

# **Maximising the Potential of Australian Clinical Quality Registries**

*Using Data to Drive Improvements in Patient Care and Outcomes*

## **A National Strategy 2019-2029**

## Acknowledgements

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## Executive Summary

The National Clinical Quality Registry (CQR) Strategy aims to maximise the considerable potential of Australian CQRs through a strategic, national, coordinated approach.

High functioning, mature<sup>1</sup> CQRs are key vehicles for:

- driving continuous improvements in patient-centred health care and outcomes;
- improving the value of health care; and
- contributing to the sustainability of health care systems.

CQRs monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting and analysing clinical performance data. They can provide clinicians, health service managers, patients and other stakeholders with ongoing, risk adjusted, benchmarked feedback on clinical practice and patient outcomes, to improve the standard of care.

CQRs may be free standing, with all components (governance, data analysis, data hosting, data collection) housed together or may have one or more of those components virtually integrated.

An economic evaluation of Australian CQRs supported the international evidence that CQRs ‘when correctly implemented and sufficiently mature’, can deliver significant **returns on investment, in relation to ‘...greater survival for patients, improvements in quality of life after treatment and avoided costs of treatment or hospital stay’.**<sup>i</sup>

To date, there has been no guiding, overarching Australian strategy to optimise the contribution of CQRs to improved outcomes for patients and ensure that returns on investment are maximised. The Strategy seeks to address issues such as the need:

- to broaden the benefits of CQRs and promote equitable improvements in patient care and outcomes, across the national health care system;
- for substantial, ongoing improvement in the efficiency of data collection, risk adjustment, quality assurance and reporting;
- for a standardised approach to governance models and governance related issues, such as the management of outliers<sup>2</sup>;
- for increased access to CQR data and information by a range of stakeholders;
- to integrate national CQRs into Australia’s health care information systems and become a part of a comprehensive picture of patient treatment and outcomes.

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<sup>1</sup> Refer to Glossary

<sup>2</sup> Refer to Glossary

This 10 year Strategy sets out national principles, stakeholder roles and responsibilities, strategic objectives and issue/action streams for achieving the **Strategy's vision:**

National clinical quality registries are integrated into Australia's health care information systems and systematically drive patient-centred improvements in the quality and value of health care and patient outcomes, across the national health care system.

The following **National Principles** will underpin the Strategy's implementation.

High functioning, mature, prioritised, national CQRs:

1. contribute to:
  - the delivery of the best possible health care, patient outcomes and value for money for all Australians, across all health settings; and
  - the long term sustainability of Australia's health care system.
2. collaborate with a range of stakeholders, with a focus on clinician/patient partnerships - clinician led and patient-centred;
3. ensure 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;
4. provide direct, timely access to data and/or tailored information to patients, health care providers, health system managers and funders, to maximise the value of national CQR data and information, in accordance with privacy legislation and the 2013 National Health Information Agreement;
5. are coupled with a clear mechanism to action available data in a timely, appropriate way to support safety and quality improvement;
6. aim to have high/full coverage of the relevant clinical population;
7. are quality assured, minimise data collection requirements on patients and frontline staff, and produce high quality, reliable outputs;
8. leverage opportunities afforded by data linkage and IT advances to facilitate transition to integrated registries;
9. are operationally efficient and cost effective; and
10. are adaptive and evolve with advances in knowledge and capabilities.

The Strategy outlines the **roles and responsibilities** of key stakeholders, including clinicians, patients, the CQR sector, and a range of others from the public and private sectors. The implementation of the Strategy will be overseen by the Australian Health Ministers' Advisory Council and COAG Health Council. The Australian Commission on Safety and Quality in Health Care and the Australian and state/territory governments will co-lead, facilitate and coordinate Strategy actions in accordance with the implementation plan (to be developed and agreed with stakeholders).

Four **strategic objectives** and associated **issue/action streams**, necessary to achieve the Strategy's vision, are summarised below and at Table 1:

1. National CQRs are based on clinician/patient partnerships - to ensure that CQRs and CQR outputs are clinician led, patient-centred and deliver outcomes that matter to patients.
2. National CQRs are quality assured, efficient and cost effective - to ensure that CQRs deliver accurate, timely and sustainable outputs, flowing to timely, reliable improvements in patient care and outcomes.
3. The potential value of national CQR data is maximised - to ensure that CQR data and outputs are integrated into Australia's health information systems, informing improvements in the quality of patient care and outcomes more equitably, across the national health care system, including through provision of, and access to, tailored information for patients, governments, funders and researchers.
4. National, prioritised CQRs are sustainably funded - to ensure they have the resources to meet national CQR requirements and fulfil their potential.

The Strategy will build upon the work of Australia's dedicated clinicians, CQR experts, the Australian Commission on Safety and Quality in Health Care and the Australian and state/territory governments. Continued leadership and commitment will be critical to the success of the Strategy.

The Strategy recognises that CQRs (including virtual registries) are one of the available, complementary approaches to improving the quality of clinical practice and that jurisdictions will continue to utilise the mechanisms which best suit their health care system arrangements.

**Table 1: Summary of objectives, actions and action leads**

Strategic objectives	Action	Action Lead
1. National CQRs are based on clinician/patient partnerships	<ul style="list-style-type: none"> <li>Support the development of effective national CQR partnerships between clinicians and patients</li> </ul>	Australian Commission on Safety and Quality in Health Care (ACSQHC)
2. National CQRs are quality assured, efficient and cost effective	<ul style="list-style-type: none"> <li>Ensure that national CQRs are quality assured: <ul style="list-style-type: none"> <li>Update ACSQHC's <i>Framework for Australian clinical quality registries</i> and develop a CQR Standard for assessment of CQRs</li> <li>Develop and implement a CQR accreditation scheme to accredit against the Standard</li> </ul> </li> <li>Develop and implement a National CQR communication and collaboration plan and hub</li> <li>Facilitate streamlining of external barriers (e.g. ethics approval and treatment site governance processes) to the efficient establishment and operation of CQRs</li> </ul>	ACSQHC ACSQHC ACSQHC, Aust. & state/territory govts Australian, state/territory govts, ACSQHC, AIHW
3. The potential value of national CQR data is maximised	<ul style="list-style-type: none"> <li>Identify and create an environment that supports the provision of, and timely access to, data and/or tailored CQR information for consumers, health care providers and funders</li> <li>Facilitate national CQR digitalisation, data linkage, interoperability and integration with Australia's health information systems and infrastructure</li> </ul>	Australian & state/territory govts, ACSQHC, AIHW AIHW, Australian Digital Health Agency
4. National, prioritised CQRs are sustainably funded	<ul style="list-style-type: none"> <li>Develop a sustainable funding model for national, prioritised CQRs, with current funders and major beneficiaries of CQR data and outputs</li> </ul>	Australian & state/territory governments, ACSQHC

## MAXIMISING THE POTENTIAL OF AUSTRALIAN CLINICAL QUALITY REGISTRIES

### Vision

National clinical quality registries are integrated into Australia's health care information systems and systematically drive patient-centred improvements in the quality and value of health care and patient outcomes, across the national health care system.

## 1. Introduction

Internationally, high functioning clinical quality registries (CQRs) are recognised as key vehicles for:

- Driving continuous improvements in the quality of patient-centred health care and outcomes;
- Improving the value of health care; and
- Contributing to the sustainability of health care systems.

The National CQR Strategy (Strategy) aims to maximise the potential of Australian CQRs through a strategic, national, coordinated approach. It will facilitate the gradual evolution of prioritised, national CQRs, into patient-centred, interactive, information systems, fully integrated into Australia's health care system.

The Strategy will build upon the work of Australia's dedicated clinicians, CQR experts, the Australian Commission on Safety and Quality in Health Care (ACSQHC) and the Australian and state/territory governments. Continued leadership and commitment will be critical to the success of the Strategy.

The Strategy is aligned with the four strategic health system reform priorities agreed by the Council of Australian Governments (COAG) in February 2018:<sup>ii</sup>

- 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.

An implementation plan will set out more detailed actions, timeframes, performance indicators and governance arrangements. Implementation of the Strategy will be overseen by the Australian Health Ministers' Advisory Council (AHMAC) and COAG Health Council (CHC).

The Strategy will be evaluated every two years to ensure that progress towards the vision is on track. It is expected that, over time, the Strategy may be modified to accommodate developing knowledge, capabilities and technologies.

## 2. National Principles

These high level, national CQR principles underpin the development and implementation of the Strategy. They complement the more detailed, operationally focused principles in ACSQHC's *Framework for Australian clinical quality registries* (Framework).<sup>iii</sup>

High functioning, mature, national CQRs:

1. Contribute to:
  - the delivery of the best possible health care, patient outcomes and value for money for all Australians, across all health settings; and
  - the long term sustainability of Australia's health care system.
2. Collaborate with a range of stakeholders, with a focus on clinician/patient partnerships - clinician led and patient-centred;
3. Promote equitable access to CQR information and improvements in patient health care and outcomes for all Australians, including Aboriginal and Torres Strait Islander people and vulnerable communities;
4. Provide direct, timely access to data and tailored information to consumers, health care providers, health system managers and funders, to maximise the value of national CQR data and information, in accordance with privacy legislation and the 2013 National Health Information Agreement;
5. Are coupled with a clear mechanism to action available data in a timely, appropriate way to support safety and quality improvement;
6. Aim to have high/full coverage of the relevant clinical population;
7. Are quality assured, minimise data collection requirements on patients and frontline staff, and produce high quality, timely and reliable outputs;
8. Leverage opportunities afforded by data linkage and IT advances to facilitate transition to integrated, virtual registries;
9. Are operationally efficient and cost effective; and
10. Are adaptive and evolve with advances in knowledge and capabilities.

## 3. What is a CQR?

Clinical quality registries:<sup>iv</sup>

...systematically monitor the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information. They use the data they collect to identify benchmarks and variation in clinical outcomes. They then feed this information back to clinicians to inform clinical practice and decision making. This clinical outcome feedback loop is the defining feature of clinical quality registries.

