CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Hepatitis D

Volume 6 (2023), Issue 3

This study was generously sponsored by Gilead Australia.

Gilead Australia provided arm's length sponsorship for the Centre for Community-Driven Research to report on the PEEK protocol data for people who have been diagnosed with hepatitis D. The sponsor had no input into the methodology, data collection, data analysis or reporting.

Thank you to each and every person that participated in this PEEK study.

PEEK study process information

Volume	6
Issue	3
Reference	Centre for Community-Driven Research (CCDR). Personal Experience Expectations and Knowledge (PEEK) study: People who have experienced hidradenitis suppurativa. Volume 6, Issue 2 (2023)
CCDR research team	Kate Holliday, Anne Holliday, Sara Riggs, Victoria Koh, Fay Miller, Ashlee Osborne, Belinda Zheng
Number of participants	16

Contents

Summary of results

Executive summary

Characterisation

There were 16 participants with hepatitis D in the study from across Australia. The majority of participants lived in major cities, they lived in areas with higher levels of socioeconomic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 25 and 64. Most of the participants had completed some university, and most were employed either full time or part time. They were mostly not carers to family members or spouses.

This is a patient group that had multiple co-morbidities, mostly, depression, anxiety and sleep problems. Less than half of this group currently had other liver conditions.

This is a group whose condition had an impact on health-related quality of life, in particular, physical health often interfered with work and other activities.

This is a patient population that were mostly asymptomatic before diagnosis. For those with symptoms, they were most commonly fatigued.

This is a patient population that experienced no symptoms before being diagnosed. Most participants were diagnosed by their general practitioner.

This is a cohort that were mostly diagnosed with hepatitis D without experiencing symptoms. On average, this group had four diagnostic tests for hepatitis D, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not a burden to them and their families. This is a group that did not have enough emotional support or information at the time of diagnosis. This is a cohort that did not have conversations about biomarker/genomic/gene testing. They did not have biomarker or genetic tests but would be interested in having them.

This is a study cohort that had limited knowledge of hepatitis D before they were diagnosed. This patient population described prognosis in terms of medical interventions they need to manage their condition, or were unclear about their prognosis.

This is a patient population that had one treatment option presented to them, and they did not participate in discussions about treatments.

This is a study cohort that took into account their ability to follow treatments, efficacy and side effects when making decisions about their treatment.

Within this patient population participants did not change their decision making over time.

When asked about their personal goals of treatment or care participants most commonly described wanting to maintain their condition or prevent their condition getting worse.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a ggastroenterologist, and it usually took less than an hour to travel to medical appointments.

Approximately half of this cohort had private health insurance, half were public patients and most were treated in the public hospital systems This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to hepatitis D were slightly or not at all a burden.

Participants in this study reduced work hours, or had to take paid leave from work due to their condition. Carers and family did not have to change employment status.

Almost all participants had drug treatments for hepatitis D, usually pegylated interferon alpha. Half of the participants used an allied health service most often a psychologist. More than half made lifestyle changes, usually diet, and approximately a third used complementary therapies, commonly massage therapy or mindfulness and relaxation techniques.

This is a cohort that had conversations about clinical trials, and 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 as those which can be self-managed and do not interfere with daily life.

This is a study cohort that most commonly could not describe severe side effects because they had not experienced any. Some described them as symptoms such as those that impact every day life, using a specific example or those that are worse than the condition.

This is a patient population which described adhering to their treatment according to the advice of their doctor or as long as prescribed. This is a study cohort that needed to see physical signs and symptoms disappear to feel that treatment is working. If treatment worked, it would allow them to do everyday activities and return to a normal life.

Participants had good knowledge about their condition and treatments, a good ability to manage the effects of their health condition, good ability to adhere to treatments and communicate with healthcare professionals, and good recognition and management of symptoms.

Participants were given information about disease management, and treatment options from health care professionals, and searched for the same topics independently. 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 their treating clinician or the internet.

This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, or a lack of new information as unhelpful.

This is a group that preferred online information or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall negative experience with health professional communication which was dismissive with one-way conversations. Those that experienced good communication with healthcare professionals was because it was holistic, two way and comprehensive.

The participants in this study had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as average, and they participants rated their quality of care as average.

This is a patient population that commonly did not receive any formal support for their condition. Some were supported by other people with hepatitis.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on themselves.

Life was a little distressing for this group, due to having hepatitis D.

This is a study cohort that experienced at least some impact on their mental health and most commonly did no activities to maintain their mental health. Some consulted a mental health professional and others used mindfulness or mediation to maintain their mental health.

Within this patient population, participants described being complying with treatment in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments. To manage vulnerability, they relied on support from family and friends, peer support or took charge of their health.

This cohort most commonly felt there was a negative impact on their relationships, because dynamics of relationships changed due to anxiety of difficult decisions.

Participants felt they were a burden on their family, but that it was only temporary or only during treatment.

Most participants felt there was some cost burden which was from the costs of treatments, 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 come with more open and informed discussions, and for treatments to be easier to administer.

This is a study cohort that would like information to be easier to understand, be more holistic and also to raise community awareness.

Participants in this study would like future communication to allow people more time to meet with their clinician, and to be more transparent and forthcoming.

Participants would like future care and support to include peer support, support groups and online forums.

This patient population was grateful for the healthcare staff, access to specialists, and low cost or free medical treatments through the government.

It was important for this cohort to control fatigue, and liver cirrhosis or fibrosis for quality of life. Participants in this study would consider taking a treatment for less than a year if quality of life is improved with no cure.

Participants' message to decision-makers was that people with hepatitis need timely and equitable access to care and treatment.

This is a patient population that wished they had known to be assertive, to be an advocate and ask their doctor questions. However, many wouldn't change any aspect of their treatment or care.

Section 1

Introduction and methods

Section 1 Introduction and methodology

Background

Hepatitis D is a viral hepatitis that can only replicate with Hepatitis B. Hepatitis D infection may occur simultaneously with hepatitis B (coinfection),or can occur in chronic Hepatitis b (superinfection)[1]. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure[2]. Superinfection is the most common form of hepatitis, and has a higher risk of cirrhosis and liver cancer[2-4].

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare[5]. The majority of hepatitis D patients are asymptomatic, symptoms can include fever, abdominal pain, nausea, vomiting, jaundice, confusion, bruising, or bleeding , loss of appetite, dark urine, and pale-coloured stools[5,6].

Hepatitis is more common in the Middle East, West and Central Africa, Amazonian river basin, Mongolia, Romania, Russia, Pakistan, Georgia, and Turkey[7].

In Australia 2016, 61 cases of hepatitis D were notified, with an average of 48 cases annually in the period 2011-2015, most cases were reported from New South Wales, Victoria, and Queensland[8]. In Australia, hepatitis D is more common in people born in Vietnam, Sudan, and Afghanistan, and there is a higher risk for anyone who has ever been in prison[9]. More males than females have hepatitis D in Australia, at a rate of 2:1[8].

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 (March 6, 2023) to identify studies of hepatitis D, or hepatitis B with patient reported outcomes, or patient experience conducted in the past five years worldwide (Table 1.1). Meta-analysis studies, studies with children, studies in developing countries, and studies of less than five participants were excluded. There were 2 studies identified that included participants with hepatitis D, and 21 studies that included participants with hepatitis B

There were two studies that included participants with hepatitis D, one study was a multi-national study that reviewed emails or social media queries from 65 people with hepatitis D focused on information[16]. The second study included 43 participants with hepatitis D, 82 participants with hepatitis B and collected health-related quality of life by survey[17].

There were 6 studies that collected qualitative data from participants with hepatitis D, there was one study that that reviewed emails or social media queries from 338 participants that was focused on information [18]. There were 28 participants that took part in focus groups that described health literacy[19]. There were four studies that interviewed between 11 and 23 people with hepatitis B that were focused on stigma[20], decision making[21], quality of life[22] and symptoms[23]

This is the only hepatitis D study of patient reported outcomes, or patient experience conducted in the last 5 years in Australia, and the only study world wide to interview people with hepatitis B about their experiences. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2

Demographics

Section 2 Demographics

Demographics

There were 16 people with hepatitis D that took part in this study, 14 completed the online questionnaire and 12 were interviewed for this study. There were 8 female participants (50.00%), participants were aged from 25 to 74 years of age, most were aged between 25 to 44 years (n=9, 56.25%).

Participants were most commonly from Victoria (n=6, 37.50%), New South Wales (n=5, 31.25%), and Queensland (n=3, 18.75%). Most participants were from major cities (n=13, 81.25%), and they mostly lived in areas with higher socioeconomic advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (12.50%) from an area with a mid to low SEIFA score of 1 to 6 (less advantage), and 14 participants (87.50%) from an area of higher SEIFA scores of 7 to 10 (more advantaged).

There were 9 participants (56.25%) that had completed university to at least an associate degree. There were 9 participants who were in paid employment. There were 4 participants (28.57%) were carers to family members or spouses, most commonly carers to children, parents (n=2, 14.29%).

Other health conditions

The majority of participants had at least one other condition that they had to manage (n=12, 85.71%), the maximum number reported was 13 other conditions, with a median of 3.50 other conditions (IQR = 5.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was depression (self or doctor diagnosed) (n=7, 50.00%), followed by anxiety (self or doctor diagnosed) (n=7, 50.00%), sleep problems or insomnia (n=6, 42.86%), and hypertension (n=5, 35.71%).

Baseline health

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 interfered 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 moderately 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 average 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.

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

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

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

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 for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

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 by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67 %). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D . Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

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 were most commonly diagnosed immediately at the consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks,2 participants (14.29%) diagnosed between 2 and 3 weeks,1 participants (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) 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 hepatitis D. 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 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

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 general practitioner (GP) (n=8, 57.14%), and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Hepatitis Vaccinations

Most participants had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

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 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) 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 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) 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 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between $50 and $150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), 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.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) 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.

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months. The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

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 (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%),that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

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 one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did no give a reason (16.67%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67 %). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

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 maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

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 gastroenterologists (n=9,64.29 %), followed by general practitioners (n=5, 35.71%).

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 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

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.

Almost all participants had access to a gasteroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were 12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

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 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

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=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 particpants (53.85%) were mostly treated as a public patient, and there were 2 particpants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 particpants (76.92%) were mostly treated in the public system, and there was 1 particpant (7.69%) that was 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. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) 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 3 participants (23.08%) 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 (Table 5.8, Figure 5.9).

The most common amount was between $1 and $150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than $100 per month.

Burden of cost

As a follow up question, for participants that 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 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

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 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2 participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) 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 3 participants (23.08%), 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=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) 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.

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Summary of treatments and management

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

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

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. Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00 , IQR=3.00).

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist , 1 participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

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.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

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 moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

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=5, 35.71%)

The most common complementary therapy used was , massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

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 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

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 (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

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 those that do not interfere with life (50.00%), and they described mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

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 according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

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 physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33 %), and night sweats (8.33%).

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/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

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 their treating clinician (58.33%), the internet (41.67%), and health charities (25.00 %). Other sources included other patient's experience (Including support groups) (16.67%), books, pamphlets and newsletters (8.33%), and Facebook or social media (8.33%).

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 hearing what to expect (e.g. from disease, side effects, treatment) (58.33%), other people's experiences (Peer-to-peer)(25.00%), and talking to a doctor or specialist or healthcare team (25.00 %). Other helpful information included information from health charities (8.33%), information about lifestyle changes (8.33%), and information about transmission (8.33%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that there was no information that wasnot helpful (50.00%). Information that was not helpful included and a lack of new information (16.67%), information from their GP or specialist (8.33%), sources that are not credible (not evidence-based) (8.33%), information that is not comprehensive (8.33%), and information that is accompanied with stigma and discrimination (8.33%).

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 (33.33%), and talking to someone plus online information (33.33%). Other preferences included online information (16.67%), all forms (16.67%), and written information (8.33%).

The main reasons for a preference for online information were that it is personalised and relevant (41.67%), being able to\have time to ask questions (Talking to someone) (25.00%), and No strong reason for preference\Personal preference (25.00 %). Other themes included Accessibility (Internet) (16.67%), Being able to digest information at their own pace (Internet) (8.33%),written information because you can refer back to/highlight important information (8.33%), and online information because it is reliable information and you are able to decide if trustworthy (8.33%).

The main reasons for a preference for online information was because of the ease of accessibility (16.67%), because it is personalised and relevant (16.67%), because it is reliable information and you are able to decide if trustworthy (8.33%), and because they are able to digest information at their own pace information at their own pace (8.33%).
The main reasons for a preference for talking to some one because they are able to ask questions (25.00%), and because it is personalised and relevant (25.00%).
The main reasons for a preference for written information because you can refer back to/highlight important information (8.33%)

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) (33.33%), and continuously (25.00%). Other times included after the shock of diagnosis (16.67%), when something needs treatment/attention/change in management (16.67%), and at a specific time in the day (8.33%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Half of the participants described communication as overall negative (50.00%), a quarter described communication as overall negative (25.00%), 16.67% had overall positive communication with the exception of one or two occasions, and 8.33% had a mix of both positive and negative communication.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had negative communication, described the reason for this was because of dismissive one way conversations (25.00%), communication was limited in time (25.00%), communication was limited in understanding (8.33%), healthcare professionals used difficult medical terms (8.33%), participants felt disrespected vulnerable (8.33%), and that information that was withheld or not freely given (8.33%).

Participants that had positive communication, described the reason for this was because of holistic two way, supportive and comprehensive conversation) (25.00%).

Partners in 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 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 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 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.

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=10, 76.92%), and 1 participant (7.69%) responded that they took medicines as prescribed most of the time. There were 2 participants (15.38%) that sometimes took medicines 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=10, 76.92%), disease management (n=7, 53.85%), interpret test results (n=5, 38.46%) and, psychological/ social support (n=4, 30.77%) were most frequently given to participants by healthcare professionals, and, information about dietary (n=2, 15.38%), hereditary considerations (n=2, 15.38%) and, complementary therapies (n=1, 7.69%) were given least often.

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 treatment options (n=7, 53.85%), disease management (n=7, 53.85%), disease cause (n=5, 38.46%) and, complementary therapies (n=5, 38.46%) were most frequently given to participants by healthcare professionals, and, information about physical activity (n=4, 30.77%), hereditary considerations (n=2, 15.38%) and, clinical trials (n=1, 7.69%) 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=10, 76.92%) and Pphysical activity (n=10, 76.92%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=4, 30.77%) and disease cause (n=3, 23.08%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=6, 46.15%) and disease management (n=6, 46.15%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=5, 38.46%) and complementary therapies (n=4, 30.77%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Medical journals and from Pharmaceutical companies were least accessed.

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 average.

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 average.

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 response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

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. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67 %), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00 %). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%). The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

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 (83.33%), and overall, there was no impact on mental health(8.33%).

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 response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67 %), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

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 complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

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 during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67 %), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

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 getting support from family and friends (8.33%). peer support (8.33 %) and taking charge of own health (8.33%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

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 a burden on their family (66.67%), overall, there was not a burden on their family(16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

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 range (median=3.00, IQR=3.50).

Fear of 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 include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

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 responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%), provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

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 allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

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 it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67 %), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

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) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67 %). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

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. 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. Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), 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 were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67 %), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

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 to ask questions (50.00%), and that they had understood the cause and risk factors of the condition (16.67%). Other themes included to be open to complementary approaches (8.33%), to look after emotional wellbeing (8.33%), that there was more community awareness of their condition (8.33%), and that they had understood the extent of the transmission risk they posed to others (8.33%).

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 theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33 %), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).

Section 1

Introduction and methods

Section 1 Introduction and methodology

Background

Hepatitis D is a viral hepatitis that can only replicate with Hepatitis B. Hepatitis D infection may occur simultaneously with hepatitis B (coinfection),or can occur in chronic Hepatitis b (superinfection)[1]. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure[2]. Superinfection is the most common form of hepatitis, and has a higher risk of cirrhosis and liver cancer[2-4].

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare[5]. The majority of hepatitis D patients are asymptomatic, symptoms can include fever, abdominal pain, nausea, vomiting, jaundice, confusion, bruising, or bleeding , loss of appetite, dark urine, and pale-coloured stools[5,6].

Hepatitis is more common in the Middle East, West and Central Africa, Amazonian river basin, Mongolia, Romania, Russia, Pakistan, Georgia, and Turkey[7].

In Australia 2016, 61 cases of hepatitis D were notified, with an average of 48 cases annually in the period 2011-2015, most cases were reported from New South Wales, Victoria, and Queensland[8]. In Australia, hepatitis D is more common in people born in Vietnam, Sudan, and Afghanistan, and there is a higher risk for anyone who has ever been in prison[9]. More males than females have hepatitis D in Australia, at a rate of 2:1[8].

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 (March 6, 2023) to identify studies of hepatitis D, or hepatitis B with patient reported outcomes, or patient experience conducted in the past five years worldwide (Table 1.1). Meta-analysis studies, studies with children, studies in developing countries, and studies of less than five participants were excluded. There were 2 studies identified that included participants with hepatitis D, and 21 studies that included participants with hepatitis B

There were two studies that included participants with hepatitis D, one study was a multi-national study that reviewed emails or social media queries from 65 people with hepatitis D focused on information[16]. The second study included 43 participants with hepatitis D, 82 participants with hepatitis B and collected health-related quality of life by survey[17].

There were 6 studies that collected qualitative data from participants with hepatitis D, there was one study that that reviewed emails or social media queries from 338 participants that was focused on information [18]. There were 28 participants that took part in focus groups that described health literacy[19]. There were four studies that interviewed between 11 and 23 people with hepatitis B that were focused on stigma[20], decision making[21], quality of life[22] and symptoms[23]

This is the only hepatitis D study of patient reported outcomes, or patient experience conducted in the last 5 years in Australia, and the only study world wide to interview people with hepatitis B about their experiences. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Background

Hepatitis D is a viral hepatitis that can only replicate with Hepatitis B. Hepatitis D infection may occur simultaneously with hepatitis B (coinfection), or can occur in chronic Hepatitis b (superinfection)[1]. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure[2]. Superinfection is the most common form of hepatitis D, and has a higher risk of cirrhosis and liver cancer[2-4].

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare[5]. The majority of hepatitis D patients are asymptomatic, symptoms can include fever, abdominal pain, nausea, vomiting, jaundice, confusion, bruising, or bleeding , loss of appetite, dark urine, and pale-coloured stools[5,6].

Hepatitis is more common in the Middle East, West and Central Africa, Amazonian river basin, Mongolia, Romania, Russia, Pakistan, Georgia, and Turkey[7].

In Australia 2016, 61 cases of hepatitis D were notified, with an average of 48 cases annually in the period 2011-2015, most cases were reported from New South Wales, Victoria, and Queensland[8]. In Australia, hepatitis D is more common in people born in Vietnam, Sudan, and Afghanistan, and there is a higher risk for anyone who has ever been in prison[9]. More males than females have hepatitis D in Australia, at a rate of 2:1[8].

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.

Participants

To be eligible for the study, participants needed to have been diagnosed with Hepatitis D, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, Cantonese or Mandarin, and be able to give consent to participate in the study.

Recruitment was difficult in this rare patient population however was possible through clinicians and groups such as LiverWELL, Hepatitis NSW, Hepatitis Queensland, and Vietnamese and Chinese community groups.

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)[10], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[11], the Short Fear of Progression Questionnaire (FOP12)[12], and the Partners in Health version 2 (PIH)[13]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by 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 gender, age, location of residence, education status and socio-economic status. Scales and subscales were calculated according to reported instructions[10-13].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[14].

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[15].

For 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 database. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in CCDR's custom database. 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 were collected between April 2022 and July 2023. Analysis and final reporting was completed in August 2023.

Position of this study

A search was conducted in Pubmed (March 6, 2023) to identify studies of hepatitis D, or hepatitis B with patient reported outcomes, or patient experience conducted in the past five years worldwide (Table 1.1). Meta-analysis studies, studies with children, studies in developing countries, and studies of less than five participants were excluded. There were 2 studies identified that included participants with hepatitis D, and 21 studies that included participants with hepatitis B

There were two studies that included participants with hepatitis D, one study was a multi-national study that reviewed emails or social media queries from 65 people with hepatitis D focused on information[16]. The second study included 43 participants with hepatitis D, 82 participants with hepatitis B and collected health-related quality of life by survey[17].

There were 6 studies that collected qualitative data from participants with hepatitis B, there was one study that that reviewed emails or social media queries from 338 participants that was focused on information [18]. There were 28 participants that took part in focus groups that described health literacy[19]. There were four studies that interviewed between 11 and 23 people with hepatitis B that were focused on stigma[20], decision making[21], quality of life[22] and symptoms[23]

This is the only hepatitis D study of patient reported outcomes, or patient experience conducted in the last 5 years in Australia, and the only study worldwide to interview people with hepatitis D about their experiences. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

Author, Year	Location	Conditions	Qualitative data collection	Surveys	Study focus								
						2: Health status, co-morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
Buti et al, 2021[17]	Spain	HBV,HDV		43 HDV, 82 HBV	HRQOL	X						X	
Kumar et al, 2020[16]	Multi-national	HDV	65 (Email/ social media queries)		Information		X		X	X		X	
Freeland et al, 2021[18]	Multi-national	HBV	338 (Email/ social media queries)		Information		X		X	X		X	
Hyun et al, 2021[19]	USA	HBV	28 (Focus groups)		Health literacy		X		X	X		X	
Alber et al, 2020[20]	USA	HBV	23 (Interviews)		Stigma					X		X	
Freeland et al, 2021[21]	USA	HBV	19 (Interviews)		Decision making			X	X				
Freeland et al, 2021[22]	USA	HBV	19 (Interviews)		Quality of life		X		X			X	
Jang et al, 2018[23]	Korea	HBV	11 (Interviews)	147	Symptoms		X					X	
Evon et al, 2021[24]	USA	HBV		1,576	Symptoms		X						
Daida et al, 2020[25]	USA	HBV		969	HRQOL	X							
Evon et al, 2020[26]	USA	HBV		876	HRQOL	X	X						
Chen et al, 2021[27]	Taiwan	HBV		503	HRQOL	X	X						
Cortesi et al, 2020[28]	Italy	Liver conditions		284 HBV	HRQOL	X	X						
Younossi et al, 2019[29]	Multi-national	HBV		229	HRQOL	X						X	
Roche et al, 2022[30]	Multi-national	HBV		195	HRQOL	X			X				
Höner Zu Siederdissen et al, 2018[31]	Germany	HBV		174	HRQOL	X							
Younossi et al, 2019[32]	Multi-national	Liver conditions		132 HBV	HRQOL	X							

Volpes et al, 2020[33]	Italy	HBV		86	HRQOL	X	X				X		
Ekerfors et al, 2019[34]	Sweden	Liver conditions		57 HBV	HRQOL		X						
McPhail et al, 2020[35]	Australia	Liver conditions		33 HBV	HRQOL	X							
Westermann et al, 2019[36]	Germany	Liver conditions		31 HBV	HRQOL	X			X			X	
Dirks et al, 2019[37]	Germany	Liver conditions		22 HBV	HRQOL	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 5significantly 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.

References

1. Mentha N, Clement S, Negro F, Alfaiate D. A review on hepatitis D: From virology to new therapies. *J Adv Res* 2019; **17**: 3-15.
2. Castaneda D, Gonzalez AJ, Alomari M, Tandon K, Zervos XB. From hepatitis A to E: A critical review of viral hepatitis. *World J Gastroenterol* 2021; **27**(16): 1691-715.
3. Fattovich G, Giustina G, Christensen E, et al. Influence of hepatitis delta virus infection on morbidity and mortality in compensated cirrhosis type B. The European Concerted Action on Viral Hepatitis (Eurohep). *Gut* 2000; **46**(3): 420-6.
4. Sureau C, Negro F. The hepatitis delta virus: Replication and pathogenesis. *J Hepatol* 2016; **64**(1 Suppl): S102-S16.
5. Hepatitis D fact sheet. In: World Health Organization: media centre [website] http://www.who.int/mediacentre/ factsheets/hepatitis-d/en/, accessed 30 May 2022) 28 July 2021 update. .
6. Masood U, John S. Hepatitis D. StatPearls. Treasure Island (FL); 2022.
7. Wedemeyer H, Manns MP. Epidemiology, pathogenesis and management of hepatitis D: update and challenges ahead. *Nat Rev Gastroenterol Hepatol* 2010; **7**(1): 31-40.
8. Group NARW. Australia's notifiable disease status, 2016: Annual report of the National Notifiable Diseases Surveillance System. *Commun Dis Intell (2018)* 2021; **45**.
9. Jackson K, MacLachlan J, Cowie B, et al. Epidemiology and phylogenetic analysis of hepatitis D virus infection in Australia. *Intern Med J* 2018; **48**(11): 1308-17.
10. 36-Item Short Form Survey (SF-36) Scoring Instructions. n.d. https://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html (accessed 10 February 2017.
11. Young JM, Walsh J, Butow PN, Solomon MJ, Shaw J. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer* 2011; **11**: 298.
12. Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months after cancer rehabilitation-a- validation study of the fear of progression questionnaire FoP-Q-12. *Support Care Cancer* 2015; **23**(6): 1579-87.
13. Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Qual Life Res* 2010; **19**(7): 1079-85.
14. Masiero M, Busacchio D, Guiddi P, et al. Quality of life and psycho-emotional wellbeing in bladder cancer patients and their caregivers: a comparative analysis between urostomy versus ileal orthotopic neobladder. *Ecancermedicalscience* 2021; **15**: 1163.
15. Wijburg CJ, Michels CTJ, Hannink G, et al. Robot-assisted Radical Cystectomy Versus Open Radical Cystectomy in Bladder Cancer Patients: A Multicentre Comparative Effectiveness Study. *Eur Urol* 2021; **79**(5): 609-18.
16. Kumar P, Freeland C, Bodor S, Farrell S, Cohen C, Frasso R. Needs of Individuals Living With Hepatitis Delta Virus and Their Caregivers, 2016-2019. *Prev Chronic Dis* 2020; **17**: E159.
17. Buti M, Stepanova M, Palom A, et al. Chronic hepatitis D associated with worse patient-reported outcomes than chronic hepatitis B. *JHEP Rep* 2021; **3**(3): 100280.
18. Freeland C, Farrell S, Kumar P, et al. Common concerns, barriers to care, and the lived experience of individuals with hepatitis B: a qualitative study. *BMC Public Health* 2021; **21**(1): 1004.
19. Hyun S, Ko O, Kim S, Ventura WR. Sociocultural barriers to hepatitis B health literacy in an immigrant population: a focus group study in Korean Americans. *BMC Public Health* 2021; **21**(1): 404.
20. Alber JM, Cohen C, Racho R, et al. Exploring the Impact of Storytelling on Storytellers in a Hepatitis B Health Communication Context. *Patient Educ Couns* 2020; **103**(9): 1760-6.
21. Freeland C, Racho R, Kamischke M, Moraras K, Wang E, Cohen C. Cure everyone and vaccinate the rest: The patient perspective on future hepatitis B treatment. *J Viral Hepat* 2021; **28**(11): 1539-44.
22. Freeland C, Racho R, Kamischke M, et al. Health-related quality of life for adults living with hepatitis B in the United States: a qualitative assessment. *J Patient Rep Outcomes* 2021; **5**(1): 121.
23. Jang Y, Boo S, Yoo H. Hepatitis B Virus Infection: Fatigue-Associated Illness Experiences Among Koreans. *Gastroenterol Nurs* 2018; **41**(5): 388-95.
24. Evon DM, Lin HS, Fontana RJ, et al. Liver disease symptoms are associated with higher risk of adverse clinical outcomes: A longitudinal study of North American adults with chronic Hepatitis B. *GastroHep* 2021; **3**(3): 196-208.
25. Daida YG, Boscarino JA, Moorman AC, et al. Mental and physical health status among chronic hepatitis B patients. *Qual Life Res* 2020; **29**(6): 1567-77.
26. Evon DM, Lin HS, Khalili M, et al. Patient-reported outcomes in a large North American cohort

living with chronic hepatitis B virus: a cross-sectional analysis. *Aliment Pharmacol Ther* 2020; **51**(4): 457-68.

27. Chen CH, Wu MS, Yang YW, et al. Longitudinal changes in physical and mental health of older adults with chronic hepatitis B infection: Trajectories and predictors. *Prev Med Rep* 2021; **23**: 101432.

28. Cortesi PA, Conti S, Scalone L, et al. Health related quality of life in chronic liver diseases. *Liver Int* 2020; **40**(11): 2630-42.

29. Younossi ZM, Stepanova M, Younossi I, et al. Long-term Effects of Treatment for Chronic HBV Infection on Patient-Reported Outcomes. *Clin Gastroenterol Hepatol* 2019; **17**(8): 1641-2 e1.

30. Roche B, Bauhofer A, Gomez Bravo MA, et al. Long-Term Effectiveness, Safety, and Patient-Reported Outcomes of Self-Administered Subcutaneous Hepatitis B Immunoglobulin in Liver Post-Transplant Hepatitis B Prophylaxis: A Prospective Non-Interventional Study. *Ann Transplant* 2022; **27**: e936162.

31. Honer Zu Siederdissen C, Schlevogt B, Solbach P, et al. Real-world effect of ribavirin on quality of life in HCV-infected patients receiving interferon-free treatment. *Liver Int* 2018; **38**(5): 834-41.

32. Younossi ZM, Stepanova M, Younossi I, et al. Patient-reported outcomes in patients chronic viral hepatitis without cirrhosis: The impact of hepatitis B and C viral replication. *Liver Int* 2019; **39**(10): 1837-44.

33. Volpes R, Burra P, Germani G, et al. Switch from intravenous or intramuscular to subcutaneous hepatitis B immunoglobulin: effect on quality of life after liver transplantation. *Health Qual Life Outcomes* 2020; **18**(1): 99.

34. Ekerfors U, Sunnerhagen KS, Westin J, et al. Muscle performance and fatigue in compensated chronic liver disease. *Scand J Gastroenterol* 2019; **54**(7): 925-33.

35. McPhail SM, Amarasena S, Stuart KA, et al. Assessment of health-related quality of life and health utilities in Australian patients with cirrhosis. *JGH Open* 2021; **5**(1): 133-42.

36. Westermann C, Nienhaus A, Treszl A. Quality of Life and Work Ability among Healthcare Personnel with Chronic Viral Hepatitis. Evaluation of the Inpatient Rehabilitation Program of the Wartenberg Clinic. *Int J Environ Res Public Health* 2019; **16**(20).

37. Dirks M, Haag K, Pflugrad H, et al. Neuropsychiatric symptoms in hepatitis C patients resemble those of patients with autoimmune liver disease but are different from those in hepatitis B patients. *J Viral Hepat* 2019; **26**(4): 422-31.

Section 2

Demographics

Section 2 Demographics

Demographics

There were 16 people with hepatitis D that took part in this study, 14 completed the online questionnaire and 12 were interviewed for this study. There were 8 female participants (50.00%), participants were aged from 25 to 74 years of age, most were aged between 25 to 44 years (n=9, 56.25%).

Participants were most commonly from Victoria (n=6, 37.50%), New South Wales (n=5, 31.25%), and Queensland (n=3, 18.75%). Most participants were from major cities (n=13, 81.25%), and they mostly lived in areas with higher socioeconomic advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (12.50%) from an area with a mid to low SEIFA score of 1 to 6 (less advantage), and 14 participants (87.50%) from an area of higher SEIFA scores of 7 to 10 (more advantaged).

There were 9 participants (56.25%) that had completed university to at least an associate degree. There were 9 participants who were in paid employment. There were 4 participants (28.57%) were carers to family members or spouses, most commonly carers to children, parents (n=2, 14.29%).

Other health conditions

The majority of participants had at least one other condition that they had to manage (n=12, 85.71%), the maximum number reported was 13 other conditions, with a median of 3.50 other conditions (IQR = 5.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was depression (self or doctor diagnosed) (n=7, 50.00%), followed by anxiety (self or doctor diagnosed) (n=7, 50.00%), sleep problems or insomnia (n=6, 42.86%), and hypertension (n=5, 35.71%).

Baseline health

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 interfered 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 moderately 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 average 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.

Demographics

There were 16 people with hepatitis D that took part in this study, 14 completed the online questionnaire and 12 were interviewed for this study. There were 8 female participants (50.00%), participants were aged from 25 to 74 years of age, most were aged between 25 to 44 years (n=9, 56.25%).

Participants were most commonly from Victoria (n=6, 37.50%), New South Wales (n=5, 31.25%), and Queensland (n=3, 18.75%). Most participants were from major cities (n=13, 81.25%), and they mostly lived in areas with higher socioeconomic advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (12.50%) from an area with a mid to low SEIFA score of 1 to 6 (less advantage), and 14 participants (87.50%) from an area of higher SEIFA scores of 7 to 10 (more advantaged).

There were 9 participants (56.25%) that had completed university to at least an associate degree. There were 9 participants who were in paid employment.

There were 4 participants (28.57%) were carers to family members or spouses, most commonly carers to children, parents (n=2, 14.29%). The demographics of participants are listed in Table 2.1.

Table 2.1: Demographics

Demographics	Definition	Number (n=16)	Percent
Gender	Female	8	50.00
	Male	8	50.00
Age	18 – 24	0	0.00
	25 – 34	5	31.25
	35 – 44	4	25.00
	55 – 64	5	31.25
	65 – 74	2	12.50
	65 – 74	0	0.00
Location	Major Cities of Australia	13	81.25
	Inner Regional Australia	2	12.50
	Outer Regional or remote Australia	1	6.25
	Remote Australia	0	0.00
State	Australian Capital Territory	0	0.00
	New South Wales	5	31.25
	Northern Territory	0	0.00
	Queensland	3	18.75
	South Australia	1	6.25
	Tasmania	0	0.00
	Victoria	6	37.50
	Western Australia	1	6.25
Socio-Economic Indexes for Areas (SEIFA)	1	2	12.50
	2	0	0.00
	3	0	0.00
	4	0	0.00
	5	0	0.00
	6	0	0.00
	7	1	6.25
	8	2	12.50
	9	6	37.50
	10	5	31.25
Race/ethnicity (n=14)	Caucasian/White	8	57.14
	African	2	14.29
	Other	4	28.57
Education	Less than high school degree	1	6.25
	High school degree or equivalent	1	6.25
	Some college but no degree	3	18.75
	Trade	2	12.50
	Bachelor degree	9	56.25
Employment (n=14)	Currently receiving Centrelink support	2	14.29
	Disabled not able to work		0.00
	Employed working full time	2	14.29
	Employed working part time	7	50.00
	Full/part time carer		0.00
	Full/part time study	1	7.14
	Not Employed looking for work	1	7.14
	Retired	3	21.43
Carer status (n=14)	I am not a carer	10	71.43
	Children	2	14.29
	Grandchildren	1	7.14
	Parents	2	14.29

Other health conditions

Participants were asked about health conditions, other than hepatitis D and liver disease 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=12, 85.71%), the maximum number reported was 13 other conditions, with a median of 3.50 other conditions (IQR = 5.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was depression (self or doctor diagnosed) (n=7, 50.00%), followed by anxiety (self or doctor diagnosed) (n=7, 50.00%), sleep problems or insomnia (n=6, 42.86%), and hypertension (n=5, 35.71%).

Table 2.2: Number of other health conditions

Number of other conditions	Number (n=14)	Percent
No other conditions	2	14.29
1 to 2	2	14.29
3 to 4	4	28.57
5 to 6	2	14.29
7 or more	4	28.57

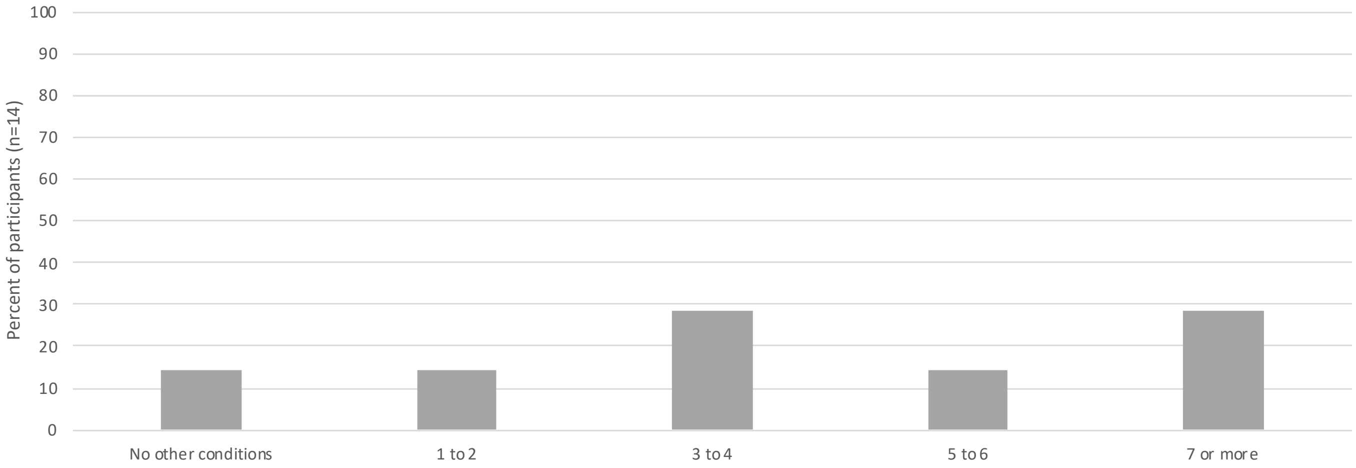

Figure 2.1: Number of other health conditions

Table 2.3: Other health conditions

Other conditions	Number (n=14)	Percent
Depression (Self or doctor diagnosed)	7	50.00
Depression (that you diagnosed yourself)	0	0.00
Depression (that a doctor diagnosed)	7	50.00
Anxiety (Self or doctor diagnosed)	7	50.00
Anxiety (that you diagnosed) yourself	1	7.14
Anxiety (that a doctor diagnosed)	6	42.86
Sleep problems or insomnia	6	42.86
Hypertension	5	35.71
Chronic pain	4	28.57
High cholesterol	4	28.57
Arthritis	4	28.57
Chronic kidney disease	3	21.43
Asthma	3	21.43
COPD (Chronic obstructive pulmonary disease)	2	14.29
Stroke	2	14.29
Cancer	2	14.29
Diabetes	1	7.14
Chronic heart failure	1	7.14
Angina	1	7.14

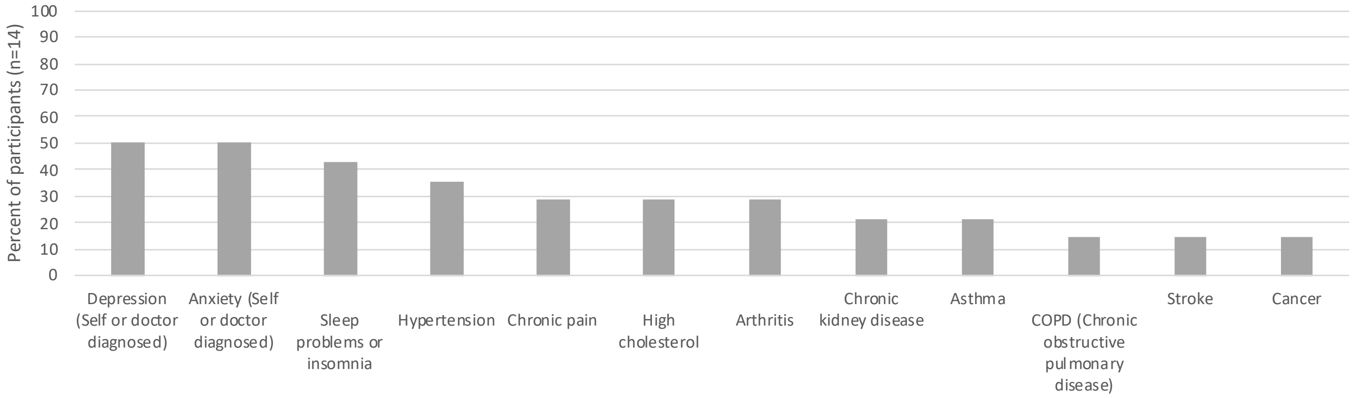

Figure 2.2: Other health conditions (% of all participants)

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.5.

Comparisons were made by Gender, there were 8 Male participants (50.00%), and 8 Female participants (50.00%).

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=9, 56.25%), and participants aged 45 and older (n=7, 43.75%).

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=7, 43.75%), and those with a university qualification, University (n=9, 56.25%).

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/rural areas, Regional or remote (n=3, 18.75%) were compared to those living in a major city, Metropolitan (n=13, 81.25%).

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=2, 12.50%) compared to those with a higher SEIFA score of 7-10, Higher status (n=14, 87.50%).

Table 2.4: Subgroups

Subgroup	Definition	Number (n=16)	Percent
Gender	Male	8	50
	Female	8	50
Age	18 to 34	9	56.25
	35 to 54	7	43.75
Education	Trade or high school	7	43.75
	University	9	56.25
Location	Regional or remote	3	18.75
	Metropolitan	13	81.25
Economic advantage	Mid to low advantage	2	12.5
	Higher advantage	14	87.5

Baseline health

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

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.5, 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 (mean=68.93, SD=29.17), SF36 Emotional well-being (mean=63.43, SD=25.00), SF36 Pain (mean=70.18, SD=24.87), indicating good physical functioning, good emotional well-being, and mild pain,

The overall scores for the cohort were in the middle quintile for SF36 Role functioning/emotional (mean=52.38, SD=36.31), SF36 Energy/Fatigue (mean=46.07, SD=25.21), SF36 Social functioning (mean=58.93, SD=29.59), SF36 General health (mean=52.50, SD=25.40), SF36 Health change (median=50.00, IQR=25.00), indicating moderate emotional role functioning, moderate energy, moderate social functioning, moderate general health, and 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=37.50, IQR=100.00), indicating poor physical role functioning.

Comparisons of SF36 have been made based on gender, age, education, location and socioeconomic status (Tables 2.6 to 2.13, Figures 2.3 to 2.29).

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 interfered 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 moderately 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 average 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 2.5: SF36 summary statistics

SF36 scale (n=14)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning*	68.93	29.17	72.50	42.50	0 to 100	4
Role functioning/physical	46.43	46.88	37.50	100.00	0 to 100	2
Role functioning/emotional*	52.38	36.31	66.67	33.33	0 to 100	3
Energy/Fatigue*	46.07	25.21	50.00	25.00	0 to 100	3
Emotional well-being*	63.43	25.00	62.00	37.00	0 to 100	4
Social functioning*	58.93	29.59	68.75	46.88	0 to 100	3
Pain*	70.18	24.87	72.50	24.38	0 to 100	4
General health*	52.50	25.40	55.00	21.25	0 to 100	3
Health change	60.71	25.41	50.00	25.00	0 to 100	3

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

SF36 by gender

Comparisons were made by Gender, there were 7Male participants (50.00%), and 7 Female participants (50.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.7).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Health change scale [W = 9.50, p = 0.046] was significantly lower for participants in the Female subgroup (Median = 50.00, IQR = 12.50) compared to participants in the Male subgroup (Median = 75.00, IQR = 50.00).

SF36 Health change scale measures health compared to a year ago. On average, participants in the male subgroup scored higher than participants in the female subgroup. This indicates that participants in the male subgroup reported that their health was a better than a year ago, and participants in the female subgroup reported that their health was about the same.

Table 2.6: SF36 by gender summary statistics and T-test

SF36 scale	Group	Number (n=14)	Percent	Mean	SD	T	dF	p-value
Physical functioning	Female	7	50.00	72.86	32.13	0.49	12	0.6337
	Male	7	50.00	65.00	27.84			
Role functioning/ emotional	Female	7	50.00	57.14	41.79	0.48	12	0.6427
	Male	7	50.00	47.62	32.53			
Social functioning	Female	7	50.00	57.14	31.34	-0.22	12	0.8316
	Male	7	50.00	60.71	30.13			
Pain	Female	7	50.00	71.79	24.69	0.23	12	0.8198
	Male	7	50.00	68.57	26.92			

Table 2.7: SF36 by gender summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=14)	Percent	Median	IQR	W	p-value
Role functioning/physical	Female	7	50.00	100.00	100.00	30.50	0.4535
	Male	7	50.00	25.00	62.50		
Energy/Fatigue	Female	7	50.00	55.00	52.50	27.00	0.7972
	Male	7	50.00	50.00	7.50		
Emotional well-being	Female	7	50.00	60.00	58.00	21.50	0.7464
	Male	7	50.00	64.00	10.00		
General health	Female	7	50.00	55.00	47.50	27.00	0.7972
	Male	7	50.00	55.00	12.50		
Health change	Female	7	50.00	50.00	12.50	9.50	0.0462*
	Male	7	50.00	75.00	50.00		

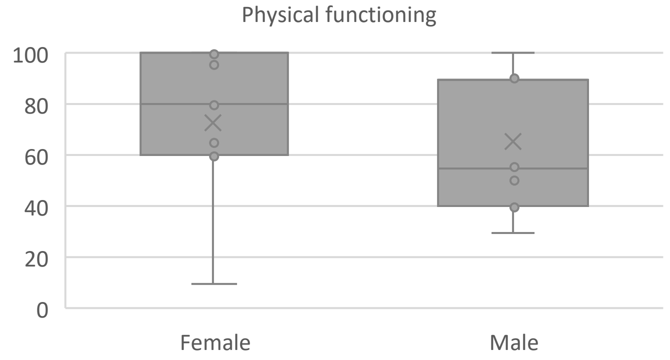

Figure 2.3: Boxplot of SF36 Physical functioning by gender

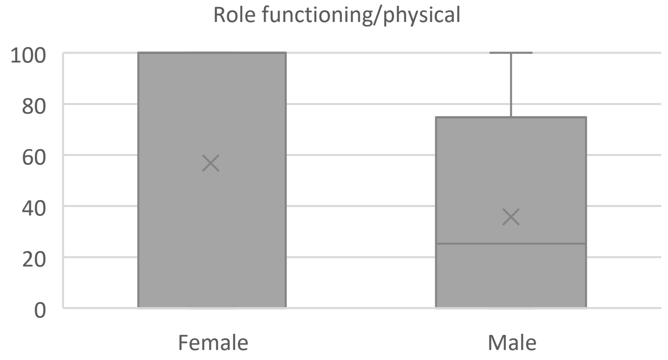

Figure 2.4: Boxplot of SF36 Role functioning/physical by gender

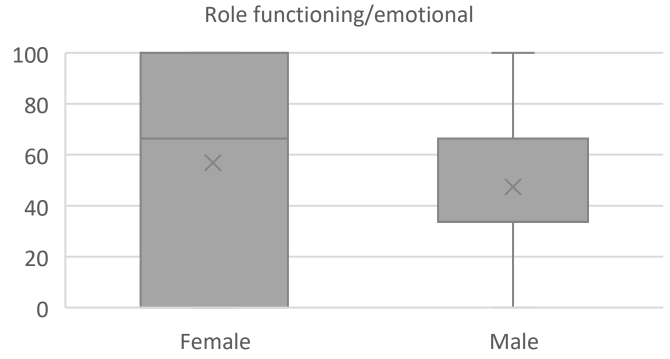

Figure 2.5: Boxplot of SF36 Role functioning/emotional by gender

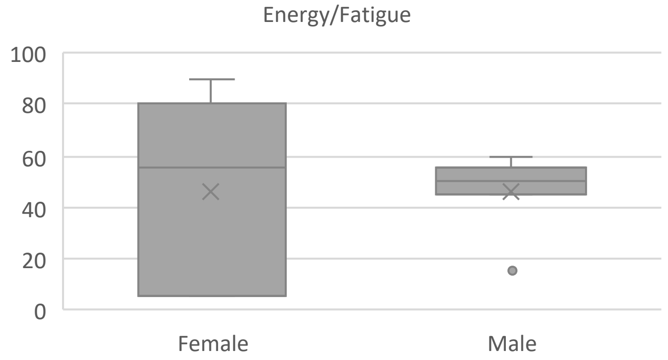

Figure 2.6: Boxplot of SF36 Energy/fatigue by gender

Figure 2.7: Boxplot of SF36 Emotional well-being by gender

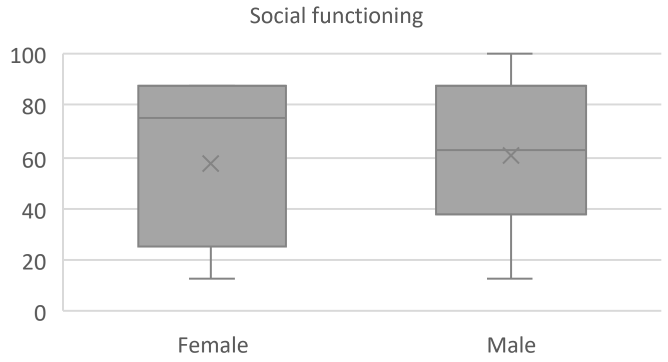

Figure 2.8: Boxplot of SF36 Social functioning by gender

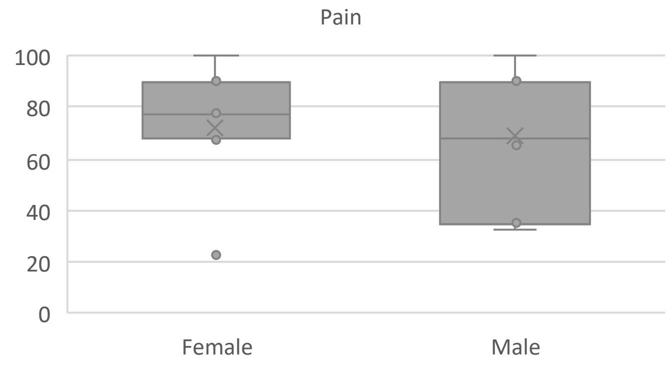

Figure 2.9: Boxplot of SF36 Pain by a gender

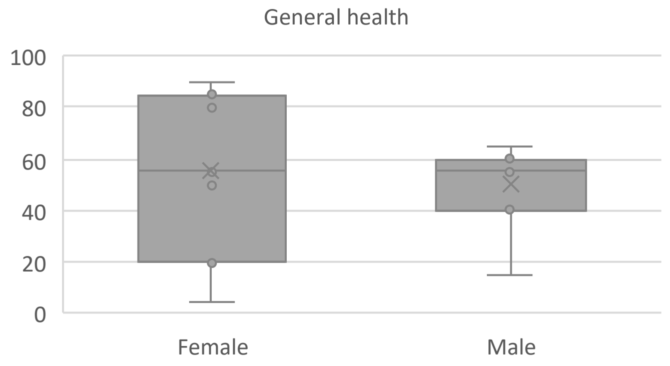

Figure 2.10: Boxplot of SF36 General health by gender

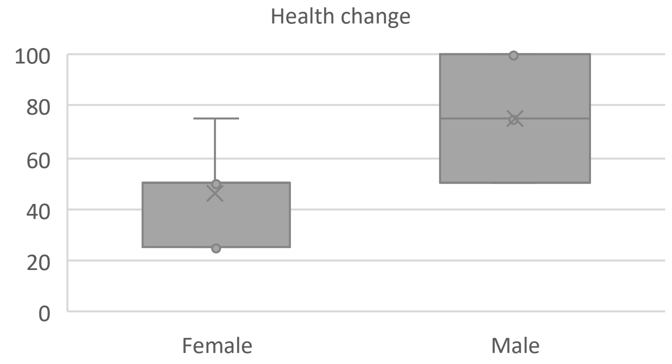

Figure 2.11: Boxplot of SF36 Health change by gender

SF36 by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=8, 57.14%), and participants aged 45 and older (n=6, 42.86%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.9).

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

Table 2.8: SF36 by age summary statistics and T-test

SF36 scale	Group	Number (n=14)	Percent	Mean	SD	T	dF	p-value
Physical functioning	Aged 18 to 44	8	57.14	70.63	24.70	0.24	12	0.8128
	Aged 45 and older	6	42.86	66.67	36.70			
Energy/Fatigue	Aged 18 to 44	8	57.14	47.50	24.05	0.24	12	0.8176
	Aged 45 and older	6	42.86	44.17	28.88			
Emotional well-being	Aged 18 to 44	8	57.14	53.00	23.30	-2.00	12	0.0687
	Aged 45 and older	6	42.86	77.33	21.42			
Social functioning	Aged 18 to 44	8	57.14	53.13	26.52	-0.84	12	0.4187
	Aged 45 and older	6	42.86	66.67	34.16			
Pain	Aged 18 to 44	8	57.14	72.81	20.37	0.44	12	0.6656
	Aged 45 and older	6	42.86	66.67	31.65			
General health	Aged 18 to 44	8	57.14	55.00	20.18	0.41	12	0.6880
	Aged 45 and older	6	42.86	49.17	32.93			
Health change	Aged 18 to 44	8	57.14	68.75	29.12	1.42	12	0.1815
	Aged 45 and older	6	42.86	50.00	15.81			

Table 2.9: SF36 by age summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=14)	Percent	Median	IQR	W	p-value
Role functioning/physical	Aged 18 to 44	8	57.14	37.50	81.25	22.50	0.8905
	Aged 45 and older	6	42.86	50.00	100.00		
Role functioning/emotional	Aged 18 to 44	8	57.14	33.33	41.67	10.00	0.0707
	Aged 45 and older	6	42.86	83.33	33.33		

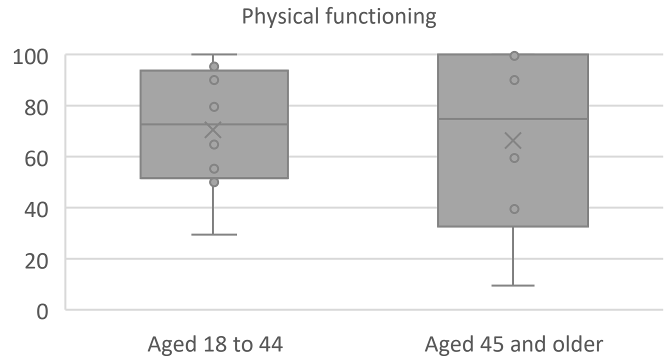

Figure 2.12: Boxplot of SF36 Physical functioning by age

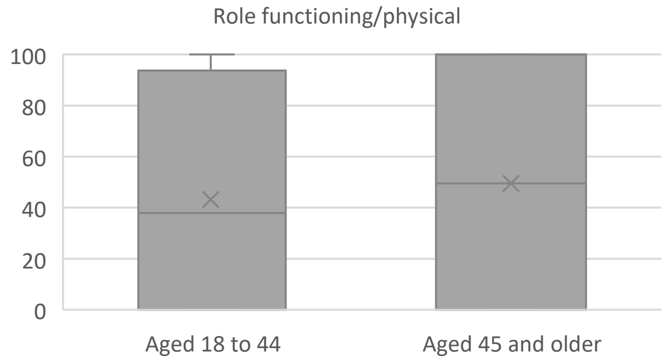

Figure 2.13: Boxplot of SF36 Role functioning/physical by age

Figure 2.14: Boxplot of SF36 Role functioning/emotional by age

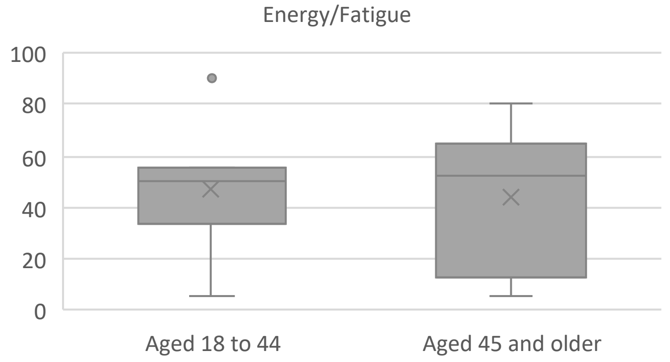

Figure 2.15: Boxplot of SF36 Energy/fatigue by age

Figure 2.16: Boxplot of SF36 Emotional well-being by age

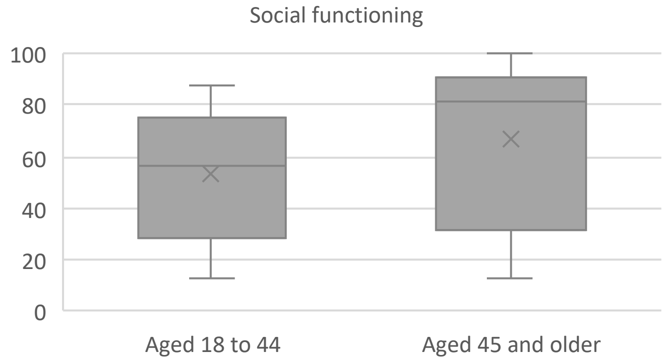

Figure 2.17: Boxplot of SF36 Social functioning by age

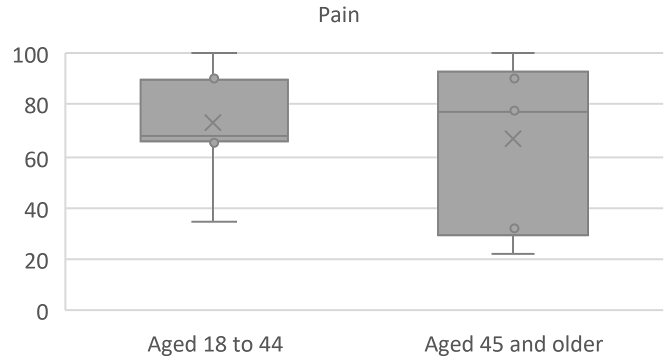

Figure 2.18: Boxplot of SF36 Pain by age

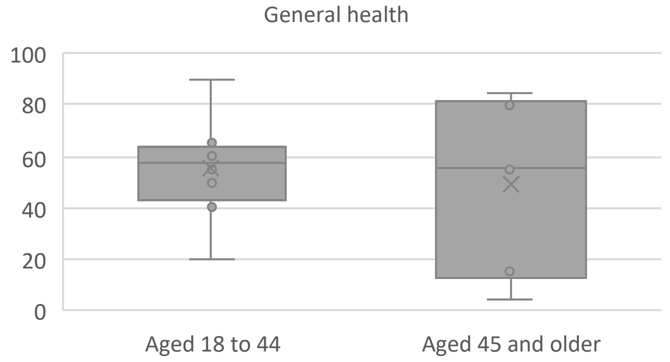

Figure 2.19: Boxplot of SF36 General health by age

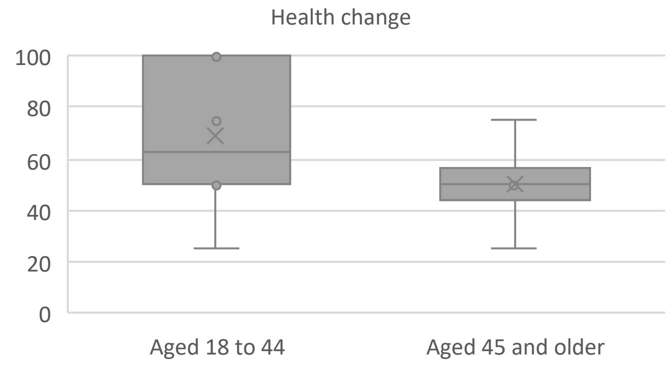

Figure 2.20: Boxplot of SF36 Health change by age

SF36 by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=6, 42.86%), and those with a university qualification, University (n=8, 57.14%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.11).

