# Consumer and Community Involvement Initiative

## Measuring the Impact of Consumer and Community Involvement in Health Research: **An assessment of available tools**

October 2021

**Project Leads**

**Other partners**

# Contents

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# Background

The Australian Health Research Alliance (AHRA) comprises seven Advanced Health Research and Translation Centres (AHRTCs) and three Centres for Innovation in Regional Health (CIRHs), accredited by Australia's National Health and Medical Research Council (NHMRC) as leaders in translating research for better health outcomes.

In 2018, AHRA members committed to working together to strengthen consumer and community involvement (CCI) in health and medical research across Australia. Phase 1 of this work, completed in 2018, included a national survey to identify existing CCI activities in health research, and an environmental scan of published literature and relevant websites about involving consumers in health research. A report is available here.

Four recommended priorities were identified for AHRA which have formed the basis of work in Phase 2, commencing in 2019:

1. develop minimum standards for good practice in consumer and community involvement in health research (Project 1 CCI Handbook)
2. facilitate sharing of existing resources and expertise to support consumer and community involvement in health research (Project 2 Knowledge Hub)
3. identify how to effectively measure the impact of CCI in health research (Project 3 Measuring Impact)
4. initiate formal alliances with leading agencies promoting CCI in health research (Project 4 International Alliances).

**This report**

This report outlines the work conducted to date for Project 3 to identify how to effectively measure the impact of CCI in health research. Specifically, we investigated whether any frameworks or models already existed for measuring CCI impact that could be used by AHRA members.

# Introduction to measuring impact

The nature of CCI in health research, and the impact of this involvement, is dependent on many factors including research context, the mechanisms employed to support CCI, and the background and skills that individual researchers and consumers bring to the process. Reflecting this context dependency, studies of the impact of CCI on health research have been mostly case studies with limited generalisability (Staley, 2015). The studies have demonstrated the value of consumer involvement in specific contexts and circumstances. Other studies have found a relationship between consumer involvement in research and participant recruitment and retention rates (e.g. Ennis & Wykes, 2013; Johns, Whibley & Crossfield, 2015). This has, however, been at a crude level of high versus low versus no consumer involvement. Such findings, whilst supporting the value of CCI, offer limited guidance to researchers, research organisations and funding bodies on how to optimise and evaluate CCI activities.

Three AHRA translation centres (Health Translation SA, NSW Regional Health Partners, and Sydney Health Partners) agreed to investigate whether any frameworks or models already existed for measuring CCI impact that would be suitable for use by AHRA members. Due to the COVID-19 pandemic the project plan was modified in mid-2020. In the latter stages of the project, Monash Partners and Brisbane Diamantina Health Partners joined the project team.

The project comprised three stages:

1. Rapid review to identify and select existing tools for measuring CCI impact (models, frameworks, guides)
2. Initial appraisal and ranking of selected tools by project team
3. Review of highest ranked tools by consumers and researchers

# Rapid review of existing tools

A literature search was undertaken to identify existing tools that could be used to evaluate the impact of CCI on health research. The review excluded tools and measures that focused only on assessing the amount and kind of CCI; opinions of researchers and consumers about CCI in research; or process evaluations (e.g. experience of participating in an advisory group, training program, etc.).

The terminology around consumer involvement in research varies between countries. While in Australia the term "Consumer and Community Involvement" or CCI is used, in other countries "Patient and Public Involvement" or PPI, and "Patient and Public Engagement" or PPE are used.

A rapid review methodology was used to search published literature, using the following terms:

- "consumer" OR "community" OR "patient" OR "public" AND "involvement"
- "research" AND "impact" AND "evaluat*"
- "framework" OR "model" OR "tool" OR "survey".

