CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

HEART & BLOOD VESSEL CONDITIONS

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CCDR research team	Kate Holliday, Anne Holliday, Sara Riggs, Fay Miller, Ashlee Osborne, Belinda Zheng, Monica Mann, Rosealie Southwell, Nicole Fidock
Number of participants	50

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Introduction

This PEEK study in heart and blood vessel conditions includes 50 people diagnosed with heart and blood vessel conditions throughout Australia.

Background

Heart and blood vessel conditions are a major cause of disease burden in Australia. Coronary heart disease and stroke are common types of heart and blood vessel conditions. In 2020 to 2021, over half a million adult Australians were living with coronary heart disease (2.9% of Australians aged 18 and over)[1]. In 2018 approximately 387,000 people aged 15 and older had a stroke in some time in their life, and in 2020 there were 39,500 stokes[1].

Many forms of heart and blood vessel conditions are caused by atherosclerosis, which is a build up of fat, cholesterol and other substances in the arteries[1]. It can reduce or block blood supply to the heart causing angina or heart attack, or reduce or block blood to the brain causing stroke[1].

Risk factors for heart and blood vessel conditions include smoking, poor diet, not enough exercise, and alcohol consumption. Other risk factors include high blood pressure, abnormal blood lipids, raised cholesterol, diabetes and being overweight[1].

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease [2]**. The Australian Atherosclerosis Society recommends Lipoprotein a testing in high risk patients including those with premature** atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]**.** The European Artherosclerotic society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3]**.**

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the 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.

Position of this study

A search was conducted in Pubmed (October 6, 2023) to identify studies of cardiovascular diseases (cardiac arrhythmia, heart attack, myocardial infarction, coronary artery disease, stroke, hypercholesterolemia, high cholesterol, or aortic stenosis) with patient reported outcomes, or patient experience conducted in the past five years in Australia. Meta-analysis studies, interventional studies, studies with children, and studies of less than five participants were excluded.

There were 56 studies identified, the majority had participants with stroke (n=45), other conditions included Atrial Fibrillation (n=3), Familial hypercholesterolaemia (n=1), and one study each on Cardiac rehabilitation, Cardiovascular disease, Coronary heart disease, Inherited heart conditions, Myocardial infarction, and Spontaneous coronary artery dissection

This PEEK study has 50 participants with heart or blood conditions, it is a very comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2

Demographics

Section 2 Demographics

Participants

There were 50 people with heart or blood vessel conditions who took part in this study. There were 12 participants (24.00%) with High cholesterol under 50 years of age, 17 participants (34.00%) with Blood vessel conditions, and 21 participants (42.00%) with Heart conditions.

Demographics

There were 50 people with heart or blood vessel conditions who took part in this study, 28 were females (56.00%). Participants were aged from 25 to over 75 years of age, most were aged between 35 to 54 years (n=26, 52.00%).

Participants were most commonly from Queensland (n=17, 34.00%), Victoria (n=10, 20.00%), and Western Australia (n=8, 16.00%). Most participants were from major cities (n=35, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 29 participants (58.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 21 participants (42.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Other health conditions

Participants were asked about health conditions, other than their main heart or blood vessel condition that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=49, 98.00%), the maximum number reported was 11 other conditions, with a median of 5.00 other conditions (IQR = 3.00) . The most commonly reported health condition was anxiety (n=33, 66.00%), followed by depression (n=31, 62.00%), insomnia (n=30, 60.00%), and high blood cholesterol (n=27, 54.00%).

Baseline health

Comparisons of SF36 have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

AQOL

The Australian Quality of Life (AQOL) 4D instrument consists of 12 items covering 4 dimensions:

- Independent living (self care, household tasks and mobility)
- Relationships (friends, isolation and family)
- Mental health (sleep, worry and pain)
- Senses (eyesight, hearing and communication.

Utility scores for each dimension and a total score have been calculated according to published instructions. The AQOL provides a utility score that ranges from 1.00 (full health) to 0.00 (death-equivalent health states) to –0.04 (health states worse than death).

The overall scores for each dimension and the total score were as follows; Independent Living (median=1.00, IQR=0.19), Social Relationships (median=0.84, IQR=0.31), Physical Senses (median=0.94, IQR=0.14), Psychological Wellbeing (median=0.87, IQR=0.15), and AQoL utility score (median=0.55, IQR=0.47).

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they consistently experienced before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed. There were 25 participants (50.00%) that had no symptoms before diagnosis. Participants had a maximum of 12 symptoms, and a median of 0.50 (IQR=4.75).

Symptoms before diagnosis

The most common symptoms before diagnosis were dizziness (n=13, 26.00%), weakness of face, arm, or leg (n=10, 20.00%), confusion (n=9, 18.00%), and trouble walking (n=9, 18.00%).

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”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 1 and 4, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was average” range. The symptoms with the worst quality of life were , weakness of face, arm, or leg and, lack of coordination, trouble seeing in one or both eyes, trouble speaking, nausea and vomiting.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select symptoms that they consistently experienced before diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis or triggered an event.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (74.47%). Others had no symptoms (21.28%), or had an unclear recollection of their symptoms or how they came to be diagnosed (2.13%).

The most common symptoms leading to diagnosis were shortness of breath (17.02%), headache (12.77%), irregular heartbeat (12.77%), fatigue (10.64%), dizziness or fainting (10.64%), and chest pain (8.51%). There were 10 participants that described not noticing any symptoms.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (51.06%), having symptoms and not seeking medical attention initially (23.40%), and having no symptoms or not noticing any symptoms before diagnosis (21.28%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed in an emergency department (55.32%), a linear diagnosis after being referred to a specialist from their general practitioner (25.53%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (8.51 %).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 19, 38.00%). There were 15 participants (30.00%) that were diagnosed less than one week after diagnostic tests, 9 participants (18.00%) diagnosed between 1 and 2 weeks, 1 participant (2.00%) diagnosed between 2 and 3 weeks, 4 participants (8.00%) diagnosed between 3 and 4 weeks, and 2 participants (4.00%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with . They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 12 diagnostic tests (median=2.00 , IQR=4.00). The most common tests were blood tests (n=33, 66.00%), electrocardiogram (n=23, 46.00%), Echocardiogram (n=15, 30.00%), and Brain CT or MRI (n=14, 28.00%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a Emergency doctor (n=17, 34.00%), and there were 15 participants (30.00%) given the diagnosis by a Cardiologist, 12 participants (24.00%) diagnosed by General practitioner (GP), and 4 participants (8.00%) by a Neurologist.

Participants were most commonly given their diagnosis in the Hospital (n=31, 63.27%), this was followed by General practice (GP) (n=10, 20.41%), and the Specialist clinic (n=8, 16.33%).

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in the table below.

Participants were diagnosed between 2001 to 2023. There were 27 participants (55.10%) that were diagnosed in the last five years.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (61.70%) and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (14.89%). Other themes included knowing a good amount about the condition at diagnosis with no reason provided (8.51%), and knowing about the condition due to professional background (6.38%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 19 participants (38.00%) who had enough support, 4 participants (8.00%) that had some support but it wasn't enough, and 27 participants (54.00%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 15 participants (35.71%) who had enough information, 19 participants (45.24%) that had Some information but it wasn't enough, and 8 participants (19.05%) had no information.

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors’ fees, and diagnostic tests.

There were 21 participants (42.00%) who had no out of pocket expenses, and 18 participants (36.00%) who did not know or could not recall. There were 4 participants (8.00%) that spent $1 to $250, 3 participants (6.00%) that spent between $251 to $500, and 4 participants (8.00%) that spent $501 or more.

Burden of diagnostic costs

For 23 participants (67.65%) the cost was slightly or not at all significant. For 7 participants (20.59%) the out-of-pocket expenses were somewhat significant, and for 4 participants (11.76%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Despite 19 participant having confirmed their LPa status, participants most commonly reported that they had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=43, 86.00%). There were 4 participants (8.00%) who brought up the topic with their doctor, and 3 participants (6.00%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=38, 76.00%). There were 10 participants (20.00%) who did not have these tests and were not interested in them, and a total of 2 participants (4.00%) that had biomarker tests.

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (31.91%), that they were monitoring their condition until there is an exacerbation or progression (23.40%), and that their prognosis was positive, that their condition is manageable (21.28 %). Other themes included that there was uncertainty around prognosis (19.15%), that it was a lifelong condition (14.89%), that they need to maintain a healthy lifestyle (12.77%), and that they would likely have a recurrence, or were in a cycle of recurrence (8.51%).

Biomarker tests

Participants were asked in the structured interview if they had any discussion about biomarkers that may be important to the management of their condition. The most common responses were that they did not have any tests and did not describe reasons (48.94%), that they did not have a test but would like to have this type of test (21.28%). This was followed by no test but family history was discussed (12.77 %), and had a test and management of condition was not changed (6.38%).

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (31.91%), or one treatment option (27.66%). Other themes included no discussions about treatment (19.15%), and that they cannot remember (12.77%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly participated in the decision-making process (19.15%), or did not give a description about participation in decision making (6.38%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (8.51 %), had a medical emergency or urgent treatment required (8.51%), or they were told what to do without discussion (8.51%).

Some participants were unable to recall discussions about treatments, this was most commonly because they were a child at the time and cannot remember the conversations (6.38%), or they were incapacitated at the time and cannot remember (6.38%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %). Other themes included quality of life (21.28%), their own research (21.28%), their ability to follow treatments (12.77%), and the impact on their family or dependents (10.64%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. More participants had changed the way that they make decisions (61.70%), than those that had not changed the way they make decisions (34.04%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (27.66%), and more aware of their health, responsibilities and/or limitations (14.89%). Other themes included more cautious and considered (8.51%), more focused impact on family and dependents (8.51%) and more accepting of their condition (6.38%). Where participants had not changed their decision making over time this was because they always been informed/assertive (6.38%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to to make lifestyle changes to be fit and healthy (14.89%), have physical improvements in their condition (12.77%), and to have quality of life or to return to normality(12.77 %). There were 4 participants, and they had no personal goals of treatment or care (8.51%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were General practitioner (GP)s (n=25,50.00 %), followed by Cardiologists (n=17, 34.00%).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 12 participants (40.00%) that travelled for less than 15 minutes, 8 participants (26.67%) that travelled between 15 and 30 minutes, 6 participants (20.00%) that travelled between 30 and 60 minutes, 1 participants (3.33%) that travelled between 60 and 90 minutes, and 2 participants (6.67%) that travelled more than 90 minutes.

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

The majority of participants had access to a General Practitioner (GP) (n=43, 86.00%), and a Cardiologist (n=32, 64.00%). There were 11 participants (22.00%) that had a Specialist nurse, and 5 participants (10.00%) that had a Care coordinator, discharge planner or key worker.

Psychologist to care for their condition (n=13, 26.00%). There were 21 participants (42.00%) treated by a Dietitian/ nutritionist, 21 participants (42.00%) with a by a Pharmacist/ chemist, 13 participants (26.00%) cared for by a Psychologist, and 13 participants (26.00%) treated by a Exercise physiologist.

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 28 participants (56.00%) that indicated that they had been treated with respect throughout their experience, and 16 participants (32.00%) that were treated with respect with the exception of one or two occasions. There were 6 participants (12.00%) that felt they had not been treated respectfully.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=34, 68.00%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=32, 64.00%), however, they were asked if they had private health insurance (n=33, 66.00%).

Throughout their treatment, there were 19 participants (38.00%) that were treated as a private patient, 22 participants (44.00%) were mostly treated as a public patient, and there were 5 participants (10.00%) that were equally treated as a private and public patient.

Throughout their treatment, there were 15 participants (30.00%) that were treated mostly in the private hospital system, 28 participants (56.00%) were mostly treated in the public system, and there were 7 participants (14.00%) that were equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire.

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 35, 70.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=43, 86.00%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 37 participants (74.00%) that never or rarely had trouble paying for essentials, and 7 participants (14.00%) that sometimes found it difficult, and 6 participants (12.00%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 9 participants (18.00%) that paid for additional carers due to their condition.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below.

The most common amount was \$100 or less (n=16, 32.00%), followed by between \$101 to \$250 (n=9, 18.00%). There were 3 participants (6.00%), that spent \$1001 or more a month.

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was an extremely significant or moderately significant burden for 13 participants (26.00%), somewhat significant for 15 participants (30.00%), and slightly or not at all significant for 22 participants (44.00%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 13 participants (26.00%) had not changed since diagnosis, and 6 participants (12.00%) were retired or did not have a job. There were 17 participants (34.00%) had to quit their job, 9 participants (18.00%) reduced the number of hours they worked, and 3 participants (6.00%) that accessed their superannuation early. There were 7 participants (14.00%) that took leave from work without pay, and 11 participants (22.00%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

There were 16 participants (32.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=26, 52.00%). There was 1 participant (2.00%) whose partner reduced the numbers of hours they worked, and 1 partner, (2.00%) that quit their job. The partners of 2 participants (4.00%) took leave without pay, and there were 3 partners (6.00%) that took leave with pay.

Reduced income due to condition

There were 20 participants (42.55%) that indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is listed in the table below.

Most commonly, participants were not sure about the amount their monthly income was reduced by $2000 to $5000 per month (n=7, 14.89%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For 11 of these participants (55.00%), the burden of this reduced income was extremely or moderately significant, for 5 participants (25.00%) the burden was somewhat significant, and for 4 participants (20.00%) the burden was slightly or not all significant.

Treatments overview

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition.

There were 17 participants (34.00%) that had surgical treatments, 40 participants (80.00%) that had drug treatments and 28 participants (56.00%) that used allied health services. The majority of participants had made lifestyle changes (n=42, 84%), and approximately a third used complementary therapies (n=42) (n=15, 35.71%).

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects.
Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 6 participants (12.00%) that had coronary angioplasty, percutaneous coronary intervention or stents, 5 participants (10.00%) that had pacemaker or an implantable cardiac defibrillator (ICD) and 4 participants (8.00%) that had surgery for pacemaker or implantable cardioverter defibrillator. Other surgical interventions included Bypass surgery (n=2, 4.00%), and Heart valve surgery (n=1, 2.00%).

On average, quality of life from coronary angioplasty, percutaneous coronary intervention or stents was in the 'life was good' range (median=5.00, IQR = 2.25), and was found to be very effective (median=5.00 , IQR=0.00).

On average, quality of life from pacemaker or an implantable cardiac defibrillator (ICD) was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00 , IQR=1.00).

Summary of drug treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 23 participants (46.00%) that had antiplatelets, 18 participants (36.00%) that had beta blockers and 18 participants (36.00%) that had statins. Participants also took ACE inhibitors (n=10, 20%), ARBs (n=8, 16%), diurectics (n=6, 12%), cholesterol absorption inhibitors (n=5, 10.00%), calcium channel blockers (n=3, 6.00%), ARNIs (n=2, 4.00%), sinus node inhibitors (n=2, 4.00%), and glycosides (n=2, 4.00%).

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”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective.

On average, quality of life from antiplatelets was in the 'life was average' range (median=4.00, IQR = 1.00), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from beta blockers was in the 'life was average to good' range (median=4.50, IQR=2.75), and was found to be effective (median=4.50 , IQR=1.00).

On average, quality of life from statins was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective to very effective (median=4.00 , IQR=1.00).

On average, quality of life from ACE inhibitors was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from ARBs e.g. candesartan, losartan, valsartan was in the 'life was average' range (median=4.00, IQR=2.25), and was found to be moderately effective to effective (median=3.50 , IQR=2.25).

On average, quality of life from anticoagulants was in the 'life was good to very good' range (median=5.50, IQR=3.25), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from diuretics was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from cholesterol absorption inhibitors was in the 'life was average' range (median=5.00, IQR=0.00), and was found to be effective (median=4.00 , IQR=0.00).

Allied health

The most common allied health service used was seeing a dietician (n=14, 28.00%), followed by physiotherapy (n=13, 26.00%), and psychology or counselling (n=12, 24.00%). There were 9 participants (18.00%) that had occupational therapy, 9 participants (18.00%) that had speech therapy, and 5 participants (10.00%) that saw a social worker.

On average, quality of life from seeing a dietician was in the 'life was average' range (median=4.00, IQR = 2.75), and was found to be effective (median=4.00, IQR = 1.00).

On average, quality of life from physiotherapy was in the 'life was a little distressing' range (median=3.00, IQR=3.00), and was found to be effective (median=4.00, IQR=3.00).

On average, quality of life from psychology or counselling was in the 'life was distressing' range (median=2.00, IQR=2.25), and was found to be moderately effective (median=3.00, IQR=2.00).

On average, quality of life from occupational therapy was in the 'life was average' range (median=4.00, IQR=3.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from speech therapy was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from social work was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00, IQR=4.00).

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them.

The majority of participants used at made at least one lifestyle change (n=42, 84.00%), and on average made 2 changes (median=2.00, IQR=1.75).

The most common lifestyle changes used were diet changes (n=29, 58.00%), and exercise (n=29, 58.00%), followed by and Quitting or cutting back on alcohol (n=19, 38.00%), and Quitting or cutting back on smoking (n=10, 20.00%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from quitting or cutting back on alcohol was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from quitting or cutting back on smoking was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them.

Approximately a third of participants used at least one complementary therapy (n=15, 35.71%). The most common complementary therapy used was Mindfulness or relaxation techniques (n=11, 26.19%), followed by Massage therapy (n=7, 16.67%), Supplements (n=6, 14.29%), and acupuncture (n=5, 11.90%)

On average, quality of life from mindfulness or relaxation techniques was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.50).

On average, quality of life from massage therapy was in the 'life was distressing' range (median=2.00, IQR=2.50), and was found to be moderately effective (median=3.00, IQR=2.50).

On average, quality of life from supplements was in the 'life was average to good' range (median=4.50, IQR=2.50), and was found to be moderately effective to effective (median=3.50, IQR=1.00).

On average, quality of life from Acupuncture was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=3.00, IQR=2.00).

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 4 participants (8%) that had discussions about clinical trials, 3 participants (6.00%) had brought up the topic with their doctor, and the doctor of 1 participant (2.00%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=46, 92.00%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There was 1 participant (2.00%) that had taken part in a clinical trial, 36 participants (72.00%) that would like to take part in a clinical trial if there was a suitable one, and 13 participants, that have not participated in a clinical trial and do not want to (26.00%).

Treatment and management following lipoprotein a test

Lipoprotein a testing

In the online questionnaire, participants noted if they had a Lipoprotein a test. There were 24 participants (43.64%) that had a Lipoprotein a test.

Lipoprotein a test results

As a follow up question, participants were asked if they knew the result of their Lipoprotein a test. There were 9 participants (16.36%) that did not know their result, 9 participants (16.36%) that knew result and gave a numerical value, and 6 participants (10.91%) that were not sure of exact result but that it was high.

Changes in treatment and management following Lipoprotein a testing

Participants noted in the online questionnaire any changes their doctor made to the treatment or management of their condition following lipoprotein a testing.

Most commonly, changes were made to medication (n=10, 41.67%), followed by recommendations for diet and lifestyle changes (n=6, 25.00%). There were 5 participants (20.83%) that were had additional monitoring, and 2 participants (8.33%), that had no made changes to treatment or management.

Participant-made changes following lipoprotein a/Lp(a) results

In the online questionnaire, participants noted the changes that they had made following getting their lipoprotein a/Lp(a) results.

The majority of participants made diet changes (n=18, 75.00%), and half the participants (50.00%) tried to exercise more. There were 8 participants (33.33%) that tried to drink less alcohol, and 8 participants (33.33%) that tried to lose weight. Other changes included tried to give up smoking (20.83%), became more careful about taking medicatins (16.67%) and became more caredful about making and attending medical appointments (12.50%). There were 2 participants (12.50%) that made no changes following thier lipoprotein a test result.

After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Participants noted the activities they had done to learn more about lipoprotein a.

More than half of the participants looked for information about it (n=13, 54.17%), and a third asked their doctor about it (n=8, 33.33%). There were 3 participants (12.50%) that joined a heart management program, and 3 participants (12.50%) that joined a patient group. There were 9 participants (37.50%) that did not do anything to find out more about Lp(a).

Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Participants were asked if family members had a lipoprotein a /Lp(a) test because of test result. There were 6 participants (25.00%) that noted other family members had this test due to their result.

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were described using a specific example (57.45%), and those that do not interfere with life (36.17%). Other themes included side effects that have a short duration (10.64%), and that they had only experienced or only described severe side effects (8.51%).

When a specific side effect was described, the most common side effects were aches and pain (23.40%), fatigue/lethargy (23.40%), headaches (6.38%), and nausea, vomiting,or loss of appetite (6.38%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of severe side effects were described using a specific example (57.45%), and those that impact everyday life or ability to conduct activities of daily living (34.04%). Other themes included those that are life threatening or result in hospitalisation (6.38%), those that cause long-term damage to their body (6.38%), those that requires medical intervention (6.38%), and those that cause a need to change or stop using medication (6.38%).

When a specific side effect was described, the most common examples were aches and pain (21.28%), cognitive difficulties, including brain fog and difficulty communicating (14.89%), the emotional or mental impact (10.64%). Other side effects included fatigue or lethargy (10.64%), nausea, vomiting,or loss of appetite (6.38%), reduced mobility or loss of independence (6.38%), and shortness of breath (6.38%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment for a specific amount of time (46.81%), adhering to treatment according to the advice of their specialist or as long as prescribed (27.66%), and adhering to treatment as long as side effects are tolerable (25.53 %). Other themes included never giving up on any treatment (21.28%), and adhering to treatment as long as treatment is working (21.28%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (14.89%), and six to twelve months (8.51%).

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 responses were needing to see a specific symptom reduction (44.68%), and needing to see physical signs and symptoms disappear or reduce side effects (27.66%). Other themes included needing to see test results (14.89%), needing to see a return to day-to-day functionality (12.77%), and needing to have a balance between benefits and potential side effects (8.51%).

When a specific side effect or symptom was described, the most common examples were fatigue or lethargy (17.02%), heart rate or regular heart beat (8.51%), aches or pain (6.38 %), and the emotional, or mental impact (6.38%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (17.02%), and it would lead to a reduction in symptoms or side effects (14.89%). This was followed by it would have positive impact on their mental health (12.77 %), and allow them to engage more with social activities and family life (8.51%).

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (55.32%), their treating clinician (42.55%), and from a specific health charity (36.17 %). Other themes included information from other patient's experience (Including support groups) (31.91%), from journals (research articles) (25.53%), from books, pamphlets and newsletters (21.28%), from allied health professionals (8.51%), and from family members (8.51%).

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 responses were other people's experiences (25.53%), talking to a doctor or specialist or healthcare team (21.28%), and information from health charities (21.28 %). Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (19.15%), information about lifestyle changes and risk prevention (14.89%), medical or scientific information (8.51%), and information presented by webinar or video (8.51%).

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 responses were no information not helpful (42.55%), information given by their GP or specialist was not helpful (12.77%), sources that are not credible or not evidence-based were not helpful (12.77 %), information that not type specific or too general (10.64%), and information with too much medical jargon as unhelpful (8.51%). Others described being confident in deciding themselves if information was not helpful (8.51%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (36.17%), talking to someone plus online information (27.66%), and written information (17.02 %). Other preferences included online information (14.89%), all forms (10.64%), and apps (2.13%).

The main reasons for a preference for talking to someone was being able to ask questions (21.28%), and the information was personalized and relevant (17.02%). Other reasons included that it was more supportive, and that body language helps with understanding (10.64%), and cognitive/sight problems make other forms not able to be used (6.38%).

The main reasons for a preference for online information were accessibility (21.28%), that you can can refer back to it and clarify information (17.02 %), and being able to digest information at their own pace (10.64%).

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 times were at the beginning (diagnosis) (27.66%), and after the shock of diagnosis (14.89%). Other themes included continuously (12.77%), 12 months or more after diagnosis (12.77%),when medical emergency over (8.51%), after treatment (6.38%), and after test results or changes to condition (6.38%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Participants gave descriptions that communication as overall positive (34.04%), overall positive, with the exception of one or two occasions(34.04%), and overall negative (27.66 %).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because it was holistic with two way, supportive and comprehensive conversations (31.91%).

Participants that had negative communication, described the reasons for this were that communication was dismissive (One way conversation) (19.15 %), limited in multi-disciplinary communication and care coordination (10.64%), limited in relation health professionals not having a lot of time (8.51%), and limited in that they have not had a lot (6.38%).

Partners in health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=28, 56.00%), disease cause (n=19, 38.00%), disease management (n=18, 36.00%) and, dietary (n=18, 36.00%) were most frequently given to participants by healthcare professionals, and, information about hereditary considerations (n=4, 8.00%), and complementary therapies (n=2, 4.00%) were given least often. No participants (0.00%) were given information about clinical trials.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease cause (n=22, 44.00%), treatment options (n=19, 38.00%), disease management (n=19, 38.00%) and, how to interpret test results (n=17, 34.00%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=11, 22.00%), complementary therapies (n=10, 20.00%) and clinical trials (n=4, 8.00%) were searched for least often

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=46, 92.00%) and complementary therapies (n=39, 78.00%).

The topics that participants were given most information from healthcare professionals but not searched for independently for were treatment options (n=16, 32.00%) and physical activity (n=15, 30.00%).

The topics that participants searched for independently after receiving information from healthcare professionals were treatment options (n=12, 24.00%) and disease management (n=8, 16.00%)

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=15, 30.00%) and interpret test results (n=13, 26.00%).

Most accessed information

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 20 participants (40.00%) that had accessed My Health Record.

Of those that had accessed My Health Record, there were 8 participants (42.11%) who found it to be poor or very poor, 4 participants (21.05%) who found it acceptable, and 7 participants (36.84%) who found it to be good or very good.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

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 sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15 %), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%), others described that they did not need or seek help or support (14.89%), and some described the challenges of finding or accessing support (10.64%).

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life(10.64%), overall positive impact on quality of life (8.51 %). overall no impact on quality of life (6.38%), and a mix of positive and negative impact on quality of life (4.26%).

The most common themes in relation to a negative impact on quality of life were emotional strain, including family or change in relationship dynamics (38.30%), reduced capacity for physical activity, needing to slow down (29.79%), and managing side effects and symptoms (23.40 %). Other themes included emotional strain on self (21.28%), reduced social interaction (17.02%), altering lifestyle to manage condition (8.51%), and inability to work or changes with their work (8.51%).

The most common theme in relation to a positive impact on quality of life were that it brings people together and highlights supportive relationships (14.89%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (70.21%). There were 4 participants (8.51%) that indicated no impact and 10 participants (21.28%) that did not describe impact on mental health or had a mixed experience.

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. The most common responses were consulting a mental health professional (21.28%), mindfulness and/or meditation(21.28%), and the importance of physical exercise (17.02 %). Other activities included remaining social and having hobbies (8.51%), and taking medication (8.51%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were doing physical exercise or being physically active (46.81%), self care for example more rest, accepting help, pacing themselves (40.43%), and maintaining a healthy diet (36.17 %). Other activities included complying with treatment or management of their condition (23.40%), mindfulness and/or meditation (19.15%), making healthy lifestyle changes (10.64%), maintaining a healthy weight (8.51%), and managing stress (8.51%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%). Other times they felt vulnerable included during diagnostic procedure (14.89%), thinking about disease course or that they have an incurable condition (14.89%), during or after treatments (10.64%) and when feeling sick/unwell (8.51%). There were 7 participants (14.89%) that did not feel vulnerable.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (10.64%), and being unsure how vulnerability can be managed (4.26 %).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (38.30%), and overall, there no impact on relationships (31.91%). Other themes included overall, there was a positive impact on relationships (14.89%), and overall, there was an impact on relationships that was both positive and negative (10.64%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (31.91%), and from people not knowing what to say or do and withdrawing from relationships (10.64%). Other themes included because of people not believing the impact that condition has on health (6.38%), and because of intimacy challenges (4.26%).

The most common themes in relation to having a positive impact on relationships were from people being well-meaning and supportive (17.02%), and from family relationships being strengthened (8.51%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was not a burden on their family (51.06%), overall, there was a burden on their family (44.68%), and overall, there was not a burden on their family now but they anticipate this will change in the future (6.38 %).

The main reason that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (17.02%), that the burden was temporary or only during treatment (14.89%), and the mental/emotional strain placed on their family (10.64%).

The main reason that participant described their condition not being a burden were that they were very independent (14.89%), and they have a very supportive family and were not a burden (6.38%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (51.06%), and overall, there was no cost burden (23.40%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (27.66%), diagnostic tests and scans (17.02%), and needing to take time off work (17.02 %). Other themes included the cost specialist appointments (14.89%), cost of gap payments (12.77%), needing to buy special equipment (10.64%), allied health care (8.51%), and GP appointments (8.51%).

Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the public health system (17.02%), the participant was able to afford all costs (10.64%), and nearly everything was paid for through the private health system (8.51 %).

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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.
The average score was in the Life was a little distressing to average range (median=3.50, IQR=3.00).

Experience of anxiety related to disease progression

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Section 9

Expectations and messages to decision-makers

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 responses were that future treatment will be more affordable (25.53%), will include having choice including availability, accessibility, transparency and discussions in relation to treatment options (21.28%), and will be more effective, targeted, or personalised (17.02 %). Other themes included have fewer or less intense side effects and more discussion about side effects (12.77%), involve a more holistic approach (10.64%), more access to rehabilitation (10.64%), involve more clinical trials, including to access new technologies and treatments and funding (8.51%), and will manage symptoms and prevention of disability (8.51%). There were 6 participants (12.77%) that were satisfied with experience.

Expectations of future information

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 expectations for future healthcare professional communication were that communication will be more empathetic (29.79%) and will allow people more time to meet with their clinician (17.02 %). Other themes included that communication will be more transparent and forthcoming (14.89%), will be more understandable (14.89%), will include a multidisciplinary and coordinated approach (10.64%), will include listening to the patient (8.51%), and will be more holistic, including emotional health (8.51%). There were 15 participants (31.91%) who were satisfied with the communication they had.

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 expectation for future care and support was that care and support will include being able to connect with other patients through peer support (17.02%), will include a multidisciplinary and coordinated approach (17.02%), and will include practical support for example home care, transport, and financial support (12.77 %). Other themes included future care and support will include more long-term condition management (10.64%), will include specialist clinics or services where they can talk to professionals, in person, by phone or online) (10.64%), will be more holistic, including emotional health (10.64%), and include more access to support services (8.51%). There were 4 participants (8.51%) who were satisfied with the care and support received (8.51%).

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 responses were that participants were grateful for healthcare staff, including access to specialists (42.55%), low cost or free medical care through the government (27.66%), and the entire health system (19.15 %). Other themes included access to private healthcare or private health insurance (12.77%), and timely access to diagnostics (6.38%).

Values in making decisions

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 Ability to follow and stick to a treatment regime and The ability to include my family in making treatment decisions.

Values for decision makers

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve 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 = 32, 64.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There was 1 participant (2.00%) that thought that medicine delivered by IV was most effective, 22 participants (44.00%) thought that pill form was most effective, and 11 participants (22%) that thought they were equally effective. There were 16 participants (32.00%) that were not sure.

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 messages to the health minister were the need for timely and equitable access to support, care and treatment (25.53%), that treatments need to be affordable (19.15%), and that they were grateful for the healthcare system and the treatment that they received (19.15 %). Other themes included to improve rural services (19.15%), to invest in prevention (19.15%), to increase investment in general (17.02%), to help raise community awareness (14.89%), to invest in health professionals to service the patient population (14.89%), and to have a holistic approach to the condition that includes emotional support (10.64%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (12.77%), and to know the early signs and symptoms of their condition (12.77 %), to understand the trajectory of the disease (10.64%), that they had known the risk factors and causes (8.51%), and they had been diagnosed sooner or had access to treatment sooner (8.51%). There were 10 participants (21.28%) that had no particular comment and were satisfied with experience (21.28%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (25.53%), and would not change any aspect of their care or treatment, with no reason given (14.89%). Other themes included would have liked to have had a better understanding of their condition (6.38%), and were not sure if they would change anything (6.38%).

Section 1

Introduction and methods

Section 1 Introduction and methodology

Introduction

This PEEK study in heart and blood vessel conditions includes 50 people diagnosed with heart and blood vessel conditions throughout Australia.

Background

Heart and blood vessel conditions are a major cause of disease burden in Australia. Coronary heart disease and stroke are common types of heart and blood vessel conditions. In 2020 to 2021, over half a million adult Australians were living with coronary heart disease (2.9% of Australians aged 18 and over)[1]. In 2018 approximately 387,000 people aged 15 and older had a stroke in some time in their life, and in 2020 there were 39,500 stokes[1].

Many forms of heart and blood vessel conditions are caused by atherosclerosis, which is a build up of fat, cholesterol and other substances in the arteries[1]. It can reduce or block blood supply to the heart causing angina or heart attack, or reduce or block blood to the brain causing stroke[1].

Risk factors for heart and blood vessel conditions include smoking, poor diet, not enough exercise, and alcohol consumption. Other risk factors include high blood pressure, abnormal blood lipids, raised cholesterol, diabetes and being overweight[1].

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease [2]**. The Australian Atherosclerosis Society recommends Lipoprotein a testing in high risk patients including those with premature** atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]**.** The European Artherosclerotic society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3]**.**

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the 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.

Position of this study

A search was conducted in Pubmed (October 6, 2023) to identify studies of cardiovascular diseases (cardiac arrhythmia, heart attack, myocardial infarction, coronary artery disease, stroke, hypercholesterolemia, high cholesterol, or aortic stenosis) with patient reported outcomes, or patient experience conducted in the past five years in Australia. Meta-analysis studies, interventional studies, studies with children, and studies of less than five participants were excluded.

There were 56 studies identified, the majority had participants with stroke (n=45), other conditions included Atrial Fibrillation (n=3), Familial hypercholesterolaemia (n=1), and one study each on Cardiac rehabilitation, Cardiovascular disease, Coronary heart disease, Inherited heart conditions, Myocardial infarction, and Spontaneous coronary artery dissection

This PEEK study has 50 participants with heart or blood conditions, it is a very comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

This PEEK study in heart and blood vessel conditions includes 50 people diagnosed with heart and blood vessel conditions throughout Australia.

Background

Heart and blood vessel conditions are a major cause of disease burden in Australia. Coronary heart disease and stroke are common types of heart and blood vessel conditions. In 2020 to 2021, over half a million adult Australians were living with coronary heart disease (2.9% of Australians aged 18 and over)[1]. In 2018 approximately 387,000 people aged 15 and older had a stroke in some time in their life, and in 2020 there were 39,500 stokes[1].

Many forms of heart and blood vessel conditions are caused by atherosclerosis, which is a build up of fat, cholesterol and other substances in the arteries[1]. It can reduce or block blood supply to the heart causing angina or heart attack, or reduce or block blood to the brain causing stroke[1].

Risk factors for heart and blood vessel conditions include smoking, poor diet, not enough exercise, and alcohol consumption. Other risk factors include high blood pressure, abnormal blood lipids, raised cholesterol, diabetes and being overweight[1].

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease [2]. **The Australian Atherosclerosis Society recommends Lipoprotein a testing in high risk patients including those with premature** atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]**.** The European Artherosclerotic society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3]**.**

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Participants

To be eligible for the study, participants needed to have been diagnosed with a heart of blood vessel condition, 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.

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).

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

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[5], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[6], the Short Fear of Progression Questionnaire (FOP12)[7], and the Partners in Health version 2 (PIH)[8]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses 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.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by condition type, number of other conditions gender, age, location of residence, and socio-economic status. Scales and subscales were calculated according to reported instructions[5-8].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[9].

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics[10].

For comparisons by condition type 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 Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, 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 CCDR's custom data analysis program. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in CCDR's custom data analysis program. The minimum coded unit was a sentence with paragraphs and phrases 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 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in June 2021.

Position of this study

A search was conducted in Pubmed (October 6, 2023) to identify studies of cardiovascular diseases (cardiac arrhythmia, heart attack, myocardial infarction, coronary artery disease, stroke, hypercholesterolemia, high cholesterol, or aortic stenosis) with patient reported outcomes, or patient experience conducted in the past five years in Australia (Table 1.1). Meta-analysis studies, interventional studies, studies with children, and studies of less than five participants were excluded.

There were 56 studies identified, the majority had participants with stroke (n=45), other conditions included Atrial Fibrillation (n=3), Familial hypercholesterolaemia (n=1), and one study each on Cardiac rehabilitation, Cardiovascular disease, Coronary heart disease, Inherited heart conditions, Myocardial infarction, and Spontaneous coronary artery dissection

There were 27 studies that collected data by interview with between 5 and 51 participants. Of these studies, 9 were focused on Quality of life[11-19], 4 studies were focused on Information[20-23], 3 studies were focused on Rehabilitation[24-26], studies each were focused on Care coordination[27,28], Decision making[29,30] and Unmet needs[31,32] and a single study each focused on Communication[33], Diagnosis[34], Health literacy[35], Phyical activity[36], and Unmet needs[31].

There were 3 studies that collected data by focus groups with between 7 and 30 participants, the studies were focused on Communication[37], Information[38], and Quality of life[39].

There were 27 studies that collected data by survey with between 19 and 28 115 participants, the largest of these studies were analysis of the Australian Stroke Clinical Registry.

There were 6 studies focused on Health related quality of life[40-45], 6 studies that were an analysis of the Australian Stroke Clinical Registry [46-51], 3 studies focused on Symptoms[52-54], 3 studies focused on treatment adherence[55-57], 3 studies focused on Unmet needs[58-60], 2 studies focused on Comorbidities[61,62], and a single study each focused on Clinical trial participation [63], Decision making[64], and Phyical activity[65].

This PEEK study has 50 participants with heart or blood conditions, it is a very comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

Author, Year	Location	Number of participants	Data collection	Focus	PEEK SECTION							
					2: Health status, co-morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
Skoss, 2022[34]	Familial hypercholesterolaemia	51	Interviews	Diagnosis		X	X					
Janssen, 2022[26]	Stroke	33	Interviews	Rehabilitation				X				
Tse, 2022[19]	Stroke	30	Interviews	Quality of life							X	
Chen, 2022[28]	Stroke	26 (26)	Interviews	Care coordination			X		X	X	X	
Quigley, 2019[27]	Stroke	24 (10)	Interviews	Care coordination					X			
Pelly, 2023[23]	Myocardial infarction	22	Interviews	Information					X			
Levy, 2022[66]	Stroke	20	Interviews	Treatment adherence				X				
Espernberger, 2023[36]	Stroke	19	Interviews	Physical activity							X	
Shipley, 2018[18]	Stroke	19	Interviews	Quality of life					X		X	X
Shipley, 2020[31]	Stroke	19	Interviews	Unmet needs								X
Yeates, 2022[30]	Inherited heart conditions	18 (2)	Interviews	Decision making			X					
Jin, 2020[35]	Coronary heart disease	18	Interviews	Health literacy					X			
Finch, 2021[17]	Stroke	17	Interviews	Quality of life					X		X	X
Jackson, 2022[16]	Stroke	15	Interviews	Quality of life							X	
Ajwani, 2021[15]	Stroke	11	Interviews	Quality of life							X	
Amoah, 2023[32]	Stroke	10 (3)	Interviews	Unmet needs			X				X	X
Geldens, 2021[22]	Stroke	10	Interviews	Information				X	X	X		

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Hutton, 2019[14]	Stroke	10	Interviews	Quality of life							X	
Pryor, 2020[13]	Stroke	9	Interviews	Quality of life							X	
Ferguson, 2022[20]	Atrial Fibrillation	8	Interviews	Information					X			
Cheng, 2023[21]	Stroke	8	Interviews	Information					X			
Hoyle, 2023[12]	Stroke	8	Interviews	Quality of life								
Chin, 2022[24]	Stroke	8	Interviews	Rehabilitation				X				
Purcell, 2020[25]	Stroke	8	Interviews	Rehabilitation				X				
Walder, 2020[33]	Stroke	6	Interviews	Communication			X		X	X	X	
Kelly, 2022[29]	Stroke	6	Interviews	Decision making			X		X	X		
Hodson, 2019[11]	Stroke	5	Interviews	Quality of life							X	
Murphy, 2022[39]	Spontaneous coronary artery dissection	30	Focus groups	Quality of life					X	X	X	
Finch, 2022[38]	Stroke	15 (4)	Focus groups	Information					X			
D'Souza, 2021[37]	Stroke	7	Focus groups	Communication					X	X		
Dwyer, 2021[50]	Stroke	28,115	Survey	Registry	X							
Dalli, 2023[49]	Stroke	13,594	Survey	Registry	X							
Lynch, 2022[51]	Stroke	8,555	Survey	Registry	X				X			
Mosalski, 2021[45]	Stroke	8,397	Survey	Health related quality of life	X							
Phan, 2021[48]	Stroke	6,852	Survey	Registry	X							
Thayabaranathan, 2018[47]	Stroke	2,853	Survey	Registry	X							
Dalli, 2022[57]	Stroke	1,500	Survey	Treatment adherence				X				
Sun, 2023[44]	Stroke	1,163	Survey	Health related quality of life	X							
Tjokrowijoto, 2023[46]	Stroke	623	Survey	Registry	X			X				

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Smith, 2019[65]	Cardiovascular disease	535	Survey	Phyical activity							X	
Weerasekara, 2021[63]	Stroke	445	Survey	Clinical trials				X				
Kadhim, 2019[62]	Atrial Fibrillation	442	Survey	Comorbidities	X							
Waller, 2023[43]	Stroke	401	Survey	Health related quality of life	X							
Thayabaranathan, 2023[42]	Stroke	244	Survey	Health related quality of life	X							
Unsworth, 2020[64]	Stroke	183	Survey	Decision making			X					
Keating, 2021[60]	Stroke	171	Survey	Unmet needs								X
Haslam, 2020[54]	Stroke	106	Survey	Symptoms		X						
Tse, 2019[61]	Stroke	100	Survey	Comorbidities	X							
Stolwyk, 2022[53]	Stroke	87	Survey	Symptoms		X						
Walters, 2019[41]	Atrial Fibrillation	78	Survey	Health related quality of life	X							
Sapuppo, 2023[59]	Stroke	76	Survey	Unmet needs								X
Minshall, 2021[40]	Stroke	72	Survey	Health related quality of life	X							
Beauchamp, 2020[56]	Cardiac rehabilitation	60	Survey	Treatment adherence				X				
O'Connell, 2020[52]	Stroke	58	Survey	Symptoms		X						
Pacleb, 2020[55]	Familial hypercholesterolaemia	54	Survey	Treatment adherence				X				
Finch, 2020[58]	Stroke	20	Survey	Unmet needs						X		X

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
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.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 7significantly different means following an ANOVA test.
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.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Demographics

Participants

There were 50 people with heart or blood vessel conditions who took part in this study. There were 12 participants (24.00%) with High cholesterol under 50 years of age, 17 participants (34.00%) with Blood vessel conditions, and 21 participants (42.00%) with Heart conditions.

Demographics

There were 50 people with heart or blood vessel conditions who took part in this study, 28 were females (56.00%). Participants were aged from 25 to over 75 years of age, most were aged between 35 to 54 years (n=26, 52.00%).

Participants were most commonly from Queensland (n=17, 34.00%), Victoria (n=10, 20.00%), and Western Australia (n=8, 16.00%). Most participants were from major cities (n=35, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 29 participants (58.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 21 participants (42.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Other health conditions

Participants were asked about health conditions, other than their main heart or blood vessel condition that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=49, 98.00%), the maximum number reported was 11 other conditions, with a median of 5.00 other conditions (IQR = 3.00) . The most commonly reported health condition was anxiety (n=33, 66.00%), followed by depression (n=31, 62.00%), insomnia (n=30, 60.00%), and high blood cholesterol (n=27, 54.00%).

Baseline health

Comparisons of SF36 have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

AQOL

The Australian Quality of Life (AQOL) 4D instrument consists of 12 items covering 4 dimensions:

- Independent living (self care, household tasks and mobility)
- Relationships (friends, isolation and family)
- Mental health (sleep, worry and pain)
- Senses (eyesight, hearing and communication.

Utility scores for each dimension and a total score have been calculated according to published instructions. The AQOL provides a utility score that ranges from 1.00 (full health) to 0.00 (death-equivalent health states) to –0.04 (health states worse than death).

The overall scores for each dimension and the total score were as follows; Independent Living (median=1.00, IQR=0.19), Social Relationships (median=0.84, IQR=0.31), Physical Senses (median=0.94, IQR=0.14), Psychological Wellbeing (median=0.87, IQR=0.15), and AQoL utility score (median=0.55, IQR=0.47).

Participants

There were 50 people with heart or blood vessel conditions who took part in this study. There were 12 participants (24.00%) with High cholesterol under 50 years of age, 17 participants (34.00%) with Blood vessel conditions, and 21 participants (42.00%) with Heart conditions.

Table 2.1: Participants

Participants and diagnosis	Number (n=50)	Percent
High cholesterol under 50 years of age	12	24
Blood vessel conditions	17	34
Heart conditions	21	42

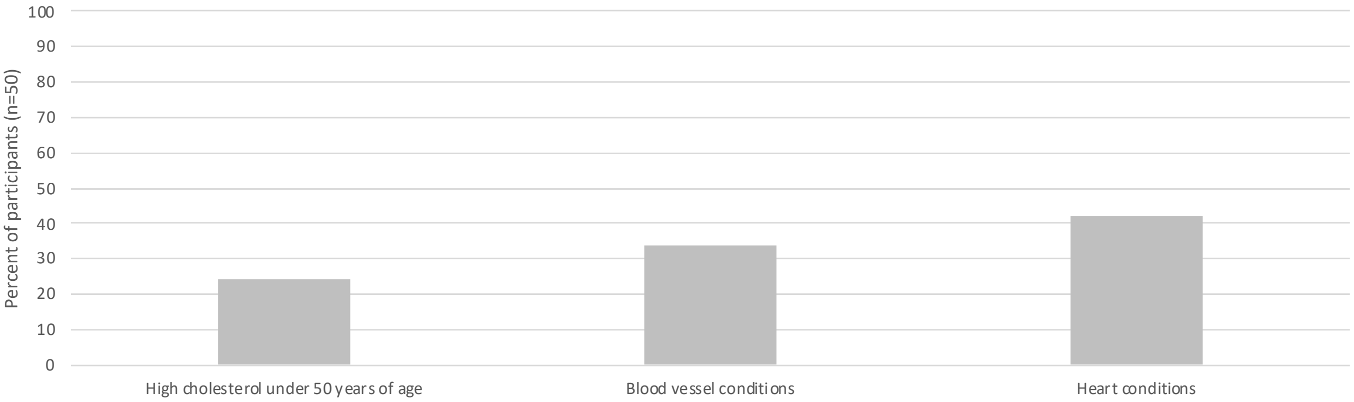

Figure 2.1: Participants

Demographics

There were 50 people with heart or blood vessel conditions who took part in this study, 28 were females (56.00%). Participants were aged from 25 to over 75 years of age, most were aged between 35 to 54 years (n=26, 52.00%).

Participants were most commonly from Queensland (n=17, 34.00%), Victoria (n=10, 20.00%), and Western Australia (n=8, 16.00%). Most participants were from major cities (n=35, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 29 participants (58.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 21 participants (42.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Table 2.2: Demographics

Demographic	Definition	Number (n=50)	Percent
Gender	Female	28	56.00
	Male	22	44.00
Age	25 – 34	11	22.00
	35 – 44	16	32.00
	45 – 54	10	20.00
	55 – 64	5	10.00
	65 – 74	6	12.00
	75+	2	4.00
Location	Major Cities of Australia	35	70.00
	Inner Regional Australia	9	18.00
	Outer Regional Australia	6	12.00
State	Australian Capital Territory	1	2.00
	New South Wales	7	14.00
	Northern Territory		0.00
	Queensland	17	34.00
	South Australia	4	8.00
	Tasmania	3	6.00
	Victoria	10	20.00
	Western Australia	8	16.00
Socio-Economic Indexes for Areas (SEIFA)	1	1	2.00
	2	7	14.00
	3	3	6.00
	4	3	6.00
	5	2	4.00
	6	9	18.00
	7	4	8.00
	8	4	8.00
	9	6	12.00
	10	11	22.00

Other health conditions

Participants were asked about health conditions, other than their main heart or blood vessel condition that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=49, 98.00%), the maximum number reported was 11 other conditions, with a median of 5.00 other conditions (IQR = 3.00) . The most commonly reported health condition was anxiety (n=33, 66.00%), followed by depression (n=31, 62.00%), insomnia (n=30, 60.00%), and high blood cholesterol (n=27, 54.00%).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=50)	Percent
No other conditions	1	2.00
1 to 2	5	10.00
3 to 4	16	32.00
5 to 6	12	24.00
7 to 8	8	16.00
9 or more	8	16.00

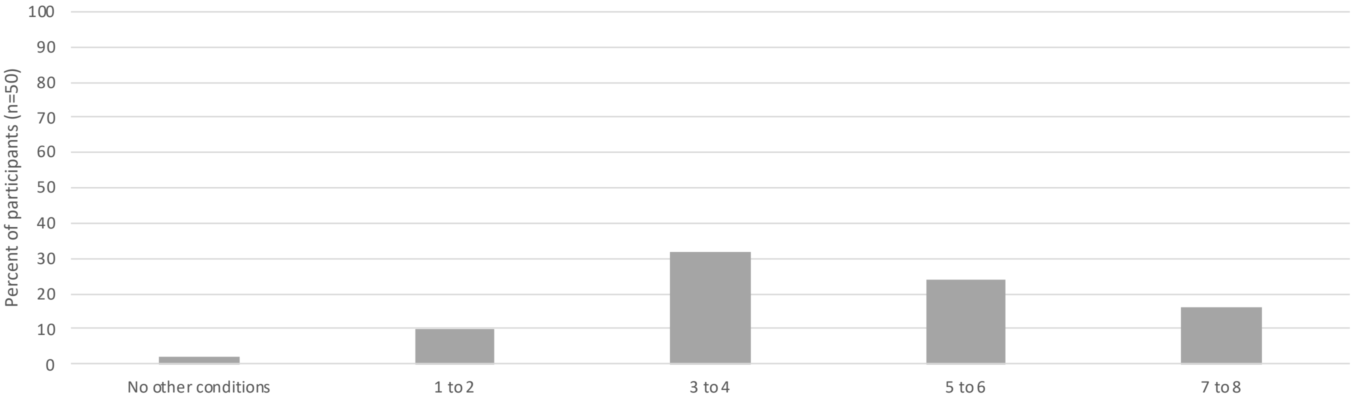

Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=50)	Percent
Anxiety (total)	33	66.00
Anxiety (doctor diagnosed)	23	46.00
Anxiety (self-diagnosed) yourself	10	20.00
Depression (total)	31	62.00
Depression (self-diagnosed yourself)	13	26.00
Depression (doctor diagnosed)	18	36.00
Sleep problems or insomnia	30	60.00
High LDL or High blood cholesterol	27	54.00
Arthritis	18	36.00
Chronic pain	14	28.00
Coronary heart disease (eg heart attack, angina)	14	28.00
Stroke	13	26.00
Back pain	12	24.00
Asthma	11	22.00
Chronic heart failure	11	22.00
Diabetes	6	12.00
Osteoporosis	5	10.00
Hypothyroidism	5	10.00
Cancer	5	10.00
Chronic kidney disease	3	6.00
COPD (Chronic obstructive pulmonary disease)	2	4.00

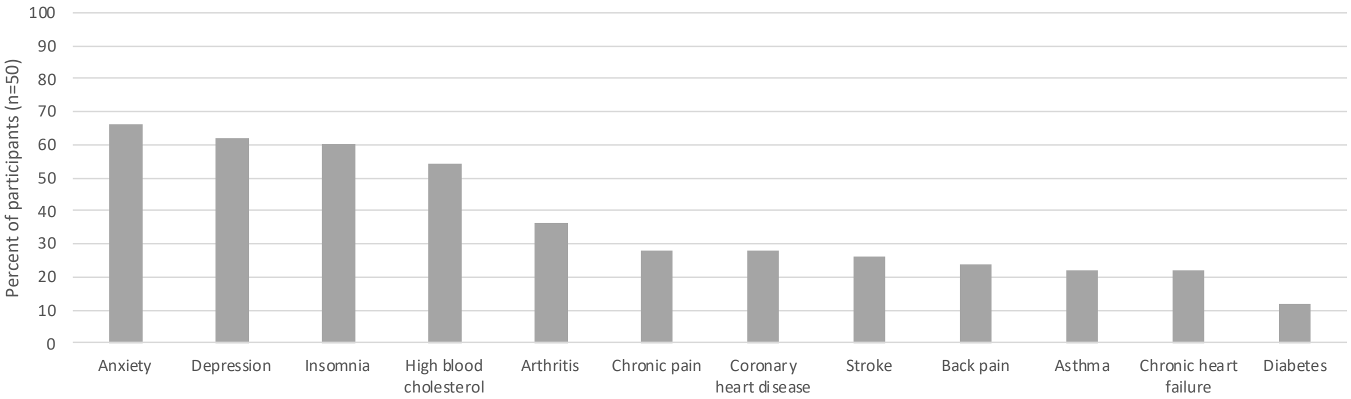

Figure 2.3: Other health conditions (% of all participants)

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in the table below.

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

Comparisons were made by **gender**, there were 28 females(56.00%), and 22 males(44.00%).

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and aged 45 and older (n=23, 46.00%).

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) compared to those in metropolitan areas (n=35, 70.00%).

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

Table 2.5: Subgroups

Subgroup	Definition	Number (n=50)	Percent
LP(a) Test status	Had LP(a) test	19	38.00
	Did not had LP(a) test	31	62.00
Condition type	High cholesterol under 50 years of age	12	24.00
	Blood vessel conditions	17	34.00
	Heart conditions	21	42.00
Number of co-morbidities	0 to 5 other conditions	27	54.00
	6 to 11 other conditions	23	46.00
Gender	Female	28	56.00
	Male	22	44.00
Age	Aged 25 to 44	27	54.00
	Aged 45 and older	23	46.00
Location	Regional or remote	15	30.00
	Metropolitan	35	70.00
Socioeconomic advantage	Mid to low socioeconomic status	25	50.00
	Higher socioeconomic status	25	50.00

Baseline health

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

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.6, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the second highest quintile for SF36 Physical functioning (median=70.00, IQR=48.75), SF36 Emotional well-being (median=72.00, IQR=31.00), SF36 Social functioning (median=68.75, IQR=62.50), SF36 Pain (median=67.50, IQR=57.50), indicating good physical functioning, good emotional well-being, good social functioning, mild pain.

The overall scores for the cohort were in the middle quintile for SF36 Role functioning/emotional (median=50.00, IQR=100.00), SF36 Energy/Fatigue (mean=40.10, SD=22.07), SF36 General health (median=55.00, IQR=35.00), SF36 Health change (median=50.00, IQR=37.50), indicating moderate emotional role functioning, moderate energy, moderate general health, about the same as a year ago

The overall scores for the cohort were in the second lowest quintile for SF36 Role functioning/physical (median=25.00, IQR=100.00), indicating poor physical role functioning.

Comparisons of SF36 have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health** scale measures perception of health. On average, participants reported moderate health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	66.40	30.03	70.00	48.75	0 to 100	4
Role functioning/physical	49.50	47.24	25.00	100.00	0 to 100	2
Role functioning/emotional	56.00	44.89	50.00	100.00	0 to 100	3
Energy/Fatigue*	40.10	22.07	40.00	33.75	0 to 100	3
Emotional well-being	64.72	24.32	72.00	31.00	0 to 100	4
Social functioning	57.75	34.15	68.75	62.50	0 to 100	4
Pain	61.90	32.72	67.50	57.50	0 to 100	4
General health	51.70	22.78	55.00	35.00	0 to 100	3
Health change	51.00	26.71	50.00	37.50	0 to 100	3

*Normal distribution, use mean and SD as central measure. Possible range 0-100

SF36 by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

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

No significant differences were observed between participants by **LP(a) test** for any of the SF36 scales.

Table 2.7: SF36 by LP(a) test summary statistics and T-test

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Had LP(a) test	19	38.00	39.47	20.34	-0.16	48	0.8771
	Not had LP(a) test	31	62.00	40.48	23.39			

Table 2.8.: SF36 by LP(a) test summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	Had LP(a) test	19	38	80.00	57.50	361	0.1843
	Not had LP(a) test	31	62	65.00	40.00		
Role functioning/physical	Had LP(a) test	19	38	25.00	100.00	284	0.8283
	Not had LP(a) test	31	62	25.00	100.00		
Role functioning/emotional	Had LP(a) test	19	38	33.33	100.00	243.5	0.2749
	Not had LP(a) test	31	62	100.00	66.67		
Emotional well-being	Had LP(a) test	19	38	64.00	28.00	218	0.1278
	Not had LP(a) test	31	62	72.00	32.00		
Social functioning	Had LP(a) test	19	38	75.00	50.00	273.5	0.6788
	Not had LP(a) test	31	62	62.50	62.50		
Pain	Had LP(a) test	19	38	67.50	72.50	277.5	0.7391
	Not had LP(a) test	31	62	67.50	45.00		
General health	Had LP(a) test	19	38	60.00	27.50	323.5	0.5674
	Not had LP(a) test	31	62	50.00	37.50		
Health change	Had LP(a) test	19	38	50.00	25.00	244.5	0.2913
	Not had LP(a) test	31	62	50.00	25.00		

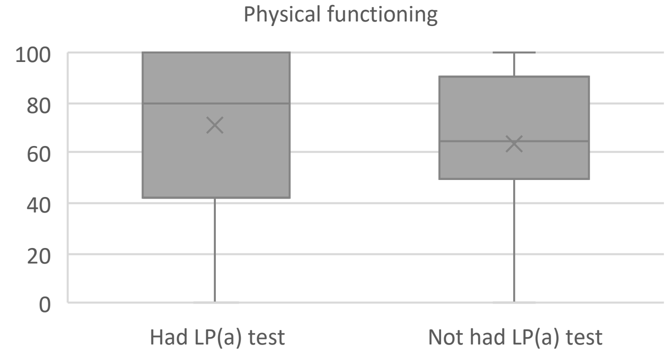

Figure 2.4: Boxplot of SF36 Physical functioning by LP(a) test

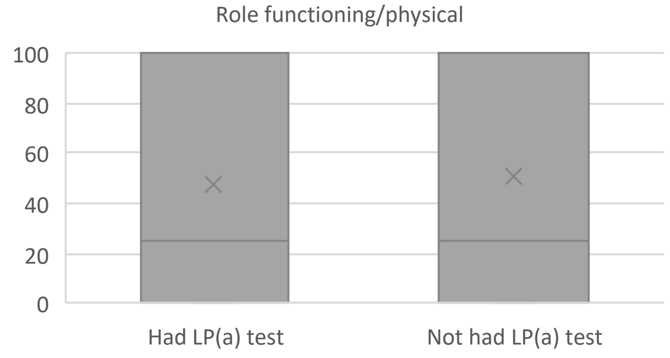

Figure 2.5: Boxplot of SF36 Role functioning/physical by LP(a) test

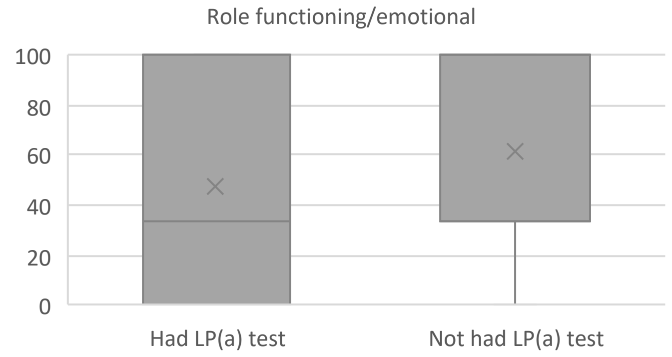

Figure 2.6: Boxplot of SF36 Role functioning/emotional by LP(a) test

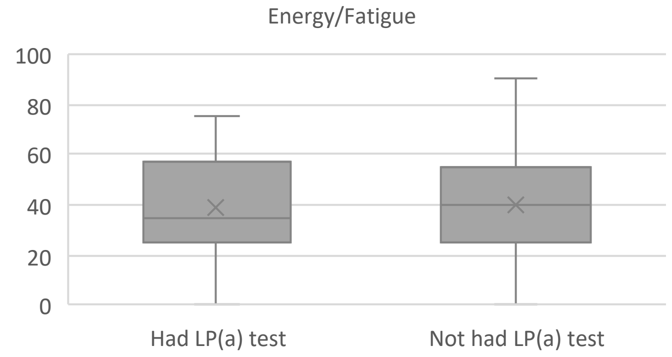

Figure 2.7: Boxplot of SF36 Energy/fatigue by LP(a) test

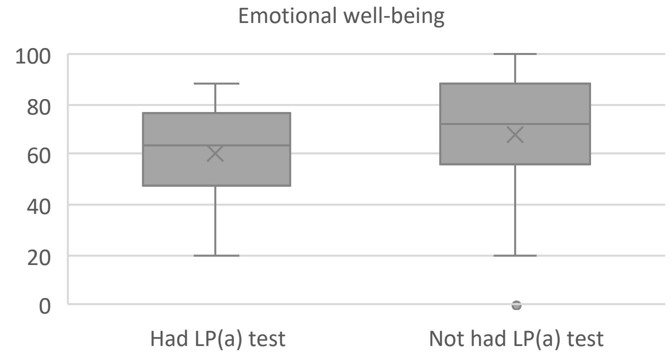

Figure 2.8: Boxplot of SF36 Emotional well-being by LP(a) test

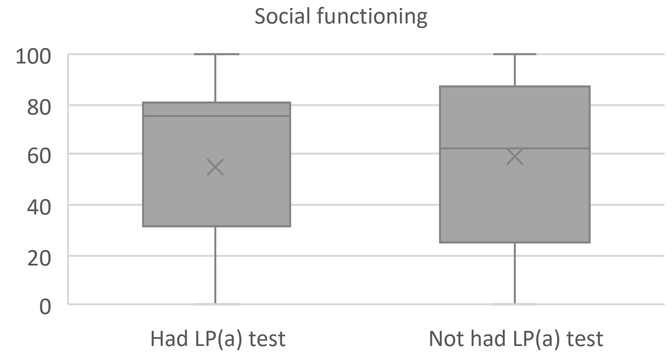

Figure 2.9: Boxplot of SF36 Social functioning by LP(a) test

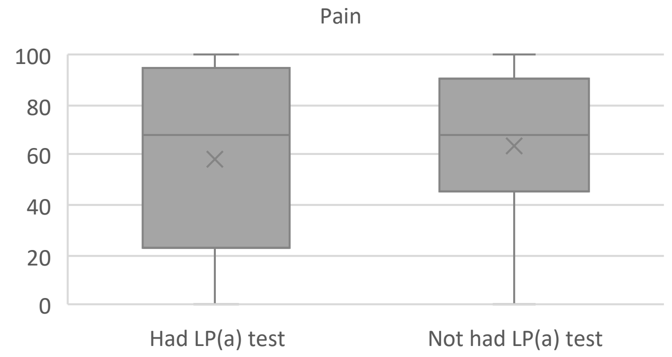

Figure 2.10: Boxplot of SF36 Pain by a LP(a) test

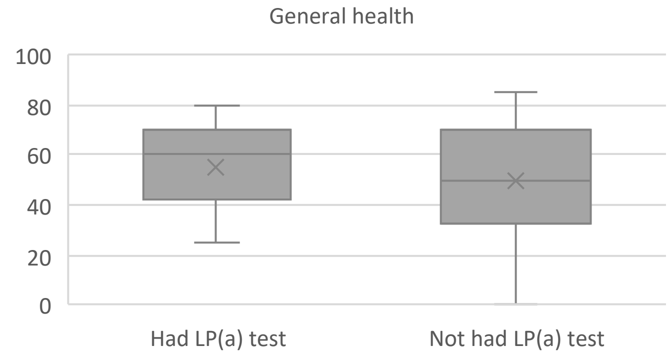

Figure 2.11: Boxplot of SF36 General health by LP(a) test

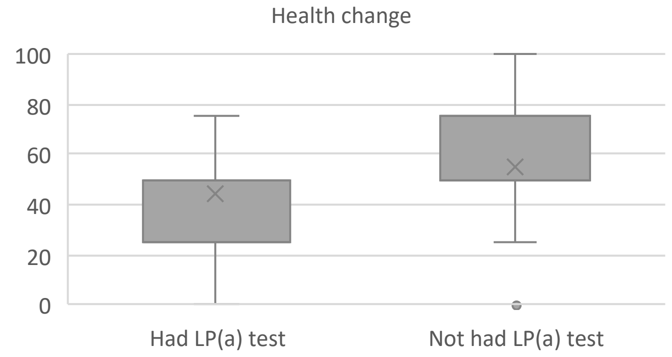

Figure 2.12: Boxplot of SF36 Health change by LP(a) test

SF36 by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used.

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

Table 2.9: SF36 by main condition summary statistics and one-way ANOVA

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/fatigue	High cholesterol under 50 years of age	8	16.33	44.58	19.00	Between groups	466.00	2	233.00	0.47	0.6290
	Blood vessel conditions	19	38.78	40.88	24.76	Within groups	23408.00	47	498.10		
	Heart conditions	22	44.90	36.90	21.94	Total	23874.00	49	731.10		

Table 2.10: SF36 by main condition summary statistics and Kruskal Wallis test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	High cholesterol under 50 years of age	8	16.33	90.00	30.00	1.28	2	0.5268
	Blood vessel conditions	19	38.78	70.00	55.00			
	Heart conditions	22	44.90	60.00	35.00			
Role functioning physical	High cholesterol under 50 years of age	8	16.33	75.00	100.00	1.50	2	0.4718
	Blood vessel conditions	19	38.78	0.00	100.00			
	Heart conditions	22	44.90	75.00	100.00			
Role functioning emotional	High cholesterol under 50 years of age	8	16.33	33.33	100.00	0.27	2	0.8738
	Blood vessel conditions	19	38.78	66.67	100.00			
	Heart conditions	22	44.90	100.00	100.00			
Emotional well-being	High cholesterol under 50 years of age	8	16.33	68.00	37.00	0.30	2	0.8608
	Blood vessel conditions	19	38.78	72.00	36.00			
	Heart conditions	22	44.90	72.00	28.00			
Social functioning	High cholesterol under 50 years of age	8	16.33	75.00	75.00	0.05	2	0.9752
	Blood vessel conditions	19	38.78	62.50	50.00			
	Heart conditions	22	44.90	50.00	62.50			
Pain	High cholesterol under 50 years of age	8	16.33	67.50	67.50	1.01	2	0.6048
	Blood vessel conditions	19	38.78	57.50	55.00			
	Heart conditions	22	44.90	67.50	57.50			
General health	High cholesterol under 50 years of age	8	16.33	57.50	23.75	2.09	2	0.3516
	Blood vessel conditions	19	38.78	60.00	30.00			
	Heart conditions	22	44.90	40.00	45.00			
Health change	High cholesterol under 50 years of age	8	16.33	50.00	25.00	0.96	2	0.6174
	Blood vessel conditions	19	38.78	50.00	0.00			
	Heart conditions	22	44.90	50.00	50.00			

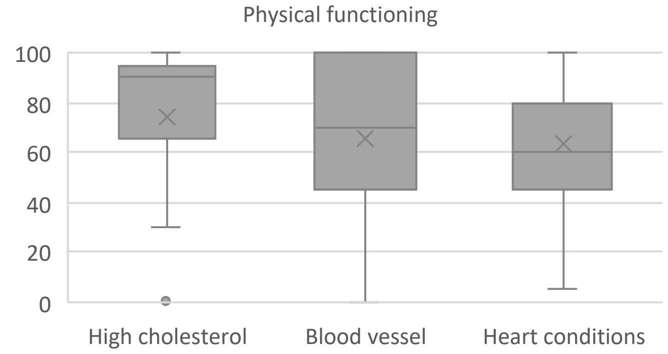

Figure 2.13: Boxplot of SF36 Physical functioning by main condition

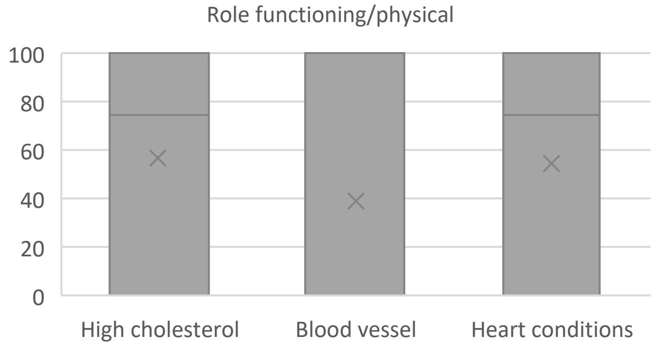

Figure 2.14: Boxplot of SF36 Role functioning/physical by main condition

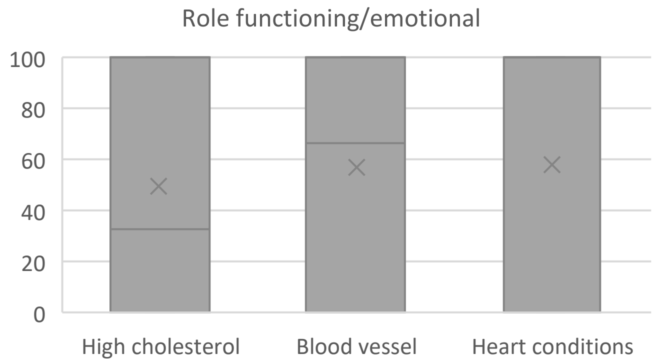

Figure 2.15: Boxplot of SF36 Role functioning/emotional by main condition

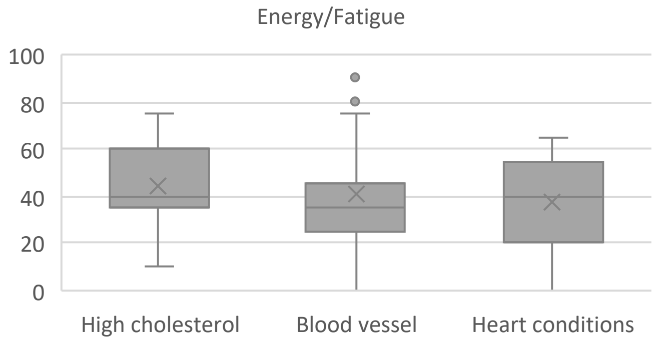

Figure 2.16: Boxplot of SF36 Energy/fatigue by main condition

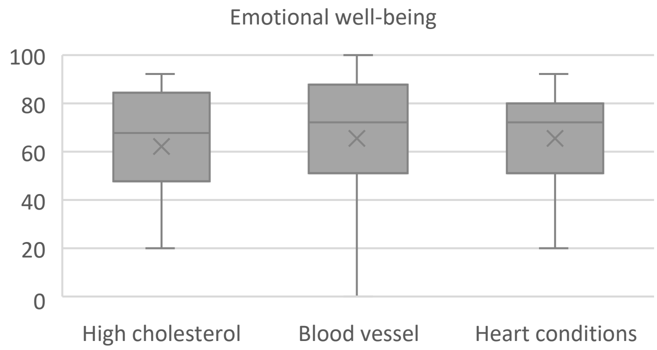

Figure 2.17: Boxplot of SF36 Emotional well-being by main condition

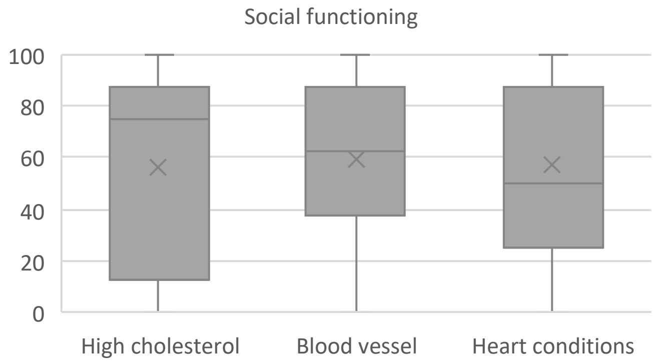

Figure 2.18: Boxplot of SF36 Social functioning by main condition

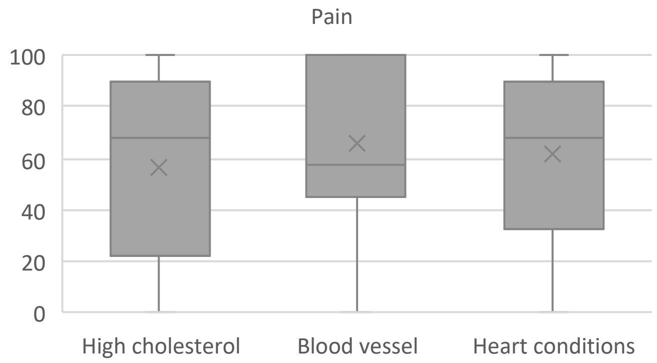

Figure 2.19: Boxplot of SF36 Pain by main condition

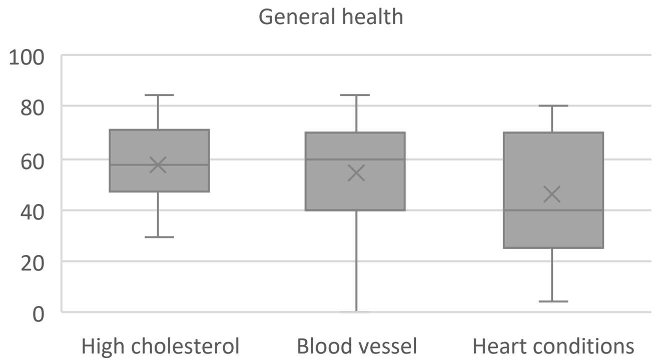

Figure 2.20: Boxplot of SF36 General health by main condition

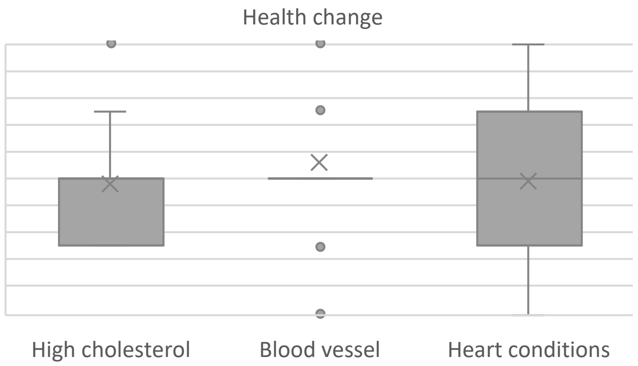

Figure 2.21: Boxplot of SF36 Health change by main condition

SF36 by number other health conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

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

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Pain scale [W = 446.50, p = 0.0077] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 90.00, IQR = 43.75) compared to participants in the 6 to 11 other conditions subgroup (Median = 45.00, IQR = 50.00).

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the 0 to 5 other conditions subgroup scored higher than participants in the 6 to 11 other conditions subgroup. This indicates that participants in the 0 to 5 other conditions subgroup had no pain, and participants in the 6 to 11 other conditions subgroup had moderate pain.

Table 2.11: SF36 by number other health conditions summary statistics and T-test

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	0 to 5 other conditions	27	54.00	41.11	24.82	0.35	48	0.7295
	6 to 11 other conditions	23	46.00	38.91	18.83			

Table 2.12: SF36 by number other health conditions summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	0 to 5 other conditions	27	54.00	80.00	52.50	363.50	0.3037
	6 to 11 other conditions	23	46.00	65.00	37.50		
Role functioning/physical	0 to 5 other conditions	27	54.00	100.00	100.00	350.50	0.4041
	6 to 11 other conditions	23	46.00	25.00	100.00		
Role functioning/emotional	0 to 5 other conditions	27	54.00	100.00	100.00	333.00	0.6432
	6 to 11 other conditions	23	46.00	33.33	100.00		
Emotional well-being	0 to 5 other conditions	27	54.00	72.00	20.00	380.00	0.1782
	6 to 11 other conditions	23	46.00	64.00	28.00		
Social functioning	0 to 5 other conditions	27	54.00	75.00	50.00	350.50	0.4371
	6 to 11 other conditions	23	46.00	50.00	62.50		
Pain	0 to 5 other conditions	27	54.00	90.00	43.75	446.50	0.0077*
	6 to 11 other conditions	23	46.00	45.00	50.00		
General health	0 to 5 other conditions	27	54.00	60.00	35.00	374.00	0.2182
	6 to 11 other conditions	23	46.00	50.00	37.50		
Health change	0 to 5 other conditions	27	54.00	50.00	25.00	393.50	0.0867
	6 to 11 other conditions	23	46.00	50.00	25.00		

*Statistically significant at p<0.05

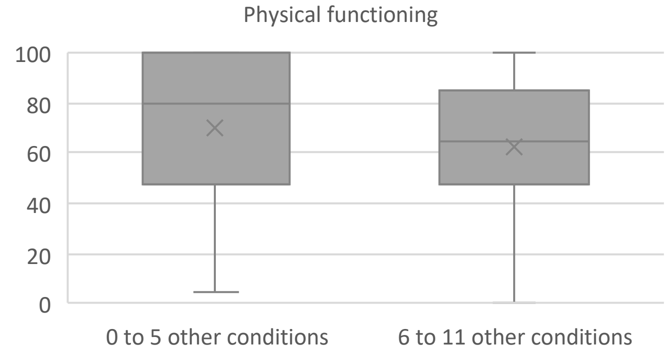

Figure 2.22: Boxplot of SF36 Physical functioning by number other health conditions

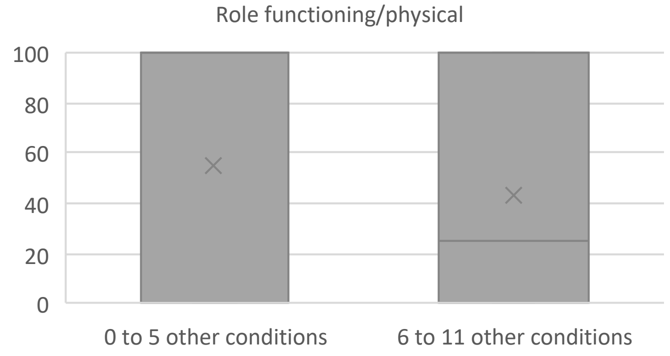

Figure 2.23: Boxplot of SF36 Role functioning/physical by number other health conditions

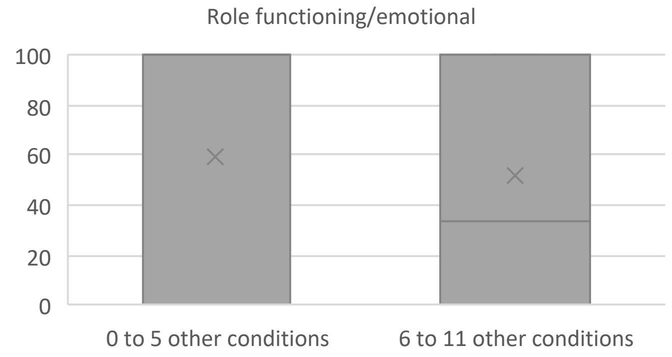

Figure 2.24: Boxplot of SF36 Role functioning/emotional by number other health conditions

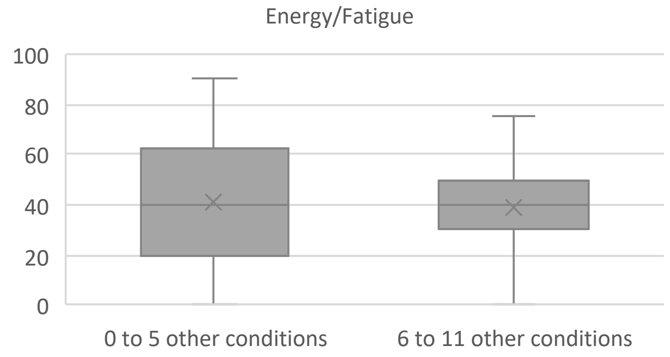

Figure 2.25: Boxplot of SF36 Energy/fatigue by number other health conditions

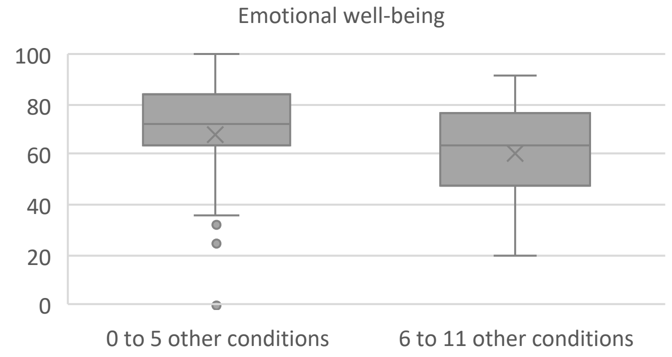

Figure 2.26: Boxplot of SF36 Emotional well-being by number other health conditions

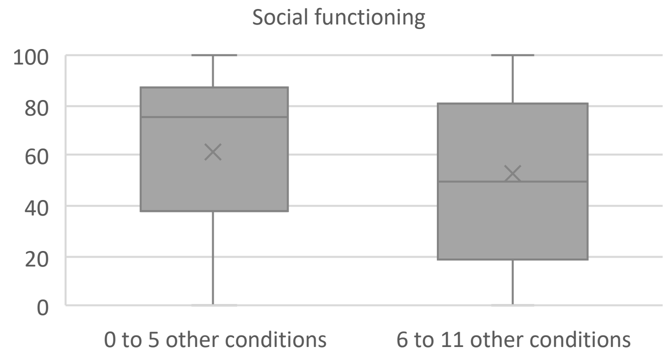

Figure 2.27: Boxplot of SF36 Social functioning by number other health conditions

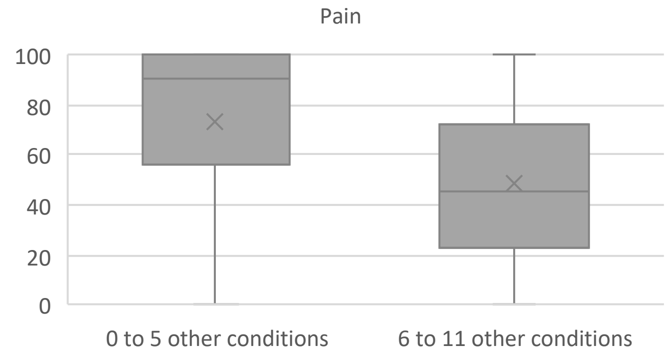

Figure 2.28: Boxplot of SF36 Pain by other conditions

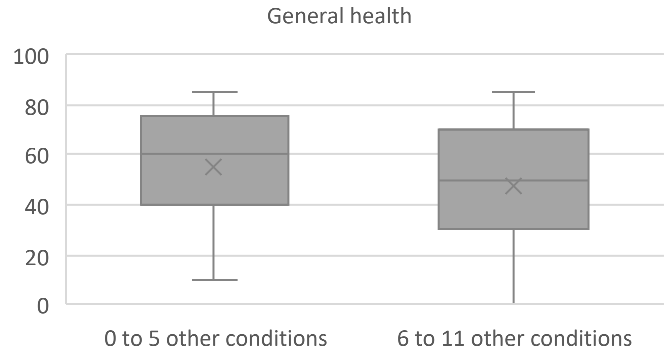

Figure 2.29: Boxplot of SF36 General health by other conditions

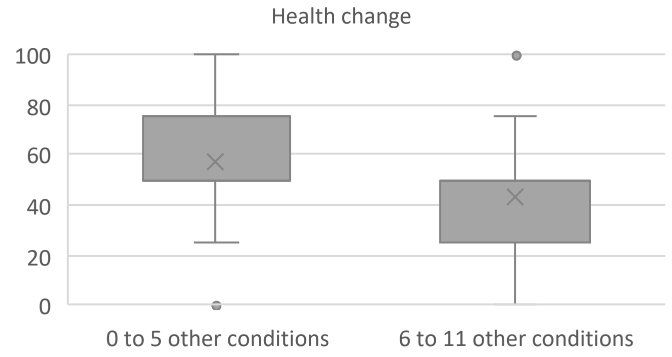

Figure 2.30: Boxplot of SF36 Health change by number other health conditions

SF36 by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

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

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

Table 2.13: SF36 by gender summary statistics and T-test

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Female	28	56	40.89	23.34	0.28	48	0.7778
	Male	22	44	39.09	20.85			
General health	Female	28	56	46.79	23.06	-1.76	48	0.0853
	Male	22	44	57.95	21.31			

Table 2.14: SF36 by gender summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	Female	28	56.00	62.50	46.25	257.00	0.3206
	Male	22	44.00	80.00	45.00		
Role functioning/physical	Female	28	56.00	25.00	100.00	262.50	0.3400
	Male	22	44.00	87.50	100.00		
Role functioning/emotional	Female	28	56.00	100.00	100.00	338.00	0.5329
	Male	22	44.00	33.33	100.00		
Emotional well-being	Female	28	56.00	72.00	30.00	335.00	0.6036
	Male	22	44.00	70.00	38.00		
Social functioning	Female	28	56.00	68.75	65.63	298.50	0.8589
	Male	22	44.00	68.75	37.50		
Pain	Female	28	56.00	56.25	60.00	261.50	0.3639
	Male	22	44.00	67.50	42.50		
Health change	Female	28	56.00	50.00	25.00	275.50	0.5047
	Male	22	44.00	50.00	25.00		

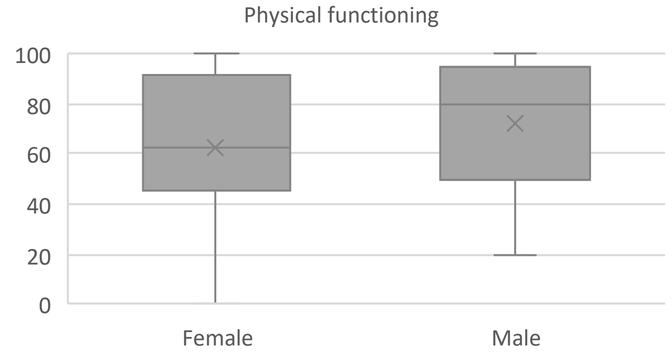

Figure 2.31: Boxplot of SF36 Physical functioning by gender

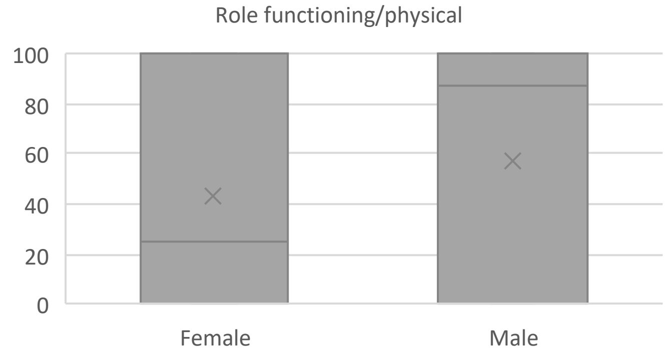

Figure 2.32: Boxplot of SF36 Role functioning/physical by gender

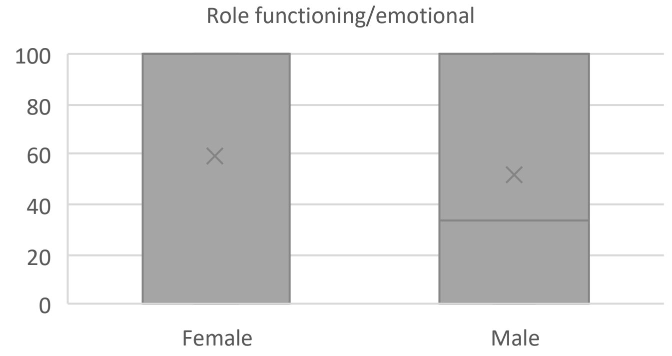

Figure 2.33: Boxplot of SF36 Role functioning/emotional by gender

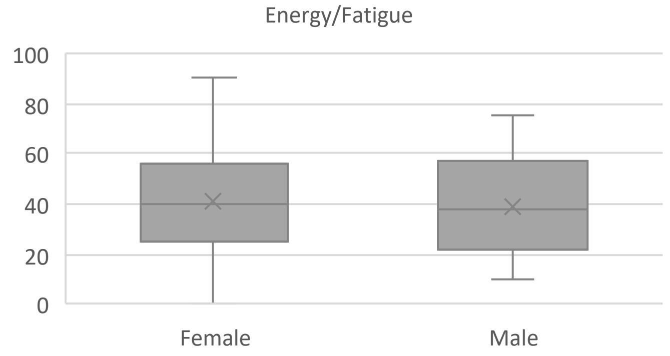

Figure 2.34: Boxplot of SF36 Energy/fatigue by gender

Figure 2.35: Boxplot of SF36 Emotional well-being by gender

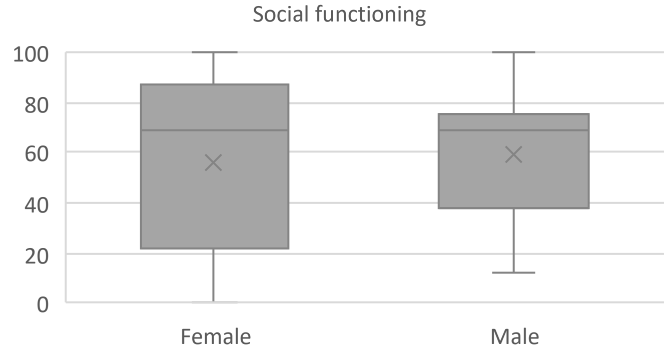

Figure 2.36: Boxplot of SF36 Social functioning by gender

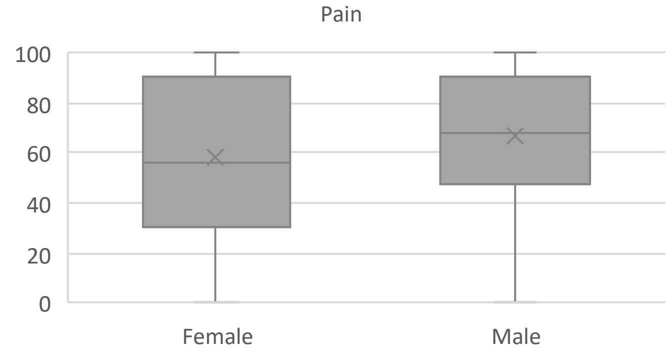

Figure 2.37: Boxplot of SF36 Pain by gender

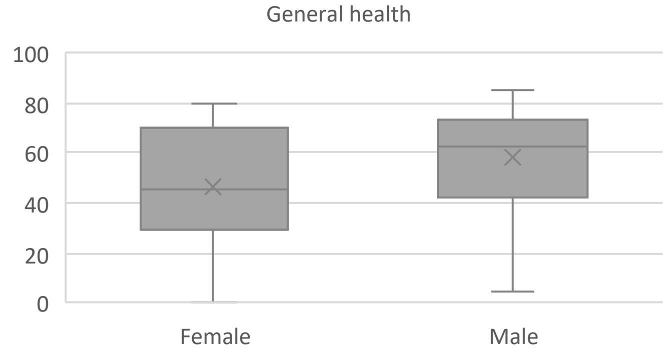

Figure 2.38: Boxplot of SF36 General health by gender

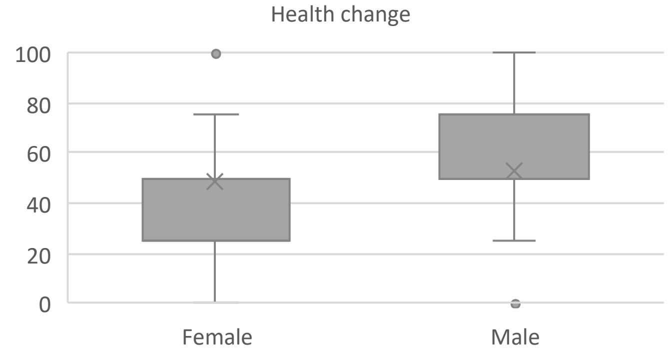

Figure 2.39: Boxplot of SF36 Health change by gender

SF36 by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

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

Table 2.15: SF36 by age summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	Aged 25 to 44	27	54.00	80.00	47.50	358.50	0.3521
	Aged 45 and older	23	46.00	60.00	45.00		
Role functioning/physical	Aged 25 to 44	27	54.00	75.00	100.00	355.50	0.3473
	Aged 45 and older	23	46.00	25.00	100.00		
Role functioning/emotional	Aged 25 to 44	27	54.00	33.33	66.67	334.50	0.6208
	Aged 45 and older	23	46.00	66.67	100.00		
Energy/Fatigue	Aged 25 to 44	27	54.00	40.00	25.00	367.00	0.2742
	Aged 45 and older	23	46.00	30.00	42.50		
Emotional well-being	Aged 25 to 44	27	54.00	68.00	28.00	291.00	0.7108
	Aged 45 and older	23	46.00	72.00	46.00		
Social functioning	Aged 25 to 44	27	54.00	75.00	50.00	338.50	0.5885
	Aged 45 and older	23	46.00	50.00	68.75		
Pain	Aged 25 to 44	27	54.00	67.50	62.50	334.50	0.6441
	Aged 45 and older	23	46.00	55.00	56.25		
General health	Aged 25 to 44	27	54.00	60.00	32.50	340.00	0.5709
	Aged 45 and older	23	46.00	40.00	37.50		
Health change	Aged 25 to 44	27	54.00	50.00	37.50	293.50	0.7319
	Aged 45 and older	23	46.00	50.00	12.50		

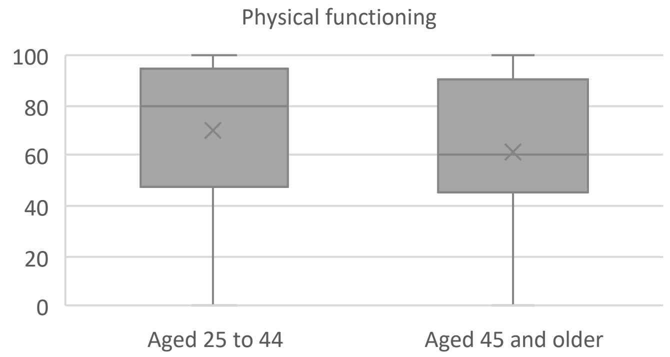

Figure 2.40: Boxplot of SF36 Physical functioning by age

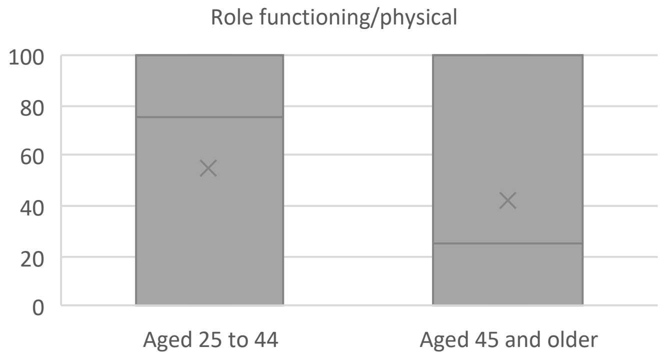

Figure 2.41: Boxplot of SF36 Role functioning/physical by age

Figure 2.42: Boxplot of SF36 Role functioning/emotional by age

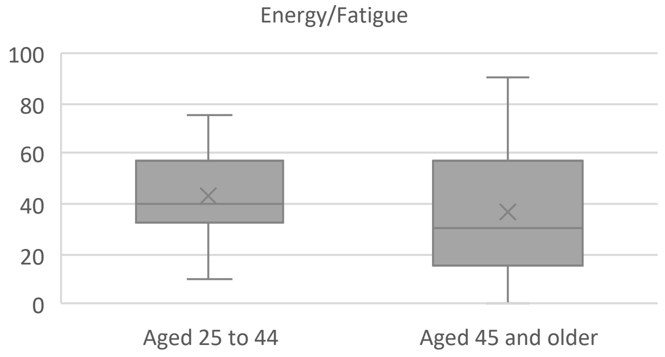

Figure 2.43: Boxplot of SF36 Energy/fatigue by age

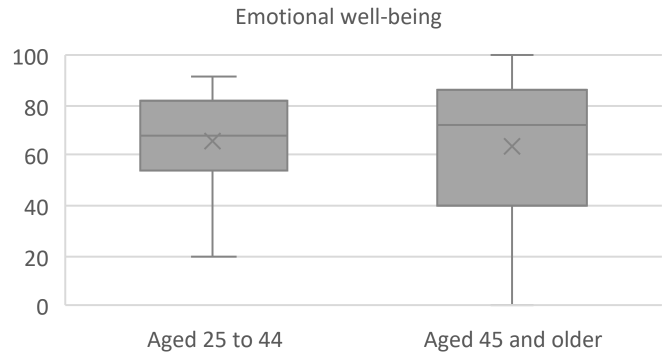

Figure 2.44: Boxplot of SF36 Emotional well-being by age

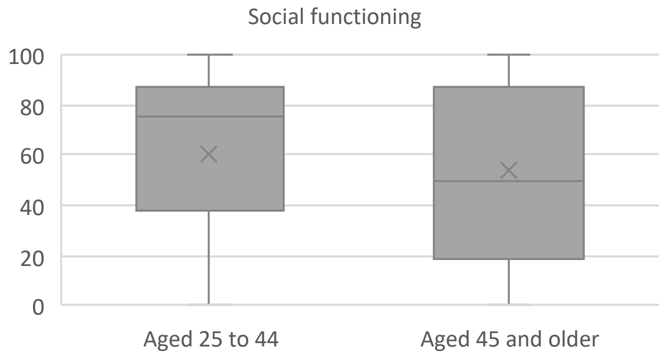

Figure 2.45: Boxplot of SF36 Social functioning by age

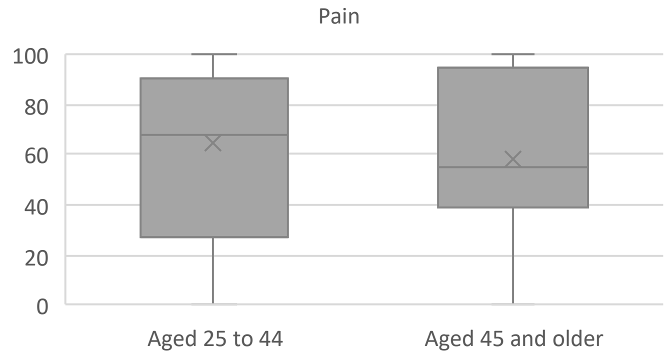

Figure 2.46: Boxplot of SF36 Pain by age

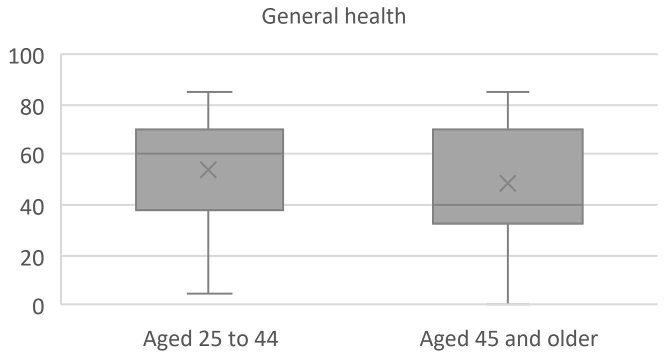

Figure 2.47: Boxplot of SF36 General health by age

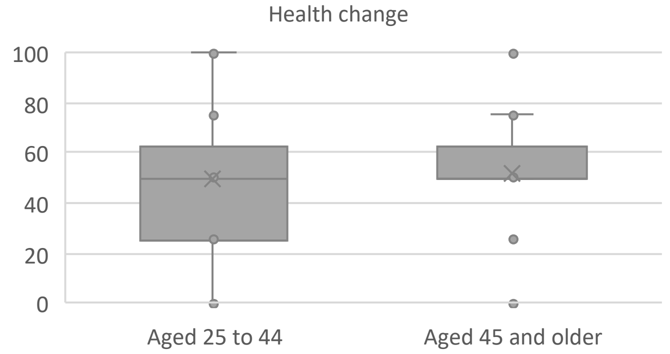

Figure 2.48: Boxplot of SF36 Health change by age

SF36 by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

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

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

Table 2.16: SF36 by location summary statistics and T-test

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Regional or remote	15	30.00	41.00	23.84	0.19	48	0.8525
	Metropolitan	35	70.00	39.71	21.62			

Table 2.17: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	Regional or remote	15	30.00	75.00	50.00	279.50	0.7252
	Metropolitan	35	70.00	70.00	42.50		
Role functioning/physical	Regional or remote	15	30.00	100.00	100.00	295.50	0.4553
	Metropolitan	35	70.00	25.00	100.00		
Role functioning/emotional	Regional or remote	15	30.00	100.00	100.00	287.00	0.5826
	Metropolitan	35	70.00	33.33	100.00		
Emotional well-being	Regional or remote	15	30.00	72.00	28.00	250.50	0.8072
	Metropolitan	35	70.00	72.00	32.00		
Social functioning	Regional or remote	15	30.00	75.00	56.25	268.50	0.9063
	Metropolitan	35	70.00	62.50	62.50		
Pain	Regional or remote	15	30.00	77.50	55.00	309.00	0.3254
	Metropolitan	35	70.00	67.50	57.50		
General health	Regional or remote	15	30.00	65.00	30.00	286.00	0.6249
	Metropolitan	35	70.00	55.00	37.50		
Health change	Regional or remote	15	30.00	50.00	25.00	297.00	0.4426
	Metropolitan	35	70.00	50.00	25.00		

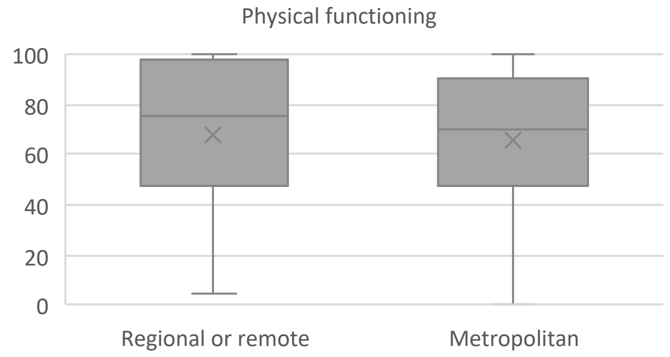

Figure 2.49: Boxplot of SF36 Physical functioning by location

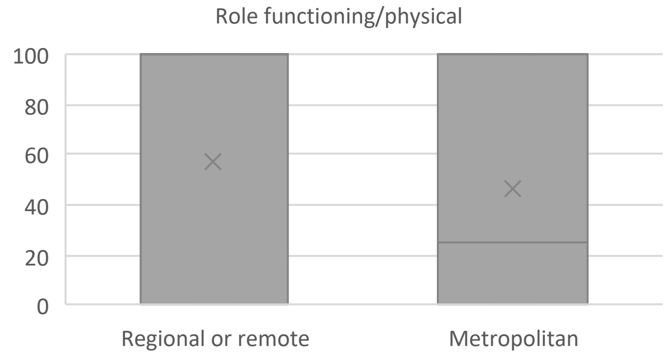

Figure 2.50: Boxplot of SF36 Role functioning/physical by location

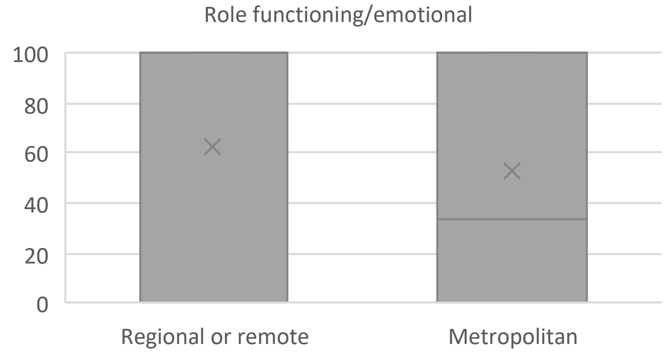

Figure 2.51: Boxplot of SF36 Role functioning/emotional by location

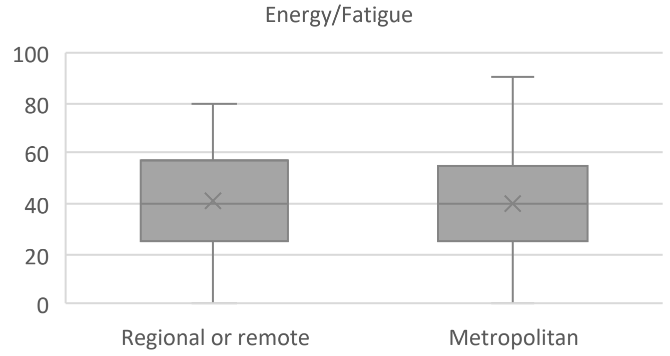

Figure 2.52: Boxplot of SF36 Energy/fatigue by location

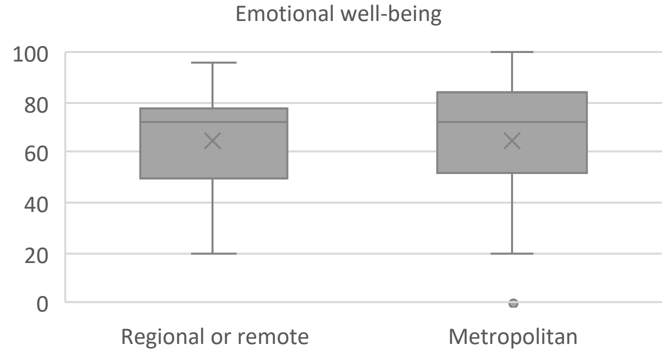

Figure 2.53: Boxplot of SF36 Emotional well-being by location

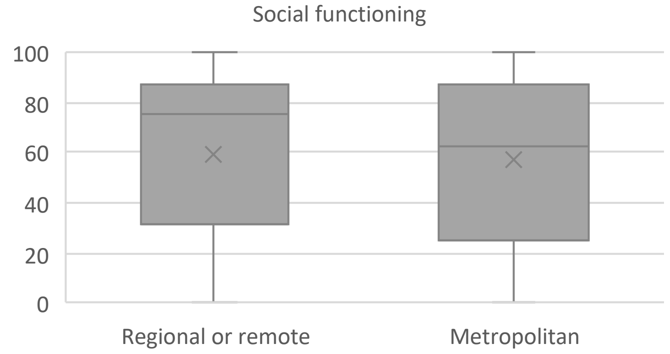

Figure 2.54: Boxplot of SF36 Social functioning by location

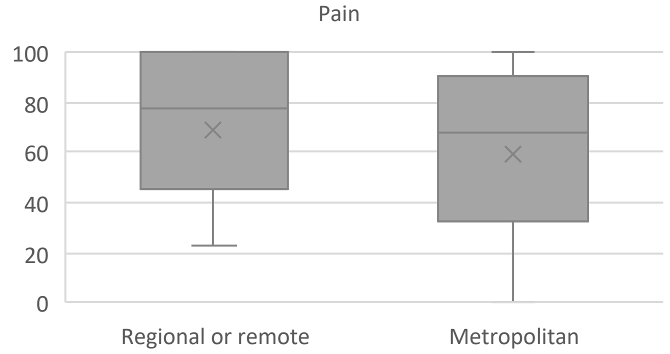

Figure 2.55: Boxplot of SF36 Pain by location

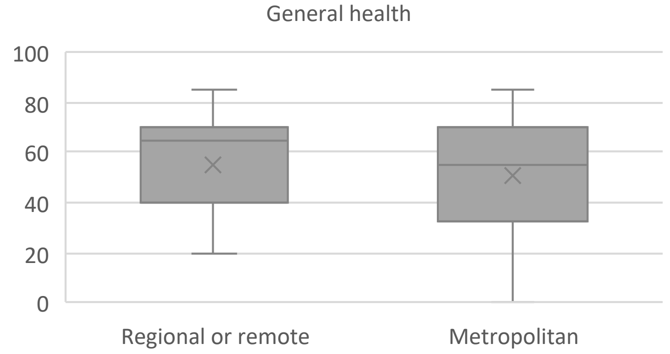

Figure 2.56: Boxplot of SF36 General health by location

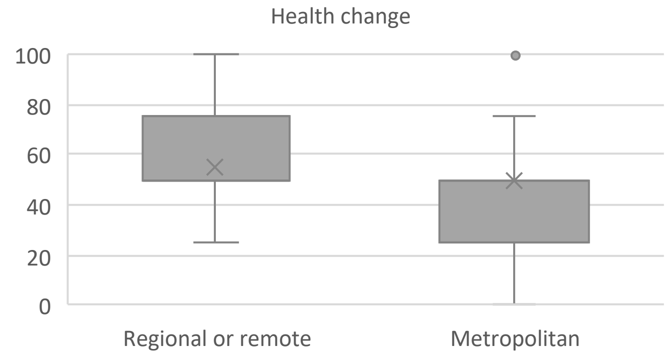

Figure 2.57: Boxplot of SF36 Health change by location stage

SF36 by socioeconomic status

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

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

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Health change scale [W = 437.50, p = 0.0100] was significantly lower for participants in the Mid to low socioeconomic status subgroup (Median = 50.00, IQR = 25.00) compared to participants in the Higher socioeconomic status subgroup (Median = 50.00, IQR = 25.00).

SF36 Health change scale measures health compared to a year ago. On average, participants in the Mid to low socioeconomic status subgroup had a higher score for health change compared to Higher socioeconomic status, however, both groups reported that their health was about the same as it was a year ago.

Table 2.18: SF36 by socioeconomic status summary statistics and T-test

SF36 scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Mid to low socioeconomic status	25	50.00	42.60	23.32	0.80	48	0.4289
	Higher socioeconomic status	25	50.00	37.60	20.92			

Table 2.19: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low socioeconomic status	25	50.00	75.00	40.00	377.00	0.2114
	Higher socioeconomic status	25	50.00	60.00	45.00		
Role functioning/physical	Mid to low socioeconomic status	25	50.00	100.00	100.00	366.50	0.2600
	Higher socioeconomic status	25	50.00	25.00	100.00		
Role functioning/emotional	Mid to low socioeconomic status	25	50.00	33.33	100.00	303.50	0.8584
	Higher socioeconomic status	25	50.00	66.67	100.00		
Emotional well-being	Mid to low socioeconomic status	25	50.00	72.00	24.00	299.00	0.8004
	Higher socioeconomic status	25	50.00	72.00	32.00		
Social functioning	Mid to low socioeconomic status	25	50.00	75.00	50.00	352.00	0.4444
	Higher socioeconomic status	25	50.00	50.00	50.00		
Pain	Mid to low socioeconomic status	25	50.00	77.50	45.00	379.50	0.1926
	Higher socioeconomic status	25	50.00	57.50	67.50		
General health	Mid to low socioeconomic status	25	50.00	65.00	35.00	411.00	0.0562
	Higher socioeconomic status	25	50.00	50.00	35.00		
Health change	Mid to low socioeconomic status	25	50.00	50.00	25.00	437.50	0.0100*
	Higher socioeconomic status	25	50.00	50.00	25.00		

*Statistically significant at p<0.05

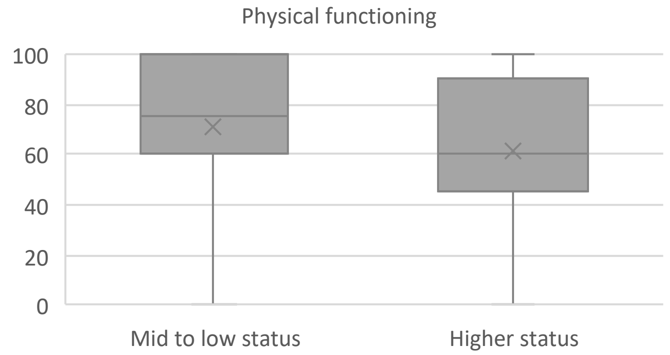

Figure 2.58: Boxplot of SF36 Physical functioning by socioeconomic status

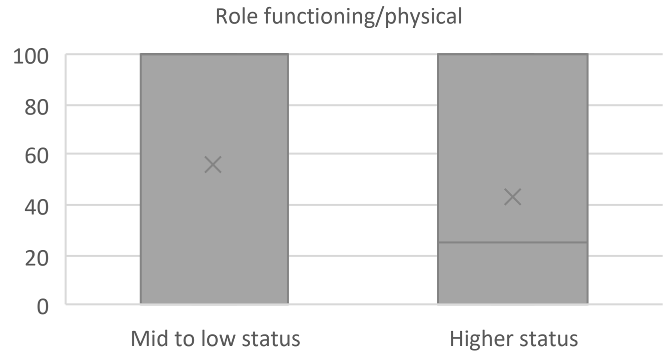

Figure 2.59: Boxplot of SF36 Role functioning/physical by socioeconomic status

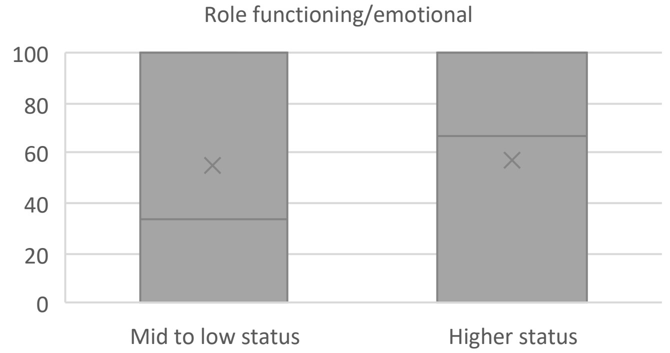

Figure 2.60: Boxplot of SF36 Role functioning/emotional by socioeconomic status

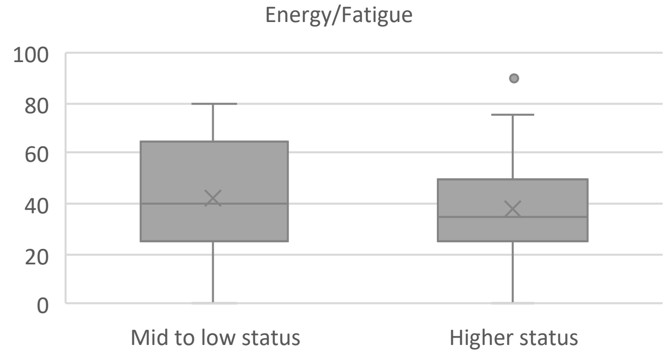

Figure 2.61: Boxplot of SF36 Energy/fatigue by socioeconomic status

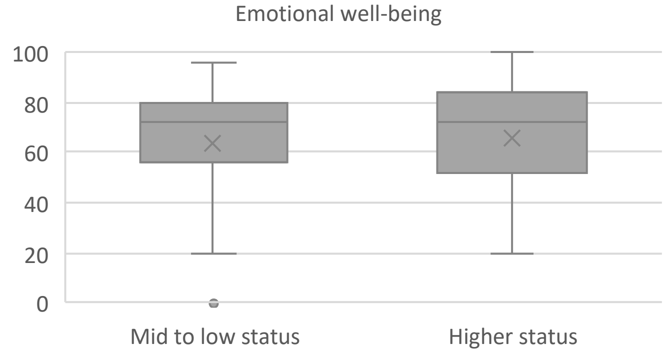

Figure 2.62: Boxplot of SF36 Emotional well-being by socioeconomic status

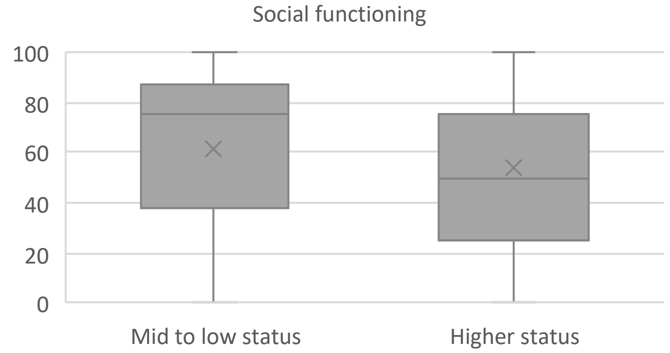

Figure 2.63: Boxplot of SF36 Social functioning by socioeconomic status

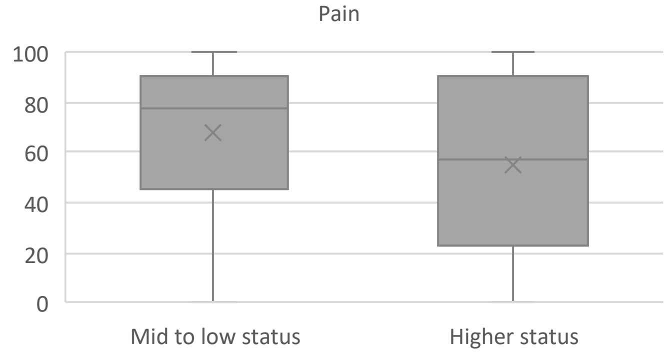

Figure 2.64: Boxplot of SF36 Pain by socioeconomic status

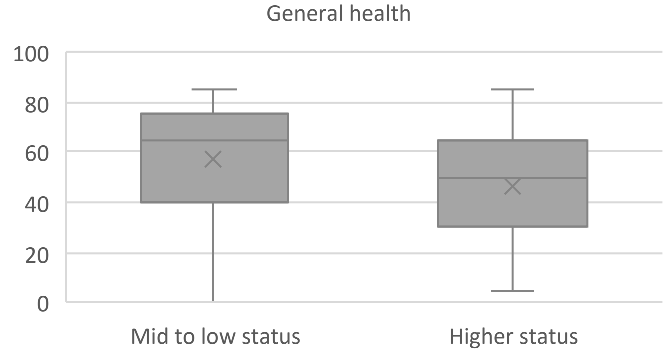

Figure 2.65: Boxplot of SF36 General health by socioeconomic status

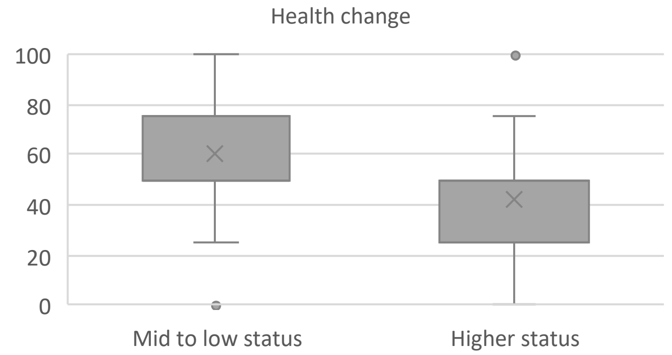

Figure 2.66: Boxplot of SF36 Health change by socioeconomic status

AQOL

The Australian Quality of Life (AQOL) 4D instrument consists of 12 items covering 4 dimensions:

- Independent living (self care, household tasks and mobility)
- Relationships (friends, isolation and family)
- Mental health (sleep, worry and pain)
- Senses (eyesight, hearing and communication.

