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Australian Centre for
Health Engagement,
Evidence & Values

Exploring the Public Interest in and Social Licence for the Use of Linked Administrative Data in Therapeutic Development through a Scoping Review, Survey of Community Attitudes, and Hypothetical Case Studies

Large public sector datasets are a rich resource for service improvement, predictive analytics and new discoveries. Effective and appropriate use of large public datasets to support therapeutic development is one area of focus for Australia’s 2016 National Research Infrastructure Roadmap.

The Population Health Research Network (PHRN) commissioned the Australian Centre for Health Engagement, Evidence and Values (ACHEEV) to develop a clearer understanding of the public interest in and social licence for the use of linked administrative government data by private companies in Australia.

The research outlined in this report, and recent studies, suggest public support in Australia for sharing government health data with private industry is equivocal.

Building a stronger support base will require concerted and nuanced public engagement. Both government and the private sector will need to address the public’s lack of understanding and lack of trust in the ways in which agencies collect, share, protect and use their personal data. We will need transparent, interactive and informed engagement that takes into account the capacity for and barriers to engagement.

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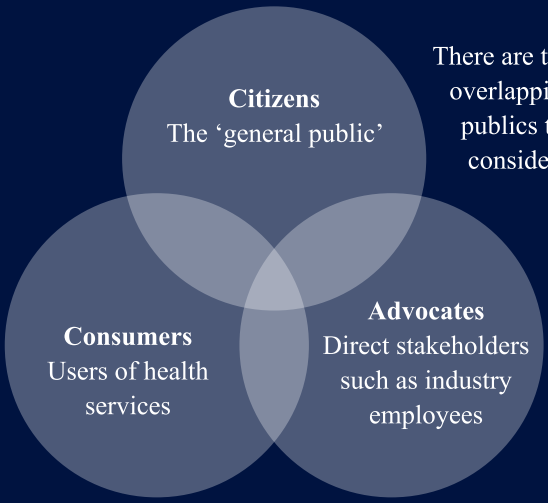
The public interest
A theoretical account

The public interest is broadly equivalent to the concept of public good or ‘goods for the public’. Claims that a case of data sharing is ‘in the public interest’ therefore need to do two things:

1. Describe the public or publics affected by data sharing.
2. Offer convincing evidence or argument regarding the balance of ‘goods’ and ‘bads’ that may result.



Citizens
The ‘general public’

Consumers
Users of health services

Advocates
Direct stakeholders such as industry employees

There are three overlapping publics to consider

Judging the public interest

Weighing research outputs and privacy protections is at the centre of public interest judgments.

In Australia, the guidance in the Commonwealth Privacy Act 1988 signals that data can only be released when the public interest in the conduct of research outweighs the public interest in privacy. It helps when doing this balancing to think about each of these goods in aggregative and corporate terms.

- Aggregative goods result from adding up all goods experienced by all individuals in a community
- Corporate goods concern the community as a whole; they arise out of the relationships that people have with each other in communities.

Health benefits for individuals arising from research using shared data.

Better health services and treatments in the future.

A culture that values confidentiality when people disclose personal information.

The privacy interests of all individuals.

What therapeutic development research conducted by private sector organisations might be in the public interest?

We combined interviews with private sector stakeholders and examples from the literature to develop hypotheticals to illustrate the ways in which government data might be shared with private companies for the purpose of developing new treatments for diseases and disabilities. The first of these hypotheticals is set out below.

An international pharmaceutical company wishes to bring its newly developed oncology drug to the Australian market. The drug extends life and has fewer side effects than existing drugs currently provided through the government-subsidised Pharmaceutical Benefits Scheme (PBS) for the same condition. The company approaches a Cancer Registry based in a State Department of Health with a request for aggregated, and therefore de-identified, data for which they will pay. They would like to have current treatment patterns in Australia, including by age of onset and additional treatments, and information on variations in care provision across Australia.

Patient data held in the Cancer Registry are collected, without patient consent, from pathology laboratories, hospitals, radiotherapy and medical oncology departments, aged care facilities and the Registry of Births, Deaths and Marriages. The data collection is authorised under an Act of Parliament.

The Cancer Registry provides the company with aggregate data which is sufficient for them to make a successful submission to have the drug funded through the PBS.

Community attitudes
An international perspective

From **6,788** initial articles we identified a total of **23** peer-reviewed papers, **7** reports, **2** conference proceedings and **1** conference paper which addressed community attitudes towards the use of government health data by private sector organisations for therapeutic development.

- No Australian studies
- International support for data sharing between 16% and 65%
- Lack of understanding of data uses in the health sector and data research in general
- Support for informed consent, with requirement for opt-in consent less important if participants in study had discussed issues with experts and deliberated at length
- Focus on need to build public trust

Concerns

Security

Data leaks, hacking, unauthorised use or disclosure, and being monitored.

