

AHRA Consumer and Community Involvement Initiative

CCI Phase 2

Integrated Project Plan

INTRODUCTION

The Consumer and Community Involvement (CCI) Phase 2 Initiative follows the Australian Health Research Alliance (AHRA) CCI Phase 1 Project completed in 2018 which determined a shared vision and priority activities to embed CCI in policy and practice across Australia. It was suggested that AHRA collaborates with the Consumers Health Forum of Australia and the Commonwealth Department of Health to design a program of work around the following recommendations. The collaboration will be underpinned by consumer and community involvement at every stage, including the adoption of these recommendations. The four recommended priorities were:

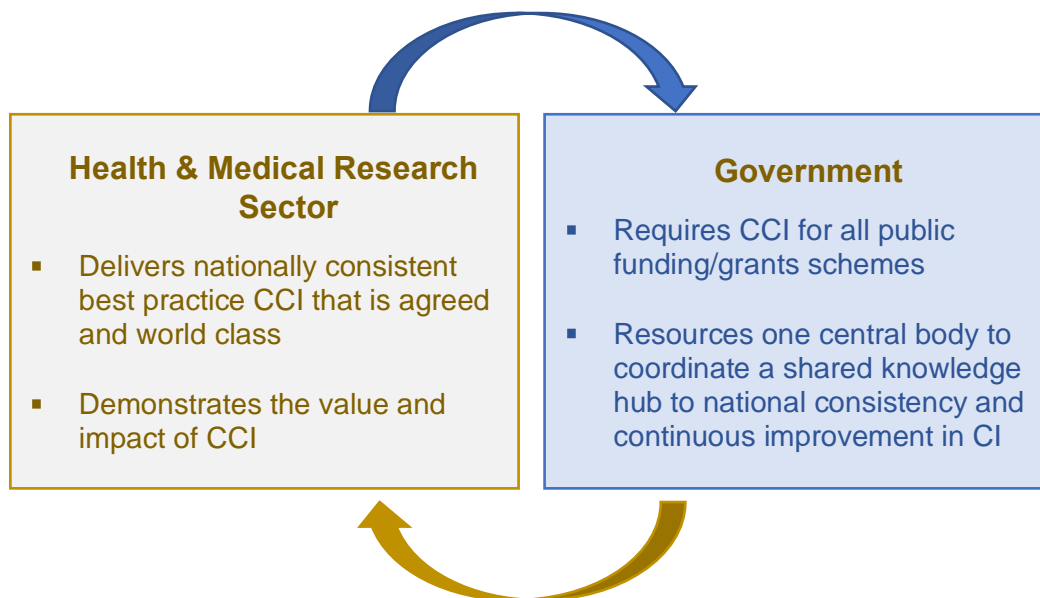
1. That AHRA develops minimum standards for good practice in consumer and community involvement in translational research in consultation with other national bodies. The standards should be a practical companion resource to the NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. The standards could include the following:
 - a position statement or policy that systematically embeds consumer and community involvement in translational research by member centres
 - guidance on incorporating consumer and community involvement across the research life cycle, and associated tools and resources to enable and support partnerships between Researchers, Health Professionals and Consumer and Community Members
 - capacity building initiatives (e.g., through training programs, webinars etc.) among Researchers, Health Professionals, and Consumer and Community Members to support effective collaborations in health and medical research
 - appointing ambassadors and mentors to support consumer and community involvement in health and medical research at AHRA member centres
 - guidance on funding consumer and community involvement in health and medical research
2. That AHRA facilitates sharing of existing resources and expertise to support consumer and community involvement in translational research. Consideration should be given to utilising existing websites and similar clearing houses to avoid duplication.
3. That AHRA sponsors research and evaluation projects to identify:
 - how to effectively increase consumer and community involvement in health and medical research
 - how to effectively measure the impact of consumer and community involvement in health and medical research
 - how to effectively measure the efficacy of existing consumer and community involvement tools and resources
4. That AHRA initiates formal alliances with leading agencies promoting consumer and community involvement in health and medical research such as INVOLVE in the United Kingdom, PCORI (Patient Centred Outcomes Research Institute) in the United States, and SPOR (Strategy for Patient Oriented Research) an initiative of the Canadian Institutes of Health Research.

The Partnership

The CCI Phase 2 Initiative is led by a partnership between the Consumers Health Forum (CHF) of Australia and the AHRA.

The Commonwealth Government (NHMRC and Department of Health) are involved in the Initiative through regular communication, knowledge-sharing and potential funding.

Project Goal



The Benefits

- A genuine co-ownership of CCI across the stakeholder groups.
- A national platform for CCI that is embedded systemically within both policy and practice.
- A model for continuous improvement and sustained best practice in CCI.
- The potential to place Australia at the international forefront in CCI.
- An opportunity for AHRA to demonstrate a collaborative model for achieving significant national reforms through Australia-wide membership of the Partnership.

