Call to action: improving the lives of people with hidradenitis suppurativa (HS) in Japan

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The Health Policy Partnership

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About this report

Research, coordination and drafting of this national summary were led by Oriana Carswell, Chris Melson and Jody Tate of The Health Policy Partnership (HPP). HPP is grateful to Yuki Kato (person living with HS, Japan), who was interviewed for this national summary; it is part of a wider project that has published a **global-level report** on the topic, guided by a multidisciplinary Steering Committee.

Call to action: improving the lives of people with hidradenitis suppurativa (HS) in Japan

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What is hidradenitis suppurativa?

What is hidradenitis suppurativa?

Hidradenitis suppurativa (HS) is a chronic and painful skin condition that can be debilitating for people living with it. HS, also known as acne inversa, is a skin condition that is thought to affect around 1 in 100 people across the world.[1 2] It can cause significant physical challenges and lead to severe psychological distress.[3-5] It is an autoinflammatory condition that contributes to inflammation below the surface of the skin.[6 7] The condition often starts in a person's teenage years and is characterised by recurrent flare-ups of painful nodules which can become abscesses that look like lumps or boils.[8 9] These abscesses can rupture, resulting in a discharge that may have an unpleasant smell and stain clothing, and can cause scarring on the body, all of which can lead people to feel embarrassed or ashamed.[4 10 11] Over time, inflammation can progress and lead to irreversible damage to the skin.[12 13] People living with HS may also develop draining tunnels under their skin that can connect between nodules, producing blood and discharge.[14] HS is associated with a range of other conditions such as depression, spondyloarthritis (painful chronic arthritis that mainly affects joints in the spine), diabetes and inflammatory bowel disease, meaning that HS can require multidisciplinary care.[15-19]

HS has a significant impact on people's lives. HS has one of the highest impacts on quality of life among all dermatological conditions.[20] A key driver of the challenges from HS is pain, which is reported by almost all people living with the condition and can make it difficult to carry out everyday activities.[21 22] HS can have a major effect on almost every part of a person's life, including their personal relationships, work and social life; this ultimately contributes to the condition being highly distressing and affecting mental wellbeing.[23-25]

HS can result in considerable system costs through the loss of productivity and frequent use of high-cost services. The condition often affects people during their most productive years, and can mean people living with HS are more likely than the general population to miss days of work, be unwell at work or be unemployed.[24 26] This means the productivity of the HS population is significantly reduced. Additionally, high-cost settings such as emergency departments and inpatient care around surgery are used more frequently by people living with HS.[27 28] This combination of factors means that HS can lead to significant costs to the health system and wider economy.

HS in Japan

HS in Japan

There is limited information on the prevalence of HS in Japan; however, data suggest that men are more likely to be affected than women. No large-scale studies of the prevalence of HS have been conducted in Japan.[29] A study using data from a health insurance claims database estimated prevalence to be just 0.0039%,[30] although this is likely to be an underestimation as this data source would not capture undiagnosed HS. Prevalence has also been reported to be higher in certain regions of Japan, which may be linked to differences in diet as well as rates of smoking and obesity, both of which are associated with HS.[31] In contrast with Western countries, men in Japan are up to three times more likely to be affected by HS than women.[32] This disparity may be due to lower rates of smoking among Asian women. Another reason may be that women in Asia are less likely than women in regions such as Europe or North America to seek medical help for skin conditions that occur in intimate areas, contributing to low rates of confirmed diagnosis.[33]

Management of HS involves a range of treatments, but fewer treatment options are reimbursed by health insurance in Japan than in many other high-income countries. Treatment primarily involves topical and oral antimicrobials as well as surgical excision.[32 34] However, compared with other high-income countries, the number of treatments covered by health insurance is limited.[35] Management of HS is guided by a national clinical guideline that is based on European guidelines.[35] There is currently no national registry collecting data on HS in Japan.

There is not an active national patient association to support people living with HS in Japan. This may mean people living with the condition lack access to appropriate local information.

What does best-practice care for HS look like?

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HS can be a frustrating condition to manage, both for people living with the condition and for the healthcare professionals treating it. While there is currently no cure for HS, its impact can be reduced if people receive best-practice care at every stage (*Figure 1*).

