



Australian Government

Maximising the Value of Australia's Clinical Quality Outcomes Data

A National Strategy for
Clinical Quality Registries
and Virtual Registries

2020-2030



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Minister's foreword

Clinical quality outcomes data is a critical component of a continuously improving health care system. The development of the first National Clinical Quality Registry and Virtual Registry Strategy highlights the importance of this data for Australia, which spent around \$196 billion on health care in 2018-19.

The integration of health outcomes data with national, state and territory health care datasets will help drive systematic improvements in clinical practice and ensure the best value care for all Australians.

The 10-year Strategy provides the rationale and national roadmap for this work. It will guide strategic investment in clinical quality outcomes datasets in areas of national priority and the gradual integration of this data with Australia's major health care datasets. It will ensure that tailored outcomes information is accessible to a range of stakeholders and facilitate the shift towards patient centred care. It will build on the excellent work of many stakeholders and help clinical quality registries (CQRs) and virtual registries (VRs) realise their significant potential.

I am impressed by the level of consultation and collaboration that has underpinned the development of the Strategy. The Commonwealth, states and territories have worked in partnership with the Australian Commission on Safety and Quality in Health Care, the Australian Institute of Health and Welfare and key stakeholders, including clinicians, the CQR sector and consumers. Its development has also been informed by an Expert Advisory Group and a national consultation process, which received more than 80 generally supportive submissions from a broad range of stakeholders. The success of the Strategy will depend on this level of collaboration and partnership going forward.

I am pleased to present Australia's first National Clinical Quality Registry and Virtual Registry Strategy. It will help shape the future of the Australian health care system that is centred on patients and driven by continuous improvement.

A handwritten signature in blue ink, appearing to read 'Greg Hunt', is positioned below the Minister's foreword text.

Acknowledgements

We gratefully acknowledge the advice, input and support of the many organisations and individuals who contributed to the development of this Strategy, including the Clinical Principal Committee Working Group, the Expert Advisory Group and those who provided submissions to the national consultation process. Special thanks to Professor Susannah Ahern, Head, Registry Science and Research, Monash University.

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About the Strategy

The National Clinical Quality Registry and Virtual Registry Strategy aims to drive continuous improvements in the value and quality of patient-centred health care to achieve better health outcomes for all Australians.

The Strategy will:

- improve the collection, monitoring, reporting and actioning of national clinical quality outcomes data in line with the best practice principles outlined in the Australian Commission on Safety and Quality in Health Care's (the Commission) [Framework for Australian clinical quality registries](#); and
- maximise efficiency and return on investment through gradually embedding prioritised clinical quality outcomes datasets into Australia's contemporary health information systems through a nationally coordinated approach.

Clinical quality outcomes datasets

"Clinical quality outcomes datasets" refer to datasets that include a combination of clinical and patient-derived data for a particular clinical domain. This universal term is inclusive of Clinical Quality Registries (CQRs)¹ and other mechanisms like virtual registries² (i.e. those that draw data from existing platforms, such as state-based Electronic Medical Records (EMRs) or data lakes and data warehouses), which are designed to report timely, actionable and risk-adjusted benchmarked data back to clinicians, health providers and other stakeholders for the purposes of quality improvement.

The Strategy also refers to "collecting, monitoring, reporting and actioning clinical quality outcomes information" as a general way to describe the *system* of using combined clinical and patient-derived data to oversee safe, high quality and effective health care that leads to improvements in clinical practice and patient outcomes, including in relation to quality of life.

Scope

The Strategy's focus is on maximising the value of **national** clinical quality outcomes datasets (or those with the potential to be expanded nationally) **in areas with the greatest burden of disease and cost to the Australian health system and/or with greatest variation in care and outcomes**. The Strategy's scope does not include national and state-based datasets created for purposes other than quality improvement, such as administration (however, it does support integration of prioritised clinical quality outcomes data with these datasets, when appropriate).

¹ See Glossary

² See Glossary

Background

The Strategy is being led in partnership with the Australian and State/Territory governments, together with the Commission, the Australian Institute of Health and Welfare (AIHW), and an Expert Advisory Group.

It recognises the excellent work of the organisations and jurisdictions who lead Australia's various clinical quality outcomes datasets, including the commitment of clinicians and health services who have contributed data via CQRs over many years. It also recognises the important leadership role of the Commission, which has set the best practice standards for CQRs for more than a decade.

The Strategy builds upon the strong foundations set by the jurisdictions, the Commission in its [Framework for Australian clinical quality registries](#), and the AIHW in its work to build and maintain national minimum health datasets, and to further drive the four strategic health system reform priorities agreed by the former Council of Australian Governments (COAG) in 2018:

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

A 2019 national public consultation process also informed the Strategy's development. Over eighty submissions were received from a wide range of stakeholders including: clinicians and medical specialist peak bodies; registries; consumer organisations; government and non-government organisations; private providers and insurers; and the medical device/technology industry. The Summary Consultation Report outlines the feedback received.

The Strategy outlines a set of agreed national priorities and actions to be implemented over a 10-year period (see Table 1). Over time, the Strategy may be modified to accommodate developing knowledge, capabilities and technologies.

Table 1: Agreed national priorities and actions to be implemented over a 10-year period

Maximising the Value of Australia's Clinical Quality Outcomes Data: A National Strategy						
Vision National clinical quality outcomes data are integrated into Australia's health care information systems and systematically drive patient-centred improvements in the quality and value of health care to achieve better patient outcomes across the health care system.						
	Patient Outcomes		Standardisation and Efficiency		Innovation and Impact	
Pillars	Patient-centred health care	Improved clinical practice care and health outcomes	Quality, efficiency and cost effectiveness	Financial sustainability	Transparency and access	Data linkage, integration and interoperability
Priorities	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Are co-designed with patients, their families and carers, and consumer organisations • Are co-led by clinicians with expertise in the relevant domain and the relevant data custodians • Promote equitable healthcare and outcomes • Include a combination of clinical and patient-derived data (including appropriate patient reported outcome and experience measures) • Support shared decision-making with patients. 	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Measure adherence to (or inform development of) national clinical care standards • Have full national coverage across public and private settings • Are accurately risk-adjusted and benchmarked against agreed performance indicators • Are coupled with a timely 'feedback loop' mechanism to action performance data for safety and quality improvement • Are accompanied by an agreed outlier management policy. 	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Are subject to nationally streamlined processes for: <ul style="list-style-type: none"> ➢ patient consent ➢ site and data governance ➢ research and clinical trials ethics approval • Are recognised as national quality assurance activities • Are systematically collected using national health data and terminology standards and definitions • Align with the Commission's National CQR Standard (under development) and jurisdictional priorities. 	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Are nationally funded: <ul style="list-style-type: none"> ➢ in partnership with multiple beneficiaries ➢ using transparent national prioritisation criteria ➢ to support digitisation, integration and interoperability • Are subject to ongoing independent evaluation (including economic evaluation). 	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Support timely data access, tailored for a broad range of stakeholders • Feed into outward facing patient and stakeholder portals • Protect patient privacy and maintain provider trust • Contribute to national reporting, including appropriate public reporting • Support national and international benchmarking, and contribute to international datasets. 	National clinical quality outcomes datasets: <ul style="list-style-type: none"> • Are captured once and used multiple times (including routine linkage with other data elements) • Are embedded in Electronic Medical Records, administrative systems and national health and clinical trial infrastructure • Automate data extraction, analysis and reporting via application programming interfaces (APIs) • Use predictive modelling to support clinical decision-making and public health design and evaluation.
Alignment with national initiatives	Guided by the Australian Commission on Safety and Quality in Health Care's Framework for Australian clinical quality registries and Clinical Quality Registry Standard (to be developed) and Schedule C of the 2020-25 Addendum to the National Health Reform Agreement.				Guided by Schedule D of the 2020-25 Addendum to the National Health Reform Agreement, the Australian Health Performance Framework, and the Office of the National Data Commissioner's Data Sharing Framework for Public Sector Data.	Guided by Schedule C of the 2020-25 Addendum to the National Health Reform Agreement, the Australian Digital Health Agency's National Health Interoperability Roadmap and the Australian Institute of Health and Welfare's National Health Information Strategy.

