THE UNIVERSITY OF
SYDNEY

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Senator Rachel Siewert
Chair, Senate Standing Committee on Community Affairs, References Committee
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Senator,

My Health Record System Inquiry

The University of Sydney wishes to register its keen interest in the Committee's review of the My Health Record (MHR) system. We do so as a large public institution of learning, deeply committed to improving patient care and community wellbeing by integrating world-class education and research throughout the health system.

We acknowledge the concerns some stakeholders have expressed about aspects of the design and implementation of the MHR system – including the adequacy of its privacy safeguards, access and use by government agencies and private firms, data quality, IT security and other system issues, the community education campaign, costs and administrative burdens for health care providers. We note, however, that even stakeholders who have been the most vocal in their criticisms of the MHR system, strongly support the underlying policy objectives of improving health outcomes and system efficiency through improved data integration, and by providing Australians with immediate access to, and control over, their health information.

We therefore believe that the Parliament's approach to the MHR system needs to strike an appropriate balance between ensuring public trust and confidence in our health record systems, and the potentially enormous benefits that could flow to patients, the community, health services, health care professionals and governments if we can improve the quality, accessibility, integration and availability of Australia's health data.

We note that the Community Affairs Legislation Committee is examining the *My Health Records Amendment (Strengthening Privacy) Bill 2018* concurrently. We are concerned to ensure that any legislative moves to restrict disclosure of MHR information to government agencies other than by our order or the healthcare recipient's consent, do not have the effect of preventing access to de-identified MHR data by Australian university researchers seeking to pursue research to improve patient and community health outcomes.

The value of the MHR data set for medical and health-system research purposes may not be significant at present, but its usefulness will increase over time – assuming the MHR system remains in place. In the short-term, from a research perspective, the real value of the MHR will come from the ability to undertake individual-level data linkage for all or selected populations.

A recently established example of this is the Scotland-wide Informatics Program (SHIP), a research platform for the collation, management, dissemination and analysis of anonymised electronic patient records.[1] Scotland pursues a strategic focus on certain cohorts of patients. For example, there is national surveillance of all who are diagnosed with diabetes, which provides patients and their health care providers with a dashboard of history, treatment, clinical features and investigation. This enables better clinical care and provides de-identified data for research.[2] Meanwhile, some Scandinavian countries have had access to whole-of-population health records for decades and they still set the benchmark for this type of research.[3]

Locally, the NSW Government-funded Centre for Health Record Linkage (CHeReL) is dedicated to helping researchers, planners and policy makers access linked health data about people in the NSW and the ACT. 'The CHeReL provides high quality data linkage services and has used data from the health, education, human services, justice and transport sectors to enable research and evaluation. Services are supported by the CHeReL's core record linkage system, which currently contains pointers to over 69 million records relating to more than nine million people, making it one of the largest systems of linked personal information from health-related databases in Australia.'[4]

Protecting the privacy of individuals' records is a critical consideration, but there are sound existing frameworks in place for de-identifying data and mechanisms such as the use trusted third party data custodians that can ensure re-identification is virtually impossible.[5] We believe that explicit provision should be made in the My Health Record Act to protect the future potential use of MHR for public good research where appropriate safeguards are in place to protect privacy and confidentiality. It is unclear whether under the proposed amendments to the Act, patients will, for example, be able to consent to the release of their data in de-identified form to government agencies (including trusted data custodians) explicitly for research purposes, or whether a court order will also be required for each individual release. If a court order is required, this is of significant concern as it would make it extremely difficult to for researchers to access data from the MHR in the future.

The MHR is by no means perfect, but it represents an improvement and offers new possibilities for linking up our fragmented and siloed health system, making the system easier for patients to navigate and enabling researchers to identify trends and correlations between better linked data sets. Patient health data is already collected through hospital and health provider data sets, the Pharmaceutical Benefits Scheme (PBS), the Medicare Benefits Scheme (MBS), the Australian Immunisation Register and the Australian Organ Donor Register. Many Australians are collecting increasingly sophisticated health and wellness data through personally-owned apps and devices that require integration with data collected during care delivery.

Integrating the MHR data together with these and other data sets for research – in ways that protect the privacy of individuals – will help improve our understanding of the causes of disease, their risk factors, the most effective approaches to treatment and how best to manage these for individual patients and at the population level. Arguably the greatest value of a functioning MHR system, however, will be in monitoring the prevalence and incidence of disease, thus enabling research into the planning and resourcing of the health system.

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[1] http://www.scot-ship.ac.uk/index.html

[2] http://www.sci-diabetes.scot.nhs.uk/

[3] See for example this Danish study of the safety of different arthritis medications is a great example: https://www.bmj.com/content/362/bmj.k3426.

[4] http://www.cherel.org.au/about-us

[5] See for example, Office of the Australian Information Commissioner: https://www.oaic.gov.au/agencies-and-organisations/guides/de-identification-decision-making-framework; and in the United States, the Health Insurance Portability and Accountability Act 1996, http://www.dhcs.ca.gov/formsandpubs/laws/hipaa/Pages/1.00WhatisHIPAA.aspx

This will be critical for the quality and cost-effectiveness of the health system as our population grows and ages, as patients' expectations about their standards of care grow and as future governments grapple with how to fund the system.

