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## ORIGINAL ARTICLE

“The surgical management of hidradenitis suppurativa in the United Kingdom: a national survey of care pathways informing the THESEUS study”

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“The surgical management of hidradenitis suppurativa in the United Kingdom: a national survey of care pathways informing the THESEUS study”

## **Structured Abstract**

**Background:** The evidence-base underpinning treatment efficacy and effectiveness for hidradenitis suppurativa (HS) is limited, as has been highlighted in the wide-ranging research priorities established by a James Lind Alliance priority-setting partnership (PSP). Understanding the landscape of surgical practice is a key step towards tackling undesired variation in care and resolving treatment uncertainties. This survey of current surgical practice aimed to describe care pathways involving surgeons for the management of HS, and surgical approaches to management.

**Methods:** In the development of the prospective cohort Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS), a bespoke electronic surgeon survey was conducted to describe variation in care pathways and surgical preferences in the management of HS. This was disseminated to a pre-defined denominator list of surgeons using local collaborators through the Reconstructive Surgery Trials Network.

**Results:** Key results were small numbers of surgeons working in formal multidisciplinary teams (MDTs) (8/198, 4%), heterogeneity of first-line intervention, low rates of guideline endorsed treatments (laser and deroofing in particular), variation in wound closure methods and follow-up length, and that over half of respondents do not use well-validated outcome instruments to determine treatment success/failure (110/198, 56%).

**Conclusions:** This survey demonstrated variation in care, which is likely to be undesirable. Surgeons treating HS patients might consider developing MDTs or referring patients to those with an interest in HS and considering routine outcome measurement. Such steps might reduce variation, increase standardisation of care, and improve access to specific treatments.

## Introduction

Hidradenitis suppurativa (HS, also known as *acne inversa*) is a common and debilitating condition. People with HS experience recurrent and persistent inflamed nodules, discharging abscesses and scarring sinuses affecting the axillae, groins and inframammary regions. In Western populations it has a prevalence of around 1%, with young adults typically affected.<sup>(1)</sup> HS has long-term adverse effects on quality of life and employment prospects.<sup>(2)</sup> A range of treatment options exist. These include topical and systemic medical therapies, non-invasive procedures such as laser to affected areas, as well as limited and extensive surgery.<sup>(3)</sup> Patients may be treated by clinicians from different disciplines, including general surgeons, plastic surgeons, dermatologists and primary care physicians.<sup>(4)</sup> Within the broad groups, there may be subspecialists involved in different aspects of disease manifestation – for example breast surgeons and colorectal surgeons treating anatomically-defined areas of HS. Multi-disciplinary clinical services may be well-integrated, giving patients from all referral pathways access to a broad range of treatments, or they may operate in a more siloed fashion.

The evidence-base underpinning treatment efficacy and effectiveness is limited, as has been highlighted in the wide-ranging research priorities established by a James Lind Alliance priority-setting partnership.<sup>(5)</sup> This makes informed treatment decision-making difficult. It is likely that there is clinician-dependent treatment variation, mainly due to the historical lack of evidence-based guidelines in the UK until recently.<sup>(3)</sup> Indeed, variation in the dermatological management of HS across the United Kingdom (UK) was demonstrated in a survey conducted in 2014 and updated in 2019.<sup>(6-7)</sup>

Understanding the landscape of surgical practice is a key step towards alleviating undesired variation in care and resolving treatment uncertainties. This study hypothesised that there is both variation in access to surgical expertise for the management of HS, and variation in the surgical management.

## Methods

### *Survey Development*

This survey forms part of an observational study of the management of HS funded following a National Institute for Health Research commissioned call. A multidisciplinary working group, including patients, methodologists and clinicians from Dermatology, General Practice (GP) and Plastic Surgery developed a study of current UK practice of HS. Prior to the prospective cohort Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS), an electronic survey was conducted to describe variation in care pathways and surgical preferences in the management of HS. This was developed by all stakeholders, in conjunction with the Reconstructive Surgery Trials Network (RSTN). This UK-based international research collaborative (UK and Netherlands) delivers multi-centre studies using local collaborators from the network to accurately determine survey denominator and encourage high response rates.

