Dermatological Nursing

OPTIMISING HIDRADENITIS SUPPURATIVA CARE

A multi-professional consensus statement

A STATEMENT FOR CHANGE

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I am delighted to be able to write an introduction for this supplement on hidradenitis suppurativa (HS). This is a condition that is often overlooked, despite it affecting nearly as many people as psoriasis.

We need to raise standards of care for everyone with HS

The BDNG has brought together several healthcare professionals and people with HS to discuss some key issues that are often not covered by other guidelines. This resulting consensus document is aimed at raising awareness of some important (often neglected) factors and provide guidance about how to improve the care of patients with HS.

There are many useful elements of this document, but from my perspective two key things have emerged. Firstly, the importance of acknowledging that this is not a rare condition and that it needs to be diagnosed in a timely fashion. That is important for people who have HS, but it is also important for colleagues working in primary care. The consensus document makes some recommendations around key diagnostic features which will be of particular importance for those working in non-specialist environments.

The second key element is the importance of wound management. The use of appropriate dressings that can be secured without additional trauma to the skin is vital for managing disease severity and improving quality of life. The panel discussed this extensively and the results of those discussions are included in this consensus. That, in itself, makes this consensus somewhat unique.

We very much hope that this supplement will provide a really useful contribution to the practical care of patients living with this challenging condition. Please share it widely with those that you work with to ensure that people are made aware of the importance of managing HS effectively. Whilst some people with more severe disease will have options for biologic therapies, there are many people for whom this will never be an option. We need to raise standards of care for everyone with HS and I hope that this consensus document will add to the body of literature that will ensure this happens. DN

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All quotes in the text come from panellists. For the purposes of this consensus document, they have been anonymised.

Panellists:

- **Alison Schofield** – Clinical Manager Mole Digital, Honorary TVN York and Scarborough NHS Foundation Trust
- **Amy Colby** – Patient with HS
- **Angelika Razzaque** – Salaried GP, Amersham Vale Practice. Clinical lead, OHL Community Dermatology Service, Lewisham. Associate Specialist in Dermatology, King's College Hospital
- **David Fitzgerald** – Consultant Dermatologist, Salford Royal NHS Foundation Trust
- **Heather Newton** – Consultant Nurse Tissue Viability, Royal Cornwall Hospitals NHS Trust. Honorary Clinical Fellow, Clinical School, University of Plymouth
- **Leila Kattach** – Advanced Nurse Practitioner, Guy's and St Thomas' NHS Foundation Trust
- **Carolyn Martin** – Dermatology Biologic Nurse Specialist, Southern Health and Social Care Trust, Northern Ireland
- **Fiona Collier** – Freelance HS researcher. Former GP with Special Interest in Dermatology, NHS Forth Valley
- **Georgina Gethin** – Professor of Nursing, School of Nursing and Midwifery, University of Galway

Optimising hidradenitis suppurativa care: A multi-professional consensus statement

Lauren Nicolle

Hidradenitis suppurativa (HS) is a poorly understood and often mismanaged chronic, inflammatory skin disease that usually presents with painful, inflamed lesions in the flexural areas of the body. While medical advances have been made to control the disease and prevent symptoms from worsening, effective wound care, ongoing support and management and diagnosis guidelines remain limited. This consensus document is a summary of the suggestions made by nine healthcare professionals and experts by experience during a meeting about how to improve outcomes and develop an ideal patient pathway for patients with HS.

Hidradenitis suppurativa (HS) is a chronic, inflammatory skin condition that causes painful, boil-like nodules on the skin. Over time, these nodules can develop into abscesses that leak discharge, often leading to tunnelling and scarring from repeat episodes.

HS develops when hair follicles become clogged and inflamed, usually in the axillae, groin, abdomen folds, buttocks and under the breasts. It can also affect other areas including the breasts, chest, back, neck and behind the ears. While HS was initially considered an inflammatory process of the sweat glands, we now know that HS is an autoinflammatory syndrome and there is no significant direct relationship between HS and sweat glands.[1] However, the sweat glands can become inflamed as a secondary part of the disease process due to their close proximity to the follicular unit. While the exact cause for the condition is not known, numerous studies have hypothesised that the disease is triggered by genetic and environmental factors.[2]

Research has shown that 30-40% of affected individuals report a family history of HS.[3] However, the actual figure may be higher, since affected individuals do not always tell their family members that they have the condition and misdiagnosis is common. Obesity and smoking are also strongly associated with the onset of HS and can affect the severity of the disease.[4]

HS can persist for many years, and the condition can have a significant impact on a person's quality of life, their mental health and wellbeing.[3] Patients with advanced stages of the disease have to regularly change their dressings and live with relentless pain and discomfort. This can make it difficult to fulfil basic day-to-day tasks, like going to work, which can have financial implications.

