

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

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 Chris Melson and Jody Tate of The Health Policy Partnership (HPP). HPP is grateful to Chevonne Smellie (Hidradenitis and Me, Canada) and Dr Susan Poelman (Canadian Hidradenitis Suppurativa Foundation, Canada) who were contributors to this national summary and are also members 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 organisations for their endorsement:



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

CONTENTS

What is hidradenitis suppurativa?	4
HS in Canada	6
What does best-practice care for HS look like?	8
How does HS impact people's lives?	10
Pain has a major effect on people's lives	11
People living with HS often struggle with mental health issues	11
Social life can be affected by HS	11
People living with HS may experience challenges around intimacy	11
HS can affect people's ability to work	11
Living with HS can result in personal financial costs	12
What are the policy and system barriers to best-practice care?	13
Low awareness among healthcare professionals is contributing to delays in diagnosis and poor-quality care	14
Limited effectiveness and unwanted side effects are contributing to low levels of treatment satisfaction	14
Access to psychological support is insufficient	15
Inadequate access to care leads to frequent use of emergency services	15
Recommendations for policymakers	17
References	19

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 Over time inflammation can progress and lead to irreversible damage to the skin and scarring.⁷ ⁸ 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.^{9,10} 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.^{4,11,12} People living with HS may also develop draining tunnels under their skin that can connect between nodules, producing blood and discharge.¹³ HS is also 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.¹⁴⁻¹⁸

HS has a significant impact on people's lives. HS has one of the highest impacts on quality of life among all dermatological conditions.¹⁹ 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.^{20,21} 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.²²⁻²⁴

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.^{23,25} 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.^{26,27} This combination of factors means that HS can lead to significant costs to the health system and wider economy.

HS in Canada

HS in Canada

HS is estimated to affect 1 in 26 people in Canada, with women and Black people significantly more likely to be affected. It is estimated that 1 in 26 people in Canada live with HS, with women up to three times more likely to be affected than men.^{28 29} In Canada, HS is four times as prevalent in Black people than in White people; the reason for this may be related to genetic predisposition or lifestyle factors, but more research is needed to determine this.³⁰

Management of HS involves a range of healthcare professionals and treatments. Dermatologists are most commonly involved in the diagnosis and management of HS, but general practitioners and surgeons also play an important role.³¹ Treatment primarily involves antibiotics for most people, but many people are also treated with surgery and biologics.³¹

There are national guidelines for HS in Canada, and a small number of centres that deliver specialist care. Management of HS is guided by clinical guidelines from the Canadian Dermatology Association and the United States and Canadian Hidradenitis Suppurativa Foundations.^{15 32} However, a dermatologist based in Canada who was interviewed for this report said they primarily refer to European guidelines.^{3 15 33} There are a small number of centres across Canada where specialist HS care is delivered, although these centres are not formally accredited.³³ Canada is involved in the international UNITE registry which is collecting data to evaluate HS in clinical practice;³⁴ however, there is currently no national HS registry in Canada.

