HERAMAAHINA EKETONE AND JESSE-JAMES PICKERY WITH EMMA H WYETH

Te pūrākau tūtahi? (The whole story?)

JESSE-JAMES PICKERY

This work of Heraamahina Eketone is formed in response to two concepts or whakaaro[1]; the first being a response to the reductive process of genetic studies involving Māori participants. The second, that the image represents two forms of knowledge in complimentary synthesis. The media were chosen to represent the colliding worlds of Western European and Te Ao Māori, and the dominance one can have over the other. Here in the work, black ink has been laid upon and fused with flax paper to illustrate perception of cultural hegemony. A process, though not overt, which is constantly present here in Aotearoa in 2017.

Heramaahina writes:

> *Whakaaro 1 – Methodology of enquiry*
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> *The inspiration for this piece came when Dr Emma Wyeth discussed with me the methods used in acquiring genetic information. I learnt that often the people who were involved in genetic studies can be treated as no more than a string of genetic information. This to me is not only a questionable treatment of tapu[2], but is a cold reduction from a living, breathing human to a lifeless material.*
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> *I feel strongly that a study which takes into account the effect of a person's environment would not only give more meaningful results, but would also be a way to reduce the possible dehumanising effect of any scientific study centred around human beings.*
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> *Being exposed to Dr Wyeth's research brought a number of questions to my mind: does science have room for principles such as tikanga, aahurutanga, kaitiakitanga, and manaakitanga? Would the information gained by a more holistic method of study produce a result closer to the reality we are faced with? And, is our current method of genetic research outdated or undermining itself, in relation to Māori health?*
>
> *(Heramaahina Eketone)*

Figure 1. Heramaahina Eketone ,*Te pūrākau tūtahi*, ink on flax paper, 2017.

There are simple, central precepts in Te Ao Māori which can guide the research process in a safer and more effective way, they can be seen as ahurutanga – the creation and maintenance of safe spaces, manaakitanga – caring for people inside this space, and tikanga – the methods of operation in this space. The employment of this system of ethics would not only cater to the people involved in the study, but also would create a safe place for the generation of as yet unknown information. Tikanga is the primary method of operation underpinning Māori values and ethics, these can be found in oral traditions which highlight specific relationships deemed fundamental to the sustainability of life. These relationships are embedded and can be refered to as kawa (primary values) and provide the foundation for the establishment of tikanga.[3] [4]

> Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga' for tikanga reflects our values, our beliefs and the way we view the world.[5]

Tikanga are locally specific practices that enhance and safeguard relationships, and ensure the preservation of mana[6]. As the environment changes or new situations arise, tikanga are enacted or adapted to provide context-specific responses. Kawa and tikanga provide the primary interface for accessing repositories of cultural knowledge and experience that can be used to inform ethical deliberations. Tikanga also provides a framework through which Māori can actively engage with ethical issues and consider the effect research may have on their values or relationships.

> Saying things like karakia and then respecting that material, not just treating it as a commodity - acknowledging where it came from and involving the person and their family. For indigenous people, what is important are relationships.[7]

Māori intellectuals are calling on tāngata whenua to become more open to supplying human tissue to improve their health but tikanga needs to continue evolving to make sure that happens. The University of Waikato's Māori and Indigenous Governance Centre's research project, *Te Mata Ira*, is focused on producing guidelines for hospitals and laboratories to ensure the correct cultural protocols are applied when using Māori tissue and blood samples.[8] Research – especially that pertaining to the body – needs to be conducted within a framework for considering cultural values in relation to other community or indigenous contexts.[9]

> Our tikanga needs to change here with technology and time - and it does and always did evolve. Because the human body is considered tapu, the process of taking and storing tissue can be complicated and medical staff need to be culturally sensitive.
>
> Robert Joseph[10]

Genetic research is an area of prime sensitivity for Māori because of the direct association with ones' whakapapa (lineage). Māori favour the recognition of both individual and collective consents, as some ethical issues can be usefully considered and consented to by an individual, other ethical issues require community engagement. A collective is likely to be involved in early decisions about the appropriateness of the study, while an individual can decide once the study has begun whether or not they wish to participate. This means that two forms of consent are required for research involving human tissue and/or genetic samples. Firstly, that of an appropriate community/collective for the study to take place (via consultation) and, secondly, those of individual Māori participating in

the study. Ongoing communication with donors/participants beyond the initial consent process, it is also important to provide a communication channel so that donors and their families are able to find out what has happened to their tissue and for which research projects it has been included.[11] Understanding the range of Māori approaches to the acquisition of knowledge will enable analysis of the entire research purchase and specify any unmet areas of priority.[12]

