



Garry Jennings (SHP) and Gary Geelhoed (WAHTN)

on behalf of the

**AHRA Consumer and Community
Involvement Steering Committee**

The Australian Health Research Alliance (AHRA)

7 Advanced Health Research Translation Centres
2 Centres for Innovation in Regional Health



CENTRAL AUSTRALIA ACADEMIC HEALTH SCIENCE CENTRE



Background

- Steering committee established late 2017
- Comprised 2 representatives from each AHRTC/CIRH
- Aim to promote greater consumer and community involvement in health and medical research to optimise the relevance of our research and its potential for translation into meaningful health outcomes

Work program 2018 – map the landscape

1. Conduct a review of published literature about consumer and community involvement in health and medical research
2. Examine 4 leading agencies in the UK, Canada, US and Australia
3. Survey AHRA members about existing types of involvement, and tools and resources used
4. Coordinate a national workshop to discuss the findings and make recommendations for a national approach going forward

1. Published literature – topics

- Concept and meaning of consumer and community involvement
- Benefits of consumer and community involvement
- Views and experiences of researchers and consumers
- Enablers and barriers at policy, systems and practice levels
- Tools and resources to support consumer and community involvement
- Need for evaluation, challenges, possible evaluation models and frameworks

1. Published literature – main findings

- Growing support for consumer and community involvement
 - intrinsic right, investment of public funds in research, policy mandating involvement as condition of funding
- Acknowledged benefits of consumer and community involvement
 - more research relevant and responsive to community needs, supports research translation and dissemination, increases public awareness and support for research
- Numerous tools and resources that encourage, enable and support involvement
 - policies, guidelines, frameworks, training courses, programs, tools, templates
- Areas of need
 - easier access to tools/resources, embedding involvement in systems and operations, benchmarks and standards for involvement, evaluation and measurement (efficacy of tools and resources, impact on research)

2. Leading agencies

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

2. Leading agencies – main findings

- websites provide access to wide array of tools and resources for researchers and consumers
 - policies, guidelines, principles, frameworks, training, templates, budgeting tools, etc.
- extent to which tools and resources have been rigorously evaluated less clear

3. National survey

- Survey developed by AHRA Consumer and Community Involvement Steering Committee
- Disseminated by AHRA member Centres through their member organisations
- Survey open from 30 July - 24 August 2018

3. National survey – who responded?

- 868 people across Australia available for analysis
 - 490 Researchers, 145 Health Professionals, 233 Consumer and Community members

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%

3. National survey - results

Is consumer and community involvement in research valued?

- Over 97 % of Researchers, Health Professionals, and Consumer and Community members valued consumer and community involvement in health and medical research
- Especially valued with respect to setting research priorities and informing research design

“[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”

3. National survey - results

Advantages and disadvantages of consumer and community involvement in research

- ✓ improved research relevance and design
- ✓ beneficial insights from consumer input
- ✓ improved translation of research into practice
- ✓ increased promotion of research and better communication with laypeople
- ✗ low research literacy and ambiguity of consumer priorities and roles
- ✗ time demands
- ✗ biases and personal viewpoints

“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”

3. National survey - results

How are consumer and community members involved in research?

- Advisor or member of an advisory committee for a project and/or organisation
- Linking research and/or researchers with consumers and community members
- Contributing to design of research, tools and resources
- Contributing to conduct of research

3. National survey - results

What factors affect consumer and community involvement?

- Having pathways for connecting with consumers and community members
- Mixed views about role of funding and payments for consumer and community involvement

“There is poor understanding in the research community of what involvement really looks like ... 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.”

3. National survey - results

Over 100 examples of tools and resources that had been used to support consumer and community involvement; those most helpful:

- Mechanisms for communicating with consumers and community members e.g. via websites, social media, newsletters, email etc.
- Networks that bring consumers and researchers together
- Training

But issues of awareness and access for some:

“I am not aware of the professional support for consumers in research ”

3. National survey - results

Less awareness of measurement or evaluation tools for consumer and community involvement



4. National workshop

- Held 12 Nov 2018, attended by 40 people
- Consensus about value of consumer and community involvement and the need to promote, strengthen and support it

Potential actions for AHRA:

- embedding consumer and community involvement in translational research
- developing minimum standards for good practice in consumer and community involvement
- sharing existing resources and expertise to support consumer and community involvement
- evaluating the effects of consumer and community involvement in translational research

Next steps

Draft project report and recommendations to:

- Consumer and Community Involvement Steering Committee for approval
- AHRA Council for approval and endorsement
- Commonwealth Dept of Health

Development and implementation of work program for 2019 and beyond

Acknowledgement

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Thank you