While there is no cure for HS, treatments that help to control the disease and lessen symptoms are available. It is therefore vital that healthcare professionals are aware of the disease, so that they can provide timely access to treatment and support, and prevent the permanent, physical side effects of HS, such as scarring and potential partial loss of function of the affected site(s).

To tackle this issue, the British Dermatological Nursing Group (BDNG) brought together a multidisciplinary panel of nine healthcare professionals and experts by experience to discuss and develop a best practice pathway for HS. This includes improving diagnosis waiting times and providing optimal wound care, mental health support and ongoing management.

Describing pharmaceutical treatments for HS is outside the scope of this document, with the main focus being pathways to better care and improving outcomes for patients with HS.

How to improve diagnosis of HS

Patients with HS need to be diagnosed as early as possible to control the disease and reduce

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systemic inflammation. Without timely treatment, symptoms can worsen, tracts can develop, and painful, deep breakouts will re-occur. Once the condition has become established, it is very difficult to bring it under long-term control. Despite this, a recent survey undertaken locally by one of the panellists found that 35% of patients with HS waited for three to 10 years before being diagnosed.

While there is no definitive test to diagnose HS, there are very clear diagnostic criteria (the Dessau criteria), and with the right training, it is not difficult to identify. Healthcare professionals should look for the following:

- Typical HS lesions (nodules, sinus tracts and scarring)
- Frequency of the lesions and whether they are recurring. For example, has the patient experienced more than one outbreak of boils or lesions in the last six months?[5]
- Where the lesions are located (common areas include the axillae, groin, buttocks and genitals, but it can also affect the breasts, chest, back, neck and behind the ears)
- Inflammation, redness and pain in the affected area
- Whether there is a family history of HS.[6]

HS will present differently in patients depending on how advanced it is. The Hurley staging system helps healthcare professionals categorise the disease into three different stages.

1. Stage I is a single or few isolated boils with no sinus tract or scarring
2. Stage II is recurring boils in multiple areas with scarring and sinus tracts
3. Stage III is widespread boils with multiple interconnected tracts across the affected area, often with malodourous discharge.

"The crux is to recognise it. Even the term 'hidradenitis suppurativa' makes things more difficult, it's hard to say and sounds like an obscure, rare disease. Healthcare professionals need to be aware of how the disease presents so they can diagnose it quickly."

"When patients first present with HS, it is likely they will be tested for diabetes or some form of underlying metabolic disorder. When these tests come back negative, that's when alarm bells should ring."

Key recommendations

To improve diagnosis rates, a diagnostic flow chart for healthcare professionals should be developed based on the criteria above. A poster or infographic that showcases diagnostic signs could also be placed in GPs, pharmacies and A&E departments, as this is where many patients first present.

Healthcare professionals across all specialities (but particularly GPs, pharmacists and A&E staff) should receive training to diagnose the condition just as they would for other common skin conditions, such as psoriasis.

A self-assessment tool for patients would help to raise awareness and enable more patients to identify the disease. Information about HS should also be added to NHS Choice's 'Boils' and 'Abscesses' pages to ensure HS symptoms are not treated in isolation.

An online directory of departments that specialise in HS would also be helpful for both healthcare professionals and patients.

Improving public awareness

A 2018 UK-based study provides the most realistic prevalence data for the UK. The study analysed 4.3 million research-standard records in the UK Clinical Practice Research Datalink, and demonstrates a HS prevalence of 0.77% using the most stringent disease definition, rising to 1.19% if probable cases are included.[7]

With a similar prevalence rate to psoriasis, HS is not a rare disease, but public awareness of the condition is poor. Impairment in the quality of life of affected people is profound and more pronounced than the impairment caused by other dermatoses including psoriasis, atopic dermatitis, acne vulgaris, alopecia, Darier disease, Hailey-Hailey disease, and even chronic urticaria. It has been described as "probably one of the worst that has been analysed and evaluated in dermatology to date."[8,9]

While HS Awareness Week runs globally on the first full week of June every year, it is predominantly promoted by HS patient groups and more work needs to be done to encourage discussions in the mainstream media.

It is important that this changes, as increasing awareness of the clinical and patient-reported features of HS would lead to prompt diagnoses and better care for patients.

"When HS was on [TV programme] Embarrassing Bodies, it was just amazing for so many patients. They felt validated and realised they weren't alone. So, the media is really important in that regard."

"I've had HS since I was 12, but I didn't receive a diagnosis until the age of 27. The only reason I got this diagnosis was because I saw a HS patient, Elise Axon, on a TV programme called The Bad Skin Clinic. When I watched the programme back, I was convinced I had the same condition, so I went to my GP and managed to get a referral."

