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 (40.52%), and this was followed by no discussions about treatment (24.92%) and one treatment option (22.77 %).

Discussions about treatment (Participation in discussions)

For those presented with multiple treatment options, descriptions included participating in the decision-making process (13.85%) and being told what to do without discussion (11.69%). This was followed by not participating in the decision-making process (3.69%).

For those with a single treatment option, descriptions included being told what to do without discussion (7.08%) and participating in the discussion (5.85 %). Some participants were presented with no treatment options as no therapies are available but allied health or complementary support offered (5.54%), while others had no therapies or options presented.

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 (46.31%), efficacy (38.64%), advice of their clinician (26.14%) and cost (21.02 %). Other themes quality of life (16.76%), impact on their family or dependents (9.09%), amount of time needed for treatment and travel times (6.53%), ability to follow treatments (10.51%), and ability to work (4.55%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 201 participants (57.10%) that had changed the way they make decisions, and 110 participants (31.25%) had not changed the way they make decisions.

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (23.01%), more aware of their health, responsibilities and/or limitations (10.80%), and more cautious and considered (8.24 %). Other themes included more focused impact on quality of life (5.40%).

Where participants had not changed the way they make decisions, the most common reason was that they had always been informed/assertive (6.25%).

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 have quality of life/return to normality (22.56%), to maintain their condition or prevent worsening of their condition (19.55%) and have physical improvements in their condition (18.05 %). Other themes included the ability to live independently (13.53%) and wanting to minimise or avoid side effects (8.27%).

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 (40.52%), and this was followed by no discussions about treatment (24.92%) and one treatment option (22.77 %).

Participant describes no treatments being discussed

Literally, he said, 'I do not deal' That's a quote. 'I do not deal with people like you, with people like you', meaning people with idiots, because the stigma around us is just overwhelmingly unbelievable. I do not deal with people like you. So now that I've delivered this diagnosis, I need you to not come back. And that was it.
Participant 003_2023AUDPA

I went to a rheumatologist, but I never was offered any treatment or like medication or anything in the beginning. I basically just was told there was no cure and I just have to learn to live with it. Which is fair enough probably because it's probably true, but I've been in hospital this year and I met a lady in there who said she's had lots of help. A lot of people get infusions and that, I've never been offered anything like that but that's okay. I'm managing.
Participant 013_2023AUDIS

At diagnosis, I was actually not given any options. I, the doctor that had diagnosed me, obviously heard of it and seen it, but she didn't give me any kind of like, this is what you can do for it. This is what can help. This is how you banded yourself. Like there was nothing. It was just this is what you have.
Participant 014_2023AUDSK

Participant describes multiple options being presented

Yep. So I think we, the gastroenterologist was just, she talked to us, I guess about the two ways you could treat it like either medication or diet management. And so we tried quite hard with the diet management at the start. So like you do a diet where you take out the top 4 triggers and then we kind of reintroduce food slowly to try and work out what he could have. So I think we, we always knew there were kind of two pathways and we've ended up kind of combining them.
Participant 079_2023AUDIS

Multiple options yes, but all of the treatment options were based around really different antibiotics or potentially hormonal treatments.
Participant 007_2023AUDSK

It was very murky in so far as he would come in to me and say I think it's this, I think I might try this treatment or that treatment. And it was very difficult to get information from him, and it was very difficult to have a discussion about the pros and cons of the different treatment options, he said to me at one stage I want to do X treatment on you, but I've got to make sure you have no cancers in your body. But more than that, he's very slippery in so far as he wouldn't stay long enough to sit down and have a chat right. So I found it very difficult…I found that very difficult, yeah.
Participant 095_2023AUDNS

Participant describes one option being presented

I honestly didn't pay that much attention because I thought it was not a big deal. Do you know what I mean? Like, I walked in there and she's like, 'Yep, you've got HS. If you take these tablets, we'll check you in six months to see if it worked or not'. And I kind of assumed that that was as easy as it was going to be …and I was just like, yep, no worries, thanks. I'll take the pills. And then after a certain period of time, it stopped working and I'd be like, crap.
Participant 026_2023AUDSK

Dr. NAME was a neurologist and he spoke with my GP about options. My GP was great in the sense that he didn't know anything about it but he certainly went and found out for us. He was quite concerned about it being treated with Botox. Then when I went down to CITY, the first neurologist that I saw there really I got absolutely nothing from that neurologist at all. His treatment was very different to what I'm receiving now. He provided no information or options of what else was available besides the Botox. He basically flew down to Brisbane. He injected three points and then that was it. There was no conversation, no anything.
Participant 006_2023AUDNS

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=352	%	n=67	%	n=81	%	n=95	%	n=32	%	n=45	%	n=32	%	n=225	%	n=127	%	n=256	%	n=94	%
No treatments being discussed	81	24.92	23	34.33	**6**	**7.41**	**34**	**35.79**	**2**	**6.25**	**5**	**11.11**	11	34.38	41	18.22	40	31.50	57	22.27	24	25.53
Multiple options	132	40.62	**5**	**7.46**	**47**	**58.02**	35	36.84	**17**	**53.13**	19	42.22	**9**	**28.13**	107	47.56	**25**	**19.69**	102	39.84	30	31.91
One treatment option	74	22.77	**8**	**11.94**	20	24.69	21	22.11	9	28.13	7	15.56	9	28.13	53	23.56	21	16.54	58	22.66	16	17.02

Discussions about treatment	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=352	%	n=94	%	n=118	%	n=90	%	n=50	%	n=172	%	n=172	%	n=95	%	n=257	%	n=178	%	n=174	%
No treatments being discussed	81	24.92	**34**	**36.17**	24	20.34	15	16.67	8	16.00	38	22.09	43	25.00	18	18.95	63	24.51	33	18.54	48	27.59
Multiple options	132	40.62	**17**	**18.09**	51	43.22	**46**	**51.11**	18	36.00	66	38.37	66	38.37	40	42.11	92	35.80	76	42.70	56	32.18
One treatment option	74	22.77	16	17.02	27	22.88	17	18.89	14	28.00	41	23.84	33	19.19	16	16.84	58	22.57	38	21.35	36	20.69

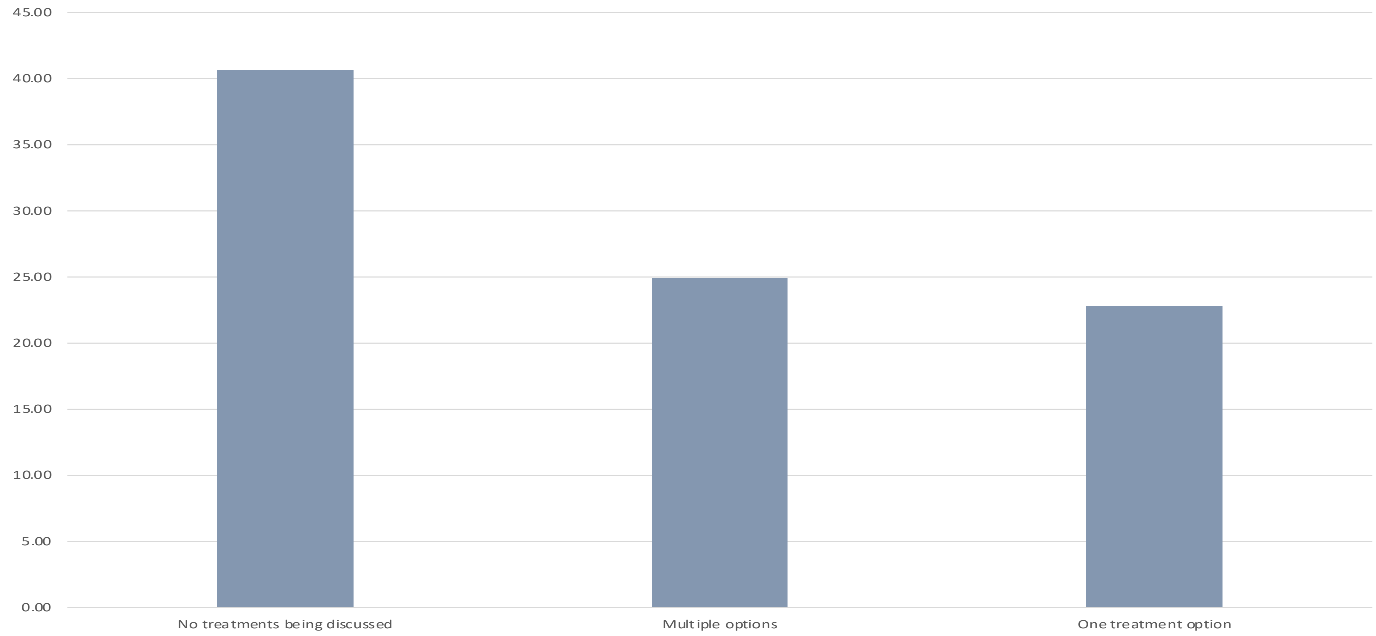

Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
No treatments being discussed	Diseases of the immune system Diseases of the skin Endocrine, nutritional or metabolic diseases	Diseases of the nervous system Aged under 18
Multiple options	Developmental anomalies Other rare condition Family or carer Aged under 18	Diseases of the immune system Diseases of the skin Aged 45 to 64
One treatment option	Developmental anomalies	

Discussions about treatment (Participation in discussions)

For those presented with multiple treatment options, descriptions included that they participated in the decision-making process (13.85%), and they were told what to do without discussion (11.69%). This was followed by not participating in the decision-making process (3.69%).

For those with a single treatment option, descriptions included being told what to do without discussion (7.08%), and participating in the discussion (5.85 %).

Some participants were presented with no treatment options as no therapies are available but allied health or complementary support offered (5.54%), while others had no therapies or options presented (6.77%).