INCIDENTAL FINDINGS (OR NOT SO INCIDENTAL)

Equity and justice are ethical principles underpinning the importance of benefit-sharing. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk versus benefit, short versus long term) and their relative distribution (researchers, participants, communities, society). Researchers will legitimately benefit from being involved in research but consideration should be given to how participants and their communities might also benefit from participation through research, education and translational activities.

Tissue, DNA and data stored within biorepositories often end up as a sample within a research project that produces an incidental finding. Incidental findings are results unrelated to the primary focus of the study but which may be significant for the individual's health. The nature of genomic[13] research, which analyses a vast number of genes across the genome, will frequently produce incidental findings.[14] The challenge is to determine whether the finding is statistically significant, clinically significant, and/or clinically actionable. Māori communities expect to be notified of any clinically significant or actionable findings. It is the responsibility of the research team to develop an ethical plan of how they will address incidental findings that emerge through their study.

BEST PRACTICE: KAITIAKI

A best practice level of 'relationship' allows Māori to take a kaitiaki role within the research project with a view to ensuring that tangible outcomes are realised within Māori communities. A relationship displaying transparency, good faith, fairness and truthfulness is captured in the concept of 'whakapono' in the following whakatauki (proverb)

> "kia u ki te whakapono me te aroha tetahi ki tetahi"
> (hold fast to the truth with respect for each other).
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> *Whakaaro 2: Importance of experiential knowledge*
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> *Knowledge falls into two basic baskets - a priori knowledge and a posteriori [15] . A priori knowledge is represented by the ink within the image. This is seen and obtained without needing to interact with the world (the flax paper). The second form of knowledge is observed knowledge; it includes the knowledge that we know we don't know. We have not learnt it yet, and so is unseen. This is an analogy for the part of the DNA molecule that doesn't code.[16] We learn through interaction, experience, collaboration and the spaces in which we belong. I have based the stylization of the double helix in Māori symbology. The missing pieces of the rauru (spiral) or awhiowhio (whirlwind) represent the knowledge yet to be ascertained. They are the places for future inquiry.*
>
> *(Heramaahina Eketone)*

HIDDEN TREASURES

What was once known as junk DNA turns out to hold hidden treasures, says computational biologist Ewan Birney. In 2000, when scientists of the Human Genome Project presented the first rough draft of the sequence of bases, or code letters, in human DNA, the initial results appeared to confirm that the vast majority of the sequence—perhaps 97 percent of its 3.2 billion bases—had no apparent function. Now, in a series of papers published in September in *Scientific American*, an arm of Nature Publishing Group, and elsewhere, the ENCODE group has produced a stunning inventory of previously hidden switches, signals and sign posts embedded like runes throughout the entire length of human DNA. In the process, the ENCODE project is reinventing the vocabulary with which biologists study, discuss and understand human inheritance and disease.[17]

> *Limitations are set by only approaching a theme from one way. In my piece we view the double helix seen from above and from no other angles. How much information is missing by only looking at things from one perspective in this reductive analysis? We can't see the full image of the spiral because we only have fragments, however it would be untrue to say it is a spiral, we can only say we have the base frame of what seems to be a spiral. One of the intentions of this piece is to voice the following question: What are we missing?, Can the missing parts of the spiral be found if we look from another perspective?*
>
> *(Heramaahina Eketone)*

Figure 2. Heramaahina Eketone ,*Te pūrākau tūtahi*, ink on flax paper, 2017.

