

*"He aha te mea nui o te
Ao? He tangata, he
tangata, he tangata"*



SHARING INFORMATION FOR WELLBEING



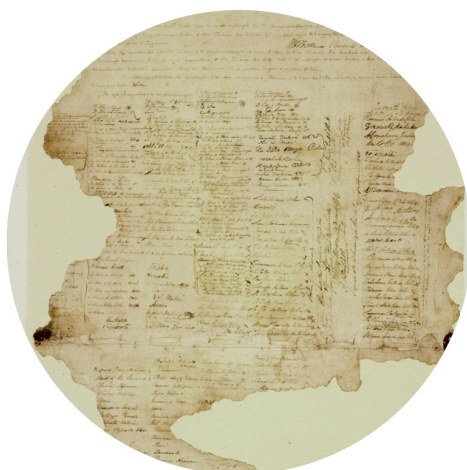
MĀORI
ENGAGEMENT ON
SOCIAL LICENSE
REPORT 2017



PREPARED BY
Tūhono Trust for
Data Futures Partnership
June 2017



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MIHI



*E ngā maunga, e ngā awa awa, e ngā pātaka o taonga tuku iho,
Tēnā koutou, tēnā koutou, tēnā koutou katoa.*

*Tēnā hoki koutou i o tātau tini mate,
Kua wehe atu ki tua o te aria,
Kua mene ki ngā pō, kua mihia rātau, kua tangihia rātau,
Kua ea te taha ki a rātau.*

*E ngā whānau whānui o ngā Iwi o te motu
Tēnā koutou, tēnā koutou, tēnā koutou katoa.*

DATA FUTURES PARTNERSHIP

DATA FUTURES PARTNERSHIP

Data Futures Partnership: Māori Engagement on Social License for Data Use and Sharing

Taking the Kaupapa to the People

The Data Futures Partnership (DFP) wished to engage with Māori to inform the drafting of social license guidelines for data use in New Zealand. This provided an opportunity to contribute perspectives of Māori to the development of guidance for all organisations in New Zealand about the collection, storage, use and sharing of data.

The Data Futures Partnership wanted to have meaningful conversations with Māori leaders and communities to explore the benefits and concerns about using data in a range of situations. This would require developing a Māori Framework, to imbue the hearts of the people, to then participate and engage.

Through this considered approach, DFP needed to understand and explore opinions around data sharing and use in New Zealand.

DFP asked for an engagement strategy which engaged and involved participants from Iwi, hapū and whānau in urban and rural communities across the country.

Central to this brief was the identification of areas of common ground, and the limits or constraints of trusted data use. DFP also required specific suggestions for principles and guidance for organisations seeking social license for data use activities.

ABOUT TŪHONO



Tūhono Trust

Representative Trust Board of 120 mandated Iwi organisations as listed in the Electoral Regulations 2002.

L-R: Lester Pohatu (Takitimu Representative), Te Taka Keegan (Tainui Representative), Druis BARrett (Taitokerau Representative), Clifford Akuhata (Mataatua Representative), Anothny Olsen - Chairperson (Te Arawa Representative), Arapata Reuben (Te Waipounamu Representative), Pahia Turia (Hauauru Representative).

ABSENT: Rikirangi Gage (Porourangi Representative), Omahuru Robinson (Hauauru Representative).

Tūhono is a Charitable Trust set up for the purpose of promoting Maori well being and identity as being a public benefit for Māori and the wider public of New Zealand. Tuhono has 3 key roles of 1) The Māori Affiliation Service 2) Research Service, and 3) Development Service. We do this through our competencies of strategic networking, data management and innovation, and offer a service which ensures inclusive access, participation and accountability across the Maori Sector network including, 100,000 Maori and 120 Iwi organisations.

Strategic Research Partner

Tūhono established a strategic research relationship with Horizon Research Limited in 2014 to enhance research capability and services.



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www.tuhono.net
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EXECUTIVE REPORT

KEY FINDINGS

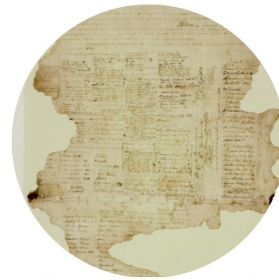
This executive report summarises the key findings and recommendations of Tūhono consultation, using a representative sample of the New Zealand Māori adult population, and responses to surveys by Māori who personally attended a hui, those who attended an online webinar hui, and those responding to an invitation to complete an online survey.



