

## 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 multiple options (31.91%), or one treatment option (27.66%). Other themes included no discussions about treatment (19.15%), and that they cannot remember (12.77%).

### **Discussions about treatment (Participation in discussions)**

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly participated in the decision-making process (19.15%), or did not give a description about participation in decision making (6.38%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (8.51 %), had a medical emergency or urgent treatment required (8.51%), or they were told what to do without discussion (8.51%).

Some participants were unable to recall discussions about treatments, this was most commonly because they were a child at the time and cannot remember the conversations (6.38%), or they were incapacitated at the time and cannot remember (6.38%).

### **Considerations when making decisions**

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %). Other themes included quality of life (21.28%), their own research (21.28%), their ability to follow treatments (12.77%), and the impact on their family or dependents (10.64%).

### **Decision-making over time**

Participants were asked if the way they made decisions had changed over time. More participants had changed the way that they make decisions (61.70%), than those that had not changed the way they make decisions (34.04%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (27.66%), and more aware of their health, responsibilities and/or limitations (14.89%). Other themes included more cautious and considered (8.51%), more focused impact on family and dependents (8.51%) and more accepting of their condition (6.38%). Where participants had not changed their decision making over time this was because they always been informed/assertive (6.38%).

### **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 to make lifestyle changes to be fit and healthy (14.89%), have physical improvements in their condition (12.77%), and to have quality of life or to return to normality(12.77 %). There were 4 participants, and they had no personal goals of treatment or care (8.51%).

## 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 multiple options (31.91%), or one treatment option (27.66%). Other themes included no discussions about treatment (19.15%), and that they cannot remember (12.77%).

### Participant describes multiple options being presented

*PARTICIPANT: Well, it was the Entresto. The first one, of course, I wasn't given an option. It was, "You need a heart transplant, but you're too old and we have to work with what we've got." It's funny how you never forget those words, isn't it?*

*Participant 033\_2023AUHBV*

*PARTICIPANT: Well, it was the Entresto. The first one, of course, I wasn't given an option. It was, "You need a heart transplant, but you're too old and we have to work with what we've got." It's funny how you never forget those words, isn't it?*

*Participant 033\_2023AUHBV*

### Participant describes one option being presented

*To be honest, it was a very expensive, quick five minute conversation, basically telling me that I'm at no serious risk of having a heart attack and that diet and exercise will keep it that way. And that was that.*

*Participant 028\_2023AUHBV*

*The first thing they wanted to do was put me on medication straight away, but I'm not super keen. I wanted to try diet and exercise first because I'm not super keen on just medications for everything.*

*Participant 020\_2023AUHBV*

*I mean, the only treatment that he discussed was whether to medicate or not, but he said that he felt that it wasn't necessary because I was very fit and healthy. Yeah. That would have been the extent of that discussion. Yeah.*

*Participant 023\_2023AUHBV*

### Participant describes no treatments being discussed

*Look, obviously I had those initial consultations with the neurologist on the ward. I didn't stay in hospital for long, I think I was only in there for a week. I was pretty keen to get out of there and I think it was fairly apparent that I didn't want to be there. He said, "Well,*

*I'm not going to stop you." Because I didn't have any physical paralysis as far as not being to walk or talk or do any...All my issues was with my vision and stuff and just feeling really sick all the time. It was okay for him to let me go and he did, which I appreciated at the time. As far as that went, as far as saying what treatment I could do, and because of the diagnosis was cryptic, there wasn't really much talk about any treatment, really.*

*Participant 043\_2023AUHBV*

*Well, I'd have to say I didn't have a particularly helpful warm relationship with the cardiologist I first saw. He was very efficient and very knowledgeable I suppose but he I didn't want to him and I suspect know him to me and he basically said well we need to keep an eye on this. You know come back every year and have an echo. We're really only treat you when you're symptomatic and you know we can talk about what surgeon you might want to go to at that point. And I I must I I don't think I I wasn't very. What's the word I want tuned into the information I needed? At that point I was just gobsmacked because I thought I didn't have a problem. I was sure there was nothing wrong with me. It was just an incidental murmur, you know, from stress. And I was going bloody hell, what? What now? So I didn't think to ask. Well, you know, time frame or? Is there anything I can do to minimize the? Actually, I think I did ask him is there anything I can do to minimize the progression? And he said basically no. So yeah, it was. It was now. I was rocked off my socks by the diagnosis.*

*Participant 010\_2023AUHBV*

### Participant does not remember discussions about treatments

*Yeah, so. First diagnosed at, probably formally first diagnosed at 8. I didn't actually find out until 9. The doctor was a bit unsure as to how it was going to progress. So I think as far as I'm aware, my mum and dad knew that I had this condition, but they just kind of said have a year, see how it goes, don't do anything differently, and if it progresses on then we got to start doing something. So I think I figured it out about 9:00 and then from about 9:00. 10/11, it was all bit of a blur to be honest.*

*Participant 012\_2023AUHBV*

*I can't recall, sorry. It was so long ago, my memory is not very good.*

*Participant 040\_2023AUHBV*

*I don't know if I remember. I was pretty out of it to start with. My husband and my family probably were more involved in that at the start because I wasn't-- I didn't have- you know how they use a blood thinning*

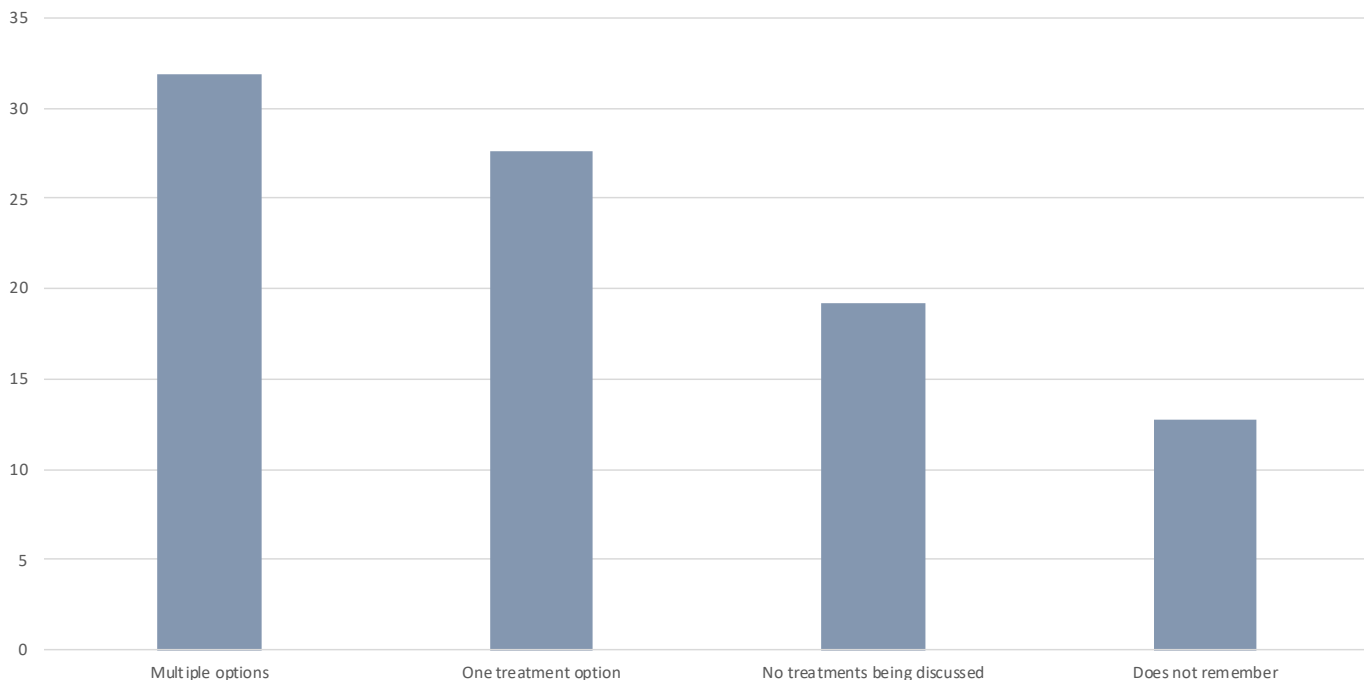
*injection? I get better. I didn't have any of that. I had my stroke during operation.  
Participant 039\_2023AUHBV*

