HIDRADENITIS SUPPURATIVA (HS)
MEDIA BACKGROUNDER

What is HS?
Hidradenitis suppurativa (HS), sometimes called “acne inversa” by dermatologists, is a chronic, often painful, immune-mediated systemic disease characterised by inflamed areas typically located around the armpits and groin. These inflamed areas often include lesions, boils and abscesses, and usually occur where many oil and sweat glands are located; as well as under the breasts, on the buttocks and on the inner thighs, where skin rubs together. Though it affects the skin, HS is a systemic inflammatory disorder, which means the condition is associated with irregularities in the body’s immune system.

HS is a debilitating, yet under-recognised disease that can be very painful for patients, has a significant impact on their quality of life and can lead to serious psychological disorders. Despite the serious and long term physical and emotional burdens HS has on the lives of patients, research and clinical studies in HS are limited. Given the lack of approved medical therapies, there is significant unmet medical need for new treatment approaches for HS patients.

Who is affected?
In the UK it is estimated that 977,900 adults have HS; 15.8% (154,500) moderate and severe HS.

HS can occur at any age, but it typically begins in the second or third decades of life, usually developing in adults in their early 20s, with declining rates after the age of 50 to 55.

Women are more likely to develop HS than men. The ratios reported range from twice as likely to five times more likely.

What causes HS?
Why people develop HS is unclear, but it is thought that an abnormal response of the body’s own immune system plays a role and the symptoms result from blockages of hair follicles. It’s not known why blockages occur, but a number of factors — including hormones, genetics, cigarette smoking and excess weight — may all play a role. Research shows that HS may run in families, as about one third of people diagnosed with HS have a family history of the condition.

What are the symptoms of HS?
Approximately 50% of all patients experience itching, burning, stinging, pain and heat up to two days before a flare up. The lesions typically last from seven to 15 days. The pain associated with HS can be intense, chronic and is seen by patients as the most significant factor contributing to impaired quality of life. The defining feature of HS is the tendency for lesions to recur at the same sites or nearby, despite surgical incision and drainage and short courses of antibiotics.

Mild cases of HS can resemble small bumps or blackheads, while patients with more severe forms can have multiple interconnected sinus tracts and abscesses, which sometimes release fluid and have an unpleasant odor. HS is typically described according to three Hurley categories:
• **Stage I (Mild):** Single or a few isolated abscesses without sinus tracts or scarring
• **Stage II (Moderate):** Recurring abscesses in multiple areas with scarring and sinus tracts
• **Stage III (Severe):** Widespread lesions, boils and abscesses (some as large as golf balls) with many interconnected sinus tracts, which may lead to scarring and release of unpleasant-smelling pus.2,4,6

**HS: Quality of life and psychological impact**

HS can have a significant emotional impact on patients and significantly affects a patient’s quality of life. Higher percentages of HS patients are diagnosed with psychiatric disorders compared to the general population.3 People with HS report feeling angry, depressed and even suicidal. HS can also lead to patients feeling helpless and dependent on others.9

People with HS report that they find their symptoms embarrassing and repulsive. They avoid talking about the disease, even with their family, and often isolate themselves because of their unpleasant symptoms. The pain and itching caused by lesions may also lead patients to avoid social situations.3 When flares occur, people with HS may also choose to stay at home because they experience a change in their mood and feel extremely tired.9 In addition, some patients find it difficult to form intimate relationships.9

HS can also impact a person’s ability to work. Patients with HS, especially those with moderate to severe disease, often have poor work productivity.3 Many patients, report increased number of absences from work due to their HS, while patients with inadequately controlled disease are often unable to work or lose their job.9

**HS: Diagnosis, management and treatment**

There is a lack of HCP awareness and experience in identifying and managing HS. This leads many HS patients to experience a lengthy delay before they are diagnosed. It can take up to eight years for people with HS to get an accurate diagnosis.1,2,10

Patients with HS should be under the care of a dermatologist as early as possible, which can help ensure an accurate diagnosis. Once diagnosed, a dermatologist is the right physician to manage the condition.11

However, research suggests that of diagnosed moderate to severe patients, in the last 12 months only 53% have seen a dermatologist, 13% have only seen their GP and 15% have not been seen by anyone.5

The lack of HCP knowledge about HS means that patients are often misdiagnosed, as they continue to present with recurring boils and lesions. Common misdiagnoses include acne or folliculitis.12 This is compounded by the fact that cases of HS can be progressive and therefore increase in severity over time.4 This can lead to major skin pain and permanent damage.4 As a result, diagnosing and properly managing HS as early as possible is vital.12

Management of HS varies considerably with limited services, no set pathway and a lack of joined up care. Access to the right HCPs is critical for HS patients. But at the moment there is lack of expertise, a small number of centres of excellence and few examples of a Multi-Disciplinary Team

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(MDT) approach. The MDT approach sees consultant dermatologists working closely with surgeons (colorectal and plastic), specialist nurses (dermatology and wound care) and psychologists with experience in psycho-dermatology, to provide holistic treatment and support.

The MDT approach has been recommended by HS experts. Based upon the established guidelines for HS treatment produced by the European Dermatology Forum, they have recommended that the diagnosis of HS should be made by a dermatologist or other health care professional with expert knowledge in HS. All patients should be offered other complementary therapy whether related to pain management, weight loss, tobacco cessation, treatment of super infections, or implementation of appropriate dressings.

**What treatments are available?**

There is currently no cure for HS. Until the approval of HUMIRA® (adalimumab), there were no approved medications for the treatment of the disease. NICE has not issued any treatment guidelines for HS.

**Antibiotic treatments**

Although antibiotics are widely used for the treatment of HS, there is limited data to support their use. Patients treated with short courses of antibiotics experience little-to-no effect long term.

**Surgical treatments**

In severe cases of HS, surgery may be considered to remove skin affected by the disease. However, it may not be an appropriate option for every patient. Surgery can be associated with high recurrence rates.

**HUMIRA® (adalimumab)**

HUMIRA® (adalimumab) is the first licensed medication for HS that addresses the underlying inflammation associated with the condition.

Adalimumab targets the TNF-α molecule, preventing it from attaching to TNF- α receptors on immune cells, which reduces inflammatory response.

**Other therapies**

Other treatments used include retinoids, contraceptive pill, immuno-suppressants and corticosteroids. There is limited research supporting the use of most of these treatments for HS.
References


14. NICE proposed health technology appraisal pre-referral, 2015

