PERSONAL EXPERIENCE EXPECTATIONS KNOWLEDGE

PEEK

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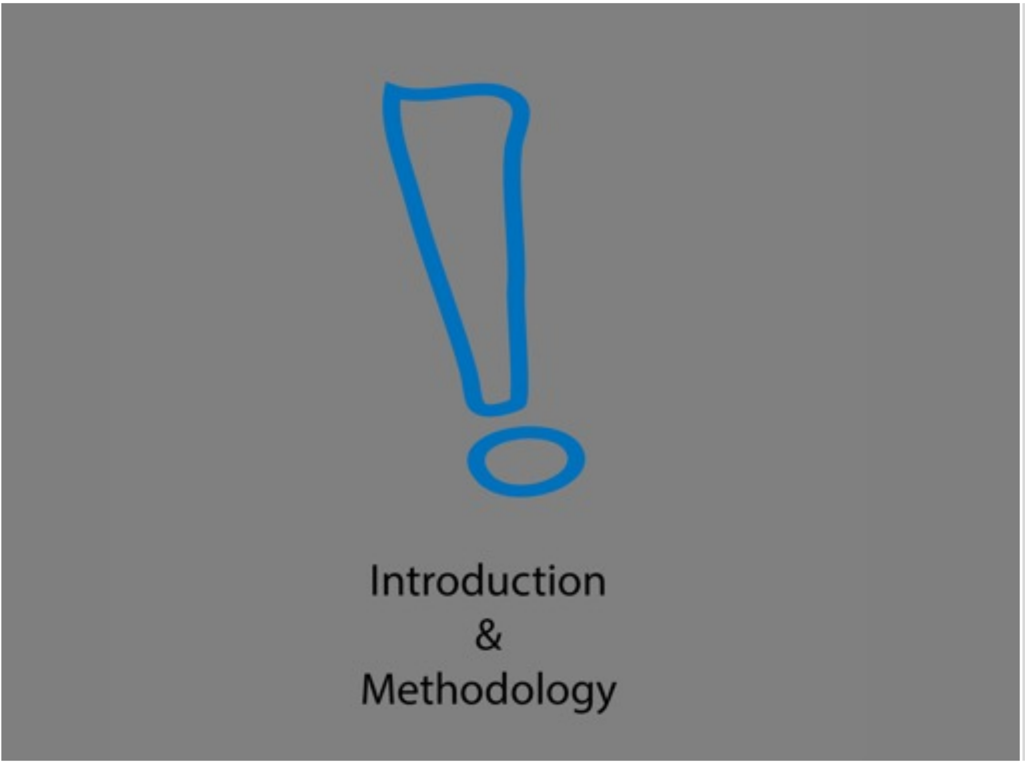
CAR-T treatable blood cancers AUSTRALIAN STUDY 2023

Section 1



This is where you can read about the PEEK methodology, information about the recruitment period and approach.

There is also a review of other mixed methodology studies in the field to identify the position of the PEEK study in the context of other literature. PEEK studies are often the largest of their kind in depth and participant numbers.

Full Report
Summary of Results
Infographic
Slide Set
Introduction & Methodology
Demographics
Symptoms & Diagnosis
Decision-making
Treatment
Communication & Information
Care & Support
Quality of Life
Expectations & Messages to Decision-Makers
Advice from current patients to patients in the future
Discussion
Where to from here?

The Centre for Community-Driven Research team for this study included:

Kate Holliday, Anne Holliday, Sara Riggs, Fay Miller, Ashlee Osborne, Belinda Zheng, Monica Mann, Rosealie Southwell, Nicole Fidock

This study was generously sponsored by Gilead Australia.

Gilead Australia provided arm's length sponsorship for the Centre for Community-Driven Research to report on the PEEK protocol data for people who have been diagnosed with CAR-T treatable blood cancers. The sponsor had no input into the methodology, data collection, data analysis or reporting.

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

Position of this PEEK study

In this PEEK study 37 participants. With CAR-T treatable blood cancers 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.

A comparison of studies is available in Section 1.

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

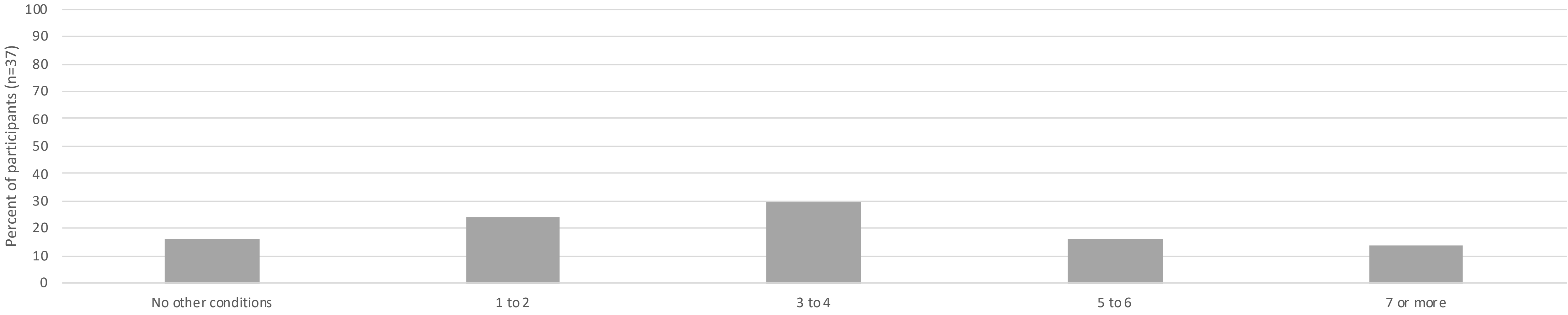
There were 65 studies identified of between 8 and 1861 lung cancer participants.

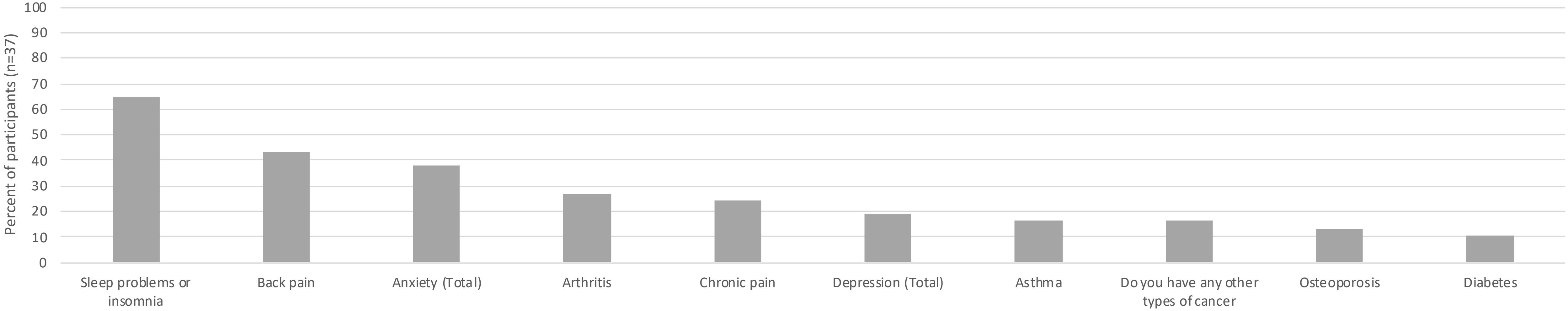
Section 2

The demographic section is where you can find information about the study cohort. This is also where the sub-groups used throughout the study are described and where the baseline health of the cohort is described, using the SF36 questionnaire.

Demographics

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





Comorbidities

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

Subgroups

Baseline health

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

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

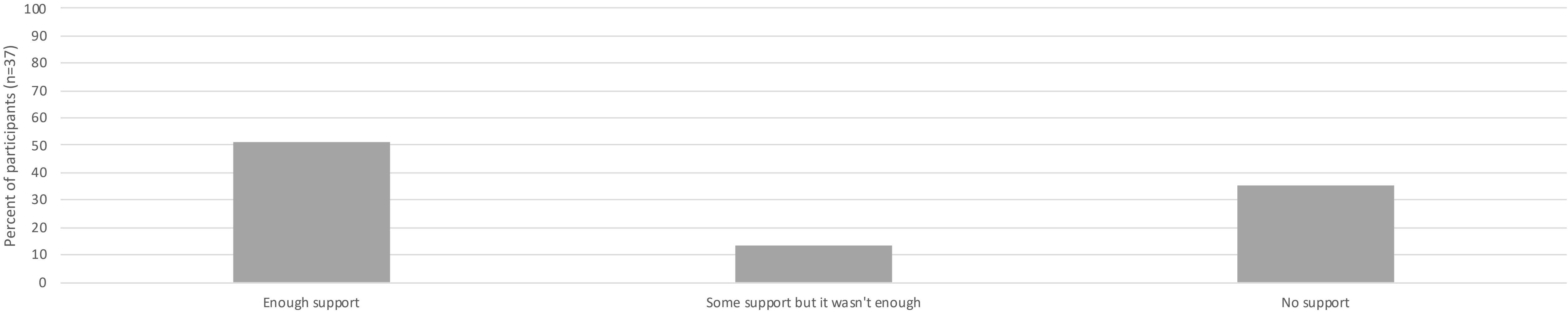
SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health sometimes interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

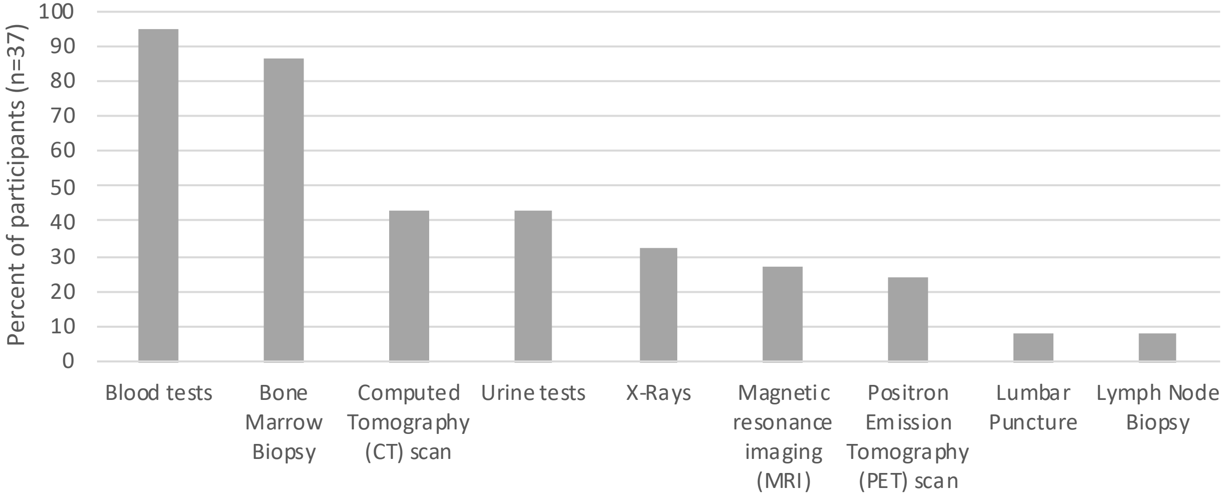
Section 3

The symptoms and diagnosis section is where you can find information about experience of symptoms before diagnosis, as well as the symptoms that led to the diagnosis. There is information about the diagnostic tests that were performed, where the tests were conducted and the time from tests to diagnosis. In this section, there is also information about the participant's understanding of their condition and their understanding of their prognosis.

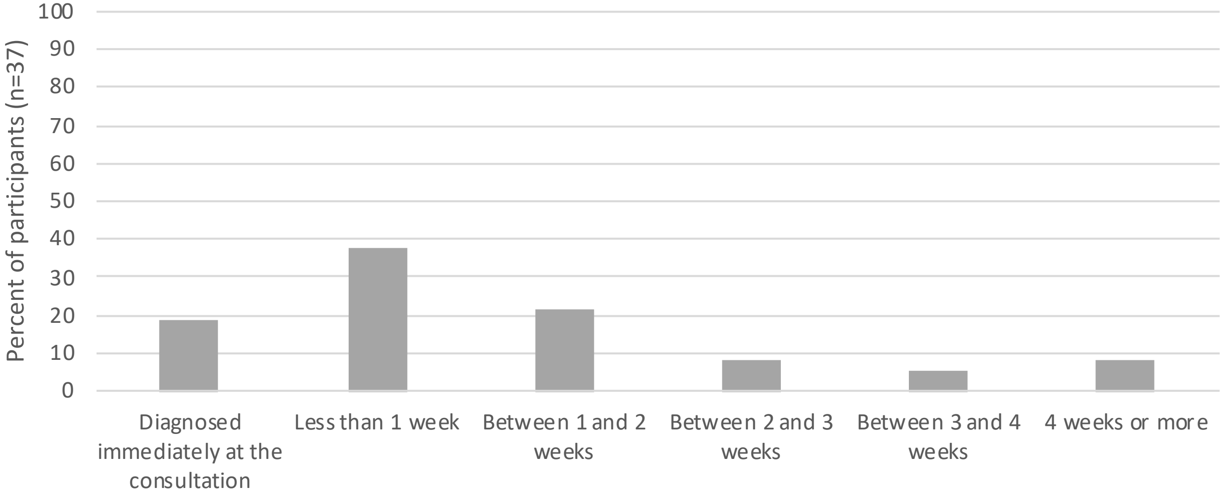
Information + support at diagnosis



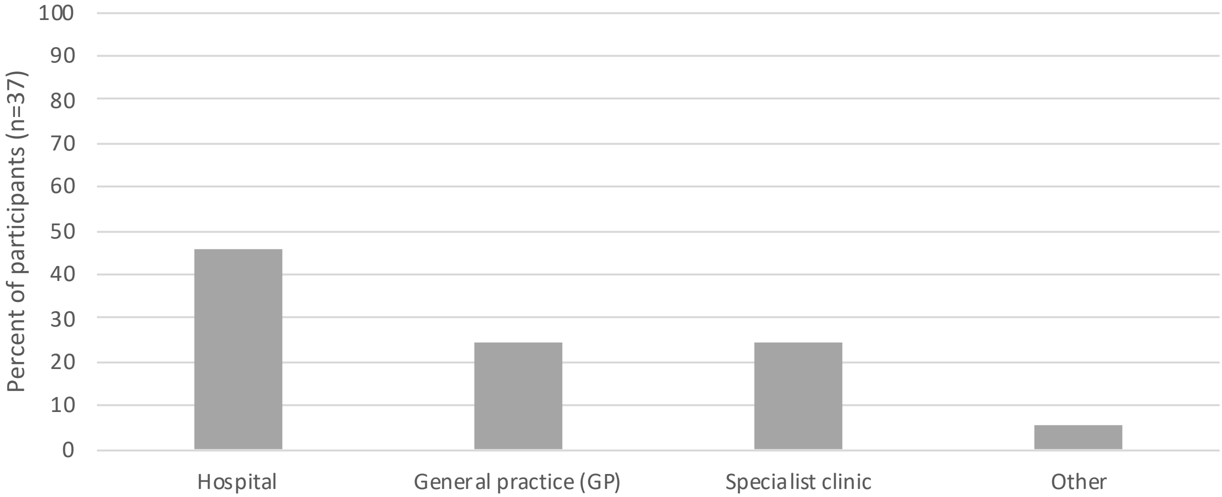
Diagnosis



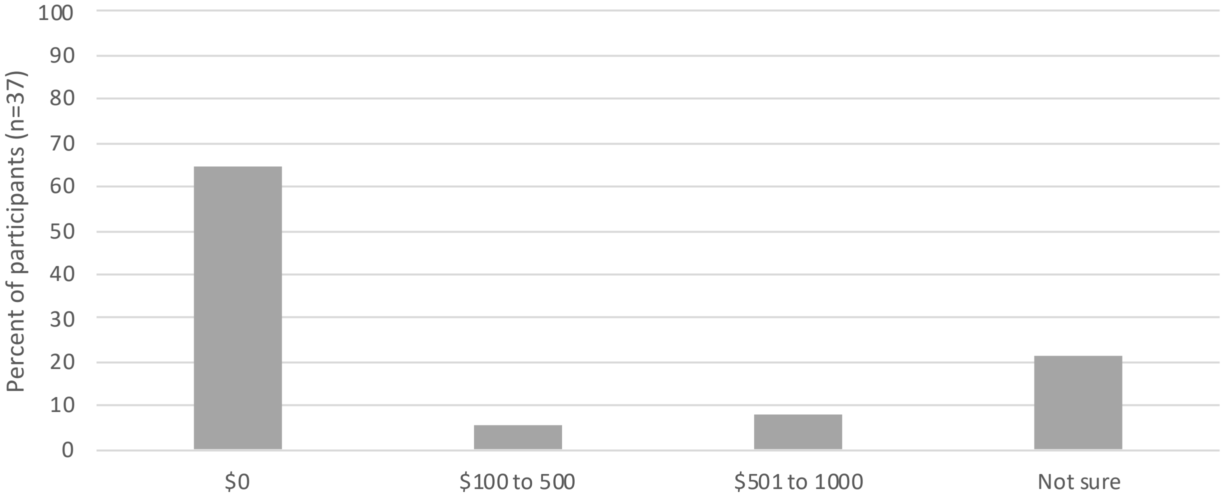
Diagnostic tests



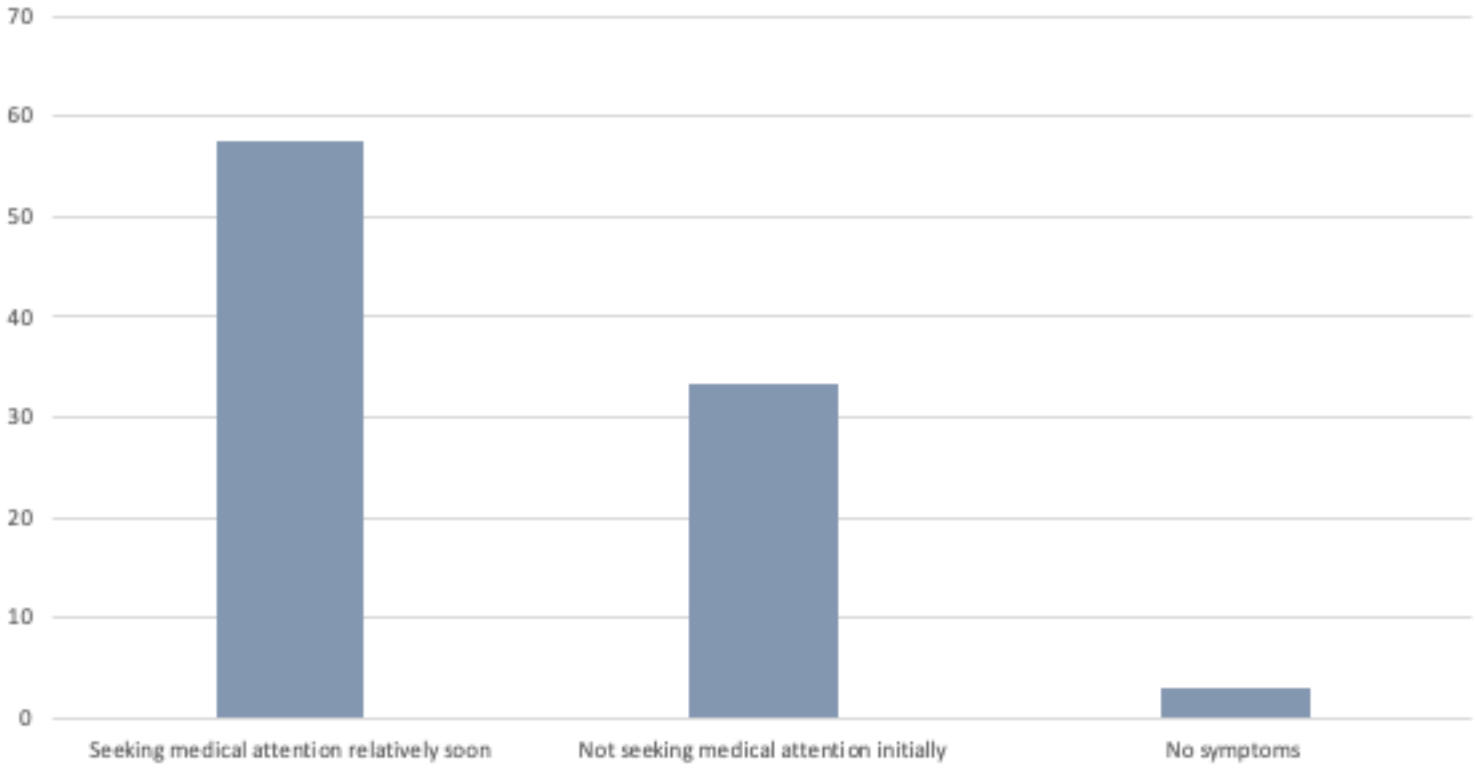
Time from test to diagnosis



Where diagnosis was given



Cost of 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 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

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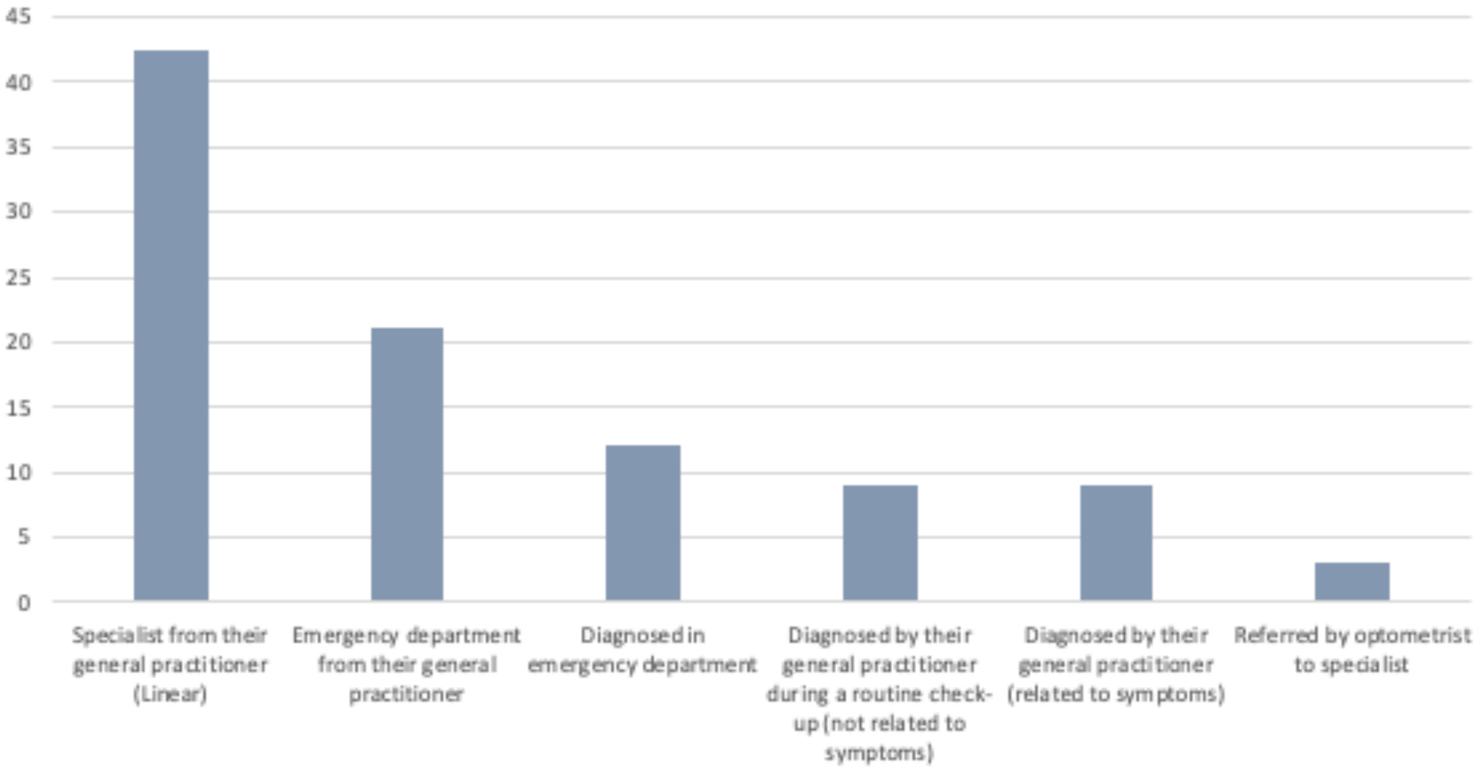
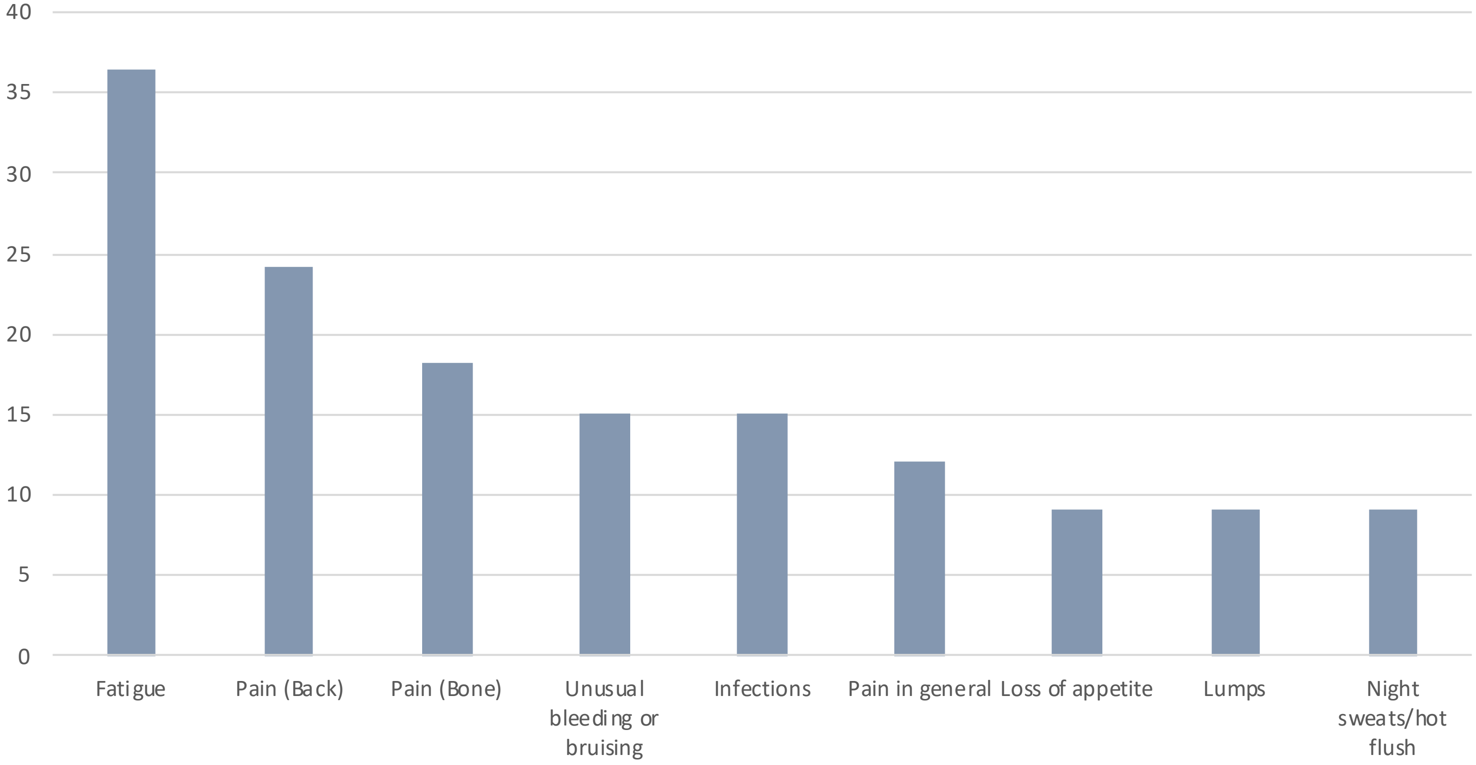
Seeking medical attention (% of all participants)



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. I was just heart attack at the last stage.