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

Table 2.10: SF36 by education summary statistics and T-test

SF36 scale	Group	Number (n=14)	Percent	Mean	SD	T	dF	p-value
Physical functioning	Trade or high school	6	42.86	76.67	22.51	0.85	12	0.4117
	University	8	57.14	63.13	33.59			
Role functioning/ emotional	Trade or high school	6	42.86	44.44	40.37	-0.69	12	0.5009
	University	8	57.14	58.33	34.50			
Emotional well-being	Trade or high school	6	42.86	67.33	25.85	0.49	12	0.6322
	University	8	57.14	60.50	25.70			
Social functioning	Trade or high school	6	42.86	60.42	32.99	0.16	12	0.8781
	University	8	57.14	57.81	29.08			
Pain	Trade or high school	6	42.86	76.25	24.23	0.78	12	0.4511
	University	8	57.14	65.63	25.97			
General health	Trade or high school	6	42.86	54.17	30.89	0.20	12	0.8413
	University	8	57.14	51.25	22.64			

Table 2.11: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=14)	Percent	Median	IQR	W	p-value
Role functioning/physical	Trade or high school	6	42.86	37.50	93.75	22.50	0.8905
	University	8	57.14	37.50	100.00		
Energy/Fatigue	Trade or high school	6	42.86	47.50	38.75	26.00	0.8456
	University	8	57.14	52.50	21.25		

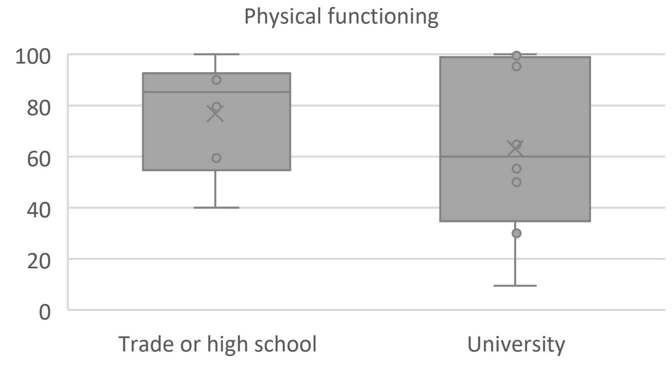

Figure 2.21: Boxplot of SF36 Physical functioning by education

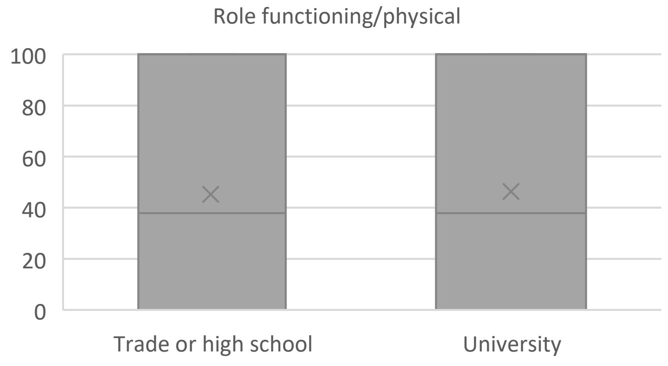

Figure 2.22: Boxplot of SF36 Role functioning/physical by education

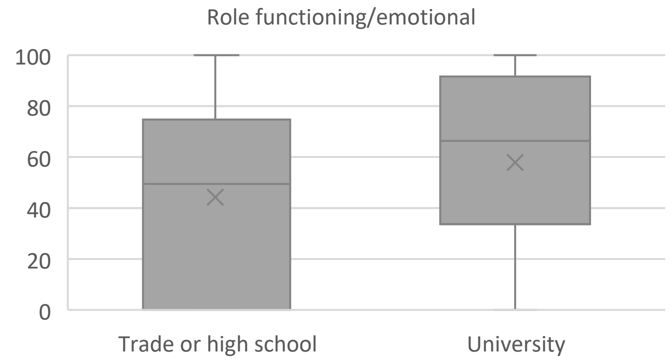

Figure 2.23: Boxplot of SF36 Role functioning/emotional by education

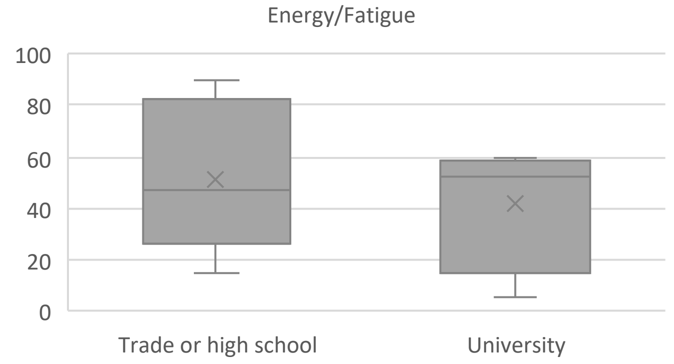

Figure 2.24: Boxplot of SF36 Energy/fatigue by education

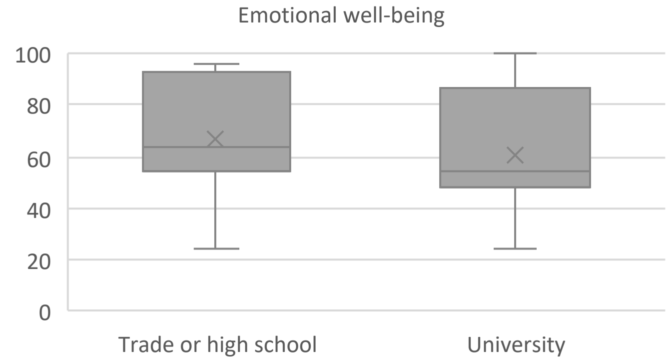

Figure 2.25: Boxplot of SF36 Emotional well-being by education

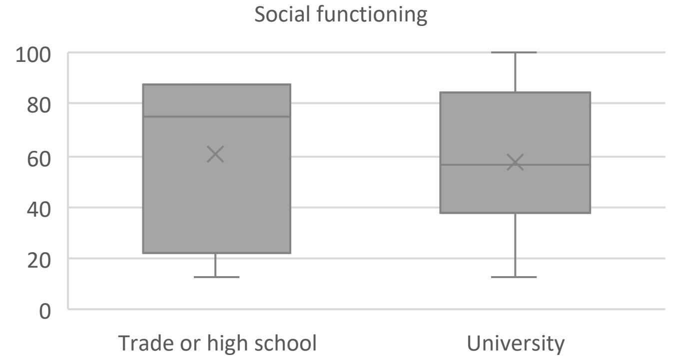

Figure 2.26: Boxplot of SF36 Social functioning by education

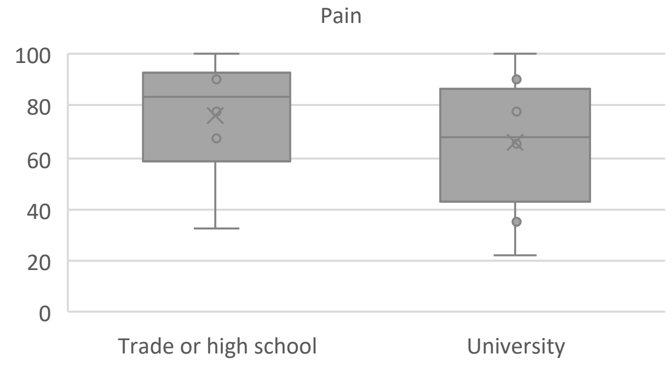

Figure 2.27: Boxplot of SF36 Pain by education

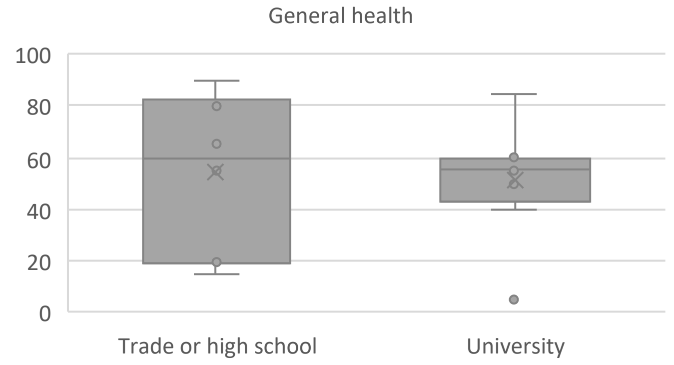

Figure 2.28: Boxplot of SF36 General health by education

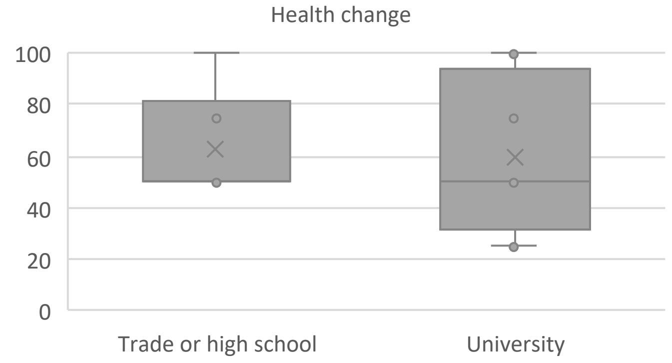

Figure 2.29: Boxplot of SF36 Health change by education

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/rural areas, Regional or remote (n=3, 24.43%) were compared to those living in a major city, Metropolitan (n=11, 78.57%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 2.12.

Table 2.12: SF36 by location stage summary

SF36 scale	Group	Number (n=14)	Percent	Mean	SD	Median	IQR
Physical functioning	Rural or remote	3	21.43	80.00	34.64	100.00	30.00
	Metropolitan	11	78.57	65.91	28.62	65.00	37.50
Role functioning/physical	Rural or remote	3	21.43	66.67	57.74	100.00	50.00
	Metropolitan	11	78.57	40.91	45.10	25.00	87.50
Role functioning/emotional	Rural or remote	3	21.43	66.67	57.74	100.00	50.00
	Metropolitan	11	78.57	48.48	31.14	66.67	33.33
Energy/Fatigue	Rural or remote	3	21.43	45.00	25.98	60.00	22.50
	Metropolitan	11	78.57	46.36	26.28	50.00	17.50
Emotional well-being	Rural or remote	3	21.43	86.67	19.73	96.00	18.00
	Metropolitan	11	78.57	57.09	22.98	60.00	16.00
Social functioning	Rural or remote	3	21.43	66.67	47.32	87.50	43.75
	Metropolitan	11	78.57	56.82	25.84	62.50	37.50
Pain	Rural or remote	3	21.43	70.00	34.37	77.50	33.75
	Metropolitan	11	78.57	70.23	23.83	67.50	23.75
General health	Rural or remote	3	21.43	51.67	35.12	55.00	35.00
	Metropolitan	11	78.57	52.73	24.33	55.00	17.50
Health change	Rural or remote	3	21.43	50.00	0.00	50.00	0.00
	Metropolitan	11	78.57	63.64	28.20	50.00	37.50

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=2, 14.29%) compared to those with a higher SEIFA score of 7-10, Higher status (n=12, 85.71%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 2.13.

Table 2.13: SF36 by socioeconomic status summary statistics

SF36 scale	Group	Number (n=14)	Percent	Mean	SD	Median	IQR
Physical functioning	Mid to low	2	14.29	70.00	42.43	70.00	30.00
	Higher	12	85.71	68.75	29.01	72.50	37.50
Role functioning/physical	Mid to low	2	14.29	50.00	70.71	50.00	50.00
	Higher	12	85.71	45.83	46.26	37.50	100.00
Role functioning/emotional	Mid to low	2	14.29	50.00	70.71	50.00	50.00
	Higher	12	85.71	52.78	33.21	66.67	33.33
Energy/Fatigue	Mid to low	2	14.29	37.50	31.82	37.50	22.50
	Higher	12	85.71	47.50	25.36	50.00	15.00
Emotional well-being	Mid to low	2	14.29	82.00	25.46	82.00	18.00
	Higher	12	85.71	60.33	24.63	60.00	23.00
Social functioning	Mid to low	2	14.29	56.25	61.87	56.25	43.75
	Higher	12	85.71	59.38	26.18	68.75	40.63
Pain	Mid to low	2	14.29	66.25	47.73	66.25	33.75
	Higher	12	85.71	70.83	22.82	72.50	23.13
General health	Mid to low	2	14.29	35.00	28.28	35.00	20.00
	Higher	12	85.71	55.42	25.00	57.50	21.25
Health change	Mid to low	2	14.29	50.00	0.00	50.00	0.00
	Higher	12	85.71	62.50	27.18	50.00	31.25

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

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

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

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 for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

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 by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67 %). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D . Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

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 were most commonly diagnosed immediately at the consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks,2 participants (14.29%) diagnosed between 2 and 3 weeks,1 participants (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) 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 hepatitis D. 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 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

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 general practitioner (GP) (n=8, 57.14%), and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Hepatitis Vaccinations

Most participants had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

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 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) 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 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) 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 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between $50 and $150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), 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.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) 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.

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months. The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

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 (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%),that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

Experience of symptoms before diagnosis

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

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=14)	Percent
No symptoms	8	57.14
1 to 2	0	0.00
3 to 4	2	14.29
5 to 6	2	14.29
7 to 8	2	14.29

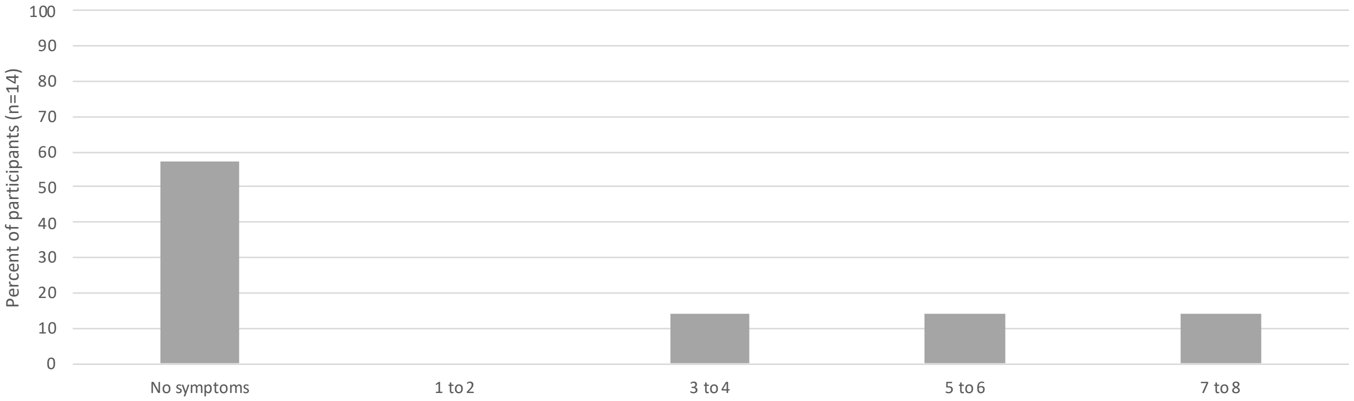

Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

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 for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=14)	Percent	Quality of life	
			Mean	SD
No symptoms	8	57.14	NA	NA
Tired, fatigued, or generally weak	6	42.86	3.00	2.25
Abdominal pain	4	28.57	NA	NA
Muscle or joint aches and pains	4	28.57	NA	NA
Loss of appetite	3	21.43	NA	NA
Nausea and/or vomiting	3	21.43	NA	NA
Fever	3	21.43	NA	NA
Yellowing skin, or eyes (jaundice)	3	21.43	NA	NA
Swollen abdomen (from a build up of fluid)	2	14.29	NA	NA
Pale, or chalky bowel movements	2	14.29	NA	NA

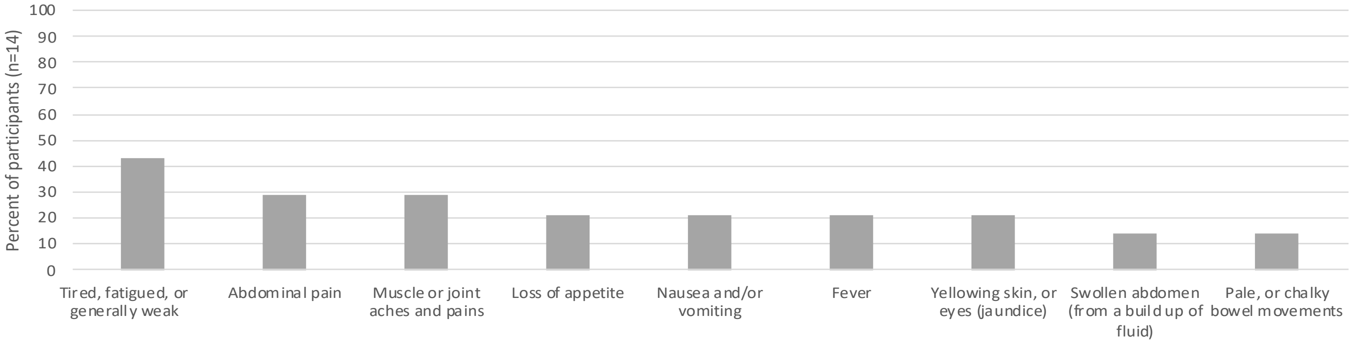

Figure 3.2: Symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Participant describes having no symptoms experienced which led to their diagnosis

Yeah, no symptom at all. I only get to know about it when I apply the visa to come to Australia and then doctor followed up with other test.
Participant 001_2023AUHDV

No, no, it came totally out of the blue.
Participant 007_2023AUHDV

Participant describes having nausea and vomiting which led to their diagnosis

Well, the very first common symptoms I experienced was mainly fatigue and, you know, dark urine and also my stool was affected and also had some other symptoms like a lot of appetite and abdominal pains. So the symptoms kept on coming and I was kind of not really knowing what was happening to me. So it just started little by little to it got severe
Participant 006_2023AUHDV

OK, the symptoms I had were so pretty much nausea and fatigue, tiredness.
Participant 012_2023AUHDV

Participant describes having brain fog which led to their diagnosis

So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010_2023AUHDV

Table 3.3: Symptom recall

Symptom recall	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
No Symptoms	6	50.00	**4**	**66.67**	**2**	**33.33**	4	50.00	2	50.00	**2**	**33.33**	**4**	**66.67**	**1**	**100.00**	5	45.45	**1**	**100.00**	5	45.45
Symptom recall strong	4	33.33	2	33.33	2	33.33	2	25.00	**2**	**50.00**	**3**	**50.00**	**1**	**16.67**	**0**	**0.00**	4	36.36	**0**	**0.00**	4	36.36
Symptom recall unclear	2	16.67	**0**	**0.00**	**2**	**33.33**	2	25.00	**0**	**0.00**	1	16.67	1	16.67	**0**	**0.00**	2	18.18	**0**	**0.00**	2	18.18

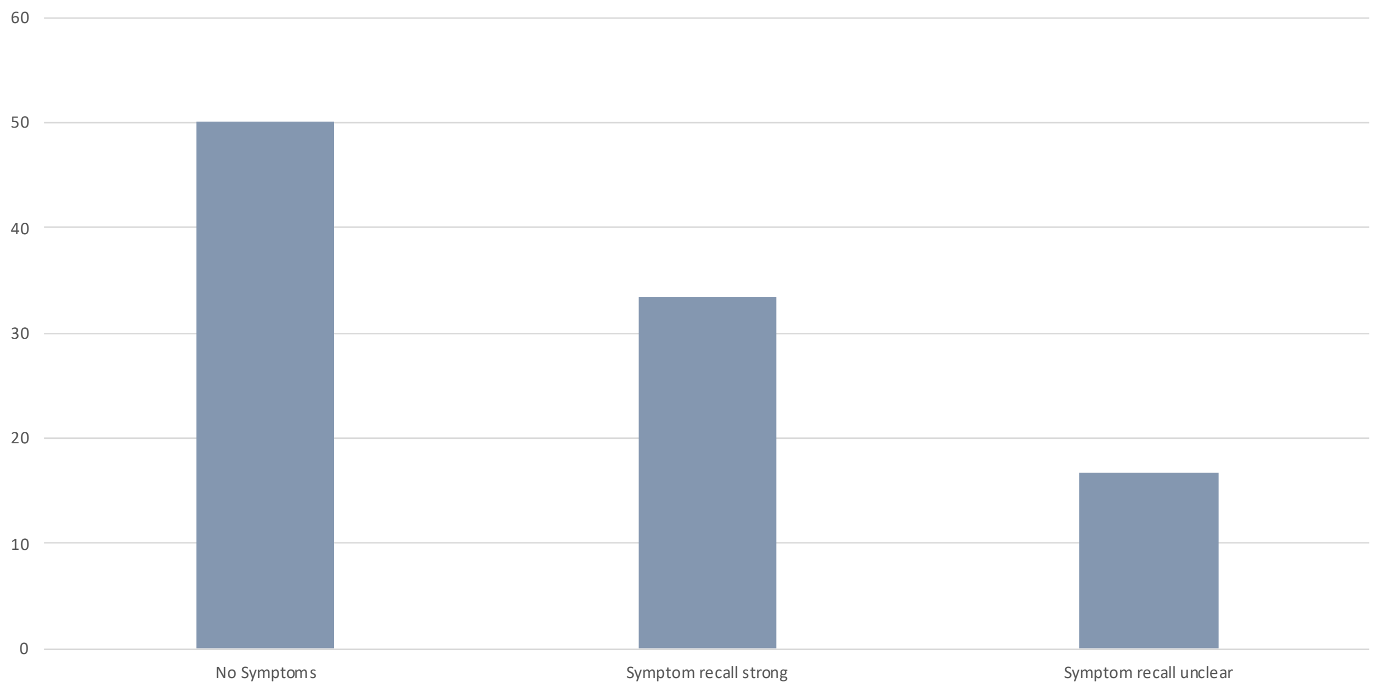

Figure 3.3: Symptom recall

Table 3.4: Symptom recall – subgroup variations

Symptom recall	Reported less frequently	Reported more frequently
No Symptoms	Male Trade or high school	Female University
Symptom recall strong	University	Aged 45 and older Trade or high school

Table 3.5: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes having no symptoms experienced which led to their diagnosis	6	50.00	4	66.67	2	33.33	4	50.00	2	50.00	2	33.33	4	66.67	1	100.00	5	45.45	1	100.00	5	45.45
Participant describes having fatigue which led to their diagnosis	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes having nausea and vomiting which led to their diagnosis	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes having appetite loss which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having brain fog which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having joint aches which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having muscle aches which led to their diagnosis	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having reflux or digestive problems which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having sleep problems which led to their diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having urine changes - dark which led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having symptoms but does not describe in detail	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not being able to recall the symptoms that led to their diagnosis	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

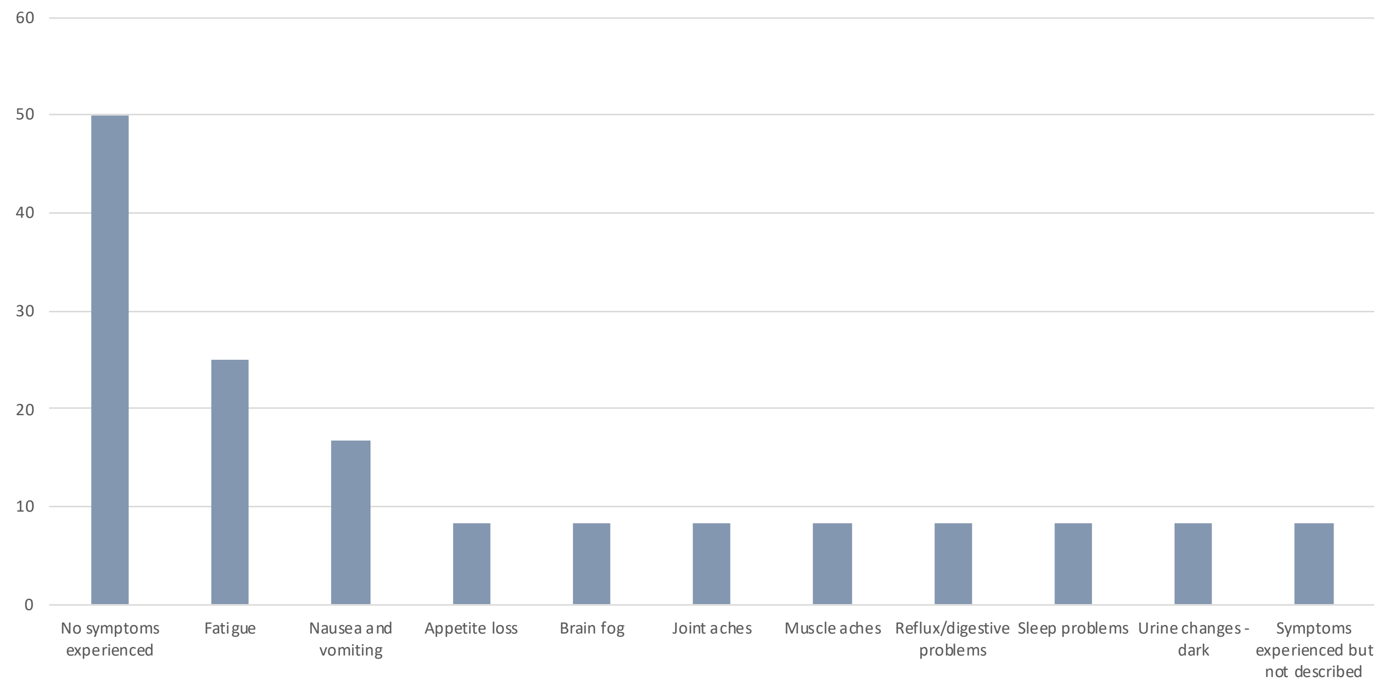

Figure 3.4: Symptoms leading to diagnosis

Table 3.6: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having no symptoms experienced which led to their diagnosis	Male Trade or high school	Female University

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

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

I don't think I noticed any immediate symptoms before I was diagnosed. I didn't notice anything.
Participant 004_2023AUHDV

No, no, it came totally out of the blue.
Participant 007_2023AUHDV

Participant describes having symptoms and not seeking medical attention initially

I actually didn't know what was going on with me and I wasn't quite very sure and a little bit scared, but I got recommended by my friend to go see a medical professional. Yeah.
Participant 009_2023AUHDV

INTERVIEWER: Okay. All right, excellent okay. And how long were you suffering with nausea and fatigue?
PARTICIPANT: It might have been months before I was before I actually got to my diagnosis.
Participant 012_2023AUHDV

Participant describes having symptoms and seeking medical attention relatively soon

So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010_2023AUHDV

Table 3.7: Seeking medical attention

Seeking medical attention	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes having no symptoms or not noticing any symptoms before diagnosis	6	50.00	**4**	**66.67**	**2**	**33.33**	4	50.00	2	50.00	**2**	**33.33**	**4**	**66.67**	1	100.00	5	45.45	1	100.00	5	45.45
Participant describes having symptoms and not seeking medical attention initially	4	33.33	**1**	**16.67**	**3**	**50.00**	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes having symptoms and seeking medical attention relatively soon	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being diagnosed as a child	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

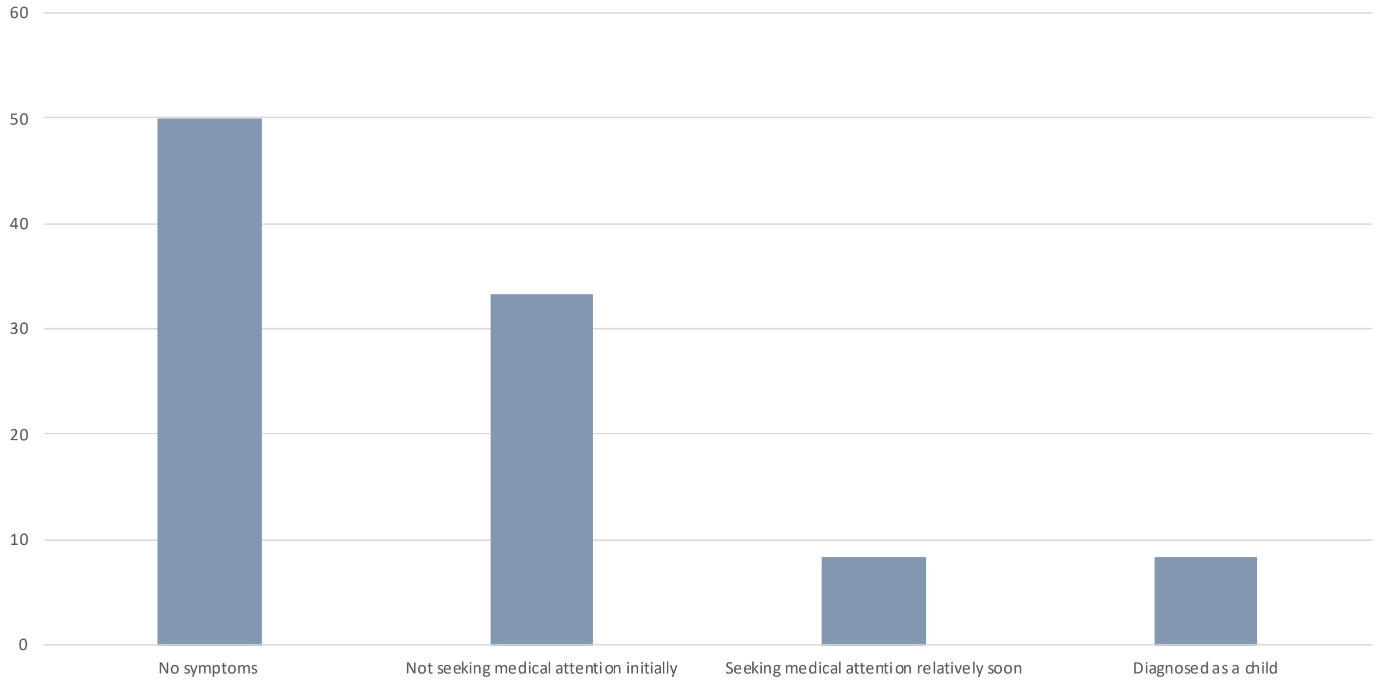

Figure 3.5: Seeking medical attention

Table 3.8: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having no symptoms or not noticing any symptoms before diagnosis	Male Trade or high school	Female University
Participant describes having symptoms and not seeking medical attention initially	Female	Male

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 by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67 %). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Participant describes being diagnosed by their general practitioner during a check-up related to symptoms

Well, all the procedures was carried out by a doctor, you know, I had to seek medical attention when I noticed all the symptoms and got into the clinic. I was kind of run…I was given some medication, you know, testing every other thing. Yeah, my it was a kind of blood test. The doctor took blood from veins and he sent it to the lab and then the both result was confirmed. Participant 006_2023AUHDV

OK, I have to my GP and I told him how I was feeling and he got me blood tested for various things I support and it came back and he said I was positive. Participant 012_2023AUHDV

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

OK, I just went to my GP to do some checkup to see if everything was fine. And there was an alteration on my blood testing like my iron was too high. OK. And

then we did extra blood testing that accused the hepatitis.
Participant 005_2023AUHDV

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

INTERVIEWER: They sent you off to a gastroenterologist.
PARTICIPANT: Yeah, and I got some blood tests
Participant 002_2023AUHDV

I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested for a stomach virus.

Anyway, it came back that I had a virus so I took the treatment for that and then I still felt unwell... in her wisdom asked me a lot more about my younger life. Not like all my medical history. And I just sort of said...I gave up drinking and abusing substances and she said, oh, what, what kind of wild child did you ever use IV drugs? And I said, yes, I did and she said, have you ever been tested for HIV or hepatitis?... Anyway she said, well let's test you the hepatitis.
Participant 010_2023AUHDV

Participant describes being diagnosed from physical as part of immigration tests

INTERVIEWER: Who ordered them for you? Sorry, which organization did the test? Like ordered? PARTICIPANT: The test first with the Australian immigration then doctor.
Participant 001_2023AUHDV

Table 3.9: Diagnostic pathway

Diagnostic pathway	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being diagnosed by their general practitioner during a check-up related to symptoms	4	33.33	1	16.67	3	50.00	3	37.50	1	25.00	1	16.67	3	50.00	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being diagnosed in an emergency department	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being diagnosed from physical as part of immigration tests	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant is not able to remember details about diagnosis	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

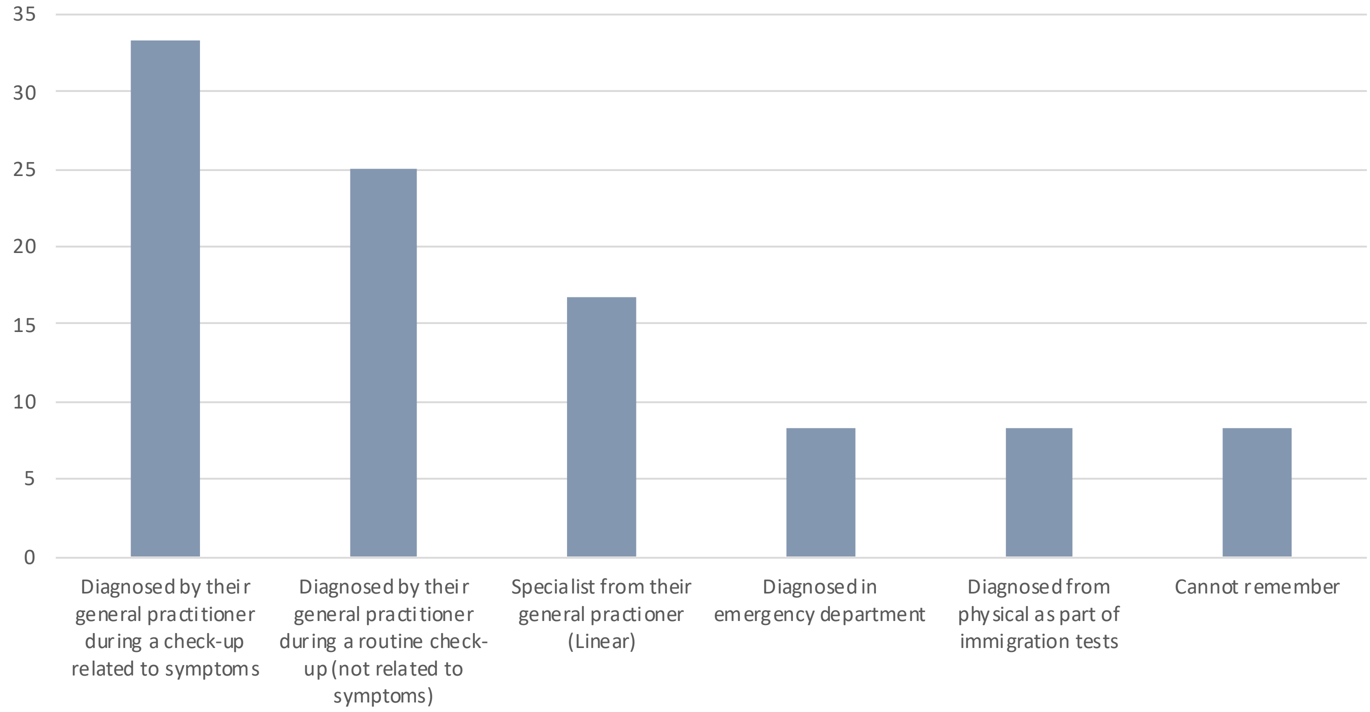

Figure 3.6: Diagnostic pathway

Table 3.10: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed by their general practitioner during a check-up related to symptoms	Female Trade or high school	Male University
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	Trade or high school	University

Timing of diagnosis

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

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 were most commonly diagnosed within a consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks,2 participants (14.29%) diagnosed between 2 and 3 weeks,1 participants (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) diagnosed more than four weeks after diagnostic testing.

Table 3.11: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=6)	Percent
Within a year	4	66.67
More than a year	2	33.33

Figure 3.7: Time from symptoms to diagnosis

Table 3.12: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=14)	Percent
Diagnosed immediately at the consultation	2	14.29
Less than 1 week	2	14.29
Between 1 and 2 weeks	3	21.43
Between 2 and 3 weeks	2	14.29
Between 3 and 4 weeks	1	7.14
4 weeks or more	2	14.29
Not specified	2	14.29

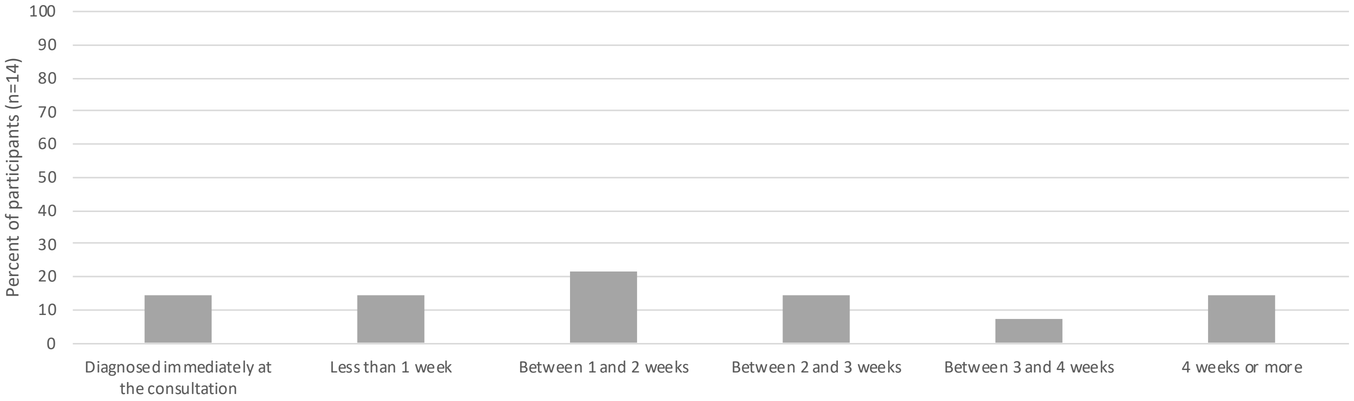

Figure 3.8: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with hepatitis D. 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 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

Table 3.13: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=14)	Percent
1 to 2	4	28.57
3 to 4	6	42.86
5 to 6	2	14.29
7 or more	2	14.29

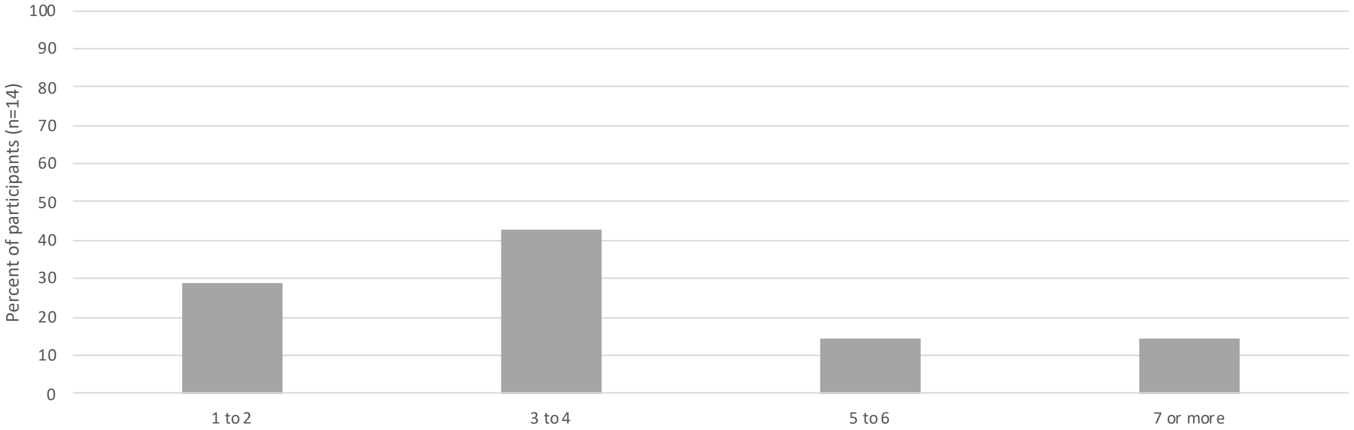

Figure 3.9: Number of diagnostic tests

Table 3.14: Diagnostic tests

Diagnostic tests	Number (n=14)	Percent
Blood tests for Hepatitis B infection	13	92.86
Blood tests for Hepatitis D infection	13	92.86
Blood tests for Liver function	6	42.86
Blood tests for Hepatitis C infection	5	35.71
Physical examinal	5	35.71
Ultrasound	5	35.71
Fibroscan (transient elastography)	4	28.57
Personal and family medical history	3	21.43
Biopsy	2	14.29
Not sure	1	7.14

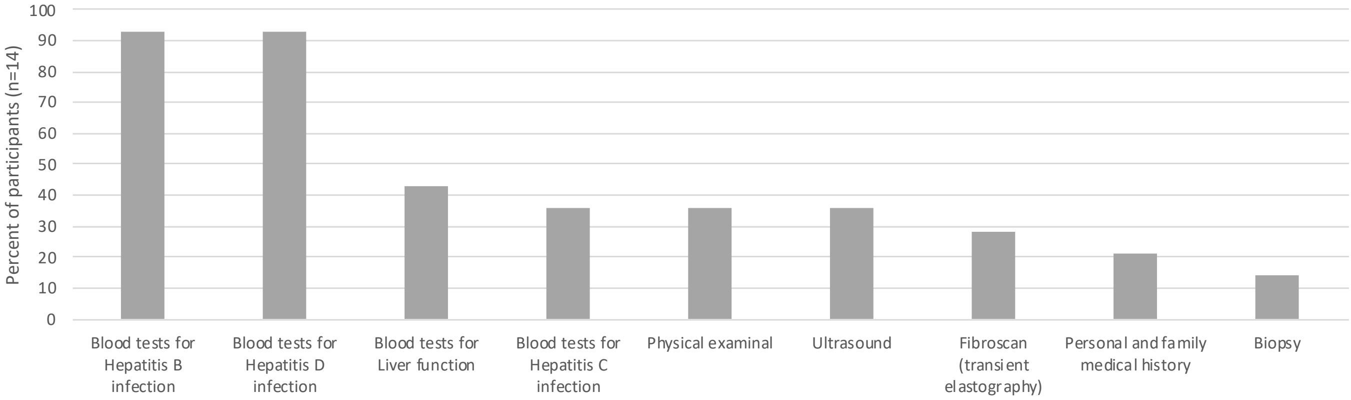

Figure 3.10: Diagnostic tests

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 general practitioner (GP) (n=8, 57.14%), and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Table 3.15: Diagnosis provider

Health professional gave diagnosis	Number (n=14)	Percent
General practitioner (GP)	8	57.14
Specialist doctor	6	42.86

Figure 3.11: Diagnosis provider

Table 3.16 Diagnosis location

Location of diagnosis	Number (n=14)	Percent
General practice (GP)	8	57.14
Hospital	3	21.43
Specialist clinic	3	21.43

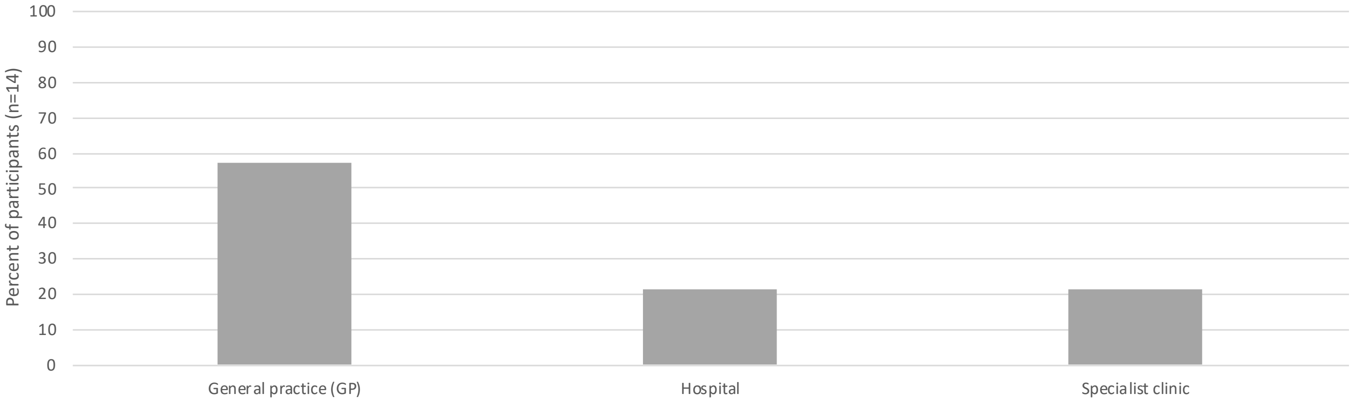

Figure 3.12: Diagnosis location

Type of infection

Type of hepatitis D infection

Participants had Chronic Hepatitis D (n=11, 78.57%), followed by Acute Hepatitis D (n=3, 21.43%).

Hepatitis Vaccinations

Most participants reported having had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Table 3.19: Vaccinations for hepatitis

Vaccinations for hepatitis	Number (n=14)	Percent
Hepatitis A	10	71.43
Hepatitis B	9	64.29

Figure 3.15: Vaccinations for hepatitis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

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

I wasn't quite sure about it. Yeah. So I quite scared. Yeah.
Participant 009_2023AUHDV

Well, like I said previously, I I didn't know anything about it when I was when I first went to the specialist. But the specialist gave me information about it and then she suggested that I do as much research as I as I could about it. Yeah, so I did.
Participant 010_2023AUHDV

Very little. Very little at all. And I'd have to say, even at that point of diagnosis, they didn't really take the time to explain it to me and how it was all interrelated. It was only kind of subsequently in conversations…that I understood it had something to do with my liver.
Participant 011_2023AUHDV

Participant describes knowing something about the condition including causes and risk factors

I was very limited. I understood that it was a blood to blood, blood disease. So and I felt a lot of shame like. Yeah. So that's pretty much I think what I recall, maybe even getting one pamphlet, but I don't think there was that much information out there for me at the time to comprehend that. It was just pretty much what the doctors said of reading your results and that was about it.
Participant 004_2023AUHDV

Table 3. 20: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes knowing nothing or very little about the condition at diagnosis	9	75.00	3	50.00	6	100.00	6	75.00	3	75.00	4	66.67	5	83.33	1	100.00	8	72.73	1	100.00	8	72.73
Participant describes knowing about the condition including causes and risk factors	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

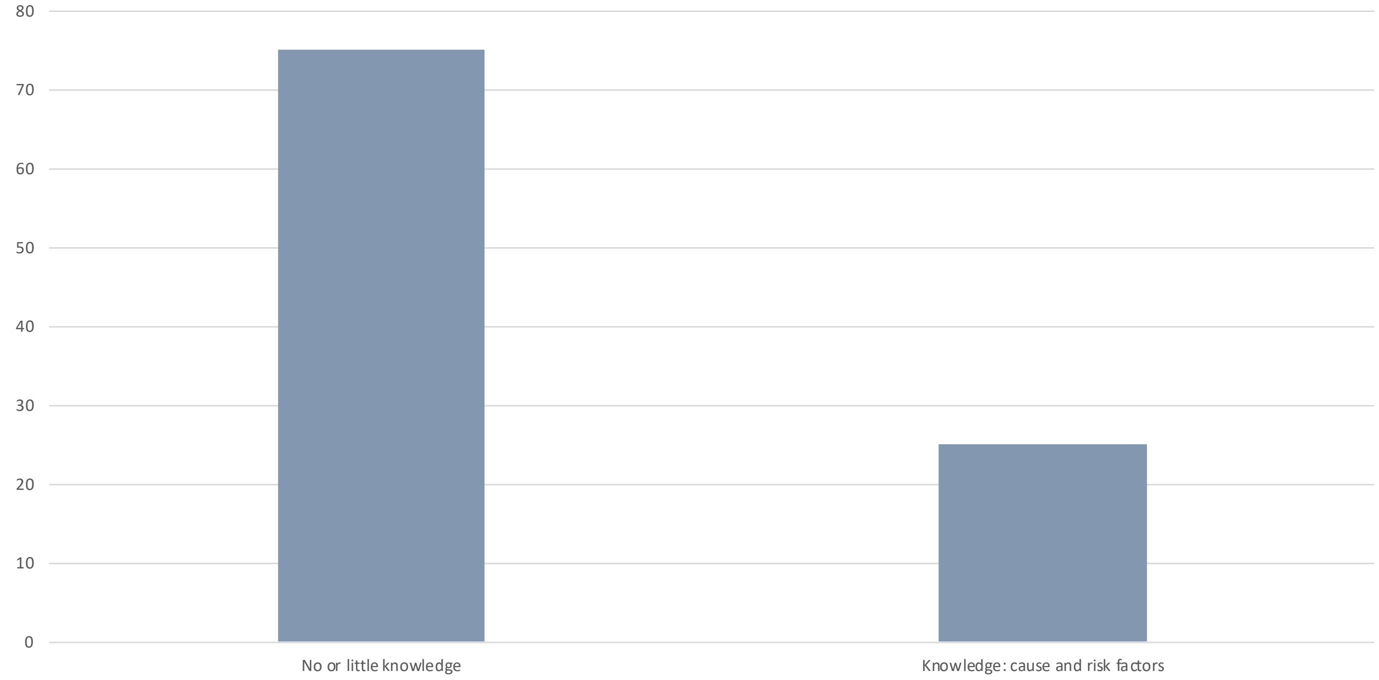

Figure 3.16 Understanding of disease at diagnosis

Table 3.21: 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	Female	Male

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 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) had no support.

Table 3.22: Emotional support at diagnosis

Information at diagnosis	Number (n=14)	Percent
Enough information	3	21.43
Some information but it wasn't enough	5	35.71
No information	6	42.86

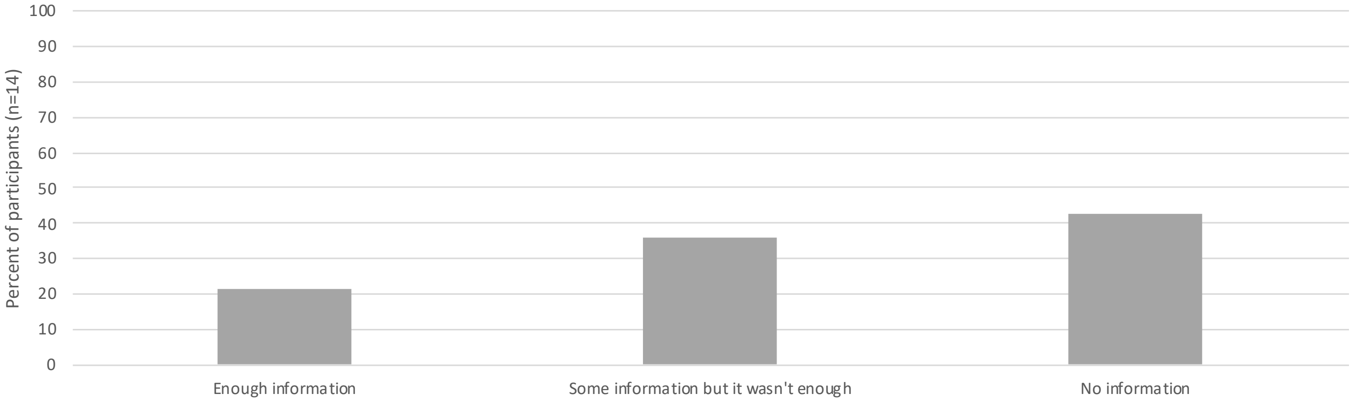

Figure 3.17: Emotional support at diagnosis

Information at diagnosis

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

There were 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) had no information.

Table 3.23: Information at diagnosis

Emotional support at diagnosis	Number (n=14)	Percent
Enough support	2	14.29
Some support but it wasn't enough	2	14.29
No support	10	71.43

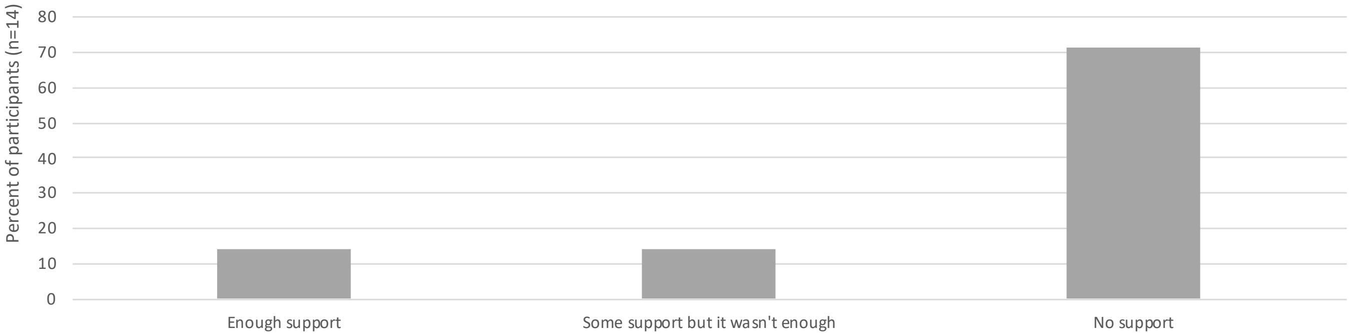

Figure 3.18: Information at diagnosis

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 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between $50 and $150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), the burden of out-of-pocket expenses were moderately or extremely significant.

Table 3.24: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=14)	Percent
$0	7	50.00
$50 to 150	2	14.29
I’m not sure	5	35.71

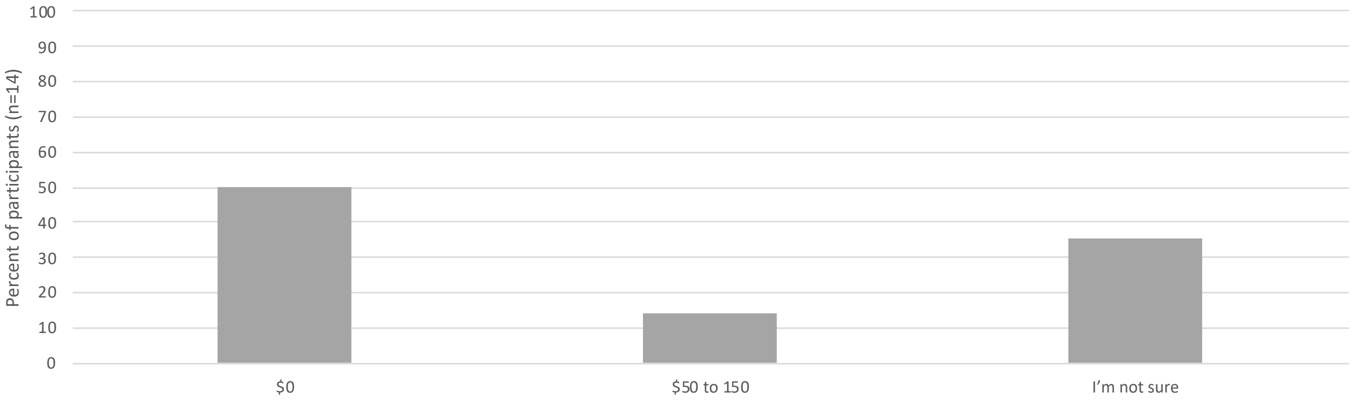

Figure 3.19: Out of pocket expenses at diagnosis

Table 3.25: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=14)	Percent
Not at all significant	3	21.43
Slightly significant	2	14.29
Somewhat significant	0	0.00
Moderately significant	1	7.14
Extremely significant	1	7.14

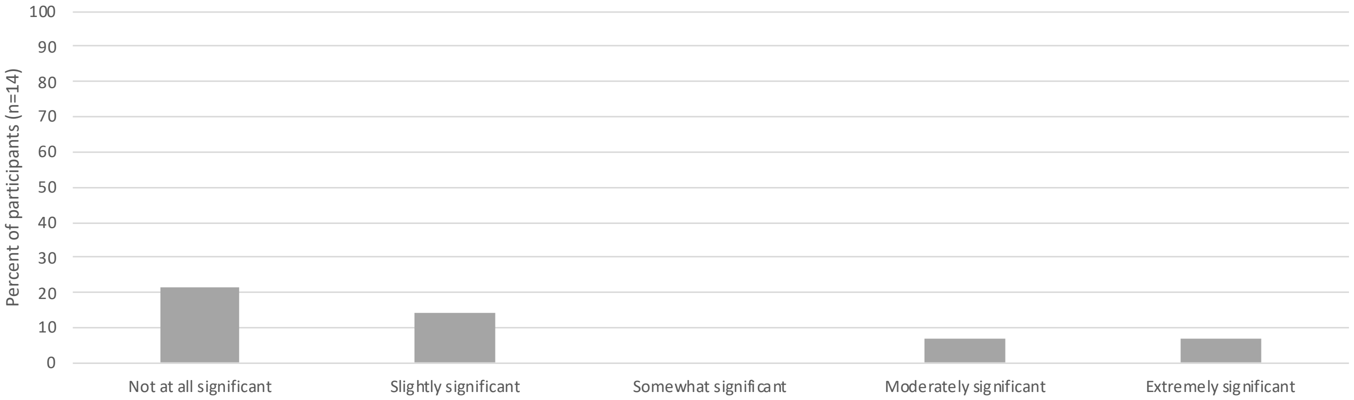

Figure 3.20: Burden of diagnostic costs

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.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) 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=5, 35.71%). There were 2 participants (14.29%) who did not have these tests and were not interested in them, and a total of 5 participants (35.71%) that had biomarker tests.

Table 3.26: Discussions about biomarkers

Discussions about biomarkers	Number (n=14)	Percent
Participant brought up the topic with doctor for discussion	1	7.14
Doctor brought up the topic with participant for discussion	5	35.71
Participant had no discussion about this type of test	8	57.14

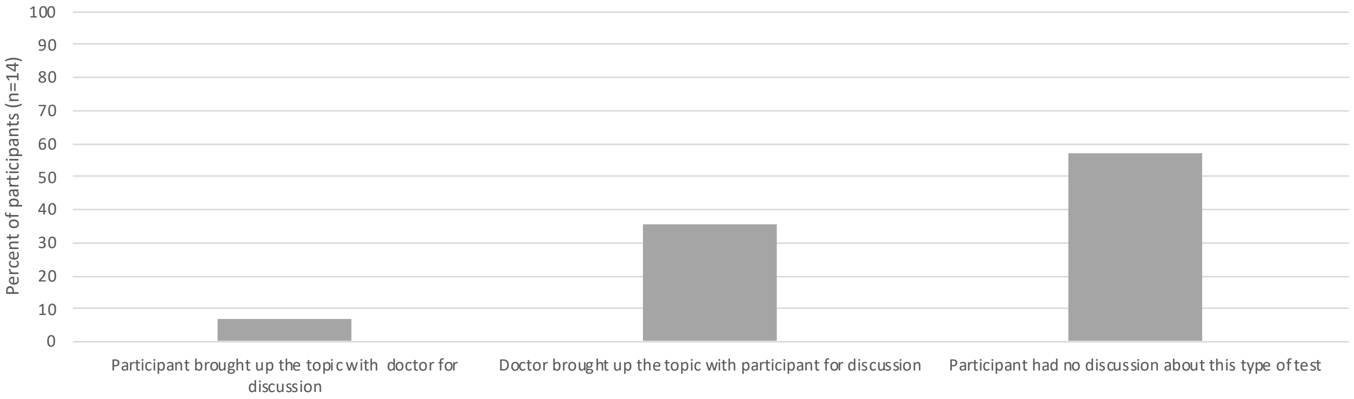

Figure 3.21: Discussions about biomarkers

Table 3.27: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=14)	Percent
Participant had this test and did not have to pay out of pocket for it	2	14.29
Participant had this test athrough a clinical trial	2	14.29
Participant had this type of test and paid for it	3	21.43
Participant did not have this test and is not interested in it	2	14.29
Participant did not have this test but would like to	5	35.71

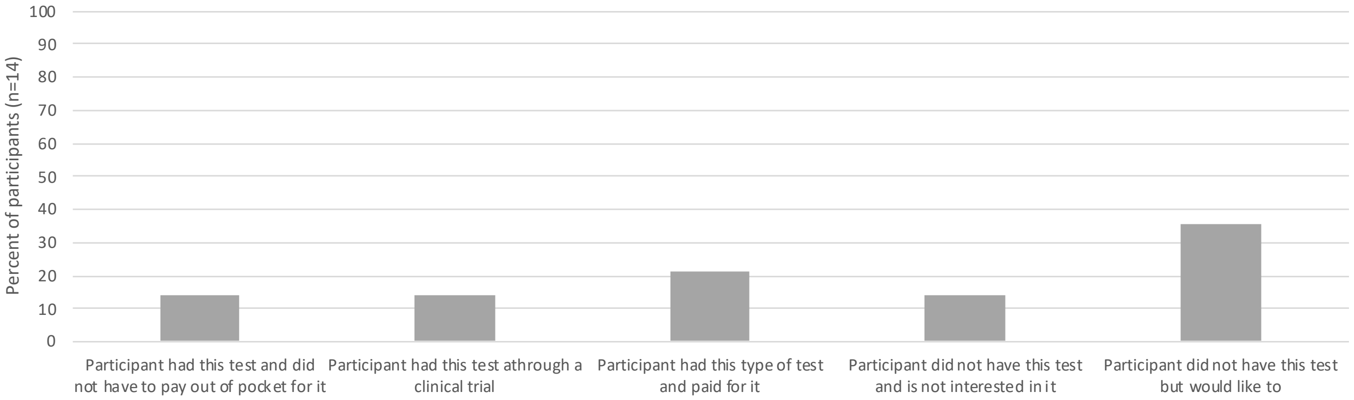

Figure 3.22: Experience of genetic tests and biomarkers

Current surveillance

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months.

