



Consumer and Community Involvement in Health and Medical Research

An Australia-wide Audit

2018

Joint Project Leaders



A MESSAGE FROM THE PRESIDENT OF THE AUSTRALIAN HEALTH RESEARCH ALLIANCE (AHRA)

On behalf of the Australian Health Research Alliance I am very pleased to present this report into consumer and community involvement in health and medical research in Australia.

The report describes a national survey involving more than 85 % of the health and medical research community, over 70% of health service providers as well as consumer and community representatives and organisations. I am not surprised, therefore, that over 800 responses were received. This has provided a rich data set that gives us a creditable evidence base and confidence in planning next steps. The survey findings have been complemented with reference to the work of colleagues in Canada, the United States of America and the United Kingdom who are leading programs to promote and support consumer and community involvement in health and medical research.

Across Australia, there are seven NHMRC-accredited Advanced Health Research and Translation Centres (AHTRCs) and two Centres for Innovation in Regional Health (CIRHs). These centres are recognised as national leaders in research-based health care and training and have been accredited by NHMRC for excellence in the translation of evidence into patient care. Together they comprise the Australian Health Research Alliance (AHRA). This project demonstrates what can be achieved through the collaborative efforts of our members and it is certainly an approach we will continue to develop.

I extend my appreciation to the following people who have individually and collectively secured the success of this project.

- Sydney Health Partners (SHP) and the Western Australian Health Translation Network (WAHTN) for working together effectively to deliver the project on time and on budget, including my colleagues Garry Jennings, SHP, and John Challis and Gary Geelhoed, WAHTN, for their great stewardship of the project.
- The Project Steering Committee which has comprised representatives of all AHRA Centres who have been instrumental in disseminating the survey to their own members. This was not a simple task and their great efforts have almost certainly secured the remarkable response rate.
- The CEOs/Directors/Managers across the AHTRCs and CIRHs for also facilitating the distribution of the survey throughout their member organisations.
- The survey participants for taking time to complete the survey which will form the basis of future actions.

My sincere thanks to you all. I look forward to further collaborations as we work to ensure best outcomes for consumer and community involvement in health and medical research.

Professor Steve Wesselingh
President, AHRA

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ACKNOWLEDGEMENT OF COUNTRY

The Australian Health Research Alliance (AHRA), together with its member Centres, acknowledges the Aboriginal and Torres State Islander nations of Australia as the traditional owners of our country. We pay respect to ancestors and Elders past, present and emerging.

OTHER ACKNOWLEDGMENTS

A national project of this scale, including this comprehensive report, would not have been possible without significant input and work from many people. The following contributions are gratefully acknowledged:

- The hundreds of people across Australia who responded to the survey about current consumer and community involvement activities in health and medical research.
- The staff of the AHRA member Centres who were involved in distributing and promoting the survey.
- The AHRA Consumer and Community Involvement Steering Committee members who gave valuable feedback on draft versions of the survey and an early draft of this report.
- Gary Geelhoed, Executive Director, Western Australian Health Translation Network (WAHTN); John Challis, former Executive Director, WAHTN; and Garry Jennings, Executive Director, Sydney Health Partners (SHP) for their leadership and oversight of the project.
- Anne McKenzie, Head, Consumer and Community Health Research Network, who has been a champion for consumer and community involvement in health and medical research in Australia, and who played an important role in the early planning of the audit project as well as being an active member of the steering committee.
- Two project officers, Jo Wilke, WAHTN, and Paris Coburn, SHP, who jointly coordinated the overall project. Jo was responsible for undertaking the comprehensive environmental scan and writing up the findings. Paris managed the survey, analysed the data and wrote the survey results. Paris also coordinated the workshop arrangements. Their contributions were enormous.
- Christina Alcover, Amy Zhong and Angela Todd, Sydney Health Partners, for assisting with analysis of the survey data, gathering case studies and writing of the report.
- John Zelcer and Michael Kitts, Deloitte Australia, for facilitating the national workshop that led to the recommendations to further strengthen consumer and community involvement in health and medical research, outlined in this report.

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.

1. PROJECT BACKGROUND

Rationale

There is growing interest in the involvement of Consumer and Community Members in health and medical research and there are many examples of this across Australia and internationally. Consumer and community involvement in health and medical research has a number of potential benefits, including improved relevance of research to patient needs, improved quality and outcomes, more effective research translation, and improved public confidence in research.

There is also an extensive body of literature that explores many facets of consumer and community involvement¹ including:

- What involvement is (and isn't)
- Strategies for encouraging, and tools for enabling, involvement
- Exploration of the concepts of assessing the value, benefits, and impact of consumer and community involvement, including development of frameworks
- Descriptions of the expectations and experiences of researchers and consumers working together
- The policy and funding environments impacting on consumer and community involvement

The increasing activity in this area has led the AHRA to consider the potential for a national approach to consumer and community involvement that offers consistency and quality through a collaborative, consensus driven approach.

In late 2017, a national steering committee was established, with representation from all AHRA member Centres² to develop a coordinated approach to strengthening consumer and community involvement in health and medical research (see Attachment 1 for the committee membership). As a first step, the committee oversaw three related activities:

- an environmental scan of relevant literature about consumer and community involvement in health and medical research and the work of leading international agencies advocating and supporting consumer and community involvement
- an Australia-wide survey to capture the extent and nature of consumer and community involvement across its membership, which includes over 90% of all researchers and around 80% of all hospitals in Australia
- a national workshop to review the findings from the environmental scan and survey, and develop recommendations for AHRA for the next 12-24 months.

¹ Consumer and Community Involvement is the preferred term in Australia; Patient and Public Involvement is more commonly used in the UK.

² The nine AHRA members are: Brisbane Diamantina Health Partners, Central Australia Academic Health Science Network; Health Translation SA, Melbourne Academic Centre for Health, Monash Partners, NSW Regional Health Partners, Sydney Health Partners, Sydney Partnership for Health, Education, Research and Enterprise; and Western Australian Health Translation Network.

The information collected through the environmental scan and the Australia-wide survey provides the baseline evidence against which future activity, including policies, programs, strategies and trends can be compared, monitored and further developed. It can ensure that future work is adding value in effective and cost-effective ways, addressing gaps and avoiding duplications.

Purpose

The stated Purpose of the Project is to better understand the extent and nature of consumer and community involvement across the AHRA membership (including more than 120 organisations across Australia affiliated with the AHRA Centres); and to agree on a program of work to strengthen consumer and community involvement nationally.

Deliverables

The agreed deliverables for this project are:

- A targeted summary of relevant published literature about consumer and community involvement in health research;
- Examples of consumer involvement in health and medical research from international comparisons, including National Institute for Health Research, Canadian Institute of Health Research and National Institute of Health;
- A survey of consumer and community involvement in health research across Australia, using the AHRA member networks as reference. The audit will be reasonably high-level but also include specific case study examples that may be at a project or team level;
- A report summarising the findings from the audit, international comparison and literature scan;
- Coordination of a national workshop to discuss the report findings and develop recommendations for AHRA moving forward.

Governance

The project was overseen by the AHRA Consumer and Community Involvement Steering Committee, comprised of two representatives from each of the nine member Centres. The Committee was co-chaired by the Chief Executives of the two Centres leading this national initiative (Sydney Health Partners and Western Australian Health Translation Centre). These two Centres each employed a project officer to jointly coordinate and deliver the project. The Steering Committee and a small working group supported the Project Officers, provided input into the design and conduct of the project and reviewed draft versions of the report.

Project report distribution and access

The final project report will be freely available via the AHRA member Centres.

2. REVIEW OF PUBLISHED LITERATURE

To provide a broader context to this project, an exploration of research, studies, surveys and activities of consumer and community involvement within and outside Australia was undertaken. This was not a scientific or systematic review of the literature, but rather a capture of information that aligned with the AHRA audit project and its purpose. These documents have added considerable information, provided thoughtful insights and raised a number of issues relating to consumer and community involvement.

More than 200 published papers and articles were accessed via the following:

- papers identified by AHRA Consumer and Community Involvement Steering Committee members
- University of Western Australia Library
- State (Western Australian) Parliamentary Library
- Google search
- papers referred to by respondents to the AHRA national survey

Consideration of which studies and papers to include was based on their relevance to:

- the value of consumer and community involvement
- the nature of consumer and community involvement
- the barriers and enablers to consumer and community involvement
- measuring consumer and community involvement
- the extent and nature of consumer and community involvement within specified communities

Using the topic areas above resulted in 97 papers being included in this project. These are listed in the Reference section of this report.

Key research themes

The following key themes emerged from the accessed literature:

Consumer rights	The intrinsic rights of consumers to be involved in research, as funders of research and as persons with lived experience.
Concept & meaning	The concept of consumer and community involvement; its meaning, its nature and its relevance across types of research.
Views & experiences	The experiences and views of key stakeholders, particularly researchers and consumers.
Benefits	The range of benefits of consumer and community involvement – drawing from a range of perspectives including researchers, research bodies, consumer organisations, consumers, and funders and investors.

