

Project Title	Epidemiology of Rare Diseases in the ACT
Supervisor	Glenn Draper, Director, Knowledge Translation and Health Outcomes, Epidemiology Section
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Lead discipline (please select one)

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|---|---|
| <input type="checkbox"/> Nursing and Midwifery | <input type="checkbox"/> Health Economics |
| <input type="checkbox"/> Allied Health | <input type="checkbox"/> Biostatistics |
| <input type="checkbox"/> Medicine | <input type="checkbox"/> Value-based Healthcare |
| <input type="checkbox"/> Pre-clinical | <input checked="" type="checkbox"/> Epidemiology |
| <input type="checkbox"/> Health Policy | <input type="checkbox"/> Other |

Outline of the project 250 words max

Rare diseases are rare, but rare disease patients are numerous. Rare diseases can be life-threatening or chronically debilitating conditions that affect a small percentage of the population. These conditions can be complex and often need special treatments. We need to better understand the distribution and burden of rare disease in the ACT to assist with advocacy on behalf of the rare disease community and to inform service planning. The project aims to examine hospital and mortality data held by ACT Health's Epidemiology Section to gain some insights into the impact of rare disease on the ACT community.

The project will include three distinct components:

1. a literature review of rare disease research and classification in Australia and internationally;
2. a statistical analysis of ACT hospital and mortality data utilising rare disease codes developed by Orphanet and
3. the preparation of a short research paper describing the findings from the literature review and data analysis.

Proposed research methods

The proposed research will include three discrete components: a literature review of rare disease research nationally and internationally, an analytical component examining ACT hospital and death data and the preparation of a short research paper. Data analysis will be undertaken in either STATA or SPSS analytical software with support from staff within the ACT Health Directorate's Epidemiology Section.

The definition of rare diseases will be based on classifications developed by Orphanet. Orphanet was established in France by the INSERM (French National Institute for Health

and Medical Research).

Preferred study discipline being undertaken by the student

Population/public health, the social sciences (sociology/psychology) research methods or disciplines that utilise the methodologies of these disciplines. Experience with analytical software (STATA/SPSS) would be an advantage.

Benefits to the student and to the department

The student will have the opportunity to work with a team of social epidemiologists, statisticians and policy professionals and gain hands on experience analysing and reporting on ACT health data.

Alignment with Government Research Priorities 100w max

The Epidemiology Section is responsible for reporting on the health status of the ACT population. This includes preparation of the two-yearly ACT Chief Health Officers report and maintenance of the HealthStats ACT website.

Department within ACT Health Directorate / Canberra Health Services where the student will be based

Epidemiology Section, Population and Preventive Health Division, ACT Health Directorate.

Please submit form to preclinical.research@act.gov.au