Heramaahina's work – *Te pūrākau tūtahi? (The whole story?)* is both a homage and a critique made in response to our current perspective on genetics. The great leaps in understanding our material nature would be impossible without genetics. Early genetic research focused on identifying single genes responsible for specific familial disorders (as performed and defined by Gregor Mendel in the 1800's). However, radical technological advancements such as high throughput testing and genome-wide scanning techniques have made it possible to examine complex conditions influenced by multiple genes and environmental factors to determine population susceptibility. In a research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development.[18]

Heramaahina Eketone of Ngāti Maniapoto and Waikato descent is currently teaching Kāwai Raupapa an introduction to the Māori arts certificate at Te Wananga o Aotearoa. She has done art works for/ in collaboration with various community organisations including The University of Otago, The Otago Polyfest and Puaka Matariki. From a young age, Heramaahina has had a passion for different Māori arts whether it be raranga, whakairo, tā moko and design.

Jesse-James Pickery seeks resonance in sound, light and earth in a cross disciplinary practice. He is in his final year of a BVA at Dunedin School of Art majoring in Ceramics.

Emma Wyeth (Ngāi Tahu, Te Ātiawa, Ngāti Tama, Ngāti Mutunga) is a Senior Lecturer in Māori Health and Director, Ngāi Tahu Māori Health Research Unit, both in the Department of Preventive and Social Medicine at the University of Otago.

1. Whakaaro can be translated as; thought; opinion; plan; understanding; idea, and/or intention.
2. Tapu is a concept in Te Ao Māori which enables the preservation of a thing's true nature. It is a quality of respect and awe which upholds sanctity and delineates boundaries.
3. This is not a universal rule, as for those of Te Arawa, the kawa is the knowledge base and tikanga is the implementation of the kawa. It can be summed as Tikanga being the counterpart of Kawa, one is the knowledge base, the other is the implementation of the protocol and practices.
4. Hirini Moko Mead (Sidney M. Mead), *Tikanga Māori: Living by Māori Values*, (Huia Publishers, 2003) 11.
5. *Te Ara Tika — Guidelines for Māori research ethics: A framework for researchers and ethics committee members*. The Pūtaiora Writing Group, Dr Maui Hudson, Ms Moe Milne, Dr Paul Reynolds, Dr Khyla Russell, Dr Barry Smith. Published by the Health Research Council of New Zealand on behalf of The Pūtaiora Writing Group, 2010, http://www.hrc.govt.nz/sites/default/files/Te%20Ara%20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf (accessed 10 August 2017) 8.
6. The concept of mana can be seen as justice and equity, reflected through power and authority.
7. Ibid.
8. Alexa Cook, "Plea for Māori engagement in tissue research," Te Manu Korihi, Radio New Zealand, http://www.radionz.co.nz/news/te-manu-korihi/274288/plea-for-maori-engagement-in-tissue-research (accessed 23 August 2017).
9. Angela Beaton, Maui Hudson, et al, "Māori in biobanking and genomic research: a model for biobanks to guide culturally informed governance, operational, and community engagement activities," *Genetics in Medicine* (2017), 19,345–351, http://www.nature.com/gim/journal/v19/n3/abs/gim2016111a.html (Accessed 17 August 2017) .
10. Alexa Cook, "Plea for Māori engagement in tissue research".
11. *Te Ara Tika*, 2010, 13.
12. Chris Cunningham, "A framework for addressing Māori knowledge in research, science and technology," *Pacific health dialog: a publication of the Pacific Basin Officers Training Program and the Fiji School of Medicine* 7(1): April 2000, 62-9, https://www.researchgate.net/publication/11645002_A_framework_for_addressing_Maori_knowledge_in_research_science_and_technology (accessed 29 July 2017).
13. While genetic research looks at the function of specific genes, genomic research looks at the functions of groups of genes and their interactions with the environment.
14. W Burke, A H Matheny Antommaria, R Bennett, et al. "Recommendations for returning genomic incidental findings? We need to talk!" *Genetics in medicine: official journal of the American College of Medical Genetics*, 2013, 15(11):10, http://www.nature.com/gim/journal/v15/n11/full/gim2013113a.html?foxtrotcallback=true (accessed 2 August 2017).
15. A priori knowledge, in Western philosophy since the time of Immanuel Kant, knowledge that is independent of all particular experiences, as opposed to a posteriori knowledge, which derives from experience.
16. "Hidden Treasures in Junk DNA," Stephen S. Hall, *Scientific American,* a division of Nature America, Inc. published Oct 1, 2012, https://www.scientificamerican.com/article/hidden-treasures-in-junk-dna/ (accessed 2 August 2017).
17. Ibid.
18. *Te Ara Tika*, 2010, 1.