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HEPATITIS D

AUSTRALIAN STUDY 2023



# Section 1

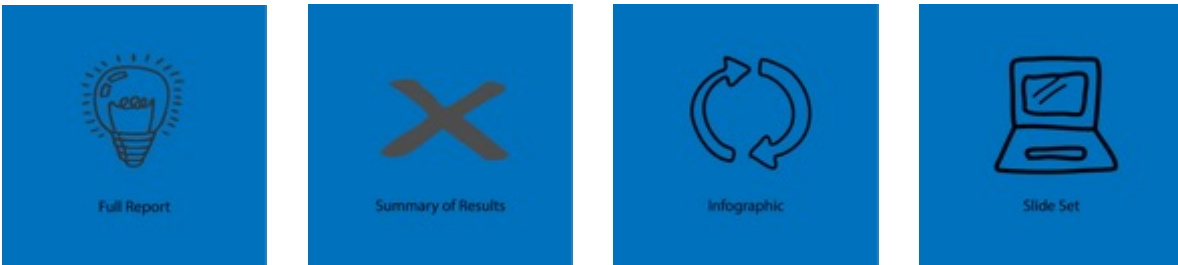


Introduction  
&  
Methodology

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.



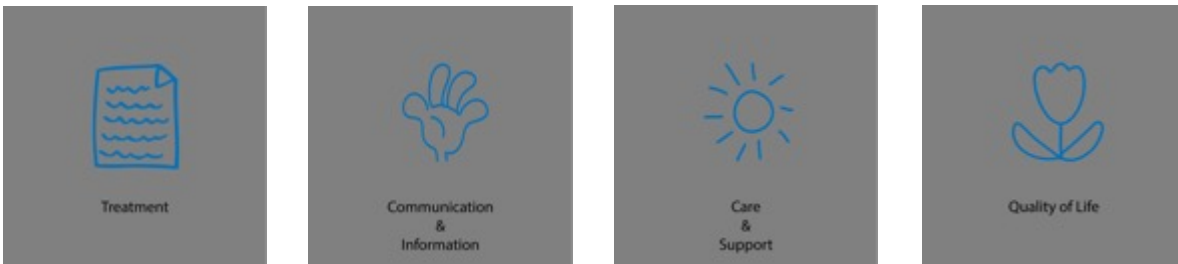


The Centre for Community-Driven Research team for this study included:

Kate Holliday, Anne Holliday, Melanie Green, Heema Gokani, Eileen Kearns, Chris Farley, Marni Cox-Livinstone, Fay Miller, Lydia Abebe, Rebecca Farz, Hai Ly Tran



Thank you to each and every person that participated in this PEEK study and partners that supported the project including Prostate Cancer Foundation Australia and all of the health professionals across Australia that also helped to spread the word about this PEEK study.



This study was generously sponsored by AstraZeneca Australia.



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



In this PEEK study, 16 people diagnosed with hepatitis D throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This is the only hepatitis D study of patient reported outcomes, or patient experience conducted in the last 5 years in Australia, and the only study worldwide to interview people with hepatitis D about their experiences. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

***A comparison of studies is available in Section 1.***

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



## Section 2



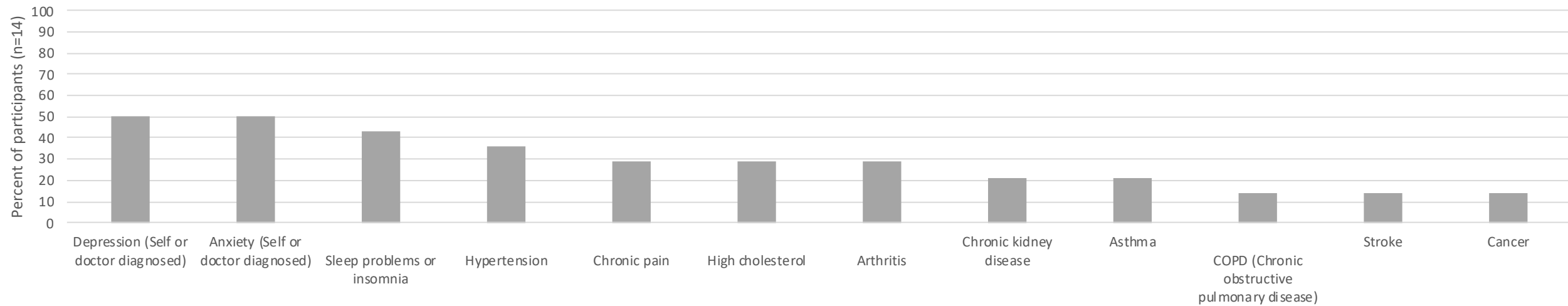
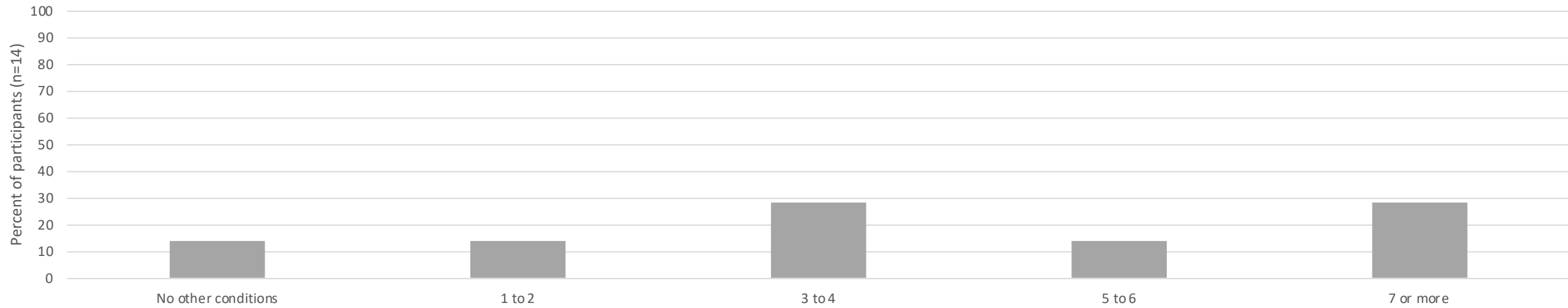
Demographics

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





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





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

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

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



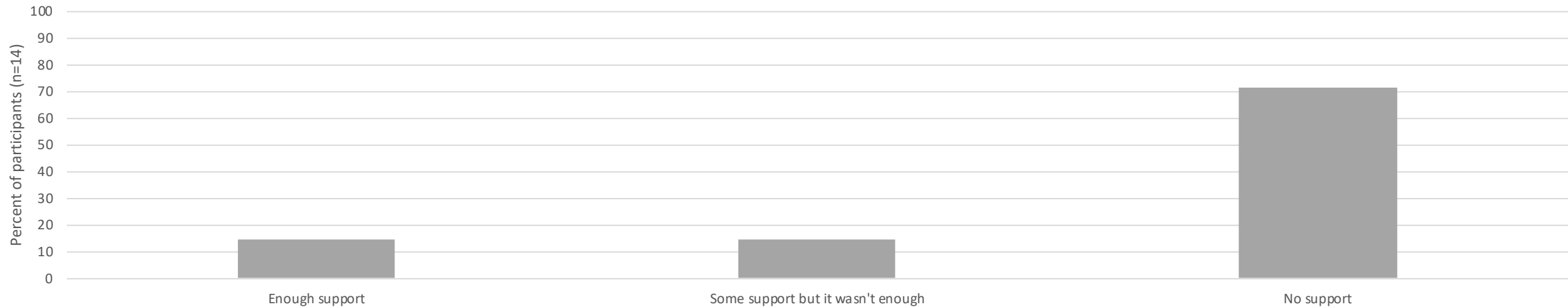
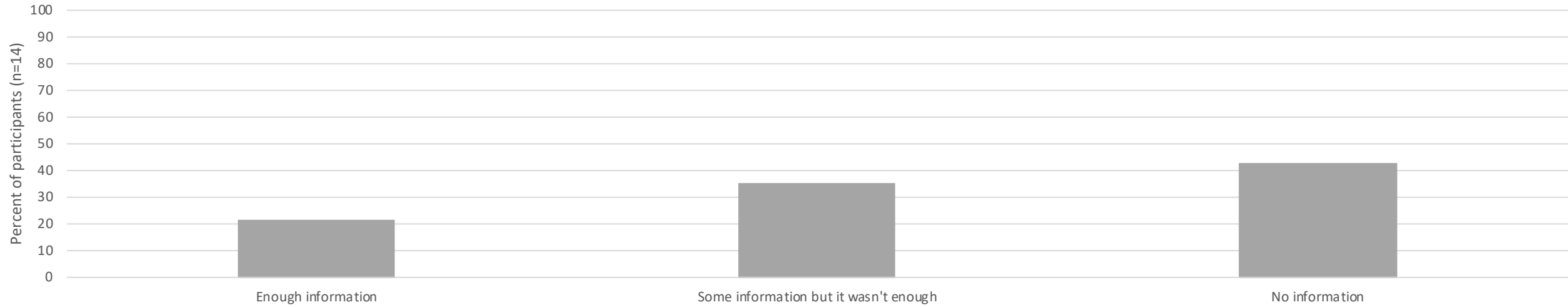
## Section 3



Symptoms &  
Diagnosis

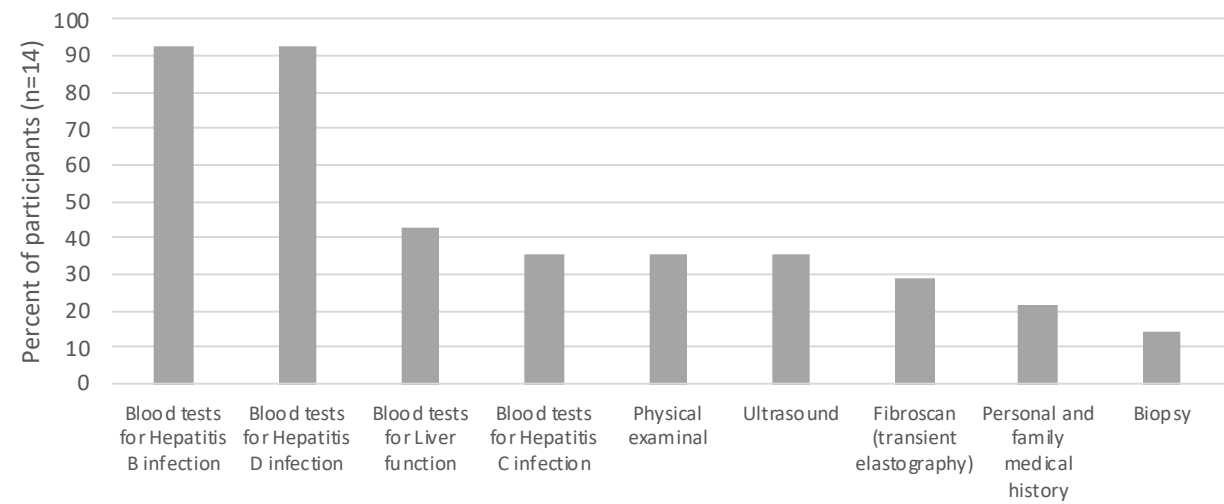
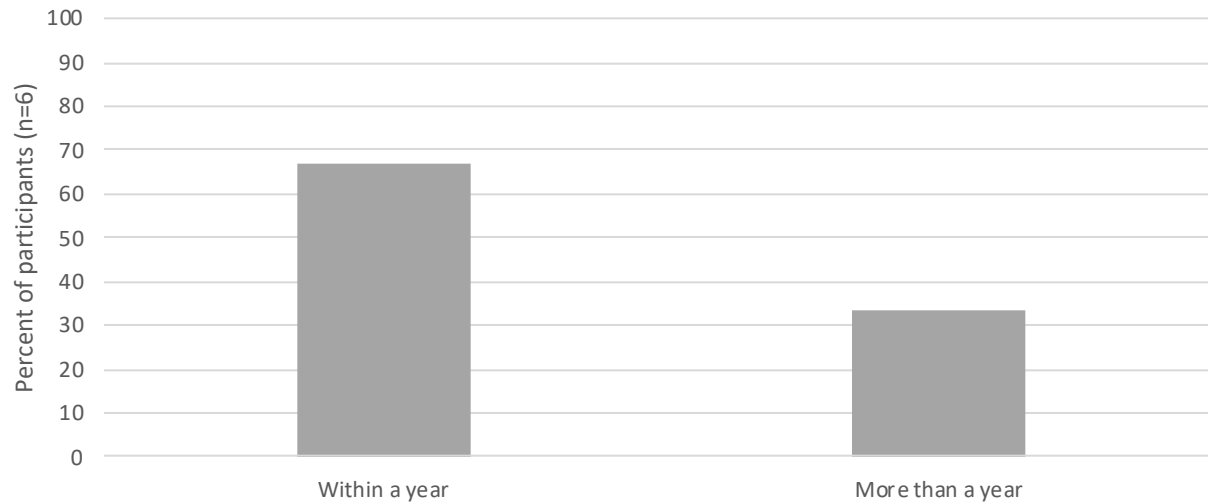
The symptoms and diagnosis section is where you can find information about experience of symptoms before diagnosis, as well as the symptoms that led to the diagnosis. There is information about the diagnostic tests that were performed, where the tests were conducted and the time from tests to diagnosis.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



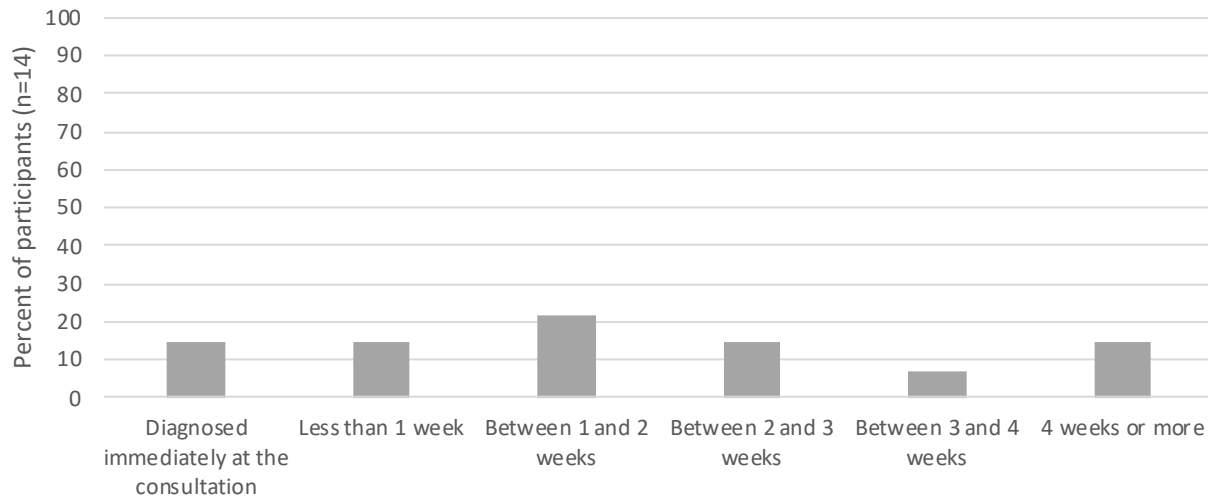


# Information + support at diagnosis

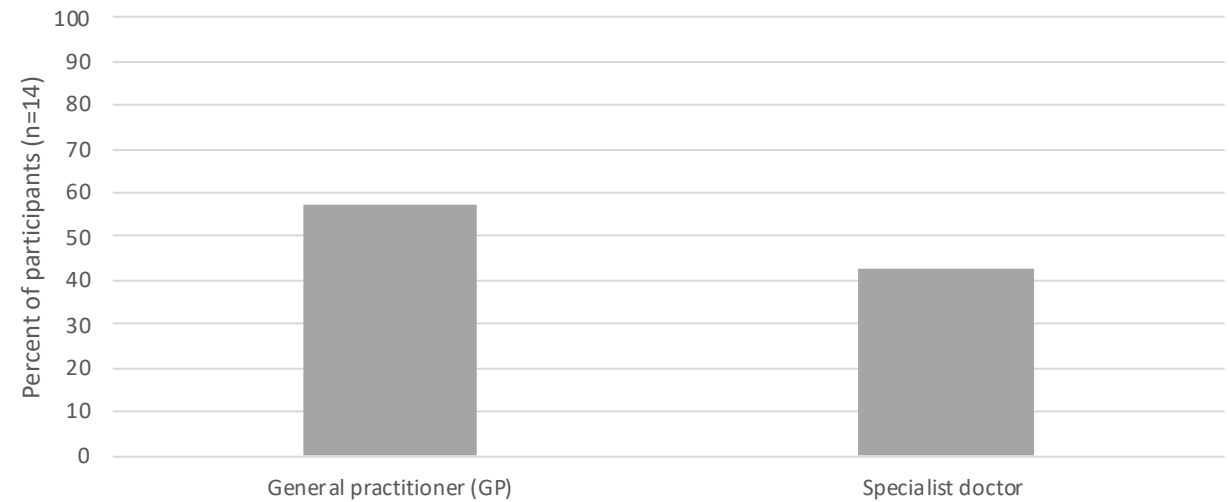




### Time symptoms to diagnosis



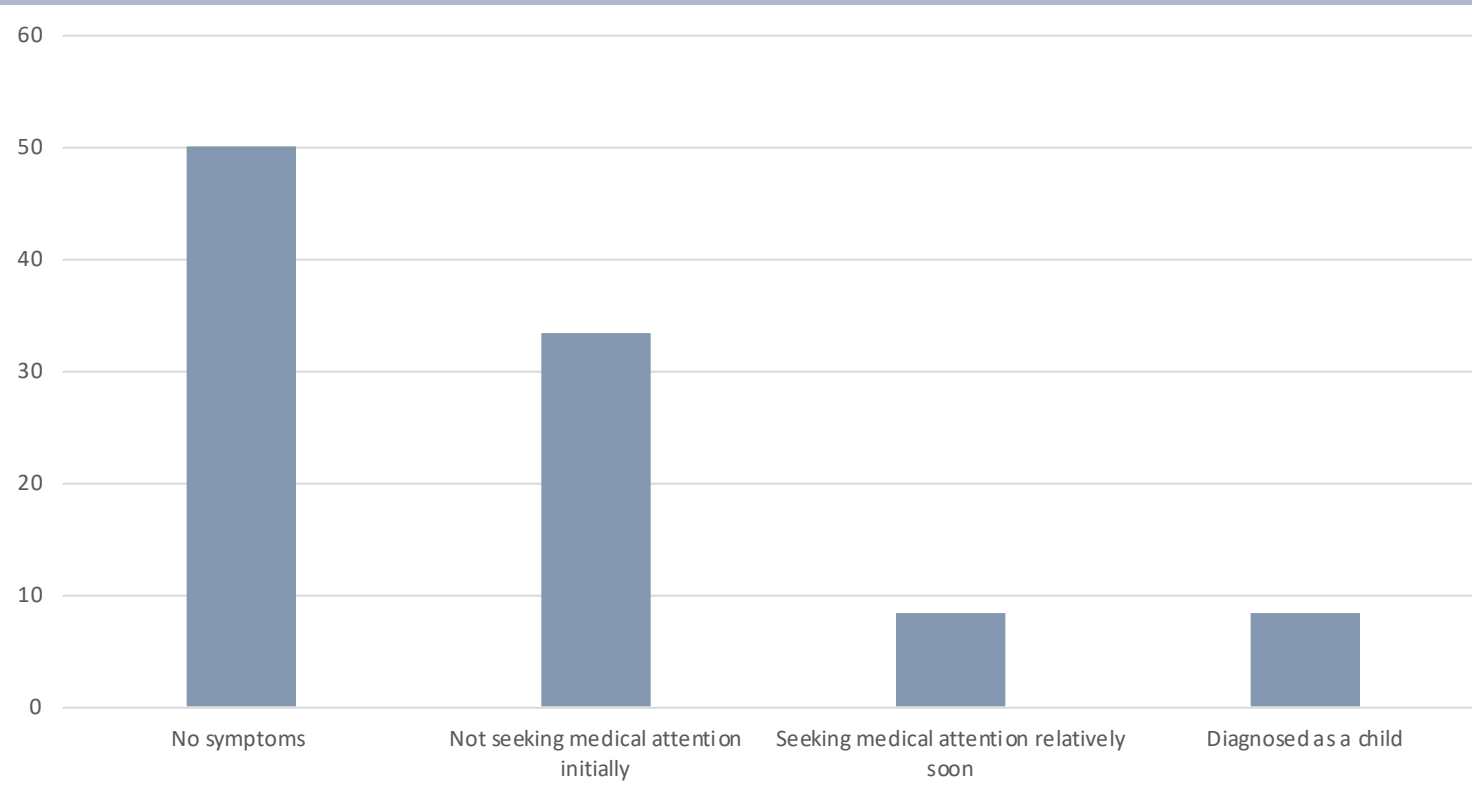
### Diagnostic tests



### Time from test to diagnosis

### Diagnosis given by

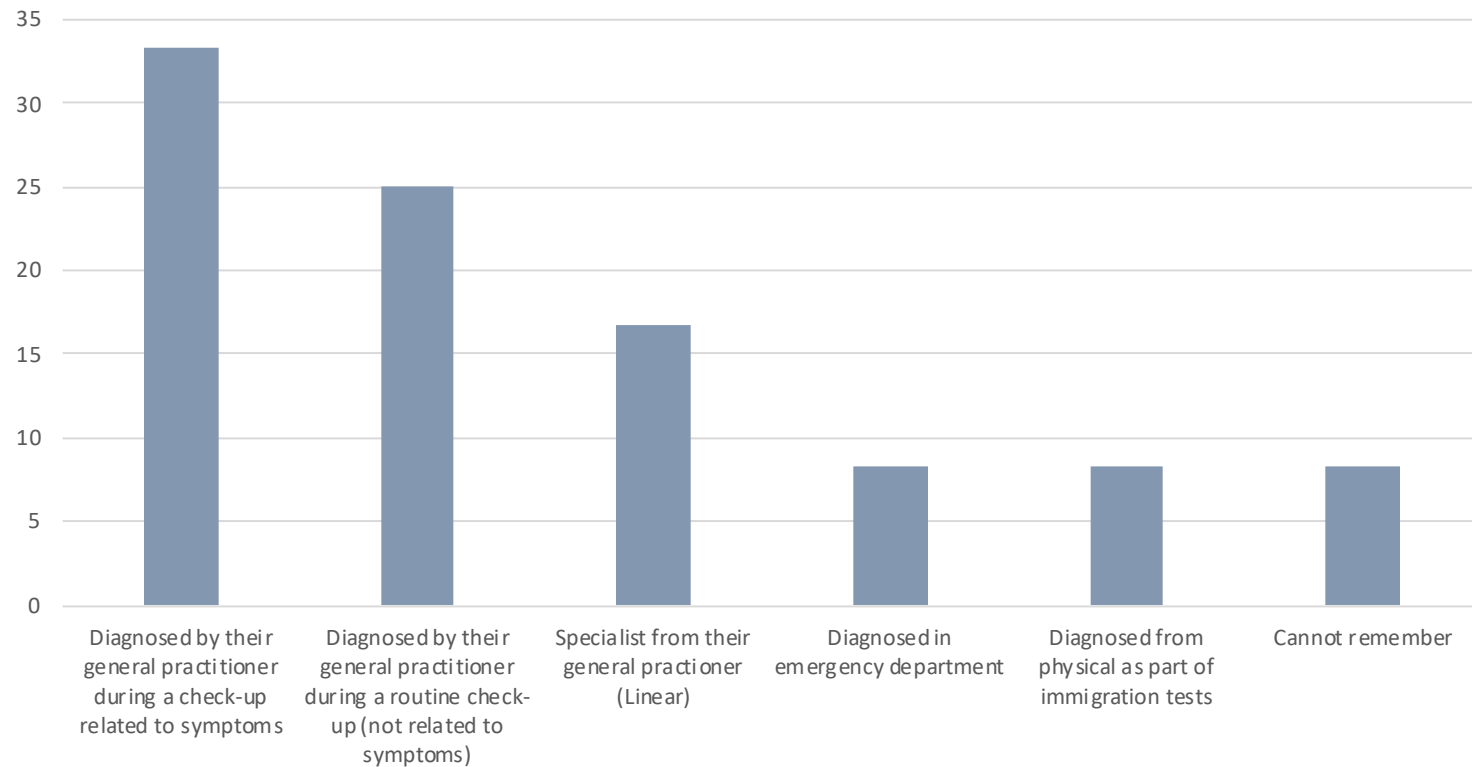




*Yes, exactly. So what happened to me was I I felt very unwell. I was working full time and I thought, you know, my my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains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

**Participant 010\_2023AUHDV**

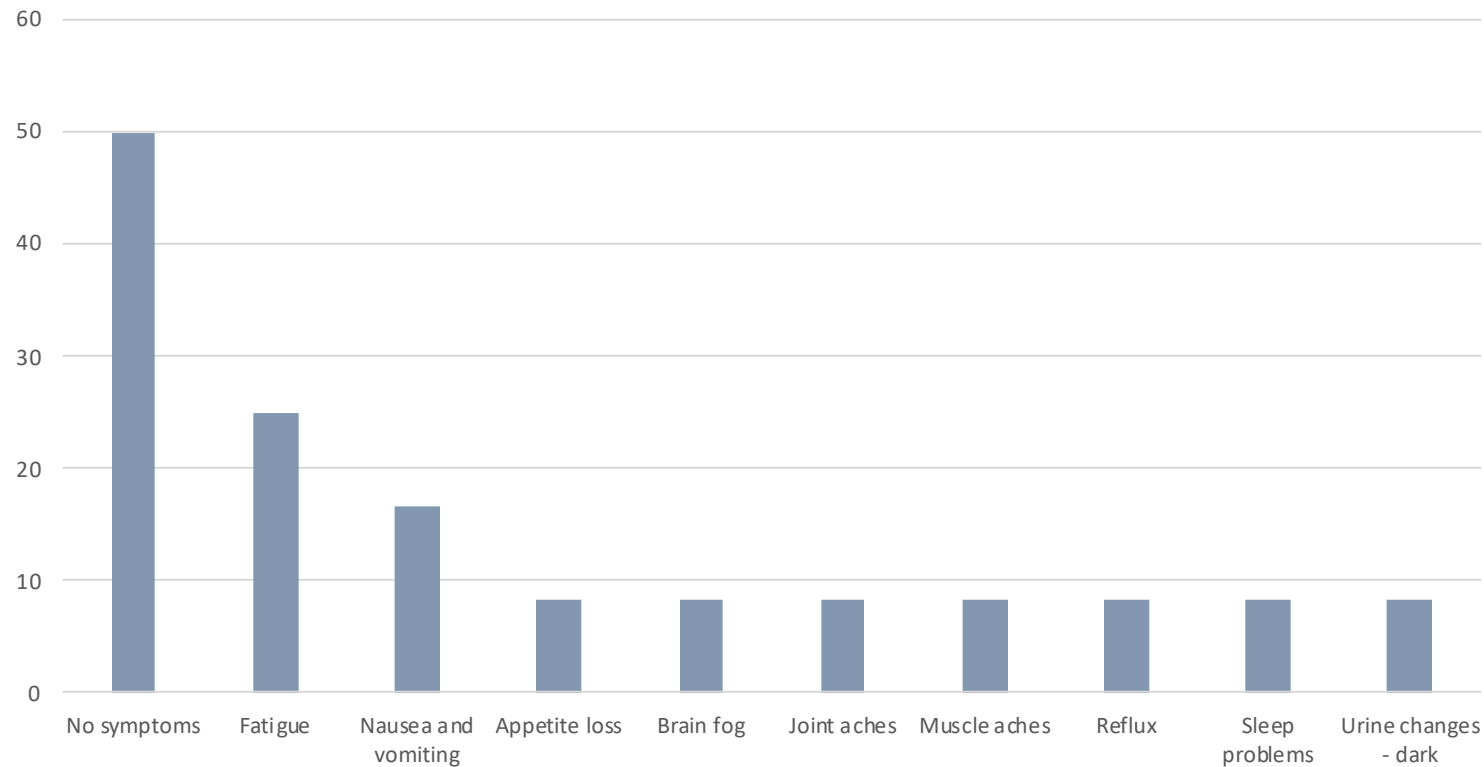




*Well, all all the procedures was carried out by a doctor, you know, I had to seek medical attention when I noticed all all the symptoms and got into the clinic. I was kind of run. I was given some medication, you know, testing every other thing. Yeah, my it was a kind of blood test. The doctor took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

