

Insights from the Whānau Ora – Ministry of Health High Court decision

The most common answer we give to privacy questions is “it depends”. It isn’t the most helpful answer, but it seems to be the best starting point into the pick-a-path story that is privacy advice. “It depends” is so common because privacy, and how you apply the Privacy Act, are so context specific and dependant on the circumstances of any given situation. Usually there will be more than one way to address a problem or to achieve your objectives in a way that maintains privacy. The trick is often finding the best path when balancing a range of interests.

One area INFO by Design is seeing as increasingly influential to privacy is Māori data sovereignty and incorporation of Te Ao Māori into information management policies and practices. How do you align and balance the privacy rights of an individual with the collective interests of a community? What happens when the objectives of the data subject community conflict with the objectives of the holders of the data? What if there is a disagreement about how to best approach shared interests or gain mutual benefit?

For a long time, the answer to these questions has been “it depends”. And then John Tamihere, as Whānau Ora CEO, asked the Ministry of Health for vaccination data and [took the fight to the High Court](#). Then won the judicial review decision and, as we write, has had the [request rejected again](#). Leaving aside the result, and the tit-for-tat media comments, what can we take away from [Justice Gwyn’s decision](#)? How did the Court answer these big privacy questions? Has this case been a ‘game changer’ for how privacy works in New Zealand?

Unfortunately, the answer will again be “it depends”. The Courts are our most traditional institution of the law. Significant decisions are generally made incrementally and in the higher Courts, and often not in judicial review cases. So this doesn’t significantly change how we interpret and must apply privacy laws, but, it does provide signposts for agencies of evolving community expectations and considerations you can include in your privacy programme.

What was it all about?

To be true to the case-by-case approach to privacy, first we need to check out what the case was all about. The Court was asked to review the Ministry’s decision to refuse to provide Whānau Ora with the personal details of unvaccinated Māori.

As background, Te Puni Kōkiri has contracted Whānau Ora to provide assistance and support to whānau to address the adverse impacts of COVID-19 restrictions, including providing vaccination related services. It is in this context that Whānau Ora asked the Ministry of Health to enter into data sharing arrangements in August. An information sharing agreement was entered into at the end of September. This provided the commitments and safeguards for the information sharing relationship between the two parties.

The agreement provided Whānau Ora with vaccination and booking status data of people who had previously used Whānau Ora partner services. Whānau Ora asked the Ministry to provide the personal details, contact details, vaccination status and vaccination booking status of all unvaccinated Māori in Te Ika-a-Māui/North Island. The Ministry refused to provide these details.

The purpose of the request for details was made quite clear by Whānau Ora – individual data enables them to go directly to unvaccinated Māori to get them vaccinated. The Ministry's response was to agree to provide anonymised street level maps showing areas where Māori are unvaccinated. The data would be anonymised, apply to areas of about approximately 100-200 people (but up to 500 in some urban areas).

The difference between the two sets of information plays out on the street with significant resourcing implications. Details would allow Whānau Ora to turn up to a house knowing the person living there was not vaccinated. The Ministry's data tells Whānau Ora what streets to go door knocking on.

The Privacy law stuff

Strictly speaking, the Ministry's approach protects the privacy of the individuals. The general rule in the Privacy Act prevents disclosure of personal information to other agencies. The Act, however, recognises there are some good reasons for allowing agencies to share information – where the public good overrides individual privacy. This includes where disclosure is necessary to prevent or lessen a serious threat to public health or safety, or the life or health of individuals.

There are additional protections given to health information under the Health Information Privacy Code 2020. The Code modifies general privacy requirements to reflect the particular characteristics of the health sector and health information. As the Privacy Commissioner and the Court noted:

- a) Most health information is collected in a situation of confidence and trust in the context of a health professional/patient relationship.
- b) Health information is often highly sensitive in nature.
- c) The collection, compilation and use of health information is ongoing and interrelated: data collected as part of one episode of care is often required by the health agency and other health providers in the future.

The Code permits the Ministry to disclose information if it believes on reasonable grounds that the following three considerations are met:

- a) It is not desirable or practicable to obtain authorisation for the disclosure from the individual concerned.
- b) There is a serious threat to public health or public safety, or the life or health of the individual concerned or another individual.
- c) Disclosure of the information is necessary to prevent or lessen that threat.

“Serious threat” is defined as a threat that an agency reasonably believes to be serious having regard to all of the following:

- (i) the likelihood of the threat being realised; and
- (ii) the severity of the consequences if the threat is realised; and
- (iii) the time at which the threat may be realised.

This exception gives the Ministry the discretion to disclose information without authorisation, where the conditions of that rule are satisfied. It does not confer a right on requestors to access such information, or a duty on agencies to disclose.

