

## **Section 9**

### **Expectations and messages to decision-makers**

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

### **Expectations of future treatment**

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

### **Expectations of future information**

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%), provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

### **Expectations of future healthcare professional communication**

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

### **Expectations of future care and support**

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67%), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

### **What participants are grateful for in the health system**

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67%). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to

experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

### **Symptoms and aspects of quality of life**

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

### **Values for decision makers**

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

### **Time taking medication to improve quality of life**

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), for a good quality of life even if it didn't offer a cure.

### **Most effective form of medicine**

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

### **Messages to decision-makers**

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67%), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

## Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

### Future treatment will be curative

*I would like to see a cure rather than treatment because I don't understand the extent of how much the treatments are effective?*  
*Participant 004\_2023AUHDV*

### Future treatment will be more affordable

*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 not working and paying full price for medication.*  
*Participant 007\_2023AUHDV*

### Future treatments will have fewer or less intense side effects/more discussion about side effects

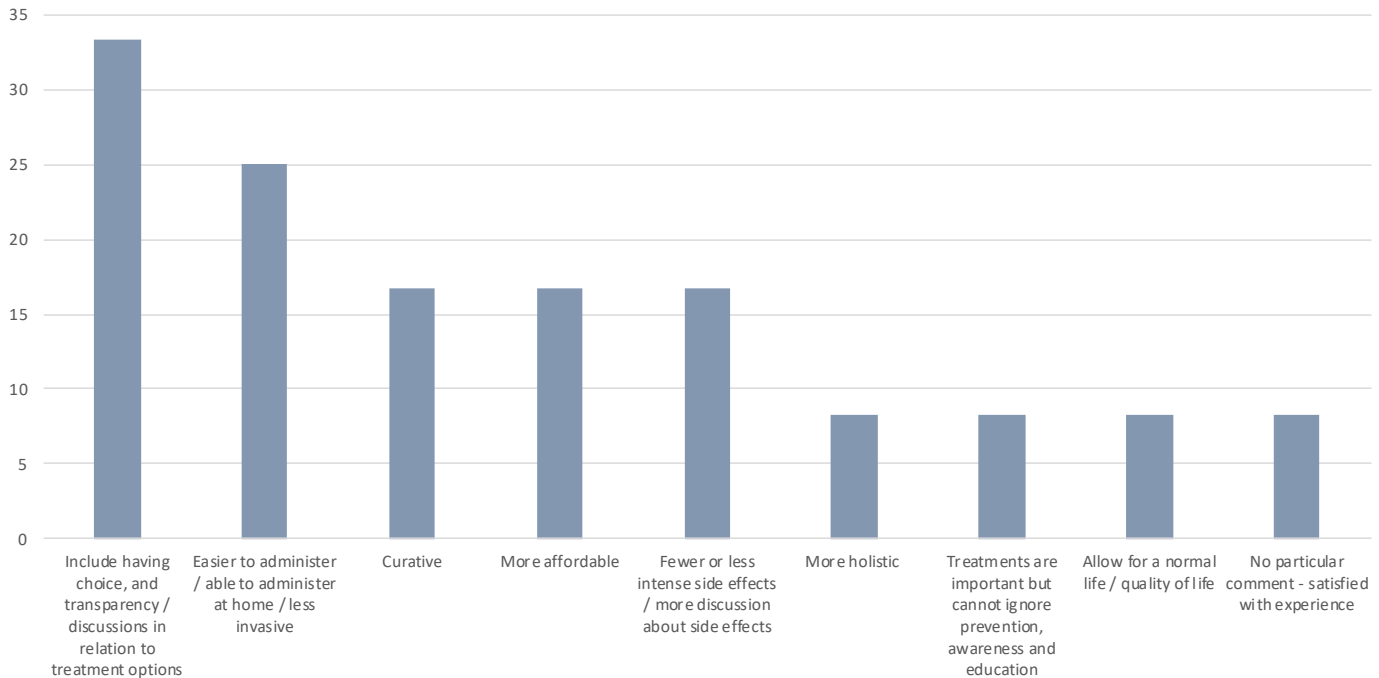
*Okay. I would love to see medications reacting effectively, and I would also like to see medication that does not go with the bad side effects, Yeah.*  
*Participant 009\_2023AUHDV*

### Future treatments are important but we cannot ignore awareness and education

*Like you know we've talked a bit today and a lot about how there wasn't a lot of people checking in with me between the diagnosis and you know years later when I got the treatment and I think that's the stigma.*  
*Participant 011\_2023AUHDV*

**Table 9.1: Expectations of future treatment**

Expectations of future treatments	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	1	16.67	3	50.00	1	100.00	3	27.27	1	100.00	3	27.27
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	3	50.00	0	0.00	0	0.00	3	27.27	0	0.00	3	27.27
Future treatment will be curative	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Future treatment will be more affordable	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Future treatments will have fewer or less intense side effects/more discussion about side effects	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future treatment will involve a more holistic approach	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future treatments are important but we cannot ignore prevention, awareness and education	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future treatments will allow for a normal life/quality of life	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09



**Figure 9.1: Expectations of future treatment**

**Table 9.2: Expectations of future treatment – subgroup variations**

Expectations of future treatments	Reported less frequently	Reported more frequently
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Trade or high school	Aged 45 and older University

**Expectations of future information**

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%),

provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

**Future information will be more holistic (including emotional health)**

*I think to really see it through the eyes of sexual health and potential partner. I think that they need some resources out there that is understood and that they've got options to go through. So I know that*