The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

Table 3.29: Offered liver cheeks every 6 months

Offered liver checks every 6 months	Number (n=14)	Percent
No	5	35.71
Yes	9	64.29

Figure 3.24: Offered liver cheeks every 6 months

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 (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%),that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

Participant describes prognosis in relation to uncertainty around prognosis

Nothing. After getting my blood testing results, the GP prescribed me the medication to treat.
Participant 005_2023AUHDV

No, that, that. No, my doctor did not tell me anything… so every time when I do blood test and everything. Nothing. Completely nothing. Yeah, nothing. Nothing at all.
Participant 001_2023AUHDV

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

Yeah, just keep going. Basically I get reviewed every six months with my 3 specialists and it's a case of they usually just see me.
Participant 007_2023AUHDV

Yeah. So I I've had, I've had treatment and that was actually quite a while ago…and that was prescribed to me for six months. So I took the six months of treatment. So there's been monitoring like I have, I have, I still get, I still get tests.
Participant 011_2023AUHDV

Participant describes prognosis in relation to it being currently controlled

Well, I had the treatment and haven't needed more.
Participant 010_2023AUHDV

Participant describes prognosis in relation to the risk of liver cancer

So I'm currently being medicated and from personal experience I have seen liver disease turns into liver cancer…so it's a very real and lived kind of experience. So the prognosis I know can be either way, depending on how your body reacts and what happens next really.
Participant 004_2023AUHDV

Table 3.30: Understanding of prognosis

Understanding of prognosis	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	3	25.00	2	33.33	1	16.67	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes prognosis in relation to uncertainty around prognosis	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes prognosis in a positive way, that their condition is manageable	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes prognosis in relation to it being currently controlled	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes prognosis in relation to the risk of liver cancer	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

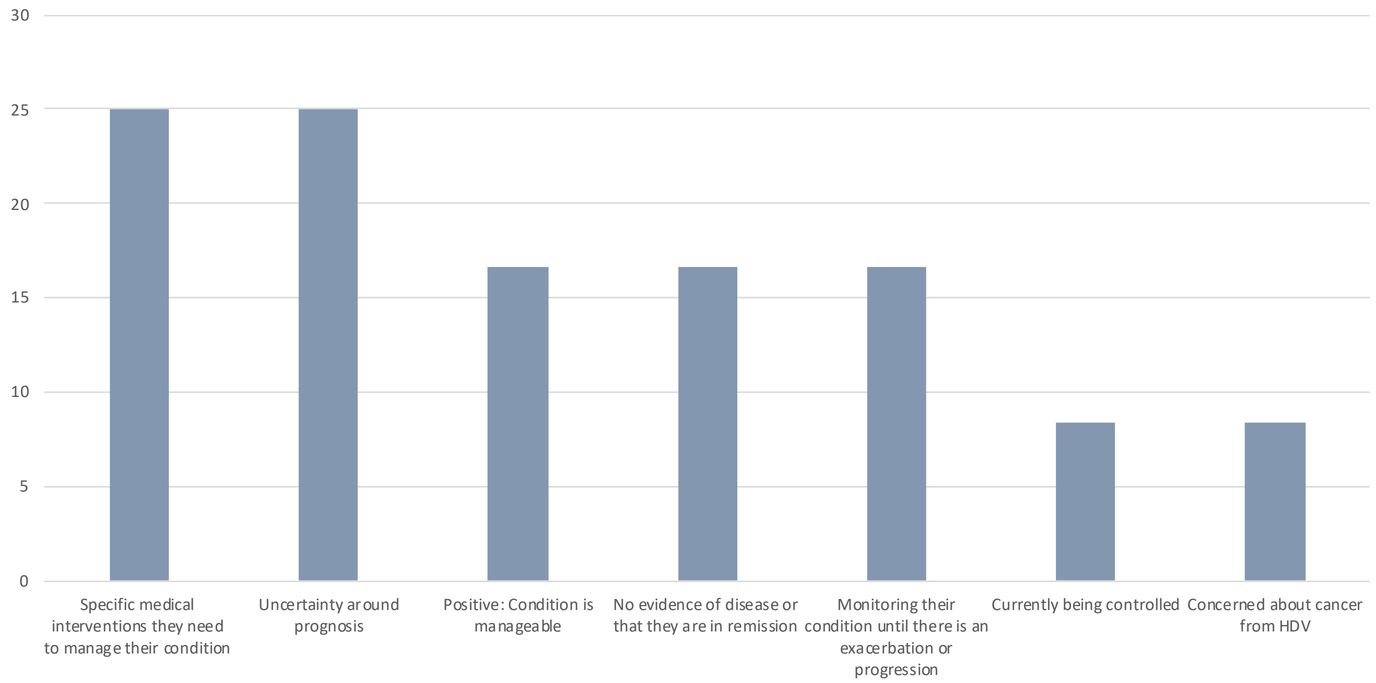

Figure 3.25: Understanding of prognosis

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 one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did no give a reason (16.67%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67 %). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

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 maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

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 one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Participant describes one option being presented

She explained me that the only treatment is taking some specific medication…it is the only treatment for this kind of hepatitis.
Participant 005_2023AUHDV

When I was first diagnosed, yeah. So when I was first diagnosed, the only thing available at that time was interferon.
Participant 010_2023AUHDV

Participant describes multiple options being presented

So what I did was to seek medical, medical help from the doctor who run the test and diagnose and everything from you know the treatment and all of the diagnosis was run and managed by the doctor because I wasn't really aware aware of you know the circumstances around kind of I can remember several antiviral medicines were kind of administered to me and now something that can help fight and slow the ability of the virus to damage my liver. All of these was administered to me by the doctor and it was strictly based on his medication.
Participant 006_2023AUHDV

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes one option being presented	6	50.00	5	83.33	1	16.67	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Participant describes no treatments being discussed	3	25.00	0	0.00	3	50.00	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes multiple options being presented	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant does not remember	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

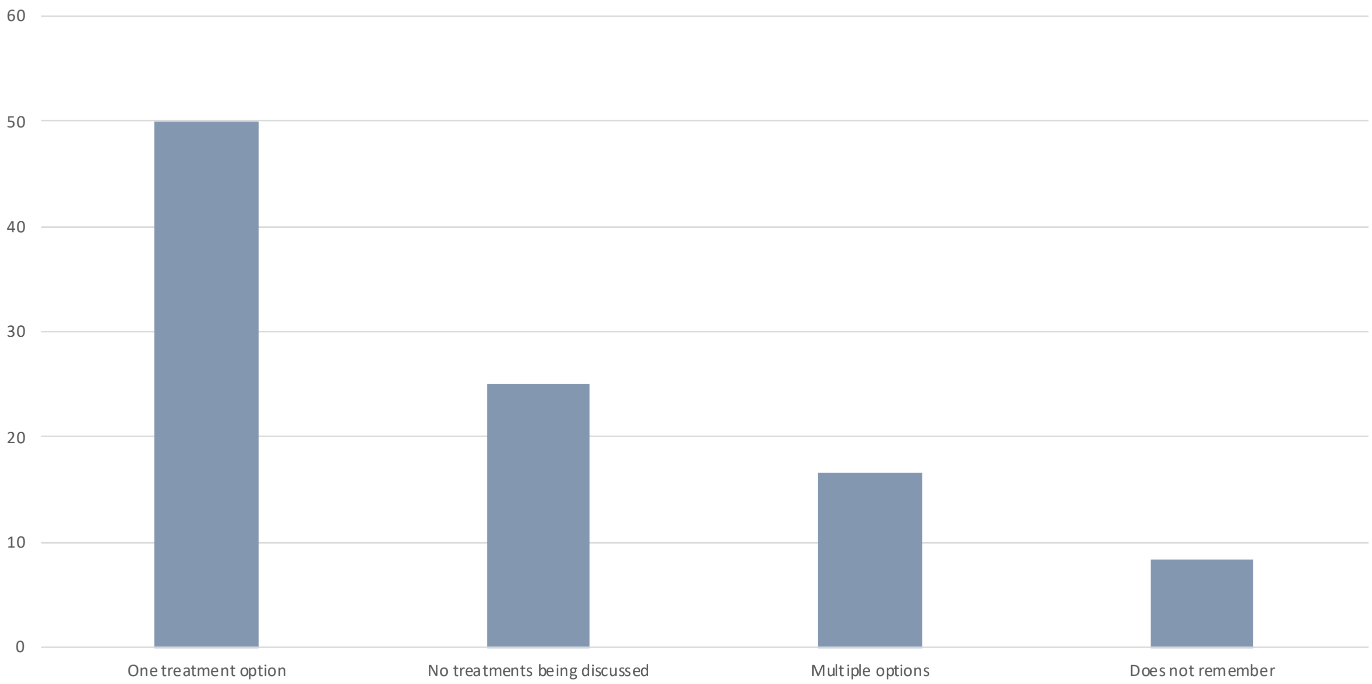

Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes one option being presented	Male Aged 45 and older	Female Aged 18 to 44

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did no give a reason (16.67%).

Participant describes being presented with one option/approach and that they participated in the decision-making process

I I just said, well, I would sit with all this information for a while and then I decide what I wanted to do. And so I did a lot of research…there was a lot of horrific stories about people who reacted badly. You sometimes had mental effects from that, in other words, depression, etcetera.
Participant 010_2023AUHDV

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being presented with multiple options but did not give a description or reason for this	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being presented with one option/approach, and did not participate in the decision-making process	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being presented with one option/approach and that they participated in the decision-making process	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being presented with one option/approach, but did not give a description or reason for this	3	25.00	3	50.00	0	0.00	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes being presented with no options/approach as there were no therapies are available	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having no discussions about treatments	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes having no discussions about treatments because of competing health issues	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes being diagnosis being a long time ago and does not remember	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

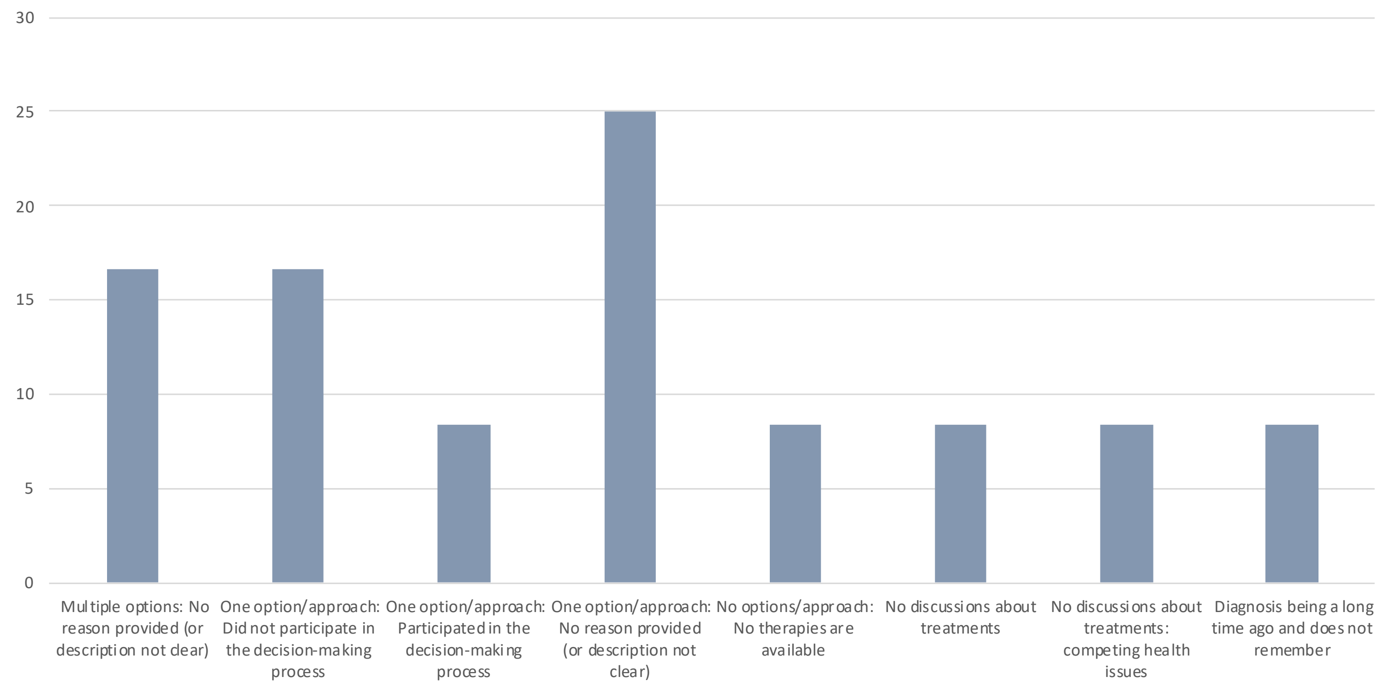

Figure 4.2: Discussions about treatment (Participation in discussions)

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67 %). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

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

The convenience because I mean… I mean there was a time when I was taking over 40 pills a day. So it comes down to you know how convenient is it going to be and it is it easy to maintain.
Participant 007_2023AUHDV

Participant describes taking efficacy into account when making decisions about treatments (Total)

The efficacy of the treatment is is a is a big concern, you know particularly like coming from the, you know from the the experience before of interferon where it was a very low like statistically very low success rate. Like I want to know that what I'm taking is going to have a you know, measurable, tangible, noticeable you know impact in my treatment yeah. And and just the and also kind of you know absolutely tied to that is you know what are what are the potential side effects.
Participant 011_2023AUHDV

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

Whether there will be any side effects of those treatments and those conditions, it is up to us to follow. It's the money that can be afforded, it's the money, and um, is there anyone else who has tried it and then there's some progress on that?
Participant 008_2023AUHDV

Participant describes taking cost into account when making decisions about treatments (Total)

If I can't afford, if he's not like the side effects, it's not that strong. That's it.
Participant 005_2023AUHDV

Participant describes taking the ability to work into account when making decisions about treatments (Total)

I might have already covered that. Yeah, just well, you know, I I wanted to continue on in my life, you know, I wanted to continue to work, you know.
Participant 010_2023AUHDV

Table 4.4: Considerations when making decisions

Considerations when making decisions about treatment	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	5	41.67	**1**	**16.67**	**4**	**66.67**	**2**	**25.00**	**3**	**75.00**	2	33.33	3	50.00	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes taking efficacy into account when making decisions about treatments (Total)	5	41.67	2	33.33	3	50.00	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	41.67	2	33.33	3	50.00	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	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 taking side effects into account when making decisions about treatments (Total)	5	41.67	3	50.00	2	33.33	4	50.00	**1**	**25.00**	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking cost into account when making decisions about treatments (Total)	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking the ability to work into account when making decisions about treatments (Total)	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
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	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking the potential impact on their familiy or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	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 descibes taking their own research into account when making decisions about treatments (Total)	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	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 taking their own research into account as the only thing that they consider when making decisions about treatment	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

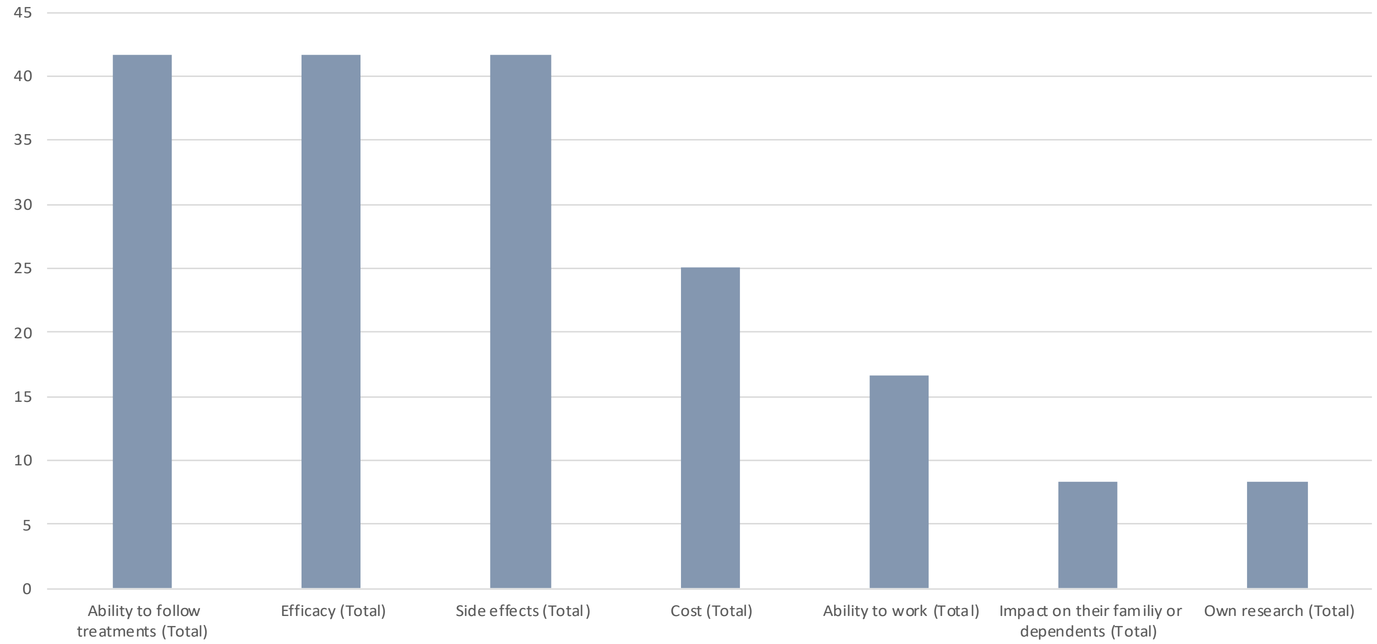

Figure 4.3 Considerations when making decisions

Table 4.5: Considerations when making decisions – subgroup variations

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	Female Aged 18 to 44	Male Aged 45 and older
Participant descibes taking efficacy into account when making decisions about treatments (Total)		
Participant descibes taking side effects into account when making decisions about treatments (Total)	Aged 45 and older	

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

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

Yeah, honestly, everything was changed. Everything was affected. I would say from the dressing to my diet, everything got to turn around. I wasn't comfortable doing certain things. I had to restrict myself, you know, just to make situation better. I had to stop certain things. I had to stop certain habits.
Participant 006_2023AUHDV

I'll look into things much more seriously now. I mean, I take responsibility for more on health. A lot more now. A lot more.
Participant 012_2023AUHDV

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

Both, you know, before, during and after because I really found like post the the course of interferon. I really, really had to really had to struggle against the people who have given me the treatment to just to get answers, to get any kind of results, to get anything in writing. So yeah, so. Yeah, it's definitely changed over time.
Participant 011_2023AUHDV

No change in decision-making over time and there is no particular reason noted

I think I would approach the same way.
Participant 005_2023AUHDV

No, I haven't changed anything. I haven't changed anything.
Participant 001_2023AUHDV

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

I approached it in the same way. And so I always make a decision, Yeah, I I, I make a decision by doing my research.
Participant 010_2023AUHDV

Table 4.6: Decision-making over time

Decision-making over time	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Change	4	33.33	**0**	**0.00**	**4**	**66.67**	2	25.00	**2**	**50.00**	2	33.33	2	33.33	1	100.00	3	27.27	1	100.00	3	27.27
No change	5	41.67	3	50.00	2	33.33	4	50.00	**1**	**25.00**	2	33.33	3	50.00	0	0.00	5	45.45	0	0.00	5	45.45
Other/no response	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

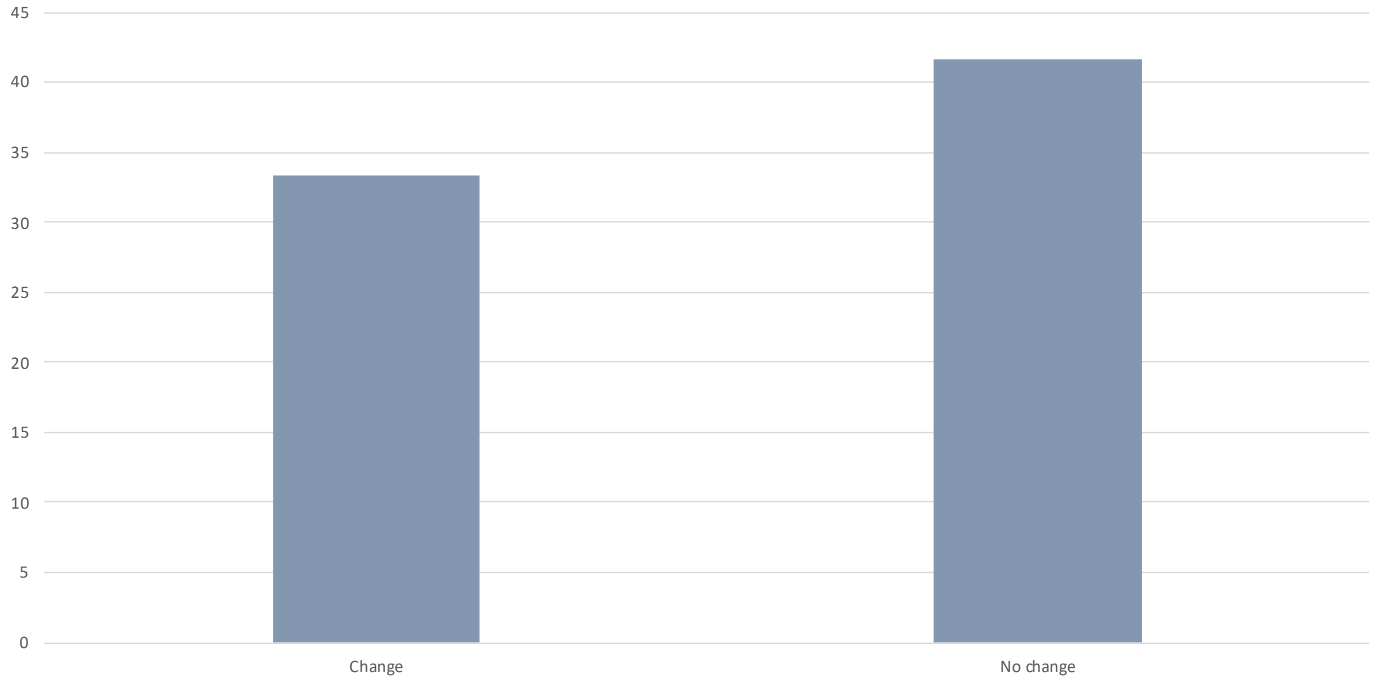

Figure 4.4: Decision-making over time

Table 4.7: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Change	Female	Male Aged 45 and older
No change	Aged 45 and older	-

Table 4.8: Decision-making over time (reasons)

Decision-making over time (reasons)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Changing over time as they are more aware of their health, responsibilities and/or limitations	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Changing over time nd there is no particular reason noted	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Changing over time as they are more accepting of their condition and choices available (however not by choice)	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Changing over time as they are more informed and/or more assertive	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No change in decision-making over time and there is no particular reason noted	3	25.00	1	16.67	2	33.33	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
No change in decision-making over time as they have always been informed/assertive	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

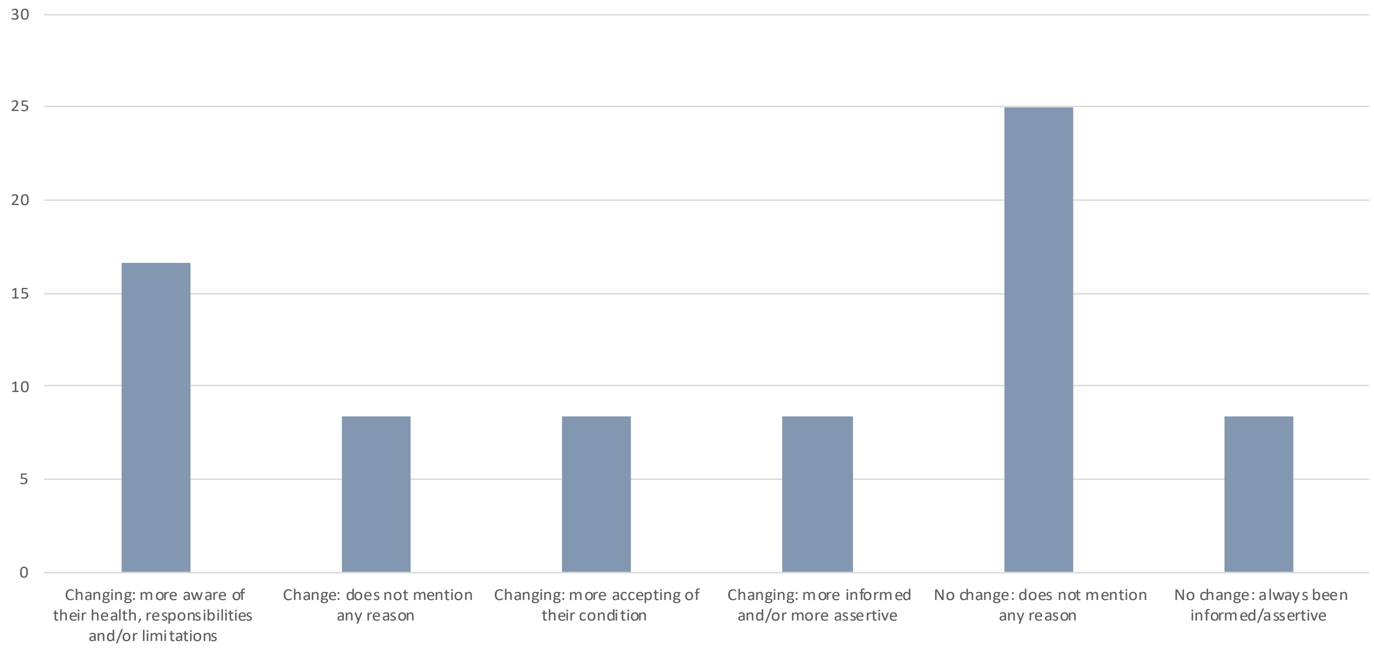

Figure 4.5: Decision-making over time (reasons)

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 maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

Participant describes wanting to maintain their condition/prevent worsening of their condition

My own concern is having cancer in the future. The other things I think is is treatable but not cancer is my only concern.
Participant 005_2023AUHDV

I've still got ongoing issues with my liver that I I think might be related to, you know, having had hep for so long. So, you know, I just want to be as healthy as possible have a fully functioning liver. Yeah. So that, that's, that's required. My understanding is that my liver issues are…chronic. Like I'm always gonna have ... So I don't drink alcohol anymore. Participant 011_2023AUHDV

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

Yes, well, I do, because I wanted to. I'm very committed to my family and I wanted to get well for them, really, not only for them, but for myself, because I love life.
Participant 010_2023AUHDV

Participant describes wanting to minimise or avoid side effects of treatment for their condition

I've been a bit the thing is I guess the side effects for me. I can't 100% link back to either the medication itself or my body as well like like as in…do I attribute that to the virus or do I attribute that to the medication? That is helping my body potentially to fight the virus or to let it not to control the virus levels like this is where I'm not sure on how I can attribute my symptoms to.
Participant 004_2023AUHDV

Participants describe wanting to make healthy lifestyle changes

Well, for me personally I had to you know kind of reduce the intake of certain diet. There was you know that I could I sense was going to was in the situation and I had to stay away from certain unhygienic activity. So it's just, it just had to do with me cutting off myself from. You know a lot of things just to, you know, maintain not towards in the situation. That's all I tried to do after this.
Participant 006_2023AUHDV

So that's, that's that's the main thing and I mean contracting hepatitis was a bit of an impetus to me to get clean and sober.
Participant 012_2023AUHDV

Participant describes no personal goals of treatment or care (no reason given)

I don't have any goal at the moment as such, but I'm just worried. I'm always worried that when is it going to affect me.
Participant 001_2023AUHDV

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes wanting to maintain their condition/prevent worsening of their condition	5	41.67	3	50.00	2	33.33	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes wanting to improve their quality of life or return to normality	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes wanting to minimise or avoid side effects of treatment for their condition	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participants describe wanting to make healthy lifestyle changes	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes no personal goals of treatment or care (no reason given)	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes wanting to see mental or emotional health improvements in their condition	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participants describe wanting to comply with treatment	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participants describe wanting to be there for family	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

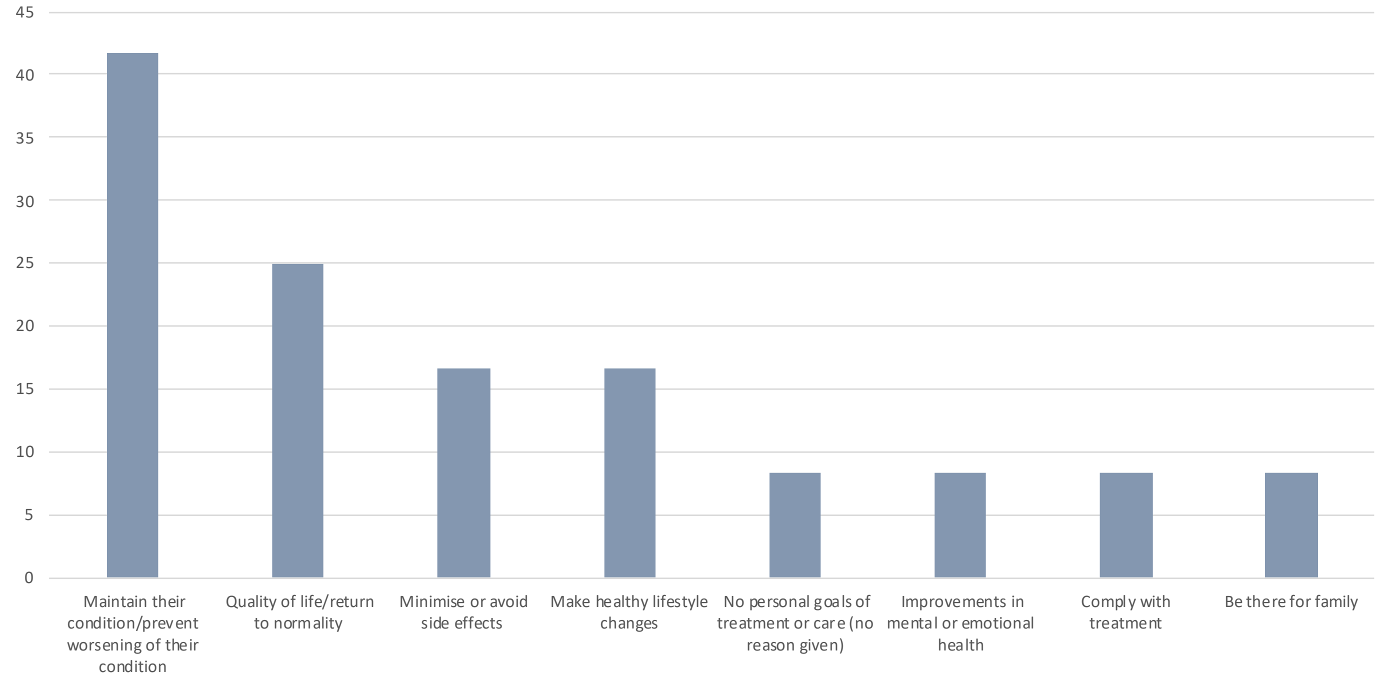

Figure 4.6: Personal goals of treatment or care

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 gastroenterologists (n=9,64.29 %), followed by general practitioners (n=5, 35.71%).

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 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

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.

Almost all participants had access to a gasteroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were 12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

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 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

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=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 particpants (53.85%) were mostly treated as a public patient, and there were 2 particpants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 particpants (76.92%) were mostly treated in the public system, and there was 1 particpant (7.69%) that was 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. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) 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 3 participants (23.08%) 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 (Table 5.8, Figure 5.9).

The most common amount was between $1 and $150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than $100 per month.

Burden of cost

As a follow up question, for participants that 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 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

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 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2 participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) 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 3 participants (23.08%), 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=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) 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.

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Summary of treatments and management

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

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

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. Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00 , IQR=3.00).

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist , 1 participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

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.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

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 moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

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=5, 35.71%)

The most common complementary therapy used was , massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

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 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

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 (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

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 those that do not interfere with life (50.00%), and they described mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

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 according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

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 physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33 %), and night sweats (8.33%).

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/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

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 healthcare professional considered to be the main provider of care were hepatologists (n=9, 64.28 %), followed by general practitioners (n=5, 35.71%).

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 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

Table 5.1: Time to travel to main provider of treatment

Main provider of treatment	Number (n=14)	Percent
Less than 15 minutes	1	7.14
Between 15 and 30 minutes	5	35.71
Between 30 and 60 minutes	4	28.57
Between 60 and 90 minutes	1	7.14
More than 90 minutes	1	7.14
NA	2	14.29

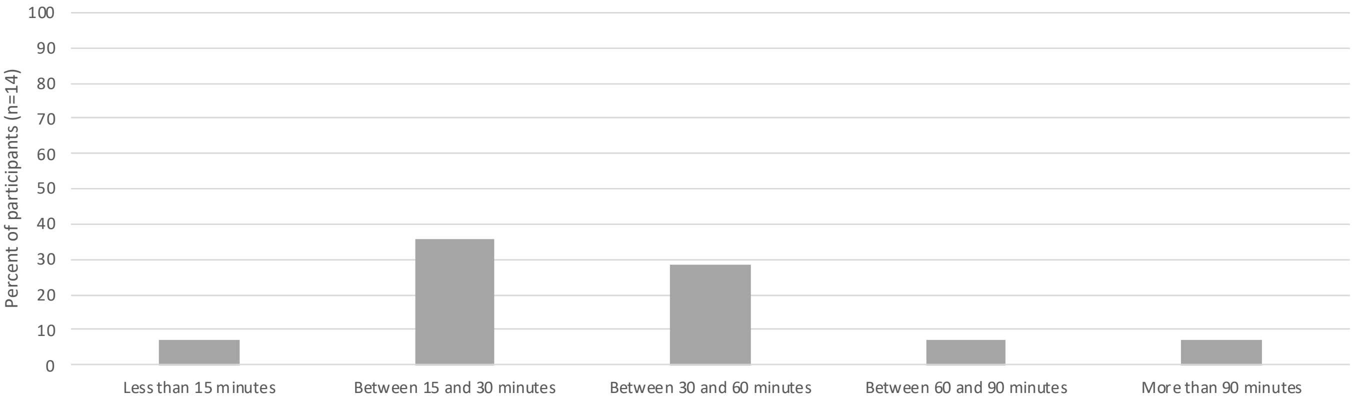

Figure 5.1: Time to travel to main provider of treatment

Table 5.2: Ease of getting medical appointments

Ease of getting medical appointments	Number (n=14)	Percent
Not very easy	3	21.43
Somewhat easy	2	14.29
Quite easy	6	42.86
Very easy	3	21.43

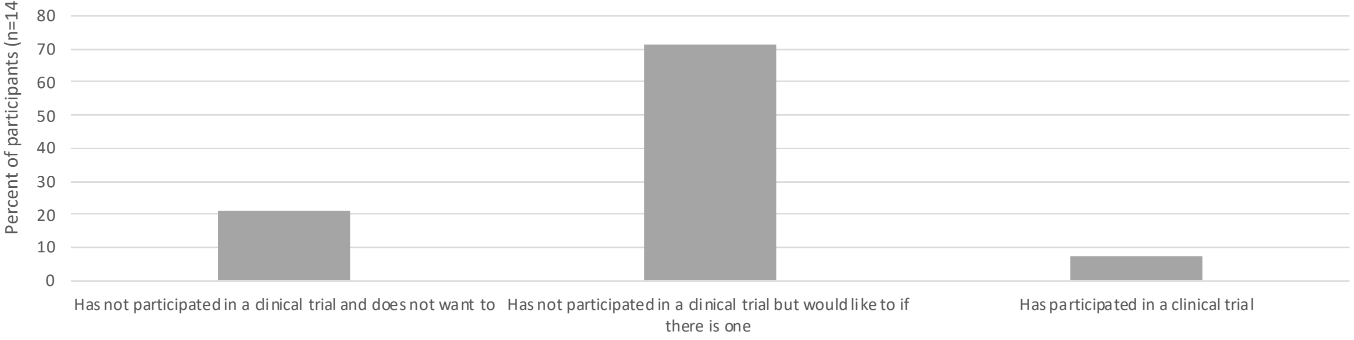

Figure 5.2: Ease of getting medical appointments

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.

Almost all participants had access to a gasteroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were 12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=14)	Percent
Gasteroenterologist	8	57.14
Hepatologist	8	57.14
Surgeon	2	14.29
General Practitioner (GP)	12	85.71
Hepatology nurse	5	35.71
Pharmacist	6	42.86
Dietitian/nutritionist	3	21.43
Exercise physiologist	2	14.29
Psychologist	2	14.29
Counsellor	1	7.14
Osteopath	1	7.14
Social worker	1	7.14

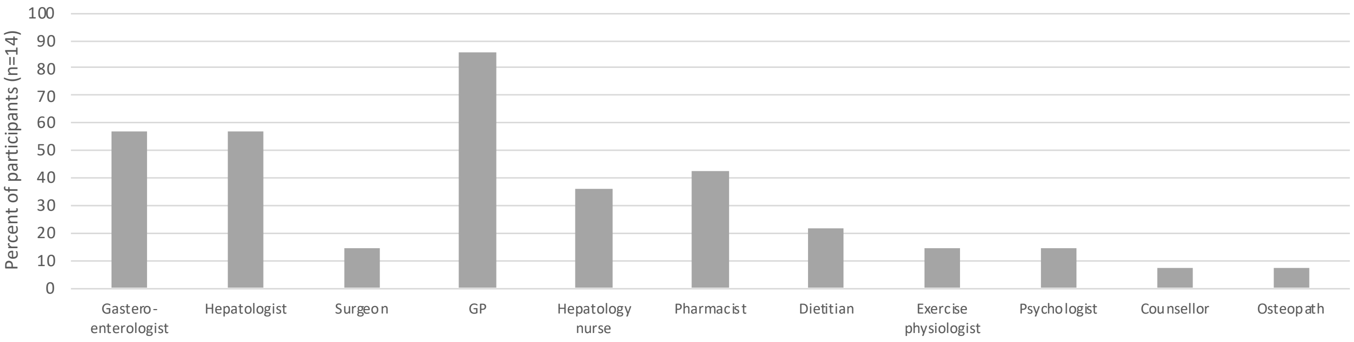

Figure 5.3: Access to healthcare professionals

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 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

Table 5.5: Respect shown

Respect shown	Number (n=14)	Percent
Respect shown	8	57.14
Respect shown, with the exception of one or two occasions	5	35.71
Respect not shown	1	7.14

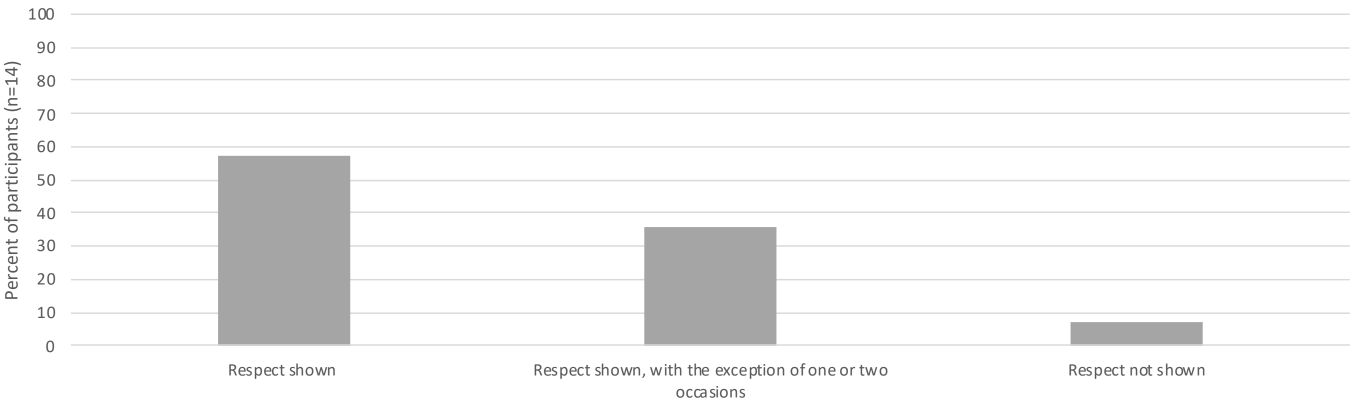

Figure 5.5: Respect shown

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.

Half of the participants had private health insurance (n=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 particpants (53.85%) were mostly treated as a public patient, and there were 2 particpants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 particpants (76.92%) were mostly treated in the public system, and there was 1 particpant (7.69%) that was equally treated in the private and public systems.

Table 5.6: Health care system

Health care services	Response	Number (n=13)	Percent
Private health insurance	No	6	46.15
	Yes	7	53.85
Asked whether you want to be treated as a public or private patient	No	8	61.54
	Yes	5	38.46
Asked whether you had private health insurance	No	3	23.08
	Yes	10	76.92
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	2	15.38
	Private patient	1	7.69
	Public patient	7	53.85
	Not sure	3	23.08
Which hospital system have you primarily been treated in	Both public and private	1	7.69
	Private	2	15.38
	Public patient	10	76.92

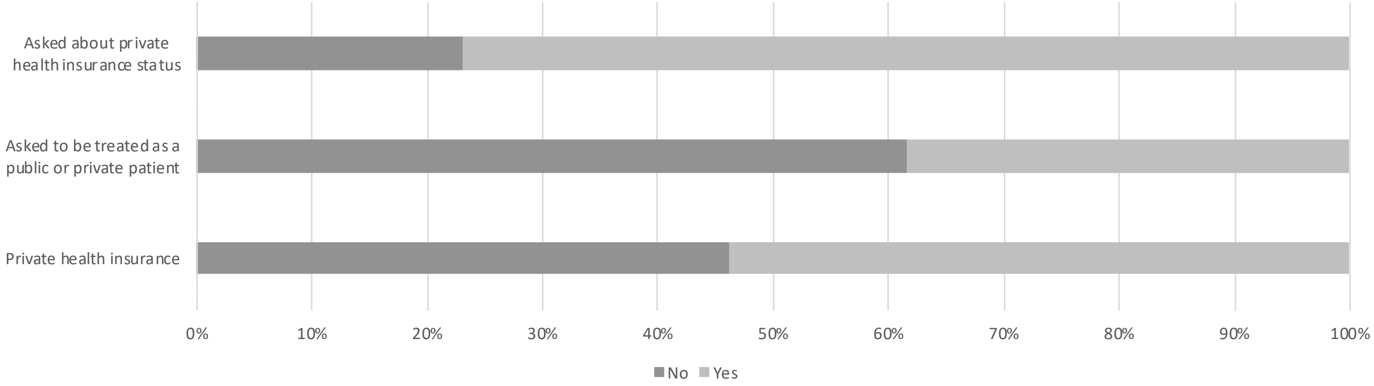

Figure 5.6: Health insurance

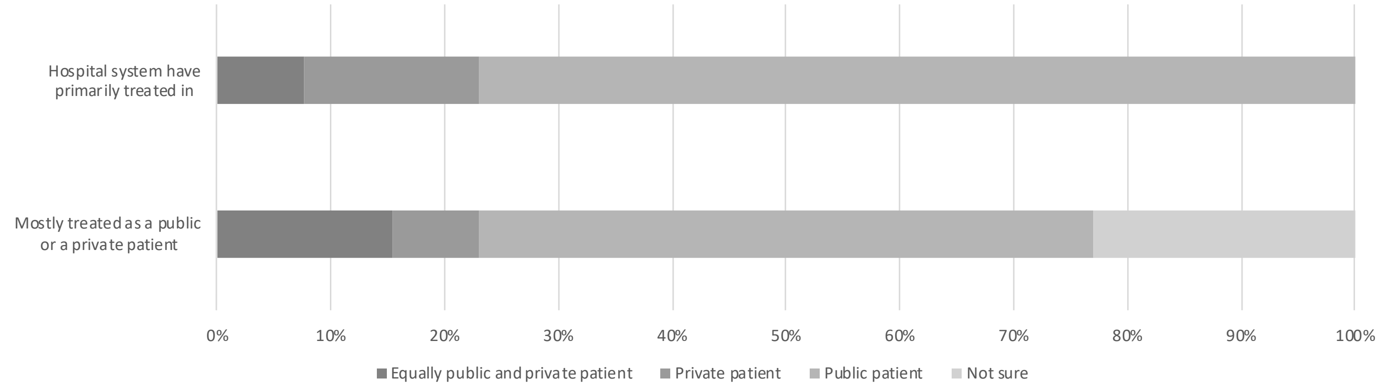

Figure 5.7: Hospital system

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 cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) 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 3 participants (23.08%) that paid for additional carers due to their condition.

Table 5.7: Affordability of healthcare

Health services and insurance	Response	Number (n=13)	Percent
Delay or cancel healthcare appointments due to affordability	Never	8	61.54
	Rarely	1	7.69
	Sometimes	3	23.08
	Often	0	0.00
	Very often	1	7.69
Did not fill prescriptions due to cost	Never	8	61.54
	Rarely	1	7.69
	Sometimes	3	23.08
	Often	0	0.00
	Very often	1	7.69
Difficult to pay for basic essentials	Never	8	61.54
	Rarely	1	7.69
	Sometimes	4	30.77
	Often	0	0.00
	Very often	0	0.00
Pay for additional carers for self or family	Yes	3	23.08
	No	10	76.92

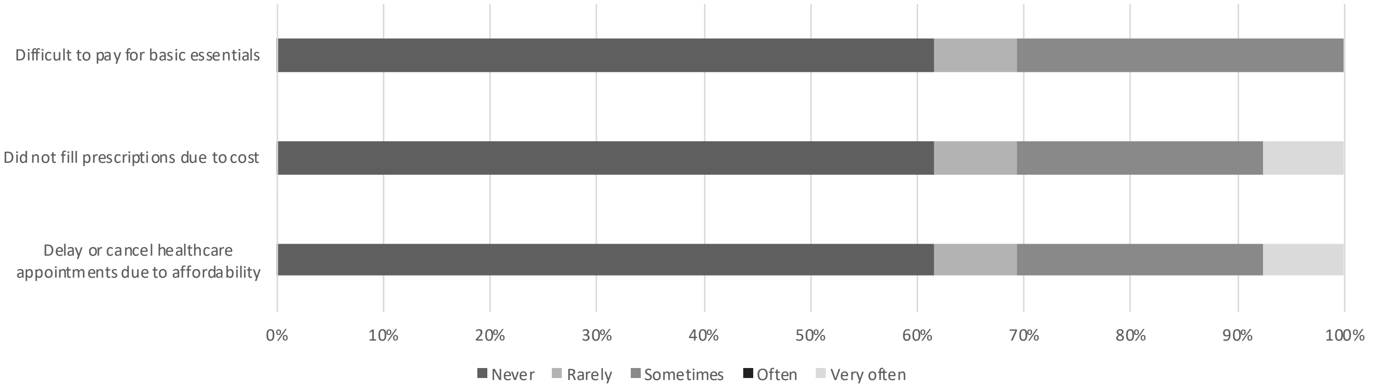

Figure 5.8: Affordability of healthcare

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 (Table 5.8, Figure 5.9).

The most common amount was between $1 and $150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than $100 per month.

Burden of cost

As a follow up question, for participants that 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 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

Table 5.8: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=13)	Percent
$0	2	15.38
$1 to $150	5	38.46
>$1000	2	15.38
Not sure/Not applicable	4	30.77

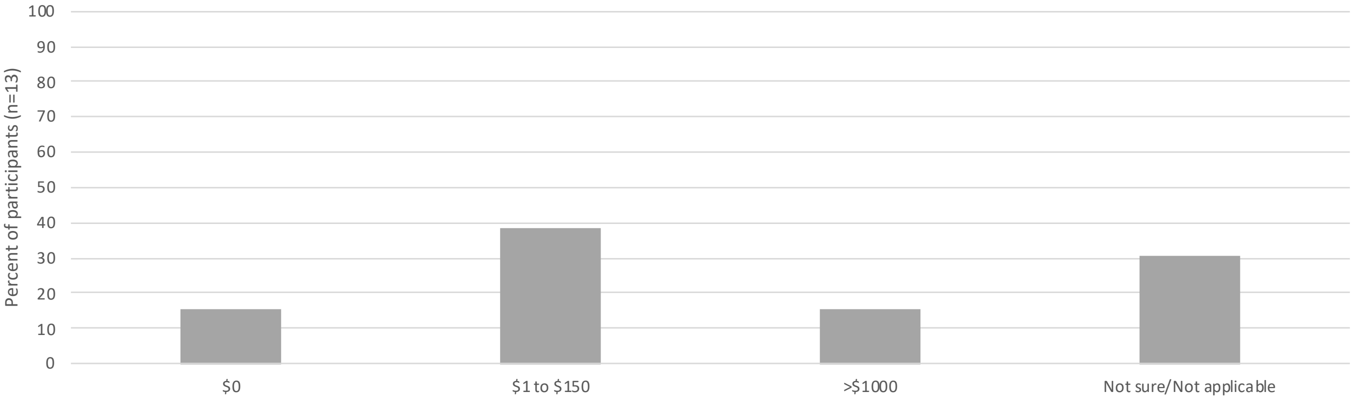

Figure 5.9: Estimated monthly out of pocket expenses due to condition

Table 5.9: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=13)	Percent
Extremely significant	3	23.08
Moderately significant	1	7.69
Somewhat significant	1	7.69
Slightly significant	3	23.08
Not at all significant	5	38.46

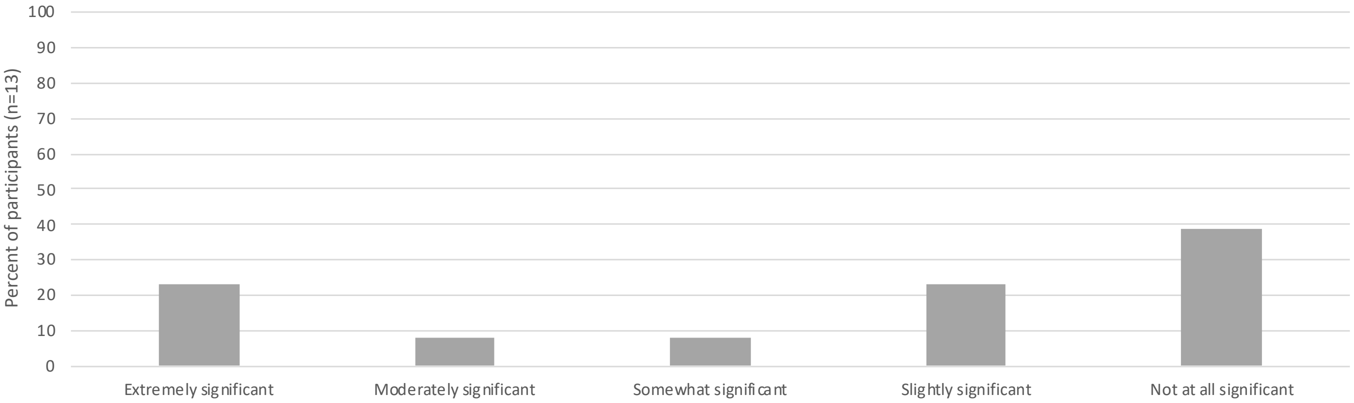

Figure 5.10: Burden of out-of-pocket expenses due to condition

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 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2 participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) 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 3 participants (23.08%), 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=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Table 5.10: Changes to employment status

Changes in work status due to condition	Number (n=13)	Percent
Work status has not changed	3	23.08
Retired or did not have a job	0	0.00
Had to quit job	1	7.69
Reduced number of hours worked	5	38.46
Leave from work without pay	2	15.38
Leave from work with pay	3	23.08
Accessed Superannuation early due to condition	2	15.38

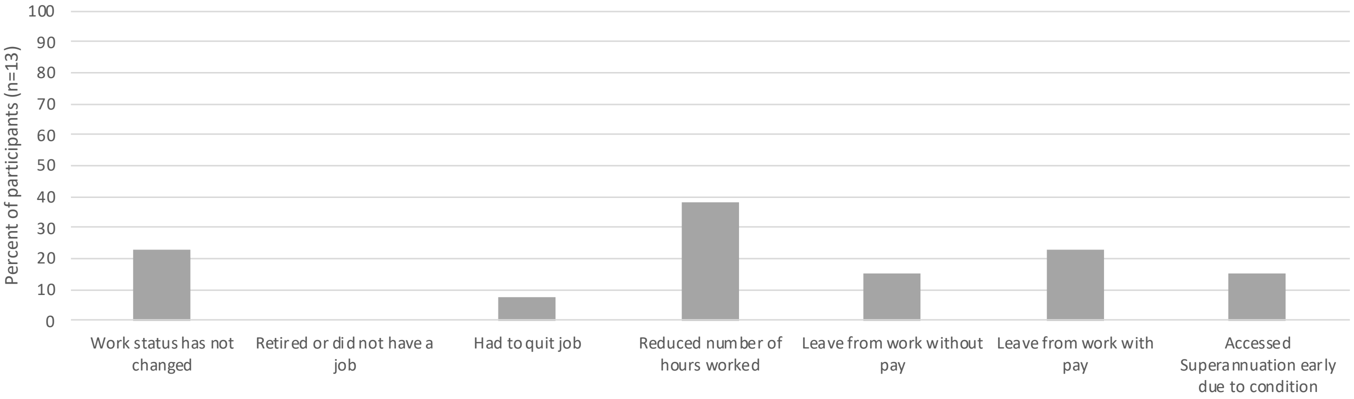

Figure 5.11: Changes to employment status

Table 5.11: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=13)	Percent
Does not have a partner/main carer	3	23.08
Work status has not changed	6	46.15
Retired or did not have a job	1	7.69
Had to quit job	1	7.69
Reduced number of hours worked	1	7.69
Leave from work without pay	0	0.00
Leave from work with pay	1	7.69

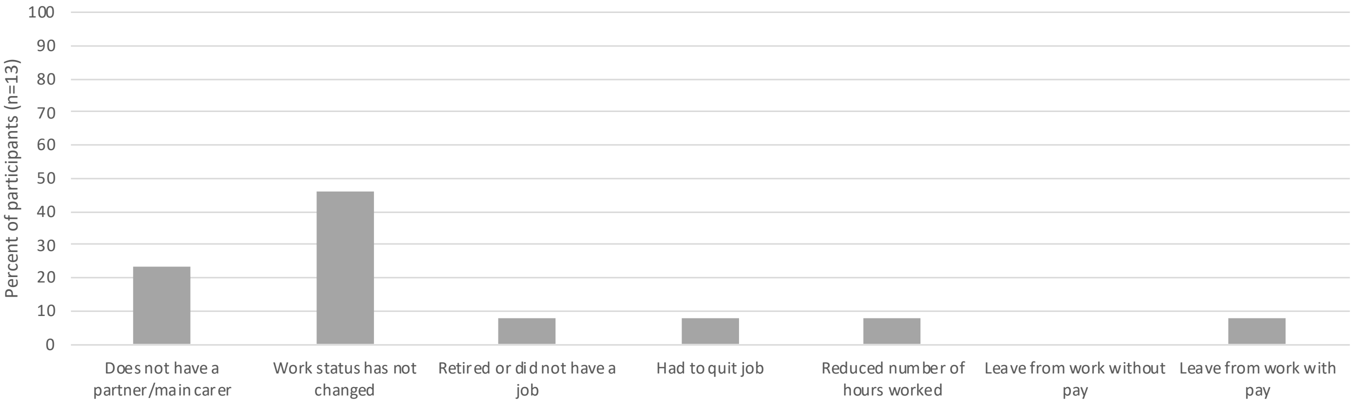

Figure 5.12: Changes to care/partner employment status

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) 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.

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Table 5.12: Monthly loss of income

Monthly loss of income	Number (n=13)	Percent
Income not reduced	9	69.23
Income reduced	4	30.77

Figure 5.13: Monthly loss of income

Summary of treatments and management

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

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

Table 5.13: Summary of treatments and management

Treatments overview	Number (n=14)	Percent
Drug treatments	13	92.86
Liver transplant	1	7.14
Allied health	7	50.00
Complementary therapy	5	35.71
Lifestyle changes	8	57.14
Clinical trials	1	7.14
No treatment	1	7.14

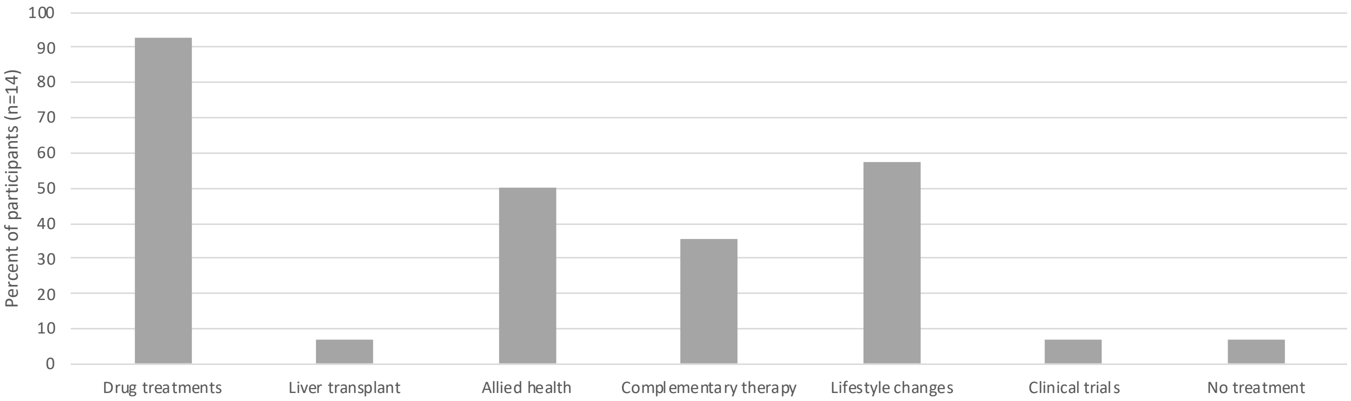

Figure 5.14: Summary of treatments and management

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

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. Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00 , IQR=3.00).

