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

March 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 Chris Melson and Jody Tate of The Health Policy Partnership (HPP). HPP is grateful to Angela Gibbons (UK patient representative), 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:

THE HS
SUPPORT NETWORK

UK & IRELAND
INFORMAL SUPPORT GROUPS

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

CONTENTS

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] 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 and scarring.[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 mainly affecting 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. The estimated annual cost of HS to the UK is around £3.38 billion based on healthcare costs and productivity losses to wider society.[29]

HS in the United Kingdom

HS in the UK

In the UK, HS is estimated to affect 1 in 130 people, with women and Black people disproportionately affected.[30 31] Women in the UK are three times more likely to have HS than men, reflecting trends in other Western countries.[30] One study found that, compared to general clinics, a significantly higher proportion of people attending HS clinics were Black.[31] This may suggest a higher prevalence of HS among Black people.

Management of HS involves a range of healthcare professionals, with treatments varying depending on disease severity. In the UK, dermatologists see and treat many people living with HS, with management decisions being directed by clinical guidelines from the British Association of Dermatologists.[32 33] Treatment for mild to moderate HS largely relies on topical and oral antibiotics.[32] For moderate to severe HS, treatments include tetracyclines, oral antibiotics, anti-androgen therapies, biologics and surgery.[32] General practitioners (GPs) report being confident in diagnosing and managing HS, but may still refer some people to dermatology.[34] Management of HS in the UK can also involve wound care, smoking cessation, pain management and psychological support.[35] There is no national registry for HS in the UK, but some centres are taking steps towards collecting data as part of the European registry for hidradenitis suppurativa.[36]

There is no active national patient association in the UK with a specific focus on HS. This may mean that people living with HS in UK lack access to appropriate information and support.

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

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[37]
- **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.[38] 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;[39 40] pain may also be managed using medical treatments such as non-steroidal anti-inflammatory drugs and opioids[3]
- **surgical interventions,**[41] depending on the location and severity of the condition[3 42]
- **laser procedures**.[39]

*Long-term and repeated use of antibiotics should be limited owing to risks of antimicrobial resistance[43]

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[39] and pain management specialist[44]
- **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?

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. Although there are no UK data available on pain, it is well understood that pain is experienced by almost all people living with HS, and is a major, debilitating symptom.[21 25 45 46] 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.[45 47]

People with HS often struggle with mental health issues

Mental health issues are common among people with HS, significantly increasing the risk of suicide. Many people living with HS experience depression and anxiety as a result of their day-to-day struggle with symptoms.[48 49] Studies show that people living with severe HS are at higher risk of taking their own lives.[48 49]

Social life can be affected by HS

HS can cause challenges around socialising, leaving people feeling isolated. People may feel that their symptoms prevent them from being able to do the things they enjoy such as socialising.[50] This can ultimately lead to people feeling isolated.[49 50] One person living with HS interviewed for this report said that having HS made some situations such as travelling abroad too difficult because they had to consider how things like hot weather could affect their symptoms – this can leave people feeling restricted as well as alone.[49]

People with HS may experience challenges around intimacy and personal relationships

HS can make intimacy difficult and affect personal relationships. Although there is a lack of UK data on how HS affects intimacy, evidence from other countries has found that almost all people living with HS report a negative impact on intimacy.[51 52] HS can develop in intimate areas of the body, leaving some people feeling embarrassed and placing a strain on personal relationships.[35] One person interviewed for this project said that their feelings around their HS prevented them from having a relationship until they were 33.[49]

HS can affect people's ability to work and study

HS symptoms and treatment can lead to challenges around work and studying, potentially impacting the socioeconomic position of people living with HS. HS flare-ups, medical appointments and surgery can cause people to take days off work or school.[29 35 50] Pain can make it difficult to concentrate, and can affect people's ability to sit or stand.[29] In professional environments, people often hide their symptoms because of the stigma that results from a lack of awareness about HS.[29] A recent study from the UK that looked at a combination of factors, including employment and education, found that people with HS had significantly lower socioeconomic positions compared with a healthy control group.[53] One person who was interviewed for this report said that their

pain from HS and their concerns around symptoms being visible led to them avoiding school and having difficulty concentrating.[49] They also said that the adverse effects from treatment had led to them taking time off work, with one extended period of sick leave driven by mental health issues.[49]

Living with HS can result in personal financial costs

HS can subject people to a range of direct and indirect financial costs. People living with HS require frequent wound dressing changes, resulting in high personal costs for wound care.[35 49] An international study that included UK participants found that one in six people needed five or more dressing changes a day.[54] In addition, an analysis carried out by the Office of Health Economics found that HS-related costs for transport to access healthcare services, wound care and prescriptions, was around £1,500 per person per year.[29] One person interviewed for this report said their HS had led to a series of other costs, including paying for hospital parking at medical appointments and increased utility bills from continuously washing clothes and bedding.[49] This means that simply living with HS can place a financial burden on people with the condition.