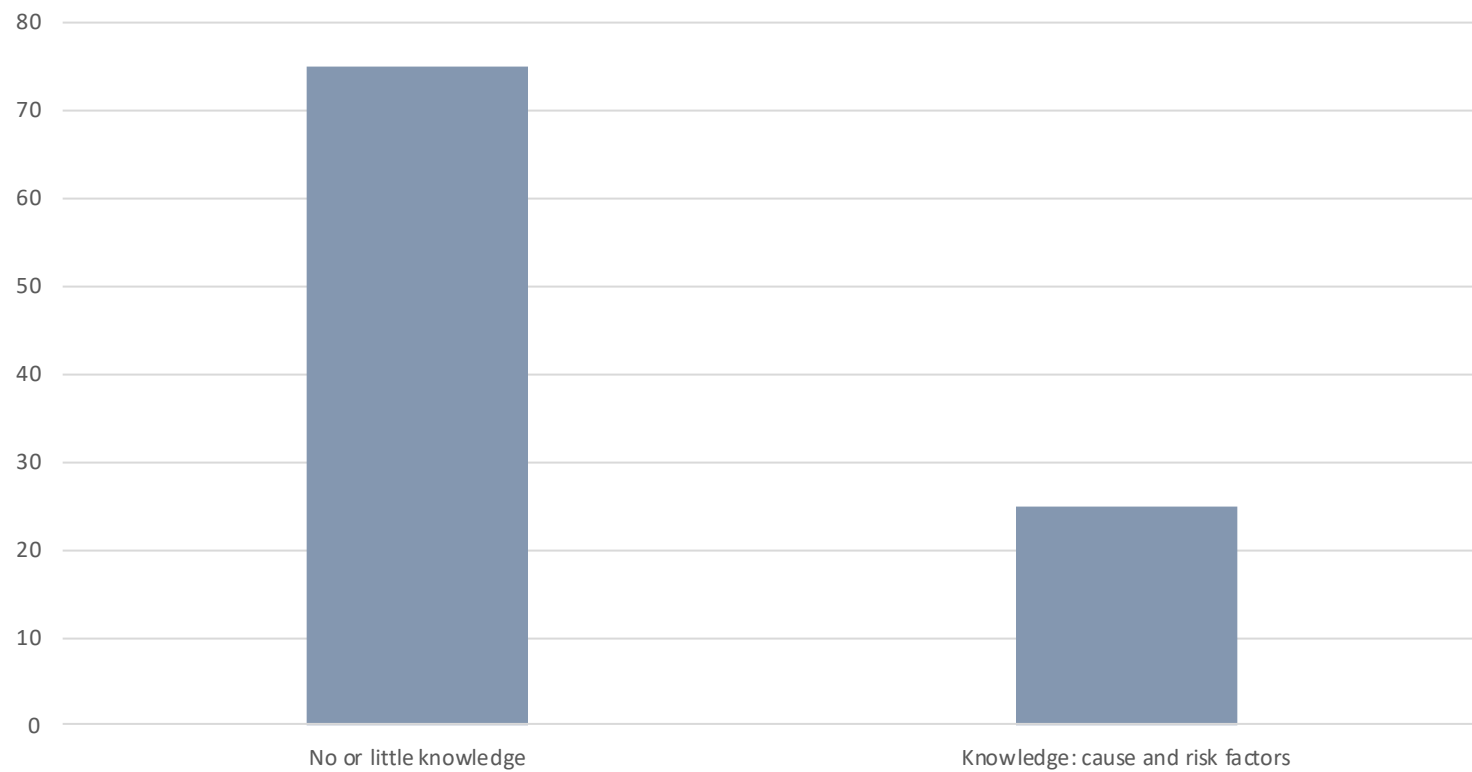
**Participant 006\_2023AUHDV**





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



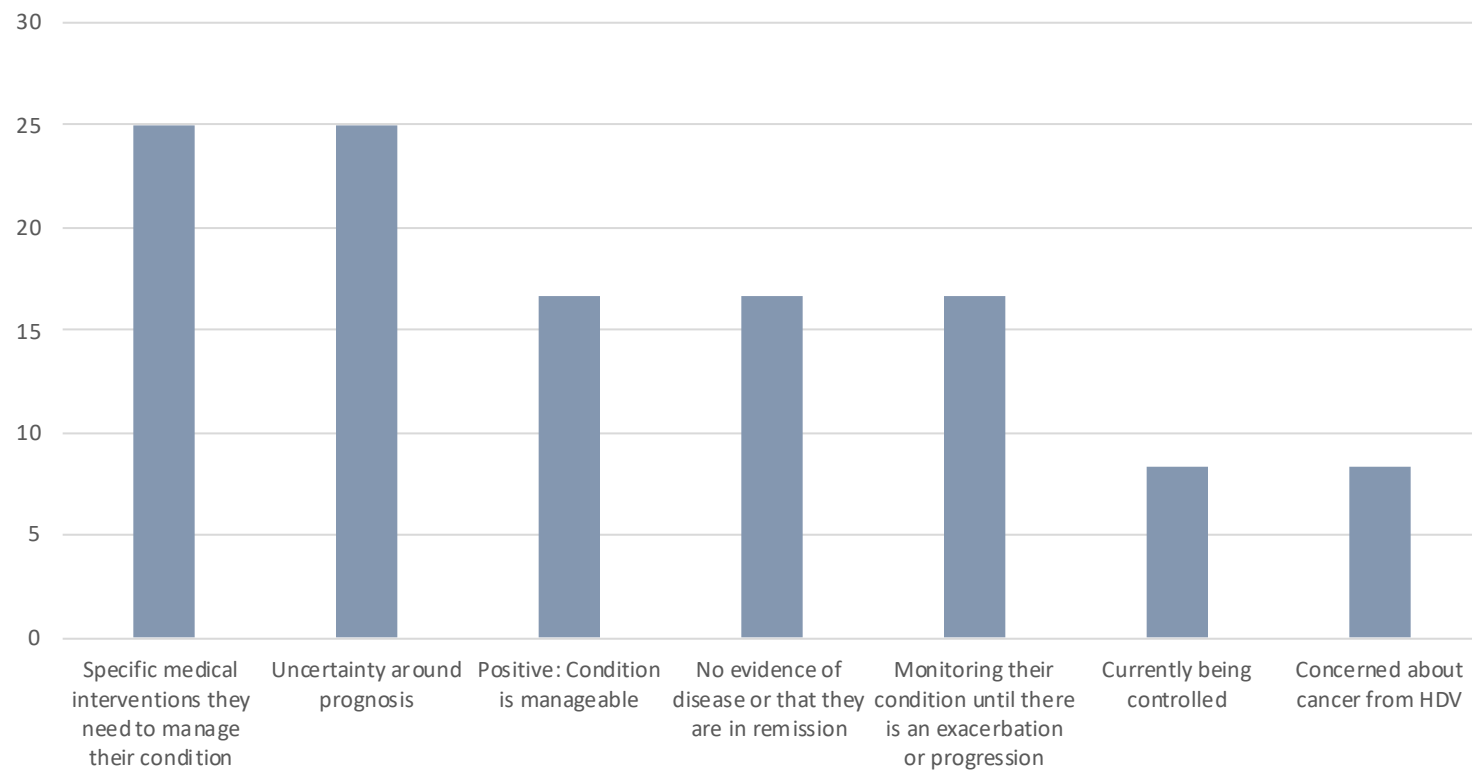


***Very little. Very little at all. And I'd have to say, even at that point of diagnosis, they didn't really take the time to explain it to me. It was only kind of subsequently in conversations with my mother afterwards that I understood it had something to do with my liver.***

***Participant 011\_2023AUHDV***







***Yeah. So I I've had, I've had treatment and that was actually quite a while ago. So I I ended up, I did end up having interferon and pegulated ribavirin as a combination therapy. And that was prescribed to me for for six months. So I took the six months off treatment. So there's been monitoring like I have, I have, I still get, I still get tests every so often so.***

***Participant 011\_2023AUHDV***



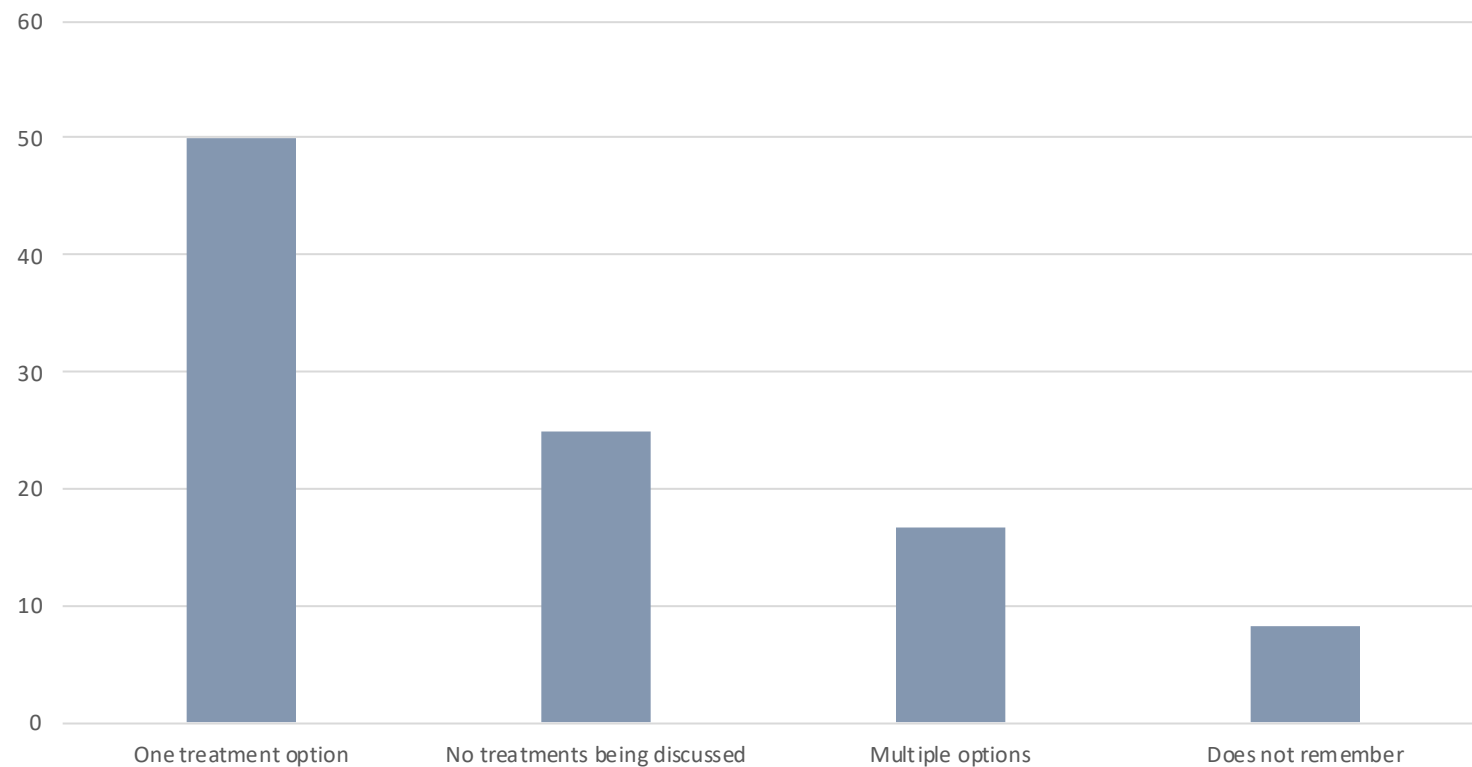
## Section 4



Decision Making

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.





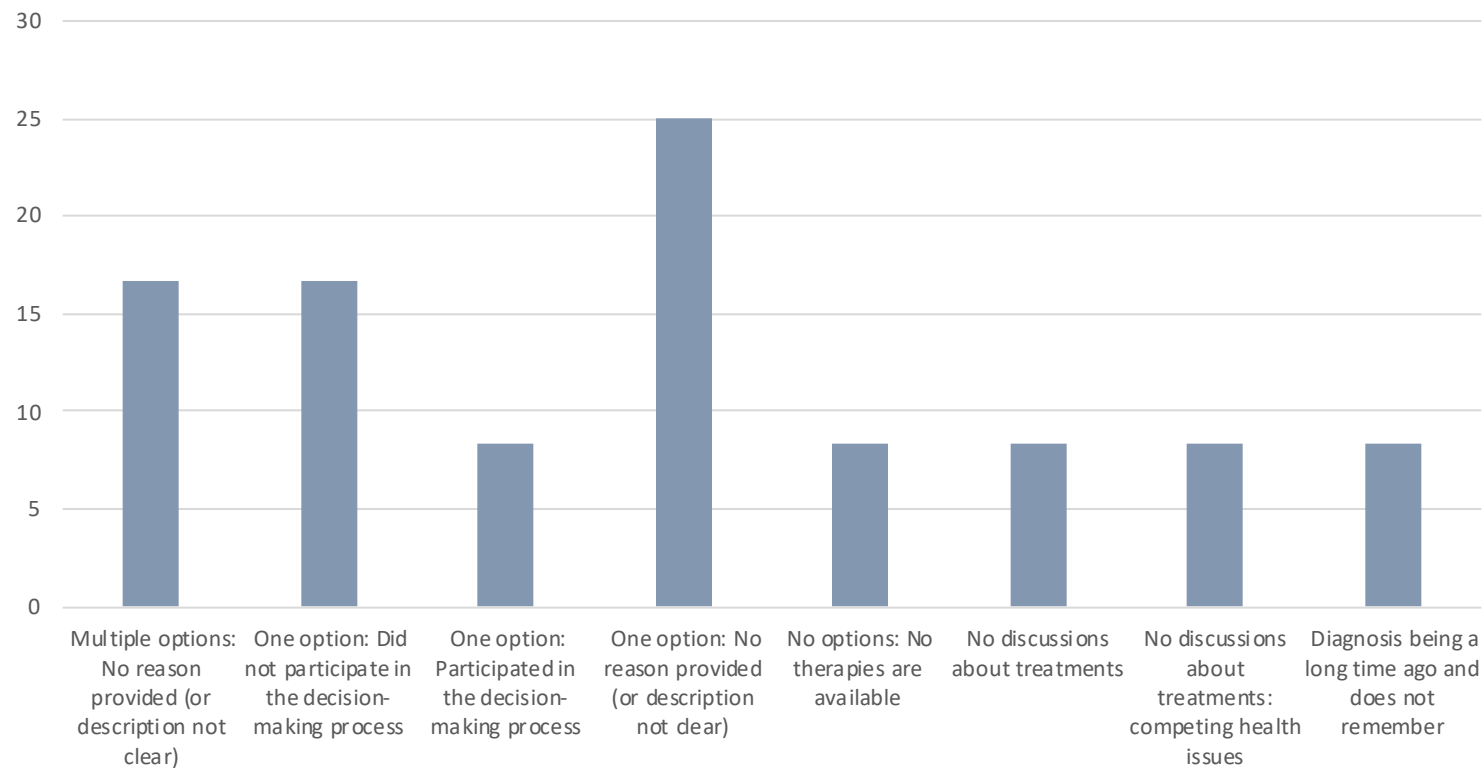
*She explained me that for hepatitis, the only treatment is taking some specific medication and in around 12 weeks under that specific medication. It is the only treatment for this case.*

*Participant 005\_2023AUHDV*

*My doctor said when, when that hepatitis come active, that's when we start treatment on you. At the moment it's not active, it's not doing anything to you, so we can't treat you. Just go.*

*Participant 001\_2023AUHDV*

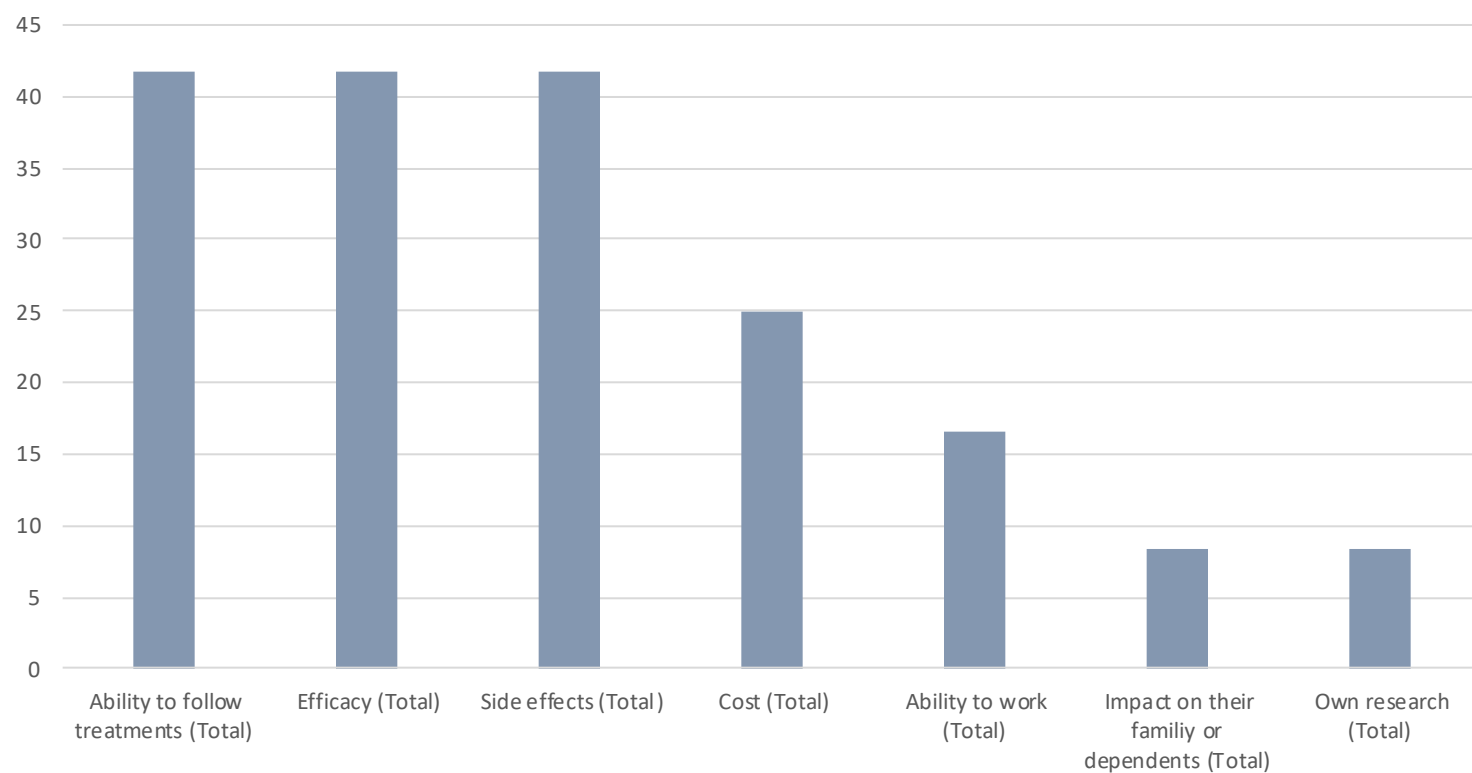




*I I just said, well, I would sit with all this information for a while and then I decide what I wanted to do. And so I did a lot of research and I also found that there was some other treatments coming up. But you know that I went to the support group every month and and there was a lot of horrific stories about people who reacted badly to the interferon and riboviron. Riboviron caused rashes. Interferon had to inject your stomach every every month for a year. You sometimes had mental effects from that. In other words, depression, etcetera. And because I was substance free for many, many years, I was not attracted to taking anything that would require me to take depression medication.*

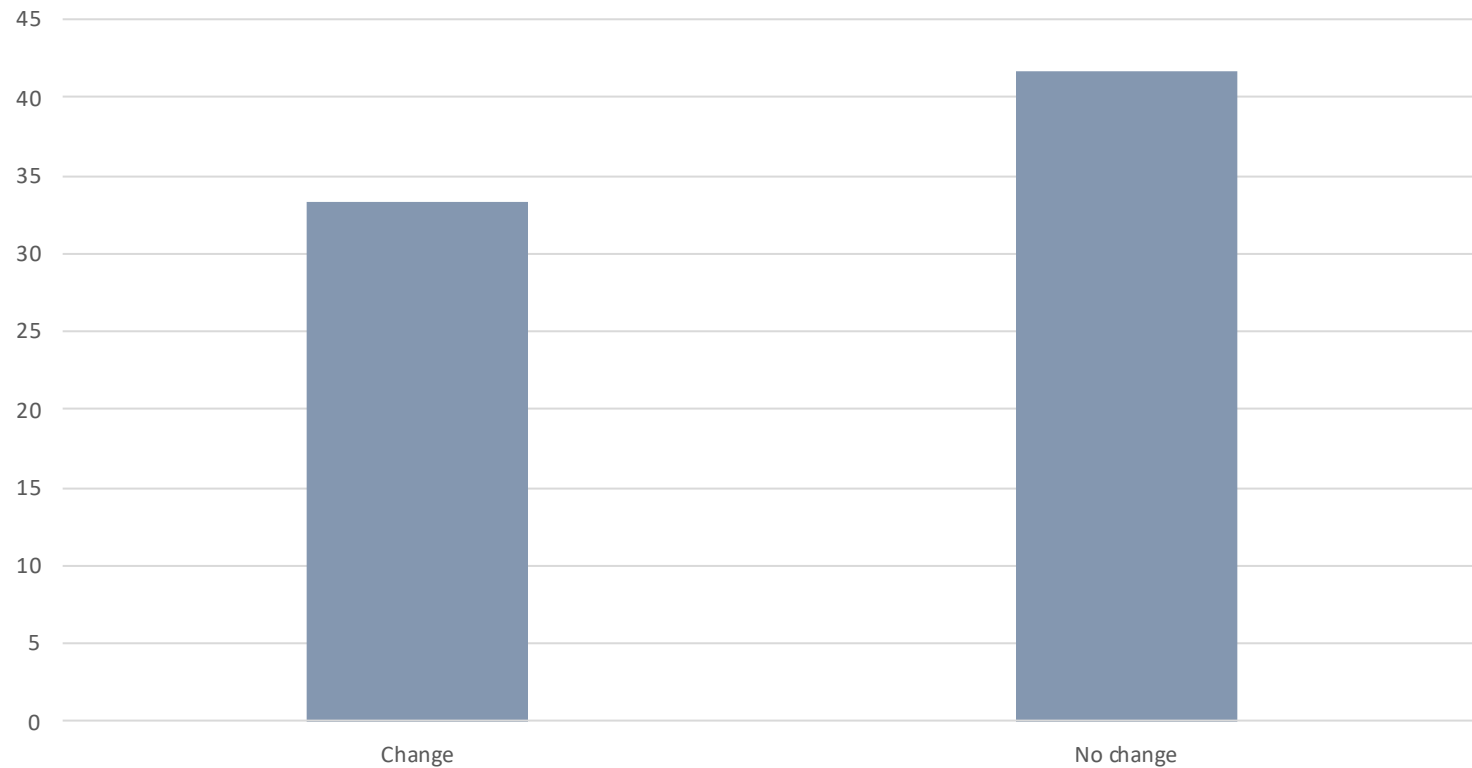
**Participant 010\_2023AUHDV**





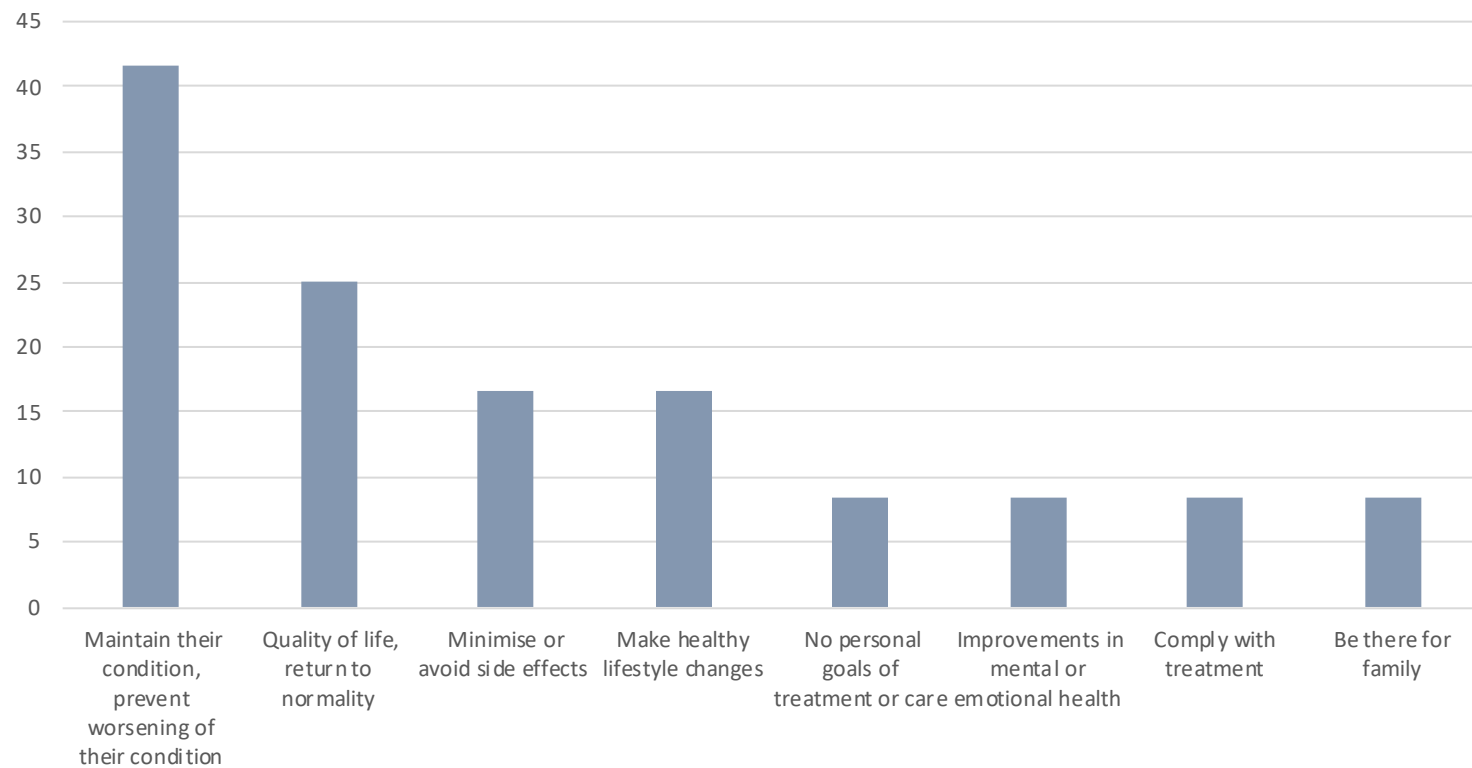
*The convenience because I mean say, well at the moment I'm basically taking the 1 pill ... I mean that there was a time when I was taking over 40 pills a day. So it comes down to you know how convenient is it going to be and it is it easy to maintain and that's that's what I found because I'm just on the the one pill basically it's it's it's not a problem at all. Okay.*  
**Participant 007\_2023AUHDV**