*there are some, some of the hepatitis associations offer a foreign counselling service, which I think can be very helpful, but I think it's targeting a bit of that and also family impacts. Just something educational for them.*

*Participant 004\_2023AUHDV*

#### **Future information will be in a variety of formats**

*I'm very old fashioned so I'm not into all the online and support chat groups online and all that sort of stuff...talking to people face to face, and I still think that's pretty important face to face, even if you are doing telehealth. Participant 007\_2023AUHDV*

#### **Future information will be more accessible/easy to find**

*I want information about all kinds of hepatitis or the information from A-Z. Everything that I need to know, everything that the patient need to know. I would love to know about this. At least I can read about it. At least I can know and understand it more better.*

*Participant 001\_2023AUHDV*

#### **Future information will provide more details about disease trajectory and what to expect**

*Yeah, one for information, I would like for you to detail the medication process and then what I should get involved with. Participant 009\_2023AUHDV*

#### **Future information will provide more details about where to find support (including peer support/support groups)**

*The more contact information for people who can offer the people who are diagnosed support you know*

*the you know. Making sure people feel connected if they feel overwhelmed technically, in whatever way, is simplest.*

*Participant 010\_2023AUHDV*

#### **Future information will be available in languages other than English**

*Yeah, I guess the the language, I mean, there's a model of thing written in. So they use both Chinese and Korean. So they understand the language if they search online. Yes. And I don't know because we are not living near the. Like a it shouldn't popular ohh we...but we don't live in near enough to those who can like those community, they provide those information. So it's always English when we attend appointment. Information are always in English. Maybe, I don't know, maybe they can have a database with different language and they just print out the education material.*

*Participant 003\_2023AUHDV*

#### **Future information will provide more details about transmission**

*The transmission pathways like specifically around how you interact with other people...I think that really needs to be made clearer to people at the point of diagnosis or immediately after that.*

*Participant 011\_2023AUHDV*

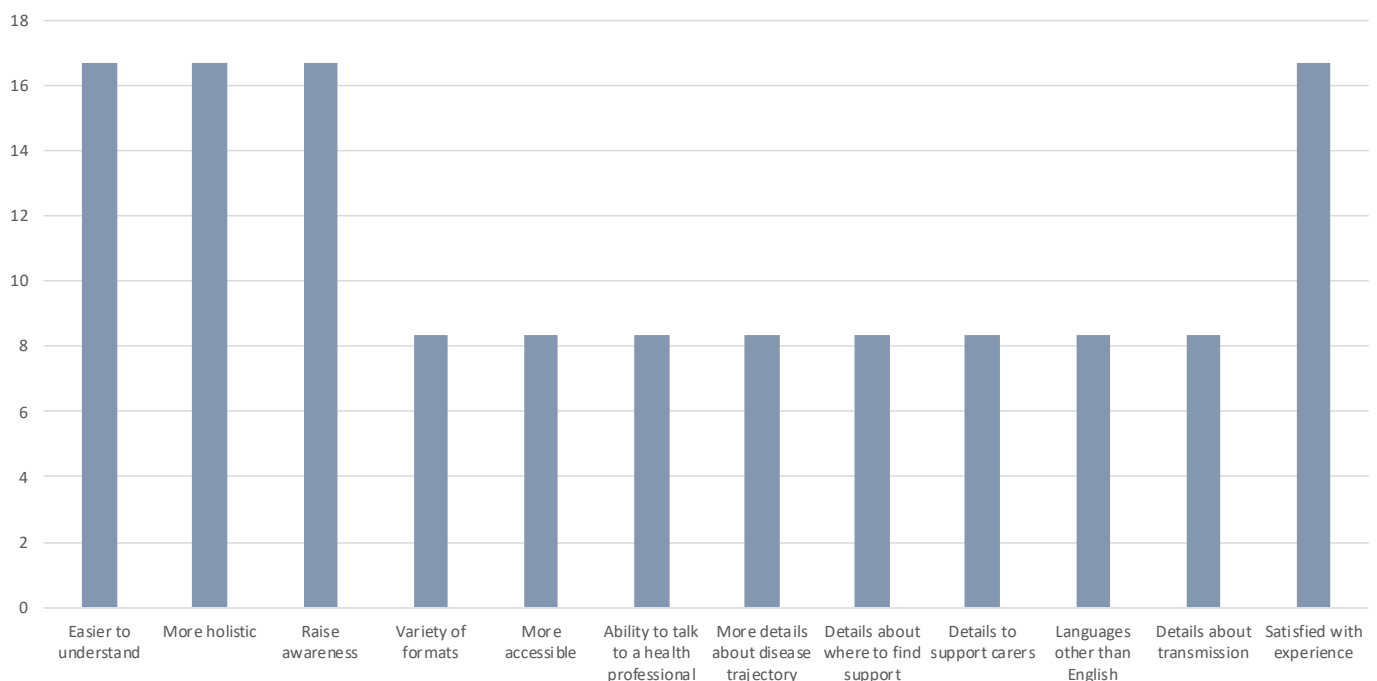
#### **No particular comment - satisfied with experience**

*No, I think the info that I've searched on Internet is fine.*

*Participant 005\_2023AUHDV*

**Table 9.3: Expectations of future information**

Expectations of future information	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future information will be easier to understand	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will be more holistic (including emotional health)	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will help to inform the community and decision-makers about their condition (raise awareness)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future information will be in a variety of formats	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future information will be more accessible/easy to find	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future information will include the ability to talk to/access to a health professional	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future information will provide more details about disease trajectory and what to expect	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details about where to find support (including peer support/support groups)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details to support carers	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will be available in languages other than English	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future information will provide more details about transmission	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09



