



ANZDATA Registry
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Information for local Human Research Ethics Committees for applications relating to the use of de-identified data from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).

A researcher at your institution is requesting a de-identified data extract from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) for use in their research project. This letter serves to give background about the Registry and our privacy policies to assist in your review of their ethics application

1. ANZDATA is a binational clinical quality registry that collects and reports the incidence, prevalence and outcome of dialysis treatment and kidney transplantation for patients with end stage kidney disease across Australia and New Zealand.
2. ANZDATA is based at the South Australian Health and Medical Research Institute (SAHMRI) and the activities of the registry have been granted full ethics approval by the Royal Adelaide Hospital Human Research Ethics Committee (reference number: HREC/17/RAH/408 R20170927, approval date: 28/11/2017)
3. ANZDATA receives demographic and clinical information through voluntary submissions from all renal units in Australia and New Zealand
4. Data collection and use is authorized through an opt-out consent process for all individuals who are included in the registry.
5. ANZDATA operates in line with the national privacy principles of both Australia and New Zealand, and details of our privacy and security policies can be found here http://www.anzdata.org.au/v1/policies_procedures.html
6. Only de-identified data is released for external research projects, except in the case of data linkage project which require separate approval and ethical oversight.
7. To ensure appropriate local governance of research, ANZDATA also require researchers to obtain approval from their own institution for projects.

ANZDATA wishes to promote and facilitate research that will benefit people with end stage kidney disease, while at the same time ensuring that research is undertaken in a responsible and ethical manner and that individual privacy is protected.

Details of our privacy, ethics and security policies can be found here:
http://www.anzdata.org.au/v1/policies_procedures.html

Please do not hesitate to contact the registry at requests@anzdata.org.au or on 08 8128 4758 if any further information is required.

Sincerely,

Prof Stephen McDonald

ANZDATA Executive Officer.