The search using Medline was limited to peer-reviewed published papers in English, published between 2010-2020. Of the 158 identified papers:

- 58 addressed consumer and community involvement in health services and patient care (not health research)
- 10 advocated for consumer and community involvement in health research
- 23 evaluated the processes associated with consumer and community involvement in health research
- 62 were not relevant to consumer and community involvement in health research
- 5 articles were retained for further review

The websites of international peak organisations promoting consumer and community involvement in health research were also accessed (e.g. the Patient-Centered Outcomes Research Institute (PCORI) in the US; INVOLVE in the UK), and various ad hoc references were provided to this review by other AHRA translation centres, including a recent systematic review of evaluation tools for CCI in health research and health services (Boivin et al., 2018). The Centre of Excellence on Partnerships with Patients and the Public (CEPPP), which provides an online resource describing and rating CCI evaluation tools, was also accessed. The CEPPP toolkit assesses evaluation tools on four domains (Scientific Rigour, Patient and Public Perspective, Comprehensiveness and Usability).

From these various search strategies, **eight evaluation tools** potentially relevant to the project were identified (see Appendix 1 for summary). The nature of the tools varied. Some are guides or frameworks for engaging in a reflective planning and review process for the specific project and research team. The benefit of these less prescriptive tools is that they can be adapted to the circumstances of each research project and can also be used as a capacity building exercise for the participants. They do, however, rely on research team members to engage in planning and designing the evaluation process. Other tools are questionnaires or surveys that are "ready to use" but are also less likely to trigger a capacity building or developmental process for participants.

# Initial ranking of selected tools

Six members of the project team rated each of the eight selected tools (0=low, 1=medium, 2=high). Overall combined ratings therefore could range from 0-12. Ratings were based on the following criteria:

- Captures both researcher and consumer perspectives
- Includes diverse consumer roles and input mechanisms
- Includes different stages in the research cycle
- Suited to different research designs/contexts
- Length/time involved to complete tool
- Need for adaptions for Australian context

Based on the aggregated responses from project team members (see Appendix 2), the four highest rated tools were:

- Popay & Collins, Public Involvement Impact Assessment Framework (PiiAF)
- Blackburn et al., Quality and Impact of PPI
- McMaster University, Public and Patient Engagement Evaluation Tool (PPEET)
- Australian Clinical Trials Alliance (ACTA), Evaluating Impact

# Feedback on highest ranked tools

AHRA translation centres were invited to nominate researchers and consumers who had experience partnering in research to participate in an online workshop to discuss the four highest rated tools. The purpose of the workshop was to gather feedback on the usefulness of tools in different circumstances, and any suggestions for refining the tools for the Australian context.

In preparation for the workshop, participants were provided with a summary and copy of each evaluation tool. Participants were asked to complete a short survey prior to the workshop, rating the usefulness of each tool on a 5-point scale from not very useful to extremely useful. The survey results, based on 17 responses, indicated similar levels of support by consumers and researchers for three of the tools but a significant discrepancy for the PiiAF tool (see Table 1).

The workshop was held on 21 April 2021 and attended by 11 researchers, 11 consumers and seven project team members. Discussion at the workshop was guided by the following questions:

- When would you consider using the tool? Is there a type of research the tool would work best for?
- What would work well? What would not work well?
- What would you need to change to make the tool relevant to your context?

Table 1: Pre-workshop ratings of the usefulness of the tools (n=17).

| Tool | Consumers average rating (n=8) | Researchers average rating (n=9) |
|---|---|---|
| Australian Clinical Trials Alliance (ACTA), Evaluating Impact | 3.0 | 3.0 |
| Blackburn et al., Quality and Impact of PPI | 3.1 | 3.4 |
| McMaster University, Public and Patient Engagement Evaluation Tool (PPEET) | 3.5 | 3.6 |
| Popay & Collins, Public Involvement Impact Assessment Framework (PiiAF) | 2.3 | 3.4 |

## Australian Clinical Trials Alliance (ACTA) – Evaluating Impact

The Australian Clinical Trials Alliance (ACTA) is the national peak body supporting clinical trial research in the health system. ACTA has developed two questionnaires (evaluation tools) for use in evaluating and improving the quality and impact of consumer involvement, one focused on the involvement process (out of scope for this project) and the other on the outcomes or impacts of consumer involvement on research (see here). The latter tool comprises seven items and seeks qualitative responses to each. Individual members of a research team or the whole team can complete the tool.

