CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

CAR-T TREATABLE BLOOD CANCERS

Volume 6 (2023), Issue 4

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

PEEK study process information

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Number of participants	37

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Section 1 Introduction and methodology

Introduction

Background

Blood cancers accounted for approximately 12% of all cancers cases in Australia 2023. In 2019, 17,705 people were diagnosed with a blood cancer, a rate of 57.7 per 100,000[1]. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females[1]. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia[1], with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Collectively, blood cancer is can occur at any age, acute lymphoblastic leukaemia was expected to be the most common cancer diagnosed in children 2023, however, incidence of blood cancer increases with age, and in 2019, the mean age at diagnosis was 67.2[1].

Five year survival was 69% in 2015 to 2019, survival rates are higher in younger age groups with five year survival of 90% for people aged under 40, 84% in 40–59 year olds to 69% in 60–79 year olds to 42% for those aged 80 years older[1].

Blood cancers have high hospitalisation and pharmaceutical costs, with myeloma and leukaemia rated in the top three most expensive cancers to treat in Australia[2].

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 (June 12, 2023) to identify studies of blood cancer with patient reported outcomes, or patient experience conducted in the past two years worldwide. Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 65 studies identified of between 8 and 1861 lung cancer participants. A single study was conducted in Australia, where 13 participants were interviewed about treatment and management.

In this PEEK study 37 participants completed surveys and 33 participants completed interviews, making this one of the largest studies interviewing participants about blood cancer. 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

There were 37 people with blood cancer who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), and 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma.

Demographics

There were 37 people with blood cancer that took part in this study, 17 were females (45.95%). Participants were aged from 25 to over 75 years of age, most were aged between 55 to 74 years (n=26, 70.27%).

Participants were most commonly from Queensland (n=10, 27.03%), Victoria (n=8, 21.62%), and New South Wales (n=6, 16.22%). Most participants were from major cities (n=21, 56.76%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 20 participants (54.05%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 17 participants (45.95%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Other health conditions

Participants were asked about health conditions, other than blood cancer 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=31, 83.78%), the maximum number reported was 10 other conditions, with a median of 3.00 other conditions (IQR = 4.00). The most commonly reported health condition was sleep problems or insomnia (n=24, 64.86%), followed by back pain (n=16, 43.24%), anxiety (n=14, 37.84%), and arthritis (n=10, 27.03%).

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 sometimes 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 never 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 slightly limited for participants in this study.

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

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

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is better now compared to 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 7 participants (24.14%) that had no symptoms before diagnosis. Participants had a maximum of 15 symptoms, and a median of 4.00 (IQR=7.00).

Symptoms before diagnosis

The most common symptoms before diagnosis were pain or weakness in muscles, bones and joints (n=20, 68.97%), tired (n=20, 68.97%), cough or breathlessness (n=14, 48.28%) and night sweats (n=14, 48.28%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Median quality of life is presented where five or more participants reported the symptom. The median quality of life was between 3.00 and 6.00, for all of the symptoms listed in the questionnaire, this is in the "Life was a little distressing" to "Life was very good" range. The symptoms with the worst quality of life were pain or weakness in muscles, bones and joints, feeling unusually tired or weak and, weight loss without trying.

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 strongly recalled their symptoms or how they came to be diagnosed (87.88%). Others had an unclear recollection of their symptoms or how they came to be diagnosed (9.09%), or had no symptoms (3.03%).

The most common symptoms leading to diagnosis were having fatigue (36.36%), back pain (24.24%), and bone pain (18.18 %). Other themes included unusual bleeding or bruising (15.15%), infections (15.15%), pain in general (12.12%), a loss of appetite (9.09%), lumps (9.09%), and night sweats or hot flushes (9.09%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (57.58%) and having symptoms and not seeking medical attention initially (33.33%), one participant described having no symptom (3.03%).

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 a linear diagnosis after being referred to a specialist from their general practitioner (42.42%) and being diagnosed after a referral to the emergency department from their general practitioner (21.21%). Other themes included being diagnosed in an emergency department (12.12%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (9.09%), being diagnosed by their general practitioner during a check-up related to symptoms (9.09%), and a linear diagnosis after being referred to a specialist from their optometrist (3.03%).

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 26 participants (participants had no symptoms before diagnosis), there were 2 participants (7.69%) that were diagnosed 1 to 3 months of noticing symptoms, 6 participants (23.08%) diagnosed 3 to 6 months from noticing symptoms, 3 participants (11.54%) that were diagnosed 6 to 12 months of noticing symptoms, and 5 participants (19.23%) that were diagnosed less than a month of 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 = 7, 18.92%). There were 14 participants (37.84%) that were diagnosed less than one week after diagnostic tests, 8 participants (21.62%) diagnosed between 1 and 2 weeks, 3 participants (8.11%) diagnosed between 2 and 3 weeks, 2 participants (5.41%) diagnosed between 3 and 4 weeks, and 3 participants (8.11%) 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 blood cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 8 diagnostic tests (median=4.00, IQR=3.00). The most common tests were blood tests (n=35, 94.59%), bone Marrow Biopsy (n=32, 86.49%), Computed Tomography (CT) scan (n=16, 43.24%), and urine tests (n=16, 43.24%).

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 haematologist (n=16, 43.24%), and there were 11 participants (29.73%) given the diagnosis by a general practitioner (GP), and 6 participants (16.22%) diagnosed by an oncologist. Participants were most commonly given their diagnosis in the general practice (n=20, 40.00%), this was followed by the specialist clinic (n=10, 20.00%).

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in the table below. Participants were diagnosed between 2000 and 2023. There were 21 participants (56.76%) that were diagnosed in the last five years.

Blood cancer diagnosis

There were 37 people with blood cancer who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), and 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma.

Blood cancer stage

Participants described the stage of their blood cancer as in remission (n=11, 39.29%), Stage 1 (n=1, 3.57%), Stage 2 (n=2, 7.14%), Stage 3 (n=4, 14.29%), and Stage 4 (n=5, 17.86%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (51.52%), and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (21.21%). Other themes included knowing a good amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (9.09%), and knowing about the condition due to public awareness (9.09%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 19 participants (51.35%) who had enough support, 5 participants (13.51%) that had some support, but it wasn't enough, and 13 participants (35.14%) 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 25 participants (67.57%) who had enough information, 7 participants (18.92%) that had some information, but it wasn't enough, and 5 participants (13.51%) 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 24 participants (64.86%) who had no out of pocket expenses, and participants (0.00%) who did not know or could not recall. There were 2 participants (5.41%) that spent $100 to 500, 3 participants (8.11%) that spent between $501 to 1000, and 8 participants (21.62%) that were not sure.

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 6 participants (16.22%) the cost was slightly or not at all significant. For 2 participants (5.41%) the out-of-pocket expenses were somewhat significant, and for 2 participants (5.41%), 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=27, 72.97%). There was one participant (2.70%) who brought up the topic with their doctor, and 9 participants (24.32%) 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.

Almost half of the participants did not have any genetic or biomarker tests but would like to (n=18, 48.65%). There were 11 participants (29.73%) who did not have these tests and were not interested in them, and a total of 8 participants (21.62%) that had biomarker tests.

Biomarker status

Participants were asked in the online questionnaire if they knew their status for named biomarkers. Very few participants knew the status for at least one biomarker (n=5, 14.29%).

Current symptoms

Number of current symptoms

Participants were asked in the questionnaire what symptoms they are currently dealing with, they could choose from a set lit of symptoms and could then specify other symptoms not listed. More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n=19, 65.52%). Participants had between 3 to 11 symptoms (median=5.00, IQR=8.00).

Type of current symptoms

The most common current symptoms, participants experienced were fatigue (n=19, 65.52%), weak or damaged bones (n=18, 62.07%), depression and anxiety (n=16, 55.17%), low resistance to infections (n=16, 55.17%), damage to organs (n=13, 44.83%), and hearing loss (n=10, 34.48%).

Quality of life from current symptoms

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”. The median quality of life was between 2.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing” to “Life was a average” range.

The median quality of life was between 4 and 2.5 for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average” range. The symptoms with the lowest quality of life were low resistance to infections, and hearing loss.

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 there was no evidence of disease or that they are in remission (51.52%), and that they had specific medical interventions they need to manage their condition (30.30%). Other themes included that they were monitoring their condition until there is an exacerbation or progression (18.18%), that they would likely have a recurrence, or were in a cycle of recurrence (18.18%), that they are in recovery from treatments and managing side effects of treatment (15.15%), their prognosis in terms of a specific timeframe that they are expected to live (12.12%), that their prognosis was positive, that their condition is manageable (12.12%), and that there was uncertainty around their prognosis (12.12%).

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 described being presented with one treatment option (63.64%), multiple options (24.24%), and no discussions about treatment (6.06 %).

Discussions about treatment (Participation in discussions)

For those with a single treatment option, most commonly they had a medical emergency/urgent treatment required (27.27%), were comfortable deferring to doctor/accept recommended approach (21.21%), or gave no reason (12.12 %). Other themes included and was well informed by doctor (12.12%), and having some but very little discussion (6.06%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (15.15%), were comfortable deferring to doctor or accept the recommended approach (6.06%).

Participants that had no treatment options offered at diagnosis described not needing treatments initially(6.06 %).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24 %). Other themes included ability to follow treatments (12.12%), and quality of life (9.09%). There were 4 participants (12.12%) described that they had not been given options, and that considerations not taken into account (12.12%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (57.58%), and had changed the way they make decisions (33.33%).

Where participants had not changed the way they make decisions, the most common themes were that they had changed but did not mention any reason (18.18%), they have always been informed/assertive (9.09%), and have always taken advice of clinicians (9.09 %).

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 (15.15%), and were more informed and/or more assertive (12.12%).

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 be cancer free, avoid recurrence, increase longevity (45.45%), have quality of life/return to normality (27.27%), and have physical improvements in their condition (21.21 %). Other themes included to minimise or avoid side effects (15.15%), maintain their condition or prevent worsening of their condition (12.12%), and not having treatment goals as they are satisfied or their condition has little impact on life (9.09%).

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 haematologists (n=26,76.47 %), followed by general practitioners (GP)s (n=4, 11.76%).

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 (20.69%) that travelled for less than 15 minutes, 12 participants (41.38%) that travelled between 15 and 30 minutes, 6 participants (20.69%) that travelled between 30 and 60 minutes, 1 participants (3.45%) that travelled between 60 and 90 minutes, and 4 participants (13.79%) that travelled more than 90 minutes.

Access to healthcare professionals

All participants had access to a haematologist (n=36, 100.00%), and almost a third had a medical oncologist (n=11, 30.56%), and a radiation oncologist (n=11, 30.56%).

Almost all participants had access to a general practitioner (GP) (n=34, 94.44%), and more than half had access to a chemotherapy nurse (n=21, 58.33%) There were 16 participants (44.44%) that had a registered nurse and 12 participants (33.33%) that had a nurse care coordinator.

Participants noted allied health professionals that treated them for blood cancer, most commonly physiotherapists (n=14, 38.89%), dieticians, counselling or psychological support, and social workers.

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 22 participants (75.86%) that indicated that they had been treated with respect throughout their experience, and 7 participants (24.14%) that were treated with respect with the exception of one or two occasions.

Health care system

The majority of participants had private health insurance (n=23, 67.65%). The majority of participants were asked if they wanted to be treated as a public or private patient (n=20, 58.82%), and they were asked if they had private health insurance (n=27, 79.41%).

Throughout their treatment, there were 5 participants (14.71%) that were treated as a private patient, 21 particpants (61.76%) were mostly treated as a public patient, and there were 6 particpants (17.65%) that were equally treated as a private and public patient.

Throughout their treatment, there were 3 participants (8.82%) that were treated mostly in the private hospital system, 27 particpants (79.41%) were mostly treated in the public system, and there were 4 particpants (11.76%) that were equally treated in the private and public systems.

Affordability of healthcare

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

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. All participants never or rarely had to delay or cancel appointments due to affordability (n = 34, 100.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=33, 97.06%).

Cost of condition

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

The most common amount was between $51 to 100 (n=4, 11.76%), followed by between $101 to 250 (n=7, 20.59%). There were 2 participants (5.88%), that spent $501 to 1000 a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 8 participants (23.53%), somewhat significant for 6 participants (17.65%), and slightly or not at all significant for 20 participants (58.82%).

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 (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 3 participants (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 8 participants (23.53%), 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=3, 8.82%). There were 6 participants (17.65%)

whose partners reduced the numbers of hours they worked, and 3 partners, (8.82%) that quit their job. The partners of 9 participants (26.47%) took leave without pay, and there were 4 partners (11.76%) that took leave with pay.

Reduced income due to condition

Half of the participants (n=17, 50.00%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=7, 20.59%), or monthly income was reduced by between $101 to 250 per month (n=7, 20.59%).

Burden of reduced income

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

For 6 of these participants (25.00%), the burden of this reduced income was extremely or moderately significant, for 7 participants (29.17%) the burden was somewhat significant, and for 11 participants (45.83%) the burden was slightly or not all significant.

Summary of treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was.

The most common types of treatments were stem cell transplants, (n=25, 71.43%), radiotherapy (n=13,37.14%), maintenance chemotherapy (n=10,28.57%), CAR T-cell therapy (n=8, 22.86%), Lenalidomide and dexamethasone (n=7, 20.00%), Zoledronic acid (n=7, 20.00%), CyBorD (Cyclophosphamide, bortezomib, dexamethasone) (n=6, 17.14%), R-CHOP (rituximab cyclophosphamide, doxorubicin, vincristine and prednisolone) (n=5, 14.29%), and Blood and platelet transfusions (n=5, 14.29%).

Participants reported having CVAD plus Imatinib: (Imatinib, Vincristine, Doxorubicin, Dexamethasone , Cytarabine, Methotrexate, and Cyclophosphamide) (n=2), or were not sure of the type (n=2) as induction therapy.

Participants reported having ALL06: Vincristine, Doxorubicin, Dexamethasone, Cytarabine, Pegaspargase, Mercaptopurine, Methotrexate, Cyclophosphamide, and Thioguanine (n=1), or were not sure of the type (n=2) as consolidation therapy.

Participants reported having Lenalidomide (n=7), CALGB: Prednisone, Vincristine, Mercaptopurine and Methotrexate (n=1) or were not sure of the type (n=2) as maintenance therapy.

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them.

Most participants used at least one type of allied health service (n=22, 64.71%), and on average used 1 service (median=1.00, IQR=2.00).

The most common allied health service used was physiotherapy (n=14, 41.18%), followed by dietary (n=11, 32.35%), and psychology/counselling (n=7, 20.59%). There were 7 participants (20.59%) that saw a social worker, 4 participants (11.76%) that saw a podiatrist, and 2 participants (5.88%) that saw a occupational therapist.

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=29, 85.29%), and on average made 2 changes (median=2.00, IQR=2.00).

The most common lifestyle change was exercise (n=22, 64.71%), followed by diet changes (n=17, 50.00%), and reducing or cutting out alcohol (n=17, 50.00%).

Complementary therapies

Participants were asked about complementary therapies they used, the quality of life from these therapies and how effective they found them.

Most participants used at made at least one complementary therapy (n=17, 50.00%), and on average used 0.5 therapies (median=0.50, IQR=2.00).

The most common complementary therapy used was Mindfulness or relaxation techniques (n=12, 35.29%), followed by Massage therapy (n=8, 23.53%), and Supplements (n=7, 20.59%).

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 17 participants (50%) that had discussions about clinical trials, 5 participants (14.71%) had brought up the topic with their doctor, and the doctor of 12 participants (35.29%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=17, 50.00%).

Clinical trial participation

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

There were 7 participants (20.59%) that had taken part in a clinical trial, 24 participants (70.59%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participanted in a clinical trial and do not want to (8.82%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were described using a specific example (69.70%), those that do not interfere with life(30.30%), and those that can be managed with self-medication or self-management (9.09 %).

When a specific side effect was described, the most common responses were aches and pain in general (18.18%), and fatigue or lethargy (18.18%). Other themes included gastrointestinal distress (15.15%), headaches (15.15%), nausea or loss of appetite (12.12%), and neuropathy (9.09%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’.
The most common description of severe side effects were described using a specific example (78.79%), and those that requires medical intervention (30.30%). Other themes included those that impact everyday life or ability to conduct activities of daily living (15.15%), and those that impact their everyday life by being bed ridden (9.09%).

When a specific side effect was described, the most common examples were nausea or loss of appetite (30.30%), aches and pain in general (24.24%), and fatigue or lethargy (15.15 %). Other themes included gastrointestinal distress (12.12%), emotional or mental impact (9.09%), impact on sleep (9.09%), neuropathy (9.09%), and swelling from fluid build up including lymphoedema (9.09%).

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 (75.76%), and never giving up on any treatment (39.39%). Other themes included adhering to treatment as long as side effects are tolerable (12.12%), needing to see test results/no evidence or reduction of disease (12.12%),adhering to treatment as long as treatment is working (9.09%), and adhering to treatment for a specific amount of time (9.09%).

When participants stated a specific amount of time to adhere to a treatment, the amount of time specified was one month (3.03%), six to twelve months(3.03%), and six to twelve months (3.03 %).

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 evidence of stable disease or no disease progression (39.39%), and needing to see physical signs and symptoms disappear or reduced side effects (33.33%). Other themes included needing to see a specific symptom reduction (27.27%), and needing to see a return to day-to-day functionality (15.15%).

When a specific side effect or symptom was described, the most common examples were aches and pain in general (12.12%), and fatigue or lethargy (12.12%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (42.42%), and that it would have a positive impact on their mental health (24.24%). Other themes included allowing them to do more exercise (18.18%), allowing them to return to work (12.12%), and allowing them to engage more with social activities and family life (12.12%).

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 from a specific health charity (60.61%), from books, pamphlets and newsletters (51.52%), and from their treating clinician (48.48 %). Other themes included the internet (Including health charities) (42.42%), from other patient's experience (Including support groups) (27.27%), from nursing staff (12.12%), at conferences or webinars (12.12%), from journals (research articles) (9.09%), and family members (9.09%).

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, talking to a doctor, specialist or healthcare team (36.36%), hearing what to expect (e.g. from disease, side effects, treatment) (33.33%), and other people's experiences (21.21 %). Other themes included scientific information, or information from medical journals (12.12%), and information from health charities (9.09%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information was not helpful (36.36%), worse case scenarios (18.18%), and other people's experiences (15.15 %). Other themes included being confident in deciding themselves (12.12%), and sources that are not credible (Not evidence-based) (12.12%).

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 (39.39%), and talking to someone plus online information (21.21%). Other themes included online information (18.18%), written information (18.18%), and all forms (12.12%).

The main reasons for a preference for talking to someone were being able to ask questions (30.30%), that it was personalised or relevant (21.21%) and because it was supportive (12.12%). The main reasons for a preference for online information were accessibility (24.24%), that it was personalised or relevant (9.09%), and being able to digest information at their own pace (6.06 %). The main reason for a preference for written information was that they could easily refer back to it (12.12%).

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) (36.36%), after the shock of diagnosis (15.15%), continuously (15.15 %), and after treatment (12.12%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having overall positive communication (75.76%), communication that was overall positive, with the exception of one or two occasions(18.18%), and overall negative communication (6.06 %).

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (60.61%), good, with no particular reason given (18.18%), good especially in

relation to multi-disciplinary communication (9.09 %). and good, yet limited in relation health to professionals not having a lot of time (6.06%). For those describing negative communication, this was because information was not forthcoming (9.09%) and limited in relation to their understanding of the condition (6.06%).

Partners in health

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

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

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

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

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

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

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=26, 78.79%), disease management (n=24, 72.73%), dietary (n=21, 63.64%), and disease cause (n=17, 51.52%) were most frequently given to participants by healthcare professionals, and information about complementary therapies (n=5, 15.15%), psychological/ social support (n=5, 15.15%), and hereditary considerations (n=1, 3.03%) 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 complementary therapies (n=16, 48.48%), disease cause (n=14, 42.42%), interpret test results (n=14, 42.42%), and treatment options (n=12, 36.36%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=10, 30.30%), clinical trials (n=9, 27.27%), and hereditary considerations (n=8, 24.24%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=25, 75.76%) and psychological/ social support (n=19, 57.58%).

The topics that participants were given most information from both healthcare professionals and searching independently were treatment options (n=10, 30.30%) and dietary information(n=9, 27.27%).

The topics that participants did not search for independently after receiving information from healthcare professionals were disease management (n=17, 51.52%) and treatment options (n=16, 48.48%).

The topics that participants searched for independently after not receiving information from healthcare professionals were complementary therapies (n=14, 42.42%) and disease cause (n=9, 27.27%).

Most accessed information

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

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 17 participants (51.52%) had accessed My Health Record, 16 participants (48.48%) had not.

Of those that had accessed My Health Record, there were 3 participants (17.65%) who found it to be poor or very poor, 12 participants (70.59%) who found it acceptable, and 2 participants (11.76%) who found it to be good or very good.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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

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

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

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from charities (45.45%), hospital or clinical setting (30.30%), and in the form of accommodation for themselves or their family while having treatment (24.24 %). Other themes included support from family and friends (21.21%), domestic services and/or home care (12.12%), transport to and from hospital appointments (12.12%), and in the form of financial advice and help with Centrelink applications (12.12%). Some participants described the challenges of finding or accessing support (18.18%), not needing or seeking help or support (15.15%), and that they did not receive any formal support (12.12%).

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negaitve impact on quality of life (33.33%). This was followed by overall a minimal impact on quality of life (6.06 %), and overall no impact on quality of life (3.03%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (45.45%), altering lifestyle to manage condition (including being immunocompromised) (21.21%), managing side effects and symptoms (21.21 %), and reduced social interaction (21.21%). Other themes included, being unable to travel or having to adapt significantly in order to travel (15.15%), fatigue (12.12%), reduced capacity for physical activity or needing to slow down (12.12%), and that quality of life was reduced temporarily (12.12%).

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 (84.85%), and overall, there was no impact on mental health (12.12%).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were mindfulness or meditation (30.30%), and the importance of physical exercise (24.24%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (15.15%), the importance of family and friends in maintaining their mental health (15.15%), consulting a mental health professional (9.09%), and the importance of keeping busy (9.09%). There were 5 participants (15.15%) that described no activities to maintain mental health (15.15%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise or being physically active (36.36%), complying with treatment and management (21.21%), and self care e.g. more rest, accepting help, pacing (21.21 %). Other themes included understanding their limitations (15.15%), maintaining a healthy diet (15.15%), mindfulness or meditation (12.12%), socialising with friends and/or family (9.09%), and maintaining a normal routine (9.09%).

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 (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%). Other themes included when having sensitive discussion (diagnosis, treatment decision) (12.12%), because of interactions with the medical team (12.12%),all the time (12.12%), and when feeling sick/unwell (9.09%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (15.15%), support from nurse or treatment team (9.09%), and getting support from family and friends (6.06 %).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (45.45%), and overall, there was a positive impact on relationships (27.27%). Other themes included overall, there was an impact on relationships that was both positive and negative (12.12%), and overall, there no impact on relationships (3.03%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (24.24%), and from people not knowing what to say or do and withdrawing from relationships (6.06 %).

The most common themes in relation to having a positive impact on relationships were from family relationships being strengthened (18.18%), and from people being well-meaning and supportive (18.18%).

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 (75.76%), and overall, there was not a burden on their family (18.18%).

The main reason that participant described their condition being a burden were that the burden on family was temporary or only during treatment (27.27%), the mental/emotional strain placed on their family(21.21%), and the extra household duties and responsibilities that their family must take on (15.15%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (63.64%), and overall, there was no cost burden (33.33%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (39.39%), the cost of treatments (including repeat scripts) (21.21%), and the cost of parking and travel to attend appointments (including accommodation) (18.18%). Other themes included a family member needing to take time off work (9.09%) and needing to access financial support from family or charities (9.09%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (45.45%), nearly everything was paid for through the private health system (12.12%), and the participant was able to afford all costs (12.12%).

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 low levels of anxiety.

Section 9

Expectations and messages to decision-makers

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

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (30.30%), have fewer or less intense side effects/more discussion about side effects (27.27%), and involve more clinical trials (including to access new technologies and treatments and funding) (24.24 %). Other themes included future treatment should be easier to administer or able to administer at home or less invasive (18.18%), will include having choice, including availability, accessibility and discussions in relation to treatment options (18.18%), and be more effective or targeted (9.09%). There were
4 participants (12.12%) that were satisfied with the treatment they received.

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 provide more details about disease trajectory and what to expect (24.24%), include the ability to talk to/access to a health professional (12.12 %), provide more details about new treatments or trials (12.12%) and provide more details on subgroups and specific classifications of their condition (12.12%). Other themes included be in a variety of formats (9.09%), and be more accessible/easy to find (9.09%). There were 6 participants (18.18%) that were satisfied with the information they received.

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 response was that they were satisfied with the communication they had with healthcare professionals (45.45%). The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (21.21%), and will include a multidisciplinary and coordinated approach (15.15%). Other themes included that communication will be more empathetic (12.12%), will allow people more time to meet with their clinician (9.09%), and will be more understandable (9.09%).

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 response was that they were satisfied with the care and support they received (27.27%). The most common expectations for future care and support were that it will include a multidisciplinary and coordinated approach (18.18%), will include more access to support services (15.15 %) and will be more holistic (including emotional health) (15.15%). Other themes included that care and support will include being able to connect with other patients through peer support (support groups, online forums) (12.12%), practical support (home care, transport, financial) (12.12%), and community awareness (9.09%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (36.36%), and low cost or free medical care through the government (33.33%). Other themes included the entire health system (30.30%), and timely access to treatment (9.09%).

Symptoms and aspects of quality of life

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were "The severity of the side effects", and "How safe the medication is and

weighing up the risks and benefits". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

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 5 to 10 years for a good quality of life even if it didn’t offer a cure (n=12, 38.71%), or for more than 10 years (n=11, 35.48%).

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants most commonly responded that they did not know (n=17, 36.96%), followed by equally effective (n=15, 32.61%).

There were 9 participants (29.03%) that thought that medicine delivered by all forms were equally effective, 4 participants (12.90%) thought that q cell or immunotherapy that uses the body's own immune defense was most effective, and 3 participants (9.678%) that thought as a stem cell/bone marrow transplant was most effective. There were 11 participants (35.48%) that were not sure.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27 %). Other themes included that treatments need to be affordable (21.21%), to invest in health professionals to service the patient population (18.18%), to help raise community awareness (12.12%), to improve rural services (12.12%), to have a holistic approach to the condition (including emotional support) (9.09%), and to increase investment (general) (9.09%).

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 understood the trajectory of the disease (27.27%), and to know the early signs and symptoms of their condition (12.12%). Other themes included to be assertive, an advocate, informed, and ask questions (9.09%), and look after their emotional well-being (9.09%).

As a follow up question, participants were asked if this knowledge would have changed their decisions. Most commonly, participants responded that it would not have changed their decision making (75.76%), for others it would have changed their decisions (18.18%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have stopped or changed treatment sooner (30.30%), and would not change any aspect of their care or treatment and were satisfied with care and treatment received (27.27%). Other themes included would not change any aspect of their care or treatment, with no reason given (9.09%), and would have liked to have had access to a specialist in their condition sooner (9.09%).

Section 1

Introduction and methods

Section 1 Introduction and methodology

Introduction

Background

Blood cancers accounted for approximately 12% of all cancers cases in Australia 2023. In 2019, 17,705 people were diagnosed with a blood cancer, a rate of 57.7 per 100,000[1]. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females[1]. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia[1], with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Collectively, blood cancer is can occur at any age, acute lymphoblastic leukaemia was expected to be the most common cancer diagnosed in children 2023, however, incidence of blood cancer increases with age, and in 2019, the mean age at diagnosis was 67.2[1].

Five year survival was 69% in 2015 to 2019, survival rates are higher in younger age groups with five year survival of 90% for people aged under 40, 84% in 40–59 year olds to 69% in 60–79 year olds to 42% for those aged 80 years older[1].

Blood cancers have high hospitalisation and pharmaceutical costs, with myeloma and leukaemia rated in the top three most expensive cancers to treat in Australia[2].

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 (June 12, 2023) to identify studies of blood cancer with patient reported outcomes, or patient experience conducted in the past two years worldwide. Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 65 studies identified of between 8 and 1861 lung cancer participants. A single study was conducted in Australia, where 13 participants were interviewed about treatment and management.

In this PEEK study 37 participants completed surveys and 33 participants completed interviews, making this one of the largest studies interviewing participants about blood cancer. 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

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Participants

To be eligible for the study, participants needed to have been diagnosed with a ***blood cancer that is treatable by CAR-T therapy***, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study.

Ethics

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

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey).

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

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[3], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[4], the Short Fear of Progression Questionnaire (FOP12)[5], and the Partners in Health version 2 (PIH)[6]. 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 blood cancer type, gender, age, location of residence, and socio-economic status. Scales and subscales were calculated according to reported instructions[3-6].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[7].

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[8].

For comparisons by blood cancer type, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into a custom-built PEEK analysis database. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in the PEEK analysis 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 analysis and final reporting was completed in August 2023.

Position of this study

A search was conducted in Pubmed (June 12, 2023) to identify studies of blood cancer with patient reported outcomes, or patient experience conducted in the past two years worldwide (Table 1.1). Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 65 studies identified of between 8 and 1861 lung cancer participants.

There were 19 studies that collected information by interview of between 8 and 72 participants. There were 6 studies focused on quality of life[9-14], 6 studies focused on treatment and management[15-20], 5 studies that focused on decision making[21-25], a single study that focused on care and support[26], and a single study that focused on information and communication[27].

There were 2 studies that collected information by focus group, on study of 18 participants was focused on quality of life[28], and one study of 8 participants was focused on decision making[29].

There were 44 studies that collected data by survey of between 15 and 1861 participants.There were 30 studies focused on health-re;ated quality of life [30-58],
4 studies focused on quality of life[28,59-61],
4 studies focused on expectations[29,62-64],
3 studies focused on decision making[65-67],

3 studies focused on treatment and management[68-70], a single study focused on care and support[71], and a single study focused on information and communication[72]

A single study was conducted in Australia, where 13 participants were interviewed about treatment and management. In this PEEK study 37 participants completed surveys and 33 participants completed interviews, making this one of the largest studies interviewing participants about blood cancer. 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	Interviews	Survey	Focus	PEEK Section							
					2: Health status, co-morbidities	3: Symptoms & Diagnosis	4: Decision making	5: Treatment & management	6: Information & communication	7: Care &support	8: Quality of life	9 Expectations
Hodge, 2022[15]	USA	72	72	Treatment and management	X			X				X
Bates-Fraser, 2023[9]	USA	21 (21 carers)	0	Quality of life							X	
Howell, 2022[27]	UK	35 (10 carers)	0	Information and communication		X			X		X	
McCaughan, 2023[16]	UK	35 (10 carers)	0	Treatment and management		X			X	X	X	
Blejec, 2023[21]	USA	29	0	Decision making			X	X	X	X		
Hoppe, 2022[10]	USA	28	0	Quality of life					X		X	X
Amonoo, 2022[26]	USA	25	0	Care and support						X		
Janssens, 2021[22]	Multinational	24	0	Decision making			X				X	
Borregaard Myrhøj, 2022[23]	Denmark	12 (11 Carers)	0	Decision making			X					
van Lieshout, 2022[17]	The Netherlands	23	0	Treatment and management				X				
Nathwani, 2022[11]	USA	22	0	Quality of life		X		X			X	
Dombeck, 2023[24]	USA	21	0	Decision making			X					
Crowder, 2022[12]	USA	20	0	Quality of life							X	
Crawford, 2022[13]	USA	20	0	Quality of life		X					X	X
Mian, 2023[25]	Canada	18	18	Decision making			X					
Bixby, 2023[18]	USA	18	0	Treatment and management				X				
Colton, 2022[19]	Australia	13	13	Treatment and management	X						X	
Booker, 2023[20]	Canada	8 (4 carers)	0	Treatment and management				X			X	
Vena, 2023[14]	USA	8	0	Quality of life		X			X	X	X	
Cheng, 2022[28]	USA	18*	0	Quality of life							X	

Wilson, 2022[29]	Canada	8*	0	Decision making			X	X			X	
Wu, 2022[30]	USA	0	1861	HRQOL	X							
Ullrich, 2023[31]	USA	0	1703	HRQOL	X							
Ullrich, 2023[31]	USA	0	1703	HRQOL	X							
Baum, 2023[71]	Germany	0	1551	Care and support	X					X		X
Mayo, 2022[59]	Canada	0	1160	Quality of life								X
Strouse, 2022[32]	USA	0	980	HRQOL								
Lohmann, 2022[33]	Germany	0	922	HRQOL	X							
Sharman, 2020[34]	USA	0	889	HRQOL	X							
LeBlanc, 2022[35]	USA	0	690	HRQOL	X							
Gatopoulou, 2022[36]	Multinational	0	514	HRQOL	X			X				
Bridges, 2023[62]	Canada	0	339 (73 carers)	Expectations								X
Janssens, 2022[63]	Multinational	0	393	Expectations								X
Ribbands, 2023[65]	USA	0	377	Decision making								
Ludwig, 2022[37]	Multinational	0	330	HRQOL	X	X						
Quinn, 2022[38]	Germany	0	330	HRQOL	X	X						
Tervonen, 2023[66]	Multinational	0	300	Decision making			X					
Barata, 2023[68]	USA	0	249	Treatment and management				X				X
Lepretre, 2021[39]	France	0	219	HRQOL	X			X				
Ashaye, 2022[67]	USA	0	201	Decision making			X					
Chantziara, 2022[40]	Multinational	0	186	HRQOL	X						X	
Sleurs, 2021[41]	Multinational	0	186	HRQOL	X						X	
O'Donnell, 2022[42]	USA	0	180	HRQOL	X	X						
Rensen, 2022[43]	Netherlands	0	139	HRQOL	X							
Pemberton-Whiteley, 2023[44]	Multinational	0	139	HRQOL	X						X	
Park, 2022[45]	South Korea	0	132	HRQOL	X						X	
Ribbands, 2023[46]	USA	0	132	HRQOL	X	X						
Damen, 2022[64]	The Netherlands	0	122	Expectations	X							X

Suzuki, 2022[47]	Japan	0	106	HRQOL	X	X						
Yusuf, 2022[48]	USA	0	104	HRQOL	X							
Jensen, 2022[49]	USA	0	98	HRQOL	X	X						
Micas Pedersen, 2023[50]	Denmark	0	88	HRQOL	X	X						
Paunescu, 2022[51]	France	0	69	HRQOL	X			X			X	
Trevino, 2022[52]	USA	0	64	HRQOL	X							
Wang, 2021[53]	USA	0	60	HRQOL	X	X						
Castelli, 2022[54]	Germany	0	58	HRQOL	X							
Coughlin, 2022[55]	USA	0	53	HRQOL	X							
Lindberg, 2022[69]	Multinational	0	51	Treatment and management	X			X				
Stamm, 2021[56]	Switzerland	0	47	HRQOL	X	X						
Biran, 2021[57]	USA	0	42	HRQOL	X							
Osaki, 2022[58]	Japan	0	32	HRQOL	X							
Nakajima, 2022[72]	Japan	0	16 (14 carers)	Information and communication					X			
Marte, 2022[60]	USA	0	26	Quality of life	X			X			X	
Ochagavía Sufrategui, 2023[70]	Spain	0	23	Treatment and management	X			X				
Bennink, 2021[61]	Netherlands	0	15	Quality of life							X	

HRQOL = Health related quality of life
*Focus groups

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 7significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Demographics

There were 37 people with blood cancer who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), and 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma.

Demographics

There were 37 people with blood cancer that took part in this study, 17 were females (45.95%). Participants were aged from 25 to over 75 years of age, most were aged between 55 to 74 years (n=26, 70.27%).

Participants were most commonly from Queensland (n=10, 27.03%), Victoria (n=8, 21.62%), and New South Wales (n=6, 16.22%). Most participants were from major cities (n=21, 56.76%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 20 participants (54.05%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 17 participants (45.95%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Other health conditions

Participants were asked about health conditions, other than blood cancer 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=31, 83.78%), the maximum number reported was 10 other conditions, with a median of 3.00 other conditions (IQR = 4.00). The most commonly reported health condition was sleep problems or insomnia (n=24, 64.86%), followed by back pain (n=16, 43.24%), anxiety (n=14, 37.84%), and arthritis (n=10, 27.03%).

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 sometimes 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 never 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 slightly limited for participants in this study.

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

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

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is better now compared to a year ago.

Participants

There were 37 people with CAR-T treatable blood cancers who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma and 18 (48.65%) with multiple myeloma.

Table 2.1: Participants

Participants and diagnosis	Number (n=37)	Percent
B-cell acute lymphoblastic leukemia (ALL)	8	21.62
Diffuse Large B-Cell Lymphoma	11	29.73
Multiple Myeloma	18	48.65

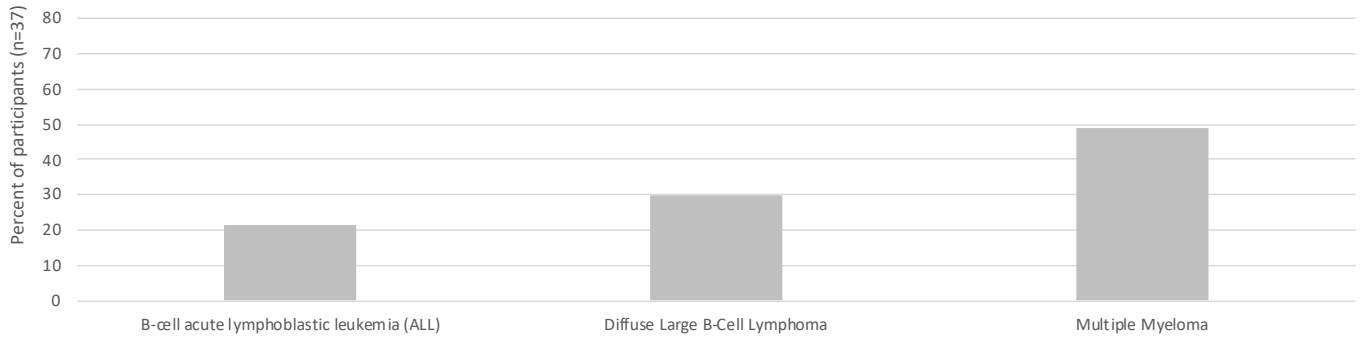

Figure 2.1: Participants

Demographics

There were 37 people with CAR-T treatable blood cancer that took part in this study, 17 were females (45.95%). Participants were aged from 25 to over 75 years of age, most were aged between 55 to 74 years (n=26, 70.27%).

Participants were most commonly from Queensland (n=10, 27.03%), Victoria (n=8, 21.62%), and New South Wales (n=6, 16.22%). Most participants were from major cities (n=21, 56.76%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 20 participants (54.05%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 17 participants (45.95%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Table 2.2: Demographics

Demographics	Definition	Number (n=37)	Percent
Gender	Female	17	45.95
	Male	20	54.05
Age	25 - 34	1	2.70
	35 - 44	1	2.70
	45 - 54	7	18.92
	55 - 64	13	35.14
	65 - 74	13	35.14
	75+	2	5.41
Location	Major Cities of Australia	21	56.76
	Inner Regional Australia	8	21.62
	Outer Regional Australia	6	16.22
	Remote Australia	2	5.41
State	Australian Capital Territory	2	5.41
	New South Wales	6	16.22
	Northern Territory	1	2.70
	Queensland	10	27.03
	South Australia	3	8.11
	Tasmania	3	8.11
	Victoria	8	21.62
	Western Australia	4	10.81
Socio-Economic Indexes for Areas (SEIFA)	1	2	5.41
	2	4	10.81
	3	2	5.41
	4	4	10.81
	5	4	10.81
	6	1	2.70
	7	6	16.22
	8	3	8.11
	9	5	13.51
	10	6	16.22
Race/ethnicity	Caucasian/White	32	86.49
	Other	3	8.11

Other health conditions

Participants were asked about health conditions, other than blood cancer 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=31, 83.78%), the maximum number reported was 10 other conditions, with a median of 3.00 other conditions (IQR = 4.00). The most commonly reported health condition was sleep problems or insomnia (n=24, 64.86%), followed by back pain (n=16, 43.24%), anxiety (n=14, 37.84%), and arthritis (n=10, 27.03%).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=37)	Percent
No other conditions	6	16.22
1 to 2	9	24.32
3 to 4	11	29.73
5 to 6	6	16.22
7 or more	5	13.51

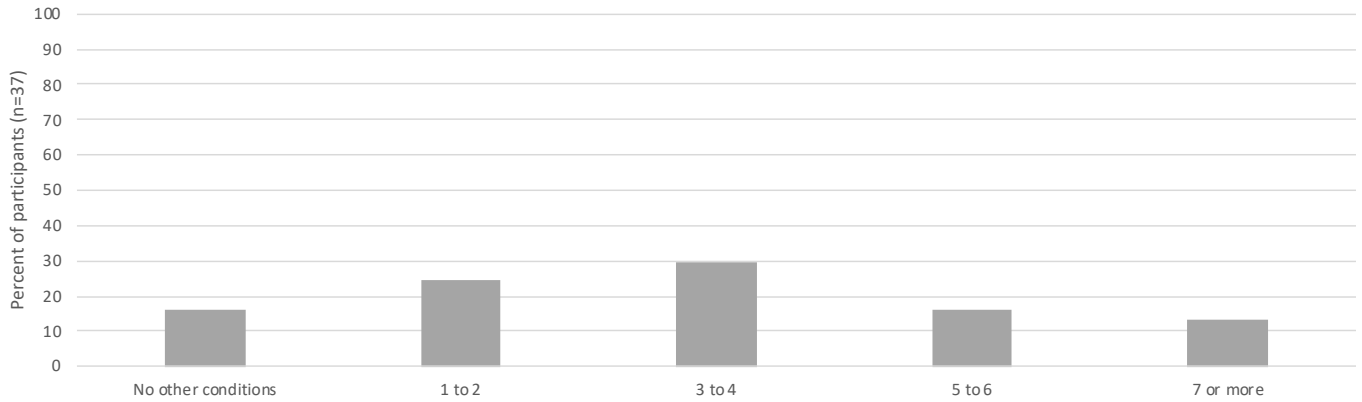

Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=37)	Percent
Sleep problems or insomnia	24	64.86
Back pain	16	43.24
Anxiety (Total)	14	37.84
Anxiety (that a doctor diagnosed)	8	21.62
Anxiety (that you diagnosed) yourself	10	27.03
Arthritis	10	27.03
Chronic pain	9	24.32
Depression (Total)	7	18.92
Depression (that you diagnosed yourself)	6	16.22
Depression (that a doctor diagnosed)	2	5.41
Asthma	6	16.22
Do you have any other types of cancer	6	16.22
Osteoporosis	5	13.51
Diabetes	4	10.81
Chronic heart failure	2	5.41
Coronary heart disease (eg heart attack, angina)	2	5.41
Chronic kidney disease	1	2.70
COPD (Chronic obstructive pulmonary disease)	1	2.70

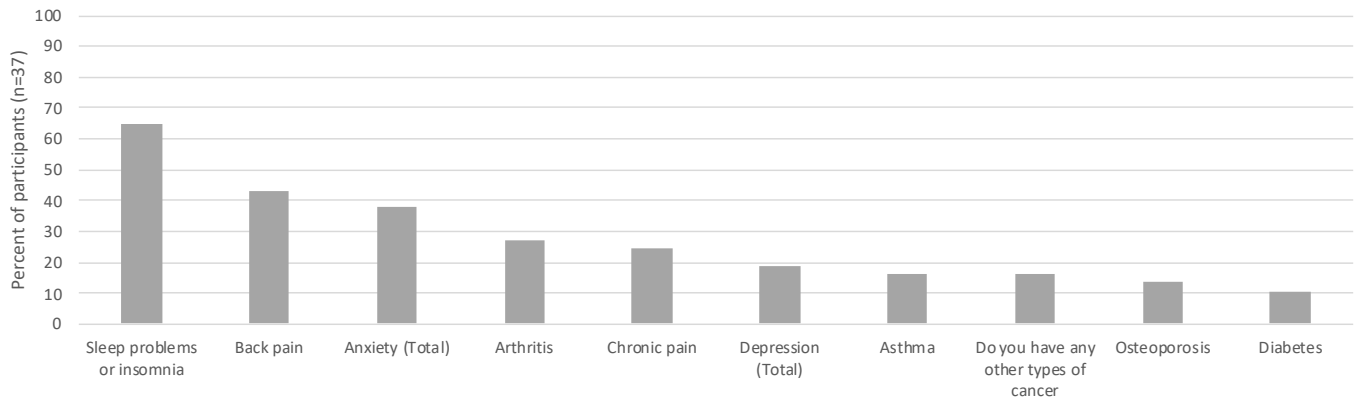

Figure 2.3: Other health conditions (% of all participants)

Subgroup analysis

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

Comparisons were made by Blood cancer. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma, and 18 participants (48.65%) with Multiple Myeloma.

Comparisons were made by CAR T-cell therapy there were 29 participants (78.38%) that had Car T-cell therapy and, 8 participants (21.62%) that did not.

Comparisons were made by gender, there were 17 female participants (45.95%) and 20 male participants (54.05%).

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=22, 59.46%), and participants aged 65 and older (n=15, 40.54%).

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 (n=16, 43.24%) were compared to those living in a major city (n=21, 56.76%).

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 (n=17, 45.95%) compared to those with a higher SEIFA score of 7-10 (n=20, 54.05%).

Table 2.5: Subgroups

Subgroups	Definition	Number (n=37)	Percent
Type of blood cancer	B-cell acute lymphoblastic leukemia (ALL)	8	21.62
	Diffuse Large B-Cell Lymphoma	11	29.73
	Multiple Myeloma	18	48.65
CAR T-cell therapy	No	29	78.38
	Yes	8	21.62
Gender	Female	17	45.95
	Male	20	54.05
Age	Aged 25 to 64	22	59.46
	Aged 65 and older	15	40.54
Location	Regional or remote	16	43.24
	Metropolitan	21	56.76
Socioeconomic advantage	Mid to low advantage	17	45.95
	Higher advantage	20	54.05

Baseline health

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

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

The overall scores for the cohort were in the highest quintile for SF36 Role functioning/emotional (median=100.00, IQR=66.67), indicating very good emotional role functioning.

The overall scores for the cohort were in the second highest quintile for SF36 Physical functioning (median=72.50, IQR=40.00), SF36 Emotional well-being (mean=76.24, SD=12.61), SF36 Social functioning (median=75.00, IQR=46.88), SF36 Pain (median=72.50, IQR=30.00), SF36 Health change (median=62.50, IQR=50.00), indicating good physical functioning, good emotional well-being, good social functioning, mild pain, better than a year ago.

The overall scores for the cohort were in the middle quintile for SF36 Role functioning/physical (median=50.00, IQR=100.00), SF36 Energy/Fatigue (mean=52.50, SD=18.96), SF36 General health (mean=53.38, SD=24.70), indicating moderate physical role functioning, moderate energy, moderate general health.

Comparisons of SF36 have been made based on type of blood cancer, treatment with Car T-cell therapy, gender, age, location, and socioeconomic status.

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

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health sometimes 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 never 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 slightly limited for participants in this study.

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

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

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is better now compared to a year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=34)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	68.68	29.34	72.50	40.00	0 to 100	4
Role functioning/physical	51.47	42.61	50.00	100.00	0 to 100	3
Role functioning/emotional	70.59	38.28	100.00	66.67	0 to 100	5
Energy/Fatigue*	52.50	18.96	50.00	25.00	0 to 100	3
Emotional well-being*	76.24	12.61	80.00	20.00	0 to 100	4
Social functioning	73.90	24.30	75.00	46.88	0 to 100	4
Pain	69.56	24.44	72.50	30.00	0 to 100	4
General health*	53.38	24.70	55.00	46.25	0 to 100	3
Health change	67.65	26.49	62.50	50.00	0 to 100	4

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

SF36 by type of blood cancer

Comparisons were made by type of blood cancer. There were 6 participants (17.65%) with B-cell acute lymphoblastic leukemia (ALL), 11 participants (32.35%) with Diffuse Large B-Cell Lymphoma, and 17 participants (50.00%) with Multiple Myeloma.

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

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

Table 2.7: SF36 by type of blood cancer summary statistics and one-way ANOVA

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Physical functioning	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	65.83	42.36	Between groups	1215.00	2	607.30	0.69	0.5080
	Diffuse Large B-Cell Lymphoma	11	32.35	77.27	22.95	Within groups	27201.00	31	877.40		
	Multiple Myeloma	17	50.00	64.12	28.46	Total	28416.00	33	1484.70		
Energy/fatigue	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	51.67	18.62	Between groups	5.00	2	2.60	0.01	0.9930
	Diffuse Large B-Cell Lymphoma	11	32.35	52.73	20.66	Within groups	11857.00	31	382.50		
	Multiple Myeloma	17	50.00	52.65	19.13	Total	11862.00	33	385.10		
Emotional well-being	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	78.67	13.54	Between groups	47.00	2	23.30	0.14	0.8710
	Diffuse Large B-Cell Lymphoma	11	32.35	75.27	13.84	Within groups	5200.00	31	167.70		
	Multiple Myeloma	17	50.00	76.00	12.17	Total	5247.00	33	191.00		
General health	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	59.17	29.23	Between groups	1940.00	2	969.90	1.65	0.2080
	Diffuse Large B-Cell Lymphoma	11	32.35	61.82	21.25	Within groups	18196.00	31	587.00		
	Multiple Myeloma	17	50.00	45.88	24.25	Total	20136.00	33	1556.90		
Health change	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	70.83	33.23	Between groups	2942.00	2	1470.90	2.26	0.1220
	Diffuse Large B-Cell Lymphoma	11	32.35	79.55	21.85	Within groups	20220.00	31	652.30		
	Multiple Myeloma	17	50.00	58.82	24.91	Total	23162.00	33	2123.20		

Table 2.8: SF36 by type of blood cancer summary statistics and Kruskal-Wallis test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	C^2	dF	p-value
Role functioning physical	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	37.50	93.75	2.46	2	0.2922
	Diffuse Large B-Cell Lymphoma	11	32.35	100.00	62.50			
	Multiple Myeloma	17	50.00	25.00	75.00			
Role functioning emotional	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	66.67	91.67	0.66	2	0.7193
	Diffuse Large B-Cell Lymphoma	11	32.35	100.00	50.00			
	Multiple Myeloma	17	50.00	100.00	33.33			
Social functioning	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	62.50	43.75	0.69	2	0.7096
	Diffuse Large B-Cell Lymphoma	11	32.35	75.00	31.25			
	Multiple Myeloma	17	50.00	75.00	37.50			
Pain	B-cell acute lymphoblastic leukemia (ALL)	6	17.65	72.50	10.00	0.65	2	0.7242
	Diffuse Large B-Cell Lymphoma	11	32.35	77.50	42.50			
	Multiple Myeloma	17	50.00	67.50	22.50			

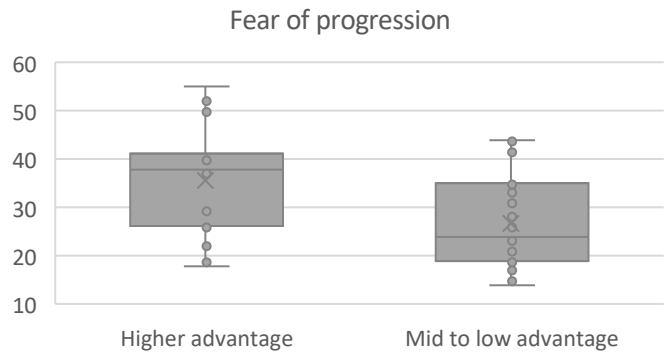

Figure 2.4: Boxplot of SF36 Physical functioning by type of blood cancer

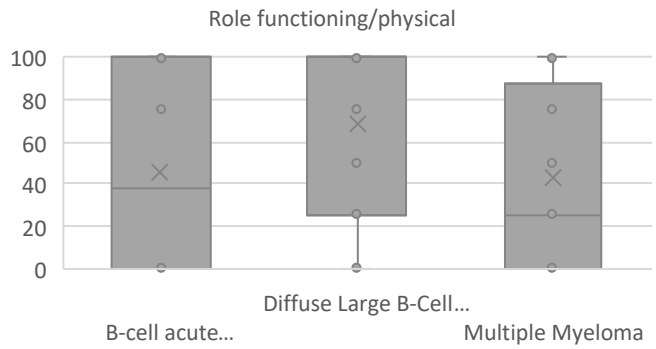

Figure 2.5: Boxplot of SF36 Role functioning/physical by type of blood cancer

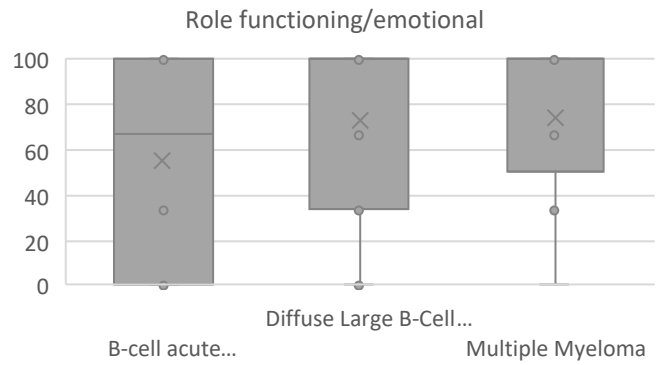

Figure 2.6: Boxplot of SF36 Role functioning/emotional by type of blood cancer

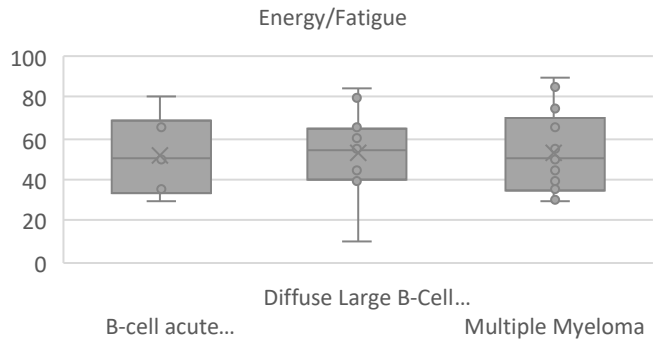

Figure 2.7: Boxplot of SF36 Energy/fatigue by type of blood cancer

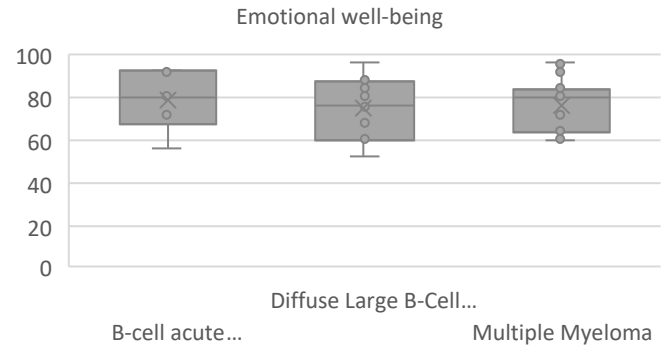

Figure 2.8: Boxplot of SF36 Emotional well-being by type of blood cancer

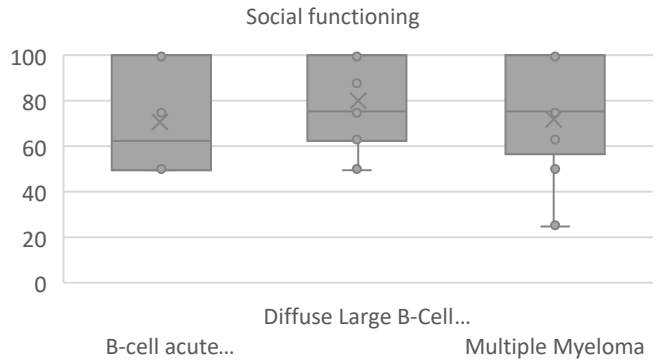

Figure 2.9: Boxplot of SF36 Social functioning by type of blood cancer

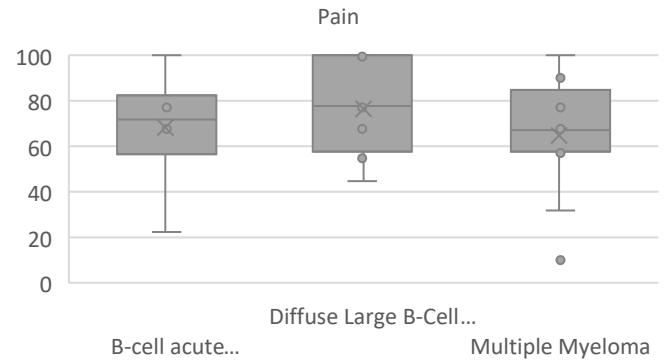

Figure 2.10: Boxplot of SF36 Pain by a type of blood cancer

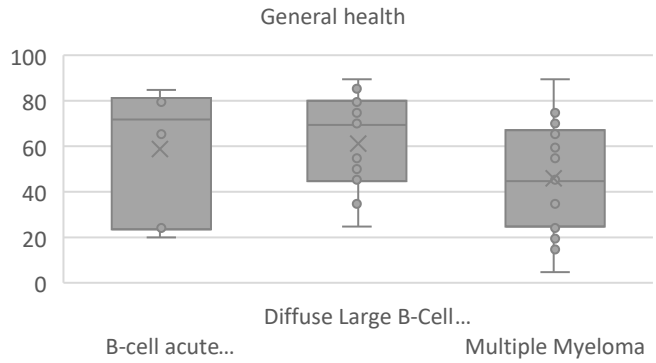

Figure 2.11: Boxplot of SF36 General health by type of blood cancer

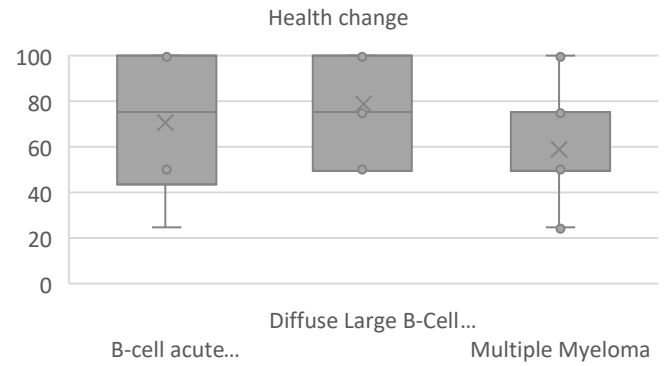

Figure 2.12: Boxplot of SF36 Health change by type of blood cancer

SF36 by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 26 participants (76.47%) that had treatment with CAR T-cell therapy and, 8 participants (23.53%) that did not .

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the SF36 scales.

Table 2.9: SF36 by CAR T-cell therapy summary statistics and T-test

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Emotional well-being	No	26	76.47	75.23	12.24	-0.83	32	0.4107
	Yes	8	23.53	79.50	14.09			
General health	No	26	76.47	51.92	23.84	-0.62	32	0.5428
	Yes	8	23.53	58.13	28.53			

Table 2.10: SF36 by CAR T-cell therapy summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Physical functioning	No	26	76.47	77.50	38.75	118.50	0.5679
	Yes	8	23.53	70.00	40.00		
Role functioning/physical	No	26	76.47	50.00	100.00	111.50	0.7677
	Yes	8	23.53	37.50	62.50		
Role functioning/emotional	No	26	76.47	100.00	58.33	112.00	0.7362
	Yes	8	23.53	83.33	66.67		
Energy/Fatigue	No	26	76.47	50.00	28.75	102.50	0.9675
	Yes	8	23.53	45.00	17.50		
Social functioning	No	26	76.47	75.00	37.50	130.50	0.2752
	Yes	8	23.53	62.50	46.88		
Pain	No	26	76.47	72.50	30.00	115.50	0.6522
	Yes	8	23.53	72.50	26.25		
Health change	No	26	76.47	50.00	43.75	83.00	0.3813
	Yes	8	23.53	87.50	50.00		

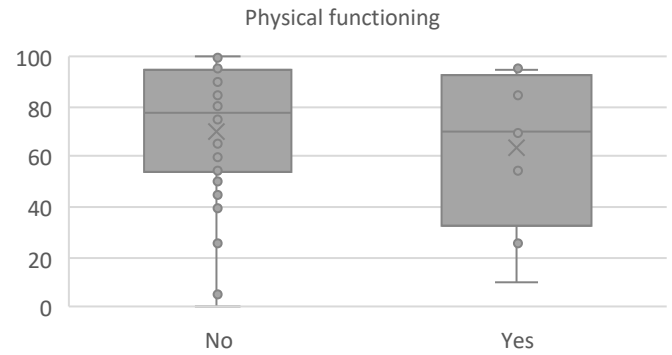

Figure 2.13: Boxplot of SF36 Physical functioning by CAR T-cell therapy

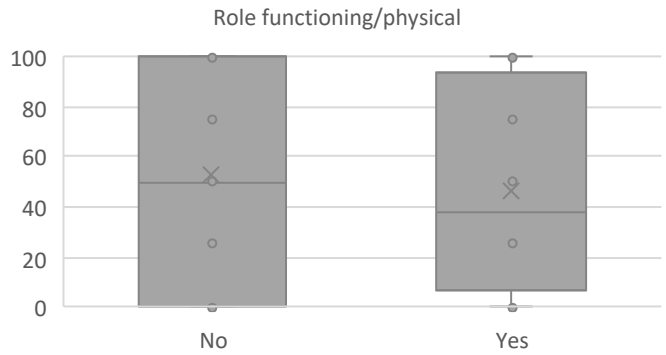

Figure 2.14: Boxplot of SF36 Role functioning/physical by CAR T-cell therapy

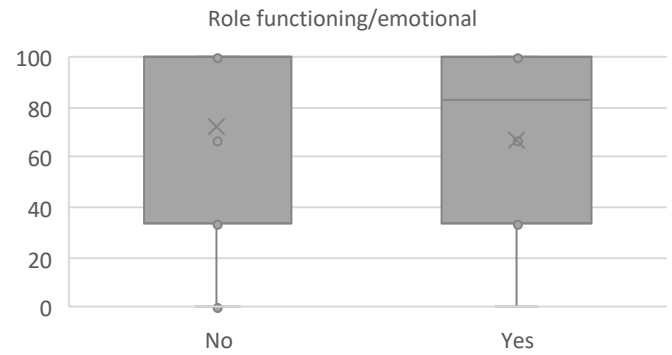

Figure 2.15: Boxplot of SF36 Role functioning/emotional by CAR T-cell therapy

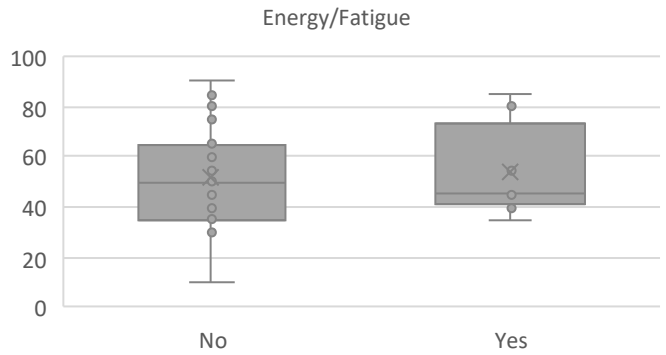

Figure 2.16: Boxplot of SF36 Energy/fatigue by CAR T-cell therapy

Figure 2.17: Boxplot of SF36 Emotional well-being by CAR T-cell therapy

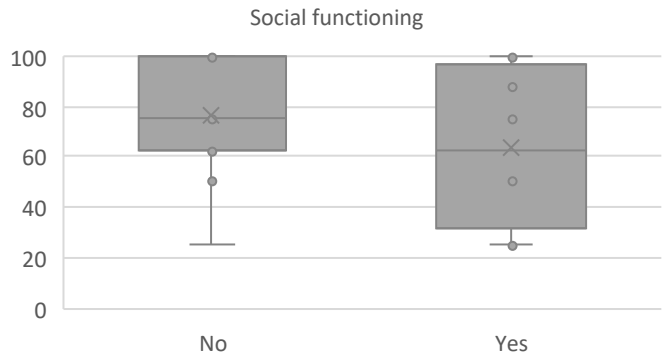

Figure 2.18: Boxplot of SF36 Social functioning by CAR T-cell therapy

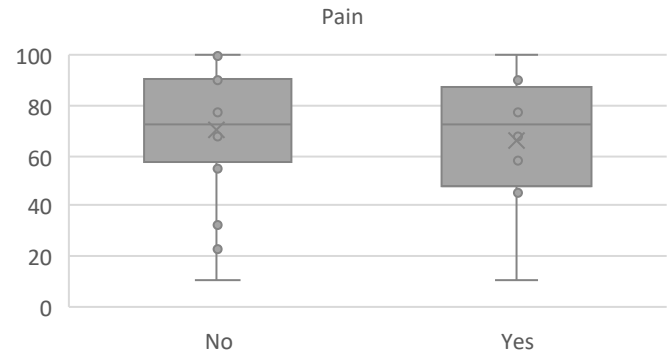

Figure 2.19: Boxplot of SF36 Pain by a CAR T-cell therapy

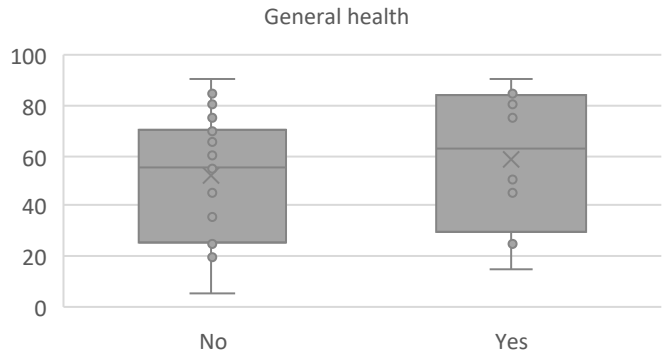

Figure 2.20: Boxplot of SF36 General health by CAR T-cell therapy

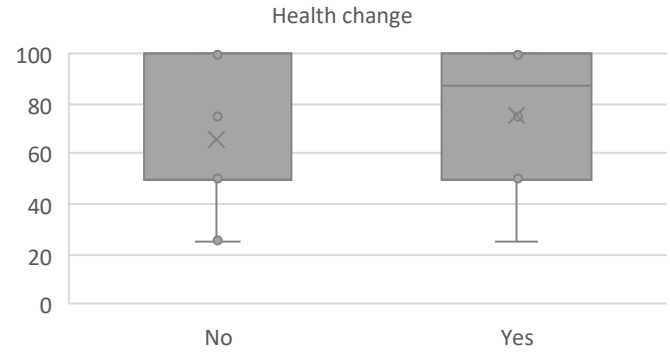

Figure 2.21: Boxplot of SF36 Health change by CAR T-cell therapy

SF36 by gender

Comparisons were made by gender, there were 15 female participants (44.12%), and 19 male particpants (55.88%).

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

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

Table 2.11: SF36 by gender summary statistics and T-test

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Emotional well-being	Female	15	44.12	77.87	12.73	0.66	32.00	0.5110
	Male	19	55.88	74.95	12.71			
General health	Female	15	44.12	62.00	22.74	1.88	32.00	0.0699
	Male	19	55.88	46.58	24.61			

Table 12.: SF36 by gender summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Physical functioning	Female	15	44.12	85.00	30.00	155.50	0.6631
	Male	19	55.88	65.00	42.50		
Role functioning/physical	Female	15	44.12	75.00	62.50	189.50	0.0937
	Male	19	55.88	25.00	75.00		
Role functioning/emotional	Female	15	44.12	100.00	16.67	192.00	0.0600
	Male	19	55.88	66.67	83.33		
Energy/Fatigue	Female	15	44.12	45.00	35.00	132.50	0.7407
	Male	19	55.88	50.00	12.50		
Social functioning	Female	15	44.12	75.00	31.25	169.50	0.3421
	Male	19	55.88	75.00	50.00		
Pain	Female	15	44.12	77.50	22.50	157.50	0.6118
	Male	19	55.88	67.50	28.75		
Health change	Female	15	44.12	75.00	50.00	173.00	0.2738
	Male	19	55.88	50.00	25.00		

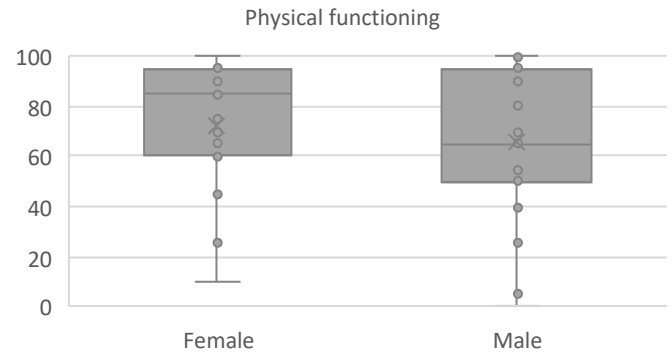

Figure 2.22: Boxplot of SF36 Physical functioning by gender

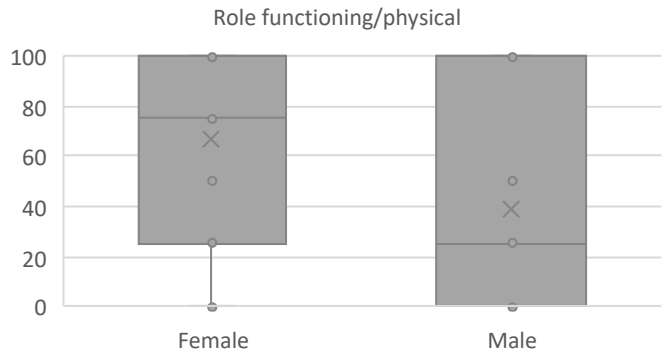

Figure 2.23: Boxplot of SF36 Role functioning/physical by gender

Figure 2.24: Boxplot of SF36 Role functioning/emotional by gender

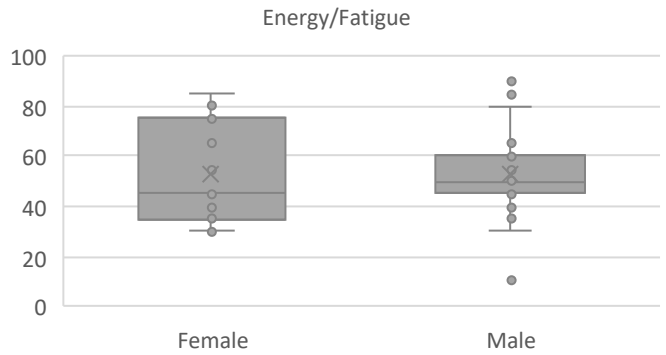

Figure 2.25: Boxplot of SF36 Energy/fatigue by gender

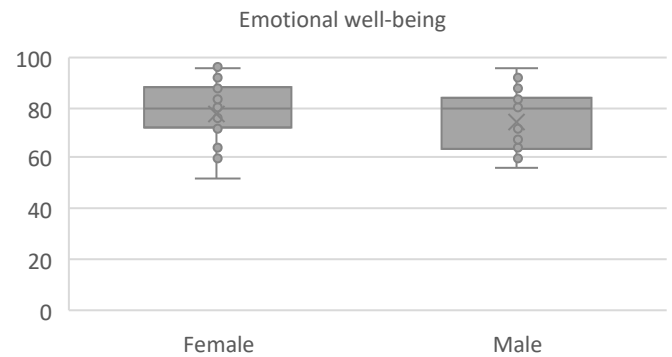

Figure 2.26: Boxplot of SF36 Emotional well-being by gender

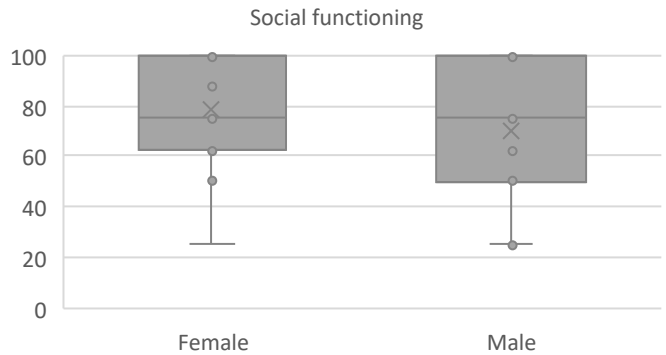

Figure 2.27: Boxplot of SF36 Social functioning by gender

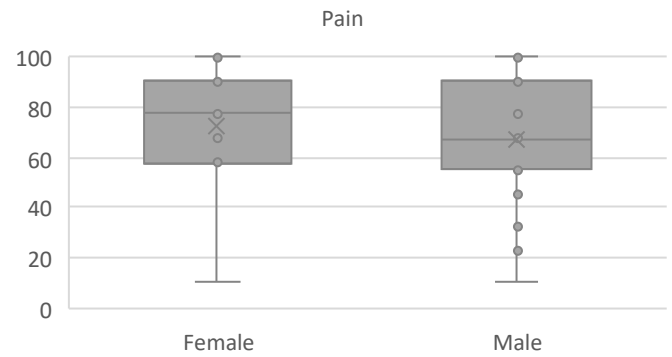

Figure 2.28: Boxplot of SF36 Pain by a gender

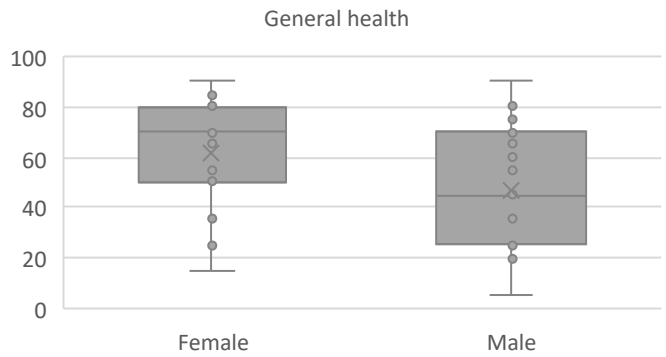

Figure 2.29: Boxplot of SF36 General health by gender

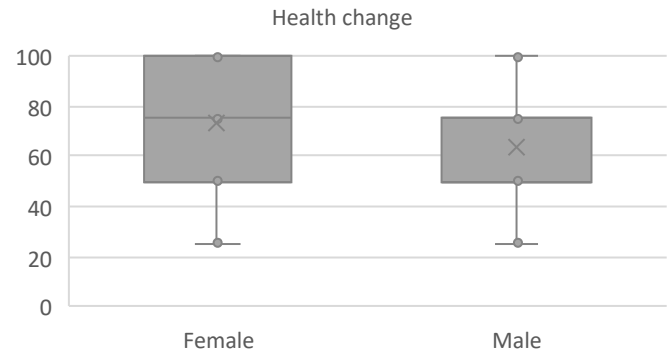

Figure 2.30: Boxplot of SF36 Health change by gender

SF36 by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=20, 58.82%), and participants aged 65 and older (n=14, 41.18%).

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

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

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

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Aged 25 to 64	20	58.82	47.75	17.36	-1.8048	32	0.08053
	Aged 65 and older	14	41.18	59.29	19.70			
Emotional well-being	Aged 25 to 64	20	58.82	73.60	12.41	-1.4829	32	0.1479
	Aged 65 and older	14	41.18	80.00	12.35			
General health	Aged 25 to 64	20	58.82	51.50	24.61	-0.52522	32	0.603
	Aged 65 and older	14	41.18	56.07	25.51			

Table 2.14: SF36 by age summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Physical functioning	Aged 25 to 64	20	58.82	82.50	42.50	148.50	0.7785
	Aged 65 and older	14	41.18	65.00	38.75		
Role functioning/physical	Aged 25 to 64	20	58.82	50.00	100.00	123.50	0.5607
	Aged 65 and older	14	41.18	50.00	75.00		
Role functioning/emotional	Aged 25 to 64	20	58.82	100.00	66.67	137.00	0.9229
	Aged 65 and older	14	41.18	100.00	58.33		
Social functioning	Aged 25 to 64	20	58.82	75.00	31.25	117.50	0.4262
	Aged 65 and older	14	41.18	87.50	46.88		
Pain	Aged 25 to 64	20	58.82	67.50	20.63	124.00	0.5841
	Aged 65 and older	14	41.18	78.75	32.50		
Health change	Aged 25 to 64	20	58.82	62.50	50.00	139.00	0.9853
	Aged 65 and older	14	41.18	62.50	43.75		

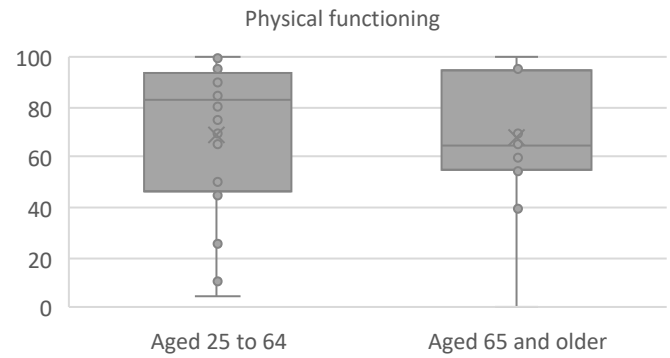

Figure 2.31: Boxplot of SF36 Physical functioning by age

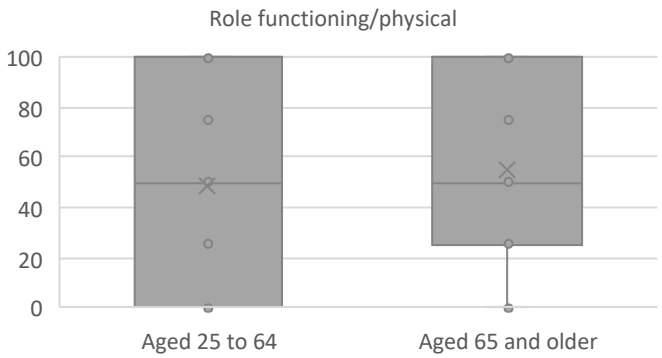

Figure 2.32: Boxplot of SF36 Role functioning/physical by age

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

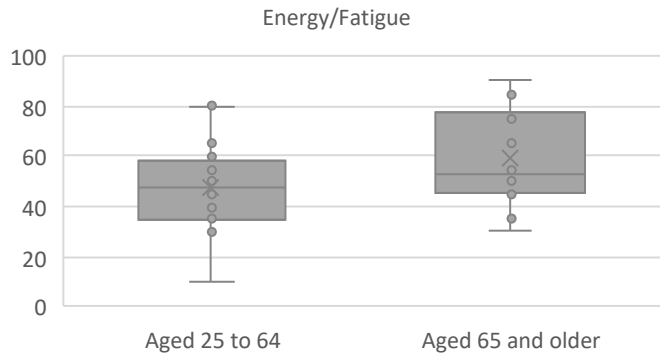

Figure 2.43: Boxplot of SF36 Energy/fatigue by age

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

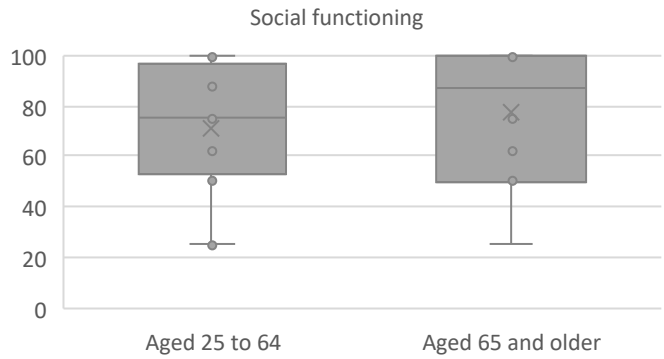

Figure 2.36: Boxplot of SF36 Social functioning by age

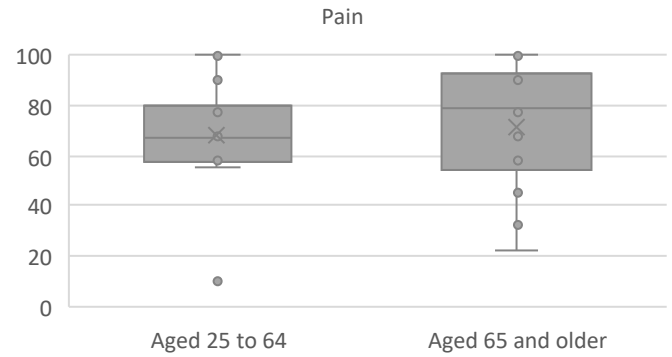

Figure 2.37: Boxplot of SF36 Pain by a age

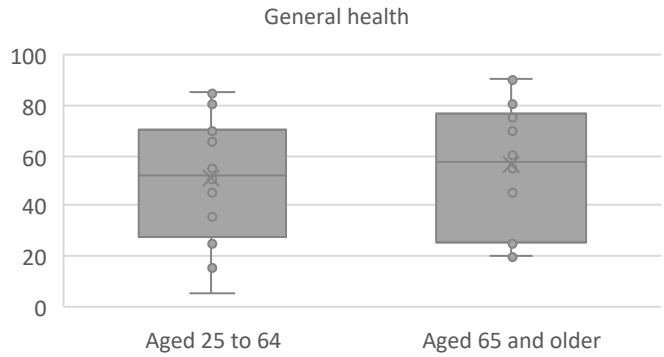

Figure 2.38: Boxplot of SF36 General health by age

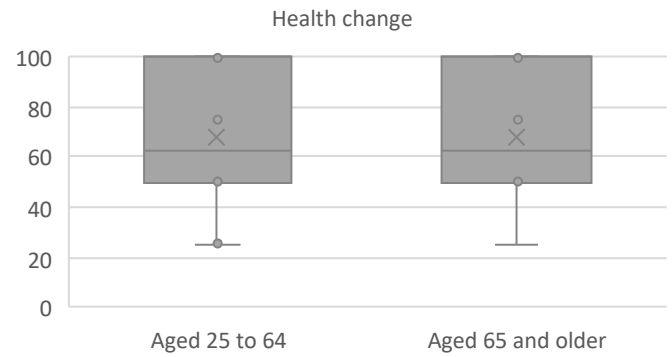

Figure 2.39: Boxplot of SF36 Health change by age

SF36 by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=16, 47.06%) were compared to those living in a major city (n=18, 52.94%).

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

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

Table 2.15: SF36 by location summary statistics and T-test

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Metropolitan	16	47.06	47.50	15.71	-1.48	32.00	0.1499
	Regional or remote	18	52.94	56.94	20.87			
Emotional well-being	Metropolitan	16	47.06	73.50	11.94	-1.20	32.00	0.2387
	Regional or remote	18	52.94	78.67	13.02			
General health	Metropolitan	16	47.06	49.38	26.89	-0.89	32.00	0.3806
	Regional or remote	18	52.94	56.94	22.76			

Table 2.16: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Physical functioning	Metropolitan	16	47.06	75.00	51.25	138.50	0.8624
	Regional or remote	18	52.94	72.50	32.50		
Role functioning/physical	Metropolitan	16	47.06	37.50	100.00	114.00	0.2901
	Regional or remote	18	52.94	62.50	75.00		
Role functioning/emotional	Metropolitan	16	47.06	66.67	75.00	94.00	0.0588
	Regional or remote	18	52.94	100.00	25.00		
Social functioning	Metropolitan	16	47.06	75.00	40.63	137.00	0.8167
	Regional or remote	18	52.94	75.00	46.88		
Pain	Metropolitan	16	47.06	67.50	25.63	127.50	0.5774
	Regional or remote	18	52.94	77.50	27.50		
Health change	Metropolitan	16	47.06	50.00	50.00	123.50	0.4679
	Regional or remote	18	52.94	75.00	50.00		

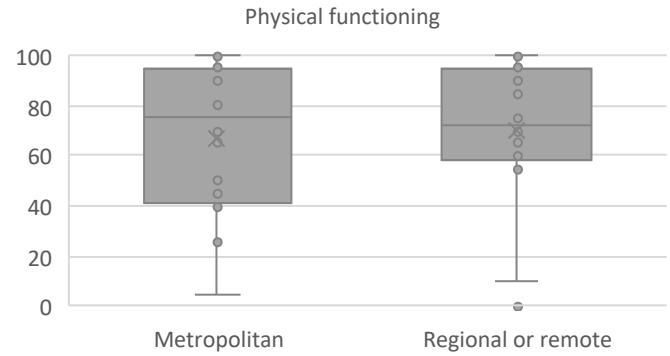

Figure 2.40: Boxplot of SF36 Physical functioning by location

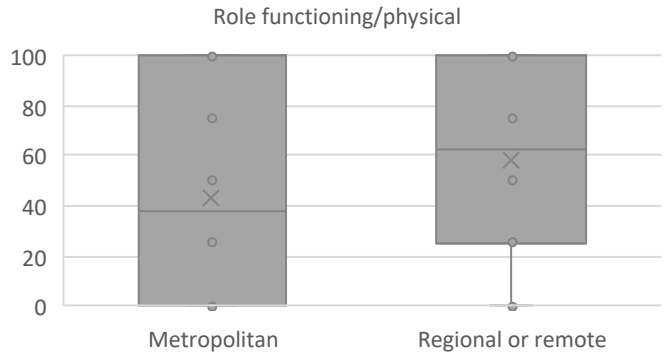

Figure 2.41: Boxplot of SF36 Role functioning/physical by location

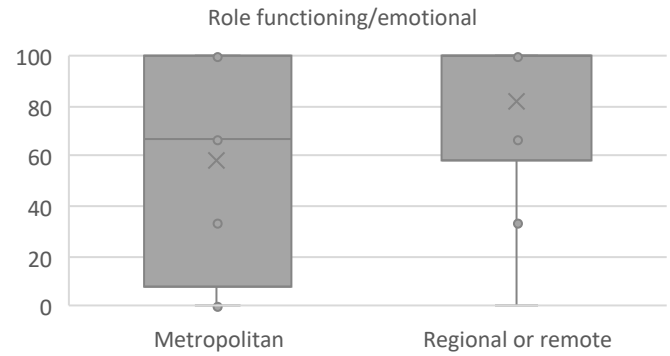

Figure 2.42: Boxplot of SF36 Role functioning/emotional by location

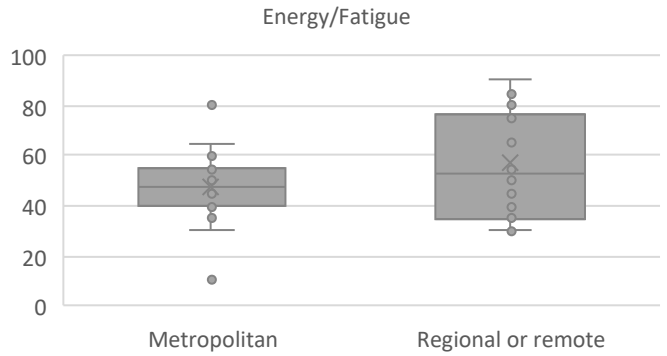

Figure 2.43: Boxplot of SF36 Energy/fatigue by location

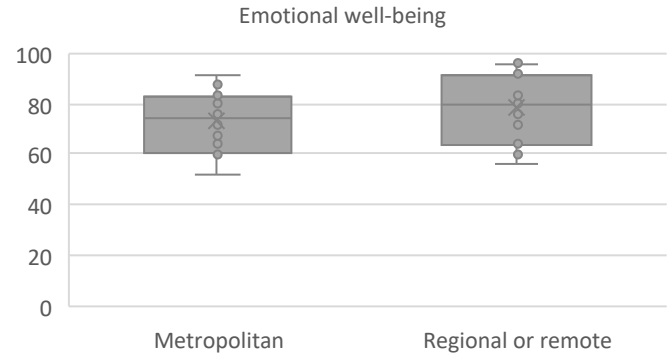

Figure 2.44: Boxplot of SF36 Emotional well-being by location

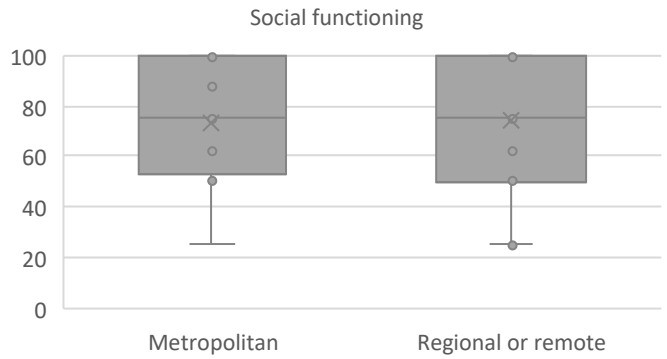

Figure 2.45: Boxplot of SF36 Social functioning by location

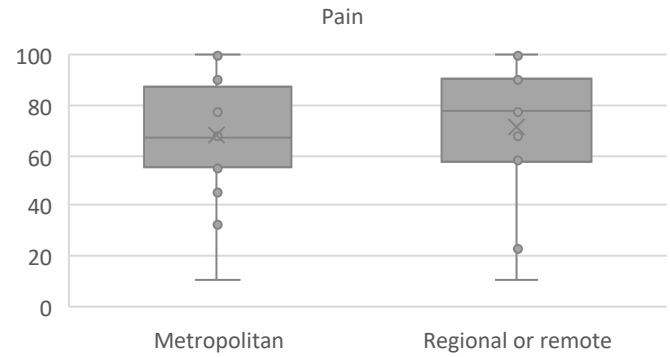

Figure 2.46: Boxplot of SF36 Pain by a location

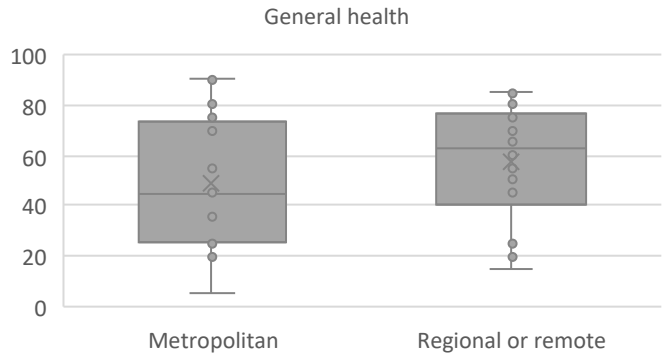

Figure 2.47: Boxplot of SF36 General health by location

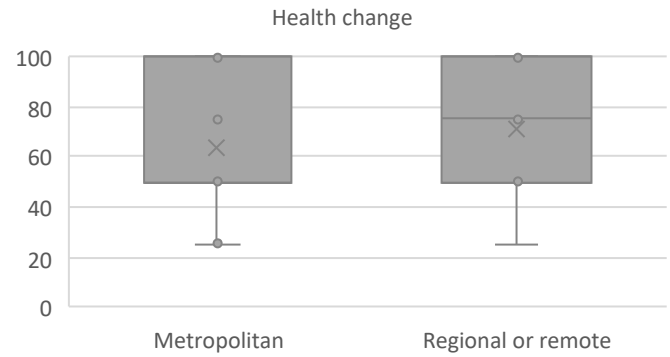

Figure 2.48: Boxplot of SF36 Health change by location

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 (n=17, 50.00%) compared to those with a higher SEIFA score of 7-10 (n=17, 50.00%).

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

A two sample t-test indicated that the mean score for the SF36 Emotional well-being scale [t(32) = -2.18 , p = 0.0366] was significantly lower for participants in the Higher advantage subgroup (Mean = 71.76, SD = 12.20) compared to participants in the Mid to low advantage subgroup (Mean = 80.71, SD = 11.68.)

SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious**.** On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that participants in the Mid to low advantage subgroup had very good emotional well-being, and participants in the Higher advantage subgroup had good emotional well-being.

Table 2.17: SF36 by socioeconomic status summary statistics and T-test

SF36 scale	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Emotional well-being	Higher advantage	17	50.00	71.76	12.20	-2.18	32.00	0.0366*
	Mid to low advantage	17	50.00	80.71	11.68			
Pain	Higher advantage	17	50.00	64.85	27.39	-1.13	32.00	0.2679
	Mid to low advantage	17	50.00	74.26	20.84			

Table 2.18: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Physical functioning	Higher advantage	17	50.00	70.00	50.00	128.50	0.5916
	Mid to low advantage	17	50.00	80.00	30.00		
Role functioning/physical	Higher advantage	17	50.00	25.00	100.00	128.50	0.5790
	Mid to low advantage	17	50.00	50.00	75.00		
Role functioning/emotional	Higher advantage	17	50.00	66.67	66.67	119.00	0.3407
	Mid to low advantage	17	50.00	100.00	66.67		
Energy/Fatigue	Higher advantage	17	50.00	50.00	15.00	128.50	0.5919
	Mid to low advantage	17	50.00	50.00	35.00		
Social functioning	Higher advantage	17	50.00	62.50	50.00	117.50	0.3454
	Mid to low advantage	17	50.00	75.00	25.00		
General health	Higher advantage	17	50.00	50.00	35.00	121.50	0.4367
	Mid to low advantage	17	50.00	65.00	50.00		
Health change	Higher advantage	17	50.00	50.00	25.00	91.00	0.0549
	Mid to low advantage	17	50.00	75.00	50.00		

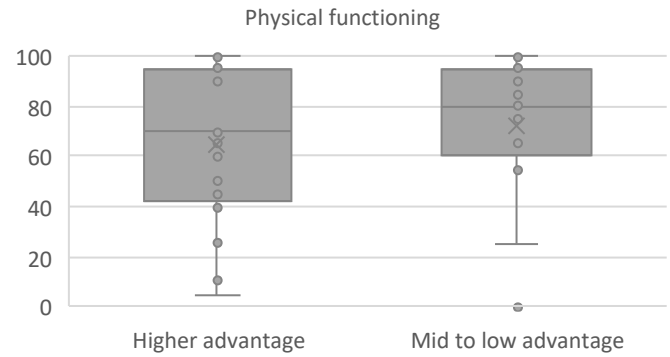

Figure 2.49: Boxplot of SF36 Physical functioning by socioeconomic status

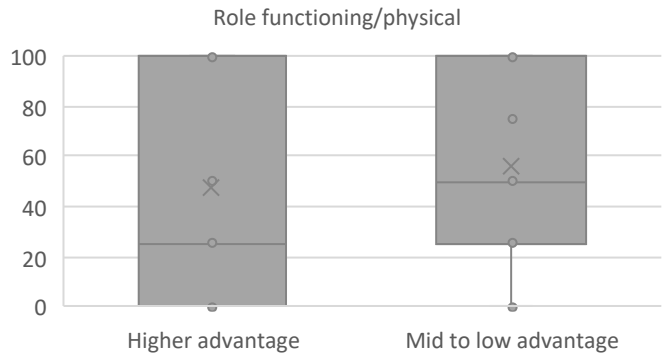

Figure 2.50: Boxplot of SF36 Role functioning/physical by socioeconomic status

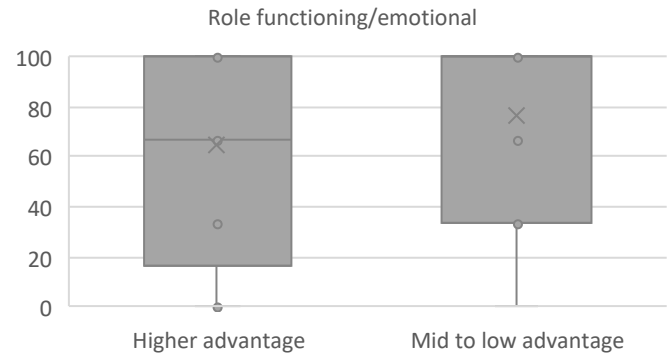

Figure 2.51: Boxplot of SF36 Role functioning/emotional by socioeconomic status

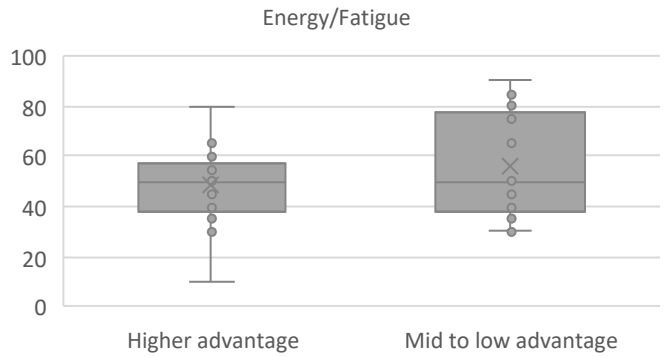

Figure 2.52: Boxplot of SF36 Energy/fatigue by socioeconomic status

Figure 2.53: Boxplot of SF36 Emotional well-being by socioeconomic status

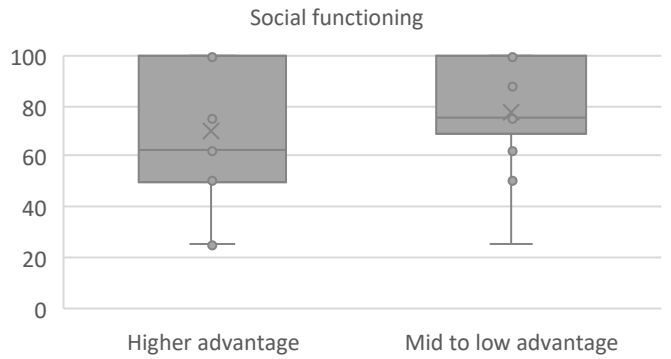

Figure 2.54: Boxplot of SF36 Social functioning by socioeconomic status

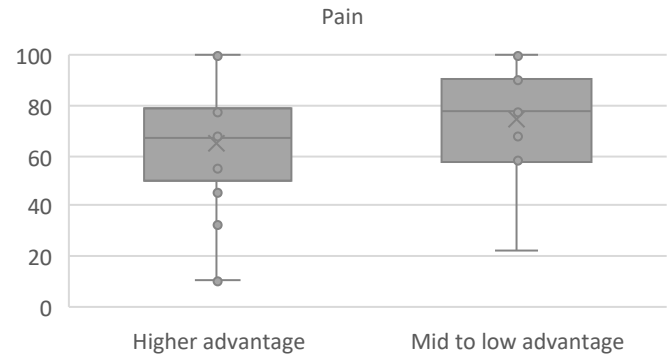

Figure 2.55: Boxplot of SF36 Pain by a socioeconomic status

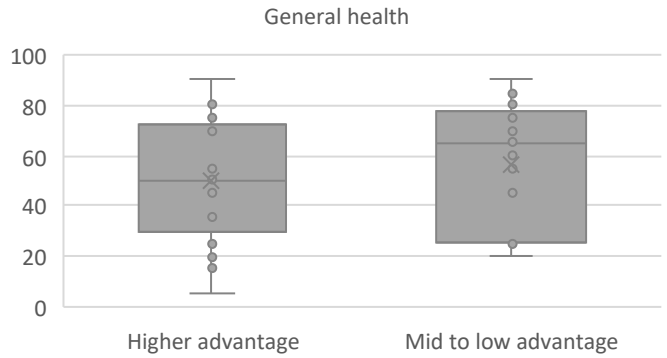

Figure 2.56: Boxplot of SF36 General health by socioeconomic status

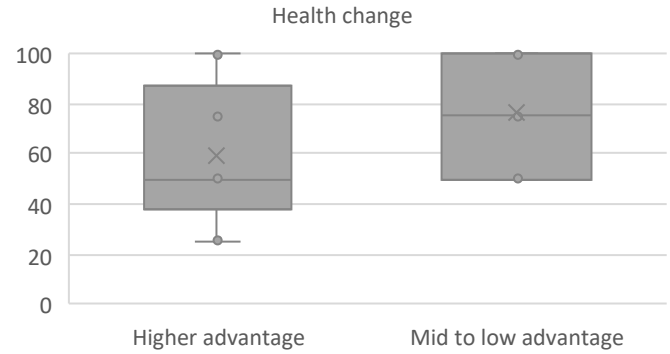

Figure 2.57: Boxplot of SF36 Health change by socioeconomic status

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed. There were 7 participants (24.14%) that had no symptoms before diagnosis. Participants had a maximum of 15 symptoms, and a median of 4.00 (IQR=7.00).

Symptoms before diagnosis

The most common symptoms before diagnosis were pain or weakness in muscles, bones and joints (n=20, 68.97%), tired (n=20, 68.97%), cough or breathlessness (n=14, 48.28%) and night sweats (n=14, 48.28%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Median quality of life is presented where five or more participants reported the symptom. The median quality of life was between 3.00 and 6.00, for all of the symptoms listed in the questionnaire, this is in the "Life was a little distressing" to "Life was very good" range. The symptoms with the worst quality of life were pain or weakness in muscles, bones and joints, feeling unusually tired or weak and, weight loss without trying.

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 strongly recalled their symptoms or how they came to be diagnosed (87.88%). Others had an unclear recollection of their symptoms or how they came to be diagnosed (9.09%), or had no symptoms (3.03%).

The most common symptoms leading to diagnosis were having fatigue (36.36%), back pain (24.24%), and bone pain (18.18 %). Other themes included unusual bleeding or bruising (15.15%), infections (15.15%), pain in general (12.12%), a loss of appetite (9.09%), lumps (9.09%), and night sweats or hot flushes (9.09%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (57.58%) and having symptoms and not seeking medical attention initially (33.33%), one participant described having no symptom (3.03%).

