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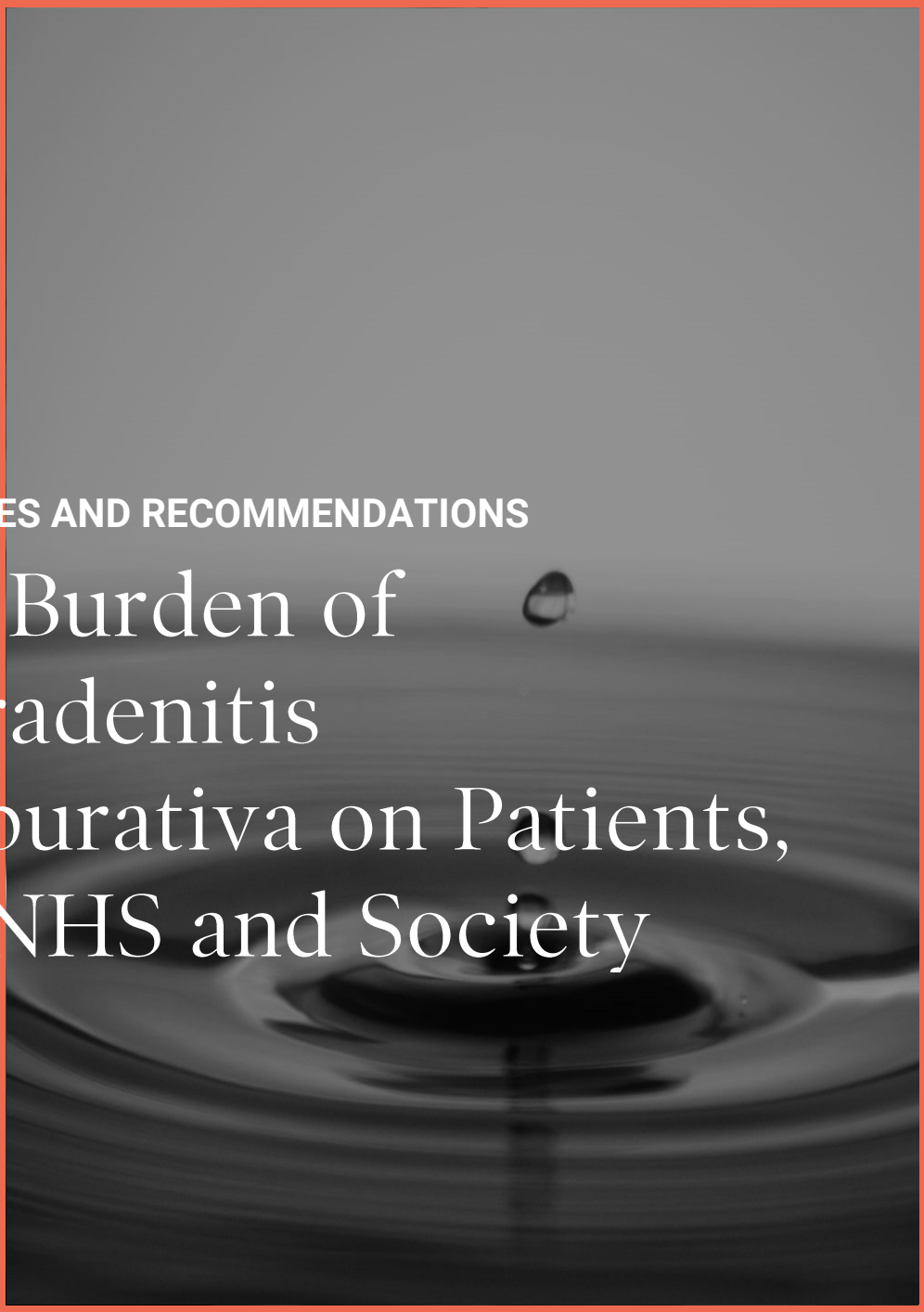

ESTIMATES AND RECOMMENDATIONS

The Burden of Hidradenitis Suppurativa on Patients, the NHS and Society

CONTRACT RESEARCH REPORT
JUNE 2023

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We'd also like to acknowledge Edward Oliver for his contributions to the project, especially the literature review.

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Foreword

I am pleased to contribute a foreword to this report and provide some of my insights on the impact of Hidradenitis Suppurativa (HS), and the profound impact on people's lives. Over my years running a support group for people living with HS, I have been able to see the significant impact of the condition on people who are affected, and their loved ones.

The impact of HS is multifaceted and complex. Whether it is the physical pain associated with flare ups of the condition or the toll that it can take on an individual's mental well-being, there are many ways in which HS can significantly reduce quality of life. Indeed, as this report highlights, the unpredictability of the condition alone can have a harmful impact on ability to work, on social relationships and on the day to day opportunities someone has to participate in the things they enjoy in life.

That is why I believe it is essential that we achieve really excellent care for people living with HS, that can look after people's physical and mental well-being and support people affected by the disease to lead life to the fullest.

At the moment, too many people face a long wait to receive a diagnosis, time where their condition may not be optimally managed and where there can be little hope of things improving. These delays damage people's confidence in services – so that when a diagnosis is finally given, there is a long way to go to rebuild trust with clinicians.

This is all the more problematic because time with clinicians is so precious – often only ten or so minutes to discuss the many ways that HS is impacting on your life and the support you might need to manage it. For this reason, there is a real need to provide holistic, joined up care to people living with HS – that enables people to manage their condition more effectively, to think about the impacts it can have across their life and, with the right services – whether mental health or someone else – secure the right support.

The findings of this report are important in underlining the overall burden of HS to the health service and to society more broadly. Front of mind, however, must also be the people who are living with HS. There is a critical need to shorten the time to diagnosis through increased awareness of the condition, to provide wider access to more holistic mental health support, and to put in place other support mechanisms such as effective wound care support that will improve the care and quality of life for all those affected by this disease.

It is, therefore, my great hope that this report will help to amplify recognition of the need to prioritise HS, that it will inspire policymakers to think about what they can do to support better HS care and that it will provide a clear path to delivering this with the urgency it deserves.

Angela Gibbons
Patient and HS Advocate

Executive Summary

Hidradenitis Suppurativa (HS) is a painful chronic inflammatory skin disease estimated to affect at least 200,000 people in the United Kingdom. It is a debilitating condition that can have a significant impact on emotional well-being and quality of life, placing a substantial burden on people living with HS, the National Health Service (NHS), and broader society. HS causes recurrent abscesses, open wounds, and scarring, especially near hair follicles and skin folds with sweat glands, including areas such as the armpits, groin, and breasts. Currently, there is no cure for HS; existing treatments primarily focus on wound and pain management. Furthermore, awareness of the condition is low among the general public, and it is under-recognised by primary care physicians, leading to a significant diagnostic delay and, consequently, more severe disease and greater burden of comorbidities.