A high functioning, national CQR currently provides clinicians, clinical units and hospitals with ongoing, timely, risk adjusted, benchmarked feedback on their clinical practice and patient outcomes, in a focused clinical domain.



CQRs should also provide feedback to, for example, health system managers (in the public and private health sectors), governments, the medical device and pharmaceutical industries (where relevant), and the broader community.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*Streamlining of ongoing monitoring requirements is important, i.e. ensure that there is no duplication / overlap between Post-Market Surveillance and CQRs by merging requirements and embedding appropriate reporting mechanisms*

A high functioning CQR is able to drive improvements in clinical practice, health outcomes, patient experiences and greater efficiency of care, when coupled with a clear mechanism to implement change.

The basic **components of a CQR** (governance/operational management, data collection, data hosting and data analysis) are set out in Box 1 below. These components may be physically housed together or **virtually integrated**, and they may be managed by one or more organisations. Virtually integrated components will allow jurisdictions to contribute data, derived from different quality improvement approaches, to a national, ‘virtual’ registry. New South Wales and Western Australia have invested in ‘virtual’ registries, which link multiple clinical, patient reported and administrative datasets (at Box 2).

The governance function is central, as it oversees CQR operation and resource application, ensures accountability, establishes the data set required to meet the needs and objectives of the CQR, and establishes key policies, including on the identification and management of outliers.

Box 1: Basic CQR components	
<b><u>Governance: overarching CQR management/leadership team and operating arrangements</u></b>	Governance is the set of relationships and responsibilities established by a health care organisation between its executive, workforce and stakeholders (including patients and consumers). It incorporates the processes, customs, policy directives, laws and conventions affecting the way an organisation is directed, administered or controlled. Governance arrangements provide the structure for setting the corporate objectives (social, fiscal, legal, human resources) of the organisation and the means to achieve the objectives. They also specify the mechanisms for monitoring performance and provide performance accountability. <sup>v</sup>
<b><u>Data Analysis</u></b>	Data analysis, data cleaning, data validation, quality assurance, data linkage, descriptive analyses and inferential analyses, including risk adjusting and benchmarking of key clinical measures, in accordance with data governance arrangements. Data analysis is undertaken by expert data analysts, in collaboration with clinicians, academic experts and the overarching management.
<b><u>Data Hosting</u></b>	Data hosting provides data storage, in accordance with data governance arrangements, relevant privacy legislation, regulation, principles, standards and guidelines. Data may be held locally or in a central repository, such as a large multi-collection data facility (cloud).
<b><u>Data Collection</u></b>	CQRs rely on the systematic collection of identical ‘minimum data sets’ using identical definitions, collected in the same way and at the same time in relation to a procedure or treatment (or disease onset). The activity required to collect a minimum data set, advised by the CQR leadership team, occurs in accordance with relevant privacy legislation, principles, standards and guidelines. Data may be

Box 2: 'Virtual registry examples	
	Initiative
<b>NSW</b>	<p>NSW's aims to embed a CQR-like function within existing, routine systems and processes, through linking administrative datasets, patient datasets, and cohort-specific clinical and other datasets (e.g. clinical audit data and EMR extracts). For example, the recently established, Registry of Outcomes, Value and Experience (ROVE) will include linked administrative, clinical and patient reported outcome and experience data for 13 clinical cohorts. This large linked data set will enable the establishment of multiple virtual registries for specific cohorts as well as for multi-morbid cohorts and population groups, such as people over 65 years. Data and analyses will be provided back to stakeholders in a timely manner.</p> <p>NSW is also working with academics, clinicians and IT experts to pilot the extraction of existing data from the EMR for a STEMI (heart attack) cohort. The data will be used to create a report for clinicians to regularly review their performance against nationally accepted quality indicators for the management of STEMI. If successful, this extraction and reporting solution will be rolled out state-wide.</p>
<b>WA</b>	<p>WA is developing several initiatives with CQR-like functions, with a common methodology of linking together routinely collected datasets with clinical data obtained through software used by clinicians as part of their day to day clinical work. Business rules are applied and risk adjusted outcomes reported back to clinicians in order to improve practice. The first project, <i>Cubes of Cancer Activity</i> (CoCA), when complete will include data for eight cancer types including lung and colorectal cancer.</p> <p>The <i>WA Clinical Quality Assessment Tool</i> is being piloted in a single tertiary hospital to assess the technical feasibility of linking data obtained from software used in the cardiac catheter lab to routinely collected data, in order to report outcomes for patients with Acute Coronary Syndrome (ACS). If feasible, the methodology will be rolled out to further hospitals. Data will be reported back to clinicians on outcomes and select quality indicators from the ACS Clinical Care Standard.</p>
Box 1: Basic CQR components	
<p>collected by hospitals and other sites and fed to the data host. It may also be appropriate for jurisdictions to collect and provide data to the data host in different ways depending on any pre-existing state registry arrangements. Electronic data input should replace paper based collection, over time. Data may be collected by clinicians, nurses, researchers, patients and their carers, or from linkage with other data sources (secondary data). The collection of data should maintain an appropriate balance between the time and cost of data collection and the impact on patient care.</p>	

CQRs are typically used in clinical domains where:<sup>vi</sup>

- There are serious consequences to the patient associated with poor quality of care;
- Inappropriate variation in outcomes can be identified and addressed;
- An evidence-based sequence of care improves patient care, or there is a need to capture national data to develop an evidence base for care;
- There is a significant cost burden associated with the condition/procedure/device;

- The clinical condition/event, triggering entry to a CQR, is able to be systematically recognised; and
- The information requirements for a successful CQR can be met, i.e. the entire population with the condition can be captured, there is an appropriate source of data, meaningful performance indicators can be defined, and there is potential for risk adjustment.

The Strategy's **focus is on prioritised, national CQRs**. A CQR with high/full coverage of the entire, national clinical population (e.g. all those undergoing treatment for a particular condition) has greater analytical power, is more efficient and cost effective and achieves a higher return on investment (refer to section 7. *Value based health care*) than a hospital or state/territory based CQR (although CQRs often begin as a state/territory based 'proof of concept').

***RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:***

*Suggest prioritisation of RDs; easier to capture high / full coverage, and significant opportunities for improvement in clinical care and cost effectiveness*

### **Framework for Australian Clinical Quality Registries**

The Framework is Australia's core CQR related resource for the establishment and operation of national CQRs. The Framework, developed by ACSQHC in collaboration with the states/territories and expert registry groups, promotes '...best practice design, development, operation and security'.<sup>vii</sup>

It outlines arrangements to enable national CQRs to satisfy minimum security, technical and operating standards and provide assurance to jurisdictions, private hospital groups, clinicians and patients about the security and reliability of the information held and provided.<sup>viii</sup> The Framework was endorsed by AHMAC in 2014 and is being updated in line with contemporary practice.

The Framework, along with the *Economic evaluation of clinical quality registries*<sup>ix</sup> and the *Prioritised list of clinical domains for clinical quality registry development*<sup>x</sup> provide the foundation for the Strategy and its strategic objectives.

## **4. Patient-centred care**

The Strategy seeks to significantly contribute to the delivery of patient-centred care in Australia. In 2017, the Organisation for Economic Cooperation and Development's *Ministerial Statement, The Next Generation of Health Reforms*, stated that:<sup>xi</sup>

Health systems...need, fundamentally, to deliver improvements that matter to patients and their changing care needs..."people-centred care" should better guide the course taken by health care in the future.

ACSQHC has defined patient/consumer centred care as 'health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers'.<sup>xii</sup> According to ACSQHC:

There is good evidence that using person-centred strategies that elicit and address consumers' needs and preferences in planning, design, delivery and evaluation of health care can lead to better health outcomes, better experiences and greater efficiency of care.<sup>xiii</sup>

The 2017 Productivity Commission's report, *Shifting the Dial: 5 Year Productivity Review* recommended that all Australian governments re-configure the health care system around the principles of patient-centred care within a five year timeframe.<sup>xiv</sup>

### **How can CQRs contribute to patient-centred care?**

CQRs can provide feedback to clinicians and clinical units, based on integrated clinical and patient derived data, including via patient reported outcome measures (PROMs) and patient reported experience measures (PREMs). PREMs are tools for capturing a patient's views of their experience of the care they received.<sup>xv</sup> PROMs:

...are questionnaires which collect patients' assessments of how health services and interventions have, over time, affected their quality of life, daily functioning, symptom severity, and other dimensions of health...[PROMs]...fill a vital gap in our knowledge about outcomes and about whether healthcare interventions actually make a difference to people's lives'.<sup>xvi</sup>

Box 3 provides an example of a high functioning CQR, which collects PROMs.

This integrated feedback then supports clinicians to make improvements in care that flows to improvements in health outcomes that matter to patients. Patient-centred CQRs also provide valuable health information and support for patients, which is relevant to patient needs and priorities.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE SECTION:**

*This section needs to include the role of research*

**Box 3: Prostate Cancer Outcome Registry-Victoria (PCOR-Vic)<sup>xvii xviii</sup>**

The PCOR-Vic systematically follows-up men after a diagnosis of prostate cancer and provides regular, benchmarked feedback to clinicians and hospitals on:

- patterns of care provided in public and private Victorian hospitals;
- variation in the care provided; and
- health related quality of life and survival outcomes.

PCOR-Vic collects quality of life PROMs on urinary, sexual, and bowel function, as key indicators of the quality of care provided to men with prostate cancer. Information on men who are suffering poor quality of life is provided back to clinicians so they can follow up directly with men.

In addition, a 2017 intervention assessed whether men who self-report poor quality of life to a Movember care coordinator improves their quality of life, 12 months later. A 70% improvement in quality of life in those with a care coordinator compared to patients receiving standard treatment in the same geographic region was demonstrated, indicating that CQRs can make a direct positive impact on patients.

The PCOR-Vic has had a significant impact on treatment variation and outcomes. For example, it identified that a major hospital was a significant outlier in terms of its positive surgical margin rate (cancer cells left behind after surgery). This led to higher levels of cancer recurrence, additional treatment and costs. The hospital investigated and identified opportunities for improvement in the supervision of trainees. This work resulted in amendments to training programs by the Urological Society of Australia and New Zealand (USANZ). The impact of this will be monitored by the registry.