**Table 4.1: Discussions about treatment**

Discussions about treatment	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes multiple options being presented	15	31.91	6	33.33	9	31.03	1	11.11	3	17.65	11	52.38	10	37.04	5	25.00
Participant describes one option being presented	13	27.66	5	27.78	8	27.59	4	44.44	2	11.76	7	33.33	5	18.52	8	40.00
Participant describes no treatments being discussed	9	19.15	2	11.11	7	24.14	2	22.22	5	29.41	2	9.52	7	25.93	2	10.00
Participant does not remember	6	12.77	3	16.67	3	10.34	1	11.11	4	23.53	1	4.76	2	7.41	4	20.00
No particular comment	4	8.51	2	11.11	2	6.90	1	11.11	3	17.65	0	0.00	3	11.11	1	5.00

Discussions about treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes multiple options being presented	15	31.91	10	38.46	5	23.81	7	29.17	8	34.78	5	33.33	10	31.25	6	24.00	9	40.91
Participant describes one option being presented	13	27.66	7	26.92	6	28.57	6	25.00	7	30.43	5	33.33	8	25.00	8	32.00	5	22.73
Participant describes no treatments being discussed	9	19.15	3	11.54	6	28.57	5	20.83	4	17.39	1	6.67	8	25.00	5	20.00	4	18.18
Participant does not remember	6	12.77	3	11.54	3	14.29	3	12.50	3	13.04	2	13.33	4	12.50	4	16.00	2	9.09
No particular comment	4	8.51	3	11.54	1	4.76	3	12.50	1	4.35	2	13.33	2	6.25	2	8.00	2	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 multiple options being presented	High cholesterol under 50 years of age Blood vessel conditions	Heart conditions
Participant describes one option being presented	Blood vessel conditions	High cholesterol under 50 years of age 6 to 11 other conditions
Participant describes no treatments being discussed	Regional or remote	Blood vessel conditions
Participant does not remember	-	Blood vessel conditions

## Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly participated in the decision-making process (19.15%), or did not give a description about participation in decision making (6.38%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (8.51%), had a medical emergency or urgent treatment required (8.51%), or they were told what to do without discussion (8.51%).

Some participants were unable to recall discussions about treatments, this was most commonly because they were a child at the time and cannot remember the conversations (6.38%), or they were incapacitated at the time and cannot remember (6.38%).

### Participant describes being presented with multiple options and participated in the decision-making process

*They pretty much gave me an option of just medication or if to be hospitalized and stay on their drips. I took the medication part of it because I'm one of those people that get better at home. So I took the medication option and they gave me a prescription for three months to take clog out. So yeah, and then I developed. I had to take two tablets of those every day.*

*Participant 029\_2023AUHBV*

*With the atrial fibrillation, I was diagnosed in LOCATION OVERSEAS but I didn't know about it, and when I went into hospital in LOCATION OVERSEAS, we didn't talk about a pacemaker. I think they just tried to get the heart rate under control. I was supposed to have a cardioversion, but because I had a clot, that wasn't possible. I came back here and waited the six weeks for the clot to dissolve, and then I had a cardioversion. The discussions in Italy were really good, because the doctors and nurses worked as a team, and they came to me as a team, and we discussed things together, and they told me what they think should happen, and they tried to reassure me, and it was all really very good. With my cardiologist here, I've had him for about 14 to 16 years now. He's pretty straight down the line and says what I need to have done, basically. I usually ask him questions, so there haven't been too many choices or options.*

*Participant 034\_2023AUHBV*

### Participant describes being presented with one option/approach and did not participate in the decision-making process

*It was pretty much, he said to me. Do you want to be on a white pill for the rest of your life or die? That was it.*

*Participant 016\_2023AUHBV*

*When you're first diagnosed the only treatment option was that was discussed, discussed was a starting on a high dose statin and I was commenced on 20 milligrams of rosuvastatin which is a just straight up really high dose and there were no actual other treatments mentioned. It was just basically start the statin, you know we need to get onto this and and I basically then become proactive looking at other ways as well that I could help myself. So you know, with regards to stress management, eating well, exercising and all that sort of thing, just to try and decrease my risk for future events.*

*Participant 011\_2023AUHBV*

### Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required

*Not much. It was basically happened all of a sudden I I was, the local doctor said I'm concerned with your heart. So we'll do we'll follow that up with a stress test as soon as possible. I went for the stress test they had. That information, my local doctors, the referral, There was no really other conversations around it. I've done the stress test and 5 minutes into it, a Vt, Does that make sense?*

*Participant 025\_2023AUHBV*

### Participant describes being presented with one option/approach, that they were told what to do without discussion

*I was given a treatment and that was it.*

*Participant 049\_2023AUHBV*

*When they first diagnosed me, it was the case of. Here's the medication. If you need to take it, take it. Or it's sort of up to you if you take it, because I think they didn't realize how bad it was to start with.*

*Participant 008\_2023AUHBV*

**Participant describes being incapacitated at the time and cannot remember**

*I see, I don't remember very well. I don't remember the first 10 days. My son, he's a doctor. He came down and he was with me. I think he helps me make a lot of decisions, but I don't remember what they were. [crosstalk] You should because I don't remember the whole thing very well. INTERVIEWER: Yes, that's okay. PARTICIPANT: Yes, I know when to have rehab that we're talking about, cutting my skull and letting the pressure out, but it stopped bleeding and they decided not to do that. I don't remember the discussion about that I...My son might have even told me that afterwards, I'm not sure. They talked about sending me to rehab and I had private health insurance but*

*because of the virus I chose to go public so that I could be in LOCATION STATE rather than LOCATION STATE, but I didn't realise that private would have meant that I had a better rehab. Anyway, I wasn't really in a fit state to understand what was going on to discuss it. It didn't really help [laughs] but if I did discuss they sit with me.*

*Participant 041\_2023AUHBV*

*I don't know if I remember. I was pretty out of it to start with. My husband and my family probably were more involved in that at the start because I wasn't...I didn't have- you know how they use a blood thinning injection? I get better. I didn't have any of that. I had my stroke during operation.*

