

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

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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%).

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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	n=20	All participants %
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

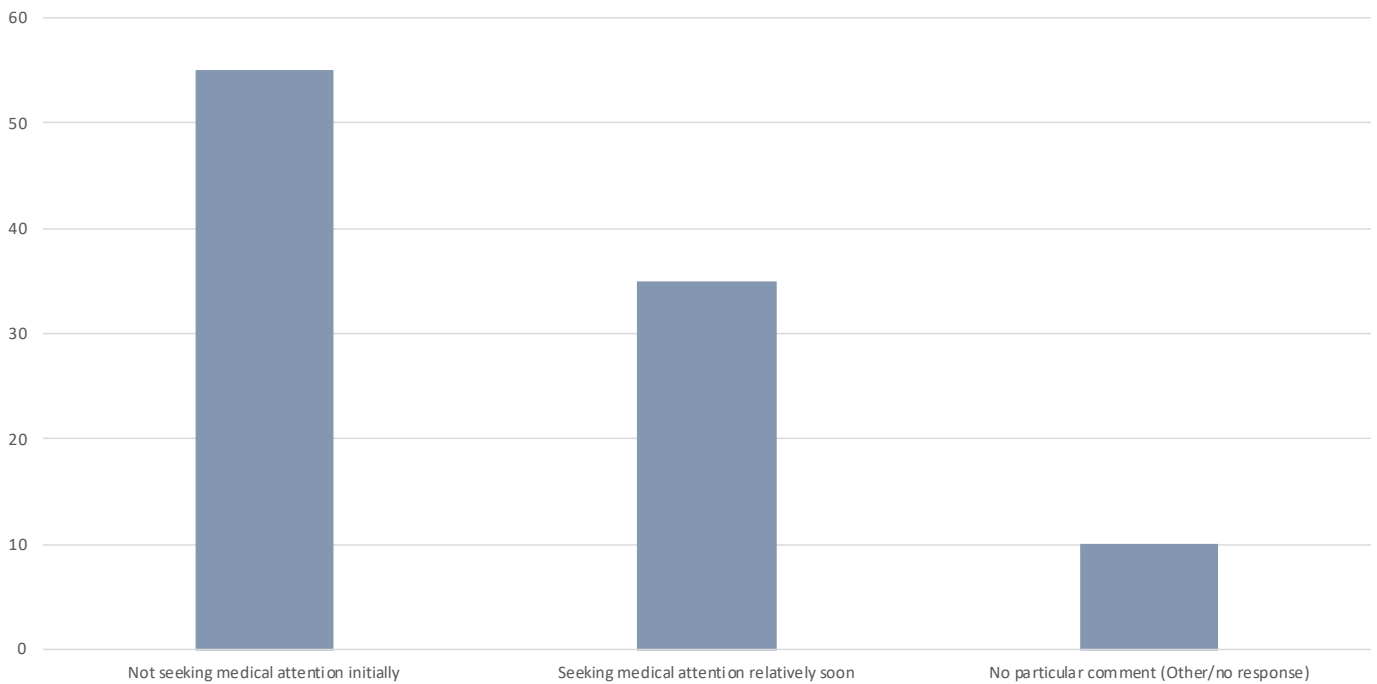


Figure 3.1: Symptom recall

Table 3.2: Symptoms leading to diagnosis

Symptoms leading to diagnosis	n=20	All participants %
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