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

The rheumatologist I had at that time, it's not the same, I have a different one now. The one I had at the time, she told me because there's no cure, there's lots of treatment available but is still on trial…it may work well, and others, there's no result. She told me at the beginning, I had to start the immunosuppressant which I'm still taking until now. Then she said maybe I have to do some infusion, which will help me. At the beginning I was scared and then I said, no, I don't want, because I had so much issues with my veins, and so much trouble getting blood tests done. I had a fear of going back and having incision, I don't know how many times, maybe once a month or I'm not sure. She said she will organize a plan for me, but I was so afraid because I had so much bad experience doing this. Even when I had to do some scan, CT scan, they had to find a vein and it was so hard. During that time I even had a surgery, I had to remove my right thyroid and I had such a bad experience. That's why I didn't want an infusion.
Participant 020_2023AUDIS

When I was, my doctor diagnosed me, she put me straight on doxycycline referred me to a dermatologist in Melbourne. This dermatologist was also doing studies on medications and treatments for HS saw a dermatologist initially who. I was not happy with because I hadn't…I went in with my own list of questions and I kind of was getting fobbed off and she was trying to push me towards one of these studies but wasn't prepared to answer the questions that I had there and then. So I had a discussion with my GP. We both felt it was was best that I asked to see a different dermatologist, which I did. So I had a consultation with this next dermatologist. I didn't fit the research program that they were doing at that time because I had only recently been diagnosed, so I was put on Humira. So I've probably been on Humira for what I don't know, for 2 1/2 years I think as far as. As far as most of the other treatments, the only other thing that we've discussed is the possibility of using sorry, my mind's going to go blank now. Steroid injections to help reduce some of the flaring or potential surgery, which is something personally I'm not keen to go down that track.
Participant 001_2023AUDSK

Participant describes being presented with multiple options, however, they were told what to do without discussion

The geneticist didn't do too much about the treatment planning. In his report, it just suggested linking into physiotherapy and some pain specialists perhaps, just from memory. It was quite a detailed report and it was just, "Consider these options," and then that was it. My GP at the time wasn't super helpful. [chuckles] I have changed GPs since then. Basically, I just run my own management now. Now that I know what I need, I know what to say, and what to ask for. That's made a big difference. Participant 004_2023AUDPA

He just wanted to cut. He just said antibiotics and then we'll cut it out. That was the end. And I thought, well, it keeps moving, so how do you just keep cutting it out? And then leaving it, they call it de-roofing. They re de-roof it. So they leave it open to to heal. And I go online have a look at some of the images. You'll be absolutely…and like some like I'm lucky I don't get it under my armpits yet or in my joints, you know, and guys can get it all over their head, on the back of their neck, wherever you've got hair. And women get in the under their boobs and and I've been lucky enough not to have that sort of thing. Mine's but lucky. I'm lucky but some it's retained to my butt, which is a bit more private. But some kids, even kids have it from an early age. Prepubescent, it's it's just awful for them and I don't know how they cope with it and nobody knew that it was acne, you know? But it's not just acne. Participant 024_2023AUDSK

Participant describes being presented with multiple options but did not participate in the decision-making process

This is about 7-8 years ago I went to HOSPITAL. You go there to outpatient. They always see a different person in about. They were kind of pimples in about a year and a half after I've been going there and they put me in all sort of… I can't even remember. Every time I went there, they put me on a different tablet and then they decided to do hydrocortisone injections on the buttocks area and they ruined my life. Not only damage the area, they created these lamps full of fluid that they were constantly oozing, oozing, oozing, oozing only a standard kind of decrease the oozing. I don't know if it is because what I'm taking at the moment, but it it's about 3-4 months ago that the ooze has decreased quite a lot.
Participant 031_2023AUDSK

The conversation was really the shoving medication down my throat. Like just it was initially taking steroids and taking like Prednisone and for reflux and taking a steroid puffer. But it so it's the whatever, the orange flixotide, but it was, yeah, but it was swallowing the flixotide instead of inhaling the flixotide.
Participant 078_2023AUDIS

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

There was nothing. No, just they was just like, here's some drugs. There's no real, nothing we can do for you. Just try these drugs and see how we go. Then once, they didn't give me any other option. Participant 018_2023AUDIS

PARTICIPANT: I haven't really been given options. It's kind of this is what the plan is…You're kind of just being spoken to.
Participant 096_2023AUDNS

Participant describes being presented with one option/approach, and had some but very little discussion

Antibiotic and they don't work for me. They did and now they don't. But I have to have that conversation every time with the doctor and still given the same ones. So like I said, I've had no medical intervention or assistance really.
Participant 018_2023AUDSK

Well, I suppose the main one was the palate and really there was the operation available, but there was no, there was no God to say, you know, this is definitely going to fix her speech. You know, it depends some, some get, you know, better results than others. She's still got a tiny little gap. So therefore her, the discussions were about the way she's going to sound because she's quite nasally in her speech. You know, if they got a a bit of, you know, less of a clearance there and closed it a little bit more than she would be less, you know, nasal sounding. So that was one of the main things. The heart we didn't really have much of a conversation on apart from one doctor thought he heard a heart murmur and so we went through cardiology and they did a lot of scans and things, but they couldn't find anything there. Participant 024_2023AUDPA

Participant describes being presented with no options/approach as there were no therapies are available but allied health or complementary support offered

So there was no real treatment because there wasn't anything that needed to be treated. I guess once once we had her her diagnosis, it explained a lot of things like her, her delays and her size. So then from then on, we've just been able to go on to things like occupational therapy, speech therapy to try and help with those delays. Yeah, and medically…I said medically there hasn't been any problems as yet.
Participant 010_2023AUDPA

That was just with the geneticists, just sort of kept us up with the pediatrician. And then we had to start like therapy, OT physio, OT physio. Just trying to think what the others were, speech pathology. We went to programs for sensory perception at the hospital. Yeah, we've got individual education plans in progress in process. Yeah. So we work with that then. And cardiology testing as well.
Participant 11_2023AUDPA

Participant describes being presented with no options/approach as there were no therapies are available

Because it's vascular, there's not much I can do. You go, "Okay. I'm just one of those that sit in the corner and wait." Yes, you look normal, you look okay, fine but they've haven't discussed what options are available. To my daughter, they discussed with her the options of if and when she wants to have children, this is what you're going to do. For me and my son being male, there's not much that we need to discuss. Participant 005_2023AUDPA

It was a bit too it was almost a bit too much soft touch as far as you know how I left the hospital, what my understanding was was a little hazy at first but they did make it clear enough that there wasn't any medication available so they they there was no treatment available they they catch that in in. Participant 011_2023AUORC

Participant describes being presented with no options/approach as there were no therapies are available but monitoring of condition was offered

There was no intervention the first couple of years. It was just regular blood tests and monitoring every six, six or 12 months. So that took me up to maybe my late 20s or early 30s. No, it would have been late 20s. It took me up to my late 20s of just regular blood tests.
Participant 004_2023AUORC

So pretty much it was, we were given a 'well this is it and this is the main things that happens. So this is, this is the boxes that you need to go and tick off. You need to go and see a cardiologist and you need to go and have a ultrasound on your kidneys and you need to go and have a cervical spine, X-ray, and you need to, you know, go and see these people like these different specialists'. Then they said, you know, of course, she was only 12 at the time, but they said, you know, when it comes to planning a family, you know, you need to come back and see us, you know, and all of that sort of stuff. And that was pretty much it at the time. We were still under the well, we were still able to go to the HOSPITAL. So yeah we were we were pretty good. I'm sure there was a wait list but of course I can't remember too much about it but yeah so that. So that was pretty much the only the only feedback we were given. Here's your condition and this is the…to see we know what are the problems there are that we need to monitor on an ongoing basis. So that's all that pretty much was given to us at the time.
Participant 37_2023AUDPA

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=352	%	n=352	%	n=81	%	n=45	%	n=32	%	n=95	%	n=32	%	n=247	%	n=105	%	n=252	%	n=98	%
Multiple: Participated in decision-making	45	13.85	**1**	**1.49**	15	18.52	15	15.79	6	18.75	6	13.33	2	6.25	35	15.56	10	7.87	36	14.06	9	9.57
Multiple : Told what to do without discussion	38	11.69	**1**	**1.49**	15	18.52	16	16.84	2	6.25	4	8.89	**0**	**0.00**	34	15.11	4	3.15	30	11.72	8	8.51
Multiple: No reason provided	26	8.00	2	2.99	11	13.58	2	2.11	5	15.63	3	6.67	3	9.38	22	9.78	4	3.15	20	7.81	6	6.38
Multiple: Did not participate in decision-making	12	3.69	0	0.00	0	0.00	4	4.21	2	6.25	5	11.11	1	3.13	10	4.44	2	1.57	8	3.13	4	4.26
One option: Told what to do without discussion	23	7.08	0	0.00	9	11.11	7	7.37	2	6.25	4	8.89	1	3.13	23	10.22	0	0.00	17	6.64	6	6.38
One option/approach: Participated in the decision-making process	19	5.85	0	0.00	2	2.47	12	12.63	1	3.13	2	4.44	2	6.25	8	3.56	11	8.66	15	5.86	4	4.26
One option: No reason provided	16	4.92	4	5.97	5	6.17	0	0.00	3	9.38	2	4.44	2	6.25	12	5.33	4	3.15	11	4.30	5	5.32
One option: Some but very little discussion	11	3.38	3	4.48	3	3.70	2	2.11	1	3.13	2	4.44	0	0.00	7	3.11	4	3.15	10	3.91	1	1.06
No options: No therapies are available	22	6.77	8	11.94	2	2.47	3	3.16	0	0.00	3	6.67	**6**	**18.75**	10	4.44	12	9.45	12	4.69	10	10.64
No options: No therapies available, allied or complementary offered	18	5.54	0	0.00	0	0.00	**18**	**18.95**	0	0.00	0	0.00	0	0.00	5	2.22	13	10.24	18	7.03	0	0.00

Discussions about treatment (Participation in discussions)	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=352	%	n=69	%	n=116	%	n=108	%	n=59	%	n=172	%	n=172	%	n=100	%	n=252	%	n=176	%	n=176	%
Multiple: Participated in decision-making	45	13.85	7	7.45	16	13.56	17	18.89	5	10.00	16	9.30	29	16.86	12	12.63	33	12.84	20	11.24	25	14.37
Multiple : Told what to do without discussion	38	11.69	2	2.13	13	11.02	16	17.78	7	14.00	19	11.05	19	11.05	12	12.63	26	10.12	20	11.24	18	10.34
Multiple: No reason provided	26	8.00	2	2.13	13	11.02	10	11.11	1	2.00	14	8.14	12	6.98	10	10.53	16	6.23	17	9.55	9	5.17
Multiple: Did not participate in decision-making	12	3.69	2	2.13	3	2.54	2	2.22	5	10.00	9	5.23	3	1.74	2	2.11	10	3.89	6	3.37	6	3.45
One option: Told what to do without discussion	23	7.08	0	0.00	8	6.78	8	8.89	7	14.00	17	9.88	6	3.49	6	6.32	17	6.61	15	8.43	8	4.60
One option/approach: Participated in the decision-making process	19	5.85	11	11.70	3	2.54	2	2.22	3	6.00	13	7.56	6	3.49	2	2.11	17	6.61	9	5.06	10	5.75
One option: No reason provided	16	4.92	1	1.06	7	5.93	5	5.56	3	6.00	8	4.65	8	4.65	3	3.16	13	5.06	7	3.93	9	5.17
One option: Some but very little discussion	11	3.38	1	1.06	7	5.93	1	1.11	2	4.00	5	2.91	6	3.49	4	4.21	7	2.72	8	4.49	3	1.72
No options: No therapies are available	22	6.77	11	11.70	5	4.24	1	1.11	5	10.00	10	5.81	12	6.98	6	6.32	16	6.23	9	5.06	13	7.47
No options: No therapies available, allied or complementary offered	18	5.54	12	12.77	4	3.39	2	2.22	0	0.00	7	4.07	11	6.40	2	2.11	16	6.23	3	1.69	15	8.62