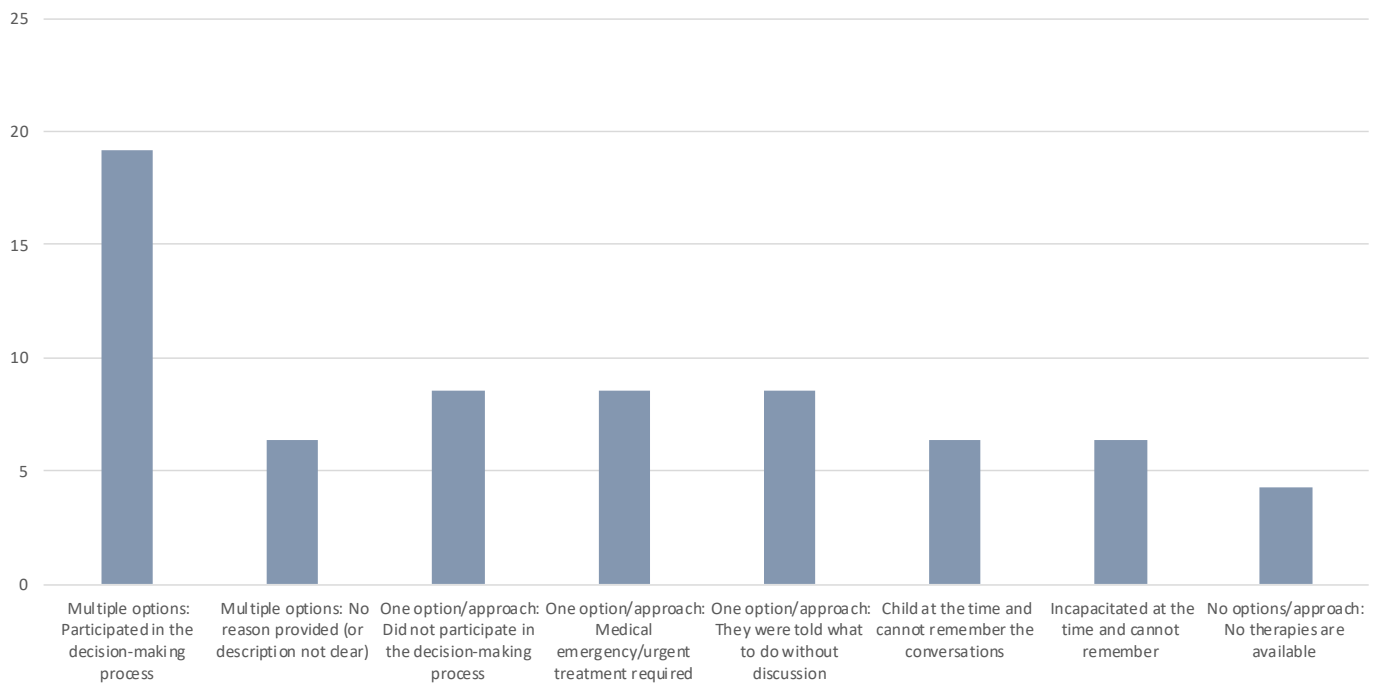
*Participant 039\_2023AUHBV*

**Table 4.3: Discussions about treatment (Participation in discussions)**

Discussions about treatment (Participation in discussions)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes being presented with multiple options and participated in the decision-making process	9	19.15	3	16.67	6	20.69	0	0.00	1	5.88	8	38.10	6	22.22	3	15.00
Participant describes being presented with multiple options but did not give a description or reason for this	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	2	7.41	1	5.00
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	2	7.41	2	10.00
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	4	8.51	2	11.11	2	6.90	0	0.00	0	0.00	4	19.05	2	7.41	2	10.00
Participant describes being presented with one option/approach, that they were told what to do without discussion	4	8.51	2	11.11	2	6.90	1	11.11	1	5.88	2	9.52	1	3.70	3	15.00
Participant describes being a child at the time and cannot remember the conversations	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00
Participant describes being incapacitated at the time and cannot remember	3	6.38	1	5.56	2	6.90	0	0.00	3	17.65	0	0.00	0	0.00	3	15.00
Participant describes being presented with no options/approach as there were no therapies are available	2	4.26	1	5.56	1	3.45	0	0.00	2	11.76	0	0.00	1	3.70	1	5.00

Discussions about treatment (Participation in discussions)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes being presented with multiple options and participated in the decision-making process	9	19.15	6	23.08	3	14.29	4	16.67	5	21.74	4	26.67	5	15.63	4	16.00	5	22.73
Participant describes being presented with multiple options but did not give a description or reason for this	3	6.38	2	7.69	1	4.76	0	0.00	3	13.04	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	3	12.00	1	4.55
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	2	8.00	2	9.09
Participant describes being presented with one option/approach, that they were told what to do without discussion	4	8.51	2	7.69	2	9.52	2	8.33	2	8.70	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes being a child at the time and cannot remember the conversations	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	1	6.67	2	6.25	2	8.00	1	4.55
Participant describes being incapacitated at the time and cannot remember	3	6.38	2	7.69	1	4.76	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes being presented with no options/approach as there were no therapies are available	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	1	4.00	1	4.55



**Figure 4.2: Discussions about treatment (Participation in discussions)**

**Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations**

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options and participated in the decision-making process	High cholesterol under 50 years of age Blood vessel conditions	Heart conditions
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	-	Heart conditions
Participant describes being incapacitated at the time and cannot remember	-	Blood vessel conditions

## Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (51.06%), efficacy (38.30%), and advice of their clinician (23.40 %). Other themes included quality of life (21.28%), their own research (21.28%), their ability to follow treatments (12.77%), and the impact on their family or dependents (10.64%).

### Participant describes taking side effects into account when making decisions about treatments

*The main thing I think about is is is I look at the I'm in a way up the pros and cons you know so you know what's the likelihood of of the side effects of a drug gonna affect me and and all that. So I mean that's the main thing I look at is the side effects. And you know, if I get one of those and like does it outweigh the price? And so far it's yeah, I always take my medication, so. Participant 028\_2023AUHBV*

*The long term effect of my health and the side effects of any medications. Participant 020\_2023AUHBV*

*Side effects of medication is something to take into consideration. I luckily haven't had any side effects, but that was something that I really did look into. That's about it really. And just I just didn't want to be fatigued and it for it to, you know, impact my life too much. So I wanted to be able to take the medication and still be still have a good quality of life. So that's they were the main things I kind of looked at with with treatment.*

*Participant 011\_2023AUHBV*

### Participant describes taking efficacy into account when making decisions about treatments

*The first thing I'll ask is, "Will it work?" Participant 040\_2023AUHBV*

*I always look at what the outcome is expected of that treatment. Participant 044\_2023AUHBV*

*I think things that would affect. Things would be the improvement, what would the benefits be of any treatment? Whether it's cognitive, or physical, or*

*emotional, to be able to make things easier would be very good.*

*Participant 047\_2023AUHBV*

**Participant describes taking the advice of their clinician into account when making decisions about treatments**

*Then what do I base my decisions on? What is medical? The medical? I'm in the care of Professor NAME, who's the leading cardiologist in the world. I placed a lot, a lot of trust in that man. He has looked. He was the guy who, when I was brought into the hospital in the emergency, he was the guy in theatre with me when it happened. So I'm still seeing the same person now. So you're just like, I guess if he tells you you were 100% tasked in that person?*

*Participant 006\_2023AUHBV*

*I actually am probably very passive and just accept that he says I need to go on this, and you need to keep your weight down and you need to exercise, and you need to keep your emotions in control, and come back if you have any problems, like. And I just see him regularly. I sort of think I've lived my life, like when that disaster surgery took six operations to try and fix my bladder etc. and I just am grateful. I just live day to day and don't really think about having anything wrong with me. I just take the medication and move on.*

*Participant 037\_2023AUHBV*

**Participant describes taking quality of life into account when making decisions about treatments**

*I'd have to say it would be like, what the treatment involved. How invasive it is and what the recovery time would be. What the risk factor is I suppose to my normal health afterwards. Like am I going to be able to function better than what I am now? Is it going to improve my lifestyle? I'm only 45 and I know now what it's like to live like an old person because that's what I was like prior to the surgery. Is it going to decrease my capabilities or is it going to increase my capabilities? I would like it to be able to improve my lifestyle. I'd like to be able to live a normal lifestyle. If not normal just better than what I'm doing now. If it's not going to improve how I am now then is it worth it?*

*Participant 036\_2023AUHBV*

*I think the main one is quality of life. And the effects that the medication, if I needed to take it, would have, And if the side effects were severe and significantly impacted my quality of life, then I would need to make choice about whether I wanted to prolong life with*

*that sort of quality or whether it would be better to have a. A better quality of life, but shorter?*

*Participant 017\_2023AUHBV*

*Just my general well-being, more than anything.*

*Participant 043\_2023AUHBV*

**Participant describes taking their own research into account when making decisions about treatments**

*Whether I can afford it. I've got medical insurance. It helps me a little bit with my physiotherapy. No, I don't think there is any treatment. There are books written about rewiring your brain and I'm reading that. I'm helping myself, really. The thing that really matters to me is whether I can do things or not. I can operate a computer. I can type. I can do a lot of things. I just can't walk well enough yet.*

