

# Is Doctor Google helpful for diagnosing Hidradenitis Suppurativa?

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## Introduction

Hidradenitis suppurativa (HS) is a debilitating chronic inflammatory and autoimmune skin disease. It manifests as recurrent painful nodules, abscesses and draining sinus tracts in intertriginous areas.(1) HS has an estimated global prevalence of 0.0003 to 4.1%. **Global delay to diagnosis is significant, ranging from 7 to 10 years.**(2) **Why do patients with this condition wait so long for a diagnosis?**

HS patients are increasingly using online sources to gather health information and for social support.

## Aims

To understand the delay in diagnosis and who is diagnosing patients with HS in a Queensland population. Further, to investigate whether patients find internet sources on HS helpful, or a hindrance.

## Methods

A cross-sectional explorative study was conducted, involving 100 HS participants aged over 18 years old at the Princess Alexandra Hospital and Central Brisbane Dermatology, between January 2018 to August 2021. The questionnaire was developed by the research team and focused on diagnosis and internet use.

## Results

The mean participants age at time of enrolment was 39 years old and 68% were female. The mean age of HS symptom onset was  $21.4 \pm 9.6$  years, mean age at diagnosis was  $31.4 \pm 11.2$  years,

resulting in a **mean delay to diagnosis of  $10 \pm 9.7$  years.**

There was a strong association with age at diagnosis and delay to diagnosis ( $p < 0.0001$ ). Participants **sought review from an average of  $7 \pm 12$  doctors before eventually being diagnosed with HS.** The source of HS diagnosis is seen in Figure 2.

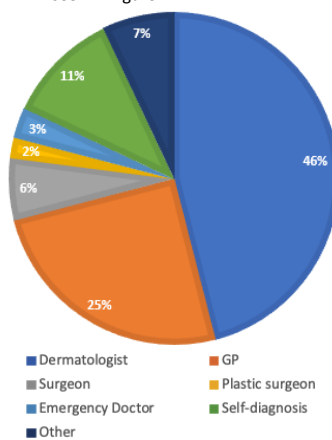


Figure 2: Source of HS diagnosis

79 participants performed self-directed internet research related to HS, their experiences were:

- 32.9% entirely positive
- 12.66% entirely negative
- 55.43% mixed

The main negative online experiences listed included:

- 19% learning that HS is incurable
- 19% inadequate resources

The main positive online experiences included:

- 59% education on HS
- 36.71% use of online support groups

## Discussion

The average delay to diagnosis is consistent with that reported in the literature.(2) Given Queensland's exceptional health system, this delay to diagnosis is unacceptable. These patients suffer poor quality of life, depression and inability to work.(2,3) More needs to be done in way of raising awareness and educating clinicians to expedite diagnosis and management. The internet appears to be helpful to patients for education and a source of support. Given the stigma associated with condition, the internet provide a safe environment to seek advice and share experiences. Further, a significant number of participants self-diagnosed their HS aided by the internet, highlighting its contribution to reducing delays in diagnosis. Limitations of the study include recall bias, small sample size and selection bias due to lack of HS patients managed in primary care settings.

## Conclusion

Diagnostic delay remains an ongoing issue for HS. The internet is an important tool for self-diagnosis and education, however additional work is required to ensure a consistent and helpful online experience.

## Selected references

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\*Consent obtained by patients to display clinical images.