## Summary of workshop feedback

**When would you consider using the tool? Is there a type of research the tool would work best for?**

- Designed for single clinical trials; could possibly be used in some other types of research with further development
- Information is collected after the research is finished
- Good tool for self-reflection
- Helpful when consumers are co-investigators in the research team
- Responses to questions could shape a 'case study' report
- Could be used for quality improvement in future projects

**What would work well? What would not work well?**

- Brevity and simplicity of tool is appealing, increased likelihood of uptake
- Captures experiences and opinions about several areas of impact in research
- Open-ended qualitative items give the tool flexibility but less helpful for measuring and comparing CCI across projects
- Lacks any items about budget/remuneration/cost of CCI (though noted this is a process measure)
- Missing item(s) to capture any negative impacts of CCI (important to learn from these)
- If completed by multiple members of the research team, analysis of qualitative data may be complex
- Not clear whether tool measures impact on quality of research, or the outcomes of the research

**What would you need to change to make the tool relevant to your context?**

- Adding quantitative items (e.g. Likert scales) would enhance the tool
- Tool has been adapted from other sources and current form needs to be tested
- Would increase usefulness if the measures of impact could inform future actions/improvements
- Address some of the identified gaps (e.g. lessons learnt, quantitative items)

## Blackburn et al. - Quality and Impact of PPI

Blackburn and colleagues at the University of Birmingham developed two questionnaires to record the nature and impact of consumer and community involvement in primary health care research. The two complementary questionnaires capture the perspectives of public contributors (consumers) and principal researchers (see here). The questionnaires are detailed and comprehensive, comprise mostly fixed-choice items, and each takes approximately 40 minutes to complete.

## Summary of workshop feedback

**When would you consider using the tool? Is there a type of research the tool would work best for?**

- Very comprehensive tool that could be used for a variety of contexts and types of research
- Captures different types of CCI roles and provides thorough assessment of impacts
- Can be completed progressively as the research project proceeds for longer term projects

**What would work well? What would not work well?**

- Good mixture of quantitative and qualitative items
- Separately provides perspectives of researchers and consumers
- Captures specific contributions from consumers that can then be linked to impacts
- Includes consideration of personal benefits of CCI for consumers and researchers
- Includes financial information
- Structure of the tool allows comparison of impact across projects
- Structure of the tool identifies different CCI roles and impacts and could be used as an educational/reflexive tool as the research progresses
- Although long, it is easy to use and much of the information easy to analyse
- Length and comprehensiveness could be daunting or too demanding for some projects

**What would you need to change to make the tool relevant to your context?**

- Although a consumer version is available, the questions are largely “researcher-facing”; need more “consumer-facing” questions
- Could perhaps reduce the number of questions based on relevance to specific projects (e.g. all financial questions may not apply to all projects)
- Could include more open-ended questions
- Change the questions that focus on “training” to “learning and development”

## McMaster University - Public and Patient Engagement Evaluation Tool (PPEET)

The PPEET was developed by Canadian researchers for use in a wide range of consumer engagement activities in health care. It is not specific to research though has been used in research contexts. It comprises three complementary questionnaires (see here):

- Participant questionnaire: obtains participants' assessments of the key features of the engagement initiative. Two versions of this questionnaire are available (one to evaluate one-time engagements and one to evaluate on-going/long-term engagements).
- Project questionnaire: reviews and assesses planning of the engagement component of a project (Module A), assessing the engagement component (Module B), and assessing the impact of the engagement component (Module C).
- Organisation questionnaire: assesses how engagement, as an organisational activity and responsibility, is being conducted.

