Australian Rheumatology Association Database (ARAD)

Enabling Grants Round 3 – Special Facilities

1. Contact Details:
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2. Description of the Facility/Activity
The Australian Rheumatology Association Database (ARAD) has been established as a national arthritis database to provide valid and reliable longitudinal clinical data of arthritis patients in Australia. The ultimate aim of ARAD is to provide better care and improved outcomes for patients. It became operational in August 2003.

ARAD collects health information from Australian patients with arthritis to monitor the benefits and safety of new treatments. All patients being treated with the new biologic agents and other patients taking conventional drugs are invited to take part in the follow up program. ARAD measures the impact of arthritis on quality of life and physical function and the long-term effects of all arthritis drugs.

The Australian Rheumatology Association owns ARAD and controls access to the data. De-identified ARAD data is available to all Australian researchers. The ARAD Scientific Advisory Committee assesses submissions from researchers wishing to access ARAD data and they may grant access to de-identified data only on a case-by-case basis for projects deemed to be of scientific merit.
3. Requirements
Submissions should comprise an “ARAD Expression of Interest & Agreement form” (available from http://arad.org.au/Public/Researchers.aspx) - a research Project Proposal outlining the background, aim(s) and hypotheses, methods and significance of the research, and ethical approval from the researcher’s institution. Ethical approval from one or all of the following ethics committees may also be required depending upon the nature of the proposal: Cabrini Hospital Human Research Ethics Committee, Melbourne; Royal North Shore Hospital Human Research Ethics Committee, Sydney; South Eastern Health Human Research Ethics Committee Southern Section, St George Hospital.

Any subsequent updates to the protocol or changes of project personnel require an amended “ARAD Expression of Interest & Agreement form” to be submitted. This must be approved by the Chief Investigator/Study Management or the ARAD Steering Committee.

Identifying information of participants will not be available for any purpose other than reports of health benefits and harms to participants’ treating rheumatologist or other recipient nominated in writing by the participating patient and rheumatologist.

If access to patient personal information is required then an “ARAD Confidentiality Agreement for External Researchers” must be completed and signed by all project staff before any data/information/analysis can be released.