



AUSTRALIAN MEDICAL
ASSOCIATION
ABN 37 008 426 793

T | 61 2 6270 5400
F | 61 2 6270 5499
E | ama@ama.com.au
W | www.ama.com.au

39 Brisbane Ave Barton ACT 2600
PO Box 6090 Kingston ACT 2604

National arrangements for clinical quality registries AMA submission to the Australian Commission on Safety and Quality in Health Care consultation on revised Framework for Australian clinical quality registries Second Edition

CQR@safetyandquality.gov.au

Australian clinical quality registries (CQR) play an important role in monitoring the quality of health care within specific clinical domains towards the health system that ensures improved health outcomes for patients and is capable of self-improvement. The AMA welcomes the Framework 2nd edition, particularly its focus on national CQRs in prioritised clinical domains and procedures. Using the available health data for the purposes of health care planning at the health system level has been an ongoing AMA policy. Better use of data can improve productivity, efficiency and experience for health practitioners and provide evidence base for quality improvement, at the practice level and across the health system alike.

Overall, the AMA supports the Framework 2nd edition as outlined in the Consultation Paper and we congratulate the Australian Commission on Safety and Quality in Health Care (the Commission) on this detailed document. The AMA is particularly supportive of the principles of governance, security and privacy compliance and technical standards.

Our submission will only address issues that the AMA considers important from the interoperability and data governance perspective.

Suggestions for strategies to support CQR operators to implement the requirements

The AMA agrees with the Consultation Paper's acknowledgement that effective national reporting and achieving CQR purpose are hampered by any lack of standardisation and uniformity of health operating systems and data structures. And while the Framework 2nd edition is future focused and aims to provide contemporary guidance to assist CQRs, the AMA contends that the key prerequisite to achieving a learning health system will be achieving health system interoperability.

The key strategies in the AMA view will be stringent standards and national conformance arrangements for digital infrastructure to ensure unification of information across the healthcare sector. Standards and conformance arrangements create challenges for software vendors but are necessary to optimise efficiency and effectiveness of the Australian healthcare system.

Furthermore, the AMA supports adoption of consistent national interoperability requirements in government ICT procurement processes.

Strategic and operating principles for national CQRs

The AMA is fully supportive of the principles outlined in the Consultation Paper, in particular the following:

- Focus on safety and quality,
- Needs of diverse communities,
- Sound governance arrangements,
- Appropriate data governance frameworks, and
- Scalability.

The Consultation Paper rightly proposes that the Australian national CQRs should source data directly from clinical information systems which are updated through the course of patient care. However, there are currently limited possibilities for this due to lack of communication/interoperability between different clinical information systems. The AMA contends that Australia needs to accelerate the process towards achieving health system interoperability.

The AMA is fully supportive of standard definitions, terminology and specifications that enable meaningful comparisons of data and benefits from data linkage to other CQRs and other health data assets. This will not only increase the value of the national CQRs but will ultimately lead to improved health system efficiencies and patient health outcomes. The AMA has continuously been calling for automation of data collection and we are glad to see the Consultation Paper supporting it.

The AMA understands that national CQRs must capture sufficient patient identifying data to achieve the CQR purpose, including the Individual Healthcare Identifier data. Deidentification of these data by building processes into the interoperability is therefore supported. Along with this, establishment of and compliance with appropriate data governance processes will be crucial.

Governance

The AMA is supportive of the principles for data governance in CQRs as outlined in the Consultation Paper, including the responsibilities of the governing body, to ensure accountability and transparency. The AMA supports data governance frameworks that have clearly identified and stated data governance roles within relevant entities. Frameworks should define who can access data, the specific circumstances in which they can access the data, the purposes they can access and use data for, and how the data can be accessed.

The AMA is particularly supportive of the data custodianship provisions, with clear, publicly available statements of data custodianship, that is also tied with and outlined in relevant funding agreements.

The Consultation Paper puts forward a proposition that mechanisms should be put in place to ensure Aboriginal and/or Torres Strait Islander people and the priorities of culturally and linguistically diverse communities are considered by the data custodians of the CQR data. The AMA is supportive of this, noting that it is the AMA position that Indigenous data sovereignty principles must be obeyed when dealing with the health data of First Nations Australians.¹

The AMA is also supportive of the provision by which third parties wishing to access the data for secondary purposes such as research must seek approval from the data custodian and obtain relevant Institutional Ethics and/or Human Research Ethics Committee (HREC) endorsement where identifiable, potentially-identifiable or re-identifiable data are sought. This is fully in line with the AMA Position Statement on Data Governance and Patient Privacy.²

Health data for safety and quality improvement

The AMA is fully supportive of the principles outlined under the health data for safety and quality improvement heading.

The AMA notes that under Data Governance Roles and Responsibilities heading (1.4.2.5.) the 'data owner' category remains unresolved. The Consultation Paper notes that "further consideration and formalisation of data ownership will be undertaken through consultation as there is a move towards centrally hosted national infrastructure for quality improvement data, including the view that ultimately the data belongs to the patient". The AMA is supportive of this approach and looks forward to engaging in the consultation process. It is the AMA position that patients are owners of their data, and that other health stakeholders are just custodians of patient data.

Logical architecture and design

The AMA is supportive of the logical architecture and design, as outlined in the Consultation Paper and in Attachment 1 to the Consultation Paper.

As outlined in the paper, for CQRs to meet their full potential in informing the state of health care in Australia, confidence is needed in the quality and relevance of the data. One of the key steps in achieving that quality and relevance will be via implementation of standards, the leading of which will be interoperability standards. The AMA is pleased to see this being recognised.

The AMA agrees that Healthcare Identifiers (HIs) will be the key requirement for an enabling infrastructure to achieve interoperability. The AMA is however concerned that the recent proposals around expansion of HIs to non-health service providers may slow down the process of HIs implementation, resulting in slowing down the achievement of health system interoperability³ and consequently a national CQR.

¹ Australian Medical Association 2023. AMA Position Statement Data Governance and Patient Privacy in Healthcare 2023 <https://www.ama.com.au/articles/ama-position-statement-data-governance-and-patient-privacy>

² Ibid.

³ Australian Medical Association 2023. AMA Submission to the Department of Health Healthcare Identifiers Framework Consultation <https://www.ama.com.au/articles/ama-submission-healthcare-identifiers-framework-project-consultation>

Security compliance

The AMA is fully supportive of the key elements of information security outlined in the consultation paper:

- Information confidentiality – data only accessible and available to authorised entities,
- Information integrity – confidence that data has not been altered,
- Information availability – available to those authorised when and where required.

These are fully in line with the AMA position which states that healthcare entities that collect and store patient data must ensure that there is a single source of truth – a single data repository, so that data are easy to find, access, use and share, within the relevant data safety and privacy principles. Appropriate data governance should enable and ensure protection of the integrity of data, preventing unauthorised access to data, data loss, data modification or deletion.

Data governance frameworks should define who can access data, the specific circumstances in which they can access the data, the purposes they can access and use data for, and how the data can be accessed.

Conclusion

The AMA thanks the Commission for the opportunity to submit to this consultation. We remain open to further consultations on patient data ownership.

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Contact

president@ama.com.au