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 a linear diagnosis after being referred to a specialist from their general practitioner (42.42%) and being diagnosed after a referral to the emergency department from their general practitioner (21.21%). Other themes included being diagnosed in an emergency department (12.12%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (9.09%), being diagnosed by their general practitioner during a check-up related to symptoms (9.09%), and a linear diagnosis after being referred to a specialist from their optometrist (3.03%).

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 26 participants (participants had no symptoms before diagnosis), there were 2 participants (7.69%) that were diagnosed 1 to 3 months of noticing symptoms, 6 participants (23.08%) diagnosed 3 to 6 months from noticing symptoms, 3 participants (11.54%) that were diagnosed 6 to 12 months of noticing symptoms, and 5 participants (19.23%) that were diagnosed less than a month of 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 = 7, 18.92%). There were 14 participants (37.84%) that were diagnosed less than one week after diagnostic tests, 8 participants (21.62%) diagnosed between 1 and 2 weeks, 3 participants (8.11%) diagnosed between 2 and 3 weeks, 2 participants (5.41%) diagnosed between 3 and 4 weeks, and 3 participants (8.11%) 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 blood cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 8 diagnostic tests (median=4.00, IQR=3.00). The most common tests were blood tests (n=35, 94.59%), bone Marrow Biopsy (n=32, 86.49%), Computed Tomography (CT) scan (n=16, 43.24%), and urine tests (n=16, 43.24%).

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 haematologist (n=16, 43.24%), and there were 11 participants (29.73%) given the diagnosis by a general practitioner (GP), and 6 participants (16.22%) diagnosed by an oncologist. Participants were most commonly given their diagnosis in the general practice (n=20, 40.00%), this was followed by the specialist clinic (n=10, 20.00%).

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in the table below. Participants were diagnosed between 2000 and 2023. There were 21 participants (56.76%) that were diagnosed in the last five years.

Blood cancer diagnosis

There were 37 people with blood cancer who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), and 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma.

Blood cancer stage

Participants described the stage of their blood cancer as in remission (n=11, 39.29%), Stage 1 (n=1, 3.57%), Stage 2 (n=2, 7.14%), Stage 3 (n=4, 14.29%), and Stage 4 (n=5, 17.86%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (51.52%), and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (21.21%). Other themes included knowing a good amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (9.09%), and knowing about the condition due to public awareness (9.09%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 19 participants (51.35%) who had enough support, 5 participants (13.51%) that had some support, but it wasn't enough, and 13 participants (35.14%) 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 25 participants (67.57%) who had enough information, 7 participants (18.92%) that had some information, but it wasn't enough, and 5 participants (13.51%) 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 24 participants (64.86%) who had no out of pocket expenses, and participants (0.00%) who did not know or could not recall. There were 2 participants (5.41%) that spent $100 to 500, 3 participants (8.11%) that spent between $501 to 1000, and 8 participants (21.62%) that were not sure.

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 6 participants (16.22%) the cost was slightly or not at all significant. For 2 participants (5.41%) the out-of-pocket expenses were somewhat significant, and for 2 participants (5.41%), 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=27, 72.97%). There was one participant (2.70%) who brought up the topic with their doctor, and 9 participants (24.32%) 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.

Almost half of the participants did not have any genetic or biomarker tests but would like to (n=18, 48.65%). There were 11 participants (29.73%) who did not have these tests and were not interested in them, and a total of 8 participants (21.62%) that had biomarker tests.

Biomarker status

Participants were asked in the online questionnaire if they knew their status for named biomarkers. Very few participants knew the status for at least one biomarker (n=5, 14.29%).

Current symptoms

Number of current symptoms

Participants were asked in the questionnaire what symptoms they are currently dealing with, they could choose from a set lit of symptoms and could then specify other symptoms not listed. More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n=19, 65.52%). Participants had between 3 to 11 symptoms (median=5.00, IQR=8.00).

Type of current symptoms

The most common current symptoms, participants experienced were fatigue (n=19, 65.52%), weak or damaged bones (n=18, 62.07%), depression and anxiety (n=16, 55.17%), low resistance to infections (n=16, 55.17%), damage to organs (n=13, 44.83%), and hearing loss (n=10, 34.48%).

Quality of life from current symptoms

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”. The median quality of life was between 2.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing” to “Life was a average” range.

The median quality of life was between 4 and 2.5 for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average” range. The symptoms with the lowest quality of life were low resistance to infections, and hearing loss.

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 there was no evidence of disease or that they are in remission (51.52%), and that they had specific medical interventions they need to manage their condition (30.30%). Other themes included that they were monitoring their condition until there is an exacerbation or progression (18.18%), that they would likely have a recurrence, or were in a cycle of recurrence (18.18%), that they are in recovery from treatments and managing side effects of treatment (15.15%), their prognosis in terms of a specific timeframe that they are expected to live (12.12%), that their prognosis was positive, that their condition is manageable (12.12%), and that there was uncertainty around their prognosis (12.12%).

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 7 participants (24.14%) that had no symptoms before diagnosis. Participants had a maximum of 15 symptoms, and a median of 4.00 (IQR=7.00).

Table 3.1: Number of symptoms per participant

Number of symptoms before diagnosis	n=29	%
0	7	24.14
1 to 2	2	6.90
3 to 4	6	20.69
5 to 6	3	10.34
7 to 8	3	10.34
9 to 10	1	3.45
11 or more	7	24.14

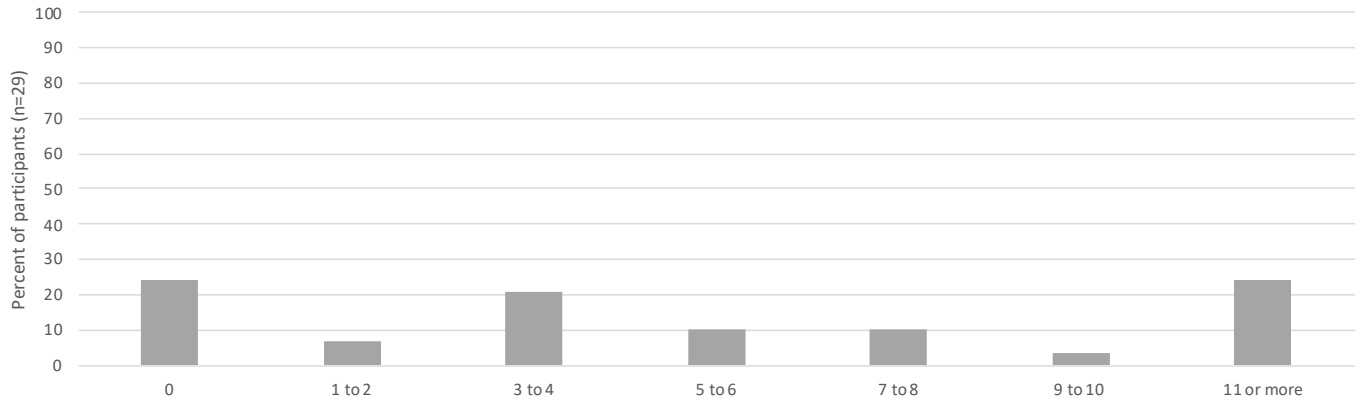

Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were pain or weakness in muscles, bones and joints (n=20, 68.97%), tired (n=20, 68.97%), cough or breathlessness (n=14, 48.28%) and night sweats (n=14, 48.28%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 3.00 and 6.00, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was very good” range. The symptoms with the worst quality of life were pain or weakness in muscles, bones and joints, feeling unusually tired or weak and, weight loss without trying.

Table 3.2: Symptoms before diagnosis

Symptoms before diagnosis	Number (n=29)	Percent	Quality of life	
			Mean	SD
No symptoms	5	17.24	NA	NA
Pain or weakness in muscles, bones and joints	20	68.97	3.00	2.50
Feel unusually tired or weak	20	68.97	3.00	1.25
Cough or breathlessness	14	48.28	3.50	1.75
Night sweats	14	48.28	4.00	3.00
Cognitive problems such as feeling confused	13	44.83	4.00	2.00
Pain in chest or abdomen	13	44.83	5.00	4.00
Lose weight without trying	11	37.93	3.00	3.50
Nausea	9	31.03	5.00	4.00
Often have fevers	9	31.03	5.00	3.00
Bleed or bruise more easily than usual	9	31.03	4.00	1.00
Had lots of infections or infections that didn't go away	8	27.59	4.50	2.75
Swollen lymph nodes or glands	8	27.59	4.50	1.25
Need to pass urine often	7	24.14	6.00	3.50
Feel more thirsty than usual	7	24.14	5.00	3.00

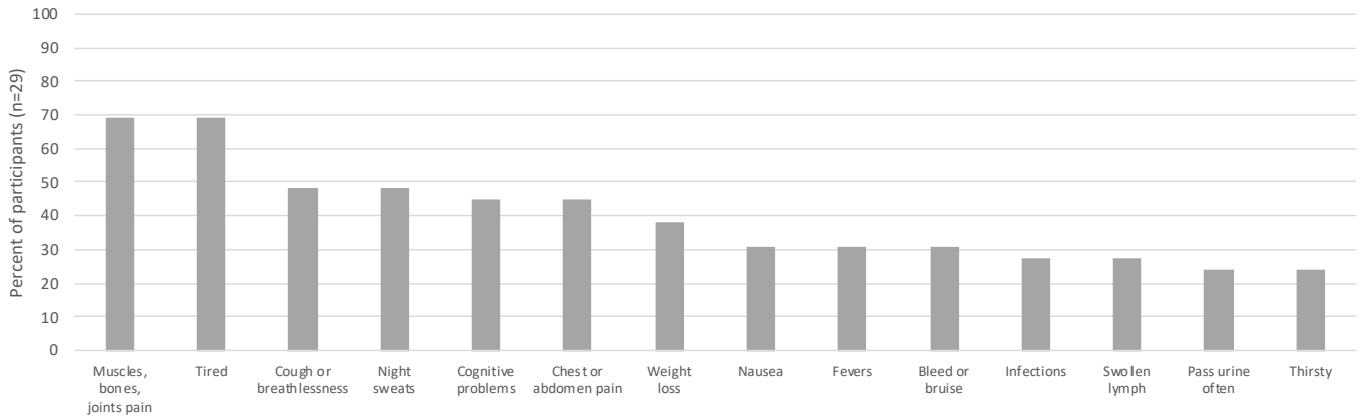

Figure 3.2: Symptoms before diagnosis

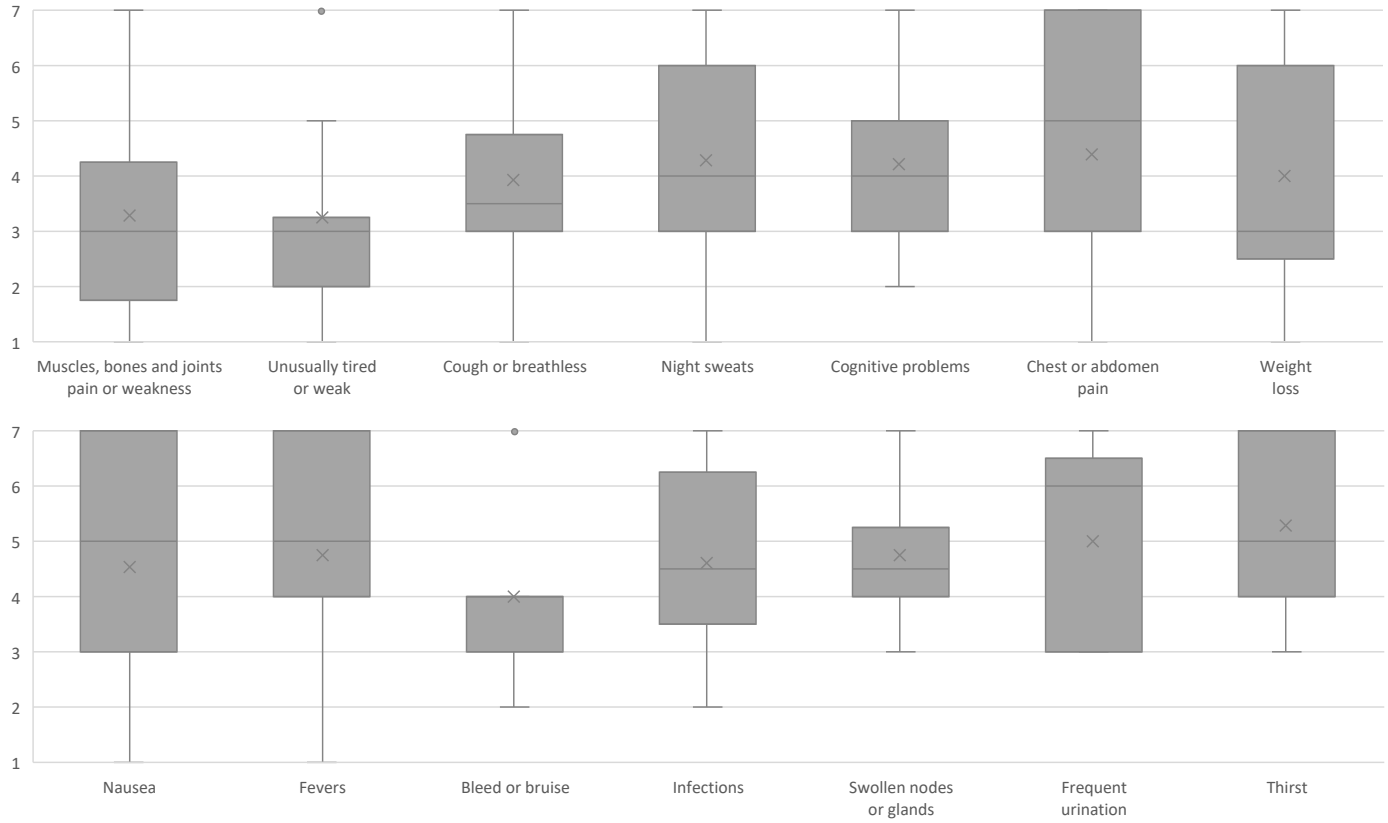

Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select 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 strongly recalled their symptoms or how they came to be diagnosed (87.88%). Others had an unclear recollection of their symptoms or how they came to be diagnosed (9.09%), or had no symptoms (3.03%).

The most common symptoms leading to diagnosis were having fatigue (36.36%), back pain (24.24%), and bone pain (18.18 %). Other themes included unusual bleeding or bruising (15.15%), infections (15.15%), pain in general (12.12%), a loss of appetite (9.09%), lumps (9.09%), and night sweats or hot flushes (9.09%).

Participant describes having fatigue which led to their diagnosis

Yep, tiredness and my strength. I've always been a fairly strong physical person and played a lot of sport, but I did find I got very tired. But at the time I just said I was tired because I was working a lot. I was working long hours, seven days a week, and I put it down to that.

Participant 025_2023AUCRT

Participant describes having back pain which led to their diagnosis

I had lower back pain for a long time. I was living on Nurofen. I went and saw a bone therapist and she said to me, if that's not better in three days, go and see your GP because that's where your kidneys are and you might have a kidney issue here. And four days later I went and saw the GP and I'd already had an MRI I think and said I need a CT scan. So she sent me for a CT scan and the CT scan come up showing that there was a tumor growing on my spine and it was deforming my spinal cord.
Participant 008_2023AUCRT

Participant describes having bone pain which led to their diagnosis

I was feeling like I hadn't been feeling right. I was very tired. No, hang on, let me think this through. I had been talking to my doctor, my GP, about menopause symptoms because I hadn't been feeling well. I had been getting hot flushes and not sleeping through the night, so just menopause stuff. And she ran some blood tests and said to me, gosh, have you had an infection? It looks like you're recovering from a really acute infection. And I said no. And she said to me, okay, let's wait two weeks, we'll we'll rerun those blood tests and then we'll talk again. So that was, what, two weeks before my diagnosis and then on Friday, so 10 days later, that was the Friday. My partner, thought that I had a blood clot because I'd spent the week that from the Monday to the Friday, I was very breathless. I had rib pain and yeah, breathless on very little exertion, rib pain and tiredness. And that had gone on from the Monday to that Friday and she made me go to the hospital. And I have to say, I'm so grateful to her because I would have just, I would…I just thought I was, you know, I was working 60 hour weeks in a very emotionally difficult circumstances and I thought that I was just tired, you know. So she made me go to the hospital and I thought she was crazy, but she's very gentle, but got very pushy with me. I was like, oh, okay, better do this. And so that was the Friday. They gave me a rough diagnosis. They thought initially that it was lymphoma on the Saturday. On the Sunday they diagnosed and I started chemo on a Monday.
Participant 016_2023AUCRT

Participant describes having unusual bleeding or bruising which led to their diagnosis

For me, being honest, the only visible signs for me were abnormal bruising.
Participant 001_2023AUCRT

Participant describes having infections which led to their diagnosis

Yeah, so it was probably about two weeks before the diagnosis. I noticed no big things, but I was very tired, like more tired. I've got a well when my job was quite full on and stressful. So it was always tiring, but I just felt way more tired than than usual. And I had a bit of a sore throat but that was really probably only in the last week. And then I got, my throat got with the point where it hurt to eat food in the last couple of days and then and also had a swollen gland under my neck which ended up getting really puffed up. But it it probably really didn't get too puffed up until basically until I went into hospital.
Participant 006_2023AUCRT

Participant describes having pain in general which led to their diagnosis

Okay. The first thing was the tiredness and also like a mental fogginess, where I didn't really want to do anything. Normally, I'm quite engaged with my friends and my family, but yet I just couldn't be bothered. I was making mistakes at work, which were not like me. It wasn't like me, but I didn't know why. I put it down to just general tiredness. I was having a lot of pain in the legs and the feet, but I put that down to plantar fasciitis because that's what I had or I thought I had.
Participant 002_2023AUCRT

Just out of nowhere really. I'd had diarrhea the week before, a tummy bug, but just it was really weird, just if that makes sense. And that was during October and I couldn't sleep because the pain was pretty strong. But so I just got up, went for a long walk hoping that that would fix it, and after a couple of days of this, it wasn't great. Went to a GP who just sort of said take painkillers. Then went to another GP in the city who thought something was going on. So referred me to a neuro person thinking I had a a crushed nerve in my back or my hip. So $400.00 later seeing a Neurosurgeon said no, that's not the case. Don't need to see me. So OK and then through November I just didn't feel like eating. I couldn't eat get like lunch. I was just sort of half eating it and I was just exhausted.

And three different times I got home from work and just collapsed on the bed and I was just a mess. So three times my wife took me to hospital and they just gave me some painkillers and sent me home. But there was something wrong with me. I knew there was and then the fourth time I was really quite ill. I just was like nothing would work properly. So she took me out to hospital and they just sort of had me in emergency all night and I thought they were going to give me a tablet and send me home.
Participant 022_2023AUCRT

Participant describes having a loss of appetite which led to their diagnosis

Yeah, some of the first signs were night sweats, probably three or four months before I realized what was going on and then lost my appetite. I was at work and I cut my little finger on a piece of wire and it wouldn't stop bleeding. And I just couldn't understand why it wouldn't stop bleeding. I also got headaches as well, so I was feeling flat and tired as well. So I went and saw my local GP at the time and he suggested a course of Prednisolone for the for the bleeding who thought it might have been thrown by the cytopenia. And then I went back probably a week later, feeling worse than ever, and he suggested a trip up to LOCATION for some tests up there. So I flew up straight away the next day.
Participant 024_2023AUCRT

Participant describes having lumps which led to their diagnosis

My son had issues with his ears with a bit of wax build up and had some infections and things like that. So I noticed a small lump on the side of my, I think it was my left side of my neck. And I said to my wife, well, look, I'll take the opportunity probably book a double appointment and just see what see what that is. And probably typical male probably hadn't been to the doctor in about 10 or 12 years and because I was a good health, so literally I had no side effects or effects at all. So and the doctor, you know, to her credit said 'Let's just take some blood'.
Participant 026_2023AUCRT

I noticed that when I sometimes when I was lifting heavy things, I had a pain across my the top of my chest and that was probably about maybe up to six months before I was diagnosed. Then I noticed a lump at the top of my sternum, a swelling in the bone, and I wondered about whether it had always been there or not. And I I asked my wife to look at it and see whether she thought it had always been there and she didn't know. And eventually I went to see my GP about it and he sent me for scans that day and it turned out that it, it was, it was myeloma, that the bone had been hollowed out by the activity of the disease. And so I started on treatment then.
Participant 014_2023AUCRT

Participant describes having night sweats or hot flushes which led to their diagnosis

I was getting, not all the time, but sometimes at night, I'd have a little bit of a night sweat around the chest area, which I thought was menopause, but turns out it wasn't. That's about it, really. The only reason I found it was because I go for a blood test every year, and this year, for some reason, I didn't go to my normal GP, and I thought, "I'll just go somewhere else that's closer to work," and a little bit earlier than I normally would have gone. That's how it was picked up. I had no bruising or anything like that.
Participant 002_2023AUCRT

Table 3.3: Symptom recall

Symptom recall	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Symptom recall strong	29	87.88	7	100.00	10	100.00	12	75.00	22	84.62	7	100.00	13	86.67	16	88.89
Symptom recall unclear	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	2	13.33	1	5.56
No Symptoms	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	0	0.00	1	5.56

Symptom recall	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Symptom recall strong	29	87.88	19	100.00	10	71.43	13	92.86	16	84.21	12	85.71	17	89.47
Symptom recall unclear	3	9.09	0	0.00	3	21.43	1	7.14	2	10.53	2	14.29	1	5.26
No Symptoms	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26

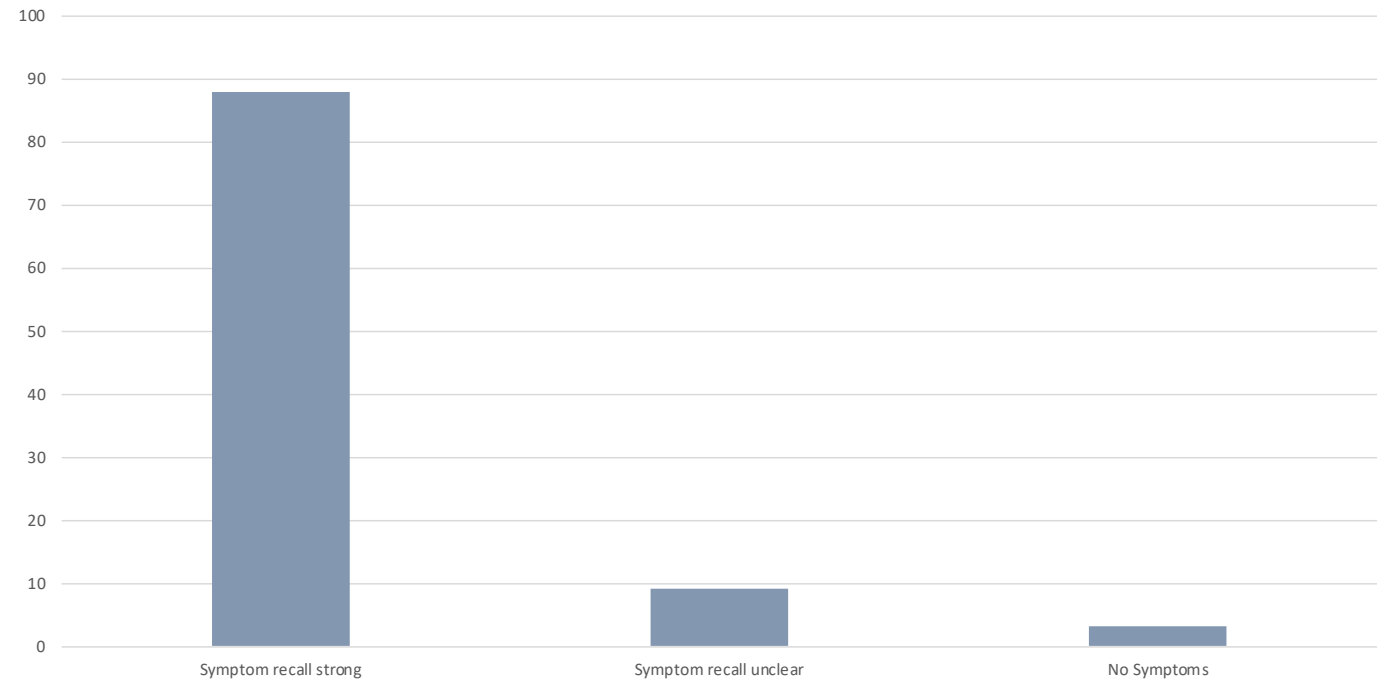

Figure 3.4: Symptom recall

Table 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes having fatigue which led to their diagnosis	12	36.36	5	71.43	2	20.00	5	31.25	12	46.15	0	0.00	5	33.33	7	38.89
Participant describes having back pain which led to their diagnosis	8	24.24	0	0.00	3	30.00	5	31.25	4	15.38	4	57.14	3	20.00	5	27.78
Participant describes having bone pain which led to their diagnosis	6	18.18	1	14.29	1	10.00	4	25.00	6	23.08	0	0.00	2	13.33	4	22.22
Participant describes having unusual bleeding or bruising which led to their diagnosis	5	15.15	3	42.86	2	20.00	0	0.00	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes having infections which led to their diagnosis	5	15.15	1	14.29	3	30.00	1	6.25	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes having pain in general which led to their diagnosis	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes having a loss of appetite which led to their diagnosis	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	0	0.00	3	16.67
Participant describes having lumps which led to their diagnosis	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11
Participant describes having night sweats or hot flushes which led to their diagnosis	3	9.09	3	42.86	0	0.00	0	0.00	3	11.54	0	0.00	2	13.33	1	5.56

Symptoms leading to diagnosis	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes having fatigue which led to their diagnosis	12	36.36	8	42.11	4	28.57	4	28.57	8	42.11	3	21.43	9	47.37
Participant describes having back pain which led to their diagnosis	8	24.24	4	21.05	4	28.57	6	42.86	2	10.53	4	28.57	4	21.05
Participant describes having bone pain which led to their diagnosis	6	18.18	5	26.32	1	7.14	3	21.43	3	15.79	3	21.43	3	15.79
Participant describes having unusual bleeding or bruising which led to their diagnosis	5	15.15	5	26.32	0	0.00	2	14.29	3	15.79	3	21.43	2	10.53
Participant describes having infections which led to their diagnosis	5	15.15	4	21.05	1	7.14	3	21.43	2	10.53	2	14.29	3	15.79
Participant describes having pain in general which led to their diagnosis	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes having a loss of appetite which led to their diagnosis	3	9.09	3	15.79	0	0.00	3	21.43	0	0.00	2	14.29	1	5.26
Participant describes having lumps which led to their diagnosis	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant describes having night sweats or hot flushes which led to their diagnosis	3	9.09	3	15.79	0	0.00	1	7.14	2	10.53	1	7.14	2	10.53

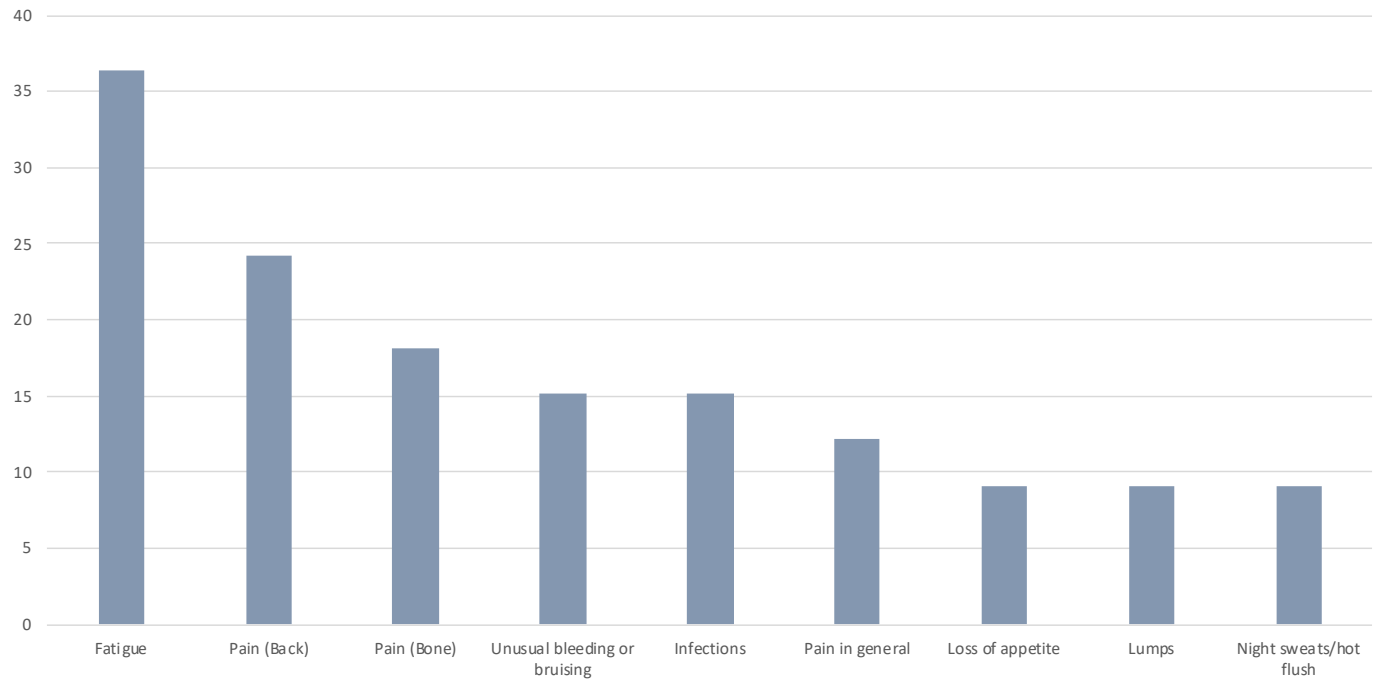

Figure 3.5: Symptoms leading to diagnosis

Table 3.5: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having fatigue which led to their diagnosis	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Higher status
Participant describes having back pain which led to their diagnosis	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan	CAR T-Cell therapy Regional or remote
Participant describes having bone pain which led to their diagnosis	CAR T-Cell therapy Aged 65 or older	-
Participant describes having unusual bleeding or bruising which led to their diagnosis	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64
Participant describes having infections which led to their diagnosis	CAR T-Cell therapy	Diffuse Large B-Cell Lymphoma Female
Participant describes having pain in general which led to their diagnosis	Aged 65 or older	-
Participant describes having a loss of appetite which led to their diagnosis	-	Regional or remote
Participant describes having lumps which led to their diagnosis	-	-
Participant describes having night sweats or hot flushes which led to their diagnosis	-	B-cell acute lymphoblastic leukaemia (ALL)

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (57.58%) and having symptoms and not seeking medical attention initially (33.33%), one participant described having no symptom (3.03%).

Participant describes having symptoms and seeking medical attention relatively soon

Well then it's sort of I sold my business and that was two years ago actually and then I thought, this is great, I'll play more golf, I've got a big Harley, ride my Harley more often and this is great. Life's wonderful. And then I was playing one day and I couldn't finish the game of golf. I just ran out. I had no energy. So I went to the GP and the GP said, oh, there's a little murmur in your heart I'm not happy with. I'm going to send you up to get some tests
Participant 031_2023AUCRT

Participant describes having symptoms and not seeking medical attention initially

Yeah, I'm an avid bushwalker and used to be a strong walker all through 2019 I noticed the effort required to do similar sorts of work walks was increasing and I said to many, many people I have just lost my mojo. And so it wasn't until at the end of 2019 that my diagnosis came about. So that's the sort of symptoms that I noticed.
Participant 013_2023AUCRT

I noticed that when I sometimes when I was lifting heavy things, I had a pain across my the top of my chest and that that was probably about maybe up to six months before I was diagnosed. Then I noticed a a lump at the top of my sternum, a swelling in the bone, and I wondered about whether it was had always been there or not. And I I asked my wife to look at it and see whether she thought it had always been there and she didn't know. And eventually I went to see my GP about it and he sent me for scans that day and it turned out that it, it was, it was myeloma, that the bone had been hollowed out by the activity of the disease. And so I started on treatment then.
Participant 014_2023AUCRT

The first symptom I had was when I was doing a push up and I had a very sharp, severe pain in my sternum and clavicle. And I first of all, I just thought I'd kind of stress the joint, you know, just overdid it. But the pain persisted for probably maybe three months and it didn't change. It just stayed the same and then I had a blood test that you know check up and it was kind of decided that I needed to start treatment.
Participant 015_2023AUCRT

Yeah, some of the first signs were night sweats, probably three or four months before I realized what was going on and then lost an appetite and I was at work and I cut my little finger on a piece of wire and it wouldn't stop bleeding. And I just couldn't understand why it wouldn't stop bleeding.
Participant 024_2023AUCRT

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

My GP questioned why my white cells were low. I didn't have any symptoms as such and I after over a few months the GP did a, you know, like a monthly test and the white cells weren't improving. So he referred me to a hematologist who checked for paraprotein and found that I had myeloma, that I was in the really early stages.
Participant 032_2023AUCRT

Table 3.6: Seeking medical attention

Seeking medical attention	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes having symptoms and seeking medical attention relatively soon	19	57.58	5	71.43	9	90.00	5	31.25	14	53.85	5	71.43	11	73.33	8	44.44
Participant describes having symptoms and not seeking medical attention initially	11	33.33	2	28.57	1	10.00	8	50.00	9	34.62	2	28.57	3	20.00	8	44.44
Participant describes having no symptoms or not noticing any symptoms before diagnosis	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	0	0.00	1	5.56
No particular comment	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	1	6.67	1	5.56

Seeking medical attention	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes having symptoms and seeking medical attention relatively soon	19	57.58	14	73.68	5	35.71	10	71.43	9	47.37	10	71.43	9	47.37
Participant describes having symptoms and not seeking medical attention initially	11	33.33	5	26.32	6	42.86	3	21.43	8	42.11	2	14.29	9	47.37
Participant describes having no symptoms or not noticing any symptoms before diagnosis	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
No particular comment	2	6.06	0	0.00	2	14.29	1	7.14	1	5.26	2	14.29	0	0.00

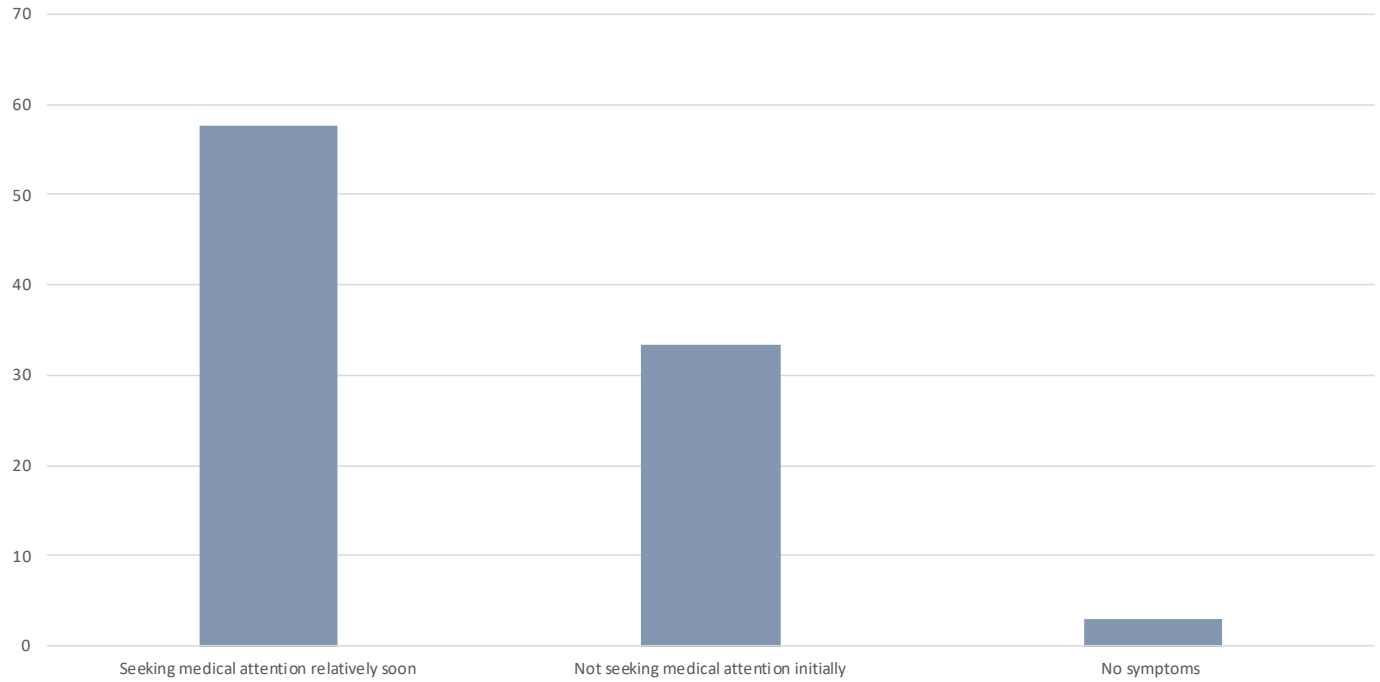

Figure 3.6: Seeking medical attention

Table 3.7: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Multiple Myeloma Male Aged 65 or older Metropolitan Higher status	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female Aged 25 to 64 Regional or remote Mid to low status
Participant describes having symptoms and not seeking medical attention initially	Diffuse Large B-Cell Lymphoma Female Regional or remote Mid to low status	Multiple Myeloma Male Higher status

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 a linear diagnosis after being referred to a specialist from their general practitioner (42.42%), and being diagnosed after a referral to the emergency department from their general practitioner (21.21%). Other themes included being diagnosed in an emergency department (12.12%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (9.09%), being diagnosed by their general practitioner during a check-up related to symptoms (9.09%), and a linear diagnosis after being referred to a specialist from their optometrist (3.03%).

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

And so it's just, yeah, just a blood test and then a biopsy of the the lump that was on the side of the neck and just in between sort of my neck and in between the two shoulder blades I suppose. So that came back, she sent me on to a hematologist where he went through and did, I think, yeah, CT scans, obviously bone marrow biopsy, more blood tests.
Participant 026_2023AUCRT

I had a blood test for something else. And the GP said to me, there's something in your blood that shouldn't be there. I don't want you to be frightened, but you're going to see a hematologist. And so that's when he said that. He explained to me what it was. And he said there's a certain chance that it could turn into multiple myeloma, cancer of the plasma.
Participant 012_2023AUCRT

Participant describes a being diagnosed after a referral to the emergency department from their general practitioner

I'd talked, she'd already gone home that day, but another doctor from the GP medical center and he just said that I needed to go straight to a hospital, it was an emergency. I was really panicking at that stage,

because he kept saying, "I can't tell you strong enough how you need to go to the hospital." I said "I'll just go tomorrow." He goes, "no, you need to go now." He said this is life and death threatening. Participant 001_2023AUCRT

Anyway, I made an appointment to go and see the doctor. This was only off, say, a week, 10 days after we got home. Anyway, I got home from work one night. My husband said, oh Gee, you're early. I said I've got to go to bed. I I feel terrible. Went to bed and the next morning he thought, this is not like me, I'm normally up gone. So he rang my girlfriend and my sister, one of my girlfriends and sister and said, look, will you check on NAME because there's something not right. And it was a Friday afternoon and my girlfriend came out, she couldn't get me out of bed. She actually got me into the shower and her and my sister, she rang the doctors and they said, oh, we haven't got the appointments. So she said I don't care, I'm bringing her in to see the doctor. Yeah, he sent me straight to HOSPITAL.
Participant 025_2023AUCRT

So I had gone to a GP like not my regular one, because I couldn't get in on the weekend because of my sore throat. And they said, oh, look, if it's not gone in a couple of days, take these antibiotics. And then by Monday, I felt really terrible. So I got the prescription, started taking those. I went into work thinking, I'll just go in there, I'll shut my door, I'll finish everything that I need to do because I know that I'm going to be sick. So went home. And then the next day I went to the doctors. Actually, no. There was a day after I think was when I can get in to my regular doctor and she still thought, oh, it's probably some sort of throat type thing but I said get a blood test just to make sure. And then I went to get the blood test ... So then a GP rung that night and said, oh look, we've got your blood test back and we need you to go straight to hospital and go to the HOSPITAL because we've got private insurance as well and I'll go there, go to the emergency department, they'll be expecting you.
Participant 006_2023AUCRT

Participant describes being diagnosed in an emergency department

I was diagnosed because I collapsed at home and I was taken to the hospital by an ambulance. When I got to the hospital, they gave me blood tests, and they diagnosed that it was probably leukaemia.
Participant 003_2023AUCRT

And three different times I got home from work and just collapsed on the bed and I was just a mess. So three times my wife took me to hospital and they just gave me some painkillers and sent me home. But there was something wrong with me. I knew there was. And then the fourth time I was really quite ill. I just was like nothing would work properly. So she took me out to hospital and. And they just sort of had me in emergency all night and I thought they were going to give me a tablet and send me home. But there was a young registrar and a neurologist there who sort of saw me and then took an interest, then saw that I'd been there three times and then saw what I was presenting with and then did a whole range of whole range of tests. And about two weeks later, I was called back to the hospital and they had the test results. And that was when I had the diagnosis of multiple myeloma which they then confirmed with a biopsy on my hip.
Participant 022_2023AUCRT

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

I was getting, not all the time, but sometimes at night, I'd have a little bit of a night sweat around the chest area, which I thought was menopause, but turns out it wasn't. That's about it, really. The only reason I found it was because I go for a blood test every year, and this year, for some reason, I didn't go to my normal GP, and I thought, "I'll just go somewhere else that's closer to work," and a little bit earlier than I normally would have gone. That's how it was picked up. I had no bruising or anything like that.
002_2023AUCRT

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

I woke up one morning it it it was a Saturday morning. I was preparing to go to work and I sneezed very hard and then extraordinary pain in the back, very excruciating pain and I couldn't breathe for a couple of minutes. Even breathing was very painful, so I just put my hand on the dining table and I sat for 5 minutes before I can breathe again. And then I thought to myself, what was that? And then on Monday morning when I went to the to see the GP, he sent me for an X-ray and in a couple of days it was clear that the L3 is broken. That's that was the source for the pain. So that's the basis for diagnosis.
Participant 017_2023AUCRT

So basically that pain that I first experienced in February, it sort of gravitated I suppose for a bit, just go to my lower back. And so I from there went and saw a, you know, variety of different people like, but ended up with a chiropractor. The chiropractor bent, twisted and cracked me left, right and center. In essence with brushing some of my bones, the pain sort of became unbearable. Sort of July, August I suppose. And I can't remember the exact testing that I was got, but I used to get different tests and it was only when I went and saw AGP sort of probably in the September she started to organize things like CAT scans and stuff like that. And the CAT scan was ultimately the thing that showed it up. And I think there was a blood test around at the same time that showed it up.
Participant 019_2023AUCRT

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

I was just about to go on my regular optometrist treatment treatment checkup for my lenses and wearing a glasses and my optometrist was not there that that moment but it was some other optometrist and first time you know I was with her and as she was checking in on my eyes she said that that she has noticed something on my eyelids on both eyes so and she she gave me referral to the eye specialist or eyelid specialist.
Participant 034_2023AUCRT

Table 3.8: Diagnostic pathway

Diagnostic pathway	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	14	42.42	1	14.29	4	40.00	9	56.25	10	38.46	4	57.14	6	40.00	8	44.44
Participant describes a being diagnosed after a referral to the emergency department from their general practitioner	7	21.21	4	57.14	2	20.00	1	6.25	7	26.92	0	0.00	3	20.00	4	22.22
Participant describes being diagnosed in an emergency department	4	12.12	1	14.29	2	20.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	3	9.09	1	14.29	0	0.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11
Participant decribes being diagnosed by their general practitioner during a check-up related to symptoms	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	1	6.67	2	11.11
Participant describes a linear diagnosis after being referred to a specialist from their optometrist	1	3.03	0	0.00	1	10.00	0	0.00	0	0.00	1	14.29	1	6.67	0	0.00
No particular comment	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	1	6.67	0	0.00

Diagnostic pathway	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	14	42.42	6	31.58	8	57.14	6	42.86	8	42.11	6	42.86	8	42.11
Participant describes a being diagnosed after a referral to the emergency department from their general practitioner	7	21.21	6	31.58	1	7.14	3	21.43	4	21.05	4	28.57	3	15.79
Participant describes being diagnosed in an emergency department	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	2	14.29	2	10.53
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant decribes being diagnosed by their general practitioner during a check-up related to symptoms	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant describes a linear diagnosis after being referred to a specialist from their optometrist	1	3.03	1	5.26	0	0.00	0	0.00	1	5.26	0	0.00	1	5.26
No particular comment	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26

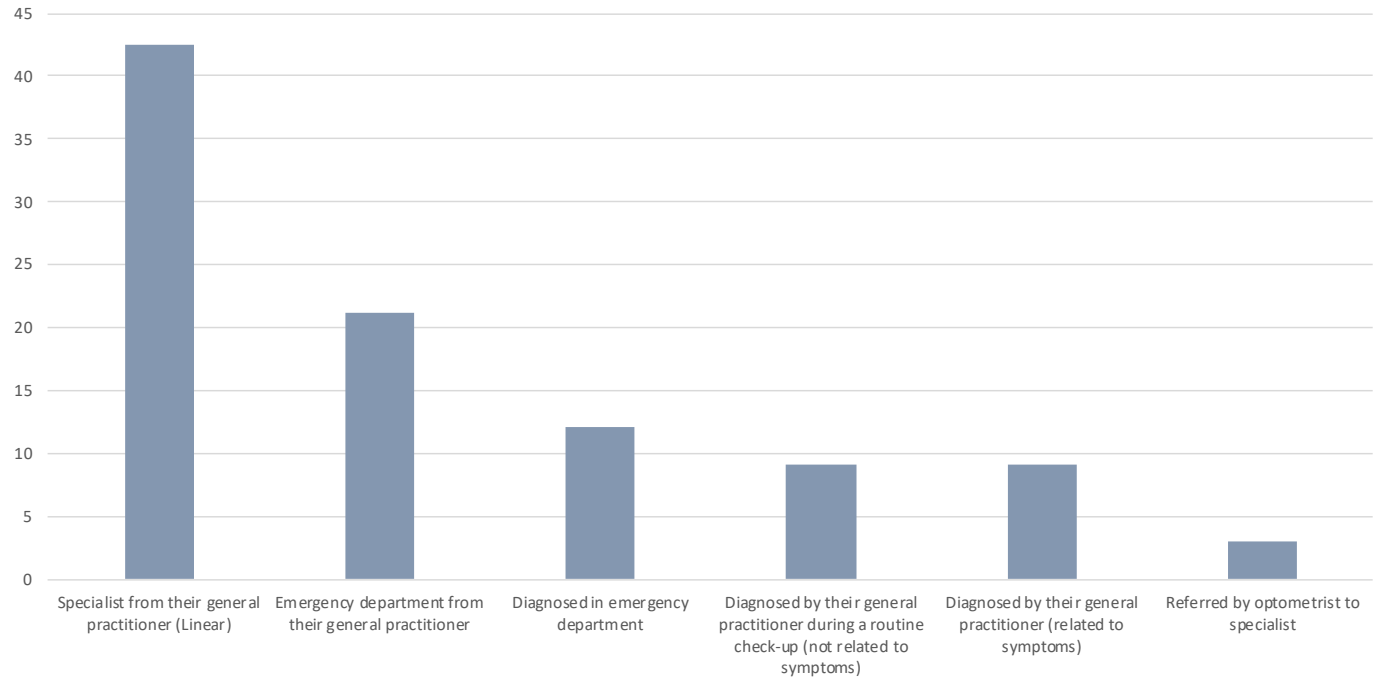

Figure 3.7: Diagnostic pathway

Table 3.9: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64	Multiple Myeloma CAR T-Cell therapy Aged 65 or older
Participant describes a being diagnosed after a referral to the emergency department from their general practitioner	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 26 participants (participants had no symptoms before diagnosis), there were 2 participants (7.69%) that were diagnosed 1 to 3 months of noticing symptoms, 6 participants (23.08%) diagnosed 3 to 6 months from noticing symptoms, 3 participants (11.54%) that were diagnosed 6 to 12 months of noticing symptoms, and 5 participants (19.23%) that were diagnosed less than a month of 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 = 7, 18.92%). There were 14 participants (37.84%) that were diagnosed less than one week after diagnostic tests, 8 participants (21.62%) diagnosed between 1 and 2 weeks, 3 participants (8.11%) diagnosed between 2 and 3 weeks, 2 participants (5.41%) diagnosed between 3 and 4 weeks, and 3 participants (8.11%) diagnosed more than four weeks after diagnostic testing.

Table 3.10: Time from symptoms to diagnosis

Time from symptoms to diagnosis	n=26	Percent
1 to 3 months	2	7.69
3 to 6 months	6	23.08
6 to 12 months	3	11.54
Less than a month	5	19.23
More than a year	10	38.46

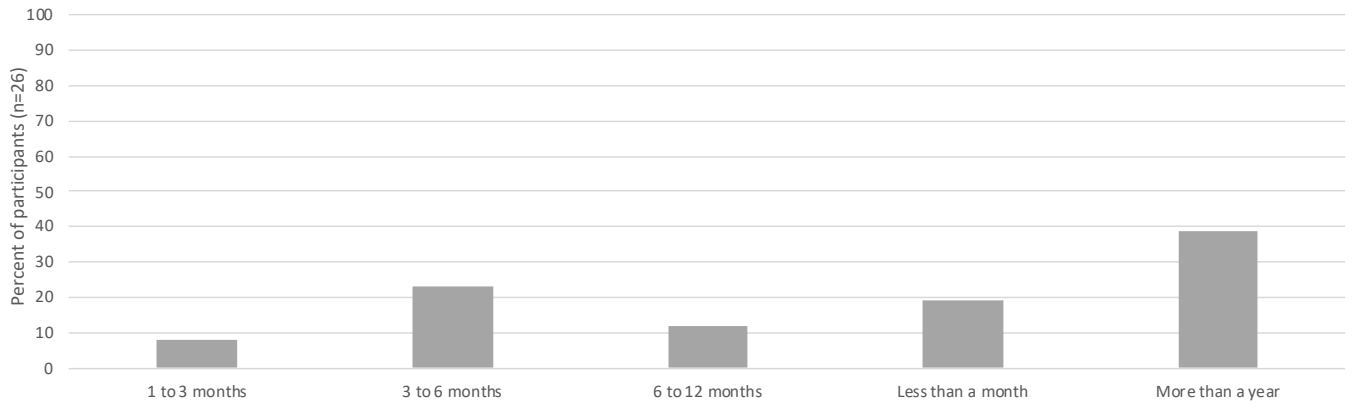

Figure 3.8: Time from symptoms to diagnosis

Table 3.11: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=37)	Percent
Diagnosed immediately at the consultation	7	18.92
Less than 1 week	14	37.84
Between 1 and 2 weeks	8	21.62
Between 2 and 3 weeks	3	8.11
Between 3 and 4 weeks	2	5.41
4 weeks or more	3	8.11

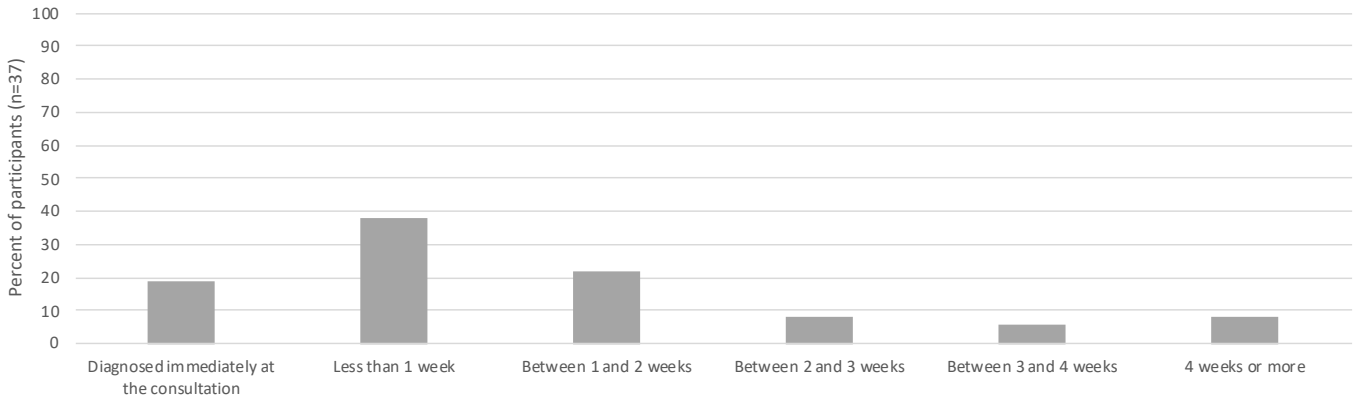

Figure 3.9: Time from diagnostic test to diagnosis

Diagnostic tests

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

Participants reported between 1 to 8 diagnostic tests (median=4.00, IQR=3.00). The most common tests were blood tests (n=35, 94.59%), bone Marrow Biopsy (n=32, 86.49%), Computed Tomography (CT) scan (n=16, 43.24%), and urine tests (n=16, 43.24%).

Table 3.12: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=37)	Percent
1 to 2	10	27.03
3 to 4	13	35.14
5 to 6	11	29.73
7 to 8	3	8.11

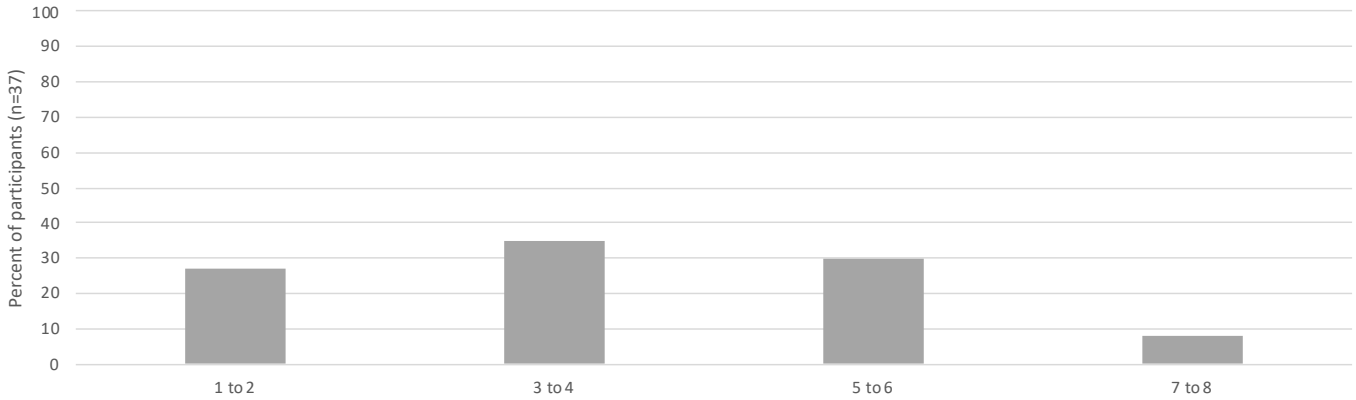

Figure 3.10: Number of diagnostic tests

Table 3.13: Diagnostic tests

Diagnostic tests	Number (n=37)	Percent
Blood tests	35	94.59
Bone Marrow Biopsy	32	86.49
Computed Tomography (CT) scan	16	43.24
Urine tests	16	43.24
X-Rays	12	32.43
Magnetic resonance imaging (MRI)	10	27.03
Positron Emission Tomography (PET) scan	9	24.32
Lumbar Puncture	3	8.11
Lymph Node Biopsy	3	8.11
Other	3	8.11
Biomarkers or genetic testing	1	2.70
Physical examination	1	2.70

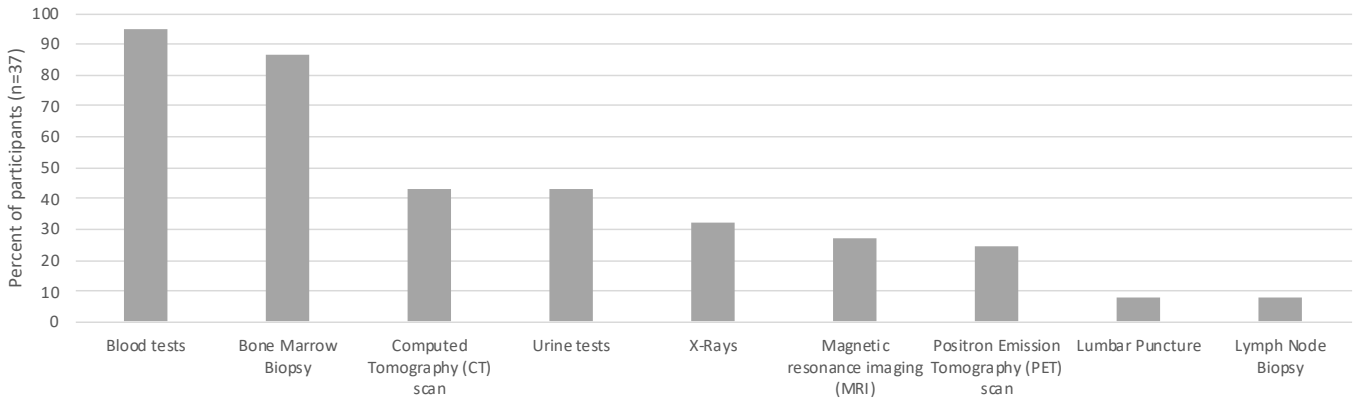

Figure 3.11: Diagnostic tests

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 haematologist (n=16, 43.24%), and there were 11 participants (29.73%) given the diagnosis by a general practitioner (GP), and 6 participants (16.22%) diagnosed by an oncologist.

Participants were most commonly given their diagnosis in the general practice (n=20, 40.00%), this was followed by the specialist clinic (n=10, 20.00%).

Table 3.14: Diagnosis provider

Health professional gave diagnosis	Number (n=37)	Percent
Haematologist	16	43.24
General practitioner (GP)	11	29.73
Oncologist	6	16.22
Other	3	8.11
Emergency doctor	1	2.70

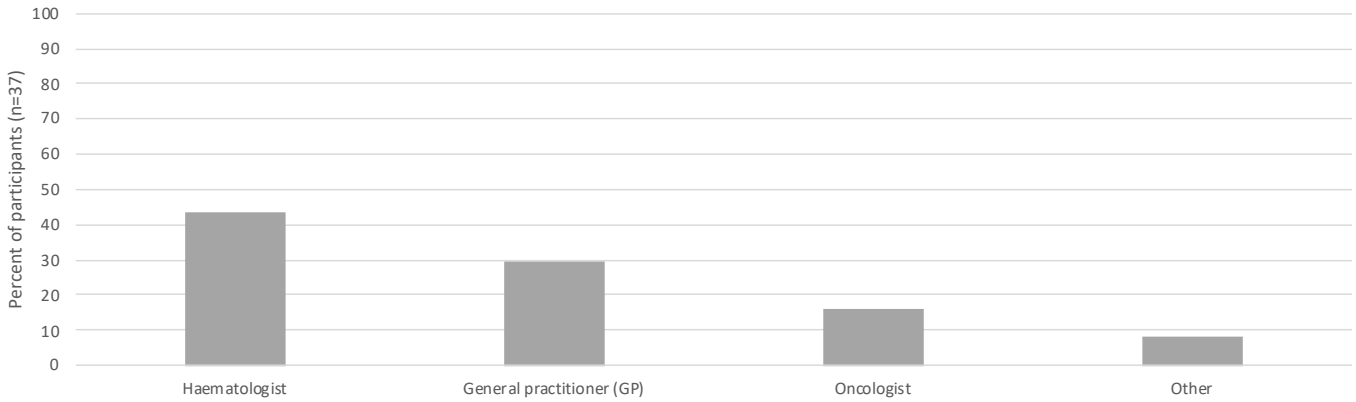

Figure 3.12: Diagnosis provider

Table 3.15: Diagnosis location

Location of diagnosis	Number (n=37)	Percent
Hospital	17	45.95
General practice (GP)	9	24.32
Specialist clinic	9	24.32
Other	2	5.41

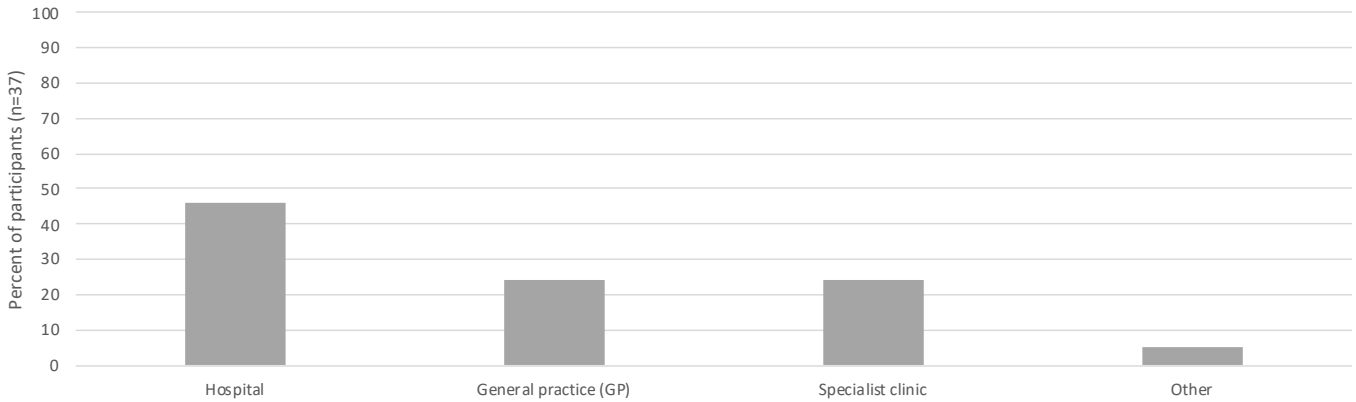

Figure 3.13: Diagnosis location

Year of diagnosis

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

Participants were diagnosed between 2000 and 2023. There were 21 participants (56.76%) that were diagnosed in the last five years.

Table 3.16: Year of diagnosis

Year of diagnosis	Number (n=37)	Percent
2000 to 2009	4	10.81
2010 to 2014	6	16.22
2015 to 2019	14	37.84
2020 to 2023	13	35.14

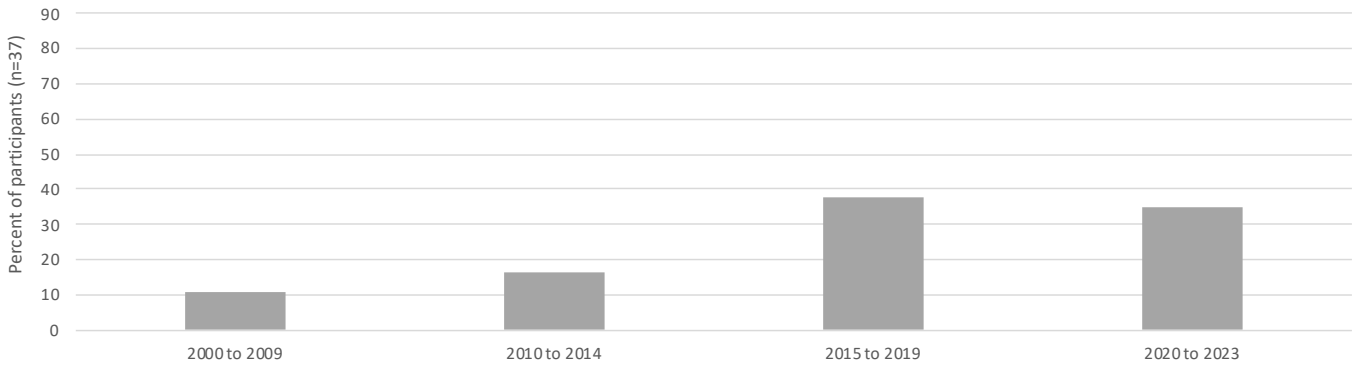

Figure 3.14: Year of diagnosis

Blood cancer diagnosis

Blood cancer diagnosis

There were 37 people with blood cancer who took part in this study. There were 8 participants (21.62%) with B-cell acute lymphoblastic leukemia (ALL), and 11 participants (29.73%) with Diffuse Large B-Cell Lymphoma and 18 (48.65%) with multiple myeloma.

Blood cancer stage

Participants described the stage of their blood cance as in remission (n=11, 39.29%), Stage 1 (n=1, 3.57%), Stage 2 (n=2, 7.14%), Stage 3 (n=4, 14.29%), and Stage 4 (n=5, 17.86%).

Table 3.17: Type of blood cancer

Participants and diagnosis	Number (n=37)	Percent
B-cell acute lymphoblastic leukemia (ALL)	8	21.62
Diffuse Large B-Cell Lymphoma	11	29.73
Multiple Myeloma	18	48.65

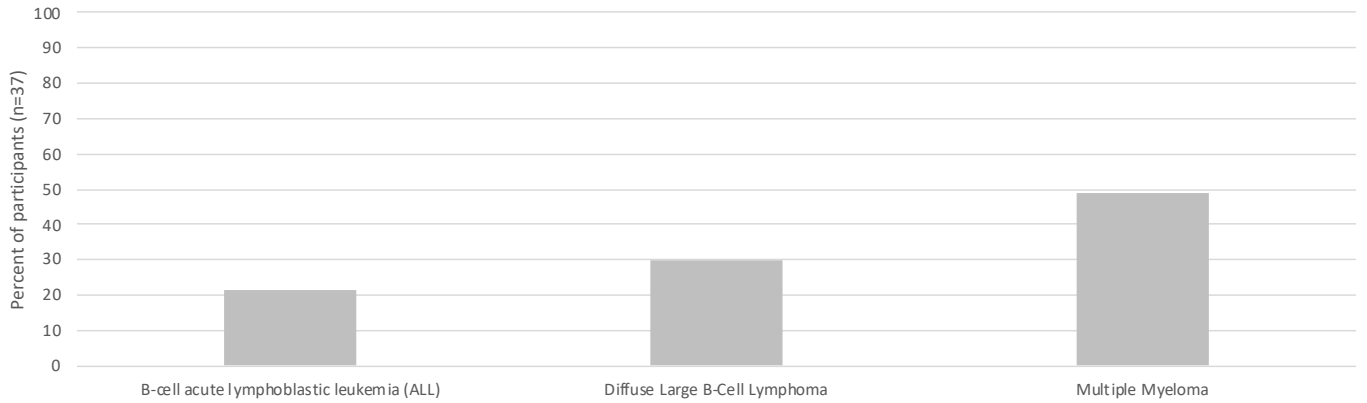

Figure 3.15: Type of blood cancer

Table 3.18: Blood cancer stage

Stage	N=28	%
In remission	11	39.29
Stage 1	1	3.57
Stage 2	2	7.14
Stage 3	4	14.29
Stage 4	5	17.86
Not clear	5	17.86

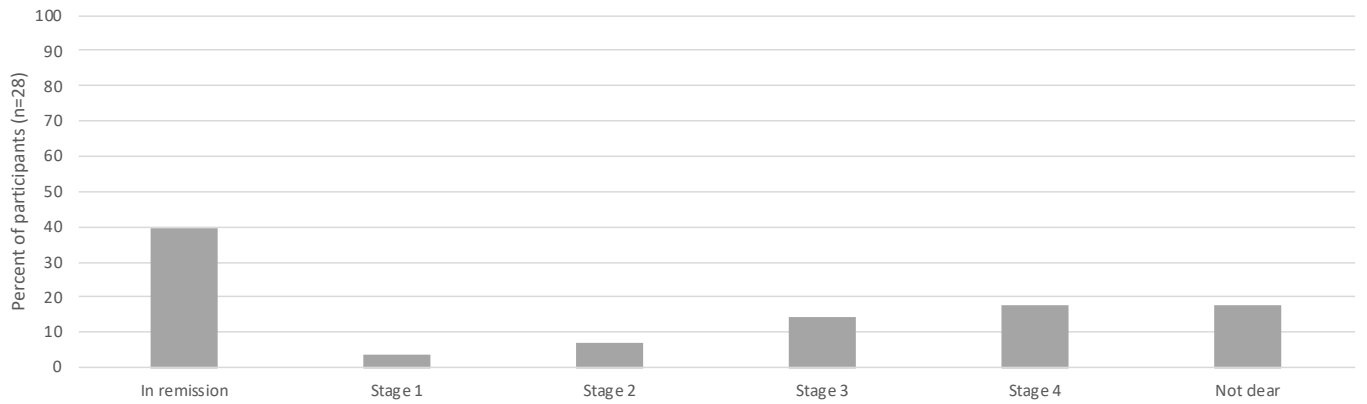

Figure 3.16: Blood cancer stage

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (51.52%), and knowing about the condition at diagnosis because they have a family history of the condition or that they know someone who has the condition (21.21%). Other themes included knowing a good

amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (9.09%), and knowing about the condition due to public awareness (9.09%).

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

Absolutely nothing. I didn't even know that, you know, blood cancer could produce the sort of pain and discomfort. I didn't realize that it was blood cancer. My first thought was it's, you know, sort of a a tumor. Like presentation and so I knew nothing. No, no one in my circle of friends or family have had it so I was newbie.
Participant 009_2023AUCRT

I didn't know anything until the doctor explained to me what it was and how it worked and so on. I mean, I've never read about it or knew anything about it.
Participant 012_2023AUCRT

Nothing. Never even heard of it.
Participant 022_2023AUCRT

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

I didn't really know anything, except that that it had had a pretty bad effect on my aunt's wife. I'd forgotten what her disease was called. I didn't connect hers with mine immediately. It was only after talking to other relatives that I was reminded that she'd had myeloma. But her skeletal system more or less collapsed. Before she went into palliative care, she was sitting up in a chair that you know, that was had been constructed to support her.
Participant 014_2023AUCRT

Very little. My brother-in-law had had a Hodgkins when he was 20 and this was some 40 years later, so it was something we'd talked about in the family, but there was no family familiar connection. I still don't know if anyone else in the family who's had anything like this. We had had a family live with us for nine months from the country whose son ultimately died of leukemia and so that you become an expert in ML as well at the time but that was that's 25 years ago now too. So that was a good 10 or 15 years before that. So not really anything.
Participant 036_2023AUCRT

Nothing really. My son had leukemia and so I'd learnt a lot about and he had bone marrow transplant and recovered fully and all the rest of it. So I I knew a lot about blood disease and and cancer and that's from what he went through of course. And so I started when I did my little bit of research on multiple myeloma, it was a little bit similar in terms of the treatment path of transplant. But prior to that I really had no real understanding.
Participant 023_2023AUCRT

Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment

Well I knew it was a form of leukemia and it's cure. It wasn't curable, but it's it's you can manage it and then that one day I would need a cell transplant and to stop it getting any worse.
Participant 015_2023AUCRT

Participant describes knowing about the condition due to public awareness

I knew nothing. I knew about shave for cause. I knew that was leukemia, but I really didn't know anything about leukemia. And I really thought it was something that just kids got, yeah.
Participant 016_2023AUCRT

No, absolutely not. I'd heard of. I'd heard of bone marrow and I had heard of bone marrow transplants at that stage only through news and, you know, like media. Yeah, right.
Participant 020_2023AUCRT

Table 3.19: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes knowing nothing or very little about the condition at diagnosis	17	51.52	4	57.14	6	60.00	7	43.75	14	53.85	3	42.86	8	53.33	9	50.00
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	7	21.21	0	0.00	3	30.00	4	25.00	6	23.08	1	14.29	2	13.33	5	27.78
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11
Participant describes knowing about the condition due to public awareness	3	9.09	2	28.57	0	0.00	1	6.25	3	11.54	0	0.00	3	20.00	0	0.00
Participant describes knowing about the condition by learning about it before or during the diagnositic process	2	6.06	1	14.29	1	10.00	0	0.00	1	3.85	1	14.29	2	13.33	0	0.00
Participant describes knowing about the condition due to professional background	2	6.06	0	0.00	0	0.00	2	12.50	1	3.85	1	14.29	0	0.00	2	11.11
No particular comment	1	3.03	0	0.00	0	0.00	1	6.25	0	0.00	1	14.29	0	0.00	1	5.56

Understanding of disease at diagnosis	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes knowing nothing or very little about the condition at diagnosis	17	51.52	9	47.37	8	57.14	8	57.14	9	47.37	8	57.14	9	47.37
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	9.09	1	5.26	2	14.29	2	14.29	1	5.26	2	14.29	1	5.26
Participant describes knowing about the condition due to public awareness	3	9.09	2	10.53	1	7.14	0	0.00	3	15.79	0	0.00	3	15.79
Participant describes knowing about the condition by learning about it before or during the diagnositic process	2	6.06	2	10.53	0	0.00	0	0.00	2	10.53	1	7.14	1	5.26
Participant describes knowing about the condition due to professional background	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26
No particular comment	1	3.03	0	0.00	1	7.14	1	7.14	0	0.00	0	0.00	1	5.26

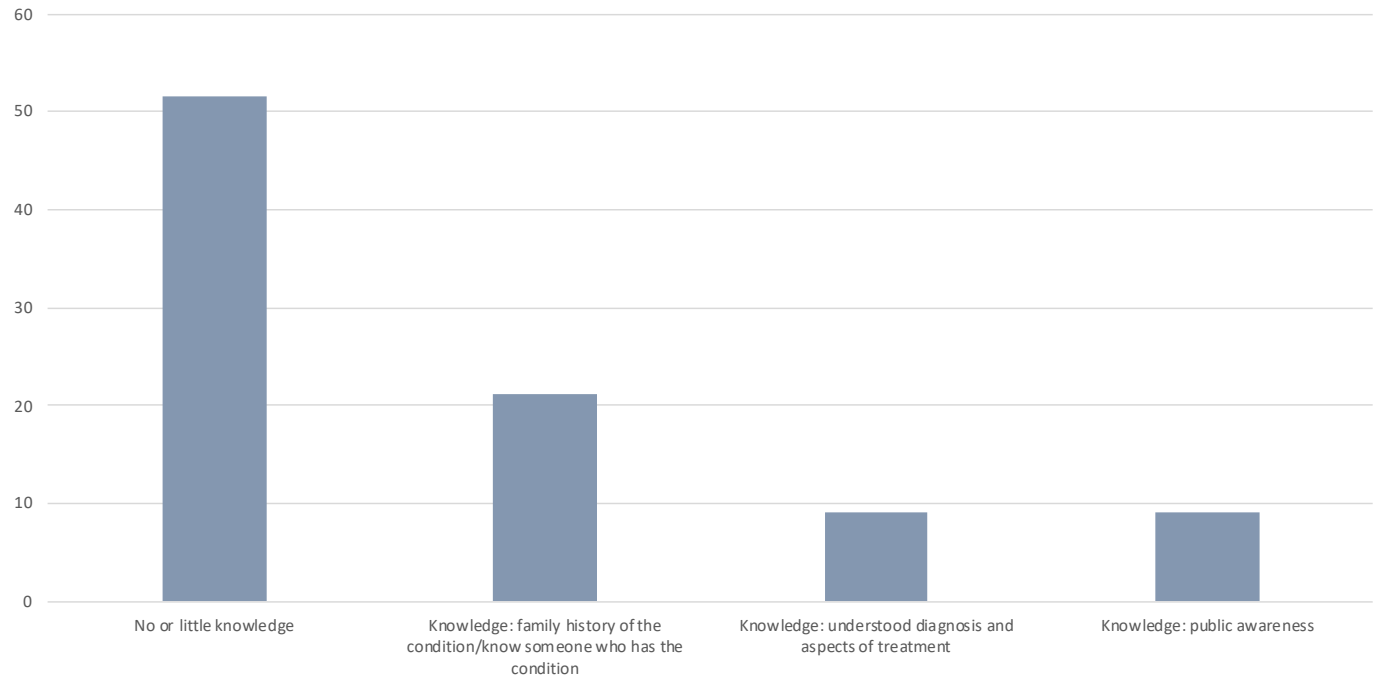

Figure 3.17: Understanding of disease at diagnosis

Table 3.20: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	B-cell acute lymphoblastic leukaemia (ALL)	-
Participant describes knowing about the condition due to public awareness	-	B-cell acute lymphoblastic leukaemia (ALL) Female
No particular comment	-	CAR T-Cell therapy

Emotional support at diagnosis

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

There were 19 participants (51.35%) who had enough support, 5 participants (13.51%) that had some support, but it wasn't enough, and 13 participants (35.14%) had no support.

Table 3.21: Emotional support at diagnosis

Emotional support at diagnosis	Number (n=37)	Percent
Enough support	19	51.35
Some support but it wasn't enough	5	13.51
No support	13	35.14

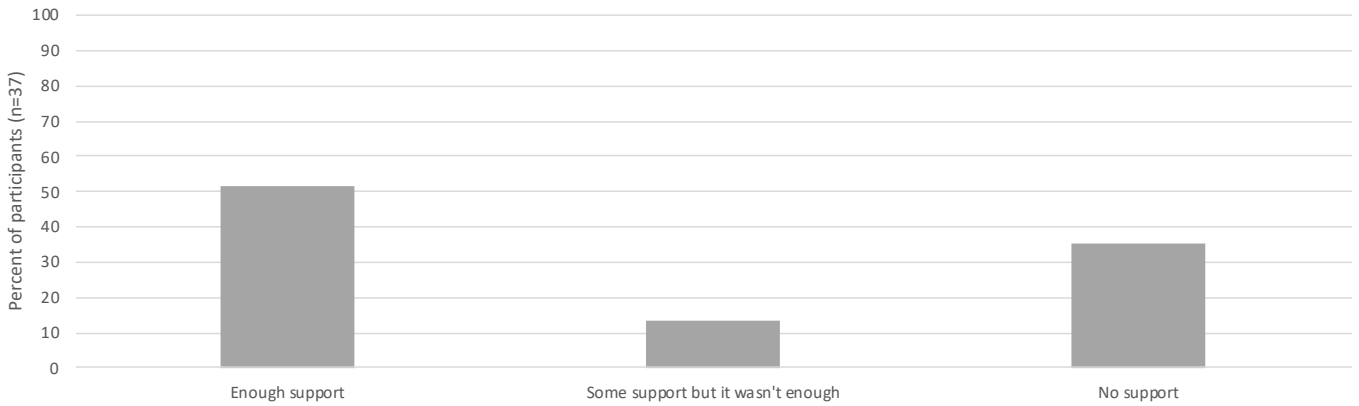

Figure 3.18: Emotional support at diagnosis

Information at diagnosis

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

There were 25 participants (67.57%) who had enough information, 7 participants (18.92%) that had some information, but it wasn't enough, and 5 participants (13.51%) had no information.

Table 3.22: Information at diagnosis

Information at diagnosis	Number (n=37)	Percent
Enough information	25	67.57
Some information but it wasn't enough	7	18.92
No information	5	13.51

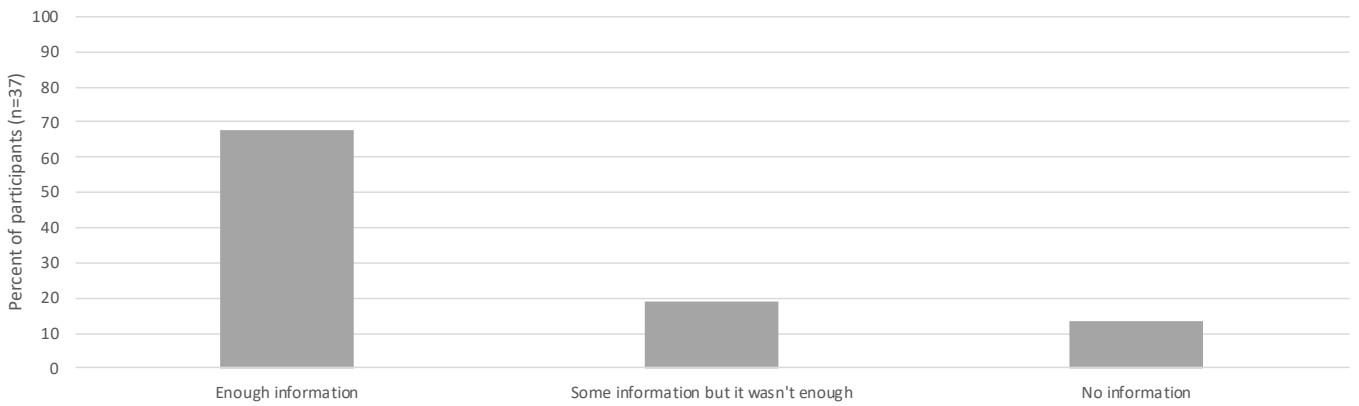

Figure 3.19: Information at diagnosis

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 24 participants (64.86%) who had no out of pocket expenses, and participants (0.00%) who did not know or could not recall. There were 2 participants (5.41%) that spent $100 to 500, 3 participants (8.11%) that spent between $501 to 1000, and 8 participants (21.62%) that were not sure.

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 6 participants (16.22%) the cost was slightly or not at all significant. For 2 participants (5.41%) the out-of-pocket expenses were somewhat significant, and for 2 participants (5.41%), the burden of out-of-pocket expenses were moderately or extremely significant.

Table 3.23: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=37)	Percent
$0	24	64.86
$100 to 500	2	5.41
$501 to 1000	3	8.11
Not sure	8	21.62

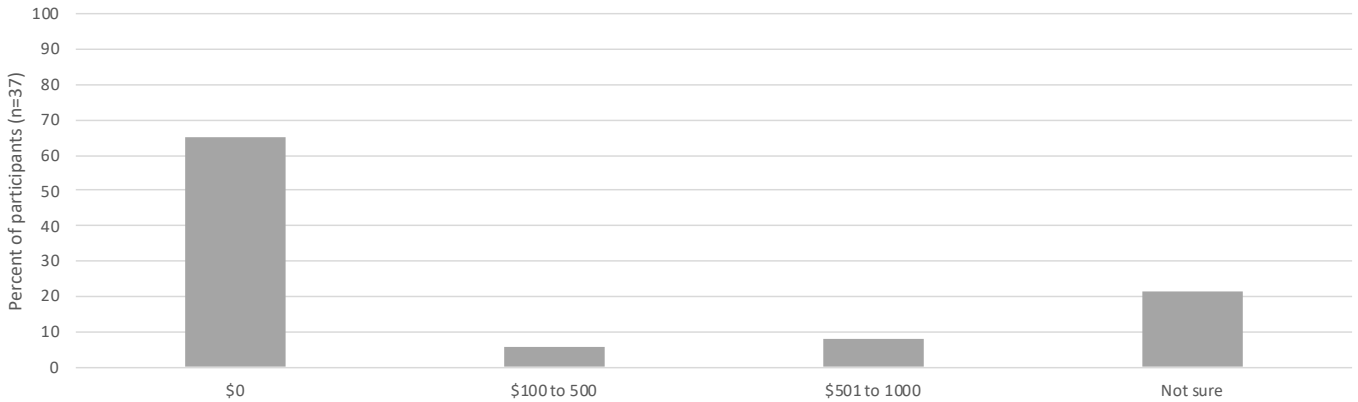

Figure 3.20: Out of pocket expenses at diagnosis

Table 3.24: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=37)	Percent
Not at all significant	2	5.41
Slightly significant	4	10.81
Somewhat significant	2	5.41
Moderately significant	1	2.70
Extremely significant	1	2.70
Not applicable: not cost or can't remember	27	72.97

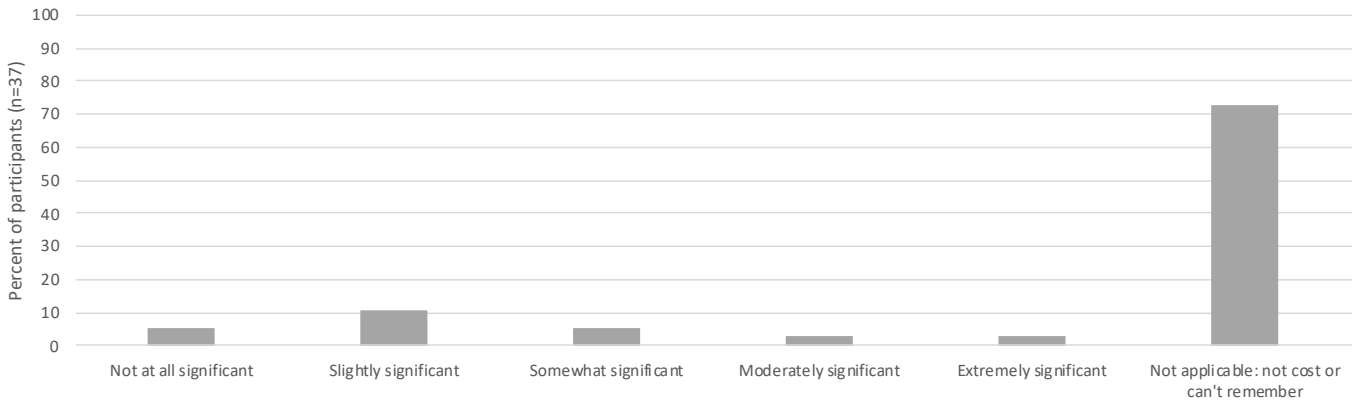

Figure 3.21: Burden of diagnostic costs

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=27, 72.97%). There was one participant (2.70%) who brought up the topic with their doctor, and 9 participants (24.32%) 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.

Almost half of the participants did not have any genetic or biomarker tests but would like to (n=18, 48.65%). There were 11 participants (29.73%) who did not have these tests and were not interested in them, and a total of 8 participants (21.62%) that had biomarker tests.

Table 3.25: Discussions about biomarkers

Discussions about biomarkers	Number (n=37)	Percent
Participant brought up the topic with doctor for discussion	1	2.70
Doctor brought up the topic with participant for discussion	9	24.32
Participant had no discussion about this type of test	27	72.97

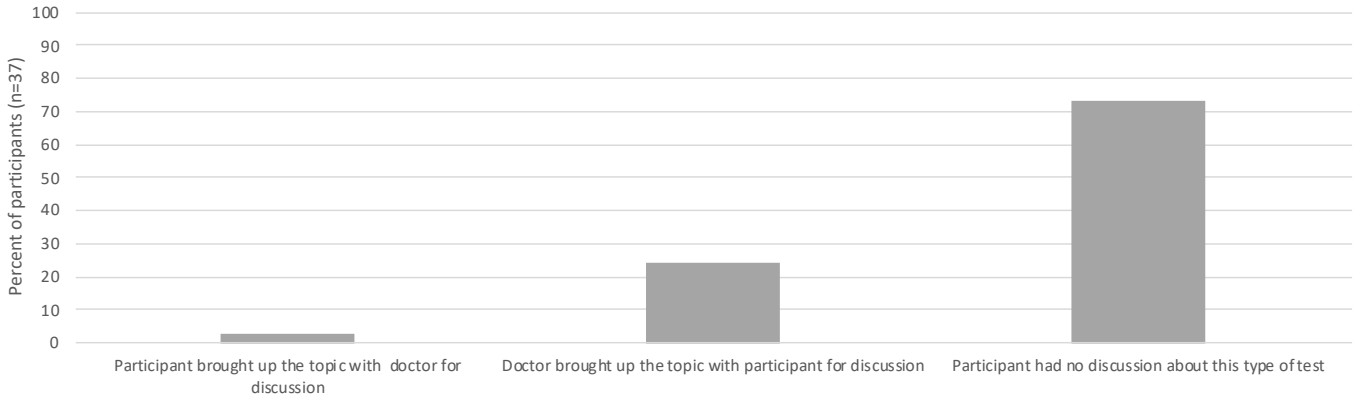

Figure 3.22: Discussions about biomarkers

Table 3.26: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=37)	Percent
Participant had this test and did not have to pay out of pocket for it	6	16.22
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	2	5.41
Participant did not have this test and is not interested in it	11	29.73
Participant did not have this test but would like to	18	48.65

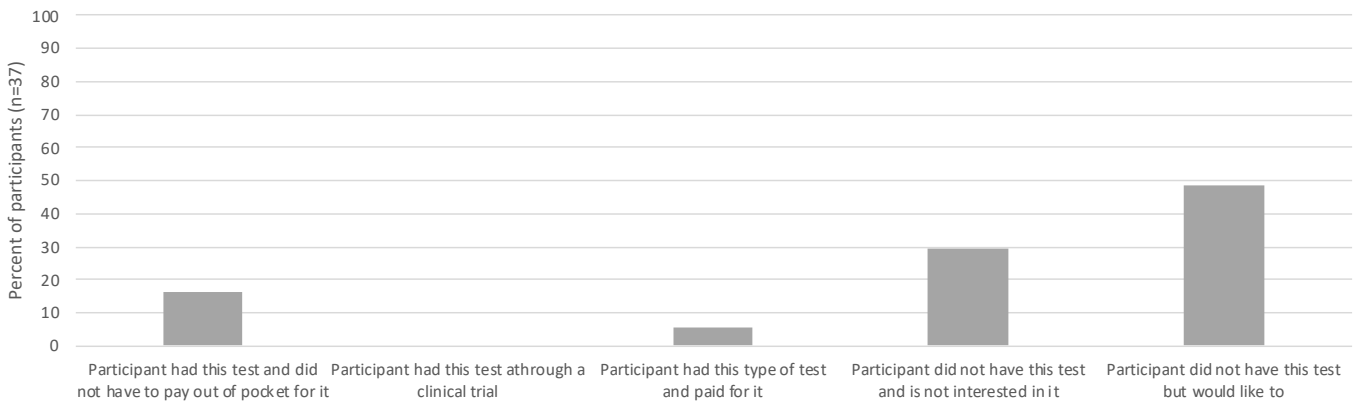

Figure 3.23: Experience of genetic tests and biomarkers

Biomarker status

Participants were asked in the online questionnaire if they knew their status for named biomarkers. Very few participants knew the status for at least one biomarker (n=5, 14.29%).

Table 3.27: Biomarker status

Biomarkers	Number (n=35)	Percent
Named specific biomarker	5	14.29
Family history	1	2.86
Not sure	29	82.86

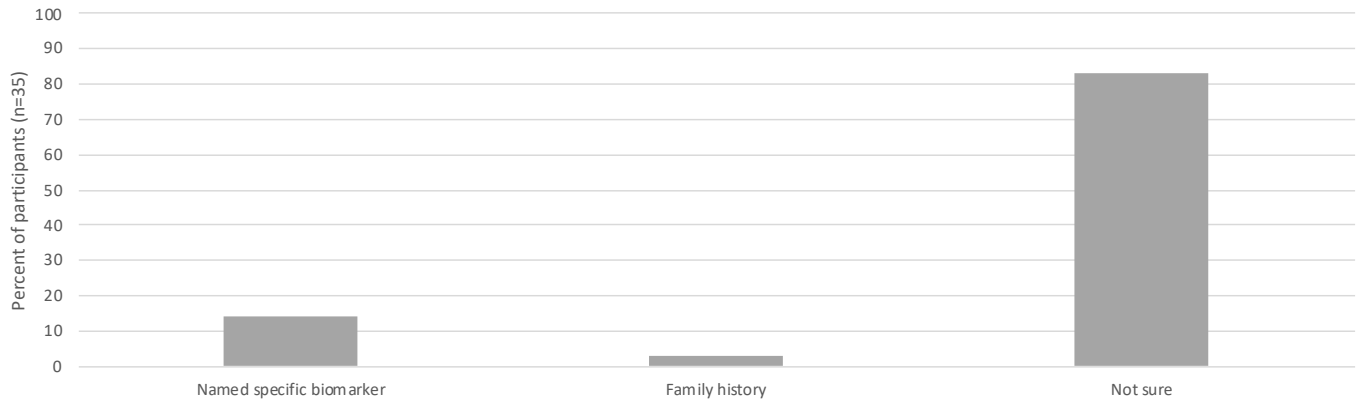

Figure 3.24: Biomarker status

Current symptoms

Number of current symptoms

Participants were asked in the questionnaire what symptoms they are currently dealing with, they could choose from a set lit of symptoms and could then specify other symptoms not listed.

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n=19, 65.52%). Participants had between 3 to 11 symptoms (median=5.00, IQR=8.00).

Type of current symptoms

The most common current symptoms, participants experienced were fatigue (n=19, 65.52%), weak or damaged bones (n=18, 62.07%), depression and anxiety (n=16, 55.17%), low resistance to infections (n=16, 55.17%), damage to organs (n=13, 44.83%), and hearing loss (n=10, 34.48%).

Quality of life from current symptoms

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”. The median quality of life was between 2.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing” to “Life was a average” range.

The median quality of life was between 4 and 2.5 for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average” range.

The symptoms with the lowest quality of life were low resistance to infections, and hearing loss.

Table 3.28: Number of current symptoms

Number of current symptoms	Number (n=29)	Percent
0	10	34.48
3 to 4	4	13.79
5 to 6	3	10.34
7 to 8	5	17.24
9 or more	7	24.14

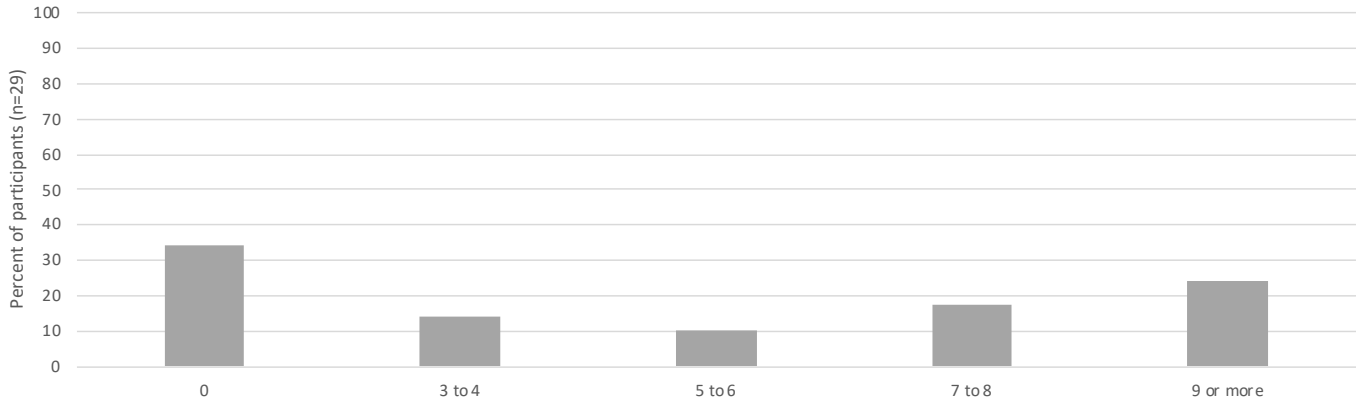

Figure 3.25: Number of current symptoms

Table 3.29: Type of current symptoms

Type of current symptoms	Number (n=29)	Percent	Quality of life	
			Mean	SD
No symptoms	10	34.48	NA	NA
Peripheral neuropathy	19	65.52	3.00	2.00
Fatigue	18	62.07	3.00	1.00
Weak or damaged bones	16	55.17	2.50	1.25
Psychological effects Including depression and anxiety	16	55.17	3.00	3.00
Low resistance to infections	13	44.83	3.00	1.00
Damage to organs (heart, lung, thyroid)	10	34.48	3.50	2.00
Hearing loss	9	31.03	4.00	3.00
Second cancer	7	24.14	4.00	1.50
Cataracts	6	20.69	3.00	2.25
Infertility, premature menopause in women and low testosterone levels and sperm counts in men	5	17.24	4.00	3.00

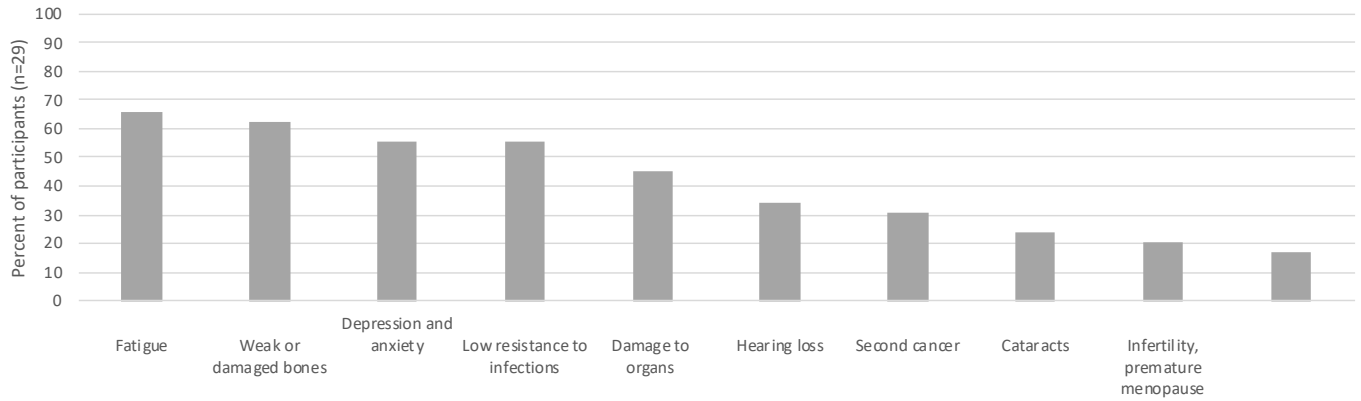

Figure 3.26: Type of current symptoms

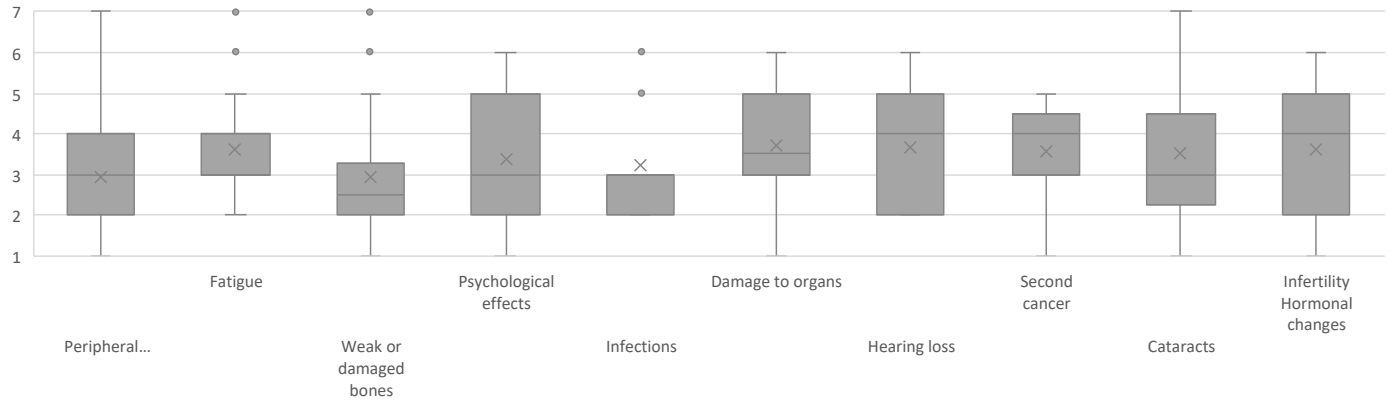

Figure 3.27: Quality of life from current symptoms

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 there was no evidence of disease or that they are in remission (51.52%), and that they had specific medical interventions they need to manage their condition (30.30%). Other themes included that they were monitoring their condition until there is an exacerbation or progression (18.18%), that they would likely have a recurrence, or were in a cycle of recurrence (18.18%), that they are in recovery from treatments and managing side effects of treatment (15.15%), their prognosis in terms of a specific timeframe that they are expected to live (12.12%), that their prognosis was positive, that their condition is manageable (12.12%), and that there was uncertainty around their prognosis (12.12%).