Angela's story

Angela was only ten years old when she first found a lump in her groin. Similar, more inflamed lumps appeared on different parts of her body, became painful and started to bleed. She didn't know what was happening to her and told no one about her symptoms, using toilet paper to manage her wounds and deal with them draining.

'I missed a lot of days at school. I looked back at school reports and there was barely a term where I'd done a full week.'

Growing up, Angela assumed that her symptoms were cancer and that eventually she would die from them. This had a significant effect on her mental health as a young person.

'Some days, I would just have rather died, and I was disappointed that it hadn't killed me yet. And I think that's just really sad for young people coming through with HS.'

Angela waited until she was 16 to see a doctor (the age at which people are able to speak to their healthcare professional confidentially), because she did not want her parents finding out. Her experience was distressing – she was asked very personal questions, given a full physical examination, told to lose weight and given a course of antibiotics, which were ineffective. This experience made her not want to go back to the doctor for another five years until she was diagnosed when she was 21.

'The whole experience was pretty horrific. I just felt embarrassed. The way I'd been treated by the GP made me not want to engage with healthcare services at all.'

HS has had an extensive impact on Angela's life – restricting her social life, shaping her career choices and increasing her personal financial costs.

'It's often easier to say what doesn't it affect.'

For Angela, one of the biggest effects of HS on her life has been that it has prevented her from being able to have a family. She felt unable to have any type of relationship until she was 33 and, when they tried for children, she was told by a fertility clinic that her egg count was too low to have children.

'I was told that I had left it too late. That's been a pretty hard thing to take because I see other people having children.'

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

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

Limited understanding of HS among GPs is contributing to poor-quality care

Low awareness of HS among GPs is leading to poor-quality care and distressing healthcare experiences, which may be affecting outcomes. GPs in the UK report high levels of confidence in diagnosing HS, but suboptimal consideration of pain management and screening for depression indicates the need for further education among this group.[34] Meanwhile, some people living with HS have raised concerns that GPs can trivialise HS, because they do not have specialist knowledge.[35] One person living with HS interviewed for this report said that GPs had asked questions about their level of hygiene, which reflects a lack of understanding around the cause of the condition.[49] This led them to avoiding seeking medical attention in the future, potentially contributing to a delay in diagnosis.[49] Educating GPs about HS could speed up diagnosis and improve quality of care.[35]

Access to multidisciplinary care is rare

People with HS are rarely cared for by multidisciplinary teams, despite this being recommended in national guidance. Guidelines from the British Association of Dermatologists and a consensus statement by the British Dermatological Nursing Group recommend that people with HS should be cared for by a multidisciplinary team.[33 35] Despite this, GPs report referring only 3% of people with HS to a specialist multidisciplinary service – this may reflect the lack of specialist multidisciplinary HS care in the UK.[34] As of May 2023, the average waiting time to see a dermatologist in England was around three months, with some people waiting almost a year.[55] A person interviewed for this report has called for more holistic care to be offered, involving psychological support, wound care and pain management for people living with HS.[49]

Treatment for HS can be ineffective and cause severe side effects for some

There are limited effective treatment options for HS, with some causing severe adverse effects. Treatment options for HS are limited.[33] In one global study of 1,418 participants from 14 countries, that included participants from the UK, almost half of people living with HS were either dissatisfied or very dissatisfied with their current treatment, with poor effectiveness and adverse effects cited as the most common reasons for dissatisfaction.[56] One person interviewed for this report said that the adverse effects from some treatments had left them in hospital for two weeks, and off work for an extended period of time with depression.[49] The Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS) is a multicentre study involving 150 participants that is currently being conducted to understand how HS treatments are used in the UK; the results of this study may lead to improvements in treatment decisions.[57] Current national guidelines do not formally take patient preference into account when making treatment decisions, which could improve people's satisfaction with their treatment.[33]

Inadequate management of HS is leading to increased healthcare costs

Insufficient management of HS may lead people to rely on emergency and inpatient care, increasing healthcare costs. HS is not adequately managed by current medical treatment options and often requires surgery, resulting in high healthcare costs.[58] One study involving 11,359 participants found that the average hospital cost for a person with HS was more than £2,000 per patient per year, largely driven by the average inpatient stay lasting more than a week.[58] The same study also found that three in four people with HS had visited emergency services at least once during the six-year study period, with people visiting emergency services an average of five times.[58] Improved management of HS may lead to a reduction in the reliance on emergency services. In addition, the experience of attending emergency services can be time-consuming and distressing, with one person raising concerns about a loss of privacy in an emergency setting and the inadvertent sharing of their diagnosis in a busy emergency department.[49]