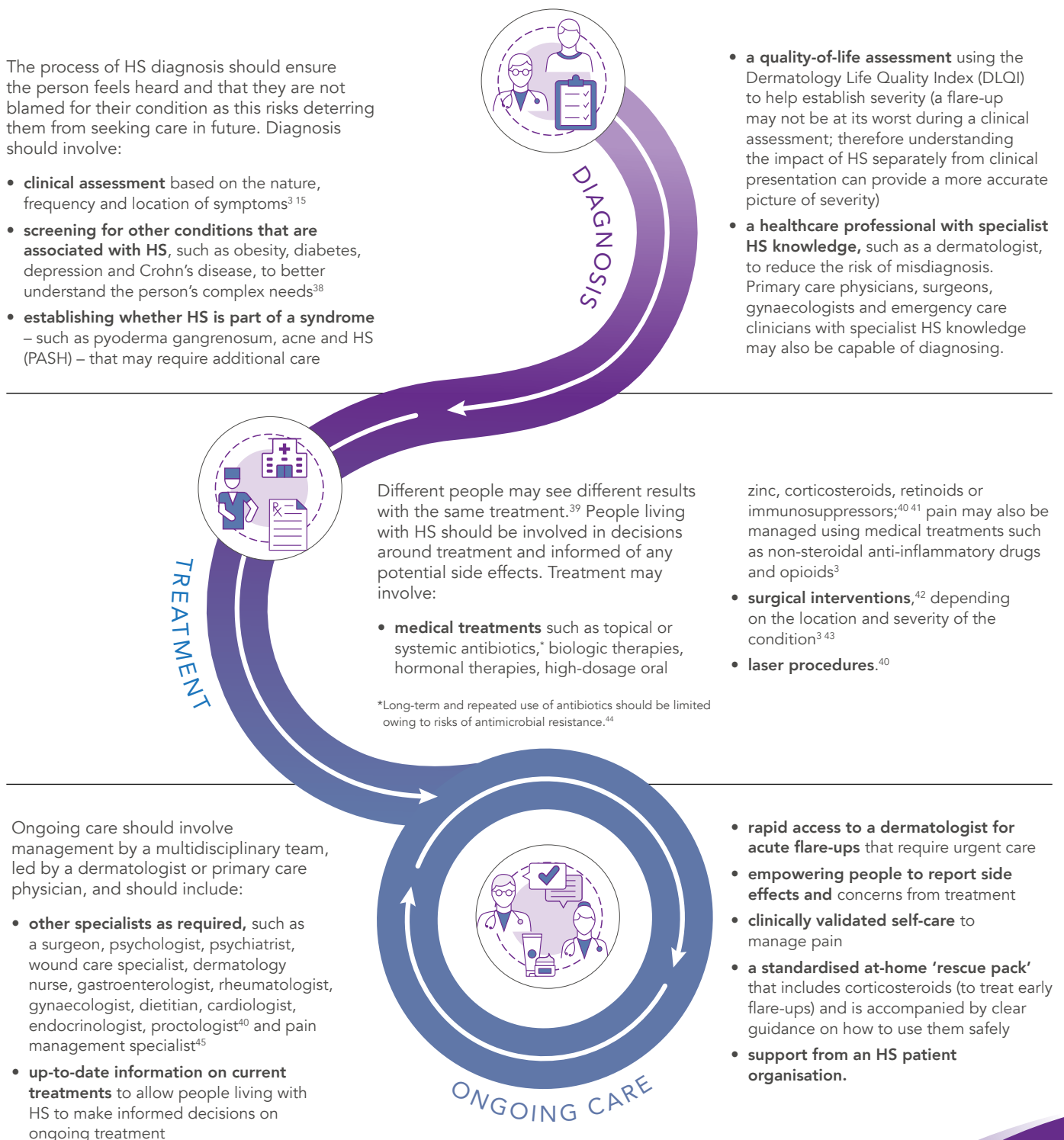
There are two active HS patient associations supporting people living with HS in Canada. Hidradenitis and Me is a patient association which hosts monthly support groups for people living with HS in Canada, provides people with information on the condition, and connects people so they can share their experiences of the condition.^{35 36} HS Heroes seeks to increase awareness of HS and support those affected by the condition.³⁷

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. Pain is regularly experienced by people living with HS.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.^{46 47}

People living with HS often struggle with mental health issues

HS can take a significant toll on people's mental health, leading to an increased risk of suicide. People with HS often experience anxiety and depression, and it is estimated that around 54–70% of people living with the condition in Canada experience feelings of depression.^{12 31 48} This may lead to people living with HS having thoughts of death or suicide.³⁹ One person with HS interviewed for this report said that the condition took control of their life and led to depression.⁴⁹

Social life can be affected by HS

Embarrassment associated with some HS symptoms can lead to people becoming socially isolated. HS-related abscesses can rupture, potentially resulting in an unpleasant smell; this is often reported as a source of embarrassment and can cause those experiencing these symptoms to feel self-conscious.^{12 49} Almost all people with HS say that their condition can make it difficult to enjoy socialising, which may contribute to them withdrawing and becoming isolated.^{31 49}

