

Section 6

Information and communication

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Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (65.00%), from other patient's experience (Including support groups) (50.00%), and from journals (research articles) (50.00 %). Other themes included from Facebook and/or social media (45.00%), from a specific health charity (20.00%), their treating clinician (15.00%), and from presentations or webinars from doctors and researchers (5.00%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (25.00%), information about triggers and managing exacerbations (20.00%), and medical journals (15.00 %) were helpful. Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (10.00%), no information especially helpful (10.00%), treatment options (5.00%), all or any (5.00%), YouTube or webinars (5.00%), lay summaries (5.00%), and information about emotional and mental health (5.00%).

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Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (20.00%), other people's experiences (15.00%), and GP or specialist (15.00 %). Other themes included confident in deciding themselves (10.00%), sources that are not credible (Not evidence-based) (10.00%), a lack of new information (5.00%), unsolicited information (5.00%), worse case scenarios (5.00%), not type specific or too general (5.00%), and information from pharmaceutical companies (5.00%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were online information (40.00%), and talking to someone plus online information (30.00%). Other themes included written information (10.00%), all forms (10.00%), and talking to someone (5.00%).

The main reasons for a preference for online information were accessibility (35.00%), being able to digest information at their own pace (20.00%), The main reasons for a preference for talking to someone was being able to ask questions (20.00 %). The main reasons for written information were being able to revisit the information (10.00%), and having pictures to help with understanding (5.00%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were continuously (40.00%), and at the beginning (diagnosis) (20.00%). Other themes included two months after diagnosis (10.00%), 12 months or more after diagnosis (10.00%), when seeing someone that was an expert in disease (10.00%), three to four months after diagnosis (5.00%), and not much information at time of diagnosis (5.00%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative (50.00%), overall positive, with the exception of one or two occasions (25.00%), and overall positive (10.00 %).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (25.00%), good, with no particular reason given(5.00%), and understood the condition (5.00 %).

Participants that had negative communication, described the reason for this was because of limited because their healthcare professional does not understand their condition (35.00%), and dismissive (One way conversation) (15.00%). Other themes included lacking respect and that they felt vulnerable (5.00%), limited support (5.00%),poor, with no particular reason given (5.00%), and limited in relation health professionals not having a lot of time (5.00%).

Partners in health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

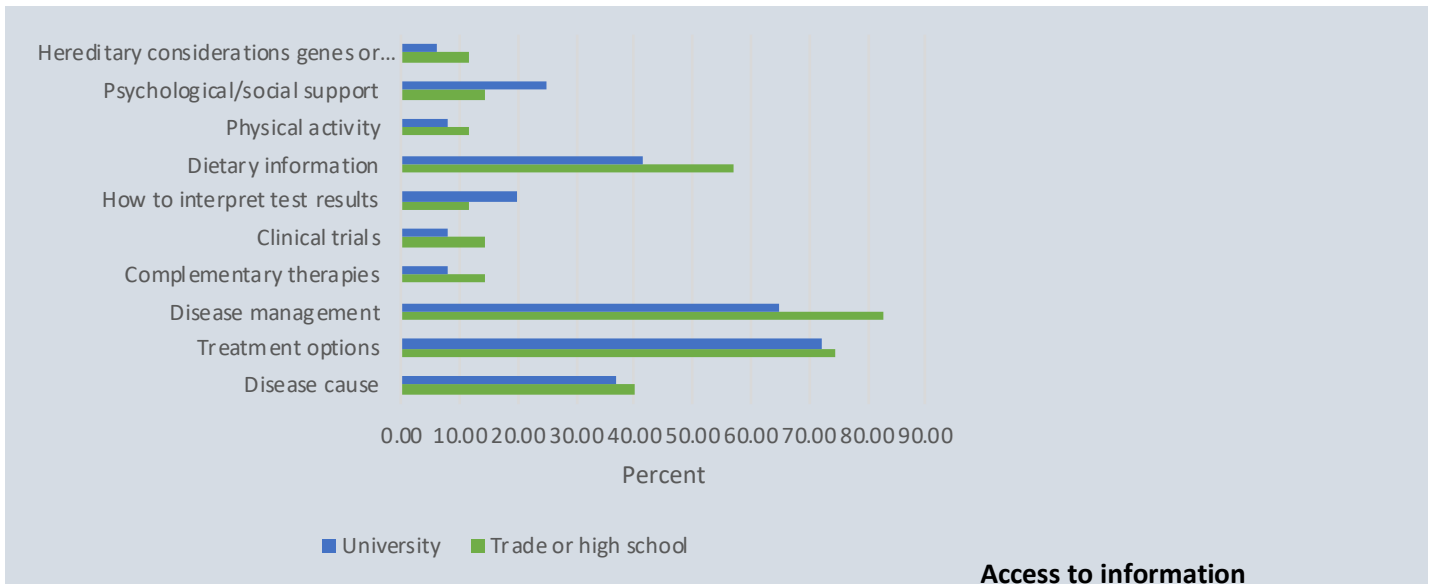
The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.



In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (65.00%), from other patient's experience (Including support groups) (50.00%), and from journals (research articles) (50.00 %). Other themes included from Facebook and/or social media (45.00%), from a specific health charity (20.00%), their treating clinician (15.00%), and from presentations or webinars from doctors and researchers (5.00%).

Participant describes accessing information through the internet in general

Just online it, it helped greatly. It it. It's clear it's out there. I knew I had it before I actually had a diagnosis, and I knew that for quite a few years and that. That to me was the frustrating part of everything was aligned, but the the the doctors didn't understand or know. The dermatologist I was originally seeing was the exact same, had didn't have knowledge of it. So it was frustrating. And then when you finally got the diagnosis, it was like, yes, someone that can actually understand and knows about what I've been. Yes, knowing I had.
 Participant 002_2023AUHIS

So most of the information I've got online over the years. The stuff that I look at or read about is kind of why I have the disease and what caused it, which, you know, there isn't much information on that. You know, the only thing that Google says is, you know, there's not much information and they don't know why people get it. It could be hereditary. It it could be an autoimmune thing. It's, you know, the only thing that it confirms is that it's not from being unclean. And things like that. I think, yeah, my whole life I've always

questioned like, why me? Why do I have this? Like what did I do? But you know, I guess there's nothing that could have really prevented it. Also just like just at home treatments. How can I kind of look after this at home and it's all just kind of the same stuff like elimination, diet, topical antibiotics and creams and. You know, taking anti inflammatories and then there's like holistic health stuff like taking turmeric tablets and putting, I don't know, just things like that.
 Participant 010_2023AUHIS

I have just researched what I could get my hands on a lot through Google, a lot through from reading HS studies and connecting to other links. There's a support group here in LOCATION. Sometimes some research things come out like this one and you get involved.
 Participant 013_2023AUHIS

Google first. I believe the most substantive information I received. I did have access to an actual medical journal. I can't quite remember if that was through a website that was dedicated to that by. It must have been a PhD student. I believe she was a. Doctor already and she was doing a PhD study. So part of that was the creation of a website and it was interviewing people and obtaining statistics and then writing report and the rest of that and the information she had on there was unreal. I remember looking at that and and feeling less glum, first of all because someone was talking about it. Second of all, she wasn't just regurgitating the same shit. So she had some stuff about the real impact on people, and I think that it was probably that that made me go. You know what? I'm not alone. I'm going to look into this and I found the group on Facebook. We're all over Australia. It's very small. I haven't done anything more. I'm not picky, not trying to find. I want more people, more sick or less sad. I'm just happy to be

connected with the group that I can feel like there are people out there, we're out there, and otherwise I really have much access to anything else. I've never been introduced to support or or any real, not even a pamphlet, not even literature of any description has ever come into my hands from a physician or provide a service provider. And I'm not aware of any, you know support other than those that I've accessed myself, so. Participant 015_2023AUHIS

Participant describes primarily accessing information through other patient's experience