Utility scores for each dimension and a total score have been calculated according to published instructions[1]. The AQOL provides a utility score that ranges from 1.00 (full health) to 0.00 (death-equivalent health states) to –0.04 (health states worse than death).

An additional 5 participants were included in this analysis for the summary statists and the comparison by LP(a) test. The five participants had LP(a) tests and only completed the AQOL questionnaire and some additional questions about managing their health after getting LP(a) test results.

The overall scores for each dimension and the total score were as follows; Independent Living (median=1.00, IQR=0.19), Social Relationships (median=0.84, IQR=0.31), Physical Senses (median=0.94, IQR=0.14), Psychological Wellbeing (median=0.87, IQR=0.15), and AQoL utility score (median=0.55, IQR=0.47).

Table 2.20: AQOL summary statistics

AQoL(n=55)	Mean	SD	Median	IQR	Possible range
Independent Living	0.83	0.26	1.00	0.19	-0.04 to 1.00
Social Relationships	0.81	0.22	0.84	0.31	-0.04 to 1.00
Physical Senses	0.89	0.15	0.94	0.14	-0.04 to 1.00
Psychological Wellbeing	0.82	0.19	0.87	0.15	-0.04 to 1.00
AQoL utility score	0.60	0.34	0.55	0.47	-0.04 to 1.00

*Skewed distribution use median and IQR as measure of central tendency

AQOL by LP(a) test

Comparisons were made by **LP(a) Test status** there were 24 participants (43.64%) that had an LP(a) test and, 31 participants (56.36%) that did not have an LP(a) test.

An additional 5 participants were included in this comparison. The five participants had LP(a) tests and only completed the AQOL questionnaire and some additional questions about managing their health after getting LP(a) test results.

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

No significant differences were observed between participants by **LP(a) test** for any of the AQOL dimensions and the AQOL total score.

- [1] Hawthorne G, Richardson J, & Osbourne R. (1999). 'The Assessment of Quality of life (AQoL) instrument: a psychometric measure of Health-Related Quality of Life'. *Quality of Life Research, 8*(3), pp 209-224. doi: 10.1023/A:1008815005736

Table 2.21: AQOL by LP(a) test summary statistics and T-test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	Had LP(a) test	24	43.64	1.00	0.19	378.50	0.9121
	Not had LP(a) test	31	56.36	1.00	0.19		
Social relationships	Had LP(a) test	24	43.64	0.91	0.33	377.50	0.9311
	Not had LP(a) test	31	56.36	0.82	0.26		
Physical senses	Had LP(a) test	24	43.64	0.90	0.13	295.00	0.1823
	Not had LP(a) test	31	56.36	0.94	0.14		
Psychological Wellbeing	Had LP(a) test	24	43.64	0.87	0.10	397.50	0.6705
	Not had LP(a) test	31	56.36	0.87	0.21		
AQOL Total score	Had LP(a) test	24	43.64	0.63	0.61	381.00	0.8852
	Not had LP(a) test	31	56.36	0.55	0.33		

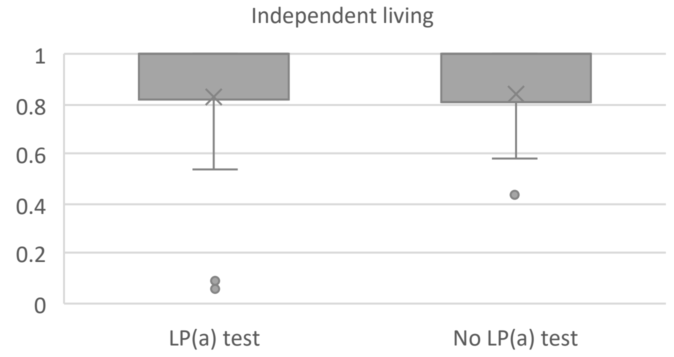

Figure 2.67: Boxplot of AQOL independent living by LP(a) test

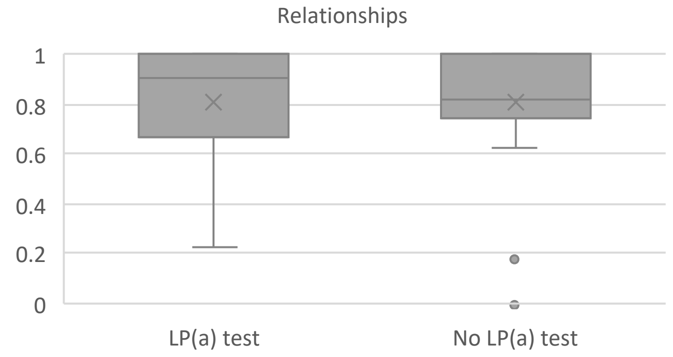

Figure 2.68: Boxplot of AQOL relationships by LP(a) test

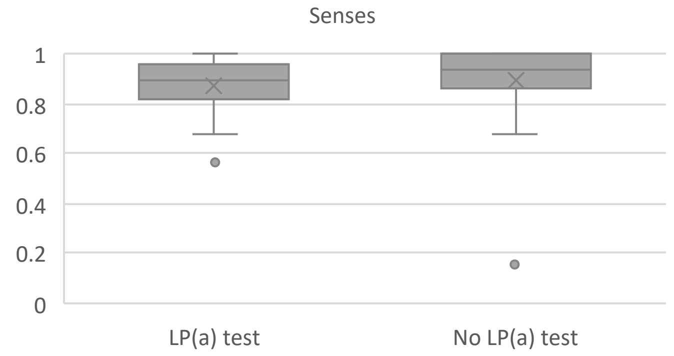

Figure 2.69: Boxplot of AQOL mental health by LP(a) test

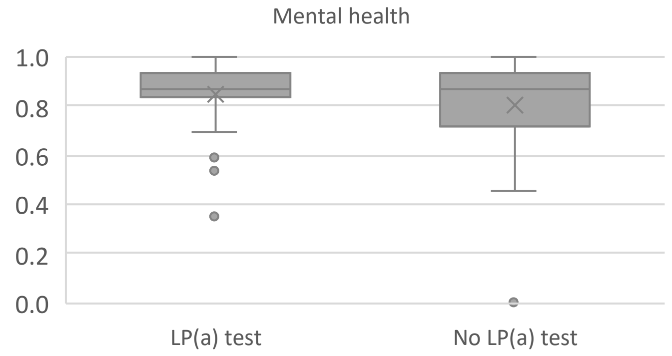

Figure 2.70: Boxplot of AQOL senses by LP(a) test

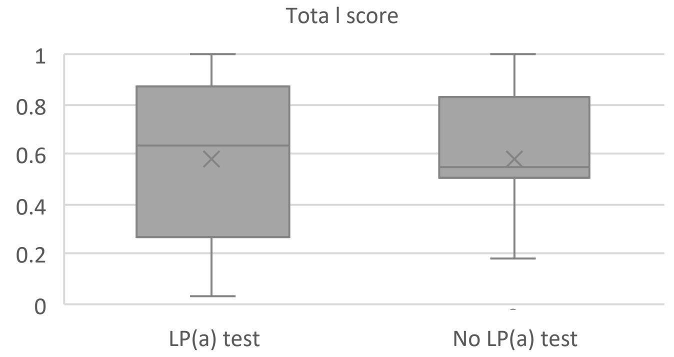

Figure 2.71: Boxplot of AQOL total score by LP(a) test

AQOL by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A Kruskal-Wallis test was used to compare AQOL utility scores between groups.

No significant differences were observed between participants by **by main condition** for any of the AQOL utility scores.

Table 2.22: AQOL by main condition summary statistics and Kruskal Wallis test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	C^2	dF	p-value
Independent living	High cholesterol under 50 years of age	8	16.33	1.00	0.03	4.43	2	0.1093
	Blood vessel conditions	19	38.78	0.88	0.40			
	Heart conditions	22	44.90	1.00	0.17			
Social relationships	High cholesterol under 50 years of age	8	16.33	0.82	0.26	0.22	2	0.8944
	Blood vessel conditions	19	38.78	0.84	0.19			
	Heart conditions	22	44.90	0.84	0.31			
Physical senses	High cholesterol under 50 years of age	8	16.33	0.91	0.14	0.20	2	0.9045
	Blood vessel conditions	19	38.78	0.94	0.12			
	Heart conditions	22	44.90	0.94	0.14			
Psychological Wellbeing	High cholesterol under 50 years of age	8	16.33	0.87	0.25	1.72	2	0.4225
	Blood vessel conditions	19	38.78	0.93	0.14			
	Heart conditions	22	44.90	0.85	0.08			
AQOL Total score	High cholesterol under 50 years of age	8	16.33	0.60	0.53	0.01	2	0.9940
	Blood vessel conditions	19	38.78	0.57	0.33			
	Heart conditions	22	44.90	0.55	0.33			

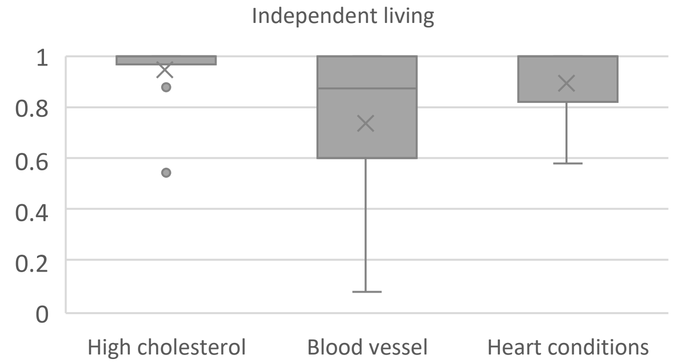

Figure 2.72: Boxplot of AQOL independent living by main condition

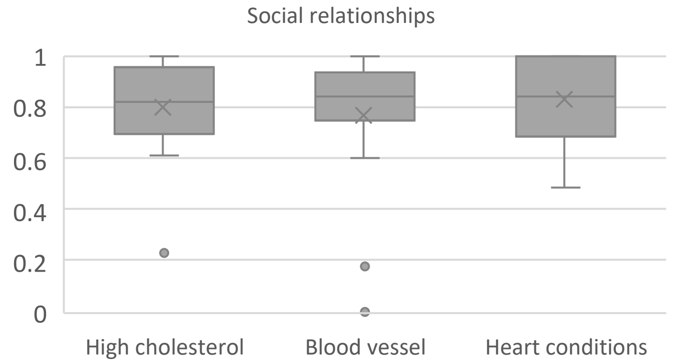

Figure 2.73: Boxplot of AQOL relationships by main condition

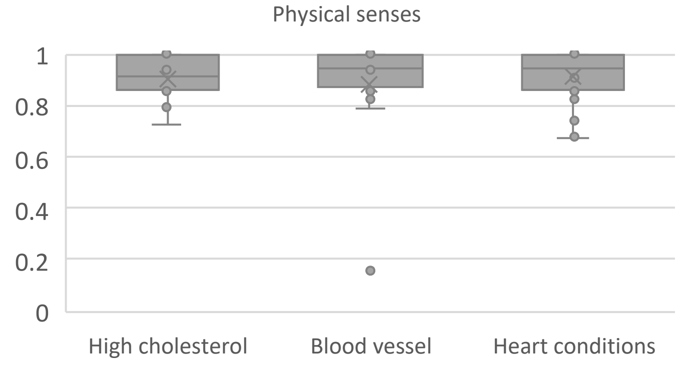

Figure 2.74: Boxplot of AQOL senses by main condition

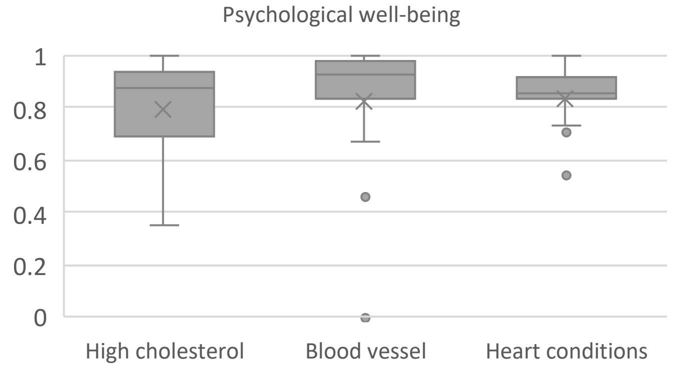

Figure 2.75: Boxplot of AQOL mental health by main condition

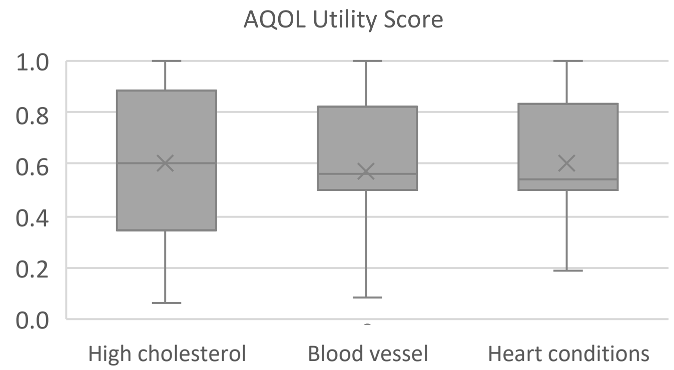

Figure 2.76: Boxplot of AQOL total score by main condition

AQOL by number other health conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL independent living dimension [W = 423.50 , p = 0.0168] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 1.00, IQR = 0.12) compared to participants in the 6 to 11 other conditions subgroup (Median = 0.88, IQR = 0.41).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL relationships dimension [W = 471.00 , p = 0.0015] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 0.94, IQR = 0.23) compared to participants in the 6 to 11 other conditions subgroup (Median = 0.79, IQR = 0.24.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL mental health dimension [W = 427.00 , p = 0.0199] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 0.94, IQR = 0.08) compared to participants in the 6 to 11 other conditions subgroup (Median = 0.88, IQR = 0.16.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL senses dimension [W = 505.50 , p = 0.0001] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 0.93, IQR = 0.10) compared to participants in the 6 to 11 other conditions subgroup (Median = 0.83, IQR = 0.20.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL total score [W = 503.00 , p = 0.0002] was significantly higher for participants in the 0 to 5 other conditions subgroup (Median = 0.82, IQR = 0.37) compared to participants in the 6 to 11 other conditions subgroup (Median = 0.42, IQR = 0.31.

On average, participants in the 0 to 5 other conditions subgroup scored higher than participants in the 6 to 11 other conditions subgroup for all of the AQOL dimensions and the AQOL total score.

Table 2.23: AQOL by number other health conditions summary statistics and Wilcoxon test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	0 to 5 other conditions	27	54.00	1.00	0.12	423.50	0.0168*
	6 to 11 other conditions	23	46.00	0.88	0.41		
Social relationships	0 to 5 other conditions	27	54.00	0.94	0.23	471.00	0.0015*
	6 to 11 other conditions	23	46.00	0.79	0.24		
Physical senses	0 to 5 other conditions	27	54.00	0.94	0.08	427.00	0.0199*
	6 to 11 other conditions	23	46.00	0.88	0.16		
Psychological Wellbeing	0 to 5 other conditions	27	54.00	0.93	0.10	505.50	0.0001*
	6 to 11 other conditions	23	46.00	0.83	0.20		
AQOL Total score	0 to 5 other conditions	27	54.00	0.82	0.37	503.00	0.0002*
	6 to 11 other conditions	23	46.00	0.42	0.31		

*Statistically significant at p<0.05

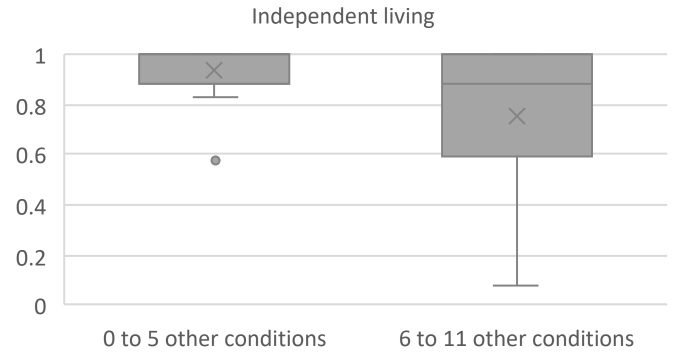

Figure 2.77: Boxplot of AQOL independent living by other health conditions

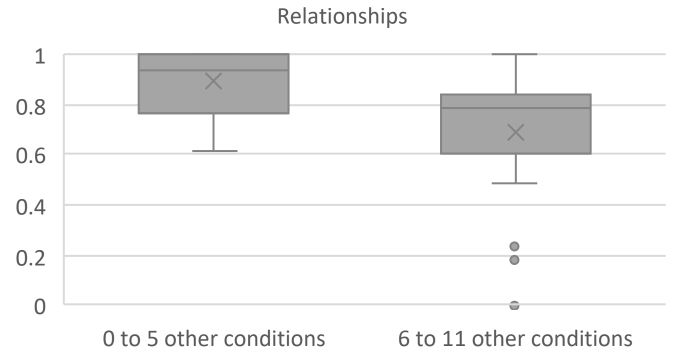

Figure 2.78: Boxplot of AQOL relationships by other health conditions

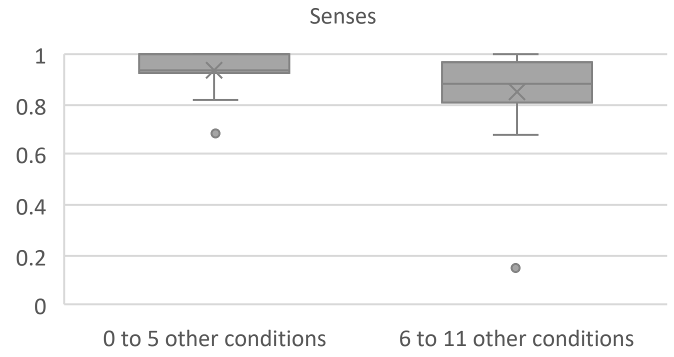

Figure 2.79: Boxplot of AQOL senses by other health conditions

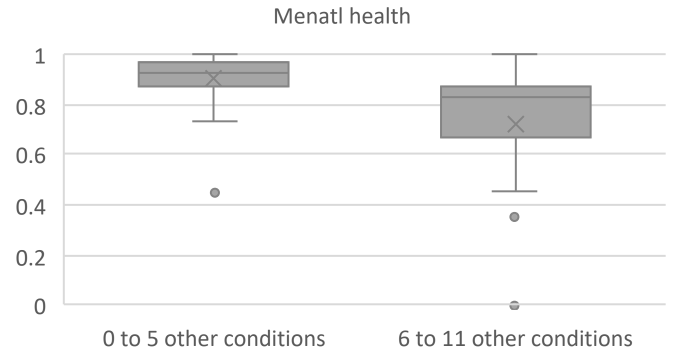

Figure 2.80: Boxplot of AQOL mental health by other health conditions

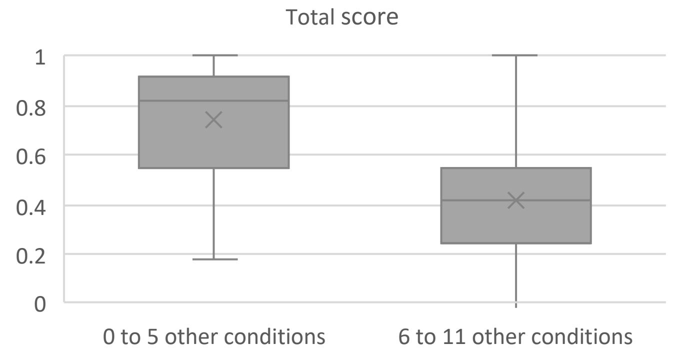

Figure 2.81: Boxplot of AQOL total score by other health conditions

AQOL by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

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

Wilcoxon rank sum tests with continuity correction indicated that the median score for the AQOL senses dimension [W = 207.00 , p = 0.0428] was significantly lower for participants in the Female subgroup (Median = 0.90, IQR = 0.11) compared to participants in the Male subgroup (Median = 0.97, IQR = 0.08).

On average, female participants had lower scores for the AQOL senses dimension compared to males.

Table 2.24: AQOL by gender summary statistics and T-test

AQOL dimension	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
AQOL Total score	Female	28	56.00	0.53	0.31	-1.70	48	0.0948
	Male	22	44.00	0.67	0.26			

Table 2.25: AQOL by gender summary statistics and Wilcoxon test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	Female	28	56.00	0.88	0.30	217.50	0.0549
	Male	22	44.00	1.00	0.12		
Social relationships	Female	28	56.00	0.81	0.27	235.00	0.1492
	Male	22	44.00	0.94	0.25		
Physical senses	Female	28	56.00	0.90	0.11	207.00	0.0428*
	Male	22	44.00	0.97	0.08		
Psychological Wellbeing	Female	28	56.00	0.85	0.13	258.00	0.3309
	Male	22	44.00	0.91	0.20		

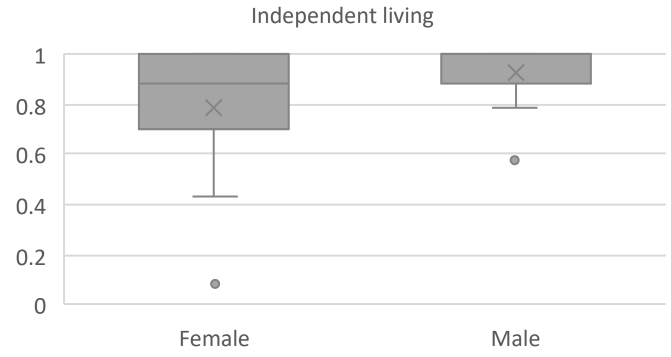

Figure 2.82: Boxplot of AQOL independent living by gender

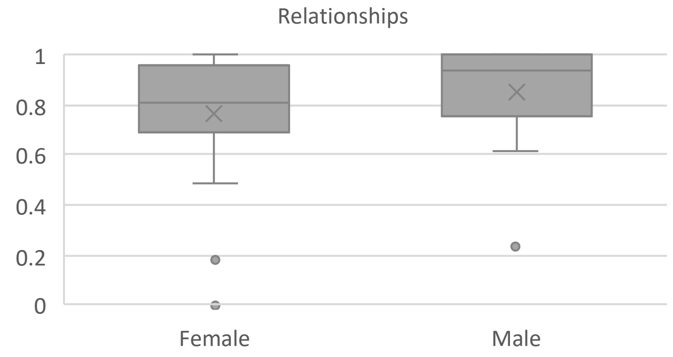

Figure 2.83: Boxplot of AQOL relationships by gender

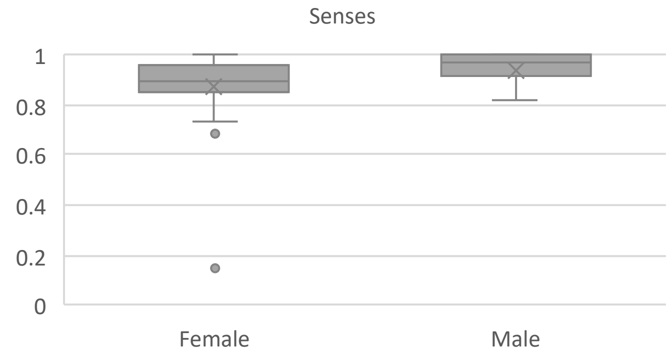

Figure 2.84: Boxplot of AQOL mental health by gender

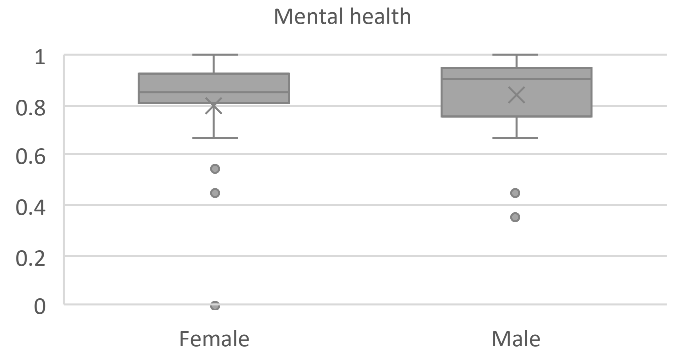

Figure 2.85: Boxplot of AQOL senses by gender

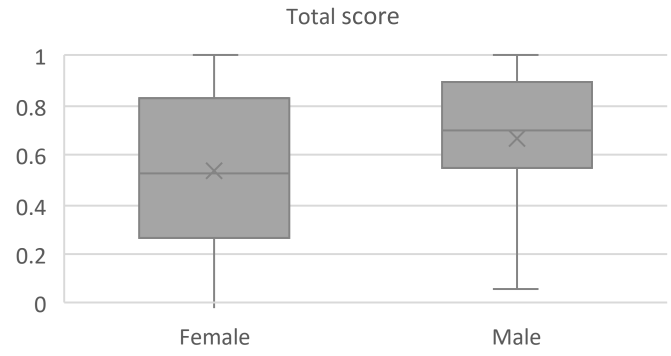

Figure 2.86: Boxplot of AQOL total score by gender

AQOL by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

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

No significant differences were observed between participants by **age** for any of the AQOL dimensions and the AQOL total score.

Table 2.26: AQOL by age summary statistics and T-test

AQOL dimension	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
AQOL Total score	Aged 25 to 44	27	54.00	0.61	0.29	0.47	48	0.6423
	Aged 45 and older	23	46.00	0.57	0.30			

Table 2.27: AQOL by age summary statistics and Wilcoxon test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	Aged 25 to 44	27	54.00	1.00	0.12	386.00	0.1111
	Aged 45 and older	23	46.00	0.88	0.24		
Social relationships	Aged 25 to 44	27	54.00	0.82	0.28	296.00	0.7815
	Aged 45 and older	23	46.00	0.84	0.28		
Physical senses	Aged 25 to 44	27	54.00	0.94	0.14	342.50	0.5271
	Aged 45 and older	23	46.00	0.94	0.14		
Psychological Wellbeing	Aged 25 to 44	27	54.00	0.87	0.20	285.00	0.6248
	Aged 45 and older	23	46.00	0.89	0.11		

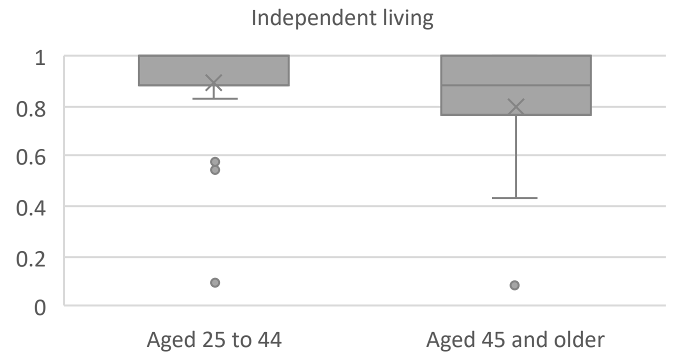

Figure 2.87: Boxplot of AQOL independent living by age

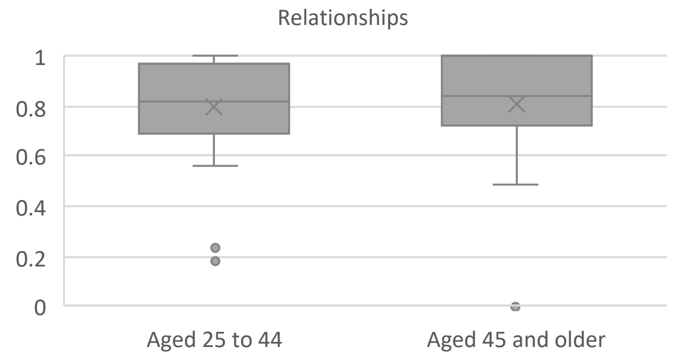

Figure 2.88: Boxplot of AQOL relationships by age

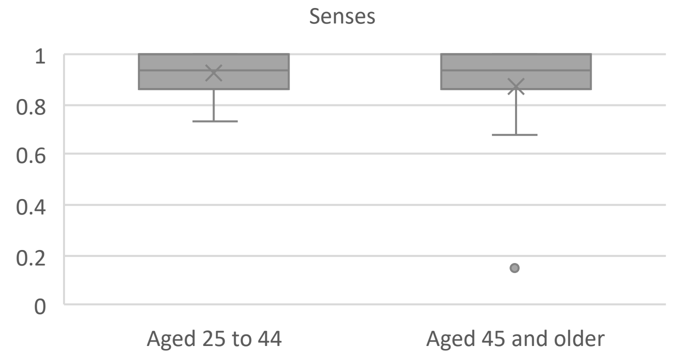

Figure 2.89: Boxplot of AQOL mental health by age

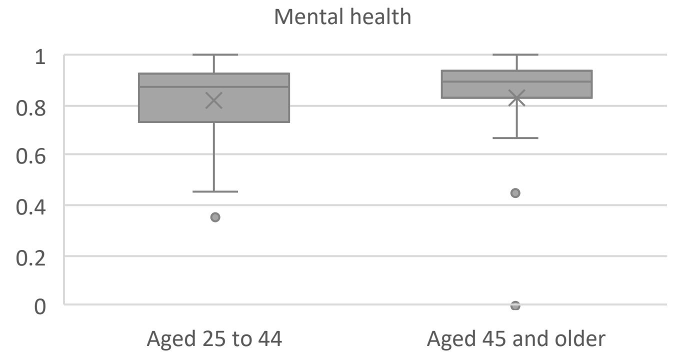

Figure 2.90: Boxplot of AQOL senses by age

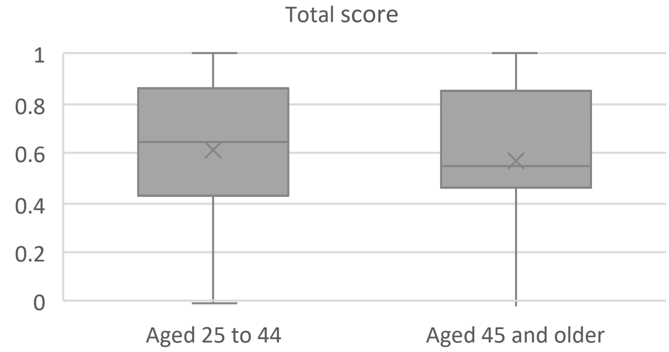

Figure 2.91: Boxplot of AQOL total score by age

AQOL by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

No significant differences were observed between participants by **location** for any of the AQOL dimensions and the AQOL total score.

Table 2.28: AQOL by location summary statistics and T-test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	Regional or remote	15	30.00	0.88	0.15	259.50	0.9539
	Metropolitan	35	70.00	1.00	0.22		
Social relationships	Regional or remote	15	30.00	0.84	0.22	291.00	0.5462
	Metropolitan	35	70.00	0.82	0.31		
Physical senses	Regional or remote	15	30.00	0.94	0.07	248.00	0.7598
	Metropolitan	35	70.00	0.94	0.14		
Psychological Wellbeing	Regional or remote	15	30.00	0.85	0.21	232.00	0.5233
	Metropolitan	35	70.00	0.89	0.10		
AQOL Total score	Regional or remote	15	30.00	0.55	0.23	245.50	0.7266
	Metropolitan	35	70.00	0.59	0.55		

Table 2.29: AQOL by location summary statistics and Wilcoxon test

Figure 2.92: Boxplot of AQOL independent living by location

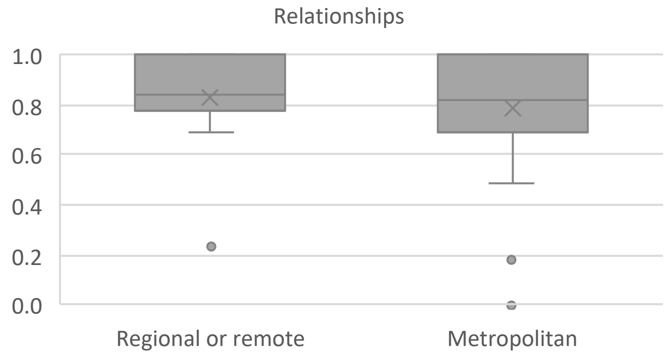

Figure 2.93: Boxplot of AQOL relationships by location

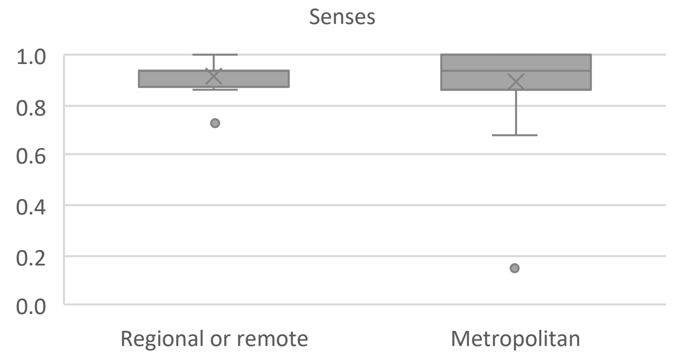

Figure 2.94: Boxplot of AQOL mental health by location

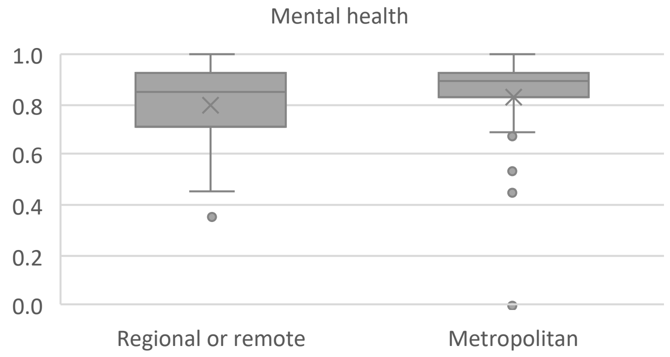

Figure 2.95: Boxplot of AQOL senses by location

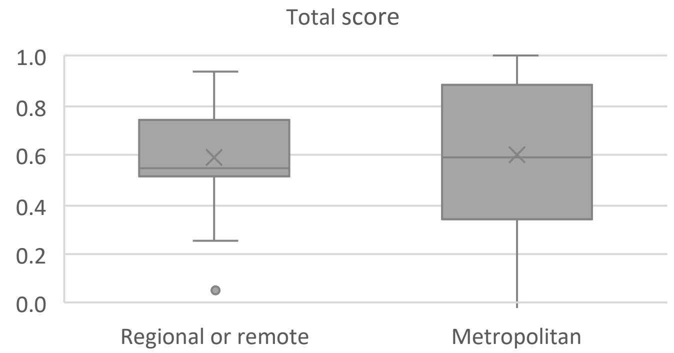

Figure 2.96: Boxplot of AQOL total score by location

AQOL by socioeconomic status

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

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

No significant differences were observed between participants by **socioeconomic status** for any of the AQOL dimensions and the AQOL total score.

Table 2.30: AQOL by socioeconomic status summary statistics and T-test

AQOL dimension	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
AQOL Total score	Mid to low socioeconomic status	25	50.00	0.58	0.30	-0.23	48	0.8164
	Higher socioeconomic status	25	50.00	0.60	0.30			

Table 2.31: AQOL by socioeconomic status summary statistics and Wilcoxon test

AQOL dimension	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Independent living	Mid to low socioeconomic status	25	50.00	1.00	0.17	322.00	0.8488
	Higher socioeconomic status	25	50.00	1.00	0.17		
Social relationships	Mid to low socioeconomic status	25	50.00	0.84	0.19	302.00	0.8434
	Higher socioeconomic status	25	50.00	0.82	0.31		
Physical senses	Mid to low socioeconomic status	25	50.00	0.91	0.08	242.00	0.1612
	Higher socioeconomic status	25	50.00	0.94	0.14		
Psychological Wellbeing	Mid to low socioeconomic status	25	50.00	0.89	0.10	331.00	0.7256
	Higher socioeconomic status	25	50.00	0.85	0.20		

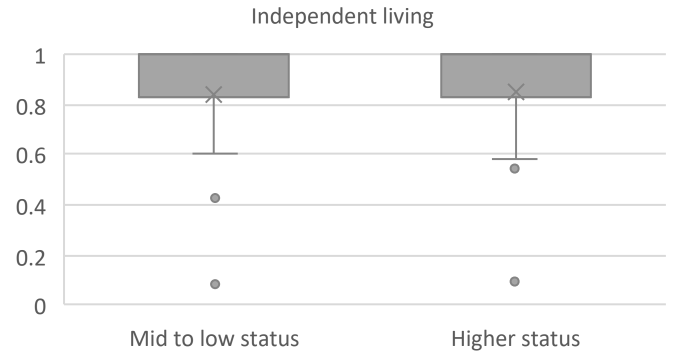

Figure 2.97: Boxplot of AQOL independent living by socioeconomic status

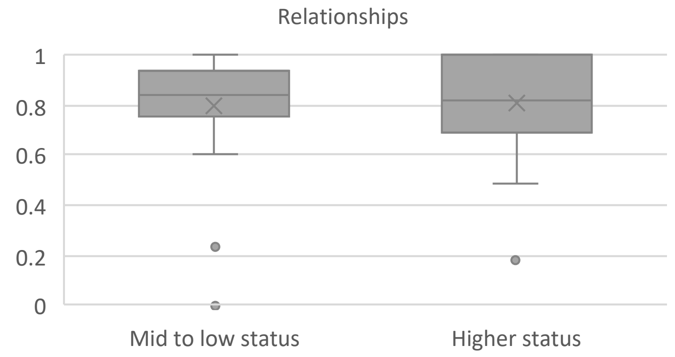

Figure 2.98: Boxplot of AQOL relationships by socioeconomic status

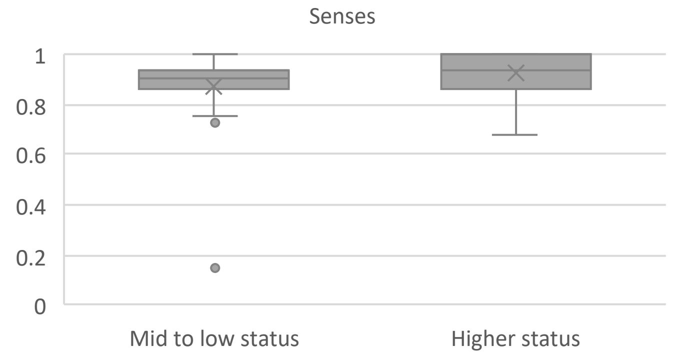

Figure 2.99: Boxplot of AQOL mental health by socioeconomic status

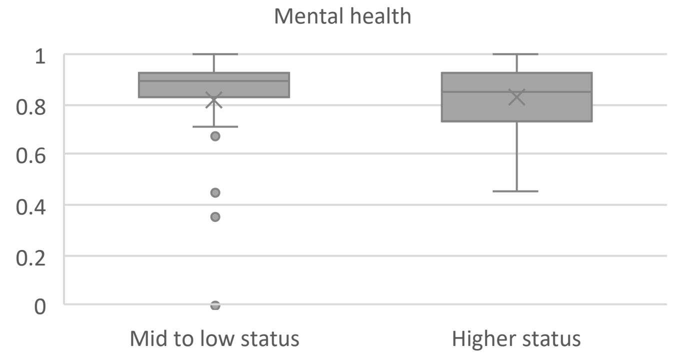

Figure 2.100: Boxplot of AQOL senses by socioeconomic status

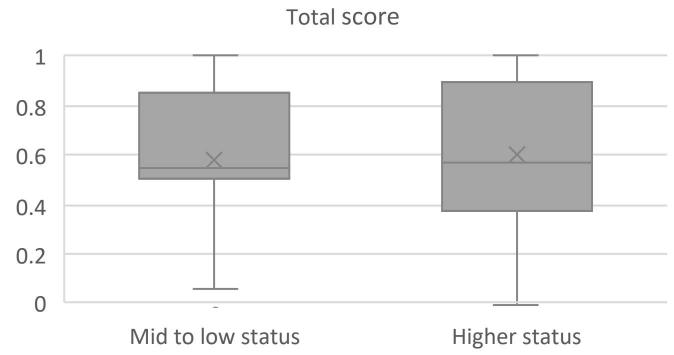

Figure 2.101: Boxplot of AQOL total score by socioeconomic status

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they consistently experienced before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed. There were 25 participants (50.00%) that had no symptoms before diagnosis. Participants had a maximum of 12 symptoms, and a median of 0.50 (IQR=4.75).

Symptoms before diagnosis

The most common symptoms before diagnosis were dizziness (n=13, 26.00%), weakness of face, arm, or leg (n=10, 20.00%), confusion (n=9, 18.00%), and trouble walking (n=9, 18.00%).

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”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 1 and 4, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was average” range. The symptoms with the worst quality of life were , weakness of face, arm, or leg and, lack of coordination, trouble seeing in one or both eyes, trouble speaking, nausea and vomiting.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select symptoms that they consistently experienced before diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis or triggered an event.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (74.47%). Others had no symptoms (21.28%), or had an unclear recollection of their symptoms or how they came to be diagnosed (2.13%).

The most common symptoms leading to diagnosis were shortness of breath (17.02%), headache (12.77%), irregular heartbeat (12.77%), fatigue (10.64%), dizziness or fainting (10.64%), and chest pain (8.51%). There were 10 participants that described not noticing any symptoms.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (51.06%), having symptoms and not seeking medical attention initially (23.40%), and having no symptoms or not noticing any symptoms before diagnosis (21.28%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed in an emergency department (55.32%), a linear diagnosis after being referred to a specialist from their general practitioner (25.53%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (8.51 %).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 19, 38.00%). There were 15 participants (30.00%) that were diagnosed less than one week after diagnostic tests, 9 participants (18.00%) diagnosed between 1 and 2 weeks, 1 participant (2.00%) diagnosed between 2 and 3 weeks, 4 participants (8.00%) diagnosed between 3 and 4 weeks, and 2 participants (4.00%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with . They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 12 diagnostic tests (median=2.00 , IQR=4.00). The most common tests were blood tests (n=33, 66.00%), electrocardiogram (n=23, 46.00%), Echocardiogram (n=15, 30.00%), and Brain CT or MRI (n=14, 28.00%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a Emergency doctor (n=17, 34.00%), and there were 15 participants (30.00%) given the diagnosis by a Cardiologist, 12 participants (24.00%) diagnosed by General practitioner (GP), and 4 participants (8.00%) by a Neurologist.

Participants were most commonly given their diagnosis in the Hospital (n=31, 63.27%), this was followed by General practice (GP) (n=10, 20.41%), and the Specialist clinic (n=8, 16.33%).

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in the table below.

Participants were diagnosed between 2001 to 2023. There were 27 participants (55.10%) that were diagnosed in the last five years.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (61.70%) and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (14.89%). Other themes included knowing a good amount about the condition at diagnosis with no reason provided (8.51%), and knowing about the condition due to professional background (6.38%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 19 participants (38.00%) who had enough support, 4 participants (8.00%) that had some support but it wasn't enough, and 27 participants (54.00%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 15 participants (35.71%) who had enough information, 19 participants (45.24%) that had Some information but it wasn't enough, and 8 participants (19.05%) had no information.

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 21 participants (42.00%) who had no out of pocket expenses, and 18 participants (36.00%) who did not know or could not recall. There were 4 participants (8.00%) that spent $1 to $250, 3 participants (6.00%) that spent between $251 to $500, and 4 participants (8.00%) that spent $501 or more.

Burden of diagnostic costs

For 23 participants (67.65%) the cost was slightly or not at all significant. For 7 participants (20.59%) the out-of-pocket expenses were somewhat significant, and for 4 participants (11.76%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Despite 19 participant having confirmed their LPa status, participants most commonly reported that they had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=43, 86.00%). There were 4 participants (8.00%) who brought up the topic with their doctor, and 3 participants (6.00%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=38, 76.00%). There were 10 participants (20.00%) who did not have these tests and were not interested in them, and a total of 2 participants (4.00%) that had biomarker tests.

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (31.91%), that they were monitoring their condition until there is an exacerbation or progression (23.40%), and that their prognosis was positive, that their condition is manageable (21.28 %). Other themes included that there was uncertainty around prognosis (19.15%), that it was a lifelong condition (14.89%), that they need to maintain a healthy lifestyle (12.77%), and that they would likely have a recurrence, or were in a cycle of recurrence (8.51%).

Biomarker tests

Participants were asked in the structured interview if they had any discussion about biomarkers that may be important to the management of their condition. The most common responses were that they did not have any tests and did not describe reasons (48.94%), that they did not have a test but would like to have this type of test (21.28%). This was followed by no test but family history was discussed (12.77 %), and had a test and management of condition was not changed (6.38%).

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they consistently experienced before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 25 participants (50.00%) that had no symptoms before diagnosis. Participants had a maximum of 12 symptoms, and a median of 0.50 (IQR=4.75).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=50)	Percent
No symptoms	25	50.00
1 to 2	5	10.00
3 to 4	7	14.00
5 to 6	4	8.00
7 to 8	5	10.00
9 or more	4	8.00

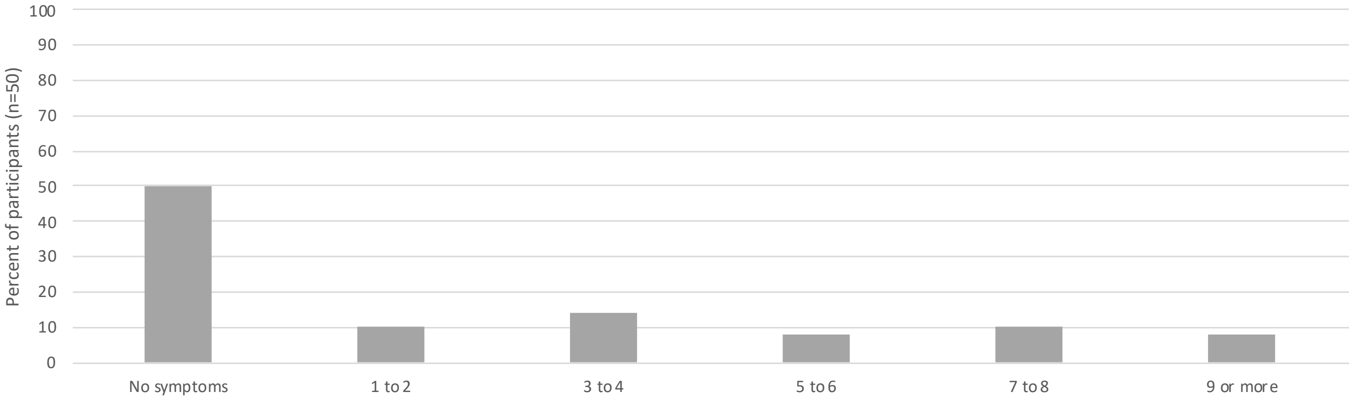

Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms, consistently experienced before diagnosis were dizziness (n=13, 26.00%), weakness of face, arm, or leg (n=10, 20.00%), confusion (n=9, 18.00%), and trouble walking (n=9, 18.00%).

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”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 1 and 4, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was average” range. The symptoms with the worst quality of life were, weakness of face, arm, or leg and, lack of coordination, trouble seeing in one or both eyes, trouble speaking, nausea and vomiting.

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=50)	Percent	Quality of life	
			Mean	SD
No symptoms	25	50.00	NA	NA
Dizziness	13	26.00	2.00	1.00
Weakness of your face, arm, or leg	10	20.00	1.00	1.75
Confusion	9	18.00	1.50	1.25
Trouble walking	9	18.00	2.00	2.00
Lack of coordination	8	16.00	1.00	1.00
Headache	8	16.00	2.00	1.25
Memory loss	7	14.00	2.00	2.00
Blurred or double vision	7	14.00	1.00	0.50
Fatigue	7	14.00	2.00	2.50
Breathlessness	7	14.00	2.00	2.75
Trouble seeing in one or both eyes	6	12.00	1.00	0.75
Weakness	6	12.00	3.00	2.75
Trouble speaking	5	10.00	1.00	2.00
Nausea and vomiting	5	10.00	1.00	2.00
Swollen ankles, legs or stomachc	4	8.00	NA	NA
Loss of appetite	4	8.00	NA	NA
Trouble understanding others talking	3	6.00	NA	NA
Weight gain	3	6.00	NA	NA
Persistent cough or wheeze	3	6.00	NA	NA

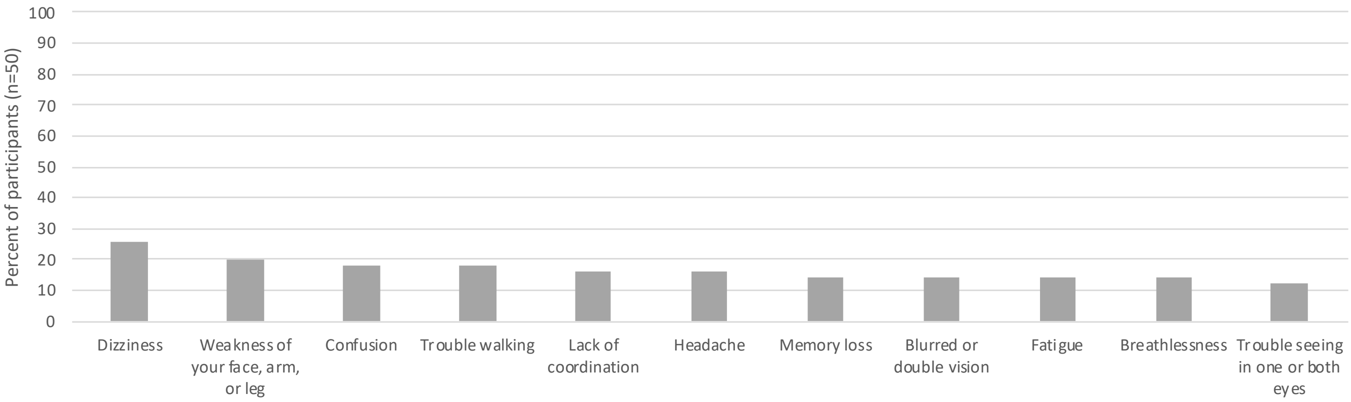

Figure 3.2: Symptoms before diagnosis

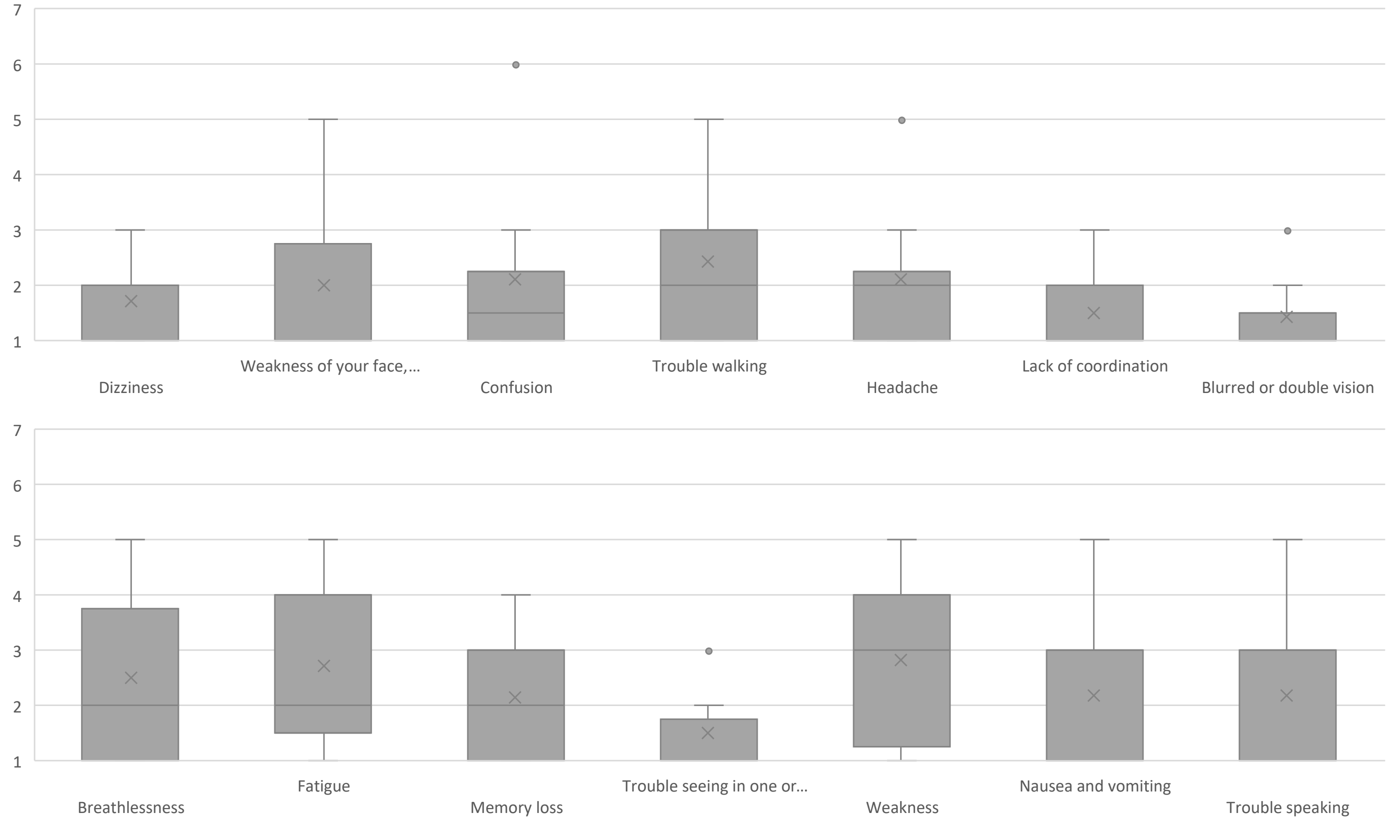

Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select symptoms that they consistently experienced before diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis or triggered an event.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (74.47%). Others had no symptoms (21.28%), or had an unclear recollection of their symptoms or how they came to be diagnosed (2.13%).

The most common symptoms leading to diagnosis were shortness of breath (17.02%), headache (12.77%), irregular heartbeat (12.77%), fatigue (10.64%), dizziness or fainting (10.64%), and chest pain (8.51%). There were 10 participants that described not noticing any symptoms.

Participant describes having no symptoms at the time

It's one of these like blood details or artifacts that where it just increases your risk factor and thankfully I have not had a cardiac event which can that's what it can lead to type of thing. So no, I haven't had any symptoms.
Participant 001_2023AUHBV

None at all. It was a circumstantial finding.
Participant 010_2023AUHBV

I didn't really have any symptoms until the actual stroke was happening.
Participant 047_2023AUHBV

I didn't notice any symptoms at all before I had a stroke. I went to sleep and I woke up and the whole right side of my body was paralysed. I laughed because I thought, "Pinch of the nerve," and then I realised that something more serious than that was going on. That's how I got a stroke.
Participant 048_2023AUHBV

Participant describes having shortness of breath which led to their diagnosis

Yeah, yes, it was breathlessness and just doing mild exercise caused me to become as you breath and my heart rate to go up more than you would expect, yeah.
Participant 017_2023AUHBV

I'll start at my 40s because that was my initial diagnosis, so in my 40s my daughter would have been about two, and there was one particular day when I was pushing the pram and I just felt like I couldn't breathe. I just literally had to hold onto the pram and just hold still for a few minutes until it passed, and then one particular day I think I had three episodes like that in the day, and I thought, "Okay, I need to go and see someone," because I do have a family history of AF from my brother had AF and my dad has AF. So I did, and initially I wore a Holter monitor for 48 hours and had the ECG and all that stuff, and then I went to a cardiologist and he diagnosed the VT.
Participant 023_2023AUHBV

Yeah. I was very short of breath. I've never been good at cardiac activity for most of my adult life. I've struggled with any kind of physical exercise. I've always put it down to the fact that I was just unfit. I always classed myself as an unfit person. I wasn't an overweight person. I'm not thin by any means, but I'm not chronically overweight or anything. There was one point where I was trying to get into the police force, so I was doing training. I was trying to run and improve my fitness.
Participant 036_2023AUHBV

The symptoms I had were just short of breath, bloating. Yeah, those were the main two. I didn't know it was heart failure obviously at the time until the doctor told me, but yeah I thought I was overweight.
Participant 038_2023AUHBV

Participant describes having headache which led to their diagnosis

Yes. I woke up that morning. I had a headache all day. I still went to work. It got worse by lunchtime, I was getting real bad, and then by I think one or two or three o'clock, I just couldn't see. I felt weird.
Participant 042_2023AUHBV

I recalled saying to her, "Got a bit of a headache, I might go and have to lie down, but call me tonight and let me know what we're doing." As I went to hang the phone up, I fell through a double glass window and that was the stroke.
Participant 050_2023AUHBV

Participant describes having irregular heartbeat which led to their diagnosis

I don't think there really wasn't mine. Like, no one's actually said what started it, but I had my third COVID vaccination and then within two or three days, the tachycardia started and it was just out of the way. All of a sudden my heart rate was 150 from just sitting on the couch. It just zoomed up and that's where it stayed.
Participant 008_2023AUHBV

Yeah. I had no idea. Because mine was pregnancy induced, every symptom that I had was a pregnancy symptom. Like a normal pregnancy symptom, so my symptoms were, I had difficulty breathing, and I had an elevated heart rate and swollen ankles. Which all three were very much just normal parts of pregnancy. And it was only the day after my little boy was born that I went, "Oh, I'm still struggling to breathe." And so then I mentioned it to the nurse saying, "It's probably nothing but I'm just having a little difficulty breathing." And then I was diagnosed the day following that.
Participant 035_2023AUHBV

Participant describes having fatigue which led to their diagnosis

I was exercising a lot, doing some extra labour work than normal and I was feeling. Extremely run down and exhausted, not recovering well from it that that was basically what started is being fatigue, extreme fatigue after slightly increasing activity.
Participant 003_2023AUHBV

I would say my early symptom without being aware of it was being tired.
Participant 005_2023AUHBV

I don't think I had any symptoms. I was a runner and the day before I had my condition I actually was actually really tired and didn't do much that day. Probably say I didn't feel well but didn't feel sick. Just it's, you know, it's just something that in hindsight I'd thought about. And then the next day I was still quite tired and made myself go for a run thinking that it would up my energy a little bit.
Participant 009_2023AUHBV

I had no symptoms at all. I had a massive heart attack... No warning whatsoever, except that I was very tired the night before.
Participant 033_2023AUHBV

Participant describes having dizziness or fainting which led to their diagnosis

I noticed that I had had dizziness for some time, and I had been monitored, and nothing came of it because during the monitor, nothing was happening.
Participant 034_2023AUHBV

I had dizziness and I kept falling over. I kept vomiting and my dizziness had increased a lot.
Participant 039_2023AUHBV

Participant describes having chest pain which led to their diagnosis

So I didn't really notice much in the initial stages. It basically came down to the fact where I had chest pain one afternoon. I basically just wandered into the hospital. Said to them that I had chest pain, which was traveling. It was actually traveling up into the jaw, through the chest, down my left leg, but down my right arm. Yeah. At the time, I think my blood pressure was 280 / 140, yeah.
Participant 018_2023AUHBV

I had pins and needles in in my arms and I had similar to to like a I was getting short pains into my chest area which. That was basically all the all of the symptoms that I know of now that would have been telling signs.
Participant 006_2023AUHBV

Table 3.3: Symptom recall

Symptom recall	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Symptom recall strong	35	74.47	14	77.78	21	72.41	**4**	**44.44**	12	70.59	**19**	**90.48**	21	77.78	14	70.00
No Symptoms	10	21.28	3	16.67	7	24.14	**4**	**44.44**	5	29.41	**1**	**4.76**	5	18.52	5	25.00
Symptom recall unclear	1	2.13	1	5.56	0	0.00	1	11.11	0	0.00	0	0.00	1	3.70	0	0.00
No particular comment	3	6.38	1	5.56	2	6.90	**2**	**22.22**	0	0.00	1	4.76	0	0.00	3	15.00

Symptom recall	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Symptom recall strong	35	74.47	20	76.92	15	71.43	16	66.67	19	82.61	**8**	**53.33**	27	84.38	18	72.00	17	77.27
No Symptoms	10	21.28	6	23.08	4	19.05	6	25.00	4	17.39	**7**	**46.67**	**3**	**9.38**	7	28.00	3	13.64
Symptom recall unclear	1	2.13	0	0.00	1	4.76	1	4.17	0	0.00	0	0.00	1	3.13	0	0.00	1	4.55
No particular comment	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	0	0.00	3	9.38	0	0.00	3	13.64

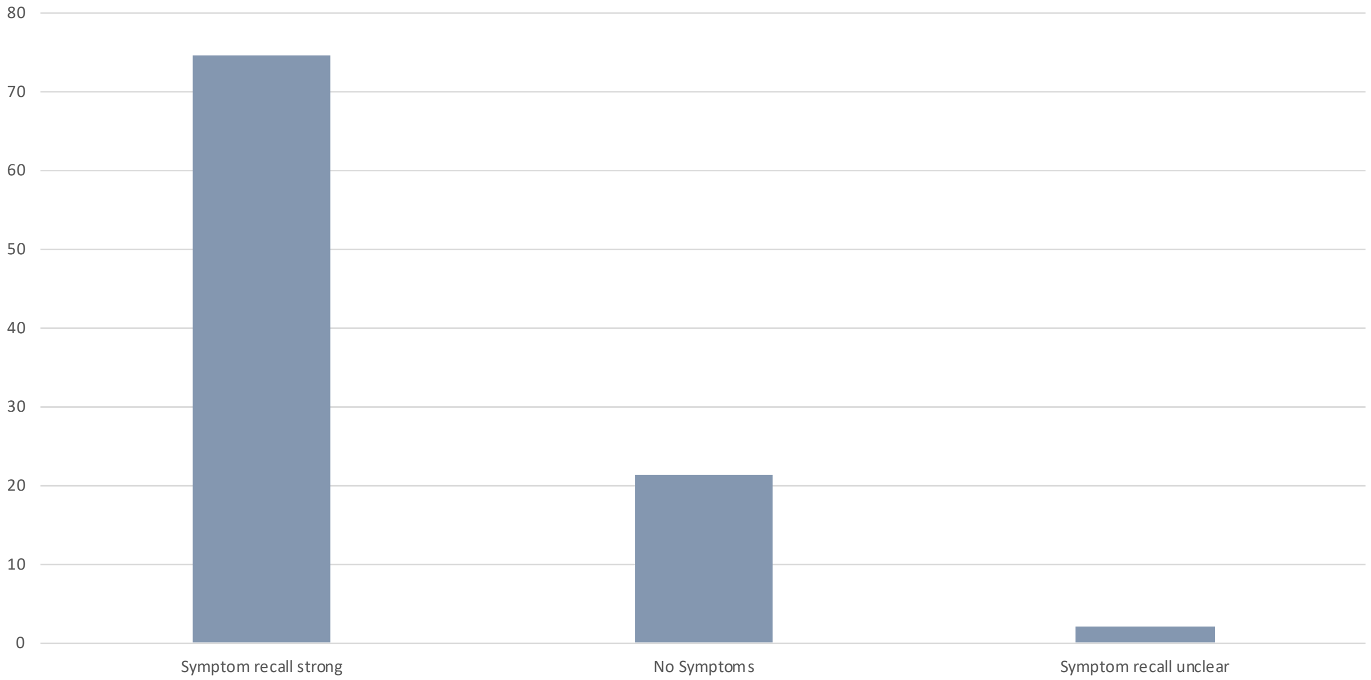

Figure 3.4: Symptom recall

Symptom recall	Reported less frequently	Reported more frequently
Symptom recall strong	High cholesterol under 50 years of age Regional or remote	Heart conditions
No Symptoms	Heart conditions Metropolitan	High cholesterol under 50 years of age Regional or remote

Table 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes having no symptoms	10	21.28	3	16.67	7	24.14	4	44.44	5	29.41	1	4.76	5	18.52	5	25.00
Participant describes having shortness of breath which led to their diagnosis	8	17.02	3	16.67	5	17.24	1	11.11	0	0.00	7	33.33	4	14.81	4	20.00
Participant describes having headache which led to their diagnosis	6	12.77	0	0.00	6	20.69	0	0.00	6	35.29	0	0.00	2	7.41	4	20.00
Participant describes having irregular heartbeat which led to their diagnosis	6	12.77	4	22.22	2	6.90	2	22.22	0	0.00	4	19.05	3	11.11	3	15.00
Participant describes having fatigue which led to their diagnosis	5	10.64	0	0.00	5	17.24	1	11.11	2	11.76	2	9.52	5	18.52	0	0.00
Participant describes having dizziness or fainting which led to their diagnosis	5	10.64	4	22.22	1	3.45	2	22.22	1	5.88	2	9.52	3	11.11	2	10.00
Participant describes having chest pain which led to their diagnosis	4	8.51	4	22.22	0	0.00	0	0.00	0	0.00	4	19.05	3	11.11	1	5.00

Symptoms leading to diagnosis	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes having no symptoms	10	21.28	6	23.08	4	19.05	6	25.00	4	17.39	7	46.67	3	9.38	7	28.00	3	13.64
Participant describes having shortness of breath which led to their diagnosis	8	17.02	5	19.23	3	14.29	5	20.83	3	13.04	2	13.33	6	18.75	2	8.00	6	27.27
Participant describes having headache which led to their diagnosis	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	0	0.00	6	18.75	4	16.00	2	9.09
Participant describes having irregular heartbeat which led to their diagnosis	6	12.77	4	15.38	2	9.52	5	20.83	1	4.35	2	13.33	4	12.50	3	12.00	3	13.64
Participant describes having fatigue which led to their diagnosis	5	10.64	5	19.23	0	0.00	1	4.17	4	17.39	2	13.33	3	9.38	2	8.00	3	13.64
Participant describes having dizziness or fainting which led to their diagnosis	5	10.64	3	11.54	2	9.52	2	8.33	3	13.04	3	20.00	2	6.25	4	16.00	1	4.55
Participant describes having chest pain which led to their diagnosis	4	8.51	1	3.85	3	14.29	3	12.50	1	4.35	0	0.00	4	12.50	2	8.00	2	9.09

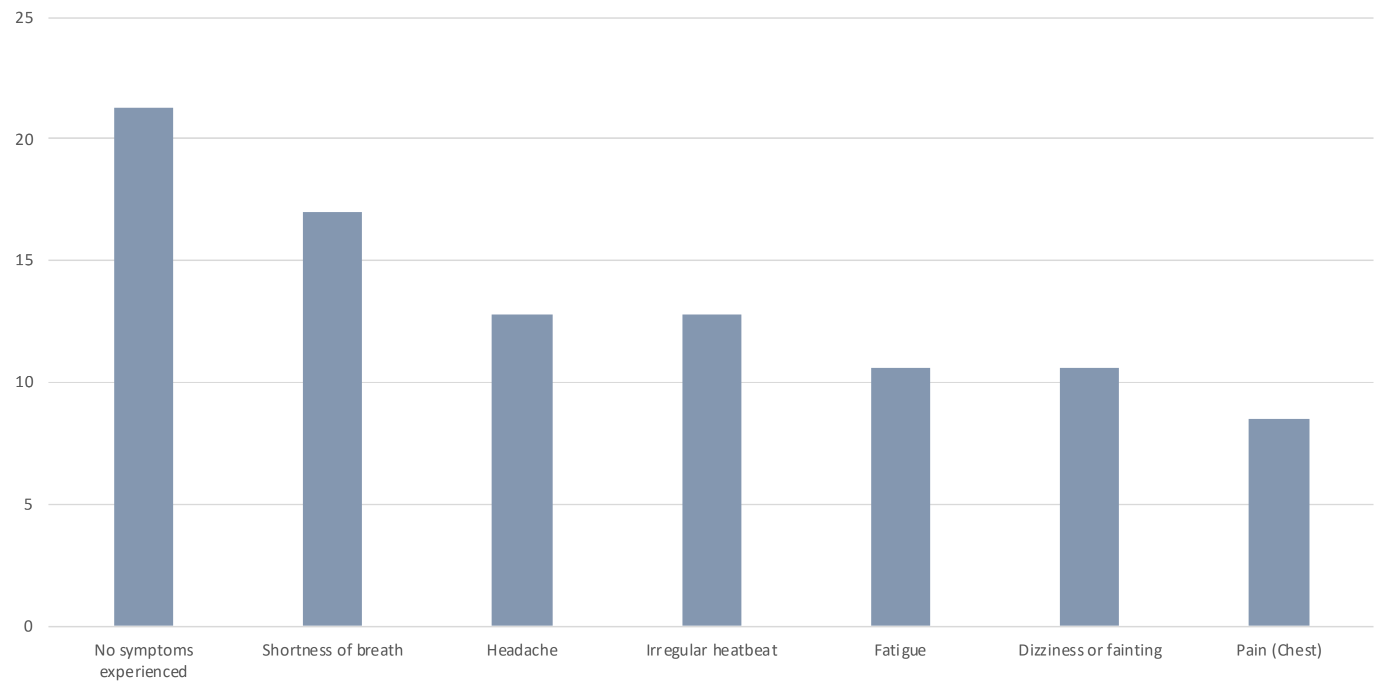

Figure 3.5: Symptoms leading to diagnosis

Table 3.5: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having no symptoms	Heart conditions Metropolitan	High cholesterol under 50 years of age Regional or remote
Participant describes having shortness of breath which led to their diagnosis	Blood vessel conditions	Heart conditions Higher socioeconomic status
Participant describes having headache which led to their diagnosis	Had LP(a) test High cholesterol under 50 years of age Heart conditions Regional or remote	Blood vessel conditions
Participant describes having irregular heartbeat which led to their diagnosis	Blood vessel conditions	-
Participant describes having fatigue which led to their diagnosis	Had LP(a) test 6 to 11 other conditions Male	-
Participant describes having dizziness or fainting which led to their diagnosis	-	Had LP(a) test High cholesterol under 50 years of age
Participant describes having chest pain which led to their diagnosis	-	Had LP(a) test Heart conditions

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (51.06%), having symptoms and not seeking medical attention initially (23.40%), and having no symptoms or not noticing any symptoms before diagnosis (21.28 %).

Participant describes having symptoms and seeking medical attention relatively soon

I don't think there really wasn't mine. Like, no one's actually said what started it, but I had my third COVID vaccination and then within two or three days, the tachycardia started and it was just out of the way. All of a sudden my heart rate was 150 from just sitting on the couch. It just zoomed up and that's where it stayed. Well, I went down to my local GP and they took me into the nurses station and hooked me up to an ECG.
Participant 008_2023AUHBV

I basically just wandered into the hospital. Said to them that I had chest pain, which was traveling. It was actually traveling up into the jaw, through the chest, down my left leg, but down my right arm. Yeah. At the time, I think my blood pressure was 280 / 140, yeah.
Participant 018_2023AUHBV

Obviously, I was quite ill for a period. I should've gone to hospital straight away and I didn't unfortunately. I didn't go to the doctor until 24 hours later. I was very ill in those 24 hours. I finally went to the doctor and the doctor basically sent me to Emergency immediately. Then they did all the tests and I think they diagnosed it in Emergency within the first couple

of hours. Then, I woke up the following day on the stroke ward in LOCATION METROPOLITAN and the neurologist came and saw me that morning and advised me that I had a double occipital lobe stroke.
Participant 043_2023AUHBV

Participant describes having symptoms and not seeking medical attention initially

Right, so I just happened to be at the doctor getting scripts filled. I was just 53 at the time and had pretty good relationship with my doctor and we just got chatting about things and I happened to mention to her that my father had a heart attack at 53 and everyone always says, you know, you're so like your dad. So I said, you know, you know, should I be concerned or anything? And she said, have you any reason to be? And I said no, absolutely not. And so she said, well, there's no, there's no point. And she said we can do a stress test if you like. So I said, oh, well, I'm not go and do that.... So he said I'd refer you to a cardiologist. And I said, oh, I might just do that. I'm sure that was my father sitting on my shoulder and go and do that. Anyway, the cardiologist took me in and he said I don't think there's anything to be concerned about either. And so he did that. And then he came out a short time later and he actually apologized to me, said I am so sorry. And you have major blockages in major arteries.
Participant 005_2023AUHBV

Yeah. I was very short of breath. I've never been good at cardiac activity for most of my adult life. I've struggled with any kind of physical exercise. I've always put it down to the fact that I was just unfit. I always classed myself as an unfit person. I wasn't an overweight person. I'm not thin by any means, but I'm not chronically overweight or anything. There was one point where I was trying to get into the police force, so I was doing training. I was trying to run and improve my fitness.
Participant 036_2023AUHBV

I was exercising a lot, doing some extra labour work than normal and I was feeling. Extremely run down and exhausted, not recovering well from it that that was basically what started is being fatigue, extreme fatigue after slightly increasing activity. After my children were born, I became more interested in health and what we were eating and I think I had a random blood test in it was like 2016 and it it it said high cholesterol...I was feeling healthy.
Participant 003_2023AUHBV

Participant describes having no symptoms or not noticing any symptoms before diagnosis

So I didn't have any signs or symptoms. It was just picked up in a general health check, my annual health check on my blood test.
Participant 020_2023AUHBV

Yeah. So for me it was quite different. So I didn't have any symptoms at all. I heart condition was picked up after I had a serious motorcycle accident and they noticed that my ECG's were quite abnormal. Obviously while they've they've caught me on the table doing whatever they got to do and that's that's when they found out that that I had what they call a right bundle branch blockage and and all that and then put me onto a cardiologist from there.
Participant 021_2023AUHBV

Table 3.6: Seeking medical attention

Seeking medical attention	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes having symptoms and seeking medical attention relatively soon	24	51.06	8	44.44	16	55.17	**1**	**11.11**	10	58.82	**13**	**61.90**	14	51.85	10	50.00
Participant describes having symptoms and not seeking medical attention initially	11	23.40	6	33.33	5	17.24	3	33.33	**2**	**11.76**	6	28.57	7	25.93	4	20.00
Participant describes having no symptoms or not noticing any symptoms before diagnosis	10	21.28	3	16.67	7	24.14	**4**	**44.44**	5	29.41	**1**	**4.76**	5	18.52	5	25.00
No particular comment	2	4.26	1	5.56	1	3.45	1	11.11	0	0.00	1	4.76	1	3.70	1	5.00

Seeking medical attention	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes having symptoms and seeking medical attention relatively soon	24	51.06	13	50.00	11	52.38	10	41.67	14	60.87	**4**	**26.67**	**20**	**62.50**	14	56.00	10	45.45
Participant describes having symptoms and not seeking medical attention initially	11	23.40	7	26.92	4	19.05	6	25.00	5	21.74	4	26.67	7	21.88	4	16.00	7	31.82
Participant describes having no symptoms or not noticing any symptoms before diagnosis	10	21.28	6	23.08	4	19.05	6	25.00	4	17.39	**7**	**46.67**	**3**	**9.38**	7	28.00	3	13.64
No particular comment	2	4.26	0	0.00	2	9.52	2	8.33	0	0.00	0	0.00	2	6.25	0	0.00	2	9.09

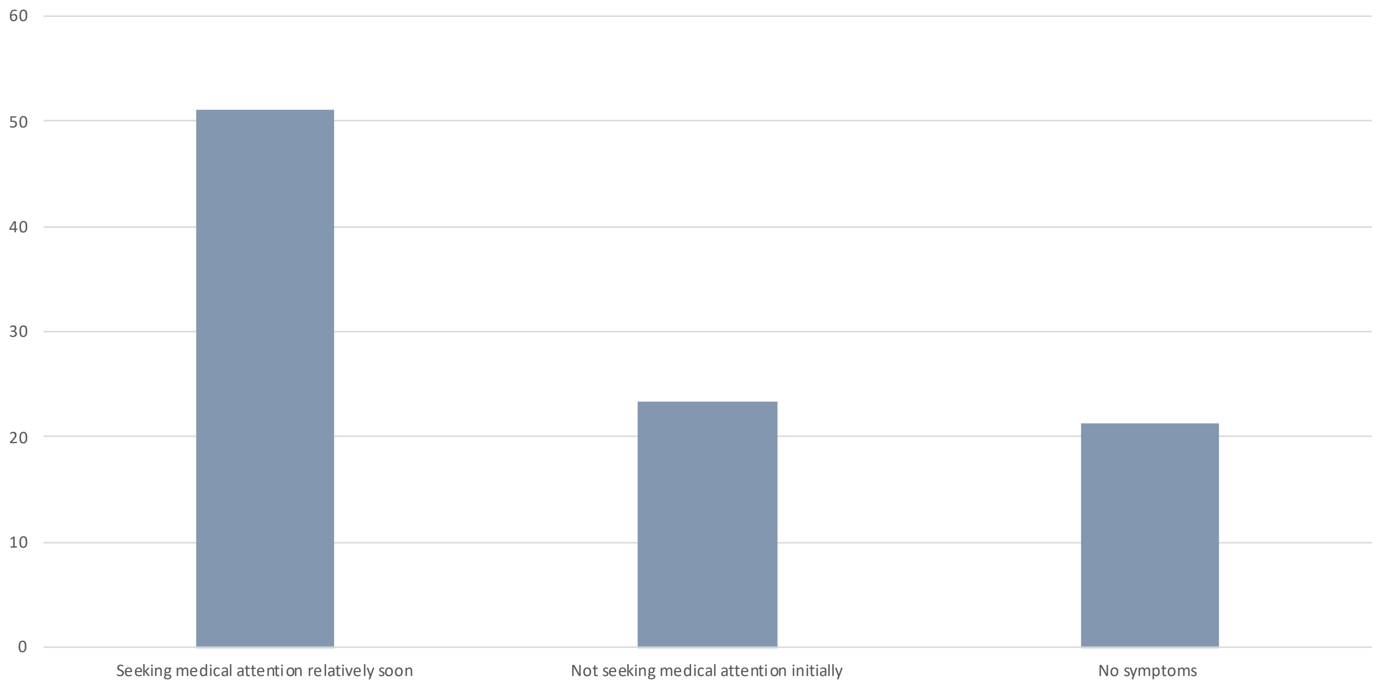

Figure 3.6: Seeking medical attention

Table 3.7: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	High cholesterol under 50 years of age Regional or remote	Heart conditions Metropolitan
Participant describes having symptoms and not seeking medical attention initially	Blood vessel conditions	-
Participant describes having no symptoms or not noticing any symptoms before diagnosis	Heart conditions Metropolitan	High cholesterol under 50 years of age Regional or remote

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed in an emergency department (55.32%), a linear diagnosis after being referred to a specialist from their general practitioner (25.53%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (8.51 %).

Participant describes being diagnosed in an emergency department

I kept vomiting and my dizziness had increased a lot. I couldn't hold my baby because that's a newborn baby. I couldn't hold it. I went to the doctor's. I went to the hospital. Our doctors are in the hospital. My family has a history of stroke. I knew that I was possibly having a stroke. had a CT scan done after going to the hospital originally where they said, "You've got an aneurysm." That's when I was rushed there of course. From there I had an angiogram. Participant 039_2023AUHBV

Yes. I had high blood pressure, very high blood pressure. I collapsed when I had the stroke, and I was diagnosed in the A&E department of the hospital. Participant 040_2023AUHBV

I was at work. My boss called an ambulance straight away. They took me to hospital straight away by ambulance. Then ambulance people took me there. They did a lot of tests. I think it was six hours of waiting and then they told me, "Yes, you've had a stroke."
Participant 042_2023AUHBV

I had a doctor's appointment in about three quarters of an hour, got out of the pool, got into the shower, went to wash my hair, started washing my hair, and an elephant sat on my chest. It was a massive heart attack. By the time the ambulance stabilised me, I had three ambulances here, it took them a while to stabilise me. I was taken to NAME HOSPITAL. The entire time in the ambulance they were trying to get permission to give me the drug. I got to the base, and I don't recall much about it except it was mad pain, of course, and I was there all night in massive pain. I had morphine pouring in. That was on a Wednesday. The Thursday morning the cardiologist, whom I'd never met before, came to me and said, "You've had a

massive heart attack and you need stents. Unfortunately today's list is full. You'll have to wait until the following Tuesday."
Participant 033_2023AUHBV

Participant describes a linear diagnosis after being referred to a specialist from their general practitioner

Well, the diagnosis came from visiting my cardiologist, and he indicated to me that I had atrial fibrillation, I had tachycardia. I had cardiovascular disease, and that's just to name a few.
Participant 031_2023AUHBV

There was a doctor there that asked me if I had a heart problem. It was during one of my hospital visits. He commented on my heart. I was almost due to have the baby, so I was more concerned with the baby at that point and didn't really think about my own health as such. He said, "Do you have a heart problem?" And, I said, "No." He said to me at the time, and I didn't remember this until all of this came up, but he said to me, "I'd like you to see a cardiologist after you've had the baby just to have a check-up." I sort of went, "Yeah. Yeah. Okay." Then it left my mind and I never thought anything of it again. It was just some doctor in the hospital he wasn't my doctor. Yeah, so anyway the doctor said, "You've got a heart murmur we're going to send you for some more tests." That just led from one thing to another, and obviously the diagnosis of HOCM. I was just very short of breath. Sorry I can't remember the original question.
Participant 036_2023AUHBV

I went back to my daughter's house and thought I suppose I should do something about this because I couldn't stop them, so I rang her and she came home and I went down to my GP, or the kids' GP because they live out on the other side of LOCATION METROPOLITAN. And he sent me for a blood test to see if I'd had a heart attack and the palpitations stopped so I drove home. The results were sent to my GP over on this side of LOCATION METROPOLITAN, and he said, "Nothing to worry about." The GP over where my daughter lives rang me up and said, "Get yourself in here." He sent me off to a cardiologist who said that I had ischemic heart disease and I needed to have an angiogram
Participant 037_2023AUHBV

Participant describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms

So I didn't have any signs or symptoms. It was just picked up in a general health check, my annual health check on my blood test
Participant 020_2023AUHBV

Yeah, it was more of some of those routine year yearly GP visits and then they ordered those, you know, blood panel tests. Those were when my blood results were looking starting to look abnormal, especially you know like with the LDL for example.
Participant 001_2023AUHBV

Table 3.8: Diagnostic pathway

Diagnostic pathway	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being diagnosed in an emergency department	26	55.32	**13**	**72.22**	**13**	**44.83**	**4**	**44.44**	11	64.71	11	52.38	14	51.85	12	60.00
Participant describes a linear diagnosis after being referred to a specialist from their general practioner	12	25.53	3	16.67	9	31.03	**0**	**0.00**	4	23.53	**8**	**38.10**	9	33.33	**3**	**15.00**
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	4	8.51	1	5.56	3	10.34	**4**	**44.44**	0	0.00	0	0.00	2	7.41	2	10.00
Participant describes a complex diagnosis, needing to see multiple specialists before diagnosis	1	2.13	0	0.00	1	3.45	0	0.00	1	5.88	0	0.00	0	0.00	1	5.00
No particular comment	4	8.51	1	5.56	3	10.34	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00

Diagnostic pathway	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being diagnosed in an emergency department	26	55.32	15	57.69	11	52.38	12	50.00	14	60.87	**10**	**66.67**	16	50.00	16	64.00	10	45.45
Participant describes a linear diagnosis after being referred to a specialist from their general practioner	12	25.53	6	23.08	6	28.57	6	25.00	6	26.09	3	20.00	9	28.13	5	20.00	7	31.82
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	4	8.51	3	11.54	1	4.76	4	16.67	0	0.00	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes a complex diagnosis, needing to see multiple specialists before diagnosis	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00
No particular comment	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	1	6.67	3	9.38	0	0.00	4	18.18

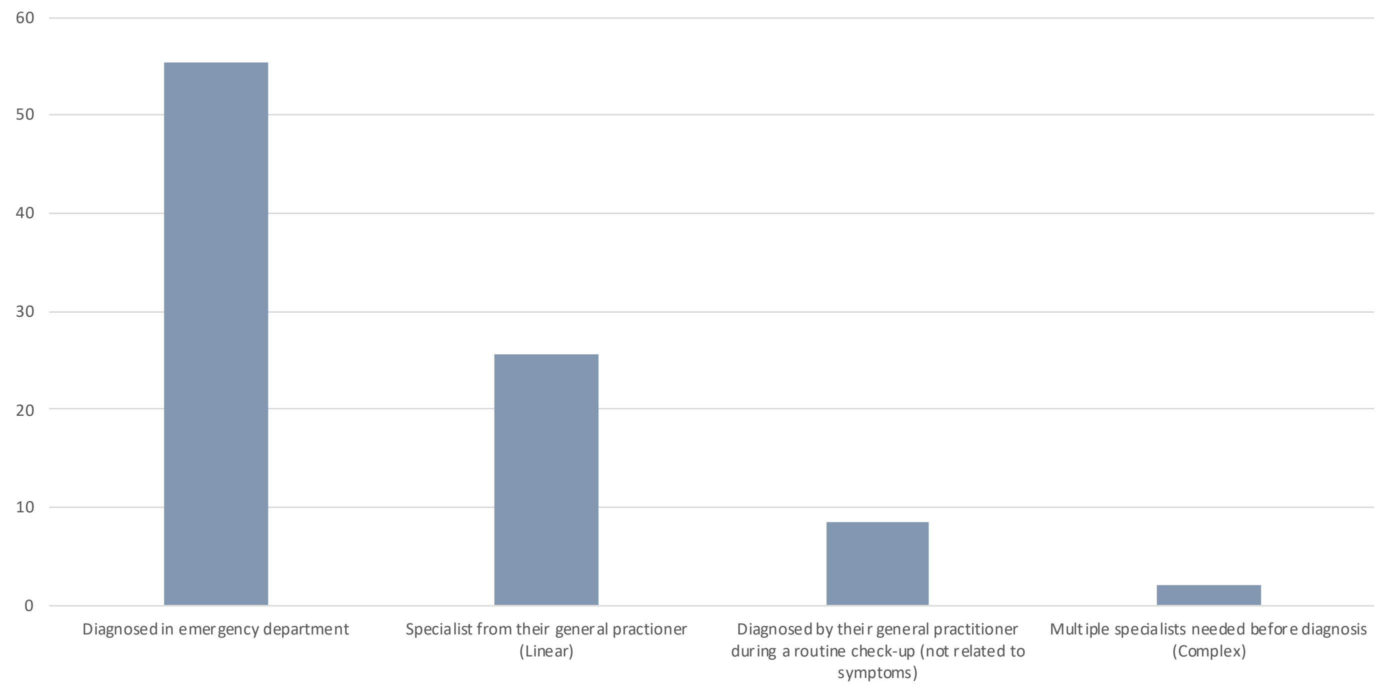

Figure 3.7: Diagnostic pathway

Table 3.9: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed in an emergency department	Did not had LP(a) test High cholesterol under 50 years of age	Had LP(a) test Regional or remote
Participant describes a linear diagnosis after being referred to a specialist from their general practioner	High cholesterol under 50 years of age 6 to 11 other conditions	Heart conditions
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	-	High cholesterol under 50 years of age

Timing of diagnosis

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 19, 38.00%). There were 15 participants (30.00%) that were diagnosed less than one week after diagnostic tests, 9 participants (18.00%) diagnosed between 1 and 2 weeks, 1 participant (2.00%) diagnosed between 2 and 3 weeks, 4 participants (8.00%) diagnosed between 3 and 4 weeks, and 2 participants (4.00%) diagnosed more than four weeks after diagnostic testing.

Table 3.10: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=50)	Percent
Diagnosed immediately at the consultation	19	38.00
Less than 1 week	15	30.00
Between 1 and 2 weeks	9	18.00
Between 2 and 3 weeks	1	2.00
4 weeks or more	4	8.00
Not sure	2	4.00

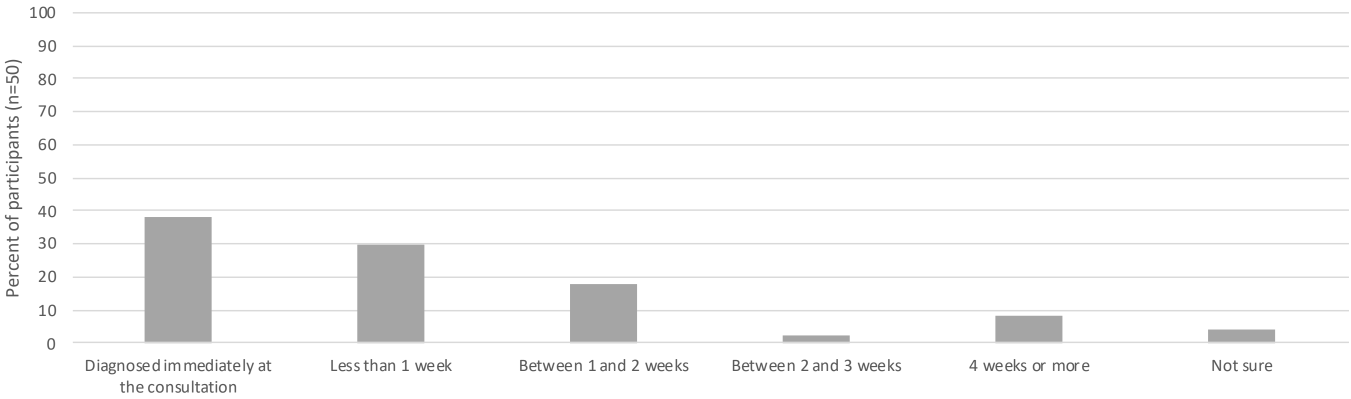

Figure 3.8: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis. They could choose from a set list of diagnostic tests and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 12 diagnostic tests (median=2.00 , IQR=4.00). The most common tests were blood tests (n=33, 66.00%), electrocardiogram (n=23, 46.00%), Echocardiogram (n=15, 30.00%), and Brain CT or MRI (n=14, 28.00%).

Table 3.11: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=50)	Percent
1 to 2	27	54.00
3 to 4	6	12.00
5 to 6	8	16.00
7 or more	9	18.00

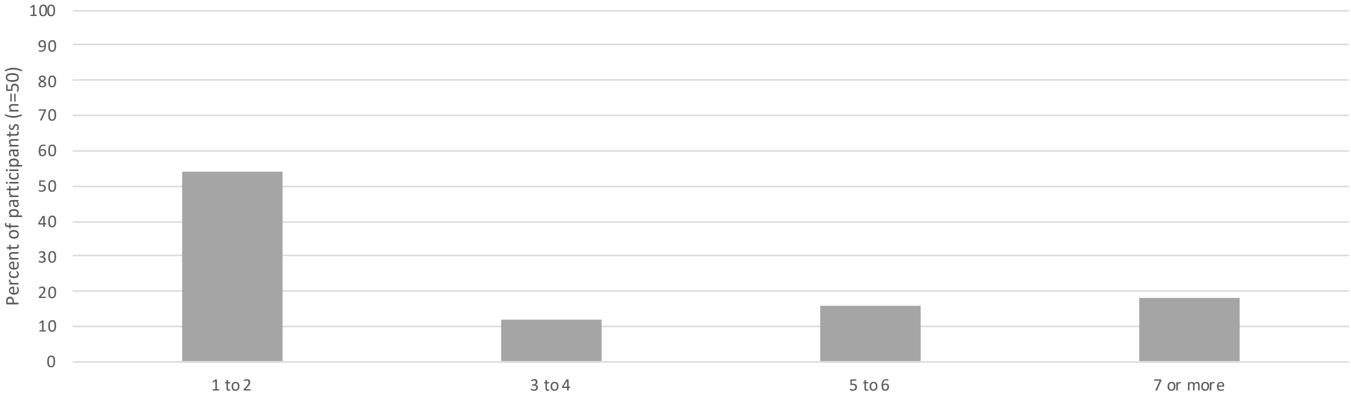

Figure 3.9: Number of diagnostic tests

Table 3.12: Diagnostic tests

Diagnostic tests	Number (n=50)	Percent
Blood test	33	66.00
Electrocardiogram (ECG)	23	46.00
Echocardiogram (Echo) (An ultrasound of your heart)	15	30.00
Brain CT or MRI	14	28.00
Coronary angiogram	10	20.00
Blood pressure monitoring	9	18.00
Physical exam	9	18.00
Assessment for rehabilitation	7	14.00
Communication assessment	7	14.00
Neuropsychological or cognitive assessment	7	14.00
Holter monitor (ECG) (A wearable device measuring your heart activity)	6	12.00
Swallowing tests	6	12.00
Screened for cognitive and perceptual deficits	5	10.00

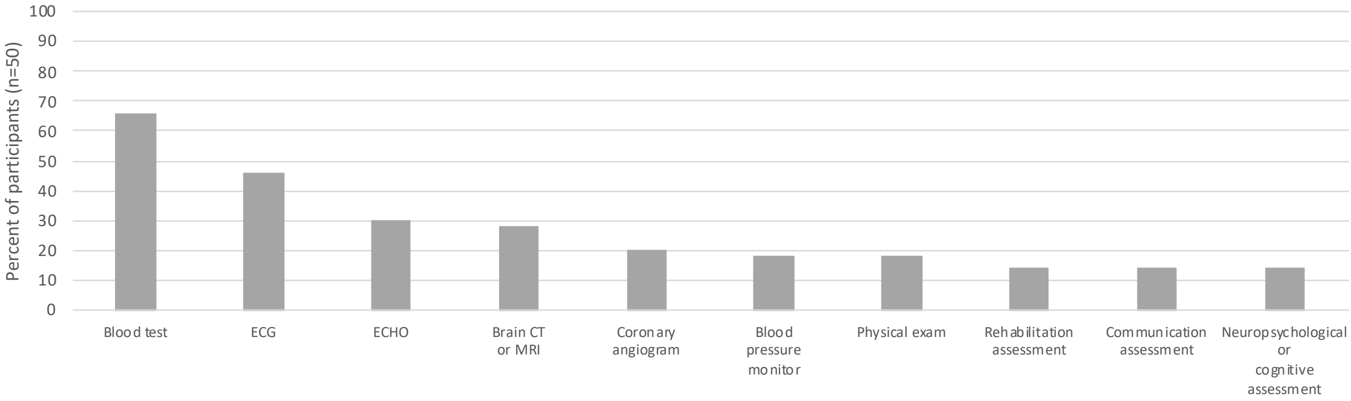

Figure 3.10: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a Emergency doctor (n=17, 34.00%), and there were 15 participants (30.00%) given the diagnosis by a Cardiologist, 12 participants (24.00%) diagnosed by General practitioner (GP), and 4 participants (8.00%) by a Neurologist.

Participants were most commonly given their diagnosis in the Hospital (n=31, 63.27%), this was followed by General practice (GP) (n=10, 20.41%), and the Specialist clinic (n=8, 16.33%).

Table 3.13: Diagnosis provider

Health professional gave diagnosis	Number (n=50)	Percent
Emergency doctor	17	34.00
Cardiologist	15	30.00
General practitioner (GP)	12	24.00
Neurologist	4	8.00
Other specialist doctor	2	4.00

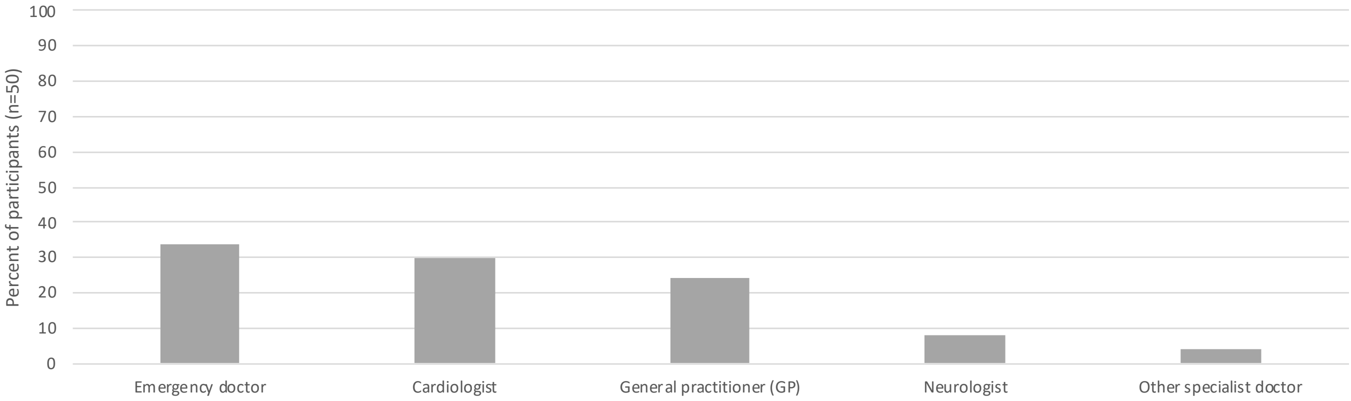

Figure 3.11: Diagnosis provider

Table 3.14: Diagnosis location

Location of diagnosis	Number (n=49)	Percent
General practice (GP)	10	20.41
Specialist clinic	8	16.33
Hospital	31	63.27

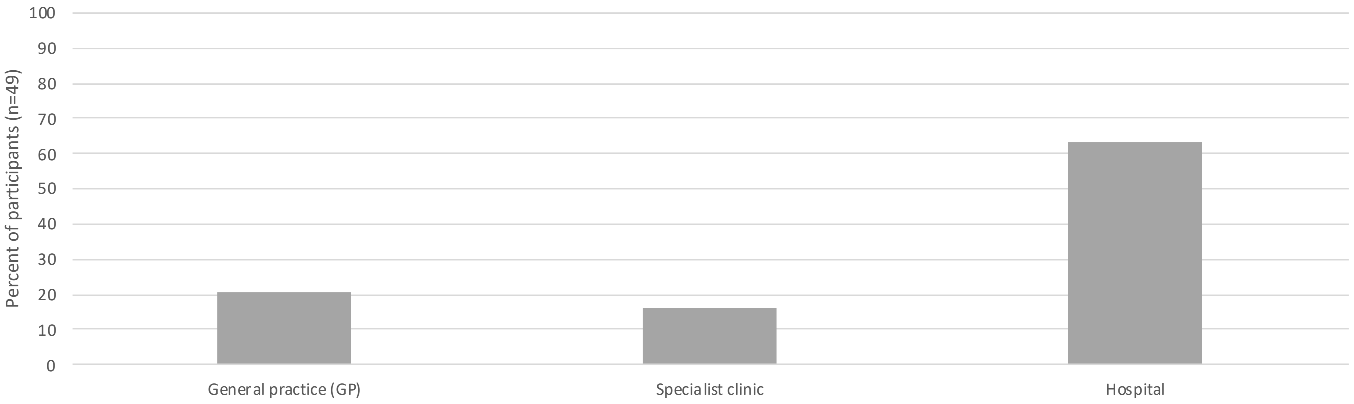

Figure 3.12: Diagnosis location

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in the table below.

Participants were diagnosed between 2001 to 2023. There were 27 participants (55.10%) that were diagnosed in the last five years.

Table 3.15 Year of diagnosis

Year of diagnosis	Number (n=49)	Percent
Before 2018	26	53.06
2018 to 2019	8	16.33
2020 to 2023	15	30.61

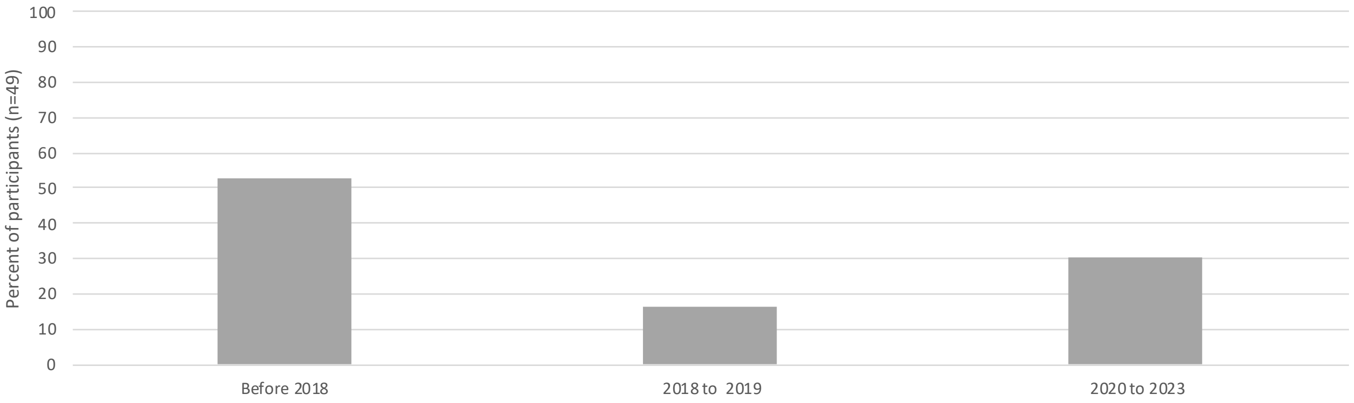

Figure 3.13: Year of diagnosis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (61.70%) and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (14.89%). Other themes included knowing a good amount about the condition at diagnosis with no reason provided (8.51%), and knowing about the condition due to professional background (6.38%).

Participant describes knowing nothing or very little about the condition at diagnosis

Absolutely nothing. I was fit, I was going to the gym, I was eating properly and doing all the right things, and I thought I'd be okay, but I have a family history of heart problems, which sort of lingered in the background all the time.
Participant 031_2023AUHBV

Very little. In fact, not very much at all. It wasn't on my radar. I simply considered that stroke was a condition that elderly people experienced. I knew nothing about the technical aspects or the medical aspects.
Participant 045_2023AUHBV

Nothing really, not much. When they told me that I had it, they basically tried to get rid of me out of the ER straight away. I insisted I had no one to go home to because my partner and I weren't in a serious relationship, and I stayed overnight, and then my mum came and got me. She lived in LOCATION REGIONAL so I wouldn't let her drive up that night because she was distraught. I made her wait until the following morning, and then she took me home.
Participant 046_2023AUHBV

Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition

It it was assumed normal for my family, but not of no concern. So knowing my mom and my sister have high cholesterol, it was just, oh, well, that's because you related. So it was very, it was not an issue.
Participant 003_2023AUHBV

No, no, no. But I knew it was, it's in the family. So that was that was OK. You know, I knew it was in the town.

My, my mother died of a heart attack. Her mother died of a heart attack. Her brother died of a heart attack. My grandparents died of a heart attack. My father's brother died of a heart attack. So like everybody, everybody but my father died of a heart attack. He had a brain tumor. Yeah. Wow. You know it's it's very functionable.
Participant 004_2023AUHBV

I knew a fair bit because my eldest brother had a triple bypass. I knew about cardiac artery disease to to a certain extent. And being the age that you are, you sort of know people that are mostly males, I might say. So I've learned a lot on the part, on the, on the, on the way. I didn't know anything about a FI can tell you, you know what I'm saying?
Participant 013_2023AUHBV

Participant describes knowing about the condition due to professional background

I knew a little bit about my I knew a little bit about coronary artery disease. Anyway, it's because I'm a PROFESSION, so it makes a bit of a difference. So I was very proactive in researching and and all that sort of thing. So I do my own literature reviews and things from back in nursing school. So I kind of was on top of it that. Participant 011_2023AUHBV

Table 3.16: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes knowing nothing or very little about the condition at diagnosis	29	61.70	15	57.69	14	66.67	15	62.50	14	60.87	11	73.33	18	56.25	13	52.00	16	72.73
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	7	14.89	5	19.23	2	9.52	3	12.50	4	17.39	0	0.00	7	21.88	6	24.00	1	4.55
Participant describes knowing a good amount about the condition at diagnosis (no reason provided)	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	1	6.67	3	9.38	1	4.00	3	13.64
Participant describes knowing about the condition due to professional background	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	2	13.33	1	3.13	3	12.00	0	0.00

Understanding of disease at diagnosis	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes knowing nothing or very little about the condition at diagnosis	29	61.70	11	61.11	18	62.07	4	44.44	11	64.71	14	66.67	20	74.07	9	45.00
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	7	14.89	3	16.67	4	13.79	2	22.22	3	17.65	2	9.52	3	11.11	4	20.00
Participant describes knowing a good amount about the condition at diagnosis (no reason provided)	4	8.51	3	16.67	1	3.45	2	22.22	0	0.00	2	9.52	1	3.70	3	15.00
Participant describes knowing about the condition due to professional background	3	6.38	0	0.00	3	10.34	1	11.11	2	11.76	0	0.00	2	7.41	1	5.00

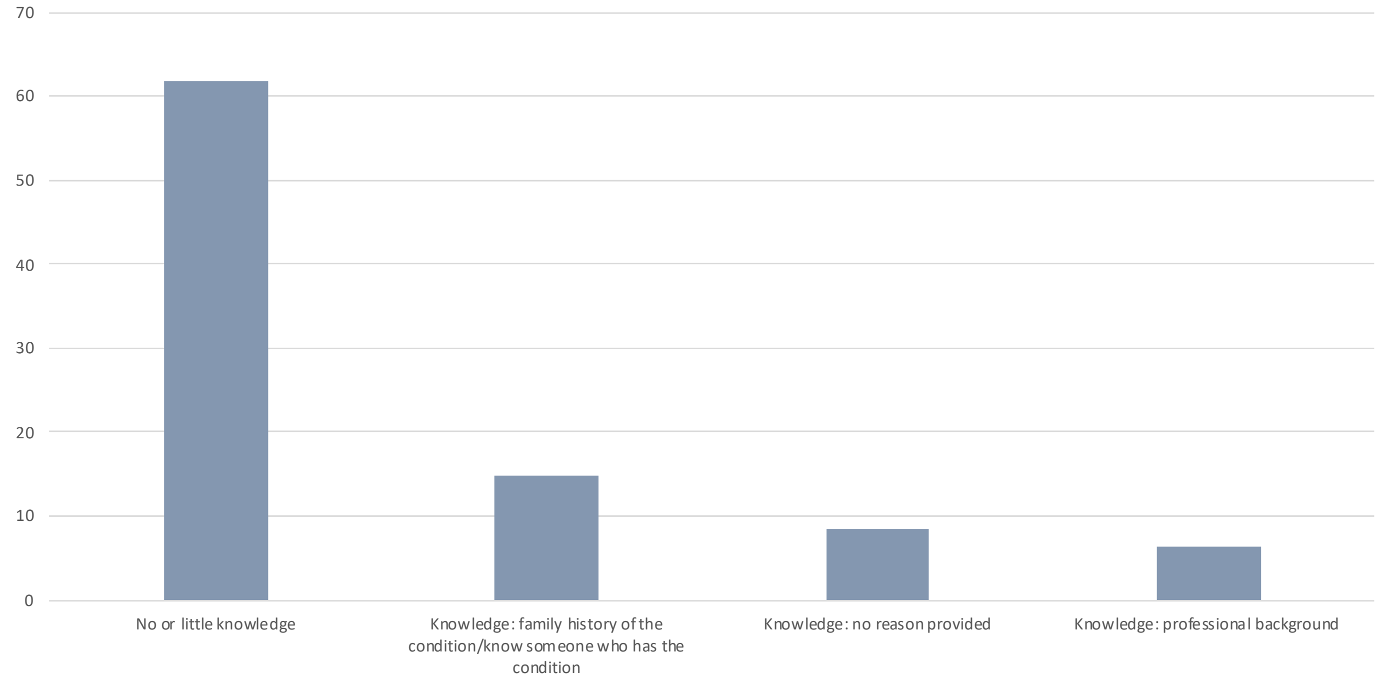

Figure 3.14 Understanding of disease at diagnosis

Table 3.17: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing nothing or very little about the condition at diagnosis	High cholesterol under 50 years of age 6 to 11 other conditions	0 to 5 other conditions Regional or remote Higher socioeconomic status
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	Regional or remote Higher socioeconomic status	-
Participant describes knowing a good amount about the condition at diagnosis (no reason provided)	-	High cholesterol under 50 years of age

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 19 participants (38.00%) who had enough support, 4 participants (8.00%) that had some support but it wasn't enough, and 27 participants (54.00%) had no support.

Table 3.18: Emotional support at diagnosis

Emotional support at diagnosis	Number (n=50)	Percent
Enough support	19	38.00
Some support but it wasn't enough	4	8.00
No support	27	54.00

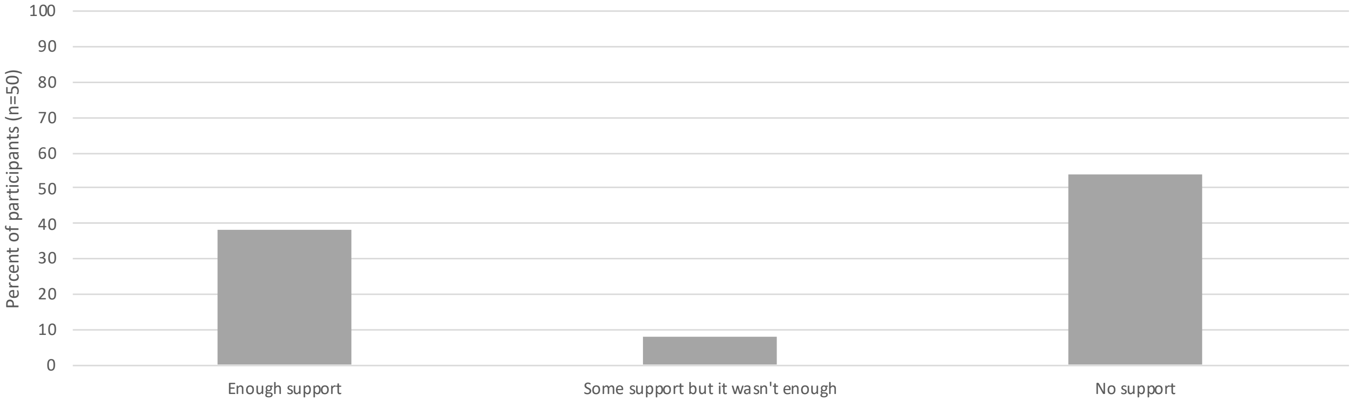

Figure 3.15: Emotional support at diagnosis

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 15 participants (35.71%) who had enough information, 19 participants (45.24%) that had Some information but it wasn't enough, and 8 participants (19.05%) had no information.

Table 3.19: Information at diagnosis

Information at diagnosis	Number (n=50)	Percent
Enough information	15	35.71
Some information but it wasn't enough	19	45.24
No information	8	19.05

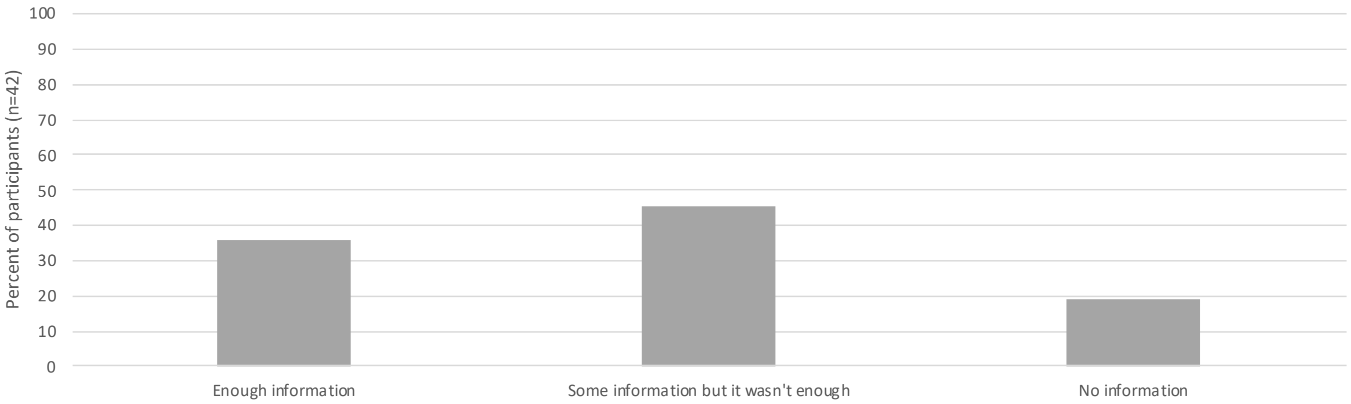

Figure 3.16: Information at diagnosis

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 21 participants (42.00%) who had no out of pocket expenses, and 18 participants (36.00%) who did not know or could not recall. There were 4 participants (8.00%) that spent $1 to $250, 3 participants (6.00%) that spent between $251 to $500, and 4 participants (8.00%) that spent $501 or more.

Burden of diagnostic costs

For 23 participants (67.65%) the cost was slightly or not at all significant. For 7 participants (20.59%) the out-of-pocket expenses were somewhat significant, and for 4 participants (11.76%), the burden of out-of-pocket expenses were moderately or extremely significant.

Table 3.20: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=50)	Percent
$0	21	42.00
$1 to $250	4	8.00
$251 to $500	3	6.00
$501 or more	4	8.00
Not sure	18	36.00

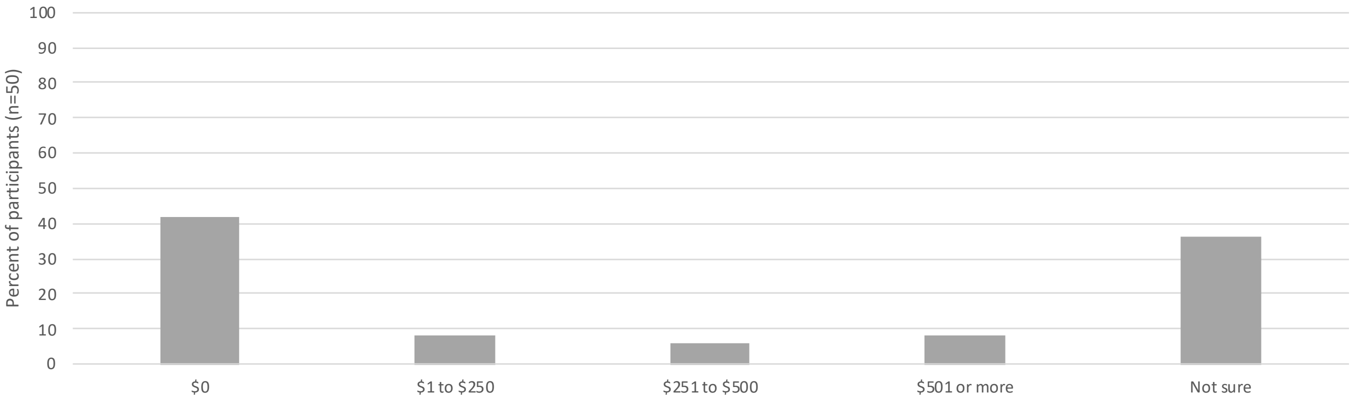

Figure 3.17: Out of pocket expenses at diagnosis

Table 3.21: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=34)	Percent
Not at all significant	14	41.18
Slightly significant	9	26.47
Somewhat significant	7	20.59
Moderately significant	2	5.88
Extremely significant	2	5.88

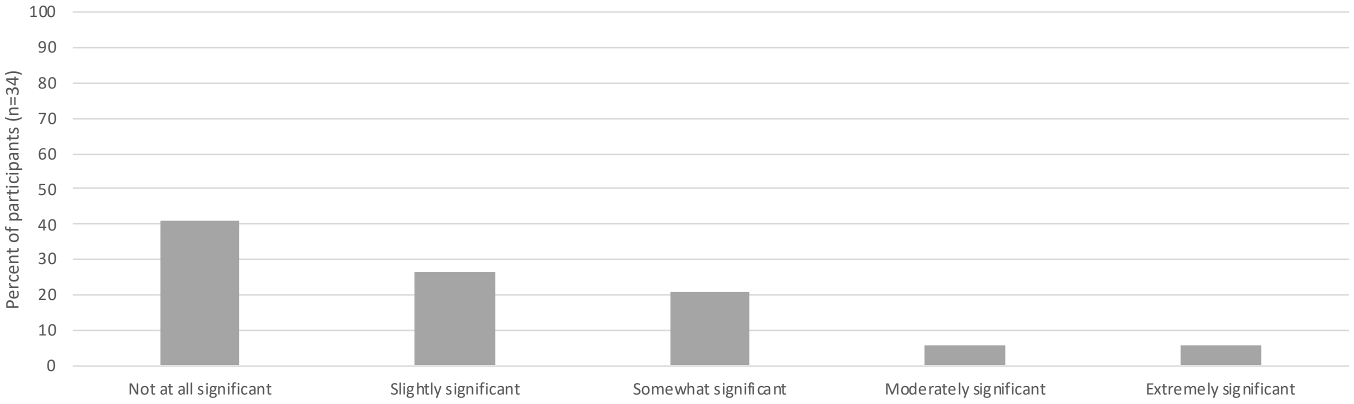

Figure 3.18: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Despite 19 participant having confirmed their LPa status, participants most commonly reported that they had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=43, 86.00%). There were 4 participants (8.00%) who brought up the topic with their doctor, and 3 participants (6.00%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=38, 76.00%). There were 10 participants (20.00%) who did not have these tests and were not interested in them, and a total of 2 participants (4.00%) that had biomarker tests.

