

CANCER RESEARCH PROGRAM

CONSUMER ADVISORY GROUP TERMS OF REFERENCE

DATE: 29TH JULY 2021
VERSION NO. 1.0

PREFACE

The Monash University Cancer Research Program is dedicated to ensuring that we have an engaging culture and way of working that proactively involves consumers in informing decisions related to the planning, delivery, and evaluation of our activities.

CONTENTS

PREFACE	2
CONTENTS	3
BACKGROUND	4
CLINICAL QUALITY REGISTRIES	4
CANCER RESEARCH PROGRAM.....	4
Cancer Registries	4
CONSUMER ADVISORY GROUP	5
ROLE.....	5
KEY FUNCTIONS	5
MEMBERSHIP	5
Invitees	5
RESPONSIBILITIES	5
To Researchers.....	6
To Consumers.....	6
CHAIRS.....	6
MEETING PROCEDURES.....	6
Frequency of Meetings	6
Quorum Requirements	6
Reporting Requirements	6
EXPENSES	7
EVALUATION.....	7
REVIEW OF TERMS OF REFERENCE.....	7
APPROVED	7

BACKGROUND

CLINICAL QUALITY REGISTRIES

A proven strategy to reduce variation in outcomes is to measure and compare high quality disease-specific data using clinical quality registries (CQRs). This strategy has been successfully tested in a range of surgical disciplines including trauma, cardiac surgery, transplantation, breast surgery, bariatric surgery, joint surgery, and cancer care. CQRs provide the most effective means of collecting high quality data and are a tool for quality improvement. Where they have been introduced at a state or national level, CQRs have become one of the most clinically valued tools for quality improvement. The Australian Commission on Safety and Quality in Health Care (ACSQHC) has advocated development of CQRs, particularly in key high burden areas including cardiac disease, musculoskeletal disease and cancers.

CANCER RESEARCH PROGRAM

The Cancer Research Program (CRP) was formed in May 2014 to enhance the cancer research focus across the School of Public Health and Preventive Medicine's clinical and public health activities. The Program is led by Professor John Zalcborg, a medical oncologist and cancer researcher with over 20 years' experience.

The CRP primarily works to create and maintain clinical quality registries with a view to improving health care and patient outcomes. Within these registries, population-based data on diagnosis, treatment and outcomes is collected and assessed. The information is used to highlight variations in care and is fed back to health services in benchmarked reports. By identifying areas for improvement, health services can implement changes to advance and streamline care.

The CRP also oversees several studies, including randomised controlled trials (RCTs), that utilise established registry infrastructure and/or data, or are related to cancer-focused health services research.

The CRP enjoys a strong connection with health service providers, patient advocacy groups, and policy makers. It is working at multiple levels to try to streamline the development of new projects and encourage the integration of research into day-to-day clinical practice.

Cancer Registries

Current registries involved in the Cancer Research Program are:

- Australian and New Zealand Thyroid Cancer Registry (ANZTCR)
- Binational Colorectal Cancer Audit (BCCA)
- Melanoma Clinical Outcomes Registry (MelCOR)
- National Gynae-Oncology Registry (NGOR)
- Prostate Cancer Outcomes Registry - Australia and New Zealand (PCOR-ANZ)
- Prostate Cancer Outcomes Registry - Victoria (PCOR-Vic)
- Upper Gastrointestinal Cancer Registry (UGICR)
- Victorian Lung Cancer Registry (VLCR)

CONSUMER ADVISORY GROUP

ROLE

The Consumer Advisory Group (CAG), representing the voice of consumers (patients, carers and family members of patients), will provide insight on the work of the CRP to all relevant staff, including research coordinators and project managers. It will be an engaged and active partner in all activities of the CRP.

KEY FUNCTIONS

The functions are based on the understanding that those affected by research have a right to be involved in all aspects of research, from being research participants in studies, through to research priority setting and research governance.