Table 5.14: Overview of treatments reported

Drug treatments	Number (n=xx)	Percent
Pegylated interferon alpha (Pegasys, Peg-Intron)	11	78.57
Entecavir (Baraclude)	4	28.57
Ribavirin (Ibavyr)	4	28.57
Tenofovir (Viread)	4	28.57
Glecaprevir/pibrentasvir (Maviret)	1	7.14
Sofosbuvir/ Velpatasvir (Epclusa)	1	7.14

Table 5.15: Side effects from treatments

Pegylated interferon alpha (Pegasys, Peg-Intron)	Number (n=11)	Percent	Ribavirin (Ibavyr)	Number (n=4)	Percent	Tenofovir (Viread)	Number (n=4)	Percent	Entecavir (Baraclude)	Number (n=4)	Percent
Muscle or joint pain	10	90.91	Fatigue/weakness/lack of energy	4	100.00	Confusion/feeling light headed	2	50.00	Diarrhoea	1	25.00
Mood changes (such as depression/anxiety/irritability)	8	72.73	Irritation of eye or eye lid	2	50.00	Headache	1	25.00	Fatigue/weakness/lack of energy	1	25.00
Hair loss	7	63.64	Allergic reaction	1	25.00	No side effects	3	75.00	No side effects	2	50.00
Changes in eyesight	6	54.55	Sore joints	1	25.00						
Sleep problems (insomnia)	6	54.55	Brain-fog	1	25.00						
Confusion/feeling light headed	5	45.45	Anxiety	1	25.00						
Nausea	5	45.45	Breathing problems	1	25.00						
Allergic reaction	3	27.27	Cough	1	25.00						
Easy bruising or bleeding	1	9.09	Hair loss	1	25.00						
Lack of energy	1	9.09	Low blood count	1	25.00						
Weight loss	1	9.09									

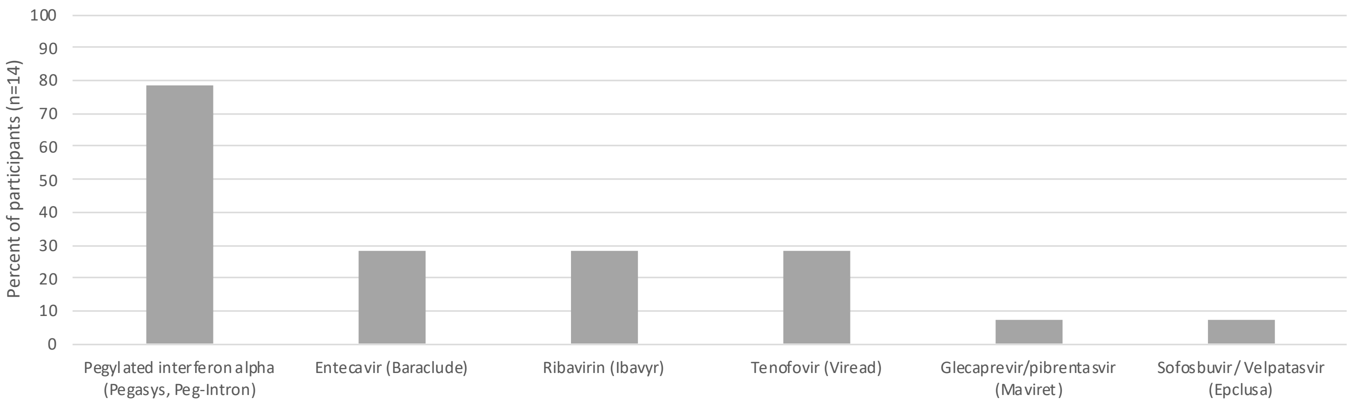

Figure 5.15: Overview of treatments reported

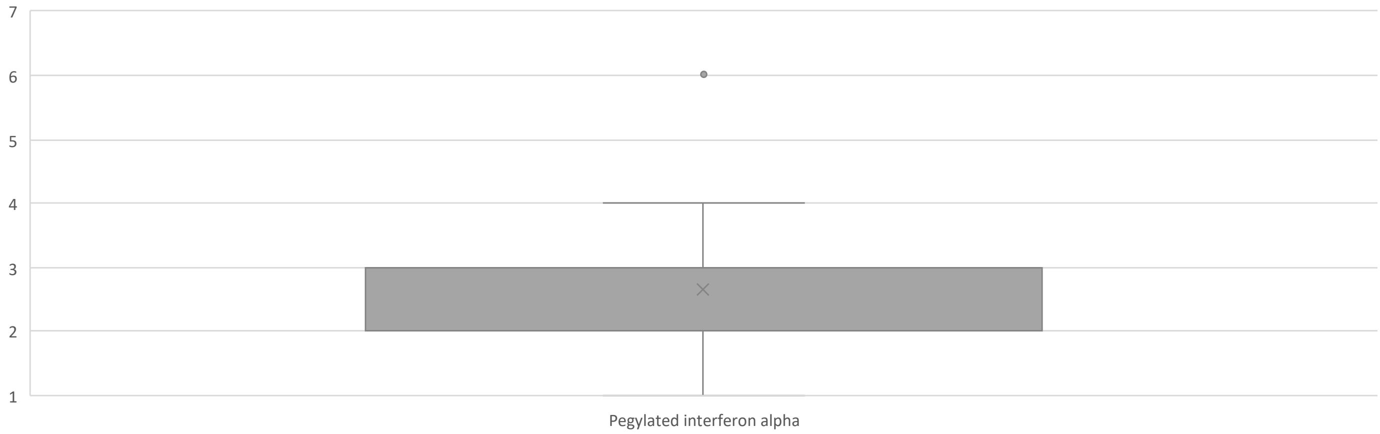

Figure 5.16: Quality of life from drug treatments (where complete data was available)

Figure 5.17: Effectiveness of drug treatments (where complete data was available)

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist , 1 participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

Table 5.16: Allied health

Allied health	Number (n=14)	Percent
Psychologist	4	28.57
Dietician	3	21.43
Social worker	2	14.29
Physiotherapist	1	7.14
Podiatrist	1	7.14
Speech pathologist or speech therapist	0	0.00
Occupational therapy	0	0.00

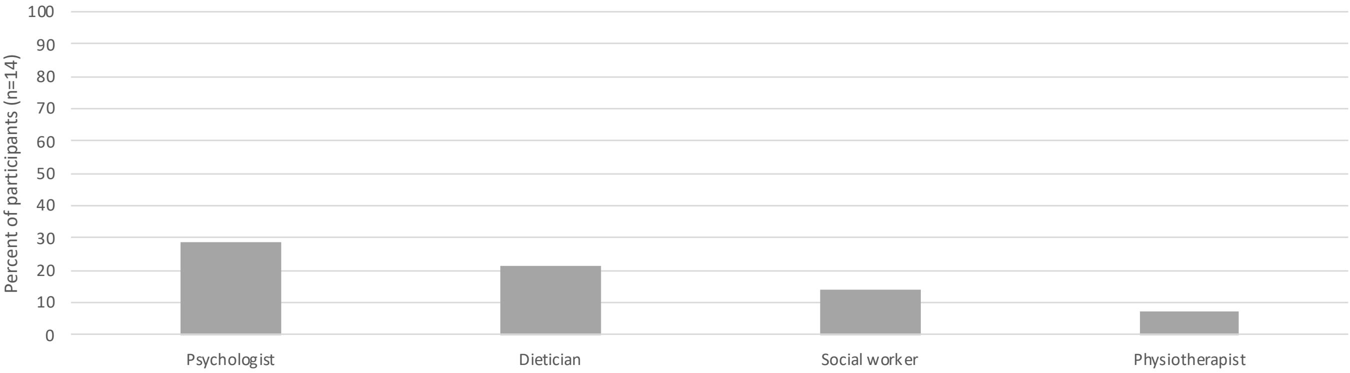

Figure 5.18: Allied health

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.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

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 moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

Table 5.17: Lifestyle changes

Lifestyle changes	Number (n=14)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Diet	7	50.00	4.00	2.00	3.00	1.50
Reduce or quit alcohol	6	42.86	4.00	1.50	5.00	0.75
Exercise	4	28.57	NA	NA	NA	NA
Quit smoking	2	14.29	NA	NA	NA	NA

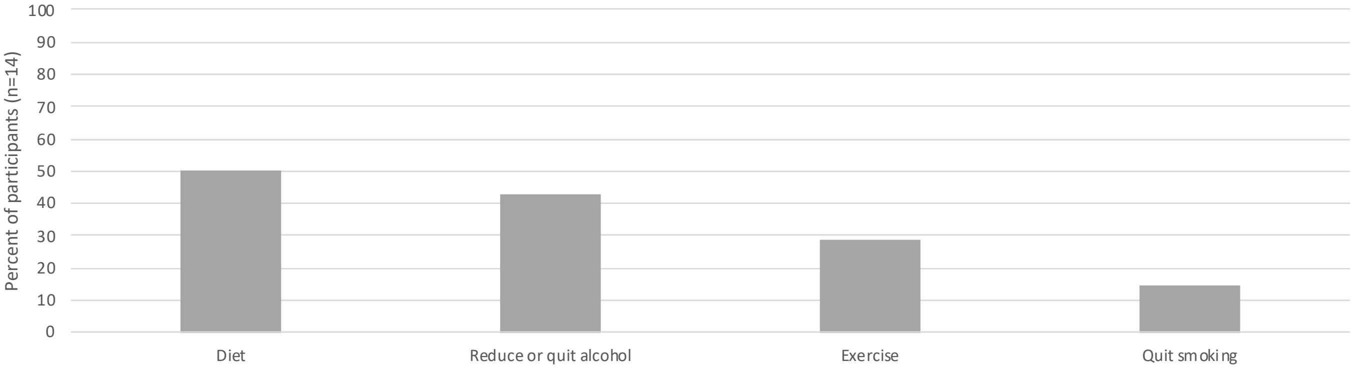

Figure 5.19: Lifestyle changes

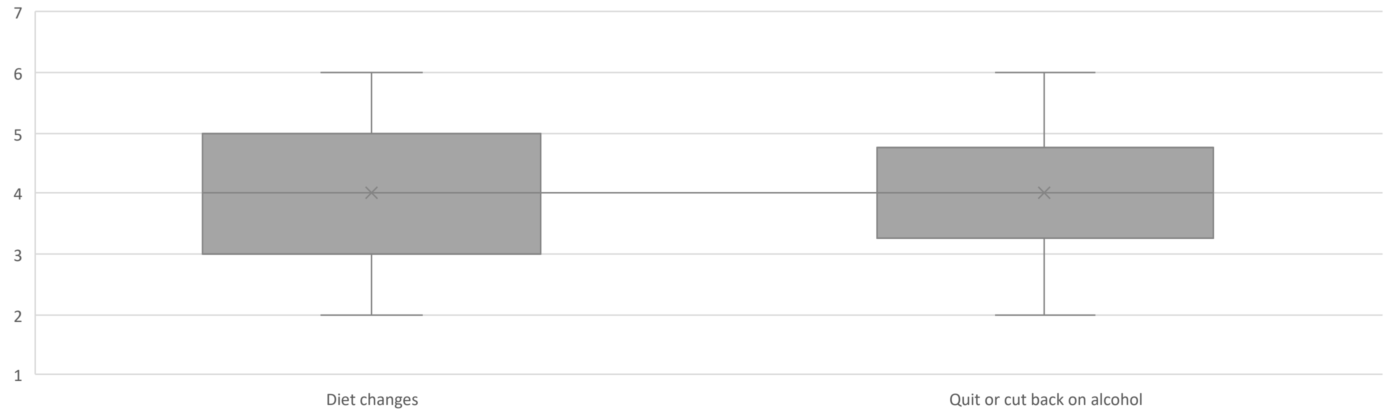

Figure 5.20: Quality of life from lifestyle changes

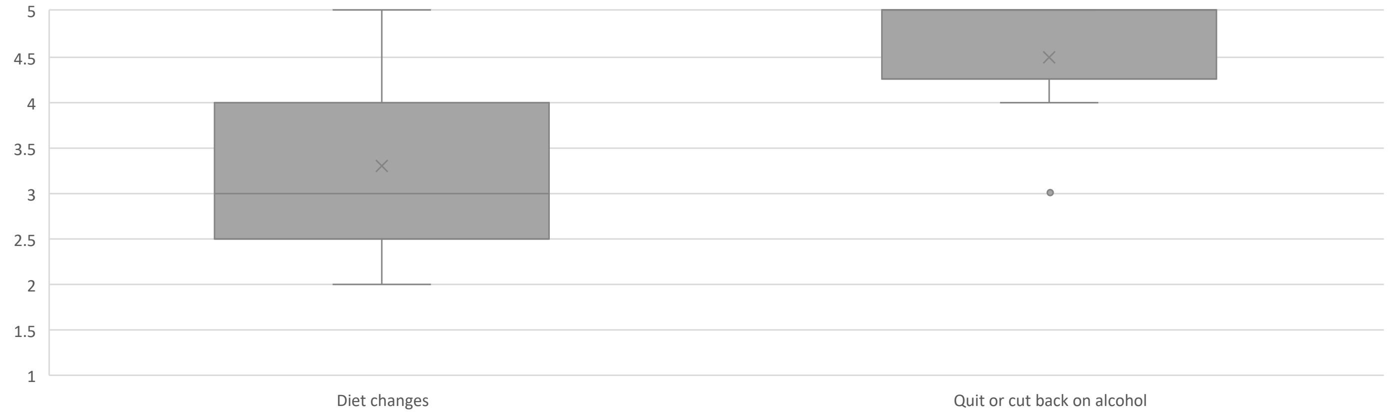

Figure 5.21: Effectiveness from lifestyle changes

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=5, 35.71%)

The most common complementary therapy used was , massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

Table 5.18: Complementary therapies

Complementary therapies	Number (n=14)	Percent
Massage therapy	4	28.57
Mindfulness or relaxation techniques	4	28.57
Acupuncture	3	21.43
Supplements	1	7.14
Naturopath	1	7.14
Homeopathy	0	0.00

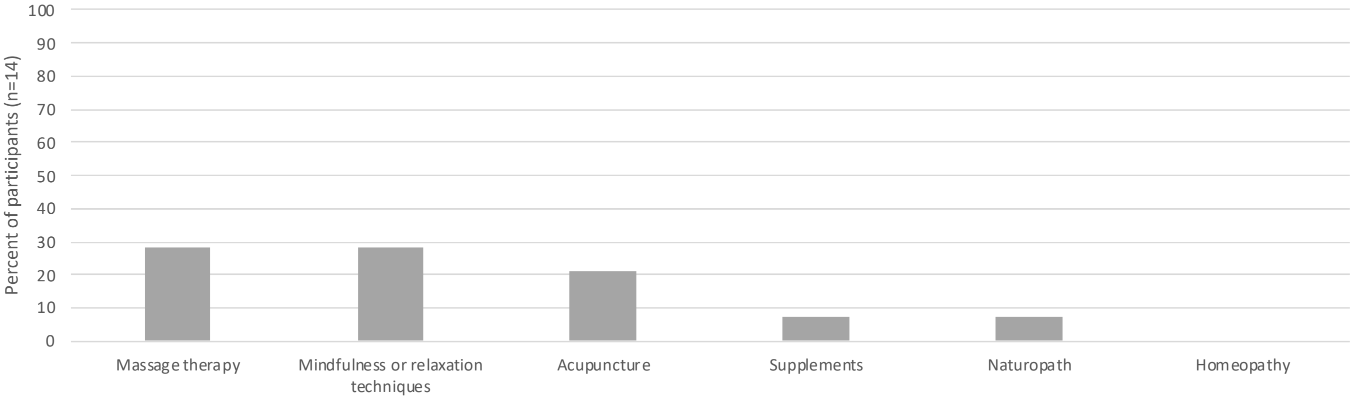

Figure 5.22: Complementary therapies

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 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

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 (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

Table 5.19: Clinical trial discussions

Clinical trial discussions	Number (n=14)	Percent
Participant brought up the topic of clinical trials doctor for discussion	3	21.43
Doctor brought up the topic of clinical trials for discussion	5	35.71
Participant has ever spoken to me about clinical trials	6	42.86

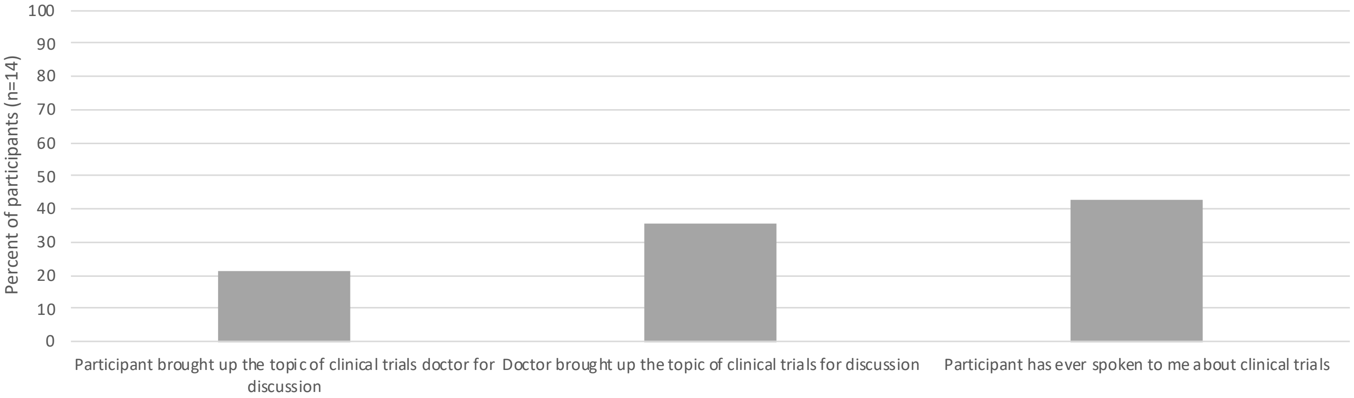

Figure 5.23: Clinical trial discussions

Table 5.20: Clinical trial participation

Clinical trial participation	Number (n=14)	Percent
Has not participated in a clinical trial and does not want to	3	21.43
Has not participated in a clinical trial but would like to if there is one	10	71.43
Has participated in a clinical trial	1	7.14

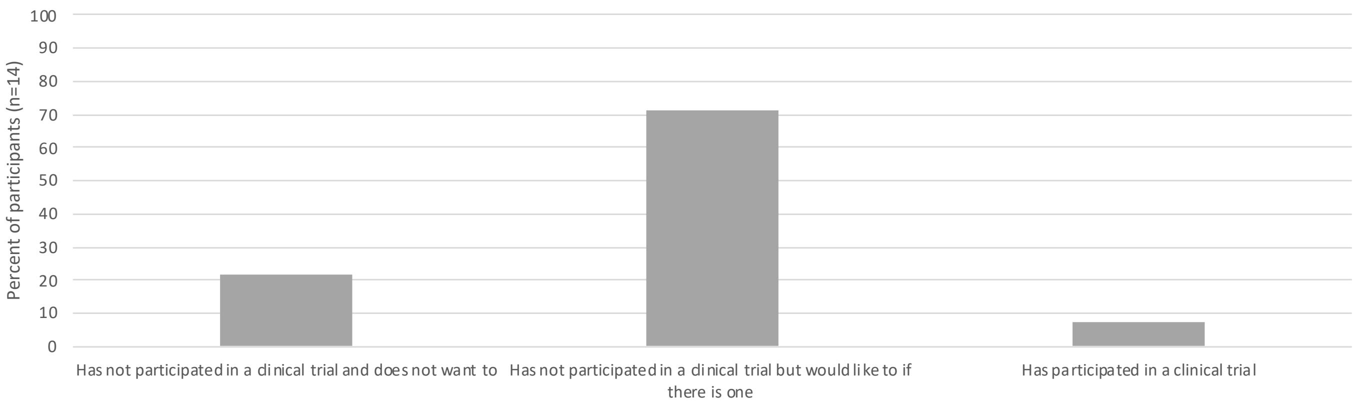

Figure 5.24: Clinical trial participation

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 those that do not interfere with life (50.00%), and they described mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

Participant describes mild side effects as those that do not interfere with daily life

Something that was a minor inconvenience. Slight diarrhea, something like that, not something that would keep you in the house, right?
Participant 007_2023AUHDV

Participant provides a specific side effect as an example

Minor side effects may be purely some physical discomfort, such as headache and dizziness. Those are so scary, if they hit it, that is, for example, it may already affect the normal? Do things, that is, those in daily life, such as possible. Get up, even if it is already affected, well, if it is serious, you may not be able to fall into bed at all. Participant 008_2023AUHDV

Well, you know, like I said, I had a I had a sort of dull headache and I didn't feel the need to take anything. And then one night I had a more severe headache. But I just took two Panadol and I was fine and increased my water. So I drank a lot of water and I didn't have any severe.
Participant 010_2023AUHDV

Participant describes mild side effects as those that can be self-managed

So like you know you break out and I don't know you're a rash or something and that's like you you know for sure that that's come from the medication and it's not just you know some you know an allergic reaction or something else.
Participant 011_2023AUHDV

Participant describes mild side effects as those that resolve in a short time

I would say mild side effects would be as a result of, you know, taking this drugs and it's upset something. Maybe there's some changes in your system which as a result of a reaction to the drugs which you've taken and this is just temporary which will go away.
Participant 006_2023AUHDV

Table 5.21: Description of mild side effects

Description of mild side effects	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes mild side effects as those that do not interfere with daily life	6	50.00	1	16.67	5	83.33	3	37.50	3	75.00	3	50.00	3	50.00	1	100.00	5	45.45	1	100.00	5	45.45
Participant provides a specific side effect as an example	6	50.00	4	66.67	2	33.33	3	37.50	3	75.00	4	66.67	2	33.33	1	100.00	5	45.45	1	100.00	5	45.45
Participants reports not experiencing any mild side effects	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects as those that can be self-managed	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects as those that resolve in a short time	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

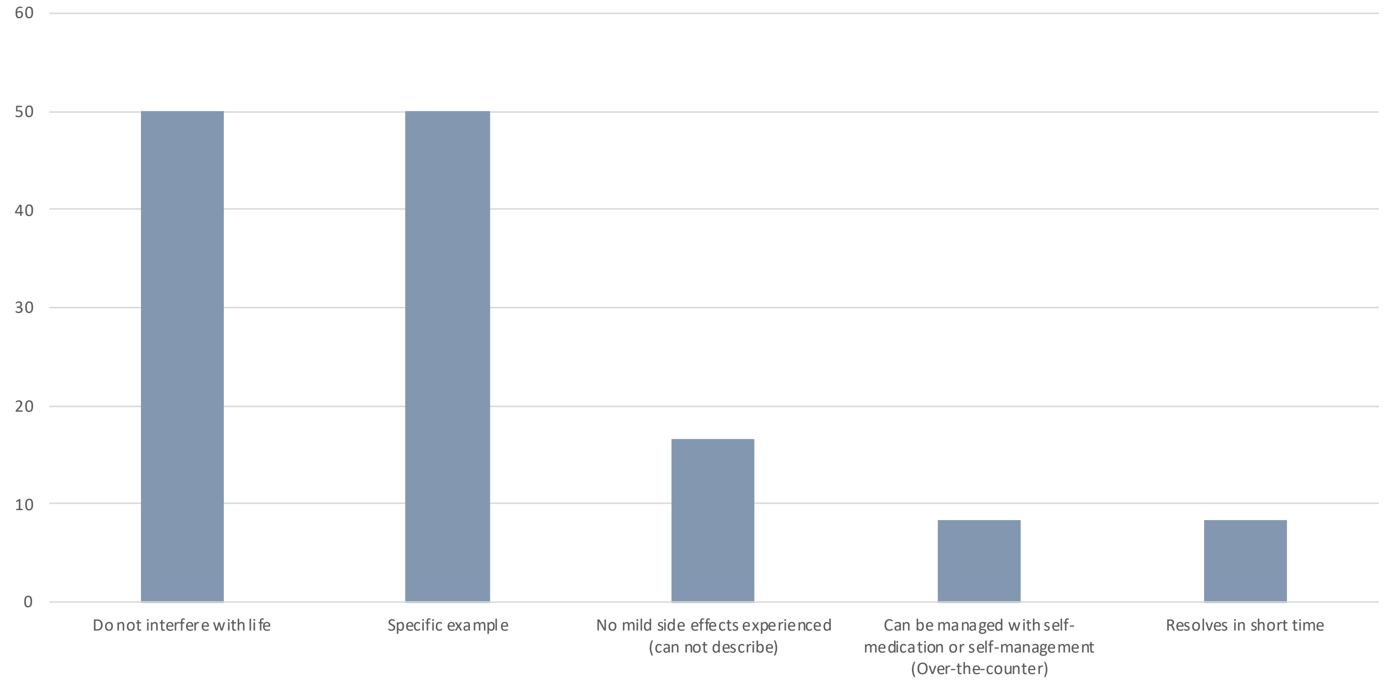

Figure 5.25: Description of mild side effects

Table 5.22: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant describes mild side effects as those that do not interfere with daily life	Female Aged 18 to 44	Male Aged 45 and older
Participant provides a specific side effect as an example	Male Aged 18 to 44 University	Female Aged 45 and older Trade or high school

Table 5.23: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes mild side effects giving the specific example of headaches	2	16.67	2	33.33	0	0.00	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects giving the specific example of a skin itch or rash	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects giving the specific example of aches/pain (general)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of emotion/mental impact	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of gastrointestinal distress	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes mild side effects giving the specific example of lightheaded and/or dizzy	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of nausea or loss of appetite	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of having a heavy period or low blood iron	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example low immunity	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

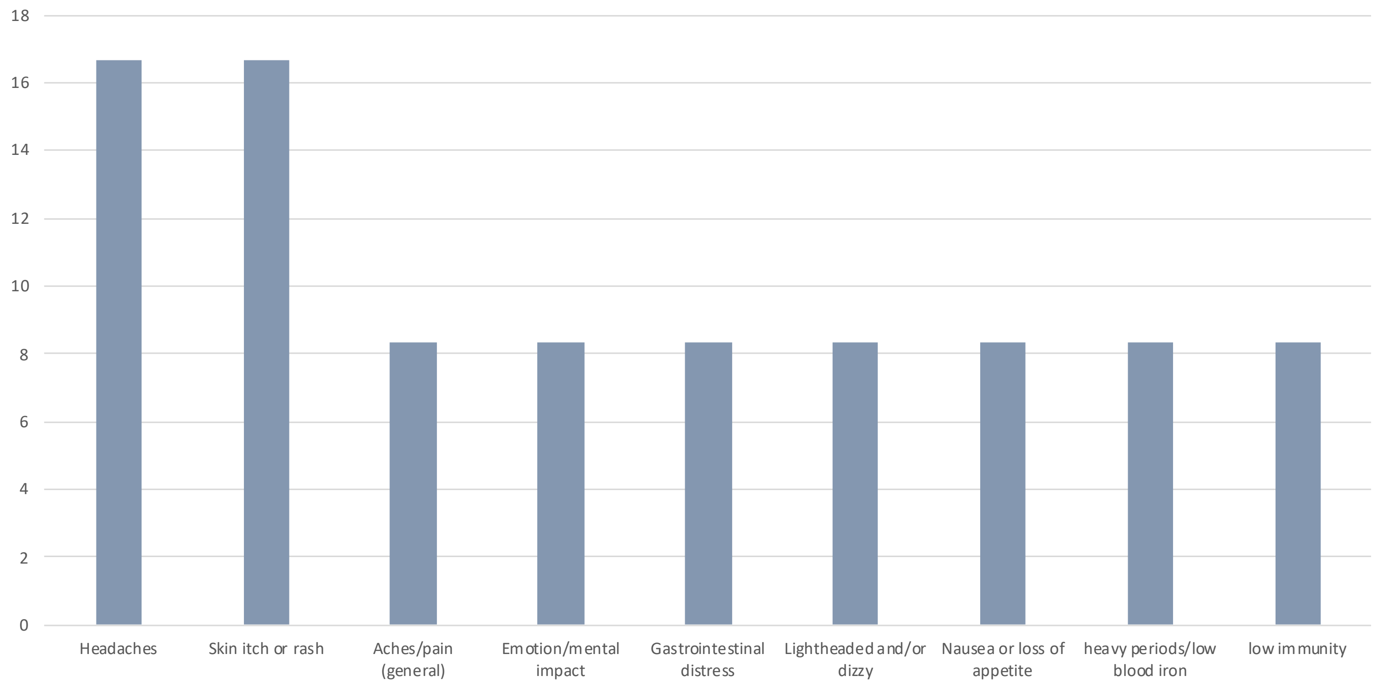

Figure 5.26: Description of mild side effects (Specific side effects)

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

Participant describes severe side effects as when treatment is worse than the condition

Severe side effects of medication would be something that makes it even worse.
Participant 004_2023AUHDV

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

Worst case scenario, allergy and an ambulance.
Participant 007_2023AUHDV

Participant identifies severe side effects as impacting their everyday life by being bed ridden

Participant describes those that cause long-term damage to their body

So yeah, where it's where it's, it's having a negative and again fairly like noticeable, measurable and immediate or long term impact on your quality of life. So it's, you know, it's it's it's having a negative impact. That's in terms of your mental health, in terms of pain and discomfort, in terms of the potential to cause other medical problems, that's what I'd call severe side effects.
Participant 011_2023AUHDV

Table 5.24: Description of severe side effects

Description of severe side effects	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participants reported not experiencing any severe side effects	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant provides a specific side effect as an example	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes severe side effects as when treatment is worse than the condition	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes severe side effects as those that are life threatening or result in hospitalisation	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes severe side effects as those that cause long-term damage to their body	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant identifies severe side effects as requiring medical intervention	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant identifies severe side effects as impacting their everyday life by being bed ridden	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other description/No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

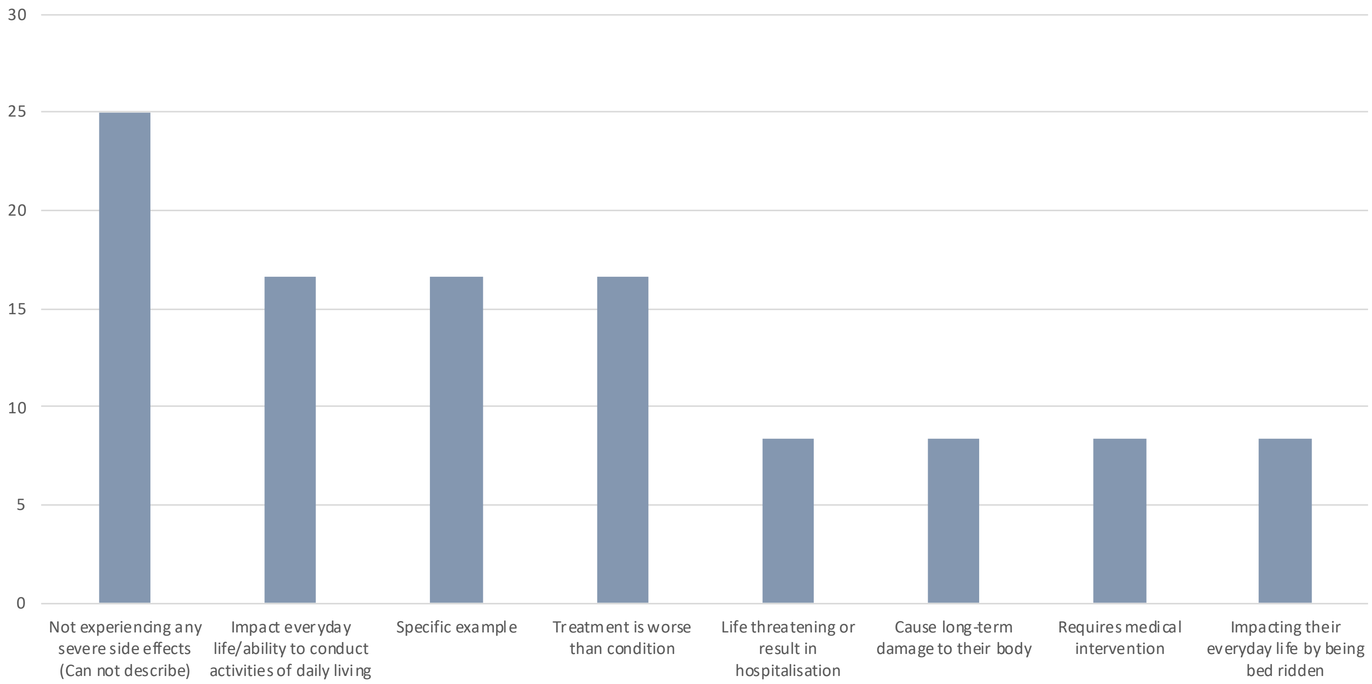

Figure 5.27: Description of severe side effects

Table 5.25: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes severe side effects giving the specific example of aches/pain (general)	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of emotion/mental impact	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of fatigue/lethargy	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of allergic reaction	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00

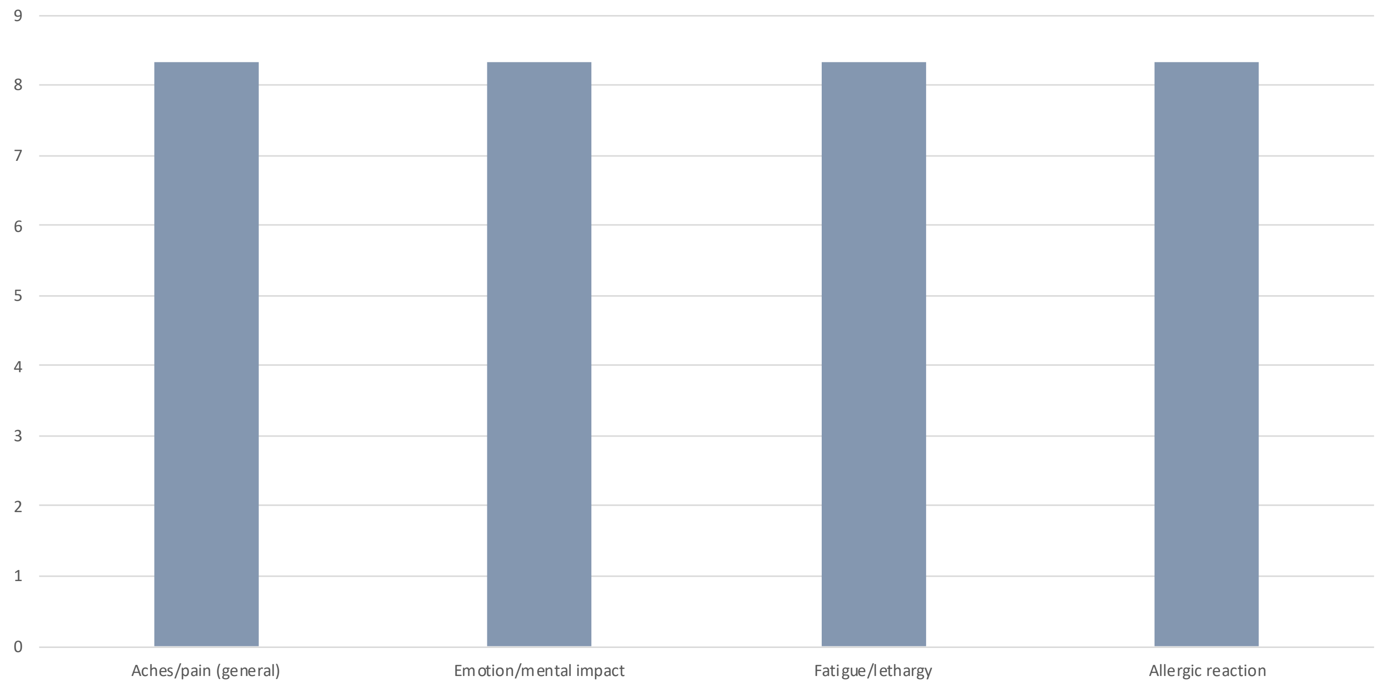

Figure 5.28: Description of severe side effects (Specific example)

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 according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

Well, if there's any new treatment, so I'll stick to it till my doctor says I have to stop it. So it's just based on my doctor.
Participant 006_2023AUHDV

Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment

I think what helps is the regular blood tests of monitoring the levels of what is happening with my body.
Participant 004_2023AUHDV

Participant describes adhering to treatment as long as side effects are tolerable

Well, I'm not that kind of person. If I get a if I get a a a treatment and I'm told to take it from the beginning to the end, I take it until it's finished. I never, I never stop unless unless it's giving me a severe side effect which really makes me ill, then I take it till it's finished.
Participant 010_2023AUHDV

Table 5.26: Adherence to treatment

Adherence to treatment	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	7	58.33	3	50.00	4	66.67	4	50.00	3	75.00	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	1	16.67	3	50.00	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes adhering to treatment as long as side effects are tolerable	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant is unable to answer because they have not had treatment and/or cannot answer hypothetical question	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

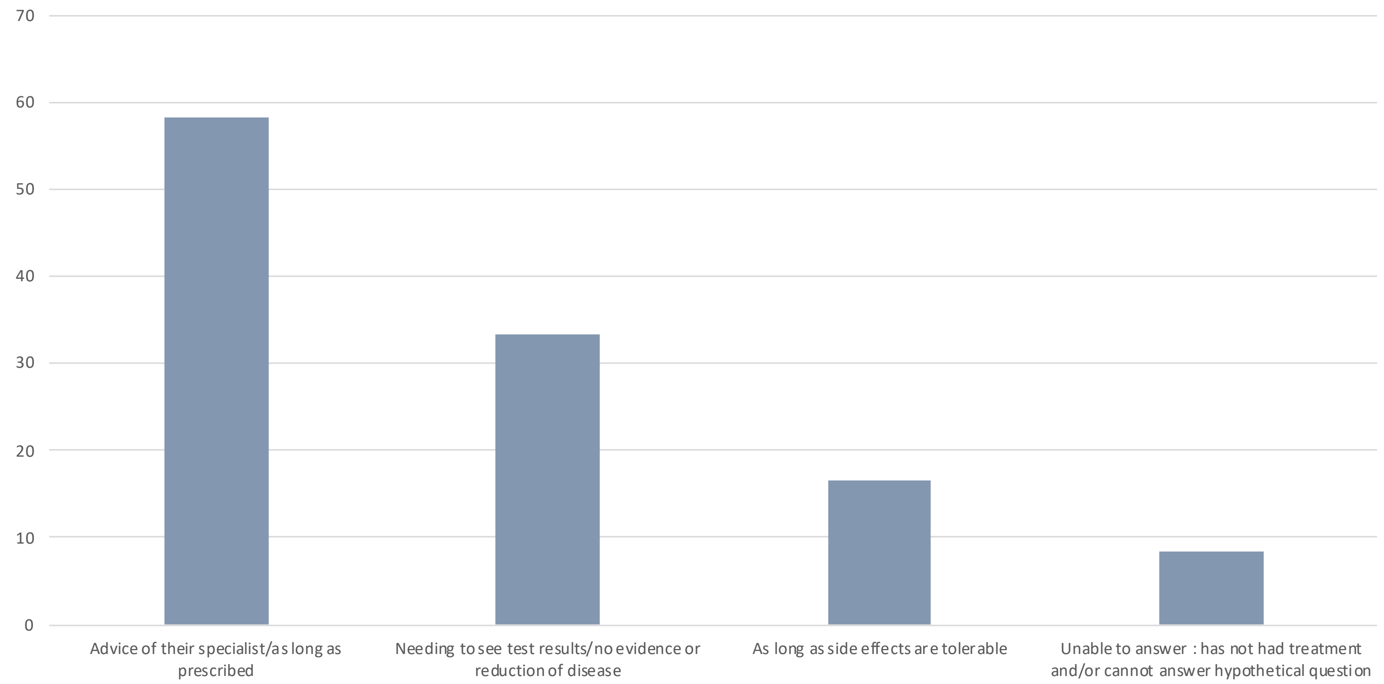

Figure 5.29: Adherence to treatment

Table 5.27: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	-	Aged 45 and older
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Trade or high school	Aged 45 and older University

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 physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33 %), and night sweats (8.33%).

Participants reported needing to see all physical signs and symptoms disappear

Well, I, I have, I have to experience a reduction in pains and a reduction in the symptoms that counts for me. If this is if this has been experienced when I take a part time medication, then I know that for sure it's it's working for me.
Participant 006_2023AUHDV

Participants reported needing to experience evidence of stable disease/no disease progression

As long as my mark is the same, I'm happy because long ago we came to realization my markers aren't going to improve, so as long as they're holding, I'm quite happy… so once they start to drop, that's when I'll start to get in a bit of a panic with doctors.
Participant 007_2023AUHDV

I think you just need to see some level of results and sometimes I think the blood test results are just a stronger indication of how I'm feeling day-to-day to attribute that. So I think the monitoring of the actual condition and knowing that, you know, when you do do my blood test, you are looking for viral load, you're looking for all the other impacts.
Participant 004_2023AUHDV

Table 5.28: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participants reported needing to see all physical signs and symptoms disappear	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participants reported needing to experience evidence of stable disease/no disease progression	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes needing to see a reduction in a specific symptom	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not having had any treatments that worked	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	5	41.67	4	66.67	1	16.67	4	50.00	1	25.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45

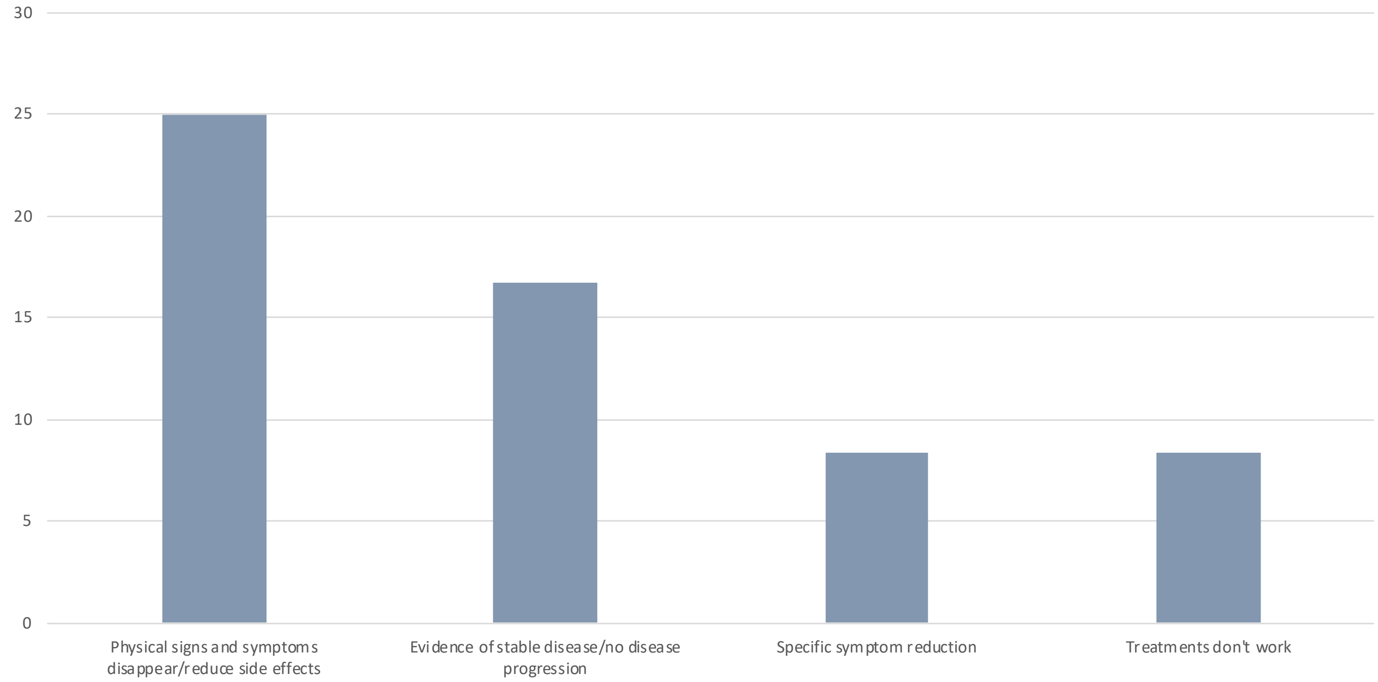

Figure 5.30: What needs to change to feel like treatment is working

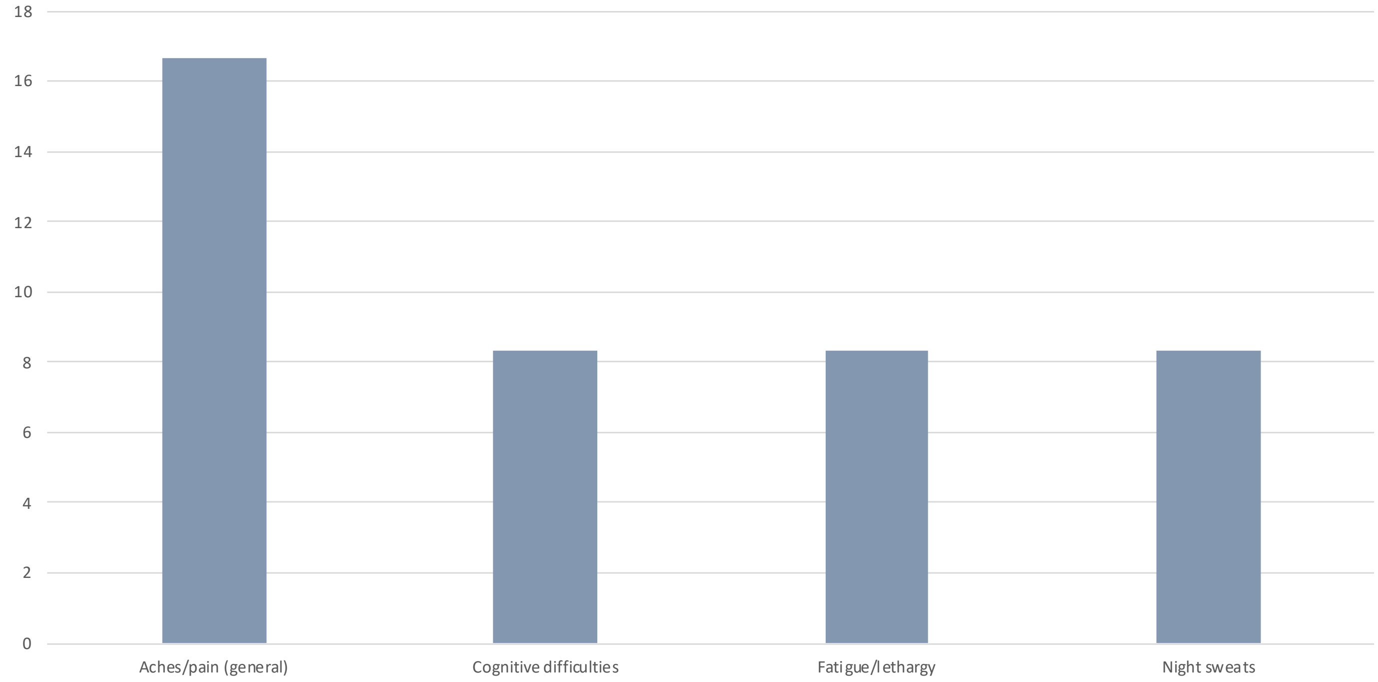

Figure 5.31: What needs to change to feel like treatment is working – specific symtoms

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/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life

Rest me, I would actually feel alive again and I would feel invincible and I would also feel that I have actually broken out of the virus and and then that I could actually go ahead and do whatever I want to do.
Participant 009_2023AUHDV

It's going to give me more energy. I won't have Brian Fog, I won't have aching limbs. I won't have night sweats. I'm, you know, I'm going to be a much more productive member of society and to my family.
Participant 011_2023AUHDV

Participant describes that if treatment worked, it would have a positive impact on their mental health

Well, it's it to be a very beautiful, you know, after experience for me to realize that the medication or drugs given is working because I know I'll be able to chat freely they the psychological stress that comes with, you know, having to bear in mind of this is quite heavy … every space in my thinking and everything. So I think to bring about a good a high degree of enough relief to me.
Participant 006_2023AUHDV

Participant describes that condition has not had an impact on their life

I've been fortunate in that I've I've maintained my energy levels, I'm still social. I get out and about, I can do things.
Participant 007_2023AUHDV

Table 5.29: What needit would mean if treatment worked

What it would mean if treatment worked	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	**3**	**50.00**	**1**	**16.67**	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes that if treatment worked, it would have a positive impact on their mental health	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes that if treatment worked, it would lead to a reduction in symptoms/side effects	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that if treatment worked, it would lead to less medical interventions/doctor visits/hospitalisation	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that condition has not had an impact on their life	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes that if treatment worked, it would allow them to live longer	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	4	33.33	3	50.00	1	16.67	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36

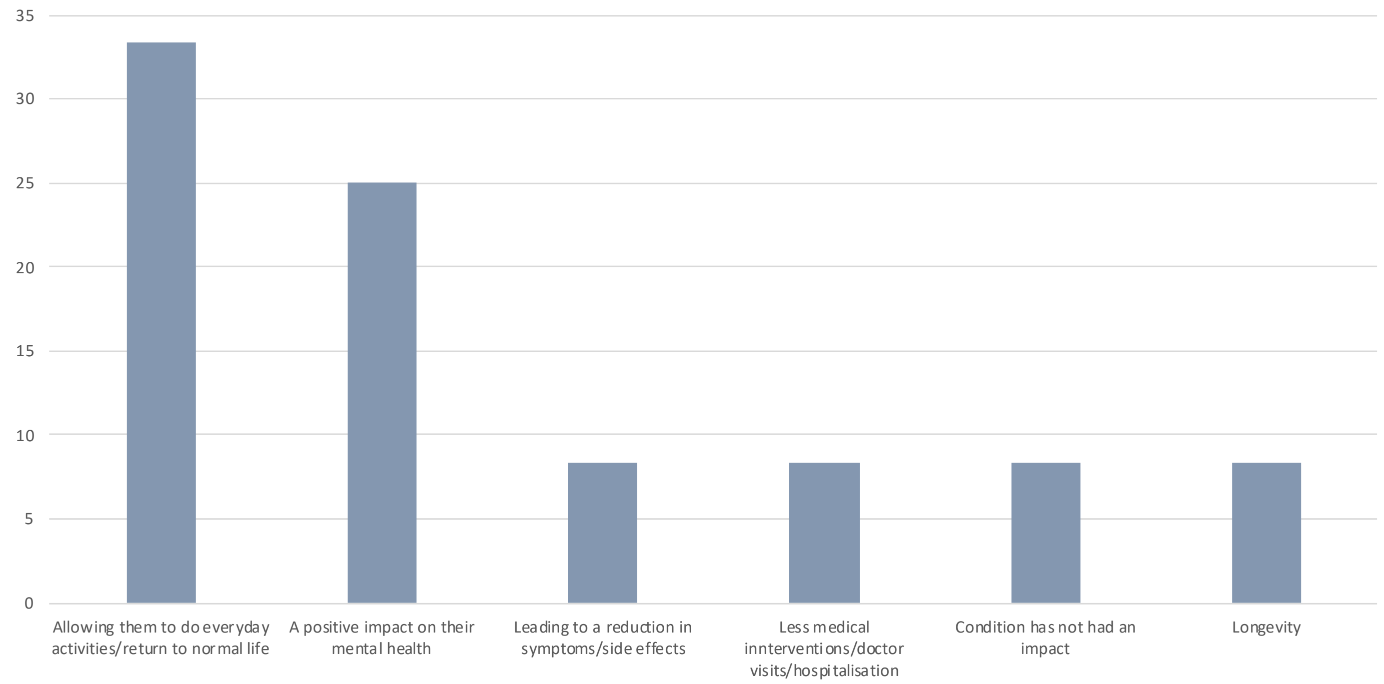

Figure 5.32: What needit would mean if treatment worked

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life	University	Trade or high school

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 their treating clinician (58.33%), the internet (41.67%), and health charities (25.00 %). Other sources included other patient's experience (Including support groups) (16.67%), books, pamphlets and newsletters (8.33%), and Facebook or social media (8.33%).

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 hearing what to expect (e.g. from disease, side effects, treatment) (58.33%), other people's experiences (Peer-to-peer)(25.00%), and talking to a doctor or specialist or healthcare team (25.00 %). Other helpful information included information from health charities (8.33%), information about lifestyle changes (8.33%), and information about transmission (8.33%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that there was no information that wasnot helpful (50.00%). Information that was not helpful included and a lack of new information (16.67%), information from their GP or specialist (8.33%), sources that are not credible (not evidence-based) (8.33%), information that is not comprehensive (8.33%), and information that is accompanied with stigma and discrimination (8.33%).

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 (33.33%), and talking to someone plus online information (33.33%). Other preferences included online information (16.67%), all forms (16.67%), and written information (8.33%).

The main reasons for a preference for online information were that it is personalised and relevant (41.67%), being able to\have time to ask questions (Talking to someone) (25.00%), and No strong reason for preference\Personal preference (25.00 %). Other themes included Accessibility (Internet) (16.67%), Being able to digest information at their own pace (Internet) (8.33%),written information because you can refer back to/highlight important information (8.33%), and online information because it is reliable information and you are able to decide if trustworthy (8.33%).

The main reasons for a preference for online information was because of the ease of accessibility (16.67%), because it is personalised and relevant (16.67%), because it is reliable information and you are able to decide if trustworthy (8.33%), and because they are able to digest information at their own pace information at their own pace (8.33%).
The main reasons for a preference for talking to some one because they are able to ask questions (25.00%), and because it is personalised and relevant (25.00%).
The main reasons for a preference for written information because you can refer back to/highlight important information (8.33%)

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) (33.33%), and continuously (25.00%). Other times included after the shock of diagnosis (16.67%), when something needs treatment/attention/change in management (16.67%), and at a specific time in the day (8.33%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Half of the participants described communication as overall negative (50.00%), a quarter described communication as overall negative (25.00%), 16.67% had overall positive communication with the exception of one or two occasions, and 8.33% had a mix of both positive and negative communication.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had negative communication, described the reason for this was because of dismissive one way conversations (25.00%), communication was limited in time (25.00%), communication was limited in understanding (8.33%), healthcare professionals used difficult medical terms (8.33%), participants felt disrespected vulnerable (8.33%), and that information that was withheld or not freely given (8.33%).

Participants that had positive communication, described the reason for this was because of holistic two way, supportive and comprehensive conversation) (25.00%).

Partners in 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 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 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 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.

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=10, 76.92%), and 1 participant (7.69%) responded that they took medicines as prescribed most of the time. There were 2 participants (15.38%) that sometimes took medicines 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=10, 76.92%), disease management (n=7, 53.85%), interpret test results (n=5, 38.46%) and, psychological/ social support (n=4, 30.77%) were most frequently given to participants by healthcare professionals, and, information about dietary (n=2, 15.38%), hereditary considerations (n=2, 15.38%) and, complementary therapies (n=1, 7.69%) were given least often.

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 treatment options (n=7, 53.85%), disease management (n=7, 53.85%), disease cause (n=5, 38.46%) and, complementary therapies (n=5, 38.46%) were most frequently given to participants by healthcare professionals, and, information about physical activity (n=4, 30.77%), hereditary considerations (n=2, 15.38%) and, clinical trials (n=1, 7.69%) 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=10, 76.92%) and Pphysical activity (n=10, 76.92%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=4, 30.77%) and disease cause (n=3, 23.08%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=6, 46.15%) and disease management (n=6, 46.15%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=5, 38.46%) and complementary therapies (n=4, 30.77%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Medical journals and from Pharmaceutical companies were least accessed.

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 their treating clinician (58.33%), the internet (41.67%), and health charities (25.00 %). Other sources included other patient's experience (Including support groups) (16.67%), books, pamphlets and newsletters (8.33%), and Facebook or social media (8.33%).

Participant describes primarily accessing information through treating clinician

I wouldn't say I've actually sought out information. It's been more I've picked up information along the way through discussion with doctors and nurses and all that. I do have some knowledge, but I wouldn't say that I've actually gone and specifically looked for it. It's what I've accumulated over the years.
Participant 007_2023AUHDV

Participant describes accessing information through the internet in general

Just read about it, you know in general like just go on the computer Google about it and then learn about it. Yeah that's when I get to know that it affect the liver.
Participant 001_2023AUHDV

Participant describes primarily accessing information through other patient's experience

I actually to read through people's experience, you know, to get us some clue and knowledge about what the thing is all about. So it's was mostly largely from the Internet. I got an idea of what this is. 006_2023AUHDV

The doctor gave me information in pamphlet form. I sought out a general support group. I think we should have more of them for all the different types of hepatitis.
Participant 010_2023AUHDV

Participant describes not seeking/researching information extensively

None
Participant 005_2023AUHDV

Participant describes receiving information from books, pamphlets and newsletters

Maybe I got some pamphlets.
Participant 002_2023AUHDV

Table 6.1: Access to information.

Access to information	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes primarily accessing information through treating clinician	7	58.33	4	66.67	3	50.00	4	50.00	**3**	**75.00**	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes accessing information through the internet in general	5	41.67	3	50.00	2	33.33	4	50.00	**1**	**25.00**	2	33.33	3	50.00	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes accessing information from a specific health charity	3	25.00	1	16.67	2	33.33	1	12.50	2	50.00	3	50.00	0	0.00	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes primarily accessing information through other patient's experience	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes not seeking/researching information extensively	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes receiving information from books, pamphlets and newsletters	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes accessing information primarily through Facebook and/or social media	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

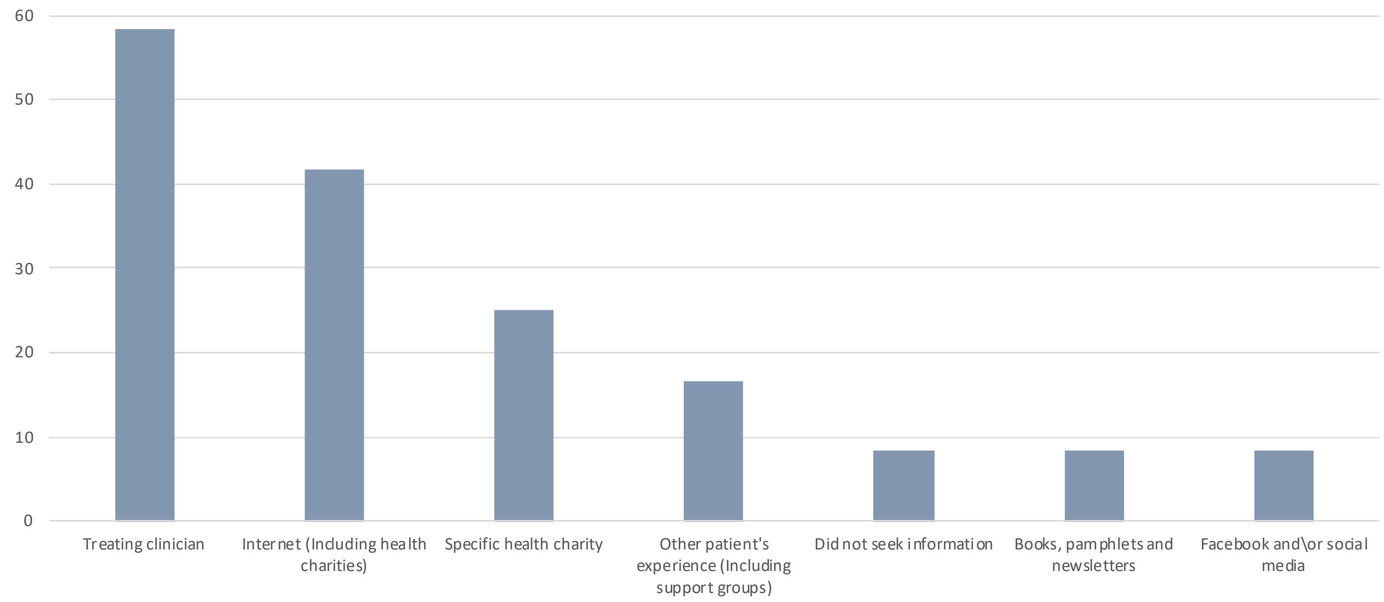

Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes primarily accessing information through treating clinician	-	Aged 45 and older
Participant describes accessing information through the internet in general	Aged 45 and older	-

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 hearing what to expect (e.g. from disease, side effects, treatment) (58.33%), other people's experiences (Peer-to-peer)(25.00%), and talking to a doctor or specialist or healthcare team (25.00 %). Other helpful information included information from health charities (8.33%), information about lifestyle changes (8.33%), and information about transmission (8.33%).

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

Explaining how is the condition, what happens with the treatment. For the kind of treatment is best. That's it.
Participant 005_2023AUHDV

Participant describes other people's experiences as helpful (Peer-to-peer)

Yeah, I certainly, you know, more like the same terms and people, you know, having to comment on their experience and what they did. I think this guided me a lot.
Participant 006_2023AUHDV

Participant describes talking to their doctor or specialist as helpful

I mean the only stuff that I really tend to look into is actual medication and the research that's been done and the the side effects and that that's about the the major thing that I I do tend to look into and apart from that…I tend to just soak it up from talking to specialists and that.
Participant 007_2023AUHDV

I think it's a it's a combination and then the information gleaned from my specialists and viral hepatitis nurses and from other people within the hepatitis community who know their stuff.
Participant 010_2023AUHDV

Participant describes health charities information as helpful

I would say the information located on the Hep website, I think it's a great overview and you can pass that to people that. Need to know, I need to teach themselves about it, because talking to potential partners about it, for some people it's a very big deal and it's it's a huge deal for them. For other people, it hasn't been a big deal… I guess the stigma from that.
Participant 004_2023AUHDV

Table 6.3: Information that was helpful

THEME	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	7	58.33	3	50.00	4	66.67	6	75.00	1	25.00	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes other people's experiences as helpful (Peer-to-peer)	3	25.00	1	16.67	2	33.33	1	12.50	2	50.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes talking to their doctor or specialist as helpful	3	25.00	2	33.33	1	16.67	0	0.00	3	75.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes health charities information as helpful	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes information about lifestyle changes as helpful	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes information about transmission of virus as helpful	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

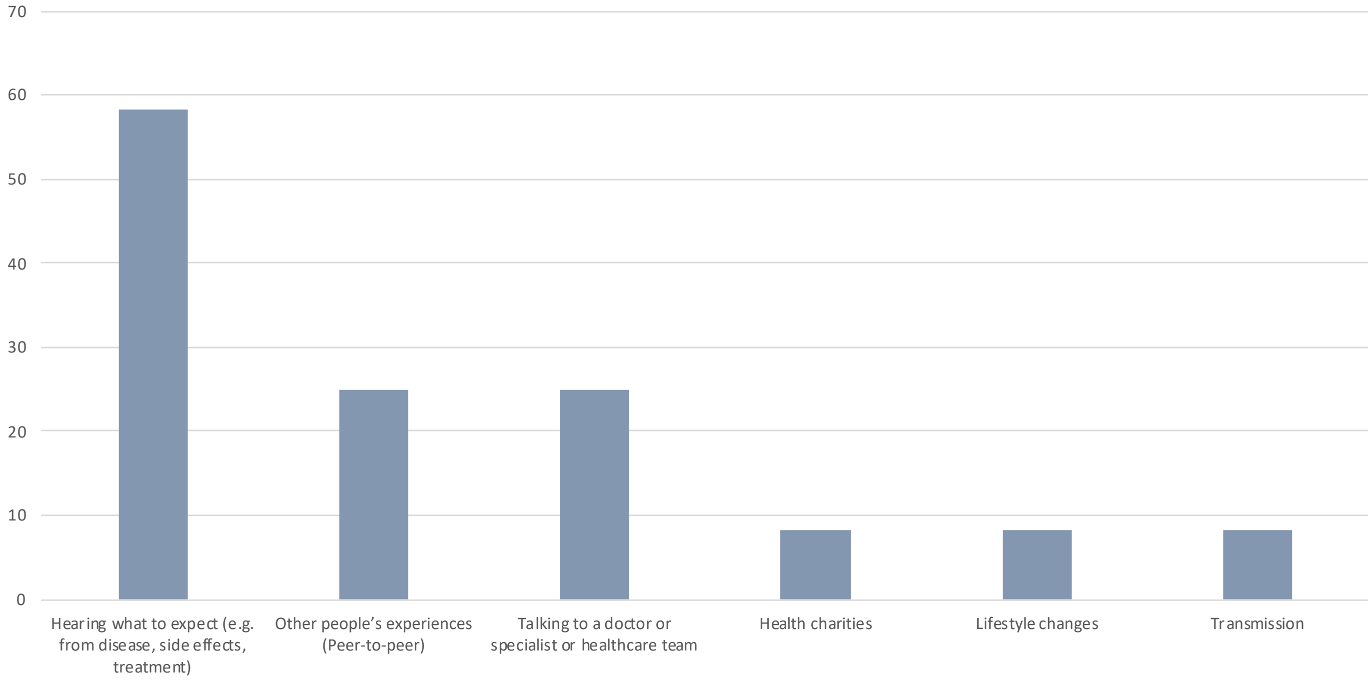

Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Aged 45 and older	Aged 18 to 44

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that there was no information that wasnot helpful (50.00%). Information that was not helpful included and a lack of new information (16.67%), information from their GP or specialist (8.33%), sources that are not credible (not evidence-based) (8.33%), information that is not comprehensive (8.33%), and information that is accompanied with stigma and discrimination (8.33%).