Yeah, so I I suppose I mainly through Google that was initially. When I got the diagnosis researching and I'd go into medical journals around treatment outcomes for when treated with antibiotics and when I was particularly interested in in the surgery because it kept getting worse and worse. So the idea of what's the likelihood that I can actually get rid of the problem and I suppose you know the the, the articles varied a bit, but some would say 80% recovery and some would say 95% recovery. So I was happy to sort of take a chance on that. So that was around the point of of, I suppose, in the year following diagnosis when I was looking at what else was there when the antibiotics were not, when I didn't feel that they were successful after. After I actually had the surgery and for the first time I had a few weeks at home, I I reached out and started sort of finding more, I suppose patient, not support groups, but information sites and and there you would there was a there was one, I think it's called my HS, where. They actually then also ran webinars and information sessions hosted by different dermatologists and practitioners and and lived experienced people mainly from the state. And so I was able to link in with some of those to hear about other people's experiences and then I, yeah, joined a couple of Facebook groups. In which did sort of hear about people lived experience and and what they were trying. Sometimes they had different sort of suggestions for things like lotions and creams and stuff that the dermatologists hadn't come up with. So there, yeah, there were a couple of times I tried some of those things but on a minor scale, whereas some of the suggestions was pretty out there. Participant 007_2023AUHIS

Mostly it's from Facebook help group. OK, that's where a lot of my information comes from, with other people going through the same thing. Participant 011_2023AUHIS

Participant describes accessing information primarily through journals (research articles)

I have a bit of a hobby of reading medical journals because I find them really interesting and I work in aged care, so understanding diseases and things like that, so I have read a lot on the Internet. I'm not really a doctor Google kind of person, but I'm also in several like social media support groups as well. So it's good to see other people's perspectives. Find out about new medications so that you can talk to your medical professionals about other options. And you know some of the things I've learned you know with with using us and. And heat and various different things from their support groups, because it's all trial and error. And Vicks vapor rub. Vicks vapor rub, one of the one of the big ones that almost everyone with HS uses. Participant 005_2023AUHIS

As much as I could from 2003. I began the database what was published on the disease up until up until the end of 2021. I was pretty update on everything that was published and I'm just not behind now. This is a lot that's being published now. I still have my own databases published stuff, so the stuff I look at is what's published in peer reviewed journals. Yeah, yeah. Participant 008_2023AUHIS

Well, I I haven't really. I haven't really sort any out as you know, because I just think there's just not a lot there. I've tried to read some papers, but you know, they're quite clinical and I've tried to, I've read up on a few trials, but I don't really understand the, the, the language, you know, the terminology. So I just find that everything that's available is quite generic. Yeah, and very limited. So I yeah, I haven't really been given, you know, I haven't, I haven't sought out that nor have I been given any information to you know I'll go and look this side up or his brochures or you know. Participant 017_2023AUHIS

Participant describes accessing information primarily through Facebook and/or social media

I've gone on to support pages on Facebook. I've gone through medical articles, medical journals, studies being conducted on the condition, testimonials about treatment, What treatments are available? Are they looking in secures? Or is it just it's a lifelong thing and I basically just dove into a rabbit hole after? Diagnosis just to figure out how can I minimize or get rid of the condition? Participant 012_2023AUHIS

I definitely joined a lot of support groups on Facebook because I figured there would just be a lot of

information posted on there all the time and I could just scroll through it and see whatever they were posting. So I guess that was my main source.

Participant 014_2023AUHIS

So I've done a lot of like Googling and looking at a few research articles, particularly to understand different treatments and why I guess things aren't necessarily. Prescribed yet and and I'm just getting I guess the severity of things as well. I have joined a couple of like Facebook groups to understand within yeah, other people that have it as well other sources. I think that's probably it my yeah, my doctor wouldn't have given that much information.

Participant 019_2023AUHIS

Participant describes accessing information from a specific health charity

Okay so much. Most of that information that I have received. I have probably looked for that myself. I've looked for that online through joining different HS like websites like HS Connect. Also support groups, so I am on a number of forums online by particularly via Facebook. There's a number of community based groups there, peer support type groups which I've joined and I also started my own peer support.

Participant 001_2023AUHIS

It's mainly just making sure I'm reading reputable articles, usually from medical journals and things like that. Like I said, the doctors here no help. They don't know what it is, and even if they do, they don't know enough to help me. Which can impact the consultation because then they get put on their back foot when I'm just sharing the information that I know. But yeah, the the HS Trust in the UK was really helpful. That was the first one that I found that actually had information on it, you know, because all I got told was, hey, it could be this. And then hey, your pathology came back as this, like I. Yeah, like, I know people say that, you know, Dr. Google, But Dr. Google was actually pretty big part of, you know, finding out how to handle this.

Participant 018_2023AUHIS

Okay so much. Most of that information that I have received. I have probably looked for that myself. I've looked for that online through joining different HS like websites like HS Connect. Also support groups, so I am on a number of forums online by particularly via Facebook. There's a number of community based groups there, peer support type groups which I've joined and I also started my own peer support.

Participant 001_2023AUHIS

Table 6.1: Access to information.

Access to information	All participants	
	n=20	%
Participant describes accessing information through the internet in general	13	65.00
Participant describes primarily accessing information through other patient's experience	10	50.00
Participant describes accessing information primarily through journals (research articles)	10	50.00
Participant describes accessing information primarily through Facebook and/or social media	9	45.00
Participant describes accessing information from a specific health charity	4	20.00
Participant describes primarily accessing information through treating clinician	3	15.00
Participant describes primarily accessing information from presentations or webinars from doctors and researchers	1	5.00
No particular comment	2	10.00

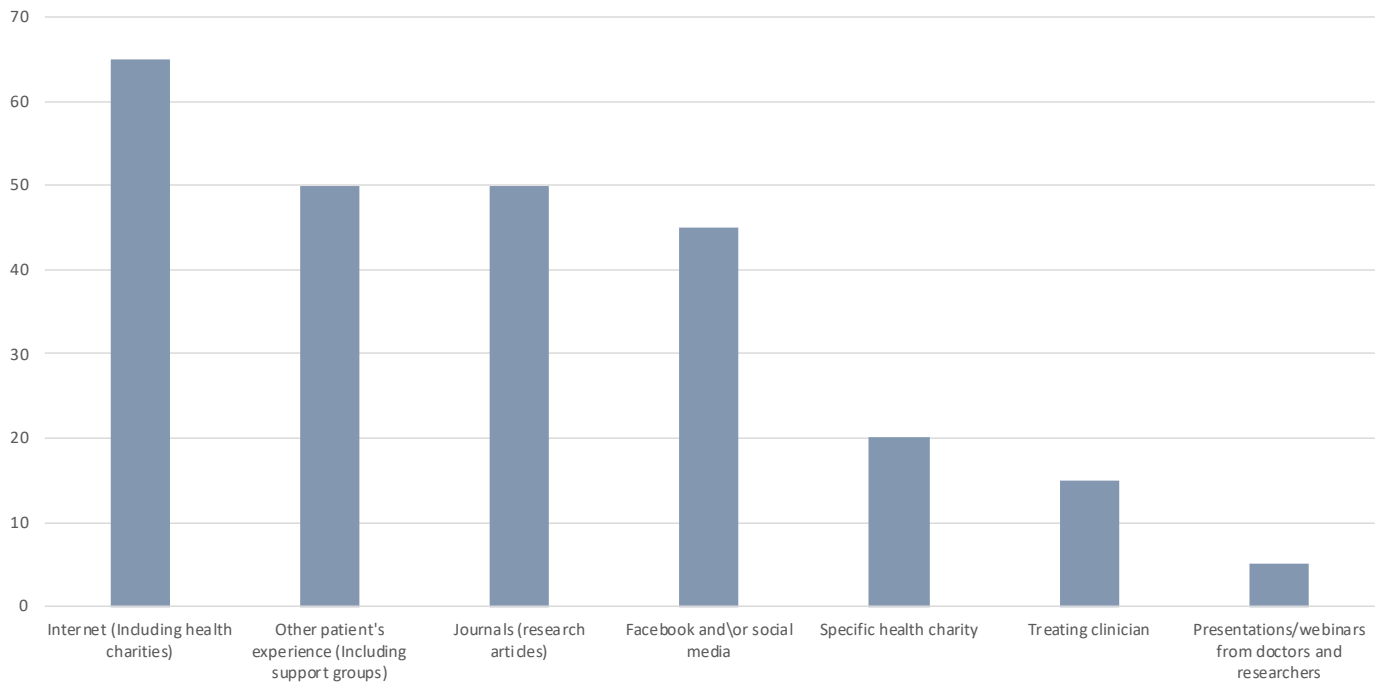


Figure 6.1: Access to information

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (25.00%), information about triggers and managing exacerbations (20.00%), and medical journals (15.00%) were helpful. Other themes included hearing what to expect (e.g. from disease, side effects, treatment) (10.00%), no information especially helpful (10.00%), treatment options (5.00%), all or any (5.00%), YouTube or webinars (5.00%), lay summaries (5.00%), and information about emotional and mental health (5.00%).