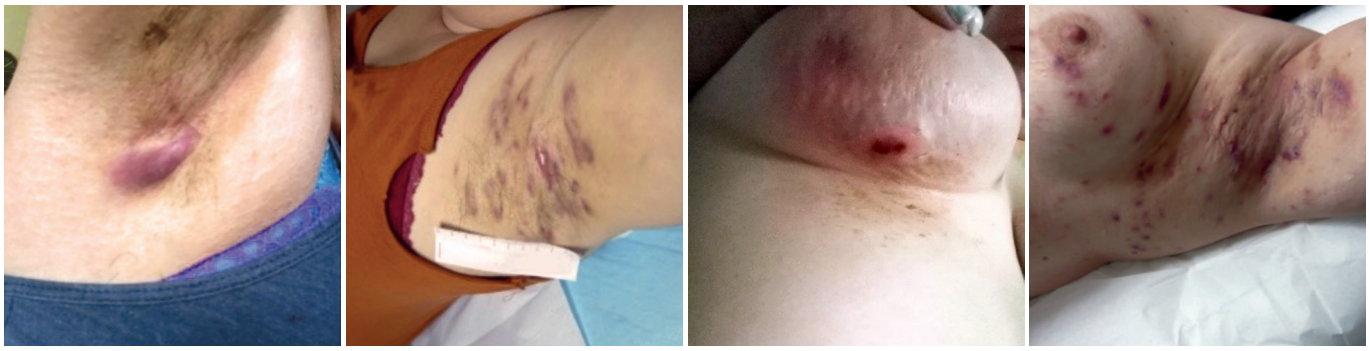
"Not only do we need to raise public awareness among healthcare professionals, but also among the general population, so that we can break down barriers and ensure patients come forward to get diagnosed."

Key recommendations

The creation of an awareness campaign designed for schools and universities would help to inform younger populations about the condition. Since the onset of HS is insidious and often starts at puberty,[10] this is an important way to increase early diagnoses.

To raise awareness in the wider population, a media campaign designed for TV, radio or the press

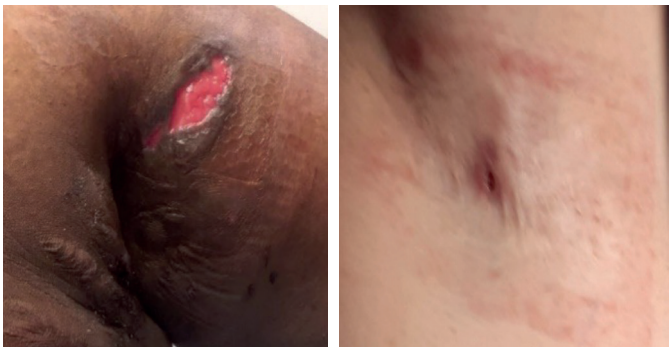
Recognising Hidradenitis in the Clinical Setting[1]
Location: Axillary Region & Breasts



Recognising Hidradenitis in the Clinical Setting[1]
Location: Buttocks, Groin, Upper thigh & Genitals

Recognising Hidradenitis in the Clinical Setting[1]
Location: Neck, Hairline, Chest & Back

Recognising Hidradenitis in the Clinical Setting[1]
MARSI: Issues with traditional dressing technologies in HS wound care



Images courtesy of HidraMed Solutions (www.hidrawearcom) and Lenicura GmbH (www.lenicura.com)

would be helpful. Amplifying patients' voices through the media would help to start a conversation about HS and reduce some of the stigma surrounding the condition.

While social media is generally well utilised by patients, it is typically used by younger patients and those who already have the condition. A large-scale social media campaign would help to bring the condition further into the public eye and signpost patients to support groups.

A national patient support group would also help to raise awareness of HS. With the HS Trust no longer in existence, a new, formal support group is needed to improve public awareness and serve as a platform for resources and support.

Educating healthcare professionals and patients

In the UK, medical students and nurses often receive very little formal education or exposure to dermatology throughout their training.[11] This has meant that healthcare professionals are less likely to be able to diagnose skin conditions when they encounter them.

Patients with HS say they often have to explain their condition to healthcare professionals, with some saying they feel the disease is trivialised by GPs and other professionals who not have specialist knowledge of the condition.

HS is a serious condition and carries a risk of metabolic syndrome, cardiovascular disease, diabetes, polycystic ovarian syndrome, depression and suicide.[12] It has also been documented that HS patients have, on average, a lower life expectancy of 15 years compared to other conditions like psoriasis.[13]

Educating healthcare professionals about the clinical symptoms of the disease, as well as the psychological affects would therefore help to improve patient outcomes and quality of life.

"Education is one of the main issues we need to tackle. Dermatology training for all doctors, but especially GPs, is very lacking. There is a huge discrepancy between what is needed in terms of service provision and what is being delivered because of this lack of education."

"We do a session on HS every year with our students on the Advanced Wound Care module and every time, there is at least one person in the room who has this lightbulb moment of realising that one of their patients has HS. I can see first-hand that when you have dermatology education on the agenda, it really makes an impact."