Key Finding #1 **Conditions Relating to Sharing** **Information**

Sharing anonymised information revealed a higher level of comfort with participants compared to sharing their private information.

Participants voiced the desire to have full control over who their private information should be shared with, if at all.



Key Finding #2 **Guidelines & Protocols** **are Essential**

That a Māori Framework should be used to develop the guidelines, in accordance with the Treaty of Waitangi.

Transparency is needed for participants to manage their own information, as an essential foundation for building trust & confidence.



Key Finding #3 **Collective Wellbeing & Cultural** **Networks Equally Important when** **Sharing Information**

Individual and collective wellbeing are equally important for Māori.

Sharing information with cultural networks is significantly important for Māori.

Higher level of trust and confidence when sharing information with Iwi.



Key Finding #4 **Multiple Engagement** **Strategies to Connect**

The merits of multiple engagements channels were confirmed.

EXECUTIVE REPORT

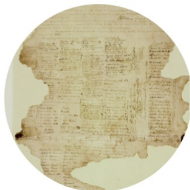
RECOMMENDATIONS



#1

Implementing social licence would benefit from further research into:

- A. More emphasis on the benefits to Māori and all New Zealanders of introducing a Social License regime.
- B. Which agencies of government, people would be prepared to share private information, how, under what circumstances and for what benefits.



#2

That a Māori framework should be used to develop these guidelines, in accordance with the Treaty of Waitangi.



#3

No One Size Fits All Solution: Guidelines address the consent, and purpose limitations:

- A. If an individual voluntarily provides information it is assumed the individual agrees to social license.
- B. Individual consent for specific purpose. It can be assumed the individual agrees to social license, for that certain purpose
- C. Use of personal data for other purposes, no social license can be assumed in this circumstance.
- D. Data that has been anonymised (data that cannot be used to identify any specific individual) can be assumed to give a social license.
- E. Emergency medical care: In the case of a life and death situation, an automatic social license is given to collect, use and share personal data.



#4

Consider a data management licensing system.

That full consideration be given to introducing a legally enforceable Data management licencing system to control the multiple levels of data management, use and sharing practices, in relation to "Social Licence" requirements.



#5

Multiple communication & engagement strategies be used when engaging with people throughout the country.

INTRODUCTION

The Data Futures Partnership (DFP) wished to engage with Māori to inform the drafting of social license guidelines for data use in New Zealand. This work was undertaken with the support and advice of the Iwi Leaders Forum on Data.

Over a eight-week period from 29 March to 25 May 2017, a national Māori engagement programme titled ***Sharing Information for Wellbeing*** was implemented in response to a brief from the DFP to raise awareness, understanding and engagement about social license.

Tūhono Consultation Process

The goal of this project was to effectively capture the voice of Māori, find common ground and key themes, and gauge insights into their thoughts and opinions about what the guidelines should be for organisations seeking to use and share their information.

Sharing Information for Wellbeing was developed and implemented by the Tūhono Trust, using a representative sample of the New Zealand Māori adult population, and responses to surveys by Māori who personally attended a hui, those who attended an online hui, and those responding to an invitation to complete an online survey, which was developed in partnership with Horizon Research Limited.

Kaupapa Māori Approach Summary

Sharing Information for Wellbeing was designed around Kaupapa Māori and Wellbeing Frameworks, with three key inter-related components, Kawa, Tikanga and Kaupapa. Participants were asked to view two animation video clips about wellbeing and Kaupapa Māori, and then asked to consider the development of the guidelines in relation to using a Kaupapa Māori Framework in accordance with the Treaty of Waitangi. In addition, to express their personal view about information sharing, participants were presented with three hypothetical scenarios and then asked to consider their personal or individual wellbeing, their collective wellbeing and their propensity to share anonymised and private information with government entities, community organisations, businesses and Iwi.

