CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Hidradenitis Suppurativa

Volume 6 (2023), Issue 2

Section 1

Introduction and methods

Section 1 Introduction and methodology

Background

Hidradenitis Suppurativa is a painful chronic inflammatory skin disease, it is associated with comorbidities, in particular obesity, acne, hyperlipidaemia, depression, insulin resistance, pilonidal sinus, poly cystic ovary syndrome, diabetes, and hypertension[1]. The estimated prevalence in Australia is 0.67%, however, diagnosis rate is low due to people with HS not seeking help, misdiagnosis, and mismanagement of cases (referral to multiple healthcare providers, undergoing unnecessary investigations and procedures) [2]; [3]; [2]. Female, young age, obesity, and being a smoker are risk factors for HS, in addition, being unemployed or having a low income is associated with HS [2]. The disease is progressive in the majority of patients if it remains untreated. Cessation of smoking seems to lead to a reduction in the severity of the disease and some patients go into remission and weight loss may have a similar effect [4]; [5].

Diagnosis

A diagnosis of HS is based on the nature and type of lesions, and includes an assessment of comorbidities[1]. The severity of disease is classed by the Hurley stage, defined as follows:

Stage 1: Abscess formation: single or multiple, no sinus tracts of scarring
Stage 2: Recurrent single or multiple abscesses with sinus tracts and scaring. Single or multiple, widely separated lesions
Stage 3: Diffuse or almost diffuse involvement or multiple interconnected tracts and abscesses.
[1]

Treatment

Treatment of HS included identification and management of comorbidities, and should also include quitting smoking, weight control, wound care, pain management, itch management and psychosocial health[6:Deckers, 2015 #823]. Stage 1 disease may be managed with topical antiseptic washes or topical antibiotic solutions[6:Deckers, 2015 #823]. Systemic antibiotics is recommended when topical treatments fail, second line therapies may include corticosteroids, and biologic agents[6:Deckers, 2015 #823]. Corticosteroids are effective for debilitating pain and acute flares[6:Deckers, 2015 #823]. Adalimumab is the only biologic registered in Australia for the treatment of HS. Surgery, laser therapy, photodynamic therapy, and intense pulsed light treatment may be used as a supplement to medical therapy. [6:Deckers, 2015 #823]

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

Section 2

Demographics

Section 2 Demographics

Demographics

There were 20 people that took part in this study, 19 were diagnosed with Hidradenitis suppurativa, and one was a carer to someone diagnosed with Hidradenitis suppurativa. Participants were aged from 25 to 65 years of age, most were aged 44 years or younger (n=13, 65.00%), 18 participants were females (90.00%)

Participants were most commonly from New South Wales (n=6, 30.00%), and Queensland (n=5, 25.00%). Most participants were from major cities (n=14, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (10.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (90.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 7 participants (35.00%) that had completed university to at least an associate degree. There were 10 participants who were employed either full time (50.00%), or part time (n=3, 15.00%). Less than half of the participants were carers to family members or spouses (n=8, 40.00%), most commonly carers to children (n=7, 35.00%).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 **Physical functioning** scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants in this study.

SF36 **Role functioning/physical** scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 **Role functioning/emotional** scale measures how emotional problems interfere with work or other activities. On average, emotional problems seldom interfered with work or other activities for participants in this study.

SF36 **Energy/fatigue** scale measures the proportion of energy or fatigue experienced. On average, participants were almost always fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had fair emotional well-being.

The SF36 **Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had quite a bit of pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Demographics

There were 20 people that took part in this study, 19 were diagnosed with Hidradenitis suppurativa, and one was a carer to someone diagnosed with Hidradenitis suppurativa. Participants were aged from 25 to 65 years of age, most were aged 44 years or younger (n=13, 65.00%), 18 participants were females (90.00%)

Participants were most commonly from New South Wales (n=6, 30.00%), and Queensland (n=5, 25.00%). Most participants were from major cities (n=14, 70.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (10.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (90.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 7 participants (35.00%) that had completed university to at least an associate degree. There were 10 participants who were employed either full time (50.00%), or part time (n=3, 15.00%).

Less than half of the participants were carers to family members or spouses (n=8, 40.00%), most commonly carers to children (n=7, 35.00%). The demographics of participants are listed in Table 2.1.

Table 2.1: Demographics

Demographic	Definition	Number (n=20)	Percent
Gender	Female	18	90.00
	Male	2	10.00
Age	25 – 34	8	40.00
	35 – 44	5	25.00
	45 – 54	4	20.00
	55 – 64	3	15.00
Location	Major Cities of Australia	14	70.00
	Inner Regional Australia	4	20.00
	Outer Regional Australia	2	10.00
	Remote Australia		
State	New South Wales	6	30.00
	Queensland	5	25.00
	South Australia	1	5.00
	Victoria	4	20.00
	Western Australia	4	20.00
Socio-Economic Indexes for Areas (SEIFA)	1	2	10.00
	2	3	15.00
	3	3	15.00
	4	2	10.00
	5	4	20.00
	6	4	20.00
	7	1	5.00
	8	1	5.00
	9	0	0.00
	10	0	0.00
Race/ethnicity	Caucasian/White	17	85.00
	Other	3	15.00
Education	Less than high school degree	3	15.00
	High school degree or equivalent	2	10.00
	Some college but no degree	4	20.00
	Trade	4	20.00
	Associate degree	1	5.00
	Bachelor degree	3	15.00
	Graduate degree	3	15.00
Employment	Currently receiving Centrelink support	4	20.00
	Disabled not able to work	3	15.00
	Employed working full time	10	50.00
	Employed working part time	3	15.00
	Full/part time carer	1	5.00
	Full/part time study	1	5.00
	Not Employed looking for work	1	5.00
	Retired	1	5.00
Carer status	I am not a carer	12	60.00
	Children	7	35.00
	Parents	1	5.00

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.2, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the second highest quintile for SF36 Role functioning/emotional (median=66.67, IQR=83.33), indicating good emotional role functioning.

The overall scores for the cohort were in the middle quintile for SF36 Physical functioning (mean=49.74, SD=29.74), SF36 Emotional well-being (mean=50.11, SD=23.45), SF36 Health change (median=50.00, IQR=0.00), indicating moderate physical functioning, moderate emotional well-being, about the same as a year ago

The overall scores for the cohort were in the second lowest quintile for SF36 Role functioning/physical (median=25.00, IQR=25.00), SF36 Social functioning (median=37.50, IQR=31.25), SF36 Pain (mean=34.21, SD=26.77), SF36 General health (mean=30.26, SD=19.89), indicating poor physical role functioning, poor social functioning, quite a bit of pain, poor general health.

The overall scores for the cohort were In the lowest quintile for, SF36 Energy/Fatigue (median=15.00, IQR=20.00), indicating very poor energy.

SF36 **Physical functioning** scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants in this study.

SF36 **Role functioning/physical** scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 **Role functioning/emotional** scale measures how emotional problems interfere with work or other activities. On average, emotional problems seldom interfered with work or other activities for participants in this study.

SF36 **Energy/fatigue** scale measures the proportion of energy or fatigue experienced. On average, participants were almost always fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had fair emotional well-being.

The SF36 **Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had quite a bit of pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Table 2.2: SF36 summary statistics

SF36 scale (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning*	49.74	29.74	50.00	50.00	0 to 100	3
Role functioning/physical	27.63	37.17	25.00	25.00	0 to 100	2
Role functioning/emotional	45.61	43.33	66.67	83.33	0 to 100	4
Energy/Fatigue	22.89	19.81	15.00	20.00	0 to 100	1
Emotional well-being*	50.11	23.45	48.00	36.00	0 to 100	3
Social functioning	42.76	30.99	37.50	31.25	0 to 100	2
Pain*	34.21	26.77	22.50	40.00	0 to 100	2
General health*	30.26	19.89	30.00	25.00	0 to 100	2
Health change	47.37	16.45	50.00	0.00	0 to 100	3

*Normal distribution, use mean and SD as central measure. Possible range 0-100

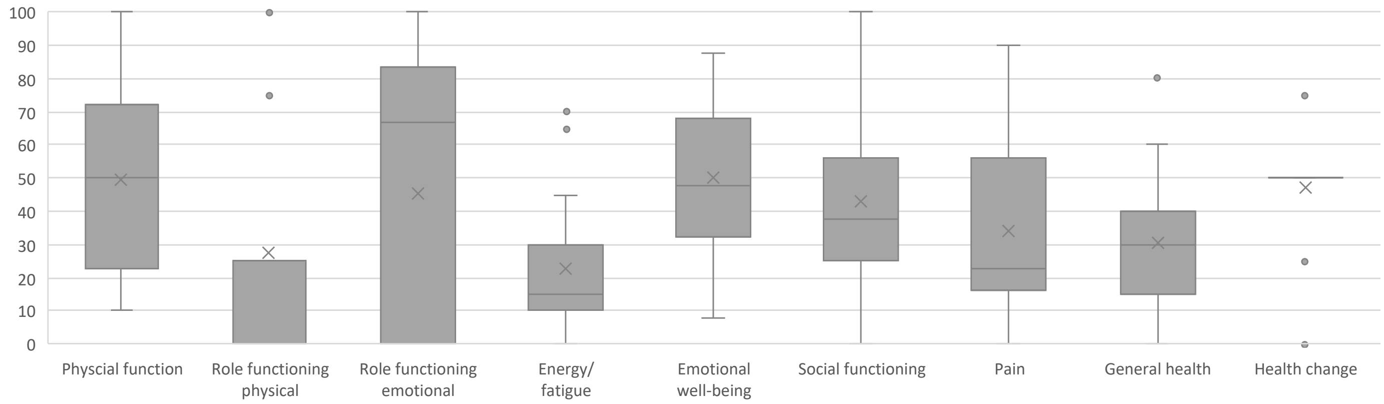


Figure 2.1: Baseline health boxplots

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (80.00%), Others had an unclear recollection of their symptoms or how they came to be diagnosed (10.00%), or did not respond to the question (10.00%).

The most common symptoms leading to diagnosis were having lumps, boils or cysts (65.00%), abscesses or slow healing abscesses (40.00%), and acne (25.00 %). Other symptoms included scarring (15.00%), and a swollen groin (5.00%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and not seeking medical attention initially (55.00%) and having symptoms and seeking medical attention relatively soon (35.00%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were a complex diagnosis, needing to see multiple specialists before diagnosis (35.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (20.00%). Other themes included being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.00%), being diagnosed in an emergency department (10.00%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (5.00%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (65.00%) and knowing about the condition by learning about it before or during the diagnostic process (15.00%). Other themes included knowing a good amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (5.00%), and knowing about the condition due to professional background (5.00%).

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (40.00%), and related to the stage of their condition (30.00%). Other themes included that it was a lifelong condition (20.00%), that it being currently controlled (20.00%) and that it was a serious condition (15.00%).

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (80.00%), Others had an unclear recollection of their symptoms or how they came to be diagnosed (10.00%), or did not respond to the question (10.00%).

The most common symptoms leading to diagnosis were having lumps, boils or cysts (65.00%), abscesses or slow healing abscesses(40.00%), and acne (25.00 %). Other symptoms included scarring (15.00%), and a swollen groin (5.00%).

Participant describes having Lumps/boils/cysts which led to their diagnosis

How did I come to be diagnosed? That was a very complicated process, very time consuming, expensive because a lot of doctors sort out with boils and they treated it for years for boils because they were uneducated in the disease. And I even got referred to a dermatologist who put me under Accutane, which is completely different related treatment for a completely different condition again and 12 months wasted with that. And you know a person who works within a skin, a dermatologist is a skin specialist and still couldn't make the correct diagnosis. And it was when, you know, all of a sudden 12 months later, there's still no improvement. I think I'll refer you to a, you know, specialist dermatologist who specialises in Hidradenitis and HS, then finally got a diagnosis through there, yet I had been questioning a HS diagnosis, diagnosis for a very long time and just kept getting told oh no, it's not that. No, frustrating, expensive and time consuming.
Participant 002_2023AUHIS

Well, I'm in stage 3 at the moment, so yeah, I've got pretty severe. When I when I first started getting the symptoms, I only had little like boil like things on my arms and my armpits to all side of my armpits pretty much.
Participant 003_2023AUHIS

1992 I saw a general surgeon for a lump on the top of my butt crack. The general surgeon said it was a pollinidal sinus. A year later I had. That's surgically removed and within three months the symptoms returned. And they kept returning and they've been returning ever since. Today, actually, when I saw the surgeon the next three times, he said wait and see. In other words, I didn't have a clue. Around about 1996, I began to get lumps all over my body, under the arms, between the legs, the map of Tassie, those sorts of places they would erupt as lumps look like boils. Bursters boils, but were not boils. Treated with antibiotics for oil for a few years and by 2002, 2001 I was diagnosed with stress by two separate dermatologists.
Participant 008_2023AUHIS

Participant describes having Abscesses/slow healing abscesses which led to their diagnosis

Very early on I was probably mid to late puberty. I was probably I would have been 15, 16. I noticed I was getting strange ingrown hair, so the hair was protruding but. The base would be infected, and when you'd pull the hair out it would come out with clumps of flesh and infection. But I didn't get my first proper Abscess with tracking until I was 18, turning 19, which was under my right arm and had to be surgically excised because it just was not going away and antibiotics weren't touching it.
Participant 012_2023AUHIS

It first started when I was about 7. I got an abscess in my groin, and then from there I was getting abscesses on my limbs and whatnot. So I was just treated as boils, whatever you want to call it.
Participant 013_2023AUHIS

I just, I kept getting abscesses on like my inner thigh kind of in my late teens and things like that. But it was pretty consistent. But yeah, just kind of had my weight blamed for it. There's no, you know, they didn't really look into it. Just give me antibiotics.
Participant 018_2023AUHIS

Participant describes having acne which led to their diagnosis

So the the earliest signs, and as you say, I didn't sort of link them to anything, was I I had a few lumps in my armpits, like a few and I suppose they they would look like big pimples. And so like I thought it was odd. I probably tolerated them for about six months before I went to the GP and and that initial GP there was a registrar and they sort of said Ohh look it's odd they've been there for so long and they put me on a a course of antibiotics I went back about.
Participant 007_2023AUHIS

Participant describes having scarring which led to their diagnosis

Everyone had just said that they were sebaceous cysts my whole life. And then this doctor was young and from China and he must have seen more things in his traveling and said that he recognized it as HS and then did some tests and then the tests come back clear, which is usually the indicator of bacteria infection. All that which is usually the indicator of it being HS. And being a teenager, I was just like, what the hell? And got a needle and got it out. And I must have got everything out because I never had another problem there. But I do have a small hole there. It's not a tunnel. It's just a scar. Yeah. OK. Like an acne scar. Like if you'd picked at your face. Yes. All right.
Participant 006_2023AUHIS

Table 3.1: Symptom recall

Seeking medical attention	All participants	
	n=20	%
Participant describes having symptoms and not seeking medical attention initially	11	55
Participant describes having symptoms and seeking medical attention relatively soon	7	35
No particular comment	2	10

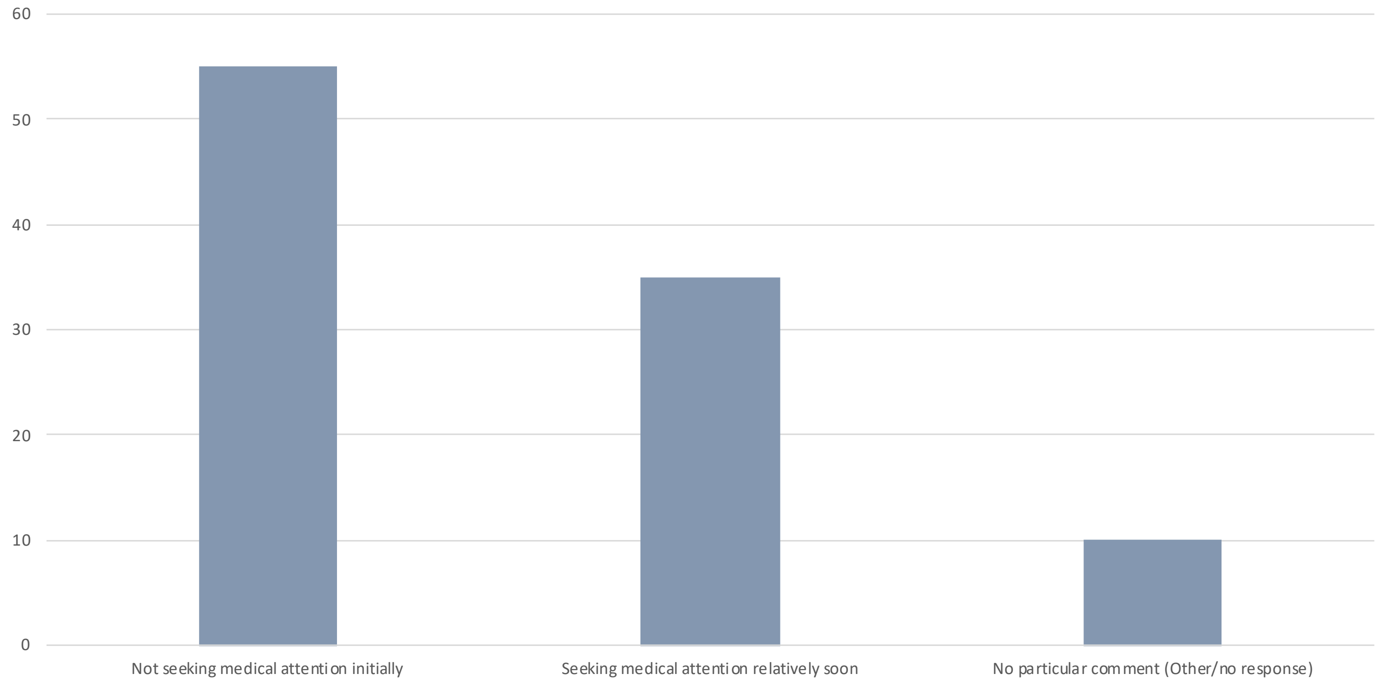


Figure 3.1: Symptom recall

Table 3.2: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants	
	n=20	%
Participant describes having Lumps/boils/cysts which led to their diagnosis	13	65
Participant describes having Abscesses/slow healing abscesses which led to their diagnosis	8	40
Participant describes having Acne which led to their diagnosis	5	25
Participant describes having Scarring which led to their diagnosis	3	15
Participant describes having Swollen groin which led to their diagnosis	1	5

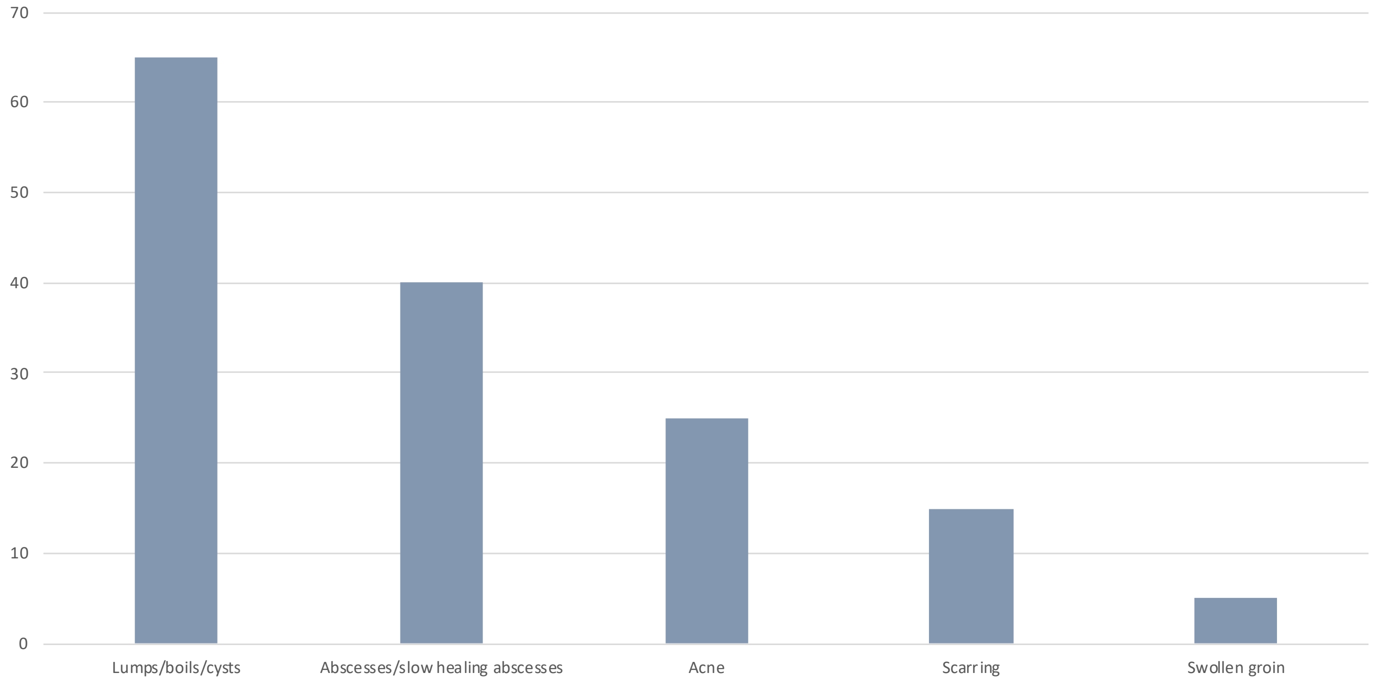


Figure 3.2: Symptoms leading to diagnosis

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and not seeking medical attention initially (55.00%) and having symptoms and seeking medical attention relatively soon (35.00%).

Participant describes having symptoms and not seeking medical attention initially

Yep, I can. So I I guess I started getting quite a lot of wounds under my particularly my arm and under my my breasts. And I actually, to be honest was quite embarrassed and chose to do my own research initially and found HS online and thought that's what I had went to my GP. And I think I went to my GP when I was about 50. I'm 53 now. I went to my GP and went in to her explaining that I thought I had HS and why I thought I had it. And she confirmed that day that she believed. That's definitely what I had. Fortunately, she had one other patient that had the condition.
Participant 001_2023AUHIS

So 14 cystic acne behind my ears under here. And other random places on my face. They were never acne. It was always a boils. And so I knew that was a bit different. And it was 19 when I got my first boil on my bum that required Lansing. I'd never had anything like that before. It was horrific. It was so horrific. And it just got worse after that, OK.
Participant 015_2023AUHIS

Yeah, so I was probably about 12 when I first started noticing. Just random things, random bumps coming up didn't obviously as a 12 year old I had no idea what it was and I didn't really understand it. I just thought, you know, coming into teenage years it was just pimples and that's what happens to teenagers and you know, it is what it is. So that was probably when I first noticed around that 12, 13 age group. Participant 005_2023AUHIS

Participant describes having symptoms and seeking medical attention relatively soon

So he when he was about, I suppose he's 16 now he was about 13 and. He started to get some swelling in his groin and painful swelling in his groin. And he went to the doctor and was told that at the GP and was told that he probably had some type of first they thought it might have been glandular and then they thought it was just a little bit of folliculitis, and then, when they kept coming back, yeah, he was referred on to a dermatologist. Participant 009_2023AUHIS

How did I come to be diagnosed? That was a very complicated process, very time consuming, expensive because a lot of doctors sort out with boils and they treated it for years for boils because they were uneducated in the disease. And I even got referred to a dermatologist who put me under Accutane, which is completely different related treatment for a *completely different condition again and 12 months wasted with that. And you know a person who works within a skin, a dermatologist is a skin. Specialist and still couldn't make the correct diagnosis. And it was when, you know, all of a sudden 12 months later, there's still no improvement. I think I'll refer you to a, you know, specialist dermatologist who specialises in Hidradenitis and HS, then finally got a diagnosis through there, yet I had been questioning AHS. Diagnosis. Diagnosis for a very long time and just kept getting told Oh no, it's not that. No, frustrating, expensive and time consuming.*

Participant 002_2023AUHIS

It started when I was about 7 years old. I don't remember a lot from back then, but I had it started with like a boil on my I think it was my butt and my mom took me to the doctors and they basically they didn't do any testing. They just said it's staph and we'll treat her for staph but the treatment obviously didn't work and. After maybe like six months or so, they kind of said it's not working and gave up and then that must be it.

Participant 014_2023AUHIS

Table 3.3: Seeking medical attention

Seeking medical attention	All participants	
	n=20	%
Participant describes having symptoms and not seeking medical attention initially	11	55
Participant describes having symptoms and seeking medical attention relatively soon	7	35
No particular comment	2	10

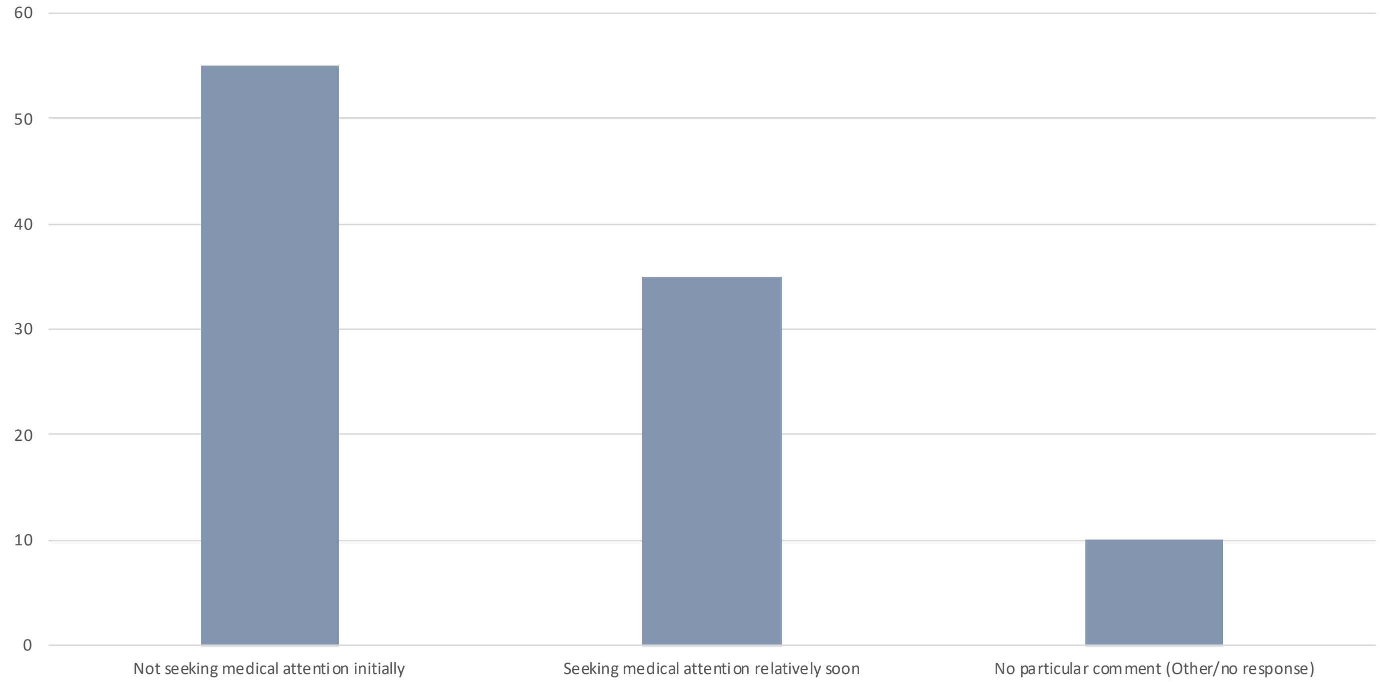


Figure 3.3: Seeking medical attention

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were a complex diagnosis, needing to see multiple specialists before diagnosis (35.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (20.00%). Other themes included being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.00%), being diagnosed in an emergency department (10.00%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (5.00%).

Participant describes a complex diagnosis, needing to see multiple specialists before diagnosis

Sure. So gosh, so I've had a lot of over the years, I've had a lot of visits to infectious diseases departments and I've been put on different treatments and it was only in I think 2021 that I actually got a diagnosis, so. Yeah, I had a couple. They kind of over the years, they've kind of gone dormant for a while and then they come back up again. Or I always kind of had one or two hanging around and it was usually on my backside or on my inner thighs. And they they kind of went through, you know, dormancy and then I'd have another one pop up. And I usually have that treated with any just antibiotics at the time through the GP. And anyhow, in 2021 I had three popped up on my low abdomen on my stomach. And then I also had a couple popped up under my bust, which I'd never had before and so. My GP referred me to infectious diseases at HOSPITAL and because with me the usually with HS there's no bacteria that that's in the pus and with me I had some really weird bacterias growing so I went to infectious diseases and I was treated by them. And she referred me to dermatology, the the infectious diseases, doctor referred me to dermatology and then I was diagnosed. Participant 017_2023AUHIS

Yeah. So the the earliest signs, and as you say, I didn't sort of link them to anything, was I I had a few lumps in my armpits, like a few and I suppose they they would look like big pimples. And so like I thought it was odd. I probably tolerated them for about six months before I went to the GP and and that initial GP there was a registrar and they sort of said Ohh look it's odd they've been there for so long and they put me on a a course of antibiotics I went back about two to three weeks later when the antibiotics were done. And that had no impact whatsoever on the lumps. And and so that doctor actually just said, look, I don't know what it is. So I had to ask for a second opinion. And when I did ask for a second opinion, a more experienced doctor came in and could have indicated that it was probably all related to hygiene issues. And that I should just improve what I was washing with and that sort of thing. Yeah. So that, like that pretty, pretty dismissive I felt and gave me a gave me a breast check. The doctor sort of said to the registrar, I'll just give her breast check and she'll feel better. She's just paranoid because she's female.
Ohh so it went. Then I went to the I went back to my my regular GP about six months after that and she referred me for scans and then to a dermatologist. So the the scans showed I guess enough then for that referral to the dermatologist and the dermatologist was able to, to label it, I suppose on their first appointment. So that's by then nearly 18 months since. Participant 007_2023AUHIS

Participant describes a linear diagnosis after being referred to a specialist from their general practitioner

OK, so prior to being diagnosed it was all very self managed. I never really saw a doctor for it because. I just couldn't afford to. I couldn't afford to see a skin specialist like my mum. She didn't really think it was a big deal, so she never took me. And then I moved out and just kind of managed it by myself and would extract the pus and stuff from the bumps and I would wash it and keep it clean and I wouldn't use anything harsh on it. And then. It wasn't until two months ago that I was actually diagnosed. So very recently, like 10 years of me having this disease, I was diagnosed. I booked in to see a skin specialist. Mainly for the acne on my face but as well as the disease. He specializes in HS. So I saw him and pretty much he just had to take one look and he was like, yes, you have HS, that's what this is. So there were no real tests done. I did do a blood test just in case, just just to clear that out of the way. But the doctor could kind of just look at it and go you have HS.
Participant 010_2023AUHIS

So I again was led to believe that it was just ingrown hairs and things like that. Doing some research of my own, just came across some Facebook groups about HS and this could be it. They asked someone who became a regular GP when I had kids with everything to looking further for me and she requested that I went and saw a dermatologist and that dermatologist pretty much confirmed it straight away.
Participant 011_2023AUHIS

Participant describes being diagnosed by their general practitioner during a routine check-up that related to symptoms

Yep, I can. So I I guess I started getting quite a lot of wounds under my particularly my arm and under my my breasts. And I actually, to be honest was quite embarrassed and chose to do my own research initially and found HS online and thought that's what I had went to my GP. And I think I went to my GP when I was about 50. I'm 53 now. I went to my GP and went in to her explaining that I thought I had HS and why I thought I had it. And she confirmed that day that she believed. That's definitely what I had. Fortunately, she had one other patient that had the condition.
Participant 001_2023AUHIS

I recall a long time physician GP she wrote it on a post it note, slipped it over to me and that was all that that was said about it. I I still remember looking at it going, I don't even know what that says and it took me ages *to hidradenitis, suppurativa hidradenitis. Super. You know, what does that mean? I mean it was probably 20, 20, 2001 maybe. And so the Internet, I I only just had to you know Vodafone, the sorry the Nokia, you know there were no smartphones. There was no Internet really. I mean at least I didn't have a computer in my home. I was living by myself at that point and even then it was probably still dial up for all I know we certainly didn't. You know. So there was no, there were no. Images, photos. What's life like? That was it? It was just a yellow postit note. I still remember very clearly That was my diagnosis. Participant 015_2023AUHIS*

Table 3.4: Diagnostic pathway

Diagnostic pathway	All participants	
	n=20	%
Participant describes a complex diagnosis, needing to see multiple specialists before diagnosis	7	35
Participant describes a linear diagnosis after being referred to a specialist from their general practitioner	4	20
Participant describes being diagnosed by their general practitioner during a routine check-up that was to symptoms	3	15
Participant describes being diagnosed in an emergency department	2	10
Participant decribes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	1	5
No particular comment	3	15

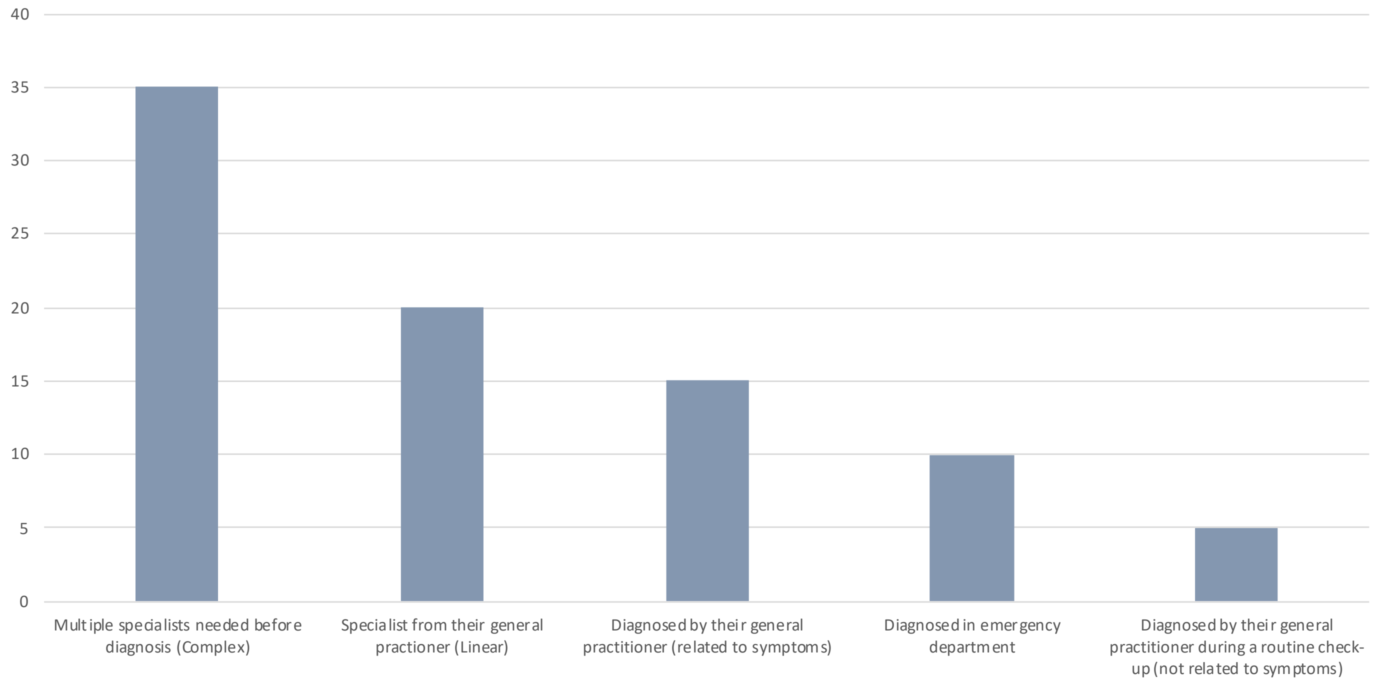


Figure 3.4: Diagnostic pathway

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were knowing nothing or very little about the condition at diagnosis (65.00%) and knowing about the condition by learning about it before or during the diagnostic process (15.00%). Other themes included knowing a good amount about the condition at diagnosis, for example they understood diagnosis and aspects of treatment (5.00%), and knowing about the condition due to professional background (5.00%).

