Introduction to Data Ethics in New Zealand

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The data ecosystem is fragmented and complex, with data increasingly being re-used, re-purposed, linked and shared in novel ways. Data can include personal and sensitive data such as health data, as well as data about businesses and the environment. This paper presents some of the ethical and tikanga considerations that should inform and guide data use.

Law prescribes what agents *can* do and the State enforces the law through various mechanisms including punishment. **Ethics** prescribes what agents *should* do. Ethics is *normative* – is makes a claim about what the morally correct course of action would be, and attributes praise or blame. **Social licence** describes whether a given data use is accepted by the public, affected community members and other stakeholders. **Cultural licence** here refers to whether given data uses are acceptable to Māori and iwi. In a pluralistic, multicultural society such as New Zealand, there will be different views on acceptable data use. Moreover, the parameters of the social licence will change over time. Often the limits of the social or cultural licence only become apparent after the boundaries have been crossed.

When law regulates areas of high speed change, practice can outstrip the regulatory framework. Data use may be within the parameters of the law, but may nonetheless be unethical and/or outside the social licence. *Ideally we want to align the social licence, ethics and the law to ensure that data use is publicly acceptable, normatively justified and legal.* Where there is misalignment of the law, ethics, and the social or cultural licence, data users need to carefully consider whether the proposed data use is justified and on what grounds.

Trust is the belief that a person or an institution is reliable, good, honest, and effective. Once lost, trust can be hard to regain. Public trust is important for the success of many government policies, programmes and regulations that depend on the cooperation and compliance of citizens (for example, by honestly disclosing information to public sector agencies). Building and maintaining trust underpins sustainable and effective public data use.

Autonomy means self-rule, and is the capacity and right of individuals and groups to make their own choices. Valid consent must be voluntary (free from coercion), informed, and offered by someone with capacity to make the decision. Getting consent at the point of data collection is often problematic because the future uses of data are often unforeseeable. Models of consent for data use include:

1. Specific consent – consent is given to a nominated data-recipient, for a clear purpose, often within a specified time frame.
2. Dynamic consent – a personalised, digital communication interface that enables two-way communication between data-subjects and data custodians where data subjects can authorise new uses of their data.
3. Broad consent – consent is given for future unspecified uses of the data, sometimes with limits (e.g. 'any research on diabetes') and sometimes without limits (e.g. blanket or open consent). Broad consent is typically given to a custodian or governing body of the data, allowing them to decide how to use, share and link the data in the future.
4. Opt-out consent – data subjects are informed about potential uses of their data and given a window of time to withdraw their data.

Privacy is linked to autonomy; privacy rights allow an individual or group to control access to, and use of, personal information. An intrusion of privacy is an intrusion into someone's personal space. A privacy impact assessment can help agencies identify potential risks arising from the collection, sharing and/or use of personal data.

Much public sector data use occurs without the consent of data subjects and is justified instead on the grounds of public interest. **Beneficence** means acting in the public good; it includes all actions which are intended to promote

the good of other people. Sharing and using data can be in the public interest when it facilitates socially valuable research.

Kaitiakitanga means guardianship and protection. Identifying when data use is in the public interest is complicated and communities will disagree. Communities can be determined for example by geography, ethnicity, religion, culture, service use, health status or disability. The Data Futures Partnership suggests that active engagement with community representatives is necessary when the data use is: (1) novel for that community and would therefore be outside the community's expectation of potential data uses; (2) has substantial impact on whānau, hapū, iwi or Māori communities; or (3) has a substantial impact on low-trust communities.[1] Māori data sovereignty refers to the idea that Māori data is subject to the rights articulated in the Treaty of Waitangi. Some have argued that Māori data (including data about Māori, data used to describe Māori collectives, and data about Te Ao Māori) is a living tāonga and should be subject to Māori governance.[2]

Non-maleficence (harm minimisation) means data collection, storage and use should be designed to minimise and manage risks of harm. Data can be used to characterize the behaviour of communities and to inform the delivery of future public services. The potential harms of data use therefore apply not only to the data subjects, but to other members of the identified community or people connected with them. For example, data can be used to stigmatize or discriminate against individuals or groups. In order to re-purpose data safely and effectively, researchers need to understand the nature and limitations of the source data and account for any biases, inequalities and/or distortions present in the source data. Failure to do this can lead to erroneous conclusions, which carry the risk of harm to communities if these false claims influence public service delivery. De-identifying data helps mitigate the risks to individuals but does little to address these risks to collectives.

Mana (justice and equity): requires that data users ensure that the benefits of their research are achieved through just means; and that the benefits and burdens are fairly distributed between individuals and communities. Data is used to tell stories to help us understand the world. This process is never ethically neutral; narratives always have embedded cultural values and ethical assumptions. The most vulnerable members of Aotearoa New Zealand often rely on multiple government services, experience the greatest surveillance of their activities, and therefore have the most data produced about them, but also have the least capacity to influence the narratives that are drawn with this data and the resulting policies and practices. **Manaakitanga** (cultural and social responsibility) requires that data research be conducted with respect for all people involved. Data users should ask: Where is the human in the data? What would this data use look like from the data subjects' perspective?

Citizens often have little understanding of how their data is used by public sector agencies. When the data use occurs without the data subjects' consent and is justified on the grounds of 'public interest', the arguments in favour of **transparency** and openness are especially compelling. Transparency can help build public trust, strengthen the social licence, ensure accountability and facilitate public debate. Data-users should consider how they can make the uses, potential benefits, harm-mitigation strategies, level of security and encryption, research results, and coding/algorithms accessible to others outside the team and to the public; and articulate the kaupapa (guiding philosophy) and justification for data use. Protecting the reputation of the data users or proprietary interests in controlling the data should not outweigh the public interest in transparency.

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[1] Data Futures Partnership (2017) *A Path to Social Licence Guidelines for Trusted Data Use* https://trusteddata.co.nz/wp-content/uploads/2017/08/Summary-Guidelines.pdf

[2] You can find more information here: Te Mana Raraunga https://www.temanararaunga.Māori.nz/