In addition, the rate of radical surgery (e.g., prostatectomy) for men with low risk disease significantly declined in Victoria, after the PCOR-Vic commenced providing benchmark reports to hospitals and clinicians. As a result, there were fewer: patients with a positive surgical margin following radical prostatectomy; men requiring secondary treatment; deaths; and low risk prostate cancer patients receiving unnecessary active treatment.

The 2016 *Economic evaluation of clinical quality registries*, found that for every dollar invested in the PCOR-Vic, a return on investment of \$2 was realised. This impact related to assessment of only two of the eleven quality indicators reported by the registry (reduction in positive surgical margin rate and reduced active intervention in low risk patients).

It is increasingly recognised that CQRs need to be based on partnerships between clinicians and patients to ensure delivery of integrated information to clinicians and patients, which reflects patient involvement in decision-making and determining outcomes.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*And researchers*

Effective clinician/patient partnerships are based on: <sup>xix xx</sup>

- the treatment of patients with dignity and respect;
- Information sharing between clinicians and patients (refer to section 5 below);
- Encouragement of patient collaboration and participation in the establishment, operation and oversight of CQRs, including CQR data sets and patient reported outcome and experience measures, to help ensure that CQR activities and outputs are patient focused.

### Clinician leadership

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 quality of health care.

Clinician leadership in the establishment, operation and oversight of CQRs is critical to ensure clinician engagement in data collection, quality improvement activities and ultimately CQR effectiveness. Where clinicians have a sense of ownership, their supply of information, investigation of the results of data analysis and application of findings is likely to be greater. Clinician leadership will also be critical to the success of the Strategy.

### Interactive CQRs based on clinician/patient partnerships

Countries such as Sweden have advanced, interactive, patient-centred CQRs based on clinician/patient partnerships. Box 4 provides an example.<sup>xxi xxii</sup>

Box 4: Swedish Rheumatology Quality Registry
<p>The Swedish Rheumatology Quality Registry (containing data from more than 66,000 patients) enables patients to become fully informed partners with clinicians in decision making and better able to self-manage their condition, particularly important for chronic diseases/conditions.</p> <p>The Registry provides patients and clinicians with a dashboard, including the patient's treatment, clinical data, self-reported outcomes and population based data, which can be considered during medical consultations. The dashboard receives clinical and patient reported data from a shared clinical database. Patients are able to input data and track early indicators of increased disease at home so that their priorities, care and outcomes can be monitored in real time.</p> <p>The registry has resulted in a halving of arthritic inflammatory activity among patients of practices participating in the registry.</p>

These interactive CQRs allow patients to:

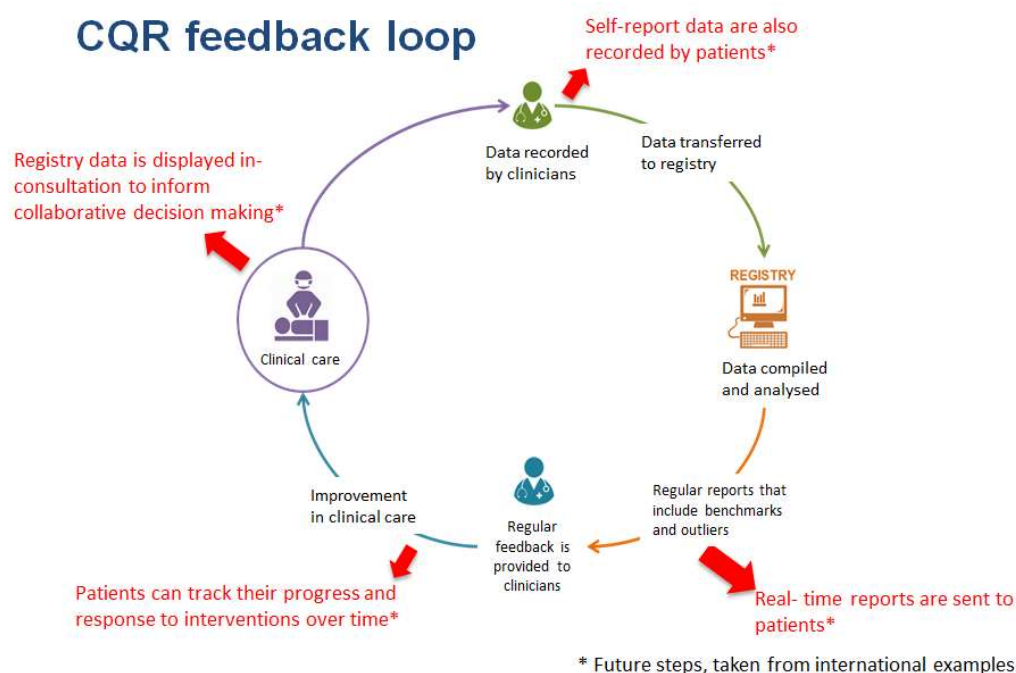
- Contribute self-reported data on treatment and health status, direct to the CQR;
- Receive real time reports on their care and outcomes;
- Track their progress and response to interventions over time; and
- View and discuss their data with their clinician during consultation visits to inform collaborative decision making.

#### **RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*This has been raised in our consultations, and would appear particularly important to RD patients given they are often more knowledgeable than their GPs / other medical practitioners on their particular disease*

Diagram 1, below depicts the clinician/patient CQR feedback loop, which is interactive and provides clinicians and patients with integrated information.<sup>xxiii</sup>

Diagram 1. CQR Feedback Loop



## 5. Providing patients with information about the quality of care

CQRs can also significantly contribute to patient-centred care through the provision of tailored, patient/consumer friendly information which supports informed choice about health care providers, treatment options and the best value care.

The ability to choose a clinician and be treated in the public or private sectors (for privately insured patients), is an important feature of the Australian health care system. However, patients, their carers and families require information on those options to make informed choices.

The Consumer Health Forum of Australia's, *National Health Plan*, states that support needs to be provided to '...enable informed decision making including access to clear and understandable information...[on]...performance outcomes'.<sup>xxiv</sup> This information needs to be tailored to people of diverse socioeconomic and cultural backgrounds and languages, including Aboriginal and Torres Strait Islander people and vulnerable communities.

Box 5 provides an example of the provision of information to patients/consumers.

### Box 5: NHS Choices<sup>xxv</sup>

England's National Health Service consumer focused website, 'NHS Choices', assists consumers to '...find, choose and compare health, support and social care services in England', and provides consumers with '...reviews and ratings across health and social care services'. In 2015, it was the most popular UK health related site with **583 million** visits.



## 6. Transparency and accountability

In countries such as Sweden, England and the US, public reporting on the quality of care plays a key role in providing information to consumers and in improving clinical practice, health outcomes and system sustainability. For example, public disclosure is a key feature of Sweden's National Quality Registries and reporting is openly available to health care providers and the public.<sup>xxvi</sup> This level of transparency and accountability has accelerated improvements in patient care and outcomes, as shown in Box 6.<sup>xxvii</sup>

### **RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*This was raised in our consultations as being very important*

#### **Box 6: Sweden's Acute Coronary Care Registry<sup>xxviii</sup>**

In 2006, Sweden's Acute Coronary Care Registry published data on how well Swedish hospitals complied with national clinical guidelines and on their patient survival rates. This was followed by an improvement of 40 per cent in quality scores of poorer performers and an overall rate of improvement for all hospitals of 22 per cent in the following two years.

However, public performance reporting at the clinician level is not available in Australia and only limited information is available at the hospital level via the My Hospitals website, some jurisdictional reports and some private hospital provider websites (for example, the Healthscope group<sup>xxix</sup>).

Stakeholders in Australia have called for more transparency and accountability around CQR reporting. Access to tailored CQR data and performance information by key stakeholders could inform improvements in patient care and outcomes across local, state/territory and the national health care systems.

This would facilitate equitable access to these improvements for all Australians, and contribute to the sustainability of the public and private health care sectors and the private health insurance industry. For example:

- State/territory governments (health system managers, responsible for ensuring the safety and quality of jurisdictional health care systems) and the public and private hospital sectors are seeking routine, timely access to their own hospital CQR data and meaningful performance information, including on outliers at the clinician, unit and hospital levels.<sup>xxx</sup>
- Governments and private health insurers are seeking routine direct access to, and provision of, CQR information on the efficiency and effectiveness of health care interventions, medical devices and medicines, to inform policy and funding/reimbursement decisions.
- CQR information could enhance the Therapeutic Goods Administration's capacity to monitor and make regulatory decisions on the performance of medical devices once they have been registered for use in Australia.

***RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:***

*Important to include the research community when talking about impacted parties.*

*Re: Dot point 3 - Important that duplication is minimised / eliminated for regulated sectors with reporting requirements (Post-Marketing Surveillance) to the TGA and CQRs*

The issue/action streams for Strategic Objective 3: *Maximising the potential value of CQR data*, outline issues related to public performance reporting and the potential to create an environment that would support access to tailored information by patients/consumers, health system managers and a range of other stakeholders.

## 7. Value based health care

The International Consortium for Health Outcomes Measurement (ICHOM) has identified CQRs as key vehicles for realising value based health care (VBHC).<sup>xxxix</sup> VBHC is increasingly considered, internationally, as a potential solution to the need to:

- improve the quality of patient care and outcomes; and
- address rising health care costs and demand, which are threatening the sustainability of health systems (a key concern in Australia).

In 2013, Porter and Lee stated:

In health care, the **overarching goal for providers, as well as for every other stakeholder, must be improving value for patients**, where value is defined as those health outcomes achieved that matter to patients relative to the cost of achieving those outcomes. Improving value requires either improving...outcomes without raising costs or lowering costs without compromising outcomes, or both.<sup>xxxix</sup>

ICHOM considers that CQRs are clinically-endorsed tools that provide the outcomes data required to identify, measure and understand value.<sup>xxxix</sup> CQRs drive better value care through significant returns on investment, relating to improvements in patient care and outcomes that matter to patients.