Enablers & barriers	The enablers and barriers to consumer and community involvement – at policy, systems and practice levels.
Tools & resources	The tools and resources relevant to consumer and community involvement.
Evaluation	Evaluating and measuring the benefits of consumer and community involvement, both qualitatively and quantitatively, and having regard to outcomes and impact.

The case for consumer and community involvement in health research

*“the people have the rights and duty to participate individually and collectively in the planning and implementation of their health care”
(World Health Organisation Declaration of Alma Ata 1978)*

The growing interest and activity in consumer and community involvement in health and medical research is driven by:

- a recognition of the intrinsic right of Consumer and Community Members to be involved in health and medical research
- increasing respect for the value that Consumer and Community Members add to health and medical research
- a shift towards mutual relationships between Consumer and Community Members, Health Professionals and Researchers, which sees them contributing as partners to best possible health outcomes
- a renewed focus on the translation of medical research and the recognition of the unique role that consumers can play as the link between academic research and the social context
- the ready access to world-wide information about health and medical research that is growing a community of informed, savvy and interested consumers who want to contribute beyond being patients or study subjects.

Governments are responding in a range of ways including, but not limited to:

- Recognition and funding of organisations with a specific focus on supporting and advancing consumer and community involvement
- Commissioning and investing in wide-ranging studies into consumer and community involvement
- Legislative reforms that have seen the establishment of major consumer and community involvement organisations through acts of Parliament, for example, Patient Centred Outcomes Research Institute (PCORI) in the US, and the National Strategy for Patient Outcome Research (SPOR) in Canada

- Policy reforms such as the (Australian) National Health and Medical Research Council's Statement on Consumer and Community Involvement in Health and Medical Research
- Mandating consumer and community involvement as a requirement for some publicly funded research health and medical research grants

Research bodies and consumer organisations are similarly developing policies and strategies aimed at involving Consumer and Community Members in research.

"Why should it be up to researchers who have no experience personally with a particular disease to decide what a study design should look like or what outcomes should be measured?"

(Dr Susan Kahn, Associate Director for Clinical Research at the Lady Davis Institute in Montreal)

There is universal support to progress the consumer and community involvement agenda at systemic, policy and practice levels. This is further affirmed through the experiences of researchers, consumers, research bodies and consumer organisations, and reported in numerous reviews and studies.

Benefits of consumer and community involvement

There is extensive reporting of the benefits of consumer and community involvement for consumers, researchers, the wider community, the funders, the policy makers and the research itself. These benefits include:

- ensuring that the research is relevant and responsive to community needs
- bringing new perspectives to the research concept, design, implementation and dissemination
- increasing public awareness of and support for research
- increasing opportunities for public and other funding
- increasing community confidence in the public funding of research
- optimising the use of limited resources

At the heart of any commitment to consumer and community involvement are the principles of:

- *shared POWER between the stakeholders*
 - *mutual TRUST between the consumers and the researchers*
 - *common BELIEF that involvement adds meaningful value*
-

Summary of reviewed literature

Consumer and community involvement is complex and differs across the research spectrum, thus requiring models that are flexible and have applicability in diverse research situations.
There is inconsistency between robust policy that encourages, supports and even requires consumer and community involvement, and the actual reporting of involvement by researchers, research bodies and consumer organisations.
There has been comparatively high focus on development of resources to support consumer and community involvement – for researchers, research bodies, consumers, consumer groups, funders, policy makers and other stakeholders.
There are different perspectives regarding whether involvement should be mandated or encouraged, either as a blanket policy or for selected research areas or types.
Without adequate resourcing, including enabling policies, a national framework and targeted funding, it is unlikely that effective consumer and community involvement can be achieved.
There is an increasing focus on the challenge to evaluate and measure the value and impact of consumer and community involvement.
There is an imperative for sustained and enhanced collaborations across jurisdictions, institutes and countries which bring together and build on the collective knowledge and learning.
At this stage of its evolution, the locus of control for involvement remains primarily with researchers and their willingness and capacity to involve Consumer and Community Members.

"Now is the time for robust measurement of the impact of consumers fully involved in the conceptualisation, theorisation and development of instruments for this purpose."

"Undoubtedly what is currently missing from the consumer involvement landscape (in both quality and quantity) is evidence of the impact of consumer involvement ... Attempts should now be made to design a substantial programme of research that sets out to systematically measure the impact of consumer involvement ..."
(Wilson C, Llewellyn P, Moskowitz H, 2011).

3. LEADING AGENCIES PROMOTING CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH RESEARCH

Four agencies that appear to be at the forefront in the development and promotion of consumer and community involvement-related resources were examined. The resources from these agencies have been used and adapted by many other organisations. The four agencies examined were:

1. INVOLVE, National Institute of Health Research, UK
2. Canadian Institute of Health Research (CIHR) and its Strategy for Patient Oriented Research (SPOR)
3. Patient Centred Outcomes Research Institute (PCORI), National Institutes of Health (NIH), USA
4. Consumer and Community Health Research Network, Australia

It is worth noting that the agencies in Canada and US both provide grants that are conditional on a suitable consumer and community involvement plan. In Australia consumer and community involvement is not a condition of funding for health and medical research except for research relating to people with Human Immunodeficiency Virus/Indigenous peoples, and people with cancer (except in Victoria). It is encouraged and supported by the National Health and Medical Research Council.

Information about these four agencies was collected by:

- Telephone and/or email discussions with key staff at: INVOLVE, Canadian Institutes of Health Research, and Patient-Centered Outcomes Research Institute
- Face to face discussions with the Consumer and Community Health Research Network

1. INVOLVE, National Institute for Health Research, (UK)

INVOLVE (<https://www.involve.org.uk/>) is a national advisory group in the UK that undertakes a range of consumer and community involvement activities (<https://www.nihr.ac.uk/>). It was established as a not-for-profit organisation in 1996 and then fully incorporated into the National Institute for Health in 2006. The Institute was established to advance health research by bringing into one body a number of research funding programs across the National Health Service (NHS). It is effectively the research arm of the NHS. The National Institute for Health was the first organisation in the world to acknowledge the importance of involving consumers in research through its relationship with INVOLVE.

Examples of resources developed by INVOLVE are summarised below.

Resource	Description
Briefing notes for researchers	Ten briefing notes for researchers including supplements, case studies and templates such as job descriptions, and terms of reference for committees. Topics include: <ul style="list-style-type: none"> - What is public Involvement in research - Why involve members of the public in research - Why members of the public get involved in research - How to involve members of the public in research - Who should I involve and how do I find people - Approaches to public involvement in research - Ways that people can be involved in the research cycle - What to do if things go wrong - Where to go for further information
Guide to recognising the contribution of Consumer and Community Members	<p>Introduction</p> <ul style="list-style-type: none"> - Good practice - Developing a policy - What you need to know about payment <p>Budgeting</p> <ul style="list-style-type: none"> - Budgeting for involvement - Cost calculator <p>Resources</p> <ul style="list-style-type: none"> - Examples of payment policies - INVOLVE payment information sheet 2018 <p>Tax and welfare benefits</p> <ul style="list-style-type: none"> - Benefits advice service - Updates on welfare benefits regulations - Tax and national insurance
Defining involvement	Clarifies difference between involvement, participation and engagement
Public information pack	Information for Consumer and Community Members interested in becoming involved in research
Videos	Personal stories from people involved in research
People in research website	Website that advertises opportunities for consumer and community involvement in research
Research Design Service (RDS)	Supports public involvement through: <ul style="list-style-type: none"> - Assistance with pre-submission review of applications - Matching researchers and consumers - Public management of the RDS - Small grant schemes for public involvement in research design
Social media	<p>Guidance on the use of social media to actively involve people in research</p> <p>Examples of projects using social media for public involvement</p>
Webinar series	Provides information about involvement in adult social care research, research with Black minority ethnic people, public involvement in End of Life Care research, User Controlled Research

Information for research commissioners	National Research Ethics Service Tip Sheet: recruiting members of the public to be involved in research funding and commissioning processes
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2. Strategy for Patient Oriented Research, Canadian Institutes of Health Research (Canada)

The Canadian Institutes of Health Research were created in 2000, via an Act of Parliament, and comprise 13 institutes across Canada. Together, the institutes act as the Canadian Government's health and medical research investment agency, distributing some \$1 billion annually for:

- investigator-driven and target priority research
- research capacity-building
- knowledge translation and innovation

The Canadian Institutes of Health Research is committed to consumer involvement through its Strategy for Patient Oriented Research (SPOR; see: <http://www.cihr-irsc.gc.ca/e/48413.html#a12>). The Strategy's central tenet, to place patients and their families at the centre of any discussion or research planning, is reflected in a funding requirement that patients must be involved in projects and processes and in shaping research priorities.

