Virtual Health Information Network (VHIN) Charter

29 November 2016

Introduction

The Virtual Health Information Network (VHIN)

New Zealand has some of the best uniquely identifiable health data in the world, but more can be done to realise the potential of this data. The VHIN is a network of researchers, analysts and other professionals who use health data to generate insights that support the health and wellness of all New Zealanders. The overall aim of the network is to facilitate sharing and collaboration amongst network members in order to enhance health research outputs and improve health service delivery and health outcomes in New Zealand.

The implementation of the SNZ Integrated Data Infrastructure (IDI) has provided the necessary infrastructure for researchers and analysts to access NZ health data more efficiently and, in addition, health data are linked to social and economic data. The VHIN aims to create an environment that maximises the value of the IDI, as well as facilitate analyses on large datasets external to the IDI.

In January 2016 the VHIN, in conjunction with the Australasian Epidemiological Association and the University of Otago, held a workshop that was attended by over 100 participants. Discussions at the workshop indicated a need to clarify the role of the VHIN and the benefits and expectations associated with VHIN membership, and importantly to develop, and consult, on the 'modus operandi' of any such VHIN, i.e. what this Charter attempts to articulate. It was agreed that VHIN members should play a key role in the process of developing this Charter.

Purpose of this 'Charter' document

This document outlines the vision, goals, and structure of the VHIN, and expected deliverables. The enclosed operating principles outline the advantages of VHIN membership, and expectations of members about their contributions to the network. These principles were established by the VHIN executive following consultation with and feedback from current and prospective VHIN members.

The VHIN has been established primarily for publically funded research and services agencies and not for private industry (e.g. pharmaceutical companies). Nonetheless, meta-data and code produced by the VHIN and archived through Statistics New Zealand's MeetaData platform will be available to all agencies which are granted access to the SNZ MeetaData platform which may include private industry or consultancy firms.

Charter

Vision for the Network

To create and sustain an environment that captures value from health data collections and related social and economic data, through world-leading health research, policy development and service planning.

Goals of the Network

- To **increase the quantity and quality of health information** arising from analysis and linking of New Zealand's large health-related and social sector datasets.

- To support the growth of New Zealand's capacity and capability to create and use information from large integrated datasets, by **increasing the number of individuals with appropriate skills**,.

- To **create an environment of open sharing,** as much as possible, of expertise, analytical products and research outputs that will encourage academics and analysts to work together to deliver health outcomes more effectively and efficiently.

- To **improve health outcomes and health service delivery** in New Zealand, and contribute to implementing the New Zealand Health Strategy, through an enhanced evidence base for policy and decision making.

Value and benefits of the Network

The network will deliver significant value at three levels.

i. Personal value: what will those engaging in the Network get from it?

- Collegial support from like-minded professionals.

- Opportunity to share with and benefit from the expertise of others.

- Better meta-data and code for administrative health and related data, leading to more competitive and efficient research grants, and more productive research.

- Simplified professional networking, through easier reach to a range of colleagues.

- Developing cross-disciplinary teams

- Facilitating researchers from non-health disciplines to be introduced to health research and data

ii. Organisation value: what will the organisations either participating in or using the Network gain?

- **Products created** (i.e. metadata, code, derived variables) through the Network will deliver more efficient and effective ways of carrying out business as usual, or create pathways to novel approaches and solutions.

- **Costs reduction** through economies of scale and through sharing amongst Network participants of intermediary and output datasets for reuse thereby reducing duplication.

- **Cost effective analytic services** through access to potential VHIN consultancy services, and general network support.

- **New research collaborations** will develop, and members will have access to colleagues beyond traditional disciplinary boundaries.

- Increasing **consistency and quality of health research** methods.

- Closer **ties between researchers, policy developers and service planners** improve the implementation of fit-for-purpose, evidence-based research.

iii. Value for New Zealand.

- **An enhanced evidence base** to support policy development and service planning, thereby reducing inequalities, improving health and well-being and delivering better targeting of resource allocation within the health sector.

- **Assisting New Zealand to be positioned as a leader** in creating and using information from large integrated datasets for health research, service planning and delivery, and policy development.

