MAXIMISING THE POTENTIAL OF AUSTRALIAN CLINICAL QUALITY REGISTRIES

A SUBMISSION IN RESPONSE TO THE DRAFT NATIONAL CQR STRATEGY

June 2019

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Research Australia is the national alliance representing the entire health and medical research pipeline, from the laboratory to patient and the marketplace.

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our role:

Engage
Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect
researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence
government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

Nadia Levin
CEO & Managing Director
02 9295 8547
nadia.levin@researchaustralia.org

www.researchaustralia.org
384 Victoria Street Darlinghurst NSW 2010

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Summary of recommendations

Clinician/Patient Partnerships	Patients should be involved in deciding the data that CQRs collect.
	CQRs should consider collecting data that goes beyond patient/clinician interactions to include patient relationships with other staff within the health system.
	The roles and perspectives of the patient's family, especially primary care givers, should also be recognised as important.
National CQRs are Quality Assured, Efficient and Effective	Incentives and support need to be provided to achieve and maintain accreditation.
	Consideration should be given to reviewing and amending the Clinical Governance Standard to support the operation of accredited CQRs and the use and adoption of CQR outputs.
	The Strategy should explicitly state that CQRs are first and foremost a quality assurance and improvement tool for the health system.
	The creation and operation of a CQR should not be subject to the approval of a Human Research Ethics Committee. The role of HRECs in relation to CQRs should be restricted to the consideration of research proposals that are using data from CQRs or otherwise undertaking research on CQRs.
	In relation to patient consent, inclusion of patient data in a CQR should be considered part of the primary purpose for which that data is collected (along with providing treatment and administrative activities such as reimbursement) and not a secondary purpose, such as research. The development and application of data governance standards should also be undertaken on the basis that CQR data are patient data.
	The Strategy needs to support the development of an appropriate governance framework for CQRs. This includes consideration of what changes may need to be made to legislation and regulations at the national, state and territory levels. At the national level, this framework could draw on and extend the provisions in the Health Insurance Act 1973 relating to Quality Assurance Activities. While these provisions are limited in their scope, they are currently utilised by a number of CQRs.

The potential value of national CQR data is maximised	Standardised data access policies and procedures will be key to improving access and should be included as part of the proposed CQR standard.
	Providing access to CQR data can be costly and requires appropriate resources to be available to extract and curate datasets. The Strategy needs to address how these costs will be met, including the circumstances in which data is to be provided at no cost to the requester of data.
	The Strategy correctly identifies the need to consider CQRs in the broader context of making better use of health data and initiatives currently being undertaken in this regard. To this end, it is important the CQR data is characterised as health data (rather than research data) and treated as such.
	Research Australia agrees with the statement in the Strategy that *'CQR digitalisation, interoperability and integration would need to be phased in over the life of the Strategy and beyond, as digital health reforms proceed and health care information systems and capabilities develop.'* (page 30) It is equally important that CQRs are explicitly included in the broader initiatives in relation to health data, to ensure that these elements are able to evolve simultaneously with the broader health data environment.
Sustainable funding for National, Prioritised CQRs	While Strategic Objective 4 specifically focuses on the National Prioritised CQRs and developing a funding model for these should be a priority, it must also address the need for a broader pool of funding and resources to help achieve the broader implementation of the Strategy.
	Beyond the patients themselves, the greatest beneficiaries of a successful CQR Strategy will be the health system and its funders. As the primary funders of Australian health care, the Commonwealth, State and Territory governments should be the primary source of funding to support the Strategy.

MAXIMISING THE POTENTIAL OF AUSTRALIAN CLINICAL QUALITY REGISTRIES

Introduction

Research Australia welcomes the opportunity to make this submission in response to the Draft National Clinical Quality Registry Strategy (the Strategy).

Action to improve the operation of Australian Clinical Quality Registries (CQRs) has a long history. Both the *Strategic Principles for Clinical Quality Registries* and the *Operating Principles for Clinical Quality Registries* were endorsed by Health Ministers in 2010, and the Framework for Australian Clinical Quality Registries was published by the Australian Commission on Safety and Quality in Health Care in 2014.[1] The current consultation on the Strategy is the next step in the evolution of CQRs in Australia.