Policy Rationale

There are more health-related data available now than ever before. The vast amount of information generated from Australian health information systems can be used to good effect for broad brush monitoring of activity and financial performance at the health system level. However, it often lacks the detailed clinical and patient reported outcomes data needed to directly support patient-centred care and clinical practice improvement. The systematic addition of clinical quality outcomes datasets into Australia's health information systems will allow for high-level monitoring of safety and performance issues at the state and national level and provide the patient-level information needed to be clinically actionable³ at the same time.

CQRs have been the primary mechanism for addressing gaps in clinical quality outcomes data to date. CQRs monitor the quality (appropriateness and effectiveness) of health care within specific clinical domains by collecting and analysing longitudinal clinical and patient-derived outcomes data. They then risk-adjust and benchmark these data against agreed clinical quality indicators to identify variation in clinical care processes and outcomes.

High-functioning, mature⁴ CQRs routinely feed this information back to clinicians, hospitals, and other health services to support clinical practice change and improvements in patient outcomes and experiences (see Box 1). The Commission's [Framework for Australian clinical quality registries](#) outlines the operations and components of CQRs in more detail.

BOX 1: PROSTATE CANCER OUTCOME REGISTRY-VICTORIA (PCOR-VIC) ^{i ii}

The PCOR-Vic, managed by Monash University, systematically follows-up men after a diagnosis of prostate cancer. It 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.

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 resulted in amendments to training programs by the Urological Society of Australia and New Zealand (USANZ). The impact of this is now being 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).

³ Data is available at the individual patient level within a comparable cohort, so that variation can be identified and actioned.

⁴ See Glossary.

CQRs have led to significant safety and quality improvements in Australia and overseas. For example, one of Australia's longest running registries, the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR), has achieved a benefit equivalent to \$600 million in savings from reduced joint revisions (see Box 2).

The same economic evaluation of Australian CQRs supports 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'.ⁱⁱⁱ

BOX 2: AUSTRALIAN ORTHOPAEDIC ASSOCIATION NATIONAL JOINT REPLACEMENT REGISTRY (AOANJRR)^{iv}

The AOANJRR is governed by the AOA, with data management provided by the South Australian Health and Medical Research Institute (SAHMRI). It improves and maintains the quality of care for individuals receiving joint replacement surgery, via provision of benchmarked, risk-adjusted feedback on clinician and device performance. Information on hip, knee, shoulder, elbow, wrist, ankle and spinal disc replacement is collected from all hospitals in Australia undertaking joint replacement surgery.

Based on AOANJRR data, Australia was the first country in the world to withdraw a metal-on-metal hip replacement device from the market in December 2009. This device, implanted in an estimated 93,000 people worldwide, led to significant adverse impacts for many people and a worldwide recall in August 2010.

An economic evaluation of Australian CQRs estimated a return on investment in the AOANJRR of \$5 for every dollar invested, in relation to reduced revision surgery for hip and knee replacements and reduced use of devices identified as requiring high rates of revision surgery. It was estimated that an overall benefit of more than \$600 million was achieved over time, compared to international benchmarks for hip and knee surgery revision.^v

The AOANJRR was instrumental in the formation of the International Society of Arthroplasty Registries (ISAR) and Professor Stephen Graves (AOANJRR Director) was the inaugural president. ISAR has over 40 members globally. It has been important to the international harmonisation of registry data and the development of shared registry infrastructure. It has also enhanced collaboration between registries and other organisations, including the US Food and Drug Administration International Consortium of Orthopaedic Registries Initiative, of which Professor Graves was also the inaugural chair.

Internationally, CQRs are recognised as key vehicles for improving the value of health care and contributing to the sustainability of health care systems.^{vi} In Sweden, Denmark and the Netherlands, they are organised and funded nationally, with a strong commitment from government. In these countries, CQRs have a high degree of integration with existing data systems, and both hospitals and clinicians are involved in data collection, reporting and improvement initiatives.

CQR data are also valuable for medical research and clinical trials, and when linked with other datasets, can be effective tools for assessing whether evidence from these activities is applied in real-world practice. For example, studies have shown that registry-based clinical trials can be undertaken more cost effectively, and with more efficient patient recruitment, than clinical trials conducted without registry infrastructure.^{vii} CQRs can also help detect safety and quality issues with new medicines or devices through post market surveillance.

However, in Australia, we are yet to unlock the full potential of CQRs and further explore their secondary use. To date, most Australian CQRs have evolved via a 'bottom-up approach', as clinician-led research initiatives to fill critical information gaps and identify issues and improve outcomes in specific domains.

While this approach has had the advantage of ensuring essential clinical engagement, the breadth of local implementation has meant there are now scores of CQRs operating across Australia.

As a result, timely, tailored access to CQR data for a broad range of stakeholders, and its systematic integration with national and jurisdictional health information systems, clinical trials and the Therapeutic Goods Administration (TGA) device and medicine safety infrastructure, has been limited. The absence of a 'top down' strategic approach has also led to significant inefficiencies and duplication across the sector and made it difficult to prioritise investment in clinical domains with the greatest burden of disease and cost to the Australian health system, or in areas with the greatest variation in care and outcomes.

Increasing recognition of the value of clinical quality outcomes data, coupled with maturing digital and information technologies, now presents an opportunity to maximise the value of this information in the delivery of patient-centred health care through a nationally coordinated approach.

