

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (70.00%), will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways) (50.00%), and have fewer or less intense side effects/more discussion about side effects (30.00 %). Other themes included remain important but we cannot ignore prevention, awareness and education (25.00%), be easier to administer and/or able to administer at home and/or less invasive (20.00%), be curative (10.00%), involve more clinical trials (including to access new technologies and treatments and funding) (10.00%), allow for a normal life/quality of life (5.00%), and be more effective and/or targeted (personalised) (5.00%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will help to inform the community and decision-makers about their condition (raise awareness) (35.00%), and be more accessible/easy to find (30.00%). Other themes included be easier to understand (20.00%), provide more details about the causes of their condition (15.00%), include more scientific and validated information (10.00%), include the ability to talk to/access to a health professional (5.00%), provide more details about where to find support (including peer support/support groups) (5.00%), and provide more details about where to find support (including peer support/support groups) (5%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (50.00%), and include health professionals with a better knowledge of the condition (45.00%). Other themes included include listening to the patient (20.00%), satisfied with experience (15.00%), and be more understandable (5.00%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include practical support (home care, transport, financial) (30.00%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.00%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (20.00%), include more access to support services (20.00%), will include access to better products such as dressings and underwear (15.00%), will be more holistic (including emotional health) (5.00%), and will include health professionals with a better knowledge of the condition (5.00%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical care through the government (65.00%), healthcare staff (including access to specialists) (40.00%), and the entire health system (25.00 %).

Some participants noted things that needed improvements. The most common responses were that participants were grateful for timely access to diagnostics (10.00%), and the importance of seeing the same doctor and having some control over appointment times (10.00%). Other themes included treatment and medical care close to home (5.00%), the need for quicker access to treatments (5.00%), not being grateful for anything (5.00%), and that regional health needs to be improved (5.00%).

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were to invest in research (including to find new treatments) (50.00%), to be compassionate and empathetic (30.00%), and the need for timely and equitable access to support, care and treatment (30.00%). Other themes included to invest in professional development so that clinicians understand the condition (25.00%), to help raise community awareness (20.00%), that treatments need to be affordable (20.00%), to take the condition seriously (15.00%), that dressings need to be affordable (15.00%), to understand the financial implications (and provide financial support) (10.00%), to have a holistic approach to the condition (including emotional support) (5.00%), to improve wait times (5.00%), to invest in health professionals to service the patient population (5.00%), and to invest in screening/early detection (5.00%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (70.00%), will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways) (50.00%), and have fewer or less intense side effects/more discussion about side effects (30.00 %). Other themes included remain important but we cannot ignore prevention, awareness and education (25.00%), be easier to administer and/or able to administer at home and/or less invasive (20.00%), be curative (10.00%), involve more clinical trials (including to access new technologies and treatments and funding) (10.00%), allow for a normal life/quality of life (5.00%), and be more effective and/or targeted (personalised) (5.00%).

Future treatment will be more affordable

Ideally in a perfect world approved by the TGA. So it's the passport for a start, preferably for everybody tablet form. So we're talking about some kind of antiinflammatory or immuno drug cost is an issue, unemployment is high and people with HS globally.
Participant 008_2023AUHIS

Probably cost is something that I would like to be worked on because a lot of the treatments are expensive. Especially the treatments that actually are effective, I would say. So I guess like the laser treatment, that's thousands of dollars. Like I don't know how I'm going to be able to afford to do that. And I wish that. I don't know, like, I know it's a big ask, but I wish that some of it was covered by Medicare or something like that for people who don't have private health. Even the surgery as well, like it's considered plastic surgery, even though I think it shouldn't be under that category, which then makes it so much more expensive. But yeah, I would say cost is something that I would wish was cheaper in terms of this disease and treatment.
Participant 010_2023AUHIS

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

I think cost and I think access being in a regional area, we're very limited what's here. Everything is expected to travel to the major capital cities for treatment

options and there's a big difference between going accessing things as a private patient versus a public patient.

Participant 013_2023AUHIS

Just that they're accessible. They really don't.

Participant 018_2023AUHIS

Future treatments will have fewer or less intense side effects/more discussion about side effects

Reduced of potential side effects would be good, but the biggest thing would be accessibility and cost. Having it so you don't have to drive to a metropolitan area like Sydney or Melbourne, which are five and six hours away respectively from where I live, and be affordable and be covered so you're not out of pocket hundreds of dollars a week or a month. To to have a quality of life and contribute to the community.

Participant 012_2023AUHIS

Future treatments are important but we cannot ignore prevention, awareness and education

Yeah, yeah. Look, I suppose cost, cost is certainly a challenge or a barrier for some I think access to information about. What the options are and what the possible side effects of of each pathway so that you can make informed decisions about what you're willing to, what you're willing to risk, but also kind of what your probabilities of success are. Yeah, I think, I think more information.and more knowledgeable practitioners.

Participant 007_2023AUHIS

I guess it'd be nice to have more options or more knowledge about it, like because I feel like there's not really much out there. You know, you have like a handful of options and then they're like, now do you want this or do you want the needle? And yeah, cost would be nice. I feel like the medications are reasonably priced, like from what I've bought so far, nothing seems like it's unreasonably priced. I know that there was a cream that I was supposed to buy from a pharmacy that was supposed to compound it, but they never called me back. So I guess I have to call them, but it was going to be expensive, but compounding usually is, I guess. Yeah, I think it's just we need a bit more knowledge out there about it, like more awareness cuz yeah.

Participant 014_2023AUHIS

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

I'd like to see something that you don't have to eat. I'd. I'd. I like to see more advancements in the topical treatments, maybe like a bleach cream or something. You know, like look at what's working and why and do something like that. I heard that someone there was some new trials going on in America or something to do with lasers. I didn't get too much information on it, it was just sort of a news article. But it would be good to see them looking into something more like that than it's all right to get hacked up and stuff if, but like sometimes, yeah, in certain areas it's not really possible. Like you need that area to be able to function, so yeah.

Participant 006_2023AUHIS

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

Yeah, probably what I'd like to see particularly within Australia is, is probably more research so that we get a better understanding of why the condition occurs? Yeah, I guess that would be that would be probably my my ultimate, you know, I think. You know not not all medication works for everyone. So we can bring out a new medication and that may work for me, but it may not work for someone else. So I think ultimately for me, I would like to see more research into the condition and so that we can get a better understanding of of why the condition is impacting so many people.

