Australian Government
Australian Digital Health Agency

Clinical Reference Group – Better and Faster access to pathology and diagnostic imaging reports in My Health Record Project. Terms of Reference

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Approved for external information
OFFICIAL

1 Purpose

The Clinical Reference Group – Better and Faster access to pathology and diagnostic imaging reports in My Health Record (the CRG) was established by the Australian Digital Health Agency (the Agency) and the Department of Health and Aged Care (DoHAC) to provide strategic advice and clinical oversight to the 'Faster access to diagnostic imaging and pathology reports in My Health Record' project and broader 'Improved Sharing of Information to My Health Record' program.

The purpose of the CRG is to provide clinical advice and guidance to the Program Control Group (PCG) on safety and quality matters related to the introduction and implementation of this initiative, and to ensure that it is aligned with consumer needs and preferences, and clinical workflows. The goal is to ensure that any recommendations made by the CRG allow for safe, more accessible and inclusive access of pathology and diagnostic imaging results by consumers.

The CRG will consist of representatives from relevant peak bodies, professional associations, consumer groups (including consumers with lived experience), and other stakeholders involved in pathology and diagnostic imaging services.

2 Background

In February 2023, the Australian Government released the Strengthening Medicare Taskforce Report, which outlined priority recommendations to improve primary care. The Report included a recommendation to "modernise My Health Record to significantly increase the health information available to individuals and their health care professionals, including by requiring 'sharing by default' for private and public practitioners and services, and make it easier for people and their health care teams to use at the point of care". This means that key health information must be shared to My Health Record as standard practice by healthcare providers, rather than as the exception.

The Australian Government responded to the recommendation of the Strengthening Medicare Taskforce by providing two years of funding to continue modernising My Health Record and improve digital health information sharing. This includes requiring healthcare providers to share diagnostic imaging and pathology results to My Health Record. The Australian Government is also making changes to allow consumers to see those reports without delay after they are uploaded to My Health Record.

Seven Day Rule

In establishing the Personally Controlled Electronic Health Record for Australians in 2012, a policy decision was made to withhold patient pathology and diagnostic imaging reports for seven days after they had been uploaded to ensure clinicians had adequate time to review the report and confer with the patient individually.

In the last 3 years, COVID-19 saw the first pathology results to be released to the consumer at the same time as the clinician – a critical step in managing infections at a time of widespread sickness and seven-day testing availability. Once armed with their results consumers could then plan to self-manage their care in line with the prevailing health advice of the time. Over the last 18 months, three further examples of how real time release of test/diagnostic information to consumers can have a positive effect occurred when International Normalised Ratio (INR), HB1Ac and respiratory infection results were released without delay. This has been well received by the community and has the potential to reduce pressure on general practice, reduce avoidable hospital admissions through an overall reduction in morbidity caused by clotting disorders, diabetes and avoidable transmission of infections. In addition, there is a consequent uplift of digital health literacy, better informed consumers and better long-term management of chronic conditions.

The real time availability model that we have seen in limited circumstances to date shows benefits to consumers and healthcare providers. The CRG will consider the views of a broad range of stakeholders and provide advice on removing the default seven-day delay on patient access to diagnostic imaging and pathology results in My Health Record.

3 Objectives

The primary objective of the CRG is to ensure the introduction of requirements to upload and the application of any delay to the upload of pathology and diagnostic imaging results is appropriately targeted, consumer centred and focused on delivering high quality information to consumers in line with their preferences, goals, and consent and is clinically safe, accessible and inclusive. The CRG will also provide advice about the clinical circumstances that may indicate that a particular result needs to be shared in a unique way to suit a consumer's needs.

The CRG will also consider matters referred to it by the PCG in relation to the broader "Improved Sharing of Information to My Health Record' program.

4 Scope

The CRG will focus on the impact of introduction of requirements to upload diagnostic imaging and pathology results and the refinement of current settings, including the seven-day rule to expedite access where clinically appropriate to support changing community expectations, clinical team-based care and consumer safety. The activities that may be required include.