Strategy Vision

The Strategy's vision is:

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

The Strategy will be successful if:

- Australians receive high quality, cost-effective, patient-centred care and outcomes;
- patients, their families and carers are more empowered to make decisions about their care, based on information about outcomes that matter to them;
- clinicians are armed with timely, comprehensive outcomes data to help optimise patient care;
- examining and addressing unwarranted variation in care becomes routine practice;
- patient and clinical outcomes data form part of national health system infrastructure – just like administrative data are now; and
- data are available, and tailored to, those who need it – including patients, clinicians, health care providers, funders, private health insurers, industry, governments and researchers – when they need it.

Value Proposition

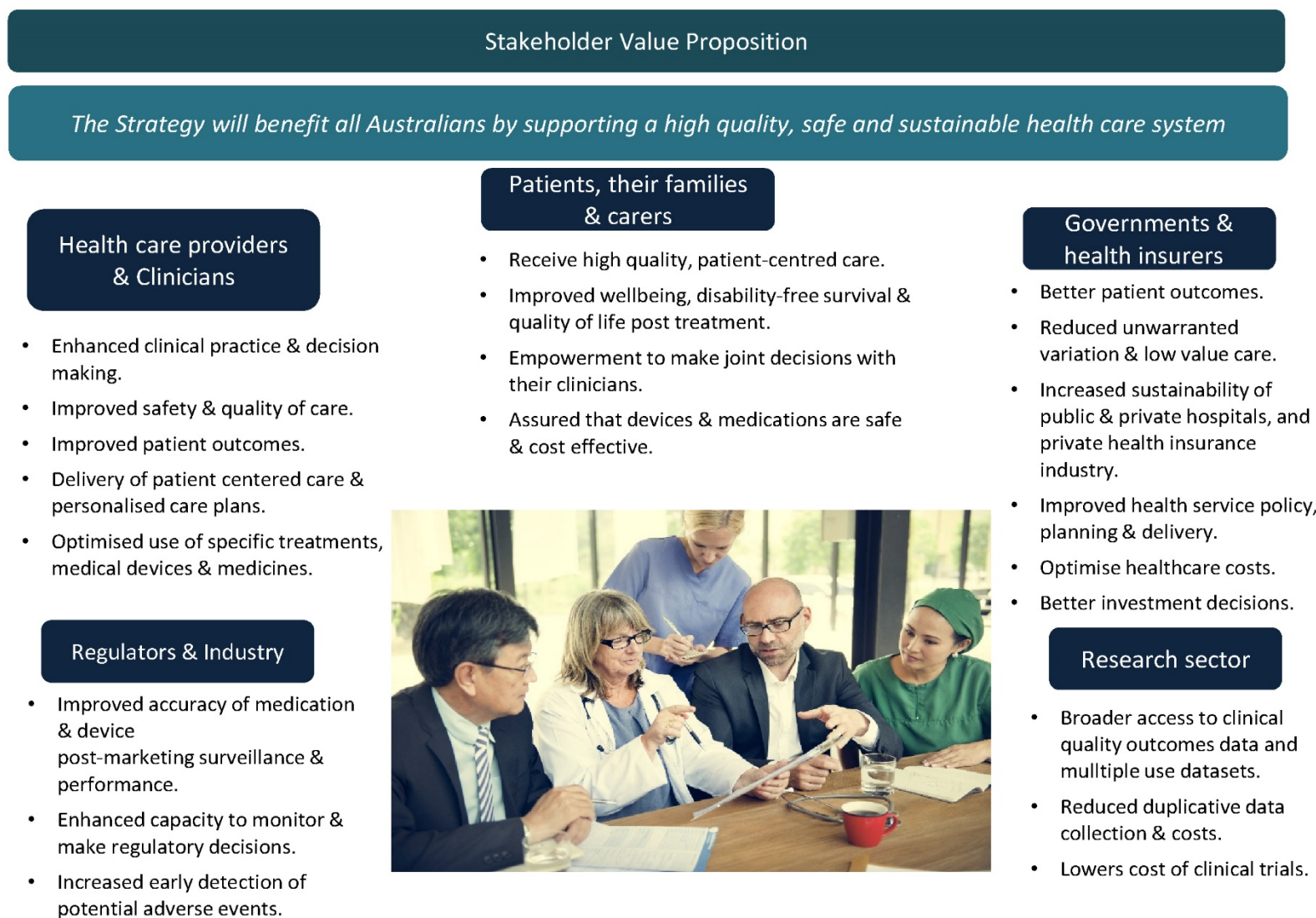
Effectively collecting, monitoring, reporting and actioning clinical quality outcomes information can increase the value of health care, inform health policy at a national and state/territory level and contribute to the sustainability of Australia's health care system.

This can benefit a range of stakeholders, including:

- patients, their families and carers through improved patient-centred care that is aligned with patient needs, preferences and priorities, and the provision of information that can better support health care choices; and
- hospitals/health system managers, funders, governments, industry and private health insurers through a safer, more sustainable health system that provides optimised care, and reduces unnecessary and ineffective treatment, health care-related complications and adverse events.

Figure 1 outlines the Strategy's value proposition for different stakeholders in more detail.

Figure 1: Stakeholder Value Proposition



Realising the Vision

The Strategy's 10-year vision involves extensive interoperability and integration of prioritised clinical quality outcomes data with administrative data, clinical trial and TGA infrastructure, state-based EMRs and potentially My Health Record (MHR) in future. New South Wales, for example, have invested in virtual registries that combine their EMRs with multiple clinical, patient and administrative datasets (see Box 3). Virtual registries commonly make use of repositories such as data lakes and data warehouses to maximise the secondary use of data and link together existing datasets to deliver a comprehensive picture of the patient journey.

However, the capability and infrastructure required to support this vision at the national level is several years away. Much will depend on the outcomes of other important national initiatives, including the development of MHR, the Australian Digital Health Agency's (ADHA), [National Health Interoperability Principles](#), the AIHW's [National Health Information Strategy](#), and the implementation of the [2020-25 Addendum to the National Health Reform Agreement](#) and the [Australian Health Performance Framework](#). It is important that this Strategy stays aligned with these initiatives as much as possible.

As a result, the Strategy takes a dual approach: it will support the CQR sector to build capacity in line with the best practice principles outlined in the Commission's Framework; and form the critical building blocks needed for national integration and interoperability at the same time. This approach will see prioritised clinical quality outcomes data gradually embedded into National Minimum Datasets, EMRs, MHR and other health information systems and data repositories over time, so that by the end of the 10-year period, the majority of prioritised clinical quality outcomes data items will be linked and automatically extracted from existing systems rather than separately collected. This will streamline data flows and reduce collection burden and cost, meaning efficiencies can be redirected towards innovation and impact activities that maximise the data's utility and accessibility, tailored to the needs of individual stakeholders.

Realising this long-term vision will require coordinated action across the sector and all jurisdictions. No single organisation or agency can deliver the vision alone; it requires stakeholders to work together in partnership in a nationally coordinated approach, and facilitate appropriate access and sharing of data. A detailed summary of stakeholder roles and responsibilities is at Appendix A.

