

A proposal for establishment of an Australian Q Fever clinical registry

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Background:

- Q fever is notified in approximately 400 – 600 persons per year in Australia. These cases predominate in the states of Queensland and New South Wales corresponding with areas where most cattle and sheep farming occurs, reflecting proximity and occupational exposure to these natural reservoirs.(1, 2)

An expert group of interested clinicians, microbiologists, public health physicians, veterinarians and researchers formed the Australian Q fever interest group (QFIG) on the 21st October 2021 in response to broad support for improved understanding of the natural history of the disease in the local context. Greater understanding is sought on geospatial and temporal differences including climate impacts, trends in potential exposure factors for those without traditional risk factors, proportion of cases and risk factors for progression to chronic Q fever or post Q fever fatigue syndrome, diagnostic markers for development of and therapeutic monitoring for chronic disease, and comparison with international data sets. QFIG aims to establish a prospective, longitudinal Australian Q Fever clinical registry for this purpose.

Methods:

A Expressions of interest will be forwarded to the full QFIG membership to form a steering committee for the establishment of the Q Fever clinical registry. The registry will be designed according to the principles outlined in the Australian Commission on Safety and Quality in Health Care's ("the Commission") framework for Australian clinical quality registries.(3) An initial planning stage will be undertaken, with consideration of the components of the framework to be determined by the steering committee including development of a project plan, governance structures, registry design and datasets, analytics and reporting, quality improvement and an implementation strategy. On agreement of these critical core components, a business case for registry establishment will be developed and funding sources explored to ensure long term sustainability of the project.

The steering committee will establish the registry in line with national and jurisdictional regulatory and legislative requirements as outlined by the Commission. Ethics and governance approvals will be sought once the datasets are agreed upon and the business case is completed.

Results:

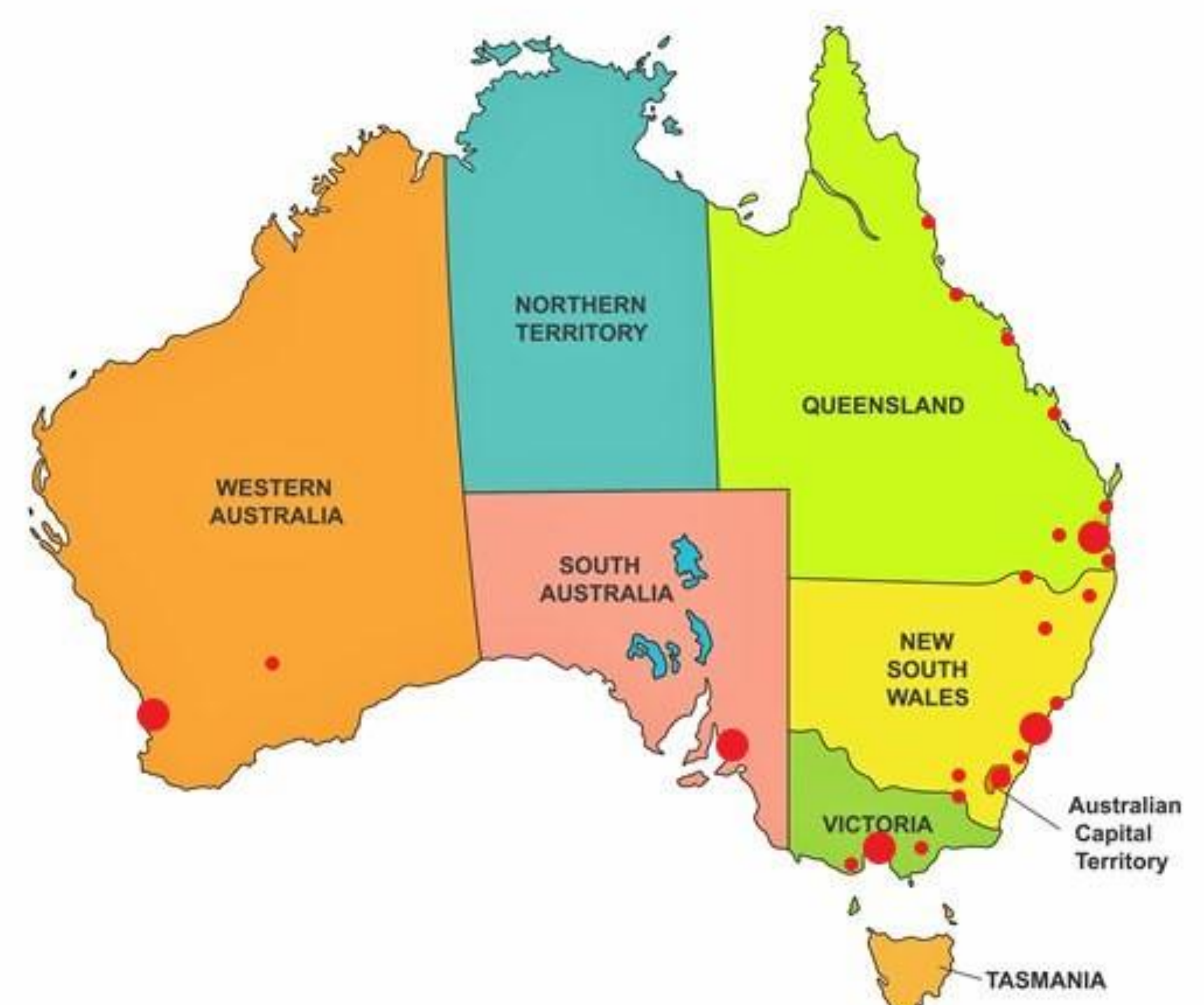
QFIG will aim to produce an annual summary of findings from the Q Fever registry in the form of a publicly available report.

Conclusion:

The establishment of a prospective clinical Q Fever registry in Australia will significantly advance the understanding of the natural history of Q Fever in the local Australian context. This will in turn enhance the understanding of non-classical risk factors and improve case detection, enable assessment of the population level impact of interventions and is anticipated to improve patient outcomes due to chronic sequelae of the disease.

Figure 1: Sites of QFIG members (note for regional members their local area may be vast).

Commonwealth of Australia



References:

1. National Notifiable Diseases Surveillance System (NNDSS): Australian Government, Department of Health; 2022 [Available from: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-pub-datasets.htm>].
2. Q Fever notifications in Queensland, 2016: State of Queensland (Queensland Health); 2019 [Available from: https://www.health.qld.gov.au/__data/assets/pdf_file/0026/936350/q-fever-qld-2016.pdf].
3. Australian Commission on Safety and Quality in Health Care. Framework for Australian clinical quality registries. ACSQHC Sydney; 2014.