The survey aimed to establish UK clinical HS practice in terms of:

1. Multidisciplinary team setup and integration
2. Patient care pathways
3. Treatment preferences for different patterns of disease
4. Insight into potential HS treatment variation among surgeons in the UK

The survey was conducted and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at Kennedy Institute of Rheumatology, The University of Oxford.<sup>(8,9)</sup> REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. REDCap software allowed the

incorporation of branching logic in the survey structure, to reduce burden on respondents and minimise redundancy of data. The survey is presented in supplementary file A.

### *Survey Deployment*

After internal testing by the study team, the survey was deployed across the RSTN network. Volunteers, comprising UK plastic surgery trainees and a small group of Dutch plastic surgery trainees, registered their interest in being collaborators via the RSTN website. Where UK plastic surgery units were not represented, the RSTN's network of regional representatives were asked to encourage participation.

Collaborators were required to provide a denominator list of surgeons who might treat HS in their unit. The aim was to build a denominator list comprising all surgeons who might be involved in the shared decision-making for treatment with HS patients, either fully-independently, or with some degree of autonomy. Operationally, this was defined as being a consultant, specialty registrar, or a staff grade/associate specialist (SAS).

As part of the denominator list, collaborators provided the contact email address of the surgeons in their department, having secured permission from them. The surgeons were emailed a weblink to the survey, and completion was encouraged by the local collaborator during the survey window of December 2017 to March 2018. Non-responders and incomplete responses were excluded. As demographics of non-responders were not collectable, analysis of the missing responses could not be undertaken. Results were exported from REDCap for descriptive analysis in Excel. Raw data can be made available on request.

## Results

### *Survey respondents*

The collaborators identified a total of 477 surgeons who agreed to be contacted, across 22 units (19 in the UK and three in The Netherlands). Of these, 237 (237/477, 50%) completed the survey fully. As the majority of completed surveys were from UK surgeons, the Dutch and UK responses were analysed together. This comprised 220 plastic surgeons (112 consultants, 108 other grades) from the UK and the Netherlands, and 17 general surgeons (seven consultants, 10 other grades) from the UK.

### *Team structure and referral pathways*

198 (198/237, 84%) surgeons managed patients with HS, mainly via referrals from GPs (165/198, 83%) or dermatologists (145/198, 73%), but only eight (8/198, 4%) worked in formal multidisciplinary teams (MDTs). Plastic surgeons managed quiescent disease (74/181, 41%), or both acute flares and quiescent disease (94/181, 52%). Of the 17 general surgeons who responded, ten (59%) managed only acute flares. Most plastic surgeons managed axilla (167/181, 92%) and groin disease (162/181, 90%), while only 59% (107/181) managed breast HS. Overall, the referral load was low with the majority of surgeons (148/198, 74%) seeing up to 10 patients annually, only 12% (24/198) reported seeing more than 10 patients with HS each year. Most people referred to surgeons had already received antibiotics and/or lifestyle modification advice (Figure 1).

### *Non-surgical treatment*

Over a third of surgeons (67/165, 39%) insisted on some form of “intervention” to manage the HS being undertaken before they would offer surgery. Most commonly, weight loss (103/198,



52%) and smoking cessation advice (116/198, 59%), based upon the belief that such changes modified both disease progression, and future operative risk. Some surgeons offered systemic treatments such as short (29/67, 43%) or long courses of antibiotics (26/67, 39%) or biologic agents (22/67, 33%).

*Figure 1: Interventions prior to surgical referral*

*Figure 2: First intervention offered by surgeon*

Amongst survey responders, only one UK respondent had used electrocautery for deroofting of lesions, and two UK respondents had used laser treatment. The laser modalities used were carbon dioxide laser for resurfacing, intense pulsed light (IPL) for hair removal, and potassium titanyl phosphate (KTP) for bacterial sterilisation.

### *Surgical treatment*

Indications to offer surgery, were satisfactory correction of modifiable risk factors for disease (89/198, 45%), and persistent disease that had failed to respond to first line treatment (95/198, 49%).

For limited disease in the axilla, the most preferred operative option was excision of disease and direct closure (97/160, 61%). Where axillary disease was more extensive, there were preferences for excision and split skin grafting (51/160, 32%), and excision and reconstruction with an axial flap (44/160, 28%) (Figure 3).