BOX 3: NSW VIRTUAL REGISTRIES^{viii}

NSW aims to embed a CQR-like function within existing, routine systems and processes, through linking administrative data sets, patient reported measures data sets, and cohort-specific clinical and other data sets (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, and made directly accessible through an analytics application (this includes benchmarked data as well as datasets).

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.

Strategy Pillars

Six pillars underpin the Strategy, each with a set of agreed national priorities and actions. These were determined together with clinicians, the CQR sector, the jurisdictions, the Commission and the AIHW in response to the key issues raised during the Strategy's national public consultation process. The Summary Consultation Report outlines these issues in more detail.

The Strategy identifies priorities and actions at the national level that will support jurisdictions to enhance local mechanisms to investigate and implement quality improvement initiatives within their existing health care system arrangements.

Underpinning Strategy actions will be a set of complementary and agile governance arrangements outlined in the Commission's CQR Framework. Note these arrangements may evolve over time as the Strategy progresses. See the Commission's [website](#) for more detail.

Finally, Strategy actions will not necessarily follow a linear path. A flexible implementation approach, coupled with ongoing monitoring and evaluation, will be required.

1. Patient-centred health care

The Strategy seeks to significantly contribute to the delivery of patient-centred care in Australia. The Commission has defined patient-centred care as "health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers".^{ix}

In 2017, the 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.^x The reforms outlined in the *2020-25 Addendum to the National Health Reform Agreement* support this approach.

While many datasets collect information on patient characteristics and details on certain procedures and treatments, they may lack the patient-derived data needed to:

- identify variability in patient reported outcomes;
- support clinicians to tailor their care to the individual needs and preferences of patients; and
- support equity of health care (see Box 4).

National clinical quality outcomes datasets should therefore include a combination of both clinical and patient-derived data, including appropriate patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) (see Box 5).

Clinician leadership must also remain a central component in deciding what national datasets should be measuring and reporting; and how outputs are peer reviewed. Likewise, as some jurisdictions are well advanced in their determination, collection and use of PROMs and PREMs, Strategy actions will need to align to jurisdictional work where possible.

BOX 4: CONTRIBUTING TO MORE EQUITABLE OUTCOMES

The AOANJRR (outlined in Box 2) and the Australia and New Zealand Dialysis and Transplantation (ANZDATA) Registry^{xi} are contributing to equitable, patient-centred outcomes for Aboriginal and Torres Strait Islander peoples and other populations. For example:

- ANZDATA receives data from all ANZ renal units on the incidence and prevalence of end stage kidney disease treatment, complications and mortality. It provides quarterly feedback reports to individual renal units on dialysis key performance indicators, dialysis outcomes, transplant care and surgery. ANZDATA identified that Aboriginal and Torres Strait Islander peoples, who have very high rates of chronic kidney disease, are less likely than non-Indigenous people to be placed on the transplantation waiting list during the first year of renal replacement therapy. It highlighted the need for changes in health care policy and practice to address these disparities, and the National Indigenous Kidney Transplantation Taskforce was convened. ANZDATA, which has an Aboriginal and Torres Strait Islander working group, includes a specific chapter on Aboriginal and Torres Strait Islander dialysis and transplantation in its annual report.
- AOANJRR identified a significantly lower rate of hip and knee arthroplasty among Aboriginal and Torres Strait Islander peoples, compared to the non-Indigenous population, despite similar reports of osteoarthritis. An AOANJRR study is planned to examine whether disparities in rates of joint replacement exist for Aboriginal and Torres Strait Islander peoples compared to non-Indigenous people in Australia and identify any contributing socioeconomic and health risk factors. AOANJRR considers that the support and advice of Wardliparingga (SAHMRI's Aboriginal and Torres Strait Islander health research unit) is critical to ensure that the work is undertaken in an appropriate manner, which acknowledges Aboriginal culture, and follows the principles of existing national statements and guidelines for conducting research with, for and by Aboriginal people.

Both registries ensure that Aboriginal and Torres Strait Islander peoples are involved with identifying and asserting Indigenous data governance.

BOX 5: PROSTATE CANCER OUTCOME REGISTRY-VICTORIA (PCOR-VIC)^{xii xiii}

PCOR-Vic (at Box 1) collects quality of life PROMs on urinary, sexual and bowel function. These are 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 these 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 per cent improvement in quality of life in those with a care coordinator compared to patients receiving standard treatment in the same geographic region was demonstrated.

Priority areas for action

Actions under Pillar 1 aim to ensure that the collection, monitoring, reporting and actioning of national clinical quality outcomes information is patient-centred, clinician-led and contributes to improvements in outcomes that matter most to patients.

Priority 1 Actions	Co-design with patients, their carers and families <ul style="list-style-type: none"> • Build capacity in engaging patients, their carers, families, and consumer organisations in the co-design of data requirements that measure outcomes that matter most to them and reflect their lived experience. • Strengthen patient participation and representation in governance activities.
Priority 2 Actions	Clinician leadership <ul style="list-style-type: none"> • Ensure national clinical quality outcomes data requirements are co-led by clinicians and craft groups with expertise in the relevant domain. • Increase engagement with Australian Health Practitioner Regulation Agency (AHPRA), medical specialist peak bodies and other stakeholders to facilitate professional pathways that support clinician participation and leadership (e.g. through credentialing requirements). • Strengthen clinician participation and representation in governance activities.
Priority 3 Actions	Equitable healthcare and outcomes <ul style="list-style-type: none"> • Engage Aboriginal and Torres Strait Islander people, people living in regional and remote areas, people with disabilities, people from socio-economically disadvantaged groups and people from diverse cultural and linguistic backgrounds to define the health outcomes that matter most to them. • Increase engagement with Aboriginal Community Controlled Health Organisations to support Aboriginal and Torres Strait Islander people to manage, protect and control their own data. • Promote culturally appropriate health care and practices to improve patient health outcomes for Aboriginal and Torres Strait Islander people, in alignment with the Closing the Gap policies and strategies. • Strengthen equitable representation in governance activities.
Priority 4 Actions	Patient reported outcomes and experiences <ul style="list-style-type: none"> • Provide incentives to increase the national capture of appropriate PROMs and PREMs, such as wellbeing, quality of life, survivorship, and experiences of health care, in accordance with Schedule C of the 2020-25 Addendum to the National Health Reform Agreement. • Support automated, validated national collection tools for PROMs and PREMs, which can be adapted to suit the needs of different jurisdictions, clinical domains and population groups. • Develop culturally validated PROMs and PREMs for Aboriginal and Torres Strait Islander people and people from diverse cultural backgrounds. • Develop national resources specifically designed to help clinicians and stakeholders to better analyse, interpret and apply patient-derived data across a range of health care settings. • Build upon and align to the existing work from leading jurisdictions, such as NSW and Victoria, and at the national level by the Commission, and align with Schedule C of the <i>2020-25 Addendum to the National Health Reform Agreement</i>, when designing nationally consistent approaches.

