



Australian Government
**Department of Health
and Aged Care**



CLINICAL QUALITY REGISTRIES: Four Key Benefits for Your Health

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Introduction

While health care in Australia is generally provided at a high standard, our health care system needs to continuously improve to ensure that all patients get the best possible care. Clinical quality registries (CQRs) provide doctors, health care teams and hospitals with the information they need to support that ongoing improvement.

What is a clinical quality registry?

A CQR collects information about the health care, health outcomes (results) and experiences of patients who have treatment for a particular health condition or disease, such as prostate cancer, joint replacement or stroke. It is then analysed and provided to doctors, teams and hospitals to help improve the standard of care, and to make sure that the health care system is continuously improving.

CQRs collect information that isn't routinely collected elsewhere. For example, CQRs collect and analyse information on whether treatment was successful and met expected standards of care.

CQRs help to improve your health in four key ways

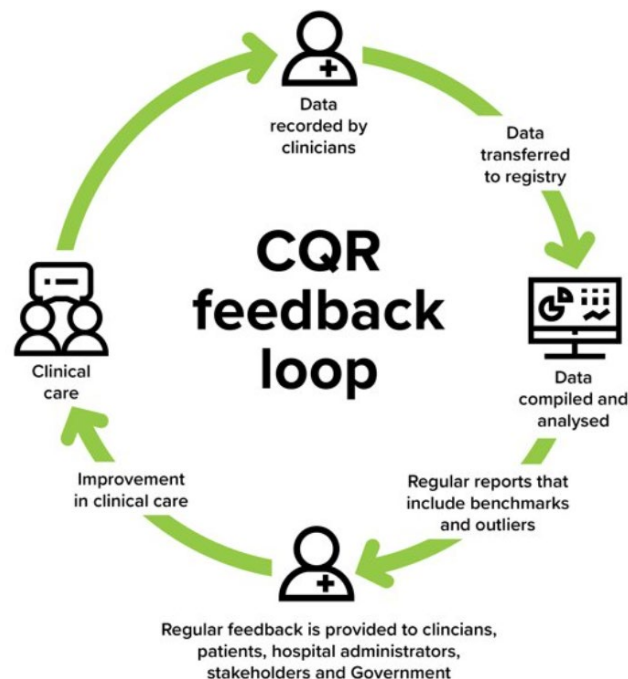
1. Improving the standard of your health care
2. Focusing health care on what is important to you
3. Helping you make more informed decisions about your health care
4. Helping you and your doctor find information on your implanted medical device if there is a safety issue



1. CQRs help improve the standard of your health care

Figure 1 shows how CQRs help to continuously improve health care. In addition to providing feedback on health care and patient outcomes to doctors, teams and hospitals, it may also be provided to health system managers, the medical device and medicine industries, the Therapeutic Goods Administrationⁱ (TGA) and the public, to help with further improvement.

Figure 1: the CQR continuous improvement cycleⁱⁱ



Here are some examples of how CQRs help improve health care and patient outcomes.

- A CQR may find that some treatments, medicines or implanted medical devices may not be as safe as expected. For example:
 - Based on information reported by the [Australian Orthopaedic Association National Joint Replacement Registry](#), Australia was the first country in the world to withdraw a metal-on-metal hip replacement device from the market in 2009. This type of device, implanted in over 90,000 people worldwide, led to significant health problems for many people and a worldwide recall in 2010.

- A CQR may find that treatment for the same type of problem differs between doctors, teams or hospitals when compared to established guidelines or recommendations.
 - The [Australian and New Zealand Hip Fracture Registry](#) monitors the care provided to older people admitted to hospital with a broken hip in Australia and New Zealand. Its [Annual Report](#) provides information on how well participating hospitals meet the [Hip Fracture Care Clinical Care Standard](#), developed by the Australian Commission on Safety and Quality in Health Care. This information helps hospitals know where they are doing well and areas for improvement.
 - The [Australian Cystic Fibrosis Data Registry](#) collects information on people living with cystic fibrosis. Standards of care for people with cystic fibrosis in Australia include recommendations to see their specialist at least four times a year, and to have particular medical treatments. The Registry monitors how well health services provide care for their patients with cystic fibrosis according to these recommendations. This information is fed back to the health services to help improve care in these areas.



- A CQR may find that some doctors, teams or hospitals have better results than others providing the same type of treatment. Box 1 provides an example.

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

[PCOR-Vic](#) monitors the care provided to men with prostate cancer in public and private Victorian hospitals. It provides regular information to doctors and hospitals on the quality of care provided and the outcomes of the care, compared to other hospitals.

The information helps improve the health care provided to men with prostate cancer, their quality of life and survival after cancer. For example, PCOR-Vic provided information to a major hospital, showing that it had a high rate of cancer cells left behind after surgery (positive surgical margin). This led to higher levels of cancer recurrence, additional treatment and costs. The hospital investigated and identified opportunities for improvement, and the Urological Society of Australia and New Zealand amended its training programs.