The Strategy has Support Units in every province to support the work of the institutes by acting as a convenor and providing administrative services. The Support Units are also, in themselves, key resources within their respective provinces:

- providing capacity-building grants for developing plans for consumer and community involvement, skills and competencies, information, and materials
- acting as facilitators, enablers and empowers of consumer and community involvement through local, provincial and national initiatives
- assisting applicants for provincial and national grants to develop consumer and community involvement plans
- continuous improvement through ongoing surveys, research and consultation

Under the Strategy, the following framework has been developed as an overarching guide to patient involvement.

Key Strategy Components

- Definitions
- What can patients contribute and why it is needed?
- Patient engagement in the Strategy for Patient Oriented Research
- Guiding principles
- Core areas for engagement
 - o Patient engagement in governance and decision-making
 - o Capacity building for patient engagement

- Tools and Resources
 - Evaluation of patient engagement in the Strategy for Patient Oriented Research
 - Appendix 1: Patient Engagement Framework Dashboard
 - Appendix 2: What does success look like?

3. Patient-Centered Outcomes Research Institute (PCORI, USA)

PCORI was established by the Patient Protection and Affordable Care Act of 2010 and operates as a non-profit, non-government organisation (<https://www.pcori.org/>). In 2017, PCORI awarded grants totalling \$379 million predominately for comparative effectiveness studies (comparisons between treatment options). PCORI not only encourages and funds research that involves consumers, but it also involves consumers and other community stakeholders in its own work including:

- funding processes, setting research priorities, assessing applications and disseminating findings
- research policy development
- research planning

PCORI offers the following tools and resources, aimed primarily at researchers.

Resource	Description
Engagement rubric for applicants	Guides researchers in planning and/or conducting research
Engagement principles	Stated principles are: Reciprocal Relationships <ul style="list-style-type: none"> - Co-learning - Partnerships - Transparency - Honesty - Trust
Compensation Framework	A guide regarding compensation for consumers involved in research projects
Budgeting for Engagement Framework	Budget planning for involvement activities
Guides for planning the study; conducting the study; disseminating the study findings	Provides specific guidance on designing these three components of a study, with patient involvement as a key element
Webinars, Roundtables, Workshops	Aim to promote involvement, engage consumers and facilitate collaboration between researchers and consumers

Methodology standards	Guide to meeting requirements for patient centredness and engagement
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4. Consumer and Community Health Research Network (Australia)

The Consumer and Community Health Research Network was founded in 1998 through a partnership between the University of Western Australia's School of Population Health and the Telethon Kids Institute. In 2016, funding from Lotterywest was provided to expand the Network across the health and medical research sector and the Network became an enabling platform within the Western Australian Health Translation Network.

The Network's stated purpose is to “support and advise consumers, community members and researchers across the Western Australian Health Translation Network to work in partnership to make decisions about research priorities, policy and practice”.

The Network is acknowledged globally for its advanced offerings of consumer and community involvement-related tools and resources, which have resulted from local and international collaborations, evidence-based research and extensive consultation with both researchers and consumers. The Network's accumulated expertise enables it to contribute meaningfully to policy development, international studies and other consumer and community involvement initiatives.

The Network delivers its consumer and community involvement activities primarily through its Involvement Program (<https://www.involvingpeopleinresearch.org.au/>). Below are some of the offerings of the Program.

Resource	Description
Fact Sheets Series	Booklet of brief 'tools' to support involvement
The Green Book	A practical guide to establishing consumer and community involvement at an organisational level
Workshops	Information about terminology, research funding processes, different types of research and contributing effectively to a research team Boosts understanding, skills and confidence to become involved in health and medical research
Support to consumers	Advice and guidance, access to training, mentoring, networking opportunities, resources and information, top tips for involvement, etc.
Information on ways to be Involved	Topics include: <ul style="list-style-type: none"> - Writing or commenting on documents - Grant application reviewers - Consumer and community forums - Consumers and Community Members on teams - Research buddies

	<ul style="list-style-type: none"> - Reference groups - Steering group or panel - Consumer or community researchers - Consumer and Community Advisory Councils
Definitions	Provides definitions of all terms used in the area of consumer and community involvement
The Purple Book	Provides guidance to researchers planning to actively involve Consumers and Community Members
Training Workshop	Training for Consumers and Community Members involved in research teams or projects
Customised training courses for researchers and clinicians	Customised courses for specific organisations or research projects on implementing consumer and community involvement Short courses i.e. Introduction to Involvement, and Writing in Plain Language
Support for researchers	Support for a range of topics including: <ul style="list-style-type: none"> - How to involve Consumers and Community Members in grant applications - Information about consumer and community involvement activities - Help to identify relevant Consumers and Community Members for your project - Advice on developing consumer and community involvement strategies - Access to range of training workshops - Advice on budgeting for consumer and community involvement - Facilitating consumer and community involvement activities

Summary of leading agencies

The review of the four leading organisations demonstrates the comprehensive and well-developed array of tools and resources that are available for researchers, health professionals 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, however they have been used and adapted by many others seeking to support consumer and community involvement in health and medical research.

4. CONSUMER AND COMMUNITY INVOLVEMENT SURVEY METHODS

An Australia-wide survey was conducted to capture the extent and nature of consumer and community involvement across AHRA's member organisations.

Survey development

A survey instrument was developed by the AHRA Consumer and Community Involvement Steering Committee to ensure the survey would be relevant and appropriate across member Centres. It was recognised, nonetheless, that an online survey tool was not likely to be the most effective model for obtaining feedback about consumer and community involvement in health and medical research for certain population groups, for example, Aboriginal and Torres Strait Islander peoples.³

The final draft survey included two versions: one for Researchers and Health Professionals, and another for Consumer and Community Members. The two versions were similar but not the same. They included limited choice questions and scaling questions, as well as open-ended questions seeking qualitative feedback. While the surveys could be completed anonymously, respondents had the option of providing contact details.

The draft surveys were pilot tested by a small number of researchers within Sydney Health Partners, and consumers from the Consumer and Community Health Research Network and the Western Australian Health Consumers Council. This process yielded useful and insightful feedback resulting in several small changes in the survey.

The survey was developed using Qualtrics, a software instrument that connects data to commonly available analytic platforms such as Google and Adobe, and can be exported to other systems such as Excel. Importantly, for a national survey, it has a highly-rated security level while at the same time allows data to be selectively shared with ease.

Survey dissemination

The survey was disseminated by the AHRA Consumer and Community Involvement Steering Committee's co-chairs to each of the AHRA member Centres. In turn, the Centres sent the survey to key contacts within their member organisations for further dissemination to Researchers, Health Professionals and Consumer and Community Members.

The Project Team worked closely with the Directors and Chief Operating Officers of the Centres to prepare processes and messaging suitable for their particular circumstances, appreciating the unique and diverse operations and protocols across the Advance Health

³ Only 1.35% of survey respondents identified as Aboriginal or Torres Strait Islander.

Research and Translation Centres and Centres for Innovation in Regional Health and their members.

The survey was distributed on Monday 30 July 2018 with the survey period scheduled to conclude on Friday 24 August 2018. Centres were encouraged to send at least two reminders about the survey to their members to help bolster responses. The survey took approximately 20 to 30 minutes to complete.

Survey limitations

The survey was developed through a highly consultative process with representatives from across Australia knowledgeable and experienced in consumer and community involvement in health and medical research. While the survey was widely circulated, it was recognised that persons with little or no experience of consumer and community involvement in research would be much less likely to respond. Thus some bias in respondents was expected. However, since the focus of the survey was to capture existing consumer and community involvement in health and medical research, and tools and resources used, those engaging with consumers are the most informed. It was also recognised that some groups would be less likely to respond to the survey including Aboriginal and Torres Strait Islander peoples (as noted above) as well as people from various cultural and marginalised groups, who are under-represented in most community surveys.

In developing a national survey tool, significant efforts were made to ensure that the tool met the needs of a wide range of stakeholders. A consequence of this, however, was a lengthy survey instrument. The subsequent results showed progressive drop-out of respondents over the duration of the survey. At the same time, many respondents provided additional qualitative comments to a range of questions up to the end of the survey, suggesting strong engagement.

Finally, the total number of people who received an invitation to participate in the survey is not known, therefore response rates and comparisons of respondents versus non-responding members of the AHRA Centres could not be performed.