## Summary of workshop feedback

**When would you consider using the tool? Is there a type of research the tool would work best for?**

- Comprehensive tools that capture a range of involvement activities
- Well suited to evaluating CCI activities across a whole program or organisation rather than individual projects
- Would also be useful for evaluating consumer panels
- Different questionnaire forms provide some flexibility for assessing shorter- and longer-term engagement activities

**What would work well? What would not work well?**

- Comprehensive tool that includes quantitative and qualitative items
- Could be used to help raise awareness of CCI across an organisation
- Questionnaires seem more like an internal evaluation than an assessment of impact
- Caters for ongoing and one-off involvement activities
- Tool not specific enough for research and individual projects, and would need further development
- Not clear, who within an organisation, would answer the questions

**What would you need to change to make the tool relevant to your context?**

- The PPEET recommends against making changes to questions, but some of the questions and language not well suited to research
- Questions about impact are broad and qualitative; unclear whether they will yield helpful and robust information
- Not clear how well both a consumer and researcher perspective could be captured with current questionnaires

## Popay & Collins - Public Involvement Impact Assessment Framework (PiiAF)

The PiiAF provides a framework and related resources for research teams to design and build their own CCI impact assessment plan specific to the intended types of consumer involvement, research characteristics and associated impacts. The PiiAF guides a research team (including consumer members) through a process of assessing and improving the quality and impact of consumer involvement both on the people involved (i.e. researchers and consumers) and on the research. The design phase requires several interactive sessions among team members and therefore involves leadership and time commitment (see here).

Due to the discrepant rankings of the PiiAF in the pre-workshop survey (see page 7), there was less consideration of this tool during the workshop.

## Summary of workshop feedback

**When would you consider using the tool? Is there a type of research the tool would work best for?**

- Provides clear process to set up and evaluate CCI tailored to a project
- Allows users to design an assessment plan tailored to their research
- Best used prospectively at the beginning of the research process, although can be implemented after research commences

**What would work well? What would not work well?**

- Structure of framework provides helpful training and guidance on issues to consider when planning and evaluating consumer involvement in research
- Most mature and robust tool
- Since the tool generates assessment plans tailored to each research project, comparisons between projects is difficult
- Likely requires previous evaluation experience and significant time commitment
- May be too difficult for less experienced researchers without specific funding and resources

**What would you need to change to make the tool relevant to your context?**

- Development of templates for different types of research designs involving consumers may reduce some of the development time

# Discussion and recommendations

There is strong support for involving consumers in health research, and growing recognition that consumers and community members have an inherent right to be informed and included in decisions affecting their health, including decisions about health research (AHRA, 2018; 2020). There is little published evidence that demonstrates how consumer involvement impacts health research outcomes, and repeated calls to fill this gap. There is a shared view among consumers and researchers that building this evidence base is important but that gathering evidence that links consumer involvement and research impacts is not easy, in part because of the many different types of consumer involvement and research contexts.

In response to this evidence gap, in 2018 AHRA recommended further work be undertaken to identify how to effectively measure the impact of CCI on health research. As a first step, it was agreed there would be value in reviewing existing tools that purport to measure the impact of CCI, to determine whether they might be suitable for use by AHRA members, either in their current form or some modified version. It was further agreed that feedback would be gathered from researchers and consumers about the tools, and that some guidance be provided on the usefulness of the tools in different circumstances.

Four potentially suitable tools were identified:

- Australian Clinical Trials Alliance (ACTA), Evaluating Impact
- Blackburn et al. Quality and Impact of PPI
- McMaster University, Public and Patient Engagement Evaluation Tool (PPEET)
- Popay & Collins, Public Involvement Impact Assessment Framework (PiiAF)

As anticipated, no single tool accommodates all types of consumer involvement and is suitable for use in all types of health research. It is also recognised that the type of consumer involvement will likely influence the type of potential impacts that might follow. For example, if consumers play an active role in identifying a research question, associated impacts could include increased participation in a study (because patients find the purpose of the study relevant to them) and more rapid translation of the research results into patient care. On the other hand, if consumer involvement is focused on the design and content of patient information sheets and consent forms for a research project, then associated impacts might be high recruitment rates (since participants find the study information easy to understand).