Priority 5 Actions	Shared decision making <ul style="list-style-type: none"> • Increase access and availability to national clinical quality outcomes data via publication of patient friendly reports (ideally on a centralised platform), which are tailored for different patient cohorts, similar to the approach already taken by NSW (also see Pillar 5). • Prioritise systems and platforms that support shared decision-making between patients and clinicians, in accordance with Schedule C in the 2020-25 Addendum to the National Health Reform Agreement.
Lead agency (partners)	The Commission (Australian and State and Territory Governments, patients and consumer organisations, clinicians, hospitals and health services, Aboriginal Community Controlled Health Organisations, disability, rural and Culturally and Linguistically Diverse (CALD) peak health bodies, craft groups and medical societies and colleges)

2. Improved clinical practice care and patient outcomes

A key Strategy priority is that the collection, monitoring, reporting and actioning of national clinical quality outcomes information purposefully support improvements in clinical care and patient-centred outcomes. This means that national clinical quality outcomes datasets should be accompanied by an effective mechanism that identifies clinical variation at the patient level, explores its cause and then translates it into actionable feedback (see Box 1 and Box 5).

This is typically achieved via a ‘feedback loop’, where clinicians, health services and other stakeholders are provided with timely risk-adjusted, benchmarked feedback on whether their care aligns with national standards, including [clinical care standards](#), and how their patient outcomes compare to that of their peers. As outlined in Pillar 5 access to these data must be timely (and ideally automated, for maximum efficiency) and tailored to the needs of individual stakeholders in order to be most effective.

In cases where a particular clinician or health service is identified as a ‘high outlier’ (that is, their performance is consistently excellent), they are encouraged to share their best practice processes so that others can learn from them.

In cases where a ‘low outlier’ is identified (i.e. persistent, significant variation has been detected), they are supported to improve their performance by their jurisdiction, organisation, peers and medical specialist college or society. Together, this drives a self-improving health system.

Given the significant time, expertise and resources required to support an effective ‘feedback loop’, stakeholders have called for more support to undertake this function at the national level. Some jurisdictions already have strong feedback and quality improvement programs in place, so it is important that national activities align with local initiatives where appropriate.

Priority areas for action

Actions under Pillar 2 aim to build national capacity in a national ‘feedback loop’ activity, by taking a best practice approach to risk adjustment, benchmarking and reporting, and the management of outliers.

Priority 6 Actions	Adherence to national clinical care standards <ul style="list-style-type: none"> Ensure national clinical quality outcomes datasets measure adherence to national clinical care standards, and/or inform the development of new standards. Implement periodic audits of compliance with these standards, with the purpose of supporting and encouraging national implementation.
Priority 7 Actions	National coverage of the in-scope population <ul style="list-style-type: none"> Improve national capture of all incidents of the relevant procedures, treatments and outcomes for patient cohorts across both public and private settings (also see Pillar 4). Increase engagement with the private sector and medical device and pharmaceutical industries to encourage participation and contribution of data. Provide support materials to encourage patient participation and consent, including guidance on culturally appropriate patient consent processes for Aboriginal and Torres Strait Islander people and other people from diverse cultural backgrounds.
Priority 8 Actions	Accurate risk adjustment and benchmarking <ul style="list-style-type: none"> Agree quality and performance indicators, and appropriate risk adjustment and benchmarking methods, with clinicians and stakeholders within the relevant clinical domain. Establish national relevant health data and terminology standards for common risk adjustment and benchmarking data items. Improve capacity for national and international risk adjustment and benchmarking through provision of best practice guidance and support materials.
Priority 9 Actions	Quality ‘feedback loop’ mechanisms <ul style="list-style-type: none"> Develop national minimum feedback reporting standards, which support automated processes and timely, tailored access for stakeholders. Implement periodic audits of national feedback reporting standards in prioritised national clinical quality outcomes datasets, for quality assurance purposes. Request the delivery of annual impact statements that demonstrate how feedback reporting is supporting improvements in clinical practice and patient outcomes. Increase engagement with clinicians, peak bodies, patients and consumer organisations, governments and other stakeholders to ensure minimum reporting standards meet their ongoing requirements.
Priority 10 Actions	Outlier management <ul style="list-style-type: none"> Support the Commission to develop best practice national outlier and reporting policies as part of the CQR Framework, including guidance on Qualified Privilege (also see Pillar 5). Encourage continual learning and improvement through sharing information on best practice, innovations and lessons learnt.
Lead agency (partners)	The Commission, Australian and State and Territory Governments (Clinicians, patients and consumer organisations, public and private hospitals and health services, data managers, funders, private health insurers, medical colleges and societies, peak health bodies and craft groups, AIHW, and medical device and pharmaceutical industries)

3. Quality, efficiency and cost effectiveness

The Strategy seeks to support ongoing improvement in the quality and efficiency of collecting monitoring, reporting and actioning national clinical quality outcomes information in line with the CQR Framework.

Stakeholders have called for a streamlined approach to site governance approvals and other related issues, such as ethics approval and patient consent, to ensure timely and efficient authorisation to collect and share data. A standardised approach to data collection and data governance is also required to accurately combine and compare data across all sites, jurisdictions and the Commonwealth. Data capture must be systematic⁵ and digital methods employed where possible, to reduce collection burden on clinicians and hospitals, and to increase the accuracy and timeliness of the data.

As data become more integrated and interoperable in line with the Strategy's vision, data capture should adhere to the 'collect once, use multiple time principle', in accordance with Schedule C of the [2020-25 Addendum to the National Health Reform Agreement](#).

In practice, this means data should be sourced from existing systems where possible, with direct collection limited to only those variables that are not collected elsewhere. Likewise, data linkage and interoperability capability should ideally be inbuilt by design, rather than made to retrofit.

Priority areas for action

Actions under Pillar 3 aim to facilitate streamlined and standardised processes for systematic data capture and collection; to ensure these processes are as efficient and cost effective as possible.

