



CONSUMER
ADVISORY
GROUP



CONSUMER ENGAGEMENT MODEL

2020-2021

CONTENTS

Purpose.....	3
1. Guiding Principles	3
2. Structure.....	3
2.1. Community Advisory Group.....	4
2.2. Consumer community	5
3. Membership.....	5
3.1. New members	5
3.2. Support for consumers	6

© PC4 2020

This material is subject to copyright laws. Other than for the purposes of and subject to the conditions prescribed under the Copyright Act, no part of it may in any form or by any means (electronic, mechanical, microcopying, photocopying, recording or otherwise) be altered, reproduced, stored in a retrieval system or transmitted without prior written permission from the Primary Care Collaborative Cancer Clinical Trials Group (PC4).

PURPOSE

We believe better clinical trial outcomes come from creating meaningful partnerships with the community. Trials with consumer and community involvement have higher levels of acceptability, lower level of burden for participants and produce outcomes more relevant for the community.

As an organisation that supports the development new cancer in primary care research our goal is to:



embed consumers in all aspects of our work

embrace the diverse **skills**, lived experience & **abilities** of our consumers to enhance the quality of our work

create opportunities to **connect** our researchers with consumers

facilitate the development of research that is created in partnership with consumers

1. GUIDING PRINCIPLES

Our approach to consumer engagement has been guided by Cancer Australia's National Framework for Consumer Engagement in Cancer Control and the Victorian Comprehensive Cancer Centre Consumer Engagement Model. A key element of these models are the levels of engagement that are the foundation of tailoring engagement to meet the needs of both consumers and researchers. These levels are *Informing, Consulting, Involving, Partnership* and *Consumer-led*. Each of these levels range across the many areas a consumer can be involved in engagement.

2. STRUCTURE

Our consumer engagement model has adopted a tiered involvement approach. Members can choose their level of involvement and which key activities they would like to participate in. We appreciate the other commitments our members have, and we aim to support balance. Part of PC4's vision is to engage with consumers in all aspects of our research. Our approach to realising this vision is summarised in the figure below. Our Consumer Advisory Group (CAG) is at the core of our engagement and it is the lynchpin of our wider community network.

To ensure a consumer voice in PC4 strategic planning and research, two consumers from the CAG represent the broader consumer group on the PC4 Advisory Committee and Scientific Committee.

MONITORING & EVALUATION

- have continued involvement with the study to maintain focus & address issues as they arise
 - collaborate with researchers to evaluate the research process
 - reflect on their role & what they have learned
- NEW PATHWAYS**

IMPLEMENTATION

- increase the likelihood that results of research are implemented, by adding validity to the findings
- develop patient information for new services/interventions within hospitals, GPs, surgeries etc.

DISSEMINATION

- advise on different avenues for disseminating results
- jointly present the findings with researchers
- write information for local patient groups/hospitals etc
- assist in getting results/findings published on charities/voluntary websites
- help distribute results within their informal networks
- produce summaries of findings

BEING A COMMUNITY ADVOCATE FOR PC4 STUDIES

ANALYSING & INTERPRETING

- assist the research team in developing themes from data
- be consulted to see if they understand/interpret data in the same way as the research team

IDENTIFYING & PRIORITISING

- through local user groups & organisations help inform research priorities
 - be consulted about research topics & priorities, important to them as service users
 - collaborate with researchers to identify topics for research
- CONSUMER ADVISORY, SCIENTIFIC & ADVISORY COMMITTEES

DESIGN

- inform the design of the research study
 - clarify the research question and affirm its importance
 - ensure the methods selected are appropriate for patients
 - assist in creating a recruitment strategy
 - review & comment on proposed questionnaires & data collection methods
- EMAIL REVIEWS