The functions of the CRP CAG are to:

- Identify priority areas and barriers to improvement and provide a consumer perspective in strategic decision-making and policy development within the CRP.
- Propose and review new research, including consumer led research, to ensure that research activities align with the areas of greater needs and meet the needs of the community.
- Provide direction and leadership to registries on how to best engage consumers in the CRP including involvement in documents, articles, conference posters and presentations.
- Raise awareness of the importance of the role of cancer registries and of the contribution that consumers can make as active partners in the research environment.
- Inform the design and development of approaches to improve and evaluate the work of the CRP.
- Review project (i.e. registries, clinical trials, cohort studies etc.) related documents for endorsement from the consumers' perspective.

MEMBERSHIP

Membership of the CRP CAG will include six to eight consumers, where possible consumers will be representative of the broader community, as well as one to two representatives of the Monash University CRP.

Appointment to the CAG will be via expression of interest (EOI). Please see Appendix A for Membership Position Description and EOI form.

Member terms of appointment will be for two years, with the possibility of two further terms, after which the person is not eligible for reappointment.

Invitees

Alternate representatives may attend meetings on the behalf of other members if agreed to by the Chair(s) at least 24 hours prior to the meeting.

RESPONSIBILITIES

To Researchers

Members of the CRP CAG must respect the confidentiality requested by the researchers when reviewing documents and must disclose any conflict of interest in any matters being considered by the CRP CAG. Members acknowledge their responsibility to maintain confidentiality of all information that is not in the public domain.

To Consumers

Members of the CRP CAG acknowledge their responsibility to advocate on behalf of all consumers including underserved populations and to consult and disseminate information to the communities they represent.

CHAIRS

The CRP CAG will be co-chaired by a Monash University CRP representative and a consumer representative. The Monash University CRP co-chair will be appointed by the CRP Management Committee. The consumer co-chair will be appointed via a nomination and election process.

The co-chairs will be the lead representatives for the CAG and a conduit for information sharing between the CRP and the CAG.

They will:

- Chair meetings and set agendas in collaboration with the CRP;
- Participate in the review of CAG functions;
- Be appointed for two-year terms and not serve for more than two terms.

MEETING PROCEDURES

Frequency of Meetings

The CRP CAG meetings will be held quarterly. Special meetings may be convened as required. Members will have the ability to attend meetings in person or via video/teleconference using an online platform (e.g. Zoom).

Quorum Requirements

A quorum consists of half (50%) of the appointed members and must include a consumer representative and Monash University CRP representative. Should the appointed Co-Chairs not be able to attend, a CAG member can act as Chair for that meeting. Should a quorum not be achieved, members may choose to hold the meeting, with any advice and recommendations made not being considered final until the next meeting with a quorum, at which time the advice and recommendations can be endorsed and recorded.

Reporting Requirements

Meeting documents (agendas, relevant documents, and minutes) will be prepared by the Monash University CRP Co-Chair and distributed to all members of the CAG electronically.

Agenda

Agenda items should be submitted to the Co-Chairs, at least six working days before a meeting. Agendas and other documentation relevant to the business of the CAG will be forwarded to members, where possible, five working days prior to a meeting.

Records of Meetings

Formal minutes will be kept of all CAG meetings, circulated to the members as a draft within ten working days after the meeting, and will be confirmed at the next subsequent meeting of the CAG.

EXPENSES

CAG members are entitled to sitting fees where appropriate and reimbursement of reasonable travelling and personal expenses that they incur as a result of their involvement in the CAG. Please refer to Appendix B for the CRP CAG Reimbursement Policy for consumers sitting fees and hourly rates.

EVALUATION

The CAG will undergo a satisfaction and evaluation process annually with CAG members and key stakeholders from the CRP registries invited to participate in the evaluation. The results of which will be presented at the next CAG meeting and the next CRP Management Committee meeting.

REVIEW OF TERMS OF REFERENCE

The Terms of Reference would be updated as required by stakeholders to reflect any changes in the environment. Proposals of Changes to the Terms of Reference will be presented to the CRP Management Committee for final approval.

APPROVED

This document has been endorsed by the Head of the Cancer Research Program.



Prof John Zalberg, Head, Cancer Research Program

Date: 20th August 2021



MONASH
University

Further information

School of Public Health & Preventive Medicine
Monash University
553 St Kilda Road
Melbourne, Victoria 3004
Australia

T: +61 3 9903 0838
E: crp-cag@monash.edu

monash.edu.au