Reducing the Gap between Research, Policy and Practice Initiative

Summary Report of

A Breakfast Conversation

Venue: Flinders Victoria Square
182 Victoria Square, Adelaide

24 November 2015

Introduction

During the 8th Health Services & Policy Research Conference, a number of researchers articulated a need to identify and learn more about effective methods for ensuring that research evidence informs policy and practice. In response to this request, *Reducing the Gap between Research, Policy and Practice Initiative* was created.

Following is a summary of feedback from our latest event which focused on including consumers' voices in designing, undertaking and translating research. This interactive semi-structured conversational event encouraged exchange between researchers, clinicians, policy makers and consumers about their personal and practical challenges experienced in addressing research-policy-practice gaps.

Professor Jon Karnon, President of the Health Services Research Association Australia and New Zealand (HSRAANZ) opened the event by reflecting on the critical importance of consumer engagement to inform research directions. He welcomed the readiness of the Health Consumer Alliance (HCA) SA to join forces with Initiative partners – PHCRIS, the South Australian Health & Medical Research Institute (SAHMRI), Cancer Voices and HSRAANZ.

Mr Michael Cousins, CEO of Health Consumer Alliance (SA) went on to discuss issues pertaining to policy beyond legislation, defacto 'policies by culture' within organisations and the importance of co-design and co-production of research. Michael and Julie Marker, Chair of Cancer Voices (SA) then invited participants to participate in an Appreciative Inquiry, focusing on what is currently working well and any inspirational ideas for how to come together in the future in order to improve health outcomes for all. Small group discussions also centred on exploring ideas and developing questions which could lead to improved research collaborations.

Discussions

Participants acknowledged that involving consumers in the design, undertaking and translation of research improved the quality and usability of the evidence. Encouragingly, a number of organisations, programs and projects were already actively encouraging consumer involvement. Participants identified several techniques currently used to assist consumers to play an active role within the research process.

Nevertheless, participants highlighted a number of ways in which consumers could be better supported to actively participate in research. Suggestions ranged from improving research literacy to encouraging researchers to actively engage with consumers and advocate for their concerns. Interesting suggestions included the idea of Consumer Ambassadors, ensuring research findings are written up for lay audiences and breaking down silos which participants believed repressed initiative and inquisitiveness.

A number of research questions were also identified. Some related to how to build better collaboration with consumers. Others focused on the general question of how to ensure research evidence made a difference to policy and practice. Finally, a small number dealt with important issues around improving care for people living with chronic disease and disabilities.

Below is a pictorial representation of the ideas that came out of the small group work. We hope you find this and the more detailed list of feedback from participants not only informing but also a useful resource to stimulate new ways of collaborating.

Inspirational ways of working

Participants identified organisations which actively supported consumers to collaborate with researchers. These included Health Consumer Alliance, Aboriginal Community Controlled Health Organisations, South Australian Health and Medical Research Institute (SAHMRI) and Wardliparingga Aboriginal Research Unit at SAHMRI.

A number of research projects and programs which were considered exemplars for collaboration more generally and consumer involvement more specifically, were also identified by participants:

- Alcohol and harm reduction programs
- Whyalla Regional Falls Prevention Program – self-management
- Sudden Infant Death Syndrome Research
- Asthma and young peoples' survey
- Access to female General Practitioners mapping
- McGrath Foundation with the inclusion of breast care nurses for immediate and ongoing care
- Optimal Care Pathways Report in Victoria.

Participants also identified a number of techniques which promote or support consumer involvement in research:

- Visual techniques such as the Story Board approach currently used to develop evidence with Aboriginal and Torres Strait Islander communities
- Consumer training provided by the Health Consumer Alliance
- Collaboration with consumers and consumer organization on the design of research studies
- Research partnerships with consumer organisations in designing and undertaking research
- Respectful relationships and true collaborations between researchers, consumers, management and planners

- Willingness to support new ideas
- Stretching the boundaries of what will be considered including 'Pets as Therapy Dogs' – a service provided by the Guide Dog Association
- A patient, consumer client focus
- Co-designed research
- Involving champions who have a voice, a vision, passion and stamina as well as the evidence and education to put forward a consumer perspective
- Strong community based responses resulting in change including HIV advertisements.

