RESEARCH
ADVANTAGE

HEALTH PROFESSIONALS RESEARCH EDUCATION PROGRAM –

Session 1:

CONSUMER AND COMMUNITY ENGAGEMENT

THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

NSW GOVERNMENT
Health
Hunter New England
Local Health District

NSW GOVERNMENT
Health
Central Coast
Local Health District

12.30 – 2.00pm Thursday 14 March 2019
HOST: John Hunter Hospital – Small Lecture Theatre [6067]
Gosford Hospital – Conference Centre
Zoom – ID 231 249 927 **https://uonewcastle.zoom.us/j/231249927**

RESEARCH
ADVANTAGE
connecting and empowering

ACKNOWLEDGEMENT OF COUNTRY

We acknowledge and pay respect to the Awabakal People, traditional custodians of the land on which the John Hunter Hospital is situated and also pay respect to the Darkinjung People, traditional custodians of the land on which Gosford Hospital is situated.

We further acknowledge and respect all other Aboriginal and Torres Strait Islander nations joining us today

PROFESSOR ROSALIND SMITH

Acting Pro Vice-Chancellor, Research and Innovation

WELCOME

Health
Hunter New England Local Health District

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connecting and empowering

Health
Central Coast Local Health District

PROFESSOR JOHN WIGGERS

Director, Clinical Research and Translation, HNELHD

SCENE SETTING

Health
Hunter New England
Local Health District

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Scene Setting

- Limited translation of research evidence
- Delay in translation of research evidence
- Relevance of research to ‘end-users’
- Enhancement of the role of ‘end-users’ in health research
  - Health system/services
    - Clinician-led research
    - System/service priorities
  - Consumers
    - Commonwealth Government research priority
    - State Government priority
    - HNE, UoN, HMRI priority

PROFESSOR BILLIE BONEVSKI

Women in Science Chair, The University of Newcastle and
National Health and Medical Research Council (NHMRC) Career Development Fellow

HORIZON SCAN
CONSUMER AND COMMUNITY ENGAGEMENT

NSW GOVERNMENT | Health Hunter New England Local Health District

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Consumer & Community Involvement in health research

Billie Bonevski

University of Newcastle Women in STEMM Chair

Co-Chair, Consumer & Community Involvement (CCI) Steering Committee, AHRA & NSW Regional Health Partners

Honorary Research & Innovation Conjoint, HNE LHD

Overview

- Who are consumers and community?
- What is consumer and community involvement?
- What is the National Statement on CCI?
- Why is CCI in research important?
- How do I involve consumers & community in my research?
- Where do I access consumers & community?
- What are the AHRA CCI committee activities and recommendations?

What this presentation is not:

- Not Aboriginal and Torres Strait Islander community consultation processes and guidelines
- Not training and up-skilling

Who are consumers and community?

- *Consumers are members of the public who use, or are potential users, of healthcare services. Eg, patients, consumers, families, carers and other support people.*[1]

- Community is the wider grouping of consumers across society. Could be based on geography, ethnicity or shared interests or values.

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1. Australian Commission on Safety and Quality in Health Care. Safety and Quality Improvement Guide Standard 2: Partnering with Consumers, Oct 2012, Sydney. ACSQHC, 2012.

What is consumer and community involvement (CCI)?

- Numerous terms in the literature > Community engagement, Community involvement, Community participation, Consumer participation, Patient participation, Public involvement [1]
- Not defined uniformly and it does not incorporate a single concept and type of activity
- CCI is a continuum

1. Sarrami-Foroushani P, et al. Key concepts in consumer and community engagement: a scoping meta-review. BMC health services research. 2014;14(1):250

NHMRC Statement on CCI

The Statement

Vision:

Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.

Our values:

Shared understanding, respect and commitment

Purpose:

To guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research.

NHMRC Statement on CCI

- Based on the Australian Code for the Responsible Conduct of Research:

“*Appropriate consumer involvement in research should be encouraged and facilitated by research institutions, and researchers*”

- Statement includes role of research institutions, researchers and consumers & community

- Section in NHMRC grant applications

Why is CCI important?

- Moral/ethically right thing to do (WHO, UN, Aus Code for Responsible Conduct of Research)
  - *"patients are at the core of our system and, as such, are part of the solution"*
- Tax payers money funds major grants schemes and charitable grants – intrinsic right to be involved
- Improves equity and diversity, therefore the representativeness and generalisability of your research
- Provides a unique user perspective to the process that an expert without the lived experience may lack
- Mandating CCI is a requirement for some publicly funded grants, eg, Cancer Council, and Cure Cancer

Why is CCI important?

- Aligns with CCI initiatives for clinical care in health services:
  - The National Safety and Quality Health Service Standards, Standard 2. Partnering with Consumers
  - To protect the public from harm and improve quality of care
  - Planning, designing, implementing, governing, redesigning, evaluating care

  - Available at: https://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/national-safety-and-quality-health-service-standard-2-partnering-with-consumers/

Why is CCI important?

- Improves implementation of research – early identification and prevention of challenges
- Increasingly viewed as a keystone to translational science:[1]