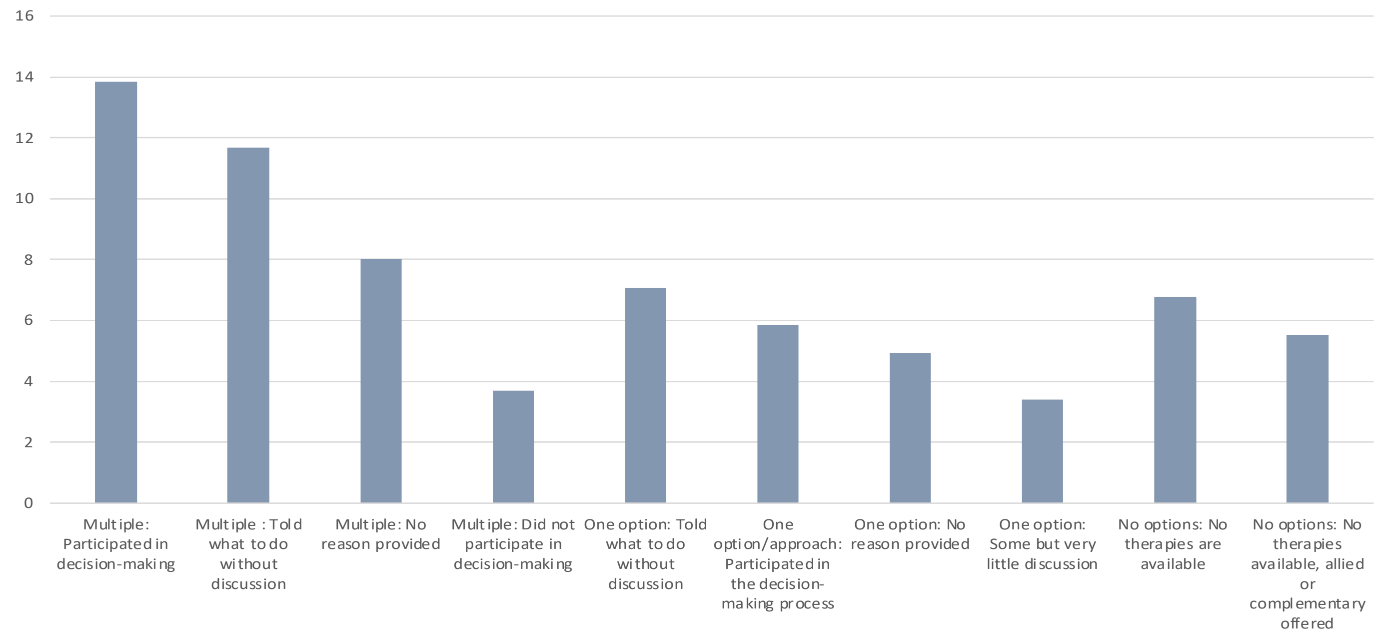

Figure 4.2: Discussions about treatment (Participation in discussions)

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

Discussions about treatment	Reported less frequently	Reported more frequently
No treatments being discussed	Diseases of the immune system Diseases of the skin Endocrine, nutritional or metabolic diseases	Diseases of the nervous system Aged under 18
Multiple options	Developmental anomalies Other rare condition Family or carer Aged under 18	Diseases of the immune system Diseases of the skin Aged 45 to 64
One treatment option	Developmental anomalies	

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 (46.31%), efficacy (38.64%), advice of their clinician (26.14%) and cost (21.02 %). Other themes quality of life (16.76%), impact on their familiy or dependents (9.09%), amount of time needed for treatment and travel times (6.53%), ability to follow treatments (10.51%), and ability to work (4.55%).

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

About the side effects, because I live on my own and I don't want to feel more sick after that because there's no one to look after me if I get sick at home. That's the main thing I look about the side effects.
Participant 020_2023AUDIS

Side effects is a big one for me. Obviously I don't want to put on heaps of weight or feel nauseous, or if I can avoid some horrible side effects, I will and I guess not so much yet. But as I said in the future, like if I can be on them while pregnant or how long I have to be off them before being pregnant, yeah.
Participant 095_2023AUDNS

Well I just the side effects of different medications and what, what you know whether the side effects are worse than the and the actual thing but in the early …you have no choice sometimes whether yeah it's just mainly the side effects that the methotrexate when I took it 16 years ago it. It may…I got I got very sick sort of like chest and I also had mouth ulcers and stuff like that, all the side effects. And also it did something to my liver. So This is why I didn't want to take it again. Yeah. So I just, I just told him and he said I don't have to take it if I don't want to. It's up to me, which is you can advocate and say what, you know, whether I wanna take this medication or not, I, I do my research.
Participant 088_2023AUENM

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

Medical and scientific evidence. Basically I read the publication. Yeah, that's how I decided it becomes difficult because still as of this date, there is only one drug approved in Australia for the treatment of HS. So…
Participant 008_2023AUDSK

Yeah. So in terms of making the decisions, I guess the efficacy and I guess I do some research in terms of…you know, not very academic research I must say, but I will look at any research papers that you know just through a search through a search engine and what their results were and also you know the period of time that it was done. Like, was it done last couple of years or was it done 10 years ago? It was ten years ago, I would ignore it and also look at different Scleroderma sites and talk to my GP. Trust my GP enormously and, you know, really talking to professionals such as the scleroderm clinic at Monash. So these are all the themes, yeah.
Participant 010_2023AUDIS

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 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, in treatment yeah. 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_2023AUORC

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

Probably cost is one currently that I've taken more of a consideration. Honestly with the side effects and everything it's it's low impact, I've got to go in open minded. There is no cure so I can't go when thinking it's going to fail, so I'll give everything a good go. And then ultimately wait to see if it pays off. With the cost component, it's more so of timing it so that I know I can afford it other than I wouldn't necessarily delay a treatment, I would just take note and make sure I got everything in order.
Participant 026_2023AUDSK

When it comes to, I think, cost when I could no longer work, a lot of decisions were around the cost of things as well because I was working full-time until three years ago where it was just too difficult. Thinking back now, I should have been more self-advocate about changing hours of work, and things like that, to assist with my ability to continue. At that stage, I was just so, "No I need to stop. I can't do it anymore."
Participant 026_2023AUDIS

Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)

Well, I guess the main one is, will it help? [chuckles] I'm willing to try almost anything as long as it's prescribed by someone reputable or someone I know. If they said, "Try a particular medication," I'd try it or whatever it might be. No one has suggested anything very startling to me, I don't think so. That's my inclination in general in terms of, I've gone into various medical sampling tests and things over the years. When I'm asked by doctors or nurses or in a hospital if I'm willing to go into a test situation, I always say yes because I think it will do good for somebody if not for me. I tend to agree with trying anything that they suggest. Participant 012_2023AUDIS

I think I'm pretty trusting as a specialist and think they know what they're doing. I know you've got to advocate for yourself. If anything's not right, I have my list and I raise it at my appointments, trying to do the right thing. In regard to medication, I did at one point make an appointment and go and see the pharmacist, only because I was getting medications from different people and I wanted to make sure the combination of them and what time of day, can some be taken next to the others because there's so many. There's only so much during the day when you can take things. The pharmacist was good. I left a list and then went back and they said, yes, basically what I was doing was right, but I was a bit nervous about it. In regard to which medications, I trust them to be recommending [crosstalk].
Participant 017_2023AUDIS

I sort of put my hands in the doctor's hands because literally I don't know what else I can do because you know what I mean, what they sort of say, like I don't know what other, what other solutions there are, if you know what I mean…I've sort of asked questions, you know, why have I got it, all that kind of stuff…I think it's just bad luck of the draw kind of thing. So it's not hereditary, it's not something that you do. It's just literally, yeah. I've just caught it out of bad luck kind of thing. So yeah.
Participant 024_2023AUORC

Participant describes taking quality of life into account when making decisions about treatments (Total)

I think the impact that whatever I'm taking has on my health. Like obviously take Humira was I guess the big one, but I was….So the, the, the decision to take Humira was because I wanted to improve quality of life. Now I think there's an element of you know, quality over quantity and my, my quantity of quality of life at that time was not good at all. So my decision to take Humira was based on that.
Participant 001_2023AUDSK

Big side effects because there's a lot of treatments today that have a lot of side effects, and I have to weigh that up. I've already been on medication that has really affected me, and in the end, it had some negative results. I'm very well-informed now. I don't just sit there and take what's next. I just say, hang on a minute, how far is this going to take me, and is it really worth? I've always said to my doctors and physicians, whoever they are, I want quality of life, not quantity.I don't need to extend my life. I want to know that I'm going to enjoy my life. It's more important to me than ever. These last 30 years have taught me that. [laughs]
Participant 001_2023AUDIS

Quality of life, quality of life is because of effective treatment. So that I wouldn't say it's been a quality of life. It was just effectively treatment directly leads to quality of life improvement.
Participant 002_2023AUDSK

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

Now we've got way too much going on, so we're having to make some prioritizing what feels either most important for her at the moment or what we're actually able to manage as a family. We're looking at, particularly at this point, it's about the school readiness and trying to prioritize the things that we think will help her fit in and thrive most in that environment, and having some of the other things take a back seat a bit more. We're fortunate that cost hasn't particularly been a factor because we've had good NDIS plans throughout and relatively speaking, financially okay. Even though we pay a fortune in dental treatment, we haven't had to use cost as a factor to decide not to have treatment.
Participant 067_2023AUDPA

The impact on the family as a whole in terms of like how we're going to manage. Like for example, I think it would be really good for her to do a sleep study, but I've never been able to take like because neither of my children will sleep without me and my husband can't really manage things when I'm not here because he struggles with all the neurodiversities in the house that like, we just haven't been able to do it because she can't sleep at a hospital for five months. So there's, you know, family management, there's affordability, there's the impact. Participant 018_2023AUDPA

A lot of, a lot of change over the years. It sort of depends on what point in time. Our main consideration of course is, is this the right thing for NAME and it's going to benefit him. Not OK well, everyone is doing this. This is what we should do, or this is what someone's recommended. It's like, is this going to benefit him or is this going to distress him or is it going to distress him for a small amount of time until he gets used to it, which is a lot of therapy. And then it's going to better fit him long term or is it going to be too much of a mental battle for the family and for myself for him to do this therapy that may or may not work?
Participant 081_2023AUDIS

