yes. Look, I've always been told that a good two-week window is decent enough time to know something is working for you or not. Participant 20*

*I'll probably give it two weeks. It depends on the drug. Some of them you need build up into your system to work. For example, the oral cortisone doesn't work straight away, but over days it does. Sometimes it doesn't work, and I've had to extend the treatment because it hasn't worked. Then I've had some really horrible side effects. I couldn't sleep and all sorts of things but at the end of the day, asthma can be life-threatening or it's not fun, but that doesn't happen very often. Participant 69*

*At least three weeks. I'll do it for at least three weeks and see if it makes an effect and if it doesn't then I'll try something else. Participant 22*

Participant describes continuing on treatment as long as side effects are tolerable

*It depends on the severity of the side effects. For example, I had to try a new antibiotic because I've started reacting to antibiotics all the time. One of them that I tried was making me have severe stomach cramps, severe headaches, and muscle spasms and I lasted three days and I went back to the doctor and I said, "I can't do any longer on this, we need to find something else." It'd depend on the severity. Participant 10*

*I usually do it under-- I've got an excellent doctor, and he'll call me in, if I'm having an episode, and I've just had a couple in the last month. He was checking on me twice a week. I go in, I would not unilaterally unless I was having adverse effects. I would not unilaterally cease treatment because I think these doctors are a hell of a lot more experienced than I am in prescribing medication. Participant 11*

*Probably a month to six weeks. I'm quite happy to give something as long as it's not having those side effects which are disrupting life. Participant 46*

Participant describes a specific amount of time (1 month)

*That's a tough one to answer. I think it changes depending on where I'm at in my mindset with how I'm managing my asthma. Generally speaking, I like to something a good go and stay at least a month. Participant 52*

*I just take the thing and then if I don't feel like my asthma has improved, I go back to my doctor. I probably maybe persevere with it for maybe a month. A month or so, three months. Participant 59*

*Normally, about a month, just because I know for some of them they needed two week build up in your system. Participant 82*

## Section 5

Participant describes a specific amount of time (2 months)

*I'll give it a two-month run and I'll know probably a month in whether it's okay or not, and then I'll just for the benefit of the doubt give it another couple of weeks. Participant 12*

*With my asthma stuff, I would say I'd probably try it a couple of months and if I'm getting worse, I go back to the doctor. I can't afford to get worse. It's too hard to come back from it, you know what I mean? Probably a couple of months. Participant 23*

*It depends how much it's not working. I'd usually stick it out for a good couple of months at least. Participant 35*

Participant describes making their own judgement on when to adhere to medication

*It probably varies depending on what it is I'm trying and then what I find out about it if I've researched about it and if I notice the difference. Sometimes it's difficult because I'm taking such a lot of medication, it sometimes takes a while to work out that something's maybe not as beneficial to me as I maybe thought. Participant 58*

*Normally, I research the bejesus out of it to figure out what the half-life of the medication is, or I discuss it with my GP, and come up with a, "I have to take this for X amount of time before I had the therapeutic dose in my system that will allow me, us, to evaluate whether it's worthwhile." I can't tell you anything else, because I do look at things from probably, a PROFESSIONAL background. Participant 87*

*Other things though like, say, asthma medication-- You have medication that's going to last for a period of time, and they're supposed to be and have a more immediate effect. If they're not doing that then I would certainly quit. Participant 66*

Participant describes a specific amount of time (6 months)

*We usually try things for at least four to six months. We do have a timeframe of reviews in between that time, but we always try to stick it through that period of time to allow a good opportunity to review it within what's considered reasonable. Participant 3*

*I would stick with it until I talk to the doctor again. That's got to be four to six months, isn't it, in between when you see the doctor. Participant 63*

*If everything else was going fine, my asthma was being managed so I wasn't having a flareup, I'd probably give it six months or something, to see. Participant 45*

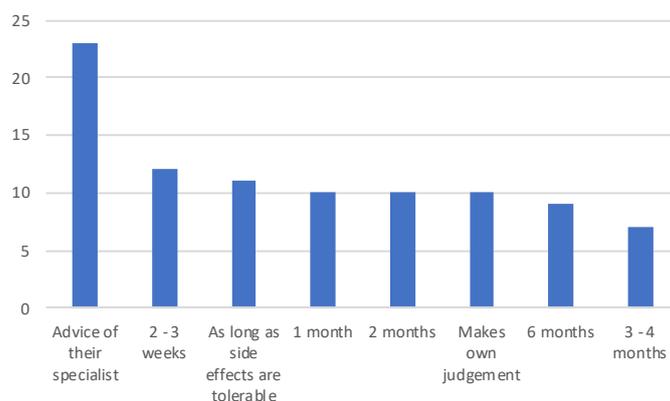


Figure 5.15: Adherence to treatment

Table 5.29: Adherence to treatment

Adherence to treatment	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes taking the advice of their specialist/adhering to treatment as long as it is prescribed	23	23.00	7	26.92	6	27.27	10	19.23	13	27.08	9	25.00	8	19.51	6	26.09
Participant describes a specific amount of time (2 - 3 weeks)	12	12.00	3	11.54	2	9.09	6	11.54	6	12.50	2	5.56	6	14.63	4	17.39
Participant describes continuing on treatment as long as side effects are tolerable	11	11.00	2	7.69	3	13.64	6	11.54	5	10.42	2	5.56	8	19.51	1	4.35
Participant describes a specific amount of time (1 month)	10	10.00	4	15.38	3	13.64	4	7.69	6	12.50	3	8.33	3	7.32	4	17.39
Participant describes a specific amount of time (2 months)	10	10.00	3	11.54	2	9.09	5	9.62	5	10.42	2	5.56	6	14.63	2	8.70
Participant describes making their own judgement on when to adhere to medication	10	10.00	2	7.69	4	18.18	4	7.69	6	12.50	5	13.89	2	4.88	3	13.04
Participant describes a specific amount of time (6 months)	9	9.00	0	0.00	2	9.09	7	13.46	2	4.17	4	11.11	5	12.20	0	0.00
Participant describes a specific amount of time (3 - 4 months)	7	7.00	0	0.00	1	4.55	6	11.54	1	2.08	5	13.89	1	2.44	1	4.35

Adherence to treatment	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes taking the advice of their specialist/adhering to treatment as long as it is prescribed	23	23.00	7	24.14	16	22.54	9	21.95	14	23.73	6	26.09	10	23.81	7	20.00
Participant describes a specific amount of time (2 - 3 weeks)	12	12.00	5	17.24	7	9.86	5	12.20	7	11.86	1	4.35	9	21.43	2	5.71
Participant describes continuing on treatment as long as side effects are tolerable	11	11.00	5	17.24	6	8.45	3	7.32	8	13.56	1	4.35	2	4.76	8	22.86
Participant describes a specific amount of time (1 month)	10	10.00	2	6.90	8	11.27	6	14.63	4	6.78	4	17.39	5	11.90	1	2.86
Participant describes a specific amount of time (2 months)	10	10.00	3	10.34	7	9.86	5	12.20	5	8.47	3	13.04	3	7.14	4	11.43
Participant describes making their own judgement on when to adhere to medication	10	10.00	1	3.45	9	12.68	4	9.76	6	10.17	1	4.35	2	4.76	7	20.00
Participant describes a specific amount of time (6 months)	9	9.00	3	10.34	6	8.45	3	7.32	6	10.17	1	4.35	7	16.67	1	2.86
Participant describes a specific amount of time (3 - 4 months)	7	7.00	3	10.34	4	5.63	1	2.44	6	10.17	3	13.04	2	4.76	2	5.71

Adherence to treatment	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes taking the advice of their specialist/adhering to treatment as long as it is prescribed	23	23.00	16	24.24	7	20.59	13	29.55	10	17.86	16	28.57	7	15.91
Participant describes a specific amount of time (2 - 3 weeks)	12	12.00	8	12.12	4	11.76	4	9.09	8	14.29	6	10.71	6	13.64
Participant describes continuing on treatment as long as side effects are tolerable	11	11.00	6	9.09	5	14.71	4	9.09	7	12.50	5	8.93	6	13.64
Participant describes a specific amount of time (1 month)	10	10.00	7	10.61	3	8.82	2	4.55	8	14.29	5	8.93	5	11.36
Participant describes a specific amount of time (2 months)	10	10.00	5	7.58	5	14.71	5	11.36	5	8.93	5	8.93	5	11.36
Participant describes making their own judgement on when to adhere to medication	10	10.00	7	10.61	3	8.82	4	9.09	6	10.71	5	8.93	5	11.36
Participant describes a specific amount of time (6 months)	9	9.00	5	7.58	4	11.76	3	6.82	6	10.71	6	10.71	3	6.82
Participant describes a specific amount of time (3 - 4 months)	7	7.00	4	6.06	3	8.82	5	11.36	2	3.57	2	3.57	5	11.36

### What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 27 participants (27.00%) was the need to experience a reduction in tightness in chest and increase in ability to breathe. There were 16 participants (16.00%) who reported needing to experience less wheezing and coughing (including nocturnal cough) and this was followed by needing to experience less sensitivity to triggers or less frequent attacks (n=13, 13.00%); less shortness of breath, often in the context of being able to remain active and conduct activities of daily life (n=13, 13.00%); and experience a general reduction in symptoms (n=8, 8.00%).

In relation to sub-group variations, participants in *Age 18 to 34* described needing to experience less wheezing and coughing (including nocturnal cough) more frequently (34.78%) than the general population (16.00%).

Participants in the *Infrequent flare-ups* (26.09%), and *Age 18 to 34* (26.09%) sub-groups described needing to experience less shortness of breath, often in the context of being able to remain active and conduct activities of daily life more frequently than the general population (13.00%).

Participant describes needing to experience a reduction in tightness in chest and increase in ability to breathe

*I have to be able to walk without puff-- That I can feel good and I can breathe. I have to be able to get around without feeling tightness on my chest. Once I get tightness on the chest I just start to panic and know I'm going to be sick, get asthma again. Participant 16*

*I definitely need to experience less tightness in my chest and things in my throat. There's a visible-- I feel the wheeze if my asthma is too bad or even if it starts playing up at all. I'll hear a slight wheeze or whistle when I breath in and out, so to not hear that while I'm getting treatment would be fantastic to get to the point where even if I do have some kind of asthma, it's a lot less frequent than what I currently get. Participant 48*

*For me the physical feeling is my chest feels like it's not as tight. That physical feeling of when something is working but it starts to not be so constricted and I feel like I can breathe better. Participant 60*

Participant describes needing to experience less wheezing and coughing (including nocturnal cough)

*I would need to be having less symptoms. Less coughing fits. Participant 4*

*Everyday symptoms like wheezing, and coughing mainly, and just asthma attacks as well if those decrease. Participant 13*

*Obviously, my breathing and chest tightness. Obviously, because I go to gym quite a lot, whether I can be more active without having to be restricted with my asthma. Not waking up in the night, not coughing as much. Participant 54*

*Prevent night attacks. The ability to get through a sentence without wheezing, to not be up all night coughing up lungs. Participant 82*

Participant describes needing to experience less sensitivity to triggers/less frequent attacks

*Generally, it's breathing. I know that if I catch a cold or something, I know that I'm going to be sick for minimum four to eight weeks depending, because a cold inevitably leads to asthma. Inevitably, as soon as I get a cold, I start on Prednisolone because it heads off the worst of the symptoms. Participant 24*

*Am I having less hospital admissions? Can I get through day-to-day without worrying about what's going to happen? I guess for me, that quality of life and reduction in emergency and hospital visits to me is successful. Participant 28*

*Less hospital admissions for me because I'm in there a lot. Less flare-ups, asthma flare-ups. Quicker to bounce back from an asthma attack and quality of life so if it's making it easier. For instance, I've got to go into the hospital for treatment once a month that's a bit of a pain in the butt. If I could do it at home, it would be a lot easier. Participant 33*

Participant describes needing to experience less shortness of breath, often in the context of being able to remain active and conduct activities of daily life

*Usually the ease of breath, less coughing throughout the day and just being able to be active without getting short of breath. Participant 15*

*Probably to walk further, which sounds stupid, but if my asthma is really good, I can walk and walk and walk, but if it's really bad, I can barely walk to the front door. If it works, like my preventer, the Seretide, normally, if I'm not sick, I'm fine. Like...It took a while. I'll take that three weeks to keep me on I think. Participant 22*

*My symptoms have to be relieved, and to be able to go about activities of daily living, where I can get out of bed, and I'm not exhausted, where I can't walk around my house. Sometimes when I've been sick, and I've gone to answer the phone, it's exhausting to get from one end of the hallway to the other. That's when I'm sick. That's not really day-to-day. Participant 86*

Participant describes needing to experience a general reduction in symptoms

*Yes. It's us, my GP and I, we track it according to what couldn't I do beforehand to what I was able to achieve during that treatment trial. A good example was, "Was I able to go to the gym and do a full hour session? Was I even able to go for a walk around the lake? Was I able to even think about jogging? Was I able to sleep through that hang-up without a descent sleep?" That is how we track it. Participant 3*

*Okay. What it'd have to do is have to keep my asthma under control, so it doesn't affect my life. Participant 87*

*I want to be as functional as possible. I am classified as disabled so I just need to be as functional as is possible for me. Participant 58*

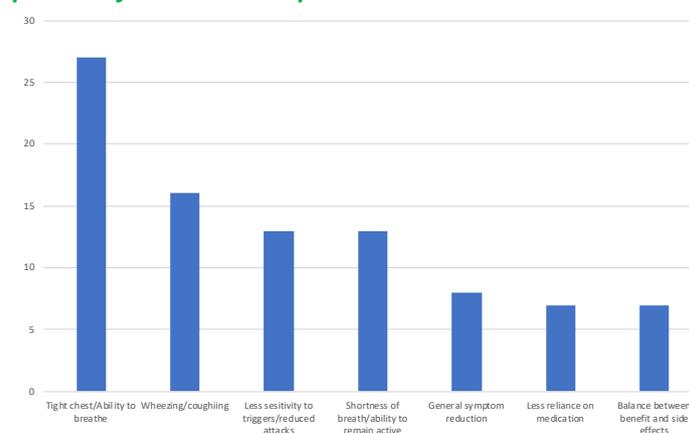


Figure 5.16: What needs to change to feel like treatment is working

Table 5.30: What needs to change to feel like treatment is working

What needs to change to feel like treatment is effective	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes needing to experience a reduction in tightness in chest and increase in ability to breathe	27	27.00	5	19.23	8	36.36	14	26.92	13	27.08	8	22.22	12	29.27	7	30.43
Participant describes needing to experience less wheezing and coughing (including nocturnal cough)	16	16.00	3	11.54	4	18.18	9	17.31	7	14.58	6	16.67	6	14.63	4	17.39
Participant describes needing to experience less sensitivity to triggers/less frequent attacks	13	13.00	2	7.69	3	13.64	8	15.38	5	10.42	6	16.67	6	14.63	1	4.35
Participant describes needing to experience less shortness or breath, often in the context of being able to remain active and conduct activities of daily life	13	13.00	5	19.23	3	13.64	6	11.54	7	14.58	2	5.56	5	12.20	6	26.09
Participant describes needing to experience a general reduction in symptoms	8	8.00	2	7.69	2	9.09	3	5.77	5	10.42	3	8.33	3	7.32	2	8.70
Participant describes needing less reliance on medication	7	7.00	1	3.85	1	4.55	5	9.62	2	4.17	3	8.33	4	9.76	0	0.00
Participant describes needing to have a balance between benefits and potential side effects	7	7.00	4	15.38	2	9.09	2	3.85	5	10.42	1	2.78	2	4.88	4	17.39

What needs to change to feel like treatment is effective	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes needing to experience a reduction in tightness in chest and increase in ability to breathe	27	27.00	9	31.03	18	25.35	13	31.71	14	23.73	5	21.74	11	26.19	11	31.43
Participant describes needing to experience less wheezing and coughing (including nocturnal cough)	16	16.00	5	17.24	11	15.49	5	12.20	11	18.64	8	34.78	3	7.14	5	14.29
Participant describes needing to experience less sensitivity to triggers/less frequent attacks	13	13.00	4	13.79	9	12.68	4	9.76	9	15.25	4	17.39	6	14.29	3	8.57
Participant describes needing to experience less shortness or breath, often in the context of being able to remain active and conduct activities of daily life	13	13.00	5	17.24	8	11.27	6	14.63	7	11.86	6	26.09	4	9.52	3	8.57
Participant describes needing to experience a general reduction in symptoms	8	8.00	2	6.90	6	8.45	3	7.32	5	8.47	1	4.35	4	9.52	3	8.57
Participant describes needing less reliance on medication	7	7.00	1	3.45	6	8.45	3	7.32	4	6.78	1	4.35	5	11.90	1	2.86
Participant describes needing to have a balance between benefits and potential side effects	7	7.00	1	3.45	6	8.45	5	12.20	2	3.39	3	13.04	3	7.14	1	2.86

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes needing to experience a reduction in tightness in chest and increase in ability to breathe	27	27.00	18	27.27	9	26.47	10	22.73	17	30.36	16	28.57	11	25.00
Participant describes needing to experience less wheezing and coughing (including nocturnal cough)	16	16.00	11	16.67	5	14.71	6	13.64	10	17.86	9	16.07	7	15.91
Participant describes needing to experience less sensitivity to triggers/less frequent attacks	13	13.00	8	12.12	5	14.71	4	9.09	9	16.07	7	12.50	6	13.64
Participant describes needing to experience less shortness or breath, often in the context of being able to remain active and conduct activities of daily life	13	13.00	11	16.67	2	5.88	6	13.64	7	12.50	7	12.50	6	13.64
Participant describes needing to experience a general reduction in symptoms	8	8.00	5	7.58	3	8.82	4	9.09	4	7.14	5	8.93	3	6.82
Participant describes needing less reliance on medication	7	7.00	7	10.61	0	0.00	3	6.82	4	7.14	5	8.93	2	4.55
Participant describes needing to have a balance between benefits and potential side effects	7	7.00	5	7.58	2	5.88	5	11.36	2	3.57	5	8.93	2	4.55

# Section 6 Information and communication

## Section 6: Information and communication

### Access to information

The most common place information was accessed was Google or the internet in general (n=43, 43.00%), and this was followed by Australian charities such as Asthma Australia (40, 40.00%). There were 31 participants (31.00%) that described accessing information through interactions with their specialist general practitioner or other healthcare professional and 18 participants (18.00%) that described accessing information through pamphlets from their specialist general practitioner or other healthcare professional.

### Information that has been helpful

The most common type of information found to be helpful by 25 participants (25.00%) was information about medication or treatment options, and this was followed by talking to a doctor or specialist (n=21, 21.00%). There were 11 participants (11.00%) that described information from Australian charities as being helpful, and there were 8 participants (8.00%) that described no particular information as being especially helpful. Other types of information described as being helpful included pamphlets, printed information and fact sheets (n=8, 8.00%), and information about triggers (n=8, 8.00%).

### Information that has not been helpful

Participants were asked if there had been any information that they did not find to be helpful. The most common response was that they had not come across unhelpful information (n=39, 39.00%), and this was followed by information from healthcare professionals when they do not take time, do not know your case or do not know a lot about asthma (n=22, 22.00%). There were 15 participants (15.00%) that described other people giving their opinion as not being helpful, 12 participants (12.00%) that described misinformation about treatments and treatment indication as not being helpful, and 9 participants (9.00%) that described deciding for themselves what is not 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. Overall, the most common theme was talking to someone (n=45, 45.00%) which included participants that described talking to someone as first choice (n=32, 32.00%) and a preference for talking to someone plus online information (n=17, 17.00%). This was closely followed by 43 participants (43.00%) that described a preference for online information.

### Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was during adulthood, often when they were ready to take responsibility for their own health (n=27, 27.00%) and this was followed by participants describing being most receptive to information during a flare-up or exacerbation of their asthma (n=22, 22.00%). There were 16 participants (16.00%) that described being receptive to information during pre-teen or teenage years. There were 8 participants (8.00%) that described being receptive from diagnosis so that they can manage and understand their condition, 8 participants (8.00%) who were receptive at all times, and 8 participants (8.00%) who were receptive when they are feeling well (when not having difficulties).

### 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 having an overall positive experience (n=43, 43.00%). There were 30 participants (30.00%) that described an overall negative experience; for 15 participants (15.00%) this was due to not having enough time or attention with healthcare professionals, and for 8 participants (8.00%) this was due to contradictory information from healthcare professionals. There were 13 participants (13.00%) that described both positive and negative experiences.

## Knowledge and confidence

### Partners in health – overall score

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.

The overall scores for the **“Partners in health: knowledge”** (median = 26.00, IQR = 7.00), **“Partners in health: adherence to treatment”**, and **“Partners in health: recognition and management of symptoms”** (median = 20.00, IQR = 5.00) were in the highest quintile, indicating very good knowledge, very good recognition and very good management of symptoms adherence to treatment (median = 15.00, IQR = 3.00). The median scores for the **“for “Partners in health: coping”** (median = 16.50, IQR = 8.00), and **“Partners in health: total score”** (median = 76.00, IQR = 12.25) were in the second highest quintile indicating good coping, and good overall knowledge and confidence for managing their health.

### Information given by healthcare professionals

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about treatment options (72.00%), disease management (55.00%), and allergies (32.00%) were most frequently given to participants by healthcare professionals, and information about hereditary considerations genes or genomic biomarker information (2.00%), clinical trials (3.00%) and complementary therapies (7.00%) were given least often.

### Information searched for independently

Information about treatment options (53.00%), disease management (41.00%) and information about allergies (39.00) were most often searched for independently by participants. Psychological/social support (14.00%), hereditary considerations genes or genomic biomarker information (15.00%), and clinical trials (17.00%) were least searched for.

### Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials (83.00%), hereditary considerations genes or genomic biomarker information (83.00%), and psychological/social support (78.00%). Participants were given most information either from healthcare professionals or independently for treatment options (87.00%). Disease cause was the topic that was most searched for independently following no information from health professionals (26.00%), followed by complementary therapies (25.00%).

### Most trusted information sources

Participants were asked to rank which information source that they most trusted. Across all participants, information from the government were most trusted, followed by information from non-profit or charities or patient organisations. 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. There were 26 (26.00%) participants that had accessed “My Health Record”, 66 (66.00%) had not, two participants did not know what it is (2.00%), and six (6.00%) were not sure. Of those that had accessed “My Health Record”, five participants (19.23%) found it good or very good, seven (26.92%) found it acceptable, and 14 (53.85%) found it poor or very poor.

## Access to information

In the structured interview, participants were asked where they accessed information since they were diagnosed. The most common place information was accessed was Google or the internet in general (n=43, 43.00%), and this was followed by Australian charities such as Asthma Australia (n=40, 40.00%). There were 31 participants (31.00%) that described accessing information through interactions with their specialist general practitioner or other healthcare professional and 18 participants (18.00%) that described accessing information through pamphlets from their specialist general practitioner or other healthcare professional.

In relation to sub-group variations, participants in the *Trade or high school* (27.27%) and *Poorly controlled asthma* (26.92%) sub-groups described accessing information from Australian charities such as Asthma Australia less frequently than the general population (40.00%), while those in the *Moderately controlled asthma* (59.09%), *Moderately to well controlled asthma* (54.17%), *Age 55 or older* (51.43%), *Infrequent sleep disruption* (51.22%), *University* (50.00%), and *Controlled asthma* (50.00%) sub-groups described this more frequently.

Participants in the *Infrequent flare-ups* sub-group described accessing information through interactions with their specialist general practitioner or other healthcare professional more frequently (43.48%) than the general population (31.00%).

### Participant describes accessing information from google or the internet in general

*Well in recent years, on the internet I have read a lot online. I don't read junk stuff, I read medical journal articles, a few relevant or similar to what I have. Sometimes there are called blogs where people can- it is like a community where you can read other people can put a question in and others would have suggestions of what works for them. I especially I have found my CPAP machine useful reading online some of those ideas. Participant 14*

*Just what I can access when I Google, just general information. How often to use what puffers, what puffers are available to me, alternatives to using my puffers, do you know what I mean? Participant 30*

*Generally on the web, but as I said, decent places, not just Google asthma and take whatever you see. Verify the source. And also not just the source but how old that information is. I don't look at clinical trials, because I don't understand them, and I think you'll see tiny little things that will alarm you more than anything else. I look at even if it's advice, I look at the date of that, because if you look at something and then you see, that was in 2009. That's 10 years ago, so there could be better things and blah, blah, blah, blah, blah. It's about looking at the authenticity of the source and also how old are these. Participant 31*

*I just access online basically. I used to look up the Asthma website just to keep in touch with what's going on but I haven't in the last ten years, I've lost time or something to go into it. Other things I guess have taken precedent but that's probably where I would go, would be to the Asthma Foundation website, start from there. Sometimes the, although it's not very good, the better health website, that's pretty basic information. Otherwise it's just the GP. Participant 40*

*I usually Google medical websites, not Wikipedia, obviously, but just looking if there's any new treatments or every time somebody says, "Have you tried this, look this out." I'll have a look at it and just quickly glance over and think, "Yes, no, maybe." They normally sound like they're for people with really chronic Asthma, not me. Participant 55*

*There is a world of information on the internet. The problem is some of it is so stupid that you have to be very wary of what you read and what you believe. There is the Asthma Foundation, which I'm not a member of, which I probably should be a member of. If I'm researching things like that, I tend to go to the Centre for Disease Control, World Health Organisation, or resources like that. Participant 8*

### Participant describes accessing information from Australian charities (Asthma Australia)

*The stuff I got from the GP which wasn't that comprehensible. My husband actually contacted the Asthma Foundation once, and that's when we found out how my medication all worked. They were the ones that actually informed us of that, but that's all the information I've had so far. Participant 72*

## Section 6

*Asthma Australia's a brilliant resource. They provide me with access to online asthma nurses and specialist care nurses and if you've ever got a question you can have it answered within a few minutes usually. They also have some really, really good resources about various drugs and what to expect. The thing I found particularly comforting is that they have these facts sheet for when you're going to certain doctors appointments what to expect. Just so you know that you're going in there with some idea. There's nothing worse than going to some of these doctors and you can't pronounce their names. You're not sure what to expect or what's going to happen. Those resources are very important. Participant 41*

*As I said, I used to look at all the scientific studies to try and see what I could find out what's out there. Been to sites like Asthma Australia. That sort of ones I look at regulations to see what new stuff coming out the national guidelines and that sort of thing I read. Probably the internet's been my best source living in regional Australia it's not as easy to get your hands-on hard copy stuff particularly when I was living in country town's a lot bigger and a lot easier to get stuff. Some of the country towns I've lived in, its usually internet-based materials that I can find. Participant 46*

*I'm pretty lucky I have a really good GP that will answer any questions I have. She has a lot of information that she can give me or I will for lack of a better word Google it but only use like the Asthma Foundation or like an Australian government website, I don't look at overseas ones because the information can be different and all that. I'm thinking better health channels that the Victorian government has or the national ones but I can't remember what that website is. You can go on and look at it's the same as the Victorian one but it's like the Australian government. Participant 60*

**Participant describes receiving information through interactions with their specialist, general practitioner or other healthcare professional**

*I haven't needed it, honestly. If I do require anything, my doctor usually gives it to me. Participant 15*

*I went to this session with the asthma educator at one of the local chemists. She did a one on one session about explaining about asthma and how to use the treatment properly, the puffers properly. Participant 37*

*I'm pretty lucky I have a really good GP that will answer any questions I have. She has a lot of information that she can give me or I will for lack of a better word Google it but only use like the Asthma Foundation or like an Australian government website, I don't look at overseas ones because the information can be different and all that. I'm thinking better health channels that the Victorian government has or the national ones but I can't remember what that website is. You can go on and look at it's the same as the Victorian one but it's like the Australian government. Participant 60*

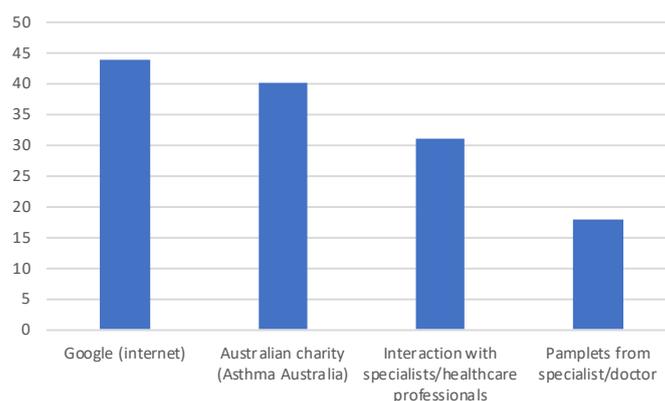
*Often I will find something else about that on that website and then ask my doctor about it and he'll explain it to me. What does that mean or da da da? I had an asthma nurse early when was that, in intensive care. I had a nurse after that come and talk to me, but it was just a one off. Participant 57*

**Participant describes receiving information through pamphlets from their specialist, general practitioner or other healthcare professional**

*Just some general things that are in the doctor's surgery. There's a little pamphlet, "Do you suffer from asthma?" or "Do you know you've got asthma?" There's a little type of pamphlets, that's all. Participant 56*

*Well, the doctor gave me a whole heap of leaflets on it and a little booklet on it to say, "This is asthma, this is what happens," but that's it. Participant 62*

*Well, I'm aware of the asthma-- Or first all, various pamphlets and stuff particularly in the specialist's clinic. NAME DOCTOR and doctor NAME DOCTOR have lots of pamphlets and I've picked up those from time to time. I've been on The Asthma Foundation's website and found a lot of very useful information there. The GP's don't seem to have that much more so probably the website and also various pamphlets at the specialists have been the main source. Participant 18*



**Figure 6.1: Access to information**

Table 6.1: Access to information

Information accessed	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes accessing information from google or the internet in general	43	43.00	10	38.46	9	40.91	24	46.15	19	39.58	15	41.67	20	48.78	8	34.78
Participant describes accessing information from Australian charities (Asthma Australia)	40	40.00	13	50.00	13	59.09	14	26.92	26	54.17	11	30.56	19	46.34	10	43.48
Participant describes receiving information through interactions with their specialist, general practitioner or other healthcare professional	31	31.00	9	34.62	7	31.82	14	26.92	17	35.42	9	25.00	12	29.27	10	43.48
Participant describes receiving information through pamphlets from their specialist, general practitioner or other healthcare professional	18	18.00	7	26.92	6	27.27	5	9.62	13	27.08	7	19.44	7	17.07	4	17.39

Information accessed	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes accessing information from google or the internet in general	43	43.00	13	44.83	30	42.25	19	46.34	24	40.68	9	39.13	18	42.86	16	45.71
Participant describes accessing information from Australian charities (Asthma Australia)	40	40.00	13	44.83	27	38.03	21	51.22	19	32.20	9	39.13	13	30.95	18	51.43
Participant describes receiving information through interactions with their specialist, general practitioner or other healthcare professional	31	31.00	10	34.48	21	29.58	15	36.59	16	27.12	8	34.78	14	33.33	9	25.71
Participant describes receiving information through pamphlets from their specialist, general practitioner or other healthcare professional	18	18.00	3	10.34	15	21.13	10	24.39	8	13.56	6	26.09	6	14.29	6	17.14

Information accessed	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes accessing information from google or the internet in general	43	43.00	25	37.88	18	52.94	18	40.91	25	44.64	22	39.29	21	47.73
Participant describes accessing information from Australian charities (Asthma Australia)	40	40.00	28	42.42	12	35.29	12	27.27	28	50.00	22	39.29	18	40.91
Participant describes receiving information through interactions with their specialist, general practitioner or other healthcare professional	31	31.00	19	28.79	12	35.29	14	31.82	17	30.36	21	37.50	10	22.73
Participant describes receiving information through pamphlets from their specialist, general practitioner or other healthcare professional	18	18.00	14	21.21	4	11.76	7	15.91	11	19.64	9	16.07	9	20.45

### Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 25 participants (25.00%) was information about medication or treatment options, followed by talking to a doctor or specialist (n=21, 21.00%). There were 11 participants (11.00%) that described information from Australian charities as being helpful, and there were 8 participants (8.00%) that described no particular information as being especially helpful. Other types of information described as being helpful included pamphlets, printed information and fact sheets (n=8, 8.00%), and information about triggers (n=8, 8.00%).

In relation to sub-group variations, participants in the *Frequent flare-ups* sub-group described information about medication or treatment options less frequently (13.89%) than the general population (25.00%).

Participants *Age 18 to 34* described pamphlets, printed information and fact sheets more frequently (21.74%) than the general population (8.00%).

Participant describes information about medication/treatment options (including new innovation) as being helpful

*Understanding what's important to me. I suppose the most helpful for me is actually reading the results of medical trials. Participant 7*

*I think just about new innovations as far as asthma goes. I guess because I've been suffering for so long, I've learnt so much that I don't-- It's more about new treatments, new ways of using current treatments. Participant 35*

*Just describing exactly what happens while you're taking the tablet, why it's important to keep going. I would just keep using Ventolin and just using it and using it and it just wasn't working. Participant 64*

*Just I think information about the medication I take. How to take it and make sure I'm doing it correct. Participant 79*

Participant describes talking to their doctor or specialist as being helpful

*Gosh, I don't know. It's just recently seeing a specialist was good because he was very clear about things and very logical in his approach. That for me, was really good and he wrote it down for me. He's very realistic about people seeing doctors and he said something, "You remember about 5% of what I say." Not me personally, "But patients remember about 5% of what I say, and so that's why I write it down." That's true, I don't know whether the 5% is true but you certainly don't remember everything that's said to you or you're a bit confused, "Did he mean this or did he mean that?" So, it's really good to have the medication written down, when there are a number of things. Participant 92*

*What information has been the most helpful? It's a combination of what I've found out from the doctors and there's Asthma Foundation as well. You'll only find the news will mention stuff about new things, but it doesn't mention much about it or if there's any issues in taking it and stuff like that. Participant 53*

*I'd say probably the more specific ones the doctor tells you. It relates more to your situation. I know you can get factsheets from the government which will also help, and I've always been interested in it because, obviously, it's something that affects me. I haven't really looked thoroughly into it. Participant 34*

Participant describes the information from Australian charities as being helpful

*Well, I got one from the Asthma Foundation the other day about-- We have a lot of dust storms out here and they'll send you warnings to say you should stay inside. I didn't realize that the dust particles are actually going into my bronchioles. I just thought it was just the weather so I find that kind of stuff interesting. Like I've got hypoallergenic dogs and stuff so I've had to get that kind of thing. Participant 22*

*Probably things like- I'm pretty sure the Asthma Australia who sends it. They send recent research that suggests say maybe a certain food might be a trigger, or here's an unusual trigger. I find them quite good, and I find them quite good for your support network as well. My fiance freaks out because he doesn't know much about asthma. He's got all these little instructions on the fridge. Bless his heart. He's found really good resources through them as well, and he feels comfortable. They've got an app that he uses so peace of mind. It's being quite good with that for me at least. Participant 26*

*Important information through the Asthma Association and that's really good because the lady there spent about half an hour just talking to me about asthma. How the reliever and the puffer work. For example, she said to me that the preventor-- It's not told for almost all of my years until about a couple of years ago when I saw a different doctor. That different doctor told me that I should take my reliever to open up my airways before I take the Seretide, which is the preventer so that I have better access to my lungs for that. Now, I wasn't aware of that, but the lady from the and Asthma Association said, "Well, actually, there's no point in that because the medication you've got, the Seretide, actually, has that in it. So, taking the reliever beforehand is of no value." Again, I didn't know that until I spoke to her. Participant 66*

*The stuff that's accurate that comes from organizations I actually trust to tell me what's what and not try and sell me something or give me evidence that's based on personal experience rather than that can actually be backed up and replicated. Participant 82*

Participant describes no particular information as being especially helpful

*Not really to be honest. Yes, nothing has to my mind where I'm like, "I'm glad I got told that and share that information out." Nothing, no. Participant 72*

*I don't know that I can say that there's a particular piece of information that I've received that I can really point to. Participant 90*

*I don't think I've had any information that's helpful. I don't think I've been given any-- I don't recall any time that I've been given information about asthma where I thought, "Oh, that's good to know." I don't know. No. I've been just given medication, that's the extent of it. No information really. How to use the medications, that's it Participant 47*

Participant describes pamphlets/printed information/fact sheets as being helpful

*I think probably the facts sheets because of somebody like me who quite likes information the fact that I can grab a sheet, read through it and then if I've got questions I can ask those questions. Participant 41*

*I have found pamphlets that are short and straight to the point have been the most helpful with links to where we can read more information. Participant 89 I like the one the doctors give you a print out of what medication you're on and it gives you all the information, like side effects. Just everything is on there. Participant 13*

Participant describes information about triggers as being helpful

*In terms of outcomes, for me, it's understanding the physiological side of asthma including the triggers. If you can come down to and this comes down to an individual what their particular triggers are because that then optimizes your treatment. Participant 11*

*I guess they're the ones with symptoms, causes, what else can help, what other causes can will flare up your asthma. Just knowing those triggers and symptoms and also just knowing more stuff like the weather can affect it as well, learning all the apps and stuff. Participant 54*

*And information about foods that can trigger it as well as, things like how I shouldn't have aspirin. I learned that the hard way. A lot of it-- just a lot of little things that you shouldn't do outside, once you get home. All the bits and pieces that, unless someone tells you, you don't know is something that can affect your asthma. Participant 85*

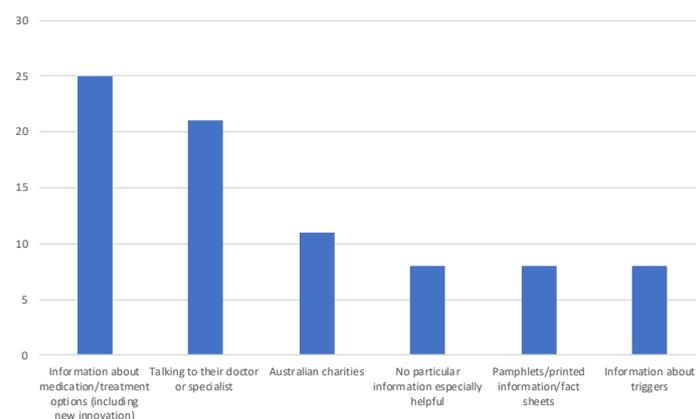


Figure 6.2: Information that was helpful

Table 6.2: Information that was helpful

Information that has been helpful	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes information about medication/treatment options (including new innovation) as being helpful	25	25.00	6	23.08	7	31.82	12	23.08	13	27.08	5	13.89	12	29.27	8	34.78
Participant describes talking to their doctor or specialist as being helpful	21	21.00	5	19.23	5	22.73	11	21.15	10	20.83	10	27.78	6	14.63	5	21.74
Participant describes the information from Australian charities as being helpful	11	11.00	2	7.69	4	18.18	4	7.69	7	14.58	2	5.56	7	17.07	2	8.70
Participant describes no particular information as being especially helpful	8	8.00	2	7.69	1	4.55	5	9.62	3	6.25	3	8.33	4	9.76	1	4.35
Participant describes pamphlets/printed information/fact sheets as being helpful	8	8.00	1	3.85	3	13.64	4	7.69	4	8.33	3	8.33	5	12.20	0	0.00
Participant describes information about triggers as being helpful	8	8.00	4	15.38	3	13.64	2	3.85	6	12.50	2	5.56	3	7.32	3	13.04

Information that has been helpful	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes information about medication/treatment options (including new innovation) as being helpful	25	25.00	8	27.59	17	23.94	12	29.27	13	22.03	6	26.09	12	28.57	7	20.00
Participant describes talking to their doctor or specialist as being helpful	21	21.00	8	27.59	13	18.31	6	14.63	15	25.42	5	21.74	7	16.67	9	25.71
Participant describes the information from Australian charities as being helpful	11	11.00	4	13.79	7	9.86	6	14.63	5	8.47	1	4.35	4	9.52	6	17.14
Participant describes no particular information as being especially helpful	8	8.00	0	0.00	8	11.27	2	4.88	6	10.17	2	8.70	3	7.14	3	8.57
Participant describes pamphlets/printed information/fact sheets as being helpful	8	8.00	3	10.34	5	7.04	3	7.32	5	8.47	5	21.74	2	4.76	1	2.86
Participant describes information about triggers as being helpful	8	8.00	0	0.00	8	11.27	5	12.20	3	5.08	4	17.39	3	7.14	1	2.86

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes information about medication/treatment options (including new innovation) as being helpful	25	25.00	15	22.73	10	29.41	10	22.73	15	26.79	15	26.79	10	22.73
Participant describes talking to their doctor or specialist as being helpful	21	21.00	17	25.76	4	11.76	10	22.73	11	19.64	12	21.43	9	20.45
Participant describes the information from Australian charities as being helpful	11	11.00	7	10.61	4	11.76	4	9.09	7	12.50	5	8.93	6	13.64
Participant describes no particular information as being especially helpful	8	8.00	6	9.09	2	5.88	3	6.82	5	8.93	5	8.93	3	6.82
Participant describes pamphlets/printed information/fact sheets as being helpful	8	8.00	6	9.09	2	5.88	4	9.09	4	7.14	4	7.14	4	9.09
Participant describes information about triggers as being helpful	8	8.00	7	10.61	1	2.94	5	11.36	3	5.36	3	5.36	5	11.36

### Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that they had not come across unhelpful information (39, 39.00%), and this was followed by information from healthcare professionals when they do not take time, do not know your case or do not know a lot about asthma (22, 22.00%). There were 15 participants (15.00%) that described other people giving their opinion as not being helpful, 12 participants (12.00%) that described misinformation about treatments and treatment indication as not being helpful, and 9 participants (9.00%) that described deciding for themselves what is not helpful.

In relation to sub-group variations, participants in the *Moderately controlled asthma* sub-group described that they did not come across unhelpful information more frequently (50.00%) than the general population (39.00%). Participants in the *Moderately controlled asthma* sub-group (9.09%), or *Age 55 or older* (8.57%) described information from healthcare professionals when they do not take time, do not know your case or do not know a lot about asthma less frequently than the general population (22.00%).

Participants in the *Moderately controlled asthma* sub-group (31.82%), described other people giving their opinion more frequently than the general population (15.00%).

### Participant has not come across unhelpful information

*Well, I don't think so. From what I've read, it actually has all been fine. Participant 22*

*Anything that's not been helpful. No, not really. That would almost fall into the what was disinformation. I haven't found anything that I've read that has not necessarily been true. Participant 29*

*No, not really. Just sometimes people think they know better than you do about your own asthma. It's probably social-- I don't know how to describe it, social attitudes I suppose and including people in my own family who think I make it up. Participant 61*

*No. I suppose I don't think of anything is unhelpful, more as irrelevant to my circumstance. Participant 77*

### Participant describes information from healthcare professionals when they do not take time, do not know your case or do not know a lot about asthma, as being unhelpful

*It's just well too dumbed down. Most people are smarter than what we give them credit to do. The medical professions seems to think that they are... Even to the point where I've had to educate all the doctors on-- no you cannot do that because this and this happens. I've had to give him them information. Participant 81*

*Yes. I'll tell you, what drives me insane and I actually put a complaint about it is when you go to the pharmacy and one day we have found here the-- What do you call it? The weather asthma, thunderstorm asthma. I react to some of that. It was put out as asthma day, this was only last year. It was an asthma alert day. I had two asthma pumps in my basket, in my work basket and both of them were all but empty. Oh my god, I called in to this pharmacy, and this is not the first time this has happened and I said, "I need Ventolin, and I need it now." The girl goes, "I need to know your name and address ...and are you doing this and that." I nearly collapsed on the ground. The pharmacist looked over went, "Oh my God, you need it now." and I went, "Yeah" They just grabbed me a spacer and took it, it's the other thing that's wrong with-- That is the most worst thing is when you've got an uneducated person telling you what to do. Participant 89*

*There's been times I've presented myself to emergency and they've gone, you find there's nothing wrong with you. You're not having an asthma attack or you don't seem that bad, because sometimes I get a silent wheeze, and it might have been that my thoracic specialist has written a letter and said "You need to go to emergency." They've virtually tried to send me away, and a couple of times I have gone away and come back in an ambulance a couple hours later, or I've just sat there in the waiting room with my book waiting for it to come because I know I've brought my whole kit. Participant 28*

*Probably just some of the GPs over the years. Some of the misinformation that you get from them about asthma such as, "This can't be your trigger because this is not an asthma trigger." Participant 82*

## Section 6

**Participant describes other people giving their opinion as being unhelpful**

*Yes, my parents always say breath out, force the air out of your lungs and then breath back in, and it helps you breathe easier. I've found every time that I do that, I'm always struggling to take air in even more so after that. Participant 48*

*When you read a lot of people who talk about their own personal experiences, sometimes they're very one-sided. If I went on and described my side effects of my antibiotics, people who read it might not want to take antibiotics which is- that's a personal experience, it doesn't happen to everybody. I think a lot of people out there talk about their personal experiences, their side effects from prednisone or whatever it might be and that may put people off taking their treatment effectively. Participant 24*

*Just generally, people's attitudes. If you have to go to work next day after you've been at the emergency room all night at the hospital, people give you this funny look like, "Why?" Nothing I can do about that. Participant 55*

*I've had people go, "Oh well, it's just asthma, can you just get over yourself." I'm just like, "No I won't because I could die." [laughs] To be honest, if I can't get to a hospital quick enough to take the emergency medicine, I can die. Because I've had a tube put down my throat to keep me alive before I'm not going to risk it. Participant 57*

*I think it's just people and their comments. [laughs] Just undermining you and expecting too much of you and just not understanding. You learn to handle that after a while but that was really difficult to handle initially when you're just accustoming yourself to the impact of the disease. Participant 58*

*No, not really. Just sometimes people think they know better than you do about your own asthma. It's probably social-- I don't know how to describe it, social attitudes I suppose and including people in my own family who think I make it up. Participant 61*

**Participant describes misinformation about treatments and treatment indications as being unhelpful**

*I know I keep mentioning this, but the non-information was the most unhelpful thing. The lack of information. I think I've just exhausted you on that one. The other thing is the doctor that told me about using the reliever before the Seretide, finding out that that was wrong, told me that that was actually incorrect information. So, it was actually unhelpful. Participant 66*

*Not really. Like I said, we've been changing my medications around, it would be nice to know why they're playing around with it. Participant 53*

*I was recommended to get another nebulizer machine. However, the Asthma Foundation said that you're better off having more Ventolin more regulator than, the way that the lungs work and that kind of thing. Also, the two big things is whether to have Symbicort or Pulmicort, but I'm told because of the way that my as-- and the fact that I have the asthma attacks where I need a lot of Bricanyl in short time that Symbicort would actually then been giving me too much of the steroid into my system. I just find that the information between the different professionals has been conflicting. I don't know which way to go, so I just go with the safer way. Participant 72*

**Participant describes deciding for themselves what is not helpful**

*Yes, I think when you research and not everything is written by people that know what they're talking about. You've got to be careful what you look at and what websites you read and stuff. Participant 13*

*Not really. Everything they put out I see can be helpful to somebody if that makes sense. I've been dealing with it for nearly 40 years, I'm pretty well versed on puffer techniques and how to use a spacer properly and how to take your medication properly, whereas somebody who's just been diagnosed would find that stuff extremely helpful. Stuff that I don't personally find helpful, absolutely the heap of stuff that comes out, I can see how it would be helpful to others. I'm probably not helping you. [laughs] Participant 33*

*Definitely by going online. Yes, but I just keep scrolling. I think it's about-- But I'd say I sort of critique it myself as much as a non-clinical person can just to make sure that I'm not looking up ridiculous things. Participant 31*

Table 6.3: Information that was not helpful

Information that has not been helpful	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant has not come across unhelpful information	39	39.00	8	30.77	11	50.00	20	38.46	19	39.58	12	33.33	18	43.90	9	39.13
Participant describes information from healthcare professionals when they don't take time, don't know your case or don't know a lot about asthma, as being unhelpful	22	22.00	8	30.77	2	9.09	12	23.08	10	20.83	9	25.00	7	17.07	6	26.09
Participant describes other people giving their opinion as being unhelpful	15	15.00	3	11.54	7	31.82	7	13.46	8	16.67	6	16.67	5	12.20	4	17.39
Participant describes misinformation about treatments and treatment indications as being unhelpful	12	12.00	4	15.38	3	13.64	4	7.69	8	16.67	4	11.11	4	9.76	4	17.39
Participant describes deciding for themselves what is not helpful	9	9.00	2	7.69	1	4.55	6	11.54	3	6.25	3	8.33	5	12.20	1	4.35

Table 6.3: Information that was not helpful (Cont.)

Information that has not been helpful	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant has not come across unhelpful information	39	39.00	12	41.38	27	38.03	14	34.15	25	42.37	8	34.78	16	38.10	15	42.86
Participant describes information from healthcare professionals when they don't take time, don't know your case or don't know a lot about asthma, as being unhelpful	22	22.00	6	20.69	16	22.54	11	26.83	11	18.64	6	26.09	13	30.95	3	8.57
Participant describes other people giving their opinion as being unhelpful	15	15.00	5	17.24	10	14.08	6	14.63	9	15.25	5	21.74	3	7.14	7	20.00
Participant describes misinformation about treatments and treatment indications as being unhelpful	12	12.00	3	10.34	9	12.68	6	14.63	6	10.17	3	13.04	5	11.90	4	11.43
Participant describes deciding for themselves what is not helpful	9	9.00	3	10.34	6	8.45	3	7.32	6	10.17	2	8.70	3	7.14	4	11.43

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant has not come across unhelpful information	39	39.00	27	40.91	12	35.29	16	36.36	23	41.07	21	37.50	18	40.91
Participant describes information from healthcare professionals when they don't take time, don't know your case or don't know a lot about asthma, as being unhelpful	22	22.00	16	24.24	6	17.65	10	22.73	12	21.43	15	26.79	7	15.91
Participant describes other people giving their opinion as being unhelpful	15	15.00	10	15.15	5	14.71	7	15.91	8	14.29	5	8.93	10	22.73
Participant describes misinformation about treatments and treatment indications as being unhelpful	12	12.00	9	13.64	3	8.82	6	13.64	6	10.71	8	14.29	4	9.09
Participant describes deciding for themselves what is not helpful	9	9.00	3	4.55	6	17.65	6	13.64	3	5.36	5	8.93	4	9.09

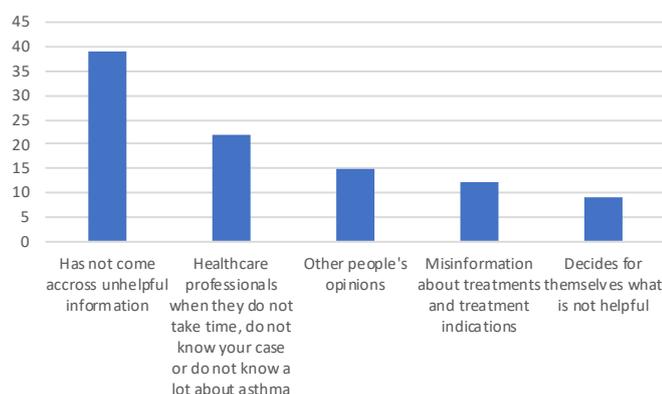


Figure 6.3: Information that was not helpful

### 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. Overall, the most common theme was talking to someone (n=45; 45.00%) which included participants that described talking to someone as first choice (n=32, 32.00%) and a preference for talking to someone plus online information (n=17, 17.00%). This was closely followed by 43 participants (43.00%) that described a preference for online information.

In relation to sub-group variations, participants in the *Moderately controlled* sub-group described a preference for online information less frequently (31.82%) than the general population (43.00%).

Participants in the *Regional or remote* sub-group described talking to someone as first choice less frequently (17.65%) than the general population (32.00%). This sub-group also described a preference for talking to someone overall less frequently (29.41%) than the general population.

**Participant describes a preference for online information – primarily due to convenience/taking at own pace & depth of information**

*For me, I think online is the way to go at the moment. I think maybe for kids in school, it's always good for somebody to go at and have a chat to students and raise awareness that way as well. I think, as I said, the post on various social media platforms has been awesome. Participant 95*

*I think online would be useful because you can pick your own hours to access it. Although talking to someone would be really great, but I just can't. That would be the best for me, but I can't see that happening. Participant 4*

*I think online because I'm terrible at remembering things. In online, I can always go back and look at it again. Plus, in this day and age of technology, I can access it from my phone, from my tablet, on the go wherever I am. Participant 52*

*Online, because it's more in depth than you can get in a conversation. I like reading this as well, but usually, I find it's pitched a bit low. I want more information at a higher level. I'm almost 73. I've had this all my life. I've read a lot over the many decades. Most of what's put in the pamphlets, it's very basic. Participant 7*

**Participant describes talking to someone as first choice**

*I actually prefer talking to somebody because you can ask questions and get that interaction and you can explain exactly what it is that you're saying. If you've got-- if you're on an app, even on the net it's hard to explain you and what you're thinking, what you're feeling and then get that interaction. Participant 9*

*I like talking to an asthma nurse when I go over to the hospital. I always feel that they see others like me, so I know that they are really switched on and I've always liked to have that chat with them, as opposed to a general nurse. Someone who works specifically in the field of breathing, respiration, and asthma. I find they are switched on ladies, so I like to chat with them. Participant 14*

*I guess I prefer talking to someone because then I can get that immediate feedback for all the things that are concerning me about my management, so I prefer to talk to someone, but I've also got information online or from the Asthma Association Foundation. Participant 44*

*I think talking to someone is probably my preference. My second option would be online, but I find that sometimes you can miss new information, so it is handy to talk face-to-face with someone. I also think when you're reading and doing information yourself, you might come to your own conclusions and have your own assumptions, which might be incorrect and might impact your treatment. Participant 51*

*I prefer talking to people. I prefer talking to my GP, because it's more personalized approach. Secondly, I don't mind looking at online information. I find it helpful to give you knowledge but speaking to my GP is my number one. That's the number one. Relying on her. She needs to make sure she's up to date. Participant 77*

## Section 6

### Participant describes a preference for talking to someone plus online

*For ease, online information for sure, because you can access it any time of the day or night, and then closely followed by talking to someone, is my preference just because I'll probably have a thousand questions about how it would relate to me personally. It's the accent stuff, they're there, that I wouldn't probably rely or use them as much. Participant 33*

*I guess phone apps are really easy. The internet has a lot of stuff available quickly. I do also, in particular, like talking to my GP who knows me. Hearing what she has to say about the research and things she's read up on. Of course, she'll have access to information that isn't on the internet and isn't on the app. I don't know that I have a preference. I think each of them has a place. Participant 45*

*These days I would look at it online, probably. Obviously, that's changed over time. If I need more information or ask questions, then I could take the information to help lines online for Asthma Australia or to the GP. There are other ways of-- If I'm not understanding what I'm finding online or I need more information about something, then I can follow up. Participant 45*

**Participant describes appreciating apps complementary to other methods**

*I've got asthma apps. I find what's really really helpful is the thunderstorm alert for asthmatics, so I get a message...they send me a message to let me know. I've even gone and got the pollen count because I find*

*that if there's more pollen in the air then I'm not as good either. Yes, so there's something in the air before it rains. Like I said, it can be three days beforehand, but there's something. I don't know. They said it was something to do with the pressure. I can't remember now, but that really sets me off. Participant 2*

*Yes, online. If it's stuff that I need to talk to somebody, I'd talk to my respiratory guy when I see him every few months. Yes, online is best for me. Apps too. If it was a really, really well-designed app, that would be fine, too, but I find a lot, everything's on a big screen and that it's floating around. Participant 78*

*I think online and apps because they're so accessible but at the end of the day, I think probably person to person when medical things are involved, they're probably the better avenues. Participant 3*

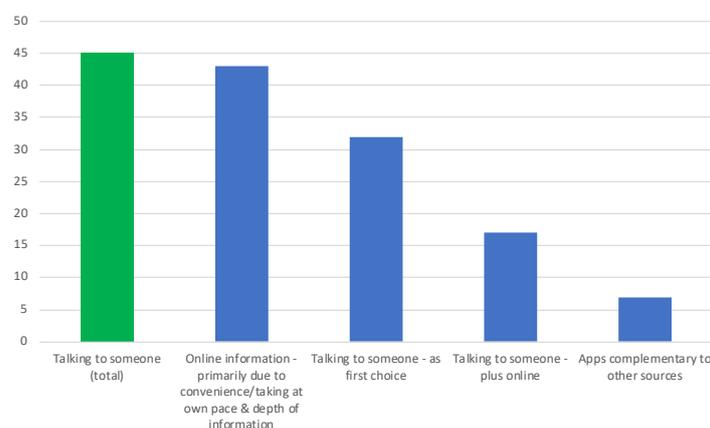


Figure 6.4: Information preferences

Table 6.4: Information preferences

Information preferences	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes a preference for online information - primarily due to convenience/taking at own pace & depth of information	43	43.00	13	50.00	7	31.82	23	44.23	20	41.67	12	33.33	20	48.78	11	47.83
Participant describes talking to someone as first choice	32	32.00	8	30.77	8	36.36	16	30.77	16	33.33	13	36.11	11	26.83	8	34.78
Participant describes a preference for talking to someone plus online	17	17.00	7	26.92	3	13.64	7	13.46	10	20.83	3	8.33	9	21.95	5	21.74
Participant describes appreciating apps complementary to other	7	7.00	1	3.85	1	4.55	5	9.62	2	4.17	2	5.56	5	12.20	0	0.00
Participant describes a preference for talking to someone (total)	45	45.00	12	46.15	11	50.00	22	42.31	23	47.92	16	44.44	18	43.90	11	47.83

Information preferences	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes a preference for online information - primarily due to convenience/taking at own pace & depth of information	43	43.00	13	44.83	30	42.25	19	46.34	24	40.68	8	34.78	22	52.38	13	37.14
Participant describes talking to someone as first choice	32	32.00	11	37.93	21	29.58	11	26.83	21	35.59	7	30.43	12	28.57	13	37.14
Participant describes a preference for talking to someone plus online	17	17.00	3	10.34	14	19.72	9	21.95	8	13.56	6	26.09	6	14.29	5	14.29
Participant describes appreciating apps complementary to other	7	7.00	3	10.34	4	5.63	2	4.88	5	8.47	1	4.35	3	7.14	3	8.57
Participant describes a preference for talking to someone (total)	45	45.00	13	44.83	32	45.07	17	41.46	28	47.46	10	43.48	17	40.48	18	51.43

Information preferences	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes a preference for online information - primarily due to convenience/taking at own pace & depth of information	43	43.00	27	40.91	16	47.06	16	36.36	27	48.21	21	37.50	22	50.00
Participant describes talking to someone as first choice	32	32.00	26	39.39	6	17.65	16	36.36	16	28.57	20	35.71	12	27.27
Participant describes a preference for talking to someone plus online	17	17.00	13	19.70	4	11.76	7	15.91	10	17.86	12	21.43	5	11.36
Participant describes appreciating apps complementary to other	7	7.00	4	6.06	3	8.82	2	4.55	5	8.93	5	8.93	2	4.55
Participant describes a preference for talking to someone (total)	45	45.00	35	53.03	10	29.41	21	47.73	24	42.86	29	51.79	16	36.36

### Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was during adulthood, often when they were ready to take responsibility for their own health (n=27, 27.00%) and this was followed by participants describing being most receptive to information during a flare-up or exacerbation of their asthma (n=22, 22.00%). There were 16 participants (16.00%) that described being receptive to information during pre-teen or teenage years (16.00%). There were 8 participants (8.00%) that described being receptive from diagnosis so that they can manage and understand their condition, 8 participants (8.00%) who were receptive at all times, and 8 participants (8.00%) who were receptive when they are feeling well (when not having difficulties).

In relation to sub-group variations, participants in the *Regional or remote* sub-group described that they were receptive during adulthood, often when they were ready to take responsibility for their own health less frequently (11.76%) than the general population (27.00%), while those in the *Controlled asthma* sub-group (38.46%) described this more frequently.

Participants *Age 18 to 34* described being most receptive to information during a flare-up or exacerbation of their asthma less frequently (8.70%) than the general population (22.00%) whereas participants in the sub-group *Severe asthma* described this more frequently (34.48%). Participants *Age 55 years or older* described that they were receptive to information during pre-teen or teenage years less frequently (2.86%) than the general population (16.00%), while those *Age 18 to 34* described this more frequently (30.43%) Participants in the *Moderately controlled asthma* sub-group described that they were receptive to information from diagnosis so that they can manage and understand their condition more frequently (18.18%) than the general population (8.00%).