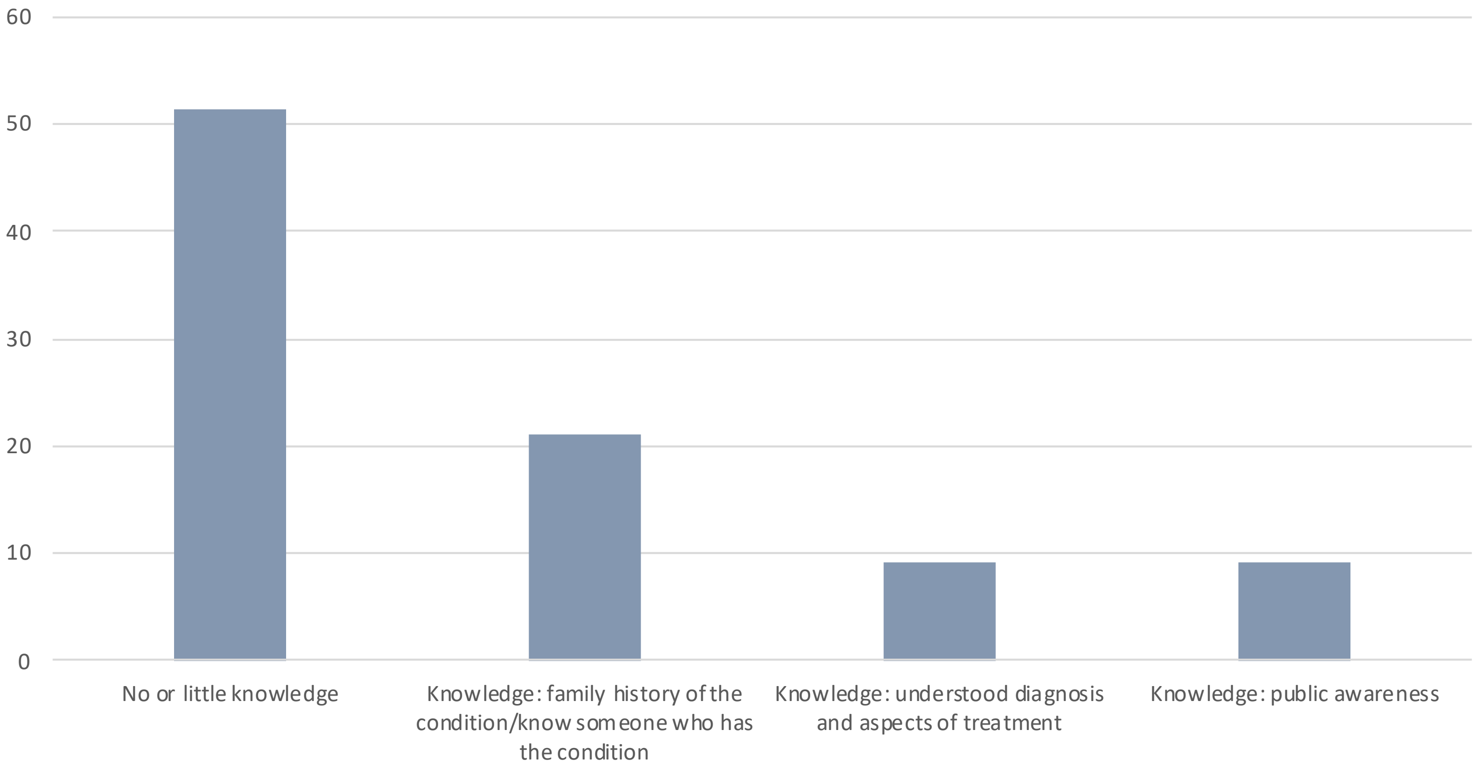
Participant 001_2023AUCRT

Diagnostic pathway



> *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 I said I 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*

Symptoms leading to diagnosis (% of all participants)



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

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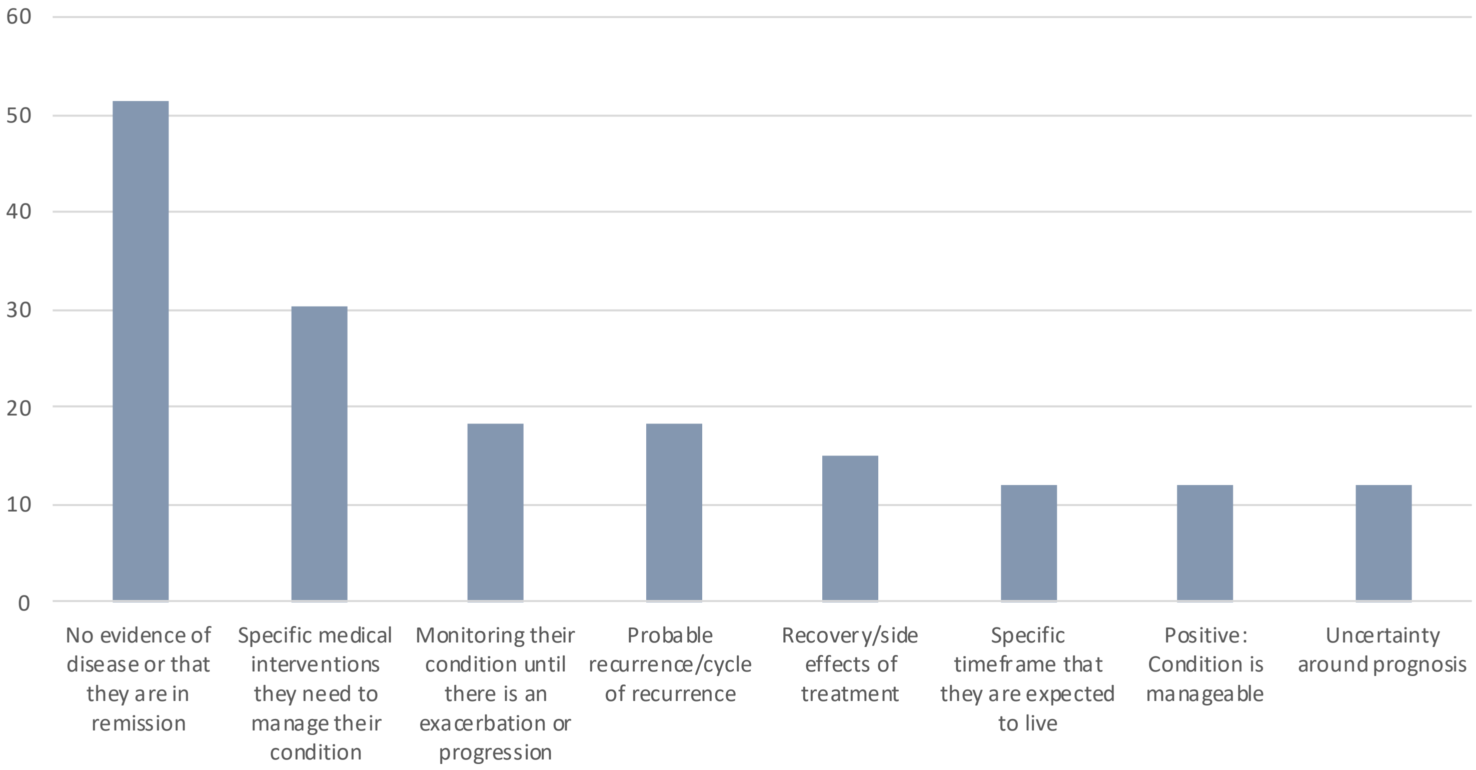
Understanding of disease at diagnosis

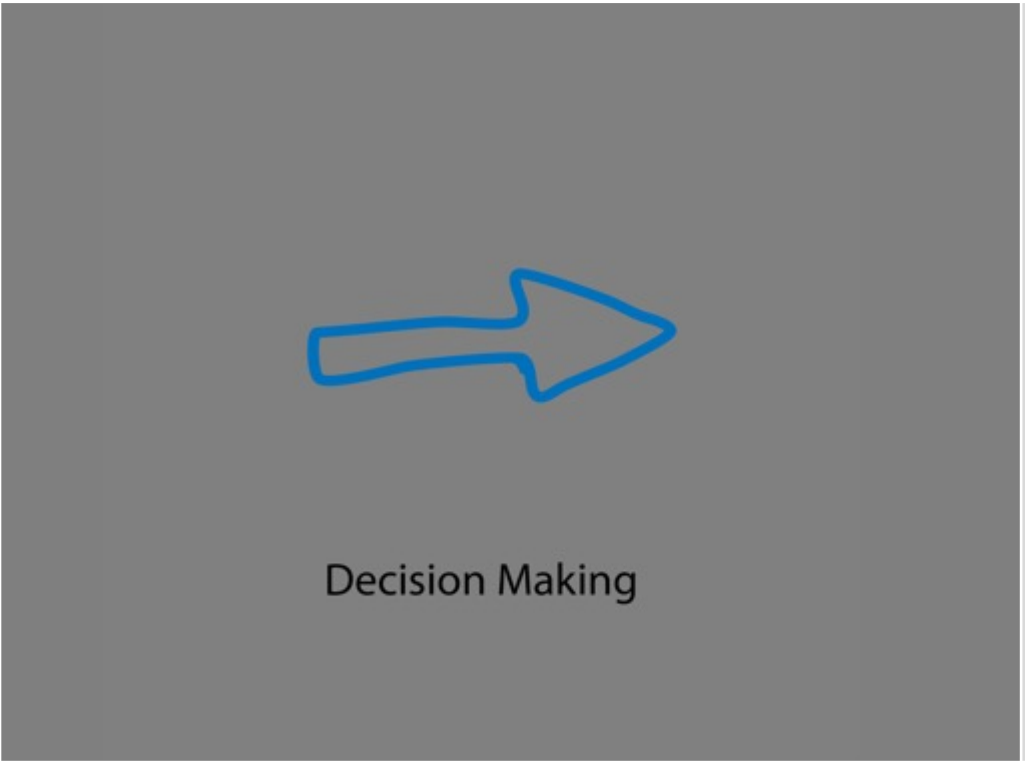
Understanding of prognosis



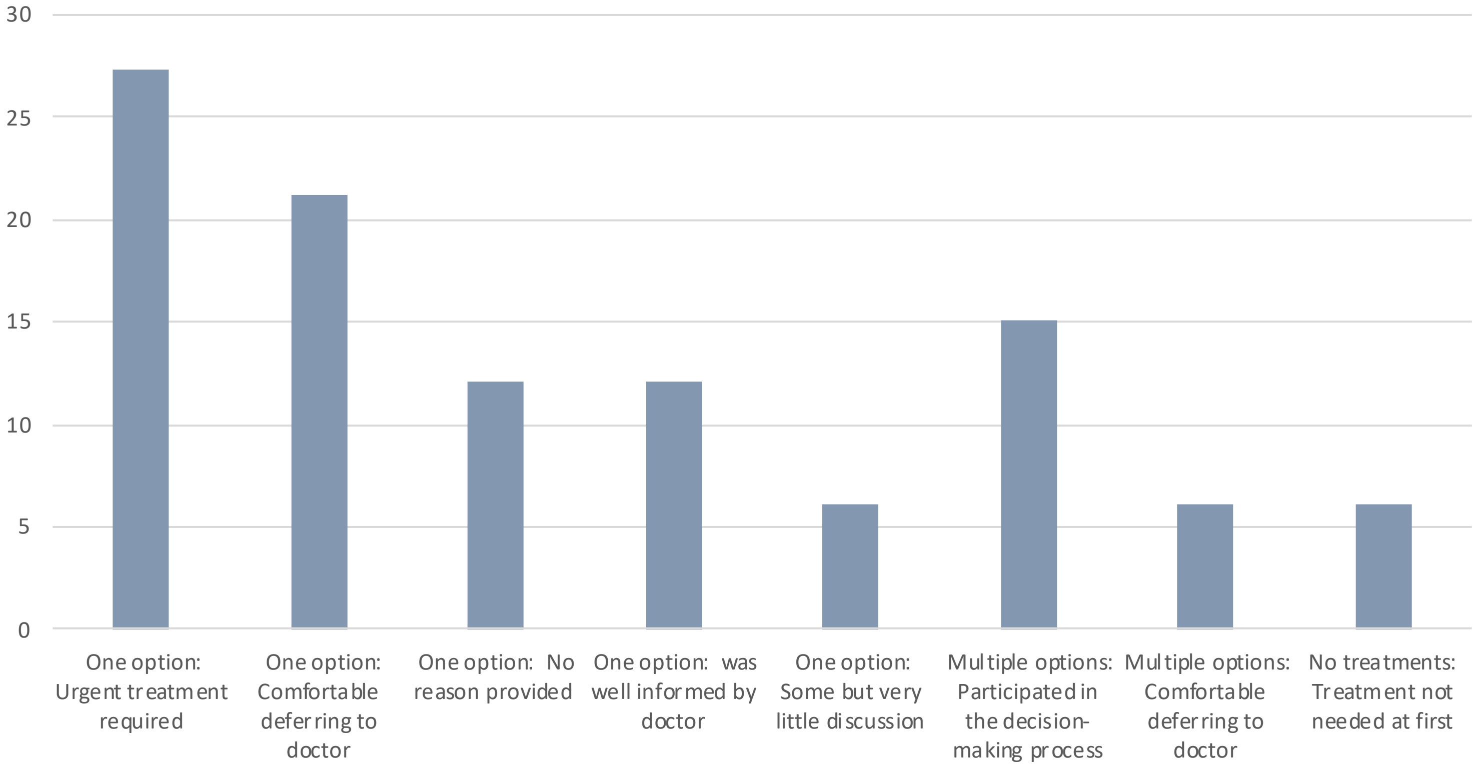
I'm in remission at the moment and by sticking to the best diet that I can, I've cut alcohol. I've stopped taking sugar as much as I can and I think I hope that it would stay in on remission for a while. And then I have another batch of stem cells in the hospital to be transferred again in future. So 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

Section 4



In the decision-making section, you can find information about the conversations that were had about treatment options at diagnosis, what is important to people when they make decisions about treatment, and whether decision-making changes over time.



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

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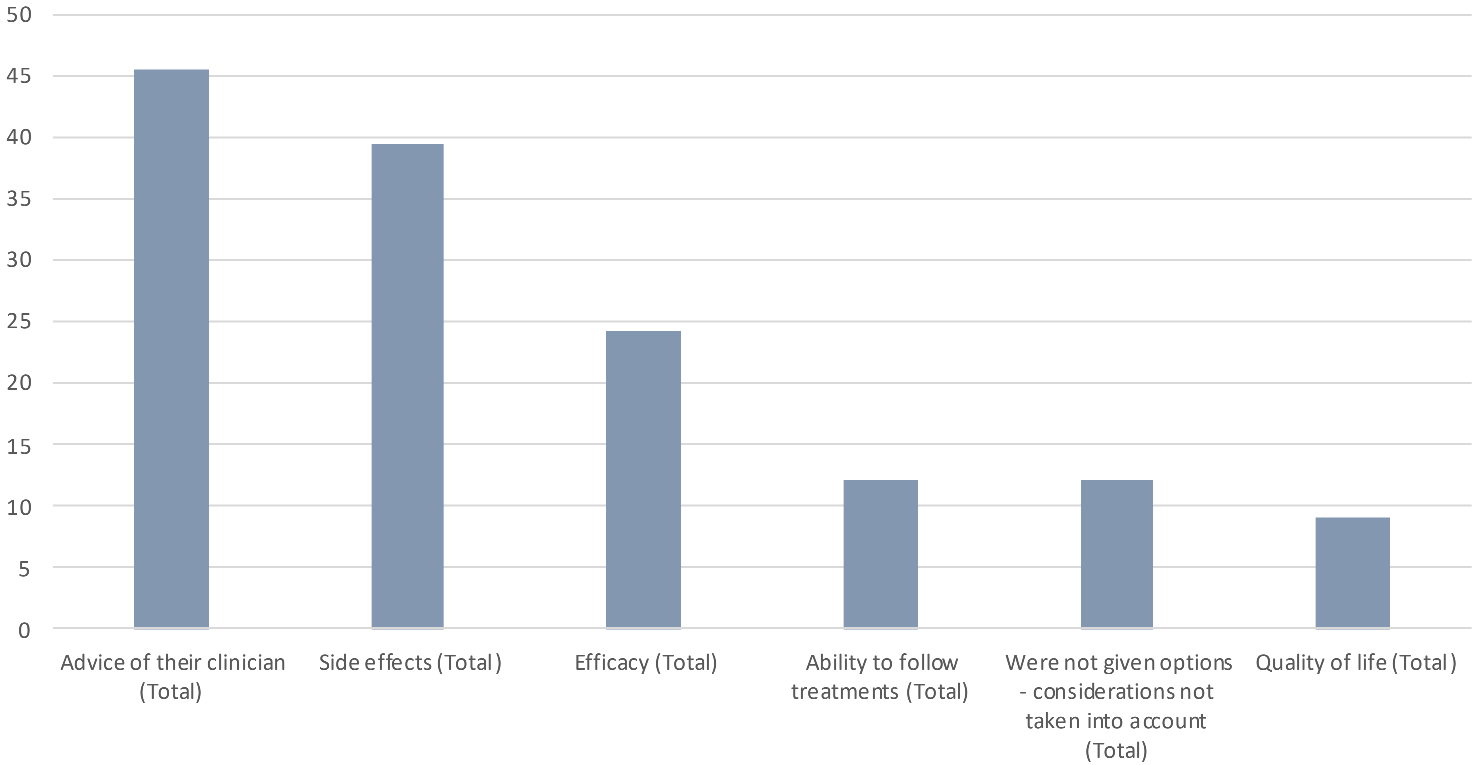
Discussions about treatment (% of all participants)



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

Considerations when making decisions about treatment

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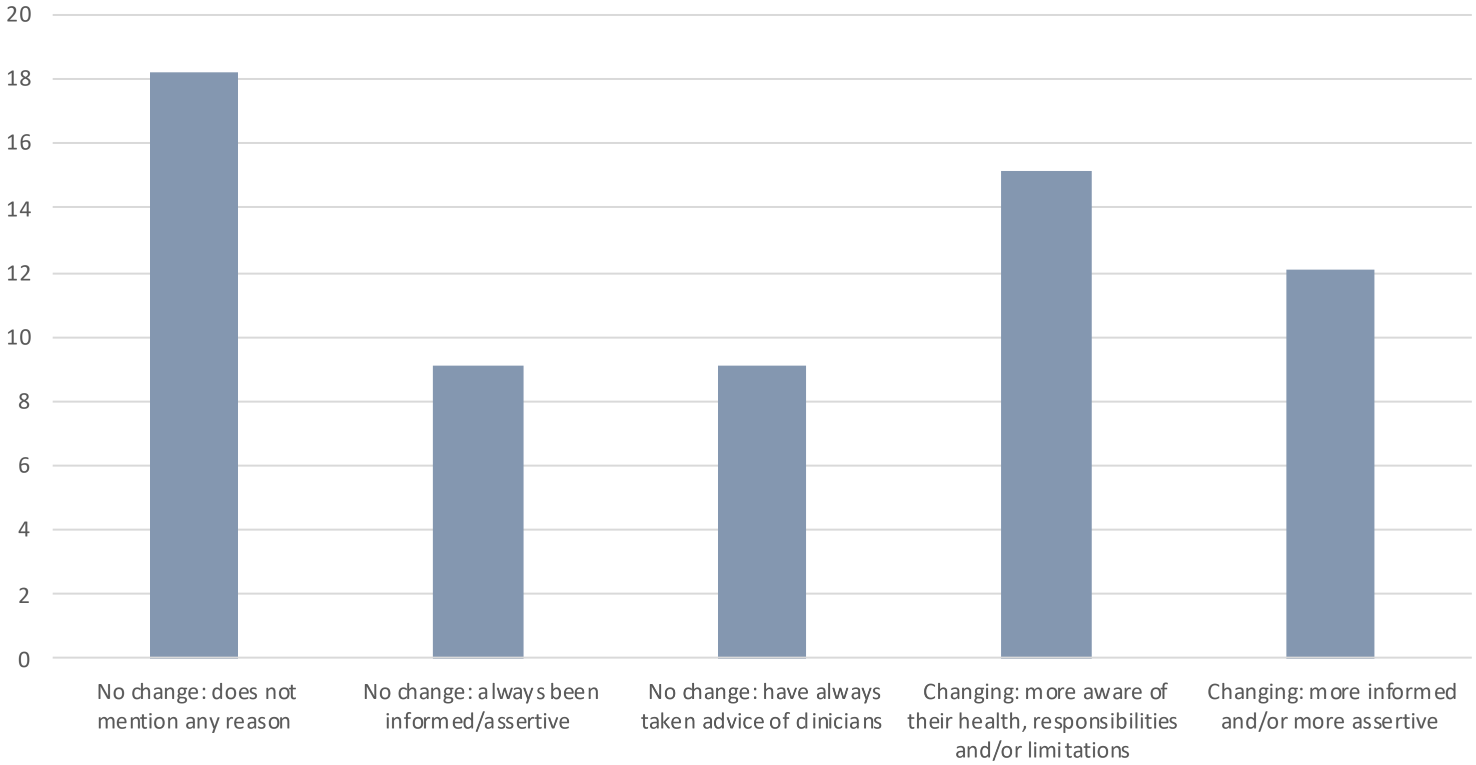

I think I asked more and more questions. So I guess as time goes, I know, yeah, I asked what. Yeah. What? I think we always ask the doctor, what would they do if you know someone they knew that's always a good indication. And yeah, just a bit more direct with is if the other side effects with the risk, yeah. It is a treatment worth of side effects etcetera etcetera. But at this stage we haven't really questioned too much.
Participant 021_2023AUCRT

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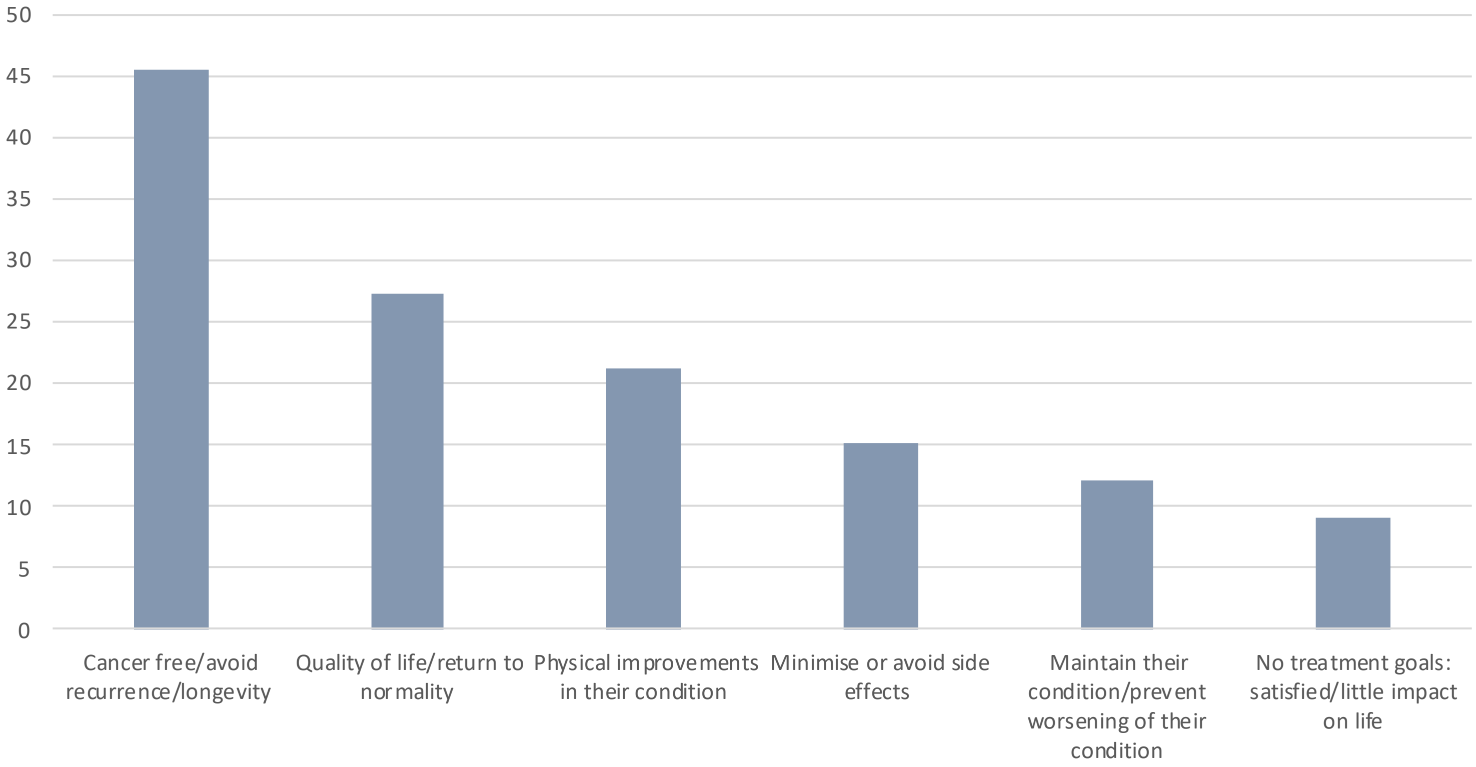
Changes to decision making over time (% of all participants)



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

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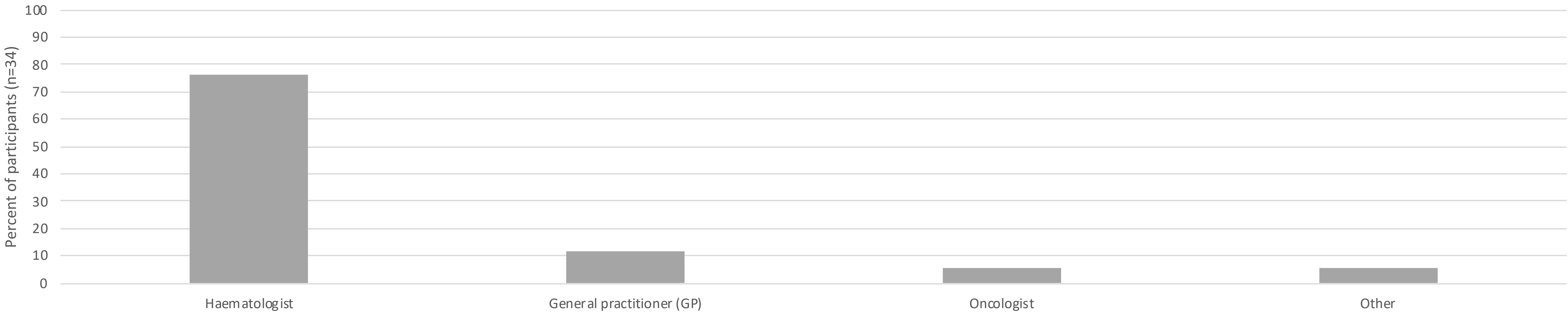
Personal goals of treatment (% of all participants)

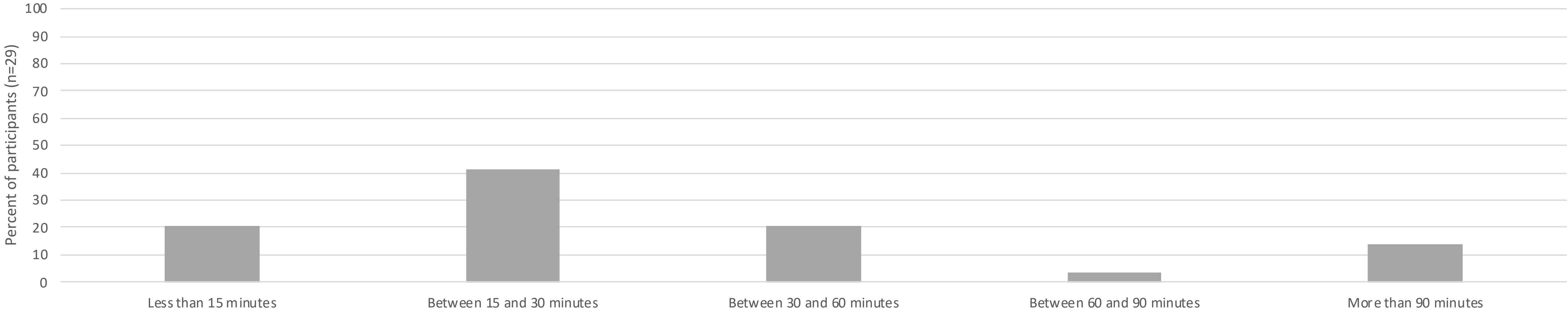
Section 5

Treatment

The treatment section is one of the largest sections in each study. Information is available in relation to the types of treatments people have experienced as well as rating quality of life and effectiveness for each treatment. There is information about the main providers of treatment, access to health professionals and information about which part of the health system participants were treated in. There is information about affordability of healthcare, any reduced income for the patient or their family, an additional costs or changes to employment. There is then also detailed information about the treatments that the participants have experienced, whether they had any side effects, their description of mild side effects and severe side effects, and any complementary therapies that they may have used. Information in relation to access to allied health is also available. Information about what needs to change to feel like treatment is effective, and adherence to treatment is also presented. In this section, there is also information on whether discussions about clinical trials were held with clinicians, and for those who have been on a trial, what their experience was like.



