

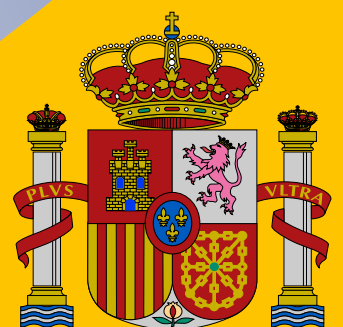


Call to action: improving the lives of people with hidradenitis suppurativa (HS) in Spain

June 2024

The
**Health Policy
Partnership**

This national summary was developed as part of a project led by The Health Policy Partnership (HPP) with guidance from a multidisciplinary Steering Committee. HPP was commissioned by UCB, which initiated and funded the project. UCB reviewed all outputs, but editorial control lies with the members of the project's Steering Committee. Contributing experts are not paid for their time.



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 Silvia Lobo Benito of The Spanish Hidradenitis Patients Association (Asociación de Enfermos de Hidrosadenitis (ASENDHI)), who was a contributor to this national summary and who is also a member of the Steering Committee that has guided the development of a **global-level report** on this topic.

We would also like to thank the following organisation for its endorsement:



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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. 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} Over time, inflammation can progress and lead to irreversible damage to the skin.^{8,9} 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.^{10,11} 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.^{4,12,13} 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 of 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. In Spain, the cost of treating HS has been estimated to exceed €1 billion per year.²⁹

HS in Spain

HS in Spain

In Spain, HS affects approximately 1 in 100 people, with women three times more likely to have the condition than men.³⁰ The actual prevalence of HS is thought to be greater, owing to high levels of underdiagnosis.^{31 32}

Management of HS in Spain involves a range of healthcare professionals and a combination of treatments which are delivered through specialist HS units. Owing to the complex nature of the condition, various treatments are used to manage HS, including lifestyle changes, antibiotics, surgery and biologics.^{33 34} In Spain, HS is most commonly diagnosed by a dermatologist, but general surgeons and primary care physicians can also be involved.³³ Management of HS may be guided by clinical guidelines from the European Academy of Dermatology and Venereology;³ there are currently no national clinical guidelines for HS in Spain. Multidisciplinary care is currently available in 50 specialist HS units across the country; to access these, people require a referral from a primary care physician or a dermatologist.³⁵ These units are not formally accredited by any official body or health organisation, and access to them may be limited. In a recent patient survey in Spain, respondents remarked that access to more specialist multidisciplinary HS centres was their most important priority.³⁰ There is currently no national registry collecting data on HS in Spain, but some of the country's centres are participating in the European Registry for HS and international UNITE registry.^{36 37}

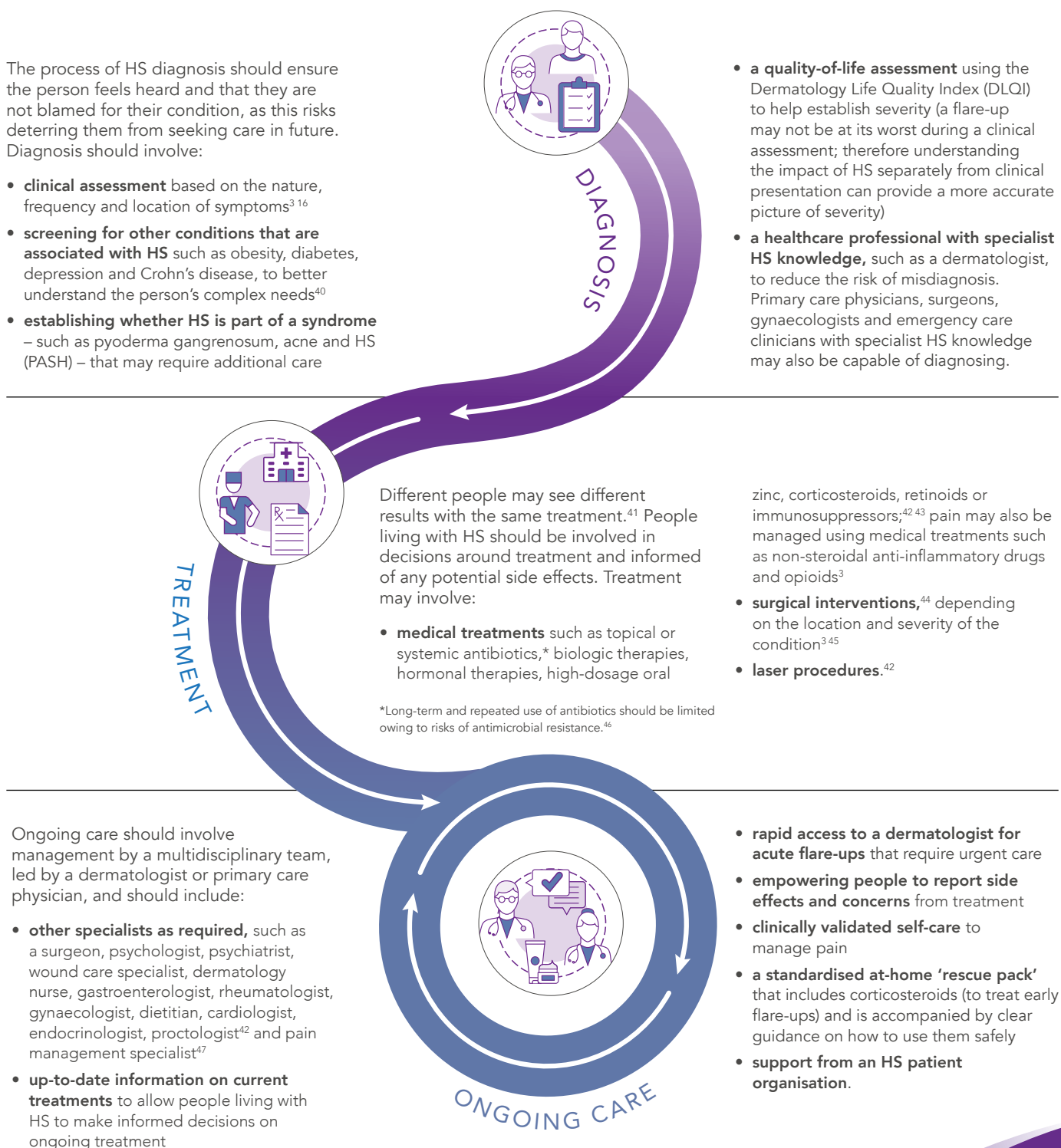
There is an active national association supporting people living with HS. The Spanish Hidradenitis Patients Association (Asociación de Enfermos de Hidrosadenitis, ASENDHI) provides people living with HS with information on the condition and how to access care. The association also regularly carries out surveys to establish the current level of care provision.^{30 33 38 39}

