

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 Kiossoglou
Consumer Representative
WEHI and Melbourne Academic
Centre of Health

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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.

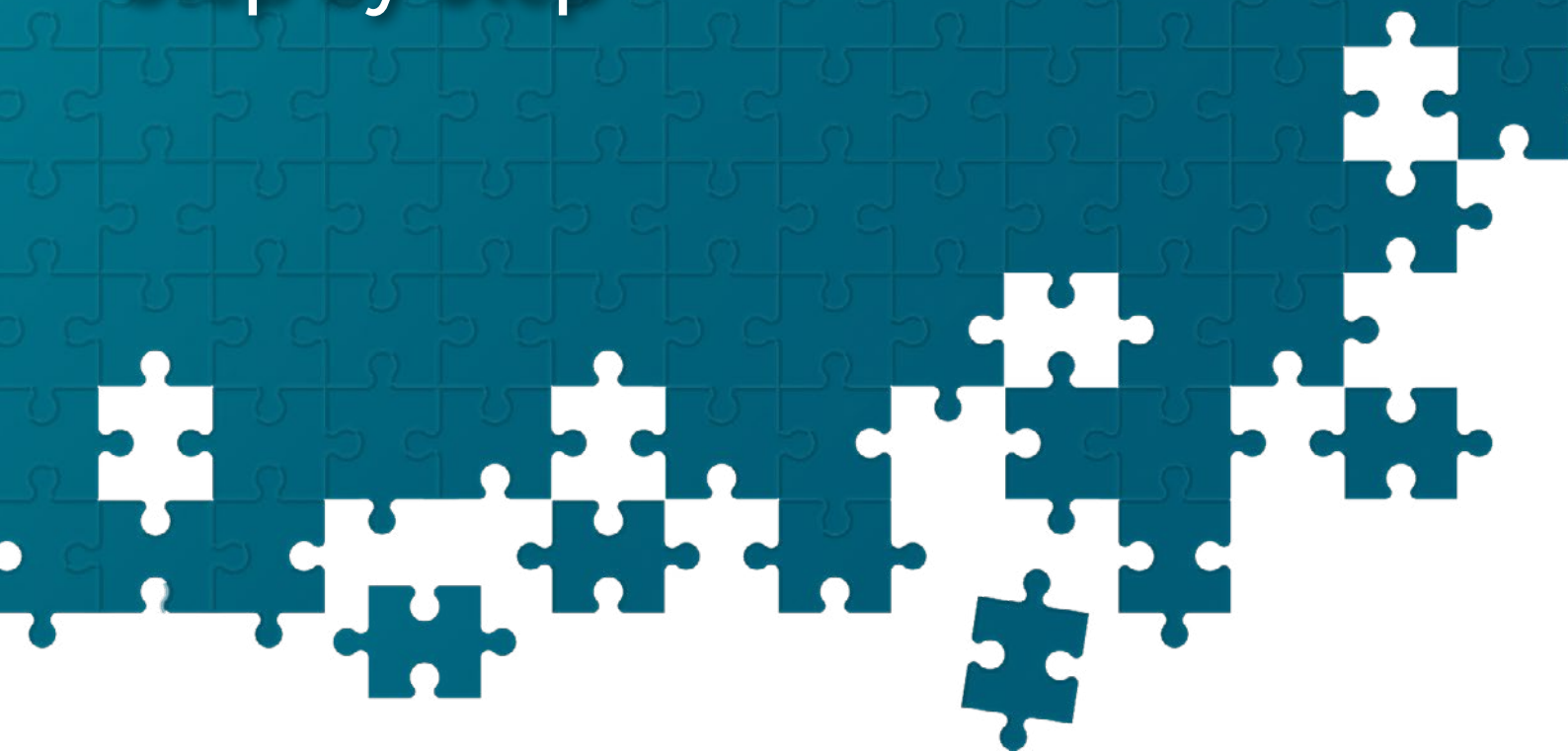
“Health research is about asking questions to uncover new information and improve outcomes. In that process, what consumers want and what researchers want is the same – ensuring that we ask the most important questions, and then bring the best available answers to the bedside. When this occurs as a partnership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





