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Committee Secretary
Senate Standing Committees on Community Affairs
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Canberra ACT 2601

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

**Re: Health Legislation Amendment (Modernising My Health Record – Sharing by Default)
Bill 2024 [Provision]**

Friday, 10 January 2025

Dear Committee Members,

The Royal College of Pathologists of Australasia (RCPA) appreciates the opportunity to provide feedback on the proposed changes to the My Health Record (MyHR) system through the Health Legislation Amendment (Modernising My Health Record—Sharing by Default) Bill 2024.

At present, there is a default seven-day delay between when a healthcare provider uploads pathology or diagnostic imaging results to My Health Record and the patient having access to those results. This delay exists to ensure patients have appropriate clinical advice and support to interpret and understand their test results, which are written by clinicians for a clinically trained audience. The Bill will remove this delay in most instances.

The RCPA supports the principle of empowering consumers with faster access to their health data. However, the removal of the seven-day delay for diagnostic imaging and pathology reports must be implemented thoughtfully, with clear exclusions for certain types of tests. Some diagnostic results are complex, sensitive, or require clinical interpretation before being shared with patients. Releasing these without adequate safeguards risks significant harm to patients.

The development of a carefully considered list of exclusions must be informed by the expertise of pathologists and clinicians who understand the nuances and implications of various types of diagnostic information. We welcome the Government's establishment of a Clinical Reference Group to help guide this work and commend their inclusion of pathologists. However, we urge them not to rush this process.

Our recommendations

We encourage the Committee to consider the following amendments to the Bill:

1. Delay the implementation of the Bill until 2026 (at the earliest) to allow careful consideration of the appropriate technical exclusions

2. Include a requirement for the My Health Records Rules to be subject to a regular and independent statutory review, which should include consultation with included clinical groups
3. Eliminate civil penalties or restrict them to cases involving deliberate and malicious withholding of patient information

Specific Recommendations for Exclusions

Not all diagnostic results are suitable for immediate release due to their complexity or sensitivity, particularly pathology reports, which are written using technical medical language intended for clinicians. These reports often require clinical interpretation, as even quantitative results can vary by testing platform or methodology, leading to potential misinterpretation by patients. Evidence shows that without proper guidance, patients may experience anxiety, delay necessary care, or make harmful self-management decisions based on misunderstood results.¹ In the case of genetic results, there is an established body of evidence against sharing such information without proper context or counselling, as it can lead to significant psychological distress, confusion, and unintended consequences for patients and their families.

The College recommends that certain categories of results be exempted from the removal of the seven-day delay, including (but not limited to):

- **Genetic Pathology Results:** Probabilistic findings that carry implications for family members and require counselling.
- **Anatomical Pathology (AP) and Cytopathology Reports:** Diagnoses such as malignancies that require multidisciplinary review before patient communication and are best communicated with the support of a medical professional. Perinatal post-mortem reports can be extremely complex, have implications for future pregnancies, and require counselling.
- **Haematology Reports:** Malignant haematological diagnoses such as leukaemia, lymphoma and myeloma may require multidisciplinary review prior to communication to the patient.
- **Clinical Chemistry Reports:** Tumour marker studies may indicate malignant disease and are best communicated by the requesting medical practitioner to the patient within the clinical context.
- **Critical Infectious Disease Results:** Diagnoses like HIV or Hepatitis C that demand immediate clinical guidance for management and psychological support.

Given the complexity of these reforms and the need for proper consultation and preparation, the College recommends that the legislation not come into effect until 2026 at the earliest. This timeline will allow for the development of clear clinical exemptions, improvements in consumer education, and adequate technical preparations.

Civil Penalties

The imposition of civil penalties on healthcare providers for non-compliance with uploading requirements is concerning. Many providers, particularly smaller practices,

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lack the necessary technical infrastructure to comply immediately. There is extensive international evidence of the adverse impact of such penalties on small providers (including from the US and the EU), and of the impact this can have on the competition in the sector. The College urges the removal or limitation of these penalties to cases of intentional withholding of patient information.

Statutory Review

The College recommends that the My Health Record Rules be subject to regular, independent statutory review. These reviews should include consultation with clinical stakeholders to ensure the system evolves to meet the needs of patients and providers effectively. Incorporating regular statutory reviews into the My Health Records Rules would align Australia with international best practice, ensuring the system remains responsive to the evolving needs of patients and healthcare providers.

In conclusion, RCPA appreciates the opportunity to contribute to this important legislative process. We look forward to working closely with the Department of Health and other stakeholders to refine the technical details of the Bill, including the development of clear clinical exclusions and safeguards. We urge the Committee to consider delaying the implementation of the Bill to ensure this can be done thoughtfully and collaboratively.

Kind regards

Dr David Andrews
RCPA CEO

¹ Liu, W., Liu, W., & Liang, H. (2020). "Impact of Online Test Results Access on Patient Behavior: A Systematic Review." *Journal of Medical Internet Research*, 22(4), e15916. <https://doi.org/10.2196/15916>