What does best-practice
care for HS look like?

What does best-practice care for HS look like?

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



How does HS impact
people's lives?

How does HS impact people's lives?

Pain has a major effect on people's lives

Pain is very common for people living with HS and drives many of the challenges related to the condition. A global study, which included participants from Spain, found that most people living with HS (91%) reported feeling pain in the previous week.⁴⁸ The large impact of HS on quality of life is primarily driven by pain,⁴⁹ and it can affect people's occupation and education.⁵⁰ In some cases, the pain is described as 'unbearable' and 'disabling', highlighting the intensity of the pain experienced by some people living with the condition.⁵⁰

People living with HS often struggle with mental health issues

HS can have a significant impact on mental health and may lead to an increased risk of suicide. People living with HS often experience a serious worsening of their quality of life as a result of the condition; this often affects women more severely than men.⁵¹ In a recent survey by ASHENDI of people living with HS, 53% of respondents reported living with anxiety and 30% were experiencing depression.³⁰ This contributes to the increased risk of suicide, with 21% of people with HS at moderate or severe risk – considerably higher than the Spanish average and above that of other chronic skin conditions.⁴⁹

Social and family life can be affected by HS

HS symptoms can make people withdraw from social situations, leading them to become isolated. Symptoms such as pain, unpleasant smell and poor mobility can place restrictions on people's daily life. As many as 60% of people living with HS in Spain report that the condition affects their daily life, including social relationships.³³ Almost half of the people surveyed had felt extremely withdrawn as a consequence of HS in the past week, while more than a quarter of people reported feeling lonely.⁴⁸ According to a person living with HS interviewed for this report, a lack of public awareness contributes to the stigmatisation of people with HS, exacerbating their feelings of isolation.³²

HS can influence a person's decision on whether to have children. Around one-third of people living with HS have a family member who also has the condition,⁵² which indicates the condition can be hereditary. One person interviewed for this report said that the risk of a child inheriting HS has led them to decide not to have children.³²

People with HS may experience challenges around intimacy

Pain, unpleasant smell and the location of symptoms can be barriers to intimacy.

As HS symptoms can be located in intimate areas of the body, the intense pain and unpleasant smell they can cause can prevent people from being intimate.⁵³ A Spanish survey found that two in five people living with HS viewed themselves as less attractive than average, and almost half reported being afraid of rejection as well as the reaction of their partner.⁵⁴ Almost all women (94%) and 81% of men believed HS negatively affected their chances of having a relationship or sexual relations, with HS causing people with the condition to associate intimacy with feeling distress.^{53 54} A survey among people living with HS found that intimacy was the aspect of their lives they felt was most strongly affected by their HS (alongside emotional issues).³⁰

HS can affect people's ability to work

HS can result in people missing days of work or school, which may have a long-term impact on their education and professional life.