Participant describes taking amount of time needed for treatment and travel times into account when making decisions about treatments (Total)

Side effects, any known side effects that they have at that point? Her age, the life, the effect on her fertility and her liver and any organs that may be life limiting access to the trial because often these things are done in Melbourne and Sydney and we live a long way away from that and what would be expected from us in person or financially comes into it as well and things like that. So access and any additional outcomes that would be expected as a result of testing the drug or the procedure.
Participant 080_2023AUDIS

Affordability. Local access, you know, like I don't want to be, you know, go driving an hour and a half to get to the treatment center because I have to manage my stress around this condition.
Participant 027_2023AUORC

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

The convenience because I mean say, well at the moment I'm basically taking the one pill…I mean that there was a time when I was taking over 40 pills a day. So it comes down to you know how convenient is it going to be and it is it easy to maintain and that's that's what I found because I'm just on the the one pill basically it's, it's it's not a problem at all.
Participant 007_2023AUORC

Probably the biggest thing is not overloading him with with too much that we've we've done a lot but just been conscious that yes still a 5 year old boy. Yeah, yeah. Became a little bit overwhelming there for a while with him.
Participant 00_2023AUDPA

Okay. I take into consideration like what, what is you know, that is evidence based I guess. And that I take into consideration all PATIENT's comorbidities and whether those have been considered when they're talking about treatment options or medication options. Whether that's going to impact on her quality of life and her function and how difficult things might be for her to tolerate or to follow through. And I'll, I'll, I'll just sort of, I'll bring up these issues, I'll question them. I will you know on her behalf, you know she's always there and also I'll explain things in language that she understands to make sure she's understanding what's going on. But we would generally, you know, always follow through with recommendations by the doctors unless we feel that they're really against her. They're not sort of considering her as a whole person, if you know what I mean.
Participant 038_2023AUDPA

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

Mostly work. So if I have to go in hospital trying to work that around to go into work and then, if I'm doing a treatment that's just like normal medications and whatnot, that would be working that around work as well, that's pretty much what I work it around.
Participant 013_2023AUORC

So when I'm employed, I feel psychologically, I feel a lot better about myself because I couldn't get a job before the pandemic. I couldn't get a job, numerous job, so I couldn't get a job. And then the pandemic happened and suddenly oh, you know, much more attractive of proposition for employment and just crazy. So now I'm employed, I feel much better about, you know, making contribution, paying tax, paying my way. Yeah. So if I'd only do a drug trial as long as it didn't compromise my health, my, you know, my mobility and my financial security…
Participant 002_2023AUDPA

I guess if treatment is going to affect my general life, like work like, you know, the doxazosin in that I was too sick to eat, or surgery, like how long will it take to recover? Time of work, that kind of thing.
Participant 006_2023AUDSK

Participant describes taking their own research into account when making decisions about treatments (Total)

I think about what would, what will happen if I do take it, what would happen if I didn't take it, so I can assess that comparison. I think about what the side effects would be. I think about where I ask about what the interactions would be with other medications that I'm on. I think about…How I take it. So there was one medication that was suggested to me at one point that I would have to self inject into my stomach and it was kind of off putting. So yeah. And I also use the squirt and the Facebook quote to get some idea of other people's reactions to it or how they've found that as well if I have the time to go away and do some research. Yeah, look into what other people's experiences have been.
Participant 009_2023AUDIS

Yeah. So in terms of making the decisions, I guess the efficacy and I guess I do some research in terms of…You know, not very academic research I must say, but I will look at any research papers that you know just through a search through a search engine and what their results were and also you know the period of time that it was done. Like, was it done last couple of years or was it done 10 years ago? It was ten years ago. I would ignore it and also look at different sites and talk to my GP. Trust my GP enormously and, you know, really talking to professionals.
Participant 010_2023AUDIS

Well, I take on board what he says because I have no option. I also have done a lot of reading on reputable websites on the Internet about seeing medication that he suggests. My observation is that there is not a lot of leeway with what I've got. There is also a lot….fairly large question mark over surgery anyway, so but I've had it done. I'm here. So great.
Participant 003_2023AUDNS

Table 4.5 Considerations when making decisions

Considerations about treatment	**All participants**		**Developmental anomalies**		**Diseases of the immune system**		**Diseases of the nervous system**		**Diseases of the skin**		**Endocrine, nutritional or metabolic diseases**		**Other rare condition**		**Person with condition**		**Family or carer**		**Female**		**Male**	
	n=352	**%**	**n=352**	**%**	**n=81**	**%**	**n=45**	**%**	**n=32**	**%**	**n=95**	**%**	**n=32**	**%**	**n=247**	**%**	**n=105**	**%**	**n=252**	**%**	**n=98**	**%**
Ability to follow treatment (including accessibility) (Multiple)	31	8.81	5	7.46	5	6.17	7	15.56	1	3.23	9	9.47	4	12.90	21	8.50	10	9.52	22	8.73	9	9.18
Ability to follow treatment (including accessibility) (Single)	6	1.70	2	2.99	0	0.00	0	0.00	0	0.00	1	1.05	3	9.68	5	2.02	1	0.95	2	0.79	4	4.08
Ability to follow treatments (including accessibility) (Total)	37	10.51	7	10.45	5	6.17	7	15.56	1	3.23	10	10.53	**7**	**22.58**	26	10.53	11	10.48	24	9.52	13	13.27
Ability to work (Multiple)	13	3.69	3	4.48	0	0.00	3	6.67	4	12.90	2	2.11	1	3.23	8	3.24	5	4.76	9	3.57	4	4.08
Ability to work (Single)	3	0.85	0	0.00	1	1.23	0	0.00	0	0.00	0	0.00	2	6.45	2	0.81	1	0.95	2	0.79	1	1.02
Ability to work (Total)	16	4.55	3	4.48	1	1.23	3	6.67	4	12.90	2	2.11	3	9.68	10	4.05	6	5.71	11	4.37	5	5.10
Advice of their clinician (Multiple)	40	11.36	11	16.42	9	11.11	8	17.78	1	3.23	8	8.42	3	9.68	25	10.12	15	14.29	26	10.32	14	14.29
Advice of their clinician (Single)	52	14.77	**20**	**29.85**	11	13.58	7	15.56	**1**	**3.23**	12	12.63	**1**	**3.23**	28	11.34	24	22.86	36	14.29	16	16.33
Advice of their clinician (Total)	92	26.14	**31**	**46.27**	20	24.69	15	33.33	**2**	**6.45**	20	21.05	**4**	**12.90**	53	21.46	**39**	**37.14**	62	24.60	30	30.61
Amount of time needed/travel times (multiple)	19	5.40	8	11.94	1	1.23	1	2.22	3	9.68	3	3.16	3	9.68	8	3.24	11	10.48	11	4.37	8	8.16
Amount of time needed/travel times (single)	4	1.14	2	2.99	0	0.00	0	0.00	0	0.00	1	1.05	1	3.23	1	0.40	3	2.86	3	1.19	1	1.02
Amount of time needed/travel times (Total)	23	6.53	10	14.93	1	1.23	1	2.22	3	9.68	4	4.21	4	12.90	9	3.64	14	13.33	14	5.56	9	9.18
Cost (Multiple)	61	17.33	14	20.90	12	14.81	7	15.56	**12**	**38.71**	9	9.47	7	22.58	44	17.81	17	16.19	47	18.65	13	13.27
Cost (Single)	13	3.69	1	1.49	1	1.23	0	0.00	1	3.23	8	8.42	2	6.45	11	4.45	2	1.90	9	3.57	3	3.06
Cost (total)	74	21.02	15	22.39	13	16.05	7	15.56	**13**	**41.94**	17	17.89	9	29.03	55	22.27	19	18.10	56	22.22	16	16.33
Efficacy (Multiple)	110	31.25	26	38.81	23	28.40	16	35.56	8	25.81	26	27.37	11	35.48	73	29.55	37	35.24	72	28.57	37	37.76
Efficacy (Single)	26	7.39	3	4.48	9	11.11	0	0.00	2	6.45	12	12.63	0	0.00	22	8.91	4	3.81	21	8.33	5	5.10
Efficacy (Total)	136	38.64	29	43.28	32	39.51	16	35.56	10	32.26	38	40.00	11	35.48	95	38.46	41	39.05	93	36.90	42	42.86
Impact on their family or dependents (Multiple)	23	6.53	5	7.46	4	4.94	0	0.00	2	6.45	10	10.53	2	6.45	13	5.26	10	9.52	15	5.95	8	8.16
Impact on their family or dependents (Single)	9	2.56	0	0.00	3	3.70	0	0.00	0	0.00	6	6.32	0	0.00	7	2.83	2	1.90	8	3.17	1	1.02
Impact on their familiy or dependents (Total)	32	9.09	5	7.46	7	8.64	0	0.00	2	6.45	16	16.84	2	6.45	20	8.10	12	11.43	23	9.13	9	9.18
Own research (Multiple)	14	3.98	2	2.99	3	3.70	1	2.22	3	9.68	1	1.05	4	12.90	11	4.45	3	2.86	10	3.97	4	4.08
Own research (Single)	6	1.70	0	0.00	1	1.23	1	2.22	0	0.00	3	3.16	1	3.23	5	2.02	1	0.95	5	1.98	1	1.02
Own research (Total)	20	5.68	2	2.99	4	4.94	2	4.44	3	9.68	4	4.21	**5**	**16.13**	16	6.48	4	3.81	15	5.95	5	5.10
Quality of life (Multiple)	49	13.92	11	16.42	10	12.35	**0**	**0.00**	5	16.13	15	15.79	**8**	**25.81**	30	12.15	19	18.10	30	11.90	19	19.39
Quality of life (Single)	10	2.84	0	0.00	4	4.94	0	0.00	2	6.45	4	4.21	0	0.00	8	3.24	2	1.90	10	3.97	0	0.00
Quality of life (Total)	59	16.76	11	16.42	14	17.28	**0**	**0.00**	7	22.58	19	20.00	8	25.81	38	15.38	21	20.00	40	15.87	19	19.39
Side effects (Multiple)	133	37.78	25	37.31	33	40.74	17	37.78	12	38.71	32	33.68	14	45.16	88	35.63	45	42.86	94	37.30	38	38.78
Side effects (Single)	30	8.52	1	1.49	13	16.05	4	8.89	3	9.68	8	8.42	1	3.23	28	11.34	2	1.90	27	10.71	3	3.06
Side effects (Total)	163	46.31	26	38.81	**46**	**56.79**	21	46.67	15	48.39	40	42.11	15	48.39	116	46.96	47	44.76	121	48.02	41	41.84