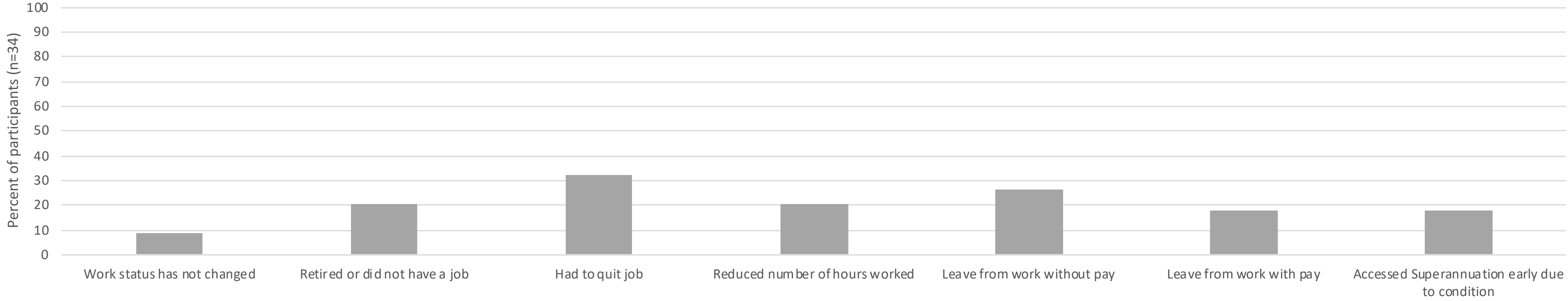
Main provider of treatment



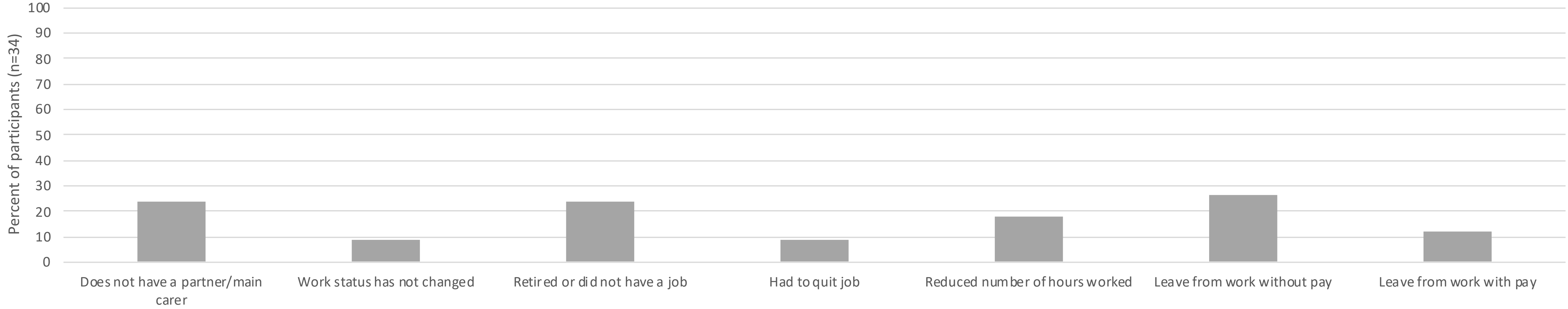
Time to travel to main provider of treatment

Access to healthcare

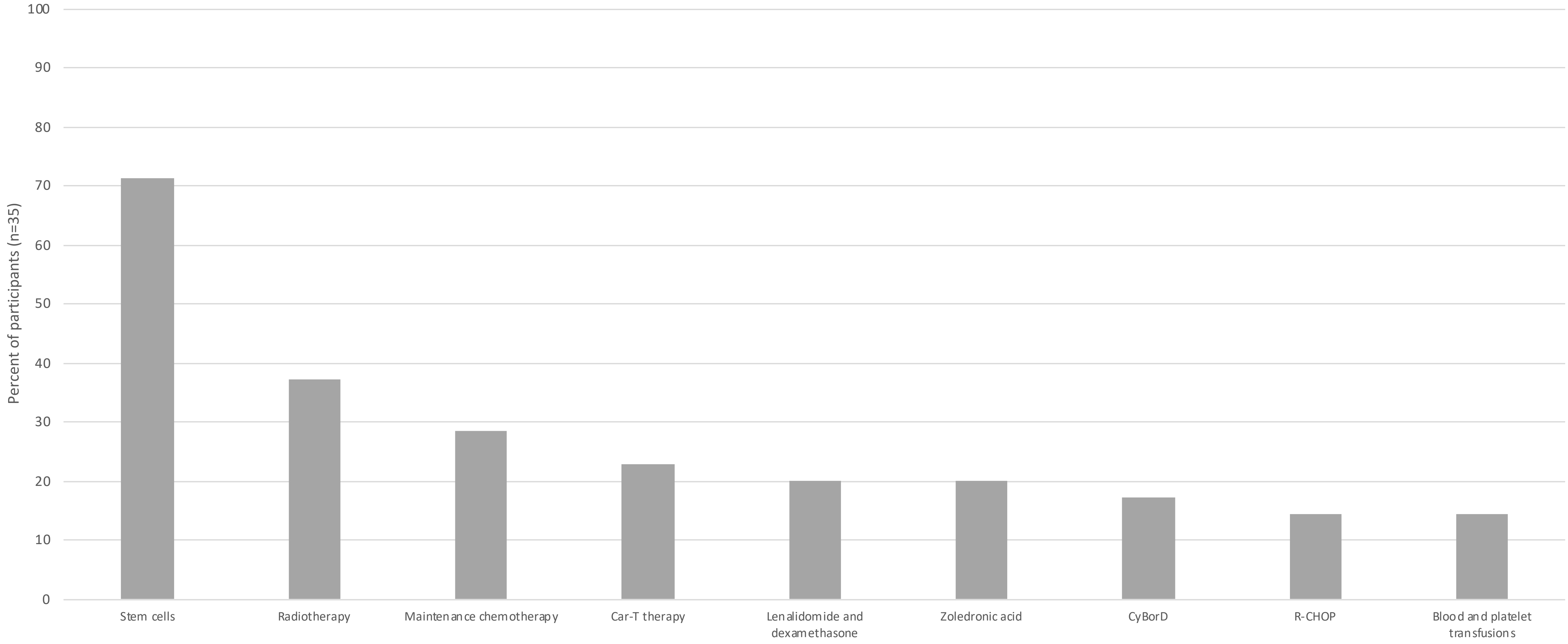
Employment status



Participant's employment



Main carer/partner's employment



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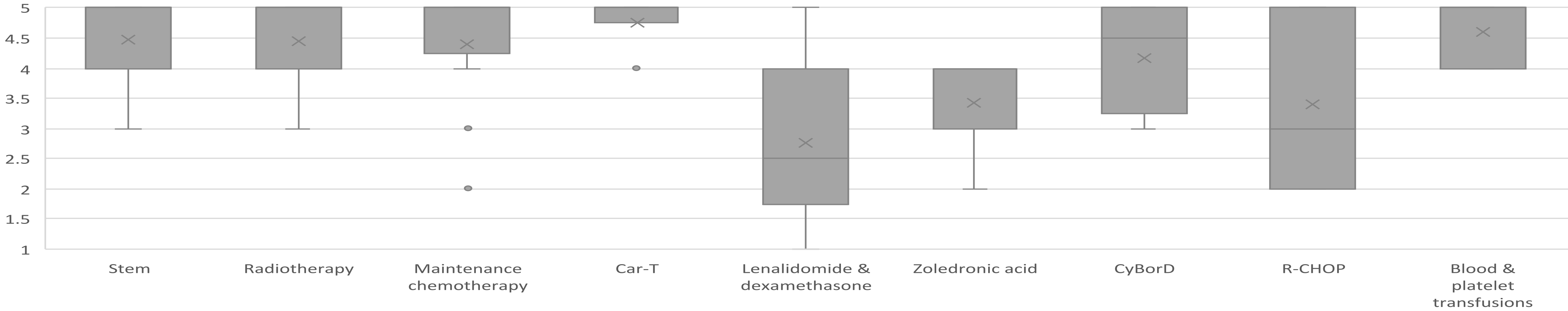
Treatment overview

Quality of life and effectiveness of treatments

Quality of life



Effectiveness

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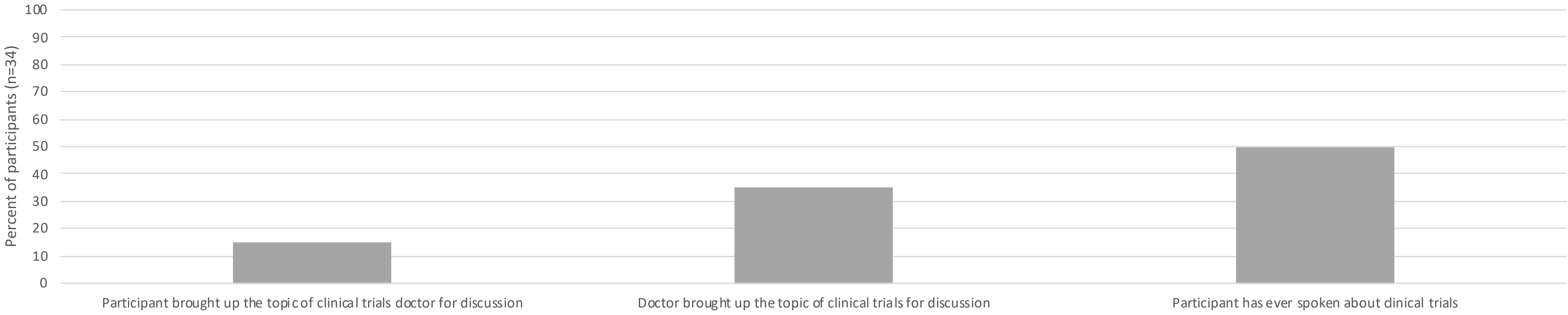
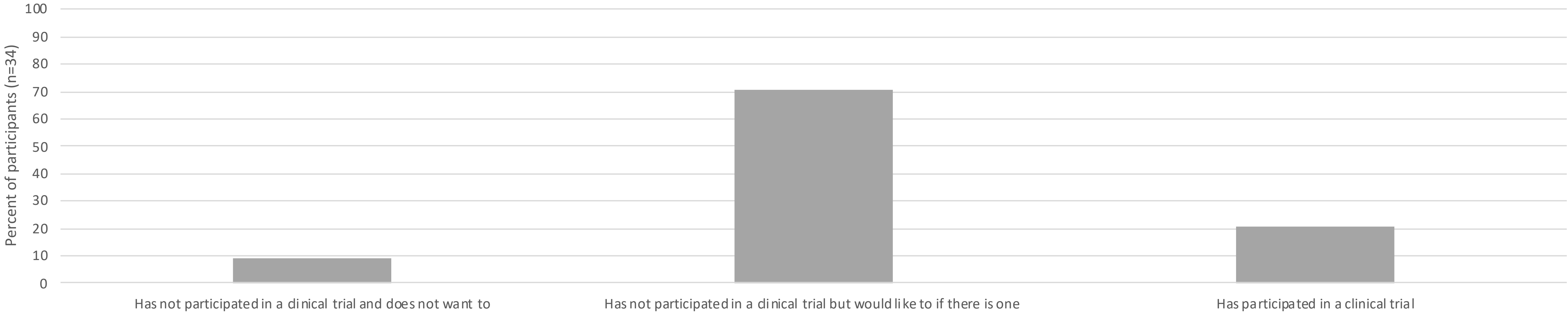
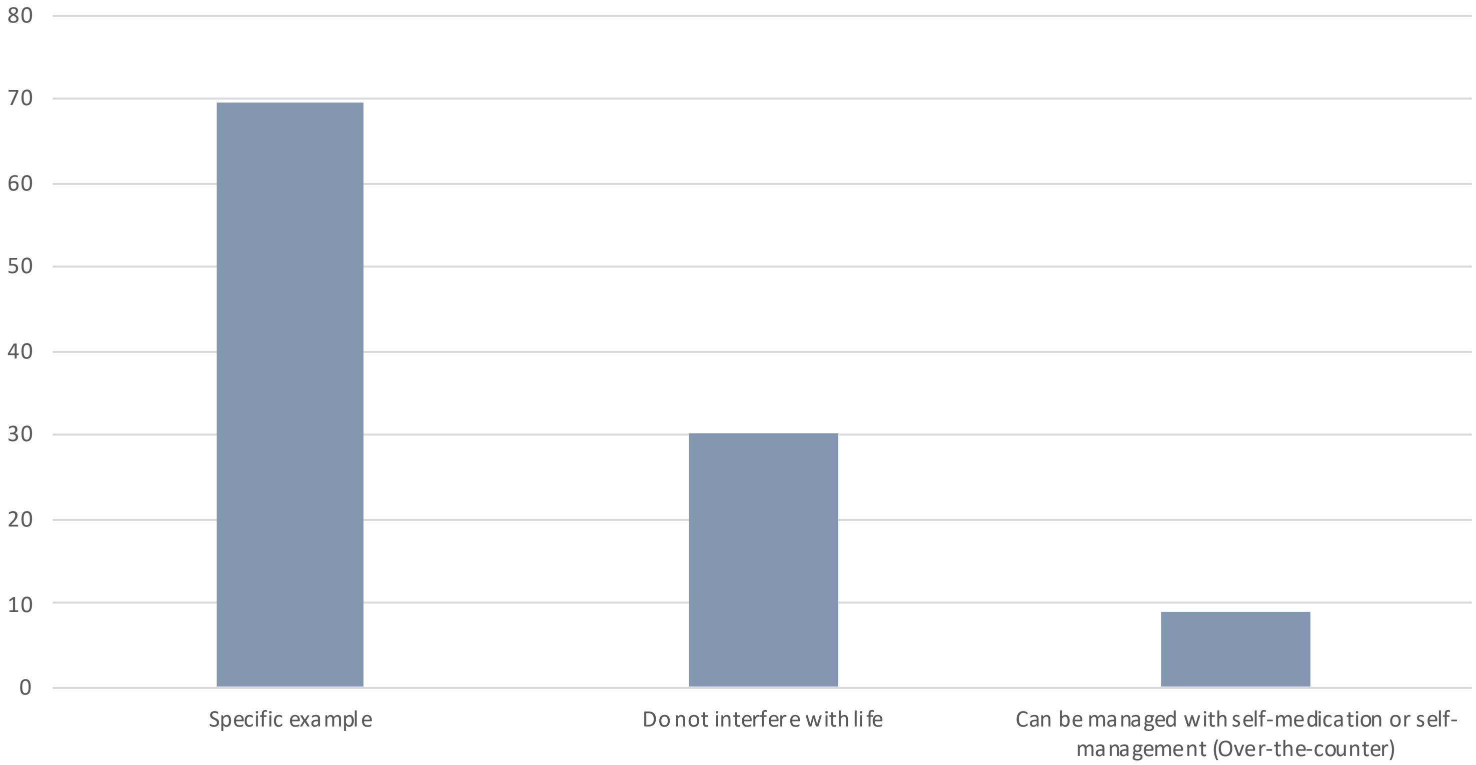
Clinical trials



Discussions about clinical trials

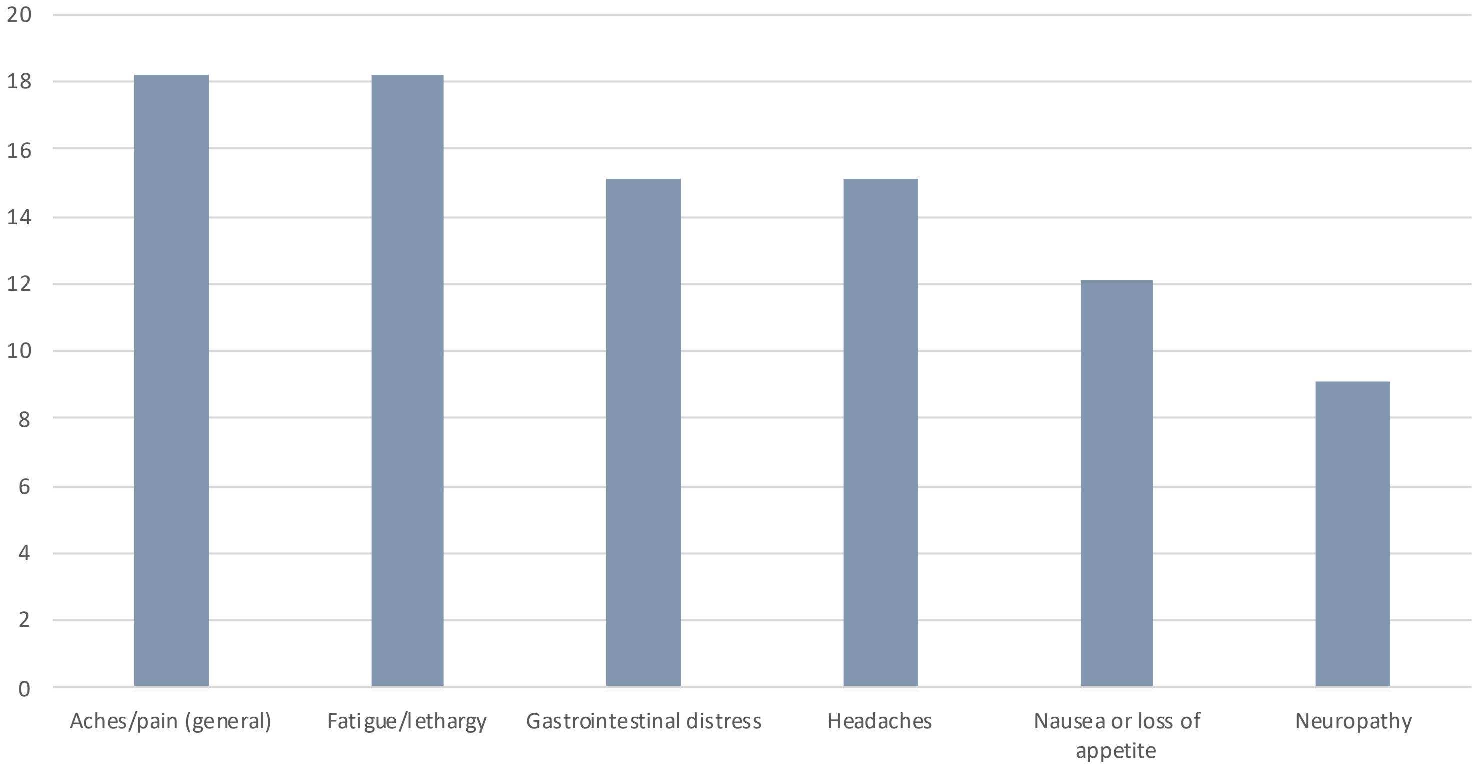


Participation in clincial trials



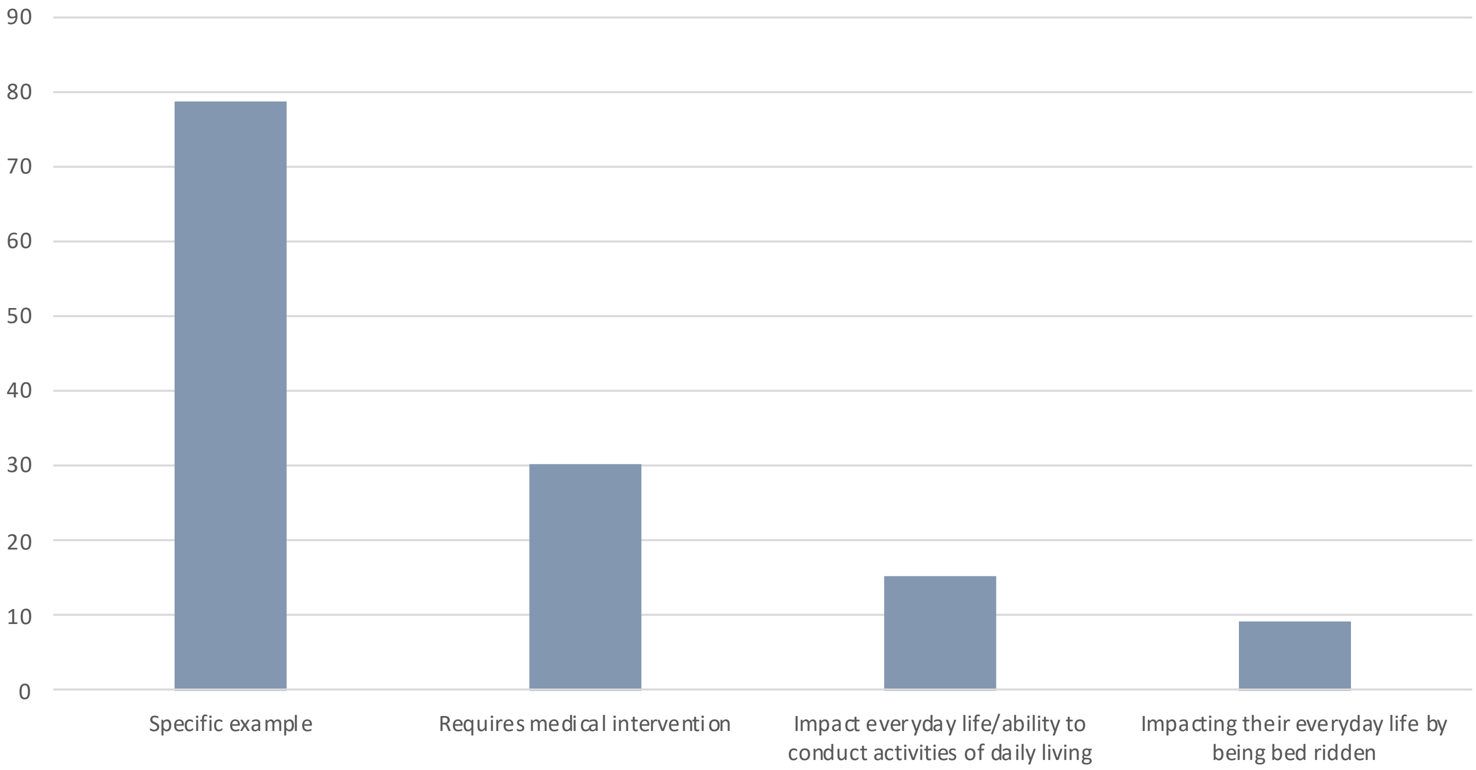
Well, to me, a mild side effects would be what I've got with my tongue or my hips, where they're annoying and they hurt a little bit, but you can live with them and not really. They're not changing my life. Like I'm still late for like, it's not stopping me eating or drinking certain things, or my hip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

Description of mild side effects (% of all participants)



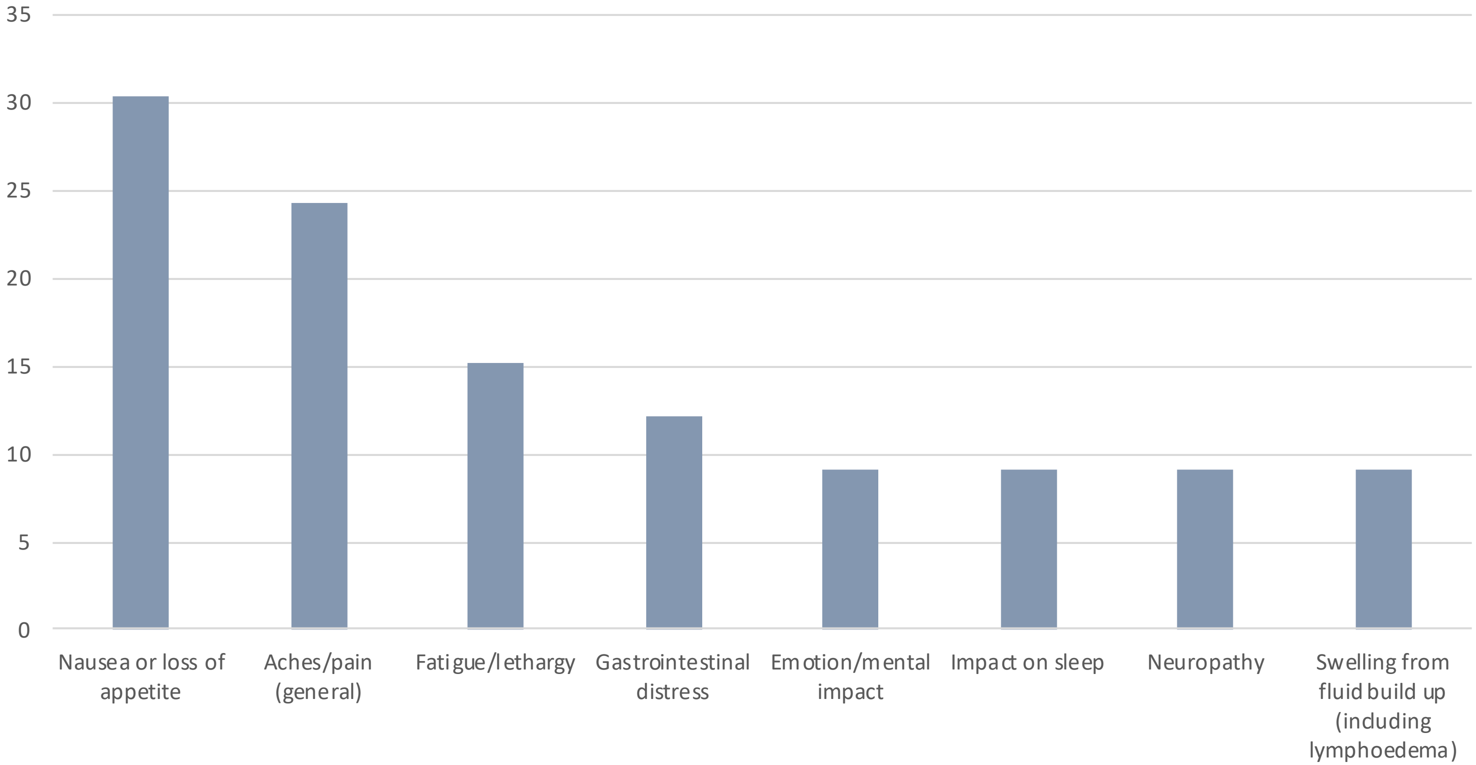
Just feeling a bit off, like, you know, like you just don't feel well, like you get headaches and yeah, like you. That's hard to describe. Like you're just, you're just not right. You know, there's something wrong. And yeah, you just don't feel Sparky and you don't feel like eating.
011_2023AUCRT

Description of mild side effects: Specific example (% of all participants)



