

Document Title:	Pathway to Cancer Screening for Hidradenitis Suppurativa Patients
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Summary / Situation	
<p>Patients with Hidradenitis Suppurativa (HS) often have additional severe comorbidities which, when added to an analysis of life expectancy, tends to translate to a reduction in life expectancy. This finding was identified in the journal article, “Substantially Reduced Life Expectancy in Patients with Hidradenitis Suppurativa: a Finnish nationwide registry study.”¹</p> <p>The retrospective case-control study described that the mean age at death was lower in individuals with HS than in controls (60.5 years vs 71.1 years in people with psoriasis.) The most common cause of death in the HS group was disease of the circulatory system, with neoplasm (cancer) being the second leading cause of death for those with HS.¹</p>	
Background:	
<p>HS is a painful, chronic skin disease that causes lumps to form under the skin. The lumps usually show up in places where the skin rubs together. In both men and women, HS lumps are most commonly found in the armpit and groin regions, as well as other areas of the body including the breast area.²</p> <p>HS usually starts after puberty and can get worse over time. The condition can be managed with certain medicines and some lifestyle changes, but there is no cure. Researchers are still working to understand the autoinflammatory disorder and its underlying cause.²</p> <p>HS frequently coexists with other health conditions. These comorbidities can interact in ways that make both conditions worse.²</p> <p>Some common HS comorbidities include:</p> <ul style="list-style-type: none"> • Diabetes • Arthritis • Inflammatory bowel disease • Polycystic ovarian syndrome (PCOS)² <p>There is also research showing that HS is associated with cancer, especially a very common type of skin cancer known as squamous cell carcinoma (SCC).²</p>	

Scientists found the risk of cancer significantly rises in people who have HS. A 2001 study found cancer risk jumps 50 percent in people living with HS. ²

Researchers in 2020 followed up on that idea, finding that not only do people with HS have an increased risk of overall cancer, but HS is associated with an increased risk of specific cancers.

People living with HS have a higher risk of developing specific cancers, including:

- Lymphomas, including non-Hodgkin's lymphoma, Hodgkin's lymphoma, and cutaneous T-cell lymphoma
- Oral cancer
- Nonmelanoma skin cancer, including SCC and basal cell carcinoma
- Prostate cancer
- Colorectal cancer²

There is a possibility that cancer and HS development are connected, as overall cancer risk increases when HS becomes more severe.²

My Story

My name is Ceri Harris. I am a 50-year-old Caucasian woman, who was officially diagnosed with HS approximately 13 years ago. It took many years to actually receive that diagnosis.

For many years I had noticed lumps and bumps around my body, particularly in the breast and groin area. When I was 32, I noticed a lump on my left breast, this lump was painful to the touch and felt very deep inside the breast tissue. Over a couple of months, I could feel several other bumps too. I worked in the National Health Service in Wales, UK where the Welsh National Breast Screening programme was based. As a result, I was able to access one of our consultants for a consultation to investigate the lumps.

What then followed was a mammogram and ultrasound examination. The conclusion was I had a large number of cysts in my breast tissue. That was it. I was then discharged, no follow up.

What I now realise is that was my unofficial HS diagnosis. It took another six years for me to get a diagnosis from a dermatologist.

My reality now, and for many with HS, is that whenever we find another lump or bump, we default to thinking this is HS-related and not something more sinister. For me in the UK, this means I don't go to my GP to be referred for a mammogram (free of charge) as I would be doing this every month. For someone in the US for example, where both GP access and screening services are often linked to substantial fees even with good insurance, it means that early detection is not always possible, and as a result health outcomes are impacted.

Assessment

Currently there are a number of research projects and areas of work looking at improving the quality of life for HS patients. However, there doesn't seem to be work being undertaken to support the life expectancy of HS patients by developing a universal pathway for HS patients to

be screened annually for cancer through mammograms, blood tests etc. This includes self-awareness campaigns to check for signs and symptoms.

In conversations with HS clinicians at the most recent IDEOM conference, I found there was awareness of the risks, as well as knowledge of increased incidents of cancer and life expectancy rates. I heard statements like, “oh yes, we know HS patients die early,” and that this was commonly related to cancer and cardiovascular disease, but this never seems to be raised as an area of research.

Recommendation & Conclusions:

It would greatly benefit patients to develop international cancer screening guidelines for HS patients. The goal would be for clinicians to support universal screening standards for all HS patients, regardless of which country they live in. In some cases, these screening guidelines would be more aggressive than a country’s general cancer screening parameters.

As one example, in the UK all women (including trans men and femme non-binary) aged 50-64 are invited for breast screening services only once every three years. In the US, women are invited for breast screening every year starting at age 40.

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