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Senator Lucy Gichuhi
Chair, Senate Committee on Community Affairs, Legislation Committee
Parliament House
Canberra ACT 2600

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

Dear Senator,

My Health Records Amendment (Strengthening Privacy) Bill 2018 Inquiry

The University of Sydney wishes to register its keen interest in the outcomes of the Committee's review of the *My Health Records Amendment (Strengthening Privacy) Bill* (the Bill).

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 have also made a submission to the References Committee's concurrent examination of the My Health Record (MHR) system and are keen to assist the Committees with both inquiries.

While we are still taking legal advice on the practical implications of the Bill for Australian universities and their researchers, our principal concern is that the proposed amendments may have the effect of preventing – or at the very least – making it extremely difficult and inefficient in the future, for researchers to access de-identified MHR data for research that seeks to save lives, improve patient care and the effectiveness and efficiency of our health system.

Protecting the privacy and security of individuals' records is of course a critical consideration, but there are sound existing frameworks in place in Australia and internationally for de-identifying data and mechanisms such as the use trusted third party data custodians that can ensure re-identification is virtually impossible.

We note in the Minister's second reading speech introducing the Bill and in the explanatory memorandum, the intention for the My Health Record System Operator to be able to disclose health information to non-law enforcement government agencies if the healthcare recipients' consent to such sharing of their data. However, we are concerned that proposed new Section 69A appears to require all other government agencies except for the offices of the Auditor General, Ombudsman and Information Commissioner to obtain a court order before the system operator may release any individual's MHR data to them in any form.

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For example, Item 12 of the explanatory memorandum states, ‘...*new sections 69A and 69B to reflect the announced policy of the Australian Government that no My Health Record information will be released to law enforcement agencies or government bodies without a court order.*’ (our emphasis)

It is therefore unclear to us whether, under the proposed amendments to the Act, healthcare recipients will still be able to give express consent for the release of their data in de-identified form to non-law enforcement government agencies (except for the three exceptions noted above) explicitly for research purposes, or whether a court order will also be required in these circumstances. If a court order will be required for such releases, this is of significant concern, as it will make it extremely difficult for researchers to access data from the MHR in the future.

While the value of the MHR data set for medical and health-system research purposes may not be significant at present, its usefulness will increase over time – assuming the MHR system remains in place.

We 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 therefore urge the Committee to consider recommending to the Government and Parliament that explicit provision is made in the My Health Record Act to protect the future potential use of MHR for public good research, where there is informed patient consent and where strong safeguards are in place to protect patient privacy and confidentiality.

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 to improve care through continuous quality and service improvement underpinned by research.

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.

We would be delighted to discuss these matters further with the Committee if that would be of assistance.

Yours sincerely,

Professor Duncan Ivison
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