**Figure 9.2: Expectations of future information**

**Expectations of future healthcare professional communication**

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

**Future communication will allow people more time to meet with their clinician**

*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*

**Future communication will be more transparent and forthcoming**

*You see what they just say. You are all good. Your blood results are all good...But they are not actually telling me what to avoid. What triggers it to be active. What should I do? What should I avoid? You know, you know, all those that information at least I know for sometimes, probably I'm doing something that makes it active. But I don't know, they never told me.*  
Participant 001\_2023AUHDV

*We don't really like the first hepatologist. No hepatologist. Yeah, hepatologist, yeah. So we think he didn't give us enough information. So the most most of the education received was from the GP. For this hepatologist, he just gave us the blood test, but he never really explained things. So that's one of the reason we want to change the hepatologist, yeah.*  
Participant 003\_2023AUHDV

**Future communication will be more empathetic**

*Just trying to make sure that the patients in that space are comfortable in that particular space.*  
Participant 009\_2023AUHDV

**Future communication will include listening to the patient**

*I think it's very much that the professionals need to realize that they're not the only ones that know*

*stuff...so I'm going to tell you exactly what you need to know and you need to do.*  
Participant 007\_2023AUHDV

**Future communication will include developing a care plan with follow-up**

*I'm really over the hospital system's rigidity in how everything's coordinated and I know it comes back down to the state and the hospital that you're being monitored for. After being monitored in two states, I just find it really, really frustrating that you have no control over your scans, your blood tests and when your appointment is coming.*  
Participant 004\_2023AUHDV

**Future communication will raise awareness of the condition**

*No, I just think like I said, most of the health professionals were fantastic. So I just think raising awareness through the not for profits and through all the various public hospitals and their support people GP's you know.*  
Participant 010\_2023AUHDV

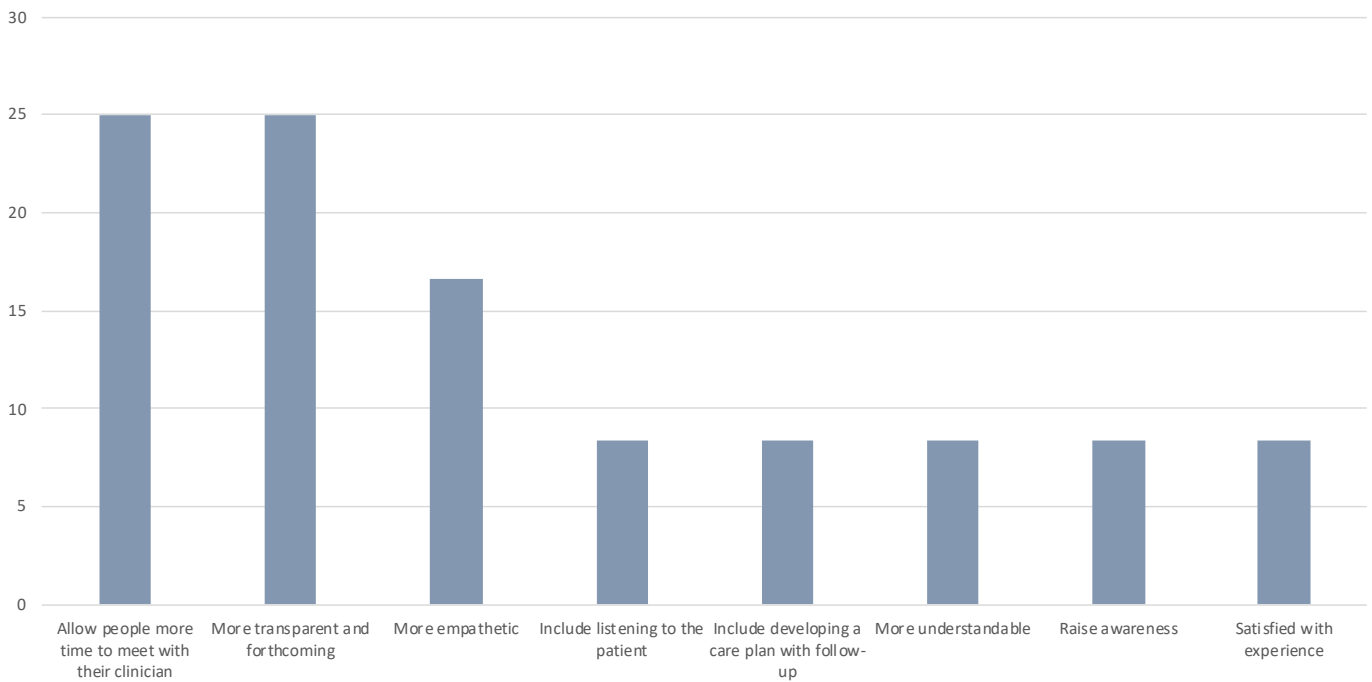
**No particular comment - satisfied with experience**

*No, at least my GP was clear.*  
Participant 005\_2023AUHDV



**Table 9.4: Expectations of future healthcare professional communication**

Expectations of future communication	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future communication will allow people more time to meet with their clinician	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future communication will be more transparent and forthcoming	3	25.00	2	33.33	1	16.67	3	37.50	0	0.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future communication will be more empathetic	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Future communication will include listening to the patient	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future communication will include developing a care plan with follow-up	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future communication will be more understandable	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Future communication will raise awareness of the condition	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment - satisfied with experience	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09