DEVELOPMENT OF GRANT PROPOSALS

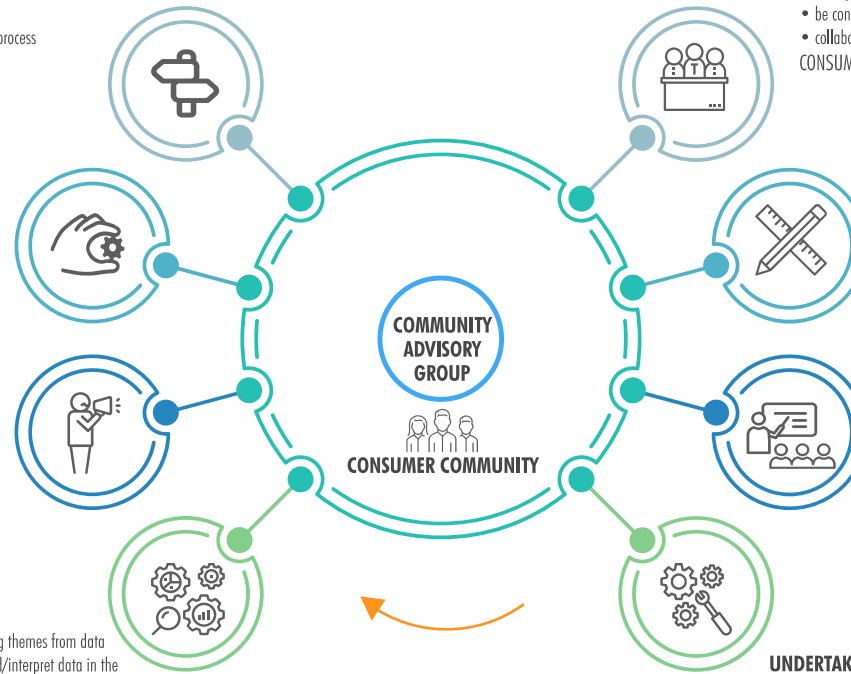
- assist research proposed & chosen methods are ethical
 - inform areas where patients/public could be involved
 - provide ongoing advice on patients/public involvement
 - define outcome measures
 - advise on the appropriateness of the Lay Summary
 - raise awareness about costs of involvement, expenses & prompt researchers to cost for involvement
 - be named as co-applicants
- ATTEND RESEARCH DEVELOPMENT WORKSHOPS

UNDERTAKING/MANAGING

Setting up a steering group to manage/monitor the research

- steer the project throughout the research process
- assist in writing the patient information and consent forms
- aid in designing the detailed protocol
- produce research updates that are patient friendly
- can assist in conducting interviews & surveys

CONSUMER REPRESENTATIVE PROJECT STEERING COMMITTEE



Adapted from National Institute of Health Research, RDS PPI Handbook, 2014

2.1. COMMUNITY ADVISORY GROUP

The purpose of the PC4 CAG is to provide a mechanism for community input on research activities and priorities for both Groups.

The activities of the CAG shall be shared amongst members with opportunities to attend workshops and participate in committee meetings where appropriate and supported by the PC4 Office as required.

Key tasks include:

- Provide input into the strategic plan and research priorities of PC4
- Reviewing research concepts and protocols from the community perspective, including the relevance of the overall research question
- Reviewing information sheets and consent forms of PC4 supported studies
- Participating in working groups
- Acting as consumer Associate Investigators for PC4 supported studies

We expect that CAG members will also be involved in other activities including:

- Facilitating links with the community and cancer community/consumer groups
- Raising awareness and advocating for community priorities among PC4 members
- Advising on ways to increase public awareness of the importance of clinical trials
- Advocating participation in research and clinical trials to consumers
- Contributing to or initiating community projects and activities
- Promote PC4 and PC4 supported studies as a consumer media representative on different platforms including- print media, radio, online, TV and social media

2.2. CONSUMER COMMUNITY

Community members may engage at different levels within PC4 and PC4 research. Our Consumer Community is a network of people interested in working with PC4. Community members may choose to engage on a project by project basis and change their level of involvement as their availability and interest allows.

3. MEMBERSHIP

3.1. NEW MEMBERS

PC4 will seek to engage with consumers that reflect a diversity of skills, experiences, demographics and location.

New members shall be required to submit an application with details of:

- Their experience with cancer
- Their experience with clinical trials or studies
- Their involvement with other community/consumer groups
- The reasons for wanting to join
- Their specific areas of interest within cancer in primary care research

Our PC4 website will provide consumer members access to:

- Consumer Advisory Group Terms of Reference
- Links to an Introductory video
- Most recent PC4 Consumer Advisory Group Annual Summary
- Any other information deemed necessary

3.2. SUPPORT FOR CONSUMERS

PC4 will endeavour to provide all consumers with appropriate learning opportunities. PC4 will endeavour to reimburse all travel expenses associated with members' participation in consumer activities related to supported studies. The PC4 Office will provide administrative support to members to minimise any other costs associated with participation. PC4 will work with our CAG to identify new resources and tools that can be developed to further educate both consumers and researchers about consumer engagement. Lastly, PC4 will work with investigators to ensure latitude for consumer involvement is built into research protocols and grant applications.