Participant 001_2023AUHIS

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants	
	n=20	%
Future treatment will be more affordable	14	70.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	10	50.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	30.00
Future treatments are important but we cannot ignore prevention, awareness and education	5	25.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	4	20.00
Future treatment will be curative	2	10.00
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	2	10.00
Future treatments will allow for a normal life/quality of life	1	5.00
Future treatment will be more effective and/or targeted (personalised)	1	5.00

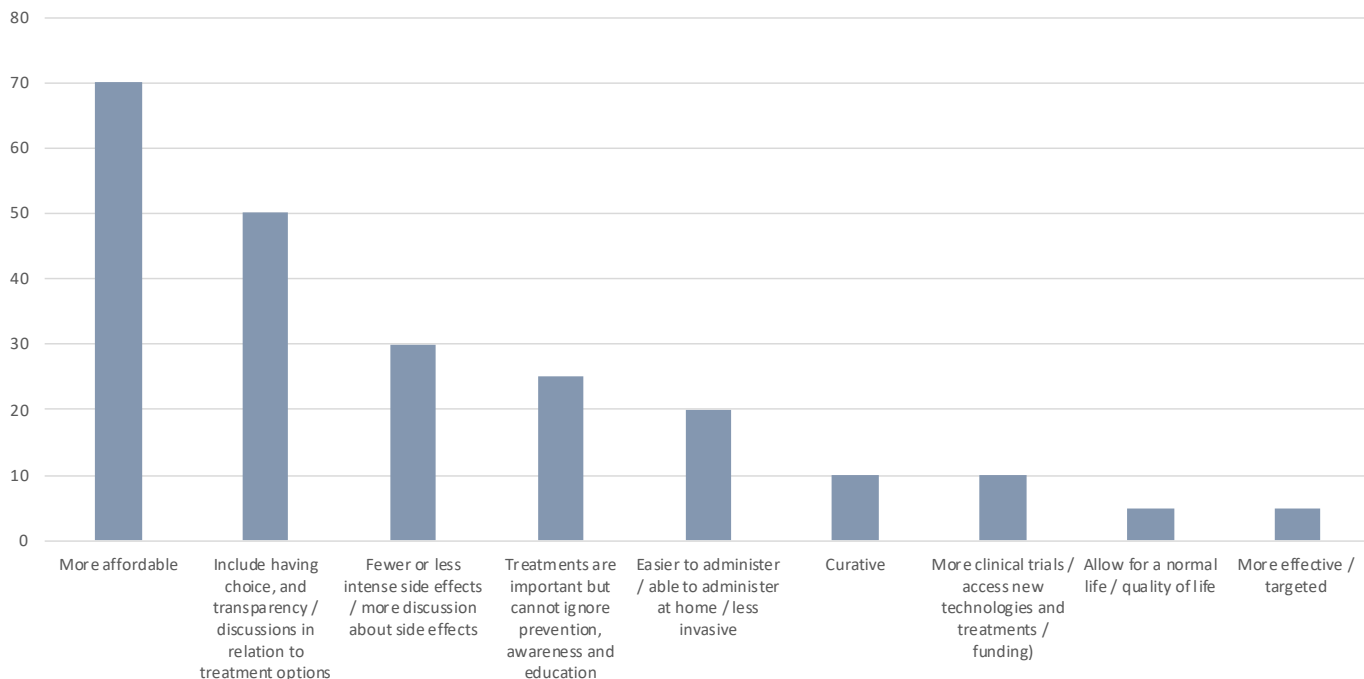


Figure 9.1: Expectations of future treatment

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will help to inform the community and decision-makers about their condition (raise awareness) (35.00%), and be more accessible/easy to find (30.00%). Other themes included be easier to understand (20.00%), provide more details about the causes of their condition (15.00%), include more scientific and validated information (10.00%), include the ability to talk to/access to a health professional (5.00%), provide more details about where to find support (including peer support/support groups) (5.00%), and provide more details about where to find support (including peer support/support groups) (5%).

Future information will help to inform the community and decision-makers about their condition (raise awareness)

I think there's like ads, TV ads in America these days. You just be watching telly and it'll come on with like an ad for Humira or something. You know, to treat hydrogen ititis. Something like that would be good just for other people. I'm already so, like, you know, used to just having to find my own information on the Internet and all that, but just someone who's never heard of it or anything. Hasn't been diagnosed. It might be bloody good for them to see an advert for this on telly and go shit, that's that might be what I've got, yeah. And then finally get some treatment or relief or help cuz yeah. So I don't know, something could be more. Yeah, it's just not out there. I mean, you'll be Googling shoes and an advert for cold sore cream will come up. Do you see what I'm getting at? Like this? Yes. Nobody. Well, I've never heard of this in my life. Yeah. So yeah, I guess that would be good. Just having, I don't know, pay Google to put put the articles where people can see them or something.
Participant 006_2023AUHIS

I have heard about and I guess about HS being like on screen like in TVs on other countries. I haven't heard about it in Australia yet, but like America or Canada or places like that. I've heard them advertising HS to bring awareness to it, so that would be interesting to see.
Participant 014_2023AUHIS

Future information will be easier to understand

PARTICIPANT: Yeah. So for me there really there was kind of a a void of information I felt until I went looking for it. Yeah and you know while I I suppose while I had the capacity to go and look out and understand the process so the medical journals I'm I'm conscious that that's that's not something that everyone can do and so I think you know having yeah having access to information in a in a more digestible way it would be.

INTERVIEWER: Really, really helpful, yeah.

PARTICIPANT: And information too, for medical practitioners, like your GPs, aren't going to come across it every day, because it's not, it's not, it's not that prevalent. But the experience that I had with with the first, like I suppose with the second GP, with the one who came for the second opinion, certainly. Took me back multiple months in seeking further support because of the, I suppose, the way that I was treated at that appointment.

Participant 007_2023AUHIS

I think like I said, information needs to be presented in a more layman type access to. Information like handouts, little information sheets or would be good when you go to appointments and whatnot because you're given all this verbal information. How much do you actually retain once you walk out the door? So leaflets or where to access more information?

Participant 013_2023AUHIS

Future information will be more accessible/easy to find

I guess just. I mean, I spent a good 14 years of my life being misdiagnosed. And you know I don't know if being diagnosed any earlier would have been more or less helpful or not you know but having professionals who are more aware of it, having that information more really available and yeah I, you know talking about health conditions shouldn't be to brew but I something I still struggle with so.

Participant 011_2023AUHIS

It's a good question. Like. I don't know what's been happening since 2018, when I last saw a dermatologist, but ideally I'd like to see information from the dermatologist like like they have in other diseases, you know, handy little pamphlet. I'll explain it. Something you enjoy. The family and friends say, look, hey, it's not in my head. It's a real disease. Have

a right mate. Instead, what we have is something that's not discussed behind closed doors in a lot of families. Ideally from dermatologist, I think it'd be better.

Participant 008_2023AUHIS

Honestly, I can't think of anything that I'd like to suppose. Probably the biggest thing for the inaccuracies and the discrepancies to be cleared up like more research put into the information presented rather than taking bits and pieces from different studies and pasting it into a PDF. Which have have come across in some instances. Participant 012_2023AUHIS

Future information will provide more details about the causes of their condition

PARTICIPANT: Well, pretty much what like the underlying issue of the condition is our hair follicles under our skin, like that's what causes. Our condition. I mean, I want that to pass everywhere because all those doctors have misinformation saying we're overweight, like we don't shower enough and all this, blah blah, blah. Like I'm very hygienic. I had two showers a day only because recently I found only

having one wasn't enough and I just felt gross still. But yeah.