The information led to fewer men with a positive surgical margin following radical prostatectomy, fewer men requiring secondary treatment and fewer deaths.



Check the online [Register of Clinical Registries](#) to see if there is a CQR that covers your health issue.

Ask your doctor if they participate in a CQR that covers your health issue.

If there is a CQR that covers your health issue, check its website to see if it publishes outcomes for consumers. If it does, ask your doctor to talk about the results with you.

2. CQRs help health care to be more focused on what is important to you

Finding out what is important to patients also helps to improve health care. CQRs do this by designing and collecting patient reported outcome measures (PROMs) and patient reported experience measures (PREMs), together with other health information. PROMs and PREMs can help doctors, teams and hospitals to monitor health care outcomes and experiences that are most important to patients and to make changes, if needed, to focus more on patient priorities.

What are patient reported outcome measures?

PROMs are voluntary questionnaires that ask patients, families and carers about the outcomes of the health care provided. They include brief questions on patient health and quality of life, for example, on level of pain and ability to carry out usual activities.

PROMs are often collected just before and soon after treatment. Sometimes they are collected again months or years later, to track long term progress (for example, to find out if a patient's health improved, got worse or stayed the same over time).



Answering PROMs questions may help doctors to better understand your progress and contribute to greater understanding of recovery and outcomes for all patients who have the same treatment.

PROMs can also help you make treatment decisions with your doctor. Box 2 provides an example.

BOX 2: AUSTRALIAN ORTHOPAEDIC ASSOCIATION NATIONAL JOINT REPLACEMENT REGISTRY (AOANJRR) PROMS

[AOANJRR](#) PROMs track how well patients recover after joint replacement surgery (for example, a knee replacement), and how much their lives did (or did not) improve because of the surgery.

Before surgery, patients answer PROMs questions about their health and quality of life, for example, level of pain and what they can and cannot do. They then answer the same questions six months after their surgery, to see what changed. Patients can track their progress and see how their recovery compares to other patients who had the same surgery, including patients of similar age and gender. Patients can also talk about the information with their doctor to help decide if any changes might be needed to their treatment and recovery plans.

Patient representatives were included on the AOANJRR steering committee that helped design the PROMs and oversee the national roll out of PROMs collection to all hospitals doing joint replacement surgery in Australia.

What are patient reported experience measures?

PREMs are voluntary questionnaires that ask patients, families and carers about their experiences of health care provided. For example, questions could ask whether you were offered pain relief, how long you had to wait for an appointment, or how well your health care provider communicated with you.

- The [Australia and New Zealand Hip Fracture Registry](#) is working with patients/ consumers and clinicians to develop PREMs for hip fracture patients. This includes:
 - exploring aspects of health care experience important to older people with a broken hip, their families or carers;
 - developing a set of questions that can be used to capture patient and carer experience after a broken hip;
 - testing the collection of the experience measures through an electronic method at a few test sites;
 - understanding the barriers and enablers of collecting the experience measures using an electronic method.

- The [Australian Dementia Network Registry](#) collects patient and carer reported information on their experience with diagnosis and early management. The survey tool was developed with people with dementia and their carers to ensure it was simple to complete and meaningful to them. The results of these surveys enable health services to see how they compare with others, and what they can do to improve the experience for their patients. Questions include:
 - What was their overall experience of care?
 - Were they treated with dignity and respect?
 - Did they have the opportunity to ask questions?
 - Were they given advice about information and help?



Why is it important for patient representatives to be involved in CQRs?

CQRs should include patient representatives on their steering committee, preferably with lived experience of the relevant health issue. CQRs should also regularly consult with patient representatives during the development and operation of the registry. This is called co-design.

For CQRs collecting PROMs and PREMs, co-design involves patients, families, carers and advocates. This will ensure the questions asked are important to patients, make sense, and are not too much of a burden to complete.

**PIP BRENNAN – LIVED EXPERIENCE CONSUMER REPRESENTATIVE,
AUSTRALASIAN PELVIC FLOOR PROCEDURES REGISTRY**

‘There is no more important role for a consumer representative than to contribute to safety and quality initiatives. Registries are ... one of the most important safety and quality measures we have. As a consumer advocate I hope to be part of initiatives to better communicate to the public what registries are, and to ensure a more universal inclusion of the consumer voice in their establishment and management.’

If you are interested, ask the CQR that monitors your health condition how you can be involved in its development and operation.

3. CQRs help you make more informed decisions about your health care

As shown in Box 2 above, patient reported information can help patients talk about their progress and make decisions about their health care with their doctor. CQRs can also help patients make decisions with their doctor about where to have treatment, through publishing hospital or clinic performance information on their websites. Box 3 below provides an example.