Guiding Values

- Consumers and community have an inherent right to be involved in health and medical research
- Consumers and community add meaningful value to all phases of health and medical research
- The translation of health and medical research is enhanced by the involvement of consumers and the community

Underpinning Principles

- CCI drives and enables translation of health and medical research
- Researchers and consumers must be supported through policy, information and resources in order to achieve optimal outcomes
- Implementation of CCI is informed by the collective and accumulated expertise of AHRA members and draws from international experience

- CCI knowledge is shared across the AHRA network and beyond to ensure a truly national and consistent approach
- Any activities/projects emerging from the CCI Phase 2 will involve community and consumers at every stage of the activity/project

STAKEHOLDERS

Initiative Partners:

- AHRA
- Health Consumers Forum

Policy

- Minister for Health
- Commonwealth State and Territory Departments of Health
- NHMRC
- MRFF (Medical Research Future Fund)

Consumers

- Consumers Health Forum
- Health Consumer Councils in all States/Territories

Project Delivery

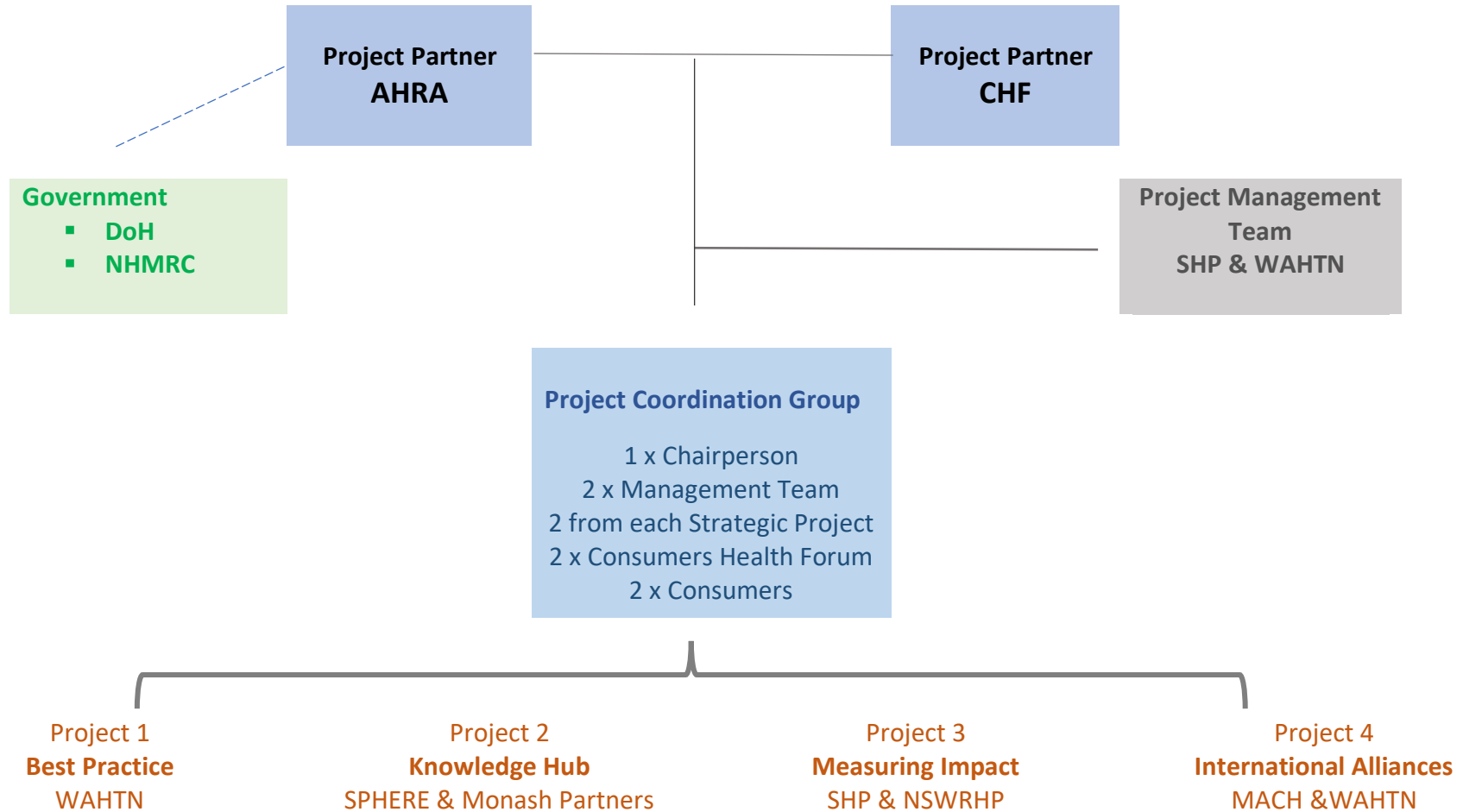
- AHRA CCI Phase 2 Co-Leads – SHP, WAHTN
- AHRA members undertaking CCI Phase 2 project streams
 - Monash Partners
 - Melbourne Academic Centre for Health (MACH)
 - Sydney Health Partners (SHP)
 - NSW Regional Health Partners (NSWRHP)
 - Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)
 - WA Health Translation Network (WAHTN)
 - Health Translation South Australia (HTSA)
- Consumers – via health consumer bodies

CCI PHASE 2 PROJECT

This initiative will be delivered via four integrated Project Streams undertaken by seven Translation Centres across four states, and their respective members, making it genuinely nation-wide.