KEY FINDINGS



In this section:



- Key Finding #1: Conditions Relating to Sharing information
- Key Finding #2: Guidelines & Protocols are Essential
- Key Finding #3: Collective Wellbeing & Cultural Networks are Equally Important when Sharing Information
- Key Finding #4: Multiple Engagement Strategies to Connect

CONDITIONS RELATING TO SHARING INFORMATION

KEY FINDING #1



The responses and comments from scenarios about organisations sharing information highlighted several main themes:

-  1. Higher Level of discomfort when sharing Private Information compared to Anonymised Information.
-  2. Participants voiced the desire to have full control over who their private information should be shared with, if at all.

1. Higher Level of Discomfort when Sharing Private Information compared to Anonymised Information

Participants expressed their rapidly decreasing comfort as scenarios progressed into sharing their private information with organisations, compared to sharing their anonymised information. Participants were very clear that sharing any information of any type with businesses did not benefit them, they were not happy to do this, and were extremely uncomfortable.



*Percentage of participants who agreed to share their anonymised & private information with organisations in the Cultural Information Scenario

Sharing Anonymised Information and Private Information

Compared to sharing anonymised information, information sharing became increasingly more sensitive for participants as the information scenarios impinged on the sharing of their private information with government entities, community organisations, and Iwi, and expressed an even higher level of discomfort when asked about sharing their private information with businesses.

Participants were asked about sharing their medical information with medical experts first, saying:

"Often we only share medical info we think is relevant at the time, we're not the doctors and this extra info could be vital" and again "Access to medical information is vital in a life threatening situation/s. I would be happy to share my information, I'm happy now."

When asked to share their anonymised medical information, participants voiced concern, but were still willing to share as explained here:

"Provided subjects are asked that anonymised information is shared with appropriate entities then this could be hugely beneficial for health outcomes- supported" and another explains "This would be useful information, but like other participants I would also be concerned around security of use of info for other purposes. But I would probably agree with fingers crossed that it is secure."

However, when asked to share their private medical information, there was a strong consensus this was not acceptable as commented here:

"I'm naturally uncomfortable with sharing that level of private information. Different scenario to anonymised"

2. Participants want Full Control over Private Information

Participants comments and opinions demonstrated that when their private information became subject to sharing by organisations, they voiced the desire to have control over their information.

'My Data, My Way'

INSIGHTS & MEANING

There was no shortage of comments and opinions that participants wanted full control over their private information and who this should be shared with, if at all. As some participants explain:

"I have voted Anonymised Info only, because I don't think private information should be shared. So it is not that any guidelines are needed, it is that I don't think it should include Private Information."

When asked about sharing their private information, a large amount of comments used the words:

*"no trust"
"want full control"
"absolutely not" and
"no benefit"*

One participant summed it up by saying:
"Private information is exactly that, Private" and another "Tapu tō te tangata".





GUIDELINES AND PROTOCOLS ARE ESSENTIAL

KEY FINDING #2:



An overwhelmingly majority of participants support that there should be guidelines and protocols for organisations wanting to use and share information. However, when developing guidelines for organisations, there were several key themes participants were very clear about:

-  1. That a Māori Framework should be used to develop these guidelines, in accordance with the Treaty of Waitangi.
-  2. Transparency is needed for participants to manage their own information, as an essential foundation for building trust and confidence.

1. Kaupapa Maori Framework should be used to develop guidelines in accordance with the Treaty of Waitangi

A significant majority of participants agreed that a Māori framework should be used to develop the guidelines in how their information was held, used and shared in accordance with the Treaty of Waitangi.



Working in Partnership for the Prosperity of Aotearoa New Zealand

Participants who commented on the Treaty, viewed the Treaty of Waitangi as an essential form of protection to ensure that Maori have the freedoms and security to participate and engage, in a way that adheres to their Kawa and Tikanga. As explained by one participant

"The use of any personal information should be governed by a set of principles that respects privacy and integrity", further saying that "these principles are currently encompassed in the Treaty." In the same light, another participant commented that "I can't see how Maori would be taken seriously or be at the 'table' if we don't have the Treaty. The Treaty is a partnership between Māori and the Government for all New Zealand".

Another participant commented on the principles of the Treaty which placed a responsibility on the Government to ensure the success of the guidelines in Partnership with Māori, as explained here:

"The principles of the Treaty of Waitangi (partnership, protection, participation) already place an onus on government departments and contracted non-government agencies to do this."

