

Section 10

Advice to others in the future: The benefit of hindsight

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Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and to ask questions (32.09%), to seek and accept help, including peer support and support groups (16.92%), to understand the trajectory of the disease (13.68%), and to try to stay positive (11.19 %).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have liked to have had access to a specialist in their condition sooner (15.41%), that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (13.16%), and they would have liked health care professionals to have had more knowledge and awareness of their condition (10.53 %). Other themes included they would have stopped or changed treatment sooner (7.89%), (5.64%), and they would have liked to have been diagnosed sooner (3.76%).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and to ask questions (32.09%), to seek and accept help, including peer support and support groups (16.92%), to understand the trajectory of the disease (13.68%), and to try to stay positive (11.19 %).

Participant wishes they had known to be assertive, an advocate, informed, and ask questions

No, I think for me it's just about knowing how to navigate the hospital system, but you don't really know that until you're in and you experience it. And in saying that, it's because in order to get care for my child in the hospital system, I need to be very knowledgeable about what to ask for. Because there is only that one specialist team that knows what to do. And if they're not available and these guys are on call 24 hours a day, seven days a week, if they're not available or if there's a minor hiccup, then that can be life threatening for my child. So I think for me, if there's anything I wish that I knew it would just be about how to be really assertive and have the information to provide anybody at point of care around what my child condition is, and I've learned that over time now.

Participant 021_2023AUORC

I think I would have just liked to have known more about, yeah, self advocacy and communication than how to ask questions as doctors and be prepared for those kinds of things. Yeah, that would have been, been helpful.

Participant 024_2023AUDIS

Yeah, well, I reckon I've had optic neuritis between 10 and 15 times in the last or since about 2015. I wish when I first had it, I had sort of pushed for more tests to find out why. And I could have started on all these preventative drugs, you know, eight years ago rather than last year. Yeah, I wish I'd sort of known that. I always just thought I had optic neuritis flare ups and that was it. I wish I'd known they could have actually been causes and it could have been prevented or tried to be prevented.

Participant 096_2023AUDNS

Participant wishes they had understood the trajectory of the disease

I wish...yeah, I, I wish I would have known that he would be able to make progress in terms of moving and communication and hearing and vision. So yeah, all things that could have been helped at the time if I'd had more information. But yeah, I guess just that, that things could progress and get better. I wish I could have known that at the time.

Participant 089_2023AUENM

Yes. I wish I'd known that it was a significant problem and not just something that I could take one tablet twice a day and it would go away.

Participant 002_2023AUDIS

Would be nice to have known that. Well, I guess I knew from the beginning there's no cure. I would just like...be a cure so that...go through what we go through, yeah.

Participant 019_2023AUDIS

That 22 Q is so broad. Every single kid is unique. They do not know one kid shares the same set of symptoms. For 22 Q, you know it's not a death sentence. Yeah.

Participant 021_2023AUDPA

Participant wishes they had known to try to stay positive

No, it's probably just the old cliché of it's not as bad as it sounds. Once it becomes your routine, it's not. It's not the end, but no one's ready to hear that in the beginning. Like there's probably hundreds of people that did say that, but you're not ready to hear it at that time. So but you think this sort of, what's that?

Participant 025_2023AUORC

It gets easier. That's probably it. You do get the hang of it.

Participant 032_2023AUDPA

Yes, everything's got to be OK and everything will work out in the end. Yeah, that's quite I wish that we had known about the diagnosis earlier because we would have, it would have just opened a lot more doors to us in her early childhood and early schooling life.

Participant 037_2023AUDPA

Participant had no particular comment and were satisfied with experience

No because the issue with getting on with life, if you know "Okay," basically, sometimes you look at what - As I said, there are people worse off than me. If they're having the gene dilution, having a gene mutation is basically a death sentence. That's actually what some people...sometimes, that is what I've thought about and this is why I'm actually the way I am. I think what I am at the moment is a miracle because as I said, if I had the mutation I wouldn't be alive. The point is it's the way you approach life is what matters and I get my ups and downs and all the rest of it. If you know the answers, then you're not going to ask the questions and if you're not going to ask questions, then you're not going to enjoy life.
Participant 005_2023AUDPA

Not, not necessarily. I think I'm I've committed myself to learning more as and, and being involved more in things like clinical studies, I'm actually quite excited that there is a clinical study happening in Australia that's amazing. So yeah, so I think just yeah for me it's it's, it's been a continual, continual growth, continual learning and continue understanding about the condition and you know if there's more opportunities to do that then I'll be involved in that as well.
Participant 001_2023AUDSK