There is currently no patient organisation for HS, meaning people may be less well supported

While some support groups exist, there is no formal patient organisation for HS in the UK. Patient organisations are crucial not only for providing information, advice and support for people living with a condition, but also for sharing personal experiences and tips. In the case of HS, this may be beneficial for pain management, wound care and psychological support. Although some small-scale support groups exist, there appears to be no active, national patient organisation for people living with HS.[35]

Recommendations for policymakers

Recommendations for policymakers

People living with HS in the UK 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 the UK should consider the following recommendations:

- **Roll out HS educational programmes for healthcare professionals** to raise awareness, increase understanding and increase early diagnosis of HS, with a focus on GPs.
- **Incorporate patient preference as part of treatment decision criteria in future updates to national HS guidelines** to support improvements in treatment satisfaction and quality of life.
- **Encourage the implementation of multidisciplinary care** that involves wound care, pain management and mental health services.

References

1. Revuz J, Canoui-Poitrine F, Wolkenstein P, *et al.* 2008. Prevalence and factors associated with hidradenitis suppurativa: results from two case-control studies. *J Am Acad Dermatol* 59(4): 596-601
2. Jemec GBE, Heidenheim M, Nielsen NH. 1996. The prevalence of hidradenitis suppurativa and its potential precursor lesions. *J Am Acad Dermatol* 35(2, Part 1): 191-94
3. Zouboulis CC, Desai N, Emtestam L, *et al.* 2015. European S1 guideline for the treatment of hidradenitis suppurativa/acne inversa. *J Eur Acad Dermatol Venereol* 29(4): 619-44
4. Gulliver W, Zouboulis CC, Prens E, *et al.* 2016. Evidence-based approach to the treatment of hidradenitis suppurativa/acne inversa, based on the European guidelines for hidradenitis suppurativa. *Rev Endocr Metab Disord* 17(3): 343-51
5. Pescitelli L, Ricceri F, Prignano F. 2018. Hidradenitis suppurativa and associated diseases. *G Ital Dermatol Venereol* 153(3 Suppl 2): 8-17
6. Zouboulis CC, Benhadou F, Byrd AS, *et al.* 2020. What causes hidradenitis suppurativa? — 15 years after. *Exp Dermatol* 29(12): 1154-70
7. Rosi E, Fastame MT, Scandagli I, *et al.* 2021. Insights into the Pathogenesis of HS and Therapeutical Approaches. *Biomedicines:* 10.3390/biomedicines9091168
8. Naik HB, Paul M, Cohen SR, *et al.* 2019. Distribution of Self-reported Hidradenitis Suppurativa Age at Onset. *JAMA Dermatol* 155(8): 971-73
9. Vinkel C, Thomsen SF. 2018. Hidradenitis Suppurativa: Causes, Features, and Current Treatments. *J Clin Aesthet Dermatol* 11(10): 17-23
10. Ingram JR. 2016. Hidradenitis suppurativa: an update. *Clin Med* 16(1): 70-3
11. Wang SC, Wang SC, Sibbald RG, *et al.* 2015. Hidradenitis Suppurativa: A Frequently Missed Diagnosis, Part 1: A Review of Pathogenesis, Associations, and Clinical Features. *Adv Skin Wound Care* 28(7): 325-32
12. Schneider-Burrus S, Tsaousi A, Barbus S, *et al.* 2021. Features Associated With Quality of Life Impairment in Hidradenitis Suppurativa Patients. *Front Med*: 10.3389/fmed.2021.676241
13. Ocker L, Abu Rached N, Seifert C, *et al.* 2022. Current Medical and Surgical Treatment of Hidradenitis Suppurativa-A Comprehensive Review. *J Clin Med*: 10.3390/jcm11237240:
14. Mayo Clinic. Hidradenitis suppurativa. Available from: https://www.mayoclinic.org/diseases-conditions/hidradenitis-suppurativa/symptoms-causes/syc-20352306 [Accessed 12/02/24]
15. Misitzis A, Katoulis A. 2021. Assessing Psychological Interventions for Hidradenitis Suppurativa as a First Step Toward Patient-Centered Practice. *Cutis* 107(3): 123-24
