

# Hidradenitis Suppurativa Policy Brief

Lack of Accurate Prevalence Data for HS Diagnosis Burdens Health Systems

## What is Hidradenitis Suppurativa?

Hidradenitis Suppurativa (HS) is a chronic, stigmatizing, and disabling skin condition that affects approximately 1 – 4% of people in the United States, though the true prevalence is still yet to be confirmed, and disproportionately impacts women of color. HS manifests as painful abscesses under the skin and can occur anywhere hair follicles are present on a person's body.<sup>1</sup> Although it can present anywhere, HS is most commonly seen in the armpits, groin, buttocks, and breasts.<sup>2,3</sup> These deeply seated lesions may develop into odorous pus-filled abscesses, indiscriminately bursting. Even with timely treatment, significant scarring often develops. The intense physical pain and social isolation due to symptoms may cause mental health comorbidities including depression, anxiety, substance use disorders, psychiatric disorders, sexual dysfunction, and increased risk of suicide.<sup>4</sup>

**There is no cure for HS.** Management of HS may include lifelong use of oral medications, injectable biologics, surgery, pain management, and specialized wound care.

## Inaccurate Prevalence Data Results in Serious Downstream Impacts

Latest prevalence percentages for HS varies widely, from a low of 0.078%<sup>5</sup> to a clinical sample pool of 1.7%.<sup>6</sup> **The generally reported 1% HS prevalence rate is inaccurate,**<sup>7</sup> due to three primary factors: clinician underdiagnosis, patient stigmatization, and conflicting data sources.

There is no laboratory test for HS; diagnosis is achieved by a clinician visit to visually confirm three lesion characteristics: presence, location, and recurrence. Medical professionals unfamiliar with HS may misdiagnose HS as herpes, MRSA, acne inversa, or blood disorders. These lapses in diagnosis cause misreporting of an accurate diagnostic code into the patient's health record, which in turn is reported into databases used for research.<sup>8</sup>

Individuals may avoid seeking care due to embarrassment and fear. Studies show stigmatization occurs due to the intimate areas of the body impacted by HS, the malodor created when an abscess bursts, and clinician's reaction to symptoms.<sup>9</sup>

Multiple data sources utilized for statistical purposes do not accurately reflect the HS patient population. Insurance claim data does not capture those who are cash-pay or uninsured; HS patient databases may over or underreport diagnoses due to demographic bias,<sup>10</sup> and self-reporting questionnaires do not capture those who do not seek out clinician confirmation.

Without accurate research and prevalence data, Hidradenitis Suppurativa will continue to be grossly underfunded,<sup>11</sup> clinically misdiagnosed, burden health systems due to treatment delays and remain incurable.

## Policy Recommendations

- Request funding for a retrospective data study employing a single data repository that includes non-insured individuals and a revisitation of specific diagnosis codes that indicate possible misdiagnosis.
- Collaborate with an academic center to create a registry of HS patients and symptoms that providers can populate to increase available data on the disease and gather more accurate prevalence figures.
- Require mandatory reporting and surveillance systems, with data sent to and maintained by a government agency to ensure all diagnosed cases are accurately counted for prevalence.

## References

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