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
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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: 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>
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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: 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 and payment process 	<p>Resource 23: Induction and Orientation</p> <p>Resource 24: Remuneration Claim Form</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: 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 the consumer • involve the grant recipient as much as you can • this will provide diverse perspectives and build a complete picture 	<p>Resource 27: Evaluating the Involvement</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: Reflecting on the Involvement</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: Concluding the Involvement – Planned</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: Concluding the Involvement – Unplanned</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

Resource 1: Overview of CCI



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

Resource 2: Types of Involvement



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

Within Government, Health Sector Bodies	<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
Within the Research Organisation	<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
Delivering the Research Project	<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 Gumat – 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/>



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



Communication

Dear

I am very pleased to advise that *(name of organisation)* has strengthened its commitment to Consumer Involvement in research projects and will be implementing a new policy to guide our activities in this area.

As with many organisations and governments worldwide, we believe that the involvement of consumers adds significant value to the relevance, quality and accountability of health and medical research and, ultimately, to improved health outcomes for our community.

Our policy, attached, reflects the importance this organisation places on identifying and creating a wide range of opportunities for Consumer Involvement. It has been co-developed by research administrators, researchers and consumers to ensure its relevance and is incorporated in our Strategic Plan.

Your support is important, so we want you to feel well informed about this process and our learnings from it. If you have any queries please contact *(name of contact person)* at *(email)* who will be happy to help.

Resource 9: Involving Consumers in Funder Activities



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:

- 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

Resource 11: Creating a CCI Culture



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>

Resource 15: Interviewing Potential 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.

Resource 16: Setting up a Consumer Register



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://bmcmmedresmethodol.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/>

Resource 17: Request for Expression of Interest



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

- | | |
|--|--|
| <ol style="list-style-type: none">1. Closing Date for EOI2. Type of Involvement
(refer to Resource 2: Types of Involvement)<ol style="list-style-type: none">a. specify how the consumer will be involved:<ul style="list-style-type: none">• 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 sought3. Period of Involvement<ul style="list-style-type: none">• commencement date• end date4. Purpose<ul style="list-style-type: none">• outline of key roles and responsibilities• outline of workload5. Expectations<ul style="list-style-type: none">• expected benefits for the organisation, the research, the consumer• deliverables | <ol style="list-style-type: none">6. Key Qualities/Attributes Sought<ul style="list-style-type: none">• knowledge about• expertise relevant to• experience in the area(s) of7. Remuneration Information<ul style="list-style-type: none">• cash• non-cash8. Information Required
(consider limiting to two pages)<ul style="list-style-type: none">• name of the consumer• relevant knowledge and/or expertise/ experience any previous consumer involvement• availability during the involvement period• any specific requirements9. Submission of EOI
Clear address for postal, email or other form of submission10. 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/>

Resource 18: The Role of the Mentor



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

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			

Resource 24: Remuneration Claim Form



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: _____

Additional Resources

ACTA

<https://involvementtoolkit.clinicaltrialsalliance.org.au/media/sbbhec00/toolkit-cost-calculator.xlsx>

Involve

<https://www.invo.org.uk/posttypepublication/budgeting-for-involvement/>
<https://www.invo.org.uk/resource-centre/involvement-cost-calculator/>



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/>

Resource 28: Reflecting on the 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.

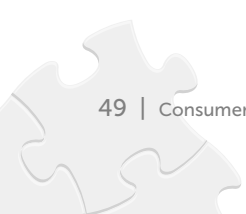
<https://ceppp.ca/en/evaluation-toolkit/a-scorecard-for-evaluating-engagement/>

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

A decorative graphic consisting of a grid of puzzle pieces. The pieces are in two colors: dark teal and white. The pieces are arranged in a pattern that is mostly solid teal, with a jagged, irregular white shape on the right side, resembling a missing section of a puzzle.