INTERVIEWER: It sounds like you've got some solutions you're trying, which is good.

PARTICIPANT: Yeah, and like, they work for a little bit, but then, you know, go stop and change, see what works.

Participant 003_2023AUHIS

Yeah, the psychological impacts and what to and signs and what to look out for. I the the fact that it's more known that it's it, you know more more females are affected by it, it makes it it hard to to find information out. Between how this affects people of the different sexes even the flare zones can be different and I'm not saying that one's got it well I think actually think women have it worse than than than men cause they've got more places to get it. But having said that it's like yeah it and and and more education more information on as you were saying initially the the the genome testing because I'd love to know. I'd love to. I would actually. That's where I'd like the treatment to go is to maybe you know, if there could be some genetic, some genetic modification to to delete it from the the genetic code.

Participant 009_2023AUHIS

Table 9.2: Expectations of future information

Expectations of future information	All participants	
	n=20	%
Future information will help to inform the community and decision-makers about their condition (raise awareness)	7	35.00
Future information will be more accessible/easy to find	6	30.00
Future information will be easier to understand	4	20.00
Future information will provide more details about the causes of their condition	3	15.00
Future information will include more scientific and validated information	2	10.00
Future information will be in a variety of formats	1	5.00
Future information will be more holistic (including emotional health)	1	5.00
Future information will be more positive/not focus on the worst case scenario	1	5.00
Future information will include the ability to talk to/access to a health professional	1	5.00
Future information will provide more details about where to find support (including peer support/support groups)	1	5.00
No particular comment - satisfied with experience	1	5.00

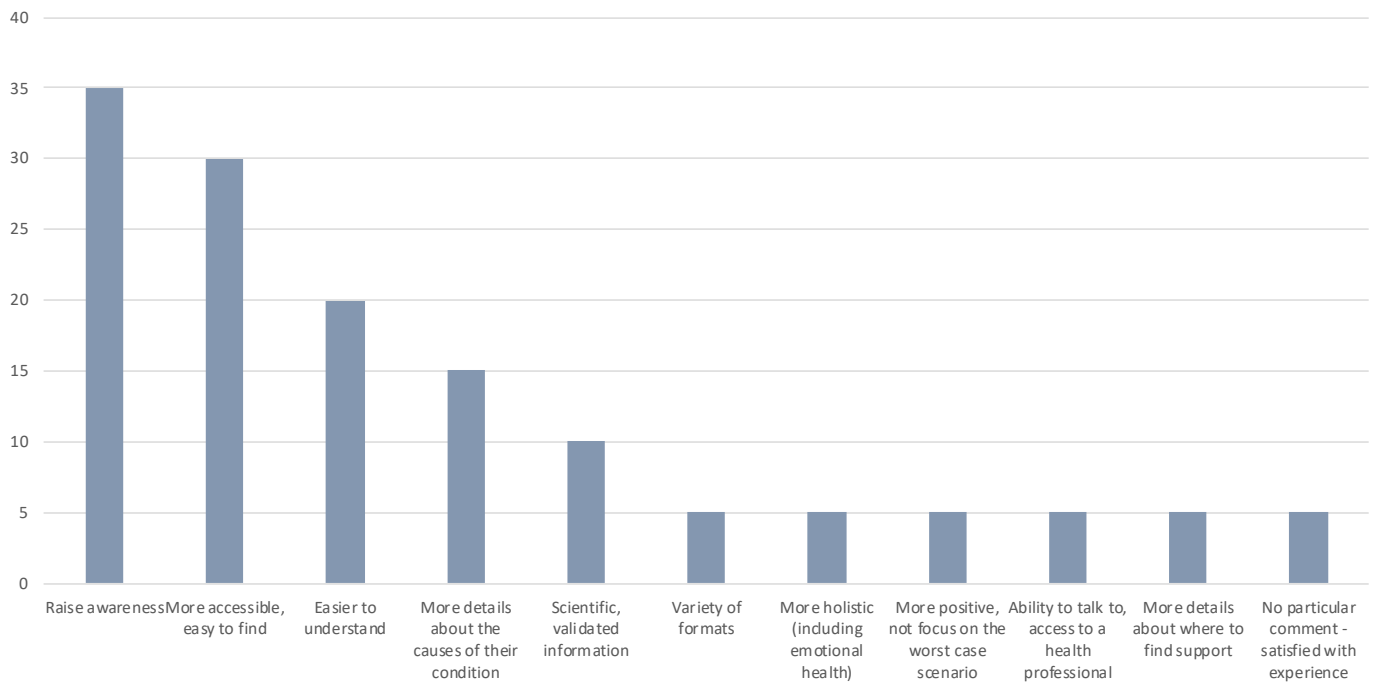


Figure 9.2: Expectations of future information

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (50.00%), and include health professionals with a better knowledge of the condition (45.00%). Other themes included include listening to the patient (20.00%), satisfied with experience (15.00%), and be more understandable (5.00%).

Future communication will include health professionals with a better knowledge of the condition

***PARTICIPANT:** Yeah, I think they need some education. They can do a lot of harm because they're not aware of the sociology, psychology and psychiatry that is being discovered about HS populations like there's a lot of commonalities.*

***INTERVIEWER:** Yeah*

***PARTICIPANT:** I just think if doctors were more informed, they might develop a higher sense of empathy and to help us without harming us. That's it. Participant 008_2023AUHIS*

That's a good one because I feel like so 99%. I feel like 90, 90% of health professionals don't really know what it is, so therefore don't know how to communicate. You know they communicate with you

on a on a clinical level and like oh, you've got, you know an infected hair follicle, which was one that I always got told it was. But they don't actually tell you why you're continually getting these infected. Do you know what I'm and then when I actually got the diagnosis, it was quite abrupt. I felt like the the doctor was quite A and I know. I know working in cancer, you can't sugarcoat these things. They have a they're not allowed to, you know. But I think this is not, this is not cancer, this is a skin and auto inflammatory disease, I think. I just think it was quite abruptly, you know this, but you've got it for the rest of your life. There's no cure for it. And so maybe a little bit more easing into the whole thing might have been. That could just be my personal receptiveness too. And I know I've had patients say to me, I don't ever want to see that doctor again because his bedside man is terrible. And that's just because they are just being honest and you know, that's what they have a duty of care to tell the truth. But I I feel like with with this, I just felt like it was quite a it just threw me. I was really. Prepared to learn that I had something that was incurable.

Participant 017_2023AUHIS

Future communication will be more empathetic

I think healthcare professionals need to understand the condition more from the patient's point of view. An example that would be my GP didn't understand that for a lot of people HS causes severe tiredness and.