Table 3.22: Discussions about biomarkers

Discussions about biomarkers	Number (n=50)	Percent
Participant brought up the topic with doctor for discussion	4	8.00
Doctor brought up the topic with participant for discussion	3	6.00
Participant had no discussion about this type of test	43	86.00

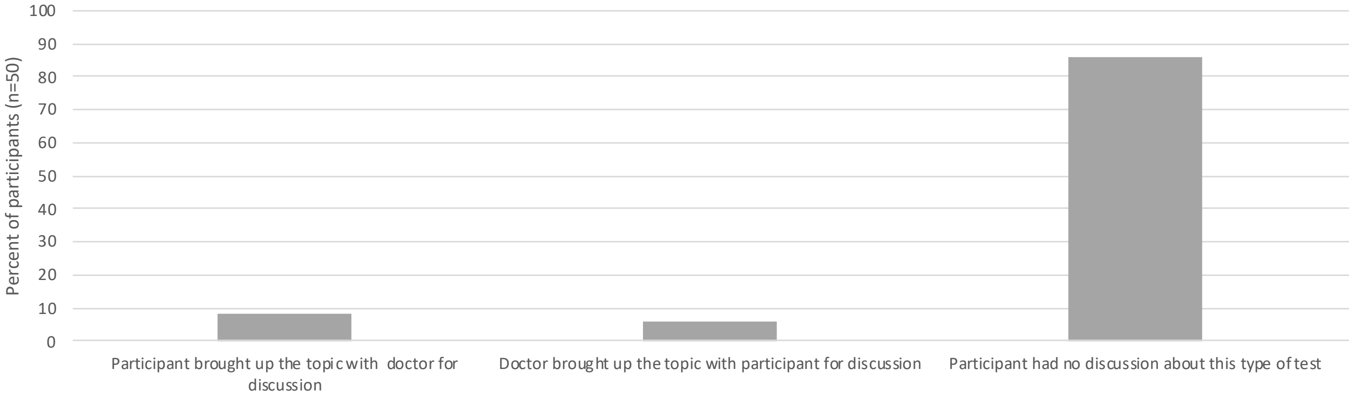

Figure 3.19: Discussions about biomarkers

Table 3.23: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=50)	Percent
Participant had this test and did not have to pay out of pocket for it	2	4.00
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	0	0.00
Participant did not have this test and is not interested in it	10	20.00
Participant did not have this test but would like to	38	76.00

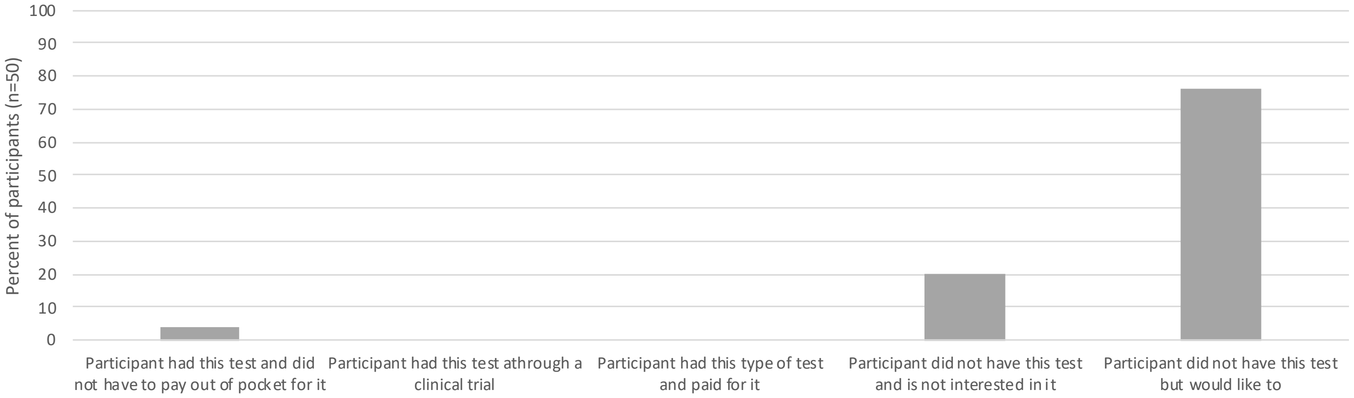

Figure 3.20: Experience of genetic tests and biomarkers

Biomarker status

Most commonly, participants had a family history of heart or blood vessel condition (n=25, 56.82%), followed by Lipoprotein A (LPa) status (n=19, 43.18%). There were 7 participants that were and not sure (15.91%), and 2 participants that had no markers (4.55%).

Table 3.24: Biomarker status

Biomarkers	Number (n=44)	Percent
Family history	25	56.82
Lipoprotein A (LPa)	19	43.18
Not sure	7	15.91
I do not have any markers	2	4.55

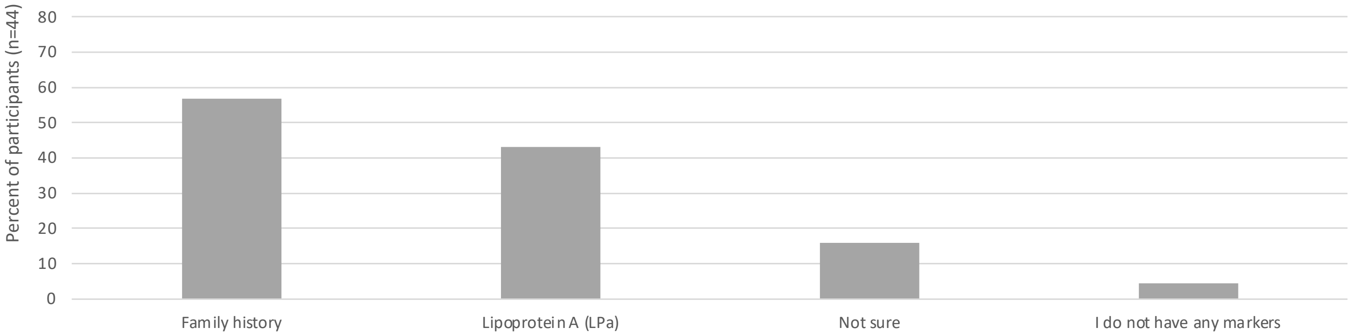

Figure 3.21: Biomarker status

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (31.91%), that they were monitoring their condition until there is an exacerbation or progression (23.40%), and that their prognosis was positive, that their condition is manageable (21.28 %). Other themes included that there was uncertainty around prognosis (19.15%), that it was a lifelong condition (14.89%), that they need to maintain a healthy lifestyle (12.77%), and that they would likely have a recurrence, or were in a cycle of recurrence (8.51%).

Participant describes prognosis in relation to specific medical interventions they need to manage their condition

At the moment, it's looking okay. A year ago, I would not have said that, and neither would my cardiologist. It actually took about six months to get the heart rate and down and to get things under control. At the moment, I'm very happy with where I am. I'm back at work. I'm going to the gym a couple times a week, and so I feel okay mostly. I don't do very well in hot weather. As far as my prognosis is concerned, I know that I have to have a valve replacement in the near future, so when that is, it will depend on the ejection fraction. Participant 034_2023AUHBV

My outlook on the future is just living with my condition and continuing taking my medication to thin my blood. Just monitor my warfarin. Participant 049_2023AUHBV

Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression

Ohh yeah, yeah. Excuse me. Yeah. I mean as it's been monitored and you know every year since I, I, I usually I get about an annual reading at least at least once a year And so that always becomes the talking point in discussion. So the GP counseling is, you know they're taking on, on board a few other factors. I mean I'm now 44 years old. So they've kind of hinted, well, they've suggested and hinted that hey, you know, there's a point at which we would like you're pretty basically they're saying that you're pretty close to a point where we, we really recommend you know, a treatment, you know, some of the statins what have you to to lower your cholesterol, some kind of like in that pretty close area. And so, yeah, I guess if it keeps repeating itself, they'll keep the volume up on that conversation as far as a pharmacological treatment.
Participant 001_2023AUHBV

My current prognosis is that they really don't know what my prognosis is. I have yearly check-ups, and each yearly check-up there is more thickening in my heart. The prognosis is anywhere from it will stay the same as this for the rest of my life, to it could continue to thicken up and I may eventually need a heart transplant. And, anywhere in between those two. It's a very unpredictable disease what I have. They can't predict what's going to happen. They just have to watch and react to what does happen.
Participant 036_2023AUHBV

Participant describes prognosis in a positive way, that their condition is manageable

I'm very stable. I'm a little bit boring. My prognosis, I have a great outlook in life. I don't see any issues going forward.
Participant 039_2023AUHBV

I have been extremely lucky that I've managed to basically, I can do pretty much everything I used to do. The only thing I can't do is drive at night. I've behaviourally accommodated it to the point where I passed a special driving test to be allowed to drive during daylight hours. That's where I'm at physically. I don't believe that I'm particularly at risk of another stroke.
Participant 046_2023AUHBV

Participant describes prognosis in relation to uncertainty around prognosis

They won't give me an answer. No one will give me an answer. When I had first went to LOCATION METROPOLITAN they wouldn't even give me six months. When I had my appointment on the 5th of October it was, it was like they both came in. It was like, "Well, I'm still here."
Participant 033_2023AUHBV

Well NAME DOCTOR has never said and I've never asked him. He's never said what my prognosis is.
Participant 037_2023AUHBV

Nothing. The doctors don't tell me a thing. My cardiologist, I believe, is a waste of $500 every six months. I go in there, he tells me I'm too fat, which is

fair enough, and you get no information. No like, what's our next procedure, do an operation, or do we -- I know it's not a transplant, but how are we going to treat my heart? "We're going to give you this. We're going to give you that." It's nothing. It's usually a case of, "Oh, okay, well just keep watching what you eat. Lose some more weight. I'll see you in six months for another 500 bucks."
Participant 038_2023AUHBV

Participant describes prognosis in relation to it being a lifelong condition

Yeah. So, so I'm on, I'm a patient, I'm a a heart patient. I'll, I'll always be a heart patient, I suppose somewhat. But as far as my condition goes, you know, I've had a CONDITION and there's a 20% chance I'll have another CONDITION. So I follow a pretty conservative heart program to try to avoid that from happening. And as far as my prognosis goes, really there's no, there's no expectation that that will cause me, you know, future issues, all the likes as long as I manage, you know, within within the guidelines I've been given, I suppose.
Participant 009_2023AUHBV

I don't know. I'm back to doing things now. I'm working again, but my outlook is pretty good. It's always been pretty good, to be honest, but I still suffer. I had a pretty ordinary day today, so yes. It's frustration is what my outlook is. Just continued frustration. I think now that I've accepted that this is how I have to be for the rest of my life.
Participant 043_2023AUHBV

I am two years passed stroke and I am able to work part-time. I have had a hole in my heart fixed that they found post-stroke. I am on preventive medication for life and I don't really see my situation improving at all from where it is now.
Participant 047_2023AUHBV

Participant describes prognosis in relation to maintaining a healthy lifestyle, including diet, exercise, reducing or quitting alcohol or smoking

It's very good. I keep my weight down, exercise, and stay on my medication.
Participant 005_2023AUHBV

My current outlook is from when I suffered. The condition is that I turned my I had to turn my whole lifestyle around. Because basically heart attacks were for older people and not for me. And that was my attitude. I was one of those disgusting smokers at the time because that all came about by the era that I grew up in. Drank alcohol, you know what I'm saying? Done nothing different to. Belly full, on, full felt lifestyle to I gave up smoking immediately. I didn't need any counseling. I didn't need to go and suck on a big bike in the end of the corridor. No, I just realized if I wanted to spend a lot of time with my children, well, I changed lifestyle straight away. And that lifestyle involved dietitian. Yeah, eating properly. Talking, buying a lot stuff for myself, cooking properly.
Participant 006_2023AUHBV

Participant describes prognosis in relation to probable recurrence, or cycle of recurrence

At the moment, because I've had three ablation procedures, I'm pretty much good. I've had the occasional. Episode, but nothing like it was.
Participant 008_2023AUHBV

Yes, I saw the neurosurgeon today and he said that I could have another one. They don't know why I had it. I've got no risk factors. They can't see on the MRI why I had a stroke. There's no haemorrhage, there's no aneurism and so they don't know what caused why?
Participant 041_2023AUHBV

Table 3.25: Understanding of prognosis

Understanding of prognosis	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	15	31.91	8	30.77	7	33.33	7	29.17	8	34.78	6	40.00	9	28.13	8	32.00	7	31.82
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	11	23.40	6	23.08	5	23.81	8	33.33	3	13.04	6	40.00	5	15.63	8	32.00	3	13.64
Participant describes prognosis in a positive way, that their condition is manageable	10	21.28	6	23.08	4	19.05	4	16.67	6	26.09	3	20.00	7	21.88	7	28.00	3	13.64
Participant describes prognosis in relation to uncertainty around prognosis	9	19.15	6	23.08	3	14.29	6	25.00	3	13.04	2	13.33	7	21.88	3	12.00	6	27.27
Participant describes prognosis in relation to it being a lifelong condition	7	14.89	2	7.69	5	23.81	1	4.17	6	26.09	2	13.33	5	15.63	3	12.00	4	18.18
Participant describes prognosis in relation to maintaining a healthy lifestyle, including diet, exercise, reducing or quitting alcohol or smoking	6	12.77	3	11.54	3	14.29	4	16.67	2	8.70	3	20.00	3	9.38	4	16.00	2	9.09
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	0	0.00	4	12.50	1	4.00	3	13.64
No particular comment	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55

Understanding of prognosis	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	15	31.91	6	33.33	9	31.03	3	33.33	3	17.65	9	42.86	8	29.63	7	35.00
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	11	23.40	4	22.22	7	24.14	4	44.44	2	11.76	5	23.81	6	22.22	5	25.00
Participant describes prognosis in a positive way, that their condition is manageable	10	21.28	3	16.67	7	24.14	0	0.00	4	23.53	6	28.57	6	22.22	4	20.00
Participant describes prognosis in relation to uncertainty around prognosis	9	19.15	3	16.67	6	20.69	2	22.22	3	17.65	4	19.05	5	18.52	4	20.00
Participant describes prognosis in relation to it being a lifelong condition	7	14.89	3	16.67	4	13.79	0	0.00	6	35.29	1	4.76	5	18.52	2	10.00
Participant describes prognosis in relation to maintaining a healthy lifestyle, including diet, exercise, reducing or quitting alcohol or smoking	6	12.77	2	11.11	4	13.79	2	22.22	1	5.88	3	14.29	3	11.11	3	15.00
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	4	8.51	1	5.56	3	10.34	0	0.00	1	5.88	3	14.29	2	7.41	2	10.00
No particular comment	4	8.51	1	5.56	3	10.34	1	11.11	2	11.76	1	4.76	2	7.41	2	10.00

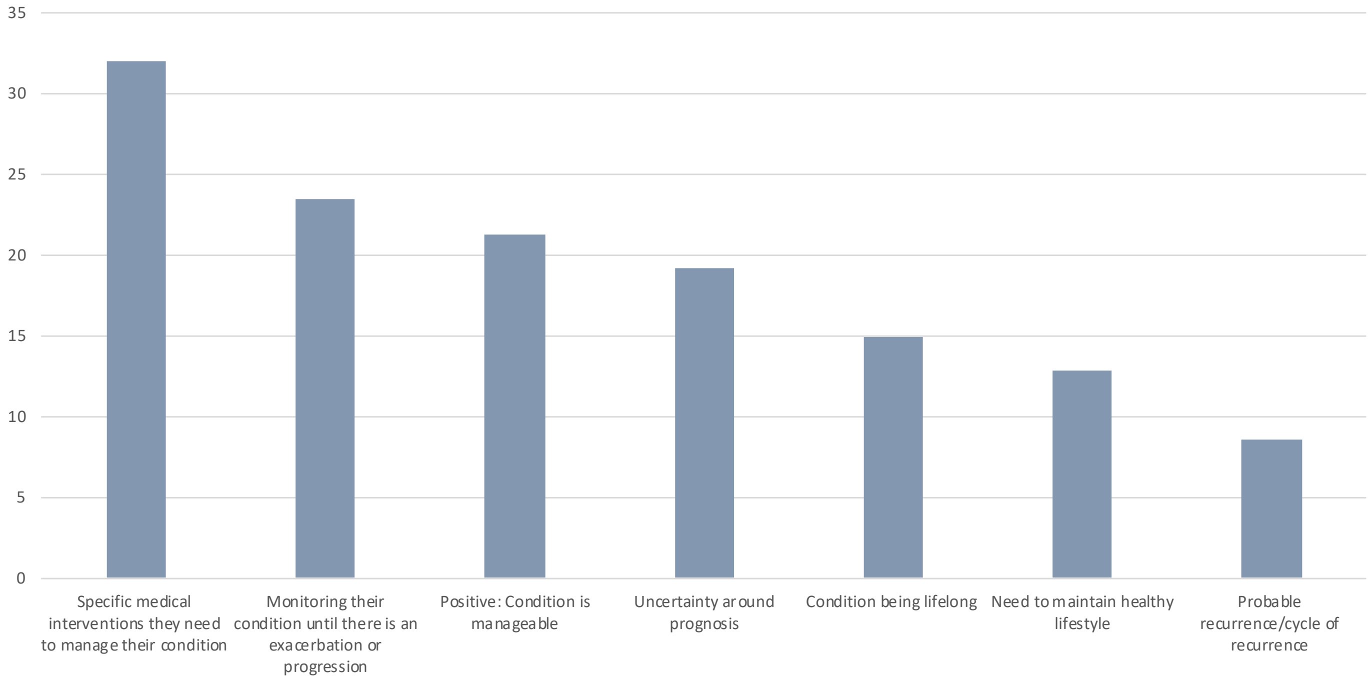

Figure 3.22: Understanding of prognosis

Table 3.26: Understanding of prognosis – subgroup variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	Blood vessel conditions	Heart conditions
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	Blood vessel conditions Aged 45 and older	High cholesterol under 50 years of age Regional or remote
Participant describes prognosis in a positive way, that their condition is manageable	High cholesterol under 50 years of age	-
Participant describes prognosis in relation to it being a lifelong condition	High cholesterol under 50 years of age Heart conditions Aged 25 to 44	Blood vessel conditions Aged 45 and older

Biomarker tests

Participants were asked in the structured interview if they had any discussion about biomarkers that may be important to the management of their condition. The most common responses were that they did not have any tests and did not describe reasons (48.94%), that they did not have a test but would like to have this type of test (21.28%). This was followed by no test but family history was discussed (12.77 %), and had a test and management of condition was not changed (6.38%).

Participant describes that they did not have a biomarker test, did not describe reasons

No, they they haven't done that...and no one else in my family has ever had. I haven't gone for genetic testing for that only because I suppose that this seems to be quite targeted to an event in my life as opposed to genetics.
Participant 014_2023AUHBV

Participant describes that they did not have a biomarker test, however would like to have this type of test

I don't know, I'm not speculating a bit, but yeah, they're probably just assuming that that's, I don't know, it's it's almost like, yeah, a lot of the population is affected with higher cholesterol. It's almost like one of these lifestyle things. But yeah, that's interesting you bring it up cuz I've definitely heard of hypercholesterol or the familial, yeah, there is like a familial link for some. There's like a portion of people percentage, yeah.
Participant 001_2023AUHBV

No, not at all. Never. And that's something I actually followed up myself to some extent, being a PROFESSION IN HEALTH and being in the role roles I've been in, I actually found out that there's only one genetic testing service in STATE, and so I rang them and I spoke to the registrar and said, is there any value in being tested? And basically he said no, you're diagnosed, you're treated, you don't have children, your family's got no symptoms. Because we went through all this. No, there's no, no point. And you know, it's very, very scarce resource. Don't waste it on someone who doesn't need it, which, you know, it made perfect sense to me. I don't want to be doing that. So yeah, no, nobody ever, ever said to me. Let's look at genetics, yeah.
Participant 010_2023AUHBV

No one's ever talked to me about any gene stuff, even though I've known that my father died from a heart attack and you know, at 50, something. And that, you know, all my siblings have heart conditions of 1 sort or another, but no one never talked about doing any sort of gene analysis or anything.
Participant 013_2023AUHBV

Participant describes that they did not have a biomarker test, however family history was discussed

Well they did ask me if my family had heart problems cuz it's to my dad's side. He also has the heart memory. He has heart publications, well all the time, but it was caused from drugs and alcohol on his behalf.
Participant 007_2023AUHBV

They did ask me a few questions and did the heart like heart conditions do, running my family through my pop. He has heart problems. Well, he did, and then he. Yeah. So I mentioned that to them and they did talk to me about it much, but I don't think we went any further with it just yet. They were very shocked by my age because I'm only 21. They were just very more shocked on what happened and where the like how did this come so early? Obviously like with no clogged arteries or anything like that, they just said it was very odd. So that they yeah, they just wanted me to come back for recent like for checkups every now and then to just. Keep on top of it, and obviously the more tests will be there.
Participant 029_2023AUHBV

No, that wouldn't be a bad idea though.
Participant 037_2023AUHBV

I should definitely have them because every woman in my family has had a stroke. I've got two girls so I think it would be really important for them to have that.
Participant 039_2023AUHBV

Participant describes that they did not have a biomarker test, however was motivated to research family history

Look, hindsight is a beautiful thing so in the heat of the moment, no, they didn't. It was all about just surviving really. Now that I am older and I do a lot of research and I'm a consumer consultant on other trials, et cetera, I know how important it is to have all that stuff done. I've done my own family tree, I've been able to see if anyone else died of a stroke or had a stroke or any of that. That doesn't seem to be relevant to my case.
Participant 050_2023AUHBV

Participant describes having had a biomarker test, and that management of condition was not changed

That's all I was being told. I've never been told anything else. The cause of my stroke, who knows? I don't know. I don't know why I had my stroke. I don't know anything. I've been just left in the never-nevers.
Participant 049_2023AUHBV

Participant describes having had a biomarker test, and as a result management of condition was changed

Yeah, that's right. He changed the way. So he started me on a statin...he actually went a lot more aggressive with my with with his approach to me. So he increased my statin dose and I'm also on ezetimibe as well for that, yeah.
Participant 011_2023AUHBV

Participant describes having had a biomarker test, and as a result surveillance of condition was increased

I've had genetic testing for hypertrophic cardiomyopathy, and this is a progression of that...the heart failure was a progression of an existing diagnosis
Participant 032_2023AUHBV

Participant describes having had a biomarker test, to identify other family members at risk

What I understand is that it doesn't help me, but it helps identify my faulty gene, and it is more of a benefit to my direct family members to eliminate them from unnecessary screening for the disease.
Participant 036_2023AUHBV

Table 3.27: Biomarker tests

Biomarker tests	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that they did not have a biomarker test, did not describe reasons	23	48.94	11	42.31	12	57.14	14	58.33	9	39.13	7	46.67	16	50.00	12	48.00	11	50.00
Participant describes that they did not have a biomarker test, however would like to have this type of test	10	21.28	5	19.23	5	23.81	4	16.67	6	26.09	1	6.67	9	28.13	7	28.00	3	13.64
Participant describes that they did not have a biomarker test, however family history was discussed	6	12.77	5	19.23	1	4.76	5	20.83	1	4.35	4	26.67	2	6.25	3	12.00	3	13.64
Participant describes that they did not have a biomarker test, however was motivated to research family history	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00
Participant describes that they did not have a biomarker test, however BMI was discussed	1	2.13	1	3.85	0	0.00	1	4.17	0	0.00	1	6.67	0	0.00	1	4.00	0	0.00
Participant describes having had a biomarker test, and that management of condition was not changed	3	6.38	0	0.00	3	14.29	0	0.00	3	13.04	1	6.67	2	6.25	0	0.00	3	13.64
Participant describes having had a biomarker test, and as a result management of condition was changed	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	1	6.67	0	0.00	1	4.00	0	0.00
Participant describes having had a biomarker test, and as a result surveillance of condition was increased	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	0	0.00	1	4.55
Participant describes having had a biomarker test, to identify other family members at risk	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	0	0.00	1	4.55

Biomarker tests	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that they did not have a biomarker test, did not describe reasons	23	48.94	8	44.44	15	51.72	2	22.22	11	64.71	10	47.62	14	51.85	9	45.00
Participant describes that they did not have a biomarker test, however would like to have this type of test	10	21.28	5	27.78	5	17.24	2	22.22	2	11.76	6	28.57	7	25.93	3	15.00
Participant describes that they did not have a biomarker test, however family history was discussed	6	12.77	4	22.22	2	6.90	3	33.33	0	0.00	3	14.29	3	11.11	3	15.00
Participant describes that they did not have a biomarker test, however was motivated to research family history	1	2.13	0	0.00	1	3.45	0	0.00	1	5.88	0	0.00	0	0.00	1	5.00
Participant describes that they did not have a biomarker test, however BMI was discussed	1	2.13	0	0.00	1	3.45	1	11.11	0	0.00	0	0.00	0	0.00	1	5.00
Participant describes having had a biomarker test, and that management of condition was not changed	3	6.38	1	5.56	2	6.90	1	11.11	2	11.76	0	0.00	2	7.41	1	5.00
Participant describes having had a biomarker test, and as a result management of condition was changed	1	2.13	0	0.00	1	3.45	0	0.00	1	5.88	0	0.00	0	0.00	1	5.00
Participant describes having had a biomarker test, and as a result surveillance of condition was increased	1	2.13	0	0.00	1	3.45	0	0.00	0	0.00	1	4.76	1	3.70	0	0.00
Participant describes having had a biomarker test, to identify other family members at risk	1	2.13	0	0.00	1	3.45	0	0.00	0	0.00	1	4.76	0	0.00	1	5.00

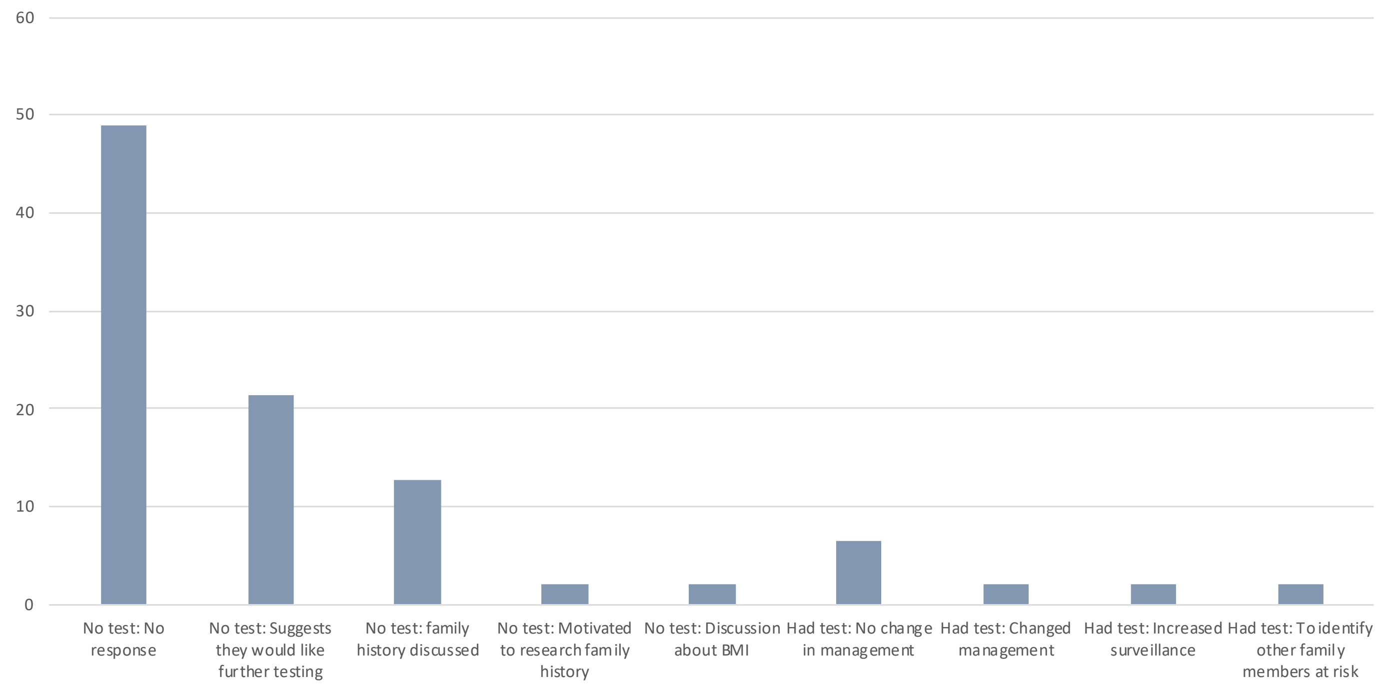

Figure 3.23: Biomarker tests

Table 3.28: Biomarker tests – subgroup variations

Biomarker tests	Reported less frequently	Reported more frequently
Participant describes that they did not have a biomarker test, did not describe reasons	High cholesterol under 50 years of age	Blood vessel conditions
Participant describes that they did not have a biomarker test, however would like to have this type of test	Regional or remote	-
Participant describes that they did not have a biomarker test, however family history was discussed	Blood vessel conditions	High cholesterol under 50 years of age Regional or remote

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (31.91%), or one treatment option (27.66%). Other themes included no discussions about treatment (19.15%), and that they cannot remember (12.77%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly participated in the decision-making process (19.15%), or did not give a description about participation in decision making (6.38%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (8.51 %), had a medical emergency or urgent treatment required (8.51%), or they were told what to do without discussion (8.51%).

Some participants were unable to recall discussions about treatments, this was most commonly because they were a child at the time and cannot remember the conversations (6.38%), or they were incapacitated at the time and cannot remember (6.38%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %). Other themes included quality of life (21.28%), their own research (21.28%), their ability to follow treatments (12.77%), and the impact on their family or dependents (10.64%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. More participants had changed the way that they make decisions (61.70%), than those that had not changed the way they make decisions (34.04%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (27.66%), and more aware of their health, responsibilities and/or limitations (14.89%). Other themes included more cautious and considered (8.51%), more focused impact on family and dependents (8.51%) and more accepting of their condition (6.38%). Where participants had not changed their decision making over time this was because they always been informed/assertive (6.38%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to to make lifestyle changes to be fit and healthy (14.89%), have physical improvements in their condition (12.77%), and to have quality of life or to return to normality(12.77 %). There were 4 participants, and they had no personal goals of treatment or care (8.51%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (31.91%), or one treatment option (27.66%). Other themes included no discussions about treatment (19.15%), and that they cannot remember (12.77%).

Participant describes multiple options being presented

PARTICIPANT: Well, it was the Entresto. The first one, of course, I wasn't given an option. It was, "You need a heart transplant, but you're too old and we have to work with what we've got." It's funny how you never forget those words, isn't it?
Participant 033_2023AUHBV

PARTICIPANT: Well, it was the Entresto. The first one, of course, I wasn't given an option. It was, "You need a heart transplant, but you're too old and we have to work with what we've got." It's funny how you never forget those words, isn't it?
Participant 033_2023AUHBV

Participant describes one option being presented

To be honest, it was a very expensive, quick five minute conversation, basically telling me that I'm at no serious risk of having a heart attack and that diet and exercise will keep it that way. And that was that.
Participant 028_2023AUHBV

The first thing they wanted to do was put me on medication straight away, but I'm not super keen. I wanted to try diet and exercise first because I'm not super keen on just medications for everything.
Participant 020_2023AUHBV

I mean, the only treatment that he discussed was whether to medicate or not, but he said that he felt that it wasn't necessary because I was very fit and healthy. Yeah. That would have been the extent of that discussion. Yeah.
Participant 023_2023AUHBV

Participant describes no treatments being discussed

Look, obviously I had those initial consultations with the neurologist on the ward. I didn't stay in hospital for long, I think I was only in there for a week. I was pretty keen to get out of there and I think it was fairly apparent that I didn't want to be there. He said, "Well, I'm not going to stop you." Because I didn't have any physical paralysis as far as not being to walk or talk or do any…All my issues was with my vision and stuff and just feeling really sick all the time. It was okay for him to let me go and he did, which I appreciated at the time. As far as that went, as far as saying what treatment I could do, and because of the diagnosis was cryptic, there wasn't really much talk about any treatment, really.
Participant 043_2023AUHBV

Well, I'd have to say I didn't have a particularly helpful warm relationship with the cardiologist I first saw. He was very efficient and very knowledgeable I suppose but he I didn't want to him and I suspect know him to me and he basically said well we need to keep an eye on this. You know come back every year and have an echo. We're really only treat you when you're symptomatic and you know we can talk about what surgeon you might want to go to at that point. And I I must I I don't think I I wasn't very. What's the word I want tuned into the information I needed? At that point I was just gobsmacked because I thought I didn't have a problem. I was sure there was nothing wrong with me. It was just an incidental murmur, you know, from stress. And I was going bloody hell, what? What now? So I didn't think to ask. Well, you know, time frame or? Is there anything I can do to minimize the? Actually, I think I did ask him is there anything I can do to minimize the progression? And he said basically no. So yeah, it was. It was now. I was rocked off my socks by the diagnosis.
Participant 010_2023AUHBV

Participant does not remember discussions about treatments

Yeah, so. First diagnosed at, probably formally first diagnosed at 8. I didn't actually find out until 9. The doctor was a bit unsure as to how it was going to progress. So I think as far as I'm aware, my mum and dad knew that I had this condition, but they just kind of said have a year, see how it goes, don't do anything differently, and if it progresses on then we got to start doing something. So I think I figured it out about 9:00 and then from about 9:00. 10/11, it was all bit of a blur to be honest.
Participant 012_2023AUHBV

I can't recall, sorry. It was so long ago, my memory is not very good.
Participant 040_2023AUHBV

I don't know if I remember. I was pretty out of it to start with. My husband and my family probably were more involved in that at the start because I wasn't-- I didn't have- you know how they use a blood thinning injection? I get better. I didn't have any of that. I had my stroke during operation.
Participant 039_2023AUHBV

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes multiple options being presented	15	31.91	6	33.33	9	31.03	1	11.11	3	17.65	11	52.38	10	37.04	5	25.00
Participant describes one option being presented	13	27.66	5	27.78	8	27.59	4	44.44	2	11.76	7	33.33	5	18.52	8	40.00
Participant describes no treatments being discussed	9	19.15	2	11.11	7	24.14	2	22.22	5	29.41	2	9.52	7	25.93	2	10.00
Participant does not remember	6	12.77	3	16.67	3	10.34	1	11.11	4	23.53	1	4.76	2	7.41	4	20.00
No particular comment	4	8.51	2	11.11	2	6.90	1	11.11	3	17.65	0	0.00	3	11.11	1	5.00

Discussions about treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes multiple options being presented	15	31.91	10	38.46	5	23.81	7	29.17	8	34.78	5	33.33	10	31.25	6	24.00	9	40.91
Participant describes one option being presented	13	27.66	7	26.92	6	28.57	6	25.00	7	30.43	5	33.33	8	25.00	8	32.00	5	22.73
Participant describes no treatments being discussed	9	19.15	3	11.54	6	28.57	5	20.83	4	17.39	1	6.67	8	25.00	5	20.00	4	18.18
Participant does not remember	6	12.77	3	11.54	3	14.29	3	12.50	3	13.04	2	13.33	4	12.50	4	16.00	2	9.09
No particular comment	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	2	13.33	2	6.25	2	8.00	2	9.09

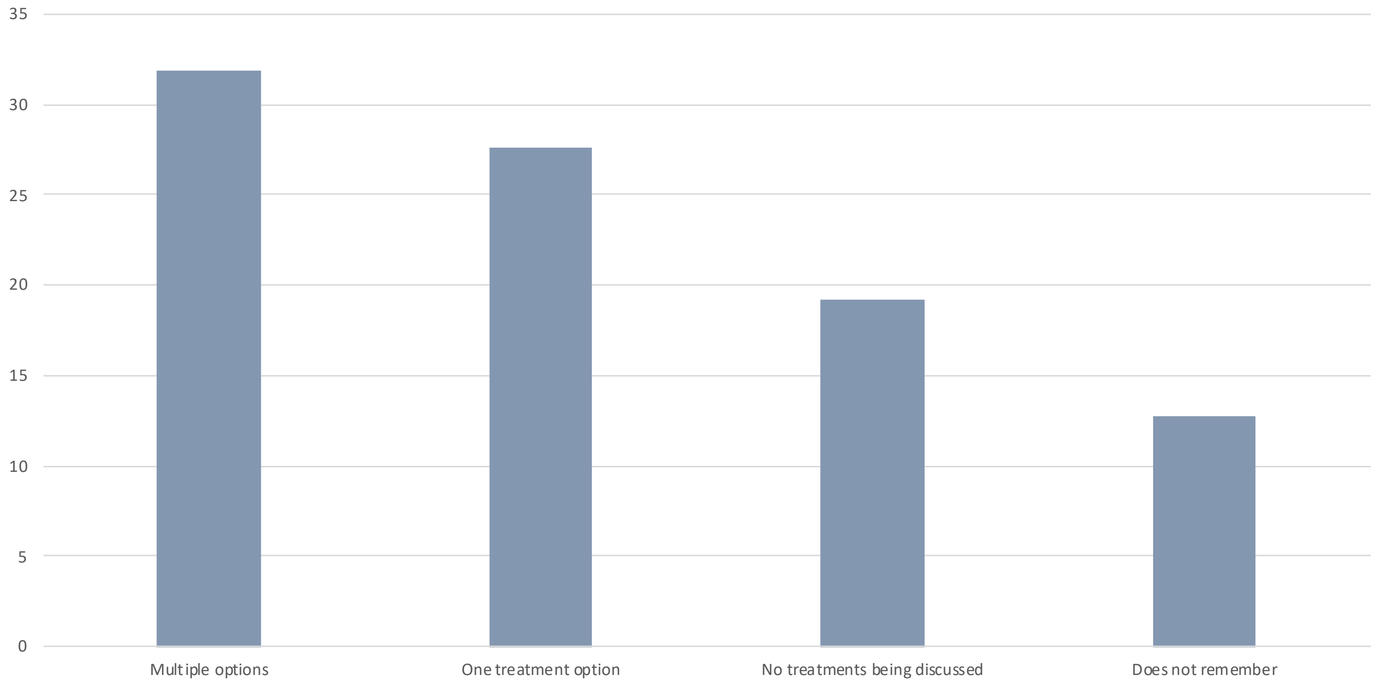

Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes multiple options being presented	High cholesterol under 50 years of age Blood vessel conditions	Heart conditions
Participant describes one option being presented	Blood vessel conditions	High cholesterol under 50 years of age 6 to 11 other conditions
Participant describes no treatments being discussed	Regional or remote	Blood vessel conditions
Participant does not remember	-	Blood vessel conditions

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly participated in the decision-making process (19.15%), or did not give a description about participation in decision making (6.38%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (8.51 %), had a medical emergency or urgent treatment required (8.51%), or they were told what to do without discussion (8.51%).

Some participants were unable to recall discussions about treatments, this was most commonly because they were a child at the time and cannot remember the conversations (6.38%), or they were incapacitated at the time and cannot remember (6.38%).

Participant describes being presented with multiple options and participated in the decision-making process

They pretty much gave me an option of just medication or if to be hospitalized and stay on their drips. I took the medication part of it because I'm one of those people that get better at home. So I took the medication option and they gave me a prescription for three months to take clog out. So yeah, and then I developed. I had to take two tablets of those every day.
Participant 029_2023AUHBV

With the atrial fibrillation, I was diagnosed in LOCATION OVERSEAS but I didn't know about it, and when I went into hospital in LOCATION OVERSEAS, we didn't talk about a pacemaker. I think they just tried to get the heart rate under control. I was supposed to have a cardioversion, but because I had a clot, that wasn't possible. I came back here and waited the six weeks for the clot to dissolve, and then I had a cardioversion. The discussions in Italy were really good, because the doctors and nurses worked as a team, and they came to me as a team, and we discussed things together, and they told me what they think should happen, and they tried to reassure me, and it was all really very good. With my cardiologist here, I've had him for about 14 to 16 years now. He's pretty straight down the line and says what I need to have done, basically. I usually ask him questions, so there haven't been too many choices or options.
Participant 034_2023AUHBV

Participant describes being presented with one option/approach and did not participate in the decision-making process

It was pretty much, he said to me. Do you want to be on a white pill for the rest of your life or die? That was it.
Participant 016_2023AUHBV

When you're first diagnosed the only treatment option was that was discussed, discussed was a starting on a high dose statin and I was commenced on 20 milligrams of rosuvastatin which is a just straight up really high dose and there were no actual other treatments mentioned. It was just basically start the statin, you know we need to get onto this and and I basically then become proactive looking at other ways as well that I could help myself. So you know, with regards to stress management, eating well, exercising and all that sort of thing, just to try and decrease my risk for future events.
Participant 011_2023AUHBV

Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required

Not much. It was basically happened all of a sudden I I was, the local doctor said I'm concerned with your heart. So we'll do we'll follow that up with a stress test as soon as possible. I went for the stress test they had. That information, my local doctors, the referral, There was no really other conversations around it. I've done the stress test and 5 minutes into it, a Vt, Does that make sense?
Participant 025_2023AUHBV

Participant describes being presented with one option/approach, that they were told what to do without discussion

I was given a treatment and that was it.
Participant 049_2023AUHBV

When they first diagnosed me, it was the case of. Here's the medication. If you need to take it, take it. Or it's sort of up to you if you take it, because I think they didn't realize how bad it was to start with.
Participant 008_2023AUHBV

Participant describes being incapacitated at the time and cannot remember

I see, I don't remember very well. I don't remember the first 10 days. My son, he's a doctor. He came down and he was with me. I think he helps me make a lot of decisions, but I don't remember what they were. [crosstalk] You should because I don't remember the whole thing very well. INTERVIEWER: Yes, that's okay. PARTICIPANT: Yes, I know when to have rehab that we're talking about, cutting my skull and letting the pressure out, but it stopped bleeding and they decided not to do that. I don't remember the discussion about that I…My son might have even told me that afterwards, I'm not sure. They talked about sending me to rehab and I had private health insurance but because of the virus I chose to go public so that I could be in LOCATION STATE rather than LOCATION STATE, but I didn't realise that private would have meant that I had a better rehab. Anyway, I wasn't really in a fit state to understand what was going on to discuss it. It didn't really help [laughs] but if I did discuss they sit with me.
Participant 041_2023AUHBV

I don't know if I remember. I was pretty out of it to start with. My husband and my family probably were more involved in that at the start because I wasn't…I didn't have- you know how they use a blood thinning injection? I get better. I didn't have any of that. I had my stroke during operation.
Participant 039_2023AUHBV

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being presented with multiple options and participated in the decision-making process	9	19.15	3	16.67	6	20.69	0	0.00	1	5.88	8	38.10	6	22.22	3	15.00
Participant describes being presented with multiple options but did not give a description or reason for this	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	4	8.51	2	11.11	2	6.90	0	0.00	0	0.00	4	19.05	2	7.41	2	10.00
Participant describes being presented with one option/approach, that they were told what to do without discussion	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	1	3.70	3	15.00
Participant describes being a child at the time and cannot remember the conversations	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00
Participant describes being incapacitated at the time and cannot remember	3	6.38	1	5.56	2	6.90	0	0.00	3	17.65	0	0.00	0	0.00	3	15.00
Participant describes being presented with no options/approach as there were no therapies are available	2	4.26	1	5.56	1	3.45	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00

Discussions about treatment (Participation in discussions)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being presented with multiple options and participated in the decision-making process	9	19.15	6	23.08	3	14.29	4	16.67	5	21.74	4	26.67	5	15.63	4	16.00	5	22.73
Participant describes being presented with multiple options but did not give a description or reason for this	3	6.38	2	7.69	1	4.76	0	0.00	3	13.04	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	2	8.00	2	9.09
Participant describes being presented with one option/approach, that they were told what to do without discussion	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes being a child at the time and cannot remember the conversations	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	2	8.00	1	4.55
Participant describes being incapacitated at the time and cannot remember	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes being presented with no options/approach as there were no therapies are available	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55

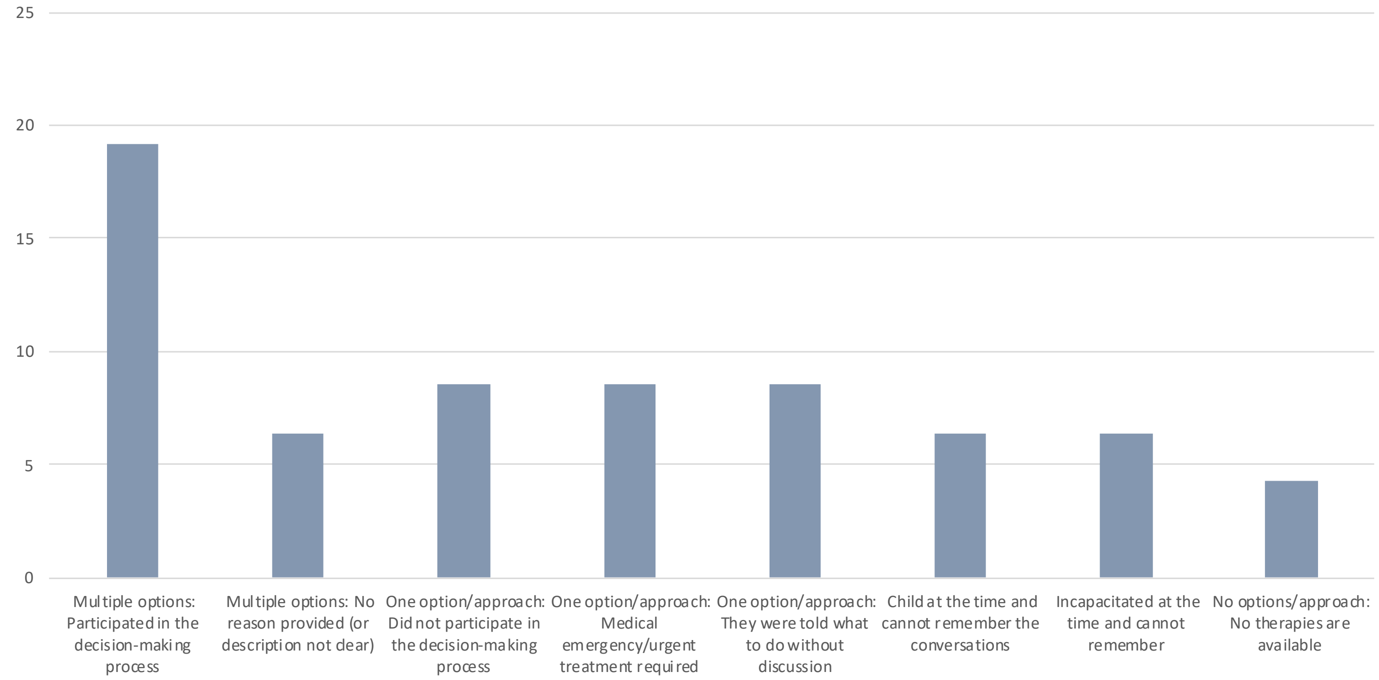

Figure 4.2: Discussions about treatment (Participation in discussions)

Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options and participated in the decision-making process	High cholesterol under 50 years of age Blood vessel conditions	Heart conditions
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	-	Heart conditions
Participant describes being incapacitated at the time and cannot remember	-	Blood vessel conditions

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %). Other themes included quality of life (21.28%), their own research (21.28%), their ability to follow treatments (12.77%), and the impact on their family or dependents (10.64%).

Participant describes taking side effects into account when making decisions about treatments

The main thing I I think about is is is is I look at the I'm in a way up the pros and cons you know so you know what's the likelihood of of the side effects of a drug gonna affect me and and all that. So I mean that's the main thing I look at is the side effects. And you know, if I get one of those and like does it outweigh the price? And so far it's yeah, I always take my medication, so. Participant 028_2023AUHBV

The long term effect of my health and the side effects of any medications.
Participant 020_2023AUHBV

Side effects of medication is something to take into consideration. I luckily haven't had any side effects, but that was something that I really did look into. That's about it really. And just I just didn't want to be fatigued and it for it to, you know, impact my life too much. So I wanted to be able to take the medication and still be still have a good quality of life. So that's they were the main things I kind of looked at with with treatment.
Participant 011_2023AUHBV

Participant describes taking efficacy into account when making decisions about treatments

The first thing I'll ask is, "Will it work?"
Participant 040_2023AUHBV

I always look at what the outcome is expected of that treatment.
Participant 044_2023AUHBV

I think things that would affect. Things would be the improvement, what would the benefits be of any treatment? Whether it's cognitive, or physical, or

emotional, to be able to make things easier would be very good.
Participant 047_2023AUHBV

Participant describes taking the advice of their clinician into account when making decisions about treatments

Then what do I base my decisions on? What is medical? The medical? I'm in the care of Professor NAME, who's the leading cardiologist in the world. I placed a lot, a lot of trust in that man. He has looked. He was the guy who, when I was bought into the hospital in the emergency, he was the guy in theatre with me when it happened. So I'm still seeing the same person now. So you're just like, I guess if he tells you you were 100% tasked in that person?
Participant 006_2023AUHBV

I actually am probably very passive and just accept that he says I need to go on this, and you need to keep your weight down and you need to exercise, and you need to keep your emotions in control, and come back if you have any problems, like. And I just see him regularly. I sort of think I've lived my life, like when that disaster surgery took six operations to try and fix my bladder etc. and I just am grateful. I just live day to day and don't really think about having anything wrong with me. I just take the medication and move on.
Participant 037_2023AUHBV

Participant describes taking quality of life into account when making decisions about treatments

I'd have to say it would be like, what the treatment involved. How invasive it is and what the recovery time would be. What the risk factor is I suppose to my normal health afterwards. Like am I going to be able to function better than what I am now? Is it going to improve my lifestyle? I'm only 45 and I know now what it's like to live like and old person because that's what I was like prior to the surgery. Is it going to decrease my capabilities or is it going increase my capabilities? I would like it to be able to improve my lifestyle. I'd like to be able to live a normal lifestyle. If not normal just better than what I'm doing now. If it's not going to improve how I am now then is it worth it?
Participant 036_2023AUHBV

I think the main one is quality of life. And the effects that the medication, if I needed to take it, would have, And if the side effects were severe and significantly impacted my quality of life, then I would need to make choice about whether I wanted to prolong life with that sort of quality or whether it would be better to have a. A better quality of life, but shorter?
Participant 017_2023AUHBV

Just my general well-being, more than anything.
Participant 043_2023AUHBV

Participant describes taking their own research into account when making decisions about treatments

Whether I can afford it. I've got medical insurance. It helps me a little bit with my physiotherapy. No, I don't think there is any treatment. There are books written about rewiring your brain and I'm reading that. I'm helping myself, really. The thing that really matters to me is whether I can do things or not. I can operate a computer. I can type. I can do a lot of things. I just can't walk well enough yet.
Participant 048_2023AUHBV

Well, for me, I wasn't tolerating the medication very well. So I sort of started doing my own research and asked them about the ablation procedure, just so that we could have the opportunity to fix it rather than.
Participant 008_2023AUHBV

I don't make decisions about treatment anymore. In fact, all the decisions that impacted my treatment were made by others, not by myself. Whilst I was in hospital I really was not part of the decision-making process. I was a patient, the decisions were made by others. When I left hospital and I went to rehab, my rehabilitation was a series of exercises which were formulated by rehab staff. My personal input into my rehabilitation was absolutely minimal. That's why when I did retire I devoted all of my time to researching stroke and to determining the sort of exercise that would benefit me. I did get through self-study.
Participant 045_2023AUHBV

Participant describes taking their ability to follow treatments into account when making decisions about treatments

That's the thing, I just really, it's just making sure I remember to take the medication. That's. Yeah, I haven't really thought about anything else.
Participant 016_2023AUHBV

Participant describes taking the impact on their family or dependents into account when making decisions about treatments

The recovery time from surgery, or the benefit that outweigh the positives and the negatives of the surgery. Also ask about alternates, like are there alternate ways of dealing with it? Like with medication. Some medications don't agree, whereas some, you know, are much better for functioning. So, you know, negotiation. My cardiologist is really good, if I say to him, "Look, you know, this isn't working for me," so we titrate the dose and he's happy with me to titrate the dose or change it slightly so that it suits me. As long as it's having an effect and it can suit me, rather than being on way too much medication and trying to function and be a mum and work and have a family life and all of that. So yeah, they're the sort of things that I'd ask. And there's also, I'm involved in an ICD support group at NAME HOSPITAL and they're excellent. And NAME there is really good, and I ring her if I've got any questions, like clinical questions, then I'll give her a call and go over with her and she's fantastic.
Participant 030_2023AUHBV

How will it affect my family, my ability to care for my family? I have a young daughter and I look after her. I'm her main carer, main caregiver. I don't care for her, she's not disabled in any way. I take care of my husband as well, a little. Making dinner, and doing washing, I look after him as far as I can.
Participant 039_2023AUHBV

Table 4.5 Considerations when making decisions

Considerations when making decisions about treatment	**All participants**		**Had LP(a) test**		**Did not had LP(a) test**		**High cholesterol under 50 years of age**		**Blood vessel conditions**		**Heart conditions**		**0 to 5 other conditions**		**6 to 11 other conditions**	
	n=47	**%**	**n=18**	**%**	**n=29**	**%**	**n=9**	**%**	**n=17**	**%**	**n=21**	**%**	**n=27**	**%**	**n=20**	**%**
Participant describes taking side effects into account when making decisions about treatments (Total)	24	51.06	**6**	**33.33**	**18**	**62.07**	4	44.44	**6**	**35.29**	**14**	**66.67**	12	44.44	12	60.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	23	48.94	**6**	**33.33**	17	58.62	4	44.44	**6**	**35.29**	**13**	**61.90**	12	44.44	11	55.00
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.13	0	0.00	1	3.45	0	0.00	0	0.00	1	4.76	0	0.00	1	5.00
Participant descibes taking efficacy into account when making decisions about treatments (Total)	18	38.30	**4**	**22.22**	14	48.28	4	44.44	8	47.06	6	28.57	10	37.04	8	40.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	31.91	**3**	**16.67**	12	41.38	**4**	**44.44**	5	29.41	6	28.57	7	25.93	8	40.00
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	6.38	1	5.56	2	6.90	0	0.00	**3**	**17.65**	0	0.00	3	11.11	0	0.00
Participant descibes taking the advice of their clinician into account when making decisions about treatments (Total)	11	23.40	4	22.22	7	24.14	2	22.22	**2**	**11.76**	7	33.33	7	25.93	4	20.00
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	14.89	1	5.56	6	20.69	2	22.22	1	5.88	4	19.05	5	18.52	2	10.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	4	8.51	3	16.67	1	3.45	0	0.00	1	5.88	3	14.29	2	7.41	2	10.00
Participant descibes taking quality of life into account when making decisions about treatments (Total)	10	21.28	4	22.22	6	20.69	**1**	**11.11**	**6**	**35.29**	3	14.29	6	22.22	4	20.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	17.02	3	16.67	5	17.24	1	11.11	4	23.53	3	14.29	4	14.81	4	20.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	4.26	1	5.56	1	3.45	0	0.00	2	11.76	0	0.00	2	7.41	0	0.00
Participant descibes taking their own research into account when making decisions about treatments (Total)	10	21.28	**2**	**11.11**	8	27.59	2	22.22	3	17.65	5	23.81	4	14.81	6	30.00
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	9	19.15	**1**	**5.56**	8	27.59	2	22.22	3	17.65	4	19.05	4	14.81	5	25.00
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	1	2.13	1	5.56	0	0.00	0	0.00	0	0.00	1	4.76	0	0.00	1	5.00
Participant descibes taking their ability to follow treatments into account when making decisions about treatments (Total)	6	12.77	2	11.11	4	13.79	1	11.11	3	17.65	2	9.52	2	7.41	4	20.00
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	0	0.00	4	13.79	0	0.00	3	17.65	1	4.76	1	3.70	3	15.00
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	2	4.26	2	11.11	0	0.00	1	11.11	0	0.00	1	4.76	1	3.70	1	5.00
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	5	10.64	3	16.67	2	6.90	**2**	**22.22**	1	5.88	2	9.52	4	14.81	1	5.00
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	2	11.11	2	6.90	**2**	**22.22**	0	0.00	2	9.52	4	14.81	0	0.00
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	1	2.13	1	5.56	0	0.00	0	0.00	1	5.88	0	0.00	0	0.00	1	5.00

Considerations when making decisions about treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes taking side effects into account when making decisions about treatments (Total)	24	51.06	16	61.54	8	38.10	11	45.83	13	56.52	12	80.00	12	37.50	15	60.00	9	40.91
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	23	48.94	15	57.69	8	38.10	11	45.83	12	52.17	12	80.00	11	34.38	14	56.00	9	40.91
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00
Participant descibes taking efficacy into account when making decisions about treatments (Total)	18	38.30	8	30.77	10	47.62	9	37.50	9	39.13	7	46.67	11	34.38	11	44.00	7	31.82
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	31.91	8	30.77	7	33.33	8	33.33	7	30.43	7	46.67	8	25.00	9	36.00	6	27.27
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	6.38	0	0.00	3	14.29	1	4.17	2	8.70	0	0.00	3	9.38	2	8.00	1	4.55
Participant descibes taking the advice of their clinician into account when making decisions about treatments (Total)	11	23.40	4	15.38	7	33.33	4	16.67	7	30.43	2	13.33	9	28.13	5	20.00	6	27.27
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	14.89	2	7.69	5	23.81	3	12.50	4	17.39	2	13.33	5	15.63	3	12.00	4	18.18
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	2	8.00	2	9.09
Participant descibes taking quality of life into account when making decisions about treatments (Total)	10	21.28	7	26.92	3	14.29	6	25.00	4	17.39	5	33.33	5	15.63	5	20.00	5	22.73
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	17.02	7	26.92	1	4.76	5	20.83	3	13.04	5	33.33	3	9.38	5	20.00	3	13.64
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09
Participant descibes taking their own research into account when making decisions about treatments (Total)	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	4	26.67	6	18.75	6	24.00	4	18.18
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	9	19.15	5	19.23	4	19.05	4	16.67	5	21.74	4	26.67	5	15.63	6	24.00	3	13.64
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	1	2.13	1	3.85	0	0.00	1	4.17	0	0.00	0	0.00	1	3.13	0	0.00	1	4.55
Participant descibes taking their ability to follow treatments into account when making decisions about treatments (Total)	6	12.77	5	19.23	1	4.76	3	12.50	3	13.04	1	6.67	5	15.63	2	8.00	4	18.18
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	4	15.38	0	0.00	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	2	4.26	1	3.85	1	4.76	2	8.33	0	0.00	0	0.00	2	6.25	0	0.00	2	9.09
Participant descibes taking the impact on their familiy or dependents into account when making decisions about treatments (Total)	5	10.64	2	7.69	3	14.29	3	12.50	2	8.70	1	6.67	4	12.50	4	16.00	1	4.55
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	1	3.85	3	14.29	3	12.50	1	4.35	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00

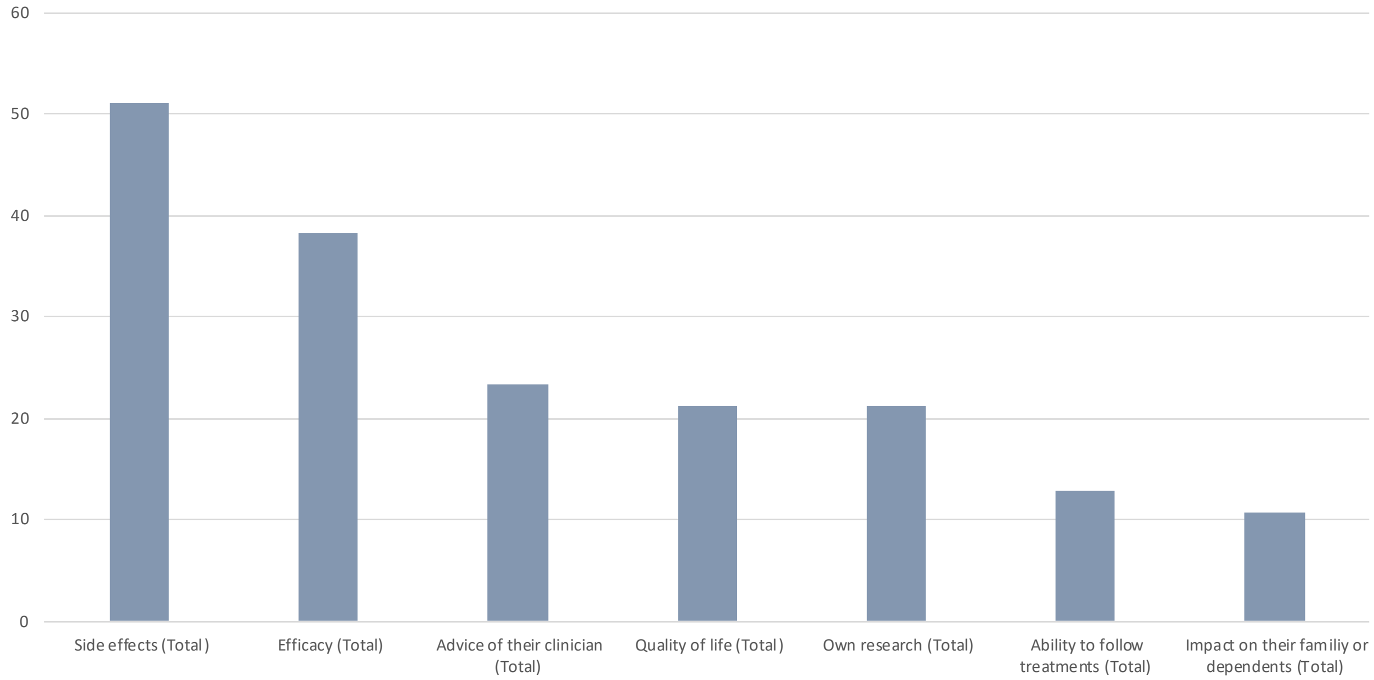

Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
Participant describes taking side effects into account when making decisions about treatments (Total)	Had LP(a) test Blood vessel conditions Male Metropolitan Higher socioeconomic status	Did not had LP(a) test Heart conditions Female Regional or remote
Participant descibes taking efficacy into account when making decisions about treatments (Total)	Had LP(a) test	-
Participant descibes taking the advice of their clinician into account when making decisions about treatments (Total)	Blood vessel conditions Regional or remote	-
Participant descibes taking quality of life into account when making decisions about treatments (Total)	High cholesterol under 50 years of age	Blood vessel conditions Regional or remote
Participant descibes taking their own research into account when making decisions about treatments (Total)	Had LP(a) test	-
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	-	High cholesterol under 50 years of age

Decision-making over time

Participants were asked if the way they made decisions had changed over time. More participants had changed the way that they make decisions (61.70%), than those that had not changed the way they make decisions (34.04%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (27.66%), and more aware of their health, responsibilities and/or limitations (14.89%). Other themes included more cautious and considered (8.51%), more focused impact on family and dependents (8.51%) and more accepting of their condition (6.38%). Where participants had not changed their decision making over time this was because they always been informed/assertive (6.38%).

Changing over time as they are more informed and/or more assertive

No, it's definitely changed. Yeah. And changed because I'm probably. Well, I'm not probably. I'm definitely more educated on my condition and I've probably gained a little bit more confidence in the fact that I can have some autonomy over the treatment. Not just these are the specialists, they're saying we need to do this, we need so that we need to do this. So you know, that's just, I guess, you know, evolving with it and feeling a bit more confident that you know, initially when you're scared it's going to happen again, you do what you're told or I did what I was told, whereas now I'm a little bit more self managed I suppose. Participant 009_2023AUHBV

Yeah I think, well I feel, I think initially, because I was quite shell shocked, I would generally just go with whatever I was told to do. I think since then, I feel like I'm, what's the word? I feel more empowered to make my own medical decisions and be able to find resources and people that I can talk to about my different options. Participant 035_2023AUHBV

Well, I think I make them a bit differently. I think I make sure I'm much more informed myself. And I've become more informed over time, I suppose. And yeah, that that's probably the thing that I've that I've become more informed and more proactive with my own treatment in a way you know don't like. I didn't hesitate to ring the caveat and say I need to come and see you even though I wasn't on A. It was. It was out of sync with my regular referral. Do you know what I mean? Yeah. So. So I I made those decisions. Yeah. So I suppose it has changed because if I think there's something wrong, I think, well, I'm going to get someone to talk to about this. I'm not going to let it go.
Participant 013_2023AUHBV

No, I think it's changed. It's changed, because I make myself more knowledgeable. I think the internet has -- I know that people make a diagnosis from the internet. I don't do that, but I do like to read up on what is available and to read scholarly articles rather than just Wikipedia or whatever it is so that I can make an informed decision, and also that when my cardiologist talks to me about something, I need to understand what he's talking about and to have a clear discussion with him. If I don't understand something, I will ask him, go back, do a research, and then make myself knowledgeable. I think that has changed because now everything is so easily accessible.
Participant 034_2023AUHBV

I don't know. I think I'm a little more proactive in asking for what I want now rather than what I was in the beginning.
Participant 008_2023AUHBV

I think I'm quite cautious, and I don't think that's changed. I don't think so. It's a bit like people say, "Well, you've been through all these things. It must get easier." Well, it doesn't actually get easier, and I

don't think, as you go on, that the way you make decisions changes. I mean, you perhaps make more informed decisions, and, yeah, so I think it would be that. It would be they've been more informed decisions and I have a greater resource pool around me of places that I can go to get answers, and I'm definitely more -- this is probably the wrong word, but I'm more -- In the beginning, I would have been reluctant to call and ask a question or something like that because I wouldn't wanna disturb anyone, whereas now I -- I mean, sometimes it causes me a lot of angst, but I do make those calls and ask all my questions, and that sort of thing. Yeah. So, yes, I guess it has changed.
Participant 023_2023AUHBV

Changing over time as they are more aware of their health, responsibilities and/or limitations

Yes, I do. I am more deliberate about my decision making. I tend to overly research and overly consider all the factors before I make a decision. Prior to the stroke, I would not do that into so much depth. Mainly because I still have a poor short-term memory and therefore I have to work harder to understand and soak up information, whereas before with a sound short-term memory you just keep building on the information. It's a more arduous task for me lately. I have to be more deliberate, more measured, more careful.
Participant 045_2023AUHBV

Changing over time as they are more cautious and considered

Yes, generally, but it's been 13 years, so my decision-making is more balanced and less impulsive, but that may just be a factor of age.
Participant 046_2023AUHBV

I'm more cautious now since my stroke. Very cautious.
Participant 049_2023AUHBV

Changing over time as they are more focused on how treatment impacts their family and dependents

I did. I obviously didn't make any decisions until I was probably 15 or 16. Most of that was Mom and Dad. And then I was mom and dad and I had a pretty good relationship where it was they sort of. Thought that I understood what was going on at around 14 and 15 and 16. So then they sort of been started to include me in that. But then since about yeah 1819 it's up to me. But most of my decision making is pretty straightforward. It's do I basically keep saying this doctor or do I go get an ECG or there. Most of that's pretty self-explanatory and that doesn't require much decision making whatsoever. But I'm sure a time will come where? I need to give it a little bit more critical thinking and then in that sense I'm a pretty pragmatic person and I like to think about things, probably overthink things sometimes and in that sense we'll we'll see what comes. But I imagine it'll be a pretty pragmatic and a an all inclusive sort of decision making process. It's not just me anymore it's my partner and mum and dad. All those people have a have a stake in my My health as well. So we'll, it'll be a sounding board sort of area.
Participant 012_2023AUHBV

It's changed. I think I've -- Yeah, I tend to ask a lot of questions whereas at first I thought, "Oh, it's my heart. The doctors know the best," and so on. But really there's other things now that you've got to factor in, like family. Not that I didn't before, but I didn't have a child when I was diagnosed, so there's a lot more to consider now, in regards to treatments and so on and what impact it'll have on my life.
Participant 030_2023AUHBV

I think it's changed to in in degree rather than in in process and method if you like. In that I I value quality of life over longevity. And I value well, I suppose it's quality of life, the enablement of activities that I want to do. So one of the things that I've found quite difficult, I I live in Toowoomba, I have a wood stove in my house and I love chopping wood. It's, you know, one of those fabulous, both constructive and destructive exercises that gives you something you need and vents your frustration. I love it and I can't shop wood anymore. My chest is just, it hurts my chest just too much. And you know, I've got some soft celtas that I've had trees cut down and I can cut that as long as I limit myself to about 10 minutes. But I can't cut hard wood and that noise. So I guess my the intensity of my decision making is around the quality of the things I want to do.
Participant 010_2023AUHBV

Changing over time as they are more accepting of their condition and choices available

PARTICIPANT: Absolutely. Yeah. I think so. As, I've become more educated. I think when you've got something like this you end up becoming a professional in your own diagnosis. You're own disease. As you learn more, you take more into account and you become a little bit more open minded I think, and not so fearful of your disease. I'm not scared of my disease anymore. I used to be terrified of

it. I used to be terrified of my own heart. But now I'm not.
INTERVIEWER: That's good.
PARTICIPANT: Yeah. For sure. I think I've definitely, definitely changed in that aspect.
Participant 036_2023AUHBV

No, it has changed a lot. Being the way my head and everything is, is I don't question anything. So if the doctors prescribing me with something, I'd take them for their word and I just take it. I don't even, I don't even really take too much thought into side effects or anything like that much anymore. I just take it.
Participant 021_2023AUHBV

No change in decision-making over time as they have always been informed/assertive

At the start, I had no idea what was going on so I wasn't really capable of making decisions properly. As long as the virus is around and the border is closed that's going to affect the decisions I make. I can't drive so that definitely affects the decisions I make about how close people are to be able to get to them because I can't…Because I'm in LOCATION REGIONAL, I can't catch a taxi to the biggest centre because it just cost too much money, in fact I don't think the taxi would take me that far. That makes decisions about who I see and what happens. About the way I make decisions? That's just the same because I would just get as much evidence about something I can at the time and then try to make the best decision and if it's not good change it and make another decision.
Participant 041_2023AUHBV

I think I am a lot more proactive in the way I approach decision making. I've always been kind of known. I don't actually. I don't think I have changed very much with regard to it because I've always been quite proactive in in my health and everything like that. So yeah, not really changed.
Participant 011_2023AUHBV

Table 4.7: Decision-making over time

Decision-making over time	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Change	29	61.70	7	38.89	22	75.86	7	77.78	11	64.71	11	52.38	14	51.85	15	75.00
No change	16	34.04	10	55.56	6	20.69	2	22.22	5	29.41	9	42.86	12	44.44	4	20.00
Other/no response	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00

Decision-making over time	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Change	29	61.70	16	61.54	13	61.90	13	54.17	16	69.57	9	60.00	20	62.50	14	56.00	15	68.18
No change	16	34.04	9	34.62	7	33.33	10	41.67	6	26.09	6	40.00	10	31.25	11	44.00	5	22.73
Other/no response	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09

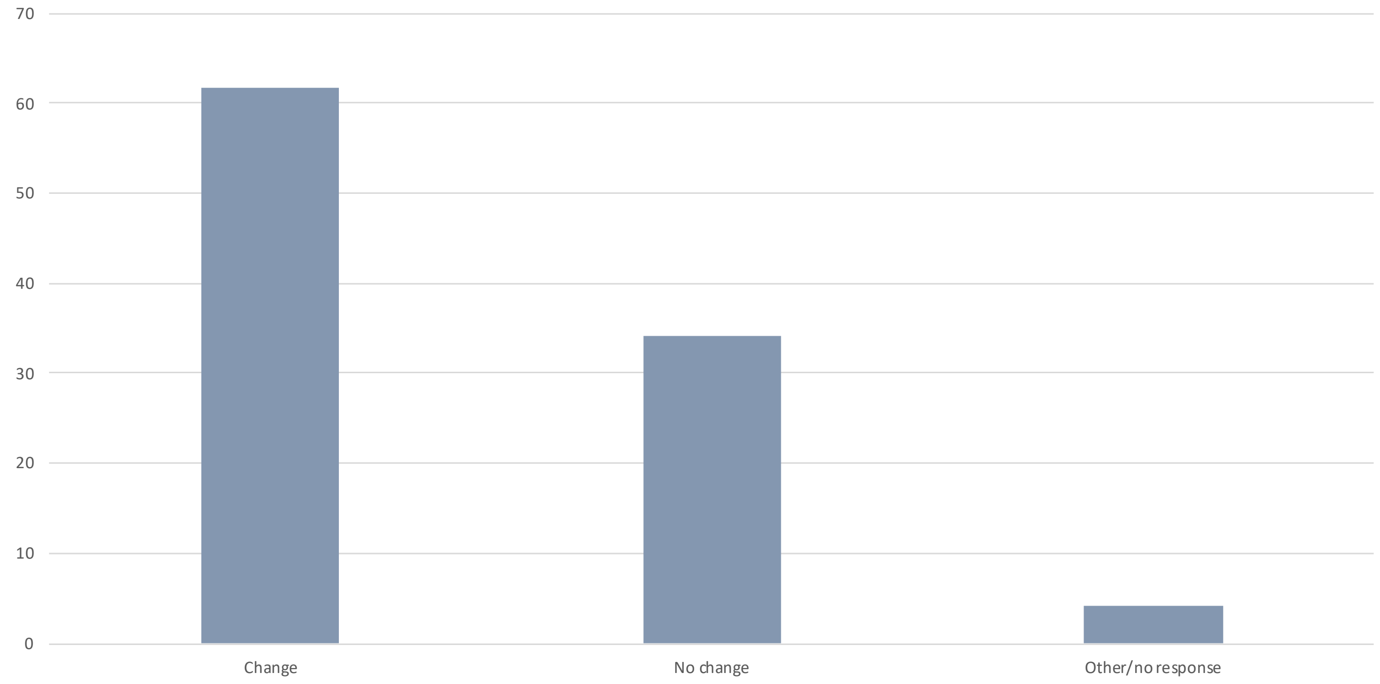

Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Change	Had LP(a) test	Did not had LP(a) test High cholesterol under 50 years of age 6 to 11 other conditions
No change	Did not had LP(a) test High cholesterol under 50 years of age 6 to 11 other conditions Higher socioeconomic status	Had LP(a) test 0 to 5 other conditions

Table 4.9: Decision-making over time (reasons)– subgroup variations

Decision-making over time (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Changing over time as they are more informed and/or more assertive	13	27.66	1	5.56	12	41.38	2	22.22	4	23.53	7	33.33	7	25.93	6	30.00
Changing over time as they are more aware of their health, responsibilities and/or limitations	7	14.89	1	5.56	6	20.69	2	22.22	4	23.53	1	4.76	3	11.11	4	20.00
Changing over time as they are more cautious and considered	4	8.51	0	0.00	4	13.79	1	11.11	3	17.65	0	0.00	1	3.70	3	15.00
Changing over time as they are more focused on how treatment impacts their family and dependents	4	8.51	1	5.56	3	10.34	2	22.22	1	5.88	1	4.76	3	11.11	1	5.00
Changing over time and there is no particular reason noted	3	6.38	3	16.67	0	0.00	2	22.22	0	0.00	1	4.76	1	3.70	2	10.00
Changing over time as they are more accepting of their condition and choices available	3	6.38	1	5.56	2	6.90	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00
No change in decision-making over time and there is no particular reason noted	8	17.02	5	27.78	3	10.34	1	11.11	4	23.53	3	14.29	7	25.93	1	5.00
No change in decision-making over time as they have always been informed/assertive	3	6.38	1	5.56	2	6.90	0	0.00	3	17.65	0	0.00	0	0.00	3	15.00

Decision-making over time (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Changing over time as they are more informed and/or more assertive	13	27.66	8	30.77	5	23.81	2	8.33	11	47.83	4	26.67	9	28.13	7	28.00	6	27.27
Changing over time as they are more aware of their health, responsibilities and/or limitations	7	14.89	4	15.38	3	14.29	4	16.67	3	13.04	2	13.33	5	15.63	3	12.00	4	18.18
Changing over time as they are more cautious and considered	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Changing over time as they are more focused on how treatment impacts their family and dependents	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	0	0.00	4	12.50	1	4.00	3	13.64
Changing over time and there is no particular reason noted	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	0	0.00	3	9.38	0	0.00	3	13.64
Changing over time as they are more accepting of their condition and choices available	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55
No change in decision-making over time and there is no particular reason noted	8	17.02	5	19.23	3	14.29	6	25.00	2	8.70	4	26.67	4	12.50	6	24.00	2	9.09
No change in decision-making over time as they have always been informed/assertive	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55

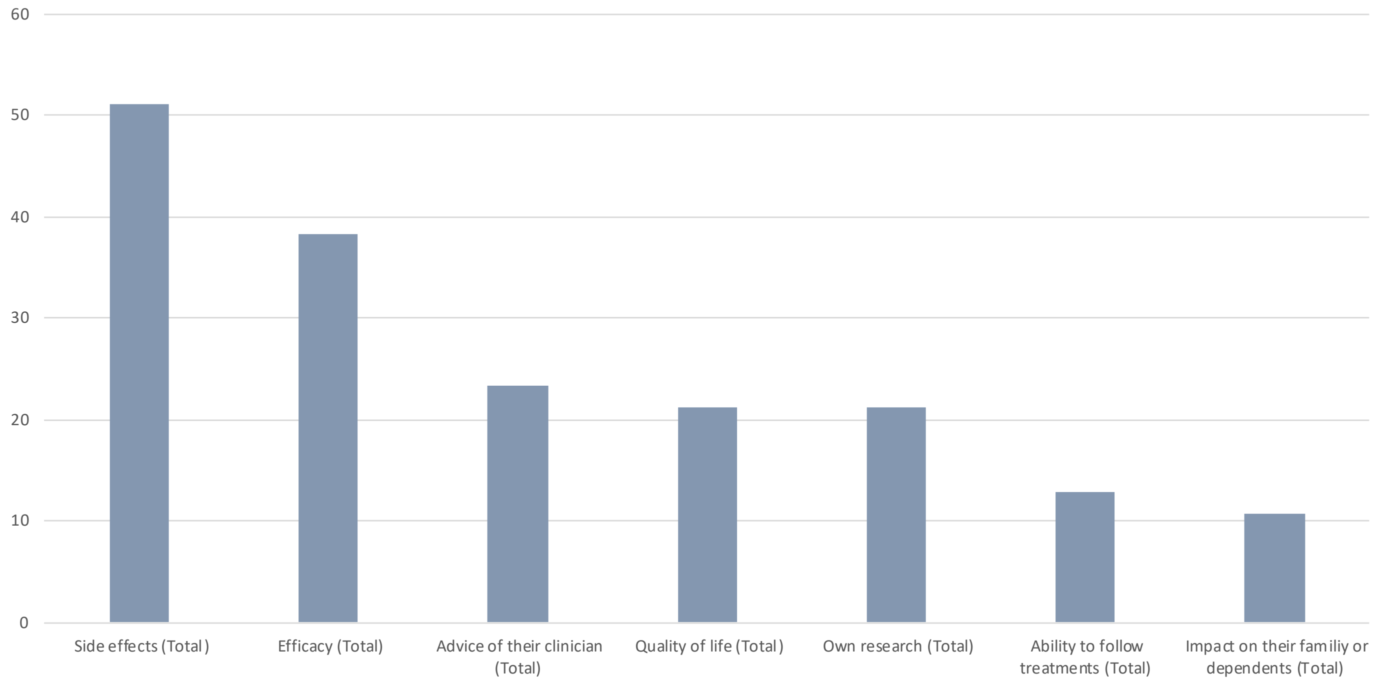

Figure 4.5: Decision-making over time (reasons)– subgroup variations

Table 4.10: Decision-making over time (reasons)– subgroup variations

Decision-making over time (reasons)	Reported less frequently	Reported more frequently
Changing over time as they are more informed and/or more assertive	Had LP(a) test Aged 25 to 44	Did not had LP(a) test Aged 45 and older
Changing over time as they are more aware of their health, responsibilities and/or limitations	Heart conditions	
Changing over time as they are more focused on how treatment impacts their family and dependents	-	High cholesterol under 50 years of age
Changing over time and there is no particular reason noted	-	Had LP(a) test High cholesterol under 50 years of age
Changing over time as they are more accepting of their condition and choices available	-	
No change in decision-making over time and there is no particular reason noted	6 to 11 other conditions	Had LP(a) test
No change in decision-making over time as they have always been informed/assertive	-	Blood vessel conditions

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to to make lifestyle changes to be fit and healthy (14.89%), have physical improvements in their condition (12.77%), and to have quality of life or to return to normality(12.77 %). There were 4 participants, and they had no personal goals of treatment or care (8.51%).

Participants describe wanting to make lifestyle changes to be fit and healthy

PARTICIPANT: Like like it's like normal gym. And I was regularly walking and I'm very now, now, now after some blood pressure issue, my all the families are very serious about our diets, right?
INTERVIEWER: Great. So fabulous. So it's exercise and diet you're doing. Did you talk to your doctor about these, the exercise and the diet?
PARTICIPANT: Yeah, the doctor told to me like I need to be regular, walk early in the morning and maybe in the evening. The one time will be the best. And she said to me, like, the walk will be in a sense, like no running, no jogging, just a walk for 30 to 35 for the 40 minutes. Yeah.
Participant 027_2023AUHBV

My goal is not to die before I'm 60, which is pretty much my mother's side. They've all died before they're 60. So, you know, my, my goal is to and I lead by example because I want to be able to eat healthy, exercise and you know, and do all that sort of stuff. And you know, if at the end of the day that doesn't help me, well, you can't beat genes. But you know, that is my main goal. You know, I was told that if I didn't make all these dietary changes, I was going to be dead by 40. I'm 44 on Sunday, so I am still here. So, yeah, I don't have any long term goals, you know, beyond that sort of, you know, take it a year by year at this stage.
Participant 028_2023AUHBV

So I know that there's no other way to treat my conditions other than take this regime of medications that I'm on and the and the other control that I have is is to stay fit and healthy like by walking exercise and and you know not. Coming overweight and you know dietary control is not drinking too much alcohol and all that sort of stuff. So I'm aware of all those things and they're the things and and I and I think I'm in a pretty good place right now. So I figured that I can manage all those things. There's only one advocate here for your health for you if your health is you. So that's how I see it. So I'm I think I'm aware of what I need to do and yeah.
Participant 013_2023AUHBV

Participants describe wanting to see physical improvements in their condition

My personal goal is to make sure my ejection fraction gets as high as it can do and that the rest of my heart is as healthy as it can be.
Participant 015_2023AUHBV

Now, I would like to be able to go through a week without feeling absolutely exhausted.
Participant 047_2023AUHBV

Participant describes wanting to improve their quality of life or return to normality

I don't get my life back so before this happens we we're caravanning, boating, family, so. Weekends look like going out in the boat and camping and having fun and all those sorts of things. Quite active. So I and even more so than going back to work. For me, going back to work is so that we could afford to do fun things again. So I love traveling. So yeah, my. I suppose my end goal is to get my life back, and in order to do that financially, I need to go back to work. I suppose is is the driving thing about wanting to go to work, because hey, who? Who? Who wouldn't like to stay home every day and be well and enjoy it at the

same time. So my big goal is to get my life back and be healthy.
Participant 014_2023AUHBV

More like a I think I'm more looking at the side of things like where I can just live a normal life without stressing with about it. Like just get it to back to normal or get it back to. Yeah, just as best as I can. So I don't have to stress about it.
Participant 029_2023AUHBV

Table 4.11: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participants describe wanting to make lifestyle changes to be fit and healthy	7	14.89	1	5.56	6	20.69	2	22.22	2	11.76	3	14.29	5	18.52	2	10.00
Participants describe wanting to see physical improvements in their condition	6	12.77	5	27.78	1	3.45	0	0.00	5	29.41	1	4.76	4	14.81	2	10.00
Participant describes wanting to improve their quality of life or return to normality	6	12.77	4	22.22	2	6.90	0	0.00	4	23.53	2	9.52	4	14.81	2	10.00
Participant describes no personal goals of treatment or care (no reason given)	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	2	7.41	2	10.00

Personal goals of treatment or care	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participants describe wanting to make lifestyle changes to be fit and healthy	7	14.89	3	11.54	4	19.05	4	16.67	3	13.04	2	13.33	5	15.63	5	20.00	2	9.09
Participants describe wanting to see physical improvements in their condition	6	12.77	3	11.54	3	14.29	2	8.33	4	17.39	1	6.67	5	15.63	3	12.00	3	13.64
Participant describes wanting to improve their quality of life or return to normality	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	3	20.00	3	9.38	4	16.00	2	9.09
Participant describes no personal goals of treatment or care (no reason given)	4	8.51	3	11.54	1	4.76	1	4.17	3	13.04	1	6.67	3	9.38	4	16.00	0	0.00

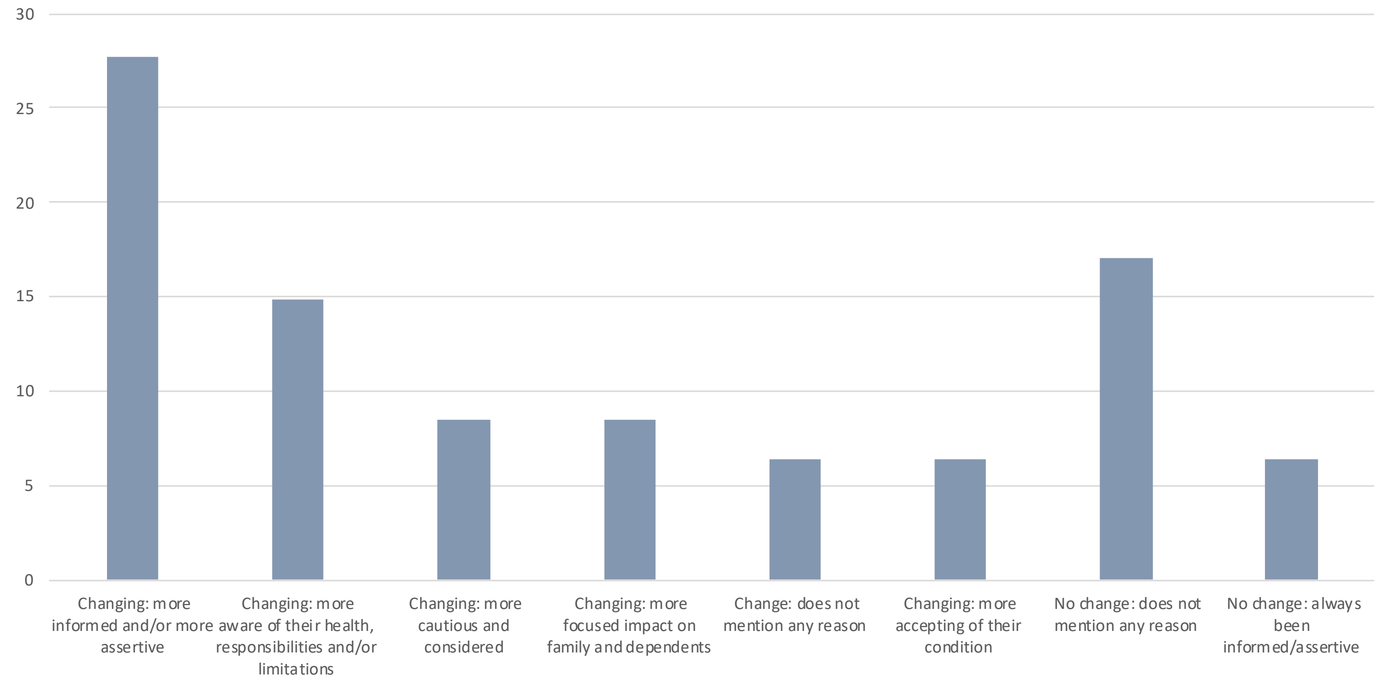

Figure 4.6: Personal goals of treatment or care

Table 4.12: Personal goals of treatment or care – subgroup variations

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participants describe wanting to see physical improvements in their condition	High cholesterol under 50 years of age	Had LP(a) test Blood vessel conditions
Participant describes wanting to improve their quality of life or return to normality	High cholesterol under 50 years of age	Blood vessel conditions

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were General practitioner (GP)s (n=25,50.00 %), followed by Cardiologists (n=17, 34.00%).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 12 participants (40.00%) that travelled for less than 15 minutes, 8 participants (26.67%) that travelled between 15 and 30 minutes, 6 participants (20.00%) that travelled between 30 and 60 minutes, 1 participants (3.33%) that travelled between 60 and 90 minutes, and 2 participants (6.67%) that travelled more than 90 minutes.

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

The majority of participants had access to a General Practitioner (GP) (n=43, 86.00%), and a Cardiologist (n=32, 64.00%). There were 11 participants (22.00%) that had a Specialist nurse, and 5 participants (10.00%) that had a Care coordinator, discharge planner or key worker.

Psychologist to care for their condition (n=13, 26.00%). There were 21 participants (42.00%) treated by a Dietitian/ nutritionist, 21 participants (42.00%) with a by a Pharmacist/ chemist, 13 participants (26.00%) cared for by a Psychologist, and 13 participants (26.00%) treated by a Exercise physiologist.

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 28 participants (56.00%) that indicated that they had been treated with respect throughout their experience, and 16 participants (32.00%) that were treated with respect with the exception of one or two occasions. There were 6 participants (12.00%) that felt they had not been treated respectfully.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=34, 68.00%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=32, 64.00%), however, they were asked if they had private health insurance (n=33, 66.00%).

Throughout their treatment, there were 19 participants (38.00%) that were treated as a private patient, 22 participants (44.00%) were mostly treated as a public patient, and there were 5 participants (10.00%) that were equally treated as a private and public patient.

Throughout their treatment, there were 15 participants (30.00%) that were treated mostly in the private hospital system, 28 participants (56.00%) were mostly treated in the public system, and there were 7 participants (14.00%) that were equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire.

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 35, 70.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=43, 86.00%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 37 participants (74.00%) that never or rarely had trouble paying for essentials, and 7 participants (14.00%) that sometimes found it difficult, and 6 participants (12.00%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 9 participants (18.00%) that paid for additional carers due to their condition.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below.

The most common amount was $100 or less (n=16, 32.00%), followed by between $101 to $250 (n=9, 18.00%). There were 3 participants (6.00%), that spent $1001 or more a month.

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was an extremely significant or moderately significant burden for 13 participants (26.00%), somewhat significant for 15 participants (30.00%), and slightly or not at all significant for 22 participants (44.00%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 13 participants (26.00%) had not changed since diagnosis, and 6 participants (12.00%) were retired or did not have a job. There were 17 participants (34.00%) had to quit their job, 9 participants (18.00%) reduced the number of hours they worked, and 3 participants (6.00%) that accessed their superannuation early. There were 7 participants (14.00%) that took leave from work without pay, and 11 participants (22.00%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

There were 16 participants (32.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=26, 52.00%). There was 1 participant (2.00%) whose partner reduced the numbers of hours they worked, and 1 partner, (2.00%) that quit their job. The partners of 2 participants (4.00%) took leave without pay, and there were 3 partners (6.00%) that took leave with pay.

Reduced income due to condition

There were 20 participants (42.55%) that indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is listed in the table below.

Most commonly, participants were not sure about the amount their monthly income was reduced by $2000 to $5000 per month (n=7, 14.89%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For 11 of these participants (55.00%), the burden of this reduced income was extremely or moderately significant, for 5 participants (25.00%) the burden was somewhat significant, and for 4 participants (20.00%) the burden was slightly or not all significant.

Treatments overview

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition.

There were 17 participants (34.00%) that had surgical treatments, 40 participants (80.00%) that had drug treatments and 28 participants (56.00%) that used allied health services. The majority of participants had made lifestyle changes (n=42, 84%), and approximately a third used complementary therapies (n=42) (n=15, 35.71%).

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects.
Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 6 participants (12.00%) that had coronary angioplasty, percutaneous coronary intervention or stents, 5 participants (10.00%) that had pacemaker or an implantable cardiac defibrillator (ICD) and 4 participants (8.00%) that had surgery for pacemaker or implantable cardioverter defibrillator. Other surgical interventions included Bypass surgery (n=2, 4.00%), and Heart valve surgery (n=1, 2.00%).

On average, quality of life from coronary angioplasty, percutaneous coronary intervention or stents was in the 'life was good' range (median=5.00, IQR = 2.25), and was found to be very effective (median=5.00 , IQR=0.00).

On average, quality of life from pacemaker or an implantable cardiac defibrillator (ICD) was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00 , IQR=1.00).

Summary of drug treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 23 participants (46.00%) that had antiplatelets, 18 participants (36.00%) that had beta blockers and 18 participants (36.00%) that had statins. Participants also took ACE inhibitors (n=10, 20%), ARBs (n=8, 16%), diurectics (n=6, 12%), cholesterol absorption inhibitors (n=5, 10.00%), calcium channel blockers (n=3, 6.00%), ARNIs (n=2, 4.00%), sinus node inhibitors (n=2, 4.00%), and glycosides (n=2, 4.00%).

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”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective.

On average, quality of life from antiplatelets was in the 'life was average' range (median=4.00, IQR = 1.00), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from beta blockers was in the 'life was average to good' range (median=4.50, IQR=2.75), and was found to be effective (median=4.50 , IQR=1.00).

On average, quality of life from statins was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective to very effective (median=4.00 , IQR=1.00).

On average, quality of life from ACE inhibitors was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from ARBs e.g. candesartan, losartan, valsartan was in the 'life was average' range (median=4.00, IQR=2.25), and was found to be moderately effective to effective (median=3.50 , IQR=2.25).

On average, quality of life from anticoagulants was in the 'life was good to very good' range (median=5.50, IQR=3.25), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from diuretics was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from cholesterol absorption inhibitors was in the 'life was average' range (median=5.00, IQR=0.00), and was found to be effective (median=4.00 , IQR=0.00).

Allied health

The most common allied health service used was seeing a dietician (n=14, 28.00%), followed by physiotherapy (n=13, 26.00%), and psychology or counselling (n=12, 24.00%). There were 9 participants (18.00%) that had occupational therapy, 9 participants (18.00%) that had speech therapy, and 5 participants (10.00%) that saw a social worker.

On average, quality of life from seeing a dietician was in the 'life was average' range (median=4.00, IQR = 2.75), and was found to be effective (median=4.00, IQR = 1.00).

On average, quality of life from physiotherapy was in the 'life was a little distressing' range (median=3.00, IQR=3.00), and was found to be effective (median=4.00, IQR=3.00).

On average, quality of life from psychology or counselling was in the 'life was distressing' range (median=2.00, IQR=2.25), and was found to be moderately effective (median=3.00, IQR=2.00).

On average, quality of life from occupational therapy was in the 'life was average' range (median=4.00, IQR=3.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from speech therapy was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from social work was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00, IQR=4.00).

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them.

The majority of participants used at made at least one lifestyle change (n=42, 84.00%), and on average made 2 changes (median=2.00, IQR=1.75).

The most common lifestyle changes used were diet changes (n=29, 58.00%), and exercise (n=29, 58.00%), followed by and Quitting or cutting back on alcohol (n=19, 38.00%), and Quitting or cutting back on smoking (n=10, 20.00%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from quitting or cutting back on alcohol was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from quitting or cutting back on smoking was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them.

Approximately a third of participants used at least one complementary therapy (n=15, 35.71%). The most common complementary therapy used was Mindfulness or relaxation techniques (n=11, 26.19%), followed by Massage therapy (n=7, 16.67%), Supplements (n=6, 14.29%), and acupuncture (n=5, 11.90%)

On average, quality of life from mindfulness or relaxation techniques was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.50).

On average, quality of life from massage therapy was in the 'life was distressing' range (median=2.00, IQR=2.50), and was found to be moderately effective (median=3.00, IQR=2.50).

On average, quality of life from supplements was in the 'life was average to good' range (median=4.50, IQR=2.50), and was found to be moderately effective to effective (median=3.50, IQR=1.00).

On average, quality of life from Acupuncture was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=3.00, IQR=2.00).

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 4 participants (8%) that had discussions about clinical trials, 3 participants (6.00%) had brought up the topic with their doctor, and the doctor of 1 participant (2.00%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=46, 92.00%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There was 1 participant (2.00%) that had taken part in a clinical trial, 36 participants (72.00%) that would like to take part in a clinical trial if there was a suitable one, and 13 participants, that have not participated in a clinical trial and do not want to (26.00%).

Treatment and management following lipoprotein a test

Lipoprotein a testing

In the online questionnaire, participants noted if they had a Lipoprotein a test. There were 24 participants (43.64%) that had a Lipoprotein a test.

Lipoprotein a test results

As a follow up question, participants were asked if they knew the result of their Lipoprotein a test. There were 9 participants (16.36%) that did not know their result, 9 participants (16.36%) that knew result and gave a numerical value, and 6 participants (10.91%) that were not sure of exact result but that it was high.

Changes in treatment and management following Lipoprotein a testing

Participants noted in the online questionnaire any changes their doctor made to the treatment or management of their condition following lipoprotein a testing.

Most commonly, changes were made to medication (n=10, 41.67%), followed by recommendations for diet and lifestyle changes (n=6, 25.00%). There were 5 participants (20.83%) that were had additional monitoring, and 2 participants (8.33%), that had no made changes to treatment or management.

Participant-made changes following lipoprotein a/Lp(a) results

In the online questionnaire, participants noted the changes that they had made following getting their lipoprotein a/Lp(a) results.

The majority of participants made diet changes (n=18, 75.00%), and half the participants (50.00%) tried to exercise more. There were 8 participants (33.33%) that tried to drink less alcohol, and 8 participants (33.33%) that tried to lose weight. Other changes included tried to give up smoking (20.83%), became more careful about taking medicatins (16.67%) and became more caredful about making and attending medical appointments (12.50%). There were 2 participants (12.50%) that made no changes following thier lipoprotein a test result.

After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Participants noted the activities they had done to learn more about lipoprotein a.

More than half of the participants looked for information about it (n=13, 54.17%), and a third asked their doctor about it (n=8, 33.33%). There were 3 participants (12.50%) that joined a heart management program, and 3 participants (12.50%) that joined a patient group. There were 9 participants (37.50%) that did not do anything to find out more about Lp(a).

Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Participants were asked if family members had a lipoprotein a /Lp(a) test because of test result. There were 6 participants (25.00%) that noted other family members had this test due to their result.

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were described using a specific example (57.45%), and those that do not interfere with life (36.17%). Other themes included side effects that have a short duration (10.64%), and that they had only experienced or only described severe side effects (8.51%).

When a specific side effect was described, the most common side effects were aches and pain (23.40%), fatigue/lethargy (23.40%), headaches (6.38%), and nausea, vomiting,or loss of appetite (6.38%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were described using a specific example (57.45%), and those that impact everyday life or ability to conduct activities of daily living (34.04%). Other themes included those that are life threatening or result in hospitalisation (6.38%), those that cause long-term damage to their body (6.38%), those that requires medical intervention (6.38%), and those that cause a need to change or stop using medication (6.38%).

When a specific side effect was described, the most common examples were aches and pain (21.28%), cognitive difficulties, including brain fog and difficulty communicating (14.89%), the emotional or mental impact (10.64%). Other side effects included fatigue or lethargy (10.64%), nausea, vomiting,or loss of appetite (6.38%), reduced mobility or loss of independence (6.38%), and shortness of breath (6.38%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment for a specific amount of time (46.81%), adhering to treatment according to the advice of their specialist or as long as prescribed (27.66%), and adhering to treatment as long as side effects are tolerable (25.53 %). Other themes included never giving up on any treatment (21.28%), and adhering to treatment as long as treatment is working (21.28%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (14.89%), and six to twelve months (8.51%).

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 responses were needing to see a specific symptom reduction (44.68%), and needing to see physical signs and symptoms disappear or reduce side effects (27.66%). Other themes included needing to see test results (14.89%), needing to see a return to day-to-day functionality (12.77%), and needing to have a balance between benefits and potential side effects (8.51%).

When a specific side effect or symptom was described, the most common examples were fatigue or lethargy (17.02%), heart rate or regular heart beat (8.51%), aches or pain (6.38 %), and the emotional, or mental impact (6.38%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (17.02%), and it would lead to a reduction in symptoms or side effects (14.89%). This was followed by it would have positive impact on their mental health (12.77 %), and allow them to engage more with social activities and family life (8.51%).

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were General practitioner (GP)s (n=25,50.00 %), followed by Cardiologists (n=17, 34.00%).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 12 participants (40.00%) that travelled for less than 15 minutes, 8 participants (26.67%) that travelled between 15 and 30 minutes, 6 participants (20.00%) that travelled between 30 and 60 minutes, 1 participants (3.33%) that travelled between 60 and 90 minutes, and 2 participants (6.67%) that travelled more than 90 minutes.

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=50)	Percent
General practitioner (GP)	25	50.00
Cardiologist	17	34.00
Neurologist	4	8.00
Multi-disciplinary	3	6.00
No main provider	1	2.00

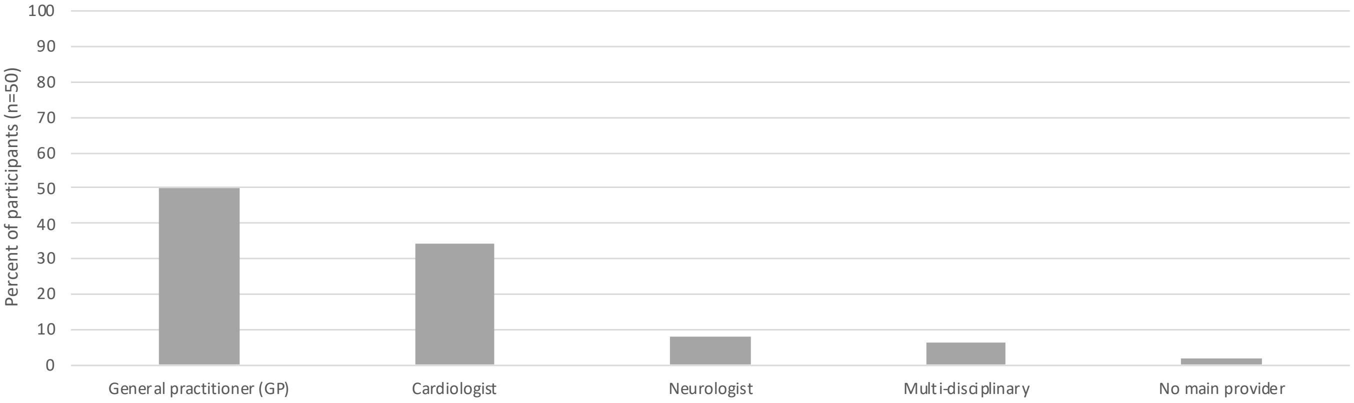

Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Main provider of treatment	Number (n=30)	Percent
Less than 15 minutes	12	40.00
Between 15 and 30 minutes	8	26.67
Between 30 and 60 minutes	6	20.00
Between 60 and 90 minutes	1	3.33
More than 90 minutes	2	6.67
No main provider	1	3.33

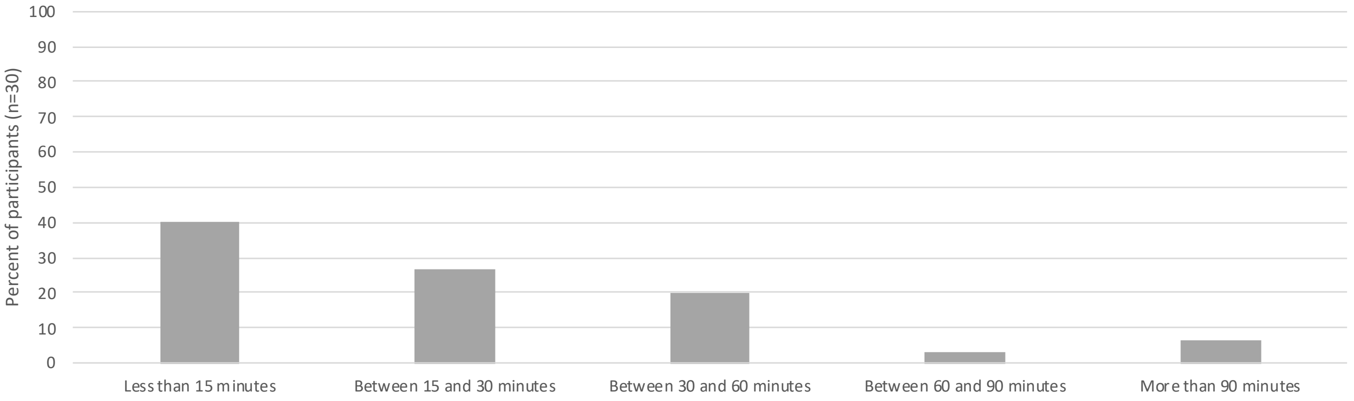

Figure 5.2: Time to travel to main provider of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

The majority of participants had access to a General Practitioner (GP) (n=43, 86.00%), and a Cardiologist (n=32, 64.00%). There were 11 participants (22.00%) that had a Specialist nurse, and 5 participants (10.00%) that had a Care coordinator, discharge planner or key worker.

Psychologist to care for their condition (n=13, 26.00%). There were 21 participants (42.00%) treated by a Dietitian/ nutritionist, 21 participants (42.00%) with a by a Pharmacist/ chemist, 13 participants (26.00%) cared for by a Psychologist, and 13 participants (26.00%) treated by a Exercise physiologist.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=50)	Percent
Cardiologist	32	64.00
Emergency doctor	14	28.00
Neurologist	12	24.00
Physiotherapist	11	22.00
Rehabilitation physician	7	14.00
Surgeon	7	14.00
General Practitioner (GP)	43	86.00
Specialist nurse	11	22.00
Care coordinator, discharge planner or key worker	5	10.00
Registered Nurse	4	8.00
Community nurse	1	2.00
Dietitian/ nutritionist	21	42.00
Pharmacist/ chemist	21	42.00
Exercise physiologist	13	26.00
Psychologist	13	26.00
Occupational therapist	10	20.00
Cardiac rehabilitation	8	16.00
Speech pathologist	6	12.00
Ophthalmologist/ orthopedist	5	10.00
Social worker	5	10.00
Neuropsychologist	4	8.00
Chiropractor	3	6.00
Counsellor	3	6.00

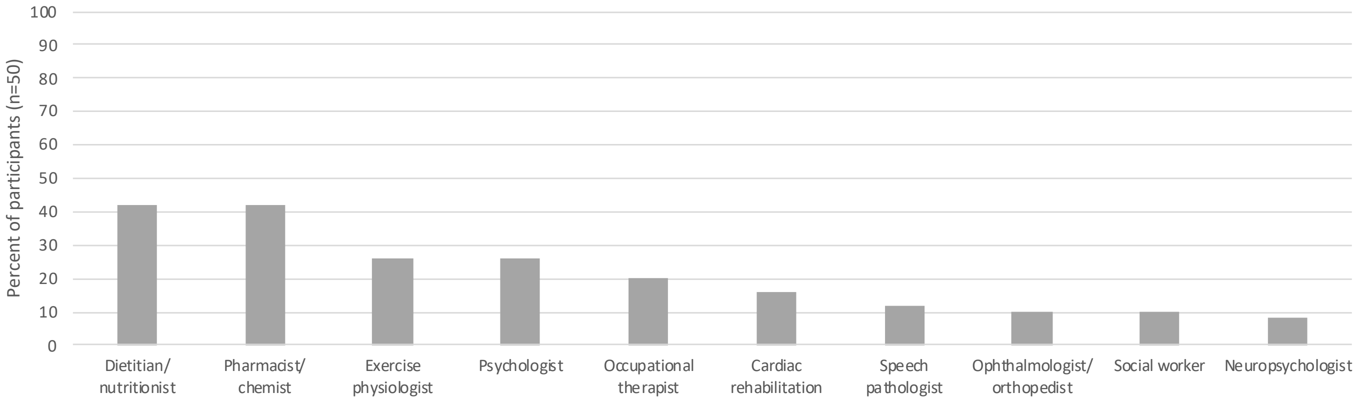

Figure 5.3: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 28 participants (56.00%) that indicated that they had been treated with respect throughout their experience, and 16 participants (32.00%) that were treated with respect with the exception of one or two occasions. There were 6 participants (12.00%) that felt they had not been treated respectfully.

Table 5.4: Respect shown

Respect shown	Number (n=50)	Percent
Respect shown	28	56.00
Respect shown, with the exception of one or two occasions	16	32.00
Respect not shown	6	12.00

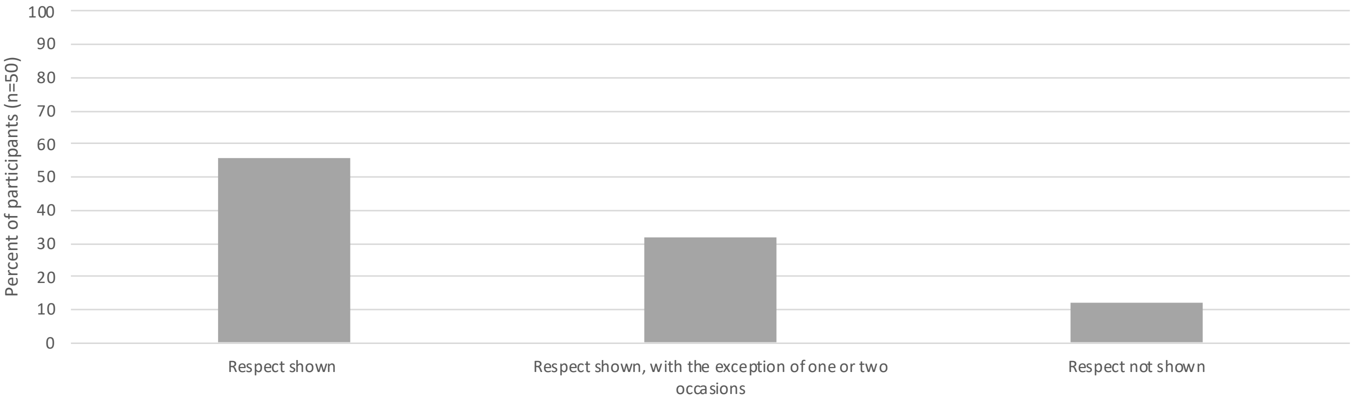

Figure 5.4: Respect shown

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=34, 68.00%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=32, 64.00%), however, they were asked if they had private health insurance (n=33, 66.00%).

Throughout their treatment, there were 19 participants (38.00%) that were treated as a private patient, 22 participants (44.00%) were mostly treated as a public patient, and there were 5 participants (10.00%) that were equally treated as a private and public patient.

Throughout their treatment, there were 15 participants (30.00%) that were treated mostly in the private hospital system, 28 participants (56.00%) were mostly treated in the public system, and there were 7 participants (14.00%) that were equally treated in the private and public systems.

Table 5.5: Health care system

Health care services	Response	Number (n=50)	Percent
Private health insurance	No	16	32.00
	Yes	34	68.00
Asked whether you want to be treated as a public or private patient	No	32	64.00
	Yes	18	36.00
Asked whether you had private health insurance	No	17	34.00
	Yes	33	66.00
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	5	10.00
	Private patient	19	38.00
	Public patient	22	44.00
	Not sure	4	8.00
Which hospital system have you primarily been treated in	Both public and private	7	14.00
	Private	15	30.00
	Public patient	28	56.00
	Not sure	0	0.00

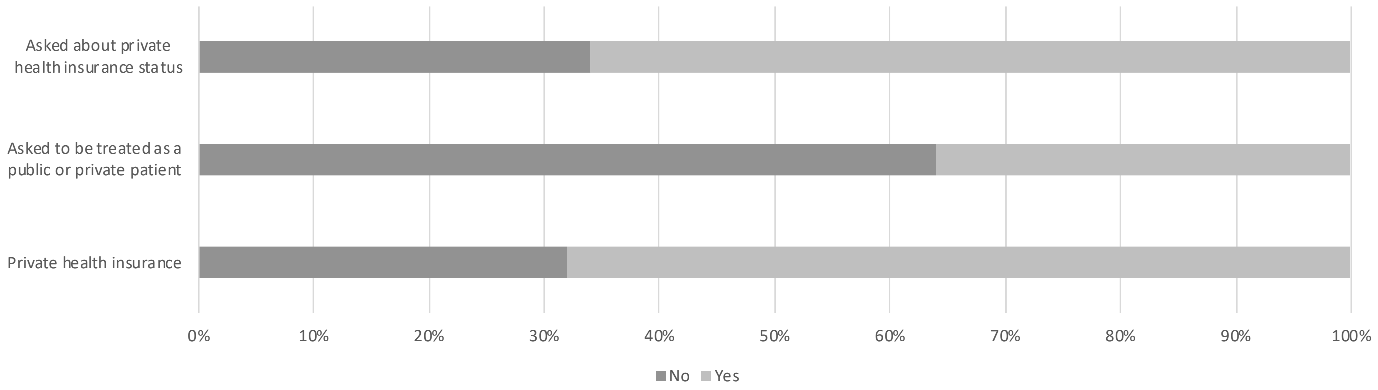

Figure 5.5: Health insurance

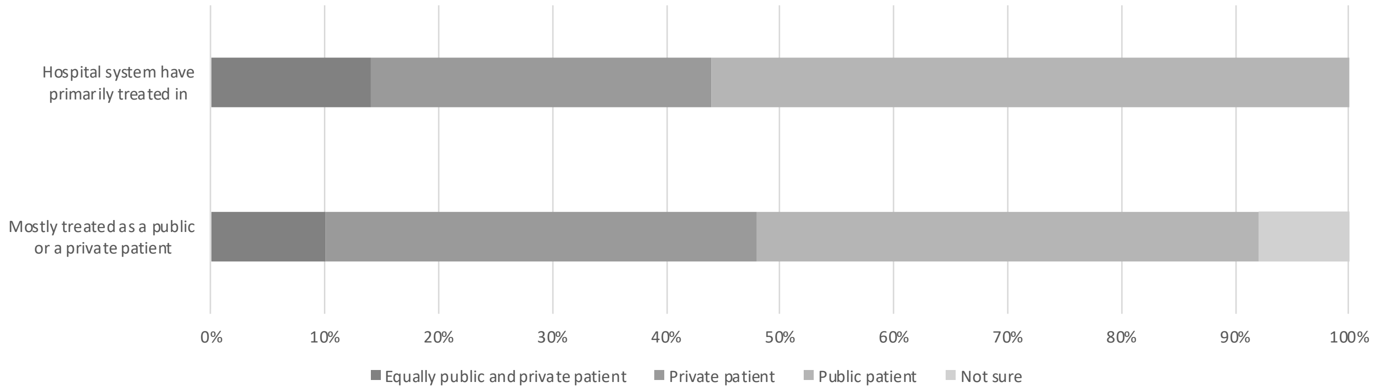

Figure 5.6: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire.

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 35, 70.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=43, 86.00%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 37 participants (74.00%) that never or rarely had trouble paying for essentials, and 7 participants (14.00%) that sometimes found it difficult, and 6 participants (12.00%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 9 participants (18.00%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=50)	Percent
Delay or cancel healthcare appointments due to affordability	Never	31	62.00
	Rarely	4	8.00
	Sometimes	10	20.00
	Often	3	6.00
	Very often	2	4.00
Did not fill prescriptions due to cost	Never	36	72.00
	Rarely	7	14.00
	Sometimes	4	8.00
	Often	0	0.00
	Very often	3	6.00
Difficult to pay for basic essentials	Never	30	60.00
	Rarely	7	14.00
	Sometimes	7	14.00
	Often	2	4.00
	Very often	4	8.00
Pay for additional carers for self or family	Yes	9	18.00
	No	41	82.00

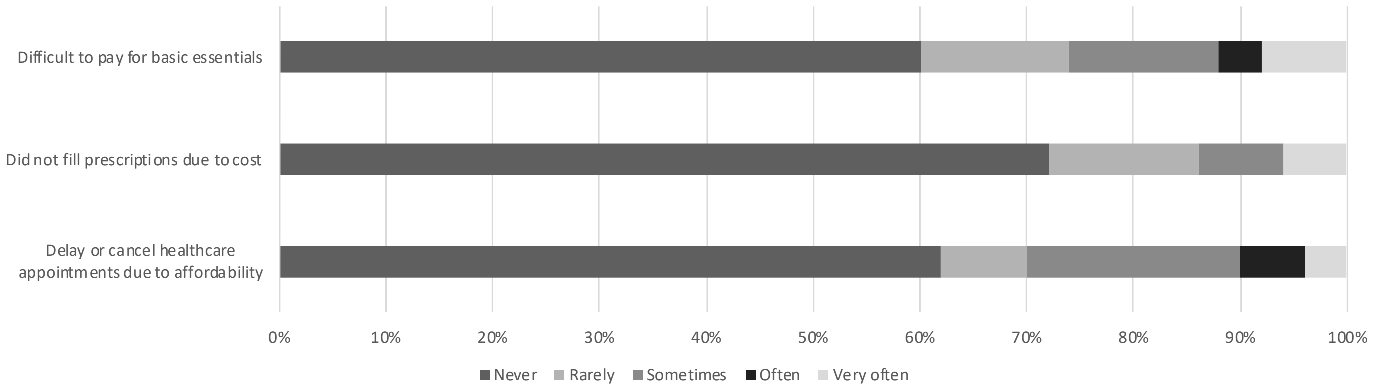

Figure 5.7: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below.

The most common amount was $100 or less (n=16, 32.00%), followed by between $101 to $250 (n=9, 18.00%). There were 3 participants (6.00%), that spent $1001 or more a month.

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was an extremely significant or moderately significant burden for 13 participants (26.00%), somewhat significant for 15 participants (30.00%), and slightly or not at all significant for 22 participants (44.00%).

