Australian Government
Department of Health, Disability and Ageing

Learning Health System Strategic Advisory Committee

Chair's Report – 10 December 2025

The Learning Health System Strategic Advisory Committee ('the committee') came together for a second time in Melbourne on 10 December 2025.

The first meeting, held on 21 August 2025 (chair report can be found here) focused on setting the scene and understanding the committee's role and purpose in the broader policy and regulatory context. The second meeting, titled Route Planning, was focused on future work: with discussion of program plans for engagement and communication, the language used to describe program activity, and the committee's forward agenda.

A recurring theme across both meetings was the importance of building public trust and professional confidence prior to any use of My Health Record data for research and public health purposes.

Update on committee's recommendations

The meeting opened with an acknowledgment of Country, and noted work actioned and ongoing from members' feedback from meeting one. This included a recommendation for an additional member appointment who has expertise in health care delivery. The Department has supported this recommendation.

The department sought advice from the Australian Digital Health Agency (the agency) to further explore user experience of connecting to My Health Record and options to improve ease of access that members raised in the first meeting. This work remains ongoing.

Describing Success and Demonstrating Value

Having formally endorsed the committee's terms of reference, members turned to consider the work needed to successfully enable and embed trusted research and public health use of data in a learning health system. At the first meeting, the committee recognised it to be important to learn from similar initiatives at home and abroad. A paper on comparable initiatives, and lessons learned, was presented for discussion and to inform forward planning. Key themes identified in the paper included the need to: earn public and professional trust, establish robust data protection and privacy safeguards, and enable uses of data capable of delivering meaningful benefits. The need for clear communication strategies, developed collaboratively with target audiences, was recognised to be central: to the research and public health program and to establishing the committee as an inclusive and trustworthy source of advice.

The Terms of Reference establish a role for the committee to advise on plans to implement research and public health use of My Health Record data. The plans are outlined in a roadmap drafted during the proof of concept. The roadmap describes a program with three goals:

i. enable researchers and government to use health data safely and securely by meeting or exceeding all relevant legislative, governance and technical requirements to protect consumer privacy and confidentiality.
ii. deliver value and benefit to consumers that all stakeholder groups support. These values and benefits will improve health equity and outcomes through a learning health system.
iii. include individual consent and control, and meet community expectations, with procedures and safeguards in place to ensure accountability and transparency.

The roadmap has four development workstreams:

1. Communications and Engagement
2. Governance
3. Data Suitability and Quality
4. Infrastructure

The first workstream was a priority for this second meeting: with a focus on communication and engagement plans and language choices.

Communication and education

Public trust and social licence are recognised to be crucial for successful implementation of the roadmap. Individual control is fundamental to the design and function of the My Health record system, and it is through comprehensive engagement and effective communication that inclusive governance principles and program requirements are to be developed in partnership with community, professionals, and the broadest range of interested groups and individuals.

Members reflected on the principles of effective and accessible communication, transparency, and quality engagement. The committee agreed that clear communication requires consistent use of accessible language, and members spent some time discussing how key terms would be used. It was agreed that context is important to the use of terms and communication should use common and ordinary meanings, rather than technically defined terminology, wherever possible to ensure greatest transparency.

It was also recognised to be important that communication and engagement plans should support ongoing conversation and effectively report both what has been heard and how any feedback has been used. In particular, content and channels of communication need to be accessible and open to all: addressing the diversity of peoples across Australia e.g. culture, language, geography, digital literacy and access to technology. Whilst also adopting a staged multifaceted approach to communication: with targeted consultations with key groups leading to a broad inclusive consultation process.

The importance of developing practical examples and testimonials on use of data for research and public health purposes was recognised.

Use cases

My Health Record data is not yet available for research or public health purposes and will only be available if appropriate governance, legislative, and technical measures are put in place. The necessary authorising environment requires a social license to operate. This depends on accessible evidence that data will be kept safe, with privacy protected, individual control over data is respected, and any permitted research or public health use is for individual or collective benefit.

The committee discussed a framework that could underpin development of ‘use cases’: examples of potential use of My Health Record data for research and public health purposes. Use cases could show the value of such use if permitted under future governance controls. Members agreed there would be value in the framework prioritising potential uses that highlight the unique attributes/benefits of My Health Record system data and discussed the criteria that could be used. Discussion included the framework testing any proposed research and public health use for its potential to:

- improve current healthcare through better outcomes
- reduce harm
- enhance surveillance
- enhanced healthcare experiences
- make care fairer
- develop new forms of care
- improve healthcare administration
- meet a need recognised by academic, government, peak bodies communities or patients’ groups

The development of the framework is to be an iterative process and as ideas mature it was recognised that there will be a need to work with others and to ensure appropriate emphasis on meaningful value.

Looking forward

The committee commitment to ongoing engagement with a diverse range of stakeholder groups remains a focus, as the program continues to develop. This includes actively seeking input from consumers, researchers, government partners and more, to ensure the program delivers maximum benefit.

A key part of this is striking the right balance between strong, rigorous protections around the use of health data and ensuring that the data remains practical and accessible enough for researchers to meaningfully use.

We see this stage of work as an important opportunity to refine and align our communication approach. This includes ensuring our language is clear, accurate and consistent, and that it helps build confidence in how the program operates. We intend to continue inviting regular input from a range of groups, using their feedback to guide how the program is explained, its safeguards and its benefits. By engaging early and often with key groups, the program can be shaped so that its trusted, transparent and genuinely useful.

Attendees

Attendees	
Prof Mark Taylor, University of Melbourne	Chair
Dr Adrian Burton, Australian Research Data Commons	Member
Ainslie Cahill, Consumer Representative	Member
Prof Dougie Boyle, Vivanti Consulting (Virtual)	Member
Gaby Carney, University of Technology Sydney	Member
Emeritus Prof Gillian Triggs, University of Melbourne and UNHCR	Member
Jacob Madden, Department of Health, Disability and Ageing	Member
Kayla Jordan, Department of Health, Disability and Ageing	Member
Michael Frost, Australian Institute of Health and Welfare	Member
Mike Lau, Australian Digital Health Agency	Member
Apologies	
Prof Emily Banks, Australian National University	Member
Prof Marcia Langton, University of Melbourne and Indigenous Data Network	Member
Associate Prof Kristen Smith, University of Melbourne and Indigenous Data Network	Member
Observers	
Simon Cleverley, Department of Health, Disability and Ageing	Observer
Secretariat and visual scribe	
Department of Health, Disability and Ageing	