Summary of results

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.

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%).