

PHRN Fact Sheet on Governance of Linked Data

WHAT IS GOVERNANCE?

Governance refers to who has the authority to establish, manage, monitor and review the Data Linkage Units, and how they will do this. It includes all the structures, rules, laws, processes, policies, systems, and controls that are used to safeguard the Data Linkage Units, participants and researchers.

Management involves the day to day running of the Data Linkage Units to achieve its goals. This can be done by a person or a group of people (e.g. a Board or Committee). Managers should follow approved scientific and ethical guidelines and financial regulations.

The PHRN is governed by a Management Council comprising a nominee from each PHRN node, a nominee of the Commonwealth Department of Health and Ageing, two researcher members and is in the process of appointing a health consumer representative. The Management Council is supported by a number of specialist committees including an Ethics, Privacy and Consumer Engagement Advisory Group, an Access Committee and an Operations Committee.

Oversight (monitoring and review) involves checking that the Data Linkage Unit and researchers are actually following guidelines and regulations. This is done by a person or a group of people (e.g. a Board or Committee). There can be different levels of oversight, such as:

- Scientific – is the linked data being used for ‘good research’?
- Financial – does the Data Linkage Unit have funds to continue as planned?
- Ethical – what benefits or harms (if any) have resulted from the linked data?

The financial activities of the PHRN nodes are monitored by the Network’s major funding body DIISR (Department of Innovation, Industry, Science and Research), through regular reporting requirements. Human Research Ethics Committees (HRECs) will consider the ethical issues required to be addressed for the linkage of data to core demographic datasets held by PHRN nodes as well as for each national data linkage project. Data Custodians and PHRN Client Services staff will evaluate each project’s scientific merit.

Legislation is the law passed by Parliament. These laws lay down the broad rules that direct or control activities. State and Federal governments have developed some legislation about privacy. At present, there are privacy laws for the collection, storage and use of data, such as personal health information.

Regulations are a type of legislation called ‘secondary legislation’. They deal with the details of the matters set out in the primary legislation (i.e. the legislation passed by Parliament). Regulations are made by the person(s) given this responsibility under the primary legislation.

Guidelines have no legal standing and no legal punishments if they are not followed. They are developed by people with specific expertise.



Data that will be used for PHRN national linkage projects is governed by a variety of legislation that can be grouped into a number of categories including privacy legislation, legislation empowering the collection, use and disclosure of administrative data collections, criminal legislation and the common law. National linkage project applications are not approved until the PHRN is satisfied that all linkage and research activities will be performed in compliance with all relevant legislation and associated regulations and guidelines.

Policies set out procedures or steps for a particular action or task. Policies are not legally binding. They are more recommendations and usually apply only to the organisation that develops them (e.g. a research institute or individual Data Linkage Unit). The PHRN has an agreed Policy Framework that has been endorsed by participants. Key policies that have or will be developed include Access and Pricing, Consumer/Community Participation, Complaints, Incidents and Breaches, Information Security and Privacy.

The PHRN has an agreed Policy Framework that has been endorsed by all participants. Key policies that have or will be developed include Access and Pricing, Consumer/Community Participation, Complaints, Incidents and Breaches, Information Security, Privacy and Ethics and Scientific Review. Each PHRN node is required to have its own set of policies and related procedures and guidelines that are consistent with the national PHRN documents and meet the expectations of their host institutions.

PHRN GOVERNANCE



Node governance

Each PHRN node has formal governance structures in place. These reflect the organisational arrangements for each node. Linkage groups are either located within a state health department and directly managed through that process (Western Australia, Queensland and Victoria) or located at a university or institute (New South Wales/Australian Capital Territory, South Australia/Northern Territory and Tasmania).