Table 5.7: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=50)	Percent
$0	1	2.00
$100 or less	16	32.00
$101 to $250	9	18.00
$251 to $500	6	12.00
$501 to $1000	7	14.00
$1001 or more	3	6.00
Not sure of amount	8	16.00

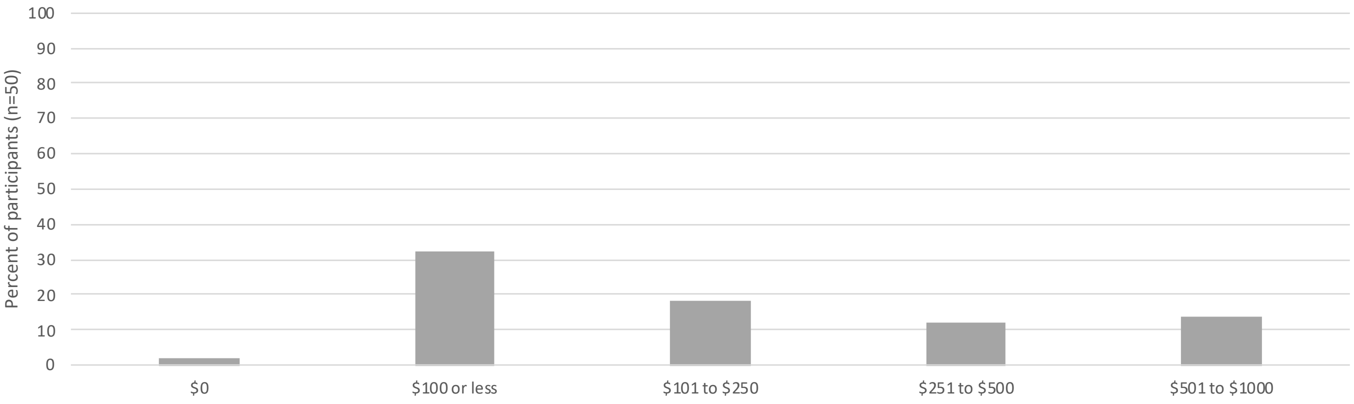

Figure 5.8: Estimated monthly out of pocket expenses due to condition

Table 5.8: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=50)	Percent
Extremely significant	8	16.00
Moderately significant	5	10.00
Somewhat significant	15	30.00
Slightly significant	8	16.00
Not at all significant	14	28.00

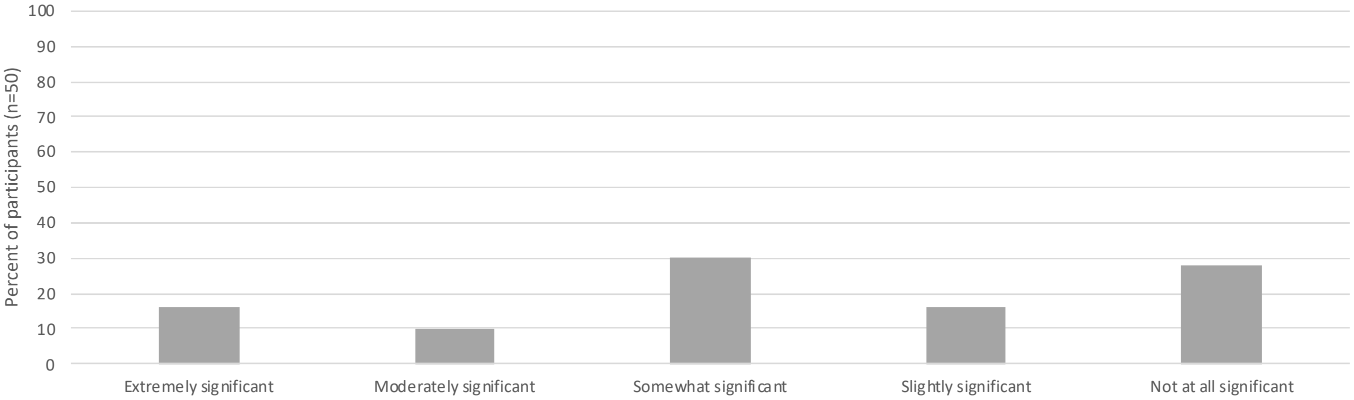

Figure 5.9: Burden of out-of-pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 13 participants (26.00%) had not changed since diagnosis, and 6 participants (12.00%) were retired or did not have a job. There were 17 participants (34.00%) had to quit their job, 9 participants (18.00%) reduced the number of hours they worked, and 3 participants (6.00%) that accessed their superannuation early. There were 7 participants (14.00%) that took leave from work without pay, and 11 participants (22.00%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

There were 16 participants (32.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=26, 52.00%). There was 1 participant (2.00%) whose partner reduced the numbers of hours they worked, and 1 partner, (2.00%) that quit their job. The partners of 2 participants (4.00%) took leave without pay, and there were 3 partners (6.00%) that took leave with pay.

Table 5.9: Changes to employment status

Changes in work status due to condition	Number (n=50)	Percent
Work status has not changed	13	26.00
Retired or did not have a job	6	12.00
Had to quit job	17	34.00
Reduced number of hours worked	9	18.00
Leave from work without pay	7	14.00
Leave from work with pay	11	22.00
Accessed Superannuation early due to condition	3	6.00

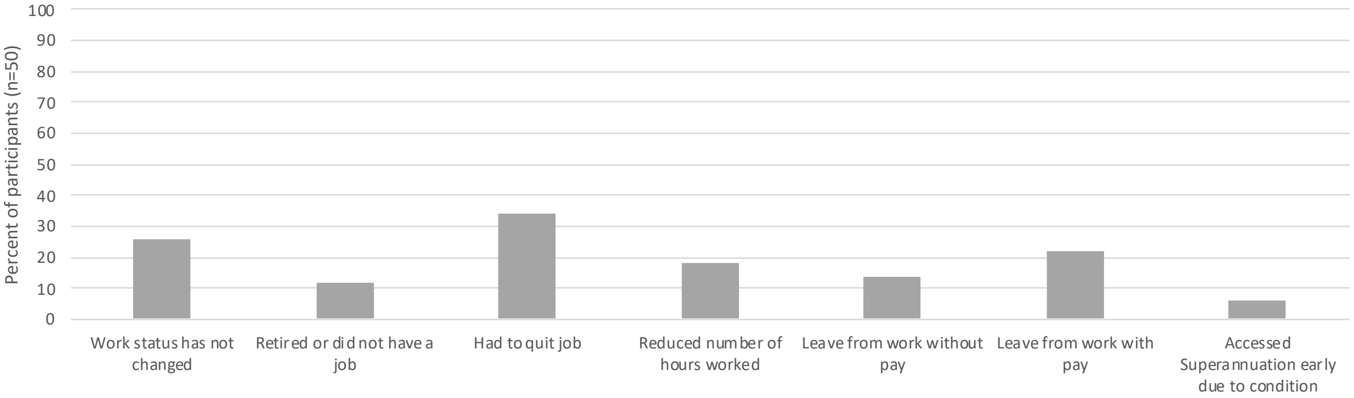

Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=50)	Percent
Does not have a partner/main carer	16	32.00
Work status has not changed	26	52.00
Retired or did not have a job	1	2.00
Had to quit job	1	2.00
Reduced number of hours worked	1	2.00
Leave from work without pay	2	4.00
Leave from work with pay	3	6.00

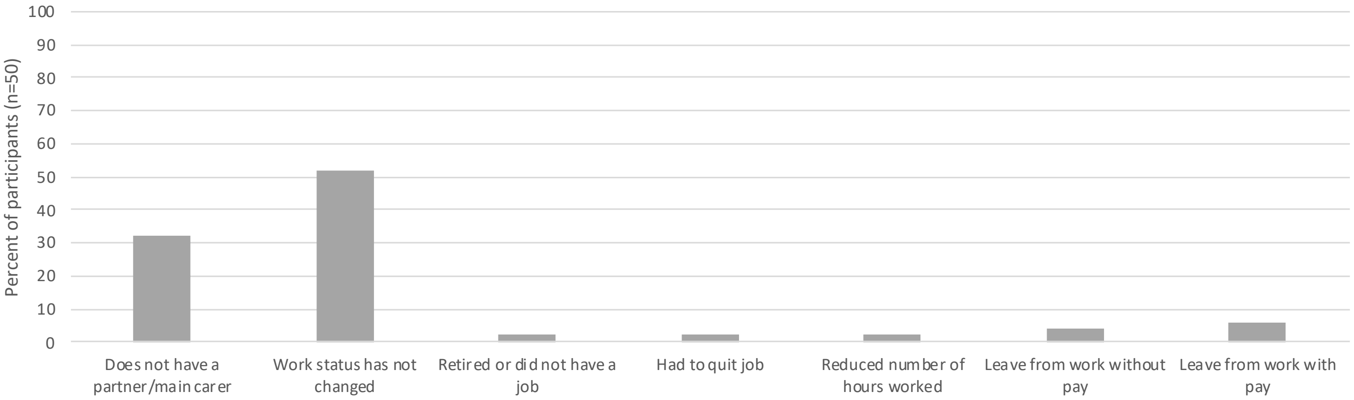

Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

There were 20 participants (42.55%) that indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is listed in the table below.

Most commonly, participants were not sure about the amount their monthly income was reduced by $2000 to $5000 per month (n=7, 14.89%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For 11 of these participants (55.00%), the burden of this reduced income was extremely or moderately significant, for 5 participants (25.00%) the burden was somewhat significant, and for 4 participants (20.00%) the burden was slightly or not all significant.

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=47)	Percent
$0	27	57.45
$800 to $1000	4	8.51
$2000 to $5000	7	14.89
More than $5000	3	6.38
Not sure/not specifed	6	12.77

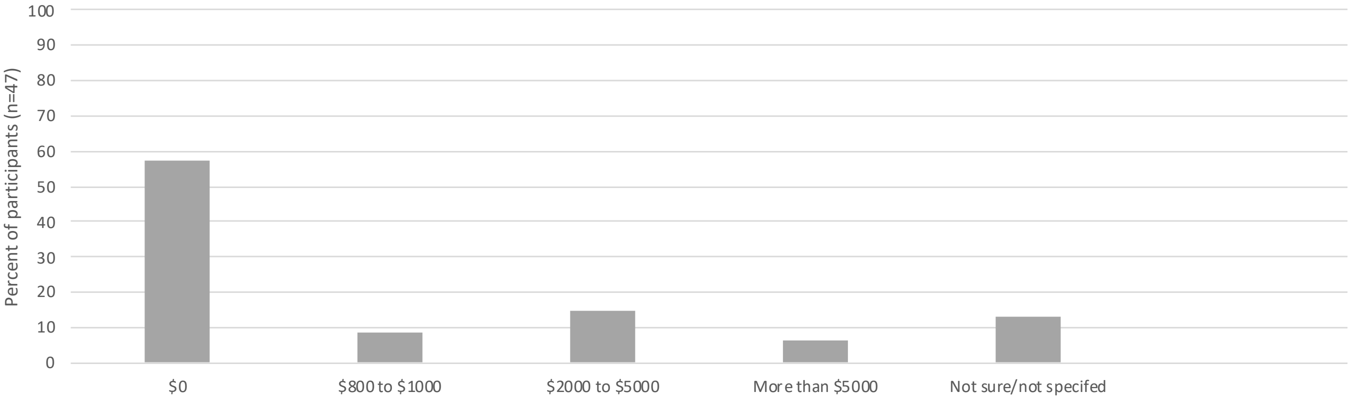

Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced income	Number (n=20)	Percent
Extremely significant	11	55.00
Moderately significant	0	0.00
Somewhat significant	5	25.00
Slightly significant	4	20.00
Not at all significant	0	0.00

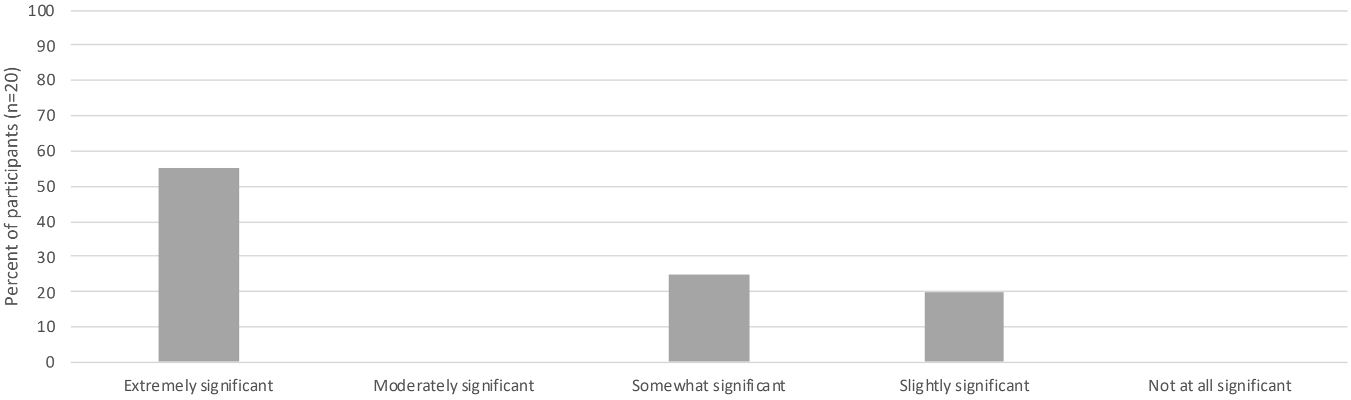

Figure 5.13: Burden of reduced income

Treatments overview

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition.

There were 17 participants (34.00%) that had surgical treatments, 40 participants (80.00%) that had drug treatments and 28 participants (56.00%) that used allied health services. The majority of participants had made lifestyle changes (n=42, 84%), and approximately a third used complementary therapies (n=42) (n=15, 35.71%).

Table 5.13: Treatments overview

Treatments overview	Number (n=50)	Percent
No surgery or medications	9	18.00
Surgery	17	34.00
Drug treatments	40	80.00
Allied health	28	56.00
Complementary therapies (n=42)	15	35.71
Lifestyle Changes	42	84.00

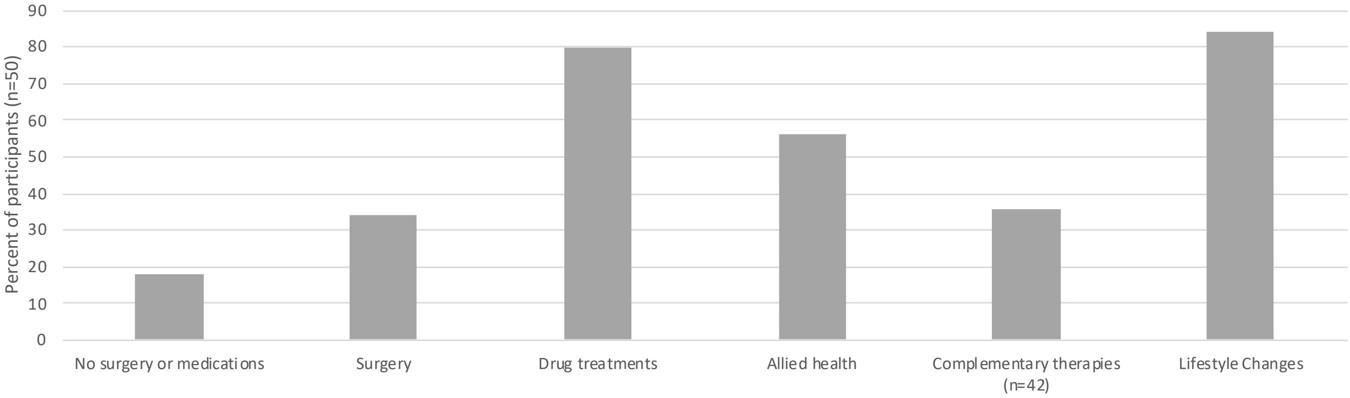

Figure 5.14: Treatments overview

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects.
Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 6 participants (12.00%) that had coronary angioplasty, percutaneous coronary intervention or stents, 5 participants (10.00%) that had pacemaker or an implantable cardiac defibrillator (ICD) and 4 participants (8.00%) that had surgery for pacemaker or implantable cardioverter defibrillator. Other surgical interventions included Bypass surgery (n=2, 4.00%), and Heart valve surgery (n=1, 2.00%).

On average, quality of life from coronary angioplasty, percutaneous coronary intervention or stents was in the 'life was good' range (median=5.00, IQR = 2.25), and was found to be very effective (median=5.00 , IQR=0.00).

On average, quality of life from pacemaker or an implantable cardiac defibrillator (ICD) was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00 , IQR=1.00).

Table 5.14 Summary of surgeries

Surgical treatments	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Coronary angioplasty, percutaneous coronary intervention or stents	6	12.00	5.00	2.25	5.00	0.00
Pacemaker or an implantable cardiac defibrillator (ICD)	5	10.00	4.00	1.00	4.00	1.00
Surgery for pacemaker or implantable cardioverter defibrillator	4	8.00	NA	NA	NA	NA
Bypass surgery	2	4.00	NA	NA	NA	NA
Heart valve surgery	1	2.00	NA	NA	NA	NA

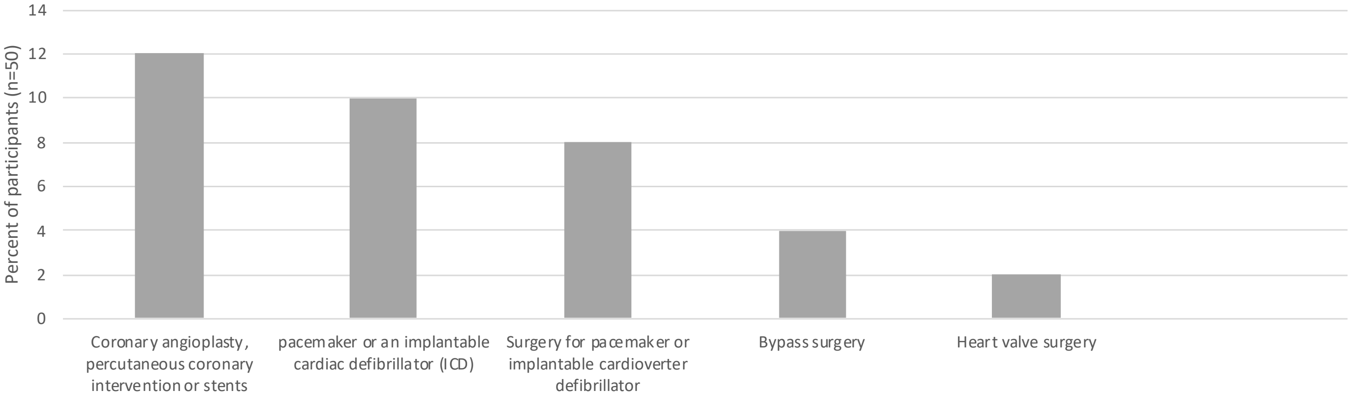

Figure 5.15: Summary of surgeries

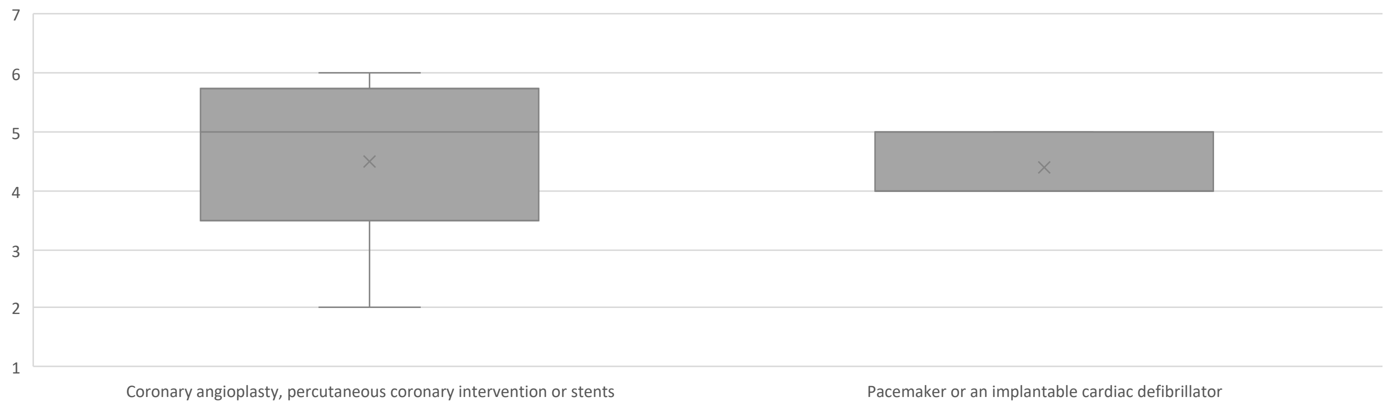

Figure 5.16: Quality of life from surgery

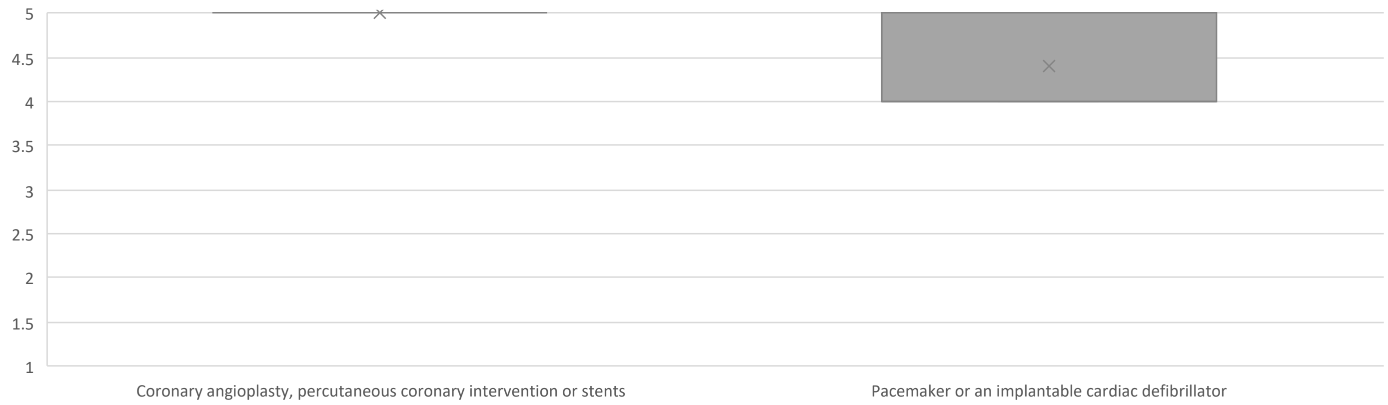

Figure 5.17: Effectiveness of surgery

Summary of drug treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 23 participants (46.00%) that had antiplatelets, 18 participants (36.00%) that had beta blockers and 18 participants (36.00%) that had statins. Participants also took ACE inhibitors (n=10, 20%), ARBs (n=8, 16%), diurectics (n=6, 12%), cholesterol absorption inhibitors (n=5, 10.00%), calcium channel blockers (n=3, 6.00%), ARNIs (n=2, 4.00%), sinus node inhibitors (n=2, 4.00%), and glycosides (n=2, 4.00%).

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”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective.

On average, quality of life from antiplatelets was in the 'life was average' range (median=4.00, IQR = 1.00), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from beta blockers was in the 'life was average to good' range (median=4.50, IQR=2.75), and was found to be effective (median=4.50 , IQR=1.00).

On average, quality of life from statins was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective to very effective (median=4.00 , IQR=1.00).

On average, quality of life from ACE inhibitors was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from ARBs e.g. candesartan, losartan, valsartan was in the 'life was average' range (median=4.00, IQR=2.25), and was found to be moderately effective to effective (median=3.50 , IQR=2.25).

On average, quality of life from anticoagulants was in the 'life was good to very good' range (median=5.50, IQR=3.25), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from diuretics was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from cholesterol absorption inhibitors was in the 'life was average' range (median=5.00, IQR=0.00), and was found to be effective (median=4.00 , IQR=0.00).

Table 5.15: Drug treatments overview

Drug treatments	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Antiplatelets	23	46.00	4.00	1.00	4.00	0.50
Beta blockers	18	36.00	4.50	2.75	4.50	1.00
Statins	18	36.00	4.00	1.00	4.00	1.00
ACE inhibitors	10	20.00	4.00	1.50	4.00	0.75
ARBs e.g. candesartan, losartan, valsartan	8	16.00	4.00	2.25	3.50	2.25
Anticoagulants	8	16.00	5.50	3.25	4.00	0.50
Diurectics	6	12.00	4.00	1.50	4.00	0.75
Cholesterol absorption inhibitors	5	10.00	5.00	0.00	4.00	0.00
Calcium channel blockers	3	6.00	NA	NA	NA	NA
Angiotensin receptor-neprilysin inhibitors (ARNIs)	2	4.00	NA	NA	NA	NA
Sinus node inhibitors (ivabradine)	2	4.00	NA	NA	NA	NA
Glycosides	2	4.00	NA	NA	NA	NA

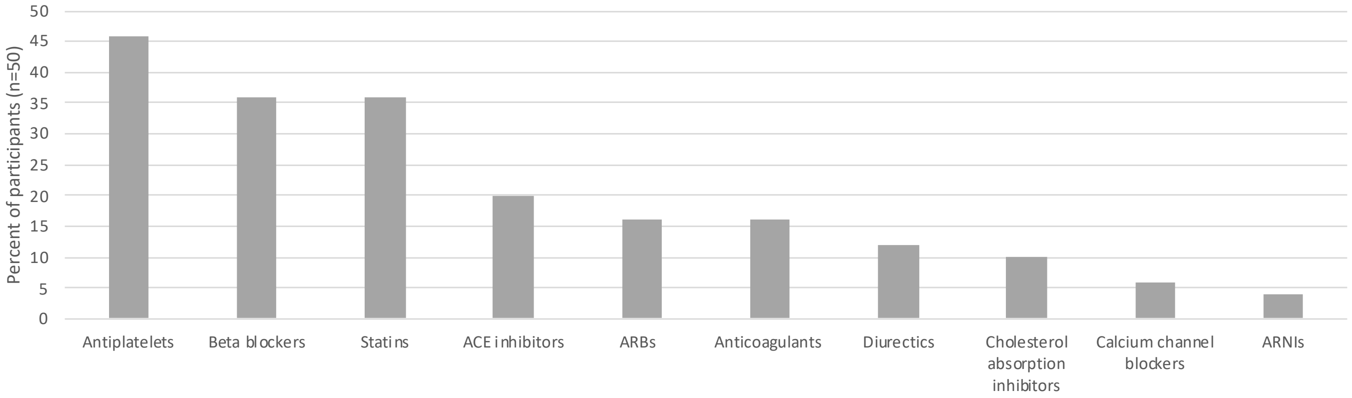

Figure 5.18: Drug treatments overview

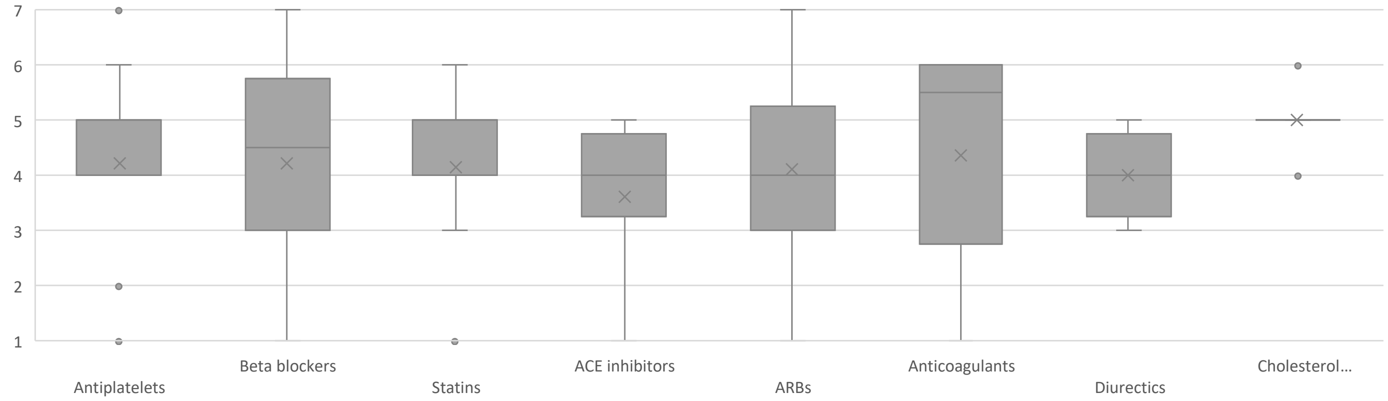

Figure 5.19: Quality of life from drug treatments (where complete data was available)

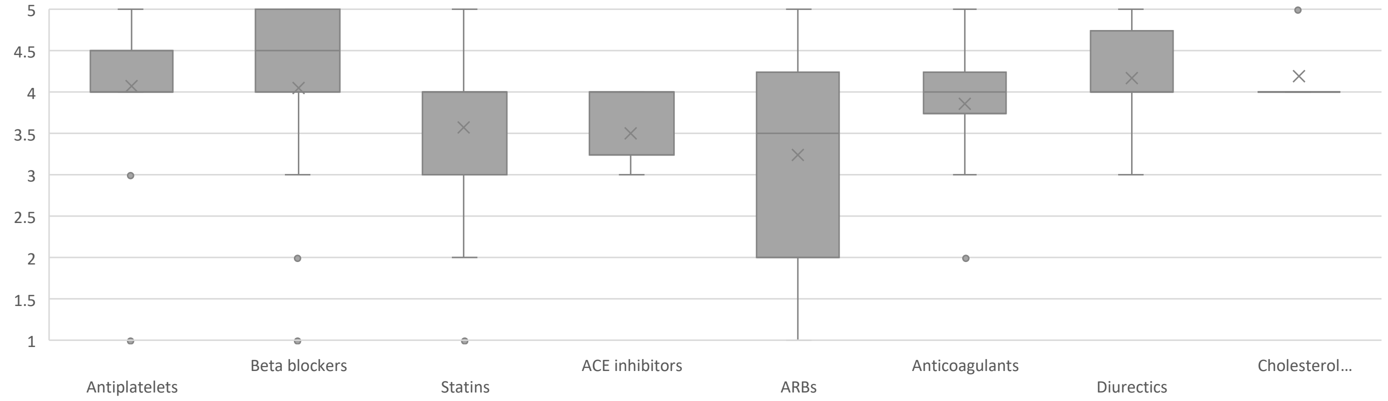

Figure 5.20: Effectiveness of drug treatments (where complete data was available)

Allied health

The most common allied health service used was seeing a dietician (n=14, 28.00%), followed by physiotherapy (n=13, 26.00%), and psychology or counselling (n=12, 24.00%). There were 9 participants (18.00%) that had occupational therapy, 9 participants (18.00%) that had speech therapy, and 5 participants (10.00%) that saw a social worker.

On average, quality of life from seeing a dietician was in the 'life was average' range (median=4.00, IQR = 2.75), and was found to be effective (median=4.00, IQR = 1.00).

On average, quality of life from physiotherapy was in the 'life was a little distressing' range (median=3.00, IQR=3.00), and was found to be effective (median=4.00, IQR=3.00).

On average, quality of life from psychology or counselling was in the 'life was distressing' range (median=2.00, IQR=2.25), and was found to be moderately effective (median=3.00, IQR=2.00).

On average, quality of life from occupational therapy was in the 'life was average' range (median=4.00, IQR=3.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from speech therapy was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from social work was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00, IQR=4.00).

Table 5.16: Allied health

Allied health	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Dietician	14	28.00	4.00	2.75	4.00	1.00
Physiotherapy	13	26.00	3.00	3.00	4.00	3.00
Psychology/counselling	12	24.00	2.00	2.25	3.00	2.00
Occupational therapy	9	18.00	4.00	3.00	4.00	1.00
Speech therapy	9	18.00	3.00	2.00	4.00	2.00
Social work	5	10.00	4.00	1.00	4.00	4.00
Podiatry	4	8.00	NA	NA	NA	NA

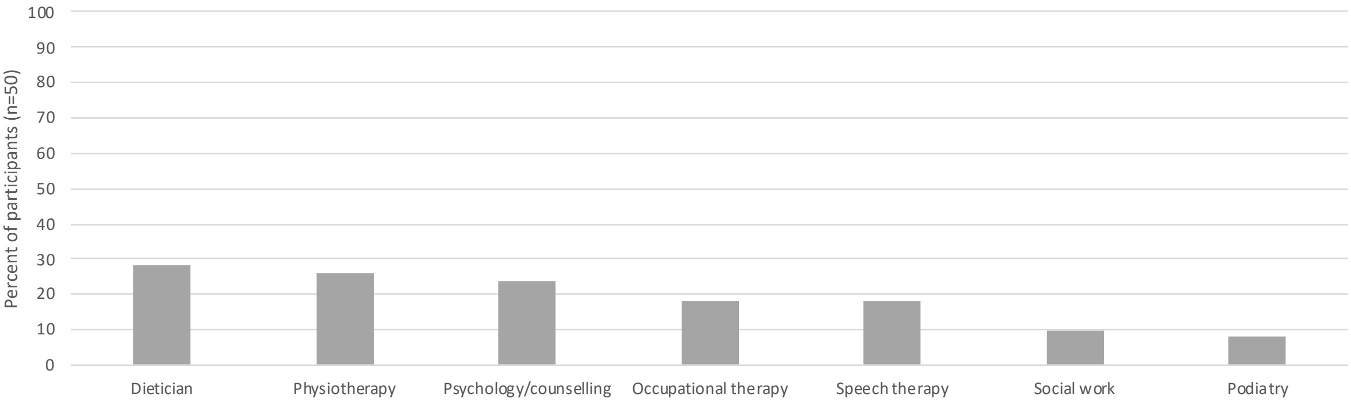

Figure 5.21: Allied health

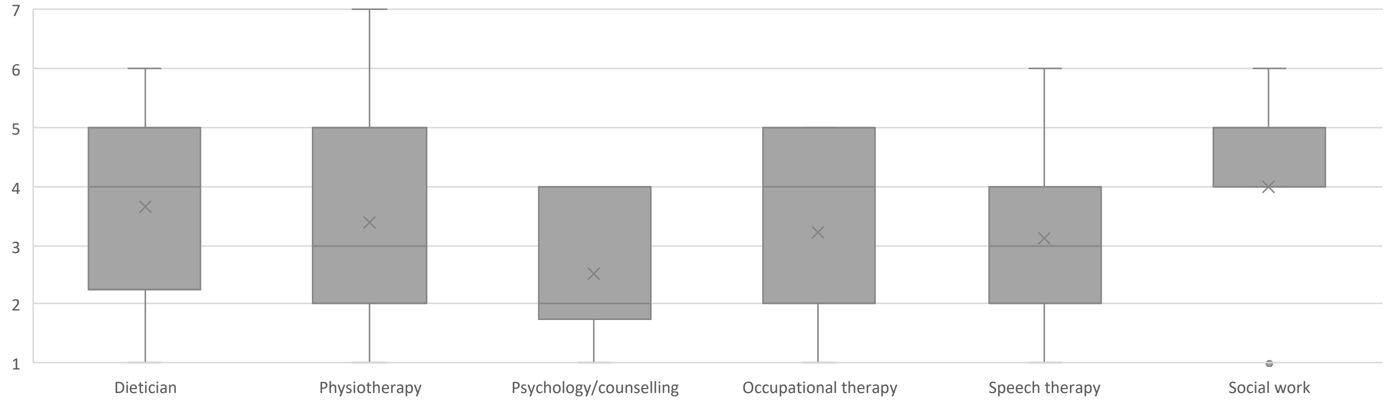

Figure 5.22: Quality of life from allied health

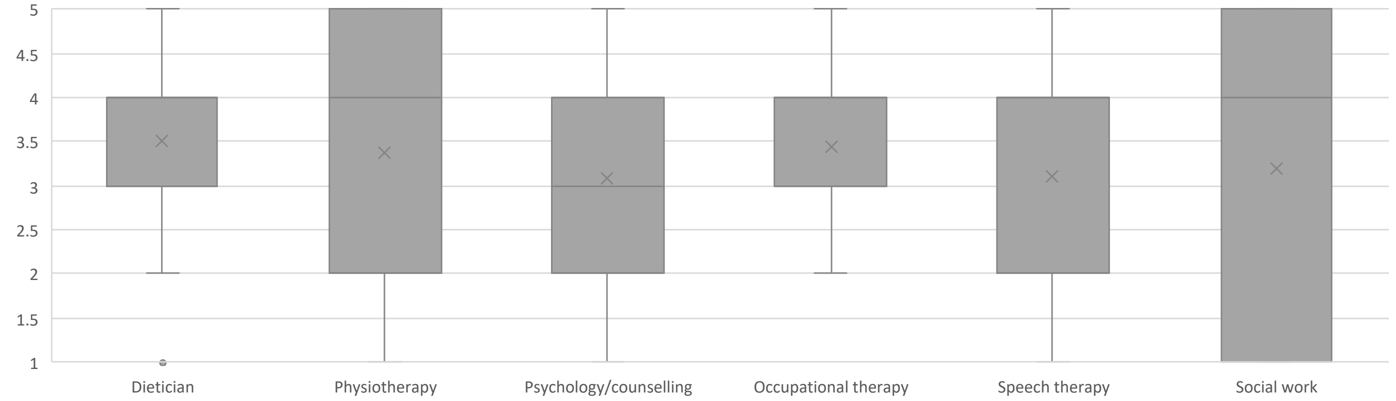

Figure 5.23: Effectiveness of allied health

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them.

The majority of participants used at made at least one lifestyle change (n=42, 84.00%), and on average made 2 changes (median=2.00, IQR=1.75).

The most common lifestyle changes used were diet changes (n=29, 58.00%), and exercise (n=29, 58.00%), followed by and Quitting or cutting back on alcohol (n=19, 38.00%), and Quitting or cutting back on smoking (n=10, 20.00%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from quitting or cutting back on alcohol was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from quitting or cutting back on smoking was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Table 5.17: Lifestyle changes

Lifestyle changes	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Diet changes	29	58.00	4.00	2.00	4.00	2.00
Exercise	29	58.00	5.00	2.00	4.00	1.00
Quitting or cutting back on alcohol	19	38.00	5.00	2.00	4.00	2.00
Quitting or cutting back on smoking	10	20.00	4.00	2.00	4.00	1.00

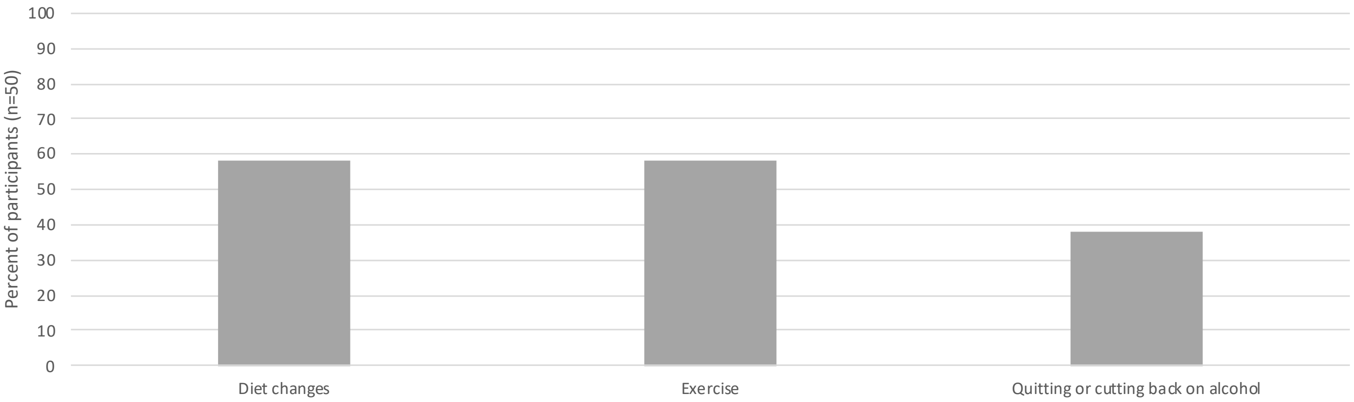

Figure 5.24: Lifestyle changes

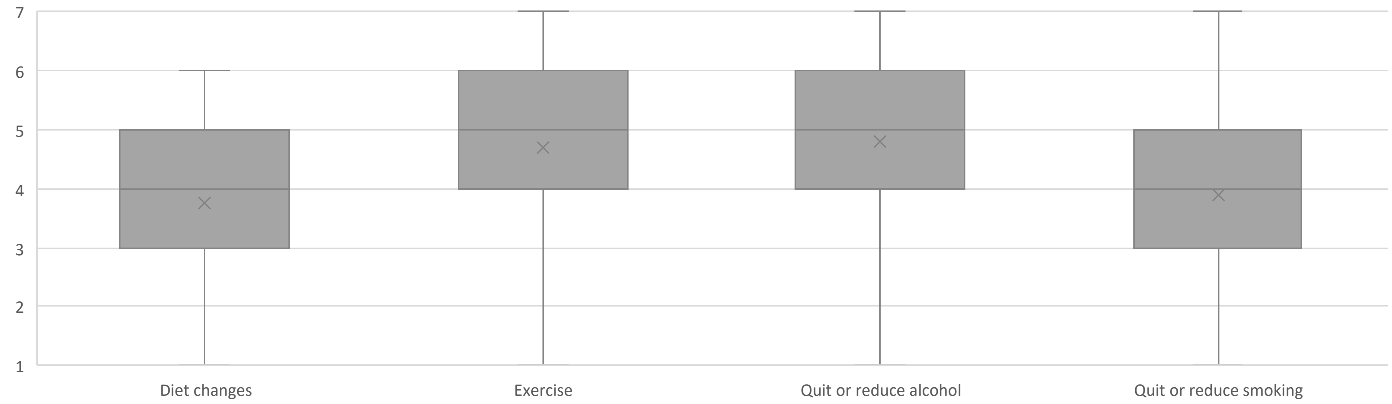

Figure 5.25: Quality of life from lifestyle changes

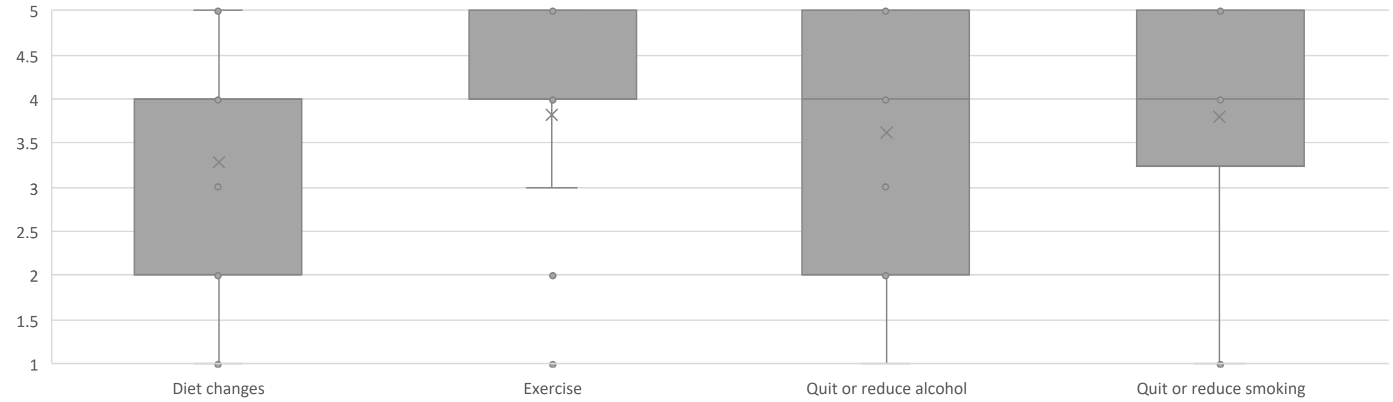

Figure 5.26: Effectiveness from lifestyle changes

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them.

Approximately a third of participants used at least one complementary therapy (n=15, 35.71%). The most common complementary therapy used was Mindfulness or relaxation techniques (n=11, 26.19%), followed by Massage therapy (n=7, 16.67%), Supplements (n=6, 14.29%), and acupuncture (n=5, 11.90%)

On average, quality of life from mindfulness or relaxation techniques was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.50).

On average, quality of life from massage therapy was in the 'life was distressing' range (median=2.00, IQR=2.50), and was found to be moderately effective (median=3.00, IQR=2.50).

On average, quality of life from supplements was in the 'life was average to good' range (median=4.50, IQR=2.50), and was found to be moderately effective to effective (median=3.50, IQR=1.00).

On average, quality of life from Acupuncture was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be effective (median=3.00, IQR=2.00).

Table 5.18: Complementary therapies

Complementary therapies	Number (n=42)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation techniques	11	26.19	5.00	2.00	4.00	1.50
Massage therapy	7	16.67	2.00	2.50	3.00	2.50
Supplements	6	14.29	4.50	2.50	3.50	1.00
Acupuncture	5	11.90	3.00	2.00	3.00	2.00
Naturopathy	2	4.76	NA	NA	NA	NA
Homeopathy	1	2.38	NA	NA	NA	NA

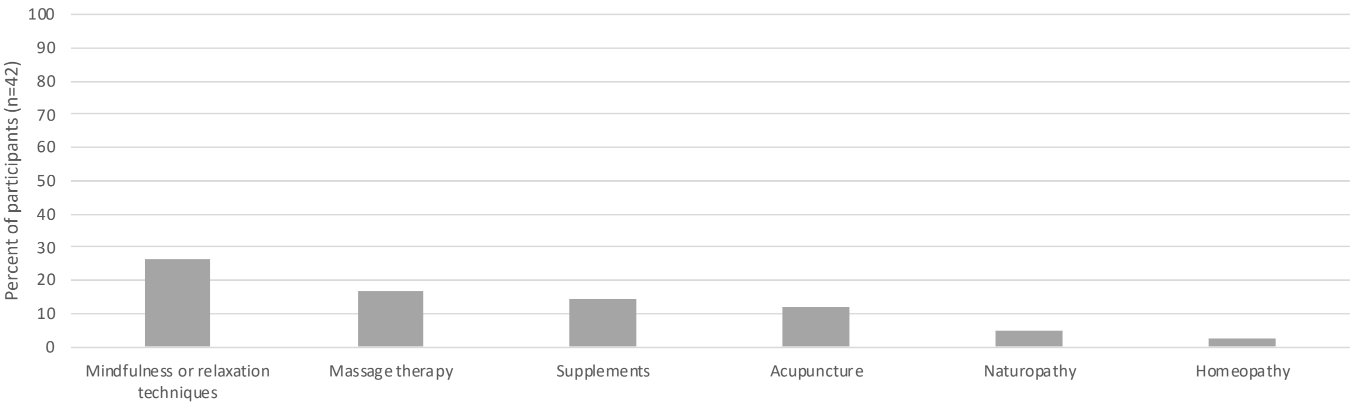

Figure 5.27: Complementary therapies

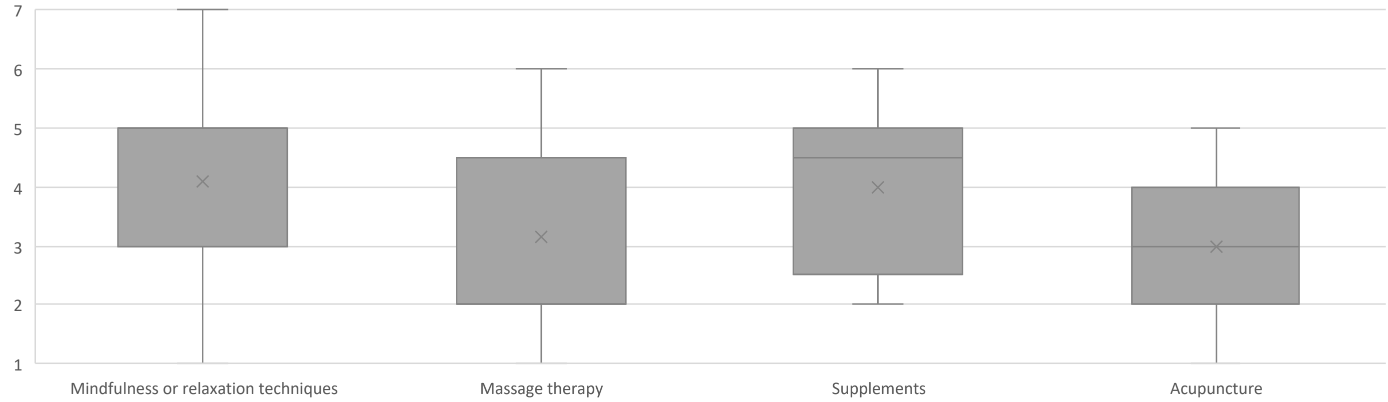

Figure 5.28: Quality of life from complementary therapies

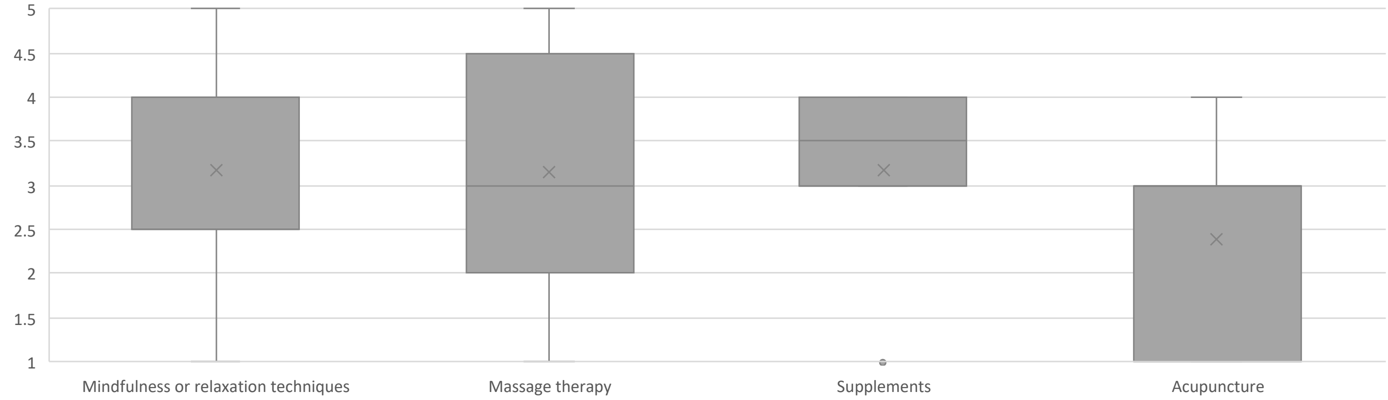

Figure 5.29: Effectiveness of complementary therapies

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 4 participants (8%) that had discussions about clinical trials, 3 participants (6.00%) had brought up the topic with their doctor, and the doctor of 1 participant (2.00%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=46, 92.00%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There was 1 participant (2.00%) that had taken part in a clinical trial, 36 participants (72.00%) that would like to take part in a clinical trial if there was a suitable one, and 13 participants, that have not participated in a clinical trial and do not want to (26.00%).

Table 5.19: Clinical trial discussions

Clinical trial discussions	Number (n=50)	Percent
Participant brought up the topic of clinical trials doctor for discussion	3	6.00
Doctor brought up the topic of clinical trials for discussion	1	2.00
Participant has never spoken about clinical trials	46	92.00

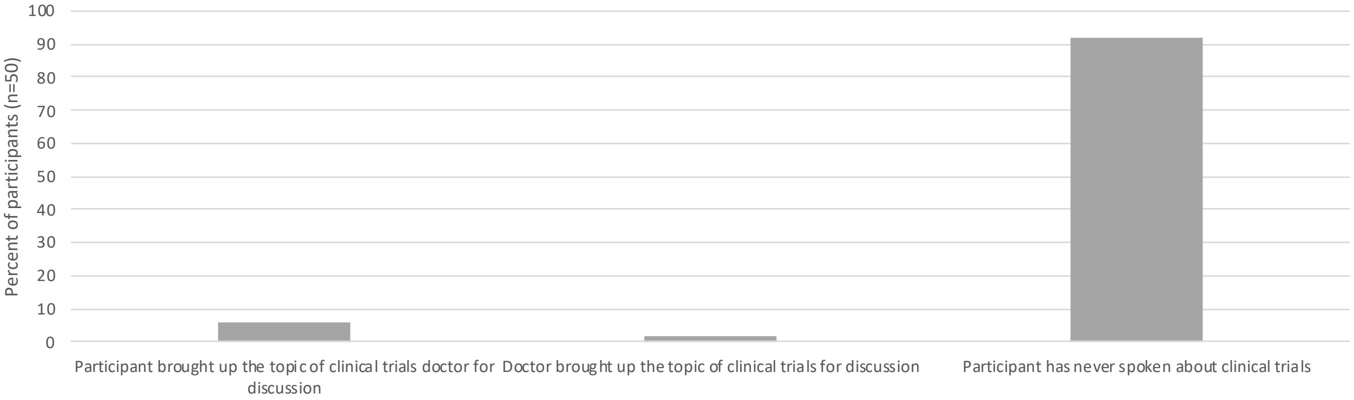

Figure 5.30: Clinical trial discussions

Table 5.20: Clinical trial participation

Clinical trial participation	Number (n=50)	Percent
Has not participated in a clinical trial and does not want to	13	26.00
Has not participated in a clinical trial but would like to if there is one	36	72.00
Has participated in a clinical trial	1	2.00

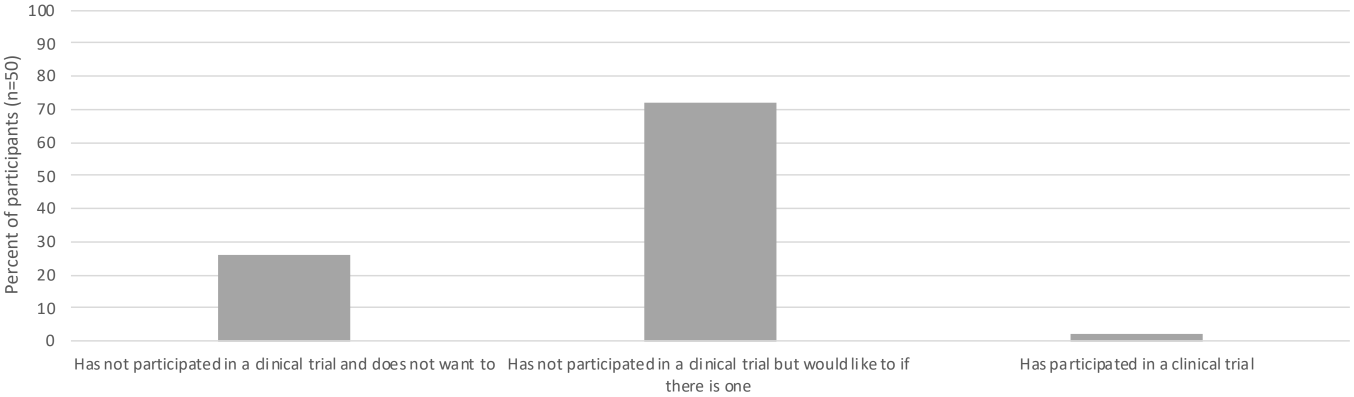

Figure 5.31: Clinical trial participation

Treatment and management following lipoprotein a test

Lipoprotein a testing

In the online questionnaire, participants noted if they had a Lipoprotein a test. There were 24 participants (43.64%) that had a Lipoprotein a test.

Lipoprotein a test results

As a follow up question, participants were asked if they knew the result of their Lipoprotein a test. There were 9 participants (16.36%) that did not know their result, 9 participants (16.36%) that knew result and gave a numerical value, and 6 participants (10.91%) that were not sure of exact result but that it was high.

Table 5.21: Lipoprotein a testing

Had a lipoprotein a/Lpa test	n=55	%
No	31	56.36
Yes	24	43.64

Figure 5.32: Lipoprotein a testing

Table 5.22: Lipoprotein a test results

Lipoprotein a/ Lp(a) level or result known	n=55	Percent
Not known	9	16.36
Knew result and gave a numerical value	9	16.36
Not sure of exact result but it was high	6	10.91

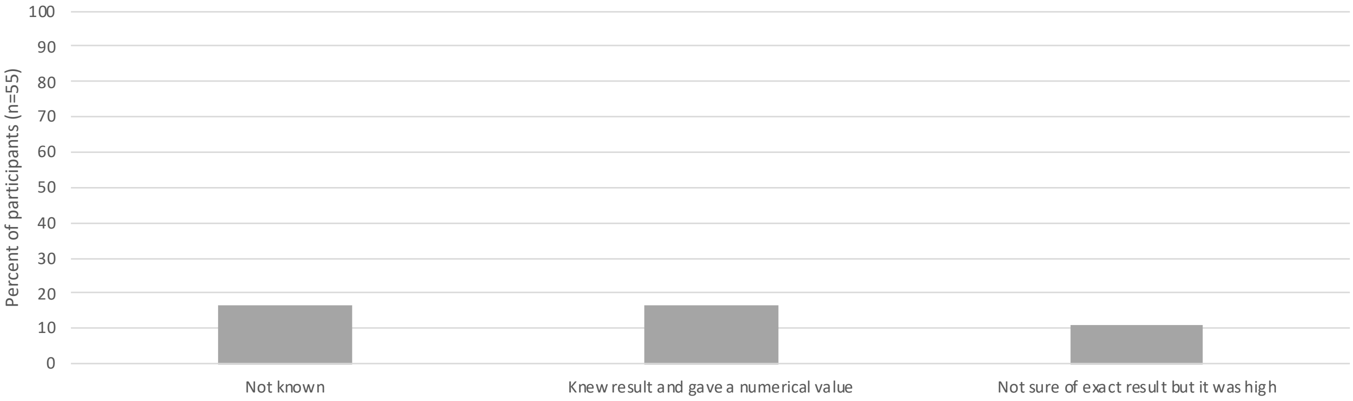

Figure 5.33: Lipoprotein a test results

Changes in treatment and management following Lipoprotein a testing

Participants noted in the online questionnaire any changes their doctor made to the treatment or management of their condition following lipoprotein a testing.

Most commonly, changes were made to medication (n=10, 41.67%), followed by recommendations for diet and lifestyle changes (n=6, 25.00%). There were 5 participants (20.83%) that were had additional monitoring, and 2 participants (8.33%), that had no made changes to treatment or management.

Table 5.23: Changes in treatment and management following Lipoprotein a testing

Types of changes to treatment or management following Lipoprotein a/ Lp(a) test	Number (n=24)	Percent
Medication changes	10	41.67
Diet and life style changes	6	25.00
Monitoring	5	20.83
No changes	2	8.33
Not clear	2	8.33

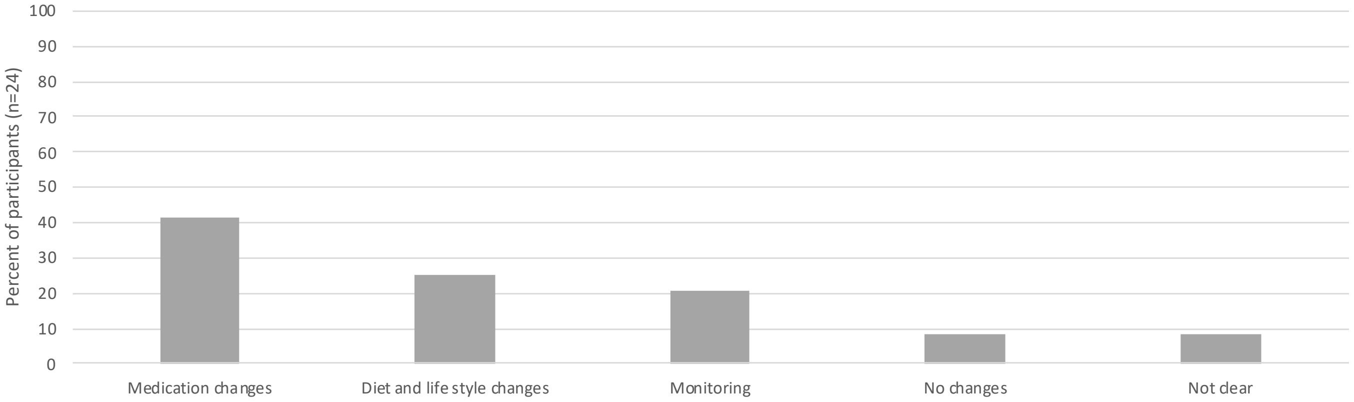

Figure 5.34: Changes in treatment and management following Lipoprotein a testing

Participant-made changes following lipoprotein a/Lp(a) results

In the online questionnaire, participants noted the changes that they had made following getting their lipoprotein a/Lp(a) results.

The majority of participants made diet changes (n=18, 75.00%), and half the participants (50.00%) tried to exercise more. There were 8 participants (33.33%) that tried to drink less alcohol, and 8 participants (33.33%) that tried to lose weight. Other changes included tried to give up smoking (20.83%), became more careful about taking medicatins (16.67%) and became more caredful about making and attending medical appointments (12.50%). There were 2 participants (12.50%) that made no changes following thier lipoprotein a test result.

After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Participants noted the activities they had done to learn more about lipoprotein a.

More than half of the participants looked for information about it (n=13, 54.17%), and a third asked their doctor about it (n=8, 33.33%). There were 3 participants (12.50%) that joined a heart management program, and 3 participants (12.50%) that joined a patient group. There were 9 participants (37.50%) that did not do anything to find out more about Lp(a).

Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Participants were asked if family members had a lipoprotein a /Lp(a) test because of test result. There were 6 participants (25.00%) that noted other family members had this test due to their result.

Table 5.24: Participant-made changes following lipoprotein a/Lp(a) results

Participant changes following lipoprotein a/Lp(a) results	Number (n=24)	Percent
Diet changes	18	75.00
Tried to exercise more	12	50.00
Tried to drink less alcohol	8	33.33
Tried to lose weight	8	33.33
Tried to give up smoking	5	20.83
Became more careful about taking medications	4	16.67
No changes	3	12.50
Became more careful about making and attending medical appointments	3	12.50

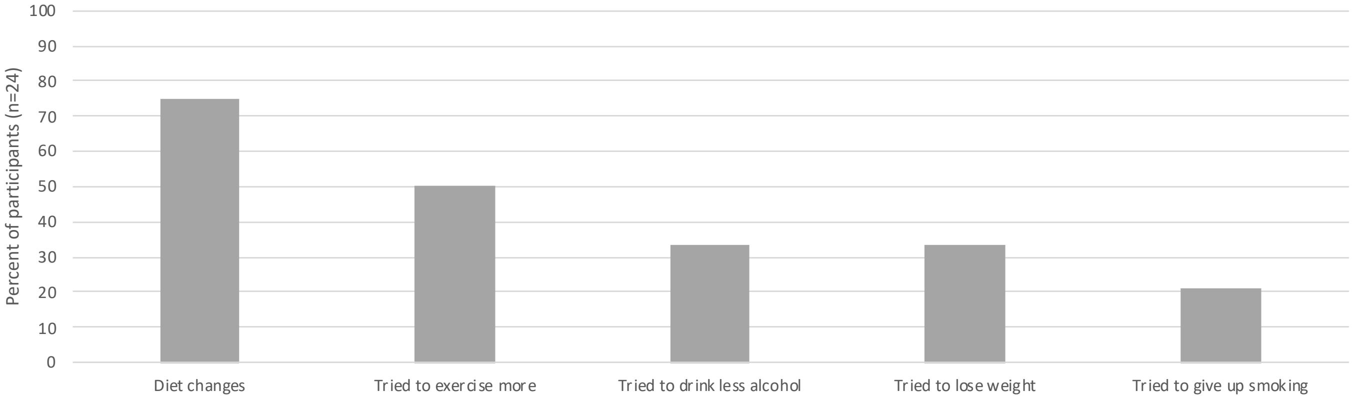

Figure 5.35: Participant-made changes following lipoprotein a/Lp(a) results

Table 5.25: After getting Lipoprotein a/Lp(a) results, activities to learn more about it

After getting Lipoprotein a/Lp(a) results, activities to learn more about it	n=24	Percent
Looking for information about it	13	54.17
Did not do anything to find out more about Lp(a)	9	37.50
Asking a doctor about it	8	33.33
Joining a heart management program	3	12.50
Joining a patient group	3	12.50

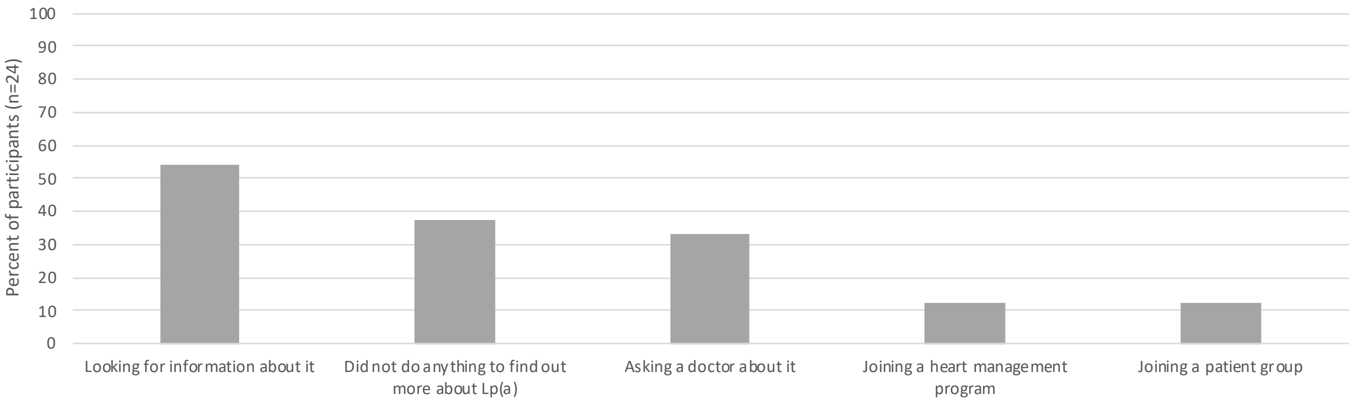

Figure 5.36: After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Table 5.26: Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Did other members of family have a Lipoprotein a /Lp(a) test because of test result	n=24	Percent
No	16	66.67
Yes	6	25.00
Not sure	2	8.33

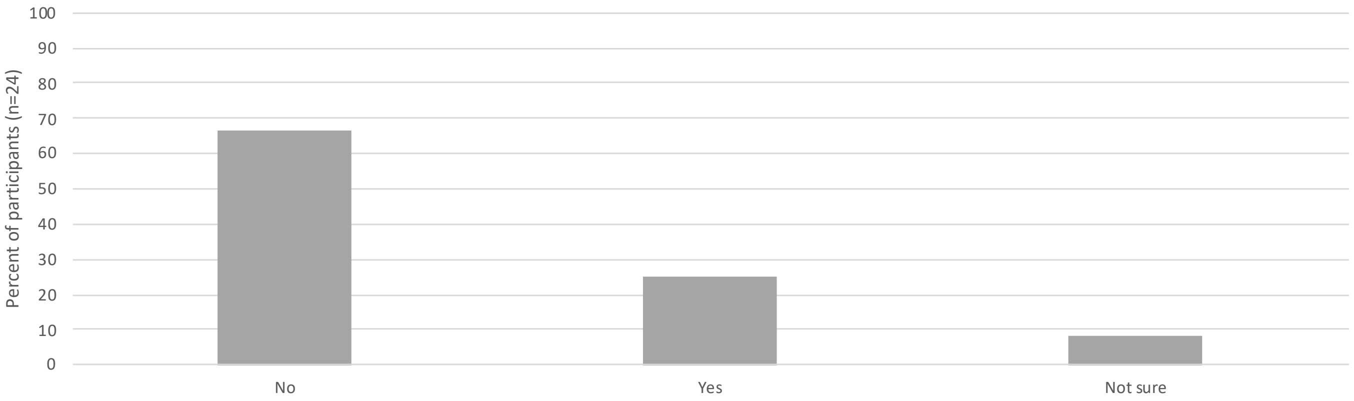

Figure 5.37: Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were described using a specific example (57.45%), and those that do not interfere with life (36.17%). Other themes included side effects that have a short duration (10.64%), and that they had only experienced or only described severe side effects (8.51%).

When a specific side effect was described, the most common side effects were aches and pain (23.40%), fatigue/lethargy (23.40%), headaches (6.38%), and nausea, vomiting,or loss of appetite (6.38%).

Participant provides a specific side effect as an example

I guess the mild side effect would be something like maybe a bit of back pain or some cramping bit of fatigue as well, maybe just feeling a little bit foggy headed, things like that. But I think a severe side effect would be something, you know, like we're cramping, that's so severe you can't walk properly, or you've got maybe breathing difficulties, things like that. Or maybe you're that fatigued that you can't get out of bed. That's the way I describe it. Participant 011_2023AUHBV

The mild side effect that I have is if I try and exercise to a certain level or if I have a big day with lots of stuff in it, the next day I'm wiped out with regard to tiredness.
Participant 015_2023AUHBV

Maybe a slight inconvenience to your life would be a mild. Side effect, maybe a little bit sick, maybe a little bit of a light headache, maybe a little bit of a lack of energy, that kind of thing.
Participant 020_2023AUHBV

Participant describes mild side effects as those that do not interfere with daily life

Something that you could just suck it up and live with, I suppose.
Participant 014_2023AUHBV

Well, I think that would be something you could easily cope with if you knew it was a side effect.
Participant 016_2023AUHBV

All all depends sort of what what the side effects are, and I think that if it's at a level that that isn't. Stopping you doing things. You're not throwing up, you haven't got diarrhea. You haven't got stomach pains or nausea or feeling unwell from the medication then that's that's the sort of things that that that level that would make me. Yeah, not want to take medication.
Participant 017_2023AUHBV

Participant describes mild side effects as those that have a short duration

A mild side effect is an ongoing and ever-present-- I can't think of any other way to describe it other than a lack of clarity in thinking. It's a cloudy thought process for me all the time. It's not impaired but I have to really concentrate when I'm going through some thinking. It's a cloud. I'm sure obviously that's a result of the stroke. It's not an impairment but it's a constant brain fatigue.
Participant 045_2023AUHBV

Yes, easy. Yeah, easy to cope with. Can deal with it. You can kind of just accept it and tell yourself that it's really gonna be over soon, whatever the side effect is.
Participant 029_2023AUHBV

Just feeling a little bit off. Maybe having a headache for a couple of days and a little bit of nausea. Symptoms that will pass.
Participant 049_2023AUHBV

Participant describes having only experienced or only describes severe side effects

I don't really have mild. I just have major side effects.
Participant 042_2023AUHBV

My cardiologist put me onto super strength statins afterwards, 8 milligrams. And my body stopped working. It just it was so painful. I could not get off the couch.
Participant 005_2023AUHBV

Table 5.27: Description of mild side effects

Description of mild side effects	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant provides a specific side effect as an example	27	57.45	9	50.00	18	62.07	6	66.67	9	52.94	12	57.14	15	55.56	12	60.00
Participant describes mild side effects as those that do not interfere with daily life	17	36.17	8	44.44	9	31.03	5	55.56	6	35.29	6	28.57	7	25.93	10	50.00
Participant describes mild side effects as those that have a short duration	5	10.64	2	11.11	3	10.34	0	0.00	4	23.53	1	4.76	2	7.41	3	15.00
Participant describes having only experienced or only describes severe side effects	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	4	14.81	0	0.00

Description of mild side effects	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant provides a specific side effect as an example	27	57.45	16	61.54	11	52.38	14	58.33	13	56.52	11	73.33	16	50.00	17	68.00	10	45.45
Participant describes mild side effects as those that do not interfere with daily life	17	36.17	14	53.85	3	14.29	10	41.67	7	30.43	7	46.67	10	31.25	10	40.00	7	31.82
Participant describes mild side effects as those that have a short duration	5	10.64	4	15.38	1	4.76	3	12.50	2	8.70	3	20.00	2	6.25	3	12.00	2	9.09
Participant describes having only experienced or only describes severe side effects	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64

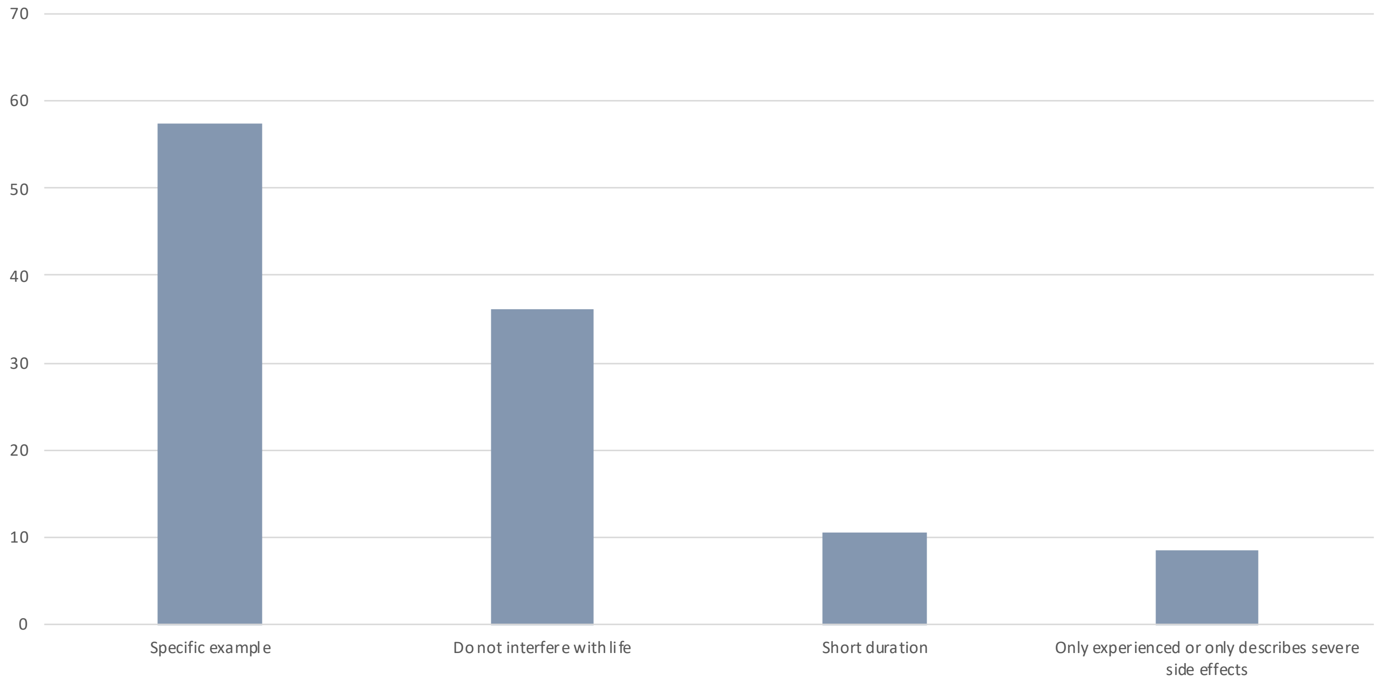

Figure 5.38: Description of mild side effects

Table 5.28: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Higher socioeconomic status	Regional or remote Mid to low socioeconomic status
Participant describes mild side effects as those that do not interfere with daily life	0 to 5 other conditions Male	High cholesterol under 50 years of age 6 to 11 other conditions Female Regional or remote
Participant describes mild side effects as those that have a short duration	High cholesterol under 50 years of age	Blood vessel conditions

Table 5.29: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes mild side effects giving the specific example of aches/pain (general)	11	23.40	5	27.78	6	20.69	3	33.33	3	17.65	5	23.81	7	25.93	4	20.00
Participant describes mild side effects giving the specific example of fatigue/lethargy	11	23.40	4	22.22	7	24.14	**4**	**44.44**	3	17.65	4	19.05	7	25.93	4	20.00
Participant describes mild side effects giving the specific example of headaches	3	6.38	0	0.00	3	10.34	**2**	**22.22**	1	5.88	0	0.00	1	3.70	2	10.00
Participant describes mild side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00

Description of mild side effects (Specific side effects)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes mild side effects giving the specific example of aches/pain (general)	11	23.40	7	26.92	4	19.05	7	29.17	4	17.39	**6**	**40.00**	5	15.63	**9**	**36.00**	**2**	**9.09**
Participant describes mild side effects giving the specific example of fatigue/lethargy	11	23.40	7	26.92	4	19.05	5	20.83	6	26.09	4	26.67	7	21.88	6	24.00	5	22.73
Participant describes mild side effects giving the specific example of headaches	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55
Participant describes mild side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55

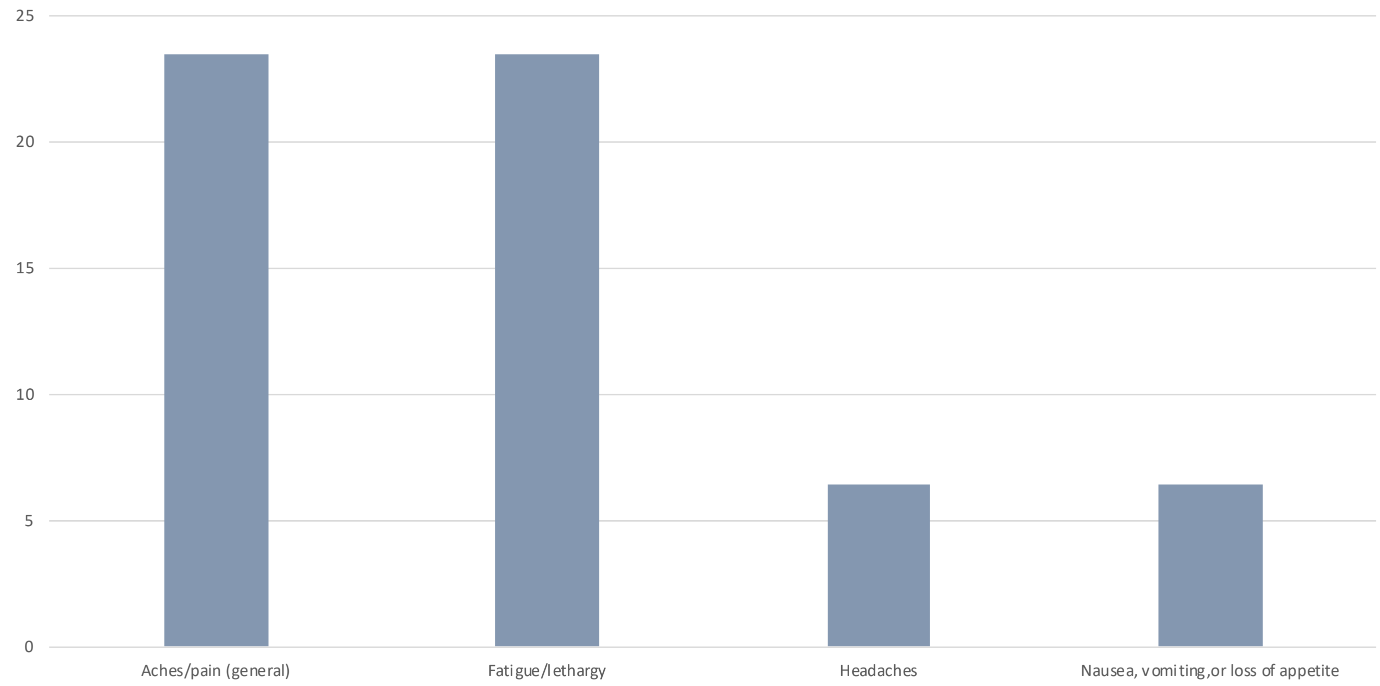

Figure 5.39: Description of mild side effects (Specific side effects)

Table 5.30: Description of mild side effects (Specific side effects) – subgroup variations

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of aches/pain (general)	Higher socioeconomic status	Regional or remote Mid to low socioeconomic status
Participant describes mild side effects giving the specific example of fatigue/lethargy	-	High cholesterol under 50 years of age
Participant describes mild side effects giving the specific example ofheadaches	-	High cholesterol under 50 years of age

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were described using a specific example (57.45%), and those that impact everyday life or ability to conduct activities of daily living (34.04%). Other themes included those that are life threatening or result in hospitalisation (6.38%), those that cause long-term damage to their body (6.38%), those that requires medical intervention (6.38%), and those that cause a need to change or stop using medication (6.38%).

When a specific side effect was described, the most common examples were aches and pain (21.28%), cognitive difficulties, including brain fog and difficulty communicating (14.89%), the emotional or mental impact (10.64%). Other side effects included fatigue or lethargy (10.64%), nausea, vomiting,or loss of appetite (6.38%), reduced mobility or loss of independence (6.38%), and shortness of breath (6.38%).

Participant provides a specific side effect as an example

I guess the mild side effect would be something like maybe a bit of back pain or some cramping bit of fatigue as well, maybe just feeling a little bit foggy headed, things like that. But I think a severe side effect would be something, you know, like we're cramping, that's so severe you can't walk properly, or you've got maybe breathing difficulties, things like that. Or maybe you're that fatigued that you can't get out of bed. That's the way I describe it.
Participant 011_2023AUHBV

Severe, severe would obviously be like I was saying with the, you know, I suppose the extreme vomiting, you know, the the extreme pain. Yeah, the full disorientation is not knowing where you are, how you are, why you are. Yeah.
Participant 018_2023AUHBV

There's severe nausea, and a general feeling of feeling fairly unwell, migraines, that sort of thing.
Participant 043_2023AUHBV

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

So severe side effects would mean that you couldn't go about your daily living, or your daily living would be severely impacted.
Participant 014_2023AUHBV

Severe heart effect. Yeah, well, I'd say this is the side effect is that I've got beta blockers, so I can't push myself as much as I want to quickly as I'd like to. I'm just thinking about sports performance.
Participant 015_2023AUHBV

Think things that that that stop you carrying out the normal. Daily routines, just looking after the house, shopping like say, meeting, meeting with friends, coffee. I'm retired, but you know, if you're a working person, being able to manage work, those sorts of things.
Participant 017_2023AUHBV

Fatigue is definitely a severe side effect for me. It changes everything. I can feel fine one minute and 15 minutes later I'll be on the couch and not being able to move. It greatly affects. I have two teenage children who still need lots of help and assistance. It definitely greatly affects their lives as well.
Participant 047_2023AUHBV

One which really prevents you from doing what you want to do.
Participant 048_2023AUHBV

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

A severe side effect is when I'm wanting to go to hospital. So something that's causing me extreme pain. Yeah, really a lot of discomfort. Yeah, a lot of distress.
Participant 021_2023AUHBV

Uh, mild side effects when I have, well, when I have, uh, sort of mild side effects, which is angina to me. Um. I kept it reasonably well because I know my, I know the routine I'm, I'm sort of I try the spray I use. If it doesn't work after twice I'll call an ambulance, you know. So that's how I deal with that. Basically I use my spray, I give it 5 minutes and if it hasn't said I'll give another spray and if hasn't worked after 10 minutes I'll be in an ambulance.
Participant 025_2023AUHBV

Participant describes severe side effects as those that cause long-term damage to their body

Well, to me, a severe side effect is now that I can't is the fact that I can't be medicated for something else Like to me that's very, like that's very detrimental to well, it's ruining my life. Honestly, I can't work as much as I would like. I am very not happy, like mentally because I can't be medicated and everyone else seems just seems to get this magical medication that fix them and I'm just not allowed to have a yeah, I'll call that a serious thing, but it doesn't hurt me other than for the rest of my life, just not physically.
Participant 007_2023AUHBV

So, so for me, like the fainting or long term health repercussions, anything that puts you in danger physically thank you.
Participant 020_2023AUHBV

Participant describes severe side effects as those that cause a need to change or stop using medication

If I had a severe side effect, I think I'd like a reaction and I would probably try another medication. I think I did have a bad side effect of one of the medications that I was originally on. I don't remember what it was called to be honest and I swapped it. Now this so much better than the other one that I was taking, but I don't remember what it was called.
Participant 016_2023AUHBV

Something that majorly impacts you and would can make you consider stopping the medication
Participant 019_2023AUHBV

Table 5.31: Description of severe side effects

Description of severe side effects	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant provides a specific side effect as an example	27	57.45	7	38.89	20	68.97	5	55.56	12	70.59	10	47.62	16	59.26	11	55.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	16	34.04	8	44.44	8	27.59	3	33.33	6	35.29	7	33.33	8	29.63	8	40.00
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	6.38	2	11.11	1	3.45	1	11.11	0	0.00	2	9.52	2	7.41	1	5.00
Participant describes severe side effects as those that cause long-term damage to their body	3	6.38	2	11.11	1	3.45	3	33.33	0	0.00	0	0.00	2	7.41	1	5.00
Participant identifies severe side effects as requiring medical intervention	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Participant describes severe side effects as those that cause a need to change or stop using medication	3	6.38	2	11.11	1	3.45	1	11.11	0	0.00	2	9.52	2	7.41	1	5.00

Description of severe side effects	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant provides a specific side effect as an example	27	57.45	14	53.85	13	61.90	10	41.67	17	73.91	11	73.33	16	50.00	16	64.00	11	50.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	16	34.04	12	46.15	4	19.05	7	29.17	9	39.13	7	46.67	9	28.13	7	28.00	9	40.91
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	6.38	1	3.85	2	9.52	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55
Participant describes severe side effects as those that cause long-term damage to their body	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55
Participant identifies severe side effects as requiring medical intervention	3	6.38	3	11.54	0	0.00	3	12.50	0	0.00	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes severe side effects as those that cause a need to change or stop using medication	3	6.38	3	11.54	0	0.00	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

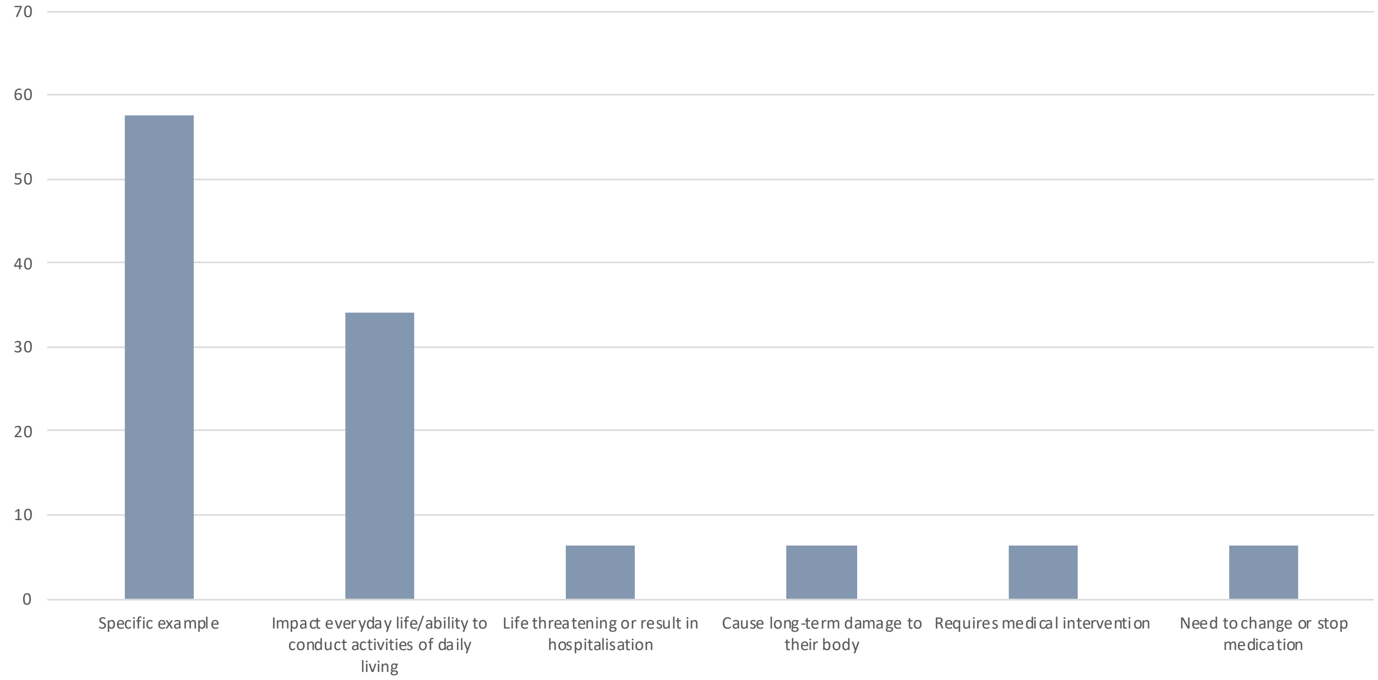

Figure 5.40: Description of severe side effects

Table 5.32: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Had LP(a) test Aged 25 to 44	Did not had LP(a) test Blood vessel conditions Aged 45 and older Regional or remote
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Male	Had LP(a) test Female Regional or remote
Participant describes severe side effects as those that cause long-term damage to their body	-	High cholesterol under 50 years of age

Table 5.33: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes severe side effects giving the specific example of aches/pain (general)	10	21.28	3	16.67	7	24.14	2	22.22	2	11.76	6	28.57	5	18.52	5	25.00
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	7	14.89	1	5.56	6	20.69	0	0.00	5	29.41	2	9.52	2	7.41	5	25.00
Participant describes severe side effects giving the specific example of emotion/mental impact	5	10.64	2	11.11	3	10.34	2	22.22	2	11.76	1	4.76	3	11.11	2	10.00
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	10.64	0	0.00	5	17.24	0	0.00	3	17.65	2	9.52	3	11.11	2	10.00
Participant describes severe side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	2	11.11	1	3.45	0	0.00	2	11.76	1	4.76	2	7.41	1	5.00
Participant describes severe side effects giving the specific example of reduced mobility/independence	3	6.38	0	0.00	3	10.34	0	0.00	2	11.76	1	4.76	1	3.70	2	10.00
Participant describes severe side effects giving the specific example of shortness of breath	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00

Description of severe side effects (Specific side effects)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes severe side effects giving the specific example of aches/pain (general)	10	21.28	7	26.92	3	14.29	5	20.83	5	21.74	3	20.00	7	21.88	7	28.00	3	13.64
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	7	14.89	4	15.38	3	14.29	3	12.50	4	17.39	2	13.33	5	15.63	5	20.00	2	9.09
Participant describes severe side effects giving the specific example of emotion/mental impact	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	5	33.33	0	0.00	4	16.00	1	4.55
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	3	20.00	2	6.25	2	8.00	3	13.64
Participant describes severe side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	0	0.00	3	14.29	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes severe side effects giving the specific example of reduced mobility/independence	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55
Participant describes severe side effects giving the specific example of shortness of breath	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09

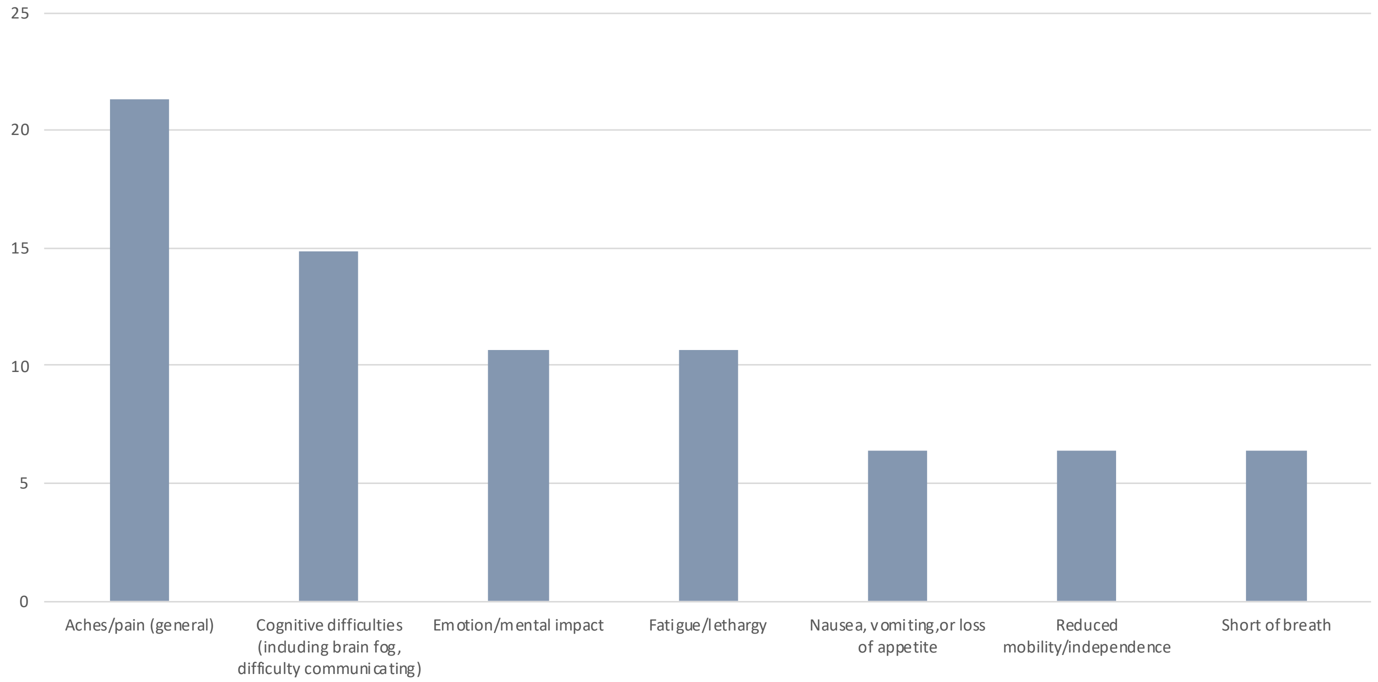

Figure 5.41: Description of severe side effects (Specific example)

Table 5.34: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of aches/pain (general)	-	-
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	High cholesterol under 50 years of age	Blood vessel conditions 6 to 11 other conditions
Participant describes severe side effects giving the specific example of emotion/mental impact	Metropolitan	High cholesterol under 50 years of age Regional or remote
Participant describes severe side effects giving the specific example of fatigue/lethargy	Had LP(a) test High cholesterol under 50 years of age	-

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment for a specific amount of time (46.81%), adhering to treatment according to the advice of their specialist or as long as prescribed (27.66%), and adhering to treatment as long as side effects are tolerable (25.53 %). Other themes included never giving up on any treatment (21.28%), and adhering to treatment as long as treatment is working (21.28%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (14.89%), and six to twelve months (8.51%).

Participant describes adhering to treatment for a specific amount of time

If you feel that it's not working, I'd give it a good six months.
Participant 021_2023AUHBV

About one year, yeah.
Participant 026_2023AUHBV

I haven't had any that causing me adverse side effects so far, so I've never given up on a medication, but I would say probably a month. Participant 039_2023AUHBV

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

Well, with all of the medications that I've been prescribed, I've just stuck with it. I've just stuck with it until the doctor's. Basically, you know, I decided to change the dose and luckily I've had no trouble with side effects. I haven't actually had to stop anything due to that, but I'm sure that if I did get a side effect, I'd probably stop it and go back to the doctor and and say hang on and you please look at this for me.
Participant 011_2023AUHBV

But hypothetically, you know, because it. Yeah, because it works, it's hard to say. But if I tried something and it wasn't working, I would probably default to the doctor. So I would say to the doctor, how long should I try this? How long should I continue before you can conclusively say, look, no, that's not working, so yeah, so I would. Because they're the ones that are going to have the information on how like every medication is going to have a different time frame. So whether it be working, yes. Yeah.
Participant 019_2023AUHBV

Like doctor said to me it will go with the over the life because so my family background so I need to be very strict about my medications or my diet or exercise.
Participant 027_2023AUHBV

Participant describes adhering to treatment as long as side effects are tolerable

Oh, you need to give it a good six weeks, I suppose. Sometimes after a week, I've felt like coming off something, but you need to give it a longer go, so probably six weeks. Just to see whether-- the thing that I battle mostly with the medications is the time. Like, you know, it's like you hit a brick wall at some stages with it, and so I need to see whether I can get over that before, and then if that doesn't go away, just affects my family life too much. Participant 030_2023AUHBV

Well, with the first medication change, I just couldn't get out of bed. After I started taking it, my blood pressure went through the floor, so I tried it for about two days, I think, before the doctor told me to stop it, when I rang him. So no, that wasn't any lack of trying, that was because it was dangerous. In other words, I wanted more evidence, so I gave that a few days, and then I thought, … And otherwise, I don't change anything else. Yeah, I go on it, and stay on it. The rest of them. Participant 032_2023AUHBV

It depends what the side effects are. Generally I will speak to the doctor if I don't think it's working or I'll make the tough choice to come off it and then I'll ring them and tell them why I've done what I've done or organise an appointment sooner rather than later. Generally if a specialist does put me on a medication, I will say, "Okay, let's reconvene in three weeks." I think three weeks is a good number of weeks to see if the medication's working, you can expect a few rough days in that three weeks, but there's lots of factors involved. It could be the stroke, it could be fatigue, it could be the drug, you just don't know. I'm also very lucky there my cardiologist and I speak weekly. I don't even wait the three weeks. If I'm having side effects straight away, he'll just be like, "I'm glad you've come off it."
Participant 050_2023AUHBV

Participant describes not giving up on any treatment

I've never give it up and I've never changed the management system.
Participant 004_2023AUHBV

PARTICIPANT: Well, I have not experienced that. INTERVIEWER: Fair enough.
PARTICIPANT: I've been on the same medication now for 15 years.
INTERVIEWER: There you go. Pretty sure it's working, huh? PARTICIPANT: It it seems to be yes, it has just increased my cholesterol medication because I've heard that people with coronary heart disease there's a new benchmark and he said. He wants me to be a little bit lower than I am at, I think. It's cholesterol is about 3.5, a bit less so OK, good.
Participant 005_2023AUHBV

PARTICIPANT: I don't think I've ever given up on anything. I don't think I've gone back and said anything about any medication. I just took it and just moved on.
Participant 037_2023AUHBV

Participant describes adhering to treatment as long as treatment is working

That would depend on the way it works in a way. If I had an infection and I was taking an antibiotic and it wasn't working within three days then I would want to go back to the doctor and say, "That antibiotic's not working." If it's a headache tablet, well, you're going to know within an hour if it's working. Then I'd give up on it in an hour. If it's something for blood pressure, I don't know long I would try, I don't know. It was till the doct"r told'me it wasn't working. It would'depend on what it was.
Participant 041_2023AUHBV

There was never any real treatment. The medications were a range of medicines. Basically blood thinners, a few other things. I haven't given up on any of the original medications. I don't feel that I'm qualified to do that. Why would I if they're working for me? I'm still on the original medication that I was taking. I realized the life-saving benefit of blood thinners. I had no side-effects from the medication so I've been very lucky.
Participant 045_2023AUHBV

I haven't been offered massive amounts of different treatments. I am willing to try anything and to stick with things to be able to get a better quality of life.
Participant 047_2023AUHBV

Table 5.35: Adherence to treatment

Adherence to treatment	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes adhering to treatment for a specific amount of time [	22	46.81	10	55.56	12	41.38	8	88.89	6	35.29	8	38.10	12	44.44	10	50.00
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	13	27.66	5	27.78	8	27.59	1	11.11	7	41.18	5	23.81	7	25.93	6	30.00
Participant describes adhering to treatment as long as side effects are tolerable	12	25.53	4	22.22	8	27.59	4	44.44	5	29.41	3	14.29	7	25.93	5	25.00
Participant describes not giving up on any treatment	10	21.28	4	22.22	6	20.69	0	0.00	6	35.29	4	19.05	7	25.93	3	15.00
Participant describes adhering to treatment as long as treatment is working	10	21.28	2	11.11	8	27.59	1	11.11	6	35.29	3	14.29	5	18.52	5	25.00

Adherence to treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes adhering to treatment for a specific amount of time	22	46.81	12	46.15	10	47.62	13	54.17	9	39.13	8	53.33	14	43.75	13	52.00	9	40.91
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	13	27.66	9	34.62	4	19.05	6	25.00	7	30.43	6	40.00	7	21.88	8	32.00	5	22.73
Participant describes adhering to treatment as long as side effects are tolerable	12	25.53	8	30.77	4	19.05	4	16.67	8	34.78	4	26.67	8	25.00	8	32.00	4	18.18
Participant describes not giving up on any treatment	10	21.28	4	15.38	6	28.57	2	8.33	8	34.78	2	13.33	8	25.00	5	20.00	5	22.73
Participant describes adhering to treatment as long as treatment is working	10	21.28	7	26.92	3	14.29	4	16.67	6	26.09	4	26.67	6	18.75	6	24.00	4	18.18

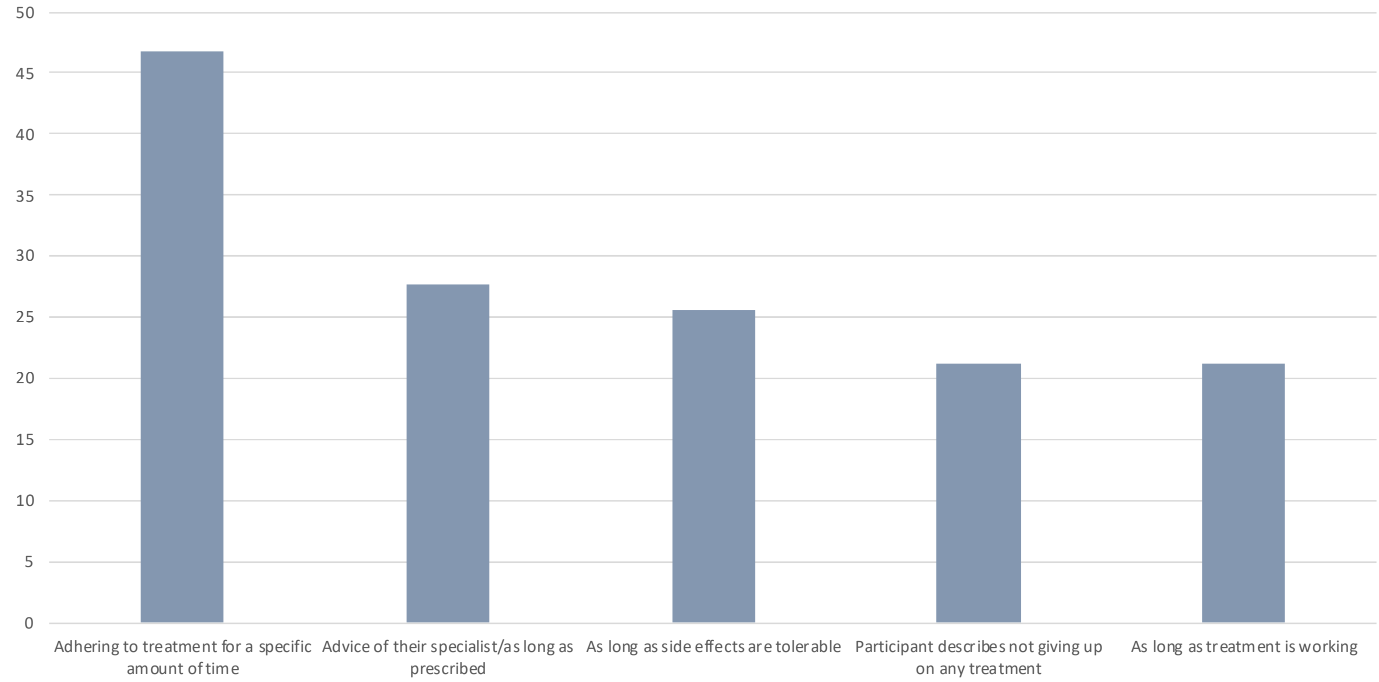

Figure 5.42: Adherence to treatment

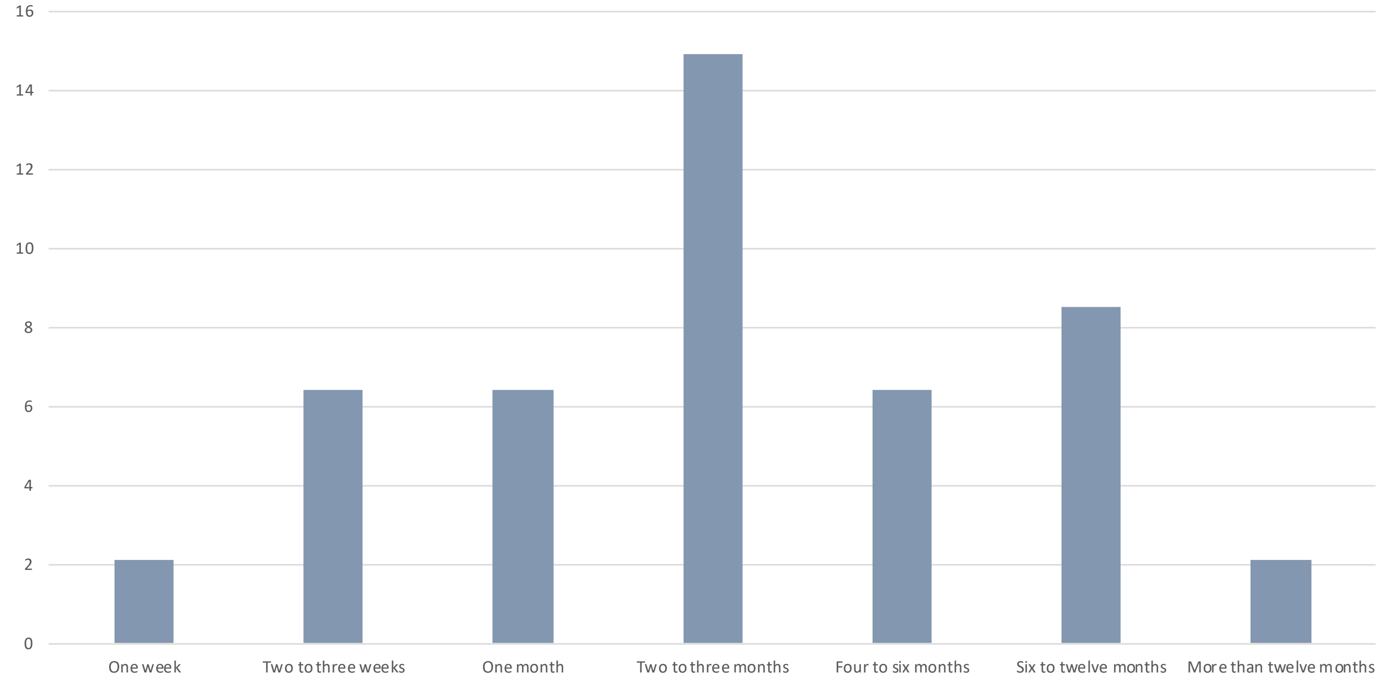

Figure 5.43: Adherence to treatment (Time to adhere to treatment)

Table 5.36: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment for a specific amount of time	Blood vessel conditions	High cholesterol under 50 years of age
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	High cholesterol under 50 years of age	Blood vessel conditions Regional or remote
Participant describes adhering to treatment as long as side effects are tolerable	Heart conditions	High cholesterol under 50 years of age
Participant describes not giving up on any treatment	High cholesterol under 50 years of age Aged 25 to 44	Blood vessel conditions Aged 45 and older
Participant describes adhering to treatment as long as treatment is working	Had LP(a) test High cholesterol under 50 years of age	Blood vessel conditions

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 responses were needing to see a specific symptom reduction (44.68%), and needing to see physical signs and symptoms disappear or reduce side effects (27.66%). Other themes included needing to see test results (14.89%), needing to see a return to day-to-day functionality (12.77%), and needing to have a balance between benefits and potential side effects (8.51%).

When a specific side effect or symptom was described, the most common examples were fatigue or lethargy (17.02%), heart rate or regular heart beat (8.51%), aches or pain (6.38 %), and the emotional, or mental impact (6.38%).

Participant describes needing to see a reduction in a specific symptom

I would want, I would need to feel like my heart. My heart rate would have to be lowered and not as sort of heavily pulsating throughout my upper body, which sort of turns into more. It's like a throbbing pain. My blood pressure would have to stabilize when I'm standing and not be consistently low, feeling like I can walk in a straight line and not something dizzy off, off kilter. Yeah, all those symptoms would have to be improved.
Participant 019_2023AUHBV

I think physically I need to feel an uptake in energy. So not being as tired, which is, you know, one of the things I deal with now is, is is being tired. I can't help the heart the way it is. Yeah. It's just an uptake in energy, you know, just a little bit, a little bit more upbeat, I guess.
Participant 028_2023AUHBV

What needs to improve. Whatever symptoms that I'm being medicated for, that has to improve, so if it's hypertension, then that has to improve over time, and I do give it four to six weeks before I see results. What else? The AF, obviously, the medication I wanted to see results immediately, but that took time. Whatever symptoms I'm being medicated for, they have to improve, and I do give it time.
Participant 034_2023AUHBV

The primary treatment for me was psychological treatment and that was repetition. When I was in rehab, I would sit down with my rehab provider and I would try and read. To enhance my memory, I would repeat, repeat, repeat, repeat. I've now realized that true repetition, that that's how the brain makes these synaptic connections. If I learned anything in my rehab, it is that I can control my brain and train my brain to improve memory.
Participant 045_2023AUHBV

Participants reported needing to see all physical signs and symptoms disappear

So a reduction in. Symptoms, but or at the AT, you know, a reduction in the numbers.
Participant 003_2023AUHBV

The side effects, I think, and for it to actually do something to alleviate the symptoms.
Participant 008_2023AUHBV

Whatever symptoms I had, improve.
Participant 041_2023AUHBV

Participant describes needing to see test results to know that a treatment is working

Yeah, I think it's looking at my blood tests is the important thing for me. Um, just checking my cholesterol levels and making sure that they're at Target or trying to get down to Target. So that would be an indicator of that. The medication's working.
Participant 011_2023AUHBV

The fact that when I have my, you know regular blood tests and my cholesterol is where it should be and that's all good. And so I keep my GP keeps a track on that. I'm just about to have a test this week to make sure that the so when all those markers are OK then it makes me feel OK.
Participant 013_2023AUHBV

Well, the results obviously from for me it was the cholesterol results. If they had worked, if they'd moved, especially with the diet, I might have been tempted to stick with it a little bit longer:
Participant 020_2023AUHBV

Participants reported needing to experience a return to day-to-day functionality

Right. I I understand that it's not all medication makes you feel better. I have some treatment for osteoporosis which on a day-to-day level doesn't affect me or or improve my health. What it does is in

the long term it stops degeneration of of the bones. So I think like like that with with the heart, the sort of things that I would hope to see is that I would be able to do more exercise. I wouldn't get out of breath so quickly, or my heart rate wouldn't go up so quickly
Participant 017_2023AUHBV

Visible improvement in my daily activity and the way I feel mentally and physically.
Participant 049_2023AUHBV

Participant describes needing to have a balance between benefits and potential side effects

In my case, it would be like to see the blood results. So if I start to see the data that literally there's at least at first there's something that's would be coming down and and there's like a trend, you know, yeah, it it might take six months, yeah, six months or a year to kind of see the trend. And I and I could, I guess I would, yeah. So that that gives me more food. So I might even go back and have to kind of give it. Yeah, even six months to see what the data would come in at. Yeah, I mean I might get a blood test after three months just to see if it's making a difference because that would that would spur me to continue that spur me on motivate me to keep going. Yeah. And then I guess, yeah, I guess I'm sorry and I guess kind of your question, I would be assessing in a sense like myself reported. You know what? I'm perceived side effects or if my quality of life from day-to-day was suffering in a way. If you know, I would definitely be keeping like a a bit of a mental tab and like a bit of a sort of a checking with myself just to just to try to notice if there are small differences. Like maybe I'm experiencing like pain in my joints or something like that, or mental fogginess or whatever or something with this. That just seems OK. And then trying to see if it's connected to this, this, if it is a drug therapy or what have you. Yeah. So maybe I would keep a little journal kind of thing and just kind of weigh that up as well. Cuz I know that's gonna be a factor in my decision making this stay on or not.
Participant 001_2023AUHBV

Table 5.37: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes needing to see a reduction in a specific symptom	21	44.68	9	50.00	11	37.93	4	44.44	7	41.18	9	42.86	11	40.74	9	45.00
Participants reported needing to see all physical signs and symptoms disappear	13	27.66	1	5.56	12	41.38	1	11.11	7	41.18	5	23.81	5	18.52	8	40.00
Participant describes needing to see test results to know that a treatment is working	7	14.89	3	16.67	4	13.79	3	33.33	1	5.88	3	14.29	3	11.11	4	20.00
Participants reported needing to experience a return to day-to-day functionality	6	12.77	5	27.78	1	3.45	1	11.11	2	11.76	3	14.29	4	14.81	2	10.00
Participant describes needing to have a balance between benefits and potential side effects	4	8.51	3	16.67	1	3.45	4	44.44	0	0.00	0	0.00	1	3.70	3	15.00

What needs to change to feel like treatment is working	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes needing to see a reduction in a specific symptom	21	44.68	13	50.00	7	33.33	12	50.00	8	34.78	6	40.00	14	43.75	11	44.00	9	40.91
Participants reported needing to see all physical signs and symptoms disappear	13	27.66	10	38.46	3	14.29	3	12.50	10	43.48	5	33.33	8	25.00	8	32.00	5	22.73
Participant describes needing to see test results to know that a treatment is working	7	14.89	3	11.54	4	19.05	6	25.00	1	4.35	3	20.00	4	12.50	4	16.00	3	13.64
Participants reported needing to experience a return to day-to-day functionality	6	12.77	3	11.54	3	14.29	5	20.83	1	4.35	1	6.67	5	15.63	4	16.00	2	9.09
Participant describes needing to have a balance between benefits and potential side effects	4	8.51	1	3.85	3	14.29	4	16.67	0	0.00	1	6.67	3	9.38	1	4.00	3	13.64

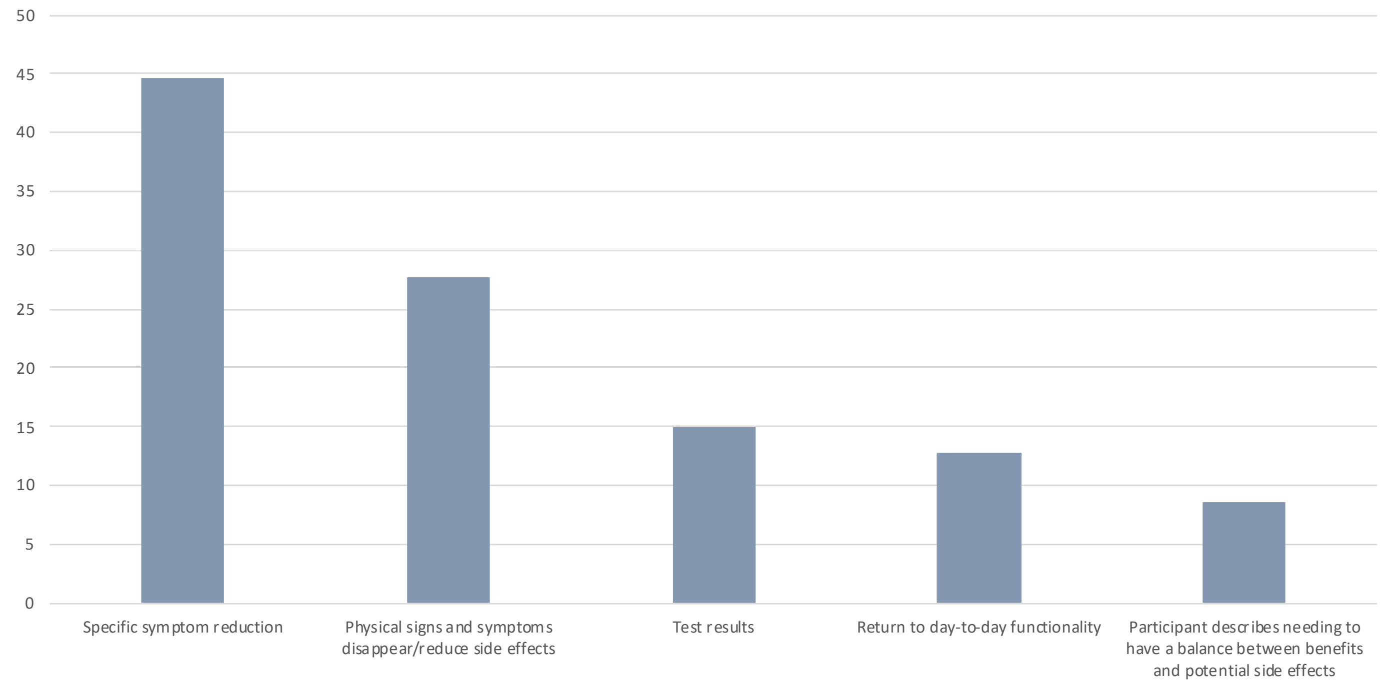

Figure 5.44: What needs to change to feel like treatment is working

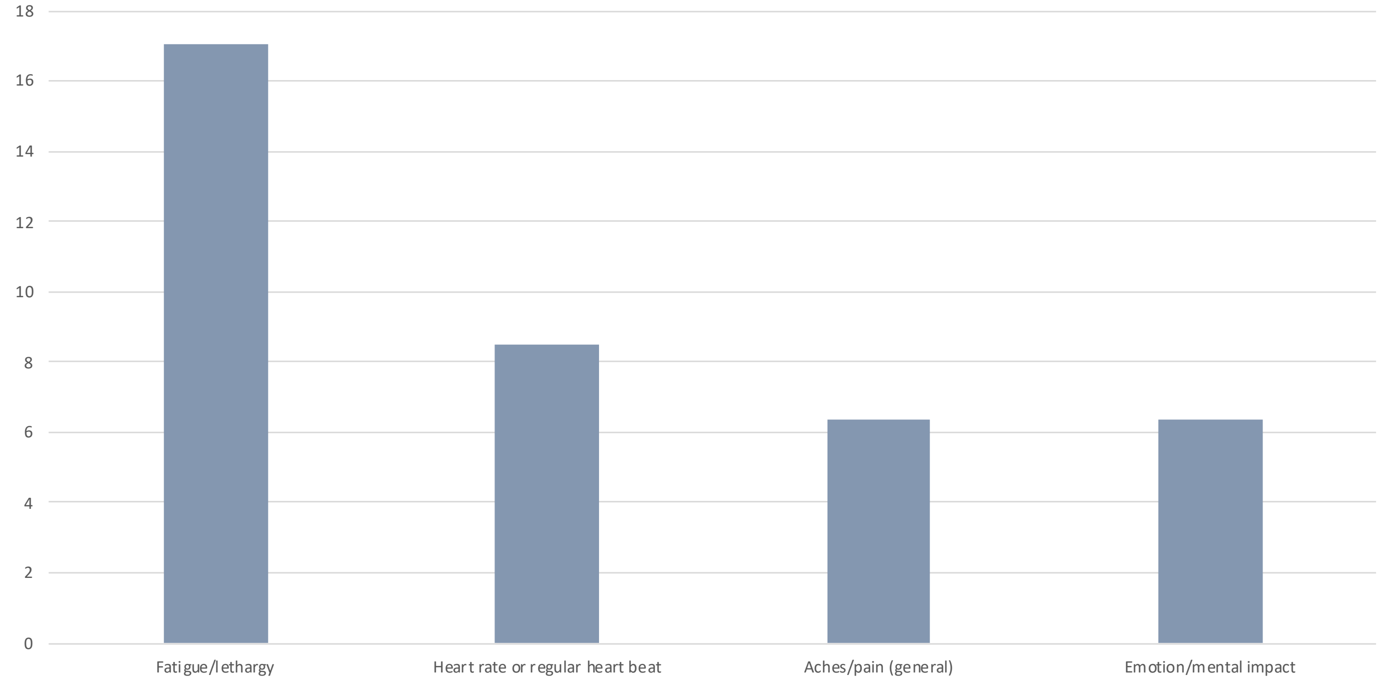

Figure 5.45: What needs to change to feel like treatment is working (Specific symptoms)

Table 5.38: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participant describes needing to see a reduction in a specific symptom	Male	-
Participants reported needing to see all physical signs and symptoms disappear	Had LP(a) test High cholesterol under 50 years of age Male Aged 25 to 44	Did not had LP(a) test Blood vessel conditions 6 to 11 other conditions Female Aged 45 and older
Participant describes needing to see test results to know that a treatment is working	Aged 45 and older	High cholesterol under 50 years of age Aged 25 to 44
Participants reported needing to experience a return to day-to-day functionality	-	Had LP(a) test
Participant describes needing to have a balance between benefits and potential side effects	-	High cholesterol under 50 years of age

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (17.02%), and it would lead to a reduction in symptoms or side effects (14.89%). This was followed by it would have positive impact on their mental health (12.77 %), and allow them to engage more with social activities and family life (8.51%).