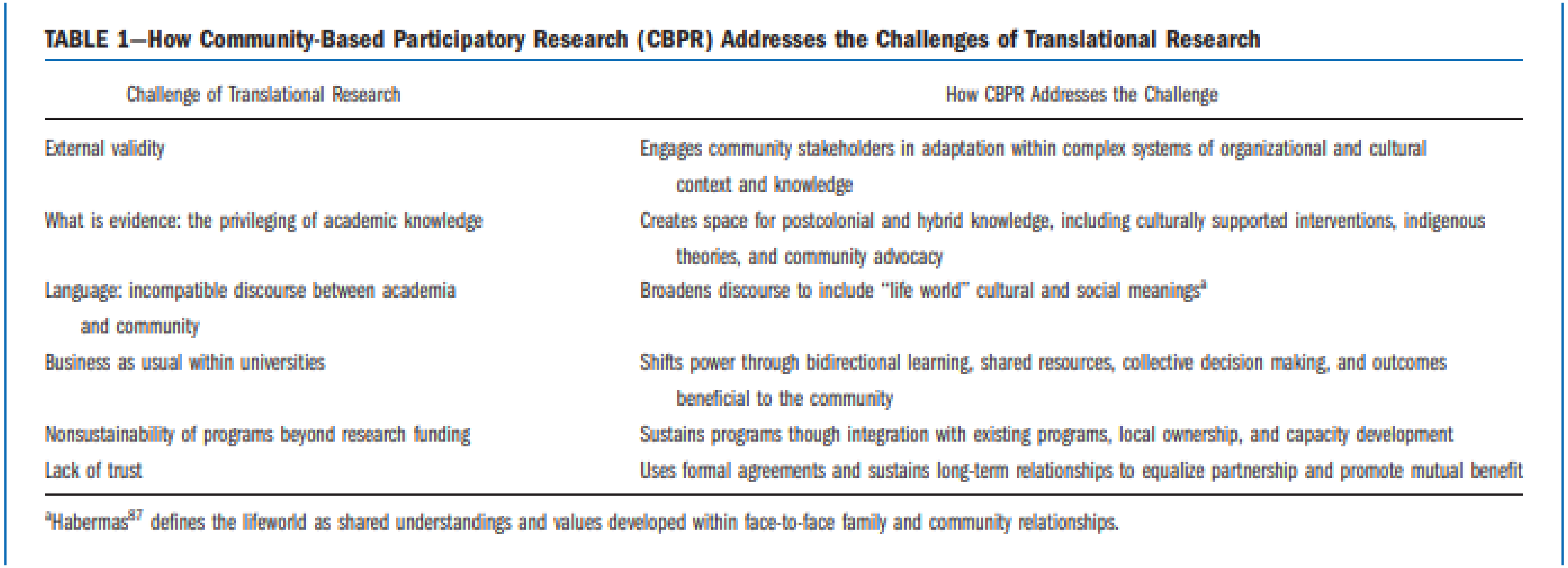

TABLE 1—How Community-Based Participatory Research (CBPR) Addresses the Challenges of Translational Research

Challenge of Translational Research	How CBPR Addresses the Challenge
External validity	Engages community stakeholders in adaptation within complex systems of organizational and cultural context and knowledge
What is evidence: the privileging of academic knowledge	Creates space for postcolonial and hybrid knowledge, including culturally supported interventions, indigenous theories, and community advocacy
Language: incompatible discourse between academia and community	Broadens discourse to include "life world" cultural and social meanings[a]
Business as usual within universities	Shifts power through bidirectional learning, shared resources, collective decision making, and outcomes beneficial to the community
Nonsustainability of programs beyond research funding	Sustains programs though integration with existing programs, local ownership, and capacity development
Lack of trust	Uses formal agreements and sustains long-term relationships to equalize partnership and promote mutual benefit

[a] Habermas[87] defines the lifeworld as shared understandings and values developed within face-to-face family and community relationships.

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1. Wallerstein N, Duran B. Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity. American J of Public Health. 2010;100(S1):S40-S6.

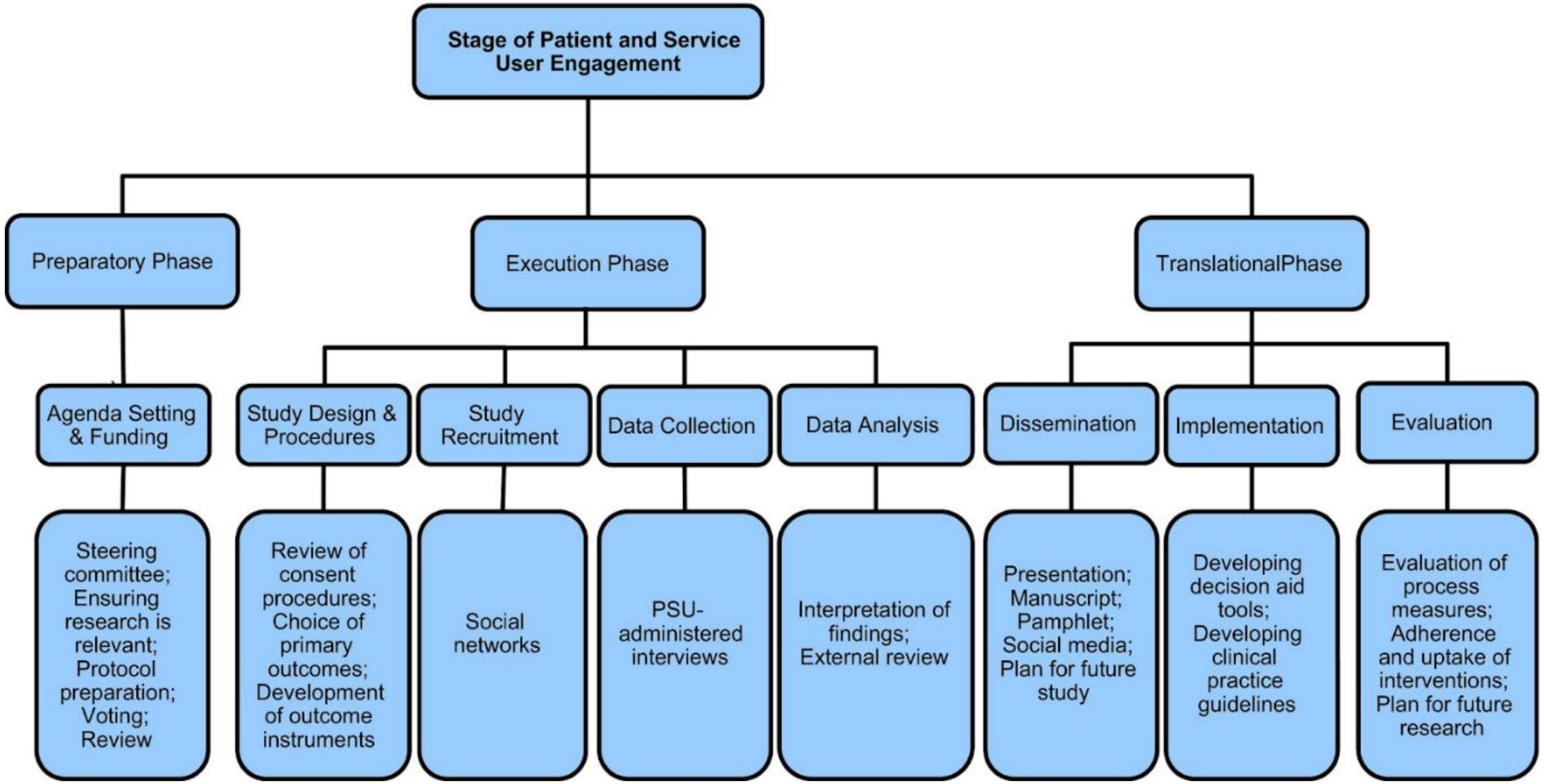
How do I involve consumers & community in my research?

