

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
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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>
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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
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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
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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>
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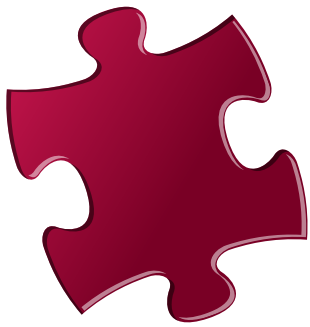
PHASE 4: Evaluating the Involvement

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
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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>