Allowing them to do everyday activities/return to normal life

Oh, it'd mean a lot of things. I can do more, be more independent.
Participant 044_2023AUHBV

Probably concentrate more and be able to get out and do activities.
Participant 049_2023AUHBV

Maybe I could use my left arm more often and carry things, at the moment, it's a pretty useless arm to be honest.
Participant 039_2023AUHBV

I would have been a lot more freer. I have more freedom. Now my pain is out of control. I really can't do much now. That was one of my big goals.
Participant 042_2023AUHBV

Leading to a reduction in symptoms/side effects

I think just have more, more energy to do things. For example, with the housework I'm only able to do sort of one or two small rooms at a time, and then I feel exhausted, and that's partly because. I can feel, you know, that I'm breathing more heavily and I'm getting that pressed and it it's like I've been running, it's that sort of tiredness. And so if the medication was working, then it would mean I would be able to do more of that and I would be able to walk further because I like walking and you know, I I would like to be able to walk for an hour at a time and that sort of thing. So they're the sort of things that I would like, like to be able to do, and I like swimming, but I can only do it for a short, a short time, you know, And aerobics, aerobics class of 45 minutes is sort of the maximum I can do, and I'd like to be able to do something like that and have a bit of energy. Left at the end.
Participant 017_2023AUHBV

The primary treatment for me was psychological treatment and that was repetition. When I was in rehab, I would sit down with my rehab provider and I would try and read. To enhance my memory, I would repeat, repeat, repeat, repeat. I've now realized that true repetition, that that's how the brain makes these synaptic connections. If I learned anything in my rehab, it is that I can control my brain and train my brain to improve memory.
Participant 045_2023AUHBV

Well, yes, it has completely removed my migraines. It means that my quality of life is probably better than it was before I had my stroke because I did not get recurrent, debilitating migraines.
Participant 046_2023AUHBV

A positive impact on their mental health

Probably wouldn't change too much in my day-to-day life, but it would remove the stress of the condition.
Participant 020_2023AUHBV

Allowing them to engage more with social activities and family life

Yeah, look, it would mean the world. Like, I've got three kids, so one of them's 18 soon. The others are quite young, so being able to do a lot more physical activity with those, those ones would be really good. So you know, I've started walking with my daughter. She's only seven, but she's already, I swear, a lot more fitter than what I am, you know. But just being able to do things with that, with the family, just means the world.
Participant 028_2023AUHBV

Table 5.39: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Allowing them to do everyday activities/return to normal life	8	17.02	5	27.78	3	10.34	1	11.11	4	23.53	3	14.29	5	18.52	3	15.00
Leading to a reduction in symptoms/side effects	7	14.89	4	22.22	3	10.34	2	22.22	4	23.53	1	4.76	2	7.41	5	25.00
A positive impact on their mental health	6	12.77	4	22.22	2	6.90	2	22.22	1	5.88	3	14.29	3	11.11	3	15.00
Allowing them to engage more with social activities and family life	4	8.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	2	7.41	2	10.00

What it would mean if treatment worked	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Allowing them to do everyday activities/return to normal life	8	17.02	4	15.38	4	19.05	4	16.67	4	17.39	3	20.00	5	15.63	6	24.00	2	9.09
Leading to a reduction in symptoms/side effects	7	14.89	6	23.08	1	4.76	4	16.67	3	13.04	3	20.00	4	12.50	5	20.00	2	9.09
A positive impact on their mental health	6	12.77	5	19.23	1	4.76	4	16.67	2	8.70	3	20.00	3	9.38	5	20.00	1	4.55
Allowing them to engage more with social activities and family life	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	2	13.33	2	6.25	3	12.00	1	4.55

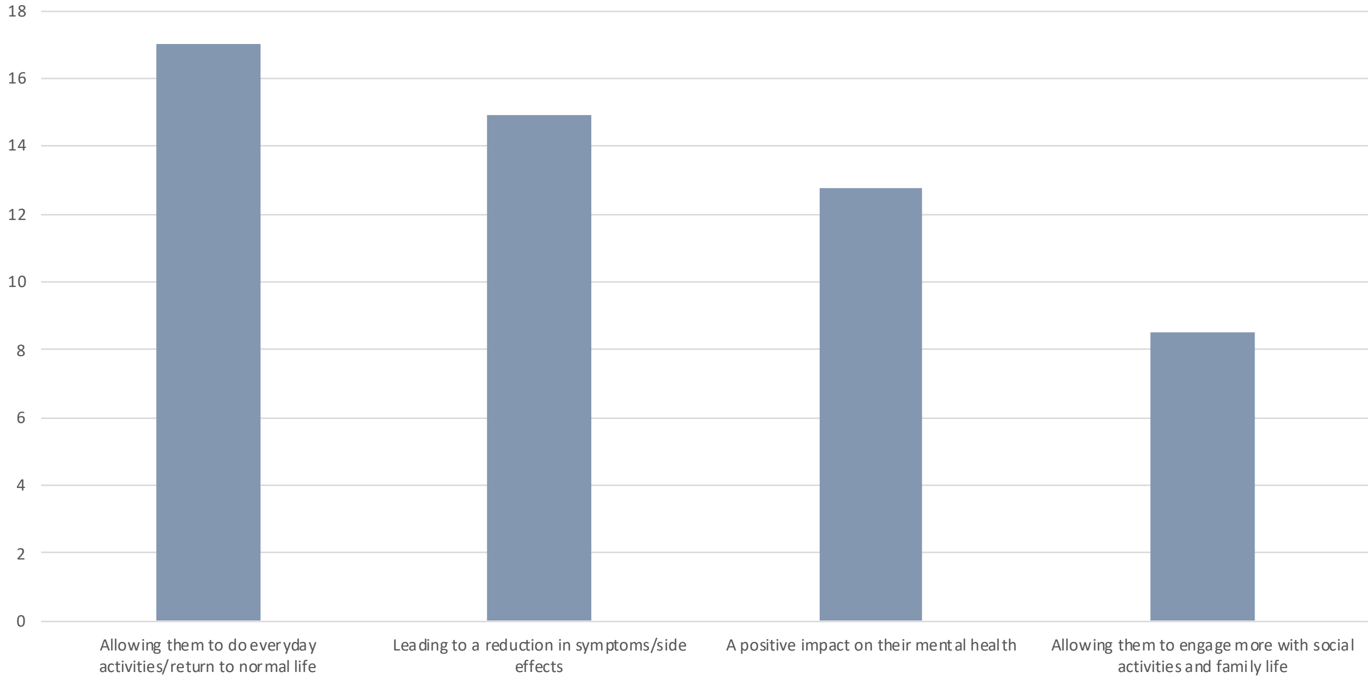

Figure 5.46: What it would mean if treatment worked

Table 5.40: What it would mean if treatment worked – subgroup variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Allowing them to do everyday activities/return to normal life	-	Had LP(a) test
Leading to a reduction in symptoms/side effects	Heart conditions Male	6 to 11 other conditions

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (55.32%), their treating clinician (42.55%), and from a specific health charity (36.17 %). Other themes included information from other patient's experience (Including support groups) (31.91%), from journals (research articles) (25.53%), from books, pamphlets and newsletters (21.28%), from allied health professionals (8.51%), and from family members (8.51%).

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 responses were other people’s experiences (25.53%), talking to a doctor or specialist or healthcare team (21.28%), and information from health charities (21.28 %). Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (19.15%), information about lifestyle changes and risk prevention (14.89%), medical or scientific information (8.51%), and information presented by webinar or video (8.51%).

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 responses were no information not helpful (42.55%), information given by their GP or specialist was not helpful (12.77%), sources that are not credible or not evidence-based were not helpful (12.77 %), information that not type specific or too general (10.64%), and information with too much medical jargon as unhelpful (8.51%). Others described being confident in deciding themselves if information was not helpful (8.51%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (36.17%), talking to someone plus online information (27.66%), and written information (17.02 %). Other preferences included online information (14.89%), all forms (10.64%), and apps (2.13%).

The main reasons for a preference for talking to someone was being able to ask questions (21.28%), and the information was personalized and relevant (17.02%). Other reasons included that it was more supportive, and that body language helps with understanding (10.64%), and cognitive/sight problems make other forms not able to be used (6.38%).

The main reasons for a preference for online information were accessibility (21.28%), that you can can refer back to it and clarify information (17.02 %), and being able to digest information at their own pace (10.64%).

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 times were at the beginning (diagnosis) (27.66%), and after the shock of diagnosis (14.89%). Other themes included continuously (12.77%), 12 months or more after diagnosis (12.77%),when medical emergency over (8.51%), after treatment (6.38%), and after test results or changes to condition (6.38%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Participants gave descriptions that communication as overall positive (34.04%), overall positive, with the exception of one or two occasions(34.04%), and overall negative (27.66 %).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because it was holistic with two way, supportive and comprehensive conversations (31.91%).

Participants that had negative communication, described the reasons for this were that communication was dismissive (One way conversation) (19.15 %), limited in multi-disciplinary communication and care coordination (10.64%), limited in relation health professionals not having a lot of time (8.51%), and limited in that they have not had a lot (6.38%).

Partners in health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=28, 56.00%), disease cause (n=19, 38.00%), disease management (n=18, 36.00%) and, dietary (n=18, 36.00%) were most frequently given to participants by healthcare professionals, and, information about hereditary considerations (n=4, 8.00%), and complementary therapies (n=2, 4.00%) were given least often. No participants (0.00%) were given information about clinical trials.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease cause (n=22, 44.00%), treatment options (n=19, 38.00%), disease management (n=19, 38.00%) and, how to interpret test results (n=17, 34.00%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=11, 22.00%), complementary therapies (n=10, 20.00%) and clinical trials (n=4, 8.00%) were searched for least often

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=46, 92.00%) and complementary therapies (n=39, 78.00%).

The topics that participants were given most information from healthcare professionals but not searched for independently for were treatment options (n=16, 32.00%) and physical activity (n=15, 30.00%).

The topics that participants searched for independently after receiving information from healthcare professionals were treatment options (n=12, 24.00%) and disease management (n=8, 16.00%)

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=15, 30.00%) and interpret test results (n=13, 26.00%).

Most accessed information

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 20 participants (40.00%) that had accessed My Health Record.

Of those that had accessed My Health Record, there were 8 participants (42.11%) who found it to be poor or very poor, 4 participants (21.05%) who found it acceptable, and 7 participants (36.84%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (55.32%), their treating clinician (42.55%), and from a specific health charity (36.17 %). Other themes included information from other patient's experience (Including support groups) (31.91%), from journals (research articles) (25.53%), from books, pamphlets and newsletters (21.28%), from allied health professionals (8.51%), and from family members (8.51%).

Participant describes accessing information through the internet in general

I got some information from the hospital. I think the doctors gave me some information and I did a bit of research online myself.
Participant 008_2023AUHBV

Yeah, sure. So I've done a lot of Googling. There's I mentioned earlier so I've I've had connections with Her Heart along the way and they they're a great resource to to connect with people and through them have come across a few groups. So I don't, you know, have got lots of information from those groups who do research in their own way. I suppose I'll look at the Victor Chang web site a little bit to see if there's any updates or what information they have... I'll go and look into whether that looks like something that they've mentioned in the research that they've published. And same with I can't think of what the research organization is, the Mayo Clinic in America is what it is. So I'll research there just to keep up to date with it if there's you know ways that I can one challenge perhaps my preventative treatment and to suggest other. There's not been much to suggest to be honest but you know things other people are doing like if I've been advised I can't run and then I see somebody else say I've been you know it's been suggested I could go back to doing things like I'll I use that as a bit of I use that information as a tool. But that's but they're the places I go and that's where I get most of my information from.
Participant 009_2023AUHBV

Ah, well, I'm a PROFESSION, so I went to the journals. I went to the, you know, the the Mayo Clinic to the Cleveland Clinic, to their websites. I went to the all the, all the evidence basis I could find, including the evidence basis for alternative options because I didn't want to have my chest cracked open if I didn't need to. Is there any way I can reverse this? Is there any, you know, kind of any inflammatory approach to nutrition I can take that might resolve it? You know, is there anything else I can do? So yes, I did. I did hours and hours and hours and hours and hours.
Participant 010_2023AUHBV

Participant describes primarily accessing information through treating clinician

I really probably have not even accessed it. I knew what I had and I dealt with it. And I had my doctor's support and my cardiologist, and I don't feel like I needed any. I needed to go there anymore.
Participant 005_2023AUHBV

So for me it's medical journals and stuff like that. I don't like doctor Google. It has to be like a peer reviewed thing or yeah, information that's credible. I've talked a lot with my GP…so we have quite good conversations about it, but sort of that's where it ends I suppose.
Participant 014_2023AUHBV

Yeah, I do a lot of research on Google with that. You know, anything like that concerns, you know, just for my own sake. All information I've received now is basically from being from my GPS, my specialist.
Participant 025_2023AUHBV

Participant describes accessing information from a specific health charity

Yeah, I as soon as I got the letter from the cardiologist, I basically copy and pasted it straight into Google just so I could understand what it was. Cuz when you're looking at a specialist's writing and diagnosis that it's all gobbledygook to me, I don't understand any of it. So I'm jumping onto the Heart Foundation website trying to understand, you know, what exactly this is and what it can cause for me. You know, like when they talk about blood pressure and all this other stuff like I have no idea what that means. Yeah, so yeah, I just start Googling everything that I know It's silly, but I mean that that's. Yeah, I just jumped straight to Google for it to start with.
Participant 028_2023AUHBV

The primary and most important source of information to me has been the Stroke Foundation. Everything I need to know comes from the Stroke Foundation. That's not only through their literature, but it's also through interaction with other people. It's a treasure of information. If the Stroke Foundation

was not there it would have been an extraordinary struggle for me.
Participant 045_2023AUHBV

Participant describes primarily accessing information through other patient's experience

A lot comes from online support groups, which I honestly find to be more beneficial than anything else because I'm talking to people who have had this longer than me and can answer my questions straight up and have that personal experience. So that's probably my #1 go to
Participant 019_2023AUHBV

I suppose because I'm a PROFESSION, I know what resources to look at. At first, when I was diagnosed, I didn't really want to know, because I didn't really, sort of put my head in a hole about it. But now I'm a lot more informed about what's going on. I use, the support group's really good and we have, I'm involved in a support group, and they will send out information on new research in the field and so on, and things to be aware of like clots. Be aware of these levels, blood levels, and make sure you're drinking lots and so on. I've found they have a really good, really great support, actually. I just, you know, there's some days, they're just fantastic. So you can, if you're having one of those really bad days, you can just email them, or you just hop on the Facebook site and people will provide encouragement or advice or whatever. So I just find that really, really helpful. I go to information sessions at HOSPITAL as well, and they're really, really good as well. My doctor's really well-informed, and the practise nurse there is really well-informed as well. Anything else that I'm concerned about, I'll look up on reputable websites and journals, yeah.
Participant 030_2023AUHBV

I've learnt a lot through meeting other people, and the information, their wealth of information. The internet, I usually just go to the Stroke Foundation's page to get the information. It's just a matter of talking to other stroke survivors and giving information. Doctors are really good nowadays with stroke things, but they weren't back in my day. No.
Participant 049_2023AUHBV

Participant describes accessing information primarily through journals (research articles)

I make informed choices about high cholesterol and on occasion if I have, if I have some doubts, I search in articles and now is excellent to have some now knowledge about that.
Participant 026_2023AUHBV

Most of the information I get is from stroke organisations and medical journals. Basically, I've done a lot of university degrees. I still had access to university library journals and that sort of thing. I've done a bit of reading there. To be honest, I haven't done any reading for probably 10 years because my symptoms are static. You can't make a dead piece of the brain not be dead. If I had symptoms that weren't static, then I would certainly be trying to stay on top of that sort of thing, and talking to my GP about it. For my particular situation, it's not really a thing anymore.
Participant 046_2023AUHBV

Participant describes receiving information from books, pamphlets and newsletters

So I've pretty much googled it because I haven't been given much officially from the doctor. A few printed handouts with some highlighted information about healthy levels and things. And you know the all the basics eat avocados and oats and and very general sort of stuff. But I haven't. I I spent a lot of more time just doing research on my own on the Internet.
Participant 020_2023AUHBV

I'm with Heart Care LOCATION STATE. They've got brochures on all different procedures and things, and my GP's pretty good with communicating and answering questions. I always go with a lot of questions in my head or written down, and I also find that I direct a lot of my questions to the technicians ... They are very, very clear and helpful, actually.
Participant 023_2023AUHBV

Yes. Like I said, I'm a researcher, so I'll go onto Heart Support Australia. All those information websites. I go on there and I use those. I do have some brochures about what it's like to live with atrial fibrillation, which is extremely informative. I go on social media, and there's a lot of support forums, and I'm involved with probably three or four of those, and I find that extremely helpful as well. Yeah, so it's print and social media, and also TV. There's quite a lot going on at the moment with the TV, as far as information about strokes and atrial fibrillation, et cetera. Yeah. So I do follow it quite well, because I'm always looking for new information about improvements in treatment and all that sort of thing. And it's up to me to do that. While it's good for the cardiologist -- well, the cardiologist has some brochures, but I find it's easier just for me to do the research myself. Because I love doing it.
Participant 031_2023AUHBV

Participant describes receiving information through allied health

When I left there, in the April or the May when I left, the physio, the whole lot. From there then I started doing the rehab after I had the clips done. I was seeing my now current cardiologist and as I said they refused me to do the heart study gym at the hospital after I was discharged. NAME go me into the normal gym and I got a lot of information from that. As I said, I was the only heart failure patient, which I found pretty frustrating. After I had an admittance at the hospital they put me under the heart failure gym at the hospital, so I've done another six weeks of heart failure gym, and information, and education,I've done both lots.
Participant 033_2023AUHBV

I've had a lot of information. I had a lot of information from cardiac rehab if since when I attended there, they had classes, they had lectures, they had everything. I actually seen private dieticians, that sort of thing. One of the women that tell me that I needed to eat healthy and do this and do that chair tucks up, arms hanging down onto the desk. You're telling me from and would have been at least about 130 kilos. And I thought you're telling me that I need what I need to be doing. Yeah. Right. OK. No, the dietitian was a young lady from came to cardiac rehab one day and while I was there I got talking to her about what was the correct foods and what was not and told her I was buying fruit and that sort of thing and what I was eating of it. And she said well that's wrong because they're for sugar and that sort of thing. So and you have just got early diabetes. She gave me. She said take this sheet, a four sheet. See on there, there foods you can have all day. They're all-day foods. They're part time foods. They're that's what you can have of that. It just immediately got me going where it was simply diagnosed. You can have these, these are as much as eat as much as this food all day long as you like this one. So this a bit with the meals once a day, you know what I'm saying? Like, so, yeah, She was just so much on the so much on to it, you know, in line with terms of where you need to be.
Participant 006_2023AUHBV

Participant describes accessing information from family members

I think it's just just growing up knowing other, you know, all our family members that, you know, going along to appointments with my dad, taking him to appointments and stuff like that and sitting in with him because he wanted me to, or just learning, you know, learning about it from a young age. Really. I haven't really thought about it since I've been on the medication.
Participant 016_2023AUHBV

In rehab, I asked them about stroke because one was talking to me about it. I was really getting myself a bit distressed about it so I asked them about the stroke and they gave me a booklet. In the booklet, there was a website for a stroke foundation I think it was. I joined it and they send out newsletters but I don't find any of that very helpful at all. Then I looked up, stroke on the internet, and found out some really horrifying statistics about survival rate which scared me. [laughs] Then I talked to my son about it and he's probably helped me the most.
Participant 041_2023AUHBV

Table 6.1: Access to information.

Access to information	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes accessing information through the internet in general	26	55.32	10	55.56	16	55.17	**6**	**66.67**	9	52.94	11	52.38	13	48.15	13	65.00
Participant describes primarily accessing information through treating clinician	20	42.55	**10**	**55.56**	10	34.48	4	44.44	6	35.29	10	47.62	13	48.15	7	35.00
Participant describes accessing information from a specific health charity	17	36.17	**2**	**11.11**	**15**	**51.72**	**2**	**22.22**	**10**	**58.82**	**5**	**23.81**	9	33.33	8	40.00
Participant describes primarily accessing information through other patient's experience	15	31.91	**3**	**16.67**	12	41.38	3	33.33	6	35.29	6	28.57	9	33.33	6	30.00
Participant describes accessing information primarily through journals (research articles)	12	25.53	4	22.22	8	27.59	3	33.33	5	29.41	4	19.05	7	25.93	5	25.00
Participant describes receiving information from books, pamphlets and newsletters	10	21.28	5	27.78	5	17.24	2	22.22	3	17.65	5	23.81	5	18.52	5	25.00
Participant describes receiving information through allied health	4	8.51	1	5.56	3	10.34	0	0.00	1	5.88	3	14.29	3	11.11	1	5.00
Participant describes accessing information from family members	4	8.51	1	5.56	3	10.34	**2**	**22.22**	1	5.88	1	4.76	1	3.70	3	15.00

Access to information	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes accessing information through the internet in general	26	55.32	**18**	**69.23**	**8**	**38.10**	12	50.00	14	60.87	**10**	**66.67**	16	50.00	13	52.00	13	59.09
Participant describes primarily accessing information through treating clinician	20	42.55	10	38.46	10	47.62	10	41.67	10	43.48	**3**	**20.00**	**17**	**53.13**	10	40.00	10	45.45
Participant describes accessing information from a specific health charity	17	36.17	10	38.46	7	33.33	8	33.33	9	39.13	**7**	**46.67**	10	31.25	9	36.00	8	36.36
Participant describes primarily accessing information through other patient's experience	15	31.91	7	26.92	8	38.10	6	25.00	9	39.13	5	33.33	10	31.25	6	24.00	9	40.91
Participant describes accessing information primarily through journals (research articles)	12	25.53	8	30.77	4	19.05	4	16.67	8	34.78	5	33.33	7	21.88	8	32.00	4	18.18
Participant describes receiving information from books, pamphlets and newsletters	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	3	20.00	7	21.88	3	12.00	**7**	**31.82**
Participant describes receiving information through allied health	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64
Participant describes accessing information from family members	4	8.51	2	7.69	2	9.52	4	16.67	0	0.00	0	0.00	4	12.50	1	4.00	3	13.64

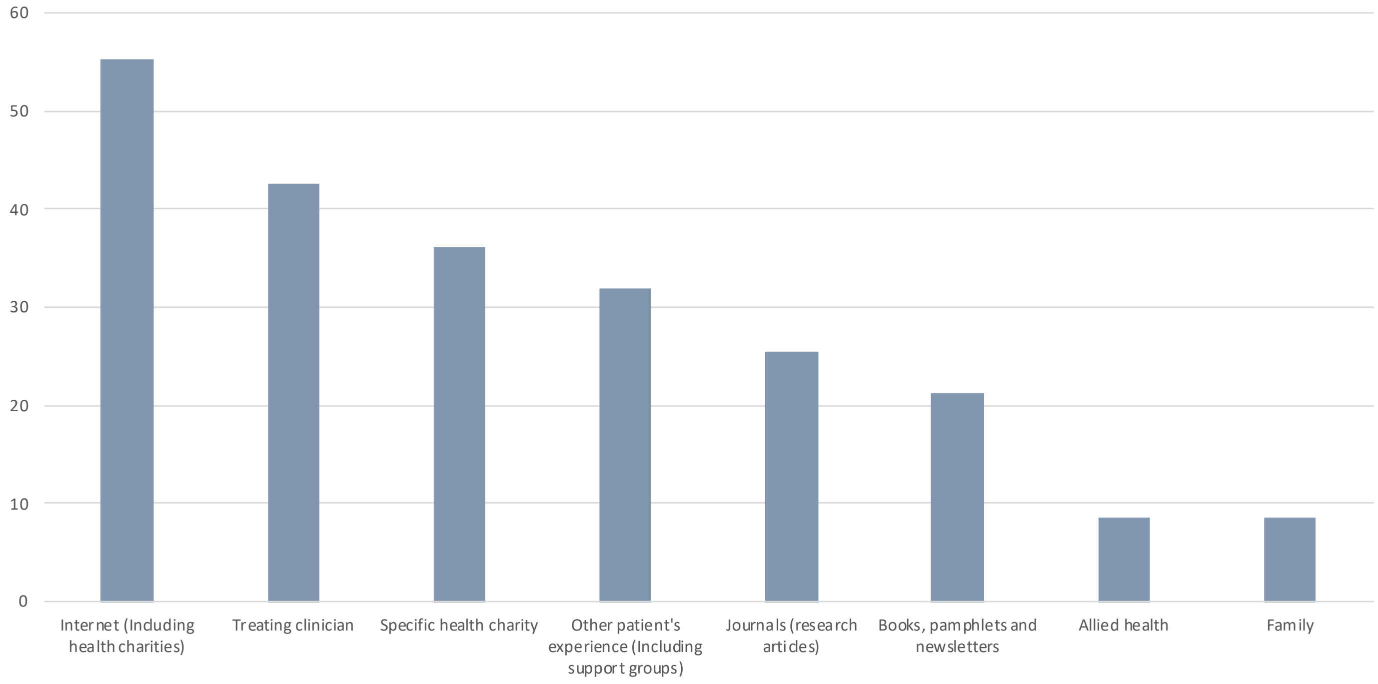

Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Male	High cholesterol under 50 years of age Female Regional or remote
Participant describes primarily accessing information through treating clinician	Regional or remote	Had LP(a) test Metropolitan
Participant describes accessing information from a specific health charity	Had LP(a) test High cholesterol under 50 years of age Heart conditions	Did not had LP(a) test Blood vessel conditions Regional or remote
Participant describes primarily accessing information through other patient's experience	Had LP(a) test	-
Participant describes receiving information from books, pamphlets and newsletters	-	Higher socioeconomic status
Participant describes accessing information from family members	-	High cholesterol under 50 years of age

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 responses were other people's experiences (25.53%), talking to a doctor or specialist or healthcare team (21.28%), and information from health charities (21.28 %). Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (19.15%), information about lifestyle changes and risk prevention (14.89%), medical or scientific information (8.51%), and information presented by webinar or video (8.51%).

Participant describes other people's experiences as helpful (Peer-to-peer)

I think to be honest, just knowing that there's lots of people all probably feeling the same way, not really sure what it all means to have had the doctor to have had a scab. So knowing that there are people asking the same questions that you're thinking in your head, you know, around lots of things you know they'll ask in a group, has anybody had a second one? How long between the years you know, how many years between? You know, just knowing that people are actually thinking, having similar thoughts and wondering the same things, I think that's the most useful thing I've taken away from it.
Participant 009_2023AUHBV

The online support group
Participant 019_2023AUHBV

To be honest, it's been more the parts that I'm not alone. There's other people out there that have strokes of all ages, even in the womb and that some are going to have really good effects with thrombolytics and all sorts of stuff and come out of their stroke with very little physical damage. Then others of us, are going to be well upstairs in the sense of have all their mental capacities but may have physical damage. Regardless, we're all in a tribe that's quite elite. For me, that's been the biggest thing, is that we're not alone. As much as we feel like we're alone because no stroke is ever the same, two strokes are never the same, it's just to remind us that we're not alone.
Participant 050_2023AUHBV

Participant describes talking to their doctor or specialist as helpful

most helpful would be, it's actually like completely non medical to be honest. Like the most helpful information I received the whole throughout my whole childhood, probably growing up, is that there are people with your condition or very similar sort of condition who are functioning day-to-day completely fine. You know, when I was a teenager, things were progressing quite quickly and probably the outlook wasn't great. So you're sort of get caught into a mindset of is this just going to be the progress forever until you get to a point where the decline is quite steep and quick and unfortunate I guess. But, you know, you hear stories or you speak to people or you just randomly come across these stories of people who have the same condition, Cardiomyopathy, It's pretty common, quite a lot of people do who are functioning in, you know, business or sport or, you know, whatever it is. Those were probably the most helpful pieces of information. And then you know your reassurances from your doctor that like things are actually going to be OK You know, you, you get a bunch of different forecasting from your doctors usually throughout and most of it was pretty positive in my sense. So I I think that was quite comforting. Participant 012_2023AUHBV

What information has been helpful? Well, I tend to -- because I follow a couple of support groups on Facebook, mostly, actually. People living with this, and that sort of thing, and I tend just to watch what's going on. Not really contribute, because I don't believe in sourcing my information like that. I like to just put my faith in someone that I trust, which is in my case my GP, and direct my questions there. Now, I know I had some questions before … this procedure now, and I find that he didn't actually call me back but one of the cardiac nurses did, and I actually found that really, really useful. Being able to chat to her. I tend to be quite focused on being specific on where I go to get my information. Participant 023_2023AUHBV

Participant describes health charities information as helpful

I guess the most helpful information was you know, I I, I love the Heart Foundation website it had a lot of great information there for me. But I guess the the main one was was knowing that the the blockage I've got in its current form isn't gonna kill me. Which gave me that relief that OK, you know, I'm not going to end up on a on an operating table anytime soon, you know. But you know it gave a lot of information regards to what you can do to reduce, you know any ongoing risks andall that sort of stuff. So you know, I mean, you can only read so many times about dietary

and exercise and things like that. Until you know, it's like if you don't do this, you know where you're going to end up.
Participant 028_2023AUHBV

In terms of websites, I go to the Mayo Clinic. And I tried out the Heart Foundation, but that's got little information about my condition -- The hypertrophic cardiomyopathy association in the US is really good. They're excellent, actually. And the cardiomyopathy association in Australia has got people -- Individuals in it with a lot of passion, and a lot of information. It's just the internet is not always -- It's often related to themselves, yeah.
Participant 032_2023AUHBV

Information received from the Stroke Foundation.
Participant 040_2023AUHBV

When I left rehab I was given some initial information which is well-written, because it takes into account that a recent stroke survivor would have difficulty reading, with memory and all the rest of it. I was given short grabs of information. Probably the most important bit of information I was given was to get onto Enable Me, which is the Stroke Foundation's website. There would not be a week that goes by where I haven't done some research onto the Stroke Foundation's website
Participant 045_2023AUHBV

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

I suppose talking to you to validate it was my big thing, and for me, information on how to live with it. So I know what it is, I know what it does, and that's all well and good, but when you're living it, you need to know the small steps you need to take to start the journey. And I think you know, starting small, not being overwhelmed. But the big thing is, so what's next? How do I get myself from bedridden? Can't do anything on my own to living a normal life. And was there anything that you found when you read the information?
Participant 014_2023AUHBV

All of it. Whatever information I can get is helpful, because if I'm reading up about ECGs and -- it's all helpful, because if I understand to some degree what is happening to me, I'm more likely to feel at ease, if that makes sense. Does that make sense? I want to know what's happening, basically. If I don't read up, I will ask.
Participant 034_2023AUHBV

That no stroke is the same, but the after effects are very similar for each person. To acknowledge your symptom, and cope and learn to live with what that condition is that is ailing you at the time.
Participant 049_2023AUHBV

Participant describes information about lifestyle changes and risk prevention as helpful

Probably something that I probably already knew. But lifestyle, you know, keeping, keeping active, you know, it's very easy. After something major like that. You just, you know, sit on the couch and yes, I will, you know, my life's half over. But it's not. So yeah, just I'm not saying I'm perfect with diet and everything like that, but I am active so.
Participant 005_2023AUHBV

I I would say the the, the the the diet information. I've I have changed my diet and I'm buying products that have the plant-based things in them that should help. To lower cholesterol is one that has those those plants steroids in so that it helps lower cholesterol and those sorts of things.
Participant 017_2023AUHBV

Participant describes medical or scientific information as helpful

But yeah, I just make sure I'm informed about new developments and yeah, and so on. So just keep up to date-with what's in the literature and so on, and my doctor will tell me about new developments as well.
Participant 030_2023AUHBV

I can't think of really anything that has been unhelpful. I'm very, I love like facts and figures and very, you know I don't get as much value from other people's experiences as I get from say a report on some of the statistics around heart failure. So I got a lot from those kinds of reports, the scientific reports.
Participant 035_2023AUHBV

Participant describes information presented by webinar or video as helpful

I think probably the most helpful information was understanding that they're currently doing trials even though lipoprotein A is not, there's not no very good treatment for it at the moment. There's it's it's actually this trials out there that are that are happening. So it's kind of gives you a bit of hope and also listening to other people's stories as well that's a big one. So I've gone on YouTube and also through the FH Foundation they've they've got often webinars that you can watch, which has been really interesting.

And it there was one particular webinar talking about the stress of people that are being diagnosed with Lipoprotein A and that was just really impressive to watch, you know, but sad at the same time for them. It was. It was kind of showed all of their emotions and yeah, it was very interesting, very insightful
Participant 011_2023AUHBV

I feel the Stroke Foundation web page has lots of short snippet videos. Some questions that other stroke survivors have posted. I feel a sense of community and sharing of knowledge has been very beneficial
Participant 047_2023AUHBV

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes other people’s experiences as helpful (Peer-to-peer)	12	25.53	3	16.67	9	31.03	**1**	**11.11**	5	29.41	6	28.57	6	22.22	6	30.00
Participant describes talking to their doctor or specialist as helpful	10	21.28	5	27.78	5	17.24	**3**	**33.33**	**1**	**5.88**	6	28.57	8	29.63	**2**	**10.00**
Participant describes health charities information as helpful	10	21.28	3	16.67	7	24.14	**1**	**11.11**	4	23.53	5	23.81	4	14.81	6	30.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	9	19.15	4	22.22	5	17.24	2	22.22	**5**	**29.41**	2	9.52	5	18.52	4	20.00
Participant describes information about lifestyle changes and risk prevention as helpful	7	14.89	3	16.67	4	13.79	2	22.22	2	11.76	3	14.29	3	11.11	4	20.00
Participant describes medical or scientific information as helpful	4	8.51	1	5.56	3	10.34	1	11.11	2	11.76	1	4.76	3	11.11	1	5.00
Participant describes information presented by webinar or video as helpful	4	8.51	0	0.00	4	13.79	1	11.11	3	17.65	0	0.00	3	11.11	1	5.00

Information that has been helpful	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes other people’s experiences as helpful (Peer-to-peer)	12	25.53	9	34.62	**3**	**14.29**	**3**	**12.50**	**9**	**39.13**	4	26.67	8	25.00	6	24.00	6	27.27
Participant describes talking to their doctor or specialist as helpful	10	21.28	3	11.54	**7**	**33.33**	6	25.00	4	17.39	2	13.33	8	25.00	3	12.00	**7**	**31.82**
Participant describes health charities information as helpful	10	21.28	7	26.92	3	14.29	4	16.67	6	26.09	4	26.67	6	18.75	5	20.00	5	22.73
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	9	19.15	5	19.23	4	19.05	5	20.83	4	17.39	**8**	**53.33**	**1**	**3.13**	6	24.00	3	13.64
Participant describes information about lifestyle changes and risk prevention as helpful	7	14.89	4	15.38	3	14.29	**6**	**25.00**	**1**	**4.35**	2	13.33	5	15.63	2	8.00	5	22.73
Participant describes medical or scientific information as helpful	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	**3**	**20.00**	1	3.13	3	12.00	1	4.55
Participant describes information presented by webinar or video as helpful	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	1	6.67	3	9.38	3	12.00	1	4.55

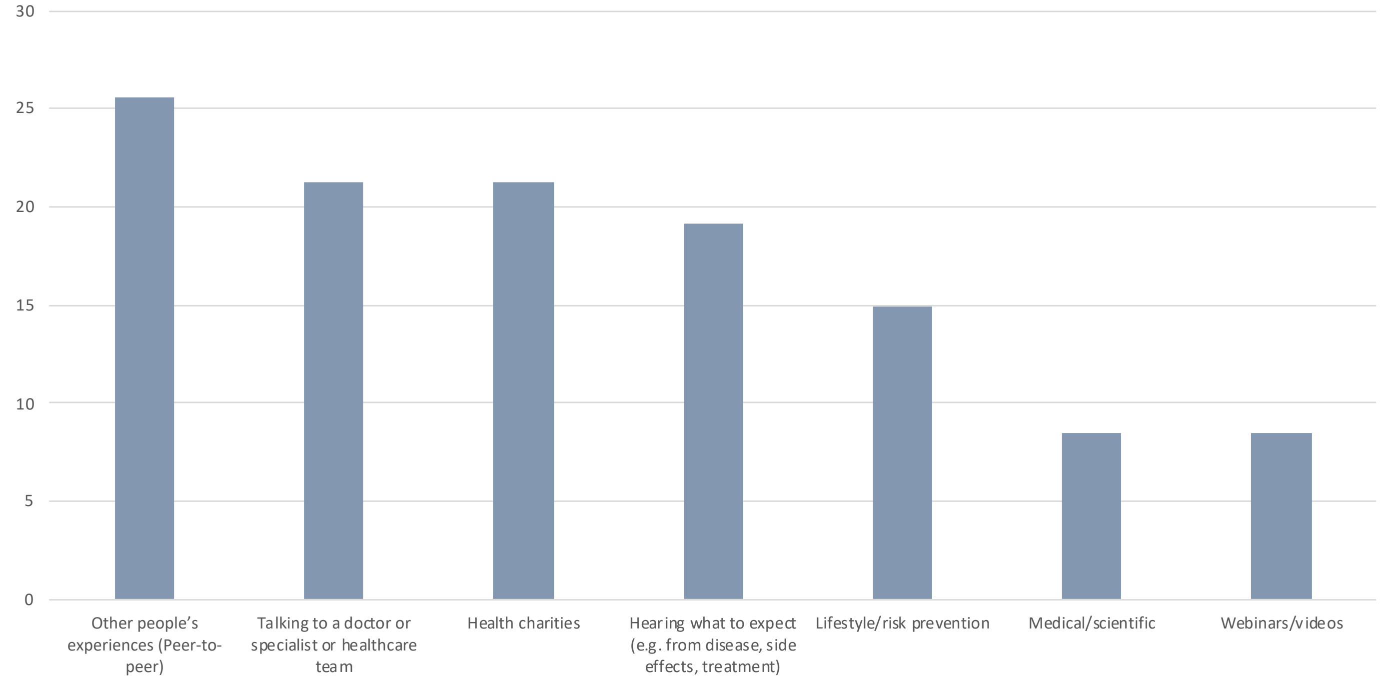

Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes other people’s experiences as helpful (Peer-to-peer)	High cholesterol under 50 years of age Male Aged 25 to 44	Aged 45 and older
Participant describes talking to their doctor or specialist as helpful	Blood vessel conditions 6 to 11 other conditions	High cholesterol under 50 years of age Male Higher socioeconomic status
Participant describes health charities information as helpful	High cholesterol under 50 years of age	-
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Metropolitan	Blood vessel conditions Regional or remote
Participant describes information about lifestyle changes and risk prevention as helpful	Aged 45 and older	Aged 25 to 44
Participant describes medical or scientific information as helpful	-	Regional or remote

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 responses were no information not helpful (42.55%), information given by their GP or specialist was not helpful (12.77%), sources that are not credible or not evidence-based were not helpful (12.77 %), information that not type specific or too general (10.64%), and information with too much medical jargon as unhelpful (8.51%). Others described being confident in deciding themselves if information was not helpful (8.51%).

Participant describes no information being not helpful

No. I don't think there's anything that's been been really unhelpful. Yeah, all of it's been very interesting to read and watch.
Participant 011_2023AUHBV

No, I don't say that anything like this. Everything was helpful for me. From a very first day when I was a go and we don't know what is the situation.
Participant 027_2023AUHBV

Look, I haven't really come across anything that's not been helpful. All the information that I've accessed has been simply helpful. Nothing's been unhelpful in any way. Yeah.
Participant 031_2023AUHBV

Yeah so, yeah I haven't had many experiences of unhelpful things. It was more, most things were helpful that I came across, yeah.
Participant 035_2023AUHBV

Participant describes the GP/specialist as being not helpful

I wish my diagnosis experience had been different with the doctors. A lot more information at the time, would've been helpful. Or, it still would be, to be honest.

INTERVIEWER: It is difficult, isn't it? Because lots of peoples causes for heart failure is very different, and yours is very particular, isn't it?
PARTICIPANT: Exactly.
Participant 032_2023AUHBV

I can discuss things with him, and he will always point me in the right direction, but I think a lot of people miss out on that. There's a reason I haven't gone to anyone else in 13 years. I've gone to multiple GPs prior to finding NAME DOCTOR and they were useless, absolutely useless.
Participant 046_2023AUHBV

The neurologist in LOCATION because we just didn't get that continuity of care.
Participant 047_2023AUHBV

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

Not really. I mean, the only unhelpful ones was when I when I stumbled across medical journals and and things like that and I just wasn't able to obviously understand what those people are talking about. You know, you just stumble across them. But yeah, I mean I take a grain of salt with I guess what they call natural remedies and things like that, you know, where you come across. I mean to me, I'm very science based. I believe doctors, you know, whereas if someone's, you know, going oh, you should have this herbal tea or whatever. To me that's kind of, you know, medieval type stuff and and and I don't take any, I don't believe any of that sort of stuff.
Participant 028_2023AUHBV

No, it leads back to that category. So I can't get the right information on these cholesterol pills, what they're doing to me with my mobility because I wake up in the my main concern with these pills I think. I've been on them too long and I believe I've, I've been suffering a lot of aches and pains in my body and my

doctor has has no idea what's happening with me, he said. You haven't got an autoimmune disease, you haven't got myalgia, things like that. We don't know what's causing this pain in your body and that's where the subject came up. Could have been caused by the medications I've been on for a lifetime since I've been using them. The only weekly that came up was the Catavas, the cholesterol pill. They believe that causes a lot of inflammation in the body. But is that true? This is all hearsay. You get all this stuff off Google and you know, I'd rather have a professional to tell me.
Participant 025_2023AUHBV

Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)

I think receiving information for generic heart attacks, and I know that that sounds really callous to say generic a standard heart attack because. And I referenced it before as well to receive information about how to be healthier, how to reduce your cholesterol, how to lose body fat, how to all of these things when that's not who you are or what your treatment plan is or what you need to do. I think that's really not useful and not helpful at all actually. An actual fact is, it's actually a little bit damaging because it's kind of.
Participant 009_2023AUHBV

No. That's the main thing really. It's the misunderstanding from a lot of different groups of people, that when they find out that you've got heart disease, that they think exercise is what's going to fix it. Whereas exercise makes our symptoms worse for HOCM patients.
Participant 036_2023AUHBV

Participant describes feeling confident in deciding if something is not helpful (or not credible)

I probably filtered that out.
Participant 015_2023AUHBV

No, I guess it's all relevant and it's anyway it's just filtering out what applies in relation to information.
Participant 020_2023AUHBV

Participant describes information that is too technical or has too much medical jargon as unhelpful

I think for someone that potentially didn't have a science background, I think that that would get completely lost in all of the medical terms. And I get that it's a medical journal, it's written that way. I get that. But I feel for people who wouldn't understand what they're saying. So for me, it wasn't a disadvantage. I'm fine. I can read that, but for someone who doesn't have that background, it would be very overwhelming to try and get through all the stuff.
Participant 014_2023AUHBV

Yeah, again, that whole, you know, technical terms and technical jargon, you know, it's kind of like, for example. So the pharmacist said something to me the other day about Spren. And I'm like. Yeah, Okay, You know, they didn't have Spren. So he had to change it to something else. And I was like, oh, okay, You know, I didn't realize that the aspirin I took was called Spren. You know, to me, I to me, it was more or less a case of, oh, okay. And what's that? You know, you could have just said we've had to change the brand of your aspirin.
Participant 018_2023AUHBV

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes no information being not helpful	20	42.55	8	44.44	12	41.38	3	33.33	**9**	**52.94**	8	38.10	12	44.44	8	40.00
Participant describes the GP/specialist as being not helpful	6	12.77	1	5.56	5	17.24	1	11.11	**4**	**23.53**	1	4.76	2	7.41	4	20.00
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	12.77	4	22.22	2	6.90	1	11.11	2	11.76	3	14.29	3	11.11	3	15.00
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	5	10.64	**0**	**0.00**	5	17.24	1	11.11	2	11.76	2	9.52	3	11.11	2	10.00
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	8.51	2	11.11	2	6.90	**2**	**22.22**	0	0.00	2	9.52	0	0.00	**4**	**20.00**
Participant describes information that is too technical or has too much medical jargon as unhelpful	4	8.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	3	11.11	1	5.00

Information that has not been helpful	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes no information being not helpful	20	42.55	11	42.31	9	42.86	11	45.83	9	39.13	6	40.00	14	43.75	11	44.00	9	40.91
Participant describes the GP/specialist as being not helpful	6	12.77	5	19.23	1	4.76	3	12.50	3	13.04	**0**	**0.00**	6	18.75	2	8.00	4	18.18
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	12.77	2	7.69	4	19.05	3	12.50	3	13.04	3	20.00	3	9.38	4	16.00	2	9.09
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	2	13.33	3	9.38	2	8.00	3	13.64
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes information that is too technical or has too much medical jargon as unhelpful	4	8.51	2	7.69	2	9.52	4	16.67	0	0.00	**3**	**20.00**	1	3.13	4	16.00	0	0.00

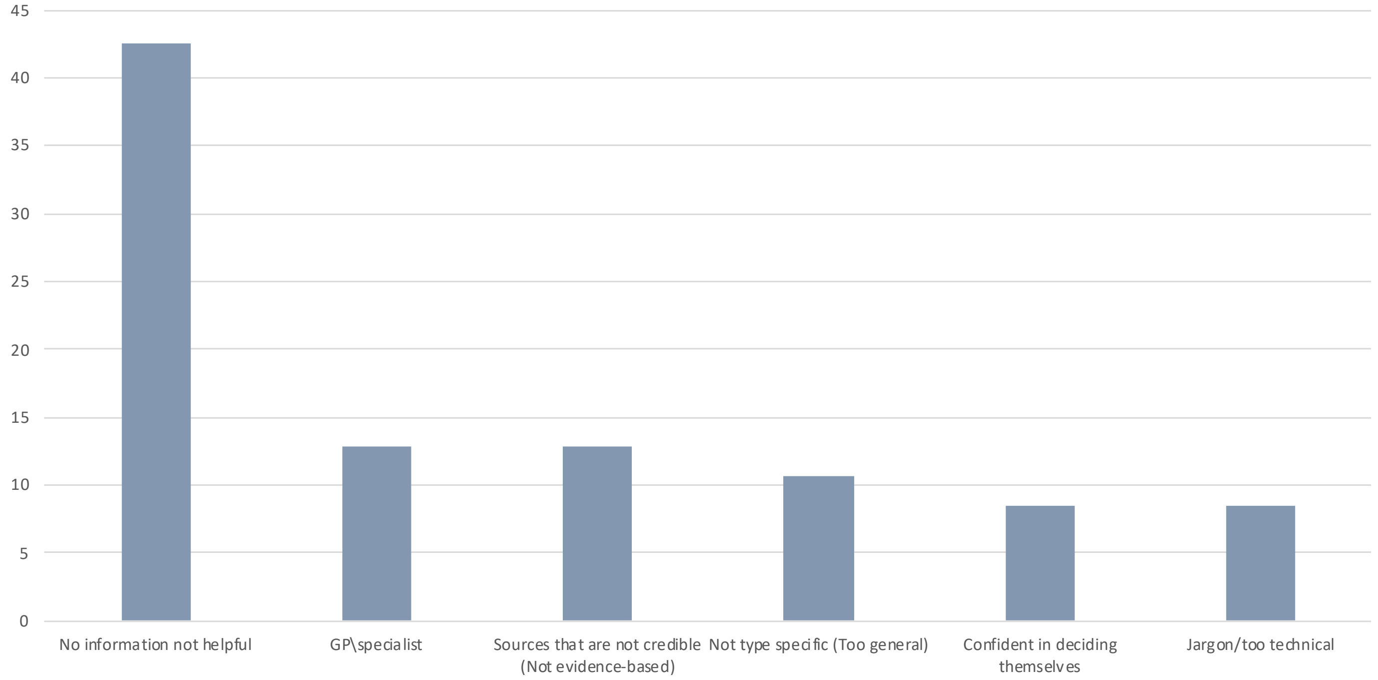

Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	-	Blood vessel conditions
Participant describes the GP/specialist as being not helpful	Regional or remote	Blood vessel conditions
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	Had LP(a) test	-
Participant describes feeling confident in deciding if something is not helpful (or not credible)	-	High cholesterol under 50 years of age 6 to 11 other conditions
Participant describes information that is too technical or has too much medical jargon as unhelpful	-	Regional or remote

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (36.17%), talking to someone plus online information (27.66%), and written information (17.02 %). Other preferences included online information (14.89%), all forms (10.64%), and apps (2.13%).

The main reasons for a preference for talking to someone was being able to ask questions (21.28%), and the information was personalized and relevant (17.02%). Other reasons included that it was more supportive, and that body language helps with understanding (10.64%), and cognitive/sight problems make other forms not able to be used (6.38%).

The main reasons for a preference for online information were accessibility (21.28%), that you can can refer back to it and clarify information (17.02 %), and being able to digest information at their own pace (10.64%).

Participant describes talking to someone as main information preference

Talking to someone primarily because at the end of the day, you can ask the questions if you need to. Where as you can't question a piece of paper. You can't question that necessarily. Yeah. Yeah.
Participant 018_2023AUHBV

No, I would definitely prefer to talk to someone, because I can ask questions, and specifics around it, then having to plough around a whole lot of irrelevant stuff. Which results in more questions than answers, very often. Because I don't have enough of a level of knowledge, and I'm not going to … to get it.
Participant 032_2023AUHBV

Talking to someone. A two-way conversation is a richer source of information than simply reading it. I prefer a conversation as my primary source of information. Secondly, I couldn't read for a long time but now I'm back reading. Of course I'll read whatever I can around this condition called stroke, and I read whatever I can around research and stories of how people have dealt with stroke.
Participant 045_2023AUHBV

Participant describes talking to someone plus online information as main information preference

Online's great because it's accessible. I think talking to someone is better because, like we're doing now, you know? When you're talking things out loud, it triggers questions for you to ask it it it, it triggers other things so that you can ask the next question, you know query what that information means, get the get the information in the right context. So, so I think that that's that's far better
Participant 009_2023AUHBV

Look, I think they all play a part. Online is easy to access because it's there 24 hours a day, but there are times when you just need to talk to someone, and just need a pep talk about what's going on and, "Yeah, it's hard, but you will get there," and it's good to talk to other people who are also suffering from similar conditions, because you realise that you are not on your own, and that provides moral support as well.
Participant 030_2023AUHBV

I think they all play a part differently. I know early on, the reading would have been really hard for me to be able to read and then cognitively understand. So different forms, seek different people at different times, I now can see the computer and read information online. Early on, that was too exhausting.
Participant 047_2023AUHBV

Participant describes written information as main preference

And why I like to read it. I find it thinks them better if I can read it and comprehend it in my own at my own pace. And then you can also refer back to it if it's in writing. So I do like anything in writing, whether that be online or in print.
Participant 019_2023AUHBV

I'm pretty easy. I'd probably do. I'm pretty good with like my reading and stuff. I'd probably like to read, whether it was online or brochures.
Participant 029_2023AUHBV

Participant describes online information as main information preference

Online because it's easier and flexible as to when I can sit down and go into it.
Participant 020_2023AUHBV

I like online, which is natural. I like talking to someone. Booklet information is okay, but to keep up with the trends, everything's online. I'm 68, and I just love the internet. I love social media because I can get so much information from it, so to me that's where the focus should be. On information. And, like I said, there's the AF Association in England who puts out a lot of stuff. That's where I got onto social media in the first place, from there, and then they have a branch in Australia and so forth. Like I said, I just love the internet. I love the information right at hand. I don't have to go looking in books or research anything anywhere else. It's online. It's in front of you. It's great.
Participant 031_2023AUHBV

I have a preference for online information. I think that's probably because I work in a scientific writing capacity. For me, I like to have the information laid out in front of me. I like to make decisions about what links I would follow. I process information faster by reading it than listening to it. Participant 046_2023AUHBV

Participant describes preferring all forms of information

No, I tend to, I gather information from all sources, just sort of make up my mind on what I'm following, if you know what I mean. Yeah
Participant 008_2023AUHBV

And why I I really don't mind whether it's sort of done by telephone, online, in person. I I think any type of communication, yeah, is is is fine
Participant 017_2023AUHBV

No, they're all good. I'm happy with all of them. I don't have a preference
Participant 048_2023AUHBV

Participant describes apps as main information preference

I prefer apps because I'm always on apps.
Participant 044_2023AUHBV

Table 6.7: Information preferences

Information preferences	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes talking to someone as main information preference	17	36.17	7	38.89	10	34.48	3	33.33	4	23.53	10	47.62	12	44.44	5	25.00
Participant describes talking to someone plus online information as main information preference	13	27.66	2	11.11	11	37.93	3	33.33	5	29.41	5	23.81	7	25.93	6	30.00
Participant describes written information as main preference	8	17.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	2	7.41	6	30.00
Participant describes online information as main information preference	7	14.89	3	16.67	4	13.79	1	11.11	3	17.65	3	14.29	3	11.11	4	20.00
Participant describes preferring all forms of information	5	10.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	1	3.70	4	20.00
Participant describes apps as main information preference	1	2.13	0	0.00	1	3.45	0	0.00	1	5.88	0	0.00	1	3.70	0	0.00

Information preferences	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes talking to someone as main information preference	17	36.17	6	23.08	11	52.38	7	29.17	10	43.48	4	26.67	13	40.63	8	32.00	9	40.91
Participant describes talking to someone plus online information as main information preference	13	27.66	7	26.92	6	28.57	5	20.83	8	34.78	6	40.00	7	21.88	8	32.00	5	22.73
Participant describes written information as main preference	8	17.02	6	23.08	2	9.52	3	12.50	5	21.74	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes online information as main information preference	7	14.89	6	23.08	1	4.76	5	20.83	2	8.70	3	20.00	4	12.50	4	16.00	3	13.64
Participant describes preferring all forms of information	5	10.64	4	15.38	1	4.76	3	12.50	2	8.70	2	13.33	3	9.38	3	12.00	2	9.09
Participant describes apps as main information preference	1	2.13	0	0.00	1	4.76	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00

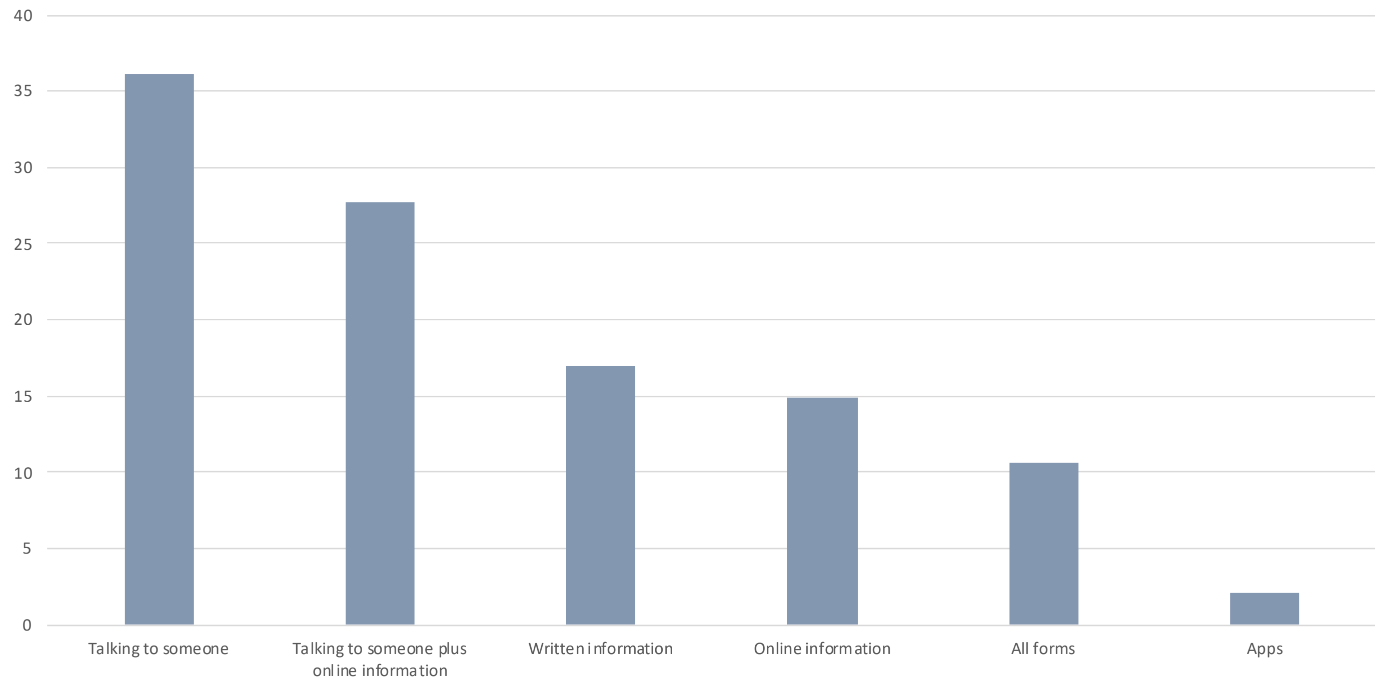

Figure 6.4: Information preferences

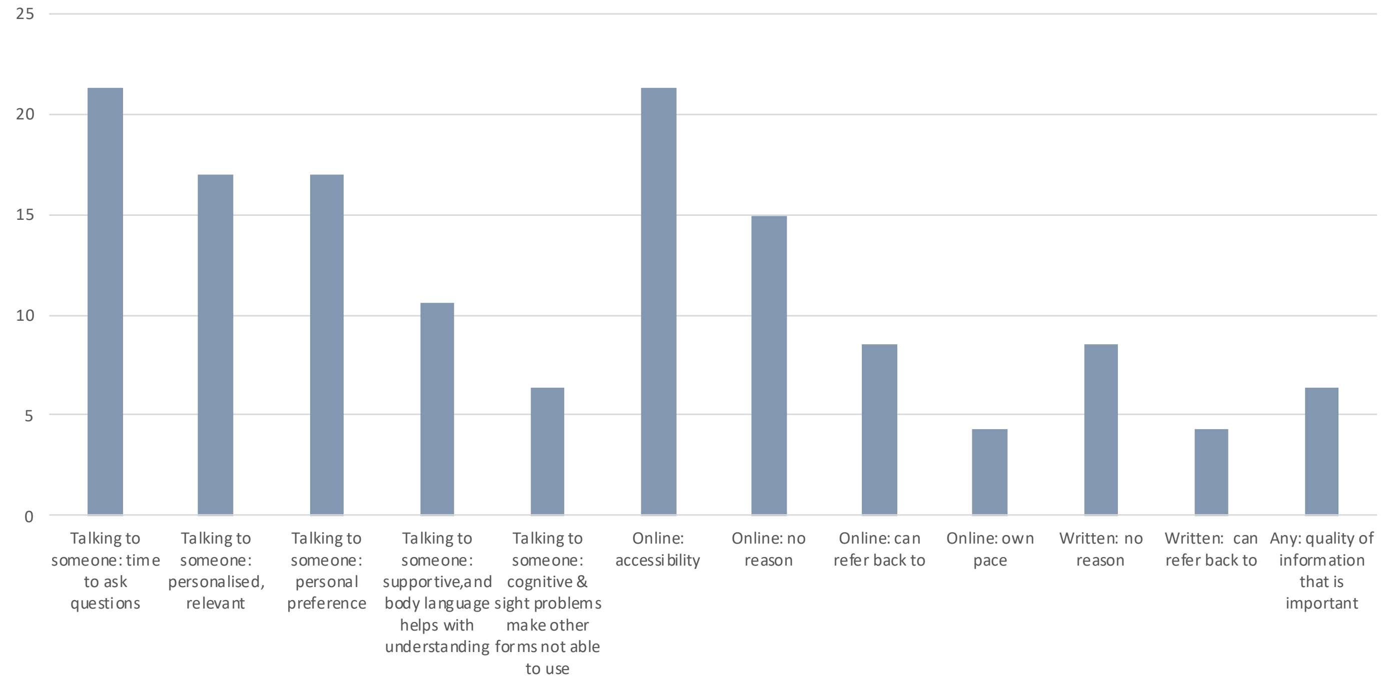

Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone as main information preference	Blood vessel conditions 6 to 11 other conditions Female	Heart conditions Male
Participant describes talking to someone plus online information as main information preference	Had LP(a) test	Did not had LP(a) test Regional or remote
Participant describes written information as main preference	-	6 to 11 other conditions
Participant describes online information as main information preference	Male	-

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 times were at the beginning (diagnosis) (27.66%), and after the shock of diagnosis (14.89%). Other themes included continuously (12.77%), 12 months or more after diagnosis (12.77%), when medical emergency over (8.51%), after treatment (6.38%), and after test results or changes to condition (6.38%).

Participant describes being receptive from the beginning (diagnosis)

I think right back in the beginning, I was really wanting to know more. Yeah. About what it was, Yeah.
Participant 008_2023AUHBV

PARTICIPANT: That's tricky because I'm always receptive to receiving information about it. I guess in the early days I was absorbing more information because I didn't know a lot of stuff. I'm probably less receptive now because I feel like I know more.
INTERVIEWER: Oh okay. Yeah. That makes sense.
PARTICIPANT: Probably on diagnosis I suppose that's when I'm the most receptive. The most receptive I suppose, because I didn't know anything. I was the most receptive about receiving any kind of information.
Participant 036_2023AUHBV

I'm always receptive, but I was going out and finding it early on. To be honest, there was no risk of being overwhelmed with information because I wasn't getting any.
Participant 046_2023AUHBV

Participant describes being receptive to information after the shock of diagnosis

Definitely the most receptive, most needing of it at the start. Definitely better at taking it in, you know, sometime time, not immediately. Not definitely, not

immediately. I think it's so overwhelming that it's hard to take it in. Yeah.
Participant 009_2023AUHBV

I think between seeing the first cardiologist and the surgery, so. But by the time I got over my shock of the diagnosis and that that, let me tell you, was a really grim day, that that was tough. By the time I'd kind of got over the emotional shock and the immediate terror of if I don't do something about this, I'm going to die, and it might be quite soon. I think by the time I saw the 2nd cardiologist and by the time I actually met the surgeon in person, I think that was probably my most receptive. Because I was questing in all sorts of different directions, including that emotional, spiritual one, which I actually said to my surgeon, this is the most important part of it. Whatever else happens if anything goes wrong. It's OK because this is the important bit and I needed him to know that because we all know how devastated clinicians are if something does. So, yeah, that was important.
Participant 010_2023AUHBV

I think initially I think it was due to the shock of being diagnosed with atherosclerosis. I think I wasn't able to take much information in for a little while. It probably wasn't till a few much a few months later that I started to become a lot more proactive in thinking, gosh, I need to really start, you know, researching this. And ever since then I've just been continuously reading, listening to patient stories, getting as much information as I possibly can to try and safeguard myself for the future. So it has been good. It's been positive as well in getting all that information.
Participant 011_2023AUHBV

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

Probably sort of depends on the information is general day-to-day information from cardiologists or specialists or whatever it was at the time was probably pretty receptive all the time. I was pretty open minded about most things when it came to my condition. But you know I was aware that of what what the future sort of held if I didn't sort of actively do something about it. So I think in that sense I was pretty receptive. But when it came to things like you know, surgery or probably like you know, the general diagnosis and the changes in lifestyle, you know, as I got older, you know, you have to sort of stop this and stop that or be more considerate about that. I think, you know, there's a little bit of time where you're angry and pissed off a little bit about the circumstances that you've been dealt. But I think once that sort of calms down and you sort of go, all right, well, I've got to do something about this here probably a few days to a few weeks after you saw the pretty receptive to hearing what's going to happen. So my circumstances was pretty quickly, Usually I was pretty pragmatic with what's going on.
Participant 012_2023AUHBV

I think it gets easier the longer you have it because you understand it and accumulated information over time. At the beginning it's all very new. So it's like any kind of new learning. It's always hard at the beginning, but the longer you've been with it, the easier it gets.
Participant 019_2023AUHBV

Participant describes being receptive to information 12 months or more after diagnosis

That information in probably honestly years after I was told that I was even sick because I didn't care at the time. OK until I was a bit older until I got with my until I got to about 21 and then I realized, oh, I've aged my body quite a lot, right?
Participant 007_2023AUHBV

I bet 12 months after my stroke.
Participant 040_2023AUHBV

I think it took me probably close to 12 months to feel comfortable to research and investigate more information about strokes.
Participant 047_2023AUHBV

Participant describes being receptive to information after the medical emergency is over

Certainly not while you're in hospital under the stress of what's happening to you at the minute. You know what I mean? Yeah. So I'm much better. When you're sort of sitting in in with the doctor or someone and there's not a crisis happening around you, you know, so much more receptive. Like you'll just accept like, like I was saying about the angiogram, I just accepted it because I got no choice. You just do it. But if, if I had that information without having a heart attack, like it wasn't urgent that I had it, then it would be a different way that I'd. Yeah. So I think when you're in the throes of having something like that happened to you, you're not very receptive then.
Participant 013_2023AUHBV

That's a good question because when you're in the full blown episode, you can't actually remember much or

take much in. I think it wasn't until maybe six months down the track that I was able to fully get my head around it and then work out a way to move forward.
Participant 014_2023AUHBV

While I wasn't in pain and anxious, you know one of the biggest things I find is, is that you know when you're in pain. And you've got people talking to you or that's more they're talking at you. And it's just it's irritating. It's obviously when. So when I'm in pain, I'm fairly anxious. And if I'm anxious, I'm easily irritated. And once I'm irritated, don't even bother. I won't understand the word you're saying. I won't retain a word. You know, I I presented, as I say I presented at the hospital a couple of times with chest pain and they sit there, you know, question, question, question, question. You know, the only thing I care about is my pain easing. The only thing I care about at that point in time is that, you know, hey, let's make this stop, you know, so to say to me, you know, oh, but this is happening, that's happening. You know what? I don't care. Make that pain stop. That's all I'm interested in. You know, I suppose once that pain's eased up or that pain slowed down, it's a lot easier to concentrate and, you know, hold a discussion on, you know, where things are, where things are going.
Participant 018_2023AUHBV

Participant describes being receptive to information after treatment

I don't think I was terribly receptive when I was first diagnosed, I think after the surgery I would take on board what I needed to hear and what people wanted me to know.
Participant 005_2023AUHBV

I think in hospital's always a good time because you've got time on your hands there. It depends on your condition in hospital, though. There would have been times for me that it wouldn't have been appropriate. There have been times where it would have. I think post a procedure. With this one I've just had done now, I got some leaflets and things that were given to me, and that was great because when I got home -- You can remember most of it, but you kind of think, "Oh, why didn't you say about that again and I could read through and just pick out the bits," so that was actually a good time to have it.
Participant 023_2023AUHBV

Participant describes being receptive to information after receiving test results or when treatment decisions need to be made

As I say, the only information I had was that my cholesterol was high and that was it. And I suppose I did change some things, but not not change that much. And then when it continued to be high and the GP said, oh, you know, if this doesn't improve or gets gets worse, you might have to go on medication. That was at the point where I thought I need to work a bit harder and that's what I thought. I needed to make more changes to my diet and increase exercise more and those sorts of things.
Participant 017_2023AUHBV

The way, yeah, I dare say it was probably the second visit to the cardiologist just just you know at that point there, you know I'd already had the you know, I'd already done all the cardio, cardio grams and and all that sort of stuff. So it was at that point there, you know when having a a better conversation around it all that you know it really sunk in and it was I guess more receptive at that time.
Participant 028_2023AUHBV

Table 6.9: Timing of information

Timing of information	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being receptive from the beginning (diagnosis)	13	27.66	**2**	**11.11**	**11**	**37.93**	2	22.22	6	35.29	5	23.81	5	18.52	**8**	**40.00**
Participant describes being receptive to information after the shock of diagnosis	7	14.89	2	11.11	5	17.24	1	11.11	4	23.53	2	9.52	4	14.81	3	15.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	6	12.77	1	5.56	5	17.24	**0**	**0.00**	3	17.65	3	14.29	2	7.41	4	20.00
Participant describes being receptive to information 12 months or more after diagnosis	6	12.77	3	16.67	3	10.34	**3**	**33.33**	3	17.65	**0**	**0.00**	5	18.52	1	5.00
Participant describes being receptive to information after the medical emergency is over	4	8.51	2	11.11	2	6.90	0	0.00	0	0.00	**4**	**19.05**	2	7.41	2	10.00
Participant describes being receptive to information after treatment	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	3	6.38	2	11.11	1	3.45	**2**	**22.22**	0	0.00	1	4.76	1	3.70	2	10.00

Timing of information	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being receptive from the beginning (diagnosis)	13	27.66	9	34.62	4	19.05	7	29.17	6	26.09	3	20.00	10	31.25	7	28.00	6	27.27
Participant describes being receptive to information after the shock of diagnosis	7	14.89	4	15.38	3	14.29	3	12.50	4	17.39	**5**	**33.33**	2	6.25	5	20.00	2	9.09
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	6	12.77	4	15.38	2	9.52	5	20.83	1	4.35	1	6.67	5	15.63	2	8.00	4	18.18
Participant describes being receptive to information 12 months or more after diagnosis	6	12.77	1	3.85	**5**	**23.81**	3	12.50	3	13.04	2	13.33	4	12.50	3	12.00	3	13.64
Participant describes being receptive to information after the medical emergency is over	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	2	13.33	2	6.25	4	16.00	0	0.00
Participant describes being receptive to information after treatment	3	6.38	2	7.69	1	4.76	0	0.00	3	13.04	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55

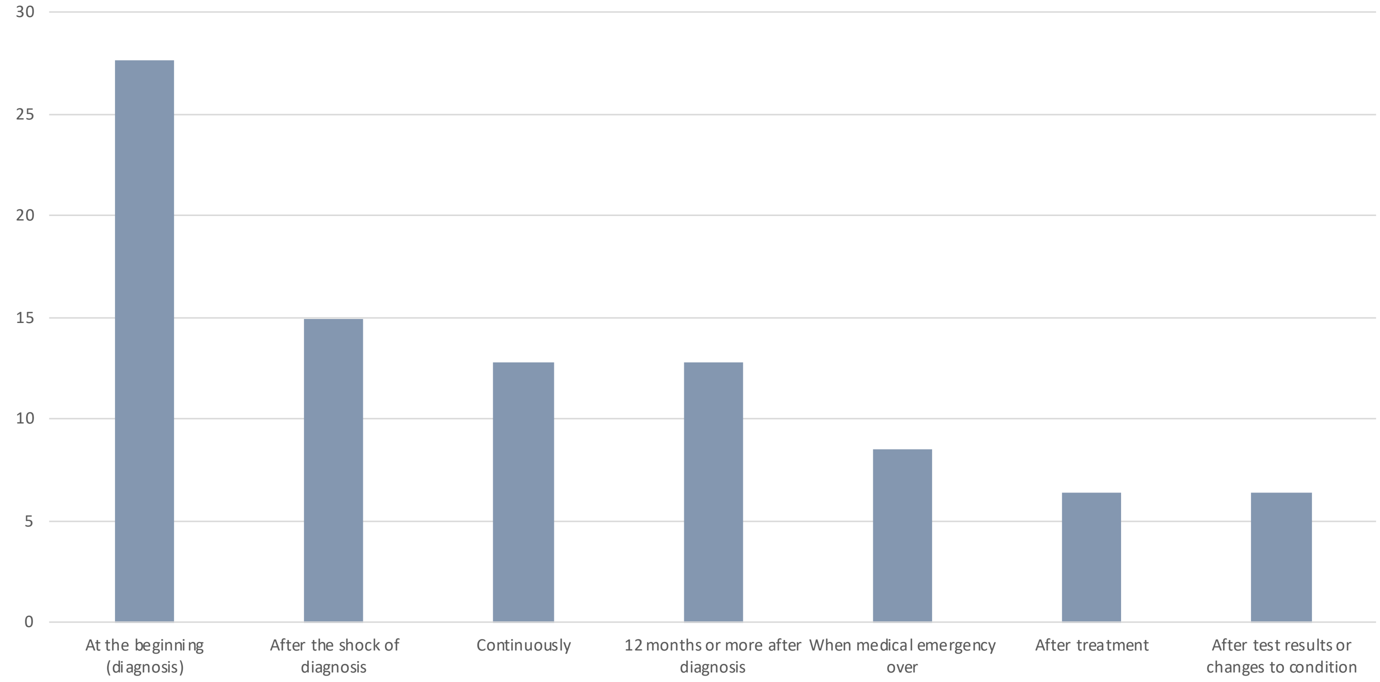

Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Had LP(a) test	Did not had LP(a) test 6 to 11 other conditions
Participant describes being receptive to information after the shock of diagnosis	-	Regional or remote
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	High cholesterol under 50 years of age	-
Participant describes being receptive to information 12 months or more after diagnosis	Heart conditions	High cholesterol under 50 years of age Male
Participant describes being receptive to information after the medical emergency is over	-	Heart conditions
Participant describes being receptive to information after receiving test results or when treatment decisions need to be made	-	High cholesterol under 50 years of age

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Participants gave descriptions that communication as overall positive (34.04%), overall positive, with the exception of one or two occasions(34.04%), and overall negative (27.66 %).

Participant describes communication with healthcare professionals as overall positive

It is. It's a good experience, you know, Because I choose to make it a good experience. I choose. I choose to be positive about what's going on and I choose to be happy about what's going on. When I choose to find out the information I want to go, we're not playing that enough. I don't need to go into the

absolute detail of it. Fair enough. That that's all I'm gonna go. Thanks very much. I'll see you later. Yeah. You're all about personal choices. You can sweat this issue and turn it into something that's really confusing, you know, and get yourself very panicky about it all. That doesn't achieve anything. So I just don't bother. Yeah, I'm pretty happy with it, you know.
Participant 004_2023AUHBV

I would say good. I mean, if anything were to come up, they'd tell me, like they do check on my heart, but nothing's ever come up. So I'd say good.
Participant 007_2023AUHBV

PARTICIPANT: Mine's been very good. Honestly. Yeah. Yeah.
Participant 013_2023AUHBV

He's really good, He's really good.
Participant 016_2023AUHBV

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

Variable. My GP's fantastic. We're on the same page. I'm very much afraid he's going to retire fairly soon. I don't know what I'm going to do. He just absolutely the right person for me. My surgeon, fantastic. I guess I I'd have liked him to be a bit more detailed in his communication, as I said, but I think that's partly personal. On his part, and partly the assumption that I sounded knowledgeable when I wasn't or I felt I wasn't. I don't know. I don't know how you make the judgment on that. How much knowledge is enough? Nothing's ever enough, is it? Not for me, anyway. There's always more, I suppose the 1st. The first appointment I had with the cardiologist was fabulous and I I was in tears with relief. The last appointment I had with the cardiologist I was in tears with misunderstanding. So it's been mixed.
Participant 010_2023AUHBV

The health professionals have all been really great, and I've found everyone to be really, really supportive, and like from my doctor to the nurses that I deal with, to you know, when I'm in hospital and so on, I just feel like I've got really good support around me, so -- But sometimes I find with GPs, is they can get into -- Like, I don't go to the doctor for no reason. So when I go to the doctor, it means I'm concerned about something. And I have found that GPs get complacent. "Oh yeah, but you've just got a heart condition," or "You've got heart failure," and I say, "But I haven't got a heart failure, and swollen ankles, I have never had them before, you know, there's something going on," and the doctor's saying, "Don't worry, we'll figure it out, you're not seeing a cardiologist for three months. You don't need to ring him. We'll work it out," and it ended up that I had major damage done to my heart in the meantime, because some-- where I realise I should have been more proactive in that since. Those GPs, even though they're great, they do get complacent and they just box you into, "Oh, you've got heart failure," when I haven't got heart failure. My heart's still really healthy, and so when we're getting signs of heart failure, it means that there's something else going on, and it needs to be investigated.
Participant 030_2023AUHBV

Participant describes communication with healthcare professionals as overall negative

When it comes to, I suppose, your your specialist field, a lot of them are fairly. Arrogant. They don't have a bedside manner in any way shape or form and they certainly don't present as if they have time to deal with you. You know, for example, you know I I was dealing with an oncologist last week, you know and he was explaining to the person that I was with that there's three options and number one's not available. Yeah, at the end of the day, you know, that person asked why not? So he gave this huge answer as to why it's not available. And this particular person got a bit of dementia, you know, and then didn't understand what was being said. And you know, he went to try and move on to the next option and they went, So what was option one? And he went, well, that's not available. You know, at the end of the day, if it wasn't available, it should have been said that there's only two options here. You know, The thing is, I suppose for myself, you know, at the end of the day, I look at things and you know, again in in such a logical way that you know something's not available, then why is it really an option? Again, you know, like the cardiologist will say, you know, use the term myocardial infection. Whereas my doctor will say, so your heart attack. Cool. What are we talking about? A heart attack? Okay. I know what that is. Straight up.
Participant 018_2023AUHBV

Not really, no. I couldn't describe it as positive.
Participant 032_2023AUHBV

Confusing, very confusing.
Participant 041_2023AUHBV

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes communication with healthcare professionals as overall positive	16	34.04	7	38.89	9	31.03	5	55.56	3	17.65	8	38.10	11	40.74	5	25.00
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	16	34.04	6	33.33	10	34.48	1	11.11	7	41.18	8	38.10	11	40.74	5	25.00
Participant describes communication with healthcare professionals as overall negative	13	27.66	4	22.22	9	31.03	3	33.33	6	35.29	4	19.05	4	14.81	9	45.00
Other/no response	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00

Healthcare professional communication	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes communication with healthcare professionals as overall positive	16	34.04	7	26.92	9	42.86	10	41.67	6	26.09	4	26.67	12	37.50	7	28.00	9	40.91
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	16	34.04	10	38.46	6	28.57	4	16.67	12	52.17	8	53.33	8	25.00	10	40.00	6	27.27
Participant describes communication with healthcare professionals as overall negative	13	27.66	9	34.62	4	19.05	8	33.33	5	21.74	3	20.00	10	31.25	7	28.00	6	27.27
Other/no response	2	4.26	0	0.00	2	9.52	2	8.33	0	0.00	0	0.00	2	6.25	1	4.00	1	4.55

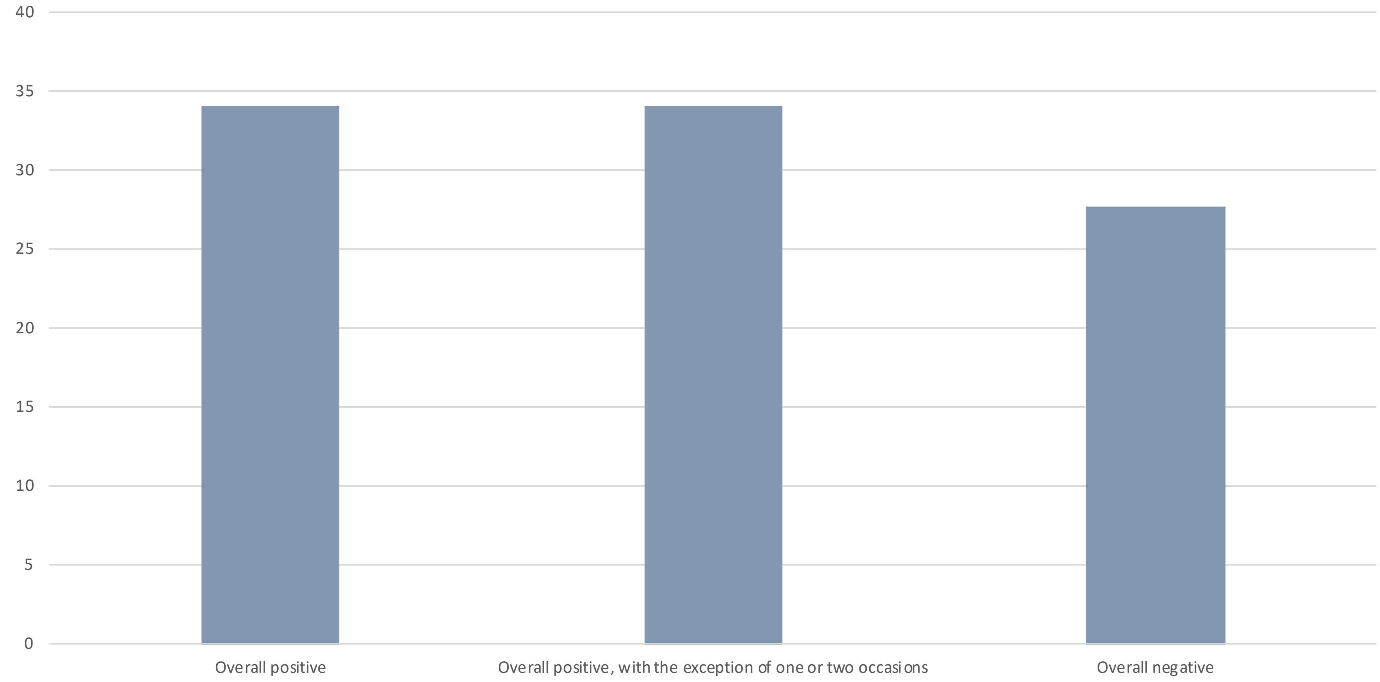

Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes communication with healthcare professionals as overall positive	Blood vessel conditions	High cholesterol under 50 years of age 0
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	High cholesterol under 50 years of age Aged 25 to 44	Aged 45 and older Regional or remote 0
Participant describes communication with healthcare professionals as overall negative	0 to 5 other conditions	6 to 11 other conditions 0

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because it was holistic with two way, supportive and comprehensive conversations (31.91%).

Participants that had negative communication, described the reasons for this were that communication was dismissive (One way conversation) (19.15 %), limited in multi-disciplinary communication and care coordination (10.64%), limited in relation health professionals not having a lot of time (8.51%), and limited in that they have not had a lot (6.38%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Yeah, Just in general, like on scale or whatever, yeah. Yeah it's it's it's been good. I mean it's a two way street and as long as myself as the patient like I I try to be respectful of them and their time and their position And because I'm like yeah I'm typically focused on you know building a decent relationship with the GP. I think there's some reciprocity and I it's been pretty good because I think because I'm. Building a relationship and I I am keen to learn about the condition what have you and I expressed that I think I'm viewed positively in the sense that like I'm just earnest to learn more so that I can help myself and so I think you know any of my conversations are are received pretty well because I I think the GP can see where I'm coming from and and they're and they're responding like in a in a good way so yeah I've I've had you know. Yeah, I've had positive communications, yeah. And just to add to that, it's just even when I was presenting the idea that I think at my last console that hey, I've been learning learning about some of this nuance and there might be some other extra information around this this, this condition, she, my GP was positive as as in you know told me just to send through. Send through what I was talking about or looking at like reference. Yeah. So that's what I've done. So they were, Yep, receptive to that. So that was another positive sign of communication.
Participant 001_2023AUHBV

Now, I write an email once a month to Team PARTICIPANT, usually on the first or the second day of the month just to give them all a brief summary of what I've done or how I feel or what's been achieved in the month leading up to that email. I do that because communication between doctors has been great. I have lots of little chats with each and every one of them. I don't know what each and every one of them is missing out on and then I'd get to appointments- for example, let's say I get to the cardiologist and he says, "You saw the gastroenterologist last week, what happened there? I haven't received any notifications
Participant 050_2023AUHBV

Participant describes health professional communication as being dismissive (One way conversation)

I don't know. I can't. Yeah, the rest of it wasn't great to be honest. Yeah, the whole this is a short term thing. Don't panic, you'll be OK. This is a short term problem. It was not beneficial. That was not that wasn't something because they're not held on to that you see. And I think that was, you know, when I tried to go back to work at the start of the year and I started passing out at work and hitting my head on things and losing vision. I think that was a false sense of security or helped me live in a bit of denial then saying don't worry, it's a short term thing. So that would, yeah.
Participant 014_2023AUHBV

Well like I say it's just been this is the information you've got high cholesterol and that's it that that's the start and finish. There's been no no broader discussions or conversations other than that.
Participant 017_2023AUHBV

Participant describes health professional communication as limited in multi-disciplinary communication and care coordination

PARTICIPANT: Generally, pretty atrocious. With NAME DOCTOR, fantastic. There was just nothing. In hospital, there was nothing. I couldn't read. I couldn't see properly. I couldn't judge distance. I couldn't cook for myself, but I was just booted out of the hospital with nothing.
INTERVIEWER: That must have been difficult.
PARTICIPANT: I'm really lucky. My mum is lovely, and we have a great relationship. She actually moved in with me for a short time, and I recovered my ability to read after a few weeks, and I actually went back to work after two and a half weeks part-time because obviously the fatigue was an issue and adjusting to the limitations that I had was an issue. My mum came and cooked for me and then helped me start getting used to cooking for myself and that sort of thing. If I hadn't had family support I don't know what would have happened.
Participant 046_2023AUHBV

PARTICIPANT: Overall, it's been fine. Yeah, sure. So initially my first two weeks I was in hospital. I've not had any proactive communication. I don't really know that I need proactive communication. It's all been based around when the appointment, like when I'm in an appointment at checkup the the communication initially in the hospital. To be honest, I don't know what the communication was like to my family, but to

me, I guess. I have a little bit of a short term memory problem which is much improved, which is probably a side effect I should have thought about earlier, but but at the time I may have got information, they may have given me information, things that I wished I'd been told. I don't remember receiving a lot of communication around things around much when I was in hospital, you know? Not about what happens when I leave hospital. Not about, you know, what happens with the physician. Not about not a lot about my about what about about what scat is. So I I think that that was probably where communication was probably lacking. But as I say, I may have received it and just can't remember receiving it. Also I think if I'd received too much. Like that. In that moment. I don't know that I would have absorbed it anyway, but I do think that it's been good, except for that little cracked part, yes.
Participant 009_2023AUHBV

Participant describes health professional communication as limited in relation health professionals not having a lot of time

It's been good whilst I've been engaged. Outside of those scheduled appointments, it's non-existent, really.
Participant 043_2023AUHBV

Participant describes healthcare communication as limited (they have not had any/a lot)

Well probably they didn't give me very much information. They just probably gave me a script and said, "Come back and see me in so many months. We'll send a letter to NAME DOCTOR." I mean to be perfectly honest, I never discussed anything really
Participant 037_2023AUHBV

I can't say I really received any information. Even when I joke around my illness, I've got more problems.
Participant 039_2023AUHBV

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes healthcare communication as good, with no particular reason given	19	40.43	9	50.00	10	34.48	**2**	**22.22**	6	35.29	**11**	**52.38**	13	48.15	**6**	**30.00**
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	15	31.91	5	27.78	10	34.48	**4**	**44.44**	5	29.41	6	28.57	9	33.33	6	30.00
Participant describes health professional communication as being dismissive (One way conversation)	9	19.15	5	27.78	4	13.79	**3**	**33.33**	**1**	**5.88**	5	23.81	6	22.22	3	15.00
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	5	10.64	1	5.56	4	13.79	**0**	**0.00**	3	17.65	2	9.52	1	3.70	4	20.00
Participant describes health professional communication as limited in relation health professionals not having a lot of time	4	8.51	2	11.11	2	6.90	0	0.00	3	17.65	1	4.76	1	3.70	3	15.00
Participant describes healthcare communication as limited (they have not had any/a lot)	3	6.38	2	11.11	1	3.45	0	0.00	2	11.76	1	4.76	1	3.70	2	10.00
Participant describes health professional communication as limited, without giving a reason	3	6.38	0	0.00	3	10.34	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00
Participant describes health professional communication as limited in relation to their understanding of the condition	2	4.26	0	0.00	2	6.90	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00
Participant describes health professional communication as limited in using language that is too technical	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00
Participant describes health professional communication as limited as it was unprofessional	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00
Participant describes health professional communication as limited in withholding information	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Healthcare professional communication (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes healthcare communication as good, with no particular reason given	19	40.43	10	38.46	9	42.86	10	41.67	9	39.13	7	46.67	12	37.50	10	40.00	9	40.91
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	15	31.91	7	26.92	8	38.10	6	25.00	9	39.13	6	40.00	9	28.13	7	28.00	8	36.36
Participant describes health professional communication as being dismissive (One way conversation)	9	19.15	3	11.54	6	28.57	7	29.17	2	8.70	3	20.00	6	18.75	4	16.00	5	22.73
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	5	10.64	5	19.23	0	0.00	1	4.17	4	17.39	1	6.67	4	12.50	3	12.00	2	9.09
Participant describes health professional communication as limited in relation health professionals not having a lot of time	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes healthcare communication as limited (they have not had any/a lot)	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55
Participant describes health professional communication as limited, without giving a reason	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55
Participant describes health professional communication as limited in relation to their understanding of the condition	2	4.26	2	7.69	0	0.00	0	0.00	2	8.70	2	13.33	0	0.00	2	8.00	0	0.00
Participant describes health professional communication as limited in using language that is too technical	2	4.26	1	3.85	1	4.76	2	8.33	0	0.00	0	0.00	2	6.25	1	4.00	1	4.55
Participant describes health professional communication as limited as it was unprofessional	2	4.26	2	7.69	0	0.00	1	4.17	1	4.35	2	13.33	0	0.00	1	4.00	1	4.55
Participant describes health professional communication as limited in withholding information	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	1	6.67	1	3.13	2	8.00	0	0.00

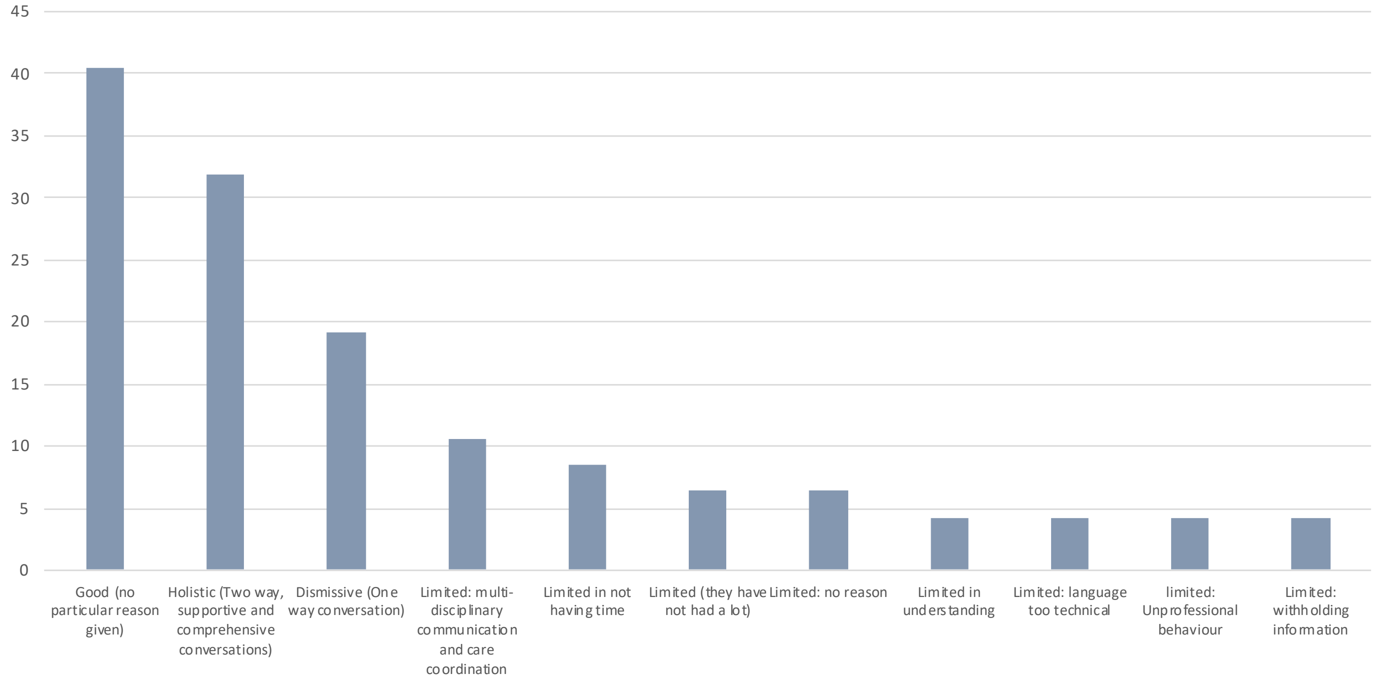

Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Healthcare professional communication (reasons)	Reported less frequently	Reported more frequently
Participant describes healthcare communication as good, with no particular reason given	High cholesterol under 50 years of age 6 to 11 other conditions	Heart conditions
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	-	High cholesterol under 50 years of age -
Participant describes health professional communication as being dismissive (One way conversation)	Blood vessel conditions Aged 45 and older	High cholesterol under 50 years of age Aged 25 to 44 -
Participant describes health professional communication as limited in multi-disciplinary communication and care coordination	High cholesterol under 50 years of age Male	-

Partners in health

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 the table below.

The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=27.00, IQR=8.75), Partners in health: Recognition and management of symptoms

(median=21.00, IQR=5.75), Partners in health: Adherence to treatment (median=15.00, IQR=3.00), indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment.
The overall scores for the cohort were in the second highest quintile for Partners in health: Coping (median=16.50, IQR=7.00), Partners in health: Total score (mean=74.46, SD=13.75) indicating good coping, good overall ability to manage their health

Comparisons of Partners in health have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.44	5.65	27.00	8.75	0 to 32	5
Coping	15.82	5.71	16.50	7.00	0 to 24	4
Recognition and management of symptoms	19.44	3.78	21.00	5.75	0 to 24	5
Adherence to treatment	13.76	2.85	15.00	3.00	0 to 16	5
Total score*	74.46	13.75	74.50	19.50	0 to 96	4

*Skewed distribution use median and IQR as measure of central tendency

Partners in health by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

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

No significant differences were observed between participants by **LP(a) test** for any of the Partners in health scales.

Table 6.16: Partners in health by LP(a) test summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Had LP(a) test	19	38.00	71.95	13.66	-1.01	48	0.3166
	Not had LP(a) test	31	62.00	76.00	13.79			

Table 6.17: Partners in health by LP(a) test summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Had LP(a) test	19	38.00	24.00	8.50	244.00	0.3157
	Not had LP(a) test	31	62.00	28.00	7.00		
Coping	Had LP(a) test	19	38.00	16.00	7.50	267.00	0.5874
	Not had LP(a) test	31	62.00	17.00	7.00		
Recognition and management of symptoms	Had LP(a) test	19	38.00	21.00	5.00	256.50	0.4501
	Not had LP(a) test	31	62.00	21.00	4.50		
Adherence to treatment	Had LP(a) test	19	38.00	15.00	6.00	263.00	0.5199
	Not had LP(a) test	31	62.00	15.00	2.00		

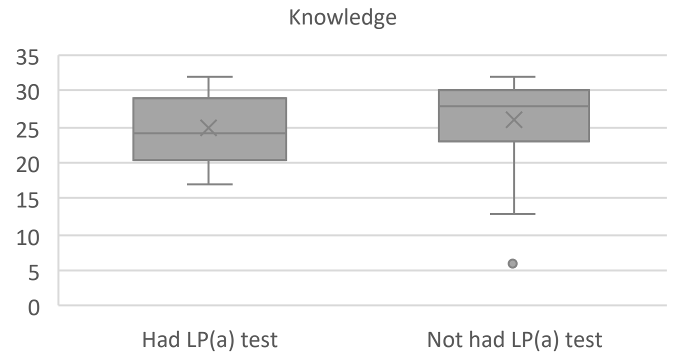

Figure 6.9: Boxplot of Partners in health: knowledge LP(a) test

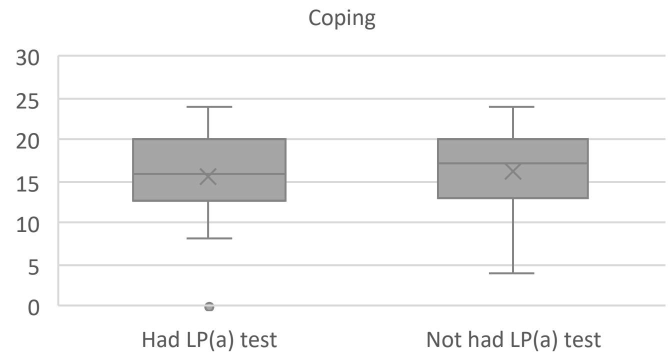

Figure 6.10: Boxplot of Partners in health: coping LP(a) test

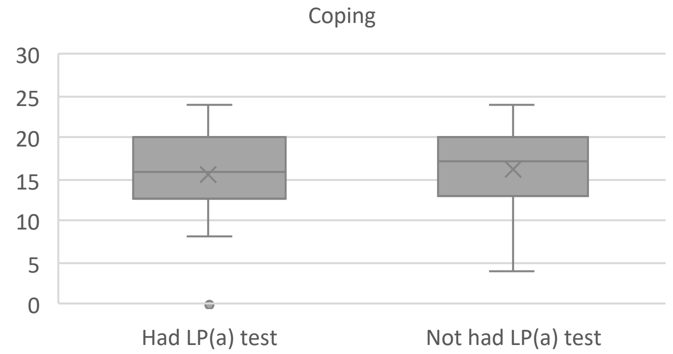

Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms LP(a) test

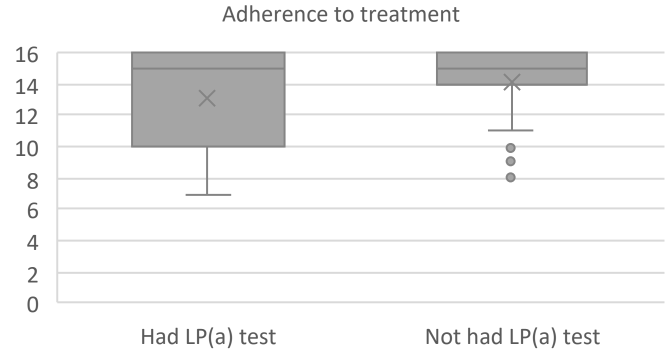

Figure 6.12: Boxplot of Partners in health: adherence to treatment LP(a) test

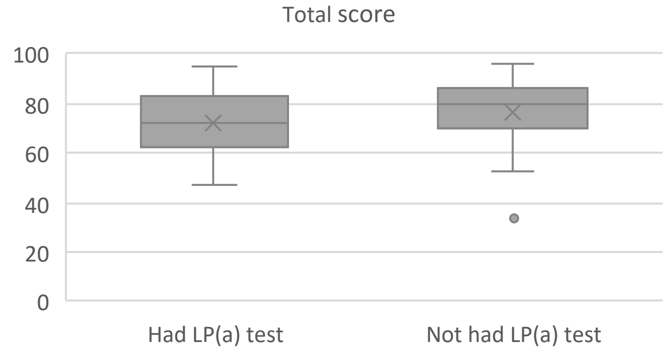

Figure 6.13: Boxplot of Partners in health Total score LP(a) test

Partners in health by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used.

No significant differences were observed between participants by **main condition** for any of the Partners in health scales.

Table 6.18 Partners in health by main condition summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	High cholesterol under 50 years of age	8	16.33	86.25	20.90	Between groups	481.00	2	240.50	1.29	0.2850
	Blood vessel conditions	19	38.78	78.78	14.48	Within groups	8779.00	47	186.80		
	Heart conditions	22	44.90	35.68	25.47	Total	9260.00	49	427.30		

Table 6.19: Partners in health by main condition summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	High cholesterol under 50 years of age	8	16.33	28.00	7.00	1.9896	2	0.3698
	Blood vessel conditions	19	38.78	28.00	7.00			
	Heart conditions	22	44.90	24.00	7.00			
Coping	High cholesterol under 50 years of age	8	16.33	18.00	6.25	0.38061	2	0.8267
	Blood vessel conditions	19	38.78	16.00	8.00			
	Heart conditions	22	44.90	14.00	9.00			
Recognition and management of symptoms	High cholesterol under 50 years of age	8	16.33	20.50	4.00	2.3413	2	0.3102
	Blood vessel conditions	19	38.78	21.00	3.00			
	Heart conditions	22	44.90	19.00	5.00			
Adherence to treatment	High cholesterol under 50 years of age	8	16.33	15.50	3.00	1.5765	2	0.4546
	Blood vessel conditions	19	38.78	15.00	2.00			
	Heart conditions	22	44.90	14.00	5.00			

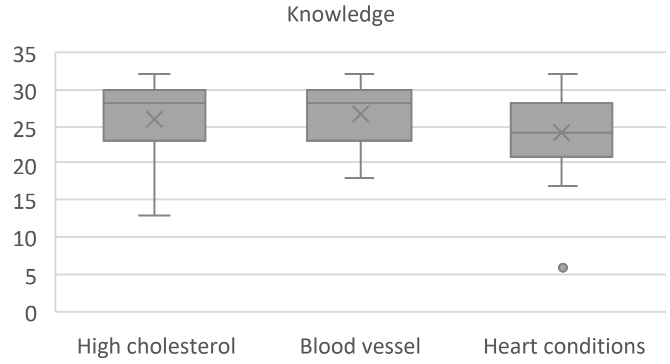

Figure 6.14: Boxplot of Partners in health: knowledge by main condition

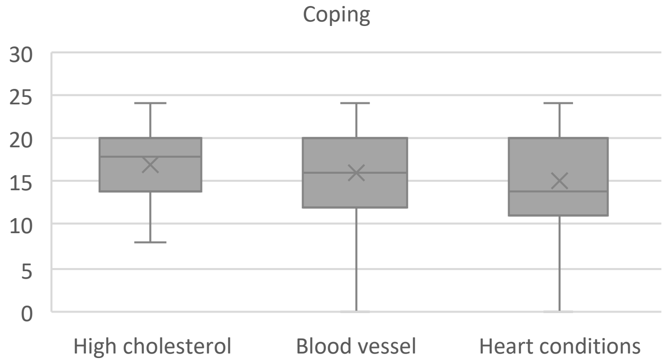

Figure 6.15: Boxplot of Partners in health: coping by main condition

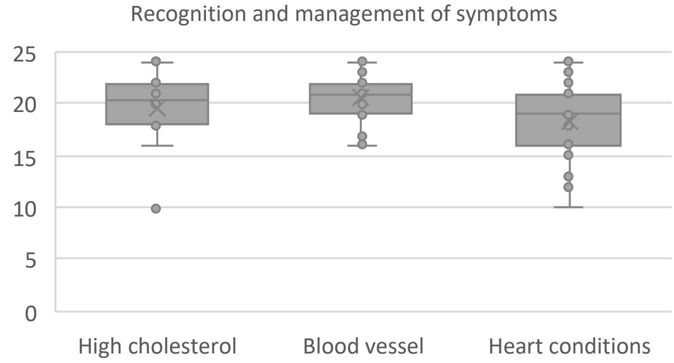

Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by main condition

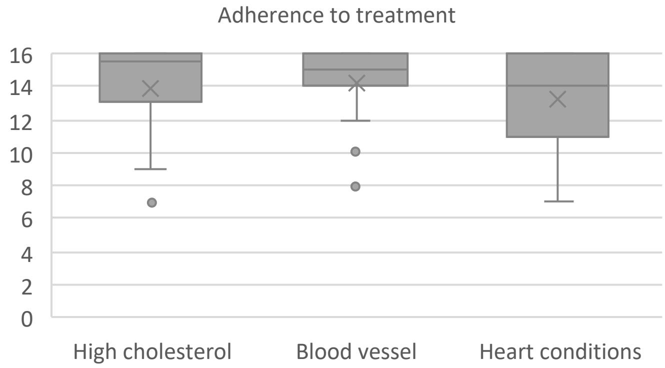

Figure 6.17: Boxplot of Partners in health: adherence to treatment by main condition

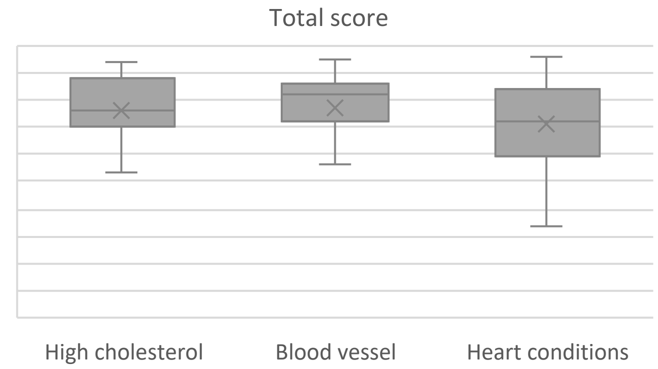

Figure 6.18: Boxplot of Partners in health Total score by main condition

Partners in health by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

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

No significant differences were observed between participants by **other conditions** for any of the Partners in health scales.

Table 6.20: Partners in health by other conditions summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	74.44	14.75	-0.01	48	0.9932
	6 to 11 other conditions	23	46.00	74.48	12.80			

Table 6.21: Partners in health by other conditions summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	0 to 5 other conditions	27	54.00	26.00	8.00	284.50	0.6182
	6 to 11 other conditions	23	46.00	28.00	9.00		
Coping	0 to 5 other conditions	27	54.00	19.00	7.50	344.50	0.5120
	6 to 11 other conditions	23	46.00	15.00	7.00		
Recognition and management of symptoms	0 to 5 other conditions	27	54.00	21.00	5.50	335.50	0.6309
	6 to 11 other conditions	23	46.00	20.00	5.00		
Adherence to treatment	0 to 5 other conditions	27	54.00	15.00	5.50	292.00	0.7160
	6 to 11 other conditions	23	46.00	15.00	2.00		

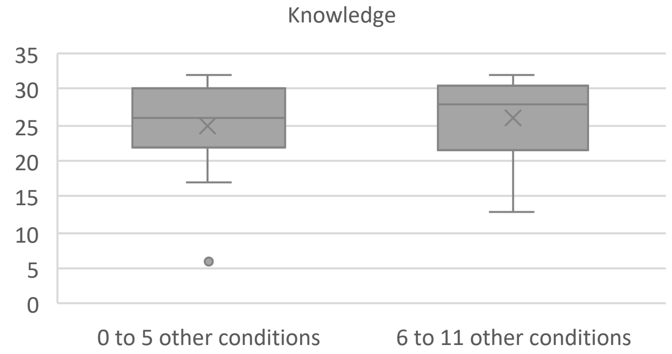

Figure 6.19: Boxplot of Partners in health: knowledge by other conditions

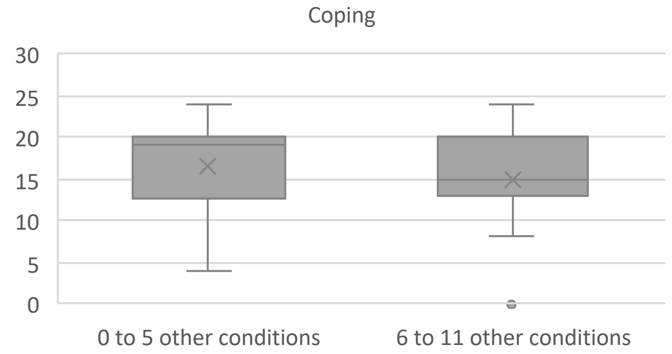

Figure 6.20: Boxplot of Partners in health: coping by other conditions

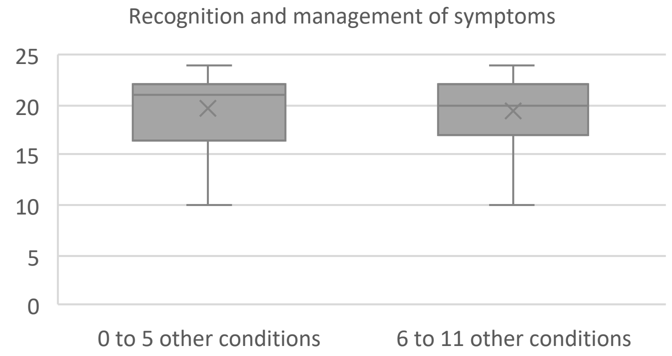

Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by other conditions

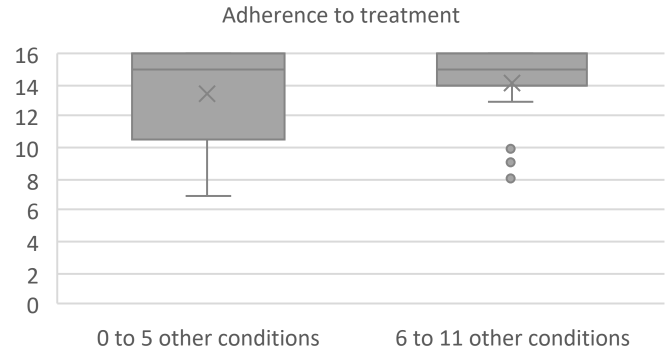

Figure 6.22: Boxplot of Partners in health: adherence to treatment by other conditions

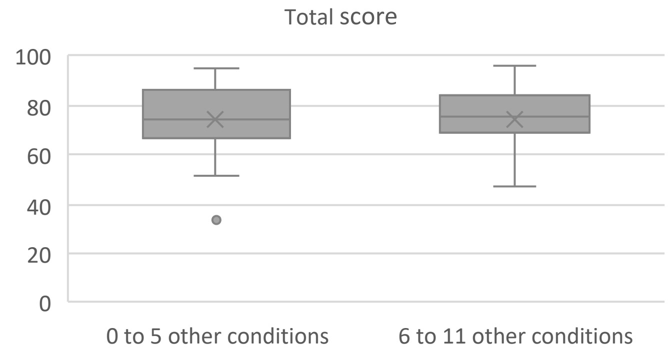

Figure 6.23: Boxplot of Partners in health Total score by other conditions

Partners in health by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

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

No significant differences were observed between participants by **gender** for any of the Partners in health scales.

Table 6.22: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Female	28	56.00	74.00	12.73	-0.26	48	0.7926
	Male	22	44.00	75.05	15.23			

Table 6.23: Partners in health by gender summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Female	28	56.00	26.50	7.25	289.00	0.7166
	Male	22	44.00	27.50	9.25		
Coping	Female	28	56.00	14.00	8.25	266.50	0.4204
	Male	22	44.00	17.50	5.75		
Recognition and management of symptoms	Female	28	56.00	20.00	4.50	299.00	0.8671
	Male	22	44.00	21.00	5.75		
Adherence to treatment	Female	28	56.00	15.00	2.00	316.50	0.8710
	Male	22	44.00	15.00	5.50		

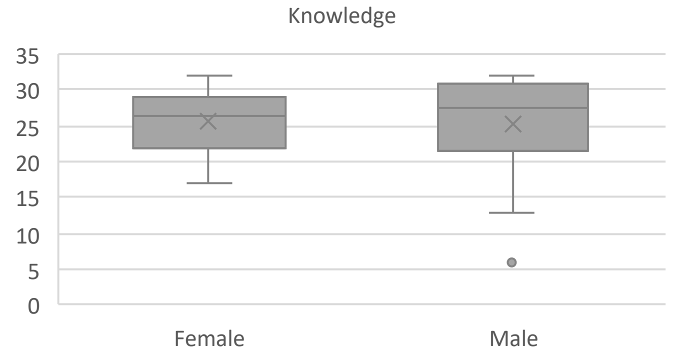

Figure 6.24: Boxplot of Partners in health: knowledge by gender

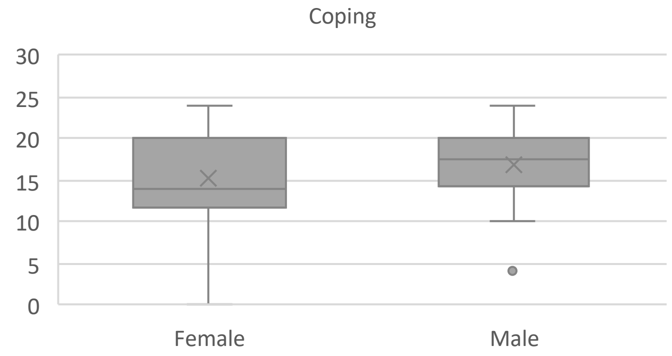

Figure 6.25: Boxplot of Partners in health: coping by gender

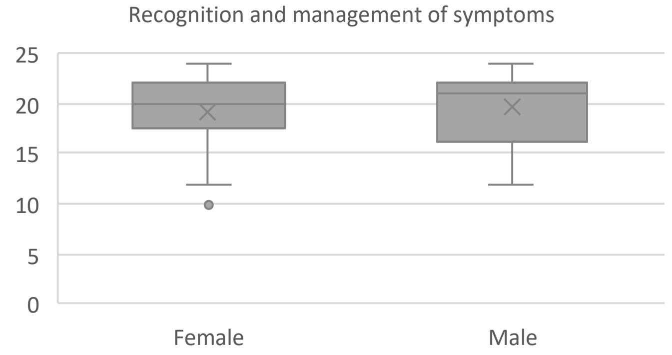

Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by gender

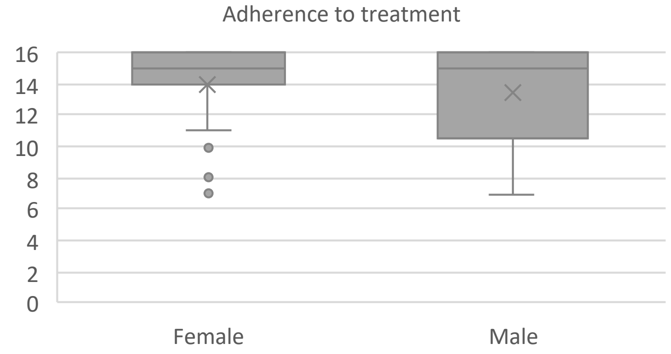

Figure 6.27: Boxplot of Partners in health: adherence to treatment by gender

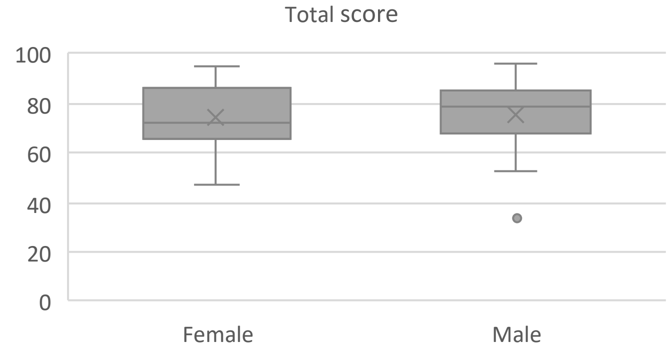

Figure 6.28: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

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

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.24: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 44	27	54.00	73.15	15.18	-0.73	48	0.4704
	Aged 45 and older	23	46.00	76.00	12.00			

Table 6.25: Partners in health by age summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 44	27	54.00	27.00	9.50	305.50	0.9299
	Aged 45 and older	23	46.00	27.00	7.00		
Coping	Aged 25 to 44	27	54.00	15.00	6.50	263.50	0.3627
	Aged 45 and older	23	46.00	18.00	7.50		
Recognition and management of symptoms	Aged 25 to 44	27	54.00	20.00	5.50	245.50	0.2059
	Aged 45 and older	23	46.00	21.00	3.00		
Adherence to treatment	Aged 25 to 44	27	54.00	16.00	5.50	358.50	0.3370
	Aged 45 and older	23	46.00	14.00	1.50		

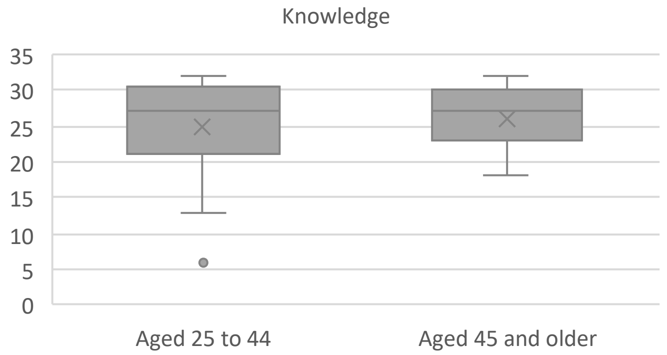

Figure 6.29: Boxplot of Partners in health: knowledge by age

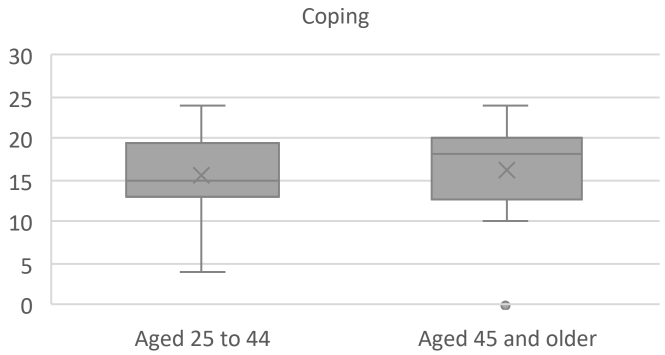

Figure 6.30: Boxplot of Partners in health: coping by age

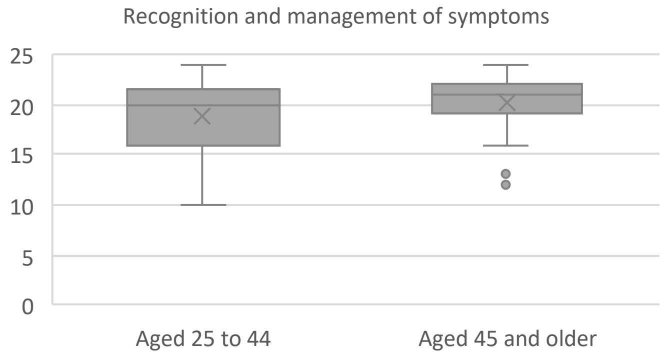

Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by age

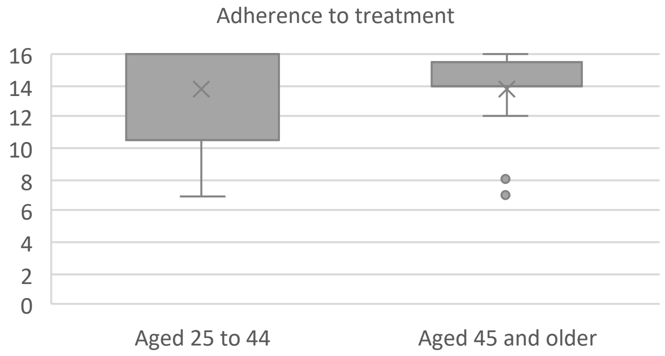

Figure 6.32: Boxplot of Partners in health: adherence to treatment by age

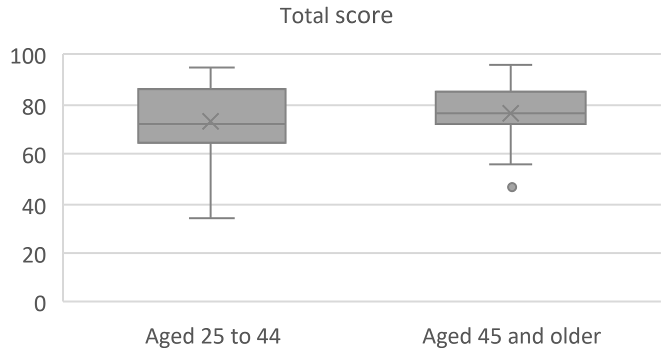

Figure 6.33: Boxplot of Partners in health Total score by age

Partners in health by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

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

No significant differences were observed between participants by **location** for any of the Partners in health scales.