"We as patients need educating too about how to treat each wound and which dressings are most appropriate."

Key recommendations

Educating healthcare professionals about HS would help to speed up diagnosis and prevent people with HS presenting with advanced stages of the disease. A small online module or information system, or a series of professional, informative videos that could be widely disseminated to relevant educational establishments would help to heighten awareness and reduce diagnosis waiting times.

Webinars and conference presentations to groups of healthcare professionals that may see patients with HS would also help to educate and inform clinicians, and would give viewers the chance to interact with the speakers and ask questions.

The development of National Institute for Health and Care Excellence (NICE) guidance for patients with HS would also help healthcare professionals to provide a well-rounded, holistic approach to treatment.

Patients with HS also require reliable information about their condition, particularly if it is newly diagnosed. The creation of one uniformed document, published on the NHS or British Association of Dermatologists' (BAD) website, would make it easier for healthcare professionals to signpost these patients.

In the meantime, patients should be signposted to existing information leaflets and online resources which explain what the condition is, how to manage it, and other factors such as taking time off work and managing personal relationships.

Finally, healthcare professionals must understand that while obesity is strongly associated with HS, it does not cause HS and people with a healthy BMI can have the condition too.

Clinicians must therefore ensure they do not blame overweight and obese HS patients for their condition, and explain that while weight loss will be beneficial for the majority of patients, the benefits may be less clear in established disease.

When should patients be referred to dermatology services/secondary care?

The COVID-19 pandemic has pushed already over-stretched dermatology services to the limit. Data shows that in 2021, dermatology services were operating at 20% below 2019 levels.[14] This has caused a huge backlog of care and long waiting times for dermatology referrals.

HS is harder to manage when it reaches the more advanced stages, so it is vital that the disease is caught early and treated appropriately. However, a recent survey undertaken by one of the panellists (the results of which will be published later this year) found that 40% of patients had 11 appointments with a GP before being referred to secondary care.

It is important that primary care practitioners do not wait too long to refer to dermatology, as this could delay essential treatment and management advice, which could affect the patient's quality of life.

Key recommendations

HS guidance implies that referrals should be based on the Hurley staging system. While this may risk delaying appropriate treatment, it is important that this process is followed to prevent dermatology services from being overwhelmed. Since there is already a shortage of dermatologists, the service would struggle to cope if GPs were referring patients without trying first-line treatments.

GPs and other primary care professionals should prescribe first-line treatments including a wound management solution they deem most appropriate, and then ask the patient to book a follow-up appointment in 12 weeks' time. Ideally, patients with draining, unhealed wounds should be seen again within four weeks by a healthcare professional with wound care competencies, but this is not always possible due to capacity challenges. If the patient does not respond to treatment and/or is experiencing repeated flares, then they should be referred to dermatology and/or wound care specialists.

The panel suggests that instead of relying on disease severity, healthcare practitioners should look

Summary of HS multi-disciplinary care provision

GP/pharmacy services	Dermatology	Wound management	Mental health services
Diagnosis and initial management Prescriptions (including dressings) BMI/weight loss: clinic/plan Referral to specialist services Smoking cessation	Confirmation of diagnosis – Hurley scale Biologics if required Surgical/debridement Active wound care management and referral to wound care specialists	Wound assessment and management: access to dressings for managing exudate, odour or infection Pain management	Psychological support

at symptoms and responsiveness to treatment. For example, if a patient is thought to have HS and requires active wound care to manage their flare up, it is recommended that the patient should be referred to a wound care specialist and appropriate wound care provision can be provided. This would help to manage the patient's symptoms while they wait for a confirmational diagnosis from a dermatologist on referral.

At this stage, clinicians should ask the patient if they need support with weight loss, smoking, psychological support, antibiotics and dressings, and if necessary, refer the patient to the appropriate department.

Weight management services vary across the UK and some clinicians are only able to refer patients for weight management if the patient's BMI is above a certain level. The panel would like to see the implementation of a regional weight management process and for HS to be added to the list of conditions that you can refer at a lower BMI. Early intervention could help to prevent further weight gain and the need for bariatric surgery, which risks exacerbating symptoms.

Improving mental health support for patients with HS

Research has shown that many people who live with chronic skin conditions often struggle with their mental health,[15] and patients should be made aware of this.

HS is painful and can be debilitating at times. During flares, patients often struggle to carry out simple day-to-day tasks and may have to take time off work. For this reason, HS is associated with a considerable indirect burden, including lower annual income and income growth, higher risk of leaving the workforce, more days of work loss and higher indirect costs.[16] Indeed, the unemployment rate of adult HS patients eligible for a job is 25.1%, compared with 6.2% in the general population.[17] An effective treatment pathway for HS patients must reduce this additional indirect burden.

