

Involving Consumers in Health and Medical Research

A practical handbook for organisations, researchers, consumers and funders.



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The value of involving consumers in health and medical research cannot be underestimated.

Consumer Involvement brings a unique perspective to all areas of research including planning, policy, funding, evaluation and reporting, as well as participation in the research project.

Extensive research in Australia and internationally provides compelling evidence that the involvement of consumers in health and medical research achieves many benefits.

These benefits are recognised across the world by governments, research bodies and health organisations that are fostering involvement of consumers through legislation, policies and financial investment.

Consumer Involvement:

- increases the relevance and responsiveness of research to health needs
- improves the quality of research and its impact on health outcomes
- strengthens the effective translation of research into policy and practice
- builds public confidence in health and medical research
- increases opportunities for research funding

As primary stakeholders, consumers have an inherent right to be involved in health and medical research and should be encouraged, supported and given opportunities to do so.

“This Handbook is the essential resource for all those who are serious about involving consumers in health and medical research.”

Professor Gary Geelhoed MBBS, FRACP, FACEM, MD
Immediate Past Chair AHRA
Executive Director WAHTN

This handbook has been developed by the Western Australian Health Research Alliance (WAHTN) as part of the Australian Health Research Alliance (AHRA) National Consumer and Community (CCI) Initiative.

The purpose of the WAHTN is to facilitate and accelerate health research translation. It operates as a unique partnership between WA's universities, medical research institutes, the WA Department of Health and its agencies and the private health sector.

AHRA facilitates the integration of healthcare, health and medical research, and health professional education to deliver better health outcomes for all Australians.

Its members comprise seven accredited Advanced Health Research and Translation Centres and three Centres for Innovation in Regional Health, which collectively encompass over 90% of researchers and 80% of acute health care services in the country.

Always Was: Always Will Be. We acknowledge the Aboriginal people as the traditional custodians of this land. We recognise the enduring connection with the land, water and skies and pay respect to elders, past and present.

Four Stakeholders: A Unique Symbiosis

Consumer Involvement has been largely focused on Researchers and Consumers as the two key stakeholders.

This Handbook recognises four stakeholders in the Consumer and Community Involvement (CCI) ecosystem: Organisations, Researchers, Consumers and Funders.



The unique symbiotic relationship between these stakeholders is at the heart of successful consumer involvement.

Meaningful and effective involvement is underpinned by four important principles:

- **Power** shared between the stakeholders
- **Trust** between the stakeholders
- **Belief** that meaningful involvement adds value
- **Understanding** of each other's roles, responsibilities and mutual obligations

Why a Handbook?

This Handbook complements the rich suite of consumer involvement research, frameworks, policies and toolkits that have been developed by governments and organisations Australia-wide and internationally. All provide strong foundations and guidance for implementing consumer involvement.

It addresses a key barrier to embedding CCI: how to start.



This Handbook – A Practical Guide

This Handbook is designed for ease of access by each of the four stakeholders. However, to achieve effective consumer involvement, it is critical that the four stakeholders understand each other's roles and mutual obligations. Familiarisation with all of the steps and resources at the start will greatly assist this.

It is designed to be adaptable and users are encouraged to make it their own, to suit their particular needs and circumstances.

This Handbook provides a step-by-step approach to embedding CCI in organisations involved in health and medical research

▶ The Five Phases

There are five critical phases, relevant to all the stakeholders, for successful embedding of Consumer Involvement:

- Phase 1** – Commitment
- Phase 2** – Planning and Preparation
- Phase 3** – Managing for Success
- Phase 4** – Evaluating the Involvement
- Phase 5** – Concluding the Involvement

▶ The Steps

Clear steps for each phase for each stakeholder

▶ The Tools

Each step is supported by practical resources

▶ Other Resources

Library of links to other useful resources

“When consumers are included as a valued part of the team, they provide a different way of looking at the research which benefits the researcher, the research organisation and, ultimately, the health consumer.”

George Kiosoglou
Consumer Representative
WEHI and Melbourne Academic
Centre of Health

The Handbook: Part 1 Step by Step

| | |
|---|----|
| Steps for Organisations Moving from good intentions to good practice | 7 |
| Steps for Researchers Getting the most out of the consumer's involvement | 9 |
| Steps for Consumers Adding meaningful value to health and medical research | 11 |
| Steps for Funders Leading by example | 13 |

The Handbook: Part 2 Resources

| | |
|---|----|
| Phase 1 Resources Commitment | 16 |
| Phase 2 Resources Planning and Preparation | 28 |
| Phase 3 Resources Managing for Success | 39 |
| Phase 4 Resources Evaluating the Involvement | 46 |
| Phase 5 Resources Concluding the Involvement | 49 |
| Library Handy Links | 52 |
| Full List of Resources | 56 |

Definitions

This Handbook uses the definitions from the Australian National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia's Statement on Consumer and Community Participation in Health and Medical Research.

Consumer and Community Involvement (CCI)

This is a common term used almost universally to describe Consumer and Community Involvement in research. Whilst this Handbook focuses more specifically on Consumer Involvement, the term CCI is used for consistency.

Involvement

In this Handbook, Involvement describes the many and varied arrangements through which consumers participate meaningfully in all aspects of health and medical research (refer to Resource 2 in this Handbook). This Handbook refers specifically to Consumer Involvement in research and related activities. Whilst there may be elements that are also relevant to Consumer Involvement in the planning and delivery of healthcare services, this is not the primary purpose of this Handbook.

Consumers

Consumers are patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.

Organisations

Formal and/or legal entities that undertake health and medical research including, but not limited to, medical research institutes academic institutions, health services and hospitals.

Researchers

Those who undertake approved health and medical research including, but not limited to, academic researchers, clinicians, undergraduate and postgraduate students.

Funders

Formal and/or legal entities that support health and medical research through funding, grants, sponsorship, donations and investments.

“Health research is about asking questions to uncover new information and improve outcomes. In that process, what consumers want and what researchers want is the same – ensuring that we ask the most important questions, and then bring the best available answers to the bedside. When this occurs as a partnership through the entire research process, the benefit and impact will be maximised.”

| Associate Professor Ed Litton, Intensive Care Specialist (Fiona Stanley Hospital) and National Health and Medical Research Council Early Career Research Fellow



The Handbook: Part 1

Step by Step



This section provides concise implementation steps for each stakeholder:



Organisation



Researcher

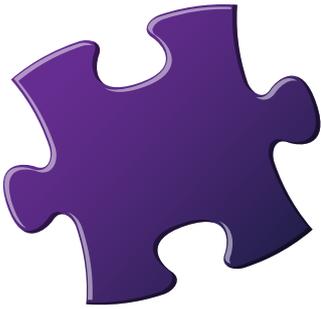


Consumer



Funder





Moving from good intentions to good practice

Leadership, a supportive culture and a resourcing commitment of the organisation are imperative to move CCI from good intentions to good practice. Indeed, effective involvement will not happen without these.

This table sets out a staged approach for establishing the leadership, governance and management required for the systemic embedding of Consumer Involvement in organisational policy and practice.

| Step | Description | Resource |
|------|-------------|----------|
|------|-------------|----------|

PHASE 1: Commitment

| | | |
|--------|---|---|
| Step 1 | <p>Understand CCI including contemporary thinking, potential benefits and types of involvement through:</p> <ul style="list-style-type: none"> published material online resources speaking directly with consumers and/or health consumer organisations | <p>Resource 1: Overview of CCI</p> <p>Resource 2: Types of Involvement</p> <p>Resource 3: Organisations Leading Consumer Involvement</p> |
| Step 2 | <ul style="list-style-type: none"> create and adopt a policy and guiding principles incorporate CCI into the organisation's Strategic and Operational Plans include CCI in all organisational policies | <p>Resource 4: CCI Policy for Organisations</p> <p>Resource 5: Policy Checklist</p> |
| Step 3 | <p>Communicate your commitment to all key stakeholders: internal and external</p> | <p>Resource 6: Communication to Key Stakeholders</p> |

PHASE 2: Planning and Preparation

| | | |
|--------|--|---|
| Step 4 | <p>Create the right environment for CCI success where:</p> <ul style="list-style-type: none"> commitment to CCI is understood and shared everyone is informed, prepared and supported there is clarity about purpose and process | <p>Resource 11: Creating a CCI Culture</p> |
| Step 5 | <p>Action the CCI policy by incorporating it into the day-to-day operations including:</p> <ul style="list-style-type: none"> management accountability budget and other resources types of involvement required/desired | <p>Resource 12: Involvement Costs and Considerations</p> |
| Step 6 | <p>Appoint someone to be responsible for CCI</p> | <p>Resource 13: CCI Coordinator Role</p> |

| | | |
|---------------|---|---|
| Step 7 | <ul style="list-style-type: none"> • recruit consumers • aim to recruit the right person for the right role at the right time • provide a mentor | <p>Resource 14: Recruiting Consumers</p> <p>Resource 15: Interviewing Potential Consumers</p> <p>Resource 16: Setting up a Consumer Register</p> <p>Resource 17: Request for Expression of Interest</p> <p>Resource 18: The Role of the Mentor</p> |
|---------------|---|---|

PHASE 3: Managing for Success

| | | |
|----------------|---|--|
| Step 8 | Clarify the involvement arrangement with a suitable document e.g. Involvement Agreement, Terms of Reference, Letter of Agreement | <p>Resource 21: Committee Terms of Reference</p> <p>Resource 22: The Involvement Agreement</p> |
| Step 9 | <ul style="list-style-type: none"> • establish trust and build effective working relationships • aim to ensure that all parties are confident, informed, equipped and empowered to be effective and successful in their roles • provide induction and orientation as early as possible • clarify remuneration process | <p>Resource 23: Induction and Orientation</p> <p>Resource 24: Remuneration Claim Form</p> |
| Step 10 | Take a proactive approach to managing the involvement to ensure its success and minimise problems along the way | <p>Resource 25: Managing for Success</p> <p>Resource 26: Managing for Success</p> |

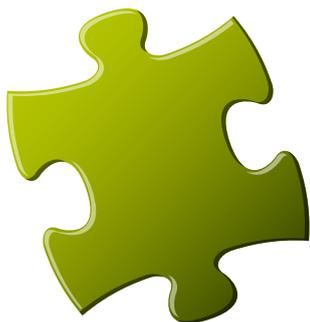
PHASE 4: Evaluating the Involvement

| | | |
|----------------|--|---|
| Step 11 | <ul style="list-style-type: none"> • take time to evaluate the involvement to build expertise and provide evidence for continuous improvement • involve all parties in the evaluation – the picture is incomplete without all perspectives | Resource 27: Evaluating the Involvement |
| Step 12 | <ul style="list-style-type: none"> • take time to reflect on the involvement • consider learnings • make changes | Resource 28: Reflecting on the Involvement |

PHASE 5: Concluding the Involvement

| | | |
|-----------------|---|--|
| Step 13a | <p>Planned Conclusion:</p> <ul style="list-style-type: none"> • acknowledge, respect and value the consumer contribution • celebrate shared success • create channels for potential future involvement • ensure the consumer is appropriately acknowledged on all reports, documents and/or presentations | Resource 29: Concluding the Involvement – Planned |
| Step 13b | <p>Unplanned Conclusion:</p> <ul style="list-style-type: none"> • protect any benefits that have been achieved • minimise any adverse impact of an unplanned ending to involvement | Resource 30: Concluding the Involvement – Unplanned |





Getting the most out of the consumer's involvement

The commitment and buy-in of researchers (including clinicians) is important to the successful involvement of consumers. These steps are designed to support researchers to optimise the involvement of consumers in research projects and programs.