As outlined at section 4 *Patient-centred care*, CQRs can provide feedback based on integrated clinical and patient derived data (patient reported measures). Patient reported measures, along with joined up or linked data across all settings of the patient journey, are key enablers of VBHC.

A number of jurisdictions are developing approaches to implement VBHC and patient reported measures in their state/territory health systems to achieve patient-centred, value based health care.

### Return on investment

Using conservative methodology, the 2016 *Economic Evaluation of clinical quality registries* evaluated the economic impact of five Australian CQRs and found they:<sup>xxxix</sup>

...delivered significant value for money, when correctly implemented and sufficiently mature...[They]...had an influence on clinical practice and improved the value of healthcare delivery at relatively low cost. Substantial benefits... [included]...**greater survival for patients, improvements in quality of life after treatment and avoided costs of treatment or hospital stay**. Benefit to cost ratios ranged from 2:1 to 7:1 – meaning that **for every dollar spent, the return on that investment ranged from \$2 to as much as \$7**. The study suggested that the return on investment would range from \$4 if national coverage were achieved by all five clinical quality registries.

Box 7 provides an example.

**Box 7: Australia and New Zealand Dialysis and Transplantation (ANZDATA) Registry<sup>xxxv</sup>**

ANZDATA receives data from all Australian and New Zealand renal units on the incidence and prevalence of end stage kidney disease treatment, complications and mortality. At the end of 2017, approximately 25,000 Australians were either receiving dialysis or had a kidney transplant.

ANZDATA provides quarterly feedback reports to individual renal units on dialysis key performance indicators (KPIs), dialysis outcomes, transplant care and surgery. Annual reports are provided to all hospitals and are publicly available on ANZDATA's website.

From 2004 to 2014, ANZDATA measured the following reductions:

- 15% in the dialysis mortality rate (1156 fewer deaths);
- 39% in transplant graft loss rate (606 fewer transplant grafts lost); and
- 40% in peritonitis rates (2573 fewer infections).

In 2011, ANZDATA introduced a program of dialysis KPIs. This included quarterly feedback of performance for critical dialysis complications to renal units in addition to the traditional annual individual hospital reports. During 2011-2013, renal units accessing ANZDATA's feedback reports, compared to units not accessing reports, recorded:

- 196 (of 770 overall) fewer dialysis mortalities (resulting in quality adjusted life year benefits);
- 76 (of 322 overall) fewer transplant grafts lost (resulting in avoided dialysis costs and incremental gains in quality of life); and
- 307 (of 1646 overall) fewer incidences of peritonitis hospitalisations (resulting in avoided treatment costs and incremental improvements in quality of life).

Based on improvements in rates of risk adjusted dialysis mortality, transplant graft loss and peritonitis over the period 2004 to 2013, the *Economic Evaluation of clinical quality registries* attributed an economic benefit of \$58 million to hospital level feedback from ANZDATA. For every dollar invested in ANZDATA, a return on investment of \$7 was realised.

Evaluations of international CQRs have also identified significant returns on investment in relation to improved outcomes, reduced health care costs and system sustainability. In addition, an economic evaluation of Sweden's National Quality Registers, conducted by Boston Consulting Group in 2010, found that a \$70 million investment in the registries, alongside IT infrastructure and data analysis resources, over ten years would produce an economic benefit of over \$7 billion.<sup>xxxvi</sup>

This investment was estimated to reduce growth in annual health expenditure from 4.7 to 4.1 per cent over the decade. In the absence of recent Australian comparative cost/benefit analyses, the Australian Government commissioned the *Economic Evaluation of clinical quality registries* to build the CQR evidence base.

## **8. Data Linkage, Interoperability and Integration**

The Strategy's vision involves extensive national CQR data linkage, interoperability and integration into Australia's health information systems, such as My Health Record (MHR) and state/territory electronic medical records (EMRs). This would aim to achieve the gradual evolution of prioritised, national CQRs to patient-centred, interactive, information systems, fully integrated into Australia's health care system.

Currently, CQR data and information may inform improvements at the individual or treatment site level, but may not reach the whole profession or across health care systems. CQR data may exist in silos, without connection to other CQR data or other valuable health data sets. However, in countries such as Sweden, Denmark and the Netherlands, CQRs are integrated into health information systems and infrastructure.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE SECTION:**  
*This section critical to the RD community*

### **Data linkage**

CQR data could be linked with other CQR data sets (for patients with co-morbidities) and with other health related data such as admitted patient data and the Medicare and Pharmaceutical Benefits data. This would include linkage of administrative, clinical and patient-reported data, across all care settings, utilising jurisdictional, Australian Government and private sector data (as patients flow between settings).

A current example includes the Victorian/Australian Government joint *Optimal Cancer Pathways Data Project*, which is examining optimal cancer pathways and variations in cancer care pathways, services, costs and health outcomes. The project links Victorian Cancer Registry data with routinely collected Victorian data sets (admitted, emergency, outpatient, death index, radiotherapy) and Australian Government Medicare Benefits and Pharmaceutical Benefits data sets.<sup>xxxvii</sup>

### **Interoperability and Integration**

Interoperability between national CQRs and with broader health care information systems, such as MHR and EMRs, would ensure that CQRs can interact, exchange and utilise information across health systems to improve patient care and outcomes. The long term vision would involve the systematic integration of national CQR data and outputs into health information systems.

### **Benefits**

Over time, data linkage, interoperability and integration could generate benefits, such as:

- A more comprehensive, longitudinal picture of patient treatment and outcomes than is currently available;
- Increased analytical power, precision of analysis and validation of findings;
- Data sharing and rapid provision of information and feedback to clinicians, patients, hospitals, governments and other stakeholders, assisting with timely improvements in clinical care and outcomes;
  - further benefits could also be realised through utilisation of Web 2.0 websites (enabling interoperability and ‘community-based input, interaction, content-sharing and collaboration’), mobile/device interfaces and health apps, which could capture and enhance patient experience;<sup>xxxviii</sup>
- Systematic, equitable improvements in clinical practice, health value and patient outcomes, across local, state/territory and national health care systems; and
- Efficiencies from reduced duplication and burden of CQR data collection and entry, via data inputs from MHR and EMRs.

### **Challenges**

However, there are numerous challenges to CQR data linkage, interoperability and integration, including:

- Privacy related legislative protections and restrictions and the need for a unique linkage key/patient identifier (such as the Individual Patient Identifier used by My Health Record for limited purposes only) to enable accurate data linkage/integration;
- The need for CQRs to fully digitalise (paper data collection and submission is still common), standardise and adopt the identification standards, architecture patterns, technical design and communication standards of the MHR system and EMRs;
- The need for further development of the MHR and EMRs around the level of coverage of patients in public and private settings and the type and completeness of information collected. Currently, these systems contain a large amount of unstructured, uncoded data, including paper records in pdf format;
- The various stages of system and infrastructure evolution and varying data standards across Australian hospitals and jurisdictions.

***RARE VOICES AUSTRALIA COMMENT ON ABOVE SECTION:***  
*Also lack of coding of RDs in Australia*

CQR digitalisation, interoperability and integration would need to be phased in over the life of the Strategy, as digital health reforms proceed and health care information systems and capabilities develop.

However, the CQR sector has called for urgent consideration of the opportunity to embed CQR data items into EMRs and the MHR, as they develop and are rolled out across Australia. This would fast track the realisation of benefits outlined above and the Strategy's vision, and would considerably reduce the duplication, cost and burden of CQR data collection.

## **9. Complementary means of improving the quality of health care**

The Strategy recognises that CQRs are one of the available, complementary approaches to improving the quality of clinical practice in Australia. A holistic picture of safety and quality performance requires triangulation of multiple measurements from multiple perspectives. Diagram 2, below, provides examples of the types of safety and quality performance measures and data collections, which are currently the focus of the ACSQHC.<sup>xxxix</sup>

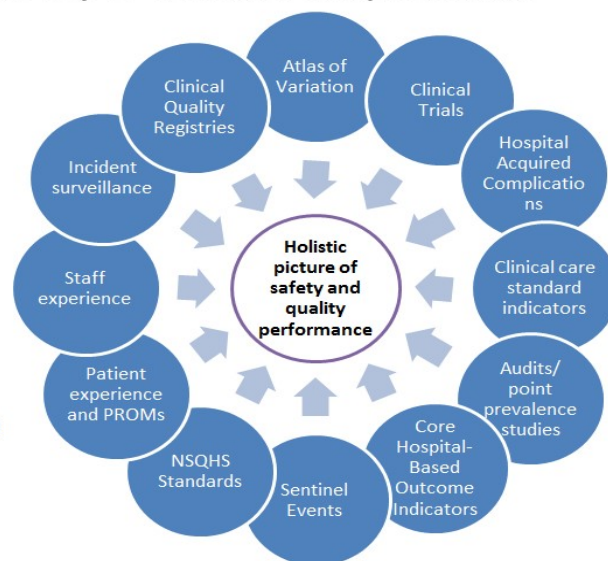
### **Diagram 2. Triangulated Measurement**

## Triangulated measurement is key to healthcare improvement

A robust safety and quality monitoring system requires triangulation of multiple measurements from multiple perspectives



**Clinical quality registries** provide an efficient mechanism for collecting several types of measures from a single clinical encounter or episode:  
**Collect once, use many times**



Box 8 provides an example of a complementary approach.

Box 8: Stroke Foundation <sup>xl</sup>
<p>The Stroke Foundation is involved in a number of initiatives that provide a complementary system to monitor and drive quality improvement in stroke care:</p> <ul style="list-style-type: none"> <li>• retrospective audits of acute and rehabilitation stroke care;</li> <li>• the Australian Stroke Clinical Registry (AuSCR), established by the Stroke Foundation, The Florey Neurosciences Institute, George Institute and the Stroke Society of Australasia, collects data for a small number of indicators for all patients admitted to acute hospitals with stroke or Transient Ischaemic Attack (TIA). Patients are routinely followed up at three to six months post-stroke and longer term outcomes are monitored; and</li> <li>• the Australian Stroke Data Tool (AuSDaT) is an online data management system that enables centralised data collection, using an agreed National Data Dictionary, that supports the monitoring of pre-hospital, acute and rehabilitative care for stroke patients to drive quality improvement in hospital care.</li> </ul>

## 10. Australian CQR Landscape

Australia has a number of high functioning CQRs, however, in the absence of a national CQR strategy and strategic prioritisation of investment, the Australian CQR landscape, including CQR funding, has developed over time, in an ad hoc<sup>3</sup> manner.

