

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 (65.00%), or one treatment option (15.00%). This was followed by no discussions about treatment (10.00 %), and no particular response (10.00%).

In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly they did not give a description about discussions (25.00%), they participated in the decision-making process (25.00%), or they changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented (10.00 %). Other themes included that they were comfortable deferring to doctor and accept recommended approach (5.00%), that they were told what to do without discussion (5.00%), and that they wanted more discussion or options (5.00%).

For those with a single treatment option, most commonly they gave no description about participation (5.00%), had some but very little discussion (5.00%), and were told what to do without discussion (5.00 %). Other themes included despite therapies being available (5.00%),and gave no reason (5.00%).

Some participants were presented with no treatment options, describing no treatments offered despite therapies being available (5.00%), and without giving any description (5.00%).

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 (50.00%), efficacy (45.00%), and cost (40.00 %). Other considerations included quality of life (25.00%), ability to work (20.00%), ability to follow treatments (15.00%), ability to remain independent (10.00%), their own research (10.00%), and impact on their family or dependents (10.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (50.00%), that they changed the way they make decisions (40.00%), and others had no particular comment (10.00 %).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed or more assertive (20.00%), they were more aware of their health, responsibilities and limitations (15.00%), and they were more focused on quality of life (10.00 %). Other themes included being more cautious and considered (5.00%) and being more focused impact on family and dependents (5.00%).

Where participants had changed the way they make decisions, the most common reasons were that they were always been informed or assertive (10.00%), that they had no treatment options available or needed yet (5.00%), that they have not had treatment options to choose from (5.00 %), and that they had always considered cost (5.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (30.00%), to have quality of life or return to normality (30.00%) and minimise or avoid side effects (25.00 %). Other themes included to have physical improvements in their condition (20.00%), to get a diagnosis, treatment plan or have better care coordination (10.00%), to not be on medication all the time or to avoid hospitalisation (10.00%), have improvements in mental or emotional health (5.00%), to get through or finish treatment (5.00%), and to make healthy lifestyle changes (5.00%).

Discussions about treatment

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In relation to participant in discussions about treatments, for those presented with multiple treatment options, most commonly they did not give a description about discussions (25.00%), they participated in the decision-making process (25.00%), or they changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented (10.00 %). Other themes included that they were comfortable deferring to doctor and accept recommended approach (5.00%), that they were told what to do without discussion (5.00%), and that they wanted more discussion or options (5.00%).

For those with a single treatment option, most commonly they gave no description about participation (5.00%), had some but very little discussion (5.00%), and were told what to do without discussion (5.00 %). Other themes included despite therapies being available (5.00%), and gave no reason (5.00%).

Some participants were presented with no treatment options, describing no treatments offered despite therapies being available (5.00%), and without giving any description (5.00%).

Multiple options: Participated in the decision-making process

So in terms of treatment options, he did recommend Accutane or Isotretinoin, which is what I'm currently taking. And then he said after I finish the course of medication that I'm on, we could look at like skin resurfacing, which is like with a laser or like. Yeah, I don't think exactly know how it works, but I assume it's with a laser. He also mentioned I could get Humira shots for it, which is which he he said he wouldn't recommend just because you can be very prone to infection on that medication and it's kind of lifelong. And I think the results with it were very mixed. And so he didn't want to risk me going on it and making my condition worse because. Some of the results of people going on that medication, it can either clear it

up or it really aggravates the disease and it can spread to other areas. So I kind of declined that one And we did also talk about surgery and having like it's called like a wide excision, which is where they would like cut out the skin that's affected by the disease and. Stitch it back up essentially. So I kind of have to wait until I finish the medication I'm on before we can discuss any like further treatment, but those are kind of the options I was given.

Participant 010_2023AUHIS

Multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented

So I chose the surgical option and then from there I didn't proceed with the surgical option. I chose to get a second opinion at from another dermatologist because I just didn't feel that this first dermatologist connected with me as an individual.

Participant 013_2023AUHIS

Multiple options: They were told what to do without discussion

Here's an antibiotic. This will fix you right up, bro. That's basically it. I did have a dermatologist performed cryotherapy to a few of the lesions. But they kept recurring. Antibiotics don't seem to affect the cause of the disease. Participant 008_2023AUHIS

One option/approach: They were told what to do without discussion

No, just see your doctor if it gets too bad, and they'll they'll give you some antibiotics to settle it there. Not that antibiotics do a particularly lot for any anything to do with HS, but he was just like just see GP for antibiotics.