You know the the people that I've I've communicated with peers that have the condition, sorry excuse me have certainly said that's one of the things that they struggle with is tiredness. So yeah I think, I think the GP's, I think GP's dermatologist, anyone dealing with it is understand it from the patient's point of view. It's it's wonderful to say we can give you this, this and this treatment but you need to understand the impact. On the condition on the person.
Participant 001_2023AUHIS

Excluding my current health professional because they're actually, they're really, really good about it. So it's the biggest thing I'd like to see changes. Health professionals taking it upon themselves to think that the condition is related to somebody's weight or somebody's hygiene practices when neither are true. And both have been disproven quite regularly because up until my current GP I've had GPs tell me I need to lose weight despite being a very healthy fit 72 kilos. Which is overweight on the BMI scale for my height, but my dress size was a size 8, so there was hardly any fat on my body at the time. But I still weighed a lot and I was still told I need to lose 10 kilos to get in front of my condition. I was told I needed to shower more. I needed to shower four times a day rather than once a day, and the once a day was problematic because the more I showered, the more my condition flares. So that that advice was pointless and people still get that advice from health, from health practitioners and it needs to to stop really. It comes across as ignorant and it really affects people's mental health. Like my weight at the moment is 96 kilos. I am pregnant. When I started pregnancy I was 90 kilos and I was that way because of medication and because of lack of mobility, because of this condition. Not because of me eating unhealthy or being unable, not wanting to exercise.
Participant 012_2023AUHIS

Yes, don't blame me on people, people's weight. And stop making them feel that something that your body creates or its own accord is their fault. The shame that

is associated is insane. I know that people's diet and exercise and weight contribute. It is not something that we made ourselves have. It's not like smoking gives you lung cancer. Like, yes, it's your fault you did that. But it's not just unfit people that have HS, it's not just people who can't afford to have a good diet.
Participant 018_2023AUHIS

Future communication will include listening to the patient

Yes, health professionals need to listen to their patients. I've lived with this disease for 33 years now, and I know pretty much every aspect of it with regards to my personal experience. But they all seem to think that they know better than me, especially when you go to a GP or the hospital. They, you know, they say, oh, it shouldn't be that painful. Well, I'm sorry about that. I'll be sure to let the lesions know that they shouldn't be painful moving forward.
Participant 005_2023AUHIS

I think this. You know, respecting their experience of it, they live the experience of it and not not making assumptions about how they might already be managing things. Yeah, just treating them as people rather than this object would be good.
Participant 007_2023AUHIS

No particular comment - satisfied with experience

So far, no. I think that's just for my personal experience. I have a really good specialist, so. In my experience, I'm quite happy with the way that I communicate with my doctor, so nothing I would really change.
Participant 010_2023AUHIS

No, I don't think so. I think it's all right from my point of view in.
Participant 013_2023AUHIS

Table 9.3: Expectations of future healthcare professional communication

Expectations of future communication	All participants	
	n=20	%
Future communication will be more empathetic	10	50.00
Future communication will include health professionals with a better knowledge of the condition	9	45.00
Future communication will include listening to the patient	4	20.00
No particular comment - satisfied with experience	3	15.00
Future communication will be more understandable	1	5.00

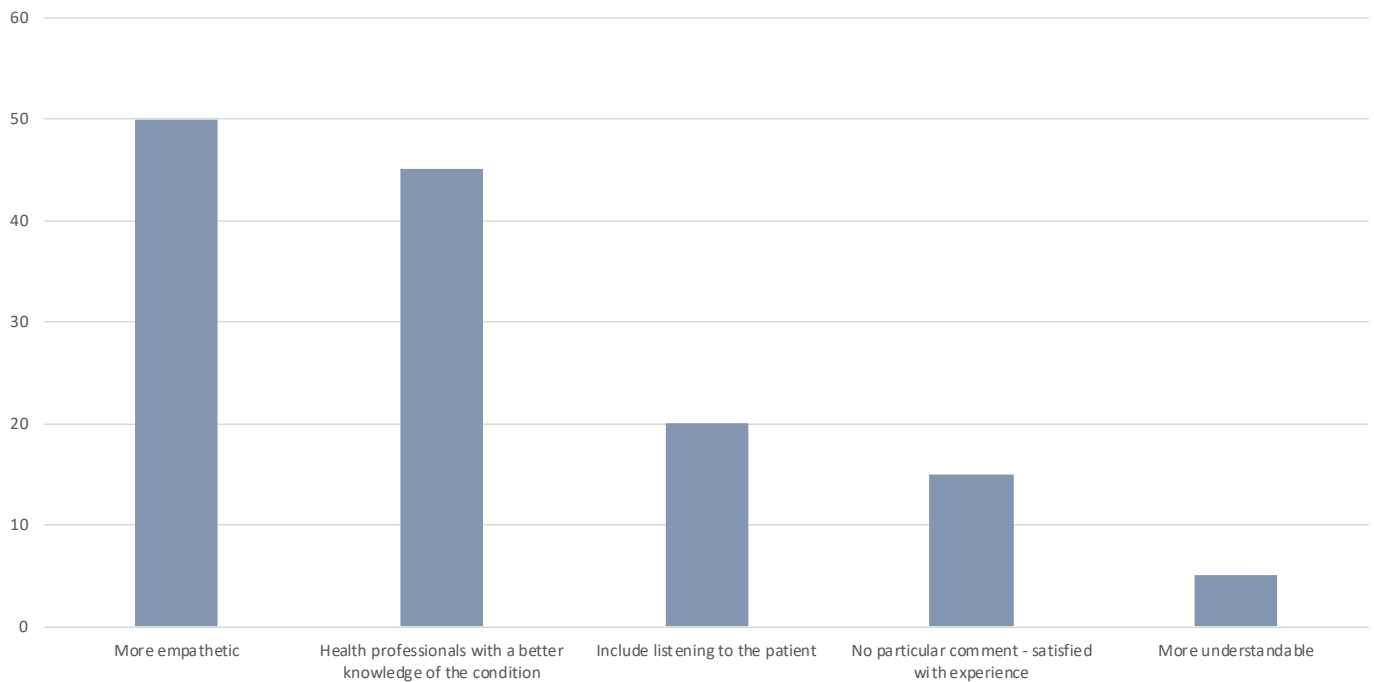


Figure 9.3: Expectations of future healthcare professional communication

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include practical support (home care, transport, financial) (30.00%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.00%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (20.00%), include more access to support services (20.00%), will include access to better products such as dressings and underwear (15.00%), will be more holistic (including emotional health) (5.00%), and will include health professionals with a better knowledge of the condition (5.00%).

Future care and support to include practical support (home care, financial)

I guess just, yeah, making things more affordable like I shouldn't have to with this pain when I am having a bad fella. I don't know that I'm. I'm not even a worst case scenario, a paycheck. You know, like I'm still pretty, you know, in the mild category compared to what I've seen other people go through. So yeah, having some sort of support having, you know, if there's a day that I literally can't put underwear on

and walk around without being in pain, being able to have a day off of work without that costing. They are costing me substantially, you know. Yeah. Because it it does feel like a bit of a, you know, disability sometimes to a lot of people that do have this in a significantly worse case.