No, not really, because we were sort of on top of it ourselves and really researched what the options were. And I was actually the one that asked whether I could have an ablation to try and fix the problem. So that that was relatively early on in the diagnosis. I think that was like my third visit to the hospital. So I think, I don't know, I guess the natural progression of things they have to try medications to see if they work. So I think, yeah, no.
Participant 032_2023AUORC

Participant wishes they had been diagnosed sooner

Yes. I wish I knew what my condition was as a teenager. I wish I'd been taken seriously at 17 when I first saw a rheumatologist because I feel like that would've guided choices around even just like work choices or when I went to backpack around Europe. I would've made more sensible decisions on like luggage, or transport and just things. I feel like since diagnosis, now that I understand what it is, I know what to look for now and I'm just a bit more preventative and that's made a huge impact on quality of life. I feel like if I'd known sooner when I had all the symptoms then I feel like that would've been really helpful so I wouldn't have physio giving up on

me because I wasn't responding to treatment how they thought I should. For example, I'd be able to say, "No, this is going to take longer" or "I just need to do this more slowly" or whatever
Participant 004_2023AUDPA

I just wish I'd been diagnosed earlier. I honestly think if I had been diagnosed with this when I had my first flare and then put on. The medication and the creams and had the area removed, I don't think that it would have progressed and I don't think I would have it anywhere else. I don't think I'll be sitting here talking to you today. I think because it took 15 years to diagnose and it was well rooted in my system and in my skin by that point that now it's a drama and nobody knows what they're doing and they're leaving bits and bobs when they cut it out and not getting it all.
Participant 006_2023AUDSK

Participant wishes they had known to ask for a second opinion or speak up during consultations

Second opinion. Getting a second opinion is really. What I could have been doing some stages. It's never too early to start intervention. It's never too early to start. It's never too early to start planning for the future. I think it's probably one of the most important takeaways from my journey. Yeah, definitely thinking more about the future I like. It's really hard in those early days, but seriously. What do you want for your kid in the future? Do you want him to be still, living at home and depending on you when they're 21, applying everything to that goal? Yeah.
Participant 028_2023AUORC

No, I just wish the rheumatologist that said you got skin thickening but you don't have Scleroderma wasn't such an idiot and actually said yes you got Scleroderma because you did ultrasounds on my arm and every and he said, 'oh, I see your skin. It's thick'. And he showed on the nurse who's doing the ultrasound. They put it on her arm and said I'll see how hers is only this thick. Yours is like twice as over, twice as thick, blah blah. And he said that you don't have Scleroderma, you just got skin thickening. So I was like on the way home in the car. I'm going. I'll look it up when I get home.
Participant 011_2023AUDIS

Participant wishes they had known the early signs and symptoms of their condition

Yes. I wish I knew the effects that it had on you. I probably maintained my health a lot better in that sense of what knowledge of what in the future. You

only look at the daily things, but you don't look at future. I think if that made me aware of more of the symptoms that I had, it probably could have been a lot better for me in the long run. Symptoms, particularly.
Participant 001_2023AUDIS

Of course, when I was 30 years old, somebody come along and say this is your trouble and this was why you've got these skin lesions and that's how we'll treat them.

Participant 003_2023AUDIS

Well, I wish I'd known back when I was having all those rashes that could have been...my rheumatologist later said, "Oh, yes, well, you can get that with scleroderma and that would've been in the active phase." Well, I spent years suffering with itchy skin, scratching, making myself bleed, and not being able to sleep because I was so itchy. That was nobody's fault that wasn't picked up, I think because who would've thought. I don't know. I hope somebody can change that.

Participant 004_2023AUDIS

Participant wishes they had known to look after emotional wellbeing

The emotional impact being diagnosed at a very formative age of 18, I think that there could have been a bit more intervention about the emotional impact. That I carried on my own for so long.

Participant 004_2023AUORC

Anything I know now well, for start that there was there would be some, some improvement, yeah. The importance of importance of managing the whole person when they develop a sudden chronic illness like yeah the importance of that. It probably takes a team to to manage a chronic health person not just one doctor giving drugs that it probably. And that that team should be more interlinked rather than me having to go off and try to source this other help that was not linked with my that there wasn't a whole treatment plan. But I accessed mental health independently. It took me a long time to find effective mental health, but they still they still didn't. There was no link, real link between that and medical help, you know.