- Identify potential issues or risks associated with sharing pathology and diagnostic imaging results via My Health Record, such as:
    - Misinterpretation or misunderstanding of results by consumers.
    - Anxiety or distress caused by viewing results without clinical context or support.
    - Delayed or missed follow-up or treatment due to lack of communication or coordination between providers.
    - Privacy or security breaches due to unauthorised access or misuse of results
    - Low levels of engagement from healthcare providers who perceive the removal of the seven-day rule to be a consumer safety issue.

- Advise on mitigation strategies for these issues or risks, such as:
    - Providing clear and consistent information and education for consumers on how to access, interpret and manage their results via My Health Record.
    - Offering options for consumers to choose when and how they want to view their results, e.g. receiving notifications for each result or when a group of tests is complete.
    - Developing guidelines and protocols for clinicians on how to communicate and share results with consumers via My Health Record, considering their clinical significance, urgency and sensitivity, including:
        - Opportunities to use existing resources and tools to provide information in plain English, such as Pathology Tests Explained
    - Ensuring that My Health Record content complies with relevant standards and legislation on data quality, security and privacy.
    - Identify existing or potential enablers or incentives for clinicians and consumers to use My Health Record for sharing pathology and diagnostic imaging results, such as:
        - Demonstrating the benefits of My Health Record for improving health outcomes, patient satisfaction, and efficiency
        - Providing technical support and training for clinicians on how to use My Health Record effectively.
        - Engaging with consumer groups and advocates to promote My Health Record.
- Provide feedback and inform functionality of the My Health Record platform and my health app, to reflect any refinement of current settings, including the application of any delay on the sharing of pathology and diagnostic imaging results to expedite access where clinically appropriate to support changing community expectations, clinical team-based care and consumer safety.
- Provide input into the development of a communication and engagement strategy for healthcare providers, consumers, carers and pathology and diagnostics imaging providers on the initiative.
- Provide advice on the development and subsequently endorse clinical support resources for clinicians and consumers on how to use My Health Record for sharing pathology and diagnostic imaging results, including guidelines, Frequently Asked Questions and case studies.
- Promote awareness and uptake of the initiative among their networks and stakeholders.
- Provide advice on a framework to monitor and evaluate the implementation and outcomes of the initiative.

5 Authority, accountability, and decision making.

The CRG is not a decision-making body rather provides advice to the PCG, Agency senior leadership and DoHAC on clinical matters related to the program including safety and quality issues, clinical care, consumer needs and preferences, enablers and obstacles to implementation and monitors for emerging clinical risks with a view to advising on suitable mitigations. The CRG advocates for the benefits of the project and reports back to the chair on matters of concern within their craft group or community.

6 Governance context

The governance context is shown below.

Program Control Group (PCG)

The DoHAC have established a PCG to oversee the program and provide strategic direction and assurance. The PCG will seek clinical advice and support from the CRG. Decisions that require clinical oversight will be referred to the CRG and that advice will be considered by PCG. Cross membership to both groups will facilitate reporting and efficient provision of advice.

Program Working Group

DoHAC will lead a weekly meeting between the Agency and DoHAC to support the running of the program including program status updates, management of risks and issues, reporting, engagement, communications activities and identifying items for escalation as required.

7 Governance pathways, reporting and escalation.

The CRG reports to the PCG. Matters for consideration will be referred from the PCG to the co-chairs for deliberation. The co-chairs will use best endeavours to reach consensus on an issue, however, where consensus cannot be reached, assenting and dissenting opinions will be recorded and reported to the PCG.

8 Guiding principles

The guiding principles for the CRG align to the Agency's Clinical Governance Framework for Digital Health. They are:

- **Leading with our people** - Leading with our people requires effective leadership and refers to how individuals behave, communicate, interact with and influence others in the context of their role. Leaders may arise from any part of the workforce.
- **System safety and quality improvement** - The system safety and quality improvement principle collectively refers to an approach that encompasses clinical safety, continuous improvement and clinical safety risk and incident management.
- **Evidence-based Practice** - Evidence-based practice in health technologies involves a structured approach to gathering, interpreting, analysing and evaluating internal and external data, insights and existing research to inform the design, development and delivery of our products and services.
- **Person-centredness** - Person-centredness means always maintaining our focus on consumers and listening to their needs, goals, values, preferences and experiences to ensure the design and delivery of clinically safe, quality products and services.
- **Partnership** - Partnership involves working with consumers and our partners in the design, development and delivery of our products and services.