⁵ Systematic collection means that information is consistently collected in the same way, at the same time and using the same definitions

Priority 11 Actions	Streamlining processes <ul style="list-style-type: none"> For CQRs conducted within a research framework, streamline site governance, patient consent and research ethics processes. Integrate national CQR data governance arrangements with national data governance arrangements for efficient collection, reporting, monitoring and data management activities, while protecting patient privacy, in accordance with Schedule C of the 2020-25 Addendum to the National Health Reform Agreement. Develop support materials, including templates for research ethics applications and standard wording for patient information sheets seeking consent for national data sharing and data linkage.
Priority 12 Actions	Recognition as national quality assurance activities <ul style="list-style-type: none"> Support the Commission and the AIHW to revise national health information arrangements together with the jurisdictions, to capture and collect national clinical quality outcomes data for quality assurance and improvement activities, and integrate these with the administrative information systems, in line with jurisdictional priorities.
Priority 13 Actions	Systematic data collection <ul style="list-style-type: none"> Provide incentives to increase the use of standardised digital data collection and capture methods for clinical quality outcomes datasets (see Pillar 6). Develop and/or apply national relevant health data and terminology standards and definitions for common data items and elements to support systematic collection, using the AIHW's Metadata Online Repository (METeOR) system where possible. Promote identification of Aboriginal and Torres Strait Islander people by capturing a standard Indigenous status item in all national clinical quality outcomes datasets. Build capacity at the site level to consistently collect, enter and transfer data in the same way, at the same time and using identical definitions.
Priority 14 Actions	National Standard and Accreditation scheme <ul style="list-style-type: none"> Support the Commission to co-design a national Standard for national clinical and outcome datasets in partnership with stakeholders, and an Accreditation Scheme (informed by a regulatory impact assessment) to assess adherence to the Standard. Align with the draft National Clinical Trials Governance Framework, where possible.
Priority 15 Actions	Communication and Collaboration <ul style="list-style-type: none"> Establish a Communication and Collaboration Hub to support local, national and international stakeholders to work together and share best practice, building on the Australian Register of Clinical Registries as the basis.
Lead agency (partners)	The Commission, the AIHW, Australian and State and Territory Governments (Data managers, patients and consumer organisations, clinicians, hospitals and health services, and researchers)

4. Financial sustainability

The Strategy recognises that sufficient, sustainable funding is required for national clinical quality outcomes datasets to maintain full data coverage of the eligible clinical population, and longitudinal outcomes data. This is critical for effective monitoring and reporting of safety and quality issues, including post market surveillance of high cost medical devices and medications, which helps reduce health care-related complications and adverse events. Ultimately, this contributes to a more sustainable health care system.

At present, funding for clinical quality outcomes datasets is provided on an ad hoc basis by a range of public, private and non-government stakeholders, with varying funding models and levels of commitment in place, and no clear strategic approach or consistency. At the same time, clinicians and data managers are increasingly approaching governments to fund activity, as interest grows in improving the quality of care and patient outcomes.

Strategic prioritisation is required to better target investment in clinical domains with the greatest burden of disease and cost to the Australian health system and/or greatest variation in care and outcomes. Activities should be supported in partnership with multiple beneficiaries, which may include governments, health services, clinicians, the medical device and pharmaceutical industries, private health insurers, medical indemnity insurers, and non-government organisations. Support can comprise both financial and in-kind contributions.

Priority areas for action

Actions under Pillar 4 aim to facilitate sustainable funding for prioritised national clinical quality outcomes datasets using transparent principles and criteria.

Priority 16 Actions	Funding in partnership with multiple beneficiaries <ul style="list-style-type: none"> Develop a sustainable funding model for prioritised, national clinical quality outcomes datasets, including ongoing commitments to funding and in-kind contributions from multiple stakeholders, where appropriate. Develop partnerships and cost recovery options with the medical device and pharmaceutical industries.
Priority 17 Actions	Transparent national prioritisation criteria <ul style="list-style-type: none"> Support the Commission to work with stakeholders to collaboratively review the prioritisation criteria underpinning the Prioritised list of clinical domains for clinical quality registry development. Develop transparent funding principles and criteria for any government investment that directs investment towards areas of agreed national priority and/or with the greatest variation in care and outcomes. Provide incentives to adopt national digital and health data reforms where appropriate, to support health system sustainability (also see Pillars 3 and 6).
Priority 18 Actions	Monitoring and evaluation <ul style="list-style-type: none"> Develop a standard process for monitoring and evaluating national clinical quality outcomes datasets against agreed performance indicators. Undertake specific independent evaluation for return on investment, including assessing contributions to improved clinical practice and patient outcomes, clinical engagement and provision of tailored information for a range of stakeholders. Consider a process for disinvestment based on evaluation outcomes.
Lead agency (partners)	Australian and State and Territory Governments (The Commission, data managers, clinicians, hospitals and health services, medical device and pharmaceutical industries, private health insurers and funders)

5. Transparency and access

The Strategy seeks to create a transparent and accountable environment that supports the timely provision of tailored information to patients, hospitals, jurisdictions, governments, funders, private health insurers, researchers and other stakeholders, while protecting patient privacy.

The potential of clinical quality outcomes data has yet to be fully realised in Australia, as clinical quality outcomes datasets can be held outside national health information systems, and not systematically fed into National Minimum Datasets, or other jurisdictional, national and international reporting mechanisms.

Some jurisdictions also require direct, ongoing access to the data to inform their local safety and quality improvement activities. Victoria, for example, has already taken active steps here, by requiring secure access to a complete dataset at the health service-level as part of their funding agreements.

Stakeholders have called for more transparency and accountability around clinical quality outcomes reporting, without jeopardising privacy or the security of the data. Publication of more aggregated outcomes data on national reporting platforms, such as the [Australian Health Performance Framework website](#), and in international datasets, would help achieve this.

Over time, health-service or hospital-level reporting may be introduced, subject to extensive engagement and co-design, and testing and evaluation via de-identified reporting first (see Box 6 for an example).

BOX 6: ANZ HIP FRACTURE REGISTRY^{xiv}

The Australian and New Zealand Hip Fracture Registry (ANZHFR) supports improvements in hip fracture care and secondary fracture prevention for older people with a broken hip. It collects data on the care provided and the outcomes of care. It provides benchmarked feedback against the [Hip Fracture Care Clinical Care Standard](#), which assists health care providers to deliver high quality care in priority areas for care improvement. In 2018, 67 hospitals were providing patient level data and 118 were providing facility level data (hospital participation is increasing).

In addition to providing real time feedback at a patient level to clinical teams and hospital executives, ANZHFR drives improvement through public reporting of key performance data on care and patient outcomes, identified at the:

- Hospital level, facilitating comparison of the structures and processes in place at a facility level to support the delivery of safe and effective care for hip fracture patients. Examples include information on the model of care, access to dedicated operating theatre time for hip fracture patients and the availability of therapy services at weekends.
- Australian state/territory level, which facilitates comparison and improvement in hip fracture care performance across the states and territories. This can reveal issues that require system level responses. For example, in 2019, the average time to surgery for hip fracture patients varied from 27 hours in South Australia to 44 hours in both NSW and Victoria, and the proportion of patients receiving surgery within 48 hours ranged from 71% in NSW to 90% in South Australia. Lack of theatre availability was the key reason for delaying surgery beyond 48 hours.

Aggregated reporting of facility level 'services, resources, policies, protocols and practices' also provides valuable information for both countries to support improvements in care, policy, service delivery and planning.

ANZHFR is hosted by Neuroscience Research Australia, UNSW Sydney and the New Zealand Orthopaedic Association Hip Fracture Registry Trust.

Priority areas for action

Actions under Pillar 5 aim to increase tailored access for a range of stakeholders, and increase transparency through national reporting, to inform improvements across local, jurisdictional, national and international health care systems.

