

Consumer and Community Involvement (CCI) Training and Resources

The aim of this document is to provide some resources that are available for consumers to help them engage in research and health care improvement activities. Researchers and health professionals, however, may also find the information contained on this page useful to assist consumers to prepare to engage in planned activities.

NATIONAL

WAHTN WA Health Translation Network

Involving Consumers in Health and Medical Research: A practical handbook for organisations, researchers, consumers and funders

The value of involving consumers in health and medical research cannot be underestimated. Consumer and community involvement (CCI) brings a unique perspective to all areas of research including planning, policy, funding, evaluation and reporting, as well as participation in the research project.

WAHTN has developed a CCI Handbook as part of an Australian Health Research Alliance national initiative funded by the Medical Research Future Fund, with additional support from our partners. It complements the rich suite of consumer involvement research, frameworks, policies and toolkits that have been developed by governments and organisations Australia-wide and internationally, and addresses a key barrier to embedding CCI: how to start. [Click here](#) to read the handbook.

Consumer and Community Involvement in Health Research Interactive course

<https://retprogram.org/training/consumer-and-community-involvement-in-health-research/>

An introductory educational module that is more informative about consumer and community involvement than it is 'training'.

- Module for consumer is free after registering online.
- Introduction to consumer engagement in research e-module
- A completion certificate is available at completion
- Quizzes and self-test to be completed

3 parts to the module

1. What is and what isn't Consumer and Community Involvement
2. Why Consumer and Community Involvement is important
3. A snapshot of Consumer and Community Involvement in practice

Monash Partners Consumer and Community Involvement Resources

Our good friends and research partners at Monash Partners Academic Health Science Centre have developed a raft of comprehensive online training tools and resources to support the partnering of consumers and community in research. To access these free resources online, please [click here](#).

Health Consumers Centre (formerly Health Issues Centre) Resources

The Health Consumers Centre have a range of valuable resources available on their website [here](#).

Telethon Kids Institute

<https://training.telethonkids.org.au/courses/>

- Training for consumer is free after registering online.
- Self-paced. Training can be left and returned to as required (will need to log into again)
- Activities and quizzes to complete

Covers a range of topics:

1. What is consumer and community involvement?
2. The different between participation, involvement and engagement
3. Why consumer and community involvement is important?
4. Why consumer and community involvement can help to improve the quality of research
5. Human research ethics committee requirements
6. Involvement can empower consumer and community members
7. How and where consumer and community members can be involved
8. Different types of research
9. Planning tools
10. The research cycle
11. Involvement spectrum
12. Methods of involvement - one or two community members/ Advisory groups/ wider community
13. Payment for consumer and community involvement
14. Being an effective member of a research team

At conclusion of the course, you should be able to state:

- Common definitions being used
- What is consumer and community involvement
- Why consumer and community involvement is important
- How and where consumers/community members can contribute to research
- How to be effective as a consumer/community member

Cancer Council NSW Cancer Voices NSW

National Breast Cancer Foundation

<https://www.cancer.org.au/online-resources/elearning/consumers-in-research-training>

Consumers in Research training:

- Free course after logging in and confirmation through email address
- All training has a cancer context. A number of the submodules that must be completed are purely about cancer in Australia

Two parts. Second part cannot be accessed without completing first part. Consumers can access the content in part one without completing all submodules or quizzes, but will not be able to access part 2. Part 1 covers:

- The role of the consumer
- The research cycle
- Terminology
- Types of research
- Research funding in Australia /applying for funding
- The research review process
- Research ethics and approval processes

Consumer Health Forum

<https://chf.org.au/guidelines-consumer-representatives>

- The site information has a heavy focus on being a consumer representative on a committee
- The site contains guidelines for Consumer Representatives and covers topics such as:

What is a consumer representative?

- The role of a consumer representative
- Consumer rights
- The first steps for consumer representation
- Who do you represent?
- Your obligations / expectations
- Expectation of the organisation
- What to do before starting
 - Obtain information about the committee
 - Your entitlements as a consumer representative
 - Plan and establish goals
 - Before meetings
 - Gather information about meeting and issues
 - Obtain a briefing
 - Submit agenda items
 - Look at the agenda and meeting minutes
 - Prepare
- Scenarios

Downloadable and useful resources on:

- Strengthening meeting skills for teleconferences
- Confidentiality guidelines
- Guidelines for consumer representatives on conference organising committees
- How committee secretariats can support consumer representatives
- The little purple book of Community Rep-ing
- A Guide for Consumers: Partnering with Health Organisations
- Resource for consumer representatives to assess the impact of new health initiatives and policies on consumers, with permission from the Australian Government Department of Health and Ageing
- Tips for consumer representatives

Australian Clinical Trials Alliance/CTIQ consumer involvement toolkit

<https://involvementtoolkit.clinicaltrialsalliance.org.au/consumers/>

- Informative 3:30 min video about 'What are clinical trials?' and 'What is randomisation?'
- Available in multiple languages

Health Consumers Queensland

Downloadable resources:

A Guide for Consumers Partnering with Health Organisations (2018)

<https://www.hcq.org.au/guides/#>

This is focused on consumers partnering with health organisations. The guide is specific to the Queensland Health System, but has many valuable topics that are general to consumer engagement. Topics include:

- The value of consumer partnerships
- How to become a consumer partner
- Roles and responsibilities
- How to prepare for committee meetings
- When a partnership is not working
- Looking after your wellbeing

Health Consumers Alliance of SA

Downloadable resources:

- Health Consumers Alliance of South Australia South Australian Consumer Advocate Guidebook (2020) <https://www.hcasa.asn.au/consumers/consumer-guidebook/>
- Aspects are contextualised to South Australia but the guidebook also contains a lot of generic and useful information

Topics include:

- About consumer engagement
- Core skills for consumer advocacy
- Working of committees
- Expectations for consumer advocated
- Skills for meetings and minutes
- Raising issues and concerns

INTERNATIONAL

PCORI Patient-Centred Outcomes Research Institute

Research Fundamentals: Preparing You to Successfully Contribute to Research

<https://www.pcori.org/engagement/research-fundamentals>

Offers self-paced education to anyone new to health research or patient-centred research to learn more about Research Fundamentals

- Module 1: Developing Research Questions
- Module 2: Designing the Research Study
- Module 3: Planning Patient-Centered Consent and Study Protocols
- Module 4: Sampling, Recruiting, and Retaining Study Participants
- Module 5: Understanding and Sharing Research Findings

National Institute for Health Research (NIHR) UK

An interactive course for new and experienced reviewers of health and social care research. The course has some NIHR context as it covers reviewing for NIHR research funding programmes (mainly in Module 1), but Module 2 includes skills and activities required at different levels and stages of research. The three modules are available as PDF, PowerPoint or online video. The website notes the training is aimed at:

- Public contributors who have been asked to provide feedback on a research document or sit on a committee that assess several research documents.
- Public contributors who are new to reviewing and those who want to know more.

Module 2: Introduction to public reviewing roles and skills

Learning outcomes

1. Define what a review is.
2. Recognise what public reviewing roles there are in the research project life cycle.
3. Identify the different research documents including a research or commissioning brief, a research proposal, a protocol and a funding application.
4. Start working with complex research documents.
5. Provide constructive feedback.
6. Review your meeting and interview skills which are useful for advisory committee meetings.