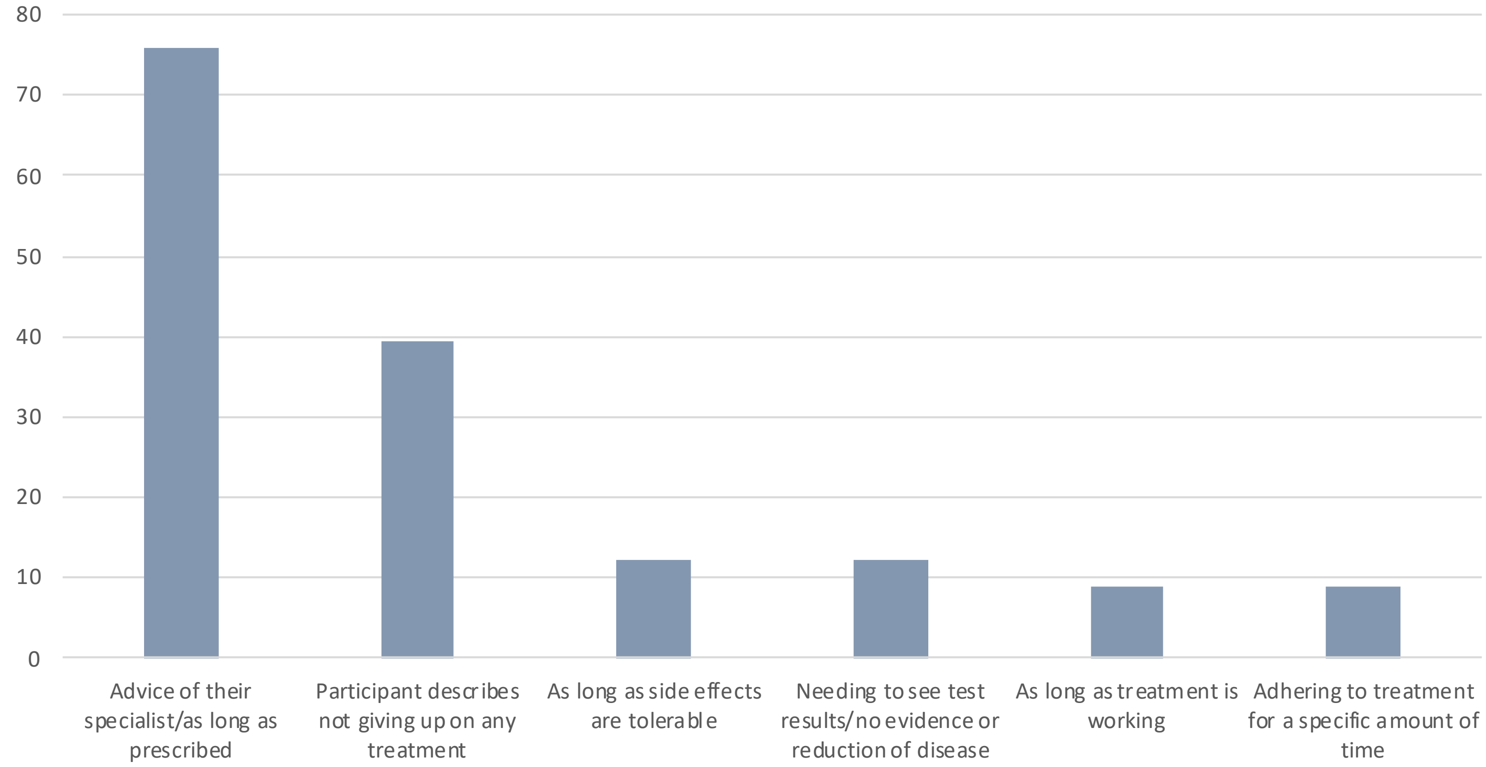
> *Well, I had a severe weekend when I was in acute care, and that was just as sick as you could imagine. Lying there feeling like you're inside to being eaten out, can't concentrate, completely fatigued, just just lying there. Just. Passing time really.*
> *022_2023AUCRT*

Description of severe side effects (% of all participants)



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

Description of severe side effects: Specific side effect examples (% of all participants)



Or perhaps you think that it's not working, Not really applicable. I've been on the same treatment and as I said before, whatever the doctors and specialists recommend, they're the experts. So I'll do it. But really, there's been no no change... There's been no change.
013_2023AUCRT

Adherence to treatment
(% of all participants)

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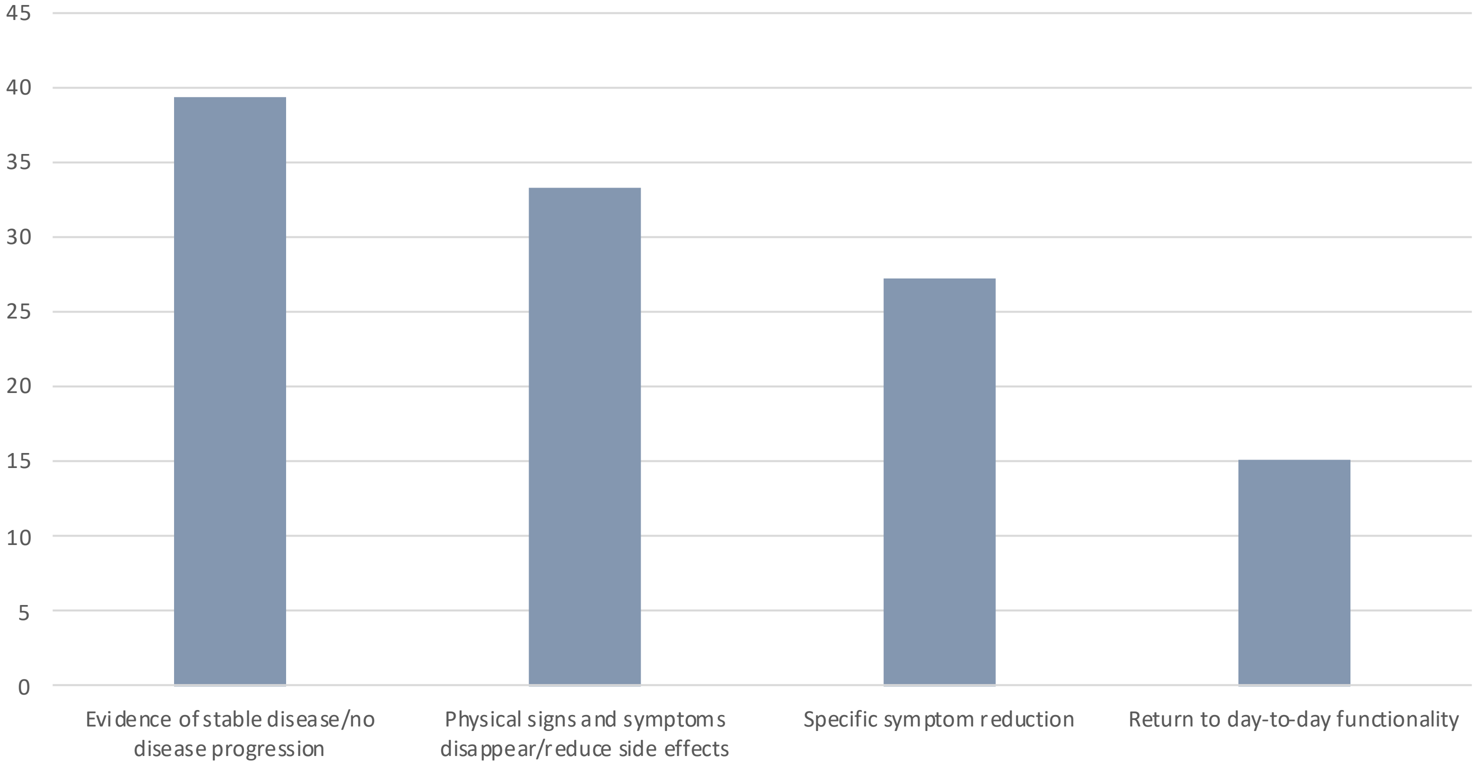
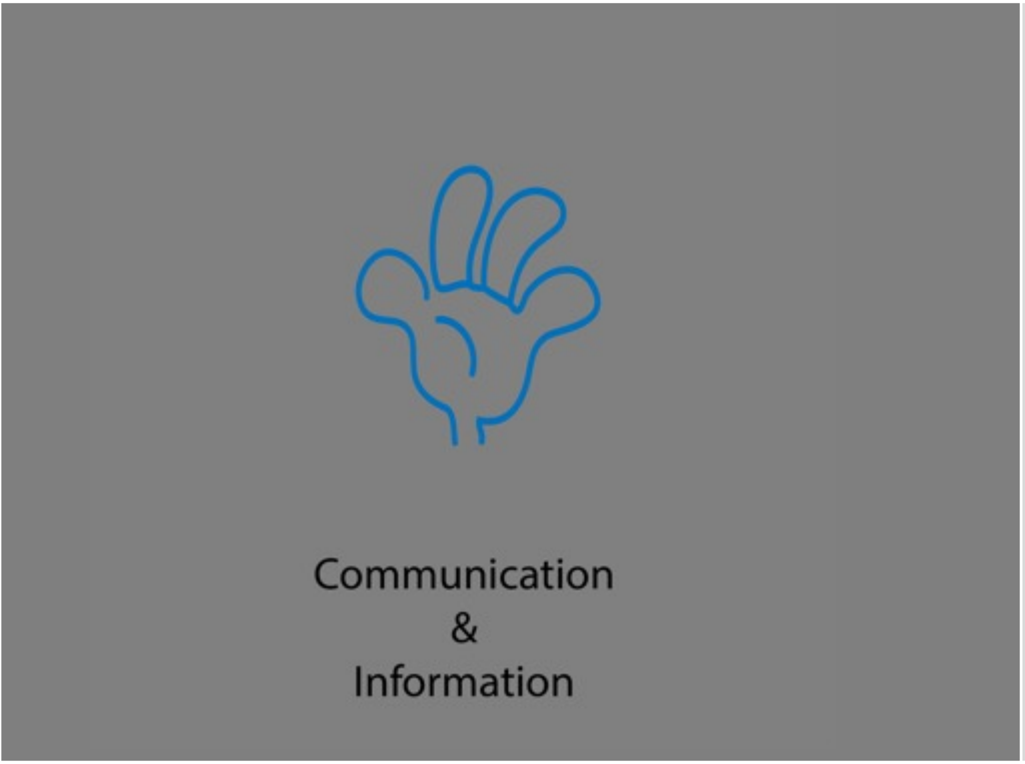


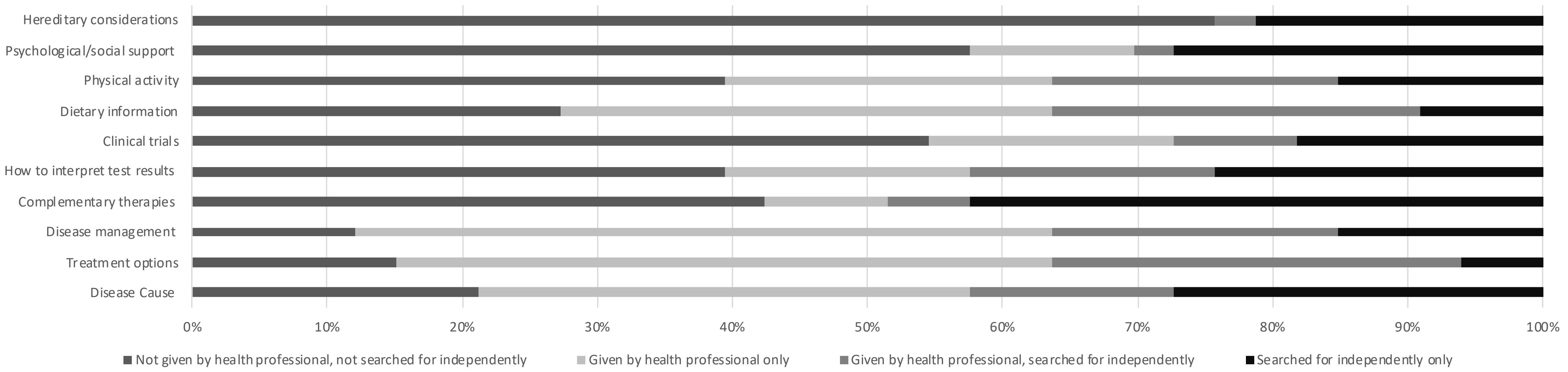
So far, just the blood biochemistry. I'm just relying on the monthly or weekly blood tests that we are receiving and my especially way of looking at the numbers. So the specialists in the state, for example, recommended having a PET scan after two years of treatment. He was recommending having a PET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

What needs to change for treatment to work (% of all participants)

Section 6



This section report access to information, information that was helpful and information that was not helpful, when participants feel they were most receptive to receiving information, information preferences, information topics for which information was received or searched for, as well as when it was received and additional information was required. This is also where there is information about healthcare professional communication and participant's knowledge and confidence in managing their own health using the Partners in Health tool.



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%).

Information gaps

Partners in health scale (n=31)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	27.58	5.01	30.00	4.00	0 to 32	5
Coping*	16.61	4.58	18.00	6.00	0 to 24	4
Recognition and management of symptoms	20.71	3.66	22.00	5.50	0 to 24	5
Adherence to treatment	15.16	1.92	16.00	1.00	0 to 16	5
Total score	80.06	12.22	85.00	12.50	0 to 96	5

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

The **Partners in health: knowledg**e 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.

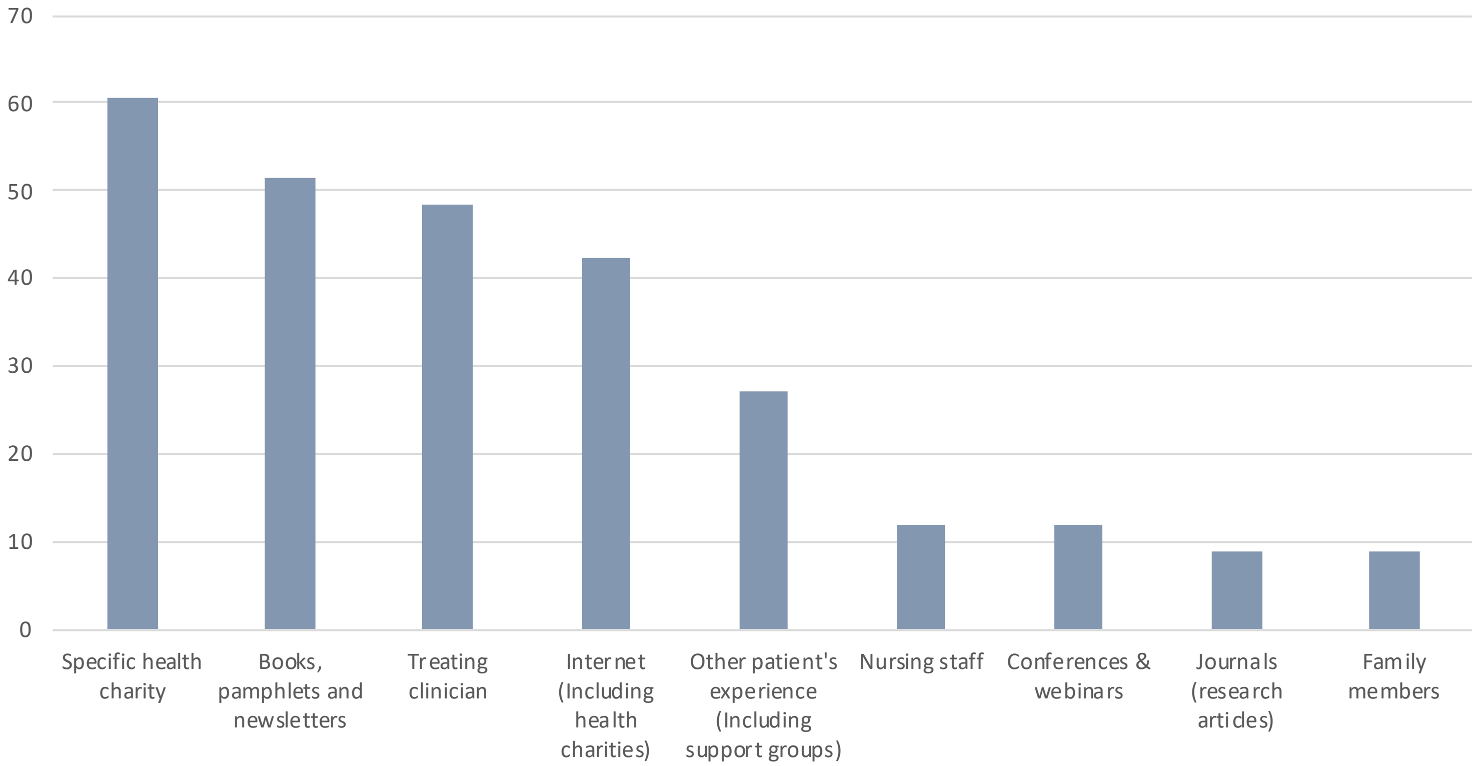
The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to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

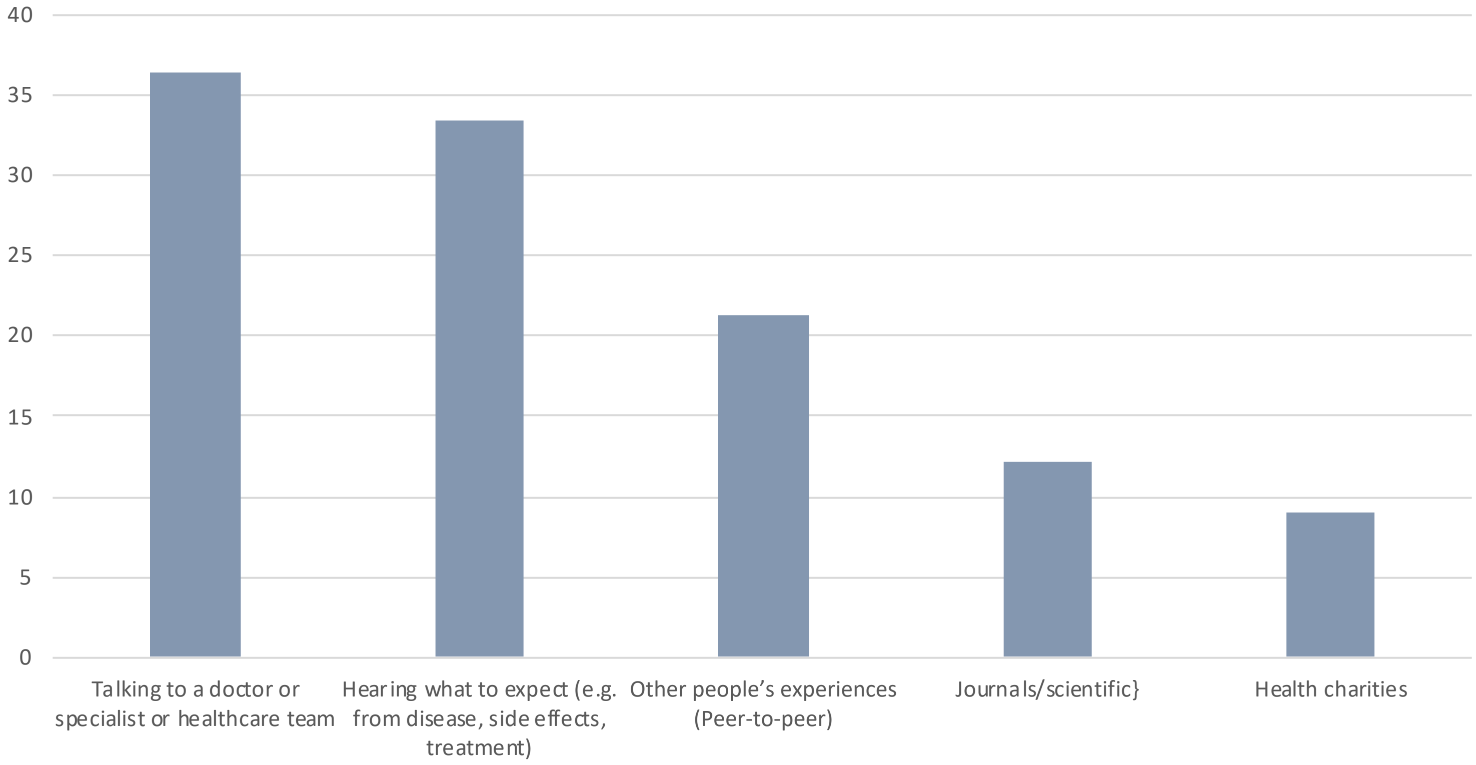
Partners in Health



OK. I I had lots of access for from the hospital so they would print out information about the type of chemo that I was having, the expected side effects, all of that sort of thing. Both hospitals were good at that the. Oh God, what's the name? I also received information from the Leukemia Foundation, and I found that also excellent. I avoided Google, yes. So I generally went to the Leukemia Foundation, the Cancer Council, and my medical team.

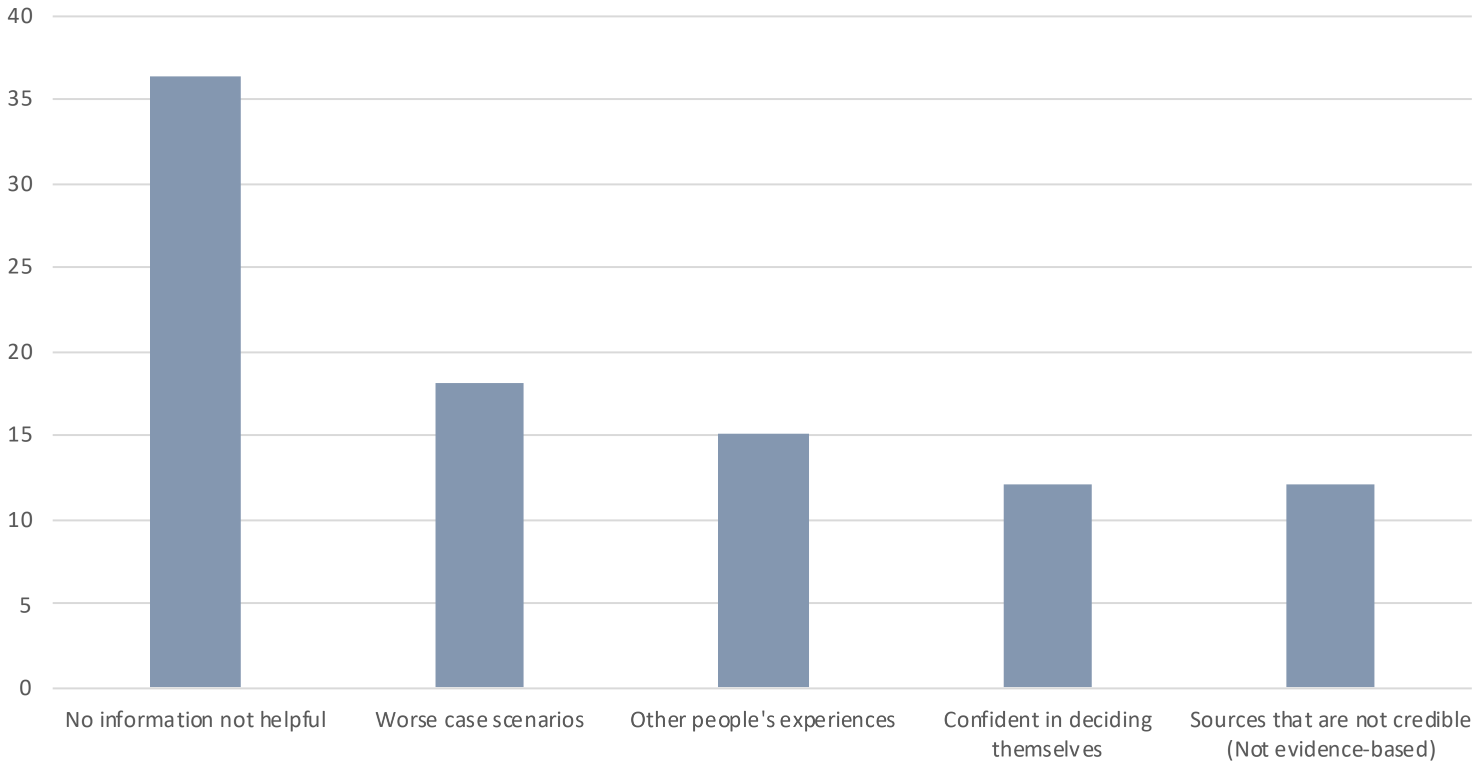
Participant 009_2023AUCRT

Access to information– specific charity (% of all participants)



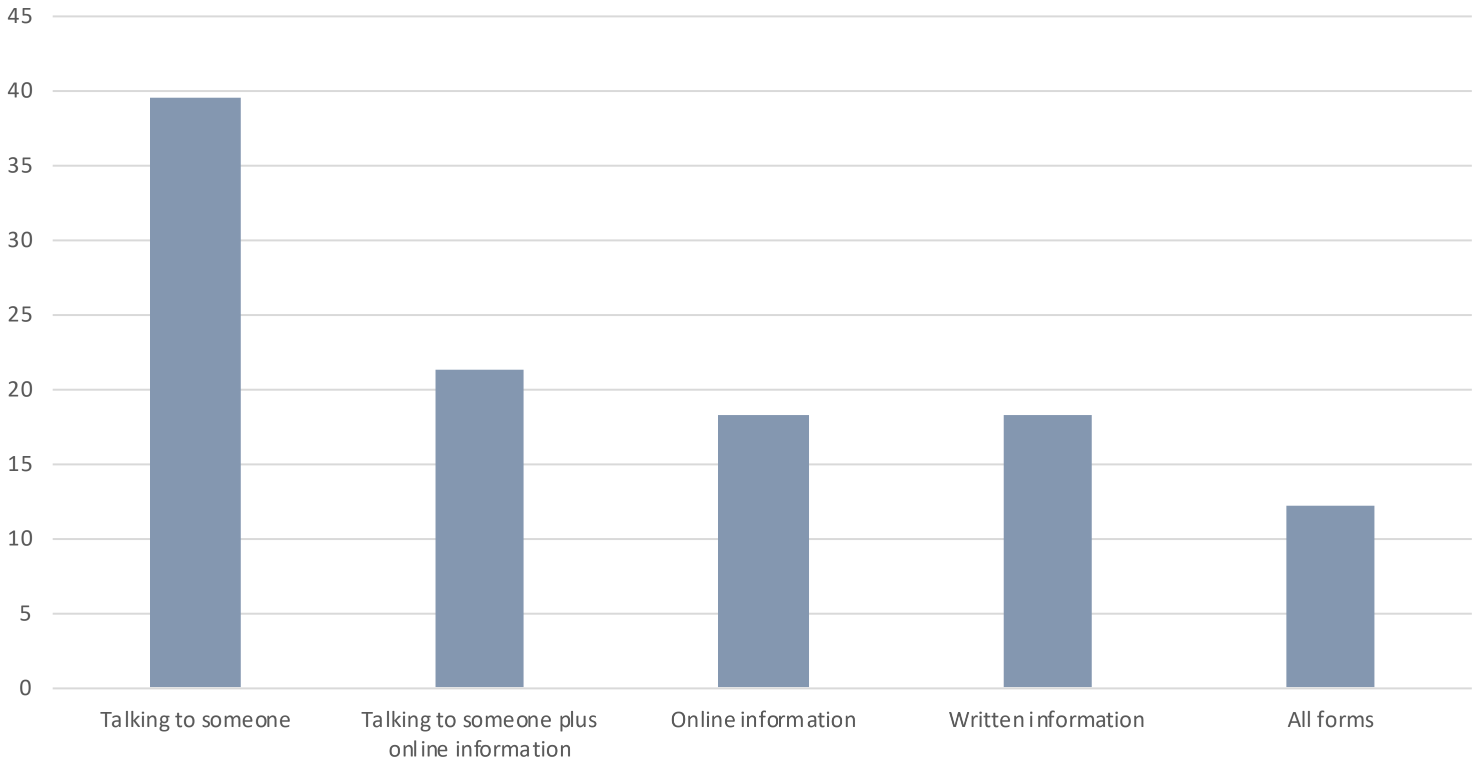
Probably at the start they had some brochures about leukaemia, but because mine is the rare sort of sub-type they didn't have a brochure particularly on it. On the Leukaemia Foundation website, there was a page. I think there was someone's story on there so that was a bit reassuring. Actually, as rare as it is, there was an 80-year-old lady that was diagnosed a month ahead of me so she was there to sort of go through the journey with me as well. She came out just fine, she hit remission as well so that was pretty cool.
Participant 005_2023AUCRT

Information that has been helpful (% of all participants)



Oodles of it out there, but we've just. Try to zero in and concentrate on reliable sources. Probably an example of that. There is as there is anything in social media, there's quite a while over Facebook page and all that and I got to a point after about two or three weeks and might not just have to turn the notifications of it just to keep out. It was just, yeah, just not helpful, yeah. On that and I just, you know some of the stuff that people are sprouting was you know, I knew was from from reliable and expert sources was complete rubbish
Participant 027_2023AUCRT

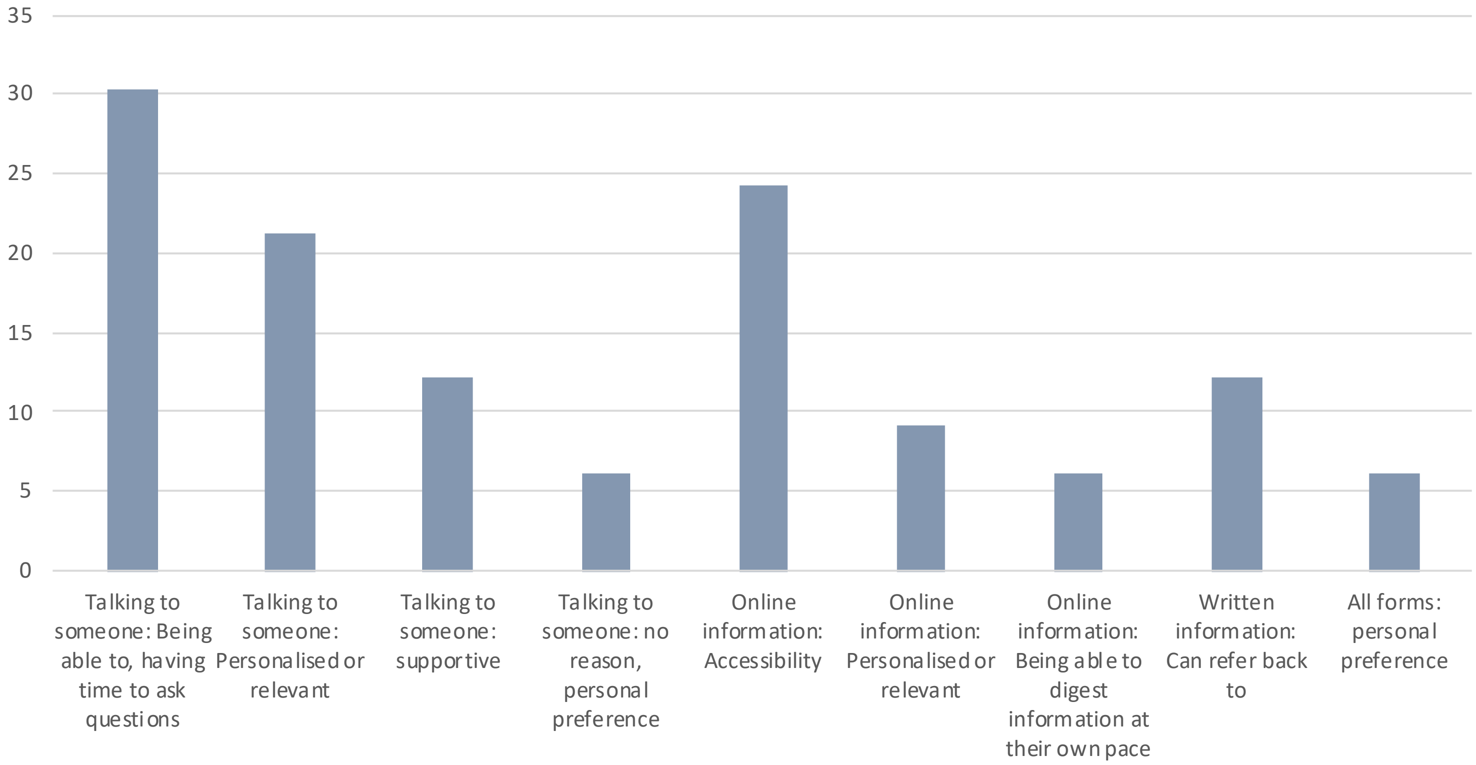
Information that has not been helpful (% of all participants)



Probably maybe talking to someone, probably would be the best option rather than an app. An app or information like that, you could press or look on the wrong information and cross your wires a little bit. Whereas talking to someone, they could make things a lot clearer, so I'd probably go with the talking with someone option.