*I think particularly, yeah, particularly related to my hep treatment experience, I'd be a lot more assertive. Both, you know, before, during and after because I really found like post the the course of interferon. I really, really had to really had to struggle against the people who have given me the treatment to just to get answers, to get any kind of results, to get anything in writing. So yeah, so. Yeah, it's definitely changed over time.*  
**Participant 011\_2023AUHDV**





*Yes, well, I do, because I wanted to. I'm very committed to my children and my grandchildren and I wanted to get well for them, really, not only for them, but for myself, because I love life. And you know, I wanted to. I didn't want the scarring to get worse. I didn't, you know. So I wanted to do the treatment clear, the virus, get well. I made an effort to eat better, lose weight, change my diet, get more sleep and, you know, be empowered.*

**Participant 010\_2023AUHDV**



# Section 5

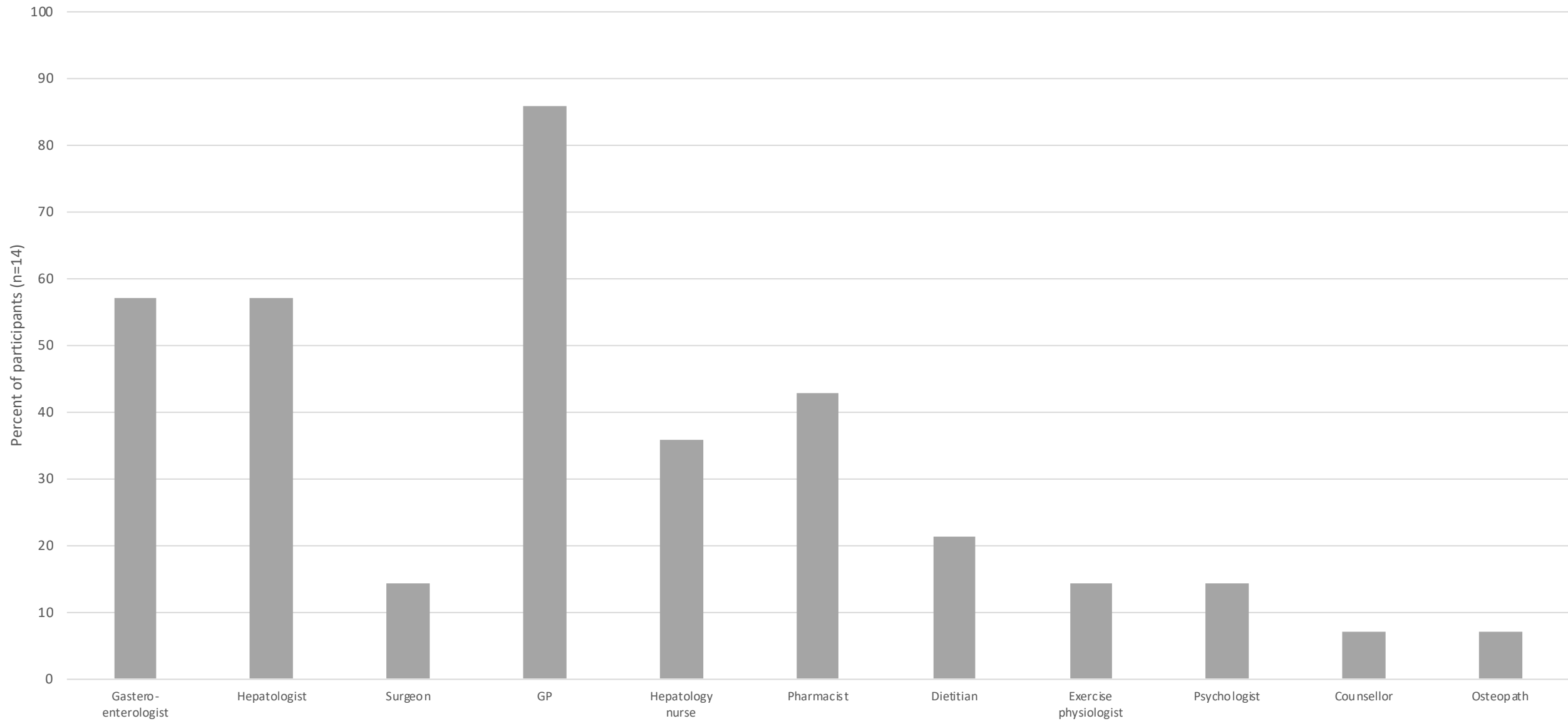


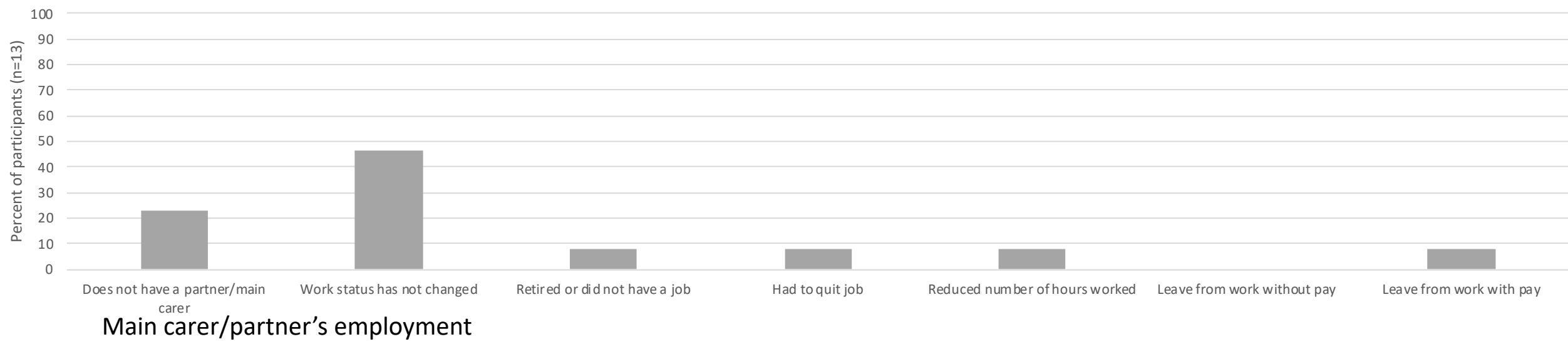
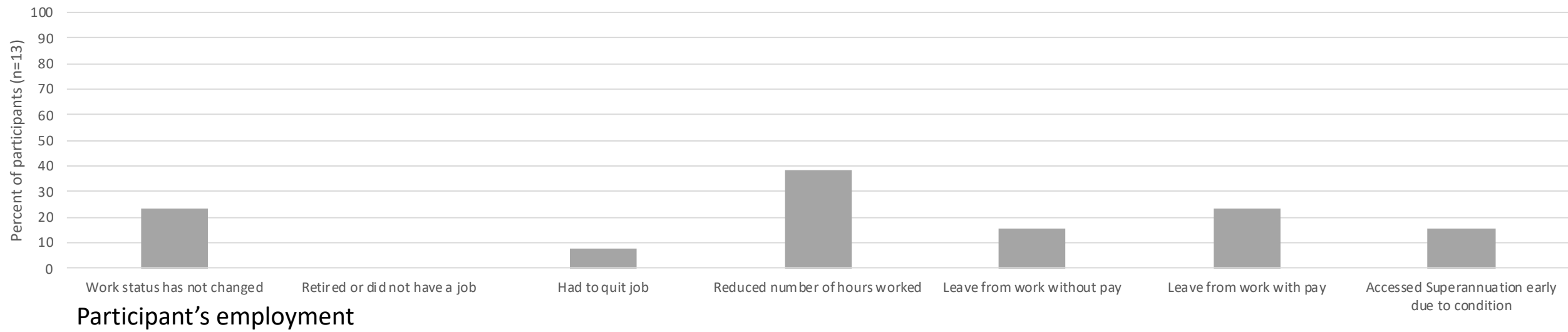
Treatment

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.



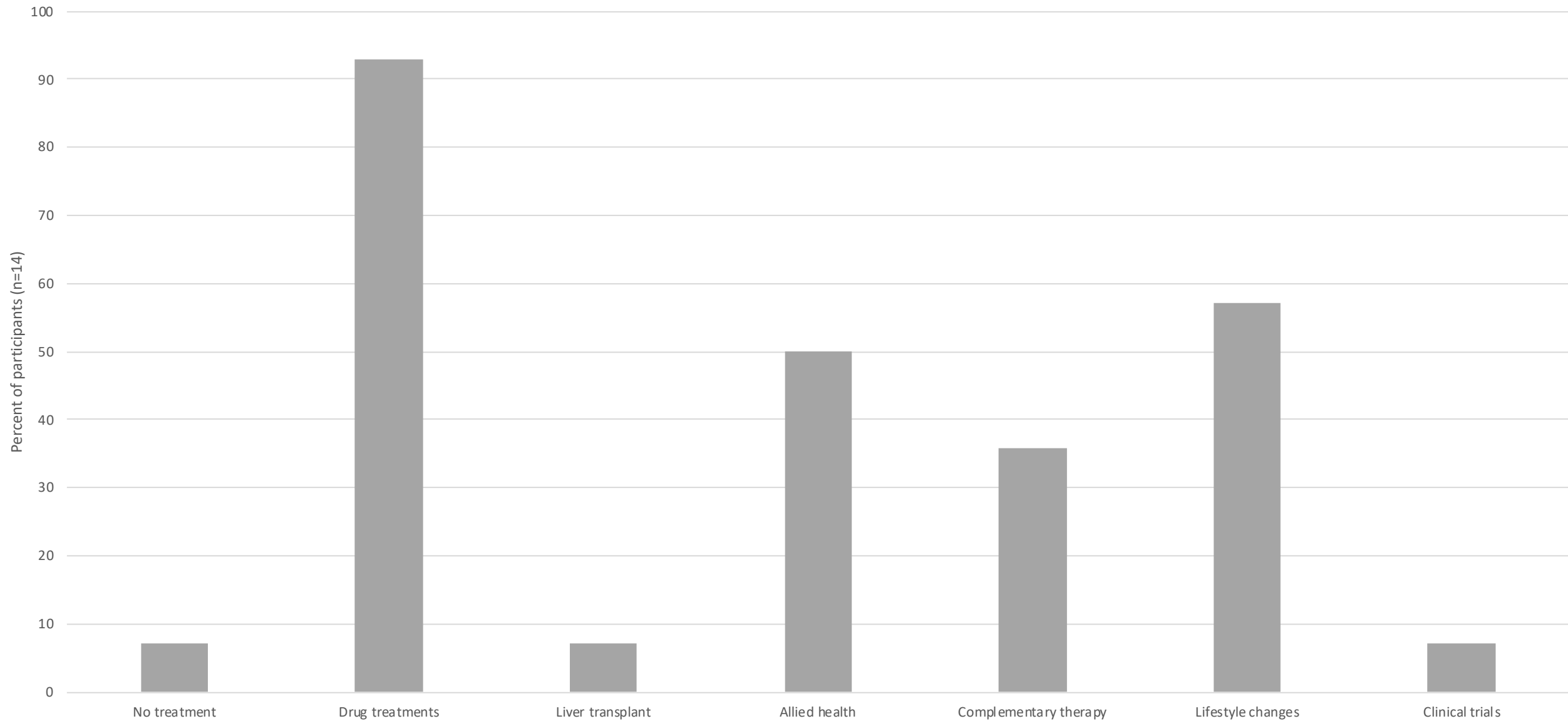


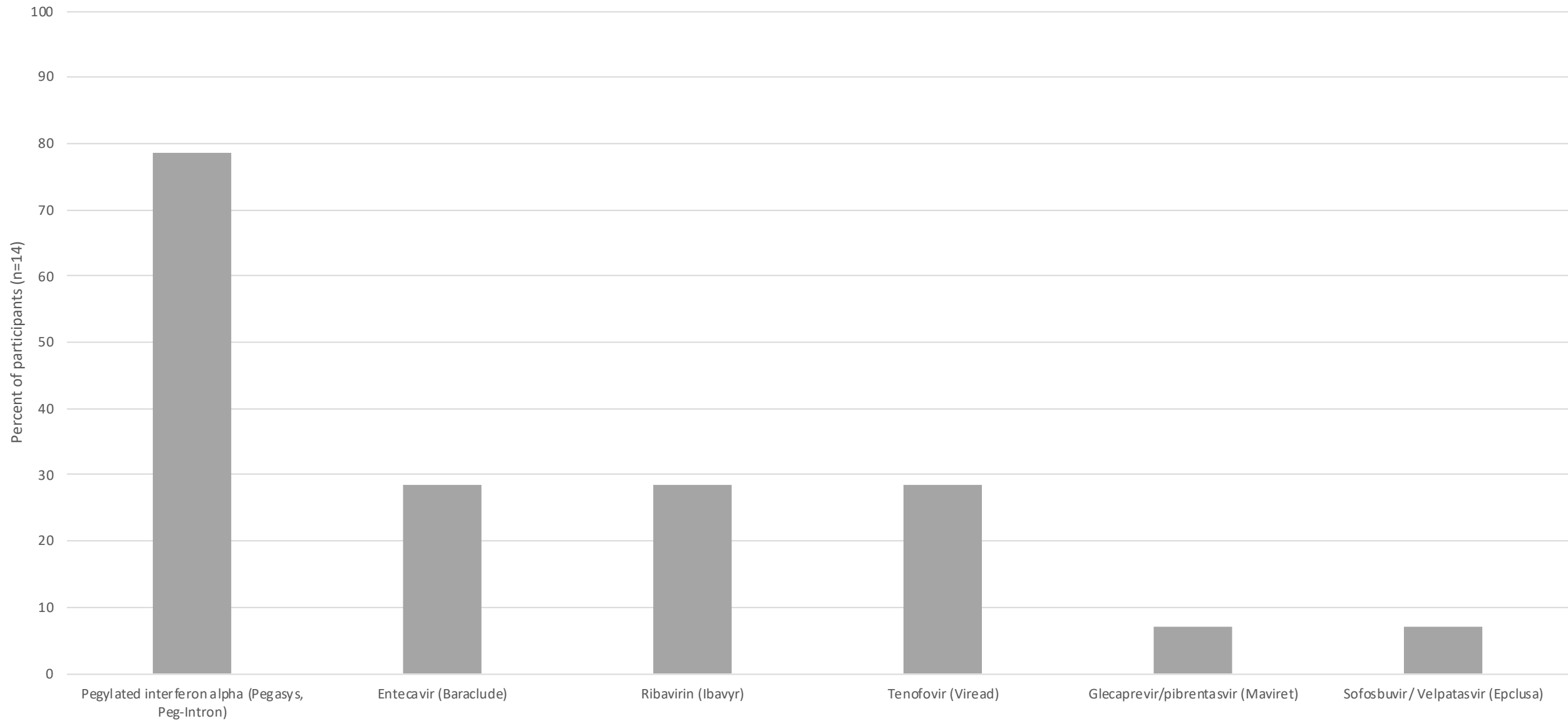


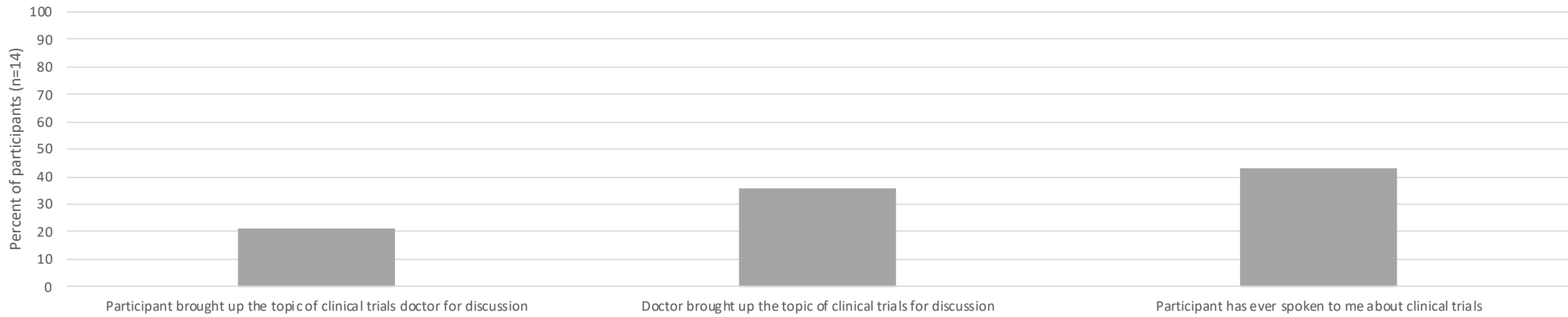


# Employment status

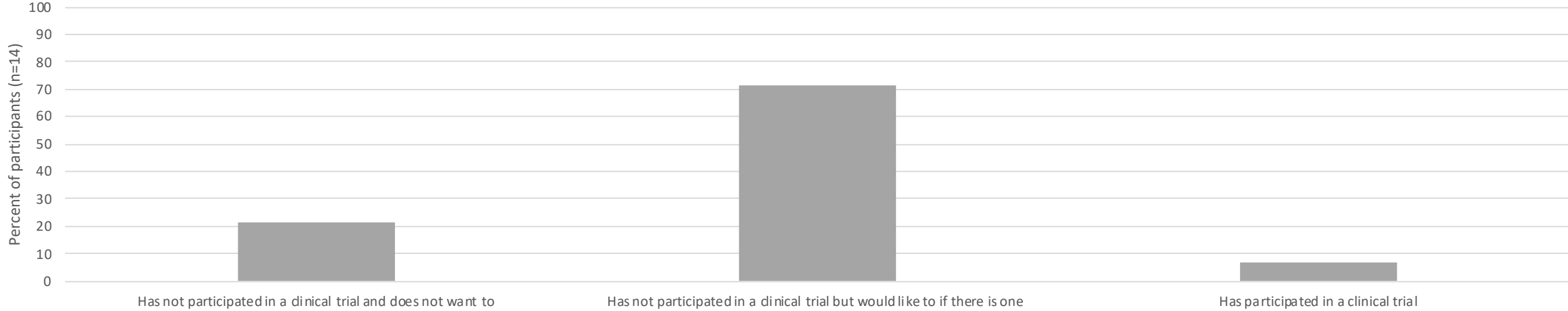




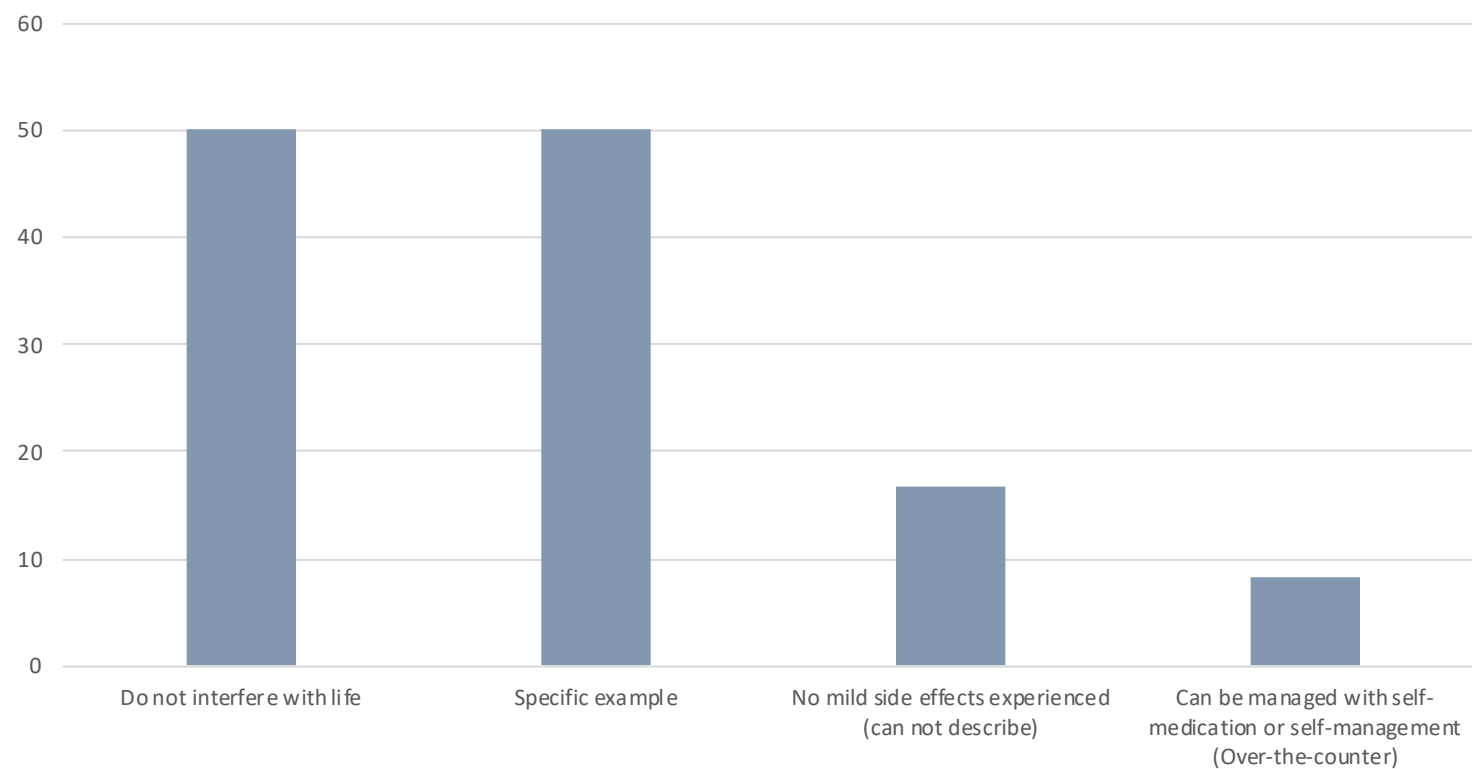




### Discussions about clinical trials

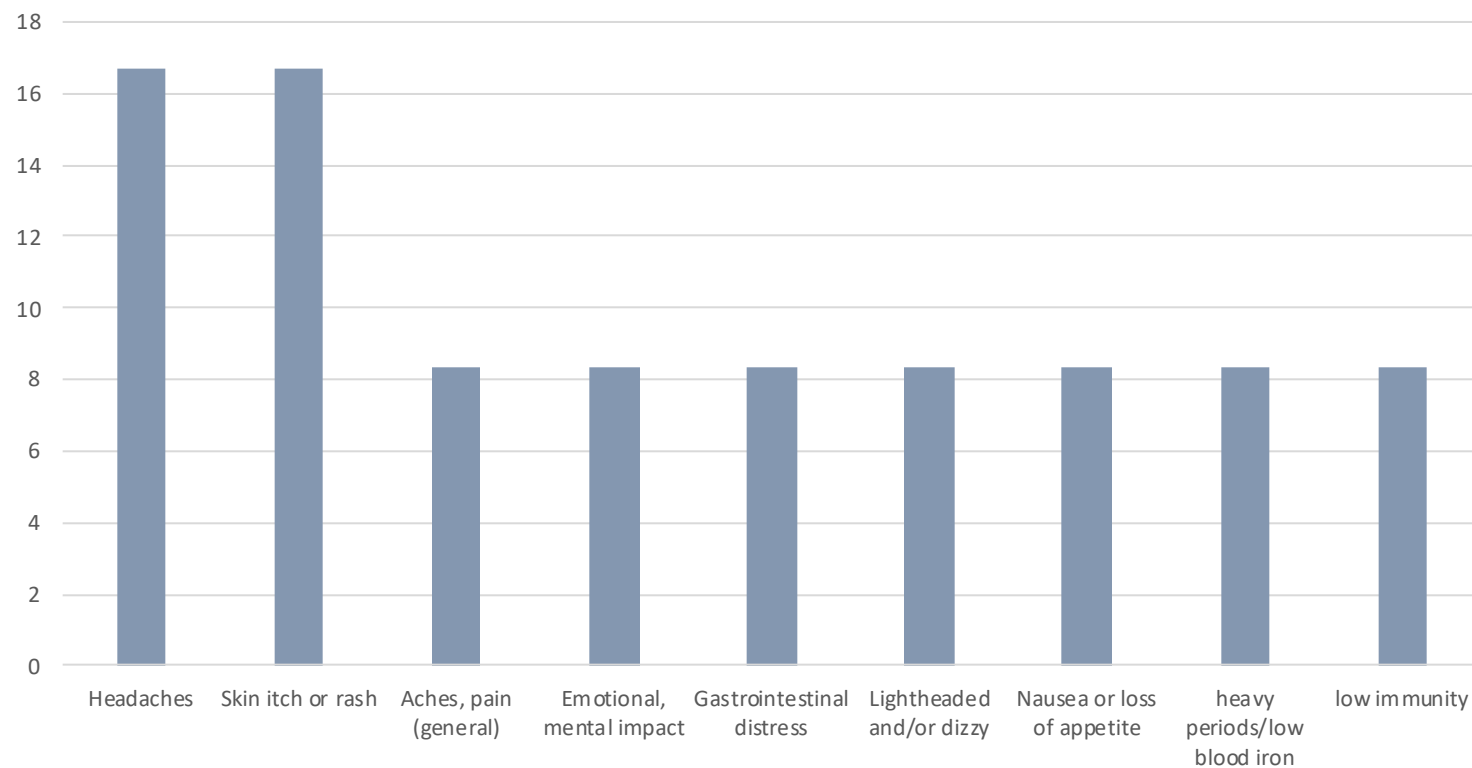


### Participation in clinical trials



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

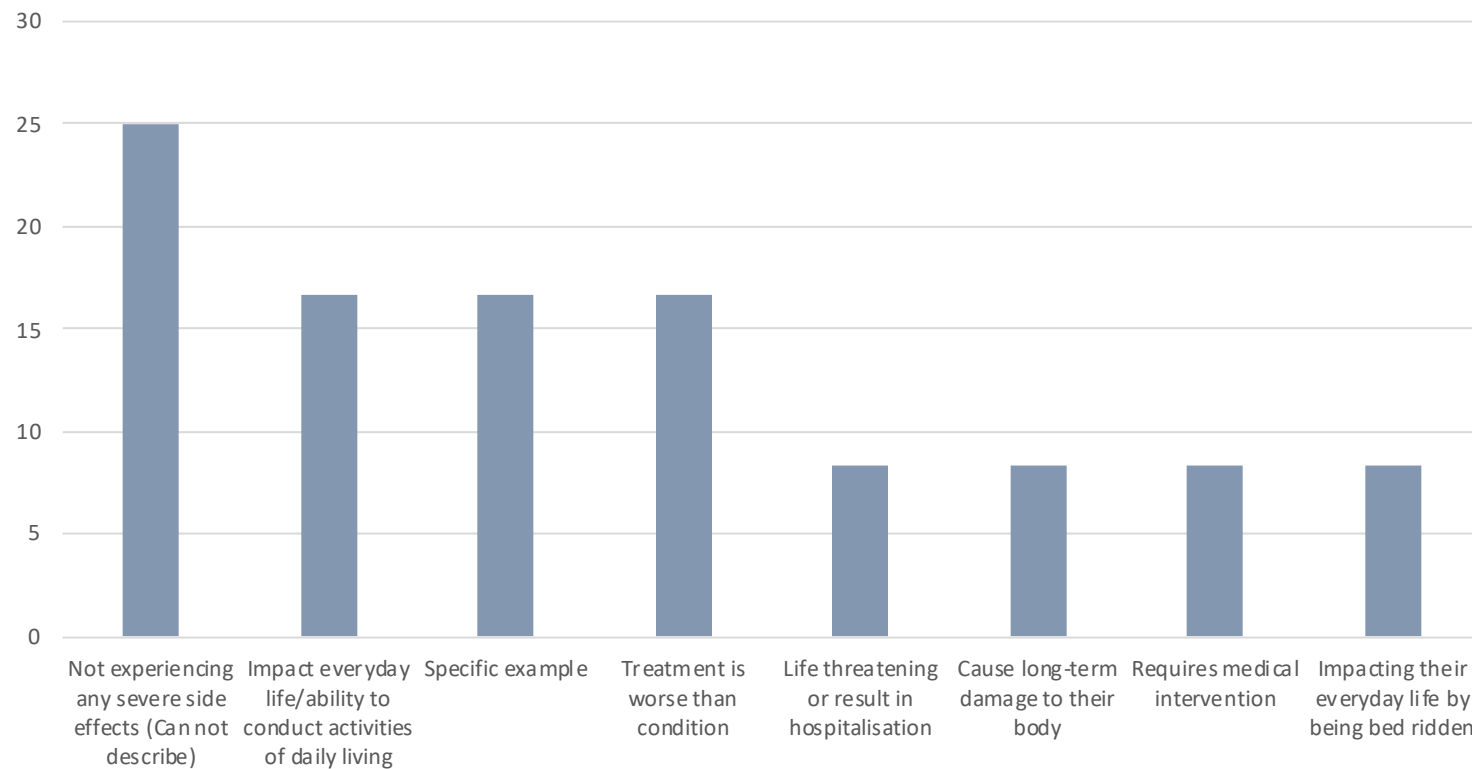




***Minor side effects may be purely some physical discomfort, such as headache and dizziness. Those are so scary, if they hit it, that is, for example, it may already affect the normal? Do things, that is, those in daily life, such as possible. Get up, even if it is already affected, well, if it is serious,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