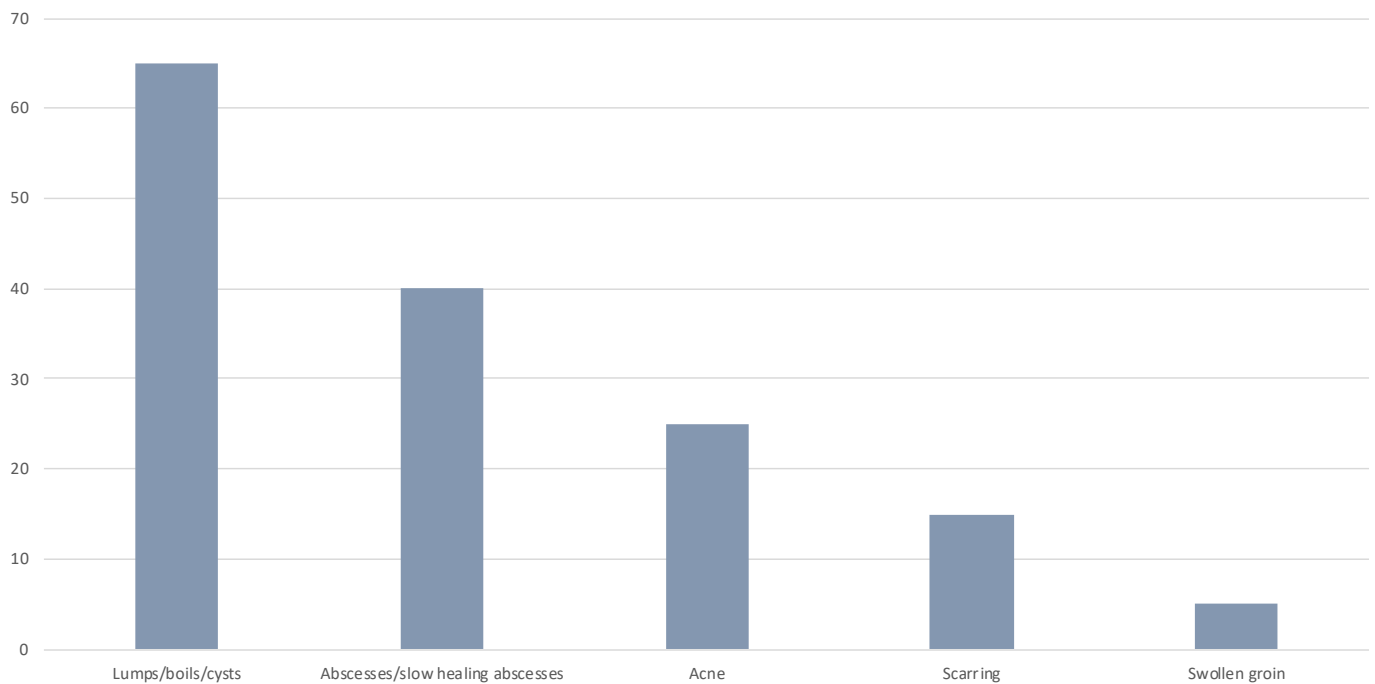


Figure 3.2: Symptoms leading to diagnosis

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

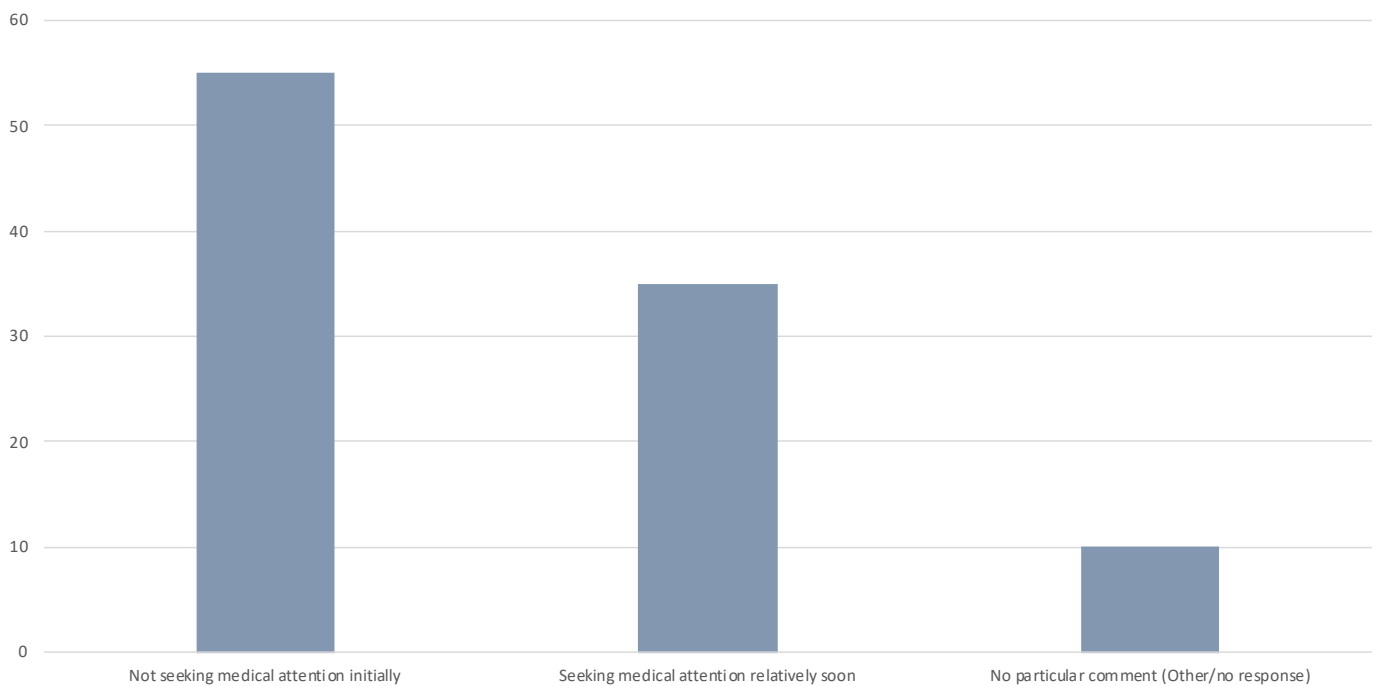


Figure 3.3: Seeking medical attention

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 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 describes being diagnosed by their general practitioner during a routine check-up that was not related to symptoms	1	5
No particular comment	3	15