Participant describes other people's experiences as helpful (Peer-to-peer)

Probably from the support groups because they are going through the same thing I am.
Participant 005_2023AUHIS

I think the most helpful information was when I posted in one of the groups because I wasn't really sure where to go from my diagnosis and someone recommended a dermatologist who I've actually that's the dermatologist that I got in to see and she's actually really great. So that was some really good information, but I guess seeing how people use different bandages and different coping mechanisms as well.

Participant 014_2023AUHIS

Funnily enough, finding that Facebook group, that Australia support group, I mean obviously we're not no one's, no one's offering any medical care on there but just to be able to have some a group to discuss it with where they understand. So and that's how I found this study was through through that Facebook group.

Participant 017_2023AUHIS

Not really. Like I joined a couple of Facebook groups during COVID time because I never even thought to search for a group and then it was helpful by way of, you know, seeing where doctors or were or specialists were in the areas. So that that's about it.

Participant 018_2023AUHIS

Participant describes information about triggers and managing or avoiding exacerbations

Probably the information that's enabled me to manage my HS on a day-to-day basis, yeah.

Participant 001_2023AUHIS

Probably the elimination diet. I didn't know that there were foods I was eating that actually cause inflammation and will flare up the disease, as well as like certain things to put in the bath. I found that putting the clay in the bathtub and like some home recipes have actually helped kind of keep the disease at like a stable level.

Participant 010_2023AUHIS

Participant describes reading medical journals or scientific articles as being helpful

Can't say. Probably anything that discusses the sociology of people with HS. You know, the psychology, the psychiatry, stuff like that. Does that make sense? Like I can read. Papers on biomarkers, genetics and all that, but I'm not an expert at that stuff.

Participant 008_2023AUHIS

Probably the research articles things like helpful.

Participant 019_2023AUHIS

Participant describes no particular information being especially helpful

I I can't really find any information helpful really. I mean there's no nothing to ease out pain or anything. I mean there is a a body wash that I've just heard about that might help, but yeah, I haven't tried it all. Got my hands on it yet.

Participant 003_2023AUHIS

Not, no. It's all very dismal prognosis. Very, very negative. What I can say as well, very, very frighteningly, is anything definitive about what your symptoms are or will be in the future? Do they get worse? What I mean is this deteriorating condition, it's gotten worse over the years. How much worse is it going to get and is it going to affect me so? That's it.

Participant 015_2023AUHIS

Table 6.2: Information that was helpful

Information that has been helpful	All participants	
	n=20	%
Participant describes other people's experiences as helpful (Peer-to-peer)	5	25.00
Participant describes information about triggers and managing or avoiding exacerbations	4	20.00
Participant describes reading medical journals or scientific articles as being helpful	3	15.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	2	10.00
Participant describes no particular information being especially helpful	2	10.00
Participant describes information about treatment options as helpful	1	5.00
Participant describes all or any information as being helpful	1	5.00
Participant describes informaton presented on YouTube or webinars as being helpful	1	5.00
Participant describes information presented in lay summaries as being helpful	1	5.00
Participant describes information about emotional and mental aspects as being helpful	1	5.00
Other\No response	2	10.00

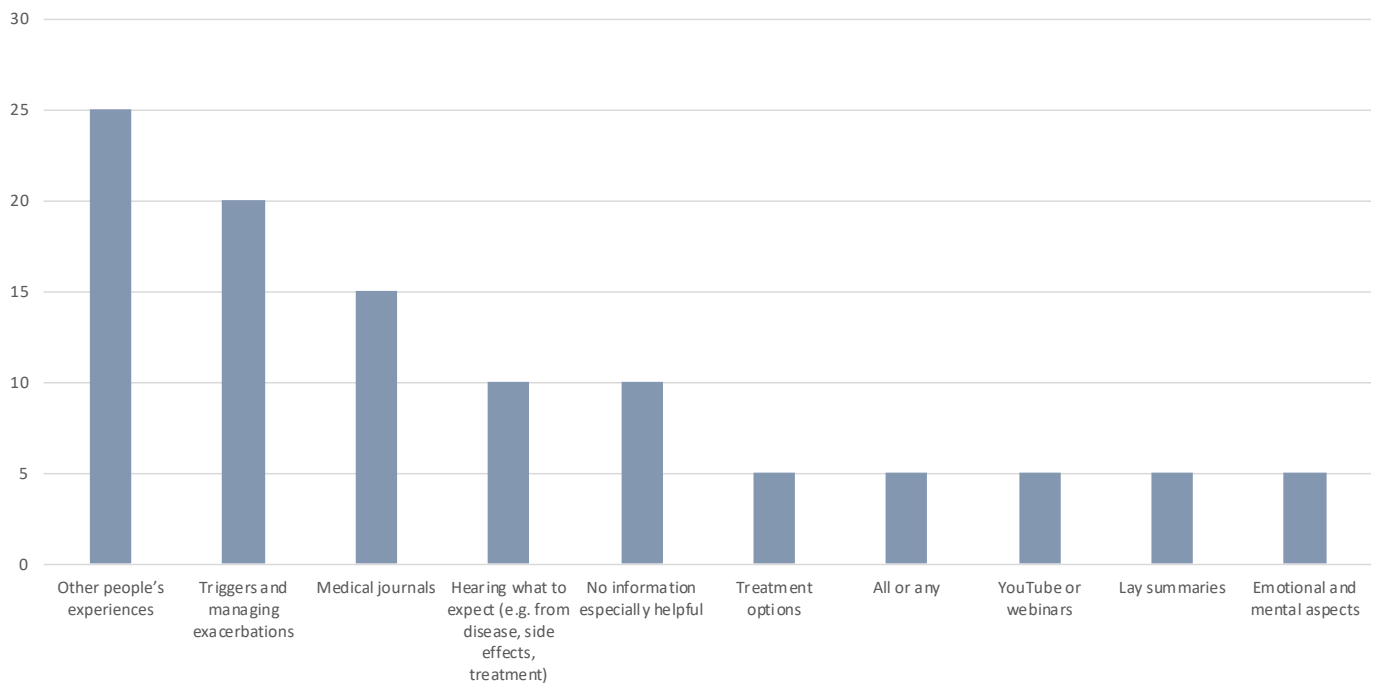


Figure 6.2: Information that was helpful

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no

information not helpful (20.00%), other people's experiences (15.00%), and GP or specialist (15.00 %). Other themes included confident in deciding

themselves (10.00%), sources that are not credible (Not evidence-based) (10.00%), a lack of new information (5.00%), unsolicited information (5.00%), worse case scenarios (5.00%), not type specific or too general (5.00%), and information from pharmaceutical companies (5.00%).

