

Research Australia response to the Health Identifiers Review

28 February 2023

Background

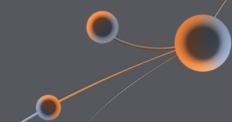
The Health Identifiers Review is being conducted by the Department of Health. The Department has provided a [consultation paper](#), with all submissions are to be made by electronic submission. The objective of the Review is to increase the usage of Health Identifiers in the health system.

Research Australia has responded to two questions in the survey. Responses to each question are limited to 500 words.) Research Australia is seeking an amendment to the Health Identifiers Act to explicitly permit Health Identifiers to be used when preparing datasets for research purposes.

Context- There are 3 types of health identifier:

- **Individual Healthcare Identifier (IHI):** IHIs identify an individual healthcare recipient for healthcare purposes. Each individual enrolled in Medicare (or the Department of Veteran Affairs) gets an IHI automatically. IHIs are also available on request to other healthcare consumers.
- **Healthcare Provider Identifier – Individual (HPI-I):** HPI-Is identify an individual healthcare provider (e.g., a doctor or specialist). A provider gets an HPI-I automatically when they register with the Australian Health Practitioner Regulation Agency (AHPRA). Members of other professional associations with certain characteristics can also apply for an HPI-I.
- **Healthcare Provider Identifier – Organisation (HPI-O):** HPI-Os identify a healthcare provider organisation (e.g., a doctor practice or a hospital). Organisations must register with the HI Service to obtain an HPI-O.

Research Australia's response to the survey questions is provided below.



Problem Statement 7 - Clarity around permitted uses and concerns about penalties

Are there areas of the Act, or supporting policy, that are unclear, confusing, or hard to interpret?

Research Australia Response

The consultation paper recognises the benefits that can be derived from using health identifiers for research. For example, *‘Widespread use of HIs will also increase researchers’ ability to connect and analyse large quantities of de-identified data on health outcomes and usage. The results of this research will guide planning and funding, for the benefit of all Australians.’* (page 9)

However, when it comes to research, at present the Act permits only a healthcare provider to use or disclose the healthcare identifier of a healthcare recipient (IHI), for the conduct of research that has been approved by a Human Research Ethics Committee. (Section 14, item 5) Furthermore, this disclosure is only to be made for the purpose of providing healthcare to a healthcare recipient. This provision is far too limited.

There are several problems with this provision. The first relates to the purpose- i.e. conducting research for the purpose of providing healthcare. While this might cover the use of a healthcare identifier of a healthcare recipient participating in a clinical trial (i.e. receiving health care), it does not appear to cover the situation where the research is for a purpose that does not involve providing health care. For example, it would not appear to cover the collection of patient data to understand trends in prescribing, the pathways of care experienced by patients with a particular diagnosis, or other research that does not directly provide care to the patient whose data is used.

The second problem is that it only applies to disclosing the identifier of a healthcare recipient. There is a range of circumstances in which data about health care providers and healthcare provider organisations would be useful for research purposes, including in the examples given above of research to understand trends in prescribing and pathways of care.

The third problem is the restriction on who can provide the health care identifier. At present, only the healthcare provider can do so. This does not support the broader types of research, where the provider of data could be the healthcare provider organisation, or the healthcare administration entity proposed by the consultation paper.

The consultation paper proposes creating a definition of a healthcare administration entity, and a definition of a **Healthcare administration purpose**: *An activity that relates to the management of:*

- *health information and services*
- *services that provide administrative, planning, research and policy functions related to healthcare.*

‘Research related to healthcare’ may be too narrow a definition. For example, will research undertaken in relation to simply understanding the incidence of a condition, or the prevention of a condition be considered as relating to ‘healthcare’?

It also seems that many organisations that undertake health and medical research, for example universities, medical research institutes and private companies, are unlikely to meet the definition of a healthcare administration entity, and yet these all can legitimately have a role in research that can use datasets of health information that are compiled, refined and/or linked using health identifiers.

General feedback

Research Australia Response

As the national peak body for Australian health and medical research, Research Australia welcomes the recognition that research can play a critical role in supporting the health system and improving healthcare.

Research is dependent on data and much of health and medical research is reliant on personal health information of individuals. In some cases, knowing the identity of the individual is necessary- for example, in a clinical trial. In many other cases, however, the identity of the individual does not need to be available to the researchers.

Deidentified datasets can provide insights into:

- The prevalence and impact of different conditions in the population
- The efficacy of different treatments, models of care and prevention strategies
- The factors affecting disease prevalence and progression in different groups (genetic, age, sex, occupation, ethnicity, socioeconomic status, geographic location etc.)
- Changes in disease prevalence and treatment success over time.

Researchers from universities, medical research institutes, publicly funded research organisations and the private sector are all engaged in research using (usually deidentified) health information, for the purposes outlined above. Often this research is funded by the Commonwealth Government and the datasets are frequently provided by government departments and agencies as the data custodian.

It is important that datasets used for research are as complete and accurate as possible. To this end, using Health Identifiers to collate, refine and link datasets created for research purposes can be critical. They will be even more critical in future if the objectives of the current review to make health identifiers more ubiquitous is achieved. In many cases it will be the data custodian (e.g. a hospital, government department or agency) that will be creating the dataset, or linking datasets. At the moment there is no broad authorisation for the use of Health Identifiers for this purpose, and effectively a prohibition on doing so for most research purposes.

Research Australia submits that the use of Health Identifiers (IHI, HPI-I and HPI-O) for research purposes should be explicitly included in the Act as a permitted purpose for the use of Health Identifiers.

This usage is separate from any consideration of when Health Identifiers can be made available to researchers for research purposes, or the question of what research should be able to use Health identifiers in this manner. In respect of Commonwealth Government agencies, the *Data Availability and Transparency Act 2022 (Cth)* provides a framework in

which the merits of data sharing for a particular purpose can be considered and parameters within which the data can be shared. These issues do not need to be addressed by the Health Identifiers Act. Enabling the use of Health Identifiers in the creation, collation, refinement and linkage of data for research purposes is sufficient.

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ABOUT RESEARCH AUSTRALIA

Established with the assistance of the Federal Government in 2002, Research Australia is the national alliance representing the entire health and medical research (HMR) pipeline, from the laboratory to the patient and the marketplace. Research Australia works to position Australian HMR as a significant driver of a healthy population and a healthy economy.

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our role:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes

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