Data Summit 2019
Legal, ethical and social license considerations for data sharing

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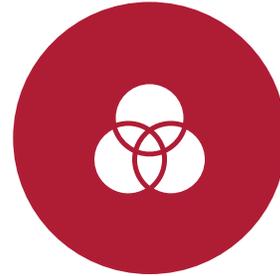Ministry of Health
Simon.Ross@health.govt.nz
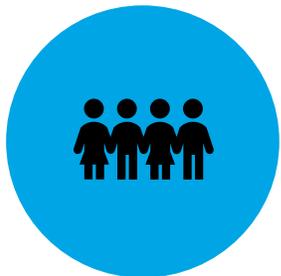
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Overview

Governance over data sharing

Resources for ethical decision-making

Forthcoming requirements – Data Protection and Use Policy

Public Deliberation for understanding social license

Privacy, social license and ethical considerations

- More data availability and more sophisticated ways to use data are accompanied by increased public expectations

- Privacy remains important but other considerations are increasingly coming to the fore

- Government is using various approaches to understand social license for data use and set expectations for users:
  - Data Futures Partnership (2016)
  - Data Protection and Use Policy (2018)
  - Algorithms stocktake (2018)
  - Data Ethics Advisory Group (2019)
  - Maori data governance and sovereignty (2019)

Maturing our approach to data sharing decision-making

From

- A siloed approach to managing and providing access to data
- Not enough rigour in some areas affecting data quality and data protection
  - Result: risk of breaches from careless use or release of data
- Too focussed on certain aspects of managing and protecting data (e.g. privacy / data quality) limiting our ability to derive public value
  - Result: good intentions, but the effect is data that is locked up

To

- New structures and processes to standardise data sharing decision-making
- Data stewards, business representatives and privacy experts with diverse perspectives are involved in decision making
- A data governance group has delegated authority to make decisions
- Principles support good decision-making
- Processes support consistent decisions
  - A template for information about data requests and for privacy impact assessments
  - A checklist to ensure key factors are considered
  - Data governance guidelines to ensure data approved for release is handled appropriately by recipients

Ministry decision-making process for sensitive data release

Structures

- Data Governance Group

Principles

- Sharing must support public good outcomes for individuals/populations (social license)
- The Ministry must be able to identify a legal mechanism that enables release
- Information is provided to established health sector entities and researchers (with appropriate approvals)
- If release is approved, data governance guidelines are provided and data is transferred securely

Processes

- Requests for new data sharing are considered by a working group of data stewards, business representatives and privacy specialists from across the organisation
- A template is used to gather consistent information to support the request
- Requests must be made in writing and be sufficiently detailed and supported by relevant documentation
- A checklist is used to ensure requests are considered consistently

Documents

- Terms of Reference
- Template for data sharing requests
- Checklist for decision-making
- Governance guidelines for organisations approved to receive NHI-level data
- Standard Confidentiality Deed (contract) for larger data sharing arrangements

Data sharing framework to help codify decision-making process

- The next level of maturity is to try and standardise and codify the factors affecting decisions to allow these to be understood and made more consistently over time

- This will also allow the Ministry to share its decision-making process with other organisations and to make decisions in new contexts

- The Data Sharing Framework will fold in legislative considerations, ethical considerations, Maori expectations and other considerations to allow more consistent decisions to be made

Infrastructure and resources targeting ethical data use

Infrastructure

- Health and Disability Ethics Committees
- Data Ethics Advisory Group (Stats NZ)

Resources

- Principles for data analytics and use (Stats NZ | Office of the Privacy Commissioner)
- Algorithms charter (Stats NZ – out for public consultation)
- National Ethics Advisory Committee – new ethical standards (forthcoming)
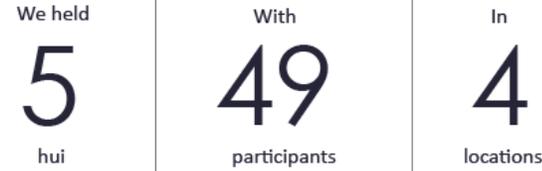- Privacy, Human Rights and Ethics Framework (PHRaE, MSD)

