

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did not give a reason (16.67%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67 %). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Participant describes one option being presented

She explained me that the only treatment is taking some specific medication...it is the only treatment for this kind of hepatitis.

Participant 005_2023AUHDV

When I was first diagnosed, yeah. So when I was first diagnosed, the only thing available at that time was interferon.

Participant 010_2023AUHDV

Participant describes multiple options being presented

So what I did was to seek medical, medical help from the doctor who run the test and diagnose and everything from you know the treatment and all of the diagnosis was run and managed by the doctor because I wasn't really aware aware of you know the circumstances around kind of I can remember several antiviral medicines were kind of administered to me and now something that can help fight and slow the ability of the virus to damage my liver. All of these was administered to me by the doctor and it was strictly based on his medication.

Participant 006_2023AUHDV

Table 4.1: Discussions about treatment

Discussions about treatment	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 one option being presented	6	50.00	5	83.33	1	16.67	5	62.50	1	25.00	3	50.00	3	50.00	0	0.00	6	54.55	0	0.00	6	54.55
Participant describes no treatments being discussed	3	25.00	0	0.00	3	50.00	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes multiple options being presented	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
Participant does not remember	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

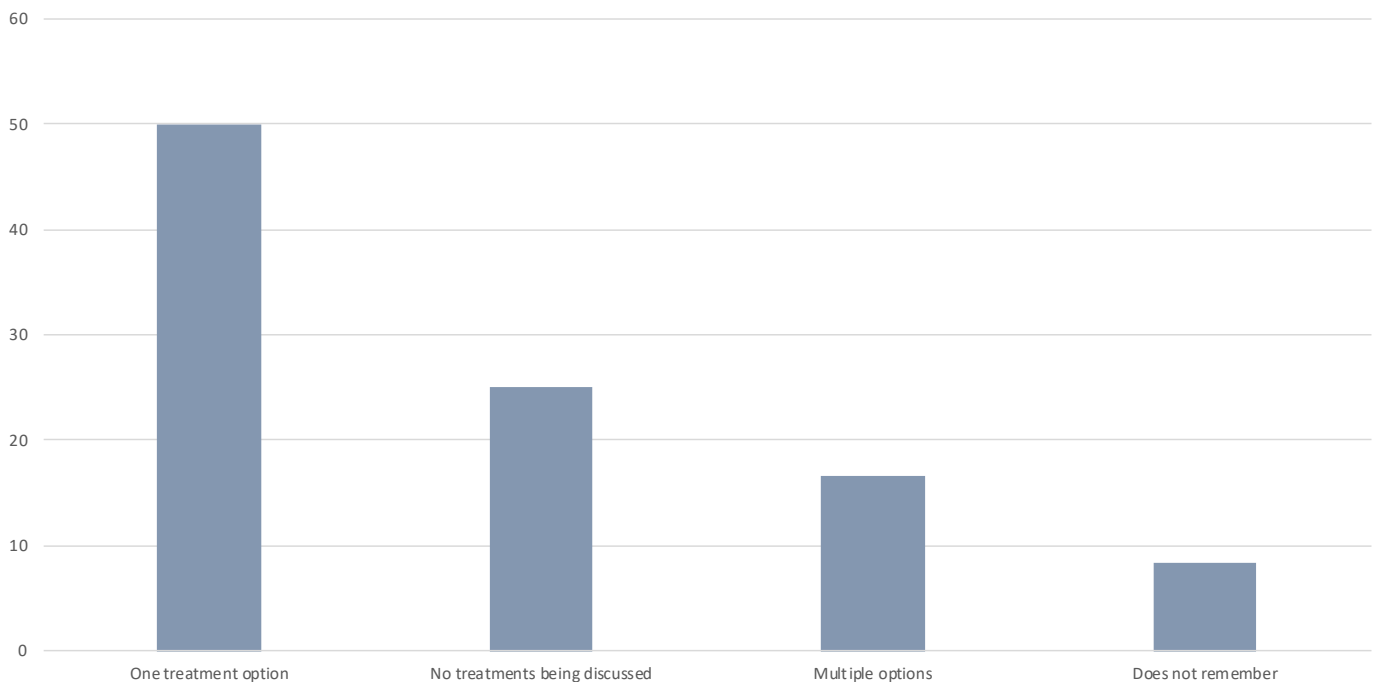


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes one option being presented	Male Aged 45 and older	Female Aged 18 to 44

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did not give a reason (16.67%).