9 Standing membership

The CRG will consist of up to 30 members, consisting of representatives from relevant peak bodies, professional associations, consumer groups (including consumers with lived experience), and other stakeholders involved in pathology and diagnostic imaging services. The members will be selected based on their expertise, experience, diversity, and ability to represent their organisations or sectors.

The confirmed membership of the CRG is below:

#	Role	Participant	Title	Organisation
1	Co-Chair	Dr Steve Hambleton	Chief Clinical Advisor	Australian Digital Health Agency (ADHA)
2	Co-Chair	Conjoint Associate Professor Carolyn Hullick	Chief Medical Officer	Australian Commission on Safety and Quality in Health Care (ACSQHC)
3	Member	Dr Andrew Hugman	Digital Health Medical Advisor	ACSQHC
4	Member	Herbert Down	Branch Manager Clinical Governance and Assurance Branch	Australian Digital Health Agency (ADHA)
5	Member	Dr Glenn Edwards	Consultant Chemical Pathologist	Independent Expert
6	Member	Jackie O'Connor	Digital Health Subject Matter Lead	Allied Health Professions Australia (AHPA)
7	Member	Associate Professor Magdalena Simonis AM	General Practitioner	Australian Medical Association (AMA)
8	Member	Dr Lawrence (Lawrie) Bott	President	The Royal College of Pathologists of Australasia (RCPA)
9	Member	Dr Helen Toyne	Medical Officer MBS Policy and Review Branch	Department of Health and Aged Care (DoHAC)
10	Member	Clare Hagon	Director My Health Record Section, Digital Health Branch	Department of Health and Aged Care (DoHAC)
11	Member	Darlene Cox	Executive Director	Health Care Consumers Association (HCCA) in ACT
12	Member	Samantha Connor	Vice President	People with Disability Australia (PWDA)
13	Member	Dr Rebecca Jacobs	Medical Officer MBS Policy and Specialist Program Branch	Department of Health and Aged Care (DoHAC)
14	Member	Dr Rob Hosking	Chair RACGP Expert Committee Practice Technology and Management	Royal Australian College of General Practitioners (RACGP)
15	Member	Jarrod McMaugh	State Manager Victoria	Pharmaceutical Society of Australia (PSA)
16	Member	Sophie Potter	Digital Health Director	LGBTIQ+ Health Australia (LHA)

17	Member	Harry Iles-Mann	Digital health expert adviser (ADHA) and Consumer representative adviser (DoHAC)	Health consumer leader
18	Member	Dr Jon Gillies	GP and public health physician	Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
19	Member	Christine Birch	Nurse Practitioner	Australian College of Nursing (ACN)
20	Member	Dr Tanya Wood	Chief Medical Officer Qscan	Australian Diagnostic Imaging Association (ADIA)
21	Member	Dr Lincoln Gillam	Radiologist	The Royal Australian and New Zealand College of Radiologists (RANZCR)
22	Member	Dr Rae Donovan	A/Chief Clinical Information Officer	eHealth Queensland
23	Member	A/Prof Kudzai Kanhutu	College Dean	Royal Australasian College of Physicians (RACP)
24	Member	Sean Mutchmor	General Manager Quality and Safety	Australian College of Rural and Remote Medicine (ACRRM)

The CRG co-chairs may invite external experts or stakeholders to attend specific meetings as observers or presenters, as required.

The CRG members will be appointed for the duration of the initiative, or until they resign or are replaced by their organisations.

10 Member responsibilities

10.1 Chairperson

The CRG will be co-chaired by a senior representative from the Agency as well as the Chief Medical Officer (or alternate senior representative when required) from the Australian Commission on Safety and Quality in Health Care. The co-chairs will be responsible for:

- Convening and facilitating the CRG meetings
- Setting the agenda and providing relevant background information for each meeting
- Ensuring that the CRG operates in accordance with these terms of reference
- Ensuring that the CRG provides timely and constructive advice to the PCG
- Reporting on the progress and outcomes of the CRG to the PCG

10.2 Secretariat

The Agency will be responsible for:

- Providing secretariat support for the CRG meetings, including organising logistics, preparing minutes and action items, and following up on outstanding matters
- Providing technical support for the CRG members on using My Health Record
- Providing relevant information and data on the initiative to inform the CRG's deliberations
- Updating the CRG on the progress and outcomes of the initiative.