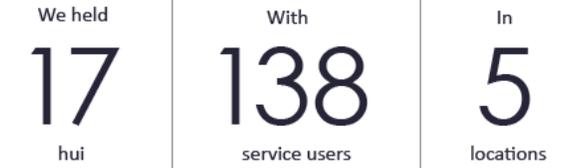# During the engagement process, you talked and we listened

Over 14 weeks, we held 83 hui in 27 locations across New Zealand. We talked to people who use social services, Māori and iwi groups, Pacific peoples, disabled people, service providers, government agencies, district health boards, local government, philanthropists and academics. In total, 1,047 people attended the hui.

We held	With	In
83	**1,047**	**27**
hui	participants	locations

Service users

We held	With	In
17	138	5
hui	service users	locations

Maori

We held	With	In
5	49	4
hui	participants	locations

Regional service providers

We held	With	In
41	568	24
hui	participants	locations

Data Protection and Use Policy to support the respectful, trusted and transparent use of people's data and information

SIA
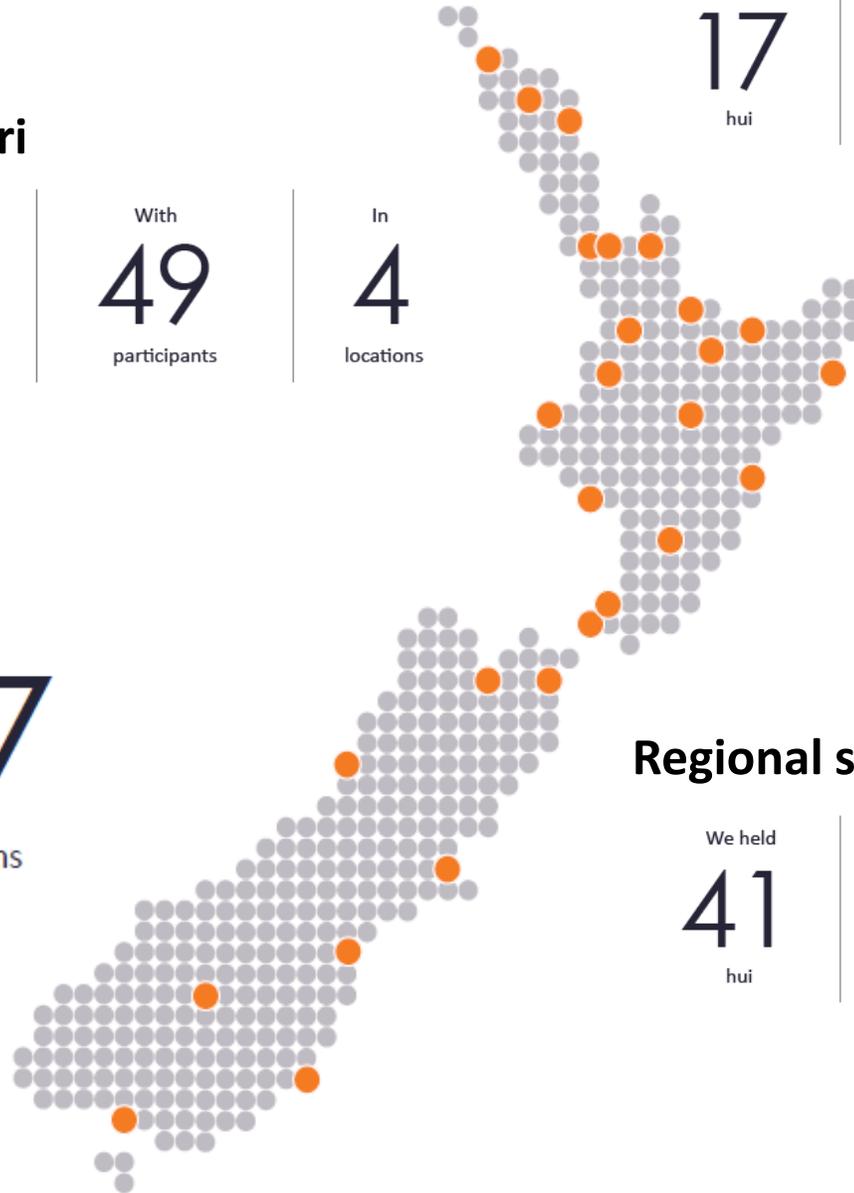
Policy Principles: articulate the values and behaviours that underpin the respectful and transparent use of people's data across the social sector.