HS symptoms can significantly affect people's work and education.⁵⁰ A Spanish study found that almost half of people with HS were regularly absent from work due to their symptoms, with an average of 33 sick days a year.⁵⁰ A survey among adolescents living with HS found that 40% had missed school or work for more than 30 days in the previous year.³⁹ According to one person living with HS interviewed for this report, frequent absences can lead to a child being removed from school, affecting their educational progress.³² The same individual suggested that schools and workplaces should be more flexible around remote work and accommodate the needs of people living with HS.³²

Unemployment as a result of HS can lead to serious financial distress, as

government support may be insufficient. A Spanish survey from 2023 found that 23% of people living with HS are unemployed owing to their condition preventing them from being able to work.³⁰ This represents an increase compared with the 19% of people who reported being unemployed in the previous survey in 2018.^{30 33} The proportion of respondents with a recognised disability increased slightly during this period, from 8% to almost 13%.³⁰ This suggests that a significant number of people living with HS may need financial support from the government, but are not currently receiving it. A patient advocate interviewed for this report highlighted that, unless you have worked for a number of years, the financial support received from the government is insufficient for people who are too sick to work.³²

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. Symptoms of HS can require frequent wound care and treatment, including bandages, creams and tape.^{29 32} Some regions subsidise the costs of this care, but other regions do not – meaning people living with HS have to cover the costs themselves.^{29 32} On average, these personal costs amount to over €500 a year.²⁹ Among people living with HS who completed a recent survey (2023) by ASHENDI, almost one third reported spending a significant proportion of their monthly income on managing their condition.³⁰ This largely consisted of costs associated with skincare products, treatments and transport to healthcare appointments.³⁰



Silvia's story

Silvia was 13 when she experienced her first HS symptoms. She saw a range of healthcare professionals before eventually being referred to a dermatologist by a surgeon. It took her 15 years to get a diagnosis and it surprised her that it had taken so long to be referred to dermatology given the condition affected her skin.

'I saw an endless number of doctors before I got to dermatology. Eventually, a surgeon said, "Today, we're going to send you to dermatology, because the problem is in the skin." It seems strange, right?'

Silvia has tried a number of treatments, including antibiotics, surgery, biologics and physiotherapy, with varying degrees of success.

'I've tried anything and everything. Either you tried it or you stayed as you were. And I wasn't very well, so I tried everything.'

HS has had a significant impact on Silvia's life. At one point her symptoms became so severe that she found it difficult to move or leave the house, leading to Silvia losing friends.

'When I had to stop going out because I couldn't move, my friends disappeared. I didn't have any friends anymore. They simply stopped being around. I think one of the biggest problems for people with HS is loneliness, because they end up feeling completely alone.'

Having HS has led to Silvia making the difficult decision to not have children, because she is worried she would pass HS on to a child.

'It has affected motherhood for me, because I decided voluntarily that I wasn't going to have children. And I wasn't going to have children because I didn't want to pass on the disease to them.'

Silvia's symptoms are stable at the moment following her sixth surgery, but she highlights that having a chronic condition involves a lifelong struggle with self-acceptance.

'Ultimately, being a chronic patient is your life. You have to learn to live with what you have. Your body is your body – you don't have another one. I think one of the most difficult things for all chronic patients is accepting themselves.'

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

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

Lack of awareness among clinicians is contributing to delays in diagnosis and gaps in care

Low awareness of HS among clinicians leads to delays in diagnosis, during which time the condition can become more severe. A 2023 Spanish study found that the average time it takes to receive an HS diagnosis is just over 10 years,³⁰ although a 2017 survey among adolescents found it to be 5 years.³⁹ Limited awareness of HS among primary care physicians contributes to these delays, making it difficult for people with symptoms to be referred to the appropriate specialist.^{29 32 55} A recent survey of people living with HS found that, on average, an individual would have more than 24 medical consultations and visited 3 specialists before receiving a diagnosis.³⁰ The same survey found that more than half of respondents felt that healthcare professionals in primary care, emergency care and working in pharmacies had little or very little knowledge of HS.³⁰ Of the 91% of respondents who had visited a primary care physician, 66% felt they were given little or very little explanation of their condition.³⁰ This lack of awareness and associated delays translate to late access to appropriate treatments, during which time HS symptoms can progress and become more severe.^{32 55} Greater awareness among healthcare professionals, particularly primary care physicians and emergency care professionals, could improve the speed of diagnosis.²⁹