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

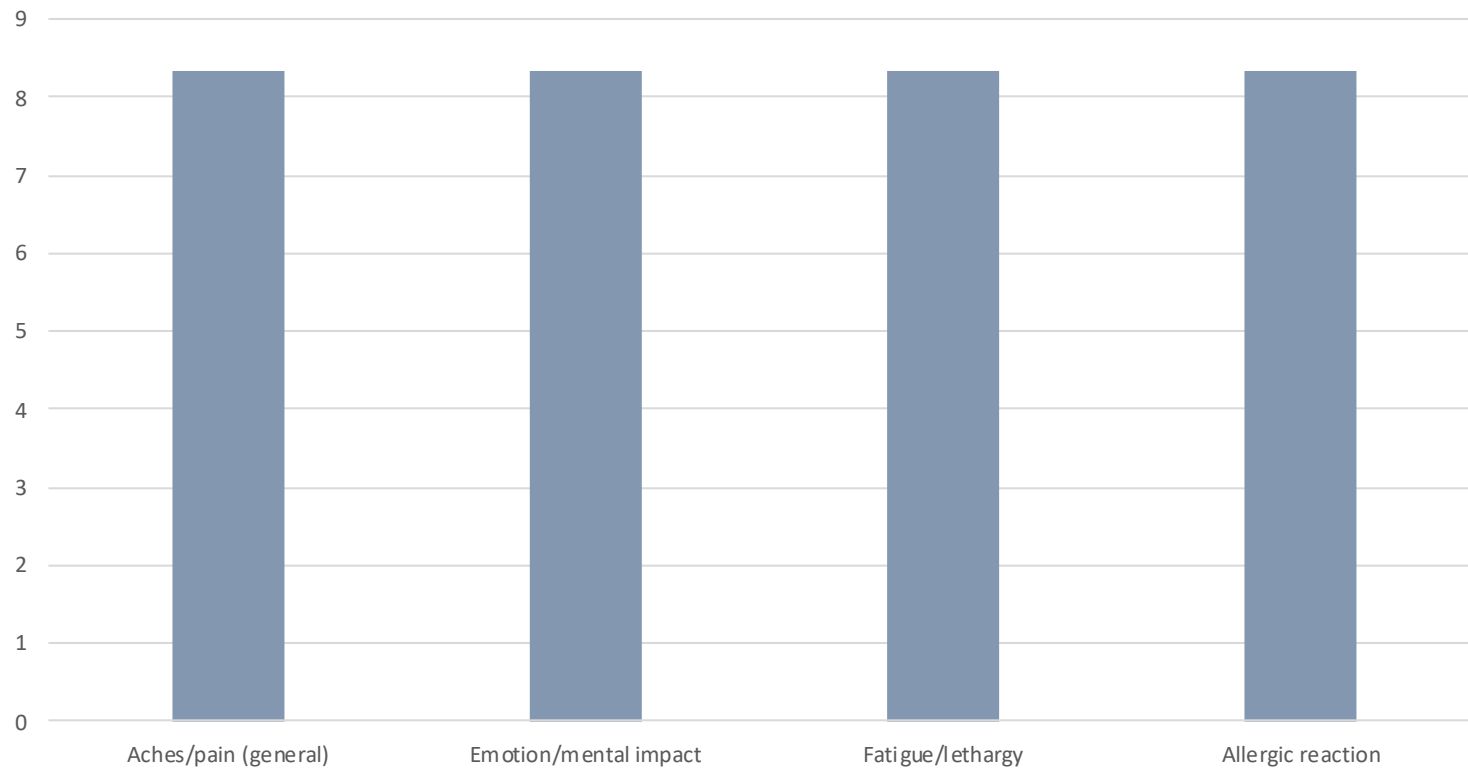




*Minor side effects may be purely some physical discomfort, such as headache and dizziness. Those are so scary, if they hit it, that is, for example, it may already affect the normal? Do things, that is, those in daily life, such as possible. Get up, even if it is already affected, well, if it is serious,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







*Yeah, kind of hinge it off what I said what we said about mild, it's like where it does interfere with your day-to-day functions. So yeah, where it's where it's, it's having a negative and again fairly like noticeable, measurable and immediate or long term impact on your quality of life. So it's, you know, it's it's it's having a negative impact. That's in terms of your mental health, in terms of pain and discomfort, in terms of the potential to cause other medical problems, that's what I'd call severe side effects.  
Participant 011\_2023AUHDV*

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



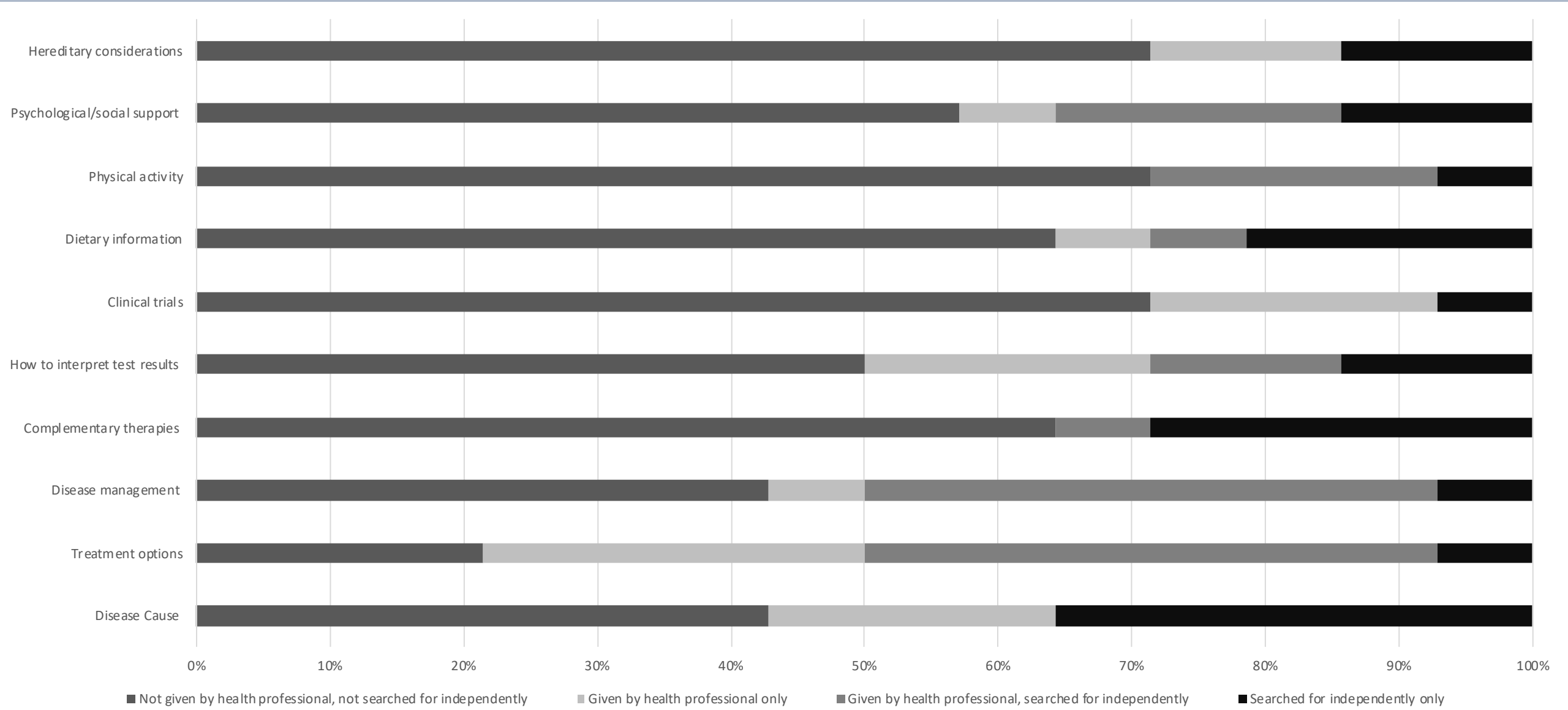
# Section 6



Communication  
&  
Information

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.



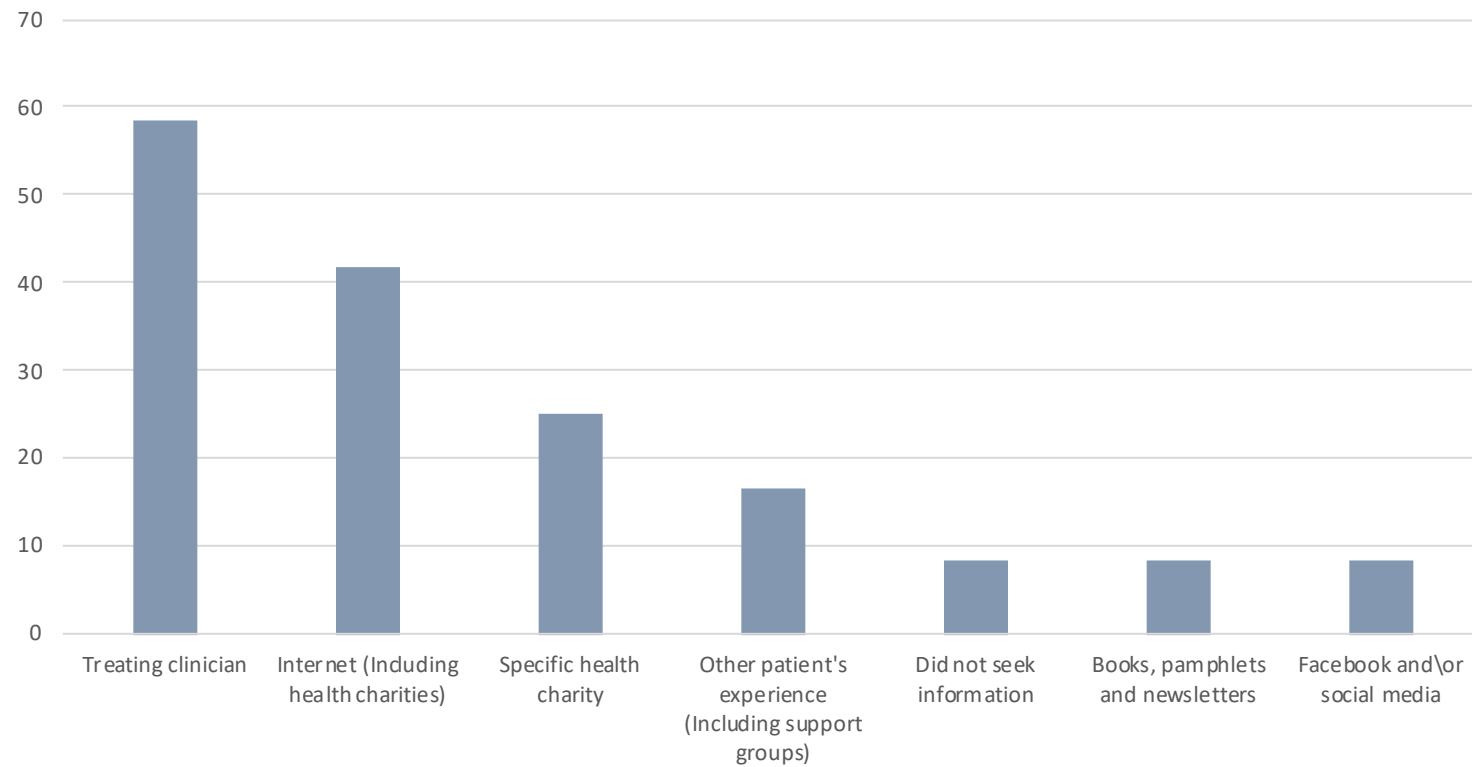


Partners in health scale (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge*	22.62	6.70	26.00	12.00	0 to 32	4
Coping*	17.08	4.70	17.00	5.00	0 to 24	4
Recognition and management of symptoms*	18.23	4.32	19.00	6.00	0 to 24	4
Adherence to treatment*	10.85	5.13	11.00	8.00	0 to 16	4
Total score*	68.77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

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

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

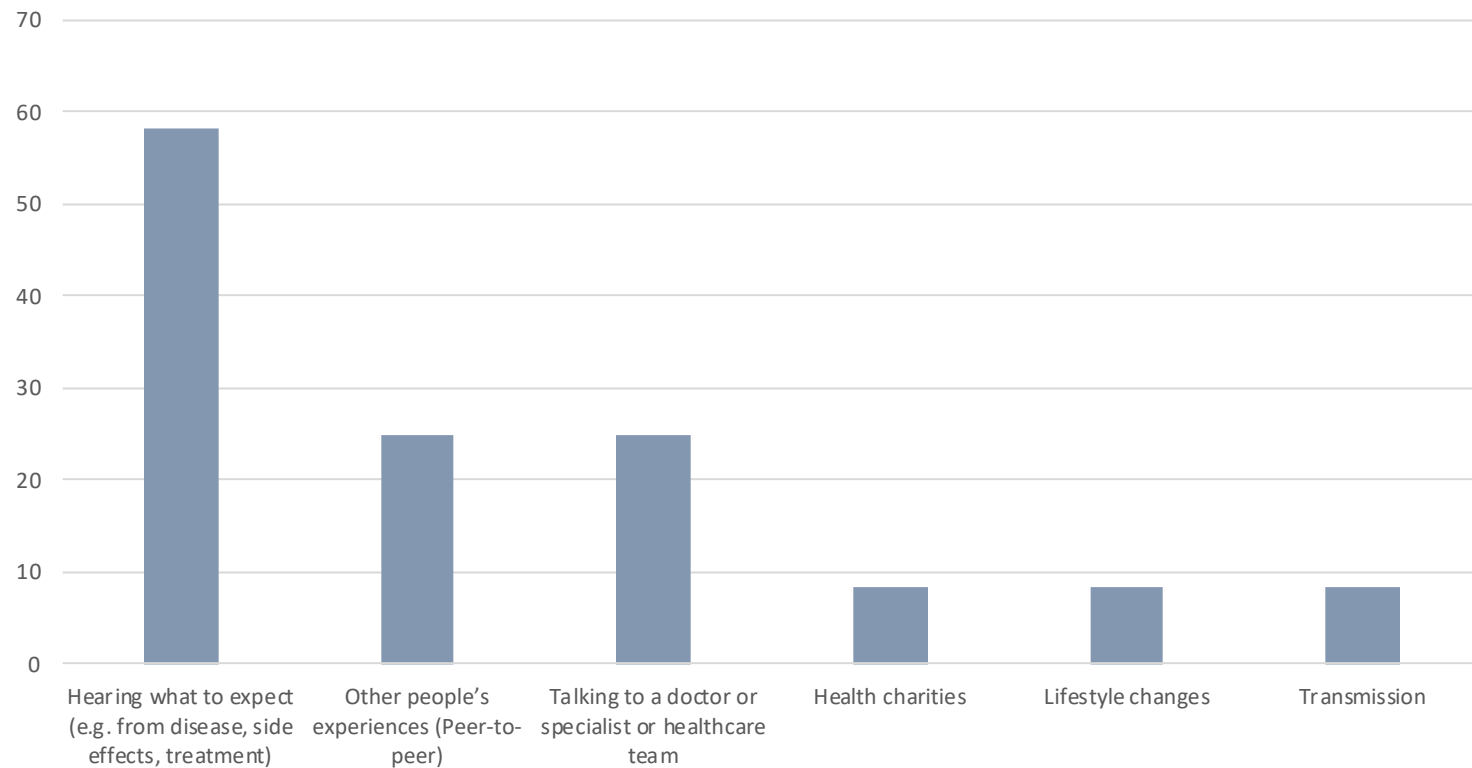




*I wouldn't say I've actually sought out information. It's been more I've picked up information along the way through discussion with doctors and nurses and all that. And having said that, I was actually part of the original hepatitis Bureau, so I do have some knowledge, but I wouldn't say that I've actually gone and specifically looked for it. It's what I've accumulated over the years.*

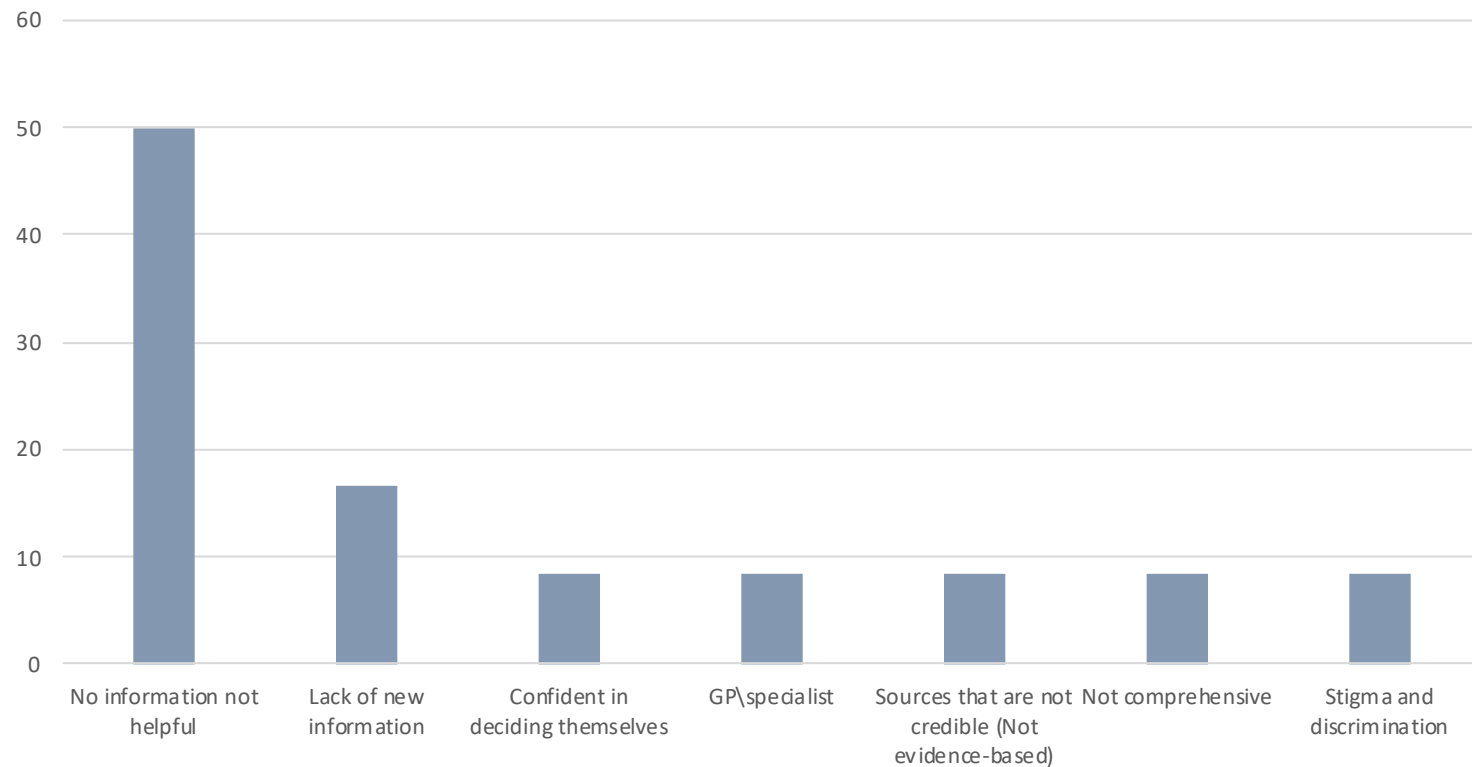
**Participant 007\_2023AUHDV**





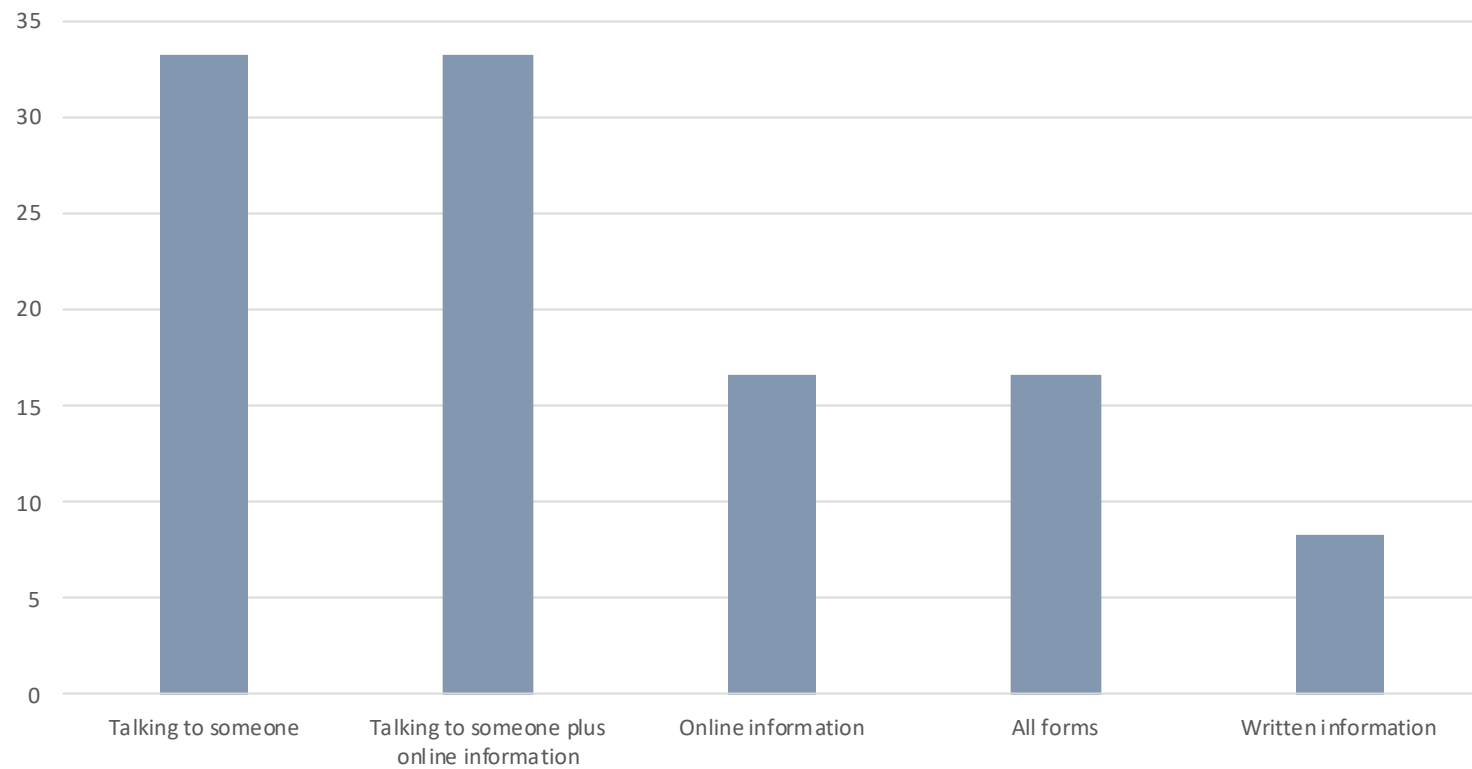
*I'm a person that likes sort of a combination of information. So I found the brochures helpful with other contacts on them so I could then do the research online. So I think it's a combination and then the information gleaned from my specialists and viral hepatitis nurses and from other people within the hepatitis community who know their stuff.*  
**Participant 010\_2023AUHDV**





*There's a lot I would say out there online that hasn't been helpful when. When those potential boyfriends have gone searching the facts that they came up with and put in front of me really made me question like how is that true and how is that accurate? So I would give them a bit more, something a bit more accredited, but yeah, I think whether the information was out of date. I'm not sure, but I think that was definitely a hard part to counterbalance.*  
**Participant 004\_2023AUHDV**