Figure 1. Best-practice HS patient pathway

DIAGNOSIS

The process of HS diagnosis should ensure the person feels heard and that they are not blamed for their condition as this risks deterring them from seeking care in future. Diagnosis should involve:

- **clinical assessment** based on the nature, frequency and location of symptoms[3 16]
- **screening for other conditions that are associated with HS** such as obesity, diabetes, depression and Crohn's disease, to better understand the person's complex needs[36]
- **establishing whether HS is part of a syndrome** – such as pyoderma gangrenosum, acne and HS (PASH) – that may require additional care
- **a quality-of-life assessment** using the Dermatology Life Quality Index (DLQI) to help establish severity (a flare-up may not be at its worst during a clinical assessment, therefore understanding the impact of HS separately from clinical presentation can provide a more accurate picture of severity)
- **a healthcare professional with specialist HS knowledge,** such as a dermatologist, to reduce the risk of misdiagnosis. Primary care physicians, surgeons, gynaecologists and emergency care clinicians with specialist HS knowledge may also be capable of diagnosing.

TREATMENT

Different people may see different results with the same treatment.[37] People living with HS should be involved in decisions around treatment and informed of any potential side effects. Treatment may involve:

- **medical treatments** such as topical or systemic antibiotics,* biologic therapies, hormonal therapies, high dosage oral zinc, corticosteroids, retinoids or immunosuppressors;[38 39] pain may also be managed using medical treatments such as non-steroidal anti-inflammatory drugs and opioids[3]
- **surgical interventions,**[40] depending on the location and severity of the condition[3 41]
- **laser procedures**.[38]

*Long-term and repeated use of antibiotics should be limited owing to risks of antimicrobial resistance.[42]

ONGOING CARE

Ongoing care should involve management by a multidisciplinary team, led by a dermatologist or primary care physician, and should include:

- **other specialists as required,** such as a surgeon, psychologist, psychiatrist, wound care specialist, dermatology nurse, gastroenterologist, rheumatologist, gynaecologist, dietitian, cardiologist, endocrinologist, proctologist[38] and pain management specialist[43]
- **up-to-date information on current treatments** to allow people living with HS to make informed decisions on ongoing treatment
- **rapid access to a dermatologist for acute flare-ups** that require urgent care
- **empowering people to report side effects and concerns** from treatment
- **clinically validated self-care** to manage pain
- **a standardised at-home 'rescue pack'** that includes corticosteroids (to treat early flare-ups) and is accompanied by clear guidance on how to use them safely
- **support from an HS patient organisation.**

How does HS impact people's lives?

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Pain has a major effect on people living with HS

Pain is very common for people living with HS and drives many of the challenges related to the condition. Although there are no Japanese data available, it is well understood that pain is experienced by almost all people living with HS and is a major, debilitating symptom.[21 25 44 45] The high intensity and frequency of pain is a persistent burden and has a huge impact on the quality of life of people living with HS.[44 46]
A person interviewed for this report highlighted that the pain and discomfort caused by their HS prevents them from being able to exercise.[47]

People living with HS often struggle with mental health issues

HS can take a significant toll on mental health. People living with HS in Japan have significantly lower mental wellbeing than the national average.[48] A person interviewed for this report highlighted the unpredictability of HS, saying that they do not know when flare-ups may occur; this leads to feeling that they lack control over their body and life.[47]

Social life can be affected by HS symptoms

The shame and embarrassment caused by some HS symptoms can lead people to become socially isolated. People living with HS may feel embarrassed by the appearance or smell associated with the condition, which can act as a barrier to relationships and contribute to isolation and lower social functioning.[35 47 48] A person interviewed for this report emphasised that scarring, abscesses and smell cause them to feel embarrassment and shame, and to be self-conscious about their body.[47]

People living with HS may experience challenges around intimacy

The pain caused by HS can make it difficult for people to be intimate, which can significantly affect their quality of life. Although there are no available data in Japan, evidence from other countries has shown that almost all people living with HS report a negative impact on intimacy.[49 50] Intimacy is an important part of the human condition and the challenges faced by people living with HS in this regard have a huge effect on their quality of life.[51]

HS can affect people's ability to work

HS symptoms can be hard to manage at work or school. Although there are no published data from Japan on the impact of HS in these settings, one person interviewed for this report highlighted that abscesses may burst at work or school. This can leave clothes soiled and make them feel dirty, which can be distracting as well as embarrassing.[47] They also shared how their symptoms would worsen due to stress around exams, making the exams harder to complete.[47]

Living with HS can result in personal financial costs

People living with HS face a range of financial pressures. HS-related employment issues may contribute to financial challenges through the loss or reduction of income. In addition, people living with HS may need to pay for medicines as well as daily wound care.[52] An international study found that one in six people needed five or more changes to their dressing every day, highlighting the potential financial burden of wound care on people living with HS.[53]

Yuki's story

Yuki was in high school when he found an abscess developing under his arm. These symptoms would subside and return, but when the abscesses were draining it would have a significant impact on how he felt about himself. His clothes became stained from the discharge, making him feel unclean, and he would think carefully about what clothes to wear to avoid his symptoms being visible.