*Participant 048\_2023AUHBV*

*Well, for me, I wasn't tolerating the medication very well. So I sort of started doing my own research and asked them about the ablation procedure, just so that we could have the opportunity to fix it rather than.*

*Participant 008\_2023AUHBV*

*I don't make decisions about treatment anymore. In fact, all the decisions that impacted my treatment were made by others, not by myself. Whilst I was in hospital I really was not part of the decision-making process. I was a patient, the decisions were made by others. When I left hospital and I went to rehab, my rehabilitation was a series of exercises which were formulated by rehab staff. My personal input into my rehabilitation was absolutely minimal. That's why when I did retire I devoted all of my time to researching stroke and to determining the sort of exercise that would benefit me. I did get through self-study.*

*Participant 045\_2023AUHBV*

**Participant describes taking their ability to follow treatments into account when making decisions about treatments**

*That's the thing, I just really, it's just making sure I remember to take the medication. That's. Yeah, I haven't really thought about anything else.*

*Participant 016\_2023AUHBV*



**Participant describes taking the impact on their family or dependents into account when making decisions about treatments**

*The recovery time from surgery, or the benefit that outweigh the positives and the negatives of the surgery. Also ask about alternates, like are there alternate ways of dealing with it? Like with medication. Some medications don't agree, whereas some, you know, are much better for functioning. So, you know, negotiation. My cardiologist is really good, if I say to him, "Look, you know, this isn't working for me," so we titrate the dose and he's happy with me to titrate the dose or change it slightly so that it suits me. As long as it's having an effect and it can suit me, rather than being on way too much medication and trying to function and be a mum and work and have a*

*family life and all of that. So yeah, they're the sort of things that I'd ask. And there's also, I'm involved in an ICD support group at NAME HOSPITAL and they're excellent. And NAME there is really good, and I ring her if I've got any questions, like clinical questions, then I'll give her a call and go over with her and she's fantastic.*

*Participant 030\_2023AUHBV*

*How will it affect my family, my ability to care for my family? I have a young daughter and I look after her. I'm her main carer, main caregiver. I don't care for her, she's not disabled in any way. I take care of my husband as well, a little. Making dinner, and doing washing, I look after him as far as I can.*

*Participant 039\_2023AUHBV*

**Table 4.5 Considerations when making decisions**

Considerations when making decisions about treatment	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes taking side effects into account when making decisions about treatments (Total)	24	51.06	6	33.33	18	62.07	4	44.44	6	35.29	14	66.67	12	44.44	12	60.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	23	48.94	6	33.33	17	58.62	4	44.44	6	35.29	13	61.90	12	44.44	11	55.00
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.13	0	0.00	1	3.45	0	0.00	0	0.00	1	4.76	0	0.00	1	5.00
Participant describes taking efficacy into account when making decisions about treatments (Total)	18	38.30	4	22.22	14	48.28	4	44.44	8	47.06	6	28.57	10	37.04	8	40.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	31.91	3	16.67	12	41.38	4	44.44	5	29.41	6	28.57	7	25.93	8	40.00
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	6.38	1	5.56	2	6.90	0	0.00	3	17.65	0	0.00	3	11.11	0	0.00
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	11	23.40	4	22.22	7	24.14	2	22.22	2	11.76	7	33.33	7	25.93	4	20.00
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	14.89	1	5.56	6	20.69	2	22.22	1	5.88	4	19.05	5	18.52	2	10.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	4	8.51	3	16.67	1	3.45	0	0.00	1	5.88	3	14.29	2	7.41	2	10.00
Participant describes taking quality of life into account when making decisions about treatments (Total)	10	21.28	4	22.22	6	20.69	1	11.11	6	35.29	3	14.29	6	22.22	4	20.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	17.02	3	16.67	5	17.24	1	11.11	4	23.53	3	14.29	4	14.81	4	20.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	4.26	1	5.56	1	3.45	0	0.00	2	11.76	0	0.00	2	7.41	0	0.00
Participant describes taking their own research into account when making decisions about treatments (Total)	10	21.28	2	11.11	8	27.59	2	22.22	3	17.65	5	23.81	4	14.81	6	30.00
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	9	19.15	1	5.56	8	27.59	2	22.22	3	17.65	4	19.05	4	14.81	5	25.00
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	1	2.13	1	5.56	0	0.00	0	0.00	0	0.00	1	4.76	0	0.00	1	5.00
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	6	12.77	2	11.11	4	13.79	1	11.11	3	17.65	2	9.52	2	7.41	4	20.00
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	0	0.00	4	13.79	0	0.00	3	17.65	1	4.76	1	3.70	3	15.00
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	2	4.26	2	11.11	0	0.00	1	11.11	0	0.00	1	4.76	1	3.70	1	5.00
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	5	10.64	3	16.67	2	6.90	2	22.22	1	5.88	2	9.52	4	14.81	1	5.00
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	4	8.51	2	11.11	2	6.90	2	22.22	0	0.00	2	9.52	4	14.81	0	0.00
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	1	2.13	1	5.56	0	0.00	0	0.00	1	5.88	0	0.00	0	0.00	1	5.00

Considerations when making decisions about treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes taking side effects into account when making decisions about treatments (Total)	24	51.06	16	61.54	8	38.10	11	45.83	13	56.52	12	80.00	12	37.50	15	60.00	9	40.91
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	23	48.94	15	57.69	8	38.10	11	45.83	12	52.17	12	80.00	11	34.38	14	56.00	9	40.91
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00
Participant describes taking efficacy into account when making decisions about treatments (Total)	18	38.30	8	30.77	10	47.62	9	37.50	9	39.13	7	46.67	11	34.38	11	44.00	7	31.82
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	31.91	8	30.77	7	33.33	8	33.33	7	30.43	7	46.67	8	25.00	9	36.00	6	27.27
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	3	6.38	0	0.00	3	14.29	1	4.17	2	8.70	0	0.00	3	9.38	2	8.00	1	4.55
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	11	23.40	4	15.38	7	33.33	4	16.67	7	30.43	2	13.33	9	28.13	5	20.00	6	27.27
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	14.89	2	7.69	5	23.81	3	12.50	4	17.39	2	13.33	5	15.63	3	12.00	4	18.18
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	0	0.00	4	12.50	2	8.00	2	9.09
Participant describes taking quality of life into account when making decisions about treatments (Total)	10	21.28	7	26.92	3	14.29	6	25.00	4	17.39	5	33.33	5	15.63	5	20.00	5	22.73
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	17.02	7	26.92	1	4.76	5	20.83	3	13.04	5	33.33	3	9.38	5	20.00	3	13.64
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	2	4.26	0	0.00	2	9.52	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09
Participant describes taking their own research into account when making decisions about treatments (Total)	10	21.28	6	23.08	4	19.05	5	20.83	5	21.74	4	26.67	6	18.75	6	24.00	4	18.18
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	9	19.15	5	19.23	4	19.05	4	16.67	5	21.74	4	26.67	5	15.63	6	24.00	3	13.64
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	1	2.13	1	3.85	0	0.00	1	4.17	0	0.00	0	0.00	1	3.13	0	0.00	1	4.55
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	6	12.77	5	19.23	1	4.76	3	12.50	3	13.04	1	6.67	5	15.63	2	8.00	4	18.18
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.51	4	15.38	0	0.00	1	4.17	3	13.04	1	6.67	3	9.38	2	8.00	2	9.09
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	2	4.26	1	3.85	1	4.76	2	8.33	0	0.00	0	0.00	2	6.25	0	0.00	2	9.09
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	5	10.64	2	7.69	3	14.29	3	12.50	2	8.70	1	6.67	4	12.50	4	16.00	1	4.55
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	4	8.51	1	3.85	3	14.29	3	12.50	1	4.35	1	6.67	3	9.38	3	12.00	1	4.55
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	1	2.13	1	3.85	0	0.00	0	0.00	1	4.35	0	0.00	1	3.13	1	4.00	0	0.00

