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

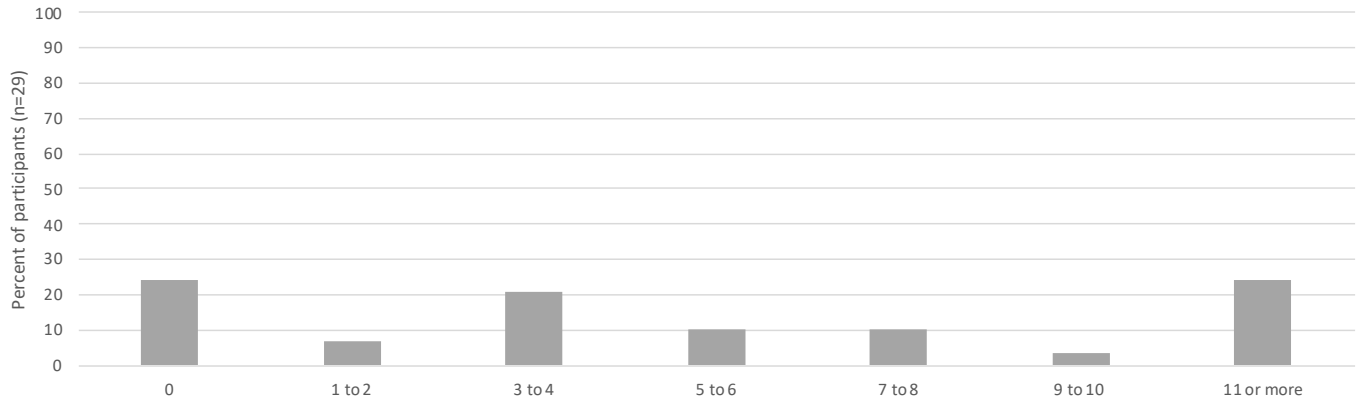

Figure 3.1: Number of symptoms per participant

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

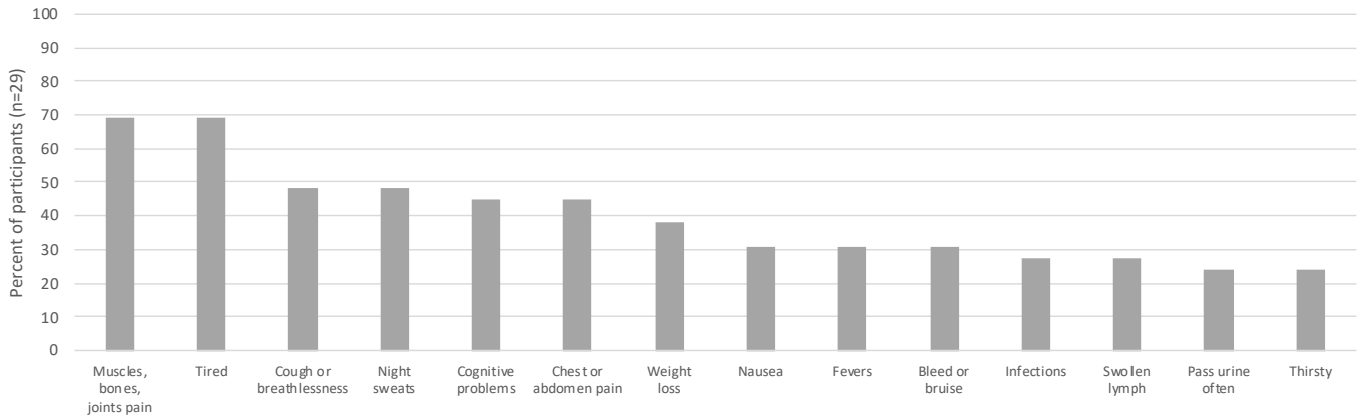

Figure 3.2: Symptoms before diagnosis

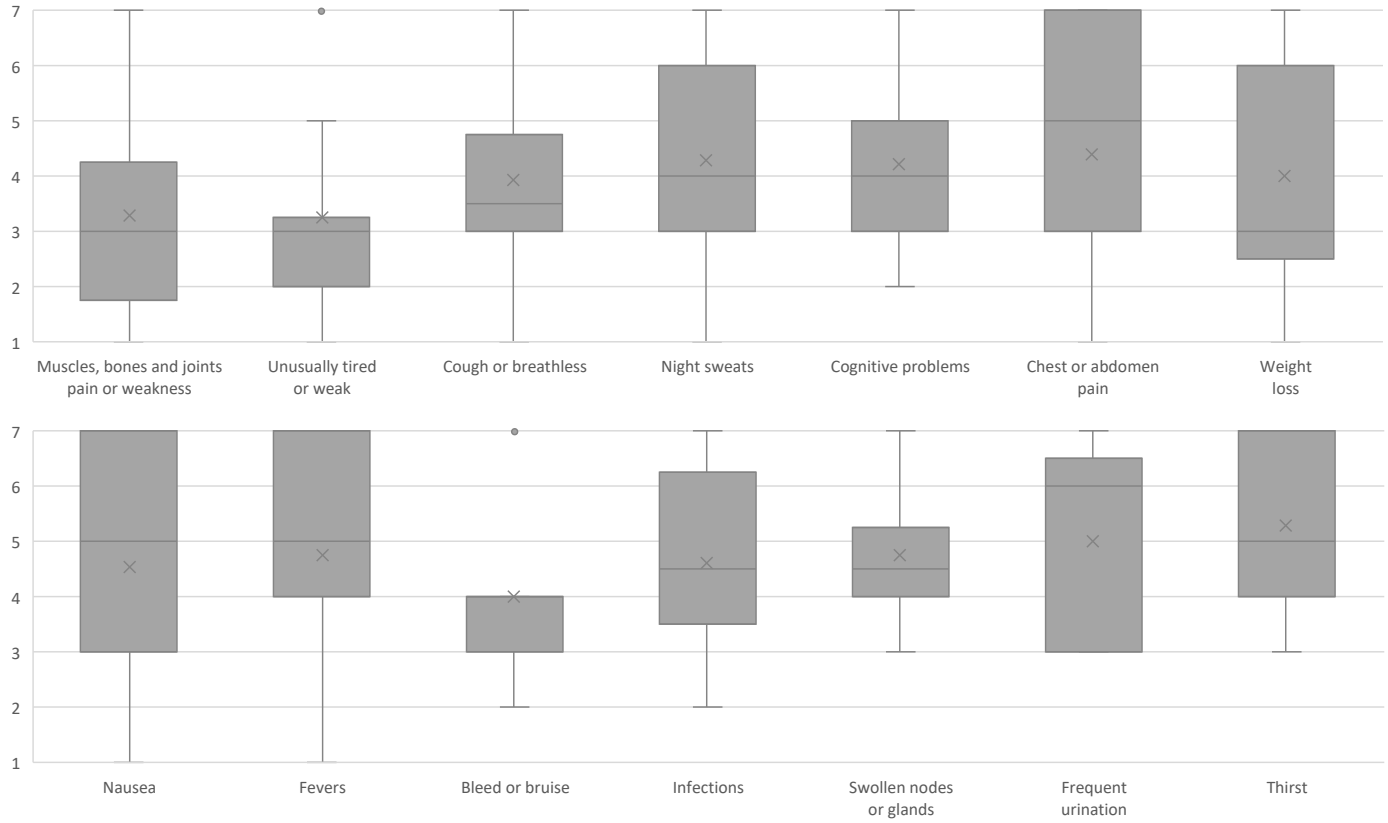

Figure 3.3: Quality of life from symptoms before diagnosis

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

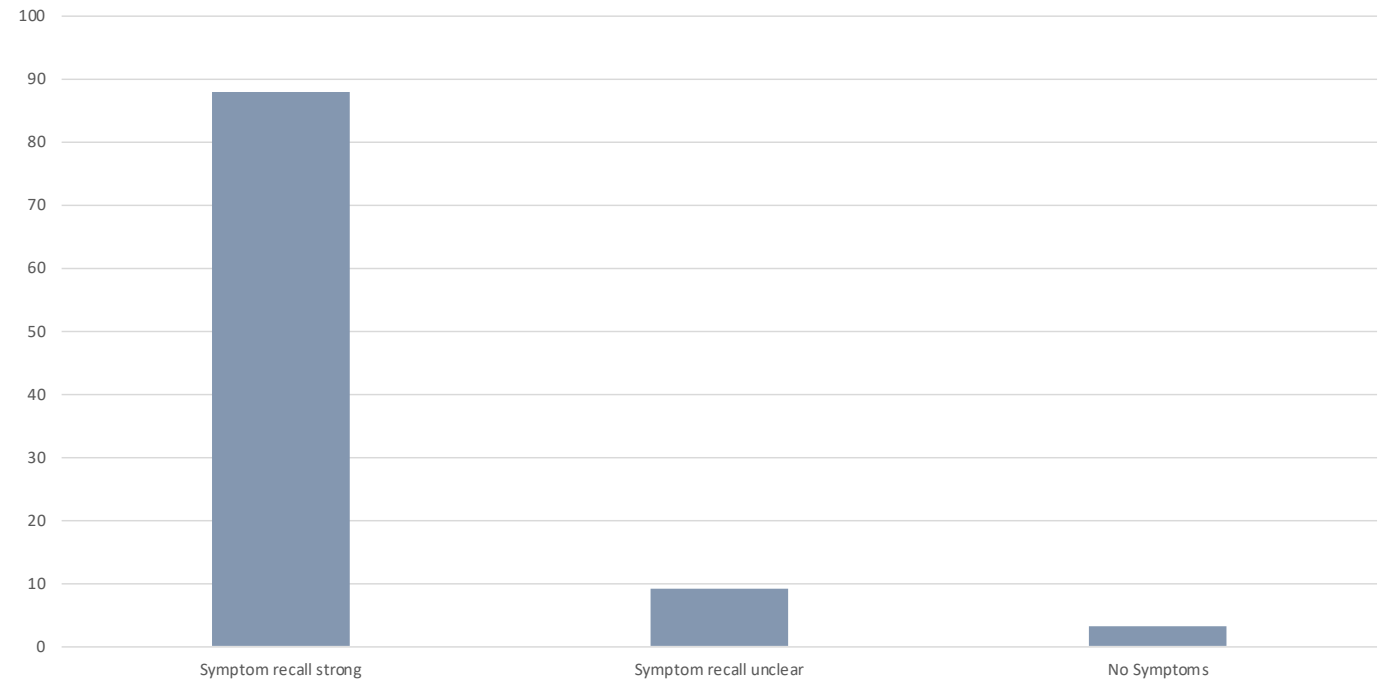