Participant describes being presented with one option/approach and that they participated in the decision-making process

*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...there was a lot of horrific stories about people who reacted badly. You sometimes had mental effects from that, in other words, depression, etcetera.
Participant 010_2023AUHDV*

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	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 presented with multiple options but did not give a description or reason for this	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
Participant describes being presented with one option/approach, and did not participate in the decision-making process	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
Participant describes being presented with one option/approach and that they participated in the decision-making process	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
Participant describes being presented with one option/approach, but did not give a description or reason for this	3	25.00	3	50.00	0	0.00	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes being presented with no options/approach as there were no therapies are available	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
Participant describes having no discussions about treatments	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
Participant describes having no discussions about treatments because of competing health issues	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
Participant describes being diagnosis being a long time ago and does not remember	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

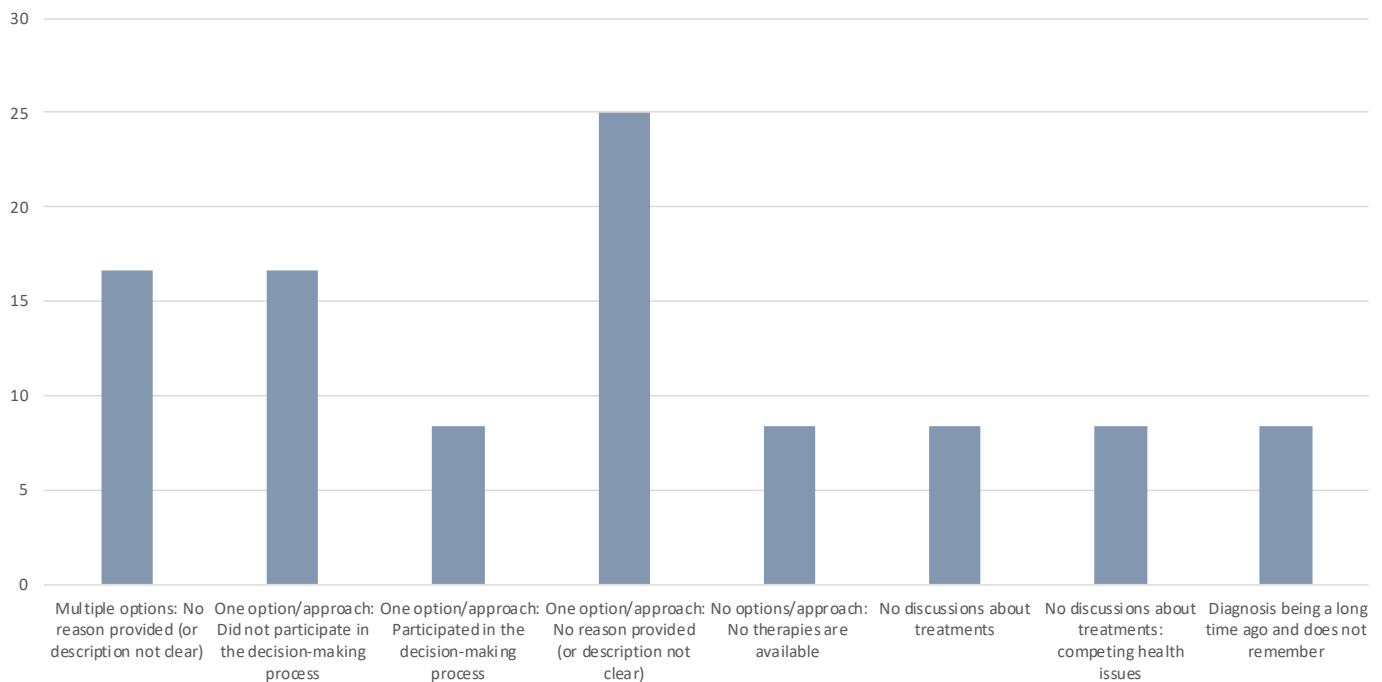


Figure 4.2: Discussions about treatment (Participation in discussions)

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67%). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)

The convenience because I mean... I mean 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.

