



## SUBMISSION

### MODERNISING MY HEALTH RECORD

OCTOBER 2023

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**The Australasian Institute of Digital Health is pleased to provide input to the Department of Health and Aged Care's consultation on *Modernising My Health Record – Sharing pathology and diagnostic imaging reports by default and removing consumer access delays.***

The Australasian Institute of Digital Health (AIDH) is the peak professional body for digital health, representing a united and influential voice for health informatics and digital health leaders and practitioners working across all aspects of the healthcare sector. The Institute has around 250 distinguished Fellows who are experts or pioneers in the field of digital health. We have a growing membership of professionals comprising doctors, health informaticians, nurses, midwives, allied health, other clinicians, administrators, and health technology business leaders.

AIDH provides objective, non-partisan, and independent advice on health informatics and the digital enablement of healthcare to not only improve the health outcomes of Australians, but to solve our healthcare system's most pressing challenges. The Institute's vision is *healthier lives, digitally enabled*. Our priority areas are leadership and advocacy, workforce advancement and community engagement.

AIDH's unique composition and reach brings together an extensive network of Australia's leading digital health experts across the private, public and community sectors to advance our nation's transition to a digital health future.

## General Comments

AIDH supports the proposed Strengthening Medicare Taskforce reforms and is pleased to see implementation progressing. Near real-time access to information enables better informed care, improving continuity of care and facilitating better outcomes. My Health Record has a vital role to play in facilitating this.

We agree with the intent to modernise My Health Record to increase health information available to consumers and their health care professionals by requiring sharing by default for private and public diagnostic providers. We agree this would make it easier for people and their health care teams to access and use at the point of care and would support self-care. Radiology and pathology reports contain vital information to support diagnosis, treatment and monitoring, and should be made available promptly via My Health Record to enhance the continuity of care. Furthermore, we believe that regular uploads of health information to the My Health Record system will increase trust in and utility of the overall system, which will ultimately aid practitioner-patient interactions.

Increasing the volume of clinical information in My Health Record will necessitate ongoing improvements to the design and usability of the system for both clinicians and consumers, which must be built into annual work plans for the Australian Digital Health Agency (Agency).

AIDH supports accompanying digital reforms with robust clinical governance, embedding changes through standards, guidelines, training for clinicians and plain-English information resources for consumers. These are important to manage change and support human-centric implementation. AIDH would welcome the opportunity to discuss how clinical governance can better support the adoption of digital health technologies with the Department of Health and Aged Care. In relation to this consultation, we support the stated intent to amend the professional standards for diagnostic imaging and pathology providers.

## Part A: Better access – sharing pathology and diagnostic imaging reports to My Health Record by default

AIDH agrees that there are significant benefits from sharing diagnostic results by default for consumers and to enable better continuity of care. We are pleased to see the increased usage of My Health Record by general practitioners. The inclusion of additional diagnostic information through sharing by default should further enhance the clinical utility of My Health Record. We also support retention of the ability for individual consumers to choose not to have their results uploaded to My Health Record. AIDH believes that the Agency should revisit an awareness campaign for consumers on the benefit of near real time sharing of clinical information via My Health Record and other platforms that enhance interoperability.

We believe that this measure should include all providers of Medicare-funded diagnostic services, including point of care testing, to provide holistic information for consumers and other clinicians involved in subsequent care.

AIDH supports the intent of the changes and the proposed approach, as detailed on page 10 of the Part A consultation document. We also agree that there may be clinical circumstances where it may be appropriate not to give immediate access to results through My Health Record. At present, this is done

by the referring practitioner ticking a “do not upload” box. AIDH believes it would be preferable for My Health Record to allow each individual consumer to opt out of automatic upload of specific test information and to change that setting in the future if desired.

The timelines for transition to sharing of diagnostic reports to My Health Record by default by June 2024, and full implementation by December 2024, seem reasonable. Each state and territory will need to work closely with the Agency to accommodate this timeline into their jurisdictional plans.

## Part B: Faster access- removing delays to accessing pathology and diagnostic imaging reports in My Health Record

AIDH supports removing the seven-day delay to access pathology and diagnostic imaging reports in My Health Record, which we agree is appropriate in most circumstances.

AIDH agrees with the perspectives shared by consumer organisations (as noted in the consultation document) that removal of the seven-day delay will enhance their access to information and allow them to be better informed when discussing diagnostic test results with their referring practitioner. Furthermore, we agree that there are specific benefits for regional, rural, and remote consumers who can make better informed decisions regarding timing and the need to travel for subsequent clinical appointments.

AIDH represents a large body of digital health professionals, including clinicians. Sharing by default and removing the seven-day delay will generate apprehension amongst some members of the clinical community, and changes to their workflow will need to be managed carefully. AIDH agrees there may be clinical circumstances, or a need to retain privacy, where it is appropriate to retain a delay (i.e., not to give immediate access via My Health Record). These should be discussed with the patient during the referral process and a rationale recorded in the health record. AIDH defers to the relevant consumer organisations and clinical peak bodies for specific clinical circumstances that would merit retention of a delay.

We should learn from countries who have already instituted these policies. Consumers should be supported in understanding the information through best practices approaches such as ensuring the results are presented in clear and plain language, including comparison to normal ranges and using color coding to highlight for example whether a result is within normal limits, and providing explanatory notes, visual aids or educational links for interpretation. AIDH believes the Department and Agency should work with relevant clinical colleges to update their reporting guidelines to incorporate these best practices. Furthermore, funding should be provided for telehealth or in-person consultations with providers to seek advice promptly if they are concerned about their test results. This should be highlighted when the referral is made and through information such as frequently asked questions (FAQs) in My Health Record.

An example from overseas of guidance for consumers on immediately available results is provided by the Center to Advance Palliative Care in the USA, available here: <https://www.capc.org/blog/tips-for-helping-patients-navigate-immediately-available-test-results/>

## Conclusion

Once a way forward is determined, AIDH believes there should be a concerted education campaign for consumers, clinicians and the general public. This campaign should be carefully co-designed with clinicians, consumer organisations and community groups, particularly those who have low trust in digital health and social care systems and initiatives. Phrases like 'sharing by default' may be interpreted by consumers as a loss of choice and control, rather than a gain of easier access to their health information, even when this phrase is preceded by 'better access'.

With extensive experience and demonstrated leadership in this field, the AIDH is well positioned and available to participate in the co-design of such education, and to assist with distribution of information and educational resources via the digital health community.

If you have any questions about this response or would wish to discuss any of the points above in more detail, please contact [ceo@digitalhealth.org.au](mailto:ceo@digitalhealth.org.au).

**Submitted on 31 October 2023**