Participant describes no information being not helpful

Yeah, everything was helpful. Actually it was all helpful.
Participant 001_2023AUHDV

Participant describes a lack of new information as not helpful

There's a lot I would say out there online that hasn't been helpful when. When those have gone searching the facts that they came up with and put in front of me really made me question like how is that true and how is that accurate? So I would give them a bit more, something a bit more accredited, but yeah, I think whether the information was out of date. I'm not sure,

but I think that was definitely a hard part to counterbalance.
Participant 004_2023AUHDV

That's a good question. Not that the others have any good questions, but that is a good question. I'm drawing a blank on that one, I mean. Okay. So like in terms of when I was diagnosed, I don't feel like I was given adequate information and you know, some of what I was told might have been out of date about specifically about sexual transmission. Yeah, so I've encountered. I've encountered bad information.
Participant 011_2023AUHDV

Participant describes feeling confident in deciding if something is not helpful (or not credible)

Well, any information that wasn't helpful to me during this. I just simply choose to ignore.
Participant 006_2023AUHDV

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher statu	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes no information being not helpful	6	50.00	4	66.67	2	33.33	4	50.00	2	50.00	3	50.00	3	50.00	1	100.00	5	45.45	1	100.00	5	45.4
Participant describes a lack of new information as not helpful	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.1
Participant describes feeling confident in deciding if something is not helpful (or not credible)	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.0
Participant describes the GP/specialist as being not helpful	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.0
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.0
Participant describes information that is not comprehensive as being not helpful	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.0
Participant describes information that is discriminatory or given with a sense of stigma as not helpful	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.0
Other\No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.0

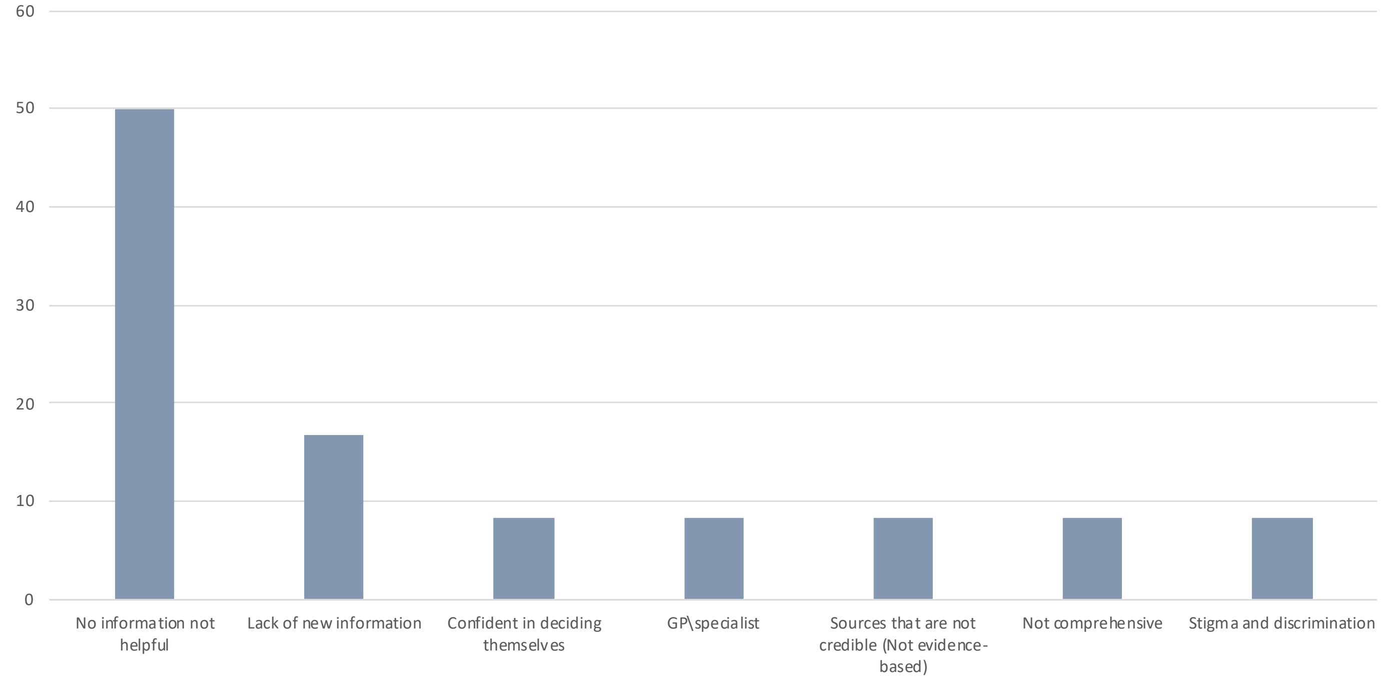

Figure 6.3: Information that was not helpful

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	Male	Female

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 (33.33%), and talking to someone plus online information (33.33%). Other preferences included online information (16.67%), all forms (16.67%), and written information (8.33%).

The main reasons for a preference for online information were that it is personalised and relevant (41.67%), being able to\have time to ask questions (Talking to someone) (25.00%), and No strong reason for preference\Personal preference (25.00 %). Other themes included Accessibility (Internet) (16.67%), Being able to digest information at their own pace (Internet) (8.33%),written information because you can refer back to/highlight important information (8.33%), and online information because it is reliable information and you are able to decide if trustworthy (8.33%).

The main reasons for a preference for online information was because of the ease of accessibility (16.67%), because it is personalised and relevant (16.67%), because it is reliable information and you are able to decide if trustworthy (8.33%), and because they are able to digest information at their own pace information at their own pace (8.33%).

The main reasons for a preference for talking to some one because they are able to ask questions (25.00%), and because it is personalised and relevant (25.00%).
The main reasons for a preference for written information because you can refer back to/highlight important information (8.33%)

Talking to someone as main preference

I'd probably prefer speaking to someone and you know that someone would be an expert or a specialist. The reason why is just simply you can interrogate for one of a better word. You know, you can prod, you can ask questions, you can ask questions about those questions, you can drill down. Participant 011_2023AUHDV

Talking to someone plus online information as main preference

Yeah, I kind of feel comfortable and I'm convenient with that talking on phone or online it actually. Makes me feel more, should I say comfortable?
Participant 009_2023AUHDV

I think it needs to be a combination of things, the online is a very good option and search option for people initially and especially depending if there's barriers with English and other things. Yeah, that is one good option, but I think the conversation.
Participant 004_2023AUHDV

Online information as main preference

Well, I I largely prefer online information because it's easily accessible, you can access it from anywhere at any time and you know, having to compare and hear from people who are first and who are first and experience about this is also helpful because the ideas and what they went through all brought together would provide a huge knowledge that can, you know, guiding the one through the process and you know, it's easily accessible.
Participant 006_2023AUHDV

All forms

Just like a combination of the three, yes, you know, and because I like to do my research in all different areas, both verbally, online and in hard copy.
Participant 010_2023AUHDV

Written information as main preference

Prefer. I actually prefer to be able to sit and talk with the doctors and nurses and that and then secondary to that would be information booklets that you can take away. But generally I'll just have the conversation and that's. That's enough for me to get what I feel I need to know.
Participant 007_2023AUHDV

Rationale for preference is due to being able to/have time to ask questions

I think you sending me the online information then you do a follow up with a call that would be better. At least I can read, I can start reading and understand when you call like this, at least I can. We can discuss and I can ask some questions, but I need to read first.

Yeah. So if I get some information, read about it, understand it, then after that you give me a call. At least we can talk. When I can ask you questions that don't understand, at least you can clarify to me.
Participant 001_2023AUHDV

Rationale for preference is due to accessibility

Well, I I largely prefer. Online information because it's easily accessible, you can access it from anywhere at any time and you know, having to compare and hear from people who are first and who are first and experience about this is also helpful because the ideas and what they went through all brought together would provide a huge knowledge that can, you know, guiding the one through the process. And you know, it's easily accessible.
Participant 006_2023AUHDV

Rational for written preference is because you can refer back to/highlight important information

Prefer. I actually prefer to be able to sit and talk with the doctors and nurses and that and then secondary to that would be information booklets that you can take away. But generally I'll just have the conversation and that's. That's enough for me to get what I feel I need to know.
Participant 007_2023AUHDV

Rational for online preference is because it is reliable information and you are able to decide if trustworthy

I can compare it myself, that is, the general content, same. Some websites are similar to the official ones, so I will feel more reliable.
Participant 008_2023AUHDV

Table 6.7: Information preferences

Information preferences	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Talking to someone as main preference	4	33.33	**1**	**16.67**	**3**	**50.00**	2	25.00	**2**	**50.00**	**3**	**50.00**	**1**	**16.67**	1	100.00	3	27.27	1	100.00	3	27.27
Talking to someone plus online information as main preference	4	33.33	2	33.33	2	33.33	**4**	**50.00**	**0**	**0.00**	**1**	**16.67**	**3**	**50.00**	0	0.00	4	36.36	0	0.00	4	36.36
Online information as main preference	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
All forms	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Written information as main preference	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00

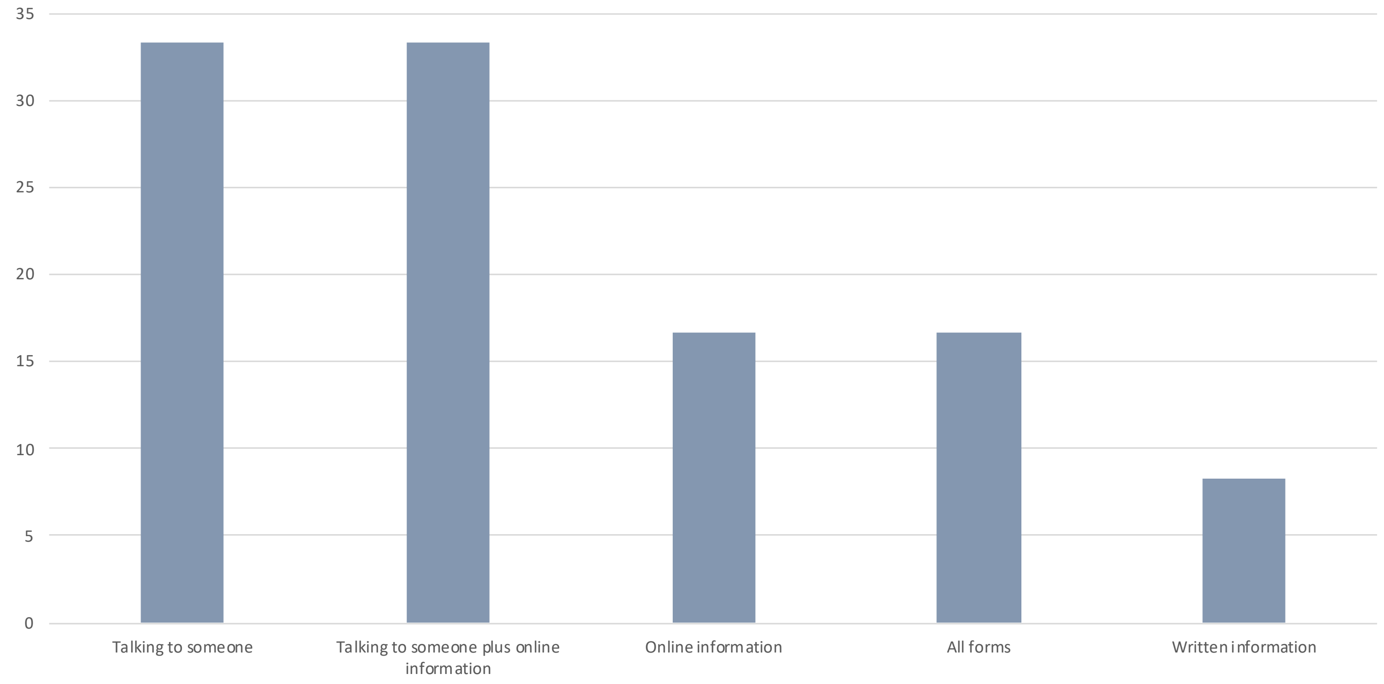

Figure 6.4: Information preferences

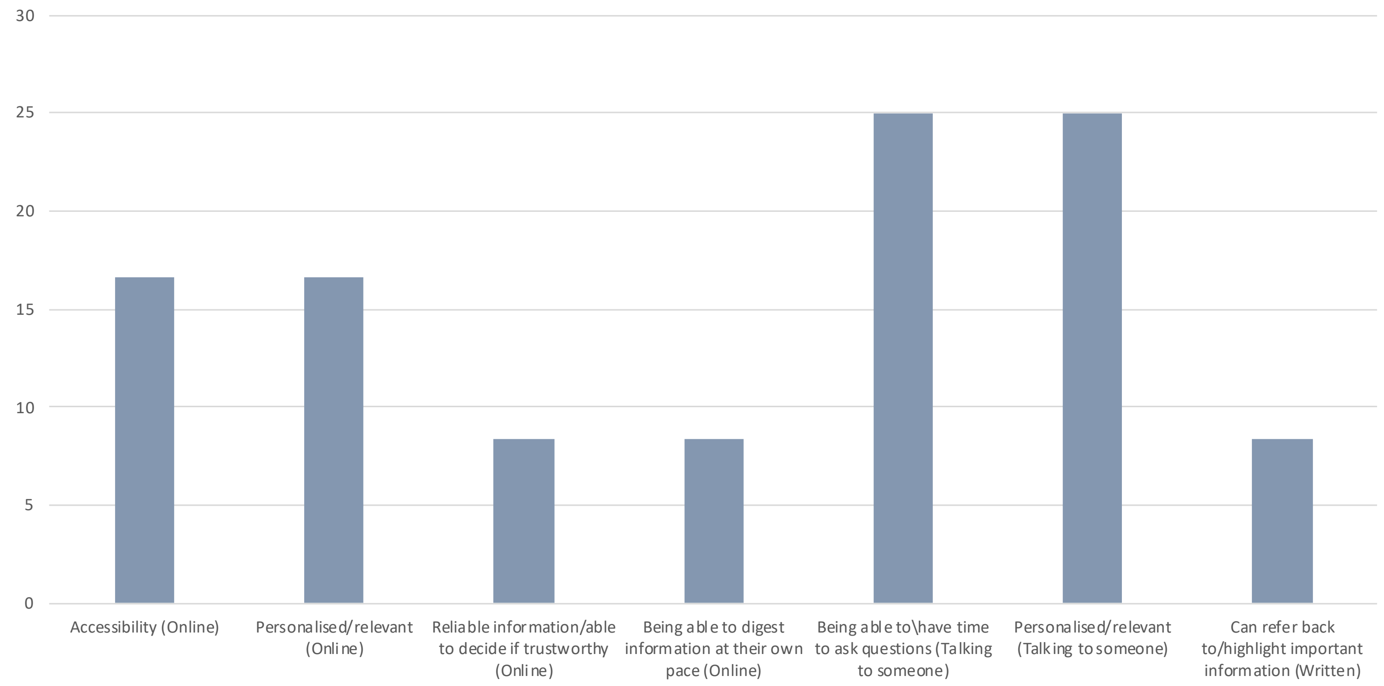

Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Talking to someone as main preference	Female University	Male Aged 45 and older Trade or high school
Talking to someone plus online information as main preference	Aged 45 and older Trade or high school	Aged 18 to 44 University

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) (33.33%), and continuously (25.00%). Other times included after the shock of diagnosis (16.67%), when something needs treatment/attention/change in management (16.67%), and at a specific time in the day (8.33%).

Participant describes being receptive from the beginning (diagnosis)

Okay for me, I will say. Yeah and the initial stage of my diagnose, yeah.
Participant 009_2023AUHDV

I think, I think when I was diagnosed, I just wanted to learn absolutely everything I could possibly learn about hepatitis and what my options were. But yeah, I think I was pretty receptive from then on.
Participant 010_2023AUHDV

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

I don't know. I think if I have a condition, any information that comes to me would be useful to understand and to take better action.
Participant 005_2023AUHDV

Participant describes being receptive to information after the shock of diagnosis

Well, it it was actually, you know, days of come and diagnosed I would say weeks or that I could you know get to learn more and and do more because I was strictly, you know, following the guide from a doctor…I just had to follow the guide from the Doctor. So it took a while before I could, you know, make research on my own.
Participant 006_2023AUHDV

Participant describes being receptive to information when something needs treatment/attention/change in management

I think. In our case, again, it's always in the background, so it never really pay attention until the GP said the blood is abnormal…and I think that's the period we try to learn more about hepatitis. Okay, again, how to control it? And if we don't fail to do so, what? We're helping, yes.
Participant 003_2023AUHDV

Table 6.9: Timing of information

Timing of information	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being receptive from the beginning (diagnosis)	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes being receptive to information after the shock of diagnosis	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being receptive to information when something needs treatment/attention/change in management	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes being receptive to information at a specific time in the day	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

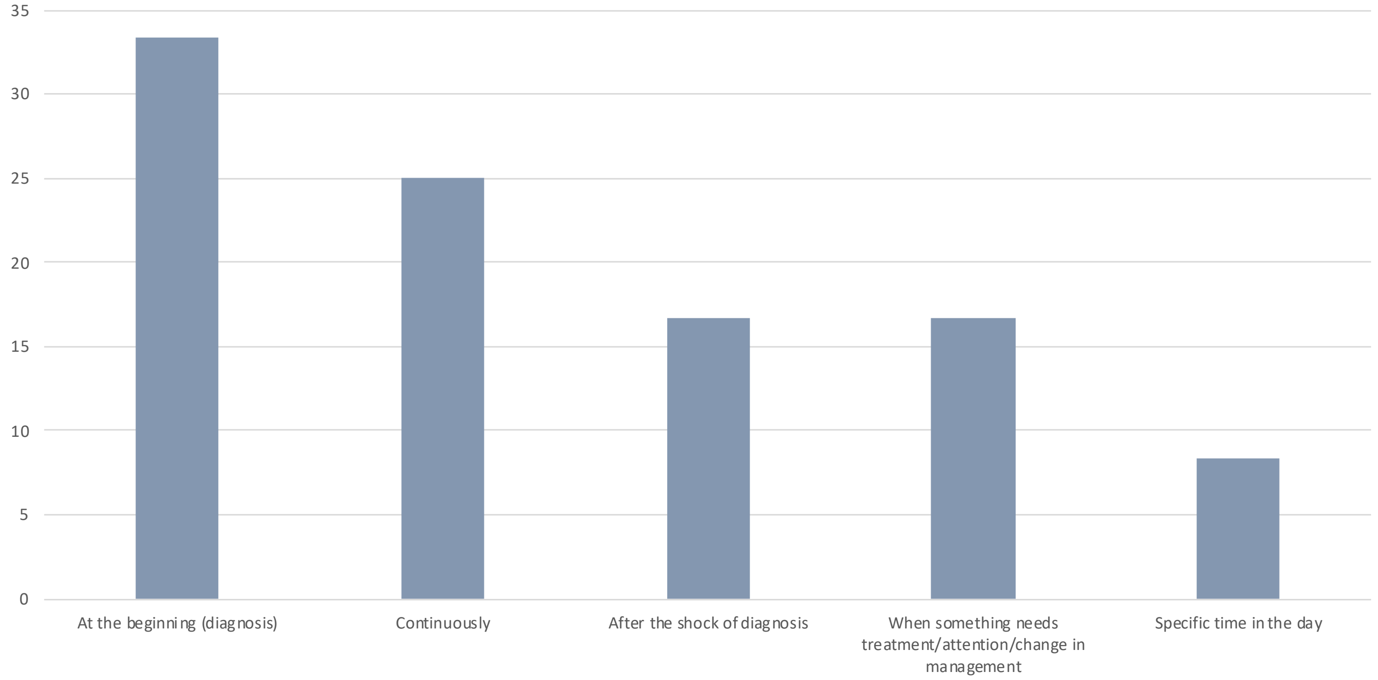

Figure 6.6: Timing of information

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Half of the participants described communication as overall negative (50.00%), a quarter described communication as overall negative (25.00%), 16.67% had overall positive communication with the exception of one or two occasions, and 8.33% had a mix of both positive and negative communication.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had negative communication, described the reason for this was because of dismissive one way conversations (25.00%), communication was limited in time (25.00%), communication was limited in understanding (8.33%), healthcare professionals used difficult medical terms (8.33%), participants felt disrespected vulnerable (8.33%), and that information that was withheld or not freely given (8.33%).

Participants that had positive communication, described the reason for this was because of holistic two way, supportive and comprehensive conversation) (25.00%).

Overall negative

PARTICIPANT: I don't feel satisfied.
INTERVIEWER: Why is that?
PARTICIPANT: Well, I feel the need to relate with someone. Someone that adds them wide knowledge about the situation. You know, frequently, not until I go to the office or something like, you know, I feel like I could, should stay out and communicate when I have to talk to someone, OK.
Participant 006_2023AUHDV

PARTICIPANT: Put very poor down. They don't listen.
Participant 012_2023AUHDV

Overall positive

Yeah, I'm happy. Actually, I am happy. It was very just to interpret my results because what I do is I do the my blood test and my liver thing before I got there, before I got there. So when I got there, they just interpret my result that I know this result, they're all good. This is your liver stuff is all good or good or good or good? How are you feeling? Then I'll just say, yeah, I'm still OK. I'm OK really. That's it. I'll see you next year. That's all.
Participant 001_2023AUHDV

I've had very good communication with them because I don't believe in the doctors, the gods, and I'll say that to their face. So they. They have a healthy respect for me and they know if I'm asking something, I'm not being frivolous, so having that sort of even playing field, even though they're a specialist, makes it a lot easier to transfer information and discuss results and all that sort of stuff.
Participant 007_2023AUHDV

Overall positive, with the exception of one or two occasions

I think we're just learning every time, yes, but I think it's quite. Good. Sometimes they use very difficult terms.
Participant 003_2023AUHDV

I've I've found most of all the health professionals communication was very positive.
Participant 010_2023AUHDV

A mixture of positive and negative

I think that me it's been really hard because I felt. A lot of shame for it that I'm not necessarily, I would say it's only recently in the last year that I've been able to ask more questions from my health professional. Not just taking it as you're fine, come back and see me in 6 to 12 months. I've been able to get more involved and learn how to be more involved in my health to actually ask some questions like when I asked 'do I have hepatitis D, can you test me for it?' So to learn more about that of where that's at, the viral loads and stuff I'm not great at tracking or understand…But yeah, I think when I've asked those questions they've been a bit more surprised of the engagement. But I would say the thing that I do understand and struggle with with the public sector is I have seen so many different doctors that I've never had a consistent specialist across the board and I can also understand that that is the way that hospitals do staffing, but it doesn't give the ability to build rapport.
Participant 004_2023AUHDV

Table 6.10: Healthcare professional communication.

Healthcare professional communication	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher stat	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Overall negative	6	50.00	**2**	**33.33**	**4**	**66.67**	**5**	**62.50**	**1**	**25.00**	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.5
Overall positive	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.1
Overall positive, with the exception of one or two occasions	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.1
A mixture of positive and negative	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.0
No response	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.0

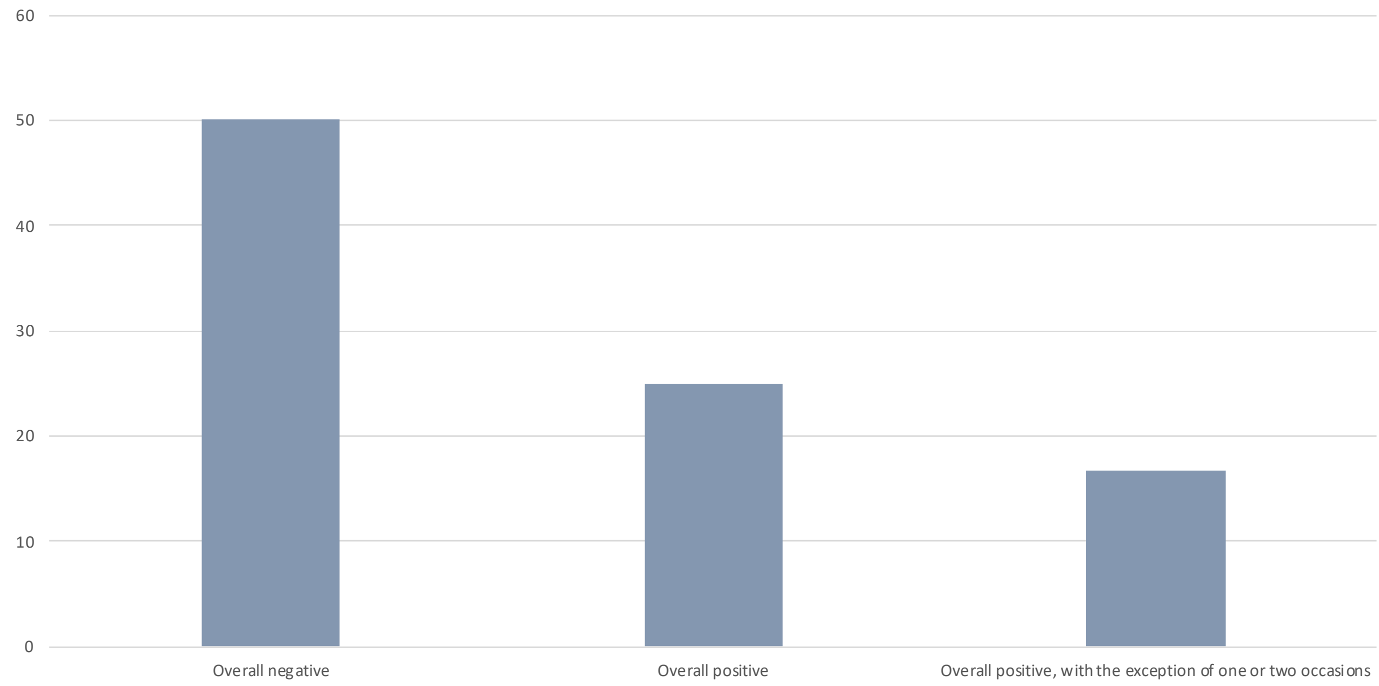

Figure 6.7: Healthcare professional communication

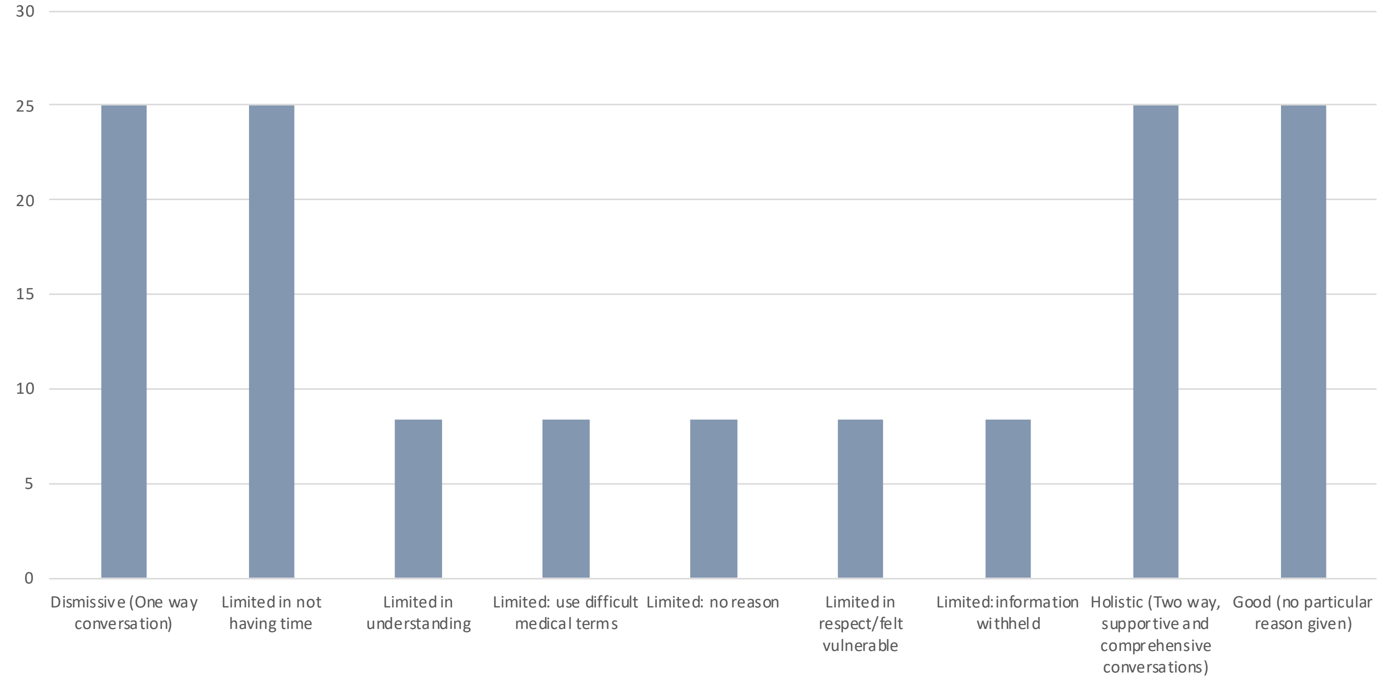

Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.11: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Overall negative	Female Aged 45 and older	Male Aged 18 to 44

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 Table 6.13.

The overall scores for the cohort were in the second highest quintile for Partners in health: Knowledge (mean=22.62, SD=6.70), Partners in health: Coping (mean=17.08, SD=4.70), Partners in health:

Recognition and management of symptoms (mean=18.23, SD=4.32), Partners in health: Adherence to treatment (mean=10.85, SD=5.13), Partners in health: Total score (mean=68.77, SD=17.70) indicating good knowledge, good coping, good recognition and management of symptoms, good adherence to treatment, good overall ability to manage their health

Comparisons of Partners in Health have been made based on gender, age, education, location and socioeconomic status (Tables 6.13 to 6.18, Figures 6.9 to 6.23).

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 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 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 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 6.12: Partners in health summary statistics

Partners in health scale (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge*	22.62	6.70	26.00	12.00	0 to 32	4
Coping*	17.08	4.70	17.00	5.00	0 to 24	4
Recognition and management of symptoms*	18.23	4.32	19.00	6.00	0 to 24	4
Adherence to treatment*	10.85	5.13	11.00	8.00	0 to 16	4
Total score*	68.77	17.70	67.00	23.00	0 to 96	4

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

Partners in health by gender

Comparisons were made by Gender, there were 6 female participants (46.15%), and 7 male participants (53.85%).

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 Partners in health scales.

Table 6.13: Partners in health by gender summary statistics and and T-test

Partners in health scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Knowledge	Female	6	46.15	22.67	7.99	0.02	11	0.9809
	Male	7	53.85	22.57	6.05			
Coping	Female	6	46.15	17.67	6.50	0.40	11	0.6939
	Male	7	53.85	16.57	2.88			
Recognition and management of symptoms	Female	6	46.15	18.67	5.05	0.32	11	0.7522
	Male	7	53.85	17.86	3.98			
Adherence to treatment	Female	6	46.15	9.33	6.44	-0.98	11	0.3466
	Male	7	53.85	12.14	3.72			
Total score	Female	6	46.15	68.33	21.95	-0.08	11	0.9387
	Male	7	53.85	69.14	14.99			

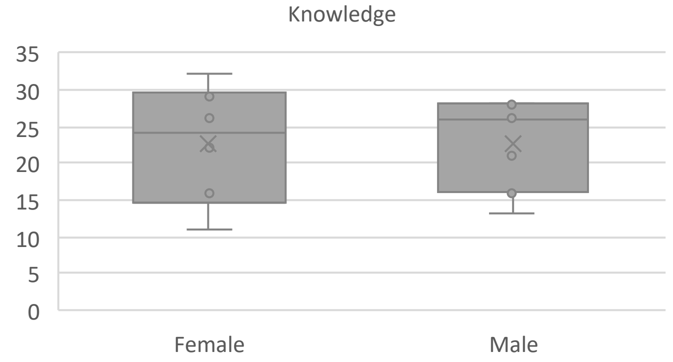

Figure 6.9: Boxplot of Partners in health: knowledge by gender

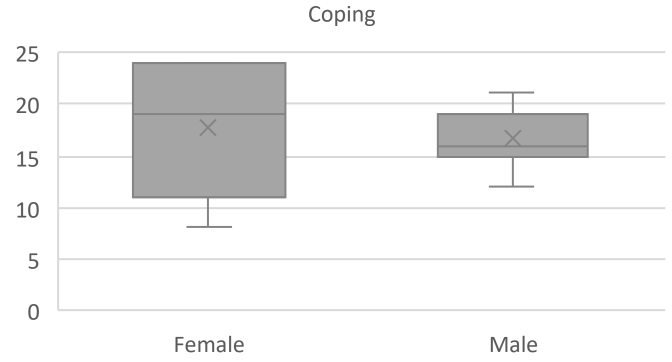

Figure 6.10: Boxplot of Partners in health: coping by gender

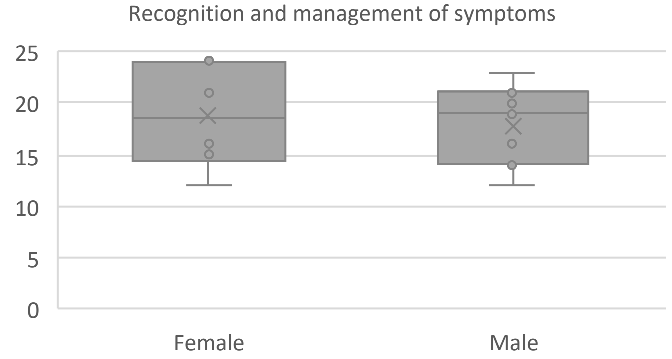

Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by gender

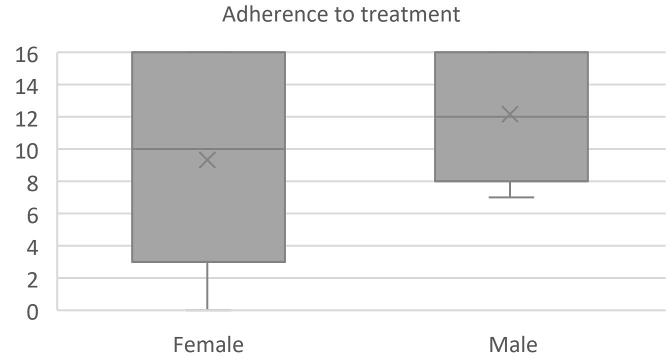

Figure 6.12: Boxplot of Partners in health: adherence to treatment by gender

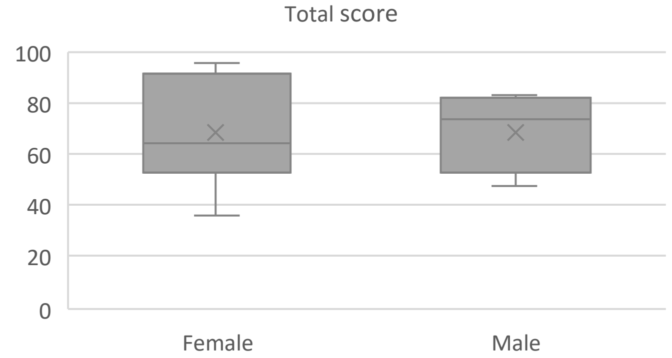

Figure 6.13: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=7, 53.85%), and participants aged 45 and older (n=6, 46.15%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.15).

A two sample t-test indicated that the mean score for the Partners in health Knowledge scale [t(11) = -2.69 , p = 0.0209*] was significantly lower for participants in the Aged 18 to 44 subgroup (Mean = 18.86, SD = 6.54) compared to participants in the Aged 45 and older subgroup (Mean = 27.00, SD = 3.69.)

A two sample t-test indicated that the mean score for the Partners in health Total score scale [t(11) = -2.28 , p = 0.0438*] was significantly lower for participants in the Aged 18 to 44 subgroup (Mean = 59.86, SD = 15.81) compared to participants in the Aged 45 and older subgroup (Mean = 79.17, SD = 14.54.)

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 the Aged 45 and older subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that participants in the Aged 45 and older subgroup had very good knowledge about their condition and treatments, and participants in the Aged 18 to 44 subgroup had average knowledge.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Aged 45 and older subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Aged 45 and older subgroup, and good for participants in the Aged 18 to 44 subgroup.

Table 6.14: Partners in health by age summary statistics and and T-test

Partners in health scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Knowledge	Aged 18 to 44	7	53.85	18.86	6.54	-2.69	11	0.0209*
	Aged 45 and older	6	46.15	27.00	3.69			
Coping	Aged 18 to 44	7	53.85	15.43	4.24	-1.42	11	0.1823
	Aged 45 and older	6	46.15	19.00	4.82			
Recognition and management of symptoms	Aged 18 to 44	7	53.85	16.71	4.50	-1.42	11	0.1824
	Aged 45 and older	6	46.15	20.00	3.69			
Total score	Aged 18 to 44	7	53.85	59.86	15.81	-2.28	11	0.0438*
	Aged 45 and older	6	46.15	79.17	14.54			

Table 6.15: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=13)	Percent	Median	IQR	W	p-value
Adherence to treatment	Aged 18 to 44	7	53.85	11.00	5.50	11.5	0.1917
	Aged 45 and older	6	46.15	15.50	5.50		

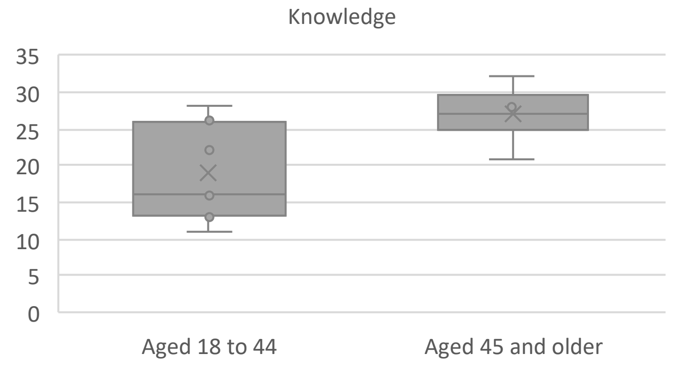

Figure 6.14: Boxplot of Partners in health: knowledge by age

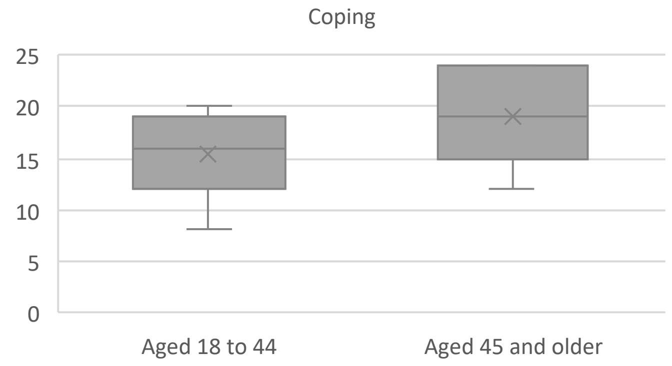

Figure 6.15: Boxplot of Partners in health: coping by age

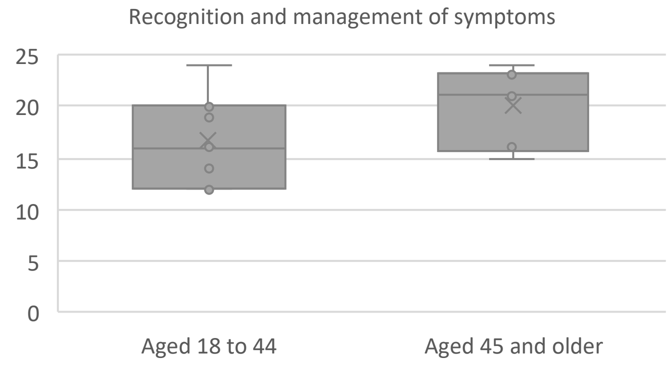

Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by age

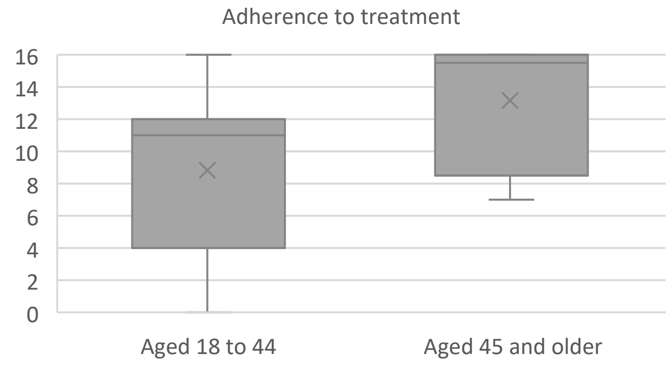

Figure 6.17: Boxplot of Partners in health: adherence to treatment by age

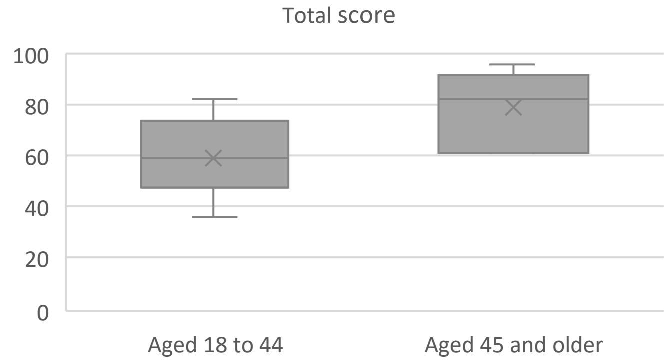

Figure 6.18: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=5, 38.46%), and those with a university qualification, University (n=8, 64.54%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.16).

A two sample t-test indicated that the mean score for the Partners in health Recognition and management of symptoms scale [t(11) = 2.51 , p = 0.0291] was significantly higher for participants in the Trade or high school subgroup (Mean = 21.40, SD = 3.44) compared to participants in the University subgroup (Mean = 16.25, SD = 3.69.)

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 trade and high school subgroup scored higher than participants in the university subgroup. This indicates that recognition and management of symptoms was very good for participants in the trade and high school subgroup, and good for participants in the university subgroup.

Table 6.16: Partners in health by education stage summary statistics and and T-test

Partners in health scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Knowledge	Trade or high school	5	38.46	23.60	8.08	0.40	11	0.6940
	University	8	61.54	22.00	6.21			
Coping	Trade or high school	5	38.46	18.60	3.44	0.92	11	0.3784
	University	8	61.54	16.13	5.33			
Recognition and management of symptoms	Trade or high school	5	38.46	21.40	3.44	2.51	11	0.0291*
	University	8	61.54	16.25	3.69			
Adherence to treatment	Trade or high school	5	38.46	10.80	5.17	-0.02	11	0.9808
	University	8	61.54	10.88	5.46			
Total score	Trade or high school	5	38.46	74.40	15.34	0.90	11	0.3877
	University	8	61.54	65.25	19.13			

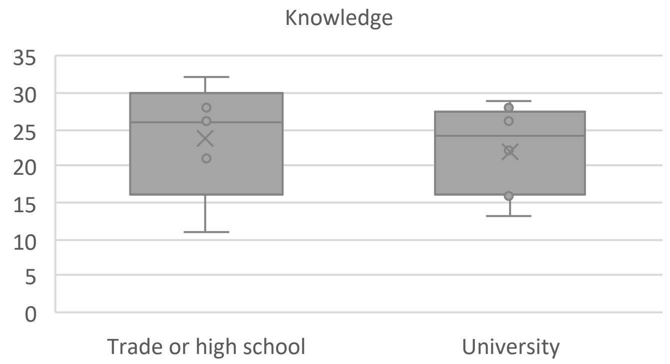

Figure 6.19: Boxplot of Partners in health: knowledge by education

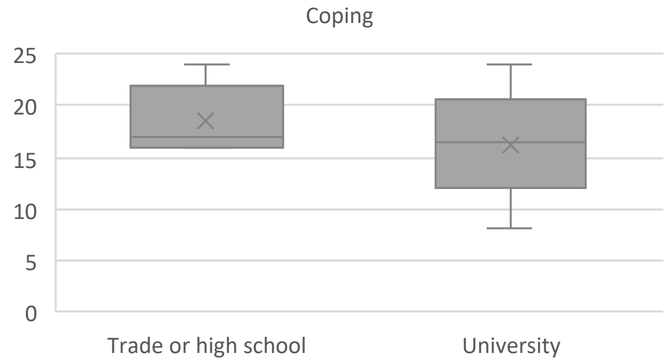

Figure 6.20: Boxplot of Partners in health: coping by education

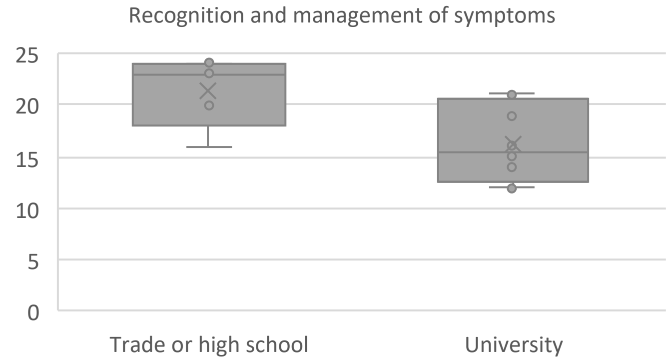

Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by education

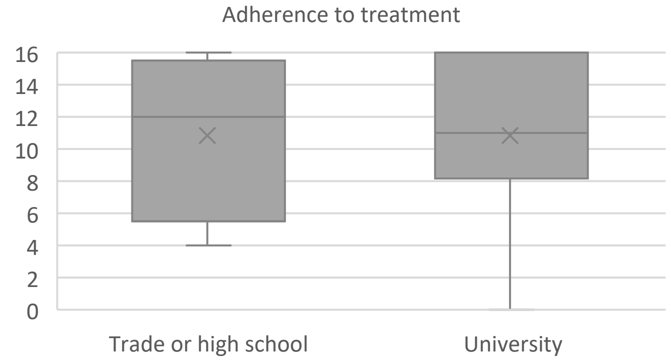

Figure 6.22: Boxplot of Partners in health: adherence to treatment by education

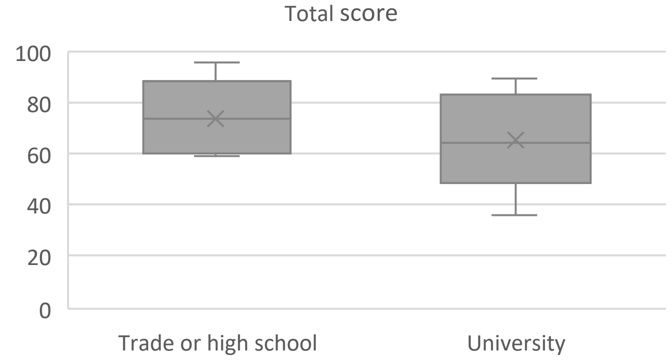

Figure 6.23: Boxplot of Partners in health Total score by education

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/rural areas, Regional or remote (n=3, 23.08%) were compared to those living in a major city, Metropolitan (n=10, 76.92%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 6.17.

Table 6.17: Partners in health by location summary statistics

Partners in health scale	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Knowledge	Rural or remote	3	23.08	27.67	1.53	28.00	1.50
	Metropolitan	10	76.92	21.10	6.95	21.50	10.00
Coping	Rural or remote	3	23.08	20.33	4.04	21.00	4.00
	Metropolitan	10	76.92	16.10	4.61	16.50	6.00
Recognition and management of symptoms	Rural or remote	3	23.08	21.67	1.15	21.00	1.00
	Metropolitan	10	76.92	17.20	4.42	16.00	5.50
Adherence to treatment	Rural or remote	3	23.08	15.67	0.58	16.00	0.50
	Metropolitan	10	76.92	9.40	4.99	10.00	4.50
Total score	Rural or remote	3	23.08	85.33	4.16	84.00	4.00
	Metropolitan	10	76.92	63.80	17.18	61.50	17.75

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=2, 15.38%) compared to those with a higher SEIFA score of 7-10, Higher status (n=11, 84.62%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 6.18.

Table 6.18: Partners in health by socioeconomic status summary statistics

Partners in health scale	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Knowledge	Mid to low	2	15.38	27.00	1.41	27.00	1.00
	Higher	11	84.62	21.82	7.01	22.00	11.00
Coping	Mid to low	2	15.38	18.50	3.54	18.50	2.50
	Higher	11	84.62	16.82	4.98	17.00	6.00
Recognition and management of symptoms	Mid to low	2	15.38	22.00	1.41	22.00	1.00
	Higher	11	84.62	17.55	4.34	16.00	6.00
Adherence to treatment	Mid to low	2	15.38	15.50	0.71	15.50	0.50
	Higher	11	84.62	10.00	5.14	11.00	6.50
Total score	Mid to low	2	15.38	83.00	1.41	83.00	1.00
	Higher	11	84.62	66.18	18.11	62.00	22.00

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=10, 76.92%), and 1 participant (7.69%) responded that they took medicines as prescribed most of the time. There were 2 participants (15.38%) that sometimes took medicines as prescribed.

Table 6.19: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	Number (n=13)	Percent
All of the time	10	76.92
Most of the time	1	7.69
Sometimes	2	15.38
Rarely	0	0.00

Figure 6.24: 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=10, 76.92%), disease management (n=7, 53.85%), interpret test results (n=5, 38.46%) and, psychological/ social support (n=4, 30.77%) were most frequently given to participants by healthcare professionals, and, information about dietary (n=2, 15.38%), hereditary considerations (n=2, 15.38%) and, complementary therapies (n=1, 7.69%) were given least often.

Table 6.20: Information given by health professionals

Information given by health professionals	Number (n=13)	Percent
Disease Cause	3	23.08
Treatment options	10	76.92
Disease management	7	53.85
Complementary therapies	1	7.69
Interpret test results	5	38.46
Clinical trials	3	23.08
Dietary	2	15.38
Physical activity	3	23.08
Psychological/ social support	4	30.77
Hereditary considerations	2	15.38
No information	0	0.00

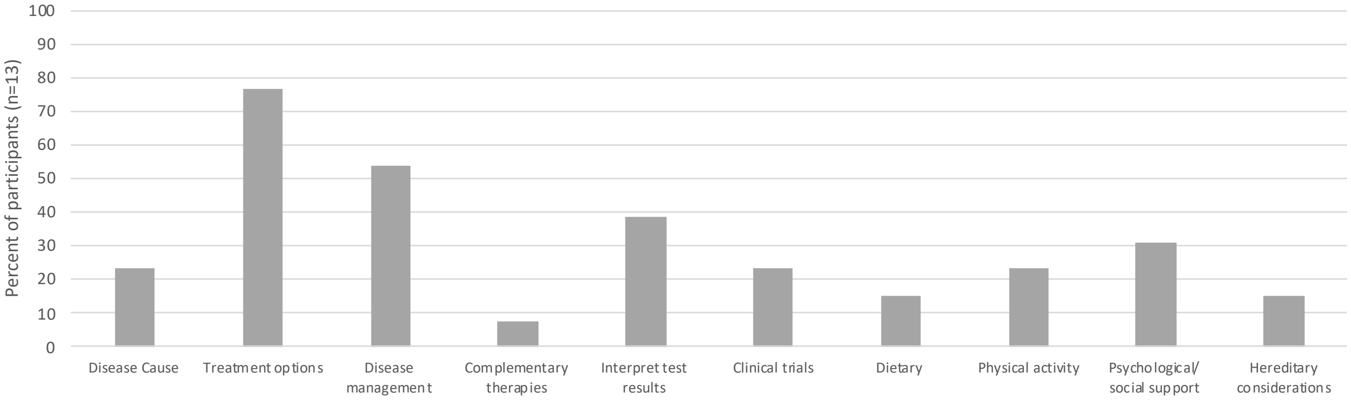

Figure 6.25: Information given by health professionals

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 treatment options (n=7, 53.85%), disease management (n=7, 53.85%), disease cause (n=5, 38.46%) and, complementary therapies (n=5, 38.46%) were most frequently given to participants by healthcare professionals, and, information about physical activity (n=4, 30.77%), hereditary considerations (n=2, 15.38%) and, clinical trials (n=1, 7.69%) were searched for least often.

Table 6.21: Information searched for independently

Information searched independently	Number (n=13)	Percent
Disease Cause	5	38.46
Treatment options	7	53.85
Disease management	7	53.85
Complementary therapies	5	38.46
Interpret test results	4	30.77
Clinical trials	1	7.69
Dietary	4	30.77
Physical activity	4	30.77
Psychological/ social support	5	38.46
Hereditary considerations	2	15.38
No information	1	7.69

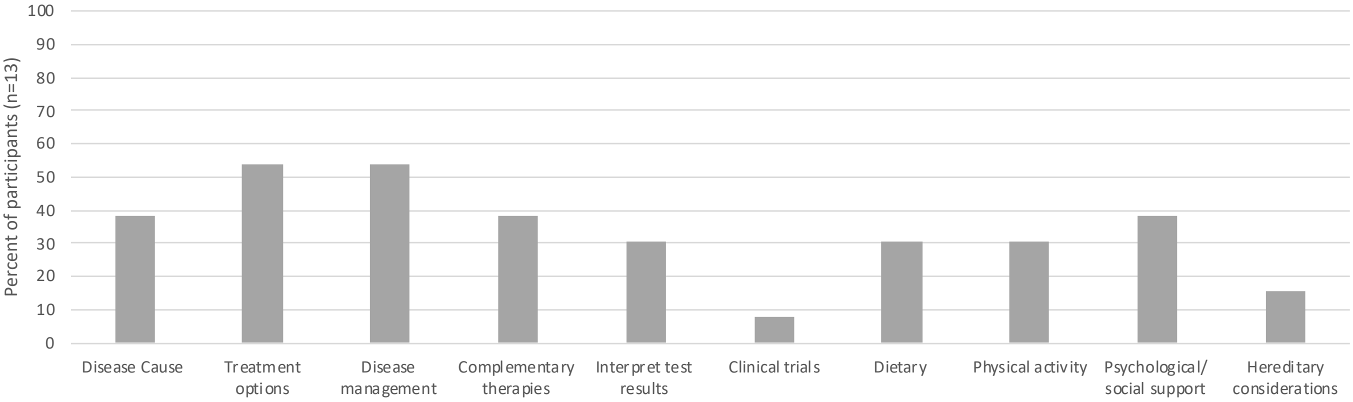

Figure 6.26: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=10, 76.92%) and Pphysical activity (n=10, 76.92%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=4, 30.77%) and disease cause (n=3, 23.08%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=6, 46.15%) and disease management (n=6, 46.15%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=5, 38.46%) and complementary therapies (n=4, 30.77%).

Table 6.22: 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	
	Number (n=13)	Percent	Number (n=13)	Percent	Number (n=13)	Percent	Number (n=13)	Percent
Disease Cause	6	46.15	3	23.08	0	0.00	5	38.46
Treatment options	3	23.08	4	30.77	6	46.15	1	7.69
Disease management	6	46.15	1	7.69	6	46.15	1	7.69
Complementary therapies	9	69.23	0	0.00	1	7.69	4	30.77
How to interpret test results	7	53.85	3	23.08	2	15.38	2	15.38
Clinical trials	10	76.92	3	23.08	0	0.00	1	7.69
Dietary information	9	69.23	1	7.69	1	7.69	3	23.08
Physical activity	10	76.92	0	0.00	3	23.08	1	7.69
Psychological/social support	8	61.54	1	7.69	3	23.08	2	15.38
Hereditary considerations	10	76.92	2	15.38	0	0.00	2	15.38

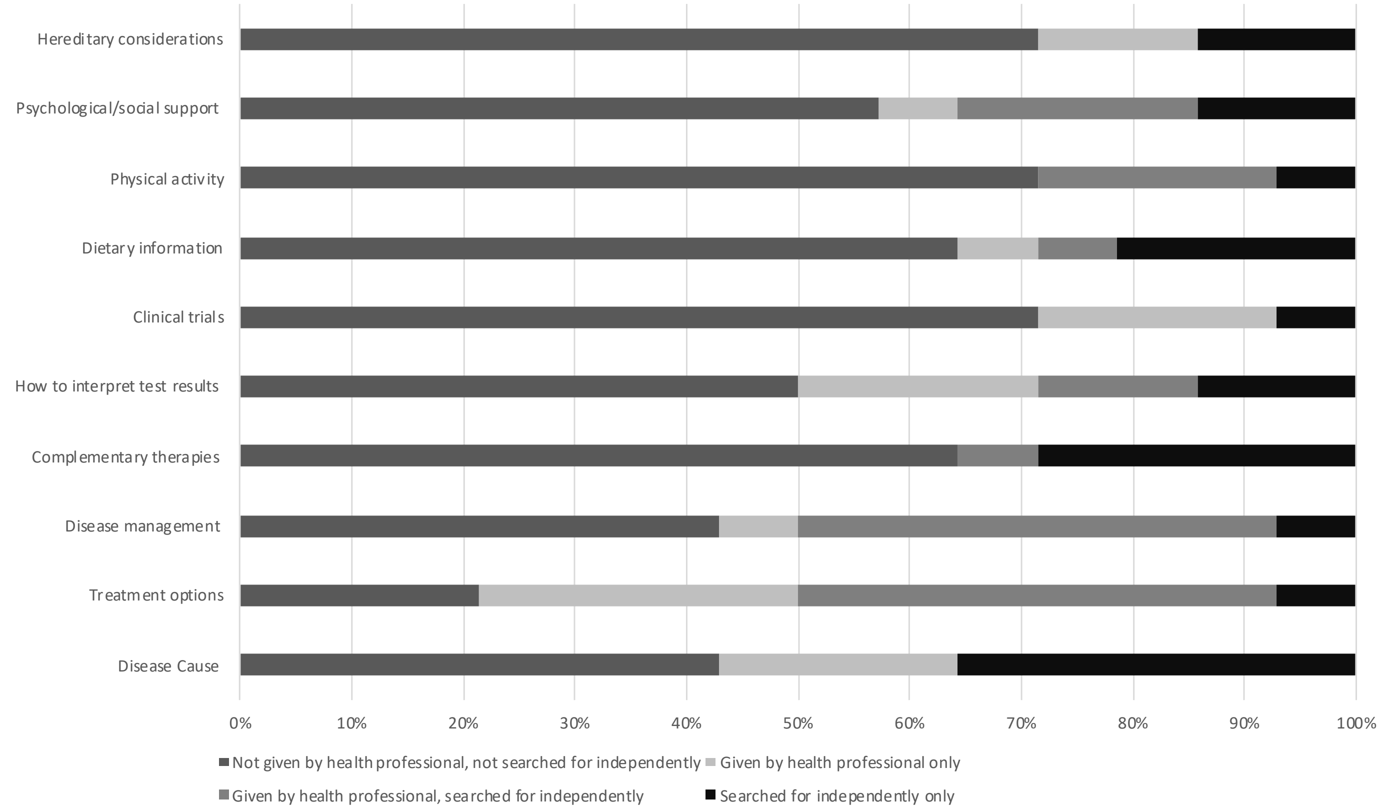

Figure 6.27: Information gaps

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 Table 6.23 and Figure 6.28. 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 Government. Information from Medical journals and from Pharmaceutical companies were least accessed.

Table 6.23: Most accessed information

Information source	Weighted average (n=13)
Non-profit organisations, charity or patient organisations	3.69
Government	3.38
Hospital or clinic where being treated	2.77
Medical journals	2.77
Pharmaceutical companies	2.38

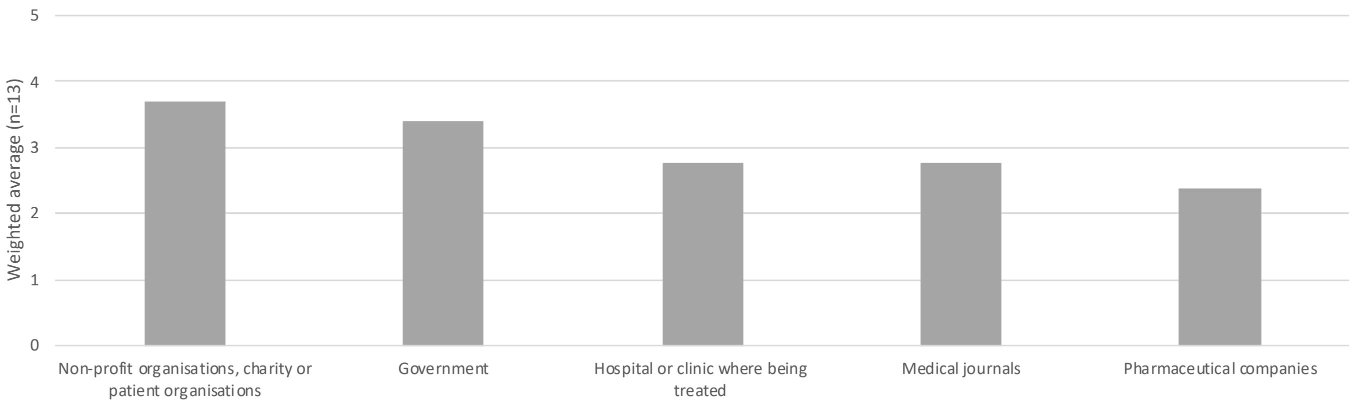

Figure 6.28: Most accessed information

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 average.

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 average.

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 response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

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.

The overall scores for the cohort were in the second highest quintile for Care coordination: Navigation (mean=24.23, SD=6.75) indicating good communication.

The overall scores for the cohort were in the middle quintile for Care coordination: Communication (mean=37.69, SD=11.14), Care coordination: Total score (mean=61.92, SD=15.24), Care coordination: Care coordination global measure (mean=6.23, SD=3.14), and Care coordination: Quality of care global measure (mean=6.00, SD=2.92) indicating moderate communication, moderate care coordination, moderate care coordination, and moderate quality of care

Comparisons of Care coordination have been made based on gender, age, education, location and socioeconomic status (Tables 7.2 to 7.6 Figures 7.1 to 7.15).

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 average.

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 average.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	37.69	11.14	38.00	12.00	13 to 65	3
Navigation*	24.23	6.75	24.00	10.00	7 to 35	4
Total score*	61.92	15.24	65.00	18.00	20 to 100	3
Care coordination global measure*	6.23	3.14	6.00	6.00	1 to 10	3
Quality of care global measure*	6.00	2.92	6.00	5.00	1 to 10	3

*Normal distribution use mean and SD as measure of central tendency

Care coordination by gender

Comparisons were made by Gender, there were 6 female participants (46.15%), and 7 male participants (53.85%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.2).

