



## Checklist for engaging consumers and community members

**New to engaging consumers on your research projects?** This checklist may provide inspiration to set your collaboration up for success. The [Involving Consumers in Health and Medical Research Handbook](#) provides more information and resources, from page 10 onwards – highly recommended reading! See next page for details on the recommended steps from this Handbook.

- **Consider consumer roles and responsibilities:** What will be the role of the consumers on your project? Consider how consumers may contribute to your project and detail this in a brief position description. (Pages 19-20 from the [Handbook](#)). Ensure your recruitment materials can be understood by non-scientific and non-medical community members – clear, simple language, free from jargon if possible.
- **Recruiting consumers:** Where are you planning on recruiting your consumers from? Consider looking at your partners/collaborators/stakeholders – could consumers be recruited through these connections:
  - Clinical partner patients (or your patients)
  - Not-for-profit organisations
  - Closed Facebook groups
  - Consumer Registries – [HTSA's registry](#), LHN registries, or others
- **Onboarding consumers:** Consider clarifying the involvement arrangement with suitable documentation; this may be Terms of Reference for an Advisory Group ([template](#)) or letter of agreement which could include:
  - Expected periodic meetings
  - Anticipated involvement activities
  - Key liaison point (Pages 41-43 from the [Handbook](#))

We recommend you co-sign a Consumer and Community Involvement Agreement to protect IP, consumer privacy and set the expectations of engagement ([template](#)).

- **Resourcing:** It is best practice to reimburse consumers for their contribution. HTSA recommends following the [SA Health Policy](#) of \$35/hour plus out of pocket expenses (December 2023).
- **Six-monthly review:** Consider building in a six-monthly review to ensure consumers are willing to remain on the project and their needs are being met. Additionally, reflect on whether the correct consumers are on the project, or their experience is relevant to the stage of the project. This could include a formal evaluation of the involvement (Page 48-49 of the [Handbook](#)).



Snippet from the [Involving Consumers in Health and Medical Research Handbook](#) – Steps for Researchers.

## Steps for Researchers



### 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	<b>Resource 1:</b> <i>Overview of CCI</i>
Step 2	Clarify why consumers are being involved in the research	<b>Resource 7:</b> <i>Researchers: Why Involve Consumers in Research</i>
Step 3	Include Consumer Involvement in all relevant research policies	<b>Resource 5:</b> <i>Policy Checklist</i>
Step 4	Determine how consumers are to be involved in the research, their role and responsibilities	<b>Resource 2:</b> <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"> <li>• everyone is informed</li> <li>• there is clarity about the roles and responsibilities of all those involved in the research including the consumer</li> </ul>	<b>Resource 11:</b> <i>Creating a CCI Culture</i>
Step 6	Consider the cash and non-cash resources that will be required	<b>Resource 12:</b> <i>Involvement Cost and Considerations</i>
Step 7	Recruit the right consumer for the right task at the right time	<b>Resource 14:</b> <i>Recruiting Consumers</i> <b>Resource 15:</b> <i>Interviewing Potential Consumers</i> <b>Resource 16:</b> <i>Setting Up a Consumer Register</i> <b>Resource 17:</b> <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	<b>Resource 18:</b> <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	<b>Resource 21:</b> Committee Terms of Reference <b>Resource 22:</b> The Involvement Agreement
Step 10	Check that all important preparations have been completed to avoid problems during the involvement Clarify remuneration process	<b>Resource 23:</b> Induction and Orientation <b>Resource 24:</b> Remuneration Claim Form
Step 11	Use the Involvement Agreement to guide periodic catch-ups and amend the Agreement as necessary	<b>Resource 25:</b> Managing for Success
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	<b>Resource 26:</b> Managing for Success

### PHASE 4: Evaluating the Involvement

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

### PHASE 5: Concluding the Involvement

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