The establishment of CQRs has typically been led by clinicians, their medical specialist societies and experts to inform improvements in clinical performance and for research purposes. Governments (particularly in response to Senate inquiry recommendations),<sup>xli</sup> consumer organisations and researchers have also contributed to CQR development, with the private sector often providing additional funding.

<sup>3</sup> 'Created or done for a particular purpose as necessary.' [https://en.oxforddictionaries.com/definition/ad\\_hoc](https://en.oxforddictionaries.com/definition/ad_hoc)

More than 40 national or state/territory based CQRs, at varying levels of

**Box 9: Monash University Registry Science Centre<sup>xlii</sup>**

Monash University, Department of Epidemiology and Preventive Medicine, provides the following for 28 clinical registries, including high functioning CQRs, such as the PCOR-Vic (at Box 3):

- operational management services and centralised infrastructure;
- governance functions and facilitation of steering groups for each registry;
- clinical and academic leadership and expertise in research, clinical quality improvement, bioethics, privacy law and research governance;
- data storage, information technology capability, statistical and data analysis and data access, including a 'collaborative model of clinician leadership and peer review, ensuring that registry data is high quality, valid, reliable and useful...';
- reporting to partners, including clinical craft groups, clinical colleges, governments, insurers; patient advocacy and consumer groups; and
- a multidisciplinary Registry Sciences Unit, which supports/advises existing registries and works with clinicians and funders to develop new registries.

development and maturity, have been identified. The exact number is unknown as there is no national CQR register or accreditation process.

Across Australia, CQRs are generally:

- hosted by universities and institutes, which provide all or some of the CQR functions (many Australian CQRs are located in the registry management centres at Monash University (Box 9) and the South Australian Health and Medical Research Institute (Box 10);
- held centrally by state/territory health departments; or
- stand-alone, clinician 'owned', and supported by a specialist medical college or society, hospital or health service.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE SECTION:**

*It is important to the RD community that, wherever possible, CQR infrastructure is shared to maximise cost-effectiveness through minimising overall administrative burden*

The Australian, state and territory governments fully or partially fund various CQRs and other registries but currently do not have an overarching strategy or systematic approach to investment. However, the Victorian Government is developing a Victorian clinical registry strategy for the registries it funds, including 12 CQRs.

Stakeholders such as the private hospital sector and private health insurers are seeking a more standardised CQR sector and have raised concerns about dealing with multiple national, state/territory or locally based CQRs with:

**RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*The RD community would agree with this*

- idiosyncratic approaches and variations in delivery and funding models;



- varying governance and data arrangements; and
- varying levels of coverage of the clinical population and duplicated areas of coverage.

### **CQR Sector Challenges**

The existence of registry management centres (for example, at Monash University and SAHMRI), has countered these concerns to an extent, through the provision of standardised guidance for their CQRs.

However, the CQR sector has highlighted the considerable challenges involved with establishing and operating CQRs and has indicated that:

- Assistance is required to resolve the lengthy delays caused by **ethics approval, treatment site governance and data collection processes**;
- Further guidance would assist in meeting the requirements of ACSQHC's Framework, for example, in relation to CQR governance issues, such as:
  - How to appropriately respond to **requests for access to CQR data** and information by, for example, researchers, health care providers and the broader community;
  - How to appropriately **identify and manage outliers**, which is a critical feature of an effective CQR. Further guidance has been requested on the development of standardised, agreed outlier policies/procedures, which outline a series of steps, known to all relevant parties, including on:
    - investigating the nature of the outlier;
    - understanding the potential legal ramifications of, for example, responding to Freedom of Information requests and legal discovery;
    - facilitating the provision of feedback to outlier clinicians;
    - supporting quality improvement action by clinicians in response to feedback; and
    - escalating the issue to appropriate medical and government bodies and health service management to ensure effective clinical governance, if required.

These issues are addressed by Strategic Objective 2: *National CQRs are quality assured, efficient and cost effective* and Strategic Objective 3: *The potential value of national CQR data is maximised*.

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*.

**RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:**

*The RD community would agree with this*

## **11. International Approach**

Internationally, countries such as Sweden, Denmark and the Netherlands have extensively invested in CQRs. Table 3 outlines their national approaches to CQR establishment and operation. These different international approaches and experiences, with regard to governance, accreditation, reporting and funding, will inform the Strategy's implementation.

**Table 3: International approaches**

	Sweden	Denmark	The Netherlands
Summary	Sweden is a pioneer in quality registry development with 108 National Quality Registries, some of which have been in operation for more than 20 years. <sup>xlvi</sup> <sup>xliv</sup> . Two thirds of the National Quality Registries cover over 80 per cent of all eligible patients. <sup>xlv</sup> The registries are initiated and led by healthcare professionals with government support and funding.	Denmark has 69 National Clinical Quality Databases, <sup>xlvi</sup> managed by the Danish Clinical Registries (RKKP) organisation, which also provides the infrastructure. The registries are required to cover at least 90 per cent of eligible patients. <sup>xlvi</sup> Clinical registries are led by a board of healthcare professions and owned and funded by the government.	The Dutch Institute for Clinical Auditing (DICA), a clinician-led, independent, non-profit organisation funded by Dutch private health insurers, manages 22 registries. <sup>xlvi</sup> DICA was established to facilitate collaboration between insurers, hospitals and clinicians around clinical quality and outcomes data.
Governance	The Swedish Office of National Quality Registries provides strategic direction and funding for registries and the National Board of Health and Welfare supports registries to improve data quality. <sup>xlix</sup>	The Danish National Health Authority regulates national clinical quality databases. <sup>li</sup>	DICA's centralised directional and scientific boards oversee the operation of DICA and the registries (which have their own steering and clinical advisory groups). <sup>li</sup>
Accreditation /Quality Assurance	Swedish National Quality Registries are certified according to criteria with higher funding attached to higher levels of certification. <sup>lii</sup>	Danish clinical quality databases must meet national criteria every three years to receive funding. <sup>liii</sup> Once registration requirements are satisfied, hospitals and clinicians are required to report patient data to the database.	DICA registries are established and operated in accordance with DICA's standardised model, with expert support. <sup>liv</sup>
Funding	Jointly by the Office of National Quality Registries and the Swedish Association of Local Authorities and Regions (representing local councils which are responsible for delivering health care), with a modest contribution by industry. <sup>lv</sup>	Regions fund and operate the registries and are responsible for health care provision. <sup>lvi</sup>	DICA registries are funded by an association of all Dutch insurers, known as the Association of Health Insurance Companies. <sup>lvii</sup>
Reporting	The Swedish Association of Local Authorities and Regions publishes registry reports. <sup>lviii</sup> The results are openly available to health care providers and the public. Public disclosure is a key feature of Sweden's National Quality Registries and data transparency has accelerated improvements in health care. <sup>lix</sup>	After extensive evaluation and auditing, annual results are released publicly on the Danish e-health portal. Patients can access their own treatment data privately via the portal. Participating health care providers also receive monthly or quarterly data. <sup>lx</sup>	DICA providers receive reports on their own data, medical societies have access to de-identified aggregated data, and insurers receive data annually via an online portal. Results are also publicised through an annual conference and an annual report for each registry. <sup>lxi</sup>

## 12.Stakeholder Roles and Responsibilities

Achieving Australia’s CQR vision will rely on key stakeholders engaging with the Strategy’s implementation and fulfilling their CQR related roles and responsibilities.

**Table 4: Stakeholder Roles and Responsibilities**

Stakeholder	Roles and Responsibilities
ACSQHC	<ul style="list-style-type: none"> <li>Leading and coordinating national CQR related improvements in health care safety and quality. Providing oversight of the Strategy’s implementation and undertaking Strategy activities</li> </ul>
Australian Digital Health Agency	<ul style="list-style-type: none"> <li>Contributing digital health care system expertise to Strategy activities</li> </ul>
Australian Government	<ul style="list-style-type: none"> <li>Co-leading oversight of development and implementation of the Strategy, with ACSQHC and states/territories. Undertaking Strategy activities</li> </ul>
AIHW	<ul style="list-style-type: none"> <li>Contributing health statistics expertise to the Strategy’s implementation</li> </ul>
Charitable foundations/NGOs	<ul style="list-style-type: none"> <li>Supporting the establishment and operation of relevant CQRs (funding and in-kind support)</li> </ul>
Clinical Quality Registry sector	<ul style="list-style-type: none"> <li>Establishing and operating patient-centred CQRs in accordance with the ACSQHC’s Framework and in consultation with patients/consumers</li> <li>Adapting and engaging with Strategy related activities</li> </ul>
Clinicians	<ul style="list-style-type: none"> <li>Leading the development and operation of patient-centred CQRs</li> <li>Partnering with patients in their care, providing data to CQRs in a timely manner and acting on CQR feedback to improve clinical performance</li> </ul>
Consumer organisations	<ul style="list-style-type: none"> <li>Supporting patient/consumer involvement in clinician/patient partnerships and patient-centred CQRs</li> </ul>
Hospitals and other treatment sites	<ul style="list-style-type: none"> <li>Contributing timely, accurate and complete data to CQRs</li> <li>Engaging with Strategy activities such as site governance streamlining</li> <li>Supporting the provision of data for research purposes and tailored CQR performance information with other stakeholders</li> </ul>
Medical device/ pharmaceutical industries	<ul style="list-style-type: none"> <li>Supporting the CQR sector</li> <li>Acting on CQR feedback and sharing tailored performance information on their products with other stakeholders</li> </ul>
Patients (carers and families)	<ul style="list-style-type: none"> <li>Engaging in partnership with clinicians and in CQR development and operation</li> <li>Consenting to their treatment and outcome related data (including patient reported measures) being used for CQR and related activities</li> </ul>
Private health insurers	<ul style="list-style-type: none"> <li>Supporting the CQR sector</li> <li>Utilising CQR information to inform a more efficient and sustainable private health insurance sector</li> </ul>
Researchers	<ul style="list-style-type: none"> <li>Researching improvements in CQR reporting and quality improvement functions</li> <li>Accessing and utilising CQR data in accordance with privacy legislation and principles</li> </ul>
Specialist colleges and societies	<ul style="list-style-type: none"> <li>Supporting the development and operation of CQRs (funding and in-kind)</li> <li>Encouraging members to contribute data to CQRs, including through continuing medical education points</li> <li>Utilising CQR information in member education and training</li> </ul>
State/territory governments	<ul style="list-style-type: none"> <li>Co-leading oversight of the development and implementation of the Strategy</li> <li>Facilitating public hospital provision of data to prioritised, national CQRs and utilising CQR information in the management of jurisdictional health care systems</li> </ul>

### **13. Realising the Vision and its Objectives**

Four strategic objectives and associated issue/action streams have been identified as critical to maximising the potential of Australian CQRs and achieving the strategy vision.

