

**Title:** The undercover skin disease

**Background:** Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease that affects approximately 0.1–4% of the population worldwide. An average 7 year diagnostic delay has been suggested, although feedback from our patients suggests it may be longer. The symptoms of HS are known to impact on quality of life, and may lead to depression or affect function. It is crucial that a holistic approach is taken for the management of HS which includes addressing lifestyle factors such as obesity and smoking, which may make symptoms worse and for clinicians to referral accordingly. Furthermore, signposting patients to where they can access psychological support may be beneficial. Early diagnosis is crucial and may lead to better outcomes for sufferers.

**Aim:** The motivation for carrying out this survey was to better understand and meet the needs of our patients with HS.

**Design & setting:** A web-based survey was designed and sent out to all patients with HS.

**Method:** All patients within the HS specialist service (n=552) at GSTT were sent a web based survey as an electronic link via text message between May - July 2021 which was sent out on 2 occasions and two weeks apart. The survey consisted of 48 quantitative and qualitative questions with the option to add a free-text comment for each question.

**Results:** 33.8% of participants reported experiencing symptoms of HS for 3 to 10 years before consulting their general practitioner (GP). 26.3% of participants reported experiencing symptoms for over 10 years. 15% of participants had on average 1 to 2 primary care appointments before being referred to a dermatologist in secondary care. 37% of participants reported they had greater than 11 appointments with their GP before referral. 28.5% of participants were given a diagnosis of HS by their GP and 58% were diagnosed by a secondary care doctor. Of those diagnosed in secondary care, 47.3% were diagnosed by a dermatologist.

**Conclusion:** Greater awareness of HS is needed in primary care as delayed diagnosis may lead to poorer outcomes for sufferers. HS requires a holistic approach to management and a focus on addressing unhealthy lifestyle behaviours.



# The undercover skin disease

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## Meeting the needs of people with hidradenitis suppurativa

### Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease that affects approximately 0.1–4% of the population worldwide, although figures may be under recorded. An average 7 year diagnostic delay has been suggested. HS has a predilection for the intertriginous regions and apocrine gland-bearing areas. It causes inflammation of the hair follicle and can affect one or more body regions. It most commonly affects the inguinal, axillary, genital, perineal, and perianal areas. The disease is insidious and primary presentation may begin with erythema to the skin. Its symptoms can include deep-seated and painful nodules, boils, abscesses or draining sinus tracts with suppuration and malodour and secondary infection at the affected site/s.

The symptoms of HS are known to impact on quality of life, and may cause depression and affect function. It is crucial that a holistic approach is taken for the management of HS which includes addressing lifestyle factors such as obesity and smoking, which may make symptoms worse. Furthermore, signposting patients to where they can access psychological support may be beneficial. Early diagnosis may lead to better outcomes for sufferers and therefore the motivation for carrying out this survey was to better understand and manage our patients with HS at Guys and St Thomas NHS Foundation trust (GSTT).

### Diagnosis

33.8% of participants reported experiencing symptoms of HS for 3 to 10 years before consulting their general practitioner (GP)

26.3% of participants reported experiencing symptoms for over 10 years

15% of participants had on average 1 to 2 primary care appointments before being referred to a dermatologist in secondary care  
37% of participants reported they had greater than 11 appointments with their GP before referral to secondary care

28.5% of participants were given a diagnosis of HS by their GP

58% were diagnosed by a secondary care doctor

Of those diagnosed in secondary care, 47.3% were diagnosed by a dermatologist and 4.3% by an accident and emergency (A&E) doctor

### Implications for practice

#### In primary care

- Targeted education for primary care clinicians
- Raising awareness of common co-morbidities and complications of HS

#### Bridging the gap

- Effective and timely communication between primary and secondary care i.e. clinic letters
- Advise patients what to do when they flare - when to contact hospital (provide contact details) and when to approach their GP or attend A&E for treatment

#### Within secondary care

- Ask about lifestyle and offer referral for support (smoking cessation referral/nutrition and dietetics/weight loss service)
- Access to psychological support - refer in house (if available) or suggest self referral to NHS talking therapies
- Book patient back with the same clinician for continuity (when possible) – consider clinical nurse specialist (CNS) follow up and support
- Offer CNS face to face/virtual follow up if they have further questions after leaving the clinic
- Reserve weekly follow ups slots for flaring patients

### Aims

To understand the management of HS across primary and secondary Care

To understand the patient experience at GSTT

To understand the referral journey into the specialist HS service at GSTT

To understand the management of associated complications and co-morbidities of HS

### Methodology

**Participants:**  
All patients within the GSTT specialist HS service (n=552)

**Timeframe:**  
May - July 2021.  
Sent out twice and two weeks apart

**Distribution:**  
An electronic link sent via text message

**Structure:**  
48 quantitative and qualitative questions

**Extras:**  
Option to add a free-text comment for each question

### The results/findings

### Referrals

For 75% of patients, GSTT was their 2<sup>nd</sup> dermatology service and 93% of patients were referred to GSTT after 1-5 years of treatment in another dermatology service

### Psychological implications

2.4% of patients currently receive psychological support. These include either a counsellor, psychiatrist, dermatology psychologist or their local mental health team

80% of patients reported that they had not received any psychological support for HS

33% of patients felt that they needed psychological support to help them cope with their diagnosis

PSYCHOLOGICAL IMPACT			
Suicide	Affects social life	No quality of life	Constant pain
Hell	Fatigue	Emotionally and physically draining	Affects clothing choice
Depression	It has ruined my career	How does HS make you feel?	Unbearable
Affects mobility	Affects mental health	Interferes with work	Limiting
Terrible	Post traumatic stress disorder	Isolating	Its ruined my life
Dirty and unattractive	Anxiety	Hard to share with family	Loneliness
	Debilitating		

### References

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### Lifestyle

#### Make every contact count and address the vital 5!

OBESITY	SMOKING	EXERCISE
<ul style="list-style-type: none"> <li>• 65% are overweight</li> <li>• 35% are average weight or less</li> <li>• 68% want to loose weight</li> <li>• 25% do not want or need to loose weight</li> </ul>	<ul style="list-style-type: none"> <li>• 32% currently smoke</li> <li>• 28% are former smokers</li> <li>• 40% have never smoked</li> <li>• 27% of smokers have been offered a referral to smoking cessation</li> <li>• 73% had not been offered a referral</li> </ul>	<ul style="list-style-type: none"> <li>• 35% carryout cardio exercise 3 or more time weekly</li> <li>• 65% do not</li> </ul>

What do our patients want?

- More awareness and better understanding of the disease amid clinicians and in primary care
- Consistency – consulted by the same doctor
- Time to ask questions during consultations
- Open access when flaring - not routine follow up
- Flexibility with appointments
- Psychological support