People living with HS may experience challenges around intimacy

HS can lead to issues around intimacy and personal relationships. Intimacy is an important part of mental wellbeing, and issues around this can have a significant impact on quality of life.⁵⁰ A Canadian survey found that 87% of people with HS said their condition had a negative effect on intimacy.³¹ This was driven by the location of symptoms in intimate areas of the body, the unpleasant smell of ruptured abscesses and the presence of pain.^{31 50} Another study found people living with HS were at higher risk of intimate partner violence when compared with people with acne.⁵¹ This finding further illustrates the impact of HS on personal relationships.

HS can affect people's ability to work

HS can result in people missing days of work or working despite feeling impaired by their symptoms, potentially leading to long-term consequences in their professional life. HS affects people at their most productive time in life, which means it can have a lasting impact on their career.²⁵ In one Canadian survey of people living with HS, the majority of respondents (59%) said they missed at least 2 days of work per month for HS-related reasons (symptoms, medical appointments etc.), while 16% reported missing more than 11 days a month.³¹ One person interviewed for this report said that HS led to them missing work and feeling pressure to go to work despite feeling unwell.⁴⁹

Living with HS can result in personal financial costs

Out-of-pocket costs for both prescription medications and wound care remain common for people living with HS in Canada. HS can involve costs for wound dressings and treatment to manage symptoms; these costs vary depending on the level of insurance coverage a person living with HS has.³¹ According to an international study, which included Canadian respondents, wound care is a daily part of managing HS, with one in six people needing five or more changes to their dressing a day.⁵² According to one survey, only 6% of people with HS in Canada were completely covered by their private health insurance and had no out-of-pocket HS-related expenses.³¹ Others spent between Can\$65 and Can\$262 each month on HS-related expenses, depending on their insurance coverage.³¹ One person interviewed for this project reported once needing to spend Can\$400 on antibiotic treatments for their HS because they were not covered by private insurance.⁴⁹



Chevonne's story

Chevonne was 15 when she got some small bumps in her groin area. She was confused by them initially and, as they became more severe and painful, she realised she needed to see a doctor. Chevonne spent years going to the emergency department or walk-in clinics for her symptoms, where she would have her abscesses lanced or be given short courses of antibiotics – none of which were helping her manage her symptoms. Many of the doctors she saw told her that her symptoms were normal and that she was overreacting; some even told her that she smelled and that she needed to shower more often. These distressing experiences led to Chevonne only going to the doctor when she was desperate. It took eight years for her to be diagnosed with HS, and the diagnosis was established by a doctor in an emergency department.

'They've made me feel dirty, or that I'm wasting their time. I've had a doctor tell me I smell – it would just cause me not to even want to go to the doctor or seek help. They can just be so mean.'

As Chevonne's symptoms got worse, so did her mental health. She felt very self-conscious about how her abscesses looked and smelled, and the pain would prevent her from being able to do everyday things such as walking or driving. She withdrew from

social situations because she was embarrassed and in pain, ultimately becoming very isolated.

'It was all I could think about. It was controlling my life – I felt like it took everything away from me. My social life dwindled completely. I shut everybody out and lost a lot of friends. I didn't want to go anywhere or do anything.'

HS also had an impact on Chevonne's work. She hated missing work but sometimes had no choice because her symptoms were so bad. Her supervisor would frequently get angry at her for coming in late, even though she was trying to deal with a flare-up. This eventually led Chevonne to feeling forced to quit and being unemployed for four months.

'I hate missing work so I would still go in – even on the worst of days. My supervisor started getting on at me for coming in late. I came in late a couple of days in a row because I had a really bad abscess. In the morning it was just bleed, bleed, bleed, and I just couldn't get to work in time. After a week of my supervisor getting on at me about that, I just quit.'

Chevonne says she is now in a good place mentally. She is on effective treatment and sees her dermatologist every three or four months. She wishes that there could be a treatment that works for everyone.