Central to the success are:

- the engagement of consumers as early as possible in the development of the research project
- the establishment of a strong positive relationship, and
- a shared understanding of roles and responsibilities amongst all members of the research team

| Step | Description | Resource |
|------|-------------|----------|
|------|-------------|----------|

PHASE 1: Commitment

| | | |
|--------|---|--|
| Step 1 | Understand CCI – latest thinking and evidence, potential benefits and types of involvement | Resource 1: <i>Overview of CCI</i> |
| Step 2 | Clarify why consumers are being involved in the research | Resource 7: <i>Researchers: Why Involve Consumers in Research</i> |
| Step 3 | Include Consumer Involvement in all relevant research policies | Resource 5: <i>Policy Checklist</i> |
| Step 4 | Determine how consumers are to be involved in the research, their role and responsibilities | Resource 2: <i>Types of Involvement</i> |

PHASE 2: Planning and Preparation

| | | |
|--------|--|--|
| Step 5 | Create the right environment for CCI success where: <ul style="list-style-type: none"> • everyone is informed • there is clarity about the roles and responsibilities of all those involved in the research including the consumer | Resource 11: <i>Creating a CCI Culture</i> |
| Step 6 | Consider the cash and non-cash resources that will be required | Resource 12: <i>Involvement Cost and Considerations</i> |
| Step 7 | Recruit the right consumer for the right task at the right time | Resource 14: <i>Recruiting Consumers</i> Resource 15: <i>Interviewing Potential Consumers</i> Resource 16: <i>Setting Up a Consumer Register</i> Resource 17: <i>Request for Expression of Interest</i> |
| Step 8 | Appoint a research mentor The consumer is part of the research team. Consider how to include and support them | Resource 18: <i>The Role of the Mentor</i> |

PHASE 3: Managing for Success

| | | |
|---------|--|--|
| Step 9 | Clarify the involvement arrangement with a suitable document e.g. Involvement Agreement, Terms of Reference, Letter of Agreement | <p>Resource 21: <i>Committee Terms of Reference</i></p> <p>Resource 22: <i>The Involvement Agreement</i></p> |
| Step 10 | <p>Check that all important preparations have been completed to avoid problems during the involvement</p> <p>Clarify remuneration process</p> | <p>Resource 23: <i>Induction and Orientation</i></p> <p>Resource 24: <i>Remuneration Claim Form</i></p> |
| Step 11 | Use the Involvement Agreement to guide periodic catch-ups and amend the Agreement as necessary | Resource 25: <i>Managing for Success</i> |
| Step 12 | Incorporate the management of the involvement within the day-to-day operations as much as possible so that it does not become an additional impost | Resource 26: <i>Managing for Success</i> |

PHASE 4: Evaluating the Involvement

| | | |
|---------|--|--|
| Step 13 | <ul style="list-style-type: none"> • consider if/how the involvement has added value to the research • measure experiences, benefits and perceptions • use evaluation results to inform continuous improvement to policy and practice | Resource 27: <i>Evaluating the Involvement</i> |
| Step 14 | <ul style="list-style-type: none"> • take time to reflect on the involvement • consider learnings • make changes | Resource 28: <i>Reflecting on the Involvement</i> |

PHASE 5: Concluding the Involvement

| | | |
|----------|--|---|
| Step 15a | <p>Planned Conclusion:</p> <ul style="list-style-type: none"> • acknowledge, respect and value the consumer contribution • celebrate shared success • create channels for potential future involvement • ensure that the consumer is appropriately acknowledged on all reports, documents and/or presentations | Resource 29: <i>Concluding the Involvement – Planned</i> |
| Step 15b | <p>Unplanned Conclusion:</p> <ul style="list-style-type: none"> • protect any benefits that have been achieved • minimise any adverse impact of an unplanned ending to involvement | Resource 30: <i>Concluding the Involvement – Unplanned</i> |





Adding meaningful value to health and medical research

The voice, experience, knowledge and perspective of the consumer, when harnessed well, can transform the quality and relevance of health and medical research.

Achieving this requires empowered, informed and well-prepared consumers, able to meet this responsibility and confident that they are the right person in the right role at the right time.

| Step | Description | Resource |
|------|-------------|----------|
|------|-------------|----------|

PHASE 1: Commitment

| | | |
|--------|---|--|
| Step 1 | Understand CCI – latest thinking, potential benefits and types of involvement | Resource 1: <i>Overview of CCI</i> |
| Step 2 | Be clear about your motivation for involvement and what you want from it | Resource 8: <i>Consumers: Why Get Involved in Research</i> |
| Step 3 | Consider the variety of ways that you can be involved | Resource 2: <i>Types of Involvement</i> |
| Step 4 | Investigate the health and medical research organisations that involve consumers and which interest you | Resource 3: <i>Organisations Leading Consumer Involvement</i> |

PHASE 2: Planning and Preparation

| | | |
|---------|--|---|
| Step 5a | <ul style="list-style-type: none"> • join consumer health organisations and/or subscribe to their newsletters etc. • register your interest with health research organisations • approach an organisation directly to express your interest | Resource 19: <i>Consumers: Approaching an Organisation</i> |
| Step 5b | Ensure you make an informed choice about the organisation and research program before you commit | Resource 20: <i>Consumers: Assessing the Opportunity</i> |

PHASE 3: Managing for Success

| | | |
|---------------|--|--|
| Step 6 | <ul style="list-style-type: none"> ensure that your involvement arrangement is clarified through a suitable document e.g. Involvement Agreement, Terms of Reference, Letter of Agreement clarify the remuneration process clarify requirements and expectations, including yours communicate regularly with the researcher or the key organisation contact or mentor use the Involvement Agreement to guide periodic catch-ups and amend the Agreement as necessary | <p>Resource 21: <i>Committee Terms of Reference</i></p> <p>Resource 22: <i>The Involvement Agreement</i></p> <p>Resource 24: <i>Remuneration Claim Form</i></p> <p>Resource 25: <i>Managing for Success</i></p> <p>Resource 26: <i>Managing for Success</i></p> |
|---------------|--|--|

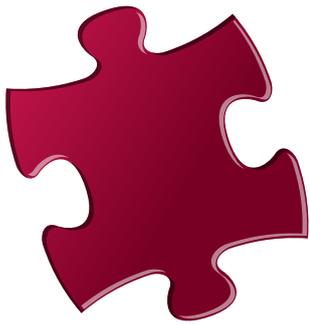
PHASE 4: Evaluating the Involvement

| | | |
|---------------|---|--|
| Step 7 | <ul style="list-style-type: none"> participate in the evaluation of the involvement your contribution is important and will inform how you approach future involvement arrangements | Resource 27: <i>Evaluating the Involvement</i> |
| Step 8 | <ul style="list-style-type: none"> take time to reflect on the involvement consider learnings make changes | Resource 28: <i>Reflecting on the Involvement</i> |

PHASE 5: Concluding the Involvement

| | | |
|----------------|--|---|
| Step 9a | <p>Planned Conclusion:</p> <ul style="list-style-type: none"> acknowledge the opportunity for the involvement celebrate shared success create channels for potential future involvement ensure that your contribution has been appropriately acknowledged on all reports, documents and/or presentations | Resource 29: <i>Concluding the Involvement – Planned</i> |
| Step 9b | <p>Unplanned Conclusion:</p> <ul style="list-style-type: none"> protect any benefits that have been achieved minimise any adverse impact of an unplanned ending to involvement | Resource 30: <i>Concluding the Involvement – Unplanned</i> |





Leading by example

The unique experiences of consumers add immeasurable benefit to the funders' objectives of improving community health through health and medical research funding. Their involvement ensures the relevance of funding policy, process and criteria. Most importantly, it provides a more holistic context for the responsible and effective allocation of funds.

Funders are powerfully placed to drive Consumer Involvement by mandating it in essential funding criteria.

Funders can set the criteria in the confidence that there is readily available, good quality information, resources and tools, including this Handbook, to provide applicants with the necessary support to meet such criteria.

| Step | Description | Resource |
|------|-------------|----------|
|------|-------------|----------|

PHASE 1: Commitment

| | | |
|--------|---|---|
| Step 1 | Understand CCI contemporary thinking, potential benefits and types of Involvement | Resource 1: Overview of CCI Resource 2: Types of Involvement |
| Step 2 | <ul style="list-style-type: none"> • create and adopt a policy and guiding principles • incorporate CCI into the Strategic Plan • incorporate CCI into the Funding Policy • require applicants to demonstrate CCI as a condition of funding <p>Involving consumers in this process will ensure effective incorporation of CCI and lead to improved funding outcomes</p> | Resource 9: Involving Consumers in Funder Activities Resource 10: CCI Policy for Funders |
| Step 3 | Communicate your commitment to all key stakeholders | Resource 6: Communication to Stakeholders |

PHASE 2: Planning and Preparation

| | | |
|--------|---|--|
| Step 4 | Create the right environment for CCI success where: <ul style="list-style-type: none"> • commitment to CCI is understood and shared • everyone is informed, prepared and supported • there is clarity about purpose and process | Resource 11: Creating a CCI Culture |
| Step 5 | Action the CCI policy by incorporating it into the day-to-day operations including: <ul style="list-style-type: none"> • management • accountability • budget and other resources • types of involvement required/desired | Resource 12: Involvement Costs and Considerations |
| Step 6 | Appoint someone to be responsible for CCI | Resource 13: CCI Coordinator Role |

| | | |
|---------------|--|---|
| Step 7 | <p>Recruit consumers</p> <p>Aim to recruit the right person for the right role at the right time</p> | <p>Resource 14: <i>Recruiting Consumers</i></p> <p>Resource 15: <i>Interviewing Potential Consumers</i></p> <p>Resource 16: <i>Setting up a Consumer Register</i></p> <p>Resource 17: <i>Request for Expression of Interest</i></p> |
|---------------|--|---|

PHASE 3: Managing for Success

| | | |
|----------------|---|--|
| Step 8 | <p>Clarify the involvement arrangement with a suitable document e.g. Involvement Agreement, Terms of Reference, Letter of Agreement</p> | <p>Resource 21: <i>Committee Terms of Reference</i></p> <p>Resource 22: <i>The Involvement Agreement</i></p> |
| Step 9 | <ul style="list-style-type: none"> • establish trust and build effective working relationships • aim to ensure that all parties are confident, informed, equipped and empowered to be effective and successful in their roles • provide induction and orientation as early as possible • clarify remuneration and payment process | <p>Resource 23: <i>Induction and Orientation</i></p> <p>Resource 24: <i>Remuneration Claim Form</i></p> |
| Step 10 | <p>Take a proactive approach to managing the Involvement. This will ensure its success and minimise problems along the way.</p> | <p>Resource 25: <i>Managing for Success</i></p> <p>Resource 26: <i>Managing for Success</i></p> |

PHASE 4: Evaluating the Involvement

| | | |
|----------------|---|---|
| Step 11 | <ul style="list-style-type: none"> • take time to evaluate the involvement to build expertise and provide evidence for continuous improvement • involve the consumer • involve the grant recipient as much as you can • this will provide diverse perspectives and build a complete picture | <p>Resource 27: <i>Evaluating the Involvement</i></p> |
| Step 12 | <ul style="list-style-type: none"> • take time to reflect on the involvement • consider learnings • make changes • communicate the changes | <p>Resource 28: <i>Reflecting on the Involvement</i></p> |

