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# Primary care management of Hidradenitis suppurativa: a cross-sectional survey of UK GPs

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## Abstract

### Background

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease which causes painful discharging nodules and skin tunnels. HS has associations with several systemic diseases, including cardiovascular (CV) disease and anxiety-depression. High levels of chronic morbidity suggest an important role for Primary Care. However, little evidence exists regarding current management of HS and its co-morbidities in UK General Practice.

### Aim

To describe current practice amongst UK GPs in treating and referring people with HS

### Design

Web-based survey circulated to UK Primary Care Dermatology Society members and GPs in Forth Valley, Scotland.

### Method

Survey responses were analysed with descriptive statistics.

### Results

134 UK GPs completed the survey. 71% (n=94) saw at least one patient with HS in the previous month. 94% (n=125) reported confidence in diagnosis, and 87% (n=120) in initial treatment of HS. Most GPs initiated topical treatments and extended courses of oral antibiotic for HS, and many advised regarding adverse lifestyle factors. A minority provided analgesia, or screening for CV disease risk factors and anxiety-depression. Most GPs referred to Dermatology if Secondary Care input was required, with few referrals to specialised multi-disciplinary services.

## Conclusion

GPs regularly diagnose and manage uncomplicated HS, but screening for important co-morbidities associated with HS is not common practice.

Keywords: Hidradenitis suppurativa, Primary Care

## How this fits in

HS is associated with multiple co-morbidities and high healthcare usage (**1, 2**). UK Guidelines for managing HS recommend first-line drugs and lifestyle interventions suitable for Primary Care (**2**). This study suggested GPs focus on treating skin disease and lifestyle factors. Tackling broader impacts of HS, including pain and psychological effects, could improve patients' outcomes.

## Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease, with a prevalence of around 1% in Western populations (**3, 4**). It often presents as recurring 'boils' in groins, breast and axillae which fail to heal with short courses of antibiotics, but persist as painful scarring nodules and chronically-discharging skin tunnels (sinuses) (**5**). Many of those affected by HS have adverse lifestyle factors, particularly smoking and obesity, and it is often associated with multiple co-morbidities including depression, cardiovascular (CV) disease and Type 2 diabetes (**3,6,7**). People living with HS are typically young to middle aged adults, and the condition can have profound and long-lasting effects on their employment

prospects and quality of life (8). HS has historically been poorly-recognised and under-researched, and delayed diagnosis and sub-optimal treatment have been noted in many studies, worldwide (1, 9). However, most patients present with characteristic features, and a firm diagnosis can usually be made in the presence of a typical history and clinical findings (Box 1). Primary Care practitioners are ideally placed to diagnose and treat HS in its early stages. They also have the skills to assess patients for the excess CV risk associated with HS (7) and to support patients in making lifestyle changes and coping with the psycho-social effects of the disease. (6). Despite this potentially important role, there has been little research into the area of Primary Care practitioners' management of HS in the UK. This study aimed to understand current practice in treating HS in Primary Care.

This is one of a series of surveys of different professional groups which aimed to inform the delivery of the Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS). THESEUS has been funded by the National Institute for Health Research to document current practice in treating HS, and assess the feasibility of future randomised controlled trials of HS treatments (<https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/theseus>) . <https://dev.fundingawards.nihr.ac.uk/award/17/98/01>. By mapping the Primary Care management of HS and the pathways from Primary to Secondary Care, we aimed to establish which treatments patients were likely to have had before reaching Secondary Care, and to which Specialties they were being referred.

### Research aims and objectives

The aim of the study was to explore the following research questions:

- What are the current drug and non-drug management options recommended by UK GPs to people with HS?
- What are the common referral pathways of HS patients from Primary to Secondary Care, in the UK?

## Method

### Questionnaire

A custom-built online open survey (**10**) was designed using the REDCap secure web application (**11**). This was anonymised, but multiple entries by individuals were prevented by requiring a 'Return Code' for revisiting the survey. The list of questions in the survey are shown in Supplementary Table 1. Due to the convenience nature of our sample, the initial part of the survey explored characteristics of respondents that may influence their experience in treating HS. Questions then explored which interventions GPs would offer in Primary Care before considering Secondary Care referral. The interventions were based on recommendations of the British Association of Dermatologists' Guidelines for the Treatment of Hidradenitis Suppurativa: extended courses of oral tetracycline-type antibiotics; 10 week courses of clindamycin and rifampicin; lifestyle advice, and surgical interventions (**2**). Questions also looked at GPs' choice of Secondary Care specialty for referral of HS patients and which factors determined their choice.

