

Connecting with Community Forum | Summary of Table Discussion Notes

Wednesday, 16 October 2019

SAHMRI Auditorium

Discussion 1: What strategies or learnings from the presentations do you think would work best in future research priority setting activities?

Table 1

The Hospital Research Foundation filming idea was interesting but needs added resources for both funder and researchers – “not merely a 10-minute activity”

Explicit and clearer mechanisms for acknowledging consumer engagement; budget/payment mechanisms/guidelines

Time to build capacity for consumer-researcher partnership

Ethical concerns; design of research is influenced right back at the ethics point

Table 2

Relationship between consumer and researcher is way behind relationship between consumer and health service

Engagement should be at all steps of the process

Get better understanding of which parts of the research process are the most critical

Giving a say for where research should be done

Change from competition to collaboration

Table 3

Advocacy to change systems as an integral issue; have the advocacy to change the system could be part of the research

Some people have little understanding of health literacy

Projects should have co-design element

Advocate to change the systems/process so this is compulsory; Do you advocate to NHMRC to make consumer engagement a compulsory section on a grant application?

Some clinical projects don't recognise consumer advocacy; How to engage clinical researchers with community engagement (some health professionals are very busy)

Projects to be presented to consumers in a language they can understand; Researchers need to know how to connect with consumers

Terminology mystifying to some consumers

Challenges of how-to engage consumers with researchers to make our projects relevant

Role of researcher:

- Consumer engagement challenge
- What do researchers do/how/to embed it?

Table 4

Include people with lived experience on all panels

Explore the barriers of researchers engaging people with lived experience (including strategies to tackle those barriers)

Training of researchers and people with lived experience

- Demystifying research
- Both researchers and consumers in the room
- Building confidence in consumers in order to be able to engage with researchers
- Choose researchers carefully for the workshops
- Level/stepped approach 1) Demystifying research/builds confidence in community, 2) Engaging researchers and consumers and 3) Project specific training
- Creating opportunities to level the power dynamics e.g. send consumers opportunities to email questions prior to the event

Strategy for funding consumers

Selection; the project applications must demonstrate “co-design” and need to attract “consumer co-design” with funding

Table 5

Stage of involvement important

How many representatives; one or two consumers

Process; Incentive versus motivation to be involved match

Avenues for advertising roles needs to be broad (communication plan)

Researchers have the power versus consumers with lived experience (co-design principles)

Framing; Market framed for The Hospital Research Foundation (only people involved are people who pay for tickets/services)

Reimbursement policy; Layer according to level of responsibility

Consumers on health ethics committee

Table 6

Consumer involvement in guiding participation in problem development

Consumer involvement in directing focus on health promotion and prevention activities e.g. community connection

Using research that has already occurred overseas and inform consumers to assist in translation

Grant applications should explicitly state need for co-design (and development of problem)

Consumer involvement/engagement needs to be genuine not tokenistic (asking consumers about barriers to involvements)

Discussion 2: Outline your “top-tips” for one of the following topics

Communication

Literacy/language – “Research speak”

Cultural issues

Acronyms

IT concerns

Does the structure of communication of engagement always need to be ‘a reference group’, ‘research team meeting’ with 1-2 consumer representatives? – Alternative community to ‘organise’ for research group (e.g. In the community setting, around the kitchen table).

Consumer representative versus a group/social media

‘Coming in’ to researcher versus ‘going out’

Communication re: outcomes of research/outcomes of applications

Rural consumers; library skype support/hub for access

Clarifying expectations of the consumer engagement/researchers need to be clear to what the project needs:

- Are they representing the voice of ‘many’ through their networks?
- Are they there as individual for their individual experience?

Clear, concise and open

Relationships

Make it genuine

Manage expectations

Use (piggy back on) existing relationships (affiliations) between consumers and peak bodies

Clarification about research; Plain English

Removing jargon

Several organisations that could benefit from knowing about the Register/ROSA e.g. Global Centre for Modern Aging, Health Foundation, Cancer Council and other charities. There are also several marketing businesses doing consumer engagement and testing of messages on community.

Research translation

More likely to happen if the research was developed to solve a consumer identified problem

Lay description so consumer can understand (definitions)

Removing jargon

Shared vision

Translation key information into ‘understandable’ language.

Developing key messages of what research translation is:

- Translating research evidence into policy/practice
- Understand of the translation process/timing

People with a lived experience – experience valuable source of knowledge

Feeling of empowerment is important to consumers seeking relationships with research groups
Important to communicate the real-world impact of the research to the community
Showcase the announcement of when the research is translated into the community rather than just the “cure for cancer”
Reflecting on why research doesn’t go further e.g. health promotion tool
Communication at all stages re progress/lack of progress (or alternative pathways)
Pathway alternative/feasibility options – HTSA help do basic feasibility testing (if one group won’t move it forward – help identify if its feasible and move it forward)
Joining dots in/across system in order to move research along the pathway to achieve impact
Consumer driven research project

Involving new people

Network of consumer organisations - All with their own pool of consumer and community
Training of consumer advocates
Not thinking of them as volunteers but as part of the team
Get out of the city; Connect to outer/regional suburbs
Regular/routine e.g. community group settings; regular presence and a coordinated approach (including remote communities)
Multicultural aspects; Communication techniques for presentations
Use of social media in some instances
Engaging with support groups e.g. professional networks
Harnessing retirees or part retirees from all works of life to become involved with community engagement (experience not wasted and still valued role)
It might be worth chatting to the Fay Fuller Foundation about their ‘Our Town’ initiative - Possible opportunity for strategic partnerships in country towns as well as leveraging dollars

Embedding engagement

Grant process should cover how consumers will be involved across the life of research
Timing of meeting to be schedule when consumer can attend – not that it is scheduled and then they come if they can
Papers; Accessibility (often a lot to print and make notes for meaningful contribution)
Don’t have the attitude that we are all consumers; If your role is as a researcher then you are not a consumer in this instance
Researchers training; Not just early career
Building collaborative capacity
Embedding consumers within the governance structure
Employ people in research as peer workers
Getting the right skills for the right roles
Training

Two-way process (both giving)

Using the IAP2 International Association of Public Participation for Guidance

Trade-offs in engagement:

- Design; Representative vs inclusive participation
- Process; Organisation/institutional vs public (power in process)
- Outcomes; Actional vs upstream