Participant describes knowing nothing or very little about the condition at diagnosis

Very little. I mean that there was no cure and that I have that. I just have to live with it. It's just part of who I am now and. The dermatologist actually used the words and I can't like I was 19 years old, so I don't have a huge amount of memory other than the bad bits. But he literally said to me, do yourself a favor, stock up on bandaids. So that was that was kind of how it was dealt with. Granted it was 25 years ago. Participant 005_2023AUHIS

Nothing. I'd never ever heard of it before. I'd never even come up on Google when I was researching like for myself, like what is wrong with me? Because it's just so similar to other cysts and things I guess in the beginning quite easily get confused with that, but no, it didn't even come up. I'd never heard of it.
Participant 006_2023AUHIS

I didn't really know much. I had to do a lot of research after I was given the name of it, pretty much like they gave me a fact sheet. But it was like 2 sided that was it.
Participant 003_2023AUHIS

Participant describes knowing about the condition by learning about it before or during the diagnositic process

Nothing. I actually had Googled it, googled skin conditions and that and had already got to the point where. I was suspecting it was HS. I have. I've got a health background. So I I was hoping against hope that it wasn't. But I was suspecting that that's what my it might be. And his they suspect that his father may have. We suspect his father may have had it. Well, probably still has it. Yeah. Not as active.
Participant 009_2023AUHIS

INTERVIEWER: HS itself? Yeah. Well, you had done a little bit of research, hadn't you?
PARTICIPANT: Yeah, I did, yeah. The research that I did beforehand, I found out that there were different stages of HS I still don't actually where which one falls in, but I think it's probably level one to two.
INTERVIEWER: Okay.
PARTICIPANT: I also found out that it's lifelong.
Participant 011_2023AUHIS

Table 3.5: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants	
	n=20	%
Participant describes knowing nothing or very little about the condition at diagnosis	13	65
Participant describes knowing about the condition by learning about it before or during the diagnositic process	3	15
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	1	5
Participant describes knowing about the condition due to professional background	1	5
No particular comment	2	50

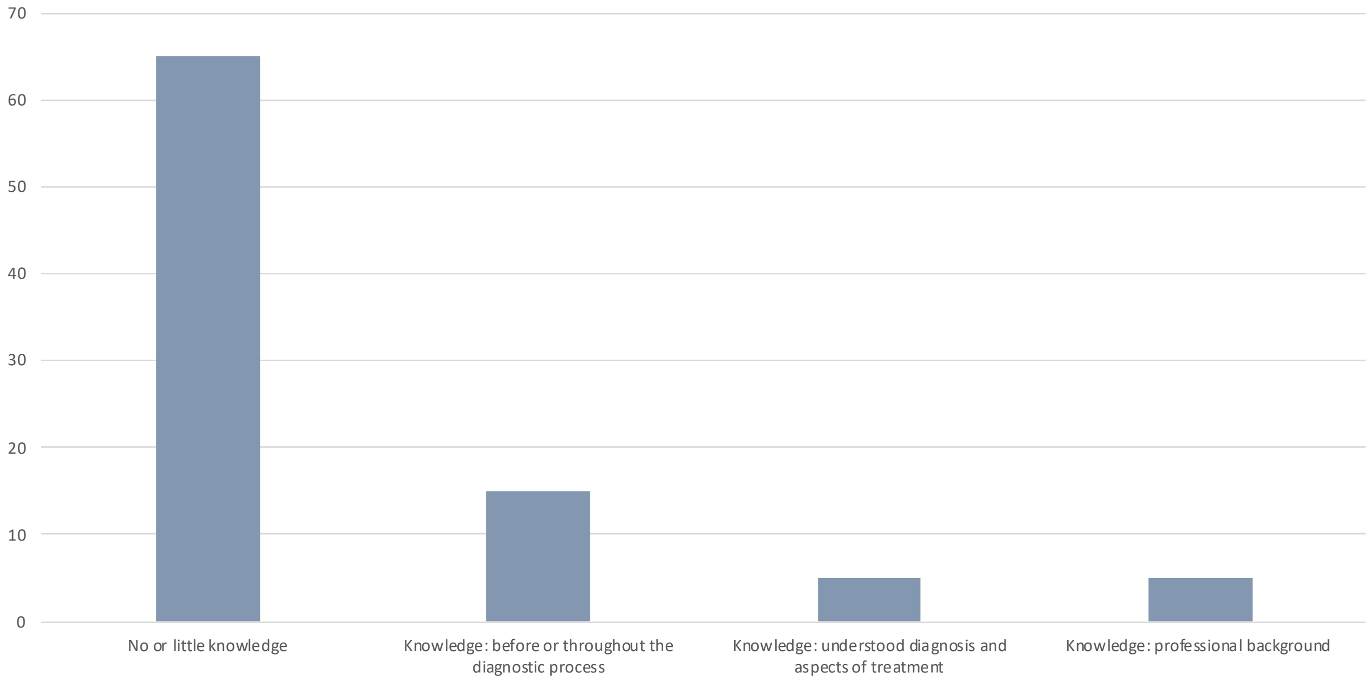


Figure 3.5 Understanding of disease at diagnosis

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (40.00%), and related to the stage of their condition (30.00%). Other themes included that it was a lifelong condition (20.00%), that it being currently controlled (20.00%), and that it was a serious condition (15.00%).

Participant describes prognosis in relation to specific medical interventions they need to manage their condition

All right, I take my injections each week and. It it is improved it dramatically, not completely. My worry is travelling like you hop on a plane and go from my home to London. It's 36 hours. How do I travel with six weeks worth of injections that need to be kept at a certain temperature for that duration of travel? It's almost it is impossible and so that in itself is going to So what? Do I not go overseas, or which I will not, not go overseas, but what happens with my treatment? Do I go back to not being able to have anything and have a huge flare up again?
Participant 002_2023AUHIS

PARTICIPANT: It's kind of just something that I know that I have and I just kind of try to look at it as like it is what it is. So I don't know it it does get depressing sometimes, like when you have like a really bad day. Yeah. But yeah, All in all, it's just kind of like there's nothing I can do about it apart from what I'm already trying. So there's no point in getting myself down about it
INTERVIEWER: Yeah, so do you know what your prognosis is? Is there a cure or is it something that you have to manage for the rest of your life?
PARTICIPANT: I've been told that it's mainly something that people have for the rest of their lives, but there are medications that can help people either get better, not completely, but to an extent where it improves the quality of life.
Participant 014_2023AUHIS

At the moment he has to have, he has to have immunosuppression therapy and it's it's difficult to say what the prognosis is I mean. Given the fact that they don't know a great deal about HS, like I can't believe and you're going to get a, you're going to get me on my soap box. I'm sorry, I can't believe that they spend all this money invested in finding out about multiple sclerosis and yet there's like three and a half 3.5 people per thousand that are diagnosed with multiple sclerosis and there's. One in 100 they suspect having HS and they think that that actually could even be one in sorry four in 100. So I I just think prognosis wise until they actually find something. There's a bit more like at the moment he's had to withdraw from his competitive sport. He was a a successful swimmer. And Surf life saver. Competitive surf life saver. And he's had to pull out of all of that because he he just can't compete anymore with the pain. No. And they and they they're debilitating. The tiredness. He's is constantly fighting tiredness and that's because his body's immune system is constantly you know, fighting itself. So yeah prognosis at this point and and some. Some people tend to think that it can settle down with hormones a bit as they like as puberty settles down. But in males. And I know that it's, it's rare or it's less less common in males than it is in females, but he's also got a double hit of it. He's got a diagnosis of cystic acne as well, on top of the hidradenitis. So yeah, it's yeah. Yeah. So, yeah, prognosis, I don't know if he's on here, NAME. It's pretty good. You know, it's that's obviously got, it's got a huge psychological impact too. And that's something that I think I significantly underestimated that psychological input because he in effect, he, he doesn't want to tell his friends about it because he's embarrassed. If he's having an active flare, he can't walk properly so he doesn't want to go to school because he'll get teased. Yeah, it's, it's, it's a it's a dreadful, dreadful condition for them.
Participant 009_2023AUHIS

Participant describes prognosis in relation to the stage of their condition

I'm severe case I'm. It's hard for me because I don't know what else will come. I'm frightened of that. I'm mindful of that and I'm at the same time I'm thankful I'm my worst area is my underarm. It's only my left. I'm right-handed and and I have just recently received one under my right arm and it thankfully went down, but it's just sitting there as a red boil. Not not particularly painful, but I have to be very mindful not to touch it, play with it or do anything with it. And so when I say severe, I'm still at the same time thankful that it could be worse and you know, any day now could be worse.
Participant 015_2023AUHIS

So currently I am so when so maybe if I just when I was diagnosed with it, I was diagnosed at severe stage 3 HS. An example would be under my right arm I had 15 plus active wounds going on. Just under my right arm I initially was put on. A course of doxycycline, then a course of keflexin, then a course of erythromycin. Also, at the time I was on doxycycline, I was on sterinoloctican. None of those really worked for me. I didn't really receive any improvement. Then once I'd gone through that process, I was being put on Humira. And I would say Humira, depending on where on my body I have the HS, Humira has given me between about, look probably a 80 and 95% improvement.
Participant 001_2023AUHIS

Participant describes prognosis in relation to it being a lifelong condition

I don't know, Like, it's a bit sad knowing that there's no cure and that I'm going to have it forever and it probably won't be fixed. So a bit depressing. But you know, I have a good partner who doesn't like judge me for the disease I have, so I think that's fine. The overall like pretty negative outlook. I don't think it'll ever be fixed, but it's just something I kind of have to manage. Participant 010_2023AUHIS

Participant describes prognosis in relation to it being currently controlled

PARTICIPANT: I guess from research that I've done myself. I I think that there's probably a a 10 to 20% chance that it may recur. I've had fairly drastic surgeries under both arms, which was which was at my own sort of request. Once I've done my own research, I wanted to treat it more aggressively then then then what the dermatologist was sort of looking at. Because going with the dermatologist for for a couple of years, it wasn't really having an impact.
INTERVIEWER: Okay so.
PARTICIPANT: So, yeah, so in terms of I suppose outlook, right now I I have no symptoms whatsoever, but I'm conscious that at some stage in the future it may recur or it may turn up in the different in a different location.
Participant 007_2023AUHIS

Well, mine seems to be pretty dormant at the moment, so I went from what they call stage 3 or probably just stage one now. It's manageable. I'm not under a specialist or anything, I just manage it myself.
Participant 013_2023AUHIS

Participant describes prognosis in terms of extent or spread of condition

So I am currently awaiting what is the debriefing surgery with the plastic surgeons at HOSPITAL. I am on hamira I have. Very few breakouts at the moment. I am stage 3, so I have lots and lots of tunneling. I have two lesions that are more than three years old, so I have one behind my behind the right nipple which has five sinus tracks, and I have one on my right side which has about 12 sinus tracks.
Participant 005_2023AUHIS

Participant describes prognosis in relation to it being a serious condition

Well, I'm screwed. That's pretty much it. Participant 004_2023AUHIS

Table 3.6: Understanding of prognosis

Understanding of prognosis	All participants	
	n=26	%
Participant describes prognosis in relation to specific medical interventions they need to manage their condition	8	40
Participant describes prognosis in relation to the stage of their condition	6	30
Participant describes prognosis in relation to it being a lifelong condition	4	20
Participant describes prognosis in relation to it being currently controlled	4	20
Participant describes prognosis in terms of extent or spread of condition	4	20
Participant describes prognosis in relation to it being a serious condition	3	15
Participant describes prognosis in terms of symptoms and function/changes in symptoms and function	2	10
Participant describes prognosis of self management, including lifestyle changes	2	10
Participant describes prognosis in a positive way, that their condition is manageable	1	5
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	1	5
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	1	5
Participant describes that there is Uncertainty around prognosis	1	5

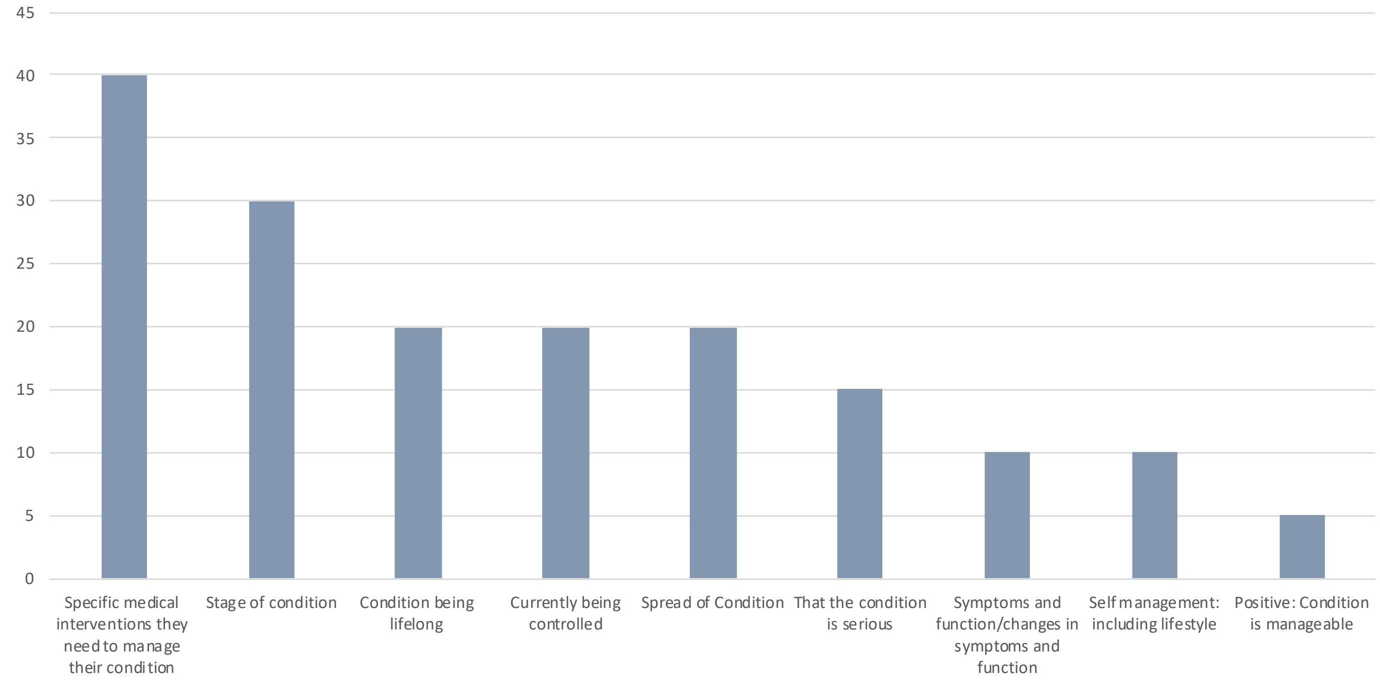


Figure 3.6: Understanding of prognosis

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (65.00%), or one treatment option (15.00%). This was followed by no discussions about treatment (10.00 %), and no particular response (10.00%).

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

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

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

Considerations when making decisions

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

Decision-making over time

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

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

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

Personal goals of treatment or care

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

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (65.00%), or one treatment option (15.00%). This was followed by no discussions about treatment (10.00 %), and no particular response (10.00%).

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

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

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

Multiple options: Participated in the decision-making process

So in terms of treatment options, he did recommend Accutane or Isotretinoin, which is what I'm currently taking. And then he said after I finish the course of medication that I'm on, we could look at like skin resurfacing, which is like with a laser or like. Yeah, I don't think exactly know how it works, but I assume it's with a laser. He also mentioned I could get Humira shots for it, which is which he he said he wouldn't recommend just because you can be very prone to infection on that medication and it's kind of lifelong. And I think the results with it were very mixed. And so he didn't want to risk me going on it and making my condition worse because. Some of the results of people going on that medication, it can either clear it up or it really aggravates the disease and it can spread to other areas. So I kind of declined that one And we did also talk about surgery and having like it's called like a wide excision, which is where they would like cut out the skin that's affected by the disease and. Stitch it back up essentially. So I kind of have to wait until I finish the medication I'm on before we can discuss any like further treatment, but those are kind of the options I was given.
Participant 010_2023AUHIS

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

So I chose the surgical option and then from there I didn't proceed with the surgical option. I chose to get a second opinion at from another dermatologist because I just didn't feel that this first dermatologist connected with me as an individual.
Participant 013_2023AUHIS

Multiple options: They were told what to do without discussion

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

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

No, just see your doctor if it gets too bad, and they'll they'll give you some antibiotics to settle it there. Not that antibiotics do a particularly lot for any anything to do with HS, but he was just like just see GP for antibiotics.
Participant 005_2023AUHIS

Participant describes no treatments being discussed

At diagnosis, I was actually not given any options. I, the doctor that had diagnosed me, obviously heard of it and seen it, but she didn't give me any kind of like, this is what you can do for it. This is what can help. This is how you bandage yourself. Like there was nothing. It was just this is what you have.
Participant 014_2023AUHIS

Table 4.1: Discussions about treatment

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

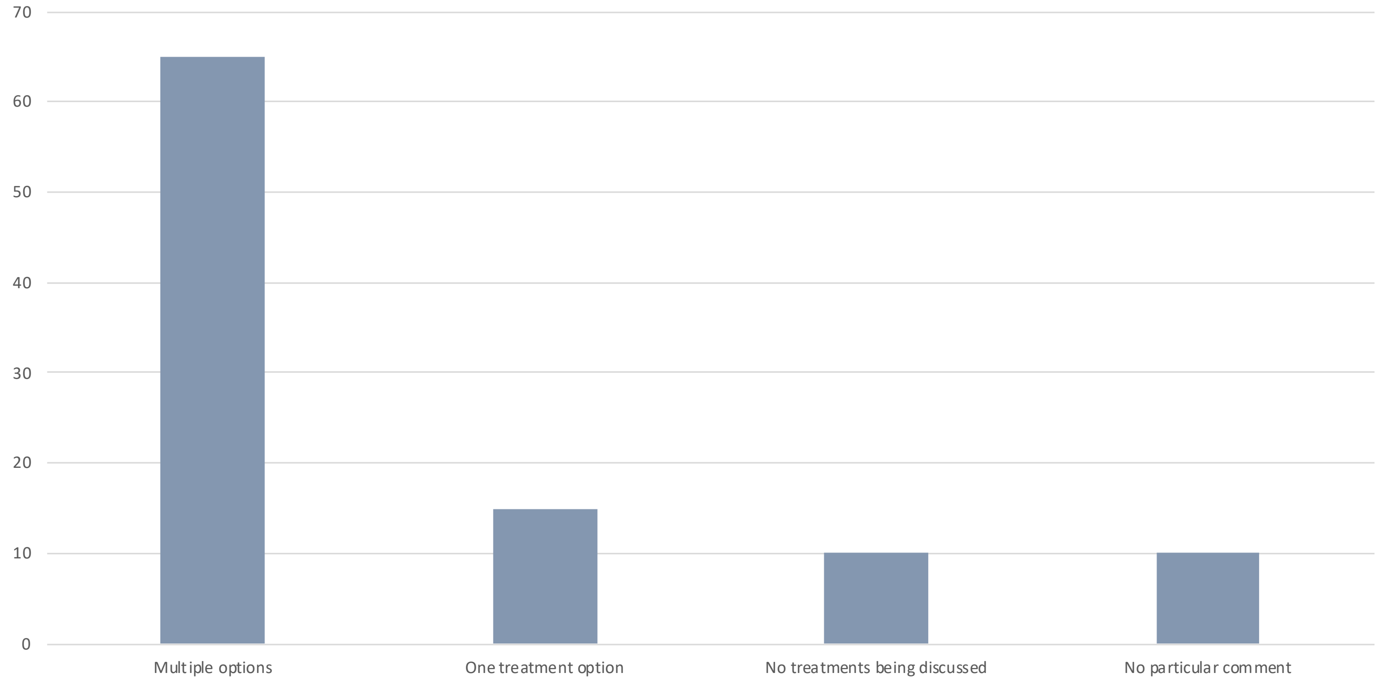


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment (Participation in discussions)

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

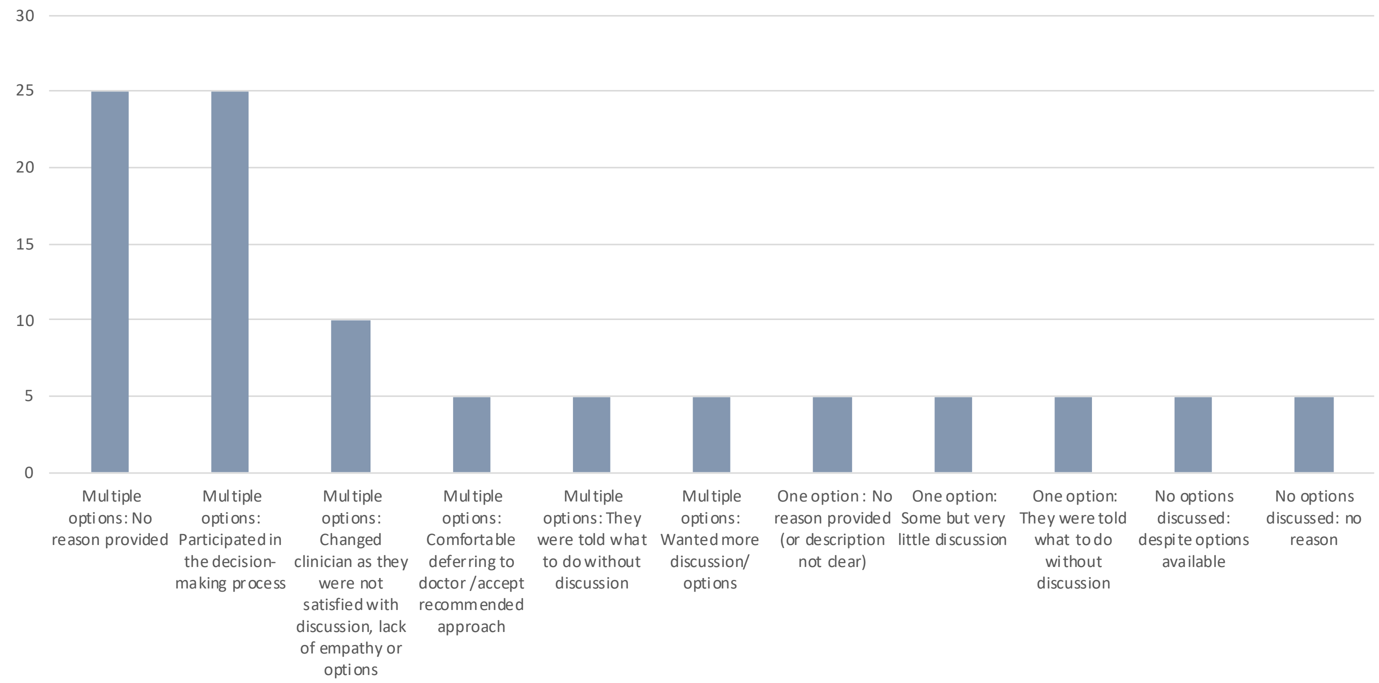


Figure 4.2: Discussions about treatment (Participation in discussions)

Considerations when making decisions

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

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

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

I guess if treatment is going to affect my general life, like work like, you know, the doxycycline in that I was too sick to eat, or surgery, like how long will it take to recover? Time of work, that kind of thing.
Participant 006_2023AUHIS

Participant descibes taking efficacy into account when making decisions about treatments

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

Medical and scientific evidence. Basically I read the publication. Yeah, that's how I decided it becomes difficult because still as of this date, there is only one drug approved in Australia for the treatment of HS.
Participant 008_2023AUHIS

Participant descibes taking cost into account when making decisions about treatments

Well, probably cost and side effects.
Participant 013_2023AUHIS

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

can't be fixed really, it can only be managed. So I guess I'm just when I think about treatment. I'm looking for something that seems most hopeful. Like I said, I'm very interested in getting the surgery done, to have it removed because it just seems like the most drastic get it done kind of treatment.
Participant 010_2023AUHIS

The potential side effects of those treatments and how those side effects can affect my quality of life if the treatments are successful and weighing up whether the side effects are worth it if on the off chance that the treatments are unsuccessful and the ability to basically afford those treatments.
Participant 012_2023AUHIS

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

I think the impact that whatever I'm taking has on my health. Like obviously take Humira has Humira was I guess the big one, but I was. I guess my quality of life Prehumira was not great. So the, the, the decision to take Humira was because I wanted to improve quality of life. Now I think there's an element of you know, quality over quantity and my my quantity of quality of life at that time was not good at all. So my decision to take Humira was based on that.
Participant 001_2023AUHIS

Quality of life, quality of life is because of effective treatment. So that I wouldn't say it's been a quality of life. It was just effectively treatment directly leads to quality of life improvement.
Participant 002_2023AUHIS

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

So I have other health conditions obviously, so it does limit me on what I can do, which is why I don't know if I'm suitable for clinical trials and things like that. So I guess that's kind of the main thing that I consider. But also, I work full time. I'm the sole provider for myself, so I have to kind of be able to work. I can't take time off work.
Participant 014_2023AUHIS

I suppose the the prognosis around how effective the treatment could be and how long it would solve the problem for. So I I wasn't. Yeah, I spent a long time on antibiotics. And I felt also that it was having a significant impact on the rest of all the rest of my body without actually managing to control or change the condition itself. So I I was quite frustrated with that and and once I sort of had in my mind that I wanted to pursue the surgery pathway. I knew that it would be actually. No, I didn't. I I had no idea how significant the surgery and the recovery from that would be. So when I initially spoke to the general surgeon and I said, do you know how long till I can go back to work and he said, oh, well, you know, you're sitting at a desk, so probably at least few days. And in actual fact it was each time it was two to three weeks. With you know, regular visits from the Community nurse and and really, yeah being quite debilitated, it's the wrong word. But they like they I think it's part of the condition of discharge. They then didn't have me driving a car until six weeks later when I'd seen the surgeon to sign off on the fact that it was okay to drive again.
Participant 007_2023AUHIS

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

Well, with, for example, with the Humira, Humira, I'm not really, I guess it's about what I'm comfortable doing. So I'm not really comfortable with the idea of giving myself injections. So that's why, like, I hate needle, you know, most, I don't think anybody like goes, oh, I love needles, you know, I'm pretty sure we all hate needles. I guess if it got to the point where maybe I was stage 3 and it was kind of like the only thing left. But as far as medication is concerned, so long as the you know I'm not getting side effects, I'm OK to you know, I generally read up on stuff and look out for side effects and up till now touch wood I've been very lucky. I haven't really had any. I don't get side effects from from the antibiotics. I haven't had any side effects from the I can't going to call them Aldeton, but they're not Aldeton, they're spiralactin.
Participant 017_2023AUHIS

Yes, the commitment the, I think the the first thing would be likelihood of success. Prospects of success and then it would also be weighed with so say, there might be a real likelihood of success with this cosmetic surgery but now we're talking cost time and recovery and the utility of that on my current living situation with my children, my work. So the impact on my life, I suppose my day-to-day. And finances are a huge thing. I think I'm on the trial. I wouldn't be able to afford the Humira if I am if I wasn't on the trial. So that's another thing about whether I would or would not continue with the the trial is, you know, it's I can't see that I'm having any negative side effects from it. I can't say exactly or truly if I'm seeing a definitive benefit from it. At the same time, it really I just every two weeks I just have a reminder of my phone to inject myself and then I go and see DOCTOR every 12 weeks. And so the impact on my life is very low.
Participant 015_2023AUHIS

Table 4.3 Considerations when making decisions

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

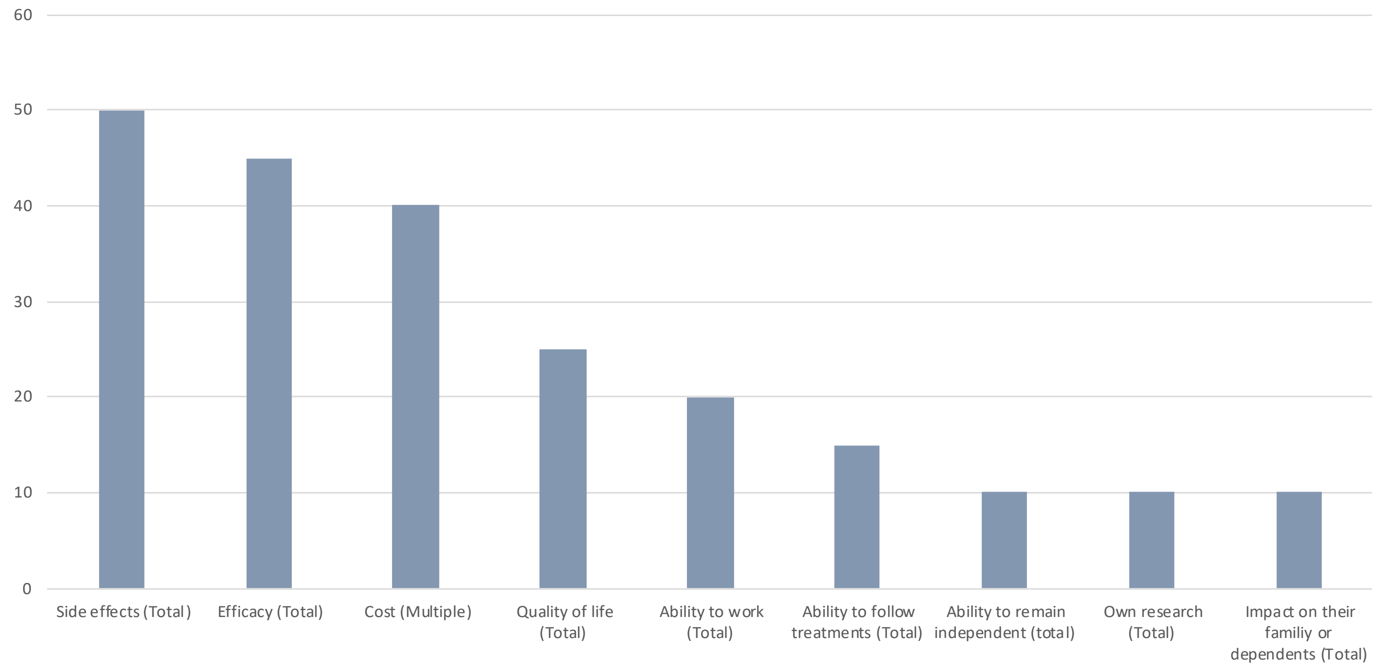


Figure 4.3 Considerations when making decisions

Decision-making over time

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

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

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

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

It's probably a bit different because I'm a bit more aware of what it is now mm.
Participant 011_2023AUHIS

Yeah, no, it's changed a lot. I was very naive and you just went to the doctor and did what he ever said. Now I have researched it myself a lot, so I'm more educated. So I make decisions based on I discussed my decisions with the doctor.
Participant 013_2023AUHIS

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

Yes, definitely. Like, I wear a mask all the time and people look at me and think I'm strange. And that's like, well, you know, I have to. I can't afford to take things.
Participant 009_2023AUHIS

It's just to completely altered my whole existence like I have to absolutely the like my clothing choices it it was, it's very much so people want to say let's catch up on the 18th of May and I say sure and then I think I don't know. I never know because I could come down with a massive flare at any given time, at any given day and it has disturbed my ability to function in that regard on a social level. And and you know, a a large portion of other things as well, like you know, my my poor husband, he's not as free as he. You know, it could be because I can only do so much with the kids, my physical ability. So decisions in that regard [Unintelligible] that he if it includes the children, you know, sure. If not it's got to be very measured and you know, those sorts of things. Also my work. I'm in a very, very supportive environment. I can work from home. I can just drop off. I'm here one day and all of a sudden I'm not what what happened to her? Right. There's always that you seemed fine yesterday and it's like, well, but you know it. I'm lucky in that regard because I don't think it would. I don't think I would survive another firm. The kinds of cultures that they have there working you to death until you bleed. And you know, if I ever needed a day, I would be pushing through that. There have been times where I've been smiling and grinning through pain and I've been in the car park at a lunch break crying on the phone and my husband, just from how exhausted I am. And so I don't, I wouldn't. I just wouldn't make it. So decisions 100%
Participant 015_2023AUHIS

Changing: more focused on quality of life

It it has changed, I've gotten a lot more cautious about looking at side effects compared to the treatment and the treatment success because. There's been because of how many treatments have been unsuccessful, but I've still suffered side effects from them, and those side effects have affected my quality of life. I consider that a lot more, and I also look at the costs of the treatments a lot more because of again, is it worth me spending a hundred $200.00 an injection when it's going to make my skin blister and make my wounds bleed more? Or is it worth it? Knowing that, that's a potential side effect, but it's from the medication, not from the condition.
Participant 012_2023AUHIS

No change

I make decisions in the same way.
Participant 002_2023AUHIS

No, I think it's the same. I think I'm the same. I mean previously there was no, there was not any other options other than just tablet taking antibiotics. So you know I I know antibiotics work so if it works then I'm I'm OK to. Taken in my decision has just been guided by my doctor, I guess. Well, you know so.
Participant 017_2023AUHIS

Table 4.4: Decision-making over time

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

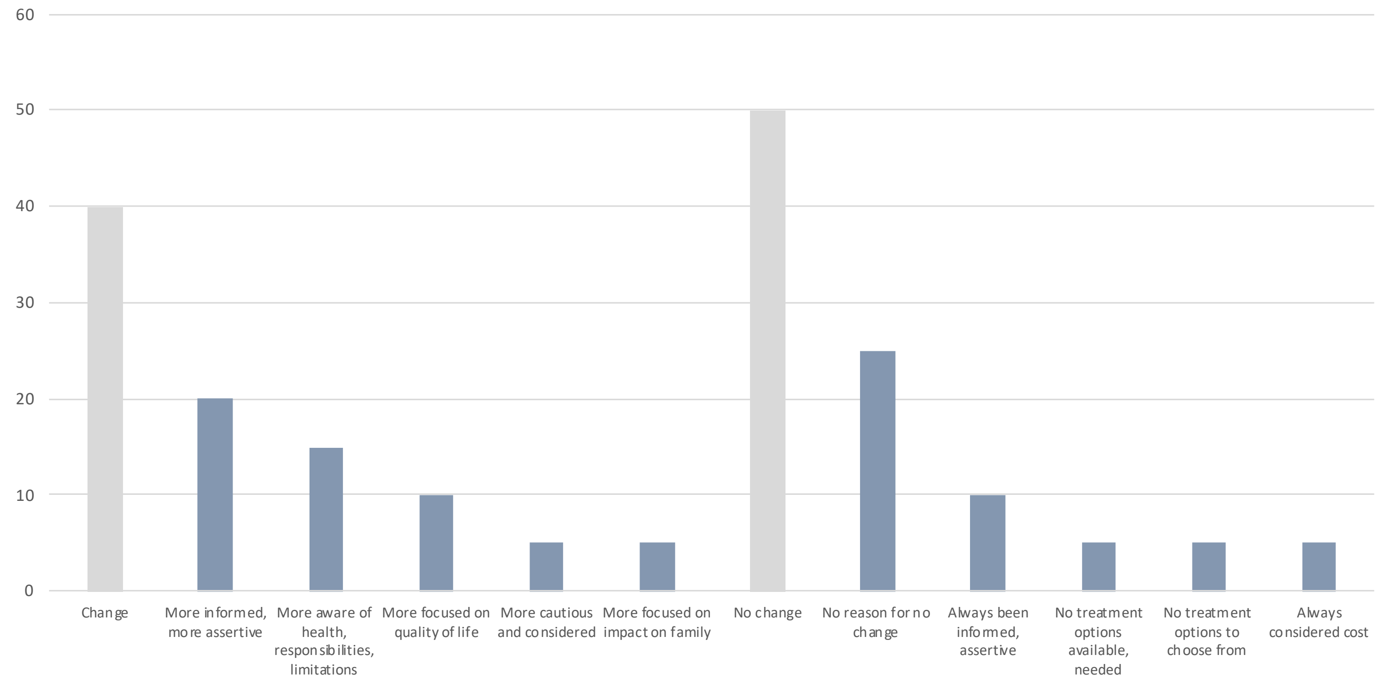


Figure 4.4: Decision-making over time

Personal goals of treatment or care

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

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

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

while I've been on it so. Yeah. So yes, the answer to your question is to not have to deal with this. That would be the ultimate goal, but just to be able to manage it and manage the pain.
Participant 017_2023AUHIS