Table 6.26: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	30.00	75.87	17.23	0.47	48	0.6406
	Metropolitan	35	70.00	73.86	12.20			

Table 6.27: Partners in health by location summary statistics and Wilcoxon rank sum test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	15	30.00	28.00	7.50	287.50	0.6025
	Metropolitan	35	70.00	25.00	8.50		
Coping	Regional or remote	15	30.00	17.00	6.50	305.00	0.3713
	Metropolitan	35	70.00	16.00	7.50		
Recognition and management of symptoms	Regional or remote	15	30.00	21.00	5.00	304.50	0.3760
	Metropolitan	35	70.00	20.00	5.50		
Adherence to treatment	Regional or remote	15	30.00	14.00	3.50	250.50	0.8004
	Metropolitan	35	70.00	15.00	3.00		

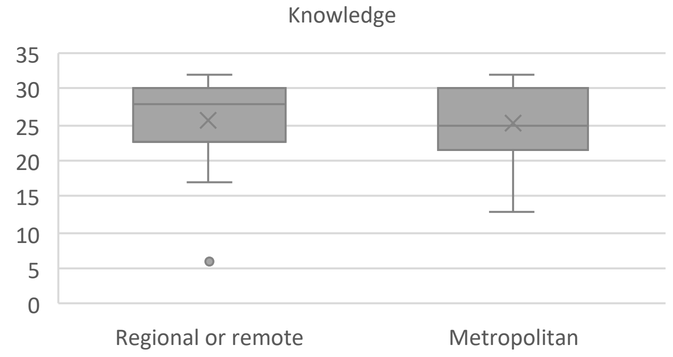

Figure 6.34: Boxplot of Partners in health: knowledge by location

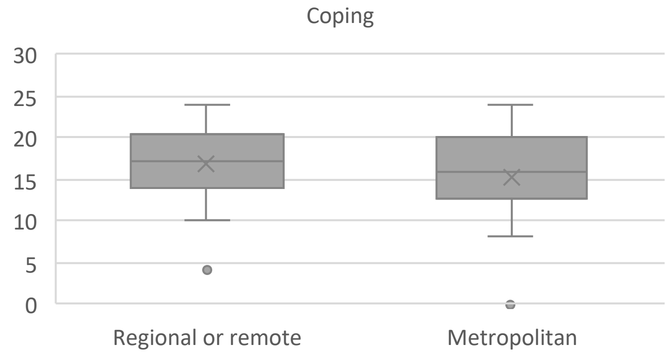

Figure 6.35: Boxplot of Partners in health: coping by location

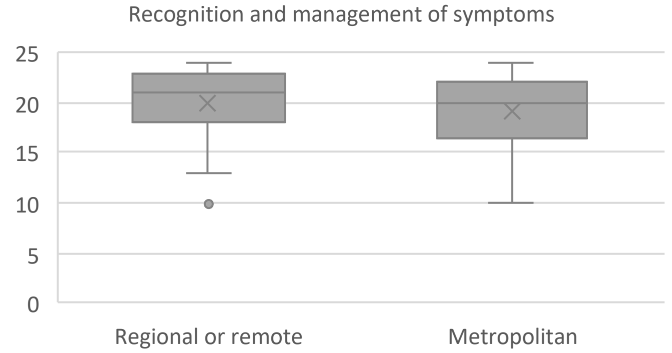

Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by location

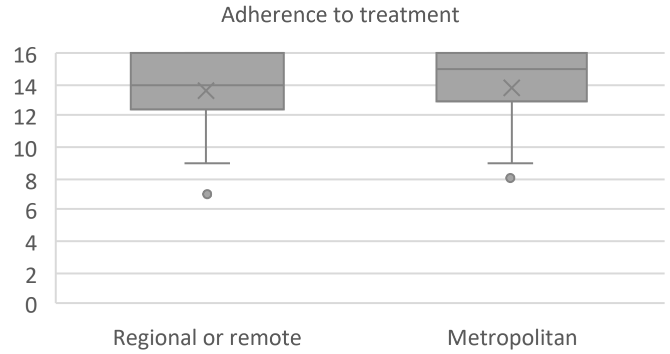

Figure 6.37: Boxplot of Partners in health: adherence to treatment by location

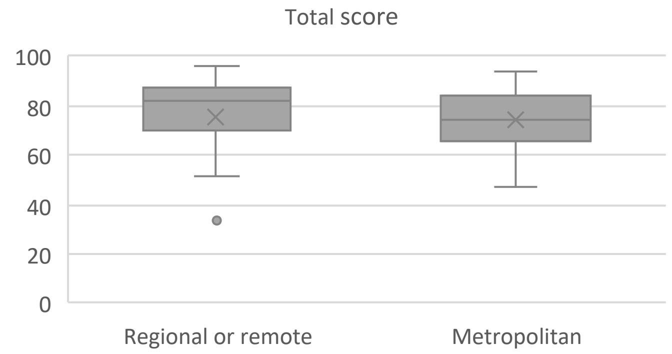

Figure 6.38: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Coping scale [W = 457.00 , p = 0.0050] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 19.00, IQR = 5.00) compared to participants in the Higher socioeconomic status subgroup (Median = 13.00, 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 scale [W = 437.00 , p = 0.0153] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 21.00, IQR = 5.00) compared to participants in the Higher socioeconomic status subgroup (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 scale [W = 422.00 , p = 0.0342] was significantly higher for participants in the Mid to low socioeconomic status subgroup (Median = 80.00, IQR = 16.00) compared to participants in the Higher socioeconomic status subgroup (Median = 72.00, IQR = 23.00.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that participants in the Mid to low socioeconomic status subgroup were good at coping with their condition, and participants in the Higher socioeconomic status subgroup were average at coping.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that recognition and management of symptoms was very good for participants in the Mid to low socioeconomic status subgroup, and good for participants in the Higher socioeconomic status subgroup.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Mid to low socioeconomic status subgroup scored higher than participants in the Higher socioeconomic status subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Mid to low socioeconomic status subgroup, and good for participants in the Higher socioeconomic status subgroup.

Table 6.28: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low socioeconomic status	25	50.00	28.00	7.00	369.00	0.2753
	Higher socioeconomic status	25	50.00	25.00	9.00		
Coping	Mid to low socioeconomic status	25	50.00	19.00	5.00	457.00	0.0050*
	Higher socioeconomic status	25	50.00	13.00	8.00		
Recognition and management of symptoms	Mid to low socioeconomic status	25	50.00	21.00	5.00	437.00	0.0153*
	Higher socioeconomic status	25	50.00	19.00	5.00		
Adherence to treatment	Mid to low socioeconomic status	25	50.00	15.00	3.00	312.50	1.0000
	Higher socioeconomic status	25	50.00	15.00	3.00		
Total score	Mid to low socioeconomic status	25	50.00	80.00	16.00	422.00	0.0342*
	Higher socioeconomic status	25	50.00	72.00	23.00		

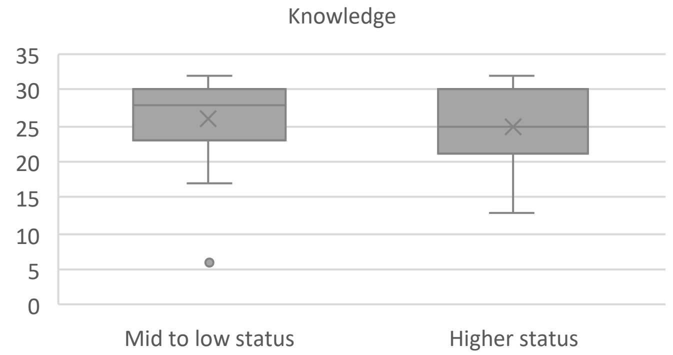

Figure 6.39: Boxplot of Partners in health: knowledge by socioeconomic status

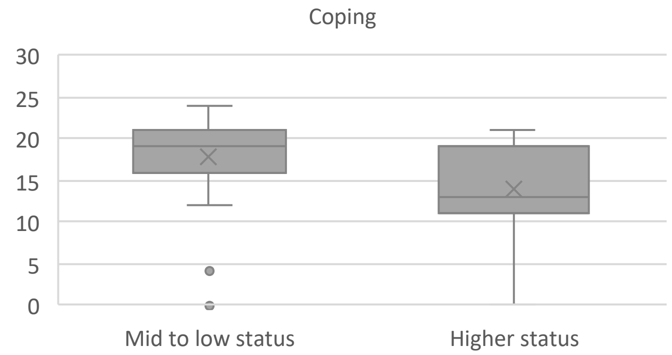

Figure 6.40: Boxplot of Partners in health: coping by socioeconomic status

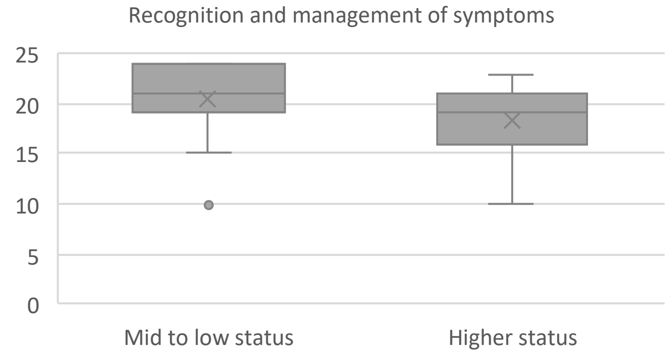

Figure 6.41: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

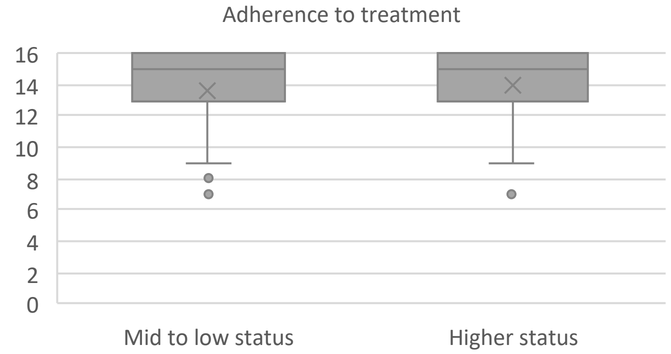

Figure 6.42: Boxplot of Partners in health: adherence to treatment by socioeconomic status

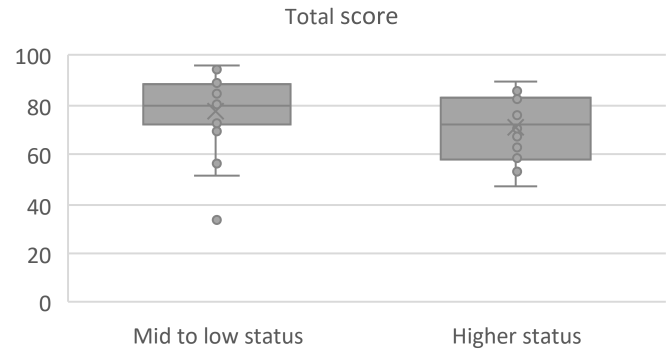

Figure 6.43: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=29, 58.00%), and 17 participants (34.00%) responded that they took medicines as prescribed most of the time. There were 2 participants (4.00%) that sometimes took medicines as prescribed.

Table 6.29: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=50	Percent
All of the time	29	58
Most of the time	17	34
Sometimes	2	4
Rarely	2	4

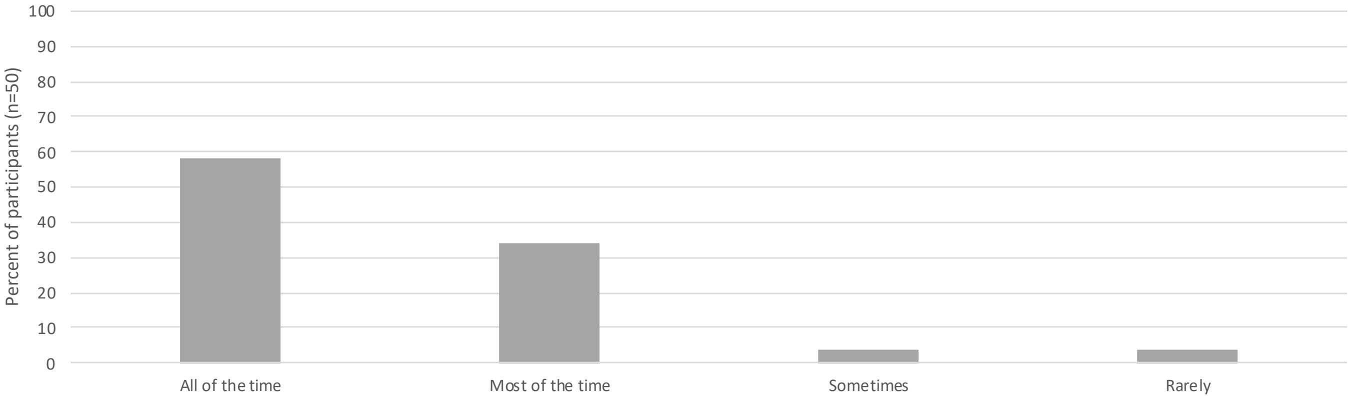

Figure 6.44: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=28, 56.00%), disease cause (n=19, 38.00%), disease management (n=18, 36.00%) and, dietary (n=18, 36.00%) were most frequently given to participants by healthcare professionals, and, information about hereditary considerations (n=4, 8.00%), and complementary therapies (n=2, 4.00%) were given least often. No participants (0.00%) were given information about clinical trials.

Table 6.30: Information given by health professionals

Information given by health professionals	n=50	Percent
Disease Cause	19	38.00
Treatment options	28	56.00
Disease management	18	36.00
Complementary therapies	2	4.00
Interpret test results	8	16.00
Clinical trials	0	0.00
Dietary	18	36.00
Physical activity	18	36.00
Psychological/ social support	10	20.00
Hereditary considerations	4	8.00
No information	1	2.00

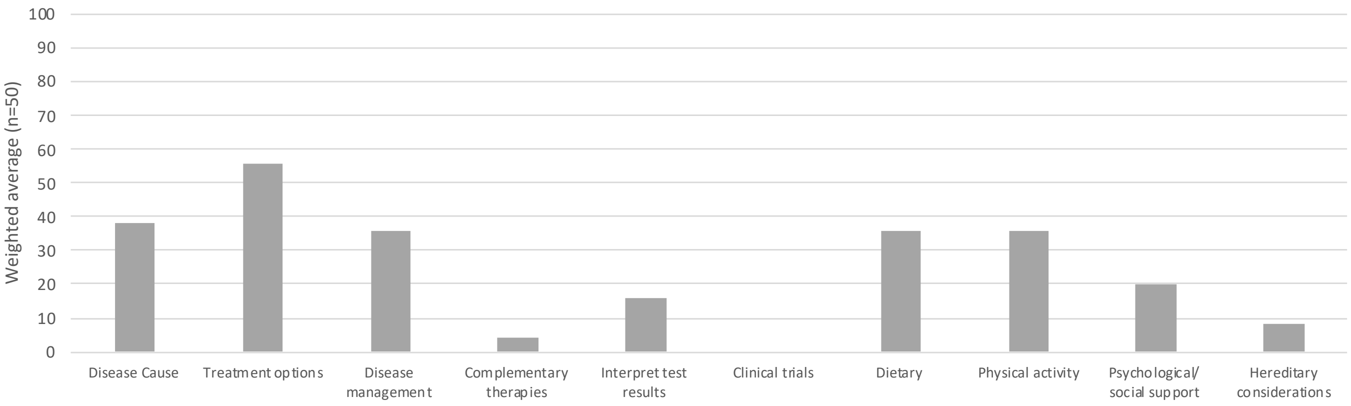

Figure 6.45: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease cause (n=22, 44.00%), treatment options (n=19, 38.00%), disease management (n=19, 38.00%) and, how to interpret test results (n=17, 34.00%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=11, 22.00%), complementary therapies (n=10, 20.00%) and clinical trials (n=4, 8.00%) were searched for least often

Table 6.31: Information searched for independently

Information searched independently	n=50	Percent
Disease Cause	22	44.00
Treatment options	19	38.00
Disease management	19	38.00
Complementary therapies	10	20.00
Interpret test results	17	34.00
Clinical trials	4	8.00
Dietary	16	32.00
Physical activity	13	26.00
Psychological/ social support	11	22.00
Hereditary considerations	12	24.00
No information	1	2.00

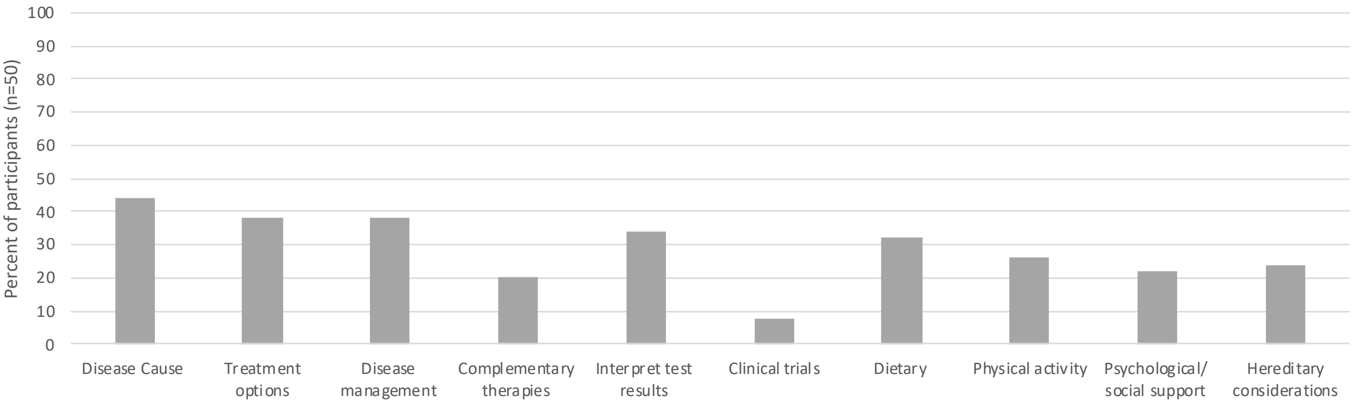

Figure 6.46: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=46, 92.00%) and complementary therapies (n=39, 78.00%).

The topics that participants were given most information from healthcare professionals but not searched for independently for were treatment options (n=16, 32.00%) and physical activity (n=15, 30.00%).

The topics that participants searched for independently after receiving information from healthcare professionals were treatment options (n=12, 24.00%) and disease management (n=8, 16.00%)

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=15, 30.00%) and interpret test results (n=13, 26.00%).

Table 6.32: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=50	%	n=50	%	n=50	%	n=50	%
Disease cause	16	32.00	12	24.00	7	14.00	15	30.00
Treatment options	15	30.00	16	32.00	12	24.00	7	14.00
Disease management	21	42.00	10	20.00	8	16.00	11	22.00
Complementary therapies	39	78.00	1	2.00	1	2.00	9	18.00
How to interpret test results	29	58.00	4	8.00	4	8.00	13	26.00
Clinical trials	46	92.00	0	0.00	0	0.00	4	8.00
Dietary information	23	46.00	11	22.00	7	14.00	9	18.00
Physical activity	22	44.00	15	30.00	3	6.00	10	20.00
Psychological/social support	31	62.00	8	16.00	2	4.00	9	18.00
Hereditary considerations	36	72.00	2	4.00	2	4.00	10	20.00

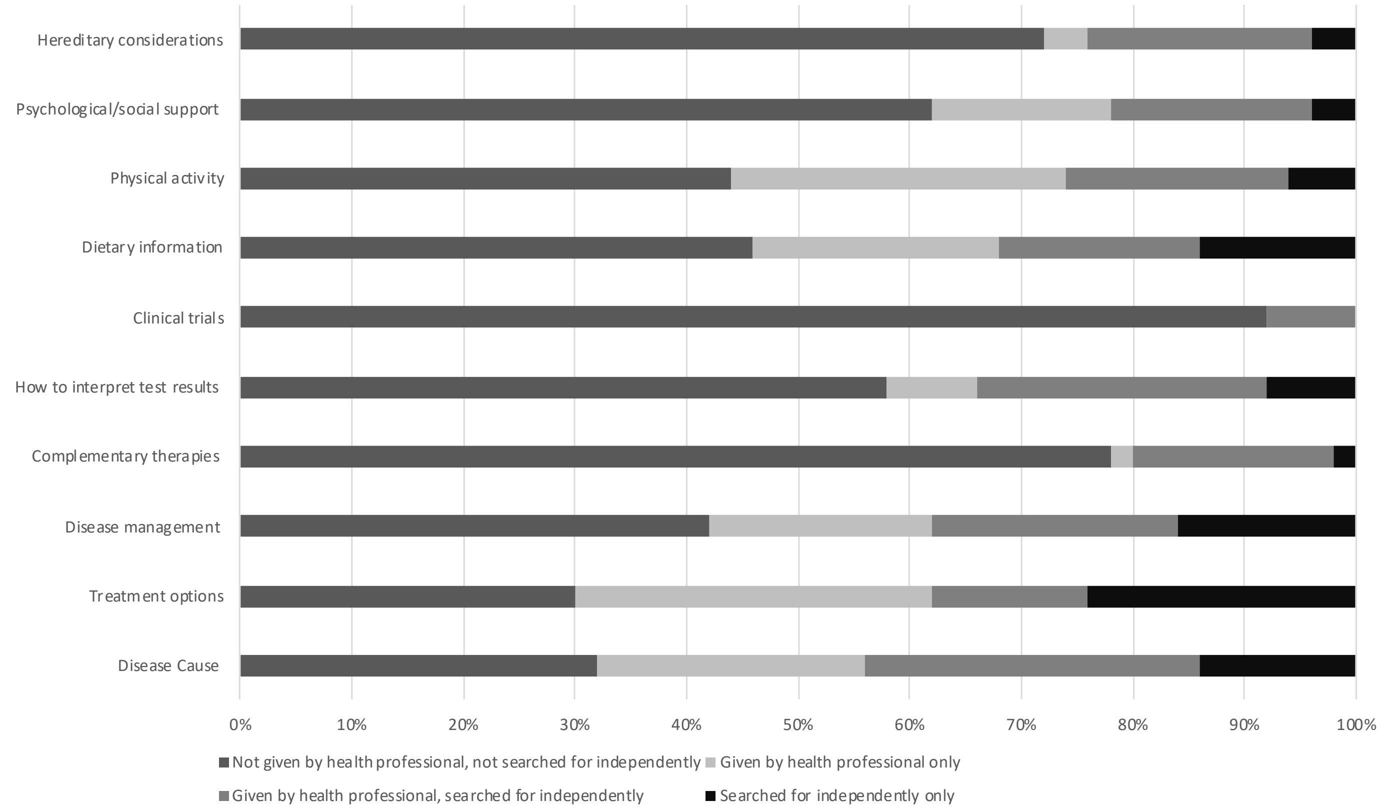

Figure 6.47: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in the table below. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

Table 6.33: Most accessed information

Information source	Weighted average (n=50)
Non-profit organisations, charity or patient organisations	3.63
Hospital or clinic where being treated	3.45
Government	3.16
Medical journals	2.95
Pharmaceutical companies	2.29

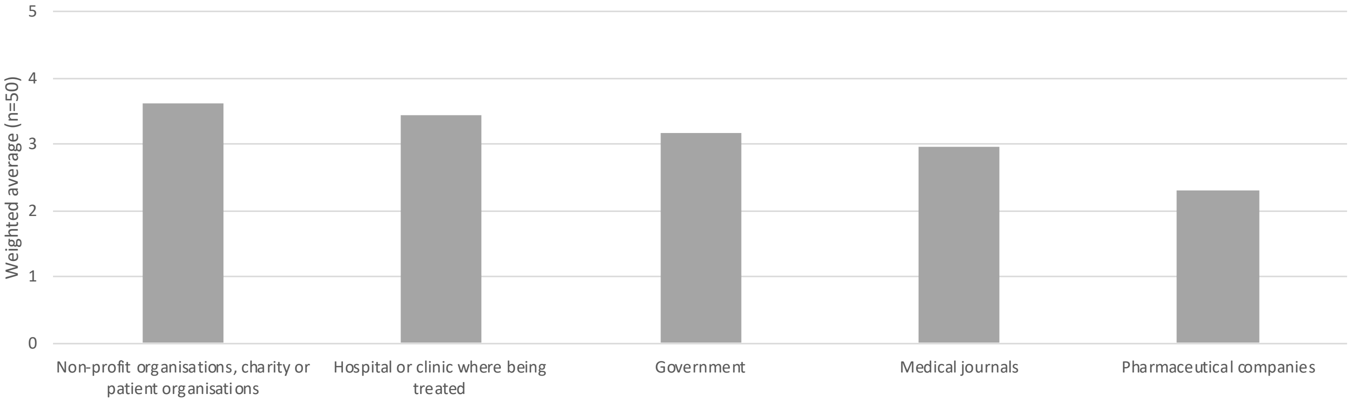

Figure 6.48: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 20 participants (40.00%) that had accessed My Health Record.

Of those that had accessed My Health Record, there were 8 participants (42.11%) who found it to be poor or very poor, 4 participants (21.05%) who found it acceptable, and 7 participants (36.84%) who found it to be good or very good.

Table 6.34: Accessed My Health Record

Accessed "My health record"	Number (n=50)	Percent
Yes	20	40.00
No	16	32.00
Not sure	9	18.00
Doesn't know what 'My Health Record' is	6	12.00

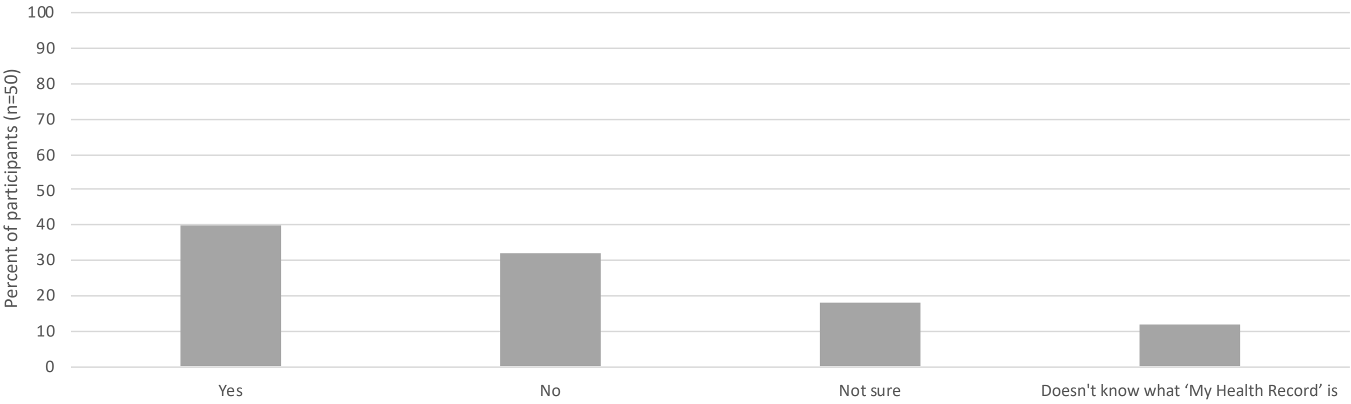

Figure 6.49: Accessed My Health Record

Table 6.35: How useful was My Health Record

How useful was "My health record"	Number (n=19)	Percent
Very poor	5	26.32
Poor	3	15.79
Acceptable	4	21.05
Good	4	21.05
Very good	3	15.79

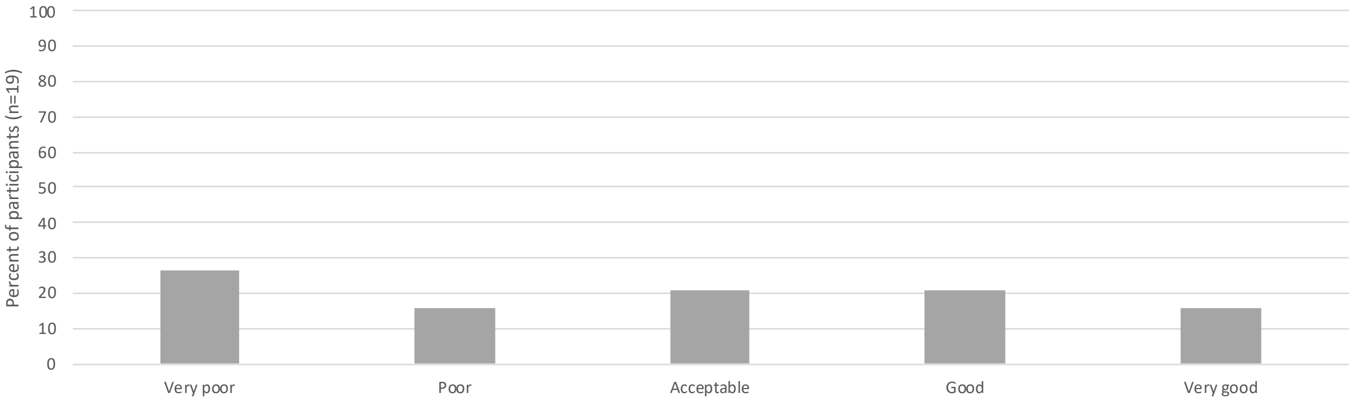

Figure 6.50: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

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 sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15 %), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%), others described that they did not need or seek help or support (14.89%), and some described the challenges of finding or accessing support (10.64%).

Care coordination

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 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 an average score in the second highest quintile for the **Care coordination: Communication** (mean = 44.72, SD = 9.18), **Care coordination: Navigation** (mean = 26.74, SD = 4.80) **Care coordination: Total score** (mean = 71.46, SD = 12.46), indicating good communication and navigation of the healthcare system.

Overall, the participants in this PEEK study had an average score in the highest quintile for the **Care coordination: Care coordination global measure** (median = 9.00, IQR = 2.00), and **Care coordination: Quality of care global measure** (median = 9.00, IQR = 1.75). indicating very good care coordination and quality of care.

Comparisons of Care co-ordination have been made based on LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	36.86	11.00	38.00	13.00	13 to 65	3
Navigation*	23.84	5.67	23.00	9.50	7 to 35	4
Total score	60.70	13.98	64.00	18.75	20 to 100	3
Care coordination global measure	6.08	2.69	7.00	4.00	1 to 10	4
Quality of care global measure	6.82	2.56	8.00	3.75	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

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

No significant differences were observed between participants by **LP(a) test** for any of the Care coordination scales.

Table 7.2: Care coordination by LP(a) test summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Had LP(a) test	19	38.00	36.95	11.03	0.04	48	0.9655
	Not had LP(a) test	31	62.00	36.81	11.17			
Navigation	Had LP(a) test	19	38.00	22.32	5.96	-1.51	48	0.1385
	Not had LP(a) test	31	62.00	24.77	5.37			
Total score	Had LP(a) test	19	38.00	59.26	15.25	-0.57	48	0.5746
	Not had LP(a) test	31	62.00	61.58	13.32			

*Statistically significant at p<0.05

Table 7.3: Care coordination by LP(a) test summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Care coordination global measure	Had LP(a) test	19	38.00	7.00	3.50	300.00	0.9197
	Not had LP(a) test	31	62.00	7.00	4.00		
Quality of care global measure	Had LP(a) test	19	38.00	8.00	3.00	275.00	0.7004
	Not had LP(a) test	31	62.00	8.00	3.50		

*Statistically significant at p<0.05

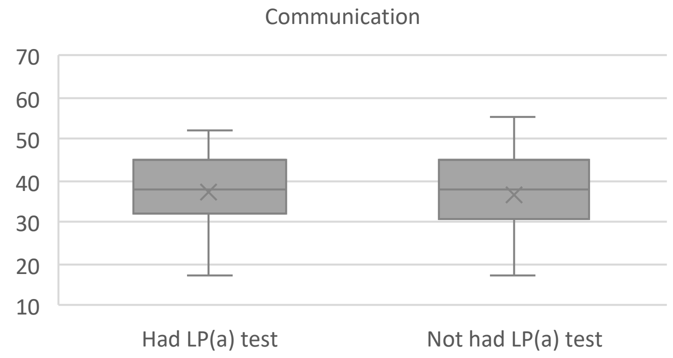

Figure 7.1: Boxplot of Care coordination: Communication by LP(a) test

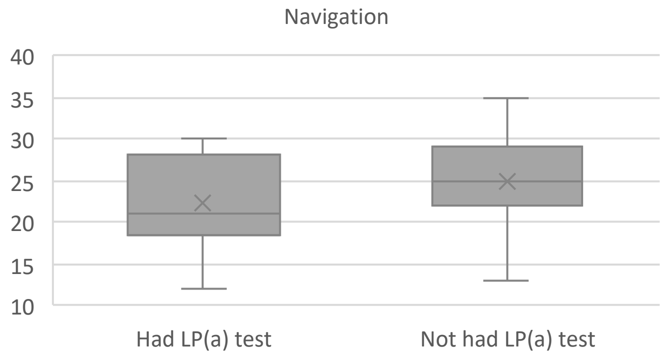

Figure 7.2: Boxplot of Care coordination: Navigation by LP(a) test

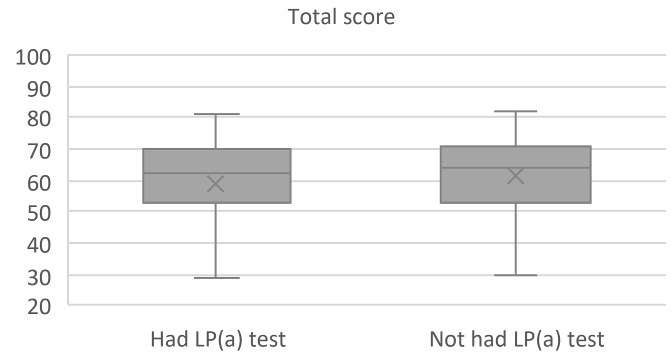

Figure 7.3: Boxplot of Care coordination: Total score by LP(a) test

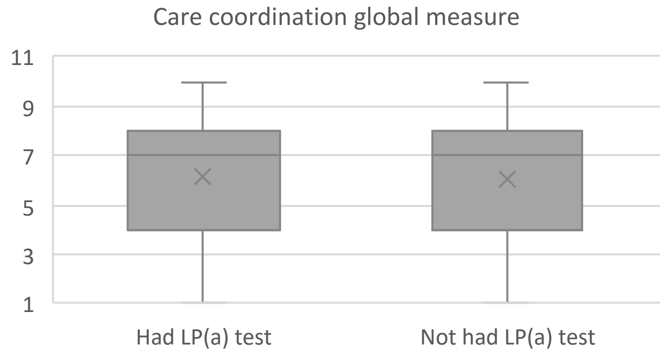

Figure 7.4: Boxplot of Care coordination: Care coordination global measure by LP(a) test

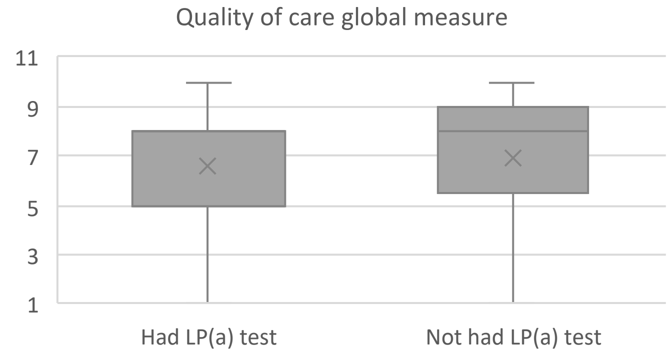

Figure 7.5: Boxplot of Care coordination: Quality of care global measure by LP(a) test

Care coordination by condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used.

No significant differences were observed between participants by **condition** for any of the Care coordination scales.

Table 7.4: Care coordination by main condition summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	High cholesterol under 50 years of age	8	16.33	22.00	5.41	Between groups	62.40	2	31.19	0.97	0.3870
	Blood vessel conditions	19	38.78	23.88	4.28	Within groups	1514.30	47	32.22		
	Heart conditions	22	44.90	24.86	6.70	Total	1576.70	49	63.41		
Care coordination global measure	High cholesterol under 50 years of age	8	16.33	6.50	2.39	Between groups	30.40	2	15.20	2.21	0.1210
	Blood vessel conditions	19	38.78	5.00	2.96	Within groups	323.30	47	6.88		
	Heart conditions	22	44.90	6.71	2.45	Total	353.70	49	22.08		

Table 7.5: Care coordination by main condition summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	C^2	dF	p-value
Communication	High cholesterol under 50 years of age	8	16.33	38.00	12.25	1.48	2	0.4781
	Blood vessel conditions	19	38.78	35.00	13.00			
	Heart conditions	22	44.90	40.00	15.00			
Total score	High cholesterol under 50 years of age	8	16.33	62.50	17.75	1.66	2	0.4364
	Blood vessel conditions	19	38.78	62.00	18.00			
	Heart conditions	22	44.90	67.00	17.00			
Quality of care global measure	High cholesterol under 50 years of age	8	16.33	7.50	1.50	2.87	2	0.2386
	Blood vessel conditions	19	38.78	6.00	4.00			
	Heart conditions	22	44.90	8.00	2.00			

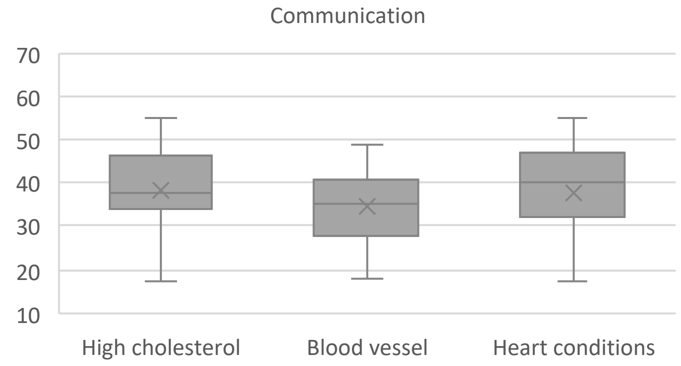

Figure 7.6: Boxplot of Care coordination: Communication by main condition

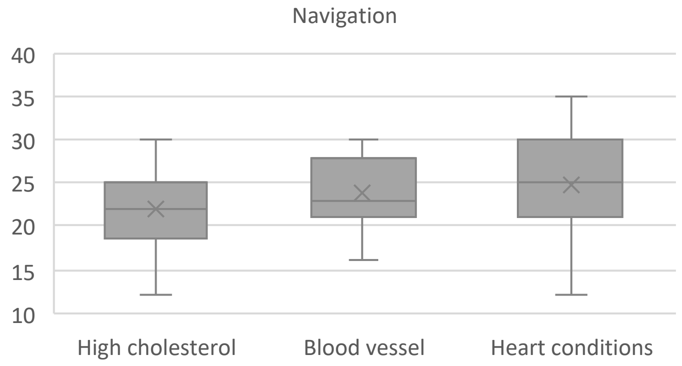

Figure 7.7: Boxplot of Care coordination: Navigation by main condition

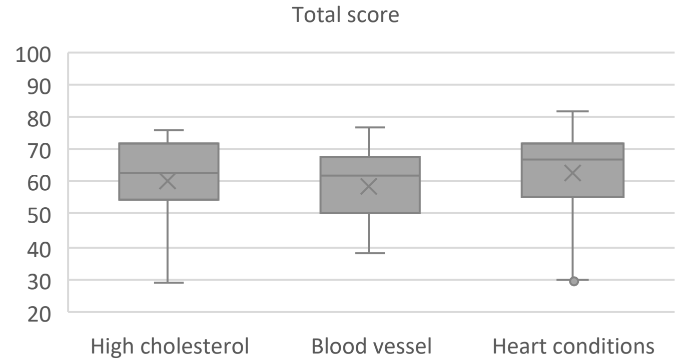

Figure 7.8: Boxplot of Care coordination: Total score by main condition

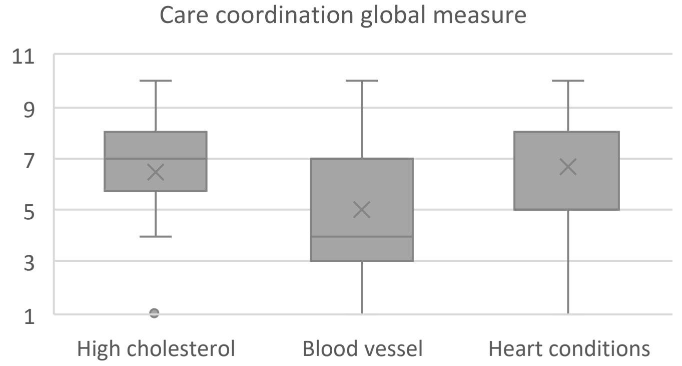

Figure 7.9: Boxplot of Care coordination: Care coordination global measure by main condition

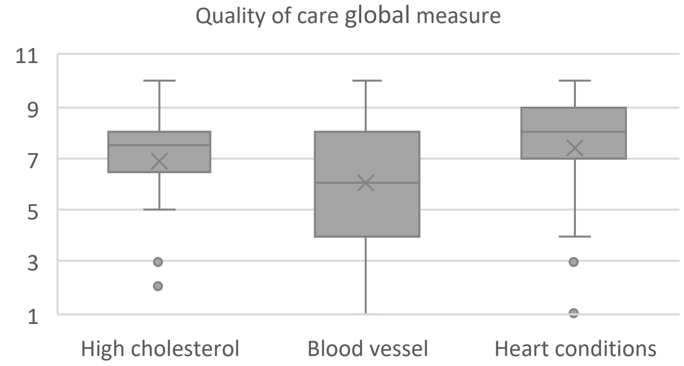

Figure 7.10: Boxplot of Care coordination: Quality of care global measure by main condition

Care coordination by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

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

No significant differences were observed between participants by **other conditions** for any of the Care coordination scales.

Table 7.6: Care coordination by other conditions summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	61.89	12.88	0.65	48	0.5202
	6 to 11 other conditions	23	46.00	59.30	15.34			
Care coordination global measure	0 to 5 other conditions	27	54.00	6.11	2.56	0.09	48	0.9304
	6 to 11 other conditions	23	46.00	6.04	2.88			

*Statistically significant at p<0.05

Table 7.7: Care coordination by other conditions summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	0 to 5 other conditions	27	54.00	40.00	11.50	343.00	0.5325
	6 to 11 other conditions	23	46.00	36.00	21.00		
Navigation	0 to 5 other conditions	27	54.00	23.00	10.00	311.50	0.9922
	6 to 11 other conditions	23	46.00	23.00	7.00		
Quality of care global measure	0 to 5 other conditions	27	54.00	8.00	2.50	378.00	0.1864
	6 to 11 other conditions	23	46.00	7.00	3.00		

*Statistically significant at p<0.05

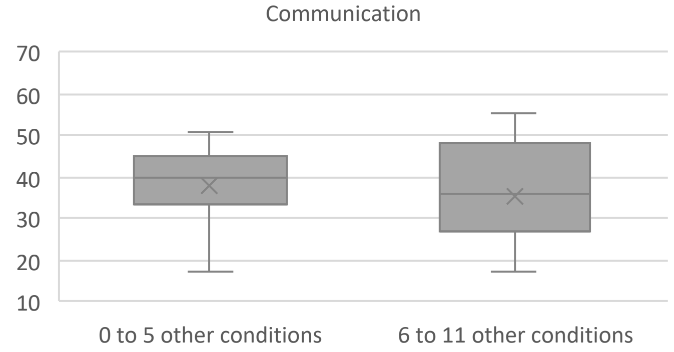

Figure 7.11: Boxplot of Care coordination: Communication by other conditions

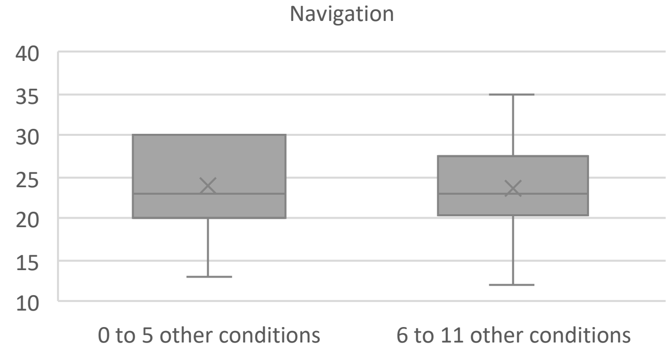

Figure 7.12: Boxplot of Care coordination: Navigation by other conditions

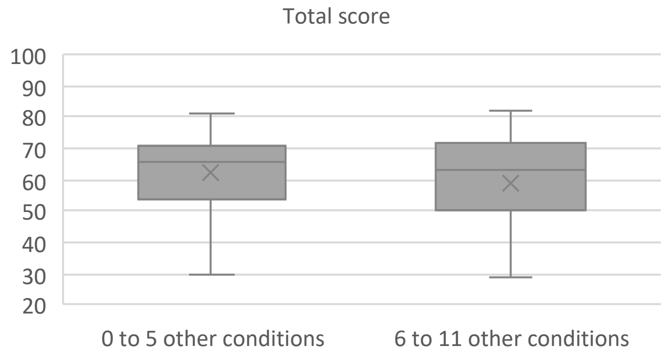

Figure 7.13: Boxplot of Care coordination: Total score by other conditions

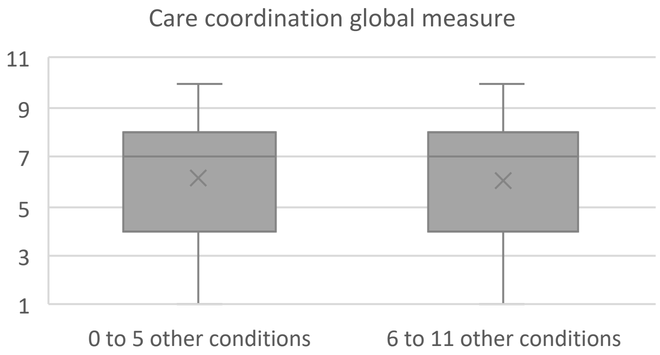

Figure 7.14: Boxplot of Care coordination: Care coordination global measure by other conditions

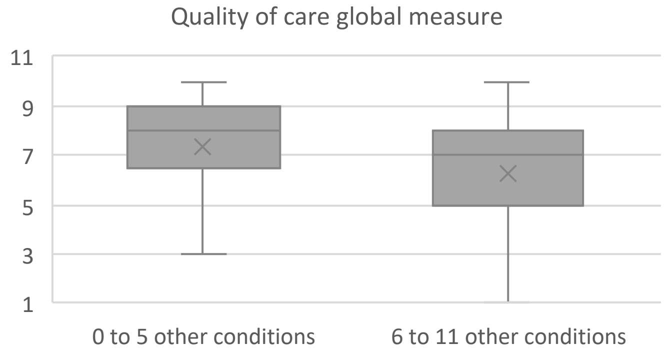

Figure 7.15: Boxplot of Care coordination: Quality of care global measure by other conditions

Care coordination by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

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

No significant differences were observed between participants by **gender** for any of the Care coordination scales.

Table 7.8: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Female	28	56	36.7142857	10.6765827	-0.10456	48	0.9172
	Male	22	44	37.0454545	11.6597691			
Navigation	Female	28	56	23.4285714	5.85901377	-0.57462	48	0.5682
	Male	22	44	24.3636364	5.51660225			

*Statistically significant at p<0.05

Table 7.9: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Total score	Female	28	56.00	64.50	18.50	294.50	0.7993
	Male	22	44.00	63.50	18.50		
Care coordination global measure	Female	28	56.00	6.50	4.25	261.00	0.3590
	Male	22	44.00	7.00	3.75		
Quality of care global measure	Female	28	56.00	7.00	4.25	281.50	0.6067
	Male	22	44.00	8.00	1.75		

*Statistically significant at p<0.05

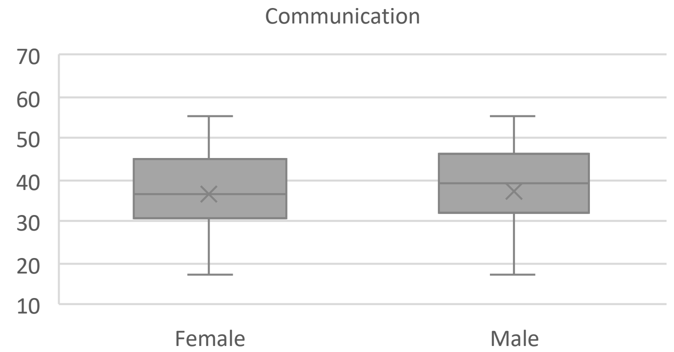

Figure 7.16: Boxplot of Care coordination: Communication by gender

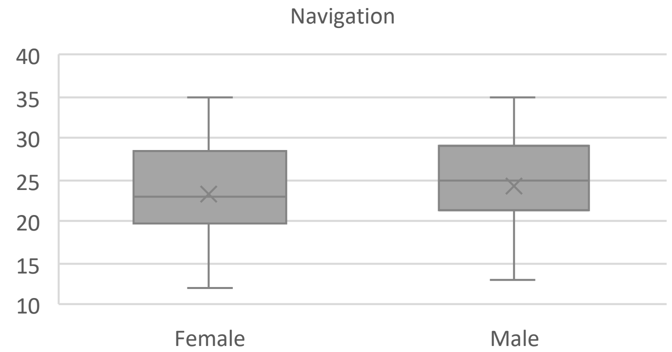

Figure 7.17: Boxplot of Care coordination: Navigation by gender

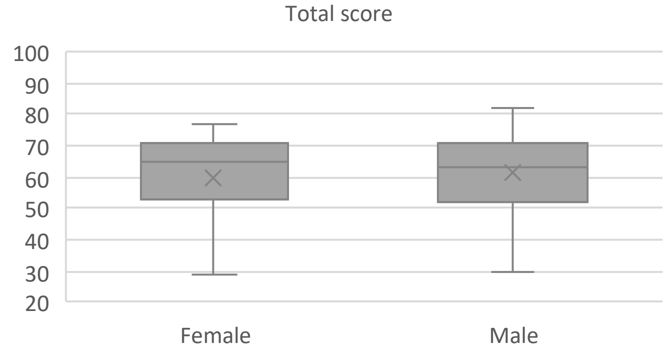

Figure 7.18: Boxplot of Care coordination: Total score by gender

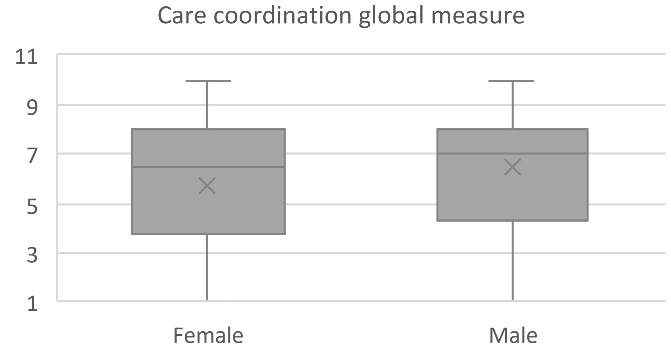

Figure 7.19: Boxplot of Care coordination: Care coordination global measure by gender

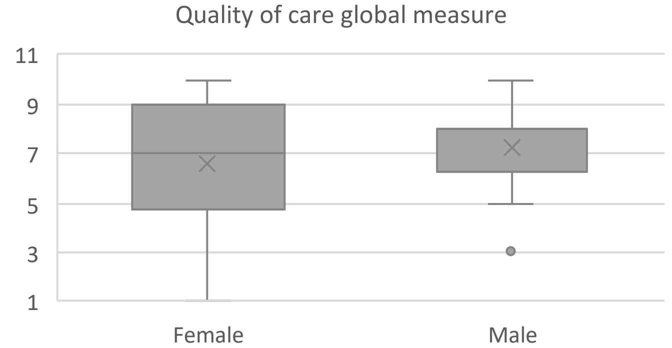

Figure 7.20: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

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

No significant differences were observed between participants by **age** for any of the Care coordination scales.

Table 7.10: Care coordination by age summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Navigation	Aged 25 to 44	27	54.00	23.30	5.90	-0.73	48	0.4684
	Aged 45 and older	23	46.00	24.48	5.45			
Total score	Aged 25 to 44	27	54.00	60.30	15.08	-0.22	48	0.8275
	Aged 45 and older	23	46.00	61.17	12.88			

*Statistically significant at p<0.05

Table 7.11: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	Aged 25 to 44	27	54.00	40.00	15.50	333.50	0.6608
	Aged 45 and older	23	46.00	37.00	12.50		
Care coordination global measure	Aged 25 to 44	27	54.00	7.00	4.00	344.00	0.5167
	Aged 45 and older	23	46.00	7.00	4.00		
Quality of care global measure	Aged 25 to 44	27	54.00	8.00	3.50	341.50	0.5475
	Aged 45 and older	23	46.00	8.00	3.00		

*Statistically significant at p<0.05

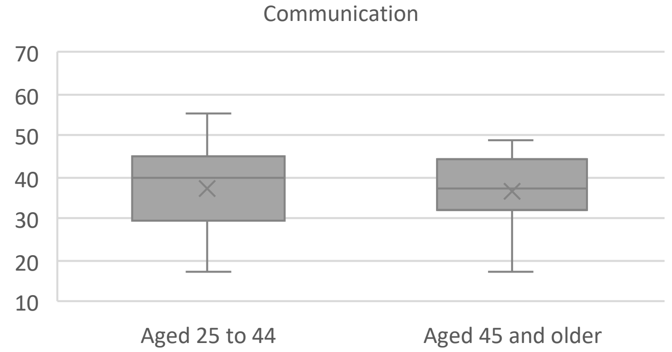

Figure 7.21: Boxplot of Care coordination: Communication by age

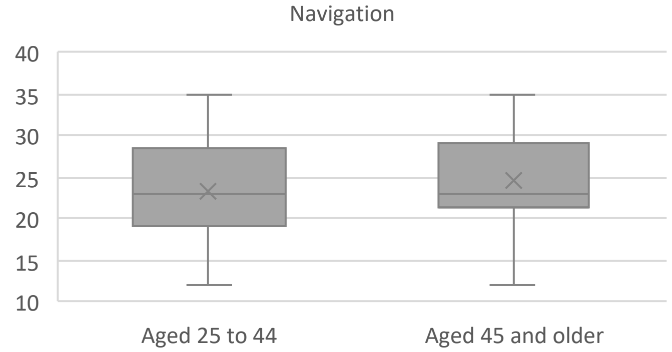

Figure 7.22: Boxplot of Care coordination: Navigation by age

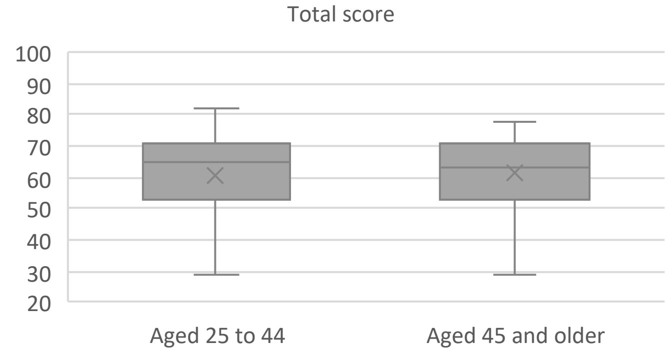

Figure 7.23: Boxplot of Care coordination: Total score by age

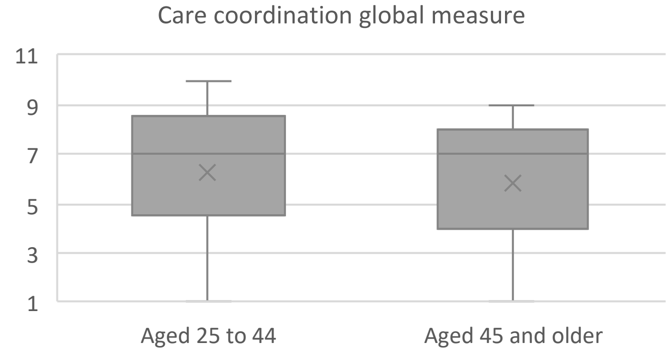

Figure 7.24: Boxplot of Care coordination: Care coordination global measure by age

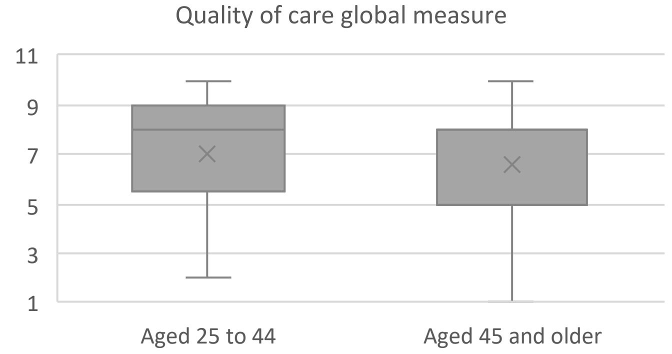

Figure 7.25: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

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

No significant differences were observed between participants by **location** for any of the Care coordination scales.

Table 7.12: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	15	30.00	40.20	10.53	1.42	48	0.1622
	Metropolitan	35	70.00	35.43	11.04			
Navigation	Regional or remote	15	30.00	23.40	5.30	-0.36	48	0.7235
	Metropolitan	35	70.00	24.03	5.89			

*Statistically significant at $p<0.05$

Table 7.13: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Total score	Regional or remote	15	30.00	67.00	14.00	320.50	0.2230
	Metropolitan	35	70.00	62.00	18.50		
Care coordination global measure	Regional or remote	15	30.00	5.00	4.00	224.00	0.4168
	Metropolitan	35	70.00	7.00	3.00		
Quality of care global measure	Regional or remote	15	30.00	8.00	4.50	281.50	0.6915
	Metropolitan	35	70.00	8.00	2.50		

*Statistically significant at $p<0.05$

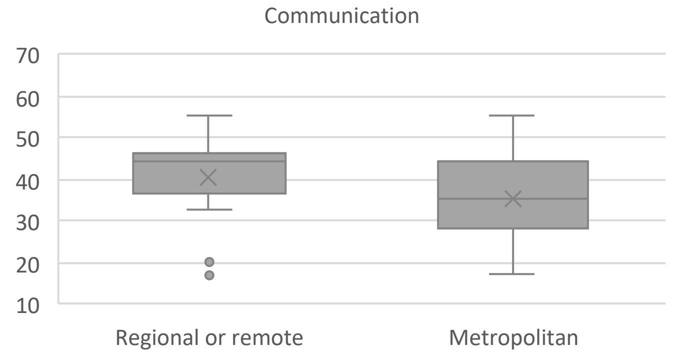

Figure 7.26: Boxplot of Care coordination: Communication by location

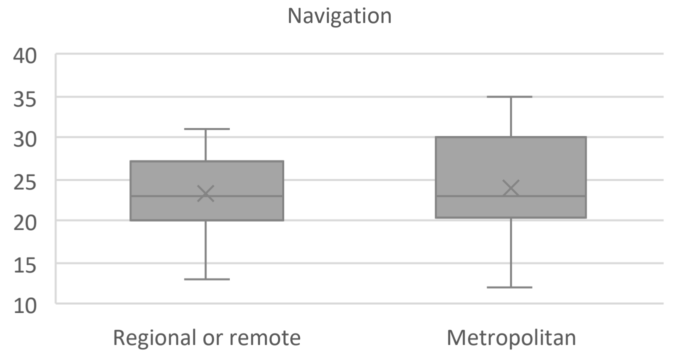

Figure 7.27: Boxplot of Care coordination: Navigation by location

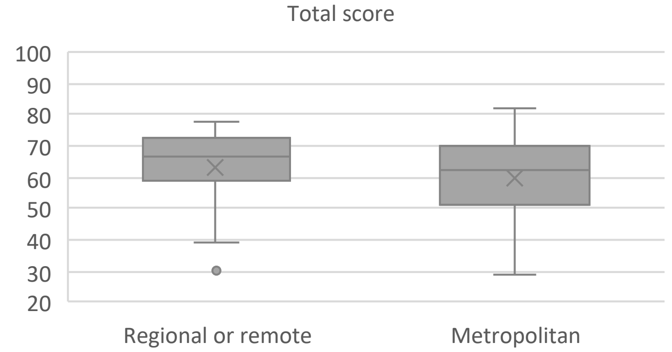

Figure 7.28: Boxplot of Care coordination: Total score by location

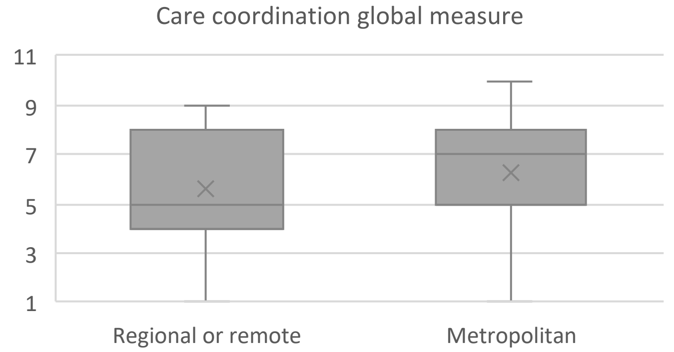

Figure 7.29: Boxplot of Care coordination: Care coordination global measure by location

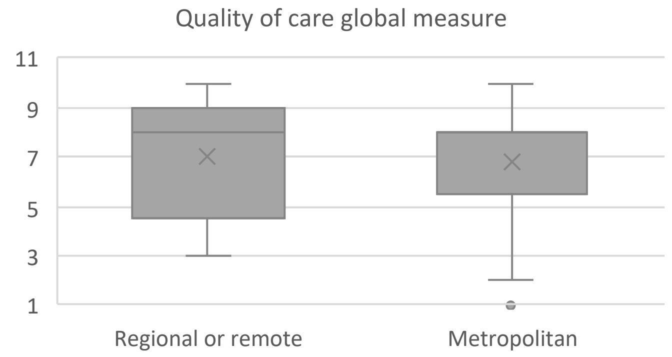

Figure 7.30: Boxplot of Care coordination: Quality of care global measure by location

Care coordination by socioeconomic status

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

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

No significant differences were observed between participants by **socioeconomic status** for any of the Care coordination scales.

Table 7.14: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Navigation	Mid to low socioeconomic status	25	50.00	24.00	5.16	0.20	48	0.8443
	Higher socioeconomic status	25	50.00	23.68	6.24			

*Statistically significant at p<0.05

Table 7.15: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=50)	Percent	Median	IQR	W	p-value
Communication	Mid to low socioeconomic status	25	50.00	40.00	15.00	386.50	0.1530
	Higher socioeconomic status	25	50.00	35.00	9.00		
Total score	Mid to low socioeconomic status	25	50.00	70.00	18.00	376.50	0.2175
	Higher socioeconomic status	25	50.00	62.00	15.00		
Care coordination global measure	Mid to low socioeconomic status	25	50.00	7.00	4.00	314.00	0.9844
	Higher socioeconomic status	25	50.00	6.00	4.00		
Quality of care global measure	Mid to low socioeconomic status	25	50.00	8.00	4.00	323.50	0.8365
	Higher socioeconomic status	25	50.00	7.00	3.00		

*Statistically significant at p<0.05

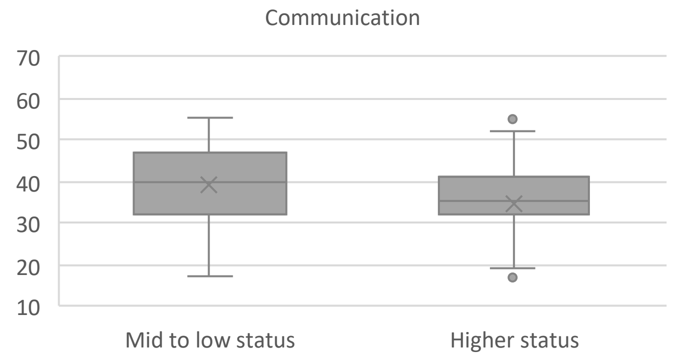

Figure 7.31: Boxplot of Care coordination: Communication by socioeconomic status

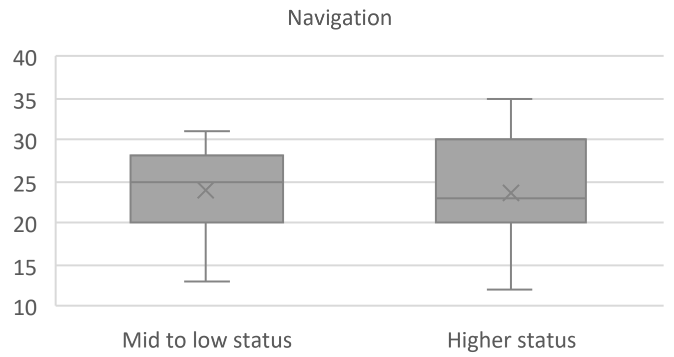

Figure 7.32: Boxplot of Care coordination: Navigation by socioeconomic status

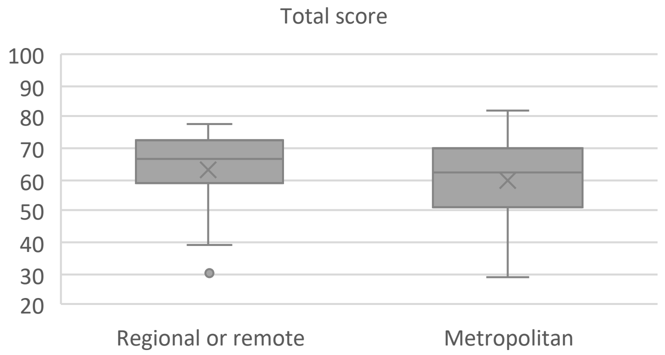

Figure 7.33: Boxplot of Care coordination: Total score by socioeconomic status

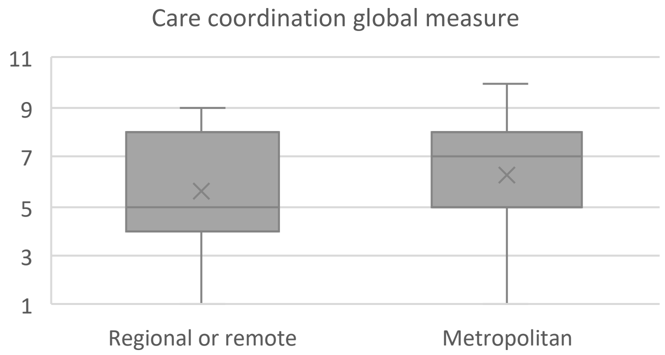

Figure 7.34: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

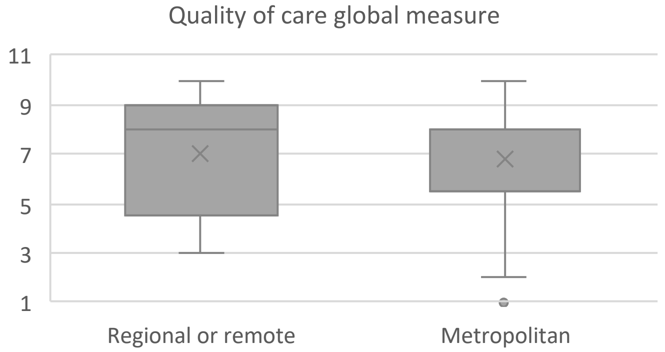

Figure 7.35: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

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 sources of support and were from their hospital or clinical setting (31.91%), from family and friends (19.15 %), domestic services and/or home care (14.89%), and peer support or other patients (8.51%). Almost a third described that they did not receive any formal support (27.66%), others described that they did not need or seek help or support (14.89%), and some described the challenges of finding or accessing support (10.64%).

Participant describes getting care and support from hospital or clinical setting

Healthcare workers have been wonderful, as I've said. I had to change GPs because I wasn't happy with one of my GP. The current GP, I had a good chat to him, and we started from the base, and that's when we discovered that I had severe hypertension and thus I had severe left ventricular hypertrophy. I'm very happy with what he's done. Support from my family, my immediate family is always very good. They make sure I don't -- sometimes they're just a bit too much and make sure I'm not carrying stuff or -- they're gushing a bit much. I think before the AF, my immediate family kind of thought she's okay, she'll be fine, and that's how it's always been done. I think that's why my brother was so devastated when I got sick, I would say, because he didn't actually realise how serious -- although, yeah. Yeah, so no. I don't know. Everyone's great.
Participant 034_2023AUHBV

No. Other than no. No other than the allied health dietitian No.
Participant 001_2023AUHBV

PARTICIPANT: My GP.
INTERVIEWER: Yup.
PARTICIPANT: My cardiologist.
INTERVIEWER: Yup.
PARTICIPANT: The team at NAME HOSPITAL.
Participant 033_2023AUHBV

Participant describes that they did not receive any formal support

No, not yet.
Participant 003_2023AUHBV

No. I can't say I have received any. No.
Participant 039_2023AUHBV

Participant describes getting care and support from family and friends

Only from my wife. My wife and children, but that's just normal love and affection, but no, nothing else.
Participant 038_2023AUHBV

No. Nothing. The only support I've really got is my daughter. It's just basically what I've got.
Participant 042_2023AUHBV

Well it's my immediate family have been my main support and carers. I stayed with my parents for a week and a half, I think it was after I had the open-heart surgery. I've got a daughter who's 26 so she came around and helped me do quite a few things when I couldn't do them. Carers. I've never had a carer. Paid care or anything like that. Just my family really. They've been my support group. My friends. Health workers I've had the cardiac nurse just after surgery so that was good. I don't think there's anyone else. Participant 036_2023AUHBV

Participant describes that they did not need or seek help or support

So only the initial cardiac rehab which which like I said earlier, I didn't find that in any way helpful or. More supportive? No. So other than that, no, no, not really. And I, but I also haven't gone and thought any. I haven't gone and thought the support either.
Participant 009_2023AUHBV

Nothing really. I mean my GP has been fantastic. We don't talk about it much. I just go there and he gives me the scripts and off I go. And family and friends, I think some of my friends don't even know. So I think it's been a non-event with everybody really.
Participant 037_2023AUHBV

Participant describes getting care and support from domestic services and/or home care

I did receive home help for about six weeks once I got home from hospital to assist with cleaning. It was very frustrating because they could vacuum most of the house but not my children's bedrooms because that didn't really impact. They were there for me and not the kids. I found that very frustrating because I would have to still vacuum after they left.
Participant 047_2023AUHBV

INTERVIEWER: My next question is, have you received any support from health and community services to help manage the impact of your stroke since getting home? PARTICIPANT: Yes.
INTERVIEWER: Where did you have that support from? PARTICIPANT: Homecare.
Participant 040_2023AUHBV

Participant describes the challenges of finding or accessing support

That's a really good question, because I haven't asked for any care, as such, and I'll tell you why. Because I'm too embarrassed, and I really feel that I should do this by myself or with my wife. We're at the stage where we have been offered home care and all that sort of stuff. But we haven't accepted it, mainly because of embarrassment. As I see it, we're in this transition period of being totally dependent, or independent, rather, independent, and it looks like we're gonna have to move across to be dependent on other people. We're in that period where -- I mean, I'm flat out cleaning the shower, and I can run around with a vacuum cleaner, but to clean the shower is a bit challenging. But then I can call on a family member and they're probably gonna do it for me.
Participant 031_2023AUHBV

I currently see a psychologist and it's NDIS. She's an amazing woman. I call it giggle therapy because I don't know how, but we manage to just sit there and giggle for nearly an hour once a fortnight, which is amazing within itself because laughter makes you feel better. She's also a listening ear. Things are a bit tough for us. The cardiologist just let me down because he hasn't rung or because the neurologist was unable to give me any new advice or thoughts and just told me, "Yes, all good. See you in another six months." Whatever the case, she's been a good ear. Apart from that, no, I've just really had to advocate for myself and really speak clearly to the professionals about what I want, how I plan on achieving it, and what I need from them.
Participant 050_2023AUHBV

Participant describes getting care and support from peer support or other patients

PARTICIPANT: Yes, the cardiomyopathy association of Australia.
INTERVIEWER: Okay. And is that all online?
PARTICIPANT: No, we have meetings
INTERVIEWER: Yeah? That's great.

PARTICIPANT: And a seminar, I've been to some.
INTERVIEWER: Yeah.
PARTICIPANT: It's really good, and through that I've met two other women my age with defibrillators, and they're good mates, so we catch up every month or so.
INTERVIEWER: Wonderful.
Participant 032_2023AUHBV

Yeah, so I think from healthcare workers, patient groups have provided support, friends and family. So, after surgery usually, the church organised a meal also. People bring around meals for us, or just come round and do the folding, or do something like that. I have a cleaner coming every fortnight, or sorry, once a month now, because I don't need them once a fortnight anymore, and so once a month, just to do the big clean of the house- --and then we just maintain it in between, which is a great help. So yeah, and they're the main supports I've had. I've never had community services in or nursing services in to help me after any of the surgeries or anything.
Participant 030_2023AUHBV

Table 7.16: Experience of care and support

Care and support received	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes getting care and support from hospital or clinical setting	15	31.91	5	27.78	10	34.48	3	33.33	4	23.53	8	38.10	10	37.04	5	25.00
Participant describes that they did not receive any formal support	13	27.66	**8**	**44.44**	**5**	**17.24**	**4**	**44.44**	4	23.53	5	23.81	7	25.93	6	30.00
Participant describes getting care and support from family and friends	9	19.15	2	11.11	7	24.14	2	22.22	**1**	**5.88**	6	28.57	4	14.81	5	25.00
Participant describes that they did not need or seek help or support	7	14.89	2	11.11	5	17.24	1	11.11	3	17.65	3	14.29	5	18.52	2	10.00
Participant describes getting care and support from domestic services and/or home care	7	14.89	3	16.67	4	13.79	1	11.11	4	23.53	2	9.52	4	14.81	3	15.00
Participant describes the challenges of finding or accessing support	5	10.64	**0**	**0.00**	5	17.24	**0**	**0.00**	**4**	**23.53**	1	4.76	3	11.11	2	10.00
Participant describes getting care and support from peer support or other patients	4	8.51	1	5.56	3	10.34	1	11.11	1	5.88	2	9.52	3	11.11	1	5.00
Participant describes getting care and support from charities	3	6.38	0	0.00	3	10.34	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes getting care and support from psychologist or counselling service	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00
Participant describes getting care and support from public or private health subsidies	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

Care and support received	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes getting care and support from hospital or clinical setting	15	31.91	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they did not receive any formal support	13	27.66	8	30.77	7	33.33	7	29.17	8	34.78	6	40.00	9	28.13	7	28.00	8	36.36
Participant describes getting care and support from family and friends	9	19.15	8	30.77	5	23.81	8	33.33	5	21.74	**2**	**13.33**	11	34.38	8	32.00	5	22.73
Participant describes that they did not need or seek help or support	7	14.89	3	11.54	6	28.57	4	16.67	5	21.74	3	20.00	6	18.75	4	16.00	5	22.73
Participant describes getting care and support from domestic services and/or home care	7	14.89	2	7.69	5	23.81	4	16.67	3	13.04	**4**	**26.67**	3	9.38	5	20.00	2	9.09
Participant describes the challenges of finding or accessing support	5	10.64	2	7.69	5	23.81	3	12.50	4	17.39	2	13.33	5	15.63	2	8.00	5	22.73
Participant describes getting care and support from peer support or other patients	4	8.51	4	15.38	1	4.76	1	4.17	4	17.39	2	13.33	3	9.38	3	12.00	2	9.09
Participant describes getting care and support from charities	3	6.38	3	11.54	1	4.76	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64
Participant describes getting care and support from psychologist or counselling service	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	0	0.00	3	9.38	0	0.00	3	13.64
Participant describes getting care and support from public or private health subsidies	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55

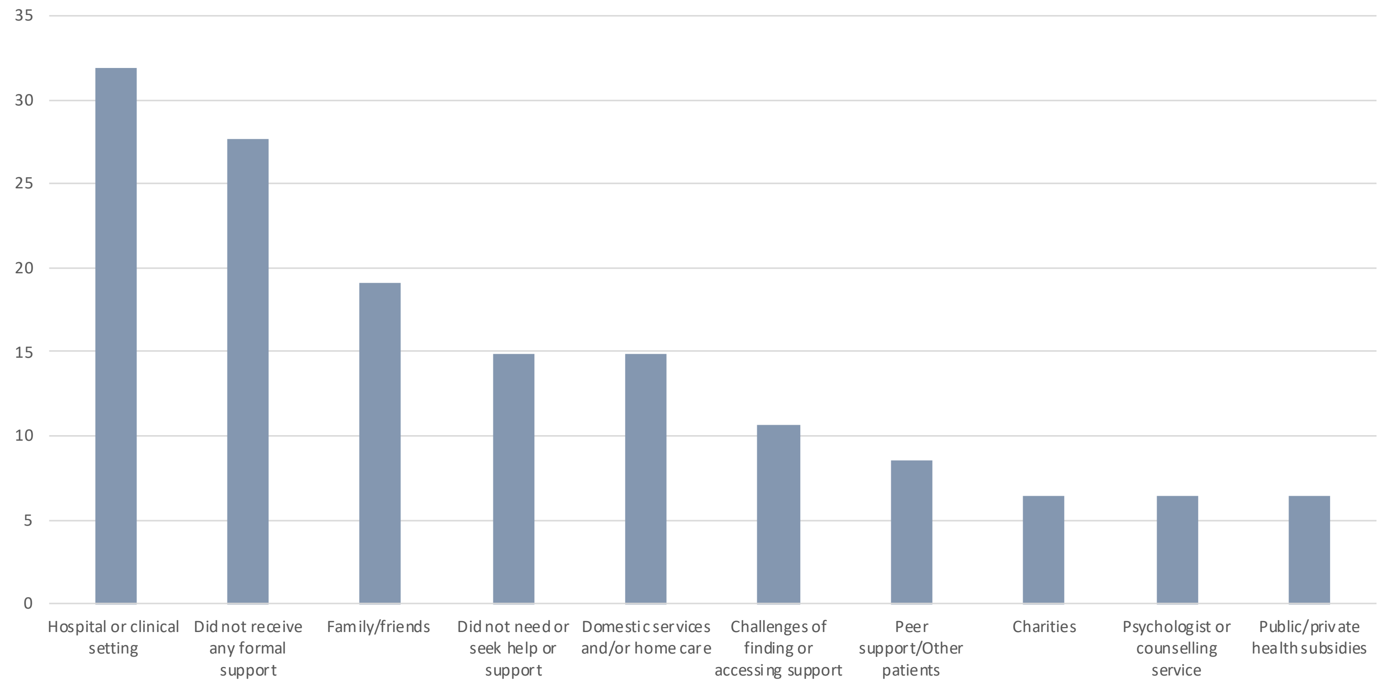

Figure 7.36: Experience of care and support

Table 7.17: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes that they did not receive any formal support	Did not had LP(a) test Regional or remote	Had LP(a) test High cholesterol under 50 years of age
Participant describes getting care and support from family and friends	Blood vessel conditions	-
Participant describes that they did not need or seek help or support	-	Regional or remote
Participant describes the challenges of finding or accessing support	Had LP(a) test High cholesterol under 50 years of age	Blood vessel conditions

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life(10.64%), overall positive impact on quality of life (8.51 %). overall no impact on quality of life (6.38%), and a mix of positive and negative impact on quality of life (4.26%).

The most common themes in relation to a negative impact on quality of life were emotional strain, including family or change in relationship dynamics (38.30%), reduced capacity for physical activity, needing to slow down (29.79%), and managing side effects and symptoms (23.40 %). Other themes included emotional strain on self (21.28%), reduced social interaction (17.02%), altering lifestyle to manage condition (8.51%), and inability to work or changes with their work (8.51%).

The most common theme in relation to a positive impact on quality of life were that it brings people together and highlights supportive relationships (14.89%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (70.21%). There were 4 participants (8.51%) that indicated no impact and 10 participants (21.28%) that did not describe impact on mental health or had a mixed experience.

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. The most common responses were consulting a mental health professional (21.28%), mindfulness and/or meditation(21.28%), and the importance of physical exercise (17.02 %). Other activities included remaining social and having hobbies (8.51%), and taking medication (8.51%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were doing physical exercise or being physically active (46.81%), self care for example more rest, accepting help, pacing themselves (40.43%), and maintaining a healthy diet (36.17 %). Other activities included complying with treatment or management of their condition (23.40%), mindfulness and/or meditation (19.15%), making healthy lifestyle changes (10.64%), maintaining a healthy weight (8.51%), and managing stress (8.51%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%). Other times they felt vulnerable included during diagnostic procedure (14.89%), thinking about disease course or that they have an incurable condition (14.89%), during or after treatments (10.64%) and when feeling sick/unwell (8.51%). There were 7 participants (14.89%) that did not feel vulnerable.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (10.64%), and being unsure how vulnerability can be managed (4.26 %).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (38.30%), and overall, there no impact on relationships (31.91%). Other themes included overall, there was a positive impact on relationships (14.89%), and overall, there was an impact on relationships that was both positive and negative (10.64%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (31.91%), and from people not knowing what to say or do and withdrawing from relationships (10.64%). Other themes included because of people not believing the impact that condition has on health (6.38%), and because of intimacy challenges (4.26%).

The most common themes in relation to having a positive impact on relationships were from people being well-meaning and supportive (17.02%), and from family relationships being strengthened (8.51%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was not a burden on their family (51.06%), overall, there was a burden on their family (44.68%), and overall, there was not a burden on their family now but they anticipate this will change in the future (6.38 %).

The main reason that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (17.02%), that the burden was temporary or only during treatment (14.89%), and the mental/emotional strain placed on their family (10.64%).

The main reason that participant described their condition not being a burden were that they were very independent (14.89%), and they have a very supportive family and were not a burden (6.38%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (51.06%), and overall, there was no cost burden (23.40%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (27.66%), diagnostic tests and scans (17.02%), and needing to take time off work (17.02 %). Other themes included the cost specialist appointments (14.89%), cost of gap payments (12.77%), needing to buy special equipment (10.64%), allied health care (8.51%), and GP appointments (8.51%).

Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the public health system (17.02%), the participant was able to afford all costs (10.64%), and nearly everything was paid for through the private health system (8.51 %).

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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.
The average score was in the Life was a little distressing to average range (median=3.50, IQR=3.00).

Experience of anxiety related to disease progression

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (65.96%). Others described overall a minimal impact on quality of life(10.64%), overall positive impact on quality of life (8.51 %). overall no impact on quality of life (6.38%), and a mix of positive and negaitve impact on quality of life (4.26%).

The most common themes in relation to a negative impact on quality of life were emotional strain, including family or change in relationship dynamics (38.30%), reduced capacity for physical activity, needing to slow down (29.79%), and managing side effects and symptoms (23.40 %). Other themes included emotional strain on self (21.28%), reduced social interaction (17.02%), altering lifestyle to manage condition (8.51%), and inability to work or changes with their work (8.51%).

The most common theme in relation to a positive impact on quality of life were that it brings people together and highlights supportive relationships (14.89%).

Experience described suggests that there was an overall negative impact on quality of life

I would say yes. I don't. I don't go to the gym anymore. So my son and my oldest son and I used to go to the gym all the time. I just a lot of strain to go there and do all that. I don't go mountain bike riding with my friends anymore. So yeah, there's it has limited my my socialization there. You know it's put a lot of I guess my kids are aware of everything as well. So you know they know when I'm tired, they know when you know how far I can walk and and all that sort of stuff. So they try to be really upbeat and everything about it for me.
Participant 028_2023AUHBV

PARTICIPANT: My quality of life now, I just stay home because I'm too embarrassed to go out and I'm too ashamed to go out. A couple of times, people, they've spoken to me in general conversation. I got more confused. I been laughed at. That's why, now, I don't go anywhere now.
INTERVIEWER: I get the sense it's been really difficult for you.
PARTICIPANT: It has been very hard.
Participant 042_2023AUHBV

Look it definitely affects it. There's a lot of stuff that I don't do. I don't go roller-skating with my daughter. I don't go jogging with my son. If, they were to go snow skiing in the winter I don't feel that I could do that. I think I'd get halfway through you know as I'm with them, and I'd be exhausted. There is a lot that I don't do. I have adapted to that fact, and there's a lot of stuff that we do, do together instead of. It doesn't affect me mentally like it used to. I've adjusted emotionally to the fact that what I can't do anymore. It definitely has affected my quality of life. For sure.
Participant 036_2023AUHBV

Well, I had to stop working immediately. Basically had close to two years without working with no income at all. Yes, my social life and everything else, I had quite a young…I had a five-year-old at the time. All that stuff that I used to be able to do was significantly impacted. Yes, from time to time even now there are times where I can't get off the couch.
Participant 043_2023AUHBV

Experience described suggests that there was overall a minimal impact on quality of life

Initially, it probably did. My children were all a bit wary about how much I could do to help with the grandchildren and stuff. But then as time went on and and all the issues were resolved and, you know, that hasn't been an issue any longer and it certainly hasn't affected anything, you know, with my husband and I.
Participant 013_2023AUHBV

With my family now? No. Maybe before.
Participant 026_2023AUHBV

Experience described suggests that there was an overall positive impact on quality of life

Yeah. Yeah. So I guess the answer, it's like I'm gonna actually just go out on the thing and say that it's affected it and in a the overall bottom line, it's like a more positive thing. Yep. Yeah. Yeah. And that's just cuz I probably have more awareness of my body. And for me I am someone that hey, like if I take the time to do some some research and you know and and take some extra steps and behavior change because I've I've I've made some positive changes. I you know I kind of get that effect that mental health effect where it's like hey like I'm getting like good endorphins. I'm doing a bit more exercise and yeah, like, I'm just receiving some, some upside because I've made some

of these behavior changes, lifestyle changes, yeah. So it's overall good. It's a plus.
Participant 001_2023AUHBV

No, I think if anything, my family's. Become a lot more closer, a lot more supportive with the diagnosis. Certainly they haven't distanced themselves which has been great. So it's all been very positive on that front. And you know, if I need to talk though, they're very good listeners.
Participant 011_2023AUHBV

My family, I've got two boys. One's in LOCATION OVERSEAS and one's in LOCATION METROPOLITAN. They both ring me. The one in LOCATION OVERSEAS rings me, and we go on FaceTime for half an hour or so, the one in LOCATION METROPOLITAN ringed me every two or three days, and I ring him too. My wife's family keep touch with me, but not a lot. My younger sister-in-law is in the same boat as me, she is very healthy but she has lost her husband, and she understands my problems, I suppose, because she's got the same things on her. She helps me and I help her
Participant 048_2023AUHBV

Experience described suggests that there was overall no impact on quality of life

No, I don't think so.
Participant 005_2023AUHBV

I don't think it has had a great deal of effect because I've been pretty active. I get tired, but I just put that down to just running around after everybody. But I don't put it down to my heart condition. I sort of don't think about it.
Participant 037_2023AUHBV

Experience described suggests that there was a mix of positive and negative impact on quality of life

PARTICIPANT: Long-term, it doesn't anymore. I think initially because I had to rely on my husband quite a lot, and he was looking after a new-born and me, it made it quite stressful for him. For me, it meant we had to rely on family a lot, a lot more than I would've liked too. But now, I mean our quality of life is fantastic. We have no, it basically doesn't really impact us long-term. That's as my health has improved.
INTERVIEWER: Just that your little boy is going to be an only child?
PARTICIPANT: Yes. But that was quite difficult initially, but we've very much come to terms with that. So we went through a grieving process, that we couldn't have any more children, but now we are okay with that and he's a very, very happy loved little boy. So there's no, we feel like there are things that we can give him more of now that we can't have, so while we have had some loss in that, we've also had some gains.
Participant 035_2023AUHBV

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Experience described suggests that there was an overall negative impact on quality of life	31	65.96	13	72.22	18	62.07	**4**	**44.44**	12	70.59	15	71.43	17	62.96	14	70.00
Experience described suggests that there was overall a minimal impact on quality of life	5	10.64	2	11.11	3	10.34	**2**	**22.22**	1	5.88	2	9.52	3	11.11	2	10.00
Experience described suggests that there was an overall positive impact on quality of life	4	8.51	2	11.11	2	6.90	**2**	**22.22**	2	11.76	0	0.00	2	7.41	2	10.00
Experience described suggests that there was overall no impact on quality of life	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	2	4.26	0	0.00	2	6.90	0	0.00	0	0.00	2	9.52	1	3.70	1	5.00
No particular comment	2	4.26	0	0.00	2	6.90	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Impact on quality of life	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Experience described suggests that there was an overall negative impact on quality of life	31	65.96	18	69.23	13	61.90	**13**	**54.17**	**18**	**78.26**	11	73.33	20	62.50	15	60.00	16	72.73
Experience described suggests that there was overall a minimal impact on quality of life	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	**0**	**0.00**	5	15.63	4	16.00	1	4.55
Experience described suggests that there was an overall positive impact on quality of life	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	2	13.33	2	6.25	3	12.00	1	4.55
Experience described suggests that there was overall no impact on quality of life	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	2	4.26	0	0.00	2	9.52	2	8.33	0	0.00	1	6.67	1	3.13	1	4.00	1	4.55
No particular comment	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55

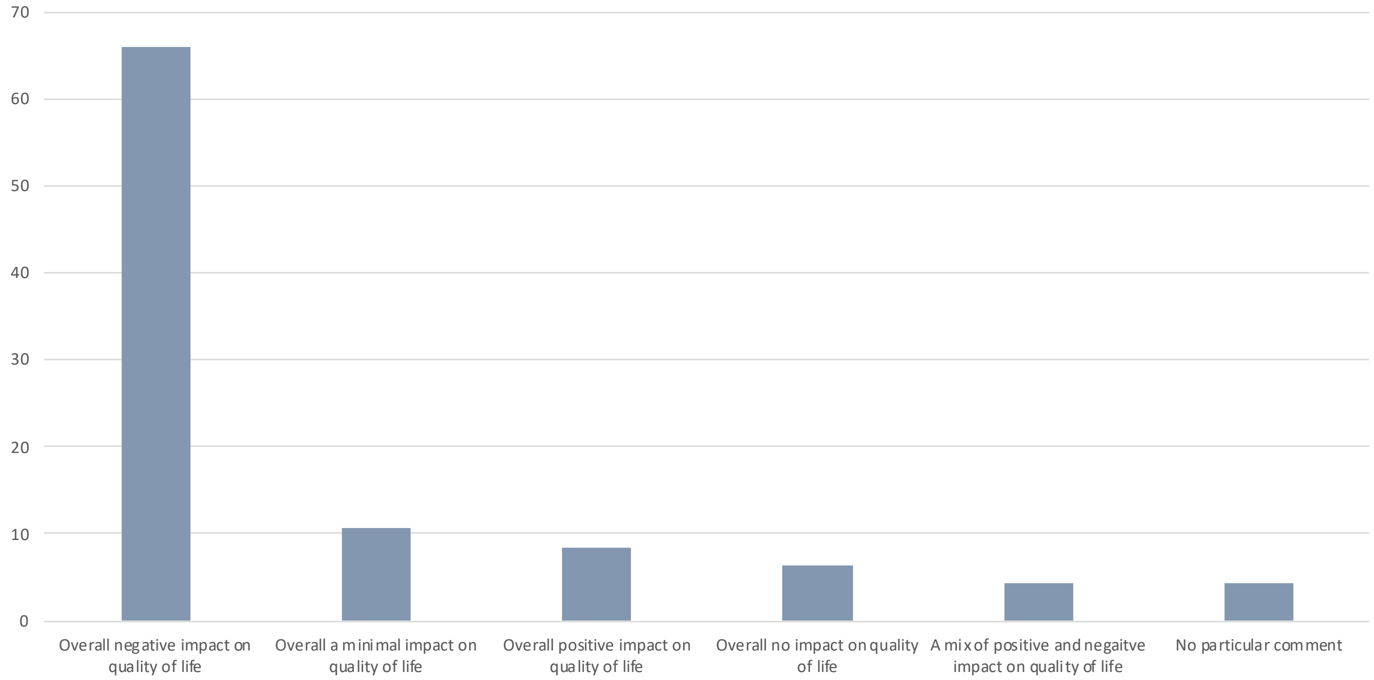

Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Experience described suggests that there was an overall negative impact on quality of life	High cholesterol under 50 years of age Aged 25 to 44	Aged 45 and older
Experience described suggests that there was overall a minimal impact on quality of life	Regional or remote	High cholesterol under 50 years of age
Experience described suggests that there was an overall positive impact on quality of life	-	High cholesterol under 50 years of age

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	18	38.30	6	33.33	12	41.38	3	33.33	6	35.29	9	42.86	9	33.33	9	45.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	14	29.79	4	22.22	10	34.48	2	22.22	4	23.53	8	38.10	7	25.93	7	35.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	11	23.40	5	27.78	6	20.69	3	33.33	4	23.53	4	19.05	6	22.22	5	25.00
Participant describes a negative impact on quality of life due to the emotional strain on self	10	21.28	4	22.22	6	20.69	**1**	**11.11**	**1**	**5.88**	**8**	**38.10**	6	22.22	4	20.00
Participant describes a negative impact on quality of life due to reduced social interaction	8	17.02	**6**	**33.33**	**2**	**6.90**	**3**	**33.33**	3	17.65	2	9.52	4	14.81	4	20.00
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	4	8.51	2	11.11	2	6.90	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00
Participant describes a negative impact on quality of life due to inability to work/changes with their work	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	4	14.81	0	0.00
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	3	6.38	0	0.00	3	10.34	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes a minimal impact on quality of life that has a general or temporary impact	5	10.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	3	11.11	2	10.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	7	14.89	3	16.67	4	13.79	2	22.22	2	11.76	3	14.29	4	14.81	3	15.00
Participant describes no impact on quality of life	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

Impact on quality of life (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	18	38.30	9	34.62	9	42.86	9	37.50	9	39.13	7	46.67	11	34.38	7	28.00	11	50.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	14	29.79	8	30.77	6	28.57	5	20.83	9	39.13	5	33.33	9	28.13	5	20.00	9	40.91
Participant describes a negative impact on quality of life due to managing side effects and symptoms	11	23.40	7	26.92	4	19.05	5	20.83	6	26.09	3	20.00	8	25.00	5	20.00	6	27.27
Participant describes a negative impact on quality of life due to the emotional strain on self	10	21.28	8	30.77	2	9.52	3	12.50	7	30.43	2	13.33	8	25.00	4	16.00	6	27.27
Participant describes a negative impact on quality of life due to reduced social interaction	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes a negative impact on quality of life due to inability to work/changes with their work	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	0	0.00	4	18.18
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes a minimal impact on quality of life that has a general or temporary impact	5	10.64	3	11.54	2	9.52	2	8.33	3	13.04	1	6.67	4	12.50	4	16.00	1	4.55
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	7	14.89	3	11.54	4	19.05	5	20.83	2	8.70	5	33.33	2	6.25	5	20.00	2	9.09
Participant describes no impact on quality of life	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

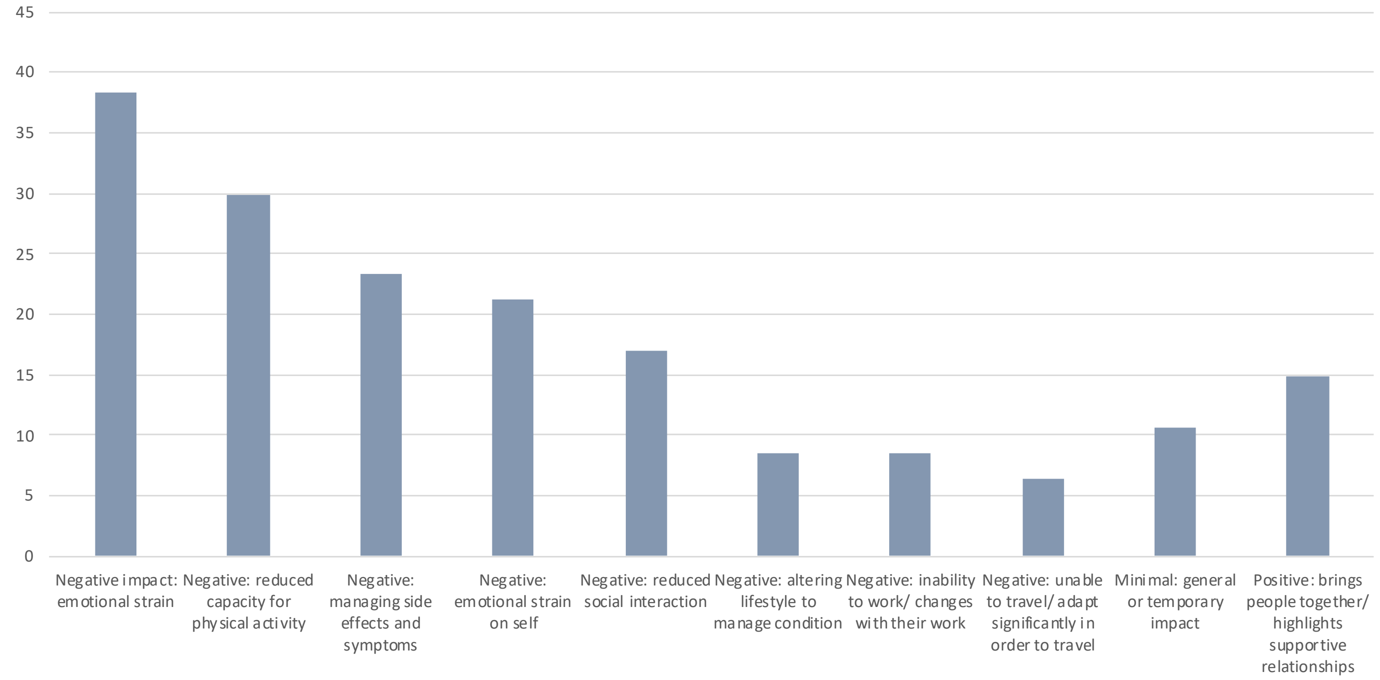

Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Impact on quality of life (reasons)	Reported less frequently	Reported more frequently
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	-	Higher socioeconomic status
Participant describes a negative impact on quality of life due to the emotional strain on self	High cholesterol under 50 years of age Blood vessel conditions Male	Heart conditions
Participant describes a negative impact on quality of life due to reduced social interaction	Did not had LP(a) test	Had LP(a) test High cholesterol under 50 years of age
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	-	Regional or remote

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (70.21%). There were 4 participants (8.51%) that indicated no impact and 10 participants (21.28%) that did not describe impact on mental health or had a mixed experience.

Table 8.5: Impact on mental health

Impact on mental health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Experience described suggests that overall, there was at least some impact on mental health	33	70.21	14	77.78	19	65.52	6	66.67	17	100.00	10	47.62	17	62.96	16	80.00
Other or mixed experience	10	21.28	2	11.11	8	27.59	1	11.11	0	0.00	9	42.86	7	25.93	3	15.00
Experience described suggests that overall, there was no impact on mental health	4	8.51	2	11.11	2	6.90	2	22.22	0	0.00	2	9.52	3	11.11	1	5.00

Impact on mental health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Experience described suggests that overall, there was at least some impact on mental health	33	70.21	21	80.77	12	57.14	18	75.00	15	65.22	12	80.00	21	65.63	20	80.00	13	59.09
Other or mixed experience	10	21.28	4	15.38	6	28.57	4	16.67	6	26.09	3	20.00	7	21.88	2	8.00	8	36.36
Experience described suggests that overall, there was no impact on mental health	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	0	0.00	4	12.50	3	12.00	1	4.55

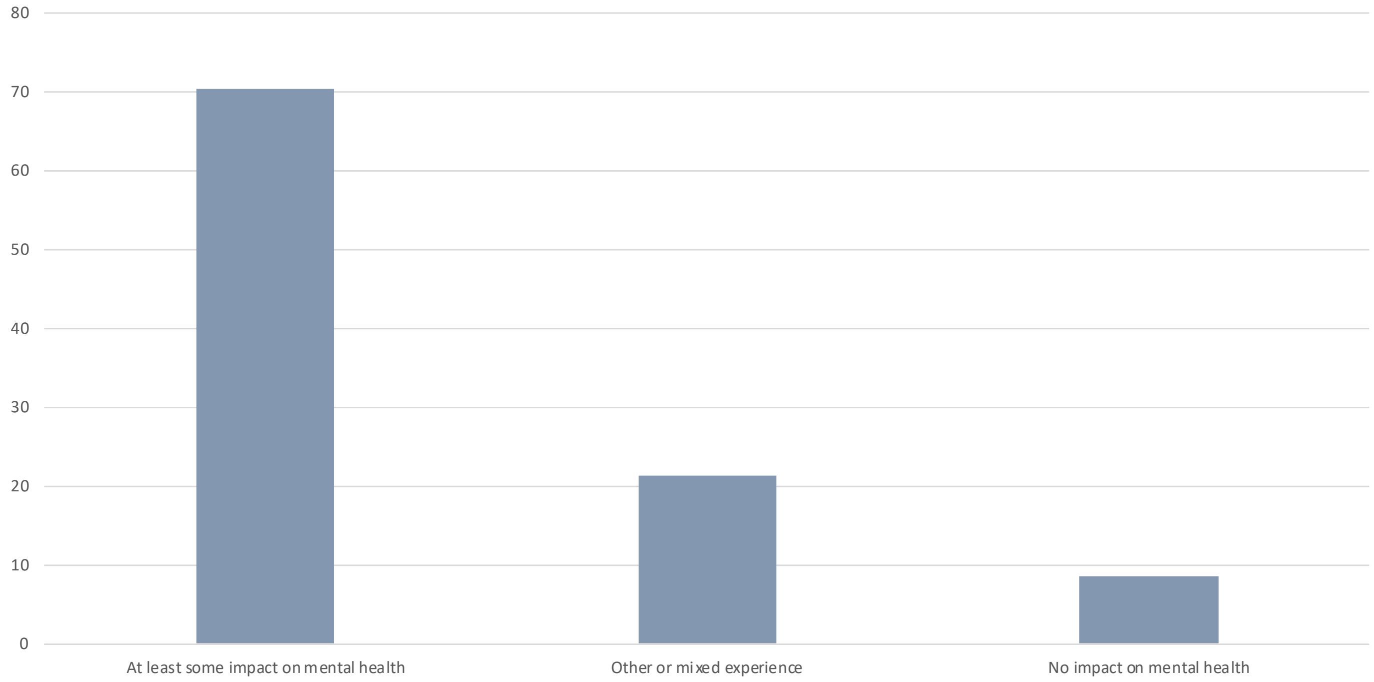

Figure 8.3: Impact on mental health

Table 8.6: Impact on mental health – subgroup variations

Impact on mental health	Reported less frequently	Reported more frequently
Experience described suggests that overall, there was at least some impact on mental health	Heart conditions Male Higher socioeconomic status	Blood vessel conditions Female
Other or mixed experience	Had LP(a) test High cholesterol under 50 years of age Blood vessel conditions Mid to low socioeconomic status	Heart conditions Higher socioeconomic status
Experience described suggests that overall, there was no impact on mental health	-	High cholesterol under 50 years of age

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. The most common responses were consulting a mental health professional (21.28%), mindfulness and/or meditation(21.28%), and the importance of physical exercise (17.02 %). Other activities included remaining social and having hobbies (8.51%), and taking medication (8.51%).

Participant describes consulting a mental health professional to maintain their mental health

Yes. It's very emotional. Some days I'm really good and others are not. I did see a psychologist for a while to help with that. Probably a grieving of how my life had changed. It is something I probably should do all the time.
Participant 047_2023AUHBV

I just see my psychiatrist every three weeks. I see my doctor every week. That's basically it.
Participant 042_2023AUHBV

Yes. And yes. It's. It's definitely increases my anxiety as I've lent into the chaos. Yeah, really wanting to find out more information. So yeah, increasing anxiety and it having regular counseling appointments and also discussing the up to date things with the close family and friends.
Participant 003_2023AUHBV

Participant describes mindfulness and/or meditation to maintain their mental health

So I work with my GP around mindfulness and breathing and meditation. She's actually quite holistic in that regard, which I quite like live near the beach. So I quite often like to, even if I'm not well enough to walk, I'm going and get a close car park and just sit and watch the world go by and and be like work on my mental health, work on stress and a big thing. Like, I wouldn't say that I suffer from anxiety, but the fact of not having an income has really been a big source of anxiety for me and the fact that I can't help that right now. So yeah, that mindfulness, I I don't go to like a psychologist or anything like that. My cardiologist, when I told him that I just wanted my life back and I ended up crying with him last last appointment. That was before I started the culture saying last appointment and he prescribed antidepressants for me and that was not helpful at all. I'm not depressed. I don't want to end my life. I want my life back. There is a huge bring the two. So my my GP was really quite upset that that happened because my mental health at that point was good and then I started doubting myself about things. But anyway, I've come, I started it, it was awful. I've come off it. I don't have depression. I'm just frustrated.
Participant 014_2023AUHBV

One of the things I learned early was I needed to retrain my brain. Setting off on that adventure and being positive about it meant that the depression disappeared. That having a goal and creating a goal was probably the most important thing I could have done in terms of my rehab. My mental health is quite sound. Mentally, I get frustrated when my memory fails. Like most stroke survivors, your memory is at its weakest when you're tired. I feel frustration. I no longer feel sadness or depression, I just get pretty bloody frustrated when I can't remember somebody's name.
Participant 045_2023AUHBV

Participant describes the importance of physical exercise to maintain their mental health

Yes, I do. I walk every morning when I'm out there. I'm meditating. Most mornings, me and my dog, we go walking. It's good for my mental health, you know, and my emotions, you know.
Participant 025_2023AUHBV

It hasn't. How would I say this? It hasn't made a big change to my mental health yet but sees it's only early days and I'm still trying to work hard being hopeful at getting back to where I was. If that doesn't work, I think I'm going to go through a grieving process. If I can't drive that's going to really affect me because I'll be-- Because I'm a single woman it'll really change my life and that will be hard. I do all most physical activities which help mental health and I keep myself busy in my house that helps mental health. I've not been a good person with social media, I don't really understand it. I've not been able to develop a social media contact with people and I don't own a computer, I just own a phone. That's probably something I need to work on otherwise I'm going to get really lonely if I can't drive.
Participant 041_2023AUHBV

I think the the the main problem that I have at the moment is not not being able to do as as much as I want. And so I'm working with a exercise physiologist because it it it it's quite hard and frustrating when because it takes a long time to build up your energy levels and what you can do. It doesn't just happen overnight. You can sometimes think oh I'm I'm never going to get get there and so I'll give up But with the exercise physiologist you know you can talk through those things and work out strategies and where where you will be and those sorts of things. So it just keep keeps you motivated to and to keep on track. And I found it going out to sort of organized app aerobics and things like that helpful because if you're just doing it at home on yourself by yourself, your motivation means and you don't do it. Whereas if you've got a fixed time, fixed day where the classes are run, you can actually make yourself get there. So I found that helpful as well. And I've been lucky because the classes that I've gone to, the people have been very sort of welcoming. They're older people and they're very welcoming and friendly and so, you know, you haven't got a sterile environment or competitive environment that you're you're going into, which is nice. You feel that you can just get on and do as much as you can. Nobody's judging or trying to make you do more that sort of thing.
Participant 017_2023AUHBV

Participant describes remaining social and hobbies to maintain their mental health

Yes, I think initially it really did. And there and and it and when I've had these I recall those whoopsie turns that that does upset me and it affects me because it's something I would rather not happen and I have to try and work out how we're going to stop it happening. But I when I'm you know identifying why the cause. Yeah. So then you think well what can I do. And it's about relieving I and I and I've worked out myself that it's stressed, so I've, you know, changed some things in my life to remove that level of stress, all those external things. I've always been a very active community person and taken on lots of jobs and things which I'm not doing now.
Participant 013_2023AUHBV

So it does on occasion, but I never have a great. Two week anniversary in July, August so and I I had my defib, my defib was implanted on my birthday. So it sort of had it. It's a bit triggering because it wasn't a great day in my life in some ways, but and I have had ups and downs along the way. When I'm told you know you, you think that there's an end goal like in 12 months time I'll be able to run again and then it's like, no, no, no, you can't do that ever again. Like so you have ups and downs, but day-to-day I I don't have an ongoing anxiety or depression or I don't feel down about it. I have days where I think you know, that was you know, you know what? What with me moments where I think, bloody hell, you know, I could have been doing. 1/2 marathon or something And you know, stop winding that you don't like running, at least you can run like I, but we all have days like that, you know. So it's really, I'd say the worst, that it's going well and to be going. And I did seek help through psychologists at at the time when it was the worst initially. I just find other ways. I can't run anymore, but I do other things just to, you know, just doing the voids. So, you know, not, not anything in particular.
Participant 009_2023AUHBV

Participant describes pacing and taking medication to maintain their mental health

From the stroke, I got anxiety. I take medication for that. I have a psychologist I see on a regular basis. I've been seeing a psychologist for 30-odd years now just to keep me on track. I hate the person I am because of the stroke, because I could do so many other things before my stroke that I can't do now and that I miss. It's also about I'm alive and I can function pretty well, so I'm lucky to be here. It has a negative and a positive thing.
Participant 049_2023AUHBV

Well, it did it. It gave me all sorts of anxiety to begin with. And I'm I was medicated for that and I've chosen to stay on that medication. So that I don't go back to being like that. Excellent, because it was quite frightening.
Participant 005_2023AUHBV

Participant describes no activities to maintain mental health to maintain their mental health

I don't and I should. I know I should because my emotion-- I've sort of developed a very short temper, unfortunately.
Participant 043_2023AUHBV

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes consulting a mental health professional to maintain their mental health	10	21.28	3	16.67	7	24.14	3	33.33	5	29.41	2	9.52	6	22.22	4	20.00
Participant describes mindfulness and/or meditation to maintain their mental health	10	21.28	4	22.22	6	20.69	1	11.11	5	29.41	4	19.05	6	22.22	4	20.00
Participant describes the importance of physical exercise to maintain their mental health	8	17.02	5	27.78	3	10.34	2	22.22	4	23.53	2	9.52	4	14.81	4	20.00
Participant describes remaining social and hobbies to maintain their mental health	4	8.51	2	11.11	2	6.90	1	11.11	2	11.76	1	4.76	2	7.41	2	10.00
Participant describes pacing and taking medication to maintain their mental health	4	8.51	2	11.11	2	6.90	0	0.00	4	23.53	0	0.00	2	7.41	2	10.00
Participant describes no activities to maintain mental health to maintain their mental health	3	6.38	3	16.67	0	0.00	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Participant describes pacing and not taking on too much/saying 'no' to maintain their mental health	3	6.38	2	11.11	1	3.45	0	0.00	1	5.88	2	9.52	2	7.41	1	5.00

Regular activities to maintain mental health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes consulting a mental health professional to maintain their mental health	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	3	20.00	7	21.88	7	28.00	3	13.64
Participant describes mindfulness and/or meditation to maintain their mental health	10	21.28	6	23.08	4	19.05	7	29.17	3	13.04	6	40.00	4	12.50	7	28.00	3	13.64
Participant describes the importance of physical exercise to maintain their mental health	8	17.02	7	26.92	1	4.76	7	29.17	1	4.35	4	26.67	4	12.50	5	20.00	3	13.64
Participant describes remaining social and hobbies to maintain their mental health	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes pacing and taking medication to maintain their mental health	4	8.51	3	11.54	1	4.76	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes no activities to maintain mental health to maintain their mental health	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	0	0.00	3	9.38	0	0.00	3	13.64
Participant describes pacing and not taking on too much/saying 'no' to maintain their mental health	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	3	12.00	0	0.00

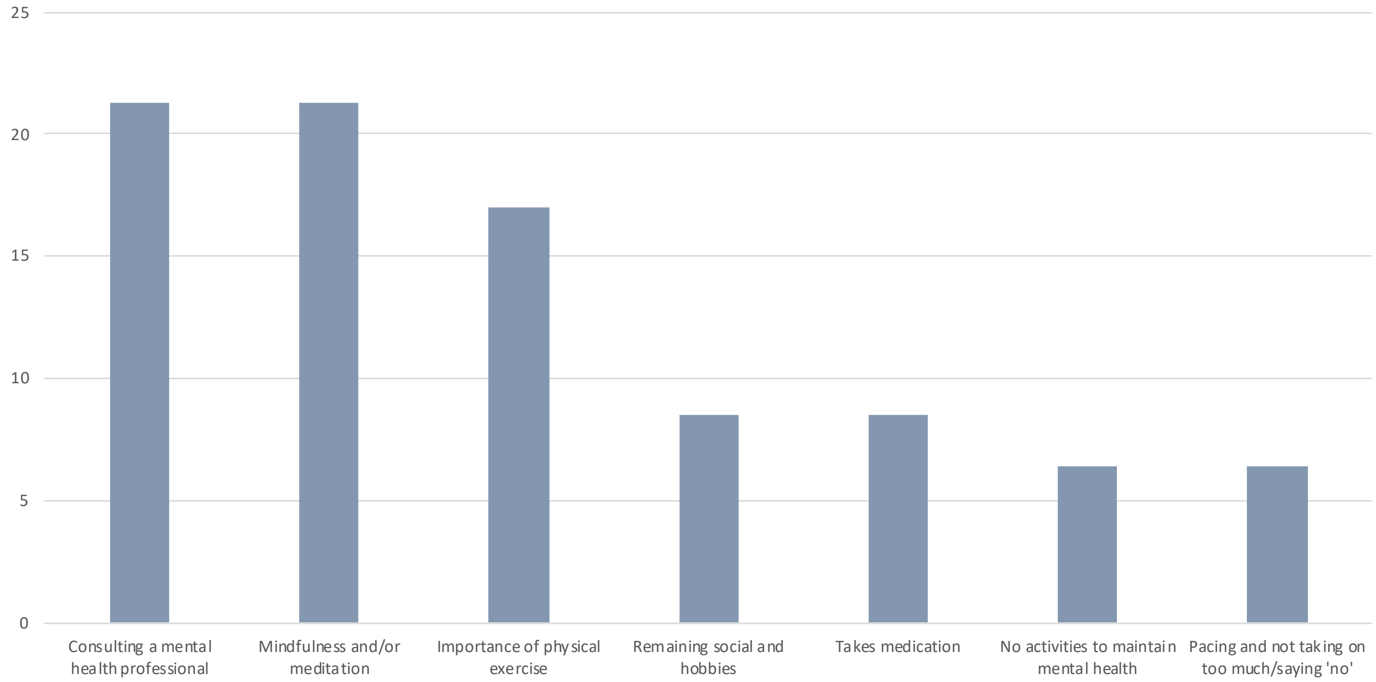

Figure 8.4: Regular activities to maintain mental health

Table 8.8: Regular activities to maintain mental health – subgroup variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes consulting a mental health professional to maintain their mental health	Heart conditions	High cholesterol under 50 years of age
Participant describes mindfulness and/or meditation to maintain their mental health	High cholesterol under 50 years of age	Regional or remote
Participant describes the importance of physical exercise to maintain their mental health	Male Aged 45 and older	Had LP(a) test Aged 25 to 44
Participant describes pacing and taking medication to maintain their mental health		Blood vessel conditions
Participant describes no activities to maintain mental health to maintain their mental health		Had LP(a) test

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were doing physical exercise or being physically active (46.81%), self care for example more rest, accepting help, pacing themselves (40.43%), and maintaining a healthy diet (36.17 %). Other activities included complying with treatment or management of their condition (23.40%), mindfulness and/or meditation (19.15%), making healthy lifestyle changes (10.64%), maintaining a healthy weight (8.51%), and managing stress (8.51%).