Since HS primarily develops in the underarms, groin area, around the anus, and beneath the breasts, some people with the condition may feel embarrassed and unwilling to be intimate with their partner. This can be very distressing for the affected individual and can put a strain on personal relationships.

Patients should regularly be asked to fill out a Dermatology Life Quality Index (DLQI)[18] to give the healthcare professional an idea of how the patient is coping. However, often no follow-up support is provided. This can leave patients battling with their mental health alone, which can have a huge impact on quality of life.

It is therefore vital that HS patients who suffer with depression and anxiety get the support they need, whether that is through counselling, cognitive behavioural therapy (CBT), or medication.

"There are guidelines for treatment plans, but not clear infrastructure or plans to manage patients' mental health."

"I had one patient who said that if she had to pick just one HS treatment to keep, it would be mental health support. She said it was worth more than anything else she had received in the first 10 years of having HS and had made the biggest difference to her quality of life."

Key recommendations

GPs and other healthcare practitioners who have regular contact with HS patients should make a conscious effort to ask patients how the condition is affecting their mental health. Patients should be encouraged to ask for help early on to prevent them from reaching crisis point.

To do this, some healthcare professionals may need extra training on how to have sensitive conversations with patients. This will ensure that healthcare professionals do not shy away from difficult discussions, ensuring patients get the help they need.

It is likely that having this initial conversation will help the patient feel heard and realise that it is normal for their condition to have some effect on their mental health. Patients should also be signposted to online support resources while they are awaiting treatment or referral.

Healthcare professionals should ask the patient what is driving their depression or anxiety. If the patient is feeling anxious about their wounds leaking, for example, the clinician can make sure they have a list of the appropriate dressings and how to apply them.

Doctors can also refer the patient to the Improving Access to Psychological Therapies (IAPT) programme for non-disease specific support. This self-referral programme informs the patient about local mental health services which may result in them getting help sooner than if they were to wait for a referral.

While the gold standard is for dermatology patients to have access to a clinical psychologist, there is not always one available. Services that do not have access to a clinical psychologist should instead try to offer group support sessions for HS patients or signpost them to online groups. Not only does this reduce pressure on services, but it also enables patients with the same condition to meet, compare coping strategies and offer support to one another. This can lead to better informed management and a lessened impact.

Improving wound care management

HS wound care management poses various challenges. While there are a plethora of dressings available on the British National Formulary, many of them do not meet the needs of patients with HS.

Firstly, most dressings come in a 10x10cm square, but few wounds fit neatly into this shape. HS wounds also usually present in areas of the body which are difficult to dress. These areas are subject to large amounts of movement and flexion, are typically hirsute and regularly perspire. As such,

retention of dressings is particularly difficult using adhesives and tapes. This means patients often have to use large quantities of dressings, which comes at a high cost. Indeed, drawing from healthcare cost estimates, the total direct wound care product cost (dressings, tapes etc.) for this subset of British patients lies between £75.6M, at a prevalence of 0.05%, to £1,164.4M at a prevalence of 0.77%.[19] If patients run out of dressings, they often have to resort to using alternative materials, such as sanitary towels, incontinence pads and tissues.

MARSI (medical adhesive related skin injury) is also an important issue to consider. If dressings with adhesive borders are used in fragile, painful areas where lesions occur, this can cause further epidermal stripping, pain and excoriation.[20]

In addition, patients with HS will often have wounds that leak malodorous fluid. These patients require dressings that are highly absorbent, deodorising, gentle on the skin and antimicrobial (to avoid secondary infections). However, patients often have difficulty getting these dressings prescribed.

Patients who do not have confidence in their dressings will avoid going out in public for long periods of time, impacting on their ability to work, exercise and contribute to society. This makes it harder for HS patients to maintain a healthy weight, good mental health and earn a living, impacting on overall quality of life.

It is critical that patients can access dressings when required. Healthcare professionals should also consider who is going to continue to prescribe dressings for patients, and when they will next be re-evaluated to see if their needs have changed.