Figure 3.4: Symptom recall

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

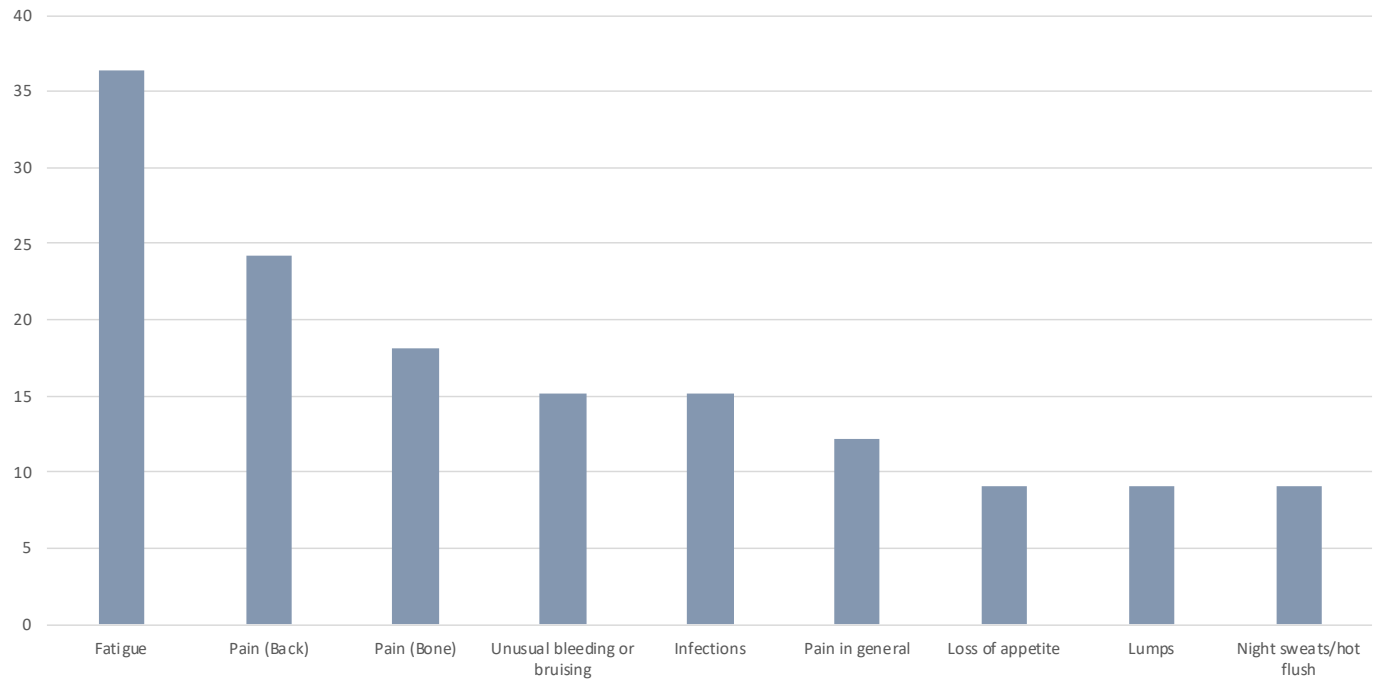

Figure 3.5: Symptoms leading to diagnosis

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

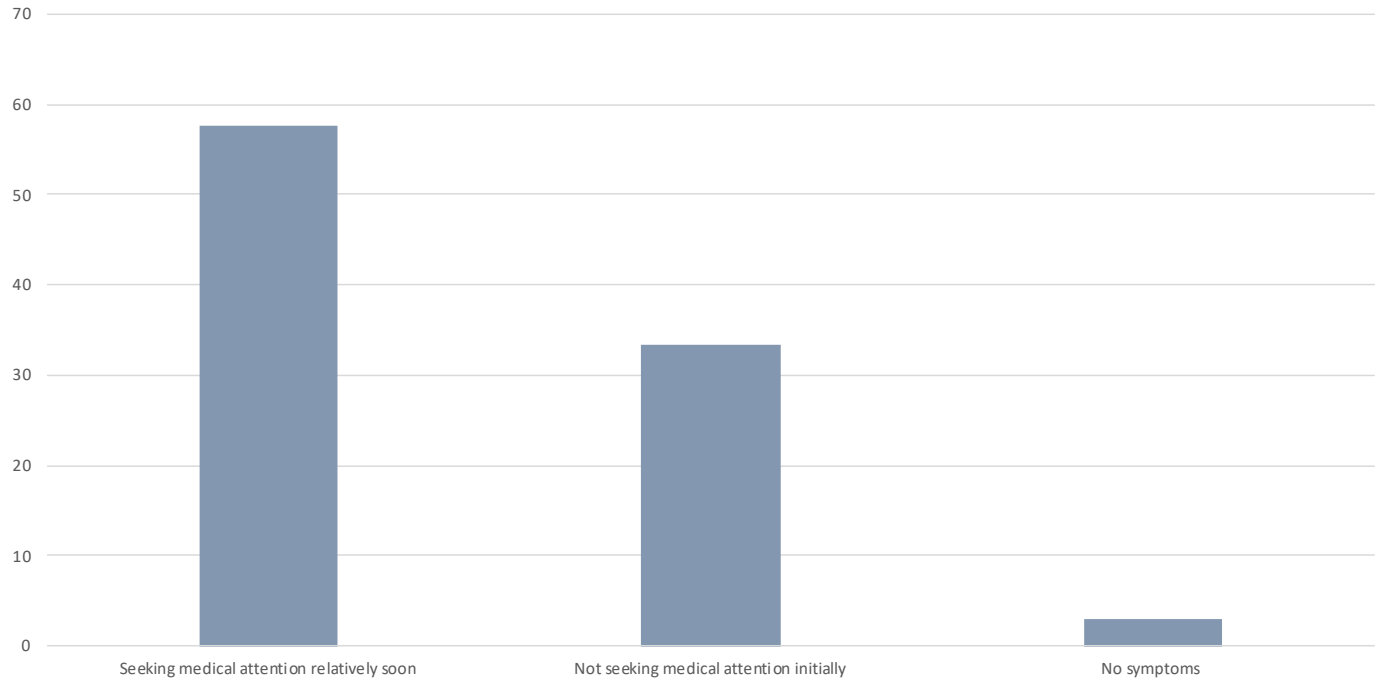

Figure 3.6: Seeking medical attention

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

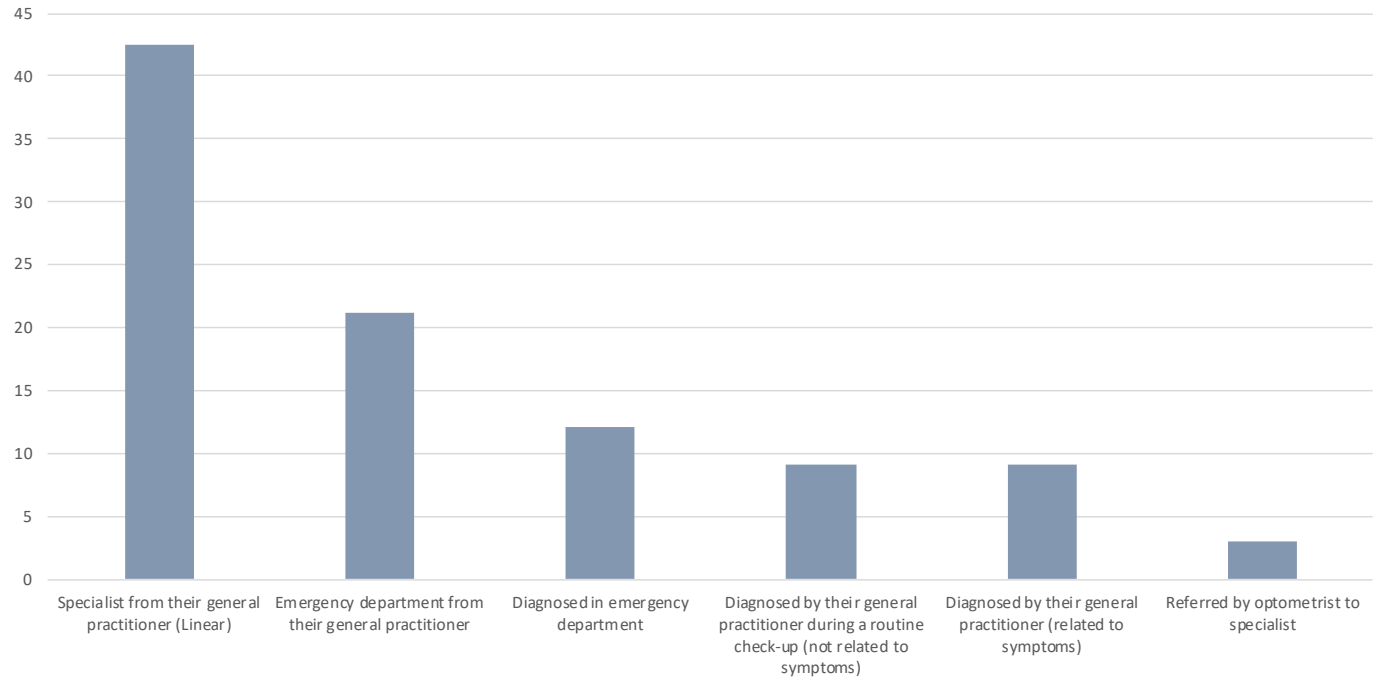

Figure 3.7: Diagnostic pathway

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