Participant 005_2023AUHIS

Our biggest cost comes from accessing poor quality dressings at astronomical prices, and we don't have access to HS specific dressings that have been created. But they're not approved or they're not allowed to be in Australia. So we're left without and it's not really fair. And Medicare won't cover any dressings at all. My previous surgeon, he tried. He tried to get me to go use the community nurse so that dressings will be covered, and every time he'd refer me, I was disbarred almost immediately from the service. Because you can dress yourself. You don't need the community nurse to dress you. Medicare doesn't cover dressings. It covers the nurses nurse doing the dressing, which isn't fair. It isn't right and it's now put us in this in more. In my instance, it's put us in a financial position where I have to. Cut back on groceries to cover dressings.

Participant 006_2023AUHIS

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I've been thinking about this interesting development in. One Danish city from 1 Danish hospital. They offer a 24 hour HS clinic. Something like that needs to happen in Australia for the future because there's people like me who just live in misery. 24 hour care the 24 hour clinic, a specialized clinic from doctors and nurses who know all about HS.

Participant 013_2023AUHIS

Maybe just awareness to more doctors and hospitals. I think when I was younger I saw a GP, they didn't even know what they were looking at and I think if they had of known, I probably would have been able to get treatment like proper care a lot sooner. Maybe having a better skin clinic services within the public hospital so that people who have this disease don't have to fork out thousands and thousands to receive treatment for something that, you know they're born with, that they can't help that they have.

Participant 004_2023AUHIS

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

It would be lovely. It would be great to see more. I would like to actually see some some more media stuff so that HS is normalized a little bit more. Yeah. So I would love to see some stuff on media so that it was it was normalized. That the community understood that the condition exists and that there were a lot of people in the community with the condition. I would like to see peer support groups. Maybe develop like face to face groups in communities would be great, particularly if there's communities that have, you know, high, high concentrations of the condition. I think, yeah, to be able to meet with others that understand and are walking that journey is absolutely valuable.

Participant 008_2023AUHIS

PARTICIPANT: I think I feel like something that was really lacking was the capacity or or the Informa or like the the the invitation. I don't know whether there's anything out there around a support groups with people that have rarer set of conditions that can be that can be very isolating. I don't it's possible that that's accessible. In more metropolitan areas, I'm not

sure, but certainly out here in this rule space is very isolating

INTERVIEWER: Yeah. Connecting like yeah.

PARTICIPANT: Yeah. And I think that I think that could certainly be a support.

Participant 010_2023AUHIS

Future care and support will include more access to support services

I think that's really difficult because you know I have that support group and you know I think it's like a centralized place, but I think at least one where it was giving constant information to patients if they in lieu of being able to get it from their doctor, what's a new study, What's a new report? ... Just awareness, you know, those sorts of things. Get in, get involved. I'd like to see some centralized place where we wouldn't have to hear it from each other or in the pipeline or by third, you know, Chinese whispers. I would like a, a service. Otherwise I'd also like, you know, inclusive, you know, current governmental or administrative policies in relation to the other kinds of healthcare that we could be receiving such as, you know, disability support or care or services or carers allowance or you know what the current position is on that, what's the threshold for it. Who can you talk to if you need advice in relation to it so that we're not alone? Just smashing our own head against the wall, trying to work out how we're supposed to help ourselves? You give up. Absolutely give up now.

Participant 015_2023AUHIS

Yeah, like proper support services, not just a group of people on Facebook that all have the same disease. So a network where you can actually. Like I've had, I've had times when I have had flares that are out of control. I can't, I don't know what to do. Like I've reached the point where I've literally, I end up at at emergency because I don't know what to do. So, you know, having a support service, you know, like I don't know if you have it up in Queensland, but like we have like a one 806 number in New South Wales that you can actually speak to registered nurses. Yes. Yeah. Having something like that specific to the disease that you can make contact with someone and say, okay, what do I do? Yeah, yeah. Have I reached the point where I don't have a choice, I have to go to hospital or is there something else that I can try? Participant 011_2023AUHIS

Access to Better products: dressing, underwear

I think the cost of dressings and support that way. So nurses at GP clinics where you tend to go educate there, they have very limited dressing supplies, chemists. Don't have much and their prices are exorbitant. So like hospitals or the GP clinic, they need to help you access a wider range of dressings at a reasonable price.

Participant 001_2023AUHIS

I think it would be good that if there was a service where. Dressings teaching people how to do do their own dressings mate you know maintaining them. Lots of people don't know it's yeah we didn't know what

type of dressings it's just within trial and error yeah I I just think maybe some educational sessions for for people and also access to actually change you know because there's some people that have. Dressing that have them, the flares in the most horrendous places that they can't get to, they can't apply easily apply a dressing to. There's a company over in, I think it's Canada and they do specific hidradenitis underwear and it's designed, but they don't, they don't sell it, they can't, they they don't send it to Australia, so. Yeah, it's designed so that you can it's it can hold the patches in place and things like that and I only found that out by looking on the like searching on the on the Internet, but they don't. Yeah deliver to Australia yet.

Participant 003_2023AUHIS

Table 9.4: Expectations of future care and support

Expectations of future care and support	All participants	
	n=20	%
Future care and support will include practical support (home care, transport, financial)	6	30.00
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	6	30.00
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	20.00
Future care and support will include more access to support services	4	20.00
Future care and support will include access to better products such as dressings and underwear	3	15.00
Future care and support will be more holistic (including emotional health)	1	5.00
Future care and support will include health professionals with a better knowledge of the condition	1	5.00