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

Table 7.2: Care coordination by gender summary statistics and and T-test

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Female	6	46.15	36.50	12.05	-0.34	11	0.7374
	Male	7	53.85	38.71	11.16			
Navigation	Female	6	46.15	26.17	5.81	0.95	11	0.3605
	Male	7	53.85	22.57	7.48			
Total score	Female	6	46.15	62.67	14.53	0.16	11	0.8788
	Male	7	53.85	61.29	16.96			
Care coordination global measure	Female	6	46.15	6.50	3.67	0.27	11	0.7884
	Male	7	53.85	6.00	2.89			
Quality of care global measure	Female	6	46.15	6.17	3.31	0.18	11	0.8581
	Male	7	53.85	5.86	2.79			

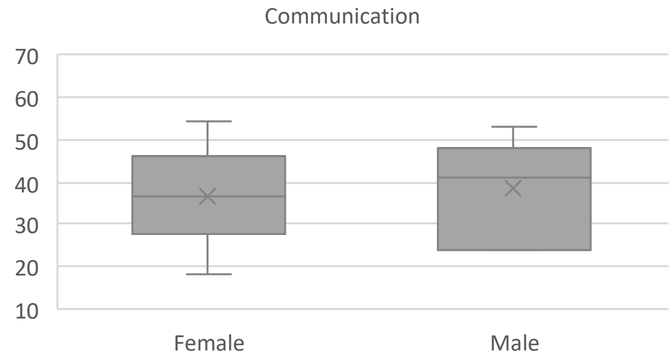

Figure 7.1: Boxplot of Care coordination: Communication by gender

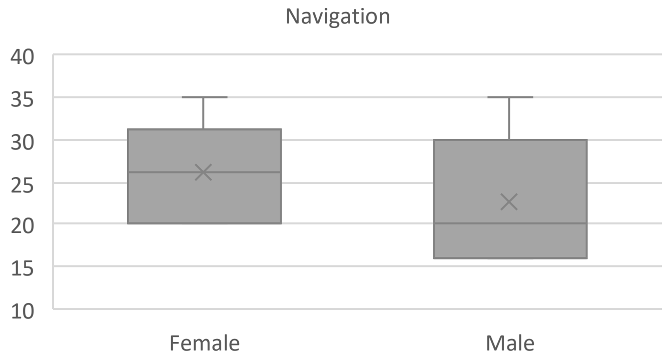

Figure 7.2: Boxplot of Care coordination: Navigation by gender

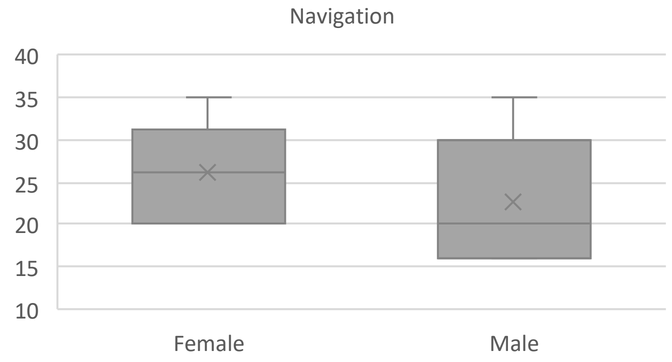

Figure 7.3: Boxplot of Care coordination: Total score by gender

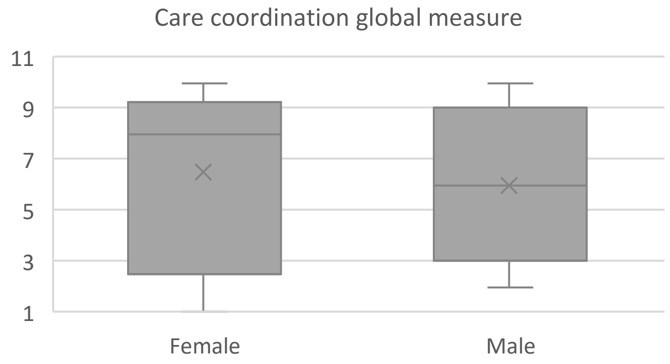

Figure 7.4: Boxplot of Care coordination: Care coordination global measure by gender

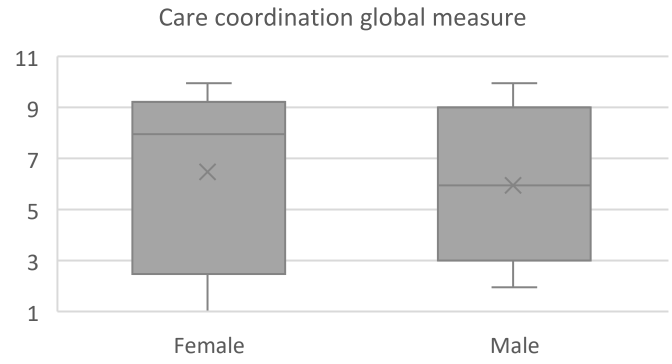

Figure 7.5: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=7, 53.85%), and participants aged 45 and older (n=6, 46.15%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.3).

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

Table 7.3: Care coordination by age summary statistics and and T-test

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 18 to 44	7	53.85	37.29	9.48	-0.14	11	0.8941
	Aged 45 and older	6	46.15	38.17	13.76			
Navigation	Aged 18 to 44	7	53.85	24.57	6.32	0.19	11	0.8539
	Aged 45 and older	6	46.15	23.83	7.81			
Total score	Aged 18 to 44	7	53.85	61.86	9.03	-0.02	11	0.9874
	Aged 45 and older	6	46.15	62.00	21.44			
Care coordination global measure	Aged 18 to 44	7	53.85	5.86	3.34	-0.45	11	0.6631
	Aged 45 and older	6	46.15	6.67	3.14			
Quality of care global measure	Aged 18 to 44	7	53.85	5.00	2.94	-1.39	11	0.1932
	Aged 45 and older	6	46.15	7.17	2.64			

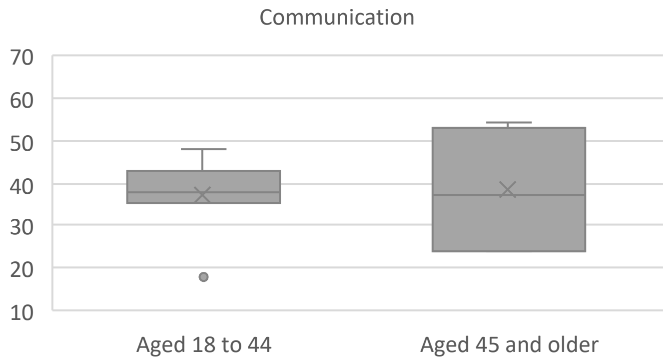

Figure 7.6: Boxplot of Care coordination: Communication by age

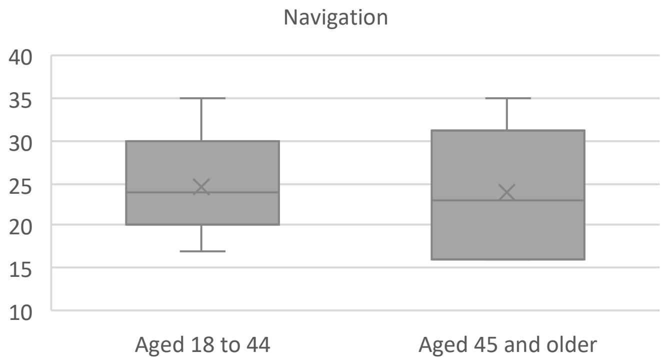

Figure 7.7: Boxplot of Care coordination: Navigation by age

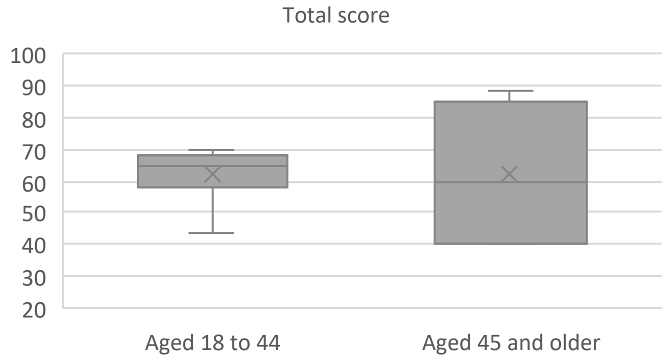

Figure 7.8: Boxplot of Care coordination: Total score by age

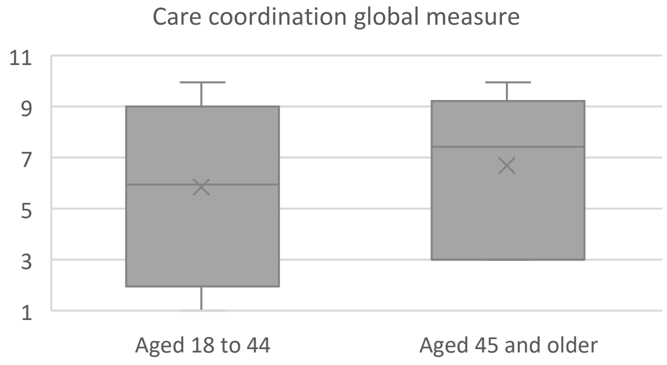

Figure 7.9: Boxplot of Care coordination: Care coordination global measure by age

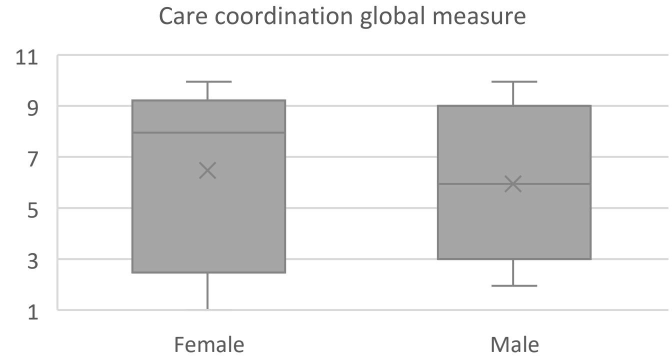

Figure 7.10: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=5, 38.46%), and those with a university qualification, University (n=8, 64.54%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 7.4).

No significant differences were observed between participants by **education** for any of the Care coordination scales.

Table 7.4: Care coordination by education summary statistics and and T-test

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 18 to 44	7	53.85	37.29	9.48	-0.14	11	0.8941
	Aged 45 and older	6	46.15	38.17	13.76			
Navigation	Aged 18 to 44	7	53.85	24.57	6.32	0.19	11	0.8539
	Aged 45 and older	6	46.15	23.83	7.81			
Total score	Aged 18 to 44	7	53.85	61.86	9.03	-0.02	11	0.9874
	Aged 45 and older	6	46.15	62.00	21.44			
Care coordination global measure	Aged 18 to 44	7	53.85	5.86	3.34	-0.45	11	0.6631
	Aged 45 and older	6	46.15	6.67	3.14			
Quality of care global measure	Aged 18 to 44	7	53.85	5.00	2.94	-1.39	11	0.1932
	Aged 45 and older	6	46.15	7.17	2.64			

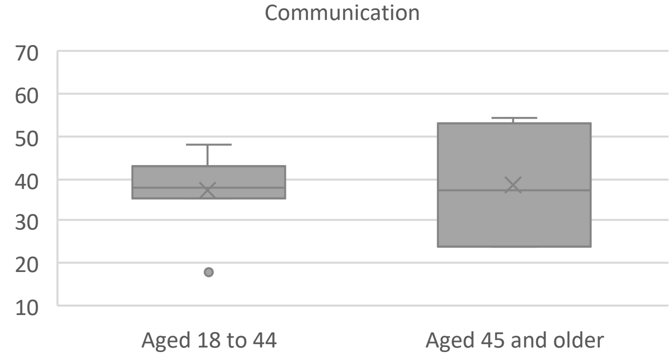

Figure 7.11: Boxplot of Care coordination: Communication by education

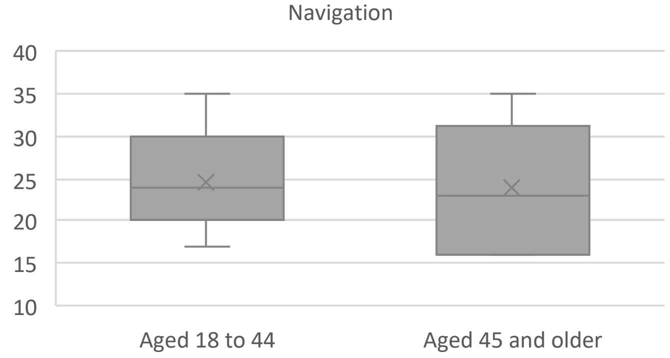

Figure 7.12: Boxplot of Care coordination: Navigation by education

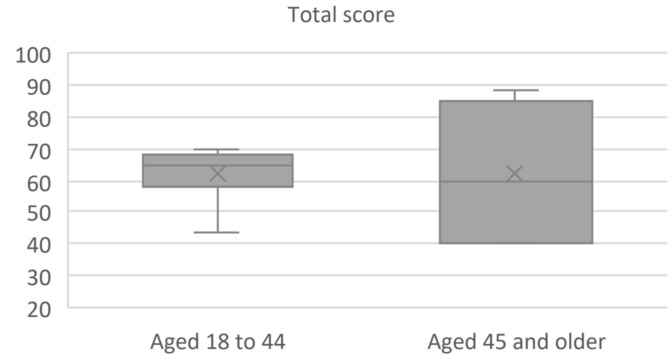

Figure 7.13: Boxplot of Care coordination: Total score by education

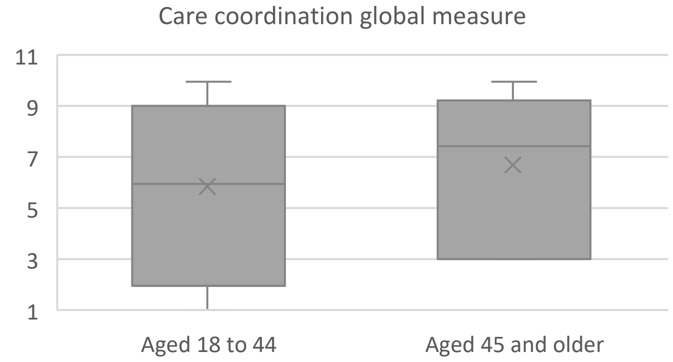

Figure 7.14: Boxplot of Care coordination: Care coordination global measure by education

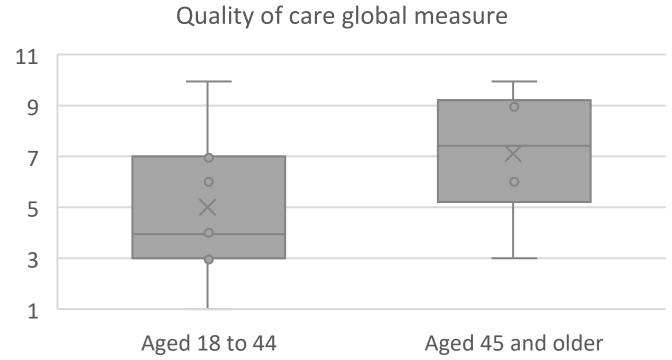

Figure 7.15: Boxplot of Care coordination: Quality of care global measure by education

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/rural areas, Regional or remote (n=3, 23.08%) were compared to those living in a major city, Metropolitan (n=10, 76.92%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 7.5.

Table 7.5: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	5	38.46	36.20	12.66	-0.37	11	0.7199
	University	8	61.54	38.63	10.89			
Navigation	Trade or high school	5	38.46	21.20	5.93	-1.32	11	0.2139
	University	8	61.54	26.13	6.88			
Total score	Trade or high school	5	38.46	57.40	18.51	-0.84	11	0.4213
	University	8	61.54	64.75	13.36			
Care coordination global measure	Trade or high school	5	38.46	6.00	3.54	-0.20	11	0.8444
	University	8	61.54	6.38	3.11			
Quality of care global measure	Trade or high school	5	38.46	5.20	2.95	-0.77	11	0.4583
	University	8	61.54	6.50	2.98			

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=2, 15.38%) compared to those with a higher SEIFA score of 7-10, Higher status (n=11, 84.62%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 7.6.

Table 7.6: Care coordination by socioeconomic status stage summary statistics

Care coordination scale	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Communication	Rural or remote	3	23.08	40.00	14.73	43.00	14.50
	Metropolitan	10	76.92	37.00	10.72	38.00	10.50
Navigation	Rural or remote	3	23.08	25.67	9.50	26.00	9.50
	Metropolitan	10	76.92	23.80	6.30	22.00	9.00
Total score	Rural or remote	3	23.08	65.67	24.17	69.00	24.00
	Metropolitan	10	76.92	60.80	13.18	62.50	15.25
Care coordination global measure	Rural or remote	3	23.08	8.00	1.73	9.00	1.50
	Metropolitan	10	76.92	5.70	3.33	6.00	5.50
Quality of care global measure	Rural or remote	3	23.08	8.00	1.73	9.00	1.50
	Metropolitan	10	76.92	5.40	2.99	5.00	3.50

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 response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

Participant describes that they did not receive any formal support

No, I've never get any support. Never, never. It's just my doctor advice from doctor when I go to for my blood test.
Participant 001_2023AUHDV

No, not really. Yeah. I mean, when I when I when I had the interferon treatment, it was all through the hospital. So no, I wasn't aware of any other community support services that were available and none, none was made was they didn't tell me about anything else was available. So, no, not not throughout.
Participant 011_2023AUHDV

Participant describes the challenges of finding or accessing support

Not really, but I would love to see there is something available, especially in the language I guess
Participant 003_2023AUHDV

Participant describes getting care and support from community or religious groups

PARTICIPANT: Not really. I haven't. Apart from it, I would say the church. I haven't really received much from the community.
INTERVIEWER: Or from church.
PARTICIPANT: Yeah, that's correct.
INTERVIEWER: OK. All right. So, So what kind of support is that? Is it like? Yeah.
PARTICIPANT: Well, it's financial and, you know, spiritual support.
Participant 006_2023AUHDV

Participant describes getting care and support from family and friends

So far I haven't actually received any stuff...support, but my family have been good.
Participant 009_2023AUHDV

Participant describes getting care and support from hospital or clinical setting

I guess the hepatitis nurse and the association, the psychologist and the sexual health clinic.
Participant 004_2023AUHDV

Table 7.7: Experience of care and support

Care and support received	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that they did not receive any formal support	5	41.67	3	50.00	2	33.33	5	62.50	0	0.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes getting care and support from peer support or other patients	2	16.67	0	0.00	2	33.33	0	0.00	2	50.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes the challenges of finding or accessing support	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from charities	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from community or religious groups	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from family and friends	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support from hospital or clinical setting	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes getting care and support in the form of financial support including financial counselling	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment (Other/no response)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

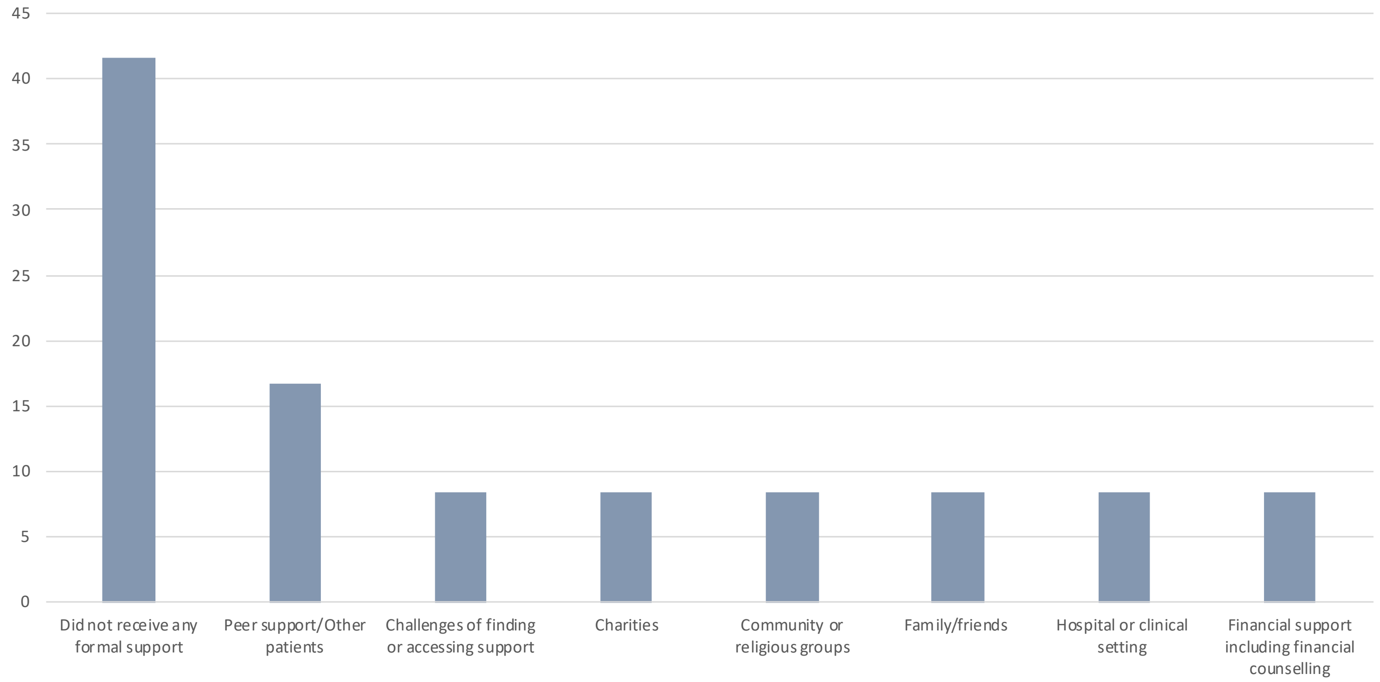

Figure 7.16: Experience of care and support

Table 7.8: 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	Aged 45 and older	Aged 18 to 44

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. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67 %), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00 %). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%). The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

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 (83.33%), and overall, there was no impact on mental health(8.33%).

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 response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67 %), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

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 complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

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 during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67 %), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

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 getting support from family and friends (8.33%). peer support (8.33 %) and taking charge of own health (8.33%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

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 a burden on their family (66.67%), overall, there was not a burden on their family(16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

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 range (median=3.00, IQR=3.50).

Fear of 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. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67 %), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00 %). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

Participant describes a negative impact on quality of life due to the emotional strain on self

But the only thing that I have is my mind. Every time I always think about it, I always think about it that when am I going to get sick? When am I going to get sick. So that is thought is always with me, but apart from that in my life is all good.
Participant 001_2023AUHDV

Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)

Well, they are just stopped as well. They are just stopped and they show a lot of concerns and it shows in the in their faces that they are worried about the situation all.
Participant 006_2023AUHDV

Participant describes a negative impact on quality of life due to reduced social interaction

Yeah, I it it actually affected affected my level of communication to the I saw outside world. I was shut down and didn't actually feel comfortable communicating anyone anymore. So I just felt shut down and turned off from all communications.
Participant 009_2023AUHDV

Yeah, that would be a big yes. Yep….I was left really in the dark about transmission pathways for the different types of hepatitis so I I wasn't I didn't have any understanding of how it was transmitted…and so I kind of I, you know, physically isolated myself from people and I didn't seek out physical contact. And yeah, so and then, you know, and then later found out that a lot of my assumptions there were incorrect. So yeah, it's had a big impact.
Participant 011_2023AUHDV

Participant describes a negative impact on quality of life from stigma and discrimination

Dealing with people who had stigma and discrimination against me. So yeah, I don't know.
Participant 010_2023AUHDV

Participant describes no impact on quality of life

No I I don't think that it's excluded me from anything that I wanted to do and you know I mean so I still travel like still get around I'm still mobile…my alcohol consumption's gone up and down and this is just an option that, well, I'm not actually drinking that much alcohol at the moment. So, but that's the only thing really.
Participant 007_2023AUHDV

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Experience described suggests that there was an overall negative impact on quality of life	6	50.00	3	50.00	3	50.00	**5**	**62.50**	**1**	**25.00**	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Experience described suggests that there was overall a minimal impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Experience described suggests that there was overall no impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Experience described suggests that there was a mix of positive and negative impact on quality of life	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

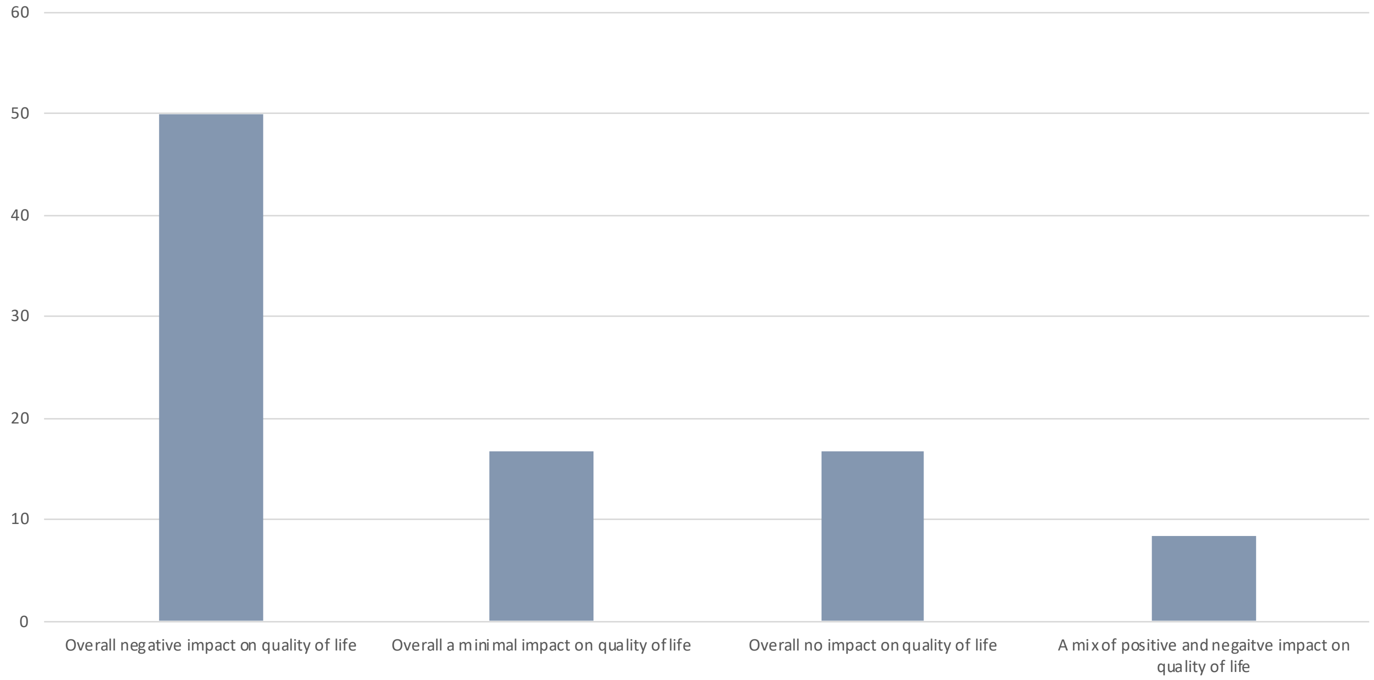

Figure 8.1: Impact on quality of life

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	Aged 45 and older	Aged 18 to 44

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes a negative impact on quality of life due to the emotional strain on self	5	41.67	2	33.33	3	50.00	4	50.00	**1**	**25.00**	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	4	33.33	**3**	**50.00**	**1**	**16.67**	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes a negative impact on quality of life due to reduced social interaction	3	25.00	0	0.00	3	50.00	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes a negative impact on quality of life due to managing side effects and symptoms	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a negative impact on quality of life from stigma and discrimination	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a minimal impact on quality of life that has a general or temporary impact	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no impact on quality of life	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

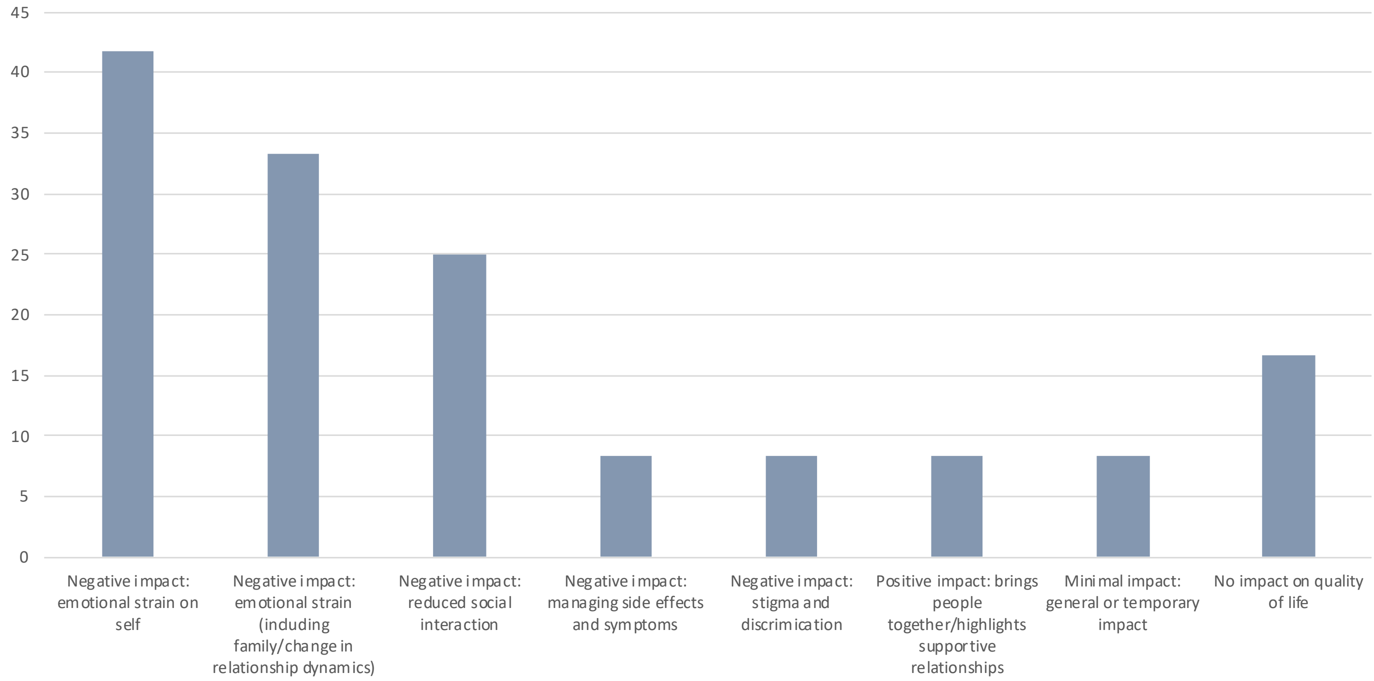

Figure 8.2: Impact on quality of life (Reasons)

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 on self	Aged 45 and older	-
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Male	Female

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 (83.33%), and overall, there was no impact on mental health(8.33%).

Table 8.5: Impact on mental health

Impact on mental health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Experience described suggests that overall, there was at least some impact on mental health	10	83.33	**4**	**66.67**	**6**	**100.00**	7	87.50	3	75.00	5	83.33	5	83.33	1	100.00	9	81.82	1	100.00	9	81.82
Experience described suggests that overall, there was no impact on mental health	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other or mixed experience	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

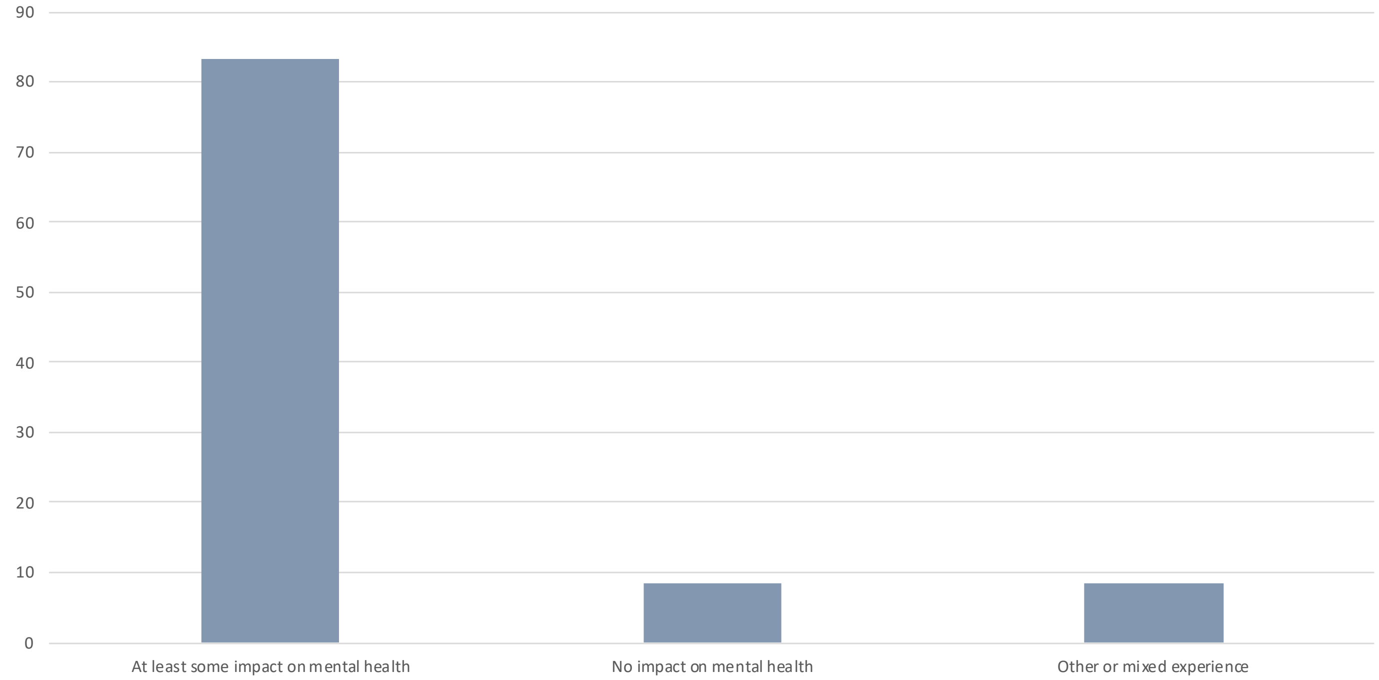

Figure 8.3: Impact on mental health

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	Female	Male

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 response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67 %), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

Participant describes consulting a mental health professional to maintain their mental health

And I did visit the therapist and he actually told me about a few things that I should go through that would actually help me is stress.
Participant 009_2023AUHDV

Participant describes mindfulness and/or meditation to maintain their mental health

Yeah, my, my mental health has been affected, that's for certain. And my emotions and everything has been affected. Yeah, I, I do certain activity once in a while, you know, to kind of, you know, soften the, the effects in my mental health, you know, let's say activity like yoga. And meditation, just to calm the calm the tension down.
Participant 006_2023AUHDV

Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health

Yes, it did affect my mental and emotional health prior to treatment…I have a spiritual understanding that I live in the moment. I I am very connected with my family and with my close friends.
Participant 010_2023AUHDV

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes no activities to maintain mental health to maintain their mental health	5	41.67	3	50.00	2	33.33	4	50.00	**1**	**25.00**	2	33.33	3	50.00	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes consulting a mental health professional to maintain their mental health	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mindfulness and/or meditation to maintain their mental health	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of physical exercise to maintain their mental health	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of a healthy diet to maintain their mental health	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No Response	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18

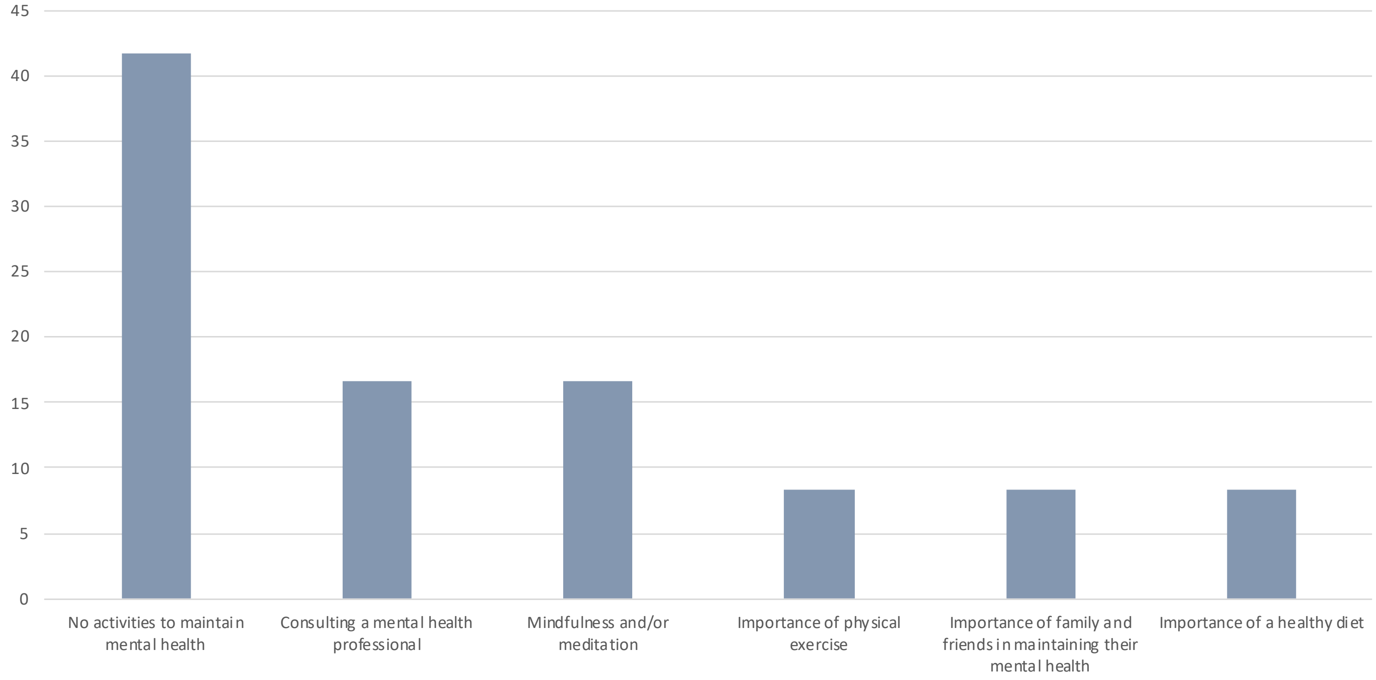

Figure 8.4: Regular activities to maintain mental health

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 no activities to maintain mental health to maintain their mental health	Aged 45 and older	-

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 complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

Participant describes the importance of complying with treatment/management in maintaining their general health

Basic took the treatment.
Participant 004_2023AUHDV

No, no. Well, that's that's it. I mean I take, I'm probably taking about 10 pills a day now, so that's not too bad. But you know, apart from that, life just goes on and I mean pills in the morning, pills at night, that's it. It's no great drama. Participant 007_2023AUHDV

Participant describes no activities to maintain their general health

No, no, I'm not doing anything because it's not treatable, so I don't even know what to do.
Participant 001_2023AUHDV

Participant describes the importance of getting help with translating health information

I think. Yeah, the only thing I do is try to translate for them I guess
Participant 003_2023AUHDV

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes the importance of complying with treatment/management in maintaining their general health	4	33.33	1	16.67	3	50.00	3	37.50	1	25.00	1	16.67	3	50.00	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes no activities to maintain their general health	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of maintaining a healthy lifestyle in maintaining their general health	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the importance of maintaining a healthy diet in maintaining their general health	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of socialising with friends and/or family in maintaining their general health	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the importance of getting help with translating health information	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

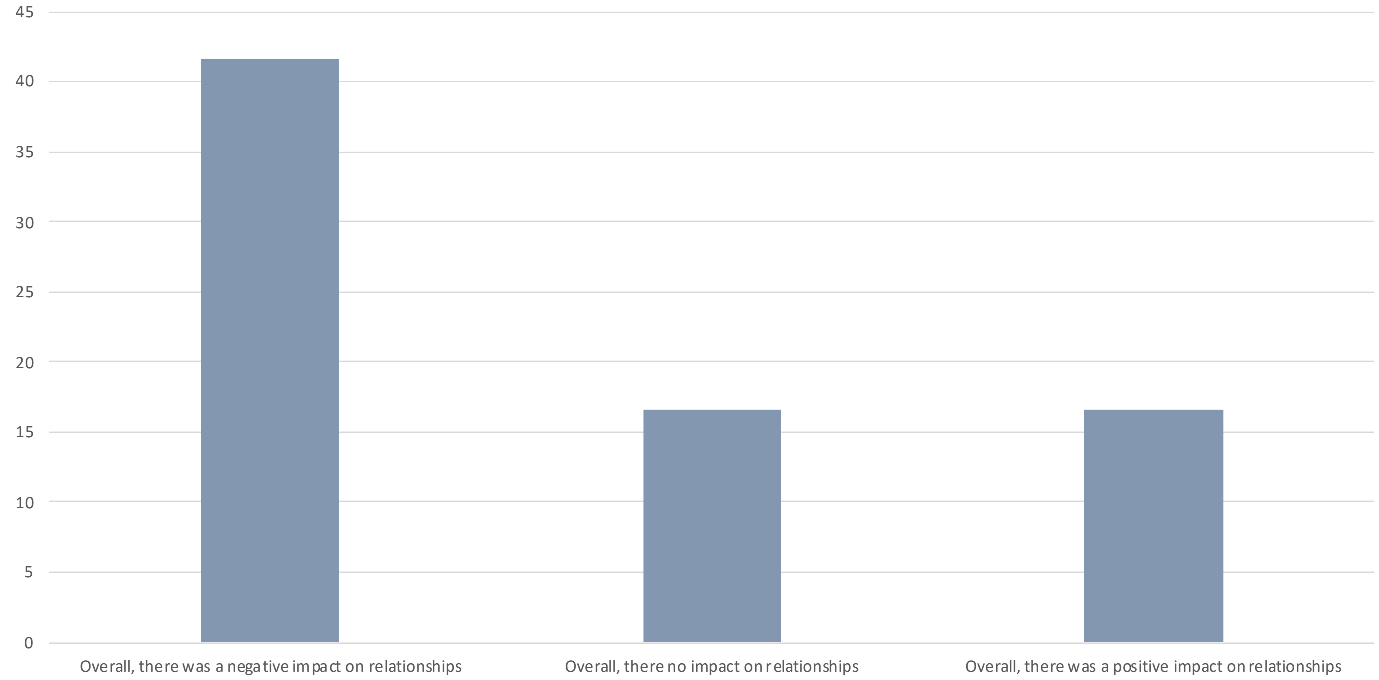

Figure 8.5: Regular activities to maintain health

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 complying with treatment/management in maintaining their general health	Female Trade or high school	Male University

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 during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67 %), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

Participant describes feeling vulnerable all the time

PARTICIPANT: Um, yeah, most of the time. I, you know, I just feel. Tired of the situation. I just feel fed up. And yeah, sometimes, sometimes.
INTERVIEWER: And what what did you do to, you know, overcome this feeling?
PARTICIPANT: Well, I I just confide in my loved ones there. They kind of reassured me that it's just for the meantime, that I'll be fine. So it's just my loved one that helped me.
Participant 006_2023AUHDV

Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)

OK, I actually felt vulnerable when I was scared and I didn't actually know what to do. I was really, really scared about hearing such information on such news. I was quite scared.
Participant 009_2023AUHDV

Participant describes feeling vulnerable because of feelings of stigma

Time all the time. I would say hepatitis has. That times kept me I felt as a prisoner from experiencing things and experiencing life. It just feels very shameful.
Participant 004_2023AUHDV

Participant describes feeling vulnerable while waiting for test results

Yeah, yeah, post post treatment there's. And I think this is true for the current treatments as well.
But there's this period of where you're waiting to find out results. So you might have an initial blood test that says you're negative…but you've still got there's

still a time, there's that window there where the thing can come back….and waiting for that and then waiting for the results.
Participant 011_2023AUHDV

Participant describes feeling vulnerable because of interactions with the medical team

Yeah, those two times where or maybe two or three times where the doctor and a couple of or couple of doctors and a couple of nurses were a bit judgmental about my past. So I just felt a bit vulnerable at that time, but I just spoke up so that was all good.
Participant 010_2023AUHDV

Participant describes that they did not feel vulnerable

I don't feel vulnerable.
Participant 005_2023AUHDV

Table 8.11: Experience of vulnerability

THEME	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a negative impact on relationships	5	41.67	2	33.33	3	50.00	4	50.00	1	25.00	4	66.67	1	16.67	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes that overall, there no impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes that overall, there was a positive impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27

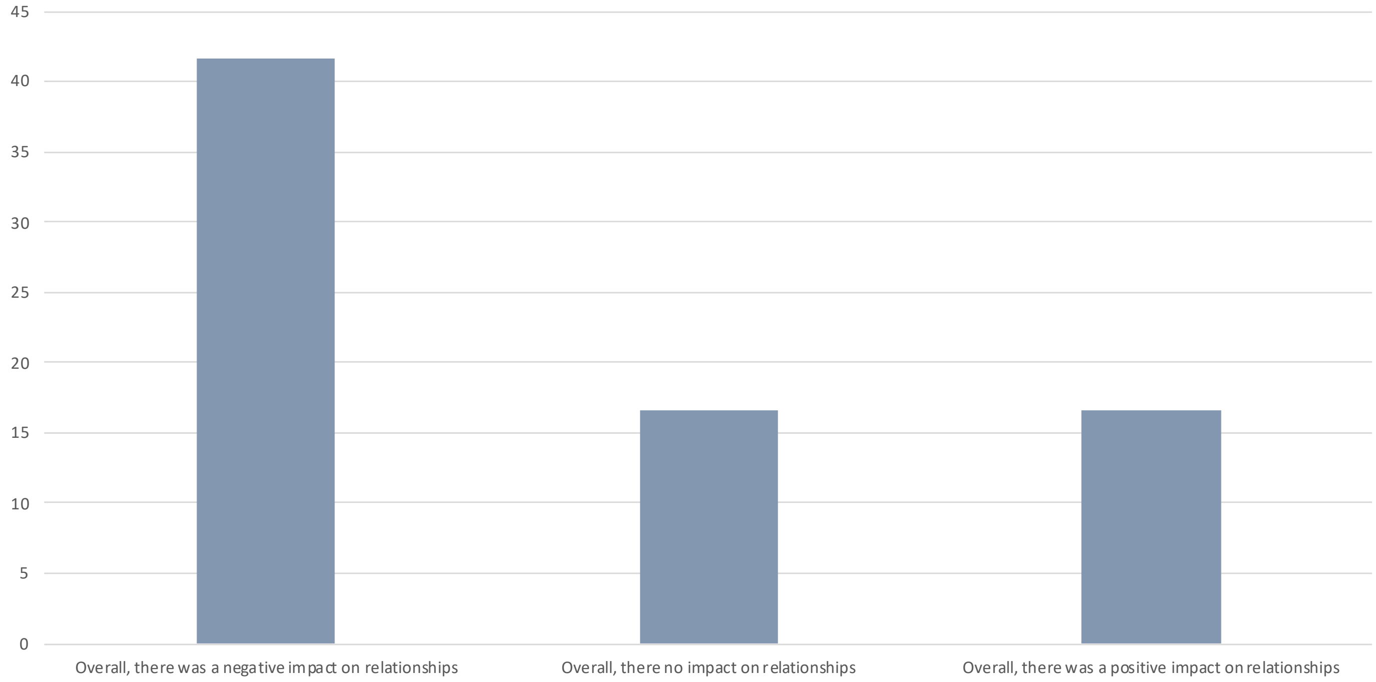

Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	Aged 45 and older University	Trade or high school

Table 8.13: Experience of vulnerability (details)

Experience of vulnerability (Details)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes feeling vulnerable during/after treatments	3	25.00	0	0.00	3	50.00	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes feeling vulnerable all the time	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes feeling vulnerable because of feelings of stigma	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes feeling vulnerable bwhile waiting for test results	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes feeling vulnerable because of interactions with the medical team	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that they did not feel vulnerable	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Other/No response	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

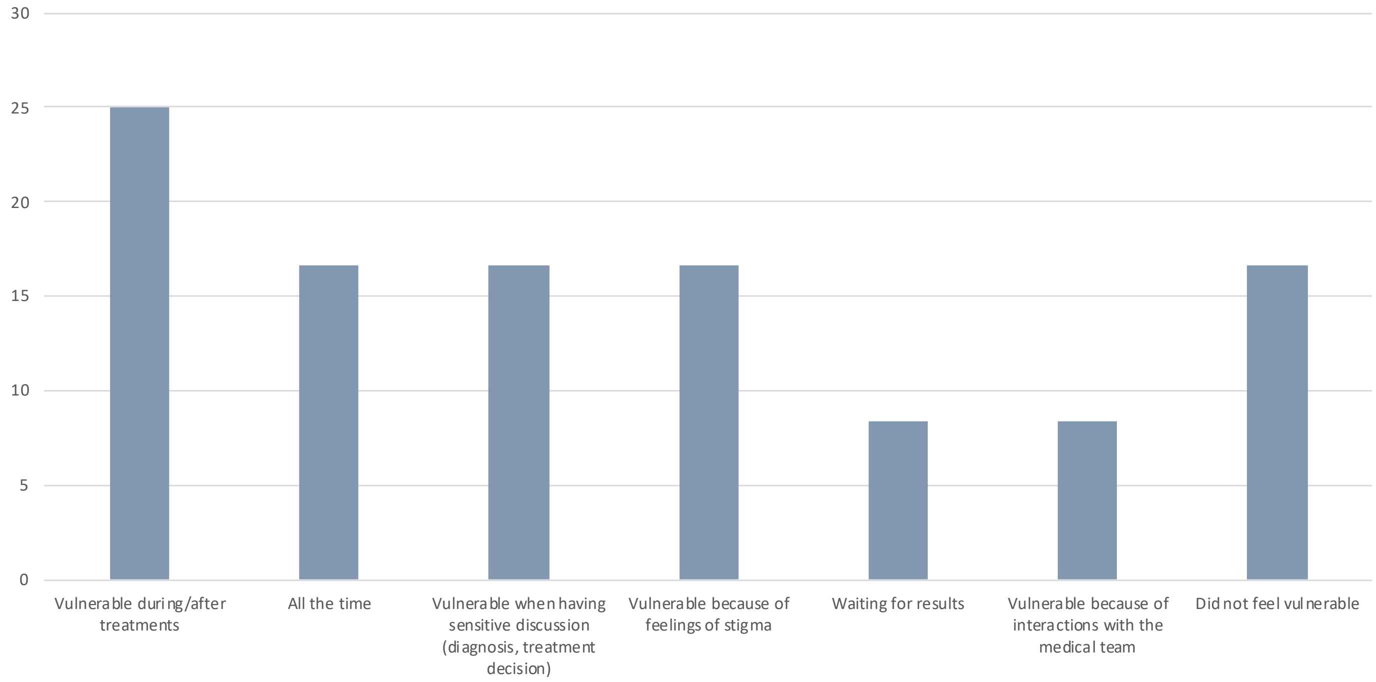

Figure 8.7: Experience of vulnerability (details)

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 getting support from family and friends (8.33%). peer support (8.33 %), and taking charge of own health (8.33%).

Participant describes getting support from family and friends to manage the feeling of vulnerability

PARTICIPANT: Um, yeah, most of the time. I, you know, I just feel. Tired of the situation. I just feel fed up. And yeah, sometimes, sometimes.
INTERVIEWER: And what what did you do to, you know, overcome this feeling?
PARTICIPANT: Well, I I just confide in my loved ones there. They kind of reassured me that it's just for the meantime, that I'll be fine. So it's just my loved one that helped me.
Participant 006_2023AUHDV

Participant describes taking charge of their own health to manage the feeling of vulnerability

That's, that's what I can do. I can speak to other people, but, you know, I mean, I really have to take charge of my own health. I have to liaison with other people too. Participant 012_2023AUHDV

Table 8.14: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes Not applicable, no vulnerability	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes getting support from family and friends to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes peer support to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes taking charge of their own health to manage the feeling of vulnerability	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other/no response	6	50.00	3	50.00	3	50.00	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55

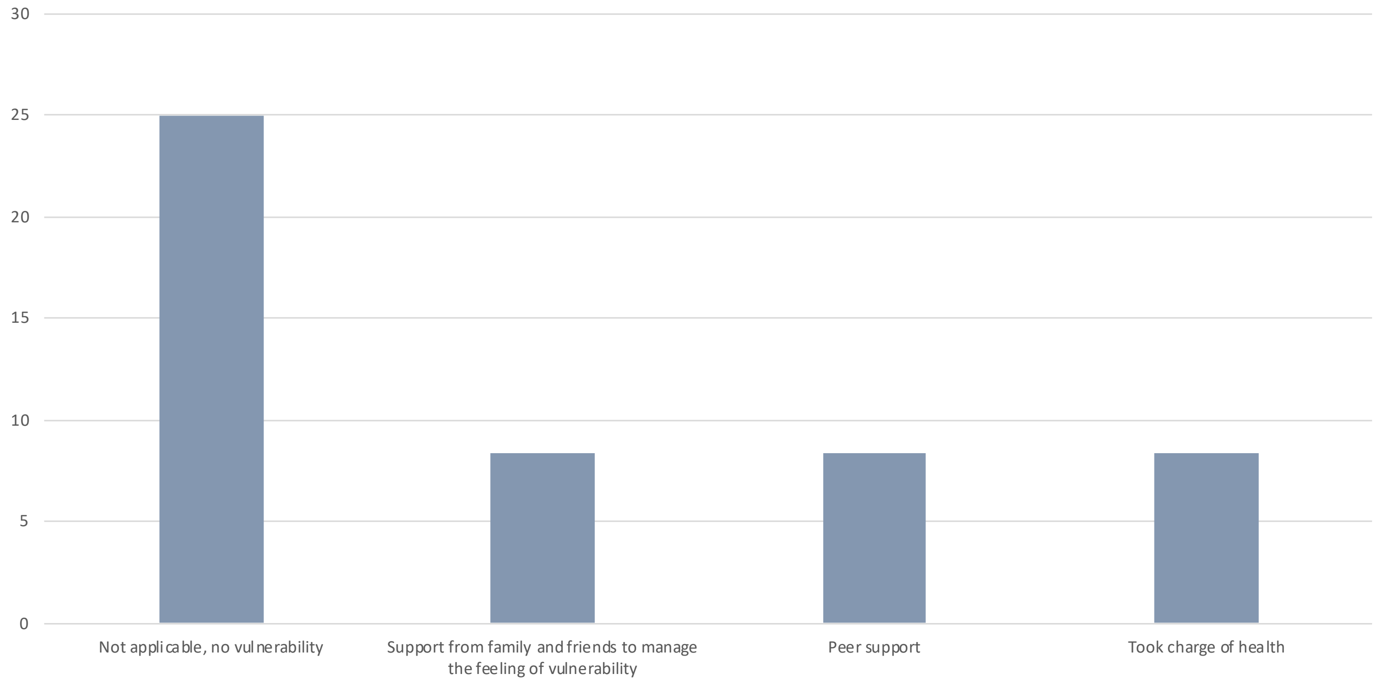

Figure 8.8: Methods to manage vulnerability

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

Participant describes a positive impact on relationships from family relationships being strengthened

PARTICIPANT: I'm. I'm not sure, but family, as I said, I think we become closer. Yeah, I care about them more.
Participant 003_2023AUHDV

I think it's actually empowered my personal relationships.
Participant 010_2023AUHDV

Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships

Yes, yes. Especially with my friends. I wouldn't say the same about my family, but. With my friends, a lot of things have been, you know, affected and a lot of things have changed. I don't associate much and I

tend to shy away from certain activity, which I always engage with my friends, you know, like hanging out and taking drinks or drinking, and all these have been limited.
Participant 006_2023AUHDV

Table 8.15: Impact on relationships

Impact on relationships	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a negative impact on relationships	5	41.67	2	33.33	3	50.00	4	50.00	1	25.00	4	66.67	1	16.67	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes that overall, there no impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes that overall, there was a positive impact on relationships	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	3	25.00	2	33.33	1	16.67	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27

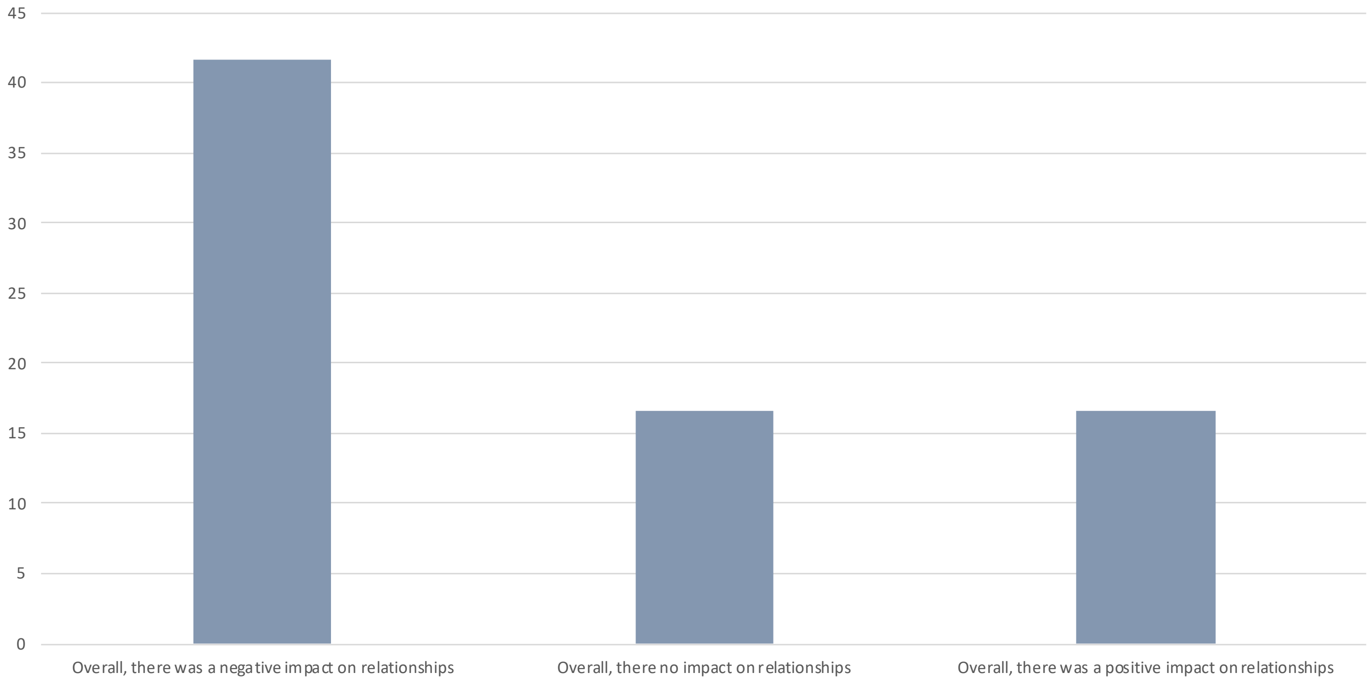

Figure 8.9: Impact on relationships

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	Aged 45 and older University	Trade or high school

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes a positive impact on relationships from family relationships being strengthened	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes a positive impact on relationships with family from assigning blame for infection	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No impact/Not applicable	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Other/No response	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36

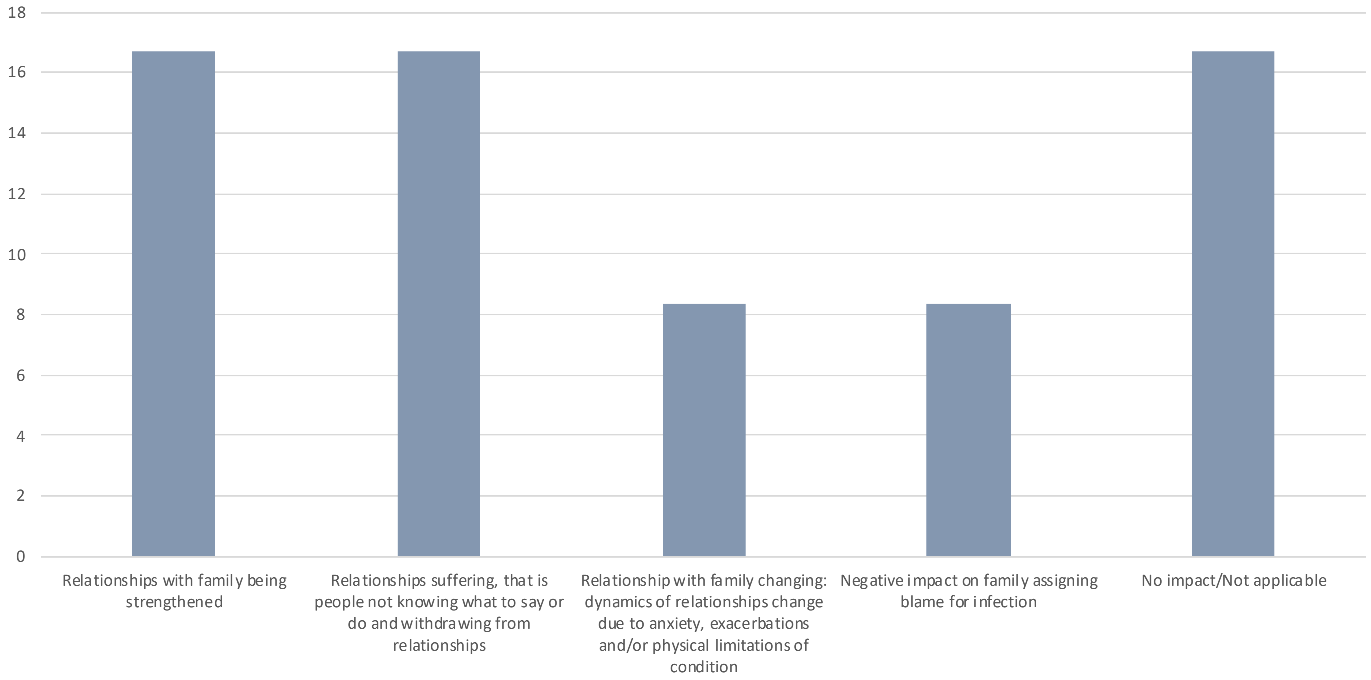

Figure 8.10: Impact on relationships

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 a burden on their family (66.67%), overall, there was not a burden on their family(16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Participant describes that the burden on family was temporary