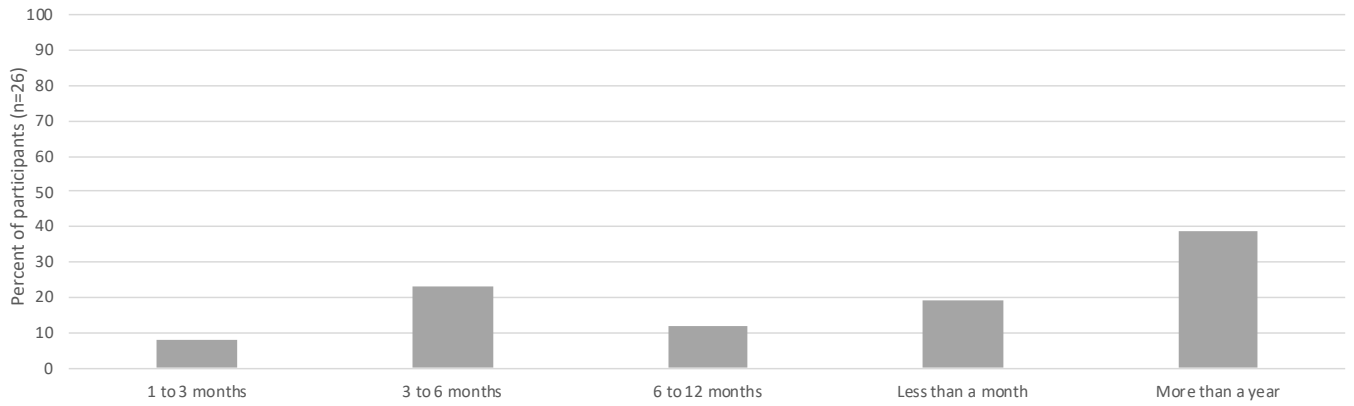

Figure 3.8: Time from symptoms to diagnosis

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

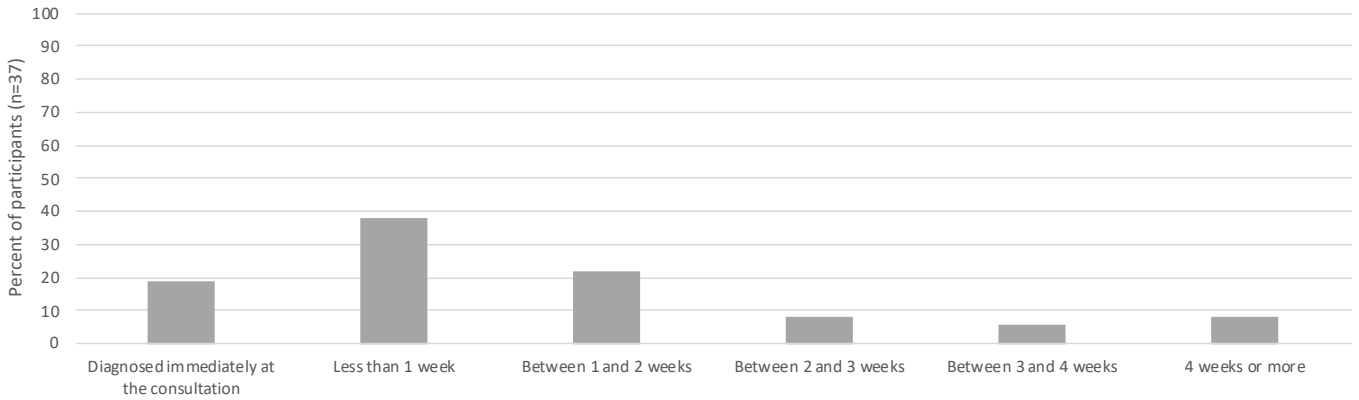

Figure 3.9: Time from diagnostic test to diagnosis

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

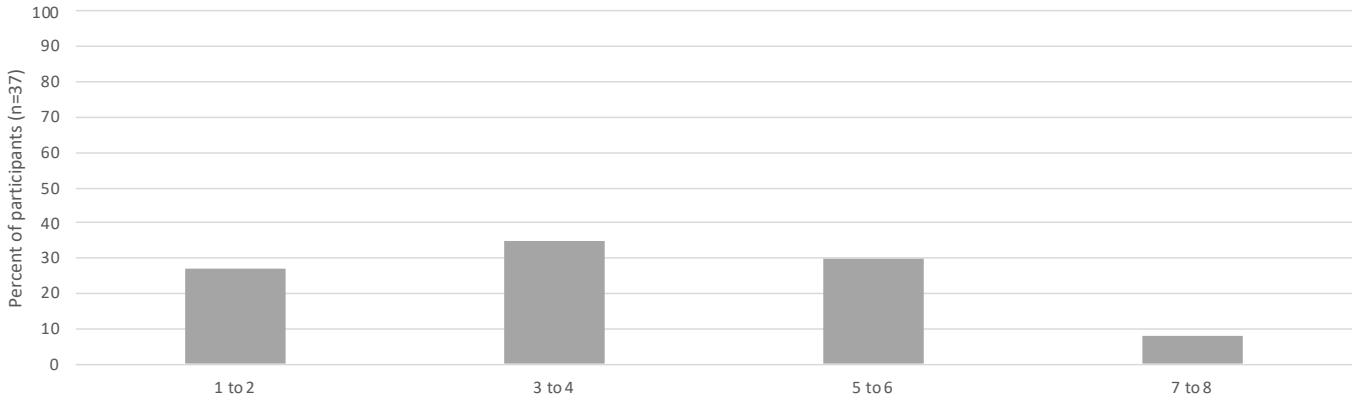

Figure 3.10: Number of diagnostic tests

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

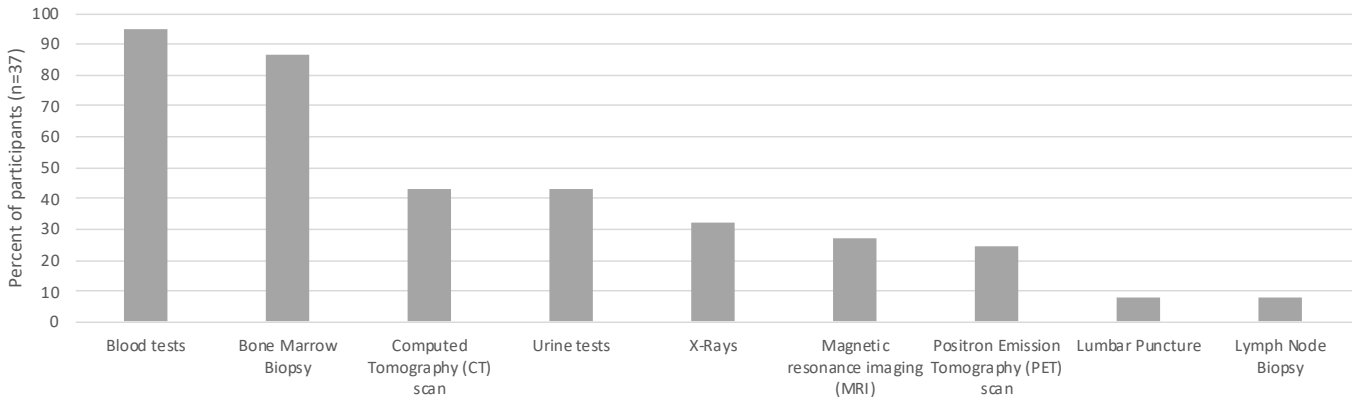