Participant 005_2023AUHIS

Participant describes no treatments being discussed

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 bandage yourself. Like there was nothing. It was just this is what you have.

Participant 014_2023AUHIS

Table 4.1: Discussions about treatment

Discussions about treatment	All participants	
	n=20	%
Participant describes multiple options being presented	13	13.00
Participant describes one option being presented	3	3.00
Participant describes no treatments being discussed	2	2.00
No particular comment	2	2.00

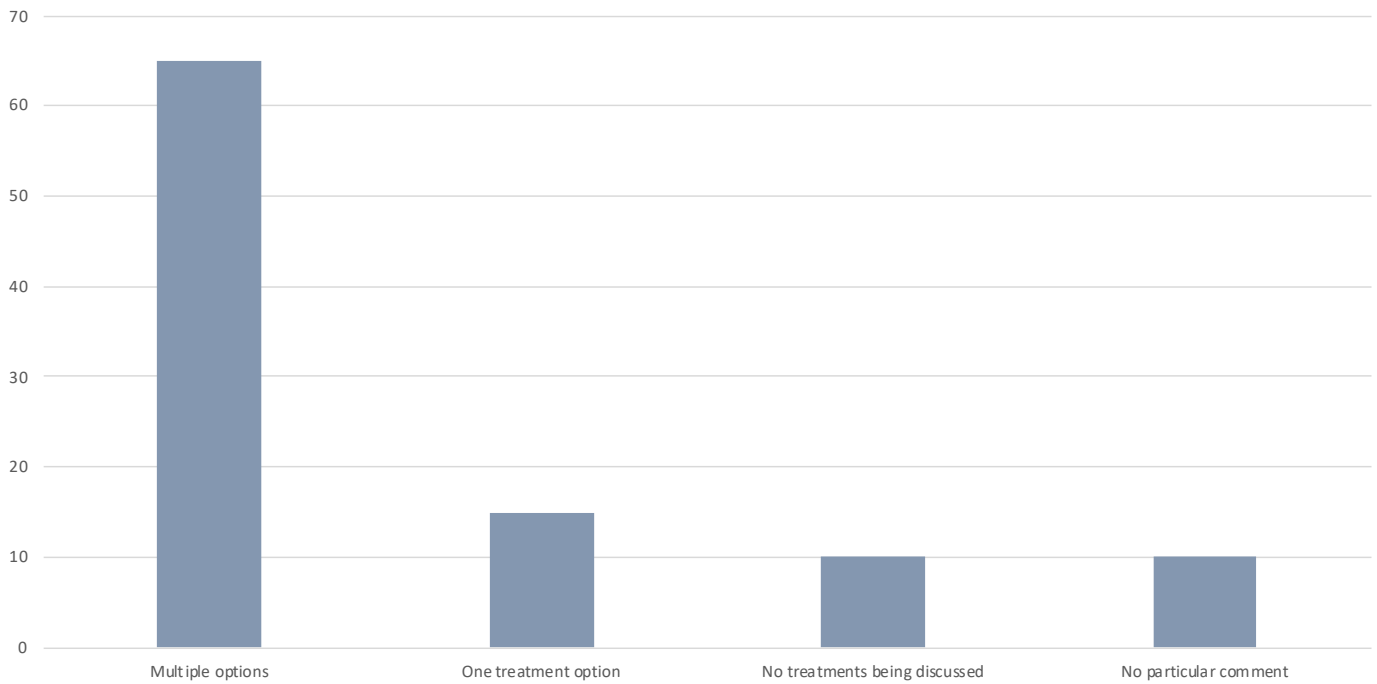


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment (Participation in discussions)

Participation in decision making	All participants	
	n=20	%
Participant describes being presented with multiple options but did not give a description or reason for this	5	5.00
Participant describes being presented with multiple options and participated in the decision-making process	5	5.00
Participant describes being presented with multiple options, however changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	2	2.00
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	1	1.00
Participant describes being presented with multiple options, however, they were told what to do without discussion	1	1.00
Participant describes being presented with multiple options, however they wanted more options and more discussions	1	1.00
Participant describes being presented with one option/approach, but did not give a description or reason for this	1	1.00
Participant describes being presented with one option/approach, and had some but very little discussion	1	1.00
Participant describes being presented with one option/approach, that they were told what to do without discussion	1	1.00
Participant describes being presented with no options/approach despite therapies being available	1	1.00
Participant describes being presented with no options/approach but did not give a description or reason for this	1	1.00
Other/No response	2	2.00

