Key informant views on biobanking and genomic research with Māori

Authors: Hudson M et al.

Summary: A New Zealand-funded research project, Te Mara Ira (2020–2015), explored Māori views on biobanking and genomic research for the development of culturally appropriate guidelines. Key informant interviews and workshops conducted with Māori explored their views on biobanking and genomic research. Interviews and workshops were subsequently held with Māori and non-Māori key informants (Indigenous Advisory Panel [IAP] members and science communities) to explore three key issues in relation to Māori participation in biobanking and genomic research:

1. Why should Māori/Indigenous communities participate in biobanking and/or genomic research?
2. What are the key issues for Māori/Indigenous participation in biobanking and genomic research?
3. How might we address these issues?

The informants felt that Māori need to be more involved in governance and decision making to ensure the wider health benefits are realised from Māori participation in biobanking and genomic research. It was identified that the level of transparency and accountability must increase in relation to these activities so that Māori communities feel that their whakapapa, rights and interests are being appropriately protected. There was acknowledgement of the need to protect Māori interests through Māori control of samples and data. It was suggested that community consent is required to gain support for participating in any genomic project. It was also perceived that greater feedback and communication with Māori participants should help to reinforce positive sentiments and trust in these research activities.

Comment: A useful reference for both researchers and whānau, the findings are already contributing to the development of policies and facilities.


Abstract
**Socio-demographic characteristics of New Zealand adult smokers, ex-smokers and non-smokers: results from the 2013 Census**

**Authors:** Tu D et al.

**Summary:** Smoking data are reported from the 2013 New Zealand Census of Population and Dwellings. These results are compared with findings from the 2006 Census, for estimating recent changes in smoking prevalence. In 2013, 15.1% of New Zealand adults aged ≥15 years reported that they were regular smokers (smoked ≥1 cigarettes per day), which translates to a 22.5% drop in smokers since 2006. Large declines in age-standardised smoking prevalence occurred among both genders in almost all ethnicity groups. However, disparities persist in smoking prevalence between population subgroups: Māori continue to have the highest age-standardised smoking prevalence (32.4%), and smoking prevalence is high among Māori women, both young adults and middle-aged. There was encouraging evidence of an acceleration in the decline of smoking prevalence between 2006 and 2013. For instance, the decrease in smoking prevalence of young adults was much greater between 2006 and 2013 than between 1996 and 2006.

**Comment:** It is encouraging to see a decline in smoking rates, though as the authors suggest, this is probably due in large to lower rates of initiation. They suggest that addressing ethnic inequalities in smoking for Māori women will require interventions that address both the “broader determinants in health (eg, improving income, housing, employment and access to healthcare) as well as tobacco control specific measures”.


**Abstract**

**Dietary intake and eating behaviours of obese New Zealand children and adolescents enrolled in a community-based intervention programme**

**Authors:** Anderson YC et al.

**Summary:** These researchers evaluated the eating behaviours of 239 obese children and adolescents (aged 5–16 years) enrolled from January 2012 to August 2014 in a community-based obesity programme in Taranaki, New Zealand. Participants had a body mass index ≥85th percentile or ≥91st percentile with weight-related comorbidities. Ethnicities included Māori (45%), NZ Europeans (45%), Pacific (3%), Asian (3%), and Other (4%). Two-thirds (67%) of participants were reported to experience hyperphagia and half (51%) were not satiated after a meal, 62% were comfort eaters, and 54% had a daily energy intake that exceeded the recommended guidelines based on age and gender. Servings of fruit and vegetable were below the New Zealand recommendations of ≥2 fruit (mean 1.8) servings per day and ≥3 vegetable (mean 1.7) servings per day. Compared with the national average, participants ate fewer breakfasts per week (mean 5.9 vs 6.5; p<0.0001) and more servings per week of fast food/takeaways (mean 1.3 vs 1.0; p=0.006) per week. Notably, Māori participants consumed a median volume of sweet drinks that was two-fold that of NZ Europeans (250 vs 125 mL/day; p=0.0002).

**Comment:** The finding that sweet drink consumption is significantly higher for Māori than NZ Europeans is alarming. Reasons for this difference are complex and published evidence suggests that education of the primary caregiver, housing stability, rurality and neighbourhood deprivation are important factors associated with sweet drink consumption and, therefore, health outcomes including obesity and dental caries. We need action on developing and testing interventions to address these basic or root causes.


**Abstract**

**Lifetime risk of diabetes among First Nations and non–First Nations people**

**Authors:** Turin AC et al.

**Summary:** These researchers sought to determine the disease burden of diabetes in Canada. They estimated the lifetime risk of diabetes among men and women in both First Nations and non–First Nations populations using a cohort of adults residing in the province of Alberta from 1997 to 2008 who were free of diabetes at cohort entry. The analysis involved 70,631 First Nations and 2,732,214 non–First Nations people aged ≥18 years. Among First Nations people, women had a higher lifetime risk of diabetes than men across all index ages (87.3% vs 75.6%), whereas among non–First Nations people, men had a higher lifetime risk of diabetes than women across all index ages (55.6% vs 46.5%).