IMPACT ON PEOPLE WITH HS

People with HS experience a major impact on their quality of life, with physical pain and social isolation among the biggest burdens. Wound management is a significant burden, requiring daily drainage and wound dressing, with most patients requiring 1-3 dressing changes per day. Many people resort to less appropriate dressings due to cost, and their clothes need to be washed and changed more often. The financial burden on people with HS includes transport costs, with many postponing critical appointments due to difficulty in planning and the uncertainty of their condition. HS also impacts social life, education, and employment prospects, with a significant impact on relationships, self-worth, and intimate relationships. The individual impacts of HS also spill over into a person's working life, productivity, and overall ability to enjoy valuable leisure time.

IMPACT ON NHS

People with Hidradenitis Suppurativa (HS) face an average diagnostic delay of 10 years, and over 70% of patients are already exhibiting moderate to severe disease when first diagnosed. Patients may see multiple physicians and face more than three misdiagnoses. Delayed diagnosis impacts mental health, with depression and anxiety twice as common in people with HS than in the general population. HS is also associated with a range of physical comorbidities, the most prevalent of which include cardiovascular disease, obesity, hypertension, arthropathies and diabetes. Furthermore, there is a shortage of dermatologists, specialist nurses, and appropriately specialised mental health practitioners. HS is under-resourced relative to other conditions, such as psoriasis or eczema.

IMPACT ON SOCIETY

HS has a significant societal impact by causing pain, mental health issues, and impairing an individual's ability to work and carry out activities. It affects the prime working ages and is associated with high unemployment, slower income growth, and a higher risk of leaving the workforce. People with HS may require adjustments at work and may need to take ad-hoc days off. They may avoid sharing their diagnosis of HS with their employers, instead referring to stress, pain, or anxiety to avoid any associated stigma. As such, employed people with HS report high levels of absenteeism, presenteeism, and overall activity impairment. There are also considerable equity concerns, given that HS is more common in women and ethnic minorities.

TOTAL COST OF HIDRADENITIS SUPPURATIVA IN THE UK PER ANNUM

The results of our economic analysis indicate that the annual cost of HS to the UK is around **£3.83 billion**, based on the resource utilisation costs directly from HS and its associated comorbidities to the NHS, out-of-pocket costs to people living with HS and productivity losses to wider society. This estimate is based on the number of diagnosed patients from the Clinical Practice Research Database. However, given the frequency of delayed and misdiagnosis, the true prevalence and, therefore, associated costs are likely to considerably higher in reality.

KEY RECOMMENDATIONS

We propose three recommendations to improve life for people living with HS and lessen the burden on the NHS and wider society based on our research and input from our patient and clinician focus group.

Increase awareness of HS

- Inform and educate the general public about HS symptoms and its impact on those living with HS
- Improve awareness among clinicians, particularly in the primary care setting
- Raise awareness among employers to decrease the social and professional stigma around the condition and the burden of associated comorbidities

Improve service integration and holistic, person focused care

- Improve access to pathways for integrated psychological services and appropriate weight loss and smoking cessation support
- Facilitate a shift towards treating the patient as a partner in treatment decisions to improve patient-physician relationships
- Ensure clinicians are able to record HS accurately and consistently in patient records; supported by improved data coding and infrastructure

Improve and expedite access to appropriate treatments

- Greater education of wound management and prescription of suitable dressings
- Address variation in uptake and use of biological medicines to ensure patient have equitable access to appropriate treatments
- Improve dermatological services by training and employing more specialist nurses and wider members of the multidisciplinary teams
- Facilitate the use of teledermatological appointments where appropriate

1 Background

1.1 What is Hidradenitis suppurativa (HS)?

Hidradenitis suppurativa (HS) is a painful chronic inflammatory skin disease. It is a debilitating condition that can have a significant impact on emotional well-being and quality of life, placing a substantial burden on people living with HS, the National Health Service (NHS), and wider society.

HS causes recurrent abscesses, open wounds, and scarring, especially near hair follicles and skin folds with sweat glands, including areas such as the armpits, groin, and breasts. According to the NHS, the condition tends to start with blackheads, spots filled with pus and firm pea-sized lumps that develop in one place. New lumps will then often develop in an area nearby; if these are not managed medically, larger lumps may develop and spread. Narrow channels called sinus tracts also form under the skin that break out on the surface and leak pus (NHS, 2023).

The exact cause of HS is unknown. There is evidence suggesting that genetics and environment have an influence. According to one study, around a third of individuals with HS report an affected first-degree relative (Ballard and Shuman, 2022). Other associated risk factors include obesity, smoking and hormones; though there is no causative clinical link, these exacerbate the condition and make disease management more difficult (Woodruff, Charlie and Leslie, 2015). HS is more prevalent among women, and the age of onset usually occurs between puberty and menopause (Ballard and Shuman, 2022).

Currently, there is no cure for HS; existing treatments primarily focus on wound and pain management. The optimal treatment pathway is not well-defined but usually aims to treat existing lesions to minimise pain and drainage, decreasing the frequency of recurrence and preventing disease progression. Guidelines from the Primary Care Dermatological Society and British Academy of Dermatologists state that treatment must be individually tailored and emphasise the importance of treating the disease, along with the management of associated comorbidities and risk factors, at an early stage to prevent disease progression. In the absence of a clear diagnostic tool, HS is currently diagnosed by clinical observation, and is currently categorised within three "Hurley stages". The first stage refers to solitary abscess formations without scarring; stage 2 is categorised by recurrent abscesses, and the most severe, Hurley stage 3, is characterised by diffuse or broad involvement and multiple connected abscess sites (Primary Care Dermatology Society, 2023; British Academy of Dermatologists, 2021).

When identified early, topical antibiotics are the first-line treatment. As the condition progresses, oral antibiotics and tumour necrosis factor-alpha inhibitors are indicated. Once these options are exhausted, surgical excision may become necessary. People living with HS often experience severe pain from numerous sources, including scarring (causing tensile pain), keloids, abscesses, open ulcerations, sinus tracts, frictional pain, and lymphedema. Clinicians also emphasise the need to manage comorbidities that accelerate the progression of the condition; this usually includes referrals to weight loss and smoking cessation support.

The diagnosis of HS can be delayed for up to 10 years, resulting in more severe disease and a greater burden of comorbidities (Kokolakis et al., 2020). There is no definitive test to help diagnose HS, and it may be mistaken for acne, boils, or ingrown hairs (NHS, 2023).