Participant describes prognosis in relation to there being no evidence of disease or that they are in remission

I'm in remission.
Participant 003_2023AUCRT

I'm in remission at the moment and by sticking to the best diet that I can, I've cut alcohol. I've stopped taking sugar as much as I can and I think I hope that it would stay in on remission for a while and then I have another batch of stem cells in the hospital to be transferred again in future. So that's the last bit of the stem cells that is left so. Yeah, yeah. Hopefully it would stay in the same situation for a while, yeah.
Participant 017_2023AUCRT

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

Yes. My prognosis is good. I'm four and a half years in remission. I can't remember the…I can look at it, I've got it written in my notes for the type that I had. It was a good prognosis without the necessity to have a bone marrow transplant. I was very happy about that. I'm being monitored very closely and I've just gone from four monthly to six monthly checkups.
Participant 004_2023AUCRT

I would well from my last checkup I'm still in remission. I've got no nondetectable cells, but that comes with I take a medication, and that has side effects of like bit of peripheral neuropathy in my feet and hands which which can be uncomfortable at times and probably a little bit of a lot of problems with my stomach with bloating and diarrhea really that's that's my and also fatigue. Quite a bit of fatigue and I have been a couple of times neutropenic where my my white blood cells drop to quite a low count. So each when that happens, they've dropped my dosage.
Participant 015_2023AUCRT

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

I still go to my specialist every three months unless I get sick or whatever and they're they're monitoring and so far it's it's pretty good touchwood.
Participant 011_2023AUCRT

It's very good after CAR T. I had CAR T in I think it was October last year. I've had checkups at three months, six months and I've been cancer free each time. Wonderful.
Participant 009_2023AUCRT

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

Yeah look I I speak…I have the point with my hematologist every couple of months and my GP every month and look it's a regular question which I ask my hematologist and obviously my understanding is that based on my blood results and pathology that's the indication in terms of where I am. We haven't sort of really discussed there's been nothing really discussed because with multiple myeloma of course as you know there's there's no cure per se. So the idea is to keep one in remission for as long as possible and from a positive point of view, we haven't sort of had any sort of discussions in terms of you know what are the next steps in terms of relapse.
Participant 023_2023AUCRT

I don't really know. Because it's stem cell transplant could last about six or seven years with me and I lead a normal life during that six or seven years. And because of all the treatments I've had, I'm eligible for the CAR T-cell transplant when it comes back. So whether that cures it or who knows?
Participant 025_2023AUCRT

Participant describes prognosis in relation to recovery from treatments and managing side effects of treatment

Sure, it's great. I'm in remission and well actually I'm I'm just going to say I'm leukemia free. I had ten months of chemo and then a bone marrow transplant. So I'm what are we. I'm 19 months post transplant. So yeah, still dealing with with the, yeah, still dealing with the, you know, transplant recovery kind of stuff is pretty big. But but yeah, I'm well, I'm alive and yeah.
Participant 016_2023AUCRT

I don't have any ongoing issues with my bloods. It's just with the some of the chemo drugs and things like that that have affected me during the course of the years since then.
Participant 024_2023AUCRT

At the moment it's probably just the the knock on effects with the condition called graft versus host disease which is settled into my, into my, into my lungs, which is causing those to sort of probably work, you know, about 40-41% capacity. So at this stage, yeah, the I still go in every fortnight and have a IVIG treatment to to keep it at bay. The the markers are coming back OK and there's I suppose that side of things is in in remission, but it's obviously dealing with sort of knock on effects with everything from from eyes to my lungs to just sort of some general health stuff that is is sort of what we're working through now.
Participant 026_2023AUCRT

Participant describes prognosis in relation to specific timeframe that they are expected to live

More than 10 years.
Participant 008_2023AUCRT

Well. When I was first diagnosed, I said you got one to three years to live. That was two years ago. I'm feeling pretty good.
Participant 031_2023AUCRT

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

Really good. Yeah, really good. I have been told. I have never been told I'm in remission, but I've put that in my form because that's the only word that I could think of. I've Never verbally been told I'm in remission. I have been told that it is treatable, not curable, right from the start. That was told right from the start. The the guy that gave me the news was not my hematologist, but he said at the time, I know someone who's lived for 12 years.
Participant 020_2023AUCRT

Participant describes prognosis in relation to uncertainty around prognosis

Well, I don't know really. And I'm seeing a doctor on Tuesday because you know how people talk about stages of cancer. He's never mentioned that to me at all. They never talked about, you know, you're at stage one or two or three or anything and what the outlook is. I said to him, what will happen now with this drug that I'm on. He said, well, we'll just keep you on this until it stops working and then we'll find another one because they keep coming up with new treatments all the time and new combinations of drugs. And he keeps, you know, he says, oh, we'll find another one and and you know, you'll go on that. But no, he's never given me an outlook.
Participant 012_2023AUCRT

Table 3.30: Understanding of prognosis

Understanding of prognosis	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	17	51.52	6	85.71	6	60.00	5	31.25	14	53.85	3	42.86	9	60.00	8	44.44
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	10	30.30	1	14.29	2	20.00	7	43.75	8	30.77	2	28.57	1	6.67	9	50.00
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	6	18.18	1	14.29	3	30.00	2	12.50	5	19.23	1	14.29	3	20.00	3	16.67
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	6	18.18	2	28.57	2	20.00	2	12.50	4	15.38	2	28.57	5	33.33	1	5.56
Participant describes prognosis in relation to recovery from treatments and managing side effects of treatment	5	15.15	3	42.86	1	10.00	1	6.25	4	15.38	1	14.29	2	13.33	3	16.67
Participant describes prognosis in relation to specific timeframe that they are expected to live	4	12.12	1	14.29	0	0.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes prognosis in a positive way, that their condition is manageable	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes prognosis in relation to uncertainty around prognosis	4	12.12	0	0.00	0	0.00	4	25.00	3	11.54	1	14.29	2	13.33	2	11.11

Understanding of prognosis	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	17	51.52	13	68.42	4	28.57	9	64.29	8	42.11	8	57.14	9	47.37
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	10	30.30	7	36.84	3	21.43	5	35.71	5	26.32	6	42.86	4	21.05
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	6	18.18	4	21.05	2	14.29	3	21.43	3	15.79	2	14.29	4	21.05
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	6	18.18	3	15.79	3	21.43	1	7.14	5	26.32	2	14.29	4	21.05
Participant describes prognosis in relation to recovery from treatments and managing side effects of treatment	5	15.15	5	26.32	0	0.00	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes prognosis in relation to specific timeframe that they are expected to live	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	1	7.14	3	15.79
Participant describes prognosis in a positive way, that their condition is manageable	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	2	14.29	2	10.53
Participant describes prognosis in relation to uncertainty around prognosis	4	12.12	0	0.00	4	28.57	0	0.00	4	21.05	1	7.14	3	15.79

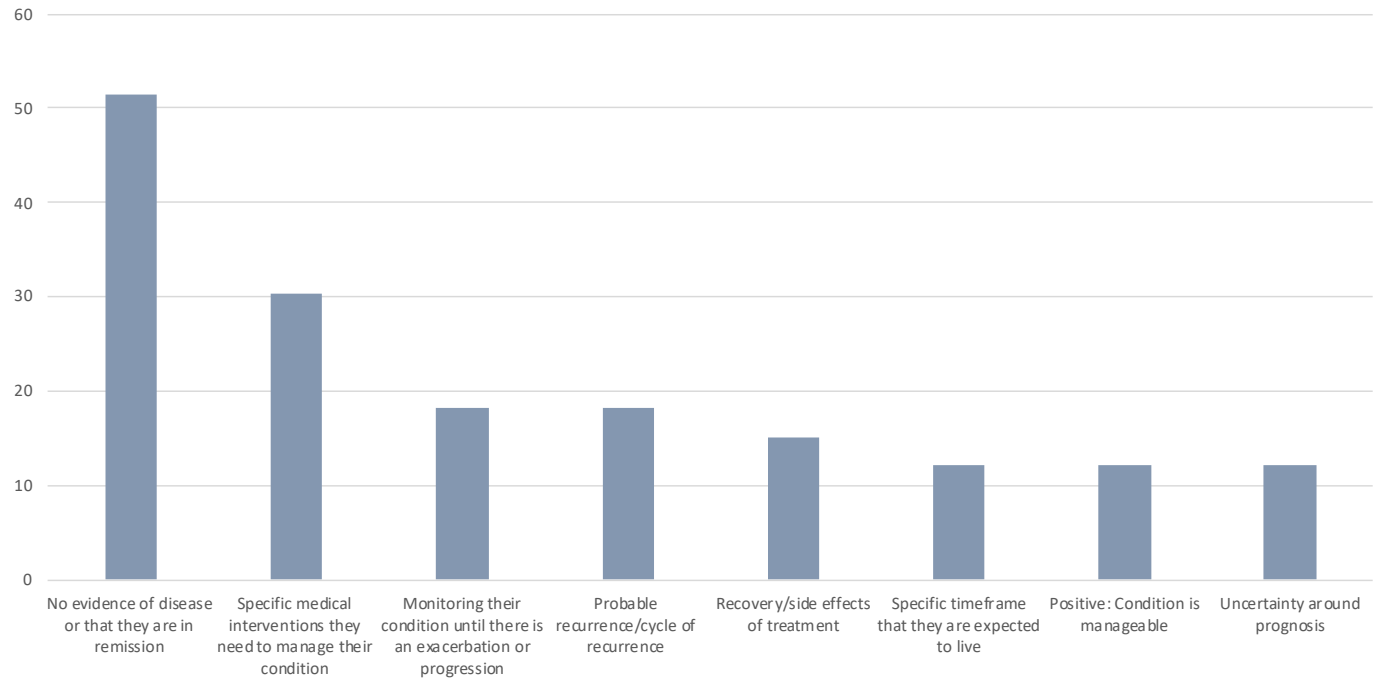

Figure 3.28: Understanding of prognosis

Table 3.31: Understanding of prognosis – subgroup variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	Multiple Myeloma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Regional or remote
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Female	Multiple Myeloma Male Mid to low status
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	-	Diffuse Large B-Cell Lymphoma
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	Male Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Female
Participant describes prognosis in relation to recovery from treatments and managing side effects of treatment	Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64
Participant describes prognosis in relation to specific timeframe that they are expected to live	Diffuse Large B-Cell Lymphoma	-
Participant describes prognosis in a positive way, that their condition is manageable	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant describes prognosis in relation to uncertainty around prognosis	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Aged 25 to 64 Regional or remote	Multiple Myeloma Aged 65 or older

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 described being presented with one treatment option (63.64%), multiple options (24.24%), and no discussions about treatment (6.06 %).

Discussions about treatment (Participation in discussions)

For those with a single treatment option, most commonly they had a medical emergency/urgent treatment required (27.27%), were comfortable deferring to doctor/accept recommended approach (21.21%), or gave no reason (12.12 %). Other themes included and was well informed by doctor (12.12%), and having some but very little discussion (6.06%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (15.15%), were comfortable deferring to doctor or accept the recommended approach (6.06%).

Participants that had no treatment options offered at diagnosis described not needing treatments initially(6.06 %).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24 %). Other themes included ability to follow treatments (12.12%), and quality of life (9.09%). There were 4 participants (12.12%) described that they had not been given options, and that considerations not taken into account (12.12%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (57.58%), and had changed the way they make decisions (33.33%).

Where participants had not changed the way they make decisions, the most common themes were that they had changed but did not mention any reason (18.18%), they have always been informed/assertive (9.09%), and have always taken advice of clinicians (9.09 %).

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 (15.15%), and were more informed and/or more assertive (12.12%).

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 be cancer free, avoid recurrence, increase longevity (45.45%), have quality of life/return to normality (27.27%), and have physical improvements in their condition (21.21 %). Other themes included to minimise or avoid side effects (15.15%), maintain their condition or prevent worsening of their condition (12.12%), and not having treatment goals as they are satisfied or their condition has little impact on life (9.09%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants described being presented with one treatment option (63.64%), multiple options (24.24%), and no discussions about treatment (6.06 %).

Participant describes one option being presented

I think it was pretty much a one way conversation. I was told what the treatment would be and I accepted that. I don't think I was given…I didn't know anyway about various treatment options, mostly I think from me looking it up on the Internet, but I was pretty much presented with a treatment plan and accepted it and this was that I would take a drug in combination with the prednisolone. So that's how I started.
Participant 014_2023AUCRT

Well, it was just a matter of initially the first line of treatment was there was only one option really was the chemo. There was no other, there was no no other trials or there was no options for CAR T Cell or various other trials that people have been on since.
Participant 032_2023AUCRT

OK, so the main conversation was the day I was diagnosed when there was the haematologist, the resident and the neurologist there and I said to them or they explained to me that it was not curable and they said there's essentially one line of treatment that can help but won't cure you. And they said this is the only treatments we have. And I said what if we don't do that? And they said, well, you know, you've got six months really.
Participant 022_2023AUCRT

Participant describes multiple options being presented

I was offered chemo. To be honest, there wasn't a lot of discussion except for me saying that I didn't want to, actually, I didn't want to do it. That was my only option. It was either that or palliative care at the time. My friends convinced me that I should have chemo. There wasn't a lot of discussion.
Participant 003_2023AUCRT

OK, so my GP deferred back to my hematologist, so they drew a line in my treatment between them. Basically the hematologist left pain management etc with my GP and the hematologist dealt with the cancer and it's byproducts of the cancer. So yeah, so there basically there was how can we say there was cross match between the two. So make sure there was no contrast with the drugs and so forth being used. But basically that's where the line was drawn.
Participant 027_2023AUCRT

Participant describes no treatments being discussed

Well, I saw an oncologist who went through what was involved and how he continued to monitor me. But he he said within the next 5-10 years you probably need some form of treatment. I went for checkups and as my markers gradually went up very slowly, but they went up each time I went to the point where it reached Stage 1 multiple myeloma. And that's when he well said I'd start chemotherapy.
Participant 015_2023AUCRT

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes one option being presented	21	63.64	6	85.71	7	70.00	8	50.00	18	69.23	3	42.86	11	73.33	10	55.56
Participant describes multiple options being presented	8	24.24	1	14.29	2	20.00	5	31.25	6	23.08	2	28.57	3	20.00	5	27.78
Participant describes no treatments being discussed	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	1	6.67	1	5.56
No particular comment	2	6.06	0	0.00	0	0.00	2	12.50	1	3.85	1	14.29	0	0.00	2	11.11

Discussions about treatment	All participants		Aged 25 to 64			Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19		%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes one option being presented	21	63.64	14	73.68	7	50.00	7	50.00	14	73.68	7	50.00	14	73.68	13
Participant describes multiple options being presented	8	24.24	3	15.79	5	35.71	6	42.86	2	10.53	6	42.86	2	10.53	4
Participant describes no treatments being discussed	2	6.06	2	10.53	0	0.00	1	7.14	1	5.26	1	7.14	1	5.26	2
No particular comment	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53	1

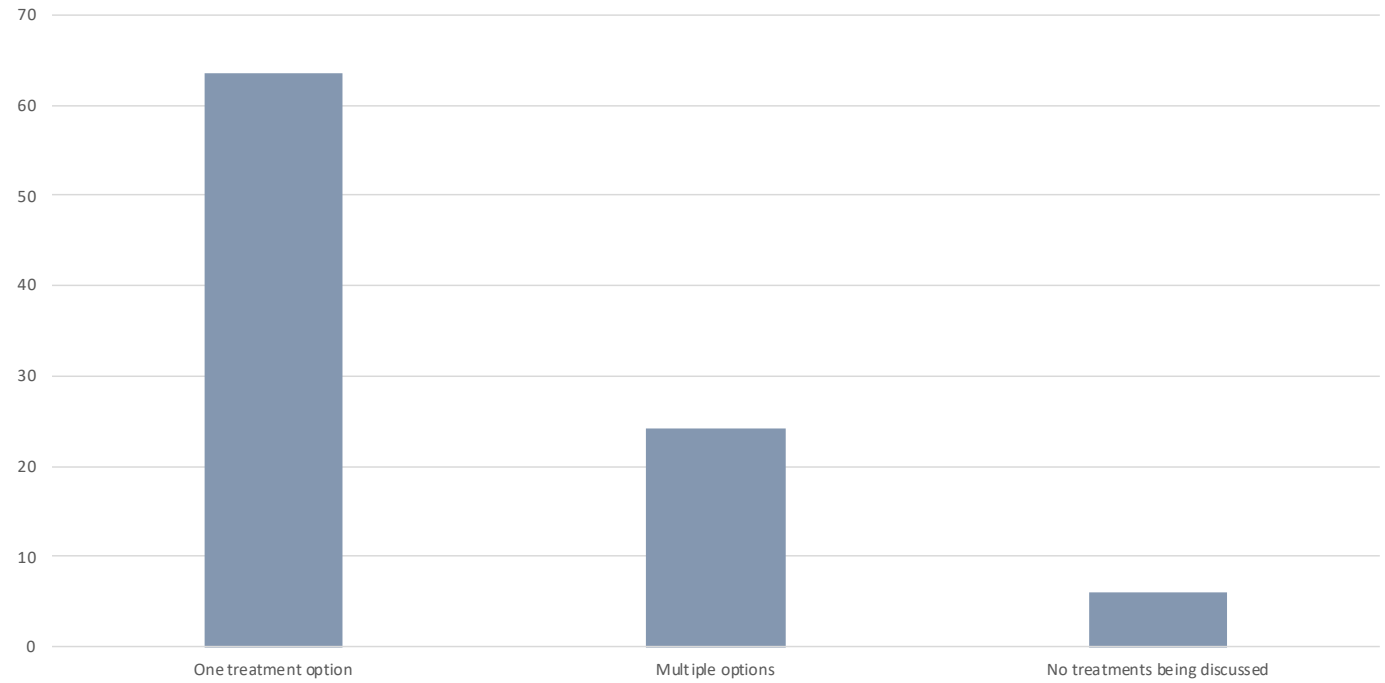

Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes one option being presented	Multiple Myeloma CAR T-Cell therapy Aged 65 or older Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Metropolitan Higher status
Participant describes multiple options being presented	Metropolitan Higher status	Aged 65 or older Regional or remote Mid to low status

Discussions about treatment (Participation in discussions)

For those with a single treatment option, most commonly they had a medical emergency/urgent treatment required (27.27%), were comfortable deferring to doctor/accept recommended approach (21.21%), or gave no reason (12.12 %). Other themes included and was well informed by doctor (12.12%), and having some but very little discussion (6.06%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (15.15%), were comfortable deferring to doctor or accept the recommended approach (6.06%).

Participants that had no treatment options offered at diagnosis described not needing treatments initially(6.06 %).

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

Well, when I was first diagnosed, I was already preparing for the treatment. That was maybe about 11:00 or midnight that night. They knew at that stage that if it was or wasn't, or more likely it was going to be what I had, that my body was going to need to be prepared. The next morning, Doctor came in and chatted to me and listed what's going to go on otherwise. He was very…just going to be brutal and said 'If you don't have the treatment, you've two to three weeks to live'
Participant 001_2023AUCRT

When I was first diagnosed, he told me I'd have to start chemo ASAP. It was a whirlwind because he organized for me to have, I think, a lung capacity test and some other test on my heart. Then on the Tuesday, I went into hospital to have the PICC line put in and then chemo pretty much started on the Wednesday.
Participant 002_2023AUCRT

Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach

Well, it was pretty well, they said, well, we've got to start chemotherapy straight away. There wasn't really any other options that that was basically that that was it. That was what they said. They've got to start it right away and they and they did tell me because of my age they said I'm I'm actually young for for this type of leukemia so that makes it better. And I was in other than the leukemia I was quite healthy and that sort of thing so but they they didn't really say. Instead of chemotherapy, you can do this or you can do that. And I mean, I just, when they said you need to have chemotherapy, I just said okay, What? I didn't have any thoughts of, Oh no, I'd rather try something else. I just talked to that they were the experts in the field and that what they would be saying was right. Participant 0_2023AUCRT

I don't really know about conversations. They just told me that I needed to do this chemotherapy and you know, I remember some of the words and I just thought, I'll just let it. I just left it up to them because they knew what they were doing and I didn't. What what was I going to say? I didn't, you know, I didn't like, you know, I was inquisitive and I read what they gave me a bit of literature and that to read, but it didn't, you know, I couldn't get my head around a lot of it, you know, like in the words, you know. The drug names and things like that, I can still recall some of them, but not all of them. Like when I filled out that, you know, that questionnaire you sent me that. Participant 010_2023AUCRT

Participant describes being presented with one option/approach, and was well informed by doctor

He explained to me what I'll be going on, what protocol and talked, talked me through what what sort of things were were happening and I sort of did a little bit of research. There's a medical library next to the hospital and there's a medical library nearby. So I went in there and and I got the regime up myself. He suggested that I keep a diary just because you're just a number in hospital and sometimes mistakes happen. So I kept the diary and just studied the drugs and their purposes and sort of got an idea of what was gonna be happening to me.
Participant 024_2023AUCRT

Basically explained to me that because of the way my health, because once I filled in the forms and they sat with them, explained to them a whole lot of things and they asked me about what other issues I've had and I have it really no other medical issues whatsoever, a slight bit of hypertension and that's it. And nothing else has ever occurred. I've actually been extremely healthy. They said I'd be a very good candidate for a stem cell transplant and they said that particular time period of time that was one of the best options for getting on getting on top of it. So I went along with it. They explained to me everything that was involved with it. I wasn't going to say no anything for me. I never say no. I was convinced they would give me the right right information at that particular time. Participant 018_2023AUCRT

Participant describes being presented with one option/approach, and had some but very little discussion

Basically, I wasn't presented with options. I was basically told that it was so advanced is not quite the right word, but so far along that they had had to hit me with pretty extreme chemo early and and that happened very quickly. I have a little bit of information about what to expect from chemo, but but nothing that you told actually prepares you for how awful that can be, the first course of chemo. Participant 009_2023AUCRT

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

Well that was that was obviously a question which I asked the the hematologist and the those that it was advised that I would be suitable. They felt that I would be suitable for a stem cell transplant and and you know the diagnosis, the diagnosis was about August 2020 and so things that have happened fairly quickly. So the treatment, the treatment options that were given to me were that I've commenced almost straight away on the course of chemotherapy and have you know different sort of blood tests done and all that stuff haveand then have stem cells recovered at the hospital and then have the then have the then have the various tests done and then have then have the transplant. So that was that was that was the treatment plan was to start with chemotherapy stem cell transplant at that stage also it was discussed. I was referred to a doctor at the hospital and she at that stag,e even prior to the transplant, she said after the transplant I signed up for for a trial drug there, but she did discuss after the transplant in terms of maintenance that there's a trial drug available. Participant 023_2023AUCRT

Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach

OK, so my GP deferred back to my hematologist, so they drew a line in my treatment between them. Basically the hematologist left pain management etc with my GP and the hematologist dealt with the cancer and it's byproducts of the cancer. So yeah, so there basically there was how can we say there was cross match between the two. So make sure there was no contrast with the drugs and so forth being used. But basically that's where the line was drawn.
Participant 027_2023AUCRT

Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed

Well, I saw an oncologist who went through what was involved and how he continued to monitor me. But he he said within the next 5-10 years you probably need some form of treatment. I went for checkups and as my markers gradually went up very slowly, but they went up each time I went to the point where it reached Stage 1 multiple myeloma. And that's when he well said I'd start chemotherapy.
Participant 015_2023AUCRT

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	9	27.27	5	71.43	3	30.00	1	6.25	8	30.77	1	14.29	7	46.67	2	11.11
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach	7	21.21	1	14.29	4	40.00	2	12.50	6	23.08	1	14.29	2	13.33	5	27.78
Participant describes being presented with one option/approach, but did not give a description or reason for this	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes being presented with one option/approach, and was well informed by doctor	4	12.12	0	0.00	2	20.00	2	12.50	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes being presented with one option/approach, and had some but very little discussion	2	6.06	0	0.00	2	20.00	0	0.00	0	0.00	2	28.57	1	6.67	1	5.56
Participant describes being presented with multiple options and participated in the decision-making process	5	15.15	0	0.00	2	20.00	3	18.75	4	15.38	1	14.29	3	20.00	2	11.11
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	2	6.06	1	14.29	0	0.00	1	6.25	2	7.69	0	0.00	0	0.00	2	11.11
Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	0	0.00	2	11.11

Discussions about treatment (Participation in discussions)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	9	27.27	9	47.37	0	0.00	3	21.43	6	31.58	3	21.43	6	31.58
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes being presented with one option/approach, but did not give a description or reason for this	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes being presented with one option/approach, and was well informed by doctor	4	12.12	1	5.26	3	21.43	4	28.57	0	0.00	4	28.57	0	0.00
Participant describes being presented with one option/approach, and had some but very little discussion	2	6.06	1	5.26	1	7.14	2	14.29	0	0.00	1	7.14	1	5.26
Participant describes being presented with multiple options and participated in the decision-making process	5	15.15	1	5.26	4	28.57	3	21.43	2	10.53	4	28.57	1	5.26
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	2	6.06	2	10.53	0	0.00	2	14.29	0	0.00	2	14.29	0	0.00
Participant describes being presented with no options/approach, as treatments were not needed when first diagnosed	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53

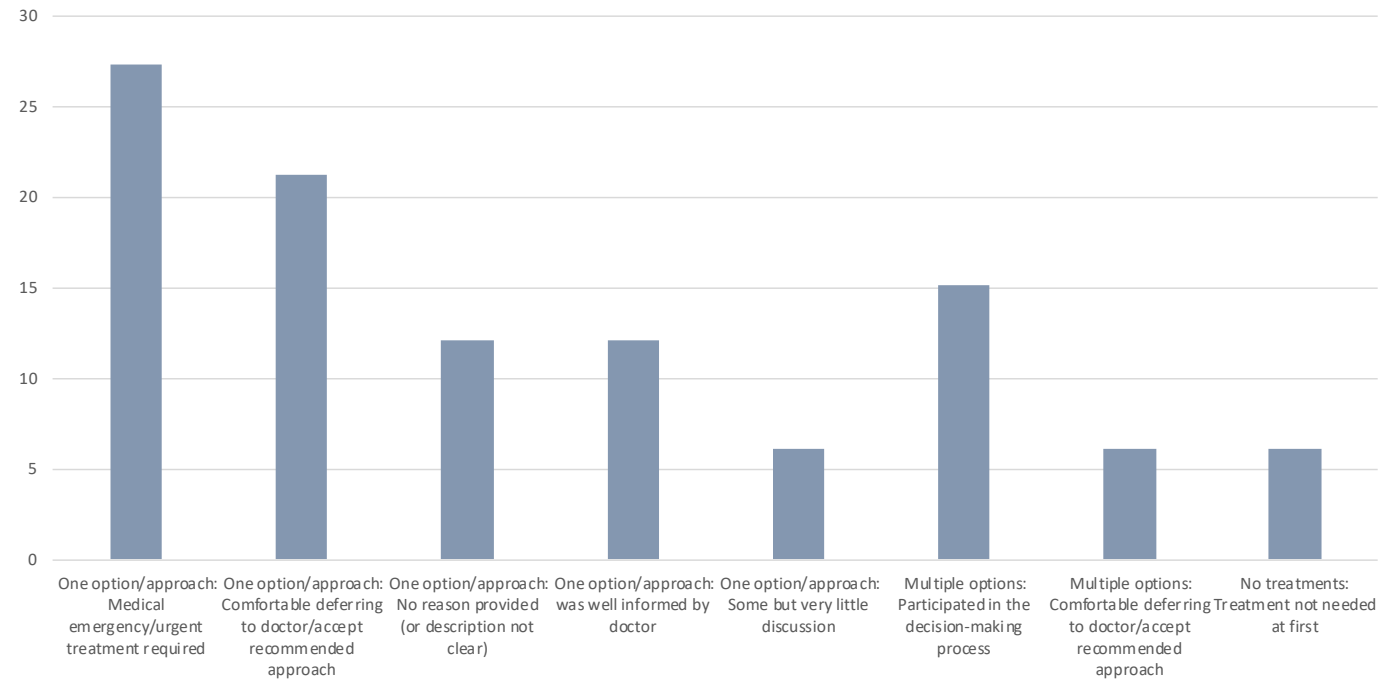

Figure 4.2: Discussions about treatment (Participation in discussions)

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

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64
Participant describes being presented with one option/approach and that they were comfortable deferring to doctor/accept recommended approach		Diffuse Large B-Cell Lymphoma
Participant describes being presented with one option/approach, but did not give a description or reason for this	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	
Participant describes being presented with one option/approach, and was well informed by doctor	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status	Regional or remote Mid to low status
Participant describes being presented with one option/approach, and had some but very little discussion		Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes being presented with multiple options and participated in the decision-making process	B-cell acute lymphoblastic leukaemia (ALL)	Aged 65 or older Mid to low status

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24 %). Other themes included ability to follow treatments (12.12%), and quality of life (9.09%). There were 4 participants (12.12%) described that they had not been given options, and that considerations not taken into account (12.12%).

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

Basically, we've always looked at the confidence of the doctors. If the doctors have recommended this is what we should do, that's what we've done. Participant 002_2023AUCRT

Do what the specialist tells me to do. Simple as that. And I mean my my current treatment and it's been similar for the last year or so as I said is is very simple a check in with the with the hematologist and the daily pill and the three monthly infusion. Participant 013_2023AUCRT

I suppose the short term and long term effects and what they could be, if that's short term, you're gonna feel pretty ordinary and you might have this, this, this and this or but the long term results are that. So that's probably what they generally look for. But yeah, certainly guided by the health professionals around all of those decisions. Participant 026_2023AUCRT

Look, I think for me, with this, I mean this is the first time I've ever been unwell, so I didn't have any experience to reference it to, which is so important in

decision making. You know, what have you done before? I did it work, blah blah. I had nothing at all to reference this to and I was so unwell. I think that I was a very passive decision maker in that process and I really did relinquish my absolute research in that decision making space. I think I really did relinquish my decision making to the professionals around me, but in terms of it retrospectively, if I say it, if somebody said to me now I had to do something, it would be the impact of the treatment on my kids and my partner.
Participant 016_2023AUCRT

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

Well, the risks of, you know, the side effects, but you sort of almost grab it in a sense because you haven't got many options. I mean, that's a fatal. Illness. So you know, I accepted that that stage just under a different hematologist and she was very good and went through it all.
Participant 035_2023AUCRT

Well, side effects? Outcomes impact on you, me and others. Cost is something I'm fortunate. I've had well paid jobs with financial and I have good medical insurance. So yeah, those things what's available is it current. I like to know that I'm having something that's up to date and and I I like to talk to the specialists about the impact of the treatment, how long it takes, all those things that's where I come to the revaccination program. It's rarely mentioned early in the piece that and the but the the thing that is mentioned in CAR T is the lack of immunoglobulins might be ongoing. And so my T cell stopped working after about six months in terms of defending my body from lymphoma tumors. And it's they've just been hanging in there and they haven't died and they could be reactivated. And I've had this conversation with my specialist, but they're they weren't actively running around in my body doing the job and my numbers equalized quite quickly comparatively to what's expected. So, you know, you'd like to know, worst case scenario, what might happen. What happens if?
Participant 036_2023AUCRT

Yeah, probably just the main thing is having all the facts to knowing. I mean, I ask a lot of questions and I take notes. So it's always knowing all the side effects and what to do, just being informed, I think that's the most important thing as I go into making decisions to know, yeah, to know what the pros and cons, I guess, to know what the side effects might be. I've never considered not taking the treatments because I don't know any better. I don't think I've had. I'm not against all this other holistic approaches, but just don't know enough. Yeah.
Participant 021_2023AUCRT

Participant descibes taking efficacy into account when making decisions about treatments

Was, I guess, what the outcome and prognosis with life.
Participant 001_2023AUCRT

Well, just saving my life. So yeah, there there probably wasn't really decisions that such it was like, well, you have to if you want to live and and if you don't have a stem cell transplant you probably won't live as well. So it was just like, OK, well that's what I need to do. That's what I need need to do. So it was there wasn't really any treatment decisions where they where there was sort of two options where they could say we can do this and this will happen and we'll do that and that'll happen. So, So yeah, the most important thing was always what was best for my health and what was going to have the best outcome.
Participant 006_2023AUCRT

Well, probably mainly the side effects and how effective it might be.
Participant 012_2023AUCRT

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

I just got to allow the time you know to allow you to diarize everything and just provide me with the with the schedule and I just write and make sure nothing clashes with my treatment. So otherwise you know when it's prescribed…but the other I mean I have a regular I, as I said before, the hydrotherapy and the exercise physiology, the regular thing, which we, you know, we pencil in and make sure nothing's gonna clash with that. So that consistency is the important thing.
Participant 032_2023AUCRT

Mostly it's it's about how I'm going to manage the logistics of it. I live alone and I don't drive. So all of those things like access, extra care. If it's needed tha,t I really worry about logistics, I'm much more concerned about that than the treatment really because fundamentally I'm, I just go with whatever the doctors are recommending to me basically.
Participant 009_2023AUCRT

Participant descibes that they were not given any treatment options

Well, I haven't had to make a decision really. Yeah, obviously it hasn't come. I'm in remission, so I haven't had to make a decision, but I'd like to know what I should be, you know, what I should be doing in regard to exercise, food and drink and stuff like that.
Participant 010_2023AUCRT

They just gave me chemo. I didn't really make a decision whether I had chemo or not. That was it.
Participant 003_2023AUCRT

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

How it's going to affect my life day-to-day
Participant 025_2023AUCRT

Well, improving life, improving, you know, just your day-to-day well-being, you know, and I sort of, I mean I had a really good friend of mine that had multiple myeloma and after a year of hospitalization and really bad times that he had was self assisted and he passed away and his choice was if he went into a coma he said 'don't wake me up'. He said I've had enough of this and look, those thoughts have crossed my mind. You know I think you know what is there in life, you know, but if you can improve your quality of life.
Participant 031_2023AUCRT

Table 4.5 Considerations when making decisions

Considerations when making decisions about treatment	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	15	45.45	3	42.86	7	70.00	5	31.25	11	42.31	4	57.14	8	53.33	7	38.89
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	30.30	2	28.57	5	50.00	3	18.75	7	26.92	3	42.86	6	40.00	4	22.22
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	2	13.33	3	16.67
Participant descibes taking side effects into account when making decisions about treatments (Total)	13	39.39	3	42.86	3	30.00	7	43.75	10	38.46	3	42.86	5	33.33	8	44.44
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	33.33	2	28.57	3	30.00	6	37.50	9	34.62	2	28.57	5	33.33	6	33.33
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	6.06	1	14.29	0	0.00	1	6.25	1	3.85	1	14.29	0	0.00	2	11.11
Participant descibes taking efficacy into account when making decisions about treatments (Total)	8	24.24	2	28.57	3	30.00	3	18.75	5	19.23	3	42.86	5	33.33	3	16.67
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	15.15	0	0.00	3	30.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Participant descibes taking their ability to follow treatments into account when making decisions about treatments (Total)	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	0	0.00	1	5.56
Participant descibes that they were not given any treatment options (Total)	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes that they were not given options, but described considerations that are important to them when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options, and did not discribe any considerations when making treatment decisions	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant descibes taking quality of life into account when making decisions about treatments (Total)	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	2	13.33	1	5.56
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	1	6.67	0	0.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	1	6.67	1	5.56

Considerations when making decisions about treatment	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	5	35.71	10	52.63
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	30.30	8	42.11	2	14.29	5	35.71	5	26.32	4	28.57	6	31.58
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant descibes taking side effects into account when making decisions about treatments (Total)	13	39.39	9	47.37	4	28.57	6	42.86	7	36.84	7	50.00	6	31.58
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	33.33	8	42.11	3	21.43	5	35.71	6	31.58	6	42.86	5	26.32
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26
Participant descibes taking efficacy into account when making decisions about treatments (Total)	8	24.24	5	26.32	3	21.43	2	14.29	6	31.58	4	28.57	4	21.05
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	3	21.43	2	10.53
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant descibes taking their ability to follow treatments into account when making decisions about treatments (Total)	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	1	7.14	3	15.79
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	1	7.14	2	10.53
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
Participant descibes that they were not given any treatment options (Total)	4	12.12	2	10.53	2	14.29	4	28.57	0	0.00	4	28.57	0	0.00
Participant describes that they were not given options, but described considerations that are important to them when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options, and did not discribe any considerations when making treatment decisions	4	12.12	2	10.53	2	14.29	4	28.57	0	0.00	4	28.57	0	0.00
Participant descibes taking quality of life into account when making decisions about treatments (Total)	3	9.09	0	0.00	3	21.43	0	0.00	3	15.79	0	0.00	3	15.79
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53

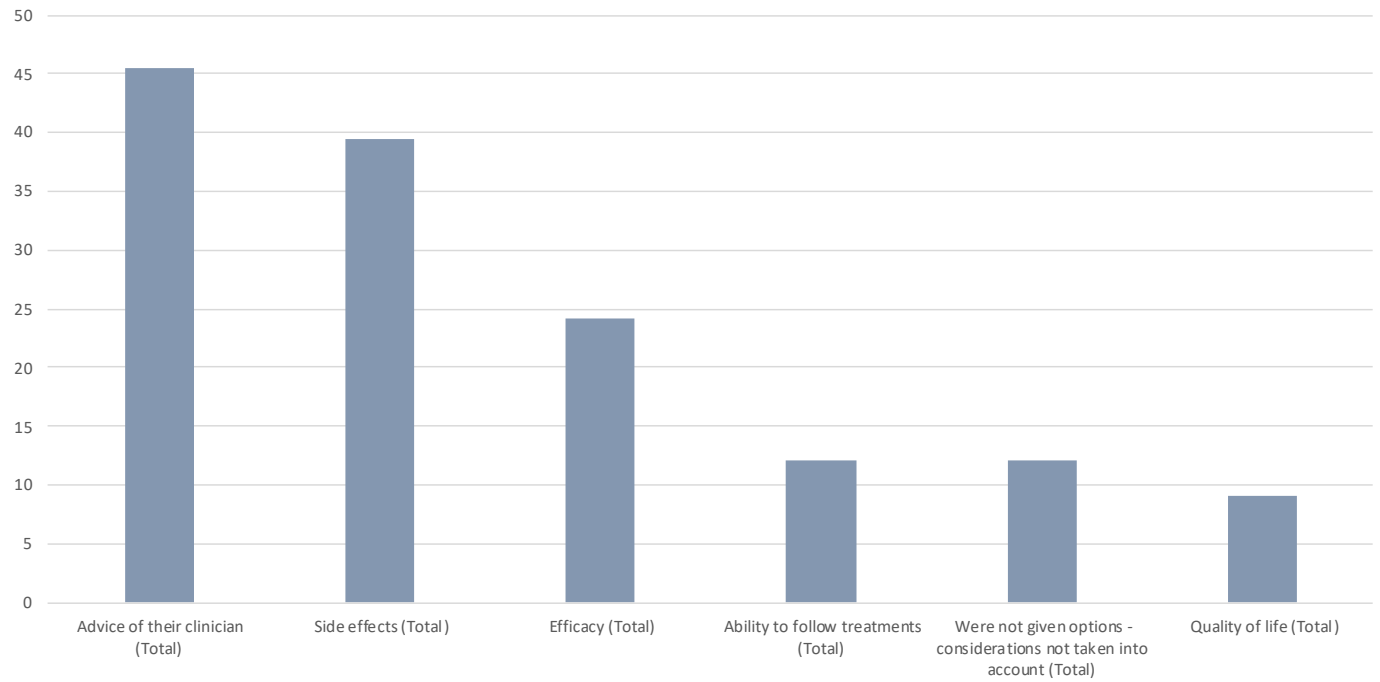

Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	Multiple Myeloma Aged 65 or older	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64
Participant descibes taking side effects into account when making decisions about treatments (Total)	Aged 65 or older	Mid to low status
Participant descibes taking efficacy into account when making decisions about treatments (Total)		CAR T-Cell therapy
Participant describes that they were not given any treatment options (Total)	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status
Participant descibes taking quality of life into account when making decisions about treatments (Total)		Aged 65 or older

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (57.58%), and had changed the way they make decisions (33.33%).

Where participants had not changed the way they make decisions, the most common themes were that they had changed but did not mention any reason (18.18%), they have always been informed/assertive (9.09%), and have always taken advice of clinicians (9.09 %).

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 (15.15%), and were more informed and/or more assertive (12.12%).

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

PARTICIPANT: Yes. I've always been quite analytical. I like to research. I like to know what's going on. I've always worked that way. It's what I do. It does work for me. It might not work for everyone. A lot of people don't want to know but I need to know. I need to know and work it all out. As I said, I knew that I have no option so, "Right, I'm going to do this and I'm going to get through it and I'm going to be fine."
Participant 004_2023AUCRT

No change in decision-making over time as they have always taken advice of clinicians

No, I mean, they're the experts that are advising me. So the only way is to express my faith in them and do what they tell me to do.
Participant 013_2023AUCRT

I think pretty much the same. I'm very clinical. I'm a I've been an academic for a long time. I'm a researcher. I want information. I'm very happy to be advised by physicians that I trust and nursing staff. You know, I've had amazing nursing care and but not always, you know, there's one or two occasions when I've I walked away from one guy, the cardiologist at the hospital and went back to my own cardiologist because he would not explain what he wanted and why he wanted it to do things. And he just got really pissed with me at the end and and that's fine. I didn't ever want to go back to him. I went along with what he asked for for a while. But I didn't know why and I found in the end I found the treatment that all the tests that he was running a bit distressing because I didn't understand why I was doing them and he couldn't tell me. So I said right. So I went back to my specialist, whom I trusted, and things are good.
Participant 036_2023AUCRT

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

I am more aware of what is happening to me and what has I'm I'm learning my lessons by looking at what has happened to me so far and what might be on the way ahead. And I'm studying more. I'm coming across more people who have had those treatments or who are going to have them and just talking to people about the things like that, studying a little bit more and adjusting my expectations and all of these things are, yeah, probably affecting the way that I'm thinking about it.
Participant 017_2023AUCRT

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

It's probably pretty much the same way, although I probably a few years ago, when I was in four, three or four years ago, I suppose I probably would have just said yes to whatever they told me. Now I probably would just question the why if if they were to say we're going to change the treatment, I'd go, well, why? What's the reasoning behind that? If, if and then if. It's just come down to the effectiveness, I'd say, well, how's this going to be different? Blah blah and that sort of thing. So I suppose I'd probably be a little bit more nuanced to a little bit more knowledgeable.
Participant 019_2023AUCRT

I think I asked more and more questions. So I guess as time goes, I know, yeah, I asked. I think we always ask the doctor, what would they do if you know someone they knew that's always a good indication. And yeah, just a bit more direct with is if the other side effects with the risk, yeah. It is a treatment worth of side effects etcetera etcetera.
Participant 021_2023AUCRT

Table 4.7: Decision-making over time

Decision-making over time	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Change in decision-making over time as they have always been informed/assertive	11	33.33	2	28.57	1	10.00	8	50.00	9	34.62	2	28.57	4	26.67	7	38.89
No change in decision-making over time as they have always taken advice of clinicians	19	57.58	5	71.43	8	80.00	6	37.50	15	57.69	4	57.14	9	60.00	10	55.56
Other/no response	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56

Decision-making over time	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Change in decision-making over time as they have always been informed/assertive	11	33.33	6	31.58	5	35.71	4	28.57	7	36.84	5	35.71	6	31.58
No change in decision-making over time as they have always taken advice of clinicians	19	57.58	13	68.42	6	42.86	9	64.29	10	52.63	8	57.14	11	57.89
Other/no response	3	9.09	0	0.00	3	21.43	1	7.14	2	10.53	1	7.14	2	10.53

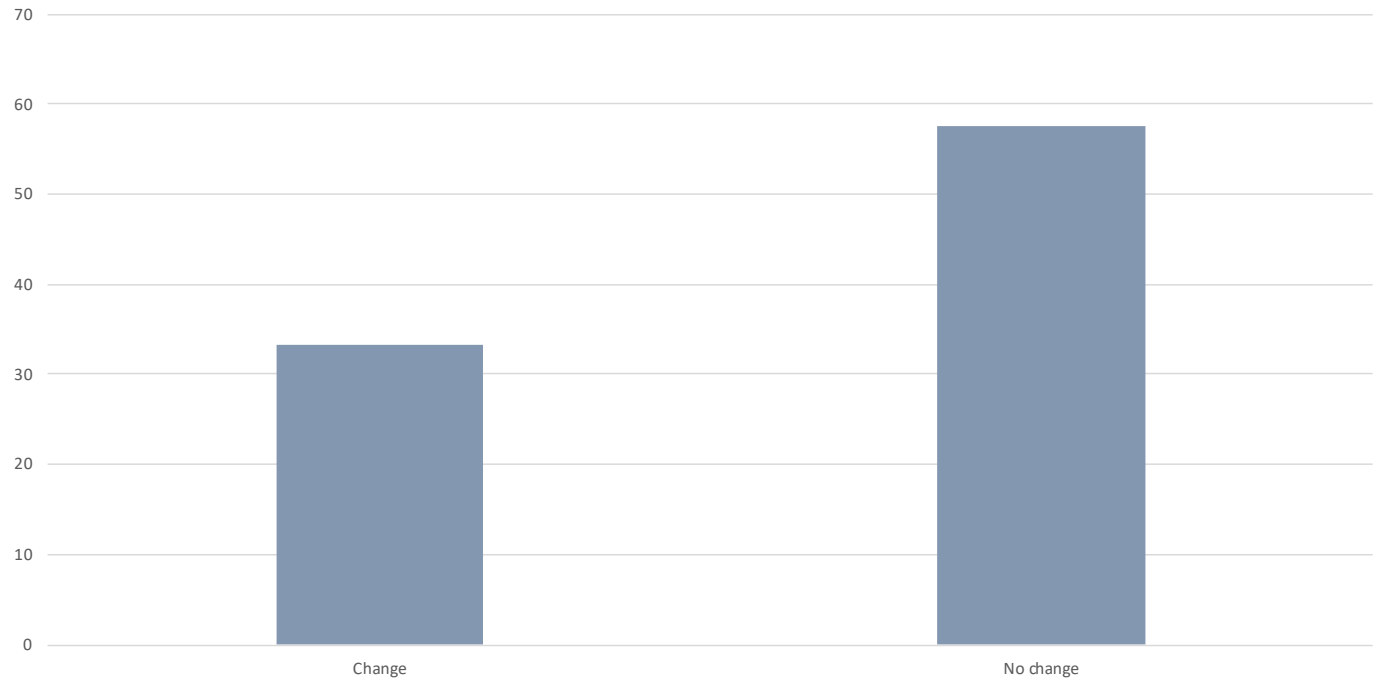

Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Change in decision-making over time as they have always been informed/assertive	Diffuse Large B-Cell Lymphoma	Multiple Myeloma
No change in decision-making over time as they have always taken advice of clinicians	Multiple Myeloma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Aged 25 to 64

Table 4.9: Decision-making over time (descriptions)

Decision-making over time (reasons)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
No change in decision-making over time and there is no particular reason noted	6	18.18	3	42.86	0	0.00	3	18.75	5	19.23	1	14.29	2	13.33	4	22.22
No change in decision-making over time as they have always been informed/assertive	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	2	13.33	1	5.56
No change in decision-making over time as they have always taken advice of clinicians	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	1	6.67	2	11.11
Changing over time as they are more aware of their health, responsibilities and/or limitations	5	15.15	0	0.00	0	0.00	5	31.25	5	19.23	0	0.00	0	0.00	5	27.78
Changing over time as they are more informed and/or more assertive	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11

Decision-making over time (reasons)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
No change in decision-making over time and there is no particular reason noted	6	18.18	5	26.32	1	7.14	3	21.43	3	15.79	2	14.29	4	21.05
No change in decision-making over time as they have always been informed/assertive	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
No change in decision-making over time as they have always taken advice of clinicians	3	9.09	0	0.00	3	21.43	0	0.00	3	15.79	0	0.00	3	15.79
Changing over time as they are more aware of their health, responsibilities and/or limitations	5	15.15	2	10.53	3	21.43	3	21.43	2	10.53	3	21.43	2	10.53
Changing over time as they are more informed and/or more assertive	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	2	14.29	2	10.53

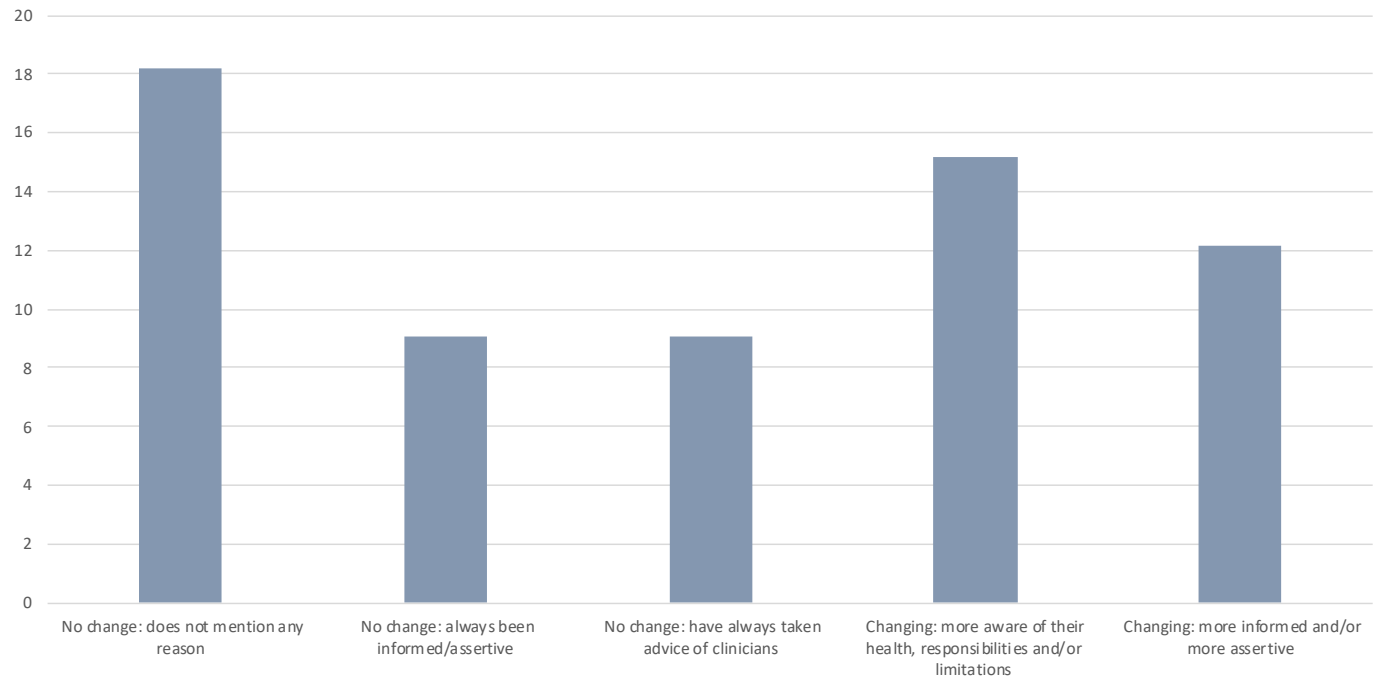

Figure 4.5: Decision-making over time (descriptions)

Table 4.10: Decision-making over time (descriptions)

Decision-making over time (reasons)	Reported less frequently	Reported more frequently
No change in decision-making over time and there is no particular reason noted	Diffuse Large B-Cell Lymphoma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)
No change in decision-making over time as they have always been informed/assertive	-	Diffuse Large B-Cell Lymphoma
No change in decision-making over time as they have always taken advice of clinicians	-	Aged 65 or older
Changing over time as they are more aware of their health, responsibilities and/or limitations	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Changing over time as they are more informed and/or more assertive	Aged 65 or older	-

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 be cancer free, avoid recurrence, increase longevity (45.45%), have quality of life/return to normality (27.27%), and have physical improvements in their condition (21.21 %). Other themes included to minimise or avoid side effects (15.15%), maintain their condition or prevent worsening of their condition (12.12%), and not having treatment goals as they are satisfied or their condition has little impact on life (9.09%).

Participants describe wanting to be cancer free, avoid recurrence or increase longevity

I hope it doesn't come back so I don't have to have that chemotherapy again.
Participant 011_2023AUCRT

My goals in treatment is to hopefully I can stay healthy enough that should they have another breakthrough in a drug or one of those things that is little in my view at that particular period of time wasn't available wasn't the PBS, it was available not on the PBS and so. As time goes by, there'll be better products coming out on the market that will hopefully look after my condition. There is a Car T cell, which is extremely expensive.
Participant 018_2023AUCRT

Yeah, I have nothing else in my mind, but just to be cancer free and to to prolong my lifespan. I mean, it's just nothing more, nothing less than that.
034_2023AUCRT

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

I'm quite independent, just like to get back to more strength, like to be able to do participate more range of activities which I was doing before…I must admit, because that's surprisingly apart from when I was undergoing treatment, I would have times when I was unwell and would have a fever, but I haven't actually caught anything in between other than that and I've managed to go. So this is a bit of a shock. Yeah, really, really annoying. And so sort of just when I was feeling like I was doing more exercise, but I'm starting to get stage where I was walking. You know, we walk every day and at least do 5 to 10 KS. And yeah, and I was just starting to do more stretching and thinking about getting back into light weights or doing some more, we've done a little bit of bike riding things. My next step was really just to go, having recovered from being very weak…going to the next being more stronger overall, I guess.
Participant 021_2023AUCRT

Participants describe wanting to see physical improvements in their condition

I think for me personally, obviously, I want to try to retain optimum health. I've still got my strength because I still get a little bit tired from time to time. Obviously, reducing medications that I'm on.
Participant 002_2023AUCRT

Now you say, yeah, yeah, look, there's definitely a limitation with what I'm at. Yeah, it's probably reduced probably by about 60% only probably the last last three to four years, up until four years ago. The the transplant, yeah, it was, you know, wasn't too bad. Fairly head stocked first and mind you, yeah and yeah, but the last four years has certainly been challenging and you just want to improve.
Participant 026_2023AUCRT

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

The difficulty also is what what are effects from cancer... So it's a bit hard to sort things like energy levels, fatigue levels. Even some of the sort of nerve painy stuff. So it it's a very complex thing and I'm not sure I can never be certain about what it is. Yeah. So I think the the complication of that makes my experience of daily living. A little bit more hard to deal with, I suppose.
Participant 009_2023AUCRT

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

Yeah, he gave me the statistics, which weren't good because I had, as you know... So he just suggested to, oh, because I was pretty fit. It was probably the fittest I've ever been, which was in my favor. And he just suggested keeping away from people and restaurants and, you know, don't go out to places where there's sort of with no immunity just to keep yourself healthy and away from other implications that could affect my health, basically. That's about it.
Participant 024_2023AUCRT

Well, I don't really have, I mean I've got side effects like brain brain fog and some neuropathy, but that's manageable. So I I don't, I choose not to pursue anything else for treatment and they are you know the treatment will. As far as I can see, we'll just keep going and then the longer I maintain almost remission sort of level of cancer, I think by the time I need something else, there'll be something equally less invasive around the the third line of treatment.
Participant 032_2023AUCRT

Participant describes no treatment goals as they are satisfied or their condition has little impact on life

In terms of the in terms of the cancer, it oh okay, one of my bloods, the various components, some of them are not that good. And so I always blame them that I can't walk uphill as fast or without puffing as I used to do but a lot of that could be because of advancing years. But look, that's the really the only effect I noticed. I live a full and contented life…so in that sense, the cancer doesn't affects me very, very little.
Participant 013_2023AUCRT

Well, I don't really. As I said before, I think it's there and it's it's just in the background, it's quiet, it's not doing anything to me when we're monitoring it now every three months. Originally it was every month and I don't really think about it, so I don't. I don't have any goals. I don't see it as a now as something that's really relevant in my in my life.
Participant 014_2023AUCRT

Table 4.11: Personal goals of treatment or care

Personal goals of treatment or care	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	15	45.45	3	42.86	5	50.00	7	43.75	12	46.15	3	42.86	8	53.33	7	38.89
Participant describes wanting to improve their quality of life or return to normality	9	27.27	1	14.29	3	30.00	5	31.25	6	23.08	3	42.86	5	33.33	4	22.22
Participants describe wanting to see physical improvements in their condition	7	21.21	3	42.86	2	20.00	2	12.50	4	15.38	3	42.86	5	33.33	2	11.11
Participant describes wanting to minimise or avoid side effects of treatment for their condition	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	4	26.67	1	5.56
Participant describes wanting to maintain their condition/prevent worsening of their condition	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	0	0.00	3	16.67

Personal goals of treatment or care	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	5	35.71	10	52.63
Participant describes wanting to improve their quality of life or return to normality	9	27.27	7	36.84	2	14.29	5	35.71	4	21.05	5	35.71	4	21.05
Participants describe wanting to see physical improvements in their condition	7	21.21	5	26.32	2	14.29	2	14.29	5	26.32	3	21.43	4	21.05
Participant describes wanting to minimise or avoid side effects of treatment for their condition	5	15.15	4	21.05	1	7.14	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes wanting to maintain their condition/prevent worsening of their condition	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	3	9.09	0	0.00	3	21.43	1	7.14	2	10.53	1	7.14	2	10.53

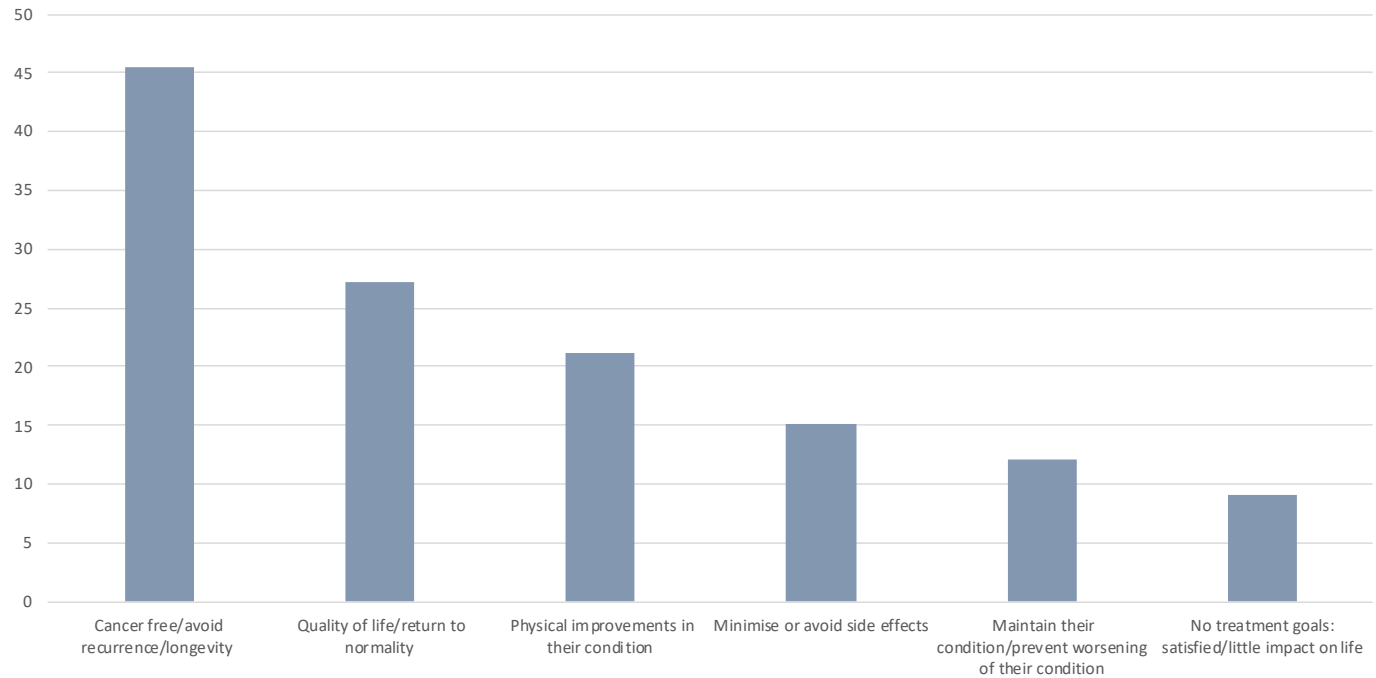

Figure 4.6: Personal goals of treatment or care

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

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	Aged 65 or older	Aged 25 to 64
Participant describes wanting to improve their quality of life or return to normality	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older	CAR T-Cell therapy
Participants describe wanting to see physical improvements in their condition	Male	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Female
Participant describes wanting to minimise or avoid side effects of treatment for their condition	-	Female
Participant describes no treatment goals as they are satisfied or their condition has little impact on life	-	Aged 65 or older

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 haematologists (n=26,76.47 %), followed by general practitioners (GP)s (n=4, 11.76%).

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 (20.69%) that travelled for less than 15 minutes, 12 participants (41.38%) that travelled between 15 and 30 minutes, 6 participants (20.69%) that travelled between 30 and 60 minutes, 1 participants (3.45%) that travelled between 60 and 90 minutes, and 4 participants (13.79%) that travelled more than 90 minutes.

Access to healthcare professionals

All participants had access to a haematologist (n=36, 100.00%), and almost a third had a medical oncologist (n=11, 30.56%), and a radiation oncologist (n=11, 30.56%).

Almost all participants had access to a general practitioner (GP) (n=34, 94.44%), and more than half had access to a chemotherapy nurse (n=21, 58.33%) There were 16 participants (44.44%) that had a registered nurse and 12 participants (33.33%) that had a nurse care coordinator.

Participants noted allied health professionals that treated them for blood cancer, most commonly physiotherapists (n=14, 38.89%), dieticians, counselling or psychological support, and social workers.

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 22 participants (75.86%) that indicated that they had been treated with respect throughout their experience, and 7 participants (24.14%) that were treated with respect with the exception of one or two occasions.

Health care system

The majority of participants had private health insurance (n=23, 67.65%). The majority of participants were asked if they wanted to be treated as a public or private patient (n=20, 58.82%), and they were asked if they had private health insurance (n=27, 79.41%).

Throughout their treatment, there were 5 participants (14.71%) that were treated as a private patient, 21 particpants (61.76%) were mostly treated as a public patient, and there were 6 particpants (17.65%) that were equally treated as a private and public patient.

Throughout their treatment, there were 3 participants (8.82%) that were treated mostly in the private hospital system, 27 particpants (79.41%) were mostly treated in the public system, and there were 4 particpants (11.76%) that were equally treated in the private and public systems.

Affordability of healthcare

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

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. All participants never or rarely had to delay or cancel appointments due to affordability (n = 34, 100.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=33, 97.06%).

Cost of condition

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

The most common amount was between $51 to 100 (n=4, 11.76%), followed by between $101 to 250 (n=7, 20.59%). There were 2 participants (5.88%), that spent $501 to 1000 a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 8 participants (23.53%), somewhat significant for 6 participants (17.65%), and slightly or not at all significant for 20 participants (58.82%).

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 (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 3 participants (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 8 participants (23.53%), 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=3, 8.82%). There were 6 participants (17.65%)

whose partners reduced the numbers of hours they worked, and 3 partners, (8.82%) that quit their job. The partners of 9 participants (26.47%) took leave without pay, and there were 4 partners (11.76%) that took leave with pay.

Reduced income due to condition

Half of the participants (n=17, 50.00%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=7, 20.59%), or monthly income was reduced by between $101 to 250 per month (n=7, 20.59%).

Burden of reduced income

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

For 6 of these participants (25.00%), the burden of this reduced income was extremely or moderately significant, for 7 participants (29.17%) the burden was somewhat significant, and for 11 participants (45.83%) the burden was slightly or not all significant.

Summary of treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was.

The most common types of treatments were stem cell transplants, (n=25, 71.43%), radiotherapy (n=13,37.14%), maintenance chemotherapy (n=10,28.57%), CAR T-cell therapy (n=8, 22.86%), Lenalidomide and dexamethasone (n=7, 20.00%), Zoledronic acid (n=7, 20.00%), CyBorD (Cyclophosphamide, bortezomib, dexamethasone) (n=6, 17.14%), R-CHOP (rituximab cyclophosphamide, doxorubicin, vincristine and prednisolone) (n=5, 14.29%), and Blood and platelet transfusions (n=5, 14.29%).

Participants reported having CVAD plus Imatinib: (Imatinib, Vincristine, Doxorubicin, Dexamethasone , Cytarabine, Methotrexate, and Cyclophosphamide) (n=2), or were not sure of the type (n=2) as induction therapy.

Participants reported having ALL06: Vincristine, Doxorubicin, Dexamethasone, Cytarabine, Pegaspargase, Mercaptopurine, Methotrexate, Cyclophosphamide, and Thioguanine (n=1), or were not sure of the type (n=2) as consolidation therapy.

Participants reported having Lenalidomide (n=7), CALGB: Prednisone, Vincristine, Mercaptopurine and Methotrexate (n=1) or were not sure of the type (n=2) as maintenance therapy.

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them.

Most participants used at least one type of allied health service (n=22, 64.71%), and on average used 1 service (median=1.00, IQR=2.00).

The most common allied health service used was physiotherapy (n=14, 41.18%), followed by dietary (n=11, 32.35%), and psychology/counselling (n=7, 20.59%). There were 7 participants (20.59%) that saw a social worker, 4 participants (11.76%) that saw a podiatrist, and 2 participants (5.88%) that saw a occupational therapist.

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=29, 85.29%), and on average made 2 changes (median=2.00, IQR=2.00).

The most common lifestyle change was exercise (n=22, 64.71%), followed by diet changes (n=17, 50.00%), and reducing or cutting out alcohol (n=17, 50.00%).

Complementary therapies

Participants were asked about complementary therapies they used, the quality of life from these therapies and how effective they found them.

Most participants used at made at least one complementary therapy (n=17, 50.00%), and on average used 0.5 therapies (median=0.50, IQR=2.00).

The most common complementary therapy used was Mindfulness or relaxation techniques (n=12, 35.29%), followed by Massage therapy (n=8, 23.53%), and Supplements (n=7, 20.59%).

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 17 participants (50%) that had discussions about clinical trials, 5 participants (14.71%) had brought up the topic with their doctor, and the doctor of 12 participants (35.29%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=17, 50.00%).

Clinical trial participation

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

There were 7 participants (20.59%) that had taken part in a clinical trial, 24 participants (70.59%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participanted in a clinical trial and do not want to (8.82%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were described using a specific example (69.70%), those that do not interfere with life(30.30%), and those that can be managed with self-medication or self-management (9.09 %).

When a specific side effect was described, the most common responses were aches and pain in general (18.18%), and fatigue or lethargy (18.18%). Other themes included gastrointestinal distress (15.15%), headaches (15.15%), nausea or loss of appetite (12.12%), and neuropathy (9.09%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’.
The most common description of severe side effects were described using a specific example (78.79%), and those that requires medical intervention (30.30%). Other themes included those that impact everyday life or ability to conduct activities of daily living (15.15%), and those that impact their everyday life by being bed ridden (9.09%).

When a specific side effect was described, the most common examples were nausea or loss of appetite (30.30%), aches and pain in general (24.24%), and fatigue or lethargy (15.15 %). Other themes included gastrointestinal distress (12.12%), emotional or mental impact (9.09%), impact on sleep (9.09%), neuropathy (9.09%), and swelling from fluid build up including lymphoedema (9.09%).

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 (75.76%), and never giving up on any treatment (39.39%). Other themes included adhering to treatment as long as side effects are tolerable (12.12%), needing to see test results/no evidence or reduction of disease (12.12%),adhering to treatment as long as treatment is working (9.09%), and adhering to treatment for a specific amount of time (9.09%).

When participants stated a specific amount of time to adhere to a treatment, the amount of time specified was one month (3.03%), six to twelve months(3.03%), and six to twelve months (3.03 %).

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 evidence of stable disease or no disease progression (39.39%), and needing to see physical signs and symptoms disappear or reduced side effects (33.33%). Other themes included needing to see a specific symptom reduction (27.27%), and needing to see a return to day-to-day functionality (15.15%).

When a specific side effect or symptom was described, the most common examples were aches and pain in general (12.12%), and fatigue or lethargy (12.12%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (42.42%), and that it would have a positive impact on their mental health (24.24%). Other themes included allowing them to do more exercise (18.18%), allowing them to return to work (12.12%), and allowing them to engage more with social activities and family life (12.12%).

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 haematologists (n=26,76.47 %), followed by general practitioners (GP)s (n=4, 11.76%).

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 (20.69%) that travelled for less than 15 minutes, 12 participants (41.38%) that travelled between 15 and 30 minutes, 6 participants (20.69%) that travelled between 30 and 60 minutes, 1 participants (3.45%) that travelled between 60 and 90 minutes, and 4 participants (13.79%) that travelled more than 90 minutes.

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=34)	Percent
Haematologist	26	76.47
General practitioner (GP)	4	11.76
Oncologist	2	5.88
Other	2	5.88

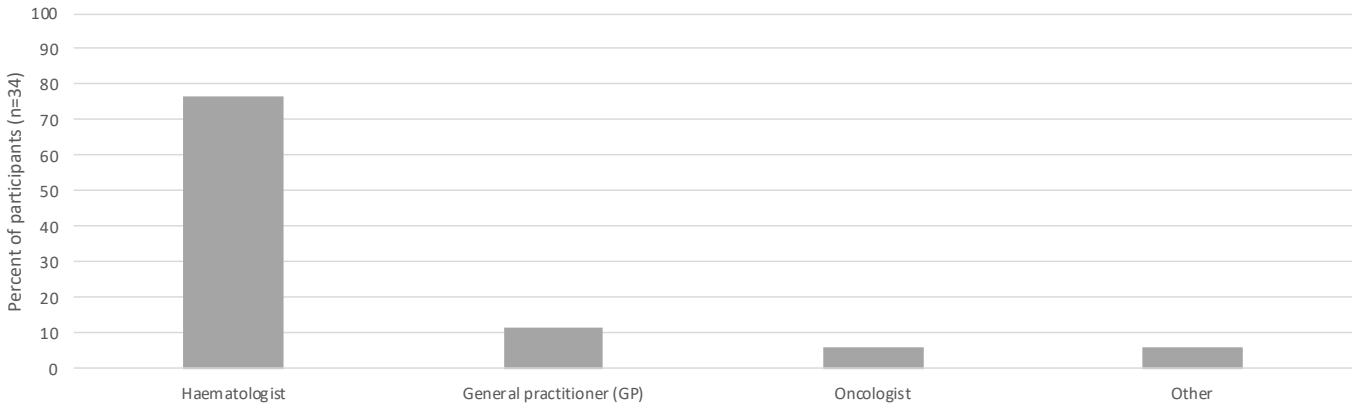

Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Time to travel to main provider of treatment	Number (n=29)	Percent
Less than 15 minutes	6	20.69
Between 15 and 30 minutes	12	41.38
Between 30 and 60 minutes	6	20.69
Between 60 and 90 minutes	1	3.45
More than 90 minutes	4	13.79

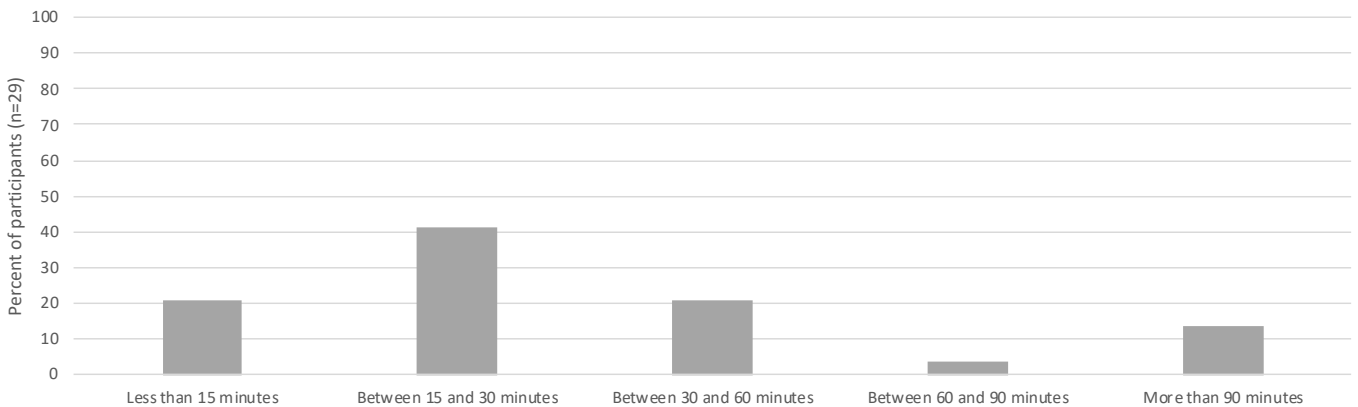

Figure 5.2: Time to travel to main provider of treatment

Access to healthcare professionals

All participants had access to a haematologist (n=36, 100.00%), and almost a third had a medical oncologist (n=11, 30.56%), and a radiation oncologist (n=11, 30.56%).

Almost all participants had access to a general practitioner (GP) (n=34, 94.44%), and more than half had access to a chemotherapy nurse (n=21, 58.33%) There were 16 participants (44.44%) that had a registered nurse and 12 participants (33.33%) that had a nurse care coordinator.

Participants noted allied health professionals that treated them for blood cancer, most commonly physiotherapists (n=14, 38.89%), dieticians, counselling or psychological support, and social workers.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=36)	Percent
Haematologist	36	100.00
Medical Oncologist	11	30.56
Radiation Oncologist	11	30.56
Cardiologist	2	5.56
Respiratory Physician	1	2.78
Surgeon	1	2.78
General Practitioner (GP)	34	94.44
Chemotherapy nurse	21	58.33
Registered Nurse	16	44.44
Nurse Care Coordinator	12	33.33
Haematology nurse	6	16.67
Community nurse	5	13.89
Physiotherapist	14	38.89
Dietician	11	30.56
Counselling or psychological support	11	30.56
Social worker	7	19.44
Pharmacist	6	16.67
Cancer care coordinator, discharge planner or key worker	4	11.11
Occupational therapist	4	11.11
Exercise Physiologist	2	5.56
Chiropractor	1	2.78
Weight loss specialist	1	2.78

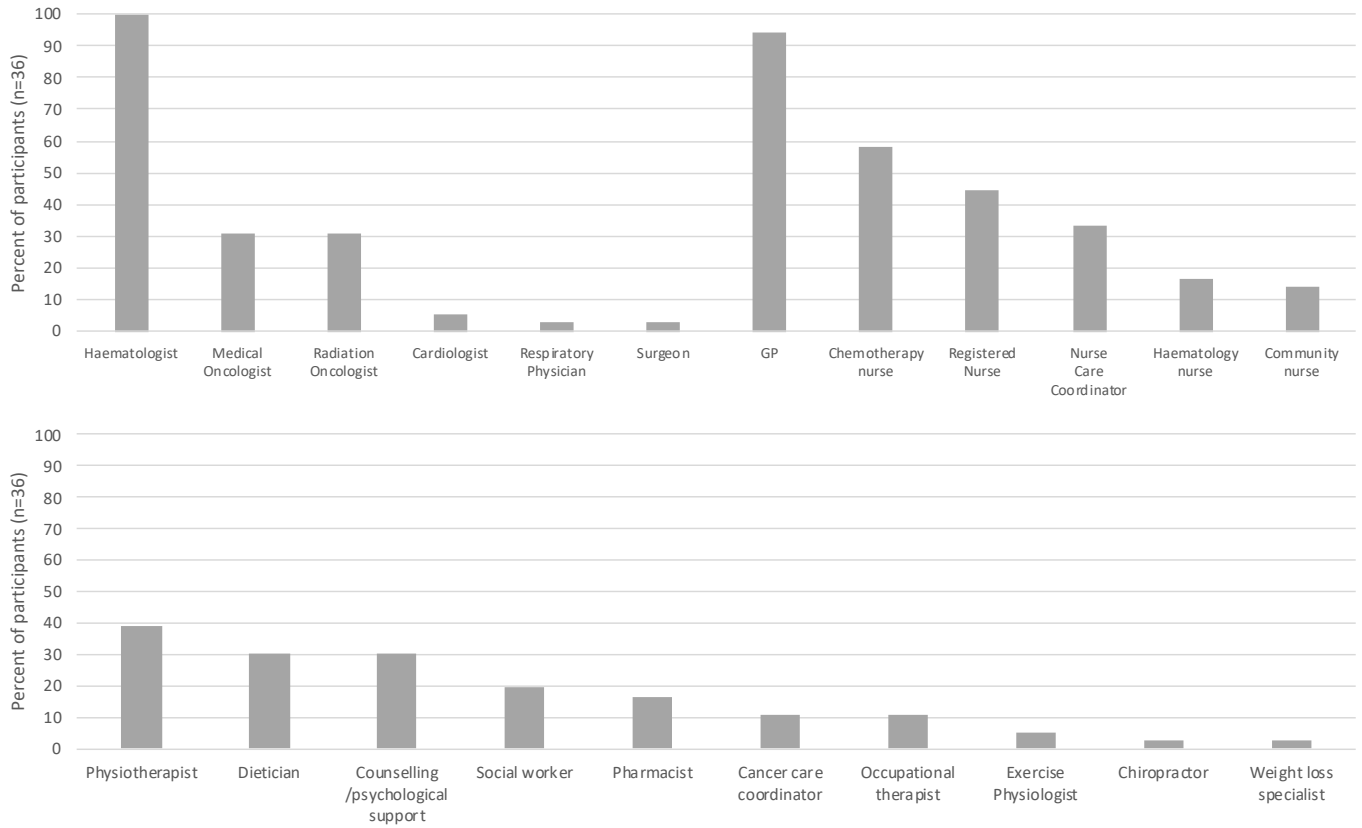

Figure 5.3: Access to healthcare professionals

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 22 participants (75.86%) that indicated that they had been treated with respect throughout their experience, and 7 participants (24.14%) that were treated with respect with the exception of one or two occasions.

Table 5.4: Respect shown

Respect shown	Number (n=29)	Percent
Yes	22	75.86
Yes, with the exception of one or two occasions	7	24.14
No	0	0.00

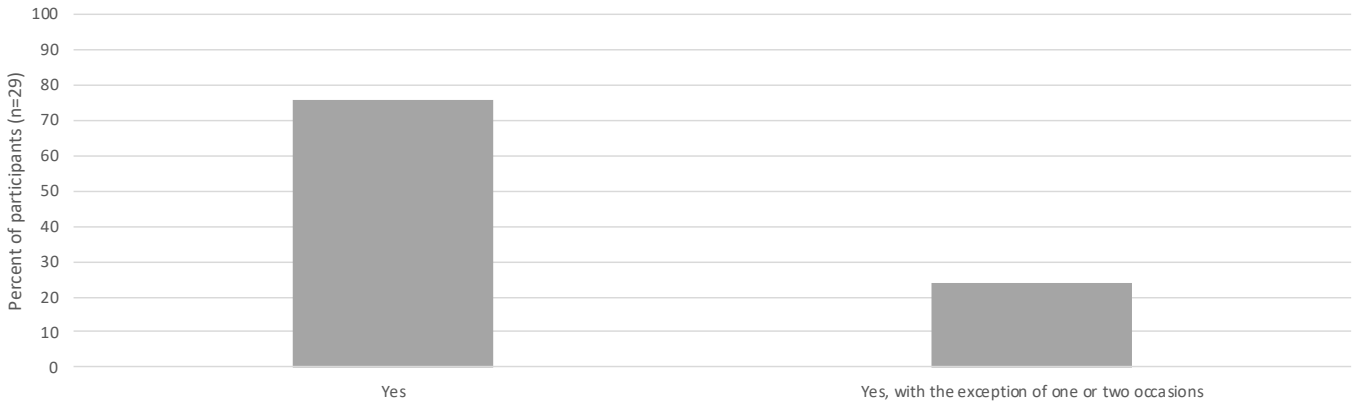

Figure 5.4: Respect shown

Health care system

The majority of participants had private health insurance (n=23, 67.65%). The majority of participants were asked if they wanted to be treated as a public or private patient (n=20, 58.82%), and they were asked if they had private health insurance (n=27, 79.41%).

Throughout their treatment, there were 5 participants (14.71%) that were treated as a private patient, 21 particpants (61.76%) were mostly treated as a public patient, and there were 6 particpants (17.65%) that were equally treated as a private and public patient.

Throughout their treatment, there were 3 participants (8.82%) that were treated mostly in the private hospital system, 27 particpants (79.41%) were mostly treated in the public system, and there were 4 particpants (11.76%) that were equally treated in the private and public systems.

Table 5.5: Health care system

Health care system	Response	Number (n=34)	Percent
Private health insurance	No	11	32.35
	Yes	23	67.65
Asked whether you want to be treated as a public or private patient	No	14	41.18
	Yes	20	58.82
Asked whether you had private health insurance	No	7	20.59
	Yes	27	79.41
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	6	17.65
	Private patient	5	14.71
	Public patient	21	61.76
	Not sure	2	5.88
Which hospital system have you primarily been treated in	Both public and private	4	11.76
	Private	3	8.82
	Public patient	27	79.41
	Not sure	0	0.00

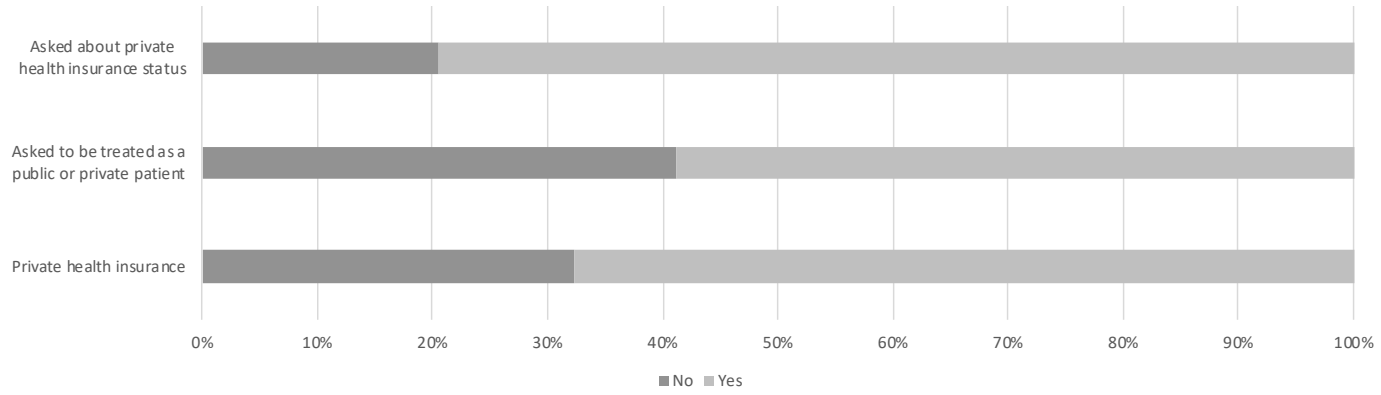

Figure 5.5: Health insurance

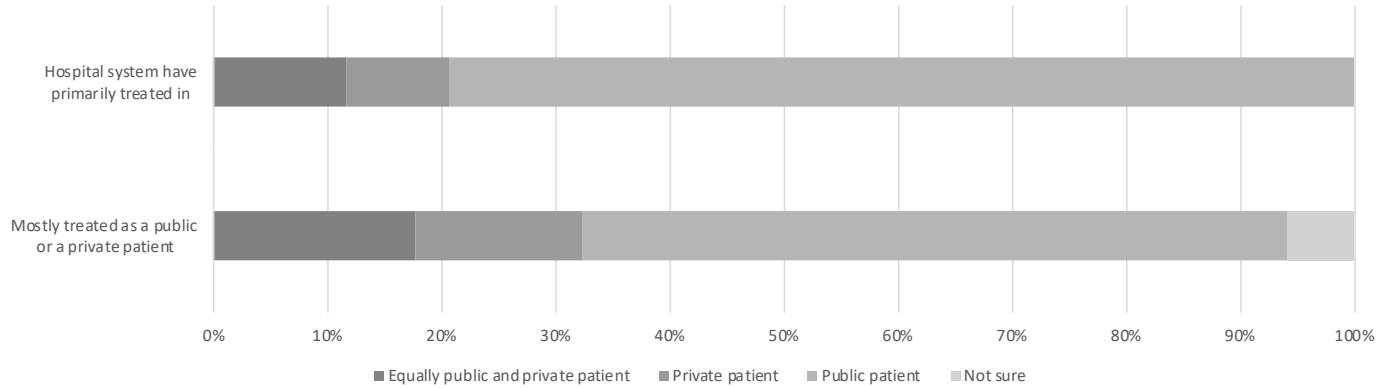

Figure 5.6: Hospital system

Affordability of healthcare

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

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. All participants never or rarely had to delay or cancel appointments due to affordability (n = 34, 100.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=33, 97.06%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 26 participants (76.47%) that never or rarely had trouble paying for essentials, and 6 participants (17.65%) that sometimes found it difficult, and 2 participants (5.88%) 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 4 participants (11.76%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=34)	Percent
Delay or cancel healthcare appointments due to affordability	Never	29	85.29
	Rarely	5	14.71
	Sometimes	0	0.00
	Often	0	0.00
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	29	85.29
	Rarely	4	11.76
	Sometimes	1	2.94
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	23	67.65
	Rarely	3	8.82
	Sometimes	6	17.65
	Often	0	0.00
	Very often	2	5.88
Pay for additional carers for self or family	Yes	4	11.76
	No	30	88.24

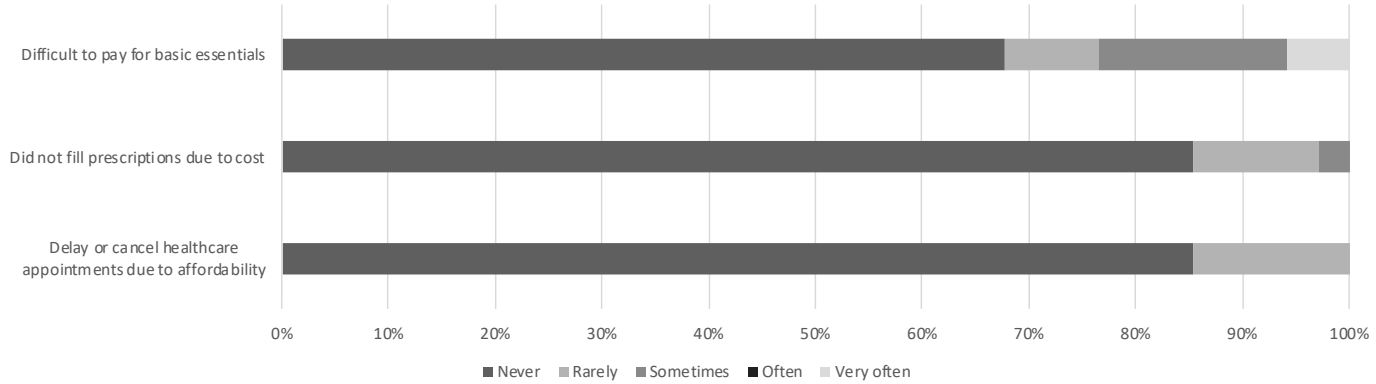

Figure 5.7: Affordability of healthcare

Cost of condition

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

The most common amount was between $51 to 100 (n=4, 11.76%), followed by between $101 to 250 (n=7, 20.59%). There were 2 participants (5.88%), that spent $501 to 1000 a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 8 participants (23.53%), somewhat significant for 6 participants (17.65%), and slightly or not at all significant for 20 participants (58.82%).

Table 5.7: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=34)	Percent
0	2	5.88
$1 to 50	4	11.76
$51 to 100	4	11.76
$101 to 250	7	20.59
$251 to 500	5	14.71
$501 to 1000	2	5.88
$1001 or more	3	8.82
Not sure/not specified	7	20.59

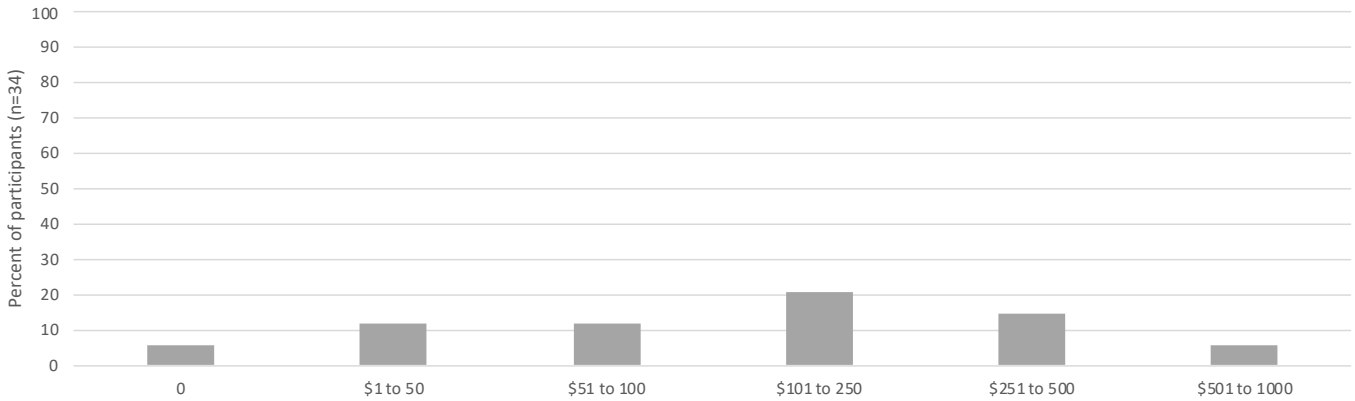

Figure 5.8: Estimated monthly out of pocket expenses due to condition

Table 5.8: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=34)	Percent
Extremely significant	7	20.59
Moderately significant	1	2.94
Somewhat significant	6	17.65
Slightly significant	10	29.41
Not at all significant	10	29.41

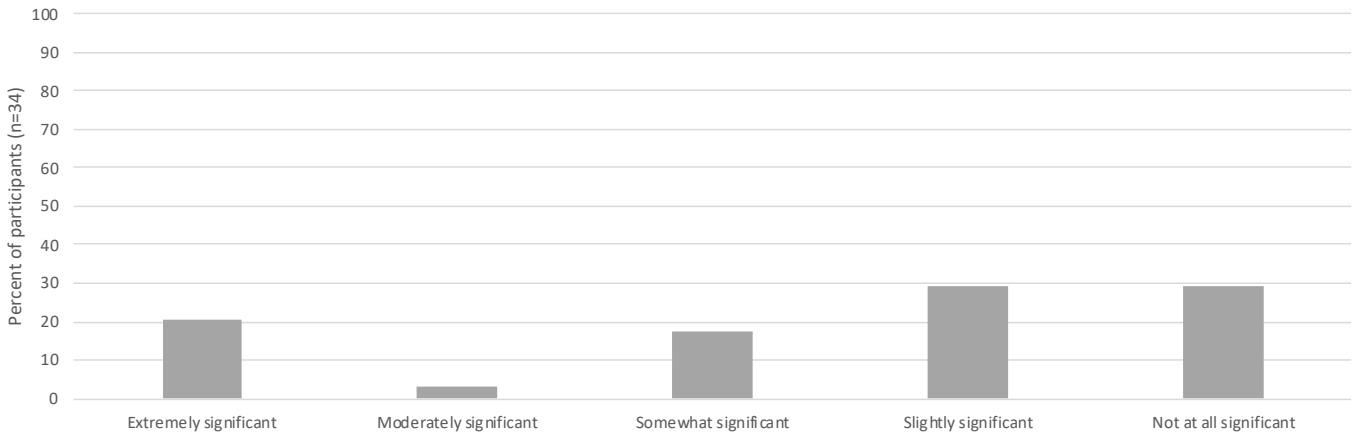

Figure 5.9: Burden of out-of-pocket expenses due to condition

Changes to employment status

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 (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 8 participants (23.53%), 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=3, 8.82%). There were 6 participants (17.65%) whose partners reduced the numbers of hours they worked, and 3 partners, (8.82%) that quit their job. The partners of 9 participants (26.47%) took leave without pay, and there were 4 partners (11.76%) that took leave with pay.

Table 5.9: Changes to employment status

Changes in work status due to condition	Number (n=34)	Percent
Work status has not changed	3	8.82
Retired or did not have a job	7	20.59
Had to quit job	11	32.35
Reduced number of hours worked	7	20.59
Leave from work without pay	9	26.47
Leave from work with pay	6	17.65
Accessed Superannuation early due to condition	6	17.65

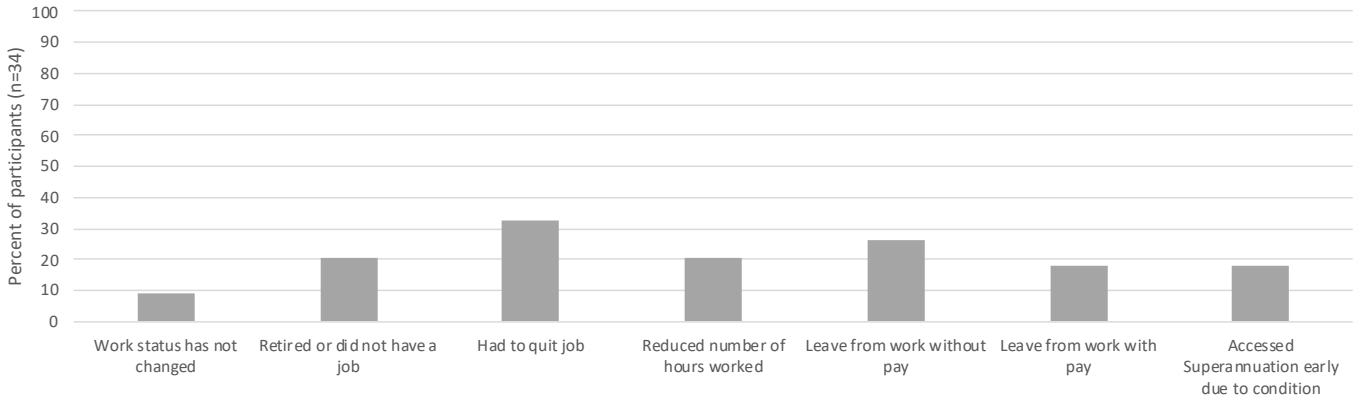

Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=34)	Percent
Does not have a partner/main carer	8	23.53
Work status has not changed	3	8.82
Retired or did not have a job	8	23.53
Had to quit job	3	8.82
Reduced number of hours worked	6	17.65
Leave from work without pay	9	26.47
Leave from work with pay	4	11.76

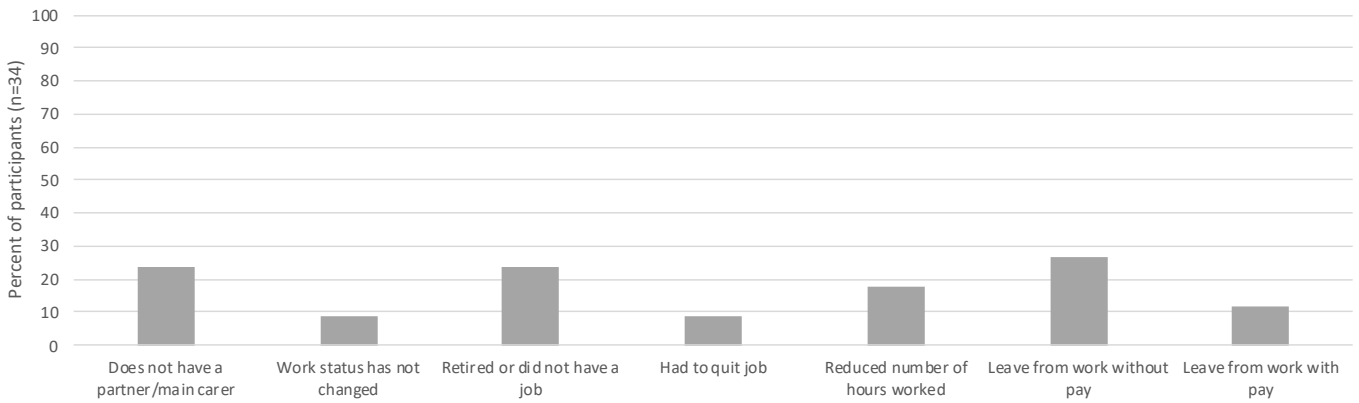

Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

Half of the participants (n=17, 50.00%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=7, 20.59%), or monthly income was reduced by between $101 to 250 per month (n=7, 20.59%).

Burden of reduced income

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

For 6 of these participants (25.00%), the burden of this reduced income was extremely or moderately significant, for 7 participants (29.17%) the burden was somewhat significant, and for 11 participants (45.83%) the burden was slightly or not all significant.

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=34)	Percent
$0	10	29.41
$1000 to 2499	5	14.71
$2500 to 4999	4	11.76
$5000 to 9999	2	5.88
$10000 or more	6	17.65
Not sure/not specified	7	20.59

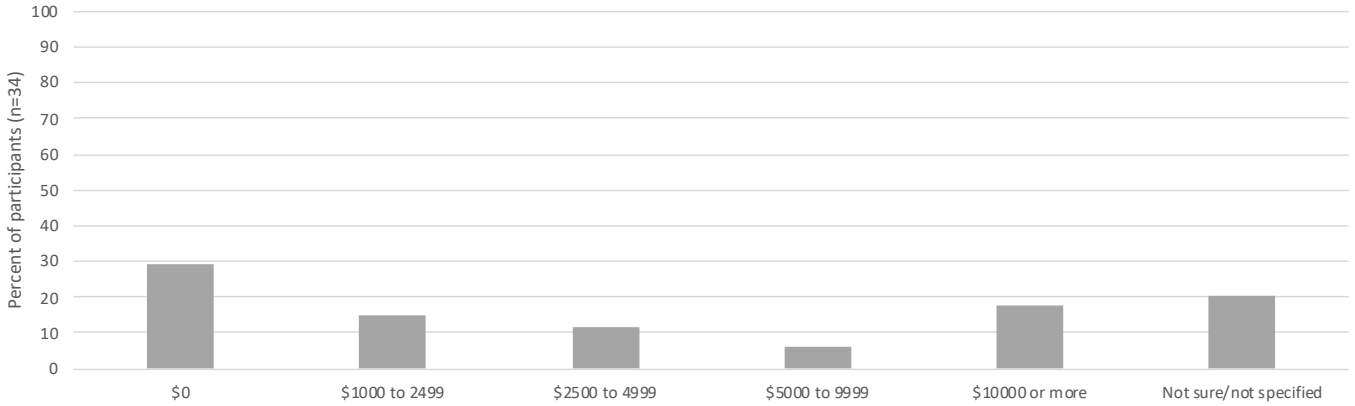

Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced monthly income	Number (n=24)	Percent
Extremely significant	8	33.33
Moderately significant	3	12.50
Somewhat significant	7	29.17
Slightly significant	5	20.83
Not at all significant	1	4.17

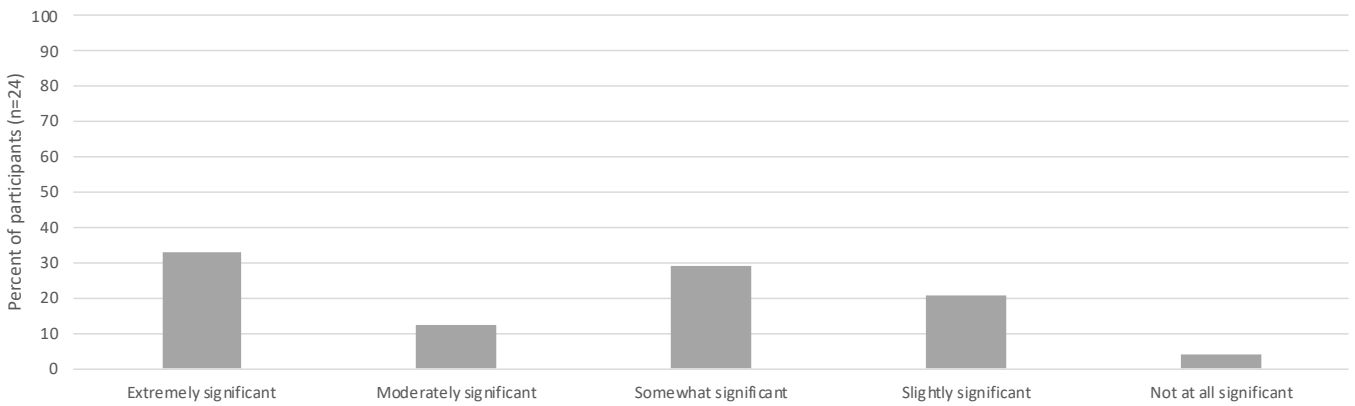

Figure 5.13: Burden of reduced income

Summary of treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was.

The most common types of treatments were stem cell transplants, (n=25, 71.43%), radiotherapy (n=13,37.14%), maintenance chemotherapy (n=10,28.57%), CAR T-cell therapy (n=8, 22.86%), Lenalidomide and dexamethasone (n=7, 20.00%), Zoledronic acid (n=7, 20.00%), CyBorD (Cyclophosphamide, bortezomib, dexamethasone) (n=6, 17.14%), R-CHOP (rituximab cyclophosphamide, doxorubicin, vincristine and prednisolone) (n=5, 14.29%), and Blood and platelet transfusions (n=5, 14.29%).

Participants reported having CVAD plus Imatinib: (Imatinib, Vincristine, Doxorubicin, Dexamethasone , Cytarabine, Methotrexate, and Cyclophosphamide) (n=2), or were not sure of the type (n=2) as induction therapy.

Participants reported having ALL06: Vincristine, Doxorubicin, Dexamethasone, Cytarabine, Pegaspargase, Mercaptopurine, Methotrexate, Cyclophosphamide, and Thioguanine (n=1), or were not sure of the type (n=2) as consolidation therapy.

Participants reported having Lenalidomide (n=7), CALGB: Prednisone, Vincristine, Mercaptopurine and Methotrexate (n=1) or were not sure of the type (n=2) as maintenance therapy.

Quality of life and effectiveness was calculated for treatments where 5 or more participants had the treatment. 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”. Values are calculated where there was adequate data available. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective.

On average, quality of life from Stem cell transplants was in the 'life was distressing' range (median=2.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=0.75).

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

On average, quality of life from Maintenance chemotherapy was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=0.50).

On average, quality of life from Car-T therapy was in the 'life was a little distressing' range (median=3.00, IQR=0.75), and was found to be very effective (median=5.00 , IQR=0.25).

On average, quality of life from Lenalidomide and dexamethasone was in the 'life was a little distressing' range (median=4.00, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=2.25).

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

On average, quality of life from CyBorD was in the 'life was average' range (median=4.00, IQR=0.75), and was found to be effective to very effective (median=4.50 , IQR=1.75).

On average, quality of life from R-CHOP was in the 'life was a little distressing' range (median=3.00, IQR=1.00), and was found to be moderatley effective (median=3.00 , IQR=3.00).

On average, quality of life from blood and platelet transfusions was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=1.00).