Participant describes being receptive during adulthood, often when they were ready to take responsibility for their own health

*It's really hard to say. I probably would say-- It's really a hard question. Probably now. I feel like I'm looking into it now in my mid to late 20s, and I'm only just caring about this kind of stuff. [laughs] I guess again, it's been normal for me. It's not been a huge thing in my life where I've gone or probably we need to know exactly what's going on. It's life or death. I remember it's never been in my mind a life or death situation, just having asthma. As I've gotten older now, and I'm done my asthma training through school, through working in a school, I've gone, "Wow. It's actually a very serious thing to have." People die from this. It didn't really cross my mind that people die from this. Participant 39*

*Definitely as I got older, probably. When I was first diagnosed, I was quite young, and I didn't think it was anything serious. It was kind of like, "All my siblings have it. My dad has it. It's just what we've got", kind of thing. Whereas an adult, I actually realize exactly what it was and that mine wasn't like the others, that mine actually is-- The fact that mine is-- I have the actual not being able to breathe, not being able to talk kind of thing whereas theirs is just the tightness of breath. Participant 72*

*When I was probably in my 30s. Probably when I actually accepted that I did have asthma, and when I just got sick and tired of struggling to breathe. I decided to do something about it. Participant 59*

*I'd say in my early 30s. That's when I took on a lot more and really tried to do a lot more and change things as it started to get worse. Where even through my teens and 20s, when I knew about it, I used to just go to the doctor, get me the tablets and get me the supplements and I'd just deal with it. But then after I turned 30- I got married when I was 29 so everything just sort of changed and I looked at my health more holistically. Participant 75*

## Section 6

Participant describes being most receptive to information during a flare-up or exacerbation of their asthma (episode)

*Probably when I've had a crisis, really. Post-crisis when I'm back on my feet, and I go for a review. Then I've got lots of questions and I'm thinking more about this is serious and I need to understand it better or discuss the medication or look at lifestyle things I can do that would assist. I'd say I'm most receptive post-crisis situation. Participant 18*

*When I was 20 and I nearly died I think that's when it became a real reality for me. After that, I was really aware of what triggered me and what didn't trigger me and all that kind of stuff. Participant 22*

*I think most receptive was probably when I was at my worst after a severe attack. Obviously, in that initial phase you're not receptive at all, but a wake-up call, "Oh my God this is serious, I now need to do something." What can I do, I guess, following from a hospital admission or for a downward turn in your health is probably the time that you're probably most receptive. Participant 28*

*Funnily enough I think it's when you had a bad run and you have been-- a couple of times when you've been admitted or gone to hospital for treatment, because it has-- I think you're a bit more open to some new ideas. When I was pregnant, I was open to it again, because I had to actually stop some of my medication. When my kids were diagnosed with it, that was another good time. As a teenager, I was probably-- I wasn't open to it, but I wasn't needing it as much. I think my fitness certainly helped. Participant 69*

*It was probably when it really started to blow right up which was probably five years after diagnosis. That's where the doctors certainly...said, "If you don't start taking this you're going to die." Participant 89*

Participant describes being receptive during pre-teen or teenage years

*I think I became a bit more receptive to my illness and learning about it. I was in, probably more so when I got into high school, I think for my duration in primary school, I really saw it as such a huge burden. I was in and out of hospital, I was on Prednisone, I was being teased, bullied. I had to be called to the office every lunchtime to have medication. I was definitely a standout kid in primary school which made the bullying even worse. I wasn't receptive to it. It was really quite traumatic for me, to be quite honest with you. I had a really traumatic time with it. Then when I got into high school, I just stopped taking my medication though I was really bad, but I still became more acceptable to knowing when my body was flaring up and when I did need help. I became a bit more self-aware, I guess. The bullying stopped and things like that, more so in high school. The trauma of primary school and everything was still so prevalent with me that it really did affect the way I took my medication all the time. Participant20*

*I'd probably say maybe early teenage years, I was probably more receptive. Because when you're looking at a young kid, you don't really understand it, you don't know. They try to do a good thing with that little booklet that I got which is long gone. I'd listen to it. Participant 53*

*I would say my teenage years, I took it in. Because I was obviously searching for it by then, so maybe it meant more to me. I think before then, I think you trust your parents and what they say or what they give you. I think before that, I just would have just accepted what they were saying, but as a teenager, I started to look. Participant 86*

Participant describes being receptive from diagnosis so that they can manage and understand their condition

*I think when I first started, and even now that I know a bit more as well, because I'm wanting to gain my knowledge. Participant 54*

*When I was first diagnosed I couldn't get enough because I wanted to know what the hell was wrong with me and how I had to look after it. Yes, right at the beginning. Participant 9*

*For me, I would want to go on an information seminar shortly after diagnosis, so that I could know exactly what I'm dealing with. So you know who you can talk to. If there's help out there, what is it, what does it look like, where is it, how much does it cost, what are the benefits to it? Just all that information. I think it needs to be fairly quick, because when you're diagnosed as an asthmatic, the reason for the diagnosis is an asthma attack. You're not going to get diagnosed otherwise. It's, very rare that you're going to get diagnosed without an asthma attack, and that's the scary time. Participant 66*

*I would say that I always ready to have more information since the starting of my diagnosis with asthma until now. I always concerned about it. Participant 96*

Participant describes being receptive to information at all times/any time

*I think that I was always just been able to take it in if it's been proffered. It isn't all that long ago that doctors were still telling me that it was emotional, that that was the basis of asthma. That's not so long ago that doctors were still saying that to me. I would have liked information probably from my team. Participant 7*

*I always chase the information because I remember as a child how distressing it was not to be able to breathe. I think I have always been open to anything that will improve my asthma. Participant 11*

*I've been receptive and thankful for information my entire life, that I recall. Participant 74*

Participant describes being receptive when they are feeling well (not when having difficulties)

*Good question. Definitely, when I'm healthy, not when I'm sick, not when I'm at my crisis point. Definitely, not when things are just at their worst and did not work for me. I'm better off when I'm healthy and able to clearly think and look at the big picture. Participant 3*

*Not in the acute stage. After an acute episode was over. Certainly not in a hospital. Certainly not when you're feeling really rotten. After that I've always felt - I would go, "Okay what do we do next time to avoid this?" Participant 57*

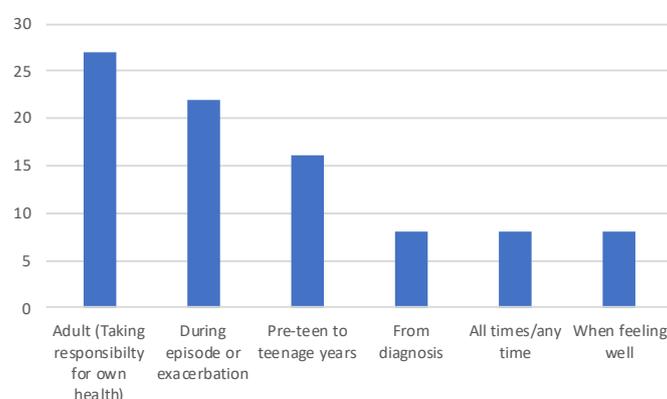


Figure 6.5: Timing of information (Specific time frame)

Table 6.5: Timing of information

Timing of information	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes being receptive during adulthood, often when they were ready to take responsibility for their own health)	27	27.00	10	38.46	5	22.73	12	23.08	15	31.25	9	25.00	10	24.39	8	34.78
Participant describes being most receptive to information during a flare-up or exacerbation of their asthma (episode)	22	22.00	6	23.08	4	18.18	13	25.00	9	18.75	8	22.22	7	17.07	7	30.43
Participant describes being receptive during pre-teen or teenage years	16	16.00	5	19.23	2	9.09	8	15.38	8	16.67	3	8.33	9	21.95	4	17.39
Participant describes being receptive from diagnosis so that they can manage and understand their condition	8	8.00	1	3.85	4	18.18	3	5.77	5	10.42	4	11.11	2	4.88	2	8.70
Participant describes being receptive to information at all times/any time	8	8.00	2	7.69	2	9.09	4	7.69	4	8.33	2	5.56	5	12.20	1	4.35
Participant describes being receptive when they are feeling well (not when having difficulties)	8	8.00	1	3.85	2	9.09	5	9.62	3	6.25	6	16.67	2	4.88	0	0.00

Timing of information	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes being receptive during adulthood, often when they were ready to take responsibility for their own health)	27	27.00	5	17.24	22	30.99	14	34.15	13	22.03	7	30.43	13	30.95	7	20.00
Participant describes being most receptive to information during a flare-up or exacerbation of their asthma (episode)	22	22.00	10	34.48	12	16.90	9	21.95	13	22.03	2	8.70	10	23.81	10	28.57
Participant describes being receptive during pre-teen or teenage years	16	16.00	5	17.24	11	15.49	6	14.63	10	16.95	7	30.43	8	19.05	1	2.86
Participant describes being receptive from diagnosis so that they can manage and understand their condition	8	8.00	2	6.90	6	8.45	3	7.32	5	8.47	2	8.70	1	2.38	5	14.29
Participant describes being receptive to information at all times/any time	8	8.00	2	6.90	6	8.45	3	7.32	5	8.47	1	4.35	1	2.38	6	17.14
Participant describes being receptive when they are feeling well (not when having difficulties)	8	8.00	3	10.34	5	7.04	2	4.88	6	10.17	3	13.04	3	7.14	2	5.71

Timing of information	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes being receptive during adulthood, often when they were ready to take responsibility for their own health)	27	27.00	23	34.85	4	11.76	13	29.55	14	25.00	17	30.36	10	22.73
Participant describes being most receptive to information during a flare-up or exacerbation of their asthma (episode)	22	22.00	15	22.73	7	20.59	7	15.91	15	26.79	12	21.43	10	22.73
Participant describes being receptive during pre-teen or teenage years	16	16.00	9	13.64	7	20.59	9	20.45	7	12.50	7	12.50	9	20.45
Participant describes being receptive from diagnosis so that they can manage and understand their condition	8	8.00	6	9.09	2	5.88	6	13.64	2	3.57	4	7.14	4	9.09
Participant describes being receptive to information at all times/any time	8	8.00	4	6.06	4	11.76	2	4.55	6	10.71	6	10.71	2	4.55
Participant describes being receptive when they are feeling well (not when having difficulties)	8	8.00	6	9.09	2	5.88	2	4.55	6	10.71	6	10.71	2	4.55

### 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 having an overall positive experience (n=43, 43.00%). There were 30 participants (30.00%) that described an overall negative experience, for 15 participants (15.00%) this was due to not having enough time or attention with healthcare professionals, and for 8 participants (8.00%) this was due to contradictory information from healthcare professionals. There were 13 participants (13.00%) that described both positive and negative experiences.

In relation to sub-group variations, participants in the *Moderately controlled asthma* sub-group described a positive experience where health professionals have been knowledgeable, attentive and forthcoming with information more frequently (59.09%) than the general population (43.00%), and those *Age 55 years or older* also described this more frequently (54.29%).

Participants in the *Regional or remote* sub-group described a negative experience due to not having enough time or attention with healthcare professionals less frequently (2.94%) than the general population (15.00%), while those in the *Controlled asthma* sub-group described this more frequently (26.92%).

#### Participant describes a positive experience where health professionals have been knowledgeable, attentive and forthcoming with information

*It's been pretty good. The GP that I've got now is really, really switched on and really good. My previous GP was lovely, but she was an older lady and I don't know-- I love her to bits, but I think she treated what was in front of her. I think I'm a bit better informed now. I've got two dogs and two cats and they all shed, so maybe I shouldn't have those animals. Maybe I should vacuum it a bit more, but that's something that I have to control. I'm not getting rid of the animals. It's in my control. Participant 55*

*I would say predominantly positive especially with my current GP. Certainly, I've never had a problem with anyone in a hospital. When I've been admitted they've always been pretty good. Apart from one occasion, but generally speaking as soon as they see your oxygen tank they are like, "Okay, let's go". They are pretty cool. On a whole pretty good at this. Participant 57*

*I think I've been pretty lucky as far as that. That's been pretty good. I've sort of changed or moved to stay with a particular GP because I've got better care or information than others in the practice or something like that. Participant 63*

*You get some doctors, that sort of thing, they know and other doctors that they think something else and they've got no idea but mostly I've found them all very, very, very helpful, very, very understanding. The doctors in the hospitals have been absolutely wonderful. I have no complaints whatsoever. I found everyone to be really very caring and careful about asthma because of the fact that you can't breathe. A bit like you're having a heart attack or something. I've always found everyone's treated me was absolutely calm and some respect. Participant 65*

#### Participant describes a negative experience due to not having enough time or attention with healthcare professionals

*I again, when I was younger, they wouldn't talk to me, they would talk to my mum. Now that I'm older, I feel like I'm more in control because I'm being spoken to then, making sure I understand as it is my body. I do appreciate that now. I wish when I was younger things were explained to me, not just my mum but just like that. A helpful little things obviously dumbed down for a kid, but that that would have been nice to understand. I don't think they really, sorry. Participant 42*

*Not very good. Certainly not very good at all. They never took the time to explain anything. If you don't know what's happening, you don't understand what's happening, you cannot medicate yourself... understanding of the disease first and why you've got it. I have no idea where I've got it from. Participant 64*

*Patchy, is probably the word that comes to mind. Doctors, GPs with the best of intent, but of course you see them for five minutes. In the past, they didn't refer me to Asthma LOCATION. I suppose I wasn't one of their serious cases and could have an attack any moment, so there was never been that kind of urgency about it. On the other hand, I was busy with other things for most of my life, and I didn't have time to fuss about it either. Participant 92*

Participant describes having a mixed experience in relation to health professional communication

*When I've encountered someone that actually knows what they're talking about, it's been really good. The stuff with the GPs where they're telling me that this is not a thing or it's a chest infection and then you take the whole course of antibiotics to go back to say, "Well, I said it wouldn't work and it hasn't." It's probably about 50/50 in terms of helpfulness. Really good and really bad. Participant 82*

*With the GP, it has been good, but with the emergency room doctors, really, really bad. I've gone in there with blue lips and well, I had fainted because I was so deprived of oxygen, and it's just an attitude that I'm just a naughty kid who hasn't done the right thing. That describes it really. Participant 6*

*It's been helpful except for the ambulance side. I've had a couple of good ambulance experiences but I've had some awful ones as well. Though I'm actually still, although they've actually sent someone out to our home to try and debrief me and talk to me and they have a really strict protocol. I'm priority one on their screen, I'm still terrified to call an ambulance. That's probably an issue for me still. We've done a couple of really scary drives with my husband. We've made insignificant respiratory distress. The ambulance would be at the bottom of my pile. Some nurses I find - It always makes me re-evaluate my CAREER IN HEALTHCARE-- had not had an idea really. That can be a real issue and I've had problems as a result of it, telling me, "You can only have you Ventolin ... in the hospital when you can go," and you know that you needed more. One nurse, one time, I had influenza A and I was really quite unwell. My doctors thought that I could come off the IV, hydrocortisone or dexamethasone and then they realized I needed to be restarted but she wouldn't restart. She said, "No, we could only come at the hospital protocol, which was 12 and 6." Participant 58*

Participant describes having a negative experience as they have received contradictory information from healthcare professionals

*Hilarious, I've got to be honest about it. [chuckles] Everyone's got a different opinion. You get contradictions, and the next thing you know, everyone wants you to do this, which contradicts the last person that-- No one's consistent. Participant 3*

*Not so great. They seem to-- They're mostly caring but I find that a lot of GPs and then even in hospitals a lot of the registers staff that you see don't know a whole lot about asthma. They're not really educated on the topic. Participant 9*

*I think the inconsistencies of how our professionals are communicating advice, asthma advice to patients and their carers need to really significantly be done. It's either one-way or not. There can't be their own version because they're convenient with the way they like to distribute material. It's this one way and that's it. If it's additional to that then you attach a separate additional note sheet or something to that. And it's frustrating. Even from when the boys got their care, they've got their own version of one as well. Participant 98*

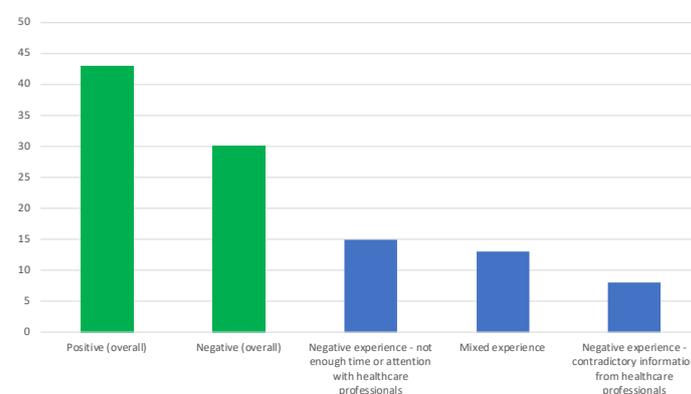


Figure 6.6: Healthcare professional communication (Positive, negative or mixed)

Table 6.6: Healthcare professional communication

Health professional communication	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes a negative experience due to not having enough time or attention with health professionals	15	15.00	7	26.92	3	13.64	5	9.62	10	20.83	4	11.11	7	17.07	4	17.39
Participant describes having a mixed experience in relation to health professional communication	13	13.00	4	15.38	2	9.09	7	13.46	6	12.50	5	13.89	5	12.20	3	13.04
Participant describes having a negative experience as they have received contradictory information from healthcare professionals	8	8.00	2	7.69	1	4.55	5	9.62	3	6.25	4	11.11	2	4.88	2	8.70
Participant describes a positive experience overall where health professionals have been knowledgeable, attentive & forthcoming with information	43	43.00	10	38.46	13	59.09	20	38.46	23	47.92	16	44.44	18	43.90	9	39.13
Participant describes an overall negative experience with health professional communication	30	30.00	9	34.62	5	22.73	16	30.77	14	29.17	11	30.56	12	29.27	7	30.43
Health professional communication	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes a negative experience due to not having enough time or attention with health professionals	15	15.00	3	10.34	12	16.90	10	24.39	5	8.47	4	17.39	6	14.29	5	14.29
Participant describes having a mixed experience in relation to health professional communication	13	13.00	5	17.24	8	11.27	6	14.63	7	11.86	2	8.70	6	14.29	5	14.29
Participant describes having a negative experience as they have received contradictory information from healthcare professionals	8	8.00	3	10.34	5	7.04	3	7.32	5	8.47	2	8.70	5	11.90	1	2.86
Participant describes a positive experience overall where health professionals have been knowledgeable, attentive & forthcoming with information	43	43.00	15	51.72	28	39.44	18	43.90	25	42.37	10	43.48	14	33.33	19	54.29
Participant describes an overall negative experience with health professional communication	30	30.00	8	27.59	22	30.99	13	31.71	17	28.81	6	26.09	16	38.10	8	22.86
Health professional communication	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA			
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%		
Participant describes a negative experience due to not having enough time or attention with health professionals	15	15.00	14	21.21	1	2.94	7	15.91	8	14.29	9	16.07	6	13.64		
Participant describes having a mixed experience in relation to health professional communication	13	13.00	9	13.64	4	11.76	4	9.09	9	16.07	9	16.07	4	9.09		
Participant describes having a negative experience as they have received contradictory information from healthcare professionals	8	8.00	3	4.55	5	14.71	3	6.82	5	8.93	2	3.57	6	13.64		
Participant describes a positive experience overall where health professionals have been knowledgeable, attentive & forthcoming with information	43	43.00	27	40.91	16	47.06	17	38.64	26	46.43	23	41.07	20	45.45		
Participant describes an overall negative experience with health professional communication	30	30.00	20	30.30	10	29.41	13	29.55	17	30.36	13	23.21	17	38.64		

## 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.

The overall scores for the **“Partners in health: knowledge”** (median = 26.00, IQR = 7.00), **“Partners in**

**health: adherence to treatment”**, and **“Partners in health: recognition and management of symptoms”** (median = 20.00, IQR = 5.00) were in the highest quintile, indicating very good knowledge, very good recognition and very good management of symptoms adherence to treatment (median = 15.00, IQR = 3.00). The median scores for the **“for “Partners in health: coping”** (median = 16.50, IQR = 8.00), and **“Partners in health: total score”** (median = 76.00, IQR = 12.25) were in the second highest quintile indicating good coping, and good overall knowledge and confidence for managing their health.

**Table 6.7: “Partners in health” summary statistics**

Partners in health scale	Mean	SD	Median	IQR	Possible range	Quintile
<b>Partners in health: knowledge</b>	24.92	5.83	26.00	7.00	0 to 32	5
<b>Partners in health: coping</b>	16.01	5.14	16.50	8.00	0 to 24	4
<b>Partners in health: recognition and management of symptoms</b>	18.87	4.12	20.00	5.00	0 to 24	5
<b>Partners in health: adherence to treatment</b>	14.05	2.33	15.00	3.00	0 to 16	5
<b>Partners in health: total score</b>	73.85	14.20	76.00	12.25	0 to 96	4

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### Partners in health by Asthma control test (three groups)

The **Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between participants that scored 20 or more “Controlled asthma” (n=26, 26.00%), between 16 and 19 “Moderately controlled asthma” (n=22, 22.00%), and those who scored 15 or less “Poorly controlled asthma” (n=52, 52.00%).

Boxplots of each Partners in health scale by the **Asthma control test** are displayed in Figures 6.7-6.11, summary statistics are displayed in Table 6.8.

The assumptions for a one-way ANOVA test were not met. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.9). 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 6.10). 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 6.11 to 6.12).

A Kruskal-Wallis test indicated a statistically significant difference in the “**Partners in health: total score**” scale between groups,  $\chi^2(2) = 9.82$ ,  $p = 0.0074$  (Table 6.9). Wilcoxon rank sum tests between groups indicated that those with *Controlled asthma* (median = 81.50, IQR = 12.00) scored significantly higher than participants with *Moderately controlled asthma* (median = 78.00, IQR = 11.25,  $p=0.0433$ ), and significantly higher than participants with *Poorly controlled asthma* (median = 74.50, IQR = 14.75,  $p=0.0071$ ).

A Welch one-way test indicated a statistically significant difference in the “**Partners in health: coping**” scale between groups  $F(2, 54.46) = 10.34$ ,  $p=0.0002$  (Table 6.11). Post-hoc pairwise t-tests with

no assumption of equal variances indicated that participants with *Controlled asthma* (mean = 18.88, SD = 3.01) scored significantly higher than participants with *Moderately controlled asthma* (mean = 16.27, SD = 4.15,  $p=0.0280$ ), and significantly higher than those with *Poorly controlled asthma* (mean = 14.46, SD = 5.75,  $p<0.0001$ ).

A Welch one-way test indicated a statistically significant difference in the “**Partners in health: adherence to treatment**” scale between groups  $F(2, 48.98) = 6.98$ ,  $p=0.0021$  (Table 6.11). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants with *Controlled asthma* (mean = 15.08, SD = 1.13) significantly higher than those with *Poorly controlled asthma* (mean = 13.65, SD = 2.52,  $p=0.0028$ ).

The mean scores for the “**Partners in health: coping scale**” was significantly higher for participants with *Controlled asthma* compared to participants with *Moderately controlled asthma* and *Poorly controlled asthma*. However, these scores fall within the good range for all groups.

The mean scores for the “**Partners in health: adherence to treatment**” was significantly higher for participants with *Controlled asthma* compared to participants with *Poorly controlled asthma*. However, these scores correspond to very good adherence to treatment for both of these groups.

The median scores for the “**Partners in health: total score**” was significantly higher for participants with *Controlled asthma* compared to participants with *Moderately controlled asthma* and *Poorly controlled asthma*. These scores correspond to very good overall knowledge and confidence for managing their health for participants with *Controlled asthma* and *Moderately controlled asthma*, and good overall knowledge and confidence for managing their health for participants with *Poorly controlled asthma*.

Table 6.8: “Partners in health” by Asthma control test scale summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Controlled asthma	26	26.00	26.62	3.73	26.50	6.50
	Moderately controlled asthma	22	22.00	23.91	5.98	24.00	6.50
	Poorly controlled asthma	52	52.00	24.50	6.51	26.00	6.00
Partners in health: coping	Controlled asthma	26	26.00	18.88	3.01	19.00	3.50
	Moderately controlled asthma	22	22.00	16.27	4.15	16.50	6.75
	Poorly controlled asthma	52	52.00	14.46	5.75	15.00	8.00
Partners in health: recognition and management of symptoms	Controlled asthma	26	26.00	20.38	2.43	20.50	3.00
	Moderately controlled asthma	22	22.00	19.18	4.09	20.00	3.75
	Poorly controlled asthma	52	52.00	17.98	4.59	19.00	5.00
Partners in health: adherence to treatment	Controlled asthma	26	26.00	15.08	1.13	15.00	1.00
	Moderately controlled asthma	22	22.00	13.77	2.62	14.50	2.75
	Poorly controlled asthma	52	52.00	13.65	2.52	14.00	4.00
Partners in health: total score	Controlled asthma	26	26.00	80.96	7.33	81.50	12.00
	Moderately controlled asthma	22	22.00	73.14	12.72	78.00	11.25
	Poorly controlled asthma	52	52.00	70.60	16.18	74.50	14.75

Table 6.9: “Partners in health” by Asthma control test scale Kruskal -Wallis test

Partners in Health scale	X <sup>2</sup>	df	p
Partners in health: knowledge	2.50	2	0.2870
Partners in health: recognition and management of symptoms	5.85	2	0.0537
Partners in health: total score	9.82	2	0.0074*

\*Statistically significant at  $p < 0.05$

Table 6.10: “Partners in health” by Asthma control test scale post-hoc pairwise comparisons using Wilcoxon rank sum test

Partners in Health scale		Controlled asthma	Moderately controlled asthma
Partners in health: total score	Moderately controlled asthma	0.0433*	
	Poorly controlled asthma	0.0071*	0.5740

\*Statistically significant at  $p < 0.05$

Table 6.11: “Partners in health” by Asthma control test scale Welch one-way test

Partners in Health scale	F	dF1	dF2	p
Partners in health: coping	10.34	2.00	54.46	0.0002*
Partners in health: adherence to treatment	6.98	2.00	48.98	0.0021*

\*Statistically significant at  $p < 0.05$

Table 6.12: “Partners in health” by Asthma control test scale post-hoc pairwise t-tests with no assumption of equal variances

Partners in Health scale	Asthma control	Controlled asthma	Moderately controlled asthma
Partners in health: coping	Moderately controlled asthma	0.0280*	
	Poorly controlled asthma	<0.0001*	0.1350
Partners in health: adherence to treatment	Moderately controlled asthma	0.0579	
	Poorly controlled asthma	0.0028*	0.8577

\*Statistically significant at  $p < 0.05$

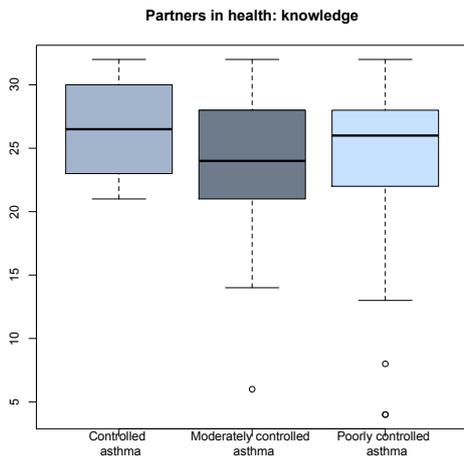


Figure 6.7: “Partners in health: knowledge” by Asthma control test

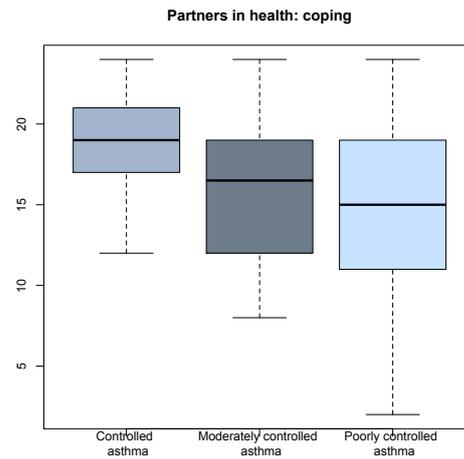


Figure 6.8: “Partners in health: coping” by Asthma control test

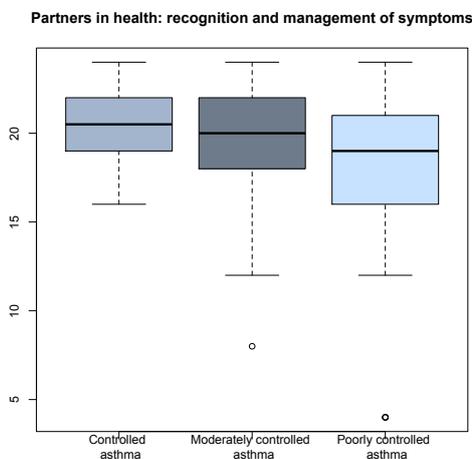


Figure 6.9: “Partners in health: recognition and management of symptoms” by Asthma control test

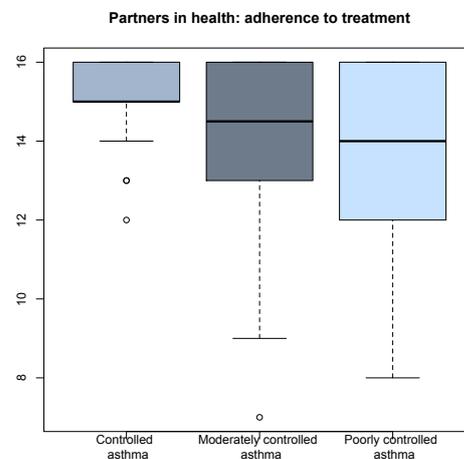


Figure 6.10: “Partners in health: adherence to treatment” by Asthma control test

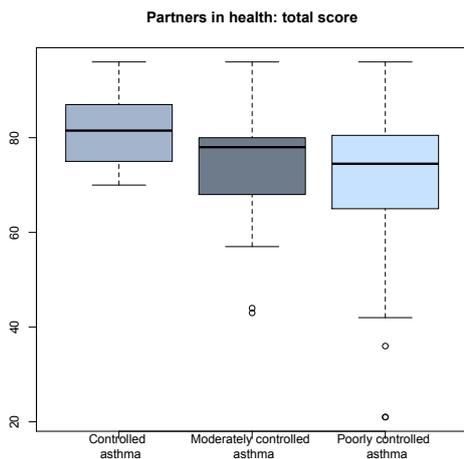


Figure 6.11: “Partners in health: total score” by Asthma control test

### Partners in health by Asthma control test (two groups)

The **Asthma control test** is a five-item questionnaire that helps determine the level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between those who scored between 16 and 25 “Moderate to well controlled asthma” (n=48, 48.00%), and those who score 15 or less “Poorly controlled asthma” (n=52, 52.00%).

Boxplots of each Partners in health scale by **Asthma control test** are displayed in Figures 6.12-6.16, summary statistics are displayed in Table 6.13. 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 6.13).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: coping”** [W=1669.50, p=0.0036] was significantly higher for those with *Moderate to well controlled asthma* (Median = 18.00, IQR =5.25) compared to those with *Poorly controlled asthma* (Median =15.00, IQR = 8.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: recognition and management of symptoms”** [W=1580.00, p=0.0214] was significantly higher for those with *Moderate to well controlled asthma* (Median = 20.00, IQR = 3.00) compared to those with *Poorly controlled asthma* (Median =19.00, IQR = 5.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in**

**health: total score”** [W=1583.00, p=0.0209] was significantly higher for those with *Moderate to well controlled asthma* (Median = 78.50, IQR =11.25) compared to those with *Poorly controlled asthma* (Median =74.50, IQR = 14.75).

The median scores for the **“Partners in health: coping scale”** was significantly higher for participants with *Moderate to well controlled asthma* compared to participants with *Poorly controlled asthma*. However, these scores fall within the good range for both groups.

The median scores for the **“Partners in health: recognition and management of symptoms”** was significantly higher for participants with *Moderately to well controlled asthma* compared to participants with *Poorly controlled asthma*. These scores correspond to very good recognition and management of symptoms for participants with *Moderately to well controlled asthma*, and good recognition and management of symptoms for participants with *Poorly controlled asthma*.

The median scores for the **“Partners in health: total score”** was significantly higher for participants with *Moderately to well controlled asthma* compared to participants with *Poorly controlled asthma*. These scores correspond to very good overall knowledge and confidence for managing their health for participants with *Moderately to well controlled asthma* and good overall knowledge and confidence for managing their health for participants with *Poorly controlled asthma*.

**Table 6.13: “Partners in health” by Asthma control test Wilcoxon rank sum test with continuity correction**

Partners in Health scale	Group	Count	Percent	Median	IQR	W	p
<b>Partners in health: knowledge</b>	Moderate to well controlled asthma	48	48.00	26.00	8.00	1281.00	0.8221
	Poorly controlled asthma	52	52.00	26.00	6.00		
<b>Partners in health: coping</b>	Moderate to well controlled asthma	48	48.00	18.00	5.25	1669.50	0.0036*
	Poorly controlled asthma	52	52.00	15.00	8.00		
<b>Partners in health: recognition and management of symptoms</b>	Moderate to well controlled asthma	48	48.00	20.00	3.00	1580.00	0.0214*
	Poorly controlled asthma	52	52.00	19.00	5.00		
<b>Partners in health: adherence to treatment</b>	Moderate to well controlled asthma	48	48.00	15.00	2.00	1475.00	0.1071
	Poorly controlled asthma	52	52.00	14.00	4.00		
<b>Partners in health: total score</b>	Moderate to well controlled asthma	48	48.00	78.50	11.25	1583.00	0.0209*
	Poorly controlled asthma	52	52.00	74.50	14.75		

\*Statistically significant at p<0.05

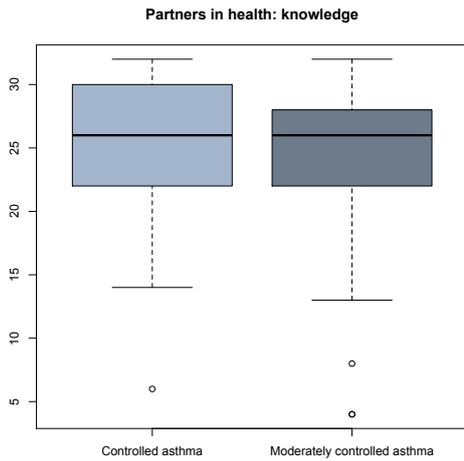


Figure 6.12: “Partners in health: knowledge” by Asthma control test

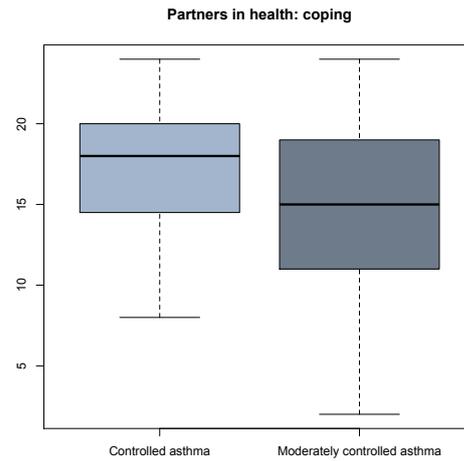


Figure 6.13: “Partners in health: coping” by Asthma control test

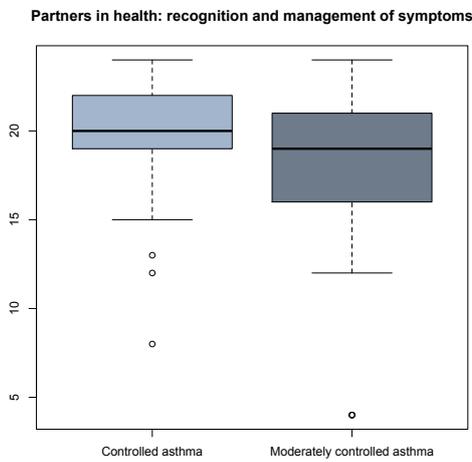


Figure 6.14: “Partners in health: recognition and management of symptoms” by Asthma control test

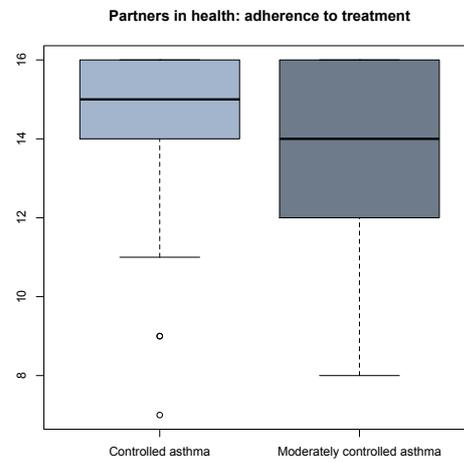


Figure 6.15: “Partners in health: adherence to treatment” by Asthma control test

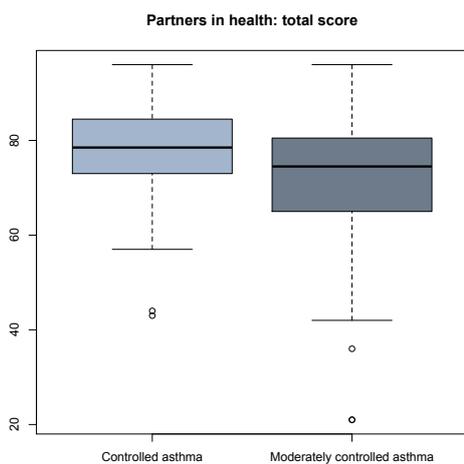


Figure 6.16: “Partners in health: total score” by Asthma control test

### Partners in health by Flare-ups

Comparisons were made by **Flare-ups**, between participants that reported having a flare-up or asthma attacks once a month or more frequently, *Frequent flare-ups* (n=36, 36.00%), those that had a flare-up once a month to once every three months, *Occasional flare-ups* (n=41, 41.00%), and those that had a flare-up once or twice a year, *Infrequent flare-ups* (n=23, 23.00%).

Boxplots of each Partners in health scale by the **Flare-ups** are displayed in Figures 6.17-6.21, summary statistics are displayed in Table 6.14.

The assumptions for a one-way ANOVA test were not met. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.15). 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 6.16 to 6.17).

A Welch one-way test indicated a statistically significant difference in the **“Partners in health: coping”** scale between groups  $F(2, 60.98) = 3.51$ ,  $p=0.0360$  (Table 6.16). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants with *Infrequent flare-ups* (mean = 17.91, SD = 3.45) scored significantly higher than participants with *Frequent flare-ups* (mean = 14.72, SD = 6.26,  $p = 0.0440$ ).

The mean scores for the **“Partners in health: coping”** scale was significantly higher for participants with *Infrequent flare-ups* compared to participants with *Frequent flare-ups*. However, these scores fall within the range of good coping for both of these groups.

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Table 6.14: “Partners in health” by Flare-ups summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Frequent flare-ups	36	36.00	23.33	7.04	25.00	6.25
	Occasional flare-ups	41	41.00	26.07	4.41	26.00	7.00
	Infrequent flare-ups	23	23.00	25.35	5.66	26.00	7.00
Partners in health: coping	Frequent flare-ups	36	36.00	14.72	6.26	15.00	7.25
	Occasional flare-ups	41	41.00	16.07	4.58	16.00	8.00
	Infrequent flare-ups	23	23.00	17.91	3.45	18.00	4.00
Partners in health: recognition and management of symptoms	Frequent flare-ups	36	36.00	18.08	5.50	19.00	5.25
	Occasional flare-ups	41	41.00	18.78	3.00	20.00	5.00
	Infrequent flare-ups	23	23.00	20.26	2.94	20.00	3.00
Partners in health: adherence to treatment	Frequent flare-ups	36	36.00	13.53	2.59	14.50	4.00
	Occasional flare-ups	41	41.00	14.02	2.27	15.00	3.00
	Infrequent flare-ups	23	23.00	14.91	1.76	16.00	1.50
Partners in health: total score	Frequent flare-ups	36	36.00	69.67	18.59	72.50	17.75
	Occasional flare-ups	41	41.00	74.95	9.92	76.00	11.00
	Infrequent flare-ups	23	23.00	78.43	11.21	79.00	11.50

Table 6.15: “Partners in health” by Flare-ups Kruskal-Wallis test

Partners in Health scale	$\chi^2$	df	p
Partners in health: knowledge	2.65	2	0.2664
Partners in health: recognition and management of symptoms	3.63	2	0.1629
Partners in health: adherence to treatment	5.62	2	0.0604

Table 6.16: “Partners in health” by Flare-ups Welch one-way test

Partners in Health scale	F	df1	df2	p
Partners in health: coping	3.51	2.00	60.98	0.0360*
Partners in health: total score	2.53	2.00	53.56	0.0894

\*Statistically significant at  $p < 0.05$

Table 6.17: “Partners in health” by Flare-ups post-hoc pairwise t-tests with no assumption of equal variances

Partners in Health scale		Frequent flare-ups	Occasional flare-ups
Partners in health: coping	Occasional flare-ups	0.2900	
	Infrequent flare-ups	0.0440*	0.1130

\*Statistically significant at  $p < 0.05$

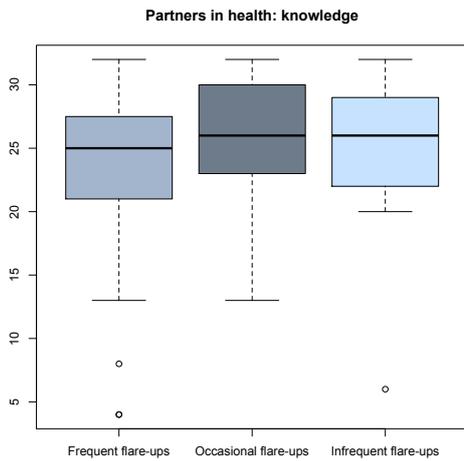


Figure 6.17: “Partners in health: knowledge” by Flare-ups

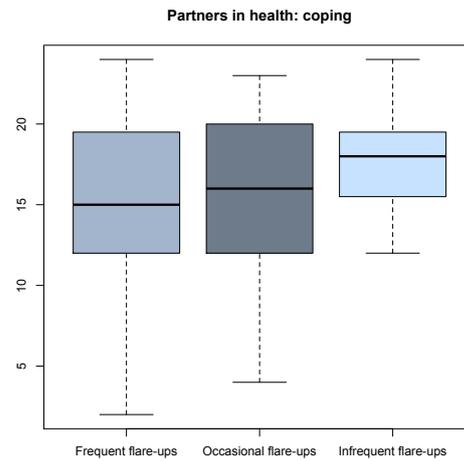


Figure 6.18: “Partners in health: coping” by Flare-ups

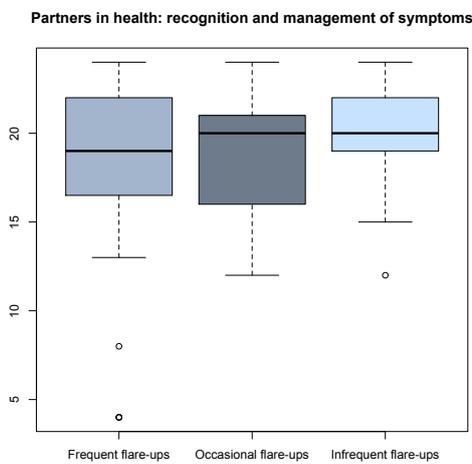


Figure 6.19: “Partners in health: recognition and management of symptoms” by Flare-ups

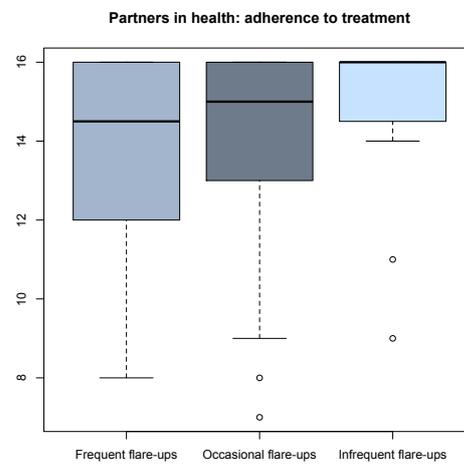


Figure 6.20: “Partners in health: adherence to treatment” by Flare-ups

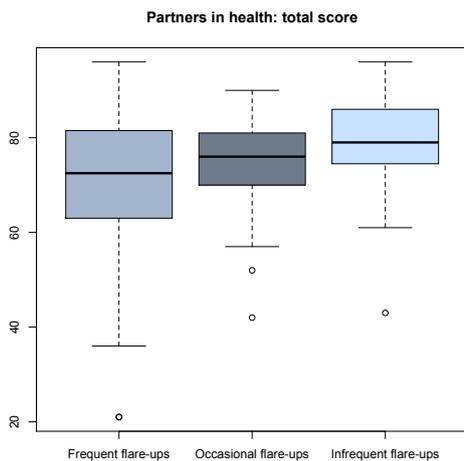


Figure 6.21: “Partners in health: total score” by Flare-ups

### Partners in health by Severity

Comparisons were made by **Severity**, between participants that reported having *Severe asthma* (n=29, 29.00%), and those that had *Non-severe asthma* (n=79, 79.00%). Participants in the *Severe asthma* sub-group included those who confirmed that they had been diagnosed with severe asthma in the semi-structured interview (this was then cross-checked with the treatments they are taking for verification), and those that were taking regular treatments beyond preventer and reliever medication including monoclonal antibodies, daily/very frequent oral corticosteroid use, long acting muscarinic antagonists, leukotriene receptor antagonists, or a high dose of regular treatment (such as high dose Seretide).

Boxplots of each Partners in health scale by **Severity** are displayed in Figures 6.22-6.26, summary statistics are displayed in Table 6.18. 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 6.18).

A two-sample t-test indicated that the mean score for Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: knowledge”** [W=1337.00, p=0.0194] was significantly higher for those with *Severe asthma* (Median = 28.00, IQR =5.00) compared to those with *Poorly controlled asthma* (Median =25.00, IQR = 6.00).

The median scores for the **“Partners in health: knowledge”** scale was significantly higher for participants in the *Severe asthma* sub-group compared to participant in the *Non-severe asthma* sub-group. These scores correspond to very good knowledge for participants in the *Severe asthma* sub-group and good knowledge for participants in the *Non-severe asthma* sub-group.

**Table 6.18: “Partners in health” by Severity Wilcoxon rank sum test with continuity correction**

Partners in health scale	Group	Count	Percent	Median	IQR	W	p
<b>Partners in health: knowledge</b>	Severe asthma	29	29.00	28.00	5.00	1337.00	0.0194*
	Non-severe asthma	71	71.00	25.00	6.00		
<b>Partners in health: coping</b>	Severe asthma	29	29.00	14.00	8.00	865.50	0.2128
	Non-severe asthma	71	71.00	18.00	6.00		
<b>Partners in health: recognition and management of symptoms</b>	Severe asthma	29	29.00	20.00	4.00	1059.00	0.8246
	Non-severe asthma	71	71.00	19.00	5.00		
<b>Partners in health: adherence to treatment</b>	Severe asthma	29	29.00	15.00	2.00	1224.50	0.1276
	Non-severe asthma	71	71.00	15.00	3.00		
<b>Partners in health: total score</b>	Severe asthma	29	29.00	76.00	13.00	1107.00	0.5584
	Non-severe asthma	71	71.00	76.00	14.00		

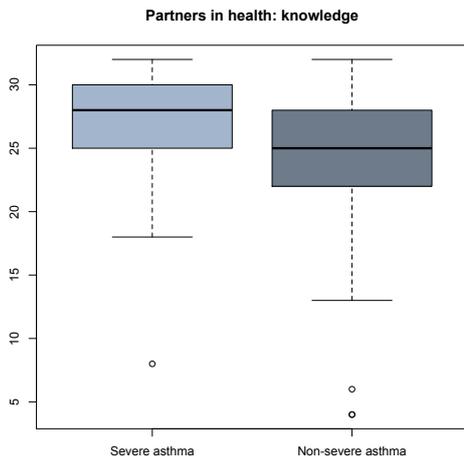


Figure 6.22: “Partners in health: knowledge” by Severity

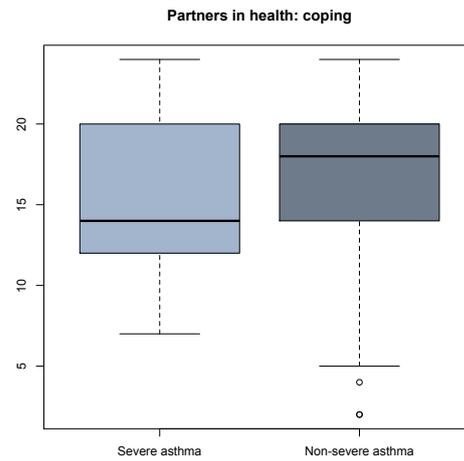


Figure 6.23: “Partners in health: coping” by Severity

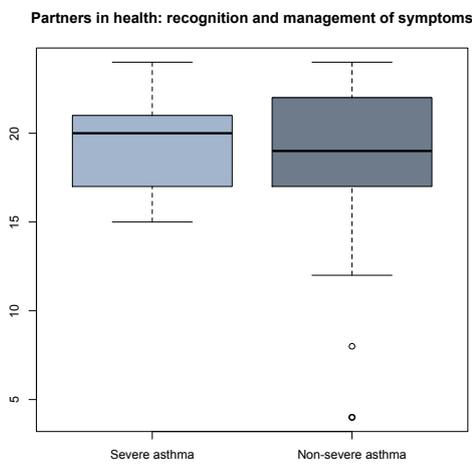


Figure 6.24: “Partners in health: recognition and management of symptoms” by Severity

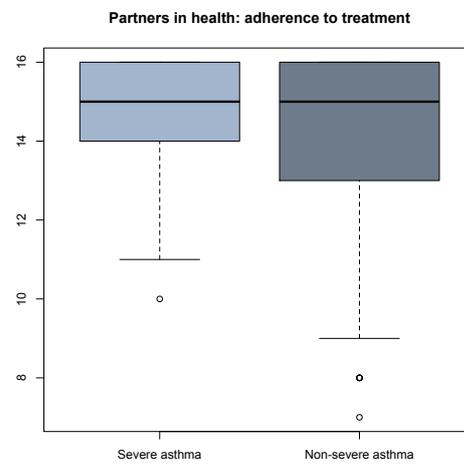


Figure 6.25: “Partners in health: adherence to treatment” by Severity

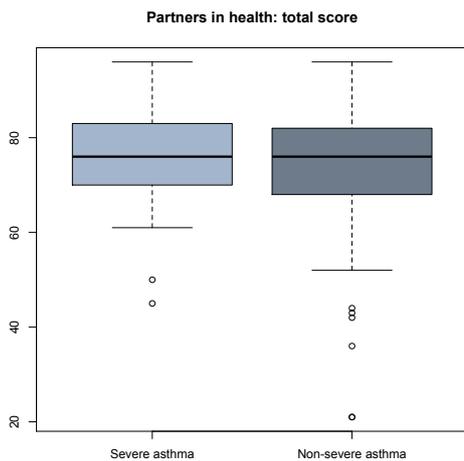


Figure 6.26: “Partners in health: total score” by Severity

## Partners in health by Sleep disruption

Comparisons were made by the frequency of **Sleep disruption**, those who noted in the Asthma control test the frequency that they had sleep disruptions due to asthma. Those that had sleep disruptions once a week or more frequently - *Frequent sleep disruption* (n=59, 59.00%) - were compared to those who responded that they had sleep disruptions once a month or not at all - *Infrequent sleep disruption* (n=41, 41.00%).

Boxplots of each Partners in health scale by **Sleep disruption** are displayed in Figures 6.27-6.31, summary statistics are displayed in Table 6.19. 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 6.19).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: coping”** [W=918.50, p=0.0411] was significantly higher for those with *Infrequent sleep disruption* (Median = 18.00, IQR =6.00) compared to those with *Frequent sleep disruption* (Median =15.00, IQR = 7.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: recognition and management of symptoms”** [W=891.00, p=0.0245] was significantly higher for those with *Infrequent sleep disruption* (Median = 20.00, IQR =3.00) compared to those with *Frequent sleep disruption* (Median =19.00, IQR = 5.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in health: total score”** [W=885.50, p=0.0233\*] was

significantly higher for those with *Infrequent sleep disruption* (Median = 79.00, IQR =12.00) compared to those with *Frequent sleep disruption* (Median =75.00, IQR = 15.50).

The median scores for the **“Partners in health: coping scale”** was significantly higher for participants with *Infrequent sleep disruption* compared to participants with *Frequent sleep problems*. However, these scores fall within the good range for both groups.

The median scores for the **“Partners in health: recognition and management of symptoms”** was significantly higher for participants with *Infrequent sleep disruption* compared to participants with *Frequent sleep disruption*. These scores correspond to very good recognition and management of symptoms participants with *Infrequent sleep disruption* and good recognition and management of symptoms participants for with *Frequent sleep disruption*.

The median scores for the **“Partners in health: total score”** was significantly higher for participants with *Infrequent sleep disruption* compared to participants with *Frequent sleep disruption*. These scores correspond to very good overall knowledge and confidence for managing their health for participants with *Infrequent sleep disruption* and good overall knowledge and confidence for managing their health for participants with *Frequent sleep disruption*.

**Table 6.19: “Partners in health” by Sleep disruption Wilcoxon rank sum test with continuity correction**

Partners in Health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	<i>Frequent sleep disruption</i>	59	59.00	26.00	7.50	1116.00	0.5133
	<i>Infrequent sleep disruption</i>	41	41.00	26.00	5.00		
Partners in health: coping	<i>Frequent sleep disruption</i>	59	59.00	15.00	7.50	918.50	0.0411*
	<i>Infrequent sleep disruption</i>	41	41.00	18.00	6.00		
Partners in health: recognition and management of symptoms	<i>Frequent sleep disruption</i>	59	59.00	19.00	5.00	891.00	0.0245*
	<i>Infrequent sleep disruption</i>	41	41.00	20.00	3.00		
Partners in health: adherence to treatment	<i>Frequent sleep disruption</i>	59	59.00	14.00	4.00	944.00	0.0555
	<i>Infrequent sleep disruption</i>	41	41.00	15.00	2.00		
Partners in health: total score	<i>Frequent sleep disruption</i>	59	59.00	75.00	15.50	885.50	0.0233*
	<i>Infrequent sleep disruption</i>	41	41.00	79.00	12.00		

\*Statistically significant at p<0.05

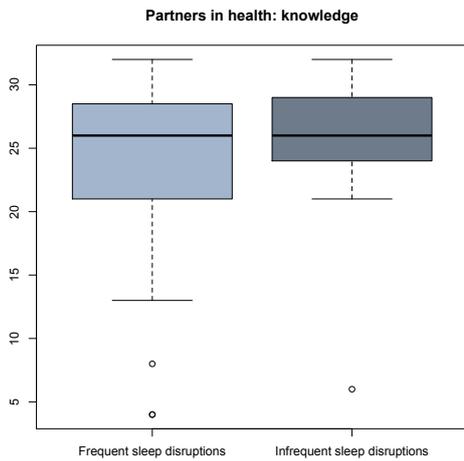


Figure 6.27: “Partners in health: knowledge” by Sleep disruption

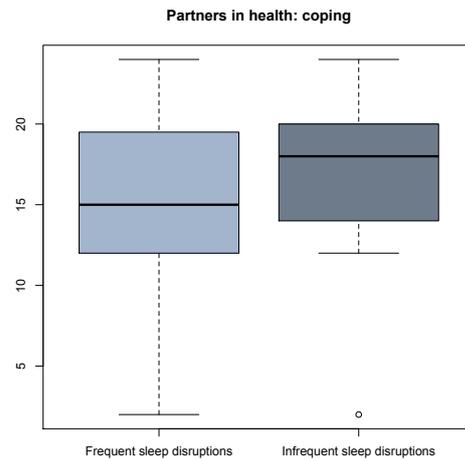


Figure 6.28: “Partners in health: coping” by Sleep disruption

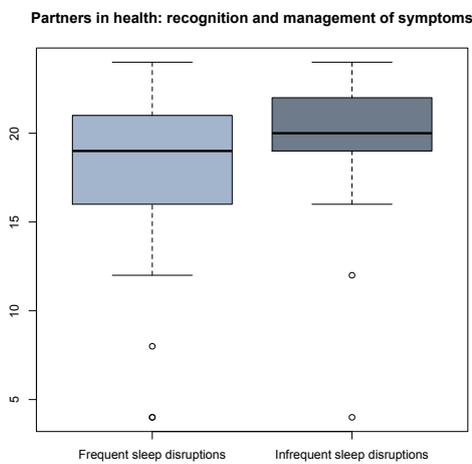


Figure 6.29: “Partners in health: recognition and management of symptoms” by Sleep disruption

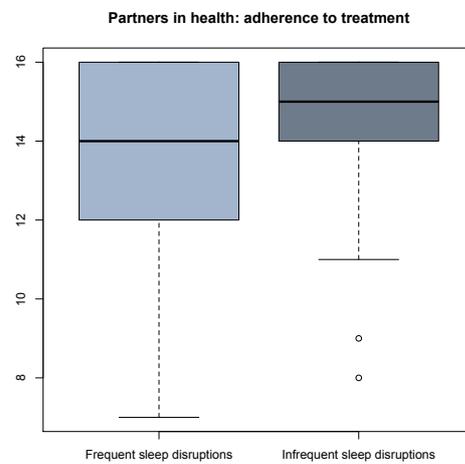


Figure 6.30: “Partners in health: adherence to treatment” by Sleep disruption

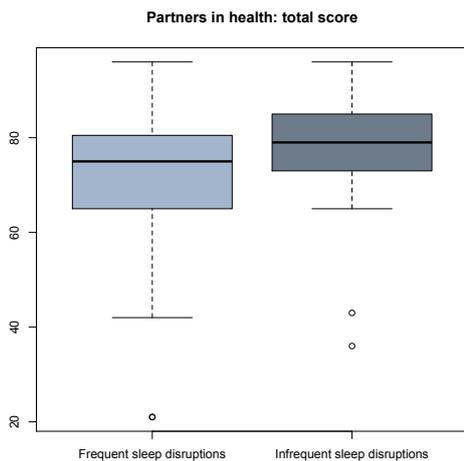


Figure 6.31: “Partners in health: total score” by Sleep disruption

### Partners in health by Age

Comparisons were made by the **Age** of the participants, those that were *Aged 18 to 34* (n=23, 23.00%), *Aged 35 to 54* (n=42, 42.00%) and participants *Aged 55 or older* (n=35, 35.00%).

Boxplots of each Partners in health scale by the **Age** are displayed in Figures 6.27-6.31, summary statistics are displayed in Table 6.20.

The one-way ANOVA test assumptions of residuals were not met, a Kruskal-Wallis test was used (Table 6.21). 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 6.22).

A Kruskal-Wallis test indicated a statistically significant difference in the **“Partners in health: knowledge”** scale between groups,  $\chi^2(2) = 8.99$ ,  $p = 0.0112$  (Table 6.20). Wilcoxon rank sum tests between groups indicated that those *Age 55 or older* (median = 28.00, IQR = 5.00) scored significantly higher than participants *Aged 18 to 34* (median = 23.00, IQR = 6.00,  $p=0.0130$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the **“Partners in health: coping”** scale between groups,  $\chi^2(2) = 7.90$ ,  $p = 0.0193$  (Table 6.20). Wilcoxon rank sum tests between groups indicated that those *Age 55 or older* (median = 18.00, IQR = 8.00,  $p = 0.0280$ ), and participants *Aged 35 to 54* (median = 18.00, IQR = 5.75,  $p = 0.0230$ ), scored significantly higher than participants *Aged 18 to 34* (median = 13.00, IQR = 7.50).

A Kruskal-Wallis test indicated a statistically significant difference in the **“Partners in health: total score”** scale between groups,  $\chi^2(2) = 9.40$ ,  $p = 0.0091$  (Table 6.20). Wilcoxon rank sum tests between groups indicated that those *Age 55 or older* (median = 80.00, IQR = 12.00) scored significantly higher than participants *Age 18 to 34* (median = 72.00, IQR = 14.50,  $p=0.0110$ ).

The median scores for the **“Partners in health: knowledge”** scale was significantly higher for participants *Aged 55 or older* compared to participants *Aged 18 to 34*. These scores correspond to very good knowledge for participants *Aged 55 or older* and good knowledge for participants *Aged 18 to 34*.

The median scores for the **“Partners in health: coping”** was significantly higher for participants *Aged 55 or older*, and participants *Aged 35 to 54* compared to participants *Aged 18 to 34*. These scores correspond to good coping for participants *Aged 55 or older*, and participants *Aged 35 to 54*, and moderate coping for participants *Aged 18 to 34*.

The median scores for the **“Partners in health: total score”** was significantly higher for participants *Aged 55 or older* compared to participants *Aged 18 to 34*. These scores correspond to very good overall knowledge and confidence for managing their health for participants *Aged 55 or older*, and good overall knowledge and confidence for managing their health for participants *Aged 18 to 34*.