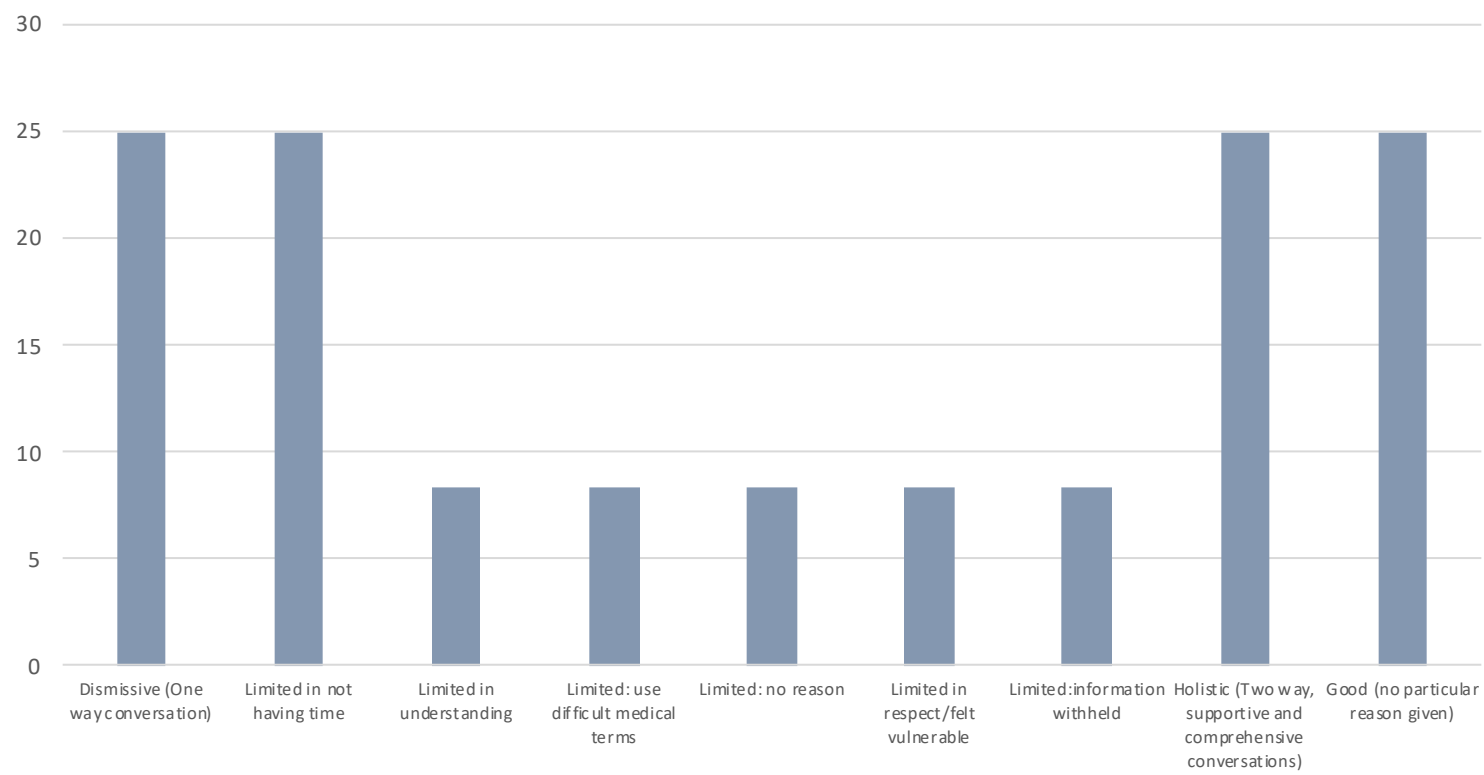


*I think it needs to be a combination. Of things, the online is a very good option and search option for people initially and especially depending if there's barriers with English and other things. Yeah, that is one good option, but I think the conversation. After the diagnosis with the nurse practitioner would have helped a bit more because you don't have a follow up and you don't know about the associations. Like one of the things I thought through was, should the GP not have given me this information? And then I was thinking, well, a GP is overwhelmed by so many different diagnosis. One of the things I think patients have struggled with is just the emotional. Toll a diagnosis can maybe take and how they problem solve against it all the resources that are available to navigate that.*

**Participant 004\_2023AUHDV**





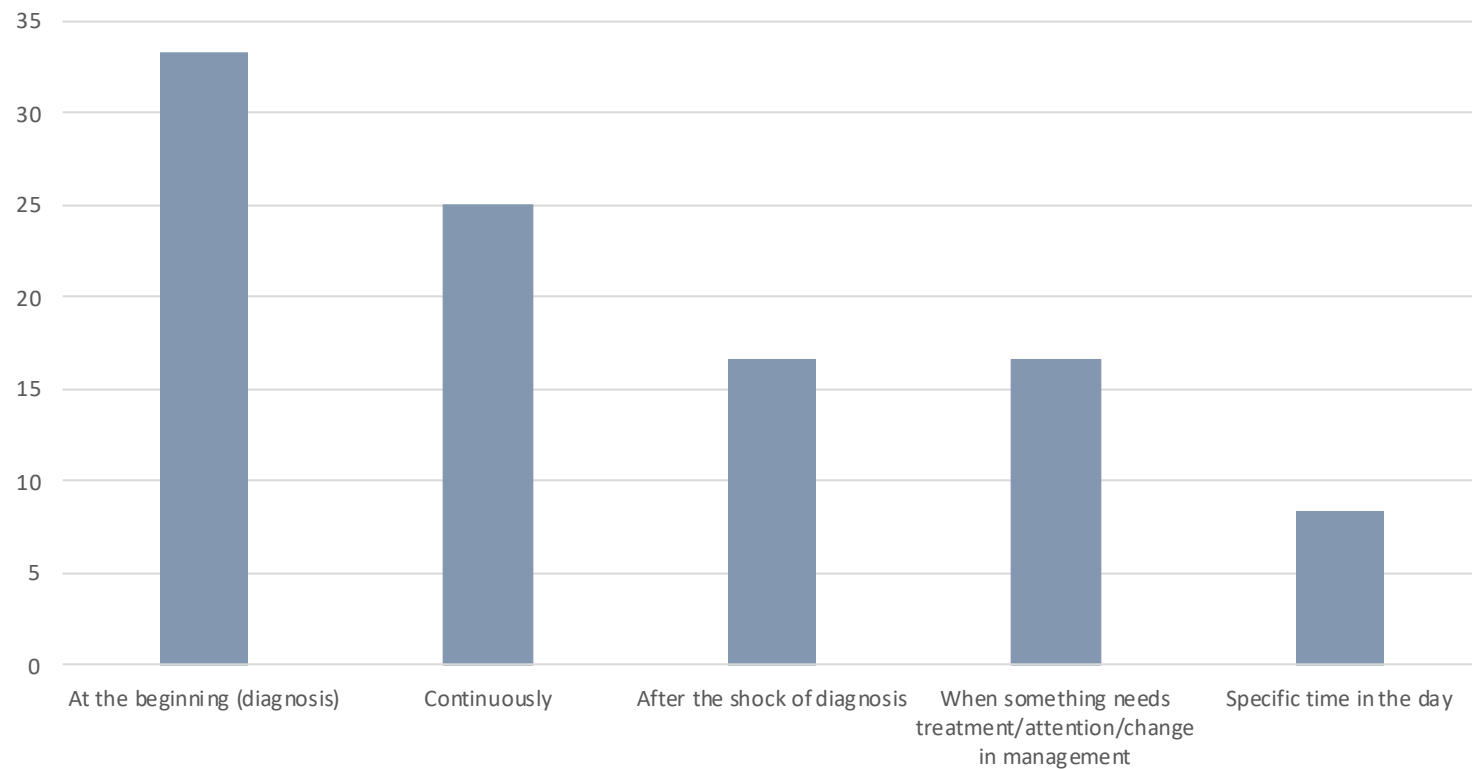


*I think you sending me the online information then you do a follow up with a call that would be better. At least I can read, I can start reading and understand when you call like this, at least I can. We can discuss and I can ask some questions, but I need to read first. Yeah. So if I get some information, read about it, understand it, then after that you give me a call. At least we can talk. When I can ask you questions that don't understand, at least you can clarify to me.*

**Participant 001\_2023AUHDV**

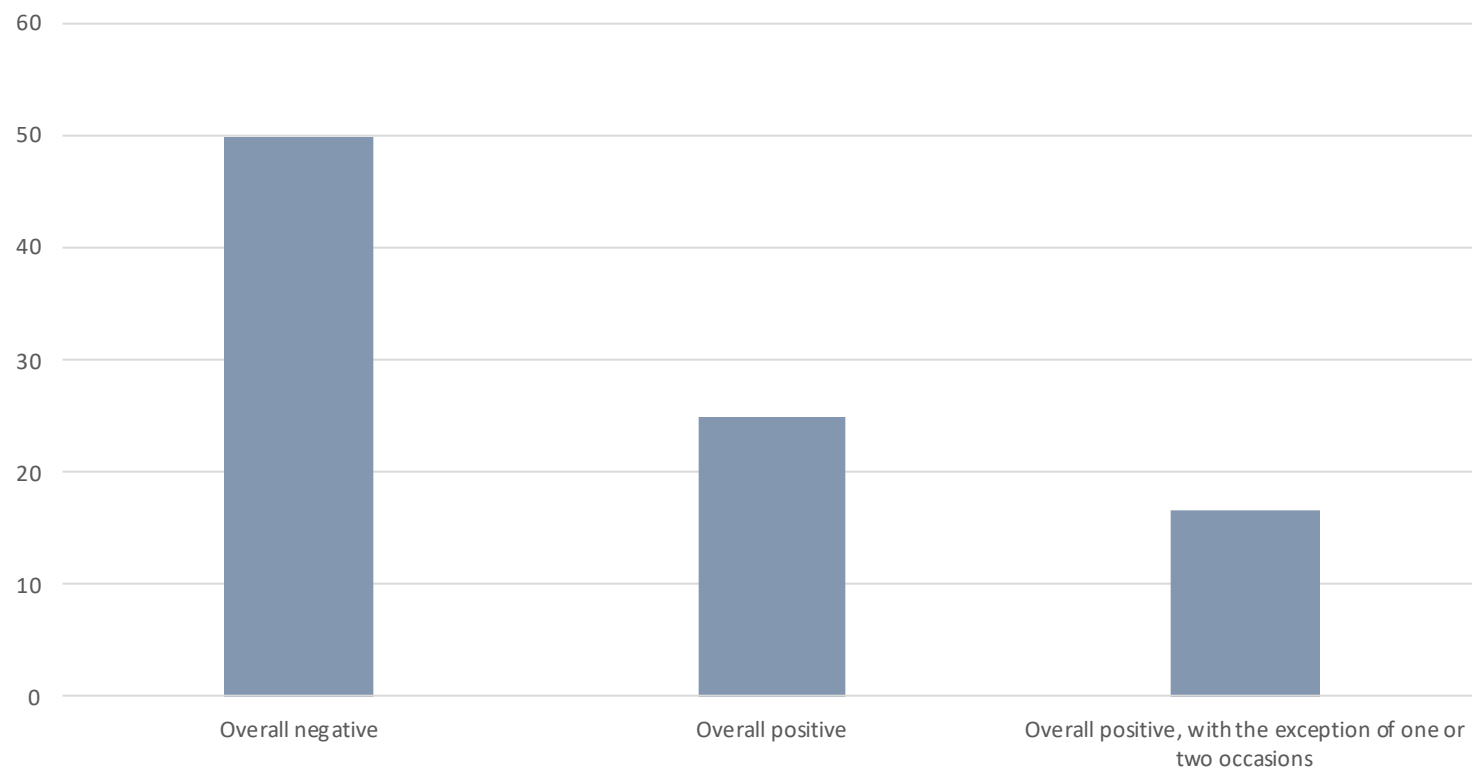


# Information preference rationale (% of all participants)



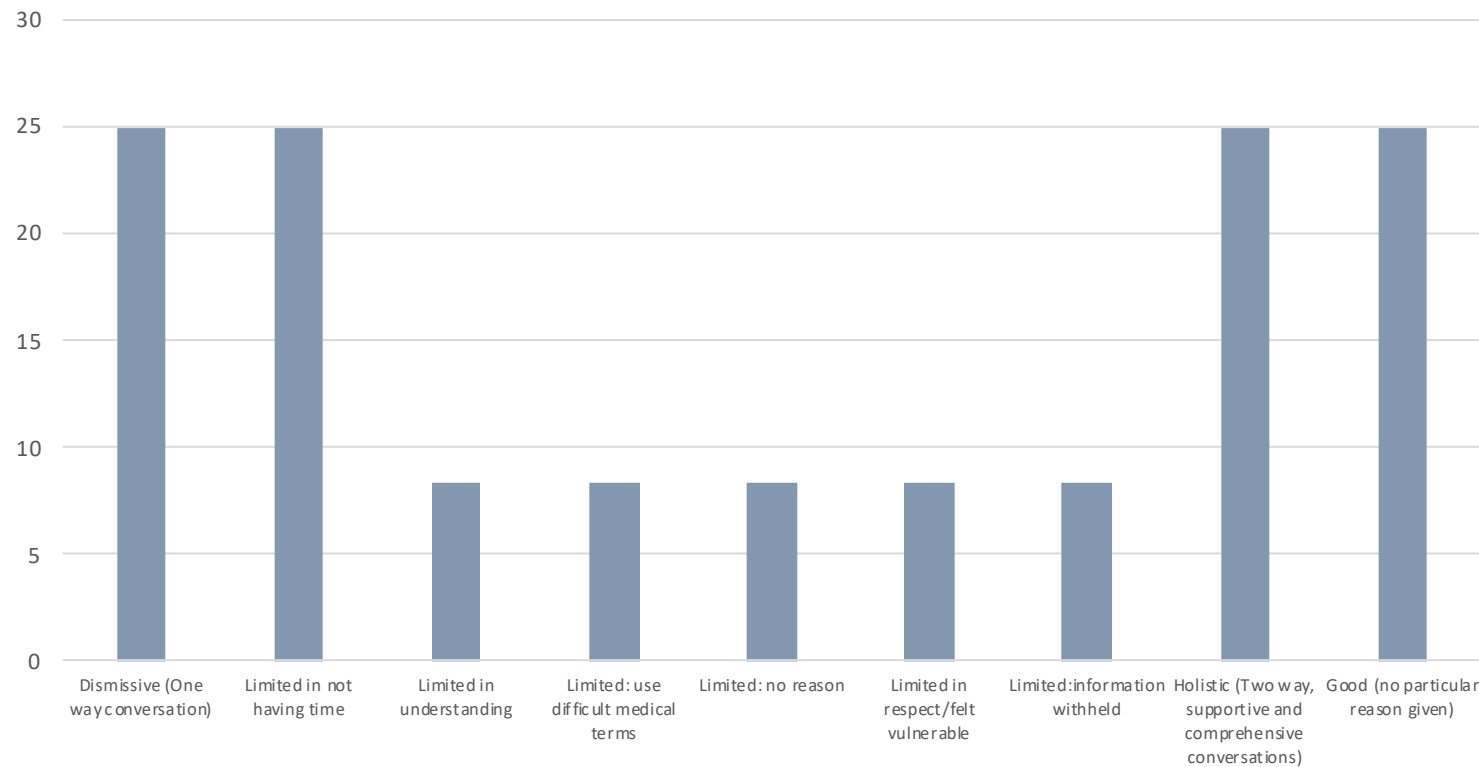
*I think. In our case, again, it's always in the background, so it never really pay attention until the GP said the blood is abnormal and it wasn't very like it wasn't very stressful. We just said also how could we control it and I think that's the period we try to learn more about hepatitis. Okay, again,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





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





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

**Participant 007\_2023AUHDV**



## 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.

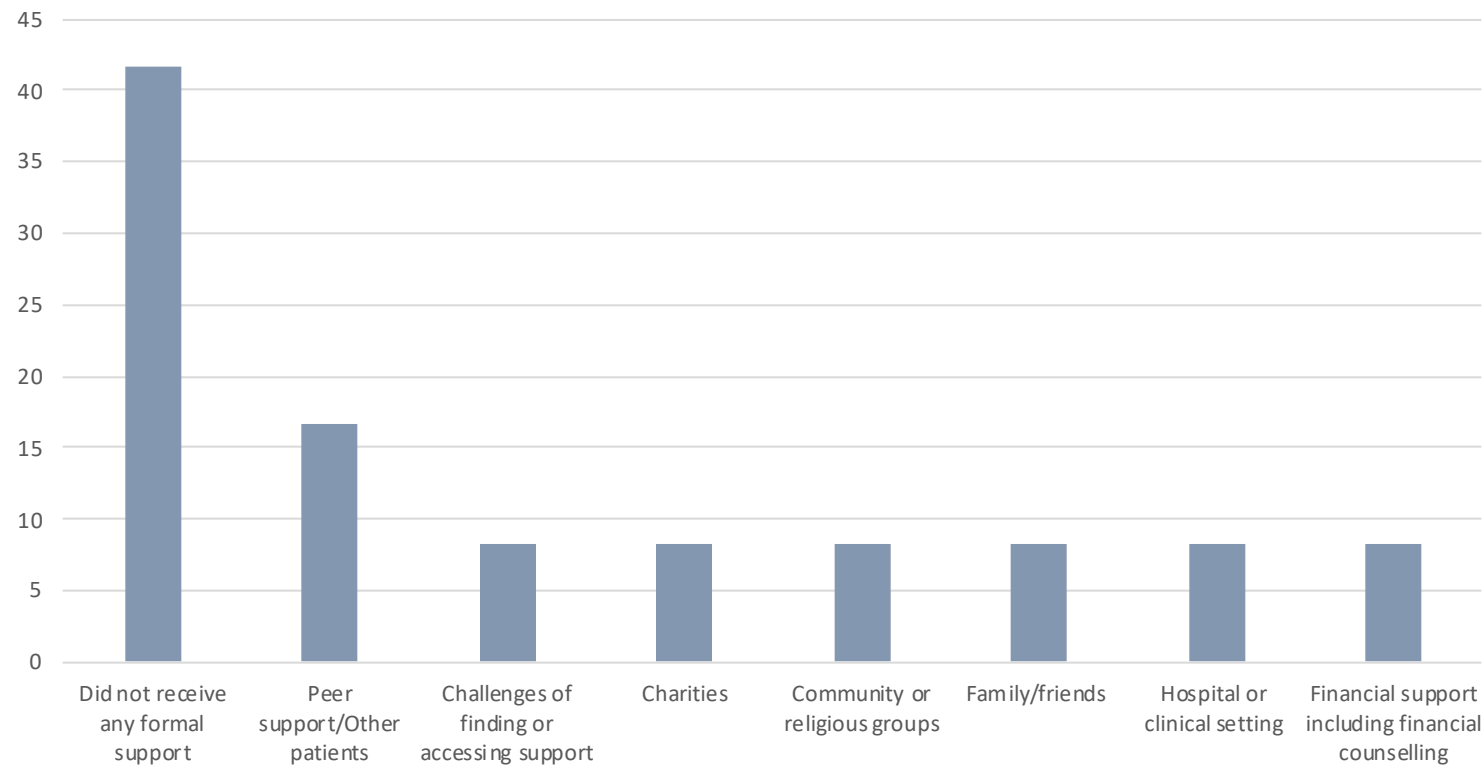


Care coordination scale (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	37.69	11.14	38.00	12.00	13 to 65	3
Navigation*	24.23	6.75	24.00	10.00	7 to 35	4
Total score*	61.92	15.24	65.00	18.00	20 to 100	3
Care coordination global measure*	6.23	3.14	6.00	6.00	1 to 10	3
Quality of care global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

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

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.





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

**Participant 011\_2023AUHDV**



## 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.



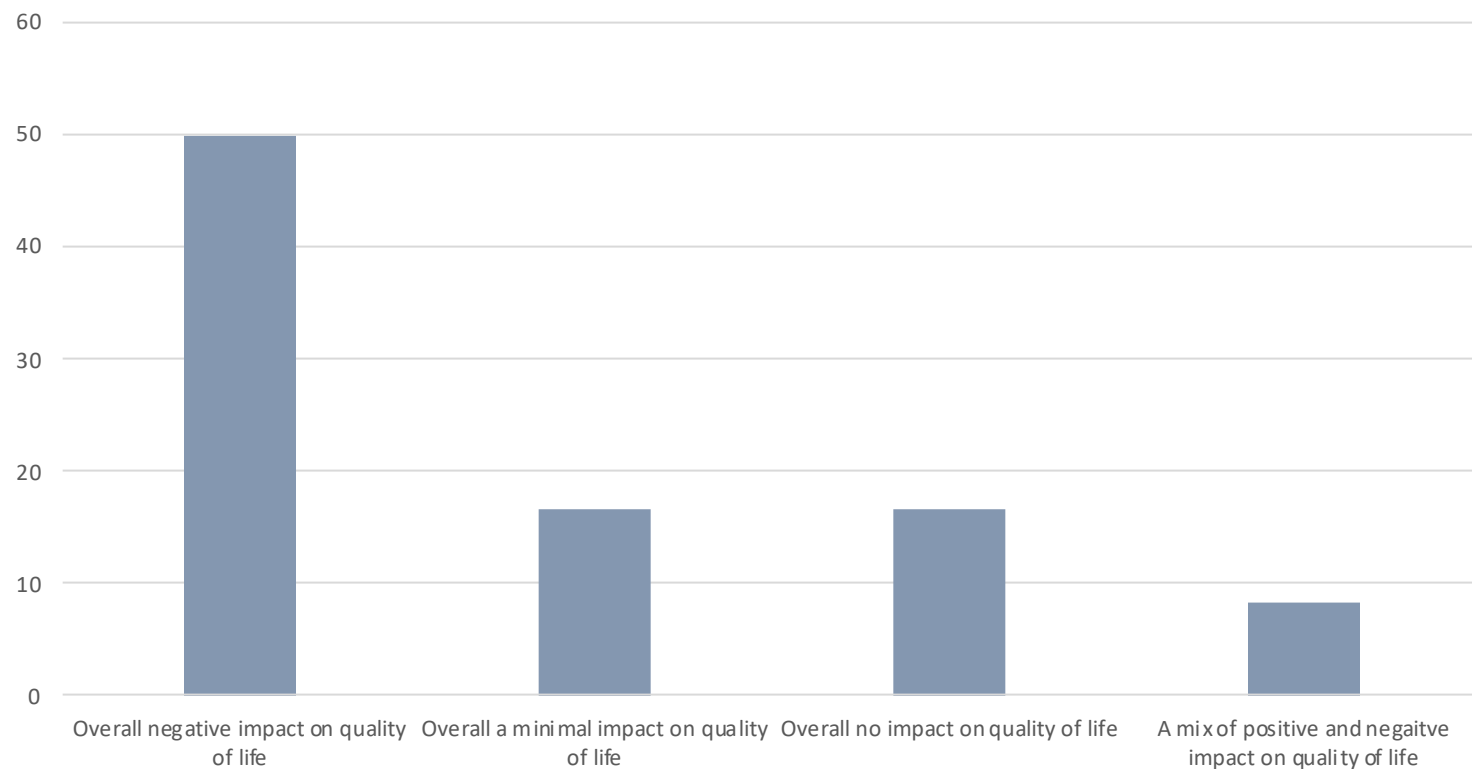


Fear of progression (n=13)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.15	13.28	34.00	21.00	12 to 60	3

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

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

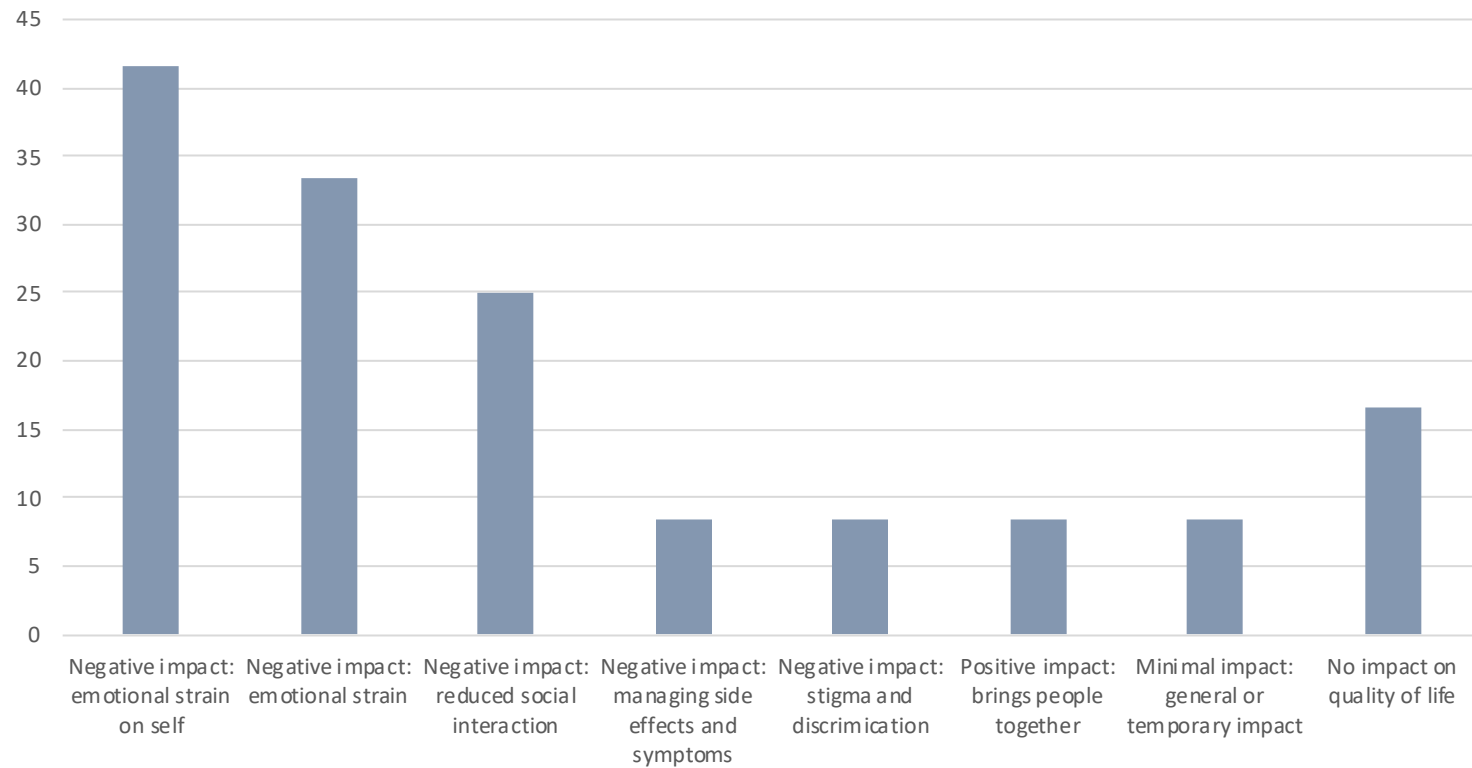




*No, it doesn't affected my life as such. But the only thing that I have is my mind. Every time I always think about it, I always think about it that when am I going to to to get sick? When am I going to get sick. So that is thought is always with me, but apart from that in my life is all good.*

*Participant 001\_2023AUHDV*





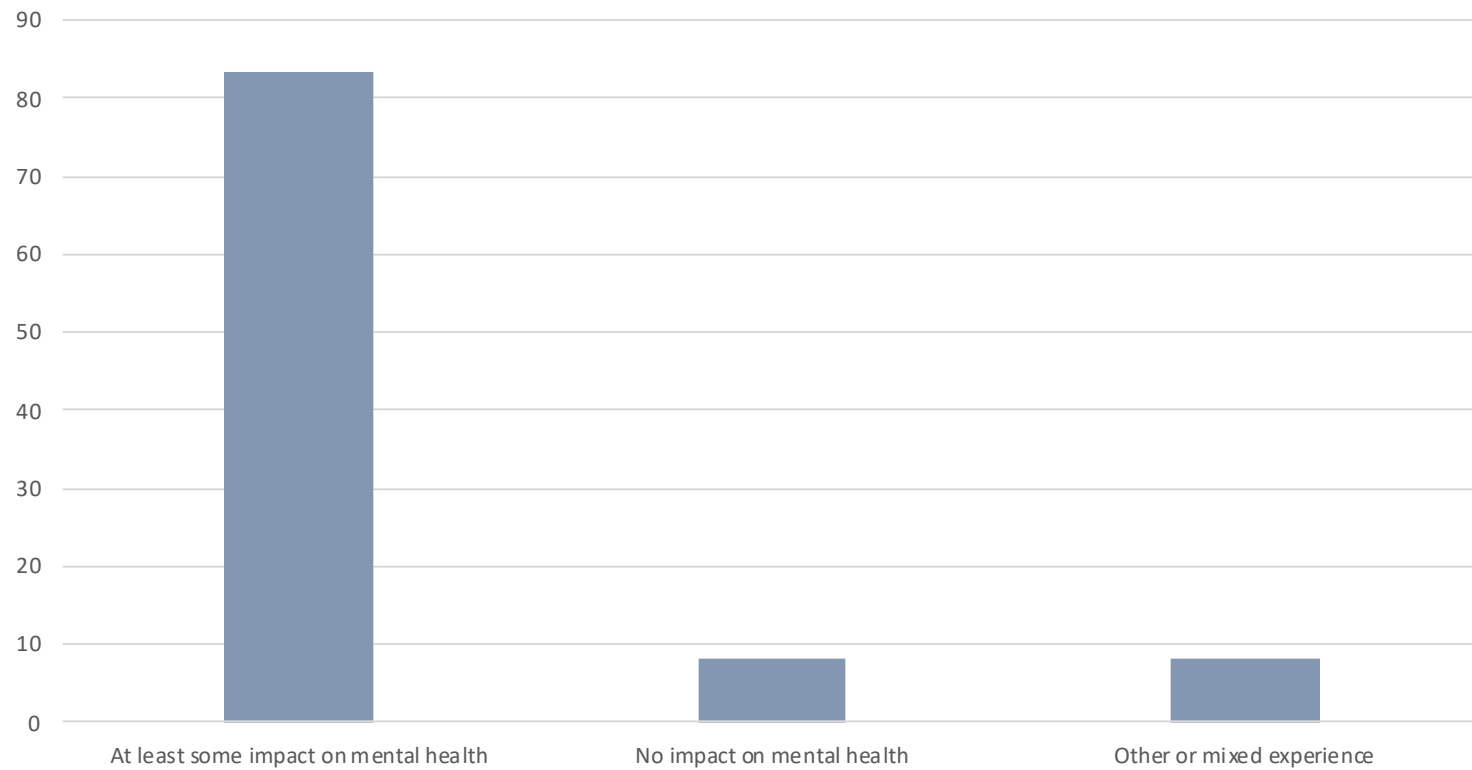
**PARTICIPANT:** Well, I don't eat what I'm supposed to eat. I don't drink what I'm supposed to drink. I don't hang out much with friends anymore. I'm always looking depressed and I stay away from a little activity that you know, could, you know, affect me more. And all of these, all of these, you know, compounded my whole life and made me restrain me to limited set of activities. So that's how far it is going to affect me.