We draw the Committee's attention to the key findings Productivity Commission's recently concluded major inquiry into data availability and use, which singled out Australia's system of health data as exemplifying our missed opportunities to make better use of data to improve policy, deliver better services and outcomes. In relation to access and use of health system data set for research for example, the Commission found that:

- There is strong support in the Australian community for the use of health data in research; a recent survey conducted by Research Australia finding that over 90% of Australians were willing to share their de-identified health data to advance medical research and improve patient care.

- Access to health data can help policy makers and researchers to identify emerging health issues within communities and factors that contribute to particular medical conditions; assess the safety of pharmaceuticals and other treatment options on an ongoing basis; and evaluate the effectiveness and efficiency of health policy.

- Due to a multitude of legal, institutional and technical reasons, Australia stands out among other developed countries as one where health information is poorly used.

- Trusted researchers in other nations — the United States, New Zealand and the United Kingdom — can and do actively analyse such data to enable the development of solutions to seemingly intractable problems in their health systems.

- Some of Australia's best health researchers use UK health datasets, as ours are unavailable to them. Others wait up to eight years for access, in areas of life-saving significance.[6]

The Commission referred to case studies including the following to demonstrate the extent of the challenges Australian health and medical researchers face currently when seeking access to health data sets:

"Nearly five years after requesting the data, researchers at the University of Melbourne received de-identified information about CT scans and cancer notifications. Their work showed there was an increased cancer risk for young people undergoing CT scans, and led to changes in medical guidelines for the use of scans. "Had [the] study been approved sooner and been able to proceed at an earlier date…, we would have had results sooner, with potential benefits in terms of improved guidelines for CT usage, lesser exposures and fewer cancers (John D Mathews, sub. 36, p. 13)."

"Since 2008, government agencies have been providing funding to the Vaccine Assessment Using Linked Data Safety Study. Among other objectives, this study examines whether there is a relationship between vaccination and admission to hospital or death. The study requires data from both the Australian and State Governments. Obtaining data from the Australian Government has taken six and a half years; State data has not yet been linked. The researchers have been waiting for the linked data for more than eight years. (Research Australia, sub. 117)"

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[6] Productivity Commission, Data Availability and Use, Inquiry Report Overview and Recommendations, March 2017, pp.5-6

"The New Zealand Treasury has used longitudinal data from anonymised linked administrative datasets (in this case, mental health program usage and pharmaceuticals) to identify young people at risk of poor outcomes in adulthood. By identifying a number of key characteristics that appear predictive of poor future outcomes, the analysis provided valuable insights into the effectiveness of various policies and interventions. The separation of data holdings across three levels of government and across different agencies within each of these jurisdictions, and the distrust that inhibits sharing of this data for linkage purposes, means that such analysis is not yet feasible in Australia."[7]

As the Commission concluded, 'the substantive argument for making data more available is that opportunities to use it are largely unknown until the data sources themselves are better known, and until data users have been able to undertake discovery of data.'[8] For example, the United States' PEDSnet – National Pediatric Learning Health System is a powerful example of how the strategic and collaborative capture, integration and analysis of patient, care and scientific data is transforming healthcare.[9] PEDSnet is a large, national community of hospitals and healthcare organisations, multidisciplinary researchers and clinicians, patients and their families. Members of the network work together to identify the most important research questions that can reduce children's suffering and support their healthy development. 'Through a learning health system (LHS) approach PEDSnet integrates research done in routine care settings, structured data capture during every patient encounter, and quality improvement processes to rapidly implement advances in new knowledge, all with active and meaningful patient participation.'[10] Its work is fundamentally reshaping outcomes for previously fatal diseases such as cystic fibrosis and many childhood cancers.

Ultimately, if future generations of Australians are to have access to the quality healthcare that is becoming available internationally due to advances in knowledge, technology and safe data usage, our healthcare system must also make the transition to be a truly digitised sector. Central to this transformation is acknowledgement of the fundamental need to access data, with strong privacy protections, to improve quality of care through continuous quality improvement underpinned by research.

Working in partnership with governments, public and private health services, medical research institutes and the community, the University of Sydney stands ready to help make the MHR system a critical resource for the Australian health system. We believe this can be achieved without compromising patient privacy – enabling best practice in the early detection of new disease problems and helping drive improvements in patient and community health outcomes Australia-wide. If it would assist the Committee, we would be delighted to assemble a panel of our experts in health and medical research, ehealth, public health, research ethics and privacy to discuss the MHR system and domestic and international developments in the use of health data to improve patient care, community health and system efficiency.

Yours sincerely,

(Signature removed)

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[7] Ibid.

[8] Ibid., p.2

[9] https://pedsnet.org/

[10] Forrest C et al, PEDsnet: a National Pediatric Learning Health System, Journal of the American Medical Informatics Association, May 2014