Participant 007_2023AUHDV

Participant describes taking efficacy into account when making decisions about treatments (Total)

The efficacy of the treatment is is a is a big concern, you know particularly like coming from the, you know from the the experience before of interferon where it was a very low like statistically very low success rate. Like I want to know that what I'm taking is going to have a you know, measurable, tangible, noticeable you know impact in my treatment yeah. And and just

the and also kind of you know absolutely tied to that is you know what are what are the potential side effects.

Participant 011_2023AUHDV

Participant describes taking side effects into account when making decisions about treatments (Total)

Whether there will be any side effects of those treatments and those conditions, it is up to us to follow. It's the money that can be afforded, it's the money, and um, is there anyone else who has tried it and then there's some progress on that?

Participant 008_2023AUHDV

Participant describes taking cost into account when making decisions about treatments (Total)

If I can't afford, if he's not like the side effects, it's not that strong. That's it.

Participant 005_2023AUHDV

Participant describes taking the ability to work into account when making decisions about treatments (Total)

I might have already covered that. Yeah, just well, you know, I I wanted to continue on in my life, you know, I wanted to continue to work, you know.

Participant 010_2023AUHDV

Table 4.4: Considerations when making decisions

Considerations when making decisions about treatment	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 taking their ability to follow treatments into account when making decisions about treatments (Total)	5	41.67	1	16.67	4	66.67	2	25.00	3	75.00	2	33.33	3	50.00	1	100.00	4	36.36	1	100.00	4	36.36
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	0	0.00	3	50.00	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes taking efficacy into account when making decisions about treatments (Total)	5	41.67	2	33.33	3	50.00	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	5	41.67	2	33.33	3	50.00	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking side effects into account when making decisions about treatments (Total)	5	41.67	3	50.00	2	33.33	4	50.00	1	25.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	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 taking cost into account when making decisions about treatments (Total)	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	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
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	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 taking the ability to work into account when making decisions about treatments (Total)	2	16.67	1	16.67	1	16.67	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	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
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	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
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	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
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	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
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account when making decisions about treatments (Total)	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 taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	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