- **Enhanced capability and capacity** to analyse large health datasets (at lower cost).

- **Better population health outcomes.**

Network commitment to Treaty principles

The Network will apply the Treaty principles of partnership, participation and protection in realising its vision and goals. This will involve the support of activities that increase Māori participation in, and benefit from, existing as well as future health data resources and research methods. The Network will work with Māori interests (including iwi mandated interests) in health data to improve the responsiveness of the health data system in informing Māori health development as defined by Māori.

Network Structure and Governance

The Network membership is distributed. Members work in their individual institutions. Individual autonomy of members is retained. Collaboration and sharing are achieved through a mix of online interactions, symposia and periodic face-to-face meetings.

Executive

The Network is governed by an Executive committee. During the start-up phase, membership of the Executive was drawn from the partner organisations (Massey, Auckland and Otago universities, and the Ministry of Health) and an additional Māori representative. Representation reflects the relative contributions of the founding partner organisations.

In addition, the Executive is supported by a core team consisting of management, operational support and analytical members.

Strategic decisions for the Network, about how the Network is structured, or functions, should be made jointly by participants where possible. Where consensus is not possible,

decisions will be made by majority vote of an Executive group representing the wider Network.

Membership

Membership will be open to publicly funded researchers, analysts and other professionals whose work requires use of health data. This will include individuals working for government organisations and universities, and may also include individuals working for Iwi, NGOs, and other not-for-profit organisations. Organisation membership will be open to organisations operating with a public good mandate and which see the value of improved use of health information. Individual and organisational membership is free and members can withdraw their membership at any time. All members must be approved by the Executive (or delegates). As indicated above, there is an expectation that network members will share as much as possible their metadata, code and other expertise..

Operating Principles

Expectations of individual members

Participants in the Network acknowledge that they will work together and support the creation of capability, tools and products that make the derivation and application of information from large health-related datasets more effective and efficient.

- Network members agree to use processes for sharing of information and resources for mutual benefit as much as possible, and share rewards, risks and responsibilities. Specifically, Network members are expected to share as much as possible their metadata, code and other expertise if they are to enjoy access to other Network members' expertise; that is Network membership involves reciprocity.

  Some examples of how members can share expertise:

  - Contribute code to the SNZ MeetaData, or if for work outside the SNZ IDI to a VHIN web-archive with member only access.
  - Contribute derived variables.
  - Contribute subject matter expertise to fellow members' projects – about datasets, about methodologies.

- Members will recognise the assistance provided by other Network members by citing specific Network resources that their work has benefited from.

- Code and derived variables will be clearly documented and will comply with the standards specified by the Network [see coding standards reference- to be developed].

- Members will make time available to support the work of other Network members on request (within reason).

- Participation in the Network will not inhibit the work of individuals or organisations, rather the Network should enhance their work.

- While the Network has a distinct way of operating, participants and partner organisations retain their distinct identity, autonomy and integrity.

- Members must comply with the data policies of data custodians e.g. Ministry of Health Data Conditions, Statistics New Zealand Microdata Access Policy.

Intellectual property

The VHIN is a forum for sharing and collaboration. It is intended that all code, cohorts, derived variables, programmes and other materials (together "VHIN Materials") will be contributed by VHIN members and made available to other VHIN members free of charge or any other encumbrance. Any VHIN member will be able to reproduce, use, modify and distribute any VHIN Materials. Any modifications of VHIN Materials must be clearly marked. Any use of any VHIN Materials for any purpose must only be done with the appropriate acknowledgement and attribution of all contributing authors.

Of note, VHIN outputs placed on SNZ's MeetaData platform are available to anyone given access by SNZ, VHIN member or not.

In no event will any author, copyright holder be liable to for any damages arising out of the use or inability to use VHIN Materials.

At the time that any materials are contributed to the VHIN, the copyright owner(s) will need to agree to a licence which reflects the principles outlined above.[1]

Network funding

The VHIN requires ongoing funding to pay staff salaries and other operational costs. Core research funding is currently sought to cover these basic costs.

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[1] One possibility is a GNU General Public Licence 3.0, full details of which are available here http://www.gnu.org/licenses/gpl-3.0.en.html.