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# A qualitative interview study exploring patients' views and experiences of treatment for hidradenitis suppurativa in the UK

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## Abstract

**Background** Hidradenitis suppurativa (HS) is a long-term skin condition where evidence for management after first-line treatment fails is limited and practice varies across the UK. Medical and surgical treatment options are potential avenues of treatment. Furthermore, patient perspectives on HS treatments have received little attention in research to date.

**Objectives** To explore patients' views and experiences of treatment for HS to inform clinical care.

**Methods** We conducted a nested qualitative study within a prospective cohort study. Interviews with 35 participants were completed by telephone. Purposive sampling was undertaken. Framework analysis was used to develop themes.

**Results** Past experiences and knowledge informed patient beliefs and whether an individual felt a treatment option was appropriate or a good 'fit' for them at a specific moment in time. Healthcare professional recommendations can influence a patient's views and which treatment option they ultimately receive. Positive experiences were reported across all treatment types covered in the study. Negative experiences included mediation side-effects, lack of efficacy, delays to procedures and burden of wound care. However, even when personal experiences were not wholly positive for an individual, participants often believed the same treatment may potentially help others with HS, owing to the importance placed on personalization of treatment.

**Conclusions** This paper has implications for how healthcare professionals discuss treatment options with people with HS. A 'one-size-fits-all' approach is inappropriate, and shared decision-making that elicits patients' beliefs and preferences is crucial.

### Lay summary

Hidradenitis suppurativa ('HS' for short) is a long-term skin condition. It causes boils on the skin and can lead to scarring. There is mixed evidence on how common HS is, but it may affect about 1 to 4 people in every 100.

We are a research team based in the UK. The aim of our study was to help us understand the views and experiences of patients who have had treatment for HS. By finding out this information we may be able to improve patient care. We used in-depth information from a study called 'THESEUS'. THESEUS was a large study that invited people with HS to choose between five different treatment options. We interviewed 35 people who took part in THESEUS to help design future clinical trials in HS. There were important findings from these interviews that could improve patient care, which we discuss in this article.

We found that choosing treatment was an individual choice. A person's choice was often influenced by which treatments they had tried before and their experiences of them. People also saw themselves on a 'treatment pathway'. Clinician views could impact on people's views and choices about treatments. Some side effects and challenges with the treatments were reported. People were nervous about laser (a new treatment) beforehand, but often found it was not as painful as they had anticipated.

Overall, these findings suggest that treatment decisions for HS need to be discussed with patients to consider their previous experiences, beliefs and preferences.

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**What is already known about this topic?**

- Hidradenitis suppurativa (HS) is a chronic skin condition that can be treated medically or surgically, but treatment options in the UK have limited evidence.
- Little is known about patient views and experiences of HS treatments.

**What does this study add?**

- This study provides insight into patient views and experiences of medical and surgical treatments for HS, including doxycycline, clindamycin and rifamycin, laser treatment, deroofing and conventional surgery.

**What are the clinical implications of this work?**

- At the microlevel, this study has implications for how patient preferences should be elicited during decision-making conversations, and emphasizes the need for personalized therapy.
- At the macrolevel, this study suggests research to explore the inclusion of laser and deroofing as treatments is welcomed by patients.
- Guidelines may also need to be flexible to personalized therapy to meet individual needs.

Hidradenitis suppurativa (HS) is a chronic condition characterized by abscesses that typically occur around flexures.[1] Its prevalence is estimated to be 0.05–4.1%.[2] HS usually develops in young adulthood, but diagnostic delays are estimated at 7.2 years, so appropriate treatment is not always initiated at onset.[2,3]

Treatment options for HS include health behaviour modifications (e.g. stopping smoking and weight loss), pharmacological treatments (e.g. oral antibiotics) and surgery (e.g. to remove scarring).[4] HS management in UK healthcare settings is variable and research to provide evidence of which treatment options to use when first-line treatment fails is a priority.[4,5]

To ensure patient-centred care, it is important that patient's perspectives are considered in the design of healthcare and research. The James Lind Alliance Priority Setting Partnership, which saw patients with HS, carers and clinicians work together to prioritize HS research, identified that a high-priority question for HS research was: 'What is the impact of hidradenitis suppurativa and the treatments on people with hidradenitis suppurativa (physical, psychological, financial, social, quality of life)?'[6]

A systematic review of the qualitative literature included studies that primarily explored the physical, psychological and social impacts of HS on individuals.[7] There were relatively few studies on patient views of healthcare and treatment. Our study aimed to explore patients' views and experiences of treatment for HS in a UK context.