**Figure 9.3: Expectations of future healthcare professional communication**

### Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67%), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

**Future care and support will include being able to connect with other patients through peer support (support groups, online forums)**

*I just think a support group at all the hospitals...You know when the hospitals are overwhelmed or whatever that meets once a month and that you know supports those people.*

*Participant 010\_2023AUHDV*

**Future care and support will include more access to support services**

*Just more support whether that's through a charity or through primary healthcare, yeah, but the short answer, yes, absolutely.*

*Participant 011\_2023AUHDV*

**Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)**

*If there's a way we can get you all the information every time and then, yeah, I can. I'm happy to receive information. I'm happy to go and sit down and. Ask questions when I feel that I need to ask something.  
Participant 001\_2023AUHDV*

*Would like to see assistance from medical professionals, from the specifically from the field of medical professionals.  
Participant 009\_2023AUHDV*

**Future care and support will be more holistic (including emotional health)**

*Well, if there is one, one of the services I think should really up and cherish to would be mental support.  
Participant 006\_2023AUHDV*

**Future care and support will include health professionals with a better knowledge of the condition**

*Have the ability to tap into the specialists and are willing to because I've found sometimes I think ohh no, well you're our patient and we're going to tell you what to do and you'll do it our way and then you talk to the specialist in CITY they say well actually you should be doing this. So you you're sort of getting mixed messages. Participant 007\_2023AUHDV*

**Future care and support will include support in non-English languages**

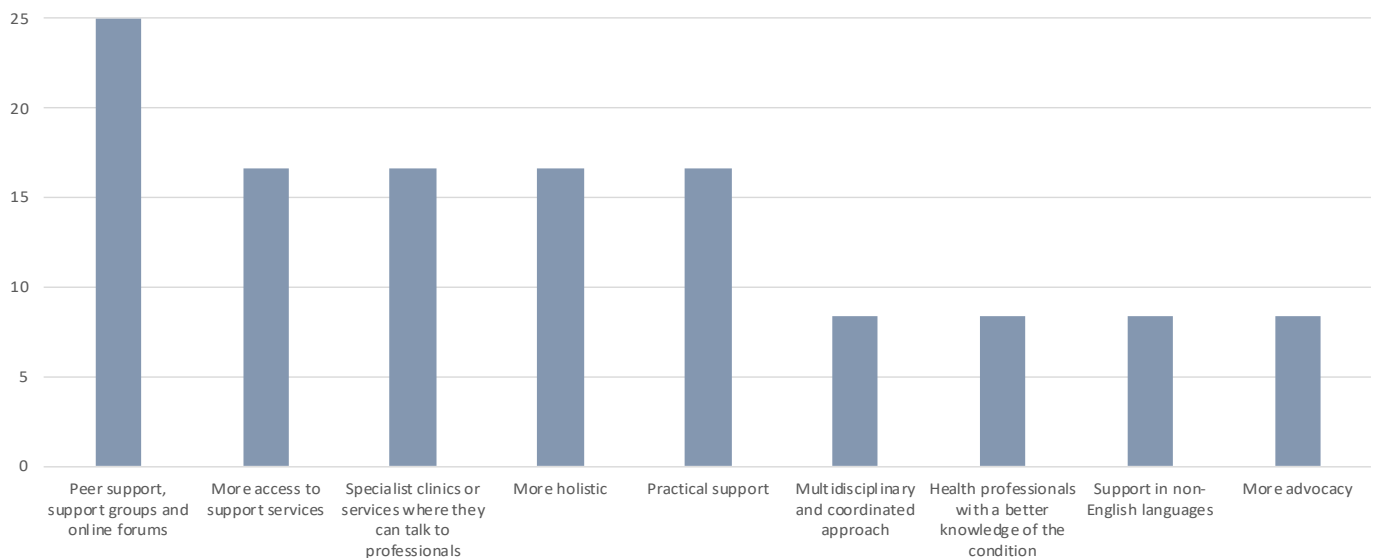
*I would love to have more again the language specific support. Yeah, maybe in the hospital if you need to like, admit to the hospital.  
Participant 003\_2023AUHDV*

**Future care and support will include more advocacy**

*I think it's just due to the amount of that shame that people are in with hepatitis. It's just a virus that has been around for too long that people haven't got that upset about and that out there with that, there's been enough noise. Participant 00\_2023AUHDV*

**Table 9.5: Expectations of future care and support**

Expectations of future care and support	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Future care and support will include more access to support services	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will be more holistic (including emotional health)	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include practical support (home care, transport, financial)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Future care and support will include a multidisciplinary and coordinated approach	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future care and support will include health professionals with a better knowledge of the condition	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Future care and support will include support in non-English languages	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Future care and support will include more advocacy	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09



**Figure 9.4: Expectations of future care and support**

### What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67 %). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

#### **Participant describes being grateful for healthcare staff (including access to specialists)**

*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 ...because even if you can't talk to the doctor, you know that if it's something that they're not familiar with especially with the hep D, they will get on the doctor and get back to you.*

*Participant 007\_2023AUHDV*

*I was particularly grateful for the specialists and their support staff They were just so transparent about everything.*

*Participant 010\_2023AUHDV*

*Yeah, first thing I am grateful for the, should I say, to the high...treatment for medical professionals. Yeah, I'm quite thankful and I'm glad for that. Yeah.*  
*Participant 009\_2023AUHDV*