Everyone acknowledged the seriousness of the Covid19 pandemic and the importance of increasing vaccination rates. At issue was whether disclosing identifiable details to Whānau Ora is necessary to prevent or lessen the acknowledged serious threat to public health (and, by extension, the life or health of individuals).

What was decided?

Ultimately, Whānau Ora won and the decision was sent back to the Ministry to reconsider (which it did, and decided it still wouldn't release identifiable information). The reason for this sits within the Ministry's decision-making process.

The Court emphasised the need for decisions under the Privacy Act must be proportionate and evidence based. It found the Ministry did not focus enough on the merits of the request, and put too much emphasis on broader policy issues and the potential for precedent setting. The Ministry's decision should have evaluated evidence of the benefits and harms associated with sharing the information for the particular purpose Whānau Ora had requested it for. The Ministry did not present any evidence of assessing what it considered the adverse consequences of disclosure to be.

So far, so expected and usual. The emphasis on having an evidential basis, avoiding general policy considerations, and evaluating reasonable options are well-established components of the "it depends" approach to privacy. The person disclosing needs is to evaluate the situation in question. The decision needs to be on the merits of the request and backed by evidence.

What is useful commentary from the Court is how it approached the Ministry's options evaluation. The Court agreed with the Privacy Commissioner's submission that taking the "least-privacy invasive" approach is the right approach where you are comparing two equally effective alternatives. It criticised the Ministry's decision to take a privacy protective approach and offer only anonymised data on the basis that there was no evidence to suggest this option was equally as effective as what Whānau Ora had proposed to do. Again, the emphasis is on the evidence of evaluation – not on the decision or approach that was reached.

The judge also noted the Ministry's position of not contacting individuals to obtain consent to release the information when they hold the information was contradictory to its position expecting Whānau Ora to contact people without having their contact details.

Why could it have been a gamechanger?

Where the case could have marked a significant shift to privacy law was in the application of Te Tiriti principles and requiring these to be incorporated into the interpretation of the public interest exceptions contained in the Act and codes.

Whānau Ora argued the principles of Te Tiriti were not applied by the Ministry in making its decision. The Court agreed and found the Ministry did not have adequate regard to Te Tiriti and its principles, as informed by tikanga.

The Court's decision here wasn't a gamechanger though. The decision did not find privacy laws should be interpreted in accordance with tikanga. It found the Ministry has specifically made commitments to uphold Te Tiriti in the vaccine programme. It is as a result of these commitments that the Ministry needed to consider Te Tiriti principles in its decision in relation to Whānau Ora's request.

This is very similar to how privacy provisions are interpreted – if you tell people you will use information for a particular purpose, you set the expectation that is how you will use their information. An agency will be held to account for using information how it said it would.

While the decision might be in line with the prevailing approach to privacy, the case can provide agencies, especially public sector agencies, with signposts of evolving expectations around privacy and information management, and how it may evolve in a context particular to New Zealand.

Social and cultural license – applying Te Ao Maori

Privacy is about meeting the expectations of the people you collect information from. This is why there is so much emphasis on transparency, doing what you say you're going to do, and consent being an overriding exception to the general rules. Exceptions are also available to permit activities we, as a society, deem to acceptable intrusions onto the right to privacy. Agencies are also exploring social license for planned uses of people's information and increasingly understanding the need to address the cultural license for using information about a community.

This case is an example of where these components are all playing out. The legislatively provided exception is being applied by both parties, with a difference of perspective regarding the social and cultural license being shown. One side is emphasising how trust and confidence could be harmed by the additional disclosure, and the other is putting emphasis on values in favour of disclosure because of the potential benefit for the people it is about.

The decision is also useful in how it demonstrates the evaluation of Te Tiriti principles in the context of privacy and information sharing. Understanding these provides an insight into this perspective and an opportunity to identify how these can inform the design of agency privacy programmes, data governance, and information systems.

The Whānau Ora position on the application of Te Tiriti principles are well set out in the decision. It applied three key principles to the Ministry's decision in relation to its request:

- 1) **the principle of options** –requires Māori be able to pursue a direction based on personal choice. In the pandemic context, it means enabling Māori to have the genuine choice of kaupapa Māori providers and actively supporting and resourcing those providers. Kaupapa Māori organisations must be sufficiently empowered and resourced, with adequate resourcing vitally including access to information.
- 2) **the principle of active protection** – the Crown has a duty to actively protect the health rights of all Māori. It is insufficient to rely on Government-controlled, mainstream, or non-kaupapa Māori services where these have failed to significantly reduce the disparate rate at which Māori are vaccinated. It is also insufficient to rely on only primary healthcare providers who have existing connections to individuals, as this leaves a significant number of Māori at risk of being excluded.
- 3) **the principle of tino rangatiratanga or partnership** –partnership is a relationship of equals; in the pandemic context it requires disclosure of the information and working together, including the design of the kaupapa Māori response to COVID-19. Providing only what the Ministry thinks will be sufficient reflects the Ministry's failure to understand the importance of tino rangatiratanga and partnership.

