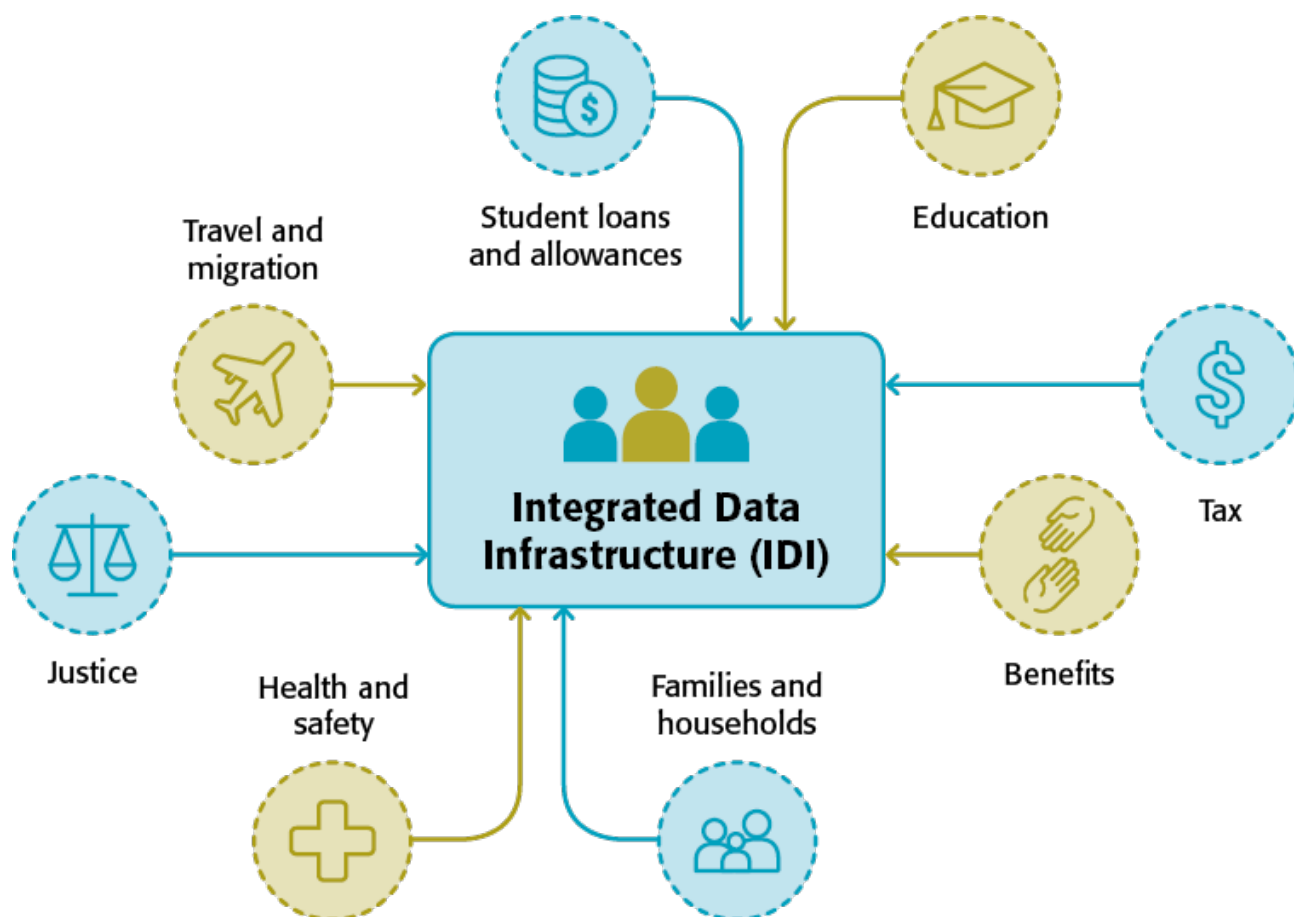# Open data, transparency and power – role of the Virtual Health Information Network

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The NZ Government is showing strong leadership on data sharing. In this blog we describe some of the opportunities and the challenges in this new data environment. We focus on how the Virtual Health Information Network (VHIN) can contribute to stronger health research and therefore benefit the health of all New Zealanders. The VHIN is a network of health data users, especially in the Statistics NZ Integrated Data Infrastructure, looking to support each other and improve the quality of 'big data' research in NZ. We highlight the benefits of VHIN membership and how you can contribute.

The diagram shows various data sources feeding into the central "Integrated Data Infrastructure (IDI)": Travel and migration, Student loans and allowances, Education, Tax, Benefits, Families and households, Health and safety, Justice.

Value and opportunity

NZ is uniquely positioned to capitalise on linked health data. The Government has set a clear direction to increase the availability of data to improve decision-making, service design and data driven innovation. Statistics NZ (Stats NZ) has a tagline; unleashing the power of data to change lives. The expansion of health data in Stats NZ's Integrated Data Infrastructure (IDI) has provided the necessary infrastructure for researchers and analysts to access NZ health data safely and more readily. In addition, the IDI links health data to the 2013 Census, a number of Stats NZ surveys and data from a range of government agencies and non-government organisations. The IDI is a large and growing research database containing data about people and households. It holds over 166 billion 'facts' and takes up 1.22 terabytes of space. There are currently 117+ research projects using the IDI, and at least 28 of these are focused on health.