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 healthcare professionals is contributing to delays in diagnosis and poor-quality care

Limited awareness of HS among healthcare professionals leads to long delays in receiving an accurate diagnosis and beginning treatment. Early diagnosis means people with HS can access treatment sooner, which can prevent symptoms becoming more severe.⁵³ Unfortunately, low awareness among healthcare professionals in Canada contributes to an average diagnostic delay of seven years from first symptoms to receiving an HS diagnosis.³¹ During this time, people living with HS will be misdiagnosed an average of three times.³¹

“People will wait for 12 months to see a dermatologist, then just be told that they don’t shower enough. It’s just horrible.”

SUSAN POELMAN,
CANADIAN HIDRADENITIS
SUPPURATIVA FOUNDATION,
CANADA

A lack of understanding of HS among some healthcare professionals can result in a frustrating and distressing healthcare experience, discouraging people from seeking care. A lack of awareness around the causes of HS may lead to symptoms being falsely attributed to an issue of hygiene, which can make people living with HS feel stigmatised.^{31 33 39} Those with HS report feeling the need to educate doctors on the condition and advocate for the best possible care.³¹ One person living with HS interviewed for this project described having highly distressing and uncompassionate experiences with healthcare professionals, which led to them avoiding healthcare until the situation became dire.⁴⁹

Limited effectiveness and unwanted side effects are contributing to low levels of treatment satisfaction

Most people living with HS are dissatisfied with the treatment options available to them, a feeling which is primarily driven by low efficacy and unwanted side effects. A 2020 Canadian survey found that 61% of people with HS were dissatisfied with current treatment options and had trialled an average of 15 different medical, surgical or lifestyle modifications for their condition.³¹ The main drivers of dissatisfaction were a lack of effectiveness, as well as side effects from the long-term use of the treatments that did offer some improvement.³¹

Many people living with HS rely on self-treatment, which can be dangerous.

In one study, over 90% of people living with HS were found to be self-treating symptoms through techniques such as squeezing and lancing their abscesses, indicating the treatments they were prescribed were insufficient.⁴⁸ Self-treatment using these techniques puts people at risk of infection and – in extreme cases – even death.⁵⁴ People living with HS could benefit from receiving information from their doctor that encourages them to avoid self-treatment methods that could be dangerous, and outlines techniques that could support people in managing their symptoms safely.

Access to psychological support is insufficient

Despite the major psychological burden of HS, the majority of people living with the condition do not have access to mental health support. HS can have a significant impact on mental health, indicating a clear need for psychological support, yet only one in five people with HS in Canada receive this as part of their treatment.³¹ Given the high prevalence of mental health issues among people living with HS, psychological services should be considered an essential part of care. Offering virtual psychological support may help to deliver holistic HS care more efficiently.³³

We're not doing a good job of managing people in the clinic, we just don't have enough time. Most of us are trying to fit 45-minute visits into 10-minute slots.

SUSAN POELMAN,
CANADIAN HIDRADENITIS
SUPPURATIVA FOUNDATION,
CANADA

Inadequate access to care leads to frequent use of emergency services

Long waiting times and a lack of dermatologist capacity are limiting access to high-quality HS care. People living with HS experience unacceptable waiting times to see a dermatologist or surgeon; the average waiting time in Canada is significantly longer than in other countries.³¹ A dermatologist interviewed for this report said waiting times to see a dermatologist can be up to 12 months in some parts of the country.³³ They added that, in their centre, dermatologists also had limited time to see people living with HS, which affects the dermatologists' ability to offer supportive services.³³ To mitigate this, the centre has developed an electronic book that can be

shared with people living with HS to teach them about diet, wound care and pain management.³³

Insufficient compensation for dermatologists managing people living with HS is exacerbating access challenges. According to one HS expert interviewed for this report, the current compensation system for dermatologists in Canada can make it financially challenging for them to see people living with HS.⁵⁵ HS consultations can take significantly longer than the average consultation, but dermatologists do not receive any additional reimbursement for these longer consultations and this can make it difficult to cover the expenses associated with delivering care.^{33 55} This may act as a disincentive for dermatologists to carry out comprehensive HS consultations.⁵⁵