Per my personal goals is is to keep my HS under under control as best as I can. So that obviously means engaging you know with my my doctor engaging with my dermatologist mental health as well can be an issue so also if I need to I I do have a counsellor that if I'm not. Not doing well that I seek to fix them as well.
Participant 001_2023AUHIS

Yeah, I guess I have a lot of side effects of treatment and I have to see other conditions as well and probably more than HS does alone. So I guess it's just management of everything more than anything. I think I'd like to be able to manage without it progressing too much worse and being able to manage whatever treatment I'm on.
Participant 019_2023AUHIS

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

My goal was just to just to get treatment. Yeah, so obviously to have a better quality of life.
Participant 002_2023AUHIS

Supposed to be able to minimize impact on my functioning so I can hold down a full time job and do normal things that I, you know, that I want to continue to be able to do.
Participant 007_2023AUHIS

My personal goals are just to manage it and last resort. I take antibiotics but otherwise I'm actually at a good stage at the moment so I'm managing it and as long as I can live comfortably and do my things then I'm happy.
Participant 013_2023AUHIS

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

Nice to get them. Like, honestly, just get the pain to stop. Participant 004_2023AUHIS

Participants describe wanting to see physical improvements in their condition

I mean, I wanted to clear the thing up from my face. I mean, it's kind of cleared up, but the scar's always gonna be there. So I mean, to get rid of the scar would be nice. Since it was, I could hide all my, you know, issues. But now I can't really hide it. It's on my face.
Participant 003_2023AUHIS

Table 4.5: Personal goals of treatment or care

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

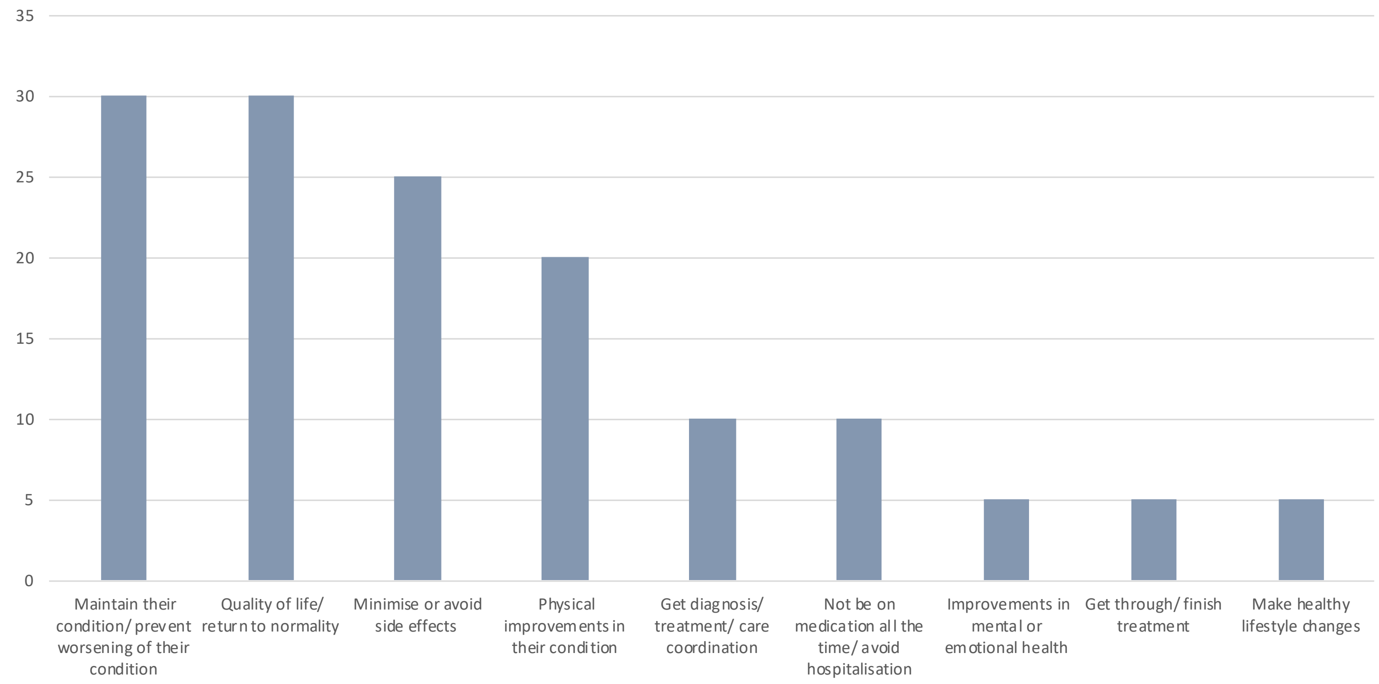


Figure 4.5: Personal goals of treatment or care

Section 5

Treatment

Section 5: Experience of treatment

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were described using a specific examples (55.00%), and side effects that do not interfere with life (35.00%). This was followed by side effects that can be managed with self-medication or self-management (25.00 %), and side effects that resolve quickly (5.00%).

When a specific side effect was described, the most common responses were rash, dry skin or itchy skin (30.00%), aches and pains (20.00%), and nausea, vomiting or loss of appetite (15.00 %). Other side effects included headaches (10.00%), indigestion (5.00%), lightheaded or dizzy (5.00%), bleeding (5.00%), bloating (5.00%), dry lips (5.00%), and thrush (5.00%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (40.00%), and described using a specific example (30.00%). Other descriptions of side effects included those that are life threatening or result in hospitalisation (15.00%), side effects that impact their everyday life by being bed ridden (15.00%), side effects that are worse than condition (10.00%), side effects that cause long-term damage to their body (5.00%), side effects that require medical intervention (5.00%), and side effects that cause them to stop taking the treatment (5%).

When a specific side effect was described, the most common examples were allergic reaction (10.00%), and skin blistering or skin eruptions (10.00%). Other side effects included arthritis (5.00%), blood clots (5.00%), fever (5.00%), loss of vision (5.00%), painful urination (5.00%), and tremors (5.00%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were adhering to treatment for a specific amount of time (55.00%), adhering to treatment according to the advice of their specialist or as long as prescribed (50.00%), and adhering to treatment as long as side effects are tolerable (30.00 %). Other themes included adhering to treatment as long as treatment is working (20.00%), needing to see test results/no evidence or reduction of disease (5.00%), and never giving up on any treatment (5.00%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (20.00%), and six to twelve months (15.00%). This was followed by one month (10.00 %), and two to three weeks (5.00%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear or reduced side effects (85.00%), and needing to see a specific symptom reduction (35.00%). Other themes included needing to see improvements in general wellbeing or quality of life (10.00%), and needing to see evidence of stable disease or no disease progression (5.00%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were described using a specific examples (55.00%), and side effects that do not interfere with life (35.00%). This was followed by side effects that can be managed with self-medication or self-management (25.00 %), and side effects that resolve quickly (5.00%).

When a specific side effect was described, the most common responses were rash, dry skin or itchy skin (30.00%), aches and pains (20.00%), and nausea, vomiting or loss of appetite (15.00 %). Other side effects included headaches (10.00%), indigestion (5.00%), lightheaded or dizzy (5.00%), bleeding (5.00%), bloating (5.00%), dry lips (5.00%), and thrush (5.00%).

Participant provides a specific side effect as an example

Yeah, like a little bit of itch. Yes, yes. Stuff that you could easily cope with might be a bit annoying, but yes, yeah.
Participant 019_2023AUHIS

Mild side effects I describe as occasional headaches, very very faint disorientation, slight skin rash, cold flu symptoms for a few days. Pain at the injection site for a few days afterwards though. Those sorts of things. The occasional headache, that that sort of stuff. I yeah, I don't know how, I haven't actually experienced many. I wouldn't know what to describe with with mild side effects other than those.
Participant 012_2023AUHIS

Participant describes mild side effects as those that do not interfere with daily life

How would I describe the term mild side effects? Yeah, I guess side effects that don't majorly impact on your life.
Participant 001_2023AUHIS

Mild side effects for me would just be anything that I noticed and is inconvenient, but I can still get on with my day. I can still function normally.
Participant 010_2023AUHIS

Basically he's he he can like still go and do his go to school and and do his things. It doesn't impact too much on his daily life.
Participant 009_2023AUHIS

Participant describes mild side effects as those that can be self-managed

So mild side effects I would kind of refer to as probably something like thrush and you can just use Caniston and you know sort it out you can, you can sort out the side effect.
Participant 017_2023AUHIS

Well, I've only had the dry lips. Mine was just mild. Just Vaseline on the lips and just live with it.
Participant 013_2023AUHIS

Table 5.1: Description of mild side effects

Description of mild side effects	All participants	
	n=20	%
Participant provides a specific side effect as an example	11	55.00
Participant describes mild side effects as those that do not interfere with daily life	7	35.00
Participant describes mild side effects as those that can be self-managed	5	25.00
Participant describes mild side effects as those that resolve quickly	1	5.00

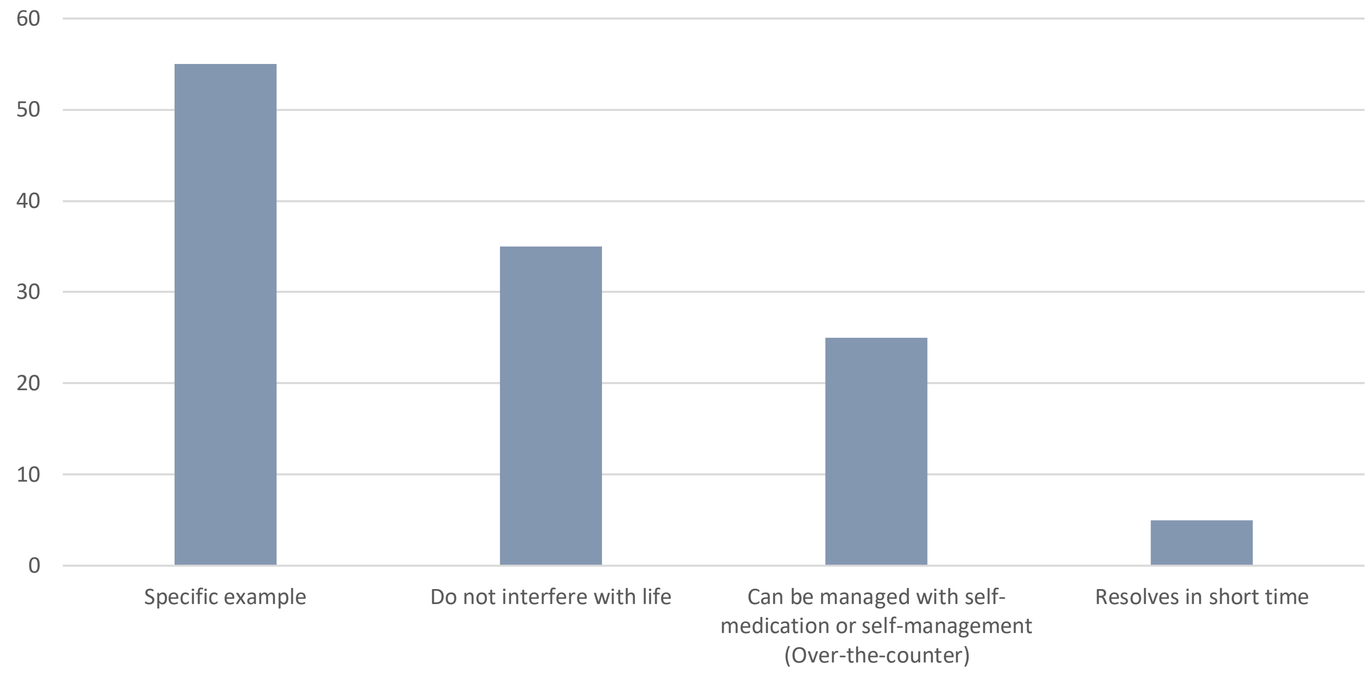


Figure 5.1: Description of mild side effects

Table 5.2: Description of mild side effects (Specific side effects)

Description of mild side effects (specific example)	All participants	
	n=20	%
Participant describes mild side effects giving the specific example of rash, dry skin or itchy skin	6	30.00
Participant describes mild side effects giving the specific example of aches/pain (general)	4	20.00
Participant describes mild side effects giving the specific example of nausea, vomiting or loss of appetite	3	15.00
Participant describes mild side effects giving the specific example ofheadaches	2	10.00
Participant describes mild side effects giving the specific example of indigestion	1	5.00
Participant describes mild side effects giving the specific example of lightheaded and/or dizzy	1	5.00
Participant describes mild side effects giving the specific example of bleeding	1	5.00
Participant describes mild side effects giving the specific example of bloating	1	5.00
Participant describes mild side effects giving the specific example of dry lips	1	5.00
Participant describes mild side effects giving the specific example of thrush	1	5.00

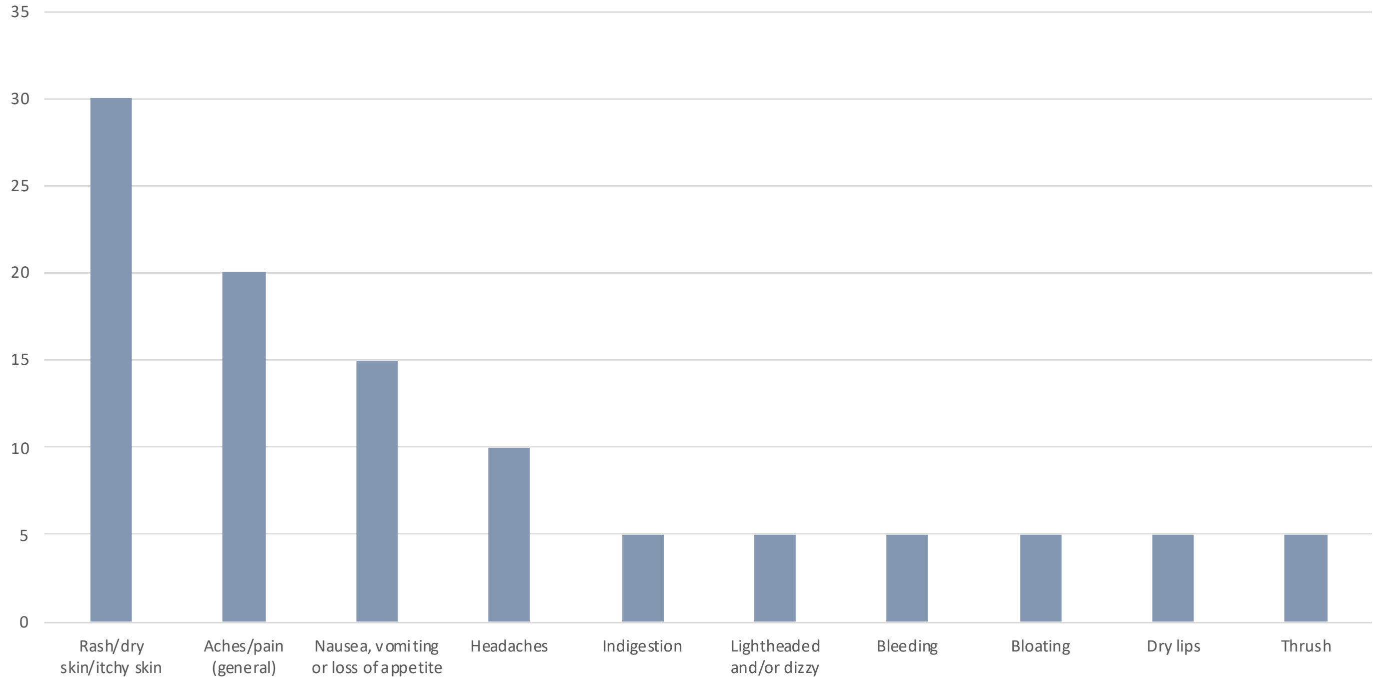


Figure 5.2: Description of mild side effects (Specific side effects)

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (40.00%), and described using a specific example (30.00%). Other descriptions of side effects included those that are life threatening or result in hospitalisation (15.00%), side effects that impact their everyday life by being bed ridden (15.00%), side effects that are worse than condition (10.00%), side effects that cause long-term damage to their body (5.00%), side effects that require medical intervention (5.00%), and side effects that cause them to stop taking the treatment (5%).

When a specific side effect was described, the most common examples were allergic reaction (10.00%), and skin blistering or skin eruptions (10.00%). Other side effects included arthritis (5.00%), blood clots (5.00%), fever (5.00%), loss of vision (5.00%), painful urination (5.00%), and tremors (5.00%).

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

Would be the ones that impact severely on your quality of life, but being able to function from day-to-day.
Participant 001_2023AUHIS

I'd say severe is when it's actually impacting what you're what you're able to do. So when it when it has an impact on your functioning.
Participant 007_2023AUHIS

Daily life severe is when he can't go to school or he can't do his daily activities.
Participant 009_2023AUHIS

Participant provides a specific side effect as an example

Bleeding, body aches, pain, shake, fever. I describe it as lack of ability, lack of being able to function on during your day-to-day life and any capacity. Loss of vision, blistering bump, blood clots, those sorts.
Participant 012_2023AUHIS

And I guess the severe one is the depression. But obviously I know what it is, I know what it feels like. I can pretty much handle it until it goes away.
Participant 014_2023AUHIS

Participant describes severe side effects as those that are life threatening or result in hospitalisation

Side effect might be a rash, OK, or vomiting. Have severe side effects, might be losing consciousness or you know.
Participant 002_2023AUHIS

So for me, a severe side effect would be, you know, obviously allergic reactions, bleeding in the stomach or severe constipation, impacted bowels, things that would affect you from living your normal day-to-day life. Participant 005_2023AUHIS

Participant identifies severe side effects as impacting their everyday life by being bed ridden

Severe would probably be something where I'm in a bit more pain where I maybe need to lay down and get a heat pack out and put it on the area or I have an intense migraine. To the point where I need to turn off the lights and put myself to sleep and I can't really do much.
Participant 010_2023AUHIS

The healing process from surgery is quite hard I it I didn't heal properly from the first scar tissue removal, so I spent probably. Over six weeks in bed, not being able to walk properly, trying to let it heal. But again, I live on my own so the healing process is quite frustrating.
Participant 018_2023AUHIS

Table 5.3: Description of severe side effects

Description of severe side effects	All participants	
	n=20	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	8	40.00
Participant provides a specific side effect as an example	6	30.00
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	15.00
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	15.00
Participant describes severe side effects as those that are worse than condition	2	10.00
Participant describes severe side effects as those that cause long-term damage to their body	1	5.00
Participants reported not experiencing any severe side effects	1	5.00
Participant identifies severe side effects as requiring medical intervention	1	5.00
Participant describes severe side effects as those that cause them to stop taking the treatment	1	5.00

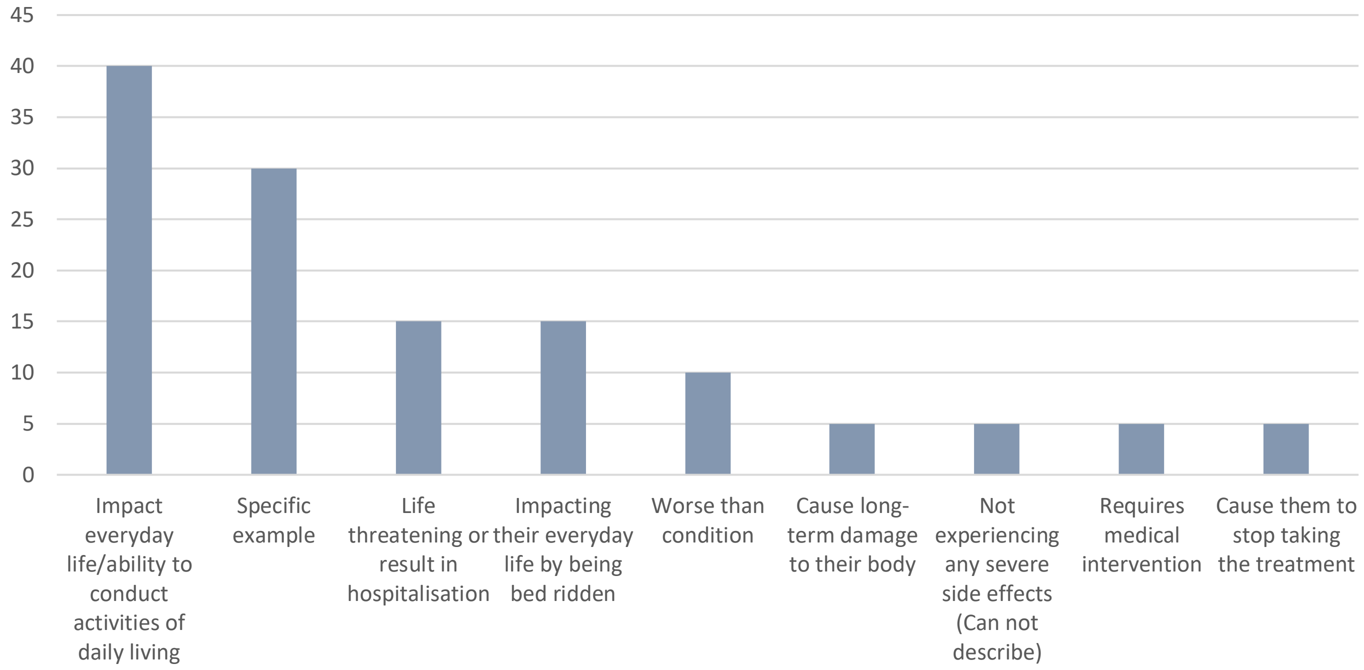


Figure 5.3: Description of severe side effects

Table 5.4: Description of severe side effects (Specific example)

Description of severe side effects (specific examples)	All participants	
	n=20	%
Participant describes severe side effects giving the specific example of allergic reaction	2	10.00
Participant describes severe side effects giving the specific example of skin blistering or skin eruptions	2	10.00
Participant describes severe side effects giving the specific example of arthritis	1	5.00
Participant describes severe side effects giving the specific example of blood clots	1	5.00
Participant describes severe side effects giving the specific example of fever	1	5.00
Participant describes severe side effects giving the specific example of loss of vision	1	5.00
Participant describes severe side effects giving the specific example of painful urination	1	5.00
Participant describes severe side effects giving the specific example of tremors	1	5.00

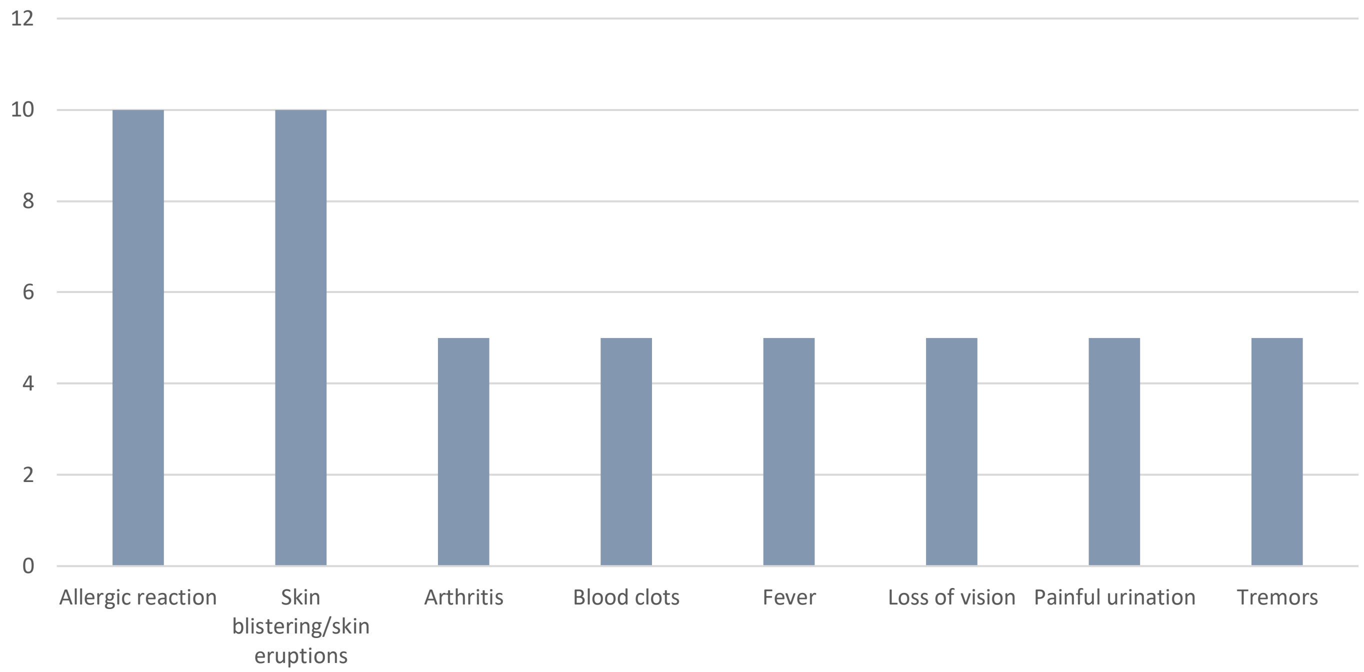


Figure 5.4: Description of severe side effects (Specific example)

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were adhering to treatment for a specific amount of time (55.00%), adhering to treatment according to the advice of their specialist or as long as prescribed (50.00%), and adhering to treatment as long as side effects are tolerable (30.00 %). Other themes included adhering to treatment as long as treatment is working (20.00%), needing to see test results/no evidence or reduction of disease (5.00%), and never giving up on any treatment (5.00%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (20.00%), and six to twelve months (15.00%). This was followed by one month (10.00 %), and two to three weeks (5.00%).

Participant describes adhering to treatment for a specific amount of time

PARTICIPANT: Depends on the treatment. Like antibiotics, I'll give I'll I'll give no more than than two to three weeks, because any longer than that and I find I start getting gut problems regardless. Steroids, I'll go the full course. Humira. The biologics like Humira. The first time I was on Humira I gave it 8 weeks. The second time, but they wanted to try it again. After my second pregnancy, I gave it three months before I just threw the town and said I can't deal with it anymore. It it really depends on on the drug, on the side effects.
Participant 012_2023AUHIS

I guess my rule for any medication is 3 months and if it's not working then it's probably not going to work. But yeah, this is my first lot of actual meds that I've tried.
Participant 014_2023AUHIS

About a month.
Participant 004_2023AUHIS

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

OK, so I've always gone. So with any of the medications I've taken to HS, I've always gone with the recommend recommendation of of my specialists and my, my, my GP or my dermatologist. So if they've said to me I need to give it three months, then I would give it three months. If they said to me I've got to give it six months, I would give it six months.
Participant 001_2023AUHIS

I mean, I finished the course typically, but then yeah, if I go back to the doctors and I told them I finished it and nothing's changed and. Yeah, I mean I I'm open noise trying something new.
Participant 003_2023AUHIS

I'd have to be recommended by the what the doctor. Would say the doctor might. Well, the doctor told us that he thought that he needed to have, I don't know, minimum of three months on unbroken stint on the Humira. We had a very rocky start last year because he's at an age where he had to have all the whole his vaccinations. And as it turns out, we ended up. And you have to go off the medication in order to have the vaccinations. So we ended up missing out on a couple of vaccinations that we've got to do in a month or two time.
Participant 009_2023AUHIS

Participant describes adhering to treatment as long as side effects are tolerable

It depends if the side effects were outweighing the attempts. So if if there were significant side effects then it would be a lot. The time scale would be a lot reduced than if there were no side effects. So like the an example I'll give you is the antibiotics. They were inefficient, they cost a lot of money, but I stuck with it for a year to prove a point. To meet criteria to to get to the next level of treatment, you know, start with the wrong Accutane visit for a year. Obviously this is not working, but what's next?
Participant 002_2023AUHIS

I will usually I follow the the prescribed course unless unless I think I've had a big reaction to it, in which case I'll reach out to the prescriber and say this is what's going on. Can I stop this or should I be stopping this?
Participant 007_2023AUHIS

Oh, you've just reminded me. Oh my goodness, sorry, I have had another another treatment. I've had this cream that they gave me. This is that you've just prompted my my thoughts on that. Everything else I've stuck with it for as long as the doctor has has recommended. And then if they've decided it's not working and that I should come off it, then I'll come off it. But I was given cream that had to be made-up at a compounding pharmacy, which is commonly and it peels your skin, Oh my gosh, what's it called? Recorsic cold, recorsic cold cream and. It's topical and it's supposed to pale your skin. I don't know. Anyway, I'm sorry, I am allergic to that and I stopped using it after the second or third time that I used it because I got a quite a bad rash and the dermatologist has continually tried to get me to go back. Onto using it and I've completely sitting on he's like why don't you you know put half Sauberlene like break it down don't use it and I'm yeah so I gave up on that one pretty quickly and because it it was just my skin was just not very very happy with that so sorry that. That's the tenth option that I've been the 10th.
Participant 017_2023AUHIS

It depends on what it does. If it has no effects and and it's causing side effects, there's no point in staying on it. Yeah, you know they put me on doxycycline at one point. And the reflux was so out of control. I slept on a kitchen chair because I couldn't lie down and I felt like here and I felt like I couldn't breathe. Yeah, so. And I was supposed to be on that for three months. And after one month I literally just stopped taking it. I rang them and said, and I'd rather, I'd rather put up with the disease than what I'm doing because it was the reflux was just horrible.
Participant 005_2023AUHIS

Participant describes adhering to treatment as long as treatment is working

So it's kind of like a hypothetical. I'd give it three months. In a bizarro universe, if if I did accept adalimumab or Humira, which is the one drug on label, I'd give it three months. Even if a dermatologist tells me, you know, you should give it seven or ten months or two to four years or whatever, that's three months. But that'd be a fair enough time. If it's not working, it's not working.
Participant 008_2023AUHIS

I think it's hard to say if this is the first time I've been given like long term medication to take for the disease, but I'm only supposed to be on it for about 6 to 8 months. I'm at months to and I'm not seeing too much of a change, but I think like I don't want to give up. I don't know what it would take for me to give up on the medication. But I'd say if it didn't work after a year, I'd probably stop taking it because there's just no point.
Participant 010_2023AUHIS

Table 5.5: Adherence to treatment

Adherence to treatment	All participants	
	n=20	%
Participant describes adhering to treatment for a specific amount of time	11	55.00
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	10	50.00
Participant describes adhering to treatment as long as side effects are tolerable	6	30.00
Participant describes adhering to treatment as long as treatment is working	4	20.00
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	1	5.00
Participant describes not giving up on any treatment	1	5.00

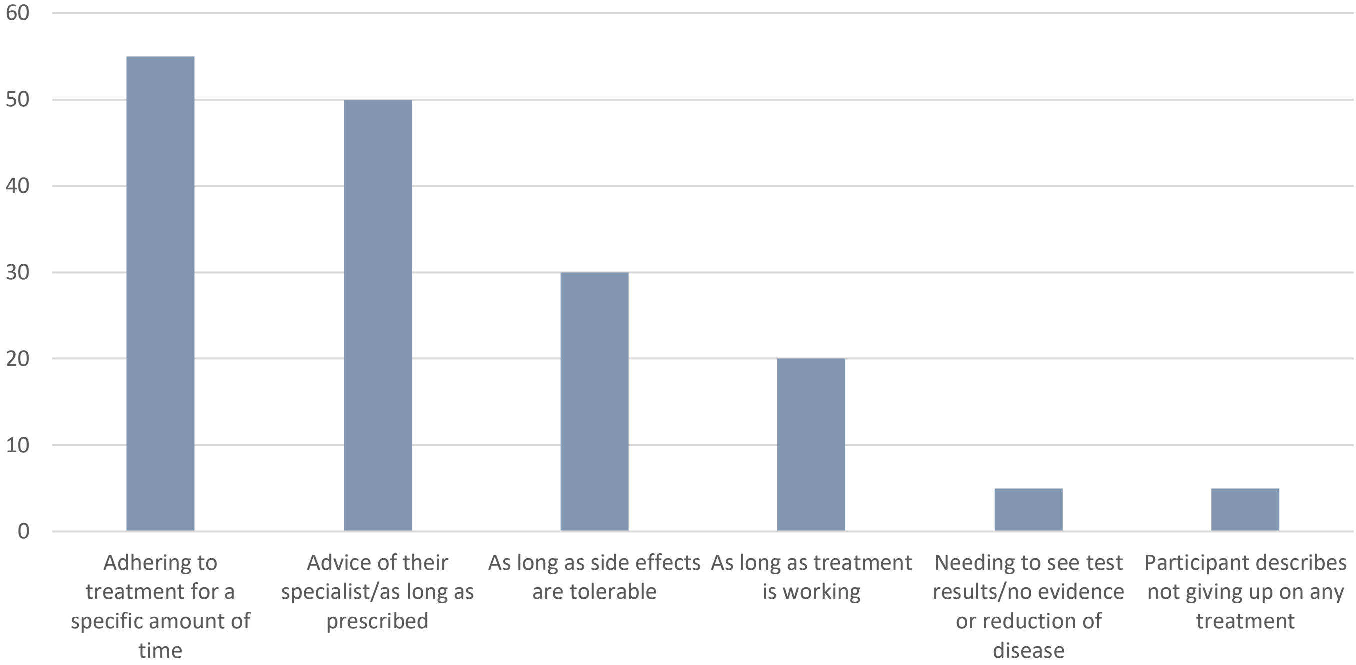


Figure 5.5: Adherence to treatment

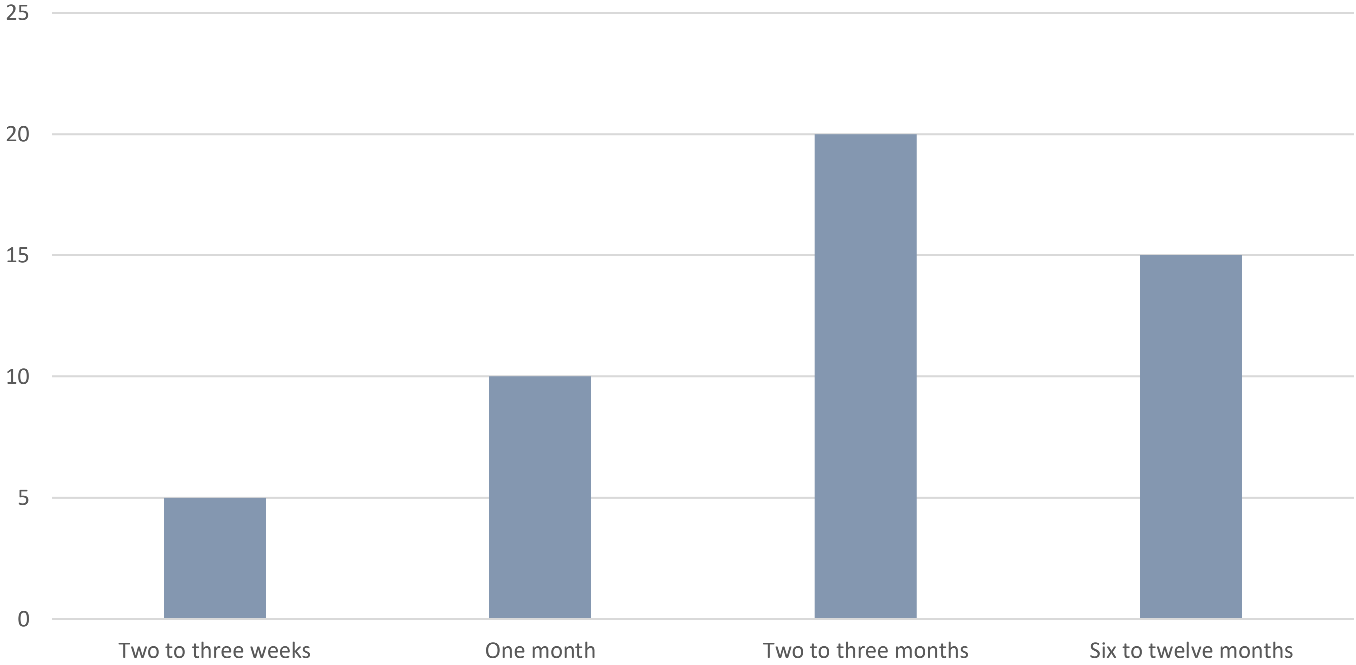


Figure 5.6: Adherence to treatment (Time to adhere to treatment)

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear or reduced side effects (85.00%), and needing to see a specific symptom reduction (35.00%). Other themes included needing to see improvements in general wellbeing or quality of life (10.00%), and needing to see evidence of stable disease or no disease progression (5.00%).

