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**Submission: National Clinical Quality  
Registry Strategy**

Australian Health Ministers' Advisory Council

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## **About The Royal Australasian College of Physicians (RACP)**

The RACP trains, educates and advocates on behalf of over 17,000 physicians and 8,000 trainee physicians, across Australia and New Zealand. The College represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

# Submission on Draft National Clinical Quality Registry Strategy

## Introduction

The College supports the development of national clinical quality registries (CQRs) and the development of a national strategy with a prescribed timeline to guide the completion of its objectives. CQRs have a significant role in reducing variation in treatment and outcomes, monitoring quality of care, being a source of credible feedback, detailing patterns of treatment and acting as a barometer for performance<sup>1</sup>. A further application is in reducing health care costs. These are core responsibilities in a universal health care system.

This is an important national initiative that will underpin the existing few national registries in Australia and support the consistent development of others. Our member physicians are aware that CQRs can propel improvements in health care quality, by reporting on both the appropriateness of care (process) consistent with clinical practice guidelines, and the effectiveness of care (outcomes)<sup>2</sup>. Some of our member physicians have been involved in the development of different registries in the last 10-15 years, for example members of the Australasian Society of Clinical Immunology and Allergy (ASCIA), and this submission draws on this experience.

The College agrees that a strategy is needed to deliver on the four strategic health system reform priorities stated by the Council of Australian Governments (COAG) in 2018:

- Improving efficiency and ensuring financial sustainability;
- Delivering safe, high quality care in the right place at the right time;
- Prioritising prevention and helping people manage their health across their lifetime; and
- Driving best practice and performance using data and research.

The potential of CQRs has most likely been underutilised for number of reasons; one being because they have not been established to report quality of care data back to health services, but rather to examine patterns of care, variation in treatment and outcomes and suggest predictors of prognosis and quality of life<sup>3</sup>. A national strategy can assist in embedding better feedback loops.

Further, a national strategy ideally will assist in addressing potential differences between administrative collections of information and clinical registries that contain information that is able to be used in research and quality monitoring projects, of peer review standard.

We anticipate that much important detail may be contained in the final strategy. This will need to be supported by an implementation plan (such as actions, timeframes, performance indicators and governance arrangements). We hope that these comments from the RACP can contribute to the development of this important national strategy.

## Overall comments

The College supports the development of national clinical quality registries through a strategic, methodical approach. Importantly, registries can assist in promoting the awareness of and development of safer responses to variations in or suboptimal outcomes of procedures. Monitoring and responding to suboptimal outcomes can prevent further hospitalisations (for recurrent angina and heart failure), thereby preventing additional costs and reduced quality of life<sup>4</sup>. For example, cardiac procedures involving angioplasty and stenting in which variations in factors such as operator skill and annual volumes of procedures had not been routinely monitored across Australia.

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<sup>1</sup> Hoque, D.M.E., Kumari, V., Hoque, M., Ruseckaite, R., Romero, L. and Evans, S.M., 2017. Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review. *PloS one*, 12(9), p.e0183667.

<sup>2</sup> Wilcox, N. and McNeil, J.J., 2016. Clinical quality registries have the potential to drive improvements in the appropriateness of care. *Medical Journal of Australia*, 205(S10), pp.S21-S26

<sup>3</sup> Hoque, D.M.E., Kumari, V., Hoque, M., Ruseckaite, R., Romero, L. and Evans, S.M., 2017. Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review. *PloS one*, 12(9), p.e0183667.

<sup>4</sup> Evans, S.M., Scott, I.A., Johnson, N.P., Cameron, P.A. and McNeil, J.J., 2011. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*, 194(7), pp.360-363

There has been several years between the development of [Framework for Australian Clinical Quality Registries](#) (2014) and this draft Strategy. The need for more nationwide clinical registries that would provide a source of valid, reliable and clinically credible measures of quality that can be compared across institutions here and overseas has been noted for some time.<sup>5</sup>

A national strategy is key to building a set of effective national clinical quality registries. Currently there are several national registries in Australia that capture a high proportion of their eligible patient populations. For example, the Australia and New Zealand Dialysis and Transplant Registry, the Australian Orthopaedic Association National Joint Replacement Registry, the adult and paediatric registries run by the Australian and New Zealand Intensive Care Society, the Australasian Rehabilitation Outcomes Centre and the Palliative Care Outcomes Collaboration<sup>6</sup>. There is also the Cancer Institute NSW's data on cancer. This is a notable model, especially in reference to the direct feedback to health service Chief Executive Officers and directors of cancer services.