No, I think, you know, like I said when I was first finding out I had it and was diagnosed, it was a bit of an emotional burden on my daughter and while she was waiting for the results of her blood test to see if she'd been, you know, if she contracted the virus. So that was very emotional. Participant 010_2023AUHDV

Participant describes their condition being a burden in general (No specific examples) as a burden on their family

Yes, yes, definitely, definitely.
Participant 006_2023AUHDV

Participant describes the mental/emotional strain placed on their family as a burden on their family

PARTICIPANT: It affected them, yeah. It affected them.
INTERVIEWER: Yeah, like how?
PARTICIPANT: Mentally.
Participant 001_2023AUHDV

Participant describes the extra financial assistance needed as a burden on their family

I think flowing on from yes I think it was and in terms of they gave me financial help. Yeah, So I'd say yes.
Participant 011_2023AUHDV

Table 8.18: Burden on family

Burden on family	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was a burden on their family	8	66.67	2	33.33	6	100.00	5	62.50	3	75.00	4	66.67	4	66.67	1	100.00	7	63.64	1	100.00	7	63.64
Participant describes that overall, there was not a burden on their family	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

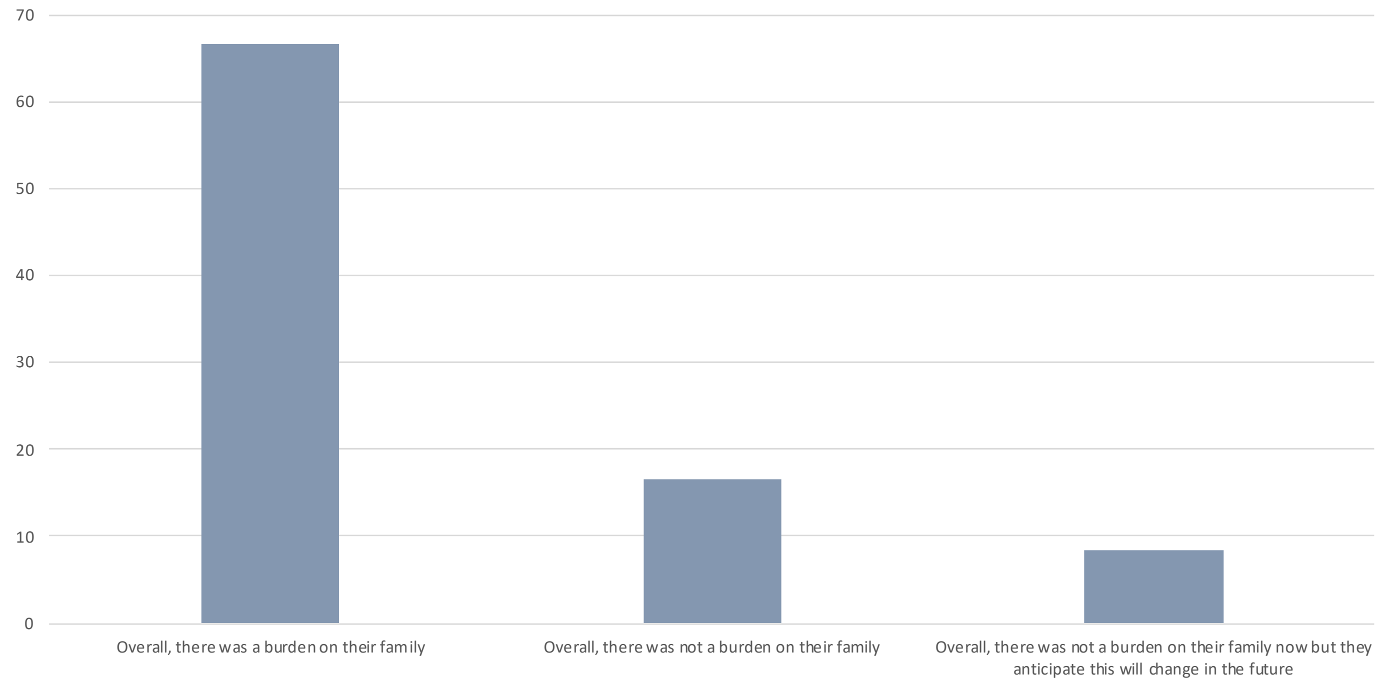

Figure 8.11: Burden on family

Table 8.19: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant describes that overall, there was a burden on their family	Female	Male

Table 8.20: Burden on family (description)

Burden on family (Description)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that the burden on family was temporary or only during treatment	5	41.67	2	33.33	3	50.00	2	25.00	3	75.00	3	50.00	2	33.33	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	3	25.00	1	16.67	2	33.33	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes the mental/emotional strain placed on their family as a burden on their family	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes the extra financial assistance needed as a burden on their family	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describesnot telling anyone about their condition and are not a burden on their family	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

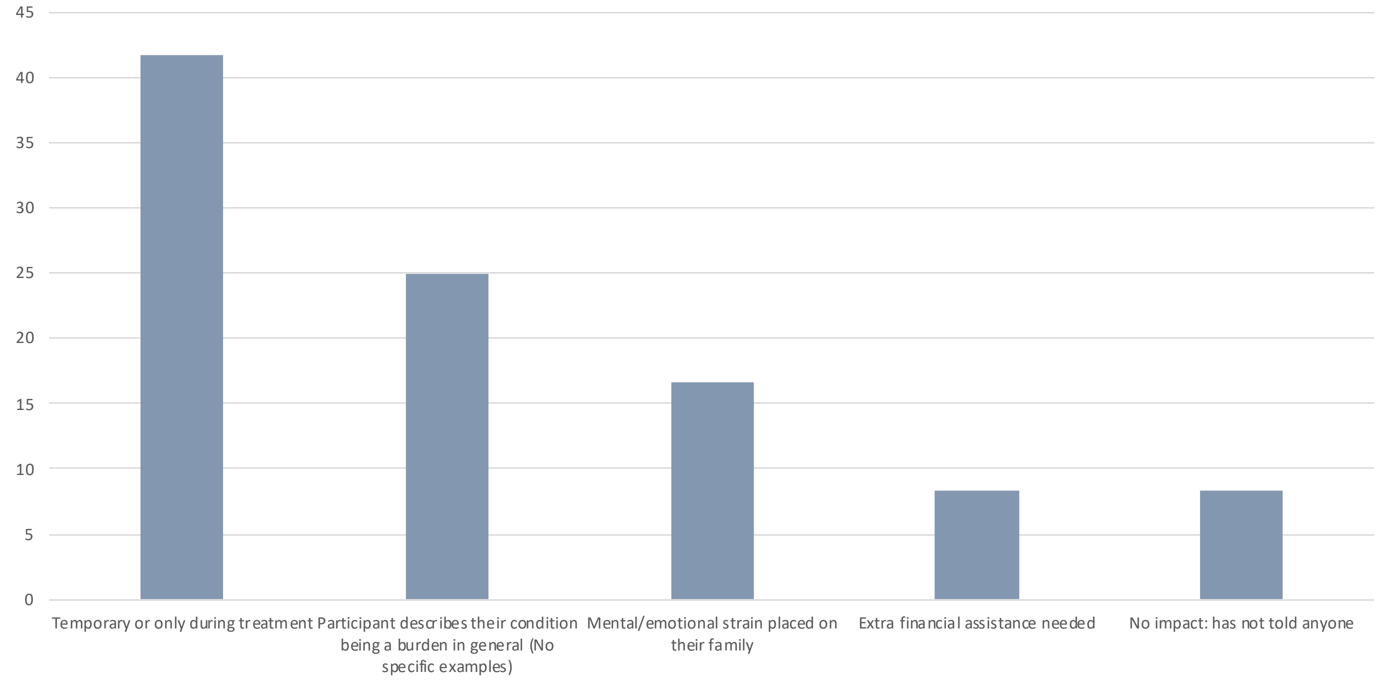

Figure 8.12: Burden on family (description)

Table 8.21: Burden on family (description)– subgroup variations

Burden on family (Description)	Reported less frequently	Reported more frequently
Participant describes that the burden on family was temporary or only during treatment	Aged 18 to 44	Aged 45 and older

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

Participant describes no cost burden and that nearly everything was paid for through the public health system

PARTICIPANT: Most of my costs have been looked after by the PBS and that I'm very fortunate.

Participant describes no cost burden and that nearly everything was paid for through the private health system

I can consider the cost actually was I've got I've got a private health for everything is just covered, so I've never encountered any cost like out of pocket so far.
Participant 001_2023AUHDV

Participant describes cost of treatments (including repeat scripts)

I would say my medication costs and it's been around the $40 mark every two months for all that I have to cover, all the conditions…I would say psychology costs of how it's impacted me.
Participant 004_2023AUHDV

Table 8.22: Cost considerations

Cost considerations	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that overall, there was at least some cost burden	7	58.33	3	50.00	4	66.67	5	62.50	2	50.00	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes that overall, there was no cost burden	4	33.33	3	50.00	1	16.67	2	25.00	2	50.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Other/No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

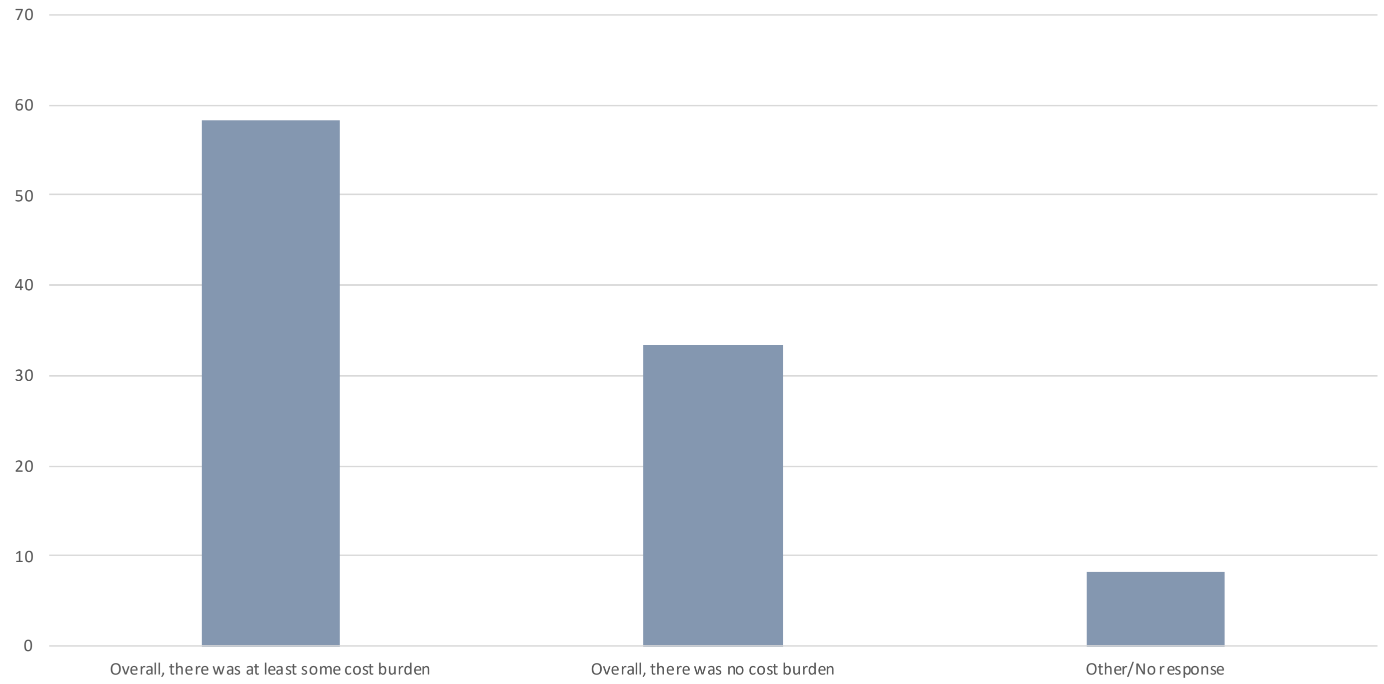

Figure 8.13: Cost considerations

Table 8.23: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was no cost burden	Male University	Female Aged 45 and older Trade or high school

Table 8.24: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes no cost burden and that nearly everything was paid for through the public health system	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes no cost burden and that nearly everything was paid for through the private health system	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no cost burden as participant was able to afford all costs	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes cost burden without giving a reason	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes cost of treatments (including repeat scripts)	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes cost burden in relation to needing to take time off work	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes cost of parking and travel to attend appointments (including accommodation)	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes cost burden in needing to access financial support from family or charities	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Cost burden in relation to allied health care	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes no cost burden without giving a reason	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

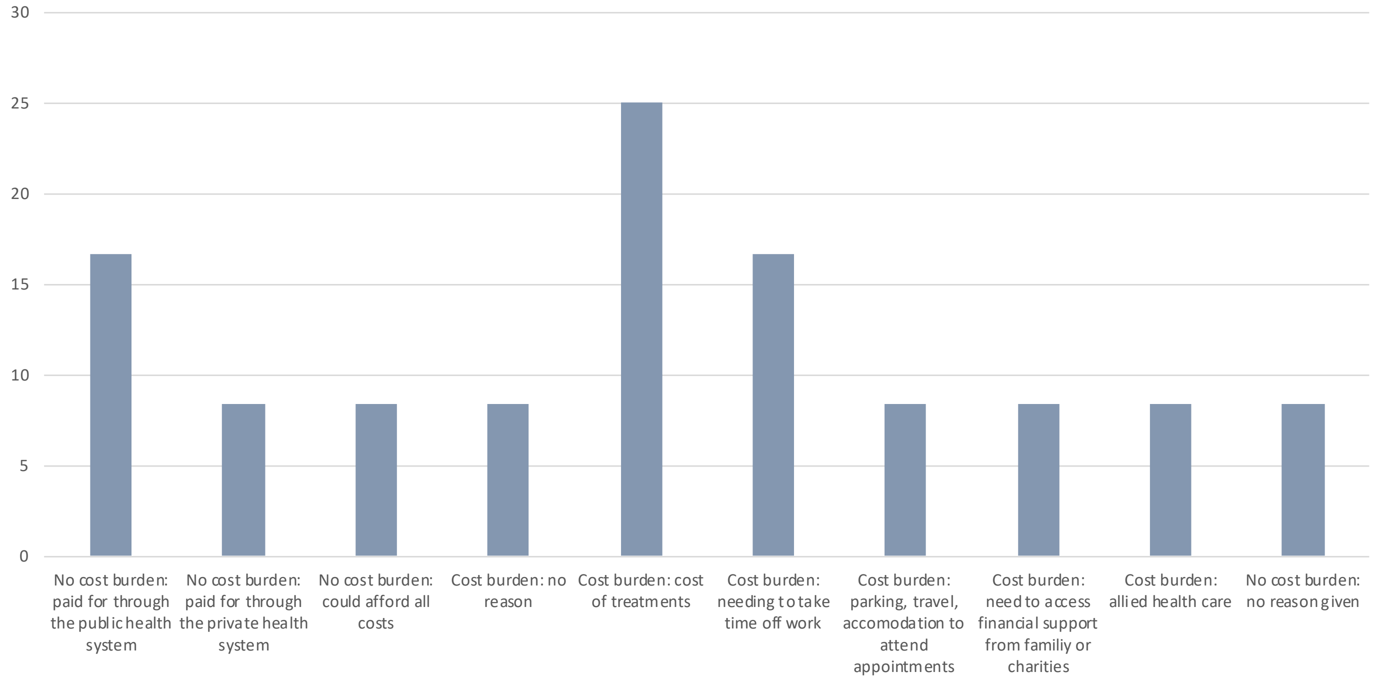

Figure 8.14: Cost considerations (Reasons for cost)

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 range (median=3.00, IQR=3.50).

Table 8.25: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=14)	Percent
1 Life is/was very distressing	2	14.29
2 Life is/was distressing	3	21.43
3 Life is/was a little distressing	3	21.43
4 Life is/was average	2	14.29
5 Life is/was good	0	0.00
6 Life is/was very good	4	28.57
7 Life is/was great	0	0.00

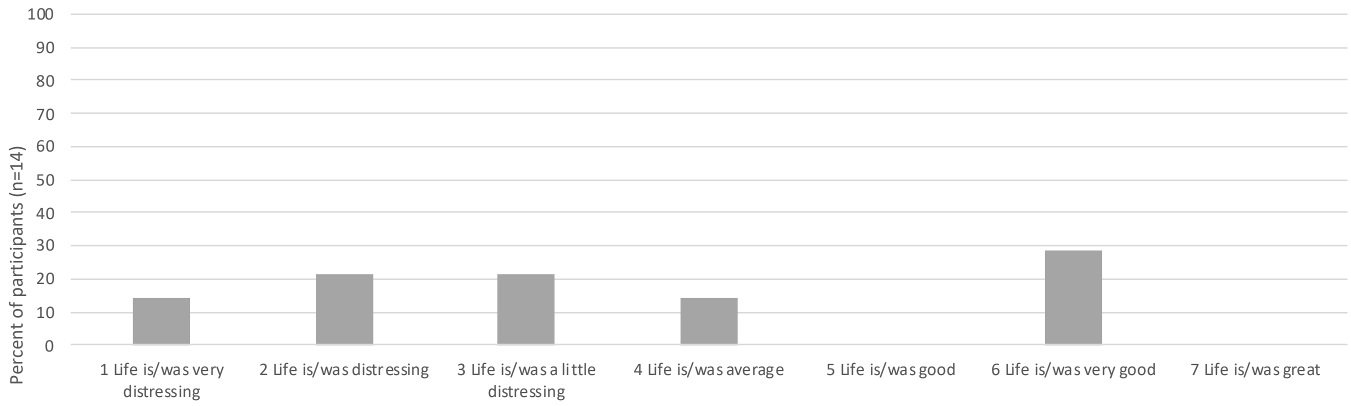

Figure 8.15: Overall impact of condition on quality of life

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. Summary statistics for the entire cohort are displayed in Table 8.26. The overall scores for the cohort were in the highest quintile for Fear of progression: Total score (mean=33.15, SD=13.28) indicating moderate levels of anxiety

Comparisons of Care coordination have been made based on gender, age, education, location and socioeconomic status (Tables 8.27 to 8.31 Figures 8.16to 8.18).

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 8.26: Fear of progression summary statistics

Fear of progression (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.15	13.28	34.00	21.00	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by gender

Comparisons were made by Gender, there were 6 female participants (46.15%), and 7 male participants (53.85%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.27).

No significant differences were observed between participants by **gender** for any of the Fear of progression scales

Table 8.27: Fear of progression total score by gender summary statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Female	6	46.15	35.00	15.72	0.45	11	0.6626
	Male	7	53.85	31.57	11.84			

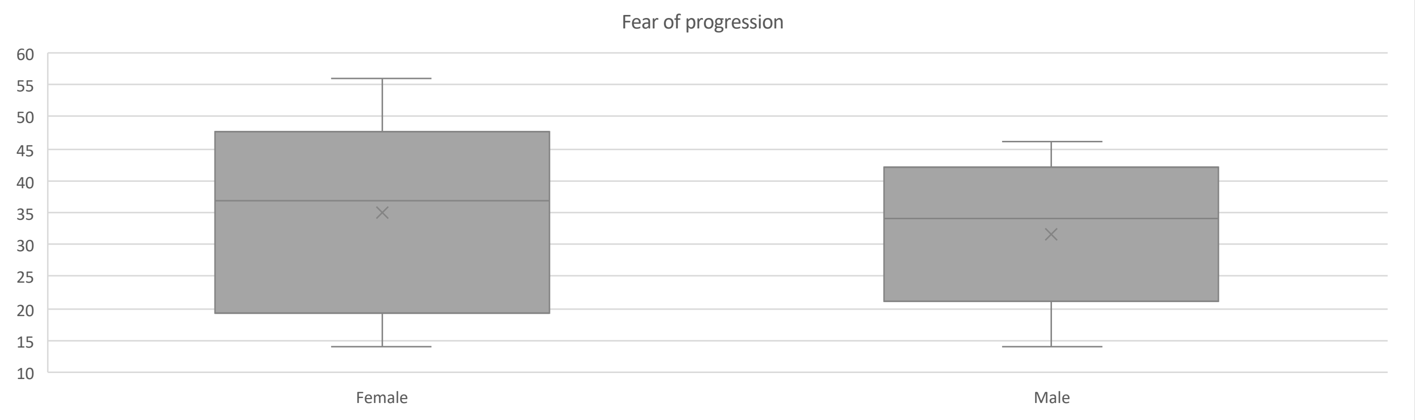

Figure 8.16: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged under 44 (n=7, 53.85%), and participants aged 45 and older (n=6, 46.15%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.28).

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(11) = 2.51 , p = 0.0289] was significantly higher for participants in the Aged 18 to 44 subgroup (Mean = 40.29, SD = 9.91) compared to participants in the Aged 45 and older subgroup (Mean = 24.83, SD = 12.29.)

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the Aged 18 to 44 subgroup scored higher than participants in the Aged 45 and older subgroup. This indicates that participants in the Aged 18 to 44 subgroup had moderate levels of anxiety, and participants in the Aged 45 and older subgroup had low levels of anxiety.

Table 8.28: Fear of progression total score by age summary statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 18 to 44	7	53.85	40.29	9.91	2.51	11	0.0289*
	Aged 45 and older	6	46.15	24.83	12.29			

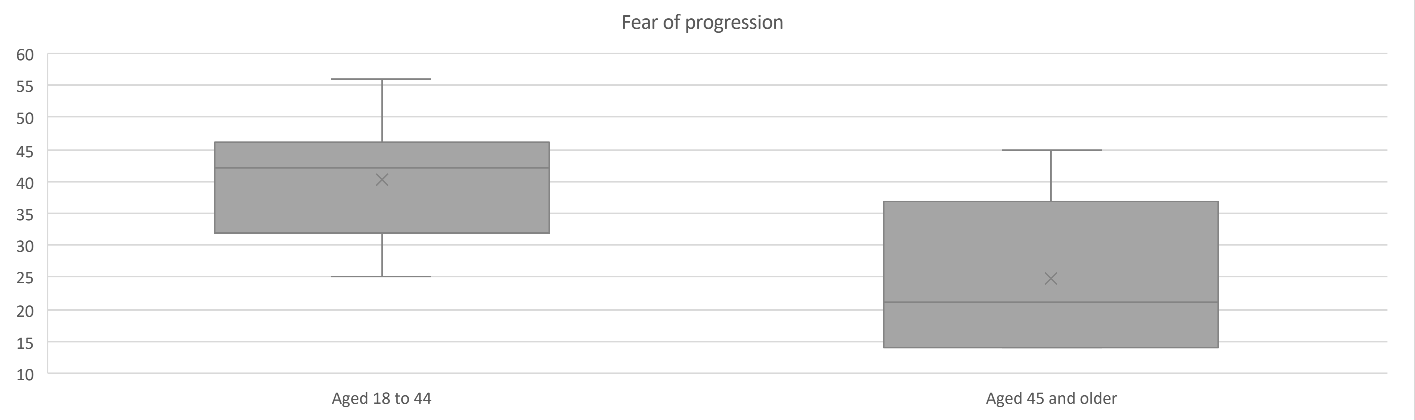

Figure 8.17: Boxplot of Fear of progression total score by age

Fear of progression by education

Comparisons were made by education status, between those with trade or high school qualifications, Trade or high school (n=5, 38.46%), and those with a university qualification, University (n=8, 64.54%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.29).

No significant differences were observed between participants by **education** for any of the Fear of progression scales

Table 8.29: Fear of progression total score by education statistics and T-test

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	5	38.46	30.00	16.23	-0.66	11	0.5222
	University	8	61.54	35.13	11.84			

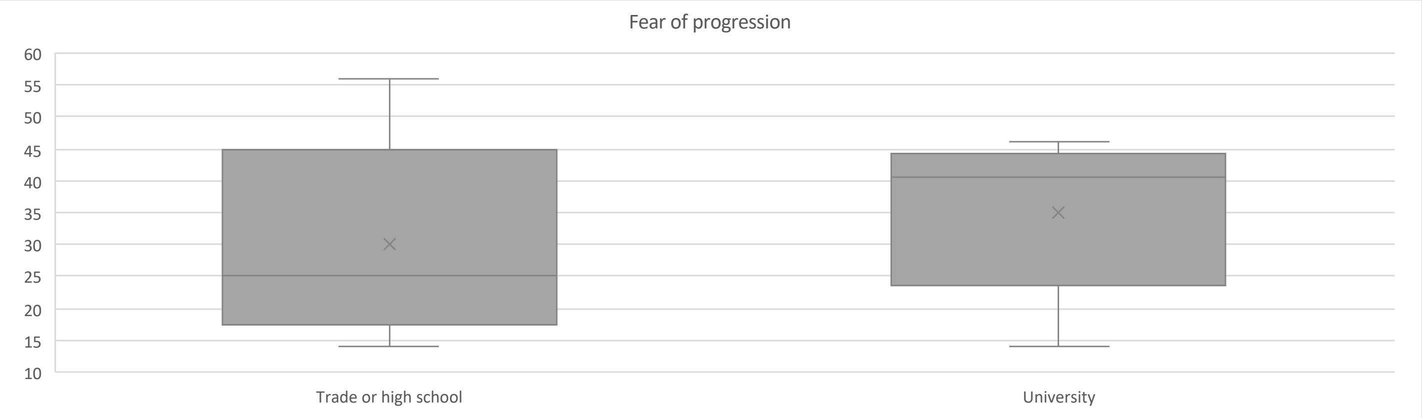

Figure 8.18: Boxplot of Fear of progression total score by education

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/rural areas, Regional or remote (n=3, 23.08%) were compared to those living in a major city, Metropolitan (n=10, 76.92%).

There were too few participants in the regional and remote subgroup to make comparison. Summary statistics are displayed in Table 8.30.

Table 8.30: Fear of progression total score by location summary statistics

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Total score	Rural or remote	3	23.08	18.67	4.04	21.00	3.50
	Metropolitan	10	76.92	37.50	11.85	40.50	11.75

Fear of progression 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=2, 15.38%) compared to those with a higher SEIFA score of 7-10, Higher status (n=11, 84.62%).

There were too few participants in the mid to low status subgroup to make comparison. Summary statistics are displayed in Table 8.31.

No significant differences were observed between participants by **socioeconomic status** for any of the Fear of progression scales

Table 8.31: Fear of progression total score by socioeconomic status summary statistics

Fear of progression	Group	Number (n=13)	Percent	Mean	SD	Median	IQR
Total score	Mid to low	2	15.38	17.50	4.95	17.50	3.50
	Higher	11	84.62	36.00	12.30	39.00	15.00

Experience of anxiety related to disease progression

Fear of progression individual questions

The average scores of the individual fear of progression questions are presented in Table 8.32 below.

On average, participants scored in the “Seldom” range for the following questions: “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=2.38, SD=1.39), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=2.00, IQR=2.00), “Anxious if not experiencing any side effects think it doesn’t work” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Becomes anxious thinking that disease may progress” (mean=3.15, SD=1.52), “Is nervous prior to doctors appointments or periodic examinations” (median=3.00, IQR=3.00), “Afraid of pain” (mean=2.85, SD=1.41), “Has concerns about reaching professional and/or personal goals because of illness:” (mean=2.62, SD=1.39), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=3.00, IQR=3.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (mean=2.54, SD=1.33), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (mean=3.00, SD=1.53), “Afraid of severe medical treatments during the course of illness” (mean=2.77, SD=1.30), “Worried that treatment could damage their body” (mean=2.92, SD=1.32), “Worried about what will become of family if something should happen to participant” (mean=2.77, SD=1.54), “The thought that they might not be able to work due to illness disturbs participant” (mean=2.85, SD=1.52).

Table 8.32: Fear of progression individual questions

Fear of progression (n=13)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.15	1.52	3.00	3.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.62	1.66	3.00	3.00	Sometimes
Afraid of pain	2.85	1.41	3.00	2.00	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.62	1.39	3.00	3.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.69	1.55	3.00	3.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.54	1.33	3.00	2.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.38	1.39	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.00	1.53	3.00	2.00	Sometimes
Afraid of severe medical treatments during the course of illness	2.77	1.30	3.00	1.00	Sometimes
Worried that treatment could damage their body	2.92	1.32	3.00	2.00	Sometimes
Worried about what will become of family if something should happen to participant	2.77	1.54	3.00	3.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.85	1.52	3.00	3.00	Sometimes
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.23	1.30	2.00	2.00	Seldom
Anxious if not experiencing any side effects think it doesn’t work	2.23	1.36	2.00	2.00	Seldom

*Normal distribution use mean and SD as measure of central tendency

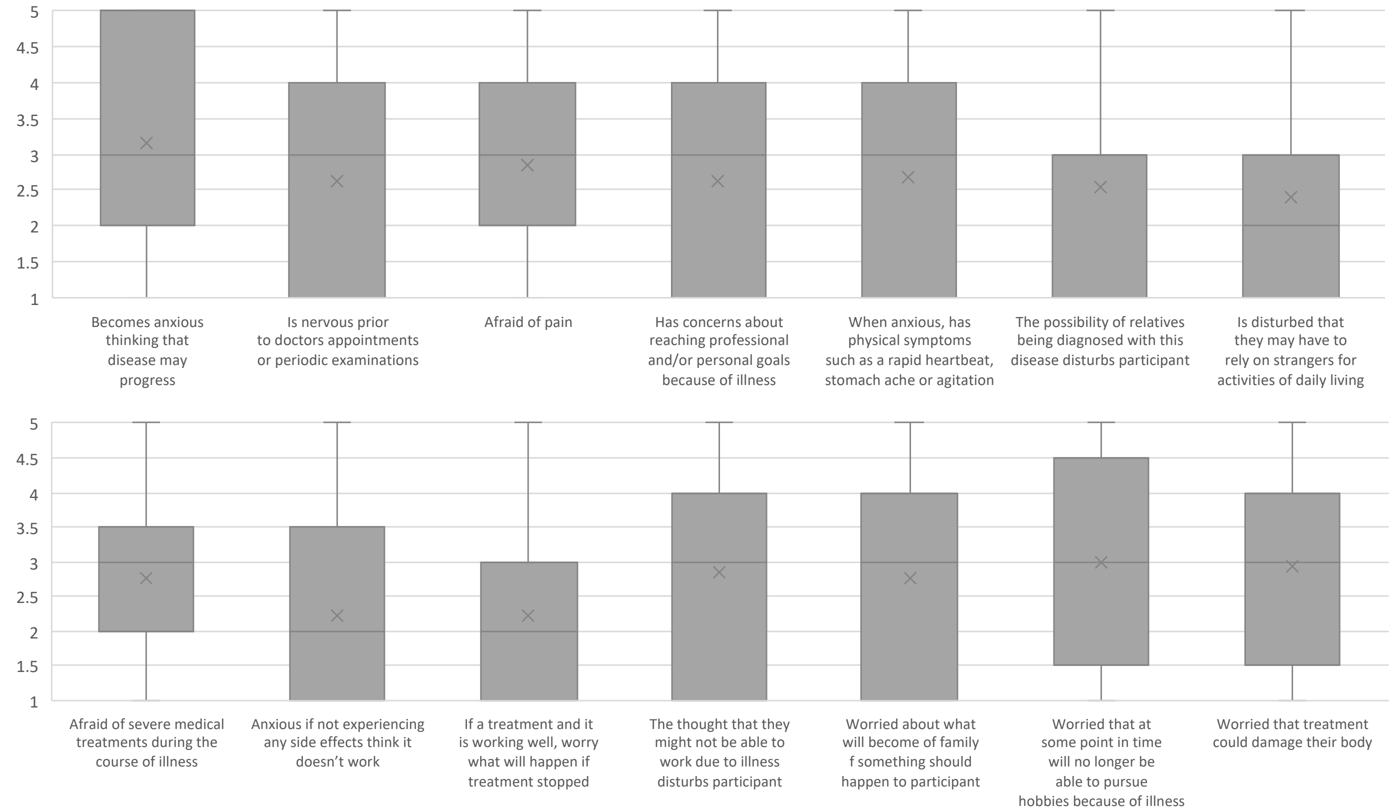

Figure 8.19: Fear of progression individual questions

Seldom worried about

- “Is disturbed that they may have to rely on strangers for activities of daily living”
- “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped”
- “Anxious if not experiencing any side effects think it doesn’t work”

Sometimes worried about

- “Becomes anxious thinking that disease may progress”
- “Is nervous prior to doctors appointments or periodic examinations”
- “Afraid of pain”
- “Has concerns about reaching professional and/or personal goals because of illness:”
- “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation”
- “The possibility of relatives being diagnosed with this disease disturbs participant”
- “Worried that at some point in time will no longer be able to pursue hobbies because of illness”
- “Afraid of severe medical treatments during the course of illness”
- “Worried that treatment could damage their body”
- “Worried about what will become of family if something should happen to participant”
- “The thought that they might not be able to work due to illness disturbs participant”

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 include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

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 responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%), provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

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 allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

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 it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67 %), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

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) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67 %). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

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. 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. Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), 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 were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67 %), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

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 include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

Future treatment will be curative

I would like to see a cure rather than treatment because I don't understand the extent of how much the treatments are effective?
Participant 004_2023AUHDV

Future treatment will be more affordable

I admit I've been in a fortunate situation. I mean, say, cost would obviously be something that would be an issue for someone that was actually not working and paying full price for medication.
Participant 007_2023AUHDV

Future treatments will have fewer or less intense side effects/more discussion about side effects

Okay. I would love to see medications reacting effectively, and I would also like to see medication that does not go with the bad side effects, Yeah.
Participant 009_2023AUHDV

Future treatments are important but we cannot ignore awareness and education

Like you know we've talked a bit today and a lot about how there wasn't a lot of people checking in with me between the diagnosis and you know years later when I got the treatment and I think that's the stigma.
Participant 011_2023AUHDV

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	4	33.33	2	33.33	2	33.33	2	25.00	**2**	**50.00**	**1**	**16.67**	**3**	**50.00**	1	100.00	3	27.27	1	100.00	3	27.27
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	3	50.00	0	0.00	0	0.00	3	27.27	0	0.00	3	27.27
Future treatment will be curative	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Future treatment will be more affordable	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Future treatments will have fewer or less intense side effects/more discussion about side effects	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future treatment will involve a more holistic approach	1	8.33	0	0.00	1	16.67	0	0.00	**1**	**25.00**	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future treatments are important but we cannot ignore prevention, awareness and education	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future treatments will allow for a normal life/quality of life	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	**1**	**25.00**	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

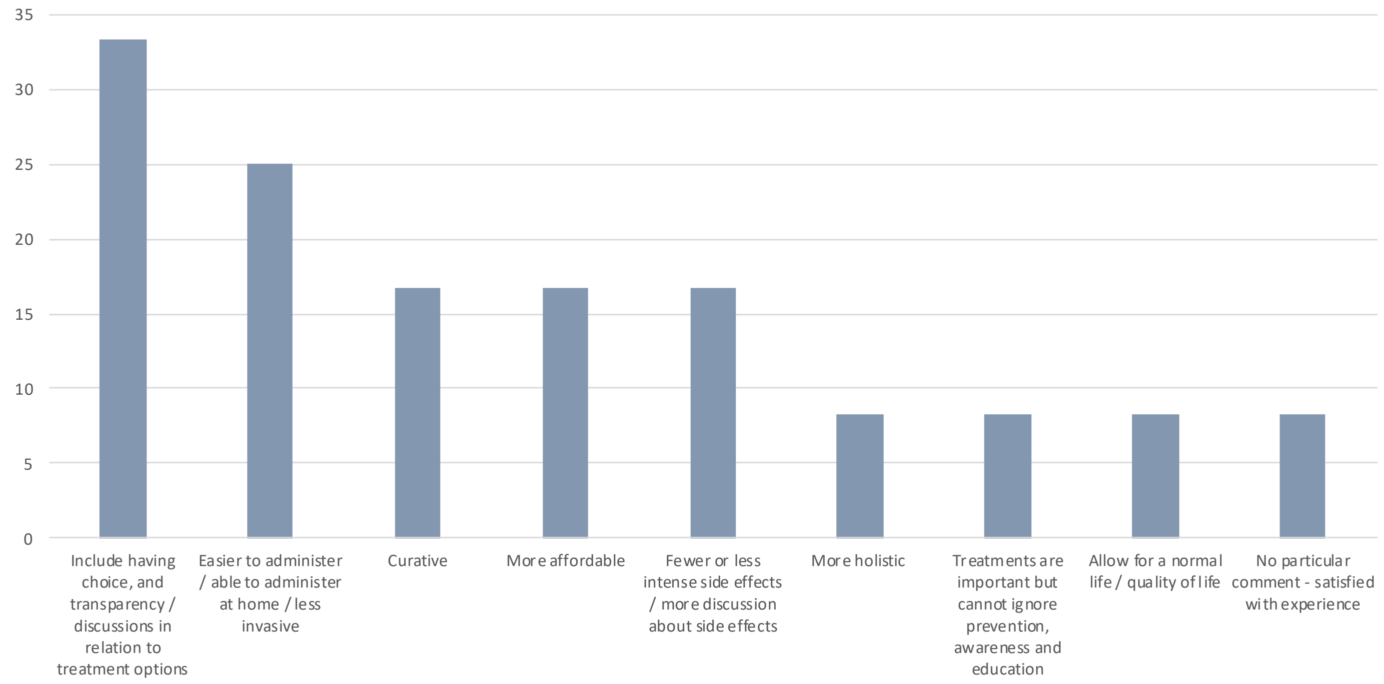

Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatments	Reported less frequently	Reported more frequently
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Trade or high school	Aged 45 and older University

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 responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%), provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

Future information will be more holistic (including emotional health)

I think to really see it through the eyes of sexual health and potential partner. I think that they need some resources out there that is understood and that they've got options to go through. So I know that

there are some, some of the hepatitis associations offer a foreign counselling service, which I think can be very helpful, but I think it's targeting a bit of that and also family impacts. Just something educational for them.
Participant 004_2023AUHDV

Future information will be in a variety of formats

I'm very old fashioned so I'm not into all the online and support chat groups online and all that sort of stuff…talking to people face to face, and I still think that's pretty important face to face, even if you are doing telehealth. Participant 007_2023AUHDV

Future information will be more accessible/easy to find

I want information about all kinds of hepatitis or the information from A-Z. Everything that I need to know, everything that the patient need to know. I would love to know about this. At least I can read about it. At least I can know and understand it more better.
Participant 001_2023AUHDV

Future information will provide more details about disease trajectory and what to expect

Yeah, one for information, I would like for you to detail the medication process and then what I should get involved with. Participant 009_2023AUHDV

Future information will provide more details about where to find support (including peer support/support groups)

The more contact information for people who can offer the people who are diagnosed support you know the you know. Making sure people feel connected if they feel overwhelmed technically, in whatever way, is simplest.
Participant 010_2023AUHDV

Future information will be available in languages other than English

Yeah, I guess the the language, I mean, there's a model of thing written in. So they use both Chinese and Korean. So they understand the language if they search online. Yes. And I don't know because we are not living near the. Like a it shouldn't popular ohh we...but we don't live in near enough to those who can like those community, they provide those information. So it's always English when we attend appointment. Information are always in English. Maybe, I don't know, maybe they can have a database with different language and they just print out the education material.
Participant 003_2023AUHDV

Future information will provide more details about transmission

The transmission pathways like specifically around how you interact with other people…I think that really needs to be made clearer to people at the point of diagnosis or immediately after that.
Participant 011_2023AUHDV

No particular comment - satisfied with experience

No, I think the info that I've searched on Internet is is fine.
Participant 005_2023AUHDV

Table 9.3: Expectations of future information

Expectations of future information	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future information will be easier to understand	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will be more holistic (including emotional health)	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will help to inform the community and decision-makers about their condition (raise awareness)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will be in a variety of formats	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future information will be more accessible/easy to find	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future information will include the ability to talk to/access to a health professional	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future information will provide more details about disease trajectory and what to expect	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details about where to find support (including peer support/support groups)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details to support carers	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will be available in languages other than English	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details about transmission	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

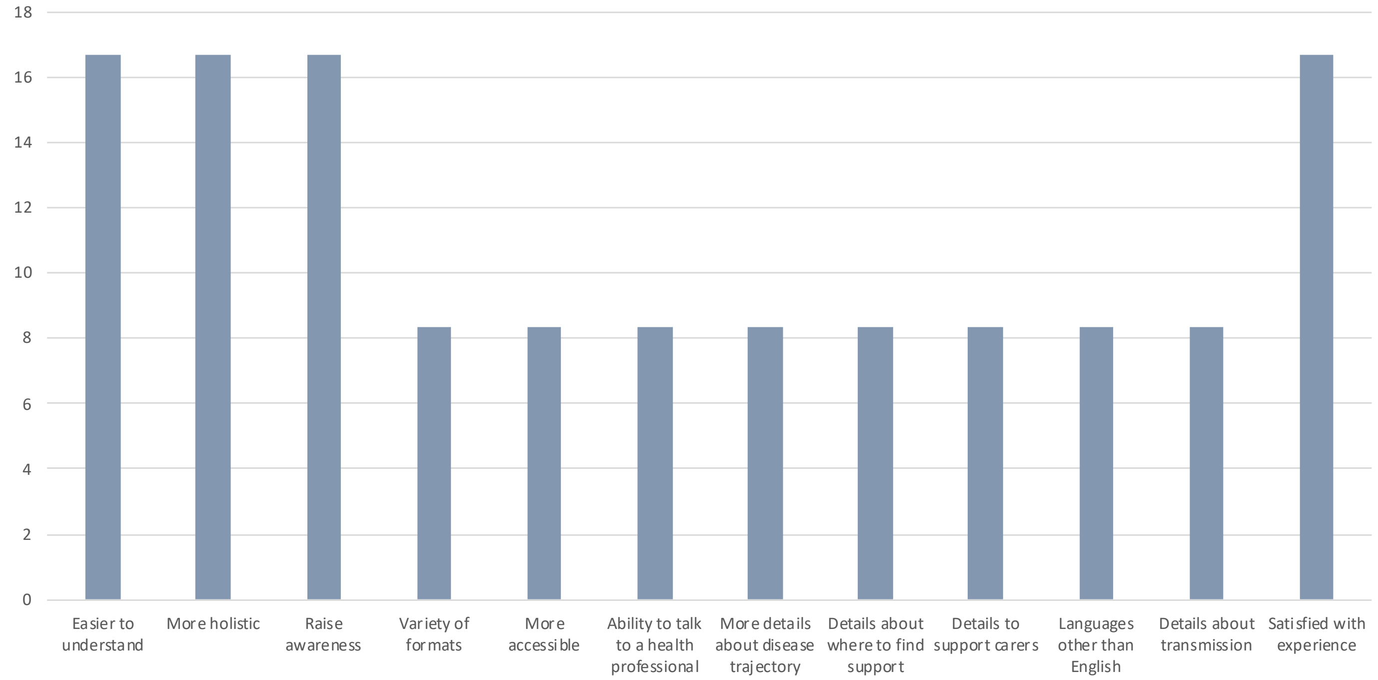

Figure 9.2: Expectations of future information

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 allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

Future communication will allow people more time to meet with their clinician

Yeah, I would just say if there is no, if the doctors would you know, create more time you know to interact with the patients, I think that would help upload or you know bringing up you know more of them. With all the means of communication instead of in person communication or visit, I think that would help because you can talk and the patients can reach out at any time and have a discussion like a friend. That would be great.
Participant 006_2023AUHDV

Future communication will be more transparent and forthcoming

You see what they just say. You are all good. Your blood results are all good…But they are not actually telling me what to avoid. What triggers it to be active. What should I do? What should I avoid? You know, you know, all those that information at least I know for sometimes, probably I'm doing something that makes it active. But I don't know, they never told me.
Participant 001_2023AUHDV

We don't really like the first hepatologist. No hepatologist. Yeah, hepatologist, yeah. So we think he didn't give us enough information. So the most most of the education received was from the GP. For this hepatologist, he just gave us the blood test, but he never really explained things. So that's one of the reason we want to change the hepatologist, yeah.
Participant 003_2023AUHDV

Future communication will be more empathetic

Just trying to make sure that the patients in that space are comfortable in that particular space.
Participant 009_2023AUHDV

Future communication will include listening to the patient

I think it's very much that the professionals need to realize that they're not the only ones that know stuff…so I'm going to tell you exactly what you need to know and you need to do.
Participant 007_2023AUHDV

Future communication will include developing a care plan with follow-up

I'm really over the hospital system's rigidity in how everything's coordinated and I know it comes back down to the state and the hospital that you're being monitored for. After being monitored in two states, I just find it really, really frustrating that you have no control over your scans, your blood tests and when your appointment is coming.
Participant 004_2023AUHDV

Future communication will raise awareness of the condition

No, I just think like I said, most of the health professionals were fantastic. So I just think raising awareness through the not for profits and through all the various public hospitals and their support people GP's you know.
Participant 010_2023AUHDV

No particular comment - satisfied with experience

No, at least my GP was clear.
Participant 005_2023AUHDV

Table 9.4: Expectations of future healthcare professional communication

Expectations of future communication	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future communication will allow people more time to meet with their clinician	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future communication will be more transparent and forthcoming	3	25.00	2	33.33	1	16.67	3	37.50	0	0.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future communication will be more empathetic	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Future communication will include listening to the patient	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future communication will include developing a care plan with follow-up	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future communication will be more understandable	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future communication will raise awareness of the condition	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

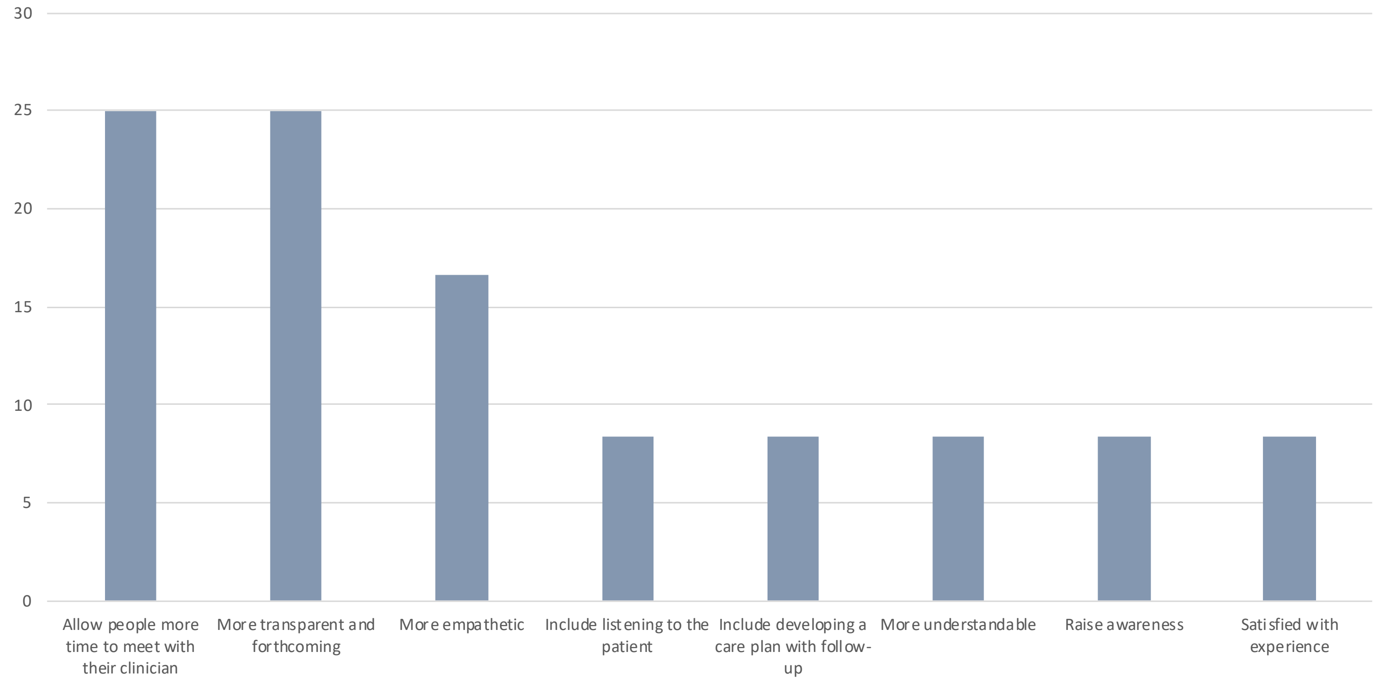

Figure 9.3: Expectations of future healthcare professional communication

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 it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67 %), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I just think a support group at all the hospitals…You know when the hospitals are overwhelmed or whatever that meets once a month and that you know supports those people.
Participant 010_2023AUHDV

Future care and support will include more access to support services

Just more support whether that's through a charity or through primary healthcare, yeah, but the short answer, yes, absolutely.
Participant 011_2023AUHDV

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

If there's a way we can get you all the information every time and then, yeah, I can. I'm happy to receive information. I'm happy to go and sit down and. Ask questions when I feel that I need to ask something.
Participant 001_2023AUHDV

Would like to see assistance from medical professionals, from the specifically from the field of medical professionals.
Participant 009_2023AUHDV

Future care and support will be more holistic (including emotional health)

Well, if there is one, one of the services I think should really up and cherish to would be mental support.
Participant 006_2023AUHDV

Future care and support will include health professionals with a better knowledge of the condition

Have the ability to tap into the specialists and are willing to because I've found sometimes I think ohh no, well you're our patient and we're going to tell you what to do and you'll do it our way and then you talk to the specialist in CITY they say well actually you should be doing this. So you you're sort of getting mixed messages. Participant 007_2023AUHDV

Future care and support will include support in non-English languages

I would love to have more again the language specific support. Yeah, maybe in the hospital if you need to like, admit to the hospital.
Participant 003_2023AUHDV

Future care and support will include more advocacy

I think it's just due to the amount of that shame that people are in with hepatitis. It's just a virus that has been around for too long that people haven't got that upset about and that out there with that, there's been enough noise. Participant 00_2023AUHDV

Table 9.5: Expectations of future care and support

Expectations of future care and support	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future care and support will include more access to support services	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will be more holistic (including emotional health)	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include practical support (home care, transport, financial)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include a multidisciplinary and coordinated approach	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future care and support will include health professionals with a better knowledge of the condition	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future care and support will include support in non-English languages	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future care and support will include more advocacy	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

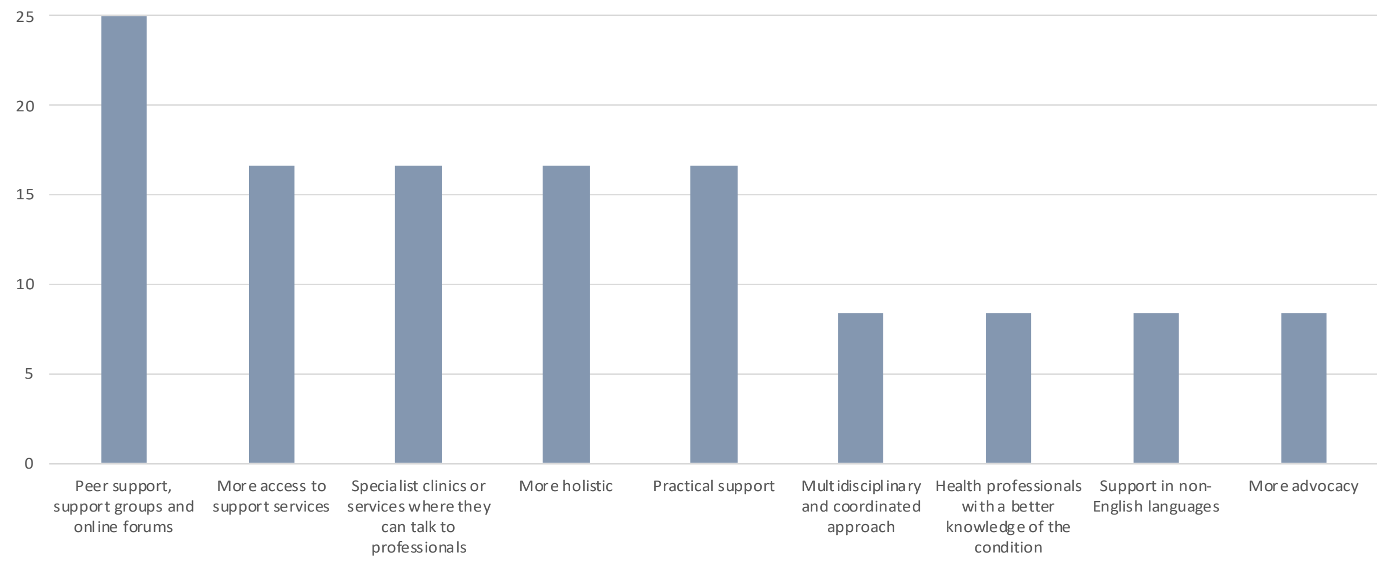

Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67 %). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

Participant describes being grateful for healthcare staff (including access to specialists)

Basically that I have been able to access things easily and the what that I've been able to link into well talking particularly the hepatitis nurses …because even if you can't talk to the doctor, you know that if it's something that they're not familiar with especially with the hep D, they will get on the doctor and get back to you.
Participant 007_2023AUHDV

I was particularly grateful for the specialists and their support staff They were just so transparent about everything.
Participant 010_2023AUHDV

Yeah, first thing I am grateful for the, should I say, to the high…treatment for medical professionals. Yeah, I'm quite thankful and I'm glad for that. Yeah.
Participant 009_2023AUHDV

Participant describes being grateful for low cost/free medical treatments through the government

For all the negatives we talked about, I mean I think one thing mentioned other is, is the is the cost as a lack thereof, I think it was, it was accessible and affordable… But the the main thing I think I'm grateful for is, is, is the affordability and I think that's critical.
Participant 009_2023AUHDV

So long as it's public and not like in America, it's like $40,000.
Participant 002_2023AUHDV

Participant describes being grateful for timely access to diagnostics

I'm grateful I do the test every time. At least I'm being monitored. That's why I'm grateful that I get monitored every time, so if something goes wrong, at least I can catch it early.
Participant 001_2023AUHDV

Participant describes the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition

It's actually hard to get another appointment in when you need one…so I would say that part has been really hard of I guess the hospital to patient ratio care. Yeah, that it is hard to get a breakthrough kind of question when you need to do so.

Table 9.6: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being grateful for healthcare staff (including access to specialists)	4	33.33	1	16.67	3	50.00	2	25.00	2	50.00	2	33.33	2	33.33	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes being grateful for low cost/free medical treatments through the government	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being grateful for access to private healthcare/private insurance	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being grateful for the entire health system	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being grateful for timely access to diagnostics	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the need for quicker access to treatments	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not being grateful for anything	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

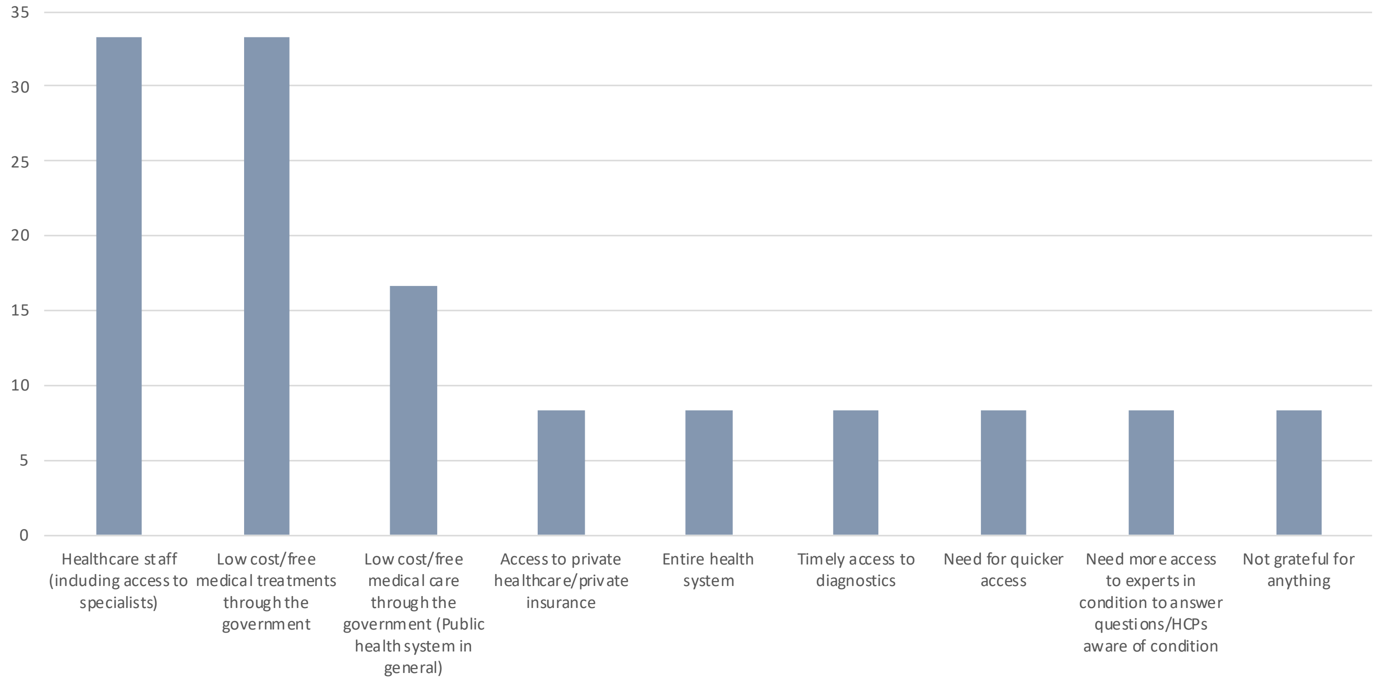

Figure 9.5: What participants are grateful for in the health system

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.7, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

Table 9.7: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=13)
Feeling tired, fatigued, or generally weak	5.38
Liver cirrhosis or fibrosis	4.54
Nausea and/or vomiting	3.92
Mood changes (such as depression, anxiety, irritability)	3.77
Swollen abdomen	3.69
Loss of appetite	3.38
Muscle or joint aches and pains	3.31

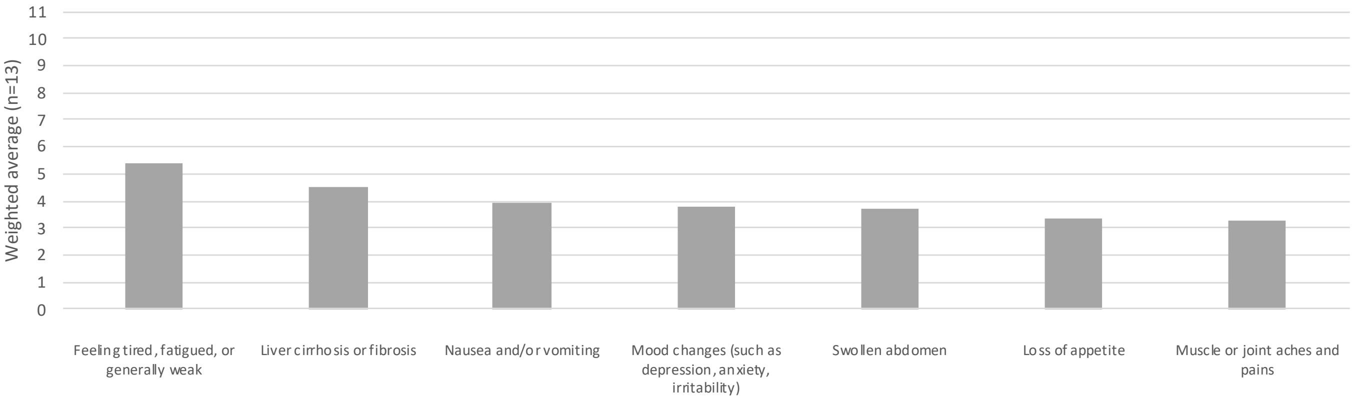

Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were “"How safe the medication is and weighing up the risks and benefits"”, and “"The severity of the side effects"”. The least important were “"The ability to include my family in making treatment decisions"” and “"Ability to follow and stick to a treatment regime"”.