Research Australia is broadly supportive of the strategy. The need for a national strategy is evident in the current health landscape. When it comes to CQRs there are pockets of excellence and evidence of positive impact on delivery of health care. But the coverage and results are patchy. A national strategy has long been lacking and is sorely needed.

The greatest opportunities for improvement and innovation in our healthcare system lie in the systematic application of evidence-based healthcare, driven by health data. With Australian healthcare expenditure in 2016/17 estimated to be $181 billion, even relatively small efficiency improvements can have significant economic benefit.[2] Clinical Quality Registries can be a valuable source of high quality, well structured data that can point the way to higher quality, more consistent, more effective and efficient care.

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[1] Australian Commission on Safety and Quality in Health Care, Framework for Australian clinical quality registries. Sydney. ACSQHC, March 2014.

[2] Australian Institute of Health and Welfare 2018. Health expenditure Australia 2016–17 Health and welfare expenditure series no. 64

Strategic Objective 1: Clinician/Patient Partnerships

Research Australia welcomes the focus of this first objective on ensuring CQRs contribute to patient centred care and outcomes.

The Strategy clearly recognises the role of patients as the contributors of information through PREMs and PROMs. It also recognises the role that patients can play in interactive CQRs as contributors of data. These are important contributions that patients can make.

What is not explicitly recognised is the role that patients can play in determining the information collected by CQRs. This includes patients not just being involved in the design of PREMs and PROMs but bringing the perspective of the patient (‘what matters to me?’) to all the information collected by the registry.

In this regard, the patient’s experience of care is influenced not just by their direct dealings with clinicians but their interactions with other hospital staff and all aspects of the hospital system, including pre-admission, during admission and post discharge. And patients’ perspectives of what constitutes quality care, including the critical issue of patient safety can be very different to the perspective of clinicians.

> *‘Progress in improving patient safety is slow, and researchers and policy-makers are arguing more vigorously for patients to be involved in reporting on all dimensions of quality and ensuring care is appropriate and safe. This is part of the call for organisational learning and meaningful involvement of patients at all levels of governance and service design, as well as a more pragmatic desire to improve safety reporting to enable its better use in prevention and improvement.*
>
> *O’Hara et al investigate patients’ concerns about safety, how their reports match those of clinicians, and how patients make sense of and categorise their concerns. The results show that patients do not ‘over-identify’ patient safety incidents (PSIs): the concordance between the proportion of patients (10%) identifying a safety issue and the proportion (10%) harmed by an incident identified via case note review or a clinical incident report is high. But patients and clinicians do not see safety incidents the same way: only one in three (35%) of the incidents patients report matches the clinicians’ PSIs, and the majority (65%) of the patients’ incidents are not considered PSIs by the clinicians.*[3]*’*

Achieving the Strategy’s vision of ‘systematically (driving) patient-centred improvements in the quality and value of health care and patient outcomes’ may require the collection of data that goes beyond purely clinical data and includes this broader perspective of the patient experience. The only way to find out is to include patients in the design and ongoing review of CQRs.

A broader implication is that we need to move beyond the focus on the clinician/patient relationship; recognising that the delivery of quality care involves a broader partnership which includes other hospital staff and administrators. The role and perspective of the patient’s family, especially carers, should also be recognised as important.

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[3] Fitzsimons B, Cornwell J What can we learn from patients’ perspectives on the quality and safety of hospital care? BMJ Quality & Safety 2018; 27:671-672.

Research Australia is not suggesting that CQRs should capture all aspects of the patient's experience of healthcare- doing so would distort the meaning and function of a clinical quality registry. We are asserting, however, that recognising the broader context within which care is provided and ensuring that this is considered in the design of a CQR is essential to achieving the Strategy's vision.

Research Australia recommends that Strategic Objective 1 be broadened to recognise the importance of, and include, patient relationships and interactions with other staff within the health system, and to include the perspective of carers where appropriate.

Strategic Objective 2: National CQRs are Quality Assured, Efficient and Effective

This strategic objective of ensuring CQRs are quality assured, efficient and effective is central to the entire Strategy.

Quality Assurance

As noted in the introduction, action to improve the operation of Australian CQRs has a long history. Research Australia is supportive to the proposal that the ACSQHC update the Framework and develop it into a Standard. We are also supportive of the proposal to develop an accreditation scheme based on the Framework Standard.