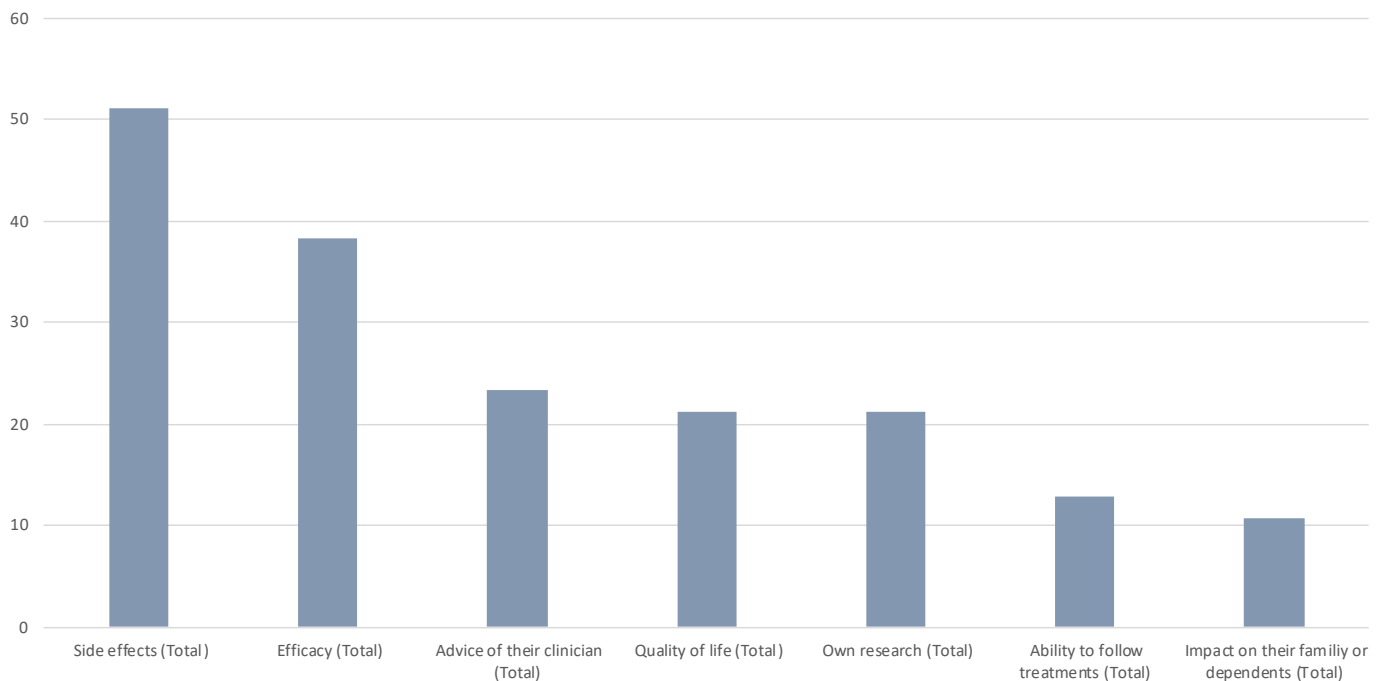


Figure 4.3 Considerations when making decisions

**Table 4.6: Considerations when making decisions – subgroup variations**

Considerations when making decisions about treatment	Reported less frequently	Reported more frequently
Participant describes taking side effects into account when making decisions about treatments (Total)	Had LP(a) test Blood vessel conditions Male Metropolitan Higher socioeconomic status	Did not had LP(a) test Heart conditions Female Regional or remote
Participant describes taking efficacy into account when making decisions about treatments (Total)	Had LP(a) test	-
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	Blood vessel conditions Regional or remote	-
Participant describes taking quality of life into account when making decisions about treatments (Total)	High cholesterol under 50 years of age	Blood vessel conditions Regional or remote
Participant describes taking their own research into account when making decisions about treatments (Total)	Had LP(a) test	-
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	-	High cholesterol under 50 years of age

## Decision-making over time

Participants were asked if the way they made decisions had changed over time. More participants had changed the way that they make decisions (61.70%), than those that had not changed the way they make decisions (34.04%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (27.66%), and more aware of their health, responsibilities and/or limitations (14.89%). Other themes included more cautious and considered (8.51%), more focused impact on family and dependents (8.51%) and more accepting of their condition (6.38%). Where participants had not changed their decision making over time this was because they always been informed/assertive (6.38%).

### Changing over time as they are more informed and/or more assertive

*No, it's definitely changed. Yeah. And changed because I'm probably. Well, I'm not probably. I'm definitely more educated on my condition and I've probably gained a little bit more confidence in the fact that I can have some autonomy over the treatment. Not just these are the specialists, they're saying we need to do this, we need so that we need to do this. So you know, that's just, I guess, you know, evolving with it and feeling a bit more confident that you know, initially when you're scared it's going to happen again, you do what you're told or I did what I was told, whereas now I'm a little bit more self managed I suppose. Participant 009\_2023AUHBV*

*Yeah I think, well I feel, I think initially, because I was quite shell shocked, I would generally just go with whatever I was told to do. I think since then, I feel like I'm, what's the word? I feel more empowered to make my own medical decisions and be able to find resources and people that I can talk to about my different options. Participant 035\_2023AUHBV*

*Well, I think I make them a bit differently. I think I make sure I'm much more informed myself. And I've become more informed over time, I suppose. And yeah, that that's probably the thing that I've that I've become more informed and more proactive with my own treatment in a way you know don't like. I didn't hesitate to ring the caveat and say I need to come and see you even though I wasn't on A. It was. It was out of sync with my regular referral. Do you know what I mean? Yeah. So. So I I made those decisions. Yeah. So I suppose it has changed because if I think there's something wrong, I think, well, I'm going to get someone to talk to about this. I'm not going to let it go.*

*Participant 013\_2023AUHBV*

*No, I think it's changed. It's changed, because I make myself more knowledgeable. I think the internet has - - I know that people make a diagnosis from the internet. I don't do that, but I do like to read up on what is available and to read scholarly articles rather than just Wikipedia or whatever it is so that I can make an informed decision, and also that when my cardiologist talks to me about something, I need to understand what he's talking about and to have a clear discussion with him. If I don't understand something, I will ask him, go back, do a research, and then make myself knowledgeable. I think that has changed because now everything is so easily accessible.*

*Participant 034\_2023AUHBV*

*I don't know. I think I'm a little more proactive in asking for what I want now rather than what I was in the beginning.*

*Participant 008\_2023AUHBV*

*I think I'm quite cautious, and I don't think that's changed. I don't think so. It's a bit like people say, "Well, you've been through all these things. It must get easier." Well, it doesn't actually get easier, and I*

*don't think, as you go on, that the way you make decisions changes. I mean, you perhaps make more informed decisions, and, yeah, so I think it would be that. It would be they've been more informed decisions and I have a greater resource pool around me of places that I can go to get answers, and I'm definitely more -- this is probably the wrong word, but I'm more -- In the beginning, I would have been reluctant to call and ask a question or something like that because I wouldn't wanna disturb anyone, whereas now I -- I mean, sometimes it causes me a lot of angst, but I do make those calls and ask all my questions, and that sort of thing. Yeah. So, yes, I guess it has changed.*

*Participant 023\_2023AUHBV*

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

*Yes, I do. I am more deliberate about my decision making. I tend to overly research and overly consider all the factors before I make a decision. Prior to the stroke, I would not do that into so much depth. Mainly because I still have a poor short-term memory and therefore I have to work harder to understand and soak up information, whereas before with a sound short-term memory you just keep building on the information. It's a more arduous task for me lately. I have to be more deliberate, more measured, more careful.*