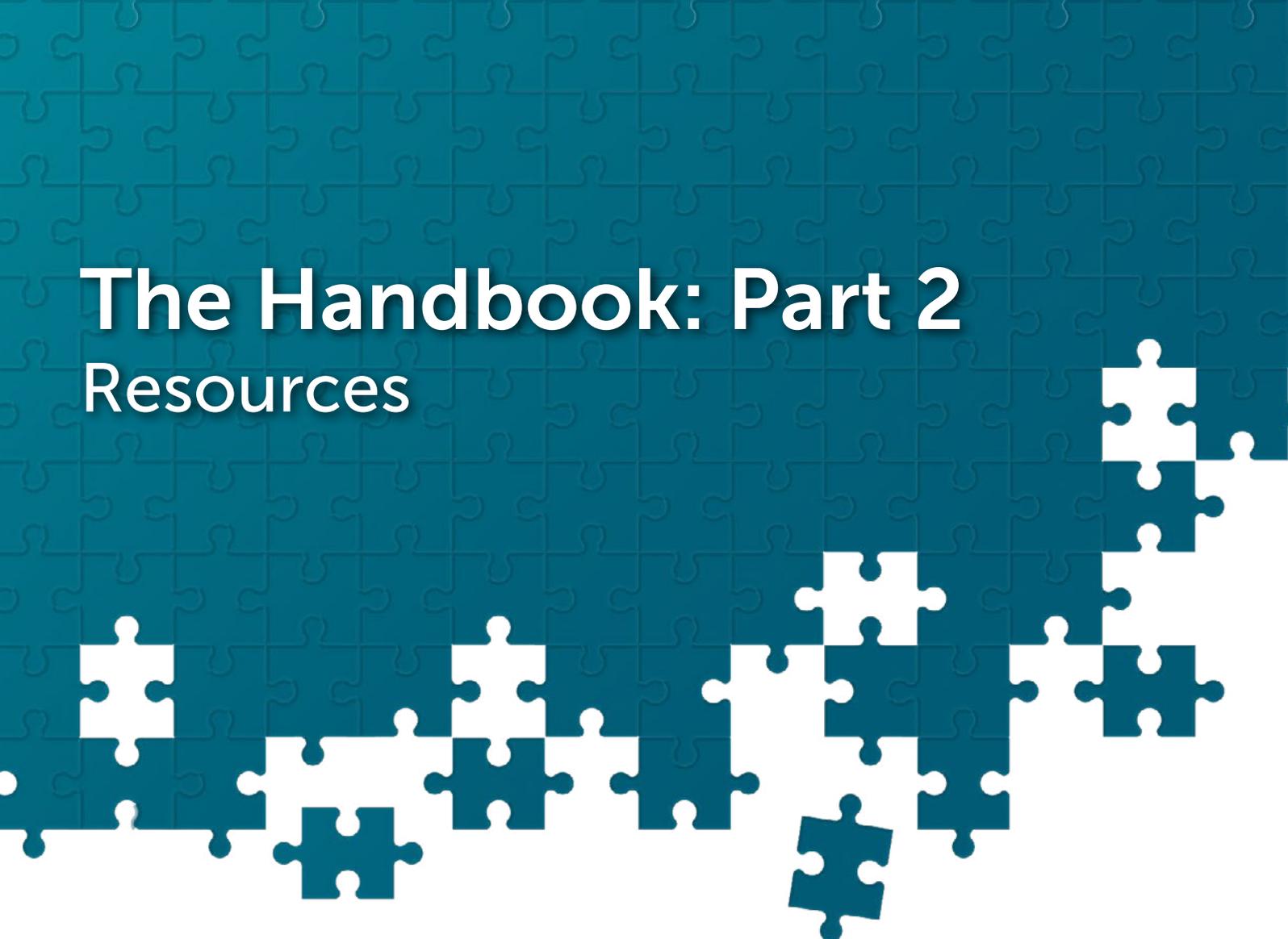
PHASE 5: Concluding the Involvement

| | | |
|-----------------|---|--|
| Step 13a | <p>Planned Conclusion:</p> <ul style="list-style-type: none"> • acknowledge, respect and value the consumer contribution • celebrate shared success • create channels and opportunities for potential future involvement | <p>Resource 29: <i>Concluding the Involvement – Planned</i></p> |
| Step 13b | <p>Unplanned Conclusion:</p> <ul style="list-style-type: none"> • protect any benefits that have been achieved • minimise any adverse impact of an unplanned conclusion to the involvement | <p>Resource 30: <i>Concluding the Involvement – Unplanned</i></p> |



The Handbook: Part 2

Resources



This section provides the practical resources for each of the steps. They are colour-coded for easy reference:

● ORGANISATIONS ● RESEARCHERS ● CONSUMERS ● FUNDERS

Resources are arranged within the five phases:

- Phase 1 Commitment
- Phase 2 Planning and Preparation
- Phase 3 Managing for Success
- Phase 4 Evaluating the Involvement
- Phase 5 Concluding the Involvement

Phase 1 Resources

Commitment



| | | | |
|---------------------|---|---------|-------|
| Resource 1: | Overview of CCI | ● ● ● ● | Pg 17 |
| Resource 2: | Types of Involvement | ● ● ● ● | Pg 18 |
| Resource 3: | Organisations Leading Consumer Involvement | ● ● | Pg 20 |
| Resource 4: | CCI Policy for Organisations | ● | Pg 21 |
| Resource 5: | Policy Checklist | ● ● | Pg 22 |
| Resource 6: | Communication to Stakeholders | ● ● | Pg 23 |
| Resource 7: | Researchers: Why Involve Consumers in Research Projects | ● | Pg 24 |
| Resource 8: | Consumers: Why Get Involved in Research | ● | Pg 25 |
| Resource 9: | Involving Consumers in Funder Activities | ● | Pg 26 |
| Resource 10: | CCI Policy for Funders | ● | Pg 27 |





CCI: What's it all about?

The following documents provide a contemporary overview of CCI relevant for organisations, researchers, consumers and funders.

Direct discussions with consumers and/or consumer organisations will also be highly beneficial. (Refer to Resource 3)

This is a dynamic environment and users are encouraged to add to, and update this list with relevant material as it is published.

Contemporary information about CCI

The Statement on Consumer and Community Involvement in Health and Medical Research (2016) NHMRC

- <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

Consumer and Community Involvement in Health and Medical Research: An Australia-wide Audit

- https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI_Final-Report_Full_Dec2018.pdf

South Australian Health and Medical Research Institute (SAHMRI) Framework

- https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf

South Australian Health and Medical Research Institute (SAHMRI) Value Statement

- <https://healthtranslationsa.org.au/wp-content/uploads/2020/11/The-value-of-CCI-report-v2.pdf>

Cancer Australia: National Framework for Consumer Involvement in Cancer Control

- https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

Miller et al (2017), Integrating consumer engagement in health and medical research – an Australian framework

- <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-017-0171-2>

“Why should it be up to researchers who have no experience personally with a particular disease to decide what a study design should look like or what outcomes should be measured?”

Dr Susan Kahn, Associate Director for Clinical Research at the Lady Davis Institute in Montreal



The power of a lived experience and so much more

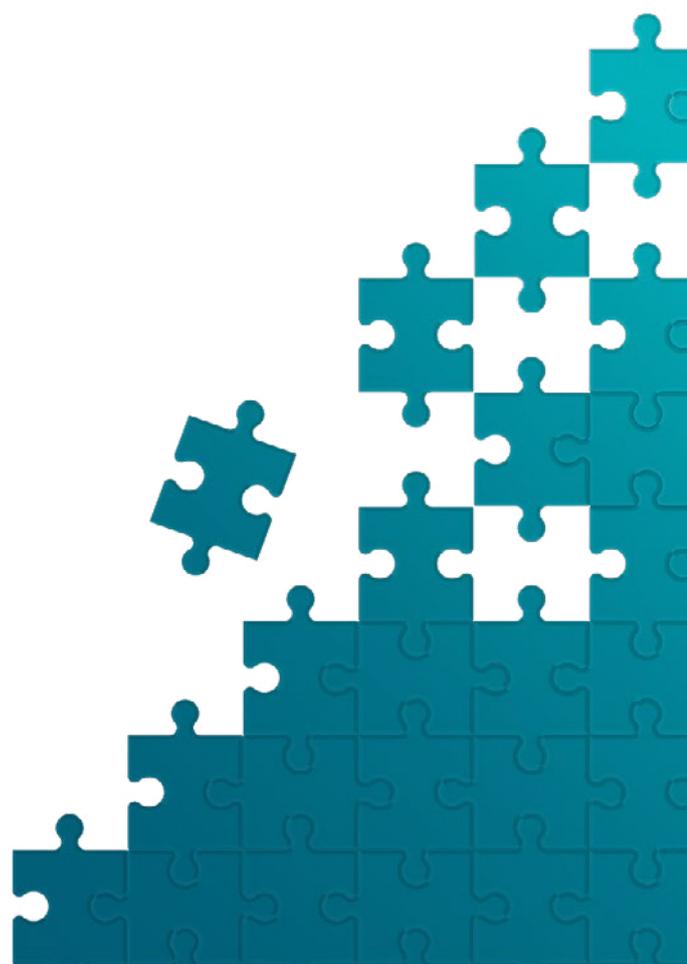
Consumers provide a unique perspective to all aspects of the planning and delivery of quality research. This table lists many of the possible ways of involving consumers. It is not exhaustive and users are encouraged to continue to explore other involvement opportunities.

Ways in which consumers can be involved in research

| | |
|---|--|
| <p>Within Government, Health Sector Bodies</p> | <ul style="list-style-type: none"> • membership on government advisory or planning or policy bodies • membership of consumer health sector advisory or planning or policy bodies • participation in periodic health research forums and workshops conducted by these bodies |
| <p>Within the Research Organisation</p> | <p>Membership of organisational groups e.g.</p> <ul style="list-style-type: none"> • Board • Board Sub-committee • Research Advisory Committee • Consumer Advisory Committee • Fundraising Committee • Ethics Committee • assessment panels for funding applications in organisations • Consumer Focus Group • Consumer Reference Group <p>One-off input into:</p> <ul style="list-style-type: none"> • relevant policies e.g. Consumer Involvement Policy • Strategic Plan • planning research program, agenda and priorities • reviews of Consumer Involvement • sharing the lived experience to inform policy, practice, marketing, fundraising • specialist consumer advisor • research ambassador or champion |
| <p>Delivering the Research Project</p> | <p>Involvement as a member of a research team including, but not limited to:</p> <ul style="list-style-type: none"> • sharing lived experience to shape the research scope, design and plan • designing the research project and developing a project plan • preparing grant applications and proposals • presenting research proposals to funders and donors • linking the researchers to community and consumer groups • collecting research information and data • analysing and reviewing data • writing or reviewing research reports • assisting with plain English writing • presenting research reports at forums, workshops and conferences • translating research findings to improve clinical practice and health <p>Membership of project-specific groups e.g.</p> <ul style="list-style-type: none"> • Focus Group • Reference Group • Advisory Group |

Resource 2: Types of Involvement (Cont.)

| | |
|--------------------------------------|---|
| Participating in the Research | <ul style="list-style-type: none">• participating in clinical trials• attending clinics where the consumer information is used for research• being a study subject in a research project |
| Research Funding | <ul style="list-style-type: none">• clarifying research needs and priorities• liaising with consumer groups• developing funding policies• designing funding/grants programs• determining program goals• designing program evaluation• evaluating the program(s)• designing internal and external communications• championing the programs in the community• designing application forms and processes• designing assessment tools and criteria <p>Participating on e.g.</p> <ul style="list-style-type: none">• assessment panels• shortlisting panels• review panels• advisory panels• evaluation panels |





The go-to organisations for CCI

A range of organisations in Australia support Consumer Involvement in health and medical research. The lists below provide an important starting place for exploring potential consumer involvement.

Organisations that provide consumer involvement opportunities

Health Consumer Organisations / Networks

Health consumer organisations and networks in Australia provide information, support, links to health research organisations and training for consumers. As a consumer, you may consider joining one of these to access resources and opportunities:

- Consumer and Community Involvement Program <https://cciprogram.org/>
- Consumers Health Forum of Australia <https://chf.org.au/>
- Health Care Consumers' Association <https://www.hcca.org.au/>
- Health Consumers Council <https://www.hconc.org.au/>
- Health Consumers NSW <https://www.hcnsw.org.au/>
- Health Consumers Queensland (HCQ) www.hcq.org.au
- Meeting for Minds <https://meetingforminds.com/>
- Safer Care Victoria <https://www.bettersafercare.vic.gov.au/>

You can also search for involvement opportunities in the following areas:

• Specific Diseases

There are many disease-specific organisations that can link you to researchers, policy makers and funders e.g. Cancer Council Australia, the Heart Foundation, Dementia Australia Limited, Rare Voices Australia.

• Medical Research Institutes

These exist in every Australian state/territory. Some are disease specific but most have a broader research scope. Many have consumer registers.

• Universities

Universities undertake a large proportion of Australia's health and medical research.

• Hospitals

Hospitals undertake research and provide opportunities for involvement in research and healthcare quality.

• Australian Health Research Translation Centre (AHRTCs) and Centres for Innovation in Regional Health (CIRHs)

These represent over 90% of health and medical researchers:

- Brisbane Diamantina Health Partners <https://brisbanediamantina.com/>
- Central Australia Academic Health Science Network <http://caahsn.org.au/>
- Health Translation SA <https://healthtranslationsa.org.au/>
- Maridulu Budyari Gumal – Sydney Partnership for Health, Education, Research and Enterprise (SPHERE) <https://www.thesphere.com.au/>
- Melbourne Academic Centre for Health <https://www.machaustralia.org/>
- Monash Partners <https://monashpartners.org.au/>
- NSW Regional Health Partners <https://nswregionalhealthpartners.org.au/>
- Sydney Health Partners <https://sydneyhealthpartners.org.au/>
- Tropical Australian Academic Health Centre <https://www.taahc.org.au/>
- Western Australian Health Translation Network <https://wahtn.org/>



Making CCI real and accountable

An organisation's commitment to CCI is made real when it's captured in a formal document like a policy. Policies are approved by the Boards and become a rule of practice for which there is reporting and accountability. Below is a template for CCI Policy that can be adapted to meet your particular situation and requirements.

Consumer involvement policy

Name of Organisation
 Approval Date:
 Policy Owner: Board of Directors
 Policy Custodians: (include a consumer)

Purpose

The purpose of this policy is to guide the involvement of consumers in the health and medical research work of this organisation.

Strategic Plan

This policy aligns with the agreed strategic priorities of this organisation.