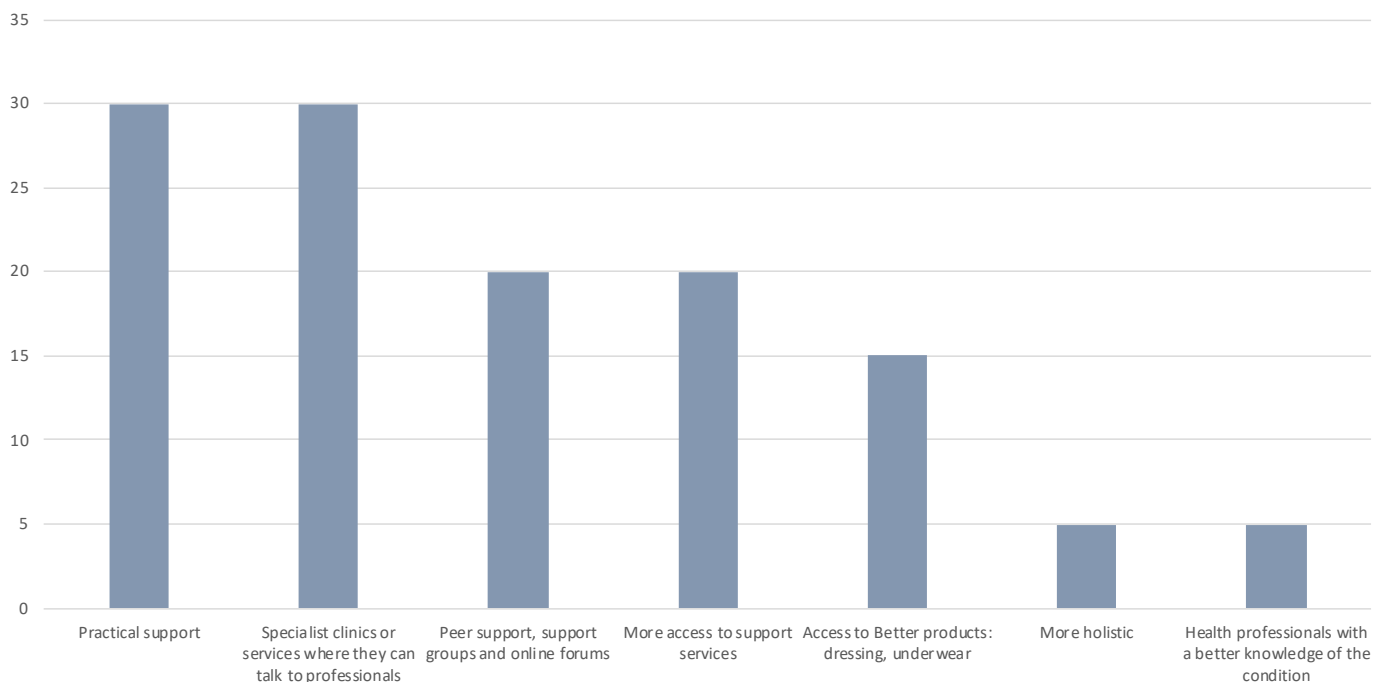


Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical care through the government (65.00%), healthcare staff (including access to specialists)(40.00%), and the entire health system (25.00%).

Some participants noted things that needed improvements. The most common responses were that participants were grateful for timely access to diagnostics (10.00%), and the importance of seeing the same doctor and having some control over appointment times (10.00%). Other themes included treatment and medical care close to home (5.00%), the need for quicker access to treatments (5.00%), not being grateful for anything (5.00%), and that regional health needs to be improved (5.00%).

Participant describes being grateful for low cost/free medical care and treatment through the government (Public health system in general)

I'm just, I'm thankful that we actually have a health system where we can access pay for the treatments. I'm extremely thankful that we have PBS where I can pay \$30.00 a month for my Humira and not, you know, the two and a half thousand a month or whatever it is for it I'm thankful for. Chronic illness program that we have where I can access other services like counseling, physiotherapy, that sort of thing.
Participant 009_2023AUHIS

Yeah, definitely the fact that I could access the public hospital system to have those surgeries, that's huge because, you know, without I never would have been able to afford to do that privately and I don't have any private health insurance. And so, you know, without that, I'd probably still be sitting here with the conditions getting worse and aware and having a much bigger impact on quality of life.
Participant 017_2023AUHIS

Well, I have been grateful that a lot of the surgery that the surgeries I've had so far have not had to pay for, but they have been covered by Medicare when I've gone to the hospital, but that. That's where my gratitude ends, because from my experiences, from my accessibility, the healthcare system, the only thing I can be grateful for is that we are not yet an American healthcare.
Participant 019_2023AUHIS

Participant describes being grateful for healthcare staff (including access to specialists)

It's been great to access dermatologists and whatnot, but I think that also depends where you live and access, cause a lot of them are bound in the capital cities. I'm a regional area so there's things like cost, travel, overnight accommodation, incidentals that aren't taken into account and once again, I think the public system, while it is great. You see doctors who are rotating through. There's no consistency versus seeing someone privately where you see the same person time after time, which is very beneficial. It's not the public system's fault that doctors move on and what not, but you're just a conveyor belt. There's no consistency and that is actually quite harmful to the sufferer because they didn't have to go through everything. Explain everything and then you've it's up to that particular doctor whether we start again from point I or whether they continue on the conveyor belt of treatment options.
Participant 005_2023AUHIS

I'm very grateful for the, very grateful for the fact that we got referred to a dermatologist very quickly from the GP and that we, the dermatologist was able to fit us in because he had a three month waiting waiting list or 4 four month waiting list and because of his age and yeah, the. They they spotted him in within like I think we got in within like 2 weeks. So I'm very grateful for that, very grateful for the the, the way a child was prioritized.
Participant 007_2023AUHIS

Definitely PBS medication. I'm like for other conditions I have. Quite a few non PBS medications. It makes big difference, yes, and I think easy access to the specialists and things like that as well.
Participant 012_2023AUHIS

Participant describes being grateful for the entire health system

Very much so. I think I said it earlier as an Australian, I feel very fortunate that we do have a good healthcare system that we do have the option of having the drug approved so that we only pay dispensary costs, not the two and a half, \$1000. We don't have to have private insurance to access hospitals. We don't, you know at the dermatology clinic I don't pay for. I see some of the best. Doctors around in my state that that understand HS and it doesn't cost me anything. Sure there's a wait and you

have to sit in line. You know the de roofing surgery that I'm waiting on at the moment will be through public health, through the plastic surgeons in public health. There's a wait. I have to wait for it. But I've waited 30 years to to get some help, so. You know, if I have to wait two more years for the surgery that sets me free, then so be it.

Participant 001_2023AUHIS

What? Now you know it? I I might sound like I'm complaining, but absolutely everything. The fact I could just rock on to HOSPITAL with a giant lump on my leg and go and they've gone right, come on in, we're just going to cut it out and it's done. And you know, nothing bad to say about the healthcare system in Australia.

Participant 003_2023AUHIS

Table 9.5: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants	
	n=20	%
Participant describes being grateful for low cost/free medical care and treatment through the government (Public health system in general)	13	65.00
Participant describes being grateful for healthcare staff (including access to specialists)	8	40.00
Participant describes being grateful for the entire health system	5	25.00
Participant describes being grateful for timely access to diagnostics	2	10.00
Participant describes the importance of seeing the same doctor and having some control over appointment times	2	10.00
Participant describes being grateful for treatment/medical care close to home	1	5.00
Participant describes that there is a need for quicker access to treatments	1	5.00
Participant describes not being grateful for anything	1	5.00
Participant describes that regional health needs to be improved	1	5.00