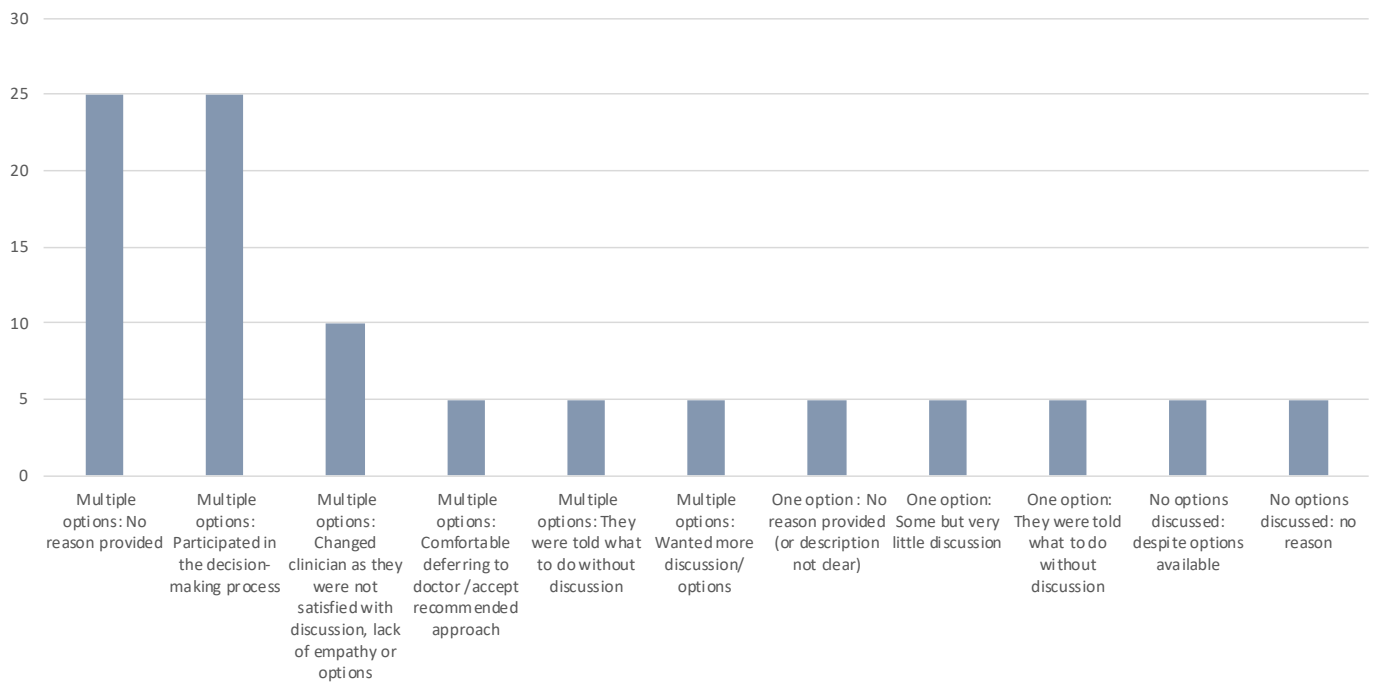


Figure 4.2: Discussions about treatment (Participation in discussions)

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were side effects (50.00%), efficacy (45.00%), and cost (40.00%). Other considerations included quality of life (25.00%), ability to work (20.00%), ability to follow treatments (15.00%), ability to remain independent (10.00%), their own research (10.00%), and impact on their family or dependents (10.00%).

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

I'm not fussed with risks of, you know, if it's a surgery and things like that that doesn't bother me, but also whether it will impact my other medical issues. I know that there's a needle that some people take for HS. I couldn't take that risk because it's one of the big side effects that seems to happen more often than not. Affects the heart. And yeah, my Graves' disease, like, I don't have heart issues, but with my Graves' disease there, it can trigger things. So yeah. Cross that one off.
Participant 018_2023AUHIS

I guess if treatment is going to affect my general life, like work like, you know, the doxycycline 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_2023AUHIS

Participant describes taking efficacy into account when making decisions about treatments

Well, I've taken into consideration the fact that it would it would help me.
Participant 004_2023AUHIS

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.
Participant 008_2023AUHIS

Participant describes taking cost into account when making decisions about treatments

