



The George Institute
for Global Health Australia

The George Institute for Global Health
Australia

Level 5
1 King Street
Newtown NSW 2050
AUSTRALIA
T: +61 2 8052 4632
www.georgeinstitute.org.au

12 March 2021

Senate Finance and Public Administration Committees
PO Box 6100
Parliament House
Canberra ACT 2600
fpa.sen@aph.gov.au

Dear Senators,

Re: Support for the Data Availability and Transparency Bill 2020 [Provisions] and Data Availability and Transparency (Consequential Amendments) Bill 2020 [Provisions]

The George Institute for Global Health welcomes the opportunity to make this submission to the *Data Availability and Transparency Bill 2020 [Provisions]* and *Data Availability and Transparency (Consequential Amendments) Bill 2020 [Provisions]* (bills) inquiry by the Senate Finance and Public Administration Committees.

The George Institute recommends the Senate support the passage of the bills. We believe they will mitigate risk and create opportunity for accredited users, that will most definitely include Australian health and medical researchers, to undertake research and development in line with community expectations.

In addition, The George Institute is pleased to outline as a case study our newly created online research register, [Join Us](#). It is a piece of national research infrastructure that securely stores de-identified health data over the long-term for ongoing health and medical research. The passage of the bills will benefit *Join Us* as a potential future accredited user, which will help Australia increase its global competitiveness as a location to do world class research.

Mitigate Risk

The passage of the bills by the Senate will mitigate risk, as it will regulate and control the release of data by the data custodian, the federal government agency responsible for the data. The George Institute understands there will always be risk in the storing, accessing and sharing of data.

Currently, there is no legislation that is of a similar nature to the bills in relation to the Australian Government held data being used to deliver government programs, services, research and development.

The passage of the bills will mitigate risk with:

- **Accountability** – it will ensure accredited users, such as health and medical researchers, to follow proper processes, principles and frameworks when using government held data;
- **Transparency** – it will provide best practice guidance of how accredited users, such as health and medical researchers, should evaluate the risks of using government held data; and
- **Independence** – it will create better decision making around the release of government held data.

In addition, the passage of the bills will help further manage and reduce any risks associated with potential data privacy breaches.

Create Opportunity

The passage of the bills by the Senate will create opportunity, as Australian health and medical researchers will most likely be accredited users with access to Australian Government held data. This access will allow for an even greater understanding of the patterns of disease and the impact of treatments, procedures and other factors influencing the health of the Australian population. Over time, this research will lead to overall better treatments, better care and healthier societies, creating opportunities that outweigh any risks.

The George Institute agrees with the Minister for Government Services second reading speech of 9 December 2021:

“Data sharing will give researchers the opportunity to collaborate with federal government agencies to solve problems and save lives, like when prescription data was shared safely with health researchers who identified five medications as potential contributors to heart failure and stroke. These insights enabled the government to work with doctors to change prescription guidelines, minimise adverse effects, enhance patient safety and avoid the costs of hospitalisation and treatment.”

Under almost all circumstances, researchers do not require data that includes an individual’s name and/or contact details. Researchers are interested in using de-identified data with the purpose health and medical information, which is in line with community expectations.

Case Study: *Join Us*: National Research Register

In 2020, The George Institute and the University of New South Wales (UNSW) Sydney developed [Join Us](#). It is a national research register designed to engage the Australian community in diverse forms of health and medical research. *Join Us* uses a similar approach to the [Scottish SHARE register](#) that has recruited over 282,000 people. The passing of the bills will allow *Join Us* to be potentially accredited users, that in turn will help Australia increase its global competitiveness as a location to do world class research.

Currently, patient recruitment is a major barrier to doing human research in Australia. Less than one percent of the population are ever involved in a clinical trial and only one in five trials meet planned recruitment timelines. Participant recruitment is repeatedly identified as a primary barrier to doing research in Australia.

Join Us will:

- consent Australians to be contacted about health and medical research projects relevant to them;
- ask permission to use participants' routinely collected health data to match them to the most appropriate projects;
- provide Australian researchers with a novel disease agnostic recruitment option for their studies; and
- seek to make better use of the wealth of routinely collected health data available in Australia.

Join Us will become a piece of national research infrastructure that will increase Australia's global competitiveness. It is hoped it will bring:

- Significant new efficiencies to the Australian medical research sector;
- Facilitate more research at scale; and
- Increase Australia's participation in multinational research studies.

To date, the initial development work has been done, start-up funding secured, ethics approval obtained and the *Join Us* website has been published online. We have signed on over 24 partner organisations, including the Consumer Health Forum of Australia, Research Australia, and the Victor Chang Cardiac Research Institute.

Join Us is designed to save lives by facilitating faster and more efficient health and medical research breakthroughs and increasing Australians' access to new treatments. The passage of the bills will benefit *Join Us* as a potentially future accredited user, which will help Australia increase its global competitiveness as a location to do world class research.

About The George Institute for Global Health

The George Institute for Global Health is a leading independent global medical research institute established 22 years ago and headquartered in Sydney, Australia. We have an international network of over 730 staff in 45 countries, with major centres in China, India and the United Kingdom. We are affiliated with the University of New South Wales (UNSW) Sydney and Peking University Health Science Center, and are in collaboration with Imperial College London.

Our mission is to improve the health of millions of people worldwide, particularly those living in disadvantaged circumstances, by challenging the status quo and using innovative approaches to prevent and treat non-communicable diseases and injury.

Contact

Please contact Matthew Cross, Head of Government Relations and Stakeholder Engagement if you require further information on 0402 155 372 or mcross@georgeinstitute.org.au.

Thank you for taking the time to consider our submission.

Yours sincerely,

Professor Bruce Neal
Executive Director
The George Institute for Global Health