16. Johnston LA, Alhusayen R, Bourcier M, *et al.* 2022. Practical Guidelines for Managing Patients With Hidradenitis Suppurativa: An Update. *J Cutan Med Surg* 26(2_suppl): 2S-24S
17. Tzellos T, Zouboulis CC. 2022. Which hidradenitis suppurativa comorbidities should I take into account? *Exp Dermatol* 31(Suppl 1): 29-32
18. Ţarcă E, Cojocaru E, Caba B, *et al.* 2021. Multidisciplinary Management of Adolescents with Hidradenitis Suppurativa - Series of Cases and Literature Review. *J Multidiscip Healthc* 14: 2205-16
19. Bertolotti A, Sbidian E, Join-Lambert O, *et al.* 2021. Guidelines for the management of hidradenitis suppurativa: recommendations supported by the Centre of Evidence of the French Society of Dermatology. *Br J Dermatol* 184(5): 963-65
20. Killasli H, Sartorius K, Emtestam L, *et al.* 2020. Hidradenitis Suppurativa in Sweden: A Registry-Based Cross-Sectional Study of 13,538 Patients. *Dermatology* 236(4): 281-88
21. Matusiak Ł, Szczęch J, Kaaz K, *et al.* 2018. Clinical Characteristics of Pruritus and Pain in Patients with Hidradenitis Suppurativa. *Acta Derm Venereol* 98(2): 191-94
22. van der Zee HH, van de Bunte M, van Straalen KR. 2022. Management of mild hidradenitis suppurativa: our greatest challenge yet. *Br J Dermatol* 186(2): 355-56
23. Alavi A, Farzanfar D, Lee RK, *et al.* 2018. The Contribution of Malodour in Quality of Life of Patients With Hidradenitis Suppurativa. *J Cutan Med Surg* 22(2): 166-74
24. Schneider-Burrus S, Kalus S, Fritz B, *et al.* 2023. The impact of hidradenitis suppurativa on professional life. *Br J Dermatol* 188(1): 122-30
25. Vekic DA, Cains GD. 2017. Hidradenitis suppurativa – Management, comorbidities and monitoring. *Aust J Gen Pract* 46(8): 584-88
26. Dufour DN, Emtestam L, Jemec GB. 2014. Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgrad Med J* 90(1062): 216-21
27. Frings VG, Schöffski O, Goebeler M, *et al.* 2021. Economic analysis of the costs associated with Hidradenitis suppurativa at a German University Hospital. *PLoS One*: 10.1371/journal.pone.0255560
28. Shalom G, Babaev M, Freud T, *et al.* 2017. Demographic and health care service utilization by 4417 patients with hidradenitis suppurativa. *J Am Acad Dermatol* 77(6): 1047-52
29. Theakston C, Henderson N, Skedgel C. 2023. The Burden of Hidradenitis Suppurativa on Patients, the NHS and Society: Estimates and Recommendations. London: Office of Health Economics
30. Ingram JR, Jenkins-Jones S, Knipe DW, *et al.* 2018. Population-based Clinical Practice Research Datalink study using algorithm modelling to identify the true burden of hidradenitis suppurativa. *Br J Dermatol* 178(4): 917-24
31. Patel NP. 2021. Remote consultations for patients with hidradenitis suppurativa during the COVID-19 pandemic: a single-centre experience. *Clin Exp Dermatol* 46(6): 1079-81
32. Hasan SB, Ingram JR. 2020. What has changed in the UK management of hidradenitis suppurativa from 2014 to 2019? *Br J Dermatol* 183(5): 973-75
33. Ingram JR, Collier F, Brown D, *et al.* 2019. British Association of Dermatologists guidelines for the management of hidradenitis suppurativa (acne inversa) 2018. *Br J Dermatol* 180(5): 1009-17
34. Collier F, Howes R, Rodrigues J, *et al.* 2021. Primary care management of hidradenitis suppurativa: a cross-sectional survey of UK GPs. *BJGP Open*: 10.3399/bjgpo.2021.0051
35. British Dermatological Nursing Group. 2022. *Optimising Hidradenitis Suppurativa Care: A Multi-professional Consensus Statement.* London: British Dermatological Nursing Group
36. Daxhelet M, Daoud M, Suppa M, *et al.* 2020. European registry for hidradenitis suppurativa: state of play. *J Eur Acad Dermatol Venereol* 35(4): e274-e76
37. Garg A, Malviya N, Strunk A, *et al.* 2022. Comorbidity screening in hidradenitis suppurativa: Evidencebased recommendations from the US and Canadian Hidradenitis Suppurativa Foundations. J Am Acad Dermatol 86(5): 1092-101