Despite numerous studies, prevalence estimates range from 0.1% to as high as 4% of the population (Cosmatos et al., 2013; Ingram et al., 2018; Jemec, Heidenheim and Nielsen, 1996; Lachaine et al.,

2016). Due to a lack of disease awareness, delayed diagnosis, and different methods of data collection, it is difficult to know the true prevalence.

1.2 Motivation

HS has an impact on people with HS, the National Health Service (NHS), and broader society, but these impacts are not well recognised. In this report, we seek to identify and quantify the humanistic and socioeconomic burdens of HS in the United Kingdom. We shed light on different dimensions of HS, including its impact on individuals and families, employers, and the healthcare system, as well as the broader societal consequences of this poorly understood and often misunderstood condition.

HS affects people in their most productive years and negatively affects a person's ability to make valuable use of their time, whether in paid employment, volunteering, caring for others, or enjoying their leisure time. People with HS tend to face higher unemployment, slower income growth, and a higher risk of leaving the workforce. HS also affects their quality of life, general activity, and social interactions, leading to physical and mental health challenges. In addition, HS patients often face substantial out-of-pocket expenses related to their condition. Combined with higher unemployment and slower income growth, this puts a substantial strain on the financial well-being of people with HS.

HS also imposes often-avoidable burdens on the NHS. The direct healthcare costs associated with HS include expenses related to treatment, surgery, and management of comorbidities. A relative lack of awareness of HS among affected people and their physicians can also lead to misdiagnosis and delayed diagnosis, leading to avoidable burdens on the NHS and those with HS.

Finally, HS imposes a burden on society as a whole. People with HS experience a high degree of work impairment, including absenteeism and presenteeism, or continuing to work while unwell, in spite of any negative consequences. The cumulative impact of absenteeism, presenteeism, unemployment, and overall activity impairment detracts from the economic potential of those with HS and society as a whole.

We hope that raising awareness of the impacts and burdens of HS will promote earlier diagnosis and appropriate treatments. This can improve patient care and reduce the economic and humanistic burdens on those with HS, the NHS, and society as a whole.

1.3 Methods

We conducted a targeted literature review to identify existing research around the economic and humanistic burdens of HS and identify any gaps in the evidence base. The next stage of the research was a focus group with clinical experts and people living with HS to verify the findings of the literature review and fill in any gaps identified. This also provided the opportunity for the elicitation of key parameters for the economic analysis. Finally, the results of the literature review and focus group were combined to inform quantitative estimates of the economic and humanistic burdens of HS at the UK population level. A detailed description of our methods is found in the Appendix.

The report is structured as follows: Firstly, we discuss the impact of HS on the NHS and issues relating to the treatment of HS. These include the diagnosis delay of HS, the burden of comorbidities and a need for a holistic approach to treatment. Then we discuss how the condition and issues surrounding treatment impact people living with HS. These include wound management, transport costs, as well as the impact on mental health and relationships. Next, we look at the spillover effects of HS on society more broadly, primarily work and activity impairment. Finally, we propose some recommendations for improving the care and prioritisation of HS patients.

2 What is the impact on the NHS?

The treatment pathway associated with HS can be highly variable, depending on the stage of the condition, the patient's previous medication and their preferences. Management of the condition spans primary, secondary, and tertiary care, with services outside of dermatology often required to achieve optimal health outcomes.

2.1 Diagnostic delay

People living with HS generally start to develop symptoms in their early to mid-20s yet face an average time to diagnosis of 10 years (Kokolakis et al., 2020; Garg et al., 2020). Women, and those with more severe disease, can expect even longer delays (Hasan, Harris and Collier, 2022). According to a survey of the US and the five biggest European countries (France, Germany, Spain, the UK, and Italy), over 70% of those with HS are already exhibiting moderate to severe disease when first diagnosed (Ingram et al., 2022). During this long period without a diagnosis, someone with HS will likely have seen more than three different physicians, including GPs, dermatologists and consultants, and have received more than three misdiagnoses (Kokolakis et al., 2020).

HS is most frequently misdiagnosed as abscesses, boils, and ingrown hairs, which can lead to patients receiving a variety of suboptimal treatments, highlighting a considerable lack of recognition of the condition, particularly at the primary care level.

> *"When you're a primary care clinician, you're not very familiar with it… if someone comes in with something there on their breast or their neck, you just don't think of HS … especially people who are not presenting with what we would class as typical HS … there would be a massive delay in referral because you just would not naturally think of that".*
>
> **GP perspective**

Unfortunately, both patients and clinicians saw this experience as the norm – a patient typically sees multiple clinicians and may be given differing information, including misdiagnoses, before finally getting a correct diagnosis of HS. Even then, these are the 'success stories' of those who do eventually manage to receive a correct diagnosis. Many never see a doctor, never receive a diagnosis or appropriate treatment, or may be discharged due to not responding to treatments. Some withdraw from the system entirely due to negative experiences. Several participants of the focus group agreed that this diagnostic delay creeps into consultation – not only affecting the patient but also creating difficult patient-physician relationships.

> *"We hear time and time again of people having been to doctors, often several different doctors, and been told all kinds of things before they get a diagnosis."*
>
> **Patient perspective**

> *"They are generally angry and frustrated because of how many different practitioners they've seen, how long it's taken, and that has an impact on my consultation with the patient because they're angry with me."*
>
> **Consultant Perspective**

This period of delayed diagnosis, and the bouncing between services accompanying it, represent a substantial cost to limited NHS resources, one that is not fully captured in the limited existing literature.

This substantial delay in diagnosis imposes a significant burden on both the NHS as well individuals with HS. The longer the delay until diagnosis, the greater the disease severity at diagnosis. There is also evidence to suggest that diagnostic delays may mean that patients miss the optimal "window of opportunity" for beginning treatment, leading to poorer health outcomes (Marzano et al., 2021). Both of these factors may mean that comorbidities are more likely to develop or become worse, for example, depression, anxiety, or obesity.

2.2 Associated comorbidities

HS imposes a high burden of physical and psychological comorbidities on top of the direct NHS resource utilisation from skin abscesses. A study by Jørgensen et al. (2020) reports that in a cohort of 302 patients, 87% had a least one comorbidity. Mental health issues are common, with reports of at least one psychiatric diagnosis found in 57% of patients (Huilaja et al., 2018; Shlyankevich et al., 2014). Depression and anxiety are at least twice as common in people with HS as compared to the general population, and the psychological burden is greater than that associated with similar conditions such as psoriasis, and again, these mental health issues are more prevalent in females than males (Huilaja et al., 2018).