The option to add a free text comment was offered for each question.

### Population and setting

This was a cross-sectional survey of UK GPs including those with, and without, a stated special interest in dermatology, selected using convenience sampling. The electronic link to the questionnaire was active between May and September 2018.

Three methods were used to distribute the survey:

1. The Primary Care Dermatology Society (PCDS) distributed an electronic link to the survey to their 4,000 members, by email.
2. An electronic link to the survey was distributed to all 247 GPs in NHS Forth Valley in Central Scotland via group email and GPs were encouraged to share the link with colleagues.
3. Members of the research group distributed the survey link to GPs in their area of the UK who might be interested in completing the survey

## Data analysis

Sample size was not pre-specified due to convenience sampling, but we aimed to get at least 100 responses. The quantitative data was analysed with descriptive statistics.

## Results

### Descriptive statistics of GP survey respondents

135 GPs responded to the invitation and 134 answered survey questions. 97% (n=130) of the respondents completed all questions, and the 4 partially-completed surveys were included in analysis. Responses from all three sources were analysed together. 21 free text comments were submitted, mostly brief and insufficient for analysis.

Due to the sampling method used, most English, Irish and Welsh GP respondents were members of the PCDS and so had a Dermatology Special Interest, whereas the Scottish respondents were largely GPs in NHS Forth Valley who reported no particular interest or experience in dermatology. The geographical distribution and special interest status of respondents is shown in Table 1. Eighty respondents (60%) reported a special interest in dermatology, including 53 who stated they had some form of postgraduate experience or training in dermatology, and 38 holding a formal 'GP with Special Interest' post.

Survey respondents were predominately experienced GPs, with 90% (n=120) having worked for over 5 years in General Practice. Most worked in medium-to-large sized practices, with 40% (n=53) of the sample having a list size of 5000-10000 patients and 36% (n=48) having over 10,000 patients. Only 1 respondent said they had never had a patient with HS, and 70% (n=94) had seen at least one patient with HS in the month preceding the survey (Table 2).

### Confidence in diagnosing and treating HS in Primary Care

The survey results showed that most GPs in the sample considered themselves to be confident in diagnosing HS whether or not they had a Dermatology Special Interest, with overall 53.4% (n=71) stating they required no Secondary Care input to diagnose the condition, and 40.6% (n=54) saying they were confident but might refer for confirmation on occasion. Confidence levels were also high in the ongoing management of HS, with 75% (n=42) of GPs with no special Dermatology interest prepared to manage uncomplicated HS

in Primary Care, either independently or following specialist diagnosis, and 94% (n=75) of 'Special Interest' GPs. GPs working in practices with a list size over 10,000 (n=48) were most likely to report confidence in managing uncomplicated HS wholly within Primary Care (n=30, 62.5%). Confidence levels declined with smaller practice size, with 41% (n=22) of the 53 GPs in medium-sized practices and 30% (n=6) of the 20 GPs in small practices of <5000 reporting this level of confidence. Of respondents who had been qualified as GPs less than 5 years, 38.5% (n=5) reported confidence in managing uncomplicated HS independently, compared with 47% (n=8) of those qualified 5-10 years, 55% (n=20) of those 10-20 years, and 47% (n=32) of those over 20 years post-qualification (Tables S2 and S3).

#### Current practice in treating hidradenitis

The majority of GPs reported that they would offer advice about smoking (n=105, 78.9%), and weight management (n=123, 92.5%) before considering specialist referral. Other aspects of holistic care were less commonly-offered, including analgesia (n=65, 48.9%), wound care (n=75, 56.4%), CV risk assessment (n=62, 46.9%) and anxiety-depression screening (n=46, 34.6%) (Figure1).

89% (n=118) of GP respondents reported treating HS patients with a 3-month course of tetracycline-type oral antibiotics prior to specialist referral, including 85% (n=46) of GPs without a Dermatology Special Interest (Table 3). Guidelines recommend a course of combined clindamycin and rifampicin following failure of oral tetracycline therapy (2). Only 27% (n=35) of our GP sample would consider prescribing this, and only 4% (n=2) non-specialist GPs would do so (Figure 1).

A minority of GPs offered minor surgical interventions for HS in Primary care: 30.8% (n=41) said they might incise and drain an acutely inflamed lesion, and 7.5% (n=10) reported that they would excise a chronic non-resolving inflammatory nodule.