Well, probably cost and side effects.
Participant 013_2023AUHIS

Cost is definitely a big one. I'm young, I don't know the support of my parents and you know, I don't make a whole heap of money. I don't have private health insurance. So I think cost of treatment is definitely the biggest factor, as well as the actual outcome and reviews of other people who have had treatment. I kind of look at the avenues they've taken and if it's actually worked or helped in any way. Like I said, there's no real cure. So I feel like treatment is a tricky one because you just like, I don't know, it sounds very depressing, but I don't have much hope with any of the treatment avenues because I know that like it, it

can't be fixed really, it can only be managed. So I guess I'm just when I think about treatment. I'm looking for something that seems most hopeful. Like I said, I'm very interested in getting the surgery done, to have it removed because it just seems like the most drastic get it done kind of treatment.

Participant 010_2023AUHIS

The potential side effects of those treatments and how those side effects can affect my quality of life if the treatments are successful and weighing up whether the side effects are worth it if on the off chance that the treatments are unsuccessful and the ability to basically afford those treatments.

Participant 012_2023AUHIS

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

I think the impact that whatever I'm taking has on my health. Like obviously take Humira has Humira was I guess the big one, but I was. I guess my quality of life Prehumira was not great. 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_2023AUHIS

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_2023AUHIS

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

So I have other health conditions obviously, so it does limit me on what I can do, which is why I don't know if I'm suitable for clinical trials and things like that. So I guess that's kind of the main thing that I consider. But also, I work full time. I'm the sole provider for myself, so I have to kind of be able to work. I can't take time off work.

Participant 014_2023AUHIS

I suppose the the prognosis around how effective the treatment could be and how long it would solve the problem for. So I I wasn't. Yeah, I spent a long time on antibiotics. And I felt also that it was having a significant impact on the rest of all the rest of my body without actually managing to control or change the condition itself. So I I was quite frustrated with that and and once I sort of had in my mind that I wanted to pursue the surgery pathway. I knew that it would be actually. No, I didn't. I I had no idea how significant

the surgery and the recovery from that would be. So when I initially spoke to the general surgeon and I said, do you know how long till I can go back to work and he said, oh, well, you know, you're sitting at a desk, so probably at least few days. And in actual fact it was each time it was two to three weeks. With you know, regular visits from the Community nurse and and really, yeah being quite debilitated, it's the wrong word. But they like they I think it's part of the condition of discharge. They then didn't have me driving a car until six weeks later when I'd seen the surgeon to sign off on the fact that it was okay to drive again.

Participant 007_2023AUHIS

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

Well, with, for example, with the Humira, Humira, I'm not really, I guess it's about what I'm comfortable doing. So I'm not really comfortable with the idea of giving myself injections. So that's why, like, I hate needle, you know, most, I don't think anybody like goes, oh, I love needles, you know, I'm pretty sure we all hate needles. I guess if it got to the point where maybe I was stage 3 and it was kind of like the only thing left. But as far as medication is concerned, so long as the you know I'm not getting side effects, I'm OK to you know, I generally read up on stuff and look out for side effects and up till now touch wood I've been very lucky. I haven't really had any. I don't get side effects from from the antibiotics. I haven't had any side effects from the I can't going to call them Aldeton, but they're not Aldeton, they're spirilactin.

Participant 017_2023AUHIS

Yes, the commitment the, I think the the first thing would be likelihood of success. Prospects of success and then it would also be weighed with so say, there might be a real likelihood of success with this cosmetic surgery but now we're talking cost time and recovery and the utility of that on my current living situation with my children, my work. So the impact on my life, I suppose my day-to-day. And finances are a huge thing. I think I'm on the trial. I wouldn't be able to afford the Humira if I am if I wasn't on the trial. So that's another thing about whether I would or would not continue with the the trial is, you know, it's I can't see that I'm having any negative side effects from it. I can't say exactly or truly if I'm seeing a definitive benefit from it. At the same time, it really I just every two weeks I just have a reminder of my phone to inject myself and then I go and see DOCTOR every 12 weeks. And so the impact on my life is very low.