## Patients and methods

### Study design

This was an interview study nested within a prospective cohort study. It was driven by the need for recommendations for future research into treatments for HS. Research findings with a focus on improving the design of future clinical trials were included in full in the THESEUS Health Technology Assessment funding report and are published elsewhere.[8] This article uses the same study data but distils key findings that offer pertinent insight to inform clinical practice.

THESEUS was a prospective cohort study that aimed to understand how HS treatments are currently used in the UK and to inform the design of future clinical trials for HS treatments.[9] Participants expressed their preference between medical and surgical options: (i) oral doxycycline 200 mg once daily; (ii) oral clindamycin and rifampicin, both 300 mg twice daily for 10 weeks initially; (iii) laser treatment aimed at reducing hair growth (e.g. Nd-YAG or alexandrite); (iv) deroofing; and (v) conventional surgery with procedure and closure methods as per the treating surgeon's usual practice. The THESEUS study was designed to mimic UK guidelines, with the exception that deroofing and laser are treatments for HS that are not used routinely in the UK.[10,11] Deroofing is a surgical procedure to open and hyfrecate skin tunnels without formally excising them.[12] Laser treatment aims to ablate the hair follicle.[10]

### Participant selection

Characteristics of the THESEUS participants who consented to be approached for an interview were reviewed. Purposive sampling aimed to recruit a diverse set of participants in terms of demographics and treatment experience (Table 1).

### Procedure

Audio-recorded telephone interviews were conducted used a semi-structured topic guide covering (i) treatment experiences prior to the study, (ii) treatment experiences during the study and (iii) experiences of taking part in the research study (Appendix S1; see Supporting Information). Debriefing

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**Table 1** Sampling framework

| Sampling characteristic | Sampling aim |
|---|---|
| Treatment arm | 20% doxycycline<br>20% clindamycin + rifamycin<br>20% laser<br>20% deroofing<br>20% conventional surgery<br>From at least 3 recruitment sites for each treatment arm |
| Age[a] | 60% aged < 40 years<br>40% aged ≥ 40 years |
| Sex[a] | 30% male<br>70% female |
| Ethnicity[a] | 75% White<br>25% other ethnic groups |
| Site | As many sites included in the THESEUS cohort study as possible |

[a] Age, sex and ethnicity distributions were chosen to reflect demographics of the population with hidradenitis suppurativa.[2,22]

at the end of the interview included signposting for medical advice and support. A trained and experienced qualitative researcher (L.H.), with no previous involvement with participants, conducted the interviews, with supervision and regular debriefing with P.L. Findings were discussed with the multidisciplinary research team, which informed subsequent interview enquiry. Participants were encouraged to share both positive and negative experiences of the study.

### Analysis

Interviews were transcribed verbatim and managed in NVivo 12 (https://lumivero.com/resources/whats-new-in-nvivo-12/). A prespecified thematic framework was used to code data (L.H.), with refinement to capture new, pertinent ideas, as per the framework analysis method.[13] A sample was reviewed by a second author (P.L.) and refinements were discussed. The interviewer used the framework to understand and interpret the data and develop themes. Different matrices for each treatment type were produced so we could compare and contrast views and experiences between treatment types. Themes were discussed regularly between L.H. and P.L., and a wider group of authors then reviewed the findings from different methodological, clinical and patient perspectives (K.S.T., J.R.I., A.G. and C.H.). In this paper, a refined subset of themes relevant to clinical practice are presented, but see themes developed for research recommendations elsewhere.[8]

### Sample size

Sample size was initially estimated at 50 participants (allowing for 10 interviews per treatment selected by participants), but data collection from 35 participants was deemed sufficient to answer research questions earlier than anticipated due to reaching saturation (defined as no new major themes identified).