Participant 027_2023AUORC

Participant wishes they had known to pace themselves or know triggers and limitations

I think I've mentioned this before, but definitely like food eliminations because I didn't know when I was younger when I first had this disease, that certain

things can make it worse. I also smoked when I was, you know, 16, 17, which is. Quite young, but I smoked cigarettes and I didn't realize that that was something that can aggravate the disease more, which I now do not smoke and I've seen improvement, slight improvement in the disease. So I guess just a bit more information about how to help or keep the disease calm.

Participant 010_2023AUDSK

I feel like, yeah, I feel like it would have helped me knowing a lot earlier as to, you know, what the causes are, how I can prevent them. And being at a younger age where I was probably a little bit more in control of my life and then control of my body. I mean, it's still something I can do. But, you know, I've got kids and family and money restrictions now, so yeah, yeah

Participant 011_2023AUDSK

Wow, a lot of things. I'm sure. I can't really think of them right now. Probably that...pace yourself. It's definitely a marathon. And just listen to your gut as well. Like people will be offering different things and just sort of know, you know, your child, don't, don't let people tell you that you don't. And trust yourself. I think it's all a bit woohoo, but I think that's what I wish I'd known. It's just, you know, it's not the sprint and just to pace yourself.

Participant 095_2023AUENM

Participant wishes they had known to seek and accept help, including peer support and support groups

I wish that my neurologist, when he had told me that it may get worse, it may get better, he would have also told me that there's no treatment and there's no cure, but it's getting researched...Just like the fact that dystonia is very common, but very uncommon at the same time...Because I just felt alone, never heard of it, never knew anyone. I ended up making a social media account to connect with people. That was the first time I'd ever spoken to other people who had it.
Participant 004_2023AUDNS

It would've been helpful to see some more lived experience stories of what life looks like for people at different life stages and how they grew up. That would've been comforting even though obviously everyone's journey and experience is different. That would've been good information, having more information around the supports and typical funding that would be available, so that you know what pathways to pursue rather than having to do your own research about that.

Participant 067_2023AUDPA

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	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=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Be assertive, an advocate, informed, ask questions & trust your instincts	129	32.09	4	5.97	32	39.51	26	27.37	13	40.63	42	44.21	12	37.50	96	35.82	33	24.63	100	34.01	29	27.36
Seek and accept help (Incl. peer support/support groups)/knew where to go for help	68	16.92	6	8.96	4	4.94	14	14.74	0	0.00	44	46.32	0	0.00	45	16.79	23	17.16	51	17.35	17	16.04
Understand the trajectory of the disease, including costs to expect	55	13.68	9	13.43	24	29.63	17	17.89	1	3.13	2	2.11	2	6.25	42	15.67	13	9.70	47	15.99	8	7.55
Try to stay positive	45	11.19	3	4.48	2	2.47	22	23.16	0	0.00	16	16.84	2	6.25	31	11.57	14	10.45	33	11.22	11	10.38

Anything participants wish they had known earlier	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=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Be assertive, an advocate, informed, ask questions & trust your instincts	129	32.09	24	24.74	46	35.11	40	35.09	19	31.67	60	30.30	67	34.18	37	33.33	92	31.62	59	29.50	70	34.65
Seek and accept help (Incl. peer support/support groups)/knew where to go for help	68	16.92	15	15.46	13	9.92	19	16.67	21	35.00	28	14.14	35	17.86	18	16.22	50	17.18	25	12.50	43	21.29
Understand the trajectory of the disease, including costs to expect	55	13.68	8	8.25	20	15.27	19	16.67	8	13.33	26	13.13	29	14.80	18	16.22	37	12.71	28	14.00	27	13.37
Try to stay positive	45	11.19	13	13.40	13	9.92	14	12.28	5	8.33	24	12.12	21	10.71	9	8.11	36	12.37	20	10.00	25	12.38

