

Health information research privacy standards should include Māori perspectives on privacy

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Secondary research using health records and other personal health data (henceforth referred to as health information research) is a valuable tool for tackling New Zealand's health and social challenges. It requires however suitable privacy standards to maintain public confidence and social license. The privacy protocols used by New Zealand district health boards have been described in this journal, as have additional safeguards that could be adopted to prevent privacy breaches.^{1,2}

Here we present a more conceptual approach for considering what 'privacy' means in health information research, particularly the importance of including Māori perspectives on privacy. The health disparities between Māori and non-Māori are well documented, and privacy standards based on a monocultural view of privacy may hinder efforts to address these. Researchers have identified previously identified instances where cultural background affects what information New Zealanders are comfortable sharing, and with whom.^{3,4}

As an example, individuals from different cultural backgrounds may have different views on:

- what information is considered private
- whether privacy should be maintained by formal laws, informal codes of conduct or both
- where and when intruding on an individual's privacy is morally justified
- the extent to which information can be shared with family

- whether they are more comfortable sharing information with public agencies or private institutions
- the likelihood of surveillance, stigmatisation and profiling.³⁻⁵

Some caveats are in order. Individuals within any culture are heterogeneous, with different perspectives shaped by their unique circumstances, and have a number of facets to their identity.^{6,7} Just as it is wrong however to assume that any aspect of a person's identity is deterministic of views or behavior, it is equally wrong to assume that it has no effect.^{5,7} With those caveats in mind, it is worth examining how past findings on cultural attitudes to privacy might be applied to health information research. Incorporating Māori perspectives into research standards from the outset is crucial if we are to progress towards equity. This helps promote the Māori voice (ensuring the story of Māori health, values and needs are not simply told from the majority perspective), and is part of the larger framework of responsiveness to Māori in health research.⁸

Individual versus community: Menkes et al found *Pakeha* [New Zealanders of European descent] were more likely than Māori to see each patient as an autonomous individual whose privacy could only be over-ridden by the needs of society in very limited circumstances such as preventing transmission of a contagious disease.³ Māori were more likely to see autonomy as best being able to be exercised with the involvement of *whānau* and community, and with due consideration

of *whakapapa* (relationships and the structures that maintain relationships, including with those who have come before and future generations).^{3,9,10} The question of when *whānau* should be informed about an individual or involved in decision making was nuanced, and often varied between generations.³ Community consent (in addition to individual consent) was valued by Māori.^{9,10} This is grounded in values of collective ownership of information, especially genetic information. This should be considered in all health information research.

Formal and informal codes

Pakeha were more likely to support formal codes governing how and when personal health information should be shared, and to believe these rules should be enough to cover most situations. At the same time, they recognised these general rules may be unworkable in some situations, with exceptions been able to be made based on the severity of the situation and the social connection of the person receiving the information to the patient.³ Māori were more likely to recognise informal codes (*Tikanga*), including those specific to an *iwi* or *hapu*. Younger Māori were likely to reference these informal codes as sitting alongside formal codes, while older Māori were more likely to consider the informal codes forming a distinct system.³ Māori were more likely to consider generalised rules to be inappropriate, and that each situation should be evaluated on its merits.³

Trust in government agencies versus private businesses

New Zealanders of all cultural groups were more likely to trust government agencies with their personal information than private businesses, while also being acutely conscious of the power imbalance between the individual and the state.^{4,11} Māori and Pasifika people were however more concerned about the amount of information government agencies held about them (and how that information could be used), and were more willing to withhold information.^{4,11} *Pakeha* were more likely to trust government agencies with their information than Māori, Pasifika or Asian New Zealanders.⁴ It is important to consider how information held in government or business databases could (for good or ill)

be combined with information individuals generate daily through wearable fitness devices, social media and communication metadata.¹ It is also important to remember that ostensibly impartial algorithms can deliver biased results if the data input or analytical frameworks reflect existing societal biases, and/or do not include enough data from minority groups. Organisations such as Te Mana Raraunga (Māori Data Sovereignty Network) have articulated principles that reduce the possibilities of such harmful outcomes. These include upholding the rights of Māori, the ability to disaggregate Māori data, due consideration of all future use of the data, and avoiding deficit or blame framing in data analysis.¹²

Surveillance, stigmatisation and profiling

One of the reasons health information research needs dedicated governance structures is that it carries different risks from the interventional research that our ethics system is designed for.¹ These include the surveillance, stigmatisation and profiling of individuals and groups.^{1,13} The burden of such could conceivably fall more heavily on some groups within society, thereby penalising those affected while socially favoring others.⁵ Māori key informants have expressed concerns about how poorly handled genomic data could be used to 'racialise' illnesses and behaviours.¹⁰ These concerns align with the concerns of Māori and Pasifika about how government information could be used.^{4,11} This is particularly true in the age of 'big data', which aims to bring different datasets together to make policy recommendations. Ideally consent for such uses would be purpose-specific and time-limited.

It is worth remembering that none of these studies specifically examined privacy expectations in health information research.^{3,4,10,11} Nonetheless, they offer a warning that the emerging governance systems for this rapidly advancing field of research need to be both robust and culturally sensitive. Such an approach is grounded in the ethical principles of beneficence (maximising the benefits of powerful technologies such as machine learning and 'big data'), non-maleficence (avoiding harms such as stigmatisation and profiling), justice

(addressing disparities) and autonomy (allowing people to participate or not participate in ways that uphold *their* values). Conversely, ignoring the variety of views on what could be considered ‘private’ risks some groups of people being more likely to exercise their right to opt out of health information research. Alternately, it risks corralling people into research that is inconsistent with their values. Neither of these

would serve either patients or researchers well.⁸ We argue therefore that research funders and institutions (in their roles as gate-keepers), research teams (in developing their internal culture and ethics), and patient and community groups (by articulating and advocating for their values) all have a role in shaping a research culture that respects New Zealanders’ diverse backgrounds and beliefs.

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