- Consumers can be engaged in research through a variety of ways, eg [1]

Phase in the IR cycle	Potential roles for community engagement
1. Problem identification	Input on key problems or issues to be addressed; understanding context, conceptualizing key issues; identifying key stakeholders to involve; conducting stakeholder mapping and analysis
2. Design and planning	Shaping key research aims, questions to meet local objectives; input into methodology, especially contextually appropriate approaches for data collection; review of research documents and tools (e.g., protocol, consent forms, instruments)
3. Implementation	Generating awareness and ownership of research project; potential involvement in an intervention being studied, pilot testing of instruments; participating as data collectors or respondents; formal partnership and collaboration with community groups
4. Analysis and	Interpreting findings; discussing implications; adding contextual depth and nuance to recommendations

1. Glandon D, et al. 10 Best resources for community engagement in implementation research. Health policy and planning. 2017;32(10):1457-65

How do I involve consumers & community in my research?



Stage of Patient and Service User Engagement

Preparatory Phase

Execution Phase

TranslationalPhase

Agenda Setting & Funding

Study Design & Procedures

Study Recruitment

Data Collection

Data Analysis

Dissemination

Implementation

Evaluation

Steering committee; Ensuring research is relevant; Protocol preparation; Voting; Review

Review of consent procedures; Choice of primary outcomes; Development of outcome instruments

Social networks

PSU-administered interviews

Interpretation of findings; External review

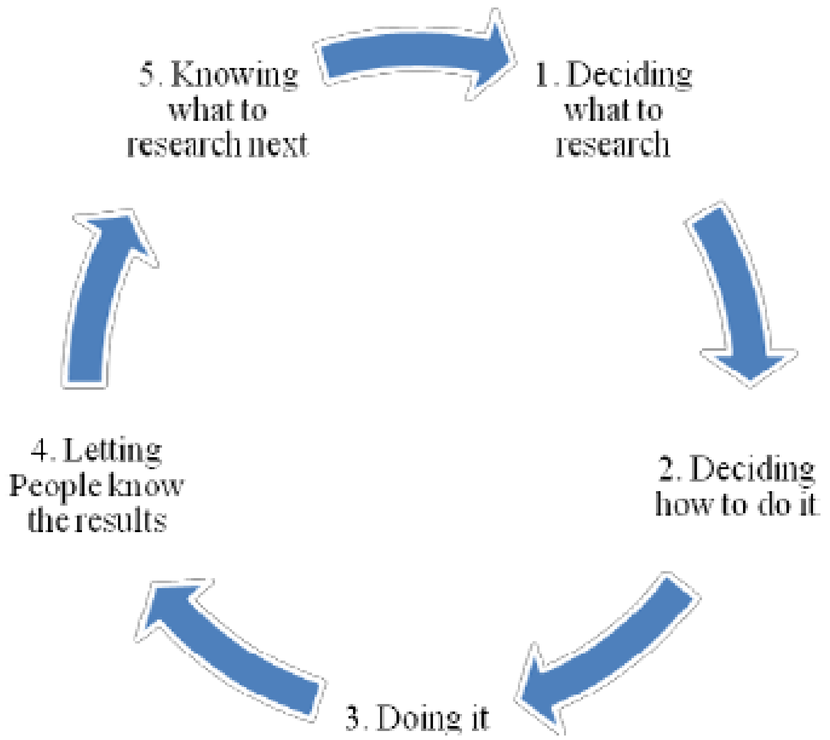
Presentation; Manuscript; Pamphlet; Social media; Plan for future study

Developing decision aid tools; Developing clinical practice guidelines

Evaluation of process measures; Adherence and uptake of interventions; Plan for future research

1. Shippee ND et al. Patient and service user engagement in research: a systematic review and synthesized framework. Health Expectations. 2015;18(5):1151-66.

How do I involve consumers & community in my research?