5. SURVEY RESULTS

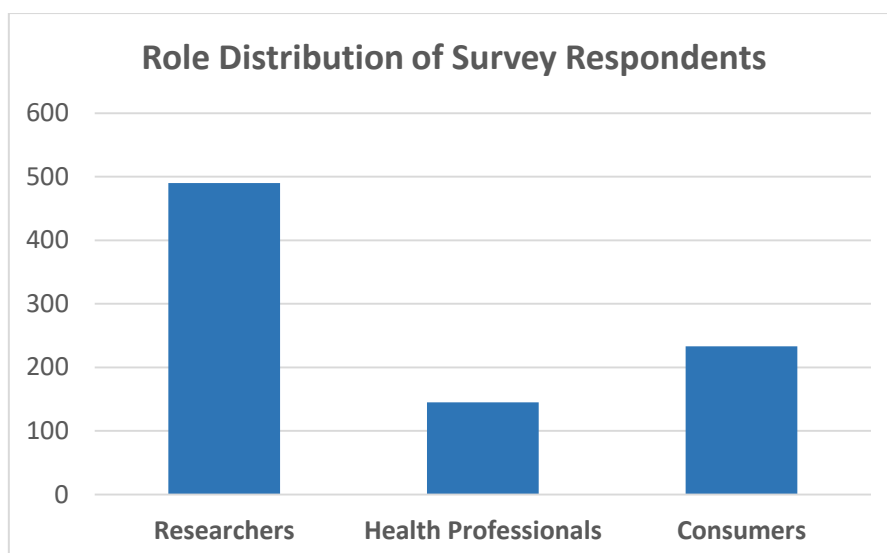
A total of 1706 people commenced the survey, however a significant number did not continue with the survey, or completed only a limited number of questions. A minimum response threshold was therefore set at 17% completion (based on visual inspection of the data). This resulted in a **total of 868 people included for data analysis**. This number also declined over the duration of the survey and in response to specific questions that were not relevant to all people.

Who responded to the survey?

The profile of survey respondents is shown below. While people can have more than one role across more than one organisation, respondents were asked to identify their main role at this time. Approximately 56% of respondents were grouped as Researchers, 17% as Health Professionals, and 27% as Consumer and Community Members (referred to subsequently as 'Consumers').

These three categories broadly capture key stakeholder groups within the AHRA Centres. For this reason, the reporting of the survey results refers to these three categories, or combines the Researcher and Health Professional groups where the results of these two groups are not significantly different. The two groups, 'Senior leader of a health and medical facility (e.g. hospital, community controlled Aboriginal health organisation)' and 'Senior leader of a health consumer and community member organisation' received several unique survey questions, but were excluded from analyses due to the relatively low numbers in these groups.

Category	Role type	Count	%
Researchers (n=490)	Health and medical researcher	244	28%
	Other academic researcher	34	4%
	Research support staff including management	113	13%
	Scientist	44	5%
	Senior leader of a research institute	38	4%
	Senior leader of an academic institution	17	2%
Health Professionals (n=145)	Health professional	104	12%
	Non-clinical health staff	15	2%
	Senior leader of a health and medical facility (e.g. hospital, community controlled aboriginal health organisation)	26	3%
Consumers (n=233)	Health consumer and/ or community member	217	25%
	Senior leader of a health consumer and community member organisation	16	2%
	Grand Total	868	100%



Researchers and Health Professionals were asked to identify the broad area(s) of research in which they were involved. As the table below shows, the most significant differences between the two groups were in the proportions engaging in discovery research and health services/health systems improvement research.

Nature of research	Researchers	Health Professionals
Discovery/lab-based research	28%	8%
Clinical trials	37%	39%
Other clinical research	24%	26%
Translational research	36%	23%
Health services/ health systems improvement	29%	55%
Other	10%	9%

Question 1: Is consumer and community involvement in research valued?

The survey asked respondents to rate whether “involving Consumer and Community Members in health and medical research has value”. All three groups (Researchers, Health Professionals and Consumers) were highly positive about the value of consumer and community involvement.

Over 97 % of Researchers, Health Professionals, and Consumer and Community Members valued consumer and community involvement in health and medical research.

There were some differences between the groups in terms of who assigned the highest value ratings: 77% of Consumers rated consumer and community involvement as "extremely valuable" compared to 58% of Researchers and 52% of Health Professionals. Significant numbers of survey respondents (406 Researchers and Health Professionals, and 124 Consumers) also provided additional comments with examples of "the value of consumer and community involvement in health and medical research as it applies to your current and recent health and medical research" (see word cloud below).

"Word cloud" of comments describing the value of consumer and community involvement in health and medical research

The three most prominent themes from the respondents' text comments were:

“Within Indigenous health research contexts it is imperative to have Aboriginal and Torres Strait Islander input (via individuals as well as organisations) to ensure that Indigenous priorities are driving the research, that Indigenous knowledges are privileged in the research process, that Indigenous research methodology underpins data collection, analysis and synthesis, and that translation of research findings is maximised at both the service and policy levels. It is unethical to do Indigenous research without partnerships with Indigenous peoples.”

(Researcher or Health Professional)

- beneficial consumer insights gained through consumer and community involvement (29% Researchers and Health Professionals, 27% Consumers)

*"[Consumers and Community Members] help us to identify or refine our research questions, they offer great insights into methodology, and they have always improved our interpretation and dissemination."
(Researcher or Health Professional)*

- increased promotion of research and better communication of research (26% Researchers and Health Professionals, 25% Consumers)

*"The [XXX] Study also has an established consumer representative group who work in partnership with [XXX] management to shape decisions around research priorities and cohort activity... data collection questionnaires and any form of communication with study members e.g. newsletters, information sheets, results, cards, competitions, websites, Facebook, meetings. This consultation process ensures research protocols and material remains relevant and acceptable to participants."
(Researcher or Health Professional)*

Other common themes from the respondents' comments about the value of consumer and community involvement in health and medical research included:

- enhanced recruitment and community involvement
- improved translation of research into practice
- increased access to funding and philanthropy
- greater validity of results and improved accuracy of results interpretation

Respondents also indicated that Consumer and Community Members play a significant role towards resourcing and supporting research, as a member of the research team, designing research, reviewing grant applications, recruiting for clinical trials, writing layperson summaries for promotion of research or through fundraising activities, etc.

"We have a [named cultural group] community reference group who are guiding all stages ...we are recruiting from the right places, using appropriate methods and that the intervention is culturally sensitive, as well as our evaluation being accepted by the target population. The intervention happened because of a community champion (a GP with a shared vision to prevent diabetes). This project would not have been possible without the consumer and community engagement; it would have failed right at the beginning. The program was so well received because we have taken a community empowerment approach. Having community

members delivering the program to their peers has made it sustainable and culturally sensitive. It also ensured the community have trust in the academic team."

(Researcher or Health Professional)

Whilst the vast majority of Consumers commented on the ways in which Consumer and Community Members have been involved in health and medical research and/or the valuable outcomes of their involvement, some respondents provided insights into how their contributions had been acknowledged by Researchers and Health Professionals.

*"My name was included on the publish paper as an author
Acknowledgement on an educational video
Co presented with the researcher at a conference
Acknowledged within a presentation at an overseas conference
Paid an hourly rate for project work
Gift voucher to acknowledge contributions to project development
Paid parking and lunch
Being asked my views and seeing them included. "*
(Consumer)

"I was involved in Youth Focus on their Youth Reference Group. We have monthly meetings to give feedback on the organisation's engagement with young people. We received an honorarium as well as an end-of-year celebration, lots of verbal feedback and encouragement, and many external opportunities such as mental health consultations with politicians."
(Consumer)

A small proportion of Consumers (6%) indicated that their involvement was not valued and/or described their involvement as 'tokenistic'.

Question 2: What are the advantages and disadvantages of consumer and community involvement in health and medical research?

"I believe consumer involvement is all about continuous improvement and achieving the very best outcomes in all projects. Consumers are generally a very economic resource with potentially priceless contribution. In any project trying to achieve an excellent result, why would consumers not be included in trying to achieve that level of excellence?"
(Consumer)

Researchers and Health Professionals were asked to identify key advantages and disadvantages of involving Consumer and Community Members in health and medical research. In order to not influence the responses, this was an open-ended question.

272 Researchers and Health Professionals, and 107 Consumers suggested various **advantages** of consumer and community involvement. The four main themes that emerged were as follows.

- improved research relevance and design (57% Researchers and Health Professionals, 51% Consumers)

*“1. Ability to ensure social and local context is relevant to the research
2. Ensure the research reaches the right groups/cohorts of participants
3. Ensure the outcomes are meaningful and impactful to the population -
not just science/research
4. Ensure maximum engagement of the community the research is
targeting
5. Co-design principles ensure maximum engagement and support”
(Researcher or Health Professional)*

- beneficial insights gained through consumer and community involvement (46% Researchers and Health Professionals, 59% Consumers)

*“research [that] reflects needs and priorities of the end user, grounded in
and informed by context and lived reality of the groups the research
intends to understand/ support, [is] more likely to have translational
impact into improved health”
(Researcher or Health Professional)*

*The consumers can give lived experience and genuine feedback about the
relevance, perceptions and impacts on the program or research to those
that research or create the policies. Often the health providers think they
know but are often too close to the service delivery and fail; to see the
external impacts that we manage and deal with outside the health system,
or when dealing with multiple service providers.
(Consumer)*

- improved translation of research into practice (32% Researchers and Health Professionals, 14% Consumers)

“It is essential to include representative end users in the research process to ensure feasibility, acceptability and usability of interventions.”
(Researcher or Health Professional)

- increased promotion of research and better communication with laypeople (27% Researchers and Health Professionals, 26% Consumers)

“The example of HIV-AIDS in the 1980s and 90s is salient. The affected communities had a degree of ownership of what was happening; community leaders were then more prepared to help with public health initiatives such as promoting protected sex, avoiding needle sharing etc.”
(Researcher or Health Professional)

Other suggested advantages included:

- increased access to funding
- compliance with research ethics
- benefits to consumer and community health literacy
- enhanced recruitment and community involvement
- improved accuracy of results interpretation
- greater validity of results.

