



Consumer and Community Involvement in Health and Medical Research

An Australia-wide Audit EXECUTIVE SUMMARY

2018

Joint Project Leaders



EXECUTIVE SUMMARY

In late 2017, the Australian Health Research Alliance (AHRA) committed to developing a coordinated approach to strengthening consumer and community involvement in health and medical research across Australia. A steering committee with AHRA representatives oversaw three related activities:

- an environmental scan of relevant literature about consumer and community involvement in health research, and the work of leading international and national agencies advocating and supporting consumer and community involvement
- an Australia-wide survey to capture the extent and nature of consumer and community involvement across AHRA member organisations
- a national workshop with relevant stakeholders to review the findings from the environmental scan and survey, and develop recommendations for AHRA to progress strengthening consumer and community involvement in health and medical research over the next 12-24 months.

Key findings from published literature

Over 200 publications and reports relevant to consumer and community involvement in health and medical research were identified, and 85 reviewed in detail. The following key themes were identified:

- **Consumer and community involvement is complex** and differs across the research spectrum.
- There is **inconsistency between robust policy** that supports consumer and community involvement and the **actual reporting** of it.
- There has been considerable focus on **development of tools and resources** to support consumer and community involvement.
- There are different perspectives regarding whether involvement should be **mandated or encouraged**.
- Effective consumer and community involvement **requires resourcing and enabling policies**.
- There is a clear need to **evaluate and measure** the value and impact of consumer and community involvement.
- There are opportunities for **enhanced collaborations** across jurisdictions, institutes and countries to share knowledge and learning.
- Currently, the **locus of control for involvement remains largely with researchers**.

Key findings from leading agencies promoting involvement

Four agencies at the forefront of the development and promotion of consumer and community involvement-related resources were examined:

- INVOLVE, National Institute of Health Research, UK
- Strategy for Patient Oriented Research (SPOR), Canadian Institute of Health Research, Canada
- Patient Centred Outcomes Research Institute (PCORI), National Institutes of Health, USA
- Consumer and Community Health Research Network (Australia)

A wide array of tools and resources are available from these agencies for Researchers and Consumers including **policies, guidelines, principles, frameworks, training, templates, budgeting tools**, etc. The extent to which these resources have been **rigorously evaluated is less clear**, but they have been used and adapted by many others seeking to support consumer and community involvement in health and medical research.

Key findings from the national survey

Responses from 868 people across Australia including 490 Researchers, 145 Health Professionals and 233 Consumer and Community Members indicated that:

- The vast majority of survey respondents (over 97%) reported that **consumer and community involvement in health and medical research has value**
- Consumer and community involvement can **improve the relevance of research** but there may be issues of low research literacy among consumers, the presence of personal views and biases, and insufficient time and resources to engage Consumers and Community Members effectively
- Consumer and Community Members **contribute to research in many ways**, including members of advisory committees, linking consumers with researchers, contributing to the design of research and associated tools and resources, and playing a role in research grant and report writing
- **The factor most commonly identified as influencing consumer and community involvement** was having clear and simple pathways for connecting people together
- A wide **range of tools and resources** exist to support consumer and community involvement, however there are opportunities to increase awareness and use
- Reports and tools for **measuring and evaluating consumer and community involvement** exist but have not been widely used.

Key outcomes from the national workshop

The one-day workshop was attended by 39 people including AHRA members and consumer advocacy groups. The following key messages emerged during the workshop discussions:

- **Clear support for consumer and community involvement** across the research cycle including determining research questions, research design and conduct, analysis and interpretation of results, and dissemination and implementation of findings.
- **Numerous models, frameworks, tools and resources exist** within Australia and internationally to support consumer and community involvement in research; facilitating access and evidence of efficacy are needed.
- The **community-driven approach that underpins Indigenous health research and existing policies for consumer involvement in cancer research** provide exemplars of how consumer and community involvement in other health and medical research might be achieved.
- **Financial support to enable involvement** needs to be secured, potentially through grant funding and/or "consumer involvement banks" created at organisational levels.
- **AHRA is in a strong position to advocate** for consumer and community involvement particularly in translational research, and to support coordinated progress across its member centres. This could include guiding principles, policy and/or standards to guide consistent practice across Australia.
- There is a need to **more effectively measure and evaluate the impact** that consumer and community involvement has across the research cycle.

RECOMMENDATIONS

As a result of the environmental scan, the survey results, and the workshop discussions, the following vision, values, principles and recommendations are proposed for AHRA and its member Centres to progress consumer and community involvement over the next 12-24 months:

Vision

- Consumer and community involvement is intrinsic to and embedded in the operations of all research bodies.
- Consumer and community involvement reflects a genuine sharing of power, a mutual trust and a shared belief in its value.
- Australian consumer and community involvement is world class.

Values

- Consumers and Community Members 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 Community Members.

Principles

- Consumer and community involvement drives and enables translation of health and medical research.
- Researchers, Health Professionals and Consumer and Community Members must be supported through policy, information and resources in order to achieve optimal outcomes.
- Implementation of consumer and community involvement is informed by the collective and accumulated expertise of AHRA members and draws from international experience.
- Consumer and community involvement knowledge is shared across the AHRA network.
- A sustainable business model underpins the implementation of consumer and community involvement Australia-wide.

Recommended priority actions

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.

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 (eg, 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 UK, PCORI in the US, and the Canadian Institutes of Health regarding SPOR.