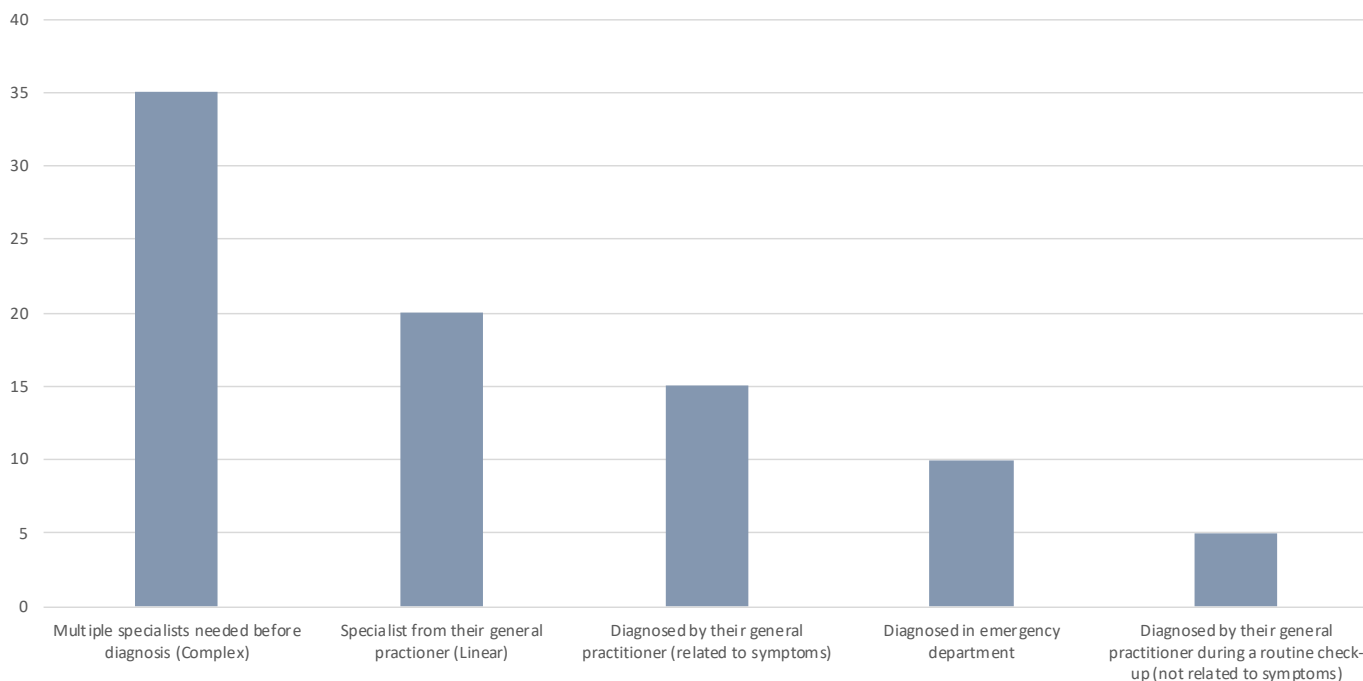


Figure 3.4: Diagnostic pathway

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 diagnostic 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 diagnostic 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