Our Position

- This organisation believes that the meaningful involvement of consumers will enhance and strengthen the quality of our research and its translation.
- We endorse the Consumer Involvement Vision adopted by the Australian Health Research Alliance in 2018.

Values

- Consumer Involvement is essential for optimal effectiveness and impact of health and medical research
- Consumers have a right to be involved in health and medical research and to have opportunities for participation
- Consumers add value to all phases of health and medical research
- Consumer Involvement reflects mutual trust, a commitment to sharing knowledge and experience and a strong belief in the value of working together.

Expectations

This organisation is committed to involving consumers in all aspects of its operations and research activities including, but not limited to:

- Governance and Operations
 - as members of the board, a sub-committee or a periodic committee
 - as members of a consumer/community advisory committee
 - as independent consultants/advisors to the organisation and/or a research project.

b. Research Related Activities

- helping to decide research needs and priorities
- contributing to the preparation of research grant applications and proposals to investors
- contributing to the design and conduct of research projects, tools and resources
- linking researchers with consumers and community
- contributing to and reviewing research reports and papers
- presenting at conferences, seminars and other forums
- participation in the preparation of newsletters, media statements and social media
- promoting research to funders, sponsors and philanthropists

Action Plan

An Action Plan describing tasks, responsibilities, targets, timeframes and budget will support the implementation of this policy. The Action Plan will form part of this organisation's Operational Plan, including a reporting line to the Board.

Reporting and Compliance

The Policy Custodians will report to Board on the progress of the Action Plan and once endorsed by the Board, this information will be distributed to all relevant staff, students and volunteers.

Relevance

To ensure that this policy is based on contemporary CCI knowledge, expertise and developments we will:

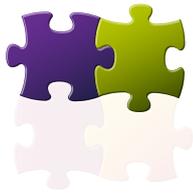
- liaise regularly with a relevant health consumer organisation and networks for guidance and support
- support our consumers, researchers and clinicians through access to CCI information, training, resources, tools, materials and expertise

Policy Review

The Policy Custodians will review the policy annually in consultation with relevant stakeholders and provide any required amendments to the Board for endorsement.

Policy Status Record

| Action | Actioner | Date | Initials |
|--------|----------|------|----------|
| | | | |
| | | | |
| | | | |



Reflecting CCI in organisational policies

The policies listed below apply to good governance in all organisations, including research-related. The list is not exhaustive and you are encouraged to add others specifically relevant to your organisation. To successfully embed CCI, these policies must be reviewed and, where necessary, amended to include CCI.

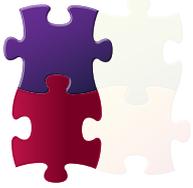
Policy checklist

| | Policy Covers CCI | Policy Requires Amendment | Amendment Date |
|---|-------------------|---------------------------|----------------|
| Governance Policy | | | |
| Strategic Planning Policy | | | |
| Conflict of Interest Policy | | | |
| Code of Ethics Policy | | | |
| Document and Information Policy | | | |
| Human Resource Policy | | | |
| Complaints and Grievances Policy | | | |
| Workplace Health and Safety Policy | | | |
| Risk Management Policy | | | |
| Financial Management Policy | | | |
| Ethical Fundraising and Sponsorship Policy | | | |
| Communications Policy (Internal and External) | | | |
| Anti-Discrimination and Inclusion Policy | | | |
| Research Policy | | | |
| Research Ethics Policy | | | |
| Copyright Policy | | | |
| Confidentiality Policy | | | |
| Intellectual Property Policy | | | |
| Research Data Management Policy | | | |

Additional Resource

NHMRC

<https://www.nhmrc.gov.au/sites/default/files/documents/reports/research-governance-handbook.pdf>

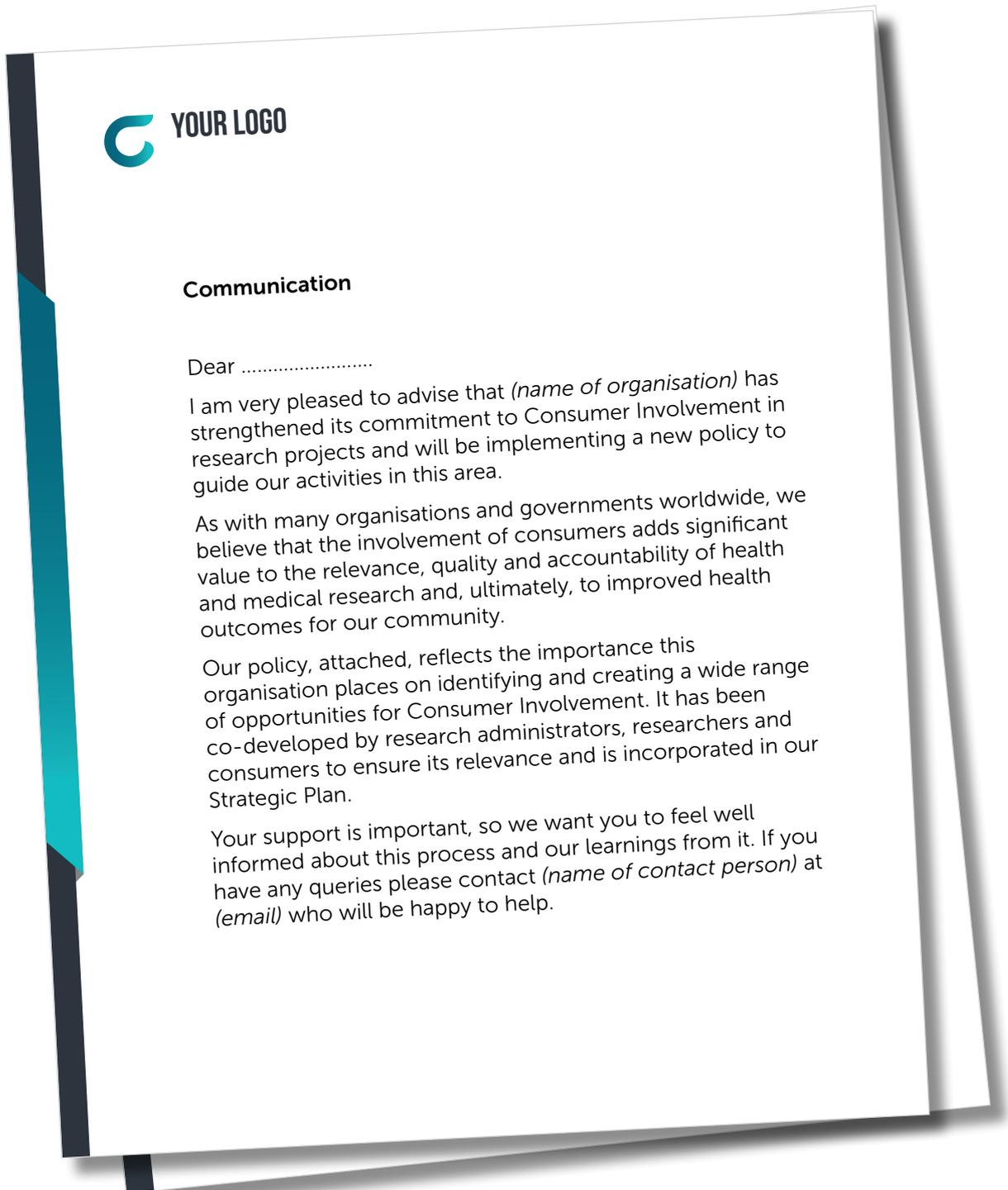


A public statement from the leader

It is important to let key stakeholders know of the organisation’s commitment to Consumer Involvement and that a policy is now in place to reflect and guide this.

Stakeholders include:

- **External:** Funders, donors, investors, partners, key suppliers, collaborators, other medical research bodies, relevant policy makers, the local community, NGOs and condition/disease specific organisations
- **Internal:** Board and committee members, staff, volunteers, consumers, researchers, students





“What’s my reason for involving consumers in my research?”

It is critical for researchers to be clear about their reasons for involving consumers as this will shape the type of involvement and the benefits that can be achieved. The checklist below provides a useful starting point.

Clarifying researcher need for consumer involvement

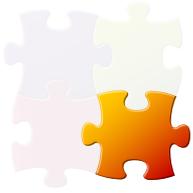
| Rating | | | | | |
|---|-------------|-------------|------------------|------------|---|
| 1 Not Important | 2 Desirable | 3 Important | 4 Very Important | 5 Critical | |
| | 1 | 2 | 3 | 4 | 5 |
| The insights and perspectives of consumer/patient cohort is important to this research | | | | | |
| Ensures that the research being conducted is relevant to community needs | | | | | |
| Ensures research generates knowledge that could improve healthcare, education or training | | | | | |
| Improves public awareness of, and support for, science and research | | | | | |
| Facilitates effective translation of research to deliver improved health outcomes | | | | | |
| Increases public confidence in research through enhanced openness and transparency in the conduct of research | | | | | |
| Increases public confidence in research through improved accountability over the use of public funds | | | | | |
| Helps develop a greater understanding and awareness of research | | | | | |
| Satisfies requirements of research funders | | | | | |
| Meets ethics requirements | | | | | |
| Complies with policy requirements of research organisation | | | | | |
| Consumers provide a different, non-scientific viewpoint | | | | | |

Additional Resource

Cancer Australia (CA)

<https://consumerinvolvement.canceraustralia.gov.au/document-library/researchers/checklist-researchers>

This quick checklist may be a helpful way of checking your readiness for involving consumers in your research.



“What’s my reason for being involved in research?”

It is critical for consumers to be clear about their reasons for being involved in research. This will ensure the best possible involvement experience for the consumer and maximise the success of the research. The checklist below provides a useful starting point.

Clarifying consumer reasons for getting involved

| | Rating | | | | |
|---|-----------------|-------------|-------------|------------------|------------|
| | 1 Not Important | 2 Desirable | 3 Important | 4 Very Important | 5 Critical |
| | 1 | 2 | 3 | 4 | 5 |
| Use my acquired skills and expertise | | | | | |
| Use my experience of a disease/health condition to inform and enhance research | | | | | |
| Be involved with and contribute to a particular organisation | | | | | |
| Be involved with and contribute to knowledge about a particular disease or health condition | | | | | |
| Find a meaningful volunteer role | | | | | |
| Learn more about a disease/health condition | | | | | |
| Learn more about research | | | | | |
| Earn income | | | | | |
| To give something back and to make a difference | | | | | |
| Develop my skills | | | | | |
| Be a voice for others | | | | | |
| Meet new people, share experiences | | | | | |
| Turn a negative experience into a positive outcome | | | | | |





Optimising the research dollar

The unique experiences of consumers ensure the relevance of funding policy, process and criteria. Most importantly, this strengthens the responsible and effective allocation of funds, public and private.

Diverse ways of involving consumers in funder activities

| | |
|-------------------|---|
| Policy | <p>Grant Assessment Policy</p> <ul style="list-style-type: none"> including consumer involvement as a key assessment criterion for grant applications and proposals, including demonstration of: <ul style="list-style-type: none"> how consumers have been involved in determining the research project and in preparing the application how consumers will be involved in the research project, the report dissemination and the research translation |
| Planning | <ul style="list-style-type: none"> consideration of research needs and priorities liaison with consumer groups landscape and situational analyses reviews of funding programs developing funding policies determining funding purpose and strategy |
| Programs | <ul style="list-style-type: none"> designing funding/grants programs determining program goals designing program evaluation evaluating the program(s) designing internal and external communications championing the programs in the community |
| Procedures | <ul style="list-style-type: none"> designing application forms designing application processes designing assessment tools determining assessment criteria and processes |
| Processes | <p>Consumer participating on:</p> <ul style="list-style-type: none"> grant application assessment panels grant application shortlisting panels funding program review panels funding program advisory panels evaluation panels |





Making CCI real and accountable

A funder’s commitment to CCI is made real when it’s captured in a formal document like a policy. Policies are approved by the Boards and become a rule of practice for which there is reporting and accountability. Below is a sample template for CCI Policy that can be used by funders – public and private.

Consumer involvement policy

Name of Organisation:
 Approval Date:
 Policy Owner: Board or Executive of the funding body
 Policy Custodians: 1 x CCI Coordinator or similar
 1 x Researcher
 1 x Consumer

Purpose

The purpose of this policy is to guide the involvement of consumers in all funding-related activities of this organisation.

Strategic Plan

This policy aligns with the agreed strategic priorities of this organisation.

Our Position

- This organisation believes that the meaningful involvement of consumers will enhance and strengthen the quality of research that is funded.
- We endorse the Consumer Involvement Vision adopted by the Australian Health Research Alliance in 2018.