Participants reported needing to see all physical signs and symptoms disappear

The condition you can improve the the the number of boils, the size of the boil, the you know quality of life because the boils are not you know there.
Participant 002_2023AUHIS

Pain reduction #1 increase mobility, better mental health, better mental alertness. It's arthritis etc etc.
Participant 008_2023AUHIS

Yeah. So with the disease. It it is quite painful the the lumps and bumps that I get on my chest. So I'd say a reduction in pain as well as physically how it looks. It's a very ugly disease. I will say it looks, you know, it's gross. There's lumps and bumps and puffs. So I would say another one would be physically if I can see that the disease is. Going away and it's calming down and I don't have as many bumps on my chest and they're not bursting open. And I can see that the skin is healing and it's not as red and inflamed.
Participant 010_2023AUHIS

Participant describes needing to see a reduction in a specific symptom

The timing of the flare, so say does it come and go in a couple of days? Does it linger for three weeks before it hovers up and down and then nothing and sits there for another couple of weeks just burning and doing nothing and? You know, are those symptoms managed? Are they better? Are they? They might come and go in a week, but it never actually burst and it actually went, you know, I need some solid evidence of change and I haven't received that yet.
Participant 015_2023AUHIS

The physical appearance of the lesions and the reduction in the number of them and the size of them and. Yeah, So that makes me think that it's working. Although they do. So they do burst, but they do scar quite badly and they eventually go down. But I think if if I'm not getting any new ones, then I feel like it's working. If I'm getting new ones because quite often they come in groups, I don't, you know, sometimes I'll get one under each bar. Under one, under each bust, one of my groin, one of my butt, all at the same time. Not getting any, then I feel like it's working.
Participant 017_2023AUHIS

Yeah, a reduction in side effects may be a difference in in what you're seeing in terms of the nodules and things like that or not flaring as often.
Participant 019_2023AUHIS

Table 5.6: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants	
	n=20	%
Participants reported needing to see all physical signs and symptoms disappear	17	85.00
Participant describes needing to see a reduction in a specific symptom	7	35.00
Participants reported needing to experience an improvement in general wellbeing (quality of life)	2	10.00
Participants reported needing to experience evidence of stable disease/no disease progression	1	5.00

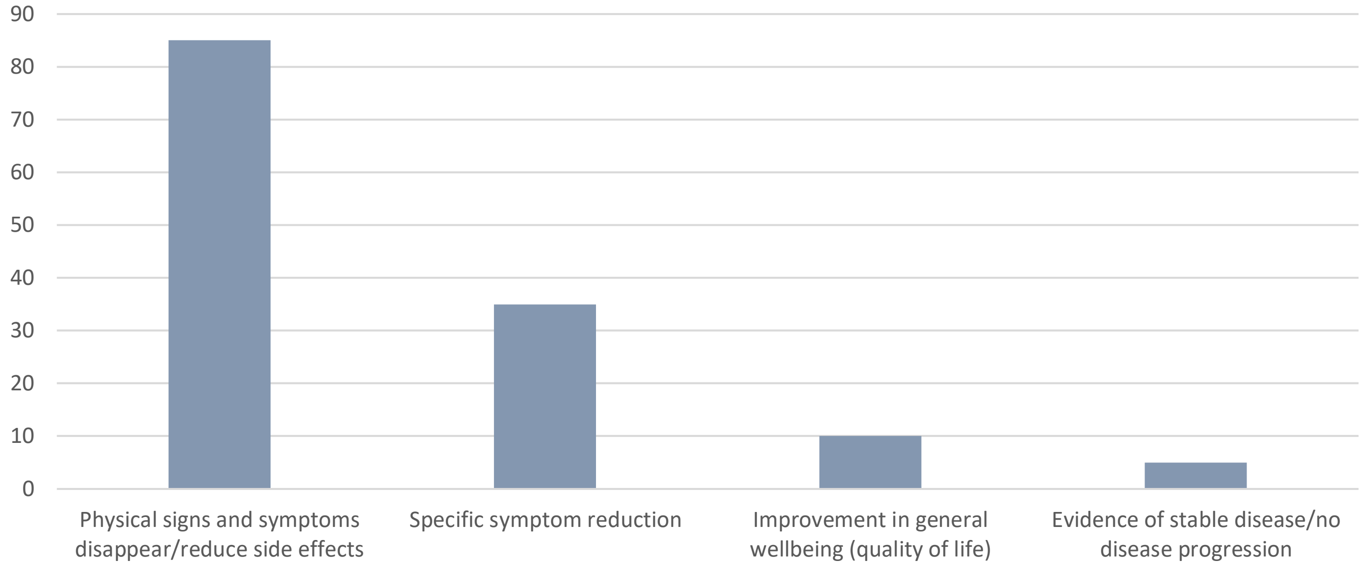


Figure 5.7: What needs to change to feel like treatment is working

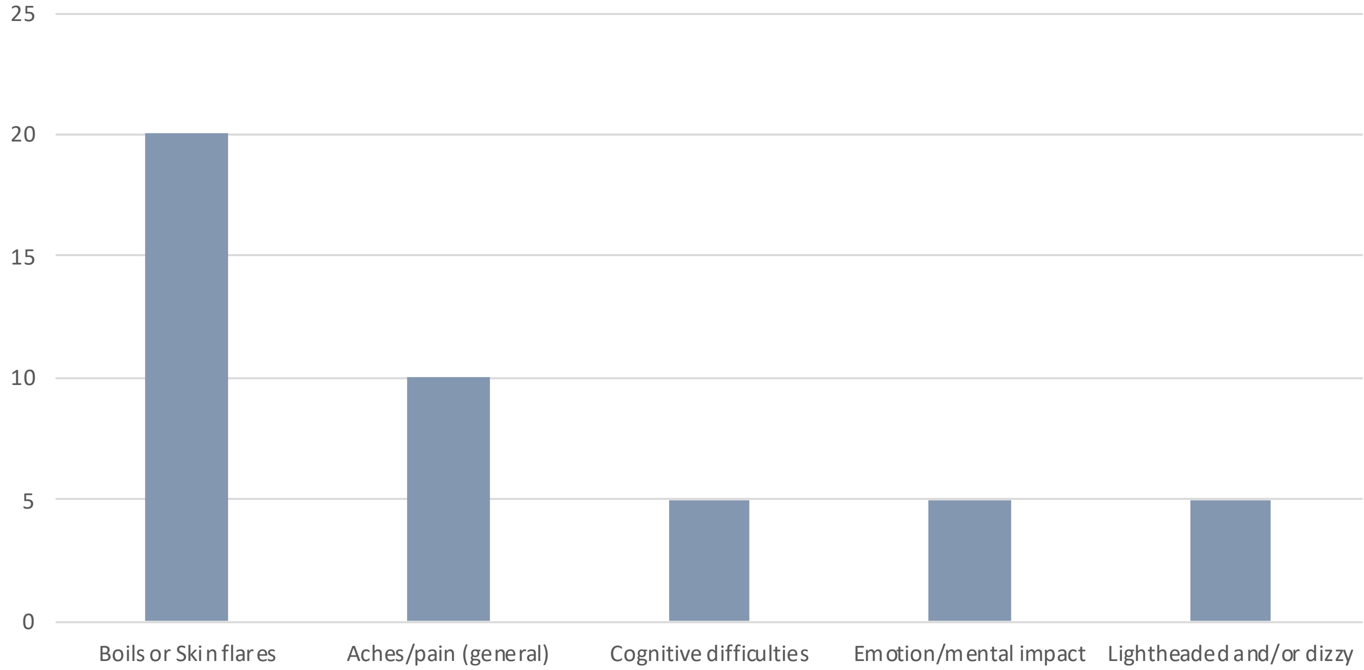


Figure 5.8: What needs to change to feel like treatment is working

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (50.00%), and allow them to engage more with social activities and family life (25.00%). Other themes included allow them to return to work (20.00%), less worried about appearance/self image (20.00%), have a positive impact on their mental health (15.00%), lead to a reduction in symptoms/side effects (15.00%), allow them to do domestic tasks (10.00%), and allow them to do more exercise (10.00%).

Allowing them to do everyday activities/return to normal life

Life. It would be life changing. I have to. I often say to my husband, I would just love to have one day of my life. Just one day. Like between now and death where I don't feel pain 24/7 so that would mean everything. To be able to live without the disease, it would probably one of the biggest breakthroughs I think for me. Like if I have to live with this disease for the rest of my life and I'm assuming I do one of the biggest things that could. Could change my life. Is GP's understanding what the disease is?

Participant 005_2023AUHIS

Well, I doubt that I would ever be able to wear a bikini, but maybe so. I do keep myself covered over very much. Like I don't wear shorts that are any shorter than my knees. My swimmers are all longer than my knees. I feel like, you know. If I was young and single and and or even if I was just single and trying to get into the dating scene, that would be a massive issue for me. Fortunately, I'm married and have a very understanding husband who doesn't care about them and but it's a self confident you know, it's definitely a self esteem because you just, I just don't want people. Seeing them, so you know I think and I did have to have some time off work during that 2021. And having to explain to. My male boss, who is a young guy, I I was very fortunate working in the hospital. My one of the female managers said, look, just tell him that you don't have to tell him what you've got. I was telling that you've got an auto inflammatory disease and that you're going to need some time off work because I did need some time off work. There was a lot of times I just couldn't wear underwear. And so I literally couldn't. I wasn't going to go to work without any underwear on, and I was on painkillers. And so to be able to just go through life without having to worry about that, if I do have now any, I now work from home four days a week, which is great, and I'm in the clinic one day a week, but. I if I do have any, I've got to make sure that I'm. I've got pads on them to make sure that they don't burst all over my clothes while I'm out, but just having not to worry about that would be amazing, yeah.
Participant 017_2023AUHIS

Allowing them to engage more with social activities and family life

I'd be able to go for walks again and be able to actually play with my kids properly clean the house. Stack the dishwasher. I can't even stack the bloody dishwasher at the moment. Be able to go horse riding again and and do the activities and and go back to competition. So like, I haven't been able to do that since I had the really bad flair in 2019. That's just gone from spot to spot to spot.
articipant 012_2023AUHIS

I just can't even explain, really. That's the saddest question, I think. You know, I often feel like when, you know, when I get a flare, I think, [UNINTELLIGIBLE], I don't think I got a flare in the last four weeks. What have I been doing with my time? I just sit there and think I'm not living my life every day to my fullest as I can. I often when I'm fine, I'm so exhausted by my previous six weeks or 8 weeks that I just want to sit without feeling pain. But I'm not motivated to go and start. Yeah, I can do roller coaster now I'm gonna go back to doing cartwheels. I'm just. I'm just wallowing in a piece of satisfaction for free. Paying free. I can lie down properly. I can put my own clothes on. I don't smell myself. You know but as sure enough as soon as I get a flare again I I think you know what the … it's been so long. I should have gone for a run and you totally could have joined a Tennis Club. What are you know and and so just having the ability to some certainty, I'd really enjoy that. I think you know it's only around May that I get upset so I'm going to do everything up until that point and then I'm just going to prepare. I have no idea what a trigger is for me. I can't avoid things. I don't understand it at all.
Participant 015_2023AUHIS

Allowing them to return to work

It would mean so much better. Like I I could go out and get an actual job which I can lift up my arms to reach something. Participant 004_2023AUHIS

Less worried about appearance/self image

If there was something I could take easily that wasn't going to have any other effects on my health that were detrimental in any way, and it just helped with my HS, it would help my life a lot. And what would you be able to do? What would you be, you know, like I would have the security to be able to go to the beach or go swimming or wear a dress because you have to wear underwear. Just, just normal things like that that I can't do and, you know, feel more confident myself if you were being intimate with somebody. I know mine isn't very bad because nobody in my life has ever noticed. So I guess that's, you know, even in a relationship for three years, no one, no one noticed. So I guess that's something. Other people have it worse than me, but I am aware of it and it's just a conversation you don't want to have to have with somebody. Because it's not like it's an STD, but you just can't help but you lean that way, can you really, if you were uninformed. So yeah, it's always in the back of my head. So yeah, something like that would just make my life a lot easier. Participant 006_2023AUHIS

I mean because like. My disease is only at stage two, which is kind of middle ground. I'm still quite active, so I feel like it's not so much physical things that I wouldn't be able to do. But if the treatment worked and it cleared up my disease, then I would be able to wear nice clothes. I would feel more confident going to the beach and wearing a bikini. I think, yeah, just kind of more of like a confidence thing because it's a very shameful. Disease. Like, I don't want to show my body. I don't want to wear nice clothes because I, you

know, I don't want people to see what I've got on my skin. So I think for me it would just be like gaining confidence and feeling pretty again to wear the things that I want to wear.
Participant 010_2023AUHIS

It would mean a lot if it worked, but it affects everything. I struggle. Having intimate partners. Because of my scars, I had somebody ask what they were once. Yeah, when? I didn't think they were noticeable. It's getting to the point where I can't even wear, you know, kind of like short his shorts to the beach. They're traveling further down my thigh. The constant concern that people can smell them. You're right with it. I can't even tell people what I have because they Google it and see horrific images.
Participant 018_2023AUHIS

A positive impact on their mental health

I would. I'd be working. I would be able to afford dental care. I could improve my mental health, my mental outlook. I could reconnect with my family. I could basically, in inverted commas, get a life. Yeah, I'm just hiding away from the world at the moment. That's what my life is.
Participant 008_2023AUHIS

Table 5.7: What it would mean if treatment worked

What it would mean if treatment worked	All participants	
	n=20	%
Participant describes that it would allow them to do everyday activities or normal life	10	50.00
Participant describes that it would allow them to engage more with social activities and family life	5	25.00
Participant describes that it would allow them to return to work	4	20.00
Participant describes that it would allow them to be less worried about appearance or self image	4	20.00
A positive impact on their mental health	3	15.00
Leading to a reduction in symptoms or side effects	3	15.00
Participant describes that it would allow them to do domestic tasks	2	10.00
Participant describes that it would allow them to do more exercise	2	10.00
Participant describes that it would allow them to live without pain	2	10.00
Participant describes that it would allow them to sleep	1	5.00
Participant describes that it would allow them to have intimate relationships	1	5.00
Participant describes that it would allow them to have fewer doctor visits	1	5.00

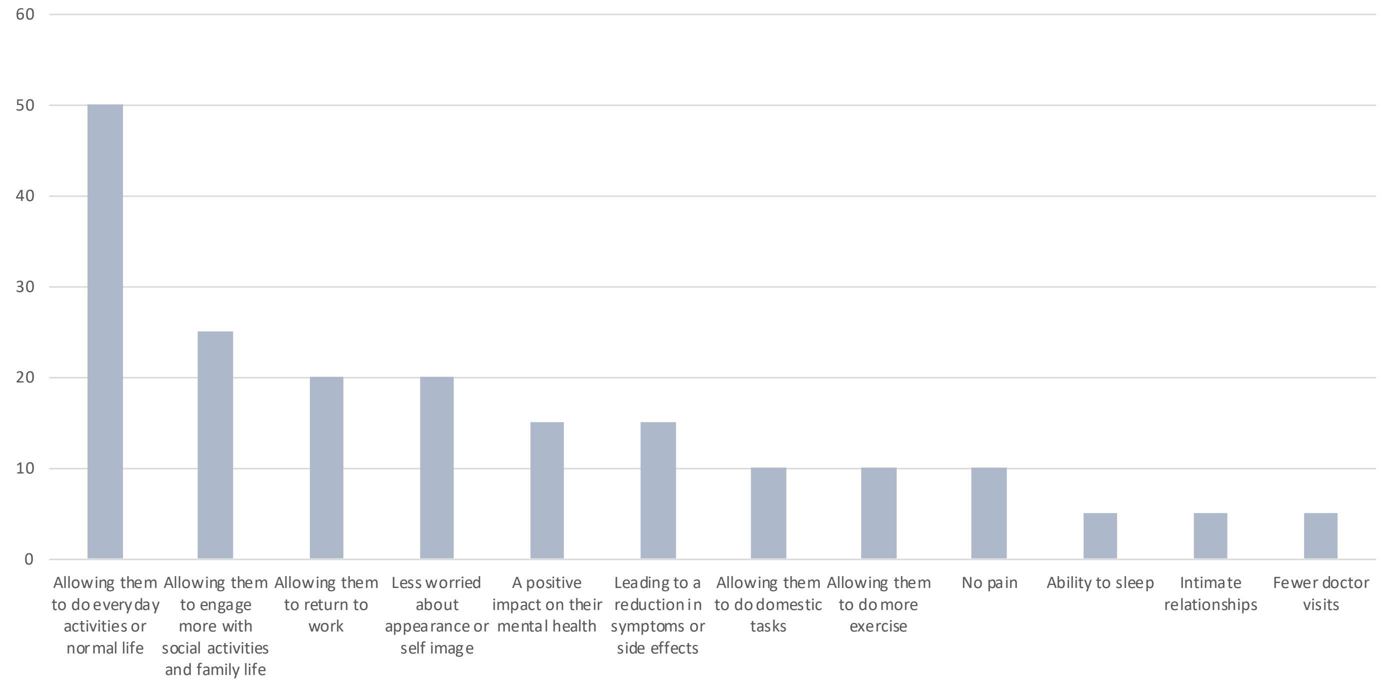


Figure 5.9: What it would mean if treatment worked

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (50.00%), and allow them to engage more with social activities and family life (25.00%). Other themes included allow them to return to work (20.00%), less worried about appearance/self image (20.00%), have a positive impact on their mental health (15.00%), lead to a reduction in symptoms/side effects (15.00%), allow them to do domestic tasks (10.00%), and allow them to do more exercise (10.00%).

Section 6

Information and communication

Section 6: Information and communication

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%).

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%).

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.

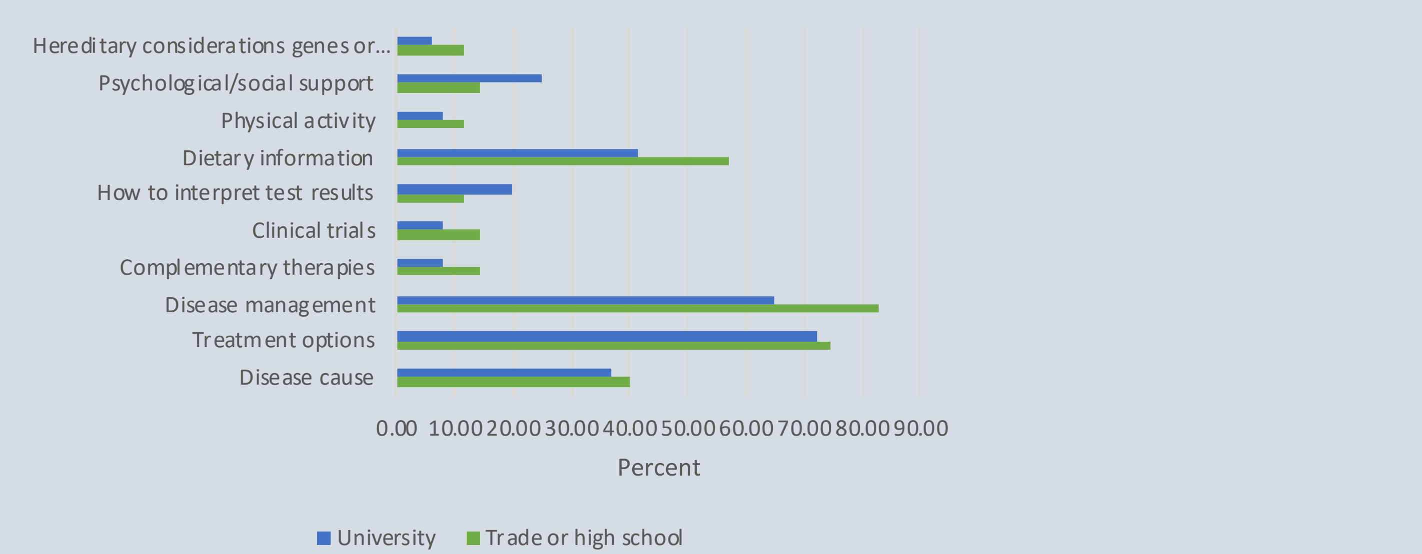
The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

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.



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%).

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 are 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 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

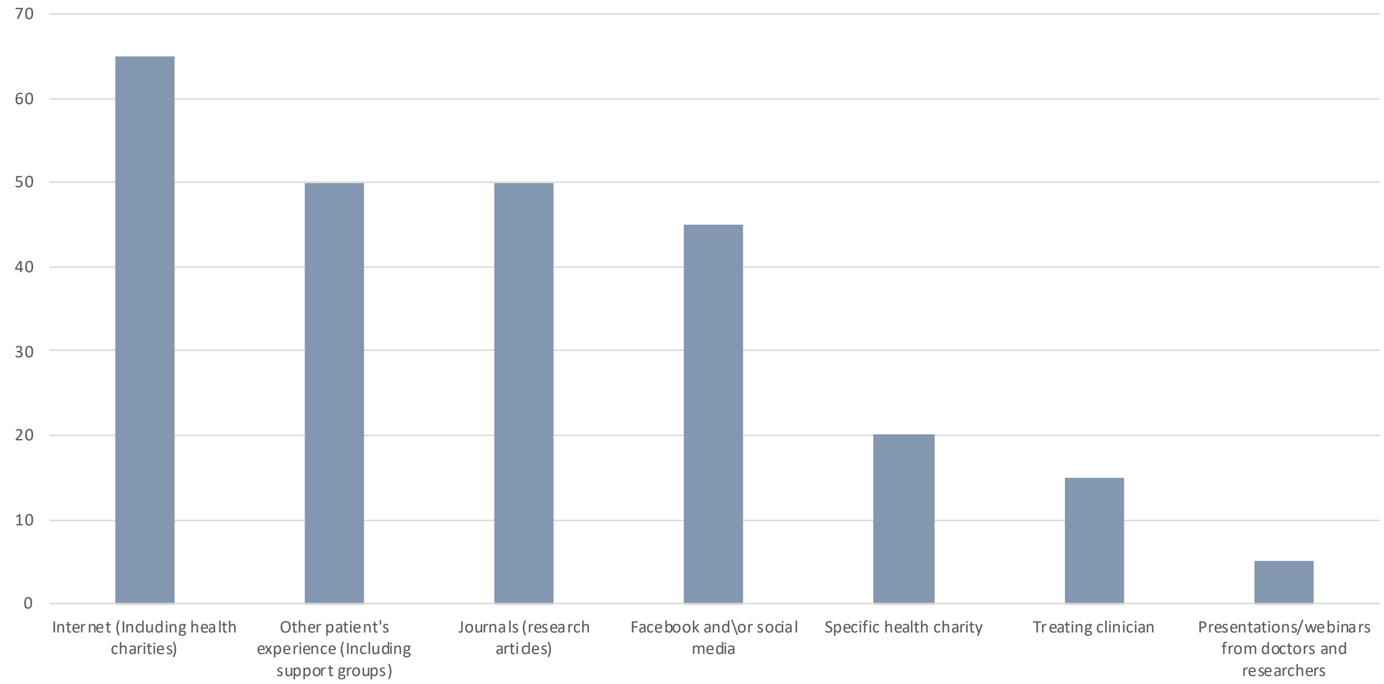


Figure 6.1: Access to information

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 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

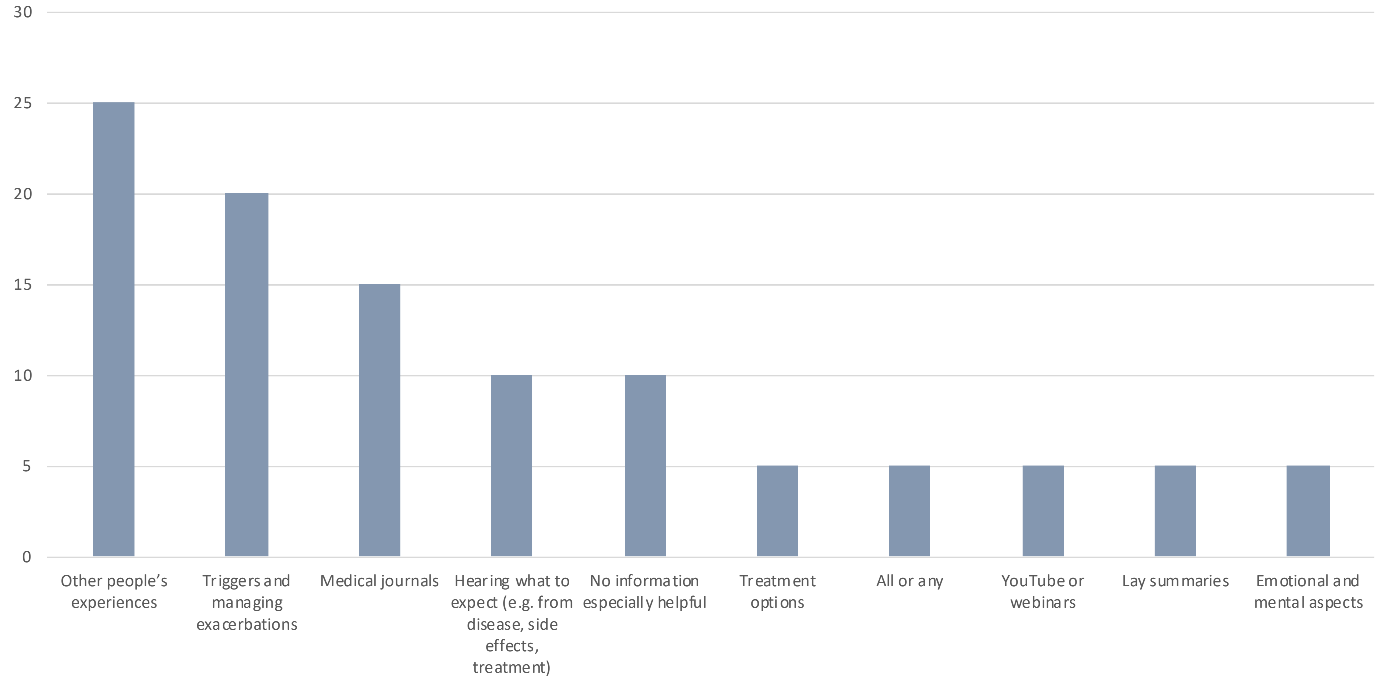


Figure 6.2: Information that was helpful

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

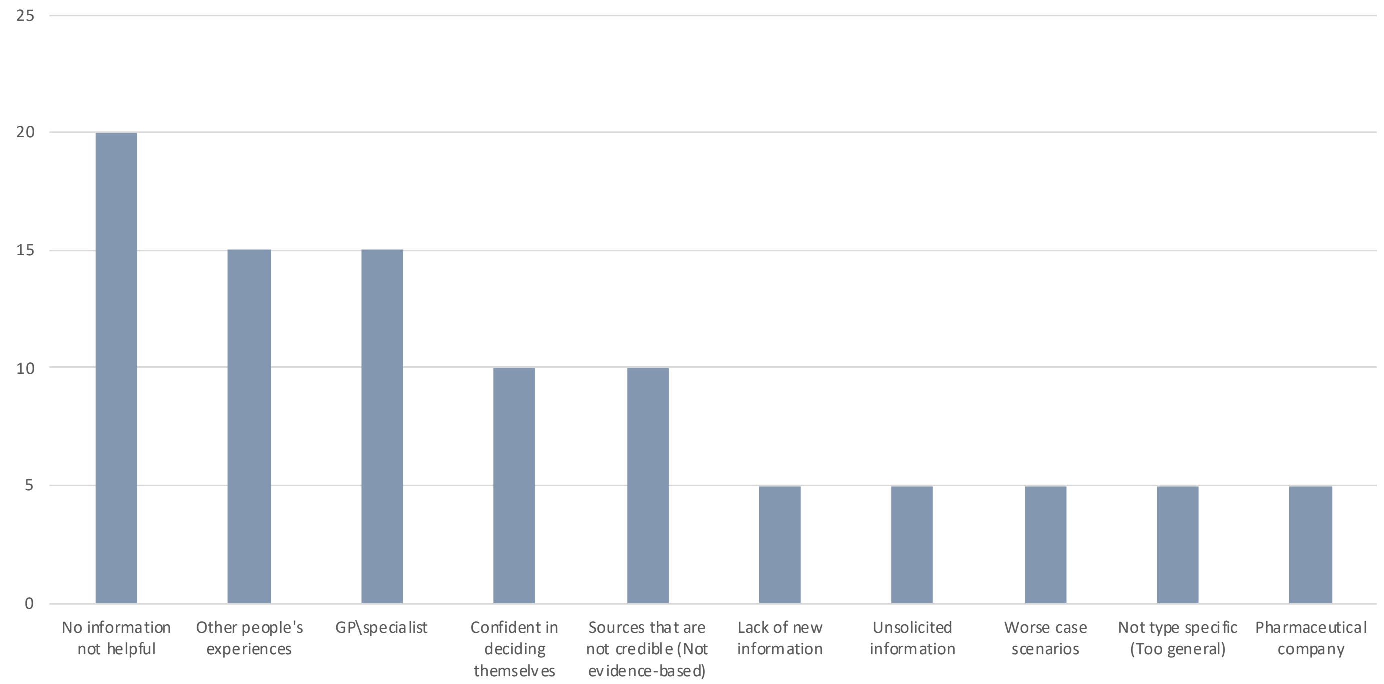


Figure 6.3: Information that was not helpful

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 prefering 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