> *"The delay from all of that, the delayed diagnosis, I think really impacts on our mental health, and there isn't a patient that I've met that isn't and hasn't had mental health difficulties and real low mental health as a result of their HS."*
>
> **Patient perspective**

Along with these psychiatric comorbidities, HS is also associated with a range of physical comorbidities, the most prevalent of which include cardiovascular disease, obesity, hypertension, arthropathies and diabetes (Kimball et al., 2018; Garg et al., 2022). Causative links and clinical relationships between these comorbidities and HS itself remain unclear. There is a recognition that weight and smoking play some role in aggravating HS (Liakou et al., 2021). However, our focus group also noted that HS itself could impact the ability to meaningfully engage in physical exercise, creating a vicious cycle of worsening HS and more limitations on activity. Physical exercise is generally recommended as part of clinical recommendations for weight loss and general health improvements, yet sweating and friction can exacerbate HS lesions and abscesses, particularly when these are in sensitive or difficult to manage regions of the body. This is a recurrent theme in qualitative research into the impact of HS. Keary et al. (2020) found that some study participants who identified themselves as overweight expressed frustration when medical professionals told them to lose weight without fully understanding or acknowledging the difficulties many patients face in undertaking physical activity.

These comorbidities present a vicious cycle, where increased disease severity influences a greater number and burden of comorbidities, each making disease management techniques more difficult and less effective. These repercussions affect physicians as well as people living with HS. A participant in our focus group mentioned that clinicians might want to provide surgical weight loss, but surgeons may refuse due to a failure to meet specific weight loss eligibility criteria, i.e., high BMI and an explicitly defined comorbidity, e.g., hypertension or diabetes. As we shall discuss later, these issues compound the stigma, sense of shame and embarrassment, and burden of mental health issues faced by people with HS.

2.3 Integrated & holistic care

Our focus group revealed that patients and clinicians recognised that treatment of HS cannot be reduced to simply dealing with individual physical symptoms, wounds or flares but instead requires a more holistic, integrated, and personalised approach to disease management. Presently, there are barriers to referral pathways between services.

> *"I mean, it takes an MDT [multidisciplinary team] approach to help people with HS, and that's significantly lacking around the UK."*
>
> **Consultant perspective**

> *"Lots of patients will talk about those ten precious minutes that they wait six or nine months for in a room which is really treatment focused… there's very little conversation and discussion around how well are you coping, how do you manage with wound management".*
>
> **Patient perspective**

During the focus group, it was revealed that based on our patient representative experience, when being seen by a consultant, GP or dermatologist, there's little discussion about how well you're coping beyond the physical symptoms you happen to be displaying at that moment in time. A more integrated approach is needed, involving disease management from the perspective of mood and mental health, including support networks as well as physical symptom management.

> *"I have attended so many appointments over the years to be asked how my treatment is going, and if it's all going well, I leave again. If it's not going well, I'm told to stop taking the meds and prescribed something new to start."*
>
> **Patient perspective**

Focus group participants also felt that there is a lack of specialist dermatologists and dermatology nurses in the UK. This is noted in the "Get It Right First Time" (GIRFT) dermatology report, which was drafted following discussion with hospital doctors, managers, nurses, and GPs at over 80 units in the UK (Levell, 2021). According to that report, one of the biggest issues for dermatology is a significant workforce shortage (even relative to wider resource pressures with the NHS); this, in turn, is impacting efficiency and leading to varying access to numerous services, including clinics for psychodermatology.

> *"It's important to acknowledge the shortages of dermatologists here in the UK and of dermatology nurses as well. So, the centres that we do have seem to be closing left, right and centre".*
>
> **Specialist nurse perspective**

The importance of such clinics and access to psychological support from practitioners experienced in dealing with dermatological conditions, especially HS. Those focus group participants with a clinical background stressed that being able to make referrals to mental health services is vital. At the time of the "GIRFT" report publication, there were only 11 dermatologists running pyschodermatology clinics in nine NHS trusts (out of 219), which indicates wide variation in access across England (Levell, 2021). Furthermore, trusts in the Northern region were flagged by participants as having particularly few psychodermatologists, leading to situations where patients from North Lancashire were referred to as far away as Birmingham.

There was interest in the potential of teledermatology to provide more easily accessible consultations for people with HS. The longer people live with HS, the fewer face-to-face consultations

they may need. In some cases, teledermatology could reduce feelings of shame or anxiety that cause some people with HS to avoid consultations. Teledermatology also offers the potential for patients to be seen more quickly and avoid the time and travel burdens associated with face-to-face appointments. In the absence of teledermatology, there can be long waits for appointments, and someone experiencing a flare may only be seen after it has passed.

A recent survey of 49 people living with HS in Italy found that 57% felt safe sharing required photos or videos when using teledermatology services (Ruggiero et al., 2023). Still, 22.5% of patients reported preferring only face-to-face visits, and of these, 90% reported HS manifestations in sensitive body areas.

While teledermatology may not be for everyone, it could be offered as part of a more holistic, patient-focused treatment plan that allows people with HS to play a greater decision-making role in how and when they are treated.

2.4 Cost of Hidradenitis suppurativa to the NHS

Current treatments for HS – primarily antibiotics – are focused on symptom control and do not address the (currently unknown) causes of HS. Symptoms are managed with wound care and pain medications, and wide surgical excisions may be required to remove larger abscesses. Commonly used wound management and antibiotic treatments do not alter the course of HS for most patients, and more than half of people with HS will require two or more surgical procedures, with many having more than one site treated at once (Burney, 2017).

The frequency of hospital resource utilisation of people with HS in England was studied across a 5.5 year period; the authors found that over 70% will have attended at least one general surgery, though individuals may be referred to a range of specialisms, including plastic surgery, dermatology, gastroenterology, as well as A&E. The same study reported 303,204 outpatient appointments, 65,544 inpatient spells and 43,773 A&E attendances (Desai and Shah, 2017).

> *"So, reducing the time from symptoms to diagnosis and tertiary centre involvement, and a personalised 'what matters to me' approach seem to be the two bits we need to address in the NHS."*
>
> **Commissioner Perspective**

Based on these frequencies of GP visits, hospital admissions and procedures, we estimated **direct annual costs in the range of £4,900 to the NHS per person with HS.** In general, these are visits, admissions or procedures that include a diagnosis of HS, but given widespread underreporting or misdiagnosis; our focus group unanimously agreed that it is likely an underestimate of the direct costs of HS to the NHS.

Accounting for the most prevalent comorbidities adds an **additional cost of between £1,200 and £2,100 per person per year to the NHS.** This figure estimates the associated comorbidity burden of the average person diagnosed with HS, therefore, does not include those who present to the NHS without having (yet) been diagnosed.

Annual direct cost to the NHS per person diagnosed with HS:
£4,900

Annual cost to the NHS due to associated comorbidities:
£1,200

3 What is the impact on people with HS?

HS is a painful long-term condition that has a profound impact on the health and well-being of people living with the condition. It affects many aspects of patients' lives and has a profound impact on mental health; it is associated with higher rates of depression, anxiety, and risk of suicide. People living with HS may also experience difficulties in their social interactions and intimate relationships.