Participant 01_2023AUCRT

Information preferences (% of all participants)



I still, I still love to read, you know, from the paper. Yeah, but of course that will go on Google. But my preferred one, I took all those, you know, paper printed booklets and I kept reading them with me and referring to them again and again.
Participant 034_2023AUCRT

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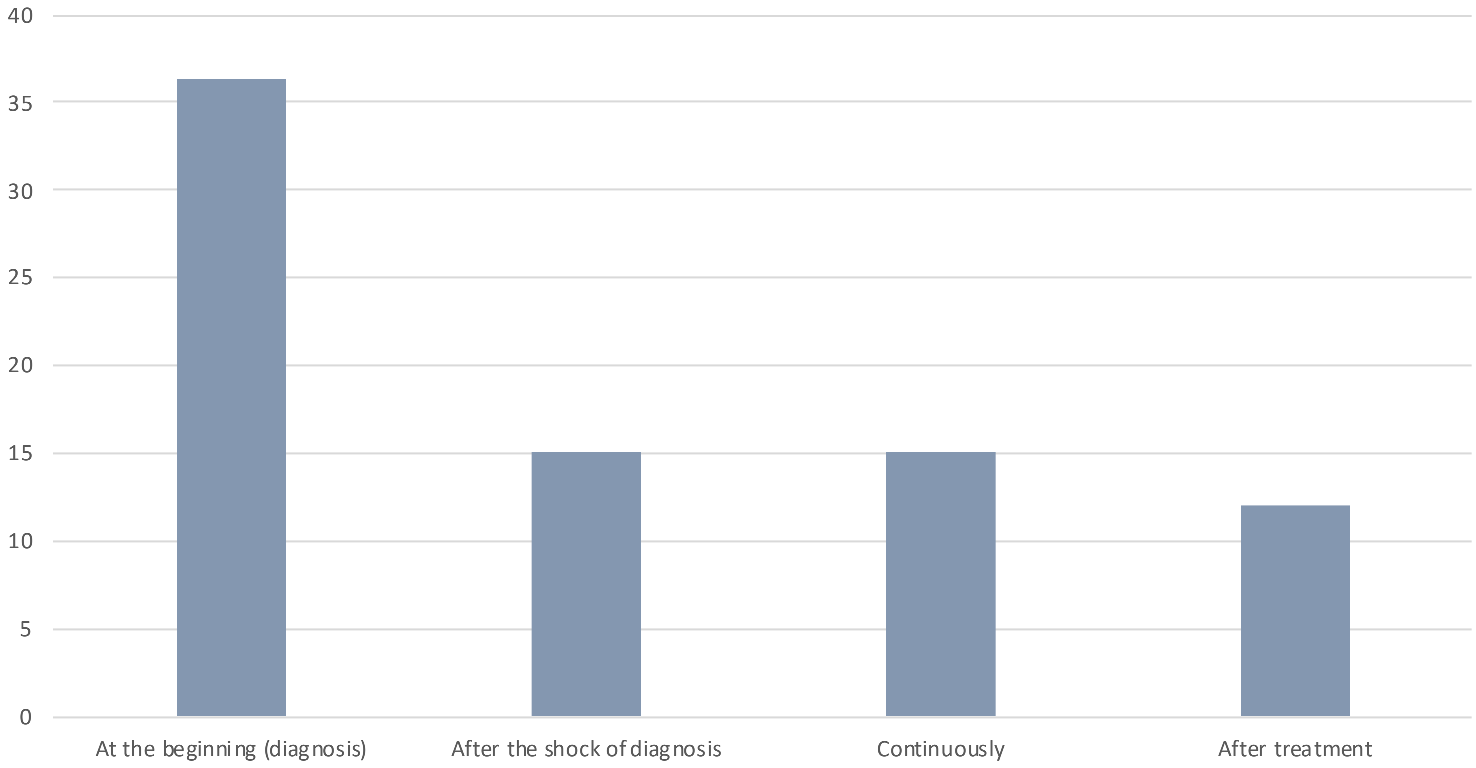
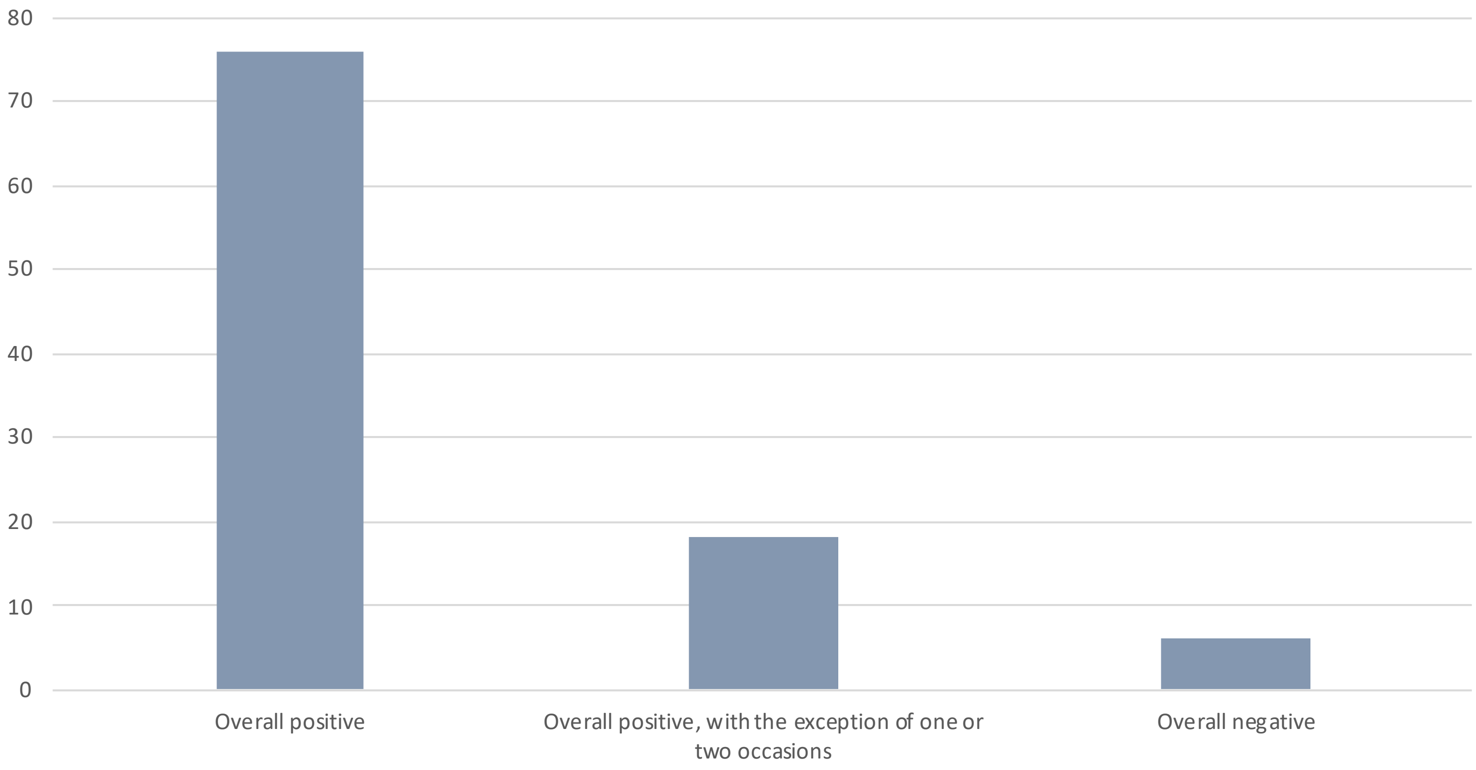
Information preference rationale (% of all participants)



Probably from day one, just cuz I just wanted to know what was going on. It's just the unknown is what's scary I suppose. Or fighting. It's unknown what's going to happen, what is this drug or what is, what is a biopsy or what is, you know, the the consequences of of taking all these drugs. What's going to happen to me? Where am I going to be on 750 kilometers from home? I don't have any family with me at the moment, things like that. So it's a bit scary at the time.
Participant 024_2023AUCRT

Timing of information (% of all participants)



Overall, like I said, a 10 out of 10 with SPECIALIST. Even with my regular GP, she doesn't do anything without consulting with him either, now.
Participant 01_2023AUCRT

About that communication overall, pretty poor. The only information I've got is because I ask the questions, not because they offer answers.
Participant 008_2023AUCRT

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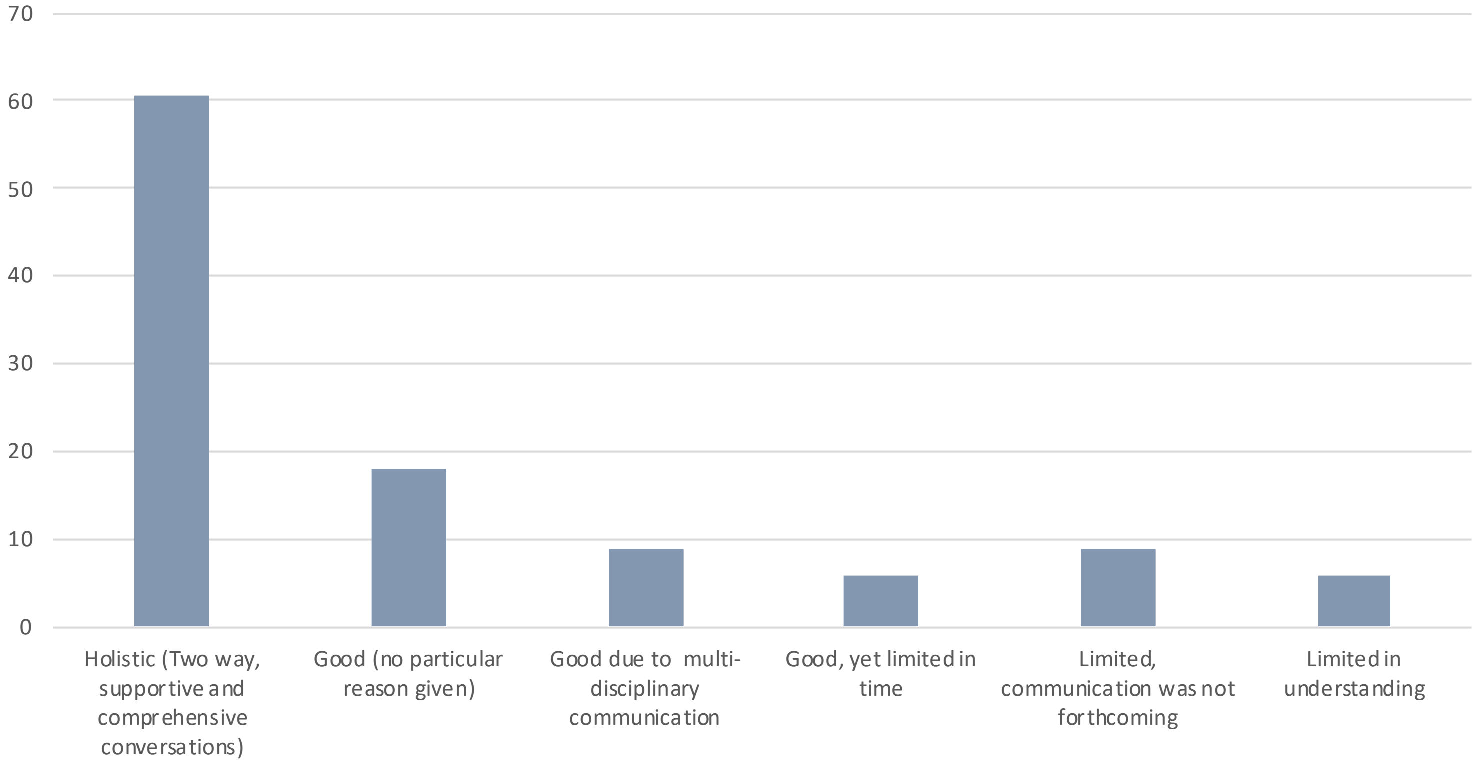
Healthcare professional communication (% of all participants)



I found the nurses really helpful, but they could only say so much. Hard to get information out of the doctors. I found the residents were easier to talk to than the specialists. I think this is a common complaint. They're very busy, and I understand that. Often I had no idea what was going on really.
Participant 003_2023AUCRT

Healthcare professional communication (Rationale for response)

Section 7

Care
&
Support

A Care Coordination questionnaire tool is used and reported in this section to demonstrate how people have been able to navigate the health system. There is also information about the care and support people have received, including from the charity sector.

Care coordination scale (n=33)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.18	9.53	47.00	12.00	13 to 65	4
Navigation*	27.09	4.69	28.00	7.00	7 to 35	4
Total score*	72.27	12.17	72.00	16.00	20 to 100	4
Care coordination global measure	7.94	1.78	8.00	3.00	1 to 10	4
Quality of care global measure	8.85	1.39	9.00	2.00	1 to 10	5

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

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.

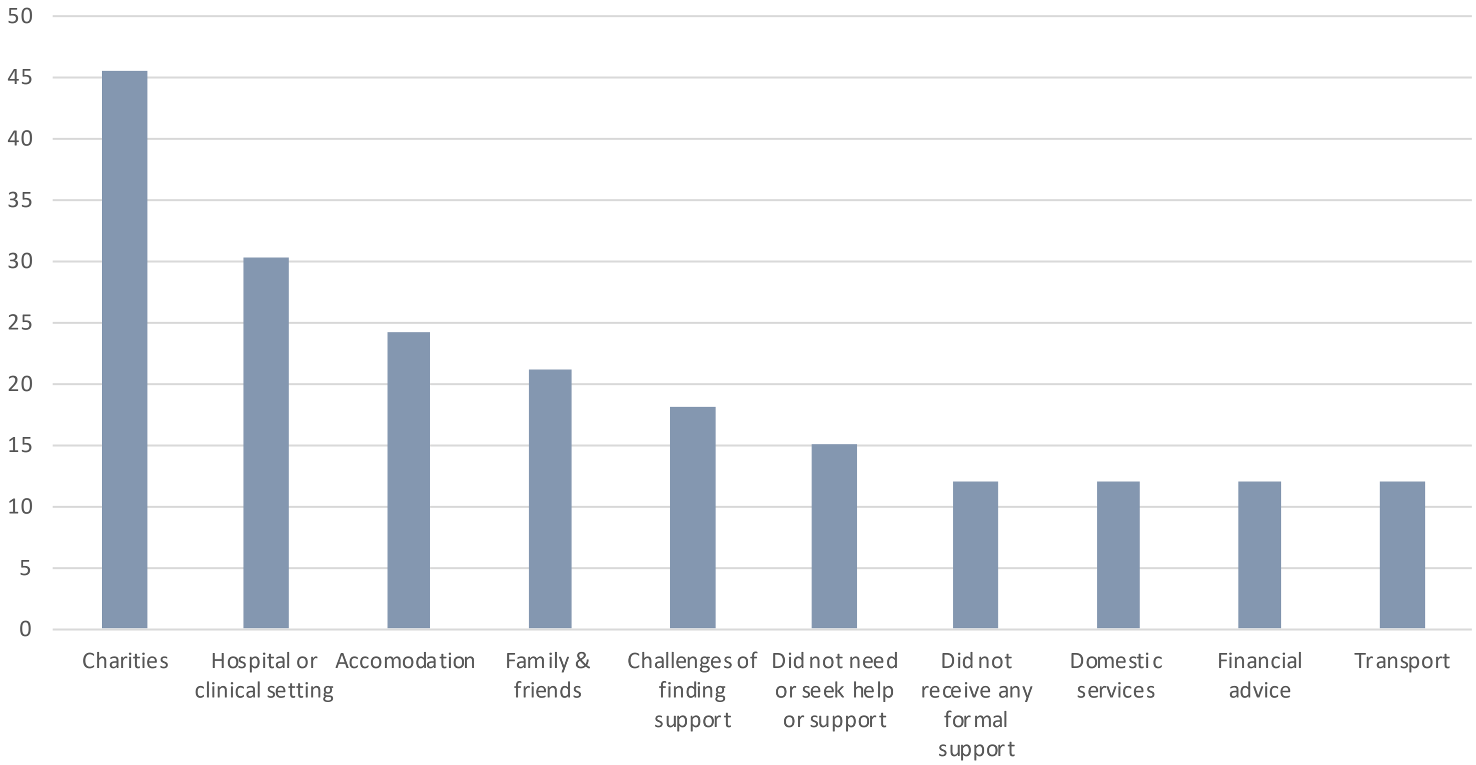
The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial 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.

Care coordination



I get help through the local council here, home care, so I have a cleaner. He comes in, he comes in once a fortnight and does some cleaning for me, which is which is good. That's only a that's only a cost to me. I think it's $6.20 an hour or something subsidized, obviously so and and apart from that I haven't had, I haven't had to rely, I haven't had to rely on any other sort of support from other organizations or other people at this stage.
023_2023AUCRT

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Care and support received (% of all participants)

Section 8

Quality of Life

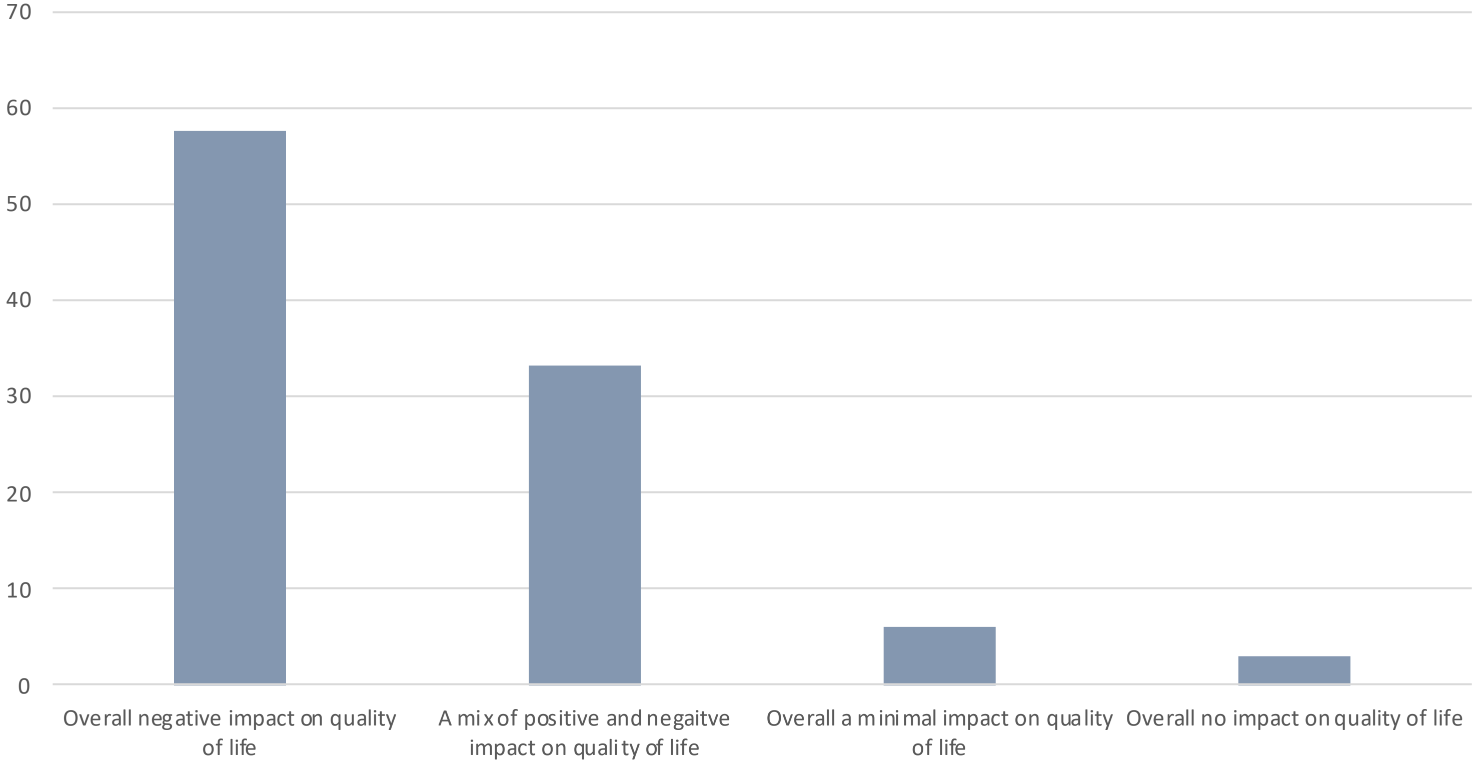
In this section, information is available in relation to the impact that the condition or disease has on quality of life, regular activities to maintain mental health, regular activities to maintain physical health, impact on relationships, impact on family and relationships, cost considerations. The Fear of Progression tool is used and reported here to describe the level of anxiety that participants may have in relation to their condition.

Fear of progression (n=34)	Mean	SD	Median	IQR	Possible range	Quintile
Total score	30.82	11.27	28.50	18.00	12 to 60	2

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

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.