Figure 3.11: Diagnostic tests

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

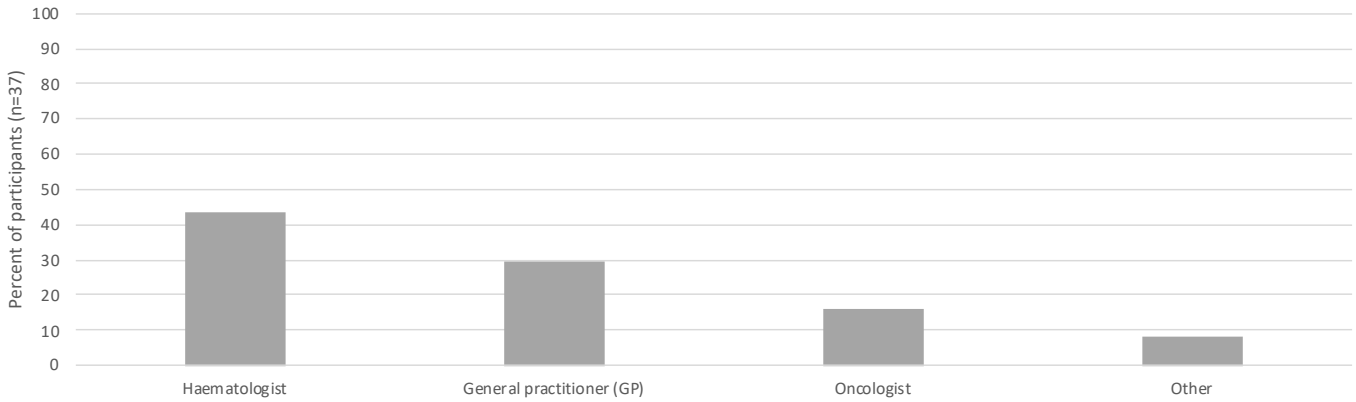

Figure 3.12: Diagnosis provider

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

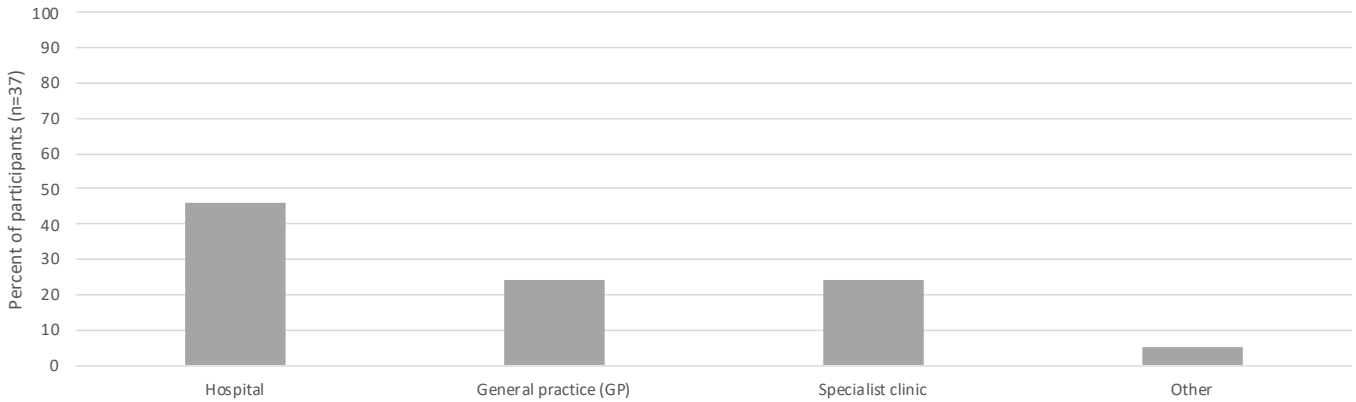

Figure 3.13: Diagnosis location

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

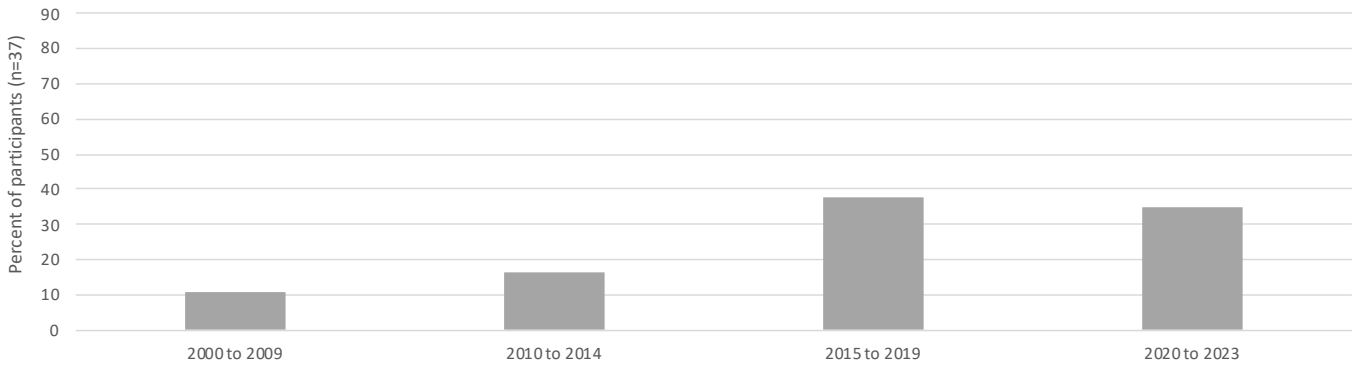

Figure 3.14: Year of diagnosis

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