### Framework analysis to develop themes

Framework matrices used to code the data are provided in Appendix S2 (see Supporting Information). A process of charting and mapping the data led to the development of interpretive themes. Sixty-seven codes were ordered hierarchically into three levels (codes, subcodes and further subcodes). Two final themes with their relevance for practice are reported here: ‘Views on treatments’ and ‘Experiences of treatments’.

## Results

### Demographic and clinical characteristics

Thirty-five interviews with people aged 19–67 years were conducted between December 2020 and October 2021. Sixty-nine per cent ($n=24/35$) of the sample were < 40 years old. The majority were women ($n=25/35$; 71%). Self-reported ethnicity was grouped as White ($n=23/35$; 66%), Asian ($n=5/35$; 14%), Black ($n=4/35$, 11%), mixed ($n=2/35$; 6%) and not declared ($n=1/35$; 3%).

Treatment options selected were doxycycline ($n=6$), clindamycin and rifampicin ($n=7$), laser ($n=9$), deroofing ($n=7$) and conventional surgery ($n=6$). At the time of interview, not all participants had received their treatment option (laser, $n=2$; deroofing $n=1$; conventional surgery, $n=4$). Treatment schedules were affected by the demands of the COVID-19 pandemic on the National Health Service (NHS). Participants were from eight different study sites across the UK. Some were dermatology-led and some were surgery-led sites.

### Theme 1: Views on treatments

Treatment beliefs could be categorized into beliefs about the necessity, concern, effectiveness or individual fit of the treatment, as illustrated by the quotes in Table 2. There was often a trade-off between needing to address symptoms and concerns about a treatment or beliefs that the treatment might not work. Individuals often gave reasons why their HS might require different treatment to others with HS, emphasizing a belief in the variable and individual nature of the condition.

#### *Doxycycline*

Doxycycline was typically preferred when individuals had limited experiences with HS (e.g. had not had previous treatments for HS). It was described as a ‘starting point’ and less invasive than surgical options, mirroring the UK clinical guidelines for HS treatment. Sometimes, there had been experiences with other treatment options, but it was not perceived as the correct time for them to have surgery (e.g. still healing or not required for symptoms).

> ‘So, start you on that one first and obviously when I go back […] I will say, not that one, so then we will look at the other options.’ (P25, male, White British)

#### *Clindamycin and rifamycin*

Some people had a strong preference to try this option due to unsatisfactory experiences of taking other medications, such as doxycycline. Some were concerned about using medication (or taking more medication), particularly in the long term, but it was considered a necessary trade-off to

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**Table 2** Participants' (P) treatment beliefs

| Belief categories | Medications | Procedures |
|---|---|---|
| Necessity | 'It's like saying if you had cancer treatment would you take the treatment. It's one of those I'll say, it's a no brainer for me I want to be better' (P15, female, White British) | 'Obviously, surgery is quite [a] drastic decision to make and it's not a decision I'd want to make if I felt it wasn't completely necessary' (P7, female, White British) |
| Concern | 'Yes, so antibiotics for a long time are not good. Like I think they are not good because the immune system goes low and then like side-effects and stuff' (P28, female, Asian/Asian British) | 'I don't like surgery, I am not good with hospitals and surgery and pain and being alone in hospital and everything; I am not good with those things' (P28, female, Asian/Asian British)<br>'Some people have had 10, 8 surgeries, I don't want to be in that position' (P13, female, Black/African/Caribbean/Black British) |
| Effectiveness | 'So all I've had is the antibiotics, I haven't tried any proper treatments' (P6, female, White British) | 'Yes, like really getting rid of it, yes, so like going really deep and getting rid of it' (P27, female, White British) |
| Individual fit | 'It could react different for someone else and it could work for them and it just may not work for me' (P22, female, White British) | 'I know everybody is different, my HS seems very much linked in with hair follicles and obviously I know people get it for different reasons. […] I think because I know all of the surgical options, it's a load of hassle and for how often they spring up in different locations, it wouldn't be practical for me I don't think' (P30, female, White British) |

stop symptoms. Reasons it was chosen over procedural options were that it was less invasive, a lack of familiarity with other treatment options, concerns about what other options would entail or other options (e.g. laser and deroofing) not being available at their site.