Misuse

General unease about becoming a “transparent citizen”, stigmatisation, and disadvantages for vulnerable groups.

The nature of private companies

Lack of public accountability and profit motive.

Conditions

Research is of public benefit and in the public interest

Prevention of diseases, development and monitoring of new treatments, improved services for vulnerable groups.

Access to data is tightly controlled

Use of trusted parties, monitoring individual access, prohibitions on passing data to third parties, vetting organisations.

Data anonymised through de-identification and aggregation

Strategies to build trust

Reassurance that every effort was being made to keep data safe.

Security measures are well publicised and communicated to the public.

Public benefits communicated clearly.

Ongoing public engagement through individuals and organisations known and trusted by the public.

Community attitudes
An Australian survey

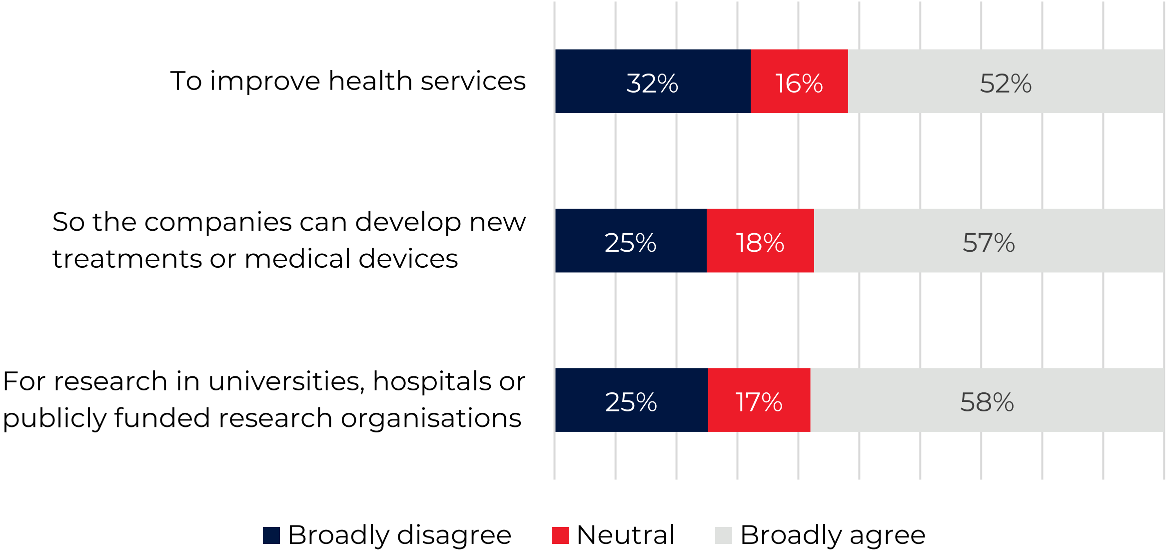
We surveyed 2,537 people online from across Australia during May and June 2019.

The gender split was roughly equal and most were in the 30-49 year age bracket, self-rating their health as good to excellent.

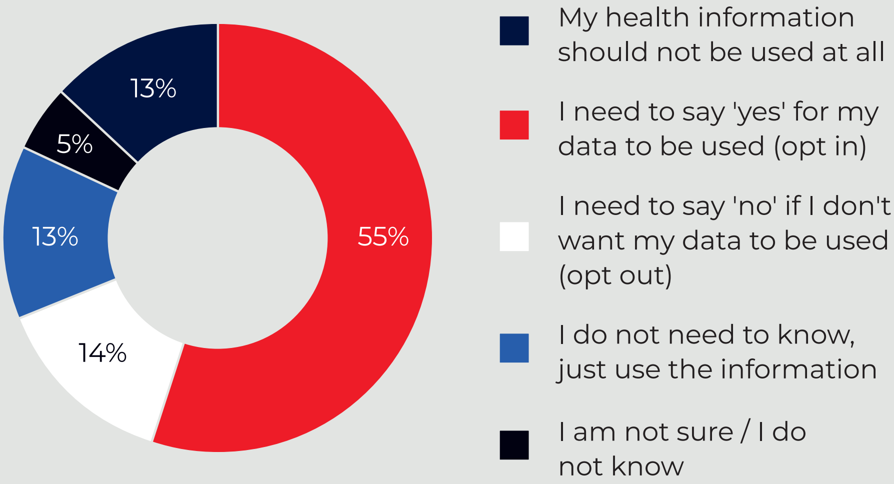
The majority lived in Metro areas such as Sydney, Melbourne and Brisbane.

Most had a University or Trade/TAFE education, were full/part-time employed and did not work in the health industry.

Willingness to share government health data



Consent preferences



Conditions on sharing

Over 80% support for:

- Knowing who has access
- Knowing how data will be used
- Publication of all results
- Approval by an ethics committee
- Research likely to yield benefits to society
- No third party sharing
- Safe storage
- Criminal penalties or heavy fines for violations