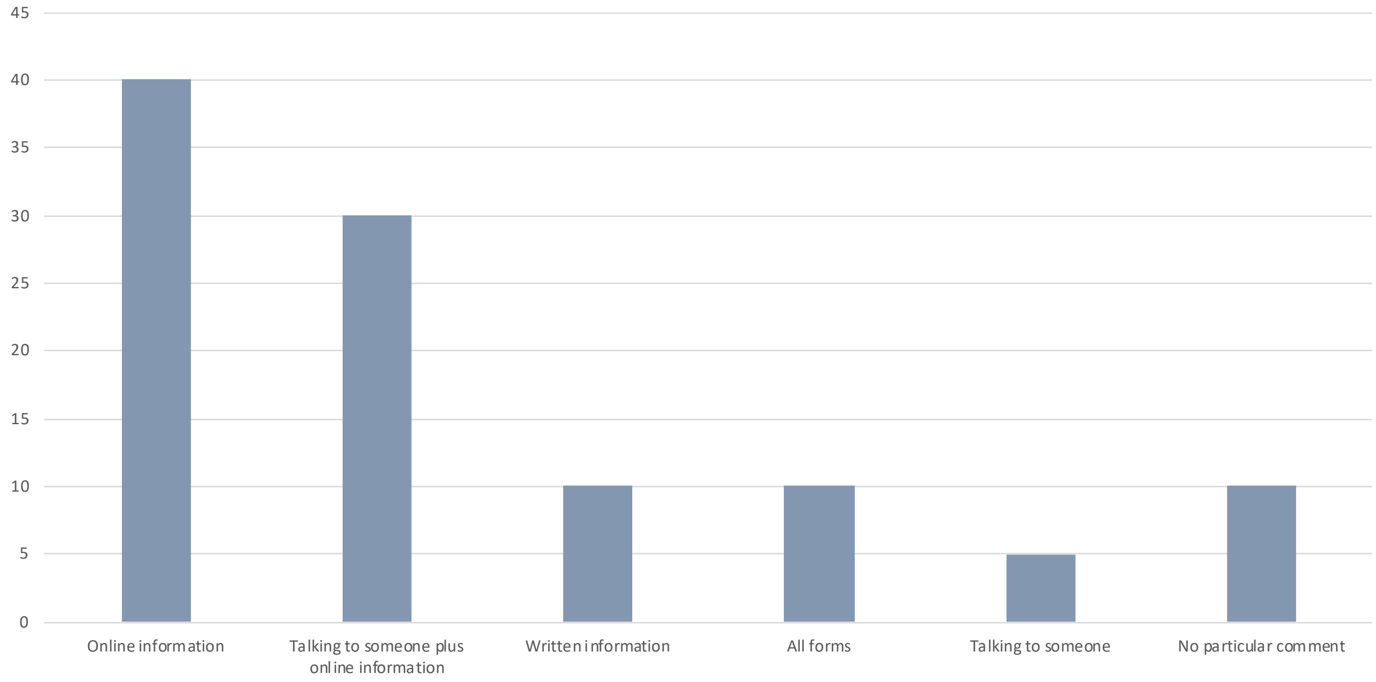


Figure 6.4: Information preferences

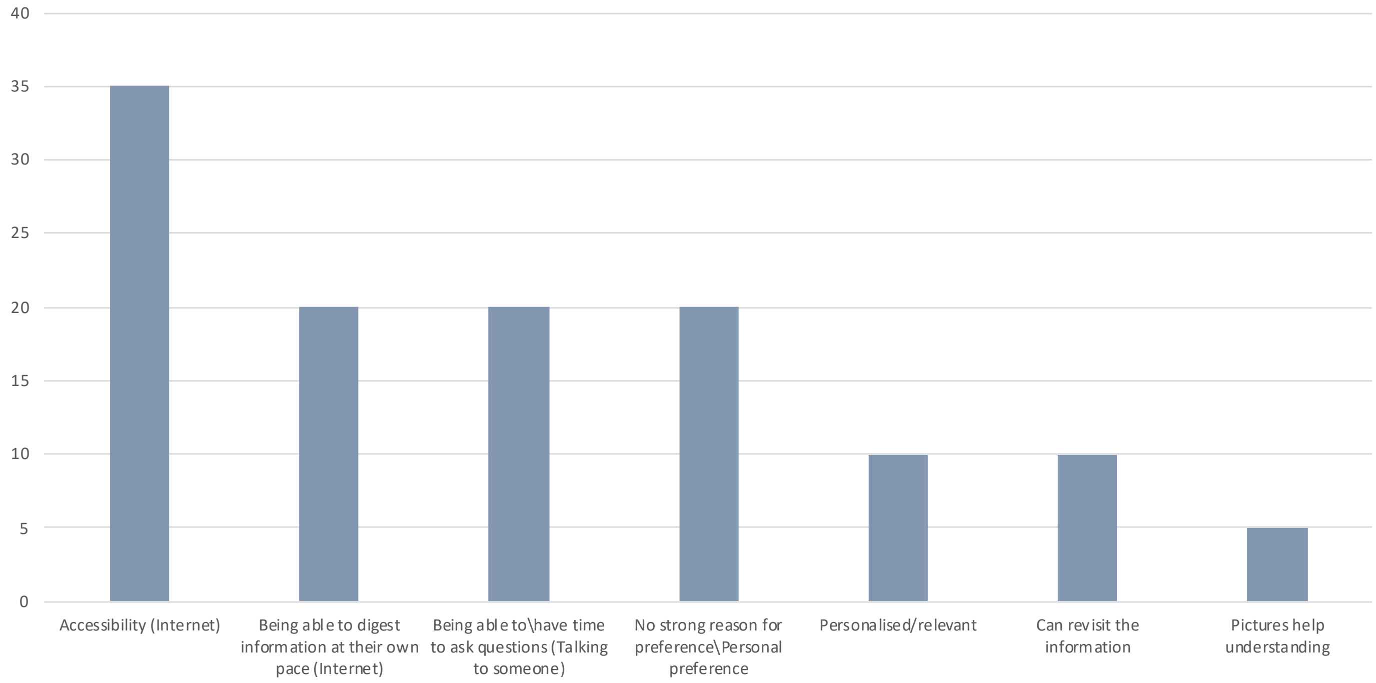


Figure 6.5: Reasons for information preferences by format

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

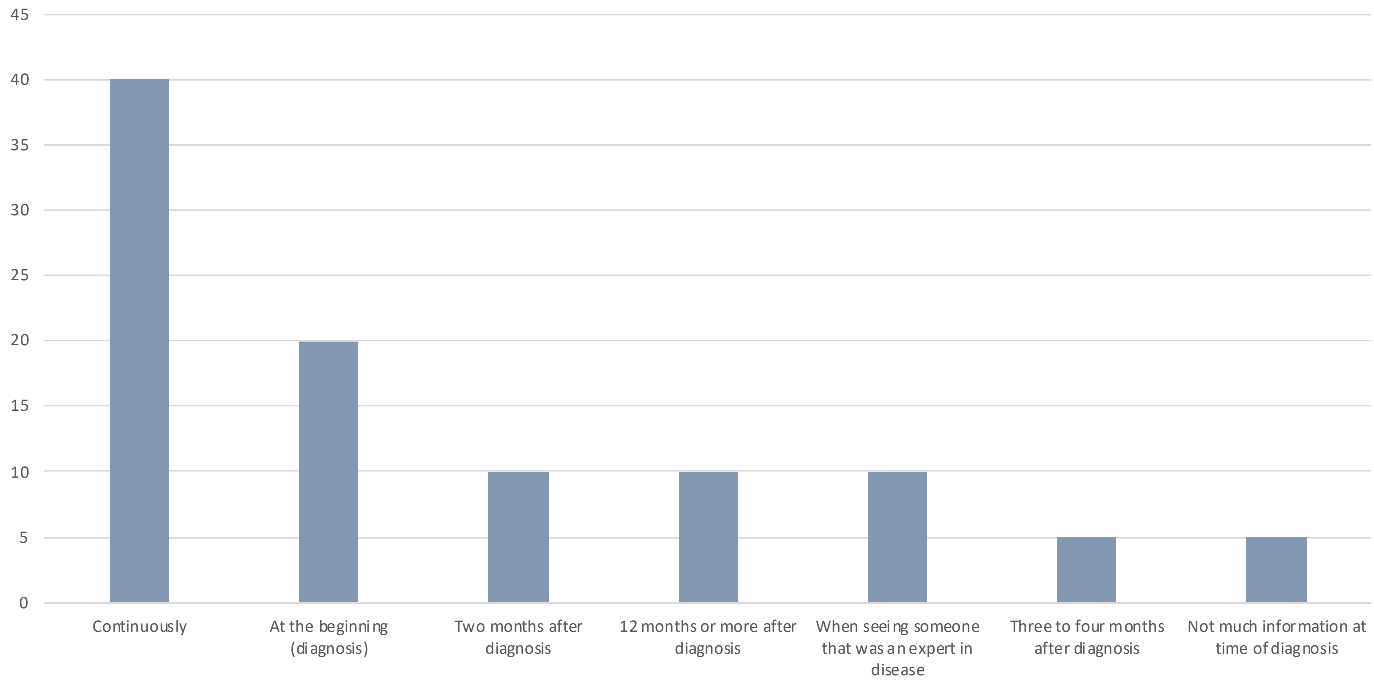


Figure 6.6: Timing of information

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 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

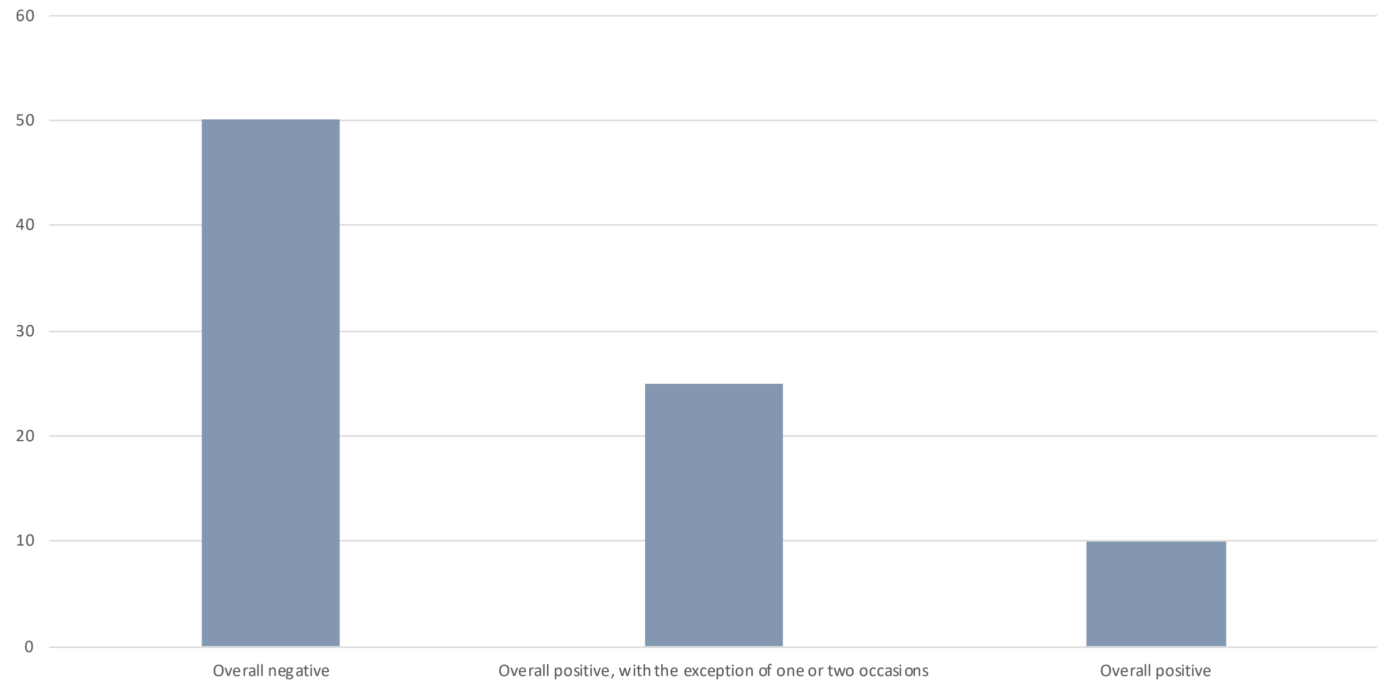


Figure 6.7: Healthcare professional communication

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 dies 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 dies 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

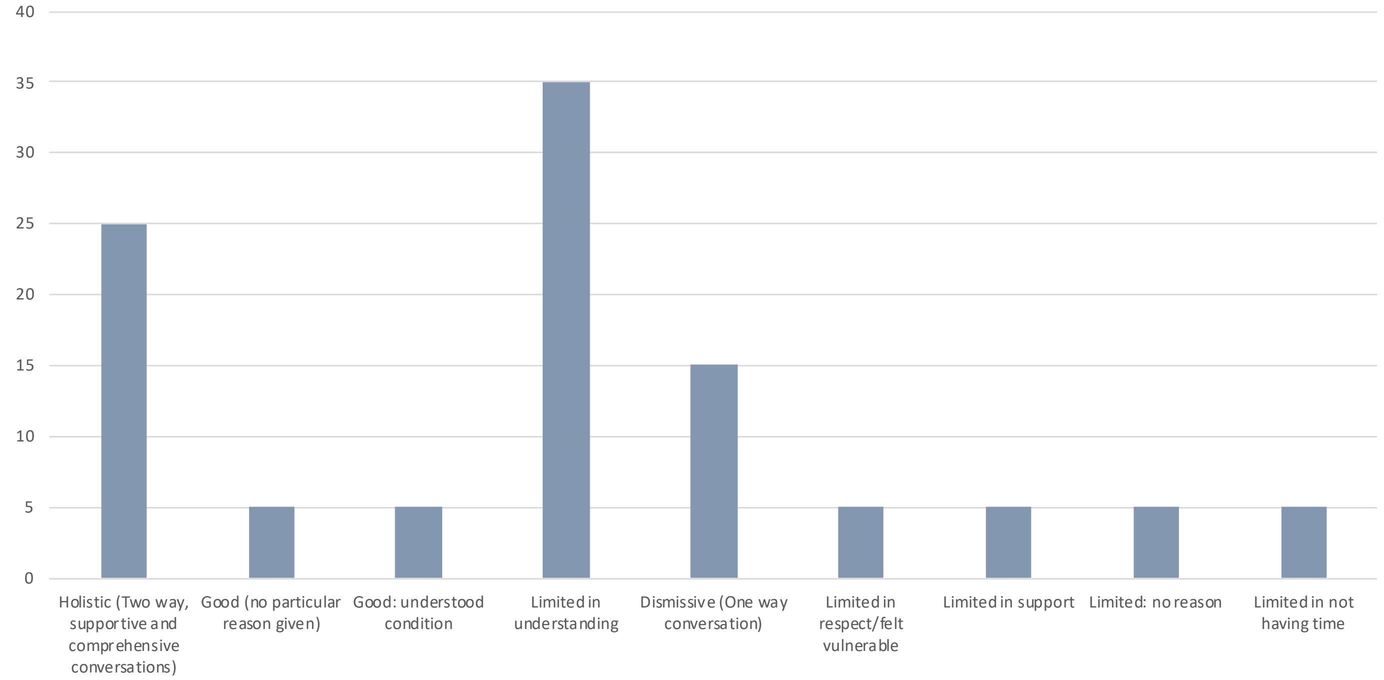


Figure 6.8: Healthcare professional communication (Rationale for response)

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

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had poor navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had poor communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as poor.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as poor.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they did not receive any formal support (50.00%), or that they found support from the hospital or clinical setting (15.00%). Other themes included peer support or other patients (10.00%), and psychologist or counselling service (5.00%).

Care coordination scale	Mean	SD	Median	IQR
Care coordination: communication*	34.40	9.31	35.00	11.25
Care coordination: navigation*	24.72	4.76	25.00	6.00
Care coordination: total score*	59.12	12.54	60.00	16.00
Care coordination: care coordination global measure	6.46	2.27	7.00	3.00
Care coordination: quality of care global measure	7.31	1.91	8.00	1.25

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the second lowest quintile for Care coordination: Communication (mean=29.21, SD=9.26), Care coordination: Navigation (mean=18.11, SD=5.52), Care coordination: Total score (mean=47.32, SD=10.48), Care coordination: Care coordination global measure (mean=3.53, SD=2.01), Care coordination: Quality of care global measure (mean=3.95, SD=2.09) indicating poor communication, poor communication, poor coordination, poor care coordination, poor quality of care.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had poor communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had poor navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had poor communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as poor.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as poor.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	29.21	9.26	31.00	14.50	13 to 65	2
Navigation*	18.11	5.52	18.00	5.50	7 to 35	2
Total score*	47.32	10.48	44.00	17.50	20 to 100	2
Care coordination global measure*	3.53	2.01	3.00	3.50	1 to 10	2
Quality of care global measure*	3.95	2.09	4.00	4.00	1 to 10	2

*Normal distribution use mean and SD as measure of central tendency

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they did not receive any formal support (50.00%), or that they found support from the hospital or clinical setting (15.00%). Other themes included peer support or other patients (10.00%), and psychologist or counselling service (5.00%).

Participant describes that they did not receive any formal support

No, because it's not a recognized condition. Nobody knows about it. It's not on any of their lists at any of their foundations or their centers. Never heard of it. So it's not something they'll come and help out with. It's not on the list. All these joints are run by the government and the government gives them a list and if it's not on the list then you know and I feel like that's. You know that one of the things with this too, it's just like nobody knows about it hurt. No one's heard of it. So yeah, yeah for it.
Participant 006_2023AUHIS

No, not really. Participant 004_2023AUHIS

Participant describes getting care and support from hospital or clinical setting

Didn't have community health. Yeah they they oh, sorry, you're right. So when I like post surgery they were coming to, they actually came back to the house to pack the wounds and but it was like hospital at home. Yes. So the release here from hospital and then they send you home and then the community nurse that's come to the house and do the packings and then I can access community health for the winds, but they only operate from like 9:00 in the morning until 5:00 at night. And I would have to stop working to be able to access them because I need great things every day.
Participant 005_2023AUHIS

The most support, probably the only support I've really received has been from. My GP and and my clinicians, they my GP especially, he has been really good at trying to help me manage my pain. He's been really good at trying to he he tries to get me dressings and supplies and and where he can he'll bulk on my appointments even though he's a private practice so that I can. Use the money I would have used on the appointment to go get medications or dressing so that way instead all.
Participant 012_2023AUHIS

Participant describes getting care and support from peer support or other patients

PARTICIPANT: Not really. I am in a support group on Facebook, so I'm not sure if that counts.
INTERVIEWER: Well, you've mentioned it, so that's good that you've got support. So is there anything else you want to add? What kind of support is that?
PARTICIPANT: It's just people sharing their experience with HS. It's just something that makes me feel like, you know, I'm not alone with what I'm dealing with. I don't know anyone in my personal life who has this. So I joined a group where other people have it and we all kind of share our thoughts and experience and inspirational quotes and stuff like that to make sure that we're all okay, I guess.
Participant 010_2023AUHIS

Just through the Facebook group and my friendships that forwards that all who are aware of the condition I have.
Participant 011_2023AUHIS

Table 7.17: Experience of care and support

Care and support received	All participants	
	n=20	%
Participant describes that they did not receive any formal support	10	50.00
Participant describes getting care and support from hospital or clinical setting	3	15.00
Participant describes getting care and support from peer support or other patients	2	10.00
Participant describes getting care and support from psychologist or counselling service	1	5.00
No particular comment	4	20.00

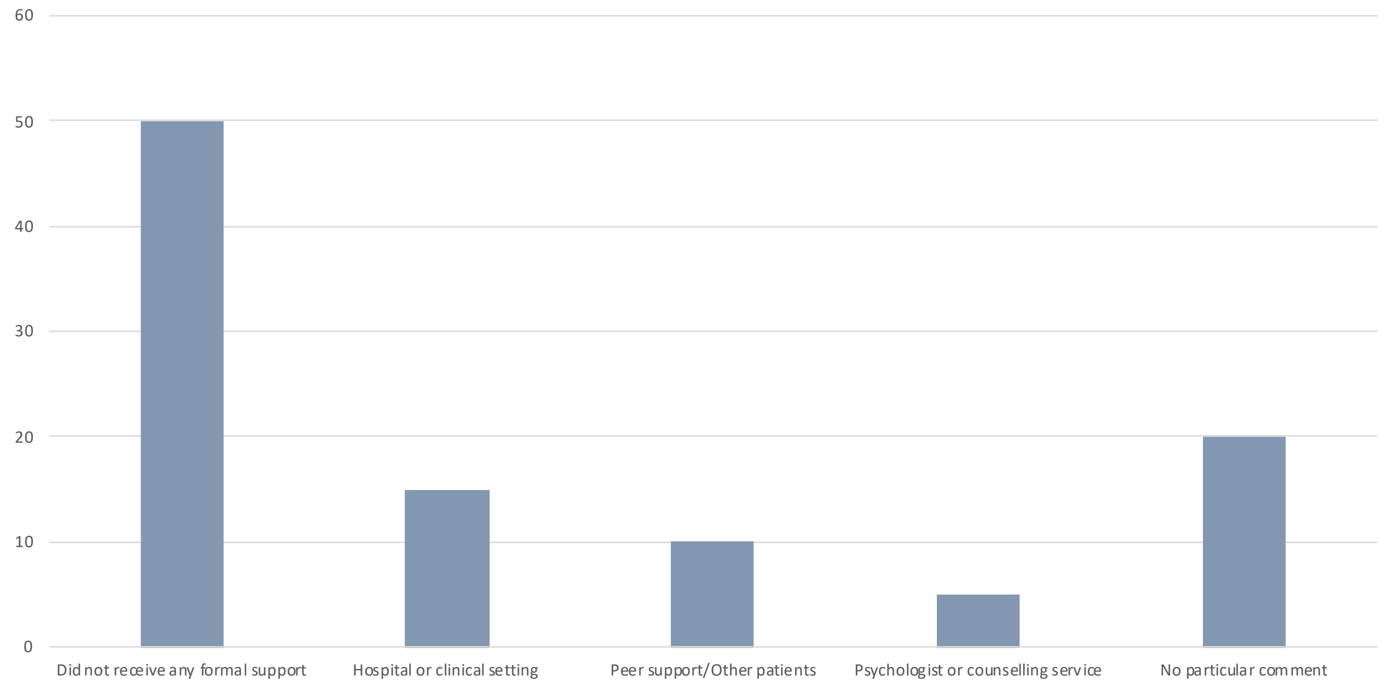


Figure 7.36: Experience of care and support

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (75.00%), and overall a minimal impact on quality of life (5.00%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (35.00%), and reduced capacity for physical activity/needing to slow down (25.00%). Other themes included intimacy challenges (20.00%), reduced social interaction (20.00%), financial strain (10.00%), managing side effects and symptoms (10.00%), and the impact on self image (10.00%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (10.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (80.00%), overall, there was no impact on mental health (5.00%), and other or mixed experience (5.00 %).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was mindfulness and/or meditation (40.00%), no activities to maintain mental health (20.00%), and the importance of family and friends in maintaining their mental health (15.00 %). Other themes included consulting a mental health professional (10.00%), allowing time to cry, then gets on with it (10.00%), keeping busy (10.00%), coping strategies such as remaining social, lifestyle changes and hobbies (5.00%), the importance of physical exercise (5.00%), and keeping informed about their condition (5.00%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were complying with treatment/management (45.00%), and hygiene routine (45.00%). Other themes included avoiding flare triggers (25.00%), understanding their limitations (20.00%), being organised and planning ahead (10.00%), using complementary therapies (10.00%), maintaining a healthy diet (10.00%), mindfulness and/or meditation (10.00%), doing physical exercise/physically active (10%), self care e.g. more rest, accepting help, pacing (10.00%), covering up lesions (10.00%), being aware of their body and limitations (5.00%), and maintaining a normal routine (5%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable experiencing side effects from treatment or symptoms from condition (25.00%), when having sensitive discussion (diagnosis, treatment decision) (20.00%), and because of interactions with the medical team (20.00 %). Other themes included during/after treatments (15.00%), during diagnostic procedure (10.00%),thinking about disease course/incurable condition (10.00%), and did not feel vulnerable (5.00%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (15.00%), and using self-help methods (resilience, acceptance, staying positive) (10.00%). Other themes included support from mental health professionals (5.00%), being informed and knowing what to expect (5.00%), and sticking to their treatment regimen (5.00%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (50.00%), and overall, there no impact on relationships (15.00%). Other themes included overall, there was a positive impact on relationships (10.00%), and overall, there was an impact on relationships that was both positive and negative (5.00%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (20.00%), from feeling dismissed or not believed by others(10.00%), and due to intimacy challenges (10.00 %). Other themes included from managing symptoms (5.00%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.00%).

The most common theme in relation to a positive impact on relationships were brings people together/highlights supportive relationships (10.00%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (60.00%), overall, there was not a burden on their family (15.00%), and having no particular comment (25.00 %).

The main reasons that participant described their condition being a burden were the extra financial assistance needed (10.00%), the mental/emotional strain placed on their family (10.00%), and that the burden on family was temporary or only during treatment (10.00 %). Other themes included the extra assistance needed getting to appointments (5.00%), intimacy problems (5.00%),managing symptoms (5.00%), and eding to take time off work (5.00%).

The main reason that participant described their condition not =being a burden were because they were independent and did not need any help (15.00%), and that they were not a burden because no one knows about their diagnosis (5.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (75.00%), and overall, there was no cost burden (15.00%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (65.00%), the cost specialist appointments (50.00%), and needing to take time off work (25.00 %). Other themes included needing a special diet or lifestyle adaptation (15.00%), a family member needing to take time off work (10.00%),the cost of parking and travel to attend appointments (including accommodation) (5.00%), and diagnostic tests and scans (5.00%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to them prioritizing going to work over attending appointments (5.00%), being able to afford all costs(5.00%), and they had no treatment or management (5.00 %).

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (75.00%), and overall a minimal impact on quality of life (5.00%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (35.00%), and reduced capacity for physical activity/needing to slow down (25.00%). Other themes included intimacy challenges (20.00%), reduced social interaction (20.00%), financial strain (10.00%), managing side effects and symptoms (10.00%), and the impact on self image (10.00%).

The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (10.00%).

Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)

Yeah, it's affected my quality of life, I guess, and my kids.
Participant 003_2023AUHIS

Yes, it has. Particularly when you're constantly having abscesses galore and you're looking like a zombie bandaged from head to toe with dressings and you don't feel. Beautiful or pretty people making comments about wounds and what not. You're in pain and discomfort, not so much with family, and you think no one's going to fall in love with you. You're not going to have a family or that sort of thing. And even friends don't. No one understands what you're going for, even if you do try and explain it to them.
Participant 013_2023AUHIS

It's ruined my life and it's ruined my family's life too, because they I can't support my family.
Participant 004_2023AUHIS

Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down

It has probably affected the quality of my life somewhat. I probably struggle to be active because I am tired quite a lot. It can struggle, you know it depending on where where I'm at at the time. If I'm flaring I can struggle to do things around the home. So it has had an impact on, on day-to-day living, has impacted relationships, yes and no. You know, my husband has has been involved in my my diagnosis from the beginning and has a fair understanding of how it impacts me. So it hasn't been easy on him. So it has impacted the relationship to some degree, but at the same time he's been involved in it and he has an understanding of what I'm going through and what it's like for me, so.
Participant 001_2023AUHIS

I don't mental and emotional pretty well fine. But where it that has become like there's times when I you know be as active as I was because I'm in significant pain and or they're best thing everywhere and disgusting. And you don't want to be and then and you're petite, when that hits, you're fatigued and they're draining and they're feral. You don't want to actually be going out and doing this and doing that. So I think there's those lost opportunities that you have to be mindful that they do have that.
Participant 002_2023AUHIS

Participant describes a negative impact on quality of life due to intimacy challenges

I don't live with my family, so, like, my mum's gone. Yeah, my dad wouldn't bother. Nothing to do with him, but I have a partner and yeah, since. Like, this is going to be crazy, but like, we haven't slept together in over a year, probably 2 years, and we're still together and we're not seeing anyone else. And that is because he understands that like when you do stuff or get hot or sweaty down there, it flares up and then I'm screwed up for days, so. Like, we just need to wait till I can get this surgery and then and then like, maybe I want to have kids. But, you know, hormones and stuff just flare this shit right up. So I'd prefer to have it gone before I'm pregnant or something, you know?
Participant 006_2023AUHIS

Yeah, it has a lot. You know, it's quite a physical presenting disease, but it's almost falls into the invisible disease category that people don't understand because you can't exactly be like, oh hey look. And trying to explain that why a little red dot that you know it's not even risen a meal out of your skin is on fire. It's really hard for people to understand. And that's just, that's just humans. You know when you say an Abscess, people just are disgusted by it. They don't hear the rest, but just my ability to do

things. And yeah, intimate relationships, like I don't. It affects a lot.
Participant 018_2023AUHIS

Participant describes a negative impact on quality of life due to reduced social interaction

Look, while symptoms were present, yeah, absolutely not. I suppose because I've seen what it could be or how bad it could be. Not to that extent. But yeah, definitely very uncomfortable. It's very painful and it sort of, yeah, it certainly had a minimizing impact. On on what you did and then how well you felt to go and to go and do usual things. And I suppose in terms of family, yeah, as a single parent, that then also meant if I didn't feel up to it, that my daughter wouldn't go places because I wasn't in a position to be able to take her and support that.
Participant 007_2023AUHIS

I would say yes, definitely. It's affected my quality of life, you know, I feel different to everyone else. I feel ashamed. When I go out going to the beach and doing fun activities like I can't really enjoy because I have to cover up this area of my body. I can't be as active as I'd like to be because when I run it's it's hodging on the area that I have the disease and it's very painful in terms of relationships with my family, I think. It's not so much the disease that caused it, but I think there's a bit of animosity between my mother and I because she didn't do anything about it when I was young. So I don't know, I kind of take it out on her for not giving me care when I was younger and it was more treatable and in intimate relationships. As well, just because the disease is in a very intimate area. So I can't enjoy, I guess, yeah, being intimate with my partner because I'm very ashamed of the disease. Even with, you know, past boyfriends and stuff, you know, they would tell me to keep my shirt on because they didn't want to see it, things like that. So yeah, I would say a lot.
Participant 010_2023AUHIS

Experience described suggests that there was overall a minimal impact on quality of life

Compared to my other conditions, I wouldn't say it's impacted with all that much. Participant 019_2023AUHIS

Table 8.1: Impact on quality of life

Impact on quality of life	All participants	
	n=20	%
Experience described suggests that there was an overall negative impact on quality of life	13	75.00
Experience described suggests that there was overall a minimal impact on quality of life	1	5.00
No particular comment	2	10.00

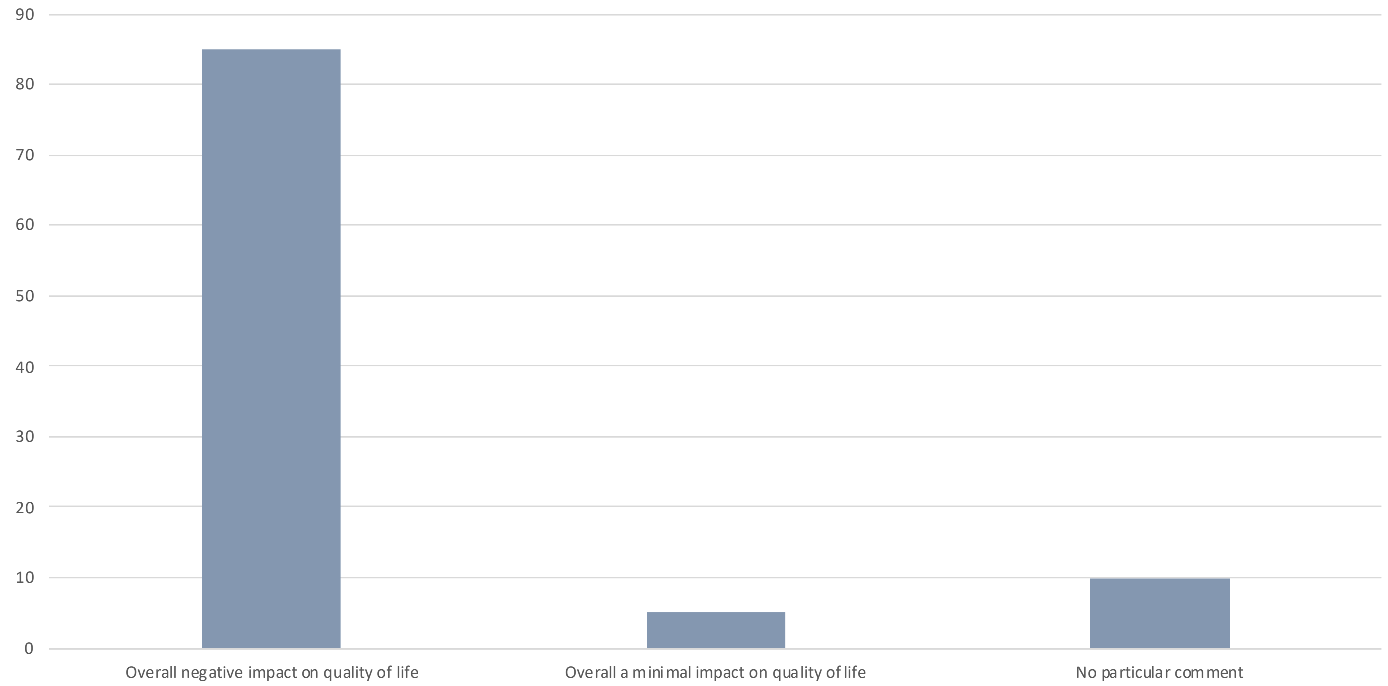


Figure 8.1: Impact on quality of life

Table 8.2: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants	
	n=20	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	7	35.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	5	25.00
Participant describes a negative impact on quality of life due to intimacy challenges	4	20.00
Participant describes a negative impact on quality of life due to reduced social interaction	4	20.00
Participant describes a negative impact on quality of life due to financial strain	2	10.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	2	10.00
Participant describes a negative impact on quality of life without giving a reason	2	10.00
Participant describes a negative impact on quality of life due to the impact on self image	2	10.00
Participant describes a negative impact on quality of life due to altering lifestyle to manage condition (including being immunocompromised)	1	5.00
Participant describes a negative impact on quality of life due to the emotional strain on self	1	5.00
Participant describes a negative impact on quality of life because people don't believe the severity of condition	1	5.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	2	10.00
Participant describes a positive impact on quality of life without giving a reason	1	5.00
Participant describes a minimal impact on quality of life that has a general or temporary impact	1	5.00

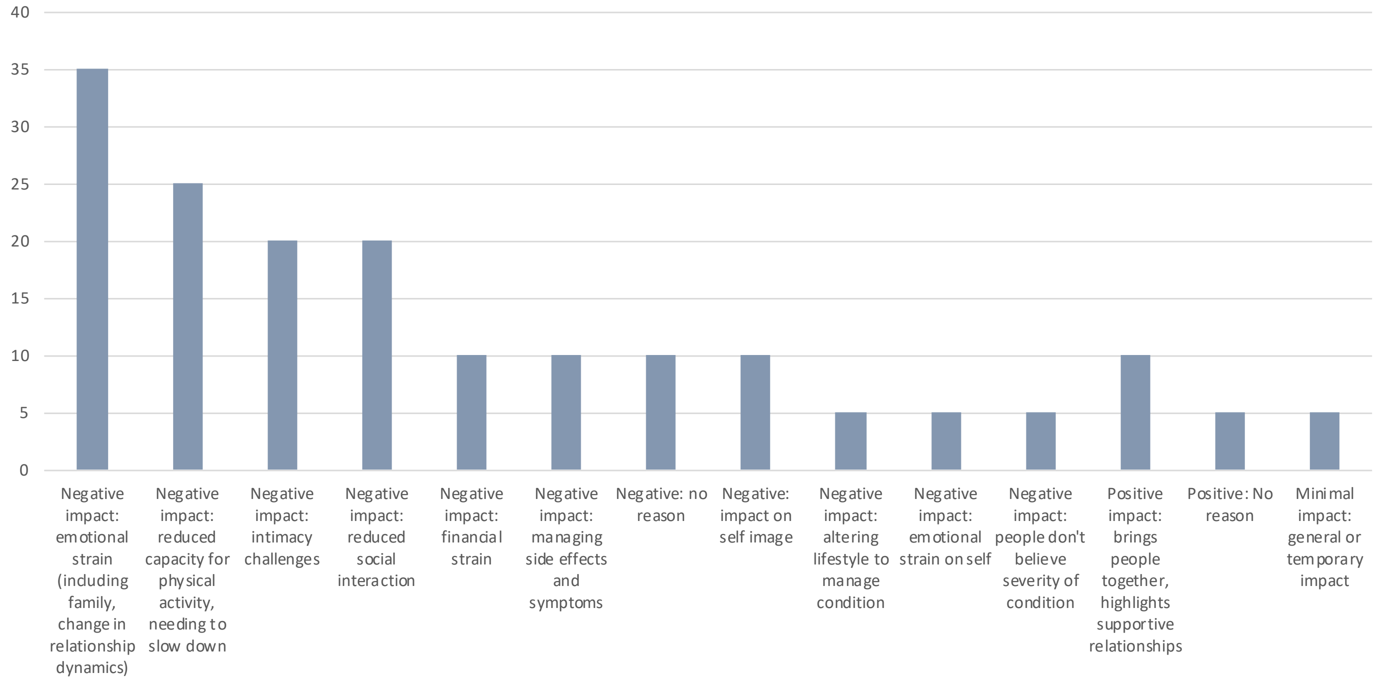


Figure 8.2: Impact on quality of life (Reasons)

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (80.00%), overall, there was no impact on mental health (5.00%), and other or mixed experience (5.00 %).

