Roadmap Update - October 2021
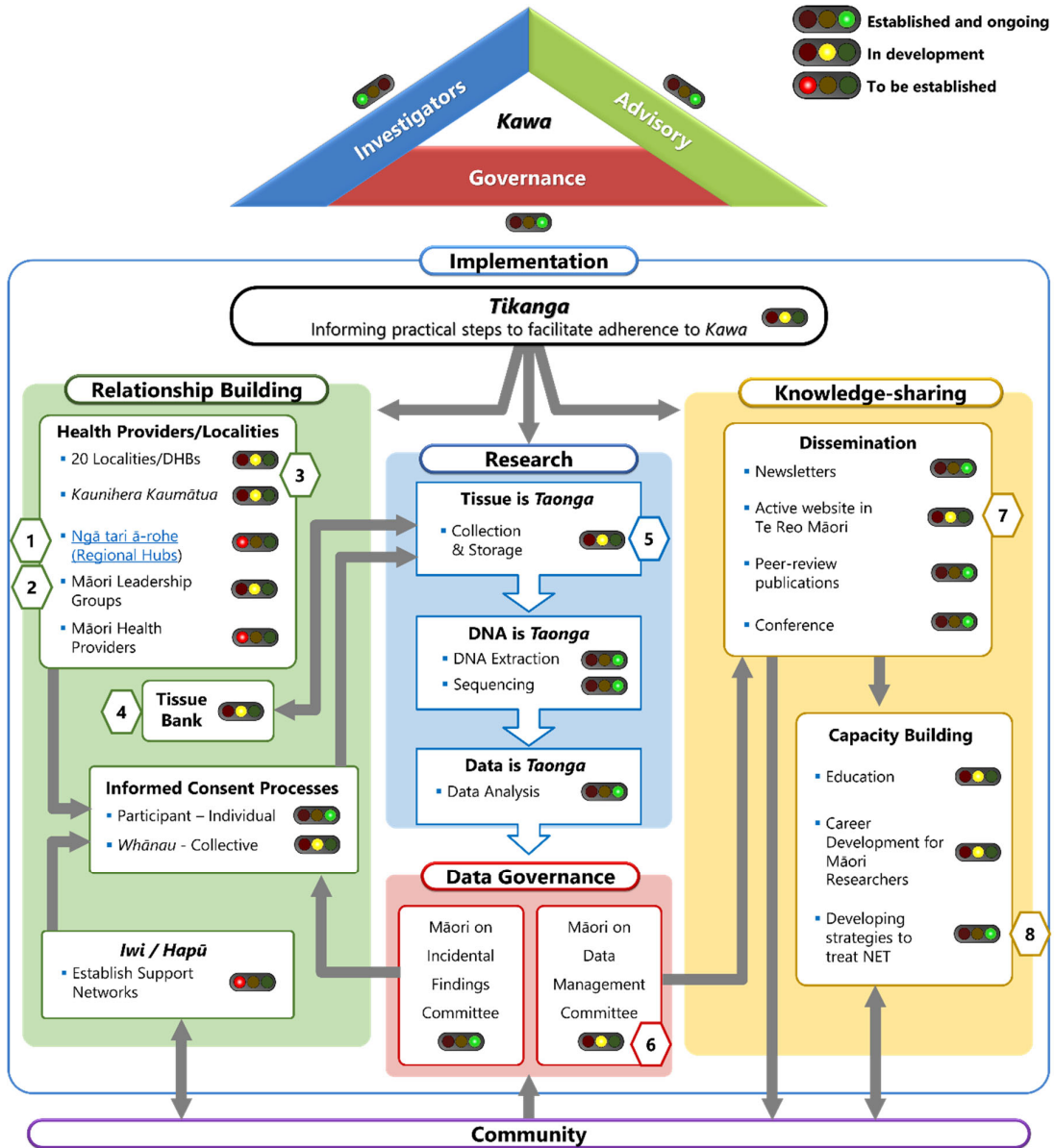

Figure 1 Roadmap changes for October 2021. These changes are discussed in the following two pages.

Rebuilding relationships in a changing leadership landscape

The establishment of [Te Aho o Te Kahu (Cancer Control Agency)](#) brings with it the need to review any existing relationships that the NETwork! Project has with Cancer Leadership in Aotearoa.

1 Regional Cancer Networks are now [Regional Hubs (Ngā tari ā-rohe) who support the implementation of the National programme set by Te Aho o Te Kahu](#).

2 Māori leadership groups for the Central and Northern hubs need to be re-established and currently do not exist. Therefore new relationships with the resulting Māori leadership groups need to be established when appropriate. However, we have established a relationship with Ira Tātai Whakaheke, the emerging leadership group of the [Rakeiora programme](#).

3 Although relationships were established for all 20 DHBs, NETwork! is currently actively engaged with 6 DHBs. This is likely to change in the future with the [government's plan to dissolve the 20 DHBs, and introduce a centralised national health organisation and a Māori Health Authority](#)

4 Te Ira Kāwai (Auckland Regional Biobank) is currently undergoing Māori Review.

Tissue is *Taonga*: Collection & Storage issue

5 Freezer space and allocation issues within the Faculty provides a challenge related to the storage of patient samples, due to limited University space and airflow issues. While long term storage of tissue samples are in freezers that contain only human tissue and not tissue from other species, currently we cannot guarantee tissue will be stored in human-only freezers at all times during their processing.

Data Governance: Rebuilding the Data Management Committee (DMC)

The project's Data Management Committee continues to operate in good-faith, however we have yet to complete our review and restructure of the project Data Management Committee addressing the following identified issues:

6 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.

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.

To address both of these concerns, we are continuing to review the composition of the project Data Management Committee with a goal to:
- better empower Māori voice
- redistribute the load of responsibility and accountability,
- carefully re-examine the conflicts of interest of Data Management Committee members (e.g. the researchers)
- 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.

We are also looking for a replacement for an outgoing member of the committee.

Knowledge Sharing: Dissemination & Capacity Building

7 **Dissemination – website:** The translational genomics landscape is changing rapidly in NZ, at the same time as NZ is undergoing significant research and healthcare reforms. The website will be updated to reflect the relationships that NETwork! have, not only with NET patients, but also in the wider cancer genomics infrastructure and services in Aotearoa.

8 **Capacity Building:** NETwork! leadership contributed to a collaborative effort to bring Peptide Receptor Radionuclide Therapy (PRRT) to Auckland for NET patients in Aotearoa. Previously, patients needed to travel to Melbourne for treatment, funded by the Ministry. The COVID-19 pandemic has resulted in border closures meaning that NET patients were unable to travel for treatment.

This has removed a significant access barrier to treatment that is effective against certain NET cancers.

Roadmap Update - November 2019

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 option of researchers having ex officio roles on the Data Management Committee, where they can provide information but do not participate in decision making.

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 Raraunga[11] .

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.

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