A thematic synthesis of the experiences of people with HS identified three main themes (Howells et al., 2021): (i) Putting the brakes on life. The multitude of physical, mental, and social impacts of HS result in people missing out or delaying major life events. (ii) A stigmatised identity: concealed and revealed. People often try to hide their HS, both visually and verbally, but this may lead to anticipation and fear of exposure. (iii) Falling through the cracks. As discussed in the previous section, delayed diagnosis, misdiagnosis, and lack of access to care are common for people with HS. They can also feel unheard and misunderstood by healthcare professionals.

3.1 Impact on mental health and relationships

Delayed diagnoses and poor healthcare experiences, difficulty managing comorbidities and the financial impact of wound management and transport all contribute to a significant psychological burden from having HS. Beyond these, the unpredictability, pain, and physical manifestations of the disease compound to worsen mental health further, and can contribute to isolation and social exclusion, difficulty having intimate relationships, and overall ability to enjoy leisure time and pursue education and employment prospects.

> *"People can feel they cannot participate in certain activities with friends and family due to physical pain, odour, and mental health arising from living with HS. They can feel unreliable, they have people who don't understand because they can't see it. They cancel plans and sometimes feel like they are excluded as others make assumptions about their condition. They worry that who they share their experience of HS with won't be treated in confidence."*
>
> **Patient perspective**

> *"With this condition, it's the unpredictability of it, so they cannot accept an invitation to a wedding in the summer because they have no idea whether or not they're going to be alright at that time. How they are this month doesn't predict how they're going to be next month."*
>
> **Consultant Perspective**

The symptoms of HS affect functioning in multiple ways, making everyday activities a struggle, largely as a result of the stigma associated with it. Qualitative research into the impact of HS has revealed that people with HS often have feelings of shame and embarrassment due to their condition, which sometimes leads to social withdrawal and isolation (Keary, Hevey and Tobin, 2020). In some cases, people with HS reported that they resort to staying in bed and wait for flare-ups to pass before they feel confident being around other people.

The abscesses, nodules, and wounds caused by HS are primarily located in the intertriginous regions, including the groin, genitals, armpits, and breasts. Because of this, they can have a severe impact on

body image, sexual positivity and intimate relationships (Schneider-Burrus et al., 2018; Matusiak, Bieniek and Szepietowski, 2010).

In our focus group, we heard that one or more of these issues impact most people with moderate-to-severe HS but particularly affect young adults in terms of their self-worth and confidence when seeking a romantic partner. In a survey looking into the impact of HS on sexuality, 94.3% of women and 80.8% of men said that HS had a negative influence on their chances of having a relationship or sexual relations (Cuenca-Barrales and Molina-Leyva, 2020). In the same study, 71.4% of those who were in stable relationships reported that HS negatively impacted their relationship. In women, the age range most affected by HS overlaps with the ages of peak fertility and childbearing – potentially having life-changing consequences for those who wish to start a family.

Depression and anxiety are among the most common comorbidities associated with HS. A recent systematic review and meta-analysis, including a total of 38 studies, found that for every four patients with HS, 1 had depression (Patel et al., 2020). The prevalence of depression in HS groups versus non-HS was 26.5% compared to 6.6%. The authors also found that the presence of anxiety in HS patients was 18% compared to 7% of the general population. HS has been shown to be significantly associated with a high suicidal risk. Research suggests that suicide is two times more common in HS patients compared to the general population (Phan, Huo and Smith, 2020). Substance abuse is also more common in HS patients compared to control groups (4% v 2%), with the most commonly abused substances being alcohol, cannabis and opioids (Garg et al., 2018).

HS imposes a significant psychosocial impact not only on patients but also on those around them, including their partners who may serve as carers. Partners may experience a wide range of emotional and social effects as a result of the disease, with greater disease severity being significantly correlated with reduced quality of life of the partners of people suffering from HS (Włodarek et al., 2020). Clinicians, therefore, need to be aware of the psychosocial implications of HS on both patients and their partners and families.

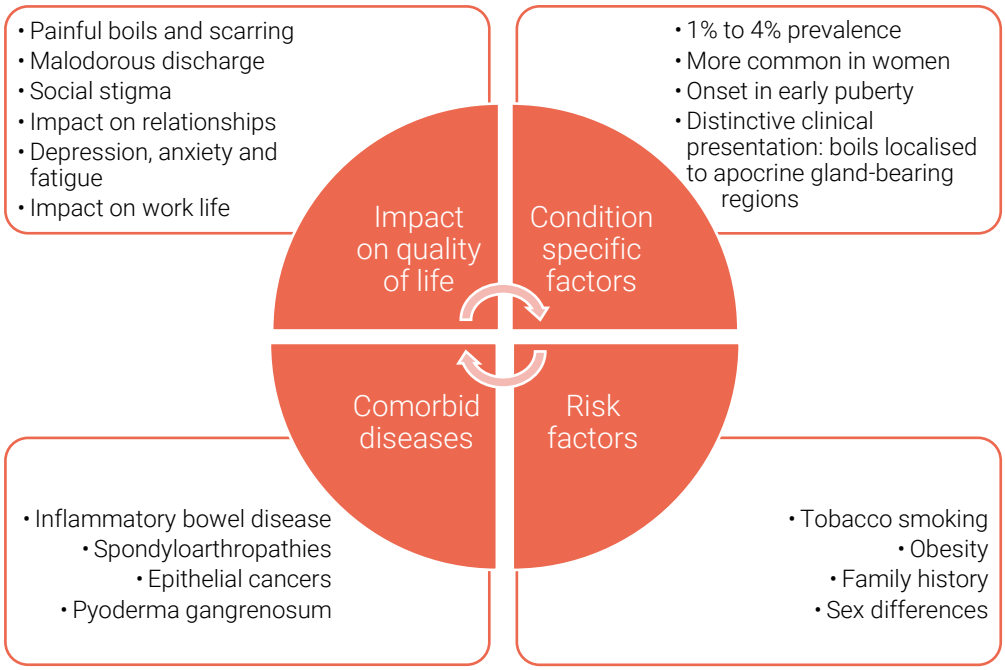

FIGURE 1 DISEASE BURDEN FOR PEOPLE LIVING WITH HS. UPDATED AND ADAPTED FROM (DUFOUR, EMTESTAM AND JEMEC, 2014)

3.2 Wound management

One of the major burdens on people with HS is the management of wounds, skin lesions and abscesses. Managing both acute flares and chronic wounds requires daily drainage and wound dressing; most people have to change dressings 1-3 times per day (Burney, 2017). A significant minority (16%) require five or more dressing changes per day (Moloney et al., 2022). People living with HS frequently find themselves having to resort to less-than-ideal methods of wound dressing due to costs. Many people resort to less appropriate dressings such as panty liners/menstrual pads, abdominal pads, tissues, and toilet paper, often because they cannot afford the type and quantity of dressings they would ideally use (Poondru, Scott and Riley, 2023).