These two initiatives provide the greatest opportunity to raise the quality, efficiency and effectiveness of CQRs. This will be most effective if incentives are provided to achieve and maintain accreditation. These incentives could include access to funding but also by making resources available to accredited CQRs. These resources could include training and technical support, and need to be considered together with Strategic Objective 4: Sustainable Funding for National, Priories CQRs. Other incentives could include the streamlining of external barriers for accredited CQRs (see below).

As part of the Strategy, consideration should also be given to reviewing and amending the Clinical Governance Standard, specifically the Measurement and Quality Improvement component, to support the operation of accredited CQRs and the use and adoption of CQR outputs. The timing of this review should follow the implementation of the accreditation framework for CQRs. Mandating a level of support by health services for accredited CQRs would emphasise the importance of CQRs as a quality improvement tool and provide an incentive for CQRs to seek and maintain accreditation.

National CQR communication and collaboration

Research Australia supports the proposals to develop and implement a national CQR communication and collaboration plan and hub. It is clear that CQRs have much they can learn from each other, and that to date this process has been hindered by the dispersed nature of many CQRs and a lack of resources. The proposed communication plan and hub will be able to play a critical role in the development and adoption of a CQR Framework and supporting accreditation. It will also provide a forum for promoting the benefits of CQRs to the health sector more generally. Needless to say, it will require ongoing funding.

Streamlining external barriers

Research Australia believes the Strategy needs to explicitly state that CQRs are first and foremost a quality assurance and improvement tool for the health system. As such, CQRs (and in particular accredited CQRs) need to be recognised as an integral part of a self-improving health system and not an activity or database that is external to the health system or incidental to the delivery of health care.

This understanding of CQRs has implications for the external barriers identified in the Strategy and how they should be addressed. These include how CQRs are governed, operated and funded.

As a consequence, Research Australia submits that the creation and operation of a CQR should not be subject to the approval of a Human Research Ethics Committee (HREC). The role of HRECs in relation to CQRs should be restricted to the consideration of research proposals that are using data from CQRs or otherwise undertaking research on CQRs.

In relation to patient consent, it means that inclusion of patient data in a CQR should be considered part of the primary purpose for which that data is collected (along with providing treatment and administrative activities such as reimbursement) and not a secondary purpose, such as research.

The development and application of data governance standards should also be undertaken on the basis that CQR data are patient data.

The Strategy needs to support the development of an appropriate governance framework for CQRs. This includes consideration of what changes may need to be made to legislation and regulations at the national, state and territory levels. At the national level, this framework could draw on and extend the provisions in the Health Insurance Act 1973 relating to Quality Assurance Activities. While these provisions are limited in their scope, they are currently utilised by a number of CQRs. They are also utilised by a range of other quality assurance activities, including clinical audits, which could be supported by an appropriate CQR. As such, they provide a partial model for how CQRs could be treated from a regulatory perspective.

Strategic Objective 3: The potential value of national CQR data is maximised

Research Australia agrees that maximising the potential value of CQRs requires improved access to CQR data by a range of different people and stakeholders, and linkage with other datasets.

Improved access to CQR data and outputs

Research Australia agrees that it is important to consider the greater use of CQR data in the broader context of data sharing and use.

Standardised data access policies and procedures will be key to improving access and should be included as part of the proposed CQR standard. Research Australia is also conscious that providing access to data can be costly and requires appropriate resources to be available to extract and curate datasets. The Strategy needs to address how these costs will be met, including the circumstances in which data is to be provided at no cost to the requester of data.

Data Linkage, CQR interoperability and integration

Research Australia welcomes the focus on data linkage, interoperability and integration. We believe now is the right time to be considering these matters, at a juncture when the value of health data is increasingly being recognised, and as steps are being taken to improve the quality, accessibility and use of data generally.

The Strategy refers to the Australian Productivity Commission's report on Data Availability and Use. While the Commission's report looked across the whole economy and all of government, it recognised that health was one of the areas where better use of data could provide the greatest benefits. It also identified that it was an area where there were significant barriers to doing so.