Cultural Practises have Contemporary Application

Participants also commented on the Kaupapa Maori Framework, and again provided valuable insight into why a vast majority of participants agreed that a Māori framework should be used to develop effective guidelines and usage, for the benefit of Maori. As one participant put it:

"Maori Kawa and Tikanga ideologies and theories should be a priority" and another saying that "Tikanga and Kawa should be incorporated in the framework to reflect our (Maori) view".

One participant summed it up by saying "I agree that a Maori Framework should be used to develop the guidelines as I believe they would have more of an understanding of how information would benefit us as a people and how we roll".

One participant went as far to say that:

"Honestly I don't like my information being shared with anyone but under a Maori kaupapa framework I am happy to do so."

INSIGHTS & MEANING

INSIGHTS & MEANING

2. Transparency:

An essential foundation for building trust & confidence

Overall, agreement was high across all 14 potential requirements to be used to develop guidelines presented to respondents.

90+%
AGREED

INSIGHTS & MEANING

A recurring theme that emerged from participants' comments was there needed to be an elevated level of transparency when managing their information, especially to build trust and confidence in information sharing. As several participants explained, that **"transparency around the use of personal data should be paramount if any government department or organisation wants the public to trust them with this information in the first place"**.

Overall participants commented frequently that guidelines and protocols are essential before sharing information which aids in building respect, as explained here:

"Any information about me, my whanau, hapu or Iwi is tapu and needs to be respected as such, and so I believe there needs to be guidelines around how our information is handled. I don't think it will be respected necessarily as it should without guidelines" and "would need a proven track record and clear protocols to share information...", **"Yes can be shared as long as...there should be guidelines about who is using this information, for what purpose and that the purpose is purely beneficial and not for marketing"**.

Many participants commented that the potential requirements were **"common sense"** or many simply said **"happy with these"**.

3 Main Requirements

99%

Being told what happens if security or privacy were breached

98%

Being able to see what data is held about them' was important

96%



Being assured that you will be informed before any further data use or sharing is allowed

COLLECTIVE WELLBEING & CULTURAL NETWORKS ARE EQUALLY IMPORTANT WHEN SHARING INFORMATION

KEY FINDING #3



Māori have unique collective and cultural networks which play an important role when considering the guidelines for organisations wanting to use and share their information. When developing guidelines for organisations, participants gave a strong around two key themes:

-  1. Individual and collective wellbeing are equally important for Māori, and sharing information with their cultural networks is significantly important.
-  2. Higher level of trust and confidence when sharing information with their Iwi.

1. Collective Wellbeing and Individual Wellbeing are Equally Important

When sharing their medical information, participants placed equal importance on the benefit to their whānau/collective wellbeing compared to their individual wellbeing. In addition, when sharing information of cultural importance, a significant majority of participants were happy to share this information with their Marae, Māori Land Trust and Iwi Organisations.



*Participants who agreed that sharing Medical Information was beneficial to their Individual & Whānau/Collective Wellbeing



INSIGHTS & MEANING

Cultural Networks and Collective Wellbeing

Comments from participants suggest that collective wellbeing has the same relevance for participants as individual wellbeing, due to the natural collective networks Māori are connected to by whakapapa. As one participant wrote: ***“I believe that Māori had a strong community resilience process which ensured that whānau and whānau whanui aspects were catered for. This allowed a more collective and collaborative sense of origin and wellbeing”.***

As a diverse nation, Māori conduct themselves as citizens of New Zealand with the same individual rights as their non-Māori counterparts, but Māori have an added cultural environment that defines their extended collective consciousness, as echoed by participants:

“We have cultural diversity. Kawa & language that distinguishes each for us as an individual, hapū and Iwi”, and “The wellbeing of the collective is of more importance than of the individual in that if the whole is all good, then the individual is all good”.