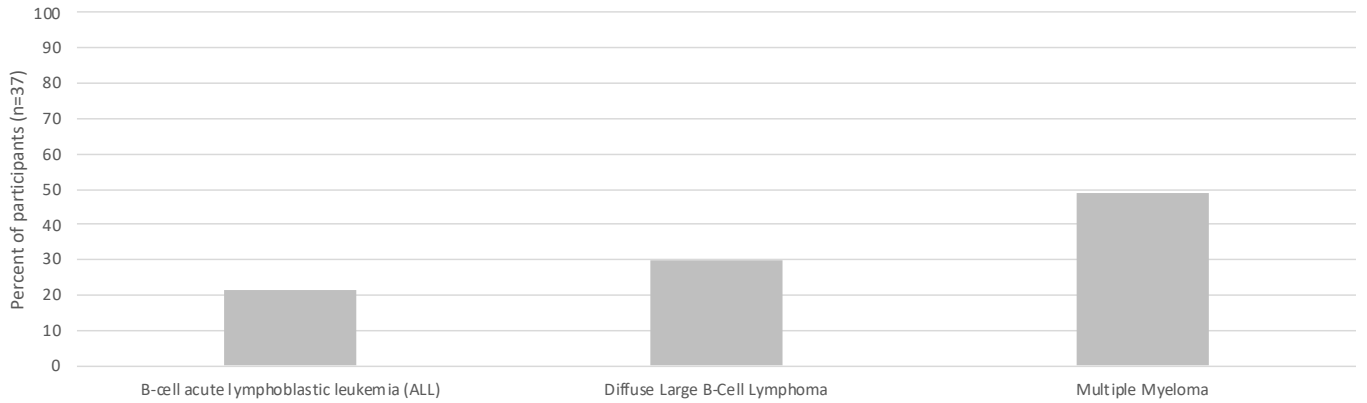

Figure 3.15: Type of blood cancer

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

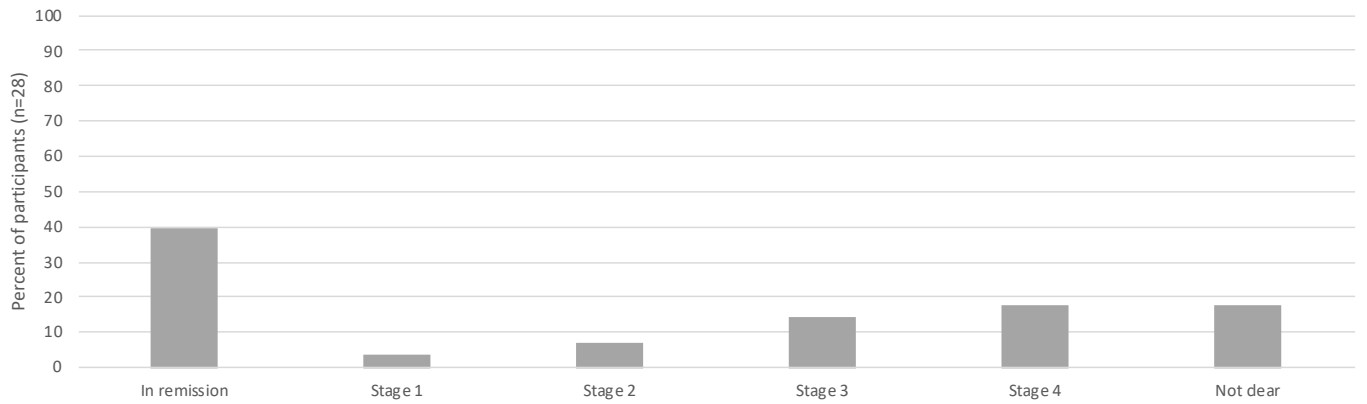

Figure 3.16: Blood cancer stage

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

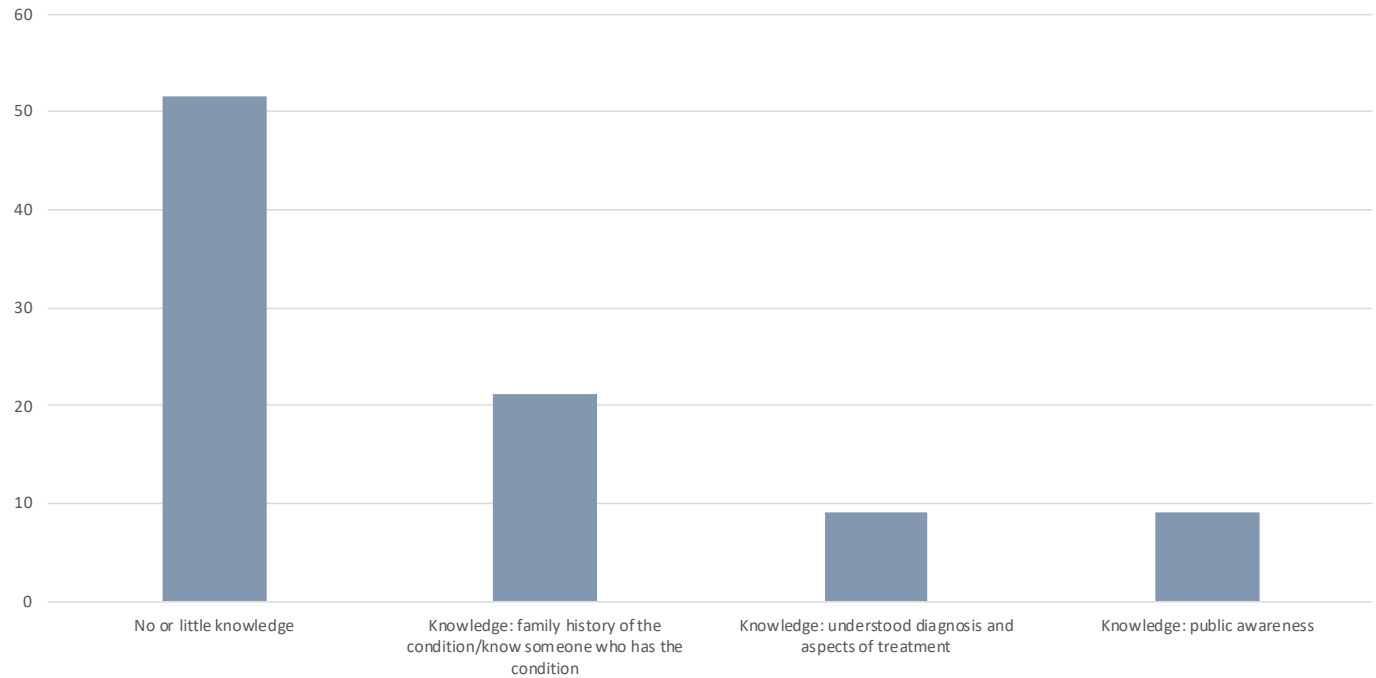

Figure 3.17: Understanding of disease at diagnosis

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

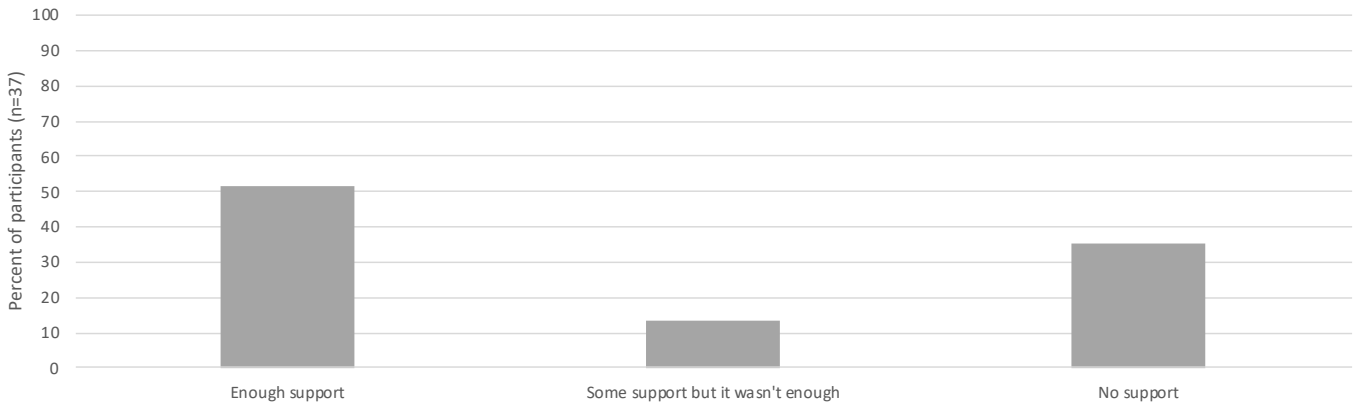