> 'I think there was another antibiotic, just the one tablet, but she said the success rate wasn't as high as the one I am on. And I think the other one was laser and operation and the laser option is not available in my area just now. And the operation is kind of the last kind of step to take if the drugs don't work or the laser doesn't work. So it was a choice between this set of antibiotics or the other one, and I chose this because they have got a higher percentage of success rate.' (P31, male, Black/African/Caribbean/Black British)

### *Laser*

Individuals reported lack of satisfaction with other treatment options they had tried. Medications had not worked well enough, were concerning regarding long-term effects or caused side-effects they could not tolerate. One person ruled out antibiotics as she planned to become pregnant. Individuals reported wanting to avoid surgery if it had not succeeded previously. Some viewed it as a more invasive option.

Laser was perceived as preventive, with hair removal potentially preventing future lesions, and favoured as a solution that was addressing the 'cause' of their HS. It was also known to some that laser was 'new' to the NHS, and so it had the added attraction of being a new treatment that was previously unavailable for HS in the UK.

> 'And the laser had just become available on the NHS for this, because obviously it is an infection of the hair follicle, so if can stop the hair follicle from growing, it's hoping we can stop the boils. That's why he is going for the main bits where they are really, really bad at the moment.' (P27, female, White British)

### *Deroofing*

There were concerns about deroofing, and surgery more generally, but it was considered a necessary 'last resort'. Reasons were that medication did not work effectively, caused unwanted side-effects and concerns about long-term use. One-person preferred deroofing over laser due to previous facial laser hair removal resulting in 'bumps' in their skin.

> 'I mean, I am kind of limited because I have never really tried. I tried one of them, I know it's some sort of cycline on the list, but it doesn't work for me and for me laser is a no-no.' (P29, female, ethnicity not reported)

### *Conventional surgery*

Some had previous experiences of conventional surgery, felt that it worked for them and understood the process, persisting with this option. It was often chosen because other options were not considered appropriate. Reasons given for choosing conventional surgery over deroofing were that deroofing was only appropriate for HS that appears in the same place each time, seemed to be deeper so they felt may be riskier, the video was scary and they did not like the idea of being awake for the procedure.

> 'I Googled that video and that was horrendous. […] This person was awake on the surgery bed, admittedly probably had anaesthetic, like local anaesthetic, so that's why they were awake. There was the smell of burning skin when you're awake; how can anybody go through that. I said to the plastic surgeon, "Please do not ever advise for me to have deroofing, I really don't think I could do that unless I was asleep".' (P21, female, White British)

### *How treatment decisions were made*

Individuals' past experiences and knowledge, sometimes informed by healthcare interactions, shaped their views and beliefs. Figure 1 shows how the views on different

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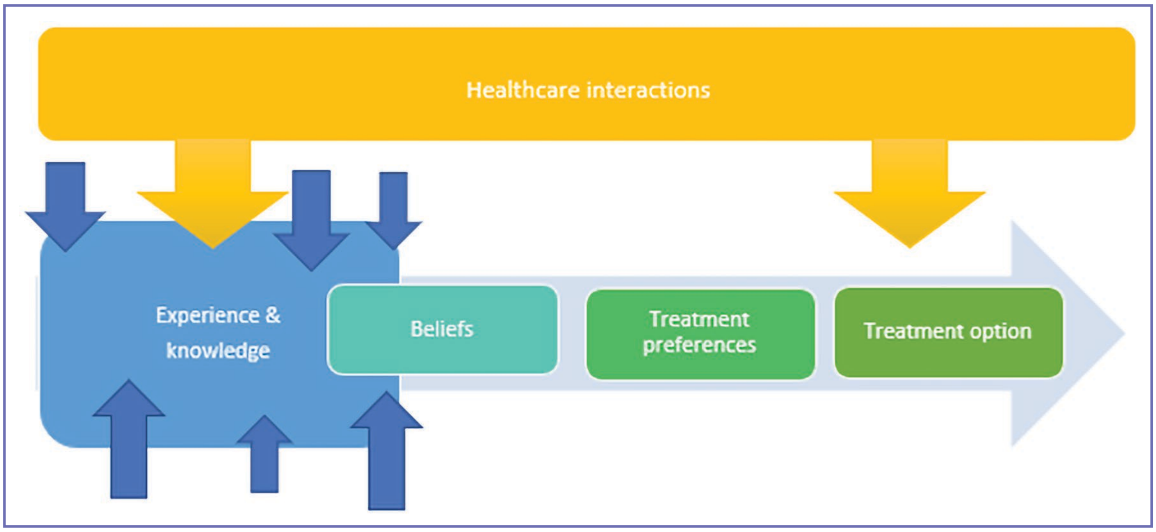