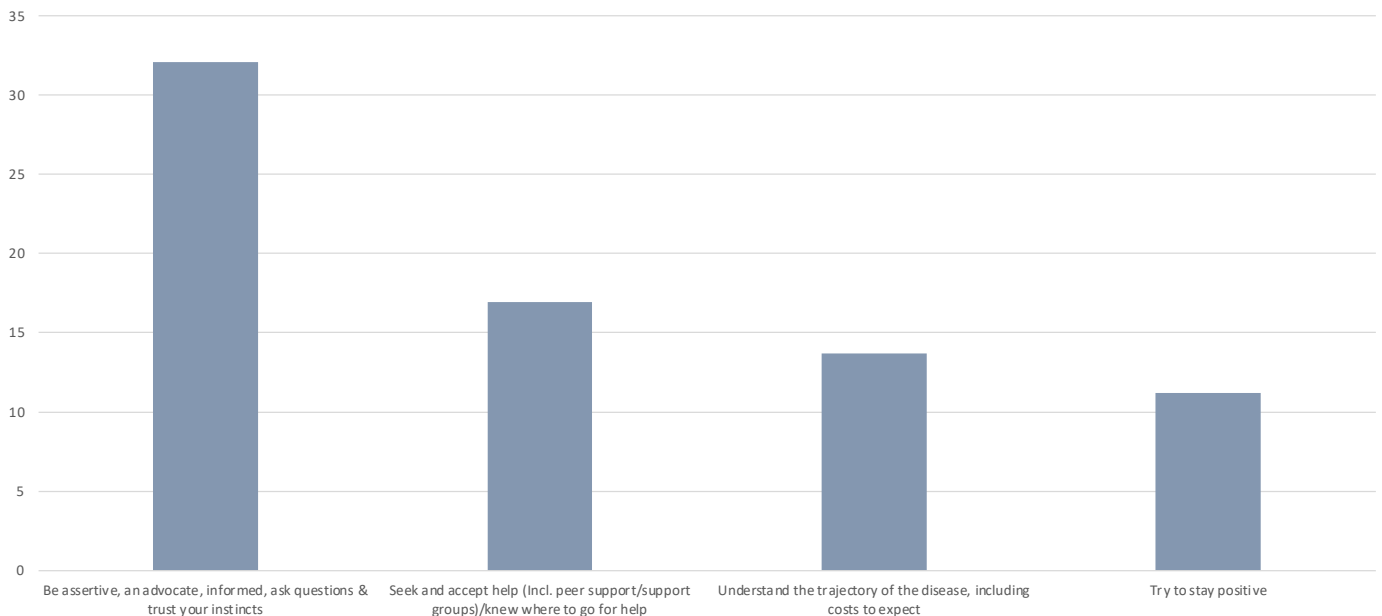


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Be assertive, an advocate, informed, ask questions & trust your instincts	Developmental anomalies	Endocrine, nutritional or metabolic diseases
Seek and accept help (Incl. peer support/support groups)/knew where to go for help	Diseases of the immune system Diseases of the skin Other rare condition	Endocrine, nutritional or metabolic diseases Aged 65 plus
Understand the trajectory of the disease, including costs to expect	Diseases of the skin Endocrine, nutritional or metabolic diseases	Diseases of the immune system
Try to stay positive	Diseases of the skin	Diseases of the nervous system

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have liked to have had access to a specialist in their condition sooner (15.41%), that they would not change any aspect of their care or treatment and were satisfied with care and treatment received (13.16%),

and they would have liked health care professionals to have had more knowledge and awareness of their condition (10.53%). Other themes included they would have stopped or changed treatment sooner (7.89%), (5.64%), and they would have liked to have been diagnosed sooner (3.76%).

Participant would not change any aspect of their care or treatment and were satisfied with care and treatment received

No, no, wouldn't I think that I was provided with the best information at that given time. I have always been taken seriously by all the doctors that I saw. I can't fault them.

Participant 026_2023AUDSK

No, I don't think so. I think, I think they, they did everything really well for us. They met us where we needed to be met and I think, I think they've I think like the hospital have done a really good job. And on our side, we've done a really good job behind the scenes as well of keeping him on track and out of hospital admissions and well.

Participant 025_2023AUORC

No, no, I think, I think I made the choice, the right choice to go into a private hospital, not a government hospital. I'm, I'm very certain about that. I'm so bad. I insisted on that first night that the ambulance take me to a private hospital. Because I think I was in the best place I could possibly wish for, but I don't know. In my treatment, I don't know. I don't know. I was, I was quite confident with the clinical haematologist who I dealt with. She was fantastic. I had every, every respect for her. But as to...you know, there's certain aspects of my hospitalization that I'd change, but my treatment and management I don't think I've got reason to be concerned.