Table 5.13: Overview of treatments

Drug treatments	Number (n=35)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Stem cells	25	71.43	2.00	2.00	5.00	0.75
Radiotherapy	13	37.14	4.00	2.00	5.00	1.00
Maintenance chemotherapy	10	28.57	4.00	2.00	5.00	0.50
Car-T therapy	8	22.86	3.00	0.75	5.00	0.25
Lenalidomide and dexamethasone	7	20.00	4.00	2.00	2.50	2.25
Zoledronic acid	7	20.00	5.00	1.00	4.00	1.00
CyBorD	6	17.14	4.00	0.75	4.50	1.75
R-CHOP	5	14.29	3.00	1.00	3.00	3.00
Blood and platelet transfusions	5	14.29	3.00	2.00	5.00	1.00
Induction chemotherapy	4	11.43	NA	NA	NA	NA
Corticosteroids	4	11.43	NA	NA	NA	NA
Antibiotics	4	11.43	NA	NA	NA	NA
ICE	3	8.57	NA	NA	NA	NA
Consolidation	2	5.71	NA	NA	NA	NA
Hyper-CVAD	2	5.71	NA	NA	NA	NA
DVd	2	5.71	NA	NA	NA	NA
Kd (Carfilzomib and dexamethasone)	2	5.71	NA	NA	NA	NA
MPB (Melphalan, prednisolone, bortezomib)	2	5.71	NA	NA	NA	NA
Pomalidomide and dexamethasone	2	5.71	NA	NA	NA	NA
Pamidronate	2	5.71	NA	NA	NA	NA
Chemotherapy for recurrence	1	2.86	NA	NA	NA	NA
DA-R-EPOCH	1	2.86	NA	NA	NA	NA
KCd	1	2.86	NA	NA	NA	NA
Sd (Selinexor and dexamethasone)	1	2.86	NA	NA	NA	NA
Methotrexate	1	2.86	NA	NA	NA	NA
Daratumumab	1	2.86	NA	NA	NA	NA
Immunoglobulin infusions	1	2.86	NA	NA	NA	NA

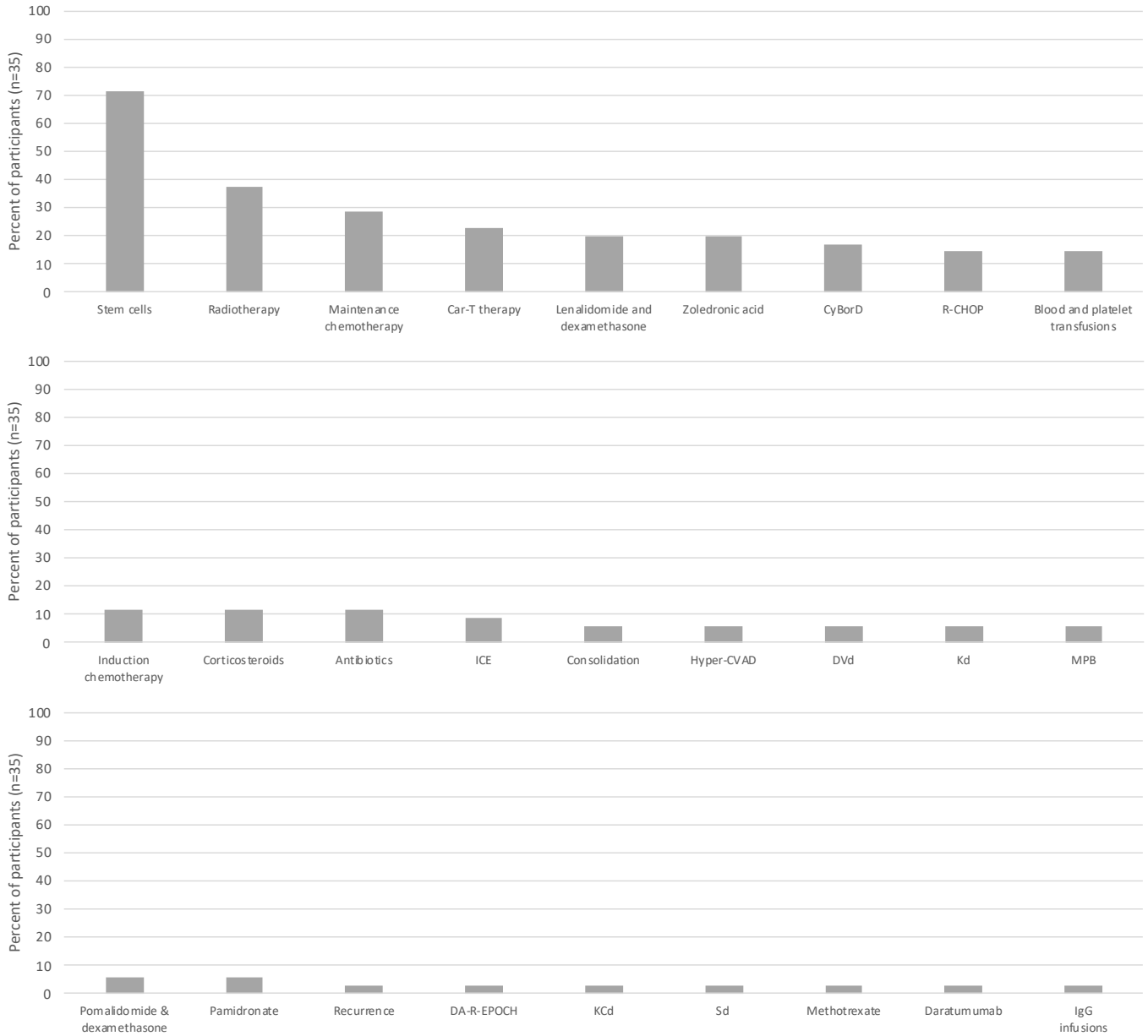

Figure 5.14: Overview of treatments

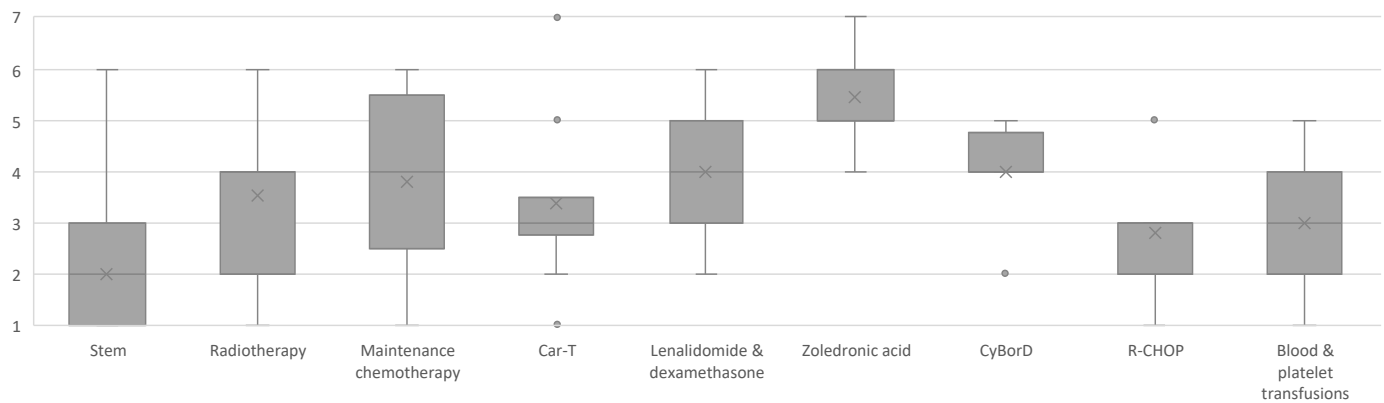

Figure 5.15: Quality of life from drug treatments

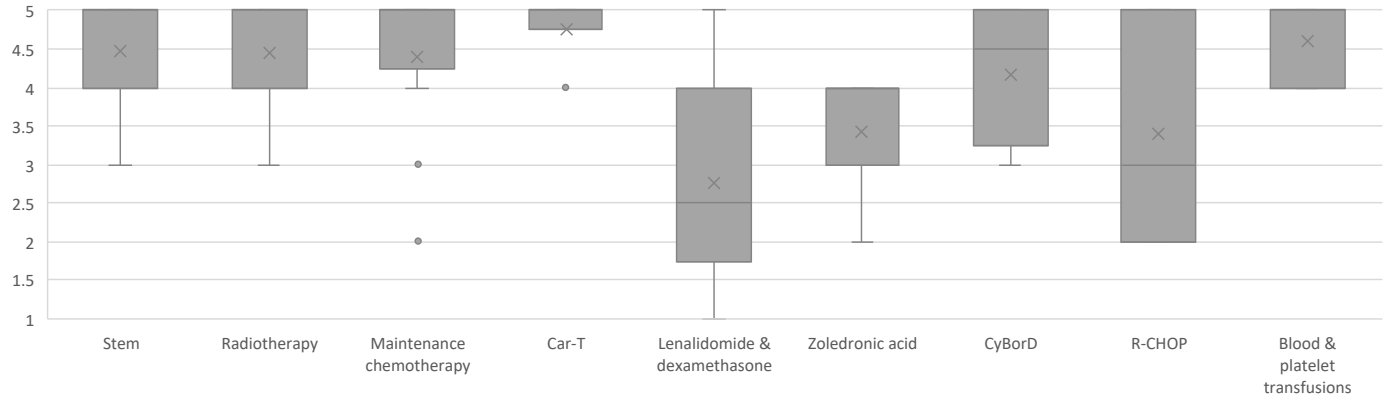

Figure 5.16: Effectiveness of drug treatments

Table 5.14: Detailed summary of drug treatments taken by 5 or more participants

Treatment details	Stem cells			Radiotherapy			Maintenance chemotherapy		
		n=25	%		n=13	%		N=10	%
Median quality of life		2.00			4.00			4	
IQR quality of life		2.00			2.00			2	
Median effectiveness		5.00			5.00			5	
IQR effectiveness		0.75			1			0.5	
2020 to 2023		10	40.00		5	38.46		7	70.00
2015 to 2020		11	44.00		3	23.08		0	0.00
before 2015		3	12.00		4	30.77		1	10.00
Not specified		1	4.00		1	7.69		2	20.00
Treatment finished as planned or not needed any more		18	72.00		10	76.92		1	10.00
Stopped due to side effects		0	0.00		1	7.69		0	0.00
Taking as prescribed		2	8.00		0	0.00		6	60.00
Stopped as it was not working		0	0.00		0	0.00		1	10.00
Not specified		0	0.00		2	15.38		1	10.00
Side effects	No side effects	2	8.00	No side effects	5	38.46	Feeling tired and weak	8	80.00
	Feeling tired and weak	17	68.00	Fatigue	4	30.77	Diarrhoea or constipation	7	70.00
	Diarrhoea or constipation	16	64.00	Nausea and vomiting	3	23.08	Trouble sleeping	7	70.00
	Difficulty eating and drinking	15	60.00	Discomfort when swallowing	2	15.38	Increased risk of infection (drop in white blood cells)	6	60.00
	Increased risk of infection (drop in white blood cells)	14	56.00	Hair loss	2	15.38	Nerve damage (peripheral neuropathy)	5	50.00
	Weight loss	11	44.00	Loss of appetite and weight loss	2	15.38	Chemo brain	3	30.00
	Nasuea and or vomiting	10	40.00	Skin problems (red irritated swollen blistered sunburned tanned)	2	15.38	Loss of appetite	3	30.00
	Breathlessness and looking pale (anemia)	8	32.00	Diarrhoea	1	7.69	Skin: dry skin, rash or itchiness	3	30.00
	Joint and muscle aches	8	32.00	Ferility issues	1	7.69	Stomach upsets	3	30.00
	Sore mouth and ulcers	6	24.00	Mouth pain or ulcers	1	7.69	Breathlessness and looking pale (drop in red blood cells)	2	20.00
	Bruising, bleeding gums or nose bleeds (drop in platelets)	4	16.00	Sexual issues	1	7.69	Changes in taste and smell	2	20.00
	Diarrhoea	4	16.00	Sore mouth	1	7.69	Hair loss or thinning	2	20.00
	Frequent infections	4	16.00	Stiff joints and muscles	1	7.69	Mood swings and behaviour changes	2	20.00
	Tiredness and lack of energy (fatigue)	4	16.00	Swollen limbs	1	7.69	Nasuea and or vomiting	2	20.00
	Bleeding and bruising more easily	3	12.00	Taste and smell changes	1	7.69	Sore mouth and ulcers	2	20.00
	Dizziness or feeling light headed	3	12.00	Tiredness and lack of energy (fatigue)	1	7.69	Weakness, numbness and pain from nerve damage, usually in the hands and feet	2	20.00
	Mouth pain or ulcers	3	12.00				General swelling/build up of fluid	1	10.00
	Nausea and vomiting	3	12.00				Joint and muscle aches	1	10.00
	Headache Irregular heartbeat	2	8.00				Nausea and or vomiting	1	10.00
	Short of breath	2	8.00				Weight gain	1	10.00

Treatment details	Car-T Therapy			Lenalidomide and dexamethasone			Zoledronic acid		
		n=8	%		n=7	%		N=7	%
Median quality of life		3			4			5	
IQR quality of life		0.75			2			1	
Median effectiveness		5			2.5			4	
IQR effectiveness		0.25			2.25			1	
2020 to 2023		8	100.00		4	57.14		3	42.86
2015 to 2020		0	0.00		1	14.29		2	28.57
before 2015		0	0.00		1	14.29			0.00
Not specified		0	0.00		1	14.29		2	28.57
Treatment finished as planned or not needed any more		7	87.50		2	28.57		4	57.14
Stopped due to side effects		0	0.00		1	14.29		0	0.00
Taking as prescribed		1	12.50		2	28.57		1	14.29
Stopped as it was not working		0	0.00		2	28.57		1	14.29
Not specified		0	0.00		0	0.00		2	28.57
Side effects	No side effects	4	50.00	Diarrhoea or constipation	5	71.43	No side effects	4	57.14
	Increased risk of infection (drop in white blood cells)	7	87.50	Feeling tired and weak	5	71.43	Joint and muscle aches	4	57.14
	Fever	3	37.50	Trouble sleeping	5	71.43	Increased risk of infection (drop in white blood cells)	1	14.29
	Blood pressure changes	2	25.00	Nerve damage (peripheral neuropathy)	4	57.14	Nerve damage (peripheral neuropathy)	1	14.29
	Confusion/disorientated	1	12.50	Joint and muscle aches	3	42.86			0.00
	Dizziness	1	12.50	Dizziness or feeling light-headed	2	28.57			0.00
	Headaches	1	12.50	Increased risk of infection (drop in white blood cells)	2	28.57			0.00
	Speech changes	1	12.50	Breathlessness and looking pale (drop in red blood cells)	1	14.29			0.00
				Bruising, bleeding gums or nose bleeds (drop in platelets)	1	14.29			0.00
				General swelling/build up of fluid	1	14.29			0.00
				Mood swings and behaviour changes	1	14.29			0.00
				Nausea and or vomiting	1	14.29			0.00
				Skin: dry skin, rash or itchiness	1	14.29			0.00
				Weight gain	1	14.29			0.00

Treatment details	CyBorD			R-CHOP			Blood and platelet transfusions		
		n=6	%		n=5	%		n=5	%
Median quality of life		4			3			3	
IQR quality of life		0.75			1			2	
Median effectiveness		4.5			3			5	
IQR effectiveness		1.75			3			1	
2020 to 2023		2	33.33		2	40.00		0	0.00
2015 to 2020		2	33.33		2	40.00		0	0.00
before 2015		0	0.00		1	20.00		0	0.00
Not specified		2	33.33		0	0.00		5	100.00
Treatment finished as planned or not needed any more		4	66.67		4	80.00		0	0.00
Stopped due to side effects		0	0.00		0	0.00		0	0.00
Taking as prescribed		1	16.67		0	0.00		0	0.00
Stopped as it was not working		1	16.67		1	20.00		0	0.00
Not specified		0	0.00		0	0.00		5	100.00
Side effects	No side effects	1	16.67	Feeling tired and weak	5	100.00	No side effects	1	20.00
	Trouble sleeping	4	66.67	Hair loss or thinning	5	100.00	Skin rash	3	60.00
	Dizziness or feeling light-headed	2	33.33	Increased risk of infection (drop in white blood cells)	5	100.00	Itching	2	40.00
	Feeling tired and weak	2	33.33	Weakness, numbness and pain from nerve damage, usually in the hands and feet	5	100.00	Chills	1	20.00
	Mood swings and behaviour changes	2	33.33	Chemo brain	4	80.00	Fever	1	20.00
	Weight gain	2	33.33	Nasuea and or vomiting	4	80.00			
	Breathlessness and looking pale (drop in red blood cells)	1	16.67	Diarrhoea or constipation	3	60.00			
	Diarrhoea or constipation	1	16.67	Sore mouth and ulcers	3	60.00			
	General swelling/build up of fluid	1	16.67	Trouble sleeping	3	60.00			
	Nausea and or vomiting	1	16.67	Changes in taste and smell	2	40.00			
	Nerve damage (peripheral neuropathy)	1	16.67	Loss of appetite	2	40.00			
	Skin: dry skin, rash or itchiness	1	16.67	Breathlessness and looking pale (drop in red blood cells)	1	20.00			
	Stomach upsets	1	16.67						

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them.

Most participants used at least one type of allied health service (n=22, 64.71%), and on average used 1 service (median=1.00, IQR=2.00).

The most common allied health service used was physiotherapy (n=14, 41.18%), followed by dietary (n=11, 32.35%), and psychology/counselling (n=7, 20.59%). There were 7 participants (20.59%) that saw a social worker, 4 participants (11.76%) that saw a podiatrist, and 2 participants (5.88%) that saw a occupational therapist.

On average, quality of life from physiotherapy was in the 'life was good' range (median=5.00, IQR = 1.00), and was found to be effective (median=4.00, IQR = 1.75).

On average, quality of life from dietary was in the 'life was average' range (median=4.00, IQR=2.50), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from psychology/counselling was in the 'life was a little distressing' range (median=3.00, IQR=1.00), and was found to be somewhat effect (median=2.00, IQR=1.00).

Table 5.15: Allied health

Allied health	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Physiotherapy	14	41.18	5.00	1.00	4.00	1.75
Dietician	11	32.35	4.00	2.50	4.00	1.00
Psychology/counselling	7	20.59	3.00	1.00	2.00	1.00
Social work	7	20.59	3.00	1.00	4.00	1.00
Podiatry	4	11.76	NA	NA	NA	NA
Occupational therapy	2	5.88	NA	NA	NA	NA
Speech therapy	0	0.00	NA	NA	NA	NA

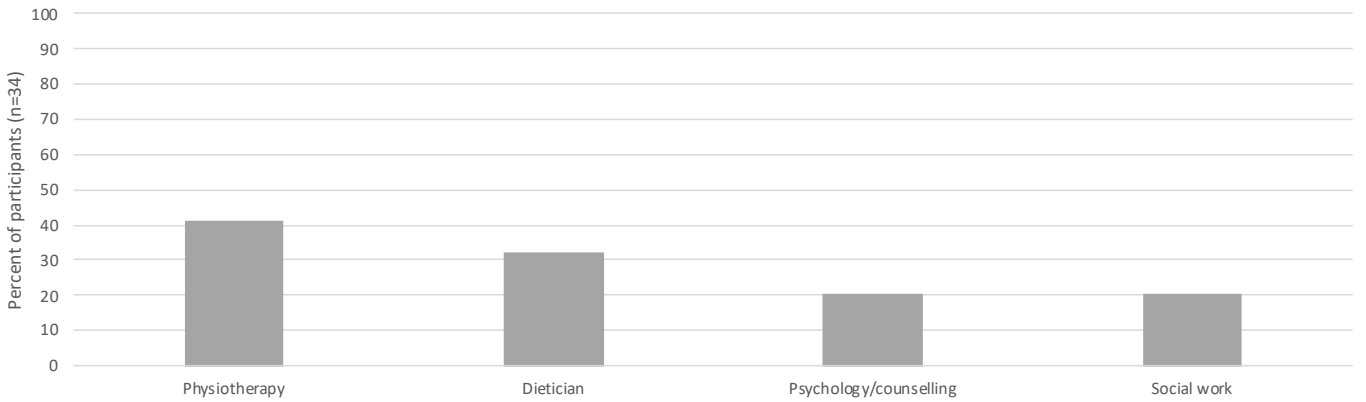

Figure 5.17: Allied health

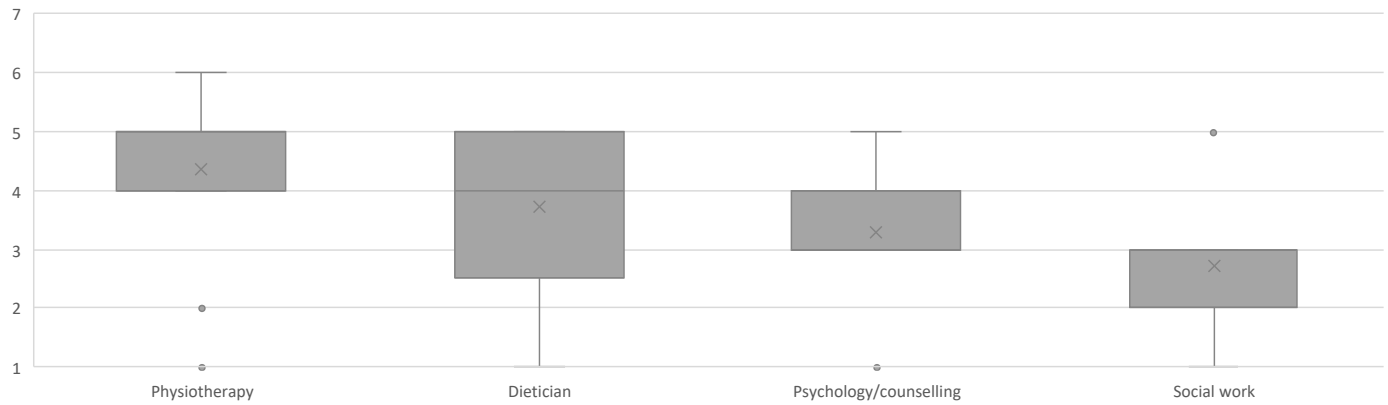

Figure 5.18: Quality of life from allied health

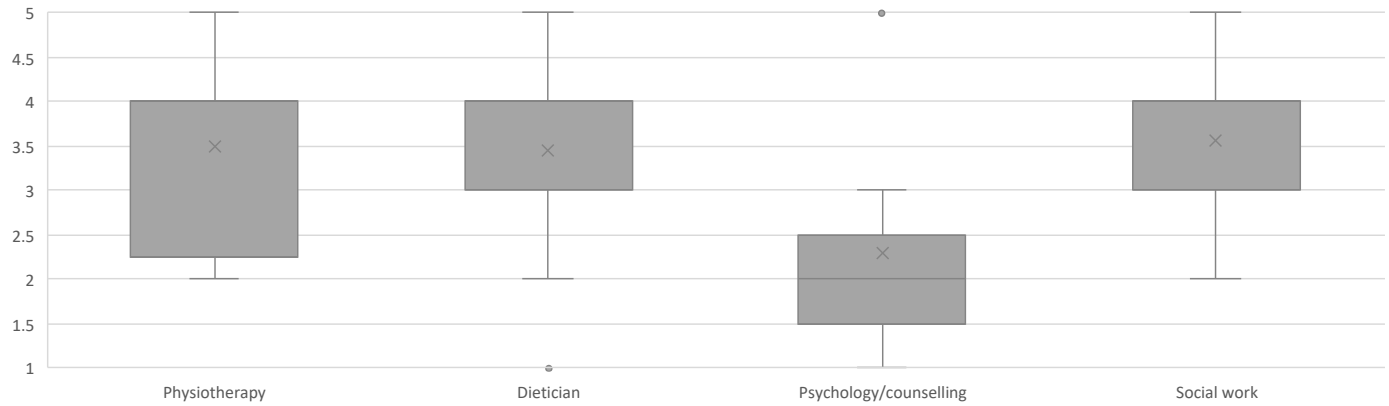

Figure 5.19: Effectiveness of allied health

Lifestyle changes

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

Most participants used at made at least one lifestyle change (n=29, 85.29%), and on average made 2 changes (median=2.00, IQR=2.00).

The most common lifestyle change was exercise (n=22, 64.71%), followed by diet changes (n=17, 50.00%), and reducing or cutting out alcohol (n=17, 50.00%).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=3.00), and was found to be very effective (median=5.00, IQR=2.00).

On average, quality of life from reducing or cutting out alcohol was in the 'life was average' range (median=4.00, IQR=3.00), and was found to be effective (median=4.00, IQR=2.00).

Table 5.16: Lifestyle changes

Lifestyle changes	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	22	64.71	5.00	3.00	5.00	2.00
Diet changes	17	50.00	3.00	3.00	4.00	1.00
Reduce or cut out alcohol	17	50.00	4.00	3.00	4.00	2.00
Reduce or quit smoking	4	11.76	NA	NA	NA	NA

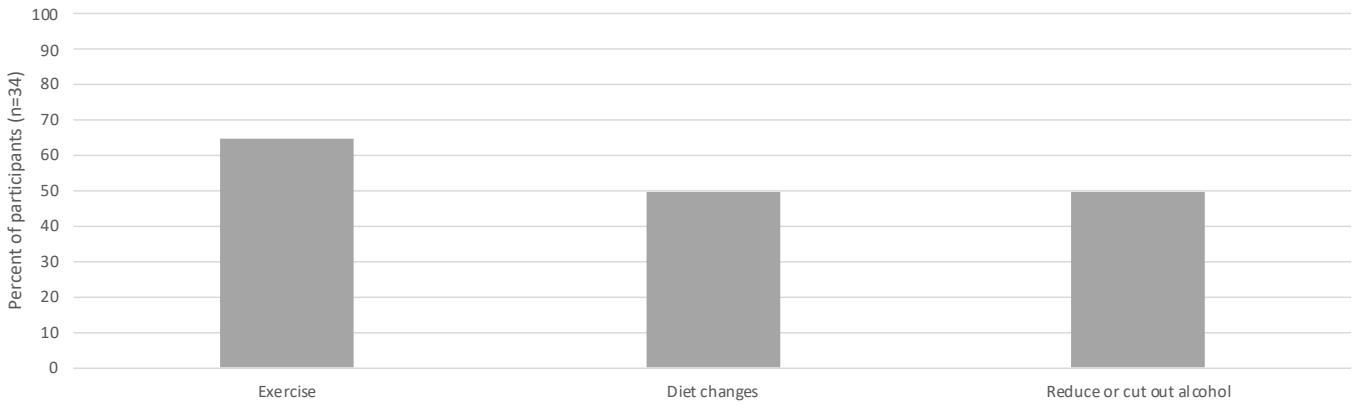

Figure 5.20: Lifestyle changes

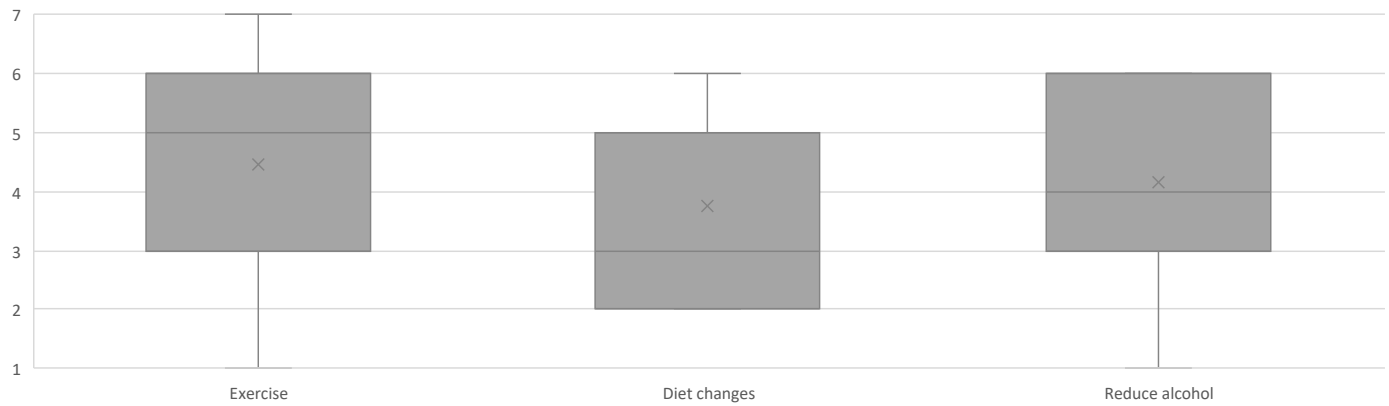

Figure 5.21: Quality of life from lifestyle changes

Figure 5.22: Effectiveness from lifestyle changes

Complementary therapies

Participants were asked about complementary therapies they used, the quality of life from these therapies and how effective they found them.

Half of the participants used at made at least one complementary therapy (n=17, 50.00%), and on average used 0.5 therapies (median=0.50, IQR=2.00).

The most common complementary therapy used was Mindfulness or relaxation techniques (n=12, 35.29%), followed by Massage therapy (n=8, 23.53%), and Supplements (n=7, 20.59%).

On average, quality of life from Mindfulness or relaxation techniques was in the 'life was average to good' range (median=4.50, IQR=3.25), and was found to be moderately effective to effective (median=3.50, IQR=2.25).

On average, quality of life from Massage therapy was in the 'life was average to good' range (median=4.50, IQR=1.75), and was found to be effective (median=4.00, IQR=0.25).

On average, quality of life from Massage therapy was in the 'life was average to good' range (median=4.50, IQR=1.75), and was found to be effective (median=4.00, IQR=0.25).

On average, quality of life from Acupuncture was in the 'life was average to good' range (median=4.50, IQR=1.00), and was found to be somewhat effective (median=2.00, IQR=1.50).

Table 5.17: Complementary therapies

Complementary therapies	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation techniques	12	35.29	4.50	3.25	3.50	2.25
Massage therapy	8	23.53	4.50	1.75	4.00	0.25
Supplements	7	20.59	4.00	2.00	4.00	1.50
Acupuncture	6	17.65	4.50	1.00	2.00	0.75
Naturopathy	3	8.82	NA	NA	NA	NA
Homeopathy	0	0.00	NA	NA	NA	NA

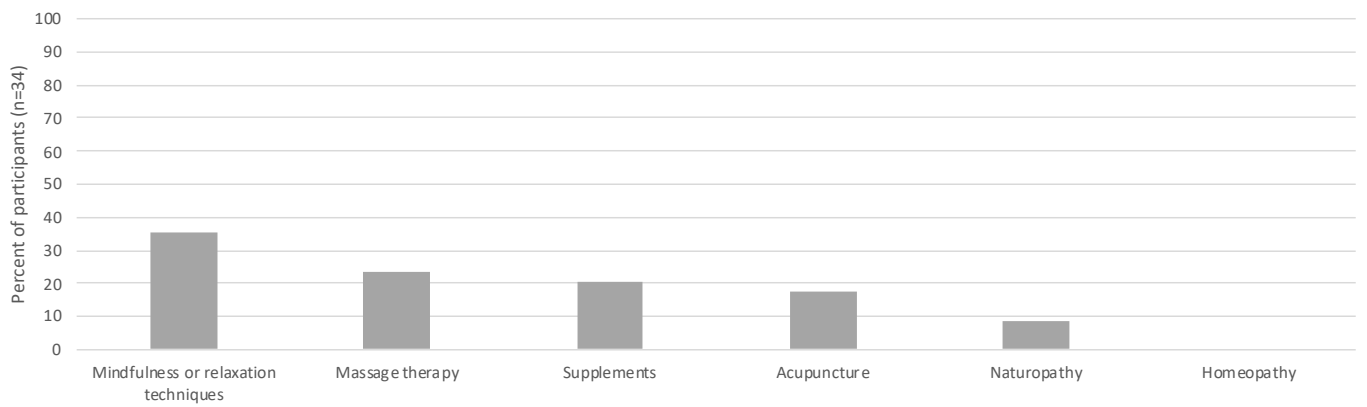

Figure 5.23: Complementary therapies

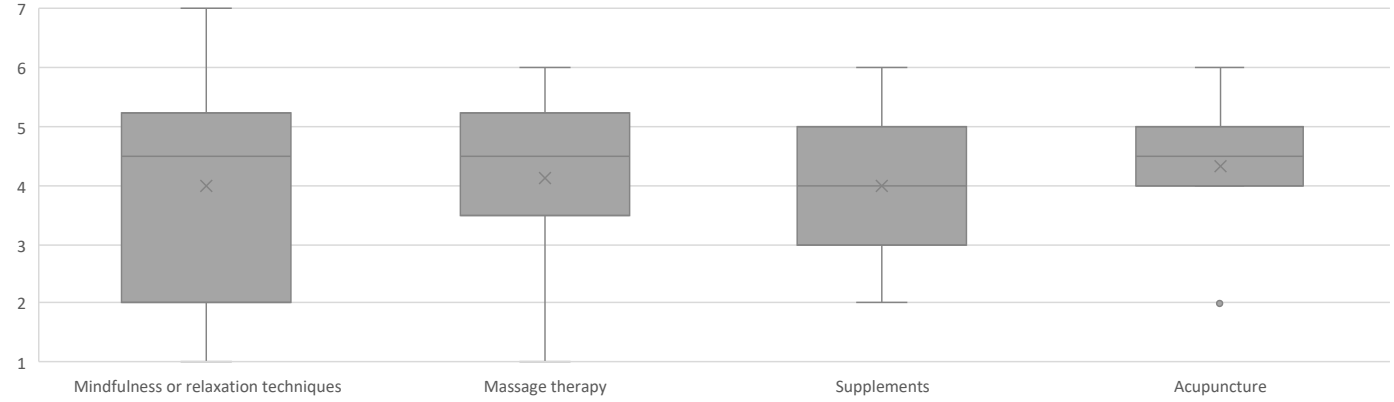

Figure 5.24: Quality of life from complementary therapies

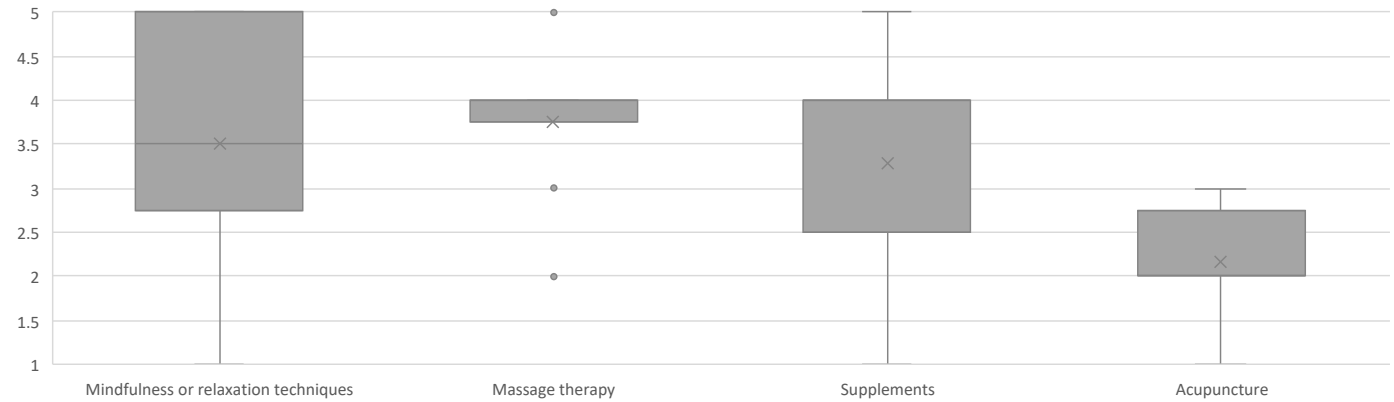

Figure 5.25: Effectiveness of complementary therapies

Clinical trials

Clinical trials discussions

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

There was a total of 17 participants (50%) that had discussions about clinical trials, 5 participants (14.71%) had brought up the topic with their doctor, and the doctor of 12 participants (35.29%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=17, 50.00%).

Clinical trial participation

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

There were 7 participants (20.59%) that had taken part in a clinical trial, 24 participants (70.59%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participanted in a clinical trial and do not want to (8.82%).

Table 5.18: Clinical trial discussions

Clinical trial discussions	Number (n=34)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	14.71
Doctor brought up the topic of clinical trials for discussion	12	35.29
Participant has ever spoken about clinical trials	17	50.00

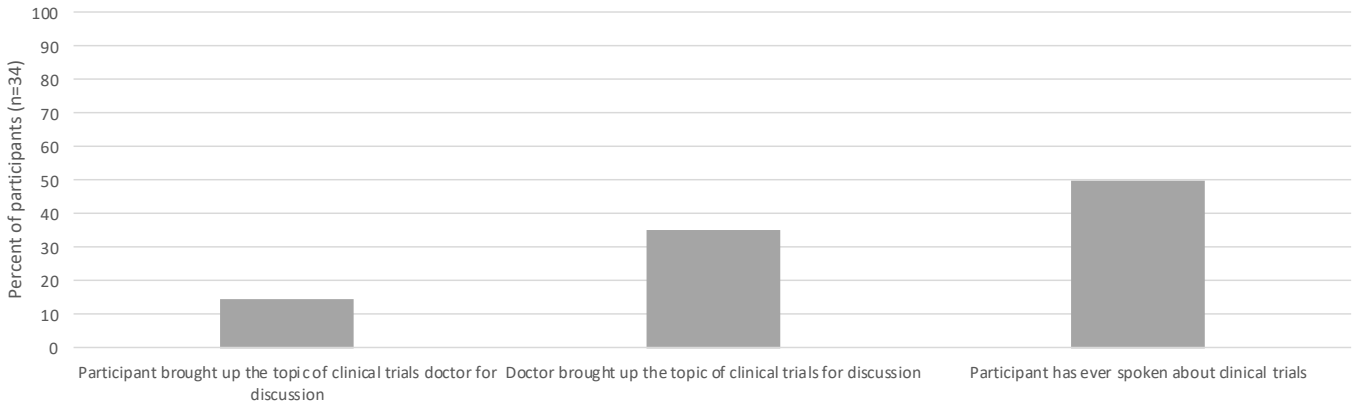

Figure 5.26: Clinical trial discussions

Table 5.19: Clinical trial participation

Clinical trial participation	Number (n=34)	Percent
Has not participated in a clinical trial and does not want to	3	8.82
Has not participated in a clinical trial but would like to if there is one	24	70.59
Has participated in a clinical trial	7	20.59

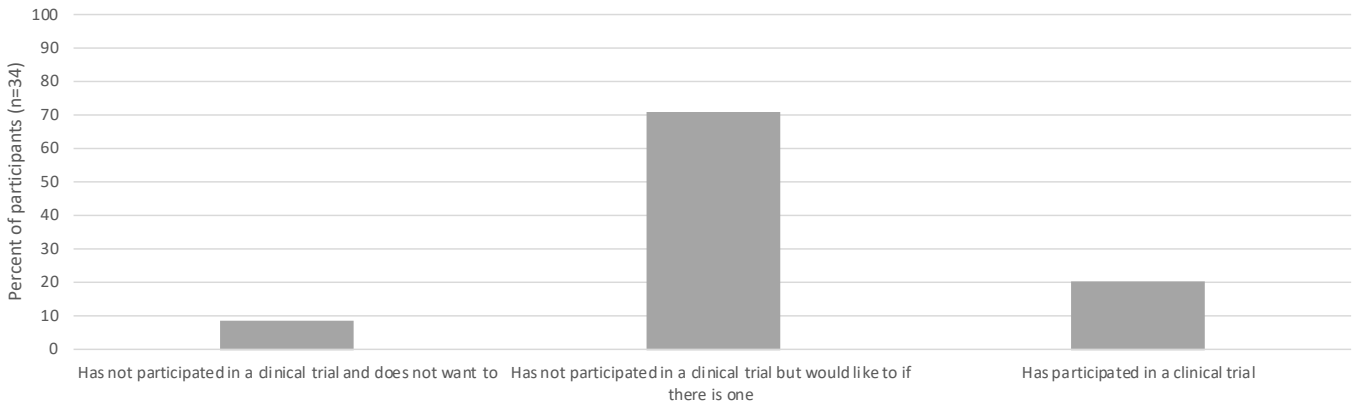

Figure 5.27: Clinical trial participation

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 described using a specific example (69.70%), those that do not interfere with life(30.30%), and those that can be managed with self-medication or self-management (9.09 %).

When a specific side effect was described, the most common responses were aches and pain in general (18.18%), and fatigue or lethargy (18.18%). Other themes included gastrointestinal distress (15.15%), headaches (15.15%), nausea or loss of appetite (12.12%), and neuropathy (9.09%).

Participant provides a specific side effect as an example

Mild were neuropathy in both hands. I guess when we we got the recipe right, I could cope with a certain amount of diarrhea, yeah. Basically, after the first lot of chemo, I became quite, you know, I managed it. 2023AUCRT

No, just I didn't really have any side effects apart from the the loss of hair. I didn't hardly notice, you know? All of a sudden it was gone. But my hair, my facial hair and my hair and my head didn't. None of that fell out. It just didn't grow. But my body hair all fell out, like on my arms, my legs, my body, everything at all, at all disappeared. 010_2023AUCRT

Just feeling a bit off, like, you know, like you just don't feel well, like you get headaches and yeah, like you. That's hard to describe. Like you're just, you're just not right. You know, there's something wrong. And yeah, you just don't feel sparky and you don't feel like eating. 011_2023AUCRT

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

Well, to me, a mild side effects would be what I've got with my tongue or my hips, where they're annoying and they hurt a little bit, but you can live with them and not really, they're not changing my life. Like I'm still like, it's not stopping me eating or drinking certain things, or my hip pain isn't stopping me from exercising or doing things I need to do.
006_2023AUCRT

Inconvenient or uncomfortable, like dexamethasone keeps me awake on Wednesday night, so I'll get two or three hours of sleep on a Wednesday night. But it's just, it's irritating and it's just that's a mild side effect, something that really is a first world problem. I don't sleep well.
019_2023AUCRT

Ohh, wow. Mild side effects is kind of something that's slightly irritating, but you get on with it.
016_2023AUCRT

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

Something I could easily cope with and wouldn't really need medication unless it was really unbearable.
002_2023AUCRT

Well, I've described the mild side effect would be something that's quite easily to control. In terms of a side effect, it's something that's you know, that's there and it's quite easy to control. Which as as an example it could be, it could be constipation, but you know, it might be it might last for it might only last, it might only last for a couple of days, or maybe three days to the maximum, probably 2 days, but where a severe side effect would be, the would be lasting longer.
023_2023AUCRT

Table 5.20: Description of mild side effects

Description of mild side effects	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant provides a specific side effect as an example	23	69.70	5	71.43	8	80.00	10	62.50	18	69.23	5	71.43	11	73.33	12	66.67
Participant describes mild side effects as those that do not interfere with daily life	10	30.30	2	28.57	2	20.00	6	37.50	7	26.92	3	42.86	5	33.33	5	27.78
Participant describes mild side effects as those that can be self-managed	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	2	13.33	1	5.56

Description of mild side effects	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant provides a specific side effect as an example	23	69.70	15	78.95	8	57.14	11	78.57	12	63.16	12	85.71	11	57.89
Participant describes mild side effects as those that do not interfere with daily life	10	30.30	5	26.32	5	35.71	1	7.14	9	47.37	2	14.29	8	42.11
Participant describes mild side effects as those that can be self-managed	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

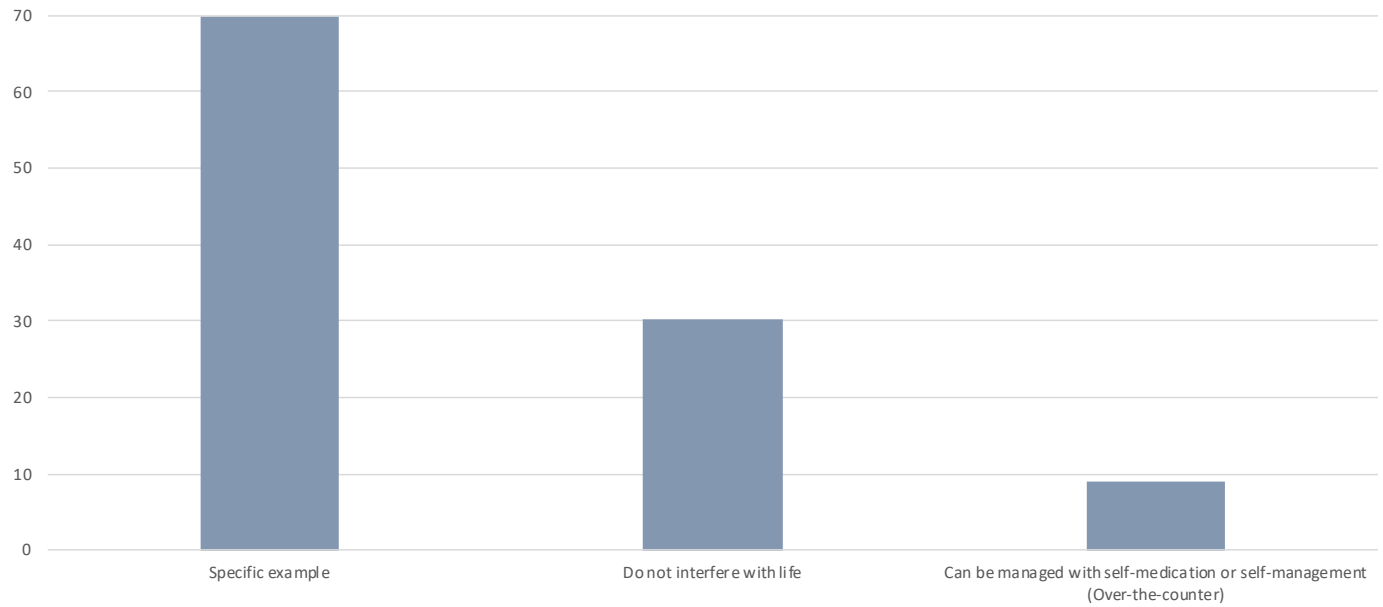

Figure 5.28: Description of mild side effects

Table 5.21: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Aged 65 or older Higher status	Diffuse Large B-Cell Lymphoma Mid to low status
Participant describes mild side effects as those that do not interfere with daily life	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status	CAR T-Cell therapy Metropolitan Higher status

Table 5.22: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes mild side effects giving the specific example of aches/pain (general)	6	18.18	3	42.86	1	10.00	2	12.50	6	23.08	0	0.00	3	20.00	3	16.67
Participant describes mild side effects giving the specific example of fatigue/lethargy	6	18.18	1	14.29	2	20.00	3	18.75	5	19.23	1	14.29	3	20.00	3	16.67
Participant describes mild side effects giving the specific example of gastrointestinal distress	5	15.15	0	0.00	2	20.00	3	18.75	3	11.54	2	28.57	4	26.67	1	5.56
Participant describes mild side effects giving the specific example ofheadaches	5	15.15	1	14.29	3	30.00	1	6.25	4	15.38	1	14.29	3	20.00	2	11.11
Participant describes mild side effects giving the specific example of nausea or loss of appetite	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes mild side effects giving the specific example of neuropathy	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56

Description of mild side effects (Specific side effects)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes mild side effects giving the specific example of aches/pain (general)	6	18.18	6	31.58	0	0.00	4	28.57	2	10.53	4	28.57	2	10.53
Participant describes mild side effects giving the specific example of fatigue/lethargy	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	3	21.43	3	15.79
Participant describes mild side effects giving the specific example of gastrointestinal distress	5	15.15	1	5.26	4	28.57	2	14.29	3	15.79	2	14.29	3	15.79
Participant describes mild side effects giving the specific example ofheadaches	5	15.15	5	26.32	0	0.00	2	14.29	3	15.79	2	14.29	3	15.79
Participant describes mild side effects giving the specific example of nausea or loss of appetite	4	12.12	4	21.05	0	0.00	3	21.43	1	5.26	4	28.57	0	0.00
Participant describes mild side effects giving the specific example of neuropathy	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

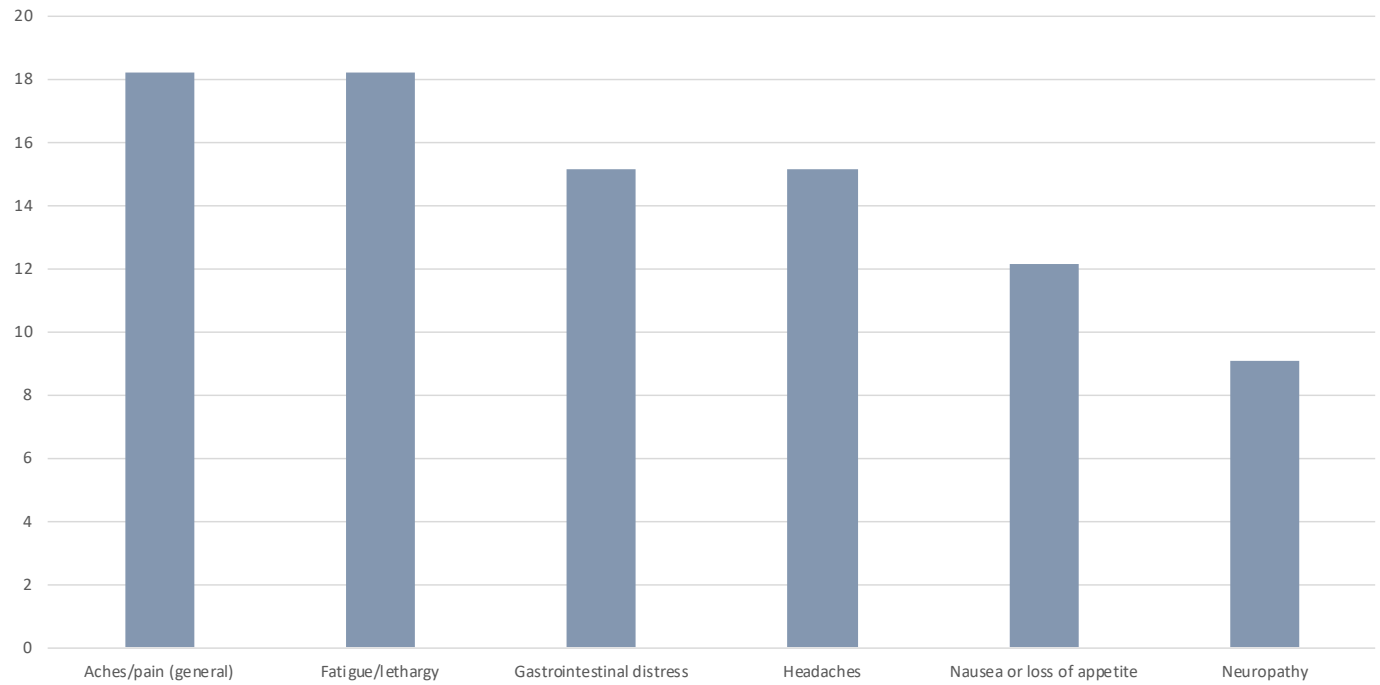

Figure 5.29: Description of mild side effects (Specific side effects)

Table 5.23: Description of mild side effects (Specific side effects) – subgroup variations

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of aches/pain (general)	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Regional or remote Mid to low status
Participant describes mild side effects giving the specific example of gastrointestinal distress	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy Female Aged 65 or older
Participant describes mild side effects giving the specific example ofheadaches	Aged 65 or older	Diffuse Large B-Cell Lymphoma Aged 25 to 64
Participant describes mild side effects giving the specific example of nausea or loss of appetite	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older Higher status	Diffuse Large B-Cell Lymphoma Mid to low status

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were described using a specific example (78.79%), and those that requires medical intervention (30.30%). Other themes included those that impact everyday life or ability to conduct activities of daily living (15.15%), and those that impact their everyday life by being bed ridden (9.09%).

When a specific side effect was described, the most common examples were nausea or loss of appetite (30.30%), aches and pain in general (24.24%), and fatigue or lethargy (15.15 %). Other themes included gastrointestinal distress (12.12%), emotional or mental impact (9.09%), impact on sleep (9.09%), neuropathy (9.09%), and swelling from fluid build up including lymphoedema (9.09%).

Participant provides a specific side effect as an example

Just like excruciating pain or severe sickness. Probably like an eight or a nine on the pain scale. To the point where you have to call like press the emergency button or something.
005_2023AUCRT

Well, to me the severe one would have been the the mucositis and the the pain of that because I couldn't couldn't eat and I couldn't even, it hurt even just to swallow water and that was so and that was even with the medication, so and they had to give me medication that was strong enough to make you feel really dopey and everything. So that was pretty severe.
006_2023AUCRT

That was when I had that last thing when I had the transplant. It was just describe it horrible. Yeah. You just you're just so sick. You wanna you just don't want to be there. You sort of you open your eyes and think ' not another day of this' and you try and sleep and you can't you're just sick and then when you do you yeah. It's just it's hard to describe how to, you know, when you haven't been through it to when you go through it. Yeah, it's just really, really bad it.
011_2023AUCRT

Participant identifies severe side effects as requiring medical intervention

I was lucky that I didn't have that really bad mucositis that a lot of people get. I think that was because of the treatment that they were giving me. One really bad side effect that shouldn't be bad, was constipation in the last three rounds. It was terrible. I also was left with fissures once they did the colonoscopy, because of the bleeding, so I actually felt like I had glass cutting me every time I went to the toilet. That was pretty horrific, that was one of the worst things actually, in the last round. The swelling of my legs probably went down after a couple of weeks. The folliculitis kept coming back, but they kept putting me on antibiotics for that. I think I did have quite a few fevers and had to go into hospital and go on the drip. 004_2023AUCRT

The only the only severe one I've had was the blood clot last year and and that was resolved in the day I went in. My doctor, my GP found it straight away sent me into he she'd already they'd already he'd already booked up to me get all these scans and then he sent me straight to hospital.
018_2023AUCRT

Severe side effects would be unable to eat food, I suppose, without excruciating pain in my stomach. So some of the foods I realized that they weren't good for me to eat at the particular time. So I was. I had to return to hospital for morphine. I couldn't physically cope with the pain anymore. Another one was the other one, I can't remember at the moment. No, that's probably, that's probably the worst one.
024_2023AUCRT

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

Things that would prevent me from doing what I want to do or have a severe impact.
013_2023AUCRT

So with pain, you know, I can't do.anything, you know, I mean, we're, yeah, a lot of people say 10 where it's not really ten level of 10 pain … you know, I mean, reality is called five or six, you know what I mean? Yeah, so what I would get what I'm saying it gets to a severe side effect. Now we're talking about debilitation.
027_2023AUCRT

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

I think there's two for me, one is you can't get out of bed…but I'd say in the simplest answer, a severe side effect is just not being able to get out of bed. 016_2023AUCRT

Well, I had a severe when I was in acute care, and that was just as sick as you could imagine. Lying there feeling like you're inside to being eaten out, can't concentrate, completely fatigued, just just lying there in bed. Just passing time really. 022_2023AUCRT

Table 5.24: Description of severe side effects

Description of severe side effects	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant provides a specific side effect as an example	26	78.79	5	71.43	7	70.00	14	87.50	21	80.77	5	71.43	11	73.33	15	83.33
Participant identifies severe side effects as requiring medical intervention	10	30.30	4	57.14	4	40.00	2	12.50	8	30.77	2	28.57	7	46.67	3	16.67
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	5	15.15	0	0.00	0	0.00	5	31.25	5	19.23	0	0.00	2	13.33	3	16.67
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	9.09	1	14.29	0	0.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Description of severe side effects	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant provides a specific side effect as an example	26	78.79	15	78.95	11	78.57	10	71.43	16	84.21	11	78.57	15	78.95
Participant identifies severe side effects as requiring medical intervention	10	30.30	7	36.84	3	21.43	4	28.57	6	31.58	3	21.43	7	36.84
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	5	15.15	1	5.26	4	28.57	1	7.14	4	21.05	2	14.29	3	15.79
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	9.09	3	15.79	0	0.00	1	7.14	2	10.53	0	0.00	3	15.79

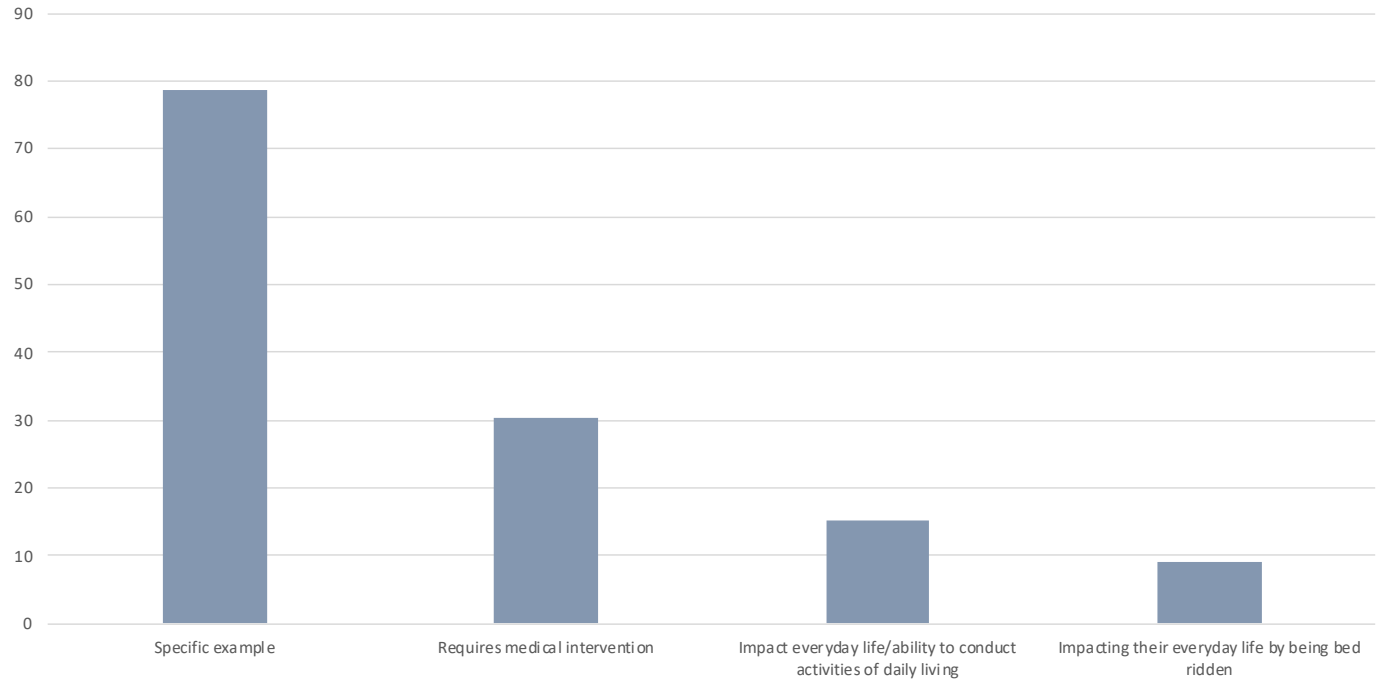

Figure 5.30: Description of severe side effects

Table 5.25: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example		
Participant identifies severe side effects as requiring medical intervention	Multiple Myeloma Male	B-cell acute lymphoblastic leukaemia (ALL) Female
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma Aged 65 or older

Table 5.26: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes severe side effects giving the specific example of nausea or loss of appetite	10	30.30	2	28.57	4	40.00	4	25.00	8	30.77	2	28.57	3	20.00	7	38.89
Participant describes severe side effects giving the specific example of aches/pain (general)	8	24.24	1	14.29	1	10.00	6	37.50	8	30.77	0	0.00	3	20.00	5	27.78
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	15.15	1	14.29	1	10.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22
Participant describes severe side effects giving the specific example of gastrointestinal distress	4	12.12	0	0.00	2	20.00	2	12.50	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes severe side effects giving the specific example of emotion/mental impact	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11
Participant describes severe side effects giving the specific example of impact on sleep	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	0	0.00	3	16.67
Participant describes severe side effects giving the specific example of neuropathy	3	9.09	0	0.00	1	10.00	2	12.50	1	3.85	2	28.57	1	6.67	2	11.11
Participant describes severe side effects giving the specific example of swelling from fluid build up (including lymphoedema)	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11

Description of severe side effects (Specific side effects)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes severe side effects giving the specific example of nausea or loss of appetite	10	30.30	7	36.84	3	21.43	5	35.71	5	26.32	4	28.57	6	31.58
Participant describes severe side effects giving the specific example of aches/pain (general)	8	24.24	4	21.05	4	28.57	5	35.71	3	15.79	6	42.86	2	10.53
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	15.15	5	26.32	0	0.00	4	28.57	1	5.26	4	28.57	1	5.26
Participant describes severe side effects giving the specific example of gastrointestinal distress	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	0	0.00	4	21.05
Participant describes severe side effects giving the specific example of emotion/mental impact	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79
Participant describes severe side effects giving the specific example of impact on sleep	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	2	14.29	1	5.26
Participant describes severe side effects giving the specific example of neuropathy	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26
Participant describes severe side effects giving the specific example of swelling from fluid build up (including lymphoedema)	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26

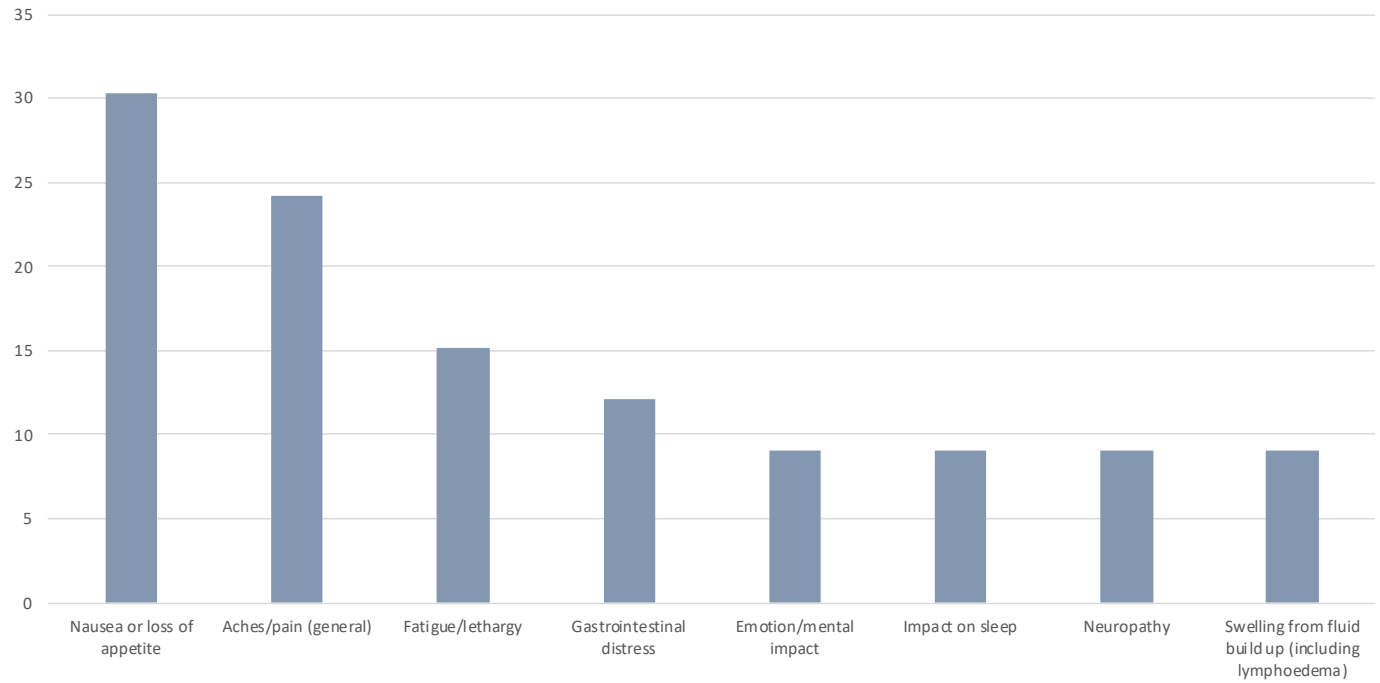

Figure 5.31: Description of severe side effects (Specific example)

Table 5.27: Description of severe side effects (Specific side effects)– subgroup variations

-	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of nausea or loss of appetite	Female	
Participant describes severe side effects giving the specific example of aches/pain (general)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Higher status	Multiple Myeloma Regional or remote Mid to low status
Participant describes severe side effects giving the specific example of fatigue/lethargy	Aged 65 or older	Aged 25 to 64 Regional or remote Mid to low status
Participant describes severe side effects giving the specific example of gastrointestinal distress	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote Mid to low status	-
Participant describes severe side effects giving the specific example of impact on sleep	-	Regional or remote
Participant describes severe side effects giving the specific example of neuropathy	-	CAR T-Cell therapy

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 (75.76%), and never giving up on any treatment (39.39%). Other themes included adhering to treatment as long as side effects are tolerable (12.12%), needing to see test results/no evidence or reduction of disease (12.12%),adhering to treatment as long as treatment is working (9.09%), and adhering to treatment for a specific amount of time (9.09%).

When participants stated a specific amount of time to adhere to a treatment, the amount of time specified was one month (3.03%), six to twelve months(3.03%), and six to twelve months (3.03 %).

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

Oh, I don't give up on it unless the doctor tells me to. 002_2023AUCRT

Probably until. Until the doctor says, I mean there's there's really the only times I've had to well with well when I had the rash the creams on the tablet work. So I did. They worked pretty quickly with the ton thing. They tried a few different ones but at that stage I was I was probably going every week anyway to see them. So within a waste nothing had happened. They'd say okay, we'll we'll give it another week or. Now let's try something different. So, well, we're pretty well guided by what they said. I have a lot of faith in the in the whole medical team, so.
006_2023AUCRT

I've been on the same treatment and as I said before, whatever the doctors and specialists recommend, they're the experts. So I'll do it. 013_2023AUCRT

Participant describes not giving up on any treatment

In my experience, I was on this protocol and they assured me if I stuck on the protocol, it was the best result I could possibly get. So I just stayed the whole distance on the medications for those three years or so. I didn't stop it on any medications at all.
024_2023AUCRT

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

No, I've never given up. I've. I've taken it for as long as I've been under orders too but I have discussed the impact on me with the people treating me you know, I reported the, you know, the rash and I guess it could be regarded as a joint decision.
014_2023AUCRT

Difficult question, I don't know. I think the specialist would tell me but I would say I haven't been thinking about it. But I would say if I get a treatment like my friend in in LOCATION and start having rashes, start having fever, start having problems with breathing or things like that, I don't want to go through them if they have too much serious and side effects.
017_2023AUCRT

I've only given up on one, which was thalidomide, because it was exacerbating the nerve damage in my legs and they swapped to a different one, which was for the nerves in my feet, but it wasn't working well. And after three months we swapped that to amitriptyline.
022_2023AUCRT

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

It's been usually around about in between 3 to six months. I suppose probably minimum of three months is probably the best way. The Thalidomide, we started that in October and we finished in January and the Lantalidomide, we started that in the May and we pulled out in the September. So that's a rough one, yeah but that was visually on my blood counts. So that was placed here on the doctor's sort of indicator if like it's not working. These are the counts and they've gone up to this sort of thing.
019_2023AUCRT

Participant describes adhering to treatment as long as treatment is working

The first one, we did it for about 3 months and then it wasn't affecting…in fact it was not improving, in fact it was spiking so, that's when the hematologist you said, look, it's not working, let's let's move to another medication.
031_2023AUCRT

Wow, depending on what doctors are telling me. Yeah, they they they as as it started with that you know chemotherapy, they explained to me that they started with that baseline the very first, you know medication. Then they monitored, then I said Okay, this one was not really affective. We are adding something stronger, then again something stronger and then they said they have exhausted all all options and nothing it's working. So that's why they had to go away from therapy to CAR-T and and even as I speak you know to you I, I have no, I have no words to express my gratitude that that did have a chance to have that treatment you know, literally to to save my life and for long. So I'm just you know so grateful I know there is new treatment and and and so on and that that I have been you know qualified you know for this one. So and that's why I so willingly participate in absolutely every clinical trial for whenever I was approached I said yes, you know for we have to support that medical advancement and because I know how was close call for me.
034_2023AUCRT

Participant describes adhering to treatment for a specific amount of time

I'd probably give something maybe about four weeks, three or four weeks.
001_2023AUCRT

Table 5.28: Adherence to treatment

Adherence to treatment	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	25	75.76	6	85.71	8	80.00	11	68.75	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes not giving up on any treatment	13	39.39	4	57.14	5	50.00	4	25.00	9	34.62	4	57.14	5	33.33	8	44.44
Participant describes adhering to treatment as long as side effects are tolerable	4	12.12	0	0.00	0	0.00	4	25.00	4	15.38	0	0.00	0	0.00	4	22.22
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes adhering to treatment as long as treatment is working	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11
Participant describes adhering to treatment for a specific amount of time	3	9.09	1	14.29	0	0.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Adherence to treatment	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	25	75.76	14	73.68	11	78.57	10	71.43	15	78.95	9	64.29	16	84.21
Participant describes not giving up on any treatment	13	39.39	8	42.11	5	35.71	6	42.86	7	36.84	6	42.86	7	36.84
Participant describes adhering to treatment as long as side effects are tolerable	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes adhering to treatment as long as treatment is working	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant describes adhering to treatment for a specific amount of time	3	9.09	3	15.79	0	0.00	1	7.14	2	10.53	2	14.29	1	5.26

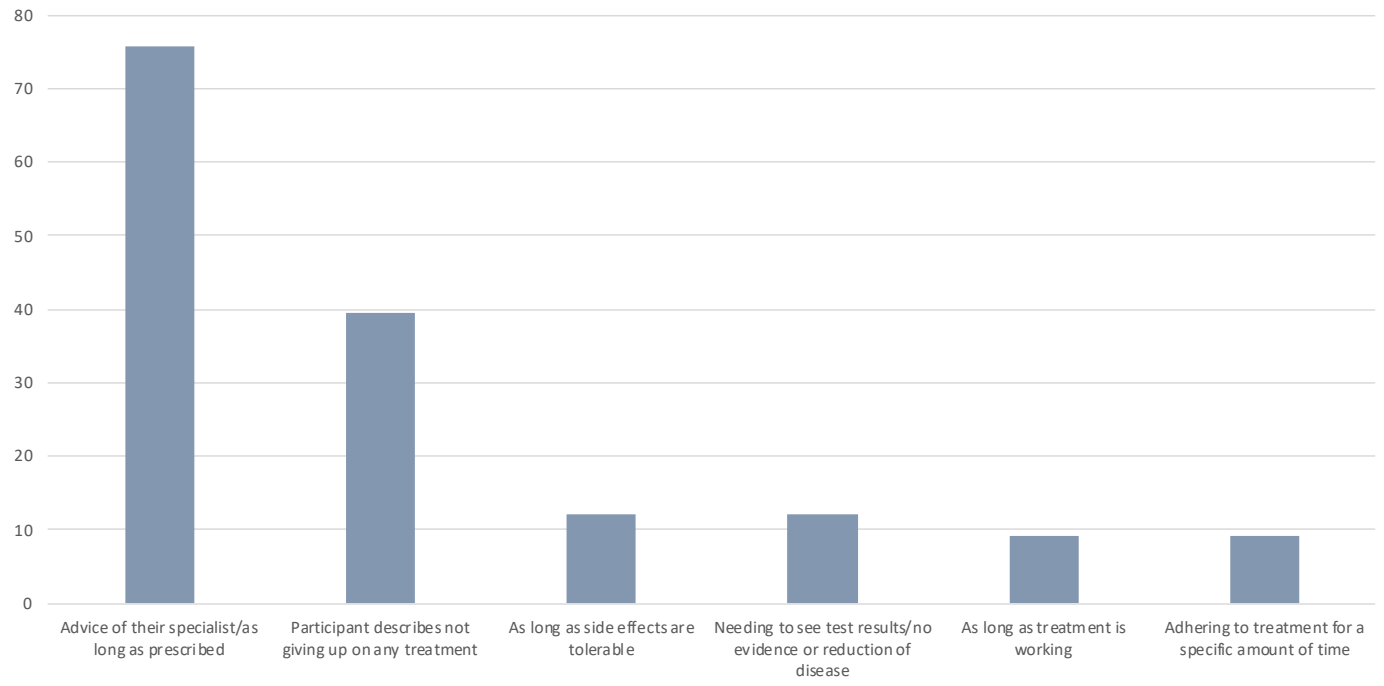

Figure 5.32: Adherence to treatment

Table 5.29 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	Mid to low status	-
Participant describes not giving up on any treatment	Multiple Myeloma	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes adhering to treatment as long as side effects are tolerable	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes adhering to treatment as long as treatment is working	-	Diffuse Large B-Cell Lymphoma

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 evidence of stable disease or no disease progression (39.39%), and needing to see physical signs and symptoms disappear or reduced side effects (33.33%). Other themes included needing to see a specific symptom reduction (27.27%), and needing to see a return to day-to-day functionality (15.15%).

When a specific side effect or symptom was described, the most common examples were aches and pain in general (12.12%), and fatigue or lethargy (12.12%).

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

The thing that really made me think it was working was the blood tests, the markers, how active myeloma was. If what he thought was working, if he thought it was working, I thought it was working.
014_2023AUCRT

So far, just the blood biochemistry. I'm just relying on the monthly or weekly blood tests that we are receiving and my especially way of looking at the numbers. So the specialists in the state, for example, recommended having a PET scan after two years of treatment. He was recommending having a PET scan, having a new bone marrow and staging your cancer again for the second time and all of these things.
017_2023AUCRT

I don't know if it's working or not. I just wait for the blood tests and I asked them, so what's the paraprotein level? And she, she will tell me what it is. And she's even given me chance to show how where the various treatments have been extremely fantastic. So she's got a full graph from when I started to where I am now, you know. And so and so she's very clear about that.
018_2023AUCRT

I suppose I measure everything on my count. So I just, I measure a couple of things in my blood counts and if they're going down, I feel great. If they're going the other way, I get determined, yeah, and go from there.
019_2023AUCRT

Participants reported needing to see all physical signs and symptoms disappear

Obviously, you need to see an improvement in yourself, but even so, if I can't see an improvement and the doctors are telling me that there's only been an improvement in my blood or whatever, then that's enough for me.
002_2023AUCRT

Yeah, I suppose a reduction in side effects and generally that you feel that there is all of a sudden, it might be a doctor saying your levels have gone from here to there, your functions gone from here to there. So I suppose again that feedback from a medical professional or you can feel it yourself that you do generally feel better.
026_2023AUCRT

Participant describes needing to see a reduction in a specific symptom

Yes. One of the ones I knew really helped me was the mouth ulcers. I was really grateful because I still had ulcers, and I still had swelling, but I still get that now, it seems to be an ongoing thing that I'm left with. I knew that that mouthwash helped enormously.
004_2023AUCRT

I think for me there's two things. I have this host disease of my gut. So for me it's a sense that I don't have to plan where the toilet is before I go out. So you know, that's kind of a bit of a gauge for me, but also my emotional well-being. All of those things that I take can make you feel really tired and worn out and cranky. So the other one is my emotional well-being.

016_2023AUCRT

Participants reported needing to experience a return to day-to-day functionality

Well, I think it's difficult to group any particular medication and it's affecting side effects on its own. I think as a whole, the fact that I'm back at work now and living a what I would call a 80% normal life means that it's worked, I think. But it's been the combination of everything…You're at a new normal.
022_2023AUCRT

Just that I'm sort of apart from the treatment I operate daily, as I would if I didn't have cancer, more or less. Apart from the mild side effects, but I can, you know, I can stay up all day and not have to rest and go out and do things and not get fatigued like a lot of people do. Yeah, like be out really late. Like, as an example, I went to the Women's World Cup and we didn't get home till 1:30 in the morning. So I was still like, didn't get tired, whereas other people would.
032_2023AUCRT

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

What needs to change to feel like treatment is working	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participants reported needing to experience evidence of stable disease/no disease progression	13	39.39	3	42.86	4	40.00	6	37.50	9	34.62	4	57.14	4	26.67	9	50.00
Participants reported needing to see all physical signs and symptoms disappear	11	33.33	4	57.14	5	50.00	2	12.50	6	23.08	5	71.43	7	46.67	4	22.22
Participant describes needing to see a reduction in a specific symptom	9	27.27	2	28.57	0	0.00	7	43.75	8	30.77	1	14.29	4	26.67	5	27.78
Participants reported needing to experience a return to day-to-day functionality	5	15.15	0	0.00	1	10.00	4	25.00	5	19.23	0	0.00	1	6.67	4	22.22

What needs to change to feel like treatment is working	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participants reported needing to experience evidence of stable disease/no disease progression	13	39.39	8	42.11	5	35.71	7	50.00	6	31.58	7	50.00	6	31.58
Participants reported needing to see all physical signs and symptoms disappear	11	33.33	7	36.84	4	28.57	3	21.43	8	42.11	3	21.43	8	42.11
Participant describes needing to see a reduction in a specific symptom	9	27.27	3	15.79	6	42.86	1	7.14	8	42.11	2	14.29	7	36.84
Participants reported needing to experience a return to day-to-day functionality	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	3	21.43	2	10.53

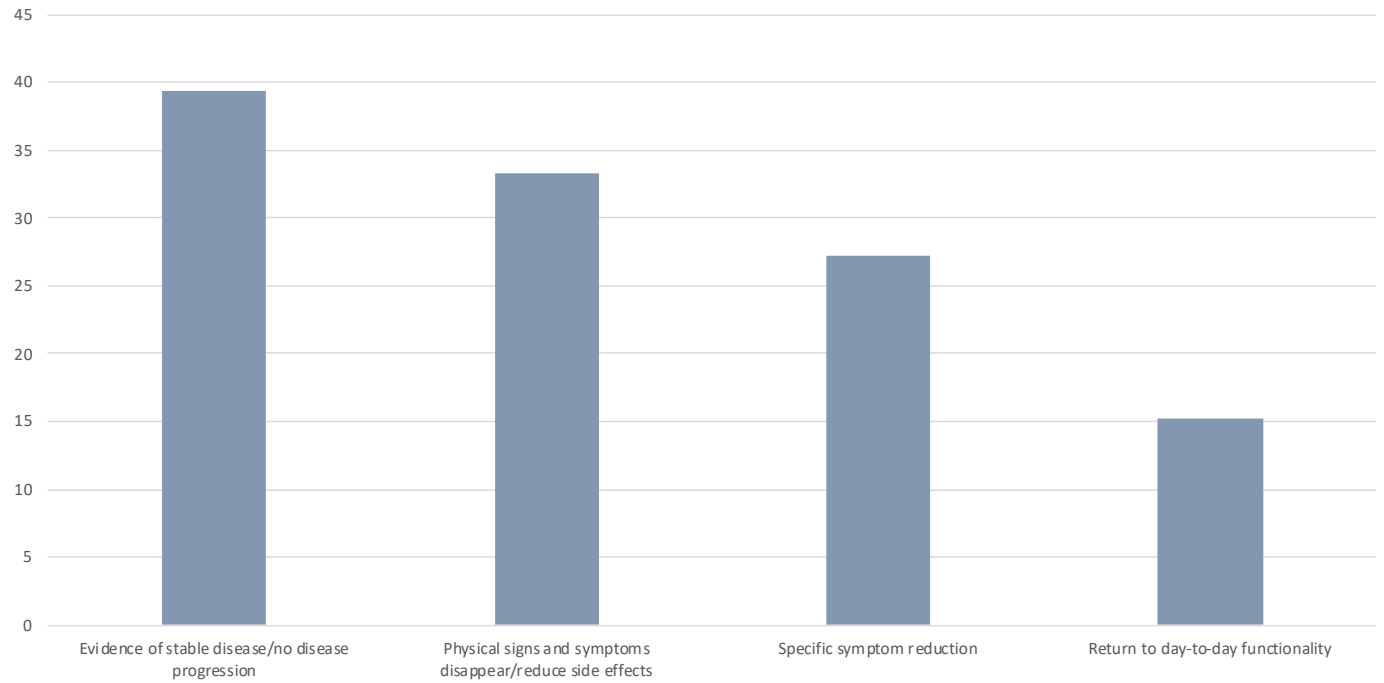

Figure 5.33: What needs to change to feel like treatment is working

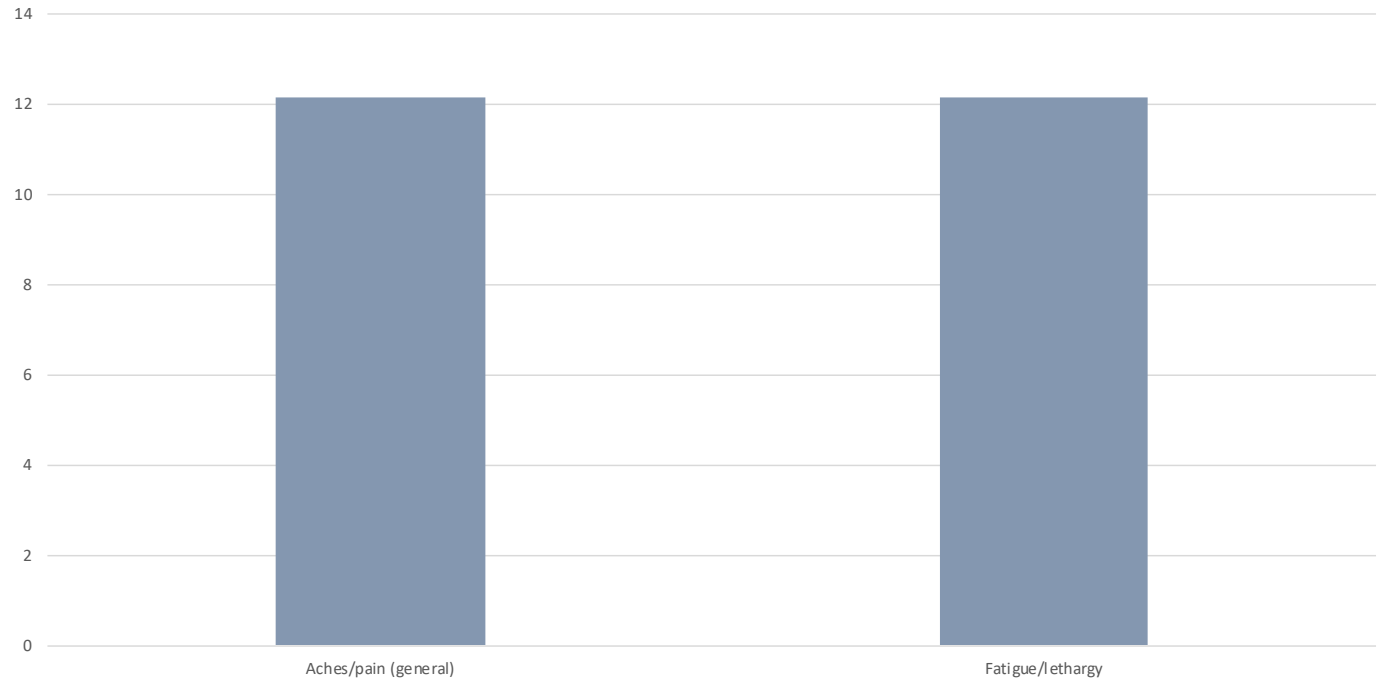

Figure 5.34: What needs to change to feel like treatment is working (specific symptoms)

Table 5.31: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Female	CAR T-Cell therapy Male Regional or remote Mid to low status
Participants reported needing to see all physical signs and symptoms disappear	Multiple Myeloma No CAR T-Cell therapy Male Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Participant describes needing to see a reduction in a specific symptom	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote Mid to low status	Multiple Myeloma Aged 65 or older Metropolitan
Participants reported needing to experience a return to day-to-day functionality	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities or return to normal life (42.42%), and that it would have a positive impact on their mental health (24.24%). Other themes included allowing them to do more exercise (18.18%), allowing them to return to work (12.12%), and allowing them to engage more with social activities and family life (12.12%).

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

Well, when I was really sick, I couldn't do anything. Like basically all I did was sit in a chair, or lay in a bed. That's all I did. And slowly over the it's taken like a couple of years, like I can get out and do a bit of garden now and do a few things. I still can't do what I used to do. 011_2023AUCRT

If you can feel well and get on with some of your activities, it certainly makes you feel like you're living a bit more of a normal life. Yes. Yeah. So it is quite important manage side effects. 021_2023AUCRT

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

I don't know whether there would be any change, but just mentally, there's that change. 002_2023AUCRT

I guess it'd just give me a bit of hope, keep planning for the future. Yes, like there's a light at the end of the tunnel, I guess.

005_2023AUCRT

I think your question was about how how how does it affect my life and I think it just, I just felt felt better when when things were, I felt happier I guess, although I wasn't, I wasn't unhappy. Once I got off the steroids I was not not unhappy but the I actually I the I did take thalidomide in conjunction with Prednisolone. So I was pleased to get off the thalidomide because of the rash and I was pleased to get off the off the Prednisolone because of the its impact on my body and putting on weight.
014_2023AUCRT

If it wasn't working I'd it'd be a constant mental battle to feel update that you feel it's spiraling downwards and and that's probably because I live with an incurable condition. So I if it's going backwards as much as I try and maintain a positive outlook in life, you know, occasionally, well it does. It catches up on you and you think you get a bit despondent if it's going the right direction it would give me hope and excitement and and and it'd be you know it may give you or may give me a reprieve from having it constantly in the back of your mind every minute of every day. You know you all cancer patients are the same and that you know we all get about laughing, get on with it. But it's just there in the back that you know that 1% or half percent in the back of your head, Be nice to be able to remove that one or half a percent in the back of your head. What you're saying, you know, it's tick, tick, tick, tick sort of thing, that's all.
019_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to do more exercise

I'm not sure I know the answer to that either. I haven't let this stop me. I took up bowls because the surgeon said you can't play golf for six months. Last time I played golf was in January this year and I found myself disoriented and with a total lack of energy to be able to play the other ten holes.
008_2023AUCRT

PARTICIPANT: It'd make me happier that I can get out into the Bush. Yes, yeah, yeah. And I mean, part of bush walking and engaging in nature is, of course maintaining mental health, as NAME just said.
I guess my major hobby would be severely limited if if the treatment wasn't working.
013_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to return to work

Oh well, I think if my life would be able to look a lot more like it did before I became unwell, you know, I'd have a bit of stamina to be able to, you know, do to finish things. You know, instead of working on something for an hour or two, I'd be able to, you know, do it all day. I'd be going back to work. I'd be, you know, thinking more. I'd be feeling more confident about going back to work. Yeah, they're the main two, I think. I mean, I try and do all the things that I used to do and I've got a really strong list of things that I've achieved but it's yeah, it's about stamina to do them and you know, not needing a day to recover or a week to recover cuz you've done one of them.
016_2023AUCRT

The only other thing I suppose, treatment that I'd like is because I still get, I still get tired quite a bit and I get a bit foggy in the brain. So yeah, I wouldn't mind a bit more energy and alertness, I suppose. Yeah, yeah, very nice. That would be good and that would make it. Easier for me because as yet I haven't gone back to work. I'll probably will will need to soon and it'll be just part time. So I suppose if I could if there could be some treatment for the for the sort of the the brain fog and that that would that would make it easier to go back to work I guess.
006_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to engage more with social activities and family life

The best thing for me was been able to get out of an isolated room in the hospital, so I needed my neutrophils to increase to a level where it was safe for me to to go out into sort of public spaces and things like that, so. Just take me away from the isolated room. That was my main goal at the start of the treatment.
024_2023AUCRT

Oh, I mean, we go for walks along the beach with family a lot and more socializing. If we go to a cinema or something, we always pick a session where there's hardly anyone there. So we can do that, so we can eat out picking where we sit, preferably outside. If you didn't have the treatment, I think you just wouldn't do anything. You know I'd just be sitting on the couch.
035_2023AUCRT

Table 5.32: What it would mean if treatment worked

What it would mean if treatment worked	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Allowing them to do everyday activities/return to normal life	14	42.42	2	28.57	4	40.00	8	50.00	12	46.15	2	28.57	7	46.67	7	38.89
A positive impact on their mental health	8	24.24	1	14.29	1	10.00	6	37.50	8	30.77	0	0.00	3	20.00	5	27.78
Allowing them to do more exercise	6	18.18	0	0.00	1	10.00	5	31.25	3	11.54	3	42.86	2	13.33	4	22.22
Allowing them to return to work	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	4	26.67	0	0.00
Allowing them to engage more with social activities and family life	4	12.12	2	28.57	0	0.00	2	12.50	3	11.54	1	14.29	0	0.00	4	22.22

What it would mean if treatment worked	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Allowing them to do everyday activities/return to normal life	14	42.42	8	42.11	6	42.86	5	35.71	9	47.37	5	35.71	9	47.37
A positive impact on their mental health	8	24.24	4	21.05	4	28.57	2	14.29	6	31.58	3	21.43	5	26.32
Allowing them to do more exercise	6	18.18	0	0.00	6	42.86	2	14.29	4	21.05	1	7.14	5	26.32
Allowing them to return to work	4	12.12	2	10.53	2	14.29	0	0.00	4	21.05	0	0.00	4	21.05
Allowing them to engage more with social activities and family life	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	2	14.29	2	10.53

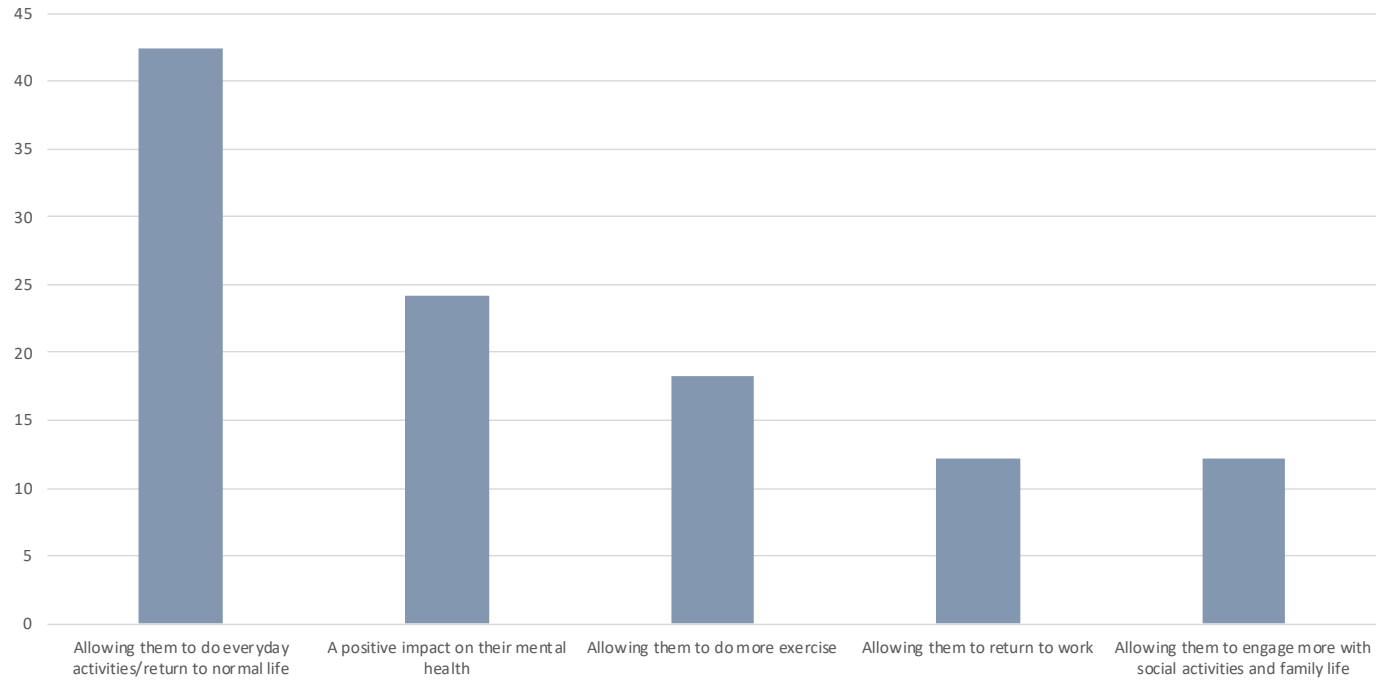

Figure 5.35: What it would mean if treatment worked

Table 5.33: What it would mean if treatment worked – subgroup variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Allowing them to do everyday activities/return to normal life	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
A positive impact on their mental health	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma
Allowing them to do more exercise	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status	Multiple Myeloma CAR T-Cell therapy Aged 65 or older
Allowing them to return to work	Male Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Female
Allowing them to engage more with social activities and family life	Diffuse Large B-Cell Lymphoma Female	B-cell acute lymphoblastic leukaemia (ALL) Male

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 from a specific health charity (60.61%), from books, pamphlets and newsletters (51.52%), and from their treating clinician (48.48 %). Other themes included the internet (Including health charities) (42.42%), from other patient's experience (Including support groups) (27.27%), from nursing staff (12.12%), at conferences or webinars (12.12%), from journals (research articles) (9.09%), and family members (9.09%).

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, talking to a doctor, specialist or healthcare team (36.36%), hearing what to expect (e.g. from disease, side effects, treatment) (33.33%), and other people's experiences (21.21 %). Other themes included scientific information, or information from medical journals (12.12%), and information from health charities (9.09%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information was not helpful (36.36%), worse case scenarios (18.18%), and other people's experiences (15.15 %). Other themes included being confident in deciding themselves (12.12%), and sources that are not credible (Not evidence-based) (12.12%).

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 (39.39%), and talking to someone plus online information (21.21%). Other themes included online information (18.18%), written information (18.18%), and all forms (12.12%).

The main reasons for a preference for talking to someone were being able to ask questions (30.30%), that it was personalised or relevant (21.21%) and because it was supportive (12.12%). The main reasons for a preference for online information were accessibility (24.24%), that it was personalised or relevant (9.09%), and being able to digest information at their own pace (6.06 %). The main reason for a preference for written information was that they could easily refer back to it (12.12%).

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) (36.36%), after the shock of diagnosis (15.15%), continuously (15.15 %), and after treatment (12.12%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having overall positive communication (75.76%), communication that was overall positive, with the exception of one or two occasions(18.18%), and overall negative communication (6.06 %).

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (60.61%), good, with no particular reason given (18.18%), good especially in

relation to multi-disciplinary communication (9.09 %). and good, yet limited in relation health to professionals not having a lot of time (6.06%). For those describing negative communication, this was because information was not forthcoming (9.09%) and limited in relation to their understanding of the condition (6.06%).

Partners in health

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

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

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

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

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

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

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=26, 78.79%), disease management (n=24, 72.73%), dietary (n=21, 63.64%), and disease cause (n=17, 51.52%) were most frequently given to participants by healthcare professionals, and information about complementary therapies (n=5, 15.15%), psychological/ social support (n=5, 15.15%), and hereditary considerations (n=1, 3.03%) 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 complementary therapies (n=16, 48.48%), disease cause (n=14, 42.42%), interpret test results (n=14, 42.42%), and treatment options (n=12, 36.36%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=10, 30.30%), clinical trials (n=9, 27.27%), and hereditary considerations (n=8, 24.24%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=25, 75.76%) and psychological/ social support (n=19, 57.58%).

The topics that participants were given most information from both healthcare professionals and searching independently were treatment options (n=10, 30.30%) and dietary information(n=9, 27.27%).

The topics that participants did not search for independently after receiving information from healthcare professionals were disease management (n=17, 51.52%) and treatment options (n=16, 48.48%).

The topics that participants searched for independently after not receiving information from healthcare professionals were complementary therapies (n=14, 42.42%) and disease cause (n=9, 27.27%).

Most accessed information

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

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 17 participants (51.52%) had accessed My Health Record, 16 participants (48.48%) had not.

Of those that had accessed My Health Record, there were 3 participants (17.65%) who found it to be poor or very poor, 12 participants (70.59%) who found it acceptable, and 2 participants (11.76%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were from a specific health charity (60.61%), from books, pamphlets and newsletters (51.52%), and from their treating clinician (48.48 %). Other themes included the internet (Including health charities) (42.42%), from other patient's experience (Including support groups) (27.27%), from nursing staff (12.12%), at conferences or webinars (12.12%), from journals (research articles) (9.09%), and family members (9.09%).

Participant describes accessing information from a specific health charity

I struggled with the information, so Leukemia Foundation makes these fantastic booklets. Really love them. They're in plain language, they're easy to understand, so that's great. Where the gap is that I kind of wanted to know a bit more, so there's nothing in the middle. There's very high level kind of information and then it very quickly degenerates to academic articles and the only thing in the middle for me I found was, you know, Doctor Google, which I didn't want to access, and the academic articles I couldn't understand, but I wanted to know more. So for example, that Philadelphia chromosome, I wanted to understand more about that and I want to understand about more about how remission occurs or could occur once since I've had a bone marrow transplant. But that information is really hard to get. I understand that, you know, everyone's experience and illness is really diverse and that makes it hard. But there really is, I think, a lack of information. You know, there needs to be more depth of information than what's there.
Participant 016_2023AUCRT

Participant describes receiving information from books, pamphlets and newsletters

OK. I had lots of access for from the hospital so they would print out information about the type of chemo that I was having, the expected side effects, all of that sort of thing. Both hospitals were good at that. I also received information from the Leukemia Foundation, and I found that also excellent. I avoided Google, yes. So I generally went to the Leukemia Foundation, the Cancer Council, and my medical team.
Participant 009_2023AUCRT

Participant describes primarily accessing information through treating clinician

I remember DOCTOR told me never to Google anything about my symptoms. He said if you want any information to ask him directly, because he said a lot of people get it confused. He said, "Don't Google anything, unless you go to the Leukemia Foundation." I've never Googled anything.
Participant 01_2023AUCRT

I've read some of the pamphlets that I got given from hospital. They're informative but not of much use. I looked at some of the stuff on the Internet and I felt that that was misleading, so I haven't bothered. … Oh, like I asked questions of my doctors and DOCTOR is pretty good at giving upfront answers. The hematologist DOCTOR, that I'm seeing doesn't like being questioned.
Participant 008_2023AUCRT

Participant describes accessing information through the internet in general

Oh yeah. Well, I read up quite a bit. I read the, there's quite a few websites out there and there's a myeloma website. There's the Mayo Clinic in America. And you know they give out lots of information, lots of people's stories, you know lots about treatments and what's available. Plus I was given a lot of lot of information by the hematologist and the oncologist about what's involved. So I was, I felt like I was pretty informed and knew knew what the the best treatment was for it.
Participant 015_2023AUCRT

Well, mostly for talking to the doctors and the nurses and then also reading the information that they give you and rereading it and then going through and thinking of questions to ask them and then asking questions. I look up a bit of stuff online, but I try to go to the things like the Queensland Health or NSW Health or the ones that are not the other, that are in Australia and that are proper medical ones as opposed to, you know, someone's crackpot theory or whatever, yeah.
Participant 006_2023AUCRT

Participant describes primarily accessing information through other patient's experience

I did actually join a support group, with the Leukemia Foundation, but that was later, I didn't know about it at the time and I really wished…Now I'm in touch with

quite a few people and we all share experiences. It makes you feel like, "Okay, it is pretty normal to be going through the things I'm still going through." You ask questions and people say, "Yes, that happened to me, and this happened to me."
Participant 004_2023AUCRT

Most of my information came from the medical library at the hospital, so I'd like I said I was just studying the drugs, looking at the statistics, things like that, looking at other people's other people's stories. I've read a story in in In Flight magazine, but a guy that had a, I think he had a lymphoma or some sort of lymphatic disease and was able to get back into his life afterwards. That's about it, basically.
Participant 024_2023AUCRT

Participant describes receiving information through nursing staff

Yes, the nurses, yes, probably more so the nurses rather than the doctors for providing information and peace of mind, yes.
Participant 005_2023AUCRT

And a couple of times when I've had questions, I've contacted the Leukemia Foundation nurses and spoken to them on the phone.
Participant 012_2023AUCRT

Participant describes receiving information through conferences or webinars

Oncologists at HOSPITAL, that was the best thing I saw about CAR-T on the web was him giving a 40 minute talk…and his talk was fantastic and he I'd still refer back to it and I send everyone there, but he said that's great, but most people find it too much. Which is fair enough. So there is somewhere in between where the facts there should be references or facts available or more information rather than…I don't want a one page thing that's warm and fuzzy.
036_2023AUCRT

Participant describes accessing information primarily through journals (research articles)

It would be my own Internet research, looking at medical papers, etc. and I sort of realized that anything that's in a few years old, it's probably out of date, especially CAR-T therapy, so recent research papers I guess.
Participant 021_2023AUCRT

Participant describes receiving information through family members

I speak to my dear wife who was a research oracle, I mean she's she's extremely intelligent researcher. Wisely, as I said at the beginning, perhaps one of the ways I manage my condition is to stick my head in the sand and not want to know about anything and just do what the specialist tells me. I see they research to the nth degree about multiple myeloma.
Participant 013_2023AUCRT

Table 6.1: Access to information.