Table 6.20: “Partners in health” by Age summary statistics

Partners in health scale	Group	Count	Percent	Mean	SD	Median	IQR
Partners in health: knowledge	Aged 18 to 34	23	23.00	22.70	6.56	23.00	6.00
	Aged 35 to 44	42	42.00	24.90	4.61	26.00	5.75
	Aged 55 or older	35	35.00	26.40	6.32	28.00	5.00
Partners in health: coping	Aged 18 to 34	23	23.00	13.09	5.78	13.00	7.50
	Aged 35 to 44	42	42.00	16.86	4.63	18.00	5.75
	Aged 55 or older	35	35.00	16.91	4.70	18.00	8.00
Partners in health: recognition and management of symptoms	Aged 18 to 34	23	23.00	17.61	5.66	19.00	4.50
	Aged 35 to 44	42	42.00	19.02	2.93	19.00	4.75
	Aged 55 or older	35	35.00	19.51	4.08	21.00	5.50
Partners in health: adherence to treatment	Aged 18 to 34	23	23.00	13.57	2.37	14.00	3.00
	Aged 35 to 44	42	42.00	13.93	2.39	15.00	3.00
	Aged 55 or older	35	35.00	14.51	2.20	15.00	2.00
Partners in health: total score	Aged 18 to 34	23	23.00	66.96	16.95	72.00	14.50
	Aged 35 to 44	42	42.00	74.71	10.98	76.50	10.75
	Aged 55 or older	35	35.00	77.34	14.50	80.00	12.00

Table 6.21: “Partners in health” by Age Kruskal-Wallis test

Partners in Health scale	$\chi^2$	df	p
Partners in health: knowledge	8.99	2	0.0112*
Partners in health: coping	7.90	2	0.0193*
Partners in health: recognition and management of symptoms	2.46	2	0.2919
Partners in health: adherence to treatment	4.31	2	0.1158
Partners in health: total score	9.40	2	0.0091*

\*Statistically significant at  $p < 0.05$

Table 6.22: “Partners in health” by Age post-hoc pairwise comparisons using Wilcoxon rank sum test

Partners in Health scale		Aged 18 - 34	Aged 35 - 54
Partners in health: knowledge	Aged 35 - 54	0.2260	
	Aged 55 or more	0.0130*	0.0610
Partners in health: coping	Aged 35 - 54	0.0230*	
	Aged 55 or more	0.0280*	0.9880
Partners in health: total score	Aged 35 - 54	0.0790	
	Aged 55 or more	0.0110*	0.0790

\*Statistically significant at  $p < 0.05$

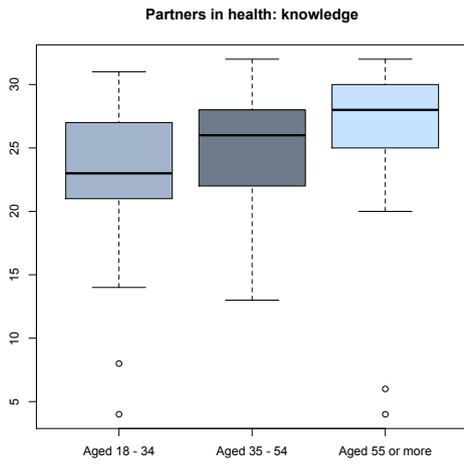


Figure 6.32: “Partners in health: knowledge” by Age

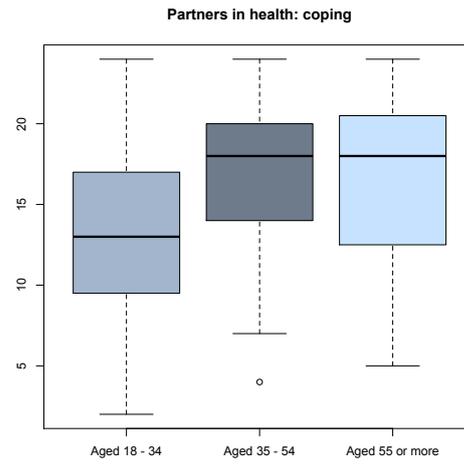


Figure 6.33: “Partners in health: coping” by Age

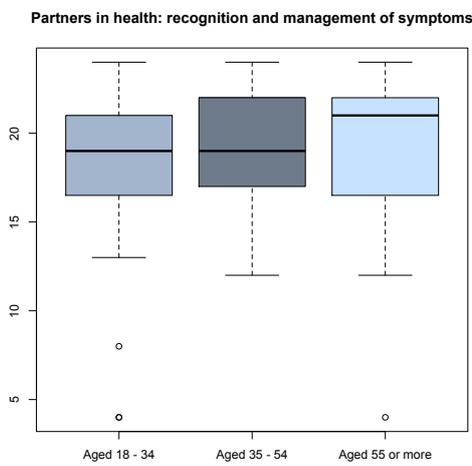


Figure 6.34: “Partners in health: recognition and management” of symptoms” by Age

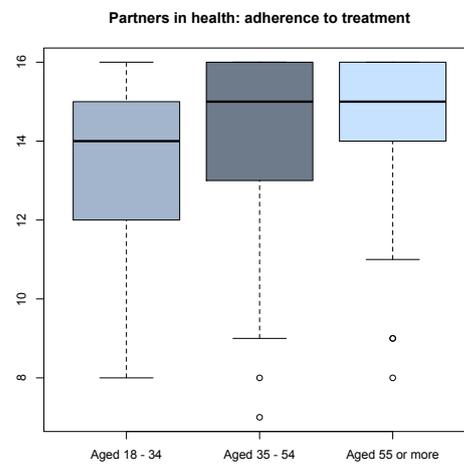


Figure 6.35: “Partners in health: adherence” to treatment” by Age

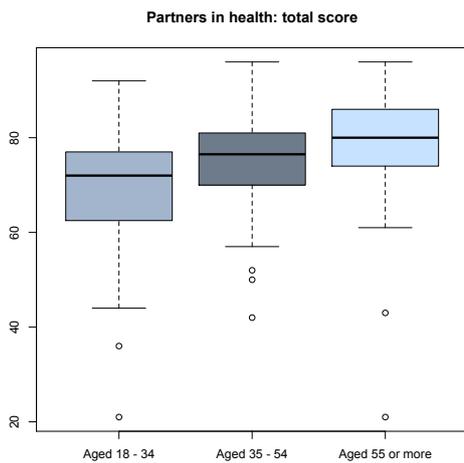


Figure 6.36: “Partners in health: total score” by Age

## Partners in health 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 major city, *Metropolitan* (n=66, 66.00%), were compared to those living in *Regional or remote* areas (n=34, 34.00%).

Boxplots of each Partners in health scale by **Location** are displayed in Figures 6.37-6.41, and summary statistics are displayed in Table 6.23. 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 6.23).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Partners in**

**health: knowledge”** [W=842.50, p=0.0418] was significantly higher for those who lived in *Regional or remote* areas (Median = 27.00, IQR =4.75) compared to those who lived in *Metropolitan* areas (Median =25.00, IQR = 6.00).

The median scores for the **“Partners in health: knowledge”** was significantly higher for participants who lived in *Regional or remote areas* compared to participants who lived in *Metropolitan* areas. These scores correspond to very good knowledge for participants that lived in *Regional or remote* areas, and good knowledge for participants in *Metropolitan* areas.

Table 6.23: **“Partners in health”** by **Location** Wilcoxon rank sum test with continuity correction

Partners in Health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	<i>Metropolitan</i>	66	66.00	25.00	6.00	842.50	0.0418*
	<i>Regional or remote</i>	34	34.00	27.00	4.75		
Partners in health: coping	<i>Metropolitan</i>	66	66.00	17.00	7.50	1072.00	0.7179
	<i>Regional or remote</i>	34	34.00	16.00	8.00		
Partners in health: recognition and management of symptoms	<i>Metropolitan</i>	66	66.00	19.00	5.75	996.00	0.3583
	<i>Regional or remote</i>	34	34.00	20.00	3.00		
Partners in health: adherence to treatment	<i>Metropolitan</i>	66	66.00	15.00	3.00	1060.50	0.6472
	<i>Regional or remote</i>	34	34.00	15.00	2.75		
Partners in health: total score	<i>Metropolitan</i>	66	66.00	76.00	13.00	939.50	0.1851
	<i>Regional or remote</i>	34	34.00	78.50	12.75		

\*Statistically significant at p<0.05

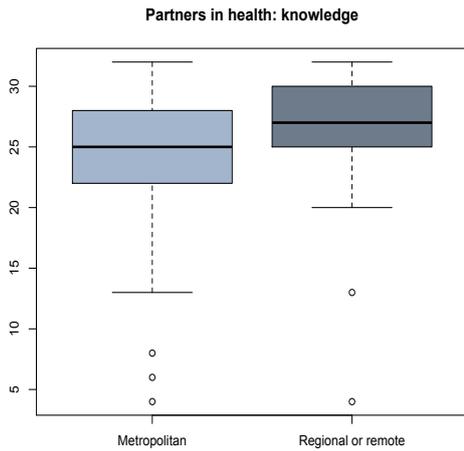


Figure 6.37: “Partners in health: knowledge” by Location

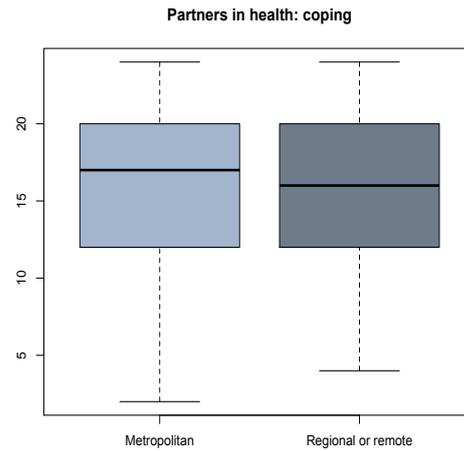


Figure 6.38: “Partners in health: coping” by Location

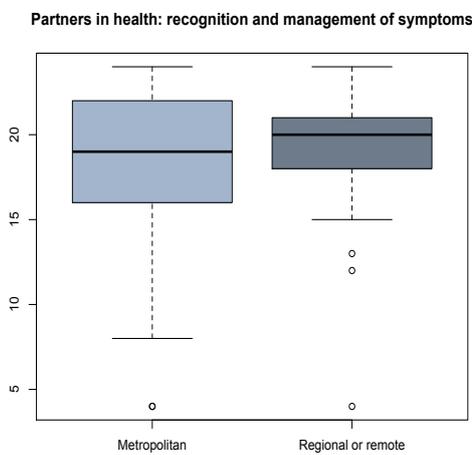


Figure 6.39: “Partners in health: recognition and management of symptoms” by Location

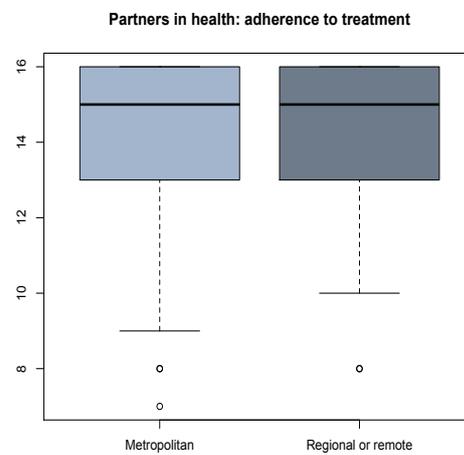


Figure 6.40: “Partners in health: adherence to treatment” by Location

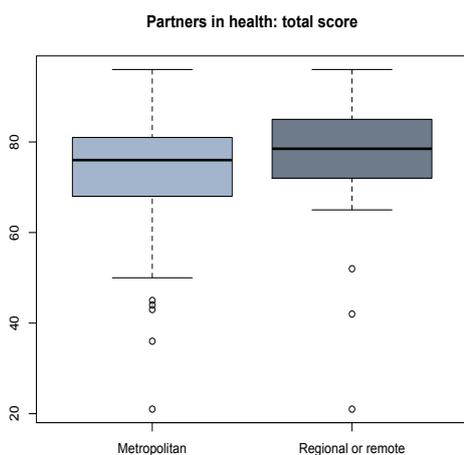


Figure 6.41: “Partners in health: total score” by Location

### Partners in health by Education

Comparisons were made by **Education** status, between those with a university qualification, “University” (n=56, 56.00%), and those with trade or high school qualifications, “trade or high school” (N=44, 44.00%).

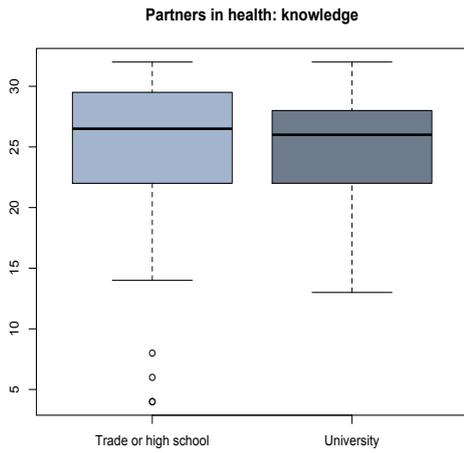
Boxplots of each Care coordination scale by **Education** are displayed in Figures 6.42-6.46, summary statistics are displayed in Table 6.24. Assumptions for normality and variance for a two-sample t-test were not met, a

Wilcoxon rank sum test with continuity correction was used (Table 6.23). No significant differences were observed between participants by **Education** for any of the “**Partners in health**” scales.

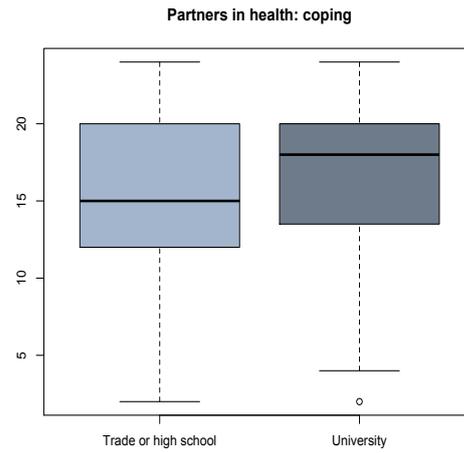
No significant differences were observed between participants by **Education** for any of the “**Partners in health**” scales.

Table 6.24: “Partners in health” by Education Wilcoxon rank sum test with continuity correction

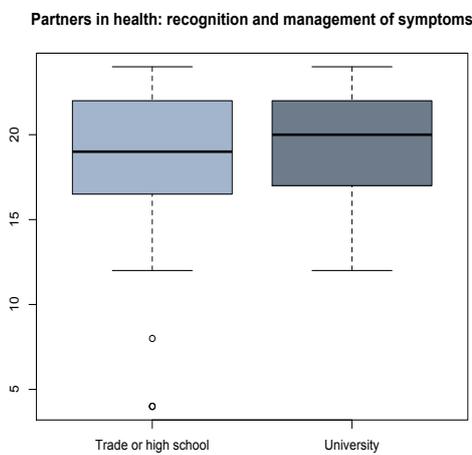
Partners in Health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	Trade or high school	44	44.00	26.50	7.25	1287.00	0.7043
	University	56	56.00	26.00	6.00		
Partners in health: coping	Trade or high school	44	44.00	15.00	8.00	1056.50	0.2229
	University	56	56.00	18.00	6.25		
Partners in health: recognition and management of symptoms	Trade or high school	44	44.00	19.00	5.25	1145.50	0.5480
	University	56	56.00	20.00	5.00		
Partners in health: adherence to treatment	Trade or high school	44	44.00	14.50	4.25	988.50	0.0819
	University	56	56.00	15.00	2.00		
Partners in health: total score	Trade or high school	44	44.00	76.00	14.25	1095.00	0.3429
	University	56	56.00	77.50	13.25		



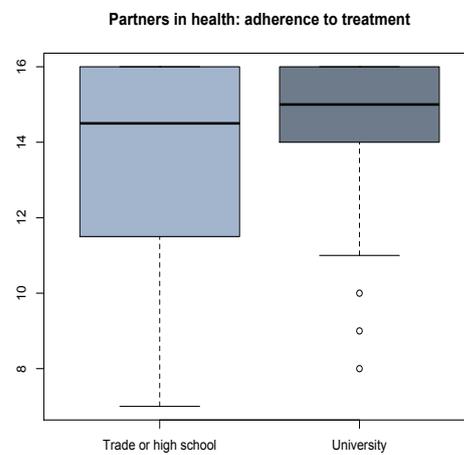
**Figure 6.42: “Partners in health: knowledge” by Education**



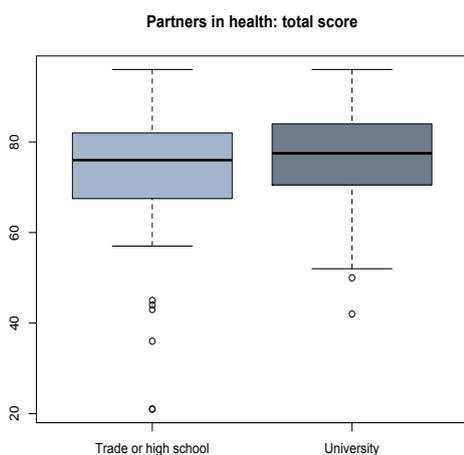
**Figure 6.43: “Partners in health: coping” by Education**



**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**

### Partners in health by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) ([www.abs.gov.au](http://www.abs.gov.au)). SEIFA scores range from 1 to 10, where a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *High SEIFA* (n=56 56.00%), compared to those with a mid to low SEIFA score of 1-6, *Mid-low SEIFA* (n=44, 44.00%).

Boxplots of each Care coordination scale by **SEIFA** are displayed in Figures 6.47-6.51, summary statistics are displayed in Table 6.25. 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 6.24). No significant differences were observed between participants by **SEIFA** for any of the “**Partners in health**” scales.

No significant differences were observed between participants by **SEIFA** for any of the “**Partners in health**” scales.

Table 6.25: “**Partners in health**” by **SEIFA** Wilcoxon rank sum test with continuity correction

Partners in Health scale	Group	Count	Percent	Median	IQR	W	p
Partners in health: knowledge	<i>High SEIFA</i>	56	56.00	26.00	6.50	1344.00	0.4375
	<i>Mid to low SEIFA</i>	44	44.00	26.00	6.00		
Partners in health: coping	<i>High SEIFA</i>	56	56.00	18.00	6.25	1433.00	0.1625
	<i>Mid to low SEIFA</i>	44	44.00	15.50	7.25		
Partners in health: recognition and management of symptoms	<i>High SEIFA</i>	56	56.00	19.00	5.00	1312.50	0.5763
	<i>Mid to low SEIFA</i>	44	44.00	20.00	4.00		
Partners in health: adherence to treatment	<i>High SEIFA</i>	56	56.00	15.00	2.00	1443.50	0.1308
	<i>Mid to low SEIFA</i>	44	44.00	15.00	4.00		
Partners in health: total score	<i>High SEIFA</i>	56	56.00	77.50	12.25	1414.00	0.2073
	<i>Mid to low SEIFA</i>	44	44.00	74.50	16.00		



Figure 6.47: “Partners in health: knowledge” by SEIFA

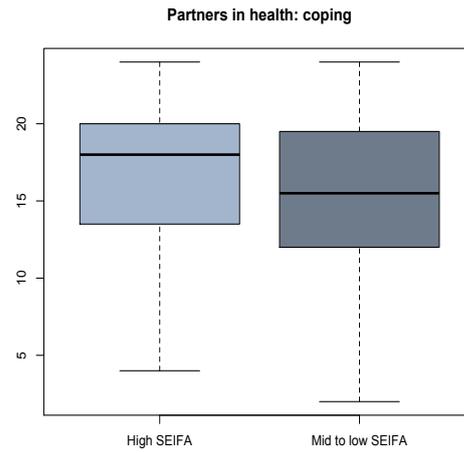


Figure 6.48: “Partners in health: coping” by SEIFA

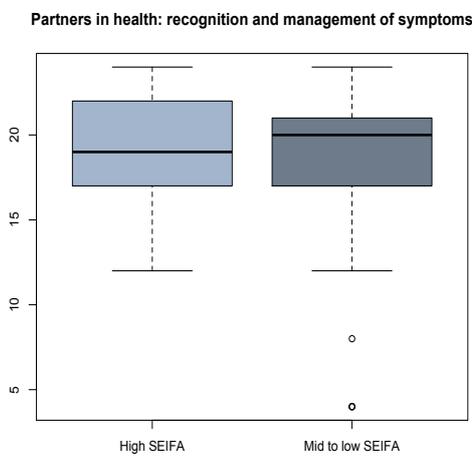


Figure 6.49: “Partners in health: recognition and management of symptoms” by SEIFA

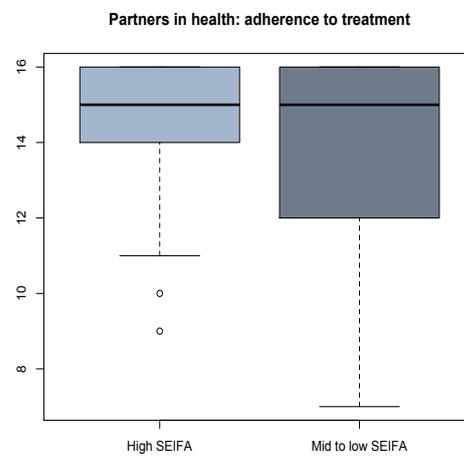


Figure 6.50: “Partners in health: adherence to treatment” by SEIFA

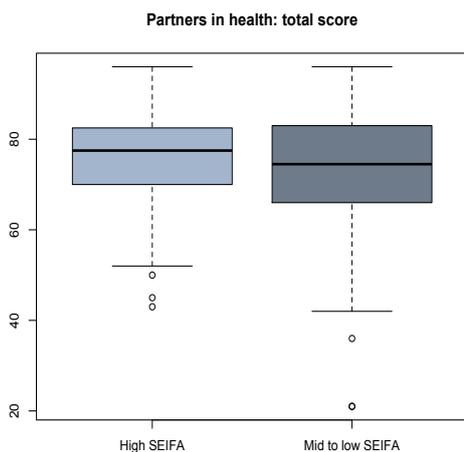


Figure 6.51: “Partners in health: total score” by SEIFA

### Information given by healthcare professionals

Participants were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. Information about treatment options (72.00%), disease management (55.00%) and information about allergies (32.00%) were most frequently given to participants by healthcare professionals, and information about hereditary considerations genes or genomic biomarker information (2.00%), clinical trials (3.00%) and complementary therapies (7.00%) were given least often (Table 6.26, Figure 6.52).

In relation to subgroup variations, participants who with *Severe asthma* (n=9, 31.03%) received information about disease cause more often than the general population (n=21, 21.00%), while those that lived in *Regional or remote* areas (n=3, 8.82%) received this information less often. Information about

treatment options was given to participants *Age 55 or older* (n=29, 82.86%) and participants with *University* qualifications (n=46, 82.14%) more often than the general population (n=72, 72.00%), and less often to participants with *Trade or high school* qualifications (n=26, 59.09%). Compared to the general population (n=55, 55.00%), information about disease management was given more often to participants with *Severe asthma* (n=19, 65.52%), and *Aged 55 or more* (n=24, 68.57%), and less often for participants *Age 35 to 54* (n=18, 42.86%) and participants with *Trade or high school* qualifications (n=19, 43.18%).

Participants with *Severe asthma* (n=5, 17.24%) were given information about complementary therapies more often than the general population (n=7, 7.00%). Participants with *Infrequent flare-ups* were given information about physical activity (n=9, 39.13%) more frequently than the general population (n=28, 28.00%).

**Table 6.26: Information given by health professionals**

Topic	All participants		Asthma control test						Asthma control test 2			
			Controlled asthma		Moderately controlled asthma		Poorly controlled asthma		Moderate to well controlled asthma		Poorly controlled asthma	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=52	%
Disease cause	21	21.00	8	30.77	3	13.64	10	19.23	11	22.92	10	19.23
Treatment options	72	72.00	18	69.23	16	72.73	38	73.08	34	70.83	38	73.08
Disease management	55	55.00	13	50.00	14	63.64	28	53.85	27	56.25	28	53.85
Complementary therapies	7	7.00	1	3.85	1	4.55	5	9.62	2	4.17	5	9.62
Clinical trials	3	3.00	0	0.00	1	4.55	2	3.85	1	2.08	2	3.85
How to interpret test results	14	14.00	3	11.54	2	9.09	9	17.31	5	10.42	9	17.31
Dietary information	13	13.00	3	11.54	2	9.09	8	15.38	5	10.42	8	15.38
Physical activity	28	28.00	7	26.92	6	27.27	15	28.85	13	27.08	15	28.85
Psychological/social support	11	11.00	1	3.85	4	18.18	6	11.54	5	10.42	6	11.54
Hereditary considerations genes or genomic biomarker information	2	2.00	0	0.00	1	4.55	1	1.92	1	2.08	1	1.92
Information about allergies	32	32.00	10	38.46	8	36.36	14	26.92	18	37.50	14	26.92

Topic	All participants		Flare-ups						Severity				Sleep disruption			
			Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups		Severe asthma		Non-severe asthma		Frequent sleep disruption		Infrequent sleep disruption	
	n=100	%	n=36	%	n=41	%	n=23	%	N=29	%	N=71	%	n=59	%	n=41	%
Disease cause	21	21.00	6	16.67	8	19.51	7	30.43	9	31.03	12	16.90	12	20.34	9	21.95
Treatment options	72	72.00	26	72.22	30	73.17	16	69.57	22	75.86	50	70.42	44	74.58	28	68.29
Disease management	55	55.00	18	50.00	23	56.10	14	60.87	19	65.52	36	50.70	34	57.63	21	51.22
Complementary therapies	7	7.00	4	11.11	2	4.88	1	4.35	5	17.24	2	2.82	6	10.17	1	2.44
Clinical trials	3	3.00	2	5.56	1	2.44	0	0.00	3	10.34	0	0.00	2	3.39	1	2.44
How to interpret test results	14	14.00	8	22.22	3	7.32	3	13.04	5	17.24	9	12.68	9	15.25	5	12.20
Dietary information	13	13.00	7	19.44	3	7.32	3	13.04	5	17.24	8	11.27	9	15.25	4	9.76
Physical activity	28	28.00	8	22.22	11	26.83	9	39.13	9	31.03	19	26.76	17	28.81	11	26.83
Psychological/social support	11	11.00	4	11.11	5	12.20	2	8.70	4	13.79	7	9.86	7	11.86	4	9.76
Hereditary considerations genes or genomic biomarker information	2	2.00	2	5.56	0	0.00	0	0.00	1	3.45	1	1.41	2	3.39	0	0.00
Information about allergies	32	32.00	11	30.56	12	29.27	9	39.13	11	37.93	21	29.58	16	27.12	16	39.02

Table 6.26 (Cont): Information given by health professionals

Topic	All participants		Age						Location			
			Aged 18 - 34		Aged 35 - 54		Aged 55 or older		Metropolitan		Regional or remote	
	n=100	%	n=23	%	n=42	%	n=35	%	n=66	%	n=34	%
Disease cause	21	21.00	4	17.39	7	16.67	10	28.57	18	27.27	3	8.82
Treatment options	72	72.00	15	65.22	28	66.67	29	82.86	48	72.73	24	70.59
Disease management	55	55.00	13	56.52	18	42.86	24	68.57	37	56.06	18	52.94
Complementary therapies	7	7.00	1	4.35	4	9.52	2	5.71	4	6.06	3	8.82
Clinical trials	3	3.00	1	4.35	1	2.38	1	2.86	1	1.52	2	5.88
How to interpret test results	14	14.00	5	21.74	4	9.52	5	14.29	12	18.18	2	5.88
Dietary information	13	13.00	3	13.04	6	14.29	4	11.43	9	13.64	4	11.76
Physical activity	28	28.00	8	34.78	8	19.05	12	34.29	19	28.79	9	26.47
Psychological/social support	11	11.00	1	4.35	5	11.90	5	14.29	7	10.61	4	11.76
Hereditary considerations genes or genomic biomarker information	2	2.00	0	0.00	1	2.38	1	2.86	2	3.03	0	0.00
Information about allergies	32	32.00	7	30.43	11	26.19	14	40.00	24	36.36	8	23.53

Topic	All participants		Education				SEIFA			
			Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=44	%	n=56	%	n=56	%	n=44	%
Disease cause	21	21.00	7	15.91	14	25.00	14	25.00	7	15.91
Treatment options	72	72.00	26	59.09	46	82.14	43	76.79	29	65.91
Disease management	55	55.00	19	43.18	36	64.29	29	51.79	26	59.09
Complementary therapies	7	7.00	4	9.09	3	5.36	3	5.36	4	9.09
Clinical trials	3	3.00	3	6.82	0	0.00	2	3.57	1	2.27
How to interpret test results	14	14.00	5	11.36	9	16.07	9	16.07	5	11.36
Dietary information	13	13.00	4	9.09	9	16.07	5	8.93	8	18.18
Physical activity	28	28.00	14	31.82	14	25.00	15	26.79	13	29.55
Psychological/social support	11	11.00	3	6.82	8	14.29	7	12.50	4	9.09
Hereditary considerations genes or genomic biomarker information	2	2.00	1	2.27	1	1.79	2	3.57	0	0.00
Information about allergies	32	32.00	12	27.27	20	35.71	20	35.71	12	27.27

### Information searched for independently

Information about treatment options (n=53, 53.00%), disease management (n=41, 41.00%) and information about allergies (n=39, 39.00%) were most often searched for independently by participants. Psychological/social support (n=14, 14.00%), hereditary considerations genes or genomic biomarker information (n=15, 15.00%), and clinical trials (n=17, 17.00%) were least searched for (Table 6.27, Figure 6.53).

In relation to sub-group variations, information about disease cause was searched for more often by participants with *Controlled asthma* (n=13, 50.00%), *Severe asthma* (n=15, 51.72%) and participants with *University* qualifications (n=25, 56.82%) compared to the general population (n=37, 37.00%); and participants with *Moderately controlled asthma* (n=4, 18.18%) searched for this type of information less frequently.

Participants in the *Severe asthma* sub-group (n=20, 68.97%) and those that lived in *Regional or remote* areas (n=27, 79.41%) searched for information about treatment options more frequently compared to the general population (n=53, 53.00%), and participants with *Controlled asthma* (n=11, 42.31%), *Infrequent flare-ups* (n=9, 39.13%) and those that lived in *Metropolitan* areas (n=26, 39.39%) searched for this type of information less often.

Information about disease management was searched for more often by participants in the *Severe asthma* sub-group (n=16, 55.17%), with *University* qualifications (n=26, 59.09%), and participants with *Occasional flare-ups* (n=22, 53.66%) compared to the general population (n=41, 41.00%), and less often by participants with *Frequent flare-ups* (n=11, 30.56%).

Participants with *Infrequent flare-ups* (n=4, 17.39%) and in the *Severe asthma* sub-group (n=15, 51.72%) searched for information about complementary therapies less often than the general population (n=29, 29.00%) and participants with *University* qualifications (n=19, 43.18%) searched for this information more frequently.

Participants in the *Severe asthma* sub-group (n=8, 27.59%) searched for information about clinical trials more often than the general population (n=17, 17.00%).

How to interpret test results was searched for more often by participants in the *Severe asthma* sub-group (n=14, 48.28%), and those with *University* qualifications (n=14, 31.82%) compared to the general population (n=20, 20.00%) and less often by those with *Moderately controlled asthma* (n=2, 9.09%) and *Non-severe asthma* (n=6, 8.45%).

Participants who had *Occasional flare-ups* (n=14, 34.15%), *Severe asthma* (n=10, 34.48%), and those with *University* qualifications (n=16, 36.36%) searched for information about physical activity more frequently than the general population (n=24, 24.00%), and participants with *Infrequent flare-ups* (n=2, 8.70%), searched for this information less often.

Information about hereditary considerations genes or genomic biomarker information was searched for more often by participants *Aged 18 to 34* (n=6, 26.09%) compared to the general population (n=15, 15.00%). Participants *Aged 18 to 34* (n=12, 52.17%) and those that lived in *Regional or remote* areas (n=17, 20.00%) searched for information about allergies more often than the general population (n=39, 39.00%) and those *Aged 55 or older* (n=10, 28.57%) searched for this type of information less frequently.

Table 6.27: Information searched for independently

Topic	All participants		Asthma control test						Asthma control test 2			
			Controlled asthma		Moderately controlled asthma		Poorly controlled asthma		Moderate to well controlled asthma		Poorly controlled asthma	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=52	%
Disease cause	37	37.00	13	50.00	4	18.18	20	38.46	17	35.42	20	38.46
Treatment options	53	53.00	11	42.31	12	54.55	30	57.69	23	47.92	30	57.69
Disease management	41	41.00	10	38.46	10	45.45	21	40.38	20	41.67	21	40.38
Complementary therapies	29	29.00	5	19.23	8	36.36	16	30.77	13	27.08	16	30.77
Clinical trials	17	17.00	4	15.38	4	18.18	9	17.31	8	16.67	9	17.31
How to interpret test results	20	20.00	5	19.23	2	9.09	13	25.00	7	14.58	13	25.00
Dietary information	23	23.00	4	15.38	3	13.64	16	30.77	7	14.58	16	30.77
Physical activity	24	24.00	5	19.23	6	27.27	13	25.00	11	22.92	13	25.00
Psychological/social support	14	14.00	3	11.54	3	13.64	8	15.38	6	12.50	8	15.38
Hereditary considerations genes or genomic biomarker information	15	15.00	3	11.54	5	22.73	7	13.46	8	16.67	7	13.46
Information about allergies	39	39.00	10	38.46	7	31.82	22	42.31	17	35.42	22	42.31

Topic	All participants		Flare-ups						Severity				Sleep disruption			
			Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups		Severe asthma		Non-severe asthma		Frequent sleep disruption		Infrequent sleep disruption	
	n=100	%	n=36	%	n=41	%	n=23	%	N=29	%	N=71	%	n=59	%	n=41	%
Disease cause	37	37.00	15	41.67	14	34.15	8	34.78	15	51.72	22	30.99	22	37.29	15	36.59
Treatment options	53	53.00	20	55.56	24	58.54	9	39.13	20	68.97	33	46.48	33	55.93	20	48.78
Disease management	41	41.00	11	30.56	22	53.66	8	34.78	16	55.17	25	35.21	25	42.37	16	39.02
Complementary therapies	29	29.00	11	30.56	14	34.15	4	17.39	15	51.72	14	19.72	19	32.20	10	24.39
Clinical trials	17	17.00	4	11.11	9	21.95	4	17.39	8	27.59	9	12.68	10	16.95	7	17.07
How to interpret test results	20	20.00	9	25.00	8	19.51	3	13.04	14	48.28	6	8.45	12	20.34	8	19.51
Dietary information	23	23.00	8	22.22	10	24.39	5	21.74	9	31.03	14	19.72	16	27.12	7	17.07
Physical activity	24	24.00	8	22.22	14	34.15	2	8.70	10	34.48	14	19.72	17	28.81	7	17.07
Psychological/social support	14	14.00	4	11.11	8	19.51	2	8.70	6	20.69	8	11.27	9	15.25	5	12.20
Hereditary considerations genes or genomic biomarker information	15	15.00	5	13.89	7	17.07	3	13.04	6	20.69	9	12.68	9	15.25	6	14.63
Information about allergies	39	39.00	16	44.44	13	31.71	10	43.48	14	48.28	25	35.21	24	40.68	15	36.59

Topic	All participants		Age						Location			
			Aged 18 - 34		Aged 35 - 54		Aged 55 or older		Metropolitan		Regional or remote	
	n=100	%	n=23	%	n=42	%	n=35	%	n=66	%	n=34	%
Disease cause	37	37.00	7	30.43	15	35.71	15	42.86	26	39.39	11	32.35
Treatment options	53	53.00	10	43.48	23	54.76	20	57.14	26	39.39	27	79.41
Disease management	41	41.00	9	39.13	17	40.48	15	42.86	26	39.39	15	44.12
Complementary therapies	29	29.00	4	17.39	14	33.33	11	31.43	18	27.27	11	32.35
Clinical trials	17	17.00	4	17.39	9	21.43	4	11.43	10	15.15	7	20.59
How to interpret test results	20	20.00	3	13.04	8	19.05	9	25.71	11	16.67	9	26.47
Dietary information	23	23.00	4	17.39	14	33.33	5	14.29	14	21.21	9	26.47
Physical activity	24	24.00	4	17.39	10	23.81	10	28.57	16	24.24	8	23.53
Psychological/social support	14	14.00	2	8.70	7	16.67	5	14.29	7	10.61	7	20.59
Hereditary considerations genes or genomic biomarker information	15	15.00	6	26.09	6	14.29	3	8.57	10	15.15	5	14.71
Information about allergies	39	39.00	12	52.17	17	40.48	10	28.57	22	33.33	17	50.00

Table 6.27 (Cont.): Information searched for independently

Topic	All participants		Education				SEIFA			
			Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=44	%	n=56	%	n=56	%	n=44	%
Disease cause	37	37.00	12	27.27	25	56.82	20	35.71	17	38.64
Treatment options	53	53.00	26	59.09	27	61.36	27	48.21	26	59.09
Disease management	41	41.00	15	34.09	26	59.09	23	41.07	18	40.91
Complementary therapies	29	29.00	10	22.73	19	43.18	16	28.57	13	29.55
Clinical trials	17	17.00	9	20.45	8	18.18	10	17.86	7	15.91
How to interpret test results	20	20.00	6	13.64	14	31.82	10	17.86	10	22.73
Dietary information	23	23.00	9	20.45	14	31.82	9	16.07	14	31.82
Physical activity	24	24.00	8	18.18	16	36.36	14	25.00	10	22.73
Psychological/social support	14	14.00	4	9.09	10	22.73	7	12.50	7	15.91
Hereditary considerations genes or genomic biomarker information	15	15.00	8	18.18	7	15.91	6	10.71	9	20.45
Information about allergies	39	39.00	16	36.36	23	52.27	18	32.14	21	47.73

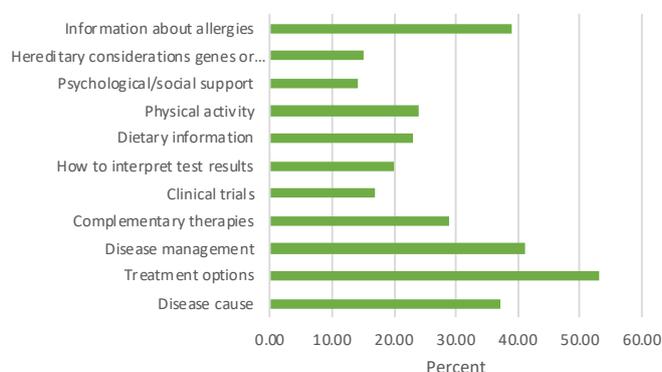
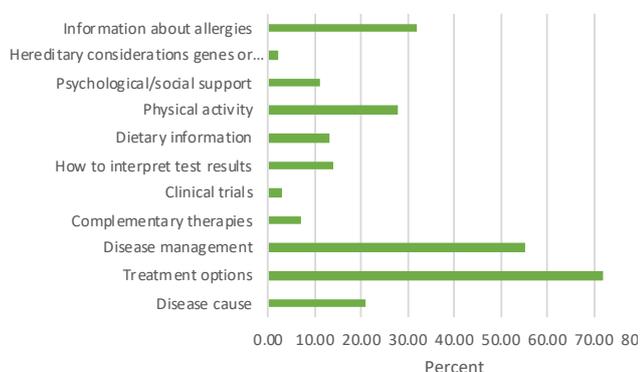


Figure 6.53: Information given

Figure 6.53: Information searched for

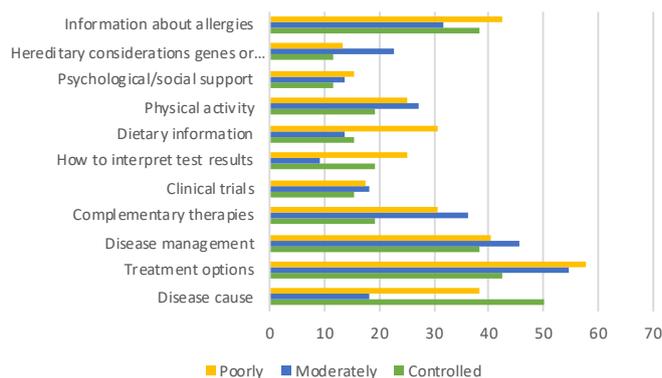
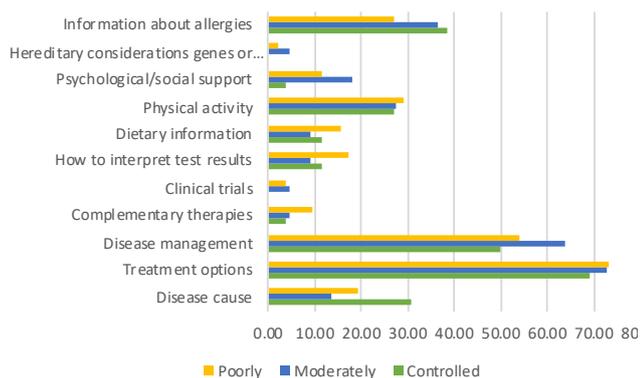


Figure 6.54: Information given by Asthma control test

Figure 6.55: Information searched for by Asthma control test

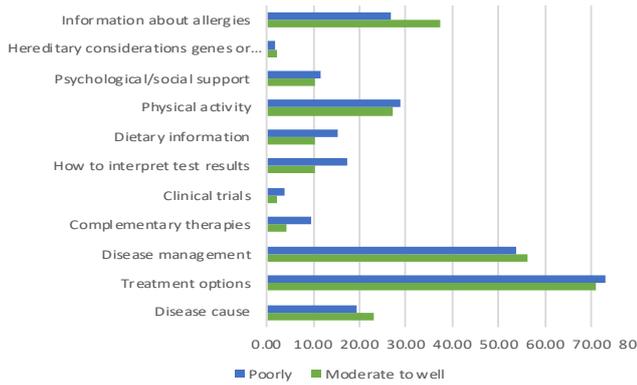


Figure 6.56: Information given by Asthma control test

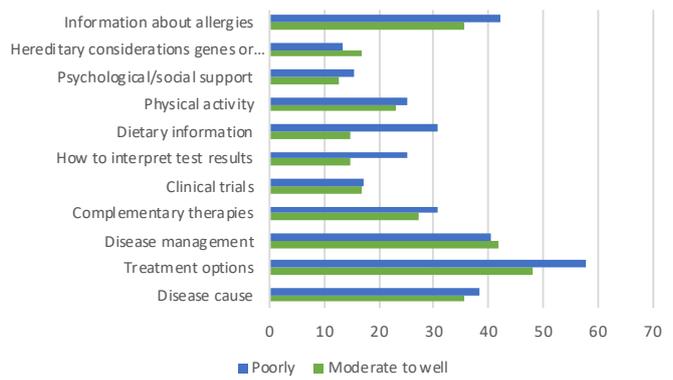


Figure 6.57: Information searched for by Asthma control test

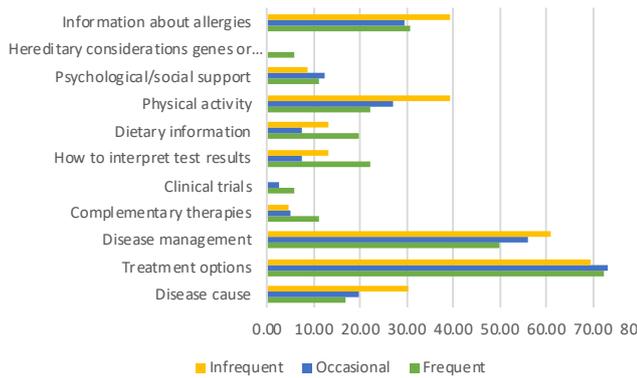


Figure 6.58: Information given by Flare-ups

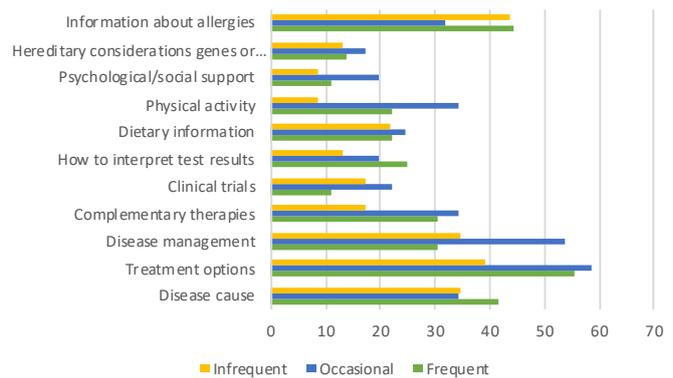


Figure 6.59: Information searched for by Flare-ups

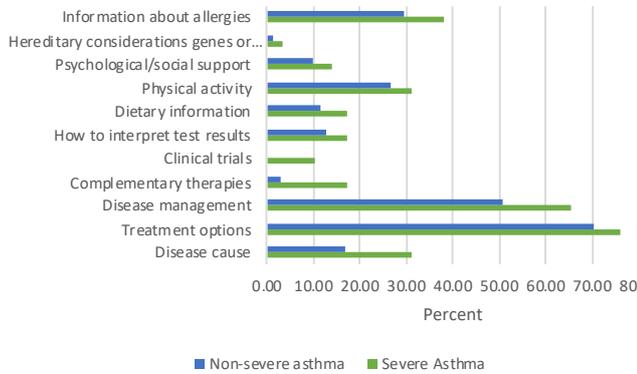


Figure 6.60: Information given by Severity

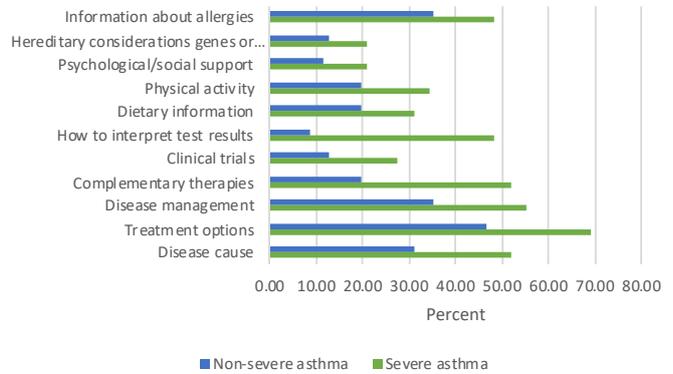


Figure 6.61: Information searched for by Severity

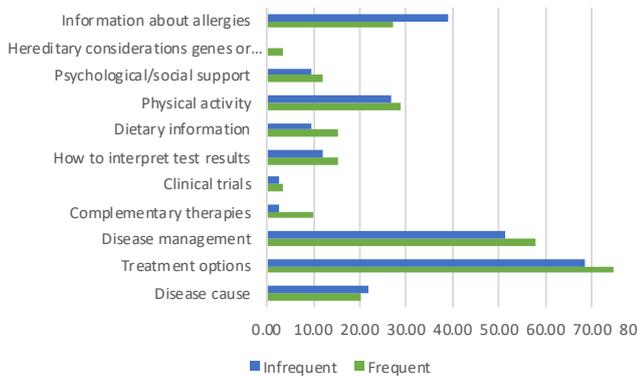


Figure 6.62: Information given by Sleep disruption

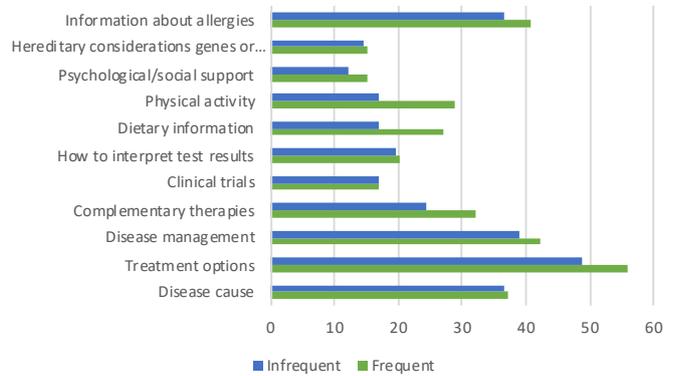


Figure 6.63: Information searched for by Sleep disruption

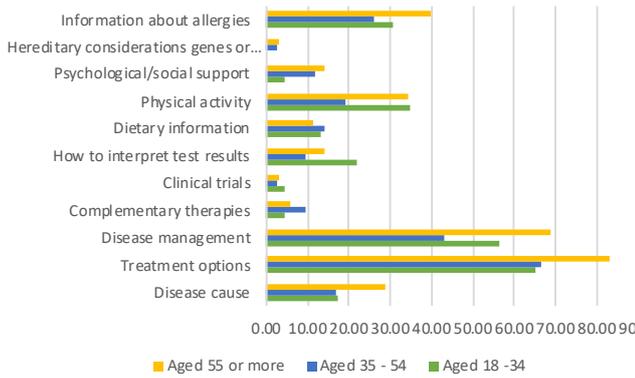


Figure 6.64: Information given by Age

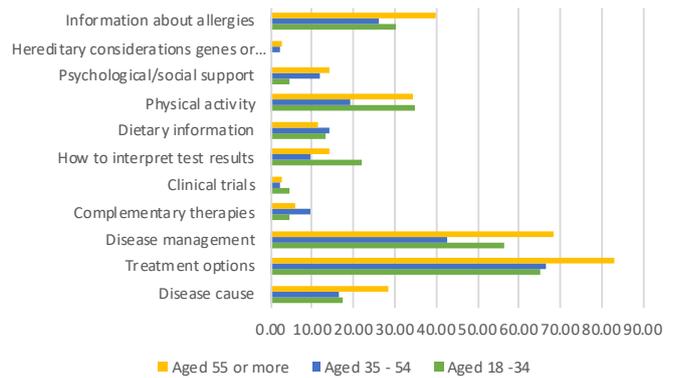


Figure 6.65: Information searched for by Age

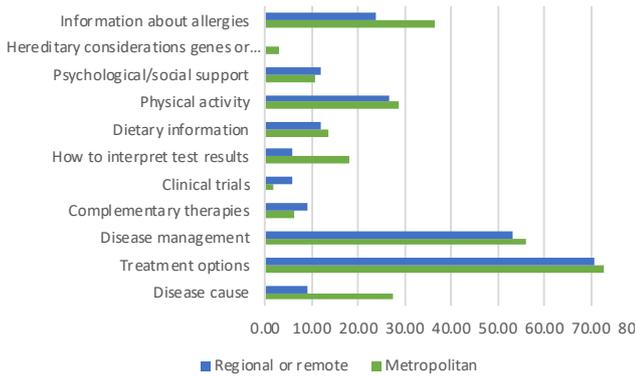


Figure 6.66: Information given by Location

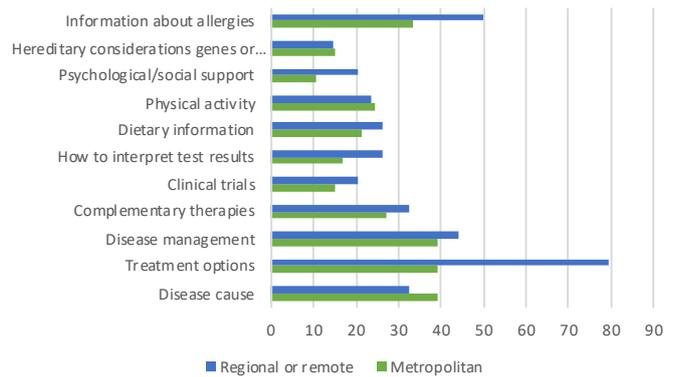


Figure 6.67: Information searched for by Location

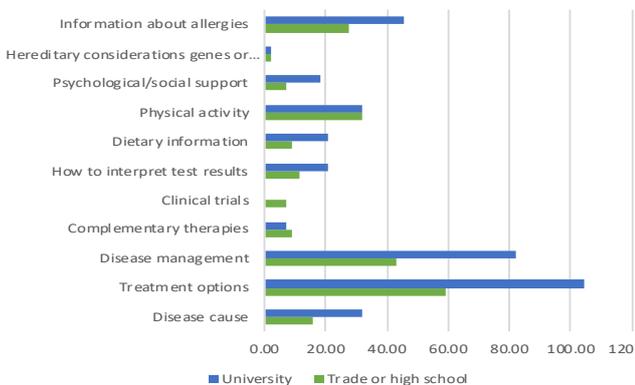


Figure 6.68: Information given by Education

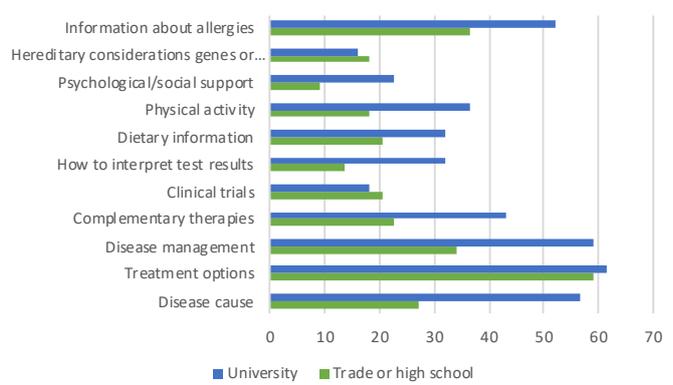


Figure 6.69: Information searched for by Education

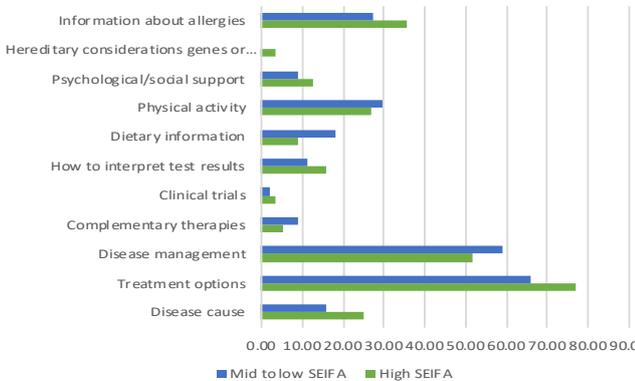


Figure 6.70: Information given by SEIFA

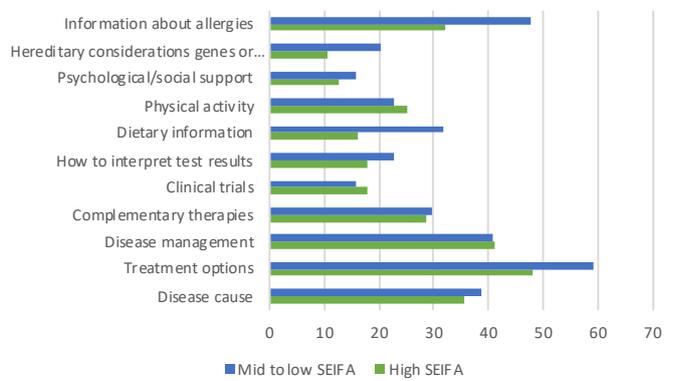


Figure 6.71: Information searched for by SEIFA

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials (83.00%), hereditary considerations genes or genomic biomarker information (83.00%), and psychological/social support (78.00%). Participants were given most

information either from healthcare professionals or independently for treatment options (87.00%). Disease cause was the topic that was most searched for independently following no information from health professionals (26.00%), followed by complementary therapies (n=25.00%) (Table 6.28, Figure 6.72).

Table 6.28: Information gaps

Information	Disease cause		Treatment options		Disease management		Complementary therapies		Clinical trials		How to interpret test results	
	n=100	%	n=100	%	n=100	%	n=100	%	n=100	%	n=100	%
Information given NOT searched	11	11.00	38	38.00	24	24.00	4	4.00	3	3.00	2	2.00
Information given AND searched	10	10.00	34	34.00	31	31.00	3	3.00	0	0.00	12	12.00
Information NOT given BUT searched	26	26.00	15	15.00	17	17.00	25	25.00	14	14.00	18	18.00
Information NOT given NOT searched	53	53.00	13	13.00	28	28.00	68	68.00	83	83.00	68	68.00

Information	Dietary information		Physical activity		Psychological/social support		Hereditary, genes or genomic biomarker		Information about allergies	
	n=100	%	n=100	%	n=100	%	n=100	%	n=100	%
Information given NOT searched	4	4.00	7	7.00	3	3.00	0	0.00	17	17.00
Information given AND searched	9	9.00	21	21.00	8	8.00	2	2.00	15	15.00
Information NOT given BUT searched	19	19.00	17	17.00	11	11.00	15	15.00	22	22.00
Information NOT given NOT searched	68	68.00	55	55.00	78	78.00	83	83.00	46	46.00

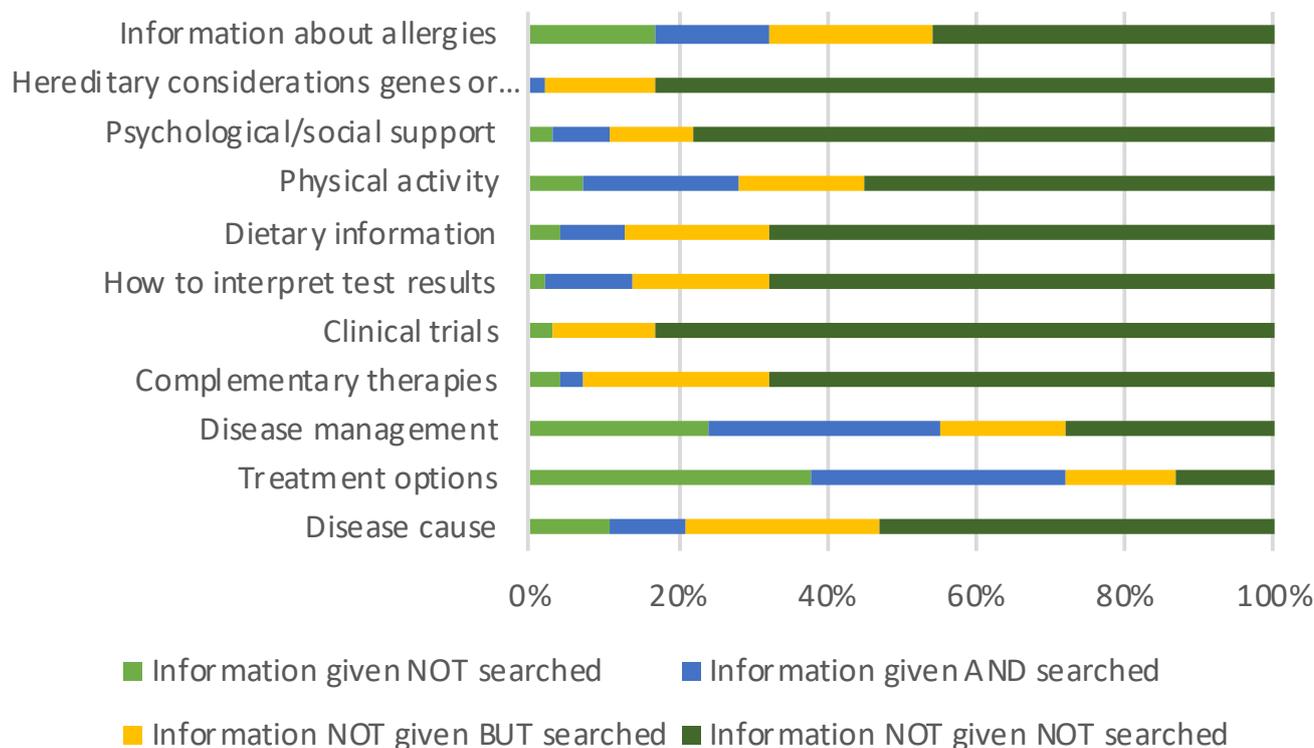


Figure 6.72: Proportion of information given by health care professionals and searched for independently.

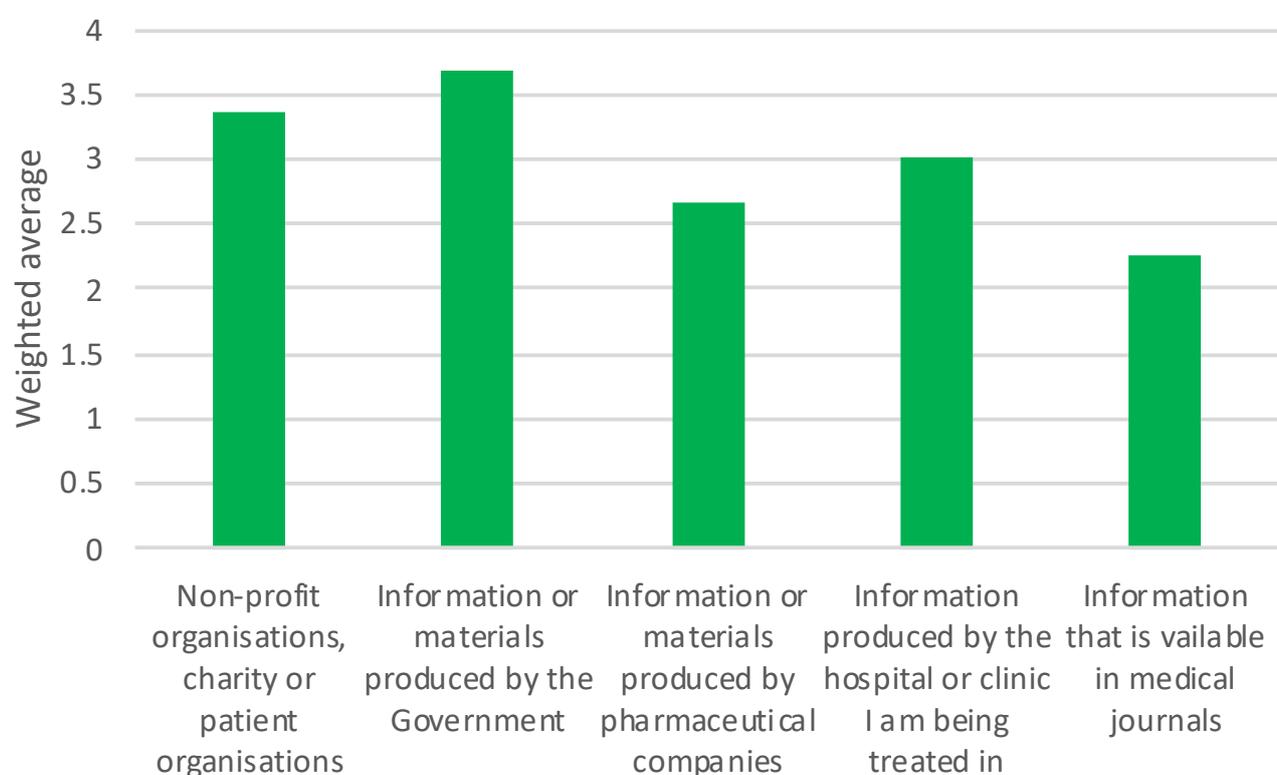
### Most trusted information sources

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 6.66. With a weighted ranking, the higher the score, the more trusted the source of information to the participant. Across all participants,

information from the government were most trusted, followed by information from non-profit or charities or patient organisations. Information from pharmaceutical companies and from medical journals were least trusted. (Table 6.28, Figure 6.73). The weighted averages were similar for all sub-groups (Figures 6.74 to 6.82).