Stream	Goal	Planned Approach
1. Best Practice Standards	To develop a CCI Best Practice Framework that includes: <ul style="list-style-type: none"> ▪ Policies ▪ Standards ▪ Guidelines ▪ Tools, resources and materials ▪ Measuring, Evaluating and Reporting 	<ul style="list-style-type: none"> ▪ Environment Scan – document gathering and review ▪ Consultation with key stakeholders ▪ Development of a draft Framework ▪ Testing the relevance and efficacy of the Framework in diverse CCI settings ▪ Finalising the Framework ready for implementation
2. Knowledge Hub	To establish a virtual central point for: <ul style="list-style-type: none"> ▪ Existing CCI tools and resources (including international) ▪ Measuring and evaluation tools ▪ Podcasts ▪ Research Papers ▪ Access to national and international expertise ▪ Access to consumer networks ▪ Information and knowledge sharing ▪ Intra-sector communications ▪ Clearinghouse 	<ul style="list-style-type: none"> ▪ Literature Review (National and International) ▪ Identify needs, gaps and priorities ▪ Conduct a national co-design workshop that is consumer-driven and involves all stakeholders ▪ Identify suitable platforms and technologies ▪ Articulate a roadmap of the Knowledge Hub including process and budget for establishing and maintaining the Hub
3. Measuring Impact of CCI	2 projects: To develop a short paper (the case) for CCI in health research (evidence summary) To develop tested tools and models for measuring the impact of CCI in health and medical research.	<ul style="list-style-type: none"> ▪ Undertake literature review ▪ Prepare draft paper for consultation ▪ Finalise draft paper ▪ Scope currently available evaluation tools ▪ Pilot 1-2 selected tools in available translation projects ▪ Prepare draft version of evidence- based optimal evaluation tools
4. International Alliances	To establish working partnerships with: <ul style="list-style-type: none"> ▪ INVOLVE in the UK ▪ PCORI in the US ▪ SPOR - Canadian Institutes of Health ▪ National Institute for Health Policy – Israel ▪ Relevant organisations in NZ 	<ul style="list-style-type: none"> ▪ Build on existing relationships ▪ Facilitate an international meeting in Australia of the five organisations to develop pathways for <ul style="list-style-type: none"> ○ benchmarking ○ international collaborations ○ sharing knowledge and resources ○ joint research and projects ▪ Prepare a <i>Compact</i> to reflect the ongoing international partnership ▪ Co-host 1 international CCI conferences

PROJECT GOVERNANCE & MANAGEMENT



Projects' Indicative Timeframe

Task	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
Best Practice Standards																		
Project Groups																		
Information/Consultation																		
Prepare Draft Framework																		
Pilot Draft Framework																		
Finalise Framework																		
Integrate into Initiative																		
Knowledge Hub																		
Design Workshops																		
Conduct workshops																		
Design & Create Platform																		
Test Platform																		
Integrate into Initiative																		
Measuring Impact of CCI																		
Steering Committee																		
Pilot Existing Tools																		
Data Analysis																		
Develop New Tool (f required)																		
Integrate into Initiative																		
International Alliances																		
Establish plan A or B																		
Determine nature of Alliance																		
Develop/Execute Action Plan																		
Prepare supporting Document																		
Integrate into Initiative																		
Launch the Alliance																		

Projects' Intersects and Overlaps

Same colour highlight = link, intersect or duplication

<p>PROJECT 1 BEST PRACTICE FRAMEWORK</p> <p>Policies Standards Guidelines Tools Resources Measuring/Evaluating Reporting</p> <p>Evaluating the efficacy of tools and resources</p>	<p>Collate & Review existing Policies, Standards Guidelines</p> <p>Collate and review existing resources</p> <p>Collate and review evaluation tools</p> <p>Pilot the Framework at 10 CCI active sites</p>
<p>PROJECT 2 KNOWLEDGE HUB</p> <p>Platform co-designed and costed Hub governance and management plan Implementation Plan Budgets for establishment and ongoing operations</p>	<p>Literature review</p> <p>Workshop sector needs, expectations & ideas for Hub</p> <p>Info about CCI Best Practice (duplicates Project 1)</p> <p>Create platform</p> <p>Evaluate impact of Hub</p>
<p>PROJECT 3 MEASURING IMPACT OF CCI</p> <p>Tool for measuring Impact of CCI</p> <p>(Need to clarify the scope and focus of this project)</p>	<p>Collate and Review Existing Impact Tools</p> <p>Pilot tools in 80 settings</p>
<p>PROJECT 4 INTERNATIONAL CCI ALLIANCE</p> <p>Compact or similar between countries</p> <p>A formalised International CCI Alliance between Peak Bodies</p>	<p>Plan A</p> <p>Inter-country CCI Compact or Alliance (Gov't to Gov't) + AHRA & CHF</p> <p>Federal Department will play major role</p> <p>Plan B</p> <p>Ascertain and review all current relationships</p> <p>Co-design a and implement a strategy for establishing an International CCI Alliance</p>