1. Deciding what to research

2. Deciding how to do it

3. Doing it

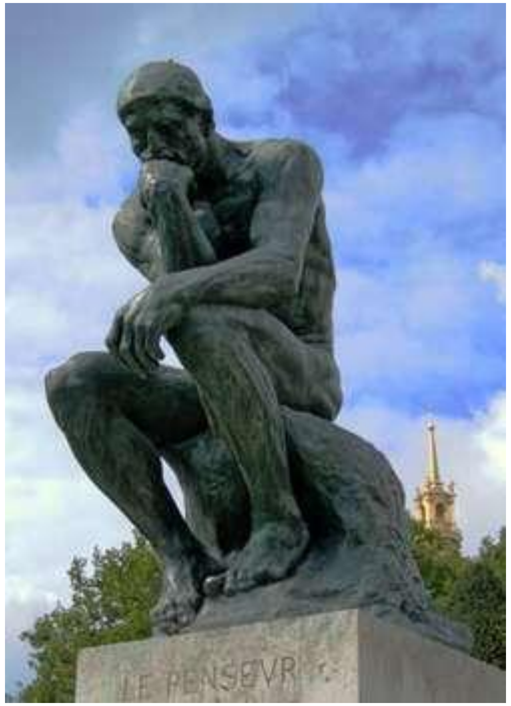
4. Letting People know the results

5. Knowing what to research next

NHMRC Statement on consumer and community involvement in health and medical research, 2016

1. Deciding what to research

- Historic model of research question generation = scientist
- Current approach is to involve consumers as early as possible



Options include:

- Community or consumer-driven research (eg, organisations calling for research)
- Community needs assessment and Priority setting (eg, service user surveys, town hall meetings, qualitative studies)
- Involvement in grant applications and distribution of funding (eg, reviewing grants)

2. Deciding how to do it

- Involve consumers as part of the research team, steering group, or include a Consumer Advocate
- Some consumer organisations train ‘Document Reviewers’ who can read and review information statements, study educational materials, plain language summaries
- Consumers are trained to provide input into protocol design, eg, WA Consumer and Community Health Research Network
- Formative research with consumers and community to guide study design process

3. Doing it

- Involve consumers as part of the research team, steering group, or include a Consumer Advocate
- Employ consumers and community members as part of the research team, eg Quitlink trial and peer workers to collect data or deliver intervention
- Engage “Research Buddies” that work as a link between consumers or communities and researchers
- Use of social media and networking for recruitment, eg Carers organisations facebook groups

4. Letting people know the results

- Plain English summaries
- Disseminate feedback, eg infographics, via consumer and community settings, eg, health services, schools, social services
- Social media and lay media (with media training for accurate and lay science communication)
- Consumer forums, peak organisations
- Involvement in developing next step tools, eg, clinical guidelines, patient education resources

5. Knowing what to do next

- Community or consumer-driven research (eg, organisations calling for research)
- Community needs assessment and Priority setting (eg, service user surveys, town hall meetings, qualitative studies)
- Involvement in grant applications and distribution of funding (eg, reviewing grants)
- Consumer forums, peak organisations, eg TNT trial and NADA
- Involvement in developing next step tools, eg, clinical guidelines, patient education resources

What amount of involvement is satisfactory?

- Variable project to project

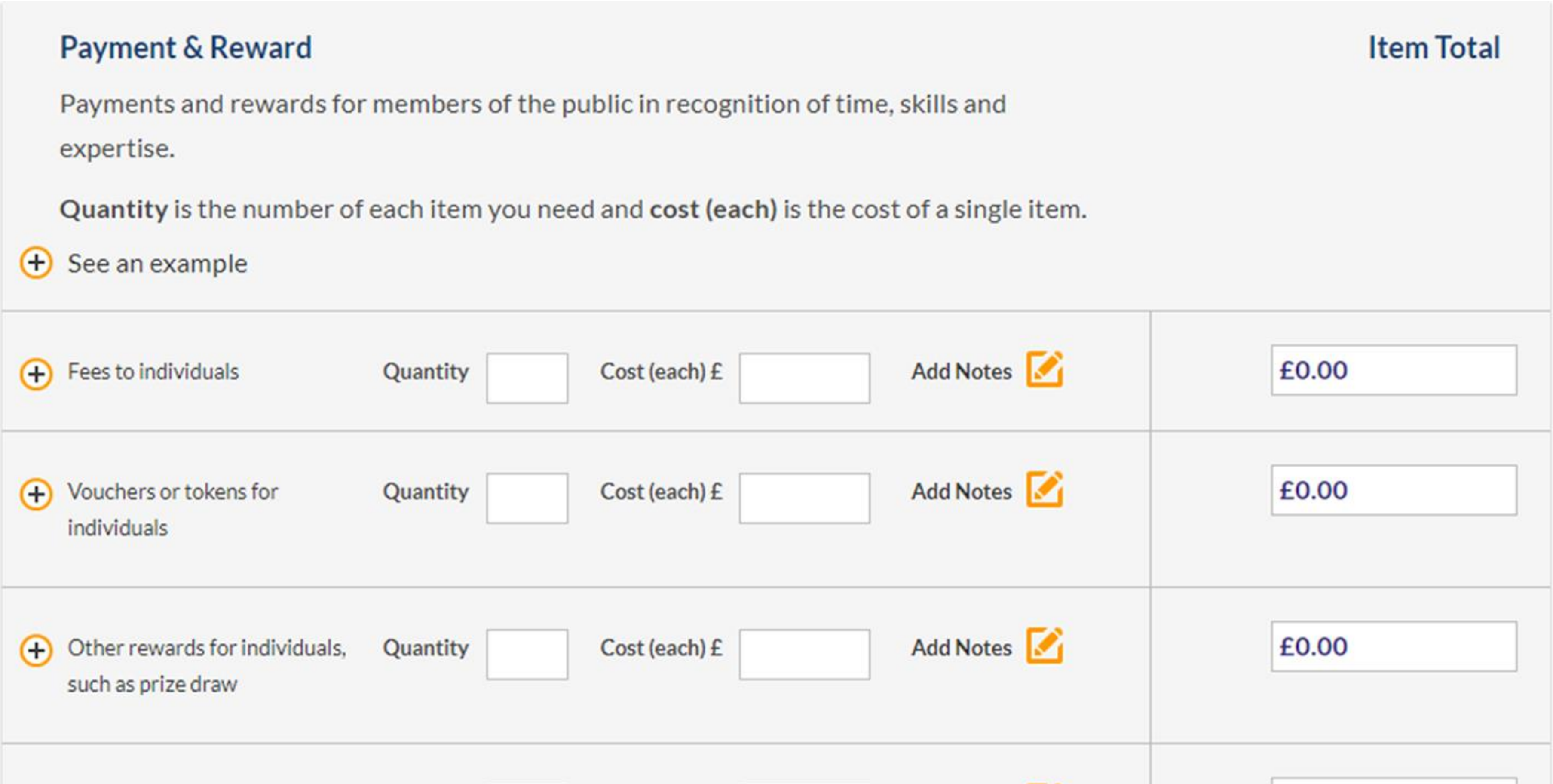
- Depends on:
  - Aims of the research
  - Nature of the research
  - Access to consumers and community
  - Budget, time, resources, etc

Where do I find people who are interested in being involved in research?