#### **Participant describes being grateful for low cost/free medical treatments through the government**

*For all the negatives we talked about, I mean I think one thing mentioned other is, is the is the cost as a lack thereof, I think it was, it was accessible and affordable... But the the main thing I think I'm grateful for is, is, is the affordability and I think that's critical.*

*Participant 009\_2023AUHDV*

*So long as it's public and not like in America, it's like \$40,000.*

*Participant 002\_2023AUHDV*

#### **Participant describes being grateful for timely access to diagnostics**

*I'm grateful I do the test every time. At least I'm being monitored. That's why I'm grateful that I get monitored every time, so if something goes wrong, at least I can catch it early.*

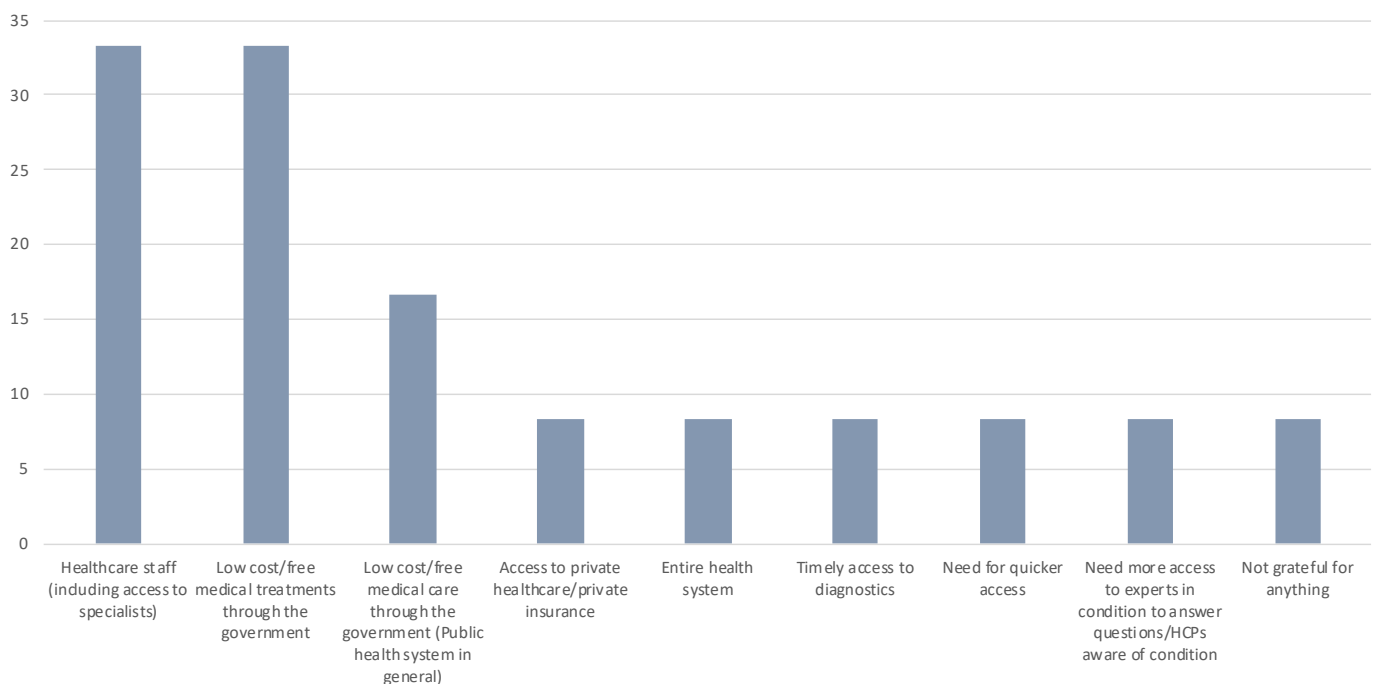
*Participant 001\_2023AUHDV*

#### **Participant describes the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition**

*It's actually hard to get another appointment in when you need one...so I would say that part has been really hard of I guess the hospital to patient ratio care. Yeah, that it is hard to get a breakthrough kind of question when you need to do so.*

**Table 9.6: What participants are grateful for in the health system**

What participants are grateful for in the health system	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes being grateful for healthcare staff (including access to specialists)	4	33.33	1	16.67	3	50.00	2	25.00	2	50.00	2	33.33	2	33.33	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes being grateful for low cost/free medical treatments through the government	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes being grateful for access to private healthcare/private insurance	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being grateful for the entire health system	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes being grateful for timely access to diagnostics	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the need for quicker access to treatments	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes the need for more access to experts in condition to answer questions and for healthcare professionals to be aware of the condition	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not being grateful for anything	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	2	16.67	2	33.33	0	0.00	1	12.50	1	25.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18