Whānau Ora also emphasised regard to tikanga is an integral part of considering and applying the principles of Te Tiriti. Application of a tikanga lens, not just a Pākehā legal lens, in assessing the rights

and obligations of the applicants and the whānau they serve is required. Tikanga requires a particular focus on Whānau Ora's kaitiaki obligations to Māori in need, based on their demonstrable expertise, capability and leadership. In evidence, Whānau Ora advised the Court:

A pandemic is a compelling example of when tikanga would say it is necessary to disclose information. Because of the foundational principle of Whānaungatanga, the relevant relationship bonds exist between those who can provide care, and those who need it. If disclosure would allow a collective with kaitiaki obligations for a Rangatira role in healthcare (such as a Whānau Ora-based agency) to reach individuals who are in need of care that the collective would otherwise not be able [to] reach, and to provide those individuals with kaitiakitanga and awhina in the form of healthcare support (such as information and vaccination care), that disclosure is consistent with tikanga.

It is worth emphasising, as the Ministry did, ideas and practices as to tikanga may differ as between iwi. The Ministry noted there can be "divergent views of Māori" as to the appropriateness of sharing individual-level data and there is "no consensus about whether it would ever be appropriate for the Crown to share individual identifiable Māori health data let alone in the context of the current pandemic."

The judge noted the engagement the Ministry had with Māori over the course of the vaccine programme and its connections with Māori health providers. Ultimately, the Court was not in a position to judge what approach was the right interpretation, however, the judge did note it was hard to see how the Ministry's decision "could have been informed by the principles of partnership and options".

What can we take from the case?

There are a number of useful insights to be drawn from the decision, and perhaps the case more broadly, an agency can apply to its own activities. Here, we discuss what we've taken from it from a privacy programme and data governance perspective:

- *Consider and manage information as an asset:* while not explicit in the decision, treating information as an asset is implied in the commentary regarding the principle of options. Whānau Ora clearly established information as a key resourcing component, which needs to be considered as part of an evaluation of adequate resourcing.
- *Design dynamic consent mechanisms and communication into your systems:* consent remains the overriding enabler for privacy and sharing personal information. Systems should be designed with mechanisms to collect consent for additional purposes and engaging with customers around consent should be an integral part of your engagement strategy. An efficient mechanism for the Ministry to seek and obtain consent to share identifiable information with Whānau Ora would have addressed at least a part of the information request in clear, unambiguous terms. Consent should always be informed, and people should have the opportunity to withdraw or update consent at any time. This drives the need for your consent mechanisms to be dynamic.
- *Ensure social and cultural license forms part of your information governance:* the case highlights the need for effective measures to provide evidence of social license and the involvement of diverse perspectives in your governance arrangements. The Ministry could not evidence the potential harm to individuals of the release. The resourcing needs for Whānau Ora were not considered within the overall vaccine strategy and plan. While easy to emphasise with hindsight, the requirement to consider evidence means something needs to

be in place to create the evidence or to make it available. Measuring levels of trust and the expectations of people whose information you hold is needed to evaluate social license from an evidential basis. This might be collected through your consent mechanisms, surveys, engagement with stakeholders, or defined metrics on trust and performance. Consultation may not be enough to provide insights regarding cultural license. Depending on your needs, you may require a co-governance model, engagement, reference, or independent oversight groups, co-designed principles for your data governance programme, or regular research on information needs and expectations.

- *Assessments for disclosure must be evidenced based:* a decision to disclose is for the disclosing agency to make. Procedures in place to disclose information, whether proactively sharing or responding to a request, must include an evidence collection and evaluation component. This is going to be an important consideration and it will be interesting to see how this plays out in relation to the new Privacy Principle 12 regarding overseas disclosure.
- *Dialogue delivers information sharing:* the Ministry and Whānau Ora entered into an information sharing agreement. Too often parties jump into the paperwork without sharing an understanding of the goals for sharing and what each is looking to achieve from the agreement. A shared understanding should then inform discussions about what information is needed for sharing and discussions around the mechanics for it. Starting from the other way around often leads to misunderstandings, delays, and disputes when parties are not 'getting what they want'. Dialogue, rather than a legalistic or policy-framed analytical approach, better supports problem-solving when setting up an information sharing relationship. There appeared to be some engagement between the Ministry and Whānau Ora, leading to a refinement over what information was needed. Getting the right people around a table to discuss the broader issues up front may have resulted in better results for everyone.

The above are all trends INFO by Design is seeing arise and expects to become more relevant in future. We are advising our clients to take these into account as part of their privacy programmes and Privacy by Design approaches to system and service development. The approach applies best practice information governance frameworks that not only allow you to easily comply, but build on your relationships with customers/clients and develop a trusted reputation.