General comments provided by our members on the draft Strategy include:

- The Strategy responds to a current limitation in the clinical data field.
- The ten year timespan of the Strategy offers sufficient planning and implementation scope.
- The four objectives are appropriate and sufficient.
- The Strategy is founded on a solid set of comprehensive principles.
- The Strategy stipulates inclusion of all stakeholders that will benefit from the CQRs.
- Recognition of the value of obtaining patient perspectives is to be commended.
- The Strategy describes the benefits that can be obtained by highlighting international good performance, for example the Swedish Rheumatology Quality Registry;
- The Strategy builds on current areas of excellence within our own system such as initiatives related to prostate cancer outcomes and renal patients.

## Suggested improvements to the Strategy

In its present state the draft document has content which is more reflective of a discussion paper, or an environmental scan, rather than a national strategy. The strategy component itself is a much smaller section and comprises a summary table. We note:

- Although the Strategy states the time frame is 2019 – 2029 there is no high-level timeline or milestones included in this draft.
- Many of the suggested actions are framed as “could do’ or ‘this would’ which is non-directive and suggests another layer of decision-making. As such there is a potential that this Strategy will not sufficiently engage the relevant stakeholders as it lacks clarity and definitive strategies. As previously noted, the document reads as a discussion paper rather than a national strategy.
- The National Principles are repeated at length on pages 2 and 5.
- The lead responsible agencies often involve several agencies and although at times the same groups are listed, their order changes in different objectives (see pages 27 and 30). Does this mean the first listed organisation has primary responsibility and the others are involved? We suggest there is a need for greater clarity and specification of leadership. Strategic plans and actions are most often not achieved where leadership and responsibility are not clear.

## Points that require further development in the Strategy

### Stakeholders

- **Patient inclusion as stakeholders.** The College is supportive of a high level of patient inclusion in the Strategy. The document states on page 10 that *CQR clinician/patient partnerships also recognise that clinician leadership is a key factor in CQR success. In Australia, CQRs are generally developed and driven by groups of dedicated clinicians and experts, who are interested in obtaining data to improve the*

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<sup>5</sup> Evans, S.M., Scott, I.A., Johnson, N.P., Cameron, P.A. and McNeil, J.J., 2011. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*, 194(7), pp.360-363

<sup>6</sup> Wilcox, N. and McNeil, J.J., 2016. Clinical quality registries have the potential to drive improvements in the appropriateness of care. *Medical Journal of Australia*, 205(S10), pp.S21-S26.

*quality of health care.* We recommend that going forward patient feedback be enlisted as a genuine, integral part of the development of national clinical quality registries.

- Diagram 1 (page 11) does not represent the kind of patient centred approach that has been described in the Strategy, depicting patients more as an aside.
- The Chief Clinical Informatics Officers in different state health departments should also be engaged as important stakeholders.

### **Domains for CQRs**

- The draft Strategy's focus is on 'prioritised, national CQRs'. The College, whose members are physicians from a broad range of specialist treatment areas, would like to see actions, for the ten year timeframe of this Strategy that extend beyond the seven domains (page 33) to address a wider range of cardiovascular diseases such as heart failure, and other high cost, high burden conditions like COPD, chronic kidney disease and combinations of chronic conditions. Some conditions may be under-diagnosed when they are co-morbid.

### **Data collection across care interfaces**

- As many of our consultant physicians work in a variety of care delivery settings we recommend the strategy places sufficient emphasis on the need for registries to collect information across care interfaces. This is important for encouraging integrated care approaches, for being able to understand patient outcomes beyond the short term, episodic service, and importantly to use data to improve coordinated health care delivery for the pressing number of patients with chronic and multiple conditions<sup>7</sup>.

### **Foundations of the CQRs.**

- The quality of the data are critical. We stress the importance of ensuring there are data dictionaries and rules for coding data and range and validation checks of data as it is entered into the registry.
- There appears to be an absence of a foundational data model that describes the relationships between clinical data entities.

### **Completeness of data**

- It is relevant to have an adequate record of what the clinician was thinking and why, i.e. provision for questions such as (a) *How sure are you that the condition is present* and (b) *Why*. We need an indication of the clinician's assessment of the priors, and their deductions.
- In the strategy's current form, there is a risk that inadequate data will be captured, and integration will become problematic or even slipshod as the data volumes grow. Badly done, there will also be progressive divergence between 'registries' on the one hand and clinical recording of data, on the other; it is highly desirable that the two move closer and closer together as we strive for clinical excellence across the board.
- **Primary care data.** This is a form of data that is not mentioned in the Strategy, nor are Primary Health Networks (PHNs). A national primary care minimum dataset is needed. Without this kind of data, the approach to care can never be patient centred because it overlooks the degree of co-morbidity and the trend towards more community based care, through integrated care models. One source of data to consider is NPS MedicineWise's MedicineInsight, a source of primary care data, that has strong governance models.
- **Information technology capacity to incorporate data changes.** Systems which build in flexibility such that changes in diagnosis and treatment which evolve over time, will be needed.