From our investigations and discussions, the following are identified as important features of an evaluation tool:

**Quality and scope of CCI:** is the nature and quality of the CCI in the research assessed? Does the tool gauge to what extent it is authentic?

**Impact of CCI on research processes:** does the tool assess how the involvement of consumers and community members has affected aspects of the research process, for example ethical conduct, design, feasibility, scientific rigour, recruitment, data collection, time and cost, etc.?

**Impact of CCI on research outputs and outcomes:** does the tool explore potential links between CCI and short-term outcomes such as meeting study recruitment targets, disseminating results, and knowledge translation activities? What about longer-term outcomes such as changes in health services, people's health outcomes, longer-term economic benefits (health cost savings, quality of life, workforce productivity, etc.)?

**Evaluation perspective:** is the impact of CCI assessed from the perspective of consumers, researchers, and/or the organisation?

**Goodness of fit:** for what types of research is the tool best suited?

**Type of evaluation data:** does the tool generate a case study built around qualitative data or collect quantitative data (e.g. ratings and rankings) that might allow comparisons between projects or over time?

**Ease of use:** how easy is the tool to use? Does it take much skill or time?

Mapping of the four existing tools identified in this project against the above features demonstrates the differences between the tools and the strengths of each (see Table 2). In terms of possible changes to the tools, at a simple level, there are some differences in language conventions in Australia, the UK and North America when referring to CCI in health research, so small wording changes could aid use in the Australian context. While some tools discourage omission of items or other modifications, all items are not necessarily relevant for all types of consumer involvement and all types of health research. Making these kinds of changes would likely require further testing and validation. There was also little evidence that these tools have been used extensively in Australia, pointing to opportunities for testing their usefulness in local settings.

The current project has made a helpful contribution to the goal of effectively measuring the impact of CCI in health research. We have identified existing tools that may be useful in measuring the impact of CCI on health research and provided some guidance on their use. However, more work needs to be done.

We make the following **recommendations** to guide further efforts:

**That** this report, the narrative review of the value of CCI in health research and the CCI Position Statement (AHRA, 2020; AHRA/CHF, 2020) be made available to all AHRA members.

**That** AHRA members promote awareness and use of the evaluation tools to researchers actively partnering with consumers in health research to build the evidence base for the impact of CCI.

**That** AHRA members explore academic interest in the development and validation of a new tool.

**That** AHRA members continue to collect and promote stories and case studies of the impact of consumer involvement on health research to grow the evidence base.

**That** AHRA encourages further scholarly work to measure the longer-term outcomes of CCI in health research, as this area is not well addressed by most existing tools.

Table 2: Features of four tools measuring the impact of CCI on health research.

| **Tool** | **Measures quality & scope of CCI** | **Measures impact of CCI on research processes** | **Measures impact of CCI on research outputs** |
|---|---|---|---|
| ACTA<br>Evaluating Impact | No<br>(a different ACTA form is available to assess the CCI process here) | Yes | Minimally |
| Blackburn et al.<br>Quality & Impact of PPI | Yes | Yes | Minimally |
| McMaster<br>PPEET | Yes | Yes | Minimally |
| Popay & Collins<br>PiiAF | Yes | Yes | Yes |

* Ease of use: the length of the tool does not necessarily indicate the amount of time needed to complete a tool (e.g., the complexity of the evaluation questions also needs to be considered) and is provided as a guide only.

Please note: The purpose of this table is to outline key features of each tool (as discussed by workshop participants). A consensus was not reached on the ideal or preferred tool.

| Measures impact of CCI from different perspectives | Measures impact of CCI in different types of research contexts | Type of evaluation data | Ease of use - length of tool (see note below *) |
|---|---|---|---|
| Yes<br>Consumers<br>Researchers | Yes<br>Developed for use in clinical trials however may be useful in other types of health research | Qualitative | 1 page, 7 items |
| Yes<br>Consumers<br>Researchers | Yes<br>Wide range of health research | Qualitative<br>Quantitative | 25 pages<br>(approx. 40 minutes to complete each questionnaire) |
| Yes<br>Consumers<br>Researchers | Possibly<br>Developed for evaluating CCI in health care, although may be applicable for some types of health research e.g. better for activities across a whole program or organisation than individual projects | Qualitative<br>Quantitative | Project questionnaire<br>10 pages (with 2 pages specific to impact) |
| Yes<br>Research teams (could include consumers) | Yes<br>Wide range of health research | Determined by research team | Multiple meetings needed to develop evaluation framework |