> *"The dressings [patients use for wounds] that tend to be helpful are expensive silicon-based ones that won't rip their skin off when they change them. They often need lots of these and the GPs, not surprisingly, are not willing to prescribe them and patients often have to purchase them privately and that is at great expense."*
>
> **Specialist Nurse Perspective**

> *"I think often as GPs, it's not that we don't want to prescribe [dressings], but it would come out the practice prescribing budget and often they have a certain pot of money for all people, for all drugs. We're not going to spend the money on an expensive dressing".*
>
> **GP Perspective**

These quotes from our focus group highlight the issue from the perspective of the NHS. The most appropriate dressings are not routinely prescribed, placing a financial burden on individuals with HS. These out-of-pocket costs also impact household bills. Our focus group's patient representative discussed how frequent dressing changes, the use of less appropriate materials, and occasionally having to use one dressing for too long necessitates much more frequent washing and changing of clothes. This leads to higher energy bills from laundry alone. These costs are significant and rising with an ongoing cost-of-living crisis, and out-of-pocket costs such as this disproportionately affect black people over white people and women over men. In the US, a recent survey of people living with

> *"Natural fibres are better [for the wounds]. Well, cotton and linen clothes cost an awful lot more than buying polyester".*
>
> **Commissioner Perspective**

HS found that nearly half of respondents reported by unable to afford the type and quantity of dressing they would ideally want (Poondru, Scott and Riley, 2023). Furthermore, black people were more likely to report being unable to afford their dressings compared to white people. Whilst we acknowledge that the health system in the UK is very different from the US, these findings may be reflected with regard to prescriptions for people with HS from ethnic minorities in England.

Even the type of clothing people with HS wear can have an impact on their condition, as we heard from the focus group and is frequently mentioned in the literature (Howells et al., 2021). Wearing natural materials and loose-fitting clothes can be beneficial but may be more expensive.

3.3 Travel costs

In addition to the costs of painkillers, dressings and laundry, another significant financial burden on people with HS is transport costs. Walking, particularly for longer distances, can be difficult because of HS, increasing general transport costs. As discussed previously, people with HS are often referred to numerous specialities and have to travel to see different practitioners in different locations.

Planning for these appointments can be difficult due to the uncertainty of flare-ups. Many patients will try to postpone or even cancel critical appointments, with cost being a major factor.

> *"We're having patients say, "I'm really sorry I can't afford the train journey to come and see you" in our HS patients more than our other immune-mediated inflammatory patients such as eczema and psoriasis."*
>
> **Consultant Perspective**

3.4 Cost associated with HS to people living with Hidradenitis Suppurativa

Whilst the impact of HS on people living with HS is primarily non-monetary, there are non-inconsequential out-of-pocket costs associated with managing pain and wounds. Our analysis of costs accounts for transport costs for accessing healthcare services, costs of dressings and baseline prescription costs, estimating an **HS-specific burden of around £1,500 per person per year.** This estimate does not include additional costs of living from other transport costs, additional OTC painkillers, or household bills.

Annual out-of-pocket costs per person diagnosed with HS:
£1,500

4 What is the impact on society?

HS seriously impairs an individual's ability to make valuable use of their time, whether paid employment, volunteering, caring, or leisure activities. The chronic pain and discomfort caused by HS make it challenging for individuals to perform physically demanding tasks and maintain concentration at work, resulting in absenteeism, presenteeism, and in some cases, unemployment. Socially, the visible symptoms, odours, and masking behaviours associated with HS can lead to self-consciousness, social stigma, and isolation, preventing individuals from engaging in and enjoying social activities. The unpredictable nature of HS flare-ups further complicates their ability to plan and participate in social events. As such, HS hinders individuals from contributing to society to their fullest potential, as their work productivity and social engagement are negatively impacted by the condition. The cumulative effect of these challenges results in a significant loss of value to society.

4.1 Impact on productivity

HS predominantly affects people in their most productive ages and is associated with higher unemployment, slower income growth, and a higher risk of leaving the workforce (Tzellos et al., 2019). It particularly makes physically demanding jobs more difficult, although a degree of work impairment is found in the majority of people with HS (Yao, Jørgensen and Thomsen, 2020; Jfri et al., 2022), and higher disease severity correlates with a greater reduction in quality of life and greater work impairment.

> *"In primary care… sick notes probably won't actually say HS on it because it potentially might not have told [to] their employer. They might have said stress or anxiety or depression or whatever else might be going on in their life."*
>
> **GP Perspective**

> *"I think a lot of people will take ad hoc days for flares as and when they kind of reach that crescendo point and say, actually, I'm crawling to my own bathroom today. I can't go to work."*
>
> **Patient Perspective**

Medical appointments are just one of the reasons people with HS may take time off work. Surgical stints can mean weeks or even months off work. Due to the painful, uncertain nature of flare-ups, people with HS may also need to take ad-hoc days off work, often giving nonspecific symptom-related reasons rather than explaining their experience with HS. This patient experience was corroborated by one physician's experience of providing sick notes. Indeed, many people with HS are entirely unable to work. Estimates of HS-related unemployment in the literature range from 12.6% (Schneider-Burrus et al., 2023) to as high as 34.4% (Yao, Jørgensen and Thomsen, 2020).

Another factor is presenteeism, or suboptimal productivity while at work. The physical and mental effects of HS both impact productivity. Pain can make concentrating and behaving in a stereotypically professional manner difficult, affecting an individual's ability to sit or stand. Moving between locations can be difficult at work. There is also the need for changing dressings and concealing odours and flares.

In our focus group, we heard that people with HS regularly mask and hide their condition, particularly in professional environments, in part due stigma associated with a lack of awareness and support from employers. By the Equality Act 2010's definition of "disability", people living with moderate to

severe HS may be protected by this legislation, which means that employers have a duty to make reasonable adjustments in the workplace (Equality Act 2010). Examples may include allowing flexible work times and locations and wearing 'less professional' but more comfortable, loose-fitting clothing. For those who are able to work from home, professional life may be more manageable, but for many working physically demanding jobs, this is not possible.

