

Roadmap Update - November 2019

1) Review of the Data Management Committee Structure

While the project's Data Management Committee currently operates in good-faith according to co-developed terms of reference, we recognise that it now needs to be reviewed for two reasons:

1. The Data Management Committee is currently unbalanced – two members are named-investigators on the NETwork! Project, and one is a senior Māori academic external to the project, but with accountabilities to the University of Auckland where the project is based.
2. In response to a request for suggestions about current practices in tissue banking and individual projects, a challenge was raised by visiting First Nations guests during a meeting about Indigenous Governance in Biobanks. Referring to conflicts of interest in governance, the following challenge was raised:

Is it appropriate for the researchers to be able to make decisions within Data Management Committees?

To address both of these concerns, we are currently reviewing the composition of the project Data Management Committee with a goal to:

1. better empower Māori voice
2. redistribute the load of responsibility and accountability
3. carefully re-examine the conflicts of interest of Data Management Committee members (e.g. the researchers)
4. explore the options of researchers having *ex officio* roles on the Data Management Committee, where they can provide information but do not participate in decision making.

2) Repatriation of NETwork! Patient Data

We recognise the Principles of Māori Data Sovereignty, and the importance of keeping NZ-derived genomic data within the reach of Māori Data Governance, including "principles, structures, accountability mechanisms, legal instruments and policies through which Māori exercise control over Māori data" - Te Mana Raraunga¹.

When our data management protocols were established there was no option for holding this data 'in trust' in Aotearoa New Zealand. However, recently several possible options in Aotearoa have been generated. Therefore, to ensure Māori Data Governance, we are in the process of repatriating NET Patient-owned data from the European Phenome-Genome Archive to an Aotearoa NZ-based archive.

¹ Te Mana Raraunga, (2018), [Principles of Māori Data Sovereignty](#), Brief #1, October 2018; Accessed 08-Nov-2019