- Peak health consumer organisations, eg, Consumers Health Forum of Australia, Health Consumers NSW
- Disease or discipline specific organisations, eg, Cancer Council NSW and Cancer Voices NSW provide consumer advocacy services, consumer training and grant reviewers OR Stroke Foundation Consumer Council
- Locally, eg, HMRI Volunteers registry, Hunter Stroke Research Volunteers Register, HNELHD Mental Health Consumer Participation Unit
- If you are a health provider – your patients, consumers and carers (but training is important)

Important considerations

- Acknowledgement and authorship
- Ownership and IP
- Payment
- Feedback



Payment & Reward | **Item Total**

Payments and rewards for members of the public in recognition of time, skills and expertise.

Quantity is the number of each item you need and **cost (each)** is the cost of a single item.

Fees to individuals	Quantity		Cost (each) £		Add Notes	£0.00
Vouchers or tokens for individuals	Quantity		Cost (each) £		Add Notes	£0.00
Other rewards for individuals, such as prize draw	Quantity		Cost (each) £		Add Notes	£0.00

AHRA Consumer & Community Involvement Committee

- AHRA is an alliance of 7 NHMRC-accredited Advanced Health Research Translation Centres and 2 Centres for Innovation in Regional Health
- 1 of its 4 MRFF-supported priorities is CCI in research and health innovation

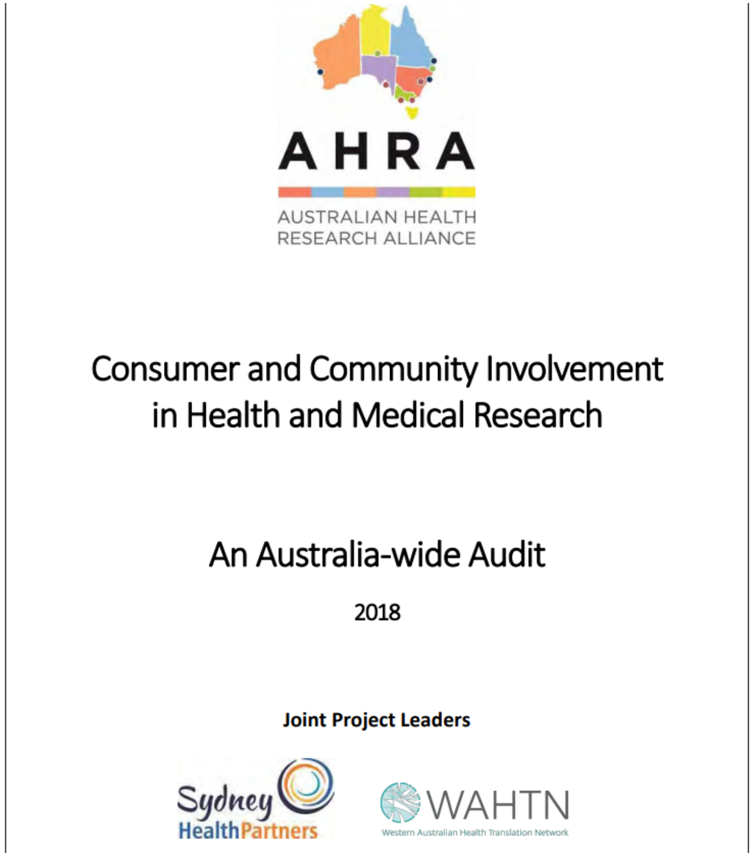
AHRA
AUSTRALIAN HEALTH RESEARCH ALLIANCE

- Prof Clare Collins & Billie Bonevski: Co-Chairs of CCI committee representing NSWRHP on AHRA

AHRA CCI Report

Activities:

1. Environment scan of the relevant literature
2. National survey of health researchers and consumers
3. A stakeholder workshop to develop recommendations



AHRA

AUSTRALIAN HEALTH
RESEARCH ALLIANCE

Consumer and Community Involvement
in Health and Medical Research

An Australia-wide Audit

2018

Joint Project Leaders

Sydney HealthPartners

WAHTN
Western Australian Health Translation Network

A report is available at: https://www.slhd.nsw.gov.au/SydneyHealthPartners/pdf/AHRA_CCI_Final_Report.pdf