For future consideration

In order to ensure that research benefited from consumer involvement, participants also identified a number of changes which could be made to the way in which research is conducted. In particular, there was a strong emphasis on increasing communication between researchers and patients/consumers, placing the emphasis on researchers proactively reaching out to consumers.

Other ways in which consumers could be better supported to participate in research co-design, co-production and translation included:

- Educating consumers about how they can contribute to research outcomes
- Supporting ways in which the research literacy of consumers could be strengthened
- Looking for consumers willing and able to contribute to research
- Evaluating how consumers' contributions improve the research process
- Ensuring effective communication with particular emphasis on the use of language which suitably conveys messages to consumers
- Empowering consumers to pursue their own health interests
- Encouraging consumers and consumer organisations to undertake their own research
- Considering ways that older consumers can participate in research
- Ensuring consumers know their rights and have confidence in their role as experts.

Some of the suggested steps that researchers could take to ensure a more inclusive research co-design and co-production process included:

- Ensuring that research always includes the consumer voice
- Learning about how consumers can contribute to research outcomes
- Being open to consumer points of view including aspects of health and wellbeing that go beyond a biomedical paradigm such as meditation or natural therapies
- Listening to consumers in order that they can influence the type of research conducted
- Making sure that researchers act as agents for consumers
- Ensuring that researchers know the consumer groups their research may impact
- Including consumer input when translating research to policy and practice
- Breaking down the barriers that come from 'research elitism'
- Overcoming some of the concerns that consumers face in operating in research and policy space - lacking confidence, knowledge of rights and not taught to ask questions
- Developing flexibility within the research process.

More general changes that researchers could make included:

- Rephrasing the term 'barriers' to 'problem solving'. The 'barrier' philosophy is a barrier
- Avoiding research duplication
- Promoting cooperation as opposed to the current competitive grant funding process
- Avoiding 'politus' whereby being polite means that people may not feel able to voice their concerns or issues
- Utilising previous research and research evidence
- Overcoming interpersonal barriers that often prevent constructive collaborations e.g. people with good ideas don't always get on well together
- Acknowledging that health services and clinicians within these health services don't always have the research skills or space in their clinical/ service delivery load to be involved in research. More sense to use researchers' research skills than try to teach clinicians to become researchers.
- Having the time and energy needed to invest in developing and maintaining networks, and also having the luxury of time to reflect in order to define the 'problem' or work on solutions
- Embedding researchers within health services, with clinicians
- Overcoming the hierarchical structures within government which prevents networking. Staff had to go under the radar with informal networks. Can't go doing things, talking to people that the line manager hasn't authorised
- Breaking down silos which repress initiative and inquisitiveness
- Measuring and then rewarding knowledge translation
- Inviting policy-makers to visit and join in meetings. However, they are always rushing to appointments, never take long enough to sit, absorb, listen and work through an issue
- Employing emotional intelligence in marketing to maintain partnerships and co-design
- Considering how meaningful the process of gathering and interpreting evidence. Research method is a key area of expertise and skills, and not always useful to continue digging deeper into isolated pockets of content knowledge that aren't really meaningful to enhance the experience of consumers.

Changes relating to the way in which the healthcare system responded to the needs of consumers were also suggested:

- People talked about their personal and family experience of services, gaps in evidence, bewilderment and frustration at not knowing what to do despite being part of the system
- Remaining locked in their 'usual contacts' and not knowing how to find 'like-minded' relevant others to connect with
- 'Believing in magic bullets'. Might be better if instead people are taught skills in self-management from the age of 10
- Struggling with cultural change which is needed, but so hard to achieve because it takes so long
- Believing that the doctor knows best – particularly evident in older generations.

Questions to consider

Questions tended to relate to the way in which research was conducted including how the research and research translation processes could be improved:

- In what way can we overcome bureaucratic limitations relating, e.g. to the tendency to accept status quo rather than improve processes?
- How can the time taken to implement research evidence into practice be improved?
- How can we ensure that policy writers also collaborate with consumers?
- How can evidence from systematic reviews be used to inform practice?

- How can we ensure that all research is published?
- How are the National Priorities set?
- How and what information is listened to by whom to inform change?
- How can you ensure there is greater consumer involvement in research?
- How can consumers have a greater say in how healthcare and research funding is used?
- How do charitable organisations decide what research to fund?