BOX 3: AUSTRALIAN AND NEW ZEALAND ASSISTED REPRODUCTION DATABASE (ANZARD)

[ANZARD](#) (a CQR) collects, analyses and reports on information on all assisted reproductive technology treatment cycles, including in vitro fertilisation (IVF), performed in accredited Australian and New Zealand fertility clinics.

The [YourIVFSuccess](#) website helps people make informed decisions about IVF treatment with their doctor. It provides fertility clinic success rates, compared to the national average, through a searchable database of all IVF clinics operating in Australia.

The YourIVFSuccess website also includes an [IVF Success Estimator](#), which allows people to enter their own information and receive an estimate of their chance of having a baby using IVF, based on over 600,000 IVF cycles performed in Australian fertility clinics.

Some CQRs also provide reports direct to the health service, which may not be published. Ask your doctor if they are aware of the performance of the hospital or clinic they are recommending. This could also help patients make decisions with their doctor about where to have treatment.

Ask your doctor if a CQR publishes information on your health issue that could help with your decision making.

Ask your doctor if they are aware of the performance of the hospital or clinic they are recommending.

Check the [MyHospitals](#) website to see how different hospitals comply with safety and quality measures.

4. CQRs help you and your doctor find information on your implanted medical device, if there is a safety issue

Thousands of medical devices are implanted in Australia each year, enabling people to lead healthy, full lives. Sometimes, though, there might be a problem with a medical device after surgery, for example, with a joint replacement. There might also be a broader issue with a medical device that the TGA has taken action on, such as recalling it from the market.



When these situations occur, patients and doctors need information on implanted devices to find out if a device should be removed or monitored. Box 4 below provides an example of a CQR providing that information.

BOX 4: AUSTRALIAN BREAST DEVICE REGISTRY (ABDR)

The [ABDR](#) tracks the long term safety and performance of breast implants. By 2022, the ABDR had collected information on over 100,000 breast implant procedures across Australia.

During 2019 and 2020 the TGA suspended and cancelled several implants linked to a rare type of cancer. The ABDR assisted surgeons and people with breast implants to quickly identify those who had the suspended or cancelled implants and offer them a clinical review. This is particularly useful when problems related to devices occur many years after the implant surgery, and the medical records may be difficult to find or access.

The ABDR is also reporting the characteristics of the types of breast implants associated with the rare cancer and is monitoring whether withdrawing these implants from the market will reduce the incidence of this cancer.

Ask your doctor if they participate in a CQR that monitors your implanted medical device.

Ask your doctor if a CQR publishes information on medical devices for your condition and how you can access it.

Ask your doctor if there is a patient implant card for your device (the card contains information about the device and will help you locate information about it in the future).

Check the [TGA's website](#) for more information on medical device safety, including breast implants.

How do registries keep your information safe?

CQRs are required by Australian law to keep patient information securely stored and confidential. They have strict privacy and security policies and procedures that must be followed. Only authorised staff can access information, and patient information cannot be identified in reports produced by the CQR.

Participation in a CQR is voluntary but most patients choose to take part. Patients are given information about the CQR, such as the types of information that will be collected, how it will be used and how it will be kept safe.

How is the National Clinical Quality Registry and Virtual Registry Strategy helping to improve your health?

The [National Clinical Quality Registry and Virtual Registry Strategy 2020-2030](#) aims to improve the quality of care to achieve better health outcomes for all Australians. The Strategy was developed by the Commonwealth, state and territory governments in consultation with the CQR sector, clinicians, patient representatives and many others. Figure 3 below shows how the Strategy benefits different groups.

Figure 3: Strategy benefits for different groups



Where can you get more information on CQRs?

If there is a CQR for your health issue, check their website for patient information.
Also check:

- [Commonwealth Department of Health and Aged Care website](#)
- [Australian Commission on Safety and Quality in Health Care website](#)
 - [Australian Register of Clinical Registries](#)
- [Monash University Registries website](#)
- [South Australian Health & Medical Research Institute Registry Centre website](#)

Endnotes

ⁱ The TGA is Australia's government authority responsible for evaluating, assessing and monitoring products that are defined as therapeutic goods. It regulates medicines, medical devices and biologicals to help Australians stay healthy and safe.

ⁱⁱ [National arrangements for clinical quality registries | Australian Commission on Safety and Quality in Health Care](#)

ⁱⁱⁱ Monash University. (2015). *Victorian Prostate Cancer Clinical Registry five year report*
<https://www.monash.edu/medicine/sphpm/assets/docs/pdf/registries/reports/2015vicpcr-fiveyearreport.pdf>

^{iv} Australian Commission on Safety and Quality in Health Care (2016) [Economic Evaluation of Clinical Quality Registries](#).

Health.gov.au

All information in this publication is correct as at November 2022