**Figure 1** Model of how treatment decisions were made in clinic. Copyright ©2023 Ingram et al.[8]

treatments, illustrated by upward and downward arrows, created a push-and-pull effect that led to individuals preferring certain treatments over others. Preferences sometimes matched the final treatment chosen within the study, but the final treatment choice was sometimes driven by healthcare professionals' (HCPs) recommendations instead.

HCPs could have an influential position, with some patients reporting that they went along with what the HCP thought was the best option for them.

> 'I saw that the laser sounds good, I don't know why I thought that. Then after speaking to the consultant they sort of said, "Well it's not the best option because it just removes the hair follicles, it doesn't remove the HS itself." They said that deroofing would be a better option, so I said, "Okay, I'll go for deroofing".' (P18, male, White British)

However, others felt that they were left to make the final decision. Some patients felt this was too much responsibility or a particularly hard decision for them and had hoped for more HCP guidance.

> 'I might have, if this hadn't been an alternative, if she'd said, "Oh, you have to go to laser surgery, you have to", I would have done that. I think I'm going to go with my doctor, I'm no specialist in this field. I just have the disease.' (P15, female, White British)

## Theme 2: Experiences of treatments

There were examples of positive treatment experiences across all treatment options, but some issues were reported. Just like past treatment experiences, treatment experiences within the study could influence whether an individual would consider using that same option in the future. However, owing to the common belief that HS treatments are down to individual fit and appropriateness, the treatment was often still considered acceptable for people with HS when expressing their views on whether it should be a management option made available for other people with HS or not.

> 'I think that's a hard question because I don't really know if it's going to work yet and if it'll work for other people. If it's suitable to their situation perhaps yes. I've only been taking it for a short time.' (P15, female, White British)

### *Medications*

Developing a new habit of regularly taking tablets and unpleasant side-effects (e.g. upset stomach or diarrhoea) were the main challenges reported with antibiotics. Some continued to use the antibiotics despite side-effects and often noticed that they improved with time, whereas others stopped using them, often on being advised by their doctor to do so. Side-effects affected people's work or were considered only manageable as they were working from home.

> 'I struggled at first. It was like you've got to take two of this tablet, one of this tablet and then another one of them tablets and two of them tablets and it's a lot to try and remember every day and then the side-effects of the two different tablets in your body threw me for six.' (P6, female, White British)

Many people experienced an improvement in their HS while taking antibiotics, although for some this was not maintained once stopping treatment. Others did not feel there was a noticeable difference in their HS. For some people a review was planned for after the course had ended, but others did not feel they had a clear understanding of what follow-up they would receive after the course of antibiotics.

### *Laser*

There were challenges with delays. The COVID-19 pandemic was often recognized as a contributing factor to these delays, but it could still be frustrating. Ahead of procedures, people reported feeling nervous about pain and having concerns about whether it would work. Some were also

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concerned about pigmentation due to having darker skin or it being on a noticeable part of their body.

> 'Oh I was constantly anxious. Is it going to hurt? Is it going to work? Like, what's the lady going to be like doing it? It was all just loads of stuff. I got really, really bad anxiety and it was just a mixture of everything.' (P27, female, White British)

People mostly found that after their experience their concerns had not occurred, and healing occurred in little-to-no time.