Several respondents noted that Consumer and Community Members should have greater access and input in research as, being taxpayers, they are the funders of the research as well as the beneficiaries of research. Some respondents also noted that connecting with the beneficiaries / 'end users' of their research helped keep them motivated and inspired.

242 Researchers and Health Professionals, and 90 Consumers suggested various **disadvantages** of consumer and community involvement. The four main themes that emerged were as follows.

- low research literacy and ambiguity of consumer priorities and roles (39% Researchers and Health Professionals, 15% Consumers)

“Can slow down the process, and can be tricky if the views of the consumers are at odds with those of researchers. Whose perspective has more weight?”
(Researcher or Health Professional)

“They [research teams] ... need to be clear about the role of the involvement of consumers / community member involvement and they need to ensure that the consumers are clear about that. You need clear documented terms of reference for the consumers. The research team need to have a genuine belief in the value of consumers and not just do this because there is an obligation to do this. At the end of the project - communicating, results (even preliminary), the value add of consumers and being clear whether or not their role has come to an end. Having one member of the team charged with the responsibility of working with the consumers - e.g. one point of contact for the consumers. If managed well, the advantages far out-weight any disadvantage.”
(Researcher or Health Professional)

“Involving consumers does come with a level of overhead and in some cases cost and difficulty, with regard to training, accessibility and time. Specifically enabling access to people with disabilities, but these are the people who offer insights that researchers cannot see.”
(Consumer)

- time demands (35% Researchers and Health Professionals, 9% Consumers)

“It takes a lot of my time to set up and manage the relationships... you can’t expect consumers straight out of the community to have a total understanding of the research environment or the research questions you are wanting their input into.”
(Researcher or Health Professional)

- biases and personal viewpoints that don't represent the 'global' consumer (29% Researchers and Health Professionals, 7% Consumers)

“Sometimes meetings might get a bit 'heated'. Consumer and community members would not always argue or put forward their view in a calm way. They were highly personally invested in some aspects of the research, and sometimes some previous negative experiences might influence their inputs. However, this was dealt with by respect in the research group. Even if we didn't understand their view, we made an attempt to understand it. I think having the time to listen to them actually made the interactions better. And over time we got to work together even better.”
(Researcher or Health Professional)

“Poorly trained consumer advocates sometimes lack the understanding and boundaries of their involvement and can hinder research, side-tracking meetings and asking irrelevant questions.

Occasionally consumer advocates use research opportunities to further their own particular views rather than understand that their role is to represent all consumers.”

(Consumer)

- insufficient resources to support consumer and community involvement i.e. funds for reimbursement (25% Researchers and Health Professionals, 5% Consumers)

“It is extremely time consuming and costly to do it well. Regardless of the increasing rhetoric regarding the value of community engagement and real world impact in academia, many universities do not truly place value on these activities, which is evidenced by the persistent judgement of researchers on the number of peer reviewed publications (e.g. in progress reviews, recruitment, grant applications etc.). Until universities start to reward consumer and community engagement, I don't think the culture will shift towards genuine community/consumer engagement.”

(Researcher or Health Professional)

“Time consuming; not always reimbursed for time, expertise or experience contributed - so personally expensive (unaffordable).”

(Consumer)

Other suggested disadvantages included:

- difficulty recruiting appropriate consumers
- managing expectations of research process, timeframes and impact
- uncertain value of consumer and community involvement
- lack of organisational support and/or not valued by organisations
- breaches to confidentiality and the spread of misinformation
- tokenistic approach to involvement
- lack of feedback and/or acknowledgement.

Question 3: How are Consumer and Community Members involved in health and medical research?

The survey presented respondents with a list of 12 high-level activities for consumer and community involvement in health and medical research. The responses from the three groups (Researchers, Health Professionals and Consumers) are shown in the following table.

Across the three groups combined, the most common consumer and community involvement activity (selected by 60% of respondents) was “as a member of a consumer and community member advisory committee of a research project / organisation”. Overall, the second and third most common involvement activities were “linking research / researcher(s) with consumer(s) and community member(s)” and “contributing to the design of research projects, tools and resources”.

However, within the three groups, there were differences in the most commonly reported activities (see following table).

Consumer and Community Involvement Activity	Researchers %	Health Professionals %	Consumers %
As a member of the board or a governance committee of a research organisation	68.6%	64.0%	13.5%
As a member of a consumer and community member advisory committee of a research project / organisation	66.3%	73.5%	59.6%
As a consultant to a research project / organisation	59.3%	66.9%	11.5%
Deciding what research should be prioritised	47.7%	63.4%	17.3%
Contributing to research grant applications	38.4%	61.5%	24.4%
Contributing to the design of research projects, tools and resources	57.0%	72.2%	21.8%
Contributing to the conduct of the research	62.8%	69.7%	17.9%
Linking research / researcher(s) with consumer(s) and community member(s)	58.1%	72.9%	23.1%
Contributing to / reviewing the research report and/or paper	39.5%	56.8%	26.9%
Presenting at conferences, seminars and other forums	47.7%	59.6%	15.4%
Preparing communications such as newsletters, media statements, social media	53.5%	63.1%	14.1%
Promoting research to funders, sponsors and philanthropists	41.9%	59.6%	3.8%

The following word cloud captures the recurring words in the free text responses provided by Researchers and Health Professionals about consumer and community involvement activities.



"Word cloud" of comments describing how Consumer and Community Members are involved in health and medical research

Question 4: Are some consumer and community involvement activities valued more highly than others?

In addition to capturing the frequency of consumer and community involvement activity across the 12 categories, Researchers and Health Professionals were asked how valued were “the listed consumer and community involvement activities to ... [their] current and recent research and/or organisation”.

All 12 consumer and community involvement activities were valued by the Researchers and Health Professionals: 84% to 97% of Researchers valued the 12 activities and 79% to 97% of Health Professionals.

Involvement needs to occur at multiple levels - in the research team, as part of project governance structures, as key stakeholders for prioritising dissemination and translation activities.
(Researcher or Health Professional)

Consumers were not asked to value each of the 12 activities, but instead were asked: “On average, has your involvement been valued by health and medical researchers and/or organisations?” Eighty-eight percent (88%) thought their involvement was valued in some way, and 34% thought it was “highly valued”.

In addition, 319 Researchers and 87 Health Professionals responded with comments about how they have involved Consumer and Community Members in their current and recent health and medical research. For example,

*I have co-written grants, conducted research and co-written research publications with consumers. I have also co-presented at conferences with consumers. Most of my work involved co-production in all aspects of the research process from planning to dissemination of research findings.
(Researcher or Health Professional)*

Researchers and Health Professionals also cited the lived experience, insights and diverse opinions of Consumer and Community Members as advantageous resources for research, as reflected in the following examples.

Case study

“On the [named University campus], members of community are greatly involved from project planning stage. The University has also linked with community members who are keen to have some fundamental research training to enable consumer and community participation in research at all stages. An example is training for Rangers in research methods which led to rangers being paid as Research Assistants on some of our archaeology projects. We also seek funds in grant budgets to remunerate community members for their contribution to some research projects as researchers, consultants etc.”

Case study

Our unit is run by people with lived experience of mental health issues who are also trained researchers, and we work in partnership with a consumer and carer advisory group and other consumers and carers to conduct mental health research. We developed and prioritised our research agenda in a forum and survey with consumers and carers, and our advisory group approves all projects associated with the unit. The advisory group members assist with advertising and recruitment of participants, disseminating research updates and findings, contributing to analyses and reports and co-authoring publications. We also look for ways that research can contribute to consumer and carer organisations, such as a current project to explore the nature of participation and representation in health, how it is valued and indicators of its value. The findings will inform new participation frameworks and evaluation within the organisations and will be co-owned.

Case study

The development of the HEALing Matters program (a knowledge exchange platform and professional development opportunity for OOHc carers) was done largely based on end user and key stakeholder engagement. Here, using surveys, focus groups, multiple steering committees and an extensive pilot study we involved the consumer (i.e., the OOHc carer) during all stages of content development. In addition, we also included young people with lived OOHc experience in the development of the intervention. In doing so, we were able to design a program that while continued to have strong

empirical and theoretical foundations was based heavily on the perspectives of those who will ultimately use and benefit from the intervention.