**Figure 9.5: What participants are grateful for in the health system**

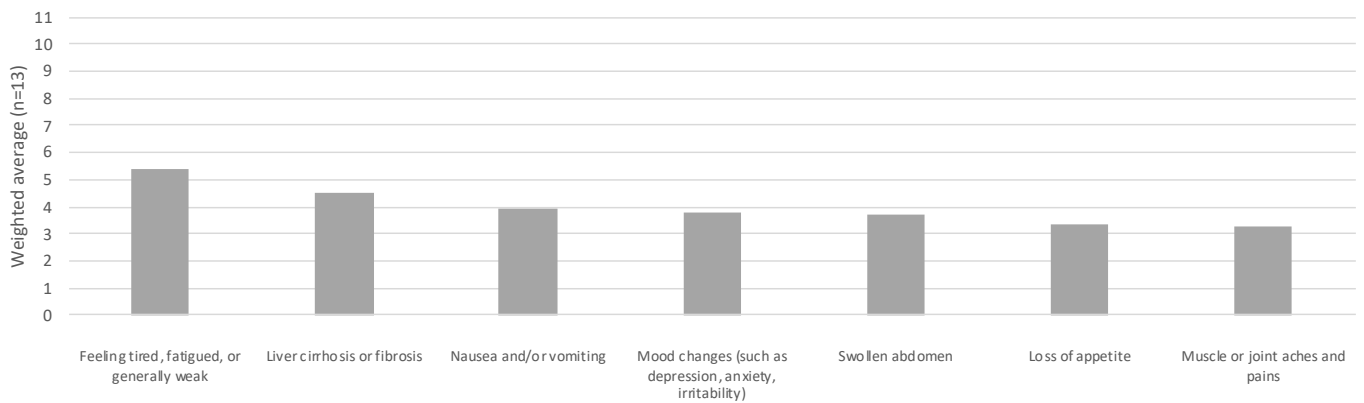
**Symptoms and aspects of quality of life**

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.7, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

**Table 9.7: Symptoms and aspects of quality of life**

Symptoms and aspects of quality of life	Weighted average (n=13)
Feeling tired, fatigued, or generally weak	5.38
Liver cirrhosis or fibrosis	4.54
Nausea and/or vomiting	3.92
Mood changes (such as depression, anxiety, irritability)	3.77
Swollen abdomen	3.69
Loss of appetite	3.38
Muscle or joint aches and pains	3.31



**Figure 9.6: Symptoms and aspects of quality of life**

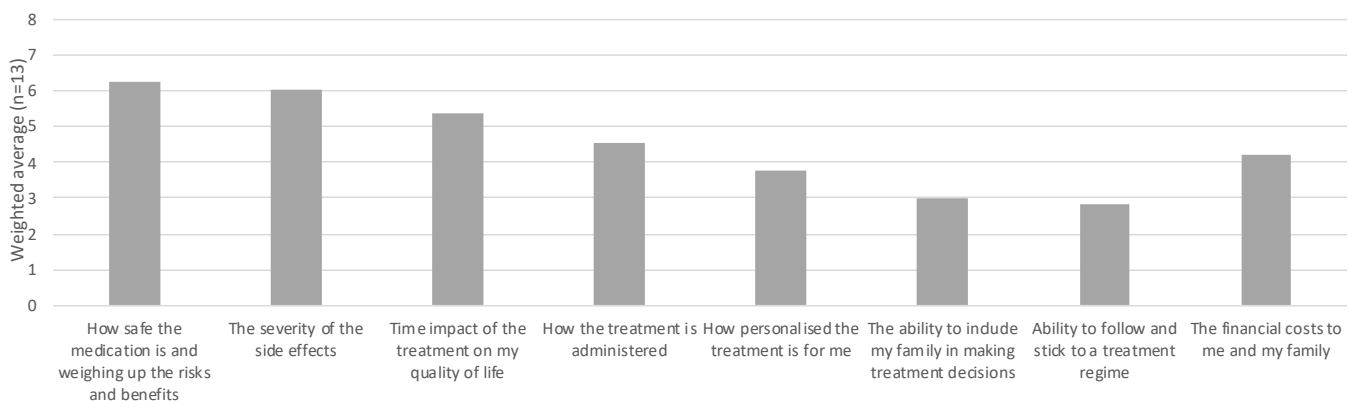
### Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important were “The ability to include my family in making treatment decisions” and “Ability to follow and stick to a treatment regime”.

**Table 9.8: Values in making decisions**

Values in making decisions	Weighted average (n=13)
How safe the medication is and weighing up the risks and benefits	6.23
The severity of the side effects	6.00
Time impact of the treatment on my quality of life	5.38
How the treatment is administered	4.54
How personalised the treatment is for me	3.77
The ability to include my family in making treatment decisions	3.00
Ability to follow and stick to a treatment regime	2.85
The financial costs to me and my family	4.23



**Figure 9.7: Values in making decisions**

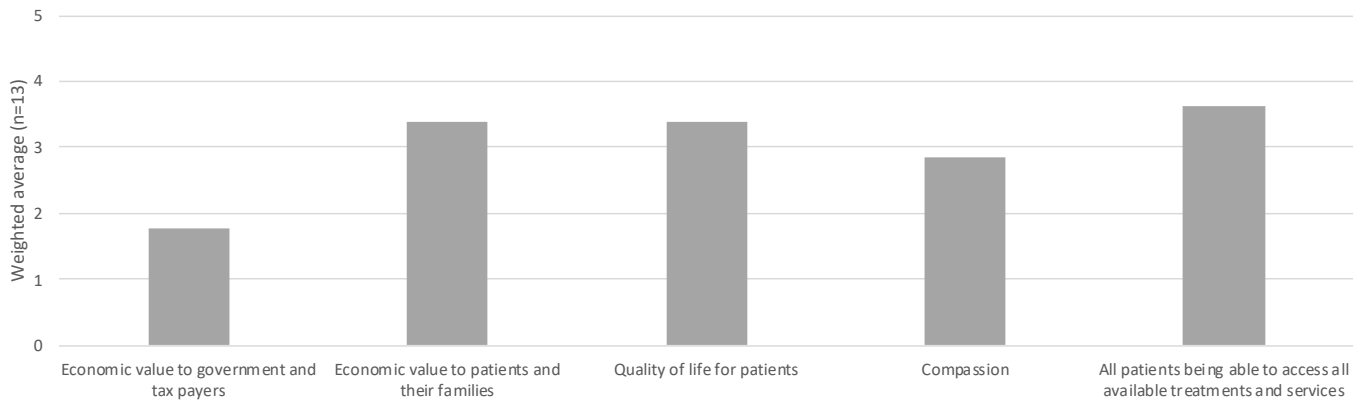
### Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