**Comment:** The BMJ recently published a paper regarding the efficacy and effectiveness of programmes to prevent type 2 diabetes, including how to screen and intervene. The authors concluded that “screen and treat polices alone are unlikely to have substantial impact”. It gave the impression, possibly not intended, that the issue was just too big. And, as this paper here clearly confirms, it is big – particularly for Indigenous peoples. A number of research programmes that focus on the management and prevention of type 2 diabetes for Māori and Pacifica whānau are about to get underway; I look forward to hearing about the results.

**Reference:** CMAJ. 2016;188(16):1147-53

**Abstract**

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Role of psychosocial work factors in the relation between becoming a caregiver and changes in health behaviour: results from the Whitehall II cohort study

Authors: Dich N et al.

Summary: This investigation obtained data from the Whitehall II cohort study, which originally recruited 10,308 British civil service workers aged 35–55 years during the period 1985–1988. Follow-ups were conducted at every subsequent phase approximately every 2 years. Phase 3 (1991–1994) served as the baseline for this present investigation, which involved 5419 subjects who were not caregivers at this point. During phase 4 (1995–1996), 304 subjects became caregivers to an aged or disabled relative. Assessments of smoking, alcohol consumption and exercise at baseline and follow-up (phase 5, 1997–1999) revealed that those who became caregivers were more likely to increase frequency of alcohol consumption, but only if they also reported low decision latitude at work (OR 1.65; 95% CI, 1.15 to 2.37 vs non-caregivers with average decision latitude), or belonged to a low occupational social class (OR 2.38; 95% CI, 1.17 to 4.78 vs non-caregivers of high occupational social class). Caregivers were more likely to quit smoking if job demands were low (OR 2.92; 95% CI, 1.07 to 7.92 vs non-caregivers with low job demands), or if social support at work was high (OR 2.99; 95% CI, 1.01 to 8.86 vs caregivers with average social support). There was no effect of caregiving on reducing exercise below recommended number of hours per week, or on drinking above recommended number of units per week, regardless of job demands. Estimates were generally unchanged after the researchers adjusted for baseline long-term illness and depressive symptoms.

Comment: Caregiving is a privilege. However, studies have confirmed the impact caregiving has on health outcomes, including increased risk for musculoskeletal injuries, heart disease and depression. This research has attempted to look beyond ‘individual choices and health behaviours’ to how environments can better support caregivers.

Reference: J Epidemiol Community Health. 2016;70:1200-6

Abstract

Independent commentary by Dr Matire Harwood

Dr Matire Harwood (Ngapuhi) has worked in Hauora Māori, primary health and rehabilitation settings as clinician and researcher since graduating from Auckland Medical School in 1994. She also holds positions on a number of boards, committees and advisory groups including the Health Research Council. Matire lives in Auckland with her whānau including partner Haunui and two young children Te Rangiura and Waimarie.

Ethnic differences in case fatality following an acute ischaemic heart disease event in New Zealand: ANZACS-QI 13

Authors: Grey C et al.

Summary: These researchers investigated ischaemic heart disease (IHD) events (acute IHD hospitalisations and/or deaths) amongst 26,685 people aged 35–84 years in high-risk ethnic populations (11.3% Māori, 4.0% Pacific, and 2.5% Indian) residing in New Zealand during 2009–2010. Within 28 days of IHD hospitalisations, 3.3% of people died; within 28 days of non-IHD hospitalisations, 5.1% died of IHD; 13.0% died of IHD without any recent hospitalisation. In multinomial logistic regression analyses, overall adjusted 28-day case fatality rates were 12.6% in Indians, 20.5% in Europeans, 26.0% in Pacific people and 27.6% in Māori. Compared with Europeans, the adjusted odds of death were approximately 50% higher in Māori and Pacific people and 50% lower in Indians, whether or not they were hospitalised.

Comment: I often hear the argument that Māori have higher death rates from heart disease than non-Māori because ‘they don’t get to hospital care in time’. The important point to take away from this paper is that Māori and Pacific are more likely to die from heart disease in the community AND in hospital than non-Māori, non-Pacific peoples. As the authors suggest, improvements in BOTH primary prevention and hospital care are required.


Abstract
Characteristics of sarcoidosis in Māori and Pacific Islanders

Authors: Wilsher ML et al.

Summary: This retrospective study examined medical data from 406 patients (mean age at presentation, 36 years) presenting with sarcoidosis to a specialist interstitial lung disease (ILD) clinic in New Zealand. Of the 69 patients with Māori or Pacific Island ethnicity, few had parenchymal lung involvement (21% Scadding stage 2, 2% stage 3), and none had extensive pulmonary fibrosis (stage 4). Computed tomographic imagery of sarcoid parenchymal lung involvement was less common amongst Māori or Pacific Island patients than among European patients. Ethnic groups did not differ as to baseline lung function or treatment requirements. Ocular and skin involvement was more commonly associated with Māori and Pacific Island ethnicity, whereas erythema nodosum occurred more frequently among Caucasian patients.