**Table 6.29: Trusted information source**

Information source	Weighted average
Non-profit organisations, charity or patient organisations	3.36
Information or materials produced by the Government	3.69
Information or materials produced by pharmaceutical companies	2.68
Information produced by the hospital or clinic I am being treated in	3.02
Information that is available in medical journals	2.25



**Figure 6.73: Trusted information source**

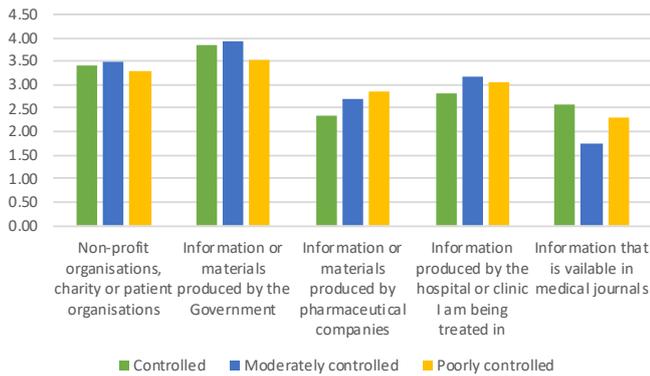


Figure 6.74: Trusted information source by Asthma control test

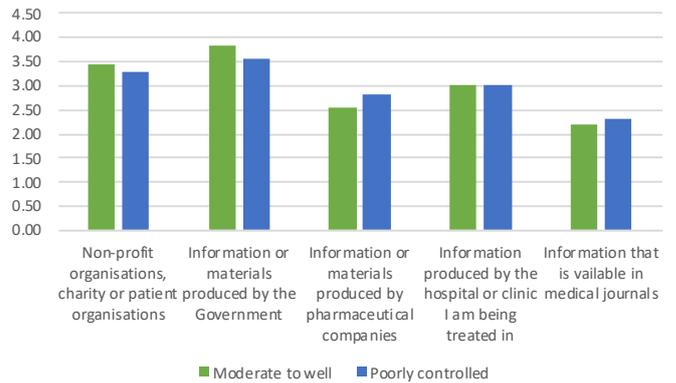


Figure 6.75: Trusted information source by Asthma control test

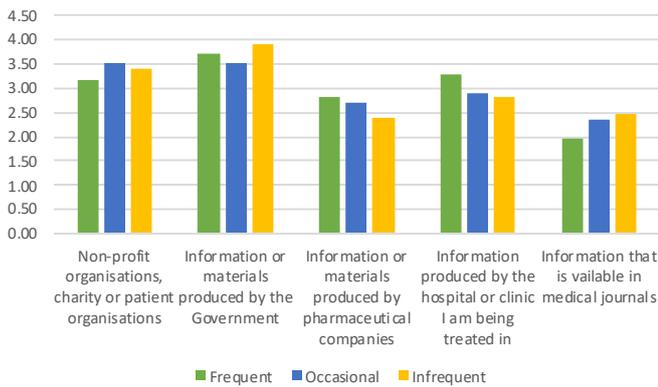


Figure 6.76: Trusted information source by Flare-ups

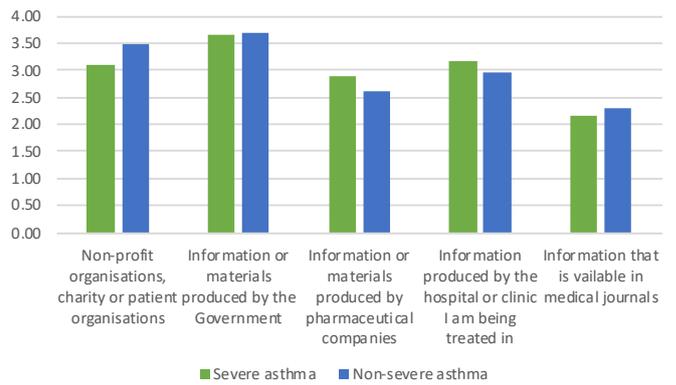


Figure 6.77: Trusted information source by Severity

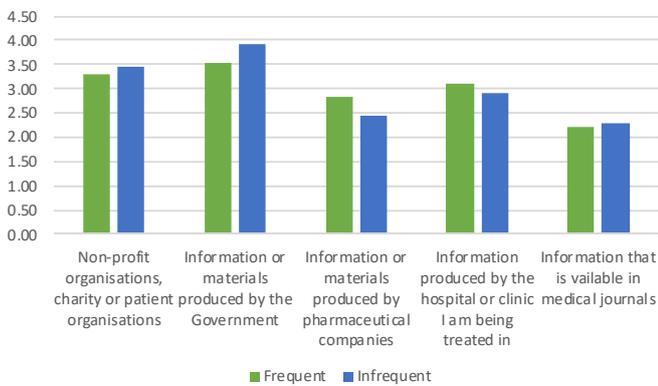


Figure 6.78: Trusted information source by Sleep disruption

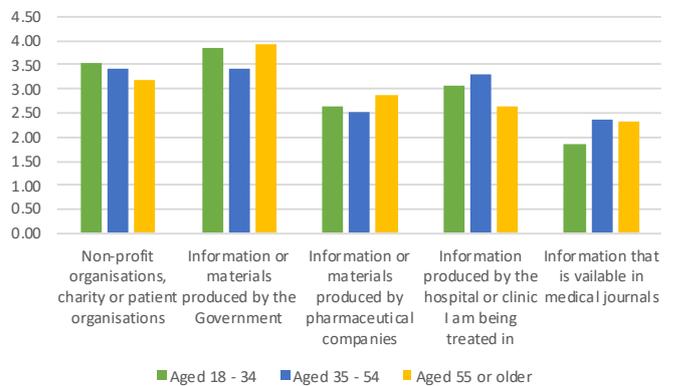


Figure 6.79: Trusted information source

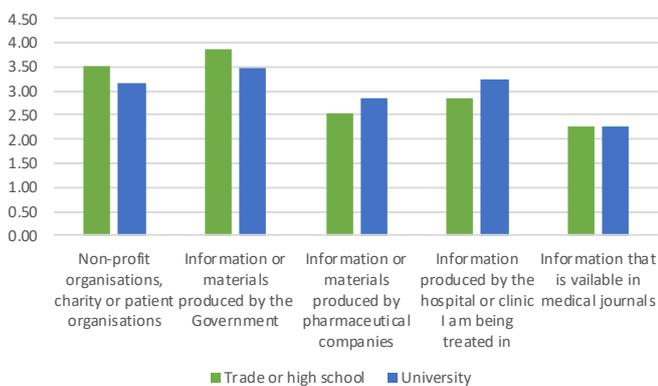


Figure 6.80: Trusted information source

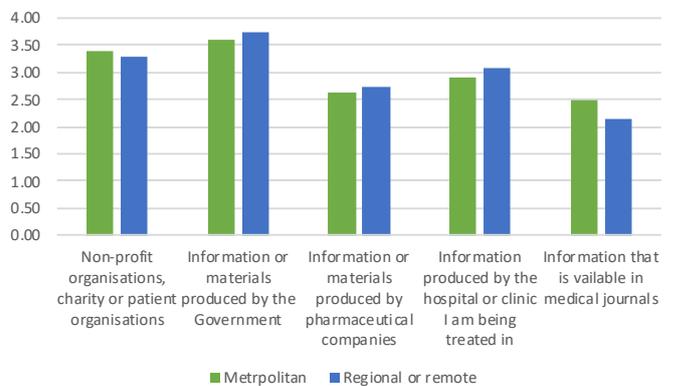


Figure 6.81: Trusted information source

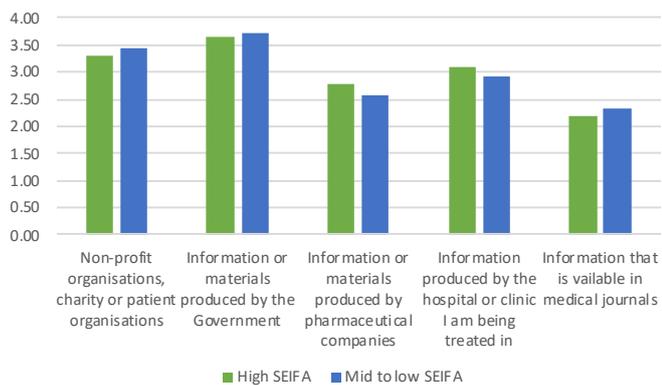


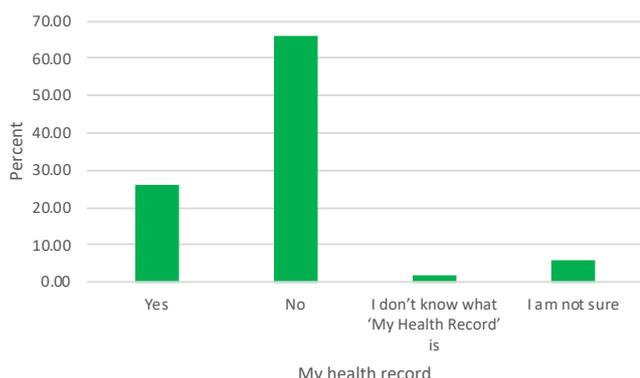
Figure 6.82: Trusted information source

**Accessed “My Health Record”**

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 26 (26.00%) participants that had accessed “My Health Record”, 66 (66.00%) had not, two participants did not know what it is (2.00%), and six (6.00%) were not sure. Of those that had accessed “My Health Record”, five participants (19.23%) found it good or very good, seven (26.92%) found it acceptable, and 14 (53.85%) found it poor or very poor.

**Table 6.30: My Health Record**

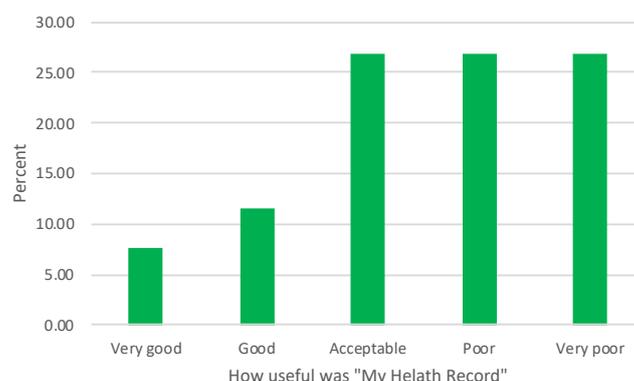
Accessed ‘My Health Record’	n=100	Percent
Yes	26	26.00
No	66	66.00
I don’t know what ‘My Health Record’ is	2	2.00
I am not sure	6	6.00



**Figure 6.83: My Health Record**

**Table 6.31: How useful was “My Health Record”**

How useful was My health record?	n=26	Percent
Very good	2	7.69
Good	3	11.54
Acceptable	7	26.92
Poor	7	26.92
Very poor	7	26.92



**Figure 6.84: How useful was “My Health Record”**

# Section 7 Care and support

## Section 7: Experience of care and support

### Care coordination

A Care Coordination questionnaire within the online questionnaire was completed by participants. 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 a better care outcome.

Overall, the participants in this PEEK study had a median score in the second highest quintile for **“Care coordination: Navigation”** (mean = 23.82, 5.43), and a median score in the second highest quintile for **“Care coordination: Care coordination global measure”** (median = 7.00, IQR = 4.00), and **“Care coordination: Quality of care global measure”** (median = 7.00, IQR = 3.00), indicating good navigation of the healthcare system, overall care coordination and overall quality of care. The mean scores for **“Care coordination: Communication”** (mean = 37.06, SD = 10.85), and **“Care coordination: Total score”** (mean = 60.88, SD = 13.79) were in the middle of the scale indicating moderate communication and overall experience of care coordination.

### Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question investigates what services patients consider to be support and care services. The most common description of care and support was support from family and friends (n=56, 56.00%). This was followed by receiving support from health professionals (general practitioner or specialist) (n=15, 15.00%), through charities (primarily Asthma Australia, n=10, 10.00%), and support from health professionals (nurses) (n=8, 8.00%). There were 9 participants (9.00%) who did not receive any care or support, and an additional 9 participants (9.00%) did not receive any additional support but did not feel as though they needed any.

### Experience of coordination of care

A Care Coordination questionnaire was completed by participants within 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 a better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

Overall, the participants in this PEEK study had a median score in the second highest quintile for “Care

coordination: Navigation” (mean = 23.82, 5.43), and a median score in the second highest quintile for “Care coordination: Care coordination global measure” (median = 7.00, IQR = 4.00), and “Care coordination: Quality of care global measure” (median = 7.00, IQR = 3.00), indicating good navigation of the healthcare system, overall care coordination and overall quality of care. The mean scores for “Care coordination: Communication” (mean = 37.06, SD = 10.85), and “Care coordination: Total score” (mean = 60.88, SD = 13.79) were in the middle of the scale indicating moderate communication and overall experience of care coordination.

**Table 7.1: Summary statistics “Care coordination” scale**

Care coordination scale	Mean	SD	Median	IQR	Possible range
Care coordination: communication*	37.06	10.85	37.00	14.25	13 to 65
Care coordination: navigation*	23.82	5.43	24.00	6.25	7 to 35
Care coordination: total score*	60.88	13.79	60.00	17.50	20 to 100
Care coordination: care coordination global measure	6.15	2.25	7.00	4.00	1 to 10
Care coordination: quality of care global measure	6.77	2.17	7.00	3.00	1 to 10

\*Normal distribution, use Mean and SD as central measure

### Care coordination by Asthma control test (three groups)

The **Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between participants that scored 20 or more - *Controlled asthma* (n=26, 26.00%) - between 16 and 19 - *Moderately controlled asthma* (n=22, 22.00%) - and those who scored 15 or less - *Poorly controlled asthma* (n=52, 52.00%).

Boxplots of each Care coordination scale by the **Asthma control test** are displayed in Figures 7.1-7.9, 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). When the assumption of equal variances was not met, a Welch one-way test was used with post

hoc pairwise t-tests with no assumption of equal variances (Tables 7.5 to 7.6).

A Welch one-way test indicated a statistically significant difference in the **“Care coordination: navigation”** scale between groups  $F(2, 57.66) = 4.04$ ,  $p=0.0227$  (Table 7.5). Post-hoc pairwise t-tests with no assumption of equal variances indicated that participants with *Controlled asthma* (mean = 25.58, SD = 4.31) scored significantly higher than participants with *Moderately controlled asthma* (mean = 22.32, SD = 3.60,  $p=0.0190$ ).

The mean score for the **“Care coordination: navigation”** scale was significantly higher for participants with *Controlled asthma* compared to participants with *Moderately controlled asthma*. These scores correspond to good navigation of the healthcare system for participants with *Controlled asthma* and moderate navigation for participants with *Moderately controlled asthma*.

Table 7.2: “Care coordination” by Asthma control test summary statistics

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	<i>Controlled asthma</i>	26	26.00	36.65	9.64	36.00	14.75
	<i>Moderately controlled asthma</i>	22	22.00	33.73	7.55	34.00	11.25
	<i>Poorly controlled asthma</i>	52	52.00	38.67	12.33	37.50	16.00
Care coordination: navigation	<i>Controlled asthma</i>	26	26.00	25.58	4.31	26.00	5.50
	<i>Moderately controlled asthma</i>	22	22.00	22.32	3.60	23.00	3.75
	<i>Poorly controlled asthma</i>	52	52.00	23.58	6.34	23.50	8.25
Care coordination: communication	<i>Controlled asthma</i>	26	26.00	62.23	11.75	66.00	18.50
	<i>Moderately controlled asthma</i>	22	22.00	56.05	8.98	58.00	16.75
	<i>Poorly controlled asthma</i>	52	52.00	62.25	15.98	60.00	17.50
Care coordination: care coordination global measure	<i>Controlled asthma</i>	26	26.00	6.35	2.13	7.00	3.00
	<i>Moderately controlled asthma</i>	22	22.00	5.64	1.73	6.00	3.00
	<i>Poorly controlled asthma</i>	52	52.00	6.27	2.50	7.00	4.00
Care coordination: quality of care global measure	<i>Controlled asthma</i>	26	26.00	6.92	1.70	7.00	2.75
	<i>Moderately controlled asthma</i>	22	22.00	6.18	2.02	7.00	3.00
	<i>Poorly controlled asthma</i>	52	52.00	6.94	2.42	8.00	2.50

Table 7.3: “Care coordination” by Asthma control test ANOVA table

Care coordination scale		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	384.00	2	192.00	1.65	0.1970
	Within groups	11268.00	97	116.20		
	Total	11652.00	99			
Care coordination: total score	Between groups	659.00	2	329.6	1.76	0.1780
	Within groups	18169.00	97	187.3		
	Total	18828.00	99			

Table 7.4: “Care coordination” by Asthma control test Kruskal-Wallis test

Care coordination scale	$\chi^2$	df	p
Care coordination: care coordination global measure	2.81	2	0.2456
Care coordination: quality of care global measure	3.03	2	0.2193

Table 7.5: “Care coordination” by Asthma control test Welch one-way test

Care coordination scale	F	dF1	dF2	p
Care coordination: navigation	4.04	2.00	57.66	0.0227*

\* Statistically significant at  $p < 0.05$

Table 7.6: “Care coordination” by Asthma control test post-hoc pairwise t-tests with no assumption of equal variances

Care coordination scale	F	dF1	dF2	p
Care coordination: navigation	4.04	2.00	57.66	0.0227*

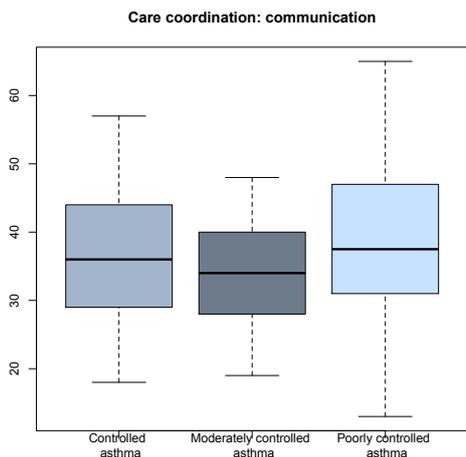


Figure 7.1: “Care coordination: communication” by Asthma control test

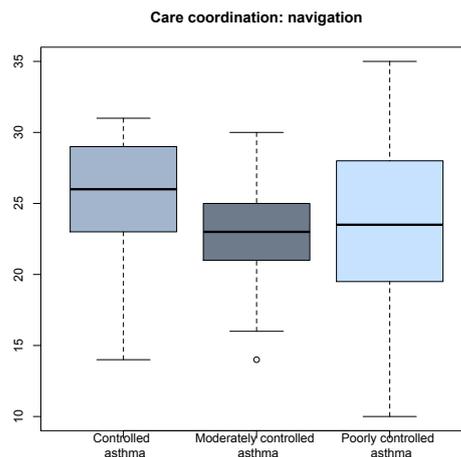


Figure 7.2: “Care coordination: navigation” by Asthma control test

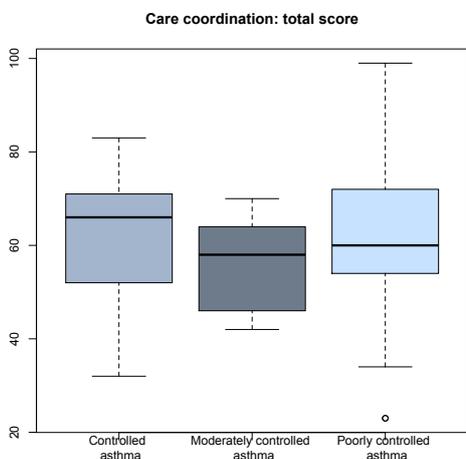


Figure 7.3: “Care coordination: total score” by Asthma control test

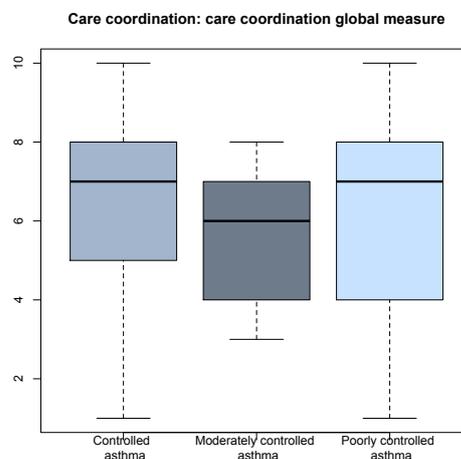


Figure 7.4: “Care coordination: care coordination global measure” by Asthma control test

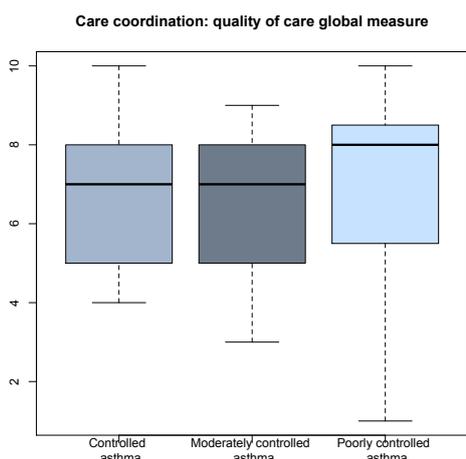


Figure 7.5: “Care coordination: quality of care global measure” by Asthma control test

### Care coordination by Asthma control test (two groups)

The **Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between those who scored between 16 and 25, *Moderate to well controlled asthma* (n=48, 48.00%); and those who score 15 or less, *Poorly controlled asthma* (n=52, 52.00%).

Boxplots of each Care coordination scale by the **Asthma control test** are displayed in Figures 7.6 to

71.0, summary statistics are displayed in Table 7.7. 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 7.7). No significant differences were observed between participants by the **Asthma control test** for any of the “Care coordination scales”.

No significant differences were observed between participants by the **Asthma control test** for any of the “Care coordination scales”.

**Table 7.7: “Care coordination” by Asthma control test Wilcoxon rank sum test with continuity correction**

Care coordination scale	Group	Count	Percent	Median	IQR	W	p
Care coordination: communication	Moderate to well controlled asthma	48	48.00	35.50	12.50	1024.50	0.1237
	Poorly controlled asthma	52	52.00	37.50	16.00		
Care coordination: navigation	Moderate to well controlled asthma	48	48.00	24.00	4.25	1302.50	0.7088
	Poorly controlled asthma	52	52.00	23.50	8.25		
Care coordination: communication	Moderate to well controlled asthma	48	48.00	59.50	16.75	1104.00	0.3219
	Poorly controlled asthma	52	52.00	60.00	17.50		
Care coordination: care coordination global measure	Moderate to well controlled asthma	48	48.00	6.50	2.00	1114.00	0.3513
	Poorly controlled asthma	52	52.00	7.00	4.00		
Care coordination: quality of care global measure	Moderate to well controlled asthma	48	48.00	7.00	3.00	1051.50	0.1700
	Poorly controlled asthma	52	52.00	8.00	2.50		

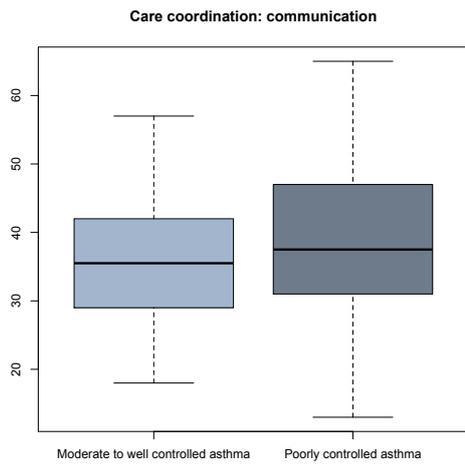


Figure 7.6: “Care coordination: communication” by Asthma control test

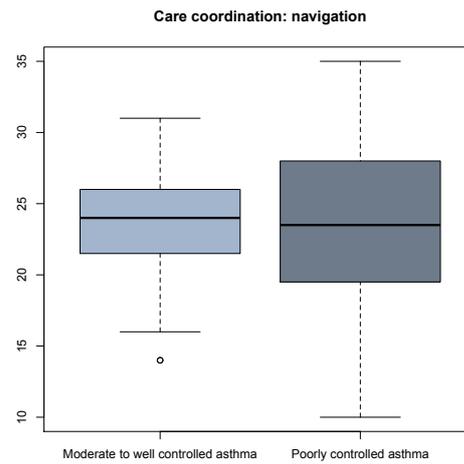


Figure 7.7: “Care coordination: navigation” by Asthma control test

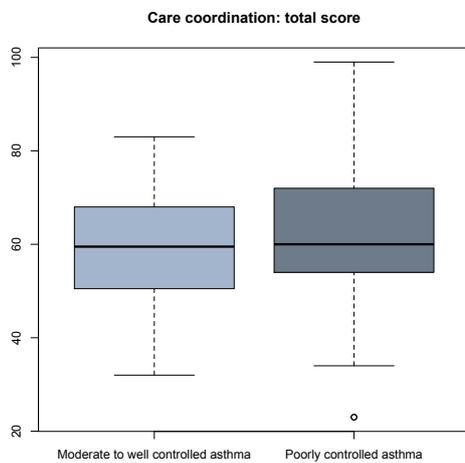


Figure 7.8: “Care coordination: total score” by Asthma control test

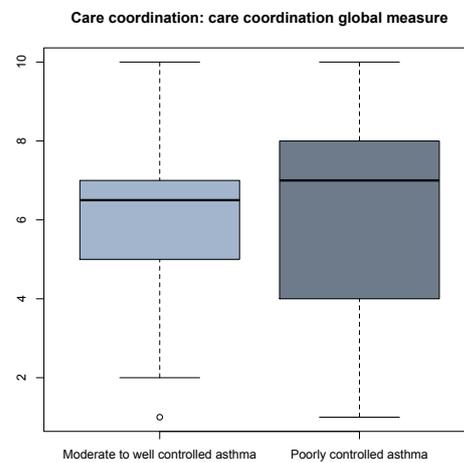


Figure 7.9: “Care coordination: care coordination global measure” by Asthma control test

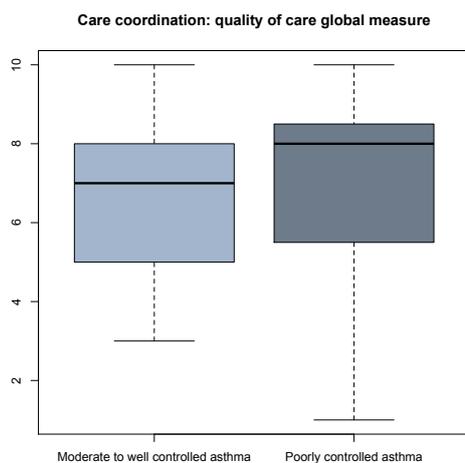


Figure 7.10: “Care coordination: quality of care global measure” by Asthma control test

### Care coordination by Flare-ups

Comparisons were made by **Flare-ups**, between participants that reported having a flare-up or asthma attacks once a month or more frequently, *Frequent flare-ups* (n=36, 36.00%), those that had a flare-up once a month to once every three months, *Occasional flare-ups* (n=41, 41.00%), and those that had a flare-up once or twice a year, *Infrequent flare-ups* (n=23, 23.00%).

Boxplots of each Care coordination scale by the **Flare-ups** are displayed in Figures 7.11-7.15, summary statistics are displayed in Table 7.8.

The one-way ANOVA test assumptions of residuals were not met, a Kruskal-Wallis test was used (Table 7.9). No significant differences were observed between participants by **Flare-ups** for any of the “**Care coordination scales**”.

No significant differences were observed between participants by **Flare-ups** for any of the “**Care coordination scales**”.

**Table 7.8: “Care coordination” by Flare-ups statistics**

Care coordination	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	Frequent flare-ups	36	36.00	37.11	12.27	37.00	18.25
	Occasional flare-ups	41	41.00	37.34	11.51	37.00	13.00
	Infrequent flare-ups	23	23.00	36.48	6.96	36.00	9.50
Care coordination: navigation	Frequent flare-ups	36	36.00	22.56	5.00	22.50	5.25
	Occasional flare-ups	41	41.00	24.10	5.88	24.00	7.00
	Infrequent flare-ups	23	23.00	25.30	5.00	26.00	6.00
Care coordination: communication	Frequent flare-ups	36	36.00	59.67	15.18	59.00	21.25
	Occasional flare-ups	41	41.00	61.44	14.89	59.00	19.00
	Infrequent flare-ups	23	23.00	61.78	9.08	63.00	10.50
Care coordination: care coordination global measure	Frequent flare-ups	36	36.00	5.69	2.33	6.50	4.00
	Occasional flare-ups	41	41.00	6.29	2.45	7.00	4.00
	Infrequent flare-ups	23	23.00	6.61	1.64	7.00	1.50
Care coordination: quality of care global measure	Frequent flare-ups	36	36.00	6.31	2.40	7.00	3.00
	Occasional flare-ups	41	41.00	7.07	2.07	8.00	4.00
	Infrequent flare-ups	23	23.00	6.96	1.92	7.00	2.50

**Table 7.9: “Care coordination” by Flare-ups ANOVA table**

Care coordination scale		Sum of squares	dF	Mean Square	F	p
Care coordination: communication	Between groups	11.00	2	5.56	0.05	0.9550
	Within groups	11641.00	97	120.01		
	Total	11652.00	99			
Care coordination: navigation	Between groups	111.40	2	55.70	1.92	0.1510
	Within groups	2807.40	97	28.94		
	Total	2918.80	99			
Care coordination: total score	Between groups	85.00	2	42.27	0.22	0.8040
	Within groups	18744.00	97	193.24		
	Total	18829.00	99			

**Table 7.10: “Care coordination” by Flare-ups Kruskal-Wallis test**

Care coordination scale	X <sup>2</sup>	df	p
Care coordination: care coordination global measure	1.54	2	0.4638
Care coordination: quality of care global measure	1.86	2	0.3953

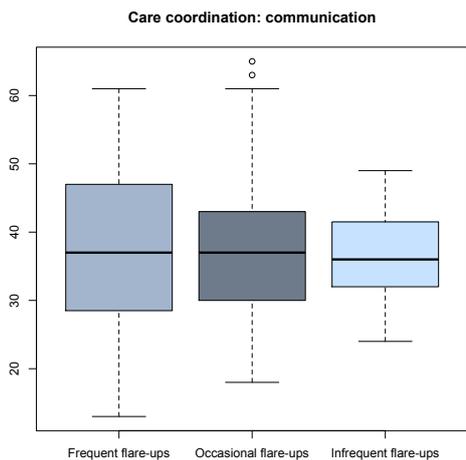


Figure 7.11: “Care coordination: communication” by Flare-ups

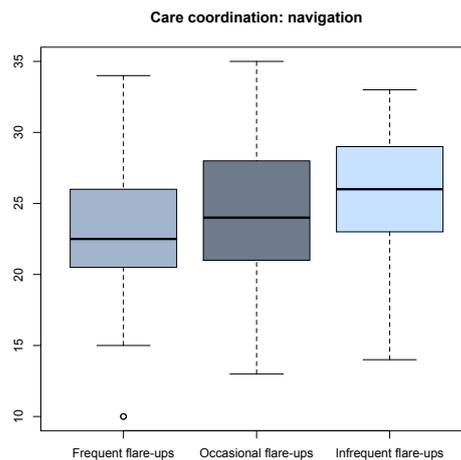


Figure 7.12: “Care coordination: navigation” by Flare-ups

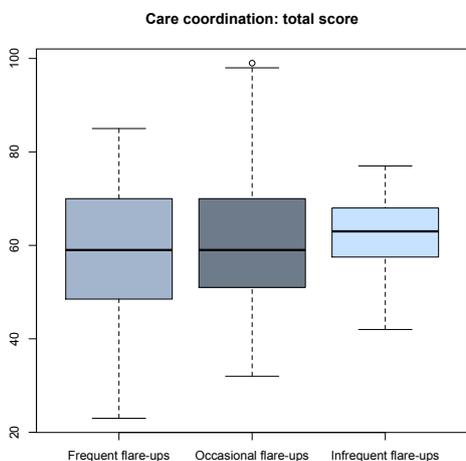


Figure 7.13: “Care coordination: total score” by Flare-ups

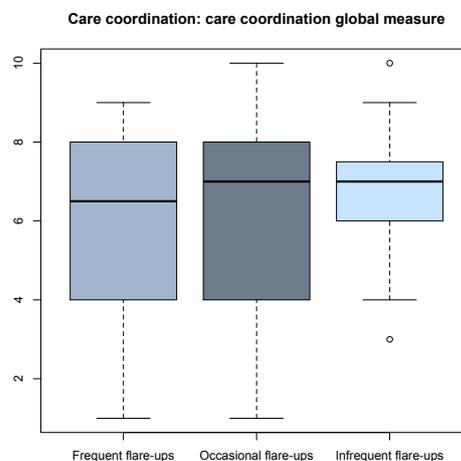


Figure 7.14: “Care coordination: care coordination global measure” by Flare-ups

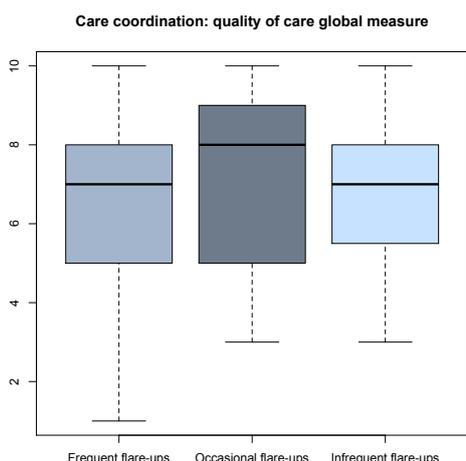


Figure 7.15: “Care coordination: quality of care global measure” by Flare-ups

### Care coordination by Severity

Comparisons were made by **Severity**, between participants that reported having *Severe asthma* (n=29, 29.00%), and those that had *Non-severe asthma* (n=79, 79.00%). Participants in the Severe asthma sub-group included those who confirmed that they had been diagnosed with severe asthma in the semi-structured interview (this was then cross-checked with the treatments they are taking for verification), and those that were taking regular treatments beyond preventer and reliever medication including monoclonal antibodies, daily/very frequent oral corticosteroid use, long acting muscarinic antagonists, leukotriene receptor antagonists, or a high dose of regular treatment (such as high dose Seretide).

When assumptions for normality and variance were met, a two-sample t-test was used (Table 7.11). When

assumptions were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

A two-sample t-test indicated that the mean scores for participants in the *Severe asthma* sub-group (mean = 40.52, SD = 11.36) were significantly higher than those in the *Non-severe asthma* sub-group (mean = 35.65, SD = 10.38) [ $t(98) = 2.07, p=0.0411$ ].

The mean score for the “**Care coordination: communication**” scale was significantly higher for participants with *Severe asthma* compared to participants with *Non-severe asthma*. However, these scores correspond to moderate communication with healthcare professionals for both groups.

**Table 7.11: “Care coordination” by Severity two-sample t-test**

Care coordination	Group	Count	Percent	Mean	SD	t	df	p
<b>Care coordination: communication</b>	Severe asthma	29	29.00	40.52	11.36	2.07	98	0.0411*
	Non-severe asthma	71	71.00	35.65	10.38			
<b>Care coordination: navigation</b>	Severe asthma	29	29.00	22.76	5.99	-1.25	98	0.2132
	Non-severe asthma	71	71.00	24.25	5.17			
<b>Care coordination: total score</b>	Severe asthma	29	29.00	63.28	15.58	1.11	98	0.2690
	Non-severe asthma	71	71.00	59.90	12.98			

**Table 7.12: “Care coordination” by Severity Wilcoxon rank sum test with continuity correction**

Care coordination	Group	Count	Percent	Median	IQR	W	p
<b>Care coordination: care coordination global measure</b>	Severe asthma	29	29.00	7.00	4.00	1148.50	0.3623
	Non-severe asthma	71	71.00	7.00	3.50		
<b>Care coordination: quality of care global measure</b>	Severe asthma	29	29.00	7.00	3.00	1158.50	0.3219
	Non-severe asthma	71	71.00	7.00	3.00		

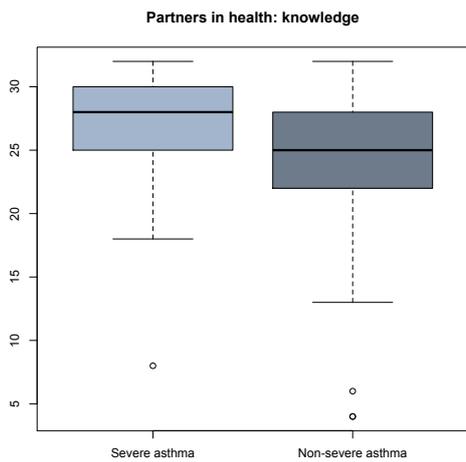


Figure 7.16: “Care coordination: communication” by Severity

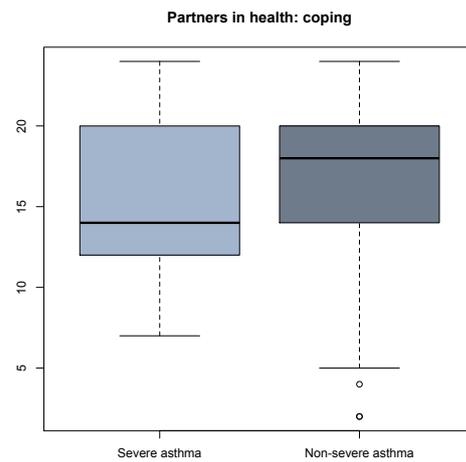


Figure 7.17: “Care coordination: navigation” by Severity

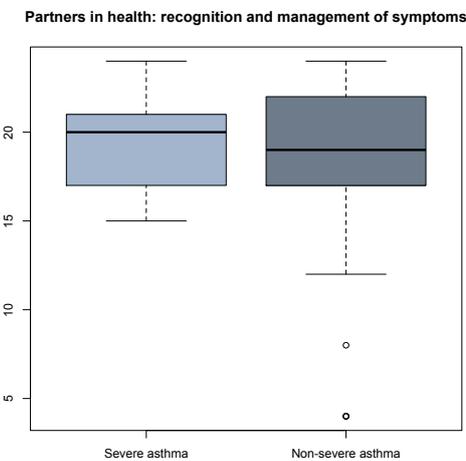


Figure 7.18: “Care coordination: total score” by Severity

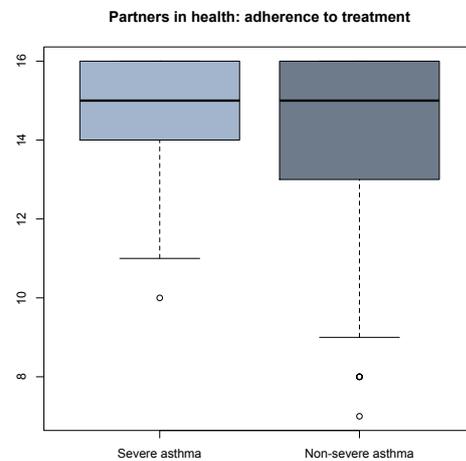


Figure 7.19: “Care coordination: care coordination global measure” by Severity

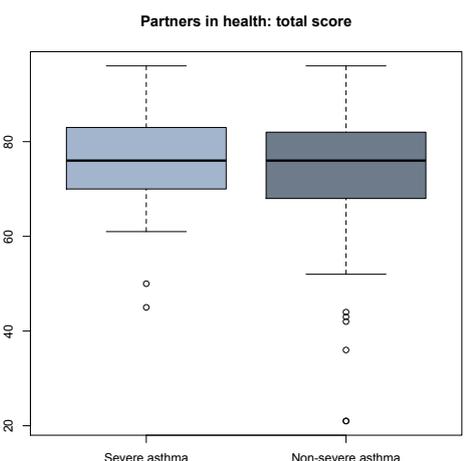


Figure 7.20: “Care coordination: quality of care global measure” by Severity

### Care coordination by Sleep disruption

Comparisons were made by the frequency of **Sleep disruption**, those who noted in the Asthma control test the frequency that they had sleep disruptions due to asthma. Those that had sleep disruptions once a week or more frequently - *Frequent sleep disruption* (n=59, 59.00%) - were compared to those who responded that they had sleep disruptions once a month or not at all - *Infrequent sleep disruption* (n=41, 41.00%).

Boxplots of each Care coordination scale by the **Sleep disruption** are displayed in Figures 7.21 to 7.25, summary statistics are displayed in Tables 7.13 to 7.14.

When assumptions for normality and variance were met, a two-sample t-test was used (Table 7.13). When assumptions were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.14). No significant differences were observed between participants by **Sleep disruption** for any of the “**Care coordination scales**”.

No significant differences were observed between participants by **Sleep disruption** for any of the “**Care coordination scales**”.

Table 7.13: “Care coordination” by Sleep disruption two-sample t-test

Care coordination scale	Group	Count	Percent	Mean	SD	t	dF	p
<b>Care coordination: communication</b>	<i>Frequent sleep disruption</i>	59	59.00	38.00	11.72	1.04	98	0.3010
	<i>Infrequent sleep disruption</i>	41	41.00	35.71	9.43			
<b>Care coordination: navigation</b>	<i>Frequent sleep disruption</i>	59	59.00	23.41	5.91	-0.91	98	0.3639
	<i>Infrequent sleep disruption</i>	41	41.00	24.41	4.65			

Table 7.14: “Care coordination” by Sleep disruption Wilcoxon rank sum test with continuity correction

Care coordination scale	Group	Count	Percent	Median	IQR	W	p
<b>Care coordination: total score</b>	<i>Frequent sleep disruption</i>	59	59.00	60.00	18.50	1259.00	0.7311
	<i>Infrequent sleep disruption</i>	41	41.00	61.00	17.00		
<b>Care coordination: care coordination global measure</b>	<i>Frequent sleep disruption</i>	59	59.00	7.00	4.00	1279.50	0.6221
	<i>Infrequent sleep disruption</i>	41	41.00	6.00	3.00		
<b>Care coordination: quality of care global measure</b>	<i>Frequent sleep disruption</i>	59	59.00	8.00	2.00	1370.00	0.2551
	<i>Infrequent sleep disruption</i>	41	41.00	7.00	3.00		

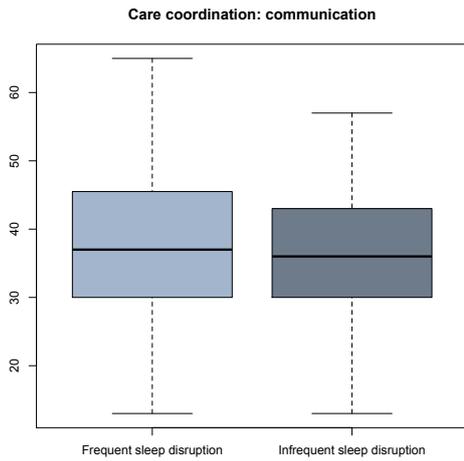


Figure 7.21: “Care coordination: communication” by Sleep disruption

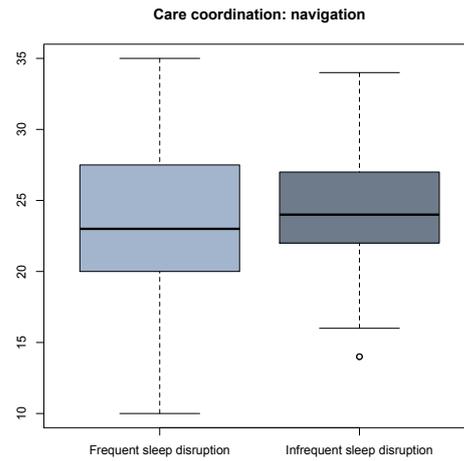


Figure 7.22: “Care coordination: navigation” by Sleep disruption

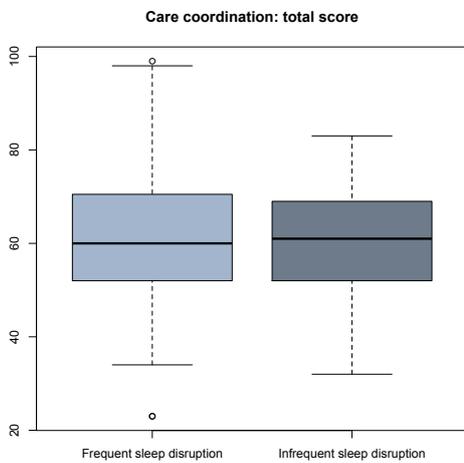


Figure 7.23: “Care coordination: total score” by Sleep disruption

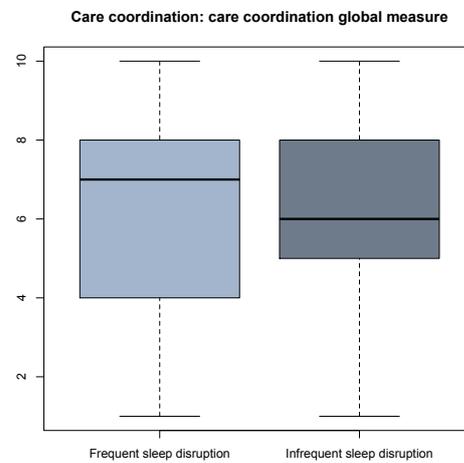


Figure 7.24: “Care coordination: care coordination global measure” by Sleep disruption

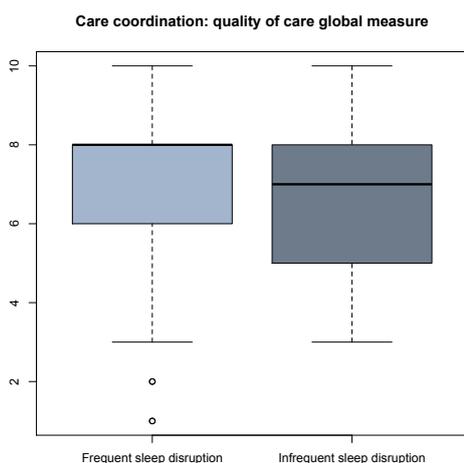


Figure 7.25: “Care coordination: quality of care global measure” by Sleep disruption

### Care coordination by Age

Comparisons were made by the **Age** of the participants, those that were *Aged 18 to 34* (n=23, 23.00%), *Aged 35 to 54* (n=42, 42.00%) and participants *Aged 55 or older* (n=35, 35.00%).

Boxplots of each Care coordination scale by **Age** are displayed in Figures 7.26-7.30, summary statistics are displayed in Table 7.15.

A one-way ANOVA test was used when the assumptions for response variable residuals were

normally distributed and variances of populations were equal (Table 7.16). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.17). No significant differences were observed between participants by **Age** for any of the “**Care coordination scales**”.

No significant differences were observed between participants by **Age** for any of the “**Care coordination scales**”.

**Table 7.15: “Partners in health” by Age summary statistics**

Care coordination scale	Group	Count	Percent	Mean	SD	Median	IQR
Care coordination: communication	<i>Aged 18 to 34</i>	23	23.00	34.91	11.32	37.00	11.50
	<i>Aged 35 to 44</i>	42	42.00	37.33	11.63	36.00	15.75
	<i>Aged 55 or older</i>	35	35.00	38.14	9.60	40.00	12.50
Care coordination: navigation	<i>Aged 18 to 34</i>	23	23.00	23.04	5.45	23.00	6.50
	<i>Aged 35 to 44</i>	42	42.00	23.64	4.83	24.00	6.00
	<i>Aged 55 or older</i>	35	35.00	24.54	6.13	25.00	7.50
Care coordination: total score	<i>Aged 18 to 34</i>	23	23.00	57.96	13.46	60.00	15.50
	<i>Aged 35 to 44</i>	42	42.00	60.98	13.91	59.00	20.50
	<i>Aged 55 or older</i>	35	35.00	62.69	13.93	64.00	14.00
Care coordination: care coordination global measure	<i>Aged 18 to 34</i>	23	23.00	6.13	2.46	7.00	3.00
	<i>Aged 35 to 44</i>	42	42.00	5.76	2.05	6.00	3.00
	<i>Aged 55 or older</i>	35	35.00	6.63	2.33	7.00	2.50
Care coordination: quality of care global measure	<i>Aged 18 to 34</i>	23	23.00	6.57	2.56	7.00	3.50
	<i>Aged 35 to 44</i>	42	42.00	6.60	2.08	7.00	3.00
	<i>Aged 55 or older</i>	35	35.00	7.11	2.01	8.00	1.00

**Table 7.16: “Partners in health” by Age ANOVA table**

Care coordination scale		Sum of squares	df	Mean Square	F	p
Care coordination: communication	Between groups	150.00	2	75.10	0.63	0.5330
	Within groups	11501.00	97	118.60		
	Total	11651.00	99			
Care coordination: navigation	Between groups	33.50	97	16.740	0.56	0.5720
	Within groups	2885.30	99	29.75		
	Total	2918.80	97			
Care coordination: total score	Between groups	311.00	99	155.50	0.81	0.4460
	Within groups	18517.00	97	190.90		
	Total	18828.00	99			

**Table 7.17: “Partners in health” by Age Kruskal-Wallis test**

Care coordination scale	$\chi^2$	df	p
Care coordination: care coordination global measure	4.38	2	0.1117
Care coordination: quality of care global measure	1.69	2	0.4305

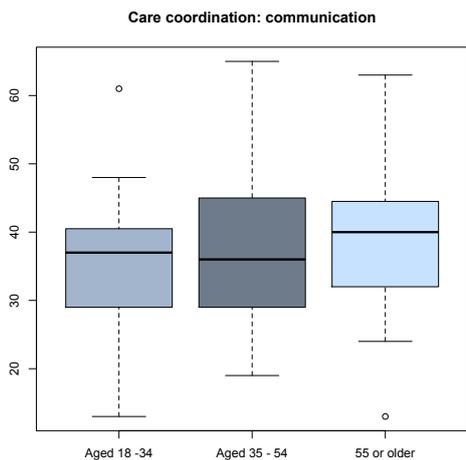


Figure 7.26: “Care coordination: communication” by Age

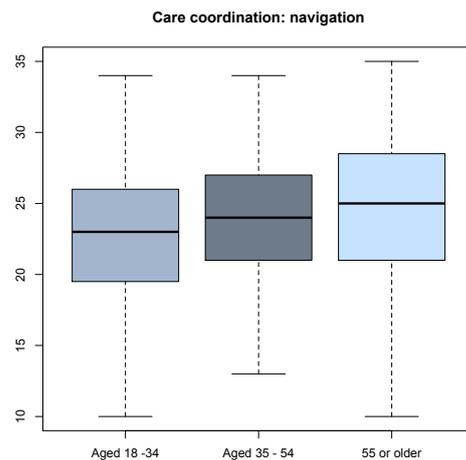


Figure 7.27: “Care coordination: navigation” by Age

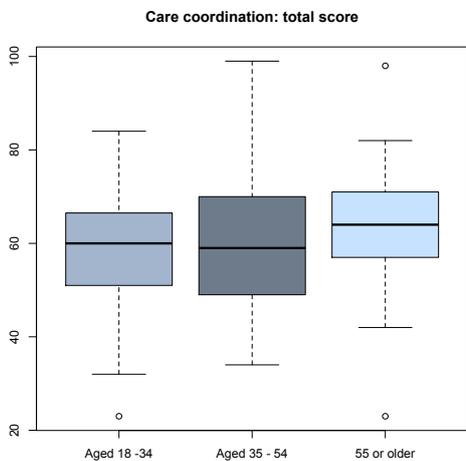


Figure 7.28: “Care coordination: total score” by Age

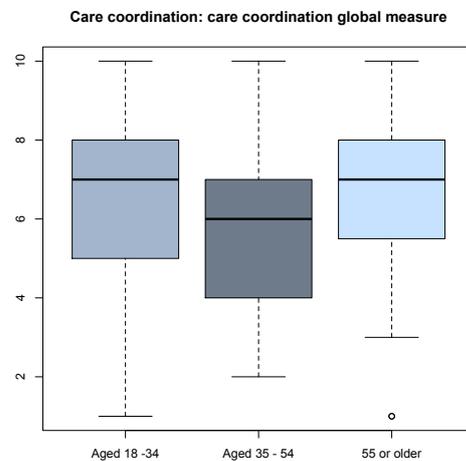


Figure 7.29: “Care coordination: care coordination global measure” by Age

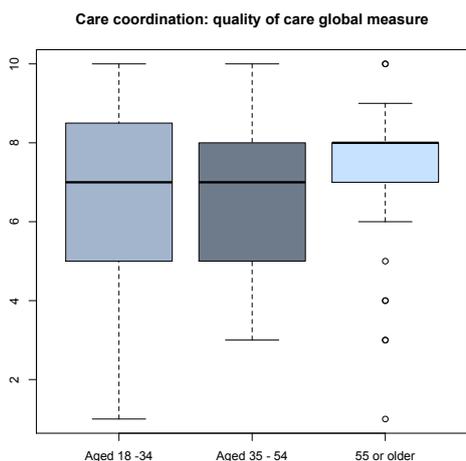


Figure 7.30: “Care coordination: quality of care global measure” by Age

### Care coordination 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 major city, *Metropolitan* (n=66, 66.00%), were compared to those living in *Regional or remote* areas (n=34, 34.00%).

Boxplots of each Care coordination scale by **Location** are displayed in Figures 7.31-7.35, summary statistics are displayed in Tables 7.18 – 7.19. When assumptions

for normality and variance were met, a two-sample t-test was used (Table 7.18). When assumptions were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.19). No significant differences were observed between participants by **Location** for any of the “**Care coordination**” scales.

No significant differences were observed between participants by **Location** for any of the “**Care coordination**” scales.

**Table 7.18: “Care coordination” by Location two sample t-test**

Care coordination scale	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: communication	<i>Metropolitan</i>	66	66.00	38.00	11.72	-1.27	98	0.2078
	<i>Regional or remote</i>	34	34.00	35.71	9.43			
Care coordination: navigation	<i>Metropolitan</i>	66	66.00	23.41	5.91	1.48	98	0.1417
	<i>Regional or remote</i>	34	34.00	24.41	4.65			
Care coordination: total score	<i>Metropolitan</i>	66	66.00	23.41	5.91	-0.41	98	0.6807
	<i>Regional or remote</i>	34	34.00	24.41	4.65			

**Table 7.19: “Care coordination” by Location Wilcoxon rank sum test**

Care coordination scale	Group	Count	Percent	Median	IQR	W	p
Care coordination: care coordination global measure	<i>Metropolitan</i>	66	66.00	7.00	3.00	1159.50	0.7853
	<i>Regional or remote</i>	34	34.00	6.50	4.00		
Care coordination: quality of care global measure	<i>Metropolitan</i>	66	66.00	7.00	3.00	1106.00	0.9089
	<i>Regional or remote</i>	34	34.00	7.00	2.00		

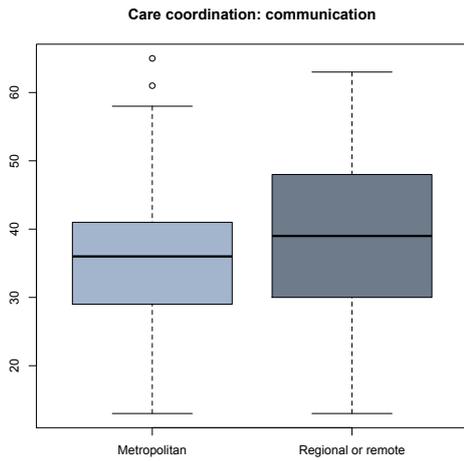


Figure 7.31: “Care coordination: communication” by Location

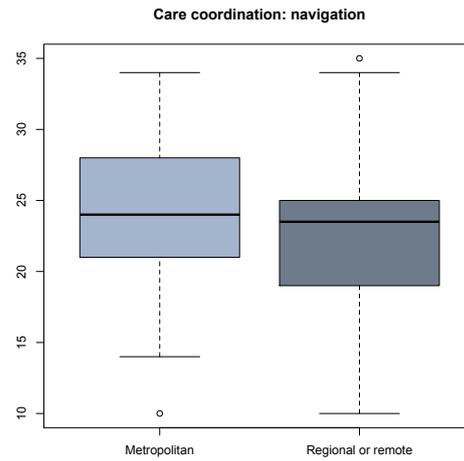


Figure 7.32: “Care coordination: navigation” by Location

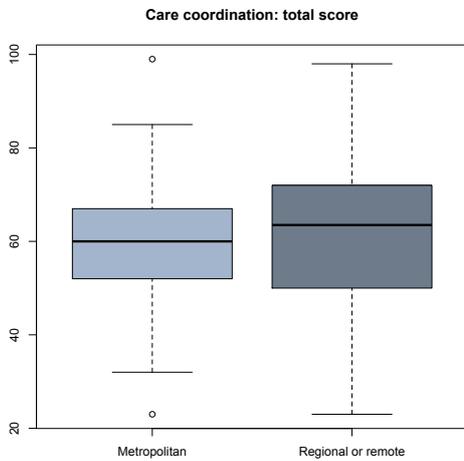


Figure 7.33: “Care coordination: total score” by Location

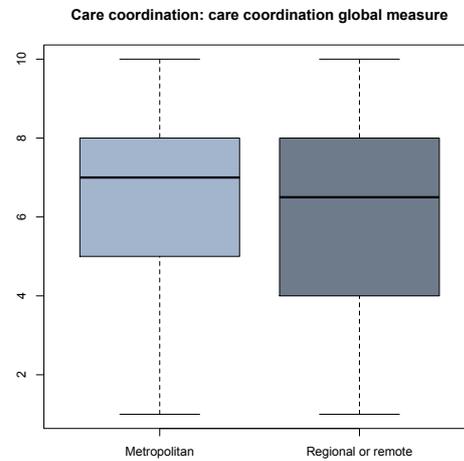


Figure 7.34: “Care coordination: care coordination global measure” by Location

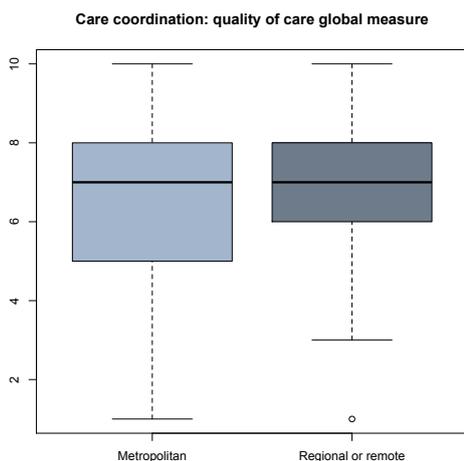


Figure 7.35: “Care coordination: quality of care global measure” by Location

### Care coordination by Education

Comparisons were made by **Education** status, between those with a university qualification, “University” (n=56, 56.00%), and those with trade or high school qualifications, “trade or high school” (N=44, 44.00%).

Boxplots of each Care coordination scale by **Education** are displayed in Figures 7.36-7.40, summary statistics are displayed in Tables 7.20 – 7.21. When assumptions for normality and variance were met, a two-sample t-test was used (Table 7.20). When assumptions were

not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.21). No significant differences were observed between participants by **Location** for any of the “Care coordination” scales.

No significant differences were observed between participants by **Location** for any of the “Care coordination” scales.