### **Data sovereignty**

Principle 3 in the Strategy refer to ensuring *equitable access to CQR information and improvements in health care and patient outcomes for all Australians, including Aboriginal and Torres Strait Islander people and vulnerable communities.*

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<sup>7</sup> Evans, S.M., Scott, I.A., Johnson, N.P., Cameron, P.A. and McNeil, J.J., 2011. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*, 194(7), pp.360-363

The College suggests that data sovereignty of Indigenous people in Australia requires further consideration in this document. This relates to the recognition of provision for Indigenous people to managing, protecting and controlling their data. The College supports Indigenous people being primary beneficiaries of the use of such data contained in CQRs. The collection of data on Indigenous people in Australia should not be viewed primarily in terms of meeting government objectives but also supporting positive evidence-based Indigenous policy-making.

We recommend consulting Maïam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective, which was established to develop Aboriginal and Torres Strait Islander data sovereignty principles and to identify Aboriginal and Torres Strait Islander strategic data assets.

### **Rural and geographically isolated communities.**

- This Strategy offers an opportunity to optimise and enhance service delivery especially for geographically isolated populations or individuals with rare diseases.

**Ethical issues** related to the establishment and maintenance of databases have in the past developed substantial barriers to the development of these tools. These include a lengthy process of approval especially when multiple sites are involved. Ethics cover is generally time limited and expiry of cover and the processes associated with regular renewals considered a disincentive to the creation and maintenance of QRs. We note that the draft Strategy refers to this problem on pages 18 and 26.

## **Strategy objectives**

The College sees these draft objectives as complete and no others are needed at this high level.

Below we provide comments and observations on each of the Objectives in the draft document, responding to the questionnaire.

### **Objective 1: National CQRs are based on clinician/patient partnerships.**

- **Facilitating and addressing good clinician/patient partnerships for CQRs.** Clinician/patient partnerships are not well defined. The reporting of clinician results can be sensitive because of a propensity for social media platforms highlighting negative reviews.
- On the question in the survey about greater clinician/patient interaction with CQRs, we support processes that prompt reflection on performance. Ideally, this should be part of peer review.
- **PROMS/EMS.** On the use of PROMS/EMS it is important to address the range of actions that might follow when these are collected.
- Clinicians must be able to access and manipulate their own data, and training and education is required in order to be comfortable in interpreting the implications. This is critical for service development as well.

### **Objective 2: National CQRs are quality assured, efficient and cost effective**

- Data collection is increasingly automated from source systems, and therefore standards for the source systems are needed.
- The College supports the establishment of an accreditation system for registries. Assessing data reliability is often less than ideal in current practice most likely due to the limited resources available to registries to undertake this important quality assurance activity<sup>8</sup>. However, accreditation should not be onerous as there are many hoops to jump through already.
- Communities of practice are important elements for engagement and communication and encouraging consistent input.
- Data linkage is a key aspect that underpins the Strategy objectives.

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<sup>8</sup> Md. Emdadul Hoque, D., Ruseckaite, R., Lorgelly, P., McNeil, J.J. and Evans, S.M., 2018. Cross-sectional study of characteristics of clinical registries in Australia: a resource for clinicians and policy makers. *International Journal for Quality in Health Care*, 30(3), pp.192-199.

- On streamlining external barriers such as ethics approval, site governance and data collection processes, we note that there are substantive interjurisdictional issues in relation to ethics on cross state registries. Site governance has deteriorated at the expense of improvement in ethics processes.