**INTERVIEWER:** How about the life of your family?

**PARTICIPANT:** Well, they are just stopped as well. They are just stopped and they show a lot of consent and it shows in the in their faces that they are worried about the situation all.

**Participant 006\_2023AUHDV**

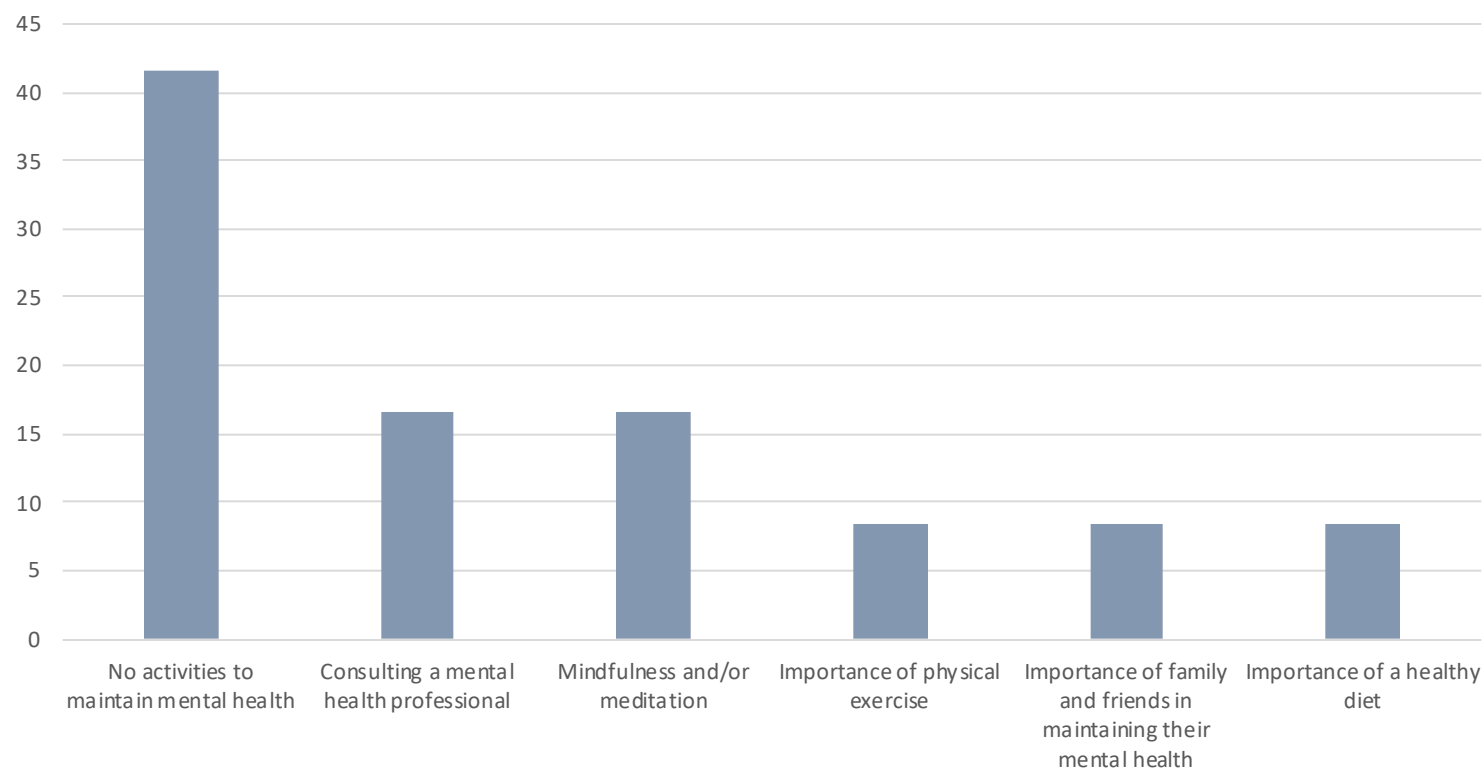




*Yeah, my, my mental health has been affected, that's for certain. And my emotions and everything has been affected. Yeah, I, I do certain activity once in a while, you know, to kind of, you know, soften the, the effects in my mental health, you know, let's say activity like yoga. And meditation, just to calm the calm the tension down.*

*Participant 006\_2023AUHDV*

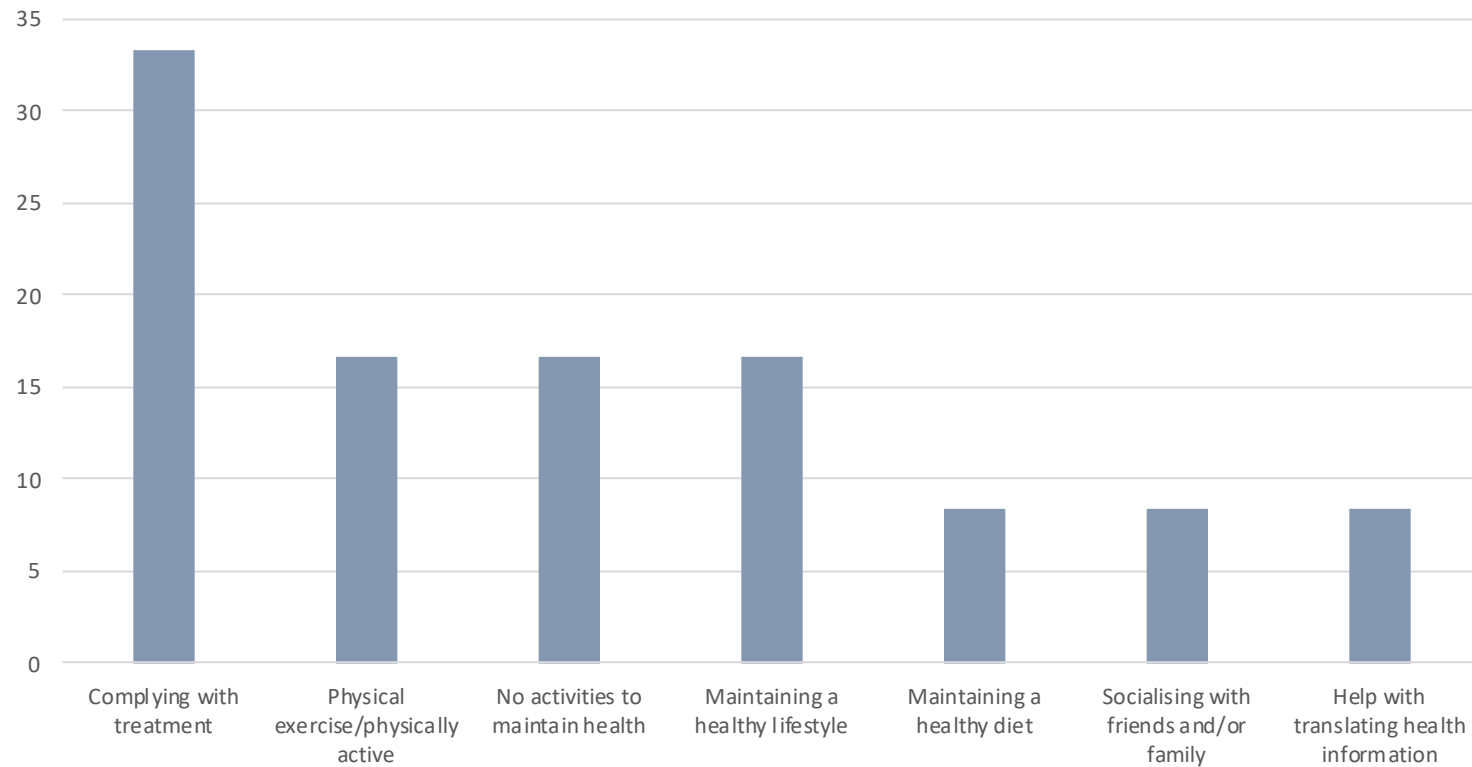




***And I did visit the therapist and he actually told me about a few things that I should go through that would actually help me is stress.***

***Participant 009\_2023AUHDV***

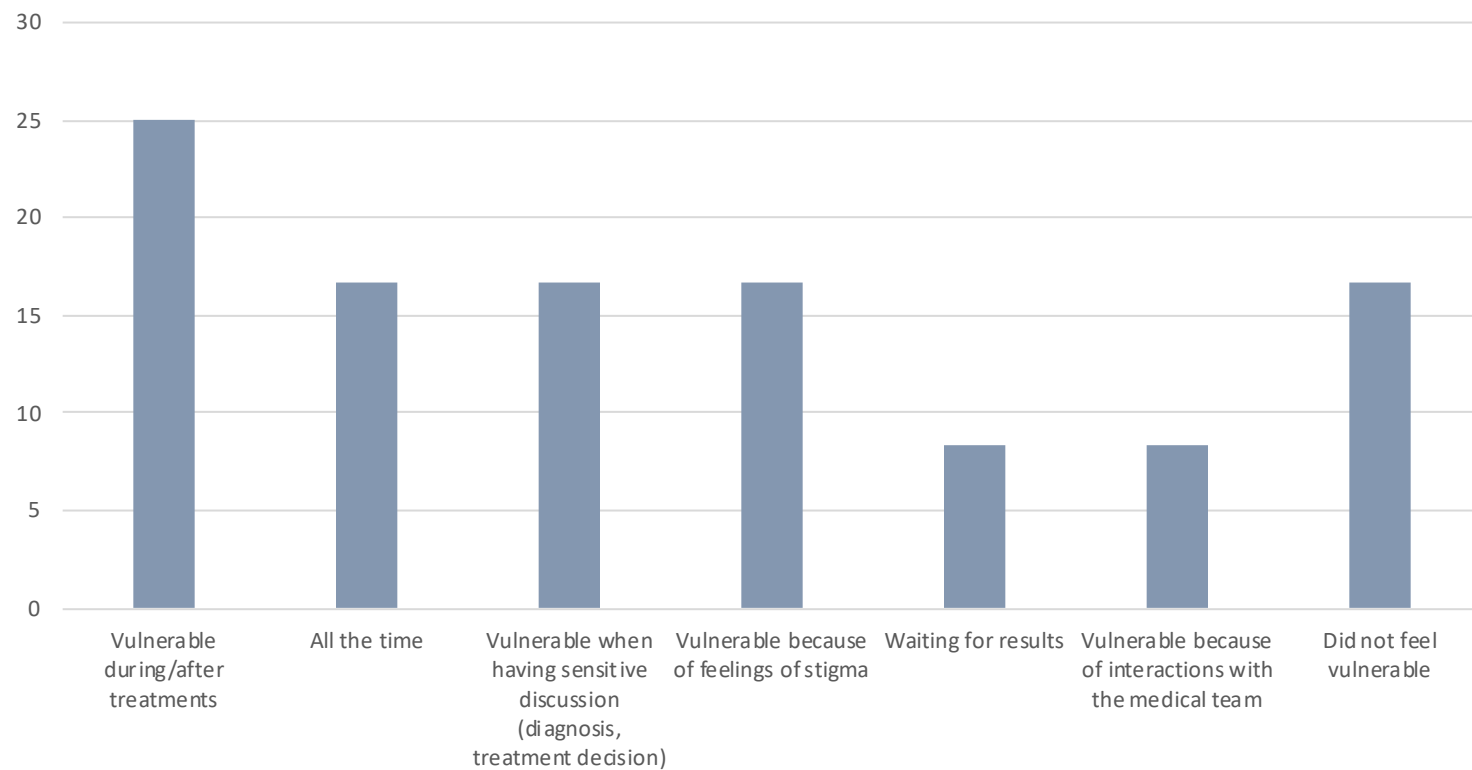




*No, no. Well, that's that's it. I mean I take, I'm probably taking about 10 pills a day now, so that's not too bad. But you know, apart from that, life just goes on. And I mean pills in the morning, pills at night, that's it. It's no great drama and it's. It's quick and easy to do.*

*Participant 007\_2023AUHDV*

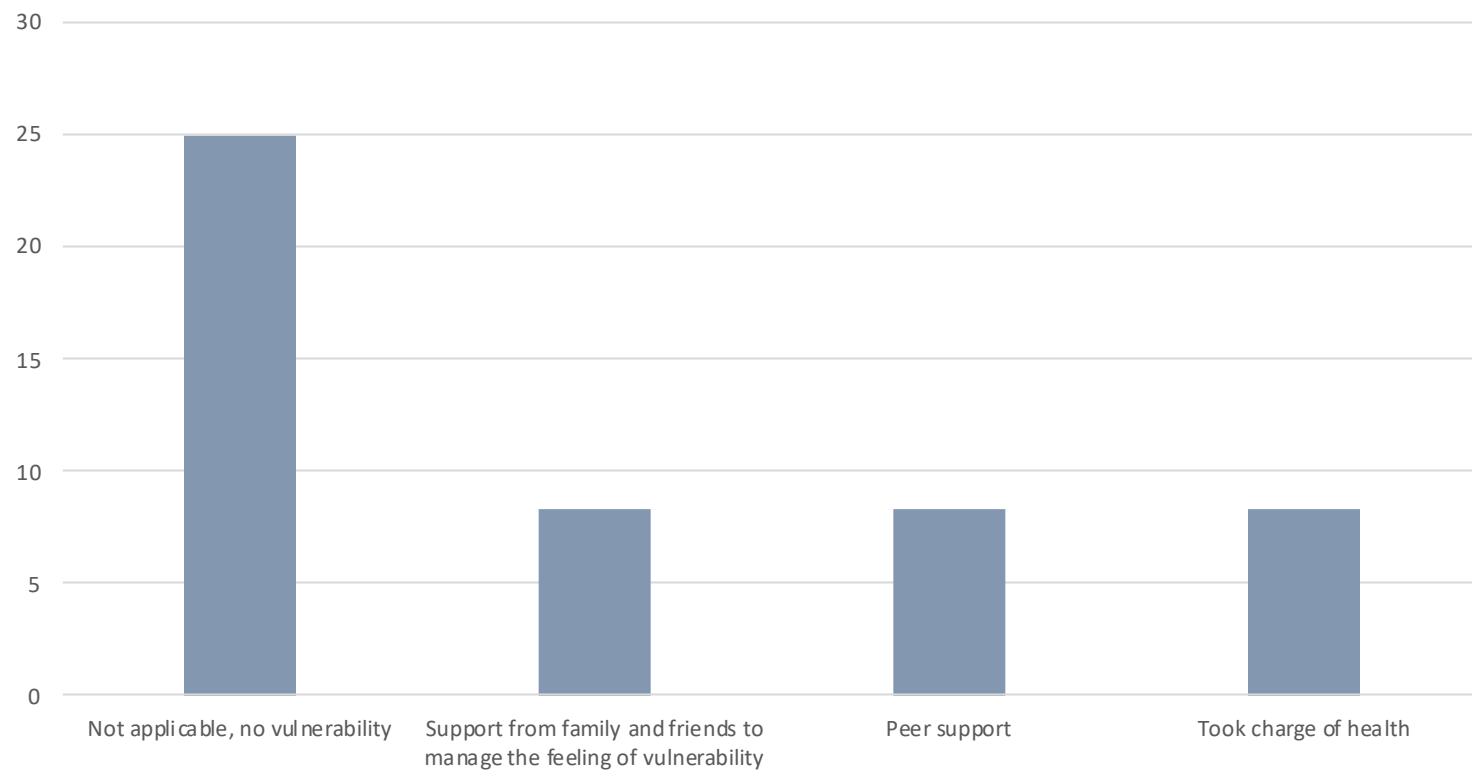




*Yeah, those two times where or maybe two or three times where the doctor and a couple of or couple of doctors and a couple of nurses were a bit judgmental about my past. So I just felt a bit vulnerable at that time, but I just spoke up so that was all good.*

**Participant 010\_2023AUHDV**





**PARTICIPANT:** Well, I have to do things for myself. I have to take charge of my own health.

**INTERVIEWER:** Yeah, Okay.

**PARTICIPANT:** That's, that's what I can do. I can speak to other people, but, you know, I mean, I really have to take charge of my own health. I have to liaison with other people too. You know, like I say, many peers, yes.

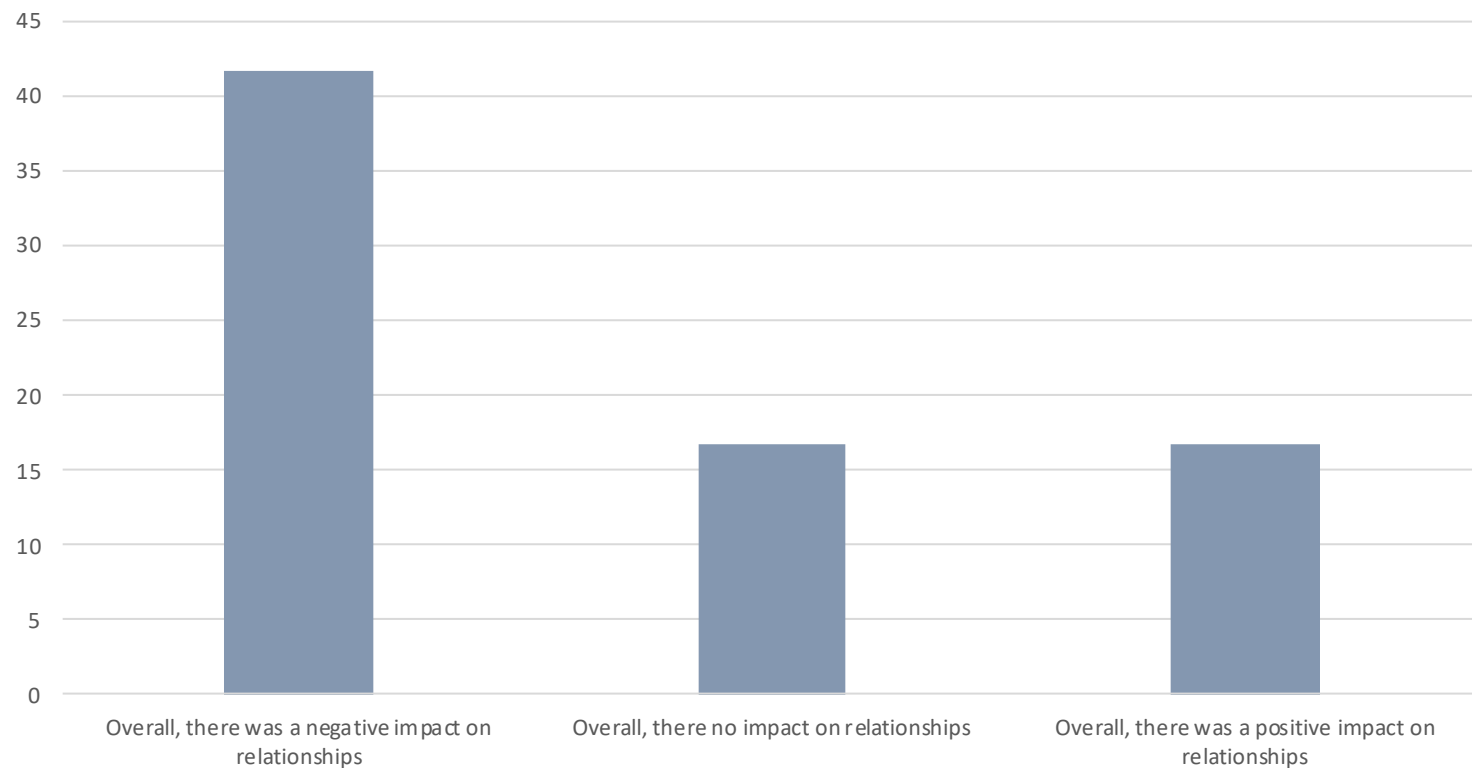
**INTERVIEWER:** But you know, Yep.

**PARTICIPANT:** Yep, Yep.

**Participant 012\_2023AUHDV**



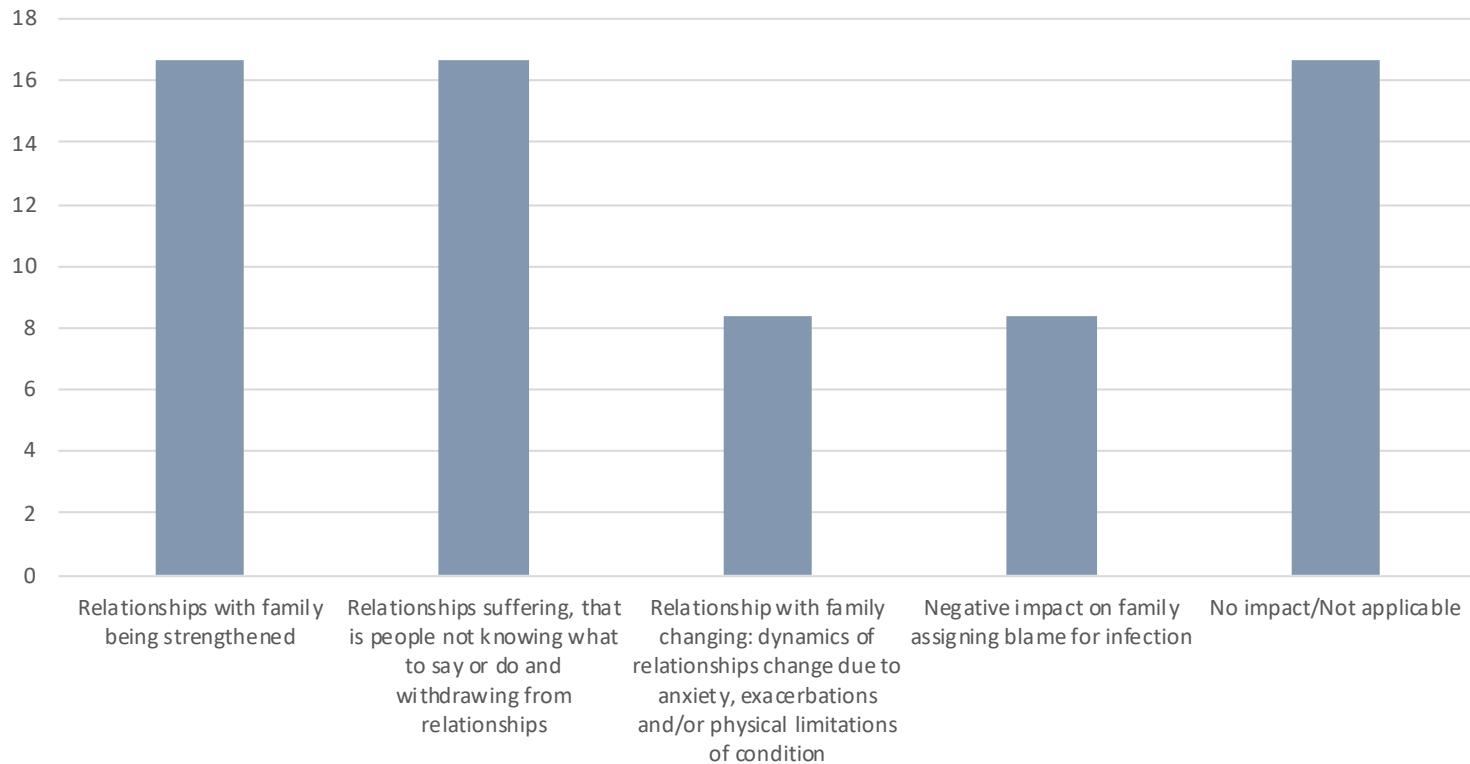




***Yes, yes. Especially with my friends. I wouldn't say the same about my family, but. With my friends, a lot of things have been, you know, affected and a lot of things have changed. I don't associate much and I tend to shy away from certain activity, which I always engage with my friends, you know, like hanging out and taking drinks or drinking, and all these have been limited and, you know, caught shut by the situation.***