Participant describes the importance of doing physical exercise/physically active in maintaining their general health

What I what I do is I I walk most days. I won't say every day, but I do walk most days. And again I set a time for that. So if I'm watching a program or or I might say right, I'll go for walk after that finished or at 12:00 I'll go for a walk. I do do my three classes a Week 2 aerobics, water aerobics and one is in in the gym. So I I do that and I'm hoping to build, build up on that, put, you know, put more weights on, make them more

strenuous. I don't think it would be every day, but at least just increasing what I do on those days.
Participant 017_2023AUHBV

I work out. I find going to the work out when I'm not- so I find going to the gym very helpful. I work out because you get your body fit can help your mind to think.
Participant 039_2023AUHBV

Yeah, it's it's just keeping up with sort of my newer habits. Yeah. Because if I can do some exercises throughout the week, I mean, I I've got my, I'm keeping my physical conditioning and and then, of course, my mental health stays intact because I already get the pleasure of knowing that I've looked after my body, you know?
Participant 001_2023AUHBV

Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health

I need to make sure that I get lots of sleep. I need to make sure that I don't overdo things and if I overdo things I need to stop and just sleep. I also need to recognise that when I can feel that I am starting to get tired that I stop then and I don't push through things.
Participant 047_2023AUHBV

Well, I have to rest a huge amount. I have to pace myself really well. So do something and then lie down and rest and and try not to do things unless I'm able to. OK, very difficult.
Participant 019_2023AUHBV

I just need to watch my workload more than anything. I really need to really monitor how much I do in a particular day to make sure I'm not really sick the following day.
Participant 043_2023AUHBV

Participant describes the importance of maintaining a healthy diet in maintaining their general health

Yeah, I think about what I do, what size of portions etcetera so that I can control my cholesterol.
Participant 026_2023AUHBV

I definitely, yeah, definitely have a better diet now. Definitely take care of myself. I don't really ever drink. I've been drinking for months now. Yeah, it's just little basics I guess like that, that I've just changed up a bit to help myself beneficial in the future.
Participant 029_2023AUHBV

PARTICIPANT: Sleep is the main one. I just need to make sure I get a good night's sleep, and not overexert myself. My daughter got married last week.
INTERVIEWER: Oh that's lovely.
PARTICIPANT: The lead up to that was exhausting. I'm still exhausted. The wedding was on Friday and we're now what, Wednesday and I still feel like I could take a nap today, because of everything that has gone on then, and since. Yeah, so rest. I need to not exert myself too much. I need to make sure that I eat healthy for the most part. I still treat myself occasionally but I usually make sure I have fruit and veg. I'm not a huge meat eater. I just make sure I eat a little bit of protein through the day. I watch the weather app a lot. I'm always checking how hot it's going to be, and LOCATION METROPOLITAN is killing me today. I watch the weather and plan my activities around the weather. Rest and food. And that's about it. That's my life is revolving doors. Watching all those through things.
Participant 036_2023AUHBV

Participant describes the importance of complying with treatment/management in maintaining their general health

Because it does take it out of me, but I've been consistently going for six months now and I think that that's why I am where I am. So exercise has really helped. Of course, taking medication when you had to take it and how frequently you had to take it. Yeah. I think that those two things have helped me get my life back because I I live here, I have no family up here and my husband works away, so he's away nine months of the year. So it's just me and the kids. And I think I have kids that are capable as well. So I think that helps.
Participant 014_2023AUHBV

So basically I need to take my medication. I need to pace myself into what I'm doing. You know at the end of the day if I go at something to pull like a ball at a gate or over exert myself, I'm going to end up out of breath and with chest pain and yeah then nothing's going to get done. You know I suppose it's that whole you know slow and steady wins the race scenario. You know I just need to be mindful of what I'm doing, how I'm doing it and yeah literally not over exert myself I suppose. And one of the best examples of that is, is lifting things is one of those, you know. So obviously if I put too much strain on my right arm, I'll cause injury and and severe pain with the painkillers I take. I don't notice it when it's happening either.
Participant 018_2023AUHBV

Participant describes the importance of mindfulness and/or meditation in maintaining their general health

I'm very lucky. There's nothing I need to do other than other than stick to not raising my heart rate above where where I'll set my DC off. There's nothing I actually need to do. I probably just need to keep my keep, keep a positive mindset, just not let it get on top of me that you know. While we've made. But no, I'm lucky in that sense.
Participant 009_2023AUHBV

I need to keep moving. I can't allow myself to dwell on this unfortunate thing that happened to me. I need to turn what was an unfortunate experience into a positive experience. The thing that I've learned to do is to, "All right. I had a stroke. It knocked me around. What are you going to do about it?" That's why I volunteered with the Stroke Foundation. I refused to allow a stroke to upset my life and the life of my friends and my family. The best thing I've discovered is to decide not to be a victim.
Participant 045_2023AUHBV

Yeah. So the main things is to make sure that I get enough sleep and I do my meditation just to control my breathing and just keep my head in check and just just just to make sure that I'm reassuring myself that everything's good.
Participant 028_2023AUHBV

Participant describes the importance of making healthy lifestyle changes in maintaining their general health

Again, Is there anything I do every day I well, like I said, I go about smoking or that happened when the heart attack happened. Yep, that's finished. OK per detail of a few other things and just hard to take. Worked on taking things a lot easier, but like impact, impulse, active, just fix the matter right now.
Participant 006_2023AUHBV

I just think I need to well manage my alcohol intake. That's that's important because I've been a drinker and not, well, we have a drink. But I'm just saying just to make sure I never, you know, exceed that limit. That's one thing. Not that I've ever had an issue then, but it is one of the things. Exercise is the other thing. And diet, Yeah, they're probably the things that I look at on a regular basis. Yeah. And and stress managing that stress.
Participant 013_2023AUHBV

Participant describes the importance of maintaining a healthy weight in maintaining their general health

First of all, I need to make sure that I am diligent with my medication. I need to make sure that I keep active and that I exercise, that I walk or keep myself fit. I also need to maintain a proper diet. Last year, since all the issues, I've put on a couple of kilos. I know that I need to lose it because it just impacts on a whole lot of things, sugar level, the way my heart works, and feeling tired, all of that, so all those things.
Participant 034_2023AUHBV

Go for a walk three times a week, lose weight. But, you know, that's all part of the fun and games. But you know, yeah, yeah, life's pretty good. You know, it could be worse, but why do people worse off for me? But you know, I'm pretty happy.
Participant 004_2023AUHBV

Participant describes the importance of managing stress in maintaining their general health

I need to have time off. Like I need to have a couple of days in a row where I don't have to do anything, so I don't have any stress. I don't have any anxiety about going to do things. And the anxiety isn't about my health. It's about like just doing stuff. I've always had that sort of thing. Like I stress. Yes, I stress about things rather. Participant 015_2023AUHBV

I think just trying to decrease my, my risk for future cardiac episodes, so ensuring that I get you know a good optimum amount of sleep every day, every night sit between 6:00 and 8:00 hours trying to decrease my stress, looking at my nutrition. So and also because lipoproteinase can be highly inflammatory. So I'm looking at things like, you know, adding more turmeric to my diet and garlic and increasing my fruit and veg and my salmon and things like that.
Participant 011_2023AUHBV

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	22	46.81	8	44.44	14	48.28	6	66.67	6	35.29	10	47.62	14	51.85	8	40.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	19	40.43	8	44.44	11	37.93	3	33.33	7	41.18	9	42.86	11	40.74	8	40.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	17	36.17	6	33.33	11	37.93	6	66.67	4	23.53	7	33.33	9	33.33	8	40.00
Participant describes the importance of complying with treatment/management in maintaining their general health	11	23.40	3	16.67	8	27.59	1	11.11	3	17.65	7	33.33	9	33.33	2	10.00
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	9	19.15	3	16.67	6	20.69	2	22.22	5	29.41	2	9.52	5	18.52	4	20.00
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	5	10.64	2	11.11	3	10.34	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes the importance of maintaining a healthy weight in maintaining their general health	4	8.51	0	0.00	4	13.79	0	0.00	0	0.00	4	19.05	3	11.11	1	5.00
Participant describes the importance of managing stress in maintaining their general health	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	1	3.70	3	15.00

Regular activities to maintain general health	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	22	46.81	12	46.15	10	47.62	12	50.00	10	43.48	9	60.00	13	40.63	11	44.00	11	50.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	19	40.43	9	34.62	10	47.62	11	45.83	8	34.78	5	33.33	14	43.75	8	32.00	11	50.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	17	36.17	11	42.31	6	28.57	11	45.83	6	26.09	6	40.00	11	34.38	8	32.00	9	40.91
Participant describes the importance of complying with treatment/management in maintaining their general health	11	23.40	6	23.08	5	23.81	5	20.83	6	26.09	3	20.00	8	25.00	5	20.00	6	27.27
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	9	19.15	4	15.38	5	23.81	4	16.67	5	21.74	6	40.00	3	9.38	6	24.00	3	13.64
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	0	0.00	5	15.63	3	12.00	2	9.09
Participant describes the importance of maintaining a healthy weight in maintaining their general health	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes the importance of managing stress in maintaining their general health	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	1	6.67	3	9.38	2	8.00	2	9.09

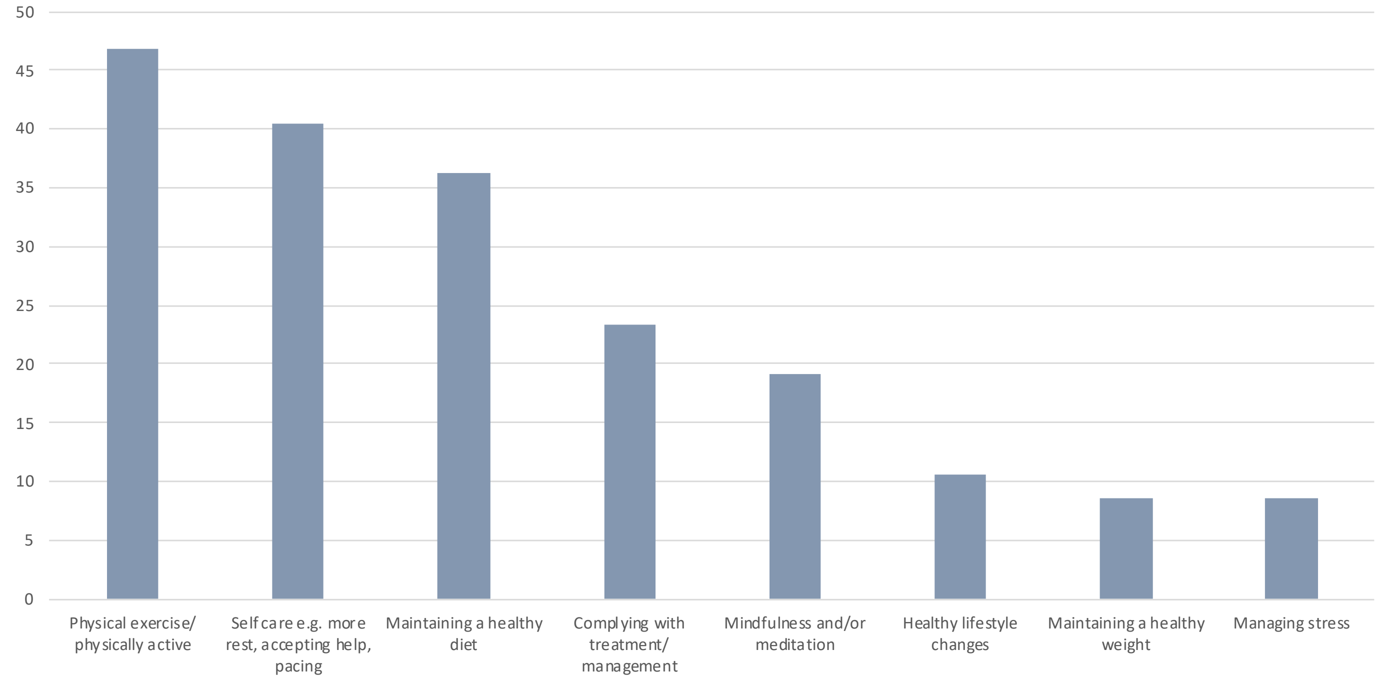

Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Regular activities to maintain general health	Reported less frequently	Reported more frequently
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	Blood vessel conditions	High cholesterol under 50 years of age Regional or remote
Participant describes the importance of maintaining a healthy diet in maintaining their general health	Blood vessel conditions Aged 45 and older	High cholesterol under 50 years of age
Participant describes the importance of complying with treatment/management in maintaining their general health	High cholesterol under 50 years of age 6 to 11 other conditions	-
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	-	Blood vessel conditions Regional or remote
Participant describes the importance of making healthy lifestyle changes in maintaining their general health	Regional or remote	-
Participant describes the importance of maintaining a healthy weight in maintaining their general health	-	Heart conditions

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable because of interactions with the medical team (17.02%), and when experiencing side effects from treatment or symptoms from condition (17.02%). Other times they felt vulnerable included during diagnostic procedure (14.89%), thinking about disease course or that they have an incurable condition (14.89%), during or after treatments (10.64%) and when feeling sick/unwell (8.51%). There were 7 participants (14.89%) that did not feel vulnerable.

Participant describes feeling vulnerable because of interactions with the medical team

I had an incident in 2019 (I think) where I experienced double vision for a few hours and had lots of follow ups, MRIs and a hospital admission. The neurologist who reviewed me at the Royal Melbourne Hospital said he believes that I never had a stroke and that it was actually an atypical migraine, and that I coincidentally have some damage in my cerebellum that is unrelated. He never saw my original scans though so it's hard to know what to make of the differing opinions between neurologists
Participant 046_2023AUHBV

I think in the beginning, when I was in and out of hospital and the medications weren't working, you sort of, I don't know, you feel like they're not listening properly to you.
Participant 008_2023AUHBV

Many times. I felt vulnerable when no-one was listening to me. I felt vulnerable when I needed help in hospital and there was no-one to help me.
Participant 032_2023AUHBV

Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition

Yeah, I've had a few moments like that, Not many. It's all to do with my surgery and if I have a major attack, which I've had a couple in the last 10, 15 years as well. I felt vulnerable then because waiting for an ambulance and after doing heart surgery and the way I felt. It felt like I was having a full on heart attack. Yeah, that made me very vulnerable. Probably twice over the last 10, 15 years I felt vulnerableParticipant 025_2023AUHBV

I tend to feel really vulnerable when I'm exhausted
Participant 041_2023AUHBV

Often when I'm fatigued and no one really understands
Participant 048_2023AUHBV

Participant describes feeling vulnerable during diagnostic procedure

Yeah, I felt vulnerable when I didn't, when they hadn't, when they didn't have a clue why I was blacking out. So you think, you know, I can't. What can I do? I can't have my grandchildren here because I had one. One time here when I had one of my grandchild was only three, you know, And it was, yeah, I felt very vulnerable after that because they didn't know what was causing it. And you know like she was pretty switched on 3 year olds and was yeah, that was pretty, pretty awful. But yeah, that's when I felt vulnerable and they didn't know what the the cause was. Yeah. Participant 013_2023AUHBV

100%? So I mean, right at the very beginning, you know, when it's kind of a shock, you know, when you're 40,41 years of age that someone tells you that you've got a heart issue. You know, you know, on top of dealing with everything that came with a motorcycle accident. You know, it was just one of those things I'm like, you know, you know, because I wasn't sure at that time, you know, whether the irregularities were caused because my heart stopped or, you know, whether whether or something else. So, you know, prior to to all the testing and that, like, I was absolutely terrified. I had no idea, you know, what was going on. So yeah, it was good after that, I guess.
Participant 021_2023AUHBV

Participant describes that they did not feel vulnerable

No, no, I wouldn't say that.
Participant 029_2023AUHBV

PARTICIPANT: No, I think I'm, uh, no, I I don't think I spend a lot of time focusing on it. Just sort of in the past and as you get older you get a bit wiser and. Yeah, 69 now, so you know it's. Yeah, it's just something that happens that. Out of the blue and you dealt with it, Yeah.
Participant 005_2023AUHBV

Participant describes feeling vulnerable thinking about disease course/incurable condition

Yeah, definitely when I was in hospital and not remembering while I was in hospital. You know, waking up in the morning and not knowing where I was, things like that, definitely very vulnerable because your life suddenly in other people's hands, you, you even, you know everything you're not and and knowing that I've been in a coma, that makes you feel very vulnerable. And I think when we first come home from when I first come home from hospital, you know, even in hospital you just. You're continually at the mercy of what other people are deciding for you, which is a good thing because I can't decide how to cure or how to fix or how to attend to what I had. But you are completely putting your hand. You know all your faith has to go into these people that are making decisions that you don't understand. So that's, you know, you do feel vulnerable. And when when I came home to come home, not really understanding what happened, what happens next? You've had people around you. You know, I've had people around me for two weeks. I was in hospital for for almost, well, for 14 days. So. And all of a sudden you're at home and your husband goes back to work and your kids are back at work and school and doing all. You've still got a support network, but you're at home on your own and you don't really know what if something happens? What if I have an arrest now? Who? So you It takes a little while to not feel like you know You know you put on a brave face, but you. I I personally felt quite vulnerable for quite a probably quite a quite a while and and when you have an arrest you lose your license. So you know becoming quite dependent and a lot of people doesn't help you you know for everything. So I'd say that. Definitely. I mean and then you get a confidence back and off you go, but but definitely that's a couple of weeks in hospital and probably the first I'd say three or four months
Participant 009_2023AUHBV

I think sometimes I feel more vulnerable like some, like I often lose sleep over it, I think. Gosh, you know what's going to happen in 10 years time or in five years time or tomorrow kind of thing. So I guess emotionally it's just been a bit of a a roller coaster. But I wouldn't say I'm depressed or anything like that. But you know how you just get you just get your lows sometimes and and I find that you, you know, I've been, I think about it at night, especially when I'm trying to go to sleep and then I'll not off to sleep and then it's happening again the next day.
Participant 011_2023AUHBV

Participant describes feeling vulnerable during/after treatments

I was involved in a car accident and spent a week in hospital
Participant 039_2023AUHBV

When your stuck in hospital and can't control anything
Participant 038_2023AUHBV

Participant describes feeling vulnerable when feeling sick/unwell

When I was really sick and potentially couldn't advocate for myself?
Participant 014_2023AUHBV

I feel vulnerable when I get sick or if I have to have a procedure. There are a couple of reasons for that: 1. Because I'm on blood thinners I have related issues such as bleeding. 2. I feel vulnerable because I now take longer to get better when I'm sick or if something happens.
Participant 034_2023AUHBV

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes feeling vulnerable because of interactions with the medical team	8	17.02	3	16.67	5	17.24	1	11.11	1	5.88	6	28.57	4	14.81	4	20.00
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	8	17.02	2	11.11	6	20.69	1	11.11	5	29.41	2	9.52	4	14.81	4	20.00
Participant describes feeling vulnerable during diagnostic procedure	7	14.89	2	11.11	5	17.24	2	22.22	1	5.88	4	19.05	4	14.81	3	15.00
Participant describes that they did not feel vulnerable	7	14.89	4	22.22	3	10.34	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes feeling vulnerable thinking about disease course/incurable condition	7	14.89	2	11.11	5	17.24	2	22.22	4	23.53	1	4.76	4	14.81	3	15.00
Participant describes feeling vulnerable during/after treatments	5	10.64	1	5.56	4	13.79	0	0.00	2	11.76	3	14.29	1	3.70	4	20.00
Participant describes feeling vulnerable when feeling sick/unwell	4	8.51	2	11.11	2	6.90	1	11.11	0	0.00	3	14.29	2	7.41	2	10.00

Experience of vulnerability	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes feeling vulnerable because of interactions with the medical team	8	17.02	7	26.92	**1**	**4.76**	4	16.67	4	17.39	2	13.33	6	18.75	4	16.00	4	18.18
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	8	17.02	5	19.23	3	14.29	5	20.83	3	13.04	3	20.00	5	15.63	4	16.00	4	18.18
Participant describes feeling vulnerable during diagnostic procedure	7	14.89	5	19.23	2	9.52	5	20.83	2	8.70	**4**	**26.67**	3	9.38	6	24.00	**1**	**4.55**
Participant describes that they did not feel vulnerable	7	14.89	5	19.23	2	9.52	4	16.67	3	13.04	1	6.67	6	18.75	3	12.00	4	18.18
Participant describes feeling vulnerable thinking about disease course/incurable condition	7	14.89	5	19.23	2	9.52	3	12.50	4	17.39	3	20.00	4	12.50	5	20.00	2	9.09
Participant describes feeling vulnerable during/after treatments	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	2	13.33	3	9.38	4	16.00	1	4.55
Participant describes feeling vulnerable when feeling sick/unwell	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	**3**	**20.00**	1	3.13	4	16.00	0	0.00

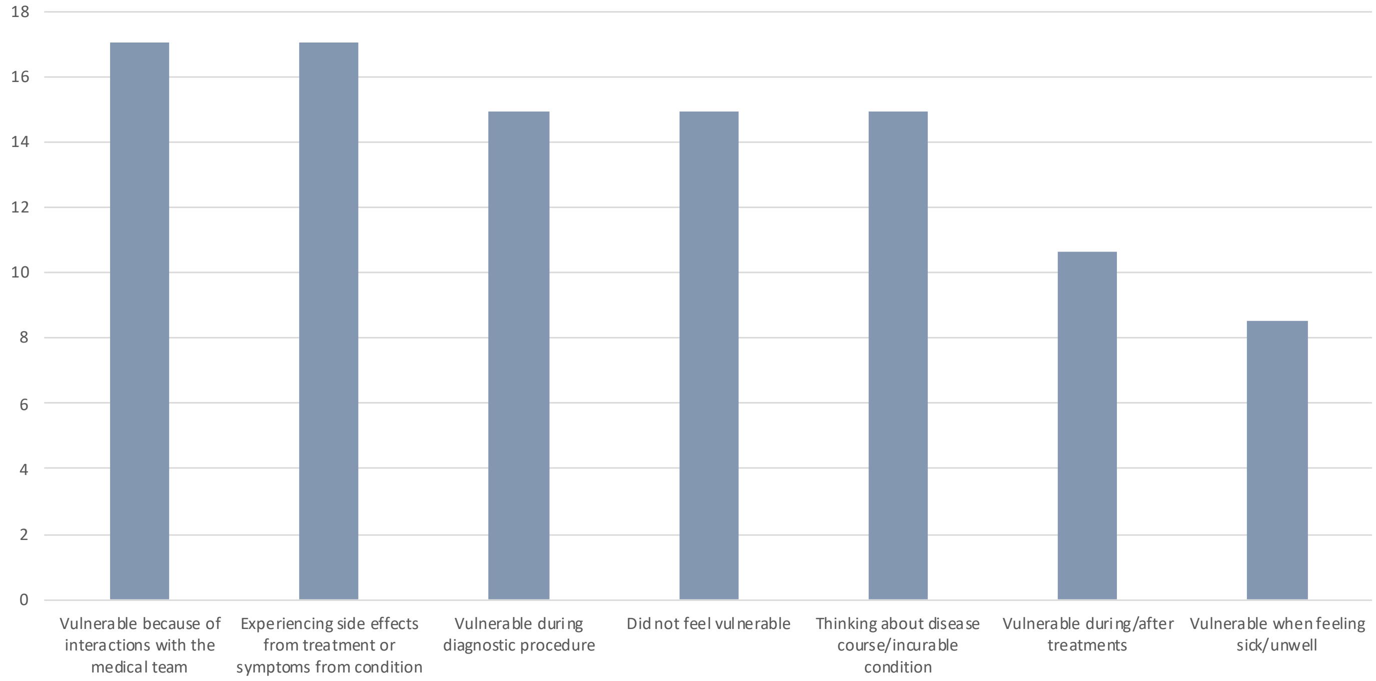

Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable because of interactions with the medical team	Blood vessel conditions Male	Heart conditions
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	-	Blood vessel conditions
Participant describes feeling vulnerable during diagnostic procedure	Higher socioeconomic status	Regional or remote
Participant describes feeling vulnerable thinking about disease course/incurable condition	Heart conditions	-
Participant describes feeling vulnerable during/after treatments	High cholesterol under 50 years of age	
Participant describes feeling vulnerable when feeling sick/unwell	-	Regional or remote

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (10.64%), and being unsure how vulnerability can be managed (4.26 %).

Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability

Yes, but I'm very motivated and try not to give in.
Participant 047_2023AUHBV

I'm a positive person. In 2022 I went overseas to a foreign country and lived in a remote jungle area. I had medical clearance from my doctor.
Participant 031_2023AUHBV

Yes, most of the time…. I'm dealing with people and everyone has emotions. I have been able to keep those feelings in check and I don't feel they have got to out of control.
Participant 049_2023AUHBV

Participant describes unsure how vulnerability can be managed

Past 9 months I have tried several different strategies not a thing works massive meltdowns 24/7 it feels like quick sand I just dig and dig I don't get anywhere.
Participant 044_2023AUHBV

When I was diagnosed with cancer on top of cardiomyopathy I felt very isolated due to Covid. Not sure that I managed my feelings of vulnerability very well.
Participant 037_2023AUHBV

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	10.64	1	5.56	4	13.79	1	11.11	3	17.65	1	4.76	4	14.81	1	5.00
Participant describes Not applicable, no vulnerability	5	10.64	4	22.22	1	3.45	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes unsure how vulnerability can be managed	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Methods to manage vulnerability	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	1	6.67	4	12.50	0	0.00	5	22.73
Participant describes Not applicable, no vulnerability	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	1	6.67	4	12.50	3	12.00	2	9.09
Participant describes unsure how vulnerability can be managed	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55

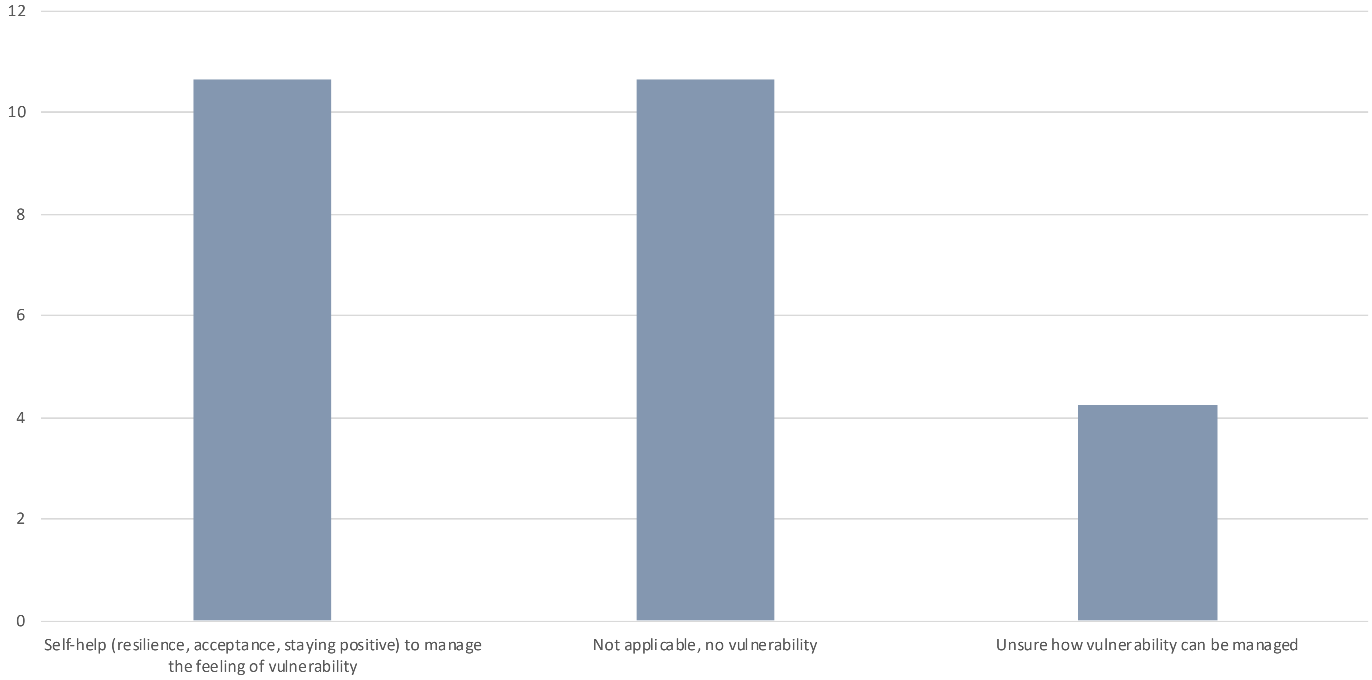

Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes Not applicable, no vulnerability	-	Had LP(a) test

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (38.30%), and overall, there no impact on relationships (31.91%). Other themes included overall, there was a positive impact on relationships (14.89%), and overall, there was an impact on relationships that was both positive and negative (10.64%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships chaning due to anxiety, exacerbations and/or physical limitations of condition (31.91%), and from people not knowing what to say or do and withdrawing from relationships (10.64%). Other themes included because of people not believing the impact that condition has on health (6.38%), and because of intimacy challenges (4.26%).

The most common themes in relation to having a positive impact on relationships were from people being well-meaning and supportive (17.02%), and from family relationships being strengthened (8.51%).

Participant describes that overall, there was a negative impact on relationships

It did it first. Going back years ago, but not so much now. I'm talking about friends, not so much the family. It affected the family, but we worked through that and we were OK with that. But with friends, I don't know. It was like, it's like getting married and all your friends went somewhere else. They just weren't around anymore, you know, They seem to just. Well, it's not like I tried to work it out, I think because all my friends, we lived the lifestyle we lived in, like drinking and smoking, you know, we're all in pubs every night and I couldn't do that anymore, you know? But naturally I stopped doing it all straight away, you know. So I think that's what separated the relationships. Yeah, makes sense. Then I found new friends at work. So I went to work and I build a new set of friends at work. But the original friends, I think it was just our lifestyle. They were still in the pubs drinking and smoking and I didn't.
Participant 025_2023AUHBV

PARTICIPANT: Yes, I do.
INTERVIEWER: In what way?
PARTICIPANT: It's sometimes hard to communicate exactly what you're feeling. They get frustrated because you can't do what they want you to do. It takes time to have a shower and get dressed and everything like that, and then it's frustrating. I can get angry and frustrated, cry and get fatigued. It takes a toll because they want you to be better than what you are, but it is what it is, and I can't change that.
INTERVIEWER: Well, PARTICIPANT, it sounds like you're doing your best. That's all we can do. Please, don't be hard on yourself.
PARTICIPANT: No, I don't anymore. I used to.
Participant 049_2023AUHBV

It certainly has, and certainly makes you know who your real friends are.
Participant 044_2023AUHBV

Participant describes that overall, there no impact on relationships

No, no, I don't think so,
Participant 007_2023AUHBV

Not overly, no. Not from my point of view. I don't think so.
Participant 043_2023AUHBV

No. No, not at all.
Participant 005_2023AUHBV

Participant describes that overall, there was a positive impact on relationships

No, I don't. If it has affected them, it's probably affected them for the better, not for the worse. Yeah.
Participant 009_2023AUHBV

Yeah, I think so. But not in a negative way. I think it's actually been, I hate saying it, but I think it was a good thing in terms of, I think my husband and I actually grew closer through our experience rather than it doing negative things. We were stronger in our relationship, and also even with my family I think I grew closer to both our families through the experience.
Participant 035_2023AUHBV

I don't think it has. I think if anything we've become a lot closer. I think I've got quite a supportive family and they listen to me and and I listen to them and we just we just have a good relationship and yeah it's it's it's been wonderful like I think that.
Participant 011_2023AUHBV

Participant describes that overall, there was an impact on relationships that was both positive and negative

Yes, we no longer do many things with friends at night because it's too tiring for me. It has brought us together as a family a lot closer. We spend more time together. We make sure we get good quality time but we have to choose what that is and what's important to do together, so that I still get that rest that I need to do.
Participant 047_2023AUHBV

That's a tricky one. I think it changes things for the positive, actually, in that there's a greater sense of appreciation for someone who has been in a life-threatening situation. It's a hard one to answer because there's people who can't deal with it, and they can't respond, and they don't know how to respond for their own reasons, but it can create more distance, but on the other hand, for me, there's a group of people who I'm probably closer to now. So it's also just where you choose to focus, I guess. Yeah. So for me it's mostly been positive, I would say.
Participant 023_2023AUHBV

Table 8.15 Impact on relationships

Impact on relationships	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was a negative impact on relationships	18	38.30	7	38.89	11	37.93	2	22.22	8	47.06	8	38.10	8	29.63	10	50.00
Participant describes that overall, there no impact on relationships	15	31.91	9	50.00	6	20.69	4	44.44	6	35.29	5	23.81	10	37.04	5	25.00
Participant describes that overall, there was a positive impact on relationships	7	14.89	1	5.56	6	20.69	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes that overall, there was an impact on relationships that was both positive and negative	5	10.64	1	5.56	4	13.79	1	11.11	1	5.88	3	14.29	3	11.11	2	10.00
No particular comment	2	4.26	0	0.00	2	6.90	1	11.11	0	0.00	1	4.76	2	7.41	0	0.00

Impact on relationships	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was a negative impact on relationships	18	38.30	13	50.00	5	23.81	6	25.00	12	52.17	6	40.00	12	37.50	8	32.00	10	45.45
Participant describes that overall, there no impact on relationships	15	31.91	9	34.62	6	28.57	10	41.67	5	21.74	3	20.00	12	37.50	7	28.00	8	36.36
Participant describes that overall, there was a positive impact on relationships	7	14.89	2	7.69	5	23.81	4	16.67	3	13.04	4	26.67	3	9.38	6	24.00	1	4.55
Participant describes that overall, there was an impact on relationships that was both positive and negative	5	10.64	1	3.85	4	19.05	3	12.50	2	8.70	2	13.33	3	9.38	2	8.00	3	13.64
No particular comment	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	2	8.00	0	0.00

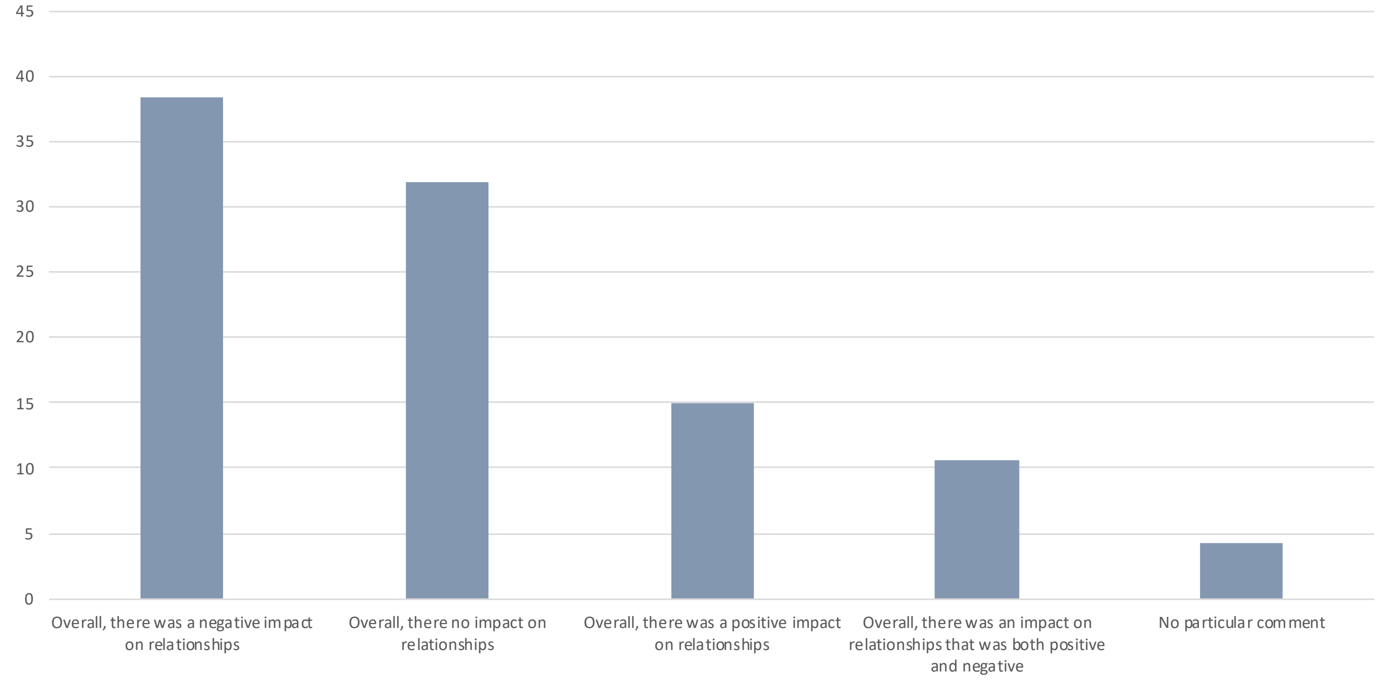

Figure 8.8: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	High cholesterol under 50 years of age Male Aged 25 to 44	6 to 11 other conditions Female Aged 45 and older
Participant describes that overall, there no impact on relationships	Did not had LP(a) test Aged 45 and older Regional or remote	Had LP(a) test High cholesterol under 50 years of age
Participant describes that overall, there was a positive impact on relationships	Higher socioeconomic status	Regional or remote

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships -(Reason for impact)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	15	31.91	6	33.33	9	31.03	3	33.33	4	23.53	8	38.10	7	25.93	8	40.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	8	17.02	2	11.11	6	20.69	2	22.22	1	5.88	5	23.81	3	11.11	5	25.00
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	5	10.64	1	5.56	4	13.79	0	0.00	4	23.53	1	4.76	2	7.41	3	15.00
Participant describes a positive impact on relationships from family relationships being strengthened	4	8.51	0	0.00	4	13.79	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00
Participant describes a negative impact on relationships because of people not believing the impact that condition has on health	3	6.38	1	5.56	2	6.90	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Participant describes a negative impact on relationships because of intimacy challenges	2	4.26	0	0.00	2	6.90	0	0.00	0	0.00	2	9.52	0	0.00	2	10.00
Participant describes a negative impact on relationships in general (no specifics articulated)	2	4.26	0	0.00	2	6.90	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00

Impact on relationships -(Reason for impact)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	15	31.91	9	34.62	6	28.57	7	29.17	8	34.78	6	40.00	9	28.13	4	16.00	11	50.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	8	17.02	3	11.54	5	23.81	5	20.83	3	13.04	4	26.67	4	12.50	6	24.00	2	9.09
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	0	0.00	5	15.63	3	12.00	2	9.09
Participant describes a positive impact on relationships from family relationships being strengthened	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
Participant describes a negative impact on relationships because of people not believing the impact that condition has on health	3	6.38	3	11.54	0	0.00	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes a negative impact on relationships because of intimacy challenges	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09
Participant describes a negative impact on relationships in general (no specifics articulated)	2	4.26	2	7.69	0	0.00	0	0.00	2	8.70	1	6.67	1	3.13	2	8.00	0	0.00

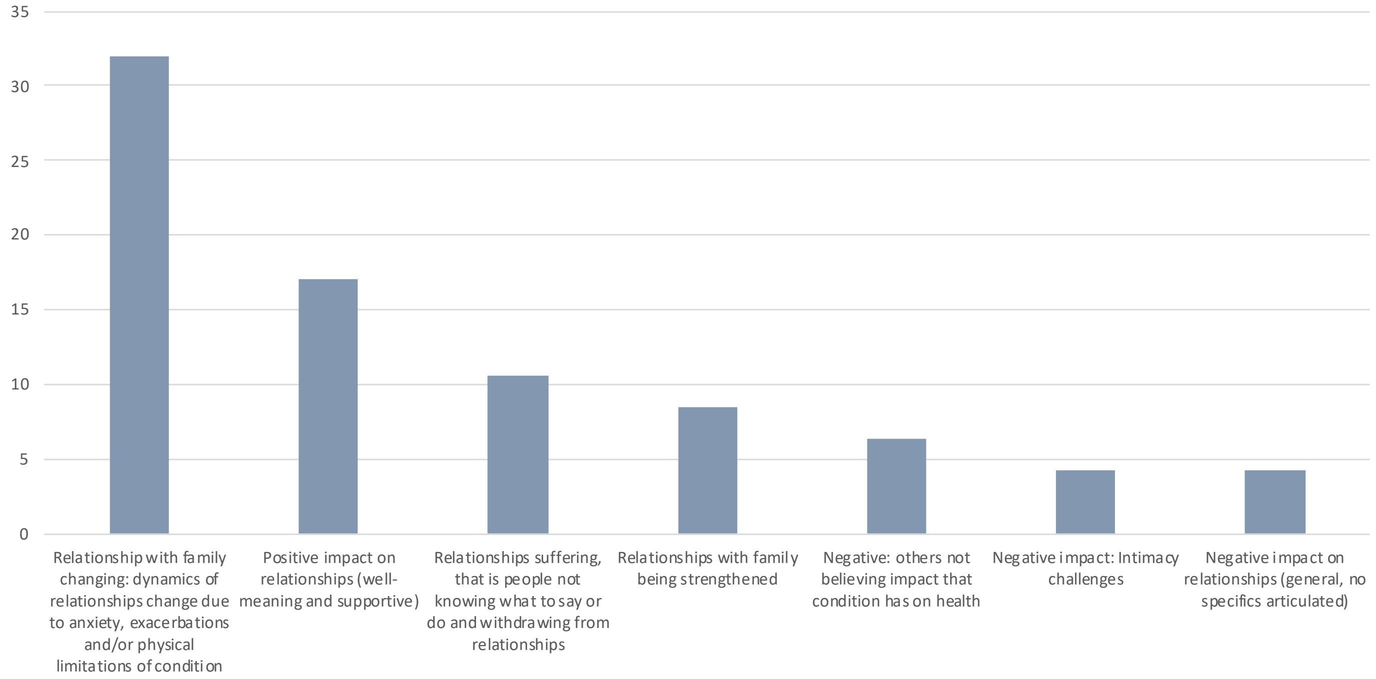

Figure 8.9: Impact on relationships

Table 8.18: Impact on relationships: Reason for impact – subgroup variations

Impact on relationships -(Reason for impact)	Reported less frequently	Reported more frequently
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	Mid to low socioeconomic status	Higher socioeconomic status
Participant describes a positive impact on relationships from people being well-meaning and supportive	Blood vessel conditions	-
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	High cholesterol under 50 years of age Regional or remote	Blood vessel conditions

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was not a burden on their family (51.06%), overall, there was a burden on their family (44.68%), and overall, there was not a burden on their family now but they anticipate this will change in the future (6.38 %).

The main reason that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (17.02%), that the burden wastemporary or only during treatment (14.89%), and the mental/emotional strain placed on their family (10.64%).

The main reason that participant described their condition not being a burden were that they were very independent (14.89%), and they have a very supportive family and were not a burden (6.38%).

Participant describes that overall, there was not a burden on their family

Look, I don't think so. Not working is really like I can't work. There's no way that I'd be able to work right now, but I think having kids that are a little bit older means that I can delegate a bit to them as well. So I don't think at this point in time I don't have people doing stuff for me. Like obviously I can't bend down. I love gardening, but I can't, I can't bend to weed or anything like that. So that sort of thing is all out of the question. But around the house, I feel like I'm functioning by myself okay. It's just that I have a little routine and a schedule and I can't. I just have to listen to my body and I can't go and be 3 hours of cleaning. I have to go and do a job and then come back and recover and I think that's just come with time.
Participant 014_2023AUHBV

Well no, I'm pretty independent. So, I wouldn't say the chronic heart failure is the burden. It's more the whole condition. And, no, when I go to the hospital, I don't even tell them until the next day.
Participant 032_2023AUHBV

No, because I find that I'm very independent. I will do stuff myself. My dad's really good. He comes around and helps me do stuff often. There's nothing I can't do that I want to do. I don't set myself unrealistic goals. I just painted my bathroom a couple weeks ago but I just took my time to do it. But I still did it. It just took me ages. As, I said I don't set unrealistic goals. I think that would be the thing. I don't feel like a burden, no.
Participant 036_2023AUHBV

Participant describes that overall, there was a burden on their family

Oh, that's periodic. There are times, yeah, when I need extra help, but I try to be very self-sufficient as well. Yeah, so that's, it varies, so there are times, especially when I've had surgery or I'm not well, that yeah, they will have a bigger role. Yeah, yeah. But then there's times when they're not well, or that they need extra help, and I'm offering them help as well, so I suppose it all works out in the end. So there's a lot of other people that are in a lot worse situation than I am, and yeah -- So I'm just very blessed that yeah, that I still function with my condition.
Participant 030_2023AUHBV

PARTICIPANT: Not anymore, no.
INTERVIEWER: But in that initial period when you were juggling your new diagnosis and your new baby?
PARTICIPANT: Yeah, that was, that definitely, yeah that was quite for long, for family. They happily did it, but I didn't like how much I needed to rely on them.
Participant 035_2023AUHBV

Yes, I do. Yeah, I try not to ask for help, just between very independent and stubborn, I suppose. But but there's times when I yeah, where I've had to and it's really hard.
Participant 019_2023AUHBV

Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future

No. Like later on, but not at the moment. I'm the one doing all the assisting. It hasn't affected them at all.
Participant 037_2023AUHBV

I'm thinking at the moment it's it's OK because I don't need extra care or assistance, but if I do worry that if anything did happen in the future I'd be. I'd feel like maybe a bit of a burden. I I kind of hope I don't feel that way. But you can't help thinking, Gee, maybe, you know, if somebody has to look after me or I wouldn't want to put them through that kind of thing. But I guess we just have to cross that path if if it happens.
Participant 011_2023AUHBV

Table 8.19: Burden on family

Burden on family	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was not a burden on their family	24	51.06	10	55.56	14	48.28	7	77.78	7	41.18	10	47.62	14	51.85	10	50.00
Participant describes that overall, there was a burden on their family	21	44.68	7	38.89	14	48.28	2	22.22	9	52.94	10	47.62	11	40.74	10	50.00
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
No particular comment	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	2	7.41	0	0.00

Burden on family	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was not a burden on their family	24	51.06	15	57.69	9	42.86	14	58.33	10	43.48	8	53.33	16	50.00	15	60.00	9	40.91
Participant describes that overall, there was a burden on their family	21	44.68	10	38.46	11	52.38	9	37.50	12	52.17	7	46.67	14	43.75	10	40.00	11	50.00
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	2	8.00	1	4.55
No particular comment	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09

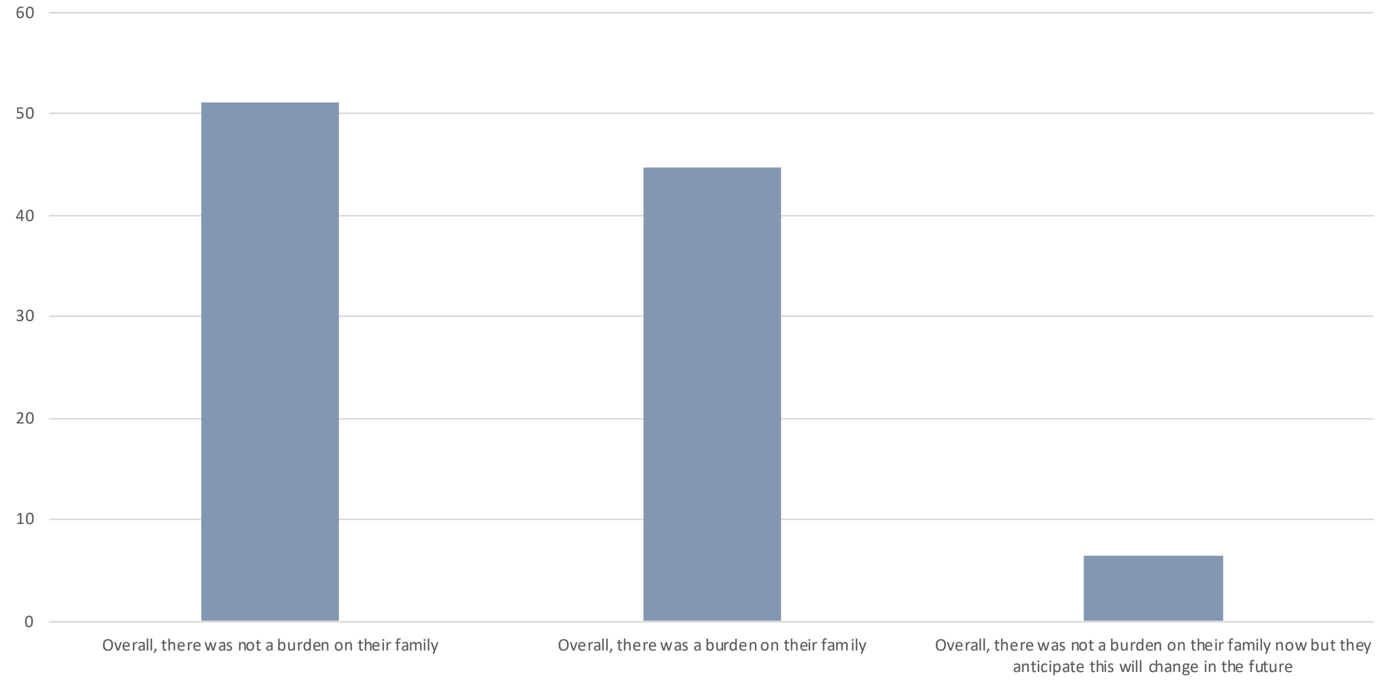

Figure 8.10: Burden on family

Table 8.20: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant describes that overall, there was not a burden on their family	Higher socioeconomic status	High cholesterol under 50 years of age
Participant describes that overall, there was a burden on their family	High cholesterol under 50 years of age	-

Table 8.21: Burden on family (description)

Burden on family (Description)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	15	31.91	7	38.89	8	27.59	5	55.56	6	35.29	4	19.05	8	29.63	7	35.00
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	8	17.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	5	18.52	3	15.00
Participant describes that the burden on family was temporary or only during treatment	7	14.89	2	11.11	5	17.24	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes being independent and not a burden on their family	7	14.89	3	16.67	4	13.79	1	11.11	2	11.76	4	19.05	4	14.81	3	15.00
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	6	12.77	1	5.56	5	17.24	0	0.00	4	23.53	2	9.52	3	11.11	3	15.00
Participant describes the mental/emotional strain placed on their family as a burden on their family	5	10.64	1	5.56	4	13.79	1	11.11	1	5.88	3	14.29	2	7.41	3	15.00
Participant describes that they have a supportive family and were not a burden	3	6.38	1	5.56	2	6.90	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00

Burden on family (Description)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	15	31.91	9	34.62	6	28.57	9	37.50	6	26.09	4	26.67	11	34.38	9	36.00	6	27.27
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	8	17.02	3	11.54	5	23.81	3	12.50	5	21.74	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes that the burden on family was temporary or only during treatment	7	14.89	3	11.54	4	19.05	2	8.33	5	21.74	2	13.33	5	15.63	3	12.00	4	18.18
Participant describes being independent and not a burden on their family	7	14.89	4	15.38	3	14.29	2	8.33	5	21.74	3	20.00	4	12.50	4	16.00	3	13.64
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	2	13.33	4	12.50	3	12.00	3	13.64
Participant describes the mental/emotional strain placed on their family as a burden on their family	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	2	13.33	3	9.38	2	8.00	3	13.64
Participant describes that they have a supportive family and were not a burden	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	3	20.00	0	0.00	3	12.00	0	0.00

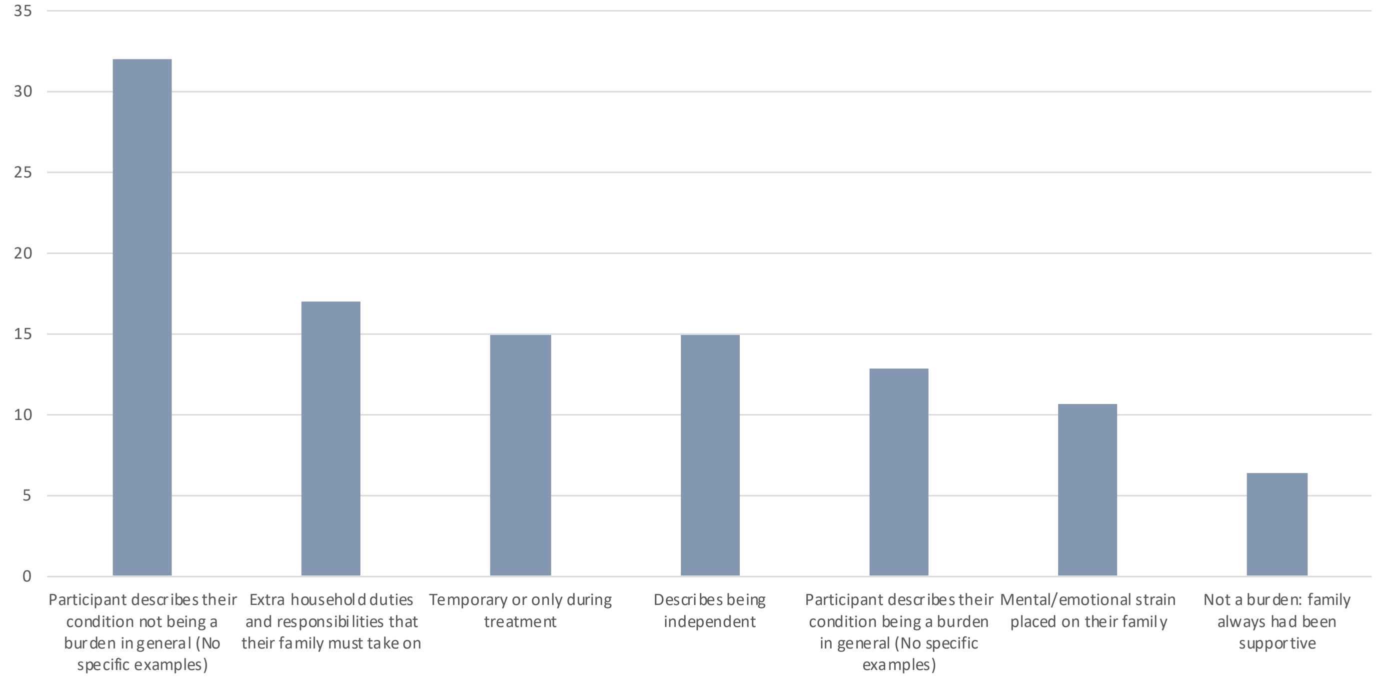

Figure 8.11: Burden on family (description)

Table 8.22: Burden on family (description)– subgroup variations

Burden on family (Description)	Reported less frequently	Reported more frequently
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	Heart conditions	High cholesterol under 50 years of age
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	High cholesterol under 50 years of age	Blood vessel conditions
Participant describes that they have a supportive family and were not a burden	-	Regional or remote

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (51.06%), and overall, there was no cost burden (23.40%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (27.66%), diagnostic tests and scans (17.02%), and needing to take time off work (17.02 %). Other themes included the cost specialist appointments (14.89%), cost of gap payments (12.77%), needing to buy special equipment (10.64%), allied health care (8.51%), and GP appointments (8.51%).

Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the public health system (17.02%), the participant was able to afford all costs (10.64%), and nearly everything was paid for through the private health system (8.51 %).

Cost burden in relation to the cost of treatments (including repeat scripts)

It's been pretty significant by the time you add up all the the emergency room visits, the medications, the. Different diagnostic tests like halter monitors and echocardiograms and things like that. So even though we had private health, the out of pocket's been pretty, pretty significant, yeah. And then the ablations and things like that as well.
Participant 008_2023AUHBV

It's been very expensive, Very, very. And it's ongoing expense because I've got whatever number of drugs I have to get every month. And then I've got my $400.00 monitor beside the bed that I pay and I've got my cardiologist and my echocardiogram. Or not that, that. It's that. What'd you say, that echo? It's it's an echo cardiogram or an angio thing. Something anyway. One of those think supposed to go to the GP every so often because they only see the specialist once a year.
Participant 015_2023AUHBV

Everyone, everyone involved, you know, needs to be paid, I guess. And then the surgeries are astronomical, like the piece of machinery in my chest is far as I'm aware, a few 100 grand. I didn't even look at the last bill because I didn't want to look at it. But and then even the thing that sits next to my bed, the little, the reader that gets sent off, as far as I'm aware that's a few $100 as well. It is, it is extremely expensive. But we we've been pretty fortunate and I think, you know I'm in a position now where luckily I can prioritize the cost of my health and those sorts of things. And then also you get pretty used to paying out extensive amounts of money. So you just sort of kitty that sort of stuff away. When you start to get a bit older and realize how how expensive it is to be someone with a condition like this, you just have a little bit of sitting somewhere just in case. But I've still got, I still pay my private health cover, which is way more expensive than anyone else's private health cover my age.
Participant 012_2023AUHBV

Cost burden in relation to diagnostic tests and scans

It's been pretty significant by the time you add up all the the emergency room visits, the medications, the different diagnostic tests like halter monitors and echocardiograms and things like that. So even though we had private health, the out of pocket's been pretty, pretty significant, yeah. And then the ablations and things like that as well.
Participant 008_2023AUHBV

Yeah, so there's been massive costs actually, but we've had, my mom and dad were pretty lucky with, I don't know why, but as little kids they put us on the private health, which was, you know, huge expense for them like mom and dad weren't. We never really went without, but they weren't overly wealthy, but they put us onto a pretty good, pretty high level of private health from a very young age. So in that sense we we were really fortunate, especially when this all started to come out. I know how much like the testing is expensive. Like the ECGs are a lot. They're for $500 now. I don't know how much they were back then. Stress tests, they were have a cost. Everyone, everyone involved, you know, needs to be paid, I guess.
Participant 012_2023AUHBV

Cost burden in relation to needing to take time off work

OMG, being chronically ill is the most expensive job in the world. Being chronically ill for me often means a period of unemployment. You think about it, you're on a pension. The 40-year olds that I know are talking about, and I know we can't do it right now, but let's

put the pandemic aside. They're talking about traveling overseas, getting married, having kids, buying houses. I'm looking for the next $5 to pay for my medication. My priorities are very different to a lot of my friends.
Participant 050_2023AUHBV

Cost burden in relation to the cost specialist appointments

Yeah, it's been OK. Probably the biggest cost for me was the coronary calcium score. I think it was about $150.00 and that was fine. The cardiologist always costs a bit of money to go to the cardiologist, but but I find out, well you know you need to do it, so just budget for it. But I know it is. It would be difficult for a lot of people, especially in today's economy, to be able to to afford a lot of a lot of those things
Participant 011_2023AUHBV

Initially, the MRI and things didn't cost because I was still a patient of the hospital. Travelling to see the neurologist had quite extensive cost because I couldn't travel down and back on one day we needed me to stay in an accommodation to let me recover enough, to go to the appointment. Which meant my husband had to take time off work. My mom and dad had to come to look after the children when we weren't here. We now have the ongoing cost of medication. Also the lack of income because I can't work full-time anymore.
Participant 047_2023AUHBV

Cost burden in relation gap payments

Yeah, for the I guess it cost me. It was all private than that, but it still cost me a few $1000 to get all this done. I just wasn't willing to go through the public system for it, so I wanted to get it sorted. I just it's one of those things I didn't wanna have to deal with if everything was OK. But yeah, it cost me. It cost me a few grand.
Participant 028_2023AUHBV

Cost burden in needing to special equipment

Yes, there's been cost. My son has had time off from work so that's costed him. I don't know how much that is. I've had costs obviously and I think I estimated about $200 a week just for equipment, for physio and for drugs and for going to doctors, the cost of doctors. That might not be accurate, that might be too little I'm not sure.
Participant 041_2023AUHBV

There has been cost involved in getting time off work. To go to doctor's appointments is probably the biggest problem.
Participant 020_2023AUHBV

Cost burden in relation to allied health care

Work would be huge. I've lost because of the I stuff up with income protection. I'm potentially losing 8 grand after tax per month by having this costs also associated with travel, so any tests I have to have, it's a three hour round trip to LOCATION 1 or 6 hour round trip to LOCATION 2 Medication so we don't have access to Chemist Warehouse or any cheaper place. I know I could go online, but when you're sick, that's too overwhelming. And sometimes you don't have your ducks in a row and you just need to put it in the hands of the local pharmacist. But I know that my IVA braiding when I get it at Chemist Warehouse in LOCATION 1 is potentially 10 to $15 cheaper than what I can get it here in LOCATION 3. So yeah, there's lots of financial thing, you know, you get 5 when you've got chronic health issue, you get 5 free sessions with the exercise physiologist, but that's nowhere near enough. If you've got a chronic health condition, you're talking long term, you're not talking. It's not like you wanna go and do weights training, you know what I mean? Like it's, I don't know that five is enough when you're living with something like this. So it all adds up.
Participant 014_2023AUHBV

Cost burden in relation to GP appointments

Yeah, I mean, obviously there's been costs involved. It costs to go to the breathing specialist, it costs to go to the GP, It costs to go to the cardiologist, It costs to purchase the medication, do the tests. Yes. So yes, there's.
Participant 019_2023AUHBV

Generally, anything that's going to cost me hundreds of dollars, I just don't do because of the fact that I can't afford to do it. As I said, the appointments with my GP are being pushed right out now because to go and see my GP is literally 10% of my income. It's actually more than 10%. But yeah, you know, I've got an appointment with my GP on Monday, which is $103.80 or something, you know, don't get me wrong, I can change GPs and that'll go back to bulk billing, but it comes down to a point of that, you know, hey, I'm comfortable with my GP. My GP knows all of my history. ... As for so medication wise, I generally I'm not too fast with the cost of the medication. Again, I

hit the PBS fairly quickly every year. So I generally generally every year by March I've hit the PBS and my medications free for the rest of the year. You know, I suppose it's it's now just literally the GP that the expensive part, if he sends me for a scan or something like that that's going to be expensive. I generally go back and say I can't afford it. He'll get one of the specialists to write the referral for whatever it is. So for example, I had to have a PET scan not long back and the cost of that was 600 odd dollars. I went back to him and said, yeah, I can't afford that. So he got one of the billonary specialists there to write the referral for me, which made it free with the specialist referral. Yeah. Anything else that's sort of like outside of the realms, he'll say to me, OK, this is what you need done, but the only way to get this done charge is to go to the hospital. So, you know, generally he'll write me the referral to the hospital, I'll go to the hospital, it'll get done that way and I'll go back to my GP a week later or whatever it is to get the results
Participant 018_2023AUHBV

The cost of equipment to use with one hand is crazy. That's extreme. I have had a lot of time off work because of fatigue. It has been a big cost in the early days up until probably 18 years ago. It was a financial burden. Now still, if I need something to assist me around the kitchen or just everyday things, to put shoes on or tie laces, it seems to cost a lot of money to get those things. It's not fair that it's so expensive.
Participant 049_2023AUHBV

No cost burden and that nearly everything was paid for through the public health system

No, I've had costs. Haven't been an issue for me. Really. No. Even when, even when I was trans, when I first had the heart attack and I was transferred over to the private hospital because I was a public patient going to that private hospital, there was no cost to me because obviously the public system paid for the feel. Yeah. So costs haven't been really an issue. We have private health cover and not that it's worth too much, but you know, yeah.
Participant 013_2023AUHBV

No, I was not out of pocket at all. I think my husband paid a $20, I was in hospital for about 12 days and I think he paid a phone, phone charge and that was all of course the medication since then it's an ongoing cost, but we reach our safety net sort of fairly about mid year. So that's not too bad either.
Participant 005_2023AUHBV

No cost burden as participant was able to afford all costs

I spend an absolute fortune on prescription drugs but that's just the way it is and I made it. To be completely honest with you, I'm a professional and I earn pretty good money so I've got no complaints. If I was not in the position that I am in, the cost of those medications would be a burden.
Participant 046_2023AUHBV

I work for EMPLOYER, so I'll work for three months, right? Yeah. And saying that I had four years worth of sick leave, that didn't seem to bother me too much at all. You know, I have 100. I have the highest level of had. I still have do I think highest level of private health cover. So you know, that didn't bother me much at all. There was a few out of pocket things that were, you know, probably for some people would probably think it was a significant amount of money, but I think it was a bad one. I think I had a pocket 25 grand something. You know, nothing
Participant 004_2023AUHBV

No cost burden and that nearly everything was paid for through the private health system

Well, luckily for me I had lots of leave for the work, so they will use that, although I did take my leave, but there was not really much cost. I just had to pay for just a blood test done to be done at a private lavatory and and just my medications as well. So it wasn't much at all because everything else was under, obviously, the health fund.
Participant 029_2023AUHBV

I was extremely lucky. I had accrued a lot of leave. I was off work for nine months. I was lucky that my employer, which was the EMPLOYER, was able to accommodate that. A lot of people aren't that lucky. I was able to use up all my leave. In terms of costs, I didn't experience any difficulty with the costs. We have medical insurance. [coughs] That wasn't an issue for me and my family
Participant 030_2023AUHBV

Table 8.23: Cost considerations

Cost considerations	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes that overall, there was at least some cost burden	24	51.06	8	44.44	16	55.17	4	44.44	12	70.59	8	38.10	12	44.44	12	60.00
Participant describes that overall, there was no cost burden	11	23.40	6	33.33	5	17.24	4	44.44	3	17.65	4	19.05	7	25.93	4	20.00
Other/No response	12	25.53	4	22.22	8	27.59	1	11.11	2	11.76	9	42.86	8	29.63	4	20.00

Cost considerations	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes that overall, there was at least some cost burden	24	51.06	14	53.85	10	47.62	13	54.17	11	47.83	9	60.00	15	46.88	15	60.00	9	40.91
Participant describes that overall, there was no cost burden	11	23.40	6	23.08	5	23.81	6	25.00	5	21.74	2	13.33	9	28.13	6	24.00	5	22.73
Other/No response	12	25.53	6	23.08	6	28.57	5	20.83	7	30.43	4	26.67	8	25.00	4	16.00	8	36.36

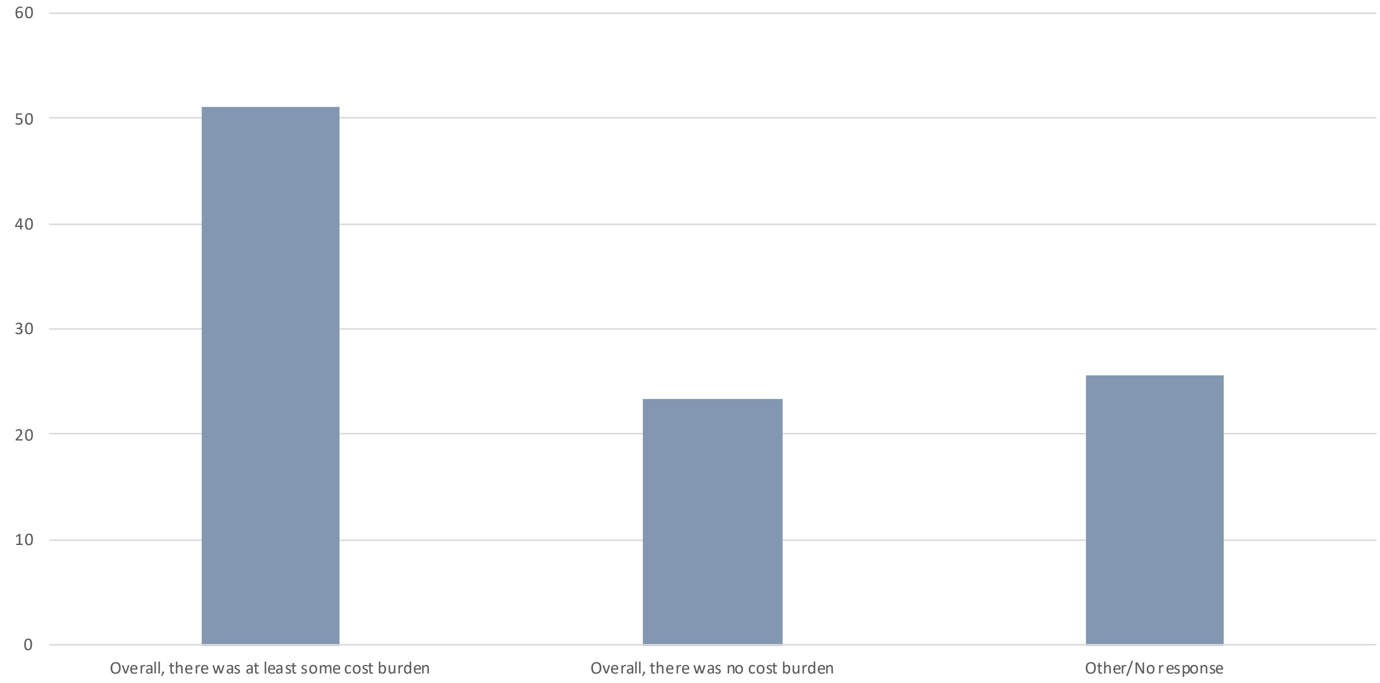

Figure 8.12: Cost considerations

Table 8.24: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was at least some cost burden	Heart conditions Higher socioeconomic status	Blood vessel conditions
Participant describes that overall, there was no cost burden	Regional or remote	High cholesterol under 50 years of age

Table 8.25: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Cost burden in relation to the cost of treatments (including repeat scripts)	13	27.66	5	27.78	8	27.59	1	11.11	6	35.29	6	28.57	6	22.22	7	35.00
Cost burden in relation to diagnostic tests and scans	8	17.02	3	16.67	5	17.24	0	0.00	3	17.65	5	23.81	4	14.81	4	20.00
Cost burden in relation to needing to take time off work	8	17.02	2	11.11	6	20.69	1	11.11	5	29.41	2	9.52	4	14.81	4	20.00
Cost burden in relation to the cost specialist appointments	7	14.89	3	16.67	4	13.79	2	22.22	3	17.65	2	9.52	2	7.41	5	25.00
Cost burden in relation gap payments	6	12.77	1	5.56	5	17.24	1	11.11	1	5.88	4	19.05	3	11.11	3	15.00
Cost burden in needing to special equipment	5	10.64	1	5.56	4	13.79	0	0.00	3	17.65	2	9.52	0	0.00	5	25.00
Cost burden in relation to allied health care	4	8.51	1	5.56	3	10.34	0	0.00	3	17.65	1	4.76	2	7.41	2	10.00
Cost burden in relation to GP appointments	4	8.51	3	16.67	1	3.45	0	0.00	1	5.88	3	14.29	3	11.11	1	5.00
Cost burden in relation to a family member needing to take time off work	3	6.38	0	0.00	3	10.34	0	0.00	3	17.65	0	0.00	1	3.70	2	10.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	3	6.38	1	5.56	2	6.90	0	0.00	2	11.76	1	4.76	3	11.11	0	0.00
No cost burden and that nearly everything was paid for through the public health system	8	17.02	3	16.67	5	17.24	4	44.44	2	11.76	2	9.52	6	22.22	2	10.00
No cost burden as participant was able to afford all costs	5	10.64	2	11.11	3	10.34	2	22.22	1	5.88	2	9.52	3	11.11	2	10.00
No cost burden and that nearly everything was paid for through the private health system	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	2	7.41	2	10.00
No cost burden as participant was able to access paid medical leave	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
No cost burden: satisfied with experience	3	6.38	3	16.67	0	0.00	1	11.11	1	5.88	1	4.76	3	11.11	0	0.00

Cost considerations (reasons for costs)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Cost burden in relation to the cost of treatments (including repeat scripts)	13	27.66	9	34.62	4	19.05	8	33.33	5	21.74	3	20.00	10	31.25	7	28.00	6	27.27
Cost burden in relation to diagnostic tests and scans	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	3	20.00	5	15.63	5	20.00	3	13.64
Cost burden in relation to needing to take time off work	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	4	26.67	4	12.50	5	20.00	3	13.64
Cost burden in relation to the cost specialist appointments	7	14.89	7	26.92	0	0.00	4	16.67	3	13.04	4	26.67	3	9.38	4	16.00	3	13.64
Cost burden in relation gap payments	6	12.77	3	11.54	3	14.29	3	12.50	3	13.04	3	20.00	3	9.38	5	20.00	1	4.55
Cost burden in needing to special equipment	5	10.64	3	11.54	2	9.52	2	8.33	3	13.04	1	6.67	4	12.50	1	4.00	4	18.18
Cost burden in relation to allied health care	4	8.51	4	15.38	0	0.00	2	8.33	2	8.70	2	13.33	2	6.25	3	12.00	1	4.55
Cost burden in relation to GP appointments	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	1	6.67	3	9.38	2	8.00	2	9.09
Cost burden in relation to a family member needing to take time off work	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	0	0.00	3	9.38	1	4.00	2	9.09
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	2	13.33	1	3.13	2	8.00	1	4.55
No cost burden and that nearly everything was paid for through the public health system	8	17.02	6	23.08	2	9.52	5	20.83	3	13.04	2	13.33	6	18.75	5	20.00	3	13.64
No cost burden as participant was able to afford all costs	5	10.64	4	15.38	1	4.76	4	16.67	1	4.35	1	6.67	4	12.50	4	16.00	1	4.55
No cost burden and that nearly everything was paid for through the private health system	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	2	13.33	2	6.25	2	8.00	2	9.09
No cost burden as participant was able to access paid medical leave	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
No cost burden: satisfied with experience	3	6.38	0	0.00	3	14.29	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55

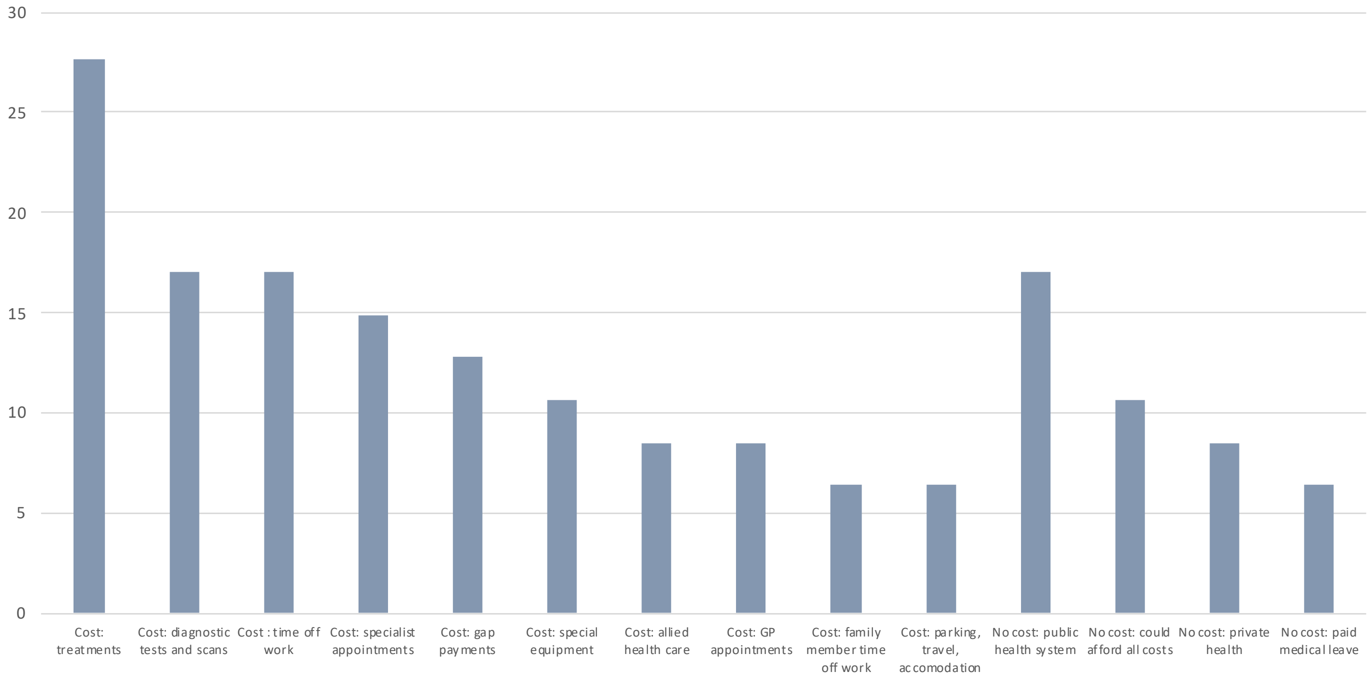

Figure 8.13: Cost considerations (Reasons for cost)

Table 8.26: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (reasons for costs)	Reported less frequently	Reported more frequently
Cost burden in relation to the cost of treatments (including repeat scripts)	High cholesterol under 50 years of age	
Cost burden in relation to diagnostic tests and scans	High cholesterol under 50 years of age	
Cost burden in relation to needing to take time off work		Blood vessel conditions
Cost burden in relation to the cost specialist appointments	Male	6 to 11 other conditions Female Regional or remote
Cost burden in needing to special equipment	High cholesterol under 50 years of age 0 to 5 other conditions	6 to 11 other conditions
Cost burden in relation to a family member needing to take time off work		Blood vessel conditions
No cost burden and that nearly everything was paid for through the public health system		High cholesterol under 50 years of age
No cost burden as participant was able to afford all costs		High cholesterol under 50 years of age
No cost burden and that nearly everything was paid for through the private health system		
No cost burden: satisfied with experience		Had LP(a) test

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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.

The average score was in the Life was a little distressing to average range (median=3.50, IQR=3.00).

Table 8.27: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=48)	Percent
1 Life is/was very distressing	5	10.42
2 Life is/was distressing	12	25.00
3 Life is/was a little distressing	7	14.58
4 Life is/was average	8	16.67
5 Life is/was good	8	16.67
6 Life is/was very good	7	14.58
7 Life is/was great	1	2.08

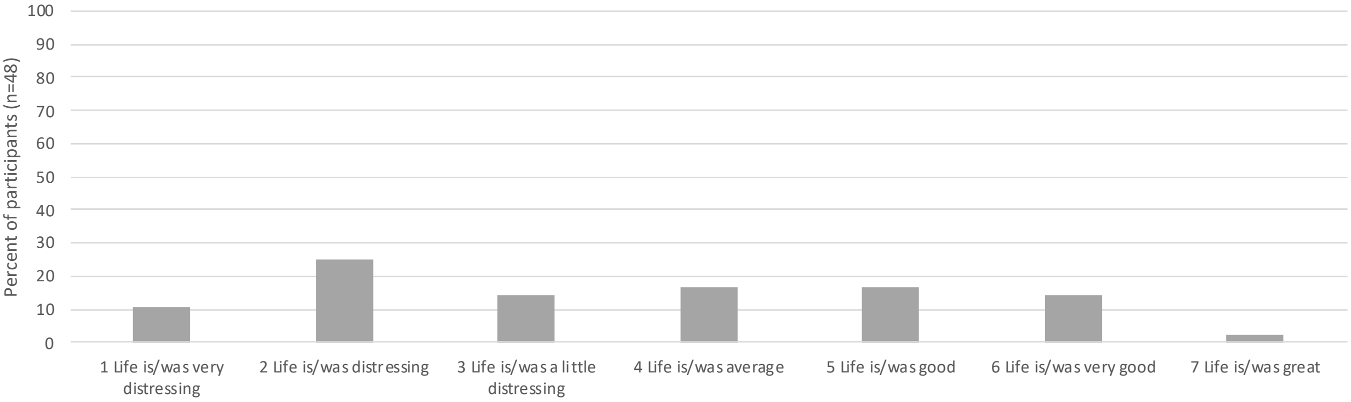

Figure 8.14: Overall impact of condition on quality of life

Experience of anxiety related to disease progression

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. The overall scores for the cohort were in the middle quintile for Fear of progression: Total score (mean=33.68, SD=11.32) indicating moderate levels of anxiety.

Comparisons of Fear of Progression have been made by LP(a) test status, main condition, number of other health conditions, gender, age, location, and socioeconomic status.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Table 8.28: Fear of progression summary statistics

Fear of progression (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.68	11.32	33.00	15.75	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by LP(a) test

Comparisons were made by **LP(a) Test status** there were 19 participants (38.00%) that had an LP(a) test and, 31 participants (62.00%) that did not have an LP(a) test.

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **LP(a) test** for any of the Fear of progression scales.

Table 8.29: Fear of progression total score by LP(a) test summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Had LP(a) test	19	38.00	34.00	10.46	0.15	48	0.8775
	Not had LP(a) test	31	62.00	33.48	11.98			

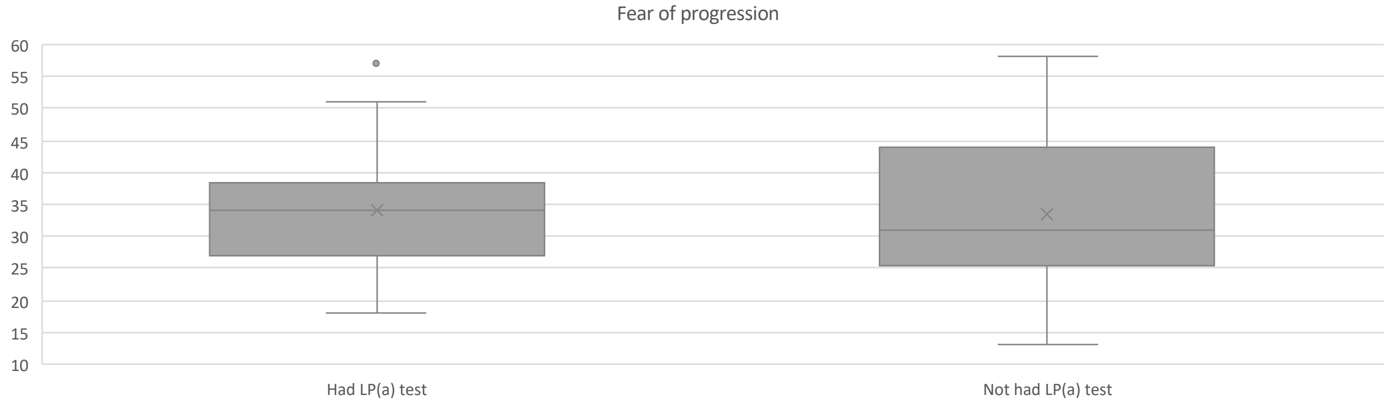

Figure 8.15: Boxplot of Fear of progression total score by LP(a) test

Fear of progression by main condition

Comparisons were made by the participants' **main condition**. There were 12 participants (24.00%) with high cholesterol aged under 50 years of age, 17 participants (34.00%) with blood vessel conditions, and 21 participants (42.00%) with heart conditions.

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

No significant differences were observed between participants by **main condition** for any of the Fear of progression scales.

Table 8.30: Fear of progression total score by main condition summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	High cholesterol under 50 years of age	8	16.33	35.00	10.78	Between groups	140.00	2	69.88	0.54	0.59
	Blood vessel conditions	19	38.78	31.35	12.97	Within groups	6139.00	47	130.62		
	Heart conditions	22	44.90	34.81	10.42	Total	6279.00	49	200.50		

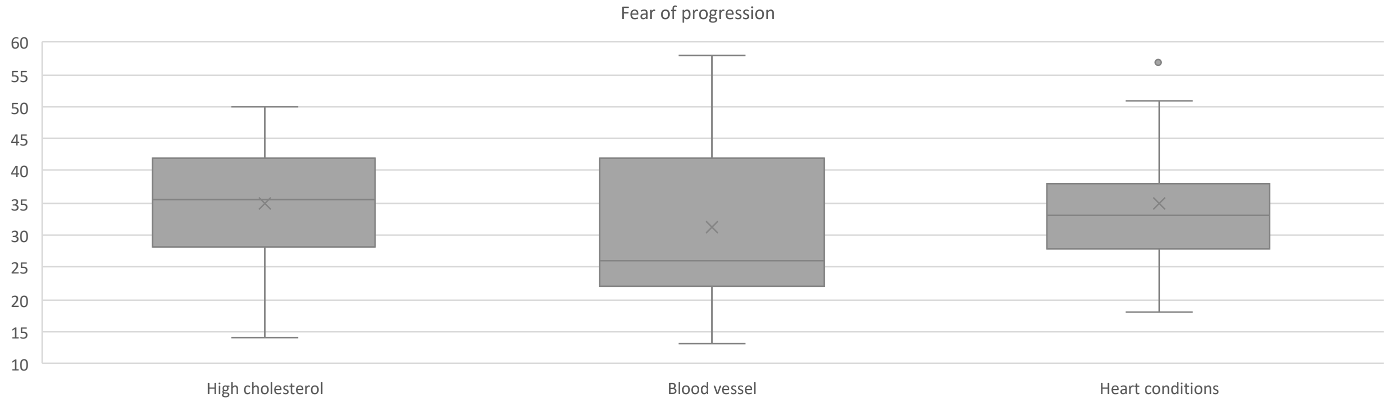

Figure 8.16: Boxplot of Fear of progression total score by main condition

Fear of progression by other conditions

Comparisons were made by **number of other health conditions** there were 27 participants (54.00%) with 0 to 5 other conditions and, 23 participants (46.00%) with 6 to 11 other conditions.

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **other conditions** for any of the Fear of progression scales.

Table 8.31: Fear of progression total score by other conditions summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	0 to 5 other conditions	27	54.00	31.07	10.98	-1.80	48	0.0775
	6 to 11 other conditions	23	46.00	36.74	11.18			

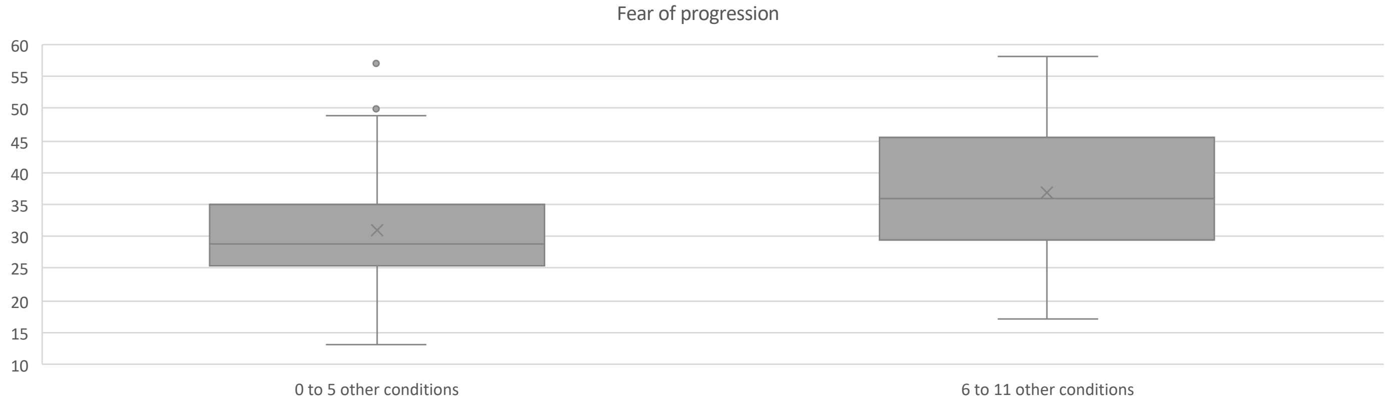

Figure 8.17: Boxplot of Fear of progression total score by other conditions

Fear of progression by gender

Comparisons were made by **gender**, there were 28 female participants (56.00%), and 22 male participants (44.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **gender** for any of the Fear of progression scales.

Table 8.32: Fear of progression total score by gender summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Female	28	56	33.82	11.89	0.10	48	0.9218
	Male	22	44	33.50	10.82			

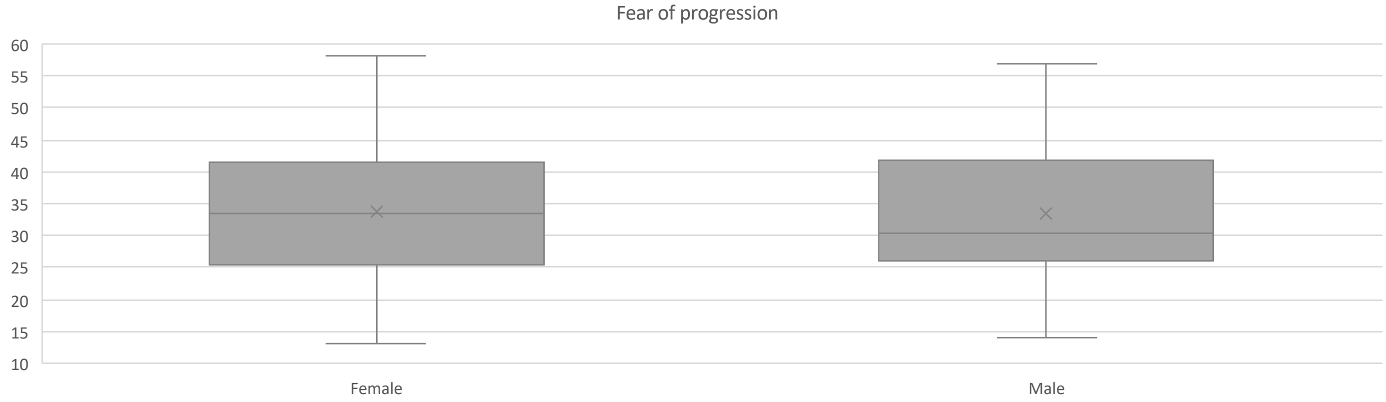

Figure 8.18: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to **age**, with comparisons made between participants aged 25 to 44 (n=27, 54.00%), and participants aged 45 and older (n=23, 46.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **age** for any of the Fear of progression scales.

Table 8.33: Fear of progression total score by age summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 44	27	54.00	33.41	11.07	-0.18	48	0.8558
	Aged 45 and older	23	46.00	34.00	11.85			

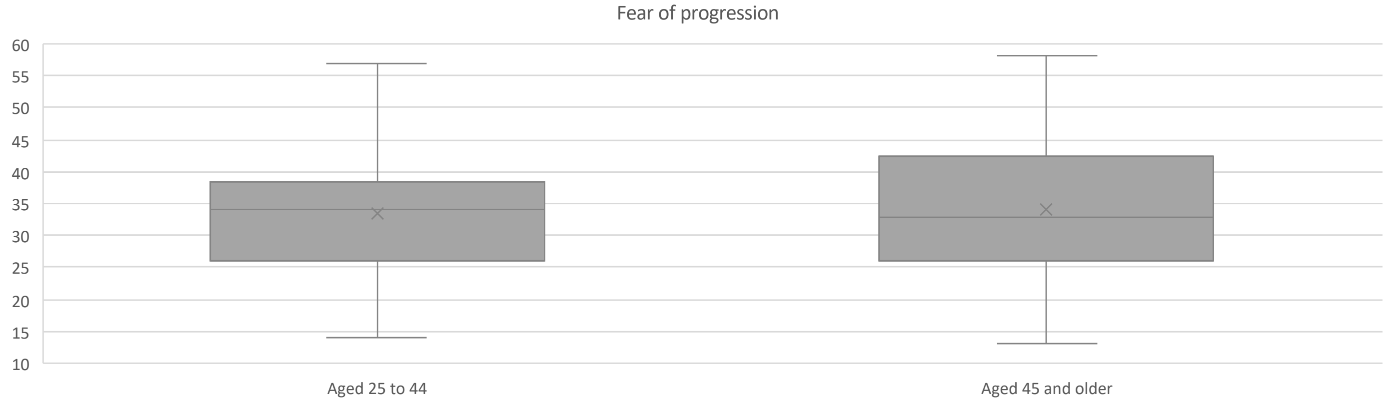

Figure 8.19: Boxplot of Fear of progression total score by age

Fear of progression by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=15, 30.00%) were compared to those living in metropolitan areas (n=35, 70.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **location** for any of the Fear of progression scales.

Table 8.34: Fear of progression total score by location summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	30.00	34.73	10.01	0.43	48	0.6712
	Metropolitan	35	70.00	33.23	11.95			

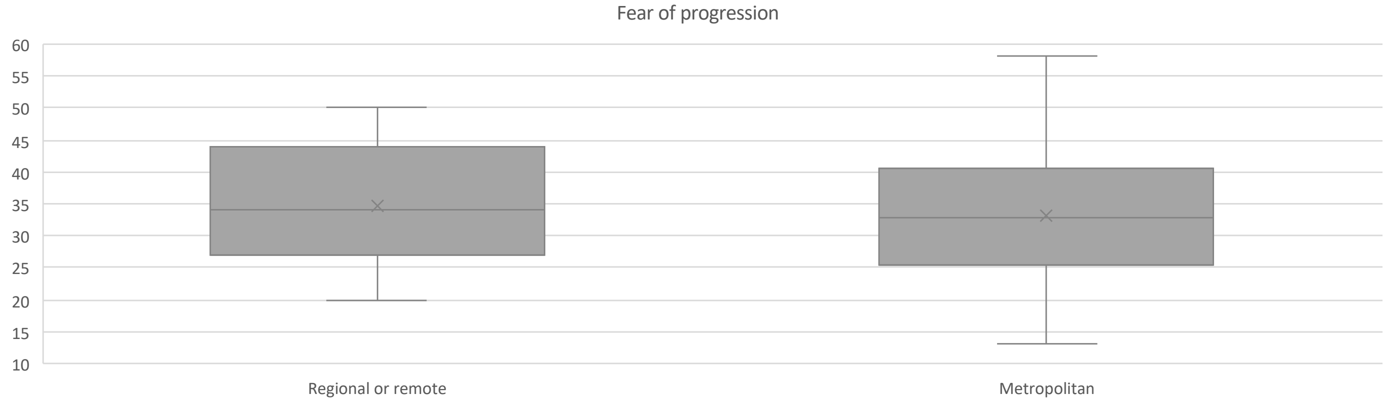

Figure 8.20: Boxplot of Fear of progression total score by location

Fear of progression by socioeconomic advantage

Comparisons were made by **socioeconomic status**, using the 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 mid to low SEIFA score of 1-6, Mid to low status (n=25, 50.00%) compared to those with a higher SEIFA score of 7-10, Higher status (n=25, 50.00%).

Assumptions for normality and variance were met, a two-sample t-test was used.

No significant differences were observed between participants by **socioeconomic advantage** for any of the Fear of progression scales.

Table 8.35: Fear of progression total score by socioeconomic advantage summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=50)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low socioeconomic status	25	50.00	31.56	11.77	-1.33	48	0.1882
	Higher socioeconomic status	25	50.00	35.80	10.67			

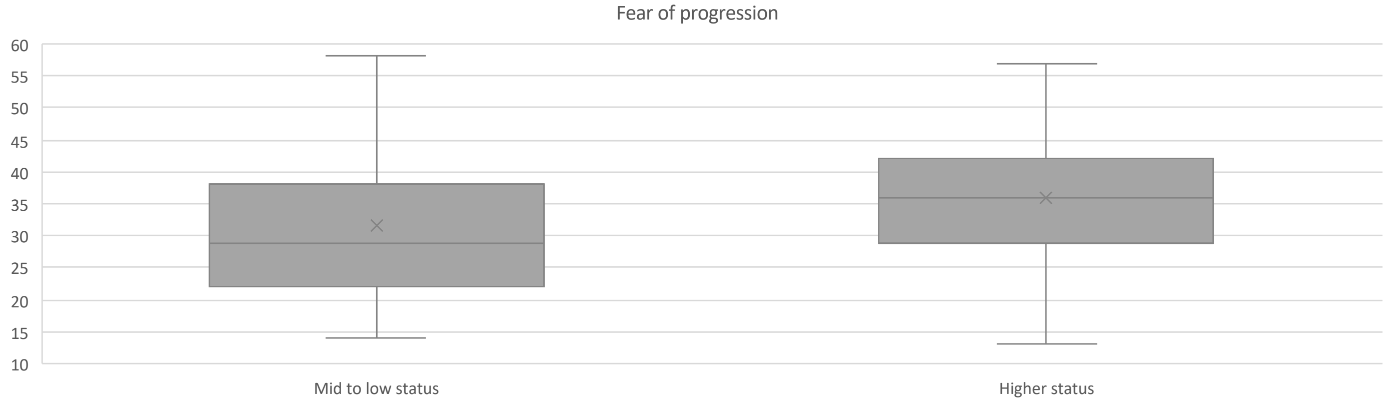

Figure 8.21: Boxplot of Fear of progression total score by socioeconomic advantage

Experience of anxiety related to disease progression

Fear of progression individual questions

On average, participants scored in the "**Never**" range for the following questions: "Anxious if not experiencing any side effects think it doesn't work" (median=1.00, IQR=0.00).

On average, participants scored in the "**Seldom**" range for the following questions: "Is nervous prior to doctors appointments or periodic examinations" (median=2.00, IQR=1.75), "Afraid of pain" (median=2.00, IQR=1.75).

On average, participants scored in the "**Sometimes**" range for the following questions: "Becomes anxious thinking that disease may progress" (median=3.00, IQR=2.00), "Has concerns about reaching professional and/or personal goals because of illness:" (median=3.00, IQR=3.00), "When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation" (median=2.50, IQR=2.00), "The possibility of relatives being diagnosed with this disease disturbs participant" (median=3.00, IQR=2.00), "Is disturbed that they may have to rely on strangers for activities of daily living" (median=2.50, IQR=2.75), "Worried that at some point in time will no longer be able to pursue hobbies because of illness" (median=3.00, IQR=2.00), "Afraid of severe medical treatments during the course of illness" (median=2.50, IQR=2.00), "Worried that treatment could damage their body" (median=3.00, IQR=2.75), "Worried about what will become of family if something should happen to participant" (median=3.00, IQR=2.00), "The thought that they might not be able to work due to illness disturbs participant" (median=3.00, IQR=3.50), "If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped" (median=3.00, IQR=1.75).

Table 8.36: Fear of progression individual questions

Fear of progression (n=50)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	2.88	1.30	3.00	2.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.56	1.30	2.00	1.75	Seldom
Afraid of pain	2.52	1.23	2.00	1.75	Seldom
Has concerns about reaching professional and/or personal goals because of illness:	3.06	1.54	3.00	3.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.72	1.23	2.50	2.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.82	1.30	3.00	2.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.54	1.49	2.50	2.75	Sometimes
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.08	1.28	3.00	2.00	Sometimes
Afraid of severe medical treatments during the course of illness	2.56	1.40	2.50	2.00	Sometimes
Worried that treatment could damage their body	2.82	1.42	3.00	2.75	Sometimes
Worried about what will become of family if something should happen to participant	3.04	1.37	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	3.02	1.57	3.00	3.50	Sometimes
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.62	1.23	3.00	1.75	Sometimes
Anxious if not experiencing any side effects think it doesn't work	1.56	1.11	1.00	0.00	Never

*Normal distribution use mean and SD as measure of central tendency

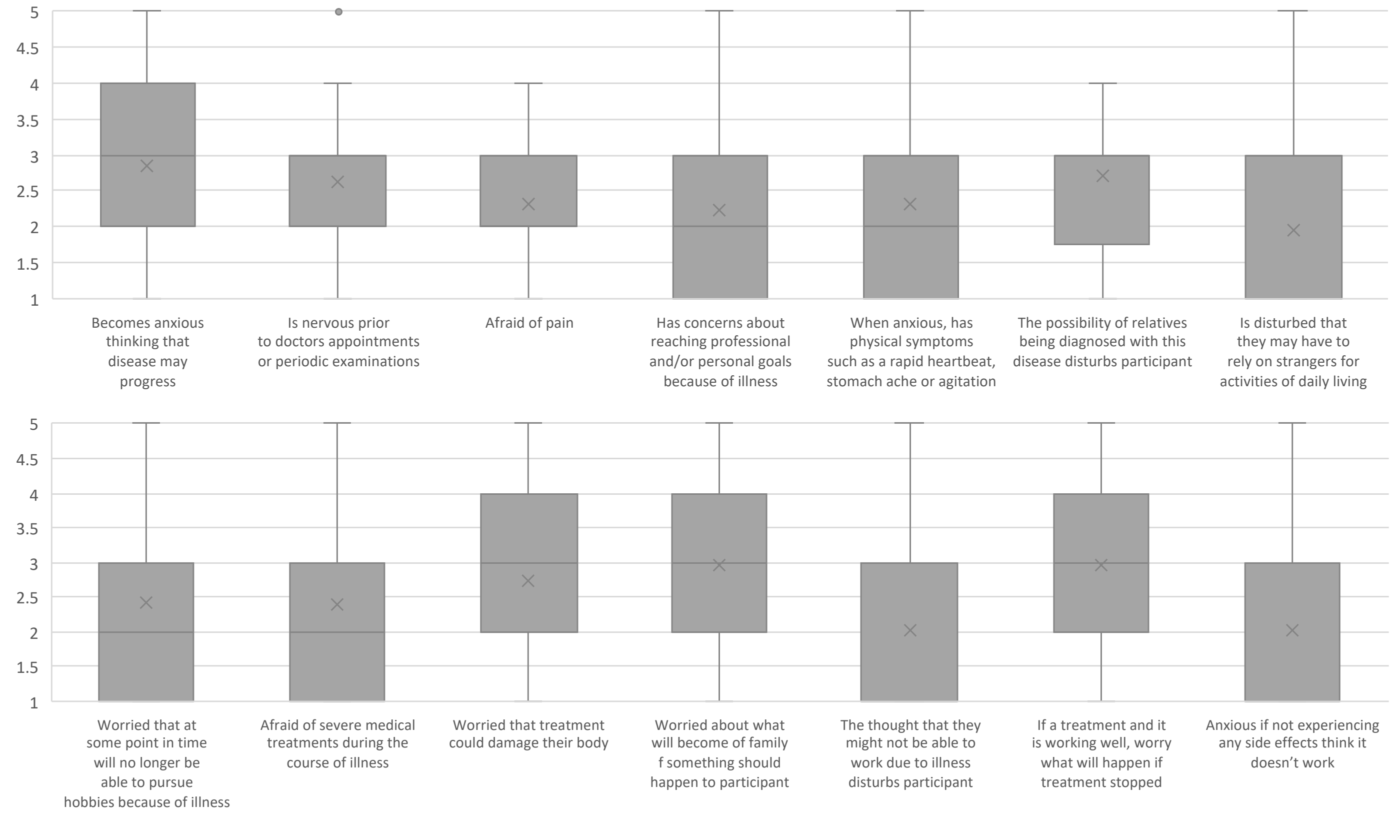

Figure 8.22: Fear of progression individual questions

Section 9

Expectations and messages to decision-makers

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 responses were that future treatment will be more affordable (25.53%), will include having choice including availability, accessibility, transparency and discussions in relation to treatment options (21.28%), and will be more effective, targeted, or personalised (17.02 %). Other themes included have fewer or less intense side effects and more discussion about side effects (12.77%), involve a more holistic approach (10.64%), more access to rehabilitation (10.64%), involve more clinical trials, including to access new technologies and treatments and funding (8.51%), and will manage symptoms and prevention of disability (8.51%). There were 6 participants (12.77%) that were satisfied with experience.

Expectations of future information

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 expectations for future healthcare professional communication were that communication will be more empathetic (29.79%) and will allow people more time to meet with their clinician (17.02 %). Other themes included that communication will be more transparent and forthcoming (14.89%), will be more understandable (14.89%), will include a multidisciplinary and coordinated approach (10.64%), will include listening to the patient (8.51%), and will be more holistic, including emotional health (8.51%). There were 15 participants (31.91%) who were satisfied with the communication they had.

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 expectation for future care and support was that care and support will include being able to connect with other patients through peer support (17.02%), will include a multidisciplinary and coordinated approach (17.02%), and will include practical support for example home care, transport, and financial support (12.77 %). Other themes included future care and support will include more long-term condition management (10.64%), will include specialist clinics or services where they can talk to professionals, in person, by phone or online) (10.64%), will be more holistic, including emotional health (10.64%), and include more access to support services (8.51%). There were 4 participants (8.51%) who were satisfied with the care and support received (8.51%).

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 responses were that participants were grateful for healthcare staff, including access to specialists (42.55%), low cost or free medical care through the government (27.66%), and the entire health system (19.15 %). Other themes included access to private healthcare or private health insurance (12.77%), and timely access to diagnostics (6.38%).

Values in making decisions

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 Ability to follow and stick to a treatment regime and The ability to include my family in making treatment decisions.

Values for decision makers

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve 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 = 32, 64.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There was 1 participant (2.00%) that thought that medicine delivered by IV was most effective, 22 participants (44.00%) thought that pill form was most effective, and 11 participants (22%) that thought they were equally effective. There were 16 participants (32.00%) that were not sure.

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 messages to the health minister were the need for timely and equitable access to support, care and treatment (25.53%), that treatments need to be affordable (19.15%), and that they were grateful for the healthcare system and the treatment that they received (19.15 %). Other themes included to improve rural services (19.15%), to invest in prevention (19.15%), to increase investment in general (17.02%), to help raise community awareness (14.89%), to invest in health professionals to service the patient population (14.89%), and to have a holistic approach to the condition that includes emotional support (10.64%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (25.53%), will include having choice including availability, accessibility, transparency and discussions in relation to treatment options (21.28%), and will be more effective, targeted, or personalised (17.02 %). Other themes included have fewer or less intense side effects and more discussion about side effects (12.77%), involve a more holistic approach (10.64%), more access to rehabilitation (10.64%), involve more clinical trials, including to access new technologies and treatments and funding (8.51%), and will manage symptoms and prevention of disability (8.51%). There were 6 participants (12.77%) that were satisfied with experience.

Future treatment will be more affordable

Cost, but I don't really know because I've never technically been on any proper treatments.
Participant 007_2023AUHBV

The main thing I would say for me is cost. So any of the treatments that I've had haven't caused the any major side effects. Yeah, one once, you know, my system got used to it.
Participant 015_2023AUHBV

They definitely need to be covered by the government cost-wise. Because when I think of stroke, I think diabetes is often involved normally. If you think about someone's diabetic and they've had a stroke, they will have insulin costs, they may have sensors. They'll have additional costs that go along with their diabetes alone. If they're on a pension, they've had a stroke, they've got diabetes, chances are they've had high blood pressure. Numerous things are going to add up to lots of pennies, lots of dollars. I know we're very lucky to live where we live.
Participant 050_2023AUHBV

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

I think providing equal access to treatments for everybody and having good, good value. In the medications too, because that's quite an issue, like some medications are quite restricted. So you've got to meet a certain criteria to be able to even get on get a medication that might work. So that could be a bit frustrating for people. So I think those sort of things are really important to be able to, to achieve equality I guess.
Participant 011_2023AUHBV

So I think the first thing that comes to mind is cost, although it doesn't have the same effect on me as it does someone else. Like it's it is a burden. If I didn't have that burden, that'd be fantastic. And I imagine it'd be even more better. It would be even more amazing. But other people didn't have to deal with it. So I think, I think cost is like probably the biggest and availability actually growing, growing up in a country, semi country, semi rural town is the availability of not having to travel 3 1/2 hours to get, you know, just to see a cardiologist or whatever would be fantastic. If you could just do it from the hospital that was literally 250 metres from my house, that would be fantastic. But that wasn't available. So you would travel, but if that was a different option, that would be great. Didn't have to miss days of school, which sometimes you wanted to as a kid, but you know whatever. And mom and dad didn't have to take days off work to take us to these appointments. That'd be that'd be fantastic. Participant 012_2023AUHBV

I think cost and accessibility to the treatments. Yes, accessibility and cost. The side effects, to me they're secondary. The cost and accessibility would be the major things I would like to see happen across the board, in the country and in the cities, even throughout the world, the states.
Participant 049_2023AUHBV

Future treatment will be more effective and/or targeted (personalised)

I think for me. So I I think a little bit of differentiated sort of care like as far as treatments go, your condition whilst maybe heart related is not the same as your condition and care more care and treatment more specific to the heart condition in my sense relative to me not an overall this is how we treat heart patients plan. I think, I think that you know, being more aligned to me and and what happened to my heart would would be a better approach. It's same with the cardiac rehab, you know, being more more specific to my treatment plan.
Participant 009_2023AUHBV

PARTICIPANT: So something that applies to my situation, not just that stereotypical Change your diet. Stop eating McDonald's. INTERVIEWER:You know, something applicable, yes. So something's effective for you.
PARTICIPANT: Yeah, yeah.
INTERVIEWER:Anything else you'd like to see from your treatments?
PARTICIPANT: That's, that's first and foremost.
Participant 020_2023AUHBV

Future treatments will have fewer or less intense side effects/more discussion about side effects

I think all, all, all drugs have have side effects but I think the if they can minimize them as much as possible and that that can be a continual ongoing process. You know it's not just the right, this is a drug, it works, but these are the side effects and not look at it anymore just continually looking at how they they can lessen the the side effects of of drugs. So that's the main thing. And then I think making the treatment as easy as possible. So for example, you're not having to go for regular hospital appointments or things like that. Things can be done within your daily routine at home.
Participant 017_2023AUHBV

Fracture-proof leads, for devices. Something to improve lead fractures. What else would I like? Yeah, less lethargy related to the medication. That would just be fantastic. Or side effects, you know, less of the side effect profile for the medications. What else would I like? A treatment that would fix my arrhythmias, so that my condition would not be there anymore. And I know that they're working towards all of that continually, so that might be something that comes along, which would be an amazing blessing.
Participant 030_2023AUHBV

Satisfied with experience

Look, no, no, I've. I've had a pretty fair run with it. So I I've got no issues. Yeah, right. So it's pretty, pretty clear, you know, the people, everyone tries their best.
Participant 004_2023AUHBV

I don't know, I'm quite happy, yeah with what my situation, I suppose. I've never really thought about it. This is working for me.
Participant 016_2023AUHBV

No, I don't. I think I believe like my care was perfectly good and perfectly fine. I probably wouldn't have me personally. I wouldn't want to change anything to do with my care, as yeah, it was pretty easy to just follow, follow with and cooperate with to get myself better. So I don't, yeah. I personally believed I would change anything.
Participant 029_2023AUHBV

Future treatment will involve a more holistic approach

From my own point of view, there's probably nothing, but I'm quite sure there are people who aren't in my situation that would need that ongoing rehabilitation if they weren't able to be proactive for themselves, that ongoing rehab services, which is you that you know that emotional and and also you know physical things that you need to do. I think that would probably be a benefit to a lot of people. And I mean it was, it was, it was truly the best thing that could happen to me after. Like to manage my condition after that and to have it ongoing, to have it not just finish after a fixed period of time and for that to be ongoing for people, I think that would be an absolute bonus.
Participant 013_2023AUHBV

I would like to see medication be cheaper. We travelled over an airline to be able to go to a different chemist to get to a big brand name chemist to get our medications cheaper because our local chemists are extremely expensive. I feel that support groups and more information would be very beneficial to people having strokes.
Participant 047_2023AUHBV

Future treatments will include more access to rehabilitation

Yeah. Up here I would like to have more support with heart failure staff as far as doing rehab.
Participant 033_2023AUHBV

I think rehab needs to be more realistic when they try and help people back into the community, because it's more clinical.
Participant 044_2023AUHBV

My only concern is the length of rehabilitation. I had three months of rehab. It's not long enough. You do your three months then you're on your own. I've spoken to the Stroke Foundation and I've spoken to seminars of medical practitioners where I've suggested that follow-up rehab. You do your treatments at rehab and that's it. If there could be a six-monthly or 12-monthly follow-up. That doesn't

happen right now, but I truly believe that that would make the stroke recovery journey a lot better.
Participant 045_2023AUHBV

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

I mean, I guess, medications with less side effects. In LOCATION METROPOLITAN, there was a pacemaker that I could use. The trend is they are getting smaller and smaller.
Participant 023_2023AUHBV

New treatment? Smaller implants. I know there is a small implant now, but I'm not sure how good that is, how effective it is, how long it'll last, all of that. I need to have a valve replaced, and I know you can do that without major surgery, so I'm happy with the progress that medicine is taking. Maybe one day they will grow a heart out of your own genes.
Participant 034_2023AUHBV

I'd probably wonder what causes it. I mean I could look it up, I guess, what causes it, and what I should be doing that I'm not doing to live longer and if there's any new drugs, like my mother took out something, so is there anything better than that? It seems to be working. I'm not having palpitations. I'm not having any chest pain. I'm not having any symptoms at all.
Participant 037_2023AUHBV

Future treatments will include managing symptoms and prevention of disability

PARTICIPANT: Yeah. Well, obviously you want more treatments, so that would be good, if there were more treatments to manage symptoms, and reduced symptoms could increase my heart function, so that would be good. So that's what I can say for myself, and I can be more proactive about it too, I just don't -- I just sort of haven't….
Participant 032_2023AUHBV

I think there's a lot of work being done on research to provide treatment to disability. That would be the best thing I'd like to see. I'd like to see whether they can get an injection that will stop our disability. As an example, the way I talk to you, my vulnerability. Those are the two things that concern me the most.
Participant 040_2023AUHBV

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Future treatment will be more affordable	12	25.53	5	27.78	7	24.14	2	22.22	**7**	**41.18**	**3**	**14.29**	5	18.52	7	35.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	10	21.28	**1**	**5.56**	9	31.03	2	22.22	2	11.76	6	28.57	**3**	**11.11**	**7**	**35.00**
Future treatment will be more effective and/or targeted (personalised)	8	17.02	**1**	**5.56**	7	24.14	2	22.22	3	17.65	3	14.29	5	18.52	3	15.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	12.77	3	16.67	3	10.34	2	22.22	1	5.88	3	14.29	3	11.11	3	15.00
No particular comment - satisfied with experience	6	12.77	3	16.67	3	10.34	1	11.11	1	5.88	4	19.05	3	11.11	3	15.00
Future treatment will involve a more holistic approach	5	10.64	**0**	**0.00**	5	17.24	**0**	**0.00**	3	17.65	2	9.52	3	11.11	2	10.00
Future treatments will include more access to rehabilitation	5	10.64	1	5.56	4	13.79	**0**	**0.00**	3	17.65	2	9.52	3	11.11	2	10.00
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	4	8.51	1	5.56	3	10.34	0	0.00	0	0.00	**4**	**19.05**	3	11.11	1	5.00
Future treatments will include managing symptoms and prevention of disability	4	8.51	2	11.11	2	6.90	1	11.11	2	11.76	1	4.76	3	11.11	1	5.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00

Expectations of future treatments	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Future treatment will be more affordable	12	25.53	7	26.92	5	23.81	6	25.00	6	26.09	**6**	**40.00**	6	18.75	7	28.00	5	22.73
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	4	26.67	6	18.75	5	20.00	5	22.73
Future treatment will be more effective and/or targeted (personalised)	8	17.02	6	23.08	2	9.52	3	12.50	5	21.74	4	26.67	4	12.50	6	24.00	2	9.09
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	1	6.67	5	15.63	2	8.00	4	18.18
No particular comment - satisfied with experience	6	12.77	4	15.38	2	9.52	2	8.33	4	17.39	**0**	**0.00**	6	18.75	3	12.00	3	13.64
Future treatment will involve a more holistic approach	5	10.64	4	15.38	1	4.76	1	4.17	4	17.39	2	13.33	3	9.38	2	8.00	3	13.64
Future treatments will include more access to rehabilitation	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	3	20.00	2	6.25	3	12.00	2	9.09
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	1	6.67	3	9.38	1	4.00	3	13.64
Future treatments will include managing symptoms and prevention of disability	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	6.38	3	11.54	0	0.00	3	12.50	0	0.00	0	0.00	3	9.38	1	4.00	2	9.09

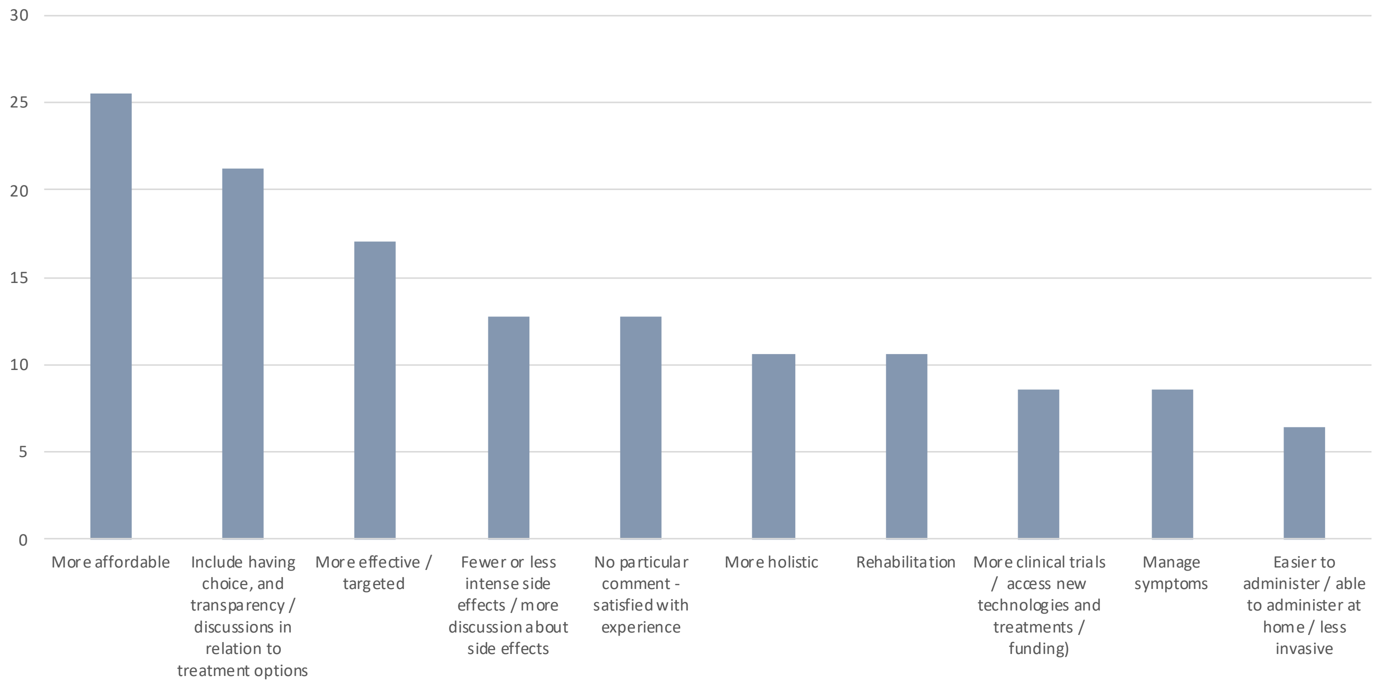

Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatments	Reported less frequently	Reported more frequently
Future treatment will be more affordable	Heart conditions	Blood vessel conditions Regional or remote
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Had LP(a) test 0 to 5 other conditions	6 to 11 other conditions
Future treatment will be more effective and/or targeted (personalised)	Had LP(a) test	-
No particular comment - satisfied with experience	Regional or remote	-
Future treatment will involve a more holistic approach	Had LP(a) test High cholesterol under 50 years of age	-
Future treatments will include more access to rehabilitation	High cholesterol under 50 years of age	-
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	-	Heart conditions

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 response was they were satisfied with the information they received (21.28%). The most common themes in relation to what they would like to see in the future were that information will be in a variety of formats (17.02%), and that information will provide more details about disease trajectory and what to expect (17.02%). Other themes included that information will be easier to understand (14.89%), will be more holistic, including emotional health (12.77%), will be more accessible/easy to find (10.64%), will include the ability to talk to or access to a health professional (8.51%), will provide more details about the causes of their condition (8.51%), and will provide more details about where to find support including peer support (6.38%).