Issues around access to care may be leading to greater reliance on emergency services, which can be both costly and time-intensive. Challenges around access to dermatology services may be contributing to a high frequency of visits to the emergency department.^{31 49} A 2020 survey found that 59% of people living with HS in Canada had visited emergency care for their symptoms, with 10% visiting more than ten times.³¹ Emergency admissions represent a significant financial burden on the health system, highlighting the importance of well-managed HS to reduce costs.⁵⁶ Additionally, emergency admissions can be time-intensive for the people using them, according to one person living with HS interviewed for this report.⁴⁹ A range of strategies may be considered to reduce reliance on emergency services. These may include the use of virtual dermatology appointments, which are supported by the Canadian Dermatology Association for some conditions, and the provision of urgent appointments in HS centres.³³ To mitigate the burden on people living with HS, one centre provides people with an information card that includes details around what HS is and the most appropriate care for that individual.³³ The card can be shared with healthcare professionals to reduce the amount of time spent in emergency care and improve the quality of care people receive.³³

Recommendations for policymakers

Recommendations for policymakers

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

- **Roll out HS educational programmes for healthcare professionals** to increase understanding of the condition, improve speed of diagnosis and reduce the stigma felt by people living with HS when interacting with health services.
- **Introduce a guide on safe self-treatment of HS symptoms** to support people in better managing their condition without risk.
- **Build psychological support services** into care pathways for people living with HS, recognising the significant impact of the condition on mental health.
- **Increase compensation received by healthcare professionals for delivering HS care** in recognition of the complex nature of HS consultations.
- **Provide all people living with HS with an information card with their individual HS requirements to support their emergency care** should they need it.
- **Ensure all centres providing HS care ringfence some dermatology appointments** to guarantee access to urgent dermatological care, as well as offering virtual appointments.

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. 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
8. 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
9. Naik HB, Paul M, Cohen SR, et al. 2019. Distribution of Self-reported Hidradenitis Suppurativa Age at Onset. *JAMA Dermatol* 155(8): 971-73
10. Vinkel C, Thomsen SF. 2018. Hidradenitis Suppurativa: Causes, Features, and Current Treatments. *J Clin Aesthet Dermatol* 11(10): 17-23
11. Ingram JR. 2016. Hidradenitis suppurativa: an update. *Clin Med* 16(1): 70-3
12. 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
13. Mayo Clinic. Hidradenitis suppurativa. Available from: <https://www.mayoclinic.org/diseases-conditions/hidradenitis-suppurativa/symptoms-causes/syc-20352306> [Accessed 05/12/23]
14. Misitzis A, Katoulis A. 2021. Assessing Psychological Interventions for Hidradenitis Suppurativa as a First Step Toward Patient-Centered Practice. *Cutis* 107(3): 123-24
15. 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
16. Tzellos T, Zouboulis CC. 2022. Which hidradenitis suppurativa comorbidities should I take into account? *Exp Dermatol* 31(Suppl 1): 29-32
17. Jarcă 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
18. 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
19. 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
20. Matusiak Ł, Szczech J, Kaaz K, et al. 2018. Clinical Characteristics of Pruritus and Pain in Patients with Hidradenitis Suppurativa. *Acta Derm Venereol* 98(2): 191-94
21. 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
22. 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
23. 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
24. Vekic DA, Cains GD. 2017. Hidradenitis suppurativa – Management, comorbidities and monitoring. *Australian Journal for General Practitioners* 46(8): 584-88
25. 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
26. 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
27. 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
28. Lachaine J, Miron A, Shear N, et al. 2016. The Prevalence And Incidence Of Hidradenitis Suppurativa In Canada: Results From A Population-Based Survey. *Value Health*: 10.1016/j.jval.2016.03.495
29. Canadian Dermatology Association. Hidradenitis Suppurativa. Available from: <https://dermatology.ca/public-patients/skin/hidradenitis-suppurativa/> [Accessed 04/07/23]
30. Sachdeva M, Shah M, Alavi A. 2020. Race-Specific Prevalence of Hidradenitis Suppurativa. *J Cutan Med Surg* 25(2): 177-87
31. Canadian Skin Patient Alliance. 2020. *Scarred for Life: 2020 Update*. Nepean: Canadian Skin Patient Alliance
32. Alikhan A, Sayed C, Alavi A, et al. 2019. North American clinical management guidelines for hidradenitis suppurativa: A publication from the United States and Canadian Hidradenitis Suppurativa Foundations: Part II: Topical, intralesional, and systemic medical management. *J Am Acad Dermatol* 81(1): 91-101
33. Poelman S. 2023. Interview with Chris Melson at The Health Policy Partnership [video conference]. 14/07/23
34. Prens EP, Lugo-Somolinos AM, Paller AS, et al. 2020. Baseline Characteristics from UNITE: An Observational, International, Multicentre Registry to Evaluate Hidradenitis Suppurativa (Acne Inversa) in Clinical Practice. *Am J Clin Dermatol* 21(4): 579-90
35. Hidradenitis and Me. About us. Available from: <https://hidradenitisandme.ca/about-us> [Accessed 14/07/23]
36. Hidradenitis and Me. Homepage. Available from: <https://hidradenitisandme.ca/> [Accessed 04/10/23]
37. HS Heroes. Homepage. Available from: <https://hsheroes.ca/> [Accessed 04/10/23]
38. Garg A, Malviya N, Strunk A, et al. 2022. Comorbidity screening in hidradenitis suppurativa: Evidence-based recommendations from the US and Canadian Hidradenitis Suppurativa Foundations. *J Am Acad Dermatol* 86(5): 1092-101
39. Canadian Hidradenitis Suppurativa Foundation. 2022. *A Guide to Hidradenitis Suppurativa: Living with HS*. Richmond Hill: Canadian Hidradenitis Suppurativa Foundation