1. National CQRs are based on clinician/patient partnerships
2. National CQRs are quality assured, efficient and cost effective
3. The potential value of national CQR data is maximised
4. National, prioritised CQRs are sustainably funded

A detailed action/implementation plan will be developed by ACSQHC and the Australian and state/territory governments (in consultation with key stakeholders), and overseen by AHMAC and CHC. Clinicians, patients and the CQR sector would have also have a leadership role. The implementation plan will set out detailed actions, operational requirements, such as data hosting, timeframes, performance indicators and governance arrangements.

The Strategy will be evaluated every two years to ensure that progress towards the vision is on track. It is expected that, over time, the Strategy may be modified to accommodate developing knowledge, capabilities and technologies.

A summary table and issue/action tables are set out below.

### Maximising the Potential of Australian Clinical Quality Registries: Summary Table

<b>Vision</b>	National clinical quality registries are integrated into Australia's health care information systems and systematically drive patient-centred improvements in the quality and value of health care and patient outcomes, across the national health care system			
<b>Overarching Driver for Change</b>	Need for a national, strategic approach to maximise returns on investment in CQRs for patients, clinicians and other stakeholders: improvements in patient care and outcomes and a more efficient and cost effective health care system			
<b>Strategic Objectives</b>	1. National CQRs are based on clinician/patient partnerships	2. National CQRS are quality assured, efficient and cost effective	3. The potential value of national CQR data is maximised	4. National, prioritised CQRs are sustainably funded
<b>How will actions benefit patients?</b>	Patient-centred CQRs deliver improved care and outcomes that matter to patients	Accurate, timely and sustainable CQR outputs support clinicians to deliver the best possible patient care and health outcomes, in a more timely manner	CQR data and reporting inform patient health care decision making and improvements in the quality of patient care and outcomes more broadly and equitably, across the national health care system, including through provision of information for patients and data for researchers	Adequate resourcing assists national CQRs to operate in accordance with ACSQHC's Framework, meet quality assurance requirements and fulfil their potential to drive improvements in the best possible patient care and outcomes

Maximising the Potential of Australian Clinical Quality Registries: Action Summary		
1. National CQRs are based on clinician/patient partnerships	Support the development of effective national CQR partnerships between clinicians and patients	<ul style="list-style-type: none"> <li>• ACSQHC</li> </ul>
2. National CQRS are quality assured, efficient and cost	Ensure that national CQRs are quality assured, efficient and effective: <ul style="list-style-type: none"> <li>• Update the Framework and Develop Framework Standard</li> <li>• Develop and implement a CQR accreditation scheme</li> <li>• Develop and implement a national CQR communication and collaboration plan and hub</li> <li>• Facilitate streamlining of external barriers to the efficient establishment and operation of CQRs</li> </ul>	<ul style="list-style-type: none"> <li>• ACSQHC</li> <li>• ACSQHC</li> <li>• Australian Government &amp; state/territory governments, ACSQHC</li> <li>• Australian &amp; state/territory governments, ACSQHC, AIHW</li> </ul>
3. The potential value of national CQR data is maximised effective	<ul style="list-style-type: none"> <li>• Create an environment that supports access to tailored CQR information for consumers, health care providers and funders</li> <li>• Facilitate national CQR data linkage, interoperability and integration with Australia's health information systems and infrastructure</li> </ul>	<ul style="list-style-type: none"> <li>• Australian &amp; state/territory governments, ACSQHC</li> <li>• AIHW, ADHA</li> </ul>
4. National, prioritised CQRs are sustainably funded	<ul style="list-style-type: none"> <li>• Develop a sustainable funding model for national, prioritised CQRs, with current funders and major beneficiaries</li> </ul>	<ul style="list-style-type: none"> <li>• Australian &amp; state/territory governments, ACSQHC</li> </ul>

Strategic Objective 1: Clinician/Patient Partnerships	
<b>Issues</b>	<ul style="list-style-type: none"> <li>• National CQRs can significantly contribute to improved, patient-centred care and outcomes (refer to 4. <i>Patient-centred care</i>)</li> <li>• Australian CQRs are increasingly including patient representatives in CQR steering committees and developing patient reported outcome and experience measures, which are essential to the delivery of patient-centred information</li> <li>• National CQRs may require systematic assistance to develop and maintain effective clinician/patient partnerships, and to gradually evolve to the advanced capability of interactive Swedish registries (at Box 4)</li> </ul>
<b>Actions</b>	<p>ACSQHC will continue to work with the CQR sector, clinicians and patient representatives to facilitate the effective development of:</p> <ul style="list-style-type: none"> <li>• CQR clinician/patient partnerships</li> <li>• CQR PROMs and PREMs, informed by ACSQHC's national PROMs/PREMs work and NSW and Victoria's state based initiatives</li> <li>• interactive CQRs, based on clinician/patient partnerships, over time</li> </ul> <p>The work will be facilitated by ACSQHC:</p> <ul style="list-style-type: none"> <li>• updating the Framework to provide further guidance on CQR governance issues, including clinician/patient partnerships</li> <li>• developing the Framework into a Standard, with associated guidance resources</li> <li>• developing a national CQR accreditation scheme, based on the Framework Standard, which is expected to require CQRs to be based on clinician/patient partnerships</li> </ul>
<b>Action Lead</b>	<ul style="list-style-type: none"> <li>• ACSQHC</li> </ul>
<b>How will it benefit patients?</b>	CQRs will significantly facilitate patient-centred care, through the provision of integrated clinical and patient derived information to clinicians and patients, which flows to improvements in patient-centred care and outcomes



Strategic Objective 2: National CQRs are Quality Assured, Efficient and Effective	
<b>Issue summary</b>	<ol style="list-style-type: none"> <li>1. Patients, clinicians and other stakeholders need to be assured that CQR data and outputs are accurate, reliable and secure.</li> <li>2. CQRs would benefit from systematic access to information on best practice CQR operation and solutions to common CQR challenges, and the opportunity to collaborate with other CQRs.</li> <li>3. External barriers to the efficient, effective establishment and operation of CQRs relating to human research ethics approval, treatment site governance, data collection and patient consent processes can create a significant, costly burden and cause delays of up to two years.</li> </ol>
<b>Issue 1:</b> Quality Assurance	<ul style="list-style-type: none"> <li>• Considerable challenges are involved with establishing and operating CQRs.</li> <li>• Evans et al (2011), surveyed 28 CQRs and found that the majority required ‘...modifications...in order to provide useful and reliable information for quality improvement purposes.’<sup>lxii</sup></li> <li>• The CQR sector has requested further guidance on meeting ACSQHC’s Framework requirements.</li> <li>• Other stakeholders, such as the private hospital sector and insurers, have requested more standardisation of the CQR sector. For example, hospitals may deal with multiple CQRs with differing delivery and funding models and levels of patient coverage.</li> </ul>
<b>Issue 2:</b> National CQR communication & collaboration	<ul style="list-style-type: none"> <li>• CQRs may not have easy access to systematic information on best practice CQR operation and solutions to common CQR challenges or have the opportunity to collaborate with other CQRs.</li> <li>• The impact of CQR related research may also be limited through lengthy publication delays and a lack of publicity.</li> </ul>
<b>Issue 3:</b> Streamlining external barriers	<ul style="list-style-type: none"> <li>• <u>Human research ethics approval and site governance</u> processes are designed for research/clinical trial purposes, not for ongoing, quality improvement purposes. <ul style="list-style-type: none"> <li>○ While most public and some private hospitals have streamlined ethics approval, some CQRs need ethics approval from many sites (e.g. public and private hospitals, day surgeries and private clinics).</li> </ul> </li> <li>• <u>Data collection</u>: patient data may be held in public, private and non-government health sectors with no single patient identifier, in disparate repositories, with varying data governance arrangements and standards; and data not always recorded systematically.</li> <li>• <u>Patient consent</u> processes for use of their data can impose a burden on patients and staff and can involve varying methods, for example, opt-in consent, opt-out consent and waiver of consent.</li> </ul>