**Table 9.9: Values for decision makers**

Values for decision makers	Weighted average (n=13)
Economic value to government and tax payers	1.77
Economic value to patients and their families	3.38
Quality of life for patients	3.38
Compassion	2.85
All patients being able to access all available treatments and services	3.62



**Figure 9.8: Values for decision makers**

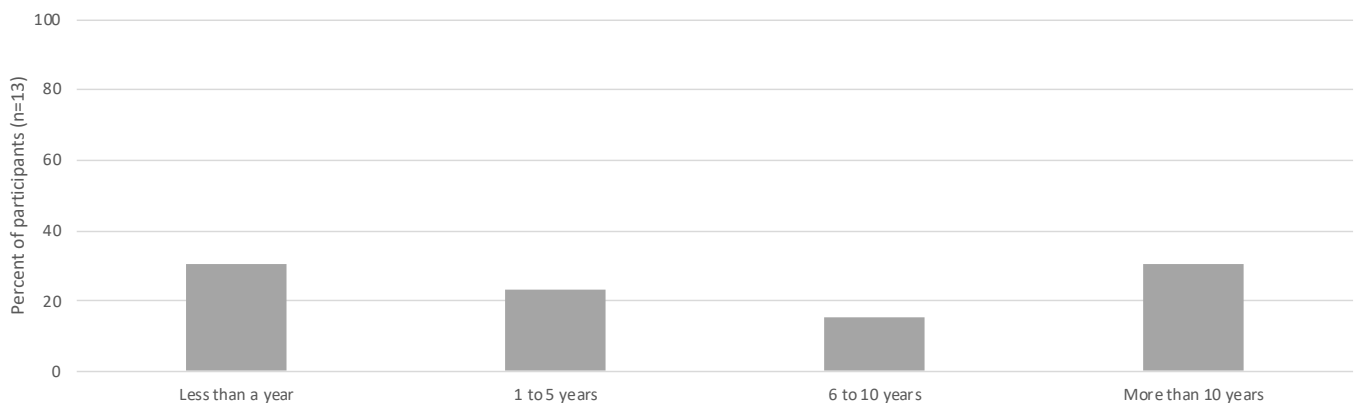
**Time taking medication to improve quality of life**

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), for a good quality of life even if it didn't offer a cure.

**Table 9.10: Time taking treatment to improve quality of life**

Time taking medication to improve quality of life	Number (n=13)	Percent
Less than a year	4	30.77
1 to 5 years	3	23.08
6 to 10 years	2	15.38
More than 10 years	4	30.77



**Figure 9.9: Time taking treatment to improve quality of life**

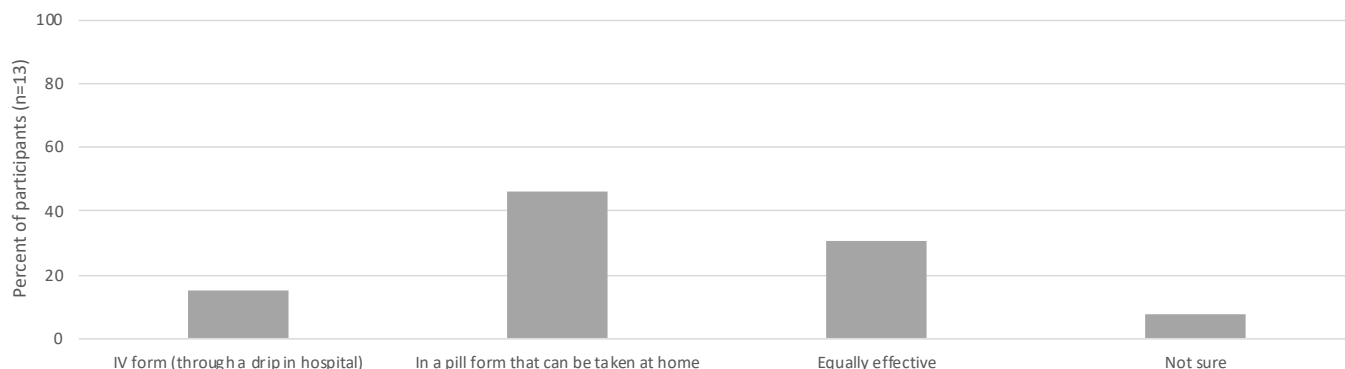
**Most effective form of medicine**

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

There were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

**Table 9.11: Most effective form of medicine**

Treatment most effective in what form	Number (n=13)	Percent
IV form (through a drip in hospital)	2	15.38
In a pill form that can be taken at home	6	46.15
Equally effective	4	30.77
Not sure	1	7.69



**Figure 9.10: Most effective form of medicine**

## Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67%), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

### Timely and equitable access to support, care and treatment

*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 of hepatitis...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, just one type. It doesn't, it doesn't cover everything. 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

*I think they should have all the support and care that they need and be given all the resources that they need and support from the beginning of their journey right to the end all.*  
Participant 010\_2023AUHDV

