



Consumers Health  
Forum **OF** Australia

# **Clinical Quality Registry Project Consumer Working Group**

General purpose and operation of the group

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*General purpose and operation of the Clinical  
Quality Registry Project consumer working  
group.* Canberra, Australia

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# Background

## *Consumers Health Forum*

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, support by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making.

CHF has previously had various consumer work groups operating at different times. These are networks of consumers who have been selected to work more intensively on specific policy issues and/or projects. This document has been developed to outline the general purpose and operation of the Clinical Quality Registry Project consumer working group.

## *The Patient Access, Consent and Outcome Measures (PACOM) Project*

The Department of Health has contracted CHF to engage in a large, multi-stage project looking at a range of health information topics from medical records access experiences to secondary data usage consent processes. This project has been called the "PACOM Project". At part of the final stage of the PACOM Project CHF has been tasked by the Department of Health to develop a consumer information resource on the Department's *National Clinical Quality Registry and Virtual Registry Strategy 2020-2030*.

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

The *National Clinical Quality Registry and Virtual Registry Strategy 2020-2030* aims to drive continuous improvements in the quality and value of health care, to achieve better health outcomes for all Australians. Recognising the importance of consumer engagement, the Department has commissioned CHF to co-design with consumers a web-ready plain English guide about the Strategy and why it is important.

## **Purpose of the Clinical Quality Registry Project consumer working group**

We are establishing Clinical Quality Registry Project consumer working group to codesign the consumer information resource with consumers, to better ensure the resource is effectively designed and targeted to be allow consumers to understand and engage with the *National Clinical Quality Registry and Virtual Registry Strategy 2020-2030*.

## **Operation of the Clinical Quality Registry Project consumer working group**

The Clinical Quality Registry Project consumer working group has the capacity to influence the CHF Clinical Quality Registry Project deliverables, with final decisions remaining with the CHF Board and CHF staff. Resourcing and support for the group will be determined by the CHF CEO.

### ***What will be the focus of the group?***

The focus of the Working Group will be the development of a plain English guide that is compliant with Web Content Accessibility Guidelines (WCAG) and includes the following elements:

1. Why a National Strategy has been developed (Rationale, Vision)
2. What CQRs can do to improve care for patients
3. How a CQR works (include an example showing feedback loop)
4. Consumer involvement in CQRs
  - a. Principles for consumer co-design in CQRs
  - b. How can consumers be involved in CQRs (i.e. involvement in steering committee decisions, co-design of minimum data sets and PROMs)?
5. Where will the data for the CQRs be collected and used (clinical data and patient reported data)
6. PROMS and PREMS in CQRs:
  - a. What are PROMs and PREMs?
  - b. Why are they collected by CQRs?
  - c. How are they collected by CQRs?
  - d. Consumer co-design principles for PROMs and PREMs
  - e. Examples
7. Strategy implementation

## Facilitators

The Clinical Quality Registry Project consumer working group will be facilitated by a CHF staff member. Members of the group may be asked to assist with the facilitation of Working Group meetings.

### ***What will their role involve?***

The co-facilitators will work closely to:

- finalise the Agenda Items for each meeting;
- facilitate discussion during and between meetings;
- document outcomes of each meeting, including any actions arising;
- distribute meeting documents / Agenda papers and other relevant documents, to members in a timely manner; and
- keep SharePoint updated and monitor group discussions.

## Members

This Working Group is open to all consumers and consumer representatives with an interest in healthcare system accessibility. The maximum number of people within the group at any time will be 10. This cap helps keep the groups manageable while assuring a diverse range of views can be included. Applicants will be chosen through expressions of interest via the CHF website.

People can choose to leave the group if they no longer have the capacity. An email should be sent to the co-facilitators of the group to advise them of your withdrawal. This will not influence your relationship with CHF.

### ***What contribution is expected from members?***

It is expected members will participate in up to six (6) meetings via videoconference, read and develop documents and contribute to discussions during and between meetings during the period January 2021-June 2021. The precise schedule and timing of the meetings will be determined as the project develops. The videoconference meetings are initially expected to take approximately 2 hours with an additional 1-2 hours between meetings of discussion, reading and preparation.

An online forum, SharePoint, may be established for members to engage in friendly discussion, share information and ideas between meetings. Members are expected to treat each other with respect and listen to each other.

## Reporting

- A draft agenda will be distributed to members two weeks prior to a meeting inviting suggestions for additional agenda topics.
- A copy of the final agenda and all papers to be discussed will be distributed to all members at least one week prior to a meeting.
- A draft document highlighting outcomes of meeting, including actions arising will aim to be distributed to attendees of a meeting within one week of a meeting.
- Other documents or activities members may work on may have reporting requirements specific to those documents and activities.
- A draft CQR consumer resource is expected to be completed by the end of March 2021
- The final CGR consumer resource is expected to be completed by the of May 2021

## Appendix 1- What is a Clinical Quality Registry Project

Clinical Quality Registries (CQRs) monitor the quality (appropriateness and effectiveness) of health care by routinely collecting and analysing clinical performance data. A mature CQR can provide clinicians, health service managers, patients and other stakeholders with ongoing, risk adjusted, benchmarked feedback on clinical practice and patient outcomes, to improve the standard of care. There are also virtual registries, which draw data from existing platforms, such as Electronic Medical Records (EMRs) or data lakes and data warehouses. Some CQRs also collect patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs).

Currently in Australia, there are a range of CQRs that measure the quality of care and medical devices, for specific diseases and conditions. Some examples of CQRs in Australia include the Australian and New Zealand Hip Fracture Registry, the Australian Breast Device Registry, and the Australian Orthopaedic Association National Joint Replacement Registry.

A detailed example of an Australian CQR is provided below:

### Box 1: Prostate Cancer Outcome Registry-Victoria (PCOR-Vic)

The PCOR-Vic, managed by Monash University, systematically follows-up men after a diagnosis of prostate cancer. They collect data and provide 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 leaving significantly more cancer cells behind after surgery than other hospitals. 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).