Participant 095_2023AUDNS

Participant would have liked to have access to a specialist in their condition, sooner

The only thing I would change is pushing to receive treatment a lot sooner, before it progressed to the stage that I'm at. But you know, when I was younger, I didn't have a choice. It was up to my parents to kind of look after me and and seek better help, but if I could go back I'd probably push harder to my parents to get me to seek.

Participant 010_2023AUDSK

Something that made me better. That's what I will change if I can find something that will improve the condition. Yes, by all mean, I close my eyes. I gave the study 10 minutes. These people don't know, they just don't treatment. As I said, I've seen so many doctors, so many specialists, no one seems to know or have they any idea about HS? So if you do know of someone that has got some idea, do send me a test message or an e-mail with the name and I wouldn't make an appointment to go and see them.

Participant 023_2023AUDSK

I would have gotten certain interventions earlier in terms of probably feeding therapy. Yeah, I think that's it. Just earlier intervention, possibly earlier OT intervention as well if I would have, if I could change things done more sooner, yeah.

Participant 089_2023AUENM

Participant would have liked health care professionals to have had more knowledge and awareness of their condition

Treatment. There needs to be a lot more research into it. It's not extremely rare and common condition. Now it needs more. More people need to look into it. The care I received, I can tell my two current providers the care I received. It could have been a lot better. It left a lot to be desired and that comes down to a lack of information available to medical practice to medical professionals on the condition. I've had to still go to the hospital tomorrow and I've been to the hospital multiple times for this condition and people still ask me, oh what's it? It just needs more awareness.

Participant 012_2023AUDSK

No, I don't think so. No. Other than that...if there was a GP that knew about scleroderma, again, because I don't see them that frequently, I would travel for that, but short of that, yes, someone who's going to advocate for you every time I'd take, and is willing to learn with you about what's happening.

Participant 017_2023AUDIS

Participant would not change any aspect of their care or treatment, with no reason given

No, I don't think so. No.

Participant 010_2023AUORC

No, I don't think so. I think we sort of went through the usual treatment option failure, yeah.

Participant 019_2023AUDSK

Participant would have stopped or changed treatment sooner

Maybe just coming away from your steroids really like finding some sort of treatment that's not steroid based.

Participant 078_2023AUDIS

No, I don't think so. I probably feel like I should have been offered more drugs, but I don't get off anything stronger than Panadol for pain and I don't even know if that's a good or bad thing. Anyhow, I'd certainly go back to my GP and tell him that I want to get some

steroids into me, but they're all scared to give you anything, I think.

Participant 013_2023AUDIS

I was on Prednisolone for so long that I have ongoing health issues from that. So weight, hair, like you think of all the side effects of Prednisolone. It's not pretty. So if I had my time again and I listened to my body, perhaps, I don't know. It's a hard one cuz a lot of my symptoms were similar to asthma symptoms so it's hard.

Participant 031_2023AUORC

Participant would have liked to be more assertive or supported

I probably would have advocated. I can see circumstances when I think back that I would have advocated differently. I would have declined certain things. I would have accepted other things that I didn't think were necessary at the time because I didn't think we had very long. I would have potentially moved closer to care earlier than I have because I didn't expect you to be here this long. Little things I would have changed earlier than I have.

Participant 080_2023AUDIS

I just, yeah. I think I would change it in asking more questions about my medication. I think that not just accepting the fact that that's the only thing I can have. Yeah. Yeah. You know, just. Yeah, I just, yeah. If I had the chance, I'd sort of, yeah.

Participant 019_2023AUDIS

I'll probably if I...I guess it's hard to say in hindsight, but I would have liked to have known earlier. So we could have pushed for those services earlier. You know, she was our first kid. We didn't know any different. You know, if I'd had my youngest first, then there would have been all sorts of red flags when we had Lily, but there wasn't. And the, you know, the healthcare professionals we saw up until that point didn't point anything out. And yeah, I think, as I said before, she's got really distinct facial features that scream 22 Q. If there had been one educated health professional there, I could have gone. Yep, that right there would have made a world difference.

Participant 021_2023AUDPA

Participant would have liked to have had a better understanding of their condition

PARTICIPANT: If I had more knowledge, yes, I would've looked after myself better if I was aware of the serious consequences.

INTERVIEWER: Is there anything else that you would change now that you know where you are and where you've got to where you were?

PARTICIPANT: I'd probably try and address my stress levels more. The cold and stress are the two worst things. I wouldn't let myself get cold and just put up with it. You go out somewhere, like a party may have it outside in winter and I'd end up with bronchitis. If I need those things, obviously I wouldn't have done them.