Data protections

The IDI is distinct from the operational data used by government agencies and health care providers for the provision or targeting of services. In the IDI, individual people's data (microdata) are de-identified (personal information such as names and addresses are removed), and output from the Data Lab is confidentialised, so no one can be identified. Access to data is only provided to bone fide researchers who have undergone confidentiality training. Researchers undertake their work in a secure Data Lab environment with access only to the data relating to their approved research project. IDI projects must demonstrate a benefit to the public. Data are protected under the Statistics Act 1975 and the Privacy Act 1993.

Issues about capacity and inequality

Concerns about big data have been raised and are relevant to the IDI. We as a country are small in scale and especially the group of people with the analytical ability to capitalise on NZ health data. There is a significant risk that limited capacity will confine the access to IDI data to a select few, thus limiting public benefits, and unfairly distributing any benefits that are realised, with potential increases in social and health inequalities. Without active engagement with Indigenous peoples, academics have warned of the risk that big data will exacerbate ethnic inequalities (1). Robust Māori governance partnership is required, along with consistent ethics processes and greater public awareness about the IDI. There is an ongoing need for public discussion on what research is appropriate using IDI data; sometimes referred to as a 'social licence'.

Data sharing

NZ is not a big enough country to rely on a competitive model, with separate groups getting their own funding from competitive sources without sharing analytical code and knowledge. The NZ research and analytical community has a culture of collegiality and sharing that we need to nurture. We need to share code, share learnings, and help each other if NZ is to yield maximal returns for research and policy from our linked data. Last month, the Government Statistician came out strongly to promote the default sharing of research findings, code and tables from microdata projects. The benefits from data sharing include greater transparency, accountability, and it stimulates development of communities of interest where researchers can work collaboratively, avoid duplication, and build capability. The VHIN is an excellent example of a community of interest for IDI users doing health research.

VHIN

The VHIN is a growing network of researchers, analysts and other professionals that share and collaborate in order to enhance health research outputs and improve health service delivery and health outcomes in NZ. As well as being about data sharing and collaboration; the VHIN aims to improve analytical capacity and support improvements in the quality of IDI research. A deeper understanding of the IDI and increased awareness of data quality issues is promoted on the VHIN website, and also through online discussions on the VHIN Facebook group, shared code from VHIN research and meetings that bring researchers together to discuss current IDI research. As a network that includes universities and academics doing IDI research, the VHIN brings analytical rigour to analysis and research methods. Conceptualisation of research questions should align with existing knowledge in the literature, an understanding of local context, and an appreciation of the potential biases in IDI datasets and in how they were collected. Data points are not some golden truth with inherent objective properties, but are set within the confines of past and present definitions and data collection methods.

Becoming a member

If you are a researcher who is new to the IDI, you can contact the VHIN (vhin@otago.ac.nz), visit the VHIN website and join the VHIN Facebook group to ask questions and seek some help to get started. You can find website resources that may help you such as how to understand the IDI, how to estimate the NZ resident population in the IDI, income measures and look at analytical code from previous VHIN research. Become a VHIN member by joining the Facebook group, connect with other VHIN members, and find out about workshops and events and newly available resources.

A strong sense of collegiality and reciprocity is a key feature of the NZ research environment and the VHIN. VHIN members are expected to contribute and help others by sharing code (eg, in the IDI wiki), sharing learnings, answering queries from others on the Facebook group, and sharing links to workshops and information that other VHIN members may find helpful. If there is a topic you would like to see covered on the VHIN website then please email us about it at – vhin@otago.ac.nz.

Mini-case study: an earthquake and cardiovascular disease

The VHIN has been an important resource for the *Healthier Lives* National Science Challenge project that examined the impact of the Canterbury earthquake damage on cardiovascular disease (CVD). The project utilised analytical code that was already available from earlier VHIN catalyst research projects to identify the NZ residential population and define cardiovascular hospitalisations. The project also benefited from the expertise of other VHIN researchers and members who helped give an understanding of the IDI and the various datasets it comprises. This was crucial when using the IDI for the first time.

Subsequently in return, the earthquake analysis will contribute back to the VHIN through code sharing, providing information to other IDI users, posting information on the VHIN website, presentation of results at workshops and publishing in a peer reviewed journal. Ultimately this type of research will support health authorities to respond more effectively to the health needs of communities that are hit by natural disasters in New Zealand and abroad.

Conclusions

The IDI provides an excellent opportunity for health researchers and the wider research community. Improvements in analytical capacity and capability of IDI users can contribute to greater benefits for all New Zealanders. Data sharing is a key step in this direction and the VHIN is an excellent example of a collaborative community that promotes data sharing, networking, and quality health research in the IDI. Interested researchers can join the VHIN

[Facebook group](#) and see the [VHIN website](#) for more information.

References

1. Zhang X, Pérez-Stable EJ, Bourne PE, Peprah E, Duru OK, Breen N, Berrigan D, Wood F, Jackson JS, Wong DWS *et al*: BIG DATA SCIENCE: OPPORTUNITIES AND CHALLENGES TO ADDRESS MINORITY HEALTH AND HEALTH DISPARITIES IN THE 21ST CENTURY. *Ethnicity & Disease* 2017, **27**(2):95-106.

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