

Chair

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Development of a Framework for Secondary Use of My Health Record Data: submission

On behalf of Innovation and Science Australia (ISA) I would like to present the following submission for consideration in response to the *Development of a Framework for Secondary Use of My Health Record Data* consultation paper.

ISA is an independent statutory board, with responsibility for providing strategic whole-of-government advice to the Government on all science, research and innovation matters. In February 2017 ISA released its first *Performance Review of the Australian Innovation, Science and Research System (ISR System Review)*¹ examining the ISR system's strengths and weaknesses and establishing a performance scorecard for tracking progress into the future. ISA will soon release a strategic plan for the Australian ISR system out to 2030. The *2030 Strategic Plan* will aim to contribute to the wellbeing and prosperity of all Australians by ensuring that Australia reaches its innovation potential. My office will provide you with a copy once released.

ISA is supportive of the aims of the Department of Health in developing a framework to support the secondary use of My Health Record data and provide guidance on potential data uses. With the My Health Record participation arrangements set to change in 2018 to an opt-out system, and the resultant increase in My Health Record participation, this growing dataset will be an important resource in driving greater health improvements for all Australians. ISA's forthcoming 2030 Plan recognises that health data resources will play an essential role in Australia's innovation system, allowing advances in technology through genomics and precision medicine to provide improved health outcomes. Greater use of data analytics in the health space also has the potential to increase personalised health care for individuals.

A framework for secondary use of My Health Record data will provide Australia with an opportunity to build on a source of global competitive advantage - our excellent healthcare system and the data held within it. Australia already has a world-class health and medical research base, which has repeatedly produced game-changing inventions such as the world's first cancer vaccine, Gardasil.² Australia has also shown that we can launch globally successful companies that draw on this base, such as Cochlear and ResMed. The Medical Research Future

¹ Innovation and Science Australia (2017), *Performance Review of the Australian Innovation, Science and Research System 2016* <http://www.industry.gov.au/isa>

² Australian Cancer Research Foundation (2006). 2006: World's First Cervical Cancer Vaccine Becomes Available. Accessed at <https://home.cancerresearch/worlds-first-cervical-cancer-vaccine-becomes-available/>

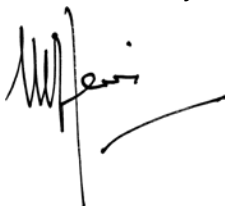
Fund is forecast to double medical research funding within a decade and \$500 million has already been committed to the Biomedical Translation Fund. This is a strong base from which Australia can pursue major medical research and medical innovation projects.

ISA considers that it is important to strike a balance in the Framework between protecting the rights of My Health Record users and increasing the opportunities for researchers and commercial players to improve health outcomes. An individual's health care record is personal and sensitive information, however when used in conjunction with other individuals' information it can become a powerful input to research to identify health issues and markers of disease. To ensure that any privacy or data security concerns are addressed promptly and appropriately it will be crucial that the rollout of the Framework is appropriately paced and supported by strong governance arrangements. This will require appropriate access processes for secondary use supported by resourced data maintenance and accountability systems. The value of the data can only be realised if the My Health Record enjoys ongoing social licence with users trusting of, and engaged in, the positive impacts secondary use can deliver. To this end, ISA supports the existing legislative limitations to the use of My Health Record data, i.e. no secondary use of the data solely for commercial purposes and limitations on secondary use by private health insurers without explicit consent from individuals involved.

ISA seeks a Framework that accommodates the secondary use of My Health Record data where commercial and health/public interest related uses overlap. This might include research and development (conducted in both the public and private sectors) designed to improve healthcare services and treatments, for example in pharmaceutical development to cure chronic disease and decision support tools for healthcare providers to support increased efficiencies in Australia's health system. Historically, Australia has underutilised data collected by government agencies and missed out on potentially innovative outcomes. Increasing Australia's ability to seize innovation opportunities and place ourselves at the forefront of the global innovation race requires us to build on our strengths and make Australia one of the best places in the world in which to undertake innovation, science and R&D across all sectors, and especially the health and medical sectors. The Framework should therefore allow for potential use for research and development purposes designed to improve healthcare services and treatments.

Thank you for the opportunity for the ISA Board to provide input into this consultation. ISA looks forward to the further development of a framework for the secondary use of My Health Record data.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Bill Ferris', with a long horizontal flourish extending to the right.

Bill Ferris AC
Chair

17 November 2017