**Table 7.20: “Care coordination” by Education two sample t-test**

Care coordination scale	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: communication	Trade or high school	44	44.00	36.30	12.22	-0.62	98	0.5349
	University	56	56.00	37.66	9.71			
Care coordination: navigation	Trade or high school	44	44.00	22.89	5.78	-1.53	98	0.1281
	University	56	56.00	24.55	5.07			

**Table 7.21: “Care coordination” by Education Wilcoxon rank sum test**

	Group	Count	Percent	Median	IQR	W	p
Care coordination: total score	Trade or high school	44	44.00	60.00	19.50	1156.50	0.6023
	University	56	56.00	60.00	16.50		
Care coordination: care coordination global measure	Trade or high school	44	44.00	6.00	4.00	1001.50	0.1060
	University	56	56.00	7.00	3.00		
Care coordination: quality of care global measure	Trade or high school	44	44.00	7.00	3.00	1183.50	0.7352
	University	56	56.00	7.00	2.00		

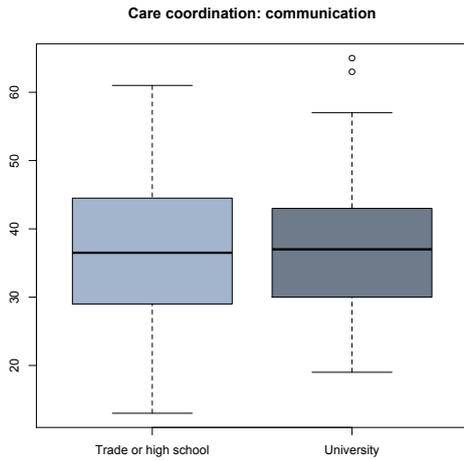


Figure 7.36: “Care coordination: communication” by Education

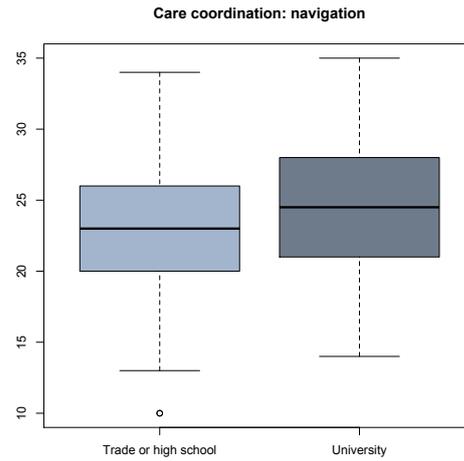


Figure 7.37: “Care coordination: navigation” by Education

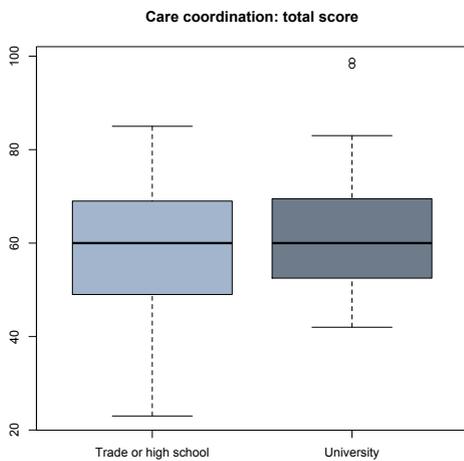


Figure 7.38: “Care coordination: total score” by Education

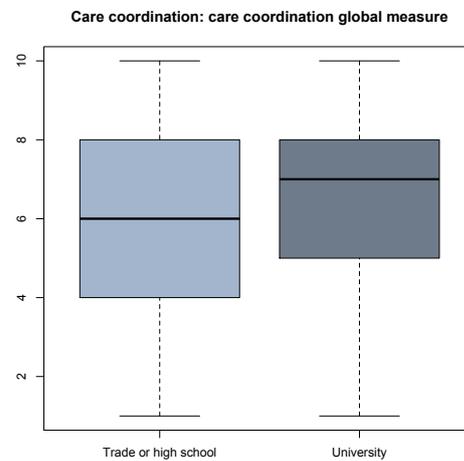


Figure 7.39: “Care coordination: care coordination global measure” by Education

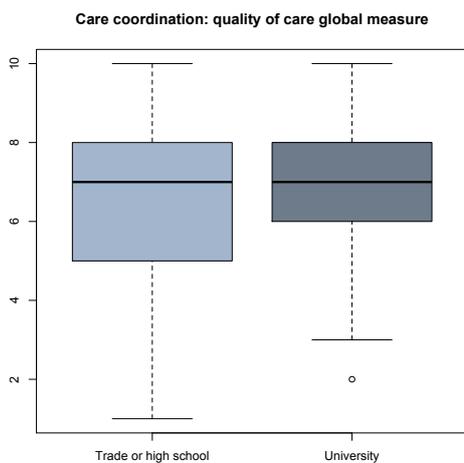


Figure 7.40: “Care coordination: quality of care global measure” by Education

### Care coordination 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=56 56.00%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=44, 44.00%).

Boxplots of each Care coordination scale by SEIFA are displayed in Figures 7.41 - 7.45, summary statistics are displayed in Tables 7.22 – 7.23. When assumptions for normality and variance were met, a two-sample t-test was used (Table 7.22). When assumptions were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.23).

A two sample t-test indicated that the mean score for the “Care coordination: navigation” [t(98) = 2.12,

p=0.0368] was significantly higher for those who lived in an area with a *High SEIFA* (mean = 24.82, SD =4.75) compared to those who lived in an area with a *Mid to low SEIFA* (mean = 22.55, SD = 6.00).

The mean score for the “Care coordination: navigation” scale was significantly higher for participants who lived in an area with a *High SEIFA* compared to participants who lived in an area with a *Mid to low SEIFA*. These scores correspond to good navigation of the healthcare system for participants who lived in an area with a *High SEIFA* and moderate navigation for participants who lived in an area with a *Mid to low SEIFA*.

**Table 7.22: “Care coordination” by SEIFA two sample t-test**

Care coordination	Group	Count	Percent	Mean	SD	t	dF	p
Care coordination: communication	<i>High SEIFA</i>	56	56.00	38.27	10.52	1.26	98	0.2107
	<i>Mid to low SEIFA</i>	44	44.00	35.52	11.18			
Care coordination: navigation	<i>High SEIFA</i>	56	56.00	24.82	4.75	2.12	98	0.0368*
	<i>Mid to low SEIFA</i>	44	44.00	22.55	6.00			
Care coordination: total score	<i>High SEIFA</i>	56	56.00	63.09	12.59	1.83	98	0.0705
	<i>Mid to low SEIFA</i>	44	44.00	58.07	14.85			

**Table 7.23: “Care coordination” by SEIFA Wilcoxon rank sum test**

Care coordination	Group	Count	Percent	Median	IQR	W	p
Care coordination: care coordination global measure	<i>High SEIFA</i>	56	56.00	7.00	3.25	1410.00	0.2123
	<i>Mid to low SEIFA</i>	44	44.00	6.00	3.25		
Care coordination: quality of care global measure	<i>High SEIFA</i>	56	56.00	8.00	3.25	1401.50	0.2337
	<i>Mid to low SEIFA</i>	44	44.00	7.00	3.00		

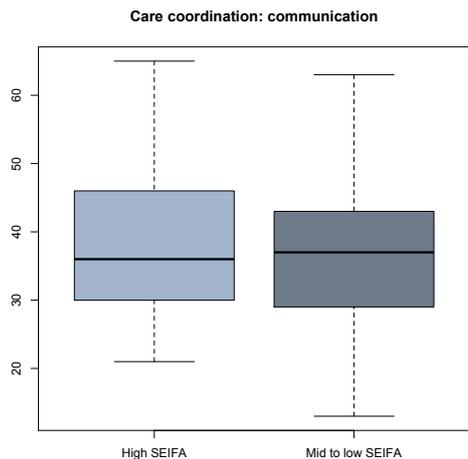


Figure 7.41: “Care coordination: communication” by SEIFA

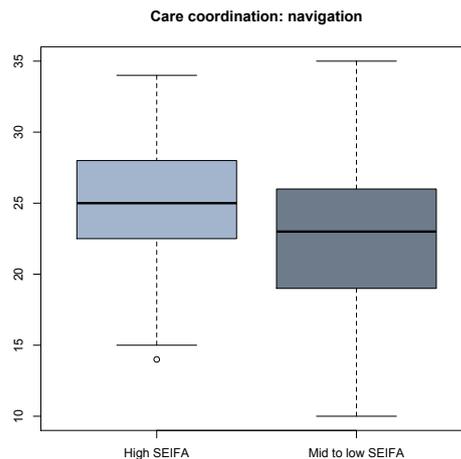


Figure 7.42: “Care coordination: navigation” by SEIFA

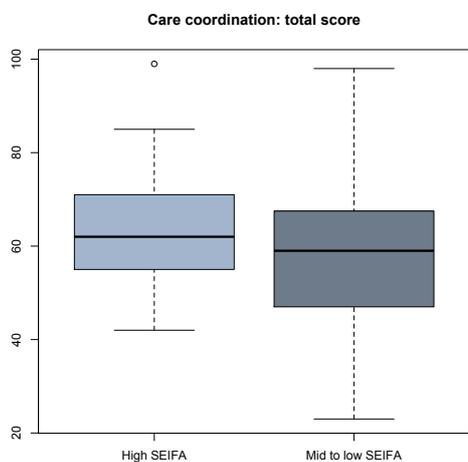


Figure 7.43: “Care coordination: total score” by SEIFA

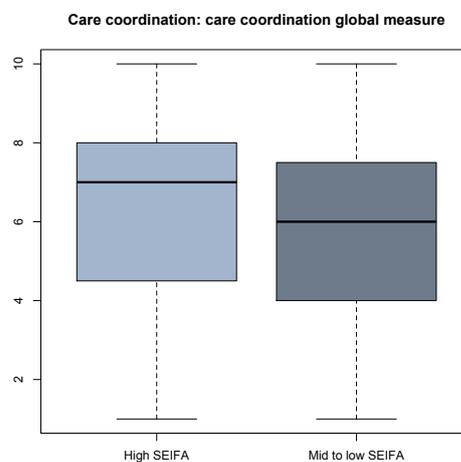


Figure 7.44: “Care coordination: care coordination global measure” by SEIFA

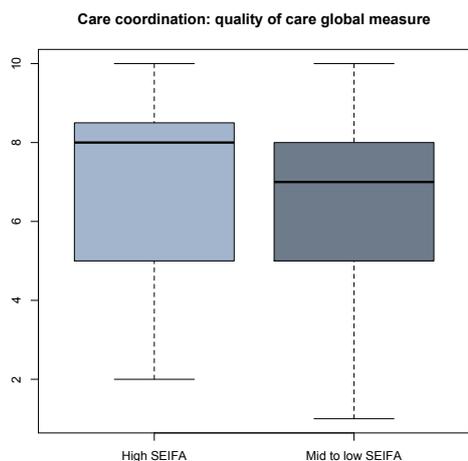


Figure 7.45: “Care coordination: quality of care global measure” by SEIFA

### Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common description of care and support was support from family and friends (n=56, 56.00%). This was followed by receiving support from health professionals (general practitioner or specialist) (n=15, 15.00%), through charities (primarily Asthma Australia (n=10, 10.00%)., and support from health professionals (nurses) (n=8, 8.00%).

There were 9 participants (9.00%) who did not receive any care or support, and an additional 9 participants (9.00%) did not receive any additional support however they did not feel as though they needed any as they can manage on their own.

In relation to sub-group variations, participants in the *Infrequent flare-ups* (39.13%), and *Moderately controlled asthma* (45.45%) sub-groups described support from family and friends less frequently than the general population (56.00%), while those in the *Age 18 to 34* (69.57%), *Frequent flare-ups* (66.67%) sub-groups described this more frequently.

Participants in the *Moderately controlled asthma* (27.27%), *Infrequent flare-ups* (30.43%) sub-groups described support from health professionals (general practitioner and specialists) more frequently than the general population (15.00%).

### Participant describes receiving support from family and friends

*I've got a friend that I do asthma classes with. She's also got asthma. She's conscious and she sometimes will notice that I'm all out of breath before I notice it myself. She often will say, "Do you need to take your puffer?" Or "Have you taken your puffer?" So I get that kind of support from someone who's experienced the same symptoms. Participant 037*

*Well, family first. My husband is a major support. It's been really interesting watching him actually take on an advocate role because he's normally a very quiet sort of man. He certainly has had no medical training, but now, he's quite a serious advocate because quite often I can't talk. He's learned to do that so that's been really quite amazing to watch. Participant 058*

*Yes. My partner is a bit far or something, he'll make sure that there's an inhaler really close to me all the time. He'll make sure I'm breathing okay. If my breathing starts going funny, he'll jump on me and be like, you need to take your puffer. Participant 062*

*The first person who cared for me was my mum. That was the primary caretaker for me. She was for my whole life a massive support even when I moved out of home. Even as an adult sometimes you kind of go, "Why can't I breathe?" I'd ring my mum and she would have the answer. She was like, "Go take your asthma medication." She's been number one, and then obviously medical practitioners that are good to you in your life are number one as well. Participant 077*

### Participant describes receiving support from health professionals (general practitioner/specialists)

*The care that I received from Dr. NAME, my current GP has been incredible. I do think she has really impacted my life by taking my asthma so seriously. Participant 051*

*I think the best support and care that I've received is from my long-term GP. That's in particular the one I've been seeing for the last 10 years, because they helped remind me at around allergy season onset, to just check in on the asthma and make sure that I'm happy with the medications I'm on and make sure I'm still remembering to take them and just that touching base. They must have an alert in their computer system that reminds them to actually. Participant 052*

*Probably the doctor specialist and the doctors in the emergency departments and throughout I found them just to be some of the most supportive doctors I've ever come across. Participant 065*

Participant describes receiving support through charities (primarily Asthma Australia)

*Recently, because at times when I can't even afford more medication. I will go and contact the local charity speak with him if I could appointment and explained to them I said, "I need some assistance. I can't even afford one medication this week." They said, "Okay, go and drop your script in, we'll sort that out." From there they paid for the scripts. That makes it easy on me. Participant 038*

*Then I guess the education stuff from the Asthma Australia, has been helpful. Participant 037*

*Asthma LOCATION has also been incredible. It was amazing to get into their system, and receive those phone calls, and receive the education that I was quite reluctant to attend anyway, but it turned out to be awesome. By being with Asthma LOCATION, I got access to the testing that would officially diagnose me with asthma, which was really great. It's great to know that my lung conditions are not something more sinister, that it is asthma, that it is something that I'm going to have to live with and manage. Because I think if we have a formal diagnosis, you do wonder like, "Is it that?" Really fantastic care across the board. Participant 51*

Participant describes not receiving any additional care or support

*I've not had anything, especially in my young years, there was no patient support, I would loved that, I would have loved to patient support groups, to talk to people who are going through what I was going through. Participant 020*

*I don't know, not too much really. If I'm having asthma and stuff, people are just like are you alright? There's not too much about it except for just buying a puffer for me really. Participant 042*

*Nobody around you knows that you've got asthma apart from the people close to you who don't know anything more than you do. There's nothing. You're telling them. The people at work, and I actually work for an organization that has eight people in the office. It's actually quite limited in terms of people being able to give me knowledge about something that I've got, rather than the other end. The fact is you don't know what you don't know and I didn't know. Yes. Participant 056*

Participant describes not receiving any additional care or support but does not feel as though they need this as they can manage on their own

*I haven't accessed any sort of care... I wouldn't say I've been a burden on my family or anything, they might tell you a different story. So probably not because of asthma. Participant 043*

*Well, nothing really. It's been off my own back. Just go to do exercise classes or yoga or something like that. No, I haven't really had any in-home support, no. Participant 049*

*Family haven't really needed to do anything specific. They're concerned on days where there's lots of dust around. The days where they say asthmatics should stay inside I tend to try and do that but other than that no. I'm certainly in no support groups or help groups or anything like that and that's probably not my style anyway. Participant 29*

### Participant describes receiving support from health professionals (nurses)

*I had an amazing nurse at hospital who always looked after me. She was phenomenal, I'm still really good friends with her today. Participant 020*

*Nurses are quite good. One time, I had an asthma attack. I was thinking "Do I call an ambulance or not?" I rang up, there's a nurse health line that you can ring up. I rang her up and she said, "Call an ambulance." after she discussed it with me. It was good because I was, "Hmm, I don't want to waste their time." She said, "No, no, no." She said, "Do this, do that." She said, "Is it any better?" I went "No." She said, "Call an ambulance." That was really good. They're the ones you just ring. Participant 069*

*Because of the trials, I've got a team of three research nurses that I've been dealing with for the good part of 12 plus years, they are amazing. Participant 028*

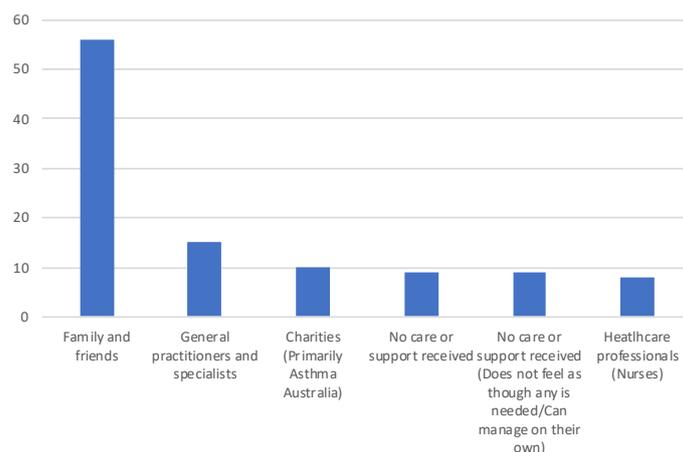


Figure 7.46: Experience of care and support

Table 7.24: Experience of care and support

Care and support received	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes receiving support from family and friends	56	56.00	14	53.85	10	45.45	32	61.54	24	50.00	24	66.67	23	56.10	9	39.13
Participant describes receiving support from health professionals (general practitioner/specialists)	15	15.00	6	23.08	6	27.27	5	9.62	10	20.83	4	11.11	4	9.76	7	30.43
Participant describes receiving support through charities (Primarily Asthma Australia)	10	10.00	1	3.85	1	4.55	7	13.46	3	6.25	3	8.33	4	9.76	3	13.04
Participant describes not receiving any additional care or support	9	9.00	2	7.69	1	4.55	6	11.54	3	6.25	5	13.89	2	4.88	2	8.70
Participant describes not receiving any additional care or support but does not feel as though they need this as they can manage on their own	9	9.00	2	7.69	3	13.64	4	7.69	5	10.42	2	5.56	5	12.20	2	8.70
Participant describes receiving support from health professionals (nurses)	8	8.00	1	3.85	1	4.55	6	11.54	2	4.17	1	2.78	6	14.63	1	4.35

Care and support received	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes receiving support from family and friends	56	56.00	18	62.07	38	53.52	19	46.34	37	62.71	16	69.57	21	50.00	19	54.29
Participant describes receiving support from health professionals (general practitioner/specialists)	15	15.00	3	10.34	12	16.90	9	21.95	6	10.17	5	21.74	6	14.29	4	11.43
Participant describes receiving support through charities (Primarily Asthma Australia)	10	10.00	4	13.79	6	8.45	1	2.44	9	15.25	2	8.70	5	11.90	3	8.57
Participant describes not receiving any additional care or support	9	9.00	2	6.90	7	9.86	4	9.76	5	8.47	1	4.35	5	11.90	3	8.57
Participant describes not receiving any additional care or support but does not feel as though they need this as they can manage on their own	9	9.00	2	6.90	7	9.86	4	9.76	5	8.47	1	4.35	4	9.52	4	11.43
Participant describes receiving support from health professionals (nurses)	8	8.00	4	13.79	4	5.63	2	4.88	6	10.17	1	4.35	5	11.90	2	5.71

Care and support received	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes receiving support from family and friends	56	56.00	37	56.06	19	55.88	23	52.27	33	58.93	27	48.21	29	65.91
Participant describes receiving support from health professionals (general practitioner/specialists)	15	15.00	10	15.15	5	14.71	7	15.91	8	14.29	10	17.86	5	11.36
Participant describes receiving support through charities (Primarily Asthma Australia)	10	10.00	8	12.12	2	5.88	6	13.64	4	7.14	5	8.93	5	11.36
Participant describes not receiving any additional care or support	9	9.00	6	9.09	3	8.82	5	11.36	4	7.14	6	10.71	3	6.82
Participant describes not receiving any additional care or support but does not feel as though they need this as they can manage on their own	9	9.00	5	7.58	4	11.76	3	6.82	6	10.71	6	10.71	3	6.82
Participant describes receiving support from health professionals (nurses)	8	8.00	6	9.09	2	5.88	3	6.82	5	8.93	5	8.93	3	6.82

# Section 8 Quality of life

## Section 8: Experience of quality of life

### Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 78 participants (78.00%) that described at least one negative impact on quality of life. The most common themes in relation to having a negative impact on quality of life included reduced capacity for physical activity (n=27, 27.00%), emotional/psychological strain (n=25, 25.00%), not being able to participate in hobbies or social activities to avoid triggers or overexertion (n=21, 21.00%) and an overall negative impact on quality of life (n=21, 21.00%). There were 21 participants (21.00%) that reported minimal impact on quality of life.

### Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotion and mental health. 22 participants (22.00%) reported that their mental health was not affected. The most common way that participants reported managing their mental and emotional health was by consulting a mental health professional (n=19, 19.00%). 15 participants (15.00%) described mindfulness, meditation or self-awareness. Other common themes included physical exercise to manage emotions (n=13, 13.00%), help from family and friends (n=13, 13.00%) and coping strategies such as remaining social, lifestyle changes and participating in hobbies (n=12, 12.00%).

### Regular activities to maintain health

In the structured interview, participants were asked what some of the things were they needed to do every day to maintain their health. The most common way that participants reported managing their health was by complying with treatment (n=60, 60.00%). There were 32 participants (32.00%) that described being aware of triggers and preventing the impact of triggers and 18 (18.00%) that described the benefits of being physically active.

### Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 46 participants (46.00%) that described a negative impact on relationships, 49 participants (49.00%) that reported no impact on relationships. The most common themes in relation to having a negative impact on relationships included change in dynamics of relationships due to anxiety in relation to exacerbations or physical limitations (n=22, 22.00%), and stress on relationship or inability to cope (n=12, 12.00%).

### Burden on family

In the structured interview, participants were asked whether they felt their condition placed additional burden on their family. Overall, 35 participants (35.00%) felt there was an additional burden and 55 participants (55.00%) felt there was no additional burden. Where participants described no additional burden, 33 (33.00%) reported no additional burden but did not specify a reason, 11 participants (11.00%) felt they had required little assistance and 10 participants (10.00%) felt that their condition is not currently a burden but is likely to be in the future. Where participants described an additional burden, this was primarily due to extra duties or responsibilities for family (n=16, 16.00%), a burden on family in general (n=12, 12.00%), and due to mental or emotional strain (n=8, 8.00%).

### Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 53 participants (53.00%) that spoke about struggling with the costs of treatments, and 38 participants (38.00%) that reported needing to take time of work. Other costs described cost of general practitioner and specialist appointments (particularly repeat scripts, travel time/cost) (20.00%), indirect costs in relation to their ability to make life choices (12.00%), and family members needing to take time of work (10.00%). There were 12 participants (12.00%) who described that they were not struggling with costs.

### 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. Summary statistics for the entire cohort are displayed in Table 8.2. Overall the entire cohort had a median total score of 31.00 (IQR = 14.00), which corresponds to low levels of anxiety.

### Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 78 participants (78.00%) that described a negative impact on quality of life 21 participants (21.00%) that reported minimal impact on quality of life. The most common themes in relation to having a negative impact on quality of life included reduced capacity for physical activity (n=27, 27.00%), emotional/psychological strain (n=25, 25.00%), not being able to participate in hobbies or social activities to avoid triggers or overexertion (n=21, 21.00%) and an overall negative impact on quality of life (n=21, 21.00%).

In relation to sub-group variations, participants in the *Regional or remote* sub-group described a negative impact on quality of life due to reduced capacity for physical activity less frequently (14.71%) than the general population (27.00%), while those *Age 18 to 34* described this more frequently (39.12%).

Participants *Age 18 to 34* described a negative impact on quality of life due to emotional/psychological strain more frequently (39.12%) than the general population (25.00%).

Participants in the *Moderately controlled asthma* sub-group described a negative impact on quality of life due to not being able to participate in hobbies and social activities more frequently (36.36%) than the general population (21.00%).

Participants *Age 18 to 24* described an overall negative impact on quality of life less frequently (8.70%) than the general population (21.00%), while those in the *Regional or remote* sub-group described this more frequently (38.24%) as did participants in the *Severe asthma* sub-group (34.48%).

### Participant describes negative impact on quality of life due to reduced capacity for physical activity

*Absolutely, I think my kids have obviously grown up knowing that their mum is not as able to do other physical activities like some other mums, so that's hugely impacted everything. I guess, the biggest thing for my kids and me have noticed is the restriction on me as a person, not being able to travel, not being able to enjoy normal activities that, say, like other people would. That in itself is hard.*

*Participant 3*

*For me personally, it maybe stops me being as active as I would like.* *Participant 8*

*It stops you, when I'm having an asthma attack, it actually stops me from doing the things I love doing. It used to be things like no more skiing.* *Participant 11*

*I've conditioned myself quite well to try and de-stress and relax, and use those types of things, myself, to try and reduce anxiety because anxiety is just, you know, your muscles tighten up and then it just gets worse. It's hard to do though, but I've tried to self-help at that when needed. As soon as you do any sort of exercise, do any work in the garden, any digging, you pick up a couple of shovels full and you're breathing heavily already. You really need to manage it early. Sometimes, like now, if I'm going to do some heavy work, I will actually use [my reliever] beforehand, sort of, to prevent it from happening.* *Participant 66*

**Participant describes negative impact on quality of life\due to emotional/psychological strain**

*I can't remember the amount of times that my kids just see me go off in the back of an ambulance and that's so hard especially with my eldest. He's chased the ambulance down the street. The one with autism. My seven-year-old just cries and cries. I get to a point that I go to hospital and they get my attack under control and they're like, "You can stay for the night." I'm like, "Can you please let me go home because my kids are just beside themselves. If I get worse, I promise I'll come back," because it's had such a big impact on their lives, and I've missed out on a lot of their school things because I can't go to them and it's hard. Participant 2*

*It has affected my mental health a little bit just because a good portion of mental health is being able to go out for walks and just clear your mind and things. I would have loved to be able to participate in sports being that slow kid and not being able to do marathons and things like that. I wish I was able to. Participant 42*

*I think it's the emotional toll. When I'm in hospital, in a bed-- I've had 10 weeks off work this year just to beat the asthma exacerbation. Not this year, in the last 12 months. I've had to get someone to look after my kids while I'm in hospital, the pets, household full of stuffs. My partner and I are separated at the moment. That have a big toll on that. Participant 44*

**Participant describes minimal impact on quality of life**

*Most of the time it's not too bad. I go to work and all that sort of stuff. It's when I get sick. I really feel for my husband and my family when I get sick because everyone panics but it's definitely if I'm hospitalized. I get hospitalized at least once a year and it's really unpleasant for them. I feel bad for them. Overall, it's not bad. We still have very much a normal life. Participant 22*

*I've nearly always managed to keep going. With the family, because we have four children and still have four children, there were a couple of times when I've had to battle through when I haven't felt that good, but because I'm lucky that I'm the person I have a lot of energy, there was always enough left in the tank to keep going. I haven't had to stop very often because of it. I would love to, but I haven't had to really. Participant 27*

*It made me more dependent during my initial years with my parents and it was very hard for me to stay focused while in boarding school. I used to get picked up from school just because I was about to get an attack or something. Over the years, I've learned to manage it on my own. Therefore, no need for anyone to help me out. Participant 68*

**Participant describes negative impact on quality of life\as they are not able to participate in hobbies/social activities to avoid triggers or overexertion**

*Before I was really incapacitated by it, I was a functioning professional, driving and very involved in community and other activities. Now, I'm feeling isolated at home and very dependent on my husband to go anywhere. I've gone from one thing right down to the other. Participant 58*

*I don't think it really does affect my quality of life unless I'm sick or environmental things will trigger, if it's really smoky I cannot leave my house or if I'm at work and it's really smoky, I cannot be outside I have to be indoors. Things like environmental factors or if I'm sick either chest infection or pneumonia, I literally cannot move, I'm so exhausted and tired from asthma that I can't move. Participant 60*

*Because I have allergies to a lot of native plants-- I'm in an area full of them and other things are like-- my main issue with going places is people who smoke. Even if they stand away, they think they're being considerate, but the smoke still moves towards you. I could be out and everything's fine and then I walk past someone smoking and the rest of it, I can't breathe. Participant 85*

### Participant describes negative impact on quality of life (overall)

*A lot of people in the community don't get. They think you've got your blue puffer, you're okay, and if you look okay because you can't see asthma, they don't understand. There's a lot of social isolation, which I know for a lot of people can lead to depression and anxiety. Because there's a lot of things you don't, perhaps you do you just have to look after your health and it's not possible with a lot of stuff I can't do. Participant 28*

*It does affect. It does affect my quality of life because there are times when having asthma makes even talking hard. It's intermittent, though. It's not all the time so I guess it's an up and down that's not consistently bad, but there has been times when it has impacted my quality of life, definitely. Participant 47*

*When I was little and there wasn't a treatment for wheezing particularly, I think that that you just felt so awful. Sick. I guess you adapt to it like when I was little I remember I used to make songs and poems to the wheezing in and out. Somebody at school, when we were 14 and 15 with asthma, she taught me this trick of putting my hands over my head and that made it easier to breathe and it does. Participant 83*

**Table 8.1: Experience of quality of life**

Impact on quality of life	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes negative impact on QOL due to reduced capacity for physical activity	27	27.00	6	23.08	7	31.82	14	26.92	13	27.08	11	30.56	11	26.83	5	21.74
Participant describes negative impact on QOL due to the emotional/psychological strain	25	25.00	7	26.92	4	18.18	14	26.92	11	22.92	10	27.78	9	21.95	6	26.09
Participant describes minimal impact on QOL	21	21.00	8	30.77	3	13.64	10	19.23	11	22.92	4	11.11	10	24.39	7	30.43
Participant describes negative impact on QOL as they are not able to participate in hobbies/social activities to avoid triggers or overexertion	21	21.00	5	19.23	8	36.36	8	15.38	13	27.08	7	19.44	9	21.95	5	21.74
Participant describes negative impact on QOL (Overall)	21	21.00	4	15.38	3	13.64	15	28.85	6	12.50	10	27.78	7	17.07	4	17.39
Participant describes at least one negative impact (total)	78	78.00	18	69.23	19	86.36	41	78.85	37	77.08	31	86.11	31	75.61	16	69.57

Impact on quality of life	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes negative impact on QOL due to reduced capacity for physical activity	27	27.00	6	20.69	21	29.58	10	24.39	17	28.81	9	39.13	10	23.81	8	22.86
Participant describes negative impact on QOL due to the emotional/psychological strain	25	25.00	9	31.03	16	22.54	8	19.51	17	28.81	9	39.13	9	21.43	7	20.00
Participant describes minimal impact on QOL	21	21.00	4	13.79	17	23.94	11	26.83	10	16.95	4	17.39	11	26.19	6	17.14
Participant describes negative impact on QOL as they are not able to participate in hobbies/social activities to avoid triggers or overexertion	21	21.00	5	17.24	16	22.54	12	29.27	9	15.25	6	26.09	6	14.29	9	25.71
Participant describes negative impact on QOL (Overall)	21	21.00	10	34.48	11	15.49	7	17.07	14	23.73	2	8.70	10	23.81	9	25.71
Participant describes at least one negative impact (total)	78	78.00	25	86.21	53	74.65	30	73.17	48	81.36	18	78.26	31	73.81	29	82.86

Table 8.1: Experience of quality of life (Cont.)

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes negative impact on QOL due to reduced capacity for physical activity	27	27.00	22	33.33	5	14.71	13	29.55	14	25.00	14	25.00	13	29.55
Participant describes negative impact on QOL due to the emotional/psychological strain	25	25.00	16	24.24	9	26.47	13	29.55	12	21.43	14	25.00	11	25.00
Participant describes minimal impact on QOL	21	21.00	16	24.24	5	14.71	7	15.91	14	25.00	13	23.21	8	18.18
Participant describes negative impact on QOL as they are not able to participate in hobbies/social activities to avoid triggers or overexertion	21	21.00	16	24.24	5	14.71	8	18.18	13	23.21	16	28.57	5	11.36
Participant describes negative impact on QOL (Overall)	21	21.00	8	12.12	13	38.24	8	18.18	13	23.21	11	19.64	10	22.73
Participant describes at least one negative impact (total)	78	78.00	49	74.24	29	85.29	36	81.82	42	75.00	43	76.79	35	79.55

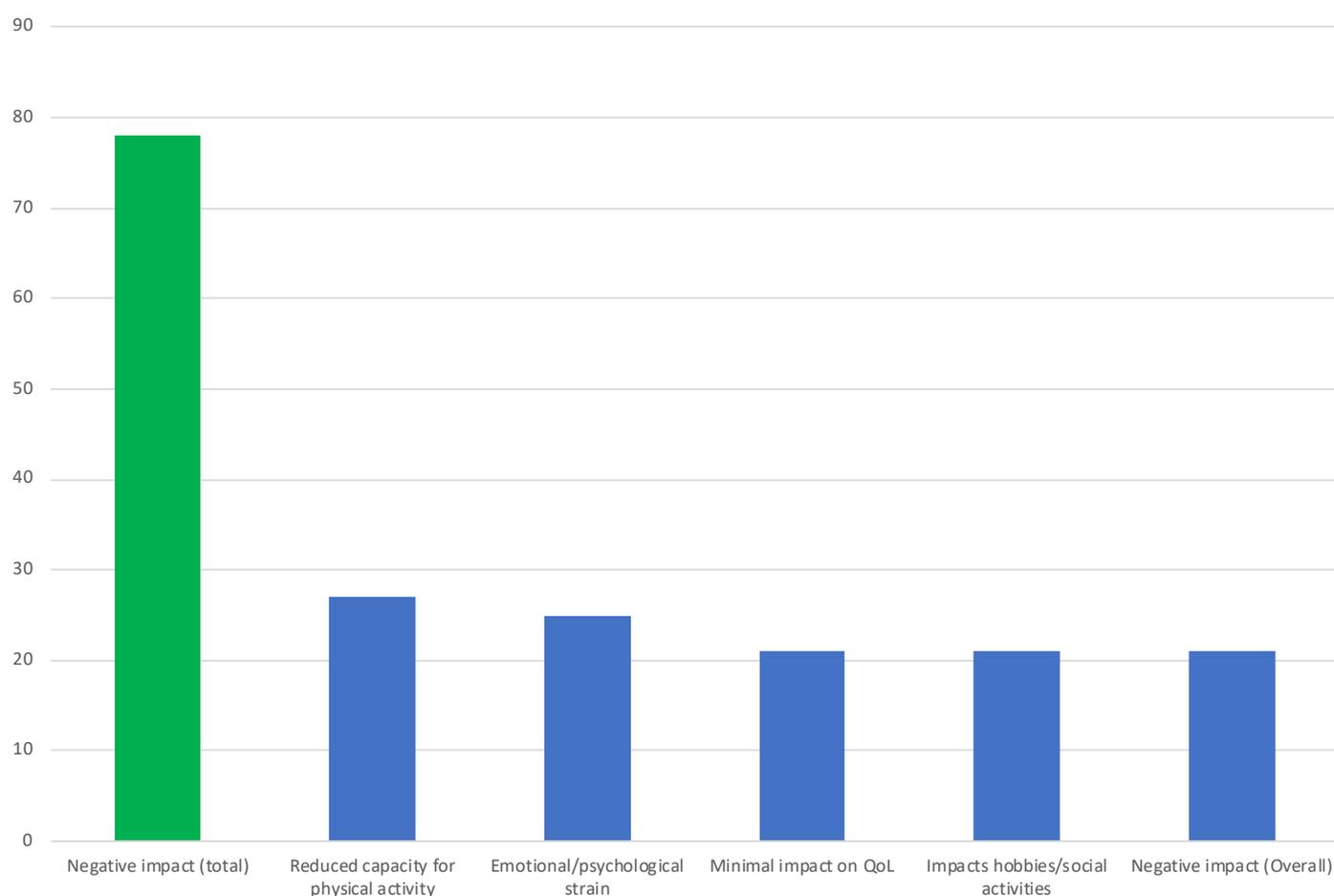


Figure 8.1: Experience of quality of life

### Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. There were 22 participants (22.00%) who described that their mental health was not affected. The most common way that participants reported managing their mental and emotional health was by consulting a mental health professional (n=19, 19.00%). There were 15 participants (15.00%) that described mindfulness, meditation or self-awareness. Other common themes included physical exercise to manage emotions (n=13, 13.00%), help from family and friends (n=13, 13.00%) and coping strategies such as remaining social, lifestyle changes and participating in hobbies (n=12, 12.00%).

In relation to sub-group variations, participants in the *Regional or remote* (8.82%), *Moderately controlled asthma* (9.09%), *Mid to low SEIFA* (9.09%), *Frequent flare-ups* (11.11%), *Severe asthma* (0.00%) and *Frequent sleep disruption* (11.86%) sub-groups described that their mental health was not affected less frequently than the general population (22.00%), while those in the *Controlled asthma* (50.00%), *Infrequent flare-ups* (39.13%), and *Infrequent sleep disruption* (36.59%) sub-groups described this more frequently. Participants in sub-group *Severe asthma* describe consulting a mental health professional more frequently (34.48%) than the general population (19.00%). Participants *Age 18 to 34* described mindfulness/meditation or self-awareness less frequently (4.35%) than the general population (15.00%). There were no participants in the *Controlled asthma* sub-group (0.00%) who described coping strategies to manage such as remaining social, lifestyle changes and participating in hobbies, compared to the general population (12.00%).

### Participant describes their mental health not being affected

*I'm a little resigned to the idea of having asthma and I take it on as something that I just live with. I don't get upset about it and I don't feel that it affects my mental health negatively anymore really, because I just accept. It's an acceptance thing. I've just resigned myself to it more than anything. I don't see the point for me in being upset about this, so I just live with it. Participant 47*

*I don't feel that asthma actually affects my mental health or emotional health. It's other stresses that might affect me. Participant 73*

### Participant describes consulting a mental health professional

*I have started seeing a counsellor. That's been absolutely instrumental to helping me with my trauma. I've had a very distressing weekend as well where I have been shutting down a lot. That then brings up a lot of those fears of death and suffocation and things like that. That's been a really hard weekend that I've just been through as well. I feel like talking about it is really helpful with people who do understand like my family, really great I've got there. Participant 20*

*Yes, I literally, in the last two weeks, I've just had a seeing a psych. just about- I didn't know what was going on every time I seem to be getting sick. You have flashbacks of intensive care or going to dying state and on life support and stuff like that. That obviously affects your mental health. Yes, spoke to the GP and he got a mental health plan and he went to a- so pretty much been diagnosed with depression, anxiety, and PTSD from my multiple ICU admissions. Not on any medication or anything for it but just to see a psych. The main thing is when you start to get sick with asthma, if it lasts for more than 48 hours and your medicine doesn't work, that's when I think everyone in that situation starts getting quite a high level of anxiousness about going to hospital and where the next step taken. Participant 33*

*I think it impacts me hugely. I have been treated for depression before. I'm not being currently treated for depression, but a lot of that stems from that impact on your life. You can go mad. For the recovery like I can have a bad attack but the recovery from that attack could take a good month and the emotional toll of not being able to do what you want to do when you want to do it and be with who you want to be is huge. Participant 35*

Participant describes using mindfulness/meditation or self-awareness to manage

*It does affect it because I get a bit self-conscious when I'm having something to do with my health. If I am wheezing or like I said if you're at someone's place you're wheezing and you don't want to make a fuss because you know how much they love their animals and all that sort of stuff. It does have an impact but I try and-- I'm just trying to do a U-turn, I'll just be a moment. Just give me a sec so I can do this illegal U-turn because I've gone the wrong way. Sorry, I just need to get my bearings and then I go this route okay that's good. I do try and do a bit of mindfulness and look at ways of not getting stressed about things but sometimes health is impacted and that means that you do have to think about looking after yourself. It's had an impact but like I said, I don't like banging on about health so I tend to keep that to myself. Participant 31*

*I don't know. Sometimes I get frustrated when I run out of breath and I forget that it could be because of asthma, I think it's just because perhaps I'm not fit, but I do do things like I do some meditation every day and try to make sure that I do activities that I enjoy, like I have some craft activities, so I make I'm regular doing those things so that that helps with managing stress. Going away for a weekend to do a craft activities. Something I really enjoy so that helps me. I always feel more relaxed and less stressed then. Participant 37*

*Yes. I meditate as often as I can remember to. I go to classes, Buddhist classes and stuff like that, just mindfulness. I try and tack into that one and correcting. Use those methods to help me. I do suffer anxiety these days and PTSD. Of course, there's depression, it's all part of that whole cycle. I don't know how asthma has affected my mental health except for, again it's just when I'm really crook, that's when it affects me and when I'm sick, it does affect my mental health. Participant 40*

Participant describes using physical exercise to manage emotion

*Definitely, trying to just unwind as much as we can, walking, I love to swim, I really do find that very therapeutic for my mental health, as well as my physical health. I do enjoy doing that when I feel safe and healthy enough to do it, which unfortunately, hasn't been much lately. Even just sitting with your emotions, even just sitting with that fear and saying that it's okay to be feeling this way. I had a falling out with one of my friends on Saturday because I was so distressed, and I was meant to meet up with them, and I had to cancel meeting them because I felt like I was going to have to go to emergency at any point. I tried to really explain that to them, and they just didn't understand, and they got very upset at me, and angry. Participant 20*

*Yes, I try to exercise regularly to increase my lung capacity maybe four-- Exercise does the same thing for me in terms of mental health. Makes me feel happier and more satisfied with myself. Participant 68*

*I would say it doesn't affect my mental and emotional health. Then, I try and maintain my mental and emotional health through just my networks, my family and friends and keeping fit and healthy. Participant 80*

### Participant reports how their family or friends have helped them

*Just talking about them, just being very, very open. I don't internalize things. I consider communication a real strong suit with my family and friends. Maybe not talking to you, but with my family, I'm quite good at expressing how I feel. Participant 51*

*I would say it doesn't affect my mental and emotional health. Then, I try and maintain my mental and emotional health through just my networks, my family and friends and keeping fit and healthy. Participant 80*

*Yes, I do, because I think that can play and impact. From time to time, I've had counselling. I'm not at the moment, but generally, I'm a fairly optimistic sort of person and I have a really supportive husband. That's made a really big difference for me but I do watch out for it and I have had some periods where I've been really down in a pit. HUSBAND'S NAME been really good in helping to support me. I know now that I need to fairly regularly plan activities that take me out of the house and things to look forward to so I keep a-- I guess I've learned how to prevent getting into that situation so instructively- Participant 58*

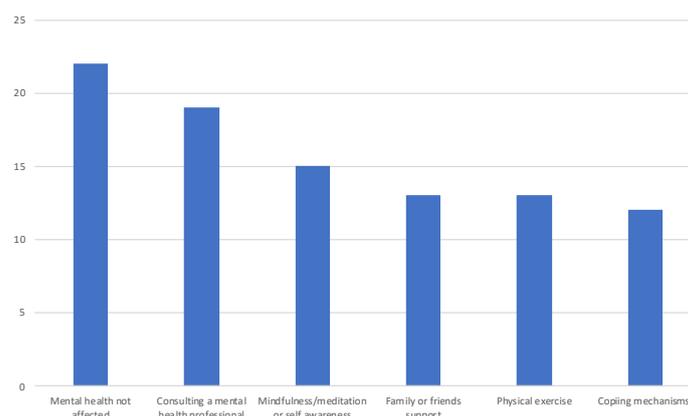
### Participant describes coping strategies they use to help manage remaining social, lifestyle changes and participating in hobbies

*I don't know. Sometimes I get frustrated when I run out of breath and I forget that it could be because of asthma, I think it's just because perhaps I'm not fit, but I do do things like I do some meditation every day and try to make sure that I do activities that I enjoy, like I have some craft activities, so I make I'm regular doing those things so that that helps with managing stress. Going away for a weekend to do a craft activities. Something I really enjoy so that helps me. I always feel more relaxed and less stressed then. Participant 37*

*I do-- I don't call it mindfulness, and I do the swimming, which I find mindful. I like taking photos with my phone. I do stuff and I love reading. At the moment, and this is a side effect, I think of the Prednisone, I can't read because my vision is going a bit wacky. When I'm talking to NAME who is my doctor the other day, he said, yes, that could be the Prednisone because it does something to your retina and cornea. What happens is like, when-- and it's funny, it's okay in the morning and then I warm up or something and it's weird. It doesn't happen all the time or if I'm very tired, but I don't know I'm tired, I'll look at your face and I can see you perfectly well but you'll have four eyes. Participant 12*

*With the mental side of it, I normally at times if I feel up to it, I might go to the local Men's Shed in tow. Participant 38*

*My garden. If I didn't have that- where I'm sitting now, I'm sitting on a sofa in my family room and just looking out I've got lovely trees that have turned autumnal colours and I've got a big pot of yellow chrysanthemums and purple chrysanthemums and it's my happy space. As long as I've got a garden I can manage. There are times when I am low and I get anxious if someone says to me I've got to find a [unintelligible 00:49:26] for a cannula. My goodness. It's never the issue with having the needle, it's just the pain involved and them trying to find some way to get it in so I get very anxious at times. Participant 14*



**Figure 8.2: Regular activities to maintain mental health**

Table 8.2: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes that their mental health has not been affected	22	22.00	13	50.00	2	9.09	7	13.46	15	31.25	4	11.11	9	21.95	9	39.13
Participant describes consulting a mental health professional to maintain their mental health	19	19.00	3	11.54	4	18.18	13	25.00	6	12.50	5	13.89	10	24.39	4	17.39
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	15	15.00	4	15.38	4	18.18	7	13.46	8	16.67	5	13.89	4	9.76	6	26.09
Participant describes family or friends support to maintain their mental health	13	13.00	4	15.38	4	18.18	6	11.54	7	14.58	5	13.89	7	17.07	1	4.35
Participant describes doing physical exercise to maintain their mental health	13	13.00	2	7.69	4	18.18	6	11.54	7	14.58	4	11.11	6	14.63	3	13.04
Participant describes coping mechanisms to maintain their mental health (Remaining social, lifestyle changes and participating in hobbies)	12	12.00	0	0.00	2	9.09	10	19.23	2	4.17	6	16.67	5	12.20	1	4.35

Regular activities to maintain mental health	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes that their mental health has not been affected	22	22.00	0	0.00	22	30.99	15	36.59	7	11.86	7	30.43	10	23.81	5	14.29
Participant describes consulting a mental health professional to maintain their mental health	19	19.00	10	34.48	9	12.68	5	12.20	14	23.73	3	13.04	11	26.19	5	14.29
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	15	15.00	3	10.34	12	16.90	8	19.51	7	11.86	1	4.35	10	23.81	4	11.43
Participant describes family or friends support to maintain their mental health	13	13.00	5	17.24	8	11.27	7	17.07	6	10.17	5	21.74	2	4.76	6	17.14
Participant describes doing physical exercise to maintain their mental health	13	13.00	3	10.34	10	14.08	4	9.76	9	15.25	2	8.70	6	14.29	5	14.29
Participant describes coping mechanisms to maintain their mental health (Remaining social, lifestyle changes and participating in hobbies)	12	12.00	4	13.79	8	11.27	2	4.88	10	16.95	3	13.04	4	9.52	5	14.29

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes that their mental health has not been affected	22	22.00	19	28.79	3	8.82	9	20.45	13	23.21	18	32.14	4	9.09
Participant describes consulting a mental health professional to maintain their mental health	19	19.00	13	19.70	6	17.65	8	18.18	11	19.64	11	19.64	8	18.18
Participant describes using mindfulness/meditation or self awareness to maintain their mental health	15	15.00	8	12.12	7	20.59	4	9.09	11	19.64	10	17.86	5	11.36
Participant describes family or friends support to maintain their mental health	13	13.00	10	15.15	3	8.82	7	15.91	6	10.71	9	16.07	4	9.09
Participant describes doing physical exercise to maintain their mental health	13	13.00	9	13.64	4	11.76	2	4.55	11	19.64	6	10.71	7	15.91
Participant describes coping mechanisms to maintain their mental health (Remaining social, lifestyle changes and participating in hobbies)	12	12.00	5	7.58	7	20.59	7	15.91	5	8.93	4	7.14	8	18.18

### Regular activities to maintain health

In the structured interview, participants were asked what some of the things were they needed to do every day to maintain their health. The most common way that participants reported managing their health was by complying with treatment (n=60, 60.00%). There were 32 participants (32.00%) that described being aware of triggers and preventing the impact of triggers and 18 (18.00%) that described the benefits of being physically active.

In relation to sub-group variations, participants in the *Controlled asthma* sub-group described the importance of complying with treatment less frequently (46.15%) than the general population (60.00%), while those in the *Moderately controlled asthma* sub-group described this more frequently (72.73%).

Participants in the *Infrequent flare-ups* sub-group described being aware of triggers or preventing the impact of triggers less frequently (21.74%) than the general population (32.00%).

Participants in the *Infrequent flare-ups* sub-group also described the benefits of being physically active more frequently (43.48%) than the general population (18.00%).

### Participant reports importance of complying with the treatment

*I'll need to make sure I take my puffers morning and night. I check my peak flow probably every second of the day. I have to make sure I've got a puffer in every handbag. [laughs]. I've got a puffer in my car. Things like that just to make sure that I've got it with me, if I'm going out somewhere. I wear a medic alert bracelet. Participant 44*

*I definitely have to make sure that I have my inhaler on me at all times. Outside of that, it's just remembering my personal limit and understanding that it's not quite as simple as some people believe it may be. Participant 48*

*I take my Preventers all the time. Make sure that I have relievers in a variety of places. Make sure that people around me know what to do. Make choices if there's environmental changes. For instance, if it's a smoky day, if there's a bushfire, if it's a really cold day, I have to cover my mouth with a scarf or something so I'm not breathing the cold air. If it's a dusty day, try and lock the house up so dust doesn't come in. [clears throat] I have to try to keep the air in the house quiet dry not moist. Environmental stuff, I think probably. Participant 57*

*I need to make sure I take my puffers every day. I make sure I've got puffers everywhere I go. I've got one in my car, one in my partner's car. I have one on top my desk at work. I have one in the drawer. I have one next to my bed. I have one in my handbag. I just make sure I've got puffers everywhere. I have puffers at my friend's house just in case as well. Participant 62*

### Participant reports being aware of triggers/prevent impact of triggers

*I have to be aware of the environment, aware of what's going on in my body. I measure my oxygen levels, I measure my peak flows, I choose my activities based on how I am on a particular day. Participant 17*

*As I said, I maintain a strict diet. That's a big thing for me. Food triggers are big whether they're affecting the asthma directly or affecting like the IBS so that the medications that are absorbed as effectively, I don't know. I just know I eat this and I get sick, and then I get the asthma kicks off. Also maintaining the cleanliness as like vacuuming regularly, changing the sheets regularly. I'm using an air purifier to maintain the environment around me and also I don't go with big groups of people. Participant 46*

*Control, not to expose myself to extreme weather especially cold and also places where there are pollen. Or during the spring, I have anti-allergens. Participant 68*

*What I really have to be careful of is allergy and cold. I have to make sure I don't get really cold. Every day I just have to be careful. I have to watch not being near smokers and smells and things like that. For me, it's more the allergies that I have to watch out for. My GP is quite worried because my Rast test-- do you know what a Rast test is, the allergy test? Mine's up to 1280 and he thinks that might lead to uncontrolled asthma. That's what I'm more worried about it at this stage. Participant 88*

*Okay. Basically making sure that my house is clean, dust free. Don't do activities where things are going to be really dusty. I actually don't clean the bathrooms, so my husband does that because of the fumes from cleaning. You just avoid things that you know are your triggers. You don't spray deodorant under your arm, you use roll-on, those sorts of things, but they're not really obtrusive in your life. Participant 99*

### Participant reports benefits of being physically active

*For me, it's very important to keep moving. I get up and take my dog for a walk every morning. I come back and I take my morning medication. I eat a quality balanced meat diet. I think all of those things contribute to how good you feel about life in general as well. For me, I'm prone to just stopping which is the worst thing that you can do especially if your lungs are unhappy with you. You really need to keep moving so everything keeps moving. When everything in your head says stop and don't do anything. Participant 41*

*I have to keep fit and I understand that I have to exercise or do something every day to increase my body fitness and just to keep healthy, eat healthy. Participant 64*

*Sports. Keeping fit is the number one thing for me. Then taking my medication is the other key. Making sure I take my preventative medication and nutritional diet too. Participant 77*

*One thing I try to do is I try to walk, not that I do it every day, but I just try to keep fairly active and I am fairly active. My other thing is to try and have a rest, so I can rest now. I work four days a week and I'll come home...for an hour. I'm sure that helps as soon as I think I've got any asthma or I'm feeling unwell, and I'll take a day off. Participant 89*

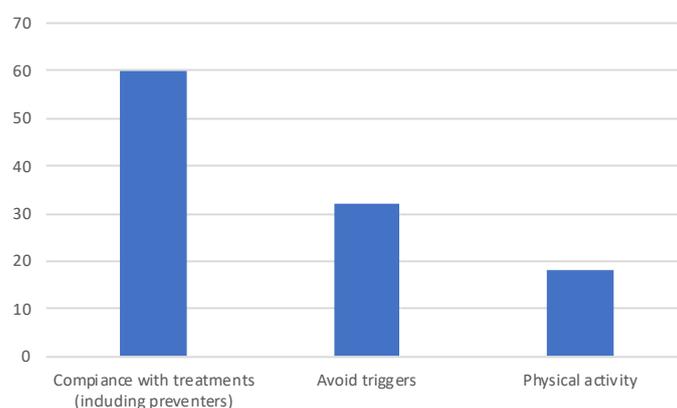


Figure 8.3: Regular activities to maintain health

Table 8.3: Regular activities to maintain health

Regular activities to maintain health	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant reports importance of complying with the treatment	60	60.00	12	46.15	16	72.73	32	61.54	28	58.33	20	55.56	26	63.41	14	60.87
Participant reports being aware of triggers/prevent impact of triggers	32	32.00	10	38.46	8	36.36	15	28.85	17	35.42	13	36.11	14	34.15	5	21.74
Participant reports benefits of being physically active	18	18.00	7	26.92	4	18.18	7	13.46	11	22.92	3	8.33	5	12.20	10	43.48

Regular activities to maintain health	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant reports importance of complying with the treatment	60	60.00	15	51.72	45	63.38	24	58.54	36	61.02	15	65.22	25	59.52	20	57.14
Participant reports being aware of triggers/prevent impact of triggers	32	32.00	12	41.38	20	28.17	15	36.59	17	28.81	8	34.78	14	33.33	10	28.57
Participant reports benefits of being physically active	18	18.00	5	17.24	13	18.31	9	21.95	9	15.25	2	8.70	8	19.05	8	22.86

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant reports importance of complying with the treatment	60	60.00	38	57.58	22	64.71	26	59.09	34	60.71	32	57.14	28	63.64
Participant reports being aware of triggers/prevent impact of triggers	32	32.00	23	34.85	9	26.47	12	27.27	20	35.71	21	37.50	11	25.00
Participant reports benefits of being physically active	18	18.00	14	21.21	4	11.76	6	13.64	12	21.43	11	19.64	7	15.91

### Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 46 participants (46.00%) that described a negative impact on relationships, 49 participants (49.00%) that reported no impact on relationships. The most common themes in relation to having a negative impact on relationships included change in dynamics of relationships due to anxiety in relation to exacerbations or physical limitations (n=22, 22.00%), and stress on relationship with partner or inability to cope (n=12, 12.00%).

In relation to sub-group variations, participants in the *Regional or remote* sub-group described no significant effect on relationships with family or friends less frequently (35.29%) than the general population (49.00%), as did those in sub-group *Severe asthma* (20.69%). While those in the *Controlled asthma* sub-group (61.54%) and in the *Non-severe asthma* sub-group (60.56%) described this more frequently.

Participants in the *Severe asthma* sub-group describe a negative impact on their relationship with their partner due to stress or inability to cope more frequently (24.14%) than the general population (12.00%).

#### Participant describes no significant effect on relationships with family or friends

*No, I don't think so. Maybe they might get-- I don't know whether they get annoyed because sometimes I have been out of breath to do things, but they never comment on that. They don't say, "Oh, you should manage your asthma better so that you can do more things." But they would never say that. Participant 37*

*No. I don't think so. My family have known about my asthma pretty much since the day of diagnosis, so they're all very, very accommodating in that regard. My friends are very understanding. A lot of them have asthma as well, so they understand everything. It's very easy to be able to reason with them so that they understand exactly what I'm going. Participant 48*

*No, a couple of my closest friends are Asthmatic, so, I think, we're all in it together. Participant 55*

*I guess. I'm very lucky in my friends. They are very supportive and very good. I think when I'm sick they hover just to make sure I'm okay. I know with two friends, in particular, I can't trust that if something goes belly up with me and my asthma that they would necessarily respond quickly or appropriately. There's I*

*suppose a degree of trepidation in like if I get really sick who can I depend on? Again, it comes down to education of people who don't have asthma. None of my friends have pulled back because of my asthma. Some of my friends actually have asthma as well. Participant 87*

*It hasn't affected relationships with friends. I've always been able to do everything that I've ever wanted to do with friends. It's never impacted my social life. You could say it's obviously impacted my relationship with my mother, but I wouldn't say that's in a negative sense. I wouldn't say that's in the negative sense. Today, that doesn't really come into effect at all, other than to hurriedly call her last night to [chuckles] seek her advice for that survey. Participant 100*

**Participant describes negative effect on relationship with family: change in dynamics of relationships due to anxiety in relation to exacerbations and/or physical limitations of asthma**

*I think so, yes. It's a tricky one, that one. I think definitely with friends. Everyone jokes about it and you take that in your stride like call you bubble boy and all that sort of stuff. They know that they can't rely- they'll invite me to something and I'll say yes, but they can't rely on myself or the family going in case I do get sick. Relationships in the past, I think there's definitely affected like partners that couldn't deal with the severity of it and me being hospitalized. I think I'm quite lucky I have a wife and family at the moment that understand all that stuff so it's quite good. Participant 33*

*Probably a little bit. My family are fairly understanding of it but I'm sure that there are people that find it hard to understand. I know I have one friend who completely does not understand why we don't have aerosols in our house and she says that every time she comes here. I am sure that has an impact. Some people don't like the way we live and that's fine. Participant 41*

*I say it has it turns, affected especially when you're getting a really bad attack, not bad, but you're affected to the point that you can't do what you want to do. It does affect your personal relationship. Participant 53*

**Participant describes negative effect on relationship with partner (stress on relationship/inability to cope)**

*If I asked my ex-husband, he would say, "Absolutely yes." His claim to fame was, "I could never get a full night's sleep with you." That contributed obviously, to my marriage break down. Absolutely. Even to my kids, my kids would tell you, "Mum, you're absolutely hopeless. We can't go to normal activities and have fun, run around the park because well, you're dying after five minutes, or ten minutes." I'm like, "Yes." That impact on them. Why? It restricts them, and it restricts my relationships, and it restricts everything else you do. Participant 3*

*Yes, I think it has, especially, not so much with my friends and my family, but relationships like partners because they sort of say, "Oh jeez, is she going to go and die on me," or "She's got this illness, she's not healthy." I think I had to overcome that sort of obstacle in the past, that thinking that since you've got asthma and it can impact on your breathing, you might be in your twenties but you're like an old woman. Participant 21*

*My husband, yes, certainly did and he'd get a bit frustrated with it. Yes, he's got a bit frustrated with it at times or when I tried to keep going when I should be resting and that sort of thing. When I try to do that, he'd go off his nut at me that I was making it worse by trying to keep going. I felt embarrassed when other people had to step in and help with children or things like that that I felt I should be doing. Participant 63*

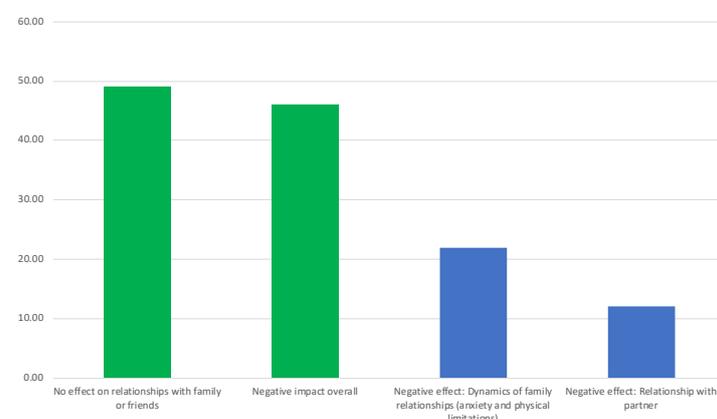


Figure 8.4: Impact on relationships

Table 8.4: Impact on relationships

Impact on relationships	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes negative effect on relationship with family: Change in dynamics of relationships due to anxiety in relation to exacerbations and/or physical limitations of asthma	22	22.00	6	23.08	3	13.64	12	23.08	10	20.83	6	16.67	11	26.83	5	21.74
Participant describes negative effect on relationship with partner (Stress on relationship/Inability to cope)	12	12.00	3	11.54	4	18.18	6	11.54	6	12.50	3	8.33	4	9.76	5	21.74
Participant describes no significant effect on relationships with family or friends	49	49.00	16	61.54	11	50.00	22	42.31	27	56.25	16	44.44	20	48.78	13	56.52
Participant describes a negative impact overall	46	46.00	9	34.62	11	50.00	26	50.00	20	41.67	19	52.78	18	43.90	9	39.13

Impact on relationships	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes negative effect on relationship with family: Change in dynamics of relationships due to anxiety in relation to exacerbations and/or physical limitations of asthma	22	22.00	13	19.70	9	26.47	10	22.73	12	21.43	10	17.86	12	27.27
Participant describes negative effect on relationship with partner (Stress on relationship/Inability to cope)	12	12.00	9	13.64	3	8.82	7	15.91	5	8.93	8	14.29	4	9.09
Participant describes no significant effect on relationships with family or friends	49	49.00	37	56.06	12	35.29	18	40.91	31	55.36	29	51.79	20	45.45
Participant describes a negative impact overall	46	46.00	26	39.39	20	58.82	25	56.82	21	37.50	26	46.43	20	45.45

Impact on relationships	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes negative effect on relationship with family: Change in dynamics of relationships due to anxiety in relation to exacerbations and/or physical limitations of asthma	22	22.00	9	31.03	13	18.31	7	17.07	15	25.42	5	21.74	12	28.57	5	14.29
Participant describes negative effect on relationship with partner (Stress on relationship/Inability to cope)	12	12.00	7	24.14	5	7.04	6	14.63	6	10.17	2	8.70	7	16.67	3	8.57
Participant describes no significant effect on relationships with family or friends	49	49.00	6	20.69	43	60.56	22	53.66	27	45.76	11	47.83	19	45.24	19	54.29
Participant describes a negative impact overall	46	46.00	22	75.86	24	33.80	18	43.90	28	47.46	11	47.83	22	52.38	13	37.14

**Burden on family**

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 35 participants (35.00%) that felt there was an additional burden and 55 participants (55.00%) who felt there was no additional burden overall. Where participants described no additional burden, 33 participants (33.00%) that reported no additional burden but did not specify a reason, 11 participants (11.00%) felt they had required little assistance and 10 participants (10.00%) that felt that their condition was not a burden at the moment but is likely to be in the future. Where participants described there was an additional burden, this was primarily due to extra duties or responsibilities for family (n=16, 16.00%), a burden on family in general (n=12, 12.00%), and due to mental or emotional strain (n=8, 8.00%).