Sharing information with Marae, Māori Land Trust and Iwi worked hand-in-hand with the collective benefits as explained by several participants:

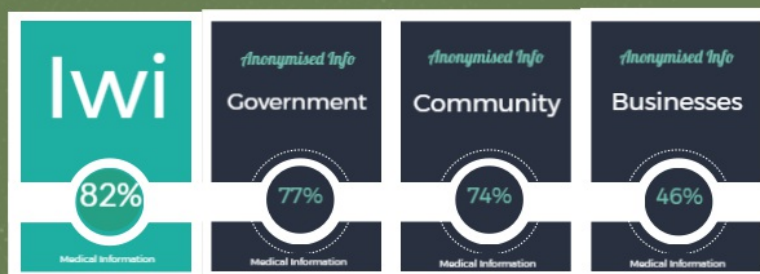
“If my information can benefit my marae/iwi and/or benefit my whānau, then it will benefit myself, my children and future generations”, “My Marae – because it will be beneficial for nga uri whakatipu, future generations”, “My Marae – yes – I trust my Marae”.

*Participants who agreed to share their Cultural Information with Marae, Maori Land & Incorporations, and Iwi

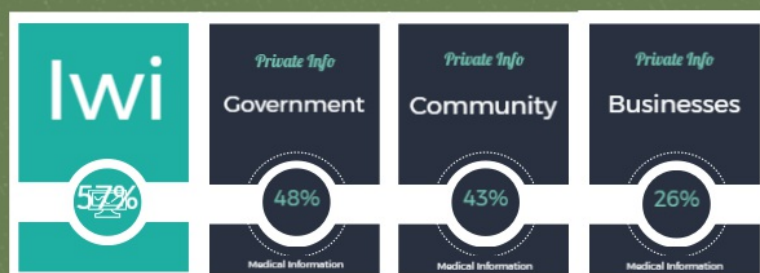
2. Higher Level of Trust & Confidence when sharing Information with Iwi



A greater percentage of participants agreed to share both their anonymised and private information with Iwi, compared to sharing information with government entities, community organisations and businesses.



*Participants who agreed to share anonymised medical information with organisations



*Participants who agreed to share private medical information with organisations

Trust & Confidence has a Cultural & Inter-generational Basis

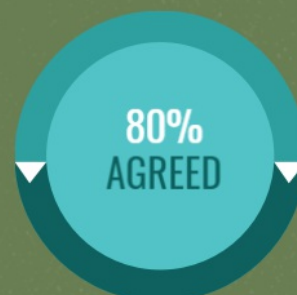
INSIGHTS & MEANING

Sharing information with Iwi was consistently high across all three information sharing scenarios. Participants trust Iwi more compared to Government entities, community organisations and businesses, simply put by a couple of participants:

"I trust what Iwi is trying to do is good for whānau", and "I believe Iwi will use our data wisely".

Cultural relationships was also a high factor in participants sharing information with their Iwi, as explained by participants:

"It's helpful because our Iwi can help connect", "I strongly agree that this will benefit my cultural wellbeing because my Iwi informs me about Poukai, organise Reo programmes to connect our whanau to, and more", and "It's good to know what is happening with your Iwi".



To share cultural information with Iwi

MULTIPLE ENGAGEMENT STRATEGIES TO CONNECT

KEY FINDING #4:



To effectively capture the voice of the people, find common ground and key themes, and gauge insights into the thoughts and opinions of people, three lines of engagement were offered to maximise the opportunity to participate. The main finding was that:



1. The merits of multiple engagement channels were confirmed.

All Engagement Channels provided different opportunities for participation & engagement

Capturing the voice of the people across three different engagement channels resulted in the following:

Capturing the Voice of the People

Online Survey

533 responses
recording
1022 comments



Face-to-Face Hui

94 attendees
collecting
503 comments



Online Hui

187 registered,
60 attendees,
401 comments &
questions



KAUPAPA MĀORI APPROACH



In this section:

- Kaupapa Māori & Wellbeing Frameworks
- Kawa: Māori Wellbeing
- Tikanga: Protocols through Delivery Methodology
- Kaupapa: Sharing Information for Wellbeing

KAUPAPA MĀORI & WELLBEING FRAMEWORKS

KAUPAPA MĀORI APPROACH

Kaupapa Māori and Wellbeing Frameworks

Social License was an unfamiliar term and does not resonate with Māori as a basis to have meaningful conversations. In response to the brief, Sharing Information for Wellbeing, was designed around Kaupapa Māori and Wellbeing Frameworks, with three key inter-related components:



KAWA: Māori Wellbeing

Places the collective aspirations of Māori at the forefront to ignite meaningful conversations and common ground. This was expressed through wellbeing.