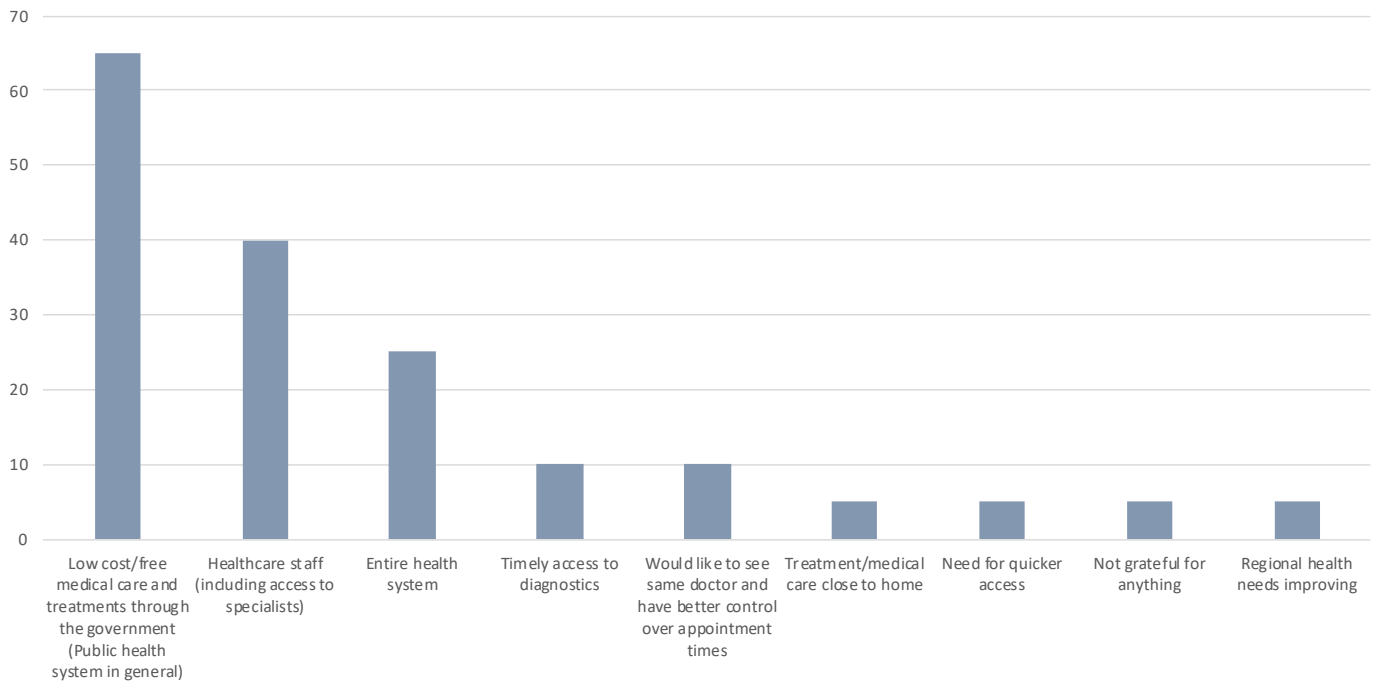


Figure 9.5: What participants are grateful for in the health system

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were to invest in research (including to find new treatments) (50.00%), to be compassionate and empathetic (30.00%), and the need for timely and equitable access to support, care and treatment (30.00 %). Other themes included to invest in professional development so that clinicians understand the condition (25.00%), to help raise community awareness (20.00%), that treatments need to be affordable (20.00%), to take the condition

seriously (15.00%), that dressings need to be affordable (15.00%), to understand the financial implications (and provide financial support) (10.00%), to have a holistic approach to the condition (including emotional support) (5.00%), to improve wait times (5.00%), to invest in health professionals to service the patient population (5.00%), and to invest in screening/early detection (5.00%).

Invest in research (including to find new treatments)

It's quite limited unless you're really severe. And I think there needs to be a bit more funding and research into the area to I guess support patients who aren't quite that bad yet.

Participant 013_2023AUHIS

There's just not enough. There's not enough. There's not enough information, there's not enough research being done. And at the end of the day, there's not enough information or solution or treatment plans because nobody's put the money in to actually research what the hell they need to be doing to fix this. So, you know, we're just going to remain in the same place where people are getting no care. They're speaking to doctors and GPs who have no idea what they're looking at, and we just go around in a circle and everyone suffers, basically because there's nobody who has the money to sit down and do research on this properly. And yeah, like, I don't think the lack of care and lack of everything that I've experienced is because it's there and I'm just not getting it. It's not there at all. It just isn't there. There's no magical medication and there's no specialist here and there's nothing. So it's just like this. It's not, I'm not getting it. It just doesn't exist. It doesn't exist because there's been no money put to it. And yeah, people don't know. We couple million on fireworks but can't sort this out. So yeah, it's stupid, really, considering how physically painful this is, it's not just like, oh, I've got a pimple or I'll just pop the pimple. It's literally like having holes burnt in you. It's it's it's it's excruciating and it's not. Yeah. Yeah. I I think that's the thing. People just think oh, you know, it mustn't be so bad. It's like if you it's the one of the most painful skin conditions on the planet that you can have. So that doesn't, you know. Yeah.

Participant 006_2023AUHIS

Compassionate and empathetic

I would just, I would just be asking him what he thought about it and when he said I have no idea, I'd say, well, I don't either. And I'm a victim and a sufferer and A and I'm living with this on a daily basis and I am lost in the weeds. About what to do who? To see what's available? What does this mean? Where can I go? How can I help myself? And if he doesn't have a clue, you know, then I want him to reflect on that and know that that is exactly how I feel with the condition that I am currently suffering on a daily basis. It's not even never heard of it before. It is literally just oblivious nothingness, covered in hopelessness and

and fear and absolute sheer will behind it. If I can be withstanding this and I'm thankful enough to be surrounded by the the loved ones that I have and as I said, I've I've got supportive. Practitioners allied health as well who absolutely hear me when I talk about my condition and and that's critical for me it's not enough you know I I'm a go getter and I am a a self improver notwithstanding you know indulgence on on chips. But it's I don't. I'm not sitting here asking somebody to make me better. I'm absolutely prepared to take steps to, to actively help myself. Just tell me where and what where, who, where is this? What am I supposed to be doing? What's available? How can I access it? So that's what I would say, OK?

Participant 007_2023AUHIS

Timely and equitable access to support, care and treatment

My message to him would be to refund Medicare again, to pull his finger out, and to stop pushing private healthcare. Because it's ridiculous. The amount of wait times that we have to see specialists, the amount of wait times that we have for surgeries, and the poor quality of life and the ignorance surrounding our condition is a lot higher than it should be. There's a lot of us that are unable to work that don't qualify for Centerlink because that's not viewed as a disability. It's not it's it's viewed as a burden on the healthcare system, but it's not viewed as enough of a burden to require any other assistance outside of to go to the ER you get and then some drainage or you get a surgery if it's emergent enough, but living with the condition every day. The pain we go through every day, it is emergent, it is constant. It's raw, blistering nerve pain that we can't mentally push through. We can't change. Like I have heard stories and read testimonies of people stabbing themselves to relieve the pain, and that's in Australia. And I was one of, I was nearly one of them. If I hadn't have been admitted to when I went to LOCATION, I would have stabbed it myself to relate the pain. Because my body was saying we need to get this infection out and it wasn't getting out. And to go to to go see a surgeon rather than to go to the emergency room were insanely high, like four to five months for a consult. When it needs to be length, it needs to be drained within four to five days.