In relation to sub-group variations, participants in the *Frequent flare-ups* (11.11%), *Regional or remote* (17.65%), *Severe asthma* (17.24%) and *Poorly controlled asthma* (19.23%) sub-groups described that they did not feel that their condition is a burden without specifying a reason less frequently than the general population (33.00%), while those in the *Moderately controlled asthma* (50.00%), *Moderately to well controlled asthma* (47.92%), *Infrequent flare-ups* (47.83%), *Controlled asthma* (46.15%), *Occasional flare-ups* (43.90%) and *Infrequent sleep disruption* (43.90%) sub-groups described this more frequently. Participants in the sub-group *Moderately controlled asthma* describes feeling their condition is a burden due to extra duties or responsibilities their family member must take on less frequently (4.55%) than the general population (16.00%). Participants in this subgroup also described feeling that their condition is a burden on family generally more frequently (22.73%) than the general population (12.00%).

**Participant does not feel that their condition is a burden\does not specify reason**

*No, I don't think so. It's just something that I need to be conscious of. No, we're pretty good, we work around that. Participant 55*

*No, my husband's very good in looking after me to ensuring that I'm safe. Participant 64*

*Well, family-wise, it hasn't really had an impact. Participant 78*

**Participant feels that their condition is a burden on family\due to the extra duties or responsibilities on their family member**

*Yes, absolutely. My kids don't have that normal upbringing like most children, where they don't have to worry about how to care for their mum. My kids have never had an opportunity of just being kids. However, I've got to train my kids on what to do in an emergency because we don't have that opportunity to pretend that emergencies don't happen at home. We have to always have our plans reviewed and up to date. My kids know better than probably most kids their age, on what to do, where the medication is, how to do it, and what to do when I really can't breathe. What to say to the paramedic and go, "You know what, Mum's--" At times, they've had to ring the paramedic and go, "She can't breathe, her peak flow was 100. She is just crashing, um, and she's legit." Almost [crosstalk]. They have to make those phone calls and it's extremely hard on me because I'm just sitting here and going, "NAME, there's nothing I can do without the medical attention and help." That's not a normal kid-thing to experience or to say, "Okay, that's my responsibility now." Participant 3*

*I don't use my family anymore, so not really them. Yes, maybe my partner having to take me to appointments, or if I needed to go to the hospital when it gets bad. Participant 54*

*I don't think so, when I get sick it's very likely that it will go straight to my chest. Sometimes my partner will have to pick up the household duties if that happens. I guess there's a burden there but otherwise no, I don't think so. Participant 93*

**Participant feels that their condition is a burden on a family**

*I try not to let it be actually. It is and it has been but I'm really conscious of making it as minimal as possible. Definitely, it's been a problem. It's not a fun disease. Participant 58*

*I feel it, but they don't. I just get frustrated that I can't do things sometimes for them that I would usually be doing, but other than that, yes. It's more frustration. Participant 32*

*Yes. Certainly, as I get older, I think it affects me harder. Therefore, the effects on my family are more difficult. Participant 24*

Participant does not feel that their condition is a burden\as they have required little assistance

*No, they haven't. I'm very very independent with it. Apart from sometimes giving my husband a prescription if he's going to the shop or the chemist, or outside with the guys, I'm very fiercely independent with it. I don't think it's something you put in someone else's hands. Participant 86*

*I try not to make it. I try not to. When I get really sick, it is because I don't have a choice, but I try not to affect them with it. Participant 22*

*I strongly resist help. I don't think I put a burden on them. I want to be as independent as I can possibly be to the effect that they get cross with me for letting things go on too long and allowing myself to get too sick before I ask for help. Participant 7*

Participant does not feel that their condition is a burden\at this stage, but likely to be in the future

*Not at the moment but finding out the information about the respiratory test, I worry about down the track, what kind of impact that it will have on my life then but at the moment there's no issues. Participant 39*

*Not a present, though I'm aware that at some point that could become an issue. Obviously, whilst it's pretty quiet now, there's every chance that it could become an issue later on in life. Participant 100*

*No, certainly not at this stage. I don't know how it's going to be going forward but no, it's not been too bad. Participant 29*

Participant feels that their condition is a burden on family\due to the mental/emotional strain it places on the family

*Yes, absolutely. My kids don't have that normal upbringing like most children, where they don't have to worry about how to care for their mum. My kids have never had an opportunity of just being kids. However, I've got to train my kids on what to do in an emergency because we don't have that opportunity to pretend that emergencies don't happen at home. we have to always have our plans reviewed and up to date. My kids know better than probably most kids their age, on what to do, where the medication is, how to do it, and what to do when I really can't breathe. What to say to the paramedic and go, "You know what, Mum's--" At times, they've had to ring the paramedic and go, "She can't breathe, her peak flow was 100. She is just crashing, um, and she's legit." Almost [crosstalk]. They have to make those phone calls and it's extremely hard on me because I'm just sitting here and going, "NAME, there's nothing I can do without the medical attention and help." That's not a normal kid-thing to experience or to say, "Okay, that's my responsibility now." Participant 3*

*No, they get panicked although, like during winter because they know at some point I'm going to have an asthma attack, during flu season. I suppose it causes them a bit of anxiety. Participant 6*

*I would like to and it has always been my dream that one day they would find a cure for asthma so from a personal perspective for my children, my grandchildren so that they don't have to go through having it. Also, I know that NAME worries when I'm sick and my friends worry when I'm sick. I think I never say much but they do, yes. Participant 11*

Table 8.5.: Burden on family

Burden on family	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant does not feel that their condition is a burden does not specify reason	33	33.00	12	46.15	11	50.00	10	19.23	23	47.92	4	11.11	18	43.90	11	47.83
Participant feels that their condition is a burden on family due to the extra duties or responsibilities their family member	16	16.00	5	19.23	1	4.55	9	17.31	7	14.58	8	22.22	6	14.63	2	8.70
Participant feels that their condition is a burden on family	12	12.00	2	7.69	5	22.73	6	11.54	6	12.50	6	16.67	4	9.76	2	8.70
Participant does not feel that their condition is a burden as they've required little assistance	11	11.00	2	7.69	1	4.55	8	15.38	3	6.25	4	11.11	3	7.32	4	17.39
Participant does not feel that their condition is a burden at this stage, but likely to be in the future	10	10.00	1	3.85	2	9.09	7	13.46	3	6.25	5	13.89	4	9.76	1	4.35
Participant feels that their condition is a burden on family due to the mental/emotional strain it places on their family	8	8.00	0	0.00	0	0.00	8	15.38	0	0.00	3	8.33	4	9.76	1	4.35
Participant does not feel that their condition is a burden on family (total)	55	55.00	15	57.69	15	68.18	26	50.00	29	60.42	13	36.11	26	63.41	16	69.57
Participant feels that their condition is a burden on family (total)	35	35.00	8	30.77	6	27.27	21	40.38	14	29.17	18	50.00	12	29.27	5	21.74

Burden on family	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant does not feel that their condition is a burden does not specify reason	33	33.00	5	17.24	28	39.44	18	43.90	15	25.42	8	34.78	11	26.19	14	40.00
Participant feels that their condition is a burden on family due to the extra duties or responsibilities their family member	16	16.00	5	17.24	11	15.49	6	14.63	10	16.95	4	17.39	9	21.43	3	8.57
Participant feels that their condition is a burden on family	12	12.00	5	17.24	7	9.86	5	12.20	7	11.86	2	8.70	6	14.29	4	11.43
Participant does not feel that their condition is a burden as they've required little assistance	11	11.00	4	13.79	7	9.86	3	7.32	8	13.56	1	4.35	5	11.90	5	14.29
Participant does not feel that their condition is a burden at this stage, but likely to be in the future	10	10.00	4	13.79	6	8.45	3	7.32	7	11.86	4	17.39	2	4.76	4	11.43
Participant feels that their condition is a burden on family due to the mental/emotional strain it places on their family	8	8.00	5	17.24	3	4.23	0	0.00	8	13.56	0	0.00	5	11.90	3	8.57
Participant does not feel that their condition is a burden on family (total)	55	55.00	13	44.83	42	59.15	24	58.54	31	52.54	13	56.52	18	42.86	24	68.57
Participant feels that their condition is a burden on family (total)	35	35.00	13	44.83	22	30.99	13	31.71	22	37.29	7	30.43	19	45.24	9	25.71

Burden on family	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant does not feel that their condition is a burden does not specify reason	33	33.00	27	40.91	6	17.65	11	25.00	22	39.29	19	33.93	14	31.82
Participant feels that their condition is a burden on family due to the extra duties or responsibilities their family member	16	16.00	12	18.18	4	11.76	9	20.45	7	12.50	8	14.29	8	18.18
Participant feels that their condition is a burden on family	12	12.00	7	10.61	5	14.71	3	6.82	9	16.07	7	12.50	5	11.36
Participant does not feel that their condition is a burden as they've required little assistance	11	11.00	6	9.09	5	14.71	8	18.18	3	5.36	7	12.50	4	9.09
Participant does not feel that their condition is a burden at this stage, but likely to be in the future	10	10.00	4	6.06	6	17.65	5	11.36	5	8.93	5	8.93	5	11.36
Participant feels that their condition is a burden on family due to the mental/emotional strain it places on their family	8	8.00	5	7.58	3	8.82	3	6.82	5	8.93	5	8.93	3	6.82
Participant does not feel that their condition is a burden on family (total)	55	55.00	37	56.06	18	52.94	24	54.55	31	55.36	31	55.36	24	54.55
Participant feels that their condition is a burden on family (total)	35	35.00	24	36.36	11	32.35	15	34.09	20	35.71	20	35.71	15	34.09

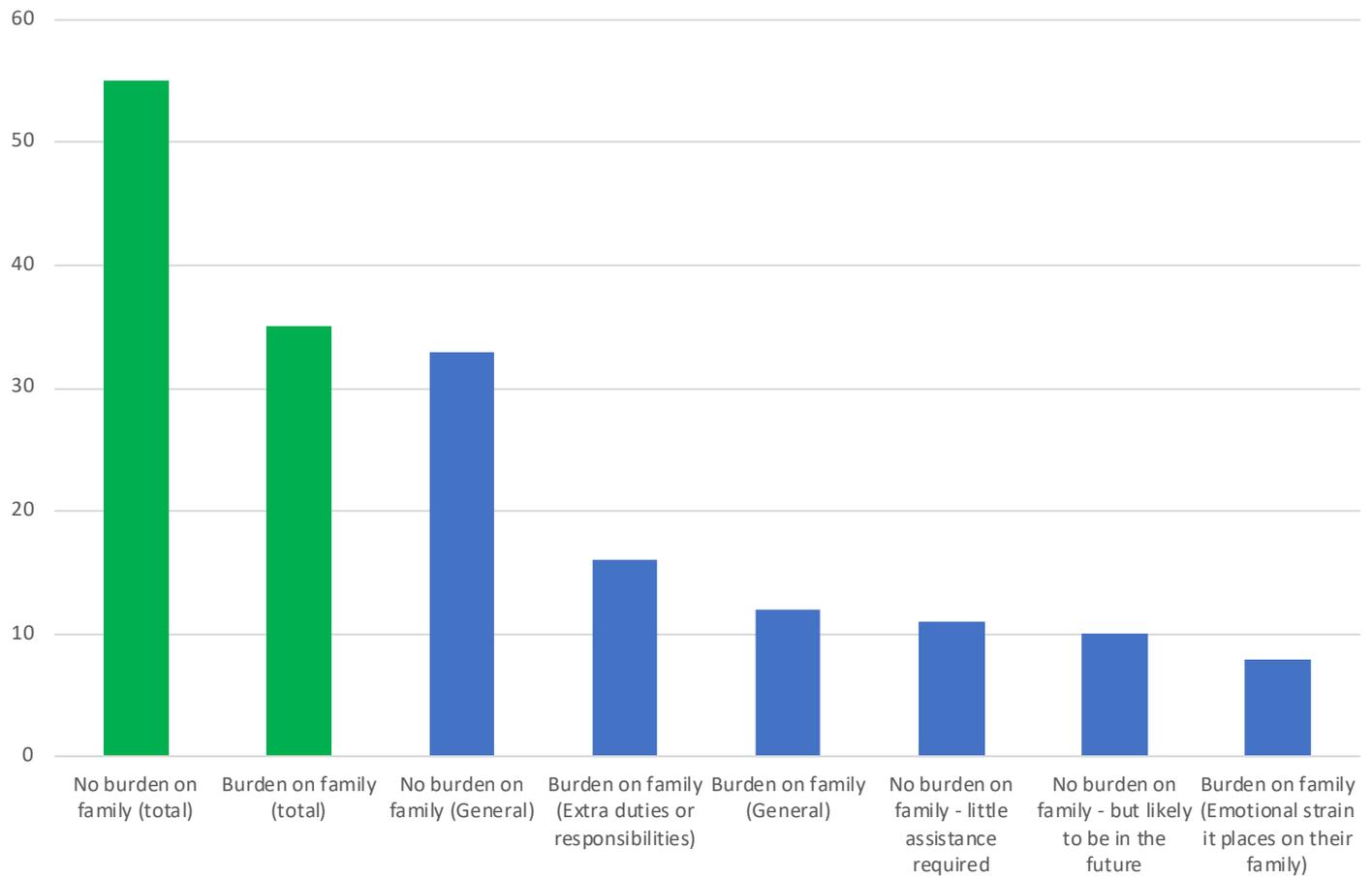


Figure 8.5: Burden on family

### Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 53 participants (53.00%) that spoke about struggling with the costs of treatments, and 38 participants (38.00%) that reported needing to take time of work. Other costs described cost of general practitioner and specialist appointments (particularly repeat scripts, travel time/cost) (20.00%), indirect costs in relation to their ability to make life choices (12.00%), and family members needing to take time of work (10.00%). There were 11 participants (11.00%) who described that they were not struggling with costs.

In relation to sub-group variations, participants in the *Controlled asthma* (38.46%), *Infrequent sleep disruption* (41.16%), *Non-severe asthma* (42.25%) and *Age 18 to 34* (39.13%) sub-groups described Struggling with the cost of treatments less frequently than the general population (53.00%). Whereas participants in the sub-group *Severe asthma* describe this more frequently (79.31%). Participants in the *Infrequent flare ups* (21.74%), *Infrequent sleep disruption* (24.39%) and *Controlled asthma* (26.92%) sub-groups described needing to take time of work less frequently than the general population (38.00%). Whereas those in the sub-group *Severe asthma* describe this more frequently (55.17%)

Participants in the *Infrequent flare ups* sub-group described costs described cost of general practitioner and specialist appointments (particularly repeat scripts, travel time/cost) less frequently (8.70%) than the general population 20.00%), while those in the *Regional or remote* sub-group described this more frequently (32.35%). Participants in the *Infrequent flare up* sub-group described not struggling with costs more frequently (21.74%) than the general population (11.00%) as do participants in the sub-group *Controlled asthma* (23.08%). However, no participants in the sub-group *Severe asthma* describe this (0.00%).

### Participant describes struggling with the cost of treatments

*I think since I've been diagnosed with asthma it has been a costly affair. I do have to spend money for my medication every month, plus time off work when I do have a really bad attack. Participant 5*

*I have a pensioners concession, even so, the drugs are a significant cost because it's so many of them. Participant 7*

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*Cost of medications, but even if you have a healthcare like I do it still adds up. I'm trying to think as well. I'm lucky the treatment I'm on at the moment is covered. Participant 13*

### Participant describes needing to take time off work

*I don't work anymore but I've had a lot of time off work. I might not have lost necessarily for lost income but I've certainly lost opportunities. The actual financial costs, a lot of the equipment is expensive to buy. Participant 7*

*I decided I needed to cut back, it was recommended by my doctor if it was possible and financially it was hard but I've beat it because the benefits of my health, I moved from a five day working week to a four day working week and I'm able to not work Wednesdays. I'm now paid for an eight-day fortnight rather than a 10 day fortnight, that's a cost. Participant 14*

*I can't put a figure on it because I have cracked in a lot of unpaid leave days over my life from work with asthma attacks. Probably just a week a year of unpaid leave, at least. Some days you might need a mental health day because you're feeling crap, that you think you're going to get hospitalized or something like that, so there's a lot of anxiety around asthma as well, and a lot of mental health issues that people aren't aware of with chronic conditions as well. Participant 33*

### Participant describes struggling with the cost of gp and specialist appointments (particularly repeat scripts, travel time/cost)

*Yes, because I'm on low income it's critical. Yes. What I actually did when I had money is, I went and got my prescriptions a bit before I should have. So, I had some in reserve. Yes, it's a big factor, because part of that, where I am is the travel costs to go and get it. Participant 4*

*Then the specialist and the traveling, days off work because I've been in hospital, they haven't always covered it. Very expensive actually. I've never think about it until now. Participant 9*

*It'd be our fuel costs into town and back twice a week. The cost of the treatments. Participant 11*

*Travel as well. Traveling to appointments, travel when you are in hospital as well, that's costing to my family to pay for parking. Participant 13*

### Participant describes indirect costs in relation to their ability to make life choices

*I guess the only other thing would have been when I've been traveling and on holidays, sometimes I've found it difficult to participate in some activities. It's a cost to enjoying the holiday because I couldn't enjoy things completely. Participant 37*

*I basically am housebound in winter because winter brings wood heaters. Wood smoke is my number one trigger and-- wood smoke and cigarette smoke. I basically end up housebound. Because of my nerve injury on my foot I can't actually go out and do work in a workplace anyway. It's hard for me to say a cost wise, but it means that I lose I suppose my quality of life in winter reduces a lot. Participant 10*

*Apart from all of the emotional turmoil and trauma that my illness has caused me in my life, which has been, like you said, very costly for how my life had developed. I haven't achieved a lot of my personal goals. A lot psychiatrists I've seen have told me that I'm doing incredibly well to someone who has been through what I've been through. They told me that most people who have had my life can't hold down a full-time job, can't go to university, things like that. I feel really proud of myself in regards to-- I have been able to achieve those things, but still I had bigger dreams. The impact of the trauma has held me back a lot from doing so much with my life. Even today, now it's impacted my social life. I have to cancel a lot of friends when I get a flare-up, and then they don't understand because they just think it's asthma or whatever. There's a lot of breakdown of relationships, that happen to do with the silent illness like this where we are in a country where so many people do have it. I do feel like it's not just the expenses paying for medications and specialists, and constantly going to the GP to get a medical certificate to be off work or whatever, there's all those other emotional things that are impacted. The work life is impacted, relationships are impacted. I'm embarrassed to have to take my Ventolin sometimes when I'm out as well. There's a real stigma. I do feel like there is a bit of a stigma still with asthma. Participant 20*

### Participant describes not struggling with costs

*It hasn't been too significant. It's just something I budget in when I think about the cost of medication so it hasn't impacted me to heavily, I think Participant 47*

*It's not significant to me, no. It's obviously a lot that I have to pay it, but it's not significant. Participant 91*

*I probably got my three-monthly cost of my preventer, but that's about the only cost, and it's not definitely not cost inhibitive. It's only like \$30 for every three months. Participant 71*

### Participant describes a family member needing to take time off work

*Exactly. Having my fiance having to take time off because he's worried he's going come home and I'm be on the floor. He's a dramatic, but I rather that. At least he cares. Participant 26*

*When my son has had to care for me, there are times when he's taken time off work to take me to appointments, to see me in hospitals look after me when I've come home so there's costs there. Plus just taking time from work to have appointments. My GP doesn't work. He isn't available on Wednesdays. He is lovely and goes to retirement villages and sees the people there. Participant 14*

*There was really no cost but, my mum did have to take off work quite regularly when I couldn't attend school. Participant 93*

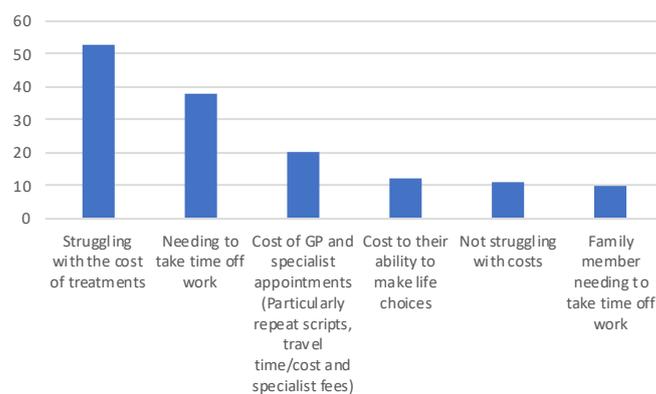


Figure 8.6: Cost considerations

Table 8.6: Cost considerations

Cost considerations	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes struggling with the cost of treatments	53	53.00	10	38.46	13	59.09	30	57.69	23	47.92	18	50.00	25	60.98	10	43.48
Participant describes needing to take time off work	38	38.00	7	26.92	7	31.82	23	44.23	15	31.25	15	41.67	18	43.90	5	21.74
Participant describes struggling with the cost of GP and specialist appointments (Particularly repeat scripts, travel time/cost)	20	20.00	5	19.23	4	18.18	11	21.15	9	18.75	8	22.22	10	24.39	2	8.70
Participant describes indirect costs in relation to their ability to make life choices	12	12.00	3	11.54	2	9.09	7	13.46	5	10.42	5	13.89	2	4.88	5	21.74
Participant describes not struggling with costs	11	11.00	6	23.08	2	9.09	4	7.69	7	14.58	4	11.11	2	4.88	5	21.74
Participant describes a family member needing to take time off work	10	10.00	3	11.54	1	4.55	6	11.54	4	8.33	3	8.33	6	14.63	1	4.35

Cost considerations	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes struggling with the cost of treatments	53	53.00	23	79.31	30	42.25	17	41.46	36	61.02	9	39.13	26	61.90	18	51.43
Participant describes needing to take time off work	38	38.00	16	55.17	22	30.99	10	24.39	28	47.46	11	47.83	15	35.71	12	34.29
Participant describes struggling with the cost of GP and specialist appointments (Particularly repeat scripts, travel time/cost)	20	20.00	7	24.14	13	18.31	6	14.63	14	23.73	4	17.39	9	21.43	7	20.00
Participant describes indirect costs in relation to their ability to make life choices	12	12.00	5	17.24	7	9.86	4	9.76	8	13.56	3	13.04	4	9.52	5	14.29
Participant describes not struggling with costs	11	11.00	0	0.00	11	15.49	7	17.07	4	6.78	2	8.70	6	14.29	3	8.57
Participant describes a family member needing to take time off work	10	10.00	2	6.90	8	11.27	5	12.20	5	8.47	4	17.39	4	9.52	2	5.71

Cost considerations	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes struggling with the cost of treatments	53	53.00	34	51.52	19	55.88	25	56.82	28	50.00	31	55.36	22	50.00
Participant describes needing to take time off work	38	38.00	25	37.88	13	38.24	20	45.45	18	32.14	20	35.71	18	40.91
Participant describes struggling with the cost of GP and specialist appointments (Particularly repeat scripts, travel time/cost)	20	20.00	9	13.64	11	32.35	11	25.00	9	16.07	8	14.29	12	27.27
Participant describes indirect costs in relation to their ability to make life choices	12	12.00	9	13.64	3	8.82	3	6.82	9	16.07	8	14.29	4	9.09
Participant describes not struggling with costs	11	11.00	8	12.12	3	8.82	4	9.09	7	12.50	7	12.50	4	9.09
Participant describes a family member needing to take time off work	10	10.00	7	10.61	3	8.82	6	13.64	4	7.14	5	8.93	5	11.36

### 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 8.7. Overall the entire cohort had a median total score of 31.00 (IQR = 14.00), which corresponds to low levels of anxiety.

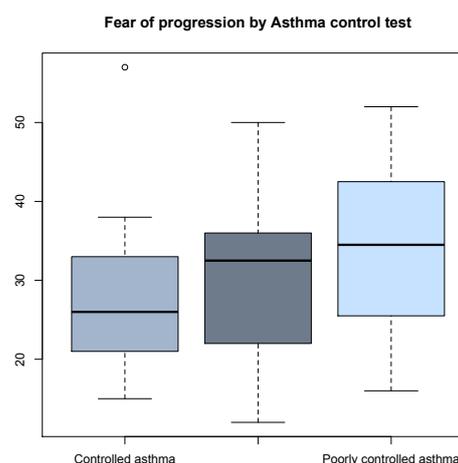
The Fear of progression total score comparisons have been made by sub-groups, summary statistics are listed in Table 8.7.

**Table 8.7: Fear of progression total score summary statistics**

Subgroups	Group	Count	Percent	Mean	SD	Median	IQR
<b>Subgroups</b>	<b>Group</b>	<b>Count</b>	<b>Percent</b>	<b>Mean</b>	<b>SD</b>	<b>Median</b>	<b>IQR</b>
<b>All participants</b>	<i>All participants</i>	100	100.00	31.38	10.19	31.00	14.00
<b>Asthma control test</b>	<i>Controlled asthma</i>	26	26.00	27.23	9.04	26.00	11.75
	<i>Moderately controlled asthma</i>	22	22.00	30.77	9.45	32.50	13.50
	<i>Poorly controlled asthma</i>	52	52.00	33.71	10.49	34.50	16.50
<b>Asthma control test</b>	<i>Moderate to well controlled asthma</i>	48	48.00	28.85	9.30	28.50	12.50
	<i>Poorly controlled asthma</i>	52	52.00	33.71	10.49	34.50	16.50
<b>Flare</b>	<i>Frequent flare-ups</i>	36	36.00	33.67	10.52	33.50	12.25
	<i>Occasional flare-ups</i>	41	41.00	30.02	10.20	28.00	17.00
	<i>Infrequent flare-ups</i>	23	23.00	30.22	9.40	30.00	10.00
<b>Sleep</b>	<i>Frequent sleep disruption</i>	59	59.00	33.56	10.22	34.00	16.50
	<i>Infrequent sleep disruption</i>	41	41.00	28.24	9.40	27.00	11.00
<b>Age</b>	<i>Aged 55 or older</i>	23	23.00	31.87	10.04	32.00	12.50
	<i>Aged 35 to 44</i>	42	42.00	31.71	9.54	31.50	13.50
	<i>Aged 18 to 34</i>	35	35.00	30.66	11.24	30.00	15.50
<b>Location</b>	<i>Metropolitan</i>	66	66.00	31.06	9.76	32.00	13.00
	<i>Regional or remote</i>	34	34.00	32.00	11.10	30.50	17.75
<b>Education</b>	<i>Trade or high school</i>	44	44.00	31.32	9.77	32.50	13.25
	<i>University</i>	56	56.00	31.43	10.59	30.00	14.00
<b>SEIFA</b>	<i>High SEIFA</i>	56	56.00	29.54	10.22	28.50	16.00
	<i>Mid to low SEIFA</i>	44	44.00	33.73	9.75	33.00	12.25

### Fear of progression by Asthma control test (three groups)

**Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between participants that scored 20 or more *Controlled asthma* (n=26, 26.00%), between 16 and 19, *Moderately controlled asthma* (n=22, 22.00%), and those who scored 15 or less *Poorly controlled asthma* (n=52, 52.00%). A one way ANOVA test indicated a statistically significant difference in the **“Fear of progression total score”** between groups,  $F(2, 96) = 3.76$ ,  $p = 0.0268$  (Table 8.5). Post hoc comparisons using the Tukey HSD test indicated that the mean score for those with *Poorly controlled asthma* (mean =33.71, SD = 10.49) was significantly higher than participants with *Controlled asthma* (mean = 27.23, SD = 9.04,  $p=0.0209$ ).



**Figure 8.7: Fear of progression by Asthma control test**

The mean **“Fear of progression total score”** was significantly lower (less anxiety) for participants with *Controlled asthma* compared to participants with *Poorly controlled asthma*. These scores correspond to low anxiety for participants with *Controlled Asthma*, and moderate anxiety for participants with *Poorly controlled asthma*.

**Table 8.8: Fear of Progression Total Score by Asthma control test ANOVA Table**

Subgroup		Sum of squares	dF	Mean Square	F	p
Asthma control test	Between groups	738.00	2	369.20	3.76	0.0268*
	Within groups	9535.00	97	98.30		
	Total	10273.00	99			

\*Statistically significant at  $p=0.05$

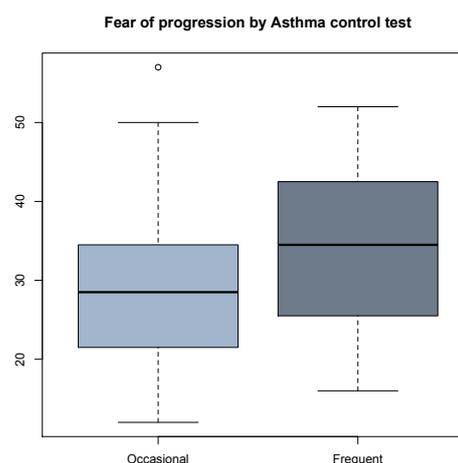
**Table 8.9: Fear of Progression Total Score by Asthma control test post hoc Tukey HSD test**

Subgroup	Sub-group comparison	Difference	Lower	Upper	P adjusted
Asthma control test	<i>Moderately controlled asthma – Controlled asthma</i>	3.54	-3.29	10.38	0.4366
	<i>Poorly controlled asthma – Controlled asthma</i>	6.48	0.81	12.15	0.0209*
	<i>Poorly controlled asthma – Moderately controlled asthma</i>	2.94	-3.06	8.941	0.4766

\*Statistically significant at  $p=0.05$

### Fear of progression by Asthma control test (two groups)

**Asthma control test** is a five-item questionnaire that helps determine level of asthma treatment required. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma. Comparisons were made between those who scored between 16 and 25 *Moderate to well controlled asthma* (n=48, 48.00%), and those who score 15 or less *Poorly controlled asthma* (n=52, 52.00%). Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Fear of progression total score”** [W=906.00, p=0.0184] was significantly higher for those with *Poorly controlled asthma* (Median = 34.50, IQR =16.50) compared to those with *Moderately to well controlled asthma* (Median =28.50, IQR = 12.50).



**Figure 8.8: Fear of progression by Asthma control test**

The median **“Fear of progression total score”** was significantly lower (less anxiety) for participants with *Moderately to well controlled asthma* compared to participants with *Poorly controlled asthma*. These scores correspond to low anxiety for participants with *Moderately to well controlled asthma*, and moderate anxiety for participants with *Poorly controlled asthma*.

**Table 8.10: Fear of Progression Total Score by Asthma control test Wilcoxon rank sum tests with continuity correction**

Group	Subgroup	Count	Percent	Median	IQR	W	p
Asthma control test	<i>Moderate to well controlled asthma</i>	48	48.00	28.50	12.50	906.00	0.0184*
	<i>Poorly controlled asthma</i>	52	52.00	34.50	16.50		

### Fear of progression by Flare-ups

Comparisons were made by **Flare-ups**, between participants that reported having a flare-up or asthma attacks once a month or more frequently, *Frequent flare-ups* (n=36, 36.00%), those that had a flare up once a month to once every three months, *Occasional flare-ups* (n=41, 41.00%), and those that had a flare-up once or twice a year, *Infrequent flare-ups* (n=23, 23.00%). No significant differences were observed by a Kruskal-Wallis test between participants by **Flare-ups** for the “**Fear of progression total score**”.

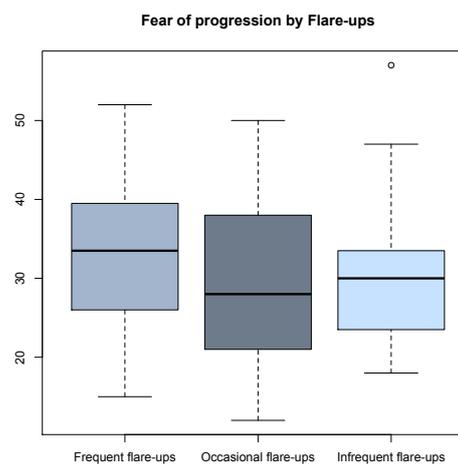


Figure 8.9: Fear of progression by Flare-ups

No significant differences were observed by a Kruskal-Wallis test between participants by **Flare-ups** for the “**Fear of progression total score**”.

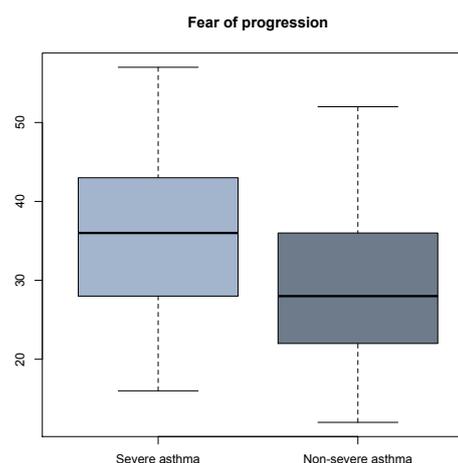
Table 8.11: Fear of Progression Total Score by Flare-ups Kruskal-Wallis test

Subgroup	$\chi^2$	df	p
Flare-ups	2.51	2	0.2850

### Fear of progression by Severity

Comparisons were made by **Severity**, between participants that reported having *Severe asthma* (n=29, 29.00%), and those that had *Non-severe asthma* (n=79, 79.00%). Participants in the Severe asthma sub-group included those who confirmed that they had been diagnosed with severe asthma in the semi-structured interview (this was then cross-checked with the treatments they are taking for verification), and those that were taking regular treatments beyond preventer and reliever medication including monoclonal antibodies, daily/very frequent oral corticosteroid use, long acting muscarinic antagonists, leukotriene receptor antagonists, or a high dose of regular treatment (such as high dose Seretide).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Fear of progression total score”** [W=1385.00, p=0.0070] was significantly higher for those with *Severe asthma* (Median = 36.00, IQR =15.00) compared to those with *Non-severe asthma* (Median =28.00, IQR = 14.00).



**Figure 8.10: Fear of progression by Severity**

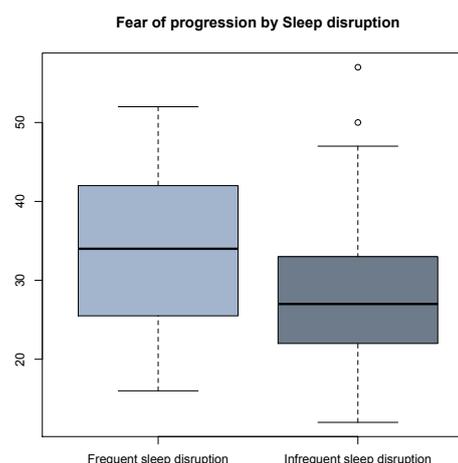
The median **“Fear of progression total score”** was significantly lower (less anxiety) for participants with *Non-severe asthma* compared to participants with *Severe asthma*. These scores correspond to low anxiety for participants with *Non-severe asthma*, and moderate anxiety for participants with *Severe asthma*.

**Table 8.12: Fear of Progression Total Score by Asthma control test Wilcoxon rank sum tests with continuity correction**

Fear of progression	Group	Count	Percent	Median	IQR	W	p
Fear of progression total score	Severe asthma	29	29.00	36.00	15.00	1385.00	0.0070*
	Non-severe asthma	71	71.00	28.00	14.00		

### Fear of progression by Sleep disruption

Comparisons were made by the frequency of **Sleep disruption**, those who noted in the Asthma control test the frequency that they had sleep disruptions due to asthma. Those that had sleep disruptions once a week or more frequently, *Frequent sleep disruption* (n=59, 59.00%) were compared to those who responded that they had sleep disruptions once a month or not at all *Infrequent sleep disruption* (n=41, 41.00%). Wilcoxon rank sum tests with continuity correction indicated that the median score for the **“Fear of progression total score”** [W=1587.00, p=0.0082] was significantly higher for those with *Frequent sleep disruption* (Median = 34.00, IQR =16.50) compared to those with *Infrequent sleep disruption* (Median =27.00, IQR =11.00).



**Figure 8.11: Fear of progression by Sleep disruption**

The median **“Fear of progression total score”** was significantly lower (less anxiety) for participants with *Infrequent sleep disruption* compared to participants with *Frequent sleep disruption*. These scores correspond to low anxiety for participants with *Infrequent sleep disruption*, and moderate anxiety for participants with *Frequent sleep disruption*.

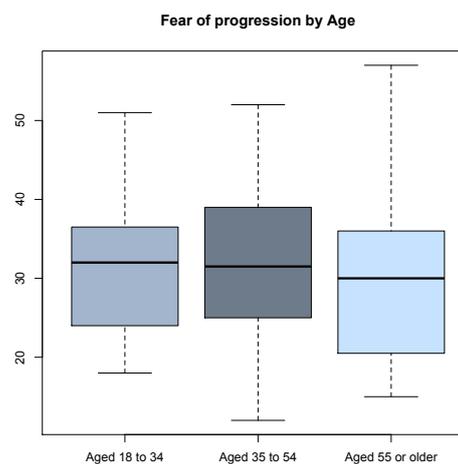
**Table 8.13: Fear of Progression Total Score by Sleep disruption Wilcoxon rank sum tests with continuity correction**

Group	Subgroup	Count	Percent	Median	IQR	W	p
Sleep	<i>Frequent sleep disruption</i>	59	59.00	34.00	16.50	1587.00	0.0082*
	<i>Infrequent sleep disruption</i>	41	41.00	27.00	11.00		

\*Statistically significant at p=0.05

### Fear of progression by Age

Comparisons were made by the **Age** of the participants, those that were *Aged 18 to 34* (n=23, 23.00%), *Aged 35 to 54* (n=42, 42.00%) and participants *Aged 55 or older* (n=35, 35.00%). No significant differences were observed by a Kruskal-Wallis test between participants by **Age** for the “**Fear of progression total score**”.



**Figure 8.12: Fear of progression by Age**

No significant differences were observed by a Kruskal-Wallis test between participants by **Age** for the “**Fear of progression total score**”.

**Table 8.14: Fear of Progression Total Score by Kruskal-Wallis test**

Subgroup	$\chi^2$	df	p
Age	0.69	2	0.7075

### Fear of progression 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 major city, *Metropolitan* (n=66, 66.00%), were compared to those living in *Regional or remote* areas (n=34, 34.00%).

No significant differences were observed by a Wilcoxon rank sum test with continuity correction between participants by **Location** for any of the “**Fear of progression total score**”.

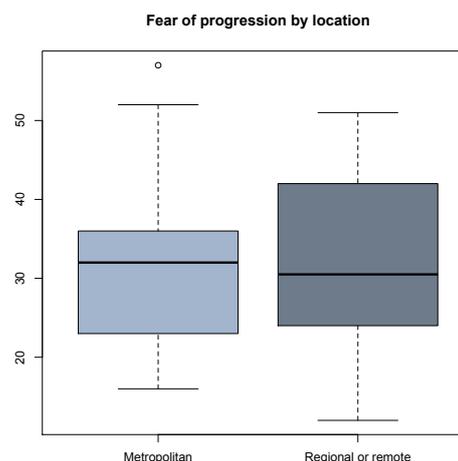


Figure 8.13: Fear of progression by Location

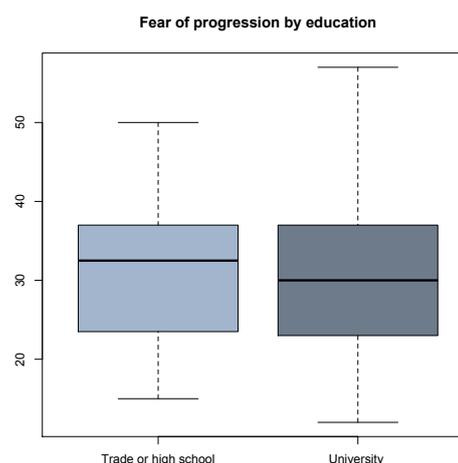
No significant differences were observed by a Wilcoxon rank sum test with continuity correction between participants by **Location** for any of the “**Fear of progression total score**”.

Table 8.15: Fear of Progression Total Score by Location Wilcoxon rank sum test with continuity correction

Group	Subgroup	Count	Percent	Median	IQR	W	p
Location	<i>Metropolitan</i>	66	66.00	32.00	13.00	1070.50	0.7104
	<i>Regional or remote</i>	34	34.00	30.50	17.75		

### Fear of progression by Education

Comparisons were made by **Education** status, between those with a *University* qualification, (n=56, 56.00%), and those with *Trade or high school* qualifications (N=44, 44.00%). No significant differences were observed by a two sample t-test between participants by **Education** for any of the “**Fear of progression total score**”.



**Figure 8.14: Fear of progression by Education**

No significant differences were observed by a two sample t-test between participants by **Education** for the “**Fear of progression total score**”.

**Table 8.16: Fear of Progression Total Score by Education two sample t-test**

Group	Subgroup	Count	Percent	Mean	SD	t	dF	p
Education	<i>Trade or high school</i>	44	44.00	31.32	9.77	-0.05	98	0.9574
	<i>University</i>	56	56.00	31.43	10.59			

### Fear of progression 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=56 56.00%), compared to those with a mid to low SEIFA score of 1-6, *Mid-low SEIFA* (n=44, 44.00%).

No significant differences were observed by a Wilcoxon rank sum test with continuity correction between participants by SEIFA for any of the “Fear of progression total score”.

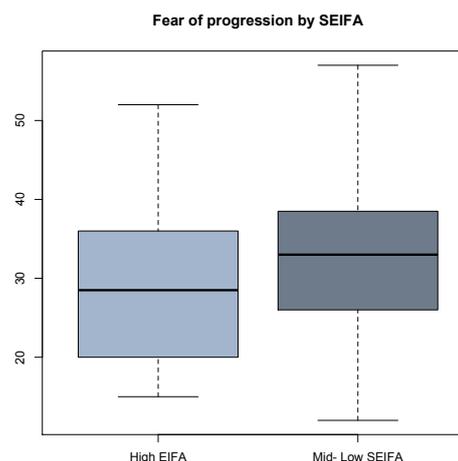


Figure 8.15: Fear of progression by SEIFA

No significant differences were observed by a Wilcoxon rank sum test with continuity correction between participants by SEIFA for any of the “Fear of progression total score”.

Table 8.17: Fear of Progression Total Score by SEIFA Wilcoxon rank sum test with continuity correction

Group	Subgroup	Count	Percent	Median	IQR	W	p
SEIFA	High SEIFA	56	56.00	28.50	16.00	1244.00	0.9363
	Mid to low SEIFA	44	44.00	33.00	12.25		

# Section 9 Expectations and messages

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

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was participants expecting treatments to become more affordable, noting that cost is currently a burden (n=45, 45.00%). This was followed by participants expecting treatments to become easier to administer with less disruption (for example injections or tablets) (n=39, 39.00%). There were 17 participants (17.00%) that recommended that treatments have less side effects, often in relation to long-term side effects of steroids and 9 participants (9.00%) that called for more effective treatments, particularly in relation to immediate and longer-lasting relief.

**Expectations of future information**

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common themes were participants recommending more detailed information about current and emerging treatments (including research and clinical trials (n=18, 18.00%), and participants recommending more information to help the community understand the severity of asthma and common triggers (n=18, 18.00%). This was followed by participants recommending comprehensive information in a language that is easy to understand (without jargon or overly scientific language) (n=16, 16.00%). There were 14 participants (14.00%) that did not have any recommendations or were satisfied with information. There were 10 participants (10.00%) that recommended information or tools to help them manage and monitor their asthma and its side effects.

**Expectations of future communication with healthcare professionals**

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were participants experiencing good communication with health professionals (n=24, 24.00%), and participants recommending that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans (n=24, 24.00%). These were followed by participants recommending that health professionals have a better understanding of the severity of asthma, emergency care, and how to manage asthma (n=17, 17.00%). There were 14 participants (14.00%) who recommended health professionals listening to patients and not dismissing their concerns, or that they have expertise in their own condition. There were 14 participants (14.00%) that recommended that health professionals should take more time to explain treatment options and share details of what to expect from their diagnosis.

**Expectations of future care and support**

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was participants not having any suggestions, or reporting being content with the care received (n=15, 15.00%), followed by participants recommending more long-term asthma management and treatment plans and/or holistic care (n=12, 12.00%). There were nine participants (9.00%) that recommended more community-based support, specifically peer support including support groups and information sessions, or family peer support, and 8 participants (8.00%) that recommended more opportunities to access specialists in asthma for treatment, information and support.

**What participants are grateful for in the health system**

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for access to treatment through Medicare (n=24, 24.00%) This was followed by being grateful for the entire health system (n=19, 19.00%), being grateful for healthcare staff (n=18, 18.00%), being grateful that the health system is low cost or free (n=17, 17.00%) and being grateful for access to hospital care through Medicare (n= 8, 8.00%).

### **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. The most important aspects reported were shortness of breath and coughing or wheezing attacks worsened by a respiratory virus. The least important was whistling or wheezing sound when exhaling.

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

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=66, 66.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

### **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.

### **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**

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was that the cost of treatment is a burden (n=35, 35.00%), followed by the message that there should be equitable funding, with specific focus on the need for long-term treatment options and cost-effective management (n=23, 23.00%). This was followed by the message that there needs to be more education within the general community so that the severity of the condition is understood (n=22, 22.00%). There were 17 participants (17.00%) described the message that there needs to be more education for medical professionals to know how to best treat asthma and empower patient awareness of treatment options or services available. The message that there should be specialist treatments or access to specialist help for management and care plan development was reported by 13 participants (13.00%).

## Section 9

### Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments were. The most common theme was participants expecting that treatments would become more affordable, noting that cost was a burden (n=45, 45.00%), and this was followed by participants expecting that treatments would become easier to administer with less disruption (for example injections or tablets) (n=39, 39.00%). There were 17 participants (17.00%) that recommended that treatments have less side effects, often in relation to long-term side effects of steroids. 9 participants (9.00%) called for more effective treatments, particularly in relation to immediate and longer-lasting relief.

In relation to sub-group variations, participants in the *Controlled asthma* (30.77%) and *University* (32.14%) sub-groups described expecting treatments to become more affordable less frequently than the general population (45.00%), while those in the *Trade or high school* (61.36%), *Severe asthma* (55.17%) and *Frequent flare-ups* (55.56%) sub-groups described this more frequently.

Participants *Age 18 to 34* (21.74%), and participants in the *Trade or high school* (25.00%) sub-group described expecting that treatments would become easier to administer with less disruption (for example injections or tablets) less frequently than the general population (39.00%), while participants *Aged 35 to 54* (52.38%), and participants in the *University* sub-group (50.00%) described this more often.

Participants in the *Controlled asthma* sub-group described recommended that treatments have less side effects, often in relation to long-term side effects of steroids more frequently (30.77%) than the general population (17.00%).

**Participant's expectation is that treatments are more affordable, noting that cost is currently a burden**

*The cost is one thing like, that was when they told me I had to wait for 12 months before the government would then, cover the cost of these injections. Then that was sort of hard because I'm like, "Oh God, that's 12 months that I've got to lie around and I'll miss out on the kids and stuff like that. Participant 2*

*Huge thing would be cost covered or substantially reduced because, for someone that has diagnosed chronic severe asthma that's uncontrollable, the cost financially is hard. Participant 3*

*It would be nice not to have to take it so often and it would be nice that it was more affordable. Participant 6*

*Things that are quite expensive, especially for families that have financial difficulties, they struggle to make ends meet, having something that's not so much breaking the bank as other families may have, that would definitely be a benefit to people that can't always afford the medication and do suffer for it. Participant 48*

**Participant's expectation is for treatments that are easier to administer with less disruption to everyday life (for example injections or tablets)**

*Okay. I would prefer to take a tablet than an inhaler. That I find the inhaler-- I don't like the taste, I don't like the feel of them. I don't like the way they make me feel breathless when I have to breathe in heavily to get it into my lungs. Everything about the inhaled stuff makes me annoyed and frustrated, so I would much rather take a tablet if I could. If I had that option, I would definitely take it. Participant 47*

*In terms of treatment, I'd like to see treatments that really and I've watched it over the years. Has enabled people's quality of life to improve simply because treatment has improved. You go back to the time in the '50s when it was seen as a psychological disease. I'd love to have a treatment whereby you have a pill or an injection once a year and you have no symptoms. That would be great. Participant 11*

*I think there has to be an alternative to steroids for a start, because not every asthmatic needs to get that because they've got to have steroids. I think an*

## Section 9

*injection would be wonderful. It would solve a lot of problems really. Participant 22*

Participant's expectation is for treatments that have less side effects, this was often in relation to long term side effects of steroids

*Fewer side effects would be good. I understand putting medication in your system is always going to do things, but I don't know. Maybe something that works a bit more long-term that you don't need to take every day. Participant 26*

*It's hard to know because the side effects of the side effects-- I'd like to be able to take something that doesn't give me awful cramps. That's really the main thing for me. It could be quite painful when they're in strange places. I've told the doctor that. They look at me like I'm a bit odd. I know a lot of people get it too, when you talk to other people, so it's not just me [laughs]. Participant 50*

*The biggest worry that I have is because I've been on these drugs 30 years, what the risk will be in the longer term, so that's probably my concern. At the end of the day, what can I do? I need to have it to survive so you're sort of, "Well, it is what it is." I don't ever worry about it, but obviously, it's something that's always in the back of your mind. Participant 99*

Participant recommends more effective treatments particularly in relation to immediate and longer lasting relief

*I think anything that can give you instant or almost instant relief is the best thing out. There's nothing*

*worse than having to wait for something to take effect. Participant 49*

*Maybe if a better effectiveness could be a good one, instead of-- I know that you've got you've preventives in that, but if someone isn't quite that bad that they need a preventer, but something that lasts a good 12 hours just to get them through a sports day or something, but not something they have to have every day. Participant 62*

*When I don't have an asthma episode, like I know I'm a lifelong asthmatic but I'm well controlled on my meds now but when I have a flare up I want something that's going to work a heck of a lot quicker so I don't have that fear, so I don't have that anxiety, so it doesn't make me sleep upright in a chair so it doesn't cause me sleeplessness, so it doesn't impact so immensely on my quality of life. That's a very broad answer to your question than you probably wanted it to be. Participant 87*

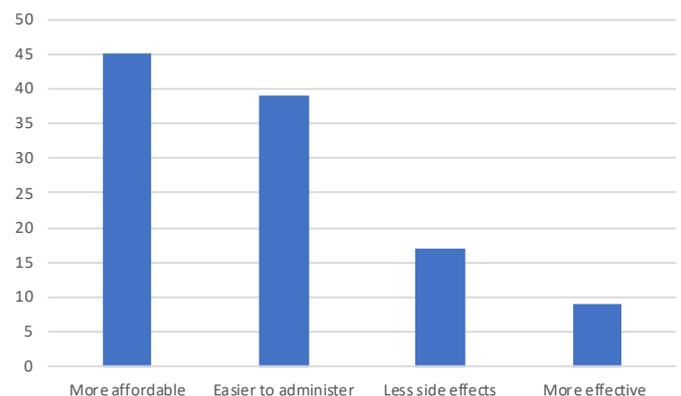


Figure 9.1: Expectations of future treatment

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant's expectation is that treatments are more affordable, noting that cost is currently a burden	45	45.00	8	30.77	11	50.00	26	50.00	19	39.58	20	55.56	16	39.02	9	39.13
Participant's expectation is for treatments that are easier to administer with less disruption to everyday life (for example injections or tablets)	39	39.00	9	34.62	7	31.82	22	42.31	17	35.42	12	33.33	19	46.34	8	34.78
Participant's expectation is for treatments that have less side effects, this was often in relation to long term side effects of steroids	17	17.00	8	30.77	3	13.64	7	13.46	10	20.83	7	19.44	4	9.76	6	26.09
Participant recommends more effective treatments particularly in relation to immediate and longer lasting relief	9	9.00	2	7.69	4	18.18	3	5.77	6	12.50	4	11.11	3	7.32	2	8.70

Expectations of future treatments	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant's expectation is that treatments are more affordable, noting that cost is currently a burden	45	45.00	16	55.17	29	40.85	15	36.59	30	50.85	12	52.17	16	38.10	17	48.57
Participant's expectation is for treatments that are easier to administer with less disruption to everyday life (for example injections or tablets)	39	39.00	12	41.38	27	38.03	14	34.15	25	42.37	5	21.74	22	52.38	12	34.29
Participant's expectation is for treatments that have less side effects, this was often in relation to long term side effects of steroids	17	17.00	3	10.34	14	19.72	9	21.95	8	13.56	4	17.39	7	16.67	6	17.14
Participant recommends more effective treatments particularly in relation to immediate and longer lasting relief	9	9.00	3	10.34	6	8.45	5	12.20	4	6.78	2	8.70	3	7.14	4	11.43

Expectations of future treatments	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant's expectation is that treatments are more affordable, noting that cost is currently a burden	45	45.00	30	45.45	15	44.12	27	61.36	18	32.14	23	41.07	22	50.00
Participant's expectation is for treatments that are easier to administer with less disruption to everyday life (for example injections or tablets)	39	39.00	25	37.88	14	41.18	11	25.00	28	50.00	25	44.64	14	31.82
Participant's expectation is for treatments that have less side effects, this was often in relation to long term side effects of steroids	17	17.00	14	21.21	3	8.82	9	20.45	8	14.29	10	17.86	7	15.91
Participant recommends more effective treatments particularly in relation to immediate and longer lasting relief	9	9.00	3	4.55	6	17.65	3	6.82	6	10.71	5	8.93	4	9.09

### Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common themes were participants recommending more detailed information about current and emerging treatments (including research and clinical trials (n=18, 18.00%), and participants recommending more information to help the community understand the severity of asthma and common triggers (n=18, 18.00%). This was followed by participants recommending comprehensive information in a language that is easy to understand (without jargon or overly scientific language) (n=16, 16.00%). There were 14 participants (14.00%) that did not have any recommendations or were satisfied with information. There were 10 participants (10.00%) that recommended information or tools to help them manage and monitor their asthma and its side effects.

In relation to sub-group variations, participants in the *Controlled asthma* sub-group recommended providing more detailed information about current and emerging treatments less frequently (7.69%) than the general population (18.00%) whilst participants in the *Severe asthma* sub-group described this more frequently (31.03%).

Participants in the *Infrequent flare-ups* sub-group recommended providing more information to help the community understand the severity of asthma and common triggers less frequently (4.35%) than the general population (18.00%), while participants from the *Trade or high school* sub-group recommended this more frequently (29.55%).

There were no participants in the *Controlled asthma* sub-group that recommended information or tools to help them manage and monitor their asthma and its side effects (0.00%) compared to 10 participants in the general population (10.00%).

### Participant recommends providing more detailed information about current and emerging treatments (including research and clinical trials)

*If we get new treatment for asthma, for example, and a new preventative or something else, it's almost hidden. It's not public knowledge. It's like, "We don't want to let the world know just in case they-- Well, we want to make it more challenging for them because they don't have it challenging enough, we're going to make it just a little bit harder." We get to the GP's and they just do the same old thing. "Here's the same script, here's the same script." Not once, until you go, "Is there--" you have to ask the question, not them ask, give you the offer, "Is there anything new on the market?" Participant 3*

*A bit of both actually. Maybe like more about the Asthma Foundation. If they could have like a-- I don't know, be on a mailing list or something like that to sort of keep you updated with advances in what research has shown, or what medications are coming out, or something like that that had more of a regular concept, because I feel a bit like these studies, genetic testing and things like that would have been a great thing. Yes, that sort of level of context would have been good. Understanding more about the actual exacerbation, what can you do earlier on or what can you do later or have you. That kind of information I don't think I ever really understood. Participant 44*

*Yes, and new drugs that might come out, or new puffers, whatever they may be, new medications. Having that more widely disseminated and not just through your GP as some people don't have access to lots of medical services all the time. Participant 24*

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Participant recommends providing more information to help the community understand the severity of asthma and common triggers

*I'd say that I would prefer more school teachers and staff to have more education on asthma, or just the whole community to realize that people can actually die from it. You've got to take it serious every time because it is serious. A lot of people don't realize how serious it is. Participant 2*

*I just think I'd like to see more of it. I'm very at deep at looking at what pamphlets are on the wall with the doctor's surgery, spending a lot of the time there. Diabetes and cancer and mental health seem to have a huge presence, and I don't think asthma does in the wider community, and I think more people need to know about that. Participant 28*

*I think I'm pretty happy with the information I got. I guess, going back, I was one of the very few people that was diagnosed with asthma. While my close friends understood, the rest of the school didn't. Try to educate teachers and other people in those environments. That would be a good thing to see. At school, we had people come and talk to us about different things. About being in a wheelchair, or being this or being injured. No one ever came to talk about what it's like to live day-to-day with chronic disease. I don't know if that would help other kids understand better or teachers understand. Participant 45*

*Well, I really want to wish there's a general awareness. The flu campaign is really effective, people know flu is a bad thing you can expect half the office is going to be off. It would be nice if people understood that Asthma can be just be as debilitation. Participant 55*

Participant recommends providing comprehensive information in a language that is easy to understand (without jargon or overly scientific language)

*I think when they give the information. I think they need to make it a little bit more readable. It's just an ordinary person can understand. Sometimes they can use big words and different things and what's that? Participant 16*

*I think initially something really simple would be good. Just take it back down to dumb and this what it is, this is what it means. These are the people that you need to see to figure out your path forward and that everybody's paths are different. Because not everybody responds to the same medication. Not everybody responds to the same doctors. I know some people that would find my experience overwhelming and hard to deal with. Participant 41*

*I think definitely there could be less in regards to the scientific words like all the jargon behind it. A lot of people don't understand it. I personally have a lot of trouble understanding certain terminology that's presented in documentation, so having very simple layout, even diagrams to help understand a little bit better. Sort of the way you would present it to a primary schooler would definitely be more convenient for the people that may not have had the right level of education or the people that struggled with that sort of education. Participant 48*

*I will say that because this information is medical, I would like the information that either I reach is easy to understand. I think it should be easy to understand. They can describe it less medical practical. Participant 96*

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Participant recommends information or tools to help them manage and monitor their asthma

*I'd like when it comes to information-- I don't know. I feel an App, some sort of monitoring App would be absolutely fantastic so you really knew how you were going because when you--My asthma, asthma takes different forms. Do you know what I mean? It depends where you are. It can be like an allergy. When I was a child I'd say it was more allergy to me because every time-- I had two aunties that lived in LOCATION. Every time I went to LOCATION I got asthma and I couldn't wait to get home. So, you know more information about that stuff. If there could be some sort of monitoring. Participant 19*

*The most useful thing that I read afterwards was a thing on asthma website that says what to do when. "If it's mild, do your usual first aid. If you are doing these things, call an ambulance. If you are doing these things, you're in a lot threatening condition" It was actually because I was actually in life threatening for about eight hours, and I didn't do anything because I'd been told, "You have whooping cough". That was something that I searched for and found afterwards. Would be really good if that was more widely known. Participant 32*

*I think not so much information, but for me I know I'm feeling very frustrated, I'd love some good apps on my phone that'd help me record accurately what's going on, because I know, and I've seen it over and over, when I can take to a doctor an accurate record over a number of weeks or months to show what's actually been going on, you get much more effective treatment out of it because they can really see-- It's much more effective to be able to show, like I did when I had an electronic peak flow meter. Participant 46*

Participant does not have any recommendations/satisfied with information

*No. It's been pretty good. It's been very easy to read, it's been very easy to understand, especially if you've had it for a while, on usually doctors, or specialists, or people like nurses and all that stuff. Are very willing to talk to you about it, and very willing to give you in layman's terms, because there are so many people who've got asthma these days, which isn't a surprise at all, especially with how the weather is going these days. So it's been a really good reception with all that kind of stuff, which is great to see because it's only been in the last maybe 8 to 10 years that that's really been happening and it's really good to see. Participant 15*

*I think the information available is pretty good these days, so I don't really have any comments to make about that. Participant 91*

*Probably because I've got-- have seen a lot of different information. I'm happy with it, but then again, someone else that is new to asthma or doesn't understand it may need more information. I think the information out there is good. Participant 63*

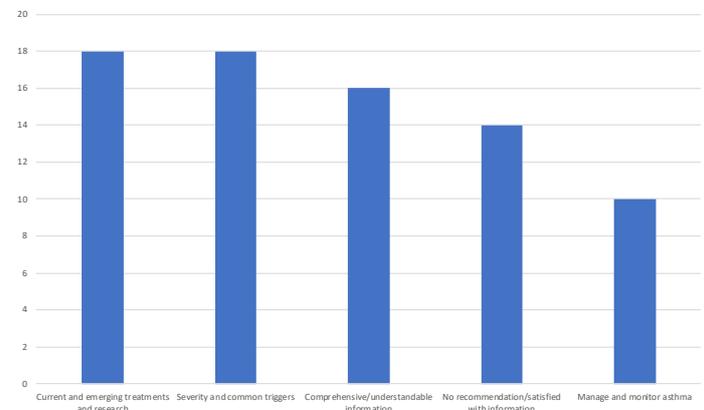


Figure 9.2: Expectations of future information

Table 9.2: Expectations of future information

Expectations of future information	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant recommends providing more detailed information about current and emerging treatments (including research and clinical trials)	18	18.00	2	7.69	3	13.64	13	25.00	5	10.42	6	16.67	10	24.39	2	8.70
Participant recommends providing more information to help the community understand the severity of asthma and common triggers	18	18.00	6	23.08	5	22.73	9	17.31	9	18.75	6	16.67	11	26.83	1	4.35
Participant recommends providing comprehensive information in a language that is easy to understand (without jargon or overly-scientific language)	16	16.00	3	11.54	2	9.09	10	19.23	6	12.50	5	13.89	6	14.63	5	21.74
Participant does not have any recommendations as they are satisfied with information	14	14.00	4	15.38	5	22.73	5	9.62	9	18.75	5	13.89	6	14.63	3	13.04
Participant recommends information or tools to help them manage and monitor their asthma and its side effects	10	10.00	0	0.00	2	9.09	8	15.38	2	4.17	5	13.89	2	4.88	3	13.04

Expectations of future information	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant recommends providing more detailed information about current and emerging treatments (including research and clinical trials)	18	18.00	9	31.03	9	12.68	5	12.20	13	22.03	4	17.39	8	19.05	6	17.14
Participant recommends providing more information to help the community understand the severity of asthma and common triggers	18	18.00	4	13.79	14	19.72	8	19.51	10	16.95	3	13.04	11	26.19	4	11.43
Participant recommends providing comprehensive information in a language that is easy to understand (without jargon or overly-scientific language)	16	16.00	5	17.24	11	15.49	5	12.20	11	18.64	3	13.04	6	14.29	7	20.00
Participant does not have any recommendations as they are satisfied with information	14	14.00	5	17.24	9	12.68	6	14.63	8	13.56	4	17.39	3	7.14	7	20.00
Participant recommends information or tools to help them manage and monitor their asthma and its side effects	10	10.00	4	13.79	6	8.45	2	4.88	8	13.56	4	17.39	2	4.76	4	11.43

Expectations of future information	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant recommends providing more detailed information about current and emerging treatments (including research and clinical trials)	18	18.00	11	16.67	7	20.59	7	15.91	11	19.64	9	16.07	9	20.45
Participant recommends providing more information to help the community understand the severity of asthma and common triggers	18	18.00	10	15.15	8	23.53	13	29.55	5	8.93	7	12.50	11	25.00
Participant recommends providing comprehensive information in a language that is easy to understand (without jargon or overly-scientific language)	16	16.00	13	19.70	3	8.82	7	15.91	9	16.07	12	21.43	4	9.09
Participant does not have any recommendations as they are satisfied with information	14	14.00	8	12.12	6	17.65	6	13.64	8	14.29	9	16.07	5	11.36
Participant recommends information or tools to help them manage and monitor their asthma and its side effects	10	10.00	8	12.12	2	5.88	2	4.55	8	14.29	5	8.93	5	11.36

### Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were participants experiencing good communication with health professionals (n=24, 24.00%), and participants recommending that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans (n=24, 24.00%). These were followed by participants recommending that health professionals have a better understanding of the severity of asthma, emergency care, and how to manage asthma (n=17, 17.00%). There were 14 participants (14.00%) that recommended health professionals listening to patients and not dismissing their concerns, or that they have expertise in their own condition. There were 14 participants (14.00%) that recommended that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis.