Participant 015_2023AUHIS

Table 4.3 Considerations when making decisions

Considerations when making decisions about treatment	All participants	
	n=20	%
Participant describes taking side effects into account when making decisions about treatments (Total)	10	10.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	9.00
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	1.00
Participant describes taking efficacy into account when making decisions about treatments (Total)	9	9.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	8	8.00
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	1	1.00
Participant describes taking cost into account when making decisions about treatments (Total)	8	8.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	8	8.00
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking quality of life into account when making decisions about treatments (Total)	5	5.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	5	5.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking the ability to work into account when making decisions about treatments (Total)	4	4.00
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	4	4.00
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking their ability to follow treatments into account when making decisions about treatments (Total)	3	3.00
Participant describes taking the ability to follow treatment into account as part of multiple aspects that they consider when making decisions about treatment	3	3.00
Participant describes taking the ability to follow treatment into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking the ability to remain independent into account when making decisions about treatments (Total)	2	2.00
Participant describes taking the ability to remain independent into account as part of multiple aspects that they consider when making decisions about treatment	2	2.00
Participant describes taking the ability to remain independent into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking their own research into account when making decisions about treatments (Total)	2	2.00
Participant describes taking their own research into account as part of multiple aspects that they consider when making decisions about treatment	2	2.00
Participant describes taking their own research into account as the only thing that they consider when making decisions about treatment	0	0.00
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	2	2.00
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	2	2.00
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00

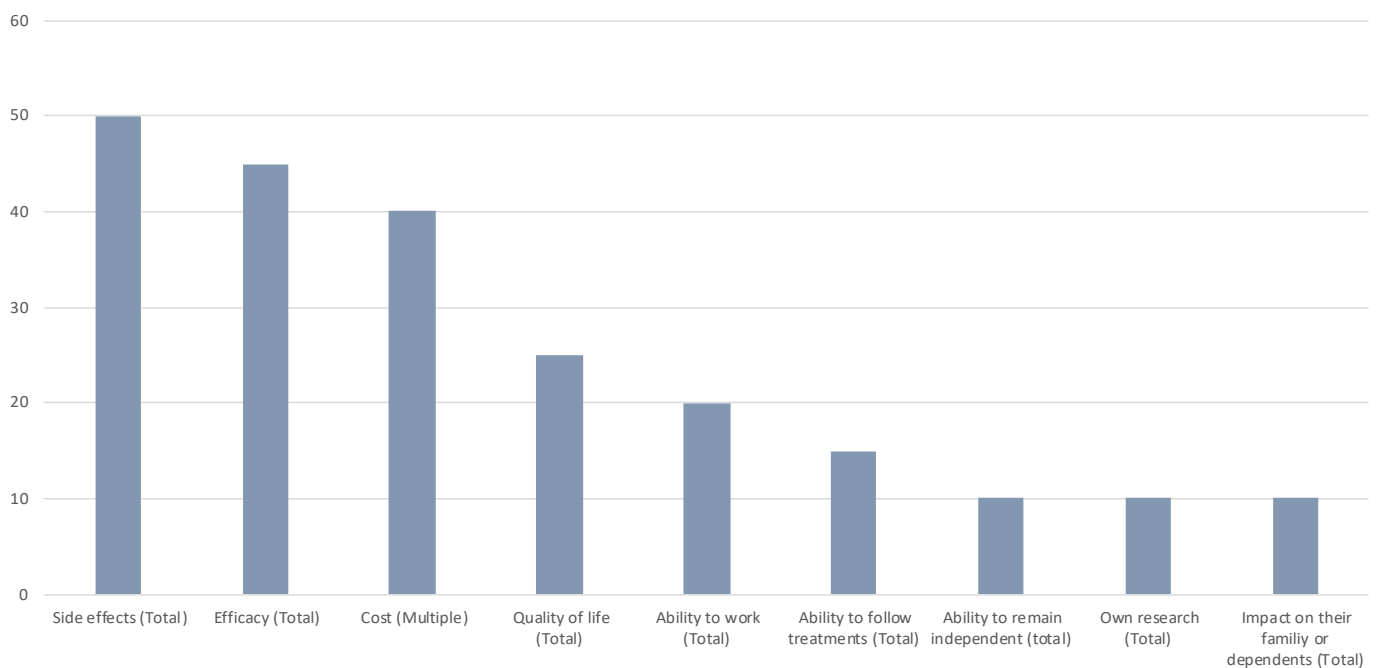


Figure 4.3 Considerations when making decisions

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they make decisions (50.00%), that they changed the way they make decisions (40.00%), and others had no particular comment (10.00 %).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed or more assertive (20.00%), they were more aware of their health, responsibilities and limitations (15.00%), and they were more focused on quality of life (10.00 %). Other themes included being more cautious and considered (5.00%), and being more focused impact on family and dependents (5.00%).