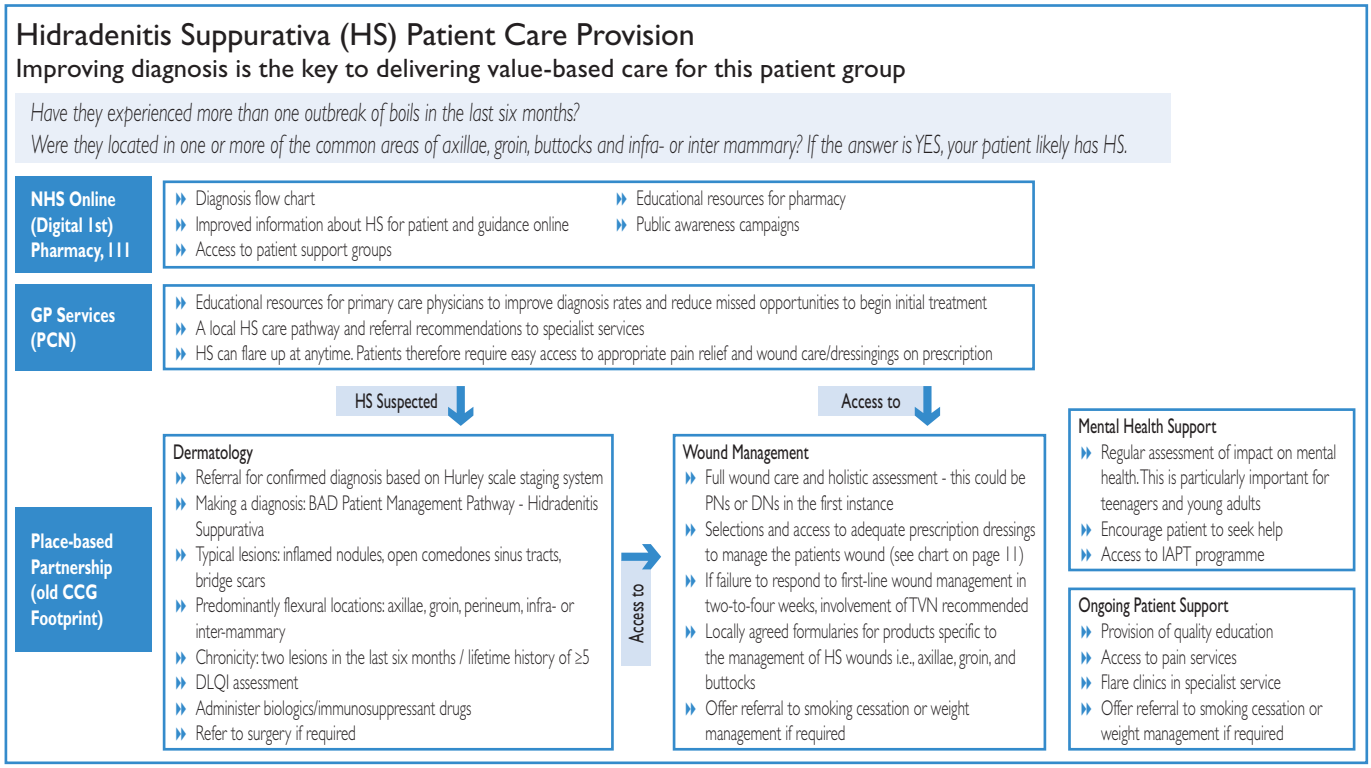
Key recommendations

It is crucial that wound care prescriptions are based on the needs of the individual. Healthcare professionals should ask themselves: 'Is odour a concern?', 'Is there a risk of infection?' and prescribe accordingly. The flowchart below will help clinicians to make these decisions, ensuring the patient receives the right dressings, rather than what is contained on a local formulary.

Formal guidance, which would provide advice about the most suitable dressing depending on the type of wound, would also help healthcare professionals to prescribe appropriate dressings. The involvement of Tissue Viability Nurses in the management of wound care, both in primary and secondary care, should be standard practice.

The continuous use of adhesive dressings can cause irritation and damage to the skin (MARSI). Removing adhesives from the wound care routine will therefore remove adhesive skin injury, reduce pain and improve quality of life. Medical dressing retention systems that use garments which hold the dressings in place offer a solution to this problem. While the initial cost is higher, the overall, long-term cost to the patient is reduced as dressing changes will be far less frequent.

It would also be helpful to consult patients with HS about which dressings work best for different wound types, e.g., which is the most comfortable? Which is best for odour? Which soaks up exudate? Which stay in place? Which cause MARSI? Answers to these questions could help to inform local wound care guidelines.