#### Referral to Secondary Care

Over 90% (n=126) of our GP sample reported referral of HS patients to dermatology, however 19% (n=25) would still choose to refer some patients to General Surgery (Figure 2). A number of factors had a strong influence on choice of referral speciality: 92% (n=123) said that disease severity was 'very' important or 'somewhat' important in determining choice,

with one GP commenting that they would usually refer a patient with a 'particularly large abscess' to Surgery. 80% (n=107) felt the patient's previous care by a specialty would influence re-referral to that specialty. HS affecting a particular body site would be 'very' or 'somewhat' important in choice of referral specialty for 80% of GPs (n=107), e.g. Gynaecology for vulval HS. The patient's preference for a particular specialty was considered an important determinant of the referral pathway by 67% of GPs (n=89), the existence of an agreed local patient pathways for HS patients by 77% (n=103); and the presence of a local clinician with a special interest in HS by 78 (n=104). Only 3% of GPs reported referring patients to a specialised multi-disciplinary service for HS (n=4).

## Discussion

### Summary

This study is the first to look at UK GP's self-reported practice in treating HS. Most GPs in the sample reported high levels of confidence in diagnosis and initial management of HS treatments, perhaps reflecting the high proportion of respondents with a special interest in dermatology.

Initial medical management of the skin manifestations of HS was largely compliant with UK Guidance (2, Figure S1) but suboptimal management of pain, psycho-social aspects and co-morbidity screening suggested an educational need amongst UK GPs, particularly those in smaller practices or in their early career years. This was particularly striking given the high levels of reported confidence in managing the condition.

Future research using Primary Care electronic prescribing data on drug therapies prescribed for HS, and surveys of regional referral pathways, would help more fully describe UK Primary Care management of HS.

### Strengths and limitations

This study breaks new ground in asking UK GPs directly about their management of HS. It is not possible to ascertain from this data how much this reflects GPs actual practice, but it does show their awareness of recommended HS management.



The preponderance, amongst respondents, of experienced GPs (90% in practice at least 5 years) and GPs working in larger practices of at least 5,000 patients (76%), may have made it more likely that they would have experience of seeing HS patients.

Due to the convenience sampling method, sampling bias is possible and respondents may not be representative of the population of UK GPs. Over half our sample had a special interest in dermatology so, where relevant, differences in responses between those with and without a special interest are highlighted (Figure 1, Table 3). However practitioners who had no knowledge of HS may have been less likely to respond to the invitation to take the survey.

Our sample included GPs throughout the UK but geographical differences in results are confounded by the predominance of non-specialist GPs in the Scottish respondents.

#### Existing literature

This study looked at self-reported rather than objectively-measured practice. Previous research into HS management in Primary Care has included a 2016 UK study, drawing on a large database of anonymised GP patient records, which demonstrated that HS patients are frequent attenders at Primary Care and often experience significant delays in receiving a diagnosis (1). A 2015 study which assessed Danish and Belgian GPs' knowledge of HS, found important deficiencies in their knowledge of the condition (12). In our study, most GPs felt they were able to diagnose HS confidently, suggesting either the sample was atypical, or GPs may be unaware of delayed or missed diagnosis in a proportion of patients.

Co-morbidities add significantly to the disease burden of HS: several studies have documented high levels of CV disease (13) and sudden cardiac death associated with HS (7). Anxiety, depression and suicidality are also more common in people with HS than in the general population (14). Pain may be experienced acutely due to inflamed lesions, and also have a chronic aspect, and has been found to be one of the most debilitating aspects of HS (15) with the HS Priority Setting Partnership process concluding that effective analgesia was one of the top 10 priorities (16).

#### Implications for practice

Recent advances in the treatment of HS have focussed on interventions for people with more severe forms of HS, and biologic drugs have been life-changing for some patients (17). However, many HS patients have milder forms of the condition which never progress to this severity. People with milder forms of HS can often be managed effectively and holistically in Primary Care, with appropriate support where required from specialists in Secondary Care (2). Prompt and effective treatment and lifestyle advice early in the course of the condition may prevent some patients progressing to more severe disease requiring second-line treatments and extensive surgery for disfiguring scars and skin tunnels (2). Management of pain, anxiety and depression will improve quality of life and patients' ability to manage their condition.

UK guidelines recommend that surgical intervention, particularly localised excisions, should be undertaken as part of an overall management plan for HS patients rather than as an isolated intervention, as the disease is very likely to recur (2). Our data suggests that some patients are still being referred for localised surgical excisions directly from General Practice, and it's unclear whether their disease is being controlled systemically prior to this, as is recommended. Local referral pathways for HS patients might be helpful in ensuring patients have a Dermatological assessment of the overall disease burden prior to surgical intervention. Very few GPs in our sample currently refer to a multi-disciplinary HS clinic as recommended by the BAD Guidelines (2), possibly reflecting the fact that few hospitals offer this service in the UK.