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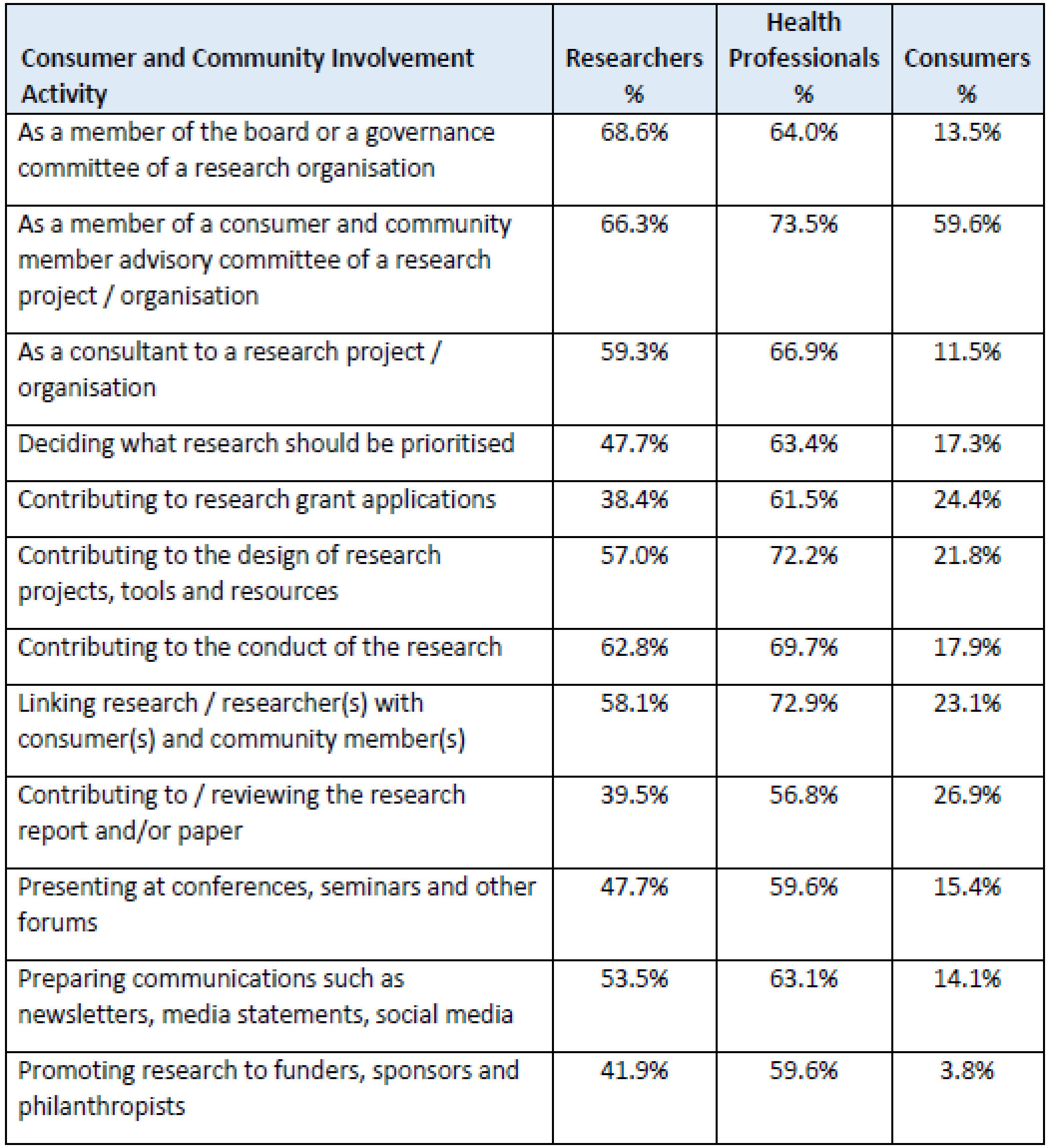
Survey results:

- N = 868
  - 490 researchers
  - 145 health prof
  - 233 consumers

- How are C&C
Involved in research?



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%

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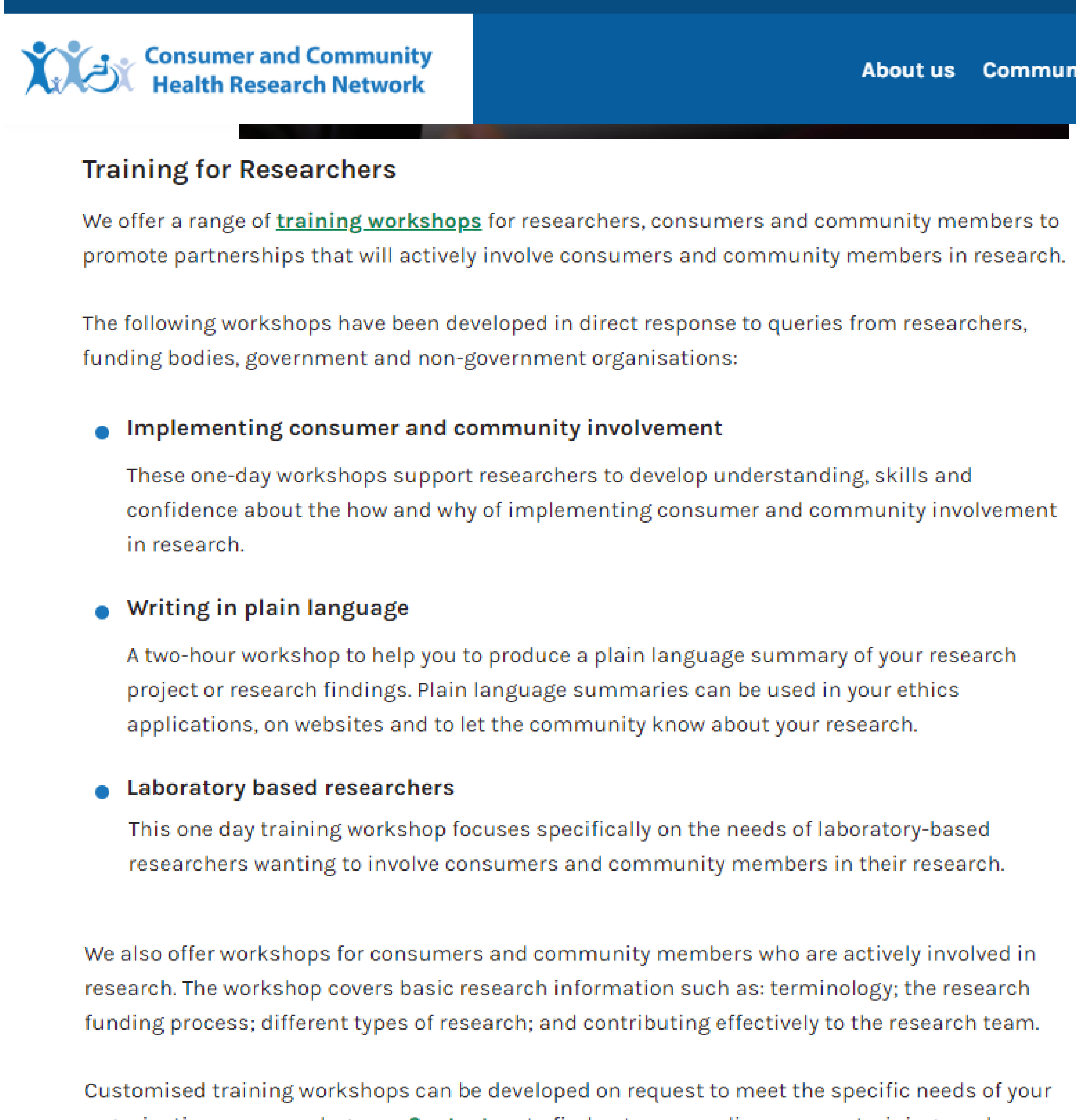
Tools and resources

