

Hidradenitis Suppurativa within the Australasian Dermatology Registry



Australasian Dermatology Registry

J. Armstrong¹, E. McMeniman^{2,3}, G. Marshman⁴, L. Spelman⁵, J. Frew^{6,7}, K. Gebauer⁸, J. Nicolopoulos⁹, D. Rubel^{10,11}, H. Saunders¹², P. Foley^{1,12}, D. Courtney¹, S. Smith^{13, 14}

¹Skin Health Institute, Carlton, VIC ²Dermatology Research Centre, The University of Queensland, Woolloongabba, QLD ³Department of Dermatology, Princess Alexandra Hospital, Woolloongabba, QLD ⁴Flinders Medical Centre, Flinders University Medical School, Adelaide, SA ⁵Queensland Institute of Dermatology, Brisbane, QLD.

⁶Department of Dermatology, Liverpool Hospital, Sydney, NSW ⁷University of New South Wales, Sydney, NSW ⁸Fremantle Dermatology, WA ⁹Dermatology Department, Royal Melbourne Hospital, Parkville, VIC 3050, Australia ¹⁰Australian National University, Canberra, ACT ¹¹Woden Dermatology, Phillip, ACT ¹²Department of Dermatology, St Vincent's Hospital Melbourne, Fitzroy, VIC ¹³Sydney Adventist Hospital Clinical School, ANU Medical School, ANU College of Health and Medicine, The Australian National University, Canberra, ACT ¹⁴The Dermatology and Skin Cancer Centre, St Leonards, NSW

Hidradenitis Suppurativa (HS) is a chronic inflammatory condition affecting approximately 1% of Australians. Patients often experience delayed diagnosis, misdiagnosis, and inappropriate treatments. Local real-world data pertaining to the diagnosis, risk factors, treatment and outcomes are limited.

In collaboration with experts in the field, the Australasian Dermatology Registry (ADR) (www.australasiadermatology.org.au) has developed a Hidradenitis Suppurativa module to capture referral and diagnosis data, the impact HS has on health-related quality of life including economic impact of dressings, treatment, and time away from work, pain and pain management, in addition to the core registry items (demographics, family history, comorbidities, vaccinations, quality of life (DLQI), medications, and surgeries).

AIM

The aim is to assist patients living with HS by producing a user-friendly registry that captures a number of new, highly relevant areas of disease impact and management fields:

- Identifying gaps in diagnosis pathways to support earlier diagnosis and intervention
- Identifying triggers that can result in disease flares
- Advocating for patient support for dressings and over the counter product access

METHODS

A modular registry has been established to capture demographic, diagnosis, comorbidity, treatment, outcome, and quality of life data. The platform includes an electronic-consent process, webforms for participant-reported and clinical data capture, and automated reporting.

Clinician input is limited to disease activity measures and treatment.

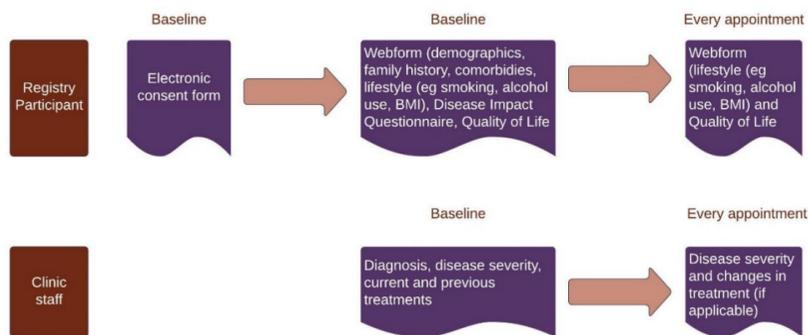


Table 1: Data collection workflow

FOR MORE INFORMATION

To find out more about the Australasian Dermatology Registry contact registry@australasiadermatologyregistry.com.au.

ACKNOWLEDGEMENTS AND REFERENCES

The Australasian Dermatology Registry would like to thank the members of the hidradenitis suppurativa scientific advisory committee who determined the minimum dataset (<https://australasiadermatologyregistry.org.au/governance/committees/>) and the sponsors who provided funding for the registry build (<https://australasiadermatologyregistry.org.au/governance/sponsors-and-partners/>).

The image shows several screenshots of the Hidradenitis Suppurativa questionnaire. The top section is titled 'Hidradenitis Suppurativa' and includes fields for 'Year of diagnosis' (2003), 'Year of first symptoms' (2003), 'Family history' (Yes), 'Who made the diagnosis of your Hidradenitis Suppurativa?' (Other), 'If diagnosed by other, please specify?' (GP), and 'If other, please specify?' (Heat). Below this is a section for 'Pain' with a visual scale from 0 (No Pain) to 10 (Worst Pain), and questions about how the patient rates their pain this week and in the last 4 weeks. There are also questions about how the patient manages their pain and how many dressings they use per week. The bottom section is titled 'HS-PTGA' and asks 'How would you rate the severity of your Hidradenitis Suppurativa right now?' with options: Complete disease control, Good disease control, Limited disease control, and Uncontrolled disease.

Figure 1: Examples of data collection questionnaires

ONLINE REPORTING

The registry online reporting enables users to view individual patient outcomes, disease specific reports and compare their clinic's outcomes with the registry aggregate data.

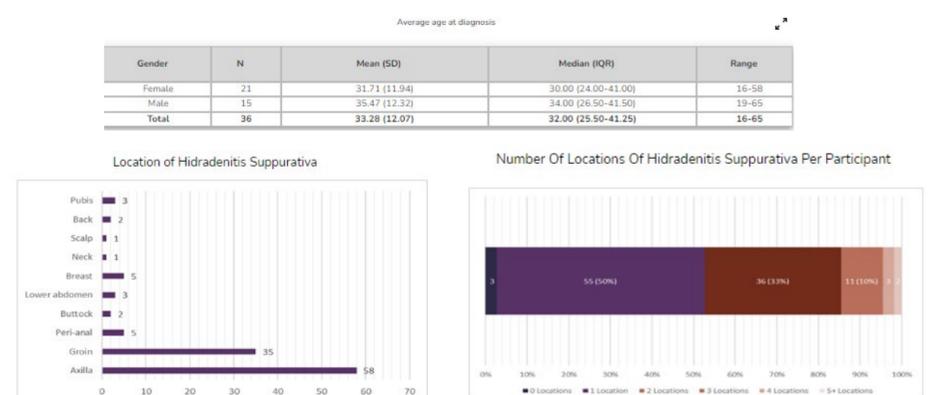


Figure 2: Examples of online reporting

CONCLUSION

The development of an Australasian Dermatology Registry provides an avenue for collecting and analysing local real-world data on the current and emerging treatment of hidradenitis suppurativa and provides a platform to support clinical research.

The easy-to-use platforms minimises the burden of data collection to improve dermatology research in Australia.