***Participant 006\_2023AUHDV***





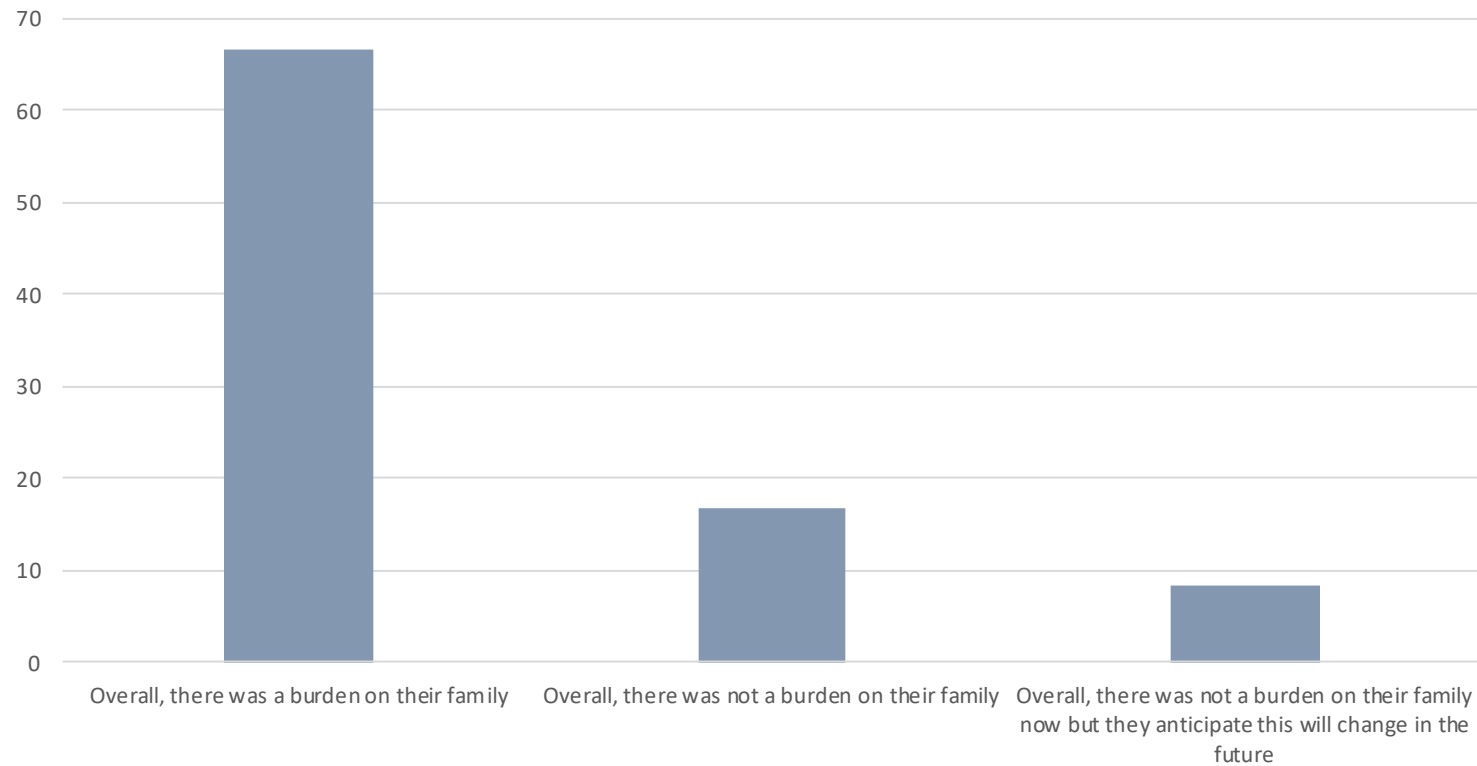
***PARTICIPANT: I'm. I'm not sure, but family, as I said, I think we become closer. Yeah, I care about them more.***

***INTERVIEWER: OK. Yeah. Yeah, that's nice.***

***PARTICIPANT: For myself because. You know, I don't have hep because I have the shot, so it doesn't really, really look like mine.***

***Participant 003\_2023AUHDV***





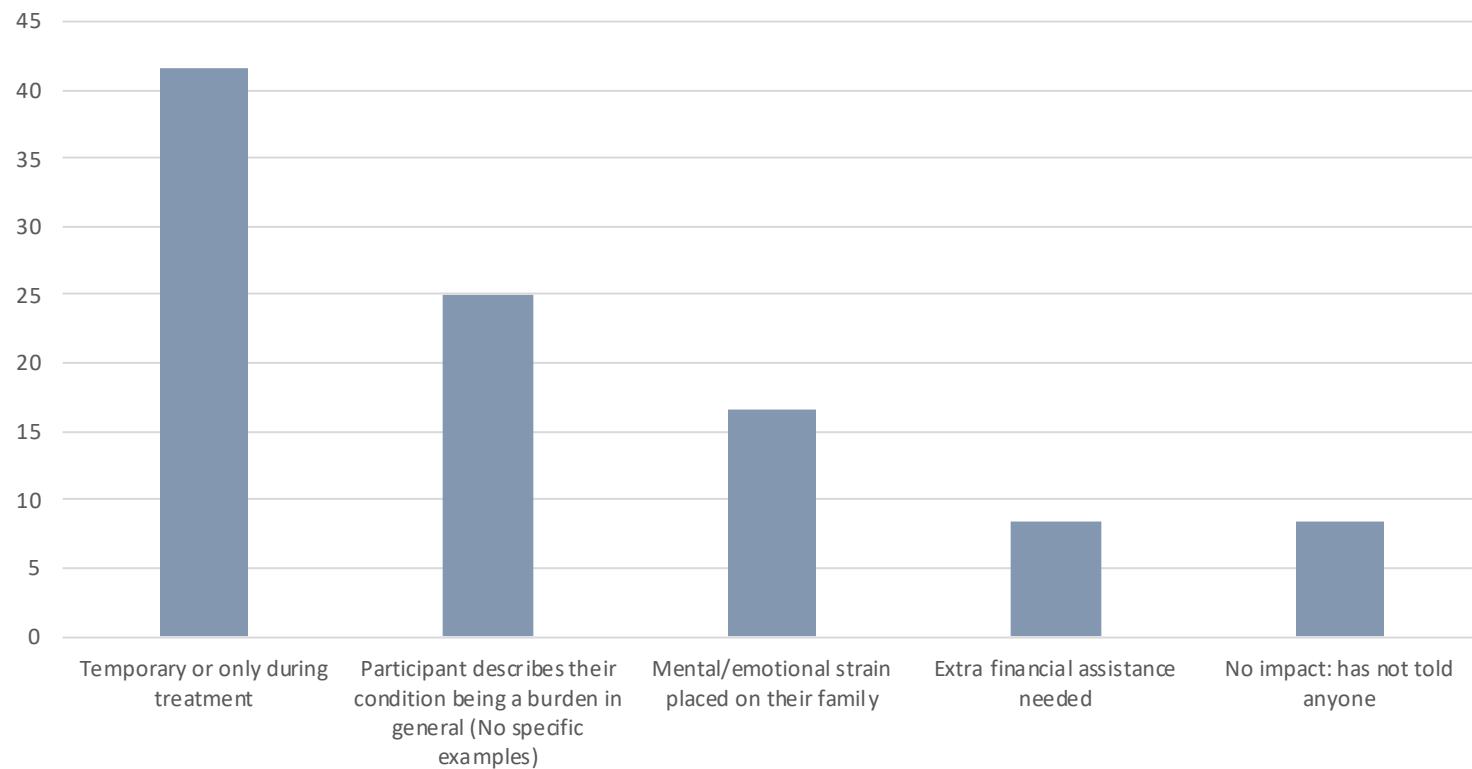
***PARTICIPANT: It affected them, yeah. It affected them.***

***INTERVIEWER: Yeah, like how?***

***PARTICIPANT: Mentally.***

***Participant 001\_2023AUHDV***

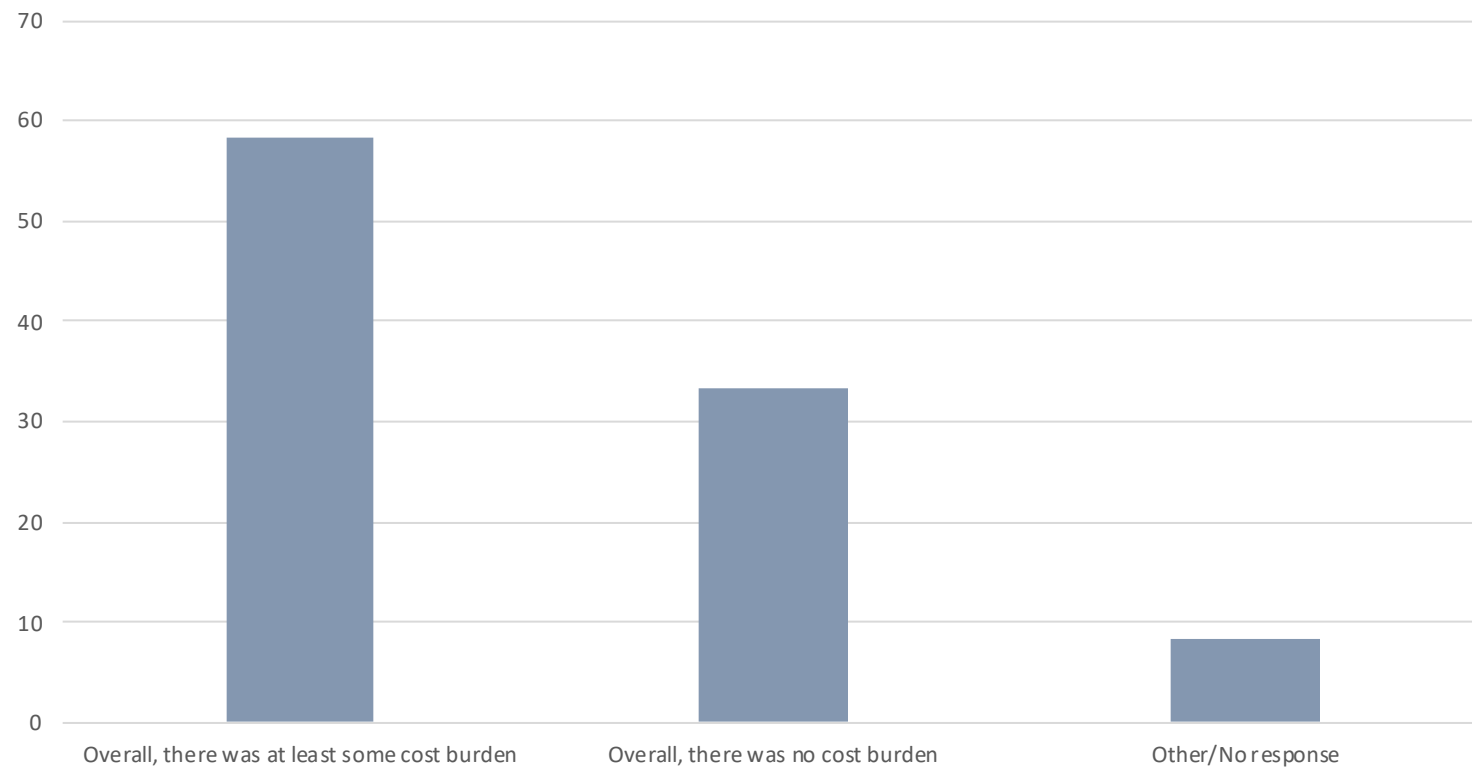




*No, I think, you know, like I said when I was first finding out I had it and and was diagnosed, it was a bit of an emotional burden on my daughter and while she was waiting for the results of her blood test to see if she'd been, you know, if she contracted the the virus by me when she was born. So that was very emotional and. But I think since since that diagnosis was clear and she was OK, and since I've, you know, cleared the virus and continued to be empowered by public speaking, it's actually had a transformative effect on my family in a positive way.*

**Participant 010\_2023AUHDV**





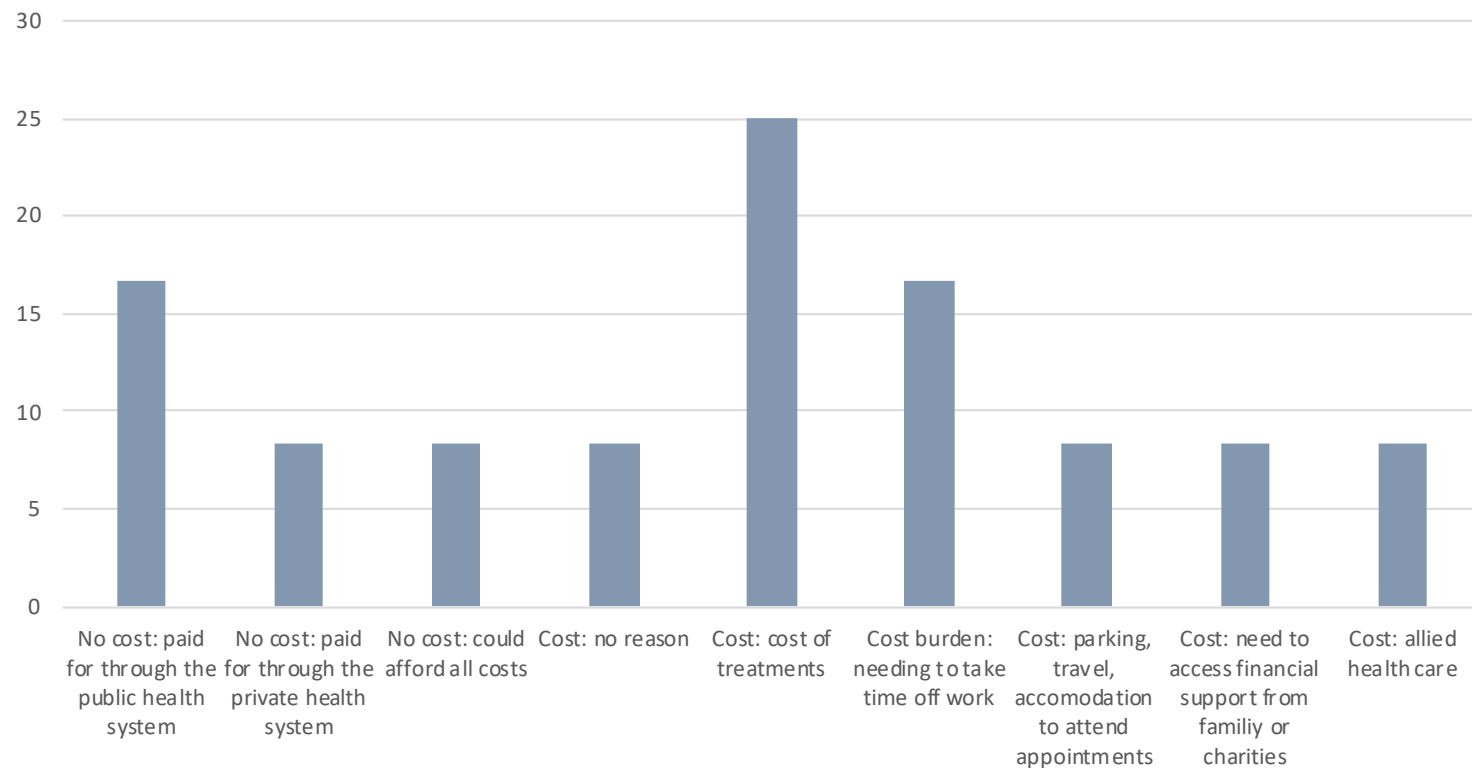
***PARTICIPANT: Most of my costs have been looked after by the PBS and and that I'm very fortunate. You know, the pill, I believe in the United States is about \$800 per pill.***

***INTERVIEWER: Oh, OK. Wow. OK.***

***PARTICIPANT: Yeah, yeah, yeah. Yeah. So over a month period, that's about \$24,000 exactly, which is a fair whack if you don't have a lot.***

***Participant 012\_2023AUHDV***





*Well, I probably would have worked until I was 65. So I suppose that was a bit of a cost. And then I just worked part time from then on. Then when I found when I was ready to have treatment, when I found I had a rheumatoid factor in my blood. I knew the only way I could continue to have the energy to even work part time because my side effects were quite strong at that time. I mean it would have been quite costly and yeah, and then just the energy to do all the things in my life I wanted to do was diminished by having viral hepatitis. So and like I said, I probably would have continued to work longer had I had the energy. So I suppose if I added it all up, it'd be quite a lot.*

**Participant 010\_2023AUHDV**



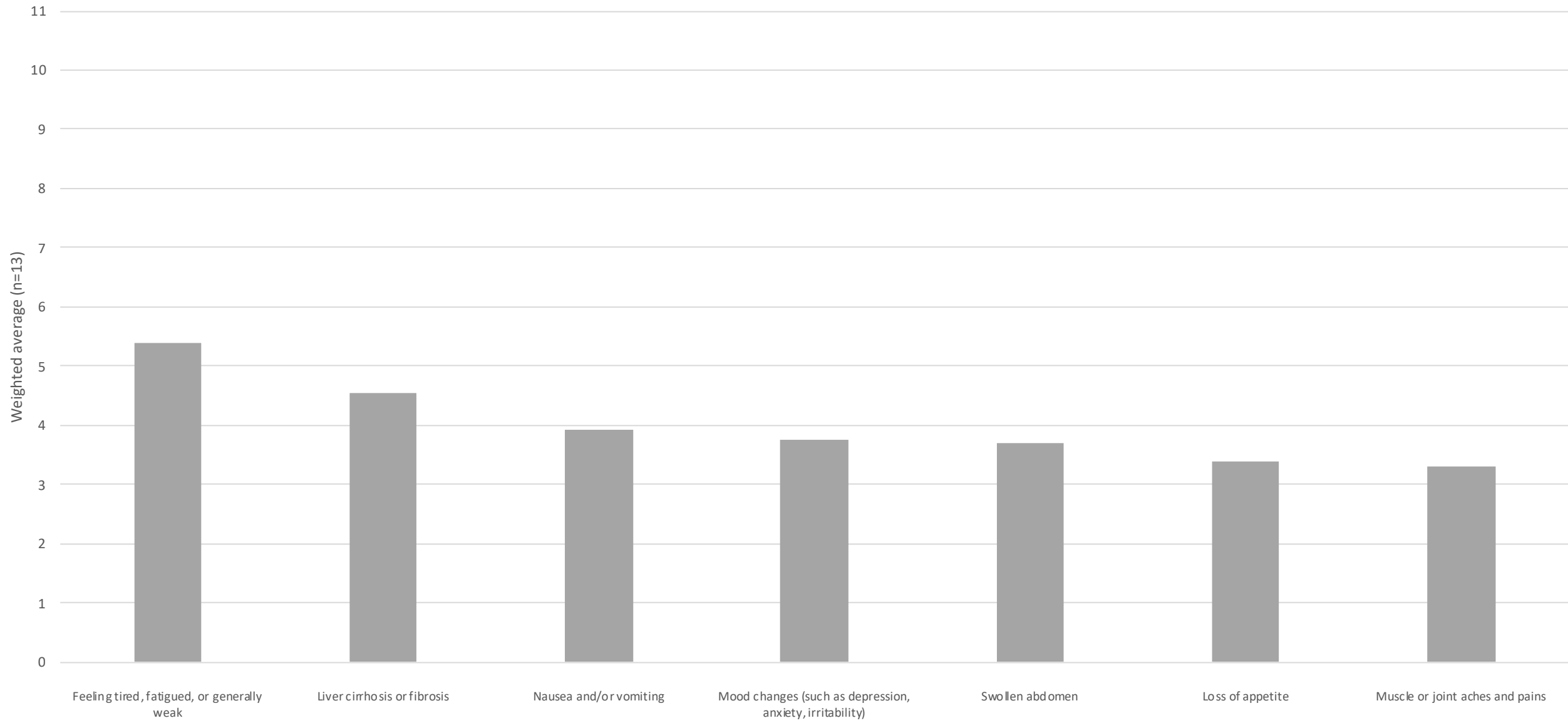
## Section 9



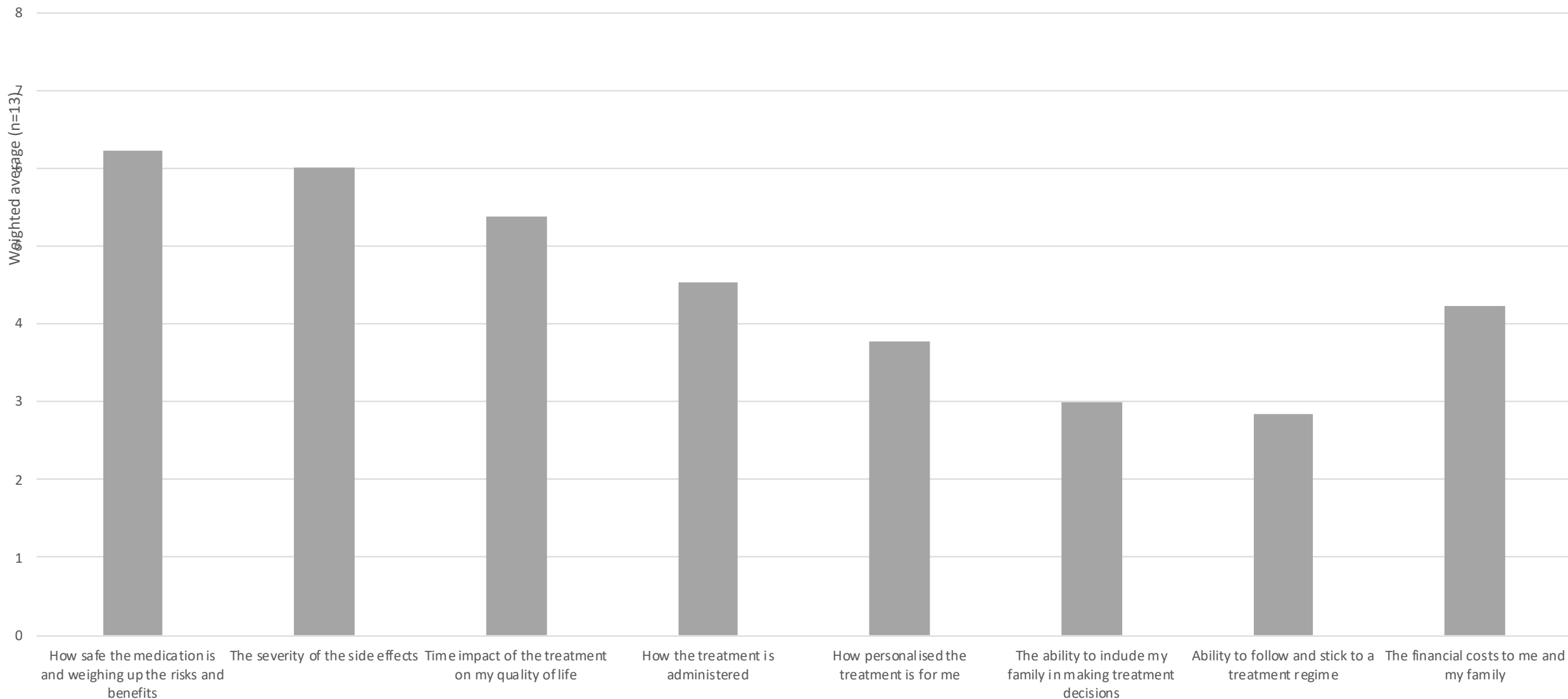
### Expectations & Messages to Decision-Makers

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.



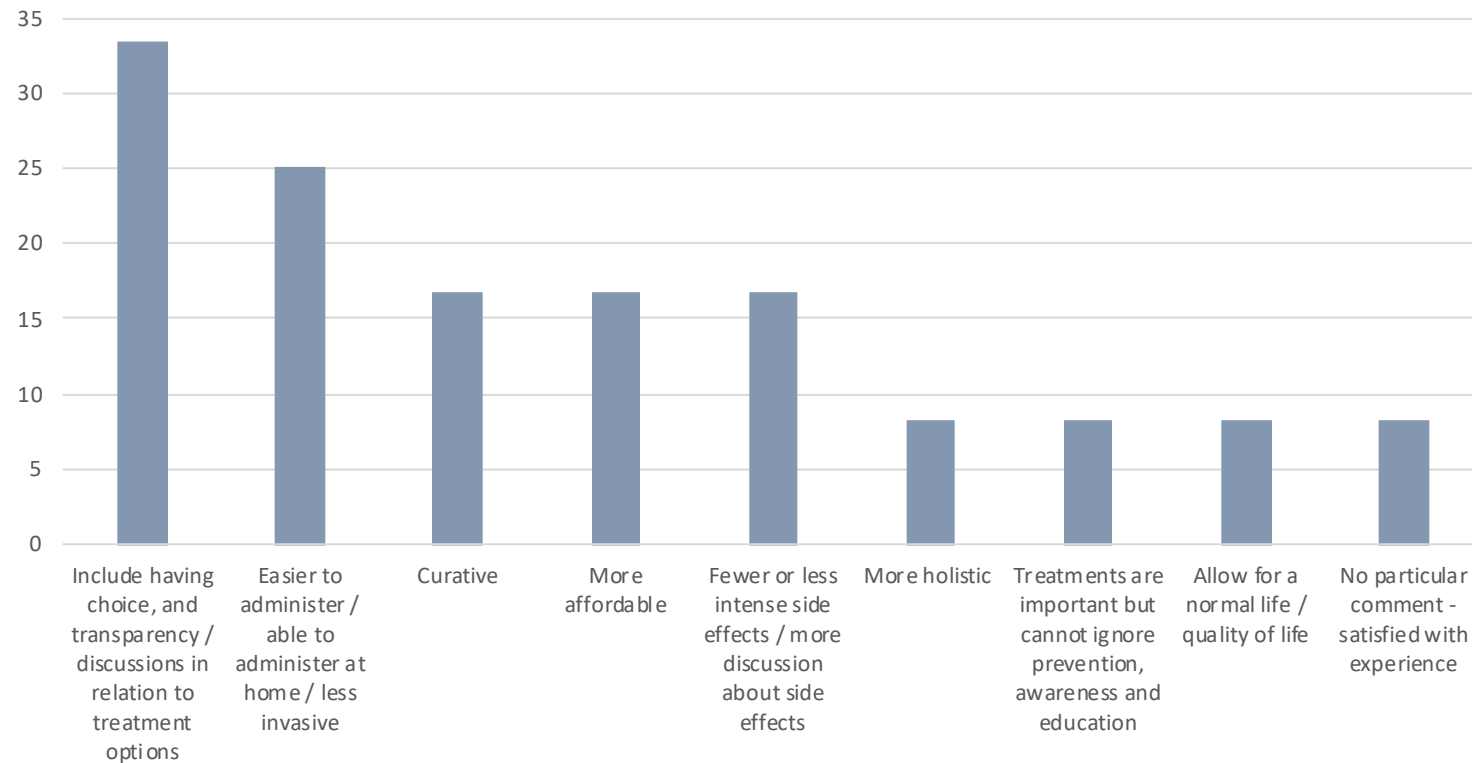






With a weighted ranking, the higher the score, the greater value it is to participants.

