Australasian Dermatology Registry

AUSTRALASIAN DERMATOLOGY REGISTRY DATA ACCESS POLICY

VERSION 1.0 APRIL 2023

PURPOSE OF THE DATA ACCESS POLICY

This data access policy describes the standard operating procedures to access data from the Australasian Dermatology Registry; this includes contributing sites and external groups.

THE AUSTRALASIAN DERMATOLOGY REGISTRY (ADR)

The ADR collects demographic, diagnosis, treatment, and quality of life data on people treated for skin conditions at participating sites within Australia and New Zealand. The registry is designed to improve the quality of care for people living with skin conditions by informing dermatologists of the efficacy and risks of current and emerging treatment, the risk factors for developing a skin condition, and the impact these conditions have on the quality of life of the patients.

CONFIDENTIALITY

The data collected by the ADR are stored in a secure password protected database to protect against potential breaches of privacy (see Data Security Policy for additional information), with access only to authorised users.

The ADR complies with strict data management processes and guidelines to protect the privacy of registry participants and contributing sites and comply with ethical approval.

Data requests for de-identified data for research purposes will be reviewed by the appropriate scientific advisory committee. However, sites can request identifiable data for participant data they contributed i.e., a clinic can request identifiable data for participants recruited and treated at that site.

ACCESS TO THE DATA FROM ADR BY PARTICIPATING SITES

The ADR supports and encourages the use of registry data for research by providing de-identified data to sites that contribute data to the registry.

Participating sites can request access to data using the data access form. The form includes the aim of study, study methodology, data items requested, analysis method, publication plan, and timeframe. All projects must have appropriate ethics approval prior to release of data.

All data requests are reviewed by the relevant scientific advisory committee for:

- Scientific merit
- Methodology

Prior to completing the data access form, we recommend researchers contact the registry at registry@australasiandermatologyregistry.com.au or (03) 9623 9470 to discuss the project design, identify if the study is already being conducted, if additional ethics approval is required, data are available, and timeline for project review and data release.

Once the data are released, researchers have 12 months to complete the research project before the data becomes available for other researchers to complete the study. This is to prevent researchers reserving the data for future studies. An extension can be applied for if there are unexpected circumstances that prevented the research from occurring.

Research groups can only have two concurrent research projects utilising ADR data at any time, unless special approval is given. This is to ensure that that all groups have access to the data for research studies.

Before a study is published the researcher(s) must provide the registry with a copy of the publication/manuscript/abstract/poster for approval by at least two members of the relevant scientific advisory committee. This is to ensure any limitations of the data are accurately represented and that the participants, participating sites, and funding sources are acknowledged.

EXTERNAL DATA ACCESS

Organisations not contributing clinical data to the registry will not have access to registry data (identifiable or de-identified).

However, external organisations can request the registry completes an analysis or research study, that will be reviewed by the scientific advisory committee for approval and prior to release. External analysis requests may incur a fee, depending on the complexity of the analysis.

ADR SCIENTIFIC ADVISORY COMMITTEES

The ADR Scientific Advisory Committees are comprised of 7-10 dermatologists specialised in the relevant condition, representing public and private clinics from across Australia, a dermatology nurse, the registry manager, and a person with lived experience of the skin condition.

The committees are responsible for determining the data to be collected, the analyses provided in the reports, developing research projects utilising the registry data, reviewing data access requests and publications, presenting the registry data at conferences and meetings, and promoting data collection and use of the registry data.

The committees formally meet four times a year with an option to contact the committee members outside of the meeting for urgent matters that can be addressed by email.

ACKNOWLEDGEMENT OF ADR

All publications utilising APR data must acknowledge the registry, including registry patient participation, the contribution of the participating sites and funding sources.

For example
“The authors of this publication would like to acknowledge the Australasian Dermatology Registry for providing the de-identified data used in the development of this publication, and to thank the registry participants who have contributed their data to the Australasian Dermatology Registry, the participating sites (www.australasiandermatologyregistry.org.au/governance/participating-sites) and registry sponsors (www.australasiandermatologyregistry.org.au/governance/sponsors-and-partners). We also appreciate the ADR staff, ADR scientific advisory committee (please name the committee) and the Skin Health Institute for their support relating to this project.”

The registry must also be acknowledged in the methodology section of the publication as the source of the data.

NOTIFICATION OF PUBLICATION

Any publications or presentations using registry data will be listed on the registry website. This will help inform dermatologists, nurses, researchers, patients, and the general population of the research being conducted utilising registry data. This information will be shared with the ethics committees as part of the annual reporting, and included in the ADR newsletter.