Priority 19 Actions	Tailored access for a broad range of stakeholders <ul style="list-style-type: none"> Engage with key stakeholders, including patients and consumer organisations, clinicians, health services, local and state governments, private health insurers and funders, to define their information and access needs to support improvements in clinical practice and patient outcomes. Agree national minimum secure access standards for clinical quality outcomes datasets, in accordance with relevant privacy legislation and principles, and Schedule C of the 2020-25 Addendum to the National Health Reform Agreement. Prioritise tailored access for jurisdictional and other clinical networks, to support clinical and public health decision-making. Define and agree common algorithms to produce automated, customised stakeholder reports.
Priority 20 Actions	Patient privacy and provider trust <ul style="list-style-type: none"> Strengthen explanatory materials for patients, clinicians and health services about how sensitive personal and clinical information is securely transferred, stored, integrated, analysed and reported, in accordance with privacy legislation and principles. Ensure ongoing clinician leadership and engagement in data access expansion activities for clinical quality outcomes data. Increase public access to aggregated clinical quality outcomes data by publishing patient-friendly dashboards and data tools (also see Pillar 6).
Priority 21 Actions	National reporting <ul style="list-style-type: none"> Increase the creation of national data assets and the use of aggregate clinical quality outcomes data in national reporting, including via the Australian Health Performance Framework, in accordance with Schedule D of the 2020-25 Addendum to the National Health Reform Agreement. Report outcomes for Aboriginal and Torres Strait islander people, and provide comparison between Indigenous and non-Indigenous Australians, where possible. Increase engagement with patients and consumer organisations, clinicians, peak bodies, governments, researchers, private health insurers and funders to ensure national data access and reporting meet the needs of different audiences, where possible. Increase international benchmarking, and contribution to international datasets.
Lead agency (partners)	Australian and State and Territory Governments, AIHW, and the Commission (Patients and consumer organisations, clinicians, hospitals and health services, data managers, medical colleges and societies and health peak bodies, private health insurers, Aboriginal Community Controlled Health Organisations and researchers)

6. Data linkage, integration and interoperability

The Strategy seeks to systematically integrate prioritised clinical quality outcomes data with national and jurisdictional health information systems, the TGA's device and medicine safety infrastructure, and (where possible) non-health datasets, for example, relating to education and justice.

Currently, CQRs may be used to inform improvements at the individual or treatment site level, but may not reach the whole profession or across health care systems because they tend to exist in silos. Likewise, health administrative datasets often lack the detailed outcomes information needed to understand and identify variation in clinical practice and patient outcomes.

Supporting these systems to harmonise and work together through data linkage, integration and interoperability would help build an end-to-end, complementary view of the health system (see Box 7).

This would generate significant 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;
- rapid data sharing and feedback to clinicians, patients, hospitals, governments and other stakeholders;
- systematic, equitable improvements across local, state/territory and national health care systems;
- efficiencies from reduced duplication and burden of data collection and entry; and
- cost effective clinical trials and more comprehensive post-market surveillance of devices and medicines.

BOX 7: EXAMPLES OF DATA LINKAGE PROJECTS

The **Victorian/Australian Government** joint [Optimal Cancer Pathways Data Project](#) is examining optimal cancer care pathways and variations in those pathways, services, costs and health outcomes. The project links Victorian Cancer Registry data with routinely collected Victorian data sets (admitted, emergency, death index, radiotherapy) and Australian Government Medicare Benefits and Pharmaceutical Benefits data sets.^{xv}

The data was used to compare patient healthcare pathways with the Optimal Care Pathway (OCP) for individuals diagnosed with colon cancer in Victoria. Findings include:

- that care aligned to a pathway based on the best principles of cancer care is associated with improved outcomes for patients with colon cancer;
- overall, 44% of patients had care which was aligned with the diagnosis and treatment phase of the OCP. Factors that were related to alignment for this phase included age, comorbidities, socio-economic status and remoteness; and
- for individuals treated with surgery, those who had healthcare activities that met the diagnostic and treatment phase had better survival and perioperative outcomes, and were more likely to have healthcare activities that aligned with the follow-up and end-of-life phases.

The **Queensland** Oncology Repository (QOR), a fully integrated centralised oncology repository (the largest of its kind in Australia), is managed and supported by the Cancer Alliance Queensland. Together with advances in information technology and improvements to the Queensland Cancer Register, QOR provides comprehensive high quality data for the analysis, monitoring and evaluation of cancer services that supports clinicians, policy makers, health system planners and researchers, to improve the performance of cancer services.

QOR contains approximately 46 million clinical records and holds data from over 60 data source systems across QLD. Key to the program of work is the ability to link population-based cancer information from multiple sources (including pathology and staging, treatment and death information). The matching and linking processes provide over 600,000 matched and linked individual cancer patient records.

The **South Australian** Registry of Senior Australians (ROSA) model brings together diverse datasets collected by organisations throughout the country (i.e. Commonwealth Aged Care datasets, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, National Death Index, State Health Authority datasets) to provide a full picture of the ageing pathway. Like other Australian CQRs, ROSA was designed to monitor the effectiveness and appropriateness of care over time, to identify variance and advise on best practices. It has also developed an “Outcome Monitoring System” of quality and safety indicators for aged care providers and facilities. This system monitors several areas of specific interest to older Australians, including for example antipsychotic use, sedative load, opioid use, antibiotic use, emergency department encounters, pressure injuries, falls, fractures, hospitalisations and premature mortality. This system is informing the Royal Commission into Aged Care Safety and Quality.

ROSA's early findings have focused on areas of national priorities in aged care. These include the effect of wait time for home care packages on mortality and entry into residential aged care; prevalence of dementia among people entering the aged care sector and its effect on mortality; the prevalence of pain; and the effectiveness of respite services, frailty, and antipsychotic use.

Priority areas for action

Actions under Pillar 6 aim to increase data linkage, interoperability and integration between national and jurisdictional health information systems and clinical quality outcomes datasets, as health reforms proceed and digital capabilities develop.