Experience described suggests that overall, there was at least some impact on mental health

It can affect my mental and emotional health and that can vary from day-to-day. I can have, you know, at the moment I have a flare and that can get me down because it's just kind of like you suddenly you're feeling well and then bang, you know, it's almost like there's no lit up. Like you, you you just go for a day and you think you're doing really well and then suddenly you've got, you know, one flare pops up and. Your arms uncomfortable or whatever. So yeah, look, it can, but I think in that for me, I've had to put things in place to help me with my mental health. So that's for me that's talking about my condition. It's practicing mindfulness and mental health and wellbeing type of activities that keep me, keep me focused on the positive rather than allowing, you know, the focus to become the HS.
Participant 001_2023AUHIS

Sorry, I'm crying, but yeah, it affects my mental health a lot. I would say. You know, I have ever an episode at least twice a month where I break down. About having the disease, because I just think, why me? Like why do I have this? And it's just it's ugly and I compare

myself to other people all the time who, you know, don't have it. I like there's not much I can do for myself in terms of having disease because it's so hard to pull myself out of this. Like mental thought that it's ugly and it's something I should be ashamed of and it's just kind of, I need to let myself cry about it and then I move on because it's not going anywhere. So I just have to, you know, get over it. I'd say my partner is definitely someone who helps a lot with my mental health. He'll just remind me that, like, I'm still a great person with or without the disease.
Participant 010_2023AUHIS

Yeah, 100% it does it affect because it affects yourself esteem. It makes you stress about. The pain you're experiencing, or even just knowing that it's coming is sometimes worse. Stressing about money, taking time off of work, it's a lot of sometimes I think the mental and emotional roller coaster puts you through sometimes worse than the physical, so that I know it's a lot worse for other people. Thankfully, I'm probably classed more as mild, especially these days. It's not as rampant as what it was, but yeah.
Participant 018_2023AUHIS

Yeah, it definitely has an impact. It sort of makes you feel like. You're a bit less lovable. I don't know. There's just a lot going on, I guess. And yeah, I see a psychologist.
Participant 019_2023AUHIS

Experience described suggests that overall, there was no impact on mental health

It would. It would affect me if I let it, like if I just dwelled. Yeah, on it. But to be honest, I'm more concerned about my leg and my mother.
Participant 006_2023AUHIS

Table 8.3: Impact on mental health

Impact on mental health	All participants	
	n=20	%
Experience described suggests that overall, there was at least some impact on mental health	16	80.00
Experience described suggests that overall, there was no impact on mental health	1	5.00
Other or mixed experience	1	5.00
No particular comment	2	10.00

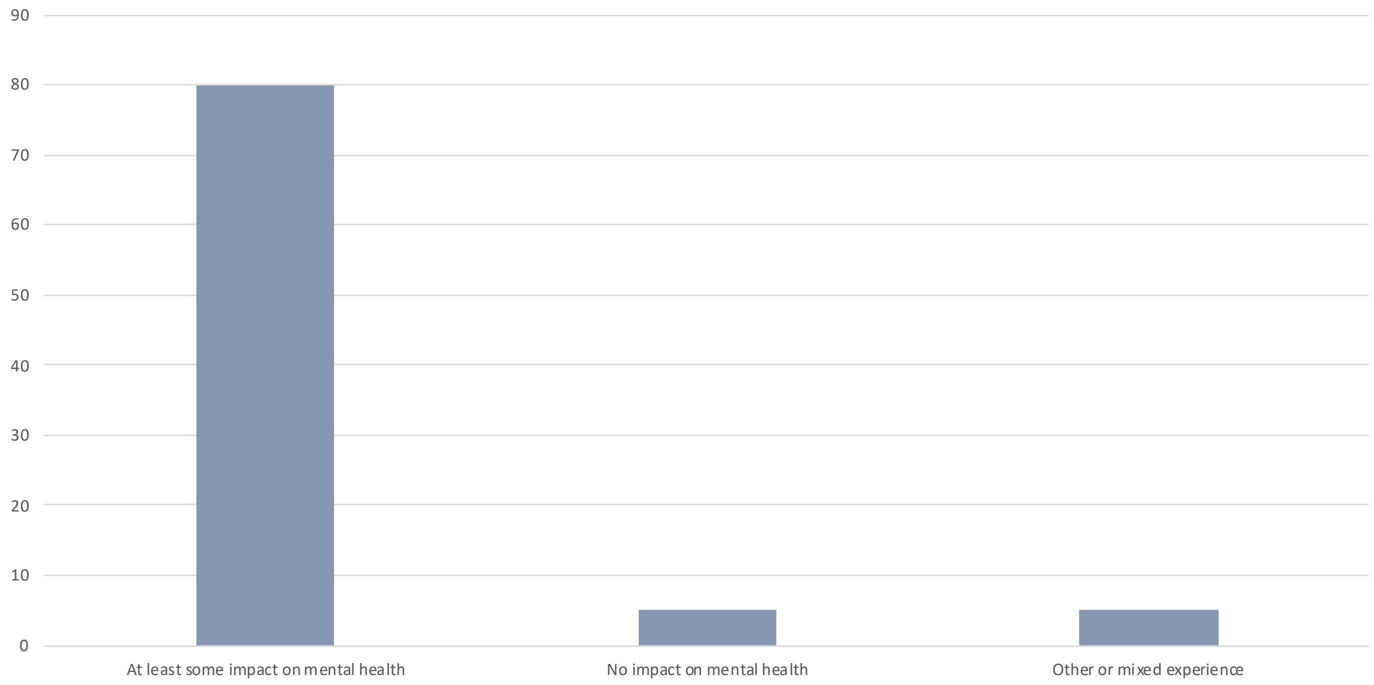


Figure 8.3: Impact on mental health

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was mindfulness and/or meditation (40.00%), no activities to maintain mental health (20.00%), and the importance of family and friends in maintaining their mental health (15.00 %). Other themes included consulting a mental health professional (10.00%), allowing time to cry, then gets on with it (10.00%), keeping busy (10.00%), coping strategies such as remaining social, lifestyle changes and hobbies (5.00%), the importance of physical exercise (5.00%), and keeping informed about their condition (5.00%).

Participant describes mindfulness and/or meditation to maintain their mental health

My mindset definitely helps my mental health, but I'm also medicated for mental health and anxiety. Participant 005_2023AUHIS

Yeah, I. I I find walking. I haven't done a lot of that lately. Walking helps mental and emotional health. Emotional health. I'm not sure exactly how to answer that because I'm self aware enough to know that I've tucked my emotions away for the most part, without seeking sympathy, I lead a sad life. I I read, watch TV, read. Stuff about HS was engaged in the whatever. It's an online community of people involved with HS advocacy and research. But I'm gradually withdrawing from that, feeling like I've done enough and there's too much politics and you don't know who's in the zoo and farmers everywhere. So pulling away from all that, I find meditation for me is easy, and that helps. It's not really an obvious meditation, but I can. I can lie down and put everything out of my head and just. Exists to be that kind of meditation, you know, no worries, no, no bad thoughts. I find that easy to do. I do it frequently there. There's there's no one thing that I do that fixes. Problems.
Participant 008_2023AUHIS

Participant describes no activities to maintain mental health to maintain their mental health

I mean, it is right now. It's certainly, yeah, we're having a flare up. It could be quite frustrating, painful and upsetting, but I don't. I don't seek out any.
Participant 011_2023AUHIS

I don't really have any strategies because until I'm not in pain it's very difficult for me to look after my mental health because the more pain I'm in, the worse my mental state gets and the more over stimulated I get, which is you can't really come back from that very often.
Participant 012_2023AUHIS

Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health

So I would say I would say yes around the time it, it probably did to maybe a mild, mild to moderate sort of severity level I through the work I do anyway and really a very strong advocate for the self care and you know catching myself with any negative self talk and and those sorts of things. I I spoke to family and close friends and was really I suppose to open and and honest and expressing where I was at so that I sort of had a sounding board and a place to and a place to share that. So I think those things were really. Important I didn't go and seek a psychologist because, like, I know them all really well around here and they're all colleagues and I supervise a lot of them. And yeah, in a small country town, that just didn't feel like an option.
Participant 007_2023AUHIS

Educating myself, making sure I have hobbies and whatnot. Getting on with life, not letting HS rule me so much, and having a supportive, understanding partner.
Participant 013_2023AUHIS

Table 8.4: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants	
	n=20	%
Participant describes mindfulness and/or meditation to maintain their mental health	8	40.00
Participant describes no activities to maintain mental health to maintain their mental health	4	20.00
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	3	15.00
Participant describes consulting a mental health professional to maintain their mental health	2	10.00
Participant describes allowing time to cry, then gets on with it, to maintain their mental health	2	10.00
Participant describes keeping busy to maintain their mental health	2	10.00
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	1	5.00
Participant describes the importance of physical exercise to maintain their mental health	1	5.00
Participant describes keeping informed about their condition to maintain their mental health	1	5.00

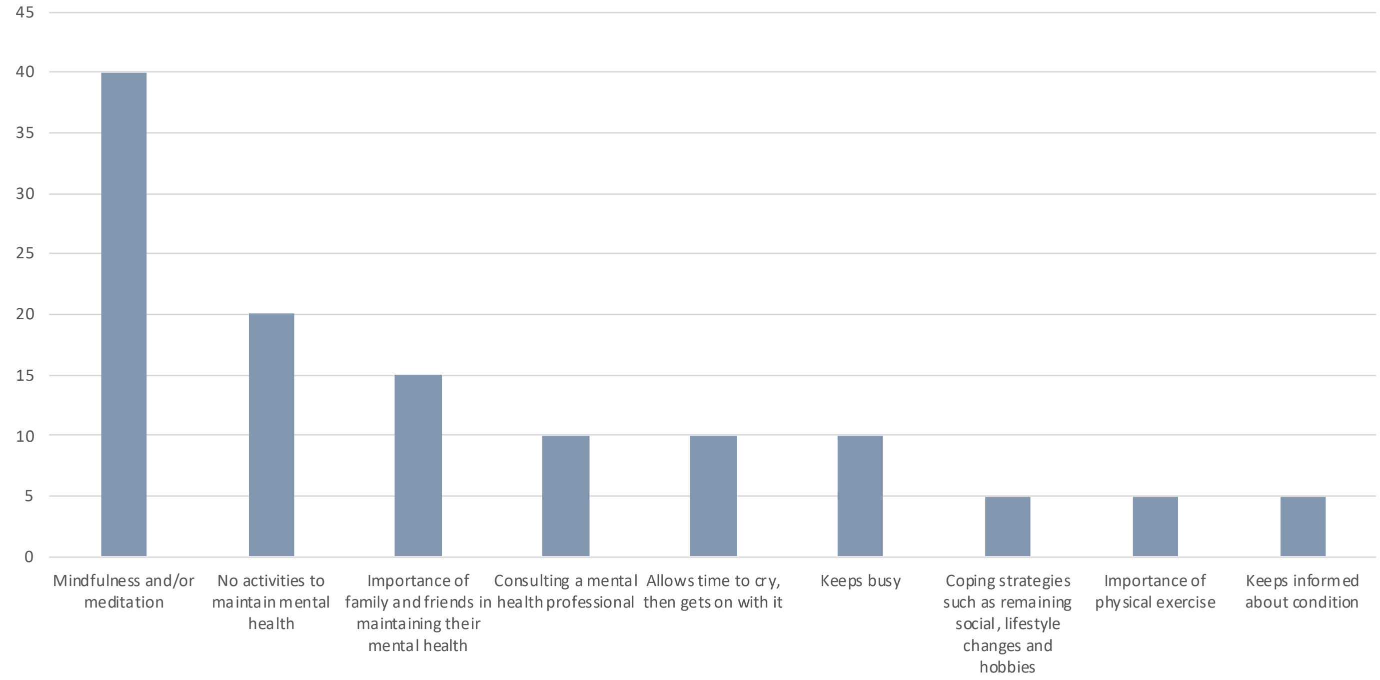


Figure 8.4: Regular activities to maintain mental health

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were complying with treatment/management (45.00%), and hygiene routine (45.00%). Other themes included avoiding flare triggers (25.00%), understanding their limitations (20.00%), being organised and planning ahead (10.00%), using complementary therapies (10.00%), maintaining a healthy diet (10.00%), mindfulness and/or meditation (10.00%), doing physical exercise/physically active (10%), self care e.g. more rest, accepting help, pacing (10.00%), covering up lesions (10.00%), being aware of their body and limitations (5.00%), and maintaining a normal routine (5%).

Participant describes the importance of complying with treatment/management in maintaining their general health

That would be bleach baths, yeah. Using my topical creams. Using the Hydrochloid bandaids or pimple patches, yeah. Not wearing underwear? Yeah. Not being overly not eating or drinking one particular thing overly if that makes sense. Like just don't gorge yourself on anything. Like I'll have whatever, but I mean don't have chocolate three days in a row and eat the whole block 3 days in a row. You know, like you're going to have toxins trying to get out of you and. Regardless of whether or not it's a flare, it's you know you're gonna get pimples or whatnot, so probably just have some bananas or I know something better than that. So I try to be mindful of what I'm eating and not have too much oil.
Participant 006_2023AUHIS

Good hygiene, as in making sure the affected areas are well cleaned and protected. I take vitamins to help counteract. I take medication when it's prescribed. Just looking after myself and getting on with life.
Participant 013_2023AUHIS

Participant describes the importance of their hygiene routine in maintaining their general health

Well, basically I mean on that one there's not a I mean I'm help him with his when he's got flares like you know, I do all these the preparation of his his patches and with he also uses just a a general body wash thing to keep the the microbes down. The chlorhexadine. So yeah keep him supplied with with all of those things and on his back to to make sure cause he's 16 on his back to make sure that he's having the the right hy hygiene stuff but as we you know as we all know hygiene doesn't even really play a part in in this so yes just making sure that he's. He's well he's pre prepared and that he's getting that emotional support so that he can keep keep moving forward and we're all about normalizing his life at the moment when you know if he's he's getting back into some some sport but not at a a a competitive level and if he can do it he can do it. If he can't well he's just got to accept that. So we're we're trying to modify expectations, etc.
Participant 009_2023AUHIS

I have to make sure I'll have to clean myself. I have to wear appropriate clothing specifically in relation to whether or not I'm wearing pads or. Or bandaids to cover lesions that are weeping. I have to make sure that I have those supplies with me at any given time. I have to be sure that I am within reach of pain medication. If we were to just go away, I would take my and don't, regardless of whether I had a flare or anything. I I am limited in my mobility, so I have to be mindful of the activities I need to do to get me from A to B or, you know, from one activity to another, whether it's, you know, working or being home. What my mobility situation is at any given time and whether I can sustain it, So I had a massive flare last week. Thursday would have been a fun day to talk to you and I couldn't shower for three days, so there was no, I was working from home. That's, you know, at any given time it it's it's just being able to cater to you, the current situation. Is that kind of what you were?
Participant 015_2023AUHIS

Participant describes the importance of avoiding flare triggers in maintaining their general health

My one rule is that I threw away all my bras that had under wire in them because that shit makes everything worse and I stopped wearing those like a year ago. So much better. So delete those from the earth and make sure like wearing appropriate clothing because some clothing will just trigger a flare like. Don't do it. It's bad choice. I put something on and I'm like, no regret. Take it off sitting on comfortable things. If I sit on the chair, I will instantly know if it's going to give me a flare from the pressure it puts on me. So I have to make those choices. It's like every day things, there's just things everywhere that you have to avoid.
Participant 014_2023AUHIS

Table 8.5: Regular activities to maintain health

Managing treatments I guess is the biggest one and and try my best to prevent further flare. Yeah, at the moment I don't feel like there's a lot I can do to prevent that, so it probably isn't having a massive impact, but I'm sure once I start the injections that will do.
Participant 019_2023AUHIS

Participant describes the importance of understanding their limitations in maintaining their general health

Try not to overheat is the big one. I don't even drink alcohol anymore because I noticed, you know, a day. If I drank on a Saturday by Tuesday, it's just really limited. A lot of social stuff just because I know just not to do it and then it it won't happen. So no real exercise, no fun stuff.
Participant 018_2023AUHIS

Participant describes the importance of being organised and planning ahead in maintaining their general health

So if I've got a break out. I need to make sure that I've got bandaging to be able to wear. I need to have. Funnily enough, I haven't had any really strong pain relief for a very long for over a year now, and I'm quite happy about that. I need to be able to maybe cancel things in short notice if if that's the case, you know. I need, I feel like I need certainly access to an endless supply of Chlorhexidine and I have the biggest Band-Aid and bandage collection in the world. So yeah, yeah, so I guess, I guess. Physically, to be able to, you know, wear undergarments, I need to be able to, you know, have enough padding to protect, you know, and I guess also obviously I need access to my medication and I need access, yeah.
Participant 017_2023AUHIS

Regular activities to maintain general health	All participants	
	n=20	%
Participant describes the importance of complying with treatment/management in maintaining their general health	9	45.00
Participant describes the importance of their hygiene routine in maintaining their general health	9	45.00
Participant describes the importance of avoiding flare triggers in maintaining their general health	5	25.00
Participant describes the importance of understanding their limitations in maintaining their general health	4	20.00
Participant describes the importance of being organised and planning ahead in maintaining their general health	2	10.00
Participant describes the importance of using complementary therapies in maintaining their general health	2	10.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	2	10.00
Participant describes the importance of mindfulness and/or meditation in maintaining their general health	2	10.00
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	2	10.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	2	10.00
Participant describes the importance of covering up lesions in maintaining their general health	2	10.00
Participant describes the importance of being aware of their body and limitations in maintaining their general health	1	5.00
Participant describes the importance of maintaining a normal routine in maintaining their general health	1	5.00

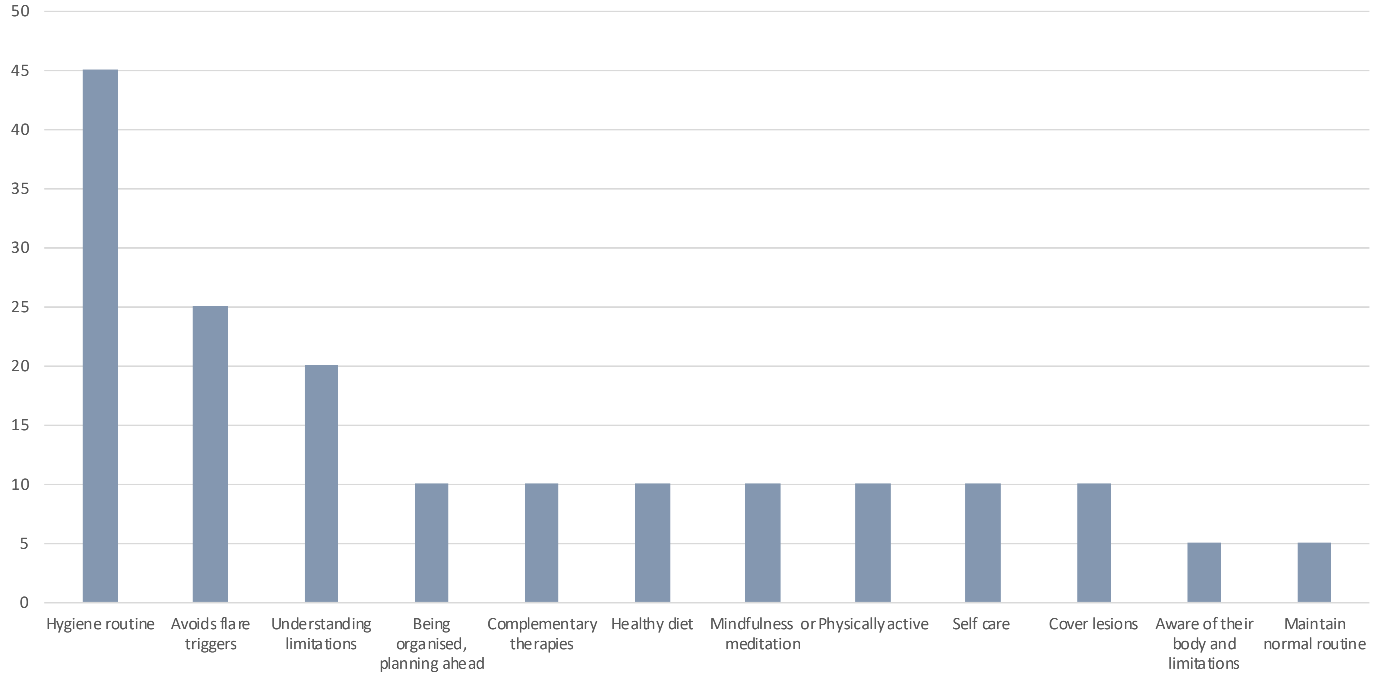


Figure 8.5: Regular activities to maintain health

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable experiencing side effects from treatment or symptoms from condition (25.00%), when having sensitive discussion (diagnosis, treatment decision) (20.00%), and because of interactions with the medical team (20.00 %). Other themes included during/after treatments (15.00%), during diagnostic procedure (10.00%),thinking about disease course/incurable condition (10.00%), and did not feel vulnerable (5.00%).

Experiencing side effects from treatment or symptoms from condition

Yeah, so I the vulnerability that I have, the disease come in my social and intimate life. So as I said, I have the disease. In my breast area, which is very intimate area, so I find it hard to be intimate with my partner. Sometimes if I'm having a flare up, I don't want to get undressed. I don't want him to see me even though I know he doesn't care and he still loves me. But it's still hard for me to feel beautiful and wanted when I'm dealing with this. As well as just going out and going to the beach. Like I can't wear a bikini because then the disease is just kind of on display. And I, you know, there was a time where I said, you know, like through it, like I'm going to wear a bikini. And then, you know, I saw people looking at it and asking questions like

what's on your chest? And yeah, it just sucks because I don't want. People to point it out or look at it or anything like that and it just makes me feel embarrassed.
Participant 010_2023AUHIS

Yes, there has. Particularly when the condition was just getting out of control and you turn to a specialist for help and their answer is there's nothing I can do. And these are that, that they don't offer alternative suggestions. For instance, hang on, I'm going to call, I was having. A chronic Abscess that just would not heal. And the surgeon I saw just said there's nothing he can do anymore. And I but he didn't offer alternative solutions like go and see this person or what not. And that I still vividly remember being very vulnerable and alone in the world, thinking no one can help.
Participant 013_2023AUHIS

Vulnerable when having sensitive discussion (diagnosis,treatment decision)

When I was told that I had to. That I really only had Humira as my only option. I did feel very vulnerable then, yeah.
Participant 017_2023AUHIS

Anytime I kinda have to ask for help because I have to start from the beginning. And yeah, I've really gotta you wait for the no and the the here's the antibiotics and the just the standard stuff that you know isn't gonna do anything, but you have to do it so they can tick off their list that they've tried that.
Participant 018_2023AUHIS

Vulnerable because of interactions with the medical team

The most vulnerable was that time I described being naked and being told that I need to keep smoking and lose weight and take Humira and then I'll be fine. I'm not sure they realise that. I left it on the opposite side of the city and it took me. An hour and a half on public transport to get there. 30 minute walk. That's a lot of effort just for doctors and nurses to point their finger at you while you're naked and tell you you're the problem, NAME. That's why I've not seen a dermatologist since.
Participant 008_2023AUHIS

Really. They treated me like I was infectious in hospital, so no one knew the their treatment of my pain level. They made me feel like I was just a heroin addict who who's come in to get some end down. So I cried so hard and then you know I followed that up with. That visit, and it was just, it was a joke. I'd never felt more, I'd never felt more unseen. Talked at like I was not a person of any circumstance. I wasn't even poorly dressed, I'd have to say if you thought I was anything other than a professional at that point. And the way he spoke to me in the presence of others, the nurse at the end of it, because he was just taking so long showing off in front of his registrar, this nurse came in and literally looked at me and said, you've taken enough of his time. And I remember laughing so hard because I was literally sitting there just being poked and prodded that no one was talking to me. You know, you regurgitated the lose weight, quit smoking. But wash yourself. And I remember just going. You have no idea what I do. And I could be just, you know, do you want my skin to be red before you'd be satisfied that the amount of bleach I'm scrubbing into myself daily and all the while still feeling extremely dirty? It's really horrific. I've quit smoking for years and never saw a difference. I was not even overweight at that time. Like, there's no rhyme or reason at that point that I could say these are contributing factors.
Participant 015_2023AUHIS

Vulnerable during/after treatments

PARTICIPANT: Probably, probably actually the most vulnerable would have felt after my first surgery when I had expected it to be like a two day recovery.
INTERVIEWER: Yeah, but do you think you needed to like, address or overcome that vulnerability?
PARTICIPANT: Probably just information.
INTERVIEWER: Yeah, more knowing.
PARTICIPANT: Knowing what to expect, yeah.
Participant 007_2023AUHIS

Table 8.6: Experience of vulnerability

Experience of vulnerability	All participants	
	n=20	%
Participant describes feeling vulnerable experiencing side effects from treatment or symptoms from condition	5	25.00
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	4	20.00
Participant describes feeling vulnerable because of interactions with the medical team	4	20.00
Participant describes feeling vulnerable during/after treatments	3	15.00
Participant describes feeling vulnerable during diagnostic procedure	2	10.00
Participant describes feeling vulnerable thinking about disease course/incurable condition	2	10.00
Participant describes that they did not feel vulnerable	1	5.00
No particular comment	2	10.00

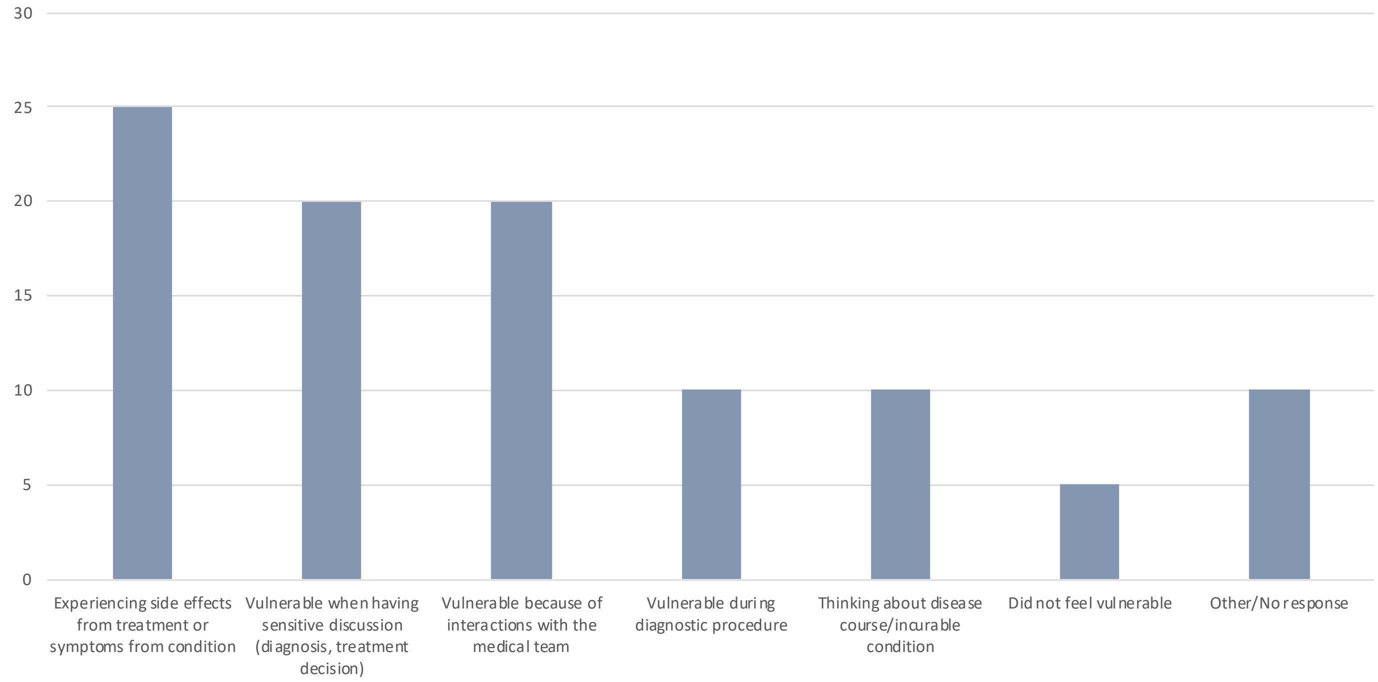


Figure 8.6: Experience of vulnerability

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (15.00%), and using self-help methods (resilience, acceptance, staying positive) (10.00%). Other themes included support from mental health professionals (5.00%), being informed and knowing what to expect (5.00%), and sticking to their treatment regimen (5.00%).

Support from family and friends to manage the feeling of vulnerability

PARTICIPANT: I'll just pull back on the people that know about it and support me I have a husband that's very accepting and understanding who comes to my condition, so I'm very lucky.
Participant 011_2023AUHIS

Self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

PARTICIPANT: I just had to take it day by day, persevere, keep fighting to get and once some he tried a new antibiotic. Fortunately it worked so that the wound could clear up. Otherwise, I was just like abandoned in a dinghy, out at sea, left alone.
INTERVIEWER: Thank you. It was very hard.
PARTICIPANT: Yeah, I think it's just that, OK, they can't help you, but it's just like slamming the door in your face. They didn't. Come up with other options that Oh well, maybe you could go and see this person or try this person. It was just slam bam, out you go.
Participant 013_2023AUHIS

Being informed, knowing what to expect

PARTICIPANT: Probably, probably actually the most vulnerable would have felt after my first surgery when I had expected it to be like a two day recovery.
INTERVIEWER: Yeah, but do you think you needed to like, address or overcome that vulnerability?
PARTICIPANT: Probably just information.
INTERVIEWER: Yeah, more knowing.

PARTICIPANT: Knowing what to expect, yeah.
Participant 007_2023AUHIS

Table 8.7: Methods to manage vulnerability

Methods to manage vulnerability	All participants	
	n=20	%
Participant describes getting support from family and friends to manage the feeling of vulnerability	3	15.00
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	2	10.00
Participant describes support from mental health professionals to manage the feeling of vulnerability	1	5.00
Participant describes Not applicable, no vulnerability	1	5.00
Participant describes being informed and knowing what to expect to manage the feeling of vulnerability	1	5.00
Participant describes sticking to their treatment regimen to manage the feeling of vulnerability	1	5.00
No particular comment	12	60.00

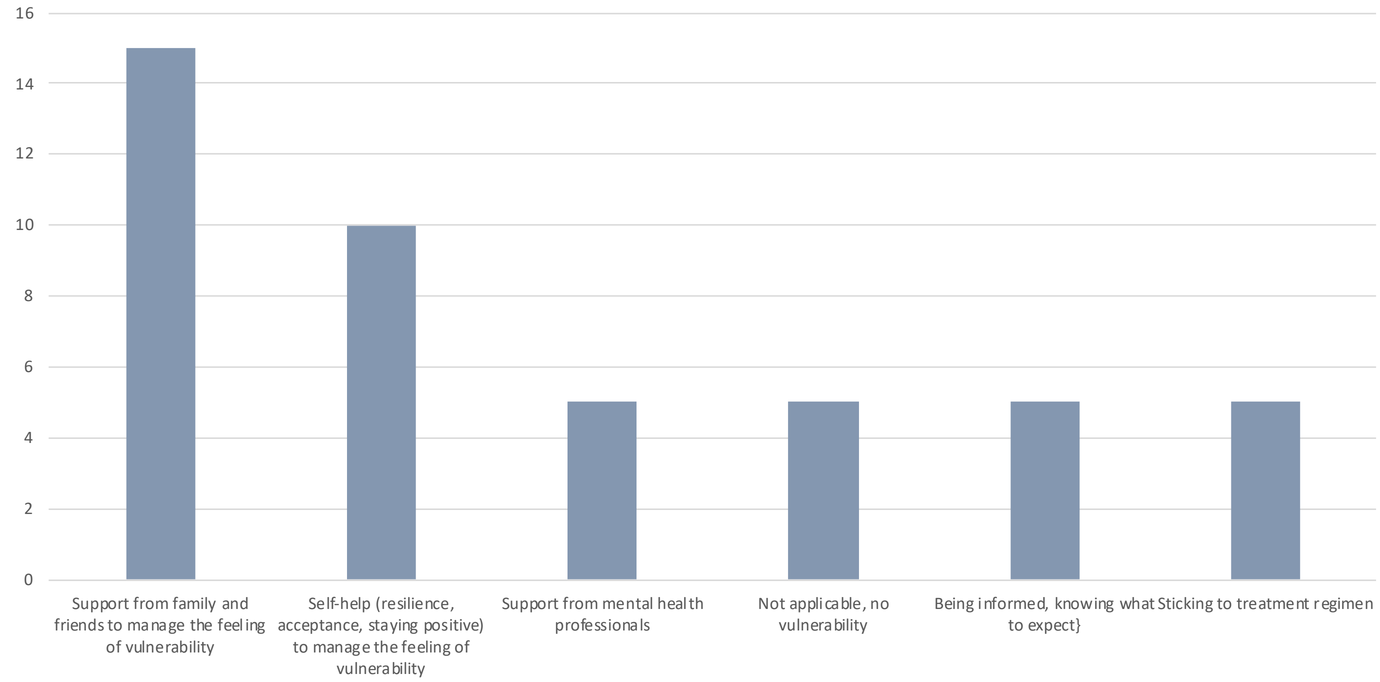


Figure 8.7: Methods to manage vulnerability

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (50.00%), and overall, there no impact on relationships (15.00%). Other themes included overall, there was a positive impact on relationships (10.00%), and overall, there was an impact on relationships that was both positive and negative (5.00%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (20.00%), from feeling dismissed or not believed by others(10.00%), and due to intimacy challenges (10.00 %). Other themes included from managing symptoms (5.00%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.00%).

The most common theme in relation to a positive impact on relationships were brings people together/highlights supportive relationships (10.00%).