Case study

We involved a consumer advisory group on a previous project summarising Cochrane Review evidence for people with multiple sclerosis. The three member consumer advisory committee (including 2 individual consumer representatives and 1 organisational representative) was convened at project commencement, and from that point, were involved in all research stages (planning, conduct and dissemination).

Examples:

- (1) planning (advising how we would recruit and run focus groups, prioritising which Cochrane Reviews to summarise),
- (2) conduct (commenting on thematic analysis, editing review summary content),
- (3) dissemination (co-authoring journal articles and speaking at website launch).

We've recently published about our consumer engagement methods and reflected on impact in this project.

Question 5: What factors affect consumer and community involvement?

*I think it is difficult to make a start on getting consumers and community involved if you don't have much experience in this area or have this knowledge in the workplace to readily tap into.
(Researcher or Health Professional)*

Survey respondents were asked to evaluate factors that affect consumer and community involvement in health and medical research. All groups responded to a list of eight factors, with further role-specific factors asked of each group (see below, tick indicates which respondents evaluated which factors).

Factors	Researchers	Health Professionals	Consumers
Researchers' awareness of the ways in which consumers and community members can be involved	✓	✓	✓
Having clear and simple pathways for connecting with consumers and community members and consumer and community member groups	✓	✓	✓
Having positive examples of consumer and community member involvement	✓	✓	✓
Research organisation's policy on consumer and community member involvement	✓	✓	✓
Government policy on consumer and community member involvement	✓	✓	✓

Factors	Researchers	Health Professionals	Consumers
Funders' policy on consumer and community member involvement	✓	✓	✓
Having assurance that the consumer and community member involvement will add value to the research	✓	✓	✓
Having the right support from the research institute e.g. mentor supervisor, access to experts in this area	✓	✓	✓
Access to training for consumer and community member involvement	✓	✓	Not asked
Access to funds and/or other resources to support any costs of involving consumers and community members	✓	✓	Not asked
Being compensated for my out of pocket expenses, stationery, travel, child care, etc.	Not asked	Not asked	✓
Being paid as a member of the research team	Not asked	Not asked	✓
Knowing what research is being planned or undertaken	Not asked	Not asked	✓
Formal agreements between consumer and community member organisations and research bodies about the involvement of consumer(s) and community member(s)	Not asked	Not asked	✓
Receiving feedback on how my involvement has contributed to health research	Not asked	Not asked	✓
Having influence over the type of research undertaken	Not asked	Not asked	✓
Being confident in my ability to contribute	Not asked	Not asked	✓
Having the right support from a health consumer and community member organisation e.g. a mentor, buddy, access to information, access to training.	Not asked	Not asked	✓

The factor “Having clear and simple pathways for connecting with consumers and community members and consumer and community member groups” was the factor most commonly identified by survey respondents in all three groups. The least common factor across all groups was “government policy on consumer and community member involvement”.

The greatest variation between groups was in relation to the importance of funding. Most Researchers and Health Professionals rated “access to funds and/or other resources to support any costs of involving consumers and community members” as an important factor (91% and 94% respectively). In contrast, the least important contributing factor reported by Consumer and Community Members was “being paid as a member of the research team”

followed by “being compensated for my out of pocket expenses, stationery, travel, child care, etc.” (55% and 75% respectively).

The following detailed comments about factors that affect consumer and community involvement are reflective of the many submitted responses.

Case study

Historically there has been a lack of substantial funding towards consumer and community involvement in research, which has impacted on our ability as researchers to do this as comprehensively and effectively as we might like. The model that has been recommended/endorsed by peak Aboriginal community organisations (e.g. the AHMRC of NSW) for population-level Indigenous research with limited budgets for comprehensive community engagement has been to form a community reference group at the project outset, with representatives from relevant stakeholder organisations or community groups with a key interest in the research. While this model has enabled valuable consumer and community input into our research, it is also important to acknowledge that the quality of the engagement is limited by issues such as inadequate budgets for travel to attend meetings in person, inadequate telecommunication facilities (particularly in more regional/remote areas) that prevent members of the group joining meetings via videoconference (which makes for better quality discussion than teleconference), and high staff turnover in community organisations/health services etc. that makes it hard to maintain the group and grow the confidence to community members to interact with researchers.

Case study

Much like findings from the Payne JM et al 2011 study: both senior leadership and operational capacity underpin success in developing consumer participation in research, building consumer participation into the structures of research funding bodies, organisations and teams strengthens and supports its implementation, resources are needed to help consumer participation to work well, developing and sustaining consumer participation often requires changes to structures and attitudes, which take time and commitment.

Payne JM, D'Antoine HA, France KE, et al. collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation. Health Res Policy Syst. 2011; 9:18.

Case study

There is poor understanding in the research community of what involvement really looks like and how to enact it. Training is also hard to access, with existing trainers and/or examples of good practice in heavy demand. The new focus on impact and engagement has magnified these issues but so far many researchers look [at] how to tack involvement on to their own processes instead of starting new ones that genuinely involve consumers and the community in appropriate ways.

Question 6: What existing consumer and community involvement tools and resources have been found to be useful?

Researchers and Health Professionals were given a list of 10 types of tools and resources, and Consumers were given a similar list of nine, and asked which ones they found useful. All of the tools and resources were rated as useful by some respondents. However, 15% of survey respondents reported either being unaware of the tools/resources or never having

accessed them, suggesting opportunities for improving awareness and access to existing tools/resources.

The three most commonly identified useful tools and resources were similar for the three groups (see table below). Responses to other tools and resources were similar across the three groups in most cases, with the exception of “Training courses for researchers seeking to involve consumers and community members in research”: more Consumers rated this resource as useful than Researchers and Health Professionals (67% compared with 40% combined).

Useful	Researchers (n=236)	Health Professionals (n=57)	Consumers (n=107)
1	Mechanisms for communicating with consumers and community members e.g. via websites, social media, newsletters, email etc.	Mechanisms for communicating with consumers and community members e.g. via websites, social media, newsletters, email etc.	Information from consumer and community member groups about research projects seeking consumer and community member involvement e.g. via websites, newsletters, email etc.
2	Presentations about consumer and community member involvement in research online and/or in-person	Information for consumers and community members interested in becoming involved in research	Information from research bodies about research projects seeking consumer and community member involvement e.g. via websites, newsletters, email etc.
3	Information for consumers and community members interested in becoming involved in research	Presentations about consumer and community member involvement in research online and/or in-person	Information for consumer and community members interested in becoming involved in research

On average, more Consumers were using existing tools and resources than Researchers and Health Professionals:

- Consumers: 46% to 76% across all tools and resources, average 61%
- Researchers: 31% to 75%, average of 44%
- Health Professionals: 33% to 77%, average of 47%

Respondents were also asked to give specific details of where they had accessed the tools and resources. The following sections provide a snapshot of the responses provided. They include comments and opinions as well as references to websites or journal publications.

For convenience, an extract listing of the websites and publications is available in Attachment 2.

Mechanisms for communicating with Consumer and Community Members

Respondents provided examples of websites, social media, newsletters, and email lists, including the following:

Resource	URL	Organisation
Website	https://www.bcna.org.au/	Breast Cancer Australia Network
Website	https://www.abloodygreatnightout.com.au/	Clinical Research Unit, Concord Hospital
Consumer Involvement Toolkit	https://consumerinvolvement.cancer australia.gov.au/	Cancer Australia
Website	https://www.dementia.org.au/	Dementia Australia
Website	https://www.carersnsw.org.au/about-us	Carers NSW
Website	https://www.involvingpeopleinresearch.org.au/	Consumer & Community Health Research Network
E-newsletter	https://www.mhcc.org.au/	Mental Health Coordinating Council (MHCC)
Mailing list	https://www.saxinstitute.org.au/our-work/45-up-study/	Sax Institute

Established networks or committees that bring together Consumer and/or Community Members with Researchers and Health Professionals

Respondents identified a wide range of established networks or committees that bring together Consumer and/or Community Members with Researchers and Health Professionals, for example:

- “Annual forums mixing consumers with clinicians, government, researchers and pharma.”
- “Breast Cancer Network Australia”
- “Dementia Australia”
- “Health Consumers NSW”
- “Rare Voices Australia”
- “Cancer Voices”
- “The Inala Community Jury for Aboriginal and Torres Strait Islander Health Research was established by our service to bring together community members with researchers”

Presentations about consumer and community involvement in research online and/or in-person

Respondents cited examples such as conferences, showcases, seminars, workshops, open days, annual meetings, etc. It was not clear from the responses if there was any kind of preference for online or in-person presentations, for example:

- "On line preferable as it reduces the time of travelling and could be done at their [Consumer] convenience."
- "One-on-one hands-on training is far better than on line training because you can see if you are being understood and demonstrate any tasks more efficiently."