Participant describes no information being not helpful

*No, not not really. No. Nothing.
Participant 004_2023AUHIS*

No, not really. No. I you know, I no, I haven't really. When when you say that, do you mean like have I been searching? No, because I I just kind of figured that I, you know, there's so little known about there's so little information available that I don't think anything's really a sort of unhelpful as such. I have oh so and so is doing this. So I'm gonna go and do that too and then found it unhelpful like I yeah, I'm kind of reliant on the clinicians to guide me on what would be what would be helpful for me. Participant 017_2023AUHIS

Participant describes other people's experiences as being not helpful

Well, yeah, I think the the fact for me like that didn't work for him or sorry I I didn't try any. I've I've only tried a few things with him and what am I trying to say there? Things that didn't work no cause. If someone said be careful there, sorry. If someone said that you know something didn't work for them a therapy didn't work for them, like you say that someone said Humira didn't work for them on the the website, on the Facebook page, I'd go well I know that

*everyone's different. So I think that what works for some one person might not might not necessarily work for another. I've been looking down the path of. Things that that trigger a flare. So I know that my son one of the triggers is yeast seems to be a trigger for him. So dietary looking at dietary stuff as well and people. Also other people have been commenting that different dietary things seem to trigger flares for them too. But again, it's different for different people.
Participant 010_2023AUHIS*

*Yeah, just a lot of, you know, the keyboard warriors with their. Personal advice when they're not clinicians, it's you see things that I can see, things that could be very harmful, but I choose not to engage in that kind of stuff.
Participant 018_2023AUHIS*

Participant describes the GP/specialist as being not helpful

*Being told to get Botox in my groin that was not helpful. The. Early stages there was quite often the treatment recommendation was get Botox and I don't know, I couldn't find how it would work, didn't understand how it work. It was always just that, well, it works for some patients, so that's why it's a recommended treatment, not the science behind it, not the how behind it. It was basically like looking into how Panadol relieves pain, which they still don't know.
Participant 012_2023AUHIS*

*Every service provider I ever visited, ever. Except for my current physician.
Participant 015_2023AUHIS*

Table 6.3: Information that was not helpful

Information that has not been helpful	All participants	
	n=20	%
Participant describes no information being not helpful	4	20.00
Participant describes other people's experiences as being not helpful	3	15.00
Participant describes the GP/specialist as being not helpful	3	15.00
Participant describes feeling confident in deciding if something is not helpful (or not credible)	2	10.00
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	2	10.00
Participant describes a lack of new information as not helpful	1	5.00
Participant describes other people giving their advice or opinions as being not helpful	1	5.00
Participant describes information about worse case scenarios and negative information as being not helpful	1	5.00
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	1	5.00
Participant describes information from pharmaceutical companies as being not helpful	1	5.00

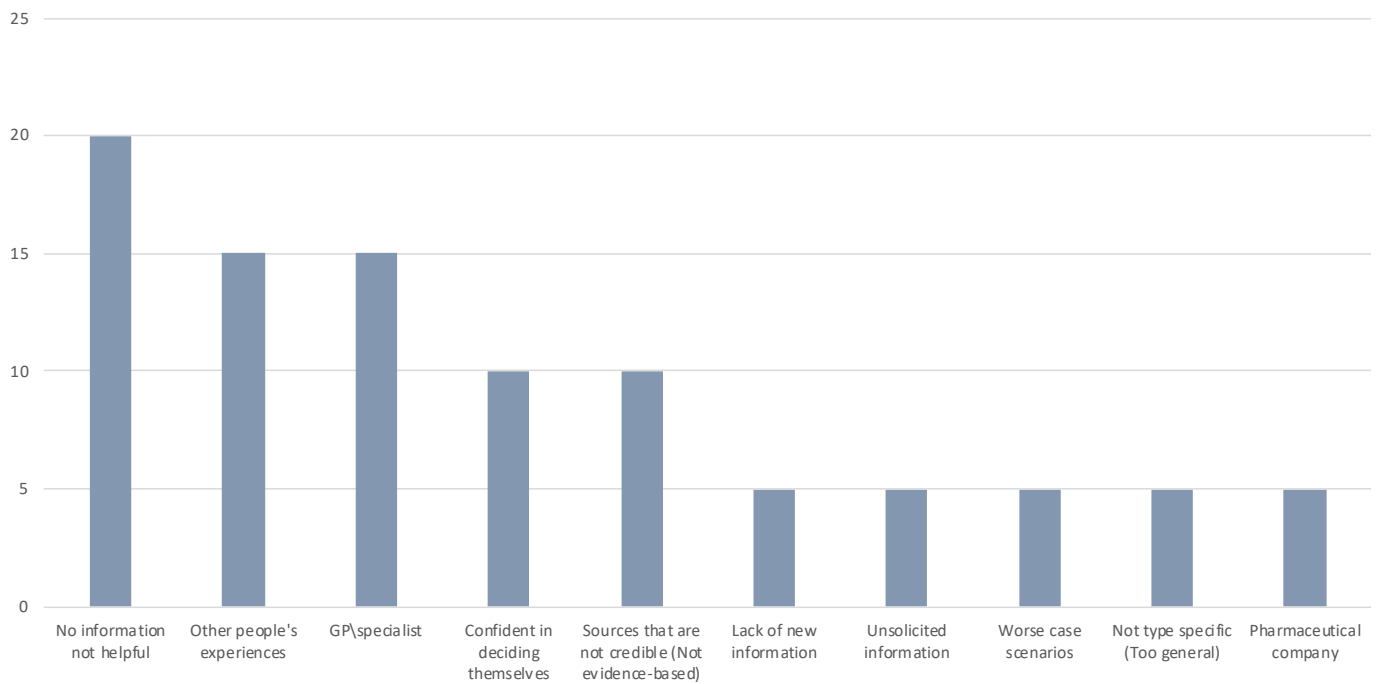


Figure 6.3: Information that was not helpful

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were online information (40.00%), and talking to someone plus online information (30.00%). Other themes included written information (10.00%), all forms (10.00%), and talking to someone (5.00%).

The main reasons for a preference for online information were accessibility (35.00%), being able to digest information at their own pace (20.00%), The main reasons for a preference for talking to someone was being able to ask questions (20.00 %). The main reasons for written information were being able to revisit the information (10.00%), and having pictures to help with understanding (5.00%).

Participant describes online information as main information preference

Look, I'd like to be able to get it from talking to someone, but I I didn't feel that that was I I felt like I was getting a very, very narrow tunnel or view of any options. I think probably I the online stuff is. It's great because there's so much out there, but then you kind of want parameters around where, you know, where do I actually access information? I can try booklets and things would be, I guess would be good if it came from a reputable source and you felt that you could then trust that information. But out here I've like, I've

I've never met anyone that's got the condition. And in terms of professionals like. Yes, my dermatologist had two or three other clients himself, but he didn't have a wealth of experience either.
Participant 007_2023AUHIS

No, it's primarily online because I wanna know, well, there's not a lot great deal that even the like. The doctors and medical, medical people, they really don't know a great deal about it. Like my GP had to our GP had to to really look it up. The psychologist that we're seeing that my son's seeing doesn't know anything, didn't know anything about it. He and he's had to to look it up. So it's a, you know, it's a, it's a condition that whilst it's common and it's very under diagnosed. And very few people know about it. Everyone knows about Ms. but nobody knows about HS.
Participant 009_2023AUHIS

Participant describes talking to someone plus online information as main information preference

I think, look, to be honest, I think for me, I mean all of those are good, but I think for me some of the best is actually being whether it's online through a peer support and also. Talk, you know, like talking to others with the lived experience of that makes a huge difference. I think that helps to put things in perspective for me as a sufferer of the condition.
Participant 001_2023AUHIS

So I do get a lot of information from medical journals from like Google Scholar. Information that has been effective has either come from face to face with medical professionals or through or face to face with other people who have the disease.

Participant 005_2023AUHIS

I don't mind. I'm pretty open up. I'm good at reading. I'm good at researching. Don't mind having a chat to people? Yeah, OK, yeah. No, all of the above's fine with me. Take any information I can get.

Participant 006_2023AUHIS

Participant describes written information as main preference

I kinda like everything so I am autistic so my style of learning changes depending on what the what I'm doing. I find though with if it's regarding treatment and things like that, I need something I can look back at and not just have that one conversation or that one question and answer session. I like to be able to go back and read it and process it a bit more and just double check.

Participant 018_2023AUHIS

Probably written down or online. Either or it's fine, just that it's easier to. I guess it's just easier to go back to it. Whereas if you have a conversation with someone, yeah, you can't come back to that conversation.

Participant 019_2023AUHIS

Rationale for preference is due to accessibility

Why online? Because it's accessible 24 hours a day and you can feed your own learning. Um, it's yeah, right.

Participant 002_2023AUHIS

PARTICIPANT: I prefer online because research things for the ease of accessing and whatnot and talking one to one with a expert in the area, like a dermatologist. INTERVIEWER: Thanks. Can you just say why that that is important for you?

PARTICIPANT: Because you can. If you've got any questions or what not talking to someone clinically, you can bounce the ideas off and get different viewpoints. The online information is very good, but it's it's that person's viewpoint and you can't. Well, why did you come up with that? What about this? What would be that you know? If you're talking to someone in the area, you can the pros and cons.