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
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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.



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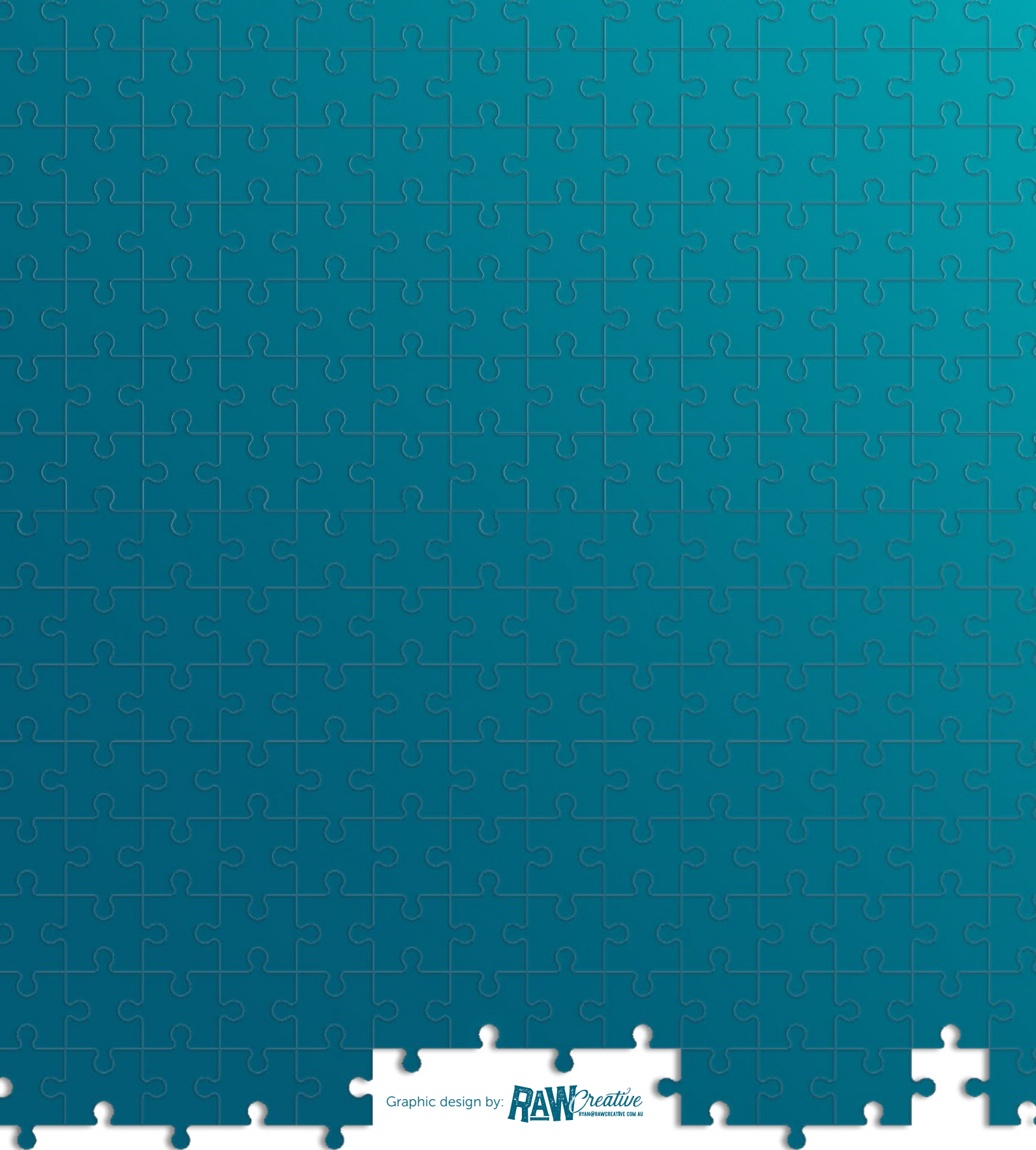
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