Examples of the range of presentations that were listed include:

- "ANZMUSC annual scientific meeting included a session profiling the value of consumers in research with panel participation from consumers. Was very enlightening"
- "Cancer Council NSW Consumer Training and Advocacy training"
- "From Health Consumers Alliance of SA"
- "At the annual meeting of the Cognitive Decline Partnership Centre (CDPC) each project gives a presentation, including the involvement of consumers, carers and community members."
- "I went to the Palliative Care Conference this year and found the speakers informative and had great understanding, especially when some of the volunteers 'told their story'."

Information for Consumer and Community Members interested in becoming involved in research

In response to this item, some of the mechanisms identified in the question "mechanisms for communicating with consumers and community members e.g. via websites, social media, newsletters, email" were replicated. In addition, other examples included disseminating information via general practitioner offices, through advocacy groups and community organisations.

Some respondents emphasised the need to consider delivering information in ways that are appropriate to the audience, for instance: "Advertising invitations through on-line websites, newsletters and email would draw most of the consumers and community members into it who are having access to these, but some groups who are in aged care facilities will be disadvantaged from this."

Some Researchers and Health Professionals mentioned the use of flyers but expressed different views about their value:

- "I have found it to be invaluable to be able to leave flyers/handouts for potential participants. I have learned how to use these resources from fellow-experienced researchers."
- "Flyers have been left at local community groups but have not been successful."

Some examples of the range of responses provided include:

- "discussion are had with individual patients at their clinic visits"
- "Eligible family members can join a confidential registry maintained by the US study site; they will receive notification of research opportunities, information updates, family conference etc."
- "Ethics approved research volunteer registry"
- "From Health Consumers Alliance of SA"
- "In-person (talking to existing groups e.g. playgroups; attending events e.g. NAIDOC week). Brochures (community designed)"

Training courses

Although some respondents identified a number of organisations providing training, 20% of the free text responses indicated that some Researchers and Health Professionals were unaware of available training or had not accessed training to involve Consumer and Community Members in research, for example:

- "I would love to attend such a course but don't know of any."

Respondents cited the Western Australian program, Involving People in Research and/or the Western Australian Health Translation Network numerous times. Other comments and examples included:

- "At our research institute, the Certificate 11 in community health research is available to community researchers and can also include community members."
- "at my umbrella institution, this largely happens incidentally by those passionate about this area, rather than being a cohesive program"
- "I received some training through the NHMRC Cognitive Decline Partnership Centre, which has strong consumer involvement in all aspects of research."
- "This is a really important question, as there is significant debate about training requirements for consumers wanting to be involved in research. There is no mandated training requirement, but training is being used as a barrier to restrict consumers wanting to be involved."

Professional support groups or networks

Some respondents identified specific groups or networks but 40% of the free text responses from Researchers and Health Professionals indicated they were unaware of or had not accessed professional support groups, for example:

- "I am not aware of the professional support for consumers in research but this is something that should be given consideration."

Examples of groups or networks include:

- "MPA have a support group that several research consumers attend"
- "Accessed through Wiser Healthcare"
- "Cancer Voices"
- "CMHDARN - joint initiative of NSW Mental Health Commission and Mental Health Coordinating Council"

Government policies on consumer and community involvement in research

Common responses included the policies of organisations like the NHMRC, the National Safety and Quality Health Service, the Australian Research Council, Cancer Australia and South Australia Health. Some respondents also commented on the usefulness of these policies, for example:

- “Community engagement is supported by the Australian Health Ministers (Australian Charter of Health care rights), the Australian Commission on Safety and Quality in Health Care (ACSQHC), and the National Health and Hospital Reform Commission (NHHRC) (McCaffery et al., 2011). The Australian Charter of Healthcare Rights implies good health outcomes are dependent on consumer’s participation in decisions about their care and health (ACSQHC, 2008).”
- “drive consumer involvement, researchers need a reason why they should do this “extra step”. Once they've done it once they are likely to see it differently”
- “Policies encouraging the inclusion of consumers in research development and implementation add impetus to following through.”
- “This has been a very important factor for us in developing a strong community engagement.”
- “Useful as long as realistic”

Research institution policies on consumer and community involvement

Responses to this type of resource were somewhat inconsistent: some viewed such policies as documents with little influence, others considered them helpful. Some of the comments provided included:

- “Currently drafting a consumer engagement framework to show researchers the importance of community involvement”
- “These are under developed and underfunded”
- “We don't have this support, but know of institutions that do, and we would like this type of support too.”

Consumer and community group policies on consumer involvement in research

Some respondents identified specific policies, for example:

- “University human research ethics committees, including accessing people from Aboriginal and Torres Strait Islander peoples”
- “Clinical trials organisations BCT, TROG”
- “Established for our Centre of Research Excellence”
- “MRV Terms of Reference”
- “Some groups like Cancer Voices Australia have policies on this”

Other respondents gave their perspective on Consumer and Community Member policies, for example:

- “I see it as critical to know their policies in order to know how to approach recruiting or promoting through any organisation. I would contact representative groups directly to understand their policies.”
- “I am pretty sure that we don't have one for our organisation but we probably should. Perhaps this could be included in funding agreements.”

- “Yes, so long as it does not become overly ritualised and burdensome.”

Evidence of the benefit of involving Consumer and Community Members in research

A significant portion of respondents indicated that the benefits were evident in the research projects in which they were involved. In contrast, some respondents questioned the existing evidence, with a number suggesting that further studies were required. In addition, 33% of the free text responses indicated that Researchers and Health Professionals were unaware of or had not accessed such evidence.

- “This is lacking. I believe it is of benefit for both the researchers and the consumers, but there isn't a lot of scientific literature or guidelines showing what success looks like and tools to measure the outcomes of consumer involvement in research.”

Evaluation forms to capture feedback from Consumer and Community Members who are involved in research

Only Consumers were asked this question, and a small number provided comments including:

- “At each meeting an evaluation form is distributed about meeting content.”
- “Evaluation forms are regularly used and provide excellent means of members to provide feedback”
- “Most definitely a valuable resource as feedback will indicate how the research is progressing and if it's on the right track”
- “We surveyed our consumers and researchers two years ago to evaluate the program. We have used their feedback to improve the program”

Case study

“Note that while the principles of consumer and community engagement are strong, the evidence for it actually improving patient outcomes is relatively weak if gold standard measures of outcomes are considered (Crawford et al., 2002, Simpson et al., 2009, Nilsen et al., 2006). At best, most evidence is mixed, meaning that the impact of consumer and community engagement is not clear, that it is context dependent or that it requires further study (Wright-Berryman et al., 2011). This demonstrates that we need to address complexity and not levels of evidence framework and traditional gold standard measures, see comment: <https://blogs.bmj.com/bmj/2018/08/10/richard-lehman-shared-decision-making-essential-hard-measure/>

At an individual level, consumers involved in engagement activities have reported that involvement in engagement activities made them feel as though they were being listened to by professionals, that their ideas were being acted upon, and that their individual experiences as a patient was being used to help others (Fudge et al., 2011, Crawford et al., 2002). Overall, building more effective consumer networks can contribute to improvements in the wider community and in the active citizenship of individuals and groups (Krebs and Holley, 2006).”

Question 7: Do you know of any measurement or evaluation of consumer and community involvement in health and medical research?

A total of 146 respondents answered three items in this section of the survey: 69 Researchers, 17 Health Professionals, and 60 Consumers. The responses of Researchers and Health Professionals were combined due to the relatively small number in the latter group. The responses to the three items were very similar for both groups (see below).

Survey Item	Researchers and Health Professionals %	Consumers %
I am aware of research or project(s) that has measured/ evaluated the benefits of consumer and community involvement.	90%	88%
I am aware of tool(s) for evaluating/ measuring the benefits of involving consumers and community members in your research.	66%	57%
I am aware of tool(s) for evaluating/ measuring methods of involving consumers and community members and community members in research	56%	50%

Summary of the survey

The results of this survey involving researchers, health professionals and consumers across Australia, indicate that:

- **Consumer and community involvement** in health and medical research is **valued** by Researchers, Health Professionals and Consumer and Community Members, especially with respect to setting research priorities and informing research design
- Consumer and community involvement can **improve the relevance of research** and help promote it to others but there may be issues in terms of low research literacy among consumers, the presence of personal views and other biases, and insufficient time and resources to engage Consumer and Community Members effectively
- Consumer and Community Members currently contribute to research through a number of **activities**, 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
- Among the **factors that influence consumer and community involvement** in health and medical research, the most commonly cited was having clear and simple pathways for connecting people together; views were mixed about the role of funding and payments for consumer and community involvement

- Survey respondents identified a wide **range of existing tools and resources** to support those engaging in consumer and community involvement in health and medical research, however considerable numbers of survey respondents were not aware of them or had not used them
- A smaller proportion of respondents reported accessing and using reports and tools for **measuring and evaluating consumer and community involvement**.