Considerations about treatment	**All participants**		**Aged under 18**		**Aged 18 to 44**		**Aged 45 to 64**		**Aged 65 plus**		**Trade or high school**		**University**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=352	**%**	**n=69**	**%**	**n=116**	**%**	**n=108**	**%**	**n=59**	**%**	**n=172**	**%**	**n=172**	**%**	**n=100**	**%**	**n=252**	**%**	**n=176**	**%**	**n=176**	**%**
Ability to follow treatment (including accessibility) (Multiple)	31	8.81	1	1.45	3	2.59	1	0.93	1	1.69	1	0.58	5	2.91	1	1.25	5	1.98	2	1.14	4	2.27
Ability to follow treatment (including accessibility) (Single)	6	1.70	6	8.70	14	12.07	11	10.19	6	10.17	19	11.05	17	9.88	9	11.25	28	11.11	18	10.23	19	10.80
Ability to follow treatments (including accessibility) (Total)	37	10.51	3	4.35	5	4.31	4	3.70	1	1.69	4	2.33	9	5.23	5	6.25	8	3.17	7	3.98	6	3.41
Ability to work (Multiple)	13	3.69	1	1.45	1	0.86	0	0.00	1	1.69	2	1.16	1	0.58	0	0.00	3	1.19	0	0.00	3	1.70
Ability to work (Single)	3	0.85	4	5.80	6	5.17	4	3.70	2	3.39	6	3.49	10	5.81	5	6.25	11	4.37	7	3.98	9	5.11
Ability to work (Total)	16	4.55	8	11.59	13	11.21	9	8.33	10	16.95	18	10.47	22	12.79	9	11.25	31	12.30	21	11.93	19	10.80
Advice of their clinician (Multiple)	40	11.36	15	21.74	18	15.52	11	10.19	8	13.56	25	14.53	26	15.12	12	15.00	40	15.87	26	14.77	26	14.77
Advice of their clinician (Single)	52	14.77	23	33.33	31	26.72	20	18.52	18	30.51	43	25.00	48	27.91	21	26.25	71	28.17	47	26.70	45	25.57
Advice of their clinician (Total)	92	26.14	9	13.04	4	3.45	3	2.78	3	5.08	10	5.81	9	5.23	4	5.00	15	5.95	14	7.95	5	2.84
Amount of time needed/travel times (multiple)	19	5.40	3	4.35	1	0.86	0	0.00	0	0.00	1	0.58	3	1.74	2	2.50	2	0.79	2	1.14	2	1.14
Amount of time needed/travel times (single)	4	1.14	**12**	**17.39**	5	4.31	3	2.78	3	5.08	11	6.40	12	6.98	6	7.50	17	6.75	16	9.09	7	3.98
Amount of time needed/travel times (Total)	23	6.53	11	15.94	24	20.69	20	18.52	6	10.17	33	19.19	27	15.70	18	22.50	43	17.06	34	19.32	27	15.34
Cost (Multiple)	61	17.33	1	1.45	3	2.59	5	4.63	4	6.78	7	4.07	6	3.49	4	5.00	9	3.57	5	2.84	8	4.55
Cost (Single)	13	3.69	12	17.39	27	23.28	25	23.15	10	16.95	40	23.26	33	19.19	22	27.50	52	20.63	39	22.16	35	19.89
Cost (total)	74	21.02	25	36.23	38	32.76	30	27.78	17	28.81	48	27.91	62	36.05	32	40.00	78	30.95	45	25.57	65	36.93
Efficacy (Multiple)	110	31.25	3	4.35	6	5.17	10	9.26	7	11.86	11	6.40	15	8.72	8	10.00	18	7.14	11	6.25	15	8.52
Efficacy (Single)	26	7.39	28	40.58	44	37.93	40	37.04	24	40.68	59	34.30	77	44.77	**40**	**50.00**	96	38.10	56	31.82	80	45.45
Efficacy (Total)	136	38.64	6	8.70	8	6.90	5	4.63	4	6.78	10	5.81	12	6.98	6	7.50	17	6.75	13	7.39	10	5.68
Impact on their family or dependents (Multiple)	23	6.53	1	1.45	4	3.45	4	3.70	0	0.00	6	3.49	3	1.74	4	5.00	5	1.98	5	2.84	4	2.27
Impact on their family or dependents (Single)	9	2.56	7	10.14	12	10.34	9	8.33	4	6.78	16	9.30	15	8.72	10	12.50	22	8.73	18	10.23	14	7.95
Impact on their familiy or dependents (Total)	32	9.09	2	2.90	5	4.31	7	6.48	0	0.00	7	4.07	7	4.07	3	3.75	11	4.37	7	3.98	7	3.98
Own research (Multiple)	14	3.98	0	0.00	3	2.59	1	0.93	2	3.39	3	1.74	3	1.74	2	2.50	4	1.59	2	1.14	4	2.27
Own research (Single)	6	1.70	2	2.90	8	6.90	8	7.41	2	3.39	10	5.81	10	5.81	5	6.25	15	5.95	9	5.11	11	6.25
Own research (Total)	20	5.68	14	20.29	10	8.62	13	12.04	12	20.34	20	11.63	26	15.12	17	21.25	32	12.70	17	9.66	32	18.18
Quality of life (Multiple)	49	13.92	1	1.45	1	0.86	6	5.56	2	3.39	3	1.74	6	3.49	2	2.50	8	3.17	3	1.70	7	3.98
Quality of life (Single)	10	2.84	15	21.74	11	9.48	19	17.59	14	23.73	23	13.37	32	18.60	19	23.75	40	15.87	20	11.36	39	22.16
Quality of life (Total)	59	16.76	30	43.48	49	42.24	37	34.26	17	28.81	65	37.79	66	38.37	36	45.00	97	38.49	61	34.66	72	40.91
Side effects (Multiple)	133	37.78	2	2.90	14	12.07	11	10.19	3	5.08	18	10.47	12	6.98	12	15.00	18	7.14	18	10.23	12	6.82
Side effects (Single)	30	8.52	32	46.38	63	54.31	48	44.44	**20**	**33.90**	83	48.26	78	45.35	**48**	**60.00**	115	45.63	79	44.89	84	47.73
Side effects (Total)	163	46.31	2	2.90	4	3.45	1	0.93	7	11.86	12	6.98	2	1.16	4	5.00	10	3.97	8	4.55	6	3.41

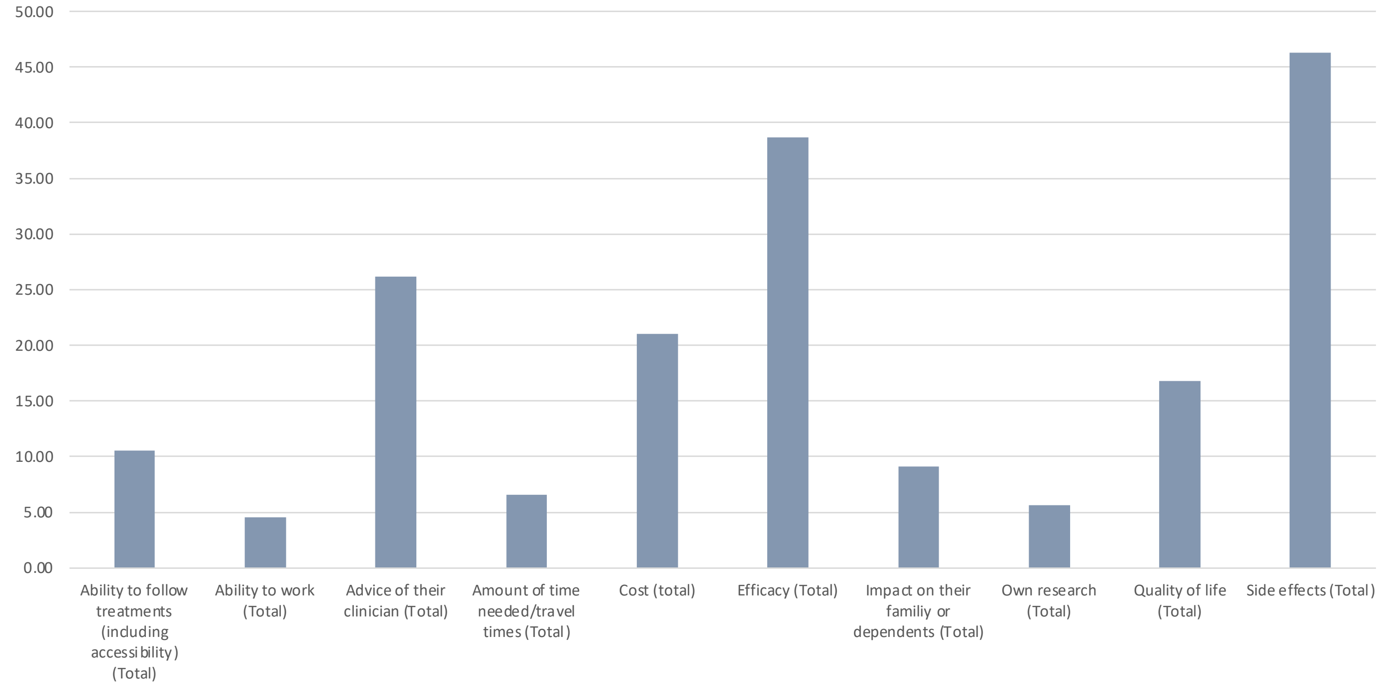

Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Ability to follow treatment (including accessibility) (Multiple)		
Ability to follow treatment (including accessibility) (Single)		
Ability to follow treatments (including accessibility) (Total)		Other rare condition
Ability to work (Multiple)		
Ability to work (Single)		
Ability to work (Total)		
Advice of their clinician (Multiple)		
Advice of their clinician (Single)	Diseases of the skin Other rare condition	Developmental anomalies
Advice of their clinician (Total)	Diseases of the skin Other rare condition	Developmental anomalies Family or carer
Amount of time needed/travel times (multiple)		
Amount of time needed/travel times (single)		
Amount of time needed/travel times (Total)		Aged under 18
Cost (Multiple)		Diseases of the skin
Cost (Single)		
Cost (total)		Diseases of the skin
Efficacy (Multiple)		
Efficacy (Single)		
Efficacy (Total)		Regional or remote
Impact on their family or dependents (Multiple)		
Impact on their family or dependents (Single)		
Impact on their familiy or dependents (Total)		
Own research (Multiple)		
Own research (Single)		
Own research (Total)		Other rare condition
Quality of life (Multiple)	Diseases of the nervous system	Other rare condition
Quality of life (Single)		
Quality of life (Total)	Diseases of the nervous system	
Side effects (Multiple)		
Side effects (Single)		
Side effects (Total)	Aged 65 plus	Diseases of the immune system Regional or remote

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 201 participants (57.10%) that had changed the way they make decisions, and 110 participants (31.25%) had not changed the way they make decisions.