He tāngata — Focus on improving people's lives - individuals, children and young people, whānau, iwi and communities

Strive to create positive outcomes from any collection, sharing or use of data and information. Use appropriate checks and balances and ensure that information is suitable and reasonably necessary for the intended outcome.

Mana whakahaere — Empower people by giving them choice and enabling their access to, and use of, their data and information

Where possible, give people choices and respect the choices they make. Give people easy access to and oversight of their information wherever possible.

Manaakitanga — Respect and uphold the mana and dignity of the people, whānau, communities or groups who share their data and information

Recognise and incorporate diverse cultural interests, perspectives and needs. Include and involve services users whenever possible. Incorporate the needs and priorities of people with a special or particular interest in what is done with their data and information.

Mahitahitanga — Work as equals to create and share valuable knowledge

Confidentially share relevant information between professionals so people get the support they want and need. Make sure there is a two-way street of sharing (de-identified) data, analysis, results and research findings to grow collective knowledge and improve services.

Kaitiakitanga — Act as a steward in a way that is understood and trusted by New Zealanders

Recognise you are a kaitiaki, rather than an owner of data and information. Be open and transparent; and support people's interest or need to understand. Keep data and information safe and secure and respect its value.

Policy Guidelines: describe good practice in undertaking key activities in accordance with the five Principles above.

Purpose Matters

Be clear about the purposes of collecting personal information, only collect what's needed, and consider how collection and use could affect people's wellbeing.

Transparency and Choice

When collecting information from people, help them understand why it's being collected, how that might help them or people in similar circumstances, and what rights they have to access and request changes. Provide them with choices whenever possible.

Access to Information

Help people to understand what personal information is held about them, to access it, to request correction of it and, where possible, to correct it themselves.

Sharing Value

Work together and be inclusive to ensure that information used to create insights is relevant and usefully describes real experiences. Share insights that deliver value and improved wellbeing.

Principles

He tāngata

Focus on improving New Zealander's lives – individuals, children and young people, families, whānau, iwi, aiga and communities.

Rangatiratanga

Empower people's choices and enable access to, and use of, their data and information.

Mahitahitanga

Work as equals to create and share valuable knowledge.

Manaakitanga

Respect and uphold the mana and dignity of the people, whānau, communities or groups who share their data and information.

Kaitiakitanga

Act as a steward in a way that is understood and trusted by New Zealanders.

Guidelines

Purpose Matters

The vital importance of purpose to collecting and using people's personal information

- Be clear about the purposes of collecting personal information, only collect what's needed, and consider how collection and use could affect people's wellbeing.

Access to Information

Make it easy for people to access and correct their information

- Help people to understand what personal information is held about them, to access it, to request correction of it and, where possible, to correct it themselves.

Transparency and Choice

Enable people to understand what's happening with their information and what choices they have

- When collecting information, help people understand why it's being collected, how that might help them or people like them, what rights they have to access and change it, and provide them with choices whenever possible.

Sharing Value

Work together for better insights and outcomes

- Be inclusive when developing new insights so that they're based on rich experiences, and used and valued by agencies working in related areas.

Understanding social license

Public deliberation on data linkage for research in Canada

- Seeking to join health and social data across the country for research purposes

- Using an approach called Public Deliberation to understand what social license they have for this approach
  - ~30 participants brought together
  - selected for diversity within the group
  - receive varied presentations on aspects of the issue(s) to be considered
  - goal is to deliberate on issues to reach collective statements or policy recommendations that accommodate their diverse views
  - A way of getting detailed public input into the development of rules and policies for data use(s)

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