6. NATIONAL WORKSHOP

A one-day workshop was held on 12 November 2018 in Sydney, NSW, to identify and recommend an agreed set of priority actions for AHRA to further support consumer and community involvement in health and medical research.

The workshop was informed by the environmental scan of relevant published literature (see Section 2), the review of four leading agencies promoting consumer and community involvement in research (see Section 3), and the results of the survey of AHRA members capturing existing involvement practices, resources and tools (see Section 5).

The meeting was attended by 39 people representing AHRA members and consumer advocacy groups (see Attachment 3 for list of attendees). The workshop was facilitated by John Zelcer and Michael Kitts, of Deloitte Australia, who have previously facilitated two other national meetings for AHRA.

Key messages from workshop discussions

Support for consumer and community involvement: There was consensus among workshop participants for the involvement of Consumer and Community Members across the research cycle including priority setting, research design and conduct, analysis and interpretation of results, and dissemination and implementation of findings. The phrase "nothing about me without me", which captures the essence of participatory medicine, should also be adopted in medical research.

Using available tools and resources: It was acknowledged that numerous models, frameworks and resources already exist within Australia and internationally to support consumer and community involvement in research, although some kind of coordinated register or portal to facilitate access and promotion would be helpful. At the same time, there is comparatively little evidence systematically evaluating the effects of consumer and community involvement on research and its translation.

For example, a range of tools have been developed by the NHMRC but many workshop attendees were not aware of them, and the tools have not yet been tested. The Consumer and Community Health Research Network (Western Australia) was established in 1989 and now has over 2,500 members, with over 460 sitting on decision-making committees. A large number of workshops and training programs have been delivered. A self-reported evaluation of training workshops by participants showed strong endorsement, and an independent evaluation of the Network's entire program is currently underway. From the Network's long history of activities, the three most critical factors for success have been: (1) top level support and champions; (2) dedicated 'consumer advocate' positions inside organisations; and (3) training workshops that have built mutual understanding and capacity for Researchers, Health Professionals and Consumer and Community Members to work

together. Network managers also noted that resources are limited, and it is important that Consumers and Community Members are involved where they can add most value.

Learning from Indigenous health and cancer research: Workshop attendees were reminded of the community-led approach that is fundamental to all Indigenous health research in Australia, which could be an exemplar for how consumer and community involvement in other health and medical research might be achieved. Cancer research agencies in Australia have also been at the forefront of involving Consumer and Community Members, providing training to support them, and including their involvement as a condition of funding.

Financial support to enable involvement: There was support for identifying costs associated with consumer and community involvement, and securing funding either via grant applications and/or through "involvement banks" created at the organisational level.

Opportunities for national leadership by AHRA: There was agreement that AHRA was in a strong position to advocate for consumer and community involvement particularly in translational research. It was important to ensure that such involvement was not tokenistic or a "tick box" activity. It was also acknowledged that the extent and nature of consumer and community involvement across member Centres of AHRA are different, and any changes over time will also likely differ. At the same time there was agreement to support coordinated progress through the specification of minimum standards and/or best practice, possibly with reference to the Maturity Model⁴ and other frameworks that support practice change.

⁴ Prosci. (2004). Change Management Maturity Model™. <http://www.change-management.com/ecmlab/ECM-Lab-Preread-M-Model.pdf>

7. 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. a position statement or policy that systematically embeds consumer and community involvement in translational research by member centres
 - b. 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
 - c. 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
 - d. appointing ambassadors and mentors to support consumer and community involvement in health and medical research at AHRA member centres
 - e. 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:
 - a. how to effectively increase consumer and community involvement in health and medical research
 - b. how to effectively measure the impact of consumer and community involvement in health and medical research
 - c. 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.

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Attachment 1

AHRA Consumer and Community Involvement Steering Committee

Committee CHAIRS	Garry Jennings, SHP Gary Geelhoed, WAHTN
Brisbane Diamantina Health Partners (BDHP)	Susan Hawes, BDHP
	Deb Cowan, Metro South HHS
Health Translation South Australia	Wendy Keech, Health Translation SA
	Caroline Miller, Health Translation SA
	Kim O'Donnell, Health Translation SA
Melbourne Academic Centre for Health (MACH)	Paul Yates, Austin Health
	Sherri Huckstep, The Royal Women's Hospital Melbourne
	Heather Whipps, MACH
Monash Partners	Angela Jones, Monash Partners
NSW Regional Health Partners	Billie Bonevski, University of Newcastle
	Clare Collins, University of Newcastle
Sydney Health Partners (SHP)	Carolyn Sue, The Kolling Institute, Northern Sydney Local Health District/University of Sydney
	Angela Todd, SHP
	Paris Coburn, SHP
Sydney Partnership for Health Education and Enterprise (SPHERE)	Megan Williams, UTS
	Meera Agar, SWSLHD/UNSW
Western Australian Health Translation Network (WAHTN)	Anne McKenzie, WAHTN/University of Western Australia
	Pip Brennan, Health Consumers' Council (WA)
	Jo Wilke, WAHTN

Attachment 2

Extract of publications and websites listed by survey respondents about consumer and community involvement in health and medical research

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Attachment 3

National Workshop Attendees

AHRA Centre	Name	Position	Organisation
Brisbane Diamantina Health Partners	Susan Hawes	Senior Operations Manager	Brisbane Diamantina Health Partners
	Deb Cowan	Senior Director Stakeholder Engagement	Brisbane Diamantina Health Partners
	Areti Gavrilidis	General Manager	Brisbane Diamantina Health Partners
Health Translation South Australia	Wendy Keech	Chief Executive Officer	Health Translation South Australia
	Ellen Kerrins	Consumer Representative	Health Translation South Australia
	Alexandra Michelmores	Principal Project Officer	Health Translation South Australia
	Julia Overton	Chief Executive	Health Consumers Alliance of South Australia
Melbourne Academic Centre for Health	Sherri Huckstep	Chief Experience Officer, The Royal Women's Hospital	The Royal Women's Hospital Melbourne
	Paul Yates	Geriatrician, Austin Health	Austin Health
	Peter Brooks	Medical Lead, Research, Northern Health	Northern Health
	Geraldine McDonald	Director Prevention & Wellbeing, Peter MacCallum Cancer Centre	Peter MacCallum Cancer Centre
Monash Partners	Angela Jones	Chief Operating Officer	Monash Partners
	Darshini Ayton	Research Fellow	Monash University
	Sandy Braaf	Research Fellow	Monash University
NSW Regional Health Partners	Billie Bonevski	Professor and Brawn Fellow, Faculty of Health & Medicine President, Society for Research on Nicotine and Tobacco (SRNT) Oceania Chapter	University of Newcastle
	Clare Collins	Professor of Nutrition and Dietetics	University of Newcastle
	Ellen Newman	Operations Manager	New South Wales Regional Health Partners
	Christine Jorm	Executive Director	New South Wales Regional Health Partners

	Frances Quirk	Professor & Director, New England Institute of Healthcare Research	University of New England
Sydney Health Partners	Angela Todd	Senior Researcher	Sydney Health Partners
	Aisling Forrest	Chief Operating Officer	Sydney Health Partners
	Nicola Straiton	Senior Project Officer (CCI)	Australian Clinical Trials Alliance
	Serena Joyner	Consumer Engagement Manager	Health Consumers New South Wales
	Leanne Wells	Chief Executive Officer	Consumers Health Forum of Australia
	Mohit Kumar	Consumer Representative	Sydney Health Partners Governing Council
	Paris Coburn	Project Officer	Sydney Health Partners
	Amy Zhong	Project Officer	Sydney Health Partners
	Christina Alcover	Project Officer	Sydney Health Partners
	Jordan Pitcher	Program Manager	Sydney Health Partners
	Mark Mathot	Media and Communications Manager	Sydney Health Partners
Sydney Partnership for Health Education Research and Enterprise (SPHERE)	Karena Conroy	Head, Commissioned Research, Executive Director's Office	The George Institute for Global Health
	Karyn Joyner	Chief Operating Officer	SPHERE
	Rowena Tucker	Strategic Program Manager, Clinical Trials	SPHERE
Western Australia Health Translation Network	Gary Geelhoed	Executive Director	Western Australia Health Translation Network
	Anne McKenzie	Head	Consumer and Community Health Research Network
	Pip Brennan	Executive Director	Health Consumers Council Western Australia
	Karen Carey	Chair	The National Health and Medical Research Council Community and Consumer Advisory Group
	Ben Horgan	Consumer Advocate	Consumer and Community Health Research Network
	Jo Wilkie	Project Officer	Western Australia Health Translation Network
Deloitte Australia	John Zelcer	Workshop Facilitator	Deloitte Australia (Melbourne)
	Michael Kitts	Workshop Facilitator	Deloitte Australia (Sydney)