Participant 013_2023AUHIS

Rational for preference is due to being able to digest information at their own pace

PARTICIPANT: Probably online information, just because I can read it at my own pace and there is a lot of information online and I think it's easily digested. Then I think I also get quite. Worked up when I think about the disease. So I think if I talk to someone, I'd probably just end up crying because it's just too much to kind of talk about. So I think just online so I can read it myself and understand it myself. So I think sometimes talking to people like, especially someone who doesn't have it, like they just don't get it. They don't understand like what you're actually going through. And the pain and the embarrassment to like. INTERVIEWER: With the disease, so yeah.

PARTICIPANT: And I'd say probably not a booklet just because then you're limited to the booklet as opposed to online. You can continually search up new things, yeah.

Participant 010_2023AUHIS

I have a preference with online information. I just prefer visual reading at my own pace, visual cues and imagery like that, and I don't process information thoroughly when I hear it. And occasionally, talking to people, I get stuck. If I hear something that they're saying that is contraindicated, or they're they're presenting their interpretation rather than just the cold straight facts. I can't gloss over it like I can if I'm reading. It gets stuck, and I obsess over it in conversation so I avoid it.

Participant 012_2023AUHIS

Rationale for preference is due to being able to/have time to ask questions

I like talking to somebody about it because I have a lot of questions and be followed up straight away is good me now, but has the access to the information of my fingertips is also ideal.

Participant 011_2023AUHIS

Probably talking to someone, because if you don't understand something, you've got the opportunity to ask them while you're there. You know, apps, phone apps. Kind of only as good as the developer. I think online online's OK, but then if if you have a question about something that you read, you have to either write it down to remember to ask somebody when you actually see them. So again, it's only online is probably only as beneficial as the. Explanation that they're giving and so they're so there are no unanswered questions, Yeah.

Participant 017_2023AUHIS

Table 6.4: Information preferences

Information preferences	All participants	
	n=20	%
Participant describes online information as main information preference	8	40.00
Participant describes talking to someone plus online information as main information preference	6	30.00
Participant describes written information as main preference	2	10.00
Participant describes preferring all forms of information	2	10.00
Participant describes talking to someone as main information preference	1	5.00
No particular comment	2	10.00

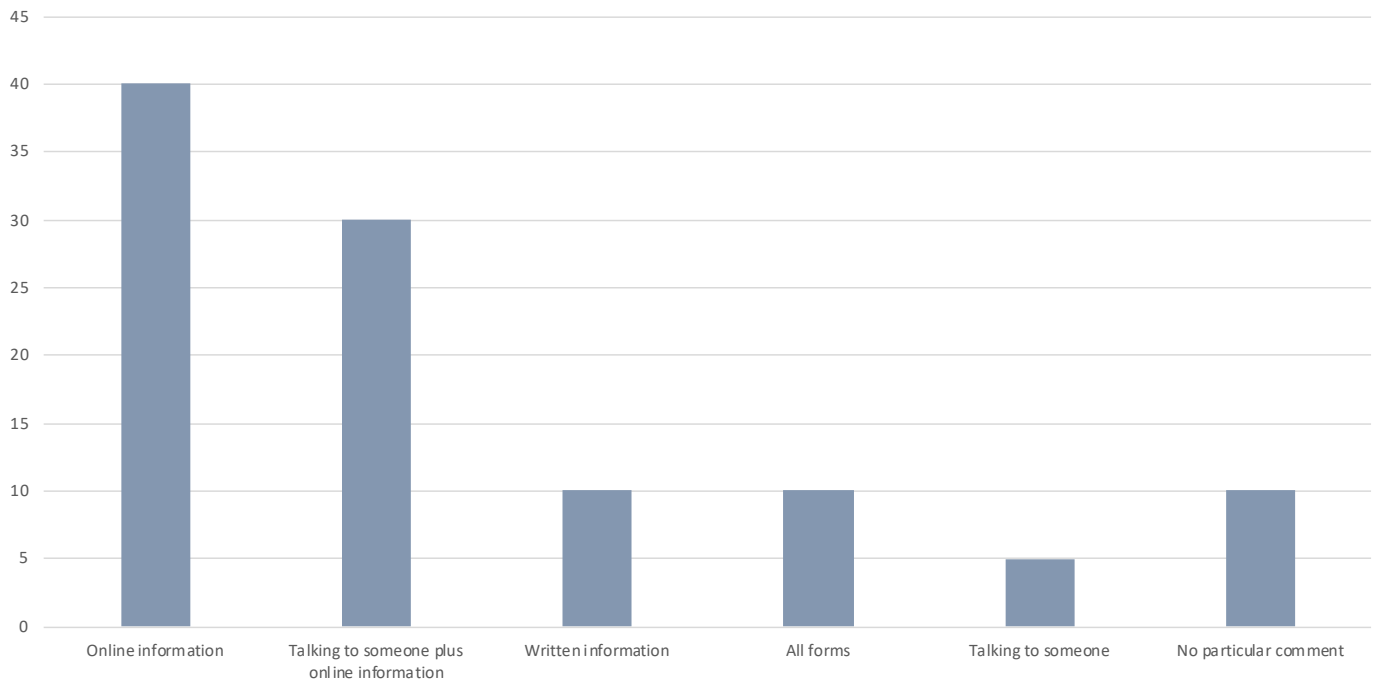


Figure 6.4: Information preferences

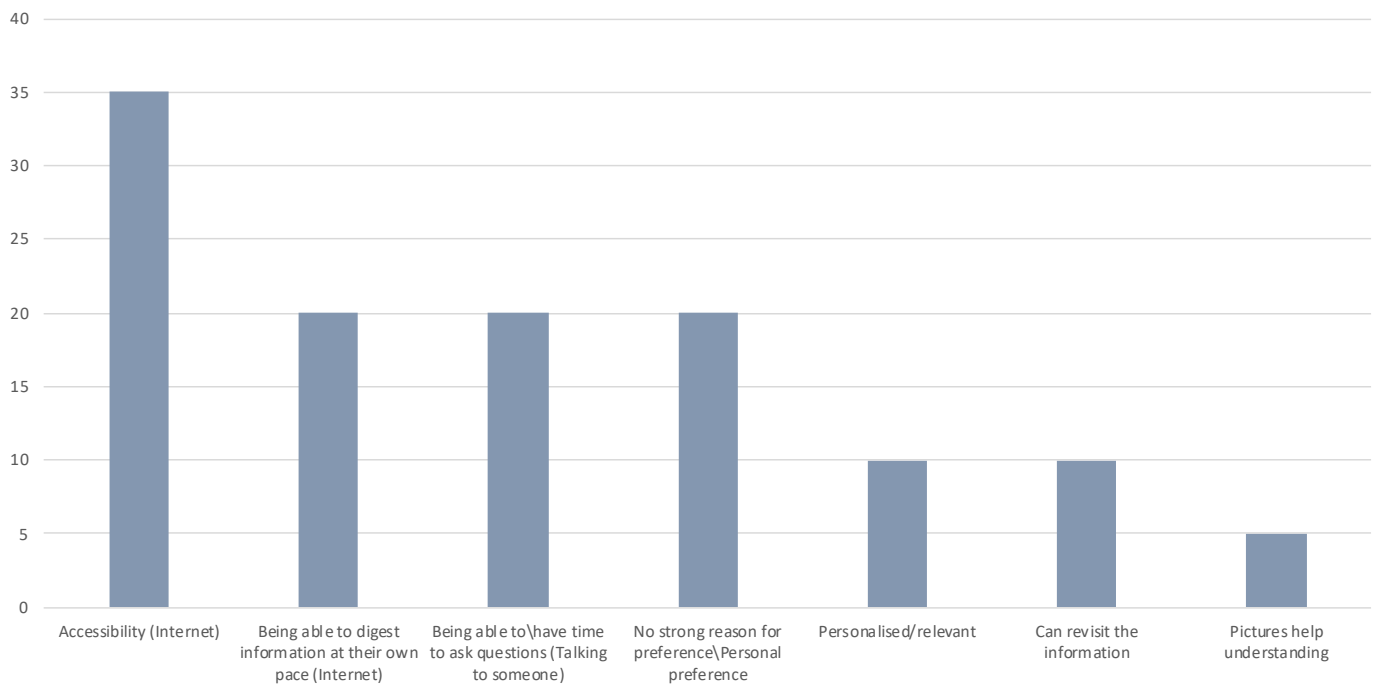


Figure 6.5: Reasons for information preferences by format

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were continuously (40.00%), and at the beginning (diagnosis) (20.00%). Other themes included two months after diagnosis (10.00%), 12 months or more after diagnosis (10.00%), when seeing someone that was an expert in disease (10.00%), three to four months after diagnosis (5.00%), and not much information at time of diagnosis (5.00%).