Satisfied with experience

PARTICIPANT: It's another hard one to answer because it's sort of didn't and doesn't really affect me…If I wanted to know something, I just have to ask
Participant 005_2023AUHBV

No, no, no. I get. I get as much information as required through a product professor of cardiology.
Participant 006_2023AUHBV

No, I think it was pretty good, actually. Like, yeah, they were pretty. They were pretty good with communication information. They were pretty good with keeping my mom in the loop as well, making her aware of they'd give her phone calls when I was there, making her aware of my test results, etcetera. So no, Yeah. Would say that they were pretty good with it all, so.
Participant 029_2023AUHBV

Nothing comes to mind. Yeah, I don't feel like there was ever anything that I couldn't get information on. Yeah.
Participant 035_2023AUHBV

Future information will be in a variety of formats

Yeah, probably what I just mentioned. So maybe a list of the top suggested. OK. Yeah, natural supports and maybe a written form, so like a pamphlet would be great, excellent.
Participant 019_2023AUHBV

I think a lot of it was all reading for me. I'm very visual, so for me I would have liked to have had some illustrations that kind of point to like I know the main heart and the main I guess arteries and all that sort of stuff. But I wasn't quite able to work out which branch or which artery is where my issue is and but if I could visualize it, it would make it a lot easier for me.
Participant 021_2023AUHBV

Future information will provide more details about disease trajectory and what to expect

Just simple things like, is it fixable or is a lifelong illness we have to control? Stuff like that. It's that simple. Yeah, 'cause it's like…Well, maybe it's just my thought, "Tablets and whatever and then it all fixes up." And then in LOCATION they said, "You've got that for life. That's just part of you now."
Participant 038_2023AUHBV

If you have a stroke at a young age and years like mine have gone by, my body is now getting-- I'm probably going backwards and not forward, information about being aware of your body will break down probably earlier than it would naturally. To have ongoing treatment every two or three years, that sort of information is not there, you have to go and find that, whether it's normal or not. I found that when I was feeling things happening in my stroke hand, affected hand, that I didn't know whether I could access services or what to do about it, whether it was normal that my hand was doing what it was doing. That thing, that what happens, having a stroke at a young age, what's your long-term effects and conditions. If that makes sense.
Participant 049_2023AUHBV

Future information will be easier to understand

Obviously, you know a lot of people learn better from reading and so forth. You know, that's not to say that I don't learn from reading or research, but I do learn better from, you know, that one-on-one environment or that environment where you're able to freely ask a question and you actually get a presented answer in an understandable format. But then that's, you know, I suppose that that comes into the ability of communication and, you know, people's comprehension of things.
Participant 018_2023AUHBV

Table 9.3: Expectations of future information

Expectations of future information	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
No particular comment - satisfied with experience	10	21.28	5	27.78	5	17.24	**0**	**0.00**	5	29.41	5	23.81	8	29.63	**2**	**10.00**
Future information will be in a variety of formats	8	17.02	4	22.22	4	13.79	**3**	**33.33**	2	11.76	3	14.29	5	18.52	3	15.00
Future information will provide more details about disease trajectory and what to expect	8	17.02	**1**	**5.56**	7	24.14	1	11.11	3	17.65	4	19.05	3	11.11	5	25.00
Future information will be easier to understand	7	14.89	3	16.67	4	13.79	2	22.22	1	5.88	4	19.05	4	14.81	3	15.00
Future information will be more holistic (including emotional health)	6	12.77	2	11.11	4	13.79	1	11.11	**4**	**23.53**	1	4.76	3	11.11	3	15.00
Future information will be more accessible/easy to find	5	10.64	3	16.67	2	6.90	**2**	**22.22**	2	11.76	1	4.76	3	11.11	2	10.00
Future information will include the ability to talk to/access to a health professional	4	8.51	1	5.56	3	10.34	0	0.00	0	0.00	**4**	**19.05**	3	11.11	1	5.00
Future information will provide more details about the causes of their condition	4	8.51	0	0.00	4	13.79	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Future information will provide more details about where to find support (including peer support/support groups)	3	6.38	1	5.56	2	6.90	1	11.11	2	11.76	0	0.00	1	3.70	2	10.00
Future information will provide more details on subgroups and specific classifications of their condition	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Future information will provide more details to support carers	3	6.38	0	0.00	3	10.34	0	0.00	2	11.76	1	4.76	3	11.11	0	0.00

Expectations of future information	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
No particular comment - satisfied with experience	10	21.28	6	23.08	4	19.05	6	25.00	4	17.39	5	33.33	5	15.63	6	24.00	4	18.18
Future information will be in a variety of formats	8	17.02	4	15.38	4	19.05	7	29.17	1	4.35	4	26.67	4	12.50	7	28.00	1	4.55
Future information will provide more details about disease trajectory and what to expect	8	17.02	5	19.23	3	14.29	4	16.67	4	17.39	1	6.67	7	21.88	4	16.00	4	18.18
Future information will be easier to understand	7	14.89	4	15.38	3	14.29	7	29.17	0	0.00	3	20.00	4	12.50	5	20.00	2	9.09
Future information will be more holistic (including emotional health)	6	12.77	4	15.38	2	9.52	0	0.00	6	26.09	2	13.33	4	12.50	4	16.00	2	9.09
Future information will be more accessible/easy to find	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	0	0.00	5	15.63	0	0.00	5	22.73
Future information will include the ability to talk to/access to a health professional	4	8.51	1	3.85	3	14.29	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Future information will provide more details about the causes of their condition	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Future information will provide more details about where to find support (including peer support/support groups)	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55
Future information will provide more details on subgroups and specific classifications of their condition	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	0	0.00	3	13.64
Future information will provide more details to support carers	3	6.38	1	3.85	2	9.52	0	0.00	3	13.04	1	6.67	2	6.25	1	4.00	2	9.09

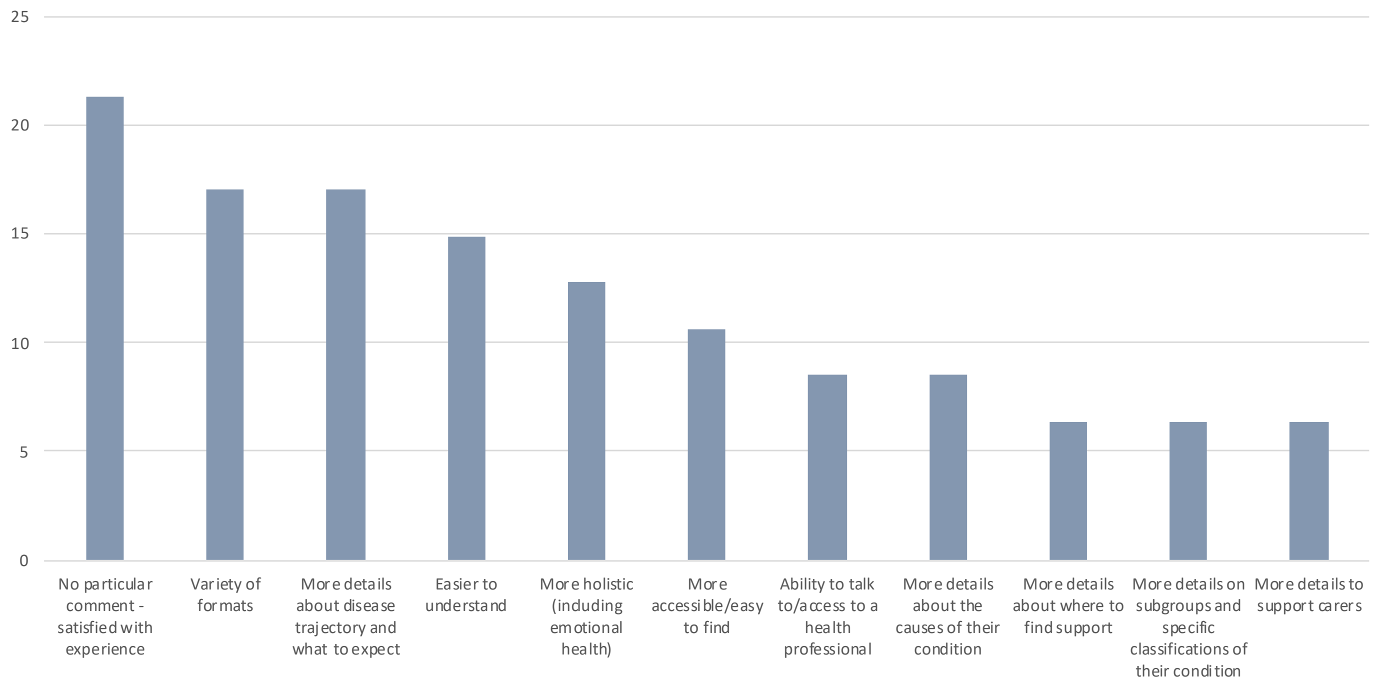

Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	High cholesterol under 50 years of age 6 to 11 other conditions	Regional or remote
Future information will be in a variety of formats	Aged 45 and older Higher socioeconomic status	High cholesterol under 50 years of age Aged 25 to 44 Mid to low socioeconomic status
Future information will provide more details about disease trajectory and what to expect	Had LP(a) test Regional or remote	-
Future information will be easier to understand	Aged 45 and older	Aged 25 to 44
Future information will be more holistic (including emotional health)	Aged 25 to 44	Blood vessel conditions Aged 45 and older
Future information will be more accessible/easy to find	Regional or remote Mid to low socioeconomic status	High cholesterol under 50 years of age Higher socioeconomic status
Future information will include the ability to talk to/access to a health professional	-	Heart conditions

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 expectations for future healthcare professional communication were that communication will be more empathetic (29.79%) and will allow people more time to meet with their clinician (17.02 %). Other themes included that communication will be more transparent and forthcoming (14.89%), will be more understandable (14.89%), will include a multidisciplinary and coordinated approach (10.64%), will include listening to the patient (8.51%), and will be more holistic, including emotional health (8.51%). There were 15 participants (31.91%) who were satisfied with the communication they had.

Satisfied with experience

No, because they're most that I've spoken to, all of them I spoke to have been pretty open and straightforward about it. You know, if you deal with people squarely, they deal with it squarely.
Participant 004_2023AUHBV

No. I think once I was diagnosed, it's all been very straightforward.
Participant 014_2023AUHBV

Not my doctors, no, no. I think they're doing a great job. Yeah.
Participant 025_2023AUHBV

No, not really. I've had a good relationship with all the health professionals who I know with.
Participant 040_2023AUHBV

No. Look, I don't think so. As I said before, I've been fairly lucky I guess. Both my neurologists have been pretty good. No, I don't think so.
Participant 043_2023AUHBV

Future communication will be more empathetic

Oh gosh, maybe some more empathy and empathy.
Participant 003_2023AUHBV

Just talk to patients. Treat them like they are a human being, not just a sample in a room.
Participant 038_2023AUHBV

Yes. In my communication with health professionals, my communication with rehabilitation people was perfect. My communication with doctors was less than perfect. The distinct lack of empathy, that when you're a stroke survivor, you need that empathy and I found my interaction with doctors lacked that empathy.
Participant 045_2023AUHBV

Future communication will allow people more time to meet with their clinician

I think in in general I would like to see put put in in into their routine opportunity for them to spend the time to do that, to spend time talking to somebody about a condition, talk to somebody about where to go for information or if not have somebody that they can refer you to that can do that. I think that's that is the thing that overall in in in health service and and other services is that there is isn't enough time and resources given to doing the sort of preventative. And I think that it's someone like me who isn't a dangerous level could get more information and do more preventative work. Know that they're on the right lines with their diet. Know that they're on the right lines with their exercise and their lifestyle changes and then less likely to have a heart attack and the cost and the the effort that that will cause in the long term.
Participant 017_2023AUHBV

I suppose that's more from the GPs, but a lot of it as an age and a personality-type issue. There's two different styles. But, I mean, I think it is important that there is a focus on that sort of communication and some time available that it is a proper consultation and just in and out. Yeah.
Participant 023_2023AUHBV

I think the main thing I see when I go to the doctor's is the massive amount of people for the short period of time. Especially at the specialist. The GP takes his time with you. You never feel rushed. At the specialist, I went to the eye specialist recently. It cost me hundreds of dollars and you wait hours for a 7 AM appointment. Then you work out that there's five 7 AM appointments and whoever arrives first gets seen first. I think health professionals need to take a step back and say we need to give quality time to each person and not book so many people because it's impossible to give quality time to people when you say, push the time yourself.
Participant 037_2023AUHBV

Future communication will be more transparent and forthcoming

We have touched on that one before with the cardiologist, but yeah, anything, anything else, just that they that they do communicate really well because I think sometimes they know in their own minds what the plan forward is or what the reasons are for doing certain things. But they don't necessarily feel the need to communicate that to the patient. You just sort of expected to go there and do what you're told, which I find difficult because I do need to. I need to understand why I'm doing what I'm doing.
Participant 019_2023AUHBV

Yes. I'd like to feel like I was a person not a condition. I feel they're more interested in the condition than me. It's not all of them but most of them. I'd like them to be able to tell me-- Give me the information rather than we have to ask for it.
Participant 041_2023AUHBV

Future communication will be more understandable

PARTICIPANT: I would like to see for other people, the medical professionals to be honest.
INTERVIEWER: Yes, honesty is very important, I agree.
PARTICIPANT: Yes, explain the medications or the treatments in a clear manner, no jargon talk. Straight points, don't do jargon. [laughs]
Participant 049_2023AUHBV

Future communication will include a multidisciplinary and coordinated approach

I think talking layman's terms, you know, and explain the next step perhaps. But yeah, that's a hard one. I don't know.
Participant 009_2023AUHBV

I'd just like them 'to' communicate. I'd just like them to just give someone some information when they leave the hospital, or somewhere to go, or someone they can call, or something. Just nothing. Again, I have to say, I'm extremely lucky. I'm smart, well-educated, successful career, family support, all of that, and it was bloody hard, and not everyone has that.
Participant 046_2023AUHBV

Future communication will include listening to the patient

Just the compassion side of things, I think like to know that someone's struggling so bad and they were in the beginning a little bit I. It wasn't until I had that second by the 1st ablation when he went in and said this is the worst case I've seen in a very long time. He was that that was the first time anyone that had, I felt like I'd been listened to properly. Do you know what I mean? Before that, it was like, I'll take this medicine, you'll be fine. It's like, no, you're not understanding. Yeah.
Participant 008_2023AUHBV

I wish they would listen to their patients. I really do. I'd love to help other people when they first have their stroke, what to expect, and be their support person, follow their journey with them.
Participant 042_2023AUHBV

Future communication will be more holistic (including emotional health)

It would be really good for some kind of pre preparation program to have someone check in like the cardiac nurse check in and say how you're traveling, what are you worried about this week? So I'd like there to be more awareness of the emotional journey.
Participant 010_2023AUHBV

What I was going to say is just to make a few more be a bit more sort of for lack of a better word like make the disclaimer be like hey, I know what I know, but like a chronic condition, you know there there's no quick fix. And yes we can offer like we we or we may be able to offer a pharmacological treatment but it's not going to be the end all be all like really you you need the the crux of it like they really need to just sort of add in the holistic side on like especially for these chronic diseases and just be like hey yes you know the there we we the the drug or the pill could be like the ambulance at the bottom of cliff or whatever. But there is a whole lot more efficacy and value if you actually focus Mr. Mrs. Patient if you focus your energy and efforts on behavior change you'll just get a lot more mileage and investment in retu'n for your investment. If you Mr. Mrs. Patient focus on some of the self-care strategies and and holistic therapies. You know some of it's just behaviour change.
Participant 001_2023AUHBV

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
No particular comment - satisfied with experience	15	31.91	**8**	**44.44**	7	24.14	2	22.22	5	29.41	8	38.10	9	33.33	6	30.00
Future communication will be more empathetic	14	29.79	5	27.78	9	31.03	**4**	**44.44**	5	29.41	5	23.81	7	25.93	7	35.00
Future communication will allow people more time to meet with their clinician	8	17.02	3	16.67	5	17.24	1	11.11	2	11.76	5	23.81	4	14.81	4	20.00
Future communication will be more transparent and forthcoming	7	14.89	2	11.11	5	17.24	2	22.22	3	17.65	2	9.52	3	11.11	4	20.00
Future communication will be more understandable	7	14.89	2	11.11	5	17.24	**0**	**0.00**	3	17.65	4	19.05	4	14.81	3	15.00
Future communication will include a multidisciplinary and coordinated approach	5	10.64	2	11.11	3	10.34	**2**	**22.22**	**0**	**0.00**	3	14.29	1	3.70	4	20.00
Future communication will include listening to the patient	4	8.51	1	5.56	3	10.34	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Future communication will be more holistic (including emotional health)	4	8.51	1	5.56	3	10.34	**2**	**22.22**	1	5.88	1	4.76	3	11.11	1	5.00
Future communication will include developing a care plan with follow-up	3	6.38	0	0.00	3	10.34	0	0.00	**3**	**17.65**	0	0.00	1	3.70	2	10.00

Expectations of future communication	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
No particular comment - satisfied with experience	15	31.91	6	23.08	**9**	**42.86**	9	37.50	6	26.09	5	33.33	10	31.25	9	36.00	6	27.27
Future communication will be more empathetic	14	29.79	8	30.77	6	28.57	9	37.50	5	21.74	**6**	**40.00**	8	25.00	8	32.00	6	27.27
Future communication will allow people more time to meet with their clinician	8	17.02	5	19.23	3	14.29	3	12.50	5	21.74	2	13.33	6	18.75	4	16.00	4	18.18
Future communication will be more transparent and forthcoming	7	14.89	5	19.23	2	9.52	3	12.50	4	17.39	3	20.00	4	12.50	3	12.00	4	18.18
Future communication will be more understandable	7	14.89	5	19.23	2	9.52	4	16.67	3	13.04	**4**	**26.67**	3	9.38	6	24.00	**1**	**4.55**
Future communication will include a multidisciplinary and coordinated approach	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	**0**	**0.00**	5	15.63	1	4.00	4	18.18
Future communication will include listening to the patient	4	8.51	3	11.54	1	4.76	0	0.00	4	17.39	0	0.00	4	12.50	2	8.00	2	9.09
Future communication will be more holistic (including emotional health)	4	8.51	3	11.54	1	4.76	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Future communication will include developing a care plan with follow-up	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	2	13.33	1	3.13	3	12.00	0	0.00

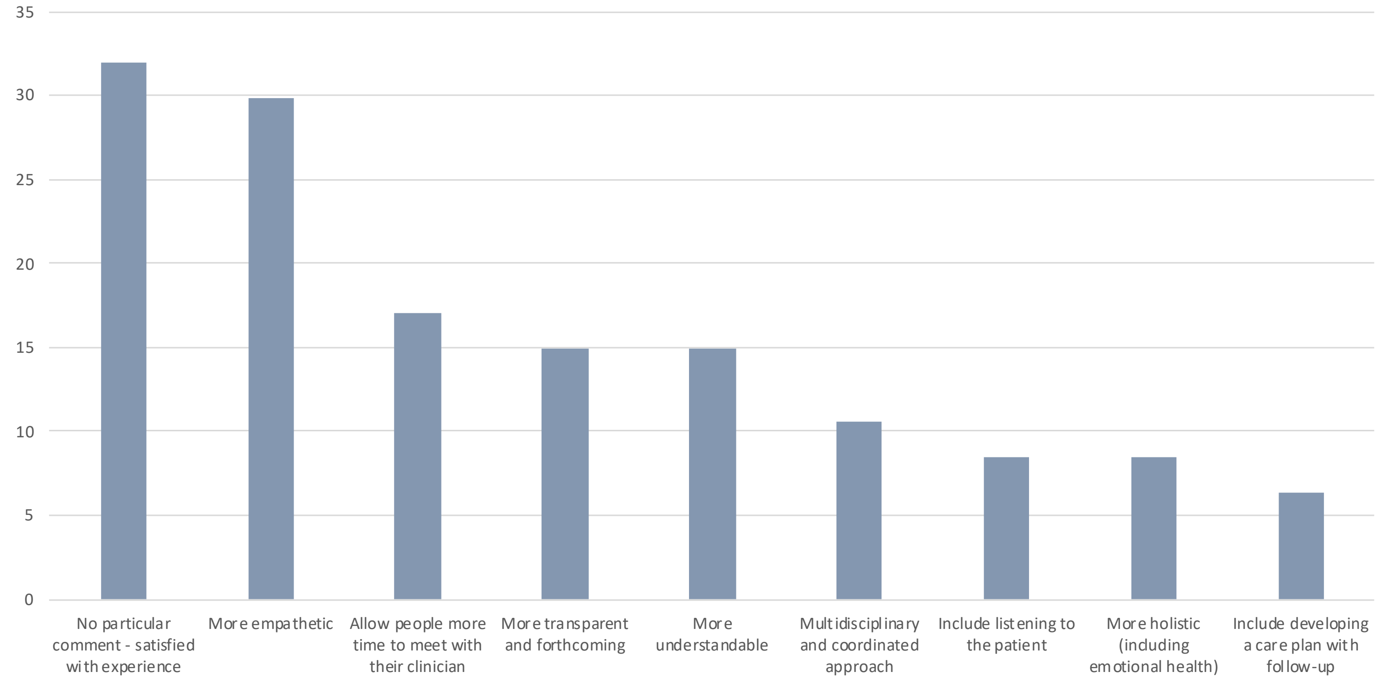

Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Expectations of future communication	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	-	Had LP(a) test Male
Future communication will be more empathetic	-	High cholesterol under 50 years of age Regional or remote
Future communication will be more understandable	High cholesterol under 50 years of age Higher socioeconomic status	Regional or remote
Future communication will include a multidisciplinary and coordinated approach	Blood vessel conditions Regional or remote	High cholesterol under 50 years of age
Future communication will be more holistic (including emotional health)	-	High cholesterol under 50 years of age
Future communication will include developing a care plan with follow-up	-	Blood vessel conditions

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 expectation for future care and support was that care and support will include being able to connect with other patients through peer support (17.02%), will include a multidisciplinary and coordinated approach (17.02%), and will include practical support for example home care, transport, and financial support (12.77 %). Other themes included future care and support will include more long-term condition management (10.64%), will include specialist clinics or services where they can talk to professionals, in person, by phone or online) (10.64%), will be more holistic, including emotional health (10.64%), and include more access to support services (8.51%). There were 4 participants (8.51%) who were satisfied with the care and support received (8.51%).

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I think again coming back to, if it's possible, a way for women with this kind of diagnosis to be able to connect. And I did find a Facebook group, but I found it quite late in my journey. By then I was pretty much well on my way to recovery. But it would've been nice to connect with people. So I'll just mention, the Facebook group, there's a lot of women on there that are suffering from PTSD and anxiety, so ' don't actually think that kind of environment is helpful to someone that's newly diagnosed. I feel like they feed on each other's anxiety a bit too much, so something that, you know, whether it was a charity or whoever put up the support, but maybe more people that have been through'similar Ies that are on the other side that can offer hope and support. Not make things worse. Yeah.
Participant 035_2023AUHBV

I'd like to see more information out there and more groups. There's no groups in LOCATION METROPOLITAN, LOCATION STATE. There's nothing whatsoever. There's absolutely nothing. Where I live now, there's nothing in my area. There's groups on the other side of the city, miles and miles, but since I had my stroke I can't drive anymore, and my wife doesn't drive as my carer. Yes, that's one thing that we've found. There's nothing whatsoever.
Participant 042_2023AUHBV

I really would like to see more information and support groups for people of young stroke and community understanding of fatigue and hidden disability.
Participant 047_2023AUHBV

Future care and support will include a multidisciplinary and coordinated approach

I think they're out there. I just think that they're in cities and I find and I know I choose to live remote, but that's my big struggle. No physio here or exercise physiologist even knew what the acronym stood for, let alone were able to give me a treatment plan. So I don't know. I don't even know how you fix that. You can't have some specialist people in every small town. I know that. But. Yeah, yeah, it could be something that they look at, could look at telehealth wise, you know, making it more available, you know.
Participant 014_2023AUHBV

Yes, I think like the community health course that I went on. And it's easier cheaper access to people like dietitians, exercise physiologists because the one I go go to having said there's no out of pocket expenses, I I do pay to see her. So it's it's it's more more access to things like that. It can help you manage I prevention.
Participant 017_2023AUHBV

Look, I think for me, I think the allied health sector is probably the key area that that I've learned to do with with heart conditions. You know, and it again it's it's accessibility to those programs, you know, where you're limited to how many sessions you get which which is understandable but you know, gaining ex access to, you know, like hydrotherapy and things like that. Like it seems like I was told that hydrotherapy would be a really good option for me. But where I am it was quite difficult and to the point where I wasn't even able to to secure that type of thing. So I was left with you know treadmills and cycling machines and things like that. So, you know, I would have preferred the water, but yeah.
Participant 028_2023AUHBV

Future care and support will include practical support (home care, transport, financial)

Yes, for the people that had a stroke in the country and can't drive, there needs to be more support for that because we don't have public transport and we have very long distances to get to doctors. I can get taxi vouchers to go around my town but I can walk everywhere in my town. What I need is a taxi to get to LOCATION METROPOLITAN to the doctor.
Participant 041_2023AUHBV

I'd like to see a service developed where people help you go back to living in your house and living independently in that first bit when you leave the hospital. Even just someone who's going to come over two days later to make sure that you've eaten some food or been able to do that sort of thing. That, I think would make a huge difference. Even just like providing food for someone for the next three or four days, while they work out what they're actually capable of in their own home.
Participant 046_2023AUHBV

Well, I live at LOCATION REGIONAL, up where the aerials are. It's a 40-minute drive to LOCATION METROPOLITAN for the treatment at the universities. I'm not allowed to drive. They want four-days notice to get me transported. Anglicare is handling that very well. They're the only ones who'll do it. There's been

no effort in trying to get me driving again. If I could drive, even if I could only go down and do my shopping or get to another thing or buy something at the shop, that's all I want to drive at.
Participant 048_2023AUHBV

Future care and support will include more long-term condition management (care planning)
Future care and support. Again I direct this at my specific heart disease. I would like there to be a follow up with the specialist that has an interest in it. I feel like they need to be following up more with what my post-operative symptoms are now. I would like more studies done in this particular disease. I think that would be great. I think there's so much that's unknown about it. But, the average GP doesn't know about it. I'd like for them to know more about what we go through and what our symptoms are. And what's normal. And how our symptoms can change. It's a very, varying disease and that can change from one day to another, and then back again. That just seems to confuse everybody. That I suppose and for us to be able to be acknowledged that it is an illness that we deal with every day. I know that's a hard thing to change. There's a lot of other illnesses I get that.
Participant 036_2023AUHBV

As I've already said, the ongoing catch-ups with stroke survivors. If somebody has a stroke, there's three months of rehab, then they're on their own. A 12-monthly meeting between a stroke survivor and a stroke professional to help that person map out the next 12 months. That doesn't happen. There's that initial interaction with health professionals then it stops. There is nothing. There needs to be an ongoing interaction. It doesn't have to be long. Just long enough to establish the new goals, to evaluate how that person's traveling. One of the overwhelming aspects for a stroke survivor is loneliness because you survived, you didn't die and you've now got a condition. It could be a very lonely, lonely place to be.
Participant 045_2023AUHBV

No. I think I would've liked to have more constant visits to the neurologist and more accessibility to physios, rejigging and reconnecting, and getting to know new treatments and things like that that weren't available when I was younger. I think that's what I would like to see happen. That's what I wanted to happen, I thought was going to happen to me, that I would have those connections ongoing throughout my life, but I haven't.
Participant 049_2023AUHBV

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

Well, at the risk of repeating myself, just being linked in with that heart failure nurse, so I have someone I could ask questions of without having to make an appointment to see the cardiologist.
Participant 032_2023AUHBV

More verbal information out of them. So they can explain everything to you, more time with you, I suppose. Rather than being just a number, you're here for 10 minutes, or for 15 so be it, or 20 so be it. If you can explain it properly, then -- yeah.
Participant 038_2023AUHBV

Future care and support will be more holistic (including emotional health)

That's a tricky one for me to answer because I had such a good family support, so I don't feel like I was lacking in that way. Yeah, but yeah, definitely. There's always the options of some charity support and keeping. Yeah, helping people with their mental health when they're going through things like that. Yeah, great, okay.
Participant 008_2023AUHBV

I think maybe like other than cardiology. For someone at my stage anyway, I think maybe support services is in specifically mental support services for that particular so for coronary artery disease or heart disease or any form of heart disease specifically and where you can link in with with other people in the community and be able to have a talk and I don't know anything around. My area at the moment or anyone that that does that and I haven't been told about anything like that but it certainly would be it would be beneficial.
Participant 011_2023AUHBV

Future care and support will include more access to support services

People with your condition too. Well yeah, I like my my other idea just to have a bit more of a. There might be some possibly some NGOs or disease sort of organizations out there, maybe the Australian Heart Association or whatever. But you know where they're. You have some offerings, you know in the community where either virtually or in person you can meet up with others. And then have a bit of an some educational sessions and explore some of the, you

know, some of the nuance and some of the yeah and some of the patient experiences. And just to hear from others and just to kind of chew some of that over and have some of those discussions, some robust discussions with other similar patients, yeah.
Participant 001_2023AUHBV

He ended up in the hospital in March. He had an abscess on his appendix totally out of the blue. He ended up in the hospital for five days. It was like, "How am I going to manage?" I don't drive. How am I going to manage? What am I going to do? He was worried about it. He rang Carers LOCATION STATE, because he's registered with them. They didn't bother to ring him back.
Participant 033_2023AUHBV

Satisfied with experience

Well, my observation is that I've been offered a lot of stuff. A lot of support. And I actually -- I'm a member of Heart Support Australia. We have monthly meetings, and we do exercise programmes. We do go and walk at a basketball stadium, because it's under cover and out of the sun. There's all that sort of support, and there's probably, I don't know, 10 of us, and we'll sit and chat and discuss our conditions sometimes, and fix all the problems of the world, but that's sort of as far as I go. I see my cardiologist, but it's really more about treatment and where are we going with things. But I don't do anything else. I don't access anything else.
Participant 031_2023AUHBV

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 othe conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	8	17.02	2	11.11	6	20.69	2	22.22	4	23.53	2	9.52	5	18.52	3	15.0
Future care and support will include a multidisciplinary and coordinated approach	8	17.02	4	22.22	4	13.79	3	33.33	1	5.88	4	19.05	3	11.11	5	25.0
Future care and support will include practical support (home care, transport, financial)	6	12.77	1	5.56	5	17.24	0	0.00	4	23.53	2	9.52	3	11.11	3	15.0
Future care and support will include more long-term condition management (care planning)	5	10.64	2	11.11	3	10.34	1	11.11	2	11.76	2	9.52	2	7.41	3	15.0
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	5	10.64	0	0.00	5	17.24	0	0.00	1	5.88	4	19.05	2	7.41	3	15.0
Future care and support will be more holistic (including emotional health)	5	10.64	0	0.00	5	17.24	0	0.00	3	17.65	2	9.52	2	7.41	3	15.0
Future care and support will include more access to support services	4	8.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	3	11.11	1	5.00
No particular comment - satisfied with experience	4	8.51	2	11.11	2	6.90	0	0.00	2	11.76	2	9.52	3	11.11	1	5.00
Future care and support will include health professionals with a better knowledge of the condition	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.0

Expectations of future care and support	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomi status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	8	17.02	4	15.38	4	19.05	3	12.50	5	21.74	3	20.00	5	15.63	6	24.00	2	9.09
Future care and support will include a multidisciplinary and coordinated approach	8	17.02	5	19.23	3	14.29	6	25.00	2	8.70	5	33.33	3	9.38	5	20.00	3	13.6
Future care and support will include practical support (home care, transport, financial)	6	12.77	5	19.23	1	4.76	3	12.50	3	13.04	2	13.33	4	12.50	4	16.00	2	9.09
Future care and support will include more long-term condition management (care planning)	5	10.64	1	3.85	4	19.05	1	4.17	4	17.39	2	13.33	3	9.38	0	0.00	5	22.7
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	0	0.00	5	15.63	1	4.00	4	18.1
Future care and support will be more holistic (including emotional health)	5	10.64	4	15.38	1	4.76	1	4.17	4	17.39	3	20.00	2	6.25	5	20.00	0	0.00
Future care and support will include more access to support services	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
No particular comment - satisfied with experience	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	0	0.00	4	12.50	1	4.00	3	13.6
Future care and support will include health professionals with a better knowledge of the condition	3	6.38	2	7.69	1	4.76	0	0.00	3	13.04	2	13.33	1	3.13	2	8.00	1	4.55

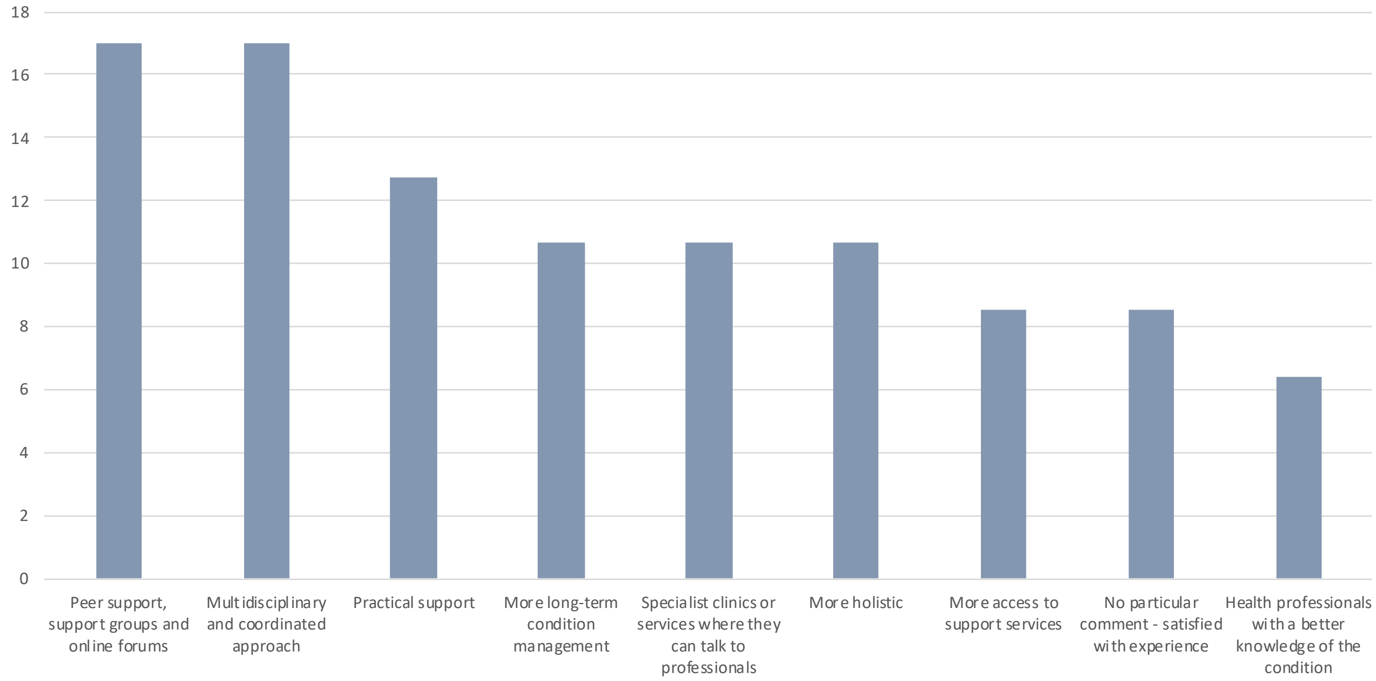

Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Future care and support will include a multidisciplinary and coordinated approach	Blood vessel conditions	High cholesterol under 50 years of age Regional or remote
Future care and support will include practical support (home care, transport, financial)	High cholesterol under 50 years of age	Blood vessel conditions
Future care and support will include more long-term condition management (care planning)	Mid to low socioeconomic status	Higher socioeconomic status
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	Had LP(a) test High cholesterol under 50 years of age Regional or remote	-
Future care and support will be more holistic (including emotional health)	Had LP(a) test High cholesterol under 50 years of age Higher socioeconomic status	-

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 responses were that participants were grateful for healthcare staff, including access to specialists (42.55%), low cost or free medical care through the government (27.66%), and the entire health system (19.15 %). Other themes included access to private healthcare or private health insurance (12.77%), and timely access to diagnostics (6.38%).

Participant describes being grateful for healthcare staff (including access to specialists)

To me it's the, I guess it's the expertise in everyone that I've dealt with. Like everyone right up from your specialists down to your physiotherapists. They know their stuff. They've they've all been very friendly, all been understanding. You know, no one, no one has shrugged me off which has been, which has been really good. Maybe I've been lucky as well in in coming across those type of people because I I do know that you can just be a tick and flick and just get them out of the room. But the professionalism I think has been, has been quite good. Like, you know, when when you're dealing with the nurses or whatever, I have no idea how many patients they've dealt with that day, that week, how they've been abused. But when it came for me walking through that door, I'll go treated, treated like it was the first person of the day. And that's good to hear that, you know, alleviates, I guess that stress a bit. You know that it's just to, you know, reassure you that everything's good. Yeah, so I I haven't had personally a bad experience.
Participant 028_2023AUHBV

I'm definitely grateful for the support that they gave me. Definitely grateful for, yeah. Just the communications that they gave me, the check up it's always making, making me aware that I was cared for and thought about a lot to make sure it's okay.
Participant 029_2023AUHBV

Well, obviously there's an abundance of quality physicians available. It's probably particularly in LOCATION METROPOLITAN, not so much here in LOCATION METROPOLITAN there are a lack of specialists here. I think there are only about three or four neurologists. Certainly in LOCATION STATE, they could do with some more specialists, absolutely. I don't think they have like most cities have a dedicated stroke unit, I'm not sure if they have one here. Yes, that's something that they could certainly work on.
Participant 043_2023AUHBV

Participant describes being grateful for low cost/free medical care through the government (Public health system in general)

That you have been able to access in the Australian health system telehealth as is by far the best Medicare having a cap on Medicare because we had some high medical consults lots of frequent consults on when I first got ill So yeah the Medicare system and and and having things close I mean not we're we're in Melbourne, Frankston that's everything is free access easy access in person if otherwise totally health is incredible.
Participant 003_2023AUHBV

Yeah, look, the public health system, public hospitals that I was in, I I wouldn't go to a private hospital again. Ever public system the public nurse, the doctors, the nurses, the teams, couldn't speak more highly of them. I've forgotten what the question actually was about.
INTERVIEWER: Is there anything you've been particularly grateful for?
PARTICIPANT: Oh yeah, no, definitely. Yeah, yeah, the public health care system for sure.
Participant 009_2023AUHBV

Just well, I was extremely thankful for the healthcare card. Other than that, not really just the therapy, haven't really gone to. Much up since all those appointments haven't any other big medical problems.
Participant 007_2023AUHBV

I am extremely grateful of the fact that I didn't have to go bankrupt to pay for my treatment, that most of that was covered. I am extremely grateful for my GP NAME DOCTOR, that I've spoken about, I'm very grateful that I've had his support. Participant 046_2023AUHBV

Participant describes being grateful for the entire health system

PARTICIPANT: I think it's been fantastic. I can't believe we've got, we have got the best health system in the world, I believe.
INTERVIEWER: And is there anything particular that you benefited from?
PARTICIPANT: Yes, I'm alive.
Participant 025_2023AUHBV

Just to say thank you. Thank you so much.
Participant 027_2023AUHBV

No. I was happy with everything.
Participant 044_2023AUHBV

Participant describes being grateful for access to private healthcare/private insurance

Well, I think the Australian health system is outstanding. It's not cheap. I have private health cover which is expensive but my understanding is, even if I didn't have the private cover, I would have had the same treatment and the same attention if I'd have been on a lesser cover. I think we're well served by the health system.
Participant 045_2023AUHBV

Oh yeah. I mean, I've only lived in Australia so I don't really know what the rest of the world lives through, but I've had friends from the US and those sorts of things and or even the UK for example, where there's just a much bigger population to service and like. We don't really like like it can be expensive but it's not as expensive as you know remortgage the house sort of thing thankfully. So in that in that sense like the the cost in itself is not as burdensome which is like fantastic and you know it's lucky that you we don't even really have to cost isn't really a consideration for a lot of people. Sometimes the wait time is a consideration and that that's unfortunate, but that's what happens when you have limited resources. I'd like to see the resources obviously increase, but there's people in positions and hopefully people smarter than me that are dealing with those issues now. But I think more so than anything, I've probably not the best person to ask because I've gone through the private system basically my whole, my whole life. …. So I think you know we haven't had to wait too long, well at all For me it was book a date and rock up sort of thing and then the cost has been minimal covered by private health but also obviously government subsidy at the same time that that's been fantastic. Participant 012_2023AUHBV

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being grateful for healthcare staff (including access to specialists)	20	42.55	11	61.11	9	31.03	6	66.67	10	58.82	4	19.05	11	40.74	9	45.00
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	13	27.66	4	22.22	9	31.03	4	44.44	6	35.29	3	14.29	6	22.22	7	35.00
Participant describes being grateful for the entire health system	9	19.15	1	5.56	7	24.14	1	11.11	3	17.65	4	19.05	3	11.11	5	25.00
Participant describes being grateful for access to private healthcare/private insurance	6	12.77	2	11.11	4	13.79	1	11.11	2	11.76	3	14.29	2	7.41	4	20.00
Participant describes being grateful for timely access to diagnostics	3	6.38	2	11.11	1	3.45	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

What participants are grateful for in the health system	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being grateful for healthcare staff (including access to specialists)	20	42.55	11	42.31	9	42.86	9	37.50	11	47.83	6	40.00	14	43.75	11	44.00	9	40.91
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	13	27.66	8	30.77	5	23.81	7	29.17	6	26.09	6	40.00	7	21.88	8	32.00	5	22.73
Participant describes being grateful for the entire health system	9	19.15	4	15.38	4	19.05	4	16.67	4	17.39	3	20.00	5	15.63	5	20.00	3	13.64
Participant describes being grateful for access to private healthcare/private insurance	6	12.77	4	15.38	2	9.52	2	8.33	4	17.39	0	0.00	6	18.75	3	12.00	3	13.64
Participant describes being grateful for timely access to diagnostics	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	2	13.33	1	3.13	3	12.00	0	0.00

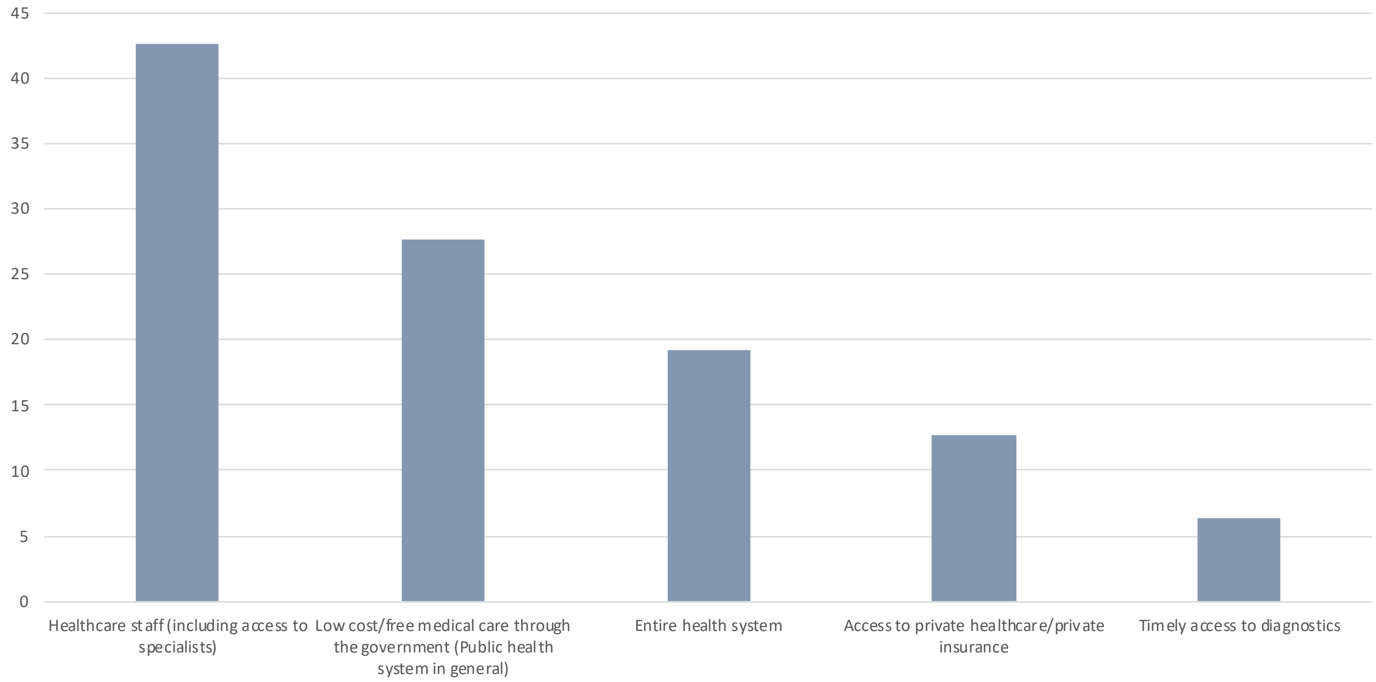

Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for healthcare staff (including access to specialists)	Did not had LP(a) test Heart conditions	Had LP(a) test High cholesterol under 50 years of age Blood vessel conditions
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	Heart conditions	High cholesterol under 50 years of age Regional or remote
Participant describes being grateful for the entire health system	Had LP(a) test	-
Participant describes being grateful for access to private healthcare/private insurance	Regional or remote	-

Values in making decisions

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 Ability to follow and stick to a treatment regime and The ability to include my family in making treatment decisions.

Table 9.11: Values in making decisions

Values when making decisions	Weighted average (n=50)
How safe the medication is and weighing up the risks and benefits	6.24
The severity of the side effects	5.90
Time impact of the treatment on my quality of life	5.30
How the treatment is administered	3.78
How personalised the treatment is for me	4.30
The ability to include my family in making treatment decisions	2.96
Ability to follow and stick to a treatment regime	3.63
The financial costs to me and my family	3.94

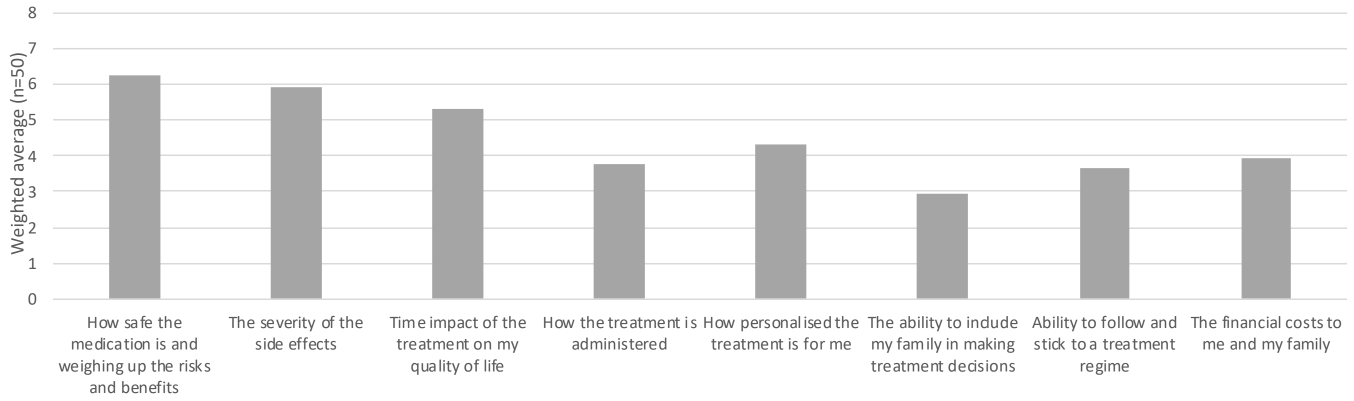

Figure 9.6: Values in making decisions

Values for decision makers

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 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Table 9.12: Values for decision makers

Values for decision makers	Weighted average (n=50)
Economic value to government and tax payers	1.56
Economic value to patients and their families	2.62
Quality of life for patients	4.1
Compassion	3.06
All patients being able to access all available treatments and services	3.66

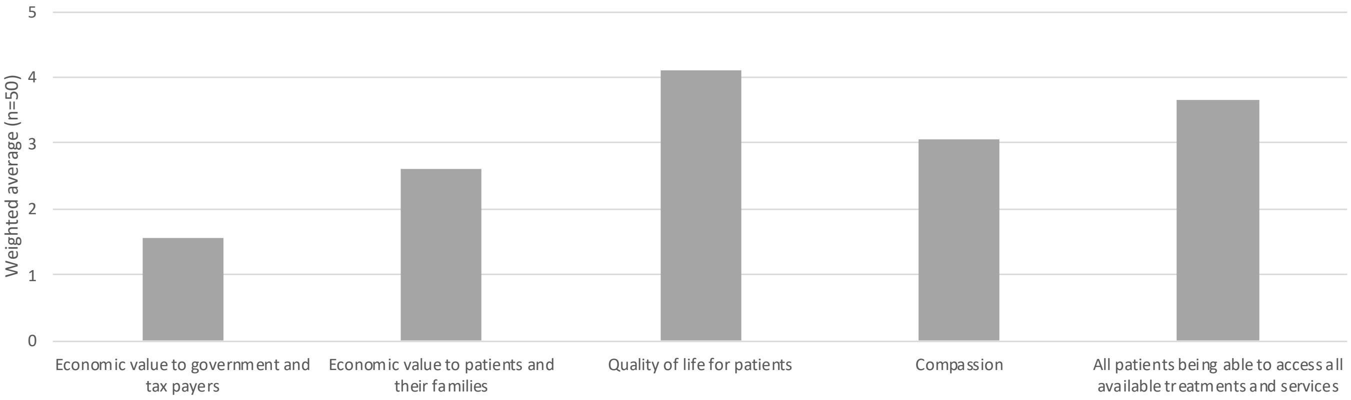

Figure 9.7: Values for decision makers

Time taking medication to improve 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 = 32, 64.00%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Table 9.13: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=50)	Percent
Not at all	3	6.00
Less than 1 year	6	12.00
1 to 5 years	9	18.00
10 years or more	32	64.00

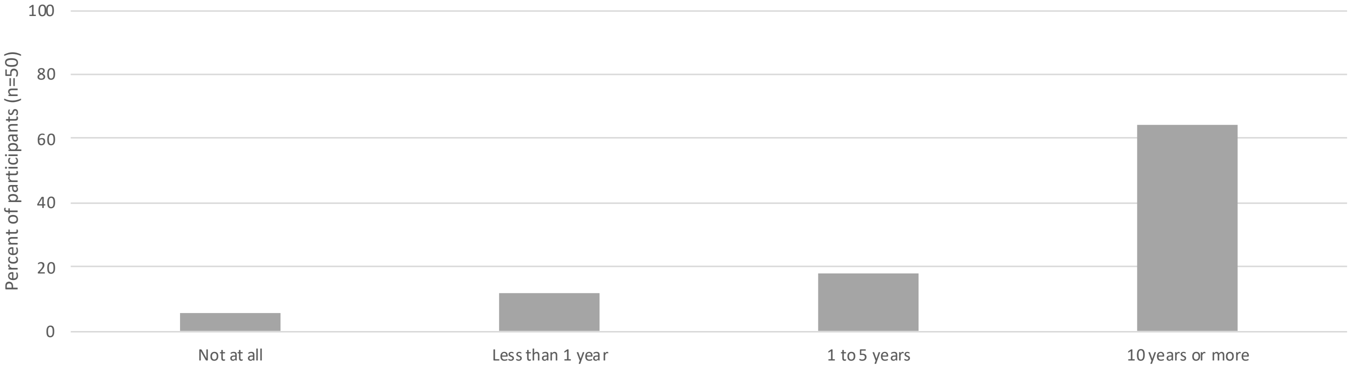

Figure 9.8: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

There was 1 participant (2.00%) that thought that medicine delivered by IV was most effective, 22 participants (44.00%) thought that pill form was most effective, and 11 participants (22%) that thought they were equally effective. There were 16 participants (32.00%) that were not sure.

Table 9.14: Most effective form of medicine

Treatment most effective in what form	Number (n=50)	Percent
IV form (through a drip in hospital)	1	2.00
In a pill form that can be taken at home	22	44.00
Equally effective	11	22.00
Not sure	16	32.00

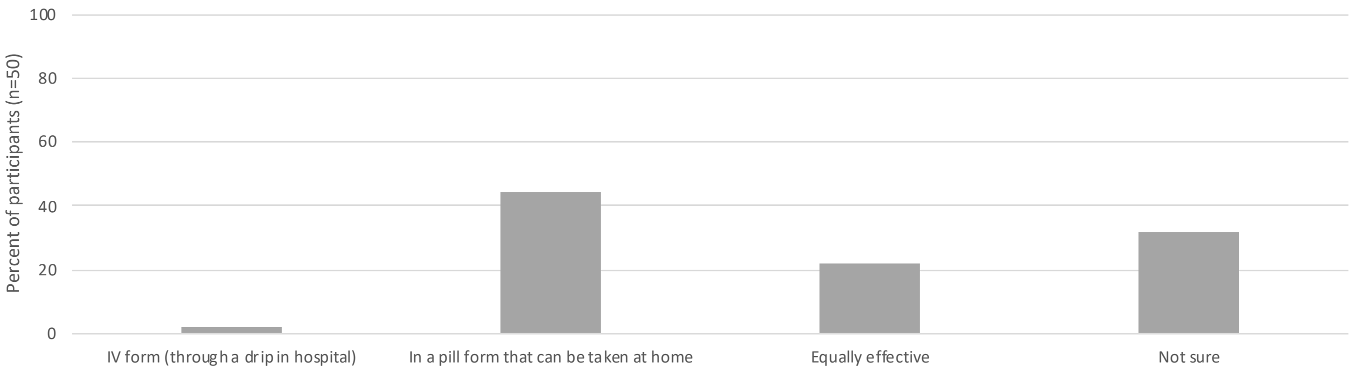

Figure 9.9: Most effective form of medicine

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 messages to the health minister were the need for timely and equitable access to support, care and treatment (25.53%), that treatments need to be affordable (19.15%), and that they were grateful for the healthcare system and the treatment that they received (19.15 %). Other themes included to improve rural services (19.15%), to invest in prevention (19.15%), to increase investment in general (17.02%), to help raise community awareness (14.89%), to invest in health professionals to service the patient population (14.89%), and to have a holistic approach to the condition that includes emotional support (10.64%).

Timely and equitable access to support, care and treatment

PARTICIPANT: Yeah. I think that absolutely ties into that question then. Because, the cardiac rehab facility. Controlled exercise because you become afraid of your body. And afraid of how far to push it. To be able to go into a controlled environment like that we're you're being told, "This is okay and your fine to push yourself that little bit further." And to be around people that are two months ahead of you with recovery, and two months behind you in recovery. You then become the mentor for people. Then other people become the mentor for you. That kind of support I found with that, within cardiac rehab was so good at that time. I was looking at the 85-year-old guy that was doing laps around me. He was power walking around the little walking course we had after his open-heart surgery. I was like, "Wow. If he can do it I can do it. I've got to try and catch up with him."
INTERVIEWER: Yeah. No it's an excellent point.
PARTICIPANT: That was really good. Then you pass that onto people that are just coming in new. They're fresh out of surgery. They're six weeks post op and they're terrified of their heart, and then they listen to your story and go, "Okay. I can do it."
INTERVIEWER: Yeah. That kind of sharing of experience is so important.
PARTICIPANT: Absolutely. It was imperative. I think that needs to be available. I was just, because I work at a private hospital close to me, and I actually had to do a blood test on a lady the other day who was one-week post op from open heart. She was in her bed crying, and scared, and her husband had her on deaths door. I actually cracked open my shirt and I showed her my scar. I'm like, "I'm three years post open heart surgery. I've had similar thing to what you've done." I said, "You can do this." I sat there and chatted with her for about 20 minutes and she was so grateful, and happy by the time I left. That kind of support just needs to be available to people when they need it.
Participant 036_2023AUHBV

I just really feel that knowledge, support and just continual access because I don't think probably that I was offered enough of that early on and I didn't realise that I probably was entitled to it.
Participant 047_2023AUHBV

Treatments need to be affordable

I think I'm not. Overall, I'm happy with how it went for me because we have private health. Yeah. One thing we have reflected on is if we didn't have private health, like it was a very tough 12 months for us. Yeah, if I didn't have private health, that would have been much, much longer if I was going through the public system. So I would say to take it a little further for the

public system to sort of help people if they don't have private health.
Participant 008_2023AUHBV

I would honestly say we need to throw more money in the public sector to be honest. Like it's. Yeah, it's easy to say that you need more money, but the waiting times and things like that are quite high and you know, and if you can't afford to go private. You could, you could be dead by the time you get around to seeing a specialist. You know, they talk about you know 12 months or more waiting lists just to get in to see someone and that's just to get a test and then you've got to wait again. You know that it it is, it is quite difficult to get in and and even even then you know there's not that many specialists available. So you know you sometimes you have to consider consider traveling quite large distances depending on which part of the country you're in.
Participant 028_2023AUHBV

For government, I guess make treatments accessible and affordable to everybody. I guess that would be not just for heart research or not just for heart treatment, but for anything else. While you're well, I think that it's easy enough to say this medication is expensive, let's not -- but I think that you need to have more compassion within government. With medical staff, I think they just need to be respectful. I'm very happy that I've had that, but I am mindful that, particularly with older people who might not know as much about their condition, they need to be treated with respect.
Participant 034_2023AUHBV

Grateful for the healthcare system and the treatment that they received

It's actually pretty excellent.
Participant 019_2023AUHBV

No, no, no as so much special. I want to tell you earlier that my experience was a fabulous like I don't need, like I want to say that we are giving the very good healthcare services in in our state like they are the fabulous. Everything was a perfect form, a very early step to the last step.
Participant 027_2023AUHBV

I think my experience has been one of, like I've been so grateful for everything that I've had exposure to. And I haven't paid for a thing apart from my medications. And to have the free healthcare that we have in this country, I'm born in LOCATION OVERSEAS, and so I know what other countries have and I think we are so fortunate to have as many resources available for free. And I feel the quality of those resources are actually quite, quite good. Yeah and so I would probably want to say that I'm grateful for those. I would hope that they would always be a priority and that they would continue to offer those resources to people.
Participant 035_2023AUHBV

Improve rural services

I'd say that they haven't had access to much at all. And I I I'd say that you know, in general hearts in general, you know there needs to be more access in a regional and rural sense as well. You know, to get, you know get the care everywhere, you know having and whether it's hearts or whether it's anything to have to, you know. Unfortunately I only had to go 2 hours in my family, but I think you know having services. Are more readily available in regions and rural areas. Would be my big, would be my big plug.
Participant 009_2023AUHBV

Hold on the lines of access, telehealth, access to probably out more allied health for people living in remote.
Participant 014_2023AUHBV

PARTICIPANT: I think I have excellent care even for someone who is living in the country like me. I had excellent care. I'm very lucky because I'm alive. The statistics on brain haemorrhages aren't good. Yes, I had very good care.
INTERVIEWER: That's great. You wouldn't tell anything to the health minister, any change?
PARTICIPANT: If people can't drive in the country they need more funding for transport to make it equal to people in the city.
Participant 041_2023AUHBV

Invest in prevention

I think more testing for lipoprotein A is a big one. Research shows that statistically, that one in five people could be walking around with lipoprotein with elevated levels of lipoprotein A. And I don't think there's enough testing for it. And if people knew that they had this elevated Lycoprotein A, you know, that would give them the chance to become more proactive with their health. So maybe exercise more if they smoke to, to try and quit good nutrition to try and eliminate all sorts of stress. Maybe, you know, get onto some medication to try and lower your LDL. I

think that's really important at the moment. I don't think there's enough enough knowledge about it as well in Australia or about lipoprotein A and its effects. So I think that's a big that would be a big message.
Participant 011_2023AUHBV

Obviously I think just the the access to more preventative medicine would be what I would put put to them and if if money and resources can be put in to do that and more preventative services and resources.
Participant 017_2023AUHBV

Increase investment (general)

I would honestly say we need to throw more money in the public sector to be honest. Like it's. Yeah, it's easy to say that you need more money, but the waiting times and things like that are quite high and you know, and if you can't afford to go private. You could, you could be dead by the time you get around to seeing a specialist. You know, they talk about you know 12 months or more waiting lists just to get in to see someone and that's just to get a test and then you've got to wait again. You know that it it is, it is quite difficult to get in and and even even then you know there's not that many specialists available. So you know you sometimes you have to consider consider traveling quite large distances depending on which part of the country you're in.
Participant 028_2023AUHBV

I went to Canberra as a delegation for the Stroke Foundation asking for money for telehealth. I think telehealth is a big thing that should be in the regional areas, and there should be more funding put into foundations like the National Stroke Foundation. There should be more funding for campaigns to help with stroke, more facilities for stroke survivors to live independently or assisted living. I believe the medication should be on the PBS and available and accessible to everyone.
Participant 049_2023AUHBV

Help raise community awareness

I think just to say that, you know, it should be a part of the every everyday conversation. You know, heart health, like, you know, they do the bowel cancer screening and all that sort of stuff. It should be. I mean it's harder to do this thing, but it I think it's an explanation as to what if you don't look after that, what it could mean in terms of other diseases and stuff like that. I think a lot of people just think, oh, that's to do with having a heart attack. I'm not going to have a heart attack. I'm fit and healthy. You'd have no clue that you had high blood pressure unless you really could feel it. And you definitely have no clue that you had high cholesterol because you can't feel it.
Participant 016_2023AUHBV

I wish he would realise-- They push on breast cancer and prostate, but stroke-wise, no, nothing. Nothing is there, no information. That's why it's frustrating. It's another illness. It's another killer and the government doesn't care. It's a hidden one. They don't talk about it, they don't mention it there, they don't acknowledge it. That's why it's frustrating.
Participant 042_2023AUHBV

Invest in health professionals to service the patient population

I think that more access to, you know, nurses, not just the doctors, to give valid, helpful information. So opening up more opportunities for learning from really intelligent people without the need of going to the doctor. So maybe people be more inclined to seek help if it's not an actual GP, but there's taking a step in preventative care and getting information from trained professionals.
Participant 003_2023AUHBV

I'd tell him to get a job, go out in the real world. Go and work with some nurses for a week and come back and tell tell me what you had to tell me. Go and stand on the front line with them and combat the idiots falling out of ambulances out the front or using the ambulance for a a taxi right to get to there they are feeling all right. Now walk down the street where they're going to go to like the gifts and then go into try out, walk in a stand at the front end and listen to what they're putting up. But that's what I'd be telling the Health Minister if I was standing in front of him. I'd say make the public aware through media, electronic media. Educate them better about these disease, what you can do to prevent it. Don't think you are too. You are on bulletproof.
Participant 006_2023AUHBV

Holistic approach to the condition (including emotional support)

There's access to those therapies, so there'd be no barriers in terms of cost or capacities of access. Yeah, I guess that it's as easy as possible for the patient. I think to also consider -- I mean, this is a hard one. The side effects and the mental state of health of patients,

and the impact certain things will have. There's a high correlation between heart disease and mental health issues or depression. Yeah, just being mindful of that. I mean, I do understand that if it's a life-threatening condition then that has to take precedence, but it's just awareness of the impacts that that has. Mental health, and patient access, and fairness and so on. That's probably all that's coming to mind.
Participant 023_2023AUHBV

I would say to the minister, "Will you please ensure that medical practitioners receive stroke education? That medical practitioners are made aware of the emotional aspects of stroke as much as they're made aware of the physical aspects."
Participant 045_2023AUHBV

Table 9.15 Messages to decision-makers

Message to decision-makers	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Timely and equitable access to support, care and treatment	12	25.53	3	16.67	9	31.03	1	11.11	3	17.65	8	38.10	6	22.22	6	30.00
Treatments need to be affordable	9	19.15	4	22.22	5	17.24	2	22.22	1	5.88	6	28.57	3	11.11	6	30.00
Grateful for the healthcare system and the treatment that they received	9	19.15	4	22.22	5	17.24	1	11.11	2	11.76	6	28.57	5	18.52	4	20.00
Improve rural services	9	19.15	3	16.67	6	20.69	1	11.11	5	29.41	3	14.29	5	18.52	4	20.00
Invest in prevention	9	19.15	3	16.67	6	20.69	2	22.22	4	23.53	3	14.29	5	18.52	4	20.00
Increase investment (general)	8	17.02	4	22.22	4	13.79	1	11.11	3	17.65	4	19.05	4	14.81	4	20.00
Help raise community awareness	7	14.89	2	11.11	5	17.24	2	22.22	3	17.65	2	9.52	2	7.41	5	25.00
Invest in health professionals to service the patient population	7	14.89	4	22.22	3	10.34	1	11.11	2	11.76	4	19.05	7	25.93	0	0.00
Holistic approach to the condition (including emotional support)	5	10.64	0	0.00	5	17.24	0	0.00	2	11.76	3	14.29	2	7.41	3	15.00
Compassionate and empathetic	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Improve care coordination	3	6.38	1	5.56	2	6.90	0	0.00	0	0.00	3	14.29	2	7.41	1	5.00
Unsure what to say	3	6.38	2	11.11	1	3.45	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00

Message to decision-makers	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Timely and equitable access to support, care and treatment	12	25.53	4	15.38	8	38.10	6	25.00	6	26.09	4	26.67	8	25.00	5	20.00	7	31.82
Treatments need to be affordable	9	19.15	4	15.38	5	23.81	3	12.50	6	26.09	4	26.67	5	15.63	5	20.00	4	18.18
Grateful for the healthcare system and the treatment that they received	9	19.15	6	23.08	3	14.29	6	25.00	3	13.04	3	20.00	6	18.75	5	20.00	4	18.18
Improve rural services	9	19.15	5	19.23	4	19.05	5	20.83	4	17.39	6	40.00	3	9.38	5	20.00	4	18.18
Invest in prevention	9	19.15	4	15.38	5	23.81	4	16.67	5	21.74	2	13.33	7	21.88	7	28.00	2	9.09
Increase investment (general)	8	17.02	4	15.38	4	19.05	5	20.83	3	13.04	4	26.67	4	12.50	3	12.00	5	22.73
Help raise community awareness	7	14.89	4	15.38	3	14.29	3	12.50	4	17.39	2	13.33	5	15.63	5	20.00	2	9.09
Invest in health professionals to service the patient population	7	14.89	3	11.54	4	19.05	3	12.50	4	17.39	0	0.00	7	21.88	3	12.00	4	18.18
Holistic approach to the condition (including emotional support)	5	10.64	3	11.54	2	9.52	0	0.00	5	21.74	2	13.33	3	9.38	2	8.00	3	13.64
Compassionate and empathetic	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55
Improve care coordination	3	6.38	3	11.54	0	0.00	0	0.00	3	13.04	1	6.67	2	6.25	0	0.00	3	13.64
Unsure what to say	3	6.38	1	3.85	2	9.52	1	4.17	2	8.70	0	0.00	3	9.38	2	8.00	1	4.55

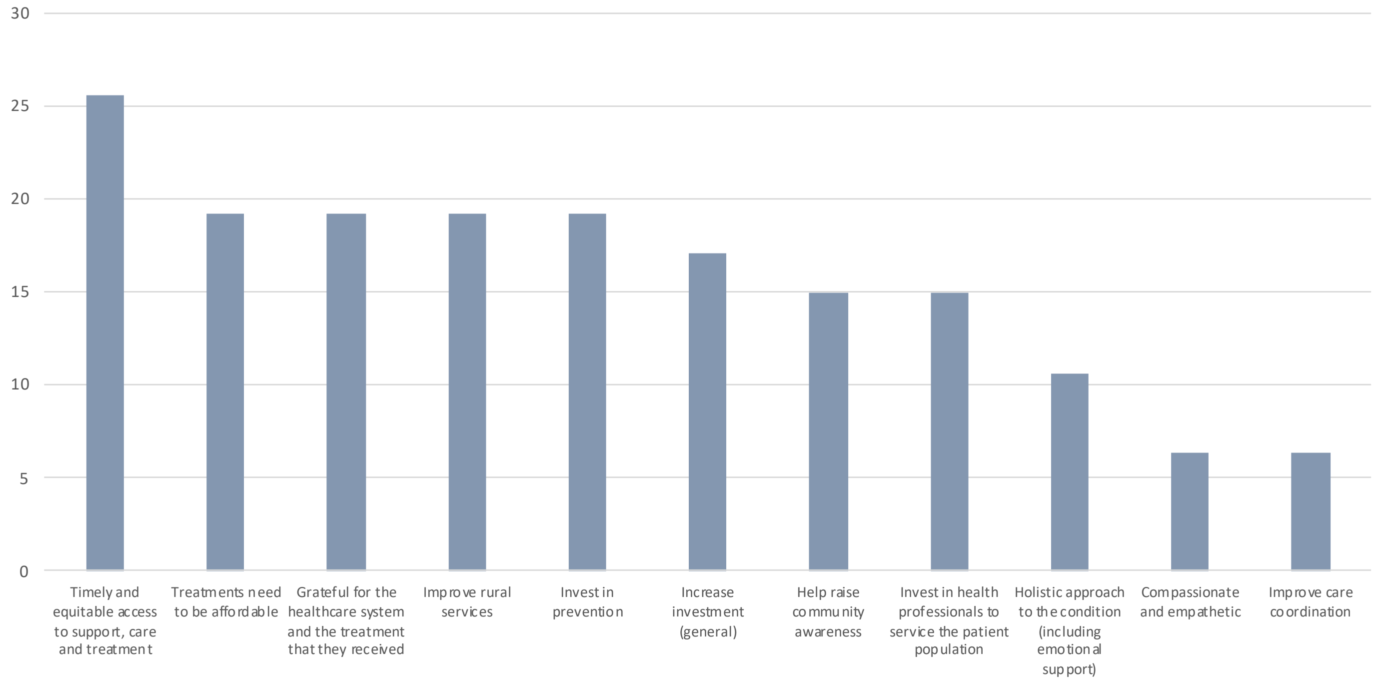

Figure 9.10: Messages to decision-makers

Table 9.16: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Timely and equitable access to support, care and treatment	High cholesterol under 50 years of age Female	Heart conditions Male
Treatments need to be affordable	Blood vessel conditions	6 to 11 other conditions
Improve rural services	-	Blood vessel conditions Regional or remote
Invest in prevention	Higher socioeconomic status	-
Help raise community awareness		6 to 11 other conditions
Invest in health professionals to service the patient population	6 to 11 other conditions Regional or remote	0 to 5 other conditions
Holistic approach to the condition (including emotional support)	Had LP(a) test High cholesterol under 50 years of age Aged 25 to 44	Aged 45 and older

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (12.77%), and to know the early signs and symptoms of their condition (12.77 %), to understand the trajectory of the disease (10.64%), that they had known the risk factors and causes (8.51%), and they had been diagnosed sooner or had access to treatment sooner (8.51%). There were 10 participants (21.28%) that had no particular comment and were satisfied with experience (21.28%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (25.53%), and would not change any aspect of their care or treatment, with no reason given (14.89%). Other themes included would have liked to have had a better understanding of their condition (6.38%), and were not sure if they would change anything (6.38%).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (12.77%), and to know the early signs and symptoms of their condition (12.77 %), to understand the trajectory of the disease (10.64%), that they had known the risk factors and causes (8.51%), and they had been diagnosed sooner or had access to treatment sooner (8.51%). There were 10 participants (21.28%) that had no particular comment and were satisfied with experience (21.28%).

Participant had no particular comment and were satisfied with experience

No. No. I've had all I need.
Participant 026_2023AUHBV

No, no, no. I want to tell you like what was the thing already everything was so good or the fabulous like everyone was a good. Like there was a doing such a cooperation and doctors was doing so good like they was doing the test and all that things. So it was a OK that was a fab.
Participant 027_2023AUHBV

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

I probably the only thing I probably would have liked from myself more than professionals was that you know from professionals as well that they had it, that they had explained a little bit more to me the chance, the lack of or how the how the stent probably would definitely almost not have worked in my case. Then, you know, they just found a Doctor Who was willing to do it. And I think in hindsight, I probably should have had a little bit more time in discussion with somebody who said, well, you know, it'll it probably worked for a short time and then I might have just bit the bullet and said, OK, let's do this.
Participant 005_2023AUHBV

I think like I say given more information at the beginning and not just left, to find it all out for myself would have been helpful because it would have made I would have got up to the lifestyle changes quicker than I did, we could make a significant difference. As I say, just just those two to increase what I received rather than any changes to what I did receive, just more, more of the same really.
Participant 017_2023AUHBV

Participant wishes they had known the early signs and symptoms of their condition

I wish to be honest. I wish I was more aware of any warning signs. You know that even the slightest discomfort, and you know on your you know over that side of your chest. You know that you should, you know, at least get it checked out and not shrug it off. Yeah, so it doesn't. The big thing for me was it doesn't have to be a great big stabbing pain. It can just be mild discomfort. That could be the warnings of like, I had no idea.
Participant 028_2023AUHBV

I just wish I knew that my headaches were a precursor for stroke. I wish I knew that my double vision was a sign that I could have been in the front line for a stroke. The fact that I was given a misdiagnosis of I was just seeking attention that-- Look, I honestly don't think that would have changed the course of treatment back then, but it might've been able to prepare my parents better. There's also a part of me that goes, "Well, you can't look back and wish on something that's already been and gone." It is what it is.
Participant 050_2023AUHBV

Participant wishes they had understood the trajectory of the disease

I wish I had have known that if this is definitely genetic, that it doesn't matter what I eat, My numbers will still be high. The risk is higher that despite what you eat.
Participant 003_2023AUHBV

At diagnosis, sorry. Yeah, yeah. I think knowing, I think knowing the day-to-day impacts of it, not so much the clinical stuff. It would be great to know you've had an arrest. You don't get to drive for the next six months. When you get, when you get, when six months is up, this is what we have to do to get Vicroads to give you license back. It would be great to know this. You know these things are short term treatments, they're short term things we need to do to keep you safe and avoid recurrence and all those things in six, you know, a six month goal. This is what happens in six months. This is so is that you're not surprised when you find out that that's for everything. Oh, that's going in three months. I think knowing what the path ahead looks like, just a bit of a timeline would be really helpful.
Participant 009_2023AUHBV

Participant wishes they had known the risk factors and causes

If I'd taken those conditions seriously, I probably wouldn't have had my stroke. Educating people about the effects of alcohol and smoking and stress and the right food. If I'd have known that prior to my stroke, I probably wouldn't have had one.
Participant 045_2023AUHBV

Yes, plaque breaking off in my arteries caused by cholesterol. if I'd known how important that was, I would-- When I got cancer, I said to the doctor, I can't take Lipitor anymore. It makes me go too much and I'm in agony. I said I'm not taking it anymore. If I'd known then a build-up of Lipitor could cause a stroke, I would not have done that.
Participant 048_2023AUHBV

Participant wishes they had been diagnosed sooner and had access to treatment sooner

I think if I had of known about lipoprotein A earlier. I think I would have asked to have been tested earlier. I wasn't asked. I wasn't. I didn't ask to be tested this time. But I do remember a couple of years ago seeing the cardiologist and he and I wasn't and I told him I said can I please be tested for lipoprotein A and he said no there's no need to test for that. But I didn't kind of go into it with him. And then it was two years later that he decided to to perform the lipoprotein a test. So. Not sure what changed his mind there. Maybe it was his own research and he was looking into it himself, but I think maybe if I had a known back then, I could have been much more of an advocate for myself instead of letting it sort of go on.
Participant 011_2023AUHBV

I wish that I hadn't just fobbed it off as asthma, but that's just me, because I'd be six months further into my journey.
Participant 014_2023AUHBV

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant had no particular comment and were satisfied with experience	10	21.28	3	16.67	7	24.14	4	44.44	2	11.76	4	19.05	4	14.81	6	30.00
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	12.77	3	16.67	3	10.34	2	22.22	3	17.65	1	4.76	4	14.81	2	10.00
Participant wishes they had known the early signs and symptoms of their condition	6	12.77	3	16.67	3	10.34	1	11.11	3	17.65	2	9.52	2	7.41	4	20.00
Participant wishes they had understood the trajectory of the disease	5	10.64	0	0.00	5	17.24	1	11.11	3	17.65	1	4.76	3	11.11	2	10.00
Participant wishes they had known the risk factors and causes	4	8.51	2	11.11	2	6.90	2	22.22	2	11.76	0	0.00	3	11.11	1	5.00
Participant wishes they had been diagnosed sooner and had access to treatment sooner	4	8.51	3	16.67	1	3.45	1	11.11	1	5.88	2	9.52	3	11.11	1	5.00

Anything participants wish they had known earlier	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant had no particular comment and were satisfied with experience	10	21.28	6	23.08	4	19.05	7	29.17	3	13.04	1	6.67	9	28.13	6	24.00	4	18.18
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	1	6.67	5	15.63	3	12.00	3	13.64
Participant wishes they had known the early signs and symptoms of their condition	6	12.77	4	15.38	2	9.52	2	8.33	4	17.39	2	13.33	4	12.50	4	16.00	2	9.09
Participant wishes they had understood the trajectory of the disease	5	10.64	2	7.69	3	14.29	2	8.33	3	13.04	2	13.33	3	9.38	2	8.00	3	13.64
Participant wishes they had known the risk factors and causes	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Participant wishes they had been diagnosed sooner and had access to treatment sooner	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	2	13.33	2	6.25	3	12.00	1	4.55

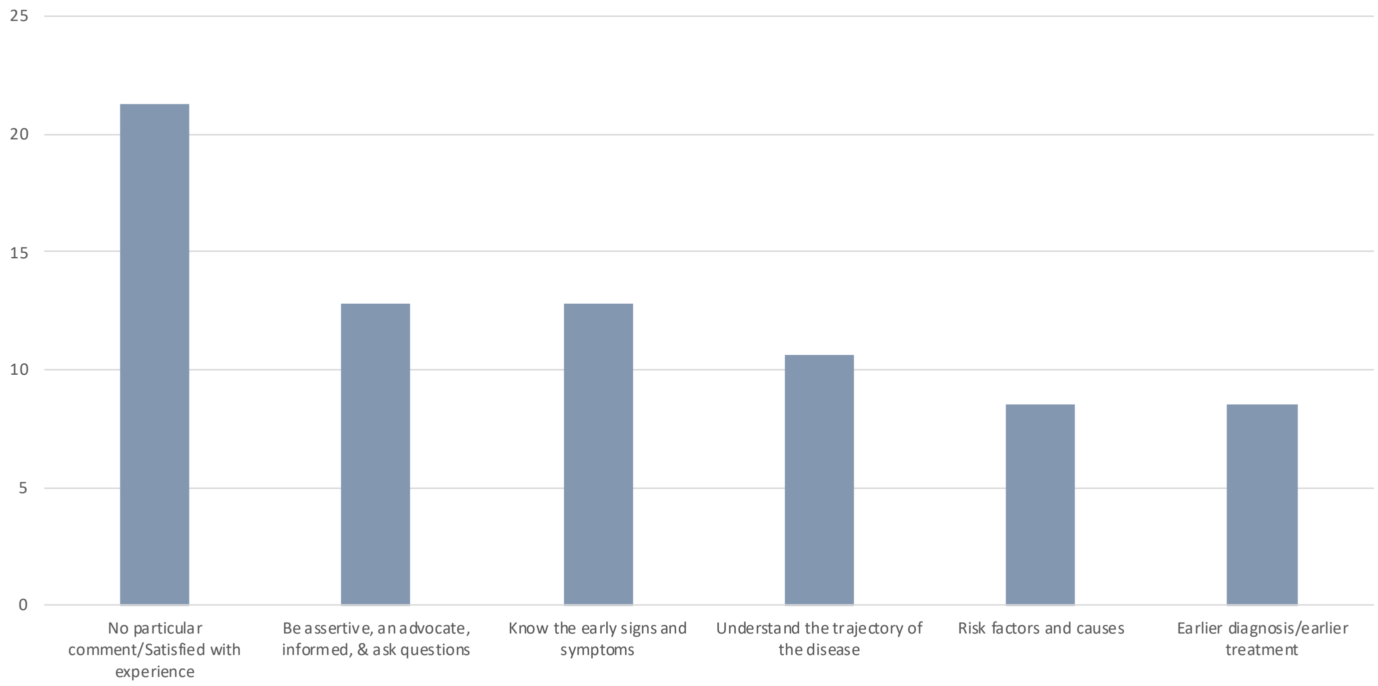

Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Participant had no particular comment and were satisfied with experience	Regional or remote	High cholesterol under 50 years of age
Participant wishes they had understood the trajectory of the disease	Had LP(a) test	-
Participant wishes they had known the risk factors and causes	-	High cholesterol under 50 years of age 0 0

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (25.53%), and would not change any aspect of their care or treatment, with no reason given (14.89%). Other themes included would have liked to have had a better understanding of their condition (6.38%), and were not sure if they would change anything (6.38%).

Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received

Yeah, I feel like, yeah, it's I'm getting sort of pretty close to optimal care.
Participant 001_2023AUHBV

I was happy with everything that happened.
Participant 007_2023AUHBV

No, I don't know. About that, to be honest, yeah. I thought I've had pretty good care and treatment. You know, the only bonus for me would be if there was a cardiologist in my area, but you know, that's more about availability.
Participant 009_2023AUHBV

Participant would have liked to have had a better understanding of their condition

INTERVIEWER: Is there any aspect of your care or treatment that you would change?
PARTICIPANT: Yes, better information.
Participant 041_2023AUHBV

Maybe we should have pushed for more information and knowledge earlier on but I think we were both in shock about my diagnosis.
Participant 047_2023AUHBV

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	12	25.53	6	33.33	6	20.69	4	44.44	3	17.65	5	23.81	6	22.22	6	30.00
Participant would not change any aspect of their care or treatment, with no reason given	7	14.89	4	22.22	3	10.34	1	11.11	4	23.53	2	9.52	3	11.11	4	20.00
Participant would have liked to have had a better understanding of their condition	3	6.38	1	5.56	2	6.90	0	0.00	2	11.76	1	4.76	2	7.41	1	5.00

Aspect of care or treatment they would change	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	12	25.53	7	26.92	5	23.81	7	29.17	5	21.74	5	33.33	7	21.88	8	32.00	4	18.18
Participant would not change any aspect of their care or treatment, with no reason given	7	14.89	3	11.54	4	19.05	3	12.50	4	17.39	1	6.67	6	18.75	4	16.00	3	13.64
Participant would have liked to have had a better understanding of their condition	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	-	High cholesterol under 50 years of age

Section 11

Discussion

Introduction

I think just to say that, you know, it should be a part of the every everyday conversation. You know, heart health, like, you know, they do the bowel cancer screening and all that sort of stuff. It should be. I mean it's harder to do this thing, but it I think it's an explanation as to what if you don't look after that, what it could mean in terms of other diseases and stuff like that. I think a lot of people just think, oh, that's to do with having a heart attack. I'm not going to have a heart attack. I'm fit and healthy. You'd have no clue that you had high blood pressure unless you really could feel it. And you definitely have no clue that you had high cholesterol because you can't feel it.
Participant 016_2023AUHBV

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the 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.

This PEEK study in heart and blood vessel conditions includes 50 people diagnosed with heart and blood vessel conditions throughout Australia.

Background

Heart and blood vessel conditions are a major cause of disease burden in Australia. Coronary heart disease and stroke are common types of heart and blood vessel conditions. In 2020 to 2021, over half a million adult Australians were living with coronary heart disease (2.9% of Australians aged 18 and over)[1]. In 2018 approximately 387,000 people aged 15 and older had a stroke in some time in their life, and in 2020 there were 39,500 stokes[1].

Many forms of heart and blood vessel conditions are caused by atherosclerosis, which is a build up of fat, cholesterol and other substances in the arteries[1]. It can reduce or block blood supply to the heart causing angina or heart attack, or reduce or block blood to the brain causing stroke[1].

Risk factors for heart and blood vessel conditions include smoking, poor diet, not enough exercise, and alcohol consumption. Other risk factors include high blood pressure, abnormal blood lipids, raised cholesterol, diabetes and being overweight[1].

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease [2]. The Australian Atherosclerosis Society recommends Lipoprotein a testing in high risk patients including those with premature atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]. The European Artherosclerotic society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3].

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have heart and blood vessel conditions.

In this PEEK study, the proportions of participants that lived in areas with higher socioeconomic status, were higher to that of Australia. There were similar proportions that lived in major cities compared to the Australian population [5,6] There were no participants from the Northern Territory, and there were a lower proportion of participants from New South Wales, while a greater proportion from Queensland compared to the proportion that live in each state[5,6].

Table 12.1: Demographics

Demographic	Australia %	Heart or blood vessel conditions PEEK %
Live in major cities	71	70
Higher socioeconomic status (7 to 10 deciles)	40	50
New South Wales	32	14
Victoria	26	20
Queensland	20	34
South Australia	7	8
Western Australia	10	16
Tasmania	2	6
Northern Territory	1	0
Australian Capital Territory	2	2

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with heart or blood vessel conditions participants.

Other health conditions

The majority of PEEK participants had at least one other condition that they had to manage, with an average of 5 other conditions. The most commonly reported health condition was anxiety (66%), followed by depression (62), and insomnia (60%). In other studies, between 26 and 47% of participants with stroke or transient ischemic attack had anxiety or depression[7-9], and 66% of participants with atrial fibrillation had sleep problems [10]. Participants in this PEEK study with more comorbidities had worse pain as measured by the SF36 Pain scale, there were no other significant differences for any other SF36 domain.

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition[11]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[11]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[11].

In this PEEK study, participants had higher levels of anxiety (66% compared to 13%), depression (62% compared to 10%), arthritis (36% compared to 15%) and asthma (22% compared to 11%)compared to the Australian population.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[12]. 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[12]. In this PEEK study, on average participants had low scores for role functioning physical health indicating that physical health often interfered with work or other activities for participants in this study. They had high scores for physical functioning, emotional well-being, social functioning and pain, indicating that physical activities were slightly limited, emotional problems sometimes with work or other activities, had good emotional well-being, social activities were slightly limited, and participants had mild pain.

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the heart and blood vessel conditions community in this PEEK study compares with the Australian population[13]. The heart and blood vessel conditions PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being and pain.

In other studies of people with heart or blood vessel conditions, subgroup differences in health related quality of life was described. Poor health related quality of life was associated with depression and anxiety[14,15], disease severity[14,16,17], having multiple comorbidities[9,16], having lower socioeconomic status[18], being unemployed[9] and being female[9]. Better health related quality of life was associated with those that had made progress in rehabilitation[19], and people living in rural locations had less pain and higher perceived health. In this PEEK study, subgroup differences were seen for comorbidities, those with fewer comorbidities had less pain measured by SF36, and had better health scores for all the AQOL domains. Females in this PEEK study had better scores for the AQOL senses domain.

Key points

- **Participants in this PEEK study had an average of 5 health conditions other than heart or blood vessel conditions that they had to manage**
- **Participants had low scores for role functioning physical health indicating that physical health often interfered with work or other activities for participants in this study**

Risks and Symptoms

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

The most common symptoms reported by participants in this PEEK study experienced before diagnosis were dizziness, weakness of face, arm, or leg, confusion (n=9, 18.00%), and trouble walking (n=9, 18.00%). Other symptoms included trouble walking, lack of coordination, headache, memory loss, vision problems, fatigue, short of breath, weakness, trouble speaking, nausea and vomiting. The symptoms with the worst quality of life were, weakness of face, arm, or leg and, lack of coordination, vision problems, trouble speaking, nausea and vomiting. The most common symptoms that led to diagnosis were shortness of breath, headache, irregular heartbeat, fatigue, dizziness and chest pain.

Screening and diagnosis

Approximately half of the participants in this PEEK study sought medical attention relatively soon after experiencing symptoms. Other participants were either did not seek medical attention initially or they had no symptoms and were diagnosed during routine health check-ups. Participants in this PEEK study had an average of 2 diagnostic tests and for the majority it was not a significant cost burden.

Understanding and knowledge

Absolutely nothing. I was fit, I was going to the gym, I was eating properly and doing all the right things, and I thought I'd be okay, but I have a family history of heart problems, which sort of lingered in the background all the time.
Participant 031_2023AUHBV

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings[20,21]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[22,23] others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience[24]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[23]. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions[23].

In this PEEK study, the majority of participants had little or no knowledge of their condition when they were diagnosed. The majority were given some information at diagnosis, however, almost half of the participants did not think they were given enough information, and nearly 20% were given no information.

In other studies, young people with stroke had a lack of awareness of stroke in young people when diagnosed[25]. Those that had a TIA had not heard of the condition at diagnosis[26]. Others described having difficulties in understanding hereditary nature of condition[27]

Support at diagnosis

More than half of the participants in this PEEK study reported having no emotional support at diagnosis, almost 40% felt they had enough support.

Biomarkers or genetic markers

I should definitely have them because every woman in my family has had a stroke. I've got two girls so I think it would be really important for them to have that.
Participant 039_2023AUHBV

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

Lipoprotein a levels increase likelihood of a stroke or heart attack, particularly with familial hypercholesterolemia or symptoms of coronary heart disease [2]. The Australian Atherosclerosis Society recommends Lipoprotein a testing in high risk patients including those with premature atherosclerotic cardiovascular disease and those at intermediate to high risk of atherosclerotic cardiovascular disease[3]. The European Artherosclerotic society recommends testing at least once in adults, and cascade testing for those with familial hypercholesterolaemia, family history of high lipoprotein a, or premature atherosclerotic cardiovascular disease[4]. Treatment of high levels of lipoprotein a includes intensifying preventative treatments such as cholesterol lowering therapy and addressing lifestyle modifications [3].

Very few participants (14%) in this PEEK study reported having discussions about biomarkers, genomic and gene testing that might be relevant to treatment, and fewer (4%) recalled having these tests. However, 43% of participants knew their lipoprotein a status. This may highlight a lack of discussion or information about the importance of some diagnostic tests and the implications the results have on treatments.

Most commonly, participants had a family history of heart or blood vessel condition (n=25, 56.82%), followed by Lipoprotein A (LPa) status (n=19, 43.18%). There were 7 participants that were and not sure (15.91%), and 2 participants that had no markers (4.55%).

In other a study of people with familial hypercholesteremia, participants described that they had been contacted for screening due to risk factors, this increased awareness in some, though others did not understand the importance of their diagnosis. They described providing information to family members which sometimes resulted in family member testing[27]

Key points

- **Participants had little or no knowledge at diagnosis and were not given enough information**
- **Participants in this PEEK study lacked discussions or information about biomarkers, genomic and gene testing relevant to treatment**
- **Three**

Decision making

Yeah I think, well I feel, I think initially, because I was quite shell shocked, I would generally just go with whatever I was told to do. I think since then, I feel like I'm, what's the word? I feel more empowered to make my own medical decisions and be able to find resources and people that I can talk to about my different options. Participant 035_2023AUHBV

The decision-making process in healthcare is an important component in care of chronic or serious illness[28]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare[29,30], highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family[31]. Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results[32,33].

Less than 20% of participants in this PEEK study described taking part in treatment decision making when first diagnosed. Sometimes they were unable to make decisions because it was a medical emergency, or that they were too young or incapacitated and unable to make decisions. Similarly, another study described people not taking part in decision making due to being toi sick to make decisions[34]. Most participants in this PEEK study described decision making changing over time, this was mostly due to them becoming more assertive and more informed over time.

Goals of treatment and decision-making

My goal is not to die before I'm 60, which is pretty much my mother's side. They've all died before they're 60. So, you know, my, my goal is to and I lead by example because I want to be able to eat healthy, exercise and you know, and do all that sort of stuff. And you know, if at the end of the day that doesn't help me, well, you can't beat genes. But you know, that is my main goal. You know, I was told that if I didn't make all these dietary changes, I was going to be dead by 40. I'm 44 on Sunday, so I am still here. So, yeah, I don't have any long term goals, you know, beyond that sort of, you know, take it a year by year at this stage.
Participant 028_2023AUHBV

Most participants in this PEEK study took multiple considerations into account when making treatment decisions. The most common considerations were side effects, efficacy, the advice of their clinician, quality of life, their own research, their ability to follow treatments, and the impact on their family or dependents.

Likewise, in other studies people with heart and blood vessel conditions considered side effects, efficacy, the advice of clinicans, ability to follow treatment, quality of life and the impact on family [27,35-37]. Other considerations were previous experience of treatment, cultural considerations, co-morbidities and conflicting health priorities, and cost[27,35-37].

When participants in this PEEK study described their goals of treatment, the most common goals were to to make lifestyle changes to be fit and healthy, have physical improvements in their condition, and to have quality of life or to return to normality. In other studies, people with heart and blood vessel conditions described having goald to improved their mobility and to do domestic tasks, some described that a lack of discussing their goals led to unrealistic expectations [34,38].

Key points

- **Participants in this PEEK changed form not being involved with treatment decision making at diagnosis to over time becoming more assertive and informed in their treatment decision making.**
- **Side effects and efficacy were the most common considerations when making treatment decisions**
- **Making lifestyle changes to become fit and healthy was an common treatment goal.**

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having heart and blood vessel conditions are collected.

Access to health professionals

Half of the participants in this PEEK study were mainly treated by a general practitioner, and 42% described a specialist as their main provider of care. For more than 80% took an hour or less to travel to appointments with their main care provider. More than half pf the participants had access to allied health care (56%), most commonly a dietician, physiotherapist or a psychologist or counsellor.

Affordability of healthcare

> ***Yeah, I mean, obviously there's been costs involved. It costs to go to the breathing specialist, it costs to go to the GP, It costs to go to the cardiologist, It costs to purchase the medication, do the tests. Yes. So yes, there's costs.***
> ***Participant 019_2023AUHBV***

Almost half of the Australian population have private health insurance with hospital cover [11].. 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 about 8% to 14%[11]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

In the online questionnaire, the majority of participants in this PEEK study noted that they did not have problems paying for healthcare appointments, prescriptions or basic essentials, however their was a significant cost burden for those that had to quit their job or reduce working hours. In the structured interviews, participants elaborated on costs, describing medications, tests and scans, healthcare appointments and time of work all adding up to a cost burden. For this population, individual costs may not be a particular burden on their own, but due to the ongoing nature, the cumulative cost may be a burden.

Treatment

PEEK participants most commonly had drug treatments (80%), more than half had allied health care (56%), and approximately a third had surgery (34%). The majority of participants had made lifestyle changes (84%), and approximately a third used complementary therapies (36%).

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of heart and blood vessel conditions.

The most common allied health services used by PEEK participants were seeing a dietician, followed by physiotherapy, and psychology or counselling. On average they found seeing a dietician and physiotherapy as effective, and psychology or counselling somewhat effective.

Lifestyle changes

Many chronic diseases share the modifiable risk factors of poor diet, little exercise, smoking , and excessive alcohol consumption. The majority of participants in this PEEK study had made lifestyle changes, most commonly diet and exercise.

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Approximately a third of PEEK participants had used complementary therapy, most commonly mindfulness or relaxation techniques.

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.

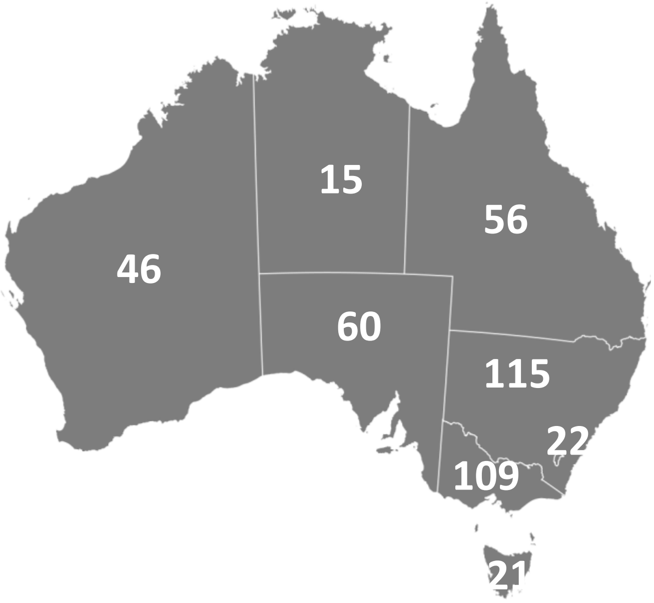

Figure 12.1: Distribution of clinical trials for heart and blood vessel conditions in Australia

To have an estimation of clinical trials available in this patient population, a search of the Australian New Zealand Clinical Trials Registry was conducted on October 11 2023. The search included interventional clinical trials registered on the ANZCTR, that were open to recruitment, were conducted in Australia, and were in the condition category "cardiovascular". A total of 370 clinical trials were currently open for recruitment. There were 115 clinical trials in NSW, 109 in Victoria, 60 in South Australia, 56 in Queensland, 46 in Western Australia, 22 in the Australian Capital Territory, 21 in Tasmania, and 15 in the Northern Territory.

Very few participants in this PEEK study had spoken about clinical trials for their condition, and only one participant had taken part in a clinical trial. In another study, people with heart of blood vessel conditions described being motibated to take part in clicnial trials to help other people, and the barriers to taking part included relevance of research question, travel and transportation to treatment, or the amount of time needed to take part[39].

Patient treatment preferences

Maybe a slight inconvenience to your life would be a mild side effect, maybe a little bit sick, maybe a little bit of a light headache, maybe a little bit of a lack of energy, that kind of thing.

Participant 020_2023AUHBV

Fatigue is definitely a severe side effect for me. It changes everything. I can feel fine one minute and 15 minutes later I'll be on the couch and not being able to move. It greatly affects. I have two teenage children who still need lots of help and assistance. It definitely greatly affects their lives as well.
Participant 047_2023AUHBV

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.[40-42] Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle[40,43].

To help inform patient preferences in the heart and blood vessel conditions community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were described by providing examples, or as side effects that have a short duration or do not interfere with life. Examples of specific mild side effects included pain, fatigue, headaches or nausea. In a similar way, participants describe severe side effects, broadly as those that impact every day life, or using the examples of pain, or cognitive difficulties, emotional impact, and fatigue,. It is interesting to note that participants described, nausea and pain as both mild and severe side effects. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

Participants in this PEEK study most commonly described adhering to a treatment for a specific amount of time, usually two to three months. They also described adhering according to the advice of their doctor or as long a side effects were tolerable. In other studies, participants with heart and blood vessel conditions described that adherence to treatment was facilitated when they were motivated to get better, when they were well informed about treatment, having support from family, and having a routine[44-49]. Barriers to treatment adherence included not being able to cope with the treatment, intolerable side effects and forgetfulness[44,46,48,49].

Participants were asked in the structured interview what their expectations of future treatments are. Some described expectations in terms of accessibility, they wanted accessibility, transparency and discussions in relation to treatment options, and more clinical trials including to access new technologies and treatments. Other described treatment expectations in terms of treatment targets or outcomes , such as treatments that are more effective, targeted, or personalised, have fewer or less intense side effects, or will manage symptoms and prevention of disability. Some participants described wanting more holistic treatments and more access to rehabilitation.

Key points

- **For this population, individual costs may not be a particular burden on their own, but due to the ongoing nature, the cumulative cost may be a burden.**
- **Very few PEEK participants had discussed or participated in clinical trials.**
- **Participants want to be informed about all available treatments and have access to them.**

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[50]. Components of self-management include information, activation and collaboration[50].

Information

I think they all play a part differently. I know early on, the reading would have been really hard for me to be able to read and then cognitively understand. So different forms, seek different people at different times, I now can see the computer and read information online. Early on, that was too exhausting. Participant 047_2023AUHBV

Information is a key component of health self-management[51,52]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[51,52].

Participants in this PEEK study accessed information from a range of sources, most commonly from the internet, their healthcare team, charities and from other people with heart and blood vessel conditions. In terms of format of information, the main preferences were online, talking to someone, written or a combination of formats. Similarly, in other studies people with heart and blood vessel conditions described getting information from a variety of sources including the internet, charities, healthcare professionals, clinical settings, family and friend, apps, videos, and workshops, and that a variety of formats is important[26,53-55].

Participants in this PEEK study described reasons why they preferred different formats for information. Participants preferred talking to someone because it allowed them to ask questions, the information given was relevant to them, body language can help with their understanding, and at times it was the only way to get information due to cognitive symptoms of their condition. Information from the internet was preferred because it was accessible, and that information could be digested at their own pace. Information from the internet and from written documents were preferred because they were easy to refer back to. Likewise, in another study, people with heart and blood vessel conditions preferred verbal information because it was reassuring, written information was easy to retain the information and could be refered back to, and online information was accessible[53].

In terms of timing of information, participants in this PEEK study wanted information at different time points. For many it was from the beginning or when the shock of diagnosis subsided, others wanted information continuously or when there were changes to their condition. Some were unreceptive to treatment for a year of more after diagnosis, or until treatment was finished. In other studies, people with heart and blood vessel conditions described wanting information during the first couple of weeks after dianosi or when being discharged from hospital[26,53,54,56], they did not want to be overwhelmed with information as it was difficult to remember everything[26,53], while others wanted information continuously was beneficial as information needs changes at different times[53].

When asked about the what information was useful, participants in this PEEK study most commonly described the sources of information they found helpful, for example information from other people's experience, talking to their doctor or specialist, health charities, medical journals, or from videos or webinars. The only topics that were described were hearing what to expect and lifestyle advice. In other studies people with heart and blood vessel conditions, people also described information from charities as helpful because it was credible[55], information from other people with their condition as helpful because it was relatable and supportive [53]. In terms of topics, practical information, information about emotional support, information that was specific to their condition or subtype of condition, and information about what to expect was described as helpful[53-55,57]

When asked about information that was not helpful, participants in this PEEK study most commonly responded that there wasn't any information that was not helpful, and some were confident in deciding what information was and was not helpful. Information that was not helpful included information from healthcare professionals, information that was not credible, that was not specific enough, or that had used too many medical terms that were not easily understood by lay people. In other studies people with heart and blood vessel conditions, people also described information that was too technical, and information that was not specific to their condition as not very helpful [53,55]. They also described a lack of information, or information that was withheld as not helpful, [26,55].

Participants in this PEEK study 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. They described that they wanted information in a variety of formats, information that is easy to understand, the ability to talk to or access to a health professional, and information that is easy to access. In terms of topics, participants wanted more information about disease trajectory and what to expect, information that is more holistic and includes emotional health, more information about the causes of their condition, and where to find support including peer support. In other studies, people with heart and blood vessel conditions described wanting more information that is specific to their condition or age group, that includes information about health risks, what to expect including emotional impact, and expected clinical pathways[25,26,55,56,58,59].

Participants in this PEEK study described a range of preferred information formats, sources, topics and different times when they were more receptive to information. This indicates that a range of different formats and sources of information are needed and that information is an ongoing need for people with heart and blood vessel conditions.

I think it gets easier the longer you have it because you understand it and accumulated information over time. At the beginning it's all very new. So it's like any kind of new learning. It's always hard at the beginning, but the longer you've been with it, the easier it gets.
Participant 019_2023AUHBV

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire[60]. On average, participants in this study had very good knowledge about their condition and treatments, had a good ability to manage the effects of their health condition, had a very good ability to adhere to treatments and communicate with healthcare professionals, and had very good recognition and management of symptoms.

Key points
- **Information needs to be presented in different formats, available from a number of sources, and offered throughout treatment and management of condition.**

Communication and collaboration

Well probably they didn't give me very much information. They just probably gave me a script and said, "Come back and see me in so many months. We'll send a letter to NAME DOCTOR." I mean to be perfectly honest, I never discussed anything really
Participant 037_2023AUHBV

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [51,52] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[61-64].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[65].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[65]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[65]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands[65]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[65]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[66]. On average participants had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as good and rated their quality of care as good.

In other studies, people with heart and blood vessel conditions described a lack of care coordination after hospital or rehabilitation discharge, with long waiting times and a lack of follow up[26,34,38]

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange. [67,68]

In this PEEK study, participants most commonly described that that overall communication with healthcare professionals was good. Good communication was described as supportive and with two way conversations, and poor communication as dismissive, one way conversations, lacking care coordination, and having a lack of time. In other studies, people with heart and blood vessel conditions described communication as good when there was empathy, friendliness, cooperation, and two-way conversations[38,69,70]. Poor communication was described when healthcare professionals did not understand the condition, did not understand the extent of physical limitations of the participant, when appointments were rushed, when information was incomplete, and when participants where dismissed [34,54,55,58,70]

Participants in this PEEK study described what they expected for future communication. Some of the expectations were about how healthcare professionals interact with patients, with participants expecting empathy, for healthcare professionals to listen to them, and to communicate with them in a way that a lay person can understand. Some expectations were about having more communication including more time, information that is transparent and forthcoming. Others wanted communication between healthcare professionals, and for their care to have multidisciplinary and coordinated approach that is holistic and includes emotional health. In other studies, people with heart and blood vessel conditions also wanted more time to talk with healthcare professionals, empathy and for healthcare professionals to listen to patients[59,71,72]

Care and support

Healthcare workers have been wonderful, as I've said. I had to change GPs because I wasn't happy with one of my GP. The current GP, I had a good chat to him, and we started from the base, and that's when we discovered that I had severe hypertension and thus I had severe left ventricular hypertrophy. I'm very happy with what he's done. Support from my family, my immediate family is always very good. They make sure I don't -- sometimes they're just a bit too much and make sure I'm not carrying stuff or -- they're gushing a bit much. I think before the AF, my immediate family kind of thought she's okay, she'll be fine, and that's how it's always been done. I think that's why my brother was so devastated when I got sick, I would say, because he didn't actually realise how serious -- although, yeah. Yeah, so no. I don't know. Everyone's great.
Participant 034_2023AUHBV

Participants in this PEEK study described support in terms of where they got support and the types of support they received. The sources of support were their hospital or clinical setting, from family and friends, peer support or other patients. The type of support most commonly described was domestic services or home care. Almost a third described that they did not receive any formal support, others described that they did not need or seek help or support, and some described the challenges of finding or accessing support. Likewise, In other studies, people with heart and blood vessel conditions described getting support from family and friends, in a clinical setting, from healthcare professionals[54,73], and also they described difficulties in accessing support and not knowing where to find support or information[55,73].

Participants in this PEEK study 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. Some participants expected care and support to be delivered through their healthcare team, where they described wanting a multidisciplinary and coordinated approach to their care, more long-term condition management, a holistic approach that included emotional health, and specialist clinics or services where they can talk to professionals, in person, by phone or online. Others wanted more practical support for example home care, transport, and financial support, and more access to support services in general.Similarly, in other studies, people with heart and blood vessel conditions wanted care coordination and follow up, and emotional health support[25,26,38,39,55,56,59,72]. In addition, they described wanting financial support, age appropriate care, access to peer support, remote support, and support for social participation[25,55,59,71,72,74]

Key points

- **Participants would like communication to have adequate time, be delivered with empathy and for transparency and forthcoming information**
- **Participants would like care and support to include a multi-disciplinary and coordinated approach**

Anxiety associated with condition

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease[75].

In this PEEK study, anxiety associated with heart and blood vessel conditions was measured by the fear of progression questionnaire[76]. The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Quality of life

Look it definitely affects it. There's a lot of stuff that I don't do. I don't go roller-skating with my daughter. I don't go jogging with my son. If, they were to go snow skiing in the winter I don't feel that I could do that. I think I'd get halfway through you know as I'm with them, and I'd be exhausted. There is a lot that I don't do. I have adapted to that fact, and there's a lot of stuff that we do, do together instead of. It doesn't affect me mentally like it used to. I've adjusted emotionally to the fact that what I can't do anymore. It definitely has affected my quality of life. For sure.
Participant 036_2023AUHBV

The majority of participants in this PEEK study described a negative impact on quality of life from having a heart or blood vessel condition. The main reasons for a negative impact were the emotional strain, the reduced capacity for physical activities, having to manage side effects and symptoms, reduced social interaction and reduced ability to work. Likewise, In other studies, people with heart and blood vessel conditions described poor quality of life due to physical limitations, cognitive problems, personality changes, changes in family dynamic, personal identity changes, loss of confidence, reduced social interaction, future goals lost, and an inability to work or work at full capacity[38,55,77,78].

Mental health

Yes. It's very emotional. Some days I'm really good and others are not. I did see a psychologist for a while to help with that. Probably a grieving of how my life had changed. It is something I probably should do all the time.
Participant 047_2023AUHBV

Participants in this PEEK study described that having a heart of blood vessel condition had at least some impact on their mental health. Participants described activities to maintain their mental health, most commonly consulting a mental health professional, meditation or mindfulness, exercise, remaining social and participating in hobbies, taking medication and pacing themselves.

Participants also described everyday activities to maintain their general health. The most common activities for general health were doing physical exercise or being physically active, self care for example more rest, accepting help, pacing themselves, and maintaining a healthy diet. Other activities included complying with treatment or management of their condition, mindfulness and/or meditation, making healthy lifestyle changes, maintaining a healthy weight, and managing stress.

Similarly, other studies described the activities for mental and general health performed by people with heart and blood vessel conditions. They described seeking help from a mental health professionals, peer support, mindfulness, seeking medical attention when experiencing symptoms[7,34,38,55,58].

Yeah, it's it's just keeping up with sort of my newer habits. Yeah. Because if I can do some exercises throughout the week, I mean, I I've got my, I'm keeping my physical conditioning and and then, of course, my mental health stays intact because I already get the pleasure of knowing that I've looked after my body, you know?
Participant 001_2023AUHBV

Impact on relationships

Participants in this PEEK study described a mix of changes to relationships die to their condition. Positive impacts were from people being supportive and well-meaning, and from family relationships being strengthened. Negative impacts were from the dynamics of relationships changing, people withdrawing from relationships and not knowing what to say, intimacy challenges, and others not believing the impact of the condition.

In other studies, people with heart and blood conditions described similar impacts on relationships. Relationships were strengthened, and also changed due to the emotional impact, changes in role and family dynamics, physical symptoms interfering with social and sporting activities, people not understanding the impact of the condition, relationship breakdowns and intimacy problems[34,55,56,58,78]

That's a tricky one. I think it changes things for the positive, actually, in that there's a greater sense of appreciation for someone who has been in a life-threatening situation. It's a hard one to answer because there's people who can't deal with it, and they can't respond, and they don't know how to respond for their own reasons, but it can create more distance, but on the other hand, for me, there's a group of people who I'm probably closer to now. So it's also just where you choose to focus, I guess. Yeah. So for me it's mostly been positive, I would say.
Participant 023_2023AUHBV

Characterisation

There were 50 participants with heart or blood vessel conditions in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. More than half were female and the majority were aged under 54.

Physical health often interfered with work or other activities for participants in this study.

Before diagnosis with a heart or blood vessel condition, participants commonly had no symptoms. For those that had symptoms, they had dizziness or weakness.

This is a group that had an average of 5 health conditions other than heart or blood vessel conditions to deal with, most often anxiety, depression, and sleep problems.

Most participants sought medical attention after noticing symptoms and were diagnosed in the hospital emergency department. This is a patient population that often had no symptoms and were diagnosed due to a routine check-up.

This is a cohort that were mostly diagnosed with heart and blood vessel conditions without experiencing symptoms, or they had shortness of breath. On average, this group had two diagnostic tests for heart and blood vessel conditions, they were diagnosed by an emergency doctor in a hospital. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with heart conditions. This is a group that did not have any emotional support, though they had some information at the time of diagnosis. This is a cohort that did not have conversations about biomarkers, genomic, or gene testing, though they are interested in having these tests.

This is a study cohort that had limited knowledge of heart and blood vessel conditions before they were diagnosed. This patient population described prognosis in terms of medications needed to manage their condition, or monitoring their condition until there is a progression.

This is a patient population that had discussions about multiple treatment options, very few described participating in the decision-making process.

This is a study cohort that took into account the side effects and efficacy as part of many considerations when making decisions about treatment.

Within this patient population, most participants had changed decision making over time, this was because they had become more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to make healthy lifestyle changes to become fit and healthy.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a general practitioner, and it usually took less than an 30 minutes to travel to medical appointments.

Two-thirds of this cohort had private health insurance, most commonly treated as public patients treated in the public hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to heart and blood vessel conditions were somewhat of a burden.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change their employment status. The loss of family income was an extremely significant burden.

Most participants had drug treatments for heart and blood vessel conditions. The majority used allied health services, and made lifestyle changes.

Very few had conversations about clinical trials, however they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using a specific example, and those that do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as pain, they also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described an amount of time they were willing to adhere to a treatment before giving up, or adhering according to their doctors' advice. This is a study cohort that needed to see a reduction in a specific symptom, or in physical signs to feel that treatment is working as well.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, disease cause, disease management, diet and physical activity from health care professionals, and searched for disease cause, treatment options, disease management and, how to interpret test results most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, their treating clinician or a health charity.

This is a study cohort that found information form other people's experience, talking to a doctor or from health charities as being most helpful.

Participants commonly found no information unhelpful, or information from their GP or specialist, and from sources that are not credible was not helpful.

This is a group that preferred talking to someone as a the main way to get information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive, or that it was a one way conversation.

The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population that most found support from the hospital or clinical setting.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

Life was a little distressing for this group, due to having heart and blood vessel conditions.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as consulting a mental health professional, and meditation and mindfulness in maintaining their mental health.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, because of interaction with their medical team, and when experiencing side effects from treatment or symptoms from their condition. To manage vulnerability, they relied on self-help, for example resilience, acceptance and staying positive.

This cohort most commonly felt there was an overall negative impact on their relationships, because the dynamics of relationships changing due to anxiety of difficult decisions.

Participants felt they were not a burden on their family. Those that felt they were a burden due to the extra household responsibilities that their family must take on.

Most participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more affordable, and for there to be more open and informed discussions about treatments.

This is a study cohort that would like more information about in a variety of formats and to have more details about disease trajectory and what to expect. Many participants were satisfied with the information they had received.

Participants in this study would like future communication to be more empathetic, and to have more time to meet with their clinician. Many participants were happy with their communication with healthcare professionals.

Participants would like future care and support to include peer support, and a multi-disciplinary and coordinated approach.

This patient population was grateful for the healthcare staff, and the public health system in general.

Participants’ message to decision-makers was the need for timely and equitable access to support, care and treatment.

This is a patient population that wished they had known what to be assertive, an advocate, informed, and ask questions. They also wished they had known the early signs and symptoms of their condition.

The aspect of care or treatment that participants in this study they would most like to change is to have had a better understanding of their condition, however, many wouldn’t change any aspect of their treatment or care.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. Care coordination and multi-disciplinary care
This is a cohort that have lifelong risk factors and often multiple comorbidities that require can medical, allied health and lifestyle interventions. There is a need for better access and coordination of healthcare services, better access to supportive GP, specialist nurses, allied health, and long term follow up after diagnosis, discharge hospital or rehabilitation to avoid future incidents.

2. Managing risk factors
This is a cohort that are at risk of stroke and heart attack. Very few had discussions about biomarkers that can inform them about risks of cardiovascular disease. This is a population that would benefit from understanding the biomarker tests available to them, and the development of initiatives to empower them to ask their treating clinician questions about these tests.

3. Support
This is a group where many did not receive any formal support, and some noted difficulties in finding support. They would benefit from being informed about practical support services available to them – including primary and secondary prevention support - in addition to being able to connect with other people with their condition.

2023 PEEK study in heart and blood vessel conditions

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2023 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 DISEASE 2023 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	66.40	70.00
	Role functioning/physical	49.50	25.00
	Role functioning/emotional	56.00	50.00
	Energy/fatigue	40.10*	40.00
	Emotional well-being	64.72	72.00
	Social functioning	57.75	68.75
	Pain	61.90	67.50
	General health	51.70	55.00
	Health change	51.00	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	25.44	27.00
	Coping	15.82	16.50
	Recognition and management of symptoms	19.44	21.00
	Adherence to treatment	13.76	15.00
	Total score	74.46*	74.50
Care coordination scale	Communication	36.86*	38.00
	Navigation	23.84*	23.00
	Total score	60.70	64.00
	Care coordination global measure	6.08	7.00
	Quality of care global measure	6.82	8.00
Fear of progression	Total Score	33.68*	33
		Percent	
Accessed My Health Record	-	40.00%	-
Participants that had discussions about biomarkers/genetic tests	-	14	-