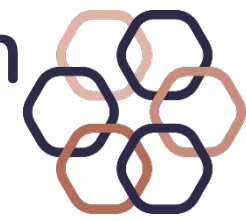


Hidradenitis Suppurativa within the Australasian Dermatology Registry



Australasian Dermatology Registry

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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.

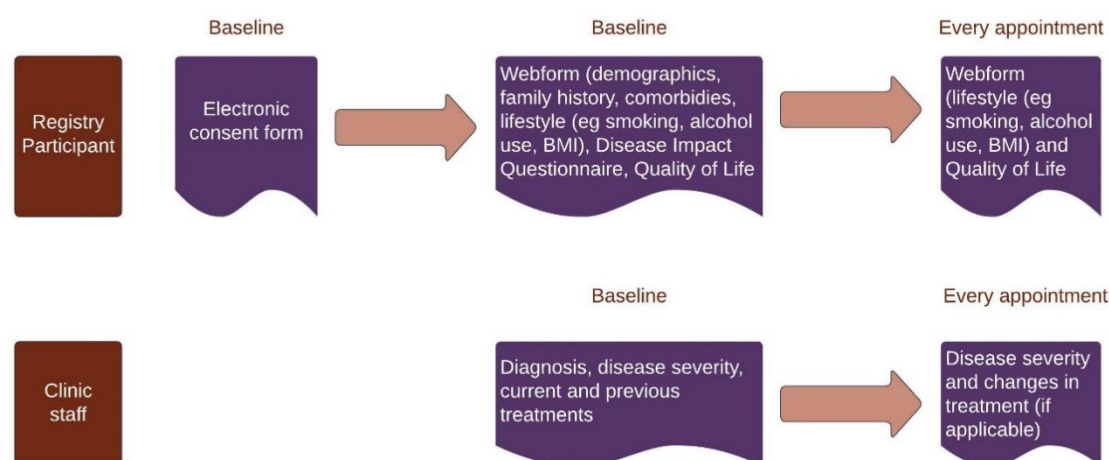


Table 1: Data collection workflow

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 online reporting questionnaires. Key sections include:

- Hidradenitis Suppurativa:** Fields for 'Year of diagnosis' and 'Year of first symptoms' (with 'Unknown' options), 'Family history' (Yes/No), 'Who made the diagnosis of your Hidradenitis Suppurativa?' (Other dropdown), 'If diagnosed by other, please specify?' (GP text input), and 'If other, please specify?' (Heat text input).
- Pain:** A visual analog scale from 0 (No Pain) to 10 (Worst Pain), with 'Moderate Pain' marked at 5. Questions ask for 'How would you rate your pain from Hidradenitis Suppurativa this week?' and 'How would you rate your pain from Hidradenitis Suppurativa in the last 4 weeks?' with 'Not recorded' checkboxes.
- Dressings:** A question: 'In the last four weeks, on average, how many dressings did you use per week?' with a 'Not recorded' checkbox.
- HS-PTGA:** A question: 'How would you rate the severity of your Hidradenitis Suppurativa right now?' with radio button options: 'Complete disease control', 'Good disease control', 'Limited disease control', 'Uncontrolled disease', and a 'Not recorded' checkbox.

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.

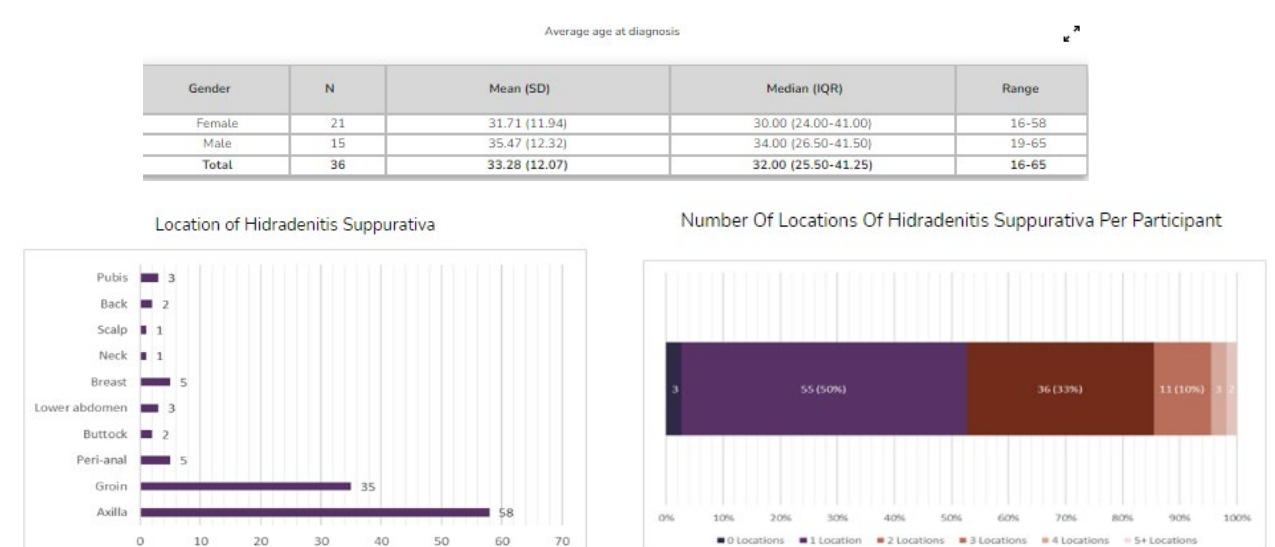


Figure 2: Examples of online reporting

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.