Guidance framework for assessing and evaluating wound care selection and solutions for best managing HS wounds			
Wound care assessment	Criteria	Challenges	Recommendations for product selection
Dressing difficulty	Clinically effective solution for managing HS wounds (in groin, buttocks and axillae).	Patients often struggle with dressings for HS due to the wound locations. Most patients require dressings for more than six months of the year, with an average of 2.8 changes per day.[21] Patients often need to use additional equipment such as a mirror, extra bandages and tapes, and need assistance with their dressings. Larger island dressings often need to be cut or cobbled together. This can make HS wound care difficult in work, social and other settings.	Choose products that are easy to apply, adjust and remove in an efficient manner. Select dressings that are suitable in size and shape for the affected area and enable movement.
Dressing pain	Pain free application and removal - does not damage wound or surrounding skin. HS wound locations are typically swollen, tender and incredibly painful to touch.	Dressings that are not retained securely can cause friction and damage the wound area and surrounding skin. Pain is regularly experienced in the management of chronic wounds, often exacerbated by dressing changes, and damage to peri wound skin.[22] Mobility can be limited when using strong adhesives or bandages on the skin. In some cases, adhesives can also cause deeper tissue injuries beyond the loss of superficial skin layers.[23] Repeated use of adhesives can cause MARSI, skin stripping and adhesive rashes, leading to patient pain, discomfort and distress.	Choose soft, flexible dressings, ideally adhesive-free, retained with garments or bandages if appropriate. If using adhesive dressings, consider barrier creams or sprays to reduce MARSI and adhesive remover if appropriate. Consider advanced dressings for wound bed if cavity or ulcerated lesions present. Ask yourself – will adhesive dressings cause this patient more pain? If the answer is yes – try garment or bandage-based solutions.
Retention and leak confidence	Manage exudate levels. Reduce the risk of maceration or delay in healing. Dressing retention to keep wound covered in axillae, groin and buttocks.	Exudate and moisture balance play a key role in wound healing,[24] but with the wrong amount, it can have a detrimental effect.[25] When fluid is trapped against the skin for sustained periods of time, it becomes soft and at risk of damage from the protein-digesting enzymes contained in exudate.[26] HS lesions frequently expel high volumes of exudate. Frequency and volume are unpredictable, and dressings often become saturated, causing embarrassing leaks. High levels of anxiety and shame are experienced by patients due to leaks and odour. Patients often limit their range of movement due to the risk of dressings peeling away or falling off.	Select an absorbent wound dressing such as a super absorber, or a foam dressing. When selecting the tape, bandage, or garment, consider what will best retain the dressing in place in the specific location. Tapes and adhesives perform well on flat, smooth areas of the body. Bandages work well when wrapped around a limb or trunk. Body conforming garments work well in difficult to dress areas.
Time consumption	Efficient dressing application, adjustment and removal.	Dressings often have to be cut and repositioned several times. HS wounds are often in difficult to dress locations. Patients can require assistance to adjust and reapply wound care by a professional, family member or friend. On average up to eight hours can be spent changing dressings per month.[27]	A wound management solution that can be applied and re-adjusted with ease, and removed in the home setting. Consider if the patient has equipment (scissors or a mirror) available to them for dressing changes as adhesives often need to be cut or modified.
Dressing comfort	Secure dressing retention – reduces slippage, chafing and leaks.	Dressings can bunch or pinch on movement causing additional skin injury. Rubbing and chafing further irritate the area.[21] Bulky bandages, pads and adhesives can restrict movement and affect posture and gait. Areas affected by HS are warm, moist, mobile and often hairy areas of the body, making it very difficult to effectively use adhesives to securely retain a dressing in place.	Soft and gentle – flexible and body conforming in difficult to dress areas.
Body confidence	Self-management and empowerment	Many dressings used in HS are bulky, thick and noticeable under clothing, leaving patients feeling self-conscious and embarrassed. Patients often require assistance with their dressings – impacting their sense of independence and autonomy. Unsightly, sticky and leaky dressings damage patients' self-confidence and body image.	Choose products that empower the patient to self-manage in the home setting. It should be a discreet option, that is not bulky or noticeable through clothing.

Wound care assessment	Criteria	Challenges	Recommendations for product selection
Quality of life (DLQI)	Adhesive free – or minimal adhesive required to securely retain dressing.	Dressing selection in HS can impact quality of life – poor dressing selection leads to adhesive skin damage, dressing related pain, leaks, lost dressings, discomfort, and lost time spent managing the wounds.	Select dressings and retention aids that remove risk of skin damage and dressing-related pain. Select comfortable, conforming and cushioned products. Select items that will securely retain the dressings in place, particularly the difficult to dress areas such as the axillae and inguinal folds.
Infection	Manage or reduce the risk of HS wounds being infected.	While HS lesions are not typically an infection, mismanagement of the lesions can lead to physical contamination or infection. Bacteria found in HS lesions are various and are usually part of the normal skin microflora. These microorganisms have been considered either as contaminants or as the result of a secondary infection.[28] If an infection is diagnosed, please follow the principles laid out in the 'Wound Infection in Clinical Practice' best practice document.[29]	For patients with active HS, healthcare practitioners should consider recommending an antiseptic wash and/or an antimicrobial dressing to help manage the disease alongside other treatment. However, these decisions should be made under specialist advice only, particularly if the patient has other dermatological conditions that could cause sensitivity in the affected area (e.g., eczema).
Value-based care	Access to wound management and skin care.	HS is a debilitating and disfiguring disease, and patients live with pain, shame, stigma and embarrassment. Wound care options that provide complete care were (up until recently) lacking. Often patients are told to use sanitary towels or other household items due to the lack of effective solutions. This is undignified. Patients deserve the best and most effective wound care that enables them to live their lives to the full.	Patients with HS will have reoccurrence and flare ups at any time. It is important that they are able to easily access wound care through their GP or specialist in a timely manner. This reduces the risk of complications that require acute hospital interventions. Patients should be empowered to manage their condition.