Where participants had changed the way they make decisions, the most common reasons were that they were always been informed or assertive (10.00%), that they had no treatment options available or needed yet (5.00%), that they have not had treatment options to choose from (5.00 %), and that they had always considered cost (5.00%).

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

It's probably a bit different because I'm a bit more aware of what it is now mm.

Participant 011_2023AUHIS

Yeah, no, it's changed a lot. I was very naive and you just went to the doctor and did what he ever said. Now I have researched it myself a lot, so I'm more educated. So I make decisions based on I discussed my decisions with the doctor.

Participant 013_2023AUHIS

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

Yes, definitely. Like, I wear a mask all the time and people look at me and think I'm strange. And that's like, well, you know, I have to. I can't afford to take things.

Participant 009_2023AUHIS

It's just to completely altered my whole existence like I have to absolutely the like my clothing choices it it was, it's very much so people want to say let's catch up on the 18th of May and I say sure and then I think I don't know. I never know because I could come down with a massive flare at any given time, at any given

day and it has disturbed my ability to function in that regard on a social level. And and you know, a large portion of other things as well, like you know, my my poor husband, he's not as free as he. You know, it could be because I can only do so much with the kids, my physical ability. So decisions in that regard [Unintelligible] that he if it includes the children, you know, sure. If not it's got to be very measured and you know, those sorts of things. Also my work. I'm in a very, very supportive environment. I can work from home. I can just drop off. I'm here one day and all of a sudden I'm not what what happened to her? Right. There's always that you seemed fine yesterday and it's like, well, but you know it. I'm lucky in that regard because I don't think it would. I don't think I would survive another firm. The kinds of cultures that they have there working you to death until you bleed. And you know, if I ever needed a day, I would be pushing through that. There have been times where I've been smiling and grinning through pain and I've been in the car park at a lunch break crying on the phone and my husband, just from how exhausted I am. And so I don't, I wouldn't. I just wouldn't make it. So decisions 100%

Participant 015_2023AUHIS

Changing: more focused on quality of life

It it has changed, I've gotten a lot more cautious about looking at side effects compared to the treatment and the treatment success because. There's been because of how many treatments have been unsuccessful, but I've still suffered side effects from them, and those side effects have affected my quality of life. I consider that a lot more, and I also look at the costs of the treatments a lot more because of again, is it worth me spending a hundred \$200.00 an injection when it's going to make my skin blister and make my wounds bleed more? Or is it worth it? Knowing that, that's a potential side effect, but it's from the medication, not from the condition.

Participant 012_2023AUHIS

No change

I make decisions in the same way.

Participant 002_2023AUHIS

No, I think it's the same. I think I'm the same. I mean previously there was no, there was not any other options other than just tablet taking antibiotics. So you know I I know antibiotics work so if it works then I'm I'm OK to. Taken in my decision has just been guided by my doctor, I guess. Well, you know so.

Participant 017_2023AUHIS

Table 4.4: Decision-making over time

Decision making over time	All participants	
	n=20	%
Change	8	8.00
Changing over time as they are more informed and/or more assertive	4	4.00
Changing over time as they are more aware of their health, responsibilities and/or limitations	3	3.00
Changing over time as they are more focused on quality of life or impact of side effects	2	2.00
Changing over time as they are more cautious and considered	1	1.00
Changing over time as they are more focused on how treatment impacts their family and dependents	1	1.00
No change	10	10.00
No change in decision-making over time and there is no particular reason noted	5	5.00
No change in decision-making over time as they have always been informed/assertive	2	2.00
No change in decision-making over time as they have not needed treatments or no treatment options available yet	1	1.00
No change in decision-making over time as they have not had treatment options to choose from	1	1.00
No change in decision-making over time as they have always considered cost of treatment	1	1.00
Other/no response	2	2.00