Table 9.8: Values in making decisions

Values in making decisions	Weighted average (n=13)
How safe the medication is and weighing up the risks and benefits	6.23
The severity of the side effects	6.00
Time impact of the treatment on my quality of life	5.38
How the treatment is administered	4.54
How personalised the treatment is for me	3.77
The ability to include my family in making treatment decisions	3.00
Ability to follow and stick to a treatment regime	2.85
The financial costs to me and my family	4.23

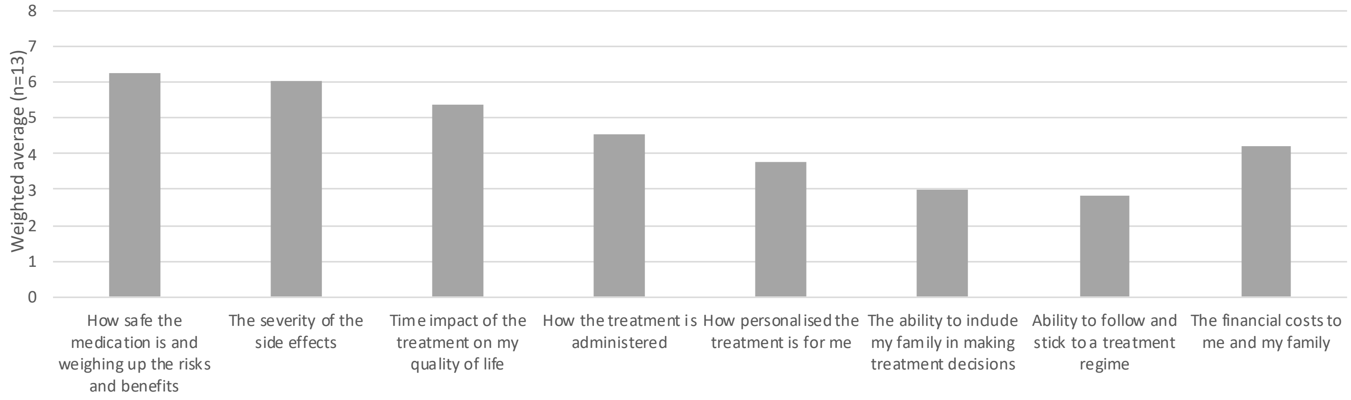

Figure 9.7: Values in making decisions

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 9.8. 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 9.9: Values for decision makers

Values for decision makers	Weighted average (n=13)
Economic value to government and tax payers	1.77
Economic value to patients and their families	3.38
Quality of life for patients	3.38
Compassion	2.85
All patients being able to access all available treatments and services	3.62

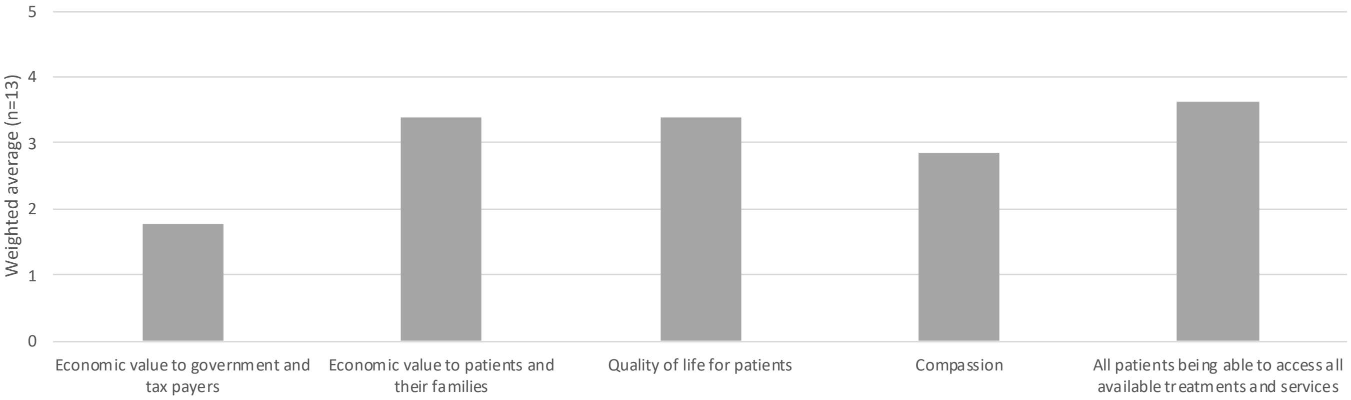

Figure 9.8: Values for decision makers

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.

Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), for a good quality of life even if it didn't offer a cure.

Table 9.10: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=13)	Percent
Less than a year	4	30.77
1 to 5 years	3	23.08
6 to 10 years	2	15.38
More than 10 years	4	30.77

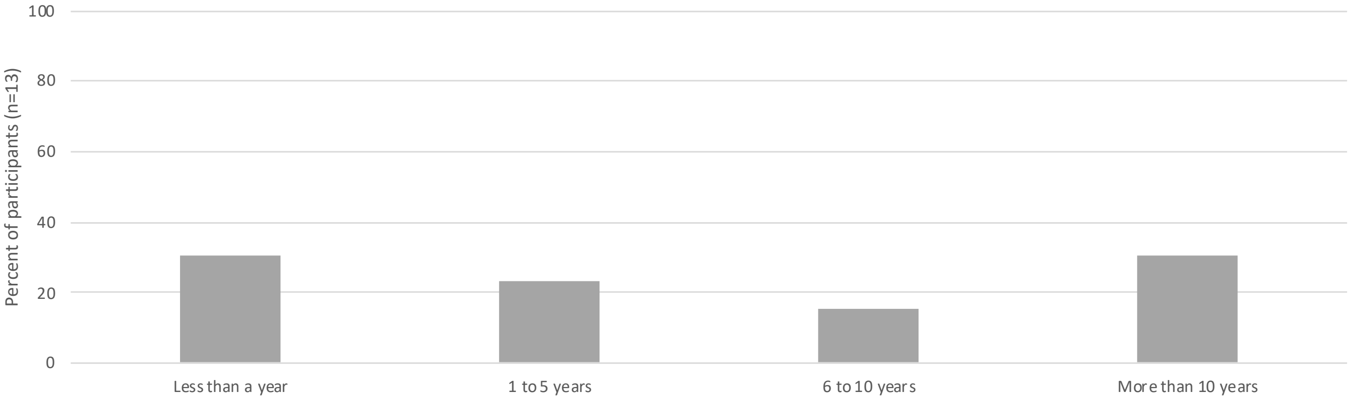

Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

There were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

Table 9.11: Most effective form of medicine

Treatment most effective in what form	Number (n=13)	Percent
IV form (through a drip in hospital)	2	15.38
In a pill form that can be taken at home	6	46.15
Equally effective	4	30.77
Not sure	1	7.69

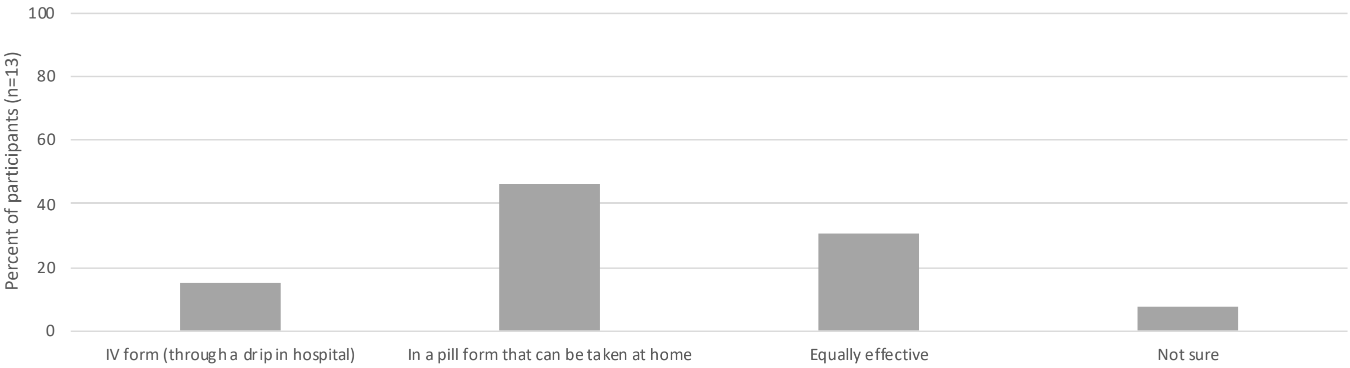

Figure 9.10: Most effective form of medicine

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 message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67 %), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

Timely and equitable access to support, care and treatment

I think that they need need to be conscious of the fact that it's a continuum of care, it's not just one type of hepatitis…I think as a the Minister, it's easy to look and say, right, well, we're giving you that for that. But that only treats part of the hepatitis, just one type. It doesn't, it doesn't cover everything. I think that's one of the big things is it's seen as a fairly narrow field to treat without realizing that you do have the extremes that need to be covered as well.
Participant 007_2023AUHDV

I think they should have all the support and care that they need and be given all the resources that they need and support from the beginning of their journey right to the end all.
Participant 010_2023AUHDV

Well, I'm not homeless or anything but most nights to the homeless free kitchen and like I know for me I got to get like a blood of your free form get a blood care and I don't know how easy I would kind of. Organize if you're like homeless for living on the street some kind of access you have. I know we got a health care type that comes and if you know LOCATION, but there's a. Like the homeless the healthcare truck comes for like couple of weeks. I don't know what they do. I know they do blood tests.
Participant 002_2023AUHDV

Treatments need to be affordable

Free medication.
Participant 005_2023AUHDV

Maybe to tell him to give free treatment to people with who need the treatment.
Participant 001_2023AUHDV

Invest in research (including to find new treatments)

We are spending too much on a disjointed healthcare system, I would say, and that we're not actually progressing with hep in treatments or in cure.
Participant 004_2023AUHDV

Holistic approach to the condition (including emotional support)

I would actually tell him that we have access to advice and the views relating to mental health issues and we

also have access to the way to cure and go about the virus and we always have access to knowing that someday somehow you would actually be cured here.
Participant 009_2023AUHDV

Well, I I would just get, you know, mention a few things. You know, like introduction of mental support. Yep. Not just to patients with hepatitis but other patients. I think these are one of the things that would, you know, first mention time.
Participant 006_2023AUHDV

Grateful for the healthcare system and the treatment that they received

We still have things to control it, so I don't have anything to complain and I'm very grateful we have Medicare system in Australia so we actually burden is less. So I don't need to worry about something really happened, like suddenly and I will be out of pocket.
Participant 003_2023AUHDV

Table 9.12: Messages to decision-makers

Message to decision-makers	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Timely and equitable access to support, care and treatment	6	50.00	**2**	**33.33**	**4**	**66.67**	**3**	**37.50**	**3**	**75.00**	**4**	**66.67**	**2**	**33.33**	1	100.00	5	45.45	1	100.00	5	45.45
Treatments need to be affordable	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Invest in research (including to find new treatments)	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Help raise community awareness	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Holistic approach to the condition (including emotional support)	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Grateful for the healthcare system and the treatment that they received	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

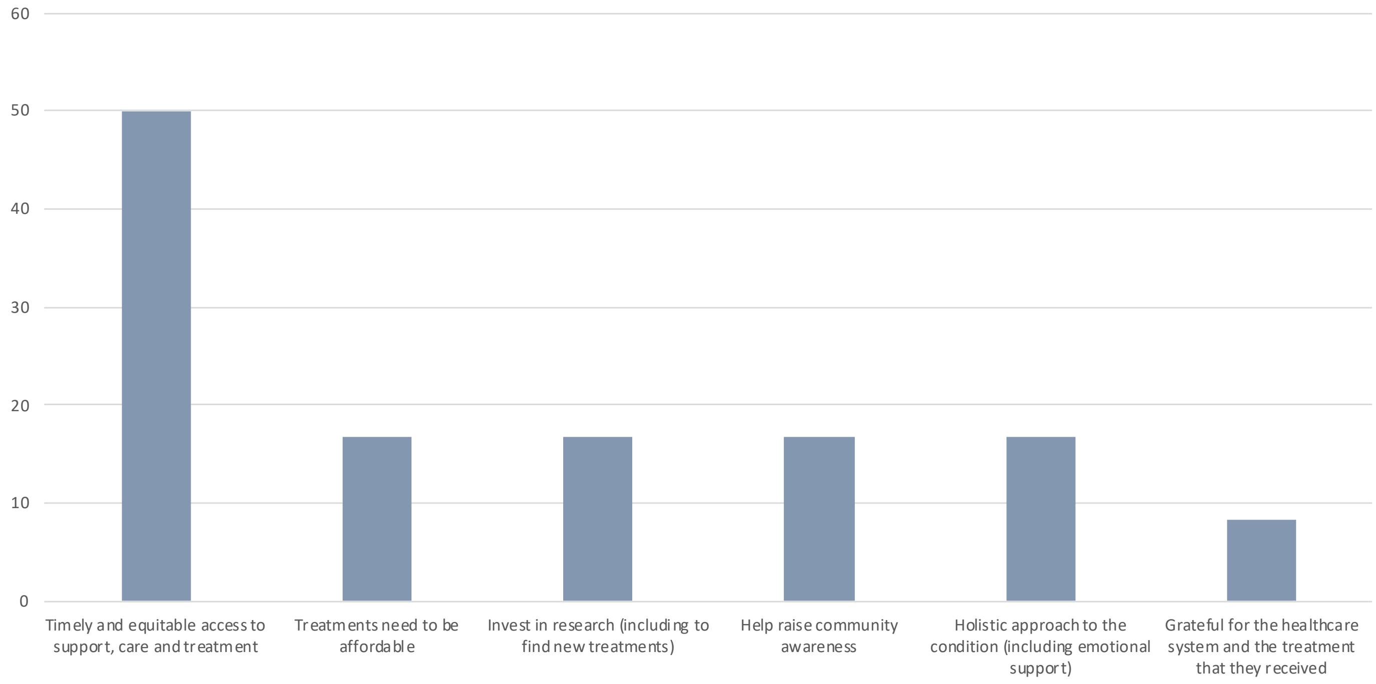

Figure 9.11: Messages to decision-makers

Table 9.13: 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	Female Aged 18 to 44 University	Male Aged 45 and older Trade or high school

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 to ask questions (50.00%), and that they had understood the cause and risk factors of the condition (16.67%). Other themes included to be open to complementary approaches (8.33%), to look after emotional wellbeing (8.33%), that there was more community awareness of their condition (8.33%), and that they had understood the extent of the transmission risk they posed to others (8.33%).

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 theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33 %), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).

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 to ask questions (50.00%), and that they had understood the cause and risk factors of the condition (16.67%). Other themes included to be open to complementary approaches (8.33%), to look after emotional wellbeing (8.33%), that there was more community awareness of their condition (8.33%), and that they had understood the extent of the transmission risk they posed to others (8.33%).

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

Maybe on how to control it and asked whether it could lead to other kinds of hepatitis. Probably I should have known earlier, yeah.
Participant 001_2023AUHDV

Participant wishes they had understood the cause and risk factors of the condition

Yeah, why I I just wish you know, there was a way. I was informed about this earlier, you know… I had no clue about this and I would have known what to do in order to prevent this from occurring in the first place. I think that would have been great if I had known, you know, stop doing this or that. I think I would have prevented, as some people would say, you know, if I could look into the future, then this situation wouldn't be occurring at all. So that's just what I wish to talk.
Participant 006_2023AUHDV

Participant wishes they had known to look after emotional wellbeing

The emotional impact being diagnosed at a very formative age, I think that there could have been a bit more intervention about the emotional impact. That I carried on my own for so long.
Participant 004_2023AUHDV

Participant wishes that there was more community awareness of their condition

I think just in general with I think they're up to about hepatitis E or F or something nowadays. There needs to be some education around the fact that there isn't just hepatitis has a disease…it's a range of conditions that basically have the one symptom.
Participant 007_2023AUHDV

Participant wishes they had understood the extent of the transmission risk they posed to others

Like specifically about physical contact and the the do's and don'ts there, because I was very much left in the dark…I would have, I would have liked, I would have liked to have known a bit more about that and had that explained.
Participant 011_2023AUHDV

Table 10.1: Anything participants wish they had known earlier

THEME	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	6	50.00	**2**	**33.33**	**4**	**66.67**	**5**	**62.50**	**1**	**25.00**	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Participant wishes they had understood the cause and risk factors of the condition	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant wishes they had known to be open to complementary approaches	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant wishes they had known to look after emotional wellbeing	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant wishes that there was more community awareness of their condition	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant wishes they had understood the extent of the transmission risk they posed to others	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant had no particular comment and were satisfied with experience	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	1	16.67	1	16.67	1	100.00	1	9.09	1	100.00	1	9.09
No particular comment/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18

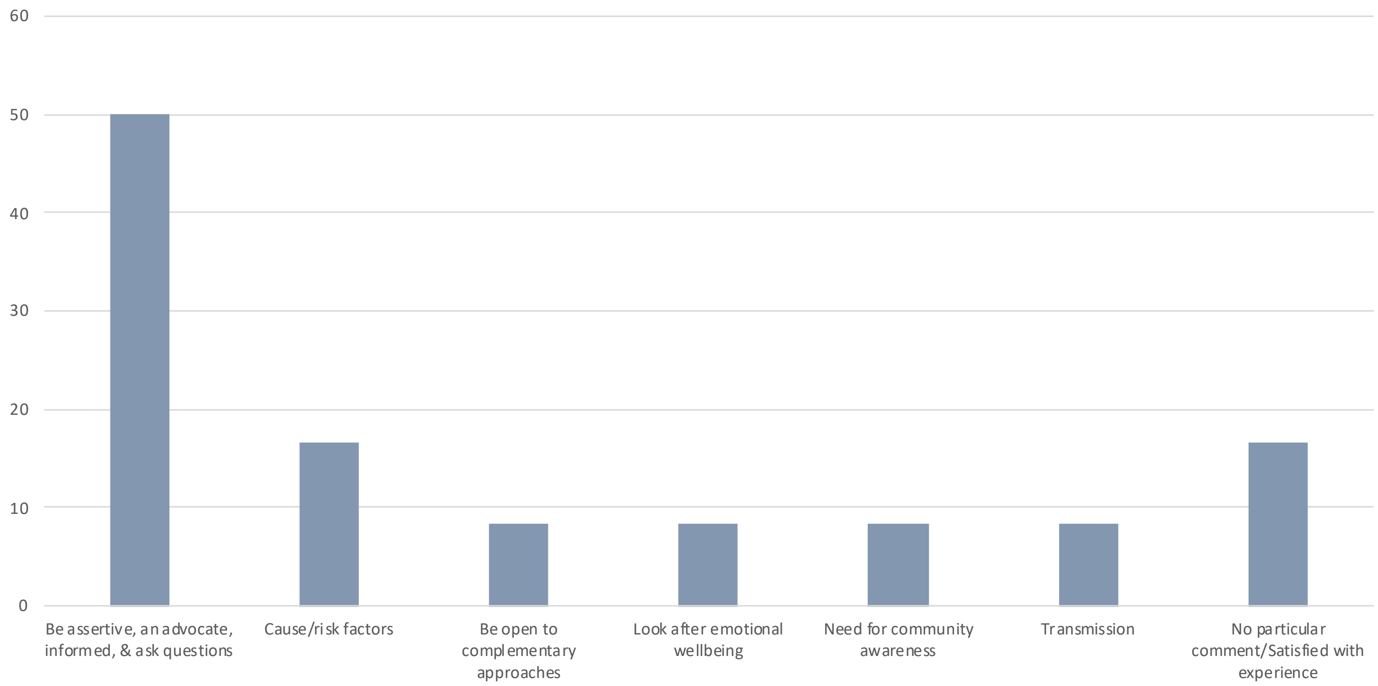

Figure 10.1: Anything participants wish they had known earlier

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 wishes they had known to be assertive, an advocate, informed, and ask questions	Female Aged 45 and older	Male Aged 18 to 44

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 theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33 %), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).

Participant would not change any aspect of their care or treatment, with no reason given

No, no, no. Not that moment of nothing.
Participant 001_2023AUHDV

Participant would have liked to have access to a specialist in their condition, sooner

The only thing possibly would be to have started treatment earlier, but that was purely a case of the circumstances at the time.
Participant 007_2023AUHDV

Participant would have liked to have access to care closer to home

PARTICIPANT: Not really. I tried to find someone who can speak that language. Yes. Yeah, but I I can't. INTERVIEWER: OK. Yeah. OK. Yeah, those. PARTICIPANT: We have some available, I think more near the city or...Um, yeah, but it just took time to travel.
Participant 003_2023AUHDV

Participant would have liked to have had more monitoring of their condition and earlier access to treatment

Yeah, definitely. Related to the question we just talked about, yeah, I would have liked more monitoring between the diagnosis and getting onto the treatment… I think it really was sort of an accident that I even got asked about it…I would have liked much more monitoring of my condition, specifically around my liver health, because I could have gone on to those treatments a bit earlier and maybe it would have been easier to treat.
Participant 011_2023AUHDV

Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received

I might have more access to clinical trials in the future, so I would still choose to be monitored by the hospital. I think one of the good things is even though I'm monitored twice a year, one point of time in the year, it should be telehealth and the rest because they want me to go in for a fibro scan at the day and everything else. So yeah I guess more to monitor the progression part and knowing about other kinds of hepatitis. Participant 004_2023AUHDV

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant would not change any aspect of their care or treatment, with no reason given	5	41.67	3	50.00	2	33.33	4	50.00	**1**	**25.00**	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant would have stopped or changed treatment sooner	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have access to a specialist in their condition, sooner	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant would have liked to have access to care closer to home	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have access to doctors that speak their language	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant would have liked to have had more monitoring of their condition and earlier access to treatment	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant is not sure if they would change anything	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09

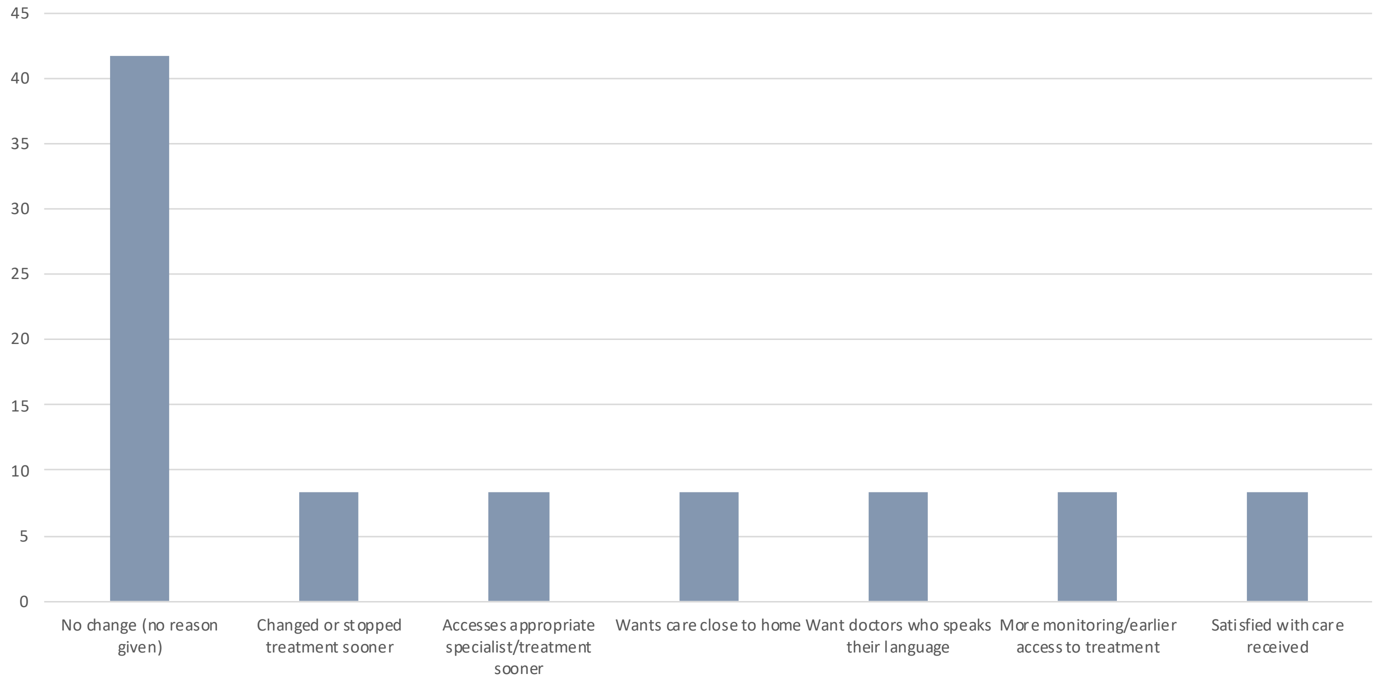

Figure 10.2: Aspect of care or treatment they would change

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, with no reason given	Aged 45 and older	-

Section 11

Discussion

Introduction

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 HER2 hepatitis D includes 16 people diagnosed with hepatitis D throughout Australia.

Following a PubMed search (March 6, 2023) very few studies of the experience of people with hepatitis D were found. As people with hepatitis D are co-infected with hepatitis B, studies of the experience of people with hepatitis B are included in this discussion.

Background

Hepatitis D is a viral hepatitis that can only replicate with Hepatitis B. Hepatitis D infection may occur simultaneously with hepatitis B (coinfection),or can occur in chronic Hepatitis b (superinfection)[1]. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure[2]. Superinfection is the most common form of hepatitis, and has a higher risk of cirrhosis and liver cancer[2-4].

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare[5]. The majority of hepatitis D patients are asymptomatic, symptoms can include fever, abdominal pain, nausea, vomiting, jaundice, confusion, bruising, or bleeding , loss of appetite, dark urine, and pale-coloured stools [5,6].

Hepatitis is more common in the Middle East, West and Central Africa, Amazonian river basin, Mongolia, Romania, Russia, Pakistan, Georgia, and Turkey[7].

In Australia 2016, 61 cases of hepatitis D were notified, with an average of 48 cases annually in the period 2011-2015, most cases were reported from New South Wales, Victoria, and Queensland[8]. In Australia, hepatitis D is more common in people born in Vietnam, Sudan, and Afghanistan, and there is a higher risk for anyone who has ever been in prison[9]. More males than females have hepatitis D in Australia, at a rate of 2:1[8].

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 hepatitis D.

In this PEEK study, the proportions of participants that lived in areas with non-school qualification qualifications (certificate, diploma or degree), and the proportion in paid employment were all similar to that of Australia. There were more that lived in major cities, and in areas with higher socioeconomic status compared to the Australian population[10,11] There were no participants from the Northern Territory, or Canberra, or Tasmania, and there were a higher proportion of participants from Victoria, and similar proportions from New South Wales, Queensland, South Australia and Western Australia compared to the proportion that live in each state[12].

Table 12.1: Demographics

Demographic	Australia %	Hepatitis D PEEK %
Live in major cities	71	81
Non-school qualification	65	69
Higher socioeconomic status (7 to 10 deciles)	40	88
Employment (aged 15 to 64)	74	75
New South Wales	32	31
Victoria	26	38
Queensland	20	19
South Australia	7	6
Western Australia	10	6
Tasmania	2	0
Northern Territory	1	0
Australian Capital Territory	2	0

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 hepatitis D participants.

Other health conditions

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[13]. 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%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[13]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[13].

In this PEEK study, participants had higher levels of anxiety (50% compared to 13%), depression (50% compared to 10%), arthritis (29% compared to 15%), asthma (21% compared to 11%), COPD 14% compared to 3%), and cancer (14% compared to 2%) compared to the Australian population.

In this PEEK study, 86% of participants had comorbidities, most commonly anxiety and depression. Another study described lower rates of 25% with comorbidities[14], the difference may be due to the types of comorbidities included. Other hepatitis B studies described listed liver disease, anxiety, and depression as common comorbidities[14-17]. In this PEEK study, 50% had depression, 50% had anxiety, and 50% had other liver disease.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[18]. 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[18].

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 hepatitis D community in this PEEK study compares with the Australian population[19]. The hepatitis D PEEK participants on average had considerably lower scores for all SF36 domains with the exception on SF36 Pain. Other studies of participants with hepatitis B have also described worse health-related quality of life compared to the general population[15,20,21].

While 75% of people in this PEEK study were in paid employment, physical health problems interfered with daily activities including work.

There was one study that described health-related quality of life for people with hepatitis D, it described that health related quality of life was lower for the functional well-being, worry, and activity impairment domains compared to those with hepatitis B [22]. This is consistent with the current PEEK study where participants had limitations in function due to physical health.

In other studies of people with hepatitis B, comorbidities, in particular anxiety, depression and liver disease were negatively associated with health-related quality of life[15,16]. The high rates of comorbidities in this PEEK study may contribute to reduced quality of life. Other studies reported that being male, having current life stressors, unemployment, low social support, and undergoing current treatment were negatively associated with health related quality of life for people with hepatitis B [21,23-25]. Health quality of life for people with hepatitis B improved following treatment[21,25-27], and being male, and younger was positively associated with health-related quality of life[21,23].

Key points

- **High rates of anxiety and depression**
- **Poor quality of life compared to general population**

Risks and Symptoms

So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010_2023AUHDV

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.

More than half of the participants in this study were asymptomatic before diagnosis. For those that had symptoms before diagnosis, the most common symptoms were fatigue, abdominal pain, muscle or joint pain, jaundice, nausea vomiting, fever, bloating, and changes to bowel movements. Similarly for studies of people with hepatitis B, other studies describe participants being asymptomatic, having pain, fatigue, jaundice, bloating, iirritability poor appetite, nausea, flu like symptoms, and being ggenerally unwell[14,28].

Screening and diagnosis

Hepatitis D is diagnosed from a blood test, where high levels od anti-HDV immunoglobulin G (IgG) and immunoglobulin M (IgM)[5]. Hepatitis B is diagnosed with a blood test, there are three serological markers, the hepatitis B surface antigen (HBsAg) which indicated active infection, , antibodies to HBsAg (anti-HBs) which show resolved infection or successful vaccination, and antibodies to hepatitis B core protein (anti-HBc) which indicates past or present infection[29]. HBV DNA testing, liver function tests, and assessment of liver fibrosis is recommended for people with chronic hepatitis B to determine eligibility for antiviral therapy[29].

In this PEEK study, almost all participants recalled having blood tests for hepatitis B and D. Less than half of the participants recalled having liver function test of assessment of fibrosis.

In this PEEK study for those that had symptoms before diagnosis, two thirds had a diagnosis within a year of noticing symptoms. Almost half of the participants had a diagnosis within 2 weeks if having a diagnostic test.

Understanding and knowledge

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[30,31]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[32,33] 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[34]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[33]. 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[33].

In this PEEK study, 75% of participants had no or little knowledge about hepatitis D when they were diagnosed. In addition, a quarter of participants were uncertain about their prognosis.

Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course. HBV DNA testing, liver function tests, and assessment of liver fibrosis is recommended for people with chronic hepatitis B to determine eligibility for antiviral therapy[29]

More than half of the participants in this PEEK study did not have any discussions about biomarkers or genetic markers, and almost a third described having these tests.

Support at diagnosis

Very few participants in this PEEK study described having enough support at diagnosis (14%), the same number described having some support but not enough (14%), but the majority of participants described having no support at diagnosis. A study of people with hepatitis B described the being shocked when diagnosed, having a sense of loss of hope, and feelings of anxiety and depression[28], indicating a need for support at diagnosis.

Half of the participants in this PEEK study described having no liver complications from hepatitis D, 36 % had cirrhosis of the liver, 14% had fibrosis of the liver, 7% had liver cancer, and 7% had fatty liver. The majority of participants in this study (64%) were offered regular liver checks

Information at diagnosis

Very little. Very little at all. And I'd have to say, even at that point of diagnosis, they didn't really take the time to explain it to me and how it was all interrelated. It was only kind of subsequently in conversations…that I understood it had something to do with my liver.
Participant 011_2023AUHDV

In this PEEK study, the majority of participants either had no information or not enough information about hepatitis D when they were diagnosed (79%), this is notable given that the study population had little or no knowledge of hepatitis D at diagnosis. In another study, people with hepatitis D described the types of information they needed at diagnosis, the topics included how to interpret test results, general information, treatment and management, and information about infection transmission[35].

Key points

- **Asymptomatic at diagnosis**
- **Lack of support at diagnosis**
- **Not enough information at diagnosis**

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness[36]. 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[37,38], 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[39].

Goals of treatment and decision-making

> ***My own concern is having cancer in the future. The other things I think is is treatable but not cancer is my only concern. Participant 005_2023AUHDV***

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[40,41]. Half of the participants in this PEEK study were presented with one treatment option, however, very few described taking part in treatment discussions. Important factors in decision making for the participants in this PEEK study were their ability to follow treatments, efficacy of treatment, side effects and costs. Likewise, in a study of people with hepatitis B, how treatments are administered, efficacy, side effects and costs, as well as impact on quality of life were important factors to consider when making treatment decisions[42]. The most common treatment goal in this PEEK study were to maintain their condition, and for quality of life or return to normalcy. Participants in this PEEK study described fatigue as the most important symptom to control for quality of life, followed by liver cirrhosis or fibrosis

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 hepatitis D are collected.

Access to health professionals

The main providers of treatment for hepatitis B for participants in this PEEK study were general practitioners (GP) and hepatologists. The majority could access their main provider of care for hepatitis D within 60 minutes (72%), and the majority found it either easy or very easy to get appointments (64%). The majority had access to either a gastroenterologist or a hepatologist (70%), and access to a GP (86%). Few participants had access to a hepatology nurse (36%).

Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover[43]. 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%[43]. In this PEEK study, a similar proportion had private health insurance compared to the Australian population.

The majority of participants in this PEEK study described that there was some cost burden to them from having hepatitis D, and for approximately 40% this was at least a moderate burden. Costs were from treatments, taking time off work, travel to and from health appointments. Nearly half the participants in this study ha either reduced the number of hours they worked or they had to quit their job adding to their cost burden. In another study, people with hepatitis B described the costs associated with their condition from loss of employment, cost of treatments, cost of health insurance and that at times other basic necessities such as food and housing take priority[23,27,44,45]..

Treatment and management

Hepatitis D is treated with pegylated interferon alpha for 48 weeks, treatment should continue regardless of response rate. [5]. There is a low response rate to the treatment, however, it is associated with a lower likelihood of disease progression treatment should continue regardless of symptoms[5]. There is no vaccine available for hepatitis D, however, hepatitis B vaccination protects against hepatitis D infection [5].

The majority of participants in this PEEK study had drug treatments (93%) for hepatitis D, 79% of participants had pegylated interferon alpha. On average, quality of life from Pegylated interferon alpha was in the 'life was distressing' range, and was found to be ineffective.

Other drug treatments used by participants in this PEEK study included Entecavir (29%), Ribavirin (29%), Tenofovir (29%), Glecaprevir/pibrentasvir (7%), and Sofosbuvir/ Velpatasvir (7%)

To highlight unmet needs, participants in this PEEK study described what they would like to see in future treatments. They described that they would like to have more choice, transparency and discussions in relation to treatment options, treatments that are less invasive, and treatments that are more affordable.

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of hepatitis D. Half of the participants in this PEEK study used allied health services, most commonly psychologists (29%), dieticians (21%), and social worker (14%).

Lifestyle changes

Many chronic diseases share the modifiable risk factors of poor diet, little exercise, smoking , and excessive alcohol consumption. In this PEEK study, approximately 60% made lifestyle changes, most commonly diet changes (50%), and reducing or quitting alcohol (43%). Quality of life for both these changes were in the life was average range, and diet changes were rated moderately effective and reducing alcohol was rated very effective.

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. In this PEEK study, approximately a third of participants used complementary therapies, most commonly massage therapy, and mindfulness and meditation.

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on July 25 2023. The search included any study that included participants with hepatitis D in the inclusion criteria, was conducted in Australia. A single study was identified that was not yet open to recruitment. This study is a randomised trial evaluating a drug treatment, has a target of 32 participants, and will have sites in New South Wales and Victoria. A search of clinicaltrials.gov was conducted on the same day with the same search criteria, one study was identified, a randomised trial evaluating a drug treatment, 79 participants had enrolled and the trial was terminated in 2016. It was an international trial with sites in New South Wales, South Australia, Victoria, and Western Australia.

Patient treatment preferences

Well, I'm not that kind of person. If I get treatment and I'm told to take it from the beginning to the end, I take it until it's finished. I never, I never stop unless it's giving me a severe side effect which really makes me ill, then I take it till it's finished.
Participant 010_2023AUHDV

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.[46-48] 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[46,49].

To help inform patient preferences in the hepatitis D 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 are self managed or do not interfere with life. Examples of sspecific mild side effects included headaches, aches and pains., emotional impact, skin rashes, dizziness, and nausea In a similar way, participants describe severe side effects, broadly as those that impact every day life, or using the examples of pain, emotional impact, fatigue, and allergic reactions. There is some similarity the descriptions and examples used to describe both mild and severe side effects, indicating the importance of describing the intensity and impact of expected side effects of treatment.

Self-management

I think it needs to be a combination of things, the online is a very good option and search option for people initially and especially depending if there's

barriers with English and other things. Yeah, that is one good option, but I think the conversation. Participant 004_2023AUHDV

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 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].

In this PEEK study participants were most commonly given information about treatment options, and disease management, these were also the most commonly searched for topics. In another study, similar to this PEEK study, participants with hepatitis D had searched for how to interpret test results, , treatment and management, psychological/ social support, disease cause, , complementary therapies, and lifestyle modifications, in addition they searched for relationship HDV to HBV, risk of liver cancer, and symptoms [35].

In a study of people with hepatitis B, participants had searched for information about treatment and management, prevention, vaccine efficacy, diagnosis, spread and protecting others, and interpreting test results[44]

Participants in this PEEK study got most of their information from their doctor or from the internet. They described that there wasn't any information that was not helpful, but noted a lack of new information was a problem. Hearing about what to expect and other peoples experiences were helpful.

To highlight unmet needs, participants in this PEEK study described what they would like to see in future information. In terms of access, they described wanting information in a variety of formats, including the ability to talk to a healthcare professional, they wanted information that was easy to find and easier to understand, including in their native language. The topics they wanted more information about were emotional health, disease trajectory and what to expect, information about transmission, where to find support and information to support carers. Additionally, they wanted information to raise community awareness. In another study, people with hepatitis B had a lack of understanding of their condition, treatment and management[45].

Prefer. I actually prefer to be able to sit and talk with the doctors and nurses and that and then secondary to that would be information booklets that you can take away. But generally I'll just have the conversation and that's. That's enough for me to get what I feel I need to know. Participant 007_2023AUHDV

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[53]. Participants had in this PEEK study had good knowledge about their condition and treatments, a good ability to manage the effects of their health condition, good ability to adhere to treatments and communicate with healthcare professionals, and good recognition and management of symptoms.

Participants in this PEEK study described how long they would adhere to a treatment, most commonly they described adhering to their treatment as per the advice of their doctor. Others needed to see evidence that treatment is working and some described only adhering to treatments if side effects were tolerable. Consistent with this, a number of participants described that they needed to see a reduction of physical signs and symptoms or evidence of stable disease to know that a treatment is working,

Communication and collaboration

Yeah, I'm happy. Actually, I am happy. It was very just to interpret my results because what I do is I do the my blood test and my liver thing before I got there, before I got there. So when I got there, they just interpret my result that I know this result, they're all good. This is your liver stuff is all good or good or good or good? How are you feeling? Then I'll just say, yeah, I'm still OK. I'm OK really. That's it. I'll see you next year. That's all. Participant 001_2023AUHDV

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[54-57].

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[58].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[58]. 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[58]. 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[58]. 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[58]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange. [59,60]

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[61]. Participants in this PEEK study had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as average, and they participants rated their quality of care as average. This is consistent with the communication descriptions in the structured interviews, where most described having poor communication at least some of the time. Communication was described as poor due to dismissive conversations, and limited time in appointments. For those describing good communication, this was due to holistic, two-way and supportive conversations.

To highlight unmet needs, participants in this PEEK study described what they would like to see in future communication. Participants described wanting more time to meet with healthcare professionals, and the need for communication to be transparent and forthcoming. They wanted to be listened to, and to be treated with empathy. Additionally, they wanted communication to raise awareness.

Yeah, those two times where or maybe two or three times where the doctor and a couple of or couple of doctors and a couple of nurses were a bit judgmental about my past. So I just felt a bit vulnerable at that time, but I just spoke up so that was all good. Participant 010_2023AUHDV

Care and support

In this PEEK study, participants described a lack of formal support and difficulty finding or accessing support. Where participants did have support this was from peer support, charities, community or religious groups, the hospital of clinical setting or in the form of financial support. In a study of people with hepatitis B, people described the need for support to adhere to the therapy[26]

To highlight unmet needs, participants in this PEEK study described what they would like to see in future care and support. They described wanting more access to support services in general , and for practical support. In terms of medical support they would like to have specialist clinics or services where they can talk to professionals, a multidisciplinary and coordinated approach, and access to health professionals with a better knowledge of the condition. In terms of emotional support they would like access to peer support, support groups and online forums, and for care to be more holistic including emotional health.

Key points

- **Lack of formal support**
- **Quality of care and care coordination are average**
- **Poor communication with healthcare professionals**

Anxiety associated with condition

Yeah, yeah, post post treatment there's. And I think this is true for the current HDV treatments as well. But there's this period of where you're waiting to find out results. Participant 011_2023AUHDV

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[62].

In this PEEK study, anxiety associated with hepatitis D was measured by the fear of progression questionnaire[63]. Participants experienced a moderate amount of anxiety in relation to their condition. In other studies, people with hepatitis D had more fear and anxiety related to disease compared to those with hepatitis B[22]. People with hepatitis D were worried and shocked by diagnosis, and worried about how the condition will progress and their life expectancy[35]

In another study, people with Hepatitis B, participants were worried at the time of diagnosis, they were anxious about treatments, complications and dying, and about who will take care of them if sick, who will take care of family[28].

In this PEEK study, participants were most worried about progression, medical appointments and treatments, symptoms and side effects, family becoming infected, what will happen to their family of anything happens to them, and not being able to work or pursue hobbies.

Quality of life

Participants in this PEEK study described a negative impact on quality of life from having hepatitis D, this was mostly from emotional strain on themselves on their family, reduced social interaction, and from stigma and discrimination experienced. This is similar to another study were people with hepatitis B described social isolation, stigma and shame in addition to feelings of hopelessness, fear of no romantic relationships and a fear of death having a negative impact on quality of life[44]. In other studies, people wit hepatitis B described the study negative impact that stigma had on employment, getting medical attention, finding emotional support, and socialising and relationships[44,45].

Yeah, my, my mental health has been affected, that's for certain. And my emotions and everything has been affected. Yeah, I, I do certain activity once in a while, you know, to kind of, you know, soften the, the effects in my mental health, you know, let's say activity like yoga and meditation, just to calm the calm the tension down. Participant 006_2023AUHDV

Participants in this PEEK study described a negative impact on their mental and emotional health, however few had regular activities to maintain their mental health. Some participants described seeing a mental health professional, using mindfulness of meditating techniques, exercising, the importance of their family and friends, and a healthy diet. In terms of maintain health, participants described complying with treatment and management, exercise, a healthy diet, and socialising with family and friends. Similarly, in another study, people with hepatitis B described mindfulness and meditation complying with treatments, and also living a life as normal as possible, stopping drinking, being organised and informed, and seeking medical attention and clinical trials to maintain physical and mental health [28]

Some participants in this PEEK study described a positive impact on relationships following their diagnosis due to relationships with family being strengthened. However,

More commonly participants described a negative impact on relationships from people withdrawing from relationships, the dynamics changing due to anxiety and physical limitations from the condition. They also described that their condition was a burden on their family. In other studies, people with hepatitis B described negative impacts on relationships from social isolation, fear of not being able to form intimate relationships and fear of transmission to family and friends[28,44,45].

Key points

- **Negative impact on mental health, no activities to manage this**
- **Negative impact on relationships and quality of life, in part due to reduced socialising**

Characterisation

There were 16 participants with hepatitis D in the study from across Australia. The majority of participants lived in major cities, they lived in areas with higher levels of socioeconomic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 25 and 64. Most of the participants had completed some university, and most were employed either full time or part time. They were mostly not carers to family members or spouses.

This is a patient group that had multiple co-morbidities, mostly, depression, anxiety and sleep problems. Less than half of this group currently had other liver conditions.

This is a group whose condition had an impact on health-related quality of life, in particular, physical health often interfered with work and other activities.

This is a patient population that were mostly asymptomatic before diagnosis. For those with symptoms, they were most commonly fatigued.

This is a patient population that experienced no symptoms before being diagnosed. Most participants were diagnosed by their general practitioner.

This is a cohort that were mostly diagnosed with hepatitis D without experiencing symptoms. On average, this group had four diagnostic tests for hepatitis D, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not a burden to them and their families. This is a group that did not have enough emotional support or information at the time of diagnosis. This is a cohort that did not have conversations about biomarker/genomic/gene testing. They did not have biomarker or genetic tests but would be interested in having them.

This is a study cohort that had limited knowledge of hepatitis D before they were diagnosed. This patient population described prognosis in terms of medical interventions they need to manage their condition, or were unclear about their prognosis.

This is a patient population that had one treatment option presented to them, and they did not participate in discussions about treatments.

This is a study cohort that took into account their ability to follow treatments, efficacy and side effects when making decisions about their treatment.

Within this patient population participants did not change their decision making over time.

When asked about their personal goals of treatment or care participants most commonly described wanting to maintain their condition or prevent their condition getting worse.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a ggastroenterologist, and it usually took less than an hour to travel to medical appointments.

Approximately half of this cohort had private health insurance, half were public patients and most were treated in the public hospital systems This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to hepatitis D were slightly or not at all a burden.

Participants in this study reduced work hours, or had to take paid leave from work due to their condition. Carers and family did not have to change employment status.

Almost all participants had drug treatments for hepatitis D, usually pegylated interferon alpha. Half of the participants used an allied health service most often a psychologist. More than half made lifestyle changes, usually diet, and approximately a third used complementary therapies, commonly massage therapy or mindfulness and relaxation techniques.

This is a cohort that had conversations about clinical trials, and 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 as those which can be self-managed and do not interfere with daily life.

This is a study cohort that most commonly could not describe severe side effects because they had not experienced any. Some described them as symptoms such as those that impact every day life, using a specific example or those that are worse than the condition.

This is a patient population which described adhering to their treatment according to the advice of their doctor or as long as prescribed. This is a study cohort that needed to see physical signs and symptoms disappear to feel that treatment is working. If treatment worked, it would allow them to do everyday activities and return to a normal life.

Participants had good knowledge about their condition and treatments, a good ability to manage the effects of their health condition, good ability to adhere to treatments and communicate with healthcare professionals, and good recognition and management of symptoms.

Participants were given information about disease management, and treatment options from health care professionals, and searched for the same topics independently. 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 their treating clinician or the internet.

This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, or a lack of new information as unhelpful.

This is a group that preferred online information or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall negative experience with health professional communication which was dismissive with one-way conversations. Those that experienced good communication with healthcare professionals was because it was holistic, two way and comprehensive.

The participants in this study had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as average, and they participants rated their quality of care as average.

This is a patient population that commonly did not receive any formal support for their condition. Some were supported by other people with hepatitis.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on themselves. Life was a little distressing for this group, due to having hepatitis D.

This is a study cohort that experienced at least some impact on their mental health and most commonly did no activities to maintain their mental health. Some consulted a mental health professional and others used mindfulness or mediation to maintain their mental health.

Within this patient population, participants described being complying with treatment in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments. To manage vulnerability, they relied on support from family and friends, peer support or took charge of their health.

This cohort most commonly felt there was a negative impact on their relationships, because dynamics of relationships changed due to anxiety of difficult decisions.

Participants felt they were a burden on their family, but that it was only temporary or only during treatment.

Most participants felt there was some cost burden which was from the costs of treatments, 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 come with more open and informed discussions, and for treatments to be easier to administer.

This is a study cohort that would like information to be easier to understand, be more holistic and also to raise community awareness.

Participants in this study would like future communication to allow people more time to meet with their clinician, and to be more transparent and forthcoming.

Participants would like future care and support to include peer support, support groups and online forums.

This patient population was grateful for the healthcare staff, access to specialists, and low cost or free medical treatments through the government.

It was important for this cohort to control fatigue, and liver cirrhosis or fibrosis for quality of life. Participants in this study would consider taking a treatment for less than a year if quality of life is improved with no cure.

Participants' message to decision-makers was that people with hepatitis need timely and equitable access to care and treatment.

This is a patient population that wished they had known to be assertive, to be an advocate and ask their doctor questions. However, many wouldn't change any aspect of their treatment or care.

References

1. Mentha N, Clement S, Negro F, Alfaiate D. A review on hepatitis D: From virology to new therapies. *J Adv Res* 2019; **17**: 3-15.
2. Castaneda D, Gonzalez AJ, Alomari M, Tandon K, Zervos XB. From hepatitis A to E: A critical review of viral hepatitis. *World J Gastroenterol* 2021; **27**(16): 1691-715.
3. Fattovich G, Giustina G, Christensen E, et al. Influence of hepatitis delta virus infection on morbidity and mortality in compensated cirrhosis type B. The European Concerted Action on Viral Hepatitis (Eurohep). *Gut* 2000; **46**(3): 420-6.
4. Sureau C, Negro F. The hepatitis delta virus: Replication and pathogenesis. *J Hepatol* 2016; **64**(1 Suppl): S102-S16.
5. Hepatitis D fact sheet. In: World Health Organization: media centre [website] http://www.who.int/mediacentre/ factsheets/hepatitis-d/en/, accessed 30 May 2022) 28 July 2021 update. .
6. Masood U, John S. Hepatitis D. StatPearls. Treasure Island (FL); 2022.
7. Wedemeyer H, Manns MP. Epidemiology, pathogenesis and management of hepatitis D: update and challenges ahead. *Nat Rev Gastroenterol Hepatol* 2010; **7**(1): 31-40.
8. Group NARW. Australia's notifiable disease status, 2016: Annual report of the National Notifiable Diseases Surveillance System. *Commun Dis Intell (2018)* 2021; **45**.
9. Jackson K, MacLachlan J, Cowie B, et al. Epidemiology and phylogenetic analysis of hepatitis D virus infection in Australia. *Intern Med J* 2018; **48**(11): 1308-17.
10. Australian Bureau of Statistics. (2020). Regional population, 2018-19 financial year. Retrieved March 4, 2021, from https://www.abs.gov.au/statistics/people/population/regional-population/2018-19.
11. Australian Bureau of Statistics, 2016, Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2016, ‘Postal Area, Indexes, SEIFA 2016 ’, data cube: Excel spreadsheet, cat. no. 2033.0.55.001, viewed 24 October 2019, https://www.abs.gov.au/AUSSTATS.
12. Australian Bureau of Statistics. (2020). National, state and territory population, June, 2020. Retrieved March 4, 2021, from https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/jun-2020.
13. Yi E, Yoo YS, Lee S, Park H. The Experiences of Illness in Korean Bladder Cancer Patients With Radical Cystectomy. *Cancer Nurs* 2022; **45**(2): 132-40.
14. Evon DM, Lin HS, Fontana RJ, et al. Liver disease symptoms are associated with higher risk of adverse clinical outcomes: A longitudinal study of North American adults with chronic Hepatitis B. *GastroHep* 2021; **3**(3): 196-208.
15. Fotos NV, Elefsiniotis I, Patelarou A, et al. Psychological Disorders and Quality of Life Among Patients With Chronic Viral Hepatitis: A Single-Center Cross-Sectional Study With Pair-Matched Healthy Controls. *Gastroenterol Nurs* 2018; **41**(3): 206-18.
16. Evon DM, Lin HS, Khalili M, et al. Patient-reported outcomes in a large North American cohort living with chronic hepatitis B virus: a cross-sectional analysis. *Aliment Pharmacol Ther* 2020; **51**(4): 457-68.
17. Jang Y, Boo S, Yoo H. Hepatitis B Virus Infection: Fatigue-Associated Illness Experiences Among Koreans. *Gastroenterol Nurs* 2018; **41**(5): 388-95.
18. 36-Item Short Form Survey (SF-36) Scoring Instructions. n.d. https://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html (accessed 10 February 2017.
19. Wulff-Burchfield EM, Potts M, Glavin K, Mirza M. A qualitative evaluation of a nurse-led pre-operative stoma education program for bladder cancer patients. *Support Care Cancer* 2021; **29**(10): 5711-9.
20. Dirks M, Haag K, Pflugrad H, et al. Neuropsychiatric symptoms in hepatitis C patients resemble those of patients with autoimmune liver disease but are different from those in hepatitis B patients. *J Viral Hepat* 2019; **26**(4): 422-31.
21. Younossi ZM, Stepanova M, Younossi I, et al. Long-term Effects of Treatment for Chronic HBV Infection on Patient-Reported Outcomes. *Clin Gastroenterol Hepatol* 2019; **17**(8): 1641-2 e1.

22. Buti M, Stepanova M, Palom A, et al. Chronic hepatitis D associated with worse patient-reported outcomes than chronic hepatitis B. *JHEP Rep* 2021; **3**(3): 100280.

23. Westermann C, Nienhaus A, Treszl A. Quality of Life and Work Ability among Healthcare Personnel with Chronic Viral Hepatitis. Evaluation of the Inpatient Rehabilitation Program of the Wartenberg Clinic. *Int J Environ Res Public Health* 2019; **16**(20).

24. Daida YG, Boscarino JA, Moorman AC, et al. Mental and physical health status among chronic hepatitis B patients. *Qual Life Res* 2020; **29**(6): 1567-77.

25. Honer Zu Siederdissen C, Schlevogt B, Solbach P, et al. Real-world effect of ribavirin on quality of life in HCV-infected patients receiving interferon-free treatment. *Liver Int* 2018; **38**(5): 834-41.

26. Volpes R, Burra P, Germani G, et al. Switch from intravenous or intramuscular to subcutaneous hepatitis B immunoglobulin: effect on quality of life after liver transplantation. *Health Qual Life Outcomes* 2020; **18**(1): 99.

27. Younossi ZM, Stepanova M, Younossi I, et al. Patient-reported outcomes in patients chronic viral hepatitis without cirrhosis: The impact of hepatitis B and C viral replication. *Liver Int* 2019; **39**(10): 1837-44.

28. Freeland C, Racho R, Kamischke M, et al. Health-related quality of life for adults living with hepatitis B in the United States: a qualitative assessment. *J Patient Rep Outcomes* 2021; **5**(1): 121.

29. ASHM (N.D.) Treatment of chronic hepatitis B infection. Available from https://www.hepatitisb.org.au/treatment-of-chronic-hepatitis-b-virus-infection/ Viewed 2 June 2022.

30. Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatr* 2010; **10**: 103.

31. Zahradnik A. Asthma education information source preferences and their relationship to asthma knowledge. *J Health Hum Serv Adm* 2011; **34**(3): 325-51.

32. Attfield SJ, Adams A, Blandford A. Patient information needs: pre- and post-consultation. *Health Informatics J* 2006; **12**(2): 165-77.

33. Schulz GB, Grimm T, Buchner A, et al. Benefits and Complications during the Stay at an Early Rehabilitation Facility after Radical Cystectomy and Orthotopic Ileum Neobladder Reconstruction. *Urol Int* 2019; **103**(3): 350-6.

34. Roddis JK, Holloway I, Bond C, Galvin KT. Living with a long-term condition: Understanding well-being for individuals with thrombophilia or asthma. *Int J Qual Stud Health Well-being* 2016; **11**: 31530.

35. Kumar P, Freeland C, Bodor S, Farrell S, Cohen C, Frasso R. Needs of Individuals Living With Hepatitis Delta Virus and Their Caregivers, 2016-2019. *Prev Chronic Dis* 2020; **17**: E159.

36. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; **284**(19): 2476-82.

37. Barnes S, Gardiner C, Gott M, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage* 2012; **44**(6): 866-79.

38. Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004; (2): CD003751.

39. Lamore K, Montalescot L, Untas A. Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient Educ Couns* 2017; **100**(12): 2172-81.

40. Griffin SJ, Kinmonth AL, Veltman MW, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Ann Fam Med* 2004; **2**(6): 595-608.

41. Wetzels R, Harmsen M, Van Weel C, Grol R, Wensing M. Interventions for improving older patients' involvement in primary care episodes. *Cochrane Database Syst Rev* 2007; (1): CD004273.

42. Freeland C, Racho R, Kamischke M, Moraras K, Wang E, Cohen C. Cure everyone and vaccinate the rest: The patient perspective on

future hepatitis B treatment. *J Viral Hepat* 2021; **28**(11): 1539-44.
43. Klein GT, Ajay D, Volk RJ, Leal V, Westney OL. Living With Urinary Diversions: Patient Insights to Improve the Perioperative Experience. *Urology* 2021; **152**: 190-4.
44. Freeland C, Farrell S, Kumar P, et al. Common concerns, barriers to care, and the lived experience of individuals with hepatitis B: a qualitative study. *BMC Public Health* 2021; **21**(1): 1004.
45. Hyun S, Ko O, Kim S, Ventura WR. Sociocultural barriers to hepatitis B health literacy in an immigrant population: a focus group study in Korean Americans. *BMC Public Health* 2021; **21**(1): 404.
46. Kim C, Armstrong MJ, Berta WB, Gagliardi AR. How to identify, incorporate and report patient preferences in clinical guidelines: A scoping review. *Health Expect* 2020; **23**(5): 1028-36.
47. Cronin RM, Mayo-Gamble TL, Stimpson SJ, et al. Adapting medical guidelines to be patient-centered using a patient-driven process for individuals with sickle cell disease and their caregivers. *BMC Hematol* 2018; **18**: 12.
48. Sleath B, Carpenter DM, Slota C, et al. Communication during pediatric asthma visits and self-reported asthma medication adherence. *Pediatrics* 2012; **130**(4): 627-33.
49. Ross CK, Steward CA, Sinacore JM. The importance of patient preferences in the measurement of health care satisfaction. *Med Care* 1993; **31**(12): 1138-49.
50. In: Adams K, Greiner AC, Corrigan JM, eds. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. Washington (DC); 2004.
51. Grande SW, Faber MJ, Durand MA, Thompson R, Elwyn G. A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient Educ Couns* 2014; **95**(2): 281-7.
52. Taylor SJC, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. Southampton (UK); 2014.
53. Petkov J, Harvey P, Battersby M. The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Qual Life Res* 2010; **19**(7): 1079-85.
54. Williams S, Weinman J, Dale J. Doctor-patient communication and patient satisfaction: a review. *Fam Pract* 1998; **15**(5): 480-92.
55. Stewart M, Brown JB, Boon H, Galajda J, Meredith L, Sangster M. Evidence on patient-doctor communication. *Cancer Prev Control* 1999; **3**(1): 25-30.
56. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000; **49**(9): 796-804.
57. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. *Jt Comm J Qual Saf* 2003; **29**(11): 563-74.
58. Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Acad Med* 2001; **76**(4): 390-3.
59. Farias AJ, Ornelas IJ, Hohl SD, et al. Exploring the role of physician communication about adjuvant endocrine therapy among breast cancer patients on active treatment: a qualitative analysis. *Support Care Cancer* 2017; **25**(1): 75-83.
60. Salgado TM, Quinn CS, Krumbach EK, et al. Reporting of paclitaxel-induced peripheral neuropathy symptoms to clinicians among women with breast cancer: a qualitative study. *Support Care Cancer* 2020; **28**(9): 4163-72.
61. Young JM, Walsh J, Butow PN, Solomon MJ, Shaw J. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer* 2011; **11**: 298.
62. DeJean D, Giacomini M, Vanstone M, Brundisini F. Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ont Health Technol Assess Ser* 2013; **13**(16): 1-33.
63. Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months after cancer rehabilitation-a- validation study of the fear of progression questionnaire FoP-Q-12. *Support Care Cancer* 2015; **23**(6): 1579-87.

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. Information: with little community awareness, most of the participants did not have an understanding hepatitis D when diagnosed and its relationship with other forms of hepatitis. There is a need for community information, and for better information to give newly diagnosed. In addition, information needs to be easy to understand and available in multiple languages

2. Support: support services, including peer support that are specific to hepatitis D and to the variety of people it affects (demographically) are needed.

3. Care coordination: there is a need for better access and coordination of healthcare services, better access to supportive GP, specialist nurses, allied health (This group had poor care coordination, low access to specialist nurses, low access to specialists, low access to allied health yet high levels of depression, anxiety and other comorbidities, and their physical health interfered with work and daily activities).

2023 PEEK study in hepatitis D

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2021 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Hepatitis D 2023 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning*	68.93	72.50
	Role functioning/physical	46.43	37.50
	Role functioning/emotional*	52.38	66.67
	Energy/Fatigue*	46.07	50.00
	Emotional well-being*	63.43	62.00
	Social functioning*	58.93	68.75
	Pain*	70.18	72.50
	General health*	52.50	55.00
	Health change	60.71	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge*	22.62	26.00
	Coping*	17.08	17.00
	Recognition and management of symptoms*	18.23	19.00
	Adherence to treatment*	10.85	11.00
	Total score*	68.77	67.00
Care coordination scale	Communication*	37.69	38.00
	Navigation*	24.23	24.00
	Total score*	61.92	65.00
	Care coordination global measure*	6.23	6.00
	Quality of care global measure*	6.00	6.00
Fear of progression *	Total Score	33.15	34.00
		Percent	
Participants that had discussions about biomarkers/genetic tests	-	42.85	-