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

I'm honestly not sure just because I'm constantly taking information about it. However, I think when I did see the Skin Specialist in February I was very open. Hearing what he had to say about the disease when I went in, it wasn't very informative though, because I already knew most things about the disease. So he didn't have to go into detail and explain to me what I have and why I have it, because I already kind of knew what was going on. But yeah, probably seeing a specialist who you know actually. Knows about the disease and works on the disease actively and has done a lot of studies, like that's why I picked the doctor I have. So I was very open to listening to him about it as opposed to just a GP or someone who doesn't really know what they're looking at or understand what comes with the disease.

Participant 010_2023AUHIS

Yeah, in Drips and draps, I think taking it in. No, I think knowing what it knowing, knowing what the diagnosis is, and then understanding what it's all about are two totally different things. So I and I think that. That's something that should be provided upfront because everyone's different. But it should also be revisited pretty very regularly because there's always going to be something that you pick up that you either missed last time or didn't take in last time because you were too, you know, focused on something else.

Participant 009_2023AUHIS

I always have been, just wasn't offered the chance at receiving information, I guess.

Participant 018_2023AUHIS

Participant describes being receptive from the beginning (diagnosis)

In at any point the basically the minute I got the diagnosis when I came home I just went straight back

and started researching and looking things up again. Thank you. I rely on information in fact, to get me through anxious situations, which is part of why they look like if I'm if I'm autistic or not.

Participant 012_2023AUHIS

Probably, probably for both then and now, because I think when I was diagnosed I I wanted answers and I wanted to know how to move forward. But at the same time, at this stage of life, I'm still in a position of wanting answers and wanting to be able to manage my HS as best as I can. So probably for me I was probably. I'm just as receptive at diagnosis as I was met as I am now.

Participant 001_2023AUHIS

Participant describes being receptive to information two months after diagnosis

I mean, I didn't really think in what I had until. At least two months after I was diagnosed. I heard the doctor. I heard what he was saying. I'm like, great. So I have to have this for the rest of my life. Like there's no cure for it. That's when it sunk in. Like, damn, you can't fix me.

Participant 003_2023AUHIS

Look, I'd probably say in the in the couple of months, proceed like following. The diagnosis was when I was really looking for information. Yeah, I I know I would have. Yeah, I suppose I would have liked to have had the confidence to act on that a bit sooner too, because it might not have gotten in the stage it did.

Participant 007_2023AUHIS

Participant describes being receptive to information 12 months or more after diagnosis

Probably within the last year or two. I mean, I would have been diagnosed around four years ago. And I mean, it took a year. I was literally tears about it for because this wasn't a sebaceous cyst anymore. This wasn't, do you know what I mean? Like, this was, this was serious, this was bad. This is. Not just gonna go away. And the doctors don't even know how to help you. So, you know, it was pretty upsetting. And yeah, I was pretty depressed about it because I was just like, what do I do? Like, there's nothing to do. Like, yeah. So yeah, I was pretty depressed about it.

Participant 006_2023AUHIS

Well, I was absolutely mortified when I was first diagnosed, when I got the diagnosis. So certainly it wasn't at that time. I think maybe two years now since I've had that diagnosis, I'm okay to, I'm certainly

happy to receive information now, but I think initially I was just, no, I was just not happy. So I think down the track after the diagnosis, show me.
Participant 017_2023AUHIS

Table 6.5: Timing of information

Timing of information	All participants	
	n=20	%
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	8	40.00
Participant describes being receptive from the beginning (diagnosis)	4	20.00
Participant describes being receptive to information two months after diagnosis	2	10.00
Participant describes being receptive to information 12 months or more after diagnosis	2	10.00
Participant describes never being receptive to information when seeing someone that was an expert in disease	2	10.00
Participant describes being receptive to information three to four months after diagnosis	1	5.00
Participant describes that much information was available at time of diagnosis	1	5.00
No particular comment	3	15.00

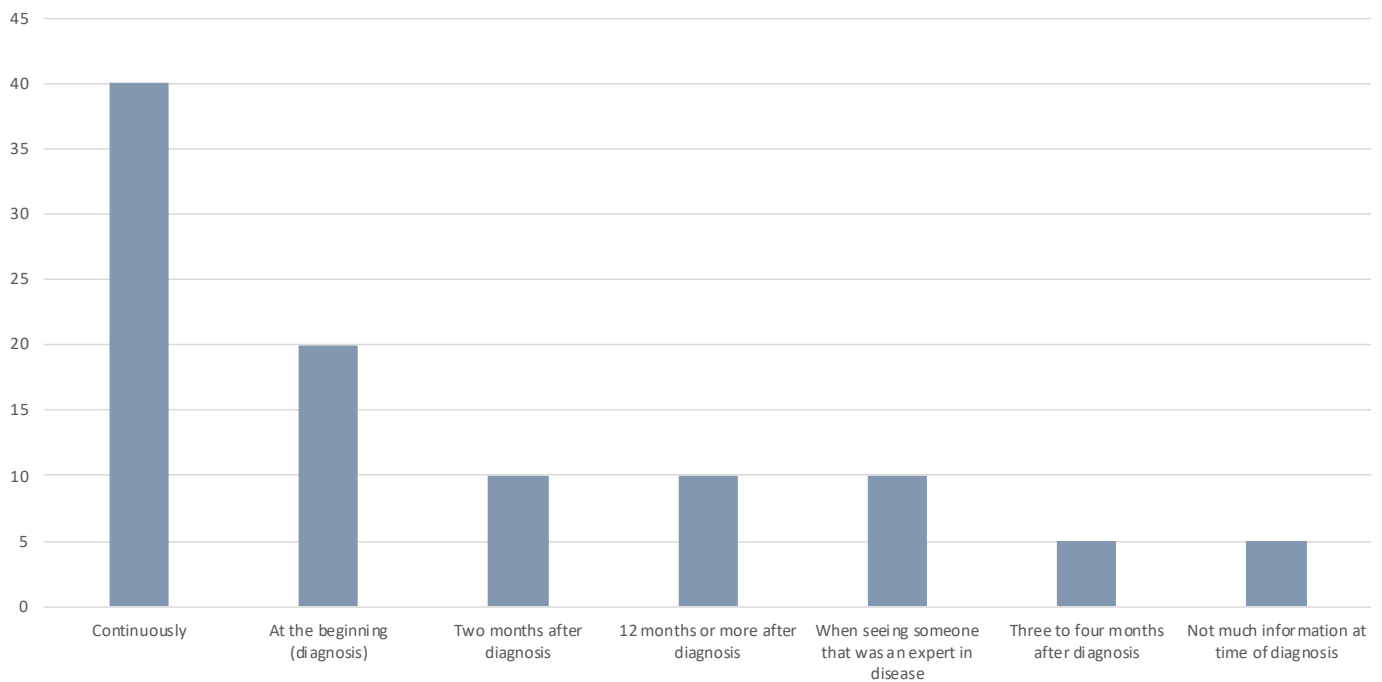


Figure 6.6: Timing of information

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall negative (50.00%), overall positive, with the exception of one or two occasions (25.00%), and overall positive (10.00 %).

Participant describes communication with healthcare professionals as overall negative

Go to all of absolutely the the additional costs of it. So you know what, every time I go go to the doctor, it's \$95, I get 30 something back from Medicare. So I'm out of pocket every time I go you know I get a flare up. I've got to go to the chemist and get. You know, all of

those bandages and pads and and cleaning things and stuff, they're expensive. You know, you just to put the the, the special bandages on it and the balls and stuff, the, you know, the medicines every. Every month they're expensive. It is. It's hot. It is. The treatment is expensive. The things you need to, you know, like to look after yourself medically with this isn't expensive, but it's not recognized as a condition of that. Does that make sense? Yeah, of course. Like you know it's got a chronic condition or it's not this. You don't get any support in that way.