## Conclusion

Dermatology services are not configured to offer support for lifestyle changes, or manage co-morbidities common in HS, such as CV disease, diabetes and depression, areas where Primary Care has expertise. Primary Care itself is at a crisis point in managing workload, however, people with HS are already being seen frequently in Primary Care : on average 8.9 times per patient annually (1). The interventions required at early stages of the disease, such as oral tetracycline-type drugs; support for lifestyle change; pain and wound management, and screening for depression and CV risk, are ones GPs are experienced in using. GPs in this study, with and without a special interest in Dermatology, were confident in initiating first line management of HS in Primary Care and offering lifestyle advice. Targeted education for Primary Care might be useful in also raising awareness of common

co-morbidities and complications of HS, and the importance of managing these to improve quality of life.

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Ethical approval was not required, as healthcare staff were recruited as research participants in the context of their professional role (18).

Competing interests: Non-personal financial: the authors have been awarded a NIHR grant to set up an observational study into current practice in treating Hidradenitis Suppurativa in Secondary Care settings, since the completion of this study. Personal financial: JRI is a consultant to Novartis, UCB Pharma, ChemoCentryx and Boehringer Ingelheim and has participated in advisory boards for Kymera Therapeutics and Viela Bio in the field of hidradenitis suppurativa. He is Editor in Chief of the British Journal of Dermatology.

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Box 1: Diagnostic features of hidradenitis suppurativa (8)

*Typical lesions*- inflamed nodules, discharging abscesses, chronic sinus tracts, rope-like scars, comedones  
*Typical sites*- groin and axillae are commonest but breasts, neck, lower abdomen and perineum are also recognised sites  
*Typical course*- skin lesions recurring /non-resolving at the same sites, despite standard short antibiotic courses. At least 2 lesions in the past 6 months or a lifetime history of at least 5 lesions