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- Vale C, Thompson LC, Murphy C, Forcat S, Hanley B. (2012). Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey. Trials, 13: 9.

# Appendix 1

## CCI Impact evaluation tools selected for consideration

(*CEPPP rating of tools: The Centre of Excellence on Partnership with Patients and the Public (CEPPP) in Canada has reviewed a number of tools that can be used in the evaluation of patient and public involvement in health care and health research. Ratings (from 1 to 5) are provided for four dimensions: scientific rigour, consumer perspective in tool design and use, comprehensiveness, and usability.)

| **Author/Name of tool** | **Country** | **Where to find the tool** | **Type of tool** |
|---|---|---|---|
| 1. Australian Clinical Trials Alliance – ACTA<br>Evaluating Impact | Australia | ACTA webpage: https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/evaluating/evaluating-involvement/ | 3 tools:<br>1. Consumer involvement questionnaire<br>2. Consumer involvement in 1-off event<br>3. CCI project evaluation form (which includes impact) |
| 2. Barber et al.<br>NHS consumer involvement national survey | UK | Barber et al. (2007) Involving consumers successfully in NHS research: a national survey. *Health Expectations*, 10(4): 380-391. https://pubmed.ncbi.nlm.nih.gov/17986074/ | Questionnaire<br>10 – 16 Yes/No indicators of whether CCI principles were followed |
| 3. Blackburn et al.<br>Quality and impact of PPI | UK | Blackburn et al. (2018). The extent, quality and impact of patient and public involvement in primary care research: a mixed methods study. *Research Involvement and Engagement*, 4: 16. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0100-8<br>Note: Researcher and Consumer versions of the tool are provided in files at the bottom of webpage. | Questionnaire<br>Lengthy – 25 pages |

| Respondents | Purpose/areas of impact | **CEPPP rating of tool:**<br>– **Scientific rigour**<br>– **Consumer perspective**<br>– **Comprehensiveness**<br>– **Usability** |
|---|---|---|
| Consumers and researchers | – Impact questions in CCI project evaluation form open-ended; could be answered Yes/No | (not rated) |
| Researchers | – Indicators for monitoring and reporting on the quality of consumer engagement/ involvement in a project<br>– Requires some revision for Australian context | 2, 3, 2, 1 |
| Researcher and Consumer versions | – Reporting on various aspects of CCI experience and impact in a project<br>– Requires some revision for Australian context<br>– Could use extracts from questionnaire to focus on particular areas of impact | (not rated) |

| Author/Name of tool | Country | Where to find the tool | Type of tool |
|---|---|---|---|
| 4. McMaster University<br>PPEET | Canada | Public and Patient Engagement Evaluation Tool (PPEET), Version 2, 2018. https://healthsci.mcmaster.ca/ppe/our-products/public-patient-engagement-evaluation-tool | Questionnaire<br>Approx. 10 pages for each version, but depends how much is relevant to project |
| 5. Patient-Centered Outcomes Research Institute (PCORI)<br>PCORnet | United States | PCORnet Engagement Assessment Project: Findings and Recommendations, 2018. https://www.pcori.org/sites/default/files/4089-PCORnet-Engagement-Assessment-Project-Findings-and-Recommendations.pdf | Questionnaire and Interview Guide (from page 21 in the report)<br>32 questions – mostly scales or multiple choice, but many with multiple components.<br>Interview guide is for qualitative data. |
| 6. Popay & Collins<br>Public Involvement Impact Assessment Framework (PiiAF) | UK | Popay & Collins with the PiiAF Study Group (Eds), 2014. The Public Involvement Impact Assessment Framework (PiiAF) Guidance. Universities of Lancaster, Liverpool and Exeter. http://piiaf.org.uk | Guide for research teams to undertake an interactive group process to review, understand and guide consumer involvement approach.<br>Resources and exercises provided to support the process.<br>Lengthy developmental process that could be facilitated by an external person. |