Strategic Objective 2: National CQRS are Quality Assured, Efficient and Effective	
<b>Action 1:</b> Quality assurance	<p><i>Standardisation</i></p> <ul style="list-style-type: none"> <li>• ACSQHC, in line with its work plan, will: <ul style="list-style-type: none"> <li>○ update the Framework to provide further guidance on CQR governance issues, (including the development of outlier and data access policies);</li> <li>○ develop the Framework into a Standard, with associated guidance resources.</li> </ul> </li> </ul> <p><i>Accreditation</i></p> <ul style="list-style-type: none"> <li>• ACSQHC, in line with its work plan, will develop a CQR accreditation scheme, based on the Framework Standard.</li> </ul>
<b>Action 2:</b> National CQR communication and collaboration	<ul style="list-style-type: none"> <li>• Stakeholders will work together to develop and implement a National CQR communication and collaboration plan and hub, which may include national CQR conferences and a best practice website, to foster: <ul style="list-style-type: none"> <li>○ continual best practice learning and improvement through sharing information on innovations, lessons learnt and CQR related research;</li> <li>○ collaboration among CQRs and with local, national and international stakeholders.</li> </ul> </li> <li>• This work will be informed by the communication and collaboration activities undertaken by: <ul style="list-style-type: none"> <li>○ The Adelaide Registry Consortium, convened by SAHMRI and ANZDATA (at Box 10 below);</li> <li>○ Monash Registry Science Unit (at Box 9) and the Registry Special Interest Group, which provides a forum for people involved with registries to discuss issues, present work, seek input, build relationships and foster collaboration.<sup>lxiii</sup></li> </ul> </li> </ul>
<b>Action 3:</b> Streamlined external barriers	<ul style="list-style-type: none"> <li>• Stakeholders will work together to streamline these processes, including consideration of: <ul style="list-style-type: none"> <li>○ <u>streamlined ethics approval and site governance</u> examples from the private and public health care sectors and international examples, such as exist in New Zealand;</li> <li>○ national and state/territory based <u>data initiatives</u>, including on data governance arrangements and standards;</li> <li>○ <u>patient consent</u> issues/processes related to My Health Record and the <i>Framework to guide the secondary use of My Health Record system data</i>, the Productivity Commission's 2018 report, <i>Data Availability and Use</i> and the Australian Government's response to that report (more information below).</li> </ul> </li> </ul>
<b>Action leads</b>	<ul style="list-style-type: none"> <li>• ACSQHC, Australian, state/territory governments, AIHW</li> </ul>
<b>How will action benefit patients?</b>	<ul style="list-style-type: none"> <li>• Accurate, timely, sustainable CQR outputs support clinicians to deliver the best possible patient care and health outcomes.</li> </ul>

Strategic Objective 3: The potential value of national CQR data is maximised	
<b>Issue summary</b>	<p>CQRs contain valuable data that could be used to achieve a greater impact on the health system through:</p> <ol style="list-style-type: none"> <li>1. improved access to tailored CQR data and outputs by patients/consumers, health care providers, system managers and researchers;</li> <li>2. linkage with other data sets and interoperability/integration with the broader health care system, to inform more insightful improvements in patient care and outcomes across the national health system.</li> </ol>
<b>Issue 1:</b> Improved access to CQR data and outputs	<ul style="list-style-type: none"> <li>• In Australia, the potential for the <b>secondary use of CQR data</b> and outputs has not been realised <ul style="list-style-type: none"> <li>○ Consumers and other stakeholders such as health system managers and CQR funders are seeking <b>transparent and accountable</b> CQR information, as outlined at section 4, <i>Patient-centred care</i>, however: <ul style="list-style-type: none"> <li>▪ Ahern et al (2017) outline a number of key limitations and benefits of clinician level performance reporting, at Table 5;</li> <li>▪ In addition, the voluntary nature of clinician participation in Australian CQRs means that clinicians may not participate if they believe there may be adverse or unintended consequences;</li> <li>▪ Some clinicians are seeking the granting of qualified privilege for CQRs at the Australian and state/territory government level, to provide reassurance that their involvement in CQR governance and decision-making is legally protected, and that the data they contribute will be protected from inappropriate release.</li> </ul> </li> </ul> </li> <li>• CQRs are also a valuable source of longitudinal, clinically relevant <b>data for research purposes</b>. Time-limited data collection can be added to the core minimum data set if required. For example, CQRs can provide an effective, efficient vehicle for inexpensive clinical trials, given that outcome measures are already available.<sup>lxiv</sup> According to Research Australia, 'Some 91 per cent of Australians would be willing to share their de-identified medical data if it went towards research purposes'.<sup>lxv</sup> <ul style="list-style-type: none"> <li>○ The 2017 Medical Research Future Fund's grant program, <i>Rare Cancers, Rare Diseases and Unmet Need Clinical Trials Program</i> (previously known as the <i>Lifting Clinical Trials and Registries Capacity Program</i>), specifically encouraged clinical trials that leveraged the data collection and management infrastructure of established CQRs, if and where these CQRs were relevant to the conduct of proposed trials.</li> </ul> </li> </ul> <div> <p><b>RARE VOICES AUSTRALIA COMMENT ON ABOVE PARAGRAPH:</b></p> <p><i>This is very important to the RD community</i></p> </div>

Strategic Objective 3: The potential value of national CQR data is maximised	
	<ul style="list-style-type: none"> <li>There is a particular need to ensure that access to CQR data is available, without jeopardising <b>privacy or the security of the data</b>. Patients, clinicians and treatment sites need to be assured that sensitive personal and clinical information will be transferred, stored and utilised, securely, in accordance with privacy legislation and principles.</li> </ul>
Strategic Objective 3: The potential value of national CQR data is maximised	
<b>Action 1:</b> Improved access to CQR data and outputs	<ul style="list-style-type: none"> <li>Key stakeholders will work together to ensure that CQR data is collected once and used often, maximising its potential value. It will be particularly important that this continues to ensure clinician leadership and engagement with CQRs and quality improvement activities.</li> <li>There are a number of relevant initiatives which would inform this work, for example:             <ul style="list-style-type: none"> <li>the <i>Framework to guide the secondary use of My Health Record system data</i>;</li> <li>the Productivity Commission's 2018 report, <i>Data Availability and Use</i>, and the Australian Government's response to. The Government has committed to invest \$65 million to reform Australia's data system, including:                 <ol style="list-style-type: none"> <li>A Consumer Data Right - to allow consumers to harness and have greater control over their data;</li> <li>A National Data Commissioner to support a new data sharing and release framework and oversee the integrity of data sharing and release activities of Commonwealth agencies;</li> <li>A legislative package to streamline data sharing and release, subject to strict data privacy and confidentiality provisions.</li> </ol> </li> <li><i>Enhanced Health Data</i> (part of the new COAG National Health Agreement, due to commence on 1 July 2020) - will develop a joint government primary and community care data set, containing the Medicare and Pharmaceutical Benefits patient-level data and state/territory data on services funded under the NHA. The joint data set will inform the development of quality indicators.<sup>lxvi</sup></li> <li>AIHW is working with the Australian and state/territory governments to develop the <i>National Integrated Health Services Information Analysis Asset</i> - an enduring data asset linking Medicare and Pharmaceutical Benefits, hospital, aged care and deaths data.</li> </ul> </li> </ul> <p><i>Standardised data access policies/procedures</i></p> <ul style="list-style-type: none"> <li>Updating of ACSQHC's Framework will involve strengthening guidance on requests for access to CQR data and detailed reports, while maintaining patient privacy and data security. This work will elaborate on the expectation of data contributors and funders to receive return on investment and demonstration of value of the work undertaken by the CQR (e.g. improvements in clinical practice and patient outcomes). Minimum standards of reasonable access to data and reports could be developed and apply to all national CQRs, granted in accordance with relevant privacy legislation and principles, and consistent with the 2013 National Health Information Agreement.</li> </ul> <p><i>Transparency and accountability</i></p>

	<ul style="list-style-type: none"> <li>Work will be undertaken to create a transparent and accountable environment that supports the provision of tailored, regular, timely national CQR performance information to consumers, hospitals, governments, funders and other stakeholders, while protecting patient privacy. The issues raised in relation to performance reporting would be carefully considered. Such an environment would focus on supporting clinicians to improve the safety and quality of their clinical practice. It would include high functioning, mature, quality assured, national CQRs, robust data governance arrangements and may only involve hospital level reporting, subject to evaluation and review.</li> </ul>
<b>Leads</b>	Australian, state/territory governments, ACSQHC, AIHW
<b>Strategic Objective 3: The potential value of national CQR data is maximised</b>	
<b>Issue 2:</b> Data linkage, interoperability and integration	<p>As outlined at section 9. <i>Data Linkage, Interoperability and Integration</i>:</p> <ul style="list-style-type: none"> <li>currently, valuable CQR data and information may inform improvements at the individual or treatment site level, but may not reach the whole profession or across health care systems. Other health data is not utilised for quality improvement purposes. However, in countries such as Sweden, Denmark and the Netherlands, CQRs are integrated into the health information system infrastructure;</li> <li>the Strategy's medium to long term vision involves extensive national CQR data linkage, interoperability and integration into Australia's health information systems and infrastructure;</li> <li>there are considerable benefits to be realised and challenges to be overcome in achieving this objective.</li> </ul>
<b>Action 2:</b> Data linkage, CQR interoperability and integration	<ul style="list-style-type: none"> <li>The AIHW and ADHA will work with stakeholders to facilitate CQR data linkage, interoperability and integration with Australia's health information systems, in accordance with privacy legislation, and informed by a substantial body of work in this area, including: <ul style="list-style-type: none"> <li>the <i>Framework to guide the secondary use of My Health Record system data</i>,<sup>lxvii</sup></li> <li>the Productivity Commission's 2018 report, <i>Data Availability and Use</i>, and the Australian Government's response to the report (outlined in the previous section);</li> <li>the National Health Agreement <i>Enhanced Health Data</i> reform;</li> <li>the AIHW led data linkage, integration and interoperability initiatives.</li> </ul> </li> <li>Further benefits could also be realised through utilisation of Web 2.0 websites (enabling interoperability and 'community-based input, interaction, content-sharing and collaboration'),<sup>lxviii</sup> mobile/device interfaces and health apps, which could capture and enhance patient experience.</li> <li>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. This will aim to achieve the gradual evolution of prioritised, national CQRs to patient-centred interactive information systems, fully integrated into Australia's health care system.</li> </ul>

<b>Action Lead:</b>	<ul style="list-style-type: none"> <li>AIHW, ADHA, Australian, state/ territory governments, ACSQHC</li> </ul>
<b>How would action patients benefit?</b>	<ul style="list-style-type: none"> <li>CQR data and reporting inform patient health care decision making and improvements in the quality of patient care and outcomes more broadly and equitably, across the national health care system, including through provision of information for patients and data for research activities.</li> </ul>

