



Extending the Benefits of Genome Science to Indigenous Australians through Appropriate and Respectful Data Sharing

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Background

The National Centre for Indigenous Genomics (NCIG) is a major new strategic initiative at ANU. It is establishing an internationally significant resource, operated under Indigenous governance, for appropriate genomic research that will benefit Indigenous Australians.

NCIG manages a collection of approximately 7,000 biospecimens from Indigenous people living in communities across northern and western Australia, associated records, and a documentary history of the collection.

Aims

1. Establish a document, metadata, access and records management plan for the NCIG resource.
2. Develop a genome browser to provide open access to aggregate data relevant to NCIG's collection and strategic objectives.
3. Provide open access to data and documents, contextually arranged and semantically linked, in the NCIG resource.

Enhancement of Research at the ANU

The MODC project has enhanced ANU's research capability and substantially improved the University's hard and soft infrastructure across a range of challenging areas.

- It is at the core of NCIG's resource – an exemplar of data and information management in both Indigenous and human genomics research.
- It represents a substantial upgrade of ANU's research repository.
- Through collaboration, it has enhanced the capabilities of the ANU Bioinformatics Consultancy (co-funded by BioPlatforms Australia) and established valuable resources available to the broader research community.

Driving the Institutional Agenda

The MODC project has made an important contribution to ANU's e-research strategy.

It serves as a model project for:

- Development of policies, practices and protocols for secure and responsible data management and sharing,
- General project and risk management in an extremely complex and sensitive area of research involving human subjects.

A tangible outcome of the project is a planned University-wide workshop to establish a community of practice in the management of large complex datasets to support research, and development of best-practice standards across the University.

Partnerships

- NCIG's close collaboration with the National Centre for Indigenous Studies, ANU has been enhanced by the MODC project.
- A valuable collaboration with the University of Melbourne eScholarship Research Centre has been established.
- The resource is enabling communication with Indigenous communities and organisations.
- Further collaborative opportunities are expected to emerge with Australian Institute of Aboriginal and Torres Strait Islander Studies, the Lowitja Institute, and local Indigenous organisations in Western Australia, the Northern Territory and Queensland.
- The NCIG Genome Browser and the genome sequence data behind it are an integral part of the collaboration with the National Computational Infrastructure to manage and provide access to large genome sequence databases.

Beneficiaries

NCIG's Open data resource:

- Provides Indigenous Australians with a means of engaging in genome research without risking social or cultural harm.
- Enables researchers to access genomic information about Indigenous people in an appropriate and respectful manner.
- Provides policy makers and funding agents with a model for the conduct of advanced biomedical research in Indigenous communities.
- Provides resources to people of Indigenous ancestry who wish to conduct genealogical research for personal reasons.

Research Questions

The principle value of NCIG's Resource is to provide reference data about genome variation in Indigenous populations that will enable variation associated with health and disease to be appropriately interpreted.

This data could be used by researchers to address a range of scientific questions about ancient human migrations to Australia and subsequent population movements.

Intended Impact

By making data and documents publically accessible, NCIG's MODC resource provides a solid foundation for future development of the Centre's strategic objectives:

1. Development of a model for the conduct of genomic research with Indigenous communities to world's best practice standards for collection, use and storage of biospecimens and sensitive information from Indigenous communities in Australia and elsewhere.
2. Development of innovative methods of dynamic consent from Indigenous people and new approaches to enable lasting community engagement that will serve as best practice guidelines for both funding agencies and researchers.
3. Ground breaking research to benefit to Indigenous Australians.
4. Improved capacity to attract Indigenous students and to engage Indigenous researchers.

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