Indigenous Ethics and Biobanking: The Aotearoa New Zealand Experience

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The recognition of indigenous Maori rights in New Zealand has led to greater consultation and involvement of those communities in the ethical review processes for health research. Maori have been contributing to the debates around research ethics and genetics for a number of years. Recent publications, Guidelines for Researchers on Health Research involving Maori (2010) and Te Ara Tika Guidelines on Maori Research Ethics (2010), provide a framework for understanding indigenous Maori views on health research and ethics. These documents note the heightened sensitivities that exist for Maori around the use of human tissue and genetic information in research but do not provide practical advice for genetic researchers or biobanks. Indigenous and Maori views on biobanking and genomic research have been explored through a Health Research Council (New Zealand) funded project 'Te Mata Ira.' The project involved a mix of interviews and workshops with Indigenous informants, Maori participants, and bio-medical researchers. This paper will present the results of the project and the cultural foundation which frames Maori guidelines for biobanking and genomic research.

Biography
Maui Hudson is from Whakatohea, Nga Ruahine and Te Mahurehure. Maui Hudson is a research developer and interdisciplinary researcher based at the University of Waikato. He holds Senior Research Fellow positions within the Maori and Indigenous Governance Centre in the Faculty of Law and the Environmental Research Institute in the Faculty of Science and Engineering. He has worked in the research sector for over 10 years in both CRI and University settings, is a member of the Whakatohea Maori Trust Board and a trustee/director on a number of their iwi entities. He has expertise in strategic thinking and innovation planning particularly around R&D for Maori collectives. Maui has a diverse range of research interests in the area of the interface between matauranga Maori and science, ethics & new technologies, traditional medicine, and Maori economic development. Maui has been a member of a number of ethics and advisory committees and was a co-author of Te Ara Tika: Guidelines on Māori Research Ethics – A framework for researchers and ethics committee members. He is the principal investigator for an HRC funded project developing cultural guidelines for biobanking and genomic research and an MBIE funded project on integration of matauranga Maori and science in the context of freshwater management. Maui is also a key researcher on a NPM funded project ‘Optimising the Maori in Maori Economic Development’ and a co-lead for the Implementation of The Mauri Ohooho Maori Economic Development Strategy for the Bay of Connections. maui@waikato.ac.nz

Biography
Lynley is a researcher on the Te Mata Ira research project exploring the views of Maori, an Indigenous population in New Zealand, on genomic research and biobanking with the aim to develop guidelines for engaging Māori in these contexts. Lynley gained a Honours (first class) in Psychology, Industrial Relations and Human Resources, and a Masters (first class) in Social Science Research exploring the experiences of people with chronic conditions in finding and keeping work.

She has been involved in and completed a number of research projects in health, education and public policy, including the application of biofeedback technology on the educational experience of Pacifica students, student evaluations in a tertiary context, the effectiveness of an Indigenous mentoring service in a tertiary education context, safety and efficacy around the use of medication in households with children, and the engagement of minority communities in public policy development. Keenly interested in research relating to the human psyche, health research, public policy, and social justice. lynleyu@waikato.ac.nz

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