Figure 3.18: Emotional support at diagnosis

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

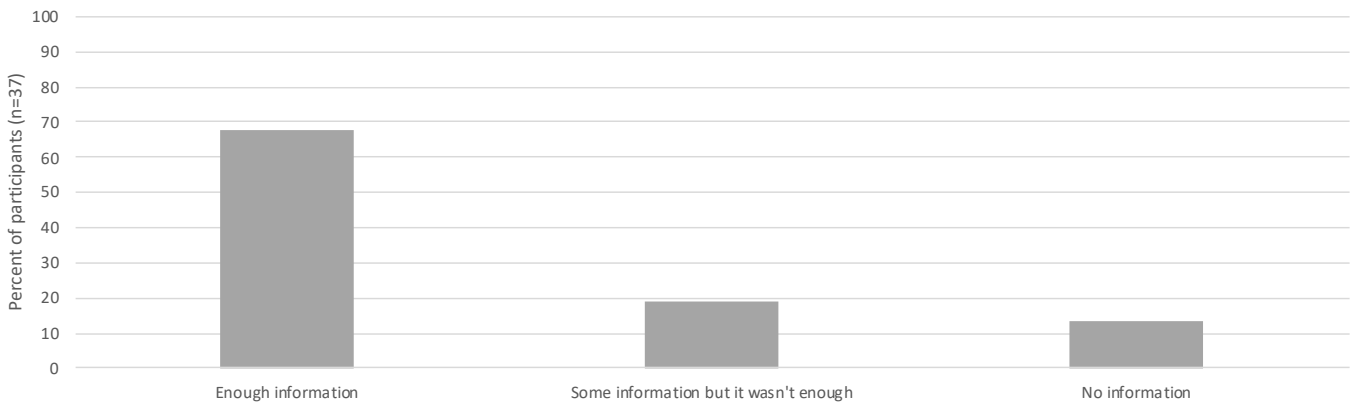

Figure 3.19: Information at diagnosis

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

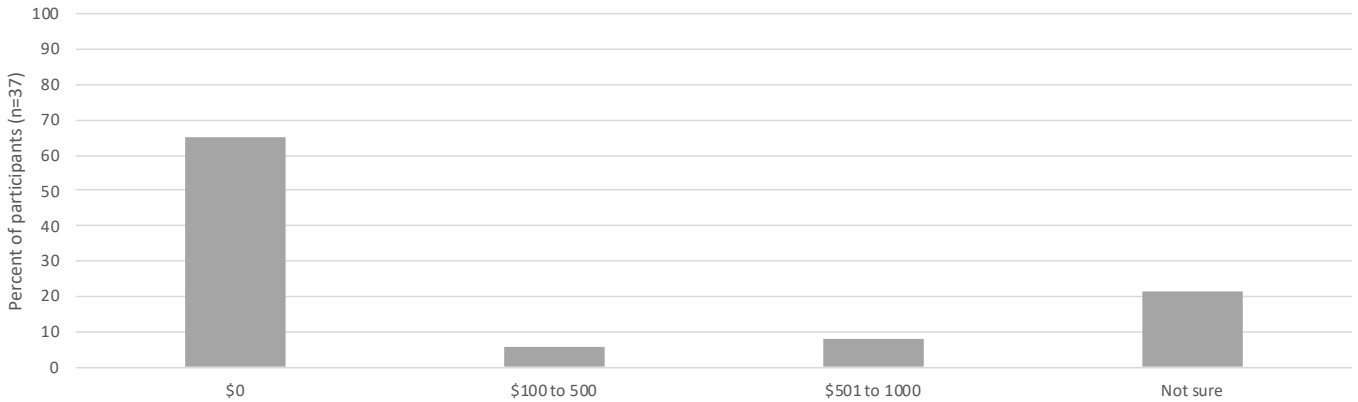

Figure 3.20: Out of pocket expenses at diagnosis

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

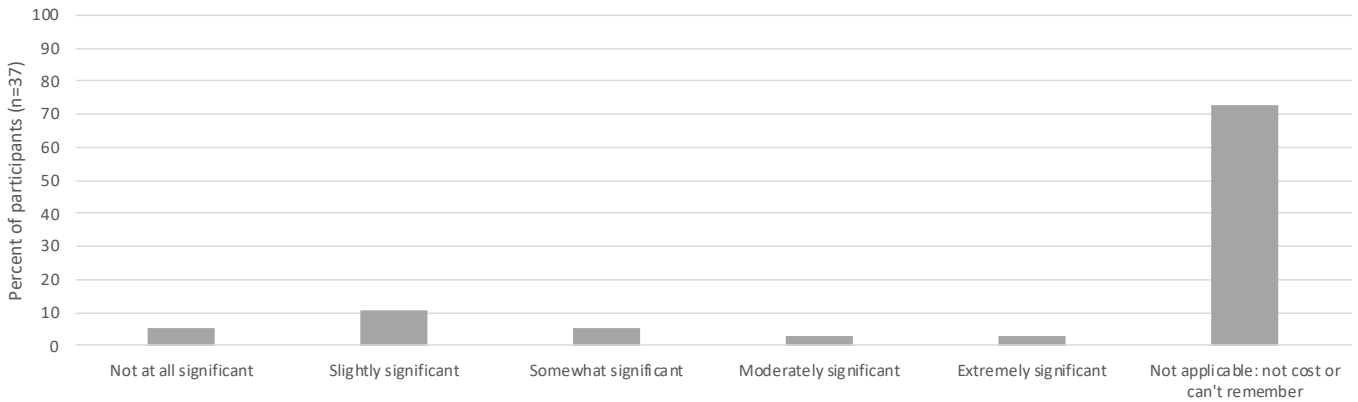

Figure 3.21: Burden of diagnostic costs