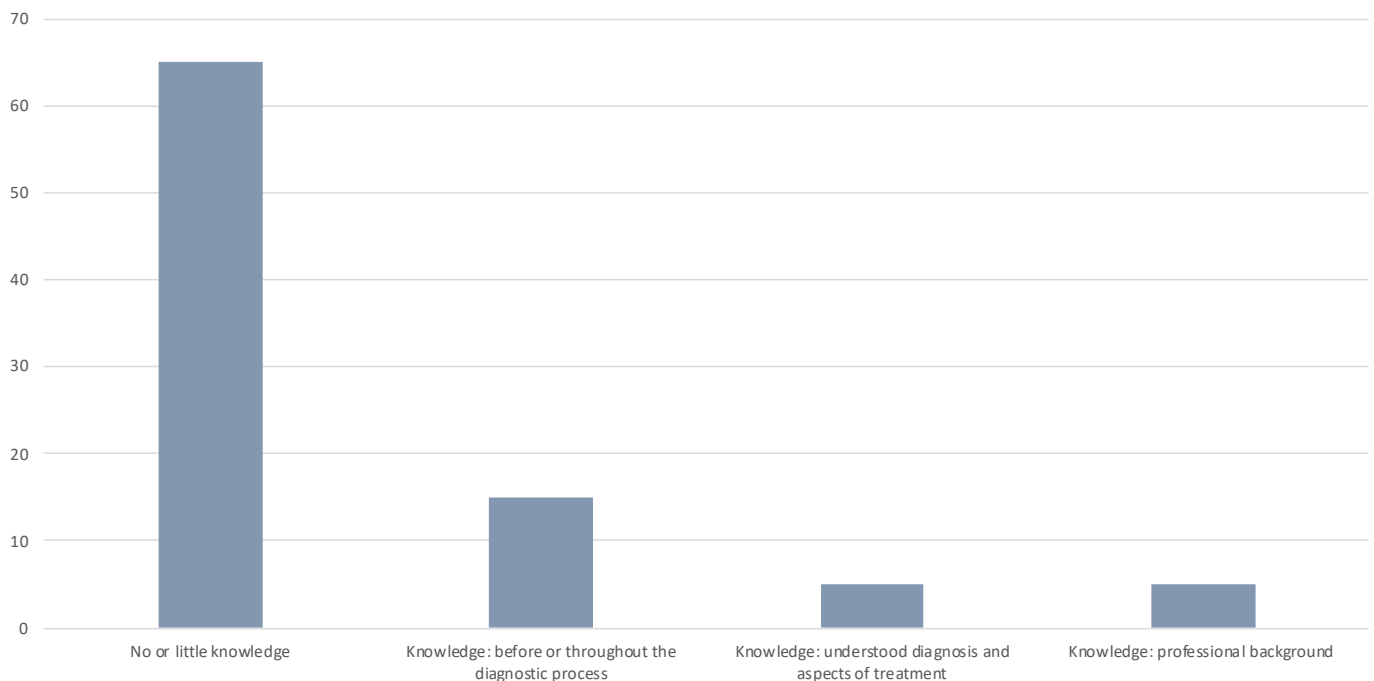


Figure 3.5 Understanding of disease at diagnosis

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 if 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 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 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

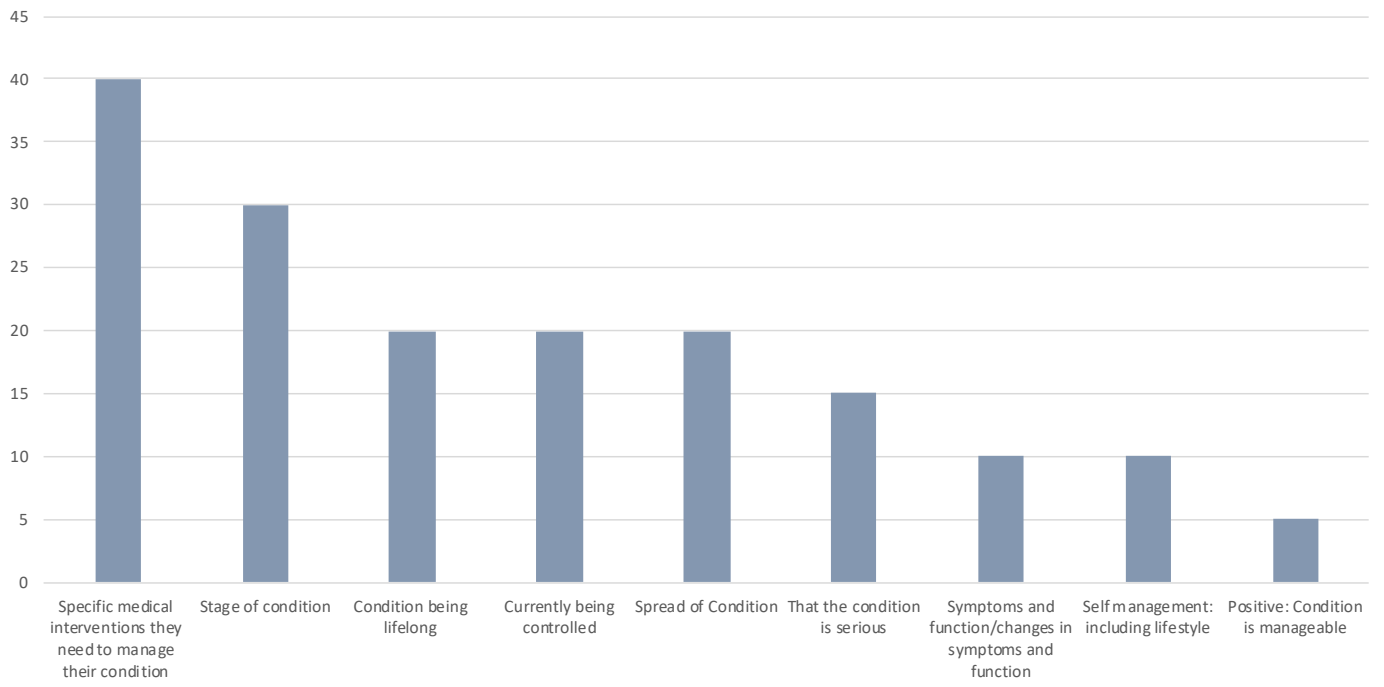


Figure 3.6: Understanding of prognosis