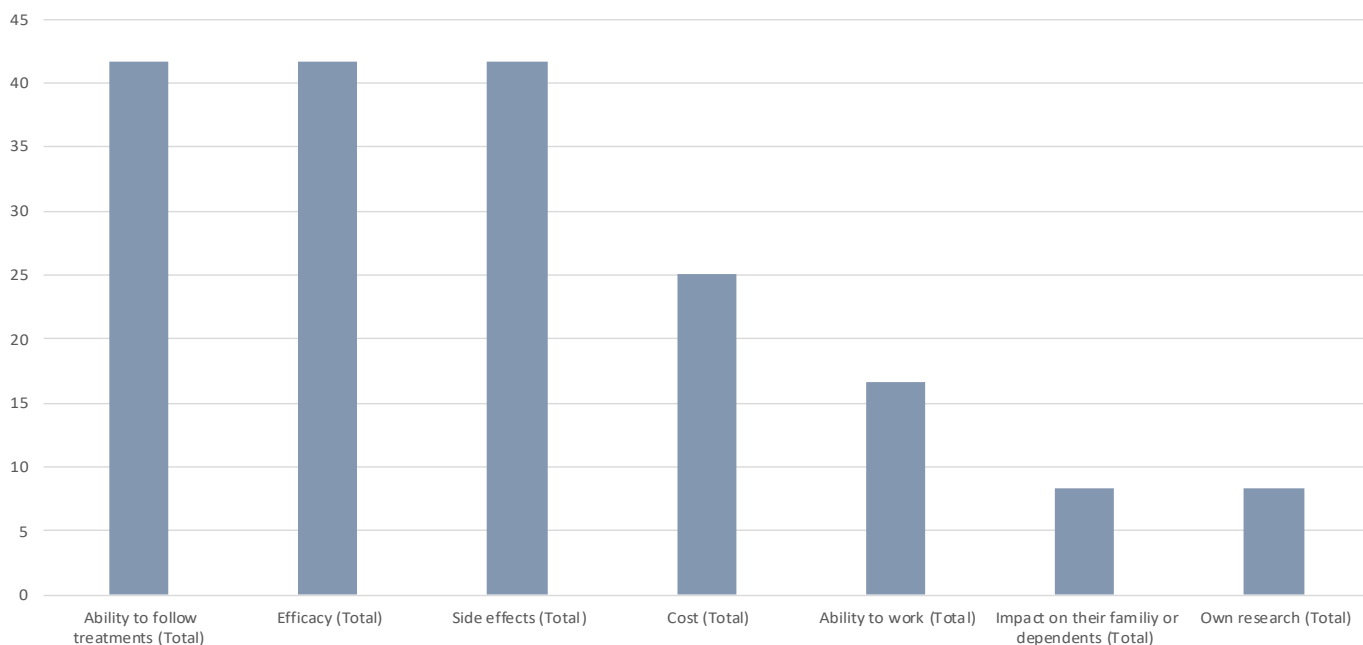


Figure 4.3 Considerations when making decisions

Table 4.5: Considerations when making decisions – subgroup variations

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
	Female Aged 18 to 44	Male Aged 45 and older
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)		
Participant describes taking efficacy into account when making decisions about treatments (Total)		
Participant describes taking side effects into account when making decisions about treatments (Total)	Aged 45 and older	

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

Changing over time as they are more aware of their health, responsibilities and/or limitations

Yeah, honestly, everything was changed. Everything was affected. I would say from the dressing to my diet, everything got to turn around. I wasn't comfortable doing certain things. I had to restrict myself, you know, just to make situation better. I had to stop certain things. I had to stop certain habits.
Participant 006_2023AUHDV

I'll look into things much more seriously now. I mean, I take responsibility for more on health. A lot more now. A lot more.
Participant 012_2023AUHDV

Changing over time as they are more informed and/or 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

No change in decision-making over time and there is no particular reason noted

I think I would approach the same way.
Participant 005_2023AUHDV

No, I haven't changed anything. I haven't changed anything.
Participant 001_2023AUHDV

No change in decision-making over time as they have always been informed/assertive

I approached it in the same way. And so I always make a decision, Yeah, I I, I make a decision by doing my research.
Participant 010_2023AUHDV

Table 4.6: Decision-making over time

Decision-making over time	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	%
Change	4	33.33	0	0.00	4	66.67	2	25.00	2	50.00	2	33.33	2	33.33	1	100.00	3	27.27	1	100.00	3	27.27
No change	5	41.67	3	50.00	2	33.33	4	50.00	1	25.00	2	33.33	3	50.00	0	0.00	5	45.45	0	0.00	5	45.45
Other/no response	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