Comment: We don’t know very much about sarcoidosis for Māori, despite anecdotal stories heard from whānau that it appears to be more prevalent and may be an important factor in the development of other disease (such as kidney failure or lung cancer). So although I’m pleased to see published research in this area, I thought the paper/research could be improved by using gold-standard ethnicity classification (Polynesian ancestry is not appropriate) and re-wording the conclusion to say that “there appear to be ethnic differences in presentation of sarcoidosis for people living in New Zealand”.


A qualitative Kaupapa Māori approach to understanding infant and young child feeding practices of Māori and Pacific grandparents in Auckland, New Zealand

Authors: Tapera R et al.

Summary: This investigation utilised a Kaupapa Māori research approach, an approach that seeks to work from a Māori foundation to discover positive outcomes for the collectives of whānau, hapū and iwi (family, sub-tribal and tribal groupings) and for Māori more generally. The study was conducted in a deprived urban neighbourhood in New Zealand and explored what barriers, facilitators, strengths and beliefs influence the way Māori and Samoan grandparents feed their grandchildren. Semi-structured interviews were held with 7 grandparents (5 Māori, 2 Samoan) living in an Auckland suburb that had a high level of socioeconomic deprivation and ethnic diversity. Each participant had provided ≥5 meals per week over the previous 3 months to grandchildren aged under 2 years. Four key themes were identified: (i) grandparents’ understanding of optimal feeding practices; (ii) economic and material factors; (iii) previous experiences and customary norms; and (iv) social support and societal pressure. Grandparents’ complementary feeding practices in caring for infant grandchildren were influenced by upstream structural elements, including government policies related to welfare and pensions, employment, income and cultural knowledge.

Comment: Another shameless plug for my own research! Hoping others find it useful, particularly the KMR methodology used by tauiwi health researchers, and the model we used to analyse data and look at the upstream factors that impact on people’s choices/behaviours around food.


Consumers with high complex needs co-create a relationship-based approach to care

Authors: Sheridan N, Kenealy T

Summary: This paper describes how a comprehensive model of healthcare successfully co-created a relationship-based approach to care with older Māori adults with high complex health and social needs. The study recruited 15 older Māori adults living with chronic conditions (on average, 4 chronic conditions each) in a poor urban and semi-rural community. All were enrolled with Ki A Ora Ngatiwai, a Māori Health Provider Organisation that embraces a community-based primary health care approach. Interviews held with the participants sought to understand their experiences about living with chronic conditions, accessing/receiving health and social services, the most important challenges faced daily and the quality of relationships with health professionals in Ki A Ora Ngatiwai. The material demonstrated that these older adults were motivated to actively engage with health professionals, seeking to build knowledge and skills to be more able to care for themselves and their extended whānau/family. They valued health professional relationships for their own sake with people who cared about them and attended to their social concerns. This relationship-based model extended beyond solely transactional healthcare services that provide access to services and entitlements. As they gained health literacy and became more self-sufficient, the participants willingly assumed new roles within the extended family and more widely, such as whānau advocate, health specialist, social support, communicator, marketer for (health) programmes and knowledge broker. The quality of healthcare delivered by Ki A Ora Ngatiwai was rated as “excellent”.

Comment: In my experience, there continue to be health professionals and managers that think health providers should attend to clinical issues only. However, the findings from this research suggest that whānau value clinicians who also attend to social issues. What this means in practice is less definite, but we have to give thought as to how we make it happen. Finally, I was a little disappointed to not see authors from Ki A Ora Ngatiwai listed here.


Wahakura versus bassinet for safe infant sleep: a randomized trial

Authors: Baddock SA et al.

Summary: This study enrolled 200 mainly Māori pregnant women living in deprived areas of New Zealand and provided them with either a bassinet or wahakura (flax bassinet). Mothers were asked to sleep the infant in this device from birth. The researchers investigated breastfeeding, infant sleep position, the amount of infant head covering during sleep, the amount of bed-sharing (without the device), and maternal sleep and fatigue. At 1, 3 and 6 months, mothers completed questionnaires about babies’ sleep and at 1 month infra-red video was used to record the baby’s overnight sleep. Between-group comparisons revealed no differences at 1, 3, and 6 months in infant-adult direct bed-sharing, but at 6 months, the wahakura group reported twice the level of full breastfeeding (22.5% vs 10.7%; p=0.04). Maternal sleep and fatigue were not significantly different between groups. Video recordings identified no increase in head covering, prone/side sleep position, or bed-sharing in the wahakura group.

Comment: This has received a lot of media attention lately, so I thought readers would like to see the original article!


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