*Well, I'm not homeless or anything but most nights to the homeless free kitchen and like I know for me I got to get like a blood of your free form get a blood care and I don't know how easy I would kind of. Organize if you're like homeless for living on the street some kind of access you have. I know we got a health care type that comes and if you know LOCATION, but there's a. Like the homeless the healthcare truck comes for like couple of weeks. I don't know what they do. I know they do blood tests.*  
Participant 002\_2023AUHDV

### Treatments need to be affordable

*Free medication.*  
Participant 005\_2023AUHDV

*Maybe to tell him to give free treatment to people with who need the treatment.*  
Participant 001\_2023AUHDV

### Invest in research (including to find new treatments)

*We are spending too much on a disjointed healthcare system, I would say, and that we're not actually progressing with hep in treatments or in cure.*  
Participant 004\_2023AUHDV

### Holistic approach to the condition (including emotional support)

*I would actually tell him that we have access to advice and the views relating to mental health issues and we*

*also have access to the way to cure and go about the virus and we always have access to knowing that someday somehow you would actually be cured here.*  
Participant 009\_2023AUHDV

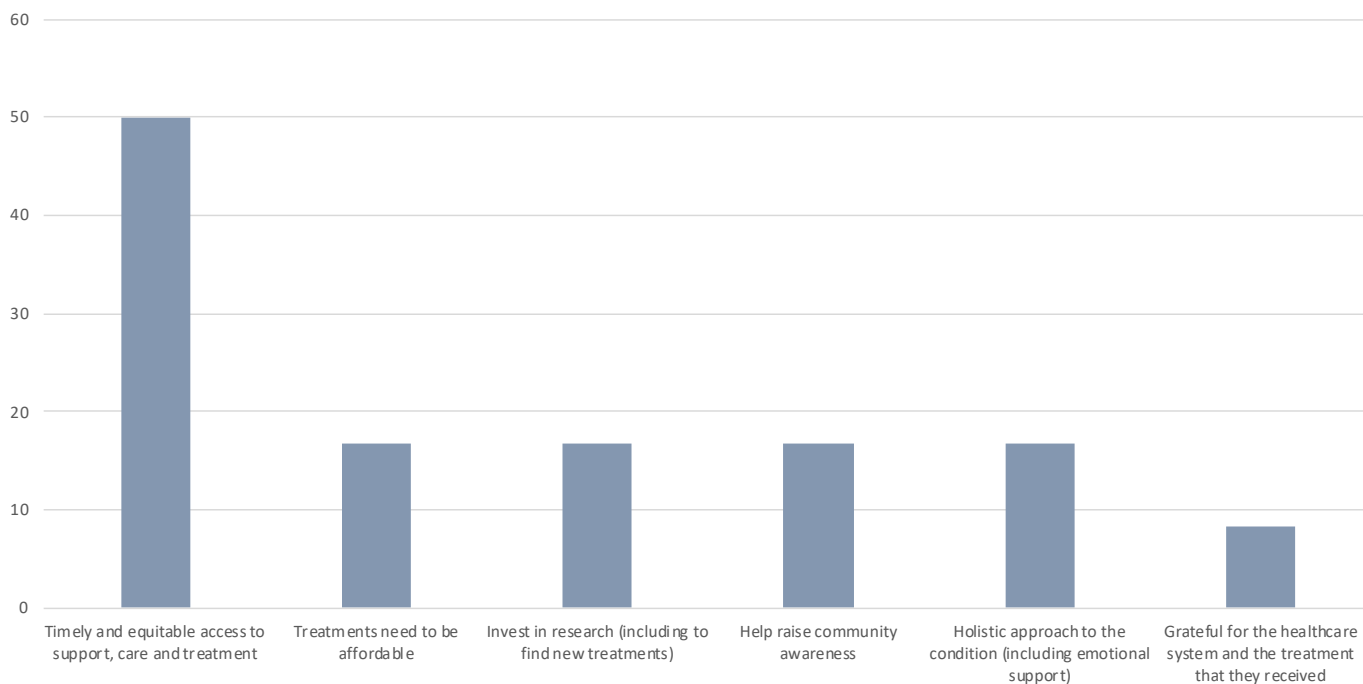
*Well, I I would just get, you know, mention a few things. You know, like introduction of mental support. Yep. Not just to patients with hepatitis but other patients. I think these are one of the things that would, you know, first mention time.*  
Participant 006\_2023AUHDV

**Grateful for the healthcare system and the treatment that they received**

*We still have things to control it, so I don't have anything to complain and I'm very grateful we have Medicare system in Australia so we actually burden is less. So I don't need to worry about something really happened, like suddenly and I will be out of pocket.*  
Participant 003\_2023AUHDV

**Table 9.12: Messages to decision-makers**

Message to decision-makers	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Timely and equitable access to support, care and treatment	6	50.00	2	33.33	4	66.67	3	37.50	3	75.00	4	66.67	2	33.33	1	100.00	5	45.45	1	100.00	5	45.45
Treatments need to be affordable	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Invest in research (including to find new treatments)	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Help raise community awareness	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Holistic approach to the condition (including emotional support)	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Grateful for the healthcare system and the treatment that they received	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
No particular comment	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09



**Figure 9.11: Messages to decision-makers**

**Table 9.13: Messages to decision-makers – subgroup variations**

Message to decision-makers	Reported less frequently	Reported more frequently
Timely and equitable access to support, care and treatment	Female Aged 18 to 44 University	Male Aged 45 and older Trade or high school