| Respondents | Purpose/areas of impact | CEPPP rating of tool:<br>- **Scientific rigour**<br>- **Consumer perspective**<br>- **Comprehensiveness**<br>- **Usability** |
|---|---|---|
| Consumer, Project (Researchers) at 3 stages of research, and Organisational versions | - Examines range of processes and impacts of CCI<br>- Versions for short term consumer engagement and longer-term involvement<br>- Can be tailored for different respondents and project types/stages | 4, 4, 5, 4 |
| Researchers | - Evaluates engagement with a range of research stakeholders including patients and the public<br>- Some questions relate to the effectiveness or impact of this engagement | 1, 3, 5, 4 |
| Research teams, which could include consumer partners | - Values, research approaches, practical issues and impacts – tailored to the research project and context<br>- Evaluation process could also be a capacity building/developmental process for research team<br>- Would require considerable commitment and investment of time | 2, 3, 4, 4 |

| Author/Name of tool | Country | Where to find the tool | Type of tool |
|---|---|---|---|
| 7. Staniszewska et al.<br>GRIPP2 reporting checklist | UK | Staniszewska et al. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ*, 358: j3453. https://www.bmj.com/content/358/bmj.j3453 | List of items to report on – long and short version. |
| 8. Vale et al. | UK | Vale, C. et al (2012). Involvement of consumers in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey. *Trials*, 13: 9. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3398265/<br>Note: Link to survey and guidance documents at bottom of webpage. | Questionnaire<br>Basic overview of consumer involvement: access to consumers, nature of involvement, types of impacts/problems |

| Respondents | Purpose/areas of impact | **CEPPP rating of tool:**<br>- **Scientific rigour**<br>- **Consumer perspective**<br>- **Comprehensiveness**<br>- **Usability** |
|---|---|---|
| Research team | - Tool aims to standardise reporting of PPI in research<br>- Reports nature and extent of consumer involvement in study aims, methods, results, conclusions and outcomes, with reflections on processes and learning for the future | (not rated) |
| Research team | - Respondents identify types of impact in open-ended questions<br>- Uses language of “trials” and some questions relate to UK guidance on trials but could be adapted for other research types and settings<br>- Would produce descriptive reporting of activities | (not rated) |

# Appendix 2

## Rating of eight selected tools by project team

| Author / Name of tool | Rating |
|---|---|
| Popay & Collins, Public Involvement Impact Assessment Framework (PiiAF) | 11 |
| Blackburn et al., Quality and Impact of PPI | 10 |
| McMaster University, Public and Patient Engagement Evaluation Tool (PPEET) | 9 |
| Australian Clinical Trials Alliance (ACTA), Evaluating Impact | 8.5 |
| Patient-Centered Outcomes Research Institute (PCORI), PCORnet | 6 |
| Vale et al., survey | 6 |
| Staniszewska et al., GRIPP2 checklist | 4 |
| Barber et al., NHS consumer involvement national survey | 0 |

**About AHRA**

The Australian Health Research Alliance (AHRA) is the voice of seven Advanced Health Research and Translation Centres and three Centres for Innovation in Regional Health - all accredited by the National Health and Medical Research Council.

Each centre is a partnership of multiple health services, connected to research centres and universities. Collectively AHRA's members encompass over 90% of researchers and 80% of acute health care services across Australia.

AHRA is uniquely positioned to address unmet needs in healthcare by helping researchers work with healthcare providers and consumers to deliver evidence-based care that offers better outcomes, best value and equity of provision.

AHRA
AUSTRALIAN HEALTH RESEARCH ALLIANCE

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