Consumer and Community Health Research Network

- West Australian Health Translation Network
- Delivers its CCI activities mainly through its Involvement Program:
- For C&C:
  - Join our network – registry of interested people
  - Training for consumers
  - Consumers can be involved in a range of activities, eg:
    - As document reviewers
    - C&C members on research teams
    - Research buddies
    - Join advisory or steering groups
    - Become a C&C researcher
    - Priority setting partnerships

Consumer and Community
Health Research Network

- For Researchers:
  - Their Consumer Advocates provide support and advice to researchers on all aspects of CCI
  - Matching Service – to link project and C&Cs
  - Advice on budgeting for CCI
  - Training Workshops for researchers and C&Cs:



Training for Researchers

We offer a range of training workshops for researchers, consumers and community members to promote partnerships that will actively involve consumers and community members in research.

The following workshops have been developed in direct response to queries from researchers, funding bodies, government and non-government organisations:

- **Implementing consumer and community involvement**

  These one-day workshops support researchers to develop understanding, skills and confidence about the how and why of implementing consumer and community involvement in research.

- **Writing in plain language**

  A two-hour workshop to help you to produce a plain language summary of your research project or research findings. Plain language summaries can be used in your ethics applications, on websites and to let the community know about your research.

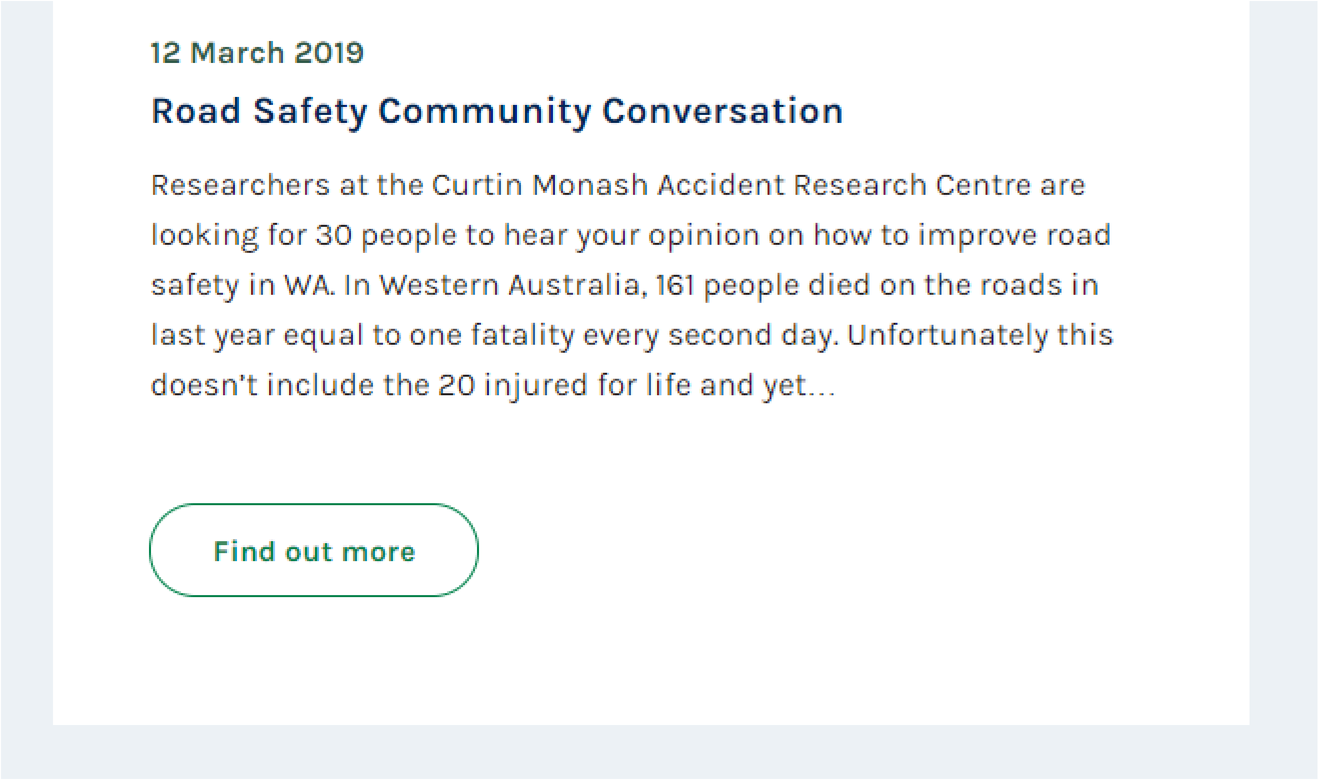
- **Laboratory based researchers**

  This one day training workshop focuses specifically on the needs of laboratory-based researchers wanting to involve consumers and community members in their research.