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (23.01%), more aware of their health, responsibilities and/or limitations (10.80%), and more cautious and considered (8.24 %). Other themes included more focused impact on quality of life (5.40%).

Where participants had not changed the way they make decisions, the most common reason was that they had always been informed/assertive (6.25%).

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

No, very different. I'm a lot more informed now, and I understand my condition. I was struggling to cope with it at first. I didn't understand what was happening and I didn't know the outcome. I didn't know how it was going to end. Whereas now I'm a lot more informed. When the neurologist, we spoke about trying this new Botox, he made sure he had all the information there for me and then we decided that together. He put it forward. I think that I'm a lot more informed. Before I just went with whatever. If they said, "Go to this doctor and see this doctor," that's what I did. Whereas now, because I'm a lot more informed, I would never go to a neurologist that did not have the nerve conductivity equipment or just treated by just pure injection. I wouldn't do…I've got enough information for myself now to be able to make that decision.
Participant 006_2023AUDNS

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 032_2023AUORC

Yes. Look, I just think I have got a lot more agency now. I just feel like now the ball is in my court a lot more than what it was. I suppose I'm more knowledgeable. I feel like when I'm discussing things with the doctors now it's more of an equal level after a team rather than just sitting there being passive. It's probably changed in that respect.
Participant 054_2023AUDPA

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

Changed over time in the sense of from the what you… things like that, you know, as you grow older, you start to monitor your diet and your exercise, you know, and things like that, and actually try to do things to to keep yourself fit and healthy, I suppose when you're young, you think differently.
Participant 14_2023AUORC

No, no, no. I 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_2023AUORC

Changing over time as they are more cautious and considered

Yeah, I think so. Yeah. I'm a little bit more cautious of some, what's in things, do I need to do it, that sort of thing. Yeah, yeah. And what…Yeah, how it's going to affect me? Yeah.
Participant 019_2023AUDIS

Yes, I'm sure it changed a lot because there's a lot more to take into consideration now. Yeah, I'm not, I'm not sure just say how my decision making's changed, but I'm sure it has changed just based on all the experiences. That we've had and the many more things that I have to take into consideration now when making most decisions. Yeah, I mean, even simple things like going on a holiday somewhere is much more complex than it used to be. So it involves, but I can't just make, make the decision that I would have made previously that, okay, I've got a holiday. There's a lot of other things that will be involved in trying to make it easier and make it work better... So yeah, I'd say a lot of things have changed with my decision making.
Participant 089_2023AUENM

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

I think my decision making process will have changed over time because it will have adapted to what is needed at that current point in time by the family and with the growing needs of the boys. So yeah, I feel it probably has changed, but it's still all vary based on PARTICIPANT.
Participant 036_2023AUDPA

Big time. It's changed. Yeah. I mean, initially it was my first child and it was a disease I've never heard of before in my life. So I could only do what the doctors suggested because I was terrified. But now I think about it when we're having a conversation and I asked them questions and I consider it for my family. If I have, you know, the opportunity, I'll try and do some research. If there's anything to research so that I can ask more informed questions, yeah. So I think it's changed definitely from just kind of doing what is suggested.
Participant 021_2023AUORC

Changing over time as their child gets older they take a greater part in decision making

I obviously didn't make any decisions until I was probably 15 or 16. Most of that was Mum and Dad. And then I was mum 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 18, 19 it's up to me. But most of my decision making is pretty straightforward. It's do I basically keep staying with 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 030_2023AUORC

No, I would say it's changed. I just think, well, I mean now for example, she can actually weigh in and, you know, give us an indication of how she feels about a particular therapist or a particular doctor or, you know, whereas when she was a baby, we just were kind of head spinning, shooting in the dark, just trying to figure out what to do and, you know, kind of just feeling like, Oh my God, every decision is so critical. It's so life and death. Whereas now it often feels a little bit more like. There's time to just kind of figure it out right and constantly be in such a like frantic panic.
Participant 018_2023AUDPA

Changing over time as they are more accepting of their condition and choices available (however not by choice)

This might sound really bad. I'm probably not as optimistic about things as to having like.. I think people sell it to you that things are going to rapidly improve. And so perhaps I'm a little bit more not pessimistic, it's not the right word, but a bit more realistic I guess. Yeah, Okay, yeah.
Participant 020_2023AUDPA

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 make a decision by doing my research.
Participant 010_2023AUORC

I'll make decisions the same way, something that no… I think there was a couple of things that didn't agree with me, which I then spoke up and said no, don't you know, I don't think this...
Participant 005_2023AUDIS

Look, I still think I make decisions in the same way, which is to get lots of different views and to get lots of different information and decide whether I trust the professional, whether the professional has expertise in that area, whether there's other evidence that supports that, you know, idea of treatments.
Participant 010_2023AUDIS

Table 4.7: Decision-making over time

Decision-making over time	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=352	%	n=352	%	n=81	%	n=45	%	n=32	%	n=95	%	n=32	%	n=247	%	n=105	%	n=252	%	n=98	%
Change	201	57.10	35	52.24	50	61.73	29	64.44	19	59.38	**42**	**44.21**	**26**	**83.87**	143	57.89	58	55.24	148	58.73	51	52.04
No change	110	31.25	16	23.88	27	33.33	10	22.22	11	34.38	38	40.00	8	25.81	81	32.79	29	27.62	82	32.54	28	28.57

Decision-making over time	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=352	%	n=69	%	n=116	%	n=108	%	n=59	%	n=172	%	n=172	%	n=100	%	n=252	%	n=176	%	n=176	%
Change	201	57.10	44	63.77	64	55.17	66	61.11	**27**	**45.76**	92	53.49	107	62.21	**59**	**73.75**	142	56.35	99	56.25	102	57.95
No change	110	31.25	15	21.74	40	34.48	32	29.63	23	38.98	65	37.79	43	25.00	29	36.25	81	32.14	58	32.95	52	29.55

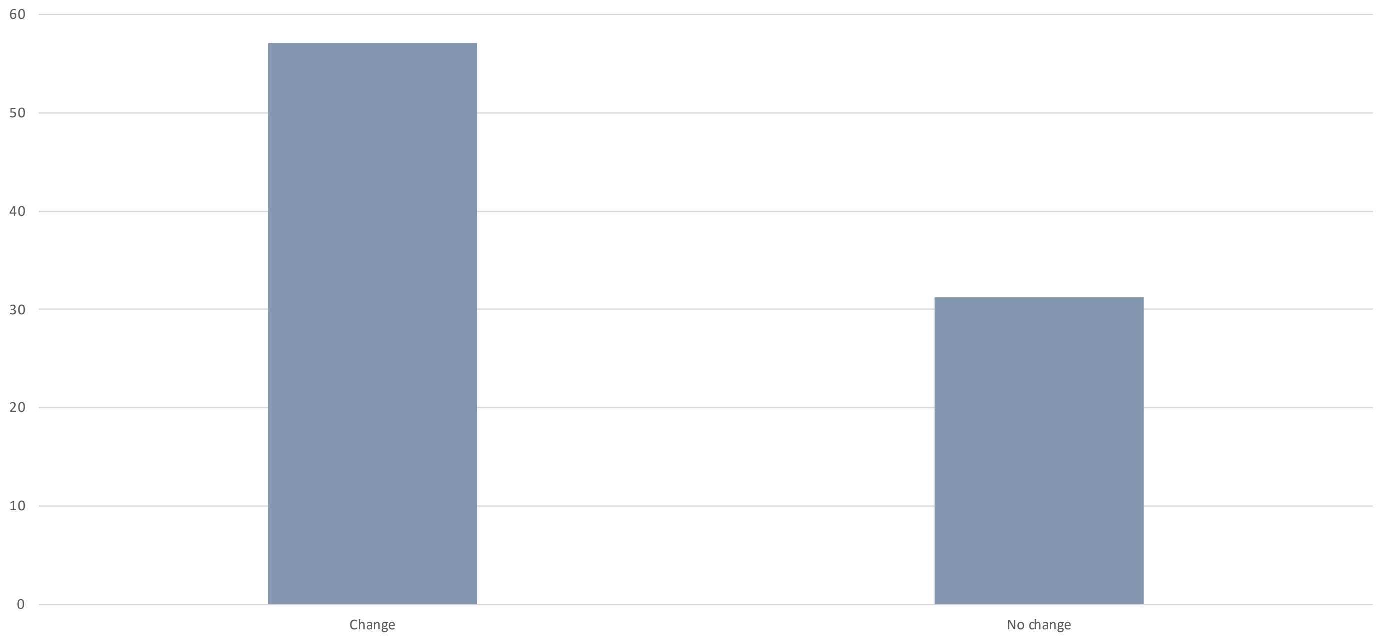

Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Theme	Reported less frequently	Reported more frequently
Change	Endocrine, nutritional or metabolic diseases Aged 65 plus	Other rare condition Regional or remote
No change		

Table 4.9: Decision-making over time (Reasons)

Decision-making over time (reasons)	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=352	%	n=352	%	n=81	%	n=45	%	n=32	%	n=95	%	n=32	%	n=247	%	n=105	%	n=252	%	n=98	%
Changing over time as they are more informed and/or more assertive	81	23.01	14	20.90	19	23.46	13	28.89	4	12.50	23	24.21	8	25.81	58	23.48	23	21.90	60	23.81	21	21.43
Changing over time as they are more aware of their health, responsibilities and/or limitations	38	10.80	5	7.46	5	6.17	7	15.56	7	21.88	5	5.26	9	29.03	26	10.53	12	11.43	22	8.73	14	14.29
Changing over time as they are more cautious and considered	29	8.24	4	5.97	16	19.75	2	4.44	2	6.25	3	3.16	2	6.45	22	8.91	7	6.67	28	11.11	1	1.02
Changing over time as they are more focused on quality of life or impact of side effects	19	5.40	3	4.48	3	3.70	2	4.44	2	6.25	9	9.47	0	0.00	13	5.26	6	5.71	13	5.16	6	6.12
No change in decision-making over time and there is no particular reason noted	54	15.34	5	7.46	8	9.88	8	17.78	8	25.00	19	20.00	6	19.35	42	17.00	12	11.43	38	15.08	16	16.33
No change in decision-making over time as they have always been informed/assertive	22	6.25	5	7.46	7	8.64	1	2.22	1	3.13	7	7.37	1	3.23	14	5.67	8	7.62	17	6.75	5	5.10