Overall, there was a negative impact on relationships

The only questions that got asked at the one of my face Oh my gosh, I hated going to Christmas. What's on your face? And it's like, Oh my gosh, I don't teach you about your conditions. Yeah. Like, half my family has psoriasis. So, I mean, they think they're worse off and they've got growing skin all the time. But I'm like, and you don't have any sympathy for me.
Participant 003_2023AUHIS

That question, yeah, it's OK. I think I'll move on to the next one. Yep. And do you think having HS has affected your personal relationships with family and friends? Yeah. Maybe up until 2005 I would have said

Nah, but I don't think I was. I think I was living in denial. I've been withdrawing from relationships a lot since then and. I don't know for certain if it's HS or personality disorder or whatever, but here I am. Yeah, it has affected sexual relationships in the past and it and it hasn't, you know, it it varies depending on how you feel on the day and whether your skin is bad. I'm trying to think 2022. It's probably been eight or nine years since I was in a sexual relationship, so. I'm still young, 55, but I just feel like you know, whatever is that HSI don't know. I mean it's it's everything. It's it's my circumstance, my poverty, my withdrawal, my skin disease and. None of it changes day by day. It's all still there when I wake up the next day, so I guess I haven't thought about it that much.
Participant 008_2023AUHIS

Well, with the HS, you see like people go to the beach and wear cozies, for instance, or clothing that they like. When you have HS, you got these ugly scars and wounds that are oozing. So you can't necessarily put on your nice bathing suit. You've got to cover up, going out anywhere. You've got to be careful if you've got a wound like, is it? Not going to leak is it covered up? And then you tend to wear clothing that covers up that area, so you can't be your genuine new. You're too busy making sure that things don't leak, that you're dressed appropriately to cover them so you can hide.
Participant 013_2023AUHIS

Yeah, I guess I would say it has. Because of making plans and having to cancel because you can't really do the things that you wanted to do. Yeah, I guess it does. And when people don't know why, you'll understand. It makes it difficult because then they just think that you're blowing them off for no reason and it's like, well, no.
Participant 014_2023AUHIS

Overall, there no impact on relationships

They have to love me because they always will, no matter what. And if they didn't do this because they wouldn't be my friends.
Participant 002_2023AUHIS

Probably not. In my case, I have chronic fatigue syndrome, so I've already quite isolated and yeah, sort of focusing on just my main friendship.
Participant 019_2023AUHIS

Overall, there was a positive impact on relationships

PARTICIPANT: Hasn't affected anything, you know, like with me Dad or whatever, you know, like he knows what's going on. He just thinks that's terrible, you know? But no, like, I have the best friend that I've been best friends with since I was six, and she understands and. If she sees any information or anything, she's like the first to be like, oh, I saw this, you know.
INTERVIEWER: That's great.
PARTICIPANT: So yeah, no. Like it's, if this was on my back or something and people were seeing it, you know, and my armpit and I had to go look, yeah, you know, like this, you know, then yeah, probably would be a lot, but it's. It's in my like Nether region. I don't get around with that out, so it's not a topic for conversation with most friends. I've got no idea that that is something that I would suffer with.
Participant 006_2023AUHIS

I don't know if it's affected it or not. I I couldn't really say. I don't think it's affected it that much. My family's still been really supportive. I. Look, the worst probably do is sometimes my family is tired of me, but that's about it.
Participant 012_2023AUHIS

Overall, there was an impact on relationships that was both positive and negative

There are some things like I won't that I won't do so like I won't go to things like water parks and so there's there's some family things that I won't go to. Obviously there are lots of times I have to cancel because as I said pants are not an option and and they kind of required when you leave the house. Very fortunate with regards to. So I've had like I've lost a lot of friendships over the years because you cancel all the time and then they just stop asking you to do things with them. I'm very fortunate in that, you know, both my first husband and my second husband are beautiful men. My first husband is still a beautiful man and and so it didn't affect my physical relationships. But certainly had an impact on my ability to spend time with friends and things like that.
Participant 005_2023AUHIS

Table 8.8: Impact on relationships

Impact on relationships	All participants	
	n=20	%
Participant describes that overall, there was a negative impact on relationships	10	50.00
Participant describes that overall, there no impact on relationships	3	15.00
Participant describes that overall, there was a positive impact on relationships	2	10.00
Participant describes that overall, there was an impact on relationships that was both positive and negative	1	5.00
No particular comment	4	20.00

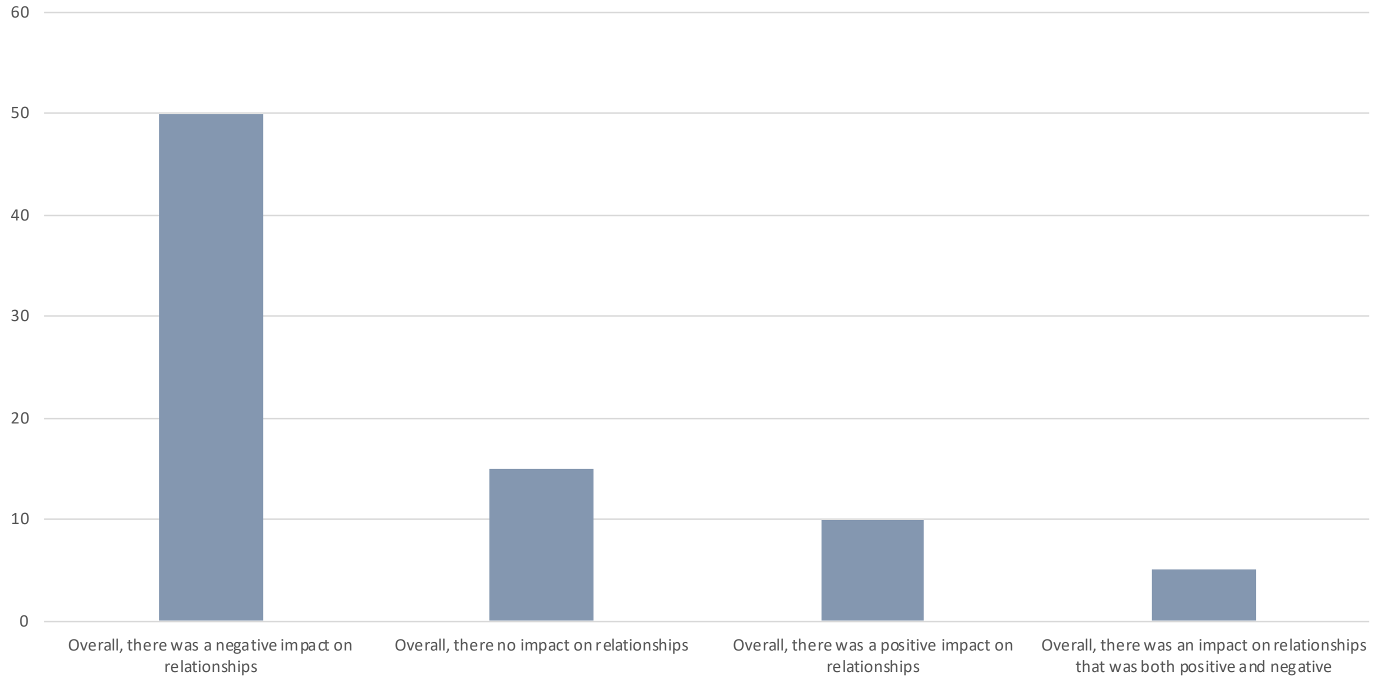


Figure 8.8: Impact on relationships

Table 8.9: Impact on relationships (Reason for impact)

Impact on relationships (reasons)	All participants	
	n=20	%
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	4	20.00
Participant describes a negative impact on relationships from feeling dismissed or not believed by others	2	10.00
Participant describes a negative impact on relationships due to intimacy challanges	2	10.00
Participant describes a negative impact on relationships from managing symptoms	1	5.00
Participant describes a negative impact on relationships from the dynamics of relationships chaning due to anxiety, exacerbations and/or physical limitations of condition	1	5.00
Participant describes a negative impact on relationships in general (no specifics articulated)	1	5.00
Participant describes a positive impact on relationships from people being well-meaning and supportive	2	10.00
Participant describes a positive impact on relationships in general (no specifics described)	1	5.00
No impact/Not applicable	3	15.00

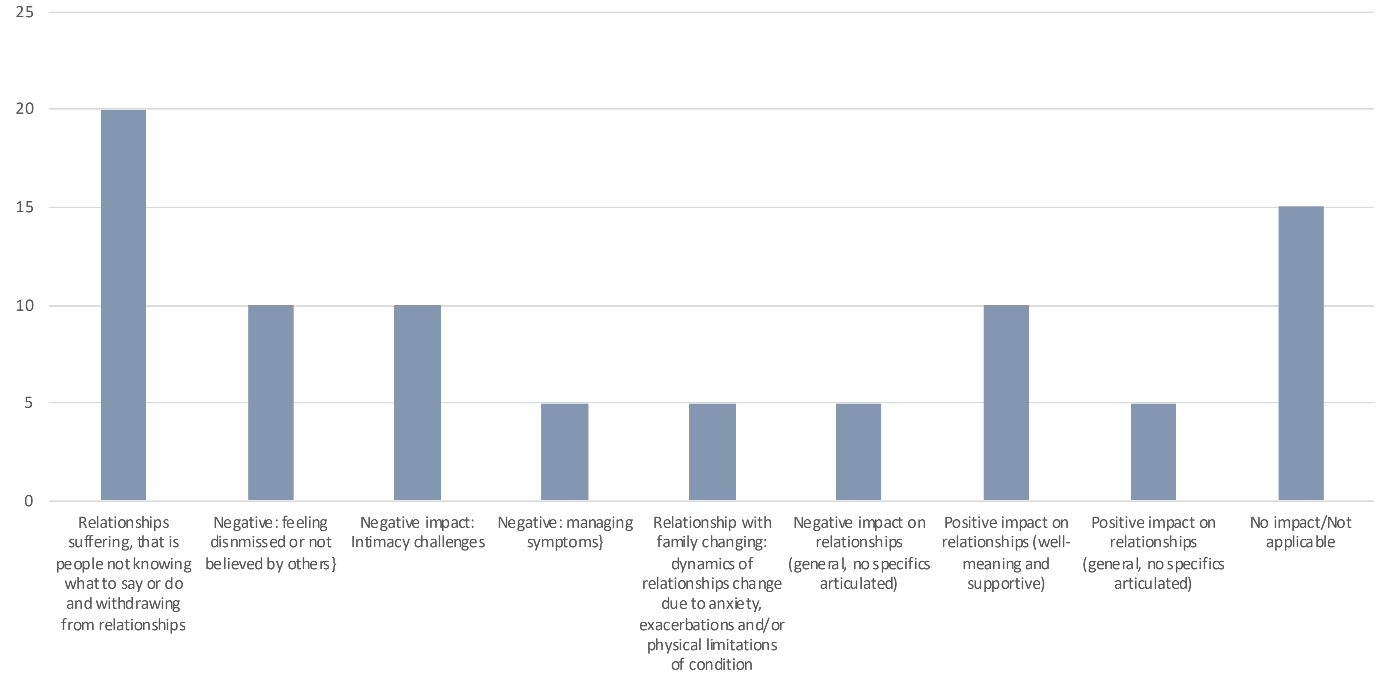


Figure 8.9: Impact on relationships

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (60.00%), overall, there was not a burden on their family (15.00%), and having no particular comment (25.00 %).

The main reasons that participant described their condition being a burden were the extra financial assistance needed (10.00%), the mental/emotional strain placed on their family (10.00%), and that the burden on family was temporary or only during treatment (10.00 %). Other themes included the extra assistance needed getting to appointments (5.00%), intimacy problems (5.00%),managing symptoms (5.00%), and eding to take time off work (5.00%).

The main reason that participant described their condition not =being a burden were because they were independent and did not need any help (15.00%), and that they were not a burden because no one knows about their diagnosis (5.00%).

Participant describes that overall, there was a burden on their family

I sometimes feel like that, but at at the most part, I mean I I can care for myself, but there. But there are times, there are times when I do feel like that because there might be times when I just you know, I I'm feeling a little bit worse less than normal. So yeah. So for the most part no, but sometimes yes.
Participant 001_2023AUHIS

Ohh well you do wonder sometimes when you're asking them to clean up certain parts you can't get to or get your daughter to take images of certain parts of your anatomy she certainly shouldn't be so that she can send you can send them through to the doctor for your Tele health. You know, I'm lucky that she just embraces it and takes it on board, but you know, it is what it is. It's it's our life.
Participant 002_2023AUHIS

Them look around the time of the surgeries, yes, I had had friends who lived nearby and my daughter that had to step up and do a lot more for me the rest of the time, not not so much in terms of kind of burden going forward. I know my daughter's quite concerned that she may be impacted by the condition. She's only she's only 11 now so you know she's she's already starting to look at things like you know at school they're being told they've got away deodorant and and she's going off. But is that going to increase the chances of of you know exacerbating that area. So yeah so there's there I suppose there's some burden more so of fear of what might come.
Participant 007_2023AUHIS

Participant describes that overall, there was not a burden on their family

No, I wouldn't say so. I guess I'm usually the carer, unfortunately. So, yeah.
articipant 014_2023AUHIS

No, my, my family and none of my friends know I have this. Only my husband. He's the only one.
Participant 017_2023AUHIS

Table 8.10: Burden on family

Burden on family	All participants	
	n=20	%
Participant describes that overall, there was a burden on their family	12	60.00
Participant describes that overall, there was not a burden on their family	3	15.00
No particular comment	5	25.00

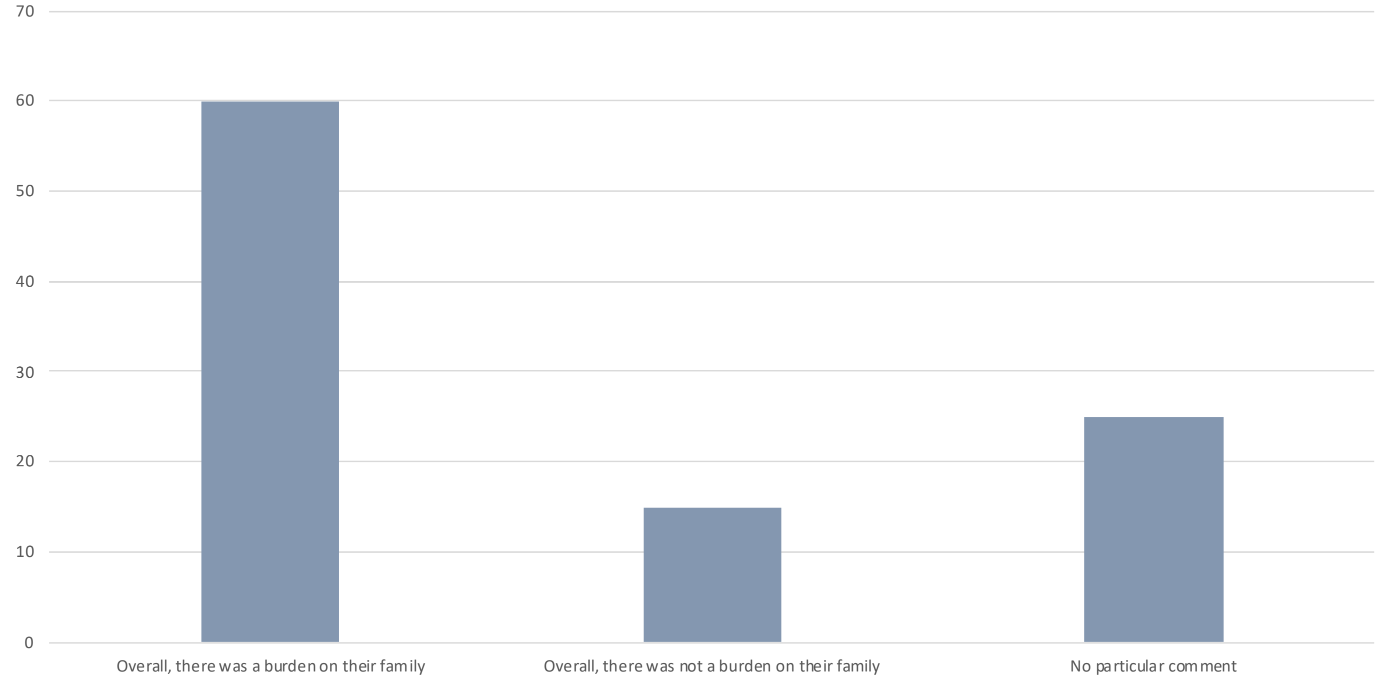


Figure 8.10: Burden on family

Table 8.11: Burden on family (description)

Burden on family (reasons)	All participants	
	n=20	%
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	5	25.00
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	5	25.00
Participant describes being independent and not a burden on their family	3	15.00
Participant describes the extra financial assistance needed as a burden on their family	2	10.00
Participant describes the mental/emotional strain placed on their family as a burden on their family	2	10.00
Participant describes that the burden on family was temporary or only during treatment	2	10.00
Participant describes the extra assistance needed getting to appointments as a burden on their family	1	5.00
Participant describes the intimacy problems as a burden on their family	1	5.00
Participant describes managing symptoms as a burden on their family	1	5.00
Participant describes needing to take time off work as a burden on their family	1	5.00
Participant describes the that there was no burden on family as they have not told anyone	1	5.00

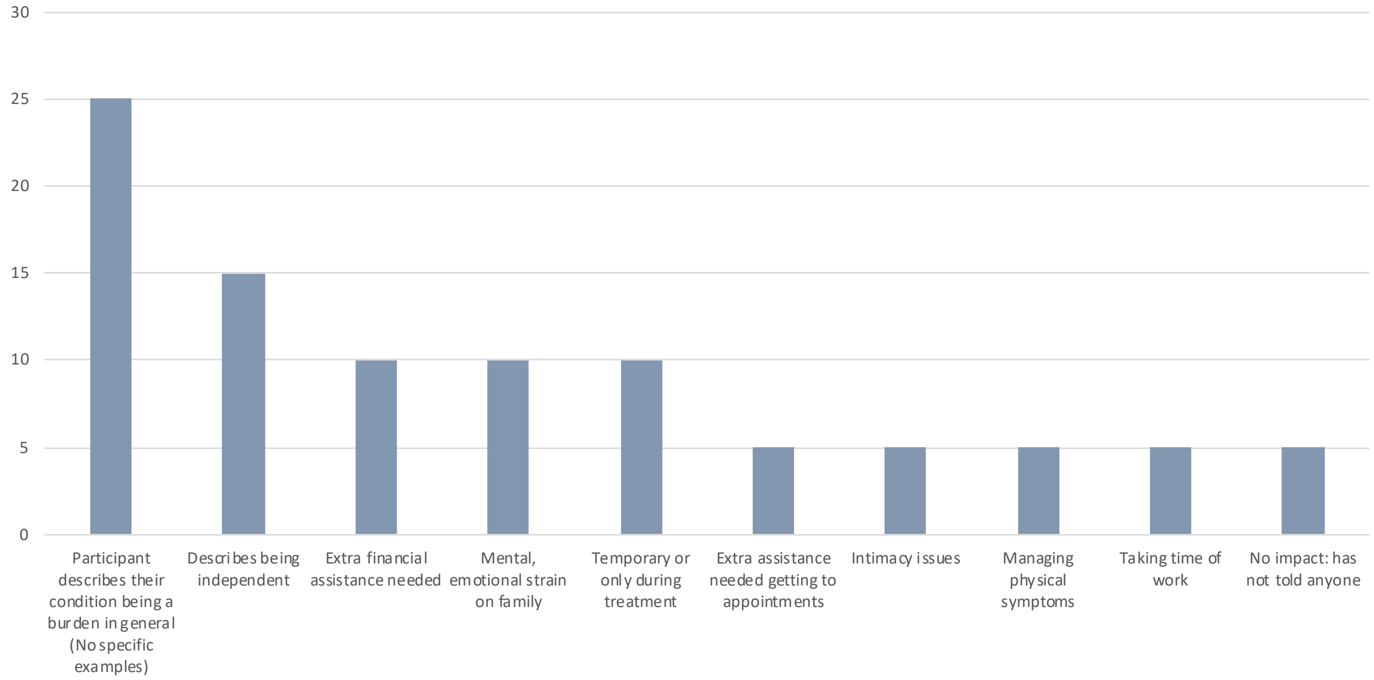


Figure 8.11 Burden on family (description)

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (75.00%), and overall, there was no cost burden (15.00%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (65.00%), the cost specialist appointments (50.00%), and needing to take time off work (25.00 %). Other themes included needing a special diet or lifestyle adaptation (15.00%), a family member needing to take time off work (10.00%),the cost of parking and travel to attend appointments (including accommodation) (5.00%), and diagnostic tests and scans (5.00%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to them prioritizing going to work over attending appointments (5.00%), being able to afford all costs(5.00%), and they had no treatment or management (5.00 %).

Cost burden in relation to the cost of treatments (including repeat scripts)

Well, my first appointment with my dermatologist was $270 and then bandages like for a three pack of the bandages that I get. Is like 11 to $12.00 which obviously isn't going to last very long. It's expensive and then meds on top of that, yeah.
Participant 014_2023AUHIS

PARTICIPANT: Look. Yeah, that's pretty. That's very subjective. I think that question, I think that there's been an overall cost for my son. It's not a financial cost, but it's an educational cost because he has not, you know, you know, in a, you know in the key time of his education he's had, he's taken time off school, his school activities. I think he actually. Got a pretty quick diagnosis. So I don't think that there was that cost there and the cost of the medication well thank God it's on the PBS and he qualified for you know we we qualified for that because he met all the the criteria. I'd like it if it was if we met the criteria to have it like at the the concession card rate because even still at $30.00 because it and and I like the fact that it's come down. Again. But even at $30.00 for a month medication, that's a lot for a family. If you, you know to put up it's, you know, it's something he's got to have so it's something he's got to have. But yeah, I if it wasn't covered under the PBS, there's no way we could afford it. Well, we would, you know, I suppose you'd have to make yourself afford it. But it's like, you know, almost. $1200 a month.
INTERVIEWER: That's a non PBS price, right?
PARTICIPANT: Non PBS price, yeah.
INTERVIEWER: And the PBS price would.
PARTICIPANT: Be it's about $30.00 a month we.
INTERVIEWER: Had a concession, yeah.

PARTICIPANT: Big difference.
INTERVIEWER: Yeah, for sure. Thank goodness for PBS.
Participant 009_2023AUHIS

Cost burden in relation to the cost specialist appointments

Well, I mean, I'm on the pension, so medication is generally cheaper, like subsidized for me. But then when the doctors don't want to take my my pension card, it doesn't get subsidized even if I give it to the chemist. And I'm like, well, I'm not paying full price or something when I'm entitled to PBS, like, so that's the only kind of annoying cost I've had to put up with. I just keep going into. I went to a different pharmacy because that was bullcrap, pretty much being told that because I've gone in with that with manuscripts like for my kids, for instance. And they don't provide their pension card because I'm they're on my pension card and they still get PBS. And I'm like, yeah, no, what what? You told me you're trying to get more money out of me, so.
Participant 003_2023AUHIS

Yeah, so I did find, I did find the costs were substantial for me on a on a single income the you know this. And as a single parent, there's not a lot of extra. So the yeah. The constant outlay for medications, none of that stuff was like, I don't have a health care card or anything like that. So nothing like that was subsidized and then yeah. Seeing all your specialists, there was always a a significant gap to pay and then I saw as I was lucky that I've been in my job for for a while. So you know over the when I had the surgeries pretty much the six weeks that I needed to take off 3 after surgery I was able to absorb that through my sick leave. I was probably lucky in that sense, but.
Participant 007_2023AUHIS

Definitely a cost of even just to see a specialist. You might get a rebate back, but it's still quite expensive to go see the specialist in the first place. Which is the reason why I haven't gone back and in there cost of medication as well. Like it's it's certainly not cheap.
Participant 011_2023AUHIS

Cost burden in relation to needing to take time off work

The major cost is because you're treated as a private patient. So every time you go, there's the consultation fee and then the ongoing fee. That was the biggest killer tests. Sometimes they were both billed, sometimes that was out of pocket. Yes, I did have to take off days off work because I couldn't work. Yeah, yeah, every. I think the biggest thing is that all the appointments, it's, it's money, and a lot of it's not covered by Medicare or even your private health insurance. So there's a lot of money being spent upfront.
Participant 013_2023AUHIS

Across Yeah, the time off work is really hard. I usually have to try and go back to work as soon as possible after a surgery, which always bites me in the arms, but I'll just deal with it. I was lucky enough to be working at a family wellbeing service that was joined with the medical clinic. So the practice nurse just, you know, she would check my stitches and things like that for me throughout the day just so I could be at work and do my dressing changes there. But yeah, being able to take leave to go to an appointment that I can't afford for the slight chance it might work, it's just not realistic for me.
Participant 018_2023AUHIS

Cost burden in relation to needing to special equipment

Yes it's expensive. So I mean look fortunately the the Humira is is affordable but the the bigger cost the bigger cost I I you know impacts things like clothing because that clothing gets ruined and impacts bedding and particularly like when when in the early stages more so just the the cost of dressings and finding the right dressings etcetera. Yeah it was was quite quite costly and quite huge on the condition and even now you know you go buy a dressing that fits in the air and you're paying you know 5 or $10.00 for one dressing. It's it's yeah. So it it, it, it does have an an impact financially. Participant 001_2023AUHIS

Across I would definitely say there's there's a few. So cost in terms of. Treatment is a big one, so seeing the specialists, I don't have health insurance, so I pay out of pocket to see a specialist, which is roughly $280 per session with this doctor. My medication costs $40 a month and you know I have to buy special bras which are very expensive like. Not very expensive, but you know, just constantly having to buy new ones as well that get a bit destroyed because I get puss and blood on them and they get a bit gross and I don't want to wear it so I have to buy new ones. Taking time off work is rare, like I won't normally take time off work for the disease. I just push through and go to work. Just trying to think, even like at home remedies. I'm always buying new creams, powders, things for the

bath, antibiotics, stuff like that. I haven't even know how much that would amount to. Over the past 10 years. I've had probably a lot, definitely in the thousands that I've spent on all these different things to try for it.
Participant 010_2023AUHIS

Cost burden in needing to special creams, ointments or complementary therapies

PARTICIPANT: I currently spend probably say that, like obviously across all of my illnesses, I probably spend close to about $250 a month on medications and I spend probably twice that on. Dressings which are not covered by the PBS and they're like $5 each
INTERVIEWER: Yes, yes, it adds up in the end, doesn't it? Your cost for the dressings.
PARTICIPANT: Dressings is probably my biggest cost
Participant 005_2023AUHIS

Overall, there was no cost burden

I don't do time of work. I don't. I forced myself to work all the time like I work full time. I'm even. I even today. I work 300 kilometres from my actual base job and I'm hopped in a car now. And I've just driven back after starting work 7:30 and jumped in the car just before I spoke to you at 6:00 tonight to do a three hour drive and I'll get up tomorrow morning and be at work early tomorrow morning. I have a very slight Dr. hard that I don't not have time off work because of my condition.
Participant 018_2023AUHIS

It hasn't been too bad because I haven't had that many treatments. Dermatologist appointments can be quite expensive, but it's it's manageable with me working at the moment. And the Humira injections that I'm about to start are very expensive, but they're on PBS them quite affordably.
Participant 019_2023AUHIS

Table 8.12: Cost considerations

Cost burden	All participants	
	n=20	%
Participant describes that overall, there was at least some cost burden	15	75.00
Participant describes that overall, there was no cost burden	3	15.00
No particular comment	2	10.00

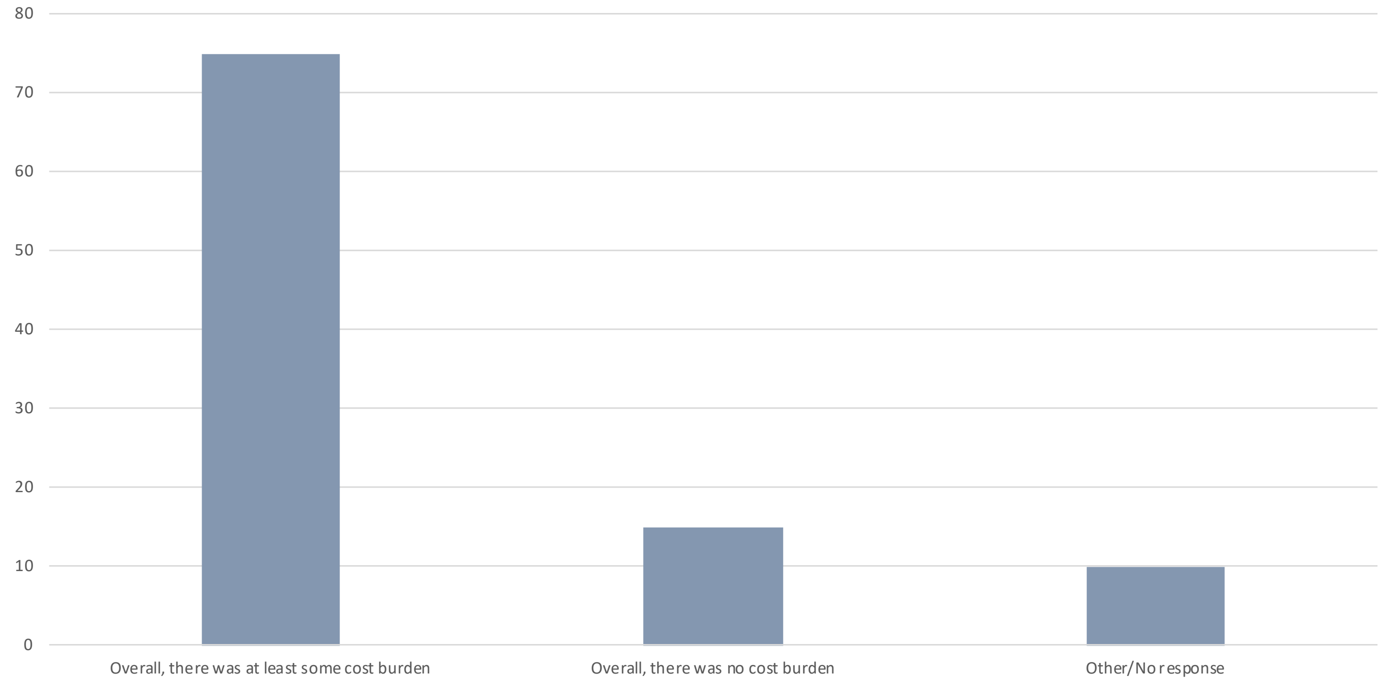


Figure 8.12: Cost considerations

Table 8.13: Cost considerations (Reasons for cost)

Cost considerations	All participants	
	n=20	%
Cost burden in relation to the cost specialist appointments	10	50.00
Cost burden in relation to needing to take time off work	5	25.00
Cost burden in needing to special creams, ointments or complementary therapies	3	15.00
Cost burden in relation to a family member needing to take time off work	2	10.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	1	5.00
Cost burden in relation to diagnostic tests and scans	1	5.00
No cost burden and that nearly everything was paid for through the public health system	2	10.00
Avoids treatment appointments that cost money	1	5.00
No cost: prioritises going to work	1	5.00
No cost burden as participant was able to afford all costs	1	5.00
No cost burden as no treatment or management	1	5.00

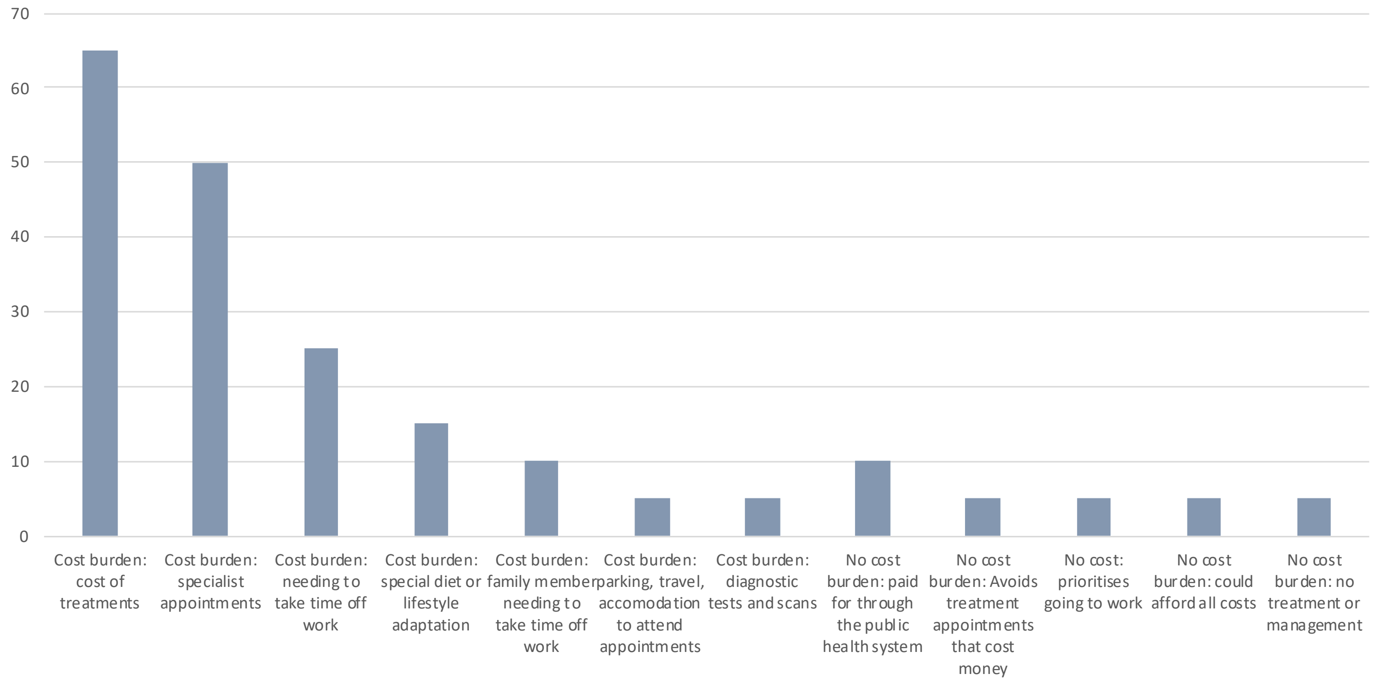


Figure 8.13: Cost considerations (Reasons for cost)

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10. Overall the entire cohort had a mean total score of 36.37 (SD = 9.94), which corresponds to moderate levels of anxiety (Table 8.30)

The overall scores for the cohort were in the second highest quintile for Fear of progression:Total score (mean=44.42, SD=8.69) indicating high levels of anxiety.

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated high levels of anxiety.

Table 8.14: Fear of progression summary statistics

Fear of progression (n=20)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	44.42	8.69	45.00	10.50	12 to 60	4

*Normal distribution use mean and SD as measure of central tendency

Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions: “Anxious if not experiencing any side effects think it doesn’t work” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Afraid of pain” (median=3.00, IQR=1.50), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=3.00, IQR=2.50), “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=3.37, SD=1.21), “Afraid of severe medical treatments during the course of illness” (median=3.00, IQR=1.50), “If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped” (median=3.00, IQR=2.00).

On average, participants scored in the “Often” range for the following questions:“Becomes anxious thinking that disease may progress” (median=4.00, IQR=2.00), “Is nervous prior to doctors appointments or periodic examinations” (median=4.00, IQR=2.00), “Has concerns about reaching professional and/or personal goals because of illness:” (median=4.00, IQR=2.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (median=4.00, IQR=1.00), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=4.00, IQR=2.00), “Worried that treatment could damage their body” (median=4.00, IQR=2.00), “Worried about what will become of family if something should happen to participant” (median=4.00, IQR=2.00).

On average, participants scored in the “Very often” range for the following questions: “The thought that they might not be able to work due to illness disturbs participant” (median=5.00, IQR=1.00).

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated high levels of anxiety.