> 'No, I thought I might be a bit red and stuff, but there was none of that. It wasn't painful afterwards I was still, like, able to do normal things as well; I haven't had any issues there. No, it's been fine since. [...] But I mean it hasn't really, in terms of the actual pigmentation, like I haven't noticed it on my skin. So, yes, that's okay for me now.' (P26, female, Asian/Asian British)

Some noticed drastic changes in their HS after the first or second treatment. There were concerns that four sets of treatments would not be enough to get rid of all the hair in the area and that future treatments would be required, but that this would not be available on the NHS.

> 'After the first two treatments, as weird as it sounds, I felt a hell of a lot more comfortable from where the old then scar tissue and that was, where it used to flare up the worst. Yeah, it seemed to calm it down, even my wife at the time said the area seemed a lot less angry and red than what it was so, since the laser treatment it's worked wonders, personally.' (P34, male, White British)

### *Deroofing and surgery*

The main challenges reported were delays in procedures and healing issues. Ahead of procedures, people reported feeling nervous about pain during the procedure and concern about wound healing after the procedure. We had limited data on the experiences of conventional surgery due to delays in this procedure.

Healing times for deroofing were variable. For the surgery, people described not feeling any pain until after the anaesthetic wore off. Some were pleased with the results of their deroofing and were surprised how effective it had been and how easy the healing process had been.

> 'No and it hasn't been, it hasn't been so invasive like other surgeries that I've had you know it's [...] I don't feel as if I've had anything done but I'm not having any problems anymore with the two areas that they've done, which was always, you know, there wasn't a day that it wasn't sort of enlarged and leaking, but at the moment I'm going to touch it but it seems fine.' (P1, female, White British)

Some were not satisfied, with a view that the procedure had not been done as intended, because they felt that all the HS had not been successfully removed or that their wounds were more challenging to deal with than the HS itself.

> 'Because it was cut underneath along the line of the tunnel and the underneath part was scraped out and the skin left on. Meanwhile deroofing is meant to take out, it's a tissue-saving surgery, so it's meant to take out the skin and scrape out whatever is in there, it fills back nicely. But the skin was left over this one and it started getting infected right from the third day. It's healed now, well it hasn't healed completely – it's still not healed inside because the whole idea is for it to heal from inside out, but because the skin was still on top of it, it was over granulating and it was healing from the outside first.' (P13, female, Black/African/Caribbean/Black British)

## Discussion

This semi-structured interview study provides insight into patient views and experiences of HS treatments within a UK context. Across our interviews, some patients perceived benefit from each of the management options. Individual circumstances influenced which were perceived as appropriate, showing a desire for personalized therapy. This study proposes a model for how treatment decisions were made in the clinic. Patients' preferences, informed by their views on treatments, could inform the treatment option received, but HCPs' recommendations could override patients' preferences. This may be because some patients feel that 'the doctor knows best'. It could also show how patients' preferences for HS treatments were not 'set in stone', and that they were willing and open to new ideas. There were differences in how involved individuals wanted to be in treatment decisions.

Individuals had mixed experiences and satisfaction across the treatments. The main issues reported with the medication options were side-effects and getting used to taking tablets regularly. The main issues with procedures were delays in receiving procedures and dealing with wounds from surgery. Some people reported feeling nervous in anticipation of procedures. For laser, it was noticeable that the fears dissipated after treatment.

Concerns about the long-term effectiveness and side-effects of current treatment options and the burden of wound care mirror the findings of a review of previous qualitative studies.[7] A more recent qualitative study of patients' and HCPs' views in the USA and Europe highlighted the unmet care needs of people with HS, and also highlighted that effective treatment was a priority for both groups.[14]

It has been identified that individuals vary in their beliefs about concern and necessity of treatment. Low necessity and high concern are factors known to be related to poor treatment adherence across a range of conditions, although more research has taken place in beliefs about medicines than surgical treatments.[15–17] Our participants had clear variations in the level of concern and beliefs about how necessary a treatment was, but there were some clear trends in the data, including (i) concerns about the consequences of being on long-term medication; (ii) concerns that medications do not offer a long-term solution for HS symptoms; (iii) a desire to avoid surgery unless it is considered 'necessary'; (iv) a desire for a treatment that prevents future symptoms rather than simply treating existing symptoms; and (v) an

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openness to trying different treatments in the hope of alleviating symptoms.