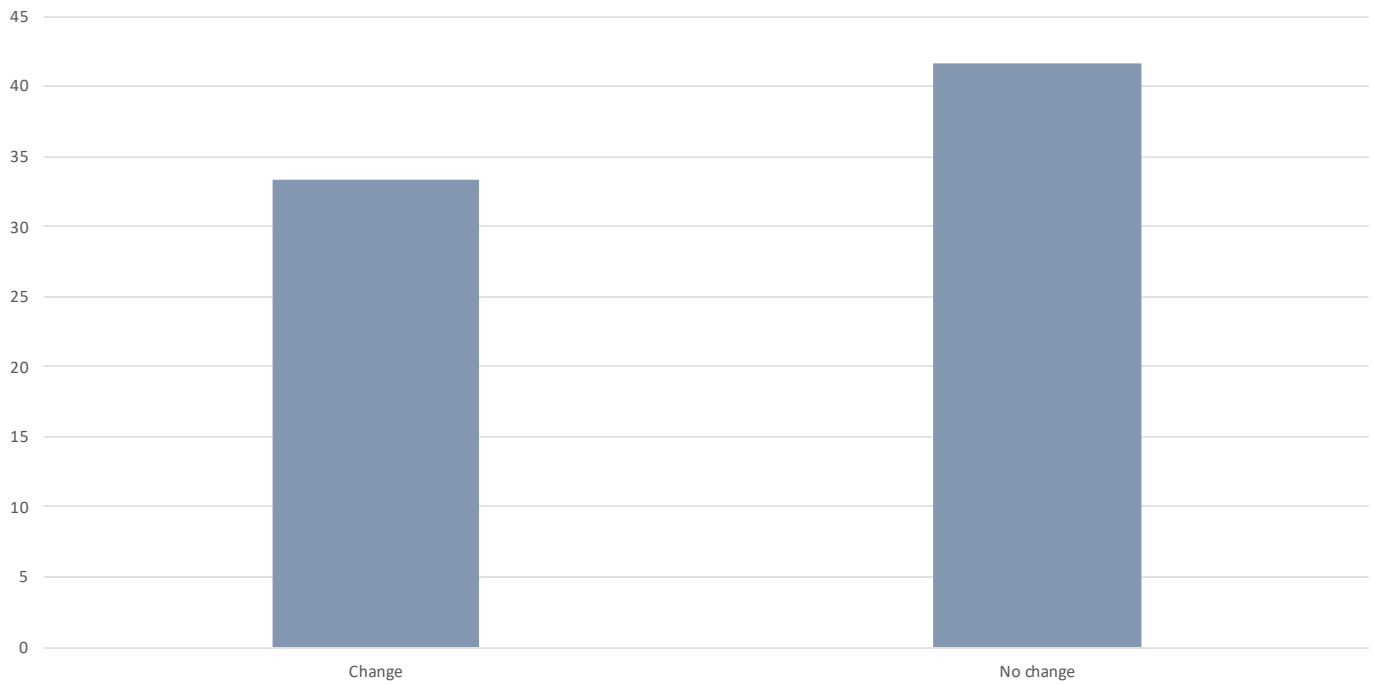


Figure 4.4: Decision-making over time

Table 4.7: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Change	Female	Male
No change	Aged 45 and older	Aged 45 and older

Table 4.8: Decision-making over time (reasons)

Decision-making over time (reasons)	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	%
Changing over time as they are more aware of their health, responsibilities and/or limitations	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
Changing over time and there is no particular reason noted	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
Changing over time as they are more accepting of their condition and choices available (however not by choice)	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
Changing over time as they are more informed and/or more assertive	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 change in decision-making over time and there is no particular reason noted	3	25.00	1	16.67	2	33.33	3	37.50	0	0.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
No change in decision-making over time as they have always been informed/assertive	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
Other/No response	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27

