

Development of an Australasian Dermatology Registry



J. Armstrong¹, C. Baker² and P. Foley^{1,2}

¹ Skin Health Institute, 80 Drummond Street, Carlton, VIC 3053, ² St Vincent's Hospital Melbourne, 41 Victoria Parade, Fitzroy, VIC 3065

AIM

Development of the Australasian Dermatology Registry to capture real world data will enable surveillance of current and emerging treatment, and provide a platform for dermatology research. Currently, randomised trial data are available for new therapeutic options. However, data are often from relatively small cohorts of patients, without any comorbidities and with limited prior treatment, whereas most real-world patients seen in the clinic have tried other treatments previously, are on concomitant therapy, and have a range of comorbidities.

METHODS

A modular registry has been designed 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.

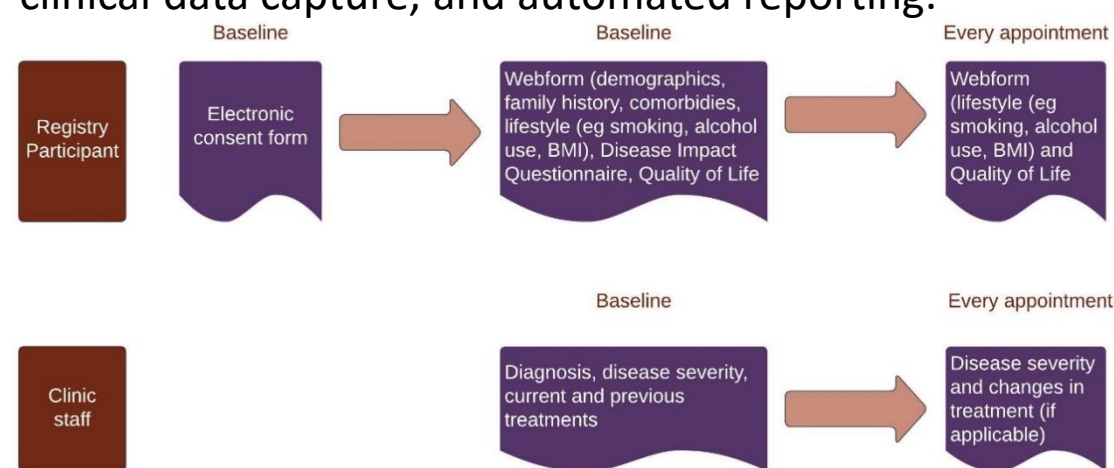


Table 1: Data collection workflow

Disease-specific scientific advisory committees have been established to include representative of public and private clinics from across Australia. These scientific advisory committees (<https://australasiandermatologyregistry.org.au/governance/committees/>) reviewed international registries, the scientific literature, and current clinical practice to determine datasets that are practical to collect and will provide valuable data to answer clinical questions.

Initially the platform will include psoriasis, atopic dermatitis, hidradenitis suppurativa, and vitiligo, with additional skin conditions to be added as funding becomes available.

In addition to participating in the registry, participants or their parent/guardian (where participants are under the age of 16 years) will be asked to provide consent to be contacted for additional studies and data linkage to large government datasets. This will enable the registry to be a catalyst for clinical trials and research studies, in addition to the primary aim of monitoring and improving patient care.

ACKNOWLEDGEMENTS AND REFERENCES

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

RESULTS

An online registry and corresponding website (www.australasiandermatologyregistry.org.au) has been developed and launched within Australia, with New Zealand sites to be recruited in 2024.

The screenshot shows the Australasian Dermatology Registry website. The top navigation bar includes 'Demographics & Consent', 'Medical History and QOL', 'Consultations', and 'Reports'. The 'Demographics' section contains various input fields for personal information: Surname, First name, Email, Address, Middle initial, Maiden/Previous Name, Mobile Number, Postcode, Date of birth (format: DDMM/YYYY), Gender (Male, Female, Other), Patient Status (Alive, Deceased), Ethnicity, Country of Birth, Preferred Language, Medicare Number (AUD), and Are You Of Aboriginal Or Torres Strait Islander Origin. The 'DLQI' section contains a series of questions about skin-related quality of life, each with a Likert scale response (e.g., Very much, A lot, A little, Not at all, Not relevant).

CONCLUSIONS

The development of an Australasian Dermatology Registry will provide local real-world data on the current and emerging treatment of skin conditions, and provide a platform to support clinical research.

FOR MORE INFORMATION

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