Access to information	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes accessing information from a specific health charity	20	60.61	3	42.86	5	50.00	12	75.00	17	65.38	3	42.86	9	60.00	11	61.11
Participant describes receiving information from books, pamphlets and newsletters	17	51.52	3	42.86	5	50.00	9	56.25	12	46.15	5	71.43	7	46.67	10	55.56
Participant describes primarily accessing information through treating clinician	16	48.48	4	57.14	4	40.00	8	50.00	13	50.00	3	42.86	6	40.00	10	55.56
Participant describes accessing information through the internet in general	14	42.42	2	28.57	6	60.00	6	37.50	10	38.46	4	57.14	4	26.67	10	55.56
Participant describes primarily accessing information through other patient's experience	9	27.27	2	28.57	2	20.00	5	31.25	9	34.62	0	0.00	4	26.67	5	27.78
Participant describes receiving information through nursing staff	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00
Participant describes receiving information through conferences or webinars	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes accessing information primarily through journals (research articles)	3	9.09	0	0.00	2	20.00	1	6.25	0	0.00	3	42.86	2	13.33	1	5.56
Participant describes receiving information through family members	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	0	0.00	3	16.67

Access to information	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes accessing information from a specific health charity	20	60.61	10	52.63	10	71.43	9	64.29	11	57.89	9	64.29	11	57.89
Participant describes receiving information from books, pamphlets and newsletters	17	51.52	9	47.37	8	57.14	7	50.00	10	52.63	6	42.86	11	57.89
Participant describes primarily accessing information through treating clinician	16	48.48	12	63.16	4	28.57	9	64.29	7	36.84	7	50.00	9	47.37
Participant describes accessing information through the internet in general	14	42.42	9	47.37	5	35.71	9	64.29	5	26.32	7	50.00	7	36.84
Participant describes primarily accessing information through other patient's experience	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Participant describes receiving information through nursing staff	4	12.12	3	15.79	1	7.14	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes receiving information through conferences or webinars	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes accessing information primarily through journals (research articles)	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	1	7.14	2	10.53
Participant describes receiving information through family members	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26

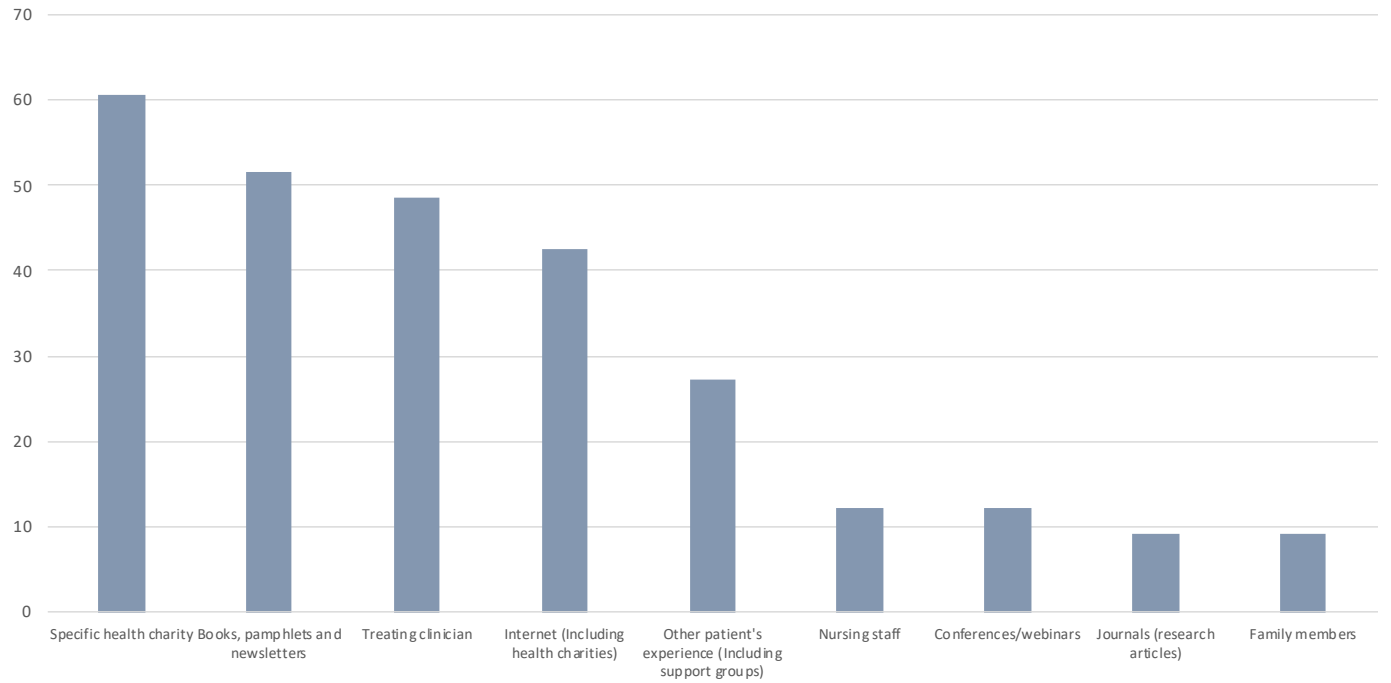

Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information from a specific health charity	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma Aged 65 or older
Participant describes receiving information from books, pamphlets and newsletters	-	CAR T-Cell therapy
Participant describes primarily accessing information through treating clinician	Aged 65 or older Metropolitan	Aged 25 to 64 Regional or remote
Participant describes accessing information through the internet in general	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote
Participant describes primarily accessing information through other patient's experience	CAR T-Cell therapy	-
Participant describes receiving information through nursing staff	CAR T-Cell therapy Male	B-cell acute lymphoblastic leukaemia (ALL) Female
Participant describes receiving information through conferences or webinars	B-cell acute lymphoblastic leukaemia (ALL)	-
Participant describes accessing information primarily through journals (research articles)	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy

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 talking to a doctor, specialist or healthcare team (36.36%), hearing what to expect (e.g. from disease, side effects, treatment)(33.33%), and other people's experiences (21.21 %). Other themes included scientific information, or information from medical journals (12.12%), and information from health charities (9.09%).

Participant describes talking to their doctor or specialist as helpful

I find the information, I guess maybe I just trust my specialist. He's the only, probably, one I would trust out of all the doctors and nurses and everyone else that I've been with. Whatever his information is, is what I go by.
Participant 01_2023AUCRT

The most helpful Just the explanation really. I think of how how the disease came about and what happens and what my doctor actually did, which I thought was quite clever when he explained to me how the disease worked. You know, he drew funny little diagrams and arrows going everywhere, but he did all that. And then he said. I think it was at the next visit you said okay, I told you all that last time. Now I want you to explain it back to me what you understood from what I've told you before. So he got me to tell him what my understanding of it was. So I thought that was a good way of testing how much I understood because I have heard of some people who when they're told they have multiple myeloma, I think that they've got Melanoma.
Participant 012_2023AUCRT

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

I guess it was good to know what what the likely side effects were, the point at which you should call for help. So monitoring your temperature, all that kind of thing. Yeah, just just basically that kind of thing.
Participant 009_2023AUCRT

Just knowing what's available and knowing what to do and because the book of the initial book explained things in good detail and the processes and what you've got to do and and how to how to look after yourself. Really it's a matter of just looking after yourself, yeah.
Participant 018_2023AUCRT

Probably just bouncing back that getting back to your point earlier about some of those side effects. Hey look if I've gone to sort of the information I'm feeling really tired or fatigued does you know does it give you fatigue and what what's the side effects what's gee, you know all the radiation and chemo and all the drugs have had is that causing this that or the other yes it can cause this that now. So I suppose it's it's more not getting an overall thing, it's just probably based around some condition I'm feeling at the the time if I yeah, if it's fatigue or dizziness or you know if my blood pressure is high or or or something like that, yeah, for sure. That's probably what I'd I'd search for it.
Participant 026_2023AUCRT

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

I think the most helpful has been information from people who have also gone through the same thing, and their way of coping and dealing with it, small things like what to eat when you're vomiting. Yes, how you feel and what to expect from that.
Participant 003_2023AUCRT

Participant describes scientific information, or information from medical journals as helpful

The medical, the actual medical stuff, without a doubt
036_2023AUCRT

Most helpful would be like yeah, reading about clinical trials I guess and what the result, Yeah, somewhere you have results and what's worked and hasn't worked I guess.
Participant 021_2023AUCRT

Participant describes health charities information as helpful

The guidebooks they've got available. They're great. There's a whole guidebook on an autologous stem cell transplant. There's a guide book on living well with myeloma. There's a guide book on living with amyloidosis like Yep and also I've. I've also done some online webinars with Leukemia Foundation and and done some online support group stuff which has been good.
Participant 022_2023AUCRT

Table 6.3: Information that was helpful

Information that has been helpful	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes talking to their doctor or specialist as helpful	12	36.36	4	57.14	1	10.00	7	43.75	11	42.31	1	14.29	6	40.00	6	33.33
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	11	33.33	2	28.57	3	30.00	6	37.50	8	30.77	3	42.86	2	13.33	9	50.00
Participant describes other people's experiences as helpful (Peer-to-peer)	7	21.21	1	14.29	3	30.00	3	18.75	6	23.08	1	14.29	4	26.67	3	16.67
Participant describes scientific information, or information from medical journals as helpful	4	12.12	0	0.00	3	30.00	1	6.25	0	0.00	4	57.14	3	20.00	1	5.56
Participant describes health charities information as helpful	3	9.09	0	0.00	1	10.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Information that has been helpful	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes talking to their doctor or specialist as helpful	12	36.36	7	36.84	5	35.71	3	21.43	9	47.37	4	28.57	8	42.11
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	11	33.33	6	31.58	5	35.71	5	35.71	6	31.58	4	28.57	7	36.84
Participant describes other people's experiences as helpful (Peer-to-peer)	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	2	14.29	5	26.32
Participant describes scientific information, or information from medical journals as helpful	4	12.12	2	10.53	2	14.29	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes health charities information as helpful	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	2	14.29	1	5.26

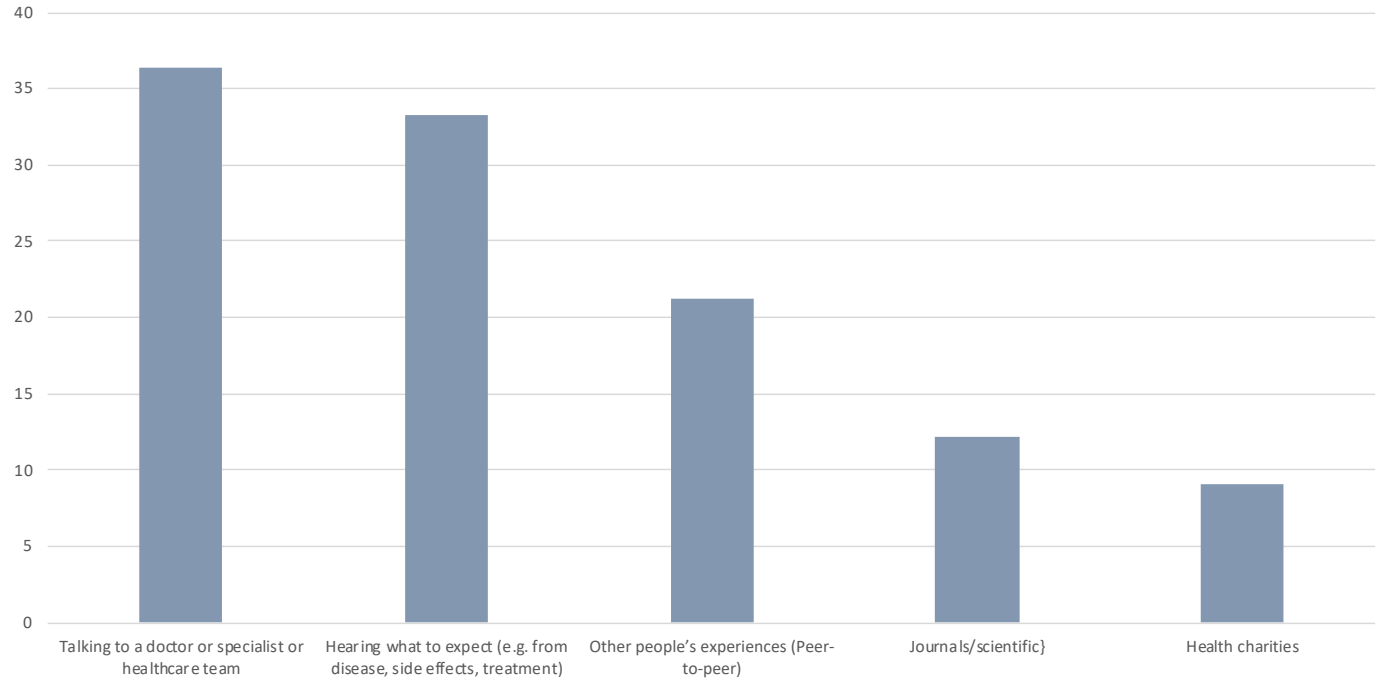

Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes talking to their doctor or specialist as helpful	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Female	Male
Participant describes scientific information, or information from medical journals as helpful	B-cell acute lymphoblastic leukaemia (ALL) No CAR T-Cell therapy Regional or remote	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes health charities information as helpful		Regional or remote

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information was not helpful (36.36%), worse case scenarios (18.18%), and other people's experiences (15.15 %). Other themes included being confident in deciding themselves (12.12%), and sources that are not credible (Not evidence-based) (12.12%).

Participant describes no information being not helpful

No. I think throughout my whole treatment, if you've asked the questions, you've always been given the answers, so I don't think so. I think it's just a matter of you as a person asking what you need to know. My problem is that I don't remember. No, I think everything's been going okay.
Participant 002_2023AUCRT

No, I haven't. I couldn't say that I…I think everything that I've looked at seem really useful. I also did a lot of research on the different genetic markers with prognosis and things like that. I was really interested in that. I've learned a lot.
Participant 004_2023AUCRT

Participant describes information about worse case scenarios and negative information as being not helpful

Sometimes there's times when there's jargon and facts and figures that are sort of just too confusing that are not helpful for a layman. I guess you would say so, yeah, yeah, there's a certain level that. Yeah, that's easier to read than others. And in relation to and something, Sorry, something's not only cause you to panic, and maybe it's not worth reading some of the statistics anyway.
Participant 021_2023AUCRT

Participant describes other people's experiences as being not helpful

Yes. Some of those support groups have horror stories. Then you go, "No. Not going to go in there anymore." [laughs]
Participant 003_2023AUCRT

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

PARTICIPANT: Oodles of it out there, but we've just… try to zero in and concentrate on reliable sources. Probably an example of that, if there is as there is anything in social media, there's quite a while over Facebook page and all that and I got to a point after about two or three weeks and might not just have to turn the notifications of it just to keep out. It was just, yeah, just not helpful, yeah. On that and I just, you know some of the stuff that people are sprouting was you know, I knew was from from reliable and expert sources was complete rubbish
Participant 027_2023AUCRT

Participant describes information from sources that are not credible as not helpful (Not evidence-based/opinions)

Well meaning friends who think they're trying to help. But have no idea.
Participant 022_2023AUCRT

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes no information being not helpful	12	36.36	2	28.57	1	10.00	9	56.25	12	46.15	0	0.00	6	40.00	6	33.33
Participant describes information about worse case scenarios and negative information as being not helpful	6	18.18	2	28.57	3	30.00	1	6.25	5	19.23	1	14.29	4	26.67	2	11.11
Participant describes other people's experiences as being not helpful	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	2	13.33	3	16.67
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	4	12.12	1	14.29	0	0.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67

Information that has not been helpful	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes no information being not helpful	12	36.36	5	26.32	7	50.00	2	14.29	10	52.63	4	28.57	8	42.11
Participant describes information about worse case scenarios and negative information as being not helpful	6	18.18	4	21.05	2	14.29	3	21.43	3	15.79	4	28.57	2	10.53
Participant describes other people's experiences as being not helpful	5	15.15	2	10.53	3	21.43	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes feeling confident in deciding if something is not helpful (or not credible)	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	2	14.29	2	10.53

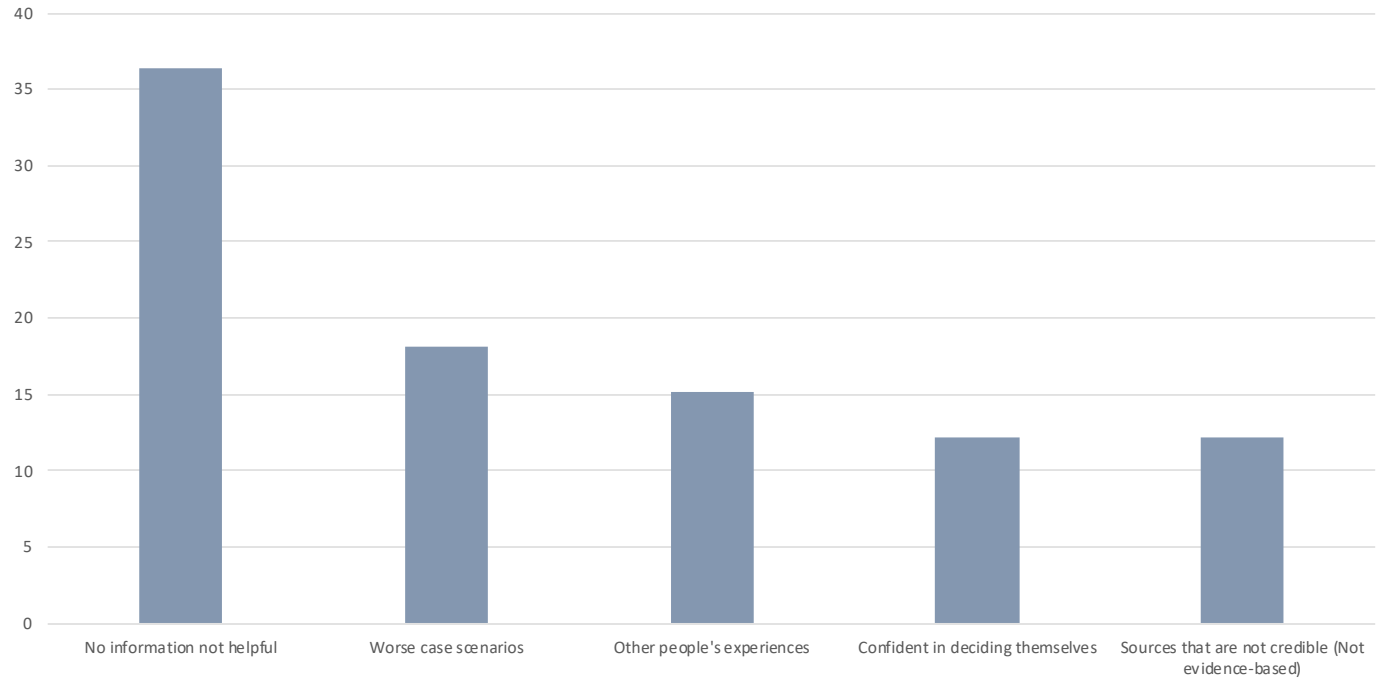

Figure 6.3: Information that was not helpful

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	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote	Multiple Myeloma Aged 65 or older Metropolitan
Participant describes information about worse case scenarios and negative information as being not helpful	Multiple Myeloma	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Mid to low status
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Diffuse Large B-Cell Lymphoma	

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 (39.39%), and talking to someone plus online information (21.21%). Other themes included online information (18.18%), written information (18.18%), and all forms (12.12%).

The main reasons for a preference for talking to someone were being able to ask questions (30.30%), that it was personalised or relevant (21.21%). and because it was supportive (12.12%).

The main reasons for a preference for online information were accessibility (24.24%), that it was personalised or relevant (9.09%), and being able to digest information at their own pace (6.06 %).

The main reason for a preference for written information was that they could easily refer back to it (12.12%).

Participant describes talking to someone as main information preference

Probably maybe talking to someone, probably would be the best option rather than an app. An app or information like that, you could press or look on the wrong information and cross your wires a little bit. Whereas talking to someone, they could make things a lot clearer, so I'd probably go with the talking with someone option.
Participant 01_2023AUCRT

I prefer talking to someone because that way, you can make sure you understand what they're saying. I also do online, but then not a Google thing. It had to be from a reputable source. Basically, I prefer talking to people. That's why I think the group is so good.
Participant 002_2023AUCRT

Talking to someone who can explain it to me so you can actually question what they're saying.
Participant 008_2023AUCRT

Probably talking to someone who's had the experience would be good because they've been through it. Booklets is just basically general like it's how would you say it comes back to an average of every, I think everyone, every individual's different, how things would treat them are you know affect them. So mainly I think the best thing would be to talk to people.
Participant 011_2023AUCRT

Well, talking to someone would be good. I think it's quite a well for me it was quite a emotional stressful experience to go through. I mean I think everybody's experience is is different. So you know for me it was, it was difficult but I think it was that was exacerbated maybe possibly by my own personal kind of situation. So but you know I possibly should have sought more help in that area than I did again you know and I didn't. So I think that's an area which it's available, but I didn't utilize it and like you know, so that the hospital does provide those things that I didn't take them up on it.
Participant 015_2023AUCRT

Participant describes talking to someone plus online information as main information preference

PARTICIPANT: Probably something written down with but that you can talk to someone about as well. So so I guess in that first instance you're talking, but then you've also got that written note to refer back to. But yeah, it's it's also good to look things up if there's, if you know where you can go online to to find the right information. So yeah.
INTERVIEWER: And is there a reason you also prefer speaking to someone?
PARTICIPANT: Probably because you can based on what they say. Then you can interact back and say, oh, so why is that? Or does that mean if I did this I could do that or? Do you do you know what I mean?
Participant 006_2023AUCRT

Participant describes online information as main information preference

Probably prefer to do it by myself rather than talking to someone, so probably online on my phone for convenience.
Participant 005_2023AUCRT

Participant describes written information as main preference

I like booklets because I'm old enough not to be too computer savvy, so I like having a hard copy of something I can look at so I can go back and revise. Yeah, so for me it's written.
Participant 009_2023AUCRT

I probably prefer personally booklets and talking that could be generational, but but the only thing I've found with with the Internet is is whoever pays the most gets up at the top. And a lot of it's American based, which again, I know myeloma is myeloma and whatever country you're in. But a lot of the American stuff, I don't know it just I didn't relate to it as well. And then it also somewhere in there there'd be something trying to sell you something and all that sort of stuff and that was just and and there's so much information on the Internet. It's like, well, you know it's just so just keep it simple. Keep it down to half a dozen different things, whatever it may be. And then I can sort of interpret what you've told me in those booklets or this person, if I unsure of something, talking to a person's a good way to get it explained to you because then I can bouncered back to them in my way of understanding. They can correct me or or or tell me it's right, whatever.
Participant 019_2023AUCRT

Yeah, probably I always do like something written, I like talking to people, but I also like to follow up with something written so you can reread, reread and digest it again later. So I think, I think both two prong approach is good and I usually go to master points with my husband and I think that's been important because we often have sometimes we'll have a different understanding and then we of what something was said and I need to clarify it. So I do think that if someone people always have someone else that they can attend appointments with, it's useful.
Participant 021_2023AUCRT

I still, I still love to read, you know, from the paper. Yeah, but of course that will go on Google. But my preferred one, I took all those, you know, paper printed booklets and I kept reading them with me and referring to them again and again.
Participant 034_2023AUCRT

Participant describes prefering all forms of information

PARTICIPANT: All of those things have their place.
INTERVIEWER: Do you have a preference at all for one or the other or do you prefer a myriad, all of them?
PARTICIPANT: A myriad, different sorts of information.
Participant 003_2023AUCRT

PARTICIPANT: All of it. [laughs]
INTERVIEWER: Okay. What's the reason for that?
PARTICIPANT: I think it's good to read things. I think it's really good to talk to people, like online talking is really good. As I said that, the leukemia, support group has been fantastic, and everyone is so supportive of each other and encouraging and it's just been really good. We felt like everybody can help each other in some way, so I find that really good. Talking to someone, I think it's really good. I haven't really spoken verbally to people about it, it's more being online, and online is good.
INTERVIEWER: It sounds like as much information in different forms is great.
PARTICIPANT: Yes, different formats.
Participant 004_2023AUCRT

Oh, no, I think they all have their place. Yeah, I'm quite used to reading things online. But yeah, I don't mind if it's printed or I don't go into it, you know, in depth. Like, I know some people, when they have their blood tests done, they know every single thing that's being measured, what it means and what up and down and all that means in those different levels. And I haven't bothered going into that because my doctor goes through it with me and he goes, well, you know, your kidneys are working well, this is working well, that's working well. The white cells are low, but that just means you have to be careful of infection. It goes through it in a general way with me. And so I don't bother wanting to know all the ins and outs of what all those blood levels mean.
Participant 012_2023AUCRT

Table 6.7: Information preferences

Information preferences	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes talking to someone as main information preference	13	39.39	3	42.86	3	30.00	7	43.75	11	42.31	2	28.57	5	33.33	8	44.44
Participant describes talking to someone plus online information as main information preference	7	21.21	3	42.86	0	0.00	4	25.00	6	23.08	1	14.29	2	13.33	5	27.78
Participant describes online information as main information preference	6	18.18	1	14.29	3	30.00	2	12.50	4	15.38	2	28.57	3	20.00	3	16.67
Participant describes written information as main preference	6	18.18	1	14.29	3	30.00	2	12.50	2	7.69	4	57.14	4	26.67	2	11.11
Participant describes prefering all forms of information	4	12.12	0	0.00	2	20.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56

Information preferences	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes talking to someone as main information preference	13	39.39	8	42.11	5	35.71	6	42.86	7	36.84	7	50.00	6	31.58
Participant describes talking to someone plus online information as main information preference	7	21.21	4	21.05	3	21.43	2	14.29	5	26.32	2	14.29	5	26.32
Participant describes online information as main information preference	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	3	21.43	3	15.79
Participant describes written information as main preference	6	18.18	5	26.32	1	7.14	1	7.14	5	26.32	1	7.14	5	26.32
Participant describes prefering all forms of information	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	2	14.29	2	10.53

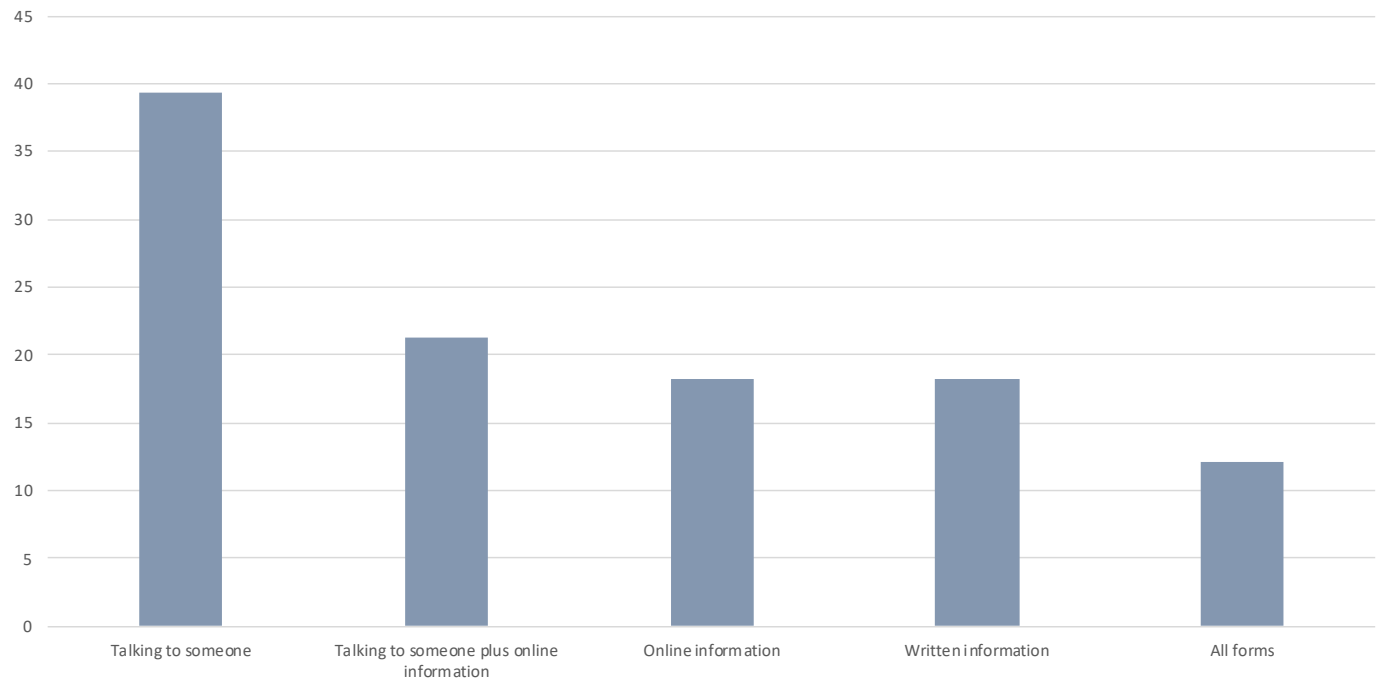

Figure 6.4: Information preferences

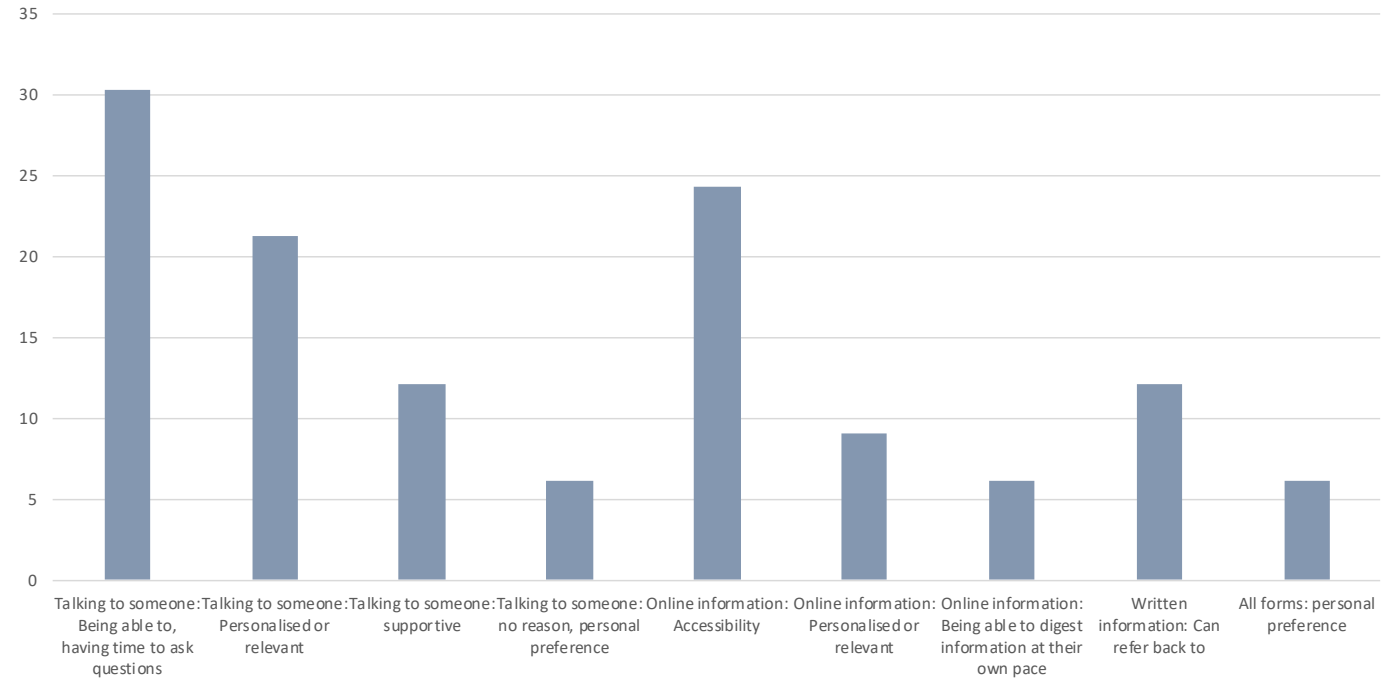

Figure 6.5: Reasons for information preferences by format

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone as main information preference	CAR T-Cell therapy	Mid to low status
Participant describes talking to someone plus online information as main information preference	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes online information as main information preference	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes written information as main preference	No CAR T-Cell therapy Aged 65 or older Regional or remote Mid to low status	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes prefering all forms of information	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-

Table 6.8: Information preferences – subgroup variations

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) (36.36%), after the shock of diagnosis (15.15%), continuously (15.15 %), and after treatment (12.12%).

Participant describes being receptive from the beginning (diagnosis)

I think straight away because I really wanted to know what was happening, but that's just the way I am. I wanted to be informed as much as possible, so I knew what I was dealing with so I took it in and read it, and read it, and read it. [laughs]
Participant 004_2023AUCRT

I think right from the word go, yeah. Yeah, Yeah. Right, Right from the word go. As soon as I got it. That's fine. You know, as I said, nothing bothers me. I'm very happy to go and do anything, you know? Yeah.
Participant 018_2023AUCRT

Probably from day one, just cuz I just wanted to know what was going on. It's just the unknown is what's scary I suppose. It's unknown what's going to happen, what is this drug or what is, what is a biopsy or what is, you know, the the consequences of of taking all these drugs. What's going to happen to me? I don't have any family with me at the moment, things like that. So it's a bit scary at the time.
Participant 024_2023AUCRT

Probably at the very beginning.
Participant 025_2023AUCRT

Participant describes being receptive to information after the shock of diagnosis

Probably a day or two after diagnosis, I guess after the initial shock had worn off.
Participant 005_2023AUCRT

Probably by about the 3rd or 4th day after I was diagnosed. I think the first day or two it was just such a shock and. I was having quite a bit of pain with my neck with that swollen bit and and just like Oh my God, what's happening. So it was it was probably a little bit of a blur then, but once I sort of got over that initial shock then I could was able to start reading the stuff and really talking to them about different options and what happens and that sort of thing.
Participant 006_2023AUCRT

Yeah, that's a really good question. Initially it is a bit overwhelming, you know, always, you know, and my wife and daughter were there when I was diagnosed and when they said, you know, you got one to three years, they were kind of very upset and shit. So we actually sold the house and we moved. We lived very close to the hospital now…So you know, because I was going to the hospital six days a week or something, but now things have, so I'm more receptive. Sorry I got off track, more receptive to overwhelming in the beginning, but as I as my health started to improve and my mobility and also my mental focus, I was able to absorb information a bit better. Participant 031_2023AUCRT

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

That never really stopped. I wasn't better or less on take it in all the way through.
Participant 022_2023AUCRT

Yeah, that's tough. I think it was overwhelming, as you said, overwhelming to start with because there was so much information in the book and then. That's what it's virtually impossible to I guess recall everything that you've read you know regarding you know finer points of everything and you know how the how it all works. But I think as you get on the they seem the the topics for each zoom meeting you can choose. You don't have to access every meeting with it is relevant, yeah. It's that's the most helpful thing and it's and this and they actually do re reiterate the basics as well over now and then just so that you know you don't if you got something that's back back on the agenda again as far as the topic. So it's really helpful to have have a like a revision every now and then. And that's obviously the you know like the people, the two organizations that do most of the Zoom meetings are aware of how how to sort of structure the like with the with Leukemia Foundation.
Participant 032_2023AUCRT

Participant describes being receptive to information after treatment

Definitely more of the back end of treatment. In the beginning, I felt bombarded with information. I was overloaded too much. It just was too much. Whereas the middle to end of my treatment, I probably absorbed it a lot more, and I was able to observe it a lot more. I was a lot more clearer thinking than probably just all being bombarded even with, I might sound rude, but ignorant people that used to come into the hospital, like the social workers. I think there was help support and then I had my PICC dressing ladies. I had problems with my PICC. It wasn't smooth sailing. I just felt like there was constantly bombarding of people all the time in there with their information and then printed off the information they would give you. It was just too much.
Participant 01_2023AUCRT

Well, at the beginning of the diagnosis, my brain was too busy with other things. So the further I get from the treatment, from the diagnosis and now I'm learning how to live with the cancer day-to-day. My brain is more capable of absorbing more information now and from now onward. But the further I go, if I live longer, the more information would be more helpful. But at the beginning I was too scared, too shocked. I was not quite sure what's happening around me. I couldn't even imagine. Yeah, thinking about other things than chemotherapy and these kind of things. So, yeah, from now on. And yeah, after the diagnosis, it's getting more and more clear and more and more.
Participant 017_2023AUCRT

Probably a couple of, well, you know, not not straight away. Obviously, the first week's just a blur. But yeah, probably a month or two into it because. Yeah. So the the first, you know, week or two, it's just simply just a blur. It's like, yeah, And that's what happened. I got diagnosed. So we're going to check in, you know, ambulance rushing off the hospital, start chemo the next day, run these tests. This is what the reliance is. And I was like whoa, because in in amongst that you've got painkillers which blow you a bit, make you bit cuzzy as well. So any all the heavy ones, Oxy and that sort of stuff. So you'd be a bit foggy at first. And

there's also it is such a blur like you've got, you know I've got my wife and daughter crying on the in the bed and the doctor telling me that I won't live to Christmas and then my my extended family which is quite large or ringing in from all over the country checking in, I mean it…and then to take it all in, it's almost secondary.
Participant 019_2023AUCRT

Table 6.9: Timing of information

Timing of information	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes being receptive from the beginning (diagnosis)	12	36.36	2	28.57	5	50.00	5	31.25	8	30.77	4	57.14	5	33.33	7	38.89
Participant describes being receptive to information after the shock of diagnosis	5	15.15	1	14.29	1	10.00	3	18.75	5	19.23	0	0.00	2	13.33	3	16.67
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	15.15	1	14.29	2	20.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Participant describes being receptive to information after treatment	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	3	20.00	1	5.56

Timing of information	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes being receptive from the beginning (diagnosis)	12	36.36	5	26.32	7	50.00	5	35.71	7	36.84	4	28.57	8	42.11
Participant describes being receptive to information after the shock of diagnosis	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes being receptive to information after treatment	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	3	21.43	1	5.26

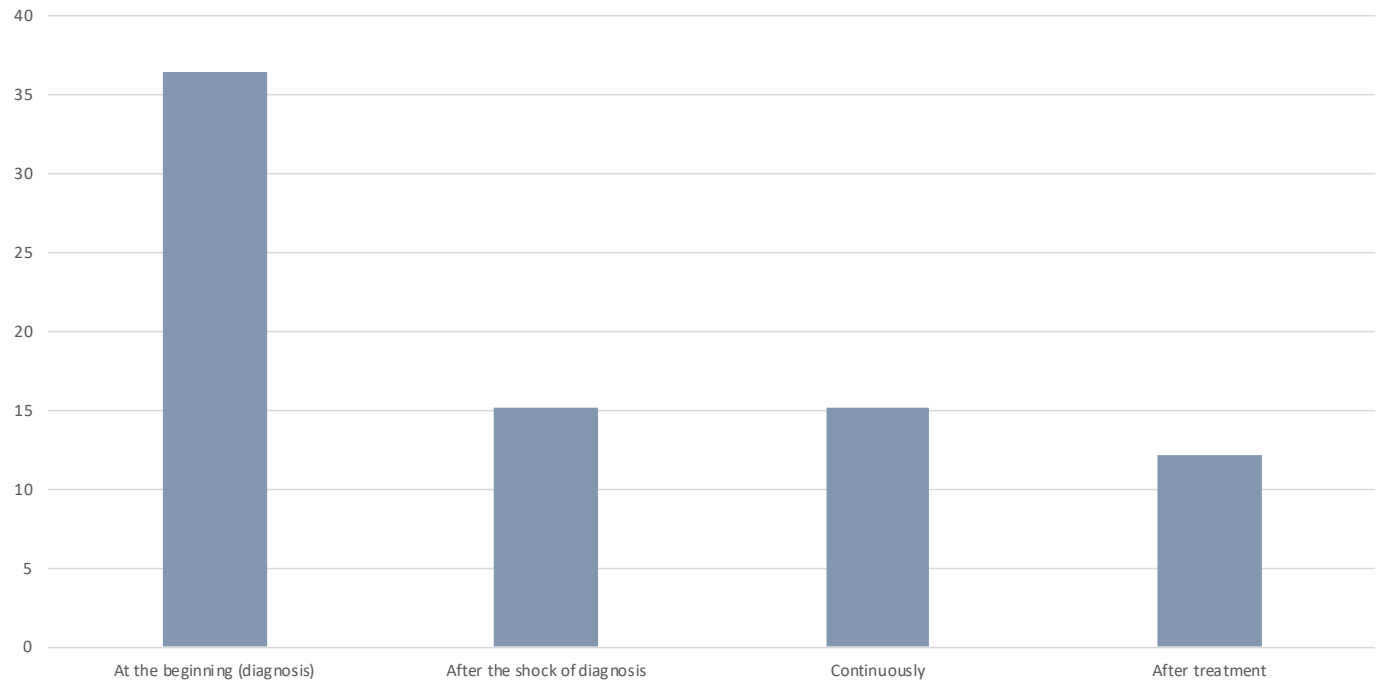

Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Aged 25 to 64	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older
Participant describes being receptive to information after the shock of diagnosis	CAR T-Cell therapy	
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	-	CAR T-Cell therapy
Participant describes being receptive to information after treatment	Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having overall positive communication (75.76%), communication that was overall positive, with the exception of one or two occasions(18.18%), and overall negative communication (6.06 %).

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (60.61%), good, with no particular reason given (18.18%), good especially in relation to multi-disciplinary communication (9.09 %). and good, yet limited in relation health to professionals not having a lot of time (6.06%). For those describing negative communication, this was because information was not forthcoming (9.09%) and limited in relation to their understanding of the condition (6.06%).

Participant describes communication with healthcare professionals as overall positive

Overall, like I said, a 10 out of 10 with SPECIALIST. Even with my regular GP, she doesn't do anything without consulting with him either, now.
Participant 01_2023AUCRT

Yes, really good. Like I said before, any questions that I've had, they had answered or got back to me with an answer.
Participant 005_2023AUCRT

Generally speaking very good. I mean you have, I mean it's it's always hard of being a patient because you're always ready for answers and doctors are not always, they do their best, but they're you know they've got timetables and sometimes only see patients one or two days a week. So within the constraints of the system I think that been very forthcoming and available the most, the best for me has been having community nurses or a nurse overseeing your your case they always answer the phone and they can always get those an answer from the doctor and get back to you. So, yeah, so I've had a nurse that there's someone that sort of coordinates the CAR T that they're always available to talk and answer the phone. And I've had someone that I've always been under, nurses, I've seen my case and now I can ring her number and she answers.
Participant 021_2023AUCRT

Fantastic. I cannot, I cannot praise them more than yeah they have been absolutely there. They they spend their time, they happy to spend time with you. They explain things in great detail. Again, it's a little bit over my head sometimes, but I always have NAME with me. So the two of us can usually put it together. And also I've always got NAME to re explain things. Yeah.
Participant 018_2023AUCRT

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

I found the nurses really helpful, but they could only say so much. Hard to get information out of the doctors. I found the residents were easier to talk to than the specialists. I think this is a common complaint. They're very busy, and I understand that. Often I had no idea what was going on really.
Participant 003_2023AUCRT

Yeah, really good. No, I've I've found I've always asked questions to the extent that you would want them answered and have given me useful information. You're able to to to give you the realistic thoughts without being too too negative but that that sort of thing. I mean I I always ask a lot of questions as well. So I suppose I probably get better value than some people because because of that whereas if you're just waiting for them to tell you stuff you probably don't get told as much but. No, I've. I've found you that the information's been good and everyone's been great with oh, except for that. As I've touched on before when I was at that rehabilitation place, I didn't really like it.
Participant 006_2023AUCRT

Look, if I talk about, look, I'm going to say overall it's been amazing. I have the phone number of the mobile for my bone marrow transplant specialist and I'm to ring him if I'm worried or if I have to go to hospital or if or text him if I've got questions. So that's amazing. And the other services at HOSPITAL are all very accessible, although trickier on the weekends, but you know on the whole really accessible. The oncologist I had though in the start pretty hopeless really. Yeah. So I've got, I've got from one extreme to the other,

amazing and but you know for everyone but him, hopeless.
Participant 016_2023AUCRT

Participant describes communication with healthcare professionals as overall negative

About that communication overall, pretty poor. The only information I've got is because I ask the questions, not because they offer answers.
Participant 008_2023AUCRT

Well, because I didn't. No, it was because it was going outside of my my capability to un to understand I suppose. You know there were I there were things that I didn't know and I wasn't going to be able to know. And it and it I think there was a brief period a couple a couple of brief periods where I was a little bit resentful about the fact that I that I didn't didn't understand everything and I guess I was I was wanting to be able to understand everything and and blaming the people who weren't weren't able to make me understand but that was that was brief and that then you know because I realized that that's that it was not really possible to for me to understand it properly in some ways they they they they just knew a lot more than I did they didn't know everything either.
Participant 014_2023AUCRT

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes communication with healthcare professionals as overall positive	25	75.76	5	71.43	9	90.00	11	68.75	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	6	18.18	2	28.57	1	10.00	3	18.75	6	23.08	0	0.00	3	20.00	3	16.67
Participant describes communication with healthcare professionals as overall negative	2	6.06	0	0.00	0	0.00	2	12.50	1	3.85	1	14.29	0	0.00	2	11.11

Healthcare professional communication	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes communication with healthcare professionals as overall positive	25	75.76	14	73.68	11	78.57	9	64.29	16	84.21	11	78.57	14	73.68
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	6	18.18	5	26.32	1	7.14	4	28.57	2	10.53	3	21.43	3	15.79
Participant describes communication with healthcare professionals as overall negative	2	6.06	0	0.00	2	14.29	1	7.14	1	5.26	0	0.00	2	10.53

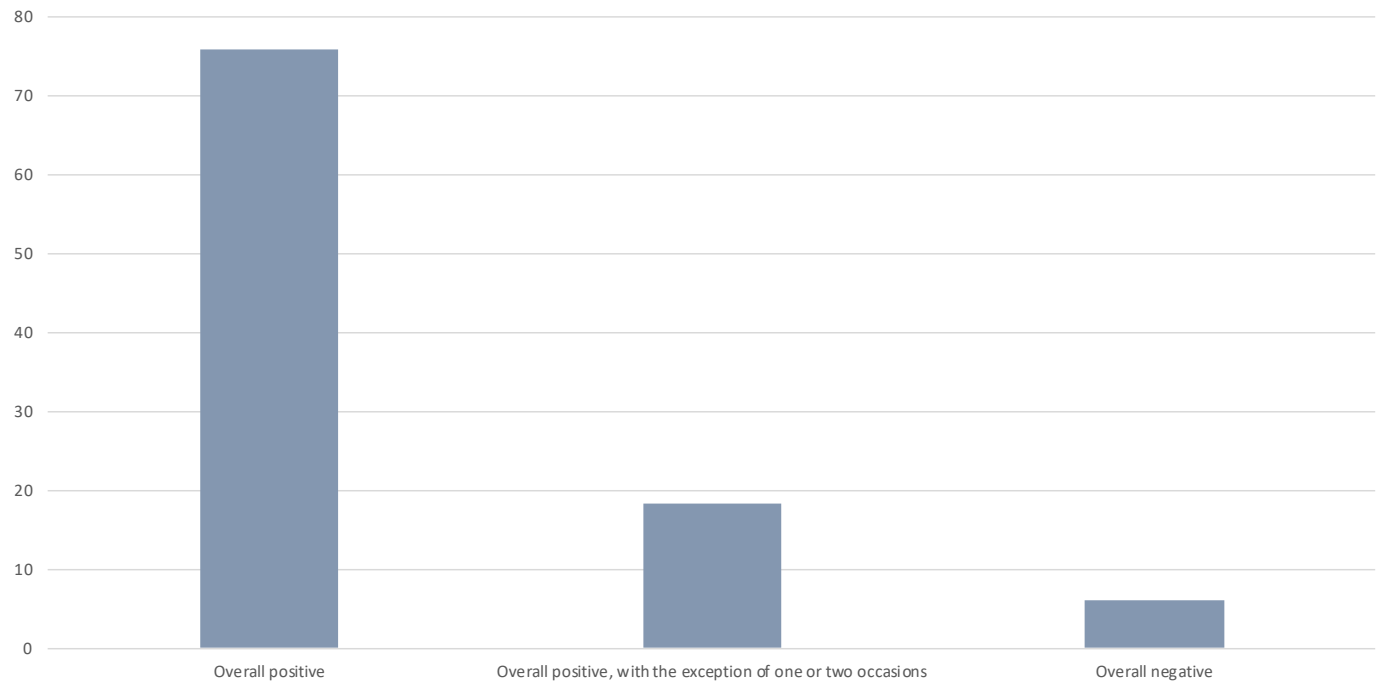

Figure 6.7: Healthcare professional communication

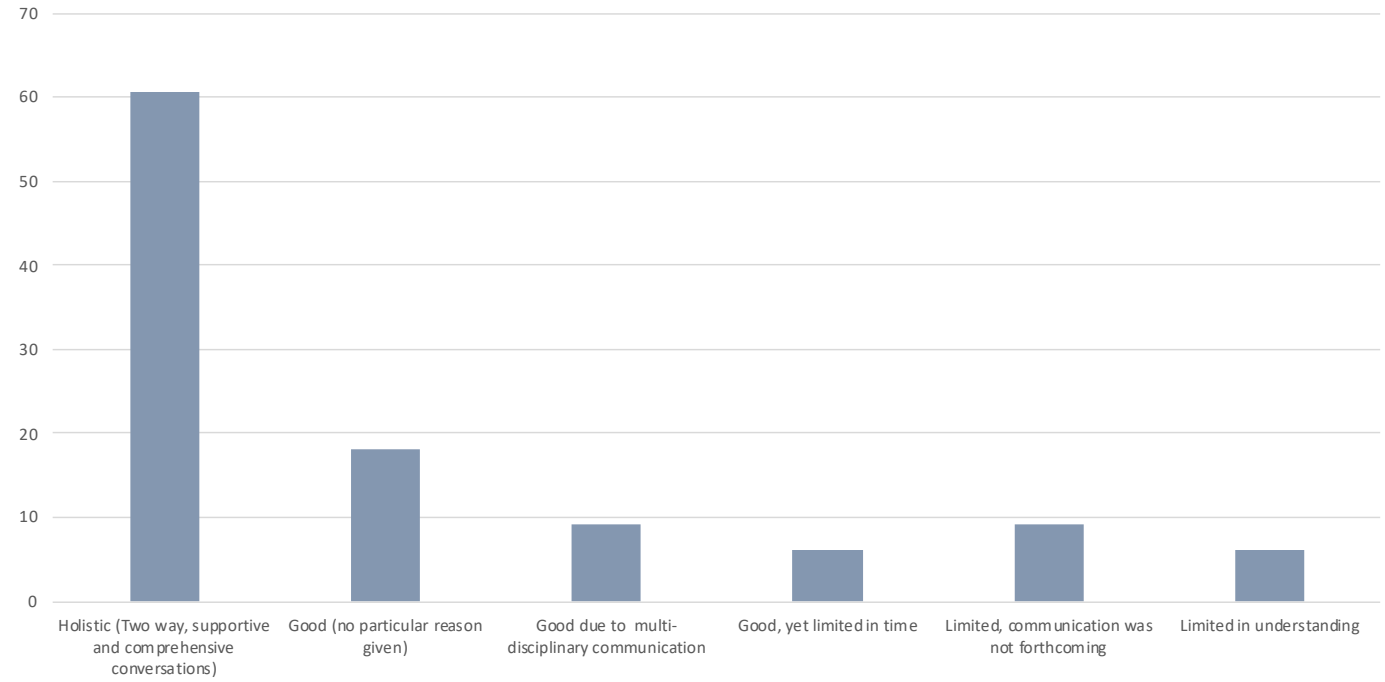

Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes communication with healthcare professionals as overall positive	Regional or remote	Diffuse Large B-Cell Lymphoma
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in the table below.

The overall scores for the cohort were in the highest quintile for Partners in health:Knowledge (median=30.00, IQR=4.00), Partners in health:Recognition and management of symptoms (median=22.00, IQR=5.50), Partners in health:Adherence to treatment (median=16.00, IQR=1.00), Partners in health:Total score (median=85.00, IQR=12.50) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health

The overall scores for the cohort were in the second highest quintile for Partners in health: Coping (mean=16.61, SD=4.58), indicating good coping.

Comparisons of Partners in health have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

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

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

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

had a good ability to manage the effects of their health condition.

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

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

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

Table 6.13: Partners in health summary statistics

Partners in health scale (n=31)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	27.58	5.01	30.00	4.00	0 to 32	5
Coping*	16.61	4.58	18.00	6.00	0 to 24	4
Recognition and management of symptoms	20.71	3.66	22.00	5.50	0 to 24	5
Adherence to treatment	15.16	1.92	16.00	1.00	0 to 16	5
Total score	80.06	12.22	85.00	12.50	0 to 96	5

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

Partners in health by blood cancer type

Comparisons were made by type of blood cancer. There were 5 participants (16.13%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (32.26%) with Diffuse Large B-Cell Lymphoma, and 16 participants (51.61%) with Multiple Myeloma.

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

No significant differences were observed between participants by **blood cancer type** for any of the Partners in health scales.

Table 6.14: Partners in health by blood cancer type summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	16.20	3.11	Between groups	11.6	2	5.81	0.26	0.7700
	Diffuse Large B-Cell Lymphoma	10	32.26	17.50	3.63	Within groups	617.7	28	22.06		
	Multiple Myeloma	16	51.61	16.19	5.54	Total	629.3	30	27.87		

Table 6.15: Partners in health by blood cancer type summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	30.00	3.00	0.31	2	0.8583
	Diffuse Large B-Cell Lymphoma	10	32.26	30.00	5.25			
	Multiple Myeloma	16	51.61	28.50	3.50			
Recognition and management of symptoms	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	24.00	5.00	2.46	2	0.2928
	Diffuse Large B-Cell Lymphoma	10	32.26	23.50	4.75			
	Multiple Myeloma	16	51.61	21.00	2.75			
Adherence to treatment	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	16.00	1.00	2.15	2	0.3405
	Diffuse Large B-Cell Lymphoma	10	32.26	15.50	1.75			
	Multiple Myeloma	16	51.61	16.00	0.00			
Total score	B-cell acute lymphoblastic leukemia (ALL)	5	16.13	85.00	9.00	0.30	2	0.8607
	Diffuse Large B-Cell Lymphoma	10	32.26	86.00	9.00			
	Multiple Myeloma	16	51.61	78.50	14.25			

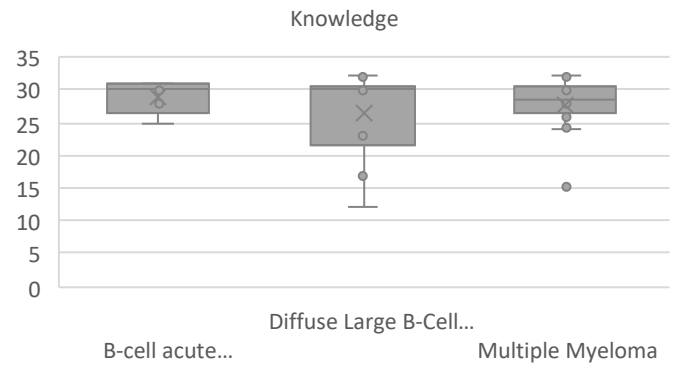

Figure 6.9: Boxplot of Partners in health: knowledge by blood cancer type

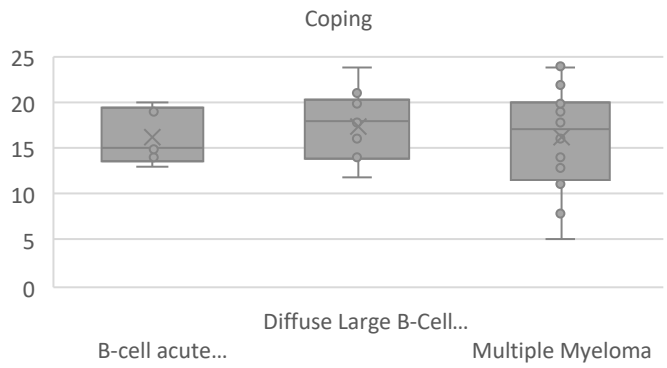

Figure 6.10: Boxplot of Partners in health: coping by blood cancer type

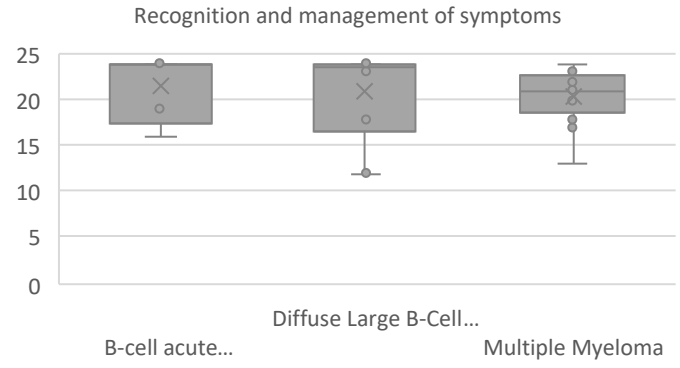

Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by blood cancer type

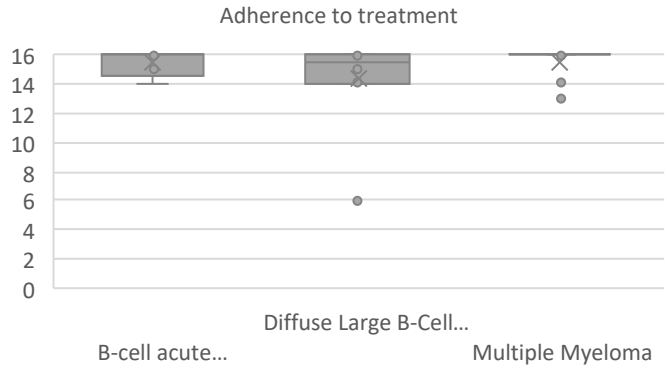

Figure 6.12: Boxplot of Partners in health: adherence to treatment by blood cancer type

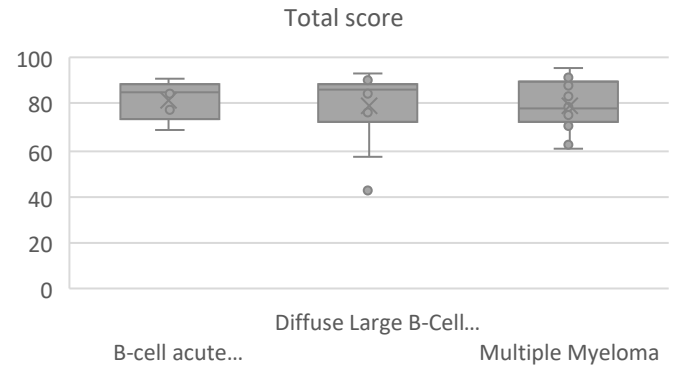

Figure 6.13: Boxplot of Partners in health Total score by blood cancer type

Partners in health by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 24 participants (77.42%) that had treatment with Car T-cell therapy and, 7 participants (22.58%) that did not .

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Partners in health scales.

Table 6.16: Partners in health by CAR T-cell therapy summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	No	24	77.42	16.17	4.70	-1.00	29	0.3234
	Yes	7	22.58	18.14	4.10			

Table 6.17: Partners in health by CAR T-cell therapy summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	No	24	77.42	29.50	4.00	101.50	0.4164
	Yes	7	22.58	30.00	11.00		
Recognition and management of symptoms	No	24	77.42	22.00	4.25	92.50	0.7010
	Yes	7	22.58	22.00	6.00		
Adherence to treatment	No	24	77.42	16.00	1.25	93.00	0.6274
	Yes	7	22.58	16.00	1.00		
Total score	No	24	77.42	84.50	12.25	82.50	0.9623
	Yes	7	22.58	86.00	19.50		

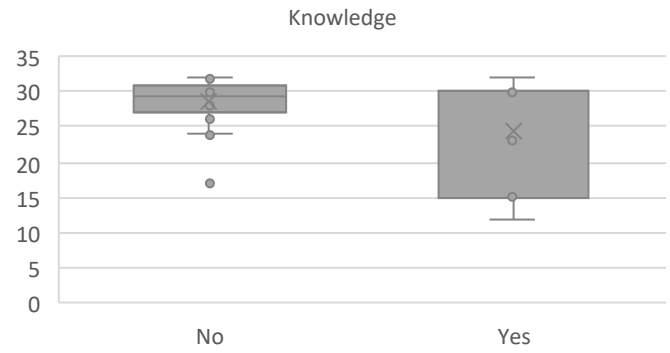

Figure 6.14: Boxplot of Partners in health: knowledge by CAR T-cell therapy

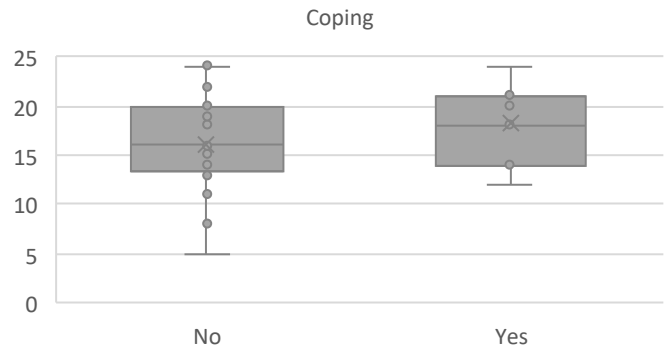

Figure 6.15: Boxplot of Partners in health: coping by CAR T-cell therapy

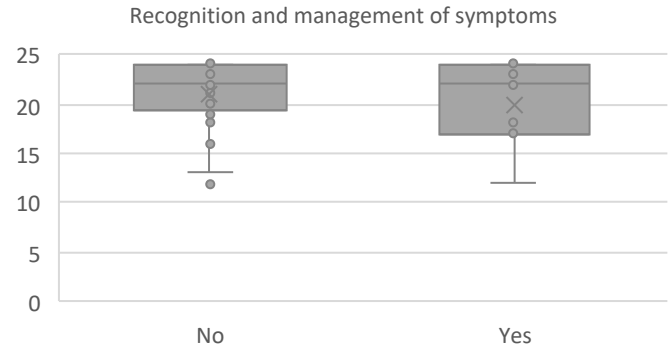

Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by vvvvvvvv CAR T-cell therapy

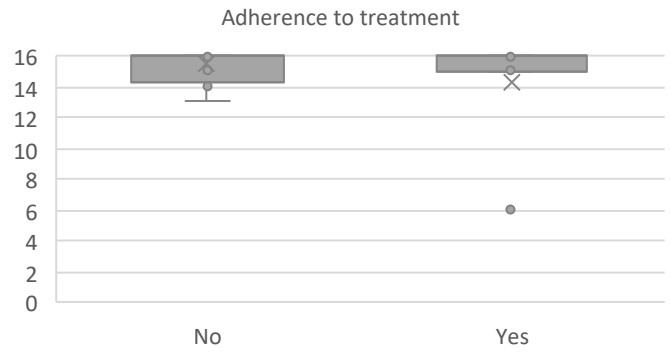

Figure 6.17: Boxplot of Partners in health: adherence to treatment by CAR T-cell therapy

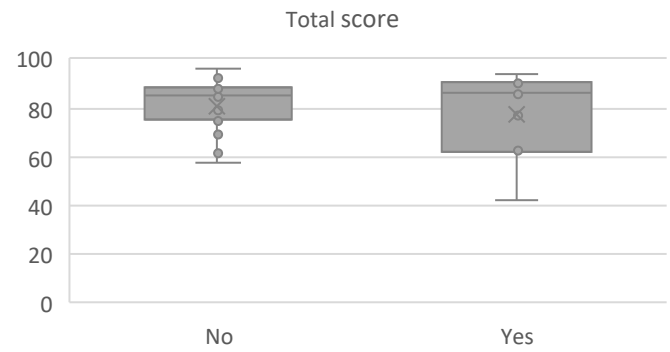

Figure 6.18: Boxplot of Partners in health Total score by CAR T-cell therapy

Partners in health by gender

Comparisons were made by gender, there were 13 female participants (41.94%), and 18 male particpants (58.06%).

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

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

Table 6.18: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Female	13	41.94	18.46	4.01	2.00	29.00	0.0546
	Male	18	58.06	15.28	4.60			

Table 6.19: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Female	13	41.94	30.00	1.00	146.50	0.2401
	Male	18	58.06	28.00	6.50		
Recognition and management of symptoms	Female	13	41.94	23.00	4.00	165.00	0.0534
	Male	18	58.06	21.00	5.50		
Adherence to treatment	Female	13	41.94	16.00	1.00	126.00	0.6809
	Male	18	58.06	16.00	1.75		
Total score	Female	13	41.94	86.00	10.00	165.50	0.0544
	Male	18	58.06	78.00	17.75		

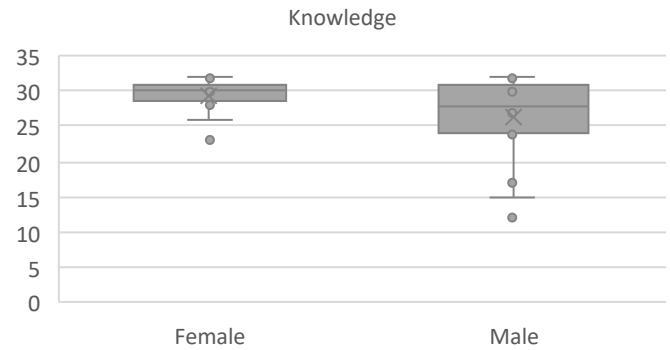

Figure 6.19: Boxplot of Partners in health: knowledge by gender

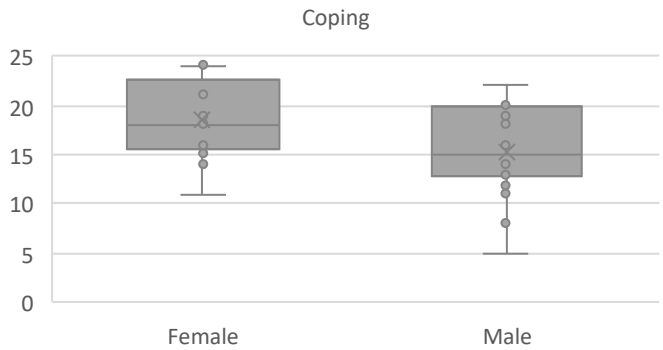

Figure 6.20: Boxplot of Partners in health: coping by gender

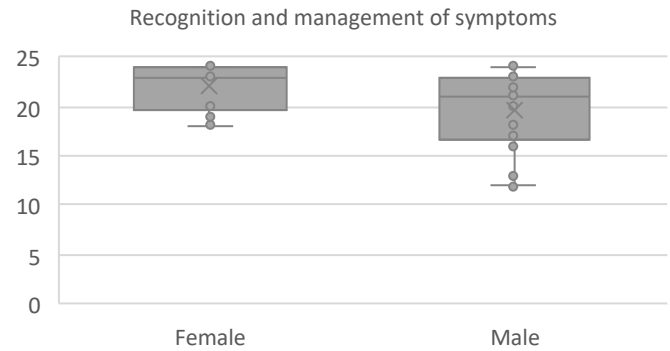

Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by gender

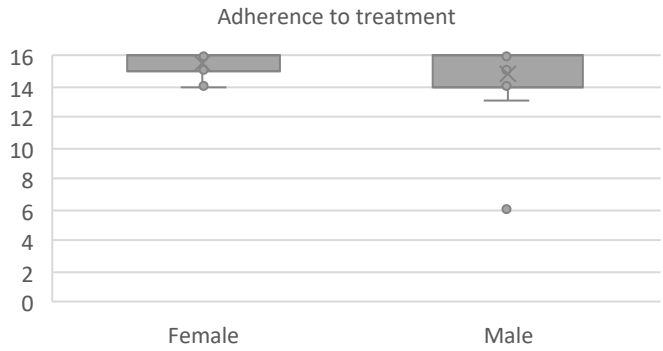

Figure 6.22: Boxplot of Partners in health: adherence to treatment by gender

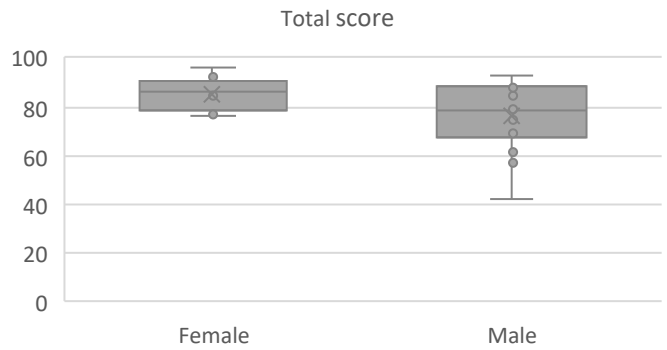

Figure 6.23: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=17, 54.84%), and participants aged 65 and older (n=14, 45.16%).

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

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

Table 6.20: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Aged 25 to 64	17	54.84	15.41	4.11	-1.65	29.00	0.1087
	Aged 65 and older	14	45.16	18.07	4.84			

Table 6.21: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 64	17	54.84	29.00	5.00	96.50	0.3769
	Aged 65 and older	14	45.16	30.00	4.50		
Recognition and management of symptoms	Aged 25 to 64	17	54.84	21.00	6.00	102.50	0.5188
	Aged 65 and older	14	45.16	22.50	3.25		
Adherence to treatment	Aged 25 to 64	17	54.84	16.00	2.00	85.00	0.1080
	Aged 65 and older	14	45.16	16.00	0.00		
Total score	Aged 25 to 64	17	54.84	78.00	11.00	80.00	0.1260
	Aged 65 and older	14	45.16	86.50	12.00		

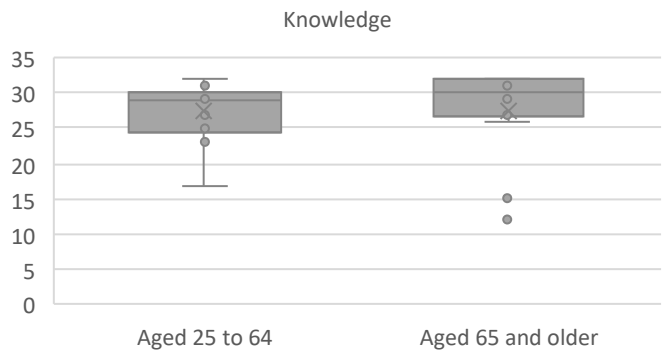

Figure 6.24: Boxplot of Partners in health: knowledge by age

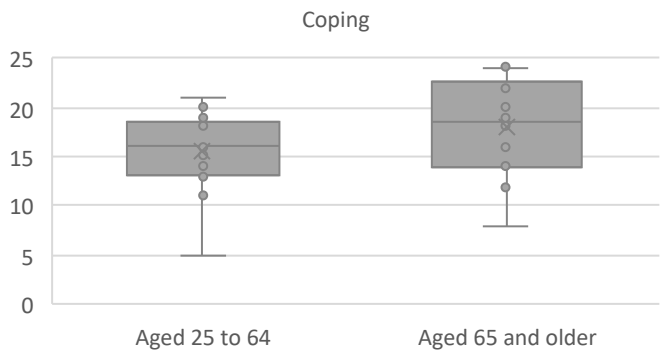

Figure 6.25: Boxplot of Partners in health: coping by age

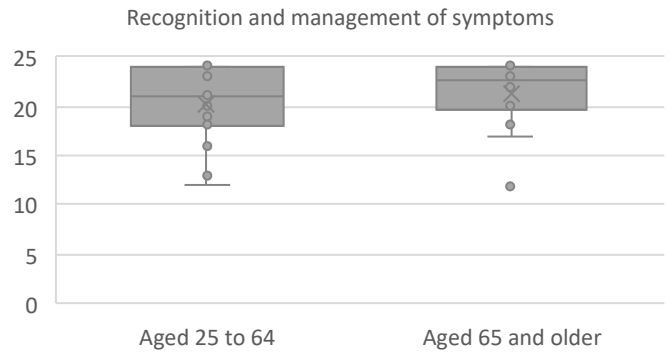

Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by age

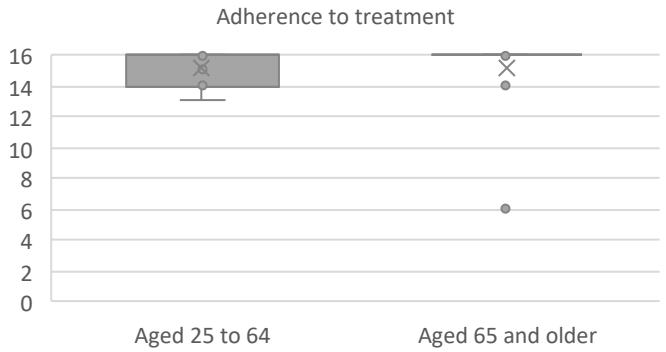

Figure 6.27: Boxplot of Partners in health: adherence to treatment by age

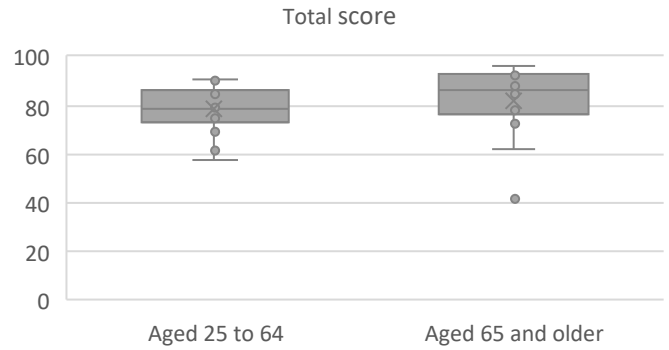

Figure 6.28: Boxplot of Partners in health Total score by age

Partners in health by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=15, 48.39%) were compared to those living in a major city (n=16, 51.61%).

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

A two sample t-test indicated that the mean score for the Partners in health Coping scale [t(29) = -2.80 , p = 0.0090*] was significantly lower for participants in the Metropolitan subgroup (Mean = 14.47, SD = 4.61) compared to participants in the Regional or remote subgroup (Mean = 18.63, SD = 3.63.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Recognition and management of symptoms scale [W = 56.50 , p = 0.0114*] was significantly lower for participants in the Metropolitan subgroup (Median = 20. 00, IQR = 5.50) compared to participants in the Regional or remote subgroup (Median = 23.00, IQR = 2.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Partners in health Total score scale [W = 44.50 , p = 0.0030*] was significantly lower for participants in the Metropolitan subgroup (Median = 76. 00, IQR = 16.50) compared to participants in the Regional or remote subgroup (Median = 86.50, IQR = 5.75).

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Regional or remote subgroup scored higher than

participants in the Metropolitan subgroup, however, coping with their condition was good for both groups.

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 Regional or remote subgroup had a higher total score for navigation compared to Metropolitan subgroup, however recognition and management of symptoms was very good for both groups.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Regional or remote subgroup scored higher than participants in the Metropolitan subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Regional or remote subgroup, and good for participants in the Metropolitan subgroup.

Table 6.22: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Metropolitan	15	48.39	14.47	4.61	-2.80	29.00	0.0090*
	Regional or remote	16	51.61	18.63	3.63			

Table 6.23: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Metropolitan	15	48.39	28.00	6.50	64.50	0.0278*
	Regional or remote	16	51.61	30.00	2.50		
Recognition and management of symptoms	Metropolitan	15	48.39	20.00	5.50	56.50	0.0114*
	Regional or remote	16	51.61	23.00	2.00		
Adherence to treatment	Metropolitan	15	48.39	16.00	2.00	84.00	0.0899
	Regional or remote	16	51.61	16.00	0.00		
Total score	Metropolitan	15	48.39	76.00	16.50	44.50	0.0030*
	Regional or remote	16	51.61	86.50	5.75		

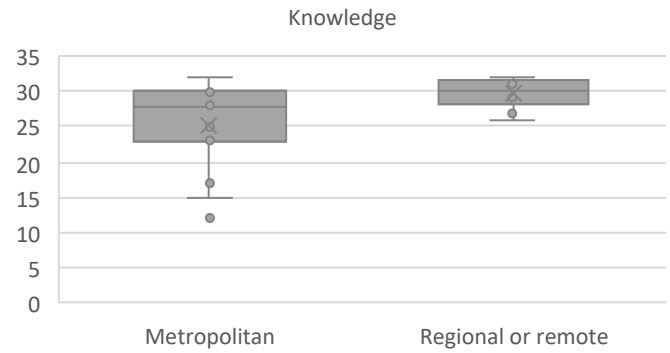

Figure 6.29: Boxplot of Partners in health: knowledge by location

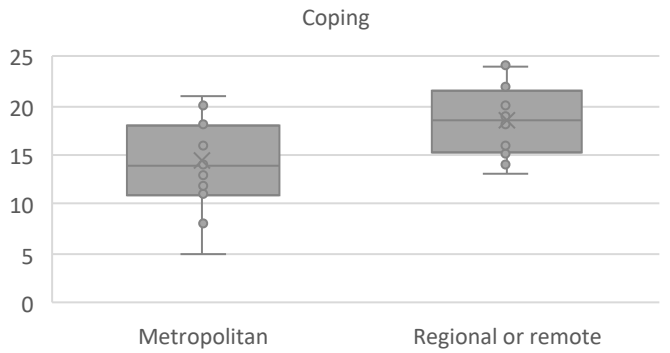

Figure 6.30: Boxplot of Partners in health: coping by location

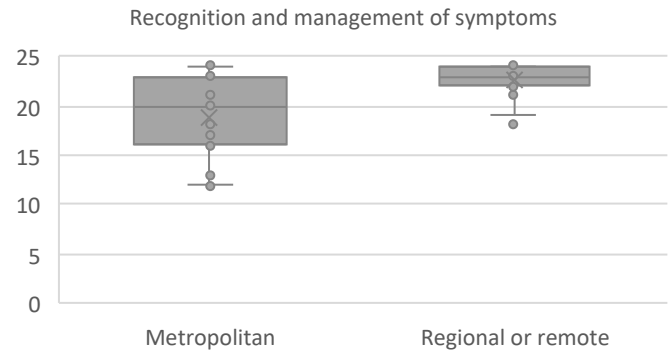

Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by location

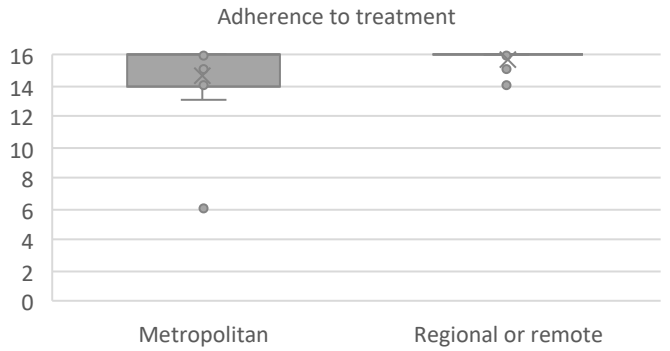

Figure 6.32: Boxplot of Partners in health: adherence to treatment by location

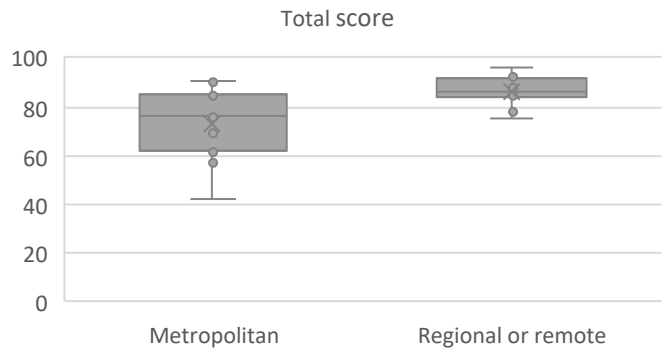

Figure 6.33: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=14, 45.16%) compared to those with a higher SEIFA score of 7-10 (n=17, 54.84%).

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

A two sample t-test indicated that the mean score for the Partners in health Coping scale [t(29) = -2.86 , p = 0.0078*] was significantly lower for participants in the Higher advantage subgroup (Mean = 14.29, SD = 4.53) compared to participants in the Mid to low advantage subgroup (Mean = 18.53, SD = 3.74.)

A two sample t-test indicated that the mean score for the Partners in health Total score scale [t(29) = -2.19 , p = 0.0367*] was significantly lower for participants in the Higher advantage subgroup (Mean = 75.07, SD = 14.02) compared to participants in the Mid to low advantage subgroup (Mean = 84.18, SD = 8.98.)

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that participants in the Mid to low advantage subgroup were good at coping with their condition, and participants in the Higher advantage subgroup were average at coping.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the Mid to low advantage subgroup, and good for participants in the Higher advantage subgroup.

Table 6.24: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Coping	Higher advantage	14	45.16	14.29	4.53	-2.86	29.00	0.0078*
	Mid to low advantage	17	54.84	18.53	3.74			
Total score	Higher advantage	14	45.16	75.07	14.02	-2.19	29.00	0.0367*
	Mid to low advantage	17	54.84	84.18	8.98			

Table 6.25: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Knowledge	Higher advantage	14	45.16	28.50	4.75	95.50	0.3556
	Mid to low advantage	17	54.84	30.00	4.00		
Recognition and management of symptoms	Higher advantage	14	45.16	20.00	5.00	83.50	0.1581
	Mid to low advantage	17	54.84	23.00	3.00		
Adherence to treatment	Higher advantage	14	45.16	15.50	2.00	78.00	0.0520
	Mid to low advantage	17	54.84	16.00	0.00		

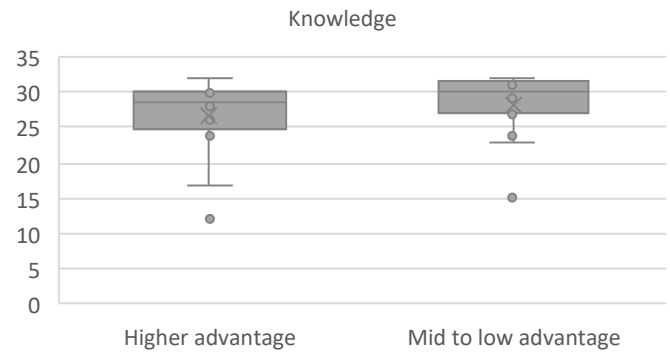

Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic status

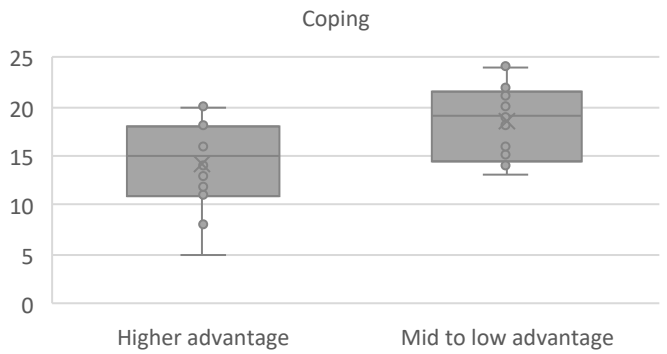

Figure 6.35: Boxplot of Partners in health: coping by socioeconomic status

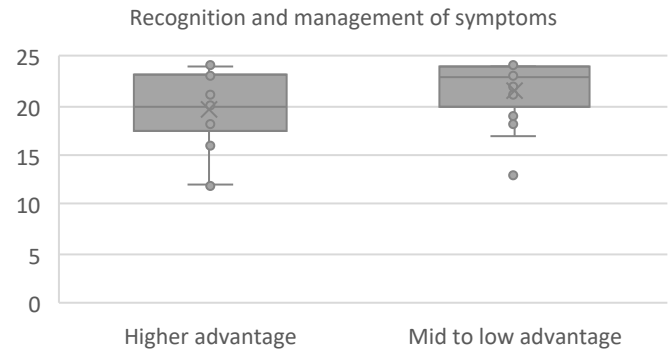

Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

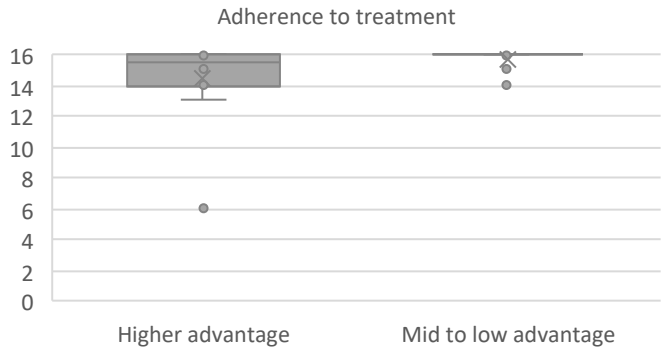

Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic status

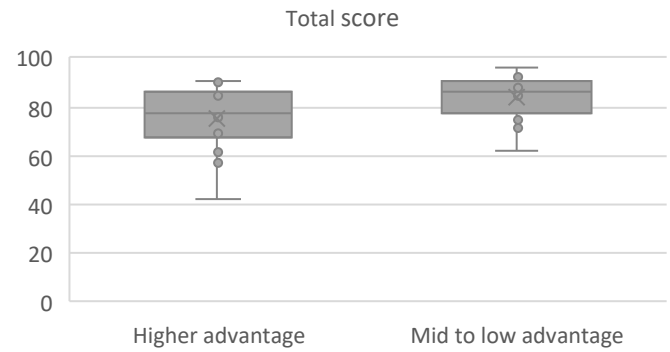

Figure 6.38: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=22, 66.67%), and 11 participants (33.33%) responded that they took medicines as prescribed most of the time.

Table 6.26: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=33	
All of the time	22	66.67
Most of the time	11	33.33
Sometimes	0	
Rarely	0	

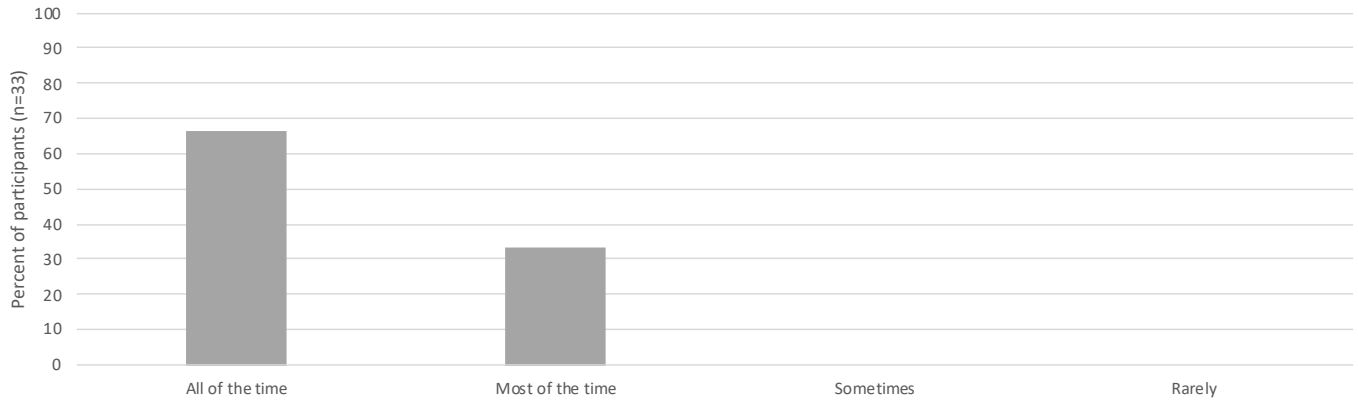

Figure 6.39: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=26, 78.79%), disease management (n=24, 72.73%), dietary (n=21, 63.64%), and disease cause (n=17, 51.52%) were most frequently given to participants by healthcare professionals, and information about complementary therapies (n=5, 15.15%), psychological/ social support (n=5, 15.15%), and hereditary considerations (n=1, 3.03%) were given least often.

Table 6.27: Information given by health professionals

Information given by health professionals	Number (n=33)	Percent
Disease Cause	17	51.52
Treatment options	26	78.79
Disease management	24	72.73
Complementary therapies	5	15.15
Interpret test results	12	36.36
Clinical trials	9	27.27
Dietary	21	63.64
Physical activity	15	45.45
Psychological/ social support	5	15.15
Hereditary considerations	1	3.03

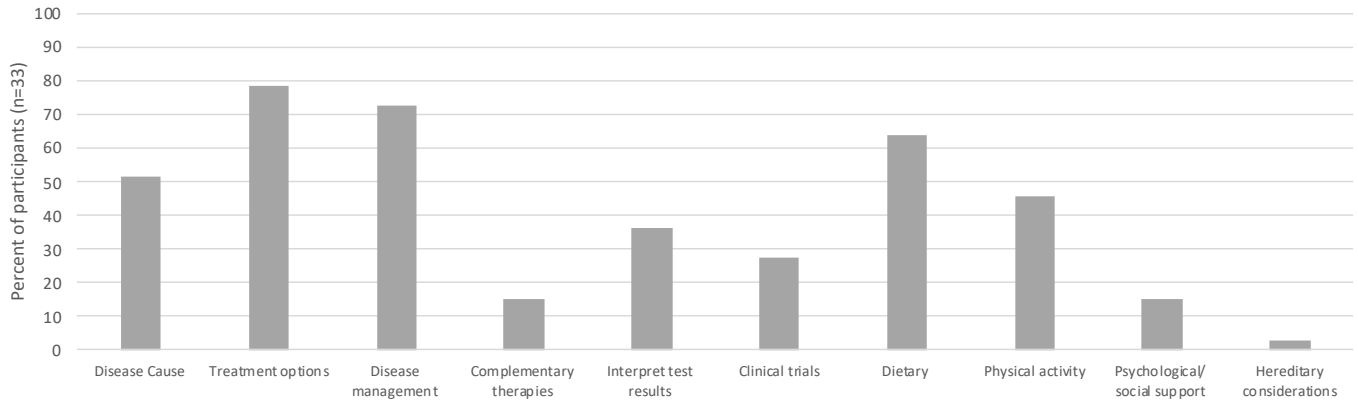

Figure 6.40: Information given by health professionals

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 complementary therapies (n=16, 48.48%), disease cause (n=14, 42.42%), interpret test results (n=14, 42.42%), and treatment options (n=12, 36.36%) were most frequently given to participants by healthcare professionals, and, information about psychological/ social support (n=10, 30.30%), clinical trials (n=9, 27.27%), and hereditary considerations (n=8, 24.24%) were searched for least often.

Table 6.28: Information searched for independently

Information searched independently	Number (n=33)	Percent
Disease Cause	14	42.42
Treatment options	12	36.36
Disease management	12	36.36
Complementary therapies	16	48.48
Interpret test results	14	42.42
Clinical trials	9	27.27
Dietary	12	36.36
Physical activity	12	36.36
Psychological/ social support	10	30.30
Hereditary considerations	8	24.24

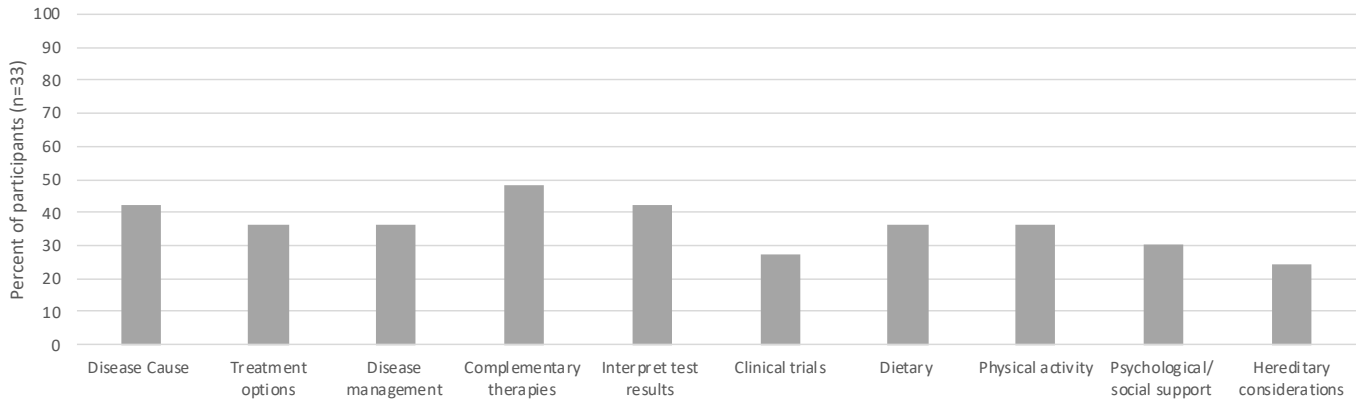

Figure 6.41: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=25, 75.76%) and psychological/ social support (n=19, 57.58%).

The topics that participants were given most information from both healthcare professionals and searching independently were treatment options (n=10, 30.30%) and dietary information (n=9, 27.27%).

The topics that participants did not search for independently after receiving information from healthcare professionals were disease management (n=17, 51.52%) and treatment options (n=16, 48.48%).

The topics that participants searched for independently after not receiving information from healthcare professionals were complementary therapies (n=14, 42.42%) and disease cause (n=9, 27.27%).

Table 6.29: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=33	%	n=33	%	n=33	%	n=33	%
Disease Cause	7	21.21	12	36.36	5	15.15	9	27.27
Treatment options	5	15.15	16	48.48	10	30.30	2	6.06
Disease management	4	12.12	17	51.52	7	21.21	5	15.15
Complementary therapies	14	42.42	3	9.09	2	6.06	14	42.42
How to interpret test results	13	39.39	6	18.18	6	18.18	8	24.24
Clinical trials	18	54.55	6	18.18	3	9.09	6	18.18
Dietary information	9	27.27	12	36.36	9	27.27	3	9.09
Physical activity	13	39.39	8	24.24	7	21.21	5	15.15
Psychological/social support	19	57.58	4	12.12	1	3.03	9	27.27
Hereditary considerations	25	75.76	0	0.00	1	3.03	7	21.21

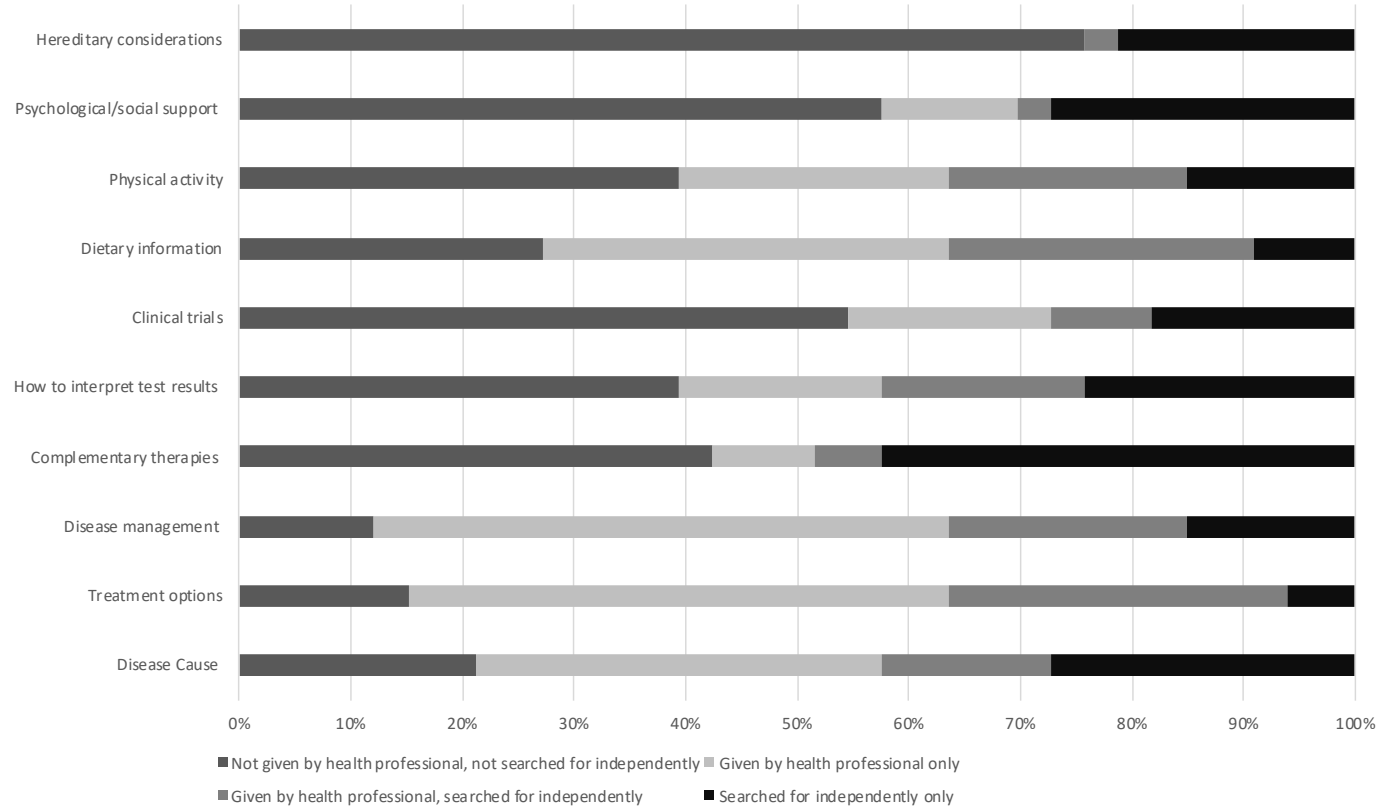

Figure 6.42: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most accessed and 5 is the least accessed. A weighted average is presented in the table below. With a weighted ranking, the higher the score, the more accessed the source of information.

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

Table 6.30: Most accessed information

Information source	Weighted average (n=33)
Hospital or clinic where being treated	3.84
Non-profit organisations, charity or patient organisations	3.47
Medical journals	2.91
Government	2.81
Pharmaceutical companies	2.09

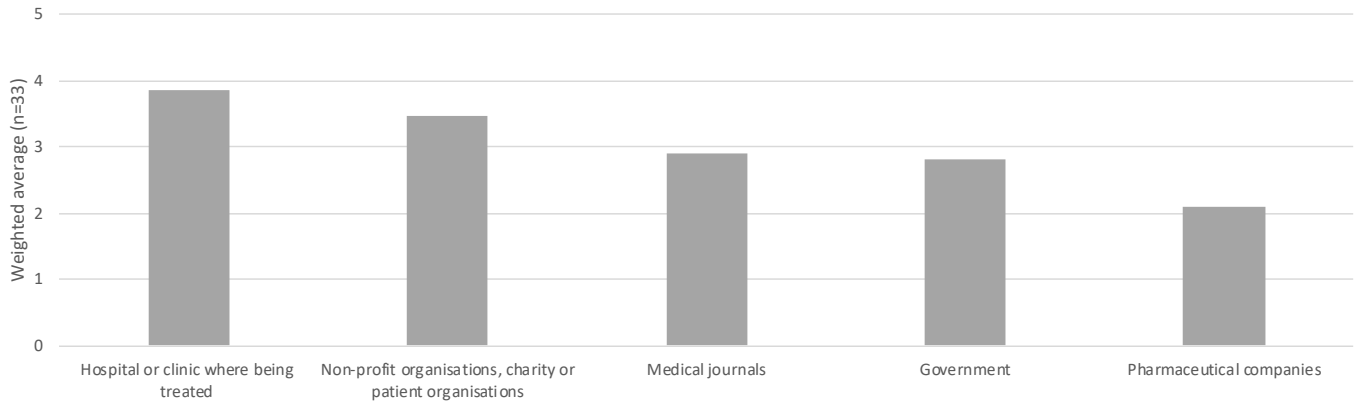

Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 17 participants (51.52%) had accessed My Health Record, 16 participants (48.48%) had not.

Of those that had accessed My Health Record, there were 3 participants (17.65%) who found it to be poor or very poor, 12 participants (70.59%) who found it acceptable, and 2 participants (11.76%) who found it to be good or very good.