We also offer workshops for consumers and community members who are actively involved in research. The workshop covers basic research information such as: terminology; the research funding process; different types of research; and contributing effectively to the research team.

Customised training workshops can be developed on request to meet the specific needs of your

- Promoting your research, eg:



12 March 2019

Road Safety Community Conversation

Researchers at the Curtin Monash Accident Research Centre are looking for 30 people to hear your opinion on how to improve road safety in WA. In Western Australia, 161 people died on the roads in last year equal to one fatality every second day. Unfortunately this doesn't include the 20 injured for life and yet...

- Written Resources on:
  - Barriers to CCI
  - Planning for CCI
  - CCI Fact Sheets (simple tools for both researchers and C&C)
  - The Green Book: CCI in health and medical research

Website: https://www.involvingpeopleinresearch.org.au/researchers/#researcher-support

AHRA Key Recommendations for its member Centres

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.

4 Recommended priority actions:

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
- capacity building initiatives (eg, through training programs, webinars etc.)
- 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

AHRA Key Recommendations for its member Centres

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.

What do consumers say?

People want to be involved in health research

1. Todd AL, Nutbeam D. Involving consumers in health research: what do consumers say? Public health research & practice. 2018;28(2).

THANK YOU

THANK YOU

University of Newcastle
Hunter New England LHD
NSW Regional Health Partners
Australian Health Research Alliance

Contact me on:
Billie.bonevski@newcastle.edu.au
or ph: 40335710

References

1. Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite J. Key concepts in consumer and community engagement: a scoping meta-review. BMC health services research. 2014;14(1):250.
2. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Affairs. 2013;32(2):223-31.
3. Wallerstein N, Duran B. Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity. American Journal of Public Health. 2010;100(S1):S40-S6.
4. Glandon D, Paina L, Alonge O, Peters DH, Bennett S. 10 Best resources for community engagement in implementation research. Health policy and planning. 2017;32(10):1457-65.
5. National Health and Medical Research Council & Consumers Health Forum of Australia. Statement on Consumer and Community involvement in Health and Medical Research, . 2016.
6. Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. Journal of comparative effectiveness research. 2015;4(2):133-45.
7. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, et al. Patient and service user engagement in research: a systematic review and synthesized framework. Health Expectations. 2015;18(5):1151-66.
8. Deverka PA, Lavallee DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, et al. Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. Journal of Comparative Effectiveness Research. 2012;1(2):181-94.
9. Health Consumers Alliance of SA Inc. A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute. 2014.
10. Sarrami-Foroushani. P, Travaglia. J, Eikli. M, Braithwaite. J. Consumer and community engagement: A review of the literature. 2012.
11. Todd AL, Nutbeam D. Involving consumers in health research: what do consumers say? Public health research & practice. 2018;28(2).
12. Markovic M, & Haby, M. M. Community engagement. An evidence summary. In: Branch PaPH, edi Melbourne Victorian Government Department of Health; 2011.

SPEAKER: MEREDITH Burke

Consumer Representative, The Hunter Stroke Research Register

I started a day just like any other

stroke

STROKE
RESEARCH REGISTER
HUNTER

Associate Investigator Meredith Burke

The development of a telehealth exercise program for people who have had a stroke

Workshop format and content

provided resources for the workshop – created a video

advising on ways to improve communication with stroke survivors

Impact so far: Improved communication, structure and content of the workshops to allow better understanding, engagement and participation

We are just people like you ……

Your skill set + **Our skill set** = **Magic**

@merry_burke

QUESTIONS

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connecting and empowering

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WHAT'S NEXT

Health Professionals Research Education Program: ***Session 2: TBC Topic***
Thursday 13 June 2019 **[Host: Gosford Hospital – TBA Room, Alternative location: John Hunter Hospital – 6067 Lecture Theatre, John Hunter Hospital and via Zoom**

Grant Accelerator Program: ***Session 1: NHMRC New Schemes - INVESTIGATOR Grant, IDEAS Grant & CLINICAL TRIALS Grant***
Thursday 21 March 2019 [Host: HMRI – Caves Theatre and via Zoom]

ECR C&E: ***Session 1: Flash Mentoring***
Tuesday 19 March 2019 **[Face – to – Face: Treehouse, Shortland Building, Callaghan Campus, UON]**

http://www.newcastle.edu.au/research-and-innovation/resources/research-advantage

NSW Regional
HEALTH PARTNERS
CENTRE FOR INNOVATION IN REGIONAL HEALTH

Consumer and Community Involvement in Research

Christine Jorm, Director NSWRHP

Our strategy includes:

2. Building consumer and community capacity to contribute to, and benefit from, research by

2.1 Providing opportunities in priority-setting, co-creation and training.

2.2 Building consumer awareness of the evidence-practice gap and consumer demand for best evidence practice.

2.3 Encouraging participation in research and raising awareness of medical research.

3.1 Training researchers in: consumer and community involvement

Australian Government
National Health and Medical Research Council
RECOGNISED AS A CENTRE FOR INNOVATION IN REGIONAL HEALTH

NSW Health Hunter New England Local Health
NSW GOVERNMENT

Proudly funded by the NSW Government in association with:
Central Coast Local Health District
Hunter New England Local Health District
Mid North Coast Local Health District

Calvary Mater Newcastle
phn HUNTER NEW ENGLAND AND CENTRAL COAST
HMRI
THE UNIVERSITY OF NEWCASTLE AUSTRALIA
une University of New England

Involvement is not optional

‘Big session in BMJ editors meeting on Thursday about now obligatory for BMJ group authors to specify extent of public and patient participation’. *Email from Prof Rod McClure - yesterday*

nswregionalhealthpartners.org.au

Let us help you – we have invested in workshops = two days of free training for researchers

Consumer Involvement Survey

Sarah Harrison /// March 13, 2019 /// No Comments

Interested in involving consumers in your research? Fill out our short survey and register your interest in training here. For further information, please contact Dave