Decision-making over time (reasons)	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=352	%	n=69	%	n=116	%	n=108	%	n=59	%	n=172	%	n=172	%	n=100	%	n=252	%	n=176	%	n=176	%
Changing over time as they are more informed and/or more assertive	81	23.01	17	24.64	27	23.28	27	25.00	10	16.95	35	20.35	46	26.74	21	26.25	60	23.81	40	22.73	41	23.30
Changing over time as they are more aware of their health, responsibilities and/or limitations	38	10.80	9	13.04	11	9.48	11	10.19	7	11.86	19	11.05	18	10.47	15	18.75	23	9.13	23	13.07	15	8.52
Changing over time as they are more cautious and considered	29	8.24	6	8.70	12	10.34	8	7.41	3	5.08	17	9.88	12	6.98	6	7.50	23	9.13	15	8.52	14	7.95
Changing over time as they are more focused on quality of life or impact of side effects	19	5.40	2	2.90	6	5.17	6	5.56	5	8.47	10	5.81	8	4.65	6	7.50	13	5.16	6	3.41	13	7.39
No change in decision-making over time and there is no particular reason noted	54	15.34	8	11.59	23	19.83	15	13.89	8	13.56	34	19.77	20	11.63	13	16.25	41	16.27	28	15.91	26	14.77
No change in decision-making over time as they have always been informed/assertive	22	6.25	3	4.35	6	5.17	6	5.56	7	11.86	7	4.07	13	7.56	6	7.50	16	6.35	9	5.11	13	7.39

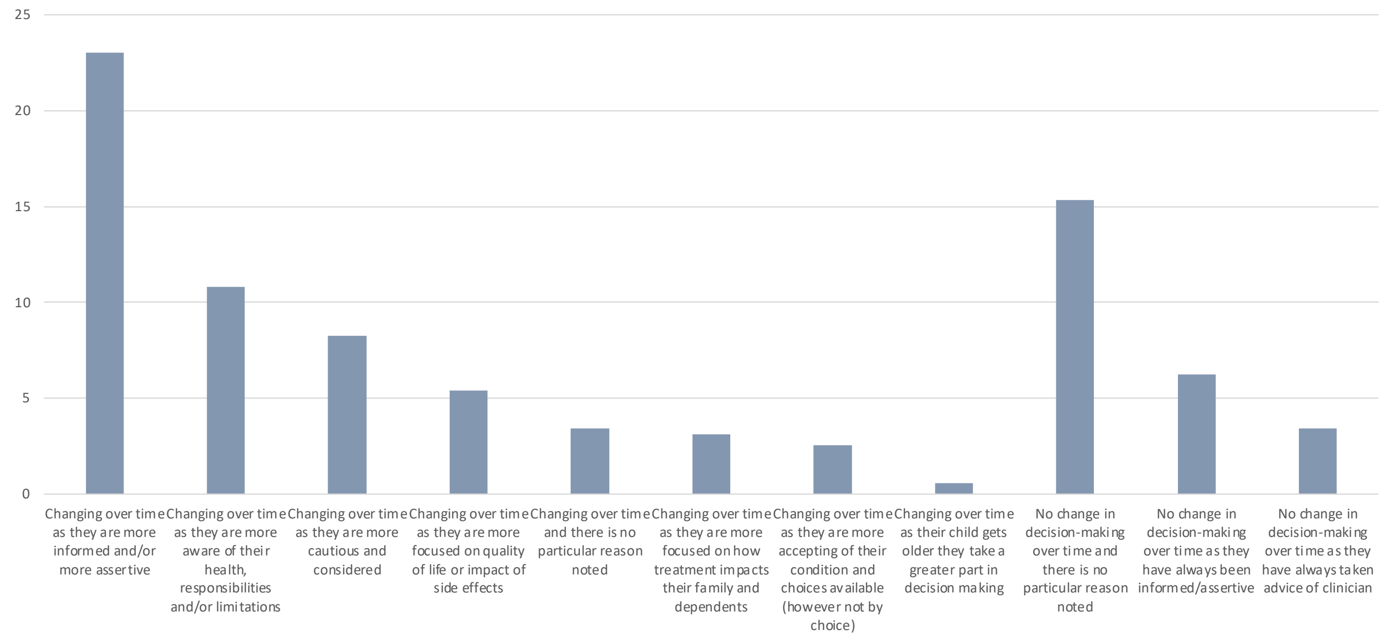

Figure 4.5: Decision-making over time (Reasons)

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	Diseases of the skin	
Changing over time as they are more aware of their health, responsibilities and/or limitations		Diseases of the skin Other rare condition
Changing over time as they are more cautious and considered		Diseases of the immune system
Changing over time as they are more focused on quality of life or impact of side effects	-	
No change in decision-making over time and there is no particular reason noted	-	
No change in decision-making over time as they have always been informed/assertive	-	

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 have quality of life/return to normality (22.56%), to maintain their condition or prevent worsening of their condition (19.55%), and have physical improvements in their condition (18.05 %). Other themes included the ability to live independently (13.53%) and wanting to minimise or avoid side effects (8.27%).

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

Yeah, it is. It's just to make his everyday life easier. Like we know even I haven't entered the physiotherapy side of things but, but you can tell when he hasn't done them. So our personal goal is to I guess get him to that, to be as healthy as he can be. So I can enjoy things you know, life as much as he can. That's pretty much our goal is just to make his life as easy as possible. And keep him health and his body as healthy as possible.
Participant 020_2023AUORC

Quality of life. Because I have things like central sleep apnea and digestive issues. I'm literally sleeping 16 hours a day and in extreme pain. And the more I do, the more I hurt. And yeah, it's it's like a catch 22 at the moment. So my quality of life is very poor and I'm very frustrated because I want to help myself, but no one's helping me. I, I would love to go back to work and I would love to. I'm happy to risk surgery. Whether it's going to have poor outcomes or not, it's my chance to have a better quality of life and I feel I should be able to sign a waiver to say I waive my right for something to go wrong. I, I accept that it can go wrong, but I want it done anyway and I'm not allowed to do that. But they could fix my back. I've got pinched nerves and bulging discs and bilaterally messed up back, and they could fix that. But they won't, because the risks too high. My neurologist won't do nerve biopsies because he's worried he'll disable me. But that's the only way I can get an answer.
Participant 016_2023AUDIS

Yeah, as as normal a life as possible.
Participant 015_2023AUDPA

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

Oh look, I'd like to just get back to what I was before. For which started 2 1/2 years ago, at least close to it. I mean, the way I understand most of these things is they're not fixable, but they are manageable. And unfortunately, yeah, my, my management that I had unbeknownst to me already been doing got thrown into disarray and, and it's got on top of me a bit. But yeah, look my, my, I'm hoping I'm going to get back to almost normal again. Yeah, okay.
Participant 014_2023AUORC

I guess is really will become more independent. I guess it's the main goal and I guess stronger in terms of if there is going to be regression, we want to make her as strong as can be. So that's really the goal of therapy, yeah.
Participant 016_2023AUORC

Yeah, I guess I have a lot of side effects of treatment and I have to see other conditions as well and probably more than HS does alone. So I guess it's just management of everything more than anything. I think I'd like to be able to manage without it progressing too much worse and being able to manage whatever treatment I'm on.
Participant 019_2023AUDSK

Participants describe wanting to see physical improvements in their condition

I'd like to be more flexible and we did talk about with rheumatologist the fact that this condition causes you to have I call them elastic bands, okay, my rubber bands, they stretch out but they but they spring back and I I want something that will help me stretch them and keep them that way rather than this constant daily battle exercise that I have of going out and doing things and then the next day, I call it climbing Mount Everest, I wake up in the morning, I have to climb Mount Everest, and then tomorrow when I wake up, I have to climb it all over again. So that's that's what I want. I want that strength is not an issue. I can, you know, do weights and that sort of thing. It's that flexibility, tightness issue that bothers me.
Participant 003_2023AUDIS

Well, I my, my emphasis is to have less attacks. I know I think eventually I'm going to have to move to a warmer climate because I know that like I'm loving the, I love the hot weather. And I feel my body heals in the warmth. I have less you know I my fingertips don't ulcerate as much obviously less Raunaud's attacks and you… if with the less Raunaud's attacks I don't get the ulcers. So I just want to yeah I just want to have my goal is to yeah have less Raunaud's attacks because they're that's what I'm really struggling with.
Participant 015_2023AUDIS

Yes. So for me, I guess as a parent, my goal is just to allow my child to be a child as much as possible, so that's managing their condition the best way that I know how, with the information that I've got and the resources that I've got. But also, you know, focusing on the, I guess, the things that my son can do, I do have him, you know, attends different therapies to help improve his functioning, like his physical functioning or his gross motor. But I don't put a lot of pressure on him or on myself to achieve a certain goal because, you know, he's an individual. So I just want him to do the best that he can. But at the same time, you know, he's a kid, he needs to be a child. So I don't really know if that answers your question, but I try not to get too caught up in the shoulds or musts or if.
Participant 021_2023AUORC

Participant describes wanting to live independently

My goals are for her to be independent, like learn independent life skills that will help her when she is older and if no one is around, which won't be the case for a long time but I still would like her to think that she could have a job in a normal life and her own home if she wanted it. That's the most important thing to me.
Participant 013_2023AUDPA

PARTICIPANT: Everything really OK could be able to be, you know, obviously function you know society and, and making sure that he's, you know, I, like he's learning to the best of his ability and getting the support he needs with that. Yeah, you know and, you know, then grow into an independent, you know, adult.
INTERVIWER: Yep. So, yeah. Yep. Excellent. So have you had that sort of discussion about those goals with your permission?
PARTICIPANT: Well, yeah, I guess so. On and off. But I mean, at the moment, because he's still young and obviously needs support, there's not a lot, you know, that can be done at the moment, you know, apart from, I mean, some psychological support just with behavior and stuff. But yeah, there's not a lot more that at the moment we can do.
Participant 014_2023AUDPA

I guess our our goals for her she doesn't have like other than occupational therapy and speech therapy, there's no other treatment involved in her care at the moment, but she's not on any medication or there's no other ongoing things. So I guess her main goals that we have for her, you know, is to make her as prepared and capable to deal with, you know, the rest of her life and and set her up to be as functioning adult as she possibly can be.
Participant 027_2023AUDPA

Participant describes wanting to be less reliant on medication and to avoid hospitalisation

I just don't want to be on medication for the rest of my life. I keep trying to come off it myself, but it's not the best idea.
Participant 078_2023AUDIS