Participant 008_2023AUDIS

I'm not sure. I might have been made more aware, in particular, the problem I'm having the most now that I've done in a, almost, in a way the least about, because it's complicated and difficult is the whole problem with digestion. I feel that my oesophagus and my gut and all of that have narrowed. I know they have, or it got harder with the hardening of the flesh as it were. I'm finding it quite difficult. No one told me about that ahead of time really or explained what it meant, and no one has yet told me what I can do about it. I'm a bit fearful of that because I fear that the first thing I'm going to be told is I need an operation on the bowel or something to make functioning possible.

Participant 012_2023AUDIS

Information? Lack of the lack of information. Yeah, you wish you had more. Yeah, It's not to have through all the Internet to find out what how you handled surgery or that's why I made-up a brochure and gave it to him. But he thought that. I think you know, he thought that was funny and I are you also, to be fair, I think the neurologist is not sure what to do. He's fiddling too.

Participant 003_2023AUDNS

Participant switched health professionals

One, I would have gone harder with the physios earlier on, I just felt like we went. I guess I would have liked higher incentive, like being more fair with them and the dietitians as well. You know, and I guess that's where it is. It is coming from the allied health where they just come in and every week every time it was a new person. And, you know, I guess I would have changed, I would have, I would have just said straight off the bat, you need to either bring in the same person every time or I'm not talking to them because it's, you know, they're not reading the case notes, whatever. So I probably would have changed the way that we handled that, I guess, earlier on in the piece.

Participant 020_2023AUORC

I think I'd get a different respiratory specialist because he decided that I had sleep apnoea and that was the only thing he'd talked to me about. From then on, he just ignored [UNINTELLIGIBLE] altogether. And I'm like, my sleep apnoea is not the biggest issue here. So, but apart from. That, well, yeah, I the cardiologist also. So the rheumatologist wants me to get echocardiogram every year to keep an eye out for pulmonary arterial hypertension and cardiologist doesn't seem to believe that it's necessary for me to do that. So it's very hard to get appointments with him because he doesn't rank me as a high priority.
Participant 009_2023AUDIS

That was definitely go back to that first doctor. If I had someone that rather than just you would just walk in there, just touch your neck, shove a couple of needles in, and that would send you on your way. If we had further information from there, that would be the only thing I would change. If I would've had access to these wonderful neurologists that I had access to later on down the track, if I would've had access them to them first, that would've been so much better. Because I think those first 18 months were probably a couple of dark years that I didn't have to have if I had a neurologist that was going to treat me and explain my condition to me.
Participant 006_2023AUDNS

Participant would have liked to have been diagnosed sooner

Probably not waiting, like leaving it so long to get an answer in the beginning, because it obviously developed quite severely then, but otherwise. No, I'm glad I found the clinical trial and I'm glad we went down that road rather than it could have meant an awful lot more surgeries. So yeah, I think we did the right thing there.
Participant 022_2023AUDSK

Yes. So definitely a vision screening a lot earlier. Even though eyes appear to look normal sometimes it can be faults in the back that impacts what they see in their vision field. We never had any idea. So maybe in a lot earlier screening for vision, especially if you are deaf or have a hearing loss.
Participant 094_2023AUENM

Well, definitely. I would have liked people to diagnose this earlier and to have, yeah, been able to to have that communicated better, what people were looking for, why they were excluding things or yeah, I think that would have been. It helped me.
Participant 024_2023AUDIS

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	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=66	%	n=102	%	n=76	%	n=22	%	n=132	%	n=134	%	n=75	%	n=191	%	n=143	%	n=123	%
Satisfied with care received	35	13.16	7	10.45	8	9.88	15	33.33	1	3.13	0	0.00	4	12.50	26	14.77	9	10.00	25	12.50	9	14.06
Accesses appropriate specialist/treatment sooner (incl. access to allied health and support)	41	15.41	17	25.37	6	7.41	2	4.44	7	21.88	3	33.33	6	18.75	21	11.93	20	22.22	31	15.50	9	14.06
More knowledge and awareness from health professionals	28	10.53	3	4.48	11	13.58	6	13.33	5	15.63	0	0.00	3	9.38	21	11.93	7	7.78	23	11.50	5	7.81
Changed or stopped treatment sooner	21	7.89	4	5.97	8	9.88	0	0.00	5	15.63	1	11.11	3	9.38	16	9.09	5	5.56	15	7.50	6	9.38