> *"The fact that many of them feel like they can't [miss] work or they lose their jobs, I think the pandemic was one of the best things that happened to my HS patients because they were able to work from home, wear comfortable clothing, no underwear, that kind of thing. And then when they had to go back into the office situations, they found it incredibly difficult."*
>
> **Consultant Perspective**

4.3 Equity concerns

Our research suggests that the treatment of HS raises significant equity concerns, as individuals affected by this chronic skin condition face various barriers in accessing appropriate care, as well as often experiencing greater severity and burdens resulting from gender, race and geography. The long diagnostic delays, potential misdiagnoses, and often insufficient treatment options exacerbate the physical and emotional burden on those who suffer from the condition. There are significant issues with current treatment options, including a reliance on antibiotics which can lead to bacterial resistance, and poor access to and knowledge of appropriate wound management techniques and materials. Access to more advanced treatments, such as biologic therapies and high-quality dressing materials, may be limited due to cost constraints within the healthcare system, despite their potential long-term benefits in disease management and improved patient outcomes.

Racial and gender disparities further compound these inequities. People of colour and women are disproportionately affected by the burdens of HS and may experience different levels of access to healthcare and support (Choi, Phan and Oon, 2022). Additionally, people from rural areas have less consistent access to specialist dermatological services, particularly at short notice (Levell, 2021).

Individuals with HS from marginalised groups experience disparities in healthcare access and quality. Consequently, they face even greater psychosocial and financial burdens, with disproportionality negative impacts on their quality of life, ability to work, and overall contribution to society.

4.3 Lost societal potential due to Hidradenitis suppurativa

We presented the results of five studies conducted in the last five years to our focus group that collected data on absenteeism, presenteeism, overall work impairment and activity impairment. There was agreement that although it is hard to measure, a high degree of work impairment is likely to be representative. We found that HS is associated with 38% total work impairment, a combined metric of absenteeism and presenteeism, and 44% overall activity impairment. When considering not just work productivity losses but also the impairment on other valuable activities, we estimated an overall **loss of value to society at £12,300 per person per year.**

Lost societal potential per person diagnosed with HS:
£12,300

5 What can be done to improve life for people with HS and their potential to contribute to society?

5.1 Use of medicines

Currently, antibiotics are prescribed for the treatment of HS, largely on the basis of their anti-inflammatory properties. However, there is evidence that the use of antibiotics such as clindamycin is associated with a high risk of bacterial resistance. In one study, patients using topical clindamycin were more likely to develop clindamycin-resistant Staphylococcus aureus (Fischer, Haskin and Okoye, 2017).

Biologic therapies are more expensive than antibiotics, but they have the potential to provide greater health benefits without the risk of antibacterial resistance (Marzano et al., 2021). Our focus group suggested that while biologics may increase NHS costs in the short-term, they could provide long-term savings by reducing the need for surgical procedures.

There is also evidence that earlier use of biologics can modify the course of HS. Biologics have been shown to slow the progression of symptoms, leading to better patient outcomes (Marzano et al., 2021), including reduced pain (Tsentemeidou et al., 2022) and fewer exacerbations, associated with improved quality of life and work productivity (Argyropoulou et al., 2019; Mrowietz et al., 2012).

People with HS may become frustrated as they see their condition and health deteriorate before being prescribed biologics, with the associated increases in comorbidities and costs to themselves and the NHS that accompany this. Currently, NICE only recommends the use of adalimumab or its equivalent biosimilar products as an option for those whose disease has not responded to conventional systemic therapy (NICE, 2016). When considered alongside the common diagnostic delay, a significant period of time may pass before patients are able to access this type of treatment.

> *"Some patients feel frustrated that they need to reach the end of the treatment pathway, over a number of years, living with their HS getting progressively worse, before being offered a biologic."*
>
> **Patient Perspective**

One focus group participant mentioned the importance of changing the approach in the budget to drug costs, stating that often drug costs are seen as the easiest cut to make to reduce costs, but often the prescription of biologics is generally the right thing to do – improving patient outcomes, slowing disease progression, and likely reducing health system costs over the longer term.

5.2 Total cost of Hidradenitis suppurativa in the UK

For the purposes of our cost estimates, we used CPRD-HES linked data, which represents 25% of the population of England (Clinical Practice Research Datalink, 2023). We adjusted this figure to represent the total population of England and then extrapolated this to the population of all four nations of the United Kingdom. Based on this calculation, we estimate that there are currently

190,000-200,000 people living with a confirmed HS diagnosis in the UK. This represents a prevalence of 0.35% of the working adult/over-25 population of the UK, which is consistent with a recent systematic review and meta-regression analyses prevalence result of 0.4% (Jfri et al., 2021). However, estimates in the literature tend to converge on a prevalence of HS of around 1% in Europe (Revuz et al., 2008; Ingram et al., 2018), suggesting our estimate is relatively conservative. Our prevalence estimate only includes those with confirmed diagnoses within the UK adult population. Given diagnostic delays and incidence of misdiagnosis, the true prevalence of HS in the UK (and socioeconomic burden) may indeed be closer to the 1% reported in the literature.

	Average annual cost in the UK per person with HS	Aggregate annual cost in the UK among HS prevalence cohort
Cost to society (productivity losses)	£12,320	£2.4 billion
Out-of-pocket costs to people with HS	£1,500	£288 million
Costs associated with comorbidities	£1,236	£238 million
Direct healthcare costs to NHS	£4,867	£935 million
Total	**£19,923**	**£3.83 billion**

5.3 Recommendations for improving care and prioritisation of HS patients

Based on the findings of the literature review, focus group and OHE's analysis, we propose the following recommendations to improve the care and prioritisation of HS within the NHS, which in turn, we hope will go some way to improving the quality of life of those living with this chronic condition.

RECOMMENDATION 1: INCREASE AWARENESS OF HS

Throughout this report, we note the frequent delay of diagnosis and misdiagnosis of HS. Therefore, the first step must be to increase awareness of HS among clinicians and people who may be experiencing undiagnosed HS. Most are aware of more common dermatologic conditions such as eczema and psoriasis, yet very few have heard of HS and will not be aware of the significant impacts it can have. We propose the following pathways to raise awareness among relevant stakeholders:

- Launch a general awareness campaign to inform and educate the general public about HS symptoms and its day-to-day impact on those living with HS. This may empower people who suspect they may have HS to seek medical support and be more confident in asking their doctor to examine them and consider HS specifically.

- Improve awareness amongst clinicians, particularly in the primary care setting. To reduce the significant delays in diagnosis, along with the associated physical, mental, and financial burdens, GPs and other clinical staff should be more aware of HS and, therefore, be more capable of accurately and promptly diagnosing.

- Raise awareness among employers to decrease the social and professional stigma around the condition and the burden of associated comorbidities. With increased awareness, there will be a greater capacity to implement reasonable adjustments for removing barriers in the workplace to help people living with HS reach their career potential.

