Mō Wai, Nā Wai Rānei Tēnei Rangahau: Whānau Māori Navigating Self-Determining Engagement With Genomics Research.

Kereama-Royal. I.R.

Ngā Wai A Te Tūī Māori Indigenous Research Centre, Unitec Institute of Technology, Auckland, NZ.

Self-determining decision making and tools to protection and control personal data as outcomes for Māori engagement in genomics research is more difficult to achieve, than it would appear. With cancer treatments, the opportunity to access precision oncology could provide a significant medical breakthrough in treatment options for Māori cancer patients, who suffer some of the poorest cancer outcomes in the developed world. However, prior to active engagement in genomics research, there is more we can do to improve how researchers and Māori can navigate forward together and fully engage in the relatively new genomics health environment. It is only on the basis that proceeding forward means full consultation and informed consent – which is both a critical engagement process and an essential ethical procedure. For Māori, the social, moral, ethical and cultural considerations associated with gaining the consent to engage, must be discussed and decided on by the collective in a whakapapa grouping, as the individuals in the group have a genetic association to each other, that gives rise to an obligation to consent to engagement, as a group.

Several initiatives from the Māori research sector in particular, have emerged in recent years to help understand the challenges, barriers and reticence experienced by Māori when considering engagement in genomics research. A strong recommendation has been made by a team of Māori researchers and practitioners to researchers working with Māori, to use a preferred practice model described as an engagement 'roadmap'. The roadmap includes:[1]

> … facilitating ongoing dialogue, Māori leadership, reciprocity, agreed kawa (guiding principles), tikanga (cultural protocols), and honest monitoring of what is and what is not being achieved. We challenge cancer researchers worldwide to generate locally appropriate roadmaps that honestly assess their practices to benefit Indigenous people internationally.

Further initiatives such as the Te Mana Raraunga Māori Data Sovereignty Group and the Te Ira Tangata genomics research guidelines, aid with improving understanding of Māori research and engagement priorities and needs and help Māori to navigate some of the challenges with helpful tools and explanations. More work is needed if Māori are to gain wide benefit and be in better control of their engagement and outcomes from genomics research in future. This is one example of how a whānau took a considered approach to their engagement with genomics research in 2017/18.

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[1] *Mapping a route to Indigenous engagement in cancer genomic research*. Kimiora L Henare, Kate E Parker, Helen Wihongi, Cherie Blenkiron, Rawiri Jansen, Papaarangi Reid, Michael P Findlay, *Benjamin Lawrence, *Maui Hudson, *Cristin G www.thelancet.com/oncology Vol 20 June 2019.

Towards A Variome Resource For Genomic Medicine In Aotearoa/New Zealand Māori

Wilcox, P.L.[1], Flavell, T.[2], Watson, H.[3], Harre-Hindmarsh, J.[3], Hudson, M.[4], Kereama-Royal, I.[5], Wihongi, H.[6], Russell, K.[7], Sporle, A.[8], Rolleston, A.[9], Robertson, S.R.[1]

[1]University of Otago, Dunedin, NZ, [2]Te Wānanga o Aotearoa, Te Awamutu, NZ, [3]Ngāti Porou Hauora, Tairawhiti, NZ, [4]University of Waikato, Hamilton, NZ, [5]Unitec Institute of Technology, Auckland, NZ, [6]Waitemata and Auckland District Health Boards, Auckland, NZ, [7]Ngai Tahu Research Consultation Committee, Dunedin, NZ, [8]University of Auckland, Auckland, NZ, [9]The Centre for Health, Tauranga, NZ.

International and national research has shown that genomic information resources developed for populations with Caucasian ancestries have limited applicability to ethnicities with non-Caucasian ancestries. Development of a library of genome-wide genetic variation (i.e., a ‘variome’) within extant NZ Māori is therefore required to implement genomic medicine for Māori, thereby offsetting further health disparities relative to ‘mainstream’ NZ. In this presentation I will describe our approach to characterising potential health benefits for Māori communities, firstly by describing the use of such an information resource for different classes of heritable diseases known to occur within Māori communities, then by reframing benefits within a Te Ao Māori framework using Durie’s Whare-Tapa-Wha holistic wellness model[1]. Mechanisms to protect against misuse of the information resource will also be discussed.

1. Mason Durie, *Whaiora: Maori health development*. Auckland: Oxford University Press, 1998, pp. 68–74

Q5: Ngā tikanga o te taiwhanga pūtaiao - Tikanga in the laboratory

Henare, K. L.[1]

[1]Auckland Cancer Society Research Centre, Discipline of Oncology, Te Kupenga Hauora Māori, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa/NZ.

The biomedical laboratory is a contentious place for Māori researchers, as we are often faced with a dilemma of conflicting worldviews. Many of the contemporary techniques used to advance biomedical knowledge may challenge Māori ethical frameworks, whether they include genetic engineering or gene editing to determine the function of a gene or its role in biology and pathology, or the use of human tissue donated for use in research to untangle the complex molecular biology or test new drugs. Anecdotally, these tensions facing Māori laboratory scientists might be one reason for Māori opting out of a path in biomedical sciences, in additional to the culturally unsafe space that laboratories are known to be for the researcher and taonga gifted by participants for research.