Participant 002_2023AUHIS

Crap not good. Like costed hundreds of dollars to see the dermatologist and I think he spent about 9-9 to 10 minutes with me. Probably not even 10 minutes. Like,

literally, like, just looked at me in and out because he's in demand and he's got a whole bunch of stuff going on. And other than that, the doctor, you know, if I'm like, oh, this is really bad, like, he doesn't want to have a look, he'll ta'e my word for it.
Participant 006_2023AUHIS

Poor, severely poor. Like, negligently poor. Like, unbelievably poor, horrifically poor. Very, very, very sad. Not just for me, like, you know, I don't care. I'm smart. I'm I'll find it myself and I understand my body, but I just think I feel very, very sorry for the rest of us, everyone involved in that.
Participant 015_2023AUHIS

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

I I yeah. I I I think it it's been it's been good. It would be nice I suppose to I I think it's yeah it's been good but I suppose it can always be be a bit better.
Participant 009_2023AUHIS

With GPs, I felt like it was. Quite shaming, yeah. With the dermatologist and the surgeon they were they were good but they were also sort of by then they were I was going to them asking specifically for what I wanted by then and and they were very respectful of that and they they worked with that. But at the same time, like I don't feel like a patient should need to do that. I I think it would be nice if they, you know, if they had no access to knowledgeable clinicians that can support them in in gaining access to that information and those options without having to go searching through that themselves.
Participant 007_2023AUHIS

Participant describes communication with healthcare professionals as overall positive

Really good. So the doctor I'm seeing now is so wonderful with me about the disease. He didn't make me feel ashamed that I have it. He, you know, off, you know, he in terms of treatment, he listened to me about what I wanted and the part that I wanted to tell. When I've asked him questions about certain methods and treatments to get rid of this, he's been open with me about what will work and what might not work, but still following the plan that I want to take, as well as being available to me on the phone if I have any questions. Yeah, he's been really good, alright.

Participant 010_2023AUHIS

Well, I only see Derm every six months, so really it's only ever at that time, so. They they're good. They spend quite a bit of time with me. I mean last time I was there for, oh, it was about an hour and a half. So it wasn't like it's not like, you know, they you know in and out in 15 minutes. But they, I guess HOSPITAL is also you know they've got students there and they've got, so every time I go in there's another young registrar who's you know like they've just. Rotation and they've come in and they're, you know, they ask you all the same questions all again. And so it's just as much for them, I suppose. And the dermatologist will come in at, you know, towards the end of the consultation, although this time around I did have, she was in there for good half an hour with me. Yeah. But it's, you know, it's only every six months and I don't really talk about it because I don't really have a GP. Now I go to a clinic where. Multiple GPs and even though I try to get to see the same one, she's not always available when I need to see a GP, so yeah.
Participant 017_2023AUHIS

Table 6.6: Healthcare professional communication.

Healthcare professional communication	All participants	
	n=20	%
Participant describes communication with healthcare professionals as overall negative	10	50.00
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	5	25.00
Participant describes communication with healthcare professionals as overall positive	2	10.00
No particular comment	3	15.00

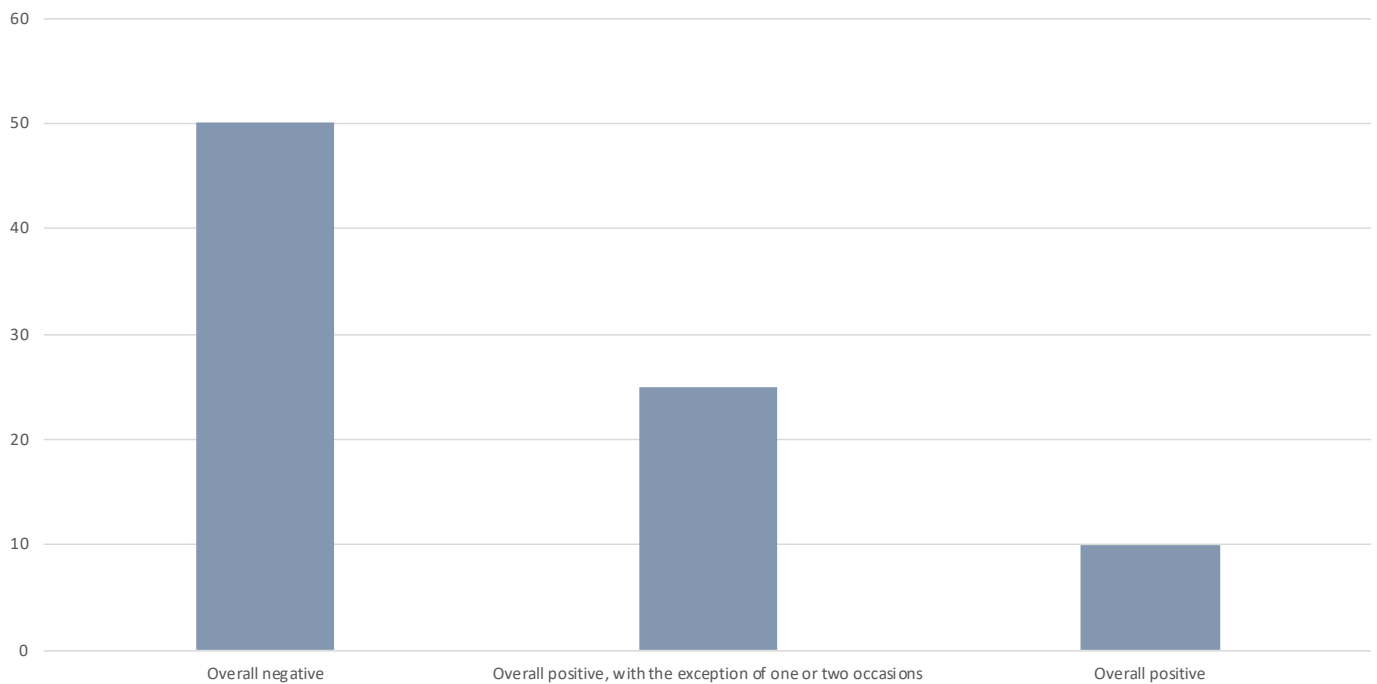


Figure 6.7: Healthcare professional communication

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (25.00%), good, with no particular reason given(5.00%), and understood the condition (5.00 %).

Participants that had negative communication, described the reason for this was because of limited because their healthcare professional does not understand their condition (35.00%), and dismissive (One way conversation) (15.00%). Other themes included lacking respect and that they felt vulnerable (5.00%), limited support (5.00%), poor, with no particular reason given (5.00%), and limited in relation health professionals not having a lot of time (5.00%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Really good. So the doctor I'm seeing now is so wonderful with me about the disease. He didn't make me feel ashamed that I have it. He, you know, off, you know, he in terms of treatment, he listened to me about what I wanted and the part that I wanted to tell. When I've asked him questions about certain methods and treatments to get rid of this, he's been

open with me about what will work and what might not work, but still following the plan that I want to take, as well as being available to me on the phone if I have any questions. Yeah, he's been really good, alright.

Participant 010_2023AUHIS

Well, I only see Derm every six months, so really it's only ever at that time, so. They they're good. They spend quite a bit of time with me. I mean last time I was there for, oh, it was about an hour and a half. So it wasn't like it's not like, you know, they you know in and out in 15 minutes. But they, I guess HOSPITAL is also you know they've got students there and they've got, so every time I go in there's another young registrar who's you know like they've just. Rotation and they've come in and they're, you know, they ask you all the same questions all again. And so it's just as much for them, I suppose. And the dermatologist will come in at, you know, towards the end of the consultation, although this time around I did have, she was in there for good half an hour with me. Yeah. But it's, you know, it's only every six months and I don't really talk about it because I don't really have a GP. Now I go to a clinic where. Multiple GPs and even though I try to get to see the same one, she's not always available when I need to see a GP, so yeah.

Participant 017_2023AUHIS

Participant describes healthcare communication as limited because their healthcare professional does not understand their condition

I think very much it's come from a clinical perspective particularly with my dermatologist I think they I think. Maybe lack of understanding of of the impact of the condition on the patient themselves. So they very much come from that clinical perspective. I do have my, my dermatologist tell me that my HS would probably just burn out and stop at some stage. Well, I'm yet to make someone with HS who has said that that's happened for them so.