In relation to sub-group variations, participants in the *Regional or remote* (11.76%), and *Age 35 to 54* (11.90%) sub-groups described experiencing good communication from health professionals less frequently than the general population (24.00%), while participants *Age 18 to 34* described this more frequently (39.13%).

**Participant describes experiencing good communication from health professionals. Where communication was described, this was often in relation to health professionals taking the time to explain options**

*Not really. They are pretty good with me. You used to go, and they never told you anything when you were a kid, but nowadays, they do. They're doing their job now. So, it's pretty good. Participant 1*

*I don't have any problems with my GP or my specialist communicating to me, but I know I have had friends say that the GP was not open to them about it, and the specialist was not open to them about it. I've suggested them to go to my GP and my specialist and stuff. I think it depends on who you go to, and how wise or how knowledgeable the doctor you go to is as well. Participant 5*

*I think everything's quite good. My specialist is great. I feel he listens. He does all the vital checks. Talks about, looks at the management plan, looks at everything. I don't have any issues and if I have a question I can ask him anytime. I don't have a problem with that at all. He's always looking at different things. Yes, he suggests different things at times. No, not awkward  
Participant 97*

**Participant recommends that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans**

*Yes, a lot. [laughs] What I'd like, in a perfect world for me in terms of chronic condition, the management of cases of chronic conditions and that sort of bad asthma for instance. To me something that would work would be if there was a senior nurse or a case toward another place at the hospital that had a number of cases, say myself for instance, that would talk to the three specialists, get them together once every six months and communicate with me when I'm wandered off with email, and I can get replies from.  
Participant 35*

*How professionals treat those with asthma. I guess they could have asthma reviews. They have reviews for those with diabetes. They review people if they're under a team of specialists for whatever reason, and they get recalled. For example, skin cancer, you have to have a yearly test. With asthma, it's just, for me, even for the kids, it's just the same. Nothing's really changing. The information hasn't really changed about prevention- a little bit of prevention, but not much- the triggers seem to be the same. I haven't seen a lot of change. What was the question again?  
Participant 40*

*Just follow up, when you go in, just the patient has asthma, "How's it going? Have you noticed any changes? Can we do anything?" Participant 62*

*Well, it's interesting because I'm being case managed for my diabetes and I think it's great because it's really put my focus on it. I've never been case managed for my asthma which I think is interesting because-- I mean I know long-term diabetes can lead to all sorts of problems, but you would have thought being case managed for asthma would also be as important. Mine's bad enough that I've never been asthma-free*

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*and I've always had to have medication. It's really interesting. Participant 69*

*Yes, I think more education around options, and I think things like I always ask asthmatics that I meet, "Have you got an asthma action plan?" Most of them don't even know what I'm talking about. So I think ensuring that every asthmatic gets an action plan and understands post what to do so they know when they seek to go to hospital, but now you've been released what do you do next? How do you then manage that moving forward and get an understanding about that? I think that's really important. Participant 28*

**Participant recommends health professionals having a better understanding of the severity of asthma, emergency care and how to manage asthma**

*When I think about my doctor, I just think they lack experience, that's what I just think. This doctor I used to go to who was specialized in asthma and he said to me because I've had pneumonia a few times, he assumed I had scarring. He said to listen to your chest a doctor must take their time, they mustn't just tap on you back with a stethoscope Participant 89*

*I think because of that, they don't really have an understanding of the physical effects of asthma over time, because they're just sitting down all the time, they haven't actually experienced how absolutely debilitating and life-changing it can be to have regular asthma issues. Participant 81*

*I just honestly think that a basic understanding of what it means to asthmatics as a regular kind of condition or chronic condition that they're dealing with and especially doctors in-- I had a bad experience with a doctor in the emergency ward. Well, an emergency at a hospital. They didn't know much about asthma but also got me in a lot of trouble for taking as much reliever as I did. Whereas my doctor at home had told me that that was okay. Just very varying opinions and thought processes on what's the right thing to do. Participant 80*

**Participant recommends health professionals listening to patients and not dismissing their concerns (or that they have expertise in their own condition)**

*Just being judgmental about that that's a chronic can be quite debilitating in that we're not always going to be perfect, and not to judge the fact that we might have done something wrong that's impacted on our health. Prepare to educate more than judge, I guess. Participant 44*

*Yes, just the way they walk like it can be very dismissive or very understanding it depends on what on a mood to get them in, as with anything, but you don't know what the person before you has been or whether they are nasty or not. Then, unfortunately, you might be the one that gets them in a bad mood but I'm just thinking just communication is important. Participant 60*

*The amount that I've sat there and I've explained what's happening, I've explained what I'm experiencing and they sit there and go to me, "You don't know what you're talking about." It's like, "Well, dude, it's my body. I'm the one that's been experiencing it." Go off book and sit down and go, "Okay. Well, if my patient's experiencing this, let's have a look at doing X, Y, Z different or something." Not just looking at putting everyone in this one box. Participant 10*

*Yes, I guess, based on my years of not having someone who really listened to me, I just think it's so important that they take that time to listen. When I went to emergency at the end of last year, they took me so seriously, and I was in a really severe state. I was so surprised by that and I shouldn't be surprised by that. You know what I mean? I shouldn't have been taken aback by being believed and being listened to and things like that, but I was. Maybe that has changed as well, I don't know, but I think, I have had some pretty negative experiences where I've basically been told to just toughen up and that was quite hard. Does it answer the question? Participant 20*

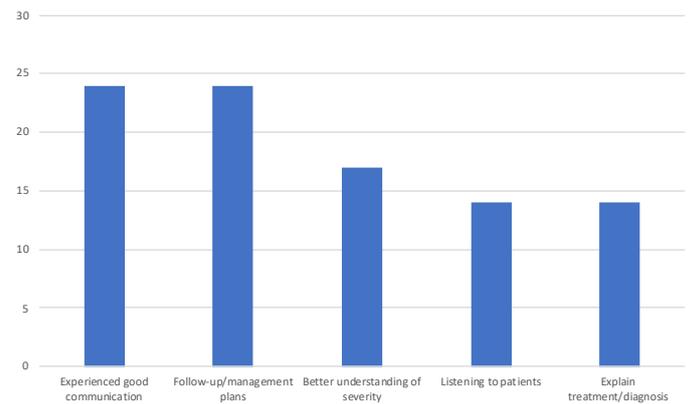
## Section 9

Participant recommends that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis

*Yes, I guess perhaps maybe not assuming that somebody knows about it because people hear the word asthma, it's kind of a common thing around. I think sometimes health professionals assume that the person with asthma knows about it because it's like a common knowledge thing but perhaps maybe to ask more questions, about what your understanding is and, just checking in with how you're managing your treatment. Participant 37*

*Maybe if they had more brochures or something to be able to hand out because the thing is I think the problem is that they can't be experts on everything, and yet they don't like to say they're not really sure. Then they tell you misleading or incorrect information. If they had brochures or even websites to refer you to, that possibly would stop that. Even when I was younger I felt bad asking questions of what they were giving me. The fact that I'd been taking one medication for several years without actually understanding how it worked and therefore not even effectively taking it. Whereas if I had have just been pointed in the right direction and read that, I would've thought, "Hang on". Participant 72*

*Yes, communicate better. [laughs] I don't know, just again the education, explain what's going on and your different treatment options, not just like, "Here, we'll just give you a preventer. There you go." No, like, "This is what's going to happen. You should wait and see if this works within a certain amount of months. If it doesn't, we can look at this treatment, this treatment, this treatment. Now with this treatment, you can do this, this, this, that," just giving you a long-term offer, not just, "Here, you go." Participant 42*



**Figure 9.3: Expectations of future healthcare professional communication**

Table 9.3: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes experiencing good communication from health professionals. Where communication was described, this was often in relation to health professionals taking the time to explain options	24	24.00	6	23.08	7	31.82	11	21.15	13	27.08	10	27.78	9	21.95	5	21.74
Participant recommends that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans	24	24.00	7	26.92	6	27.27	11	21.15	13	27.08	8	22.22	10	24.39	6	26.09
Participant recommends health professionals having a better understanding of the severity of asthma, emergency care and how to manage asthma	17	17.00	7	26.92	2	9.09	8	15.38	9	18.75	6	16.67	8	19.51	3	13.04
Participant recommends health professionals listening to patients and not dismissing their concerns (or that they have expertise in their own condition)	14	14.00	4	15.38	3	13.64	8	15.38	6	12.50	6	16.67	4	9.76	4	17.39
Participant recommends that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis	14	14.00	3	11.54	5	22.73	6	11.54	8	16.67	3	8.33	7	17.07	4	17.39

Expectations of future health professional communication	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes experiencing good communication from health professionals. Where communication was described, this was often in relation to health professionals taking the time to explain options	24	24.00	7	24.14	17	23.94	10	24.39	14	23.73	9	39.13	5	11.90	10	28.57
Participant recommends that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans	24	24.00	7	24.14	17	23.94	13	31.71	11	18.64	4	17.39	14	33.33	6	17.14
Participant recommends health professionals having a better understanding of the severity of asthma, emergency care and how to manage asthma	17	17.00	6	20.69	11	15.49	7	17.07	10	16.95	2	8.70	6	14.29	9	25.71
Participant recommends health professionals listening to patients and not dismissing their concerns (or that they have expertise in their own condition)	14	14.00	4	13.79	10	14.08	7	17.07	7	11.86	4	17.39	6	14.29	4	11.43
Participant recommends that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis	14	14.00	2	6.90	12	16.90	5	12.20	9	15.25	3	13.04	6	14.29	5	14.29

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes experiencing good communication from health professionals. Where communication was described, this was often in relation to health professionals taking the time to explain options	24	24.00	20	30.30	4	11.76	12	27.27	12	21.43	15	26.79	9	20.45
Participant recommends that health professionals follow-up and provide more options, and personalised, comprehensive asthma management plans	24	24.00	13	19.70	11	32.35	10	22.73	14	25.00	13	23.21	11	25.00
Participant recommends health professionals having a better understanding of the severity of asthma, emergency care and how to manage asthma	17	17.00	8	12.12	9	26.47	7	15.91	10	17.86	10	17.86	7	15.91
Participant recommends health professionals listening to patients and not dismissing their concerns (or that they have expertise in their own condition)	14	14.00	10	15.15	4	11.76	6	13.64	8	14.29	8	14.29	6	13.64
Participant recommends that health professionals should take more time to explain treatment options and details of what to expect from their diagnosis	14	14.00	10	15.15	4	11.76	7	15.91	7	12.50	6	10.71	8	18.18

### Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was participants not having any suggestions, or reporting being content with the care received (n=15, 15.00%), followed by participants recommending more long-term asthma management and treatment plans and/or holistic care (n=12, 12.00%). There were nine participants (9.00%) that recommended more community-based support, specifically peer support including support groups and information sessions, or family peer support, and 8 participants (8.00%) that recommended more opportunities to access specialists in asthma for treatment, information and support.

In relation to sub-group variations, participants in the *Severe asthma* subgroup described having no suggestions or content with care received less frequently (3.45%) than the general population (15.00%).

### No suggestions or content with care and support received

*I don't think so. Again, it was quite good with the process I had. Participant 79*

*Not really. I think the services-- especially, if you live in a large capital city, are there. You've just got to seek them out. Participant 92*

*I don't think so. I don't think my asthma is ever been severe enough or big enough to impact on my life or lifestyle, that I've ever felt there was something lacking in terms of support or care. I'm probably the most boring survey person you could have spoken to, aren't I? Participant 43*

### Participant's recommendation is for more long-term asthma management and treatment plans and/or holistic care

*I would like for-- whatever, big families or big hospitals, to take a better interest in people that have got a lifelong condition like me, seeing if our quality of life and our quality of everyday living can be stepped up on, without medication and all that kind of stuff. So that we can get along with the things that we need to do, because it does really hinder us a lot more than people think. Participant 15*

*I would have thought physiotherapy and probably counselling would be almost like a GP says, "Well, you'll need a physio. So we'll line that up and actually make that a part of the treatment for asthma." Probably for counselling, if people are going to sit and eat and not exercise, the outcomes from- their general health is going to suffer. Having asthma is bad enough but if that has an impact on your general health and your quality of life, generally, I think it's not just a physical medical breathing problem. It's much more than that. Participant 18*

*When I was a child, I had access to Swimming Australia asthma swimming classes in order for improving my health. It was sponsored by Asthma Australia I believe. It was these kind of like, I'm sorry, by qualified swimming instructors and it was accessed-- We just had to prove that we were asthmatic to join that swim class. I think if they could do that again, swimming being a number one way of trying to combat asthma in young people. I think if they could re-establish that program, that would be awesome. Participant 98*

## Section 9

Participant's recommendation is for more support community-based support\Peer support (including support groups and information sessions)/Family peer support

*Probably not so much. We can ask me about my asthma because I've never really met anyone else, and not only that I think it'd be really important too for the family to have a support network or meet other parents. I think that would be important as well* Participant 13

*I can't really think of any, just more support groups and maybe even more informational support groups for families of asthmatics. It'd be good to have a few people that my wife could talk to about how they're dealing with severe asthmatic husband or wife or what have you, your partners. Something for the families or the partners or that sort of support I think is always handy.* Participant 35

*Sometimes talking to others makes you realize-- Because I tend to be sort of the denier, that it's not so bad, it's not that bad and then suddenly I'm in big water. I've caused a lot of stress for my family because I was, "I'm not going to the hospital. I'm all right. You go and do that and that and I'll go later." I think it was unnecessary stress and I could have actually prevented myself from getting quite so impacted if I had actually acted a bit earlier.* Participant 58.

Participant's recommendation is for more opportunities to access specialists in asthma for treatment, information and support

*I guess it would have been nice to have a service or something like an asthma center or something that you could just ask them for information or go there, and to know that there's someone with the same thing as you, because I thought I was the only one in the world with this and it turns out I'm not. I think there must be a lot of different forms of asthma that I don't know about, so probably something like an asthma center. Then even the quacks would love that because that's where they're refer people, so they could refer you to that and that takes them off any decision making.* Participant 4

*I'd like some sort of forum where you could ask questions, whether it be online, or something like that. There's online groups for diabetes and so on, now they're not always fabulous, because you get some unusual people sometimes responding. If I were to ask a question of someone who's been there, done that, is really worthwhile. We need asthma nurses here.* Participant 17

*Maybe, and because I live in regional Australia now there's nothing out here. I travel an hour to get to my specialist because there's not one in the town that I live in which is okay for me because I drive. I'd like to see at least in one doctor's practice and ask for education clinic, that would be great.* Participant 9

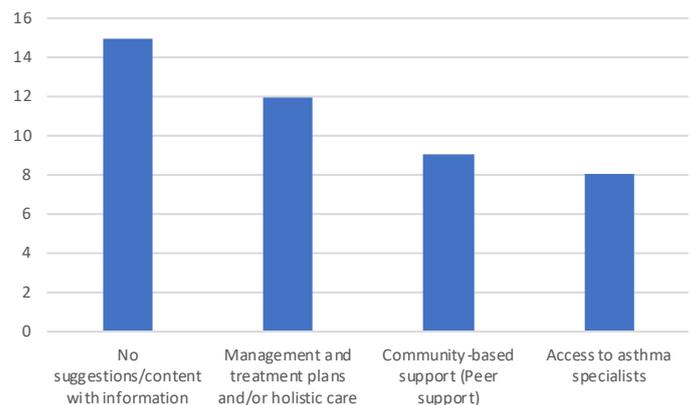


Figure 9.4: Expectations of future care and support

Table 9.4: Expectations of future care and support

Expectations of future care and support	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
No suggestions or content with care received	15	15.00	4	15.38	3	13.64	8	15.38	7	14.58	6	16.67	6	14.63	3	13.04
Participant's recommendation is for more long term asthma management and treatment plans and/or holistic care	12	12.00	5	19.23	1	4.55	6	11.54	6	12.50	4	11.11	3	7.32	5	21.74
Participant's recommendation is for more support community-based support\Peer support (including support groups and information sessions)/Family peer support	9	9.00	0	0.00	3	13.64	6	11.54	3	6.25	5	13.89	2	4.88	2	8.70
Participant's recommendation is for more opportunities to access specialists in asthma for treatment, information and support	8	8.00	1	3.85	3	13.64	4	7.69	4	8.33	5	13.89	1	2.44	2	8.70

Expectations of future care and support	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
No suggestions or content with care received	15	15.00	1	3.45	14	19.72	5	12.20	10	16.95	2	8.70	8	19.05	5	14.29
Participant's recommendation is for more long term asthma management and treatment plans and/or holistic care	12	12.00	3	10.34	9	12.68	6	14.63	6	10.17	1	4.35	5	11.90	6	17.14
Participant's recommendation is for more support community-based support\Peer support (including support groups and information sessions)/Family peer support	9	9.00	7	24.14	2	2.82	3	7.32	6	10.17	3	13.04	3	7.14	3	8.57
Participant's recommendation is for more opportunities to access specialists in asthma for treatment, information and support	8	8.00	2	6.90	6	8.45	4	9.76	4	6.78	2	8.70	2	4.76	4	11.43

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=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
No suggestions or content with care received	15	15.00	13	19.70	2	5.88	5	11.36	10	17.86	9	16.07	6	13.64
Participant's recommendation is for more long term asthma management and treatment plans and/or holistic care	12	12.00	7	10.61	5	14.71	7	15.91	5	8.93	7	12.50	5	11.36
Participant's recommendation is for more support community-based support\Peer support (including support groups and information sessions)/Family peer support	9	9.00	3	4.55	6	17.65	6	13.64	3	5.36	3	5.36	6	13.64
Participant's recommendation is for more opportunities to access specialists in asthma for treatment, information and support	8	8.00	4	6.06	4	11.76	5	11.36	3	5.36	4	7.14	4	9.09

### What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for access to treatment through Medicare (n=24, 24.00%). This was followed by being grateful for the entire health system (n=19, 19.00%), being grateful for healthcare staff (n=18, 18.00%), being grateful that the healthcare system is low cost or free (n=17, 17.00%) and being grateful for access to hospital care through Medicare (n= 8, 8.00%).

In relation to sub-group variations, participants in *Age 55 or older* (11.43%) and participants in the sub-group *Severe asthma* (13.79%) described being able to access treatment through Medicare less frequently than the general population (24.00%), while *Aged 18 to 34* sub-group described this more frequently (34.78%).

Participants in the *Infrequent flare-ups* sub-group described being grateful for the entire health system more frequently (30.43%) than the general population (19.00%).

Participants in the *Aged 18 to 34* (4.35%), and *Controlled asthma* (7.69%) sub-groups described being grateful for healthcare staff less frequently than the general population (18.00%), while those in the *Moderately controlled asthma* sub-group described this more frequently (40.91%) as do those in the sub-group *Regional or remote* (32.35%).

Participants in the *Poorly controlled asthma* (3.85%), and *Frequent flare-ups* (5.56%) sub-groups described being grateful that the healthcare system is low cost or free less frequently than the general population (17.00%), while those in the *Controlled asthma* (34.62%), *Moderate to well controlled asthma* (31.25%), *Occasional flare-ups* (29.27%), *Frequent sleep disruption* (29.27%), and *Moderately controlled asthma* (27.27%), sub-groups described this more frequently.

### Participant describes being grateful for access to treatment (through Medicare)

*Well, back when the medication was on the PBS, if you showed an asthma card it was very cheap, but that's all gone. So I was grateful for it when it was there but I'm really missing it now.. Participant 84*

*Medicare. Medicare is absolutely brilliant. It's amazing. I've lived in the States for three years. Trying to get medication over there was ridiculously hard. The fact that we have that is amazing. The best way to bulk bill is amazing. Medicare and bulk billing, they're the two things that make life so easy for us here. The fact that with our concession system as well, it really gives us a great knock off discount kind of thing on our medication, which is fantastic. It makes life so much easier. You don't have to stress as much. Participant 15*

*This is a weird one but I think there has been a few times when I've not had my Ventolin puffer with me and for most of those times the local first aid kit, whether it was at a sports club or a school or even at some other event, the first aid kits always had a Ventolin puffer. That was super helpful because in case of an emergency Ventolin is the ultimate savior. I have been quite grateful for those things being around. Not to say that that's the best thing that's happened to me because obviously the treatment I've received when I've had my asthma attacks was very good but I think that thing has saved me more often than not. Participant 79*

*Probably the biggest one that's helped me out of a jam a few times is the fact that we can get Ventolin without a prescription. Participant 82*

**Participant describes being grateful for entire health system**

*I don't know Yes, we are lucky. Everything is within a sort of arm's length. It's very close. I think we have got access to good specialists, good medical, good hospitals. look, there's not the waiting list. If you're a private patient, you will get into see someone pretty quickly and I'm not sure about the public system, but you definitely have access to good doctors quickly. Participant 97*

*I'm so grateful for all of them to be honest. Even at the end of the scale when you're going to a hospital having a flare-up, you think so quickly going in there with restricted breathing, like I have never ever had to wait in an ER when I'm having an asthma flare-up. Participant 51*

*I'm grateful for everything that I've been able to access like and that we do have that, you know better health system in Australia. Anything and everything that I can access and all the help and support I'm grateful for everything. I can't pinpoint one thing because anything that anybody is willing to try and help and just even to support, then to listen and whatever else, are just everything. Participant 2*

**Participant describes being grateful for healthcare staff**

*I just think accessibility to a health professional, that has been monumental because if you're ill you can get to a GP somewhere and quick, then that's the biggest thing and especially with asthma, if you get somewhere quick and have someone look at you and be medicated. I think that's important. Actually, most emergency departments that I have unluckily had to go to in a few hospitals, they've been brilliant, down in emergency, they're fantastic. When you get up to the wards, the level of care and the level of understanding of the condition that's where it goes downhill but all the emergencies have been fantastic. I'd say that. Participant 9*

*I guess it was once I'd got to the lung specialist and then him treating me for a period of I think it was six months and then working with me on how-- I didn't just go from what I was on to what I'm on now, it was a progression. Also, he was open to the alternative of the physiotherapy to help me build my lung capacity with the breathing and other things that complement each other. I think that was more it, having those other services available to complement what I needed. It wasn't just taking drugs. Participant 61  
I think the nursing staff are admirable. What they do in the care that you get in hospital is just the highest standard. It's amazing what we have here. It really is. It's just amazing. Participant 64*

**Participant describes being grateful that the health system is low cost/free**

*What I might say is, it doesn't matter how much or how little you earn, you can always get some help from the doctor. You can get help from hospital system. Number one is, definitely, do not ignore your symptoms. Participant 53*

*Yes, I'm very grateful it's subsidized. [chuckles] I do still think there's a lot of confusion out there in the mainstream public because it's still around 40 bucks. I think a lot of patients are still confused that it's not subsidized. That's just from reading comments on recent Asthma Australia article. There's quite a few patients that were commenting saying it should be on the PBS. I don't know if that something that could be highlighted in a future article that it is actually subsidized. I'm very appreciative of that, that's for sure. Participant 95*

*I'm grateful for it's generally speaking reduced the subsidized costs of it. That's pretty much it really. Participant 91*

*Probably that we don't have to pay the outrageous amount that they do for instance, in America. I think although I whinge about the cost of some of the medications, we are very lucky. Yes. Participant 88*

### Participant describes being grateful for access to hospital care (through Medicare)

*Yes, I've found in the past when I have had to go to hospital, that everybody was very knowledgeable. They knew what to do to help me, to save me, even if I did rush up to the ICU with a ventilator. I still made it. They knew what they were doing and just got through it, and were able to get me through it afterwards. Participant 8*

*Every time I've had to go to hospital I've been taken care of, no question asked. That's been great. I'm very happy that my particular preventer is on the PBS. I thought that was fantastic as well. Then they ask the Council that we have, they're forever putting out*

*really good resources, so that's really helpful as well and a good resource to have. Participant 93*

*To the honest, the public hospital system has been really good. I'm lucky where I live. I'm sort of in between about five different hospitals. I've got taken to a public hospital initially, obviously, because I didn't really know anything about ... where I was going. I found that actually, to be honest, I probably got better care there than I did in the private hospital. Yes, the emergency department just seemed more onto it. Whether it's I've just had bad luck or bad experience, I don't know, but I was really comfortable with the hospital system. They've saved my life for a few times now. I get really upset when people moan about the system. Participant 26*

**Table 9.5: What participants are grateful for in the health system**

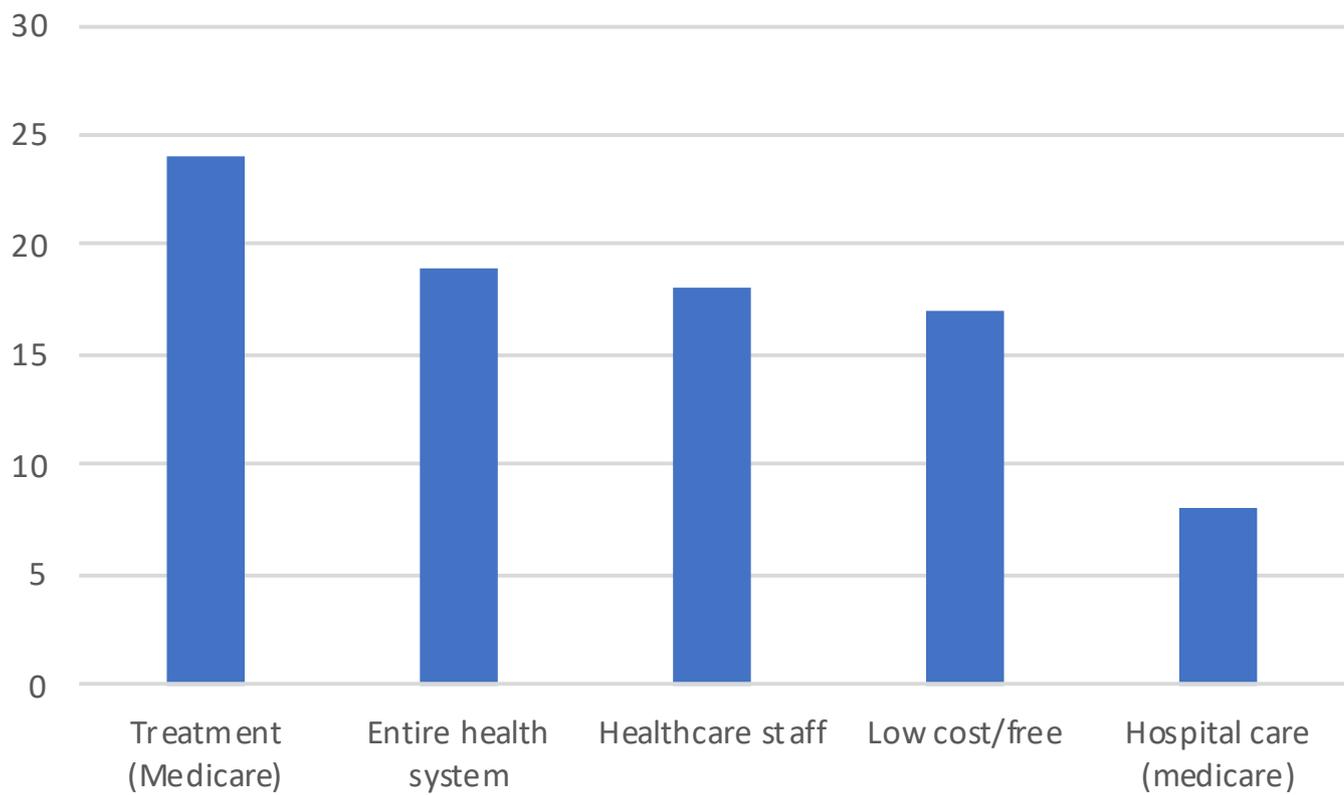
Aspects of the Australian health system that patients are grateful for	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant describes being grateful for access to treatment (through Medicare)	24	24.00	6	23.08	4	18.18	14	26.92	10	20.83	11	30.56	8	19.51	5	21.74
Participant describes being grateful for entire health system	19	19.00	5	19.23	2	9.09	12	23.08	7	14.58	6	16.67	6	14.63	7	30.43
Participant describes being grateful for healthcare staff	18	18.00	2	7.69	9	40.91	8	15.38	10	20.83	8	22.22	7	17.07	3	13.04
Participant describes being grateful that the health system is low cost/free	17	17.00	9	34.62	6	27.27	2	3.85	15	31.25	2	5.56	12	29.27	3	13.04
Participant describes being grateful for access to hospital care (through Medicare)	8	8.00	1	3.85	0	0.00	7	13.46	1	2.08	5	13.89	3	7.32	0	0.00

Aspects of the Australian health system that patients are grateful for	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant describes being grateful for access to treatment (through Medicare)	24	24.00	4	13.79	20	28.17	11	26.83	13	22.03	8	34.78	12	28.57	4	11.43
Participant describes being grateful for entire health system	19	19.00	7	24.14	12	16.90	6	14.63	13	22.03	5	21.74	5	11.90	9	25.71
Participant describes being grateful for healthcare staff	18	18.00	7	24.14	11	15.49	5	12.20	13	22.03	1	4.35	8	19.05	9	25.71
Participant describes being grateful that the health system is low cost/free	17	17.00	4	13.79	13	18.31	12	29.27	5	8.47	5	21.74	6	14.29	6	17.14
Participant describes being grateful for access to hospital care (through Medicare)	8	8.00	2	6.90	6	8.45	1	2.44	7	11.86	3	13.04	3	7.14	2	5.71

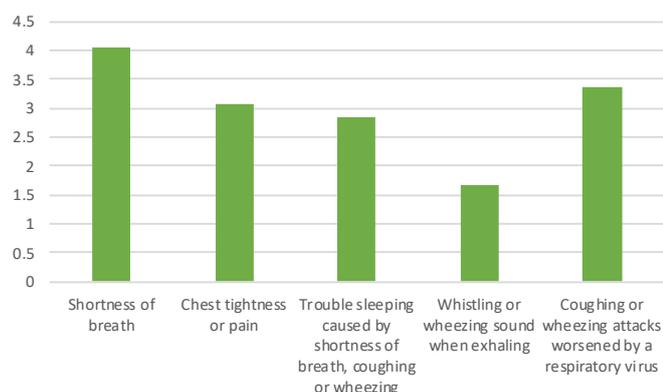
Aspects of the Australian health system that patients are grateful for	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant describes being grateful for access to treatment (through Medicare)	24	24.00	18	27.27	6	17.65	8	18.18	16	28.57	14	25.00	10	22.73
Participant describes being grateful for entire health system	19	19.00	14	21.21	5	14.71	5	11.36	14	25.00	12	21.43	7	15.91
Participant describes being grateful for healthcare staff	18	18.00	7	10.61	11	32.35	9	20.45	9	16.07	10	17.86	8	18.18
Participant describes being grateful that the health system is low cost/free	17	17.00	14	21.21	3	8.82	11	25.00	6	10.71	10	17.86	7	15.91
Participant describes being grateful for access to hospital care (through Medicare)	8	8.00	6	9.09	2	5.88	5	11.36	3	5.36	4	7.14	4	9.09



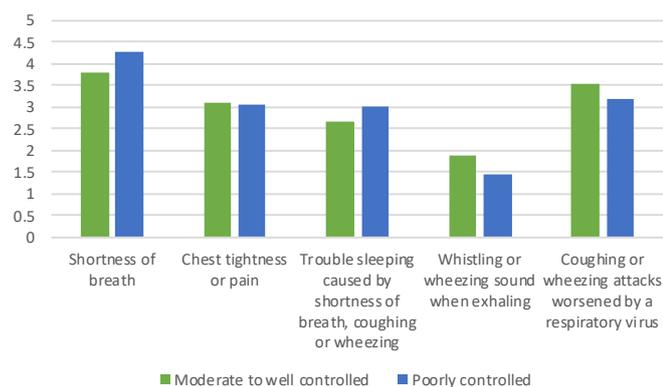
**Figure 9.5: What participants are grateful for in the health system**

**Symptoms and aspects of quality of life important for treatment considerations**

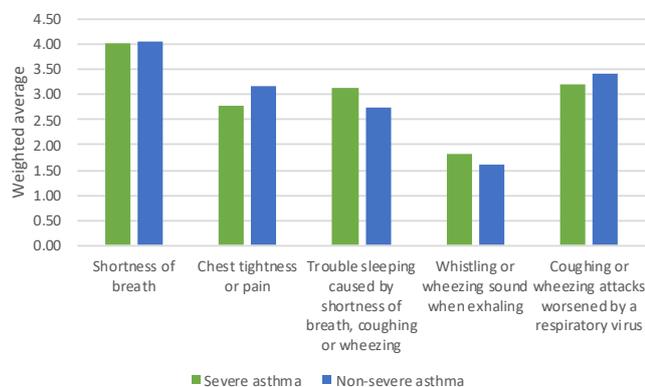
Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 5 is the least important. A weighted average is presented in Figure



**Figure 9.6: Symptoms/aspects of quality of life important for treatments all participants**

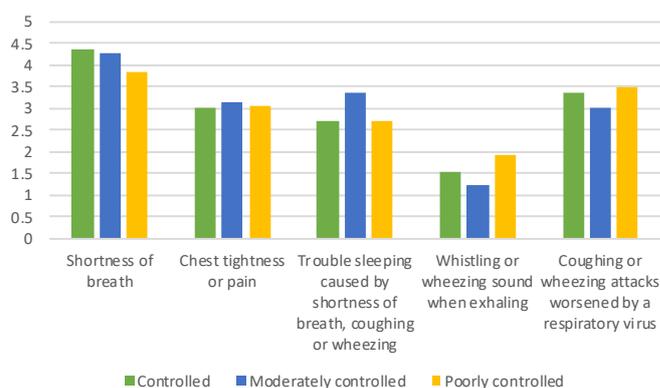


**Figure 9.8: Symptoms/aspects of quality of life important for treatments by Asthma control group**

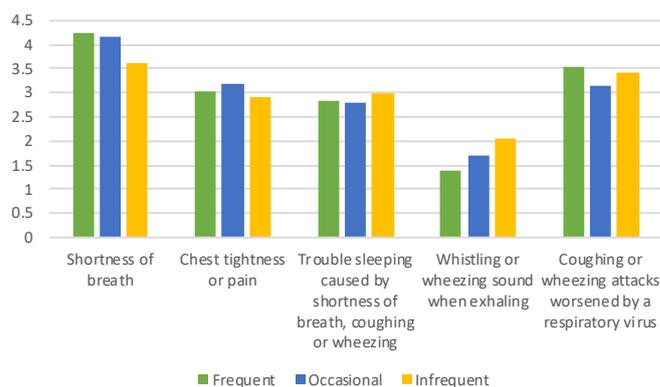


**Figure 9.10: Symptoms/aspects of quality of life important for treatments by Severity**

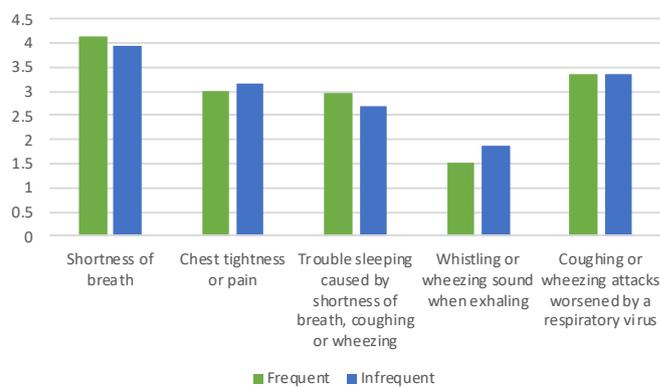
9.6. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported were shortness of breath and coughing or wheezing attacks worsened by a respiratory virus. The least important was whistling or wheezing sound when exhaling. The values for making decisions on their behalf are similar within sub-groups and are similar to the overall cohort.



**Figure 9.7: Symptoms/aspects of quality of life important for treatments by Asthma control group**



**Figure 9.9: Symptoms/aspects of quality of life important for treatments by Flare-ups**



**Figure 9.11: Symptoms/aspects of quality of life important for treatments by Sleep disruption**

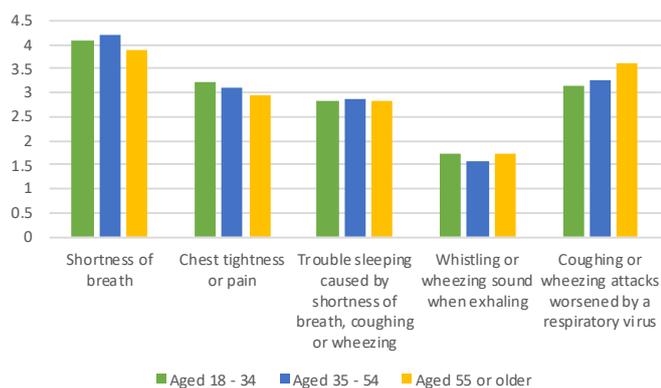


Figure 9.12: Symptoms/aspects of quality of life important for treatments by Age

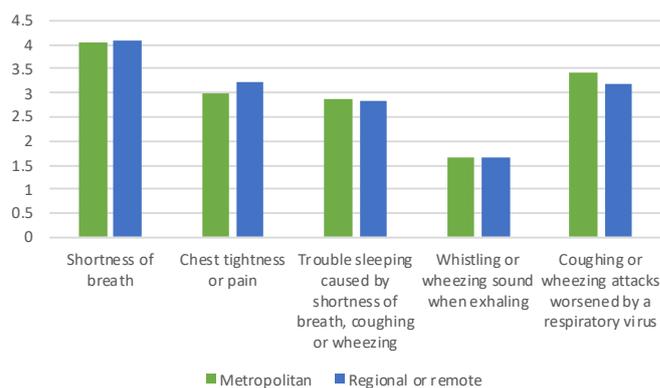


Figure 9.13: Symptoms/aspects of quality of life important for treatments by Location

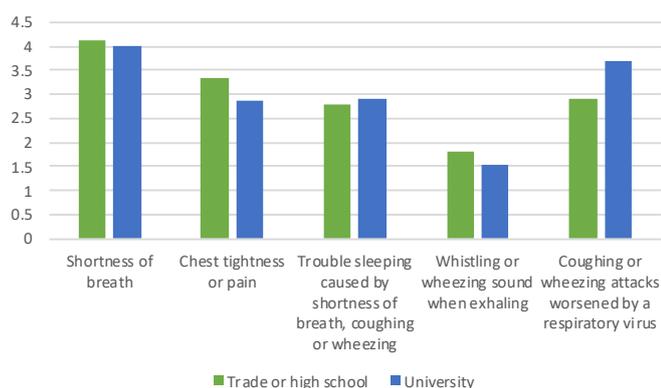


Figure 9.14: Symptoms/aspects of quality of life important for treatments by Education

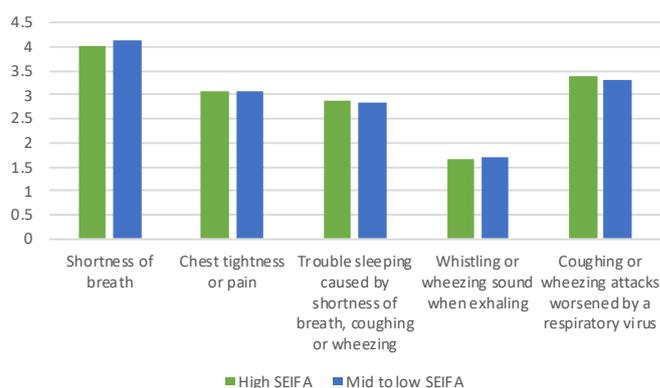


Figure 9.15: Symptoms/aspects of quality of life important for treatments by SEIFA

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

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=66, 66.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Table 9.6: Length of time to take a treatment for good quality of life

Time to take medication	Count (n=100)	Percent
Less than 1 year	14	14.00
1 year	9	9.00
2 - 5 years	11	11.00
10 years or more	66	66.00

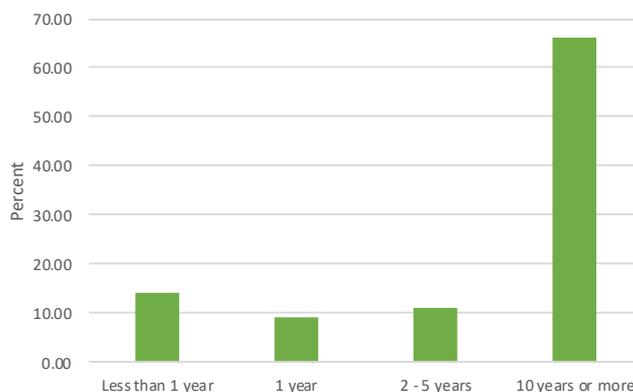


Figure 9.16: Length of time to take a treatment for good quality of life.

**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.

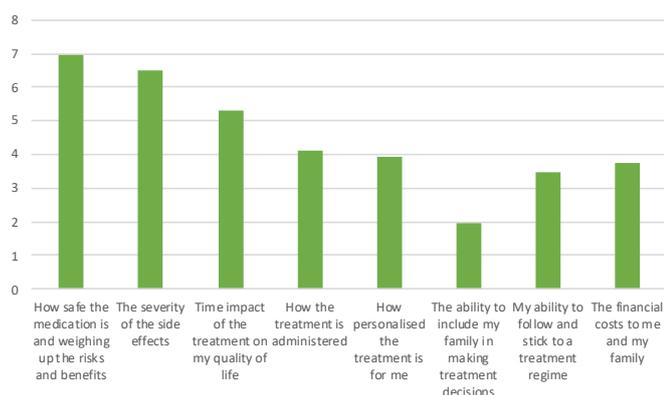


Figure 9.17: Decision making considerations

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” Figures 9.17 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.

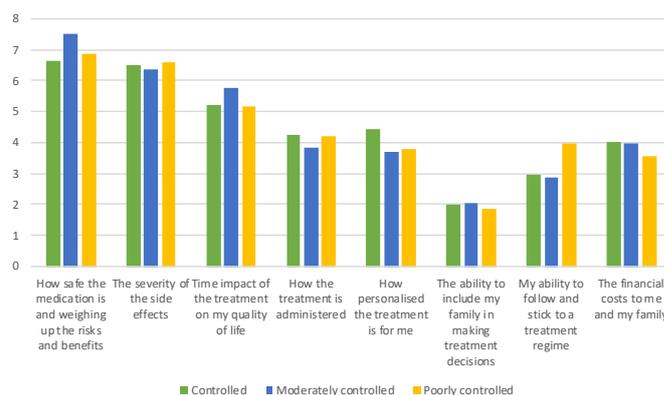


Figure 9.18: Decision making considerations by Asthma control group

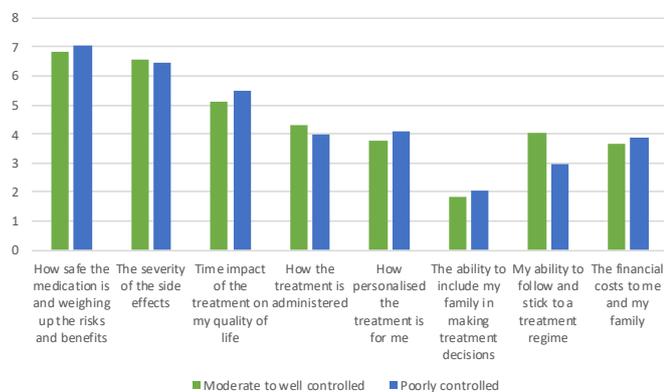


Figure 9.19: Decision making considerations by Asthma control group

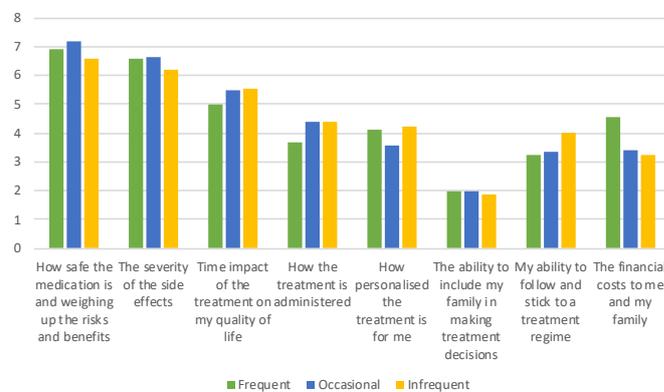


Figure 9.20: Decision making considerations by Flare-ups

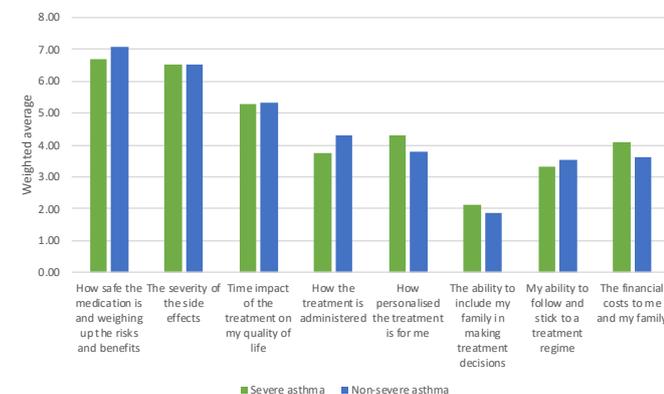


Figure 9.21: Decision making considerations by Severity

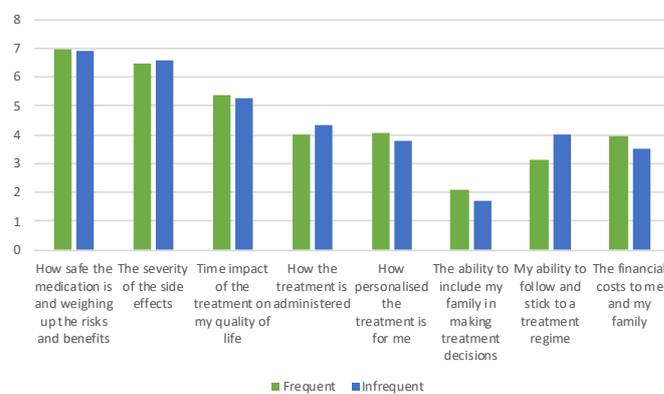


Figure 9.22: Decision making considerations by Sleep disruption

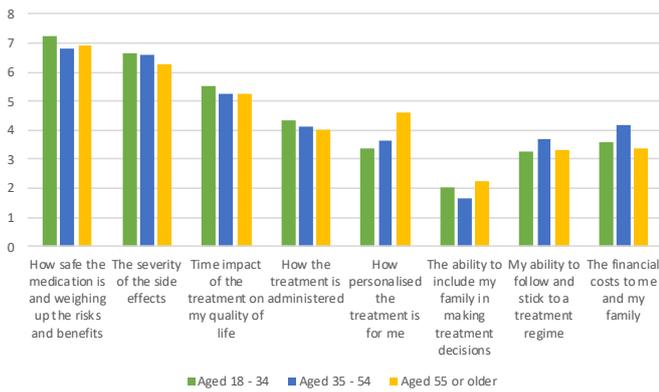


Figure 9.23: Decision making considerations by Age

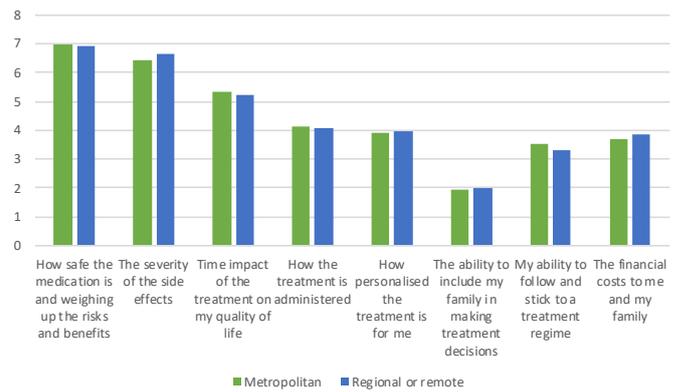


Figure 9.24: Decision making considerations by Location

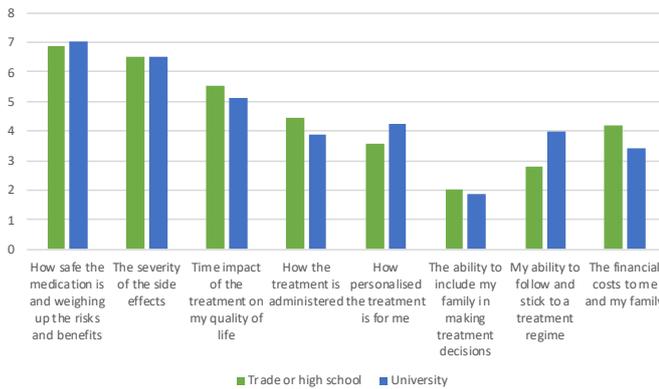


Figure 9.25: Decision making considerations by Education

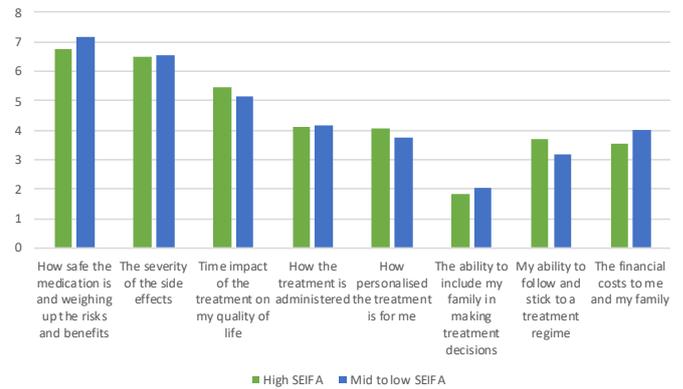
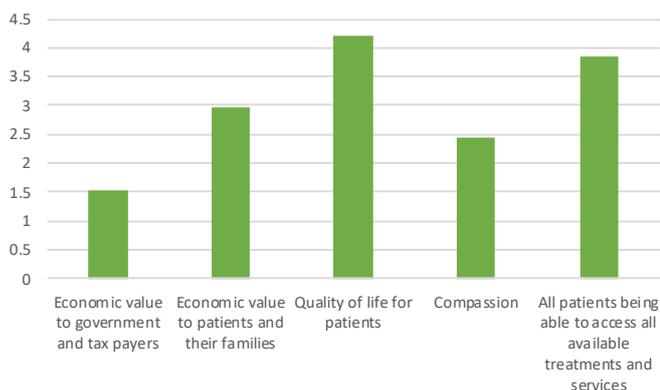


Figure 9.26: Decision making considerations by SEIFA

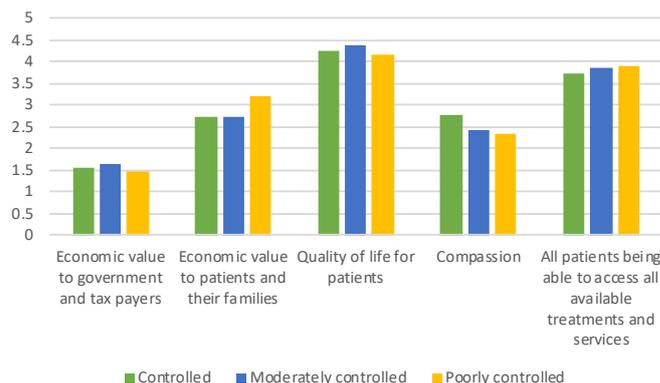
**Values that are important to patients when others are making decisions on their behalf**

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 9.25. With a weighted ranking, the higher the score, the greater value it is to

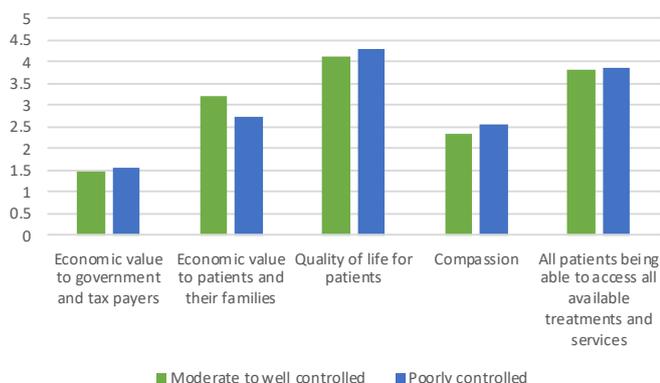
participants. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government. Figures 9.25 to 9.33 show the weighted rank by all participants and by subgroups. The values for making decisions on their behalf are similar within sub-groups and are similar to the overall cohort.



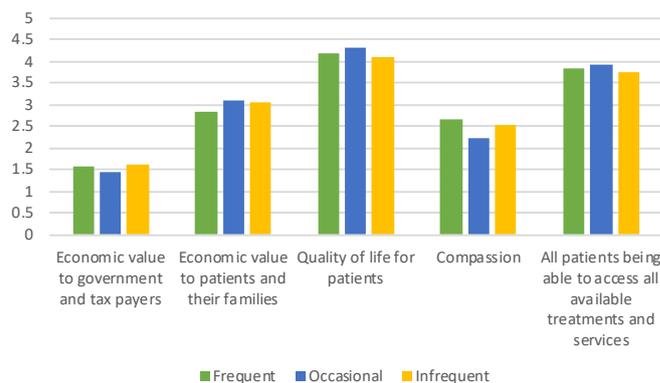
**Figure 9.27: Decision making on patient behalf**



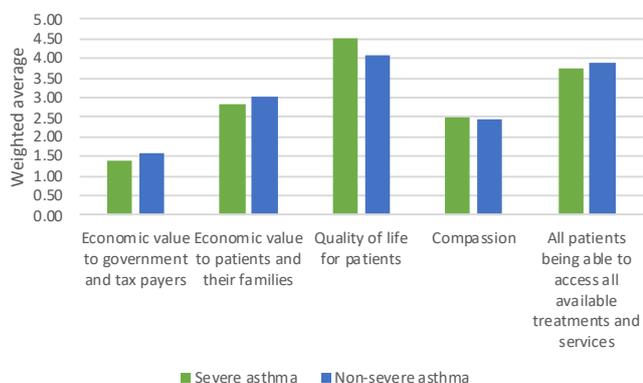
**Figure 9.28: Decision making on patient behalf by Asthma control group**



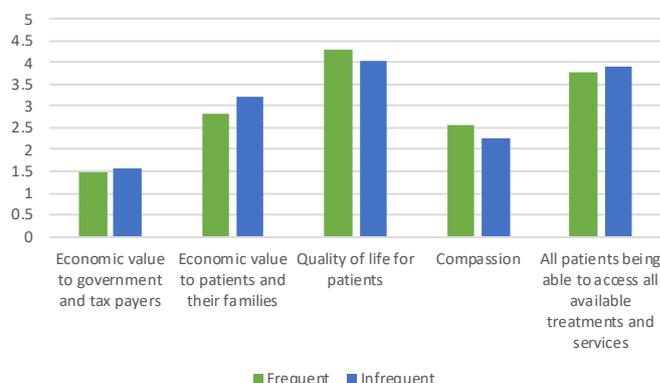
**Figure 9.29: Decision making on patient behalf by Asthma control group**



**Figure 9.30: Decision making on patient behalf by Flare-ups**



**Figure 9.31: Decision making on patient behalf by Severity**



**Figure 9.32: Decision making on patient behalf by Sleep disruption**

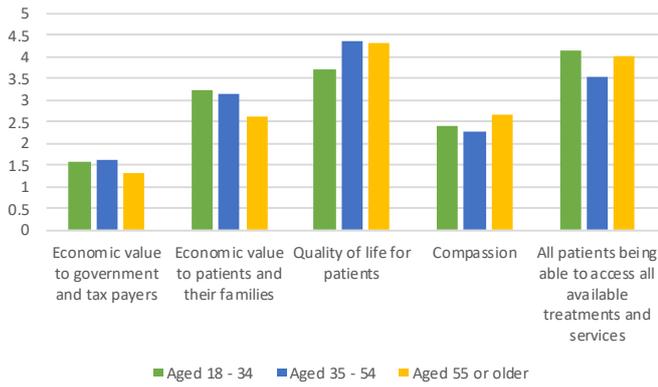


Figure 9.33: Decision making on patient behalf by Age

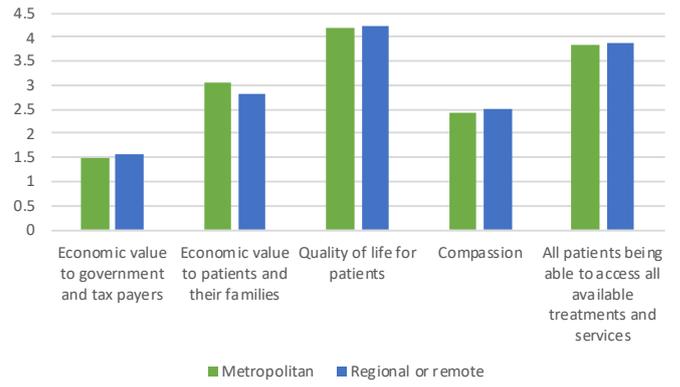


Figure 9.34: Decision making on patient behalf by Location

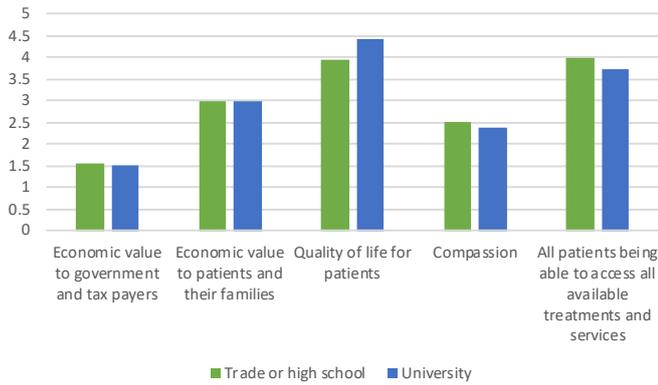


Figure 9.35: Decision making on patient behalf by Education

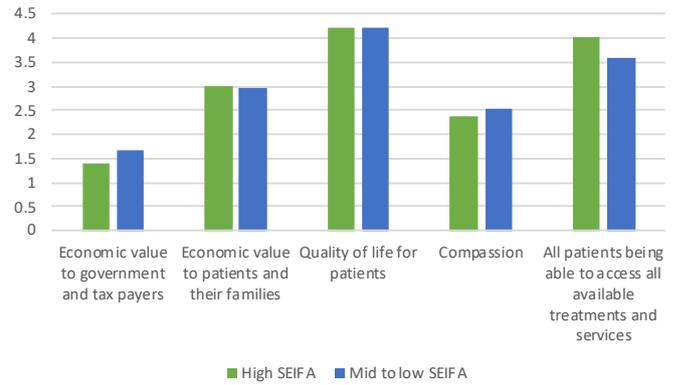


Figure 9.36: Decision making on patient behalf by SEIFA

## Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was that the cost of treatment is a burden (n=35, 35.00%), followed by the message that there should be equitable funding, with specific focus on the need for long-term treatment options and cost-effective management (n=23, 23.00%). This was followed by the message that there needs to be more education within the general community so that the severity of the condition is understood (n=22, 22.00%). There were 17 participants (17.00%) described the message that there needs to be more education for medical professionals to know how to best treat asthma and empower patient awareness of treatment options or services available. The message that there should be specialist treatments or access to specialist help for management and care plan development was reported by 13 participants (13.00%).