Specific research questions pertaining to improving health outcomes were also identified:

- How can we improve the way in which disabled people, particularly those in wheelchairs, navigate our built environment?
- Is there a need for 'cancer care' nurses for other cancers other than breast care nurses?
- How much should we expect people to take responsibility for their own health?
- Where should the ethical consideration 'to treat or not to treat' sit particularly given the current health over expenditure?

Ideas for moving forward

A number of ideas which could bring about substantial improvements to research outcomes were also identified. Ways in which consumers could be brought into the research process included:

- Consumer ambassadors who are able to articulate needs for a group of people/patients/consumers including people who have experienced a particular condition so they have a true understanding of the patient journey
- An Ambassador Business Plan to ensure appropriate processes for identifying and supporting ambassadors
- Condition specific support groups which work with researchers to develop resources and implement evidence into practice
- Personal stories from patients in order to trigger research questions
- Lifting restrictions so that consumers can access research information
- Respect other forms of evidence, not just randomized control trials, which are not always the most appropriate research method
- 'Nudge Theory' which aims to make it easy for people to do what is needed.

Ways in which consumers could be better informed and supported were also articulated:

- Community education through interactions with 'survivors'
- Research findings written for a consumer audience including tailored and targeted health messages, peer education programs and support for consumer education
- Follow up support by people who have survived a serious illness
- Building and maintaining networks between consumers, clinicians, policy makers, researchers
- Facilitators responsible for disseminating research information to patients
- Successive upskilling of consumers.

Finally, there were a number of ideas which focused on improving the translation of research into policy and practice:

- Developing methods for effectively measuring research translation
- Identifying research translation that goes beyond publications
- Involving policy makers throughout the research in a reference group
- Using both informal and formal pathways for disseminating information

- Reducing or simplifying implementation plans and processes
- Inspiring advocates and public figures like Maggie Beer. Public profile. Generate focus and interest with their enthusiasm and the power of their networks, media connections and persuasion.

Perceptions about this and potential future Initiatives

Out of the 44 participants which attended this event 68% (n=30) responded to the short feedback survey. Below is a pictorial representation of the expectations that participants felt were fulfilled through this event, followed by a more detailed summary.

Survey feedback was received from the following types of participants:

Researcher	9
Consumer representative	8
Manager	4
Practitioner	2
Researcher/Policy	3
Not answered	4
Total	**30**

Respondents were very positive about the workshop:

- 96% agreed the workshop was useful
- 90% agreed the discussion was useful
- 90% indicated they had gained some new insight from attending the event
- 96% would attend another similar event

Meeting participant expectations

"I expected stimulating discussion and I got it!"

While a few participants had never attended an event organised by this Initiative before and therefore had very few expectations, others came with very specific ideas and believe that these expectations had been met. Most of the expectations related to meeting a range of people from a variety of different backgrounds, hearing about their ideas and experiences and then discussing and exchanging information. Participants also particularly appreciated the informal interactive sessions with small groups discussing ideas.

Suggestions for other functions

Participants that responded to the survey suggested that in future events we should consider:

- More presentations on research that informs policy and practice
- Including suggestions about how to begin to get involved in research
- Detailing what has been implemented as a result of the Initiative
- Focusing on one problem at a time through different lens – e.g. aging
- Creating space for smaller specific discussion groups
- Identifying how to set research priorities
- Discussing how to translate international evidence into the Australian context
- Identifying what people participating in the Initiative are already doing to reduce the research gap
- Focusing on issues which have already been identified through this Initiative
- Presenting practical examples of how individuals are already tackling the research pathway
- Including more outcome oriented discussions
- Providing recent examples of policy changes that have come through research focusing on:
    - What are the processes in writing policy at an SA Health level
    - How to effect policy
- Thinking about policy officers as consumers
- Understanding the political agenda and hierarchy of the way Government works in SA in relation to Research, Policy & Practice
- Providing examples of current research and how it might be translated.

Suggestions for improving future events

Participants who responded to this survey suggested:

- Providing opportunities to change groups during the small group discussions
- Connecting via email chat or other electronic method to keep the flow of ideas going between sessions
- Increasing the length of these sessions – possibly from breakfast through to before lunch
- Increasing the time for discussions
- Increasing the opportunities to speak with individual researchers about what they are doing
- Decreasing the reliance on individual participation
- Better coffee!!!