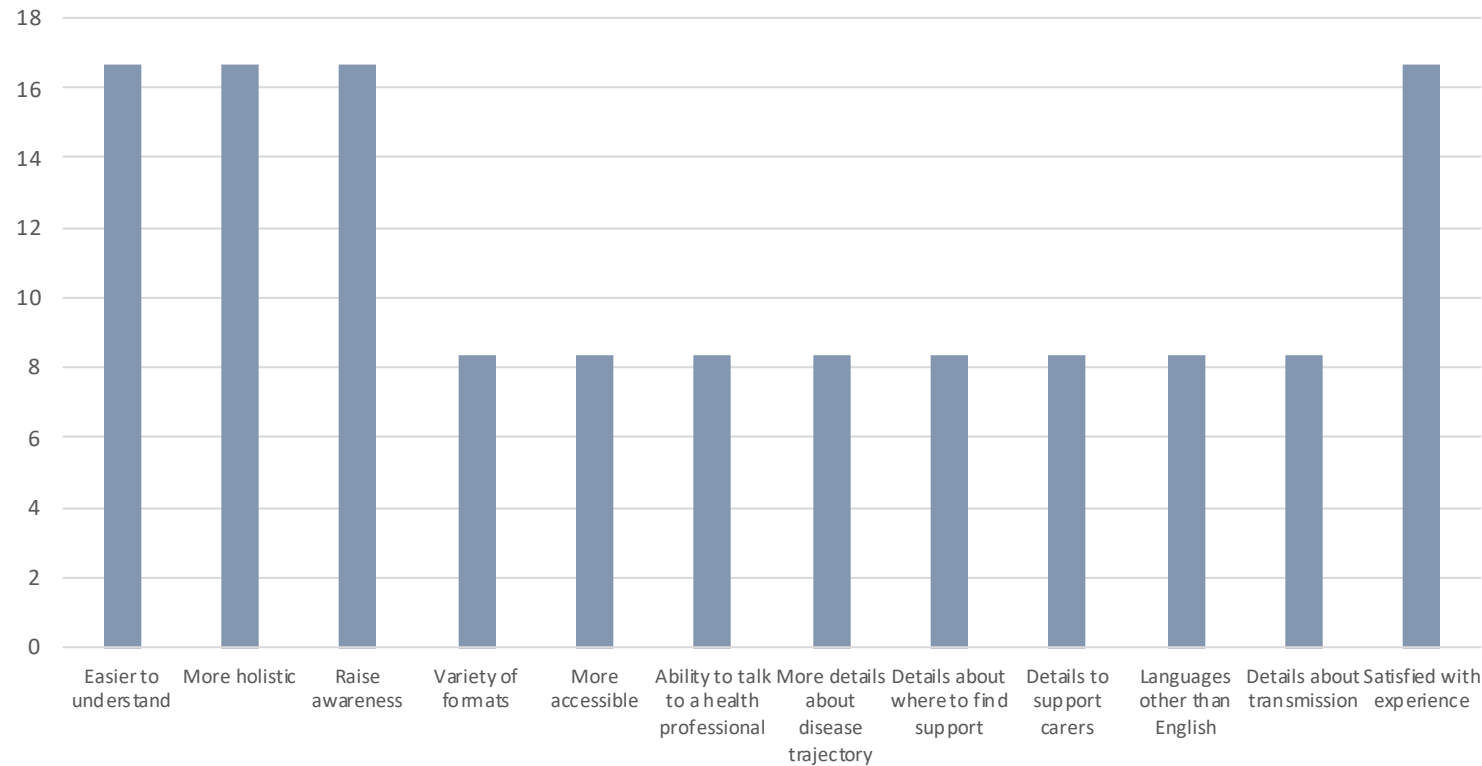




*I admit I've been in a fortunate situation. I mean, say, cost would obviously be something that would be an issue for someone that was actually working and paying full price for medication. And my problem is that I'm too knowledgeable about things and I tend to forget that some people don't know basic information, so that that would probably be something to to consider is just having. Very simple, basic information that someone can take away with them when they're diagnosed and not too too detailed or too technical would be one suggestion.*

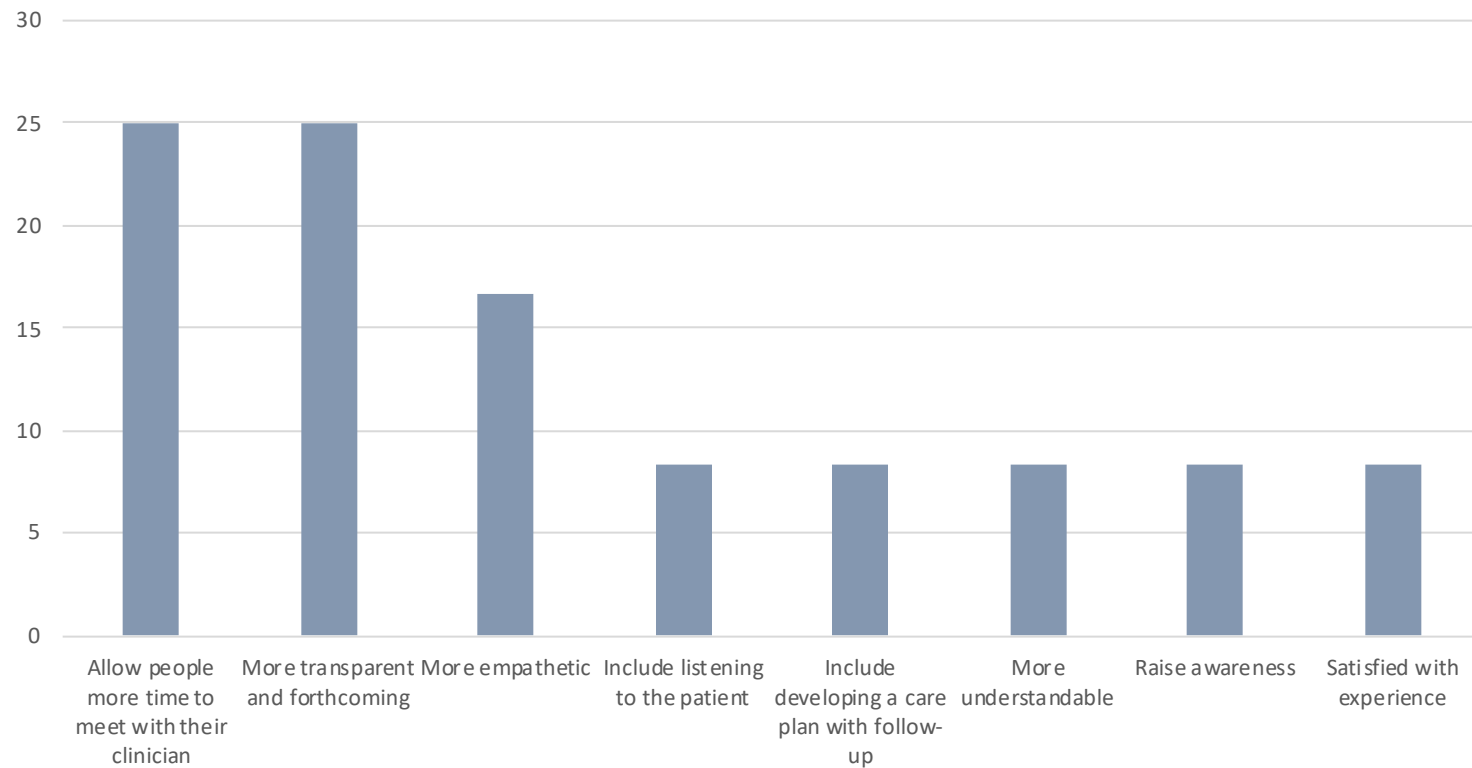
**Participant 007\_2023AUHDV**





*I'm very old fashioned so I'm not into all the online and support chat groups online and all that sort of stuff. I'm the old. Printed brochure, talking to people face to face, and I still think that's pretty important face to face, even if you are doing telehealth and all that, nothing really beats that one-on-one to emulate the conversation, to actually get you to think about what you want to ask the doctor. I find with telehealth you always forget something and you tend to go off on tangents, I've found.*  
**Participant 007\_2023AUHDV**

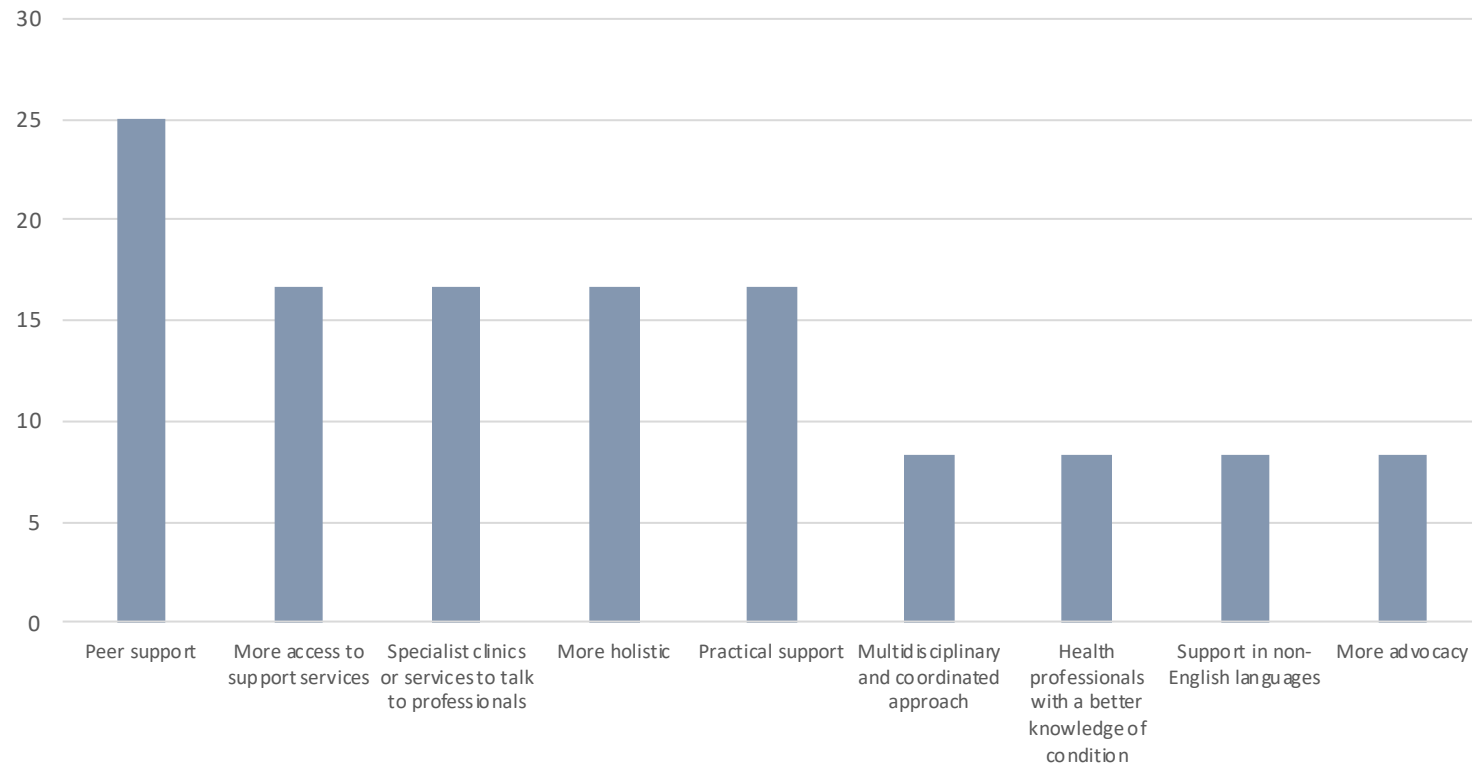




*Yeah, I would just say if there is no, if the doctors would you know, create more time you know to interact with the patients, I think that would help upload or you know bringing up you know more of them. With all the means of communication instead of in person communication or visit, I think that would help because you can talk and the patients can reach out at any time and have a discussion like a friend. That would be great.*

**Participant 006\_2023AUHDV**

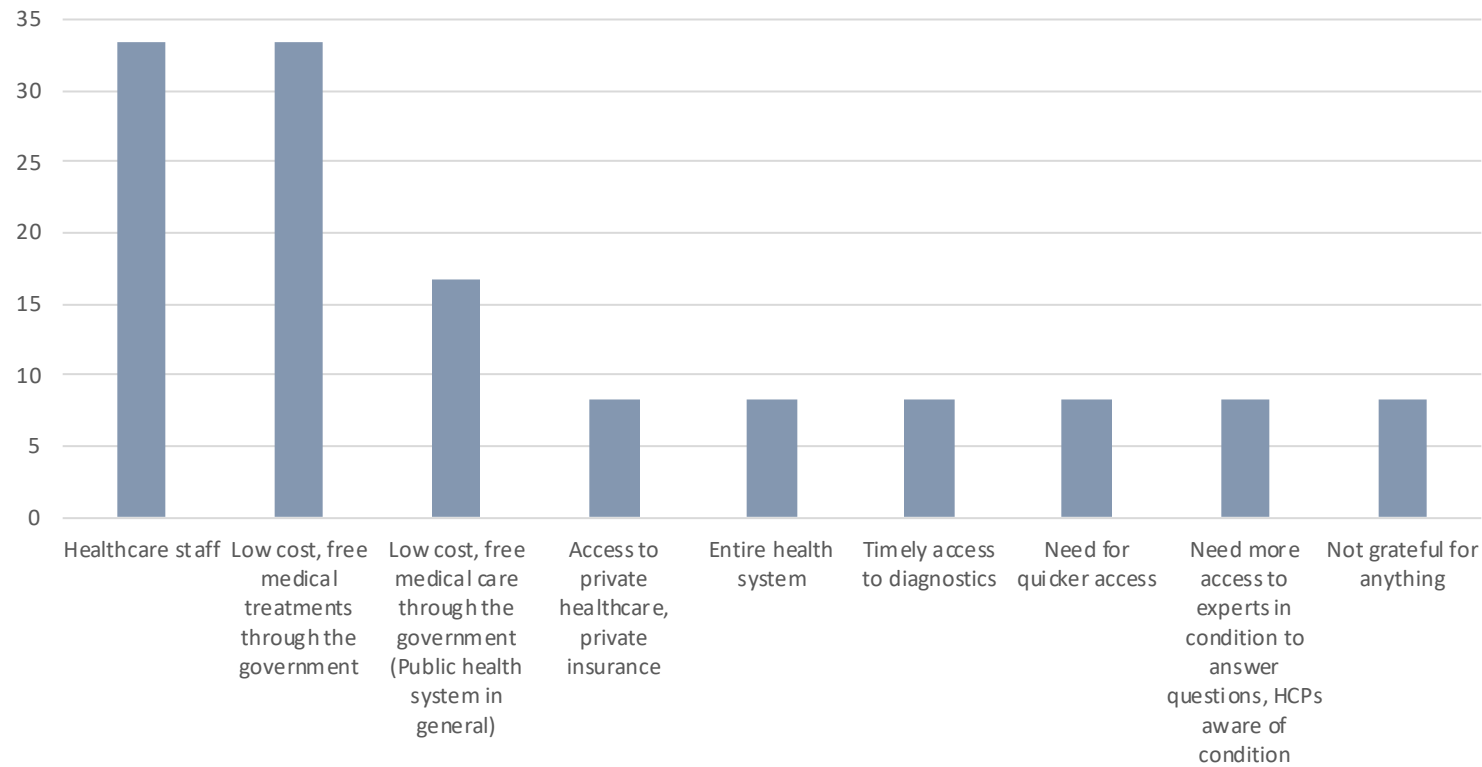




*Yeah, I mean, again, short answer, yes, I would have liked more active support as far as like really really all that stuff, just just more and more active help. As far as checking in with me about, you know, the the mental health burden of the whole thing, more I think definitely more social support. I mean, I looking back on it, I was actually extremely lucky as far as my circumstances went. I know a lot of people just have been unable to function while taking some of those treatments and that's financially and like just logistically physically. So yeah, just just more support whether that's through a charity or through primary healthcare, yeah, but the short answer, yes, absolutely.*

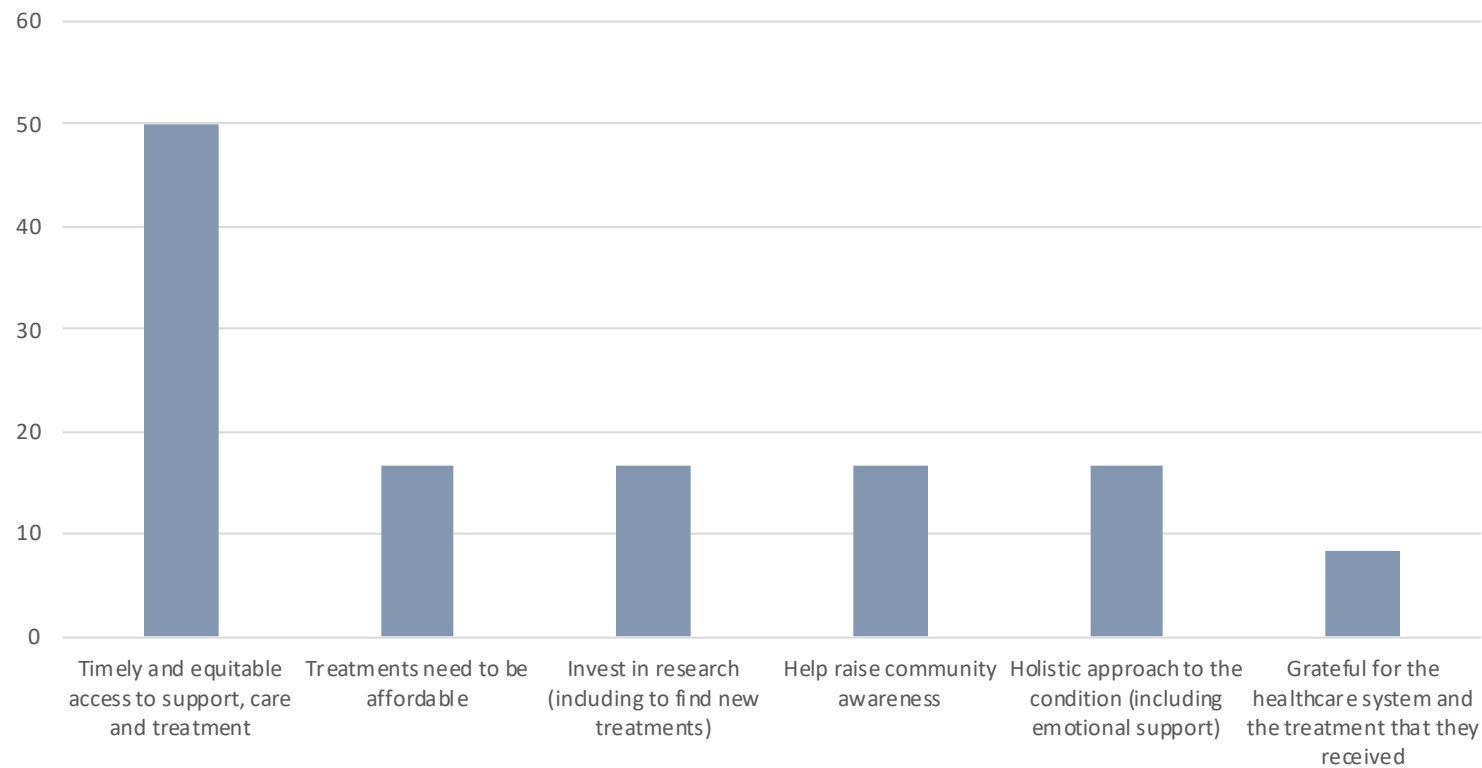
**Participant 011\_2023AUHDV**





*Basically that I have been able to access things easily and the what that I've been able to link into well talking particularly the hepatitis nurses that because I was regional I was able to ring them up and. Always chat with them if I had any issues or if I was worried about something or that they were available. And I I think that probably one of the good things about the way they've set it up that there are always those peptides nurses available. Because even if you can't talk to the doctor, you know that if it's something that they're not familiar with, they will get on the doctor and get back to you.  
Participant 007\_2023AUHDV*





*I think that they need need to be conscious of the fact that it's a continuum of care, it's not just one type. Because I know I haven't needed any in hospital care really, or to go to a hospital have home care or that. That's something that I I think as a the Minister, it's easy to look and say, right, well, we're giving you that for that. But that only treats part of the hepatitis. It doesn't, it doesn't. Cover everybody. I think that's one of the big things is it's seen as a fairly narrow field to treat without realizing that you do have the extremes that need to be covered as well.*

**Participant 007\_2023AUHDV**



## Section 10

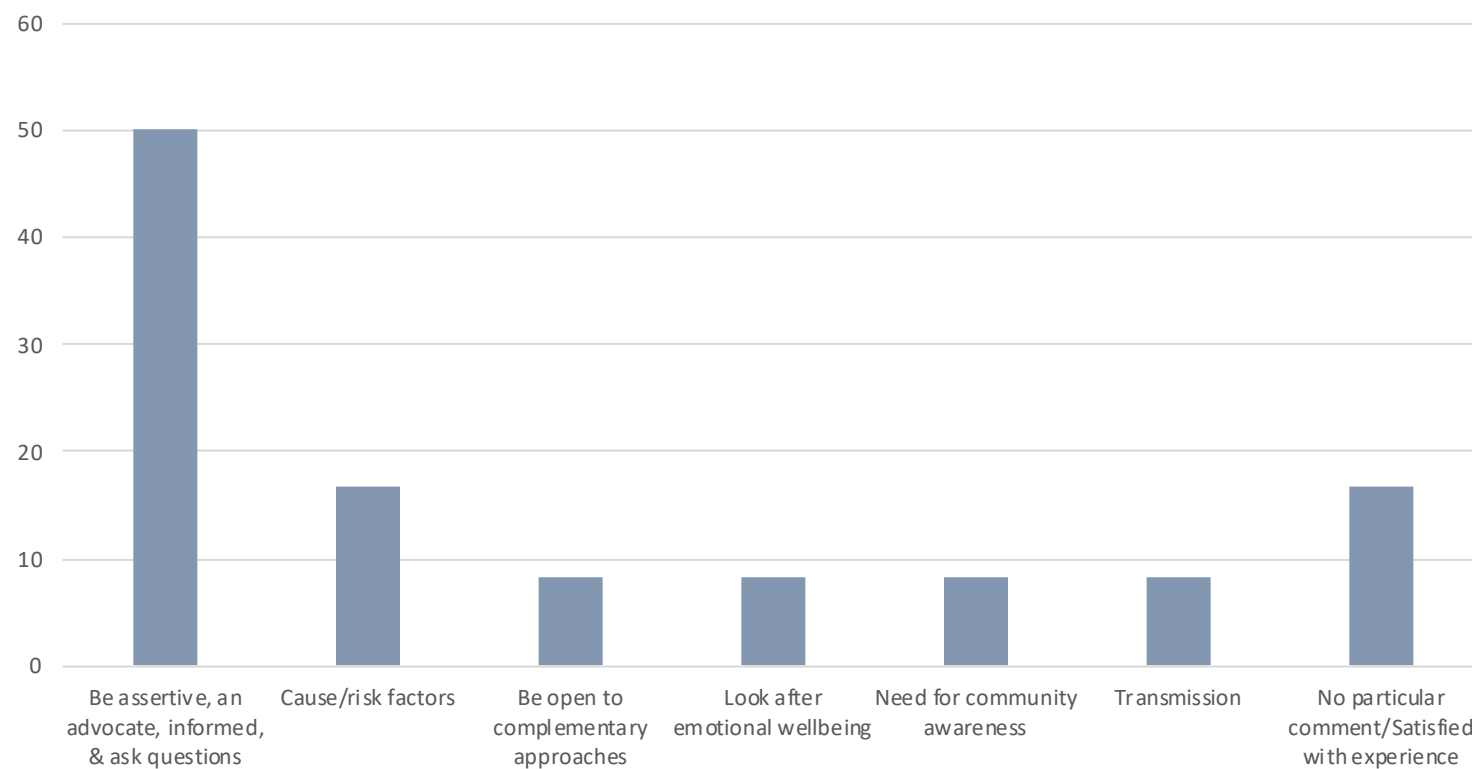


Advice from current patients  
to  
patients in the future

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.



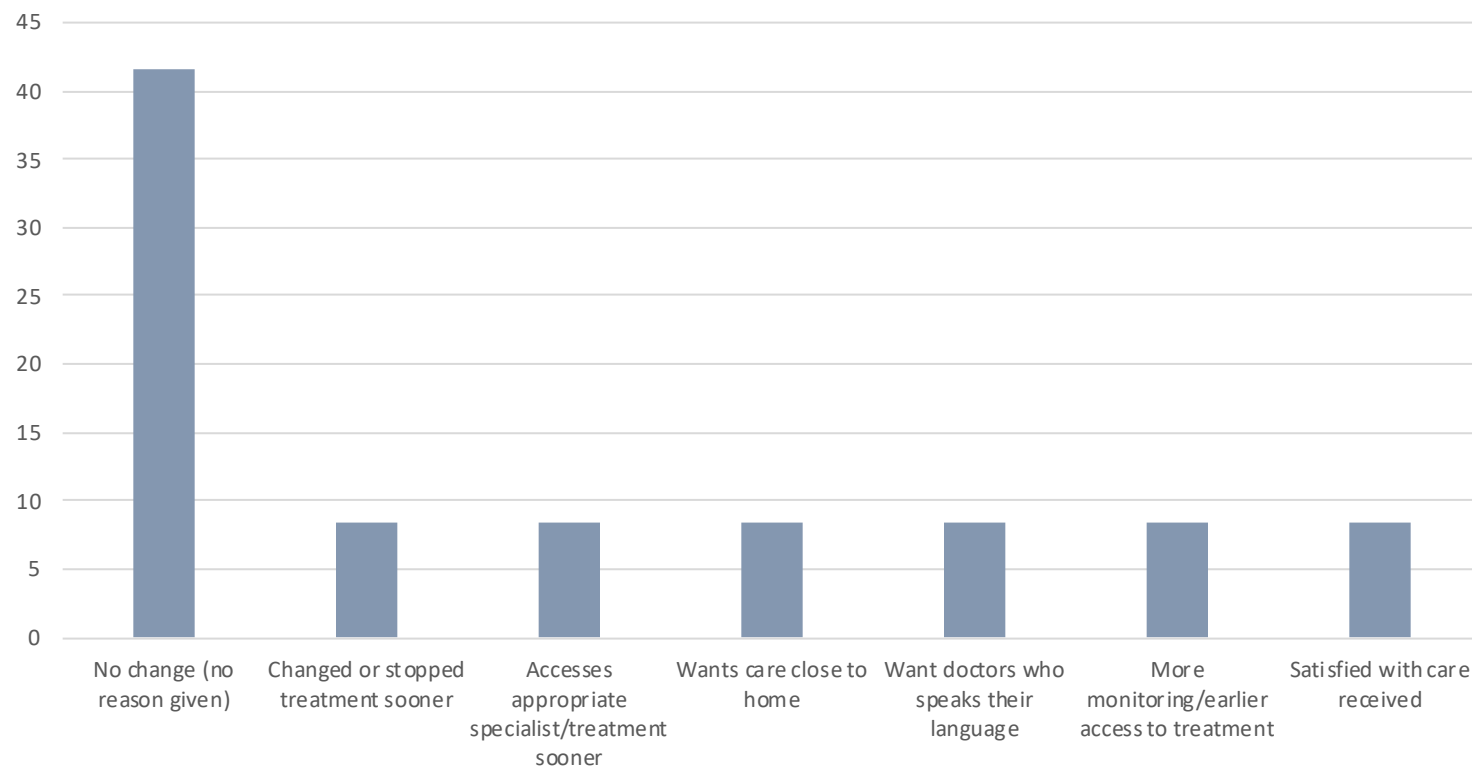




*No, I don't think so, because it's it's all evolved fairly smoothly. Without any real major hiccups. So but I I think just in general with I think they're up to about hepatitis E or F or something nowadays. There needs to be some education around the fact that there isn't just hepatitis has a disease, it's a it's a Myriad's the right word, but it's a range of conditions that basically have the one symptom. So I'm not sure how you go about that. But that's something to consider.*

**Participant 007\_2023AUHDV**





**PARTICIPANT:** *Not really. I tried to find someone who can speak that language. Yes. Yeah, but I I can't.*

**INTERVIEWER:** *OK. Yeah. OK. Yeah, those.*

**PARTICIPANT:** *We we have some available, I think more near the city or...Um, yeah, but it just took time to travel.*

**Participant 003\_2023AUHDV**



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



- 1. Information:** with little community awareness, most of the participants did not have an understanding hepatitis D when diagnosed. There is a need for community information, and for better information to give newly diagnosed. In addition, information needs to be easy to understand and available in multiple languages
- 2. Support:** support services, including peer support that are specific to hepatitis D and to the variety of people it affects (demographically) are urgently needed.
- 3. Care coordination:** there is a need for better access and coordination of healthcare services, better access to supportive GP, specialist nurses, allied health (This group had poor care coordination, low access to specialist nurses, low access to specialists, low access to allied health yet high levels of depression, anxiety and other comorbidities, and their physical health interfered with work and daily activities).