Anxiety (measured by FOP)
Overall quality of life



It affected the family, obviously, when I was diagnosed and being in hospital all the time. Now that I'm home, things are slowly returning back to normal. I'm at home most of the day and managing to do the daily activities and whatever, like cooking dinner and things like that, which I wasn't able to do before. Probably the worst for them is over, but I'm a bit concerned that I think they're a little bit overcautious at times about me being able to do things.
Participant 002_2023AUCRT

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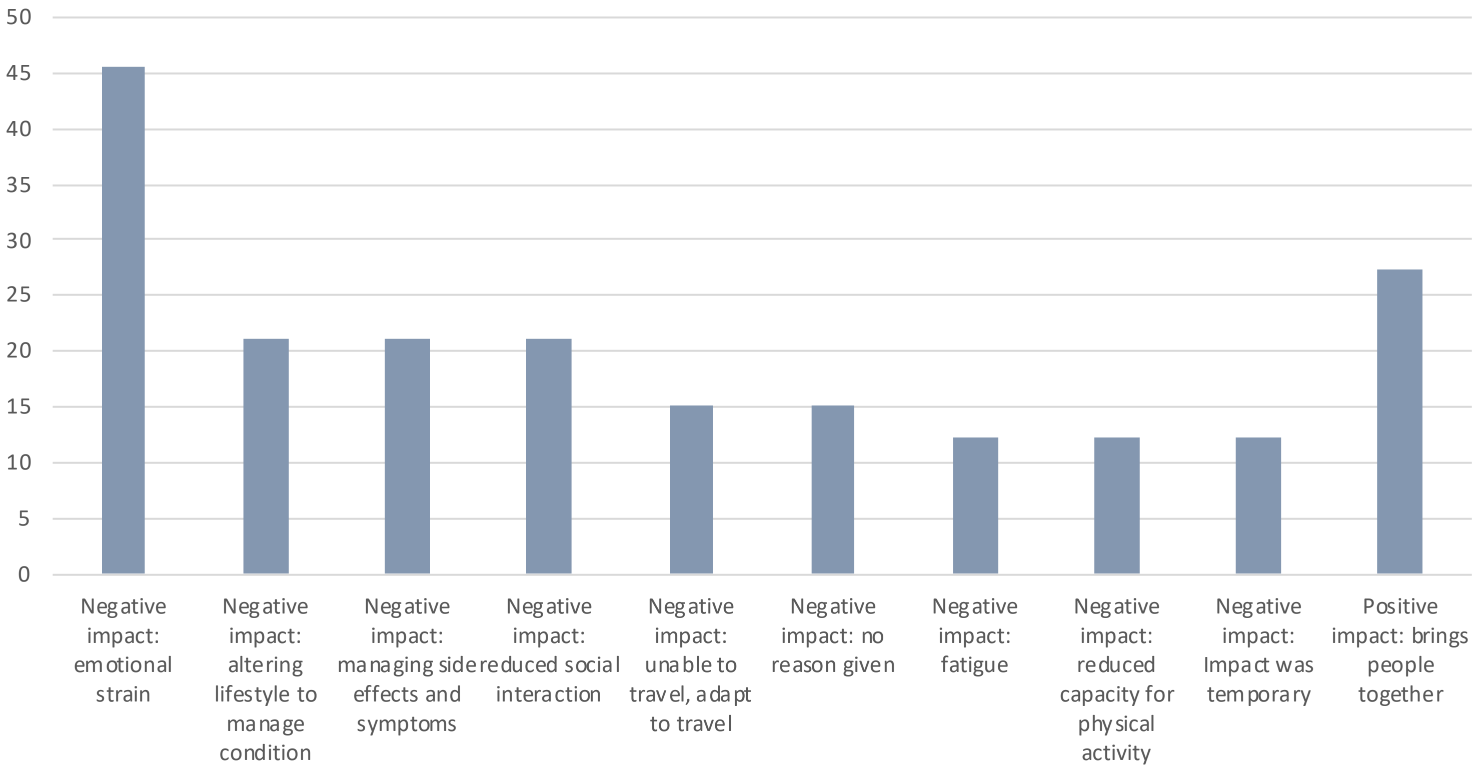
Impact on quality of life (% of all participants)



During treatment and probably a couple years past the treatment, yes, it has affected my quality of life with what I've been able to do and to achieve with regards to work, my physical activity, socializing, things like that. About we had to give up everything that I was doing for three 3 1/2 years to maybe 4 1/2 years, right?
Participant 024_2023AUCRT

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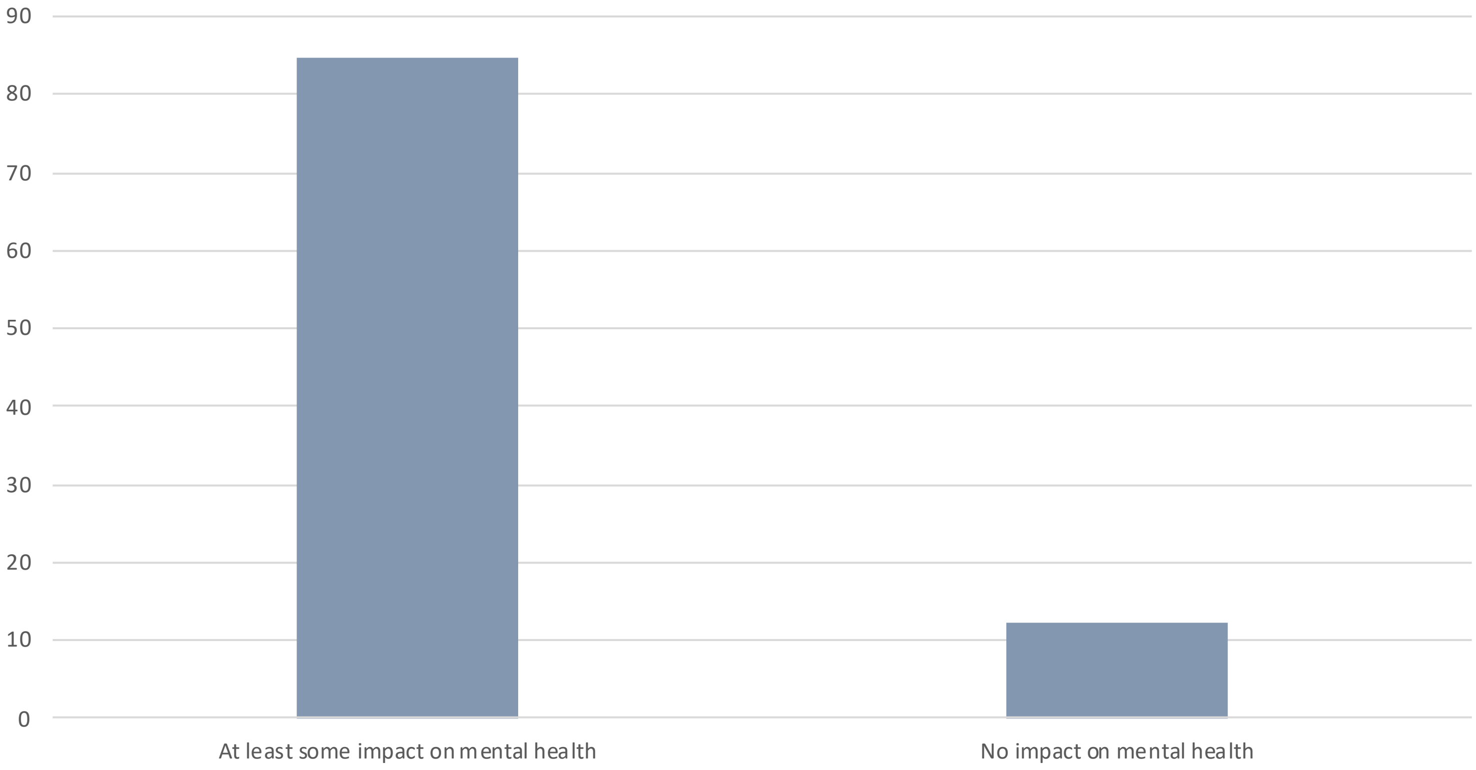
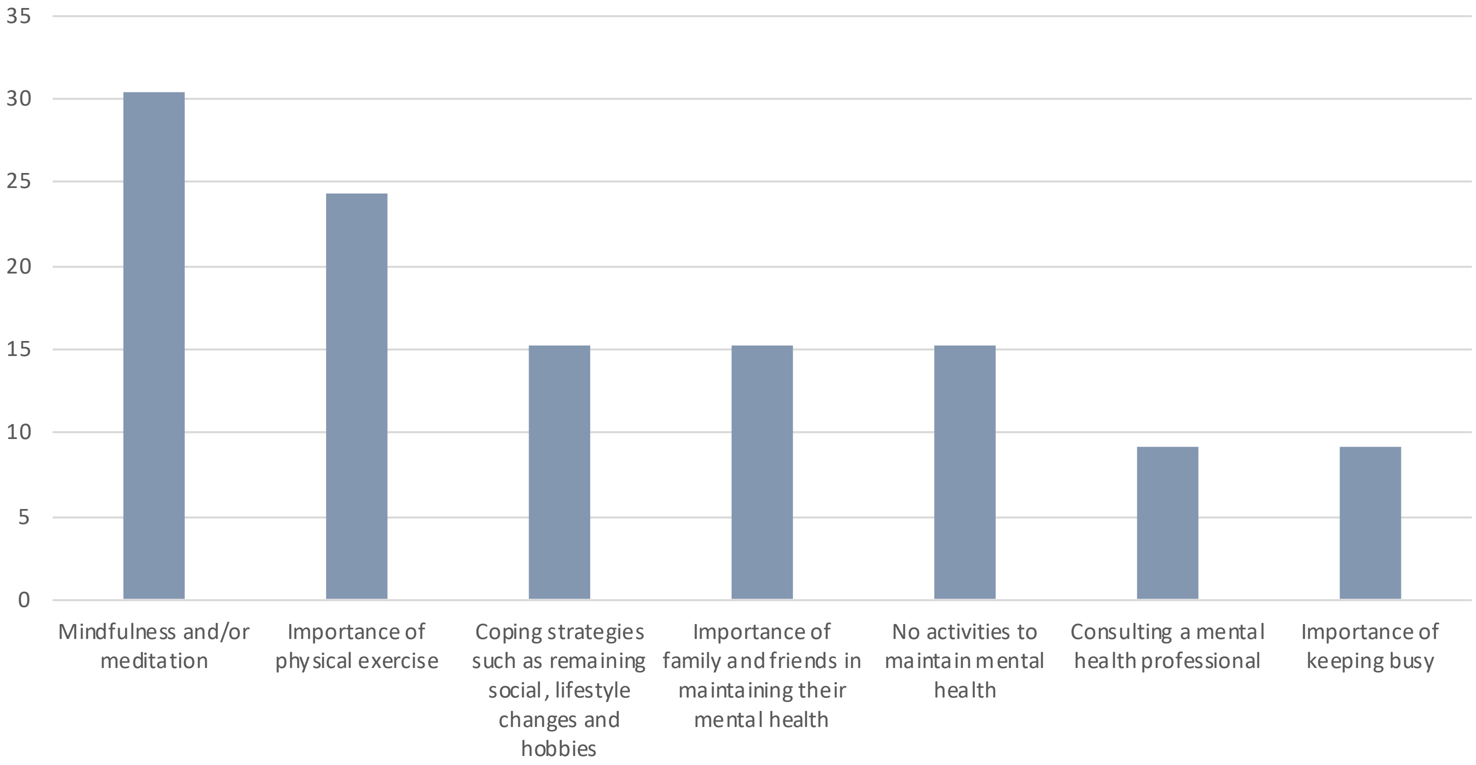
Impact on quality of life (Main reasons) (% of all participants)



Yes. My mental health, I find I don't worry about stupid things anymore like I used to. I think I've calmed down that way. I still keep myself quite active mentally. I watch a lot of documentaries on TV, do a lot of word puzzles and whatever. Yes, I'm just taking each day as it comes just trying to get a little bit stronger just so I can start doing a little bit more.
Participant 002_2023AUCRT

Impact on mental health (% of all participants)



Ride the bike. That sounds weird, but. You can. You can solve it. And bought a new puppy too. But yeah, yeah, you can solve the world's problems when you're out riding a bike off the land over sort of many years.
Participant 022_2023AUCRT

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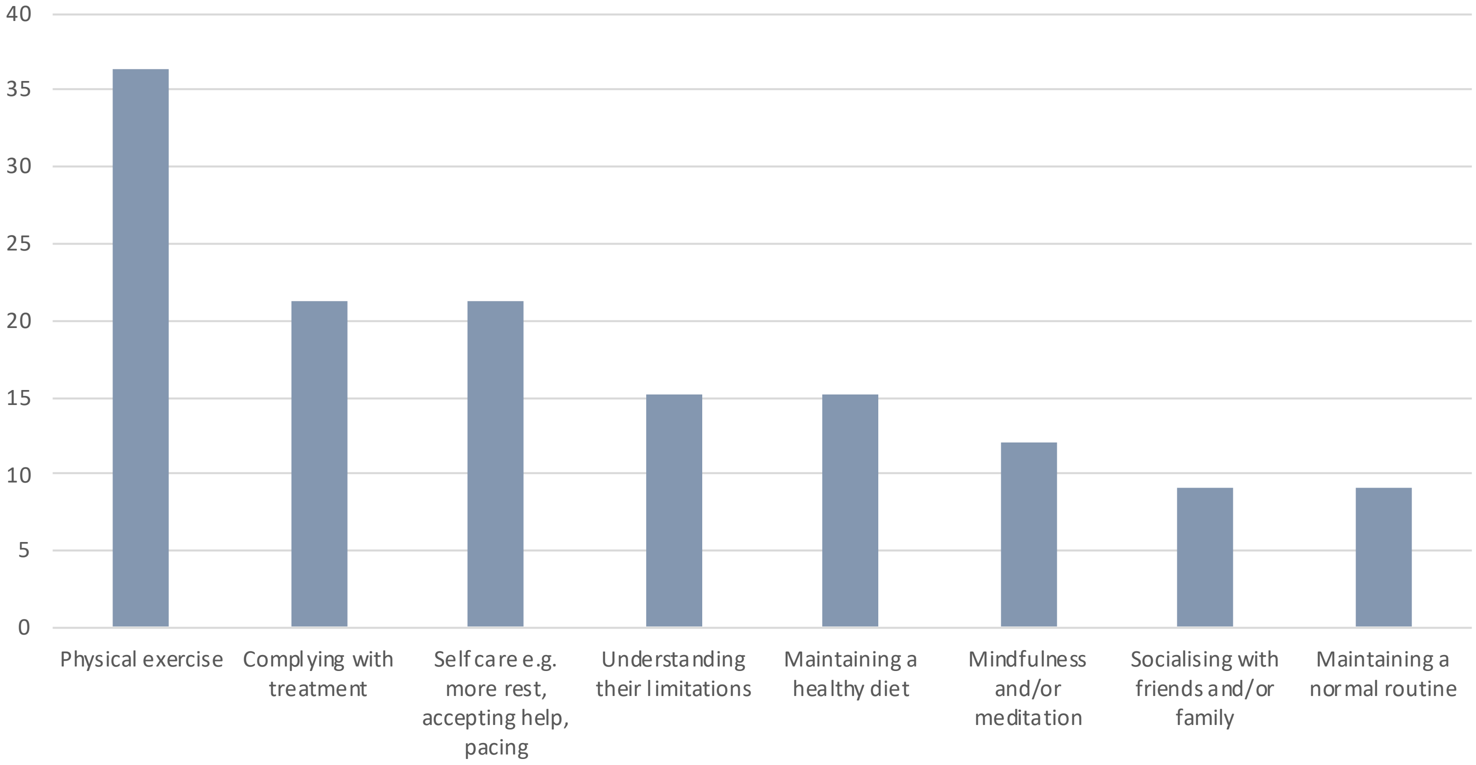
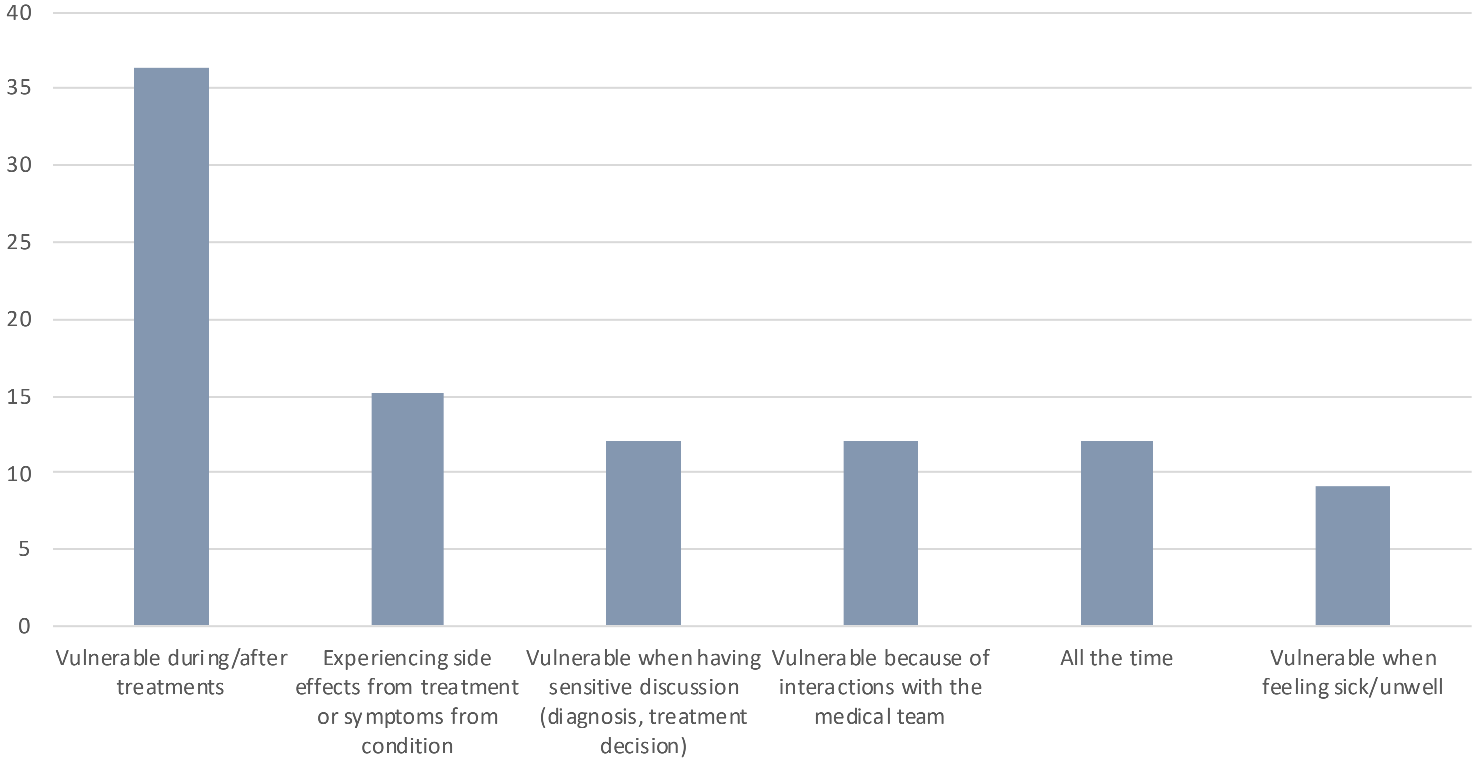
Regular activities to maintain mental health (% of all participants)

Regular activities to maintain general health (% of all participants)



I think I've learned that I need to only do things in small doses, and I need a lot of rest because I still get really tired. Sometimes I'm great, I'm full of energy, then all of a sudden I'll just come to a halt. I used to be a real multi-tasker and do loads of things at once, but now I've learnt that I can't do that now

Participant 004_2023AUCRT



Yeah. Most of the time was undergoing for chemotherapy because it's just the unknown of what's going to be happening next week or the next month or how you're feeling. Because when you're if you're getting basically smashed by all these drugs so you don't know how quickly like if you have a cold, you can say oh we're going to recover in a week. But when you're having this chemo for three years, you go, well, how long is this going to affect me for? So it's just the unknown place that's the. The bit that you're frightened on. Well, not frightened, but you just wanna know more information than no one can really tell you.¶
Participant 024_2023AUCRT

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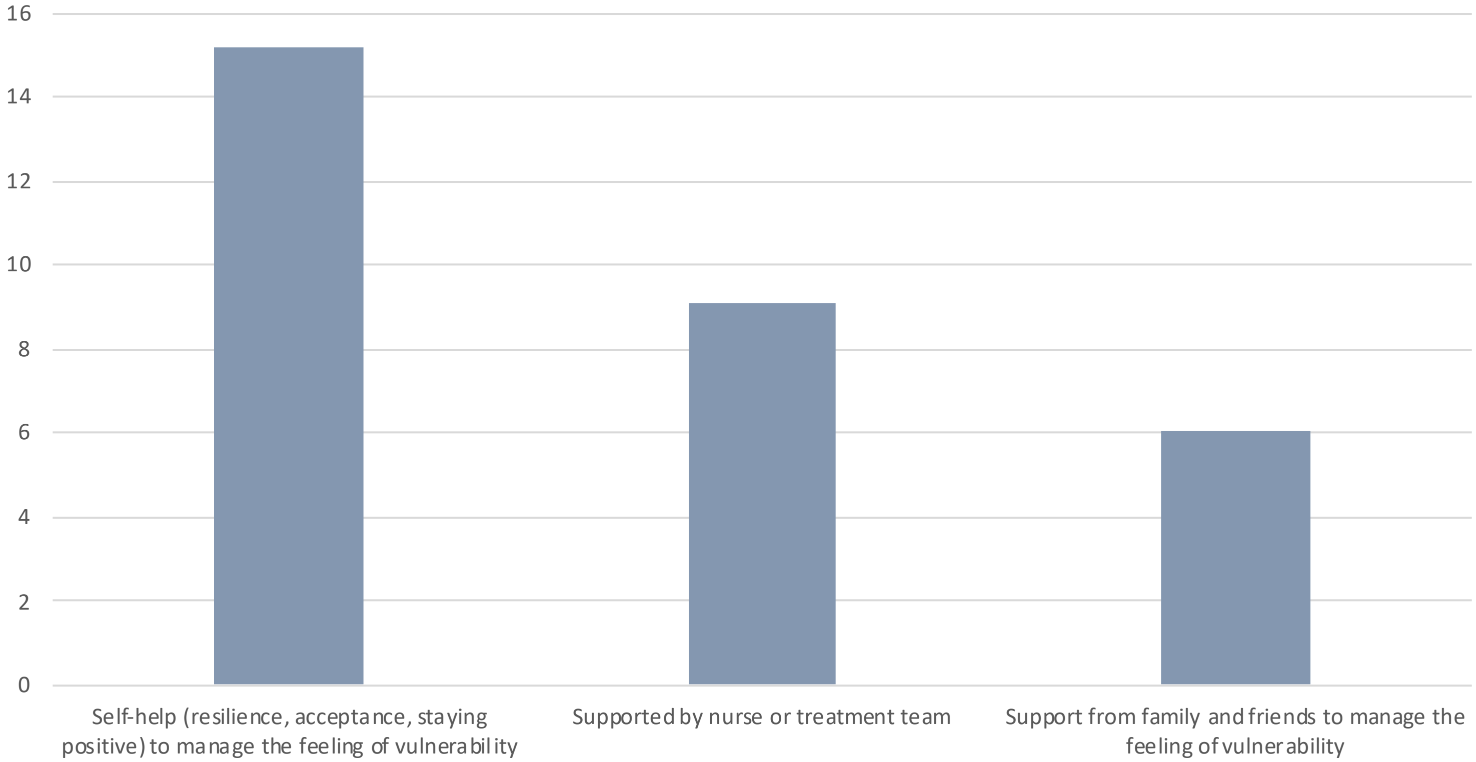
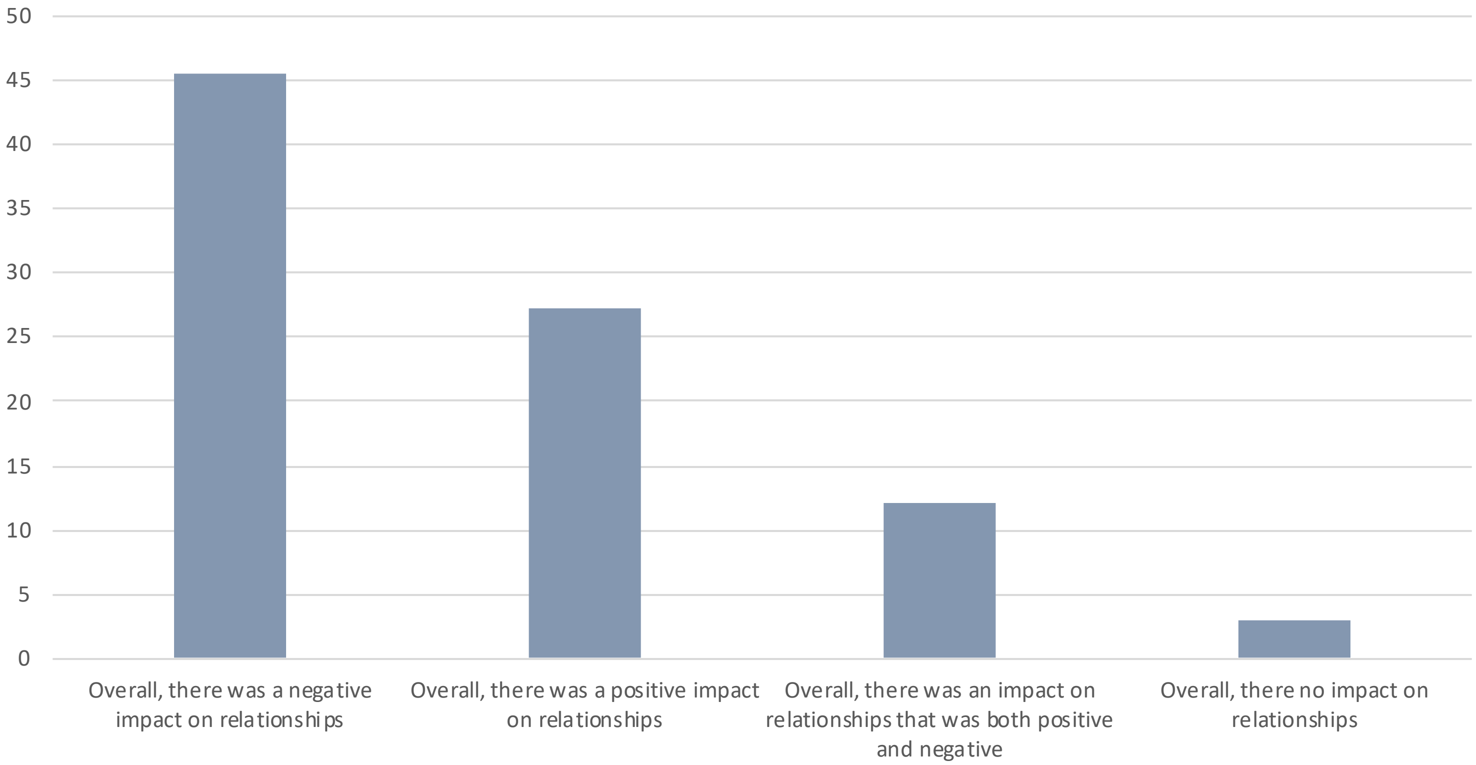
Vulnerability
% of all participants

Vulnerability
% of all participants



Well, I had a few friends that came and helped, which was good. And yeah, a few of them have stayed with me and they help with transport and everything and and food and everything. So yeah, that was, that was good. I should say. I always have. Yeah, my son was there as well and he was ok. He didn't understand. Possibly.