Values

- Consumer Involvement is essential for the optimal effectiveness of medical research funders and investors.
- Consumers have a right to be involved in health and medical research and to have opportunities for participation.
- Consumers add value to all phases of health and medical research funding.
- Consumer Involvement reflects mutual trust, a commitment to sharing knowledge and experience and a strong belief in the value of working in partnership.

Expectations

(Name of the organisation) is committed to involving consumers in all aspects of its operations and funding activities including, but not limited to:

- a. Organisation Governance and Operations
 - being a member of the board, a sub-committee, a periodic committee,
 - being an independent consultant/advisor to this organisation
 - presenting at conferences, seminars and other forums

b. Funding related activities

- determining research needs and priorities
- liaising with consumer groups
- developing funding policies
- determining funding purpose and strategy
- designing funding/grants programs
- determining program goals
- designing program evaluation
- designing internal and external communications
- designing application forms
- designing application processes
- designing assessment tools
- determining assessment criteria and processes
- participating on:
 - funding application assessment panels
 - shortlisting panels
 - funding review panels
 - funding advisory panels
 - program evaluation panels

Action Plan

An Action Plan describing tasks, responsibilities, targets, timeframes and budget will support the implementation of this policy. The Action Plan will form part of this organisation’s Operational Plan, including a reporting line.

Reporting and Compliance

The Policy Custodians will report to Board on the progress of the Action Plan and once endorsed by the Board, this information will be distributed to all relevant staff, students and volunteers.

Policy Review

The Policy Custodians will review the policy annually in consultation with relevant stakeholders and recommend any required amendments to the Board for endorsement.

Policy Status Record

| Action | Actioner | Date | Initials |
|--------|----------|------|----------|
| | | | |
| | | | |
| | | | |

Phase 2 Resources

Planning and Preparation



| | | |
|--|-------|-------|
| Resource 11: Creating a CCI Culture | ● ● ● | Pg 29 |
| Resource 12: Involvement Costs and Considerations | ● ● ● | Pg 30 |
| Resource 13: CCI Coordinator Role | ● ● ● | Pg 31 |
| Resource 14: Recruiting Consumers | ● ● ● | Pg 32 |
| Resource 15: Interviewing Potential Consumers | ● ● ● | Pg 33 |
| Resource 16: Setting up a Consumer Register | ● ● ● | Pg 34 |
| Resource 17: Request for Expression of Interest | ● ● ● | Pg 35 |
| Resource 18: The Role of the Mentor | ● ● ● | Pg 36 |
| Resource 19: Consumer Approaching an Organisation | ● | Pg 37 |
| Resource 20: Consumer Assessing the Opportunity | ● | Pg 38 |





Walk the talk

At the heart of successful involvement of consumers is an enabling culture. A commitment to involving consumers in your organisation needs to be expressed, enacted and experienced. Below are some strategies for achieving this culture.

Embedding CCI culture

- Be clear about your reasons for involving consumers and state these overtly to create a consistent and strong belief. Include it in the organisation's *mantra*.
- Convey the commitment to involvement via a robust policy.
- Incorporate CCI in the organisation's Strategic Plan including targets and key performance indicators.
- Incorporate the commitment to consumer involvement in your organisation's Operational Plan including:
 - strategies
 - management
 - reporting and accountability
 - budget and other resources
- Make the Consumer Involvement Policy widely known, visible and accessible. Incorporate the commitment to consumer involvement in the Strategic Plan.
- Incorporate consumer involvement in all staff and volunteer induction and training.
- Establish respectful and enduring relationships with consumers.
- Acknowledge consumer participation, recognising that they are important contributors to the organisation's success.
- Set out consumer involvement in clear agreements to ensure clarity about expectations, roles, responsibilities and conditions.
- Provide opportunities for consumers to interact socially or informally with others in the organisation.
- Adopt a top down, lead-by-example approach, beginning with the Board and leadership team.

Additional Resource

Cancer Australia (CA)

<https://consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/finding-and-forming-staff-%E2%80%98consumerchampions%E2%80%99-getting-right>



Commitment without resourcing is a fast-fading dream

One of the key barriers to involvement is the lack of resources. It is critical that CCI is appropriately resourced if it is to achieve its potential. Embedding CCI in Strategic and Operational Plans will require consideration of the resources required – cash or non-cash. Here are some key resourcing considerations.

Involvement costs and considerations

1. Have clear process for determining involvement resourcing e.g.

- clarify the budgeting processes and rules in your organisation
- decide the specific activities in which consumers will be involved
- for each activity, identify the specific costs that you will need to include in the budget
- estimate the cost or range of costs against each involvement activity
- incorporate involvement costs in the research project budget and (if required) the organisation's operating budget

2. Consider the types of costs for which resources may be required e.g.

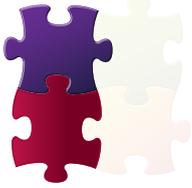
- a. Consumer costs
 - payments for consumer time e.g. time at meetings, time preparing or reviewing documents, time on research tasks, training
 - reimbursement of consumers for out-of-pocket expenses such as travel, meals, childcare, accommodation, carer support
- b. Organisational costs
 - administrative support
 - Consumer Involvement Coordinator
 - staff and researcher time for working with consumers
 - training of staff
 - advertising and recruitment process
 - equipment and furniture
 - other costs: catering, venue hire, conference fees/costs
- c. Costs related to regulatory or contractual conditions e.g.
 - any taxation requirements that may apply
 - any funders'/investors' conditions that may apply

Additional Resource

NHMRC Guidelines for Guidelines

A useful guide to preparing a budget for a research project.

<https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>



Making it happen

Having committed to CCI, it is imperative that an organisation assigns responsibility for achieving the CCI policy to a person/team. It can be part of an existing role or a new role. Here is a simple statement of the role and responsibilities of a CCI Coordinator to get started.

CCI coordinator role and responsibilities

| Role | Responsibilities |
|---|--|
| <ul style="list-style-type: none"> • champion CCI in the organisation • oversee the development of a positive CCI culture within the organisation • oversee and support the implementation of CCI in both policy and practice • ensure that Consumer Involvement is incorporated in the organisation’s Strategic Plan including: goals, targets, strategies and measures • ensure the effective implementation of the organisation’s Consumer Involvement policies and practices • lead the continuous improvement of CCI • be the organisation’s go-to person for Consumer Involvement • liaise with funders and investors about CCI | <ul style="list-style-type: none"> • lead the planning and coordination of consumer involvement activities • cultivate a sense of belonging among consumers • manage consumer involvement • manage relationships, including formal agreements, with health consumer organisations • coordinate access to Consumer Involvement training and development opportunities for staff, volunteers, researchers and consumers • manage the Consumer Involvement budget |



Resource 14: Recruiting Consumers



The right person for the right role at the right time

Recruitment can be an obstacle to involvement when organisations and researchers don't quite know where to start, or the process involved is time-consuming and costly. Below are some simple strategies for recruiting consumers.

Strategies for recruiting consumers

| Recruitment Option | Considerations |
|--|--|
| Establish a Consumer Register (Refer to Resource 16) | <p>Consider the resources needed to meet the legislative, privacy and maintenance requirements of a register</p> <p>Consider sharing a register with other similar organisations to maximise capacity and minimise costs</p> <p>Consider collaborating with a similar organisation to establish a shared register to achieve efficiencies, cost benefits and wider reach</p> |
| Access Consumer Registers of other organisations | This may involve a small fee but could be more cost effective and efficient than having your own register |
| Use existing consumer matching services | These are usually on a fee-for-service basis but can ensure that you find the right and best consumer |
| Connect with a health consumer organisation | There are many consumer organisations that will readily assist with this task – refer to Resource 3 for a list of Australian organisations |
| Advertise for specific projects or roles via: <ul style="list-style-type: none"> • your website • websites of other organisations • e-newsletters of community health organisations • community newspapers • notice boards of health and medical centres (clinics, hospitals) • social media | <p>Consider disease-specific organisations or general consumer health groups</p> <p>Consider engaging already registered consumers to recruit peers</p> |

Additional Resources

Cancer Australia (CA)

Finding Consumer Champions: A helpful, practical tool to help identify key qualities in staff champions of consumer involvement.

<https://consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/finding-and-forming-staff-%E2%80%98consumerchampions%E2%80%99-getting-right>

Cancer Australia (CA)

<https://consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/recruitment-and-selection-process-consumers>



Finding the perfect match

The purpose of the interview is to assess suitability, compatibility and readiness of both parties. Aim to provide and seek the information both parties need to allow an informed decision about progressing the involvement.

A guide to interviewing consumers

1. Preparation

- It is important to call the meeting an interview to reflect the professional nature of the involvement arrangement that may follow.
- Avoid a panel approach to the interview. It creates an unfavourable group dynamic. Two interviewers are ideal as that enables them to support each other and reflect together. It also provides the consumer with more than one perspective.
- Ask the consumer to complete an EOI or provide a short bio before the interview. This should provide important information about their skills, experience, expectations and availability. Use the interview to clarify any information provided in the EOI but do not repeat it.

2. Introductory Questions

- Make sure all interview participants are properly introduced – name, title and why they are there.
- Create a professional but relaxed environment.
- Adopt a respectful, open and transparent approach. Without breaking confidentiality and protocols, be clear and give as much information as possible about the involvement/research/project.
- Clarify any information provided in the EOI or bio that is not going to be covered in the interview.
- Check if the consumer has undertaken any preparation for the interview e.g. looked up the organisation, its research activities, read any annual reports or similar etc.
- Invite the consumer to describe their interest and motivation for being involved in the organisation's research and research-related activities. What expectations do they have?

3. Involvement Role

- Discuss the involvement role and seek the consumer's thoughts on their own suitability for the role.
- Clarify any known and potential impediments to the involvement – for both parties. Consider if any of these are an obstacle to the involvement and if they can be overcome.
- Clarify any specific or unusual requirements that the consumer may have in order to fulfil the involvement role. Be clear about whether or not these requirements can be met. It may prevent the involvement from going ahead.
- Consider what support and training the consumer may need and if there are resources available for this. If not, you may be setting the involvement up to fail.

4. Suitability

- Seek information that will help you to consider fit – with the organisation's culture and values, with the Board or Committee if relevant, with the research team if relevant, with other consumers who may be already involved.
- Invite the consumer to also seek the same information from you.
- Clarify with the consumer what they will bring with their involvement and what value this will add to the organisation and its research. Make this an informative discussion. At this point in the interview all parties have enough information to be able to talk about this matter.
- If the consumer is considered suitable, and before they are engaged, invite the consumer to meet informally with two or three other members of the organisation and/or research team. It provides a less stressful opportunity for both parties to further appraise one another.
- Provide a response to the consumer in as short a time as possible. Two weeks is considered standard.



Pros and cons

Having your own consumer register or database will provide ready access to consumers. However, the establishment and maintenance of a register requires dedicated resourcing and a number of ethical, legal and statutory compliances. It is important to consider whether this is the best option for your organisation.

Important considerations for setting up a register

Important First Step

Involve consumers in the design, set-up and ongoing management of the register.

Purpose

The register must have a defined and agreed purpose.

Governance and Management

- a clear governance and management structure with roles and responsibilities and accountabilities
- a stated policy that covers:
 - what information will be kept on the register and how this will be used
 - privacy and confidentiality
 - how consumers will be added to and removed from the register
 - how the data on the register will be kept up to date
 - authorisation and consent
 - responsibilities and accountabilities
 - measures for ensuring that the register will be protected and maintained in a secure environment

Ethical, Legal and Regulatory

All ethical and legal and regulatory requirements should be met before recruiting consumers to the register.

Establishing the Register

- recruitment strategies, ideally co-developed with consumers, should be set out clearly
- the purpose and scope of the register should be made clear to all who join it
- data should be subject to quality control
- establish the rules of the register including members' rights and obligations
- provide clear terms of reference for members

Communication

- prepare a simple Communication Plan for sharing information, news, notices etc.
- communicate regularly with register members so they remain engaged
- provide easy access for register members to communicate with you

Operation

- ensure sufficient resources to support all of the operations of the register including keeping it up to date
- develop a business plan to ensure sustainability of the register, including how will it be managed and maintained
- prepare a risk management plan to avoid issues and pitfalls that may have legal consequences
- decide on the length of the term of membership
- ensure all members have adequate privacy protection

Closing the Register

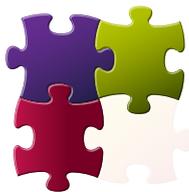
Decide the shelf life of the register, circumstances for its termination and how the records will be securely destroyed when no longer required.

