Summary of results

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.

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%).