Participant 015_2023AUCRT



> ***No, but it was hard sometimes with some friends that live very close by. I felt over that period of that 10 months, my life was just going to the hospital every day. That was a bit like Groundhog Day every day. You could see them going off doing what they wanted. Only a few friends, not all of them but a couple of them, probably distanced our friendship because of that, because I was away for that long period. I guess like anything, if you don't associate with someone for 10 or 11 months. Participant 001_2023AUCRT***

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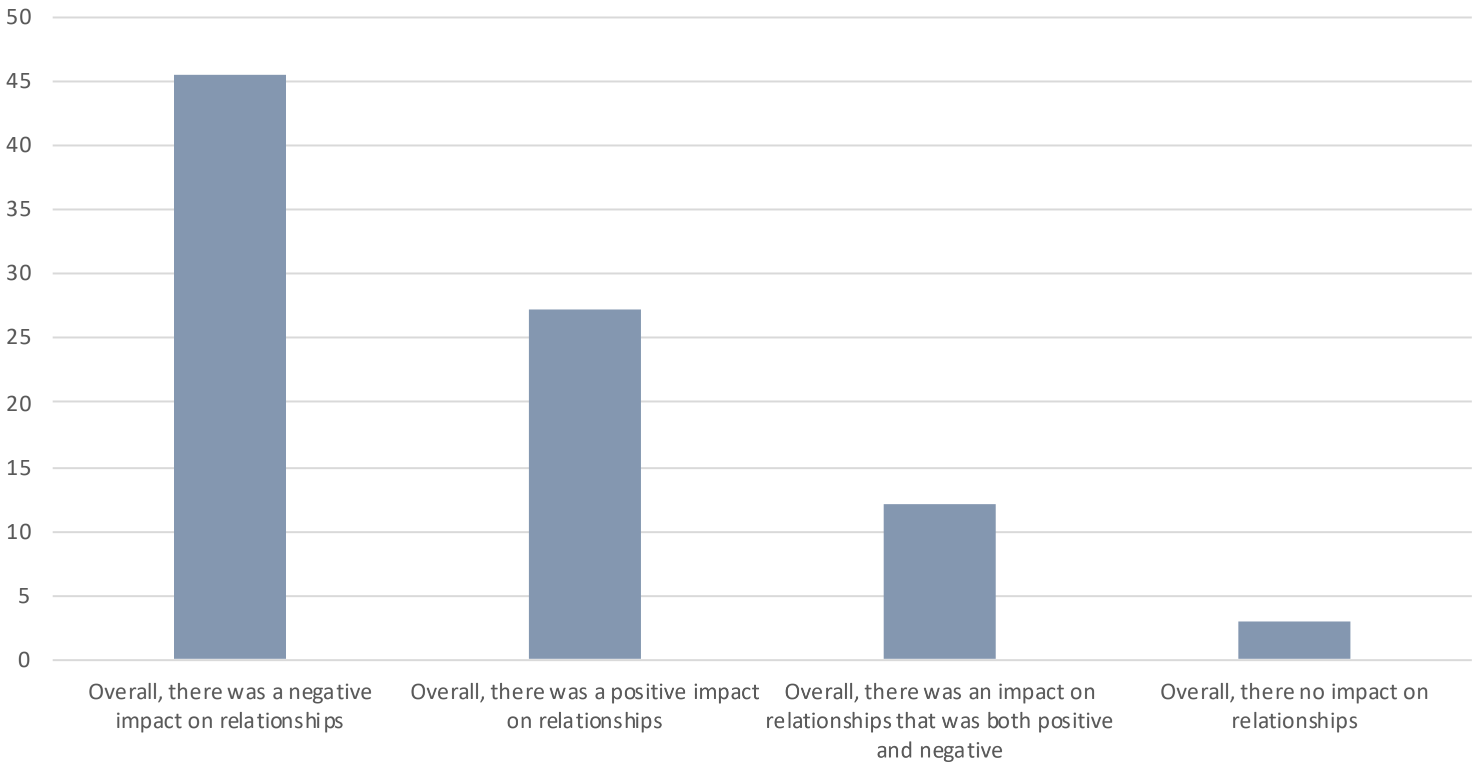
Impact on relationships
% of all participants



In the sense we've become closer, I think, which is lovely, you know, grandchildren will take me by the arm or help me down steps, you know, automatically. I love you, Pop. It's beautiful, really. So we're very close. We always have been close, but that's been enhanced. It's I'm aware that it's not easy for NAME because she's had to give up a lot, but we do enjoy being with each other and you know, we'll go out to lunch or whatever.
Participant 035_2023AUCRT

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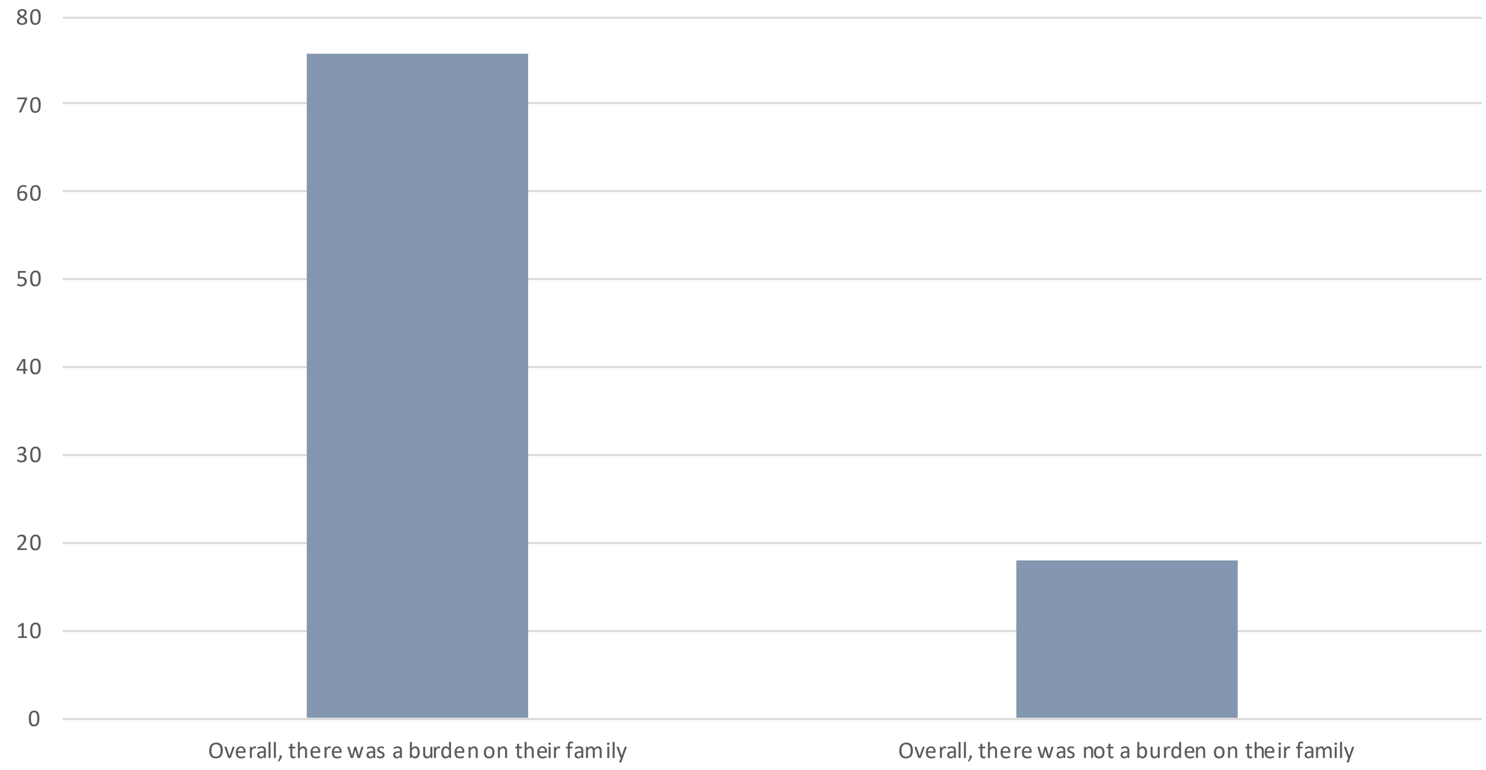
Impact on relationships - reasons (% of all participants)



Well, I suppose as far as them stress wise, you know worrying about the if if you know you're going to survive that that that would be a burden to them and that's something I don't want for them. But yeah, that that's the only area and yeah it's I suppose it's just how they feel about how you're feeling or what's going to happen to you. It's more more of the problem. Participant 015_2023AUCRT

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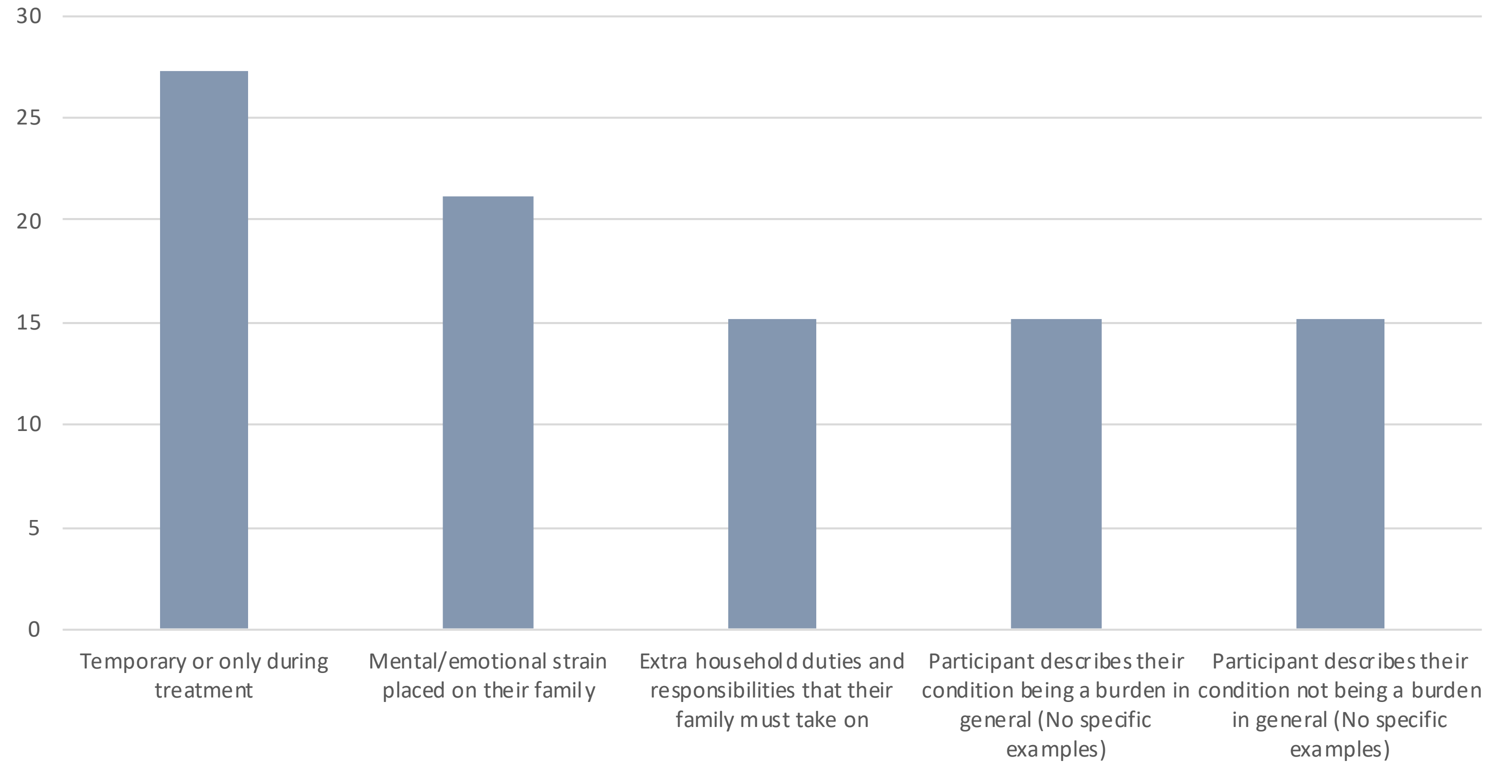
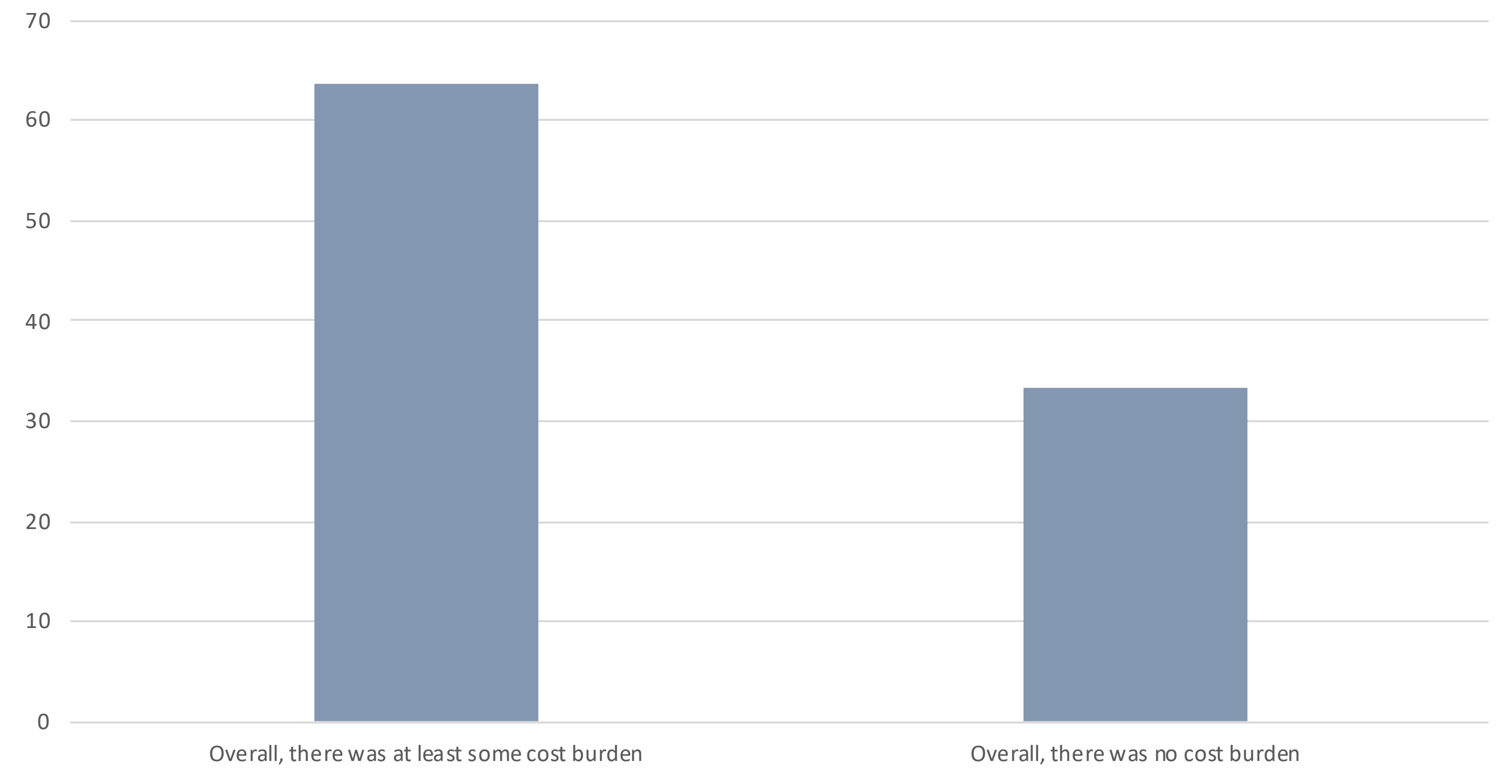
Burden on family (% of all participants)



Initially yes, like when mum took the year off to look after me, because she really, really enjoys her job, but now not so much only because I'm fortunate, there's no longer any treatment required or anything and the just the every three months going back to LOCATION for checkup biopsies. Participant 005_2023AUCRT

Centre for Community-Driven Research

Burden on family (% of all participants)



I haven't really incurred many costs at all. Some of the medications are little bit pricey, but given the big picture, they're only one $40, $50. My big thing for me is that I've had to leave work. It's just that sense of independence, that's all, but no other costs really that have been of a worry.

Participant 002_2023AUCRT

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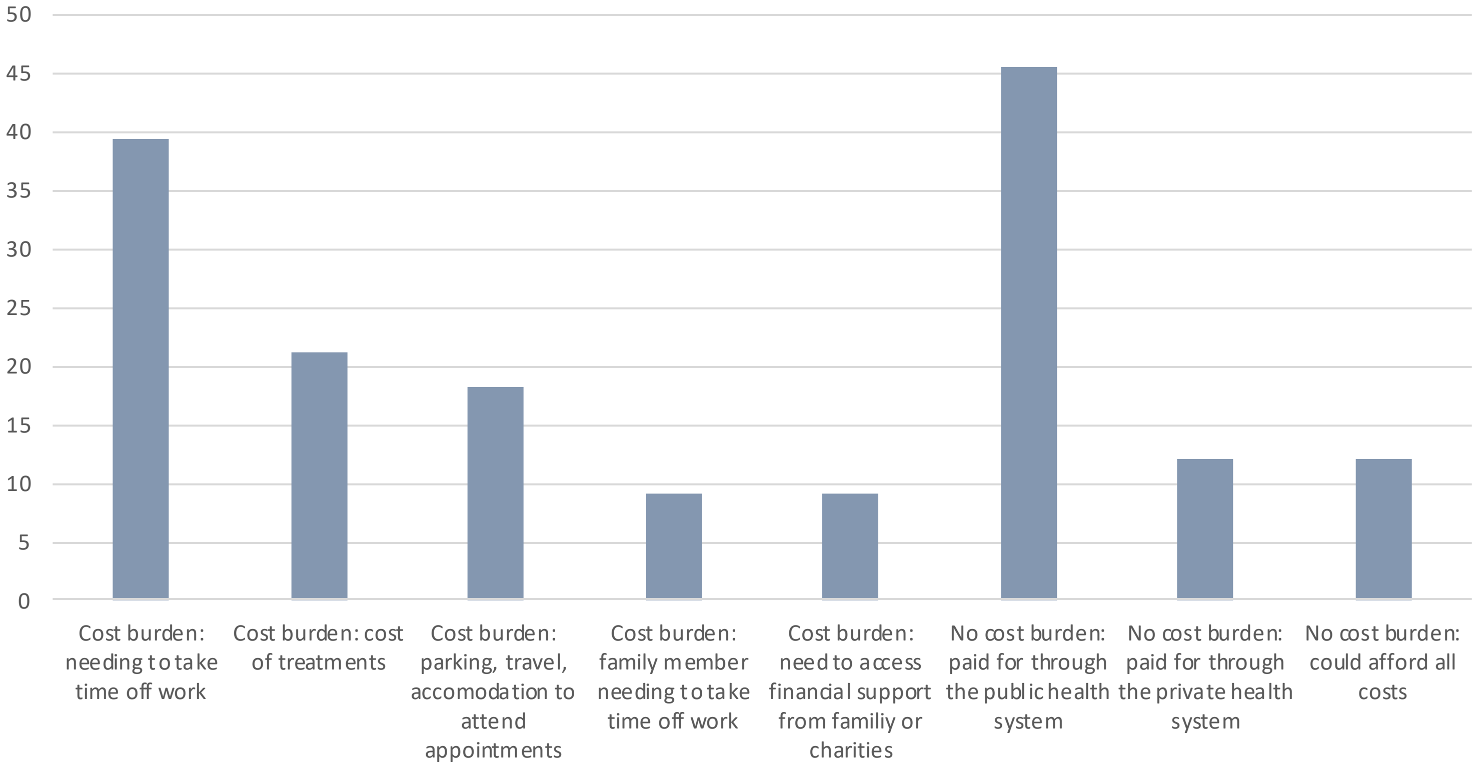
Cost considerations (% of all participants)



OK. The only cost that I've had to bear is really for medications, and I never quite reached the whatever the limit is which reduced. The cost of medication, so that that that was sort of like a regular cost that that I did feel particularly as interest rates have gone up. So I was, I was getting a little anxious about that. But yeah, now I'm not taking anywhere near the medication, so it's not a problem.
Participant 009_2023AUCRT

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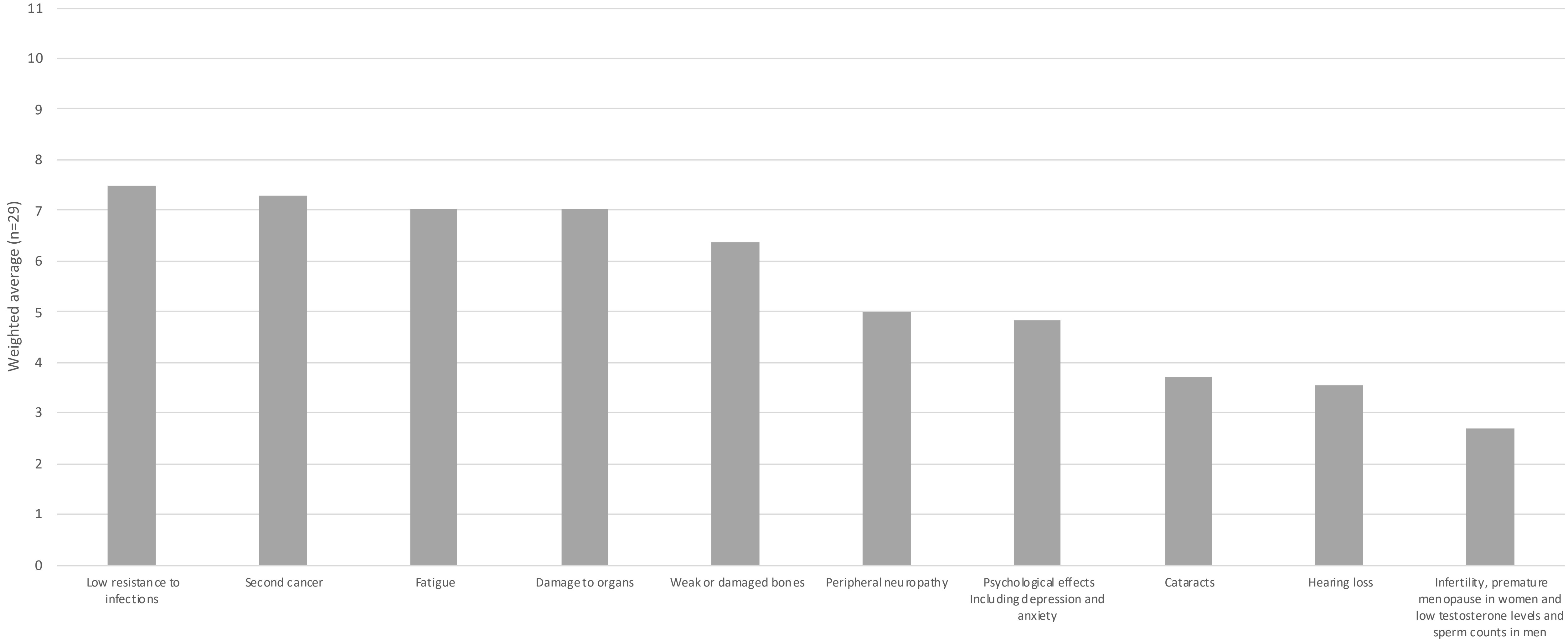
Cost considerations - reasons (% of all participants)

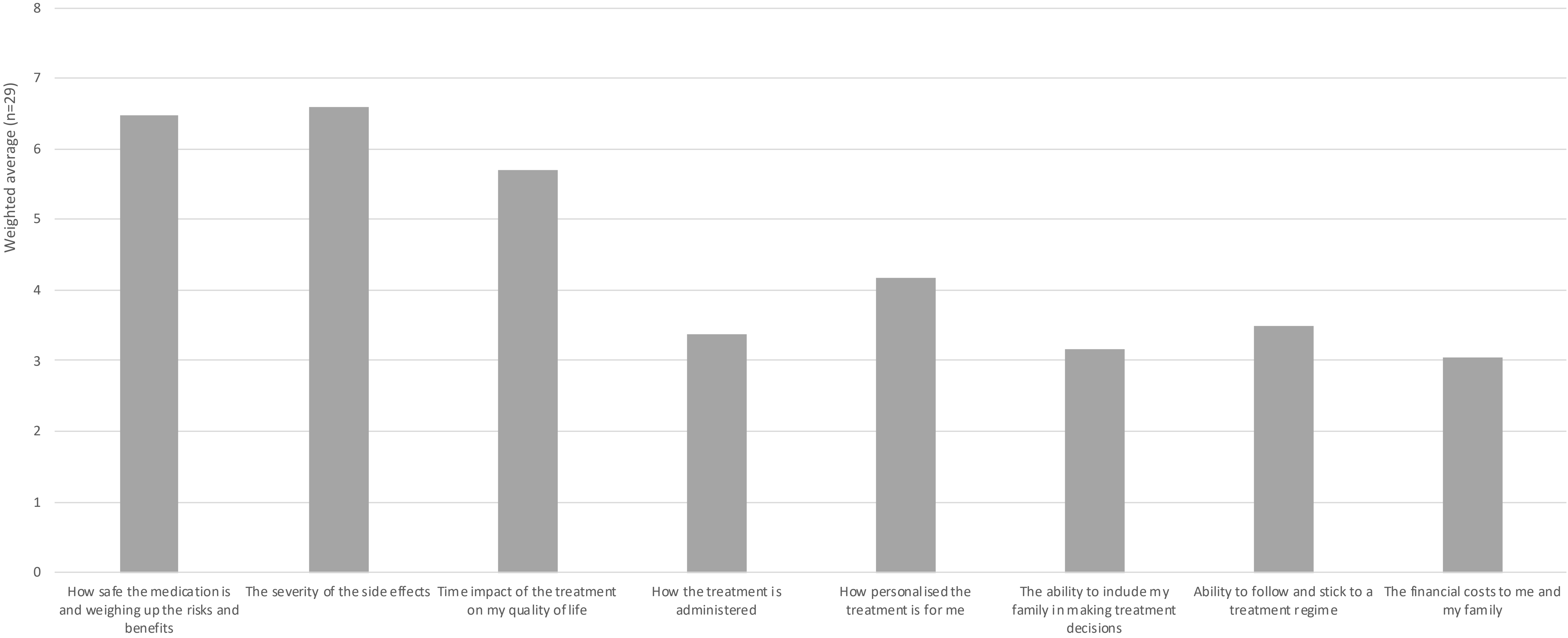
Section 9

Expectations
&
Messages to Decision-Makers

By the time participants are asked questions about their expectations of the future, they have had the chance to talk about everything that they have been through. It means that they have been able to reflect on what worked for them and what was potentially not so great. In this section there is information about what participants would like to see from future treatments, information, care and communication. We present the cohorts message to decision-makers about their condition and the values that are important to them when they make decisions about treatment and care. In this section there is also information about what people have been grateful for.



Symptoms and aspects of quality of life



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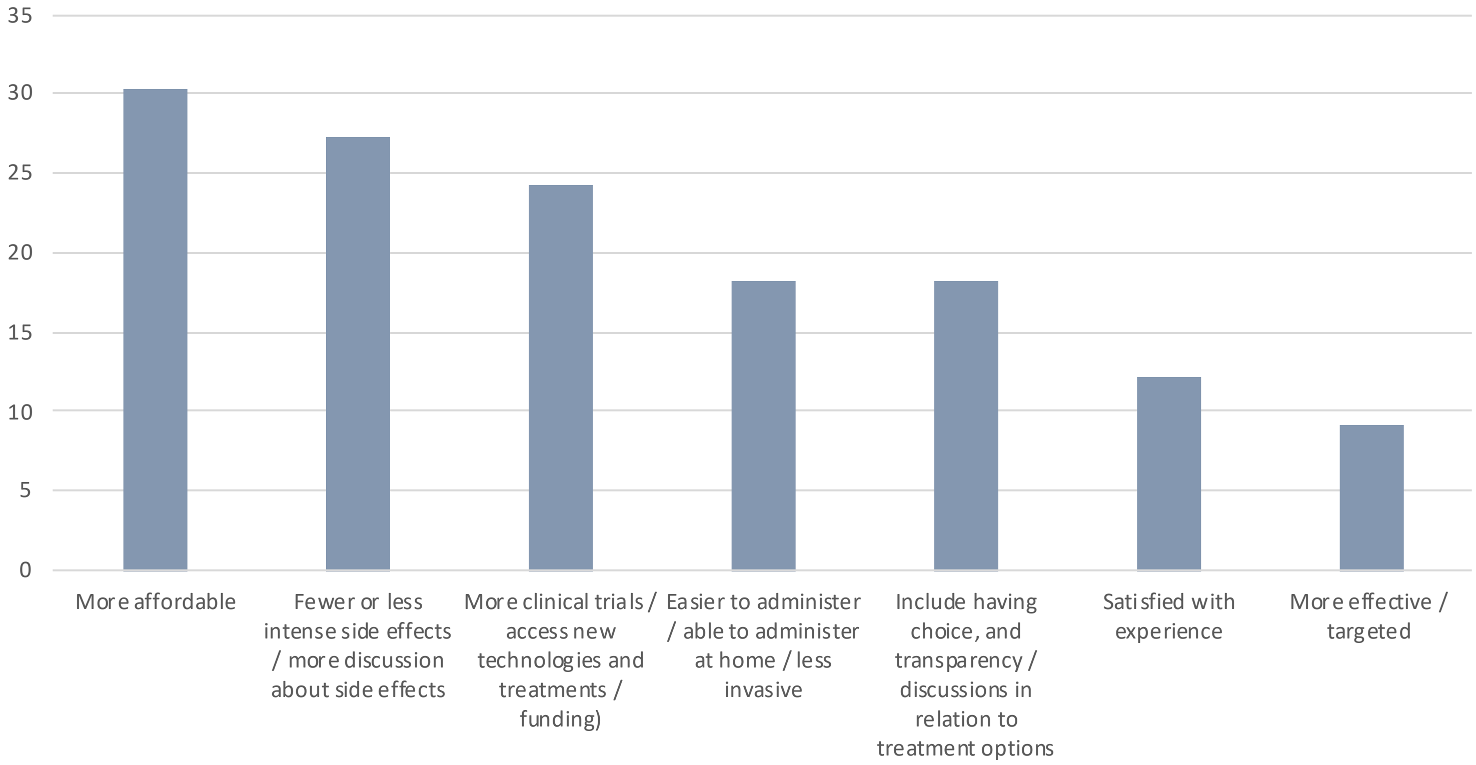
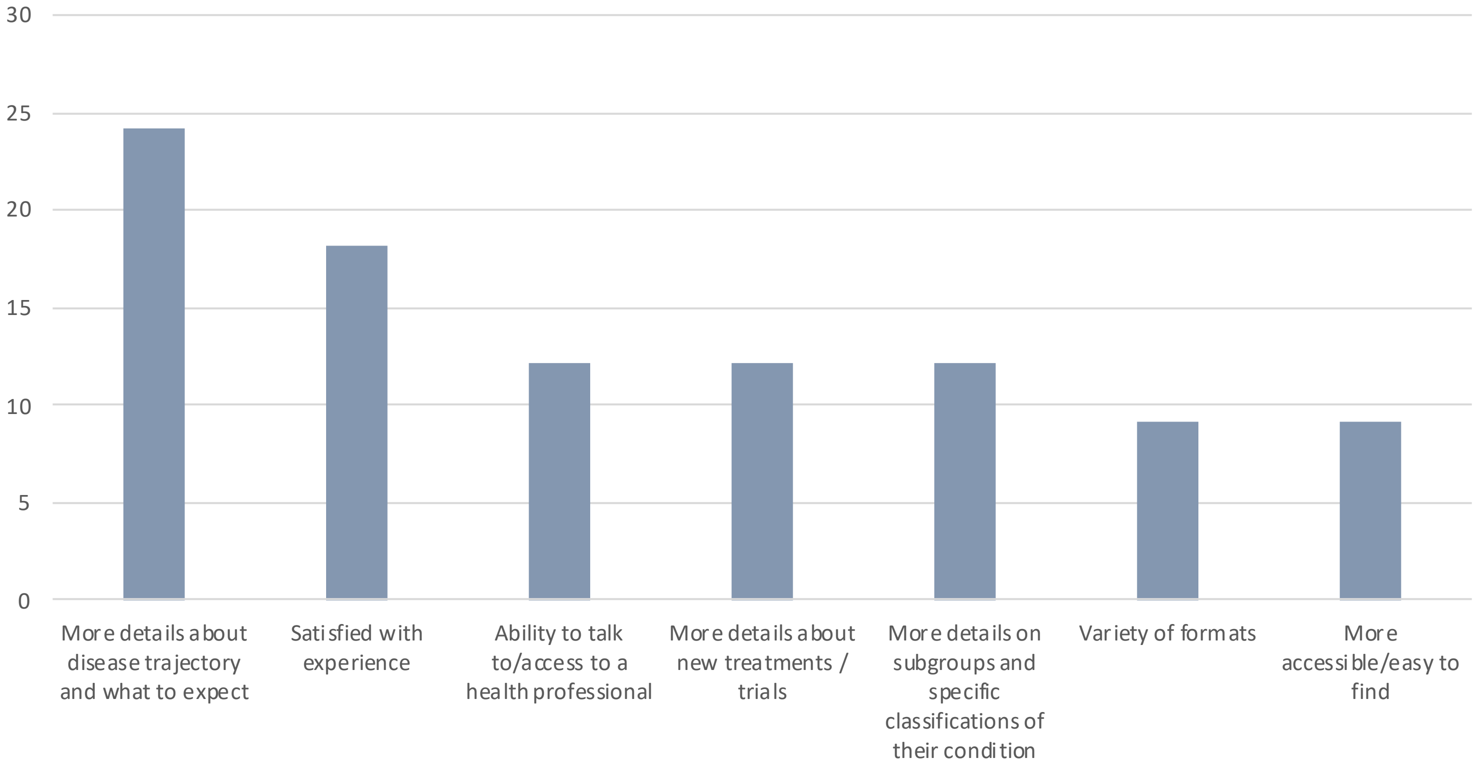
Values for decision to consider