40. 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
41. Hessem 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
42. 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
43. 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
44. 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
45. 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
46. 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
47. Jemec GB. 2017. Quality of life considerations and pain management in hidradenitis suppurativa. *Semin Cutan Med Surg* 36(2): 75-78
48. Huang CM, Kirchoff MG. 2021. Hidradenitis Suppurativa From a Patient Perspective Including Symptoms and Self-Treatment. *J Cutan Med Surg* 25(6): 591-97
49. Smellie C. 2023. Interview with Chris Melson at The Health Policy Partnership [video conference]. 27/04/23
50. Alavi A, Farzanfar D, Rogalska T, et al. 2018. Quality of life and sexual health in patients with hidradenitis suppurativa. *Int J Womens Dermatol* 4(2): 74-79
51. Susic M, Tan J, Lafreniere KD. 2017. Hidradenitis Suppurativa, Intimate Partner Violence, and Sexual Assault. *J Cutan Med Surg* 21(5): 383-87
52. Moloney S, McGrath BM, Roshan D, et al. 2021. The Personal Impact of Daily Wound Care for Hidradenitis Suppurativa. *Dermatol* 238(4): 762-71
53. Kirsten N, Petersen J, Hagenström K, et al. 2020. Epidemiology of hidradenitis suppurativa in Germany – an observational cohort study based on a multisource approach. *J Eur Acad Dermatol Venereol* 34(1): 174-79
54. HS Connect. Self Lancing: Why This Isn't a Good Idea. Available from: <https://www.hsconnect.org/post/self-lancing-why-this-isn-t-a-good-idea> [Accessed 20/06/23]
55. Poelman S. 2023. Personal communication by email: 23/09/23
56. Kirby JS, Miller JJ, Adams DR, et al. 2014. Health care utilization patterns and costs for patients with hidradenitis suppurativa. *JAMA Dermatol* 150(9): 937-44

© UCB Biopharma SRL, 2024. All rights reserved.
Date of preparation: March 2024.
CA-BK-2300012

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

The
Health Policy
Partnership
[research, people, action]