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Strategic Objective 4: Sustainable Funding for National, Prioritised CQRs	
<b>Issues</b>	<ul style="list-style-type: none"> <li>National CQRs require sufficient, sustainable funding to meet the requirements of ACSQHC's Framework, including achieving accurate, complete data sets, full data coverage of the eligible clinical population and meaningful longitudinal data on patient outcomes.</li> <li>Funding is frequently provided on an ad hoc and short term basis by a range of public, private and non-government stakeholders, with varying funding models and levels of commitment, without reference to national priorities or a strategic framework.</li> <li>Public and private hospitals require recognition of the need for resourcing for in-kind activities such as data collection, entry, submission and information systems. Some private hospitals are concerned that CQR activities may not be covered by their private health insurance funding. The sector considers that a CQR funding model should: <ul style="list-style-type: none"> <li>take account of benefits/costs to and contributions required of both government and private sectors, in particular the considerable cost to hospitals of data collection and submission to a large number of CQRs.</li> </ul> </li> <li>Clinicians and CQR managers are increasingly approaching governments to fund CQRs, as interest grows in improving the quality of care and patient outcomes.</li> <li>In contrast to countries such as Sweden, Denmark and the Netherlands, Australia does not have a strategy or mechanism in place to guide standardised, prioritised funding of CQRs and maximise returns on investment (refer to section 10, <i>International approach</i>).</li> <li>Strategic prioritisation is required to target investment at clinical domains with the greatest burden of disease and cost to the health system. ACSQHC's <i>Prioritised list of clinical domains for clinical quality registry development</i><sup>lxix</sup> outlines the process for creating an initial prioritised list of clinical domains for potential development of national CQRs and the prioritised list (at Box 11). Ischemic (coronary) heart disease and musculoskeletal disorders are the equal top priorities.<sup>lxix</sup></li> </ul>
<b>Actions</b>	<p>Governments and ACSQHC will work with key CQR beneficiaries of CQR data/information and funders to develop a strategic, sustainable funding model for prioritised, national CQRs, involving ongoing commitments to funding and in-kind contributions. It would include:</p> <ul style="list-style-type: none"> <li>funding principles and criteria;</li> <li>pre and post accreditation arrangements;</li> <li>funding for CQRs with differing levels of maturity;</li> <li>how international benchmarking activities may be supported;</li> <li>consideration of funding for embedding CQR data items into developing EMR systems, as they are rolled out;</li> <li>evaluation requirements; and</li> <li>funding recipient responsibilities, including the need to demonstrate returns on investment around key issues such as clinical engagement, patient focus, provision of tailored information for a range of stakeholders and improvements in clinical practice and patient outcomes.</li> </ul>

Strategic Objective 4: Sustainable Funding for National, Prioritised CQRs	
<b>Actions</b>	<ul style="list-style-type: none"> <li>Major beneficiaries and current funders include: <ul style="list-style-type: none"> <li>clinicians and specialist medical societies and colleges;</li> <li>charitable foundations and not for profit organisations;</li> <li>governments;</li> <li>hospital and other treatment site providers;</li> <li>medical device and pharmaceutical industries;</li> <li>private health insurers and medical indemnity insurers.</li> </ul> </li> <li>Consideration of the strengths and weaknesses of international and domestic funding arrangements will inform the development of the funding model.</li> <li>Further CQR prioritisation work, including targeted consultation with the relevant clinical groups and consideration of government requirements, will be undertaken by ACSQHC. An emerging priority process will also be established to ensure the ongoing relevance.</li> </ul>
<b>Action Lead</b>	<ul style="list-style-type: none"> <li>Australian and state/territory governments, ACSQHC</li> </ul>
<b>How will patients benefit?</b>	Adequate resourcing assists national CQRs to operate in accordance with ACSQHC's Framework, meet quality assurance requirements and fulfil their potential to drive improvements in the best possible patient care and outcomes.



### Action: Table/Boxed Examples

Box 10: Adelaide Registry Consortium
<p>The South Australian Health and Medical Research Institute (SAHMRI) and the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA, at Box 2) have convened the Adelaide Registry Consortium to facilitate sharing of information, build relationships and foster collaboration in the establishment, management, operations and administration of registries in SA</p> <p><b>SAHMRI</b></p> <p>SAHMRI partners with a number of organisations to deliver centre based management services for registries, including high performing, national registries, such as ANZDATA and the Australian Orthopaedic Association (AOA) National Joint Replacement Registry, and support services for other registries. Services include:</p> <ul style="list-style-type: none"> <li>operational management services, centralised infrastructure and support, including legal, financial and quality assurance services;</li> <li>assistance with governance functions and facilitation of registry committee meetings;</li> <li>expertise in clinical and epidemiological research;</li> <li>statistical and data analysis services;</li> <li>data management services; and</li> <li>information technology services, including data storage.</li> </ul>

Box 11: Clinical domain priorities for national CQRs development	
1	Ischemic heart disease
	Musculoskeletal disorders
2	Trauma
	Adult critical care
	High burden cancers
3	Stroke
	Renal disease
4	Neonatal critical care
	Mental health
5	Maternity
6	Dementia
7	Major burns
	Diabetes

Table 5: Strengths and limitations of clinician-level reporting <sup>hxi</sup>	
Strengths	Limitations
Evidence of improvement in patient outcomes is enhanced with public reporting	Low procedural/activity volume may lead to false complacency for low morbidity/mortality clinical indicators
Increased clinician and hospital engagement in quality improvement activities	Low procedural/activity volume may extend reporting periods required for robust statistical analysis, and reduce timeliness of feedback
May lead to recognition and remediation of poor performers	Appropriate clinical indicators are not routinely available for all medical specialties or activities, and may not provide a comprehensive picture of clinician performance
Supports college continuing professional development programs	Clinical indicators frequently reflect performance of team or system rather than an individual
Data are highly valid and trustworthy when using appropriately selected, risk-adjusted clinical indicators	Risk adjustment is complex and difficult to undertake; unintended consequences of inadequate risk adjustment may include avoidance of high risk patients, particularly if results are public
Fosters discussion and learning within clinical communities	Potential employment consequences for clinicians detected as outliers or poor performers

## GLOSSARY

Terminology	Definition
Administrative data	Information collected routinely from the patient's medical record, primarily for administrative (not research) purposes. This type of data is collected by hospitals, government departments and other organisations for the purposes of registration, transaction and record keeping, usually during the delivery of a service.
Benchmark	A measurement taken at the outset of a series of measurements of the same variable, sometimes meaning the best or most desirable value of the variable. A standard or point of reference.
Clinical quality registry (also see Virtual registry)	A CQR systematically monitors the quality (appropriateness and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information. The information is used to identify benchmarks and significant outcome variance, and inform improvements in healthcare quality. <sup>lxxii</sup>
Clinical register	A clinical register aims to recruit all patients with the disease or condition, or undergoing the procedure. A clinical register is observational in nature. It observes practice in the real world without dictating the care to be given.
Clinician	A health professional whose practice is based on direct observation and treatment of a patient, as distinguished for other types of health workers, such as laboratory technicians and those employed for research.
Clinical trial	Any research project that prospectively assigns human participants or groups, in highly controlled setting, to one or more health-related interventions to evaluate the effects on health outcomes.
Consumer representative	A health consumer who has taken up a specific role to provide advice on behalf of consumers, with the overall aim of improving health care. A consumer representative is often a consumer member of a committee, project or event who voices consumer perspectives and takes part in co-design and/or decision making on behalf of consumers.
High functioning, mature CQR	A CQR: with strong governance arrangements in place; with a data management system that complies with privacy and security requirements associated with personal health information; with a high level of coverage of the relevant patient population; that provides regular risk adjusted, benchmarked feedback to clinicians; publicly reports fit-for-purpose information; and with policies in place to guide the identification and management of outliers and to respond to requests for access to CQR data.
Minimum data set	A minimum data set is a minimum set of data elements agreed for mandatory collection and reporting. <sup>lxxiii</sup>
Outliers	Extreme, or atypical data value(s) that are notably different from the rest of the data. <sup>lxxiv</sup>
Patient Reported Experience measures (PREMs)	PREMs are tools for capturing a patient's views of their experience of the care they received. <sup>lxxv</sup>

Terminology	Definition
Patient Reported Outcome Measures (PROMs)	PROMs ‘...are questionnaires which collect patients’ assessments of how health services and interventions have, over time, affected their quality of life, daily functioning, symptom severity, and other dimensions of health...[PROMs]...fill a vital gap in our knowledge about outcomes and about whether healthcare interventions actually make a difference to people’s lives’. <sup>lxxvi</sup>
Quality assurance	System of procedures, checks, audits, and corrective actions to ensure that all research, testing, monitoring, sampling, analysis, and other technical and reporting activities are of the highest achievable quality. The term is used in health services with the same meaning.
Quality of care	The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. <sup>lxxvii</sup>
Quality of life	The degree to which persons perceive themselves able to function physically, emotionally, mentally, and socially.
Register	The file of data concerning all cases of a particular disease or other health-relevant condition in a defined population such that the cases can be related to a population base.
Registry	The system of ongoing registration for individuals entered into a register.
Research	A class of activities designed to develop or contribute to knowledge. In applied science, the goal is generalisable knowledge, where the latter consists of theories, principles, relationships, products, or the accumulation of information on which these are based that can be corroborated by acceptable scientific methods of observation, inference, or experiment. When humans are the subjects of epidemiological research, ethical review is mandatory. However, while CQRs are required to seek ethics approvals via NHMRC - ethics committees, they are not considered research activities by the NHMRC.
Risk Adjustment	A statistical process that accounts for factors beyond the control of the health care team, such as patient related and disease related factors (e.g. disease stage). These factors can be statistically adjusted for when benchmarking CQIs to allow more accurate comparisons of care and outcomes between patients with the same disease/condition.
Value based health care	Health outcomes achieved that matter to patients relative to the cost of achieving those outcomes. Improving value requires either improving one or more outcomes without raising costs or lowering costs without compromising outcomes, or both. <sup>lxxviii</sup>
Virtual registry	A registry which virtually integrates one or more of its components (governance, data analysis, data hosting, data collection). The governance function is central, as it oversees registry operation and resource application, ensures accountability, establishes the data set required to meet the needs and objectives of the CQR, and establishes key policies around, for example, the identification and management of outliers.

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