Data Ethics Governance Workshop Summary – 15 June 2017

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Change happening

The nature of research: from individual control and consent to constant observation and real-time service provider access to data, with future data uses unpredictable

Blurring of boundaries: between 'public and private' and 'research and operational' use within a highly fragmented data ecosystem

Control: be strategic about where we try to intervene in data pathways and when to attempt to exert control

Ethical challenges: increased data volume, greater data linkage and decreased entry costs for research present risks to protecting privacy, maintaining research quality, and meeting an agreed 'public good' use criterion

Consensus on consent: increasing conflict about the role of consent – a primary ethical value or an artefact requiring reinvention?

Ethical issues identified

People-centred approach: 'Nothing about us, without us'
- Data users should ask: Where is the human in the data? What would this data use look like from the data subjects' perspective?
- The most vulnerable New Zealanders have the most data produced about them but the least capacity to influence the resulting narrative
- Focus on defining the 'public good', taking account of different perspectives, power asymmetries, and opportunity for participation
- Iterative cycles of consultation with stakeholders are essential

Kaitiakitanga: Māori Data Sovereignty
- Māori Data Sovereignty refers to the idea that Māori data is subject to the rights articulated in the Treaty of Waitangi. Māori data is a living tāonga and should be subject to Māori governance.
- What data arrangements (collection, storage, use and interpretation of data) will best serve the interests of Māori? Who has the authority to answer this question?

Trust and transparency
- Governance structures should improve transparency and enable public trust in data use
- Government policy regarding data use appears to be moving ahead of the public conversation and social and cultural 'licence'
- Transparency is particularly important in the absence of consent – it can support accountability for government data use, facilitate public debate and critique and improve knowledge sharing
- Considerable interest in a cross-sector Data Ethics Review Committee

Actions required

Principles: develop common ethical principles to underpin data use and governance processes

Integrated review: a cross-sector data review committee to provide advice on data use for research, service provision, data linking, and sharing data (with the private sector or internationally)

Expertise and training: increased knowledge of data research methods (possibilities and limitations); *and* increased knowledge of data ethics, especially issues regarding bias and stigmatization for data users. Stronger awareness of Māori data sovereignty for everyone

Focus: more attention to collective interest – community benefit, profiling, access to data

Transparency: enhanced information on public and private sector use of personal data. Publish minutes of government data ethics committees

Next steps:
- 2-page framework of key ethical issues
- Day-long training workshop
- Work on transparency as an ethical tool
- Contribute to consultation on the Statistics Act 1975 review
- Explore idea for cross-sector Data Ethics Review Committee