PARTICIPANT: My goal was just to stay out of hospital more, I guess.
INTERVIEWER: Okay, have you had a discussion about this with your clinician?
PARTICIPANT: Yes. Well, I certainly want to go to the hospital. Yeah. And I wanted to try to start a family this year. I was speaking to them about that recently.
Participant 013_2023AUORC

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

My personal is more…obviously, to be well-informed, but the treatment is certainly helping me now in making sure that I can walk and be physically fit. That's a big one because I've got to keep myself active. The other one is obviously to stop some of these issues in my body from affecting me and particularly in the cold, of course. It doesn't actually have to be cold. It's actually the first day of summer today, and it's actually cold.[laughter]
Participant 001_2023AUDIS

Nice to get them. Like, honestly, just get the pain to stop.
Participant 004_2023AUDSK

I think my main goal is to figure out how to work with bandaging, because I'm allergic to pretty much all adhesives, regardless of whether they contain silicone or allergen friendly or whatever it may be.
Participant 014_2023AUDSK

Participant describes wanting improvements in communication and engagement on community or school

Yeah, look better have the ability to self determine what she wants to do with her life and to be able to communicate that to the people around her and be able to access the appropriate support as, and when she needs it. But you know, basically for her to feel part of society and loved and have a good and happy life, same as for my other daughter.
Participant 018_2023AUDPA

There are multiple avenues of support that is required across the whole lifespan. So we were seeing up to 12 specialists for him…sometimes two or three a week. They come to my home or I'd be going to see specialists. And so life was very, very busy. I had a husband, I had a kid and I also was working from home and 18, you know. So I'm getting him onto eating properly or being [unintelligible] or doing speech therapy. We couldn't do it all and so I probably sacrificed some of his ability to eat safely and speech therapy by putting more energy into learning sign language and having him, helping him to to learn a total communication approach to life. I don't regret that in one little bit. But what I do know now is that he probably will never have a very safe swallow, to ever eat fully anyway. So if we would have to have pushed down that road or 18 normally, like everybody else, he would have been in hospital more times than he had been in the first five years. That would be gradually reducing over those years from, you know, five times a year to three times a year. So it was the right choice to make for us. Yeah, but this is what families are faced with the pressures of of my child must speak, my child must speak. What else? It's something, something will be sacrificed to meet that fully, that goal fully. So anything else that we did for goals, I think that's probably enough as an example from for for me.
Participant 028_2023AUORC

At the moment it's working on trying to increase her ability with speech and talking and language and being able to do things for herself. So you get a bit more independent and confident with that.
Participant 010_2023AUDPA

Participant describes wanting to see mental or emotional health improvements in their condition

Currently, I'm going to do everything I possibly can to keep myself healthy, fit, and eat well since my goal is to survive and get through this. I have to remain positive. Otherwise, I'm going to be like a little-- my other friends that have it and I don't want to get depressed. I'm just going to fight, keep fighting.
Participant 007_2023AUDIS

So our personal goals would be that he feels fulfilled in employment, that he feels like a valued member of society and that he is contributing in some way, but also has good mental health and some stress and pressures taken off him so that he feels that he is secure in his own living arrangements. So you know basically it's going to be at home with us for at least the next 10 years and then you know sort of working towards that independent living and and what that will look like we don't really know all.
Participant 022_2023AUDPA

Yeah sure. So with obviously with the the varying, the varying ailments or symptoms that that comes along with 22Q deletion you there's specific things. So we've wiped out a bunch of them already that she does, isn't affected by, but the ones moving forward, she has a thyroid disease. So I want her to be able to be able to get access to people readily and easily that can help her manage that because what happens when we're gone, she's got to have some some way of managing that. And also her, her psychiatric medication, for instance. We need to find something and people and professionals that know how to prescribe medicine properly to people with intellectual disabilities and not just throw drugs at them that are going to make them drowsy the whole time just you know subdue their personalities and things like that. It it's a bit…and there's a lot of autism and ADHD in in 22 Q as well. So there's a lot of all that's just sort of Ritalin outcome and this but that, that has massive side effects and that can also affect her personal life in social skills and ability to communicate as well. So they, they're the things I I want to say. I want to say her be able to access in my head a clinic of some sort…whereas coordinated approach, where they look at all the different sides of it, medically, socially, psychologically that that would be my ultimate goal and geez, wouldn't it be lovely if we could all have that.
Participant 025_2023AUDPA

Participant describes wanting to returning to work

So now, I mean, even back then, it was about finding answers. That was a goal. Finding answers, finding treatment, finding support, finding a therapist. Because back then we didn't have therapy money, you know, we just had nothing. And finding bowel support, finding enemas, you know, like finding help with all this. There's no continence nurses back then, but now his main goals are to be safe. Because he's not safe unless he's supported well to be healthy, and he's not healthy ever. So we aim to keep him to the best health as possible and to be have a healthy. So it's basically safe, healthy and happy and to have a meaningful day. So we've got four goals, but there's some other goals in NDIS land as well. You know about that, building his functional capacity to the best of his abilities. To ensure he has a meaningful day through social participation, civic and community access and economic participation. And he doesn't have a job, but I've certainly set up something for him with a ABN.
Participant 006_2023AUDPA

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 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 031_2023AUORC

Table 4.11: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=266	%	n=67	%	n=81	%	n=45	%	n=32	%	n=9	%	n=32	%	n=176	%	n=90	%	n=200	%	n=64	%
Quality of life/return to normality	60	22.56	11	16.42	23	28.40	**4**	**8.89**	**11**	**34.38**	2	22.22	9	28.13	44	25.00	16	17.78	47	23.50	13	20.31
Maintain their condition/prevent worsening of their condition	52	19.55	**2**	**2.99**	17	20.99	11	24.44	**10**	**31.25**	1	11.11	**11**	**34.38**	44	25.00	**8**	**8.89**	40	20.00	11	17.19
Physical improvements in their condition	48	18.05	10	14.93	12	14.81	11	24.44	8	25.00	**0**	**0.00**	7	21.88	33	18.75	15	16.67	36	18.00	11	17.19
Live independently	36	13.53	**16**	**23.88**	10	12.35	6	13.33	**0**	**0.00**	2	22.22	2	6.25	17	9.66	19	21.11	31	15.50	5	7.81
Minimise or avoid side effects	22	8.27	1	1.49	7	8.64	6	13.33	5	15.63	0	0.00	3	9.38	21	11.93	1	1.11	20	10.00	2	3.13

Personal goals of treatment or care	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=266	%	n=66	%	n=102	%	n=76	%	n=22	%	n=132	%	n=134	%	n=75	%	n=191	%	n=143	%	n=123	%
Quality of life/return to normality	60	22.56	14	21.21	17	16.67	24	31.58	5	22.73	31	23.48	29	21.64	23	30.67	37	19.37	41	28.67	19	15.45
Maintain their condition/prevent worsening of their condition	52	19.55	**5**	**7.58**	23	22.55	20	26.32	4	18.18	24	18.18	28	20.90	16	21.33	36	18.85	31	21.68	21	17.07
Physical improvements in their condition	48	18.05	12	18.18	10	9.80	14	18.42	**12**	**54.55**	24	18.18	24	17.91	12	16.00	36	18.85	29	20.28	19	15.45
Live independently	36	13.53	10	15.15	15	14.71	9	11.84	2	9.09	14	10.61	22	16.42	9	12.00	27	14.14	21	14.69	15	12.20
Minimise or avoid side effects	22	8.27	1	1.52	10	9.80	9	11.84	2	9.09	10	7.58	12	8.96	3	4.00	19	9.95	11	7.69	11	8.94

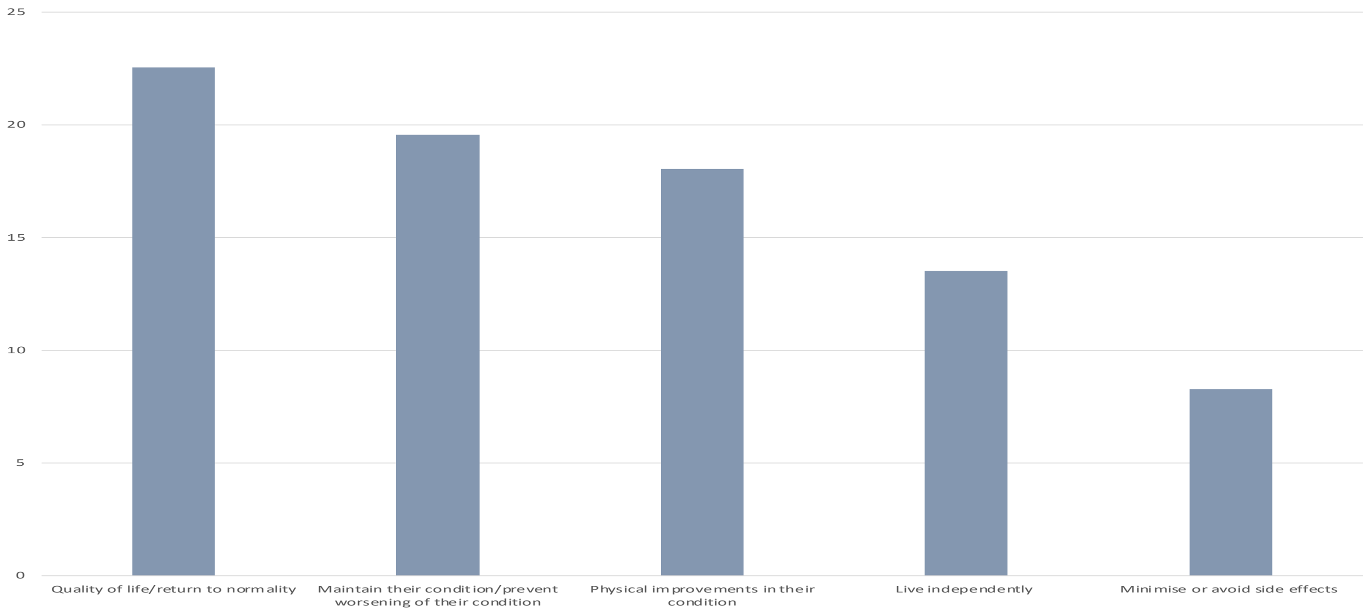

Figure 4.6: Personal goals of treatment or care

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

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Quality of life/return to normality	Diseases of the nervous system	Diseases of the skin
Maintain their condition/prevent worsening of their condition	Developmental anomalies Family or carer Aged under 18	Diseases of the skin Other rare condition
Physical improvements in their condition	Endocrine, nutritional or metabolic diseases	Aged 65 plus
Live independently	Diseases of the skin	Developmental anomalies
Minimise or avoid side effects		