RECOMMENDATION 2: IMPROVE SERVICE INTEGRATION AND HOLISTIC, PERSON-FOCUSED CARE

A holistic, person-focused approach to HS and dermatology as a discipline is an opportunity to improve outcomes for patients and reduce pressures on NHS resources. Holistic dermatology takes a broader approach compared to traditional medicine, focusing on understanding the broader needs and lifestyle of the patient as well as taking a shared approach to treatment decisions. To facilitate a holistic approach, integrated care boards will need to take steps towards improving dermatology services and create pathways for patients to access the support they need to manage their condition more effectively.

- Improve access to pathways for integrated psychological services, including mental health practitioners with experience of dermatological conditions.
- Improve referral pathways and access to appropriate weight loss and smoking cessation support, ensuring that these interventions are specific to the challenges faced by people living with HS.
- Support greater access to mood and symptom management support networks.
- Facilitate a shift towards treating the patient as a partner in treatment decisions; reducing stigma and shame on people with HS who struggle to manage the condition; improving patient-physician relationships that currently come under strain from delayed diagnoses, bouncing between services, weight loss stigma etc.
- Ensure that clinicians are recording HS accurately and consistently in patient records to facilitate patient follow-up from primary to secondary and tertiary care as well as support research into the prevalence and resource utilisation associated with HS. This should be supported through improved coding and data infrastructure to identify HS patients within health systems and support planning for local population need.

RECOMMENDATION 3: IMPROVE AND EXPEDITE ACCESS TO APPROPRIATE TREATMENTS

The diagnosis and treatment pathway for HS is not well established. Many patients are prescribed a variety of medicines until they find something that works for them and then feel like they are back to square one when that medicine becomes ineffective. This recommendation should be implemented in parallel with recommendation two, given that the holistic approach requires the patient to be involved in treatment decisions. A key aspect of this recommendation is addressing the variation in access to biologic treatments; this is the joint responsibility of the NHS, NICE and manufacturers to ensure patient access is equitable and affordable.

- Greater education and prescription of appropriate wound management techniques and materials, including suitable dressings, particularly for those lower-income patients who suffer a greater financial burden as a result of wound management.
- Address variation in uptake and use of biological medicines and ensure patients have equitable access to appropriate therapies.
- Make specialist dermatologists aware of the merits of different treatment options, particularly the potential beneficial health outcomes associated with the use of biologics, especially when used early in the treatment pathway.

- Improve dermatological services by training and employing more specialist dermatological nurses and wider members of the dermatology multidisciplinary teams and increasing geographical coverage of psychodermatology clinics.

- Facilitate the use of teledermatological appointments and examinations where appropriate and wanted by patients whilst acknowledging potential equity issues in access to technology

5.4 Action for change

FOR PARLIAMENTARIANS:

- Engage with local commissioners to understand how they are planning to prioritise HS within local health systems and support access to holistic, joined up care – including access to mental health services, wound care and pain management as well as broader disease and comorbidity management support for HS patients.

FOR NATIONAL GOVERNMENT:

- Support the dissemination of the Getting it Right First Time (GIRFT) Dermatology report recommendations to help reduce variation in practice.

- Address the workforce capacity pressures in dermatology, including shortages of dermatologists and dermatology nurses, and ensure that dermatology is a key part of the government's ongoing workforce planning efforts, including the NHS workforce plan.

FOR LOCAL COMMISSIONERS

- Ensure HS is reflected within ICB Joint Forward Plans and that plans recognise the need to reduce delays in diagnosis and provide joined-up, holistic care to patients.

- Use HS prevalence data to understand the expected HS population within the ICS and measure potential unmet need.

- Identify and share examples of HS service delivery best practice, including collaborative and integrated working between community, primary, secondary and tertiary services.

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Appendix

TARGETED LITERATURE REVIEW

We conducted a Targeted Literature Review to complement existing information on the economic and humanistic burdens of HS and identify gaps in this information that could be elicited from expert stakeholders, to inform our economic analysis. We searched Google Scholar and PubMed, for published literature on HS and our key areas of impact, targeting three key areas impacted by HS: i) health care system impact; ii) patient impact; iii) societal impact. We began using the following search terms:

i. hidradenitis suppurativa AND the United Kingdom; Hidradenitis Suppurativa AND resources; Hidradenitis Suppurativa AND costs

ii. hidradenitis suppurativa AND quality of life

iii. hidradenitis suppurativa AND productivity; hidradenitis suppurativa AND absenteeism; hidradenitis suppurativa AND presenteeism

To inform our economic analysis, we used resource use estimates from the most recent and robust studies, using figures extracted from the UK where possible, and included other evidence as necessary, expanding our literature review organically.

FOCUS GROUP

The project team conducted a focus group including patient, clinical, and commissioner representatives. During the focus group, we presented the findings of our literature review in 3 sections: (i) What (we think) we know, (ii) Where we are seeking clarity, and (iii) What we might not know. We asked the participants to comment on the validity of our findings (including estimates of prevalence, frequency of accessing services and costs) based on their knowledge and experience, and to add any further information or insights on each topic. The focus group used a "Modified Delphi-process" that encouraged participants to reflect on the estimates provided by other participants with an opportunity to adjust their estimates in the context of these other estimates.

ECONOMIC ANALYSIS

For our economic analysis, we divided costs into the three categories outlined above. We split NHS costs into direct utilisation of NHS resource use, primarily considering hospital and GP resource use, using estimates from Desai and Shah (2017) and Bewley et al. (2016). Unit costs were taken from the NHS National Schedule of Costs and PSSRU Unit Costs.

We also considered indirect costs to the NHS as a result of comorbidities. To do so, we used recent estimates of the overall cost of each comorbidity. We found data estimating the overall prevalence of each of the most common comorbidities among people with HS and calculated the percentage of the overall cost to the UK HS patients represented. To estimate patient costs, we used the results of our focus group and literature review to identify the primary financial burdens on people with HS and found recent resource estimates. To estimate societal costs, we used a human capital approach from a broad societal perspective. We averaged the overall work impairment percentage score from 5 studies that met our criteria of including WPAI scores for absenteeism, presenteeism, overall work impairment and overall activity impairment. We used the average overall activity impairment multiplied by the average UK salary to find the overall loss of value to society as a result of activity impairment.

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- The economics of health care systems
- Health technology assessment (HTA) methodology and approaches
- HTA's impact on decision making, health care spending and the delivery of care
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- The costs of treating, or failing to treat, specific diseases and conditions
- Drivers of, and incentives for, the uptake of pharmaceuticals and prescription medicines
- Competition and incentives for improving the quality and efficiency of health care
- Incentives, disincentives, regulation and the costs of R&D for pharmaceuticals and innovation in medicine
- Capturing preferences using patient-reported outcomes measures (PROMs) and time trade-off (TTO) methodology
- Roles of the private and charity sectors in health care and research
- Health and health care statistics

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