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

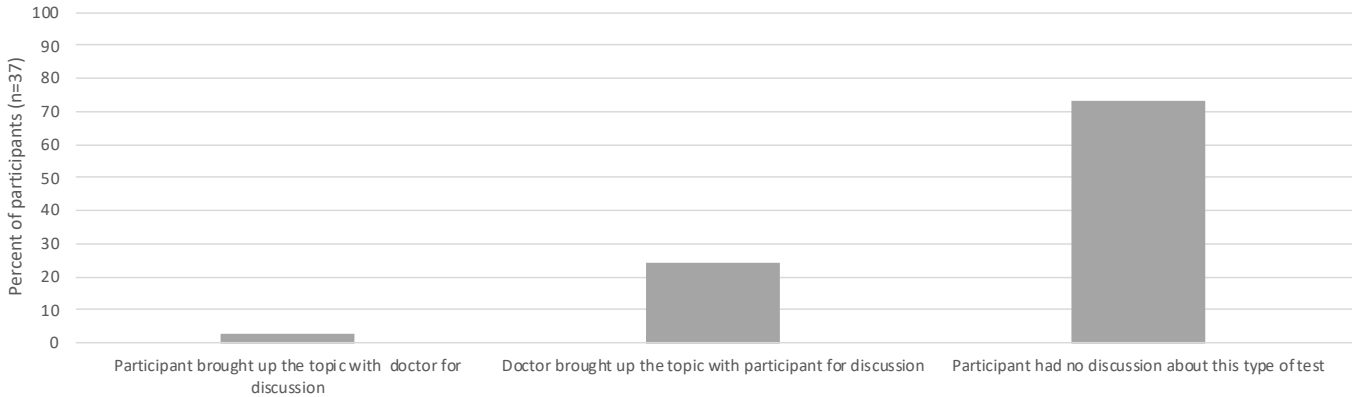

Figure 3.22: Discussions about biomarkers

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

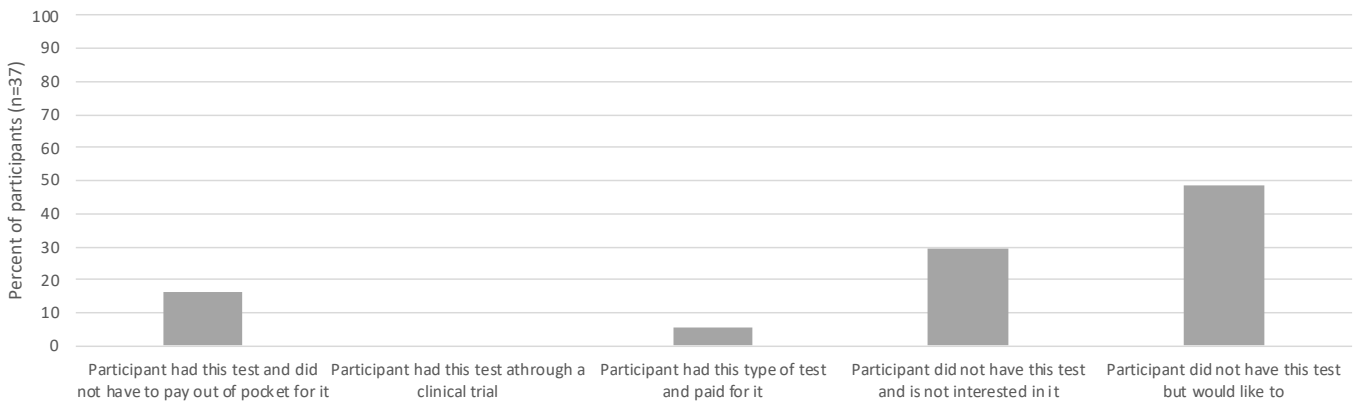

Figure 3.23: Experience of genetic tests and biomarkers

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

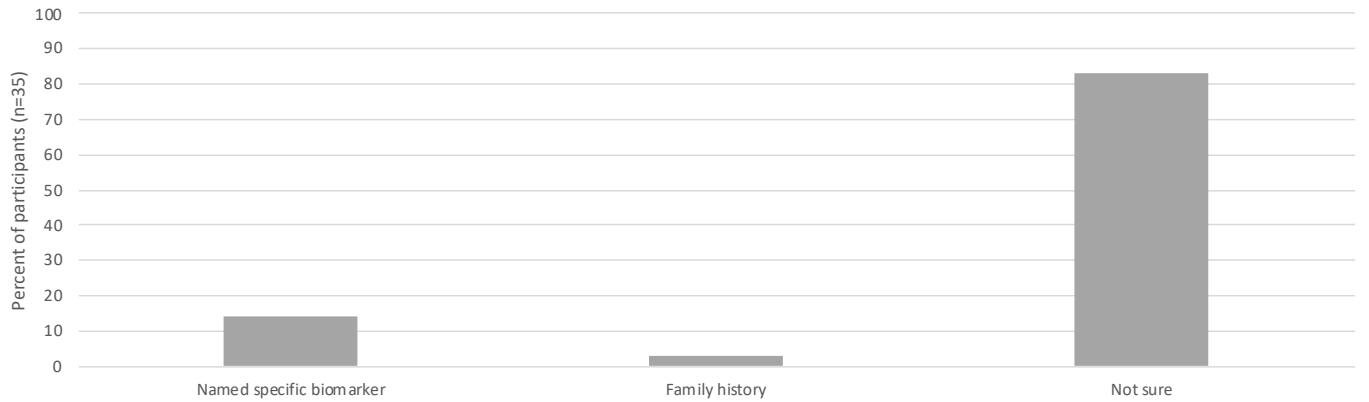

Figure 3.24: Biomarker status

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

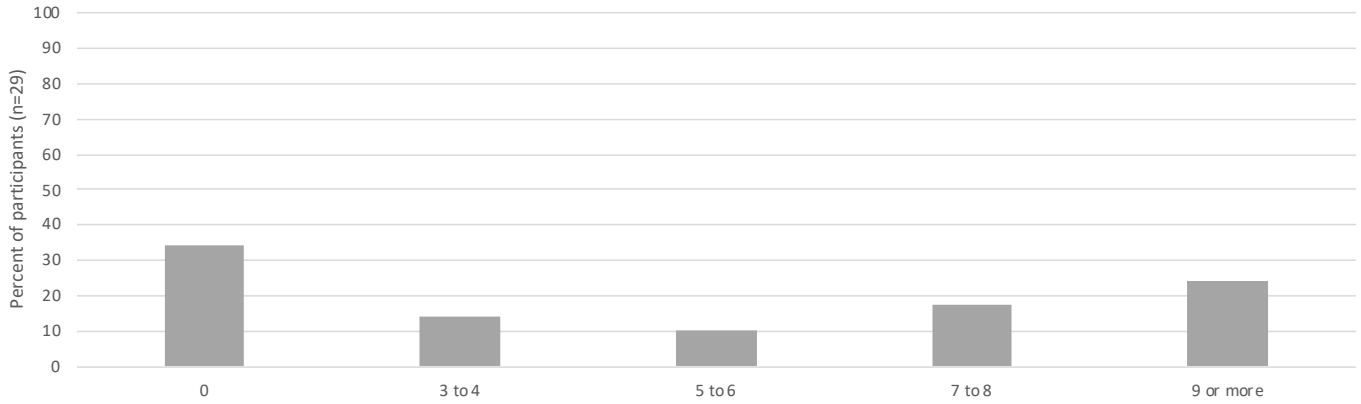