Priority 22 Actions	Capture once, use multiple times <ul style="list-style-type: none"> Facilitate strategic data linkage projects between clinical quality outcomes data and administrative data, including that in jurisdictional EMRs or data lakes, Commonwealth datasets, such as Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS), and non-health datasets. Streamline national data sharing and linkage approval processes to help improve the flow of data between data custodians, data linkage units/accreditation authorities and the Commonwealth and jurisdictions, in accordance with Schedule C of the 2020-25 Addendum to the National Health Reform Agreement. Develop a suite of supporting materials, including best practice examples and international learnings, as well as information on the broader benefits of sharing and linking clinical quality outcomes data.
Priority 23 Actions	Interoperability and integration with EMRs and national infrastructure <ul style="list-style-type: none"> Increase national standardisation and harmonisation of data items, elements and transfer processes to make reviewing, synthesising and interpreting secondary data from multiple sources easier (also see Pillar 3). Embed standardised, prioritised national clinical and outcome data items into: <ul style="list-style-type: none"> ➤ EMRs as they are rolled out across jurisdictions and potentially MHR as it develops over time; and ➤ Australia's National Minimum Datasets. Increase connectivity and integration of clinical quality outcomes datasets with clinical trial infrastructure. Harness the work of the ADHA National Health Interoperability Principles and Framework to guide the secondary use of My Health Record system data to facilitate a more connected healthcare system.
Priority 24 Actions	Automation and innovation <ul style="list-style-type: none"> Increase the use of application programming interfaces (APIs) for automated data extraction, linkage, analysis and reporting at the national level (see Pillar 5). Provide incentives to adopt common mobile/device interfaces and health apps, and other digital solutions, to support electronic capture of data (see Pillar 3). Develop predictive modelling and other innovative methodologies for using integrated clinical quality outcomes and administrative data to support clinical diagnosis and management, and health policy development and evaluation.
Lead agency (partners)	Australian and State and Territory Governments, AIHW, the Commission (The ADHA, data managers, clinicians, hospitals and health services, researchers, accreditation authorities, medical device and pharmaceutical industries and the TGA)

Appendix A – Stakeholder roles and responsibilities

Stakeholder	Roles and Responsibilities
ADHA	<ul style="list-style-type: none"> Contributing digital health care system expertise to Strategy activities
AIHW	<ul style="list-style-type: none"> Contributing health statistics expertise to the Strategy's implementation
Australian Government	<ul style="list-style-type: none"> Co-leading oversight of development and implementation of the Strategy, with the Commission and states/territories. Undertaking Strategy activities
Clinical Quality Registry sector	<ul style="list-style-type: none"> Establishing and operating patient-centred clinical quality outcomes datasets in accordance with the Commission's Framework for Australian clinical quality registries and in consultation with patients and consumer organisations Adapting and engaging with Strategy related activities
Clinicians	<ul style="list-style-type: none"> Leading the development and operation of patient-centred clinical quality outcomes datasets Partnering with patients in their care, providing clinical quality outcomes data in a timely manner and acting on feedback to improve clinical performance
The Commission	<ul style="list-style-type: none"> Leading and coordinating national improvements in health care safety and quality Providing oversight of the Strategy's implementation and undertaking Strategy activities
Consumer organisations	<ul style="list-style-type: none"> Supporting patient involvement in clinician/patient partnerships and patient-centred clinical quality outcomes datasets
Hospitals and other treatment sites	<ul style="list-style-type: none"> Contributing timely, accurate and complete data to clinical quality outcomes datasets Engaging with Strategy activities such as site governance streamlining Supporting the provision of clinical quality outcomes data for research purposes and tailored information with other stakeholders
Medical device/ pharmaceutical industries	<ul style="list-style-type: none"> Supporting the CQR sector Providing input to data collection, measurement and performance standards, reporting mechanisms and the relationship between clinical quality outcomes datasets and regulatory policy and practices Acting on feedback and sharing tailored information on their products with other stakeholders
Medical Indemnity Insurers	<ul style="list-style-type: none"> Contributing expertise on how clinical quality outcomes datasets fit within the healthcare system, and on medico-legal and other regulatory implications and considerations Insuring, advising, educating and advocating for the medical and other health professions

Stakeholder	Roles and Responsibilities
Patients (carers and families)	<ul style="list-style-type: none"> Engaging in partnership with clinicians and in development and operation of clinical quality outcomes datasets Consenting to their treatment and outcome related data (including patient reported measures) being used in clinical quality outcomes datasets
Non-Government Organisations (NGOs)	<ul style="list-style-type: none"> Supporting the establishment and operation of relevant clinical quality outcomes datasets (funding and in-kind support)
Private health insurers	<ul style="list-style-type: none"> Supporting the CQR sector Utilising clinical quality outcomes data to inform a more efficient and sustainable private health insurance sector
Researchers/academics	<ul style="list-style-type: none"> Researching improvements in reporting and quality improvement functions Accessing and utilising clinical quality outcomes data in accordance with privacy legislation and principles
Specialist colleges and societies / craft groups	<ul style="list-style-type: none"> Supporting the development and operation of clinical quality outcomes datasets (funding and in-kind) Encouraging members to contribute data to clinical quality outcomes datasets, including through continuing medical education points Utilising clinical quality outcomes information in member education and training
State/Territory governments	<ul style="list-style-type: none"> Co-leading the development and implementation of the Strategy Facilitating public hospital provision of data to prioritised, national clinical quality outcomes datasets and utilising their information in the management of jurisdictional health care systems
TGA	<ul style="list-style-type: none"> Advise on the development of clinical quality outcomes data elements for medical devices to ensure capture of useful data for regulatory purposes Utilise clinical quality outcomes information for regulatory purposes, including assessment and monitoring of safety and performance of devices, and be informed as soon as it becomes clear that a device is an outlier.

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.
Application Programming Interfaces	'An interface or communication protocol between different parts of a computer program intended to simplify the implementation and maintenance of software.' ^{xvi}
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.
Big Data	'Large volumes of high velocity, complex and variable data that require advanced techniques and technologies to enable the capture, storage, distribution, management, and analysis of the information' ^{xvii}
Clinical audit	'A quality improvement cycle that involves measurement of the effectiveness of healthcare against agreed and proven standards for high quality, and taking action to bring practice in line with these standards so as to improve the quality of care and health outcomes.' ^{xviii}
Clinical quality outcomes datasets	A universal term inclusive of CQRs and other mechanisms like virtual registries, which collate data from repositories such as state-based EMRs or data lakes, and then reports risk-adjusted benchmarked outcome measures back to clinicians, health service providers and other for the purposes of quality improvement.
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. ^{xix} 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.

Terminology	Definition
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.
Interoperability	'The ability of computer systems or software to exchange and make use of information'. ^{xx}
Minimum data set (for a CQR)	A minimum data set is a minimum set of data elements agreed for mandatory collection and reporting. ^{xxi}
Outliers	Extreme, or atypical data value(s) that are notably different from the rest of the data. ^{xxii}
Patient Reported Experience Measures (PREMs)	PREMs are tools for capturing a patient's views of their experience of the care they received. ^{xxiii}

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’. ^{xxiv}
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. ^{xxv}
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.
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 most CQRs are required to seek ethics approvals via the National Health and Medical Research Council (NHMRC) registered Human Research 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 Clinical Quality Indicators (CQI) to allow more accurate comparisons of care and outcomes between patients with the same disease/condition.
Variation in care	Clinical variation is a difference in healthcare processes or outcomes, compared to peers or to a gold standard such as an evidence-based guideline recommendation.

Terminology	Definition
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. ^{xxvi}
Virtual registry	A registry that draws data from existing repositories, such as EMRs, data lakes and data warehouses, to maximise the secondary use of data, and then reports risk-adjusted benchmarked outcome measures back to clinicians, health service providers and other stakeholders for the purposes of quality improvement.

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