Participant 001_2023AUHIS

At times like running into a brick wall, especially with GPs, they don't really know what the disease is, and in fact even a hospital like general. You know turn up at HOSPITAL most of the doctors there don't have any idea. I remember the first time I told a doctor that I have HS he thought I had herpes so and went on to treat me went on to went on to say so when did you contract the STD and I was like what STD. He thought I had herpes so I I there's a lot of. Lack of understanding in the medical world and there are very few doctors that actually know what the disease is and or anything about how the disease impacts a human being, what they read in textbooks and what actually happens to a human and not the same thing.

Participant 005_2023AUHIS

Yeah, it's like. Not great to start with, but I guess it got better once I was actually diagnosed. And then people actually knew what it was. But I don't think that there's a lot of information out there and a lot of people don't know what it is because I didn't even know it existed. And some doctors that I see have not even heard of it. And I'm like, okay, okay.

Participant 014_2023AUHIS

It my GP has been supportive, but she doesn't know very much about it. The dermatologist. Definitely doesn't seem to understand the impact that it can have both, yeah, like socially and physically. And yeah, I definitely don't feel like there's a lot of understanding and I don't that the same across the board.

Participant 019_2023AUHIS

Participant describes health professional communication as being dismissive (One way conversation)

Yeah, not that great. Like my appointments keep getting rescheduled. They say I'm high priority and I need to always go to my appointments, but they always reschedule them normally like I was supposed to. My last appointment was last October. I was supposed to be going this month, but then they rescheduled for some unknown reason and now it's in April and it's like, well, my condition could get, can't get any worse because it's at the worst stage of what it is, but it's like. Kids still get worse. My body could get worse. Like I have an active flare on my neck that keeps leaking and and I'm like what do I do? Do I put like do I call the hospital to tell them my problems and wait possibly two weeks for them to fix it when it could be fixed by itself then like I don't know.

Participant 003_2023AUHIS

God it it's a long story. I'll I'll just give an example. So 2017, I reengaged with dermatology. I saw a Professor in CITY, who I had invited onto the medical board of the HS Foundation in LOCATION. He's a nice bloke, you know, take out the doctor thing and he's a nice bloke, you know, he's a real good bloke. While I was undressed, he started photographing my body and my internal conversation was this is great. No one has ever done that to my skin disease before this. This is a step forward. And then the nurse part of me said there's something wrong here. He never asked my permission. And I just like that slide. And if I didn't have HS and if I wasn't so reserved talking about it, I would have had that conversation with him and he probably would have apologized. But that being treated like a piece of meat that that's not a nice feeling. The other example is. I got a second opinion by going to dermatology department at a LOCATION hospital and the first thing they said to me was that the doctor I saw was no longer involved internationally in research and later on I discovered that was a lie. So there's this kind of politics going on. While I'm here desperate for somebody to finally take my disease seriously now that the FDA in America has approved the first drug for HS, which means the disease I have HS is not imaginary because a lot of doctors I've gone to. Treat me as if it's an imaginary drug, an imaginary disease. It's in my mind that all I have to do is just get on with things. So I I've got that second opinion.

Participant 008_2023AUHIS

Table 6.7: Healthcare professional communication (Rationale for response)

Healthcare professional communication (rationale for response)	All participants	
	n=20	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	25.00
Participant describes healthcare communication as good, with no particular reason given	1	5.00
Participant describes healthcare communication as good, that their healthcare professional understood their condition	1	5.00
Participant describes healthcare communication as limited because their healthcare professional does not understand their condition	7	35.00
Participant describes health professional communication as being dismissive (One way conversation)	3	15.00
Participant describes health professional communication as lacking respect and that they felt vulnerable	1	5.00
Participant describes health professional communication as having limited support	1	5.00
Participant describes healthcare communication as poor, with no particular reason given	1	5.00
Participant describes health professional communication as limited in relation health professionals not having a lot of time	1	5.00

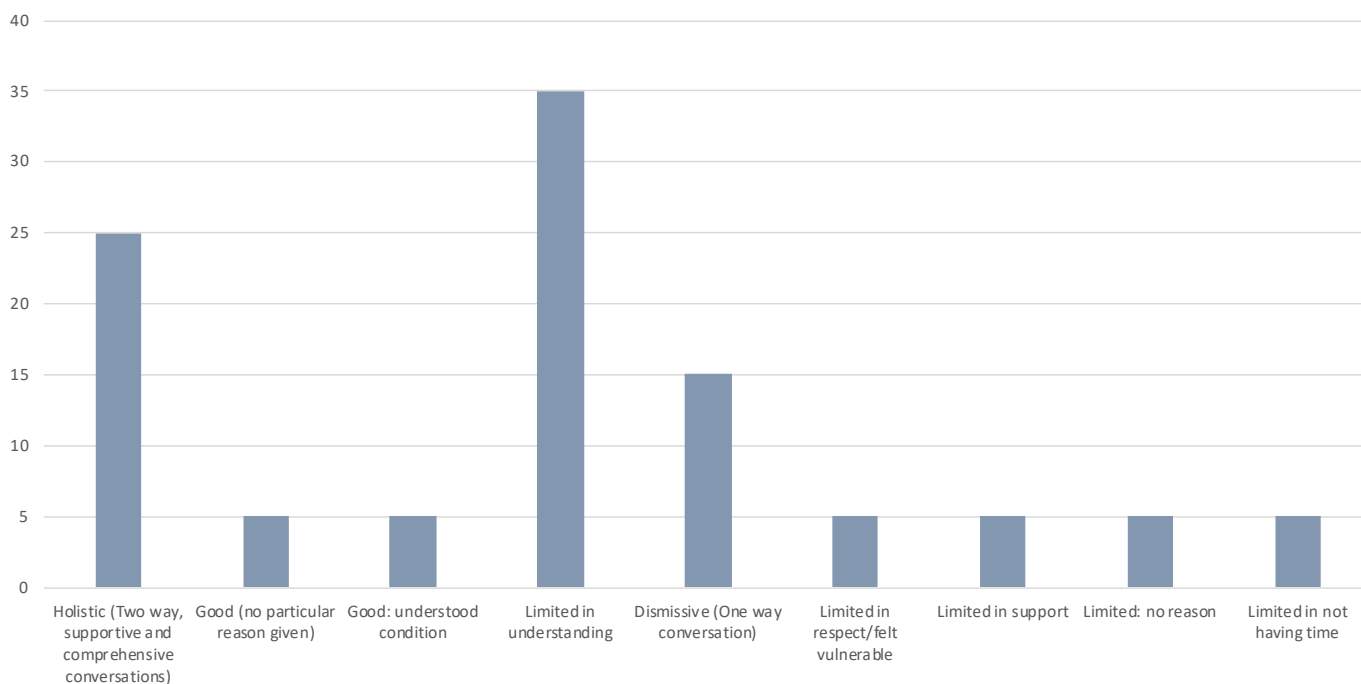


Figure 6.8: Healthcare professional communication (Rationale for response)

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the second highest quintile for Partners in health: Knowledge (median=24.00, IQR=5.50), Partners in health: Recognition and management of symptoms (mean=17.95, SD=2.68), Partners in health: Adherence to treatment (mean=10.95, SD=3.57), Partners in health: Total score (mean=60.84, SD=11.54) indicating good knowledge, good recognition and management

of symptoms, good adherence to treatment, good overall ability to manage their health

The overall scores for the cohort were in the middle quintile for Partners in health: Coping (mean=10.37, SD=5.14), indicating moderate coping

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a moderate ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere

to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Table 6.8: Partners in health summary statistics

Partners in health scale (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	21.58	5.12	24.00	5.50	0 to 32	4
Partners in health: coping*	10.37	5.14	10.00	5.50	0 to 24	3
Partners in health: recognition and management of symptoms*	17.95	2.68	18.00	2.50	0 to 24	4
Partners in health: adherence to treatment*	10.95	3.57	11.00	6.50	0 to 16	4
Partners in health: total score*	60.84	11.54	58.00	11.50	0 to 96	4

*Skewed distribution use median and IQR as measure of central tendency