Expectations of future treatments (% of all participants)



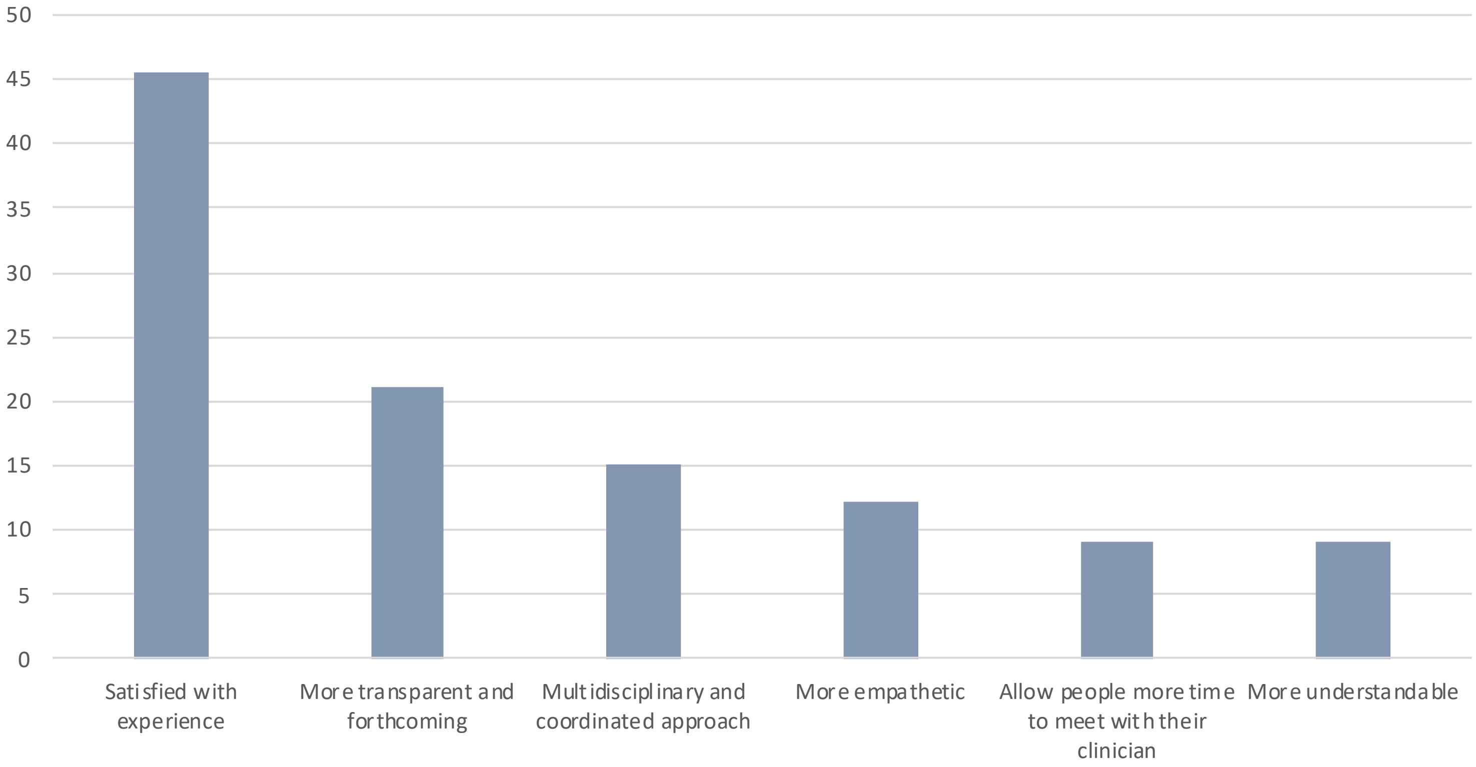
I'd like to see CAR T go on the PBS. And I'd like to see it more readily available earlier. And I would also like to see the, and I'm trying to think of the name of them, the group that recommend and approve new drugs to go on the PBS. Yeah, my my sense is that there's large lobby groups around breast cancer and prostrate cancer and all the biggies. But if you cop a rare one, you know there's not a lot of money to be made from a really rare drug that's only gonna be used by a few people. So there isn't that push and that promotion to get stuff on the list.
Participant 022_2023AUCRT



> *The emotional after-effects once you've been through the treatment, that I think is the most important, because I thought I'd just bounce back. I thought, "Great, I'm finished, get on with my life and I'll bounce back," but I didn't. I did and I didn't. I was always up and down. I wasn't prepared for that. I think it's like a shock, you go into a bit of a shock afterwards. You deal with it at the time, and then you go into shock later.*
> *Participant 004_2023AUCRT*

Expectations of future information

Centre for Community-Driven Research



Yeah. Well, that that, that'll be it I think to to to you know to to give information about the latest developments in the in the disease.
Participant 014_2023AUCRT

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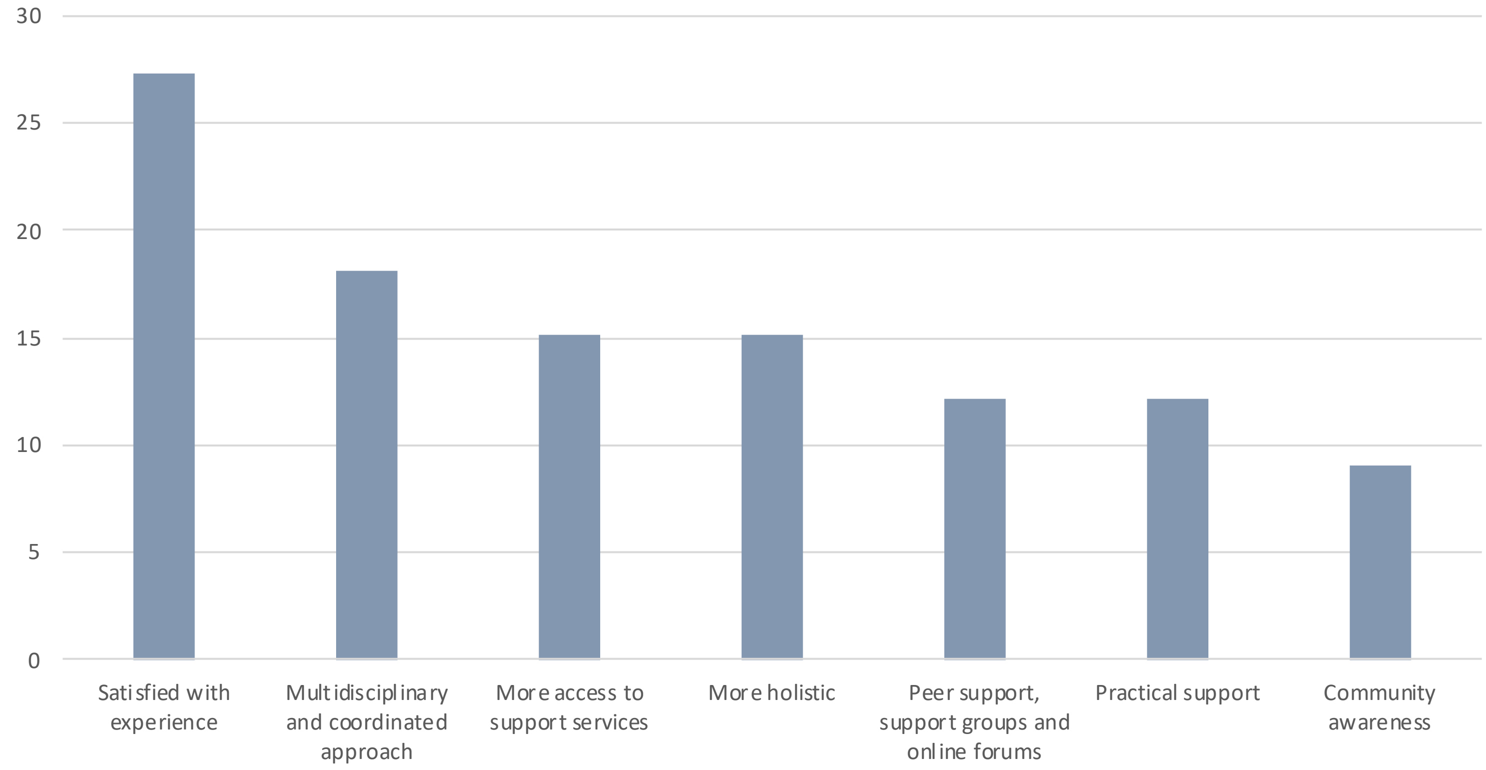
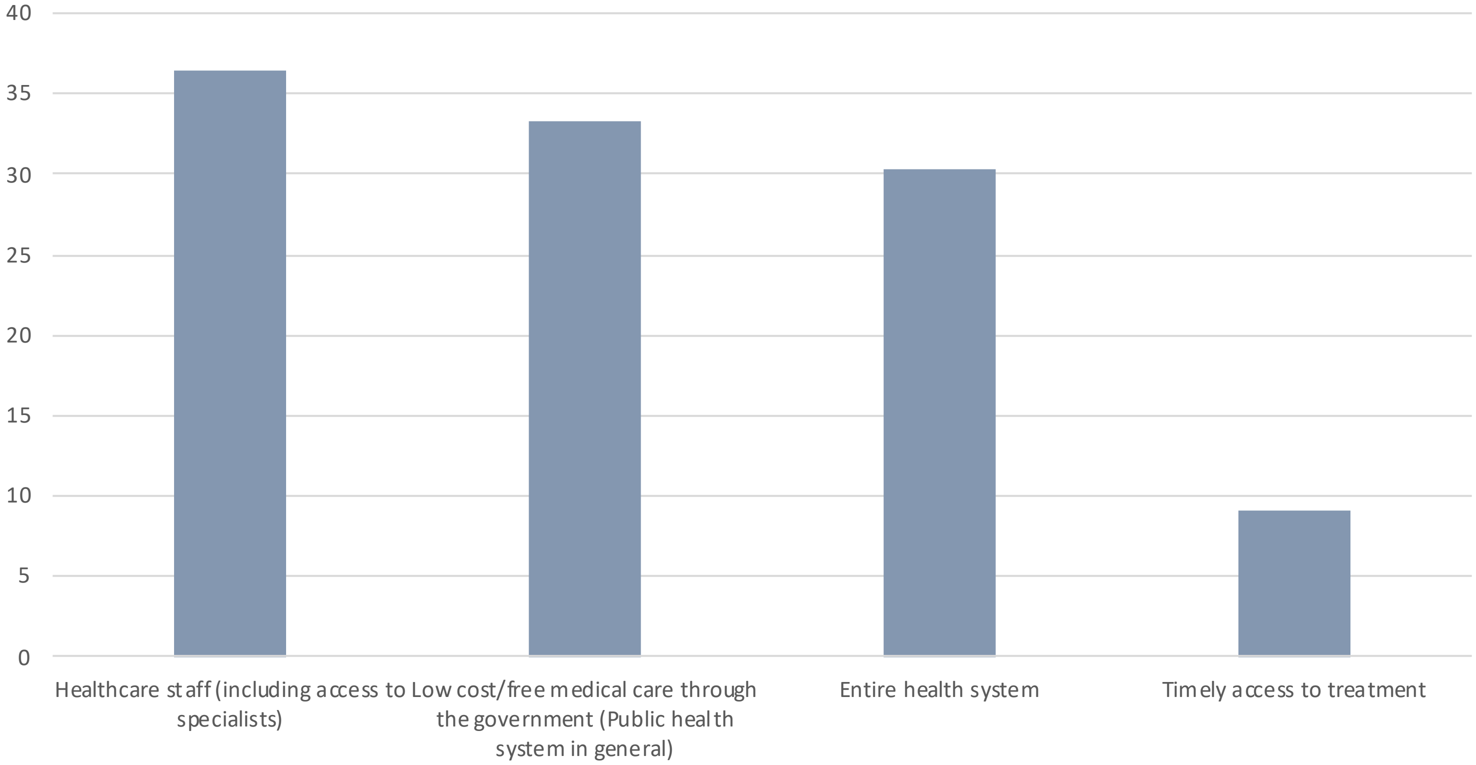
Expectations of future communication



So it might be through charities of the hospital system or like, I think when we first had that and the Leukemia Foundation, it was a lot of humming and haaring to see if we were eligible or not. And it turned out we were. But yeah, people need that reassurance that there's someone there to look up like to help you out where you're not just well with us. We just weren't left on our way. Like the Leukemia Foundation. They're just marvelous.
Participant 011_2023AUCRT

Expectations of future care and support

Centre for Community-Driven Research



The people are amazing, from the cleaners and the ward staff, right through to specialists and nurses and doctors. I feel so safe and cared about and respected, you know, And grateful. Yeah, I've had. Yeah, I can't say that enough.
Participant 016_2023AUCRT

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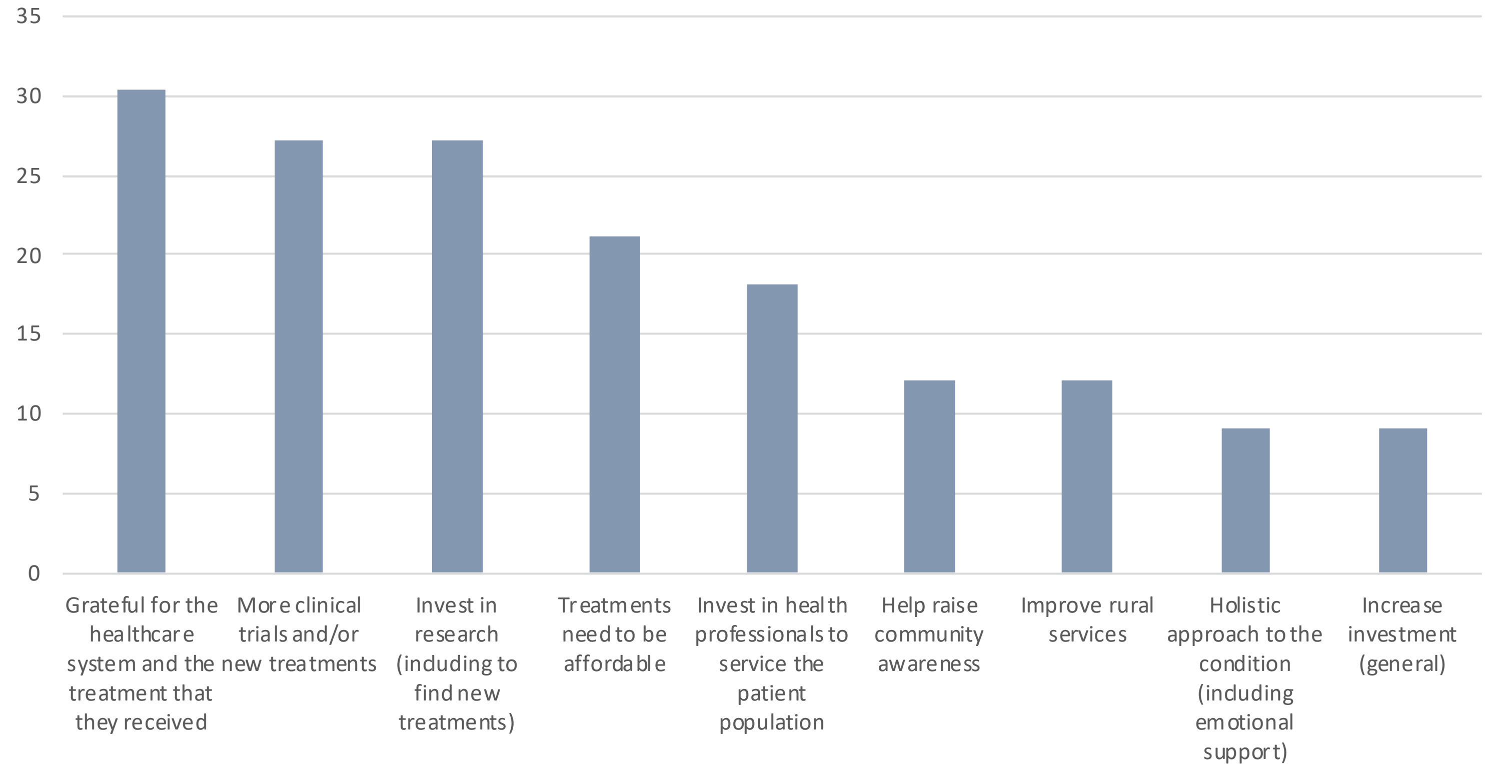
Grateful for in health system

Message to decision-makers (% of all participants)

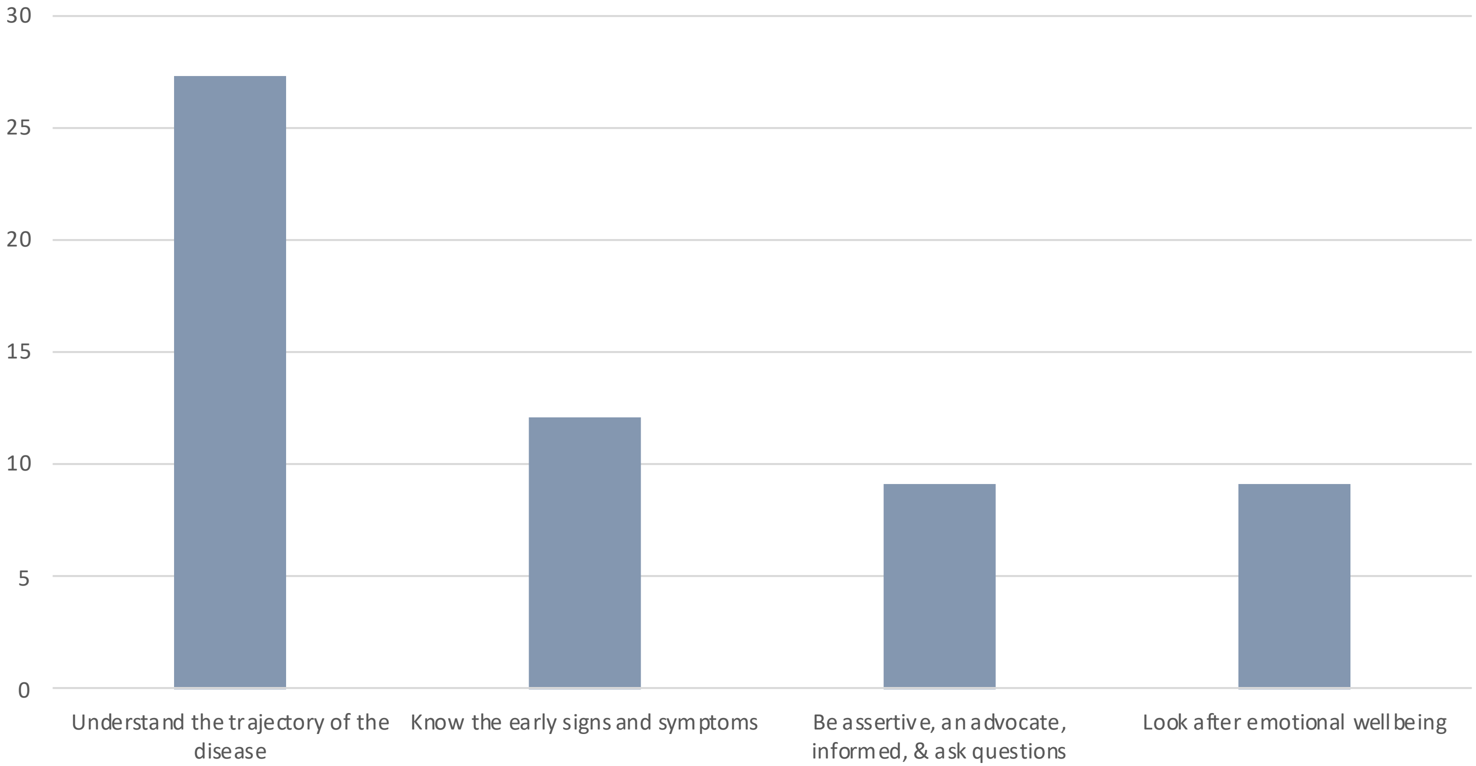


Yes, getting pharmaceutical drugs in approved you know the approved of certain drugs which the CAR T cell and stuff all that kind of thing that's coming in. It took way too long to get approval to get it Participant 020_2023AUCRT

Section 10

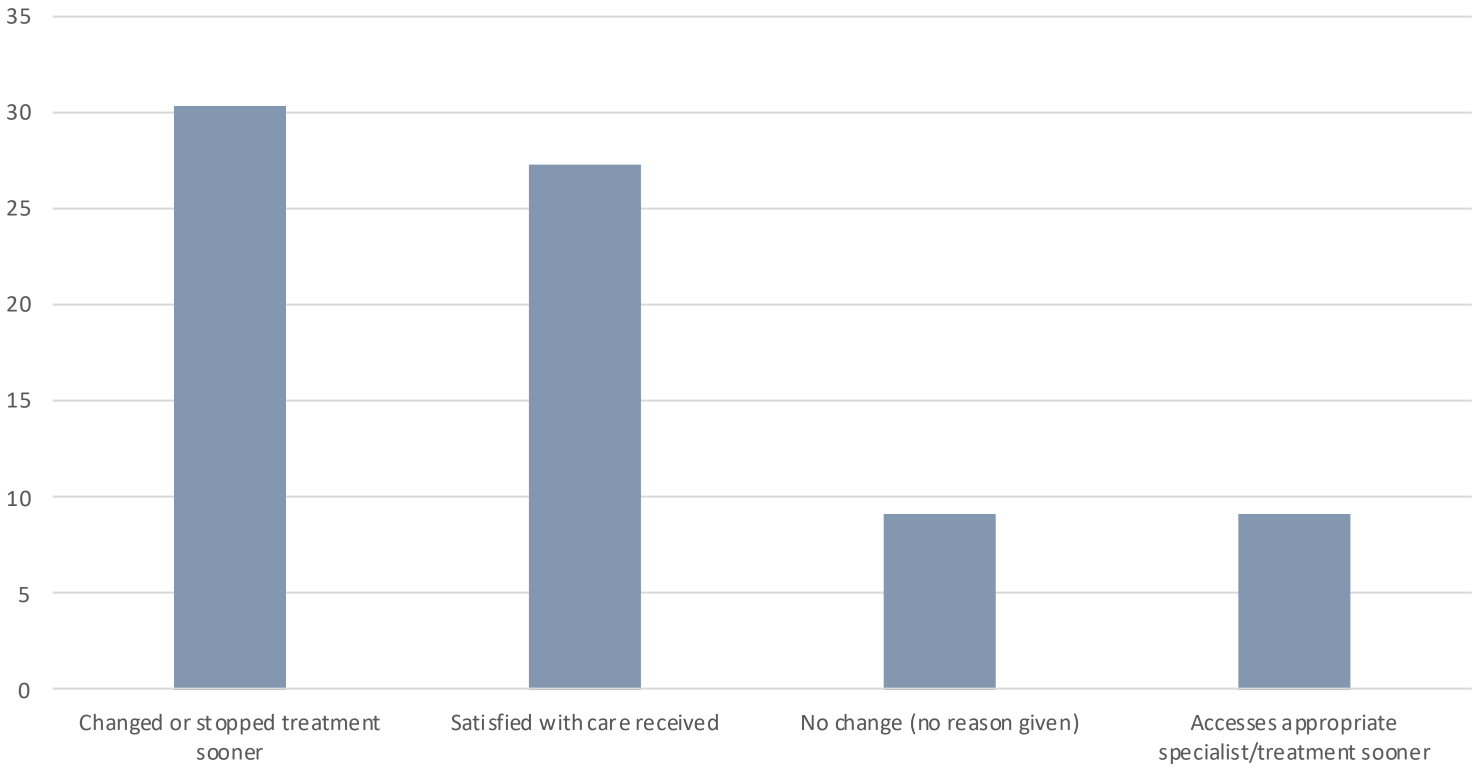
Advice from current patients
to
patients in the future

In this section we present the response to the question 'what is your advice to other people who are diagnosed in the future?' This gives participants the chance to impart knowledge and for patients to feel connected with others in the community.



Yes, but I don't know if it would have been possible for me to know a lot at diagnosis, because as I said, I was very very ill. For me and my sons and daughter-in-laws, none of us knew what was going on really. Nothing was really explained properly or well. As I've found out now, it's up to you to ask the right questions, but you don't know the right questions, so it takes a while to work all that out.
Participant 003_2023AUCRT

Wish they had known earlier (% of all participants)



Yes, I would just like to go into CAR T given now my reading sort of indicates that the chance, you know, it might have worked, but the chances were lower for for the chemo treatment for my particular cancer. So I think it's unfortunate, but it's sort of a, you know, the system as it is now, but as time goes on that I imagine that people would be more readily referred to a CAR T program. Participant 021_2023AUCRT

Anything to change about treatment or care (% of all participants)

- Discussion in the context of existing literature
- Key points
- How the PEEK study relates to existing literature
- Characterisation of the patient cohort

Discussion

Information

This is a cohort that accessed printed information from charities and from the hospital or clinic where they were being treated. They valued being able to talk to a healthcare professional as this gave them the opportunity to ask questions. It is important to this community to have up to date printed materials, relevant to their specific type of blood cancer. Question prompts in printed material may also be of value to increase conversations about all available treatments.

Managing side effects

This is a group where side effects were important in decision making, adherence, and minimising side effects was an important treatment goal. Side effects had a negative impact on quality of life, relationships and made people with blood cancer feel vulnerable. Support and information to help manage side effects and access to treatments with fewer side effects may have a positive impact on quality of life. This may be achieved by increased awareness and access to allied health professionals given this cohort, on average, accessed only one allied health service.

Impact on daily life

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family took leave with and without pay. The loss of family income was an extremely significant burden. CAR-T treatable blood cancers are characterised by fatigue and exhaustion, with treatments taking up a significant amount of time for patients who may need to interrupt family life or stop work to accommodate this. This domain of a patient’s life needs to be recognised and addressed through appropriate, practical support services.

Next steps