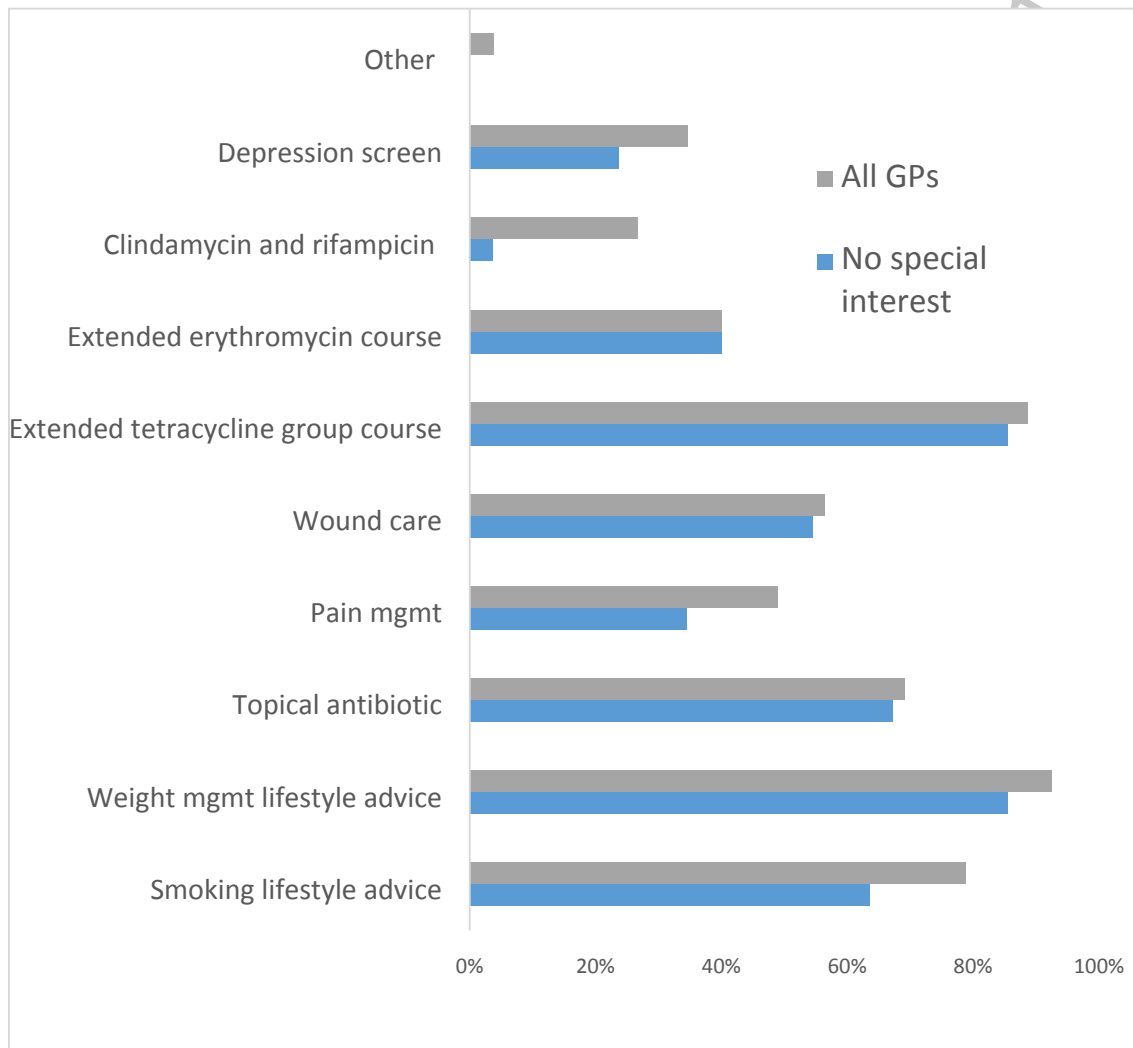


Figure 1: Medical interventions for HS: GPs choice of options that they would try before referral, comparing overall GP sample with subgroup of GPs with no Dermatology Special Interest

'Other'= free text replies: metformin, 'botox', isotretinoin, co-morbidity screening

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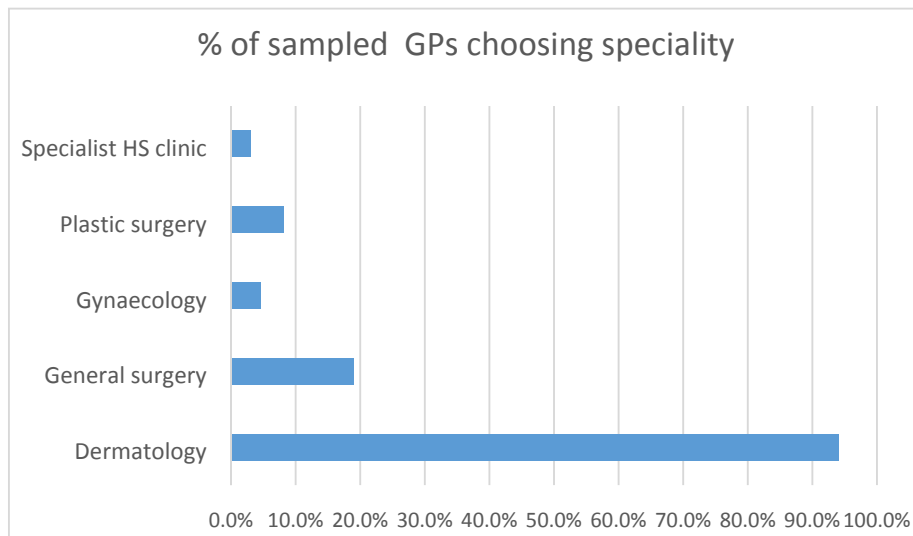


Figure 2: GPs' choice of speciality when referring HS patients to Secondary Care

Location of GP participants	No Derm special interest	Derm special interest	Total
England	7	58	65
N Ireland	0	2	2
Scotland	46	16	62
Wales	2	4	6
<b>Total</b>	<b>55</b>	<b>80</b>	

Table 1: Proportion of GPs with Dermatology Special Interest and location of practice in sample

No. of HS patients seen in past month	Total n	Total %
None	40	29.9%
1	45	33.6%
2	32	23.9%
3 to 5	14	10.4%
>5	3	2.2%
<b>Grand Total</b>	<b>134</b>	<b>100%</b>

Table 2: Number of patients with HS seen by GPs in month before survey

Intervention Offered	GP Dermatology special interest	
	Special interest	No special interest
Weight management advice	96.3% (n=77)	85.5% (n=47)
Tetracycline antibiotic 3 months	90.0% (n=72)	85.5% (n=47)
Smoking lifestyle advice	87.5% (n=70)	63.6% (n=35)
Topical antibiotic	68.8% (n=55)	67.30% (n=37)
Wound care	57.5% (n=46)	54.5% (n=30)
Pain Management	57.5% (n=46)	34.5% (n=19)
Depression screen	41.3% (n=33)	23.6% (n=13)

Table 3 Key interventions offered to HS patients by GPs prior to specialist referral

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