"Patients really struggle to access dressings and many of them have to resort to using sanitary and incontinence pads, tissues and gauze. When they do get access, there's volume and continuity problems, meaning patients often run out. Patients also often have to layer dressings which can come at a huge cost."

"We have a plethora of dressings available on the British National Formulary, but many do not meet the needs of the patient."

"We have massive problems persuading GPs to prescribe dressings. The big problem is that patients end up having to buy them because GPs do not realise the severity of the disease, and local formularies disallow the prescribing of certain dressings. This needs to change."

Ongoing patient support and management

Since HS is a chronic inflammatory condition, patients will require ongoing support and management. A local survey undertaken by one of the panellists found that three out of five HS patients would value a support group, because they often feel isolated and want to meet people with the same condition.

While there are small scale support groups created by patients on social media, currently, there is no formal patient support group for patients with HS in the UK.

Support groups are not only valuable in preserving the mental health of patients with HS but can also offer pain and wound care management tips. For example, patients can discuss alternative pain management therapies, such as hot and cold compresses to reduce inflammation.

Healthcare professionals should also offer ongoing support to their patients, particularly with re-prescribing dressings and mental health check-ins.

Key recommendations

Resources on how to deal with different wounds, change dressings and at-home pain relief methods would therefore be extremely valuable for patients during a flare. Healthcare professionals should manage pain relief with the World Health Organization's (WHO) pain ladder.[30] If patients are suffering with high levels of pain, they should be referred to a specialist for advice.

Clinicians should also advise patients to keep a diary and write down how they are feeling each day, noting when they are experiencing a flare. This can help patients to identify a pattern and predict when a flare might be coming. For some people, stress or hormones may trigger a flare, and there may be certain steps which could help to control these factors.

Ideally, dermatology departments would have a flare clinic that would allow patients with HS to access services when they require support. Healthcare practitioners could then see patients and prescribe the appropriate treatment, for example

antibiotics, pain medication or extra dressings.

Staff working in flare clinics should be well-trained and able to take a holistic approach to treatment. This includes discussing things like weight management, smoking cessation and mental health, which would help to reduce the number of patients presenting in emergency departments with more severe disease.

Conclusion

HS is a chronic, painful condition that requires ongoing treatment and management. Despite HS having a similar prevalence rate to psoriasis, awareness among healthcare professionals and the wider public is severely lacking. This leads to delayed diagnoses and missed opportunities for treatment which can have a significant impact on a patient's quality of life.

While there is some guidance in place surrounding medications and treatments, this panel discussion has revealed a clear need for distinct guidelines surrounding long-term care, pain management, wound care and mental health support. First and foremost, however, awareness of the condition must improve so that healthcare professionals can identify HS early in the course of the disease and provide timely treatment and support.

There is still a long way to go before HS is more widely recognised and receives the wound care attention that it deserves. Combining awareness of the condition and the relatively simple diagnostic criteria with the HS treatment pathway outlined in this document will almost certainly lead to a meaningful improvement in the lives of this underserved, highly distressed and often overlooked patient group.

By ensuring there is a clear patient pathway for those affected by HS, healthcare professionals will be better equipped to provide ongoing support and management and improve outcomes for those living with this chronic, debilitating condition. DN

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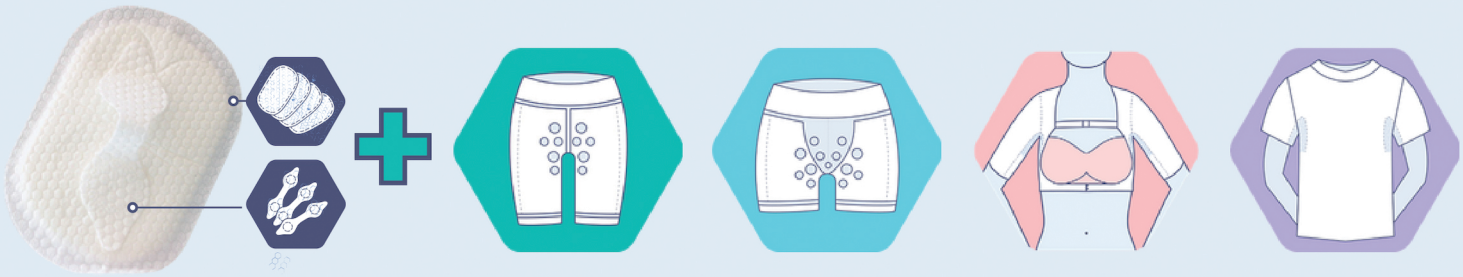

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