

Privacy, Ethics and Information Sharing of New Zealand's Integrated Data Infrastructure (IDI): A discussion of the issues, challenges and opportunities

Atkinson, J¹

¹University of Otago

Introduction

New Zealand's (NZ) Integrated Data Infrastructure (IDI) has rapidly expanded since our 2016 IPDLN conference update. Researchers have available a wide range of administrative and survey data. Even major earthquake damage to a Statistics NZ building in late 2016 has not halted progress with expanding the IDI and its usage.

Objectives and Approach

To provide an update on the current state of the IDI and its use by the NZ research community.

To highlight some key areas that need further discussion because of the IDI's rapid growth, especially concerning :

- **Privacy, regulation and governance:** how to make progress within appropriate regulatory constraints, especially around maintaining confidentiality, data sovereignty, data ethics and data security.
- **Capacity building:** what are the best ways to build multidisciplinary skills for new IDI users, share code and knowledge and what types of networking options work best?
- **Cross-sectoral data linkage:** to maximise the value of the IDI.

Results

In the last two years there has been a rapid expansion of external datalabs with access to the IDI (now around 33) and with the number of researchers using these datalabs (around 650). This has resulted in many useful research outputs; but it has also highlighted some areas that need more consideration including:

- **Data sovereignty:** NZ needs to ensure a strong role of Māori (Indigenous NZers) in data governance to ensure that IDI data are used to maximise reduction in health and social inequalities.

- Options for assisting new IDI users and exploring the best ways of sharing code, knowledge and networking.
- To maximise value there needs more focus on use of cross-sectoral data linkage (to better understand the impact of social determinants on long-term health).

Conclusion/Implications

There has been rapid expansion of the scope and use of the IDI in New Zealand. But to ensure the continuation of the success to date, even more attention needs to be paid to such issues as data governance and data protection.