Table 6.31: Accessed My Health Record

Accessed "My health record"	Number (n=33)	Percent
Yes	17	51.52
No	13	39.39
Not sure	2	6.06
Doesn't know what 'My Health Record' is	1	3.03

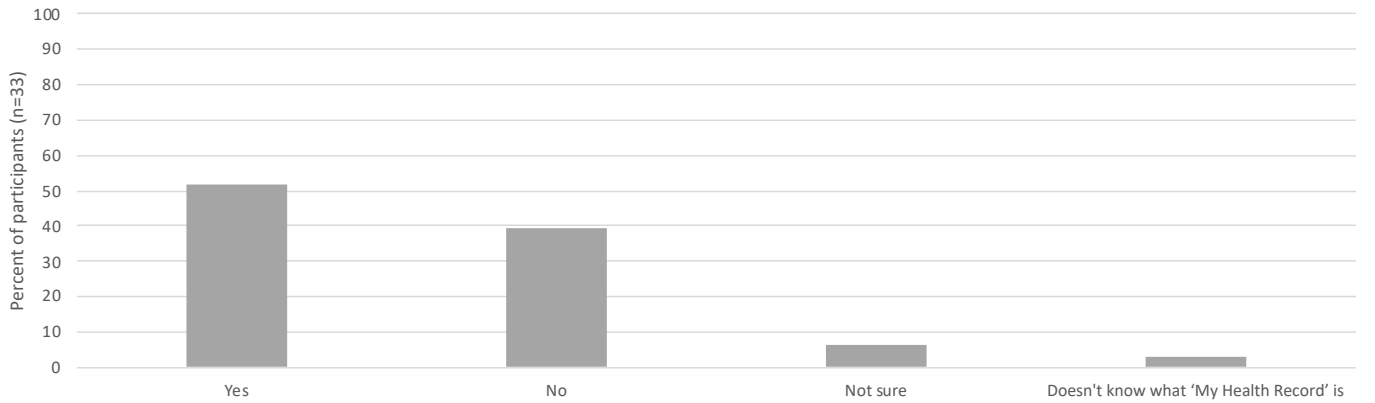

Figure 6.44: Accessed My Health Record

Table 6.32: How useful was My Health Record

How useful was "My health record"	Number (n=17)	Percent
Very poor	2	11.76
Poor	1	5.88
Acceptable	12	70.59
Good	2	11.76
Very good	0	0.00

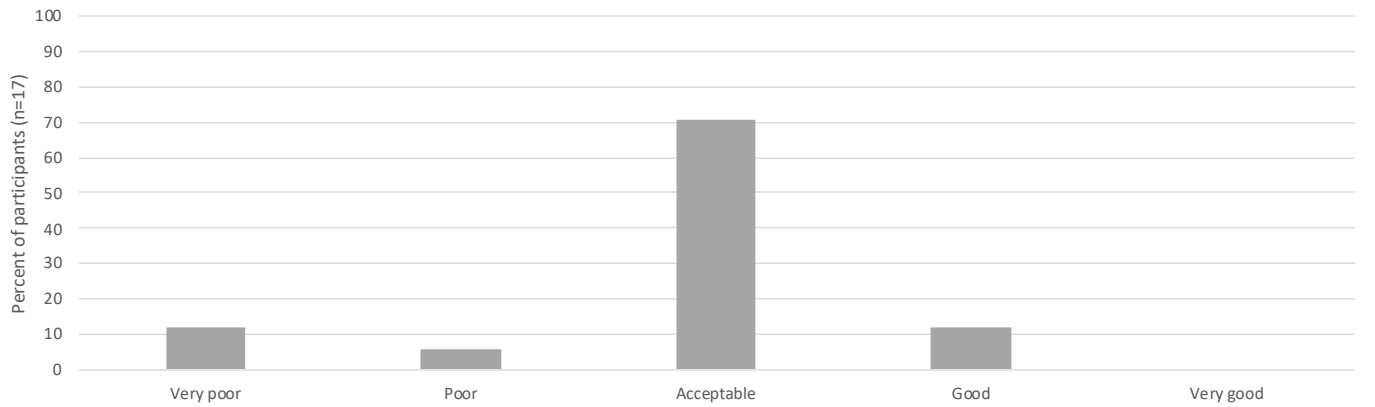

Figure 6.45: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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

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

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

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from charities (45.45%), hospital or clinical setting (30.30%), and in the form of accommodation for themselves or their family while having treatment (24.24 %). Other themes included support from family and friends (21.21%), domestic services and/or home care (12.12%), transport to and from hospital appointments (12.12%), and in the form of financial advice and help with Centrelink applications (12.12%). Some participants described the challenges of finding or accessing support (18.18%), not needing or seeking help or support (15.15%), and that they did not receive any formal support (12.12%).

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 highest quintile for Care coordination: Quality of care global measure (median=9.00, IQR=2.00) indicating very good quality of care

The overall scores for the cohort were in the second highest quintile for Care coordination: Communication (mean=45.18, SD=9.53), Care coordination: Navigation (mean=27.09, SD=4.69), Care coordination: Total score (mean=72.27, SD=12.17), Care coordination: Care coordination global measure (median=8.00, IQR=3.00), indicating good communication, good communication, good coordination, good care coordination.

Comparisons of Care co-ordination have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

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

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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 very good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=33)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.18	9.53	47.00	12.00	13 to 65	4
Navigation*	27.09	4.69	28.00	7.00	7 to 35	4
Total score*	72.27	12.17	72.00	16.00	20 to 100	4
Care coordination global measure	7.94	1.78	8.00	3.00	1 to 10	4
Quality of care global measure	8.85	1.39	9.00	2.00	1 to 10	5

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

Care coordination by blood cancer type

Comparisons were made by type of blood cancer. There were 6 participants (18.18%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (30.30%) with Diffuse Large B-Cell Lymphoma, and 17 participants (51.52%) with Multiple Myeloma.

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

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

Table 7.2: Care coordination blood cancer type summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	45.00	8.32	Between groups	97.80	2	48.88	0.52	0.5990
	Diffuse Large B-Cell Lymphoma	10	30.30	47.70	10.06	Within groups	2809.20	30	93.64		
	Multiple Myeloma	17	51.52	43.76	9.85	Total	2907.00	32	142.52		
Total score	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	70.67	10.65	Between groups	81.00	2	40.29	0.26	0.7730
	Diffuse Large B-Cell Lymphoma	10	30.30	74.60	12.48	Within groups	4658.00	30	155.27		
	Multiple Myeloma	17	51.52	71.47	12.96	Total	4739.00	32	195.56		
Care coordination global measure	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	7.67	1.86	Between groups	1.97	2	0.99	0.30	0.7460
	Diffuse Large B-Cell Lymphoma	10	30.30	7.70	2.06	Within groups	99.90	30	3.33		
	Multiple Myeloma	17	51.52	8.18	1.67	Total	101.87	32	4.32		

Table 7.3: Care coordination blood cancer type summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	C^2	dF	p-value
Navigation	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	25.00	5.50	1.57	2	0.4553
	Diffuse Large B-Cell Lymphoma	10	30.30	28.00	3.50			
	Multiple Myeloma	17	51.52	29.00	7.00			
Quality of care global measure	B-cell acute lymphoblastic leukemia (ALL)	6	18.18	8.00	1.50	1.32	2	0.5175
	Diffuse Large B-Cell Lymphoma	10	30.30	9.50	1.75			
	Multiple Myeloma	17	51.52	9.00	2.00			

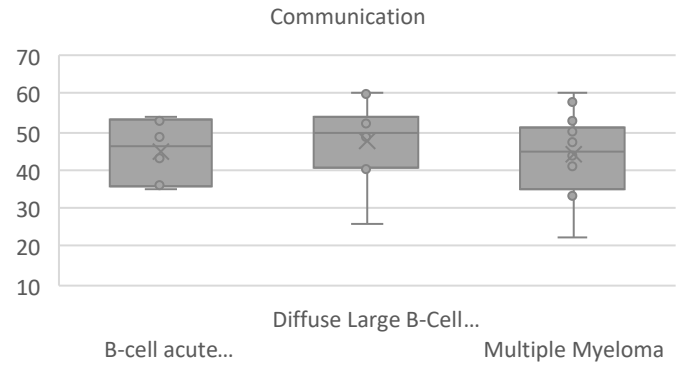


Figure 7.1: Boxplot of Care coordination: Communication by blood cancer type

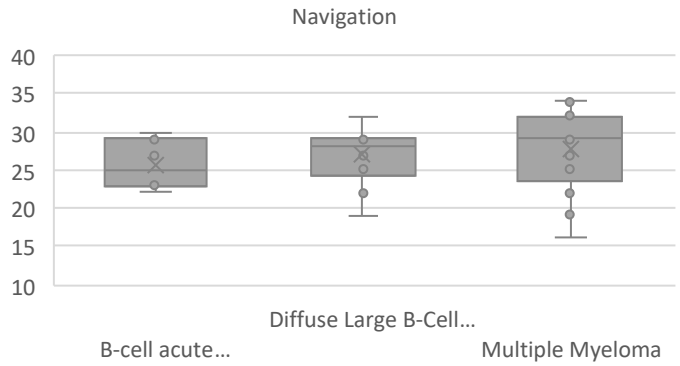


Figure 7.2: Boxplot of Care coordination: Navigation by blood cancer type

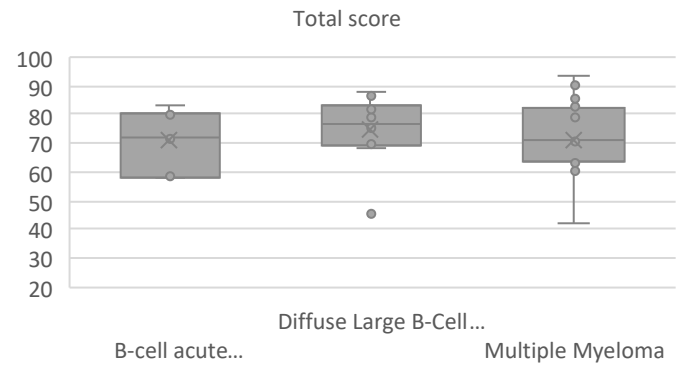


Figure 7.3: Boxplot of Care coordination: Total score by blood cancer type

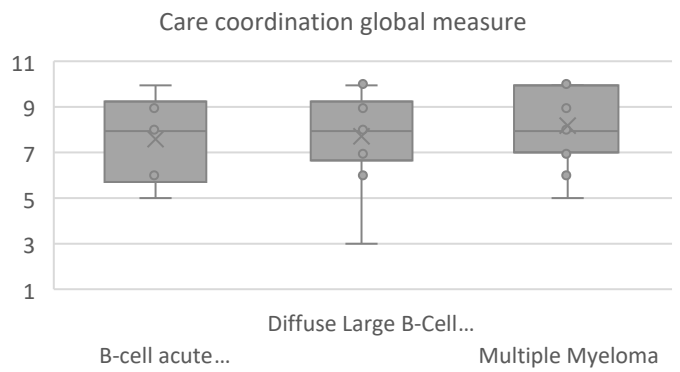


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by blood cancer type

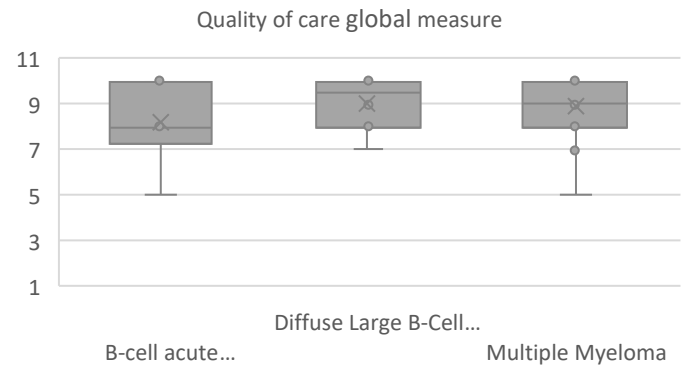


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by blood cancer type

Care coordination by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 25 participants (75.76%) that had treatment with Car T-cell therapy and, 8 participants (24.24%) that did not .

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Care coordination scales.

Table 7.4: Care coordination by CAR T-cell therapy summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	No	25	75.76	45.04	8.36	-0.15	31	0.8827
	Yes	8	24.24	45.63	13.23			
Navigation	No	25	75.76	26.72	4.64	-0.80	31	0.4302
	Yes	8	24.24	28.25	4.95			
Total score	No	25	75.76	71.76	10.90	-0.42	31	0.6757
	Yes	8	24.24	73.88	16.30			

Table 7.5: Care coordination by CAR T-cell therapy summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	No	25	75.76	8.00	3.00	121.00	0.3765
	Yes	8	24.24	8.00	2.25		
Quality of care global measure	No	25	75.76	9.00	2.00	80.50	0.3965
	Yes	8	24.24	10.00	1.25		

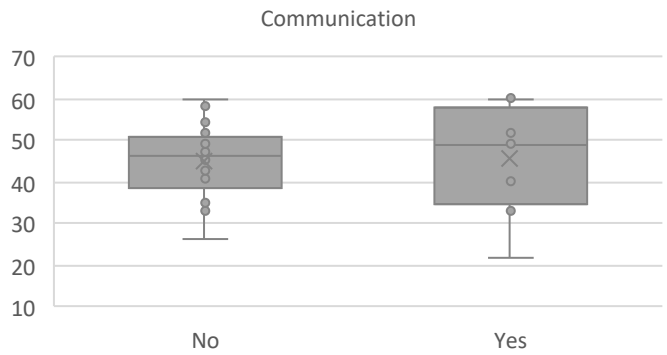


Figure 7.6: Boxplot of Care coordination: Communication by CAR T-cell therapy

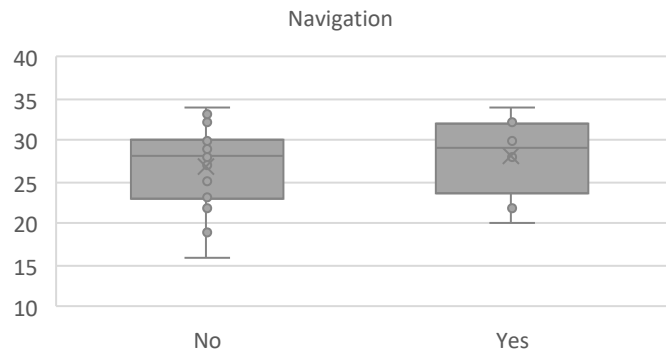


Figure 7.7: Boxplot of Care coordination: Navigation by CAR T-cell therapy

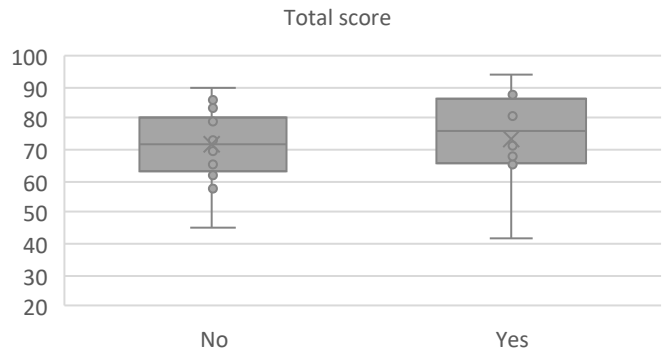


Figure 7.8: Boxplot of Care coordination: Total score by CAR T-cell therapy

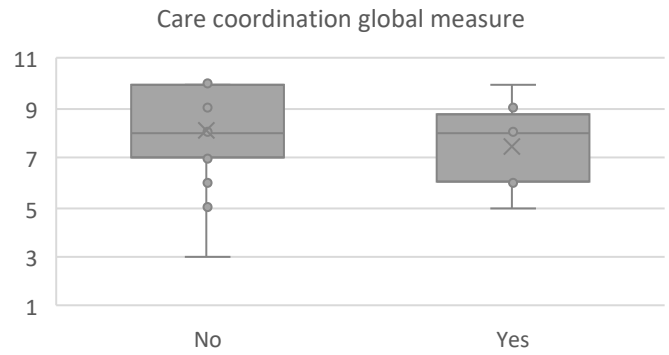


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by CAR T-cell therapy

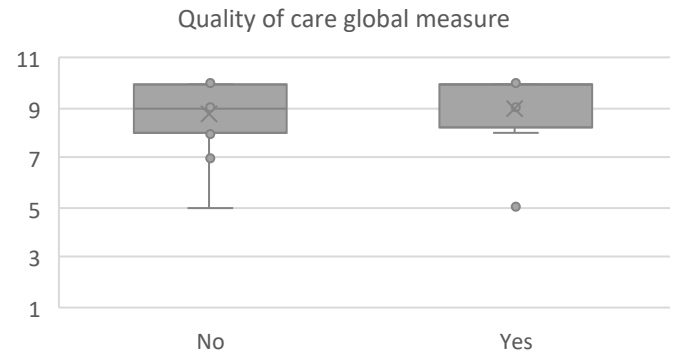


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by CAR T-cell therapy

Care coordination by gender

Comparisons were made by gender, there were 15 female participants (45.45%), and 18 male particpants (54.55%).

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

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

Table 7.6: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Female	15	45.45	44.73	11.51	-0.24	31.00	0.8095
	Male	18	54.55	45.56	7.85			
Total score	Female	15	45.45	71.33	14.13	-0.40	31.00	0.6923
	Male	18	54.55	73.06	10.62			

Table 7.7: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Navigation	Female	15	45.45	28.00	5.50	118.00	0.5491
	Male	18	54.55	28.00	8.50		
Care coordination global measure	Female	15	45.45	8.00	2.50	112.50	0.4140
	Male	18	54.55	8.00	2.75		
Quality of care global measure	Female	15	45.45	9.00	2.00	127.00	0.7733
	Male	18	54.55	9.00	2.00		

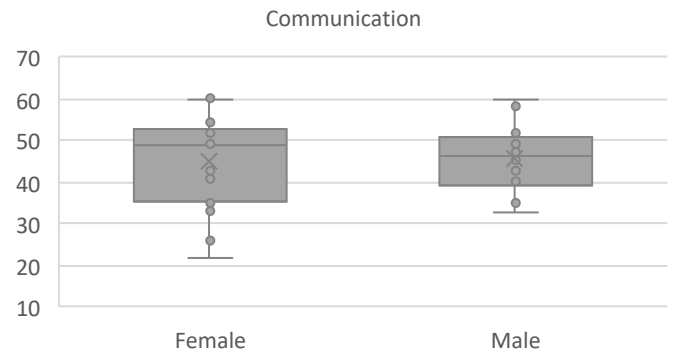


Figure 7.11: Boxplot of Care coordination: Communication by gender

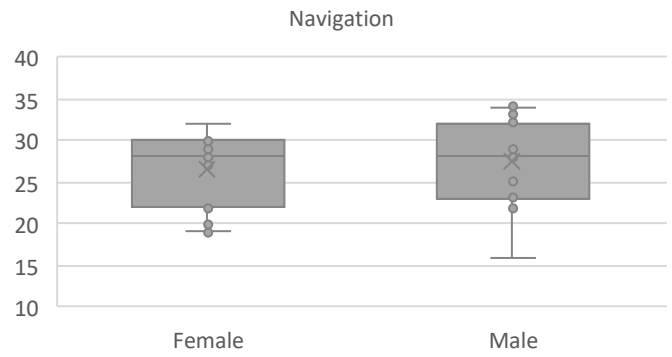


Figure 7.12: Boxplot of Care coordination: Navigation by gender

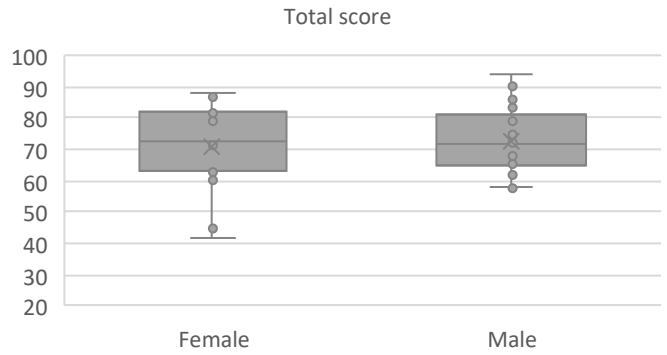


Figure 7.13: Boxplot of Care coordination: Total score by gender

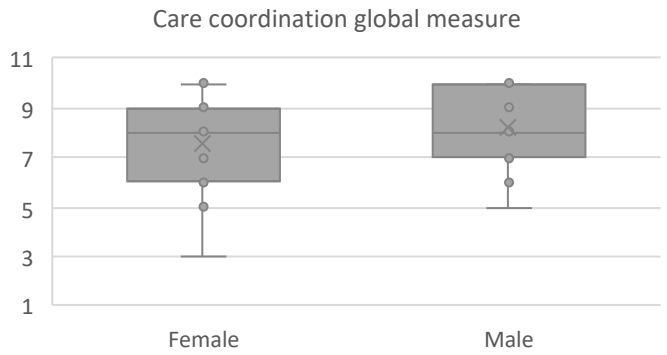


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by gender

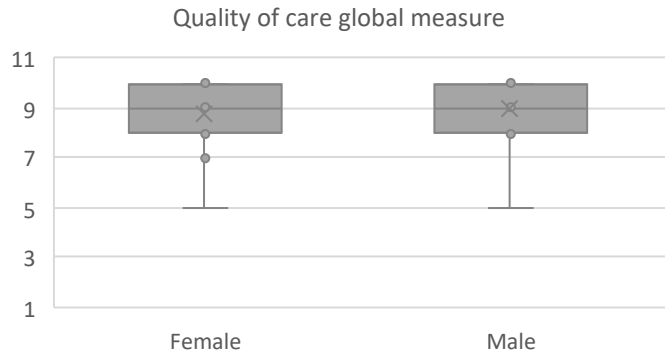


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=19, 57.58%), and participants aged 65 and older (n=14, 42.42%).

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

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

Table 7.8: Care coordination by age summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 25 to 64	19	57.58	45.21	8.94	0.02	31.00	0.9843
	Aged 65 and older	14	42.42	45.14	10.63			
Navigation	Aged 25 to 64	19	57.58	26.37	4.37	-1.03	31.00	0.3097
	Aged 65 and older	14	42.42	28.07	5.08			
Total score	Aged 25 to 64	19	57.58	71.58	11.12	-0.38	31.00	0.7092
	Aged 65 and older	14	42.42	73.21	13.84			

Table 7.9: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	Aged 25 to 64	19	57.58	8.00	2.50	139.00	0.8370
	Aged 65 and older	14	42.42	8.00	3.50		
Quality of care global measure	Aged 25 to 64	19	57.58	9.00	2.00	103.00	0.2537
	Aged 65 and older	14	42.42	10.00	1.75		

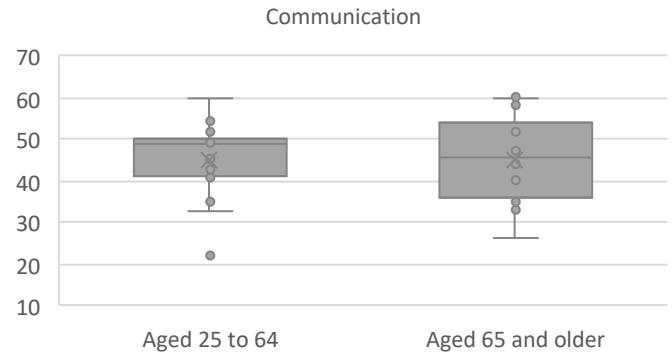


Figure 7.16: Boxplot of Care coordination: Communication by age

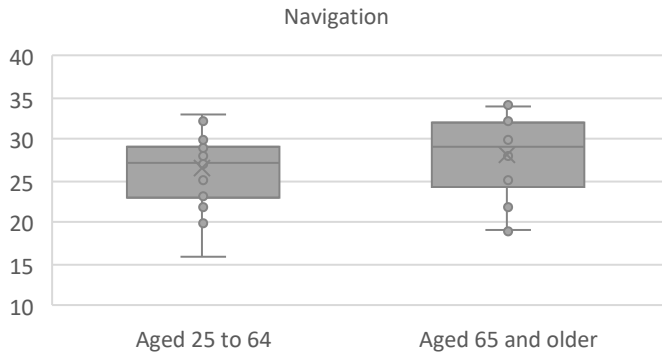


Figure 7.17: Boxplot of Care coordination: Navigation by age

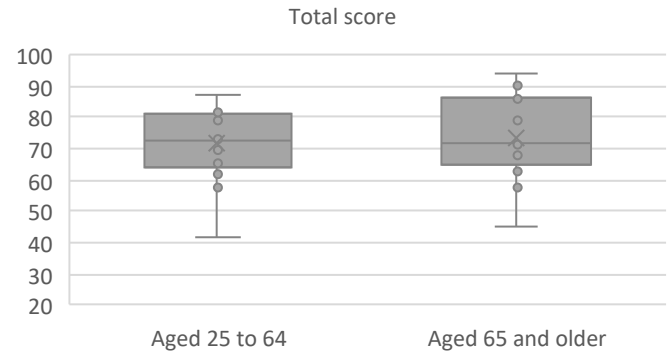


Figure 7.18: Boxplot of Care coordination: Total score by age

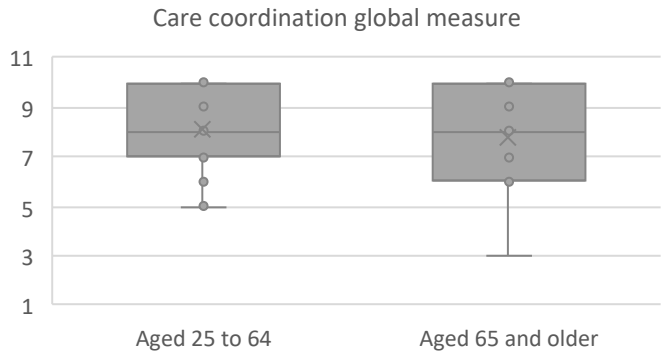


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by age

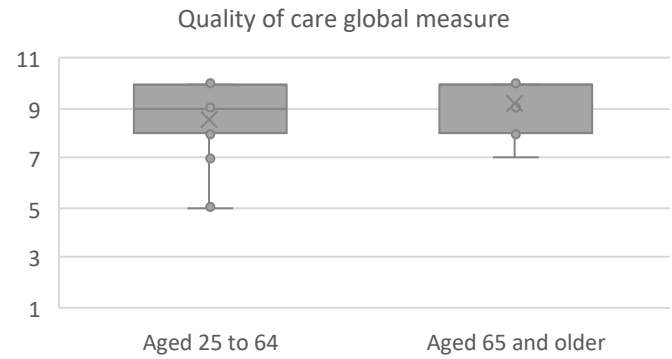


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=15, 45.45%) were compared to those living in a major city (n=18, 54.55%).

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

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

Table 7.10: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Metropolitan	15	45.45	41.93	8.00	-1.85	31.00	0.0733
	Regional or remote	18	54.55	47.89	10.06			
Navigation	Metropolitan	15	45.45	26.80	3.90	-0.32	31.00	0.7504
	Regional or remote	18	54.55	27.33	5.36			
Total score	Metropolitan	15	45.45	68.73	9.90	-1.56	31.00	0.1292
	Regional or remote	18	54.55	75.22	13.34			

Table 7.11: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Care coordination global measure	Metropolitan	15	45.45	8.00	2.00	99.00	0.1875
	Regional or remote	18	54.55	8.00	2.00		
Quality of care global measure	Metropolitan	15	45.45	9.00	2.00	99.00	0.1727
	Regional or remote	18	54.55	10.00	1.75		

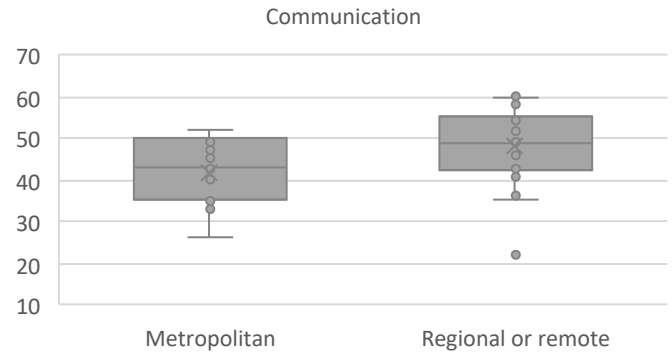


Figure 7.21: Boxplot of Care coordination: Communication by location

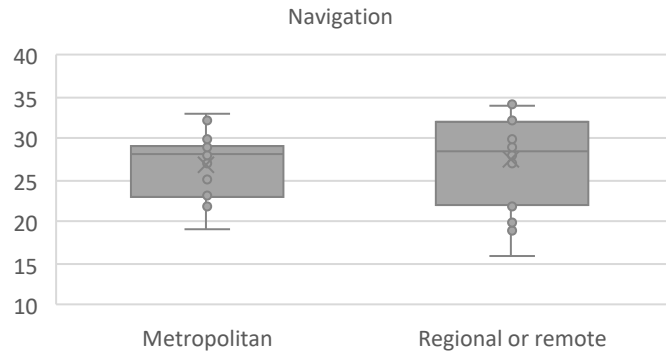


Figure 7.22: Boxplot of Care coordination: Navigation by location

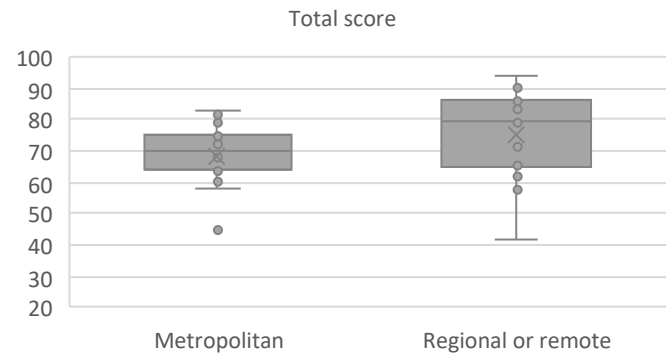


Figure 7.23: Boxplot of Care coordination: Total score by location

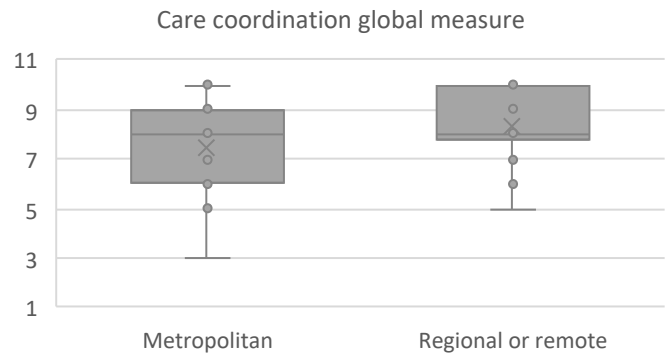


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by location

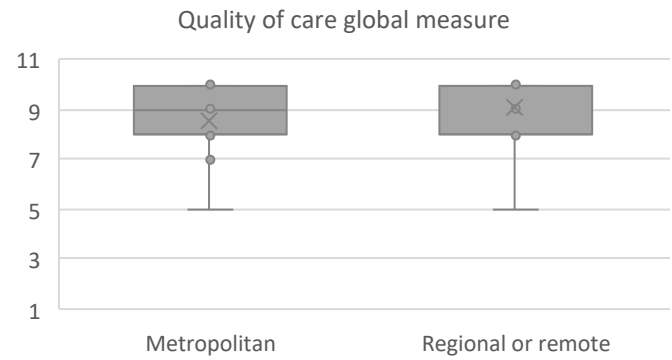


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by location

Care coordination by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=16, 48.48%) compared to those with a higher SEIFA score of 7-10 (n=17, 51.52%).

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

A two sample t-test indicated that the mean score for the Care coordination Communication scale [t(31) = -2.77 , p = 0.0094*] was significantly lower for participants in the Higher advantage subgroup (Mean = 40.88, SD = 8.71) compared to participants in the Mid to low advantage subgroup (Mean = 49.24, SD = 8.64.)

A two sample t-test indicated that the mean score for the Care coordination Total score scale [t(31) = -2.78 , p = 0.0091*] was significantly lower for participants in the Higher advantage subgroup (Mean = 66.75, SD = 11.08) compared to participants in the Mid to low advantage subgroup (Mean = 77.47, SD = 11.03.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Quality of care global measure scale [W = 67.00 , p = 0.0088*] was significantly lower for participants in the Higher advantage subgroup (Median = 8.00, IQR = 1.50) compared to participants in the Mid to low advantage subgroup (Median = 10.00, IQR = 1.00.

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. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that healthcare communication was good for participants in the Mid to low advantage subgroup, and average for participants in the Higher advantage subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that communication, navigation and overall experience of care coordination was good for participants in the Mid to low advantage subgroup, and average for participants in the Higher advantage subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Mid to low advantage subgroup scored higher than participants in the Higher advantage subgroup. This indicates that, quality of care was very good for participants in the Mid to low advantage subgroup, and good for participants in the Higher advantage subgroup.

Table 7.12: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=33)	Percent	Mean	SD	T	dF	p-value
Communication	Higher advantage	16	48.48	40.88	8.71	-2.77	31.00	0.0094*
	Mid to low advantage	17	51.52	49.24	8.64			
Total score	Higher advantage	16	48.48	66.75	11.08	-2.78	31.00	0.0091*
	Mid to low advantage	17	51.52	77.47	11.03			

*Statistically significant at p<0.05

Table 7.13: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=33)	Percent	Median	IQR	W	p-value
Navigation	Higher advantage	16	48.48	26.00	6.25	91.50	0.1114
	Mid to low advantage	17	51.52	29.00	5.00		
Care coordination global measure	Higher advantage	16	48.48	8.00	2.00	107.00	0.2917
	Mid to low advantage	17	51.52	8.00	2.00		
Quality of care global measure	Higher advantage	16	48.48	8.00	1.50	67.00	0.0088*
	Mid to low advantage	17	51.52	10.00	1.00		

*Statistically significant at p<0.05

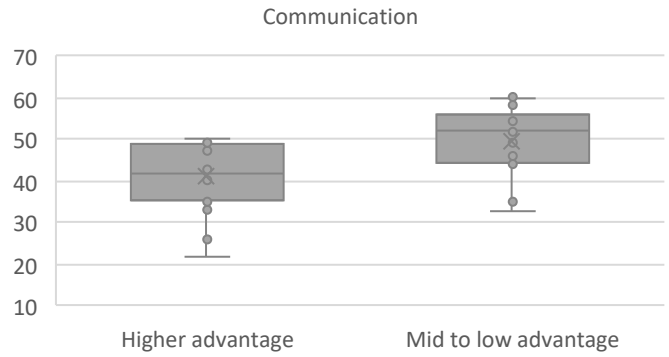


Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic

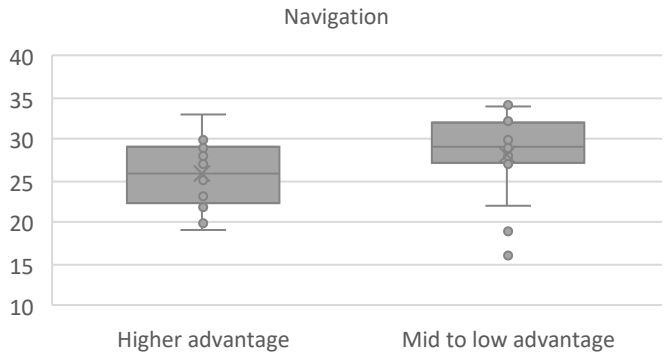


Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic

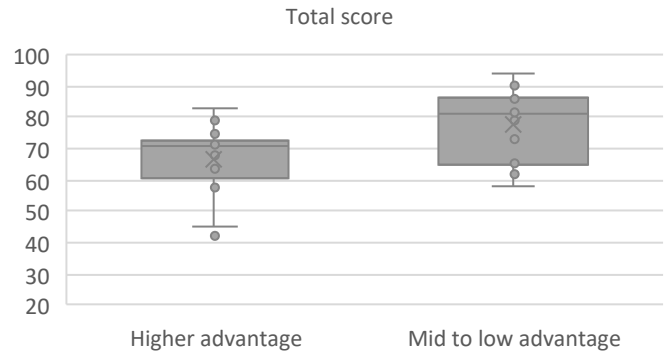


Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic

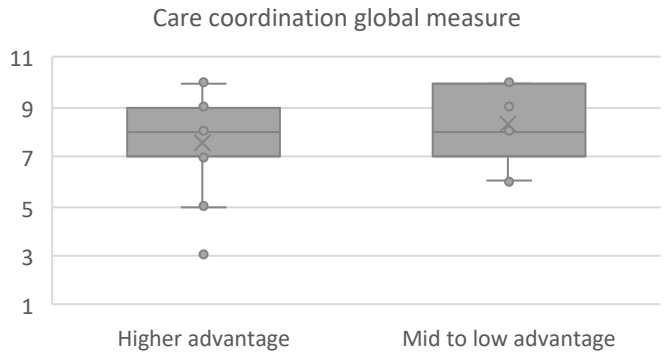


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic

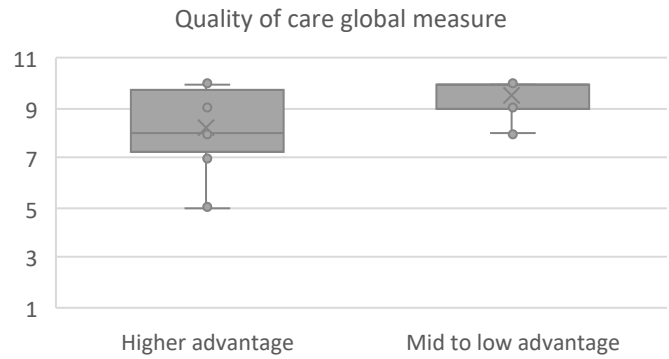


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic

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 responses were that they found support and care from charities (45.45%), hospital or clinical setting (30.30%), and in the form of accommodation for themselves or their family while having treatment (24.24 %). Other themes included support from family and friends (21.21%), domestic services and/or home care (12.12%), transport to and from hospital appointments (12.12%), and in the form of financial advice and help with Centrelink applications (12.12%). Some participants described the challenges of finding or accessing support (18.18%), not needing or seeking help or support (15.15%), and that they did not receive any formal support (12.12%).

Participant describes getting care and support from charities

We've got a local Vinnie's here. Handout vouchers. The local church, he financially helped us out. Yeah, had a fundraiser here for me, like a football club. 037_2023AUCRT

Leukemia Foundation would be the key one. I had some legal advice through the Cancer Council to sort

out my will. The Cancer Council, they provided, I mean, Leukemia Foundation, were amazing. They provided accommodation for NAME and I, when we had to be in LOCATION, I would have backed out of my transplant because I got so scared without there counsellors. The counsellors were amazing and their ongoing social support post transplant has been great. I came across your study through them. I've joined the Leukemia Foundation consumer group. So yeah, those two would be the main two, I think.
016_2023AUCRT

PARTICIPANT: No, I haven't used any support no at all. But I've been. I know when you say support, I've been to a thing where they have, like they have trials, they have tests or studies with the Brain and Mind Institute and things like that. And I've always joined up with that. And they give you good results. Yeah, you get a bit of feedback.
INTERVIEWER: Mentioned earlier the multiple Myeloma association, is that right?
PARTICIPANT: Yeah, that's right. They put, they put, they put a webinar on or they put sessions on, they come to LOCATION. So I get invited. We always go to those but we don't use their services. Oh, they did a cooking thing once we went to that one because that was worthwhile. But then really they I haven't had to use them, you know, for they offer a lot of services that really they don't apply to me, They apply to other people and probably sicker than me. So yeah, I'm. I'm fine, yeah.
018_2023AUCRT

When you say health community, you talk about overall, because the biggest support I've received was from the Leukemia Foundation. But yeah I have had help from I don't think it was but local charities just in like support I think they I mean I'm trying to get their name but any they're but they they just provided I think what they did they part of it something probably just cheap alternatives but they just I think it was like a yeah moderate just like they spoke to NAME and my wife and just showed her where and how to access sort of services with the government and cheap sort of options available to to us and that sort of stuff. I don't know I think there's no million yet doesn't it. And then blue meals maybe. Yeah. Blue meals maybe it was. Yeah, sorry. And then I said Leukemia Foundation was one that provided this accommodation with LOCATION while doing a transplant. But also there was a lady there that was like support for my wife, just through the emotional turmoil of the transplant. That was huge. The Leukemia Foundation, I'm totally grateful for because they've done a lot that way plus providing information. The there was lady at the hospital who's like a coordinator I suppose back in the day she helped my wife a little bit with actually going through the process with Centrelink. 019_2023AUCRT

Participant describes getting care and support from hospital or clinical setting

Yes, I have telehealth appointments too every six to eight weeks so that's good to just check-in and have the hematologist reviewing my blood. It's a little bit of peace of mind, I guess.
005_2023AUCRT

Community Nursing would attend when I needed that. Let me think just the the General Medical and nursing staff at the hospital throughout the treatment was, as I said before, just awesome. Let me think. No, I think that that that's about about it and friends and family, particularly in the the middle of the bad time.
009_2023AUCRT

Participant describes getting care and support in the form of accomodation for themselves or their family while having treatment

We came your foundation are very supportive as well I there if it wasn't for them like people in the country of remote people in remote areas wouldn't would have a great deal of expense staying in the cities to get treatment because some of the some of them leukemia pay like to stay for three months you know close to the hospital So that's that would be very expensive if they didn't have the the support of the government subsidised scheme where which then the leukemia foundation only charge what the government gives you as an allowance for their accommodation so it doesn't cost you anything to stay the leukemia lodge. So that's a big benefit for us people outside, people outside, you know, in the rural areas.
032_2023AUCRT

Participant describes getting care and support from family and friends

The main support for me has been my family, just with taking me to appointments and to the clinic and when I had to go to hospital and things like that. I haven't had any help from outside organizations. I've had a few good friends that have come over to help me when I needed help, but other than that, we pretty much looked after ourselves.
002_2023AUCRT

So obviously family and friends have been supportive as far as sending me messages or and either coming to visit in hospital when they can or if they can't, sending things so people would get, you know, nice, just nice little things like warm socks or a nice spray to spray on your face when you're feeling uncomfortable and those sorts of things
006_2023AUCRT

Participant describes the challenges of finding or accessing support

PARTICIPANT: I've had a chat with a social worker.
INTERVIEWER: Okay.
PARTICIPANT: And it was only one chat.
PARTICIPANT: And then and she sort of said, look I don't think you need any any support NAME and I see at the hospital sometimes you know you know walk and say G'day, but I've never had any any sort of sit down. Yeah, it was a just sort of a general. I think every patient, they go along and see them and they, I think they make a decision on whether this person needs ongoing support or whether he's able to cope with life without a social worker. So they made that decision, not me.
031_2023AUCRT

There was Leukemia Foundation. When I was on treatment, when I wasn't working, they did give me some vouchers for food and fuel, fuel for when I'm traveling up and things like that. It was a little bit difficult as well, because I'm on the border of STATE 1, I'm literally minutes from STATE 2. The Leukemia Foundation were from STATE 2, they said I wasn't eligible for all of the funding that they normally would give to a patient because I'm a STATE 1 patient going into STATE 2. Even with their assistance with drivers and things like that, if I ever needed them, they could only meet me at the border. They weren't allowed to come to my house, so I still had to arrange for someone to drive me to the boarder, and then getting a vehicle at the boarder and go into STATE 2. If anything could be fixed, that would be a big one for me, border residency. I think it should be an Australian-wide thing. Money's Wish, they provided six weeks of house cleaning. That was amazing, because you came home after treatment, you had a nice clean house. The last thing you felt like you had energy for. I got to pick what I wanted. It was either that or the canteen lunches for X amount of weeks for the kids, the school had already arranged that for me. That's why I went with the cleaning. Those two helped. The five dollars off that the hospital offered did help.
001_2023AUCRT

I could get some help contact from the Leukemia Foundation one One of the problems with that was I live I live on the border with STATE 1 and STATE 2 and I live in in LOCATION which is STATE 2 and there was a I was I suppose transport was an issue and I couldn't access transport so I had to get my own transport that's the only but they were very supportive they they did help with some of the accommodation which which was really really appreciated but the transport from well it's bloody living over the border. If I lived in STATE 1 I could access transport, but living in new STATE 2 I was unable to do that. And I suppose my experience was that when I went down for my transplant I had to catch the train and I had a unfortunate incident on the train where this, oh, I wasn't feeling that good. Someone decided that they wanted my seat….but lucky enough for someone else there to help me out, send them off kind of thing. So that was possibly the only kind of problem I, you know, had with all that. 015_2023AUCRT

Participant describes that they did not need or seek help or support

But I haven't reached out for it either. Yeah, I'm managing it.
008_2023AUCRT

No, not really. I haven't asked for it.
010_2023AUCRT

No, I didn't ask for it. No one, didn't look for it.
034_2023AUCRT

Participant describes getting care and support from domestic services and/or home care

Okay. When I was first diagnosed and I couldn't do all the things that I normally would do, I did approach the council and the lady come in and help do some cleaning because my husband at that stage was working full time as well. And you know, I had, I'm just trying to remember now I didn't have any children living at home. No, I didn't have any children living at home. They'd all flown by then. Oh, I didn't have the support from them that I because they were working as well. So yeah. So I okay help. Yeah.
020_2023AUCRT

I get help through the local council here, home care, so I have a cleaner. He comes in, he comes in once a fortnight and does some cleaning for me, which is

which is good. That's only a that's only a cost to me. I think it's $6.20 an hour or something subsidized, obviously so and and apart from that I haven't had, I haven't had to rely, I haven't had to rely on any other sort of support from other organizations or other people at this stage.
023_2023AUCRT

Participant describes getting care and support in the form of financial aid

Yeah, there's a place in in in LOCATION next to the hospital called NAME. It's a building that is funded by some farmers from the LOCATION region, I believe, and without that support I don't know what I've done. It was provided free, so when I was able to leave the hospital once, I had some immunity. I was able to stay there free of charge as a government patient. This and travel scheme was a huge help. Instead of forking out three to $500.00 for an air flight, I could get one for $50. Things like that. Yeah, social workers with access to government funding, I suppose, to support us financially during that period of time.
024_2023AUCRT

Participant describes getting care and support in the form of transport to and from hospital appointments

When I got the the cancer back the second time in 2020, you know, I couldn't drive. So there's a volunteer transport service near where I live. And so I contacted them and a few times they took me to appointments and picked me up and took me home. And I found a lovely taxi driver who took me to hospital for my radiotherapy and took me home. But you know, a very caring man, Pakistani man, who stopped and bought food for me on the way home and things like that, you know, So and some of the volunteer work I used to do, like the community garden and exercise classes at the Community Center, those people have come around and visited me and you know, brought me pot, planted Christmas and things like that just to sort of show I haven't been forgotten.
012_2023AUCRT

Table 7.14: Experience of care and support

Care and support received	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes getting care and support from charities	15	45.45	4	57.14	3	30.00	8	50.00	14	53.85	1	14.29	6	40.00	9	50.00
Participant describes getting care and support from hospital or clinical setting	10	30.30	1	14.29	5	50.00	4	25.00	7	26.92	3	42.86	5	33.33	5	27.78
Participant describes getting care and support in the form of accomodation for themselves or their family while having treatment	8	24.24	3	42.86	1	10.00	4	25.00	8	30.77	0	0.00	3	20.00	5	27.78
Participant describes getting care and support from family and friends	7	21.21	2	28.57	4	40.00	1	6.25	6	23.08	1	14.29	7	46.67	0	0.00
Participant describes the challenges of finding or accessing support	6	18.18	2	28.57	2	20.00	2	12.50	6	23.08	0	0.00	4	26.67	2	11.11
Participant describes that they did not need or seek help or support	5	15.15	0	0.00	2	20.00	3	18.75	2	7.69	3	42.86	1	6.67	4	22.22
Participant describes that they did not receive any formal support	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes getting care and support from domestic services and/or home care	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Participant describes getting care and support in the form of transport to and from hospital appointments	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00

Care and support received	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes getting care and support from charities	15	45.45	11	57.89	4	28.57	6	42.86	9	47.37	9	64.29	6	31.58
Participant describes getting care and support from hospital or clinical setting	10	30.30	6	31.58	4	28.57	5	35.71	5	26.32	5	35.71	5	26.32
Participant describes getting care and support in the form of accomodation for themselves or their family while having treatment	8	24.24	7	36.84	1	7.14	4	28.57	4	21.05	4	28.57	4	21.05
Participant describes getting care and support from family and friends	7	21.21	5	26.32	2	14.29	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the challenges of finding or accessing support	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	3	21.43	3	15.79
Participant describes that they did not need or seek help or support	5	15.15	1	5.26	4	28.57	2	14.29	3	15.79	1	7.14	4	21.05
Participant describes that they did not receive any formal support	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes getting care and support from domestic services and/or home care	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	4	12.12	4	21.05	0	0.00	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes getting care and support in the form of transport to and from hospital appointments	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	2	14.29	2	10.53

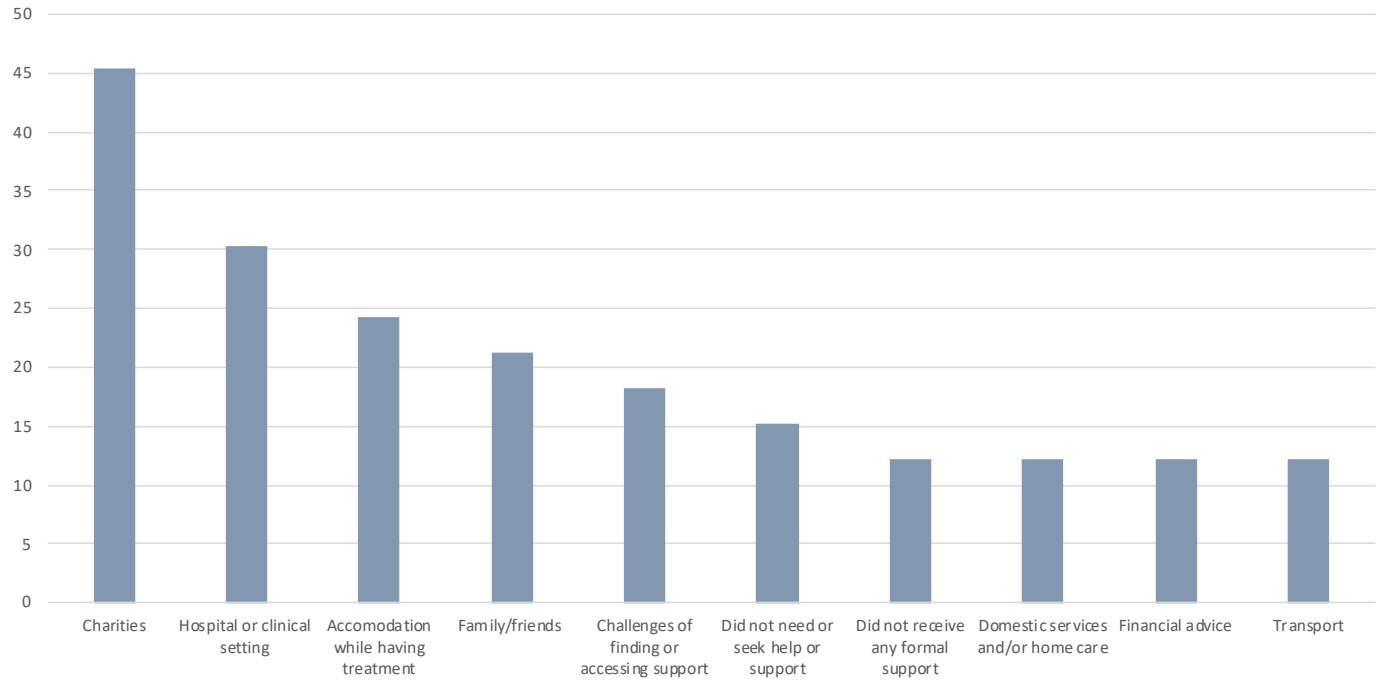


Figure 7.31: Experience of care and support

Table 7.15: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes getting care and support from charities	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older Higher status	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status
Participant describes getting care and support from hospital or clinical setting	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes getting care and support in the form of accomodation for themselves or their family while having treatment	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64
Participant describes getting care and support from family and friends	Multiple Myeloma Male	Diffuse Large B-Cell Lymphoma Female
Participant describes the challenges of finding or accessing support	CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes that they did not need or seek help or support	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy Aged 65 or older
Participant describes getting care and support from domestic services and/or home care	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes getting care and support in the form of financial advice and help with Centrelink applications	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes getting care and support in the form of transport to and from hospital appointments	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Female

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negaitve impact on quality of life (33.33%). This was followed by overall a minimal impact on quality of life (6.06 %), and overall no impact on quality of life (3.03%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (45.45%), altering lifestyle to manage condition (including being immunocompromised) (21.21%), managing side effects and symptoms (21.21 %), and reduced social interaction (21.21%). Other themes included, being unable to travel or having to adapt significantly in order to travel (15.15%), fatigue (12.12%), reduced capacity for physical activity or needing to slow down (12.12%), and that quality of life was reduced temporarily (12.12%).

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 (84.85%), and overall, there was no impact on mental health (12.12%).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were mindfulness or meditation (30.30%), and the importance of physical exercise (24.24%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (15.15%), the importance of family and friends in maintaining their mental health (15.15%), consulting a mental health professional (9.09%), and the importance of keeping busy (9.09%). There were 5 participants (15.15%) that described no activities to maintain mental health (15.15%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise or being physically active (36.36%), complying with treatment and management (21.21%), and self care e.g. more rest, accepting help, pacing (21.21 %). Other themes included understanding their limitations (15.15%), maintaining a healthy diet (15.15%), mindfulness or meditation (12.12%), socialising with friends and/or family (9.09%), and maintaining a normal routine (9.09%).

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 (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%). Other themes included when having sensitive discussion (diagnosis, treatment decision) (12.12%), because of interactions with the medical team (12.12%),all the time (12.12%), and when feeling sick/unwell (9.09%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (15.15%), support from nurse or treatment team (9.09%), and getting support from family and friends (6.06 %).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (45.45%), and overall, there was a positive impact on relationships (27.27%). Other themes included overall, there was an impact on relationships that was both positive and negative (12.12%), and overall, there no impact on relationships (3.03%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (24.24%), and from people not knowing what to say or do and withdrawing from relationships (6.06 %).

The most common themes in relation to having a positive impact on relationships were from family relationships being strengthened (18.18%), and from people being well-meaning and supportive (18.18%).

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 (75.76%), and overall, there was not a burden on their family (18.18%).

The main reason that participant described their condition being a burden were that the burden on family was temporary or only during treatment (27.27%), the mental/emotional strain placed on their family(21.21%), and the extra household duties and responsibilities that their family must take on (15.15%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (63.64%), and overall, there was no cost burden (33.33%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (39.39%), the cost of treatments (including repeat scripts) (21.21%), and the cost of parking and travel to attend appointments (including accommodation) (18.18%). Other themes included a family member needing to take time off work (9.09%) and needing to access financial support from family or charities (9.09%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (45.45%), nearly everything was paid for through the private health system (12.12%), and the participant was able to afford all costs (12.12%).

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 low levels of anxiety.

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negaitve impact on quality of life (33.33%). This was followed by overall a minimal impact on quality of life (6.06 %), and overall no impact on quality of life (3.03%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (45.45%), altering lifestyle to manage condition (including being immunocompromised) (21.21%), managing side effects and symptoms (21.21 %), and reduced social interaction (21.21%). Other themes included, being unable to travel or having to adapt significantly in order to travel (15.15%), fatigue (12.12%), reduced capacity for physical activity or needing to slow down (12.12%), and that quality of life was reduced temporarily (12.12%).

Experience described suggests that there was an overall negative impact on quality of life

Not now, but I would say during the time of treatment, because I was very tired, I wanted to keep doing so much of everything that I had done prior to, but I couldn't keep up with my active children. I couldn't keep up with going out for dinners or going away on weekends. I was just too tired. When I'd go away, I'd have to take my medication with me or check my temperature. I couldn't eat certain foods. I tried not to let it get me down, but at times it would. I just used to think, "Well, it's only a short term thing. Hopefully everything goes well for long term gain." Over that period, that was very draining.
Participant 001_2023AUCRT

It affected the family, obviously, when I was diagnosed and being in hospital all the time. Now that I'm home, things are slowly returning back to normal. I'm at home most of the day and managing to do the daily activities and whatever, like cooking dinner and things like that, which I wasn't able to do before. Probably the worst for them is over, but I'm a bit concerned that I think they're a little bit overcautious at times about me being able to do things.
Participant 002_2023AUCRT

Not so much now, but certainly in the initial stages because nobody knew the, you know, the long term ramifications. So certainly that first couple of years was pretty, it's real tricky. And I had more very young grandchildren. They're all a little bit older now. Of course, I had more young grandchildren and I was helping out a bit with babysitting and all that sort of stuff. And so I couldn't do that anymore because for, you know, for quite a while that relationship was very… look, my kids are great, they're wonderful, but but it was hard on everyone, I mean, it was hard on my husband. It was hard on me. It was hard on a family.
Participant 020_2023AUCRT

During treatment and probably a couple years past the treatment, yes, it has affected my quality of life with what I've been able to do and to achieve with regards to work, my physical activity, socializing, things like that. About we had to give up everything that I was doing for three 3 1/2 years to maybe 4 1/2 years.
Participant 024_2023AUCRT

Experience described suggests that there was a mix of positive and negaitve impact on quality of life

I guess in a way I thought maybe…my husband works a lot. I thought maybe after getting home, he took a little bit of time off but he still works a lot whereas it sort of made me reassess a little bit and I would like to spend a bit more time together but it's a bit difficult just having a business and everything. Yes, it's quality of life, my energy levels aren't like what they used to be. I guess spending a year doing nothing, it'll take a little while to get them back up to what they were. Other than that, yes, nothing else has changed too much since I've finished treatment.
Participant 005_2023AUCRT

Yeah, probably. It's it's getting better now. But obviously I felt when I've got three kids … So it was very hard because that first year I spent more time in hospital than at home, so I felt like. I wasn't a very good mother to them and especially the youngest one. He had a lot of anxiety and depression and he's still sort of suffering from that. So I still feel that I feel guilty about that and I feel like that I haven't done the right. I never know that it's not my fault but and and just I guess with I feel I feel bad for like my husband and all my kids and my mom and dad and that how much how much worry and stress. Of course, even

though it's not my fault, but it's it's it's made me feel sort of bad. On the other hand then there's things like say now my husband is not that he was ever bad but he said I never realized how much I loved you until you almost died. So in a lot of ways I've brought it closer I guess so and it's he always made me feel like even when when I was. I had horrible hairy face because of steroids and no eyelash and eyebrows and just looked awful. He still made me feel good. So that's probably made things better. And yeah, I mean some friends and stuff. Obviously there's a lot of people I haven't seen as much or had as much to do with because because I was pretty well by the time I was past my danger neutropenic stage and COVID started so and I'm still immuno suppressed. I'm not vaccinated. So it makes you less social and like you can't sort of see as many people or you miss out or think on things a bit more and and then you feel like we'll probably some of your family's missing out on things because of that. Participant 006_2023AUCRT

It's certainly, I'm lucky enough to have both parents and they're in their mid 80s and I guess the anxiety that it it caused them. That in itself caused me more anxiety. Yeah, relationship with with my close friends have they were good, but they're really powerful….Relationships with all of the other people who are important in my life have been fantastic. Participant 009_2023AUCRT

Well, it's definitely affected mine because I can't do what I used to do. Yeah, like being active how I was and gone away and stuff like you just. I just can't do it anymore. I can't do stuff with my son like I used to. Like you'd go away for a week camping and stuff. That'd be a real struggle now. Yeah, like my wife and I were always really energetic, like we were traveling. And like there was, it would be nothing for us to walk 14 to 20 days today in a day to look at a National Park or whatever.And we did that all the time, like when we were traveling. And like we just can't do that now. I hear you, but I'm glad we got to do it before it happened. Family were, they were really supportive, I think. How would you explain it? Some worries about about me, said it's my wife, but I think my wife now just accepts this is what we have to deal with now, you know, like she's pretty, she's pretty positive about everything. You know, like this is what we're going to do, and this is how it's going to happen. Participant 011_2023AUCRT

Experience described suggests that there was overall a minimal impact on quality of life

Not really. I thought. I haven't let it. Apart from when you have the transplants, Do you know what I mean? That's the only time, yeah. And so when you when I've been on chemo, I like I was on the last time I was on it for a couple of two years, I suppose. And I was doing it every Monday. I tried to lead as normal life as I could. Participant 025_2023AUCRT

To a point, COVID. I meant that I had advantages they didn't have. The immune system depletion that I have had with both stem cells and CAR T has limited what I do, but I've been really comfortable with it. I might say, but I don't go to pubs or footy matches or, and I probably wouldn't anyway. So I don't feel like I'm missing out. Participant 036_2023AUCRT

Experience described suggests that there was overall no impact on quality of life

Look, I live on my own. I've lived on my own for 12, 13 years. I've got two daughters, I've got grandchildren. It hasn't affected any of those relationships. I've got some good friends who sort of bonded together around me and supported me and helped me, but not quality of life. I don't think that it has had a particular impact on me, simply because I'm get out there and do it and if it kills me, it kills me. Participant 008_2023AUCRT

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Experience described suggests that there was an overall negative impact on quality of life	19	57.58	4	57.14	5	50.00	10	62.50	16	61.54	3	42.86	8	53.33	11	61.11
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	11	33.33	3	42.86	4	40.00	4	25.00	9	34.62	2	28.57	5	33.33	6	33.33
Experience described suggests that there was overall a minimal impact on quality of life	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	2	13.33	0	0.00
Experience described suggests that there was overall no impact on quality of life	1	3.03	0	0.00	0	0.00	1	6.25	0	0.00	1	14.29	0	0.00	1	5.56

Impact on quality of life	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Experience described suggests that there was an overall negative impact on quality of life	19	57.58	10	52.63	9	64.29	8	57.14	11	57.89	9	64.29	10	52.63
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	11	33.33	9	47.37	2	14.29	5	35.71	6	31.58	5	35.71	6	31.58
Experience described suggests that there was overall a minimal impact on quality of life	2	6.06	0	0.00	2	14.29	0	0.00	2	10.53	0	0.00	2	10.53
Experience described suggests that there was overall no impact on quality of life	1	3.03	0	0.00	1	7.14	1	7.14	0	0.00	0	0.00	1	5.26

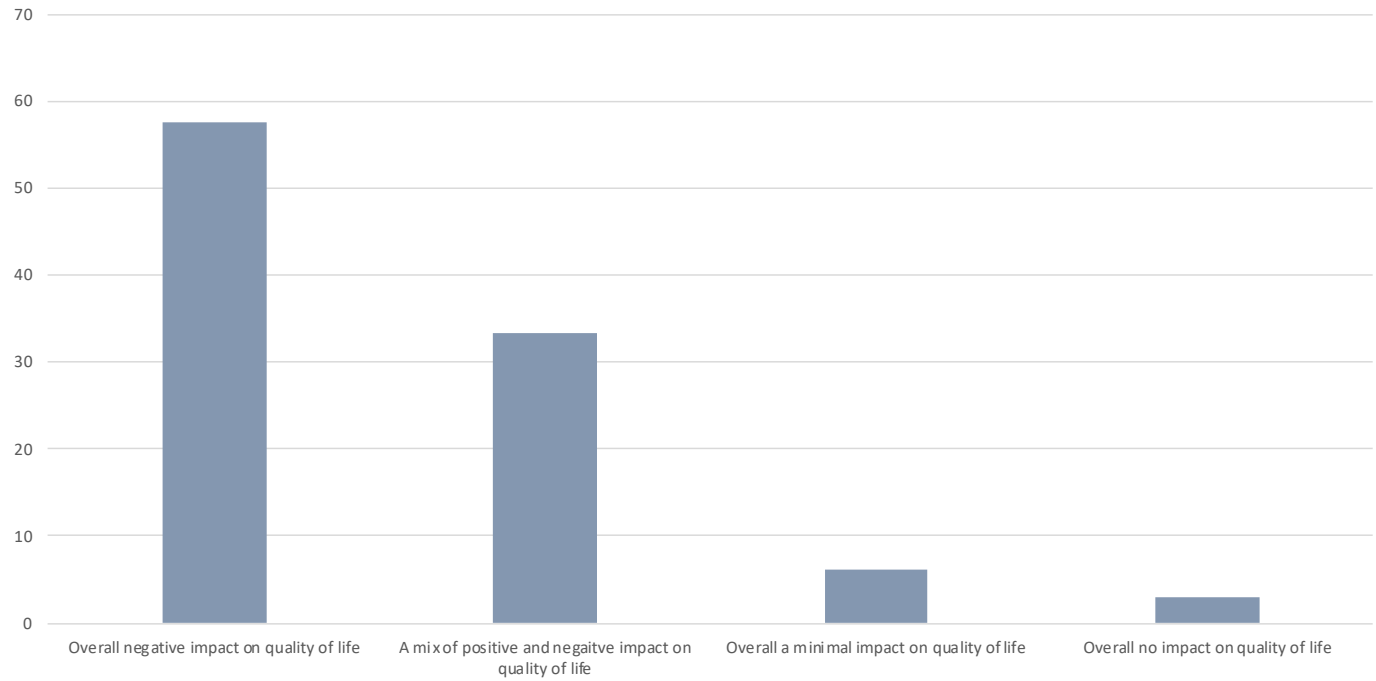


Figure 8.1: Impact on quality of life

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	CAR T-Cell therapy	-
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	Aged 65 or older	Aged 25 to 64
Experience described suggests that there was overall no impact on quality of life	-	CAR T-Cell therapy

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	15	45.45	5	71.43	3	30.00	7	43.75	14	53.85	1	14.29	8	53.33	7	38.89
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	7	21.21	2	28.57	3	30.00	2	12.50	3	11.54	4	57.14	5	33.33	2	11.11
Participant describes a negative impact on quality of life due to managing side effects and symptoms	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes a negative impact on quality of life due to reduced social interaction	7	21.21	3	42.86	2	20.00	2	12.50	4	15.38	3	42.86	4	26.67	3	16.67
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	5	15.15	1	14.29	1	10.00	3	18.75	5	19.23	0	0.00	2	13.33	3	16.67
Participant describes a negative impact on quality of life without giving a reason	5	15.15	0	0.00	2	20.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22
Participant describes a negative impact on quality of life due to fatigue	4	12.12	1	14.29	1	10.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	4	12.12	2	28.57	1	10.00	1	6.25	4	15.38	0	0.00	1	6.67	3	16.67
Participant describes a negative impact on quality of life that was only temporary	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	9	27.27	3	42.86	3	30.00	3	18.75	7	26.92	2	28.57	4	26.67	5	27.78

Impact on quality of life (reasons)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	15	45.45	10	52.63	5	35.71	4	28.57	11	57.89	4	28.57	11	57.89
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	7	21.21	4	21.05	3	21.43	0	0.00	7	36.84	1	7.14	6	31.58
Participant describes a negative impact on quality of life due to managing side effects and symptoms	7	21.21	4	21.05	3	21.43	1	7.14	6	31.58	0	0.00	7	36.84
Participant describes a negative impact on quality of life due to reduced social interaction	7	21.21	5	26.32	2	14.29	1	7.14	6	31.58	2	14.29	5	26.32
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	5	15.15	4	21.05	1	7.14	2	14.29	3	15.79	4	28.57	1	5.26
Participant describes a negative impact on quality of life without giving a reason	5	15.15	1	5.26	4	28.57	4	28.57	1	5.26	4	28.57	1	5.26
Participant describes a negative impact on quality of life due to fatigue	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes a negative impact on quality of life that was only temporary	4	12.12	3	15.79	1	7.14	1	7.14	3	15.79	2	14.29	2	10.53
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	9	27.27	7	36.84	2	14.29	4	28.57	5	26.32	4	28.57	5	26.32

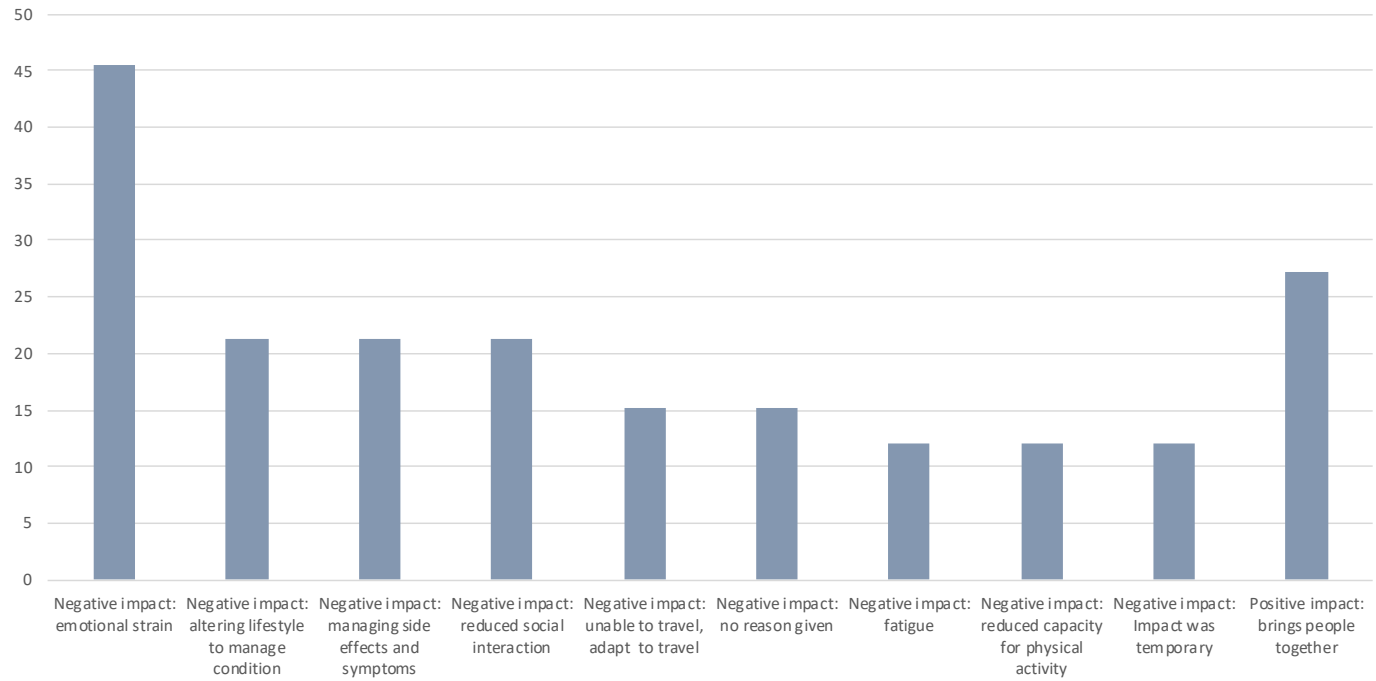


Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Impact on quality of life (reasons)	Reported less frequently	Reported more frequently
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Metropolitan Higher status
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	Male Regional or remote Mid to low status	CAR T-Cell therapy Female Metropolitan Higher status
Participant describes a negative impact on quality of life due to managing side effects and symptoms	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status	Multiple Myeloma Metropolitan Higher status
Participant describes a negative impact on quality of life due to reduced social interaction	Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Metropolitan
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	CAR T-Cell therapy	Mid to low status
Participant describes a negative impact on quality of life without giving a reason	B-cell acute lymphoblastic leukaemia (ALL)	Aged 65 or older Regional or remote Mid to low status
Participant describes a negative impact on quality of life due to fatigue	CAR T-Cell therapy	
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a negative impact on quality of life that was only temporary	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL)

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 (84.85%), and overall, there was no impact on mental health (12.12%).

Table 8.5: Impact on mental health

Impact on mental health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Experience described suggests that overall, there was at least some impact on mental health	28	84.85	4	57.14	10	100.00	14	87.50	21	80.77	7	100.00	12	80.00	16	88.89
Experience described suggests that overall, there was no impact on mental health	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11

Impact on mental health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Experience described suggests that overall, there was at least some impact on mental health	28	84.85	16	84.21	12	85.71	13	92.86	15	78.95	12	85.71	16	84.21
Experience described suggests that overall, there was no impact on mental health	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	2	14.29	2	10.53

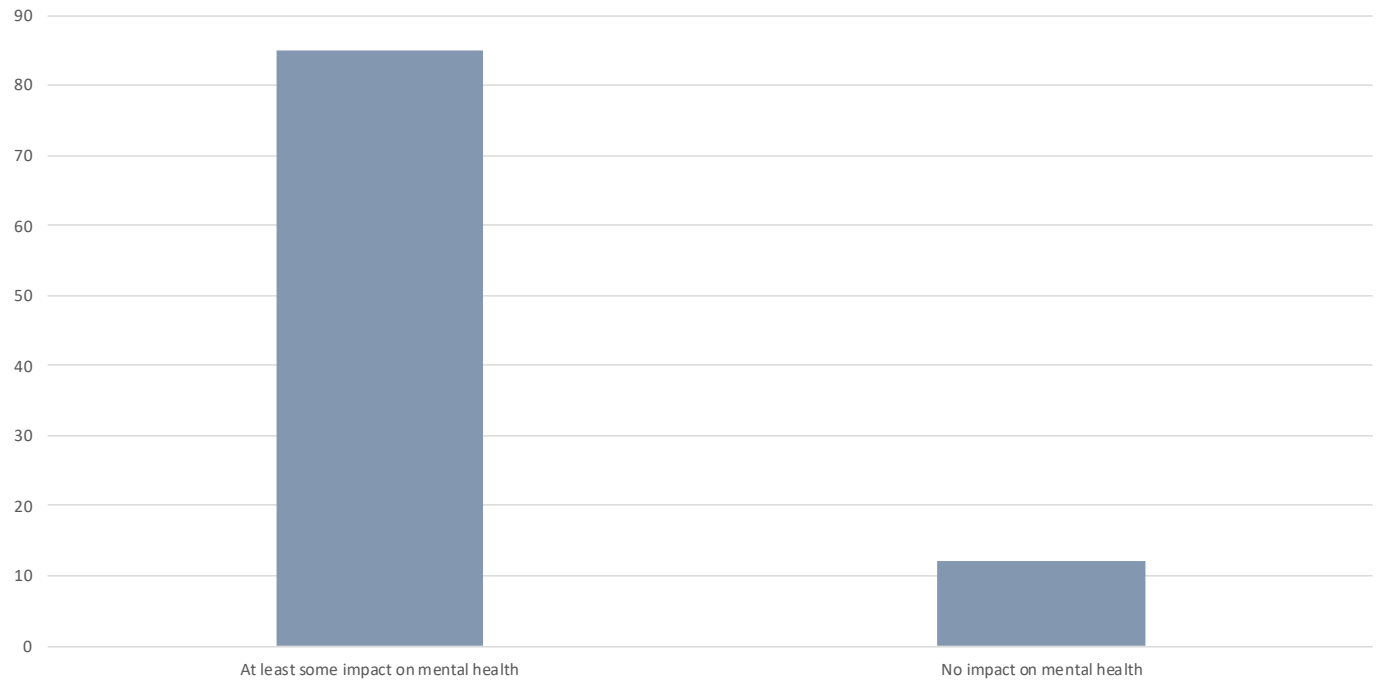


Figure 8.3: Impact on mental health

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	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Experience described suggests that overall, there was no impact on mental health	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common responses were mindfulness or meditation (30.30%), and the importance of physical exercise (24.24%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (15.15%), the importance of family and friends in maintaining their mental health (15.15%), consulting a mental health professional (9.09%), and the importance of keeping busy (9.09%). There were 5 participants (15.15%) that described no activities to maintain mental health (15.15%).

Participant describes mindfulness and/or meditation to maintain their mental health

Uncertainty is a big problem. I just tried to keep that under control, but I realize that's a problem now. My blood count started to drop. I thought I was cured, and getting into that level of the uncertainty again, I could feel myself going down a hole. I decided the best thing to do was do meditation. I'm doing a meditation course which I haven't started yet. I am starting on Friday.
Participant 003_2023AUCRT

Just sometimes if I find myself getting anxious, I've got coping techniques, breathing exercises, just learning my limits now compared to what they used to be.
Participant 005_2023AUCRT

No. I just keep thinking back to how I think I feel. Although, I don't ever feel sorry for myself, because I think I've got a positive outcome. I get to watch my two girls grow up, so that's all. I've won there so I don't really need anything else…I'm more of a positive person generally anyway.
Participant 001_2023AUCRT

Participant describes the importance of physical exercise to maintain their mental health

Ride the bike. That sounds weird, but you can, you can solve it. And I bought a new puppy too. But yeah, yeah, you can solve the world's problems when you're out riding a bike.
Participant 022_2023AUCRT

I was involved with martial arts from a young age, so I was able to use that energy, I suppose, to focus on things. Yeah, that's about it. Really.
Participant 024_2023AUCRT

Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health

Yes. My mental health, I find I don't worry about stupid things anymore like I used to. I think I've calmed down that way. I still keep myself quite active mentally. I watch a lot of documentaries on TV, do a lot of word puzzles and whatever. Yes, I'm just taking each day as it comes just trying to get a little bit stronger just so I can start doing a little bit more.
Participant 002_2023AUCRT

We've got a little dog or more. You know, I take the dog out morning and afternoon or sometimes depending on my wife works four days a week. She can just walk walk to work. But so we're out with the dog, you know and and there's so many dogs in the area. You know we live in a beautiful area. It's sort of like canal waterways and lovely walkways. So you when you go out, you know it's by heaps of dogs and the way dogs want to stop and then you you have a chat to people and I usually I'm in my mobility scooter and I don't have the dog on the lead. She just runs along beside me. She's very good. So people stop and have a chat and that's kind of therapeutic, you know. Well, at least I can get out and do that. Some people couldn't.
Participant 031_2023AUCRT

Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health

You know, I've never been a person to ring people up and chat on the phone and that sort of thing. I'm not terribly good at that when I can't see the person and I think I was just a good time for them or not. So but I've made a bit more of an effort with that. And also just contacting people, you know, sending a text, how are you going, blah, blah. And if they say, oh, can I come down and see you or can you come and meet me somewhere? I make an effort to do it…I hope now I'll make a bit more of an effort to keep in touch with people. It's really good to hear, yeah. You know, I think that's important. I just for my mental well-being. Otherwise it would be easy to be just come a bit isolated..
Participant 012_2023AUCRT

Oh, well, we see, see, see a lot of our children, our two married children down here, live within a walking distance for this. We moved out here to be near them and that's been wonderful. We were involved as participants of our grandchildren's sports, and there we go along to the soccer or basketball, which we enjoy. That's probably the biggest thing for mental health for both of us, because we're cut out a lot of other things. So the family's become a pivot for they're very good, the kids.
Participant 035_2023AUCRT

Participant describes no activities to maintain mental health to maintain their mental health

No, it doesn't have any effect now, not not now that I'm not having any treatment and I don't, I don't do anything now because there is no impact. But when there was, I don't, I don't think I did anything significant about it. I think I just, you know, put up with it.
Participant 014_2023AUCRT

Participant describes consulting a mental health professional to maintain their mental health

Yeah, well I see the the psychologist and I do relaxation and she's also taught me a few techniques of how to manage things when they are when when you're getting anxious about about stuff. So that's very helpful and I also find I do I do a bit of exercise and yoga and that sort of thing to try and. I guess for relaxation, but also for us to make me feel like I'm doing something positive to contribute to my mental health. But yeah, it certainly does. I mean it's it's always there. I don't know. I guess at one stage you feel better. But the last few days I felt a bit tired and my throat was a bit sore the other day and I thought, Oh no, this is just like when I got diagnosed. Am I having a relapse or where is? Most likely it's nothing, but normally most people, if they have a little minor thing happens, I wouldn't think anything of it. Whereas I tend to have to really draw myself back from not thinking the worst every time something happens. So yeah.
Participant 006_2023AUCRT

Participant describes the importance of keeping busy to maintain their mental health

OK, my mental the mental side of things seems OK. If I'm feeling lethargic and tired, then it's hard to keep the mental strong. So to me they seem to go hand in hand. So daily walking and getting on with doing things, yeah, it seems to me, and trying to get away now and again, it seems to be the most important thing for the mental health for me.
Participant 021_2023AUCRT

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	2	28.57	4	40.00	6	37.50	10	38.46	2	28.57	5	33.33	7	38.89
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	0	0.00	3	30.00	4	25.00	5	19.23	2	28.57	4	26.67	3	16.67
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	3	42.86	1	10.00	1	6.25	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	0	0.00	3	30.00	2	12.50	1	3.85	4	57.14	3	20.00	2	11.11
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	1	14.29	1	10.00	2	12.50	2	7.69	2	28.57	2	13.33	2	11.11
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11

Regular activities to maintain mental health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	7	36.84	5	35.71	5	35.71	7	36.84	7	50.00	5	26.32
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	10.53	5	35.71	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	6	31.58	1	7.14	5	35.71	2	10.53	3	21.43	4	21.05
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	4	21.05	1	7.14	0	0.00	5	26.32	0	0.00	5	26.32
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	1	7.14	3	15.79
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26

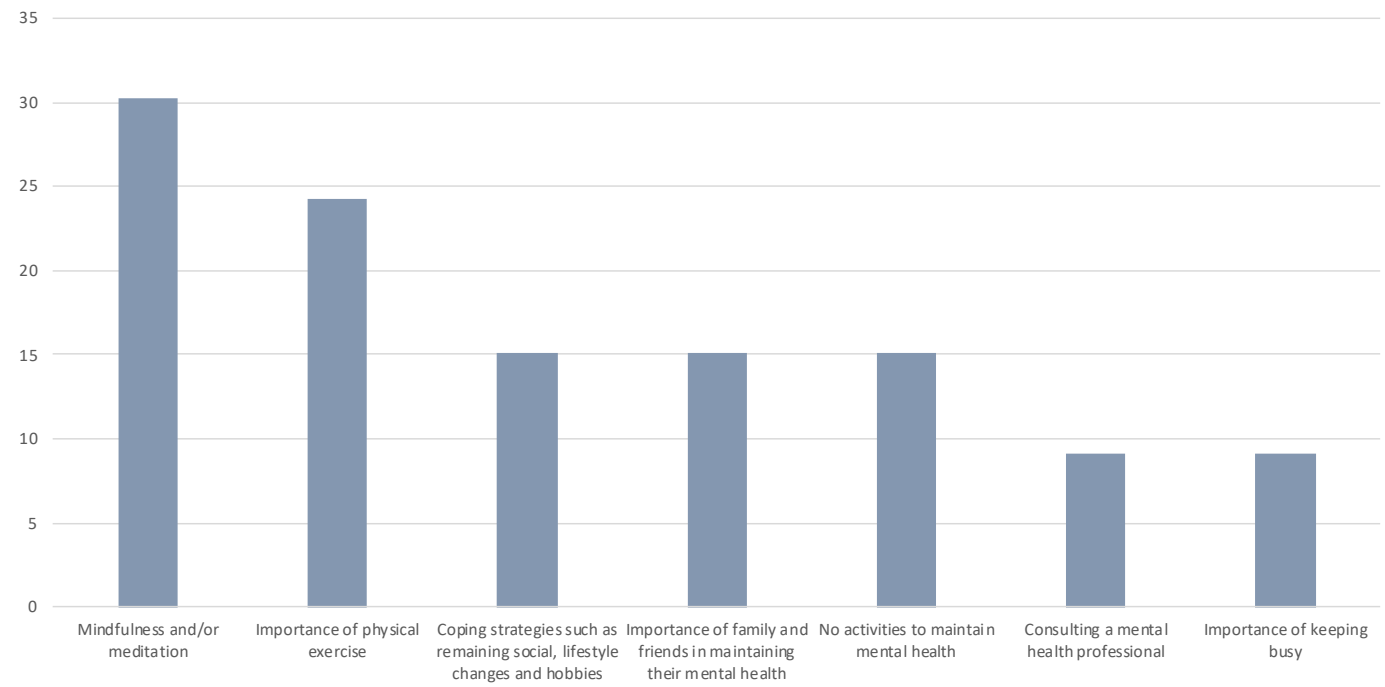


Figure 8.4: Regular activities to maintain mental health

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 mindfulness and/or meditation to maintain their mental health	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	Diffuse Large B-Cell Lymphoma Regional or remote	Aged 65 or older Metropolitan
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	CAR T-Cell therapy Aged 65 or older Metropolitan
Participant describes the importance of keeping busy to maintain their mental health	-	CAR T-Cell therapy

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise or being physically active (36.36%), complying with treatment and management (21.21%), and self care e.g. more rest, accepting help, pacing (21.21 %). Other themes included understanding their limitations (15.15%), maintaining a healthy diet (15.15%), mindfulness or meditation (12.12%), socialising with friends and/or family (9.09%), and maintaining a normal routine (9.09%).

Participant describes the importance of doing physical exercise/physically active in maintaining their general health

I would say I'm somewhat back to normal. After I eased off the medication, which has been a year and a half now, I went back into the gym. It didn't take long. Once that medication went, it didn't take too long. Then just a little bit of different looking with my face with the steroids and stuff like that. Once all that, everything slipped quite quickly into place, back to what I know is normal.
Participant 001_2023AUCRT

I found that I really need to exercise, so I've been doing laps. I've done laps in the pool. I try to do it every day, but it's probably usually about four times a week. Ride a bike. I found exercise is, it's really important actually.
Participant 003_2023AUCRT

That's a hard one…Like I force myself to do things at times when I don't want to. Like I try and exercise every day now and that was because of my knees and stuff. And I bought like a rower machine and a bike and I sort of do that every day religiously, you know, just to try and keep a little bit of a fitness up.
Participant 011_2023AUCRT

Well, you know, we've got this very good physiotherapy app, so doing that every day, most

days, you know, do exercises for balance as well as just core, you know, strength. And we try and we've got an exercise bike. So we either go on the exercise bike or so we actually live on the beach. We'll go for a walk along the beach, which is lovely. We must look and enjoy that. And I do, you know, light housework and light gardening, just to keep up my stamina.
Participant 035_2023AUCRT

Participant describes the importance of complying with treatment/management in maintaining their general health

The things that I need to do well, I have to stick to my medication. I have to make sure I have the blood tests when they do keep my doctor's appointments. They're the main things.
Participant 012_2023AUCRT

Well, take medication, keep exercising. I still have to be very aware of who I'm mixing with because I'm sorry, I am off immunosuppressants now, but I'm still, I don't have that immunity yet. I'm also, I haven't been vaccinated for, and I can't have for quite a while yet any of the live vaccines. So I have to be very aware of besides from COVID but I don't go near anyone who may have or be carrying chicken pox, measles, mumps or ruella anything like that. So you have to be a lot more careful. I'm a lot more limited in what you do and and I'll find even before COVID well I was wearing the mask so that was a a limiting thing and I'm just trying not to get too close to people sort of always if you're out somewhere and. You need to get to the other side of the park and there's a group of people there. You're always looking at ways to walk right away from people and not close to people. So yeah, so just things like that. Not not big, major things, I suppose.
Participant 006_2023AUCRT

Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health

I guess just getting enough sleep or just taking it easy if I'm stressed out or I'm tired.
Participant 005_2023AUCRT

Look after myself, know when I've got a rest, get more sleep than I used to have.
Participant 022_2023AUCRT

So we tried to do things to keep myself active and keep my mind active. And sometimes I struggle with things, things that I could do probably in a day now takes a week to do sometimes. And a lot of that's just with the fact that I only have, you know, I just run out of puff and fatigue and I've got to go up and down in nap or something like that … But we we can chip away and not find if I keep myself active you keep doing something we can keep on top of something we can do it.
Participant 027_2023AUCRT

Participant describes the importance of understanding their limitations in maintaining their general health

Basically, I tend to keep to myself. No, I don't keep to myself a lot, but I know what triggers me. I have a friend that's really overwhelming at times. She means well, but she's overwhelming, so I limit my exposure to that. I don't want to sit on the phone and talk for two hours. Even people in the family that I don't particularly want to associate with, I don't. I just try to keep my home life very peaceful and very quiet.
Participant 002_2023AUCRT

I think I've learned that I need to only do things in small doses, and I need a lot of rest because I still get really tired. Sometimes I'm great, I'm full of energy, then all of a sudden I'll just come to a halt. I used to be a real multi-tasker and do loads of things at once, but now I've learnt that I can't do that now
Participant 004_2023AUCRT

Participant describes the importance of maintaining a healthy diet in maintaining their general health

Diet. I walk 5 to 8 ks a day taking care of my bones, my teeth. I'm seeing a podiatrist for the first time today. I should have seen maybe 10 years ago. But yeah, thinking about and it's partly, I mean I'm nearly 70, so it's partly about age, but it's also and my daughters are 40 and point their finger and you have to do this and you have to do that. So it's encouraging and it's so there's not really anything else. I do, Except eat well. I haven't been on a diet in five years, haven't even thought about it's it's a different world.
Participant 036_2023AUCRT

Well, I eat well, but I'm not a, you know, I'm not a I'm not a sort of anal about it. I mean, I eat really well, but I'm happy to have a pizza or an ice cream or something here in there. Yeah. So you know, I I suppose it's 90% good, 10% not good.
Participant 019_2023AUCRT

Participant describes the importance of mindfulness and/or meditation in maintaining their general health

Not to react to…how can I put this? Not to be so demanding of myself in terms of the time it takes me to do things, so allowing myself more time, allowing myself more rest and making sure I do two or three positive things in any given week.
Participant 009_2023AUCRT

I accept that I need to keep taking their medication. I've always maintained a a fairly healthy diet and I continue to do so. I spend time each day just sitting and thinking and meditating, and the rest of the time I just get on with life.
Participant 008_2023AUCRT

Participant describes the importance of socialising with friends and/or family in maintaining their general health

Yeah. So I guess it's for me, I make sure I eat healthily, try and have a healthy diet because I don't feel like eating at the moment. And yeah, and exercise. So yeah, if I can keep the good balance of those things and social contact, yeah, everything's doable then.
Participant 021_2023AUCRT

Participant describes the importance of maintaining a normal routine in maintaining their general health

I need to sleep, I need to exercise and move. I try, I try and walk. I walk every day. I try and do at least 10,000 plus steps. So I'm looking to walk at least 8 to 10K a day, which I I do generally and that does help. It helps with sleep. It helps with the your emotions and yeah, generally makes you feel good. So yeah, I I suppose I I enjoy still working. I have to admit that that that's the, you know, I had the choice to retire, but I prefer to work. I think that helps me, you know, socially and also helps me mentally. So I'm happy to do that. Generally I'm okay.
Participant 015_2023AUCRT

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	2	28.57	4	40.00	6	37.50	10	38.46	2	28.57	5	33.33	7	38.89
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	28.57	0	0.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	0	0.00	3	30.00	4	25.00	5	19.23	2	28.57	4	26.67	3	16.67
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	3	42.86	1	10.00	1	6.25	5	19.23	0	0.00	4	26.67	1	5.56
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	0	0.00	3	30.00	2	12.50	1	3.85	4	57.14	3	20.00	2	11.11
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	1	14.29	1	10.00	2	12.50	2	7.69	2	28.57	2	13.33	2	11.11
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11

Regular activities to maintain general health	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	12	36.36	7	36.84	5	35.71	5	35.71	7	36.84	7	50.00	5	26.32
Participant describes the importance of complying with treatment/management in maintaining their general health	7	21.21	2	10.53	5	35.71	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	7	21.21	6	31.58	1	7.14	5	35.71	2	10.53	3	21.43	4	21.05
Participant describes the importance of understanding their limitations in maintaining their general health	5	15.15	4	21.05	1	7.14	0	0.00	5	26.32	0	0.00	5	26.32
Participant describes the importance of maintaining a healthy diet in maintaining their general health	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	1	7.14	3	15.79
Participant describes the importance of socialising with friends and/or family in maintaining their general health	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26
Participant describes the importance of maintaining a normal routine in maintaining their general health	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26

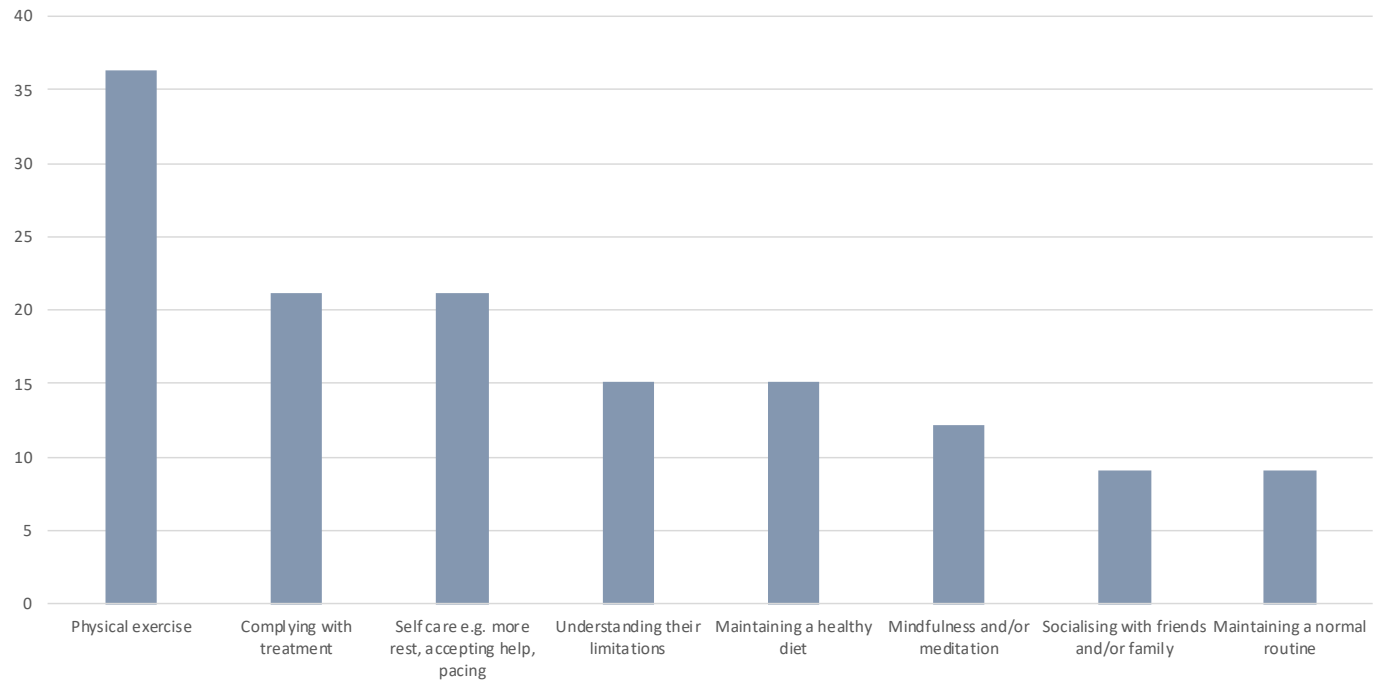


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Regular activities to maintain general health	Reported less frequently	Reported more frequently
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	Higher status	Mid to low status
Participant describes the importance of complying with treatment/management in maintaining their general health	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older Metropolitan	Aged 25 to 64 Regional or remote
Participant describes the importance of understanding their limitations in maintaining their general health	CAR T-Cell therapy Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan Higher status
Participant describes the importance of maintaining a healthy diet in maintaining their general health	B-cell acute lymphoblastic leukaemia (ALL) No CAR T-Cell therapy	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	-	CAR T-Cell therapy

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 (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%). Other themes included when having sensitive discussion (diagnosis, treatment decision) (12.12%), because of interactions with the medical team (12.12%),all the time (12.12%), and when feeling sick/unwell (9.09%).

Participant describes feeling vulnerable during/after treatments

Most of the time was undergoing for chemotherapy because it's just the unknown of what's going to be happening next week or the next month or how you're feeling. Because when you're if you're getting basically smashed by all these drugs so you don't know how quickly like if you have a cold, you can say oh we're going to recover in a week. But when you're having this chemo for three years, you go, well, how long is this going to affect me for? So it's just the unknown place that's the. The bit that you're frightened on. Well, not frightened, but you just wanna know more information than no one can really tell you.¶
Participant 024_2023AUCRT

Yeah, I did when I was on the dexamethasone. I've I felt well, I just felt bad in every way and I you know for part of the thalidomide time too with the rash I was, which by the way, I'd forgotten about until I was reminded by my wife who's sitting in the next room.

But I felt I felt pretty bad then too. But, but yeah, they were in, when you look back over for pretty brief periods in that time.
Participant 014_2023AUCRT

Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition

Yes. At one stage my blood sugar levels went went high and I ended up in casualty. And that that was scary because both things were happening. So I was new to having blood sugar problems and certainly new to lymphoma and the combination of the two was a bit much, yeah. But that that only happened once.
Participant 009_2023AUCRT

When I was going through the stage where I didn't have any immunity, I felt really ill and I was, I have to admit, when I was on medication, I had a lot of hallucinations and just some weird, weird thoughts and no concentration. I couldn't watch anything on television. I was just just uncomfortable, a lot of pain. I spoke to at times you think, oh, you know, if I'm going to die, I'm going to die kind of feeling. But things did improve.
Participant 015_2023AUCRT

Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)

That's an interesting question. I mean in the beginning, possibly you know, but only because there's so much to take in and you know you, you feel. It's hard to say, but you feel pissed off, I suppose you know. Why me? Why? Why? Why me? Why? Yeah. What have I done to deserve this? And and so you sort of feel feel pretty bad. But you know, since I've been coming two years now since I was diagnosed, almost coming up early September, it was so early September is when I was first diagnosed. So now you only have to look around every day that I'm in hospital and there's always someone worse off than you are. So that's my sort of philosophy on, on feeling to say, you know, what could be worse or we could be living in America and where I mean, I'd use my private health insurance, but Even so, Medicare is fantastic and a lot of people, you know, a lot of people don't have that. If you live in America, there's no Medicare. You'd hate to be in that situation.
Participant 031_2023AUCRT

I remember that that moment when they said that chemotherapy didn't work and I still didn't know what the what's next that was that was that that moment that that was kind of reality check. Yeah, but but then they said, you know, for that CAR T and all the stuff.
Participant 034_2023AUCRT

Participant describes feeling vulnerable because of interactions with the medical team

Like I know when I was in the the HOSPITAL getting chems and my specialist, that first specialist, the oncologist was away for the weekend and they had a part time one. And I come in and I said, he said to me, I said ohh, the lymphoma is in my heart and he said 'no it's not you don't like you don't get lymphoma in the heart', and I said, well, I have. And he said no you haven't, no you haven't. And just walked away. And I thought he didn't know. And then I asked my specialist said, yeah, well, here's the PET scans, yeah, he didn't know what he was talking about and you lose a bit of confidence.
Participant 011_2023AUCRT

I think that time when I was in, when I went to have the stem cell transplant, I had to be admitted to hospital, on a public holiday and they didn't have a bed for me. So I had to go and stay at the cancer accommodation in CITY and it was like being on a parallel universe because it was a public holiday. Practically everything was closed. There was no nothing to eat there and and I just turned on the television and watched one movie after another after another must have watched about 8 movies in a row. And I felt like I was in and out of space. And a friend went out and got me some food and I had to be at the hospital the next day at 10:00 o'clock to be admitted and I went there, I was there at 10:00 o'clock. I sat in the waiting room there till 6:00 o'clock that night and finally someone brought me some dinner, which I ate there and then about 7:00 o'clock, I got admitted to the room that I was to be in. So that I guess that time I felt the most vulnerable because it was kind of all out of my control. I just had to go with it.
Participant 012_2023AUCRT

As I said, there was one doctor that that probably should think about the words he chooses when he's talking to his patients is probably, makes you feel a bit despondent. I suppose there's once I went out there not not in tears but but teary eyed is probably the right word because I'd had a great response from a treatment and I thought, ohh, this is really good. I'm

doing really, really well. And then for some reason he just saw it in his way to say, 'well look yeah, but there's no you sugar coating this it's it's going to get you'. I said what you mean. He said, well you said it's going to get you. He said you have this condition and there is no cure. And then after that I felt really I was quite devastated and and it actually shocked me a little bit and I it's just stuff like that which I know he's he no he's not right but he could be right. But I just sometimes you don't need it shoved in your face. Like we we live with cancer and a lot of people with cancer don't have much hope. But to hang on to a little bit of it is something that keeps us ticking. Even if it keeps us ticking for another six months it's better than giving up. So to tell us that, you know it's going to get you is sort of took the wind out of my sails a little bit and you know, I had to talk it out with my wife just I was quite upset about it. And then I did raise it with him and he apologized, but he did, he said, well, this, you know, I said his explanation was, you know, I don't want to give you false hope. And I said I understand that. And I said, you don't have to give me no hope so. Yeah, so stuff like that, just it's sometimes doctors just need to be a little bit empathetic in their wording that they use, that was all.
Participant 019_2023AUCRT

Participant describes feeling vulnerable all the time

I think from the date of my diagnosis until now, I continue to feel vulnerable. In different ways I am vulnerable.
Participant 016_2023AUCRT

I am. Most of the time, yes. When there is no, I don't know when. But yeah, most of the time I'm not. I'm very vulnerable, yeah.
Participant 017_2023AUCRT

Yeah. Every day, yeah. Yep.
Participant 027_2023AUCRT

Participant describes feeling vulnerable when feeling sick/unwell

Like you're lying in hospital, really, really sick. As sick as you can get. It's not great, but you know, there's always something, there was always something to find some joy in, to look forward to, to get you out of it.
Participant 022_2023AUCRT

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes feeling vulnerable during/after treatments	12	36.36	2	28.57	2	20.00	8	50.00	10	38.46	2	28.57	4	26.67	8	44.44
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	15.15	0	0.00	1	10.00	4	25.00	3	11.54	2	28.57	1	6.67	4	22.22
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	12.12	0	0.00	2	20.00	2	12.50	2	7.69	2	28.57	1	6.67	3	16.67
Participant describes feeling vulnerable because of interactions with the medical team	4	12.12	0	0.00	1	10.00	3	18.75	4	15.38	0	0.00	1	6.67	3	16.67
Participant describes feeling vulnerable all the time	4	12.12	1	14.29	0	0.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant describes feeling vulnerable when feeling sick/unwell	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	1	6.67	2	11.11

Experience of vulnerability	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes feeling vulnerable during/after treatments	12	36.36	5	26.32	7	50.00	5	35.71	7	36.84	4	28.57	8	42.11
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	15.15	2	10.53	3	21.43	2	14.29	3	15.79	1	7.14	4	21.05
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	12.12	2	10.53	2	14.29	1	7.14	3	15.79	1	7.14	3	15.79
Participant describes feeling vulnerable because of interactions with the medical team	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	3	21.43	1	5.26
Participant describes feeling vulnerable all the time	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes feeling vulnerable when feeling sick/unwell	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

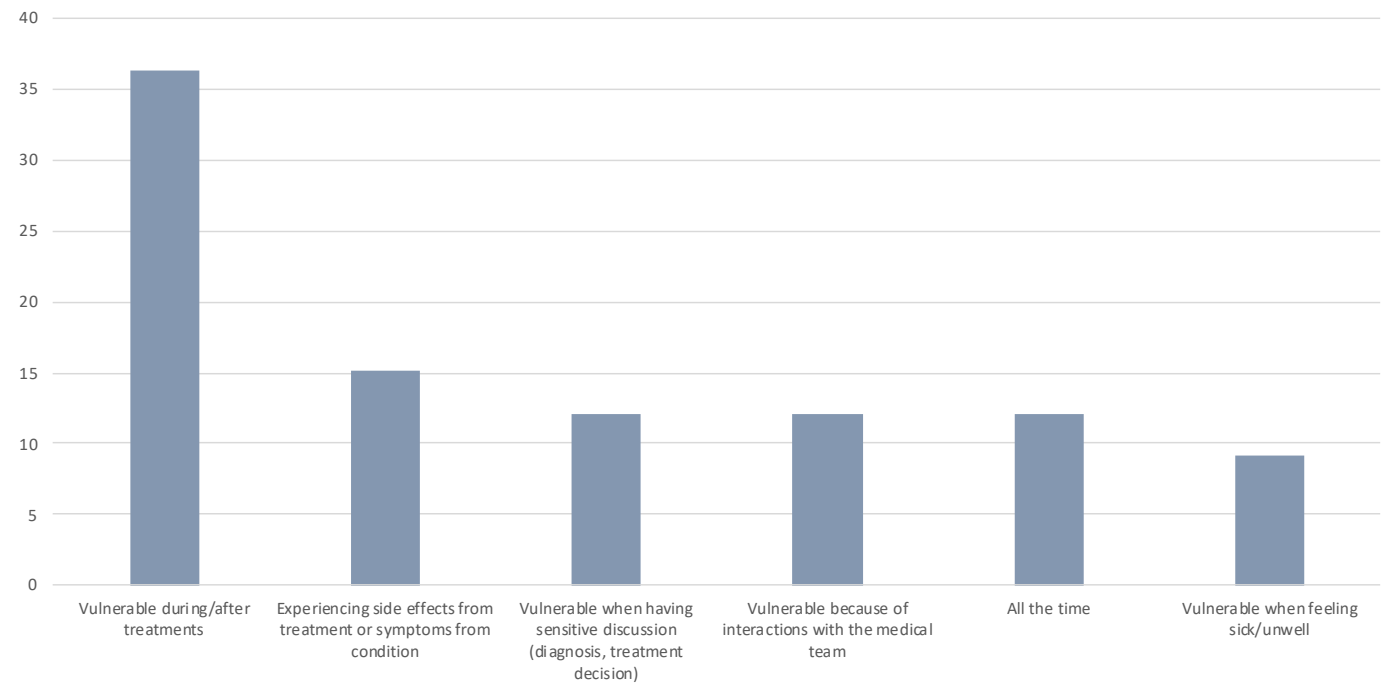


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatments	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy
Participant describes feeling vulnerable because of interactions with the medical team	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	
Participant describes feeling vulnerable all the time	Diffuse Large B-Cell Lymphoma	

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (15.15%), support from nurse or treatment team(9.09%), and getting support from family and friends (6.06 %).

Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability

I think the only defense that I have is meditation and exercise and probably physical activities that I do and I do something related to my 5 senses. It distracts me if I'm doing a little bit of gardening or I'm working on my car or doing. These are the moments that I totally forget about what's going on. And after four hours, five hours…all of a sudden you come back to the reality that, oh, I've been sick.
Participant 017_2023AUCRT

Participant describes support from nurse or treatment team to manage the feeling of vulnerability

I was in a ward with a lot of other people. We talked to other people and to talk to health professionals. Participant 020_2023AUCRT

Participant describes getting support from family and friends to manage the feeling of vulnerability

Well, I had a few friends that came and helped, which was good and yeah, a few of them have stayed with me and they help with transport and everything and and food and everything. So yeah, that was, that was good. I should say. I always have my son was there as well and he was ok but he didn't understand possibly. Participant 015_2023AUCRT

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	15.15	0	0.00	2	20.00	3	18.75	3	11.54	2	28.57	1	6.67	4	22.22
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56
Participant describes getting support from family and friends to manage the feeling of vulnerability	2	6.06	0	0.00	0	0.00	2	12.50	2	7.69	0	0.00	0	0.00	2	11.11

Methods to manage vulnerability	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	5	15.15	3	15.79	2	14.29	2	14.29	3	15.79	3	21.43	2	10.53
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	3	9.09	1	5.26	2	14.29	1	7.14	2	10.53	0	0.00	3	15.79
Participant describes getting support from family and friends to manage the feeling of vulnerability	2	6.06	2	10.53	0	0.00	1	7.14	1	5.26	1	7.14	1	5.26

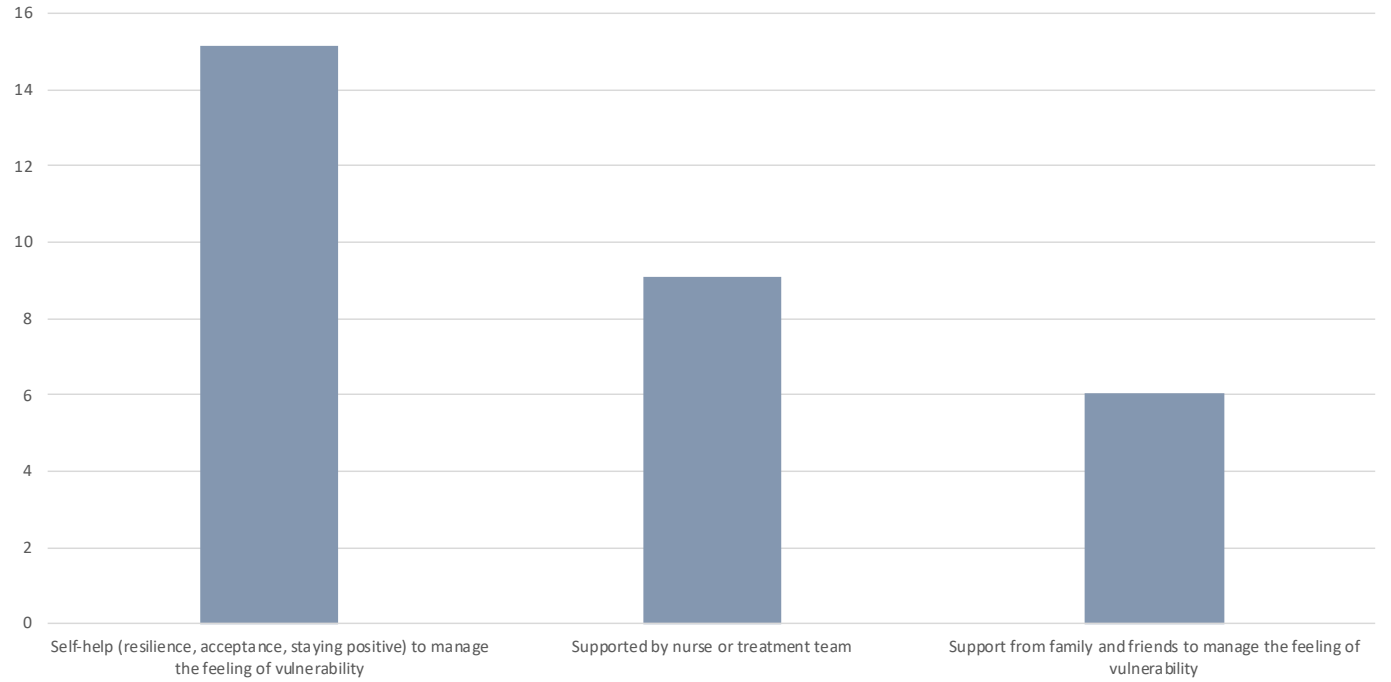


Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	B-cell acute lymphoblastic leukaemia (ALL)	Multiple Myeloma Aged 65 or older

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (45.45%), and overall, there was a positive impact on relationships (27.27%). Other themes included overall, there was an impact on relationships that was both positive and negative (12.12%), and overall, there no impact on relationships (3.03%).

The most common themes in relation to having a negative impact on relationships were from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (24.24%), and from people not knowing what to say or do and withdrawing from relationships (6.06 %).

The most common themes in relation to having a positive impact on relationships were from family relationships being strengthened (18.18%), and from people being well-meaning and supportive (18.18%).

Participant describes that overall, there was a negative impact on relationships

No, but it was hard sometimes with some friends that live very close by. I felt over that period of that 10 months, my life was just going to the hospital every day. That was a bit like Groundhog Day every day. You could see them going off doing what they wanted. Only a few friends, not all of them but a couple of them, probably distanced our friendship because of that, because I was away for that long period. I guess like anything, if you don't associate with someone for 10 or 11 months.
Participant 001_2023AUCRT

We don't see a lot of friends as much as we used to. Yeah, I mean we'll have, we'll have friends perhaps maximum of four in our home, but we we're active churchgoers and so we don't go into that environment. We have to live stream church services. So there are a lot of friends that we haven't seen face to face.
Participant 013_2023AUCRT

It does, yes. So we changed my whole plans of life and I don't get to get too much social time with my friends anymore because of the fatigue and the timing that I'm considering for my bedtime and so yeah, I'm a different person to what I used to be. Yeah, but I guess, yeah, life is like that makes you to be a different person every now and then.
Participant 017_2023AUCRT

Yeah, the biggest thing it takes from you, and I think probably all cancers probably do, that is your confidence. When I was diagnosed, I generally thought I was bulletproof and I actually probably generally believed I hadn't been to a heart doctor at all in any sort, GP for whatever, for probably five or six years. I just don't go like it was just I never got sick or never got cold, never got anything. And so I just bulletproofly went about life in an arrogant way, that sort of thing. But it it's just the way I did. So I was actually quite confident. And you know, we're obviously socialized with friends a lot and we, you know, for no reason just live life as you do with good friends and good family. But when once I was diagnosed, it was like, just tread warily to, you know, what your body can do. And with that came this sort of lack of bulletproofness. And so I was always, so I withdrew in a little bit. I don't like coming out of my shell as much as I used to. So I my friendships haven't deteriorated. But I used to be probably more outgoing than I was. But now I'm more conservative and withdrawn because it's sort of safe.
Participant 019_2023AUCRT

Participant describes that overall, there was a positive impact on relationships

No, everyone was really supportive. Really, really supportive at the time. It was actually wonderful the support that I got like emotional support from people wishing me well and cards and little gifts and things like that, so that was good.
Participant 004_2023AUCRT

Not really. I mean, I have to say my friends have been very supportive. My, my, sorry, there's an airplane just passing now, so I just come outside. I'll just wait for that pass. That's Qantas…. Sorry, Sorry. My friends have been very good, very supportive. My my children have been very good. My daughter only lives about 5 minutes away from me. She we're in regular contact. So then I had a PET scan that is, I think it is. And that showed up I had lesions in my neck, in my spine, in my shoulder, and in my sternum and clavicle okay. But anyway I'm good I'm I'm good in that regard….
Participant 015_2023AUCRT

I don't think so. They, my siblings worry like crazy and some of our friends do worry, no matter how I try to assure them not to. So it's that's nice. Sometimes it's it's too much. But the attention…. I keep saying I'm not going to die, I'm not going to die. I'll let you know if I'm going to die….So yeah, it's it's nice that that they care so much.
Participant 036_2023AUCRT

It's actually it's made a bit of a I guess I never used to be home, you know, I'd always be working, you know, and I guess now I'm always at home so. But I guess my wife and I bonded actually, better. Well, I say better, but you know, we, I suppose I listened to her more than I ever did. Which probably from the man saying that it probably that's a bit that's just my thoughts there, whereas I probably didn't listen to him much before.
Participant 031_2023AUCRT

In the sense we've become closer, I think, which is lovely, you know, grandchildren will take me by the arm or help me down steps, you know, automatically. I love you, Pop. It's beautiful, really. So we're very close. We always have been close, but that's been enhanced. It's I'm aware that it's not easy for NAME because she's had to give up a lot, but we do enjoy

being with each other and you know, we'll go out to lunch or whatever.
Participant 035_2023AUCRT

Participant describes that overall, there was an impact on relationships that was both positive and negative

Not so much family I feel very cared about. It's with friends. It has two reasons. One, COVID, you know, I just don't do the social thing as much as I used to. I probably could start to. I don't have the energy and there's kind of probably friendships that I had. I just don't have the energy to engage. I'm really, really selective now about who I give my energy to. Where I was once, I'm very generous person and that I really has kind of I just can't do that. And so if people can't accept that change in me, well, they have. That's kind of how it is now. So there's probably a few friendships that are slowly fizzling and dying that, you know, my energy is primarily for my family. You know, my children, my family, my partner and a few close friends. And then after that we see what happens.
Participant 016_2023AUCRT

Table 8.15: Impact on relationships

Impact on relationships	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that overall, there was a negative impact on relationships	15	45.45	4	57.14	4	40.00	7	43.75	12	46.15	3	42.86	5	33.33	10	55.56
Participant describes that overall, there was a positive impact on relationships	9	27.27	1	14.29	4	40.00	4	25.00	7	26.92	2	28.57	5	33.33	4	22.22
Participant describes that overall, there was an impact on relationships that was both positive and negative	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes that overall, there no impact on relationships	1	3.03	0	0.00	0	0.00	1	6.25	1	3.85	0	0.00	1	6.67	0	0.00
No particular comment	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67

Impact on relationships	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was a negative impact on relationships	15	45.45	9	47.37	6	42.86	8	57.14	7	36.84	10	71.43	5	26.32
Participant describes that overall, there was a positive impact on relationships	9	27.27	5	26.32	4	28.57	3	21.43	6	31.58	3	21.43	6	31.58
Participant describes that overall, there was an impact on relationships that was both positive and negative	4	12.12	4	21.05	0	0.00	2	14.29	2	10.53	0	0.00	4	21.05
Participant describes that overall, there no impact on relationships	1	3.03	0	0.00	1	7.14	0	0.00	1	5.26	0	0.00	1	5.26
No particular comment	4	12.12	1	5.26	3	21.43	1	7.14	3	15.79	1	7.14	3	15.79

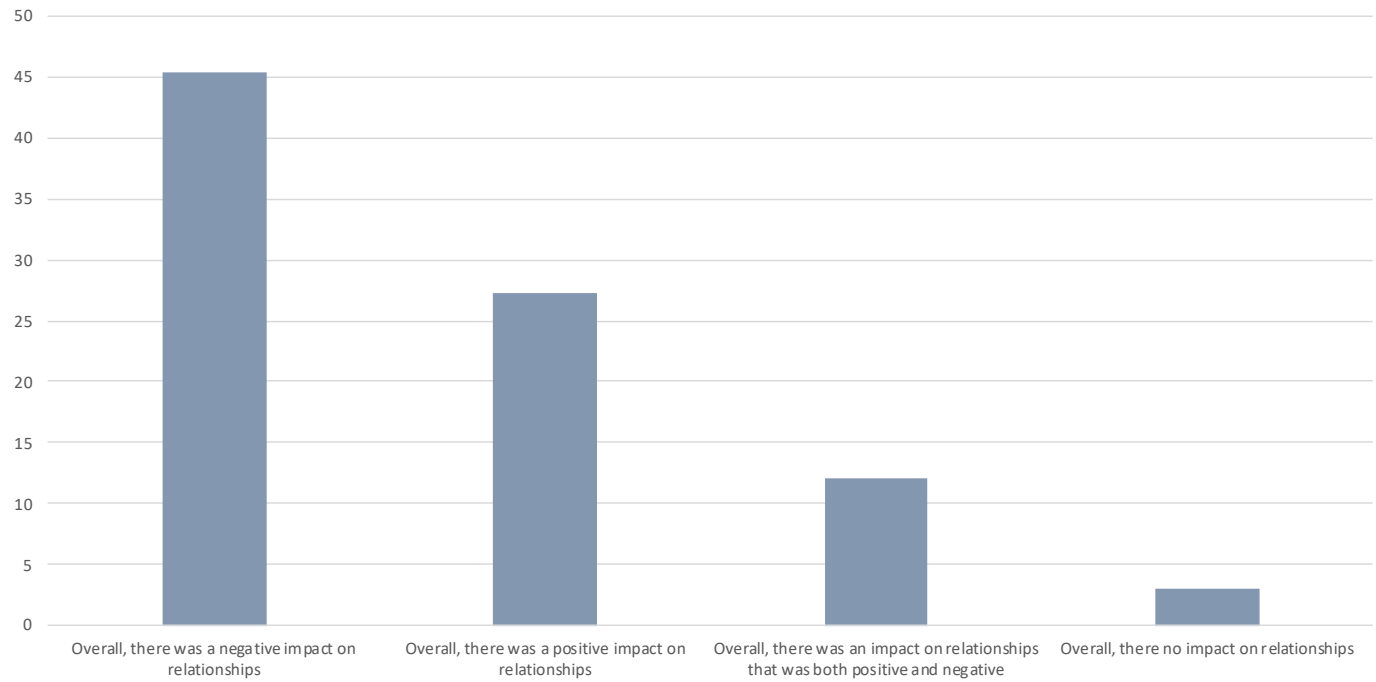


Figure 8.8: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	Female Higher status	B-cell acute lymphoblastic leukaemia (ALL) Male Regional or remote Mid to low status
Participant describes that overall, there was a positive impact on relationships	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant describes that overall, there was an impact on relationships that was both positive and negative	Aged 65 or older Mid to low status	B-cell acute lymphoblastic leukaemia (ALL)

Table 8.17: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	8	24.24	3	42.86	1	10.00	4	25.00	7	26.92	1	14.29	3	20.00	5	27.78
Participant describes a negative impact on relationships in general (no specifics articulated)	7	21.21	1	14.29	3	30.00	3	18.75	6	23.08	1	14.29	3	20.00	4	22.22
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	6.06	1	14.29	1	10.00	0	0.00	1	3.85	1	14.29	1	6.67	1	5.56
Participant describes a positive impact on relationships from family relationships being strengthened	6	18.18	2	28.57	2	20.00	2	12.50	5	19.23	1	14.29	3	20.00	3	16.67
Participant describes a positive impact on relationships from people being well-meaning and supportive	6	18.18	1	14.29	3	30.00	2	12.50	5	19.23	1	14.29	4	26.67	2	11.11
Participant describes a positive impact on relationships in general (no specifics described)	2	6.06	0	0.00	1	10.00	1	6.25	1	3.85	1	14.29	1	6.67	1	5.56

Impact on relationships (Reason for impact)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	8	24.24	6	31.58	2	14.29	2	14.29	6	31.58	3	21.43	5	26.32
Participant describes a negative impact on relationships in general (no specifics articulated)	7	21.21	5	26.32	2	14.29	6	42.86	1	5.26	5	35.71	2	10.53
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26
Participant describes a positive impact on relationships from family relationships being strengthened	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	2	14.29	4	21.05
Participant describes a positive impact on relationships from people being well-meaning and supportive	6	18.18	4	21.05	2	14.29	2	14.29	4	21.05	2	14.29	4	21.05
Participant describes a positive impact on relationships in general (no specifics described)	2	6.06	2	10.53	0	0.00	2	14.29	0	0.00	0	0.00	2	10.53

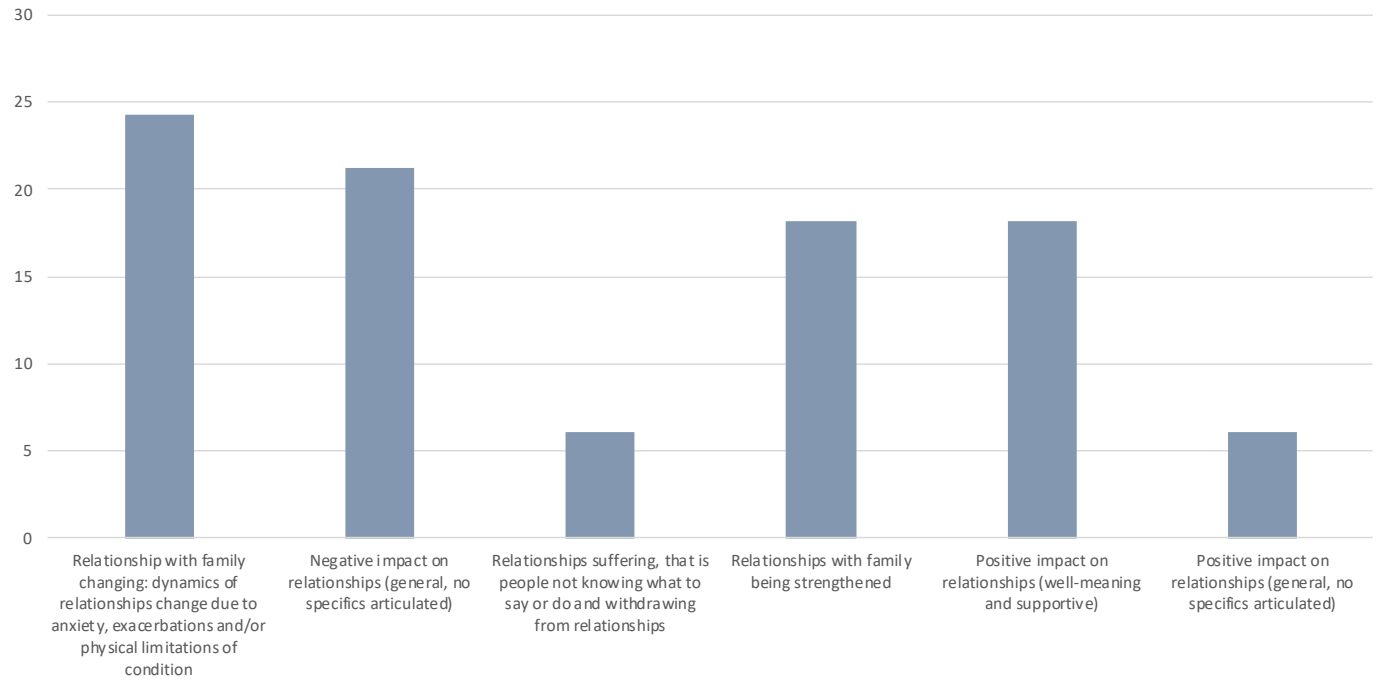


Figure 8.9: Impact on relationships

Table 8.18: Impact on relationships: Reason for impact – subgroup variations

Impact on relationships (Reason for impact)	Reported less frequently	Reported more frequently
Participant describes a negative impact on relationships from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a negative impact on relationships in general (no specifics articulated)	Metropolitan Higher status	Regional or remote Mid to low status
Participant describes a positive impact on relationships from family relationships being strengthened	-	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes a positive impact on relationships from people being well-meaning and supportive	-	Diffuse Large B-Cell Lymphoma

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 (75.76%), and overall, there was not a burden on their family (18.18%).

The main reason that participant described their condition being a burden were that the burden on family was temporary or only during treatment (27.27%), the mental/emotional strain placed on their family(21.21%), and the extra household duties and responsibilities that their family must take on (15.15%).

Participant describes that the burden on family was temporary or only during treatment

Well, probably not not as much now as it was. I mean it definitely was when I was was really unwell because they had to do everything. Now it's more just I suppose they've got that extra burden of they've just got to make sure that they don't get me sick or. That sort of thing, just just being more careful with with those things. So I have to remind them and I have to make sure and say okay, yeah, well, yes, we know we've been vaccinated for chicken pox, but they could still get it slightly and pass it on to me. So I have to be very aware of that. But I'm not a burden now in that, yeah, I cook, I cook, I cook the meals, I clean the house. I go with my husband for his appointment. So I do whatever. So I'm I'm sort of almost almost normal, just with just the fact that I'm more tired and have to be a bit more cautious with stuff.
Participant 006_2023AUCRT

No, not really. There's been that obviously when there's you know that when there's treatment and different levels of pain and that's the stuff, there's there is an extra requirement in terms of perhaps help that one needs. And because I'm by myself, you know I need to rely on the NAME. My son is always helpful for that. But nothing, Nothing too great.
Participant 023_2023AUCRT

Well, it was certainly before, but not anymore.
Participant 014_2023AUCRT

Not at this stage, no. Earlier in the earlier days, yeah, yeah. Possibly yes.
Participant 020_2023AUCRT

Participant describes the mental/emotional strain placed on their family as a burden on their family

Well, I suppose as far as them stress wise, you know worrying about the if you know you're going to survive that that that would be a burden to them and that's something I don't want for them. But yeah, that that's the only area and yeah it's I suppose it's just how they feel about how you're feeling or what's going to happen to you. It's more of the problem.
Participant 015_2023AUCRT

Not care and assistance. It's more my, if I had to worry, it's my worry that they worry too much about me. That's it, you know. But other than that, no no.
Participant 018_2023AUCRT

No, not really. The burden is mental stress in a way, because my wife worries about me and my daughter worries about me and they carry that and they she annoys me. Like if I I'd groaned or something, I was standing up and I'd just groaned. They go, 'You all right?' You know, I'll go for my take my bike rides on a Saturday morning and sometimes I come back looking a bit worse away, just sweated too much or the wind was too much. My eyes and they go, oh, you OK? You OK? You feeling alright? Take it easy, don't rush. Yeah. And it's like now with my cold I wanna train, but I can't because I've been there. And no, you should be just taking it easy. Just rest, you know. All this sort of stuff so it causes a lot of mental anguish rather than anything else, that's all.
Participant 019_2023AUCRT

No, not now. At the time, it was my husband was the one who looked after me, so he was the one that did it all, but he did it without any complaint. He wanted to, but it was stressful for him, very stressful.
Participant 004_2023AUCRT

Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family

Yeah, yeah, I think it is. I don't think that 14 year old boys should have to, you know. You know, my kids kind of pick up and just clean the house, which in one way is every mom's dream, but in another way, that's not what they should be doing, you know? Yeah. So, no, I do. I think they feel very responsible for me and my children. Yeah.
Participant 016_2023AUCRT

Well, yes and no. Yes. My partner, my husband has been amazing. He's been the right arm and he's had he's a very fit. Healthy man generally, but he's a couple of things where I've had to look after him. But in the main he's been the store because CAR T needs you have to have someone attend with you for 30 days. Everything, everything. And he hates hospitals so he happily did that. Well, happily might be going too far, but we worked. He did it without an issue and that was great. That was and. Yeah, he's always been there, brings me everything, you know, when I was in for stem cells, he'd bring me before lunch and dinner and no matter what I'd ordered I'd say to him, I'll bring this, bring that and he would bring it and I'm just going to blow my nose through. He, he just has been fantastic in that way. So I've been very fortunate.
Participant 036_2023AUCRT

Initially yes, like when mum took the year off to look after me, because she really, really enjoys her job, but now not so much only because I'm fortunate, there's no longer any treatment required or anything and the just the every three months going back to LOCATION for checkup biopsies.
Participant 005_2023AUCRT

Participant describes that overall, there was not a burden on their family

Well, not on my family because they're not here. But you know, I, for instance, I've got all my financial affairs in order and I've had the advanced care directives done and I've had the, the will done and I've had them, you know, authorized to make decisions for me. And also the, you know, giving them access to my financial accounts and things like that. So that if I do need to ask them to do things, that it's all set up and they're ready to do that.
Participant 012_2023AUCRT

Yeah. No. So far we are managing, you know, it would be in in that life, so say for instance, you know, going for camping you know holidays and just last night you know my husband just said that he already booked this one for March next year. You know that they go for holidays. So we we tried to you know of course outside of season where there are no school holidays you know those you know grey nomads you know just moving the quiet times you know to those you know places. So that that works for us. It's not.
Participant 034_2023AUCRT

Table 8.19: Burden on family

Burden on family	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that overall, there was a burden on their family	25	75.76	4	57.14	9	90.00	12	75.00	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes that overall, there was not a burden on their family	6	18.18	2	28.57	1	10.00	3	18.75	5	19.23	1	14.29	3	20.00	3	16.67
No particular comment	2	6.06	1	14.29	0	0.00	1	6.25	2	7.69	0	0.00	0	0.00	2	11.11

Burden on family	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was a burden on their family	25	75.76	15	78.95	10	71.43	12	85.71	13	68.42	10	71.43	15	78.95
Participant describes that overall, there was not a burden on their family	6	18.18	3	15.79	3	21.43	1	7.14	5	26.32	3	21.43	3	15.79
No particular comment	2	6.06	1	5.26	1	7.14	1	7.14	1	5.26	1	7.14	1	5.26

Figure 8.10: Burden on family

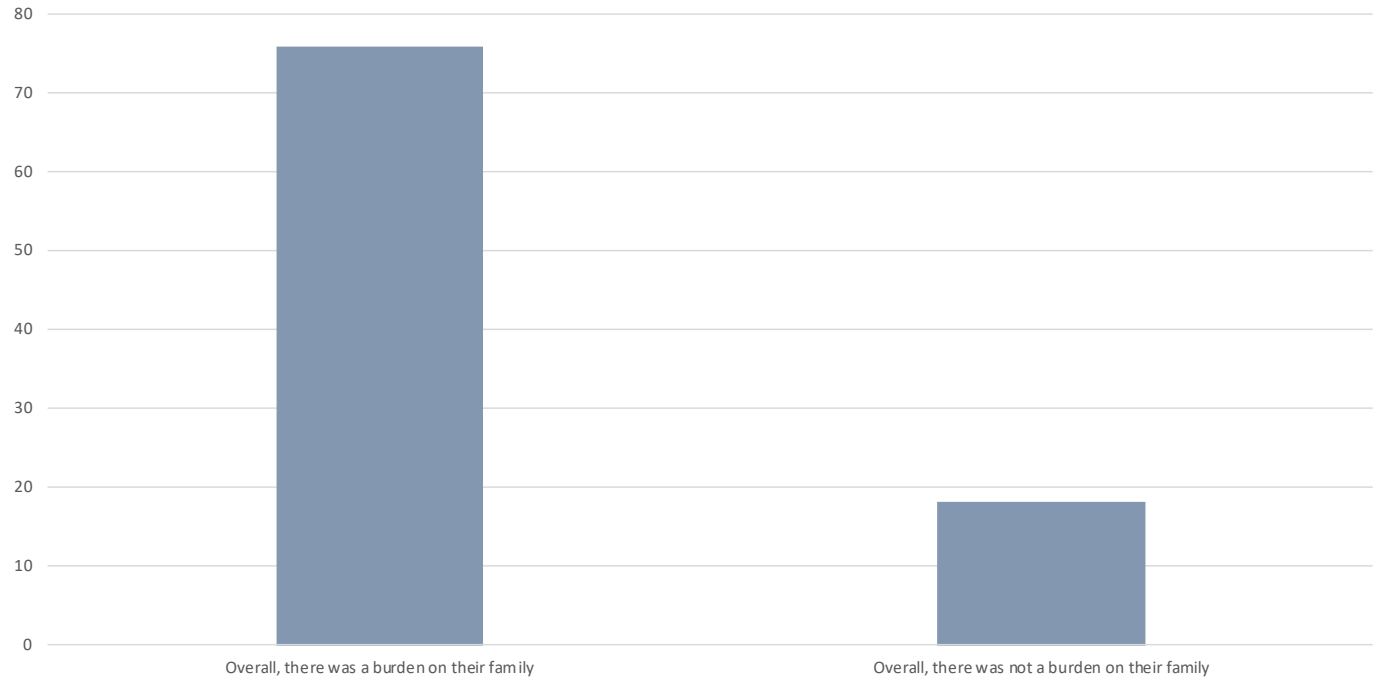


Table 8.20: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant describes that overall, there was a burden on their family	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant describes that overall, there was not a burden on their family	Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)

Table 8.21: Burden on family (description)

Burden on family (description)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that the burden on family was temporary or only during treatment	9	27.27	2	28.57	4	40.00	3	18.75	7	26.92	2	28.57	6	40.00	3	16.67
Participant describes the mental/emotional strain placed on their family as a burden on their family	7	21.21	0	0.00	3	30.00	4	25.00	7	26.92	0	0.00	3	20.00	4	22.22
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	15.15	1	14.29	3	30.00	1	6.25	3	11.54	2	28.57	4	26.67	1	5.56
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	15.15	1	14.29	2	20.00	2	12.50	4	15.38	1	14.29	2	13.33	3	16.67
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	5	15.15	2	28.57	0	0.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22

Burden on family (description)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that the burden on family was temporary or only during treatment	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	3	21.43	6	31.58
Participant describes the mental/emotional strain placed on their family as a burden on their family	7	21.21	4	21.05	3	21.43	3	21.43	4	21.05	3	21.43	4	21.05
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	15.15	3	15.79	2	14.29	1	7.14	4	21.05	1	7.14	4	21.05
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	15.15	5	26.32	0	0.00	3	21.43	2	10.53	3	21.43	2	10.53
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	5	15.15	2	10.53	3	21.43	2	14.29	3	15.79	2	14.29	3	15.79

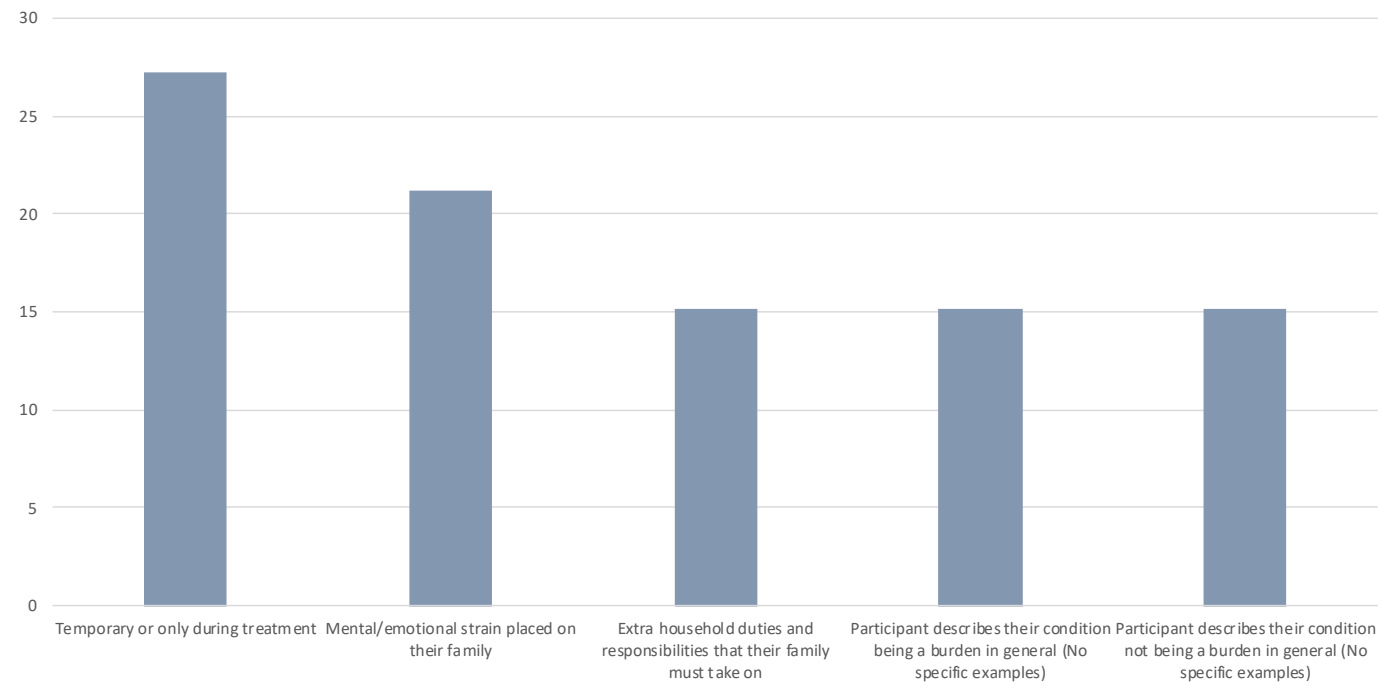


Figure 8.11: Burden on family (description)

Table 8.22: Burden on family (description)– subgroup variations

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes that the burden on family was temporary or only during treatment	Male	Diffuse Large B-Cell Lymphoma Female
Participant describes the mental/emotional strain placed on their family as a burden on their family	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	Aged 65 or older	Aged 25 to 64
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	Diffuse Large B-Cell Lymphoma	B-cell acute lymphoblastic leukaemia (ALL)

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (63.64%), and overall, there was no cost burden (33.33%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (39.39%), the cost of treatments (including repeat scripts) (21.21%), and the cost of parking and travel to attend appointments (including accommodation) (18.18 %). Other themes included a family member needing to take time off work (9.09%) and needing to access financial support from family or charities (9.09%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (45.45%), nearly everything was paid for through the private health system (12.12%), and the participant was able to afford all costs (12.12 %).

Cost burden in relation to needing to take time off work

I haven't really incurred many costs at all. Some of the medications are little bit pricey, but given the big picture, they're only one $40, $50. My big thing for me is that I've had to leave work. It's just that sense of independence, that's all, but no other costs really that have been of a worry.
Participant 002_2023AUCRT

Pretty limited actually, because I have private health and a private hospital. You pay the first 250 each year and then medications, vaccinations, those things on paid as you go. So pretty minimal and but if I didn't have fabulous superannuation and investments and a

good job and you know I think I've said in the thing I probably lost two years of two to three years of income that I would have had, I probably would have retired 2020, that was my plan. End of 2020 I would have retired. So 18/19/20. That's a fair chunk.
Participant 036_2023AUCRT

Cost burden in relation to the cost of treatments (including repeat scripts)

OK. The only cost that I've had to bear is really for medications, and I never quite reached the whatever the limit is which reduced. The cost of medication, so that that that was sort of like a regular cost that that I did feel particularly as interest rates have gone up. So I was, I was getting a little anxious about that.
Participant 009_2023AUCRT

Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)

It's expensive, very expensive. Even though we had private health and we had so much support from the Leukemia Foundation or just wonderful. Yeah, it's really expensive. It's all the little things, you know, that just added, like for instance, like park in your car to go to appointments, you travel to appointments, your medications.
Participant 011_2023AUCRT

Cost burden in relation to a family member needing to take time off work

My mum did take the year off of work because to stay at the leukemia village, I needed a carer. So my husband could keep working, mum took the year off to look after me. I just helped, I paid the groceries and helped mum out with bills and that. Mum's not in a great financial spot but my husband and I are quite comfortable. He has a business and we both work full time so yes, we definitely didn't suffer in the way that some other people do so we were quite fortunate.
Participant 005_2023AUCRT

Cost burden in needing to access financial support

But the biggest cost is your time off work because ultimately we dipped into my super I think for the 12 to 18 months that from diagnosis to the stem cells transplant and beyond. And my wife, she did work part time but when I was in depths of heavy treatment she would take time off work. So unfortunately I had good friends that supported us in ways but also we dipped into my super stuff like that just to get us through financially. We took to recover it away because you know we borrowed a bit of money off mum and dad and sit the Super and stuff like that. So but we got there and you know and then we just sort of paid mum and dad back and retopped up the Super. But it's it's taken a while, like it's probably taking the whole 12 years, so.
Participant 019_2023AUCRT

No cost burden and that nearly everything was paid for through the public health system

It's been entirely amazing. I really have a big appreciation of the Australian medical system, really. I didn't pay anything. That was many many months, many persons, and the only money I've paid is when I've come back into a regional area. Then it's glaringly obvious that the regional areas don't get the same support as the city hospitals in things like scans or blood tests or any of that sort of stuff. Luckily, that's all I've needed down here. I've had to pay for that. Whereas if I was in the city, I wouldn't have to pay for any of that.
Participant 003_2023AUCRT

Across well, really the only cost that I've had because I've been, well I was I've been traded in the public health system. We we did use our private health cover for the…I said the hospital gets the money from Bupa, but I haven't had any private appointments or private hospital thing. So the only cost that I've found has been the the medication when you come home. So and that is quite expensive and when I first came out of the hospital until I got to the safety net, it was probably $500 a month or something….So yeah, so, so, so really the the cost of just being medication.
Participant 006_2023AUCRT

No cost burden and that nearly everything was paid for through the private health system

No, well I didn't have to have any time off work because I had retired by the time I was diagnosed and and I don't have any family members here. So nobody has had to take, you know, time off to do anything with me And the cost. I've got the top medical benefits and I've never queried any expenses or anything.
Participant 012_2023AUCRT

No cost burden as participant was able to afford all costs

It didn't really cost anything. I think you know we got reimbursed some money for fuel and stuff when we were traveling back on. My wife was traveling to and from LOCATION, from up here and they they helped her with accommodation that was cheap and near the hospital and and and and and fuel and stuff like that. We would have been out of pocket a little bit, but it was nothing we really noticed and I had savings that could cover all that.
Participant 010_2023AUCRT

I guess we're fortunate enough that that we have sufficient. So there's no financial issues, pressures at all. Participant 013_2023AUCRT

Table 8.23: Cost considerations

Cost considerations	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes that overall, there was at least some cost burden	21	63.64	5	71.43	7	70.00	9	56.25	18	69.23	3	42.86	11	73.33	10	55.56
Participant describes that overall, there was no cost burden	11	33.33	1	14.29	3	30.00	7	43.75	7	26.92	4	57.14	4	26.67	7	38.89
Other/No response	1	3.03	1	14.29	0	0.00	0	0.00	1	3.85	0	0.00	0	0.00	1	5.56

Cost considerations	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes that overall, there was at least some cost burden	21	63.64	16	84.21	5	35.71	9	64.29	12	63.16	8	57.14	13	68.42
Participant describes that overall, there was no cost burden	11	33.33	2	10.53	9	64.29	4	28.57	7	36.84	5	35.71	6	31.58
Other/No response	1	3.03	1	5.26	0	0.00	1	7.14	0	0.00	1	7.14	0	0.00

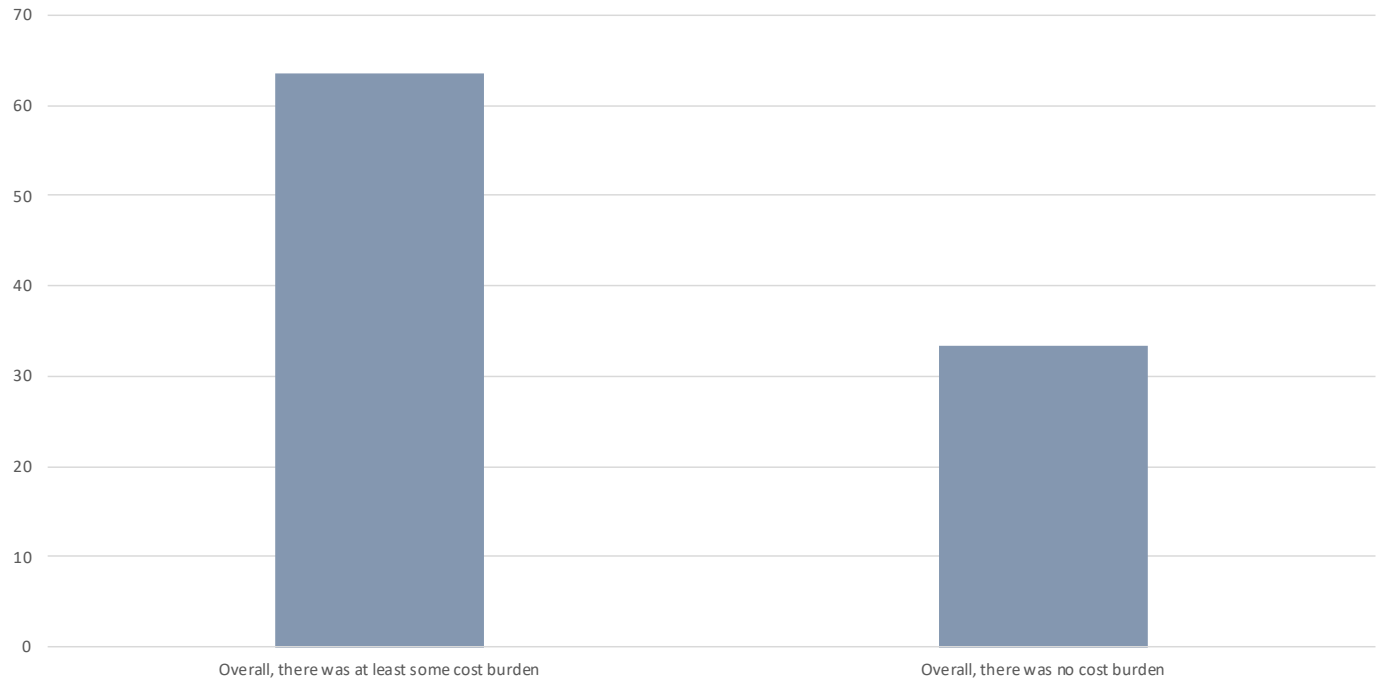


Figure 8.12: Cost considerations

Table 8.24: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was at least some cost burden	CAR T-Cell therapy Aged 65 or older	Aged 25 to 64
Participant describes that overall, there was no cost burden	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64	Multiple Myeloma CAR T-Cell therapy Aged 65 or older

Table 8.25: Cost considerations (Reasons for cost)

Cost considerations (reasons for costs)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Cost burden in relation to needing to take time off work	13	39.39	5	71.43	4	40.00	4	25.00	11	42.31	2	28.57	9	60.00	4	22.22
Cost burden in relation to the cost of treatments (including repeat scripts)	7	21.21	2	28.57	2	20.00	3	18.75	6	23.08	1	14.29	3	20.00	4	22.22
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	18.18	3	42.86	2	20.00	1	6.25	6	23.08	0	0.00	2	13.33	4	22.22
Cost burden in relation to a family member needing to take time off work	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11
Cost burden in needing to access financial support from familiy or charities	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11
No cost burden and that nearly everything was paid for through the public health system	15	45.45	2	28.57	5	50.00	8	50.00	13	50.00	2	28.57	6	40.00	9	50.00
No cost burden and that nearly everything was paid for through the private health system	4	12.12	0	0.00	2	20.00	2	12.50	2	7.69	2	28.57	3	20.00	1	5.56
No cost burden as participant was able to afford all costs	4	12.12	0	0.00	1	10.00	3	18.75	2	7.69	2	28.57	0	0.00	4	22.22

Cost considerations (reasons for costs)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Cost burden in relation to needing to take time off work	13	39.39	10	52.63	3	21.43	3	21.43	10	52.63	4	28.57	9	47.37
Cost burden in relation to the cost of treatments (including repeat scripts)	7	21.21	6	31.58	1	7.14	4	28.57	3	15.79	3	21.43	4	21.05
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	18.18	5	26.32	1	7.14	3	21.43	3	15.79	4	28.57	2	10.53
Cost burden in relation to a family member needing to take time off work	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26
Cost burden in needing to access financial support from familiy or charities	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26
No cost burden and that nearly everything was paid for through the public health system	15	45.45	7	36.84	8	57.14	8	57.14	7	36.84	6	42.86	9	47.37
No cost burden and that nearly everything was paid for through the private health system	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
No cost burden as participant was able to afford all costs	4	12.12	0	0.00	4	28.57	2	14.29	2	10.53	1	7.14	3	15.79

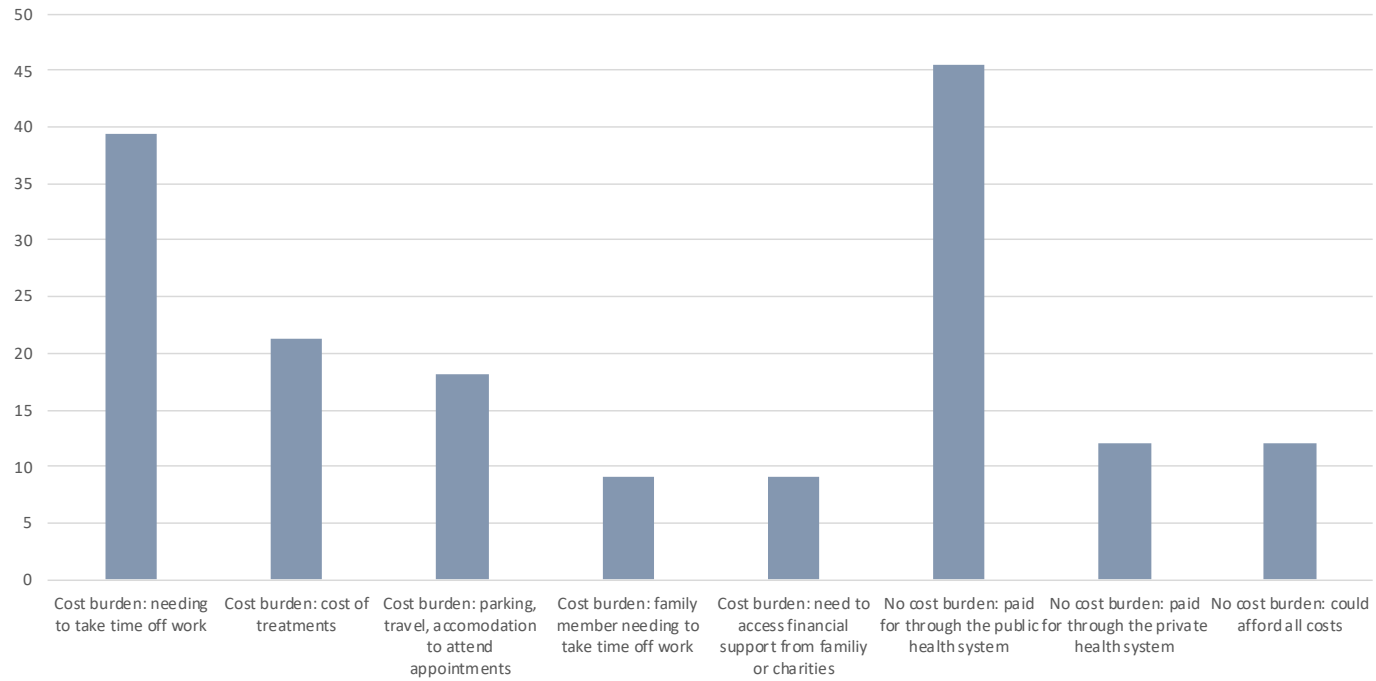


Figure 8.13: Cost considerations (Reasons for cost)

Table 8.26: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (reasons for costs)	Reported less frequently	Reported more frequently
Cost burden in relation to needing to take time off work	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64 Metropolitan
Cost burden in relation to the cost of treatments (including repeat scripts)	Aged 65 or older	Aged 25 to 64
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	Multiple Myeloma CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Mid to low status
No cost burden and that nearly everything was paid for through the public health system	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	Aged 65 or older Regional or remote
No cost burden and that nearly everything was paid for through the private health system	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote	CAR T-Cell therapy
No cost burden as participant was able to afford all costs	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64	CAR T-Cell therapy Male Aged 65 or older

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 the table below. The overall scores for the cohort were in the second lowest quintile for Fear of progression: Total score (mean=30.82, SD=11.27), indicating low levels of anxiety

Comparisons of Care co-ordination have been made based on blood cancer type, CAR T-cell therapy, gender, age, location and socioeconomic status.

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

Table 8.27: Fear of progression summary statistics

Fear of progression (n=34)	Mean	SD	Median	IQR	Possible range	Quintile
Total score	30.82	11.27	28.50	18.00	12 to 60	2

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

Fear of progression by blood cancer type

Comparisons were made by type of blood cancer. There were 8 participants (23.53%) with B-cell acute lymphoblastic leukemia (ALL), 10 participants (29.41%) with Diffuse Large B-Cell Lymphoma, and 16 participants (47.06%) with Multiple Myeloma.

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

No significant differences were observed between participants by **blood cancer type** for any of the Fear of progression scales.

Table 8.28: Fear of progression total score by blood cancer type summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	B-cell acute lymphoblastic leukemia (ALL)	8	23.53	36.88	8.82	Between groups	496.00	2.00	248.10	2.08	0.1420
	Diffuse Large B-Cell Lymphoma	10	29.41	31.60	10.30	Within groups	3696.00	31.00	119.20		
	Multiple Myeloma	16	47.06	27.31	12.10	Total	4192.00	33.00	367.30		

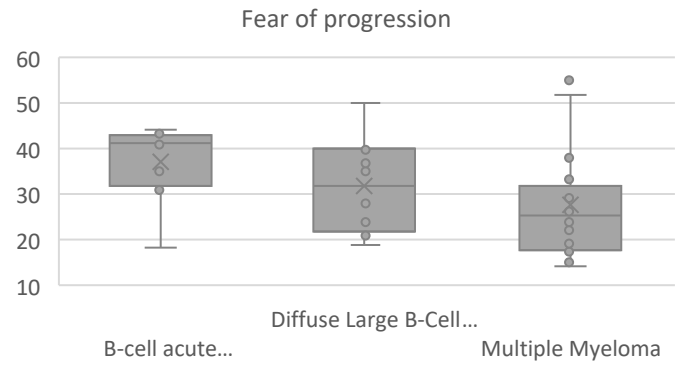


Figure 8.14: Boxplot of Fear of progression total score by blood cancer type

Fear of progression by CAR T-cell therapy

Comparisons were made by CAR T-cell therapy there were 27 participants (79.41%) that had treatment with Car T-cell therapy and, 7 participants (20.59%) that did not .

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

No significant differences were observed between participants by **CAR T-cell therapy** for any of the Fear of progression scales

Table 8.29: Fear of progression total score by CAR T-cell therapy summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	No	27	79.41	32.22	11.01	131.00	0.1250	0.1584
	Yes	7	20.59	25.43	11.44			

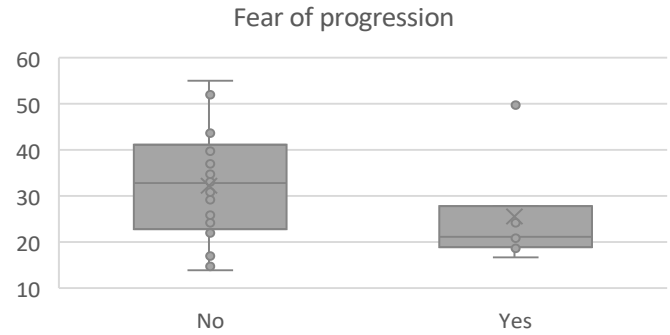


Figure 8.15: Boxplot of Fear of progression total score by CAR T-cell therapy

Fear of progression by gender

Comparisons were made by gender, there were 16 female participants (47.06%), and 18 male particpants (52.94%).

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

No significant differences were observed between participants by **gender** for any of the Fear of progression scales

Table 8.30: Fear of progression total score by gender summary statistics and Wilcoxon test

Fear of progression	Group	Number (n=34)	Percent	Median	IQR	W	p-value
Total score	Female	16	47.06	35.00	12.75	190.00	0.1162
	Male	18	52.94	23.50	18.25		

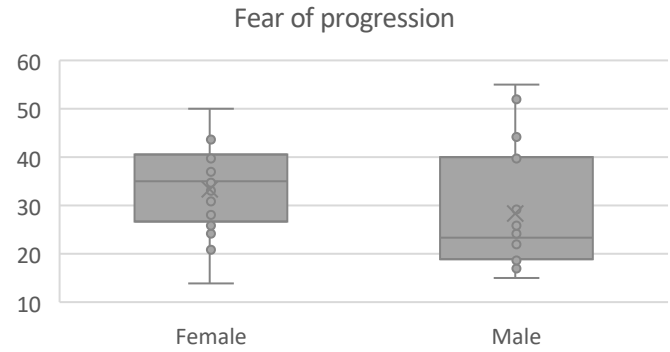


Figure 8.16: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged 25 to 64 (n=20, 58.82%), and participants aged 65 and older (n=14, 41.18%).

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

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(32) = 3.34 ,

p = 0.0021] was significantly higher for participants in the Aged 25 to 64 subgroup (Mean = 35.55, SD = 10.51) compared to participants in the Aged 65 and older (Mean = 24.07, SD = 8.81.)

conditions. On average, participants in the Aged 25 to 64 subgroup scored higher than participants in the Aged 65 and older. This indicates that participants in the Aged 25 to 64 subgroup had moderate levels of anxiety, and participants in the Aged 65 and older had low levels of anxiety.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their

Table 8.31: Fear of progression total score by age summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 64	20	58.82	35.55	10.51	3.34	32.00	0.0021*
	Aged 65 and older	14	41.18	24.07	8.81			

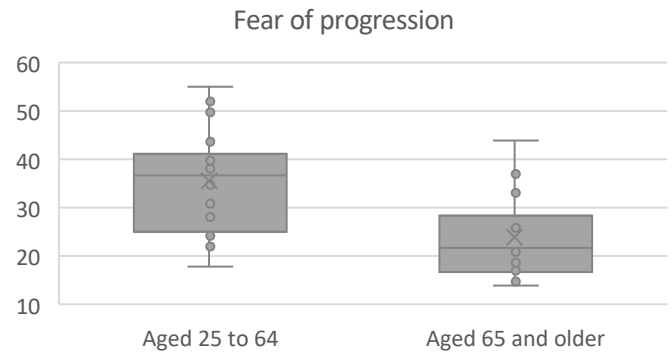


Figure 8.17: Boxplot of Fear of progression total score by age

Fear of progression by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas (n=15, 44.12%) were compared to those living in a major city (n=19, 55.88%).

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

No significant differences were observed between participants by **location** for any of the Fear of progression scales

Table 8.32: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Metropolitan	15	44.12	32.20	12.10	0.63	32.00	0.5352
	Regional or remote	19	55.88	29.74	10.78			

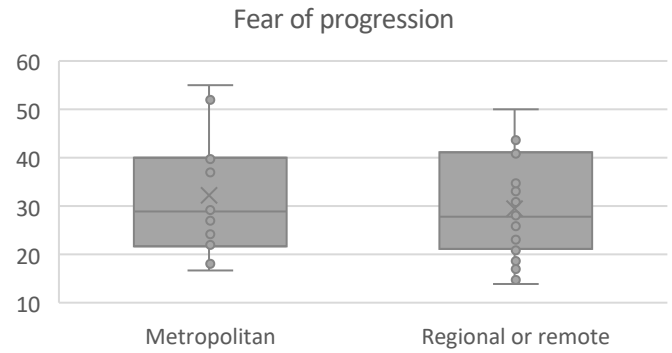


Figure 8.18: Boxplot of Fear of progression total score by location

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 (n=15, 44.12%) compared to those with a higher SEIFA score of 7-10 (n=19, 55.88%).

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

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(32) = 2.38 , p = 0.0236] was significantly higher for participants in the Higher advantage subgroup (Mean = 35.67, SD = 11.76) compared to participants in the Mid to low advantage subgroup (Mean = 27.00, SD = 9.50).

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the Higher advantage subgroup scored higher than participants in the Mid to low advantage subgroup. This indicates that participants in the Higher advantage subgroup had moderate levels of anxiety, and participants in the Mid to low advantage subgroup had low levels of anxiety.

Table 8.33: Fear of progression total score by socioeconomic status summary statistics and T-test

Fear of progression	Group	Number (n=34)	Percent	Mean	SD	T	dF	p-value
Total score	Higher advantage	15	44.12	35.67	11.76	2.38	32.00	0.0236*
	Mid to low advantage	19	55.88	27.00	9.50			

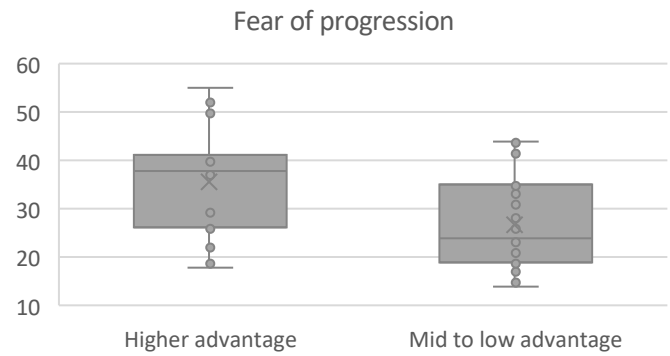


Figure 8.19: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

Fear of progression individual questions

An overview of responses to individual fear of progression questions is given in the table below.

On average, participants scored in the "Never" range for the following questions: "Anxious if not experiencing any side effects think it doesn't work" (median=1.00, IQR=1.00).

On average, participants scored in the "Seldom" range for the following questions:, "Is nervous prior to doctors appointments or periodic examinations" (median=2.00, IQR=1.50), "Afraid of pain" (median=2.25, IQR=1.00), "The possibility of relatives being diagnosed with this disease disturbs participant" (median=2.00, IQR=1.75), "Is disturbed that they may have to rely on strangers for activities of daily living" (median=2.00, IQR=2.00), "Worried that at some point in time will no longer be able to pursue hobbies because of illness" (median=2.00, IQR=2.38), "Afraid of severe medical treatments during the course of illness" (median=2.25, IQR=2.88), "The thought that they might not be able to work due to illness disturbs participant" (median=2.00, IQR=2.75), "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).

On average, participants scored in the "Sometimes" range for the following questions:"Becomes anxious thinking that disease may progress" (median=3.00,

IQR=2.00), "Has concerns about reaching professional and/or personal goals because of illness:" (median=3.00, IQR=2.00), "When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation" (median=3.00, IQR=3.00), "Worried that treatment could damage their body" (median=3.00, IQR=1.88), "Worried about what will become of family if something should happen to participant" (median=3.00, IQR=2.00).

Table 8.34: Fear of progression individual questions

Fear of progression (n=34)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	2.99	1.16	3.00	2.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	2.65	1.33	2.00	1.50	Seldom
Afraid of pain	2.60	1.20	2.25	1.00	Seldom
Has concerns about reaching professional and/or personal goals because of illness:	2.79	1.33	3.00	2.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.65	1.33	3.00	3.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	1.93	1.02	2.00	1.75	Seldom
Is disturbed that they may have to rely on strangers for activities of daily living	2.16	1.16	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	2.49	1.30	2.00	2.38	Seldom
Afraid of severe medical treatments during the course of illness	2.49	1.35	2.25	2.88	Seldom
Worried that treatment could damage their body	2.82	1.25	3.00	1.88	Sometimes
Worried about what will become of family if something should happen to participant	2.76	1.31	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.50	1.42	2.00	2.75	Seldom
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.09	1.20	2.00	2.00	Seldom
Anxious if not experiencing any side effects think it doesn't work	1.46	0.68	1.00	1.00	Never

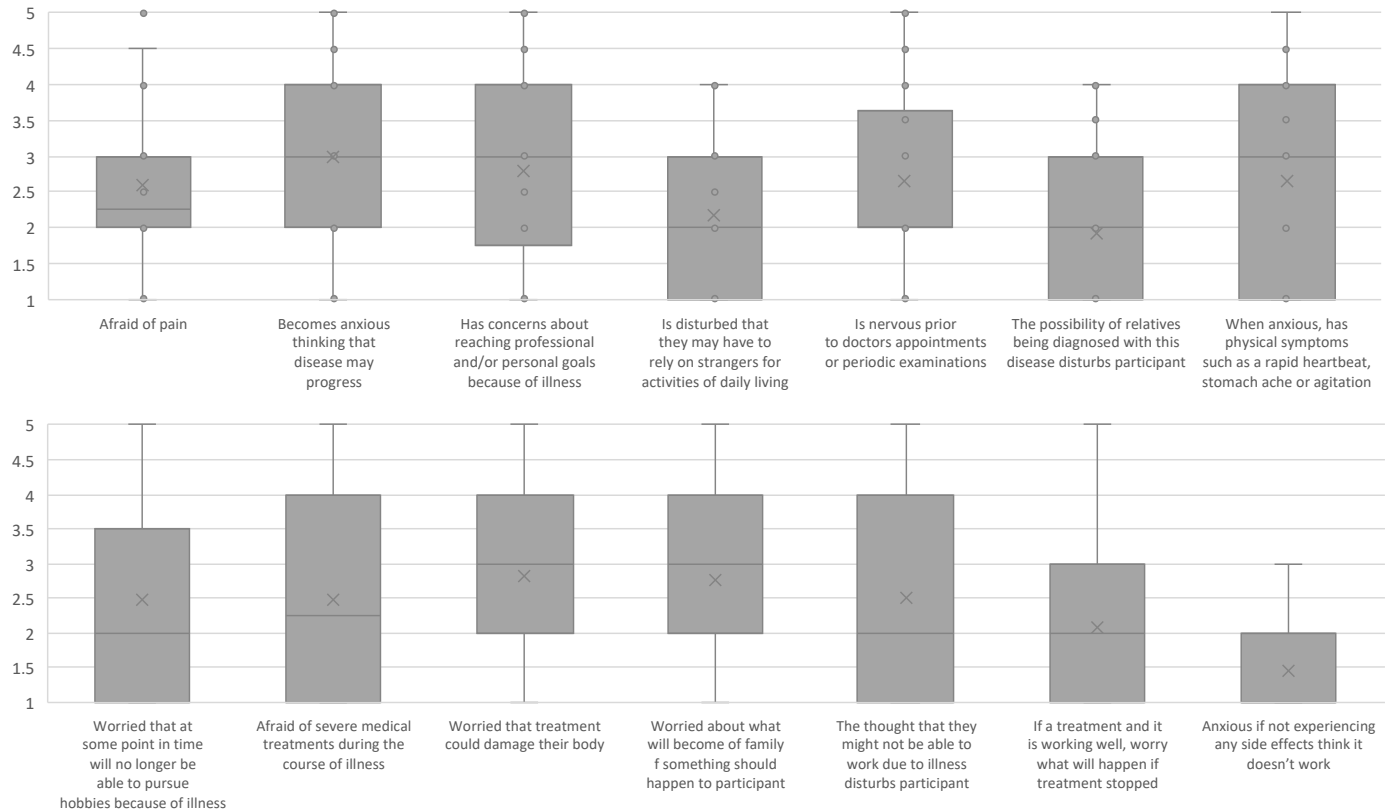


Figure 8.20: Fear of progression individual questions

Section 9

Expectations and messages to decision-makers

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

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (30.30%), have fewer or less intense side effects/more discussion about side effects (27.27%), and involve more clinical trials (including to access new technologies and treatments and funding) (24.24 %). Other themes included future treatment should be easier to administer or able to administer at home or less invasive (18.18%), will include having choice, including availability, accessibility and discussions in relation to treatment options (18.18%), and be more effective or targeted (9.09%). There were
4 participants (12.12%) that were satisfied with the treatment they received.

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 provide more details about disease trajectory and what to expect (24.24%), include the ability to talk to/access to a health professional (12.12 %), provide more details about new treatments or trials (12.12%) and provide more details on subgroups and specific classifications of their condition (12.12%). Other themes included be in a variety of formats (9.09%), and be more accessible/easy to find (9.09%). There were 6 participants (18.18%) that were satisfied with the information they received.

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 response was that they were satisfied with the communication they had with healthcare professionals (45.45%). The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (21.21%), and will include a multidisciplinary and coordinated approach (15.15%). Other themes included that communication will be more empathetic (12.12%), will allow people more time to meet with their clinician (9.09%), and will be more understandable (9.09%).

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 response was that they were satisfied with the care and support they received (27.27%). The most common expectations for future care and support were that it will include a multidisciplinary and coordinated approach (18.18%), will include more access to support services (15.15 %) and will be more holistic (including emotional health) (15.15%). Other themes included that care and support will include being able to connect with other patients through peer support (support groups, online forums) (12.12%), practical support (home care, transport, financial) (12.12%), and community awareness (9.09%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (36.36%), and low cost or free medical care through the government (33.33%). Other themes included the entire health system (30.30%), and timely access to treatment (9.09%).

Symptoms and aspects of quality of life

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were "The severity of the side effects", and "How safe the medication is and

weighing up the risks and benefits". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

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 5 to 10 years for a good quality of life even if it didn’t offer a cure (n=12, 38.71%), or for more than 10 years (n=11, 35.48%).

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants most commonly responded that they did not know (n=17, 36.96%), followed by equally effective (n=15, 32.61%).

There were 9 participants (29.03%) that thought that medicine delivered by all forms were equally effective, 4 participants (12.90%) thought that q cell or immunotherapy that uses the body's own immune defense was most effective, and 3 participants (9.678%) that thought as a stem cell/bone marrow transplant was most effective. There were 11 participants (35.48%) that were not sure.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27 %). Other themes included that treatments need to be affordable (21.21%), to invest in health professionals to service the patient population (18.18%), to help raise community awareness (12.12%), to improve rural services (12.12%), to have a holistic approach to the condition (including emotional support) (9.09%), and to increase investment (general) (9.09%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (30.30%), have fewer or less intense side effects/more discussion about side effects (27.27%), and involve more clinical trials (including to access new technologies and treatments and funding) (24.24 %). Other themes included future treatment should be easier to administer or able to administer at home or less invasive (18.18%), will include having choice, including availability, accessibility and discussions in relation to treatment options (18.18%), and be more effective or targeted (9.09%). There were 4 participants (12.12%) that were satisfied with the treatment they received.

Future treatment will be more affordable

I think they should look at the cost of things. An example is, I think I was on one medication. I had a prescription and my son went over to the chemist to fill it for me and it had come off the PBS list and it was…the cost was $4,000, and I'm just wondering how people could afford that cost. I think treatment is what it is, and then every day, it's evolving and they're finding new treatment and things that work better on some people, but it's mainly, I think, people need to afford the cost of things. Participant 002_2023AUCRT

Well, I guess for people who you know for who the cost is a burden, I would like that to be a consideration so everyone would have access to the best treatments that are available.
Participant 012_2023AUCRT

Well, I think that anyone who has a a thing like this like like leukemia or diabetes or not those sorts of things. I don't think that you should have to wait till you get to the safety net. I think that you should have that immediately rather than having having to wait. I I don't think that it's fair that some people get their medications for free for $6 all year round, whereas we have to pay that high amount of money until we get to that that point. So yeah, at the moment, because it's the start of the year between because my husband's got a few things as well, even though a lot of it died down, we're probably still spending 3 or $400.00 a month on medication. So I think that that's not right. That should be better subsidised. No, that's not. There's not too many other things that that that I would would would probably criticise or change, yeah, no, I think that the treatment that that I've that I've had been good and the support that I've had and that sort of thing so.
Participant 006_2023AUCRT

Yeah, making the cost affordable. But lots of new treatments are not apparently, in the Medicare system. My friend had to pay out of pocket for the immunotherapy because they believe that this is not a treatment that works for that sort of cancer that my friend's wife has got. Not recommended by Medicare or during one of these webinars I was listening to a lady who had to pay like 1500 a month for her treatment….So understanding these things and well, when your life is online and you you would sell your house, I don't know, you would forget everything and then try to stick to life of course. But yeah, I think this is something that Medicare needs to find out and understand that people like me and need probably it would be expensive people to keep alive, but that is life. So that's why we have paid and tax for many years. And so it's not, it's not good enough to say that this is this treatment is too expensive or we cannot afford it by the government. It should be brought in if it is a treatment.
Participant 017_2023AUCRT

Future treatments will have fewer or less intense side effects/more discussion about side effects

For example, the way that they're administered or reduction in side effects…yeah, I suppose one of the things I did, I used to try and travel myself to CITY, but it got too much. As in fatigue and concentration. Yes, the cost is the fatigue.
Participant 015_2023AUCRT

All of that, like if they come up with a miracle drug that wasn't chemo and it didn't have the side effects and it was cheap, would be great.
Participant 011_2023AUCRT

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

I think that probably. CAR-T should be offered before your half dead from chemo. I had to fail three courses of chemo to qualify for CAR-T and by the time I got to CAR-T. I was running very low on reserves.
Participant 009_2023AUCRT

I'd like to see CAR-T go on the PBS and I'd like to see it more readily available earlier. And I would also like to

see the, and I'm trying to think of the name of them, the group that recommend and approve new drugs to go on the PBS. Yeah, my my sense is that there's large lobby groups around breast cancer and prostrate cancer and all the biggies. But if you cop a rare one, you know there's not a lot of money to be made from a really rare drug that's only gonna be used by a few people. So there isn't that push and that promotion to get stuff on the list.
Participant 022_2023AUCRT

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

I think the hardest thing to wrap my head around was the length of the treatment protocol. Because it went from February through till November, it was almost a full year. Once you've finished each round of treatment you know that you're getting a bit closer but then you know that you've got to go through it again and feel sick again and everything, so that was a bit of a hard slog. Everything else was incredible, I couldn't have asked for a better outcome. After I finished treatment and obviously I was still in remission, they offered me if I wanted to freeze some of my stem cells, do a stem cell collection, just like a rainy day harvest, I guess. [chuckles]
That was incredible. I ummed and aahed, just the thought of laying down for another four or five hours after I'd spent a whole year laying down with needles in my arm, I baulked at it a little bit, then I thought, "When else am I going to have this opportunity? It's a good insurance policy, I guess, having healthy stem cells frozen, just in case I ever need them." Yes, that was really wonderful to be able to do that.
Participant 005_2023AUCRT

Yeah, I don't think I would have changed really much in from my situation because I found it was all kind of working quite well. I mean, if you have to have an infusion for a chemotherapy, I don't think there's another way you can actually possibly have it unless I have change where it might be a tablet form or some other form of self medicating perhaps, but I don't. I think the drugs are that sort of, you know, when someone walks in and they're wearing the suit and the mask and things like that and you're not, you're thinking, well, this can't be a good drug.
Participant 024_2023AUCRT

I'd love to be able to do everything at at home. Like I said earlier it'd be lovely to be able to just take a pill each day and and that's it. Not not have to go in for my infusions but I still have to get my blood test. So I don't think there's a way around that unless a nurse turned up and did it here at our place. I don't think I deserve that. So I no, I I'm, I'm sort of losing the plot here. But I I would say no. The way things are are good. If if they can continue with the way things are, I'm very happy with it. It's working well, yeah.
Participant 018_2023AUCRT

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

I really don't. I can't think of anything. I think it's just information. I really think information is power. Knowledge is power and if there's a new treatment then how do you get knowledge of it and yeah, how do you access it and and more equitable. I'd like to see a much more equitable and inclusive approach to medical treatment that's proactive in those ways rather than accidental. You get it because you asked or you happen to be in the city. I mean, I'm a white privileged woman. Seriously. I'm not representative of the Australian community and I know the privilege I have because of my education, age, experience, all those things.
Participant 036_2023AUCRT

I don't know that I'm qualified to answer that to be honest. What would be good overall is if the various parties could actually talk to each other and make it easier for people to navigate through the system to have an understanding of what's coming next. Because right through this whole process, I've had to ask, and what happens now? What happens next? Nobody offers that information. Participant 0_2023AUCRT

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7		n=15	%	n=18	%
Future treatment will be more affordable	10	30.30	4	57.14	3	30.00	3	18.75	9	34.62	1	14.29	7	46.67	3	16.67
Future treatments will have fewer or less intense side effects/more discussion about side effects	9	27.27	1	14.29	2	20.00	6	37.50	8	30.77	1	14.29	3	20.00	6	33.33
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	8	24.24	0	0.00	5	50.00	3	18.75	5	19.23	3	42.86	4	26.67	4	22.22
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	6	18.18	1	14.29	1	10.00	4	25.00	6	23.08	0	0.00	2	13.33	4	22.22
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	18.18	1	14.29	2	20.00	3	18.75	3	11.54	3	42.86	3	20.00	3	16.67
Participant describes being satisfied with the information they received	4	12.12	1	14.29	1	10.00	2	12.50	3	11.54	1	14.29	0	0.00	4	22.22
Future treatment will be more effective and/or targeted (personalised)	3	9.09	0	0.00	0	0.00	3	18.75	2	7.69	1	14.29	0	0.00	3	16.67

Expectations of future treatments	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Future treatment will be more affordable	10	30.30	9	47.37	1	7.14	3	21.43	7	36.84	5	35.71	5	26.32
Future treatments will have fewer or less intense side effects/more discussion about side effects	9	27.27	6	31.58	3	21.43	5	35.71	4	21.05	4	28.57	5	26.32
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	8	24.24	7	36.84	1	7.14	5	35.71	3	15.79	3	21.43	5	26.32
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	6	18.18	3	15.79	3	21.43	2	14.29	4	21.05	2	14.29	4	21.05
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	18.18	2	10.53	4	28.57	2	14.29	4	21.05	1	7.14	5	26.32
Participant describes being satisfied with the information they received	4	12.12	1	5.26	3	21.43	2	14.29	2	10.53	2	14.29	2	10.53
Future treatment will be more effective and/or targeted (personalised)	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79

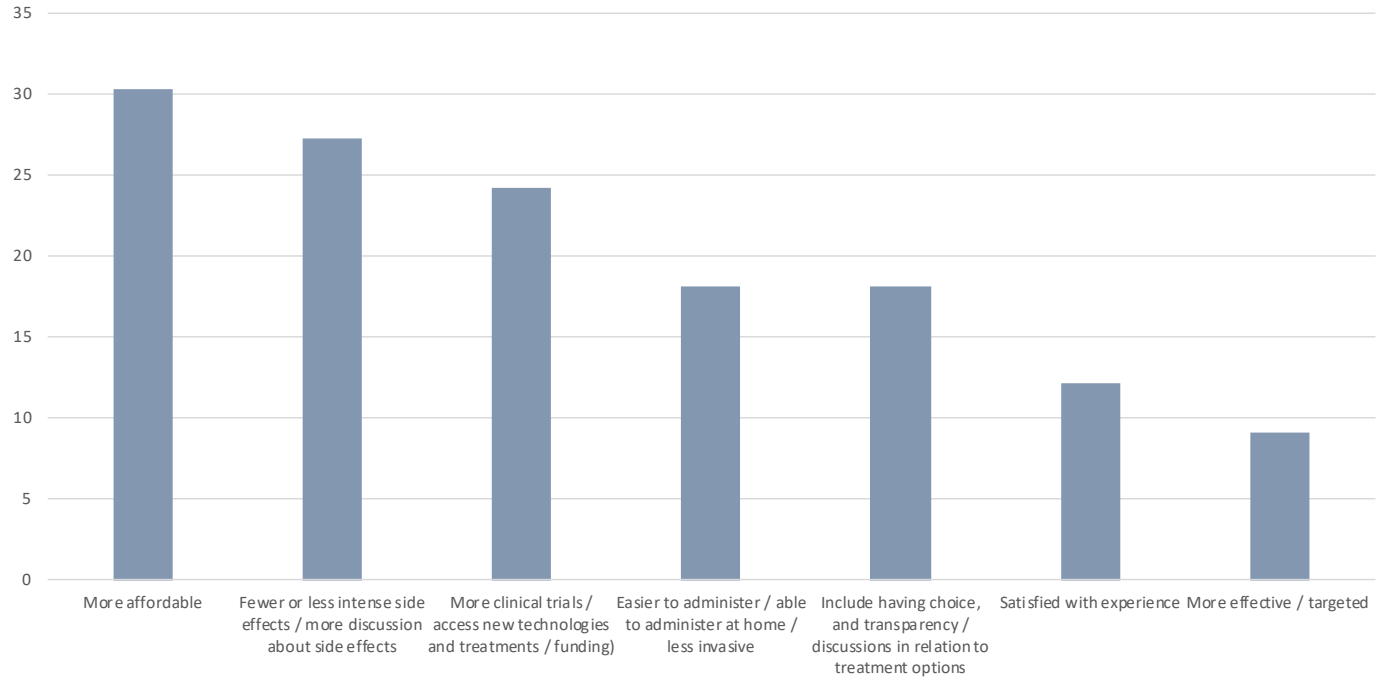


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatments	Reported less frequently	Reported more frequently
Future treatment will be more affordable	Multiple Myeloma CAR T-Cell therapy Male Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64
Future treatments will have fewer or less intense side effects/more discussion about side effects	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	Multiple Myeloma
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	CAR T-Cell therapy	-
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Mid to low status	CAR T-Cell therapy Aged 65 or older
Participant describes being satisfied with the information they received	Female	Male

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 provide more details about disease trajectory and what to expect (24.24%), include the ability to talk to/access to a health professional (12.12 %), provide more details about new treatments or trials (12.12%) and provide more details on subgroups and specific classifications of their condition (12.12%). Other themes included be in a variety of formats (9.09%), and be more accessible/easy to find (9.09%). There were 6 participants (18.18%) that were satisfied with the information they received.

Future information will provide more details about disease trajectory and what to expect

I didn't have a problem with that at all from office because I presume I went looking for it. So maybe a booklet of some sort saying these are some of the complications. That might be associated with having chemotherapy to inform, although it's not just one thing.
Participant 024_2023AUCRT

The emotional after-effects once you've been through the treatment, that I think is the most important, because I thought I'd just bounce back. I thought, "Great, I'm finished, get on with my life and I'll bounce back," but I didn't. I did and I didn't. I was always up and down. I wasn't prepared for that. I think it's like a shock, you go into a bit of a shock afterwards. You deal with it at the time, and then you go into shock later.
Participant 004_2023AUCRT

PARTICIPANT: Yeah, more information about side effects. So side effects often kind of just get listed off. You might experience these, but what do they actually look like in your day-to-day life?
INTERVIEWER: Yeah, yeah, that practical.
PARTICIPANT: The stuff about the stuff around my libido like that and that can be quite. I would never talk to some people about that. I'm happy talking to the bone marrow transplant specialist about it. But those kinds of things can be quite difficult for people to talk about and then they don't get talked about and then it becomes something that just impacts you. But if you've got some stuff about what they look like, that would be great. What does it look like to live with graft versus host disease? And you got what does it look like to go through hypercevad chemotherapy? It's a really commonly used one. What might that look like? Especially for your carer as well and your kids, so that they know what's coming?
Participant 016_2023AUCRT

Participant describes being satisfied with the information they received

No. I think everything was presented really well. None of these guys verbally explain things. They gave you a lot of paperwork and a proper folder that you could refer back to all the time. Your medication list, they updated that all the time. I think the information was pretty good. As I said, if you weren't sure, you could always ask someone. They'd always find out for you.
Participant 002_2023AUCRT

No, no, I I think it's OK in terms of the information that's available it it it's hard to cover without. Sort of becoming too overwhelming. I think they got the the balance right between being positive and being honest. Yeah, I think that was actually well done by both the the medical side and the things like the Leukemia Foundation.
Participant 009_2023AUCRT

No. I think with certainly with multiple myeloma that the and I can only speak through Myeloma Australia here that the the, the, the the information is is very, very clear very very well put together there seems to be very accurate and and up to date and they they have quite 3 multiple alignment. They have regular online seminars with groups getting together online with talks and that sort of thing too. So no, I think I think the level of information that's given out in our particular cases is very good.
Participant 023_2023AUCRT

Future information will include the ability to talk to/access to a health professional

I don't really like watching seminars and and listen to video. Yeah like and they do have those things with the leukemia Foundation. You wanna join us for a you know we've got an online meeting. It doesn't interest me. I'm a sort of a one-on-one. Sit down and have a chat to somebody, but I've never had that from the Leukemia Foundation. The only thing that they offer is those online.
Participant 031_2023AUCRT

Future information will provide more details about new treatments and/or trials

I think they haven't told me anything about the other options of treatment so far, so I am still at the early stages of the treatment. It's only two years for me. But yeah, I would like to hear about the things that are available or the new medications that are coming into the market. If I receive something like an e-mail every month or every, I don't know a couple of months, six months about the new medications, the new options, getting more into details with CAR T cells with immunotherapy, I don't know that much about immunotherapy or the other treatments that are coming to the market. So this would be nice to receive them as. Yeah, to be notified, yeah, yeah.
Participant 017_2023AUCRT

Well, I think new treatments people people should know about new treatments and should know about clinical trials. And probably the best way for this to be done would be via the the treating clinician, but that certainly wasn't how my mine worked. I had to find out about new treatments, really the breadth of new treatments available. Not that I had to access access in the oven, but I found that out by myself.
Participant 014_2023AUCRT

Future information will provide more details on subgroups and specific classifications of their condition

I think a lot more information. I guess it's hard for any doctors or nursing people to know every possible thing, but even the information that I was given at the hospital, a lot of it was other leukaemia, which, that's what DOCTOR was saying, they're totally opposite with outcomes and what you have to get done and all the rest of it. I would probably say more information on my condition. Leukemia in general with adults, and maybe exploring the word haematology, can be linked with cancer. That was me. Oncology, I just put with cancer. I never put hematology with cancer.
Participant 001_2023AUCRT

Not necessarily. There wasn't that much information just because not many people are diagnosed with this so there's not that much information out there as some of your other leukemia, like Hodgkin's lymphoma or AML. Yes, different, types of blood cancer like that. For it being quite rare, I think there is enough information if you go looking.Participant 005_2023AUCRT

Future information will be in a variety of formats

Yeah, I think it needs to be in multiple formats. I mean, I really like digital, obviously, but not everyone does and many and people need to be able to refer back. So paper form is critical, is important, and you know a booklet that is easy to read with further reading options. Because I think that that's often missing. You know, you can find out more about this or find out more about revaccination, where to go to the Australian government website for revaccination. It's fantastic.
Participant 036_2023AUCRT

Future information will be more accessible/easy to find

I think that what they could have done more is giving out information was I didn't find out until afterwards, but there's a lot of the hospital has a lot of online stuff as well as the brochure. So it would have been more useful if right from the start they could have said, and I mean I probably should have looked at it, but go to go to the HOSPITAL to the website and then you'll be able to get more information about your treatments and your what's going on with you and what happens at hospital and that sort of thing. So yeah, if there was more available that that that way that would or if if I was made more aware of that.
Participant 006_2023AUCRT

Table 9.3: Expectations of future information

Expectations of future information	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Future information will provide more details about disease trajectory and what to expect	8	24.24	3	42.86	4	40.00	1	6.25	6	23.08	2	28.57	4	26.67	4	22.22
Participant describes being sastified with the informatin they received	6	18.18	1	14.29	2	20.00	3	18.75	4	15.38	2	28.57	3	20.00	3	16.67
Future information will include the ability to talk to/access to a health professional	4	12.12	1	14.29	0	0.00	3	18.75	4	15.38	0	0.00	2	13.33	2	11.11
Future information will provide more details about new treatments and/or trials	4	12.12	0	0.00	0	0.00	4	25.00	3	11.54	1	14.29	0	0.00	4	22.22
Future information will provide more details on subgroups and specific classifications of their condition	4	12.12	2	28.57	2	20.00	0	0.00	4	15.38	0	0.00	3	20.00	1	5.56
Future information will be in a variety of formats	3	9.09	0	0.00	2	20.00	1	6.25	1	3.85	2	28.57	3	20.00	0	0.00
Future information will be more accessible/easy to find	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	3	20.00	0	0.00

Expectations of future information	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Future information will provide more details about disease trajectory and what to expect	8	24.24	7	36.84	1	7.14	4	28.57	4	21.05	5	35.71	3	15.79
Participant describes being sastified with the informatin they received	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	2	14.29	4	21.05
Future information will include the ability to talk to/access to a health professional	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	1	7.14	3	15.79
Future information will provide more details about new treatments and/or trials	4	12.12	1	5.26	3	21.43	2	14.29	2	10.53	1	7.14	3	15.79
Future information will provide more details on subgroups and specific classifications of their condition	4	12.12	3	15.79	1	7.14	3	21.43	1	5.26	4	28.57	0	0.00
Future information will be in a variety of formats	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	2	14.29	1	5.26
Future information will be more accessible/easy to find	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79

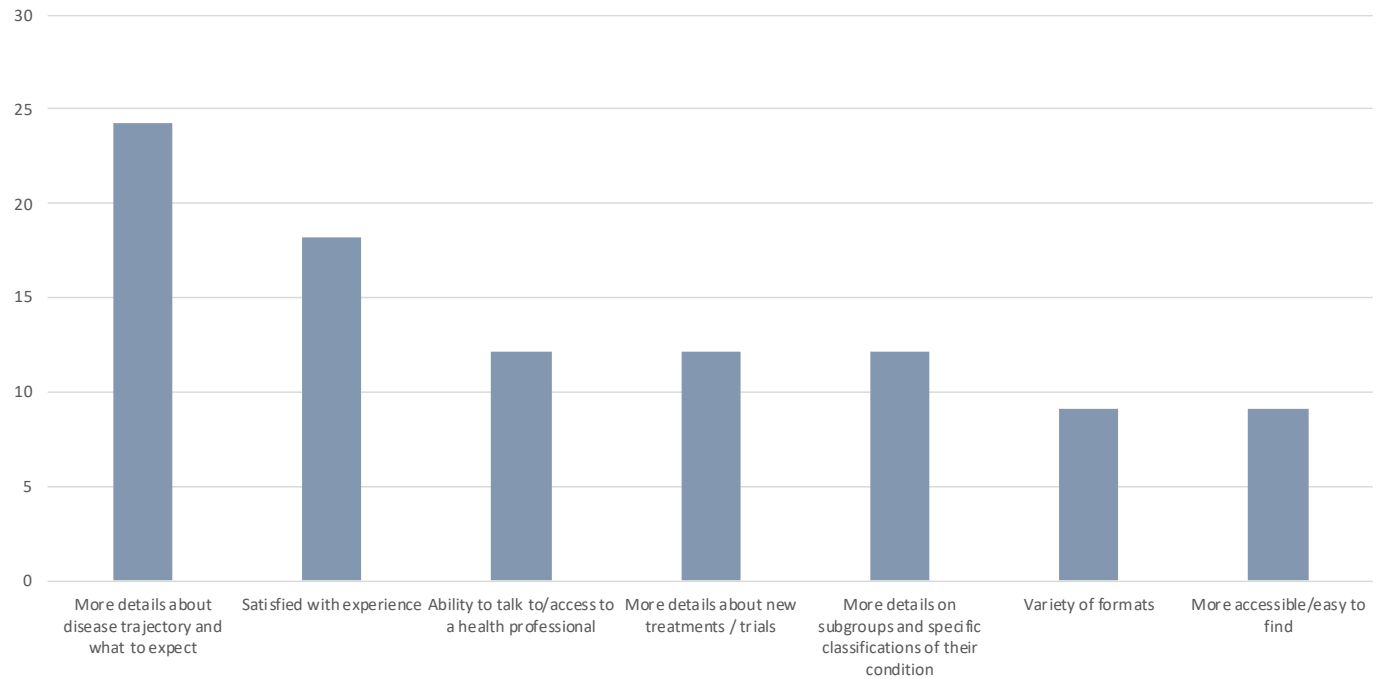


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
Future information will provide more details about disease trajectory and what to expect	Multiple Myeloma Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Aged 25 to 64 Mid to low status
Participant describes being sastified with the informatin they received	-	CAR T-Cell therapy
Future information will include the ability to talk to/access to a health professional	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	-
Future information will provide more details about new treatments and/or trials	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma Female	Multiple Myeloma Male
Future information will provide more details on subgroups and specific classifications of their condition	Multiple Myeloma CAR T-Cell therapy Higher status	B-cell acute lymphoblastic leukaemia (ALL) Mid to low status
Future information will be in a variety of formats	-	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Future information will be more accessible/easy to find	-	Female

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 response was that they were satisfied with the communication they had with healthcare professionals (45.45%). The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (21.21%), and will include a multidisciplinary and coordinated approach (15.15%). Other themes included that communication will be more empathetic (12.12%), will allow people more time to meet with their clinician (9.09%), and will be more understandable (9.09%).

Participant describes being satisfied with communication

No. I think from my experience, they've all been wonderful.
Participant 002_2023AUCRT

No, not necessarily. The experience that I had was pretty positive with the communication. They were always quite open and answered the questions the best that they could.
Participant 005_2023AUCRT

No, not really. I mean in general they've been, they've been very good and I haven't, I haven't had any any any issues or anything that no that I would say that they would need to change so. No, no. That's all being good.
Participant 006_2023AUCRT

No, not really. I think it just depends on the on the on the personal qualities of the doctor or the nurse or or whoever is treating you at the time. Because they're all human as well and if they had an argument before coming to work, they might not be in the best frame mindset or things like that. So I don't think I'll change anything.
Participant 024_2023AUCRT

Future communication will be more transparent and forthcoming

Yeah. Well, that that, that'll be it I think to to to you know to to give information about the latest developments in the in the disease.
Participant 014_2023AUCRT

Yeah, I think people, you know, for people's well-being mentally and physically, they need to be kept informed. Like a lot of people on people in the public system sort of get less, you know, get less sort of hanging out there to with no information, even though they've had a blood test or a scan. Or they might, they might have to wait three months for the results. Or they should be able to just get an e-mail or something or a quick Tele call to say stop worrying, everything is good. Or if there is a problem they should, they should should be acted on immediately. Like the three months can be a long time in and you can deteriorate a lot with myeloma in three months. If you're not, you know, say for example you were just picked up and you had no damage in three months time. Your level could be you know, from you know go from 20 to 100 and your bones are being affected before you even see the specialist again or the hematologist. That I was lucky because mine was always monthly. Initially when I was on smoldering it was six months here, but then when I got the symptoms, as I said previously, it was acted on straight away it. Wasn't just and my hematologist said if I would have left it for another three months for the next scheduled checkup, it would have been much worse. So that's the way I sort of. That's why I see people should be given more information quicker. Yeah, and the site mean people. It's the psychological, so not knowing it's terrible like.
Participant 032_2023AUCRT

Future communication will include a multidisciplinary and coordinated approach

The only thing I would like from the the medical system is is is basically to. And I don't know this is probably unrealistic, but I think the fact that where you're managing sort of three or four different sets of appointments in a week, that somehow your patient number ought to be, they should be able, for example, to print out all your appointments for that week that can be booked. Should you should be giving them once a week? Yeah. Because managing your equipments when various pieces of the system don't talk to each other like chemo and nuclear medicine. And I, I don't know that that all becomes a bit much. So yeah. Yeah, honestly, you it it was basically a lot of any energy that you had left went into managing those kind of things and that drove me mad. I thought it's got to be easier than this, even though I know medical systems

have to cope with the unexpected. That was that was a major source of stress for me.
Participant 009_2023AUCRT

I mean public health system, operating in silos, that makes sense…Connection, connection between those silos is very limited in many ways. So the left hand doesn't talk to the right hand, you know. So OK, good example, I'm in hospital with massive back pain and I have to have an appointment with the oncology center in the exact same hospital.
Participant 027_2023AUCRT

Future communication will be more empathetic

Yeah, my couple of my doctors are good, but I had some other ones there that need to learn how to talk to patients.
Participant 011_2023AUCRT

Clear and balanced is probably all I really asked for is I I like clear information. What, you know, when you say this, what does that actually mean? And yes, you don't have to pay rises and tell me I'm going to live to 150 and you know, yeah, this is all great. This is all going to be wonderful. You don't have to that. But you don't also have to be the other way and say, look, you have cancer, you're going to die sort of stuff. So try and try and realize there is a scared human being on the other end of the conversation and that scared human being just wants to know what's going on. It's no different from a, you know, a 5 year old kid first day of kindy sort of like what the hell is this? So it's the same thing we just to be older and a bit wiser and a bit grumpier. We just really wanna know what the hell's going on and what's the future is where we go from.
Participant 019_2023AUCRT

Future communication will allow people more time to meet with their clinician

I probably needed to ask more questions in my follow-up visits. I always felt a bit guilty taking up too much time when I go in for my appointments because I know I'm just having a check-up and I know there's a lot of people who are in the middle of treatment and I feel like I shouldn't take up the doctor's time so that they have more time with him. I feel like I needed to talk about things a bit more with my hematologist, NAME, when I had some things. I'd sort of touched on them lightly, but I probably needed to talk more. That's something I needed to do, and I'm sure they would have been great. Participant 004_2023AUCRT

Bit more time. I think this the hardest thing for health clinicians is the 10 minute appointment. You know when they look relaxed because you're there, you feel more inclined to ask the had a question and might have the appointment, but the 10 or 15 minute appointment is rushed for them. I don't know how they manage it. Getting the information systems to talk to each other between the health providers is still got a long way to go. It's there, it exists, and I'm on a committee that's looking at that at HOSPITAL. But getting them to actually talk HOSPITAL to talk to the GP, to talk to the cardiologist to talk to the dermatologist, you know, having all that stuff available now, I've set myself up so I fewer clinics involved. So you've got some hope, but it doesn't work. And my health record is a joke, you know? Does for. Some things are there. Some things aren't and. Hospital, some doctors included. Other doctors don't. It's fine. I end up entering stuff in there. So I've at least got that on the record. But I keep it all myself. I have my record.
Participant 036_2023AUCRT

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes being satisfied with communication	15	45.45	4	57.14	2	20.00	9	56.25	13	50.00	2	28.57	6	40.00	9	50.00
Future communication will be more transparent and forthcoming	7	21.21	1	14.29	1	10.00	5	31.25	6	23.08	1	14.29	3	20.00	4	22.22
Future communication will include a multidisciplinary and coordinated approach	5	15.15	0	0.00	3	30.00	2	12.50	3	11.54	2	28.57	3	20.00	2	11.11
Future communication will be more empathetic	4	12.12	0	0.00	2	20.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11
Future communication will allow people more time to meet with their clinician	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Future communication will be more understandable	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56

Expectations of future communication	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes being satisfied with communication	15	45.45	9	47.37	6	42.86	6	42.86	9	47.37	6	42.86	9	47.37
Future communication will be more transparent and forthcoming	7	21.21	2	10.53	5	35.71	2	14.29	5	26.32	2	14.29	5	26.32
Future communication will include a multidisciplinary and coordinated approach	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	3	21.43	2	10.53
Future communication will be more empathetic	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	3	21.43	1	5.26
Future communication will allow people more time to meet with their clinician	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79
Future communication will be more understandable	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

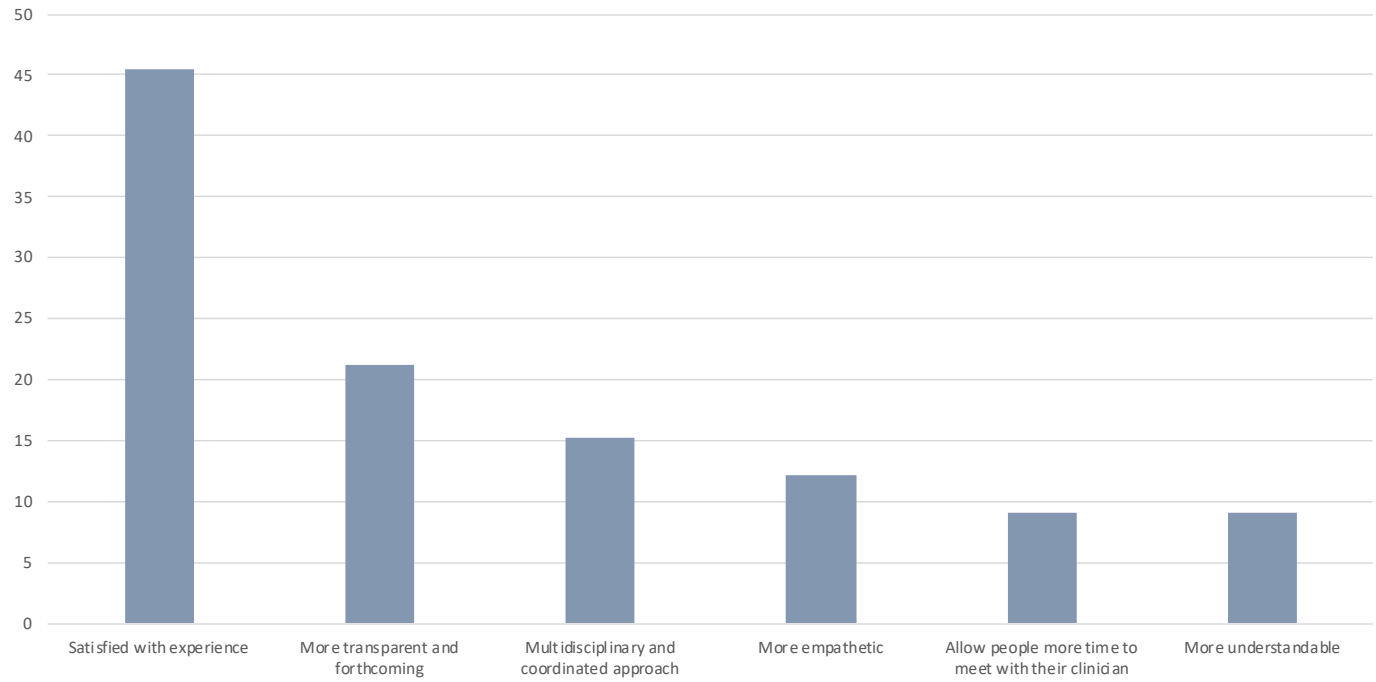


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Expectations of future communication	Reported less frequently	Reported more frequently
Participant describes being satisfied with communication	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL) Multiple Myeloma
Future communication will be more transparent and forthcoming	Diffuse Large B-Cell Lymphoma Aged 25 to 64	Multiple Myeloma Aged 65 or older
Future communication will include a multidisciplinary and coordinated approach	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Future communication will be more empathetic	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
Future communication will allow people more time to meet with their clinician	-	Diffuse Large B-Cell Lymphoma
Future communication will be more understandable	-	B-cell acute lymphoblastic leukaemia (ALL)

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 response was that they were satisfied with the care and support they received (27.27%). The most common expectations for future care and support were that it will include a multidisciplinary and coordinated approach (18.18%), will include more access to support services (15.15 %) and will be more holistic (including emotional health) (15.15%). Other themes included that care and support will include being able to connect with other patients through peer support (support groups, online forums) (12.12%), practical support (home care, transport, financial) (12.12%), and community awareness (9.09%).

