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The Aotearoa Genomic Data Repository: A haven for digital sequence information enabling Māori Data Sovereignty

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The Aotearoa Genomic Data Repository (AGDR, https://data.agdr.org.nz/) provides secure within-nation storage, management, and sharing of non-human genomic data generated from biological and environmental samples originating in Aotearoa New Zealand. Te ao Māori, the worldview of the Indigenous people of Aotearoa New Zealand, recognises all living entities as taonga (treasured or precious) that require protection through kaitiakitanga (guardianship). This responsibility extends to any data generated through the study of taonga species. For genomic data derived from taonga species, there is also the potential to obtain additional information about whakapapa (genealogy, social and ecological relationships, and ancestral inheritances), which is itself taonga, and must also be protected as part of the kaitiaki (guardian) role. The creation of a within-nation data storage facility provides Māori iwi, hapū and whānau (tribes, kinship groups and families) with the crucial ability to control access to these taonga.

The AGDR was jointly established by Genomics Aotearoa (https://www.genomics-aotearoa.org.nz/) and the New Zealand eScience Infrastructure (https://www.nesi.org.nz/), with funding from the Ministry of Business Innovation and Employment (https://www.mbie.govt.nz/). The repository has been designed with the FAIR Guiding Principles for scientific data management and stewardship in mind —making data findable and interoperable with data held in other genomic repositories. However, its development has been guided primarily by the principles of Māori Data Sovereignty. The decision-making process regarding who can access each data set is entirely in the hands of the iwi, hapū and whānau that are kaitiaki of the data, thus upholding the globally-relevant CARE Principles for Indigenous Data Governance.

In this presentation, we will provide an overview of the approach and development activities in support of the AGDR, and describe the benefits of the repository, along with proposed future developments. Our presentation will be relevant to researchers generating and managing genomic data in partnership with Indigenous communities, repository developers who work with Indigenous data, and data scientists who operate in contexts where Indigenous Data Sovereignty is relevant. Four years since its initial launch, we will describe the uptake and use of the AGDR, development features and adherence to established best-practices that ensure interoperability of the AGDR datasets with those of other genomic data repositories, and the mechanisms used to support Indigenous Data Governance, such as the use of Local Contexts (https://localcontexts.org/) Biocultural Notices and Labels and the formation of an AGDR Advisory Board to provide oversight and cultural guidance.

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