*Participant 045\_2023AUHBV*

### **Changing over time as they are more cautious and considered**

*Yes, generally, but it's been 13 years, so my decision-making is more balanced and less impulsive, but that may just be a factor of age.*

*Participant 046\_2023AUHBV*

*I'm more cautious now since my stroke. Very cautious.*

*Participant 049\_2023AUHBV*

### **Changing over time as they are more focused on how treatment impacts their family and dependents**

*I did. I obviously didn't make any decisions until I was probably 15 or 16. Most of that was Mom and Dad. And then I was mom and dad and I had a pretty good relationship where it was they sort of. Thought that I understood what was going on at around 14 and 15 and 16. So then they sort of been started to include me in that. But then since about yeah 1819 it's up to me. But most of my decision making is pretty straightforward. It's do I basically keep saying this*

*doctor or do I go get an ECG or there. Most of that's pretty self-explanatory and that doesn't require much decision making whatsoever. But I'm sure a time will come where? I need to give it a little bit more critical thinking and then in that sense I'm a pretty pragmatic person and I like to think about things, probably overthink things sometimes and in that sense we'll we'll see what comes. But I imagine it'll be a pretty pragmatic and a an all inclusive sort of decision making process. It's not just me anymore it's my partner and mum and dad. All those people have a have a stake in my My health as well. So we'll, it'll be a sounding board sort of area.*

*Participant 012\_2023AUHBV*

*It's changed. I think I've -- Yeah, I tend to ask a lot of questions whereas at first I thought, "Oh, it's my heart. The doctors know the best," and so on. But really there's other things now that you've got to factor in, like family. Not that I didn't before, but I didn't have a child when I was diagnosed, so there's a lot more to consider now, in regards to treatments and so on and what impact it'll have on my life.*

*Participant 030\_2023AUHBV*

*I think it's changed to in in degree rather than in in process and method if you like. In that I I value quality of life over longevity. And I value well, I suppose it's quality of life, the enablement of activities that I want to do. So one of the things that I've found quite difficult, I I live in Toowoomba, I have a wood stove in my house and I love chopping wood. It's, you know, one of those fabulous, both constructive and destructive exercises that gives you something you need and vents your frustration. I love it and I can't shop wood anymore. My chest is just, it hurts my chest just too much. And you know, I've got some soft celtas that I've had trees cut down and I can cut that as long as I limit myself to about 10 minutes. But I can't cut hard wood and that noise. So I guess my the intensity of my decision making is around the quality of the things I want to do.*

*Participant 010\_2023AUHBV*

### **Changing over time as they are more accepting of their condition and choices available**

*PARTICIPANT: Absolutely. Yeah. I think so. As, I've become more educated. I think when you've got something like this you end up becoming a professional in your own diagnosis. You're own disease. As you learn more, you take more into account and you become a little bit more open minded I think, and not so fearful of your disease. I'm not scared of my disease anymore. I used to be terrified of*

it. I used to be terrified of my own heart. But now I'm not.

INTERVIEWER: That's good.

PARTICIPANT: Yeah. For sure. I think I've definitely, definitely changed in that aspect.

Participant 036\_2023AUHBV

No, it has changed a lot. Being the way my head and everything is, is I don't question anything. So if the doctors prescribing me with something, I'd take them for their word and I just take it. I don't even, I don't even really take too much thought into side effects or anything like that much anymore. I just take it.

Participant 021\_2023AUHBV

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

At the start, I had no idea what was going on so I wasn't really capable of making decisions properly. As long as the virus is around and the border is closed

that's going to affect the decisions I make. I can't drive so that definitely affects the decisions I make about how close people are to be able to get to them because I can't...Because I'm in LOCATION REGIONAL, I can't catch a taxi to the biggest centre because it just cost too much money, in fact I don't think the taxi would take me that far. That makes decisions about who I see and what happens. About the way I make decisions? That's just the same because I would just get as much evidence about something I can at the time and then try to make the best decision and if it's not good change it and make another decision.

Participant 041\_2023AUHBV

I think I am a lot more proactive in the way I approach decision making. I've always been kind of known. I don't actually. I don't think I have changed very much with regard to it because I've always been quite proactive in in my health and everything like that. So yeah, not really changed.

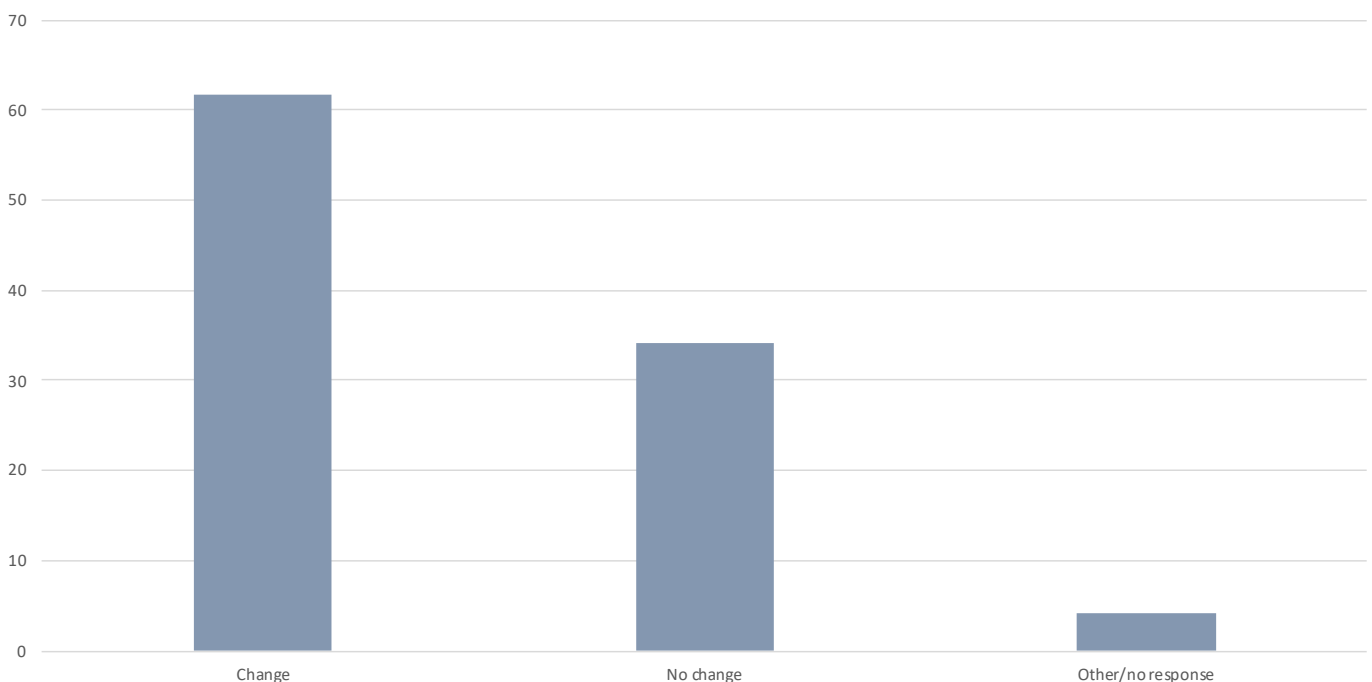
Participant 011\_2023AUHBV

**Table 4.7: Decision-making over time**

Decision-making over time	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Change	29	61.70	7	38.89	22	75.86	7	77.78	11	64.71	11	52.38	14	51.85	15	75.00
No change	16	34.04	10	55.56	6	20.69	2	22.22	5	29.41	9	42.86	12	44.44	4	20.00
Other/no response	2	4.26	1	5.56	1	3.45	0	0.00	1	5.88	1	4.76	1	3.70	1	5.00