Figure 3.25: Number of current symptoms

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

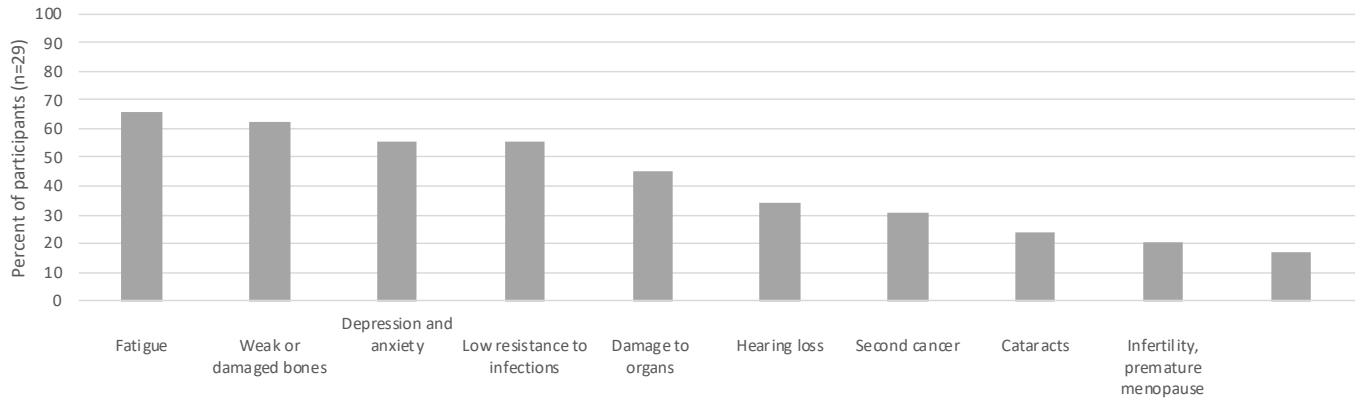

Figure 3.26: Type of current symptoms

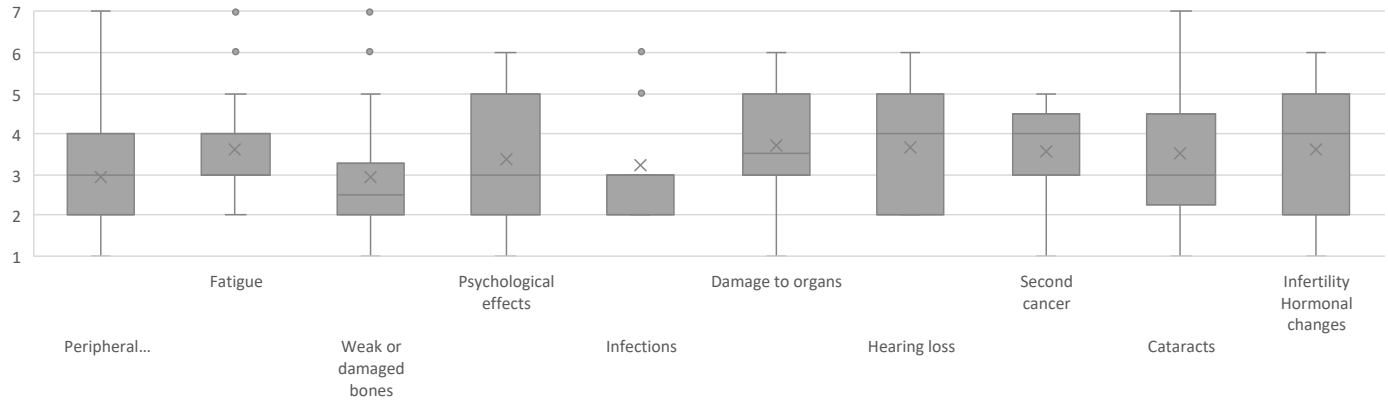

Figure 3.27: Quality of life from current symptoms

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

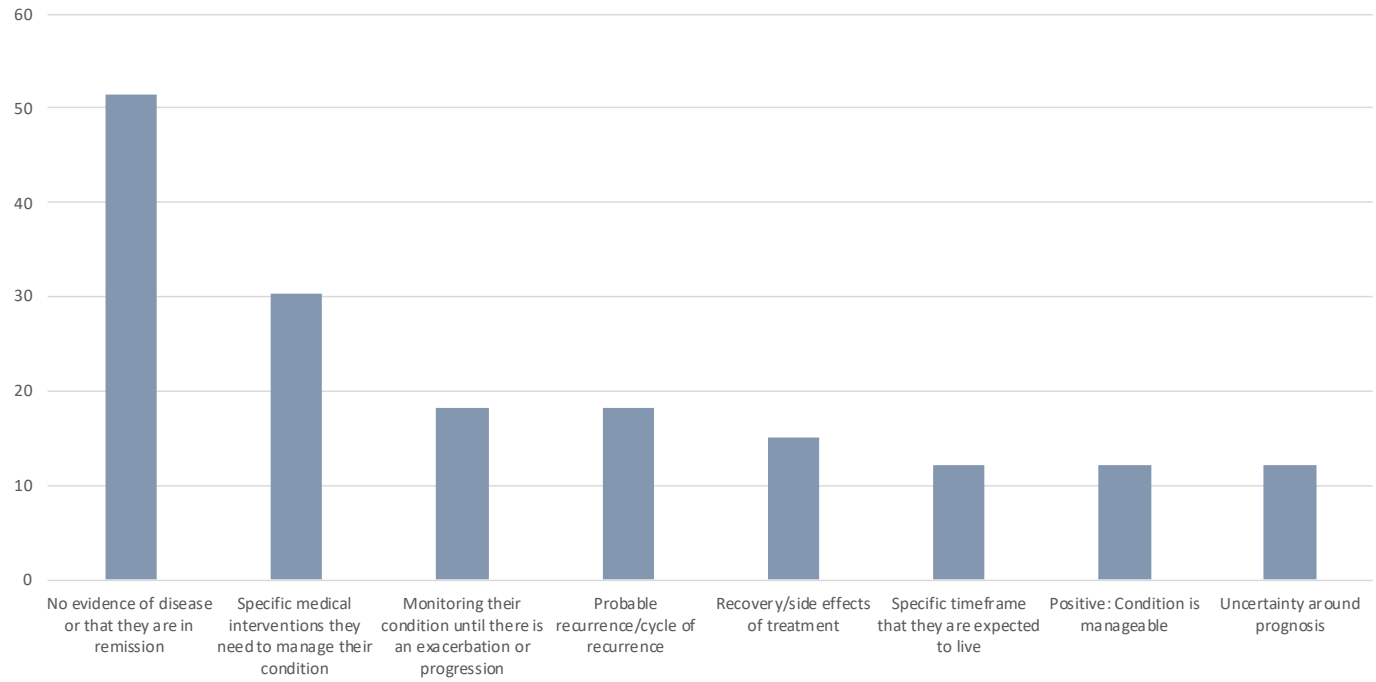

Figure 3.28: Understanding of prognosis

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