TIKANGA: Protocols through Delivery Methodology

These are the shared values and beliefs of Māori which are the protocols and rituals Māori practise to nurture relationships and create deeper connections, create a safe and welcoming environment to participate and engage. Engagement based on shared values and beliefs ensures an approach which adapts to the situation of participants, and allows for ease to iterate during the trial and error stage.



KAUPAPA: Sharing Information for Wellbeing

This is the topic or issue of the day, and this is where a conversation of sharing information, or social license, took place. “Sharing information for Wellbeing”, was series of face-to-face hui, online hui and online survey to start a national conversation about social license, utilising the Tūhono’s relationships, trust and confidence with 13,877 online members, 2,667 research panel members and 120 Iwi organisations.

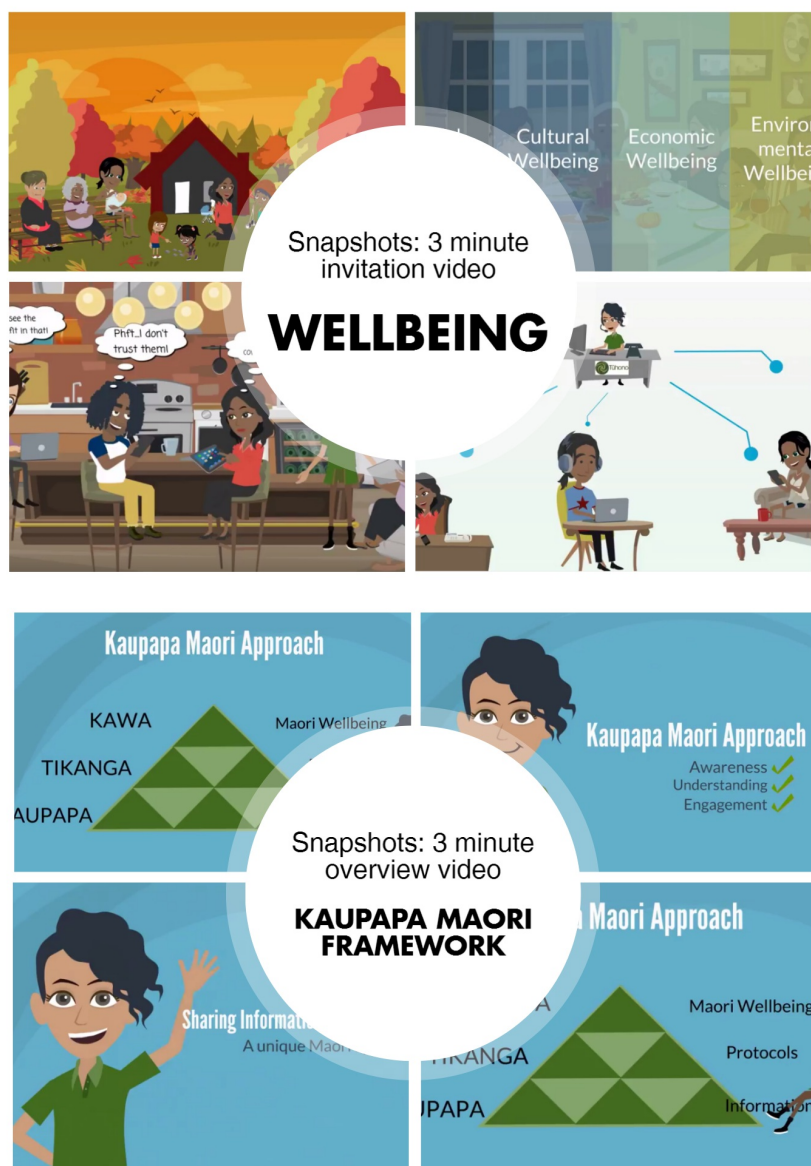
KAWA

KAUPAPA MĀORI APPROACH

KAWA: Māori Wellbeing

“He aha te kai o te Rangatira? He kōrero, he kōrero, he kōrero”

Noted in the whakatauki “He aha te kai o te Rangatira? He kōrero, he kōrero, he kōrero”, the Kawa of the project was expressed through starting a conversation about the wellbeing of whānau – their cultural, economic, social and environmental wellbeing.