'When I was at school or when I went to work, it was impossible to keep the affected area clean. I felt like I was dirty. This was something I cared about a lot.'

Yuki did not understand what was causing his symptoms. He searched on the internet for answers but found no one else that was experiencing what he was and nothing that led him to HS. He felt very isolated.

'I did not know how this would stop or how long it would continue. Sometimes I felt that it may continue forever, and I'm the only one who is affected.'

During his time at school and university, HS restricted Yuki from being able to take part in sports and affected his ability to study. His HS symptoms became more severe when he became more stressed during exam periods.

'I was taking my exams at university when the symptoms were the worst. I was very stressed out and the symptoms got worse as a result.'

Yuki had surgery to remove an abscess and, although it alleviated the symptom, he was unhappy about the scar that it left.

'When I take a shower or change my clothes, I can see myself in the mirror. So even when there is no symptom of HS, the scar reminds me of HS.'

It took two and a half years before Yuki got a diagnosis of HS, and he now sees a dermatologist at Tsukuba University. He is hoping for a treatment that can give him more control over his symptoms, or to have better wound care to deal with his abscesses draining. Yuki also wants to find other people with HS and to understand more about their experiences of the condition.

'We don't have any patient groups in Japan. I want to get some kind of connection to those groups. I really wonder how other people deal with these symptoms.'

What are the policy and system barriers to best-practice care?

What are the policy and system barriers to best-practice care?

Low awareness among clinicians is contributing to delays in diagnosis and poor-quality care

A lack of awareness of HS among healthcare professionals in Japan can lead to misdiagnosis and delayed diagnosis. HS is not well known among healthcare professionals, and this may contribute to underdiagnosis of the condition, particularly for mild cases.[32] In Japan, unlike in many Western countries, the buttocks are the most common region of the body where people are affected by HS.[34] Despite this, dermatologists in Japan are often unfamiliar with the diagnosis of HS on the buttocks.[34] This can lead to misdiagnosis, with HS symptoms often being mistaken for an infectious disease.[32 35] Furthermore, knowledge of appropriate treatments for HS seem to be limited among some healthcare professionals.[32]

Current guidelines do not reflect the situation in Japan

Japan's national guidelines are based on European guidelines, despite HS presenting differently in the Japanese population. The first national clinical guideline for HS was developed in 2020, with content based on European guidelines.[35] There are many differences between HS in Japan and in Europe. The condition affects more men than women in Japan,[32] in contrast with many European countries,[1 2] and its symptoms present in different areas of the body.[34] National guidelines should reflect what is known about the disease burden in Japan to ensure effective diagnosis.

Comprehensive data on HS in Japan are limited, restricting policymakers' ability to meet the needs of people living with the condition

The lack of comprehensive data on HS in Japan means that national policymakers are not able to understand the disease burden and the areas of greatest need for people living with the condition. The limited amount of data leads to significant gaps in understanding the prevalence of HS, the quality of life of people living with the condition, the quality of services, and trends in treatment use and outcomes. There also seem to be limited national data on patient-reported outcome measures.

Availability of treatments in Japan is limited

Treatments for HS are less widely available in Japan than in other countries. Many of the treatments for HS that are available in other high-income countries are either not yet approved for use in Japan or not covered by health insurance.[35] Treatment policies are therefore different from those of other countries.[35] People living with HS should have access to a range of treatment options, particularly as a combination of treatments is often required.

Recommendations for policymakers

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People living with HS in Japan are significantly affected by their condition, with policy barriers preventing them from accessing high-quality care.

To improve the lives of people with HS, policymakers in Japan should consider the following recommendations:

- **Roll out HS educational programmes for healthcare professionals** to increase understanding of the condition and improve the speed of diagnosis and quality of care.
- **Develop national guidelines that reflect the nuances of HS among people living with the condition.** These guidelines should be developed by a multidisciplinary group of experts and encourage the involvement of people living with HS in decisions over their treatment and care.
- **Develop a registry to support the collection and use of data on HS,** including prevalence, treatment outcomes and patient-reported outcomes, which would allow policymakers and decision-makers to understand how to plan and deliver effective services.
- **Support research to understand the effectiveness and efficacy of different treatment options and combinations** in Japan to ensure that people living with HS have access to the treatments that could be most beneficial to them.

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