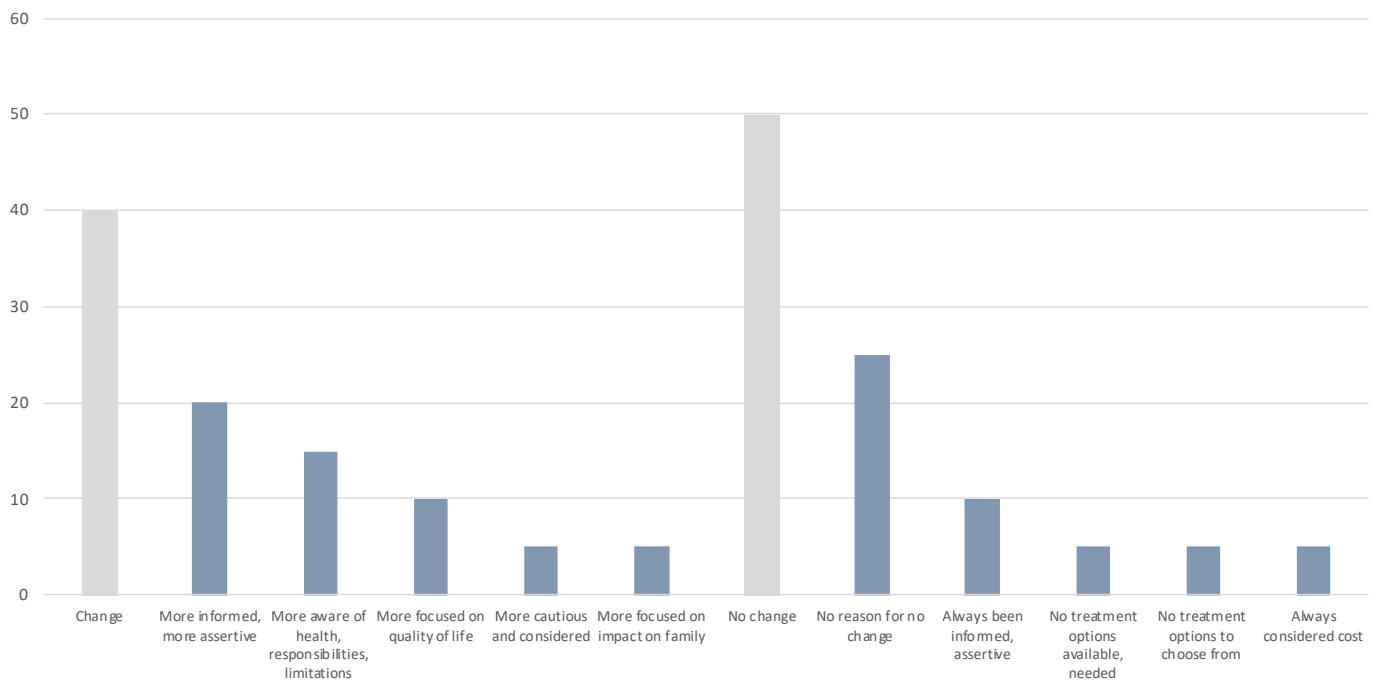


Figure 4.4: Decision-making over time

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (30.00%), to have quality of life or return to normality (30.00%), and minimise or avoid side effects (25.00 %). Other themes included to have physical improvements in their condition (20.00%), to get a diagnosis, treatment plan or have better care coordination (10.00%), to not be on medication all the time or to avoid hospitalisation (10.00%), have improvements in mental or emotional health (5.00%), to get through or finish treatment (5.00%), and to make healthy lifestyle changes (5.00%).

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

Look, I just, so I just like to keep it, you know, dormant really. And just, I mean, obviously I would love for it to be completely gone and not having to, you know, go on another course of antibiotics and use Chlorhexidine, wash every time I've, you know, wash myself and I'm also now using clean detect topical as well. So you know, I'd like to get off the antibiotics and I'd like to get off all the medications. I was already taking diabex. And I'm not diabetic, I was pre, I was insulin resistant quite a few years ago. And so they've said to me just to even though I'm not diabetic, they've taught me to just stay on the diabex as an extra kind of attack. But I think I've had, I've, I don't know whether or not the diabex is actually helping because I've had you know breakout and flareups

while I've been on it so. Yeah. So yes, the answer to your question is to not have to deal with this. That would be the ultimate goal, but just to be able to manage it and manage the pain.

Participant 017_2023AUHIS

Per my personal goals is to keep my HS under control as best as I can. So that obviously means engaging you know with my my doctor engaging with my dermatologist mental health as well can be an issue so also if I need to I do have a counsellor that if I'm not. Not doing well that I seek to fix them as well.

Participant 001_2023AUHIS

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_2023AUHIS

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

My goal was just to just to get treatment. Yeah, so obviously to have a better quality of life.

Participant 002_2023AUHIS

Supposed to be able to minimize impact on my functioning so I can hold down a full time job and do normal things that I, you know, that I want to continue to be able to do.