Table 8.15: Fear of progression individual questions

Fear of progression (n=20)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	4.11	0.99	4.00	2.00	Often
Is nervous prior to doctors appointments or periodic examinations	3.53	1.17	4.00	2.00	Often
Afraid of pain	3.47	1.12	3.00	1.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	3.95	1.13	4.00	2.00	Often
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	3.21	1.44	3.00	2.50	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	3.58	1.07	4.00	1.00	Often
Is disturbed that they may have to rely on strangers for activities of daily living*	3.37	1.21	3.00	1.50	Sometimes
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.79	1.08	4.00	2.00	Often
Afraid of severe medical treatments during the course of illness	3.53	1.17	3.00	1.50	Sometimes
Worried that treatment could damage their body	3.95	1.08	4.00	2.00	Often
Worried about what will become of family if something should happen to participant	3.68	1.29	4.00	2.00	Often
The thought that they might not be able to work due to illness disturbs participant	4.26	1.05	5.00	1.00	Very often
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	3.37	1.50	3.00	2.00	Sometimes
Anxious if not experiencing any side effects think it doesn’t work	2.11	1.37	2.00	2.00	Seldom

*Normal distribution use mean and SD as measure of central tendency

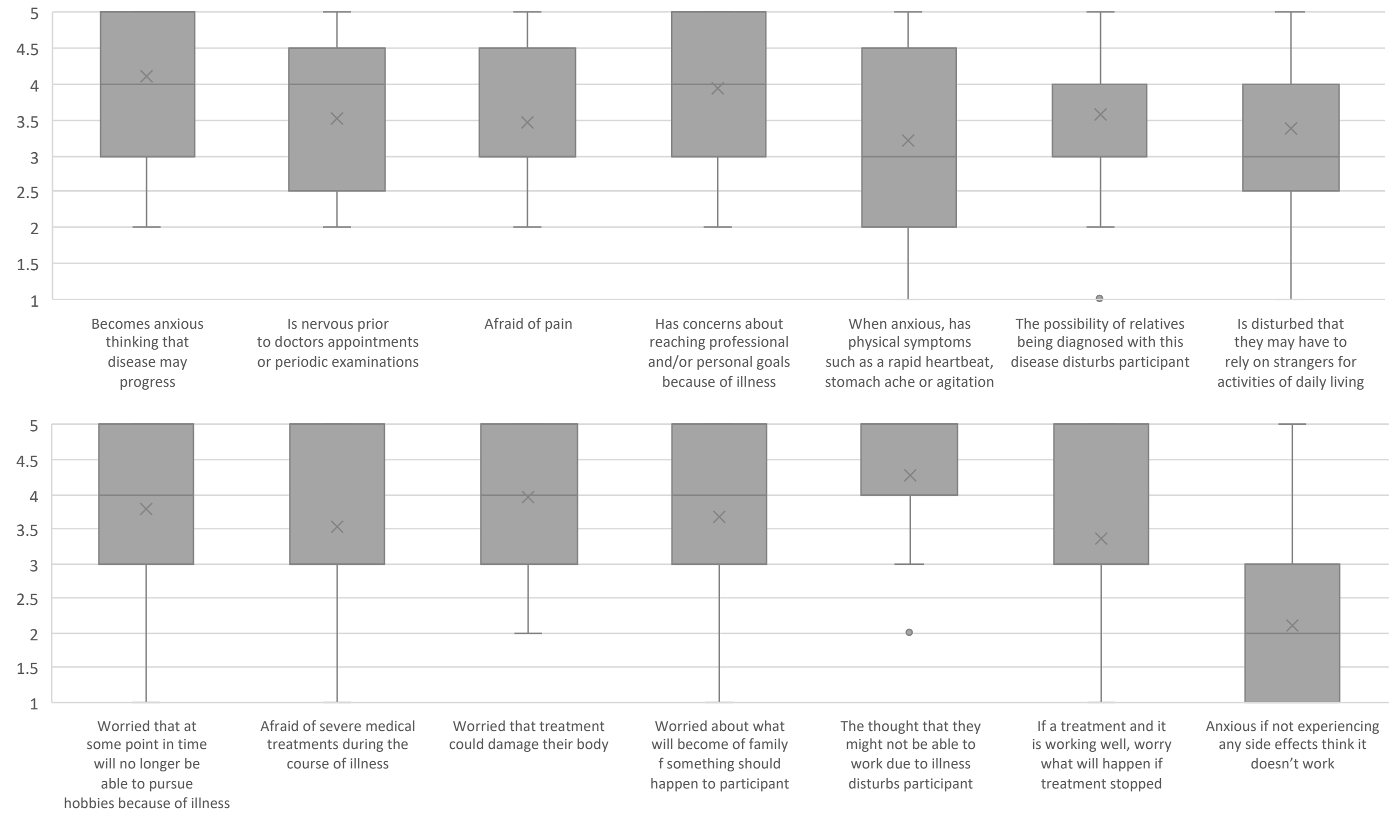


Figure 8.14: Fear of progression individual questions

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 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

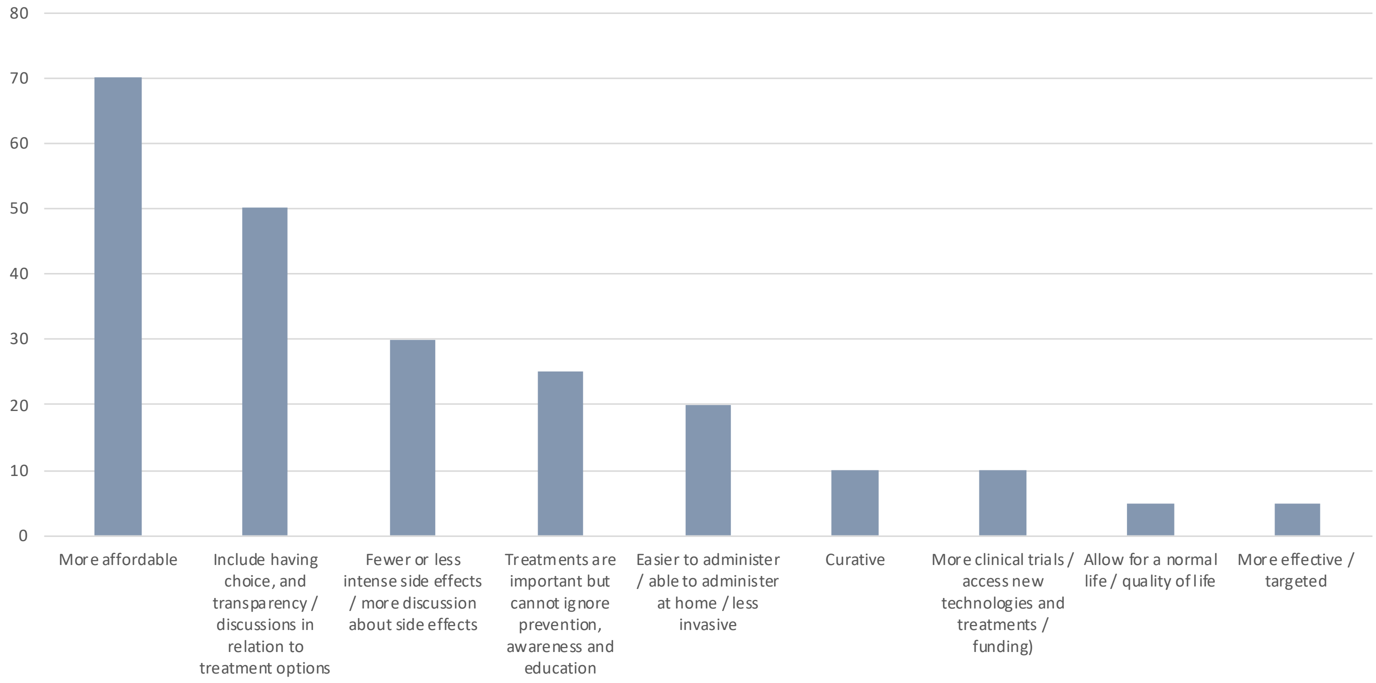


Figure 9.1: Expectations of future treatment

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

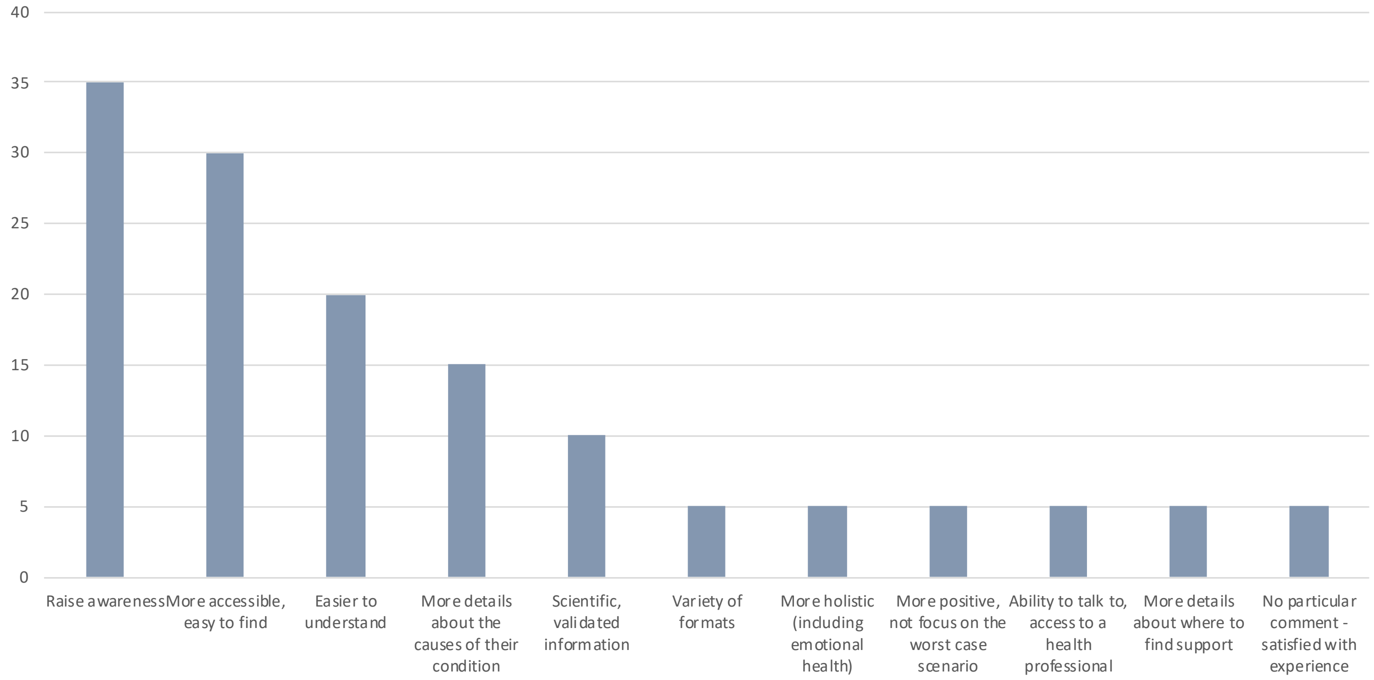


Figure 9.2: Expectations of future information

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

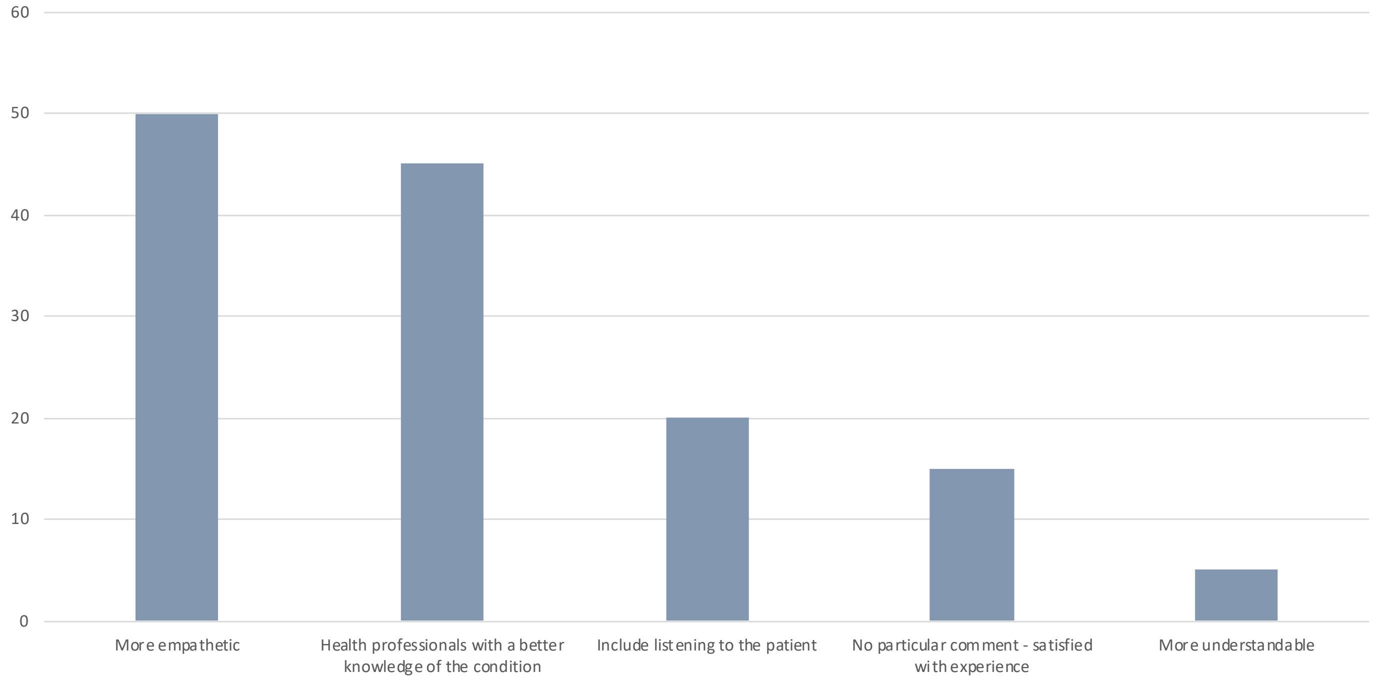


Figure 9.3: Expectations of future healthcare professional communication

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 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

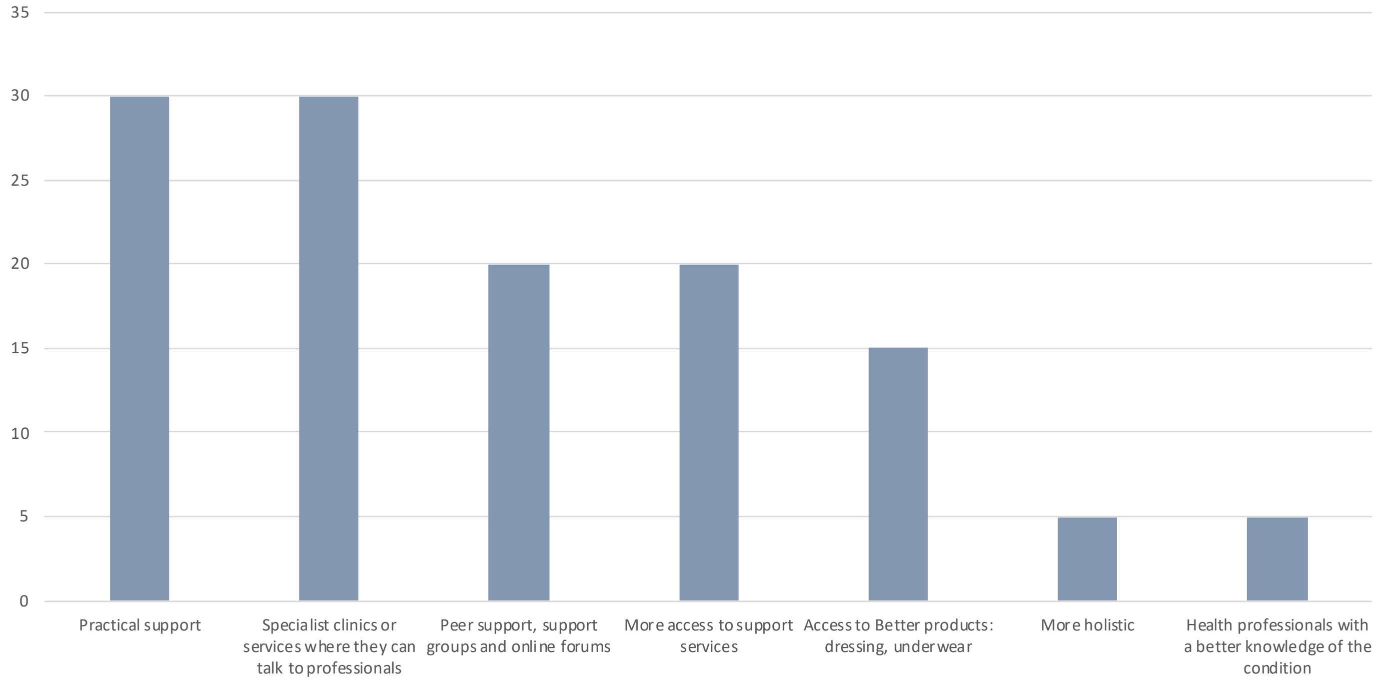


Figure 9.4: Expectations of future care and support

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 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

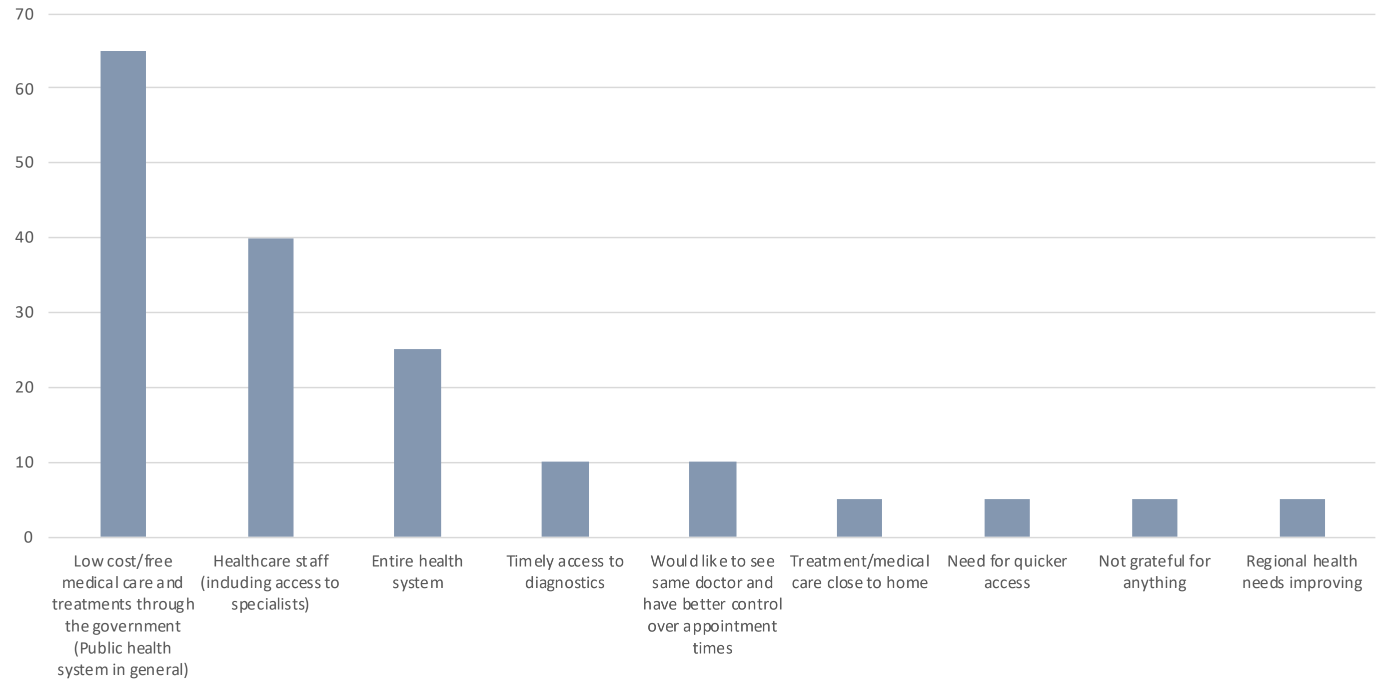


Figure 9.5: What participants are grateful for in the health system

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 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 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

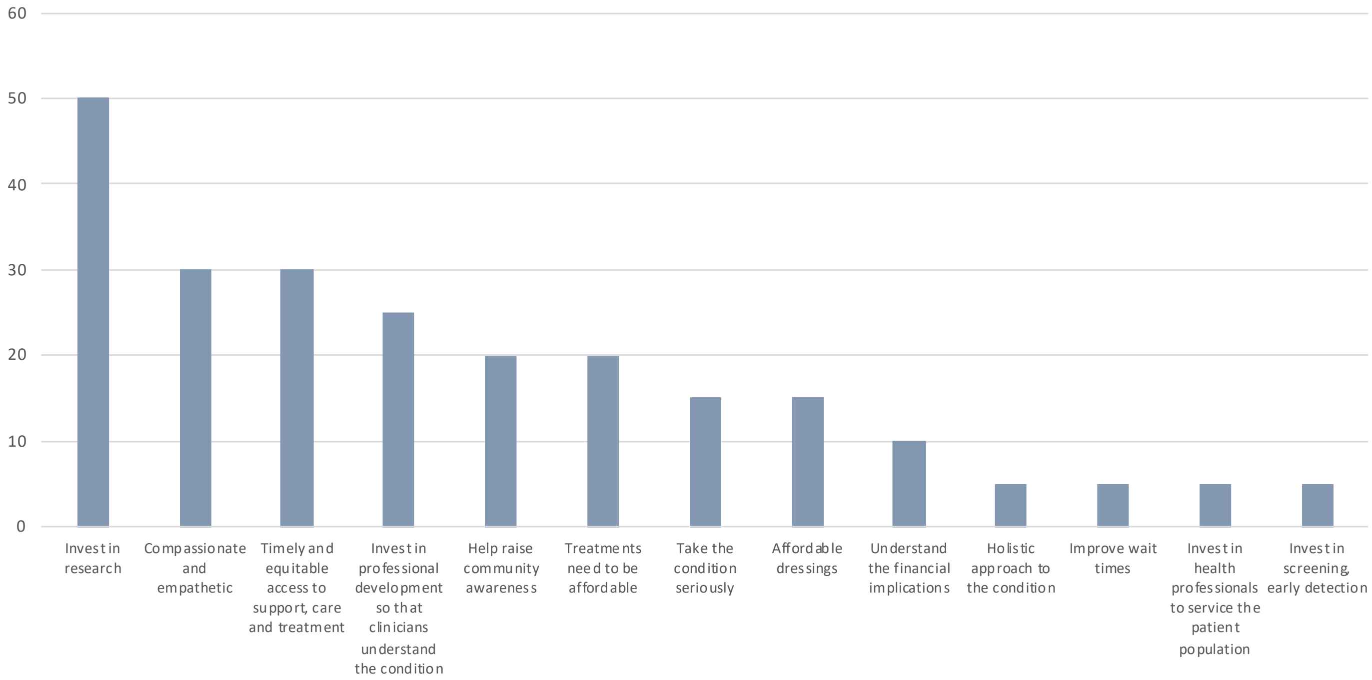


Figure 9.6: Messages to decision-makers

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (45.00%), and wished they had gotten a diagnosis sooner (25.00%). Other themes included to pace themselves or know triggers and limitations (20.00%), had no particular comment and were satisfied with experience (10.00%), and to understand the costs of treatment and management (5.00%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have liked to have had access to a specialist in their condition sooner (25.00%), and would have liked health care professionals to have had more knowledge and awareness of their condition (20.00%). Other themes included would have stopped or changed treatment sooner (10.00%), would have liked to have had a better understanding of their condition (10.00%), would not change any aspect of their care or treatment, with no reason given (5.00%), would have liked more time and personalised attention with healthcare professionals (5.00%), would have switched health professionals (5.00%), would like to change a lot or all of their treatment, without giving specific details (5.00%), would have changed a single negative experience (5.00%), and wanting treatment closer to where they live (5.00%).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and ask questions (45.00%), and wished they had gotten a diagnosis sooner (25.00%). Other themes included to pace themselves or know triggers and limitations (20.00%), had no particular comment and were satisfied with experience (10.00%), and to understand the costs of treatment and management (5.00%).

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

Yes, I wish that I had have known that the treatments had been developed. But nobody ever tells you anything because most people, most GPS, don't even know what the disease is. So. You go to the doctors or to the hospital. I mean, I can tell you I've been to the hospital on dozens of occasions throughout my life, and not one until until, like three years ago, not one of the doctors, surgeons or otherwise ever told me that there was actually commitment for the disease. It wasn't until this nurse told me about the HS clinic. And that nurse was from community health.
Participant 005_2023AUHIS

That's, that's a big question. Yeah, I wish that. Look, I I just think I I just wish I'd been given clearer information about what treatment options were. And you know and knowledge about what what supports were out there.
Participant 007_2023AUHIS

I wish I had a known that more about the disease process before making a decision to subject my son to surgery. When? Yeah, because he his wounds kept breaking down and then because it was in the groin like he has like a 22 11 centimetre scars that overlap each other in the groin and yeah they would. And also the scar tissue that is formed now, he's got flares and constant nodules underneath the scar and I. Yeah. If I had of known more about the disease process, I'm wondering, well, I don't know more. I'm just wondering the what if if he hadn't have done the surgery and we had to put him onto the Humira six weeks, six months earlier, would he, would he have these hard nodules underneath the scar? I don't know. So yes, I would would want to know about the disease process a bit more before making those types of decisions.
Participant 009_2023AUHIS

Participant wishes they had gotten a diagnosis sooner

I guess I wish I knew what it was sooner, yeah. Because, you know, being seven years old and having to deal with it on my own was not a fun time.
Participant 014_2023AUHIS

I wish I got this diagnosed earlier.
Participant 004_2023AUHIS

I just wish I'd been diagnosed earlier. I honestly think if I had been diagnosed with this when I had my first flare and then put on. The medication and the creams and had the area removed, I don't think that it would have progressed and I don't think I would have it anywhere else. I don't think I'll be sitting here talking to you today. I think because it took 15 years to diagnose and it was well rooted in my system and in my skin by that point that now it's a drama and nobody knows what they're doing and they're leaving bits and bobs when they cut it out and not getting it all and. It's just would have been a lot easier when it was just a little pee and yeah, if we'd all just known. But yeah, apparently there's no way to know until it gets this bad because it looks like a cyst. So I'm not blaming health professionals, but it'd be cool if there was a blood test or something. That you know, could just identify straight up and instead of going oh, that's a sebaceous cyst or an ingrown hair go we're going to test in case it's HS because not not wait till going Oh no, it mustn't be those things then and we've tried to treat it now it's HS. It's like no, try and find out if it's HS first, eliminate that and then go off on your sebaceous cyst journey. And because it's, it's, it's. Yeah, that's where this is. It's just the lack of care and just being on my own with it for nearly 20 years hasn't, you know, been good. It would have been good to know what was going on back then.
Participant 006_2023AUHIS

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

I think I've mentioned this before, but definitely like food eliminations because I didn't know when I was younger when I first had this disease, that certain things can make it worse. I also smoked when I was, you know, 16, 17, which is. Quite young, but I smoked cigarettes and I didn't realize that that was something that can aggravate the disease more, which I now do not smoke and I've seen improvement, slight improvement in the disease. So I guess just a bit more

information about how to help or keep the disease calm.
Participant 010_2023AUHIS

PARTICIPANT: Yeah. Had it done a lot earlier, yeah.
INTERVIEWER: And that would have changed the way that you made decisions.
PARTICIPANT: I I feel like, yeah, I feel like it would have helped me knowing a lot earlier as to, you know, what the causes are, how I can prevent them. And being at a younger age where I was probably a little bit more in control of my life and then control of my body. I mean, it's still something I can do. But, you know, I've got kids and family and money restrictions now, so yeah, yeah.
INTERVIEWER: And you waited 14 years.
PARTICIPANT: Yeah, that's right.
Participant 011_2023AUHIS

Table 10.1: Anything participants wish they had known earlier

Wish they had known earlier	All participants	
	n=20	%
Participant wishes they had known to be assertive, an advocate, informed, and ask questions	9	45.00
Participant wishes they had gotten a diagnosis sooner	5	25.00
Participant wishes they had known to pace themselves or know triggers and limitations	4	20.00
Participant had no particular comment and were satisfied with experience	2	10.00
Participant wishes they had understood the costs of treatment and management	1	5.00
No particular comment/No response	1	5.00

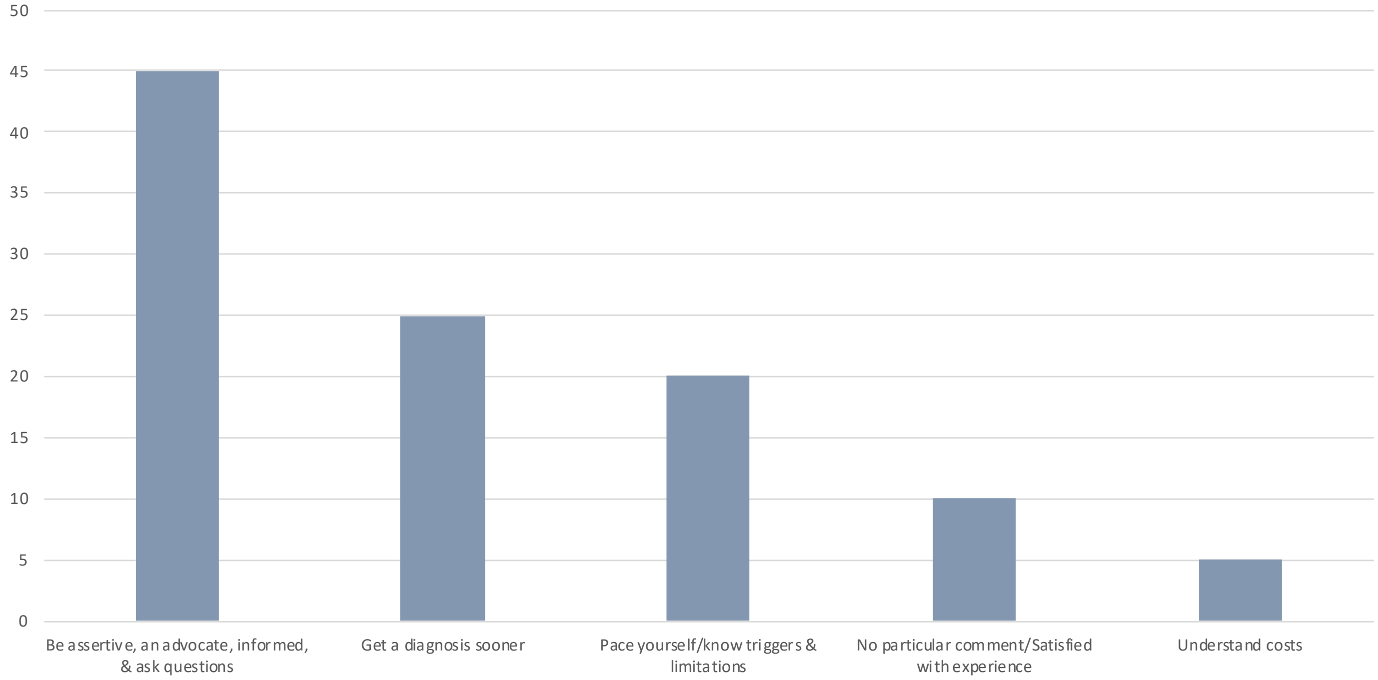


Figure 10.1: Anything participants wish they had known earlier

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would have liked to have had access to a specialist in their condition sooner (25.00%), and would have liked health care professionals to have had more knowledge and awareness of their condition (20.00%). Other themes included would have stopped or changed treatment sooner (10.00%), would have liked to have had a better understanding of their condition (10.00%), would not change any aspect of their care or treatment, with no reason given (5.00%), would have liked more time and personalised attention with healthcare professionals (5.00%), would have switched health professionals (5.00%), would like to change a lot or all of their treatment, without giving specific details (5.00%), would have changed a single negative experience (5.00%), and wanting treatment closer to where they live (5.00%).

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

I suppose, yeah. Again, just at that very first stage and seeking support. But you know, if I don't know what they're doing. That's OK. But then make a referral to someone who might, yeah, rather than minimizing the patient, yeah.
Participant 007_2023AUHIS

The only thing I would change is pushing to receive treatment a lot sooner, before it progressed to the stage that I'm at. But you know, when I was younger, I didn't have a choice. It was up to my parents to kind of. Look after me and and seek better help, but if I could go back I'd probably push harder to my parents to get me to seek.
Participant 010_2023AUHIS

No, I think just having, yeah, having access to being able to receive more accessible care and treatment and yeah, money wise and things like that. But otherwise, yeah, I think I also like as a personal level instead of leaving it to the point where I'm in excruciating pain and just dealing with it going, getting that support sooner and that helps sooner. Participant 011_2023AUHIS

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

So yeah, surgery plus imaging, ultrasound. MRI or whole body scans to uncover the damage under the skin, because we can talk about it, we can say what's happening and until you have a picture which demonstrates what your skin is doing to you. There's always kind of these doctors who get down on you and think nothing. This is a serious disease and I'm glad you CCDR is taking it seriously.
Participant 008_2023AUHIS

Treatment. There needs to be a lot more research into it. It's not extremely rare and common condition. Now it needs more. More people need to look into it. The care I received, I can tell my 2 current providers the care I received. It could have been a lot better. It left a lot to be desired and that comes down to a lack of information available to medical practice to medical professionals on the condition. I've had to still go to the hospital tomorrow and I've been to the hospital multiple times for this condition and people still ask me, oh what's HS? It just needs more awareness.
Participant 012_2023AUHIS

Well, in the beginning probably not because that that stage it was just antibiotics and where Accutane came out, there wasn't clinical trials. It's only the last, I I believe 10 years that clinical trials have come out and my condition has been quite dormant. So clinical trials are not an option for me, but I think better education and the specialists need to get these. Offer these trials to people.
Participant 013_2023AUHIS

Table 10.2: Aspect of care or treatment they would change

Anything they would change about treatment or care	All participants	
	n=20	%
Participant would have liked to have access to a specialist in their condition, sooner	5	25.00
Participant would have liked health care professionals to have had more knowledge and awareness of their condition	4	20.00
Participant would have stopped or changed treatment sooner	2	10.00
Participant would have liked to have had a better understanding of their condition	2	10.00
Participant would not change any aspect of their care or treatment, with no reason given	1	5.00
Participant would have liked more time and personalised attention with healthcare professionals	1	5.00
Participant would have switched health professionals	1	5.00
Participant would like to change a lot or all of their treatment, without giving specific details	1	5.00
Participant describes a single negative experience that they woud have changed	1	5.00
Participant describes wanting treatment closer to where they live	1	5.00
Other\No response	4	20.00

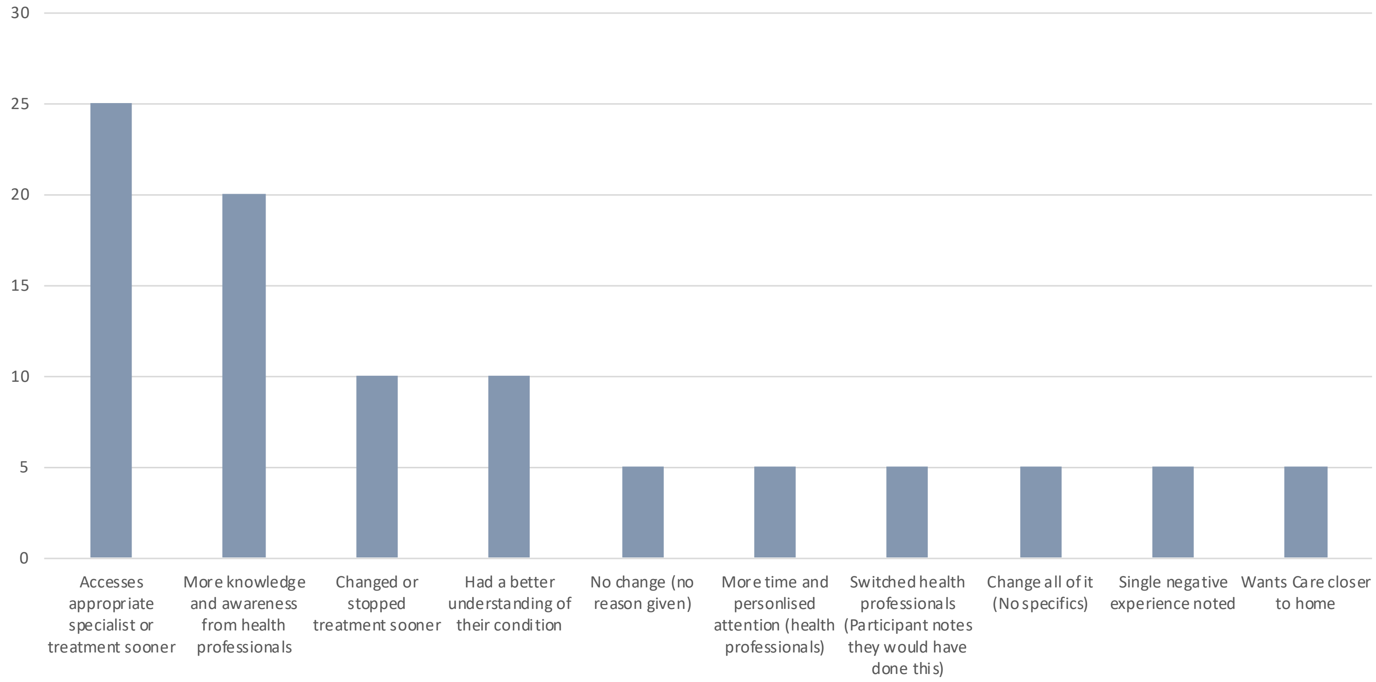


Figure 10.2: Aspect of care or treatment they would change