Participant 012_2023AUHIS

Invest in professional development so that clinicians understand the condition

Okay, yeah. Look, I think that's a hard one. I think the. The biggest things are having a like an an upskilled General practitioner network, or a place where they can, you know, access information that they're not familiar with. Would be would be eonderful to have that, because I think that information were available earlier it would make a difference to people. I think you know, being able to to create the spaces were like support groups. The peer support groups are supported by then professional like medical practitioners who can guide and support those kind of conversations. So it doesn't also become a really scary space, but I think, I think that could be a great support from a mental health perspective for people. So. So one thing I did think when I when I then started connecting with more of the lived experience, I went, okay, if I need a career change and I need to and I need to. Kind of pivot so I can work from home because I can no longer move and function in the community. I thought it'd be great to sort of specialize in in actually providing psychology services for patients that are experiencing those sort of health concerns from really rare conditions where they're so unsupported. And I guess I saw that as a big gap. Yeah, but for others, for patients across that board, that was quite the most hysterical on the end of their keyboard.

Participant 010_2023AUHIS

I definitely feel like there needs to be more awareness within the medical industry, because people with HS are going, you know, 10 plus years without a diagnosis or being misdiagnosed with things like staff or whatever else it be. Because people just don't know what it is and they're showing medication after medication at you, which is just destroying your insides instead of actually helping you. So we need the actual help instead of guesses.

Participant 011_2023AUHIS

Help raise community awareness

Education. More awareness? Yeah, more support for when you physically can't get up and do the activities you need to do cuz you're in so much pain.

Participant 008_2023AUHIS

Treatments need to be affordable

My gosh, probably just making the treatment cheaper and providing more options to people with this treatment. Because as far as I'm aware there aren't

many. There's three routes that this treatment kind of can go in and also just push for funding treatment, funding for research of the treatment because like I said so far, they don't have any cure or any, you know, 99% effective treatment. Everything is kind of just it's just like a Band-Aid. You know, it helps for a bit and then it comes back and there's no real trick that keeps it away for good. And I know that's, you know, a huge ask, but I just wish that there was more research going into the disease and how to prevent it and how to kind of stop it as soon as you see it come up, I guess.
Participant 015_2023AUHIS

We need to have better access. Costs need to be reduced and better education. We're getting there, but we've got a long way to go.

Participant 019_2023AUHIS

Take the condition seriously

PARTICIPANT: OK. I'd say did you know there's a skin disease? Which probably has more people than psoriasis in Australia and there's only one drug available for treatment and there's a lot of people out there in pain and in misery. I don't know. I'm not sure.
INTERVIEWER: No, no, that's good. Thank you.
PARTICIPANT: I get emotional about this stuff.
Participant 014_2023AUHIS

Well. They need access. Oh, that's one they need. They need subsidised access to to dressings. They need extra sick leave. They need additional sick leave to for for their their flares. Well, I don't care if it has to be that it has to be a doctor, certificate one or whatever, but they need additional and they need because it is a, it's a, it is a hidden disability and it needs to be much more made, much more aware of in the workplace that people have hidden disabilities and they get special consideration, parking, everything. Disabled parking is another one because when they're having an active flare they are as disabled as anybody else who is disabled. But when they're not having an active flare then yeah they they they shouldn't be using it. But I think access to disabled parking when required should be available.
Participant 009_2023AUHIS

Dressings need to be affordable

I would say. You need to put more money into HS research and there needs to be more help financially for things like dressings and at home care like for hecsadine, those sorts of things.
Participant 001_2023AUHIS

Table 9.6 Messages to decision-makers

Message to decision-makers	All participants	
	n=20	%
Invest in research (including to find new treatments)	10	50.00
Compassionate and empathetic	6	30.00
Timely and equitable access to support, care and treatment	6	30.00
Invest in professional development so that clinicians understand the condition	5	25.00
Help raise community awareness	4	20.00
Treatments need to be affordable	4	20.00
Take the condition seriously	3	15.00
Dressings need to be affordable	3	15.00
Understand the financial implications (and provide financial support)	2	10.00
Holistic approach to the condition (including emotional support)	1	5.00
Improve wait times	1	5.00
Invest in health professionals to service the patient population	1	5.00
Invest in screening/early detection	1	5.00
Unsure what to say	1	5.00

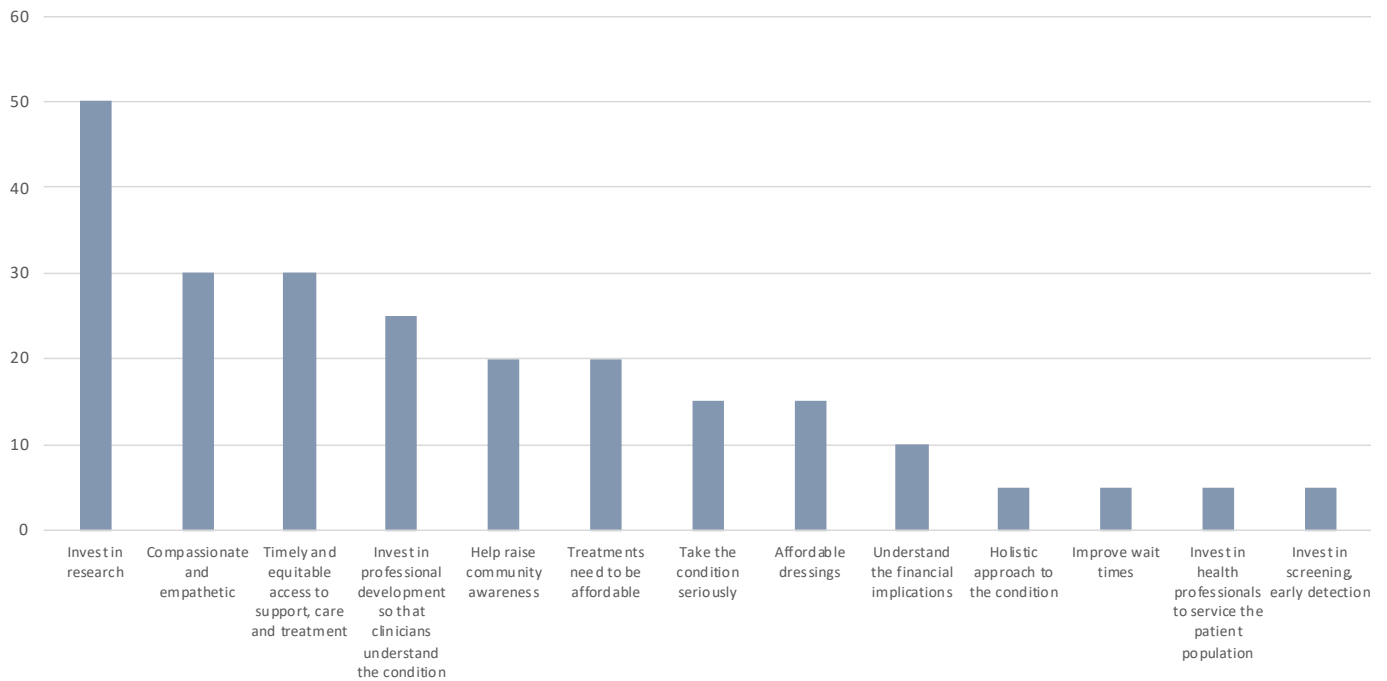


Figure 9.6: Messages to decision-makers