This presentation will discuss some examples of how tikanga Māori might be incorporated into the lab in order to appropriate prepare and support the Māori biomedical researcher to work with these tools, and why these steps are important. As the Māori workforce continues to grow in these spaces, the incorporation of tikanga into the laboratory environment will be discussed in the context of creating a culturally safe space (i) for Māori to apply their skills and mātauranga and (ii) for kaitiakitanga and manaakitanga of taonga gifted for research. To illustrate these possibilities and challenges, the journey of Māori scientists before us as well as that guiding a recent biomedical/cancer research project will be discussed.

Q6: Cultural and Intellectual Property - Tikanga considerations, "What does the tikanga interface look like and how will it be applied?"

Taiuru, K.N.[1].

[1]Te Whare Wānanga o Awanuiārangi, NZ.

Taonga Species is an undefined term that is often misunderstood. Within Genomics is no exception.

By introducing a well-defined definition of Taonga Species based on traditional knowledge and whakapapa; researchers and academics will be able to clearly identify when appropriate tikanga is required and where and how to seek assistance.

Interviews with leading tikanga practitioners, Iwi and Māori leaders, in addition to international Indigenous Leaders, about their perspectives of gene extraction and genomic research were conducted.

The results closely reflect those of a Te Ao Maori belief of genes in the early 2000's regarding Genetic Modification consultation by Iwi and Maori. Genetic Data is IP that belongs to Maori and is a taonga such as moteatea, waiata, whakatauki and whakapapa, it lives intergenerationally.

There is no new tikanga for human genetics and species. Traditional Māori beliefs are still applicable and to ensure the physical and spiritual wellbeing of Maori and taonga species existing health frameworks such as Masons Durie's Ngā Tapa Whā and Sir Hirini Moko Mead's Tikanga Test are relevant to genomic research. The customary tikanga needs to be adapted into modern day facilities and considerations of Data Sovereignty are vital. A range of useful interfaces will be discussed.

Understanding genomic data management – an indigenous perspective of "data protection" and "data sovereignty."

Te Aika, Ben

Vision Mātauranga, Genomics Aotearoa, Kati Urihia, Kati Matamata, Kati Wairaki, Kati Mamoe, Waitaha, Ngati Mutunga, Ngati Tama, Te Ati Awa, Ngati Ruanui.

"What should culturally appropriate genomic data protection look like for indigenous species, data sovereignty?"

Unbundling the myriad of views is a sizable commitment. Understanding the ambiguity in these non-Māori terms such as "culturally appropriate protection" and "data sovereignty" is also a considerable task. Both these terms are discussed and compared to terms more consistent with mātauraka Māori. We consider terms such as "mana Māori" and various traditional expressions offer an improved cultural context and match when translated into English.

Understanding what may be considered "culturally appropriate" is important for Genomics Aotearoa. Quality engagement practices with takata whenua is crucial in reaching this understanding. Understanding the barriers to Māori participation in the science is key to facilitating an environment which fosters Māori exercising rakatirataka and kaitiakitaka.

Maintaining the delicate relationship between the researcher and takata whenua is essential. Ensuring that biological whakapapa is maintained under the best cultural conditions possible. New standards for quality engagement in place, which assists the researcher to better integrate the desires of takata whenua with the science is important.

A trusted environment is essential, where takata whenua exercise kaitiakitaka and rakatirataka over the biological whakapapa with the research engagement practices being at the highest standards possible. Responding effectively is the best possible solution in a rapidly evolving science and research environment.

"Appropriate protection" or enabling practices, may mean greater institutional ***responsibility*** in facilitating the nexus point where the researcher – takata whenua – data repository oversite develop a shared agreement on the use and storage of data.

Q10: Whakaora Te Whenua, Whakaora Te Whānau: Healing the land, healing the people – developing novel treatments and pharmaceutical manufacturing in an isolated Māori community.

Caddie, M.[1]

[1]Hikurangi Bioactives Limited Partnership, Ruatōrea, Aotearoa/NZ.

Hikurangi Group is a collective of commercially-driven social enterprises based in and around Ruatōrea in the Tairāwhiti region of Aotearoa New Zealand. Over the past four years a range of research initiatives have focused on the utilisation of indigenous resources in the development of novel therapeutic products and intellectual property. Hikurangi enterprises are focused on truly sustainable high-value product development as a strategy for environmental, social, economic and cultural revitalisation. By securing private investment to partner with world-leading scientists and research institutions, Hikurangi has been able progress pre-clinical and clinical research on a diverse array of bioactives.

The presentation will provide an overview of the ethical imperatives driving Hikurangi initiatives, key research projects undertaken to date and commercialisation strategies. Challenges faced by indigenous communities aiming to commercialise indigenous organisms and undertake genomics research in Aotearoa will be explored along with reflections on research relationships and principles for productive partnerships.