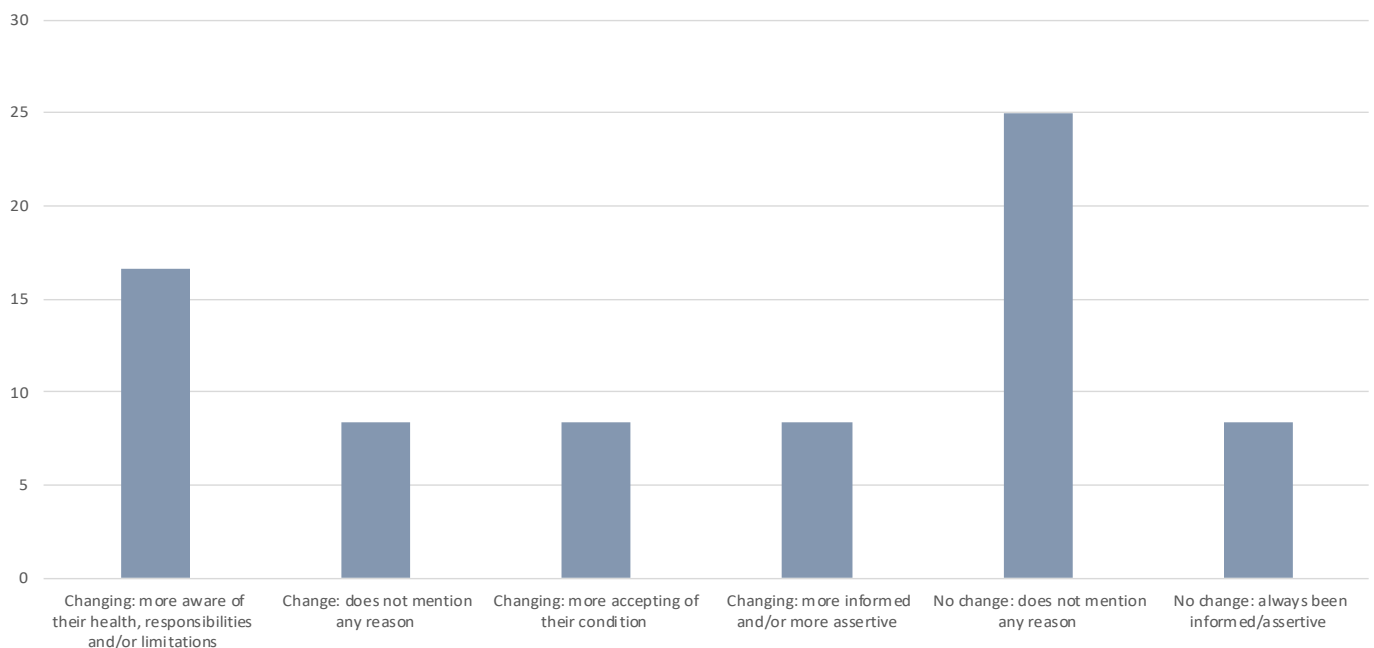


Figure 4.5: Decision-making over time (reasons)

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

Participant describes wanting to maintain their condition/prevent worsening of their condition

My own concern is having cancer in the future. The other things I think is is treatable but not cancer is my only concern.

Participant 005_2023AUHDV

I've still got ongoing issues with my liver that I think might be related to, you know, having had hep for so long. So, you know, I just want to be as healthy as possible have a fully functioning liver. Yeah. So that, that's, that's required. My understanding is that my liver issues are...chronic. Like I'm always gonna have ... So I don't drink alcohol anymore. Participant 011_2023AUHDV

Participant describes wanting to improve their quality of life or return to normality

Yes, well, I do, because I wanted to. I'm very committed to my family and I wanted to get well for them, really, not only for them, but for myself, because I love life.

Participant 010_2023AUHDV

Participant describes wanting to minimise or avoid side effects of treatment for their condition

I've been a bit the thing is I guess the side effects for me. I can't 100% link back to either the medication itself or my body as well like like as in...do I attribute that to the virus or do I attribute that to the medication? That is helping my body potentially to fight the virus or to let it not to control the virus levels like this is where I'm not sure on how I can attribute my symptoms to.

Participant 004_2023AUHDV

Participants describe wanting to make healthy lifestyle changes

Well, for me personally I had to you know kind of reduce the intake of certain diet. There was you know that I could I sense was going to was in the situation and I had to stay away from certain unhygienic activity. So it's just, it just had to do with me cutting off myself from. You know a lot of things just to, you know, maintain not towards in the situation. That's all I tried to do after this.

Participant 006_2023AUHDV

So that's, that's that's the main thing and I mean contracting hepatitis was a bit of an impetus to me to get clean and sober.

Participant 012_2023AUHDV

Participant describes no personal goals of treatment or care (no reason given)

I don't have any goal at the moment as such, but I'm just worried. I'm always worried that when is it going to affect me.