Aspect of care or treatment they would change	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=67	%	n=81	%	n=45	%	n=32	%	n=9	%	n=32	%	n=176	%	n=90	%	n=200	%	n=64	%
Satisfied with care received	35	13.16	6	9.09	14	13.73	10	13.16	5	22.73	18	13.64	17	12.69	8	10.67	27	14.14	17	11.89	18	14.63
Accesses appropriate specialist/treatment sooner (incl. access to allied health and support)	41	15.41	12	18.18	18	17.65	7	9.21	4	18.18	17	12.88	24	17.91	12	16.00	29	15.18	26	18.18	15	12.20
More knowledge and awareness from health professionals	28	10.53	4	6.06	12	11.76	8	10.53	4	18.18	15	11.36	13	9.70	10	13.33	18	9.42	18	12.59	10	8.13
Changed or stopped treatment sooner	21	7.89	5	7.58	6	5.88	8	10.53	2	9.09	10	7.58	11	8.21	6	8.00	15	7.85	12	8.39	9	7.32

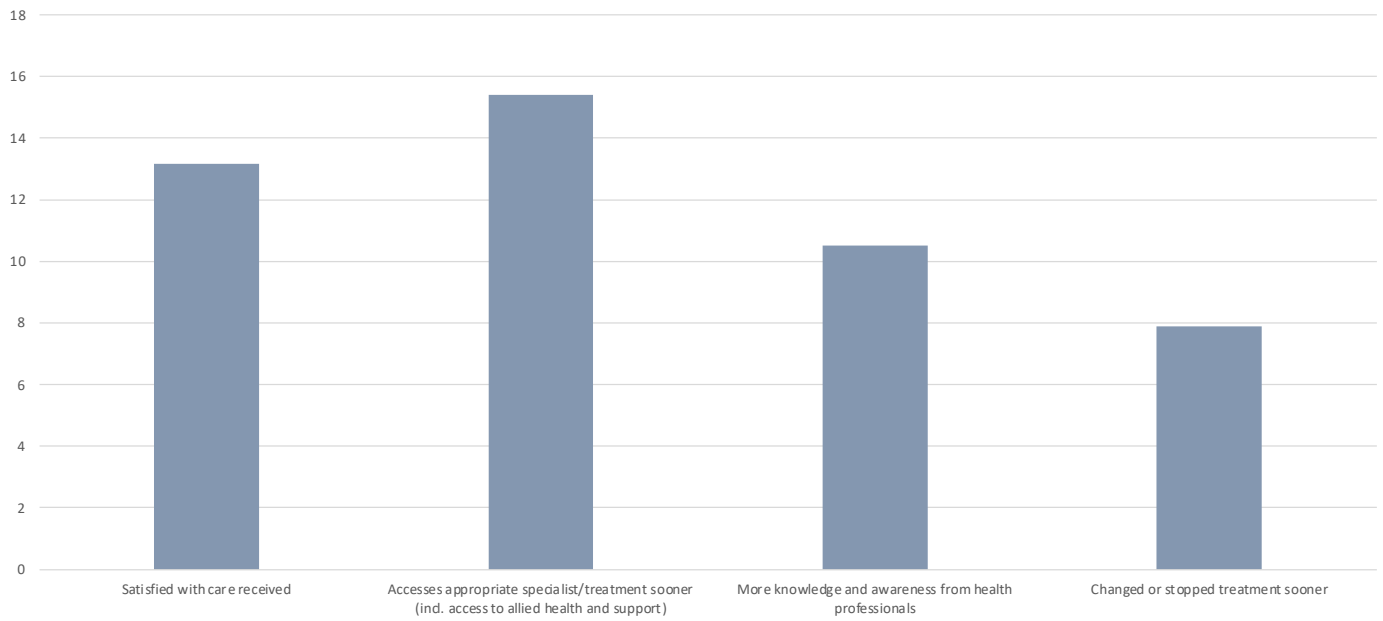


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Satisfied with care received	Diseases of the skin Endocrine, nutritional or metabolic diseases	Diseases of the nervous system
Accesses appropriate specialist/treatment sooner (incl. access to allied health and support)	Diseases of the nervous system	Endocrine, nutritional or metabolic diseases
More knowledge and awareness from health professionals	Endocrine, nutritional or metabolic diseases	
Changed or stopped treatment sooner		