Learning Health System Strategic Advisory Committee

Chair's Report – 21 August 2025

The Learning Health System Strategic Advisory Committee ('the committee') has been established as a time-limited forum to advise on the use of health data, specifically data held in the My Health Record system, for research and public health purposes. The committee will advise on the requirements of robust and trustworthy data governance and management, to support uses of data that individuals and communities want, and expect, to improve future care for all.

My Health Record data is not currently being used for research or public health purposes, and future use is subject to a decision of government. The ideas discussed in this report have not yet been considered by Government. The department will consider the recommendations and advice of the committee to inform advice to Government.

The committee membership (see list of attendees below) consists of nationally and internationally esteemed experts in fields such as consumer advocacy, privacy, data governance, governance of Indigenous data, health and medical research, and use of artificial intelligence. The committee also includes representatives of government agencies who have partnered to explore how we can facilitate use of My Health Record system data for research and public health. These include

- the Department of Health, Disability and Ageing (the department, who provide policy and governance leadership),
- the Australian Digital Health Agency (the agency, who are system operators of the My Health Record system), and
- the Australian Institute of Health and Welfare (AIHW, who are the My Health Record data custodians).

The committee will focus firstly on how data from the My Health Record System can be used for research and public health purposes in ways that contribute to a sustainable 'learning health system'. There are various definitions of learning health systems, but in essence, we are referring to the positive feedback loop that is created when every patient interaction offers an opportunity to learn how to improve future care. Every GP visit, hospital stay, pathology or radiology test, and medicine dispensed creates information. This information can be used to create new knowledge, understanding and evidence, which guides us to take actions that enhance safety, quality, and equitable health outcomes for all Australians.

Digital health reforms are laying the foundations for a learning health system by improving secure data sharing to better support:

- individuals to take control of their own health,
- healthcare providers' access to data at the point of care,
- uses of data to support medical breakthroughs and innovations in clinical practice,

- new insights for public health planning, resourcing, and
- continuous and sustainable quality improvements.

The Department and its partners will use the committee's advice to:

- create strong rules for how health data from My Health Record is used in research and public health,
- guide discussions with people and organisations affected by these changes.

In providing advice to the department on what is needed to realise fully the benefits of an effective and trusted learning health system, the committee will work in a way that is inclusive, collaborative, and transparent. Any advice given, while focused on My Health Record data, may take a broad view of how digital health systems contribute to a learning health system and be generalisable to other digital health datasets. After each meeting, there will be a Chair's report summarising key topics of conversation, actions arising, and advice given.

This is the first Chair's report and provides a high-level summary of the committee's inaugural meeting, in Melbourne on 21st August 2025.

Setting the Scene

The meeting was the first opportunity for members to meet and to discuss the committee's role and purpose. It gave the committee the opportunity to hear about related programs of work and policy priorities and to start shaping its forward agenda.

The meeting opened with an acknowledgment of Country, welcome and formal member introductions, and then presentations from First Assistant Secretary Daniel McCabe and Assistant Secretary Simon Cleverley, Department of Health, Disability and Ageing. These presentations summarised the history of My Health Record and the work currently transforming digital health, with data and digital a critical enabler of a modern and connected health system. The importance and potential of My Health Record was described in the context of putting people first and building a learning health system.

The presentations made clear how integration of digital platforms can enable useful data sharing, increase health and digital literacy and empower patients and health professionals. With the application of modern technologies (such as AI), improved access to meaningful digital health data has significant transformative potential to:

- improve equitable access to healthcare,
- provide earlier interventions to keep Australians' healthy,
- offer real-time insights and feedback loops, and
- reduce duplication and waste.

Current programs of work, following the Digital Health Blueprint, are increasing opportunities to learn across a more connected and interoperable system. This work includes:

- establishing national data standards for clinical systems (including FHIR and clinical terminology),
- modernising the Healthcare Identifiers Framework to support consistent and reliable identification across systems, and
- modernising My Health Record, including by Sharing by Default.

There followed a presentation on the Proof of Concept (PoC) activities that occurred from 2021 to 2023 between the Department of Health, Disability and Ageing (the Department), the Australian Institute of Health and Welfare (AIHW), and the Australian Digital Health Agency (the Agency). These activities showed the data quality, technical infrastructure and governance requirements needed to use My Health Record data for research and public health purposes. The PoC highlighted the potential value of My Health Record data, but also the strong public engagement and consultation needed to earn trust in governance and uses of health data for purposes beyond an individual's immediate care.

Initial reflections on earning trust

Every patient interaction offers an opportunity to learn how to improve future care but fully realising the benefits of a learning health system will require the 'buy-in' and trust of professionals, patients, carers and the public. The committee noted topics critical to building public and professional confidence. These included the need for clear language, clarity on a shared vision of a learning health system, and participatory governance processes that are transparent, accessible and accountable to the public.

Priority was attached to future work articulating a clear, compelling, and authentic vision of the good that can be done with My Health Record data. This will require an understanding of how My Health Record data sits within the broader data ecosystem and the existing availability of similar data for research and public health purposes. It will also require meaningful engagement with diverse communities and a strong open process grounded in real possibilities: capable of proving tangible real-world impact.