In relation to sub-group variations, participants in the *Aged 18 to 34* described having the message that the cost of treatment is a burden less frequently (17.39%) than the general population (35.00%), while those in the *Age 55 or older* sub-group described this more frequently (45.71%).

Participants in the participants in the *Age 18 to 34* described having the message that there needs to be more education within the general community less frequently (8.70%) than the general population (22.00%), while participants in the *Age 35-45* sub-group described this more frequently (35.71%).

Participants in the *Moderately controlled asthma* sub-group described having the message that there needs to be more education for medical professionals in order that they understand how to best treat asthma and empower patient awareness of treatment options/services available more frequently (31.82%) than the general population (17.00%).

There were no participants in the *Moderately controlled asthma* sub-group (0.00%) who described having the message that there should be specialist treatment centres/access to specialist help for management and care plan development compared to 13 participants (13.00%) in the general population.

## Participant's message is that the cost of treatment is a burden

*We need more opportunities to look at longer-term effective medication, instead of short-term effective medication. We need opportunities to explore more trials and I guess, more cost-effective financial long-term because the impact on us financially is huge. If I gather all my-- I keep every receipt, by the way. If I gather all my receipts for one year and looked at the cost I spent at the chemist just on Ventolin and my Flixotide and my steroids I've been looking over, I think last year, we averaged \$2,000 or something. Participant 3*

*I would like to say to the Health Minister that we need to really make sure that people understand the severity of the condition. I think also, I would say to the Health Minister that the costs can be incredibly debilitating to people access and care, that greater subsidies need to be made available for people and that people don't take medicine for fun. We actually have to do this to stay alive, to be able to function and to be able to contribute to our society and our community. If you don't actually treat the symptoms, we're going to end up more sick and we're going to end up costing a lot more. Perhaps if we're a bit more proactive, things would be a lot better. We'd have healthier, happier people in our communities living with a chronic and debilitating condition. Participant 57*

*I'd say make it cheaper because it's not something that we ourselves can control. It, unfortunately, is something out of their control. It's an expense that we all have to live with. It's not optional, it is a necessity. Make it cheaper for us. Participant 62*

*I definitely bring up the cost. I think the cost is a big thing. I know that there's a lot of people out there that won't take their medication or try and cut it down because of the cost. Cost is a huge burden for a lot of people. Participant 97*

Participant's message is that there should be equitable funding\More long-term treatment options and cost-effective management

*We need more opportunities to look at longer-term effective medication, instead of short-term effective medication. We need opportunities to explore more trials and I guess, more cost-effective financial long-term because the impact on us financially is huge. If I gather all my-- I keep every receipt, by the way. If I gather all my receipts for one year and looked at the cost I spent at the chemist just on Ventolin and my Flixotide and my steroids I've been looking over, I think last year, we averaged \$2,000 or something. Participant 3*

*We need to have a better quality of life and a better treatment plan that is available. We don't wish to have daily medications when it's not necessary, because there are people that have heart problems and all that kind of stuff. We have lung problems, it's just as bad. It's always boggled my mind that we don't have a better system available to us than people that have got heart problems, it boggles my mind. We're just as much an issue as those people that have got the heart and gland problems and all that kind of stuff, and kidney problems. We have just as much of an issue. The lungs are a massive piece of our bodily systems, we need to get the same care. Participant 15*

*I think there should be a well-thought through asthma plan like a care plan that people with mental illness are used to getting. It doesn't mean you always get the services and it works out, but the idea is a good one. To get these other integrated services that GPs and others might miss out and you'd hope the specialist would be aware of. Perhaps, to have a health plan that is specific for asthma people and that's well understood and well-funded. That'd be three things. Participant 18*

*I think it needs to be a clearer and a better system administrating. Like when you say a needle, like if you were to talk to a hundred asthmatics, they'd all take the needle because it's such hard work and it's hard on your body all the time and it's got to be affordable. Participant 22*

Participant's message is that there needs to be more education\General community to understand the severity of the condition

*Education, you need to know stuff. You need to educate the public about the reality of asthma so that those persons who know and those who are with somebody who's having an asthma attack that they know exactly what it is they have to do. Participant 7*

*I think I just want to say that it needs to be taken seriously, it needs to be taken seriously just as serious as mental health and other chronic illnesses as well. It is a severe illness, and I don't think there's enough awareness or education around it, which is very few people who've lived with the illness and detrimental to their quality of life as well. Participant 20*

*Well, I would tell him first of all that asthma is a silent disease. You can't see it and therefore it's not probably thought of or known as well, and every asthmatic is only one asthma attack away from death or potential death, and that it is a real problem. We need to be supporting all the asthma community in education, in costs, and ensuring their support is a lot easier for them. That it is a priority, and that it is a life-threatening unit. Participant 28*

*To my experience, it feels in some ways like it's almost taken for granted and it's not seen as a serious illness. It can have impact on lifestyle, even with mild asthma like mine. Perhaps, if it is treated a bit more seriously. There's a general perception out there where people say to you, "Do you have any illness?" If you say, "Asthma," they'll say, "Well, any real illness and this sort of thing." You know what I mean? I don't think it's necessarily treated and taken as seriously as maybe it sometimes should be. That perspective in some ways is more-- my son is eight years old and he's got asthma. When he was about two or three he was hospitalized maybe six times in the space of a year. It was that sort of like-- we just felt at times it wasn't treated as much of a priority. It was like, "Well, we'll get to you when we get to you. Sit over there." Participant 43*

Participant's message is that there needs to be more education\Medical professionals in how to best treat asthma and empower patient awareness of treatment options/services available (Empowerment)

*It's amazing if the treatments that people have asthma to-- are amazing if you can get them. I don't think they're readily available. I think you have to know the right questions to ask. I think you have to know or you have to have found the doctor that really cares. I think people need to be empowered to find information on their own. To be able to reach out to organizations like Asthma WA and say, "Can I come in? Can I receive these sessions?" Does that answer the question? Sorry, I don't know if I spoke to that very clearly. Participant 51*

*I definitely would like the health minister to underpin a process where everybody who is diagnosed with asthma is given the same consistent message, so they have the information, the knowledge they need to be able to properly manage their asthma that they've been diagnosed with. After all it's only with the proper knowledge and information that they can use that information to, not just manage and self-manage as much as possible, but also utilize the healthcare professionals in the right way. It's not about taking up the time of those healthcare professionals, but if you know the right people to talk to you are not wasting everybody else's time either. Yes, they really need to look at that and say, "Well, why do we have certain things that affect so many people in Australia, where they are. They have this coordinated approach. Why don't we have that for asthma? Why don't we have that across the board, so that a lot of asthmatics don't have problems? We can reduce the amount of asthma attacks that people have in this country, because they're getting the right information from the right people, so that they are taking their medications in the right way at the right time. They're also better able to self-manage what they're dealing with because they understand it." Participant 66*

*Well, probably that one I was just talking about. The lack of consistency between the people who are dealing with asthma sufferers. One's saying black and the other one's saying white. That's not helpful...perhaps that comes down to professional development and training and education for all of those who are involved in asthma management. That includes people doing lung puncture tests. One of the issues with the lung function test that was in question was that it was not done inside a cabinet. That's not the textbook term but I'll describe it as a cabinet. The specialist said that therefore the results are not valid. Now, I don't know. I mean he's the specialist, I suppose I have to take his word for it, but I really don't know. Participant 92*

Participant's message is that there should be specialist treatment centre/access to specialist help for management and care plan development

*That there's a plan of treatment and care, and that there must be an asthma center or something like that, preferably government supported. I think my phone might be about to stop. Yes, so for this sorts of disease there needs to be a specialist referral center. Participant 4*

*There needs to be some sort of 24-hour service for people that are having asthma attacks that they are pretty certain on the emergency rooms. That'll be it. Participant 6*

*I would say it's good when I actually get it. I need to be automatically referred. There's got to be a system where they are evaluated. The doctor evaluates them, they've just come into my clinic so many times and many months. I'm going to send them or refer to a specialist. You categorize them after they meet you often. You need to see a specialist. We get that specialist care. People who have been diagnosed and are taking medication every single day. They should automatically see a specialist twice a year to check that everything is going okay and maybe they do need their medication changed. A GP looks after every disease. Sometimes when you've got a disease you need a specialist who's just looking at that one. That everyone has access to a specialist and dental care. Participant 86*

Table 9.10: Messages to decision-makers

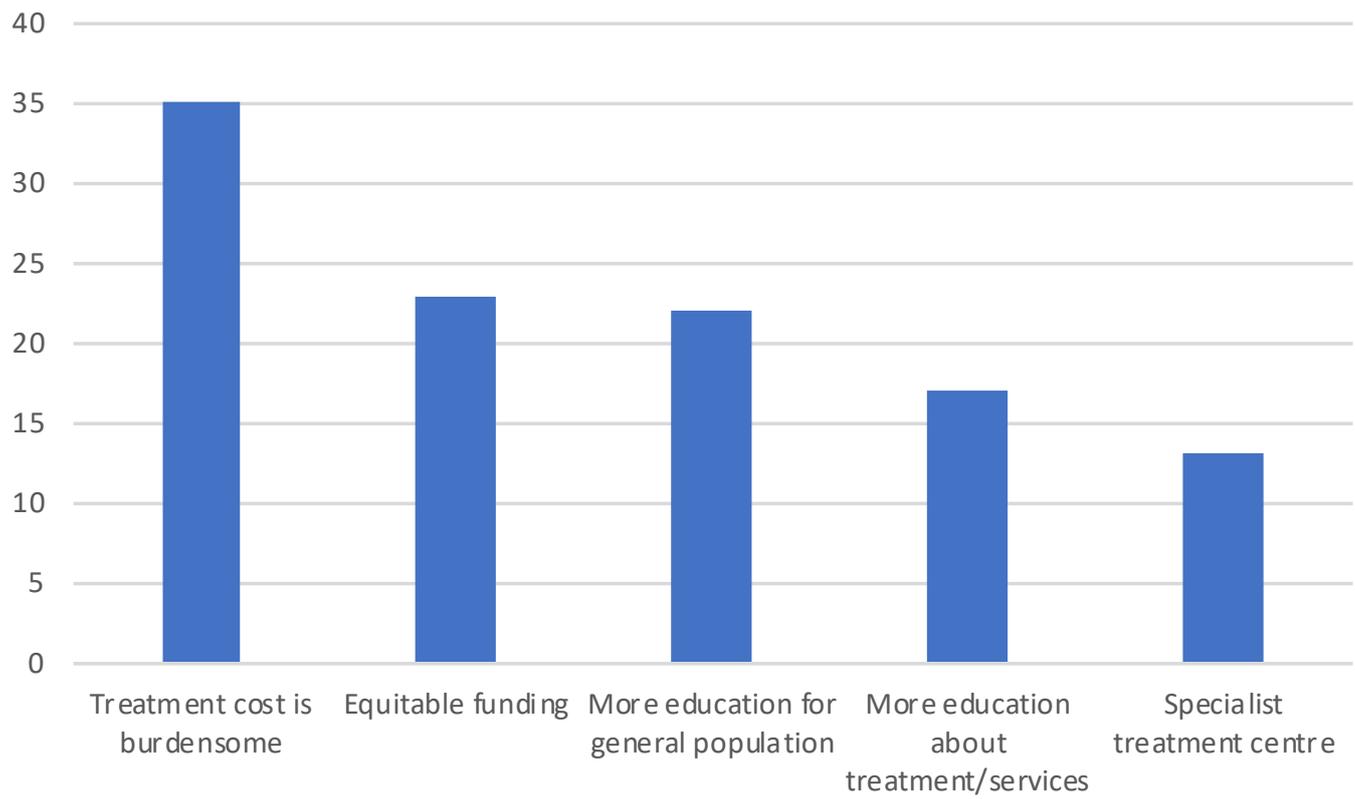
Message to decision-makers	All participants		Controlled Asthma		Moderately controlled Asthma		Poorly controlled Asthma		Moderate to well controlled Asthma		Frequent flare-ups		Occasional flare-ups		Infrequent flare-ups	
	n=100	%	n=26	%	n=22	%	n=52	%	n=48	%	n=36	%	n=41	%	n=23	%
Participant's message is that the cost of treatment is a burden	35	35.00	9	34.62	7	31.82	19	36.54	16	33.33	11	30.56	17	41.46	7	30.43
Participant's message is that there should be equitable funding with a focus on more long-term treatment options and cost effective management	23	23.00	6	23.08	5	22.73	13	25.00	10	20.83	8	22.22	9	21.95	6	26.09
Participant's message is that there needs to be more education\general community to understand the severity of the condition	22	22.00	5	19.23	5	22.73	12	23.08	10	20.83	10	27.78	9	21.95	3	13.04
Participant's message is that there needs to be more education for medical professionals in how to best treat asthma and empower patient awareness of treatment options/services available	17	17.00	2	7.69	7	31.82	8	15.38	9	18.75	4	11.11	8	19.51	5	21.74
Participant's message is that there should be specialist treatment centre/access to specialist help for management and care plan development	13	13.00	5	19.23	0	0.00	8	15.38	5	10.42	5	13.89	3	7.32	5	21.74

Message to decision-makers	All participants		Severe Asthma		Non-severe Asthma		Infrequent sleep disruption		Frequent sleep disruption		Aged 18 to 34		Aged 35 to 54		Aged 55 or older	
	n=100	%	n=29	%	n=71	%	n=41	%	n=59	%	n=23	%	n=42	%	n=35	%
Participant's message is that the cost of treatment is a burden	35	35.00	13	44.83	22	30.99	13	31.71	22	37.29	4	17.39	15	35.71	16	45.71
Participant's message is that there should be equitable funding with a focus on more long-term treatment options and cost effective management	23	23.00	7	24.14	16	22.54	8	19.51	15	25.42	6	26.09	9	21.43	8	22.86
Participant's message is that there needs to be more education\general community to understand the severity of the condition	22	22.00	7	24.14	15	21.13	9	21.95	13	22.03	2	8.70	15	35.71	5	14.29
Participant's message is that there needs to be more education for medical professionals in how to best treat asthma and empower patient awareness of treatment options/services available	17	17.00	4	13.79	13	18.31	7	17.07	10	16.95	4	17.39	7	16.67	6	17.14
Participant's message is that there should be specialist treatment centre/access to specialist help for management and care plan development	13	13.00	4	13.79	9	12.68	6	14.63	7	11.86	2	8.70	5	11.90	6	17.14

Message to decision-makers	All participants		Metropolitan		Regional or remote		Trade or high school		University		High SEIFA		Mid to low SEIFA	
	n=100	%	n=66	%	n=34	%	n=44	%	n=56	%	n=56	%	n=44	%
Participant's message is that the cost of treatment is a burden	35	35.00	21	31.82	14	41.18	15	34.09	20	35.71	18	32.14	17	38.64
Participant's message is that there should be equitable funding with a focus on more long-term treatment options and cost effective management	23	23.00	14	21.21	9	26.47	7	15.91	16	28.57	13	23.21	10	22.73
Participant's message is that there needs to be more education\general community to understand the severity of the condition	22	22.00	14	21.21	8	23.53	7	15.91	15	26.79	11	19.64	11	25.00
Participant's message is that there needs to be more education for medical professionals in how to best treat asthma and empower patient awareness of treatment options/services available	17	17.00	11	16.67	6	17.65	6	13.64	11	19.64	9	16.07	8	18.18
Participant's message is that there should be specialist treatment centre/access to specialist help for management and care plan development	13	13.00	9	13.64	4	11.76	5	11.36	8	14.29	10	17.86	3	6.82



**Figure 9.37: Messages to decision-makers**

## Section 10 Advice to other patients and families

### **Section 10: Advice to other patients and families**

In the structured interview, participants were asked what advice they would give to other patients and families in the future. The most common advice was to be assertive and ask a lot of questions (n=22, 22.00%), followed by take medication (n=19, 19.00%). There were 12 participants (12.00%) who advised to get as much information as you can. An equal number of participants (n=9, 9.00%) advised getting as much information as possible, and to understand triggers.

**Advice to other patients and families in the future**

In the structured interview, participants were asked what advice they would give to other patients and families in the future. The most common advice was to be assertive and ask a lot of questions (n=22, 22.00%), followed by take medication (n=19, 19.00%). There were 12 participants (12.00%) who advised to get as much information as you can, and 9 participants (9.00%) advised to get as much information as possible and to understand triggers (9.00%).

**Participant's advice is to be assertive and ask lots of questions**

*I think every case is totally individual. I know what triggers mine and I know how to deal with mine but I would say to everybody, and especially every parent, don't just take for granted what the doctor is telling you. Ask questions and advocate for your child or yourself because you know your body better than anybody else. If they give you one reason you ask questions about that and make sure that what they're telling you is correct. You have to be your biggest advocate. Participant 9*

*I just tell them to research heaps and find what's out there. When you see doctor talk, tell them what you found and just advocate for yourself. Participant 13*

*I make a little list of things to ask the doctor or to bring to his attention before I go. I have found that it was worthwhile. It might just be a couple of things I think worth mentioning or could be something more significant. Where I've had a reaction to medication or something that really hasn't much there. Because I've been on the same stuff for so long but some Yes, having a little list of things that you want to make sure you mentioned because it costs so much to see a doctor. \$30 and then you get a rebate of 35 so you're out of pocket over \$50. Participant 14*

*I've had to be really open about it with people, and I think that's really important. Christmas Day, we went down to my son's, and I knew all his wife's family were going to be there, so I sent a message and said, "Can you please ask them to make sure they don't wear strong perfume." You have to be assertive about your needs, and things like perfumes and so on, you just have to take action to protect yourself. Participant 17*

**Participant's advice is to take medication/specific medication**

*The message I've had really recently is even if you feel better, don't stop taking medication, that is what's making you feel better, it means it's working. Don't be complacent with your asthma, you can shut down at the click of your fingers. It's that serious. I just think a take-home message really has to be, "Listen to your healthcare professional, do what they tell you to do, but also listen and trust your body. If something's not working for you, you need to speak up and talk about that. If you need help, you need to speak up about that. Don't be embarrassed by it either, I think." Personally, taking the medication can be quite embarrassing, coughing and wheezing is embarrassing, but you've just got to own it. [laughs] Own it and listen to your body. Participant 20*

*Just to really keep in touch with your specialist. If you wanted to see him yearly, see him every year. Keep up-to-date with those medications, making sure you're taking the medication as prescribed...just keep up to all your tests that you have to have done and or your blood tests. Yes, just keep checking out regularly to find out. Participant 97*

*Take your preventer every day. Even when you feel good, take it. Participant 95*

*To stay on the preventives, preventives are definitely something that I have assisted me, that would be my main advice to avoid the triggers of asthma. Participant 73*

**Participant's advice is to get as much information as you can**

*What advice would I give? Educate yourself as much as possible. Don't wait for somebody to help you, you've got to help yourself when you're in the grips of an attack. To know what to do. Participant 7*

*I only suggest that they see a respiratory nurse or physio and access extra information. I think that should be a priority, really. I think that those two made the biggest difference. Participant 58*

*Look, I've often said to people, the Asthma Foundation is a really good place to start. Also, if I was talking about, I thought the Lung Foundation was great. Have you looked at that? Participant 12*

Participant's advice is to get as much information as you can\Participant's advice is to understand triggers

*I'd say just look at your living and your work conditions. Really really understand and notice what your triggers are because they're different personally and for different people. Stay away from them or learn about them and really understand the medications is part of it. Obviously know what to do and have steps like, I know if I have asthma, I know what kind of coughs to take a few puffs, I wait 20 minutes, four puffs. And that by certain time, I just go, "You know what, I need to call an ambulance." Having a general plan for yourself or something. Participant 75*

*I think it's learn about your own asthma. Learn about what triggers you. Learn and be more self-aware of, "Hey, this is going downhill, and I need to do something about it". It's that self-awareness and knowing your own triggers and limits, I think. Participant 63*

*I would say keep a trigger diary or a journal to try to pinpoint what is going on. Don't ignore symptoms just because you haven't had an asthma attack in two months doesn't mean that another one isn't going to come, so don't turn your back on your treatment. If you have questions, try and find a doctor or someone who can help you answer them. Don't doctor Google. Participant 57*

Table 10.1: Advice to other patients and families in the future

Advice to patients in the future	All participants	
	n=100	%
Participant's advice is to be assertive and ask lots of questions	22	22.00
Participant's advice is to take medication/specific medication	19	19.00
Participant's advice is to get as much information as you can	12	12.00
Participant's advice is to get as much information as you can\Participant's advice is to understand triggers	9	9.00

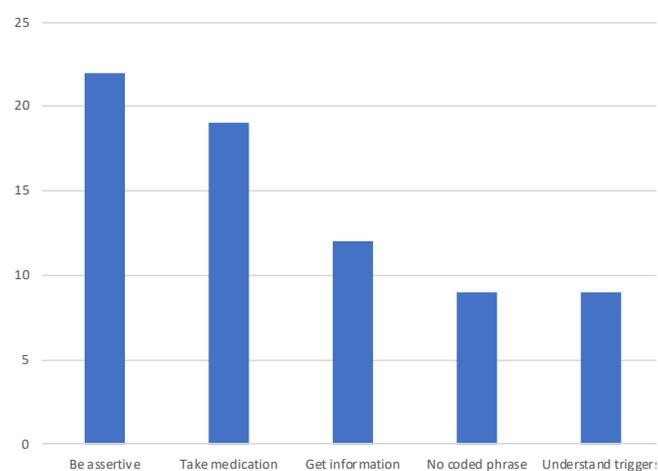


Figure 10.1: Advice to other patients and families in the future

# Section 11 Discussion

## Background

Asthma is a chronic lung condition in which inflammation causes widespread narrowing of the airways. It is characterised by episodes of breathlessness, wheezing, chest tightness and cough, often referred to as flare-ups<sup>1</sup>.

In 2014-2015, 1 in 9 Australians reported as having asthma<sup>2</sup>. In children, aged 5 to 14 years, asthma is a leading cause of burden of disease and is more common in males<sup>3</sup>. Comparatively, in adults, asthma is more common in females<sup>2</sup>. In the female population, asthma is more prevalent in outer regional and remote areas and higher in those of a low socioeconomic status<sup>2</sup>. In the male population, there is insignificant variation by remoteness and socioeconomic status<sup>2</sup>.

## Comorbidities

Asthma in adults is associated with comorbid conditions including: obesity, mental illness, arthritis and cardiovascular disease<sup>4 5</sup>. Asthma with one or more additional chronic conditions is associated with older age<sup>2</sup>. In Australia 2014-2015, six out of ten people with asthma reported having at least one other chronic condition, it is estimated that 29% of people with asthma had mental health problems, 23% had cardiovascular disease and 22% had arthritis<sup>6</sup>.

In this PEEK study, nine out of ten participants reported having at least one other health condition other than asthma. This includes non-chronic conditions which may be why the proportion is higher than that reported by the Australian Bureau of Statistics in 2014-2015. More than half of the participants reported experiencing sleep disruption or insomnia, this could be due to asthma symptoms at night. Anxiety and or depression diagnosed by a doctor were reported by 48% of participants, this is higher than that the mental health problems reported in Australia 2014-2015<sup>6</sup>. A quarter of participants reported having heart-related disease (hypertension, arrhythmia, chronic heart failure or angina), similar to that reported in Australia 2014-2015<sup>6</sup>.

Comorbidities have a negative impact on asthma symptom control, flare-up rates and quality of life<sup>7</sup>. Treating comorbidities in the diagnosis and management of asthma and could improve asthma control<sup>7,8</sup>, for example in obese people with asthma, improvements in asthma control and asthma quality of life have been demonstrated with short-term weight loss and exercise interventions, with

significant improvements seen with 10% body weight loss, and bariatric surgery<sup>9,10</sup>. A prospective study indicates that symptoms of anxiety and depression have a significant impact upon medication adherence and self-management capacity, this may result in a poorer quality of life for people with both asthma and depression and/or anxiety<sup>11,12</sup>. However, there is limited research to relate interventions for anxiety and depression to improved asthma outcomes<sup>7</sup>.

## Asthma Control

While asthma cannot be cured, for most people asthma can be controlled. This means very few symptoms, flare-ups, and lifestyle limitations<sup>1</sup>. Good asthma control is defined as daytime symptoms needing reliever medication two days or less per week, no night-time symptoms, and no interference with daily activities. Partially controlled asthma has one or two of the following symptoms: symptoms on two or more days per week, symptoms during the night and upon waking, symptoms that require reliever medication two days or more per week, and symptoms that interfere with daily activities. Poor asthma control is defined as three or more of these symptoms.

The Asthma Control Test is a five-item questionnaire that helps determine level of control that a person with asthma has on their asthma. The lowest possible score is five, indicating poor asthma control and the highest score is 25, indicating controlled asthma<sup>13</sup>. The majority of the participants in this PEEK study, scored between 5 and 19, which indicated that their asthma may not have been controlled, and a quarter scored more than 20, indicating moderately to well-controlled asthma.

## Flare-ups

Flare-ups are experienced at varying levels of severity, classified as mild, moderate, or severe. A mild flare-up is defined as worsening of asthma control whereby the individual experiences an increase in symptoms and uses their reliever more often. Symptoms may begin to interfere with their usual activities. A moderate flare-up does not require hospitalisation but causes distress and results in a change to treatment, there are more symptoms than usual that result in difficulty breathing and interrupted sleep. A severe flare-up is life-threatening and requires immediate action in order to prevent hospitalisation<sup>14</sup>.

Participants in this PEEK study indicated the frequency of flare-ups, the most common response was once a month, and over half of the participants reported having flare-ups once a month or more frequently. The majority of participants had been hospitalised due to their asthma, most commonly two to five times throughout their life.

### **Severe Asthma**

The Australian Centre of Excellence in Severe Asthma describe severe asthma as poor asthma control, airflow obstruction, frequent exacerbations and life-threatening episodes<sup>15</sup>. Patients are also commonly identified as living with lung and non-lung comorbidities. Common lung comorbidities include; bronchiectasis (widening of airways causing persistent cough with phlegm)<sup>16</sup>, incompletely reversible airflow obstruction, and allergic bronchopulmonary aspergillosis (a fungus). Common non-lung comorbidities include; sinus and nasal disease, dysfunctional breathing, obstructive sleep apnoea, anxiety and/or depression, gastro-oesophageal reflux disease and obesity<sup>15</sup>. The assessment and management of comorbidities should be considered in the treatment of severe asthma. In addition, allergic and non-allergic factors which play a 'trigger role' in inducing and exacerbating symptoms as well as airway inflammation should be identified and controlled<sup>15,16</sup>.

### **Risk factors and symptoms**

The pathophysiology of asthma is complex and the role of genetic, environmental and lifestyle factors is acknowledged but not well understood<sup>17</sup>. Common risk factors include a family history of asthma, smoking or exposure to cigarette smoke, overweight or obesity, sedentary lifestyle and exposure to environmental hazards such as air pollutants<sup>17</sup>.

The symptoms of asthma are variable in presence and severity. They may be experienced in a mild, intermittent form or be persistent and severe<sup>1</sup>. Symptoms are usually non-permanent and may be reversible with or without medication. The main symptoms of asthma are episodic breathlessness, wheezing, chest tightness and cough<sup>1</sup>.

The most common symptoms reported by participants in this PEEK study were coughing or wheezing attacks that are worsened by a respiratory virus, such as a cold or the flu, trouble sleeping caused by shortness of breath, coughing or wheezing and shortness of breath. Whistling or wheezing sound

when exhaling and chest tightness or pain were experienced by most participants. The quality of life from the most common symptoms experienced by participants in this PEEK study was in the "Life was distressing" range. The most common symptom leading to diagnosis experienced by participants in this PEEK study was difficulty breathing, including shortness of breath, wheezing, and cough not related to a cold or flu.

Before diagnosis, almost half the participants or their parents knew either nothing or very little about asthma. When participants did have some knowledge about asthma it was usually because they knew a family member or friend with asthma.

### **Asthma Triggers**

A number of factors have been identified as triggers for asthma symptoms. While triggers may differ between people with asthma, they may include; cold, flu and respiratory infections, cigarette smoke, allergies, exercise, weather, workplace exposure to chemicals, irritants in the air such as bushfire smoke, some medicine, and stress<sup>17 18 19</sup>.

Control measures that reduce the effect of environmental triggers on asthma are limited<sup>18</sup>, a home-based environmental intervention shows promising results. Where other studies have focussed on single allergens<sup>18</sup>, a US randomised controlled trial assessed the effect of patient education and household remediation for dust mites, passive smoking, cockroaches, pets, rodents and mould exposure<sup>20</sup>. There were fewer demonstrated symptoms of asthma during and after the intervention as well as a reduction in unscheduled asthma-related visits to health services. Thus, the control of environmental triggers through patient education and household remediation may assist in reducing asthma exacerbations.

### **Diagnostic pathway**

The National Asthma Council Australia have produced the Australian Asthma Handbook, which describes diagnostic pathways and management of asthma in Australia<sup>1</sup>. In the absence of a single diagnostic test, asthma diagnosis is confirmed on the basis of patient history, physical examination and lung function. Generally, a diagnosis of asthma is applied if the patient has a history of symptoms (breathlessness, wheezing, chest tightness and cough), demonstrates variable expiratory airflow limitation that is lower than the normal limit for age. Other and results do

not suggest an alternative diagnosis other causes of respiratory problems include poor fitness, cardiovascular diseases, comorbid conditions, lung cancer and other respiratory conditions such as COPD, and in children congenital conditions and infections<sup>1</sup>.

Participants in this PEEK study, most commonly three tests or five tests. The most common diagnostic test was a physical examination, followed by spirometry tests. Approximately a third of participants in this PEEK study had enough support between diagnostic testing and diagnosis, a quarter had some support but not enough, however, most commonly participants had no support. Approximately a third of participants had enough information at diagnosis, a quarter no information, and most commonly participants had some information but not enough.

An asthma diagnosis is often overlooked in adults, particularly those that are over 65, despite older adults presenting with the same symptoms as younger adults<sup>21,22</sup>. This could be due to underreporting of symptoms or attributing symptoms to old age or co-morbidities<sup>21-23</sup>.

Guidelines for severe asthma suggest that at diagnosis, contributory factors and comorbidities should be assessed prior to identifying the pattern of inflammation<sup>8</sup>. However this is commonly completed in a time-consuming and resource intensive manner through either unstructured or exhaustive assessment, improvements may be made by using a screening questionnaire followed by a specialist assessment with tailored referrals<sup>7</sup>.

### Biomarkers

Biomarkers can be used for diagnosis, to determine the type, to predict response to treatments. In the case of asthma treatment, biomarkers may predict the response to corticosteroids and biological therapies<sup>24</sup>. Sputum and blood eosinophils, and fraction of exhaled nitric oxide (FENO) are biomarkers of Th2 cell high eosinophilic airway inflammation<sup>25</sup>. Sputum eosinophils may predict response to corticosteroids and T2-targeting therapies, and may also predict flare-up risk<sup>24,26-28</sup>. Blood eosinophils can predict disease severity and flare-up risk, response to corticosteroids and IL-5 targeting biologicals, and mepolizumab<sup>24,29,30</sup>. Fraction of exhaled nitric oxide (FENO) may predict response to corticosteroids, and can monitor the correct use of corticosteroid inhalers, compliance to therapy, and corticosteroid resistance<sup>31,32</sup>. Immunoglobulin E (IgE) can be used to

give optimal dose of omalizumab, and predict response to therapy<sup>24,31,33</sup>.

Almost all the participants in this PEEK study did not have any conversations about biomarker/genomic/gene testing that might be relevant to treatment. The majority of participants did not have any testing but would like to and were not sure they had specific biomarkers. However, while not sure of any specific biomarkers, over half of the participants had a family history of asthma and/or allergies.

### Treatment

Following diagnosis, medications play a significant role in improving quality of life, minimising symptoms and reducing the risk of flare-ups. The goal of asthma management and treatment is asthma control.

Asthma management involves the assessment of asthma control, the development of management goals as well as the selection and periodic review of treatment<sup>1</sup>. Standard initial treatment involves the use of relievers (commonly short-acting beta agonists) and preventers (commonly inhaled corticosteroids)<sup>1</sup>. Relievers have a bronchodilatory effect, which increase airflow to the lungs, and are taken as a fast-acting relief from symptoms<sup>1</sup>. Preventers are incorporated into regular treatment to maintain asthma control and minimise symptoms<sup>1</sup>. Other medicines may also be used to treat risk factors and co-morbidities or to manage difficult-to-treat asthma<sup>1,17</sup>. For severe asthma, long acting reliver such as Tiotropium or Spiriva, or a non-steroid preventer such a Montelukast should be trialled before referral to a specialist for monoclonal antibody treatment<sup>1</sup>.

Almost all participants in this PEEK study used a reliver puffer like Airmol or Ventolin. The next most common treatment was a preventer puffer like Breo or Flutiform. About a third of participants used a non-steroidal preventer, and very few participants used monoclonal antibodies to treat their asthma. The quality of life from using a reliver puffer was in the life was average to life was good range and was found to be an effective treatment. The quality of life from a preventer puffer was rated in the life was good range and was found to be effective.

## Self-management

Self-management is a significant component of successful asthma management and control. This requires healthcare professionals to equip asthma patients with information, training and tools that maximise treatment adherence. Generally, this may include training on correct inhaler technique, written asthma plans and a discussion about triggers and risk factors<sup>1</sup>.

A written asthma action plan is a personalised guide which is developed by a doctor in consultation with a person with asthma. An asthma action plan includes current medications (including dosages) and asthma triggers as well as asthma symptoms or peak flow levels which indicate level of severity<sup>34</sup>. The recommendations in the Australian Asthma Handbook is that every adult and child with asthma should have an individualised written action plan that provides clear instructions about responding to symptoms including how to adjust medication and when and how to get medical care<sup>1</sup>.

Regular reviews of the asthma action plans are recommended<sup>1</sup>. This provides health care professionals with the opportunity to evaluate the patient's knowledge of medication and treatment plans as well as identifying and advising on any negative lifestyle behaviours<sup>35</sup>. An asthma action plan supports patients in self-management compliance by improving personalised asthma education as well as simplifying care through simple instructions<sup>36</sup>. Asthma action plans have been demonstrated to reduce a patient's risk of exacerbations and hospitalisation, decrease the need for emergency services and enhance patient quality of life<sup>37</sup>. Despite these outcomes, it is estimated that only 21% of Australians with asthma aged 15 and older have an asthma action plan<sup>19</sup>.

The majority of participants in this study (about three quarters) had a discussion about their asthma at least once a year, most commonly, four times a year, however, approximately a fifth of participants had conversations less often than annually.

The lack of asthma action plans may be due to a lack of awareness of current recommendations as well as insufficient access to plan templates, time constraints during consultations, poor motivation, patient forgetfulness, and a perception that adults will view the plans as unnecessary. There is reluctance and inconsistency in implementation of treatment plans as a result of concerns for safety and side effects,

personal health beliefs, other health conditions (e.g. mood and memory), and discomfort with prescribed medication<sup>35,38-45</sup>. In order to reduce the burden for people with asthma and the health care system, the provision and use of asthma action plans must be improved. Health care providers play a pivotal in improving asthma education through the increased development of asthma action plans for asthma patients.

Participants In this PEEK study would like to see more options, and personalised comprehensive asthma management plans. They would like health professionals to listen to them and not dismiss their concerns, take longer to explain treatment options and what to expect from their diagnosis. In addition, they would like health professional to have a better understanding of the severity of asthma, emergency care, and how to manage asthma.

## Allied health

Allied health professionals are distinct from doctors and nurses, they are professionals who perform a range of services within the healthcare system including diagnosis, treatment and support.

Physiotherapy may be of benefit for asthma management, therapy can include breathing techniques, symptom management, exercise advice, and the use and maintenance of medication devices such as puffers. Physiotherapy may improve quality of life, fitness and medication use<sup>46</sup>. Physiotherapy is recommended by the National Asthma Council Australia for people with severe asthma who have mucous production<sup>1</sup>. Less than a fifth of the participants had seen a physiotherapist for their asthma, for those that did on average it was moderately effective.

## Complimentary therapies

Complementary and alternative medicines are healthcare therapies or devices that are not considered conventional medicine such as acupuncture, aromatherapy, homeopathy, massage, meditation and relaxation therapies, naturopathy and nutritional supplements. The use of complementary therapies for asthma is more common in women<sup>47</sup>. People with asthma perceive complementary alternative medicine therapies including meditation and relaxation methods as safer than conventional medicine with some patients often using complementary therapies before taking reliever

medication<sup>45,47</sup>. In addition, a qualitative study indicates that many patients support the integration of complementary and alternative medicines with pharmaceutical treatment<sup>47</sup>. Key perceived benefits of complimentary alternative medicine include a reduced sense of dependence on medication and a more tailored treatment<sup>48</sup>. Contrasting this, some patients view complementary alternative medicine medicines as ineffective in asthma management with particular concern for the lack of recommendations supported by scientific evidence.

The most commonly used complementary therapy was relaxation techniques, on average, participants found this to be somewhat effective. Other complimentary therapies reported were massage therapy and acupuncture, these were used by about 10% of participants.

### Lifestyle interventions

Lifestyle interventions that may help with managing asthma include smoking cessation, a diet rich in fruit and vegetables and low in processed foods that are high in saturated fats, physical activity and exercise and weight loss for those that are obese.<sup>1</sup> A review of current evidence suggests that asthma patients should be encouraged to consume a healthy diet, including fruits and vegetables to help manage asthma<sup>9,49,50</sup>. The addition of exercise to healthy eating has demonstrated an improvement in both asthma control and quality of life.<sup>51</sup> Obesity is highly prevalent in the asthmatic population, with a US study finding more than half of adults with asthma were obese<sup>52</sup>. In Australia, people with asthma are more likely to be obese than people without asthma<sup>6</sup>. Obesity with asthma is associated with increased severity, poorer asthma control and poorer quality of life<sup>49,53</sup>

### Adherence to treatment

To achieve the best possible asthma control, asthma management requires identification of an individual treatment plan and support for self-management<sup>1</sup>. Factors that encourage adherence to asthma treatments include being proactive, for example being informed about asthma management, having an asthma management plan and monitoring disease, for example with a peak flow meter.<sup>54</sup> Routines that help with taking medications and managing triggers, such as avoiding activities or environments that trigger flare-ups can help with being able to maintain activities of daily living<sup>38,54</sup>.

Health care professionals, asthma patients and their carers can experience significant barriers to the implementation of treatment guidelines and asthma action plans. This may include consult time restrictions, inconvenient clinic times, the geographical location of health services and inability to attend clinics due to worsening disease state<sup>48,55,56</sup>. The cost of medication may be prohibitive for some that can result in not taking the medication or using a different type medication that is less expensive<sup>54</sup>. In addition, people who experience severe asthma, have difficulty dealing with the side effects of corticosteroids, in particular anxiety, depression and irritability<sup>40</sup>. People with asthma who minimise the condition, for example they do not believe that they need medications and that they are not sick enough for any medications<sup>54</sup>.

The participants in this study most commonly described 'mild side effects' as those that can be self-managed and do not interfere with daily life. Specific mild side effects were shakiness or rapid heart rate, and headaches with or without nausea. Severe side effects were described by participants in this PEEK study as side effects that impact everyday life or the ability to conduct activities of daily living. Side effects that were life threatening, resulted in hospitalization, that were long lasting, and those that affected mental health were also described.

Most participants (about 80%) in this study responded that they were good at taking their asthma medications, either all the time or most of the time. Despite this, about half the participants had poorly controlled asthma. Participants in this PEEK study described stopping treatments if they felt it was not working or if it caused intolerable side effects. The treatments would stop with or without a discussion with their doctor. This highlights the importance of information about the expected benefits, side effects of treatments, and generally what a person can expect to happen when they take a specific medication. In addition, the importance of communication about what to do when the treatment is not working, and when to seek follow-up medical attention when using a treatment.

Inconsistent advice, and a lack of continuity in care can result in frustration, non-adherence to treatment and advice for people with asthma and their carers. In addition, this can impede the ability of clinicians to effectively assess patients<sup>42,48</sup>

## Seeking medical attention

A 2012 survey of over 2,500 Australians living with asthma identified that approximately a third required urgent healthcare due to their asthma in the year previous<sup>57</sup>. Despite this, in 2014–15 only 28% of Australians living with asthma reported having an asthma action plan<sup>58</sup>. In the adult asthma population, those aged 25-34 were least likely to have a written action plan, while children aged 0-14 were most likely<sup>58</sup>.

Severe shortness of breath, chest tightness or pain, and coughing or wheezing were the symptoms that had led most participants to seek medical attention. The most common symptoms that led to participants seeking medical attention quickly were the inability to speak more than short phrases due to shortness of breath, and symptoms that failed to respond to use of a quick-acting (rescue) inhaler.

In terms of barriers to adhering to treatment due to cost or financial issues, the majority of participants in this study did not have to cancel medical appointments or not fill prescriptions for asthma medications due to cost. Nor did they have difficulties paying for basic necessities such as housing, food, and electricity as a result of their asthma diagnosis. There were few that had to pay for additional carers for either themselves or their family due to their asthma diagnosis. A quarter of participants had a reduced family income due to asthma, and for the majority of participants who had a reduced income, this reduction was extremely or moderately significant. Participants estimated the amount they spend per month on asthma. The most common amount was less than \$50, although there were some who spent more than \$500 a month. For the majority of participants, this amount was not at all or a slightly significant burden. Two thirds of the participants of this PEEK study have made changes to their employment that has resulted in a reduced income (taking leave without pay, reducing hours or quitting their job). The partners or main carers of some of the participants had also made changes to their employment that resulted in a reduced income.

For future treatments, participants in this PEEK study would like to see treatments that are more affordable, noting that costs are currently a burden, they would like treatments that are easy to administer with less short and long-term side effects.

## Clinical trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 17 April 2019. The search included any study that included asthma participants, was conducted in Australia, and was open for recruitment in the last five years. A total of 27 studies were identified or between 5 and 1200 participants (median n=60), one study of 675 participants was an international study, the remaining 26 studies were conducted exclusively with in Australia. There were seven studies that listed asthma as a condition in the inclusion criteria but also included other chronic conditions.

There were 17 studies conducted in New South Wales, seven in Queensland, six in Victoria, two in the Australian Capital Territory, and one each in Western Australia, South Australia, Tasmania and the Northern Territory. There were 11 studies of allied health interventions, five drug trials, five treatment pathway studies, four studies that monitored disease levels, one imaging study and one vaccine study.

Very few participants had discussions about clinical trials, and only eight participants had taken part in a clinical trial. However, the majority of participants would like to take part in a clinical trial if one was available to them. Most clinical trials held in the past five years in Australia have been conducted in New South Wales, there is a need to broaden the geographical location of clinical trials to allow more opportunities for people with asthma.

Patient-reported outcome instruments have been identified as a valuable tool in a clinical trial setting<sup>59</sup>. By capturing a patient's perceived response to treatment, patient-reported outcomes can provide an insight into treatment effects for which there are no observable or physical measures<sup>59</sup>. A review of 300 clinical trials published in an 18 month period<sup>60</sup>, 20 studies included a patient-reported outcome evaluation using validated tools. The comparison of recent studies suggests a need for consistent evidence in support of the inclusion of patient-reported outcome evaluation in clinical trials<sup>60</sup>. This will be crucial in the implementation of clinical trials

to meet a growing demand for individualised and targeted treatments<sup>60</sup>.

### Healthcare coordination and services

Asthma is primarily treated and managed by GPs, with respiratory specialists for poorly controlled and severe asthma. Community pharmacists and primary health care nurses have a role in providing advice, education, and information for self-management. In addition, teachers, home and community care workers are involved in asthma care<sup>61</sup>. Some people with asthma have a preference for asthma clinics, where there is a perception that the healthcare professionals are more informed about asthma compared to General Practice, and that they receive better information and explanations from asthma clinics. While others report they self-manage due to the perception they are more informed than their General Practitioner<sup>54</sup>.

For most of the participants in this study, their main provider of asthma related care was their general practitioner. Participants commonly had access to a pharmacist and respiratory specialist.

Almost half of the Australian population have private health insurance with hospital cover. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from 8% to 14%<sup>62</sup>. Hospitalisation or emergency department treatment is required when flare-ups are life-threatening and cannot be managed by a GP or at home<sup>17</sup>.

While two-thirds of the participants in this PEEK study had private health insurance, only a third were asked if they want to be treated as a public or private patient. In addition, less than half were asked if they had private health insurance. The majority of participants had been hospitalised for asthma, and were mostly treated as public patients, and most were treated in the public hospital system (n=60, 74.07%). Participants had been hospitalised for asthma most commonly two to five times throughout their life, and the most common length of admission was one day.

A mutually trusting relationship between healthcare professionals and patients increases adherence to self-management plans<sup>63</sup>. To build this relationship and improve adherence to treatment, people with asthma have suggested that healthcare professionals

need to listen to and understand their personal circumstances, and build this into their self-management plans<sup>48,64,65</sup>. This is particularly important for young people, those with low health literacy and intellectual disability and those from ethnic minorities<sup>48</sup>. Poor communication between healthcare provider and asthma patient can limit the intended effect of services<sup>66,67</sup>. This is particularly prevalent in patients with poor health literacy<sup>68</sup>. A randomized controlled trial of a 'literacy-sensitive' self-management interventions suggests that this can be overcome through the use of simple language, teach-back methods and visual aids<sup>55,56,69-72</sup>.

Having sufficient time in healthcare consultations is important for the person with asthma to feel like they are being listened to, and for satisfactory explanations and information to be given<sup>54</sup>. Delayed or avoided medical consultations asthma occur for some people with asthma due to a fear of being judged by healthcare professionals, reasons for this include past experiences when concerns have not been taken seriously by healthcare<sup>54</sup>.

On the whole, participants in this PEEK study were treated with respect throughout their treatment.

### Healthcare/decision-making

When making decisions about healthcare, people with severe asthma reported that they weighed up the pros and cons of the treatment to achieve a normal life, to be able to do their usual daily activities and employment. Many wanted a two-way conversation with their doctor to help them make the decisions, and felt helpless when their doctor was authoritarian or paternalistic<sup>38</sup>. Having adequate information given aids self-participation in healthcare management and decision-making<sup>54</sup>.

In his PEEK study, participants on average the most important aspects considered when making decisions about their asthma treatment 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". When others are making treatment decisions on their behalf, such as government departments or healthcare professionals, 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.

The majority of participants in this study had very little discussion about their treatment options, with only a single option or approach presented. Side effects were often cited as a consideration for making treatment decisions, other factors included quality of life, cost, and efficacy. Decision making changed over time for a number of participants in this study. Participants became more aware of their health, more informed and assertive and also changed with life stage for example retirement or starting a family.

While participants in this study had an overall positive experience of healthcare communication, it was important that adequate time was given, that healthcare professionals are well informed both about asthma and about the individual patient's medical history. Participants in this PEEK study reported that they were overall content with the information they received, in the future they would nevertheless like more detail about current and emerging treatments, and for treatments to be more affordable.

### Quality of life

There are multiple risk factors for people with asthma that reduce health quality of life, including socio-economic status, physical activity, comorbidities, smoking, anxiety and depression and being overweight or underweight<sup>73 74-76</sup>. Some report the burden from physical aspects of asthma, these include unpredictable symptoms, and reduced capacity for activities of daily living including work function and hobbies<sup>54</sup>. Younger people with asthma are more likely to have anxiety and depression compared to older people with asthma<sup>76,77</sup>, however, other studies have found no differences in health related quality of life<sup>73</sup>.

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The average score for the participants in this study corresponded to low levels of anxiety. Participants that had poor asthma control, and frequent sleep disruption had higher levels of anxiety to compare to participants with moderately to well controlled asthma and infrequent sleep disruption respectively. There were no differences observed in anxiety levels by age, education or socio-economic advantage.

People with severe asthma have worse health related quality of life. Standard treatments for asthma often do not work for people with severe asthma, they often have poor symptom control, affecting all

aspects of their life including their work life and social life<sup>78</sup>. The health-related quality of life for people with severe asthma is reduced due to poor symptom control, flare-ups, and the impact that this has on physical activities, social lives and work lives<sup>78</sup>.

Symptom control for participants in this PEEK study were important for health-related quality of life. The majority of participants in this study would continue to use a treatment for more than ten years if it offered a good quality of life, even if it did not offer a cure. The most important symptoms and quality of life aspects reported in this study were shortness of breath, and coughing or wheezing attacks worsened by a respiratory virus. The least important was whistling or wheezing sound when exhaling.

### Support/Psycho-social care

People with asthma have reported feeling a negative stigma associated with having asthma. Some feel they are judged by many aspects of society including family, employers and health professionals as a result of seeking medical attention, and being judged by family about the seriousness (or lack of seriousness) of their condition, or needing to take time of work<sup>54</sup>. Others have the burden of self-judgement, this includes feeling like they are wasting health professional time with their health concerns, needing to prioritise asthma management over family responsibilities, embarrassment about having asthma and feeling damaged<sup>54</sup>. People with asthma may conceal medications from others, to avoid judgement in social situations and in fear of employment implications at work<sup>54</sup>.

A population-based study in Sweden reported that coping strategies for people with both severe and non-severe asthma included acceptance of having asthma. Social support was highly rated from partners, family members and healthcare professionals, people with non-severe asthma had more social support compared to those with severe asthma, the least amount of perceived support was from authorities and from patient organisations<sup>79</sup>. Support from family, friends and healthcare professionals help manage asthma in acute and non-acute situations, and unsupportive health professions can be a barrier to managing asthma<sup>80</sup>.

Social support for asthma was an important factor for mood and stress, an increase of perceived social support was associated with decreased negative mood and stress, and also fewer reported symptoms<sup>81</sup>. A review of social support for asthma

## Information and education

reported both positive and negative influences on asthma management. Positive influences were reported more often and included the support from family and friends in a practical way, for example medication reminders, help with physical tasks, remaining calm during flare-ups and as an education source. Family and friends also offered emotional support. The kind of social support reported that was a negative influence on asthma included unhelpful behaviours from family and friends for example smoking. Employers perception of increased time away from work reduces employment opportunities due to absenteeism and employment opportunities for people with asthma. Differing health beliefs of family and friends from health professionals may make adherence to treatment more difficult<sup>48</sup>

A Sydney based study reported that while people with asthma trusted healthcare professionals, they interacted more often with family and friends and relied on these personal relationships for monitoring symptoms, emotional and physical support. Physical and emotional support was particularly important during flare-ups or worsening of symptoms. Support from family and friends who have similar health conditions, especially for advice was also important.<sup>82</sup>

Over half of the participants in this PEEK study described receiving care and support from their family and friends. Support came from a range of health professionals, mostly general practitioners, specialists, nurses and also from community pharmacists and physiotherapists. Many reported in a positive way, continuous care from healthcare professionals over a number of years. Other sources of care and support was from health professionals, and charities (primarily Asthma Australia). The type of support from charities included information, accessing services and financial support.

Participants in this PEEK study were asked whether there was any additional care and support that they thought would be useful in the future, including support from local charities. Most commonly, participants were content with what was available. Suggestions to improve what was available included more long-term asthma management and treatment plans and/or holistic care, more community-based support, specifically peer support including support groups and information sessions, or family peer support and more opportunities to access specialists in asthma for treatment, information and support.

Information and education are important for asthma self-management. In order to reduce emergency department re-admittance and improve adherence to treatment plans<sup>83</sup>, there is a need for improved patient and carer education in asthma self-management. Asthma self-management education can be characterised by three components; self-monitoring or peak expiratory flow education, a written asthma plan and regular medical review. A Cochrane review of programmes incorporating all three components suggests that self-management education is associated with significant improvements in asthma outcomes<sup>84</sup>. While costly to implement<sup>85</sup>, asthma self-management programs are relatively cost-effective<sup>55,86</sup>. Benefits include a reduced risk of hospitalisation, a reduction in emergency hospitalisation, unplanned leave and an improvement in quality of life. Asthma exacerbations and hospitalisations are also associated with a high cost to both healthcare and the patient.

By routinely assessing patient knowledge and providing relevant information, patients are empowered to self-monitor symptoms and correctly adhere to treatment plans<sup>55</sup>. In particular, the Global Initiative for Asthma report recommends the prioritisation of a physical demonstration of inhaler techniques. This is supported by a Sydney based study of physician-diagnosed asthma patients in which a total of 87.5% of patients were unable to demonstrate the correct inhaler technique<sup>63,87</sup>.

Participants in this PEEK study were asked about what type of information they were given by healthcare professionals and what type of information they searched for independently. The most common information given to participants by healthcare professionals was about treatment options disease management, and information about allergies. Information about hereditary considerations genes or genomic biomarker information, clinical trials (3.00%) and complementary therapies, were given least often. Information about treatment options, disease management and information about allergies were most often searched for independently by participants. Psychological/social support, hereditary considerations genes or genomic biomarker information, and clinical trials were least searched for. The largest gaps in information, where information was neither given to patients nor searched for independently were for clinical trials, hereditary considerations genes or genomic biomarker information, and psychological/social

support. Participants were given most information either from healthcare professionals or independently for treatment options. Disease cause was the topic that was most searched for independently following no information from health professionals, followed by complementary therapies.

People with severe asthma reported that healthcare professionals are important for learning about their condition. A qualitative study of patient perspectives relating to asthma treatment<sup>47</sup> indicates that simple, printed information as well as oral information from the general practitioner is the preferred method of education. However, information may not seem relevant, or the information may be too technical to understand. The amount of time available in consultations with general practitioners was important and often reported as too rushed for adequate information, however, some reported that nurses had more time and gave more information<sup>38</sup>. People with severe asthma searched for more information in addition to what they were given from their healthcare professions, the common sources were medical journals, websites, family and friends, and information leaflets<sup>38</sup>.

Some general practitioners and people with asthma view internet interventions as being beneficial to asthma self-management. However, this is limited to those comfortable using technology<sup>41,48,88</sup>. Electronic applications and online support can provide a source of educational material, asthma monitoring and support with 24-hour access and feedback from specialised health professionals<sup>89</sup>. There is mixed evidence about the value of these in increasing adherence to treatment and healthcare facility use<sup>90-92</sup>.

In the US, telephone-based self-management support interventions have been trialled as a method of overcoming practical barriers to support and education services<sup>93,94</sup>. While clinical outcomes were not observed, an improvement in the ratio of preventer to reliever treatment was demonstrated<sup>93</sup>. Thus, telephone-based interventions may provide a potential method of improving asthma education<sup>95</sup>.

Self-management interventions such as telemonitoring and telephone follow ups, in-home health support and assisted discharge schemes, lay educators as well as simple patient prompts such as mail outs), can reduce hospital admissions, cost of care and may improve patient outcomes<sup>55</sup>. Electronic applications used by either healthcare professionals or patients have demonstrated improvements in

healthcare coordination, clinical outcomes and patient quality of life<sup>96</sup>. These applications include documenting patient records, treatment reminders and guidance and home monitoring of symptoms<sup>92,96,97</sup>.

Participants in this PEEK study found most of their information about asthma on the internet, from Asthma Australia or from health professionals. Information about medications or treatments was most commonly found to be helpful. Participants in this study had a first preference for speaking to a healthcare professional to get their information about asthma. Information to supplement talking to a healthcare professional such as information on the internet, written information sheets and apps was preferred. However, participants were careful about the information they used, by judging for themselves the quality of information, with recent information from trusted sources such as patient organisation being valued.

In terms of changes in information that participants in this study would like to see in future, participants would like to have more detailed information about current and emerging treatments, and also some information or tools that help manage and monitor their asthma and its side effects. Some would like to see information in an easy to understand language.

### Characterisation of this PEEK study patient population

There were 100 participants in this study from across Australia, lived in all levels of socio-economic advantage or disadvantage. Most participants were women, most participants were aged between 35 and 64. Most participants had asthma that could be better controlled.

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

Before diagnosis, this is a patient population that commonly experienced breathing difficulties in breathing, however a number of participants that were too young when they were diagnosed and could not remember symptoms. The condition was most commonly diagnosed by a general practitioner and this patient population had between one and seven diagnostic tests, with two thirds having three or more diagnostic tests. The most common diagnostic tests

were physical examination and spirometry tests, with very few participants recalling having any discussions in relation to biomarker or genetic tests.

This is a patient population that had very little discussion about their treatment options. That considered cost, side effects, quality of life and efficacy when making treatment decisions. Participants changed the way they made treatment decisions over time as they became more informed, assertive and changed life stages (e.g. having children, retirement).

Almost all the participants in this study used a reliever puffer, and a preventer puffer. Very few participants used monoclonal antibodies. Physiotherapy was only used by about a fifth of the participants. Complementary therapy use was largely relaxation techniques, while close to half did not report using complementary therapies at all.

Very few participants in this study population reported having discussions about clinical trials with their clinician and only eight 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 patient population that defined 'mild side effects' as those that they can self-manage, and do not interfere with daily life and 'severe side effects' as those that impact everyday life of the ability to conduct activities of daily living.

This is a study cohort that needed to experience less asthma symptoms to know that the treatment was working, in particular less tightness in chest and increase in ability to breathe.

This is a study cohort that commonly knew (or their parents knew) nothing or very little at all about asthma when they were diagnosed. Within this patient population, there was an awareness that asthma is controlled, it is managed by medication. Participants in this PEEK study found most of their information about asthma on the internet, from Asthma Australia or from health professionals. They found information about medication or treatments to be most helpful, and appreciated any information but needed adequate time with healthcare professionals to get information. To get information, they had a preference for talking to a health professional but appreciated combining this with other forms of written information. The timing of information was important, for some as they became adults they

became more receptive, others were more receptive after a flare up.

This is a patient population that experienced a negative impact on their quality of life due to asthma. However, they had an overall positive experience communicating with their healthcare professionals, and they experienced care and support mostly from their family and friends.

This is a patient population that would like to see more affordable treatments, more detail about current and emerging treatments. They would like to have more options, and personalised, comprehensive asthma management plans

The participants in this study would like to send the message to the health minister that the cost of treatment is a burden.

Participants in this study were grateful for access to treatment through Medicare, the healthcare system and the healthcare staff they have encountered.

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# Section 12 Next steps

## Next steps

At the end of each PEEK study, CCDD 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 asthma community, these three areas are:

1. Development and regular revision of holistic Asthma Management Plans that encourage discussions about treatment options and usage, access to allied health and address the emotional and psychological impact of asthma (including side effects of the condition and of treatments, fear caused by attacks, stress on families, depression, anxiety etc.)
2. Mechanisms to address the burden of treatment costs in the context of a chronic disease, acknowledging other factors including that there are patients with comorbidities and patients that have multiple family members with asthma.
3. Longer-term and longer lasting asthma management options to reduce the impact and interruption that asthma has on everyday life.

## 2019 Asthma 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 asthma metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1: Asthma 2019 Metrics

Area of evaluation	2018 data	
<b>Baseline health</b>	<b>Mean</b>	<b>Median</b>
<b>Physical functioning</b>	<b>65.05</b>	<b>65.00</b>
Role functioning/physical	43.00	50.00
<b>Role functioning/emotional</b>	<b>62.67</b>	<b>100.00</b>
Energy/fatigue*	41.30	40.00
<b>Emotional well-being</b>	<b>67.28</b>	<b>68.00</b>
Social functioning	63.00	68.75
<b>Pain</b>	<b>61.15</b>	<b>57.50</b>
General health	42.05	35.00
<b>Health change</b>	<b>55.25</b>	<b>50.00</b>
<b>Percentage of participants that have accessed My Health Record</b>	<b>26.00%</b>	
<b>Percentage of participants that have a discussion about biomarkers/genetic tests</b>	<b>3.00%</b>	
<b>Knowledge of condition and treatments (Partners in Health)</b>	<b>Mean</b>	<b>Median</b>
<b>Knowledge</b>	<b>24.92</b>	<b>26.00</b>
Coping*	16.01	16.50
<b>Recognition and management of symptoms</b>	<b>18.87</b>	<b>20.00</b>
Adherence to treatment	14.05	15.00
<b>Total score*</b>	<b>73.85</b>	<b>76.00</b>
<b>Care Coordination and care received</b>	<b>Mean</b>	<b>Median</b>
<b>Communication*</b>	<b>37.06</b>	<b>37.00</b>
Navigation*	23.82	24.00
<b>Total Score*</b>	<b>60.88</b>	<b>60.00</b>
Care coordination global measure	6.15	7.00
<b>Quality of care global measure</b>	<b>6.77</b>	<b>7.00</b>
<b>Fear of progression</b>	<b>Mean</b>	<b>Median</b>
<b>Total Score*</b>	<b>31.38</b>	<b>31.00</b>

\*Normal distribution, use mean as measure of central tendency