Additional Resources

A consumer register: an acceptable and cost-effective alternative for accessing patients.
<https://bmcmredresmethodol.biomedcentral.com/articles/10.1186/s12874-016-0238-8>

Join Us

A national register established by the George Institute and UNSW.
Provides useful information about how registers work including risks and obligations.
<https://www.joinus.org.au/join-us/>



Clarifying the involvement opportunity

Using a simple Expression of Interest (EOI) will enable you to provide the relevant information about the involvement and assist the consumer to formally indicate their interest in the role. The chart below provides the key elements of an EOI.

Request for expression of interest

- 1. Closing Date for EOI**
- 2. Type of Involvement**
(refer to Resource 2: Types of Involvement)
 - specify how the consumer will be involved:
 - participating in the organisation
 - participating in the research project
 - participating in the research (as a study subject)
 - describe the committee, group or research project for which involvement is sought
- 3. Period of Involvement**
 - commencement date
 - end date
- 4. Purpose**
 - outline of key roles and responsibilities
 - outline of workload
- 5. Expectations**
 - expected benefits for the organisation, the research, the consumer
 - deliverables
- 6. Key Qualities/Attributes Sought**
 - knowledge about
 - expertise relevant to
 - experience in the area(s) of
- 7. Remuneration Information**
 - cash
 - non-cash
- 8. Information Required**
(consider limiting to two pages)
 - name of the consumer
 - relevant knowledge and/or expertise/ experience any previous consumer involvement
 - availability during the involvement period
 - any specific requirements
- 9. Submission of EOI**
Clear address for postal, email or other form of submission
- 10. Contact**
Name, email address, telephone number, availability for interview

Additional Resources

Australian Clinical Trials Alliance (ACTA)

Simple poster template for recruiting consumers into a research project.

<https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/resources/#involvement-resources>

Victorian Comprehensive Cancer Centre (VCCC)

A useful template for a consumer participation request form.

<https://www.viccompcancerctr.org/about-vccc/consumer-engagement/resources/>



The human factor for embedding CCI

Having a mentor can greatly enhance the effectiveness of the involvement. Whilst mentoring is commonly perceived to be provided to the consumer, it is important to note that consumers can also be mentors – to researchers, other consumers and administrators.

The role of the mentor

Attributes of a good mentor

- a genuine commitment to the role and capacity to take it on
- good listening skills, openness to learning and ability to identify learning opportunities
- good time management and self-management skills
- relevant knowledge and experience to provide the right level of support
- an honest and considerate approach to giving constructive feedback and asking challenging questions
- patience

Roles and responsibilities of a mentor

- a. A good mentor is willing to adopt the role and is prepared to be:
 - a go-to contact
 - a friendly face
 - an informal source of information
 - someone who knows how things work in the organisation and/or the project and is prepared to share that information
- b. The mentor role will be varied but could involve:
 - helping a new colleague find their way around the organisation, the committee/group or research project
 - showing how to perform aspects of the role
 - answering and encouraging questions to help newcomers get started and stay in touch
 - providing information and informal support
 - introducing consumers to people important to their role and explaining the formal and informal culture and structures
 - arranging to go for coffee or lunch sometimes so consumers can enjoy the social side of working and feel part of the team

Support for mentors

It's important for mentors to have access to professional support. Consider providing this via:

- a peer or peer network
- the organisation's HR/Development/Training teams
- online mentor forums and other resources
- mentor training programs

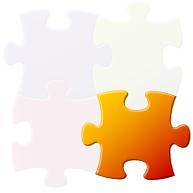
Pitfall: a mentor is NOT a line manager, counsellor, advisor, best friend, confidante or advocate

Additional Resource

Manchester Metropolitan University

Mentoring Guidelines – a useful handbook.

https://www.mmu.ac.uk/media/mmuacuk/content/documents/human-resources/a-z/guidance-procedures-and-handbooks/Mentoring_Guidelines.pdf



Taking the initiative

Consumers can take the initiative and approach research organisations themselves. Here are some strategies for this.

Consumer - tips for approaching an organisation

1. Initial Contact

Consider any or all of these strategies:

- telephone the organisation
- email the organisation
- attend any community information forums that the organisation holds
- ask a consumer health network to provide an introduction to the organisation (the network may have contacts there)

2. Communication

In all your communication ensure that you provide important basic information including:

- that you are a consumer
- why you are contacting the organisation
- your interest in becoming involved in the organisation's research
- the type of involvement you are keen to pursue
- interest in meeting with them or sending them a brief summary about yourself

3. Follow Through

Prepare a brief bio or statement about yourself that you can provide as a follow-up to the initial contact. It should be no more than one page long and include:

- name and contact details
- why you are contacting the organisation
- your interest in becoming involved in the organisation's research
- the type of involvement you are keen to pursue
- what you have to offer
 - knowledge
 - expertise
 - experience, including a lived experience
- any other involvement you may have had
- any special requirements you have
- any restrictions on your availability (e.g. time, location, about to go on holiday, mobility, health etc.)



Look before you leap

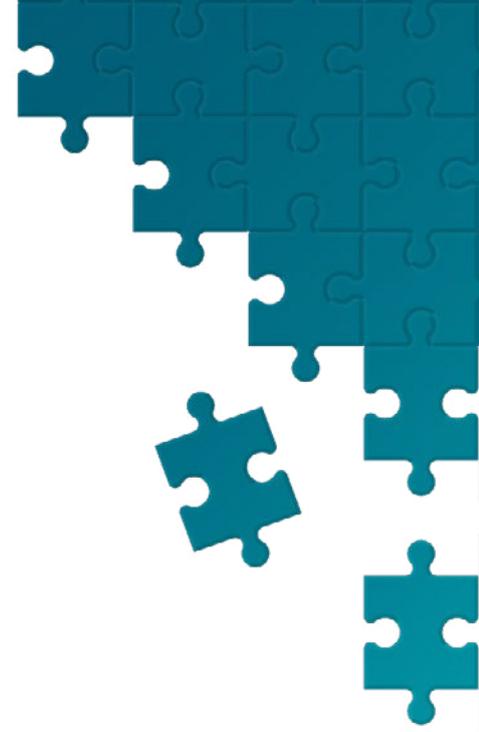
This checklist will assist consumers to make informed decisions about taking up an involvement opportunity that is offered to them.

Consumer - assessing an involvement opportunity

| Considerations | Yes/No |
|--|--------|
| About You | |
| Does the role align with my values? | |
| Does the role fit with my consumer aspirations? | |
| Is the role interesting and challenging? | |
| Do I have the skills and knowledge for the role e.g. IT skills, writing skills, management skills? | |
| Do I have the time to fulfil the role well? | |
| Are there any reasons why I may not be able to fulfil this role? e.g health | |
| What is my passion for the role? | |
| Am I ready for this role? | |
| Am I a current patient and does this involvement affect my ability to contribute? | |
| Will involvement in this research affect me personally and am I ready? | |
| What is my gut feeling? | |
| About the Organisation | |
| Have I researched the organisation and am I comfortable with it? | |
| Do the organisation's values align with mine? | |
| Has the organisation or researcher clarified why they are seeking consumer involvement? | |
| Has the role been made clear? | |
| Have I met the key people? | |
| Have the conditions about the involvement been made clear? | |
| Has remuneration been clarified? | |
| Do I need support to fulfil the role and is this available? | |
| Do I have enough information to make a confident decision? | |

Phase 3 Resources

Managing for Success



| | | |
|--|---------|-------|
| Resource 21: Committee Terms of Reference | ● ● ● ● | Pg 40 |
| Resource 22: The Involvement Agreement | ● ● ● ● | Pg 41 |
| Resource 23: Induction and Orientation | ● ● ● ● | Pg 42 |
| Resource 24: Remuneration Claim Form | ● ● ● ● | Pg 43 |
| Resource 25: Managing for Success | ● ● ● ● | Pg 44 |
| Resource 26: Managing for Success | ● ● ● ● | Pg 45 |





Getting on the same page

Terms of Reference clarify the purpose of a committee, advisory body, reference group etc. and help to keep activities focused. These need to be provided at the time of recruiting potential members and before they agree to join it. The following chart provides the key headings and content for Terms of Reference.

Terms of reference - key elements

1. Background

- name of organisation
- purpose of the organisation
- vision
- values

2. Name of Committee/Advisory Group/Reference Group/etc.

3. Purpose of the Committee or Group

- role of the Committee/Group
- what it is expected to deliver
- who the Committee/Group reports to
- what matters the Committee/Group considers
- any matters that the Committee/Group decides

4. Committee/Group Membership Members

- Chairperson
- Deputy Chairperson
- General Members

5. Obligations

- attendance at meetings
- preparation for meetings
- participation in meetings
- any requirements additional to attending meetings

6. Meeting Arrangements

Meeting dates, times, duration and venues

7. Remuneration (if applicable)

- hourly rate
- out-of-pocket reimbursement
- travel and parking vouchers
- member voluntary contribution

8. Term

- commencement date
- conclusion date
- any changes to the Terms of Reference

9. Contact

- key contact person for matters relating to this Committee/Group
- name, phone number and email



Put it in writing

It is critical that the involvement arrangement is captured in a suitable document so that all parties are clear about what has been agreed. The document is central to achieving the best possible involvement outcomes for all. Below is a simple template that can be easily adapted for specific situations.

Involvement agreement

1. Parties to this Agreement

Select whichever is applicable.

- a. Organisation
- b. Consumer
- c. Researcher
- d. Funder

2. Involvement Purpose

This Agreement clarifies the involvement arrangement between:
(*name of consumer*) and (*name of organisation*).

3. Type of Involvement

Refer to Resource 2: Types of Involvement
The Consumer will be involved in the following ways:

- participating in an Organisation Committee or Group
- participating in the Research Project
- participating in the Research as a study subject

4. Involvement Period

The period for this involvement commences on (date) and concludes on (date).
A new agreement will be negotiated for any further involvement.

5. Contact Person

Name of contact person for matters relating to this involvement.

6. Involvement Details

- name of the Committee/Group or Research Project
- roles and responsibilities of each party (attach)

7. Obligations

- a. the Organisation has all necessary insurances to support this involvement
- b. the project has all the necessary approvals, including ethics, to proceed
- c. the Consumer confirms that there are no legal, health or other impediments to their involvement

8. Conflict Resolution

Procedure for dealing with issues, concerns and conflict (attached or see link to Organisation's policy)

9. Changing the Agreement

Changes to this Agreement can be proposed by any of the parties but any change requires agreement by all parties.

10. Remuneration

- a. amount of cash and non-cash remuneration
- b. payment arrangements

11. Privacy and Confidentiality

- a. privacy requirements of the Consumer
- b. confidentiality requirements of the Organisation

12. Acknowledgement

Acknowledgement of the consumer and the involvement (e.g. on report, papers, documents)

13. Other Conditions

14. Signatures of Parties and Date

Additional Resource

Australian Clinical Trials Alliance (ACTA):

A useful template for a consumer involvement agreement.

<https://www.viccompccancerctr.org/about-vccc/consumer-engagement/resources/>



Setting up for success

The right preparation will ensure that the involvement gets off to a good start. The checklist below will help with this important step.

Induction and orientation

| | Required Y or N | Responsible Person Name | Completed Date |
|--|--------------------|-------------------------------|-------------------|
| Checking | | | |
| Involvement Agreement, or similar, is in place | | | |
| consumer’s information records are in place | | | |
| Information about | | | |
| organisation | | | |
| committee/group | | | |
| research project | | | |
| Introductions to | | | |
| person responsible for CCI | | | |
| CEO of organisation | | | |
| head of research project | | | |
| research mentor | | | |
| Access to | | | |
| building | | | |
| specific rooms | | | |
| workspaces | | | |
| systems and networks | | | |
| IT support | | | |
| vehicles | | | |
| parking | | | |
| stationery materials | | | |
| Clarification of | | | |
| relevant policies and procedures | | | |
| workplace rules | | | |
| organisation protocols | | | |
| Provision of | | | |
| materials | | | |
| equipment | | | |
| tools | | | |





Keep it simple

Keeping the remuneration process clear and simple will minimise red tape and avoid unnecessary frustration. Below is a simple claim form that meets financial accountability requirements.