Studies looking at patient preferences for involvement in treatment decisions suggest that while most patients want some degree of involvement, there is a subset of patients who want to be less involved, and this study saw similar variation across participants.[18] A systematic review identified a trend that a higher proportion of patients wish to participate in treatment decisions when it involves invasive procedures.[19]

At the microlevel, clinicians should be aware that past experiences will influence how patients perceive current treatment options and may make them feel concerned about taking a certain treatment or believe that a certain treatment is unlikely to work for them. In common with many chronic skin conditions, people with HS value long-term solutions and treatments that address the cause of their HS. HCPs should allow for these hopes to be expressed within the decision-making conversation. This can serve two purposes: it can not only help direct treatment choices in a way that is in line with patient preferences, but it can also allow for conversations that may help to manage patients' expectations of treatments where they may not get the desired outcome (i.e. to be cured of HS).

Despite a trend toward patient-centred care and shared decision-making, many patients with HS may feel obliged to follow clinician recommendations.[20] It is important that patients' preferences are encouraged, to ensure true shared decision making and patient buy-in to care. Some patients will prefer clear recommendations from doctors. Shared decision-making aids for HS practice in the UK would be beneficial to support treatment decisions. A patient decision aid has been previously been developed in North America.[21]

At the macrolevel, the expansion of laser and deroofing via the THESEUS study led to patients being offered more treatment options, and this increase in choice was welcomed. Guidelines about treatment pathways may need to offer a more flexible approach to allow for more personalized care.

The sampling framework resulted in diversity of participants, reflecting the THESEUS cohort study and the wider HS community, including different ages, sexes, ethnicities, HS treatments and study sites. A multidisciplinary team approach to analysis ensured meaningful and trustworthy findings by including the perspectives of patients, HCPs, clinical trialists, a psychologist and qualitative researchers.

The generalizability of the data to regular clinical practice may be limited, as although the THESEUS study was pragmatically designed to mimic current practice, the study may have altered the nature of healthcare conversations, and some participants mentioned that they had received more attention from their healthcare team by taking part in the study. Another limitation was the timing of the interviews. Not all participants had received their treatment at the time of the interview due to COVID-19-related delays, and so only limited information could be gathered about the experiences of some treatments (particularly conventional surgery). Some of the content discussed may also have been hard for people to recall, because of the time gap between starting their treatments and the original conversation with their HCP about treatment choice. Conducting interviews by telephone may also have affected the findings.

Patient perceptions of treatments will vary and are largely determined by past experiences. Patients' views influence treatment decisions, but so does the HCP's recommendation. HCPs need to carefully elicit the beliefs and preferences of patients and understand the experiences and beliefs driving these preferences to engage in best-practice shared decision making. Decision-making aids could support conversations in practice.

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## Conflicts of interest

L.H. has received consultancy fees from the University of Oxford for an educational grant funded by Pfizer, unrelated to the submitted work. J.R.I. received a stipend as Editor-in-Chief of the *BJD* at the time of manuscript writing and submission, and an authorship honorarium from UpToDate. He is a consultant for Boehringer Ingelheim, ChemoCentryx, Citryll, Novartis and UCB Pharma, and has served on advisory boards for Insmed, Kymera Therapeutics and Viela Bio. He is co-copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments for hidradenitis suppurativa (HS). His department receives income from copyright of the Dermatology Life Quality Instrument (DLQI) and related instruments. K.H. was a member of the National Institute for Health and Care Research Health Technology Assessment General Committee from 2016 to 2022. A.G. is patient advisory board member for Novartis and UCB. C.H. is a patient advisory board member for Novartis. F.C. is a consultant for UCB Pharma (from February 2023) and was paid an honorarium by the British Dermatology Nursing Group to take part in a HS consensus meeting in September 2022.

## Data availability

Please contact the study team for enquires about data sharing.

## Ethics statement

The Wales Research Ethics Committee 4 provided ethical approval for THESEUS on 26 September 2019 (reference number 19/WA/0263).

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## Patient consent

Participants provided informed consent to take part in the interviews.

## Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website.

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