38. Canadian Hidradenitis Suppurativa Foundation. 2022. *A Guide to Hidradenitis Suppurativa: Living with HS*. Richmond Hill: Canadian Hidradenitis Suppurativa Foundation
39. Chiricozzi A, Micali G, Veraldi S. 2019. The patient journey: a voyage from diagnosis to hidradenitis suppurativa multidisciplinary unit. *J Eur Acad Dermatol Venereol* 33 Suppl 6: 15-20
40. Hessam S, Sand M, Meier NM, *et al*. 2016. Combination of oral zinc gluconate and topical triclosan: An anti-inflammatory treatment modality for initial hidradenitis suppurativa. *J Dermatol Sci* 84(2): 197-202
41. Bechara FG, Podda M, Prens EP, *et al*. 2021. Efficacy and Safety of Adalimumab in Conjunction With Surgery in Moderate to Severe Hidradenitis Suppurativa: The SHARPS Randomized Clinical Trial. *JAMA Surg* 156(11): 1001-09
42. Scholl L, Schneider-Burrus S, Fritz B, et al. 2023. The impact of surgical interventions on the psychosocial well-being of patients with hidradenitis suppurativa. *J Dtsch Dermatol Ges* 21(2): 131-39
43. Fischer AH, Haskin A, Okoye GA. 2017. Patterns of antimicrobial resistance in lesions of hidradenitis suppurativa. J Am Acad Dermatol 76(2): 309-13.e2
44. Patel ZS, Hoffman LK, Buse DC, *et al*. 2017. Pain, Psychological Comorbidities, Disability, and Impaired Quality of Life in Hidradenitis Suppurativa [corrected]. Curr Pain Headache Rep: 10.1007/s11916-017-0647-3
45. Johnston L, Dupuis E, Lam L, *et al*. 2023. Understanding Hurley Stage III Hidradenitis Suppurativa Patients' Experiences With Pain: A Cross-Sectional Analysis. *J Cutan Med Surg*: 10.1177/12034754231188452
46. Howells L, Lancaster N, McPhee M, *et al*. 2021. Thematic synthesis of the experiences of people with hidradenitis suppurativa: a systematic review. *Br J Dermatol* 185(5): 921-34
47. Jemec GB. 2017. Quality of life considerations and pain management in hidradenitis suppurativa. *Semin Cutan Med Surg* 36(2): 75-78
48. Rowland Payne P. 2019. Hidradenitis suppurativa treatment - medical or surgical? *J Eur Acad Dermatol Venereol* 33(6): 981-82
49. Gibbons A. 2023. Interview with Chris Melson at The Health Policy Partnership [video conference]. 15/06/23
50. Guy's and St Thomas' NHS Foundation Trust. Physical, emotional and social effects of HS. Available from: https://www.guysandstthomas.nhs.uk/health-information/hidradenitis-suppurativa/physical-emotional-and-social-effects-hs [Accessed 12/02/24]
51. Canadian Skin Patient Alliance. 2020. *Scarred for Life: 2020 Update*. Nepean: Canadian Skin Patient Alliance
52. Cuenca-Barrales C, Molina-Leyva A. 2020. Sexuality in Patients with Hidradenitis Suppurativa: Beliefs, Behaviors and Needs. *Int J Environ Res Public Health*: 10.3390/ijerph17238808:
53. Kearney N, McGrath B, McCourt C, *et al*. 2023. Hidradenitis suppurativa is associated with lower socioeconomic status using the MacArthur scale of subjective social status. British Association of Dermatologists; June, 2023; Liverpool, UK
54. Moloney S, McGrath BM, Roshan D, *et al*. 2021. The Personal Impact of Daily Wound Care for Hidradenitis Suppurativa. *Dermatol* 238(4): 762-71
55. Lane Clark & Peacock. Waiting list tracker. Available from: https://waitinglist.health.lcp.com/ [Accessed 12/02/24]
56. Midgette B, Strunk A, Akilov O, *et al*. 2022. Factors associated with treatment satisfaction in patients with hidradenitis suppurativa: results from the Global VOICE project. *Br J Dermatol* 187(6): 927-35
57. Bates J, Stanton H, Cannings-John R, *et al*. 2022. Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS): protocol for a prospective cohort study. *BMJ Open*: 10.1136/bmjopen-2022-060815
58. Desai N, Shah P. 2017. High burden of hospital resource utilization in patients with hidradenitis suppurativa in England: a retrospective cohort study using hospital episode statistics. *Br J Dermatol* 176(4): 1048-55

Date of preparation: March 2024
GB-DA-2300073

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

The Health Policy Partnership
[research, people, action]