Remuneration or reimbursement claim for consumer involvement activities

| Consumer Details | |
|---|------------|
| Name | |
| Address | |
| Email Address (for payment confirmation) | |
| Bank Account Details | Name |
| | BSB |
| | Account No |

| Type of Involvement | |
|--------------------------|--|
| Name of Research Project | |
| Name of Committee/Group | |

| Fees/Expenses | | | |
|---------------|------|-------------|------------------|
| Description | Date | Amount (\$) | Receipt provided |
| | | | |
| | | | |
| Total (\$) | | | |

Taxation Considerations

Signature _____ Date _____

Please return to: _____

| | |
|------------------------------------|---|
| <p>Additional Resources</p> | <p>ACTA https://involvementtoolkit.clinicaltrialsalliance.org.au/media/sbbhec00/toolkit-cost-calculator.xlsx</p> <p>Involve https://www.invo.org.uk/posttypepublication/budgeting-for-involvement/ https://www.invo.org.uk/resource-centre/involvement-cost-calculator/</p> |
|------------------------------------|---|



It's everyone's responsibility

The importance of good planning cannot be overstated. It will enable a smooth management of the involvement. The chart below summarises how each party contributes to managing it.

Managing the involvement – a shared responsibility

| Organisation | Funder | Researcher | Consumer |
|--|--------|--|---|
| Build and nurture the relationship, the single most important factor for successful Consumer Involvement | | Deliver against the Involvement Agreement and refer to it as you go | Deliver against the Involvement Agreement and refer to it as you go |
| Deliver against the Involvement Agreement and refer to it as you go | | Ensure one main contact person is known to the consumer and other stakeholders | Appreciate the value that you add |
| Adopt a proactive approach and avoid constantly putting out fires | | Maintain lines of information flow between all relevant people | Adopt a proactive approach to anticipated and unexpected challenges |
| Incorporate the involvement in usual day-to-day operations where possible to minimise additional effort | | Schedule times to discuss progress of the involvement against agreed expectations, roles, responsibilities | Establish and maintain regular communication with the named contact person or research mentor |
| Plan for unexpected issues and challenges | | Adopt a proactive approach to anticipated and unexpected challenges | Confirm lines of information flow between all relevant people |
| Ensure one main contact person is known to consumers and all other key stakeholders | | Communicate any changes to the research project that affect the Involvement Agreement | Participate in scheduled discussions about the progress of the involvement against the agreed expectations, roles, responsibilities |
| Establish clear lines of information flow and make them known | | Recommend and negotiate changes to the Involvement Agreement as necessary | Communicate any changes to circumstances that affect the Involvement Agreement |
| Schedule times to discuss progress of the involvement against agreed expectations, roles, responsibilities | | Promote opportunities for ongoing input from consumers | Negotiate and recommend changes to the Involvement Agreement as necessary |
| Recommend and negotiate changes to the Involvement Agreement as necessary | | Build on learnings and successes | Take opportunities to provide ongoing input |
| Use learnings from problems and challenges for continuous improvement | | Keep good records of reviews and discussions to inform reporting, evaluation and improvement | Invest in yourself and take all formal and informal learning opportunities provided – learn as much as you can |
| Provide opportunities for ongoing input from stakeholders | | | Keep good records of reviews and discussions to inform reporting, evaluation and improvement |
| Keep good records of reviews and discussions to inform reporting, evaluation and improvement | | | |





Avoiding the pitfalls

Managing the involvement does not need to be complex or arduous. Below are some common pitfalls to avoid.

Common pitfalls

| |
|--|
| Lack of adequate preparation – of processes, policies and people |
| Rushing the process |
| A culture that does not understand or support involvement |
| Lack of an Involvement Agreement |
| Poor communication with internal and external stakeholders – they hear things second or third-hand |
| Over-focus on the long-term and ignoring the now |
| Lots of fanfare followed by little or no action |
| Ineffective, invisible or absent leadership |
| Over-complicating the implementation process |
| Failure to include the right people in the involvement process |
| Failure to adequately resource the involvement process |
| Over-focus on processes and systems at the expense of people and culture |
| Not addressing cynicism or resistance |
| Assuming that all stakeholders will see things the same way |
| Straying from the Involvement Agreement without the agreement of the parties |
| Words and actions that don't match |
| Lots of communication at the start followed by lack of ongoing communication |
| Failing to be flexible and responsive to changing circumstances – always have a Plan B |

Phase 4 Resources

Evaluating the Involvement



Resource 27: Evaluating the Involvement



Pg 47

Resource 28: Reflecting on the Involvement



Pg 48



How did we perform?

This table provides a simple way of measuring the involvement experience of each party. This evaluation takes place at the end of the involvement/project. It is important that each party participates in the evaluation to provide a holistic and complete picture, which is important for continuous improvement.

Evaluating the involvement

| Involvement Agreement Item | Rating | | Action Required |
|--|--------|------------|-----------------|
| | Low | 0 – 5 High | |
| Was the Involvement Agreement clear, relevant and comprehensive? | | | |
| Was the purpose of the involvement achieved? | | | |
| Were the expectations met? | | | |
| Was the Consumer Involvement Policy clear, relevant and helpful? | | | |
| Were there sufficient resources to achieve optimal involvement? | | | |
| Were roles and responsibilities clear and well understood? | | | |
| Was the remuneration clear and were payment arrangements followed? | | | |
| Were any issues, concerns and conflicts addressed effectively? | | | |
| Were changes to the Involvement Agreement well managed? | | | |
| Were privacy and confidentiality arrangements clear and respected? | | | |
| Was the involvement experience positive? | | | |
| Did the involvement add value? | | | |

Additional Resources

Cancer Australia (CA)

A resource to inform decisions about how evaluation will be best assessed and why.
https://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m9-46_guide_evaluationconsumerinvolvement.pdf

Australian Clinical Trials Alliance (ACTA)

Evaluating involvement from the Consumer and Researcher perspectives.
<https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/evaluating/evaluating-involvement/>



Did the involvement make a difference?

This table provides a simple tool for reflecting on what has been achieved by the involvement. For maximum benefit, each party should complete it to provide a holistic picture.

Reflecting on the involvement

| Achievements | Describe | Learning What was learnt | Action What will we • stop doing • keep doing • start doing |
|--|----------|-----------------------------|---|
| Benefits achieved for the Organisation | | | |
| Benefits achieved for the Researcher | | | |
| Benefits achieved for the Consumer | | | |
| Benefits achieved for the Funder | | | |
| Benefits achieved for the Research | | | |
| Value of the involvement | | | |
| Legacy of the involvement | | | |
| How do you think the involvement has/ will improve health outcomes? | | | |
| Did the benefits achieved justify the cash and non-cash investment? | | | |
| Was it worth it? | | | |
| Does the commitment to Consumer Involvement remain? | | | |

**Additional
Resources**

Australian Clinical Trials Alliance (ACTA)
An alternative evaluation tool.
<https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/resources/>

Centre of Excellence on Partnership with Patients and the Public
A scorecard for evaluating Involvement.
<https://ceppp.ca/en/evaluation-toolkit/a-scorecard-for-evaluating-engagement/>

Phase 5 Resources

Concluding the Involvement



| | | |
|--|---------|-------|
| Resource 29: Concluding the Involvement – Planned | ● ● ● ● | Pg 50 |
| Resource 30: Concluding the Involvement – Unplanned | ● ● ● ● | Pg 51 |





Wrap-up and consolidate

Concluding the involvement is an important step. It wraps up the involvement experience and achievements and builds foundations for future involvement.

Concluding the involvement

| |
|---|
| Treat the ending as a normal business process and manage it accordingly |
| Manage the ending as a normal business process, keeping to any requirements of the Involvement Agreement |
| Take a professional and mutually respectful approach |
| Ensure appropriate acknowledgement and recognition of the consumer’s contribution |
| Put absolutely everything in writing including notes of any verbal communications |
| Protect any benefits that have been achieved through the involvement |
| Mitigate against damage to reputation |
| Honour any agreements in place regarding confidentiality and privacy |
| Consider any future involvement opportunities and how these will be communicated |
| Ensure the consumer participates in the evaluation |
| Provide an opportunity for the consumer to provide both open and confidential feedback |
| Ensure that there is appropriate closure for all parties involved; don’t just have the consumer just slip out unnoticed |
| Keep bridges intact and doors open – one does not know what the future holds |
| Provide a brief report to the relevant people in the organisation to keep them informed and engaged with Involvement |

**MOVE FORWARD WITH
CONFIDENCE**





Manage disruption, avoid derailment, protect the benefits

An unplanned ending to an involvement may be due to:

- A serious breach of the Involvement Agreement by one of the parties
- Changing circumstances requiring the involvement to be concluded
- Unresolvable differences between the parties

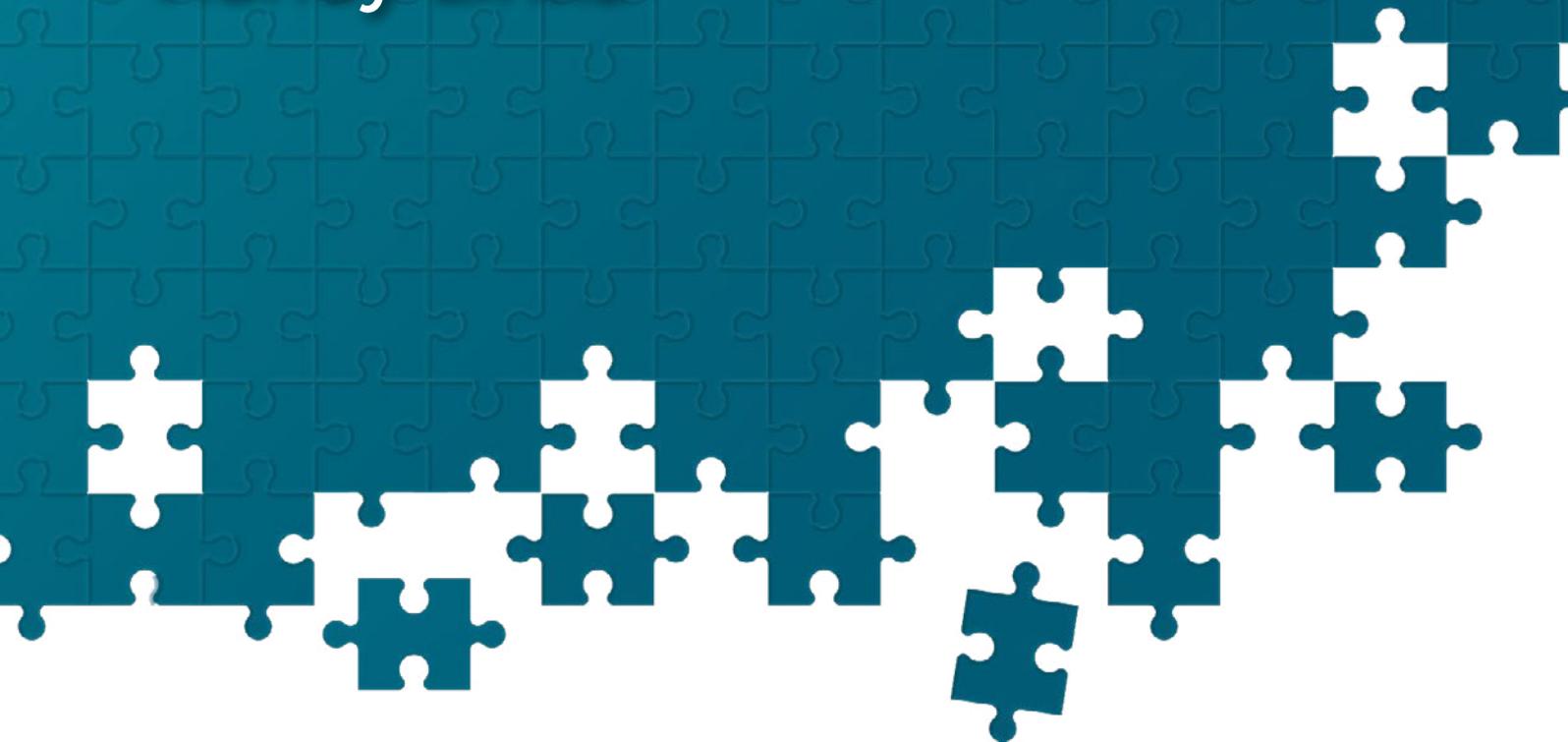
The parties have invested personal, professional and organisational resources in the involvement and should seek to retain as much of the benefit as possible while minimising the risk of reputational damage to all parties.