*Figure 3: Preferred surgical option for axillary disease*

For limited disease in the groin, excision and direct closure (112/160, 70%) was again the preferred operative option for the majority of surgeons. For more extensive groin disease, the most common preferred option was excision and split skin grafting (49/160, 31%) (Figure 4).

*Figure 4: Preferred surgical option for groin disease*

Limited breast disease, similar to other sites, was most commonly treated with excision and direct closure (73/101, 72%). For more extensive breast disease, most surgeons had no preferred operative option (38/101, 38%) (Figure 5).

*Figure 5: Preferred surgical option for breast disease*

Notably, a few surgeons stated that they would avoid surgery in any of these sites (4/160, 3%) as they believed it did not control the disease process well. There were similar numbers of surgeons who would operate on multiple sites in a single procedure (52/164, 32%), compared to multiple sites as staggered procedures (46/164, 28%), some surgeons would only operate on the most troublesome sites (66/164, 40%).

There was variability with respect to surgical follow up protocols, with similar numbers following patients up for three months (38/164, 23%), six months (34/164, 21%), one year (57/164, 34%) and more than one year (33/164, 20%) following surgery. There was variation in how surgeons measured treatment success, with most not using a formal physician-reported instrument or patient-reported outcome measure (PROM) (110/198, 56%).

## Discussion

This survey provides an insight into the surgical management of HS. The key findings were small numbers of surgical participation in MDTs for HS, a heterogeneity of initial intervention, variation in wound closure methods and length of follow up, and that over half of respondents were not using well-validated outcome instruments to determine treatment success/failure.

Based on our data, a number of plastic surgeons do contribute to the care of people with HS. The data is clearly limited by the small number of general surgeons both in the denominator and in the respondent group, which should be remembered when designing future studies. However, harnessing this willingness to contribute to care pathways may be an important aspect of improving joined-up and patient-centred care in HS, especially as very few surgeon respondents worked in coordinated MDTs. Currently, this may be a barrier to people with HS accessing surgical services. Conversely, as surgeons are less likely to offer treatments such as long courses of antibiotics and biologic agents, people who are referred early to surgeons may not readily access systemic therapies. Connecting care delivered by surgeons and other healthcare professionals might also support standardisation of pre-surgical interventions including lifestyle modification strategies, as well as the indications for surgery.

The patterns of formal surgical preference that we report are similar to other recent data from the Netherlands.<sup>(10)</sup> Where disease is limited in its extent, excision and direct closure was a common preference. The approach to more extensive disease varied by body site. In the axilla, there has been evidence that excision of all hair bearing skin may achieve better disease control.<sup>(11)</sup> Preference for reconstruction of the resulting defect was divided between skin grafting and local flaps. There have been numerous studies of different flap options to reconstruct the axilla, but we have not identified high quality evidence comparing flaps and split skin grafts directly.<sup>(10)</sup> The 2018 BAD HS Clinical Guideline recommends patients with severe HS, unresponsive to medical systemic therapies, be considered for extensive surgical

excision, with either secondary intention healing or local flap reconstruction. The guideline states that surgical interventions are relatively under-represented due to the lack of RCT-level evidence to support their use.<sup>(3)</sup> In the other sites, preferences for treating extensive disease in the groin or breast were less consistent. This may represent the indistinct boundaries of potential involvement in these areas compared to the well-defined hair-bearing area of the axilla, and the challenges of extensive operations in functionally and cosmetically sensitive sites at the breast and groin/perineum. These patterns support there being treatment uncertainties around surgical options and are in keeping with there being equipoise for certain surgical uncertainties, such as whether to reconstruct axillae using skin grafts or flaps or employing secondary intention healing.