Participant describes being satisfied with the care and support they received

I can't really think of anything. I mean, that probably would be, but there's nothing that sort of jumps out at me, no
Participant 006_2023AUCRT

Can't think of anything. The transport service was great when we needed it. Remember the leukemia? Fantastic. Oh yeah, yeah, to and from hospital that was excellent. But that's all we needed.
Participant 013_2023AUCRT

Future care and support will include a multidisciplinary and coordinated approach

No, as aside from that coordination part of it. When you're in the the public system, I honestly think that if that could be somehow more streamlined that would that would have made the most difference to me.
Participant 009_2023AUCRT

Yeah, more exercise physiology. The exercise physiologist was amazing at just getting me started when my balance was so shit and everything was really hard. I just yeah, I think that's probably the biggest one the the exercise Physiology and the and the allied health stuff to the physio that just that physical movement and again I'd say actually the the into the cognitive stuff. It's that kind of thing about oh you get cognitive deficit it it's temporary it's highly distressing especially for someone like me and and scary. So it'd be really great to have some things in place that are less or they're just side effects put up with them. I would like to be proactive about those things to make them last less long.
Participant 016_2023AUCRT

Yeah, probably access to exercise physiology for people in the public system. And also I've just done the practice where I am, has just done a pilot art therapy for six weeks, and that was, it wasn't just art therapy, it was there's there's different psychological exercises that you can do with with the art or with and they get a bit of poetry and there's quite a few I guess techniques that you can use to self improve self help. You know that can be that could be a big assistance and as I said exercise physiology is being recognized as it helps your helps the drugs sort of you know circulated because you're active and gives you more, gives you a positive, more of a positive angle on on the treatment because you're feeling better.
Participant 032_2023AUCRT

Future care and support will include more access to support services

So it might be through charities of the hospital system or like, I think when we first had that and the Leukemia Foundation, it was a lot of humming and haaring to see if we were eligible or not. And it turned out we were. But yeah, people need that reassurance that there's someone there to look up like to help you out where you're not just well with us. We just weren't left on our way. Like the Leukemia Foundation. They're just marvelous.
Participant 011_2023AUCRT

The Leukemia Foundation was generous enough to offer my wife an apartment while I was in the HOSPITAL in CITY for two weeks and then one week for the expensive total 3 weeks. We were living in an apartment. I was in the hospital, She was living in an apartment nearby, so that was very generous, which was very helpful. And they offered some tax taxi vouchers and something like that, that we didn't didn't pick because she was just getting on the bus, 5 minutes later she was at the hospital. So we didn't want to bother about the other things. But I think, yeah, those kind of financial support for traveling for people who are living in more rural areas than us of course and would be critical. And I I came across this ad on the TV a few months ago and Medicare was telling that we have reduced all the prices of all the

medication is below $30.00 and don't postpone your treatment because of the expenses. So I then I realized that there are people who cannot afford even $30,000 and they are postponing the treatment and that is that is unfair. Again, I think so, yeah. Considering these sort of patients, I think it would be good. I don't need too much support apart from very expensive treatments like $150,000 or whatever that would be out of my imagination to pay for. But for a daily medication or my daily life, I'm still, thanks God, I'm still not in the situation that I need charity or yeah, financial.
Participant 017_2023AUCRT

Future care and support will be more holistic (including emotional health)

I think there needs to be psychological help, definitely. The Leukemia Society came in for me, and they did offer me some help, but when I actually reached out to them it wasn't there. I think maybe they went off their feet or whatever. That's how we reason for it. I think it should be part of it. It's quite a hard thing to go through. I think you need to be treated as a whole person rather than just a body. A body that's sick.
Participant 003_2023AUCRT

Yes, I think that's it mainly because all the other support's been there, but I think emotional support was lacking for me. It could have been there, but I wasn't-- I think it's something that they need to rather than say, "We're here if you need us," I think they need to say, "This is what you might feel." It could be in a pamphlet or-- and basic care for it to take longer than you think it's going to be, all of this like there's a clinical side which I think-- Of course, as my hematologist says, everyone reacts so differently.
At the time I went through it really well, but then I've had these lingering things which aren't serious, but they do interfere with my life, with me trying to get back on top, with me trying to earn a living because I'm self-employed, all those sorts of things. I think that there needs to be something about the after-effects. There's probably a bit of post-traumatic stress I imagine that most people go through from when I've spoken to all the other people online who have experienced similar. Someone will ask a question say, "Did you feel stress," or, "Did you have this," or, "Do you think you might have had this?" I think everyone is a bit frightened to talk about it, but it's something that needs to be talked about. I think also the primary care is too-- I had little burns in my arm, and he looked at me and he went, "Oh, you weren't worried?" I'm going, "No, it's fine. Look at my blood tests, they're all fine." That's something I do if I'm in-between visits, if I'm not feeling 100%, that goes on for a little while, a couple of weeks, I'll just go and have a blood test, pick up the results, know everything is all right, so I find that quite reassuring to me and my husband.
Participant 004_2023AUCRT

The support person seems to be the the biggest thing. It's like say we're we're tell someone they got cancer. It's pretty scary and the first thing is oh God, I'm going to die. Which to actually face mortality the first time is a bit like confronting and it changes a lot of perspectives in your life and you don't realize it. Well, from my point of view, like I was 46 or something at the time and yeah, bulletproof like I was just gonna conquer the world sort of thing. Then you actually have shoved in your face and say well in two months time you're potentially gonna not gonna be here. What's important to you now. So it's very, very scary.
Participant 019_2023AUCRT

I think it's just that that after support if anything can you know probably the counseling support sort of things just depend on where people were on their journey with any form of catch. I think there's there's a big big need for for that. But probably, you know, just having access to it all all being sort of more front of mind because it said you you you're worried about the. The actual treatment itself, but obviously the psychological impacts of it, The aftermath is probably something that can get underestimated, I reckon.
Participant 026_2023AUCRT

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I don't know whether there's a thing even for children to go to with other children that have had parents affected. With my girls, it would have been nice for children to talk to other children in that same situation. My girls were very frightened in the beginning, but then in saying that, they actually got a lot of comfort from some of the nurses. After being there a month, and they'd come up every day. They explained it very basic in the beginning, and then they really got in depth to it, the nurses and my children. Maybe some way that the kids could probably go and talk to. For me, again, living on the border, the Leukemia Foundation did send me dates of catch up with other people with Leukemia in the area, but they're up the coast, not in STATE 1 where I'm living.

The STATE 1 one are in CITY, but not where I am. I'm only minutes from the STATE 2 boarder.
Participant 001_2023AUCRT

Well, there was a support group here many years ago, which I did at hand, but I was possibly, well, 20 years younger than everybody else there. So it was I suppose a bit of A and you know that everybody was pretty well supported. But yeah, I didn't quite fit into any of that kind of area. And I think for younger people it's it's a lot harder. Not that I'm young now, but at the time I was a lot younger than most people. You could suffer from multiple myeloma, so yeah, but I'm not aware of any support group around this area anymore, so I'm not sure.
Participant 015_2023AUCRT

Well, I think with the Leukemia Foundation, I think if they could have the opportunity to have some discussions one-on-one or even a group, a group discussion, but in person not on, not a webinar.
Participant 031_2023AUCRT

Future care and support will include practical support (home care, transport, financial)

I would have loved help with transport so I wasn't so reliant on family all the time. When the Leukemia Foundation did contact me the one time, they said that nobody could help me because the person who looks after my area was on maternity leave and she had been replaced. Then COVID hit and so they couldn't transport patients, but that would be what I would have really benefited from.
Participant 002_2023AUCRT

Absolutely. Financially is massive. Yeah. Charities, I don't know, just, yeah, can't survive without money. So we got through, but yeah. That was hard.
Participant 037_2023AUCRT

Future care and support will include community awareness

For more information on media. That would be really good. Because it's suddenly people were starting to talk about it and they didn't hadn't heard about it before.
Participant 020_2023AUCRT

Actually, Well, yeah, everyone I know has done the great shave and we've donated that way. I don't know. Sometimes I think about donating blood needs a bigger campaign because I certainly I went through my fair share of infusions and I don't think people realize the value and how easy it is. So I think, I think that that side could be pushed more and you know, especially when it's so easy for so many to give as far as yeah, leukemia seems. See, I don't know, like in CITY, they're quite well resourced, so it seems to me, well, they have a like, well, they have a lot of services anyway, so I'm not sure if they if they're finding their present fundraising significant. Seems like it might be enough at the moment, but I'm not sure.
Participant 021_2023AUCRT

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes being satisfied with the care and support they received	9	27.27	3	42.86	2	20.00	4	25.00	6	23.08	3	42.86	4	26.67	5	27.78
Future care and support will include a multidisciplinary and coordinated approach	6	18.18	1	14.29	1	10.00	4	25.00	5	19.23	1	14.29	3	20.00	3	16.67
Future care and support will include more access to support services	5	15.15	0	0.00	1	10.00	4	25.00	5	19.23	0	0.00	1	6.67	4	22.22
Future care and support will be more holistic (including emotional health)	5	15.15	1	14.29	2	20.00	2	12.50	5	19.23	0	0.00	3	20.00	2	11.11
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	12.12	1	14.29	1	10.00	2	12.50	4	15.38	0	0.00	2	13.33	2	11.11
Future care and support will include practical support (home care, transport, financial)	4	12.12	1	14.29	2	20.00	1	6.25	4	15.38	0	0.00	2	13.33	2	11.11
Future care and support will include community awareness	3	9.09	0	0.00	1	10.00	2	12.50	2	7.69	1	14.29	2	13.33	1	5.56

Expectations of future care and support	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes being satisfied with the care and support they received	9	27.27	4	21.05	5	35.71	3	21.43	6	31.58	2	14.29	7	36.84
Future care and support will include a multidisciplinary and coordinated approach	6	18.18	3	15.79	3	21.43	2	14.29	4	21.05	2	14.29	4	21.05
Future care and support will include more access to support services	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	4	28.57	1	5.26
Future care and support will be more holistic (including emotional health)	5	15.15	3	15.79	2	14.29	2	14.29	3	15.79	3	21.43	2	10.53
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	3	21.43	1	5.26
Future care and support will include practical support (home care, transport, financial)	4	12.12	4	21.05	0	0.00	3	21.43	1	5.26	3	21.43	1	5.26
Future care and support will include community awareness	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26

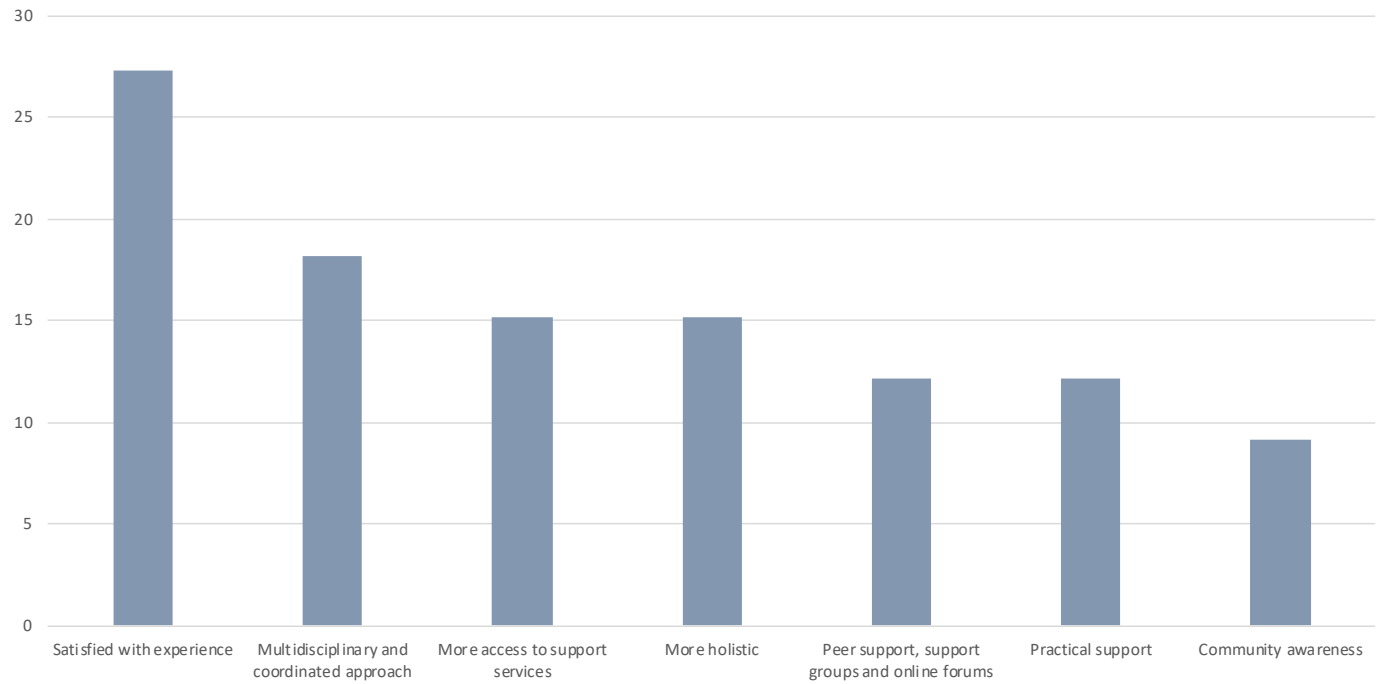


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant describes being satisfied with the care and support they received	Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy
Future care and support will include more access to support services	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	Mid to low status
Future care and support will be more holistic (including emotional health)	CAR T-Cell therapy	-
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	CAR T-Cell therapy	-
Future care and support will include practical support (home care, transport, financial)	CAR T-Cell therapy Aged 65 or older	-

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) (36.36%), and low cost or free medical care through the government (33.33%). Other themes included the entire health system (30.30%), and timely access to treatment (9.09%).

Participant describes being grateful for healthcare staff (including access to specialists)

I was really really really grateful for the care I received. It was outstanding, amazing staff, just such beautiful people. I'm really really grateful.
INTERVIEWER: Yes. I'm glad that you had, despite what you went through, a good experience with that.
PARTICIPANT: Yes. They all deserve gold medals. The incredible patience that those nurses have is just amazing.
Participant 003_2023AUCRT

The people are amazing, from the cleaners and the ward staff, right through to specialists and nurses and doctors. I feel so safe and cared about and respected, you know, And grateful. Yeah, I've had. Yeah, I can't say that enough.
Participant 016_2023AUCRT

I'm grateful for every bit of service that I get from the, from the people at HOSPITAL and their their associates who've been looking after me. And then I must under what I'm allowed to say this. But I reward them every, every every time I go there. Every month I take packets of biscuits, chocolates, bottles of wine at Christmas time. Every time I go there for the last eight years, I've rewarded everyone who looks after me. It'll be little little tokens. So I just it's an appreciation of me giving back, you know, I can afford that and I think they're very happy with it. I'll turn them all into diabetics.
Participant 018_2023AUCRT

Participant describes being grateful for low cost/free medical care through the government (Public health system in general)

The financial side of the treatment, cost of the treatment, not costing anything, that's been amazing. Also, it was very accessible, everyone there is so accessible. I can still ring the center if I've got a problem or I'm worried about something and they'll pass the message on or whatever. The ongoing care is really good that way, clinical care.
Participant 004_2023AUCRT

Well, I think I hinted at this before. I think the Medicare system is, although it's, you know, it's it's the cracks of widening in it now it it really has been a marvelous thing for me. It, you know, I was able to get the treatment that I needed without having to worry about what it was costing, without it sort of, you know, affecting other aspects of my life any more than, you know, being unhealthy.
Participant 014_2023AUCRT

I think just not outlaying any costs, I don't know if that was just all covered by my private health or if the public system was just that good that there was no outlay that was required but for the incredible treatment that I received, for not having to pay anything really is just out of this world. Also the Leukaemia Foundation, I think they do get a little bit of government support but the majority is fundraizing and donations and the facilities there are just incredible. I think, yes, the public system and the Leukaemia Foundation just, yes, definitely, helped out immensely.

Participant describes being grateful for the entire health system

Yeah, I think it's excellent healthcare system. I've been treated very well. I can't complain at all.
Participant 015_2023AUCRT

I think despite all the knockers, Australia has probably 1 or if not one of the best health systems in the world and it's not all American, which is just private only. But it's not all Scandinavian, which is just all state. We have a like education. We have a mix of public and private and it seems to serve us well. I think we've got a pretty good system and I don't mind paying the Medicare levy all for private health insurance. So I do get annoyed when you get really sick. You can't use it for all that money you put. Yeah.
Participant 022_2023AUCRT

Like we had a system like America's. There's no way known I could have. Yeah, I think we got pretty lucky with our health system. Medicare. It's, yeah, unreal.
Participant 037_2023AUCRT

Participant describes being grateful for timely access to treatment

I think the speed at which it is all being dealt with has been something I've been grateful for, like I haven't had to wait a long time for things when I need a test. They've been organized quickly and I've been able to, you know, do everything quickly and get all the treatment moving quickly. That's good. You know you'll hear horror stories of people having to. Wait a year to see somebody, but I haven't had any of that. So I've been very grateful. And I think our health system, you know, obviously it's got its downsized and people who live remotely don't have good access and all that, but I think we are very lucky really.
Participant 012_2023AUCRT

Yeah, When I think the the overall care was pretty good, like I've done both. I've done the public and the private, like private. We went private the first time and it was public the second time because I flew there. Probably we went public the first time. I wouldn't be here because the private sector, everything happened so quickly with all the tests and everything and if I would have been having to wait like a day for another test before they acted and all that, I wouldn't be here. Like it's something that I didn't know what happened to me and I certainly didn't write it on my bucket list. And I I just listened to the doctors and what I read and thought, you know what chance it, you know, if I don't have the treatment, what's going to happen? But I think the biggest thing like that is it's frustrating when you go because it is a public system and you're going to wait so long to see the doctor. And yeah, it's private sectors better. Like you have your appointment, you go there, you basically get straight in and there's a lot of waiting and yeah.
Participant 011_2023AUCRT

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes being grateful for healthcare staff (including access to specialists)	12	36.36	4	57.14	3	30.00	5	31.25	8	30.77	4	57.14	5	33.33	7	38.89
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	11	33.33	4	57.14	3	30.00	4	25.00	10	38.46	1	14.29	6	40.00	5	27.78
Participant describes being grateful for the entire health system	10	30.30	2	28.57	4	40.00	4	25.00	7	26.92	3	42.86	3	20.00	7	38.89
Participant describes being grateful for timely access to treatment	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	2	13.33	1	5.56

What participants are grateful for in the health system	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes being grateful for healthcare staff (including access to specialists)	12	36.36	6	31.58	6	42.86	5	35.71	7	36.84	3	21.43	9	47.37
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	11	33.33	8	42.11	3	21.43	3	21.43	8	42.11	4	28.57	7	36.84
Participant describes being grateful for the entire health system	10	30.30	7	36.84	3	21.43	6	42.86	4	21.05	4	28.57	6	31.58
Participant describes being grateful for timely access to treatment	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26

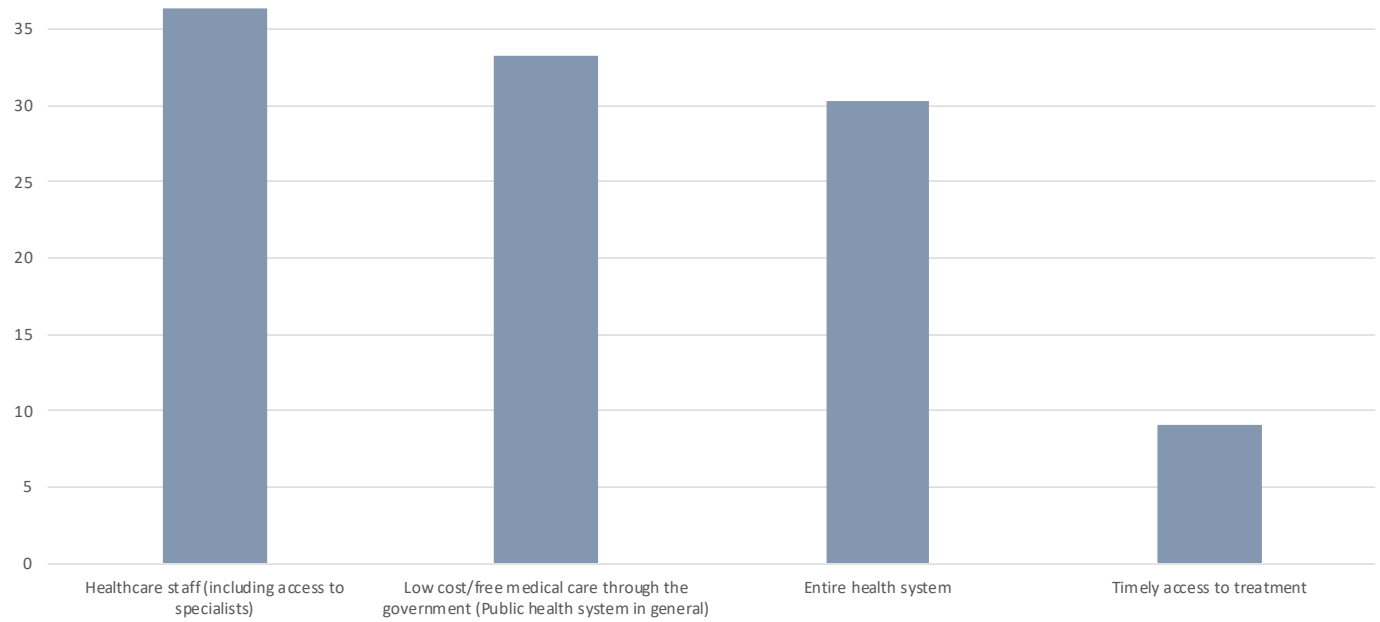


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for healthcare staff (including access to specialists)	Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy Higher status
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	CAR T-Cell therapy Aged 65 or older Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes being grateful for the entire health system	Female	CAR T-Cell therapy Regional or remote

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 10 is the least important. A weighted average is presented in the table below. With a weighted ranking, the higher the

The most important aspects reported were fatigue pain, lymphoedema, and fertility. The least important were heart problems, memory loss and cognitive function, and effects on bones and joints.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=29)
Low resistance to infections	7.48
Second cancer	7.28
Fatigue	7.03
Damage to organs (heart, lung, thyroid)	7.03
Weak or damaged bones	6.38
Peripheral neuropathy (weakness, numbness, or tingling from nerve damage, usually in the hands and feet)	5.00
Psychological effects Including depression and anxiety	4.83
Cataracts	3.72
Hearing loss	3.55
Infertility, premature menopause in women and low testosterone levels and sperm counts in men	2.69

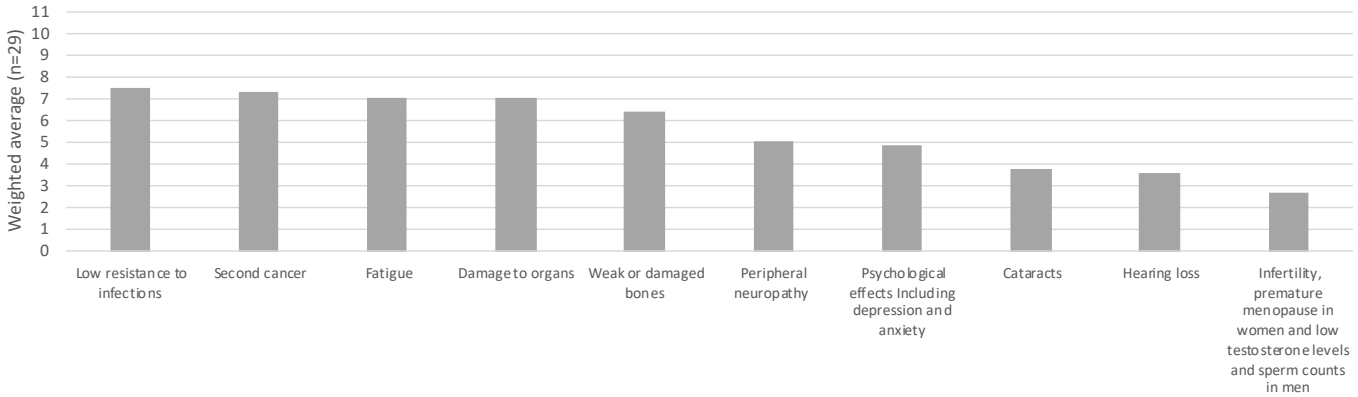


Figure 9.6: Symptoms and aspects of quality of life

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 the table below. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "The severity of the side effects", and "How safe the medication is and weighing up the risks and benefits". The least important were "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

Table 9.12: Values in making decisions

Symptom	Weighted average (n=29)
How safe the medication is and weighing up the risks and benefits	6.48
The severity of the side effects	6.59
Time impact of the treatment on my quality of life	5.69
How the treatment is administered	3.38
How personalised the treatment is for me	4.17
The ability to include my family in making treatment decisions	3.17
Ability to follow and stick to a treatment regime	3.48
The financial costs to me and my family	3.03

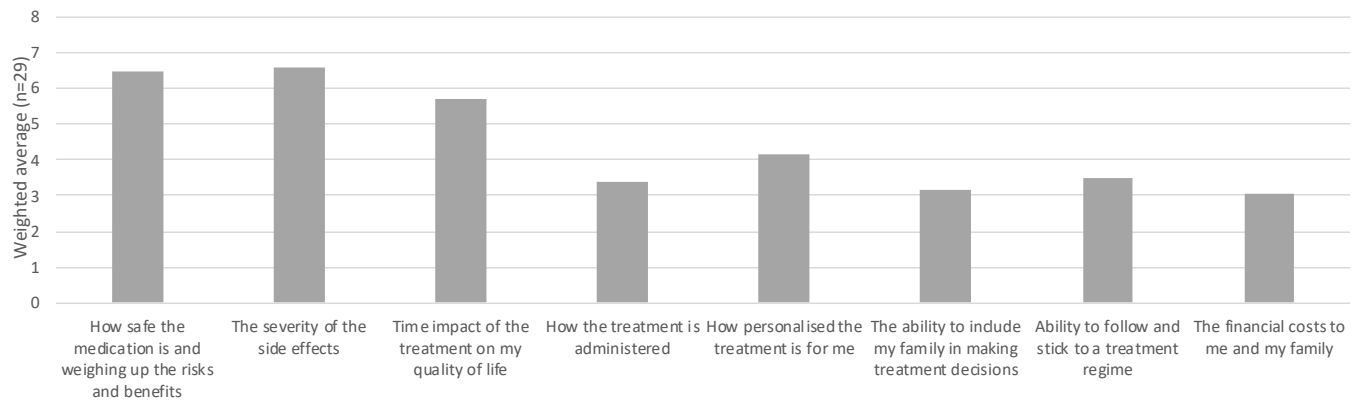


Figure 9.7: Values in making decisions

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 the table below. 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 9.13: Values for decision makers

Values for decision makers	Weighted average (n=29)
Economic value to government and tax payers	1.55
Economic value to patients and their families	2.38
Quality of life for patients	4.14
Compassion	2.93
All patients being able to access all available treatments and services	4.00

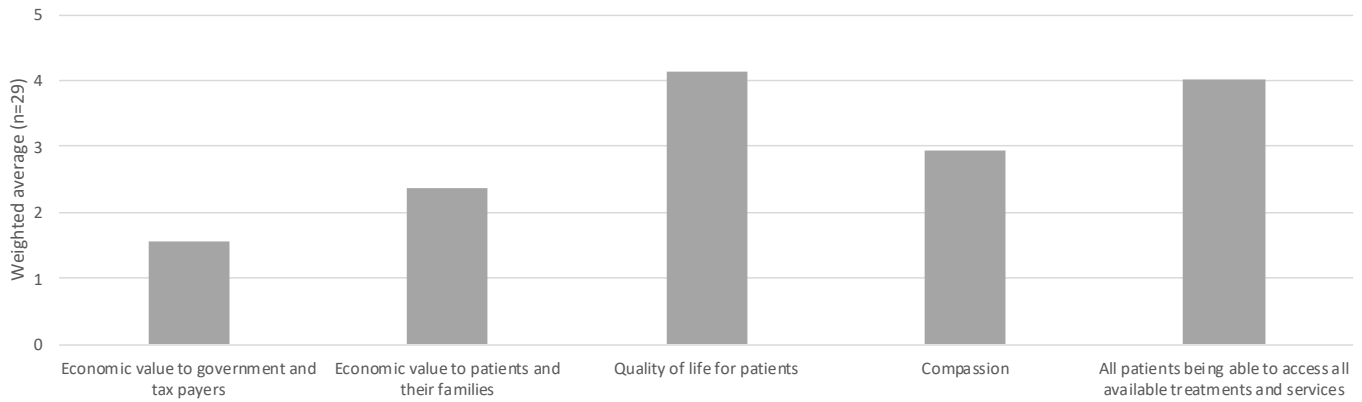


Figure 9.8: Values for decision makers

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 5 to 10 years for a good quality of life even if it didn't offer a cure (n=12, 38.71%), or for more than 10 years (n=11, 35.48%).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=31)	Percent
Less than 1 year	4	12.90
1 to 5 years	4	12.90
5 to 10 years	12	38.71
More than 10 years	11	35.48

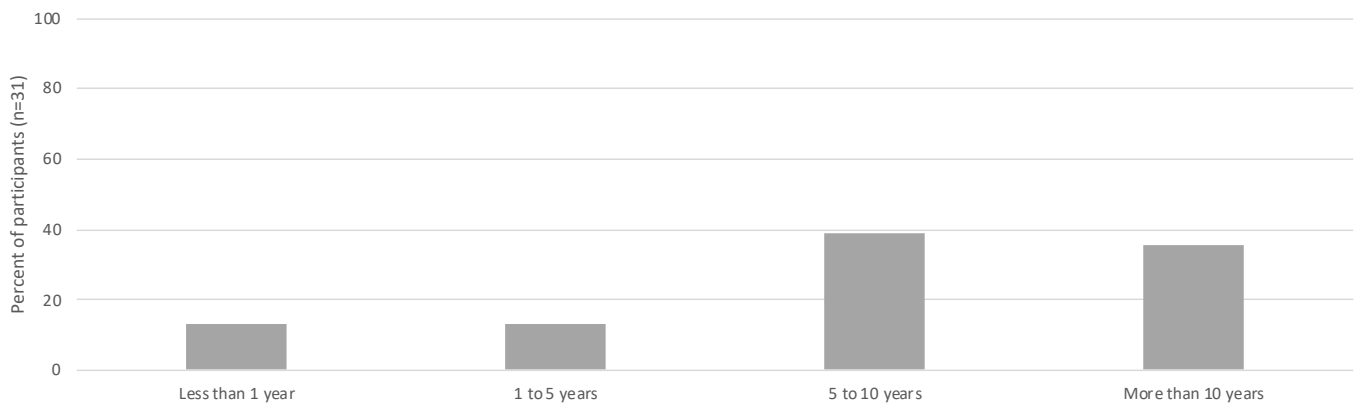


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants most commonly responded that they did not know (n=17, 36.96%), followed by equally effective (n=15, 32.61%).

There were 9 participants (29.03%) that thought that medicine delivered by all forms were equally effective, 4 participants (12.90%) thought that q cell or immunotherapy that uses the body's own immune defense was most effective, and 3 participants (9.678%) that thought as a stem cell/bone marrow transplant was most effective. There were 11 participants (35.48%) that were not sure.

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Number (n=31)	Percent
Equally effective	9	29.03
A cell or immunotherapy that uses the body's own immune defenses	4	12.90
As a stem cell/bone marrow transplant	3	9.68
As drug therapy	2	6.45
IV form (through a drip in hospital)	1	3.23
I'm not sure	11	35.48

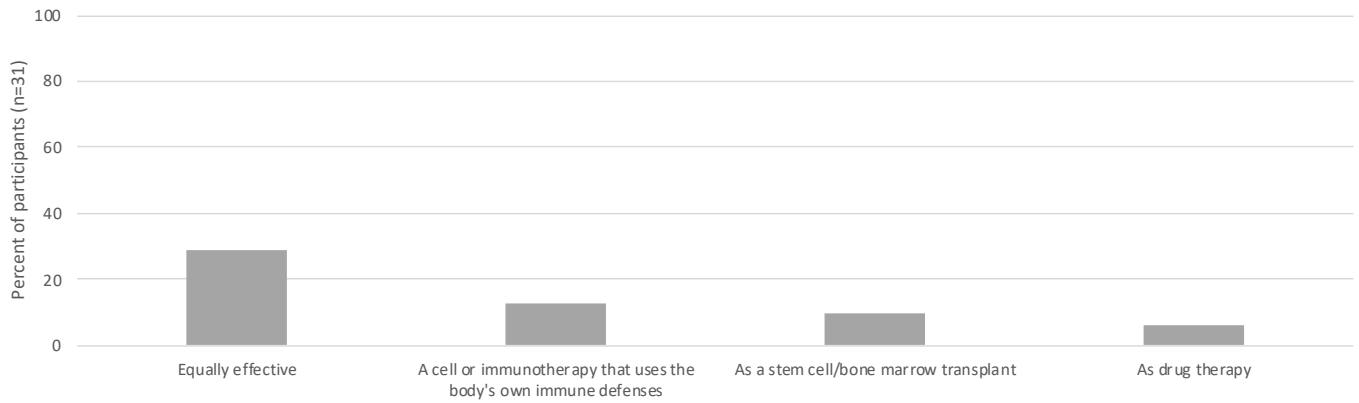


Figure 9.10: Most effective form of medicine

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 messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27 %). Other themes included that treatments need to be affordable (21.21%), to invest in health professionals to service the patient population (18.18%), to help raise community awareness (12.12%), to improve rural services (12.12%), to have a holistic approach to the condition (including emotional support) (9.09%), and to increase investment (general) (9.09%).

Grateful for the healthcare system and the treatment that they received

I can't really complain about anything. I think they've been fantastic since diagnosis, the information. Also, too, the good thing is, they've always given you their emails and their mobile number that you could call them at any time. Even the [unintelligible], it's a matter of a text message and you get your reply. You didn't feel like you were on your own. Especially, as I said, I forget a lot of things when the family would ask things. Even, they were never worried about speaking to a family member on my behalf, which was great.
Participant 002_2023AUCRT

I think I had the best access to care. I was in HOSPITAL. I think it was outstanding, really. I'd just say, "Thank you." Hopefully, everyone who gets leukaemia has the access to that care.
Participant 003_2023AUCRT

Well, I'm reminded of how well it works for me and that he needs to do everything he can to preserve the Medicare system and strengthen it so that it can do that for other people.
Participant 014_2023AUCRT

Yeah, yeah, I mean I think what we get here in Australia is amazing. My daughter's got a friend in America. She's head of, would you believe hematology LOCATION in America? And way back ages ago, years ago, she said to her, her friend in America, if mum, we can't have get things for Mum here, should we bring her over to America? And she said you leave her right way here, she's got the best treatment In the world.
Participant 025_2023AUCRT

More clinical trials and/or new treatments

It's always a money, money situation. I imagine so, but you certainly wouldn't hesitate on, yeah, going with the leading leading medical research and putting money behind it to make it available to as many people as possible.
Participant 021_2023AUCRT

I think I would just say please give consideration to the new drugs as they come along that can help people who are living with the condition. You know, they always ask us when a new treatment's going before the TGA to write something in support of their submissions. And I know that there's a lot of things that different illnesses and rare cancers and so on that don't get the consideration that more common cancers do. But I'll just especially, I think I would say about cancers that affect children. Yeah, you know, that's what I where I think we really need to. It's bad enough when people my age get something, but you know, we've lived a good life. It's when small children or young people get things and if there's a treatment that could help them, give consideration and funding to that where possible and try and equalize things so that people who don't have as ready access to treatment as what I do have a better chance of getting it.
Participant 012_2023AUCRT

Now when I say that you need to put more funding into research, well they probably that what they need to do is support like the likes of Leukemia Foundation more so they can look after the people. Medications need to be cheaper. You know, like I know when you get the healthcare card, it's only 7 bucks or anything, but you know when you go to when you when you crook. Like, even with all my healthcare card that I had with some medications, when you walk out, you go to the chemist, when you're on it, it's still like 60 or $70.00 worth of pills that you know, sometimes more and like they should just, I don't know if there was funding there to make them even cheaper again. Because, you know, like different people you spoke to. Like it was lucky that we had savings and that that there was an old fellow next to me. We were talking, sitting in the sun one day, getting there, just sitting at the hospital, and we were just chatting. And even with his healthcare card, he did his pension, he did his medication and like, he had like $15 a week left for food after his medication and he had a healthcare card. And I mean, there's a lot of people like that. And that's what, yeah, they need to concentrate more on.
Participant 011_2023AUCRT

Invest in research (including to find new treatments)

I'd say pretty well done. Keep on looking for a cure. Keep on funding research.
Participant 013_2023AUCRT

I would I would just be encouraging encouraging them to give all the all the support that was necessary in terms of dollars and and research given there's no there's no cure for multiple myeloma but like with with all with all with all cancers there's massive massive amount of research being done and eventually one day based on trials and all that that and that base is based on dollars with the research. So that continues to to to keep patients like me on a safe trip, but to improve the prove the life of others in the future with with research.
Participant 023_2023AUCRT

Treatments need to be affordable

Well I think in the present time it it it there's a lot of good treatment and and out there and you know it it it it well for me it's worked and I I have I'm just the example of how how did the treatment system is but difficult one because I think can becoming more prominent than it used to be so and then that comes into it is the costing of how much it costs and you know how viable is especially in this day and age.
Participant 015_2023AUCRT

Generally speaking, as I explained, there are there is not much that I know about the other medications for multiple myeloma that is in PBS or not. I know that the second line is Daratamabob as I said by talking to a few specialists overseas and I know that it since I came back two months ago. I just discussed that in my specialist and he said yes, this is included in PBS. So I'm happy that there is a second line of treatment, but we all know that it would fail again after a while. And then we need to go to the next stage and next stage, and this is the tough way that people like me have

ahead of their life to fail again and again and again. Still there is no more treatment. So I'm not quite sure if all of these third and 4th and 5th layers are covered in the PBS, but are hopeful that the minister could think about things ahead and yeah, make it fair and affordable for everyone to be able to have the treatment according to their needs. Yeah, I think Australia is a very wealthy country and looking at the number of the people who are living here, we can afford to support people who are sick with these unprecedented situations like me. So I think this is something that can be included in the expenses of the country.
Participant 017_2023AUCRT

Invest in health professionals to service the patient population

Oh God, I'd say look after your staff to make sure that the treatment is as optimal as it can be and staff are not exhausted by simply doing their jobs.
Participant 009_2023AUCRT

I would. I would tell them to probably plan the nurses more, more money that you probably. I think they deserve it and forget about the interiors of the buildings and keep working on them on the facilities that are really important, you know the equipment that they need etcetera. But really we're very fortunate, we're on quite fortunate HOSPITAL. We've got a good hospital there. The facilities there are excellent. So you know, I'm sure people who work there would probably say they could, they could be improved. The regional areas, what I would think there's a lot of regional areas that are really missing out. They could, they can't do some of the trials. There's lots of things like that that I think that could be improved. Yeah, once you get outside the the CITY design, it doesn't, doesn't work that well. So, and I don't know how to, I don't know what I'd say, look, start to look after those people as well, but pay the nurses more money, but definitely.
Participant 018_2023AUCRT

Help raise community awareness

I'd just say, again, maybe just more make people are aware, whether it's on ads or things like that. Putting the word out there, different types of leukemias and that is associated with adults making more it aware, rather than you don't really hear much about, even on TV. I mean, the shaved one's just come up recently for leukaemia, but generally most people associate that. I think people need to be aware that it can be an adult thing as well as a child thing, leukaemia. That there are different types of, leukemias and that when you do have any particular little signs, people need to be more aware and probably go to the doctor. If they play with fire like I was, I would've just went to sleep one night and that would have been it. So maybe just more awareness through media about leukaemia in general rather than just trusting people. I think, honestly, 8 out of 10 people would that I've spoken to and even after diagnosis, they've just associated it with an adult.
Participant 001_2023AUCRT

Improve rural services

So it would be to make it more available for people living in regional remote Australia and to be quicker off the mark to get new drugs and treatments through the PBS.
Participant 022_2023AUCRT

INTERVIEWER: How do you make it so that it's more accessible to everybody? You know, it's the remote from the transplant game. You know, I found it hard going from RURAL LOCATION 1 to CITY. 1 I met someone who had to go to camp from RURAL LOCATION 2 to CITY. 2. How do you do that? So it's how do we get those support people who are regional and remote? That's the first thing. And the other one that comes up to me is people who are vulnerable with mental health issues or disability. Like if I was so hard to get diagnosed and I've struggled to get through this process, how do they get diagnosed? You know, people with intellectual disability die, have such low mortality rates, low high mortality rates and everyone else. And that would be why?
Participant 016_2023AUCRT

Holistic approach to the condition (including emotional support)

You can't explain fear and there is nothing available to help you come to terms with that. You watch nurses on cancer wards run 10 or 12 hours a day because there's not enough of them. My message would be you need to put money into mental health and you need to put more money into having good quality nursing care available. That would be my message.
Participant 008_2023AUCRT

Yeah, look, support them. It's a dealing with HOSPITAL and no doubt there's other. Facilities around Australia, but yeah certainly, certainly that sort of

things, yeah to support it for sure. But also look at strip it back would be the thing to look at the individual side of things. Where are they coming from for treatment, what are they made, what extra support and what's their their home sort of demographic side of things. Because again sometimes it can just be unfortunately just be a number in the system.
Participant 026_2023AUCRT

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Grateful for the healthcare system and the treatment that they received	10	30.30	3	42.86	4	40.00	3	18.75	9	34.62	1	14.29	7	46.67	3	16.67
More clinical trials and/or new treatments	9	27.27	0	0.00	2	20.00	7	43.75	6	23.08	3	42.86	4	26.67	5	27.78
Invest in research (including to find new treatments)	9	27.27	1	14.29	5	50.00	3	18.75	6	23.08	3	42.86	5	33.33	4	22.22
Treatments need to be affordable	7	21.21	0	0.00	2	20.00	5	31.25	5	19.23	2	28.57	1	6.67	6	33.33
Invest in health professionals to service the patient population	6	18.18	0	0.00	2	20.00	4	25.00	3	11.54	3	42.86	1	6.67	5	27.78
Help raise community awareness	4	12.12	3	42.86	0	0.00	1	6.25	4	15.38	0	0.00	4	26.67	0	0.00
Improve rural services	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	1	6.67	3	16.67
Holistic approach to the condition (including emotional support)	3	9.09	2	28.57	0	0.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11
Increase investment (general)	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	0	0.00	3	16.67

Message to decision-makers	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Grateful for the healthcare system and the treatment that they received	10	30.30	5	26.32	5	35.71	3	21.43	7	36.84	3	21.43	7	36.84
More clinical trials and/or new treatments	9	27.27	4	21.05	5	35.71	3	21.43	6	31.58	3	21.43	6	31.58
Invest in research (including to find new treatments)	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Treatments need to be affordable	7	21.21	5	26.32	2	14.29	5	35.71	2	10.53	4	28.57	3	15.79
Invest in health professionals to service the patient population	6	18.18	1	5.26	5	35.71	3	21.43	3	15.79	1	7.14	5	26.32
Help raise community awareness	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	1	7.14	3	15.79
Improve rural services	4	12.12	3	15.79	1	7.14	2	14.29	2	10.53	1	7.14	3	15.79
Holistic approach to the condition (including emotional support)	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	1	7.14	2	10.53
Increase investment (general)	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

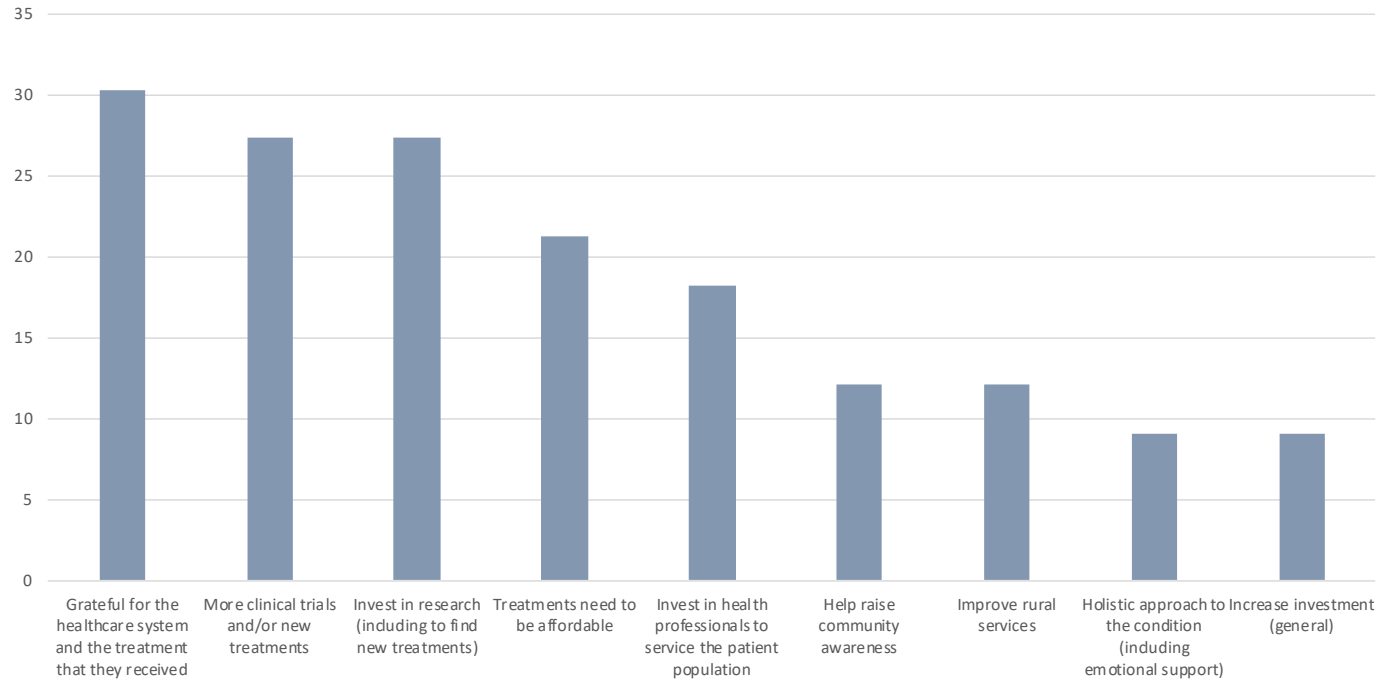


Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Grateful for the healthcare system and the treatment that they received	Multiple Myeloma CAR T-Cell therapy Male	B-cell acute lymphoblastic leukaemia (ALL) Female
More clinical trials and/or new treatments	B-cell acute lymphoblastic leukaemia (ALL)	Multiple Myeloma CAR T-Cell therapy
Invest in research (including to find new treatments)	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Treatments need to be affordable	B-cell acute lymphoblastic leukaemia (ALL) Female Metropolitan	Multiple Myeloma Male Regional or remote
Invest in health professionals to service the patient population	B-cell acute lymphoblastic leukaemia (ALL) Female Aged 25 to 64 Mid to low status	CAR T-Cell therapy Aged 65 or older
Help raise community awareness	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Male Regional or remote	B-cell acute lymphoblastic leukaemia (ALL) Female
Improve rural services	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	B-cell acute lymphoblastic leukaemia (ALL)
Holistic approach to the condition (including emotional support)	-	B-cell acute lymphoblastic leukaemia (ALL)

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 understood the trajectory of the disease (27.27%), and to know the early signs and symptoms of their condition (12.12%). Other themes included to be assertive, an advocate, informed, and ask questions (9.09%), and look after their emotional well-being (9.09%).

As a follow up question, participants were asked if this knowledge would have changed their decisions. Most commonly, participants responded that it would not have changed their decision making (75.76%), for others it would have changed their decisions (18.18%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have stopped or changed treatment sooner (30.30%), and would not change any aspect of their care or treatment and were satisfied with care and treatment received (27.27%). Other themes included would not change any aspect of their care or treatment, with no reason given (9.09%), and would have liked to have had access to a specialist in their condition sooner (9.09%).

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 understood the trajectory of the disease (27.27%), and to know the early signs and symptoms of their condition (12.12%). Other themes included to be assertive, an advocate, informed, and ask questions (9.09%), and look after their emotional well-being (9.09%).

As a follow up question, participants were asked if this knowledge would have changed their decisions. Most commonly, participants responded that it would not have changed their decision making (75.76%), for others it would have changed their decisions (18.18%).

Participant wishes they had understood the trajectory of the disease

Probably, probably just those impacts on life a little bit, I suppose again everyone's an individual but hey look you might be able to do this you might be able to do that. This could be the side effects in my circumstance. Yes I did mention graft versus host disease but it can be anything from your skin to your mouth to your lungs. So you got what are the what are the impacts. So probably that and that's probably where the specialists are very, very good. This needs… having suggestion would be like having a branch out sort of support person. That yeah, it can can help you look at that choices you have…just somebody Who sits down, you know pre post and all sort of things and just generally have a, you know it could be a two monthly or a quarterly check in with you to make sure that you know both physically and certainly mentally that you're OK
Participant 026_2023AUCRT

No. Probably the long-term effects of the tiredness. They did say to me it takes you two years to get back to somewhat normal, but it's just the little things like the tiredness all the time.
Participant 002_2023AUCRT

No, no, I wish I'd know it was going to turn out as well as it did. I know we're all pretty worried about it. At the beginning there was all this stuff about, you know, three to five years and all this sort of stuff…
Participant 014_2023AUCRT

Participant wishes they had known the early signs and symptoms of their condition

I think yes. I would like the fact that there's not really one blood test for lymphoma because I have four blood tests and keep thinking over different times and they're all normal. And yeah so I think that, yeah, knowing that would have been a good, a good thing. Heads up, most people have a swollen gland and I didn't, which is unfortunate, but yeah, so just, you know, people to act on as a gland, I guess it doesn't go down after a couple weeks, a week or so. But yeah, certainly that there is not one blood test, because I think the other thing I've found is that doctors don't know either. And I've spoken to a couple people when they would have gone down the same line of treatment for my sore knee and like cancer was the last thing that they would think of. And so not that you want cancer be the first thing you think of, but certainly doctors need doctors I think need to know how to read blood tests a bit better as well.
Participant 021_2023AUCRT

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

Yes, but I don't know if it would have been possible for me to know a lot at diagnosis, because as I said, I was very very ill. For me and my sons and daughter-in-laws, none of us knew what was going on really. Nothing was really explained properly or well. As I've found out now, it's up to you to ask the right questions, but you don't know the right questions, so it takes a while to work all that out.
Participant 003_2023AUCRT

Participant wishes they had known to be look after their emotional well-being

Just the emotional side I think, all the other stuff I got pretty good. That was all great, it was really really good.
Participant 004_2023AUCRT

Weirdly, this is going to sound strange. The chemo wards are absolutely if you oh how can I put this? I expected chemo wards to be very depressing and I found the nursing staff somehow magically make it not depressing for most of their patients and I think it was the same in CITY 1 as in CITY 2 and I think I was just overcome by how positive that experience was for me and just how positive the people working in the area are. I also got COVID in the middle of it. So, yeah,

yeah, So. I think that perhaps. I could have asked for help a little earlier when I was having, say, a bad week instead of, you know, being being strong. And yeah, yeah, so I actually have got better at asking for help. Yeah. So that was the biggest lesson for me. Participant 009_2023AUCRT

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant wishes they had understood the trajectory of the disease	9	27.27	0	0.00	4	40.00	5	31.25	7	26.92	2	28.57	5	33.33	4	22.22
Participant wishes they had known the early signs and symptoms of their condition	4	12.12	0	0.00	1	10.00	3	18.75	3	11.54	1	14.29	1	6.67	3	16.67
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56
Participant wishes they had known to be look after their emotional well-being	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11

Anything participants wish they had known earlier	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant wishes they had understood the trajectory of the disease	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	5	35.71	4	21.05
Participant wishes they had known the early signs and symptoms of their condition	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	1	7.14	3	15.79
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	0	0.00	3	15.79
Participant wishes they had known to be look after their emotional well-being	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	3	21.43	0	0.00

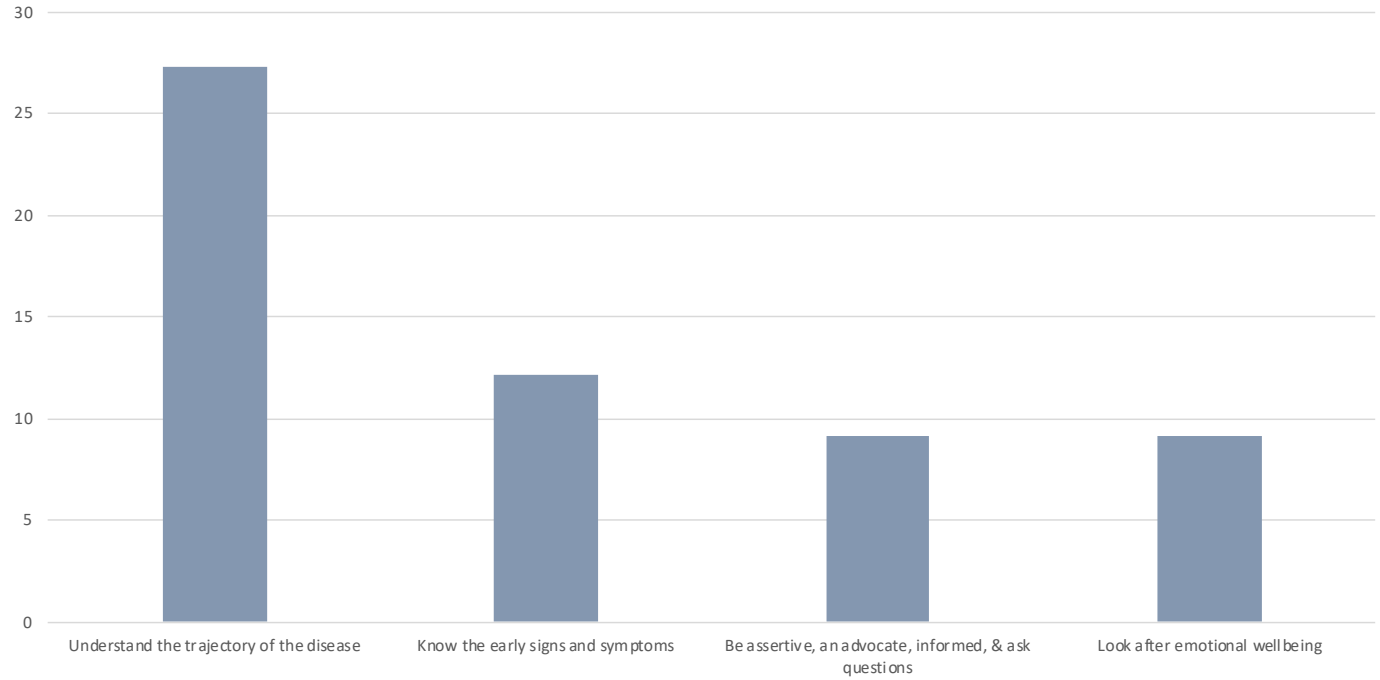
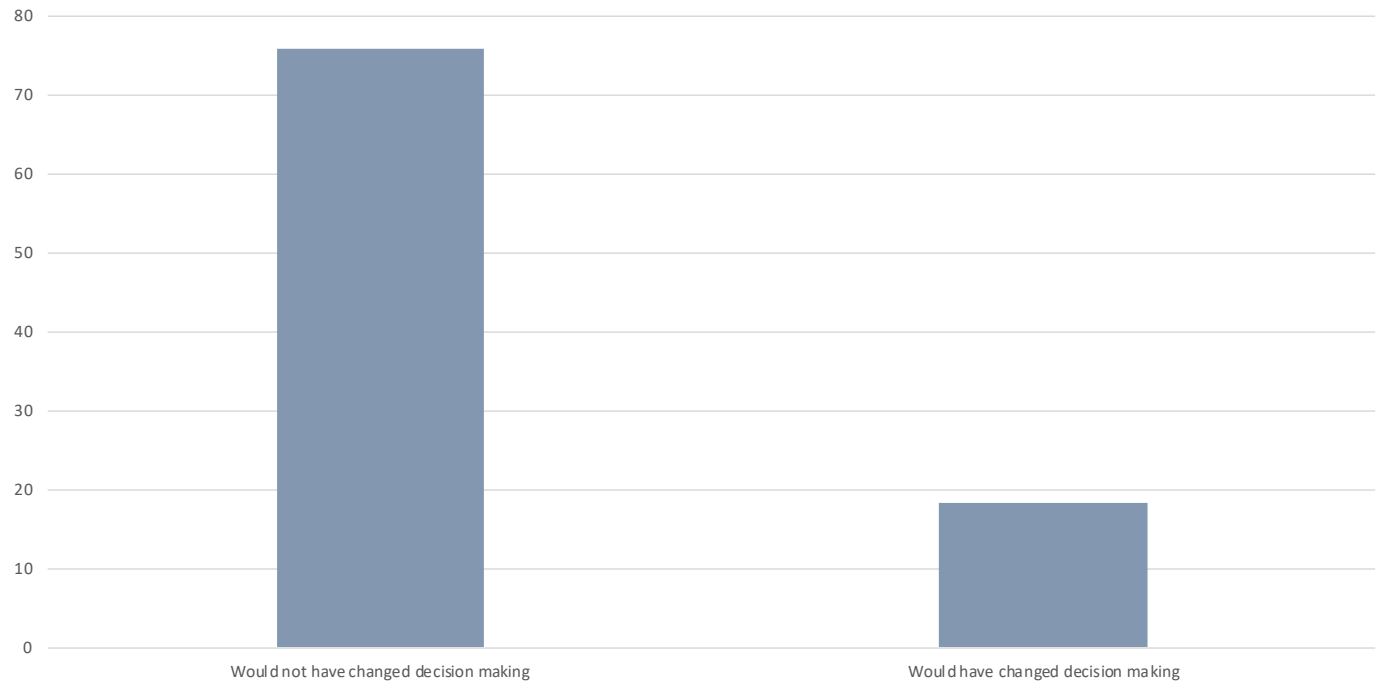


Figure 10.1: Anything participants wish they had known earlier

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 understood the trajectory of the disease	B-cell acute lymphoblastic leukaemia (ALL)	Diffuse Large B-Cell Lymphoma
Participant wishes they had known the early signs and symptoms of their condition	B-cell acute lymphoblastic leukaemia (ALL)	
Participant wishes they had known to be look after their emotional well-being	-	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status

Figure 10.2: Would that knowledge have changed decision making



Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have stopped or changed treatment sooner (30.30%), and would not change any aspect of their care or treatment and were satisfied with care and treatment received (27.27%). Other themes included would not change any aspect of their care or treatment, with no reason given (9.09%), and would have liked to have had access to a specialist in their condition sooner (9.09%).

Participant would have stopped or changed treatment sooner (incl. starting CAR-T earlier)

Look, the only thing I thought we'll probably could have would have looked into more was maybe when I was sent to the rehabilitation place to see if I could have done the same sort of rehabilitation that had a private facility. Because it was quite horrible there and we had private health cover, so we weren't. I didn't ask enough questions and they didn't really talk to us about okay. Well you need rehab. We can't help you here. So you can either go to the rue or or we can if you've got private health cover you can go to we can make this is a place where you can go to and you can do it that way. So it was sort of like. And I've heard other people say this they don't the two sides don't like the the public don't really offer the options of private. So so that that that that wasn't sort of really suggested to me and that would have that would have been helpful to be able to do that we are.
Participant 006_2023AUCRT

As I said before, not having to go through three failed grounds of chemo before CAR T was available.
009_2023AUCRT

No. I probably with hindsight I would have you know would have asked more questions and would have got the hematologist to refer me to other people. But you know I've kind of just gone with with things and while I haven't been suffering too much I've just gone with it. But as I said, I've been proactive and looked at different other therapies that might help with the pain and found a solution for myself. And you know, anything that I think I can do to help my situation, yeah, I'll do it. You know I can be proactive and find an answer you.
Participant 012_2023AUCRT

Well, I think I would have if if I jumped up and down early enough, I wouldn't have been on having diarrhea for 10 years. You know, I think I would have liked to have maybe been taken off it earlier.
Participant 020_2023AUCRT

Yes, I would just like to go into CAR T given now my reading sort of indicates that the chance, you know, it might have worked, but the chances were lower for for the chemo treatment for my particular cancer. So I think it's unfortunate, but it's sort of a, you know, the system as it is now, but as time goes on that I imagine that people would be more readily referred to a CAR T program. Participant 021_2023AUCRT

Yeah, I would like that that CAR T cell procedure, it's available from the beginning so that we don't have to go through through chemotherapy that would be you know more available another just for those you know critical.
Participant 034_2023AUCRT

Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received

No, I don't think so, I've really got no complaints. They've pulled me out of the worst thing that could probably happen to anyone. Yes, definitely no complaints there.
Participant 005_2023AUCRT

No, I don't think so. It's keeping me alive.
Participant 013_2023AUCRT

No, there isn't. I'm very happy with it.
Participant 014_2023AUCRT

Participant would have liked to have access to a specialist in their condition, sooner

I would have liked to have been admitted to HOSPITAL earlier, but that was just a process that we had to undergo.
Participant 002_2023AUCRT

I think the, the waiting around in waiting rooms for pathology when people need it urgently and they're sick, that's got to change. Greater equity, an inclusion within the hospital environment, it's very good at hospitals, but it's got a long way to go. So they're the things and the data access across clinicians I think is going to be improved.
Participant 036_2023AUCRT

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7		n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant would have stopped or changed treatment sooner	10	30.30	1	14.29	4	40.00	5	31.25	6	23.08	4	57.14	7	46.67	3	16.67
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	9	27.27	2	28.57	1	10.00	6	37.50	9	34.62	0	0.00	2	13.33	7	38.89
Participant would not change any aspect of their care or treatment, with no reason given	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	1	6.67	2	11.11
Participant would have liked to have access to a specialist in their condition, sooner	3	9.09	1	14.29	2	20.00	0	0.00	2	7.69	1	14.29	2	13.33	1	5.56

Aspect of care or treatment they would change	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant would have stopped or changed treatment sooner	10	30.30	6	31.58	4	28.57	3	21.43	7	36.84	3	21.43	7	36.84
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	9	27.27	5	26.32	4	28.57	4	28.57	5	26.32	4	28.57	5	26.32
Participant would not change any aspect of their care or treatment, with no reason given	3	9.09	2	10.53	1	7.14	2	14.29	1	5.26	2	14.29	1	5.26
Participant would have liked to have access to a specialist in their condition, sooner	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

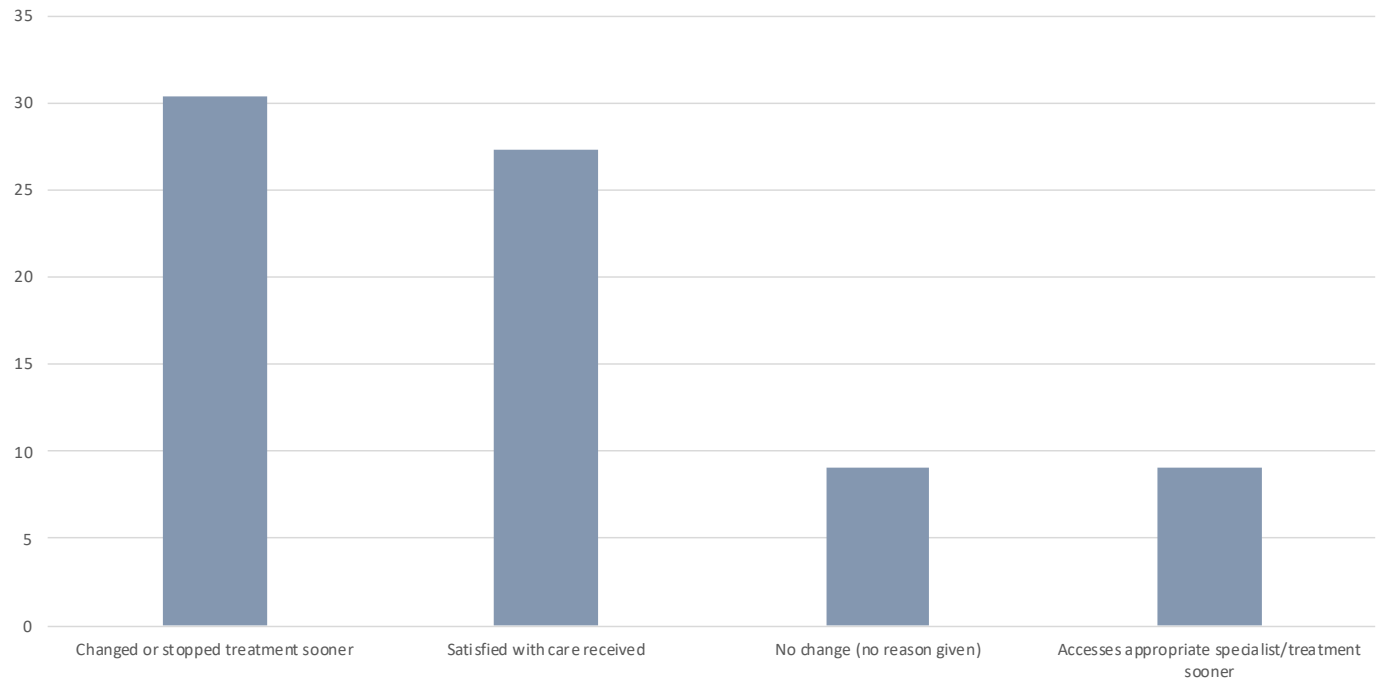


Figure 10.3: Aspect of care or treatment they would change

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 have stopped or changed treatment sooner	B-cell acute lymphoblastic leukaemia (ALL) Male	CAR T-Cell therapy Female
Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Participant would not change any aspect of their care or treatment, with no reason given	-	Diffuse Large B-Cell Lymphoma
Participant would have liked to have access to a specialist in their condition, sooner	-	Diffuse Large B-Cell Lymphoma

Section 11

Discussion

Introduction

During treatment and probably a couple years past the treatment, yes, it has affected my quality of life with what I've been able to do and to achieve with regards to work, my physical activity, socializing, things like that. About we had to give up everything that I was doing for three 3 1/2 years to maybe 4 1/2 years.
Participant 024_2023AUCRT

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 blood cancer includes 37 people diagnosed with CAR-T treatable blood cancer throughout Australia.

Background

Blood cancers accounted for approximately 12% of all cancers cases in Australia 2023. In 2019, 17,705 people were diagnosed with a blood cancer, a rate of 57.7 per 100,000[1]. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females[1]. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia[1], with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Blood cancer is can occur at any age, acute lymphoblastic leukaemia was expected to be the most common cancer diagnosed in children 2023, however, incidence of blood cancer increases with age, and in 2019, the mean age at diagnosis was 67.2[1].

Five year survival was 69% in 2015 to 2019, survival rates are higher in younger age groups with five year survival of 90% for people aged under 40, 84% in 40–59 year olds to 69% in 60–79 year olds to 42% for those aged 80 years older[1].

Blood cancers have high hospitalisation and pharmaceutical costs, with myeloma and leukaemia rated in the top three most expensive cancers to treat in Australia[2].

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 blood cancer.

In this PEEK study, there were smaller proportions of participants that lived in major cities and higher proportions that lived in areas with higher socioeconomic status, compared to that of Australia[3,4] Participants lived in all Australian states and territories. There was a lower proportion of participants from NSW, while a greater proportion from Queensland compared to the proportion that live in each state[5].

Table 12.1: Demographics

Demographic	Australia %	Blood cancer PEEK %
Live in major cities	71	57
Higher socioeconomic status (7 to 10 deciles)	40	54
New South Wales	32	16
Victoria	26	22
Queensland	20	27
South Australia	7	8
Western Australia	10	11
Tasmania	2	8
Northern Territory	1	3
Australian Capital Territory	2	5

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 blood cancer 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[6]. 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%)[6]. The Australian Bureau of statistics reports that 10% of Australians have

depression or feelings of depression and 13.1% have an anxiety-related condition[6].

In this PEEK study, participants had higher levels of back pain (43% compared to 16%), arthritis (27% compared to 15%), anxiety (38% compared to 13%), and osteoporosis (14% compared to 4%) compared to the Australian population. Other studies reported comorbidities in people with blood cancer, in particular, anxiety and depression of between 5 and 70% of participants[7-15], and fatigue in between 44% and 91% of participants[13,16,17]. Participants in this PEEK study had an average of 3 other conditions that they managed.

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].

Participants in this PEEK study completed Short Form Health Survey 36 (SF36) questionnaire, 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. Participants had very high scores for role functioning emotional, high scores for physical function, emotional well-being, social functioning, and pain, and average scores for role functioning physical, energy/fatigue, and general health. In contrast, other studies reported poor health related quality of life in the following domains; physical function[13,19-21], emotional impact[19,20], pain[21], and energy/fatigue[21]

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 blood cancer community in this PEEK study compares with the Australian population[22]. Compared to the Australian population, participants =in this PEEK study had lower physical function, role functioning physical, energy/fatigue, and general health, they had higher scores for role functioning emotional, and social functioning, and similar scores for emotional well-being, and pain. In other studies, compared to the general population , people with blood cancer have poorer health related quality of life[23-28], in contrast one study described not significant differences compared to the general population[29].

Lower socioeconomic status, lower income and having financial difficulties were associated with poorer health related quality of life[10,23,30-32]. In contrast, in this PEEK study participants with higher socioeconomic status had worse emotional well-being compared to those with mid to low socioeconomic status, no other significant differences were observed in subgroups for any SF36 domains in this PEEK study. Other studies described that younger age was negatively associated with health related quality of life [30,33], specifically emotional, cognitive and social functioning[34,35], and older age was negatively associated with pain, physical function, and mobility [34-36]. Female gender was negatively associated with health related quality of life [30,37,38], in particular worse physical function [33], in contrast, another study described worse health related quality of life in males. [32]. Having comorbidities in general was negatively associated with health related quality of life[23,32,35,37-43], in particular anxiety and depression[10,17,32,35,40,42,44-49], pain[12,13,35,36,48-50], fatigue[10,12,16,37,46,51], sleep impairments[24,46], poor appetite[37,46], muscle weakness[37], constipation[17], hearing issues[24], obesity[38,52], and erectile dysfunction[53]. Having a relapse and having a recent diagnosis or being in early treatment was negatively associated with health related quality of life[23,35,49,54,55]. Some studies have described poorer health related quality of life for those undergoing treatment [12,40,56], while another study described poor health related quality of life while in active surveillance[57]. In addition, poor health related quality of life was associated with those that had radiotherapy[23,38], those that have had multiple lines of treatment[41], and those that were post treatment[55,58]. A number of studies described that quality of life improved over time in patients that received cancer treatments[32,57,59-61], and for those in remission[41,62]. Physical activity and social support were positively associated with health related quality of life[26,63,64]

Key points

- **Health related quality of life domains that were lower than the Australian population: physical function, role functioning physical and energy/fatigue. Social functioning and role functioning emotional were higher in this PEEK population compared to the Australina population.**
- **Most common comorbidities are sleep problems, back pain, and anxiety**

Risks and Symptoms

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

In this PEEK study, participants had an average of 4 symptoms before diagnosis, the most common symptoms leading to diagnosis were fatigue, back pain and none pain. The most common symptoms experienced overall (that sis not necessarily lead to a diagnosis) were pain in muscle, bone and joint, fatigue, and coughs and breathlessness. In other studies symptoms leading to diagnosis included bone pain, fatigue, headaches, sleep problems, dizziness, weight loss, diarrhea, and emotional problems[20,48,50,65]

In this PEEK study, participants had an average of 5 current symptoms, similar to another study of people with blood cacner that also averaged 5 current symptoms[66]. The most common symptoms reported by participants in this PEEK study included peripheral neuropathy, fatigue, weak or damaged bones, psychological effects, and being prone to infections. Similarly, other studies described common symptoms that people with blood cancer currently experienced. Most commonly these were fatigue, back pain, nerve symptoms, breathlessness, muscle weakness, cognitive problems, emotional problems, infections, sexual dysfunction, diarrhoea and vomiting[13,19,35,48,66-70].

The most important symptoms to control for quality of life reported by participants in this PEEK study were fatigue, pain, lymphoedema, and fertility. The least important were heart problems, memory loss and cognitive function, and effects on bones and joints. Similarly, other studies report pain, and fatigue as the most troublesome symptoms and in contrast to the PEEK study also include cognitive problems[67,71].

Screening and diagnosis

Half of the participants in this PEEK study were diagnosed withing 6 months of noticing symptoms. The most common diagnostic pathway was being sent to a specialist or to an emergency department by their general practitioner. Some were diagnosed during a routine check up unrelated to any symptoms. In other studies, people with blood cancer described delays in diagnosis due to healthcare professional that were unfamiliar with symptoms, delays from referral to specialists, delays from multiple doctor visits and tests[72,73]. Like participants in this PEEK study, other studies described that their diagnosis was unexpected, they were diagnosed through adroutine check up[74,75]

Understanding and knowledge

Absolutely nothing. I didn't even know that, you know, blood cancer could produce the sort of pain and discomfort. I didn't realize that it was blood cancer. My first thought was it's, you know, sort of a a tumor. Like presentation and so I knew nothing. No, no one in my circle of friends or family have had it so I was newbie.
Participant 009_2023AUCRT

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[76,77]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[78,79] 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[80]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[79]. 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[79].

Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

In this PEEK study, more than a quarter of participants had discussions about biomarkers with their doctors. Approximately 21% ad a biomarker test, and about half were interested in having biomarker test if they had not already had one. In another study, people with blood cancer demonstrated knowledge of their test results and the importance of positive laboratory and imaging findings[81].

Support at diagnosis

In this PEEK study, the majority of participants described having enough support and information at diagnosis. Another blood cancer study described that diagnosis was the time when information and support needs were greatest[82].

Key points

- **Participants have an average of 5 symptoms to manage, the most important to control for improved quality of life were fatigue, pain, lymphoedema, and fertility.**

Decision making

Basically, I wasn't presented with options. I was basically told that it was so. Advanced is not quite the right word, but so far along that they had had to hit me with pretty extreme chemo early and and that happened very quickly. I have a little bit of information about what to expect from chemo, but but nothing that you told actually prepares you for how awful that can be the first course of chemo and I've I've had many was absolutely awful and that that sort of they they tweaked it and that made it more manageable so they they they changed the mix of drugs. From the first time. So I didn't have such severe reactions, you know, especially in the stomach and the, you know, nausea, diarrhea, that sort of thing. Because that was truly awful.
Participant 009_2023AUCRT

The decision-making process in healthcare is an important component in care of chronic or serious illness[83]. 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[84,85], 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[86].

In this PEEK study, the majority of participants had no or very little knowledge about their blood cancer at the time of diagnosis. This was also reported in other blood cancer studies[69,72,74,87].

In this PEEK study, participants most commonly described their prognosis in terms of being in remission, specific medical interventions needed to manage their condition, and possible recurrence. In other studies, people with blood cancer described their understanding of prognosis. Similar to the PEEK study, other people with blood cancer described their prognosis in terms of there being no cure and that their condition was chronic[56,74,75,88], they described it in terms of likely recurrence[75,88], that their condition could be managed with treatment [74], or that there was uncertainty around their prognosis[87,89]. Some had difficulty understanding prognosis, especially in terms of the lack of surgical cure[74,87], some misunderstood or over estimated their chance of cure Hermann, #1082;Loh, #1183;O'Donnell, #1127}.

Goals of treatment and decision-making

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[90,91].

Participants in this PEEK study were most commonly presented with one treatment option when first diagnosed, often it was a medical emergency and urgent treatment was required. Some participants were happy to accept the approach recommended by their doctor, others participated in decision making.In other studies, people with blood cancer described varying degrees of participation in decision making from leaving it up to their doctor [82,92,93], shared decision making[93], to full partication in decision making Mian, #1070;Loh, #1183}. The amount of information was important in decision making with some describing not knowing enough to be able to make an informed decision[82], to others feeling confident in decision making because they were well informed[82] Mian, #1070}.

Considerations when making decisions

Look, I think for me, with this, I mean this is the first time I've ever been unwell, so I didn't have any experience to reference it to, which is so important in decision making. You know, what have you done before? Did it work, blah blah. I had nothing at all to reference this to and I was so unwell. I think that I was a very passive decision maker in that process and I really did relinquish my absolute research in that decision making space. I think I really did relinquish my decision making to the professionals around me, but in terms of it retrospectively, if I say it, if somebody said to me now I had to do something, it would be the impact of the treatment on my kids and my partner.
Participant 016_2023AUCRT

In this PEEK study, participants described their considerations when making treatment decisions. The most common considerations were the advice of their clinician, side effects, efficacy, ability to follow treatments, and quality of life.

In other studies, people with blood cancer noted a number of considerations when making treatment decisions. Some consider the efficacy and survival benefit [94-99], the period of expected remission[94,100], the advice of their doctor[92,99], whether the treatment was the standard treatment or if it was personalised [101], how the treatment was admistered and how easy it was to access the treatment [94-96,99,100] and the cost of treatment [94,97]. The impact that the treatment has was an important consideration with people with blood cancer describing taking into account side effects[81,92,94-97,99-101], the impact on quality of life [81,96,98,99,101], the ability to function during treatment[99], and the impact on family[97].

Treatment goals

People with blood cancer have described their treatment goals, often the most important goal was to be cancer free and improve survival[81,89], others want to return to normality or improve quality of life[88], to be able to take part in family life[81], and return to work[81]. Likewise, in this PEEK study, the most common treatment goals described were being cancer free or avoid recurrence, quality of life, and physical improvements.

Participation in decision making

One study described decision making over time, the majority had not changed over time as they continued to take multiple factors into consideration[99]. Some noted changes, because different factors such as quality of life became more important over time or that they were more willing to treat the cancer aggressively to improve their chances [99]. Similarly, in this PEEK study the majority of participants did not change decision making over time.

Key points

- **Participants had little to no knowledge of blood cancer at time of diagnosis**
- **Advice of doctor, side effects and efficacy important considerations for treatment decision making**

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 blood cancer are collected.

Almost half of the Australian population have private health insurance with hospital cover[6]. 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%[6]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

The majority of the participants in this PEEK study had at least some cost burden from their condition. Most commonly this was from having to take time off work, or family members needing to take time off work. Other costs included the cost of treatments, the cost of parking, travel, accommodation to attend appointments. Almost half described that a lot of the cost burden had been absorbed by the public health system. Other studies described the impact of blood cancer on personal finances. A major source of financial distress was the inability to work or having to make changes to work resulting in income loss[87-89,102-104]. Other sources of financial stress were from the costs of treatment, management and specialist appointments [102,105], gap payments from public or private healthcare[102,105], and costs involved with treatment and management such as transport, accommodation and food[102]. Some described needing to get financial support from government or charities[102,105].

I haven't really incurred many costs at all. Some of the medications are little bit pricey, but given the big picture, they're only one $40, $50. My big thing for me is that I've had to leave work. It's just that sense of independence, that's all, but no other costs really that have been of a worry.
Participant 002_2023AUCRT

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of blood cancer

Approximately two thirds of participants in this PEEK study had used allied health to manage their condition. Most commonly they had physiotherapy, advice from a dietician, psychology or counselling, and social work.

Other studies described that people with blood cancer wanted a specialised exercise program for their condition led by a physiotherapist or exercise physiologist, though less than half had access to a allied health professional for physical activity[67], and that only a quarter of people with blood cancer that were in distress received formal mental health treatment[7]

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship[106]**,** and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors[107]**.** In this PEEK study, participants described using physical exercise for both maintaining mental and physical health, as well as maintaining a healthy diet to manage their general health.

In this PEEK study, the majority of participants (85%) had made lifestyle changes to manage their condition, they made 2 changes on average, most commonly exercise diet and reducing alcohol.

Others studies described using diet to manage side effects such as Diarrhoea, constipation , nausea and vomiting[88]. Another study described that very few people with blood cancer did the recommended level of exercise, the level of exercise dropped during treatment but improved when treatment ended though did not reach pre-treatment levels[67].

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Complementary therapies have been reported to be used by between 40% and 80% of people with cancer, with reports of improvements in stress or side effects of treatments[108-111]. In this PEEK study, half of the participants used complementary therapies, most commonly mindfulness or relaxation techniques, massage therapy, supplements and acupuncture.

Clinical Trials

Well, I think new treatments people people should know about new treatments and should know about clinical trials. And probably the best way for this to be done would be via the the treating clinician, but that certainly wasn't how my mine worked. I I had to find out about new treatments, really the breadth of new treatments available. Not that I had to access access in the oven, but I found that out by myself.
Participant 014_2023AUCRT

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.

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 I7 June 2023. The search included any study that included participants with ALL, DLBCL, Mantle Cell lymphoma, and multiple myeloma, was conducted in Australia, and was open to recruitment in the last five years. A total of N studies were identified that had a target recruitment of between 12 and 3000 participants (median=255), there were 22 studies that were international, and 8 studies that were conducted exclusively with in Australia. There were 9 studies that included liver cancer and other conditions. The most common types of studies were investigating drugs (n=22), other studies were investigating radiotherapy (n=3), surgery (n=2), allied health (n=1), imaging (n=1), and registries (n=1).

There were 23 studies conducted in New South Wales, 12 studies in Victoria, 13 in Queensland, 10 in South Australia, 12 in Western Australia. There were no studies conducted in Tasmania, the Australian Capital Territory, or the Northern Territory.

Figure 12.1: Distribution of clinical trials for blood cancer in Australia 2016-2021

Half of the participants in this PEEK study had discussions about clinical trials with their doctor. More than a fifth had participated in a clinical trial, and the majority of those that had not participated would participate if there was a trial appropriate for them.

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.[112-114] 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[112,115].

Side effects of treatment

Debilitating. So you know I probably use examples of nausea, migraine headaches those sort of things. If I was to if those something that would keep me in bed, I'd find that cruciatingly frustrating. But but yeah just it it's the the physical side of those sort of side effects is one thing. Yes, they knock you out and they put you in bed sort of thing, but that's the mental side of things that would would play on me the most in that it's if I'm experiencing severe side effects from my condition, it messes with your hope and your future outlook sort of thing, this and belong into that sort of thing. So it's a mental battle as well as physical.
Participant 019_2023AUCRT

To help inform patient preferences in the blood cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. In this PEEK study, participants described the terms mild and severe side effects. For both mild and severe side effects, participants used specific examples to describe the terms, most commonly using aches and pain or fatigue to describe mild, and nausea or aches and pains to describe severe side effects. Other ways to describe these terms were the impact on daily activities, where mild allowed these activities and severe did not, and the ability to self manage (mild) or the need for medical intervention (severe). In other studies, people with blood cancer described side effects in terms of the impact on ability to work or do usual activities[13,88,116], the impact on quality of life[41,53,116], the duration of side effects[59,65,88,116], and that they considered side effects to be impact physical and mental health [88]. One study described that doctors commonly underestimated the severity of side effects [68].

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[117]. Components of self-management include information, activation and collaboration[117].

Information is a key component of health self-management[118,119]. 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[118,119].

Treatment adherence

No, I've never given up. I've. I've taken it for as long as I've been under orders too. But I have. I have discussed the impact on me with the people treating me and in the case of the thalidomide, you know, I reported the, you know, the rash and I guess it was it could be regarded as a joint decision, but effectively

it was it was his decision really I I I as I said before, I really did as I was told and I think wisely.
Participant 014_2023AUCRT

In this PEEK study, participants described adhering to treatment according to the advice of their specialist or as long as prescribed, they described not giving up on any treatments, adhering to treatment as long as side effects are tolerable, needing to see test results, and as long as the treatment is working. Similarly in other studies, people with blood cancer would adhere to treatments while side effects are tolerable, according to the advice of healthcare team, and if they had enough support while undergoing treatment[120,121].

What needs to change to know that treatment has worked

Yes, if I can do things without being in pain. I mean if I. You know, try and walk too far. I just get very tired and and something starts to wake and I think, oh, that's enough. I can't do anymore now, you know, I just have to stop doing that. I just have to taste myself like I'm, I like working in the garden. And normally I could just work all day in the garden, but now I just do as many things as I can and then I go and take a break and you know, I sort of taste myself.
Participant 012_2023AUCRT

Participants in this PEEK study described what changes they needed to see to know that their treatment is working. Participants described needing to see evidence of stable disease/no disease progression, physical signs and symptoms disappear/reduce side effects, specific symptom reduction and return to day-to-day functionality. This is similar to descriptions in other studies, people with blood cancer described need to see physical improvement, side effects and symptoms[19,65,81], the ability be independent, do normal activities[65], evidence from tests and scans [19,81], and improvements in mental health[81].

Expectations of future treatment

The way it'd be nice not to travel 3 1/2 thousand kilometers for a stem cell transplant. That would be nice. And it would be nice if they make CAR T therapy more widely available.
Participant 022_2023AUCRT

When asked what they would like to see in future treatments, PEEK participants described wanting more affordable treatments, treatments with fewer or less intense side effects, more access to new treatments and clinical trials, and more effective or targeted treatments. In addition, they wanted more choice, transparency and discussions in relation to treatment options. In other studies, people with blood cancer described their expectations of future treatments, these included that new treatments will provide a cure, have greater efficiency and improve life expectancy[81,88,122]. New treatments will be more targeted or personalised, amnd will have fewer side effects[88,122] [81,123]. New treatments will consider the psychological and emotional impact and quality of life[88]. New treatments will be more affordable[88], will be closer to home[65], and have less invasive or time consuming modes of administration[65,88].

Key points
- **Tolerence of side effects is important for treatment adherence**
- **Reduction of side effects and symptoms is an important sign to participants that their treatment is working.**

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[124]. On average, participants in this study had very good knowledge about their condition and treatments, they had a good ability to manage the effects of their health condition, a very good ability to adhere to treatments and communicate with healthcare professionals, and had very good recognition and management of symptoms. Others studies described that people with blood cancer had a good knowledge of their diagnosis, treatment and side effects, and symptoms associated with progression[74,125].

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [118,119]

Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[126-129].

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[130].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[130]. 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[130]. 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[130]. 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[130]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication

You need to be treated as an intelligent human being. I think there's a lot of talking down that goes on. I didn't find that so much with the nurses, just about, they were amazing. They were fantastic, but of course, they can only give out so much information. I definitely thought with the doctors, there seemed to be an assumption that you wouldn't understand what they were saying.
Partcicpant 003_2023AUCRT

In this PEEK study, the majority of participants had overall positive communication, mostly from holistic, two way, supportive and comprehensive conversations. Negative communication was described as communication that was not forthcoming or that was limited in understanding.In other studies, people described good communication as being empathetic and optimistic [87,131], they described feeling equal with their healthcare professional and trusting them, in addition, the importance of having enough time in appointments[131].Some described the value of preparing for medical appointments in improving communication [131], and the benefits included more discussions about end of life care and the improvements in ability to communicate about their condition with their family and friends [131]. Poor communication was described as lacking empathy, lacking time and the inability to ask questions between appointments [87].

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[132]. Participants had good communication with healthcare professionals, they had good navigation of the healthcare system, they rated their care coordination as good, and rated their quality of care as very good.

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange. [133,134]

Expectations of future communication

Almost half of the PEEK participants were satisfied with the communication they had with healthcare professionals. Some would like communication to be more transparent and forthcoming, to have a multidisciplinary and coordinated approach, for communication to be more empathetic, to have more time to meet with their clinician and for communication to be more understandable. In other studies, people with blood cancer described their expectations of future communication. It was important that communication is respectful, had empathy, was in lay language, and took into consideration prvacy and choice[8,82].

Information

Well, mostly for talking to the doctors and the nurses and then also reading the information that they give you and and rereading it and then going through and thinking of questions to ask them and then asking questions. I I look up a bit of stuff online, but I try to go to the things like the. Queensland Health or NSW Health or the ones that are not the other, that are in Australia and that are proper medical ones as opposed to, you know, someone's crackpot theory or whatever, yeah.
Participant 006_2023AUCRT

Participants in this PEEK study described getting information from health charities, books, pamphlets and newsletter, their healthcare team, the internet and from other people with blood cancer. Other studies described information from treatment teams[73,120].

In terms of information that was helpful, PEEK participants found talking to their treatment team helpful, as well as hearing what to expect and other people's experiences. Likewise, other studies described information that was helpful included other people's experiences and information about what to expect[97].

I think the most helpful has been information from people who have also gone through the same thing, and their way of coping and dealing with it, small things like what to eat when you're vomiting. Yes, how you feel and what to expect from that.
Participant 003_2023AUCRT

Participants in this PEEK study most commonly described that no information was not helpful, they also described that worse case scenarios, other people's experiences and sources that are not credible are not helpful. Unhelpful information was described in other studies as information that was out of date[97], conflicting information [97,135], that used medical or technical language[97], that described worst case scenarios[69,135], and healthcare professionals that do not have time or answer questions[69,97].

In terms of information format preferences, people in this PEEK study had a preference for talking to someone, online information or a combination of both, written information was also a preferred format for some participants. Talking to someone was preferred because it enabled time to ask questions, it was personalised and relevant, and was supportive. Online information was preferred because of accessibility, it can be personalised and relevant, and allows for information to be digested at their own pace. Written information was preferred because it is easy to refer back to. In another study, most people with blood cancer described preferring to talk to someone to get information, other forms of information were also popular, including the internet, printed materials, and attending information sessions[136]. Other studies described reasons for information preferences, a preference for speaking with some one was because they can ask questions, the information is personalised and relevant[73,97], and a preference for written information because they can refer back to it, take time to digest information at own pace, add notes and help prepare for appointments[82,97].

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Expectations of future information

Peek participants wanted future information to include more details about disease trajectory and what to expect, the ability to talk to/access to a health professional , more details about new treatments and clinical trials, more details on subgroups and specific classifications of their condition information in a variety of formats and for information to be more accessible and easy to find. In other studies, people with blood cancer described their expectations of future information, they described the need for more information about the following topics; what to expect including treatments, side effects and symptoms, and costs[8,82,97,136-138], psychological care [82,136,137], lifestyle factors including diet and exercise[136], complementary therapies[136], and peer support[82,137].

Care and support

The main support for me has been my family, just with taking me to appointments and to the clinic and when I had to go to hospital and things like that. I haven't had any help from outside organizations. I've had a few good friends that have come over to help me when I needed help, but other than that, we pretty much looked after ourselves.

Participant 002_2023AUCRT

Participants in this PEEK study described the support they had received for their blood cancer. Most commonly, participants had support from charities, they also found support in the clinical setting and from family and friends. The types of support included accommodation while having treatment, domestic services, financial advice and transport. There were some that did not get any support, that did not need any support, and others described the challenges of finding or accessing support. In other studies, people with blood cancer described getting support from peer support[139,140], their clinical team[73,87,140], and from family and friends [69,73,87]. The type of support included information, emotional support, and support attending appointments[26,87,139], some described finding it difficult to find appropriate support[139,140].

Expectations of future care and support

Almost a third of PEEK participants were satisfied with the care and support received. Some would like future care and support to include a multidisciplinary and coordinated approach, they would like more access to services, more holistic care and support, more peer support and more practical support.In other studies, people with blood cancer described their expectations of future care and support, this included developing a care plan for future[141], access to allied health to manage symptoms[82], and the need for help accessing and navigating healthcare services [82]. They described wanting practical support, including financial help[14,75,123], and assistance with transport and overnight accommodation[82]. Others described the need for emotional support for themselves and for their families, and the need for peer support[14,82,123,141].

Anxiety associated with condition

I'm about 130 days post-transplant. I attended the clinic last week, they told me that I'm in remission or have 100% of my donors DNA. They're very happy with my results, but me as a person, I'm feeling very vulnerable, because up until a month ago, I was going to the clinic every Monday and having blood tests, and then it progressed to every fortnight. I only had one fortnightly visit and now I'm on monthly. I'm feeling really vulnerable about if something happens in between visits, because I don't know what signs to look for. I think from what I've been talking to people, that it's quite natural to feel that way.
Participant 002_2023AUCRT

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[142].

In this PEEK study, anxiety associated with blood cancer was measured by the fear of progression questionnaire[143]. 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 low levels of anxiety. A couple of studies reported that women had more anxiety about their condition compared to men[33,39]. In this PEEK study, there was no significant difference in the fear of progression total score by gender, younger participants had significantly more disease related anxiety compared to older participants, and those that lived in areas with higher socioeconomic status had more disease related anxiety compared to those that lived in mid to low socioeconomic areas.

Participants in this PEEK study described feeling vulnerable during or after treatments, when experiencing side effects, when having sensitive discussion, and because of interactions with their medical team. In addition, they were most often concerned about disease progression, not being able to achieve professional and personal goals, symptoms and side effects and long term damage from treatments. In other studies, people with blood cancer described anxieties surrounding their blood cancer. A major cause of anxiety was the fear or recurrence[9,74,82,87,135,144,145], in addition, uncertainty about survival[70,81]. Side effects and symptoms were also a cause of anxiety due to the impact on day to day life and the fear that it signifies a recurrence or progression[88,116,135,144-147]. People with blood cancer worried about whether their treatment was working[146], undergoing treatment and going to hospital[145], waiting for results [73,135], and transitioning from patient to survivor [135].

Quality of life

No now, but I would say during the time of treatment, because I was very tired. I wanted to keep doing so much of everything that I had done prior to, but I couldn't keep up with my active children. I couldn't keep up with going out for dinners or going away on weekends. I was just too tired. When I'd go away, I'd have to take my medication with me or check my temperature. I couldn't eat certain foods. I tried not to let it get me down, but at times it would. I just used to think, "Well, it's only a short term thing. Hopefully everything goes well for long term gain." Over that period, that was very draining.
Participant 001_2023AUCRT

The majority of PEEK participants described a negative impact on quality of life from blood cancer. The impact was from the emotional strain on their family, having to manage side effects and symptoms, and having reduced social interactions. In other studies, people with blood cancer described the impact of their condition on quality of life. An important theme was the burden of living with side effects and symptoms which impacted many aspects of their life[20,88,89,105,135,140,146,148].[102] [71,75,81]. They described the changes to work or education[71,75,82,105,135], theoir ability to take part in family life[20,140,145,147], to conduct daily activities and household tasks, [20,30,88,89,102,145] [65,71], their ability to take part in activities they enjoyed such as hobbies and sports[30,65,71,89,102,116], and feelings of isolation and inability to take part in social activities[30,65,140,145]. Some described the negative impact that the burden of treatment had on quality of life[20,140,148].[102], and costs associated with treatments and not being able to work[105,135,147]. PEEK participants also described positive impacts from supportive relationships and bringing people together.

Activities for mental and physical health

Well, take medication, keep exercising. I still have to be very aware of who I'm mixing with because I'm sorry, I am off immunosuppressants now, but I'm still, I don't have that immunity yet. I'm also, I haven't been vaccinated for, and I can't have for quite a while yet any of the live vaccines. So I have to be very aware of besides from COVID but I don't go near anyone who may have or be carrying chicken pox, measles, mumps or Bella anything like that. So you have to be a lot more careful. I'm a lot more limited in what you do and and I'll find even before COVID well I was wearing the mask so that was a a limiting thing and I'm just trying not to get too close to people sort of always if you're out somewhere and. You need to get to the other side of the park and there's a group of people there. You're always looking at ways to walk right away from people and not close to people. So yeah, so just things like that. Not not big, major things, I suppose.
Participant 006_2023AUCRT

In this PEEK study, participants described the activities they do for their physical and mental health. They described the importance of being physically active, complying with treatment, self care (more rest, accepting help and pacing themselves), understanding their limitations, maintaining a healthy diet, mindfulness or meditations, socialising with family and friends, hobbies, consulting a mental health professional, and maintaining a normal routine. This similar to what has been reported in other studies people with blood cancer; the importance of social support, family and friends, and engaging in activities and remaining social[89,145,149], others the importance of routine, normality, keeping busy and distracted[89,135,145,149], and of mindfulness, spirituality and accepting their condition Koll, #1166;Crowder, #1156;Hermann, #1082;Maatouk, #1085;Raphael, #1111}. People with blood cancer described the importance of adhering to their treatment, seeking medical attention, and being informed about their condition Crowder, #1156;Andres-Jensen, 2020 #1048;Raphael, #1111;Hermann, #1082;Koll, #1166}, and others had made lifestyle changes including diet, exercise, reducing alcohol and quitting smoking to maintain mental and physical health[116,145,150].

Burden

Well, probably not not as much now as it was. I mean it definitely was when I was was really unwell because they had to do everything. Now it's more just I suppose they've got that extra burden of they've just got to make sure that they don't get me sick or. That sort of thing, just just being more careful with with those things. So I have to remind them and I have to make sure and say okay, yeah, well, yes, we know we've been vaccinated for chicken pox, but they could still get it slightly and pass it on to me. So I have to be very aware of that. But I'm not a burden now in that, yeah, I cook, I cook, I cook the meals, I clean the house. I yeah. Go with my husband for his appointment. So I do whatever. So I'm I'm sort of almost almost normal, just with just the fact that I'm more tired and have to be a bit more cautious with stuff.
Participant 006_2023AUCRT

The majority of participants in this PEEK study felt that their condition was a burden on their family, for some, this was temporary or only during treatment. For others, the burden was from the mental and emotional strain place on their family, and the extra household duties and responsibilities that their family must take on. Likewise, other studies describe the emotional impact on family [89,146], and the extra responsibilities others took on and having to rely on others[140,146]. In one study, participants noted that they did not want to be a burden and worried about being able to look after themselves[87]

Relationships

I don't think so. They, my siblings worry like crazy and. Some of our friends do worry, no matter how I try to assure them not to. So it's that's nice. Sometimes it's it's too much. But the attention. But I keep saying I'm not going to die, I'm not going to die. I'll let you know if I'm going to die. My brotherinlaw had Hodgkin's died last year from really the side effects of all the treatments he had 40 years ago. Years ago, his heart gave out, his arteries, gave out everything just but he had a good life and he was well all that time. So yeah, it's it's nice that that they care so much.
Participant 036_2023AUCRT

PEEK participants described a mix of positive and negative impacts on relationships as a result of their diagnosis. Positive impacts included family relationships being strengthened, and well-meaning and supportive relationships. Negative impacts were from dynamics of relationships changing due to anxiety, exacerbations or physical limitations of condition, and from suffering, that is people not knowing what to say or do and withdrawing from relationships. In other studies, people with blood cancer described the negative impact that blood cancer had on their relationships. This was from people being dismissive or not understanding their condition, especially when in remission[69,116], being socially isolated because of treatments, side effects and risk of infections[71,88,116,138,146], not being able to fully participate in family life[138], and the financial impact[102]. Some described that their condition had brought their family and relationships closer together[102].

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

Information
This is a cohort that accessed printed information from charities and from the hospital or clinic where they were being treated. They valued being able to talk to a healthcare professional as this gave them the opportunity to ask questions. It is important to this community to have up to date printed materials, relevant to their specific type of blood cancer. Question prompts in printed material may also be of value to increase conversations about all available treatments.

Managing side effects
This is a group where side effects were important in decision making, adherence, and minimising side effects was an important treatment goal. Side effects had a negative impact on quality of life, relationships and made people with blood cancer feel vulnerable. Support and information to help manage side effects and access to treatments with fewer side effects may have a positive impact on quality of life. This may be achieved by increased awareness and access to allied health professionals given this cohort, on average, accessed only one allied health service.

Impact on daily life
Participants in this study had to quit, reduce hours, or take leave from work. Carers and family took leave with and without pay. The loss of family income was an extremely significant burden. CAR-T treatable blood cancers are characterised by fatigue and exhaustion, with treatments taking up a significant amount of time for patients who may need to interrupt family life or stop work to accommodate this. This domain of a patient's life needs to be recognised and addressed through appropriate, practical support services.

2023 PEEK study in blood cancer

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2023 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 blood cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	68.68	72.50*
	Role functioning/physical	51.47	50.00*
	Role functioning/emotional	70.59	100.00*
	Energy/fatigue	52.50*	50.00
	Emotional well-being	76.24*	80.00
	Social functioning	73.90	75.00*
	Pain	69.56	72.50*
	General health	53.38*	55.00
	Health change	67.65	62.50*
Knowledge of condition and treatments (Partners in Health)	Knowledge	27.58	30.00*
	Coping	16.61*	18.00
	Recognition and management of symptoms	20.71	22.00*
	Adherence to treatment	15.16	16.00*
	Total score	80.06	85.00*
Care coordination scale	Communication	45.18*	47.00
	Navigation	27.09*	28.00
	Total score	72.27*	72.00
	Care coordination global measure	7.94	8.00*
	Quality of care global measure	8.85	9.00*
Fear of progression	Total Score	30.82	28.50*
		Percent	
Accessed My Health Record	-	51.52	-
Participants that had discussions about biomarkers/genetic tests	-	27.03	-

*Best measure of centrality