10.3 Standing members

The CRG members will be responsible for:

- Attending and actively participating in the CRG meetings
- Providing their expertise, perspectives, and feedback on the initiative
- Advising on the development of clinical support resources for the initiative
- Communicating with their respective organisations and stakeholders on the initiative
- Escalating any issues or concerns to the cochairs or the Secretariat as appropriate.

11 Quorum

A quorum includes one co-chairperson, and at least 50% of the standing members.

12 Meetings

12.1 Frequency and location

The CRG will meet at least quarterly, or more frequently as indicated and agreed to by the CRG. Frequency will be reviewed by the co-chairs and Secretariat at six months and adjusted to suit the needs of the program. The meetings will be held via videoconference or teleconference, unless otherwise agreed by the CRG.

12.2 Meeting pack

CRG members are supplied with a “meeting pack” at least five working days before each meeting to provide time for members to review the content.

The meeting pack includes:

- meeting agenda.
- previous meeting minutes, including actions and decisions, as draft for approval.
- supporting information, as necessary for agenda items.

12.3 Agenda

The co-chairs will set the agenda.

Members are required to submit proposed agenda items to the chairperson at least 30 days before the meeting.

The following items will be included in every agenda:

- Apologies and absences.
- Conflict of interest
- Approval of previous meeting minutes.
- Report from PCG
- Other business.
- Summary of decisions and actions; and
- Confirmation of next meeting date and location.

The CRG members will endeavour to reach consensus on their advice and recommendations. If consensus cannot be reached, the co-chairs will record the different views and report them to the PCG.

The CRG will operate in a transparent and collaborative manner, respecting the views and contributions of all members. The CRG members will abide by the Agency's code of conduct and confidentiality agreement.

12.4 Minutes

Minutes of the meeting will record all decisions made and assigned actions to group members, along with the target due date for reporting back to the group.

Meeting minutes will be circulated to members within seven working days after the meeting. Copies of minutes will be made available on request to:

- Agency Senior Leadership
- DoHAC program team
- PCG members
- External presenters and guests as required.

12.5 Out-of-session papers

Urgent matters that cannot be deferred until the next CRG meeting can be managed as an out–of-session paper. The out-of-session paper and cover sheet will be sent to members via email with a requested response date.

For a resolution to be approved, most members must acknowledge approval of the resolution by email by the response due date.

If approved, the resolution will be entered into the minutes of the next meeting.

13 Confidentiality and transparency

The CRG considers and discusses material that should be of a sensitive or commercial nature. Treatment of documents and knowledge associated with the Agency’s Work Programme will comply with the Agency’s standing policy on information handling. Members and attendees acknowledge their responsibility to maintain confidentiality of all information that is not in the public domain.

Sensitive information will be managed to ensure only employees with a valid reason to access and handle the information can access the material.

Approved information will be made available to support integrated and effective business operation.

The CRG will be formally minuted to ensure good governance practices are carried out, and to support effective operations of the committee in terms of creating a record of discussions aligned to the formal action and decision record.

Exclusions from the minutes may be made and in-camera sessions conducted at the committee chairperson's discretion.

Version history

Version	Date approved	Comments
0.1		First draft prepared for internal Agency and Department consultation.
0.2	22/9/2023	Second draft for Department consultation and endorsement. Comments from SC, BS, LT and JC incorporated.
0.3	26/10/2023	Third draft circulated with the Department and approved by SC.
0.4	30/10/2023	Feedback from BS and SC incorporated, updated participant list. Circulated with HD for final approval.
0.5	06/11/2023	Feedback from LT and CH actioned.
0.6	14/11/2023	Approved by HD for distribution as draft
0.7	23/11/2023	Updates applied and approved by Co-Chairs
0.8	28/11/2023	Updated to include full list of confirmed CRG Membership
0.9	15/12/2023	Suggested additions from membership actioned, final approved by PCG and CRG Co-Chairs

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Australian Digital Health Agency ABN 84 425 496 912, Level 25, 175 Liverpool Street, Sydney, NSW 2000 digitalhealth.gov.au
Telephone 1300 901 001 or email help@digitalhealth.gov.au

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