Participant 001_2023AUHDV

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	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 wanting to maintain their condition/prevent worsening of their condition	5	41.67	3	50.00	2	33.33	3	37.50	2	50.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45
Participant describes wanting to improve their quality of life or return to normality	3	25.00	2	33.33	1	16.67	1	12.50	2	50.00	2	33.33	1	16.67	1	100.00	2	18.18	1	100.00	2	18.18
Participant describes wanting to minimise or avoid side effects of treatment for their condition	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participants describe wanting to make healthy lifestyle changes	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
Participant describes no personal goals of treatment or care (no reason given)	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 wanting to see mental or emotional health improvements in their condition	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
Participants describe wanting to comply with treatment	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
Participants describe wanting to be there for family	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

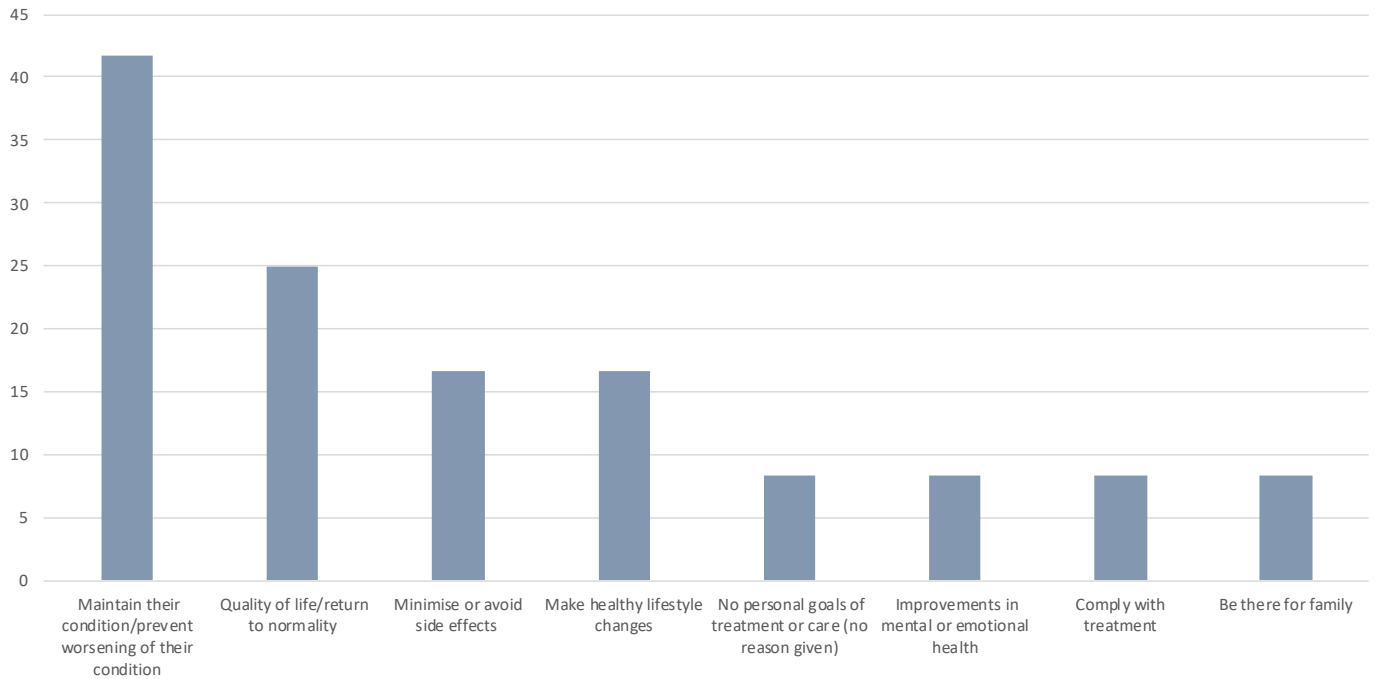


Figure 4.6: Personal goals of treatment or care