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

- In Table 1 (page 3) under 'actions' for Objective 3 it is not apparent why an *environment* that supports the provision of data needs to be 'identified' if it is also being 'created' through the Strategy actions.
- **Completeness and accuracy of data.** The CQRs must be more than tools for internal quality assurance assessment, and rather must become tools used to monitor and benchmark performance and stimulate improvement in service delivery. Therefore, quality of the data should be complete and accurate, provide for risk adjustment and be subjected to quality control checks. It will be important that the focus of the registry is on improving patient outcomes and not on emphasising the poor performance of particular caring services<sup>9</sup>.
- **Data provided to health services.** It is important CQRs collect data that is meaningful to health services and is reported back to them, allowing services to self-monitor and benchmark themselves<sup>10</sup>. We recommend this feedback loop be explicit in the Strategy. Often population-based registries store data for reporting to government and for research purposes but fail to collect data which is meaningful to health services to assess their performance. If the data is not made available to the health services, they cannot see how they compare with others and with themselves over time.
- **Including data on sequenced steps of condition management.** We note there is specific inclusion of the need to include registries that focus on areas of medicine where achievement of good outcomes depends on a well performed sequence of care from different providers. In some managed care conditions and health pathways, it can be critical that sequenced steps are followed. This sort of data will be increasingly important as we emphasise the need for more integrated care across healthcare sectors.
- **Specific devices, procedures and drugs.** It will be important the strategy makes provision for the medium to long-term monitoring of specific devices, procedures and drugs. This is to maximise safety<sup>11</sup>, and consumer protection.
- **Engaging clinicians.** The Strategy recognises the importance of collecting data on entire patient populations. To do this strategies and actions will need to support the engagement of clinicians who care for the patient population.<sup>12</sup>
- **Administrative health care data.** There should be more detail or guidance on how administrative health care data can be interfaced and form part of the Strategy. For example, administrative health care data could be a valuable and cost-efficient method of collecting data on conditions such as COPD, both for health care quality monitoring and for epidemiological research. Administrative registries are a source of readily available data on target populations, although quality standards may vary for example, in relation to research and in quality measurements.
- **Relevance to health system costs.** We support the use of CQRs as a means of documenting and capturing health system costs that may not be confined to siloed places defined by location.
- To maximise the potential value of CQR data, we suggest using the outcomes/outputs from CQR as measures of value in health care system rather than the present focus on volume.

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<sup>9</sup> Evans, S.M., Bohensky, M., Cameron, P.A. and McNeil, J., 2011. A survey of Australian clinical registries: can quality of care be measured?. *Internal medicine journal*, 41(1a), pp.42-48.

<sup>10</sup> Hoque, D.M.E., Kumari, V., Hoque, M., Ruseckaitė, R., Romero, L. and Evans, S.M., 2017. Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review. *PloS one*, 12(9), p.e0183667.

<sup>11</sup> Evans, S.M., Scott, I.A., Johnson, N.P., Cameron, P.A. and McNeil, J.J., 2011. Development of clinical-quality registries in Australia: the way forward. *Medical Journal of Australia*, 194(7), pp.360-363

<sup>12</sup> ACSQC 2016 Prioritised list of Clinical Domains for Clinical Registry Development <https://www.safetyandquality.gov.au/wp-content/uploads/2016/12/Prioritised-list-of-clinical-domains-for-clinical-quality-registry-development-Final-report-Nov-2016.pdf>

- **Access to data.** To support the creation of an environment that supports access to tailored CQR information for consumers, health care providers and funders, we need:
  - Better health and digital literacy
  - Websites, apps and portals with improved interfaces
  - To translate the outputs of CQR into shared decision-making tools.
- **Benchmarks.** The questionnaire asks for key actions that would facilitate the use of CQR data for clinical care improvements via benchmarking. On this matter the College recommends that clinicians decide the benchmarks. These need not be not 'one size fits all'. For example, in the surgical space there are different benchmarks for different operations. Further, public reporting will also facilitate the use of CQR data for clinical care improvements via benchmarking.
- On Diagram 2, page 16 we suggest reducing the duplication implied in the diagram, which can impact on quality and safety. In this diagram many of the bubbles overlap (such as HACS and NSQHS standards).
- The questionnaire asks for key actions that would facilitate the **use of CQR data for clinical trials and research purposes**. On this, natural experiment studies can be enabled. Comparative effectiveness research (CER) would be enabled (that is comparing existing health care interventions on which works best for which patients, and also to determine those with more benefits than harms).

#### **Objective 4: National, prioritised CQRs are sustainably funded**

- This objective is vital and arguably should be addressed earlier as it underpins this Strategy.
- To facilitate national CQR data linkage, interoperability and integration with Australia's health information systems and infrastructure, we would like to see this initiative treated like other major infrastructure and for it to have secure recurrent funding. Many Registries and databases in the past have relied on funding from Pharmaceutical companies. Independent funding would be optimal.
- It is also important that high standards are imposed on software vendors.
- Included in a sustainable CQR funding model for national, prioritised CQRs, there will need to be incentives for clinicians and patients to contribute quality data.
- The collection of data should be embedded into source systems
- For a co-ordinated, prioritised approach to the funding of CQRs, we note the relevance of the Medical Research Future Fund (MRFF).