In 2017, a multidisciplinary panel of experts developed HERCULES (Iniciativa Estratégica de Salud para pacientes con Hidrosadenitis Suppurativa), a strategic health initiative to determine the standard of care for people with hidradenitis suppurativa. This initiative identified some additional priorities including faster referrals, greater use of functional reference units which provide specialist HS advice to other dermatology units, and the implementation of a common standard of care for HS across Spain.²⁹

Low effectiveness of treatment is contributing to high levels of dissatisfaction

People living with HS often have to try a myriad of different treatments due to ineffectiveness. Effective treatments are limited, particularly for moderate to severe HS, and pain management is challenging.^{34 50} People living with HS may have to try multiple treatments or combinations of treatment to find something that works better for them. These may include lifestyle changes, antibiotics, hormonal therapy, surgery and biologic therapy.³²⁻³⁴ A 2018 survey by ASHENDI found that 64% of people living with HS had used between two and four different treatments since their symptoms started, with 21% having used more than five treatments.³³ The same survey found that the vast majority of people (87%) were dissatisfied with their current care.³³ This proportion had reduced in a more recent 2023 survey, although a majority of people living with HS (52%) remain dissatisfied.³⁰ Worryingly, 17% of people living with severe HS are not currently receiving any treatment, while 73% reported lacking access to psychological support.³⁰

A current lack of shared decision-making in HS care may also be contributing to low treatment satisfaction among people with the condition. According to an HS patient advocate, people living with the condition are rarely provided with explanations around HS treatment and management by healthcare professionals.³² This suggests there is currently a lack of shared decision-making in HS care. People living with HS may benefit from receiving more education on potential treatments and being more involved in treatment decision-making, as studies have shown this can improve levels of satisfaction with care.⁵⁶

Inadequate management of HS leads to significant healthcare costs

Poor HS management and delays in diagnosis result in the condition becoming more severe, requiring more expensive treatment. The treatment of HS often involves surgery, with more severe HS requiring more frequent surgeries.³³ A 2023 survey by ASHENDI found respondents underwent an average of seven surgeries from first experiencing symptoms, and 23% had more than ten surgeries.³⁰ Among adolescents who responded to a survey in 2017, 72% had undergone a surgery in the previous year.³⁹ Surgery can require inpatient care and long periods of hospitalisation; almost 5% of respondents to the 2023 survey had required hospitalisation for more than five days.³⁰ This can result in considerable costs to the health system; the cost of treating HS is estimated to amount to more than €1 billion per year in Spain.²⁹ Earlier diagnosis may lead to fewer cases of HS progressing to a more severe stage, meaning such costly interventions might be required less.^{57 58}

There is no national clinical guideline for HS, potentially impeding quality of care and resource planning

There is currently no clinical guideline for HS in Spain, which may be hindering care quality and resource planning. Clinical guidelines are an effective way of supporting healthcare professionals in making informed decisions on treatment, and help health system leaders plan and allocate resources more efficiently.²⁹

There is currently no national clinical guideline for HS in Spain, despite this being recommended by a multidisciplinary panel of experts in 2017.²⁹ The introduction of a national guideline could improve the quality of HS care and better inform healthcare planning.²⁹

The absence of an HS national registry hampers research and resource allocation

The lack of a national registry for HS data makes research for new treatments and resource allocation more difficult. There is currently no national registry collecting data on HS.²⁹ Without comprehensive data, it is difficult for high-quality clinical research to be carried out on new HS interventions. Additionally, without a clear picture of the current state of play for HS, health system leaders may struggle to effectively allocate resources to the areas that need them most.

Recommendations for policymakers

Recommendations for policymakers

People living with HS in Spain 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 Spain should consider the following recommendations alongside those recommended by the HERCULES initiative:

- **Improve access to specialist HS care** by improving rapid referrals to dermatologists from primary care, promoting the use of functional reference units which can offer specialised advice to other dermatology departments, and implementing a common standard of care.
- **Roll out HS educational programmes for healthcare professionals**, targeted at primary care physicians and emergency care professionals, to increase understanding of the condition and improve speed of diagnosis.
- **Incorporate a formal shared decision-making process in HS treatment decisions** to build knowledge of HS among people living with the condition and improve their satisfaction with care.
- **Ensure government support is adequate** for people living with HS who are unable to work.
- **Subsidise wound care supplies for people living with HS in all regions** to ensure equitable access to high-quality wound care.
- **Encourage schools and workplaces to provide flexible working and learning conditions** for people living with HS.
- **Advocate for the implementation of a national clinical guideline for HS** to support treatment decisions and health system planning.
- **Promote the implementation of a national HS registry** to support research and planning.

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Date of preparation: March 2024.
ES-DA-2300130

Carswell O, Melson C, Tate J. 2024. *Call to action: improving the lives of people with hidradenitis suppurativa (HS) in Spain*. London: The Health Policy Partnership

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