Decision-making over time	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Change	29	61.70	16	61.54	13	61.90	13	54.17	16	69.57	9	60.00	20	62.50	14	56.00	15	68.18
No change	16	34.04	9	34.62	7	33.33	10	41.67	6	26.09	6	40.00	10	31.25	11	44.00	5	22.73
Other/no response	2	4.26	1	3.85	1	4.76	1	4.17	1	4.35	0	0.00	2	6.25	0	0.00	2	9.09



**Figure 4.4: Decision-making over time**

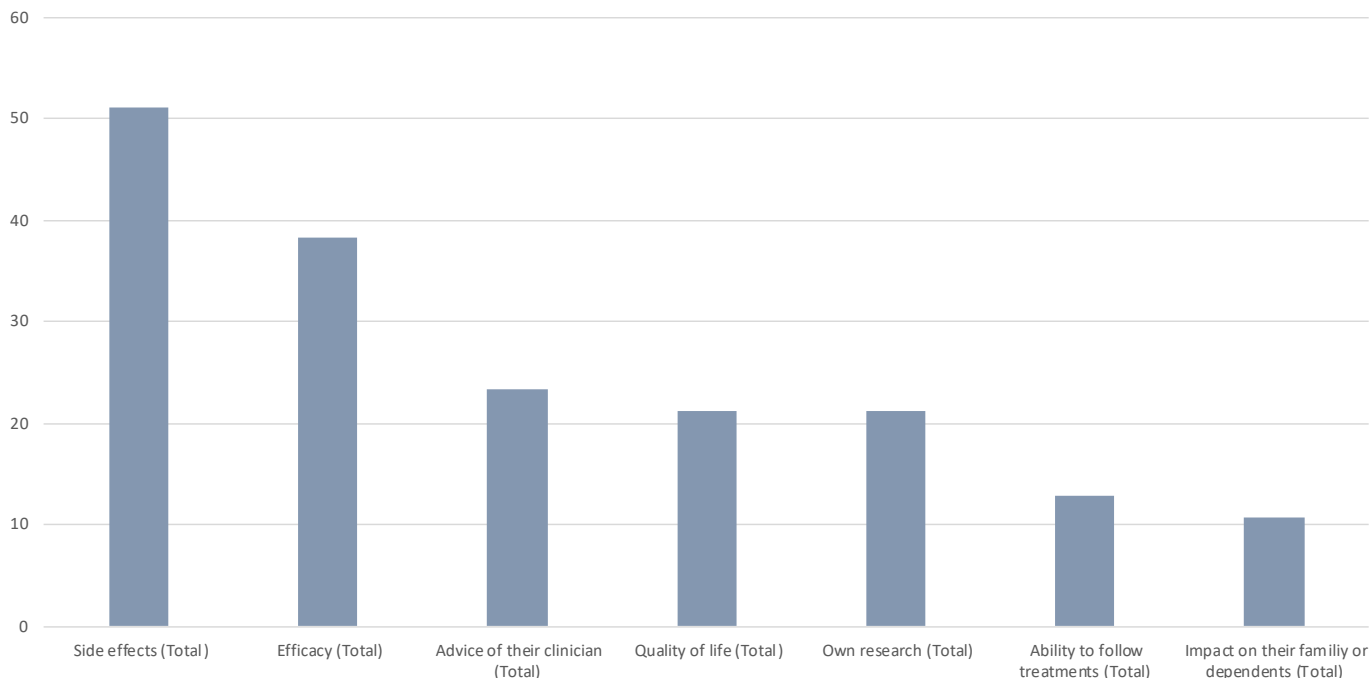
**Table 4.8: Decision-making over time – subgroup variations**

Decision-making over time	Reported less frequently	Reported more frequently
Change	Had LP(a) test	Did not had LP(a) test High cholesterol under 50 years of age 6 to 11 other conditions
No change	Did not had LP(a) test High cholesterol under 50 years of age 6 to 11 other conditions Higher socioeconomic status	Had LP(a) test 0 to 5 other conditions

**Table 4.9: Decision-making over time (reasons)– subgroup variations**

Decision-making over time (reasons)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Changing over time as they are more informed and/or more assertive	13	27.66	1	5.56	12	41.38	2	22.22	4	23.53	7	33.33	7	25.93	6	30.00
Changing over time as they are more aware of their health, responsibilities and/or limitations	7	14.89	1	5.56	6	20.69	2	22.22	4	23.53	1	4.76	3	11.11	4	20.00
Changing over time as they are more cautious and considered	4	8.51	0	0.00	4	13.79	1	11.11	3	17.65	0	0.00	1	3.70	3	15.00
Changing over time as they are more focused on how treatment impacts their family and dependents	4	8.51	1	5.56	3	10.34	2	22.22	1	5.88	1	4.76	3	11.11	1	5.00
Changing over time and there is no particular reason noted	3	6.38	3	16.67	0	0.00	2	22.22	0	0.00	1	4.76	1	3.70	2	10.00
Changing over time as they are more accepting of their condition and choices available	3	6.38	1	5.56	2	6.90	1	11.11	0	0.00	2	9.52	1	3.70	2	10.00
No change in decision-making over time and there is no particular reason noted	8	17.02	5	27.78	3	10.34	1	11.11	4	23.53	3	14.29	7	25.93	1	5.00
No change in decision-making over time as they have always been informed/assertive	3	6.38	1	5.56	2	6.90	0	0.00	3	17.65	0	0.00	0	0.00	3	15.00

Decision-making over time (reasons)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Changing over time as they are more informed and/or more assertive	13	27.66	8	30.77	5	23.81	2	8.33	11	47.83	4	26.67	9	28.13	7	28.00	6	27.27
Changing over time as they are more aware of their health, responsibilities and/or limitations	7	14.89	4	15.38	3	14.29	4	16.67	3	13.04	2	13.33	5	15.63	3	12.00	4	18.18
Changing over time as they are more cautious and considered	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	2	13.33	2	6.25	2	8.00	2	9.09
Changing over time as they are more focused on how treatment impacts their family and dependents	4	8.51	1	3.85	3	14.29	2	8.33	2	8.70	0	0.00	4	12.50	1	4.00	3	13.64
Changing over time and there is no particular reason noted	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	0	0.00	3	9.38	0	0.00	3	13.64
Changing over time as they are more accepting of their condition and choices available	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55
No change in decision-making over time and there is no particular reason noted	8	17.02	5	19.23	3	14.29	6	25.00	2	8.70	4	26.67	4	12.50	6	24.00	2	9.09
No change in decision-making over time as they have always been informed/assertive	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	2	8.00	1	4.55



**Figure 4.5: Decision-making over time (reasons)– subgroup variations**

**Table 4.10: Decision-making over time (reasons)– subgroup variations**

Decision-making over time (reasons)	Reported less frequently	Reported more frequently
Changing over time as they are more informed and/or more assertive	Had LP(a) test Aged 25 to 44	Did not had LP(a) test Aged 45 and older
Changing over time as they are more aware of their health, responsibilities and/or limitations	Heart conditions	
Changing over time as they are more focused on how treatment impacts their family and dependents	-	High cholesterol under 50 years of age
Changing over time and there is no particular reason noted	-	Had LP(a) test High cholesterol under 50 years of age
Changing over time as they are more accepting of their condition and choices available	-	
No change in decision-making over time and there is no particular reason noted	6 to 11 other conditions	Had LP(a) test
No change in decision-making over time as they have always been informed/assertive	-	Blood vessel conditions

## 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 to make lifestyle changes to be fit and healthy (14.89%), have physical improvements in their condition (12.77%), and to have quality of life or to return to normality(12.77 %). There were 4 participants, and they had no personal goals of treatment or care (8.51%).