The committee suggested important things to consider included how advancing a learning health system would:

- meet public perceptions and expectations,
- build trust across diverse communities,
- avoid duplicative siloed infrastructure and systems, and
- provide an ethically compelling shared vision of how a patient centric system will deliver improved care in the best interests of all Australians.

Why My Health Record data?

The committee was given information about how the My Health Record system can bring together health data at a personal and a population level. It was described as a unique dataset, capable of holding data in near to real time, and in a form that is both pre-linked and person centred. The committee thought it important to be able to clearly describe the value of My Health Record system data compared to other datasets in the health data ecosystem, along with the controls and opportunities that exist in relation to each for improvements to care and public health. It was suggested that there may be a general lack of awareness in the community of different systems, the relationship between them, and whether data is now available to be used safely for the benefit of individuals and communities. The committee noted complexity and useability issues for members trying to access their My Health Record through the mobile app and recognised these to be important issues for public confidence and engagement with the system overall.

Looking forward

After lunch, there was a presentation by Deputy Secretary Penny Shakespeare, Department of Health, Disability and Ageing on initiatives in digital health to improve sharing information, noting the opportunities and challenges to seeking better outcomes from how we reuse the data. This was followed by a presentation by CEO Amanda Cattermole, Australian Digital Health Agency. This presentation gave an overview of the Agency and how it shapes infrastructure including information sharing, improving connectivity and advancing real time data exchange.

Following these presentations there were questions and general discussion, before the committee turned to consider its forward agenda. My Health Record data will only be available for research and public health purposes when the required legislative, governance, security, privacy, and technical arrangements are in place, and subject to future decisions of government. Committee members saw the importance of being a forum for the conversations needed to provide high quality advice and to earn public and professional trust in future proposals for a learning health system. There was general agreement that topics to be considered by the committee in future meetings include:

- consumer consent and control
- individual and collective benefit
- Indigenous data governance
- public trust and public benefit, and
- learning health data governance: how governance can be improved through evidence.

There is a need to understand how national proposals align with the best learning health systems globally. There is a need to learn from the 'cautionary tales' and emulate the 'lighthouses' that are beacons of international excellence and good practice.

The committee will continue to develop its forward agenda and confirm terms of reference and ways of working. It will also progress agreement on terminology and a shared understanding of what a successful learning health system looks like. There was agreement on the need for a clear explanation of why reusing health data is valuable, but also how individual and community control is to be maintained. Progress needs to provide accessible evidence that data is being kept safe and used to deliver the individual and collective benefit that people want and expect in terms of improvements to future care and public health.

It was acknowledged that fully realising the potential of using My Health Record data for research and public health purposes, to improve the health of all Australians, represents an extraordinary governance challenge. The reuse of sensitive health data collected by public and private providers, across both state and commonwealth, must be enabled in a way that can earn public and professional trust across the entire country. The approach must be broadly supported by diverse public and private sector entities with existing digital health agendas. Against this background, the Committee will work to provide the highest quality advice on the requirements of enabling trustworthy governance: what will allow us as a nation to capitalise on new technical possibility and learn what works best, when, for whom, and to share that knowledge safely across the health ecosystem to the benefit of all.

Committee Recommendations

The committee has recommended:

Appointing an additional member with expertise in health care delivery

Further exploration of the user experience of connecting to My Heath Record and options to improve ease of access.

Development of simple factsheets or summaries about the potential benefit and risks of using My Heath Record system data for research and public health purposes, examples of international best practice in establishing learning health systems, and a map of health data available in the Australian context highlighting what is unique to My Health Record

Development of a framework for developing case studies to demonstrate the value of My Health Record system data, and development of case studies with Aboriginal Community Controlled Organisations.

Attendees

Committee Member	Role
Professor Mark Taylor	Chair
Kayla Jordan	Assistant Secretary Department of Health, Disability and Ageing (the department)
Mike Lau	Chief Data and Analytics Officer, Australian Digital Health Agency (the Agency)
Michael Frost	Group Head, Australian Institute of Health and Welfare (AIHW)
Jacob Madden	Expert in emergency and health crisis data needs
Professor Marcia Langton	Expert in First Nations Data Governance
Ainslie Cahill	Expert in consumer advocacy
Professor Dougie Boyle	Expert in health research and data
Professor Emily Banks	Expert in health research and epidemiology
Emeritus Professor Gillian Triggs	Expert in Privacy/ Privacy advocate
Gaby Carney	Expert Data Privacy and AI Governance
Dr Adrian Burton	Expert in health data and researcher perspectives
Member Apologies	**Role**
Associate Professor. Kristen Smith	Expert in First Nations Data Governance
Presenters	**Role**
Penny Shakespeare	Deputy Secretary, Department of Health, Disability and Ageing
Daniel McCabe	First Assistant Secretary, Department of Health, Disability and Ageing
Simon Cleverley	Assistant Secretary, Department of Health, Disability and Ageing
Amanda Cattermole	Chief Executive Officer, Australian Institute of Health and Welfare
Secretariat and visual scribe	
Department of Health, Disability and Ageing	