Concluding the involvement

| |
|--|
| Treat the ending as a normal business process and manage it accordingly |
| Take a professional and mutually respectful approach |
| Act cleanly and swiftly – don't drag it out |
| Be aware of not wasting considerable time and resources attempting to resuscitate an unrecoverable relationship – call it when it's time |
| Avoid emotion-driven actions or statements |
| Put absolutely everything in writing including notes of any verbal communications |
| Mitigate against damage to reputation |
| Protect any positive outcomes and achievements |
| Take responsibility for your contribution to the involvement breakdown |
| Adhere to the agreements in place around intellectual property and privacy and confidentiality |
| Honour any agreements in place regarding confidentiality and privacy |
| Protect any benefits that have been achieved through the involvement |
| Be aware of any policies, regulations, standards and laws that may apply and ensure compliance with them |
| Keep bridges intact and doors open – one does not know what the future holds |
| Meet with key stakeholders, especially the other staff, team members and volunteers, to provide information and reassurance |
| If there is potential risk to reputation, advise all relevant external parties (funders, regulators, authorities) in writing |

**MOVE FORWARD WITH
CONFIDENCE**

Library: Handy Links



| | | |
|-------------------|------------------------------|-------|
| Library 1: | Contemporary Overview of CCI | Pg 53 |
| Library 2: | Major CCI Statements | Pg 54 |
| Library 3: | Leading CCI Organisations | Pg 55 |





The development of this Handbook is preceded by AHRA's 'Consumer and Community Involvement in Health and Medical Research: An Australia-wide Audit' in 2018, which included an extensive review of CCI literature.

That report, and a selection of other publications considered both contemporary and relevant to the purpose of this Handbook, are listed here.

This is a dynamic environment and users are encouraged to add to, and update this list with relevant material as it is published.

- **AHRA 'Consumer and Community Involvement in Health and Medical Research: An Australia-wide Audit' in 2018**
https://www.wahtn.org/wp-content/uploads/2019/03/AHRA-CCI_Final-Report_Full_Dec2018.pdf
- **Cancer Australia: National Framework for Consumer Involvement in Cancer Control**
https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf
- **South Australian Health and Medical Research Institute (SAHMRI) Framework**
https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf
- **Miller et al (2017), Integrating consumer engagement in health and medical research – an Australian framework**
<https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-017-0171-2>
- **INVOLVE (2014): Taking stock of the evidence base for the impact of public involvement in research: An invoNET roundtable discussion, Eastleigh: INVOLVE**
https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf
- **SPOR Strategy for Patient-Oriented Research – Patient Engagement Framework**
<https://cihr-irsc.gc.ca/e/48413.html>
- **The RAPPORT Study (2015) Wilson et al: ReseArch with patient involvement: a RealisT evaluation – the RAPPORT study**
<https://pubmed.ncbi.nlm.nih.gov/26378332/>
- **Shippee et al (2013), Framework for Patient Involvement in Research**
<https://pubmed.ncbi.nlm.nih.gov/23731468/>
- **Hamilton et al (2017), An empirically based conceptual framework for fostering meaningful patient engagement in research**
<https://pubmed.ncbi.nlm.nih.gov/28984405/>



There is a growing commitment to Consumer Involvement by Australian Federal, State and Territory governments and their agencies, leading health and medical research bodies and health consumer organisations.

- **AHRA CCI Statement**
<https://ahra.org.au/wp-content/uploads/2021/02/AHRA-CHF-Position-Statement-Final.pdf>
- **NHMRC The Statement on Consumer and Community Involvement in Health and Medical Research (2016)**
<https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>
- **NHMRC CCI Resources Toolkit**
<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>
- **NHMRC CCI Guidelines for Guidelines**
https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement#toc__492
- **South Australian Health and Medical Research Institute (SAHMRI) Value Statement**
<https://healthtranslationsa.org.au/wp-content/uploads/2020/11/The-value-of-CCI-report-v2.pdf>
- **Health Consumers' Council**
<https://www.hconc.org.au/what-we-do/policy-development/position-statements/#research>

“The key ingredients for implementing Consumer and Community Involvement are senior level champions, funding for dedicated roles, resources and training, and staying on message that ‘consumers add value to research’.”

Anne McKenzie AM
Manager, Community Engagement,
Telethon Kids Institute



As awareness of CCI grows, government, corporate and community organisations locally, nationally and internationally are advancing CCI. Below is a selection of organisations that continue to champion CCI and are, for the purposes of this Handbook, considered among the world leaders. This selection is a valuable resource for those seeking to increase their understanding of CCI.

- **Australian Clinical Trials Alliance (ACTA)**
<https://clinicaltrialsalliance.org.au/resource/consumer-involvement-toolkit/>
- **Cancer Australia**
<https://www.canceraustralia.gov.au/about-us/who-we-work/consumer-engagement>
- **Consumer and Community Involvement Program (CCI Program)**
<https://cciprogram.org/>
- **Meeting for Minds**
<https://meetingforminds.com/>
- **National Health and Medical Research Council (NHMRC)**
<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>
- **South Australian Health and Medical Research Institute (SAHMRI)**
<https://www.sahmri.org/consumer-community-engagement/>
- **Telethon Kids Institute (Western Australia)**
<https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/the-green-book-mar08.pdf>
https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf
- **Victorian Comprehensive Cancer Centre**
<https://www.viccompcancerctr.org/about-vccc/consumer-engagement/>
- **INVOLVE – United Kingdom**
<https://www.involve.org.uk/>
- **Patient-Centred Outcomes Research Institute (PCORI) – United States**
<https://www.pcori.org/>
- **Strategy for Patient-Oriented Research (SPOR) Canada**
<https://cihr-irsc.gc.ca/e/48413.html>

Full List of Resources

| | | ORGANISATIONS | RESEARCHERS | CONSUMERS | FUNDERS | |
|---------------------|--|---------------|-------------|-----------|---------|-------|
| Resource 1: | Overview of CCI | ● | ● | ● | ● | Pg 17 |
| Resource 2: | Types of Consumer Involvement | ● | ● | ● | ● | Pg 18 |
| Resource 3: | Organisations Leading Consumer Involvement | ● | | ● | | Pg 20 |
| Resource 4: | CCI Policy for Organisations | ● | | | | Pg 21 |
| Resource 5: | Policy Checklist | ● | ● | | | Pg 22 |
| Resource 6: | Communication to Stakeholders | ● | | | ● | Pg 23 |
| Resource 7: | Researchers: Why Involve Consumers in Research | | ● | | | Pg 24 |
| Resource 8: | Consumers: Why Get Involved in Research | | | ● | | Pg 25 |
| Resource 9: | Involving Consumers in Funder Activities | | | | ● | Pg 26 |
| Resource 10: | CCI Policy for Funders | | | | ● | Pg 27 |
| Resource 11: | Creating a CCI Culture | ● | ● | | ● | Pg 29 |
| Resource 12: | Involvement Costs and Considerations | ● | ● | | ● | Pg 30 |
| Resource 13: | CCI Coordinator Role | ● | | | ● | Pg 31 |
| Resource 14: | Recruiting Consumers | ● | ● | | ● | Pg 32 |
| Resource 15: | Interviewing Potential Consumers | ● | ● | | ● | Pg 33 |
| Resource 16: | Setting up a Consumer Register | ● | ● | | ● | Pg 34 |
| Resource 17: | Request for Expression of Interest | ● | ● | | ● | Pg 35 |
| Resource 18: | The Role of the Mentor | ● | ● | | ● | Pg 36 |
| Resource 19: | Consumer: Approaching an Organisation | | | ● | | Pg 37 |
| Resource 20: | Consumer: Assessing the Opportunity | | | ● | | Pg 38 |
| Resource 21: | Committee Terms of Reference | ● | ● | ● | ● | Pg 40 |
| Resource 22: | The Involvement Agreement | ● | ● | ● | ● | Pg 41 |
| Resource 23: | Induction and Orientation | ● | ● | | ● | Pg 42 |
| Resource 24: | Remuneration Claim Form | ● | ● | ● | ● | Pg 43 |
| Resource 25: | Managing for Success | ● | ● | ● | ● | Pg 44 |
| Resource 26: | Managing for Success | ● | ● | ● | ● | Pg 45 |
| Resource 27: | Evaluating the Involvement | ● | ● | ● | ● | Pg 47 |
| Resource 28: | Reflecting on the Involvement | ● | ● | ● | ● | Pg 48 |
| Resource 29: | Concluding the Involvement – Planned | ● | ● | ● | ● | Pg 50 |
| Resource 30: | Concluding the Involvement – Unplanned | ● | ● | ● | ● | Pg 51 |

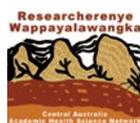


We hope this Handbook becomes a valuable tool as you work to embed CCI in your research.

The WAHTN is proud to have led this project on behalf of AHRA.



We are indebted to our AHRA colleagues for their important contribution to this Handbook.



We sincerely thank the organisations, researchers and consumers who have patiently and enthusiastically road-tested many versions of this Handbook and provided valuable input and advice. You made this Handbook possible.



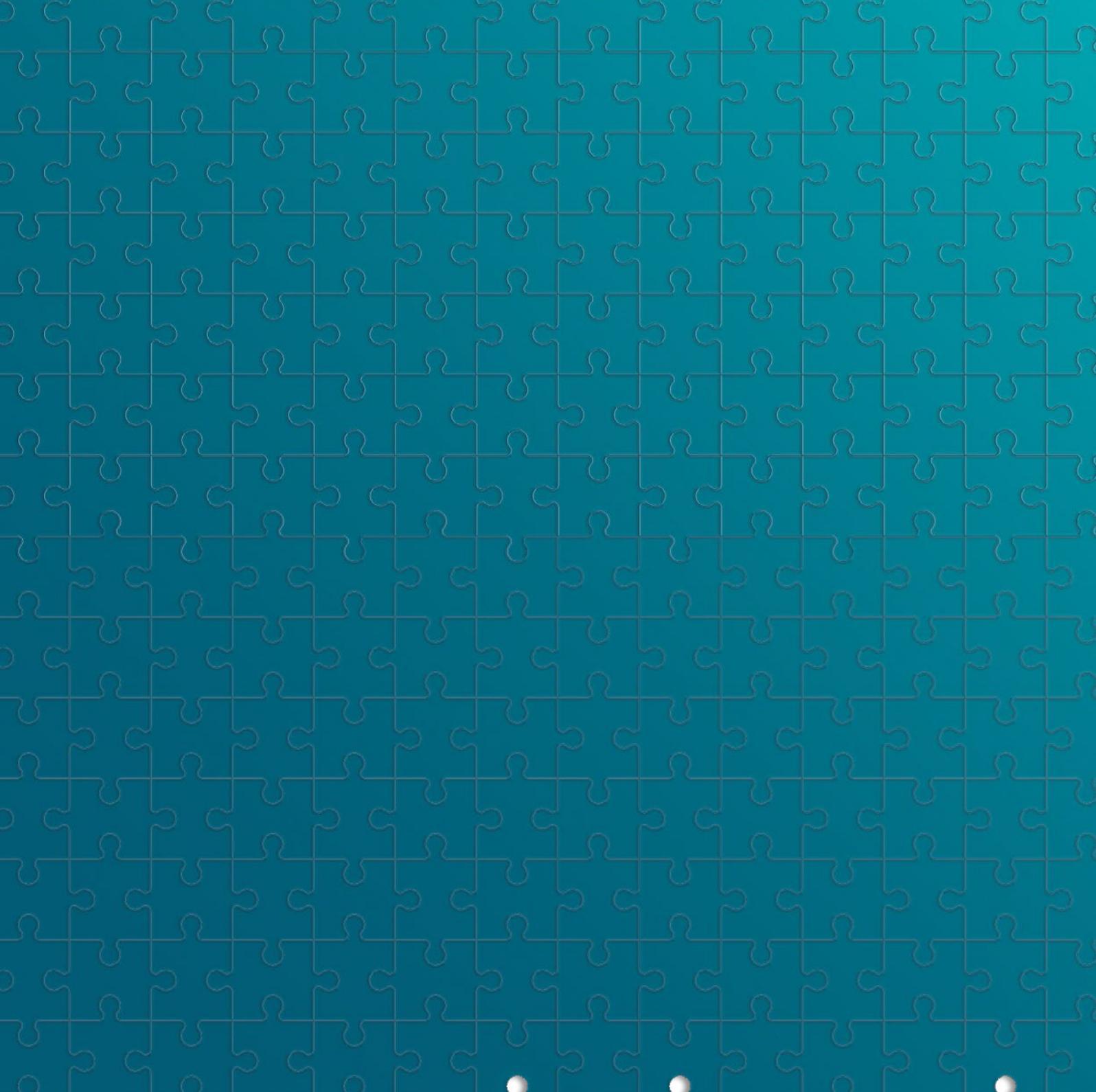
Consumers Health Forum of Australia is a valued partner in this project.

We acknowledge the work of the Project Team members who have created this remarkable resource.

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