Only two surgeons in our survey provided laser treatment for HS, and these involved different laser modalities. Only one strategically aimed to remove hair from the area, as is suggested as an option in the European guidelines.<sup>(12)</sup> The surgeon used IPL, which may relate to accessibility of this modality, or based on its use having been published in plastic surgery.<sup>(13)</sup> Besides this, other hair removal modalities were not used at all by the surgeons in our study. This may reflect doubts about the effectiveness of hair removal laser therapy in HS by surgeons, limited training in the use of laser, a lack of access to the hardware required to deliver laser to patients, or a combination of these issues. While surgeons may have a good working relationship with other team members, such as the GPs or dermatologists that they receive their referrals from, it is possible that some treatment options, such as laser, may not be readily accessible through care pathways that do not involve a full MDT. It may be useful to understand the barrier to laser treatment for HS patients better through future research. Additionally, only one surgeon provided electrocautery derroofing. This is despite it being well-described,<sup>(14,15)</sup> and it being one of the recommended options for the management of Hurley Stage I and II lesions in the S1 European guideline for HS.<sup>(12)</sup> The very low level of its deployment in the UK may reflect a lack of familiarity with the technique.

Our study informs our understanding of the HS treatment pathways in the UK, especially when considered alongside other published data. The suggestion of undesirable variation in care from our results aligns with there being a limited evidence base for treatment, as indicated from the James Lind Alliance priority setting partnership,<sup>(5)</sup> and stated in the 2018 BAD HS Guideline.<sup>(3)</sup> A similar survey of dermatologists identified that only a minority would provide operative wide local excision, and that this remained consistent when the survey was repeated recently.<sup>(7,6)</sup> Few surgeons who completed this survey would avoid operating on HS, so there is potential to build local networks to complement the services provided by many dermatologists.

In terms of applying our findings to clinical practice, surgeons referred HS patients might consider developing MDTs with other clinical stakeholders or referring patients to a number of surgeons with an interest in HS. Developing such networks may facilitate access to treatments recommended in guidelines but currently not widely available, such as laser and derofreezing. General trends such suggest that local excision is widely used for local disease, and that more extensive surgery with skin grafts or flaps may be reasonable for axillary disease, but there is more variation in approaches to extensive groin and submammary disease.

There are limitations to this study. The denominator list was dependent on local collaborators identifying surgeons. While the Reconstructive Surgery Trials Network is a dynamic and effective system for conducting such work, to date, it has predominantly focused on plastic surgery studies. This is consistent with the majority of those invited to complete our survey being plastic rather than general surgeons. Furthermore, the response rate was 50%, so there was considerable missingness. However, this is actually a higher response rate than is usually achieved for online surveys, which typically achieve 30-40% completion at best.<sup>(16)</sup> Furthermore, it is likely that those who responded have a more active interest in treating HS. This would be supported by the fact that very few of those who completed our survey would avoid operating on HS at any anatomical site or extent of disease. If this is the case, it may

prove useful for advancing this area of care, as the perspective of surgical enthusiasts are critical to achieving this. We deliberately minimised free text response options in the survey, to avoid the need to interpret and categorise responses as we were concerned that might introduce bias. However, it is possible that the response options we provided did not always allow surgeons to accurately describe their practice. For example, it may be that some surgeons who follow up patients for shorter time frames do so if longer follow up care is provided by the referring General Practitioner or Dermatologist. Nevertheless, we believe that this survey struck a balance between delivering granular data, while avoiding excessive burden on surgeons to complete it.

This study, and its relation to the existing literature and research priorities, suggests areas for future work, which have been incorporated into the design of THESEUS, an NIHR funded observational study into the management of HS in the UK. Increasing awareness of the recently published guidelines among surgeons treating HS is important, in order to encourage multi-disciplinary working when managing these patients. Understanding barriers to implementation of guideline-recommended aspects of care such as laser and deroofting may help to improve uniform access to treatments. If knowledge and skills in deroofting need to be developed, then systems like the IDEAL framework, and its stage 2b element in particular, provide a potential roadmap to grow experience and uptake of this existing option in future.<sup>(17)</sup> This would increase treatment options for people with HS. Generating high quality evidence to determine the role of different treatments would also pave the way for reducing undesirable variation in care. THESEUS aims to further investigate these issues and inform the design of successful future trials of HS treatments in the UK.

Overall, this study provides a cross-sectional perspective of the current practice and variation in care for hidradenitis suppurativa referred to, and managed by, surgeons. We hope to incorporate the surgical, dermatological and primary care perspectives with the preferences

and experiences of people with HS, in order to recommend evidence-based care pathways focussed on patients needs.

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