Participant 007_2023AUHIS

My personal goals are just to manage it and last resort. I take antibiotics but otherwise I'm actually at a good stage at the moment so I'm managing it and as long as I can live comfortably and do my things then I'm happy.

Participant 013_2023AUHIS

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

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

Participant 004_2023AUHIS

Participants describe wanting to see physical improvements in their condition

I mean, I wanted to clear the thing up from my face. I mean, it's kind of cleared up, but the scar's always gonna be there. So I mean, to get rid of the scar would be nice. Since it was, I could hide all my, you know, issues. But now I can't really hide it. It's on my face.

Participant 003_2023AUHIS

Table 4.5: Personal goals of treatment or care

Personal goals of treatment	All participants	
	n=20	%
Participant describes wanting to maintain their condition/prevent worsening of their condition	6	6.00
Participant describes wanting to improve their quality of life or return to normality	6	6.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	5	5.00
Participants describe wanting to see physical improvements in their condition	4	4.00
Participants describe wanting to get a diagnosis, treatment plan or care coordination	2	2.00
Participants describe wanting to not be on medication all the time or to avoid hospitalisation	2	2.00
Participant describes wanting to see mental or emotional health improvements in their condition	1	1.00
Participants describe wanting to get through or finish treatment	1	1.00
Participants describe wanting to make healthy lifestyle changes	1	1.00

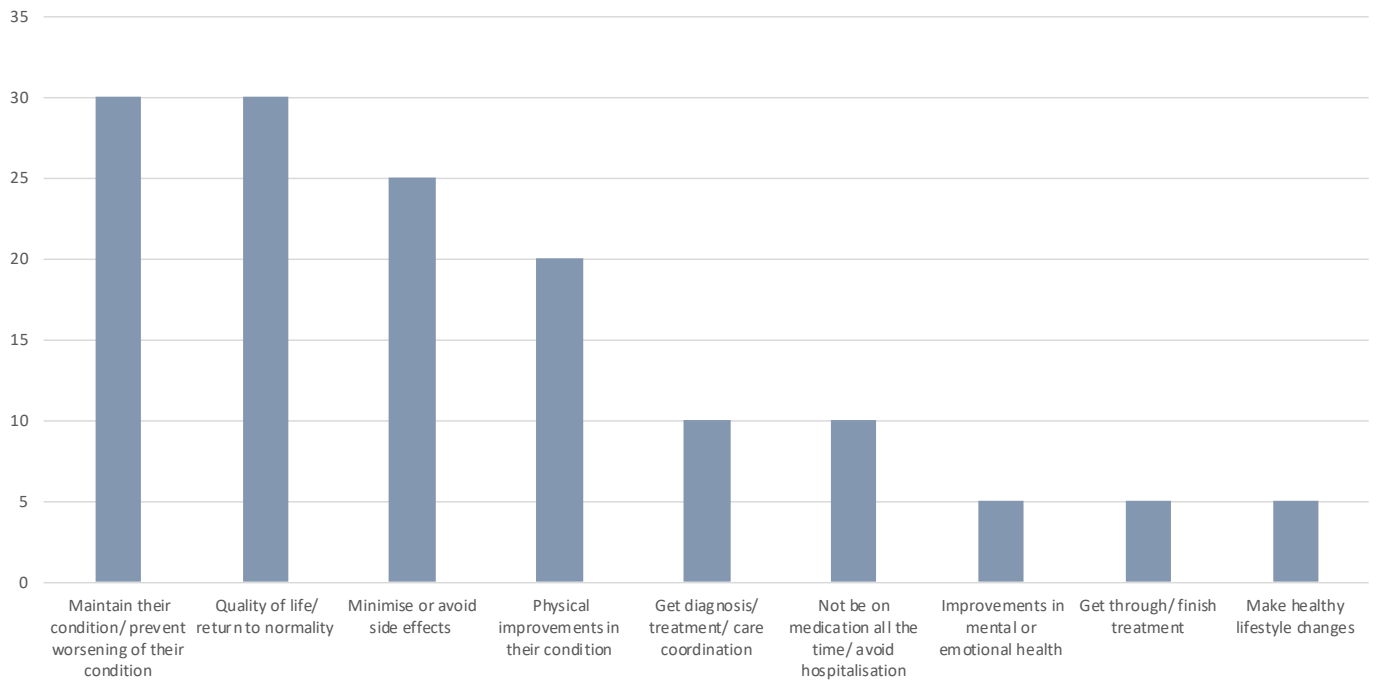


Figure 4.5: Personal goals of treatment or care