> *'The technical inability of different parts of the health system to share information to improve patient care is an indication of how poor Australian health information systems can be.*
>
> - *IT system design and contracting place deliberate limits on interoperability. Some contract terms actively preclude proprietary systems exchanging data with other systems.*
> - *Health service providers face limited incentives in regard to interoperability and data transfer, and may have entrenched governance and service delivery models that do not place great emphasis on, or provide rewards for, data portability. Government procurement policies are similarly at fault.*
> - *The complexity of healthcare data means that standards development is a necessary part of any interoperability solution*[4]*'*

While the above comments were not made specifically in relation to CQRs but about health information systems as a whole, they are nonetheless applicable to CQRs.

The Strategy correctly identifies the need to consider CQRs in the broader context of making better use of health data and initiatives currently being undertaken in this regard. To this end, it is important the CQR data is characterised as health data (rather than research data) and treated as such.

Research Australia agrees with the statement in the Strategy that *'CQR digitalisation, interoperability and integration would need to be phased in over the life of the Strategy and beyond, as digital health reforms proceed and health care information systems and capabilities develop.'* (page 30)

It is equally important that CQRs are explicitly included in the broader initiatives in relation to health data, to ensure that these elements are able to evolve simultaneously with the broader health data environment.

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[4] Productivity Commission 2017, Data Availability and Use, Report No. 82, Canberra, page 509

Strategic Objective 4: Sustainable Funding for National, Prioritised CQRs

Achieving a sustainable and adequate funding mechanism for CQRs underpins the whole of the CQR strategy. The absence to date of a coherent funding mechanism for CQRs is a key reason why the CQRs that currently exist are so disparate, poorly coordinated and frequently poorly resourced; preventing them from better communicating their findings and having a greater positive impact on health care.

This situation is recognised by the Strategy.

> *'The **lack of sustainable, sufficient funding** is another key challenge hindering the efficient and effective operation and the ability of CQRs to reach their potential, addressed by Strategic Objective 4: Sustainable Funding for National, Prioritised CQRs.' (page 19)*

While this statement asserts that this issue is addressed by Objective 4, in fact Objective 4 deals only with funding for the national **prioritised** CQRs, and not the broader group.

While Strategic Objective 4 specifically focuses on the National Prioritised CQRs and developing a funding model for these should be a priority, it must also address the need for a broader pool of funding and resources to help achieve the broader implementation of the Strategy. For example, funding will be required to help CQRs achieve accreditation and to fund an accreditation process. Post accreditation, funding will be needed for activities and initiatives that support accredited CQRs and help them improve their quality and efficiency, and increase their impact, as envisaged by the Strategy. Accreditation should not be limited to the National, Prioritised CQRs.

As Research Australia has argued above, CQRs are primarily a quality improvement tool for the health system. This is reflected in the benefits section for each of the Strategic Objectives, '*How will action benefit patients?*', with the identified benefits being improvements in patient care, better health outcomes, and greater equity in outcomes across the health system. Research Australia believes that other benefits for the health system will be from greater efficiency and effectiveness in the delivery of health care.

Beyond the patients themselves, the greatest beneficiaries of a successful CQR Strategy will be the health system and its funders. And as the primary funders of Australian health care, the Commonwealth, State and Territory governments should be the primary source of funding to support the Strategy.

Conclusion

The role CQRs can play in supporting a self-improving health system are evident in many parts of the world, but despite pockets of excellence these benefits have largely been unrealised to date in Australia. A clear and appropriately resourced strategy with the backing of the key stakeholders in Australian health care can change this.

While the current draft strategy has many of the necessary elements, there are some key areas in which it needs to be amended and strengthened. The first is a recognition that the focus has to be broader than the patient/clinician relationship and capture the interactions of patients and their carers throughout the course of their experience with our health system.

The second is an explicit recognition that CQRs are an integral part of a modern, self-improving health system, and that the activities of CQRs and the purpose for which they capture data are integral to the delivery of health care and the operation of health systems. The datasets produced by CQRs are also a valuable resource or health and medical research but this is a secondary purpose.

CQRs, the data they hold and the datasets they produce need to be considered in the broader context of initiatives to improve the availability and use of data, particularly health data.

Finally, the Strategy is going to require ongoing sustainable funding. This funding must not be restricted solely to the identified national prioritised CQRs. Some funding must be available to supporting other CQRs, particularly those that are accredited or applying for accreditation.

RESEARCH AUSTRALIA LIMITED
384 Victoria Street, Darlinghurst NSW 2010
P +61 2 9295 8546 **ABN** 28 095 324 379
www.researchaustralia.org