### Participants describe wanting to make lifestyle changes to be fit and healthy

***PARTICIPANT:** Like like it's like normal gym. And I was regularly walking and I'm very now, now, now after some blood pressure issue, my all the families are very serious about our diets, right?*

***INTERVIEWER:** Great. So fabulous. So it's exercise and diet you're doing. Did you talk to your doctor about these, the exercise and the diet?*

***PARTICIPANT:** Yeah, the doctor told to me like I need to be regular, walk early in the morning and maybe in the evening. The one time will be the best. And she said to me, like, the walk will be in a sense, like no running, no jogging, just a walk for 30 to 35 for the 40 minutes. Yeah.*

*Participant 027\_2023AUHBV*

*My goal is not to die before I'm 60, which is pretty much my mother's side. They've all died before they're 60. So, you know, my, my goal is to and I lead by example because I want to be able to eat healthy, exercise and you know, and do all that sort of stuff. And you know, if at the end of the day that doesn't help me, well, you can't beat genes. But you know, that is my main goal. You know, I was told that if I didn't make all these dietary changes, I was going to be dead by 40. I'm 44 on Sunday, so I am still here. So, yeah, I don't have any long term goals, you know, beyond that sort of, you know, take it a year by year at this stage.*

*Participant 028\_2023AUHBV*

*So I know that there's no other way to treat my conditions other than take this regime of medications that I'm on and the and the other control that I have is is to stay fit and healthy like by walking exercise and and you know not. Coming overweight and you know dietary control is not drinking too much alcohol and all that sort of stuff. So I'm aware of all those things and they're the things and and I and I think I'm in a pretty good place right now. So I figured that I can manage all those things. There's only one advocate here for your health for you if your health is you. So that's how I see it. So I'm I think I'm aware of what I need to do and yeah.*

*Participant 013\_2023AUHBV*

### Participants describe wanting to see physical improvements in their condition

*My personal goal is to make sure my ejection fraction gets as high as it can do and that the rest of my heart is as healthy as it can be.*

*Participant 015\_2023AUHBV*

*Now, I would like to be able to go through a week without feeling absolutely exhausted.*

*Participant 047\_2023AUHBV*

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

*I don't get my life back so before this happens we we're caravanning, boating, family, so. Weekends look like going out in the boat and camping and having fun and all those sorts of things. Quite active. So I and even more so than going back to work. For me, going back to work is so that we could afford to do fun things again. So I love traveling. So yeah, my. I suppose my end goal is to get my life back, and in order to do that financially, I need to go back to work. I suppose is is the driving thing about wanting to go to work, because hey, who? Who? Who wouldn't like to stay home every day and be well and enjoy it at the*

same time. So my big goal is to get my life back and be healthy.

Participant 014\_2023AUHBV

stressing with about it. Like just get it to back to normal or get it back to. Yeah, just as best as I can. So I don't have to stress about it.

Participant 029\_2023AUHBV

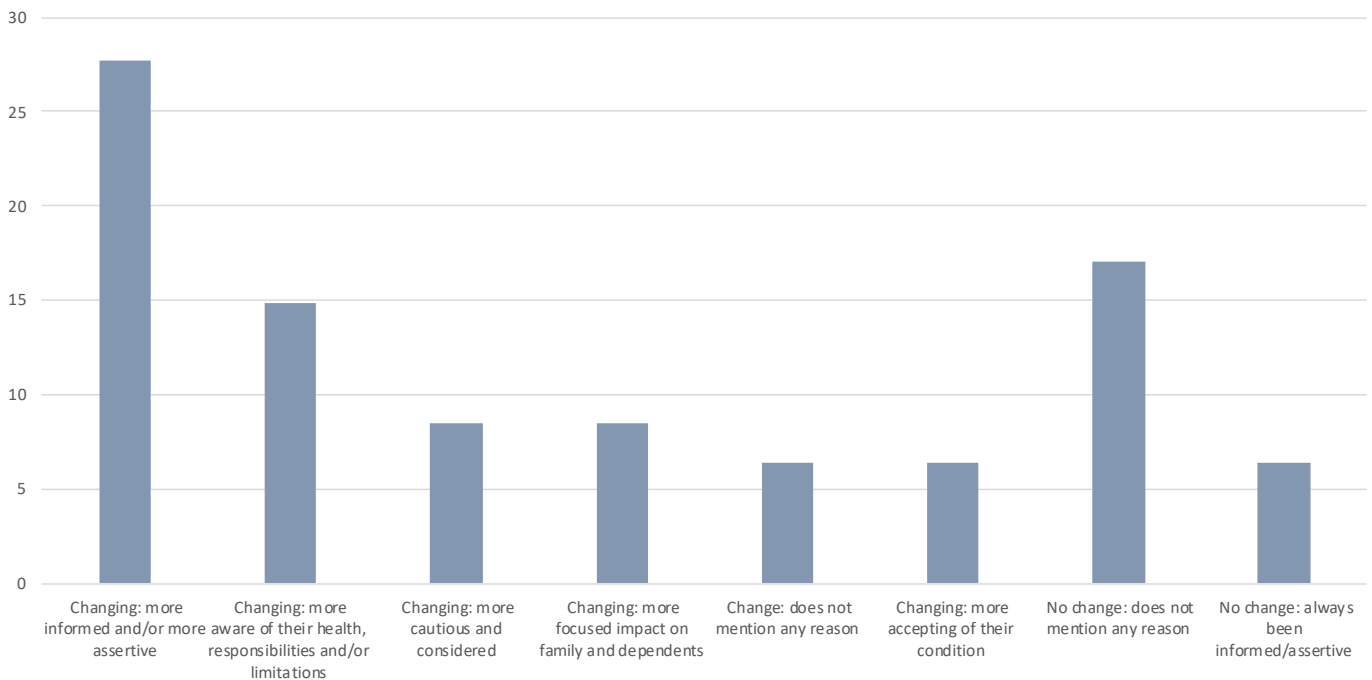
More like a I think I'm more looking at the side of things like where I can just live a normal life without

**Table 4.11: Personal goals of treatment or care**

Personal goals of treatment or care	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participants describe wanting to make lifestyle changes to be fit and healthy	7	14.89	1	5.56	6	20.69	2	22.22	2	11.76	3	14.29	5	18.52	2	10.00
Participants describe wanting to see physical improvements in their condition	6	12.77	5	27.78	1	3.45	0	0.00	5	29.41	1	4.76	4	14.81	2	10.00
Participant describes wanting to improve their quality of life or return to normality	6	12.77	4	22.22	2	6.90	0	0.00	4	23.53	2	9.52	4	14.81	2	10.00
Participant describes no personal goals of treatment or care (no reason given)	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	2	7.41	2	10.00

Personal goals of treatment or care	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participants describe wanting to make lifestyle changes to be fit and healthy	7	14.89	3	11.54	4	19.05	4	16.67	3	13.04	2	13.33	5	15.63	5	20.00	2	9.09
Participants describe wanting to see physical improvements in their condition	6	12.77	3	11.54	3	14.29	2	8.33	4	17.39	1	6.67	5	15.63	3	12.00	3	13.64
Participant describes wanting to improve their quality of life or return to normality	6	12.77	4	15.38	2	9.52	3	12.50	3	13.04	3	20.00	3	9.38	4	16.00	2	9.09
Participant describes no personal goals of treatment or care (no reason given)	4	8.51	3	11.54	1	4.76	1	4.17	3	13.04	1	6.67	3	9.38	4	16.00	0	0.00



**Figure 4.6: Personal goals of treatment or care**

**Table 4.12: Personal goals of treatment or care – subgroup variations**

Personal goals of treatment or care	Reported less frequently		Reported more frequently	
	High cholesterol under 50 years of age	Had LP(a) test	Blood vessel conditions	Heart conditions
Participants describe wanting to see physical improvements in their condition	High cholesterol under 50 years of age	Had LP(a) test	Blood vessel conditions	Heart conditions
Participant describes wanting to improve their quality of life or return to normality	High cholesterol under 50 years of age	Blood vessel conditions	Blood vessel conditions	Heart conditions