TIKANGA

KAUPAPA MĀORI APPROACH

TIKANGA: Protocols through Delivery Methodology

“Mā te manaaki, ka tū ai te mana o te tangata, o te whānau, o te lwi”

Recording the Voice of the People

The main objective of the hui was to not just record the thoughts and opinions of participants, but to synthesize and extract meaning, insights, themes and find common ground amongst participants.



Face-to-Face Hui

To ensure the accurate recording of participants' responses, a Record booklet was provided for participants to complete. To ensure participants could expand on their responses, they were invited to comment further by writing on post-it notes, which were categorised and stored.



Online Hui

All comments were written by the participant and electronically recorded through the online webinar system.



Online Survey

Participants were invited to complete an online survey and given the opportunity to comment after each section of questions they answered, to provide more indepth meaning and insight about their answers. All responses and comments were electronically recorded through the Horizon Research platform.

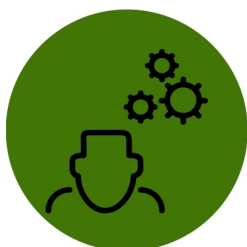
KAUPAPA

KAUPAPA MĀORI APPROACH

KAUPAPA: Sharing Information for Wellbeing

“Mahia te mahi, hei painga mo te Iwi”

Wrapped in the cloak of Kawa and Tikanga, facilitators were now ready to engage with Māori by raising awareness, promoting the importance of understanding and engagement, when gathering the views and opinions of Māori about what the guidelines should be for organisations seeking to use and share their information.



Raising Awareness:

2,667 opt-in Research Panel members.

13,877 online members.

120 Iwi organisations.



Promoting the Importance of Understanding:

Several 2-3 minute video clips were produced to assist in communicating to Māori and Iwi why sharing information was of critical importance, and encourage participation in an online webinar, or complete an online survey.



Options for Engagement:

3 options to engage were provided:

- 1) Face-to-face hui
- 2) Online webinar hui and
- 3) An online survey.

SCENARIOS

Data Futures Partnership provided very clear direction on the template for the scenarios which were used to provide engaged participants an insight into different situations of their information use.

| | | |
|--|---|--|
| Cultural Information <p>Respondents were asked about three scenarios in which their iwi or Trust Board shared their name, date of birth, address and email with their marae, with Māori Land Trusts and Māori Incorporations, and anonymised and private information were shared with Government ministries, community organisations and businesses.</p> | Medical Information <p>Respondents considered three scenes in which personal private medical information was shared with hospitals and medical specialists; anonymised information was shared with Government ministries, businesses and iwi and community organisations, and private information was shared with Government ministries, business, community groups and iwi organisations (in the latter case to ensure to speed up application processing to ensure people got all benefits they were eligible for and reduce benefit fraud)</p> | Road Safety <p>Participants were asked questions and to comment about three scenes in which the New Zealand government wanted to install a 'smart' road safety device on each registered car in New Zealand, to monitor road safety and road conditions in New Zealand. The first scene would be to share this information with the Ministry of Transport and the NZ Transport agency. The following scenes progressed where the device gathered data about road quality, pollutants and noise, individuals for purposes of crime, civil defence notifications and health related notifications. This information would then be shared with other government entities, community or organisations, businesses and Iwi.</p> |
|--|---|--|

PROJECT TIMELINE

Stage 1: March 2017

- Discussion & Meeting
- Confirm Final Proposal
- Confirm Engagement Strategies
- Confirm Methodology
- Face-to-face hui #1, 29 March

1

Stage 2: April 2017

- Trial, Error & Iteration
- Face-to-Face Hui #2, 7 April
- Face-to-Face Hui #3, 10 April
- Online Survey Launch: 19 April
- Face-to-Face Hui #4, 24 April

2

Stage 3: May 2017

- Online Hui 1-7 complete
- Face-to-face #5, 17 May
- All hui Complete
- Online survey closed 25 May
- Start to gather data & results
- Analyse comments & opinions
- Synthesis common ground, themes, insights & meaning

3

Stage 4: June 2017

- Key findings & recommendation
- Final Report 9 June 2017
- Feedback & Follow Up

4