

Strengthening Consumer Involvement in Health Research across Sydney Health Partners

Summary report of Stage 1 work: environmental scan and introductory training

Report prepared March 2021

Sydney HealthPartners

HEALTH CONSUMERS NSW

Summary

Evidence shows that the design, conduct, and outcomes of health and medical research are significantly improved by the involvement of consumers and community members throughout the research process.[1] Across Australia, local and national policy and funding initiatives are underway to strengthen consumer involvement in research.

Sydney Health Partners (SHP), an advanced health research and translation centre, is committed to promoting the consumer voice in health research and is the co-lead for a nationally coordinated program of work undertaken by the Australian Health Research Alliance.

In 2020, SHP partnered with Health Consumers NSW (HCNSW), the peak organisation and advocacy body for health consumers, to undertake two initial projects – an environmental scan of current consumer involvement activity within health research across SHP, and the development and delivery of an introductory training module for consumers, clinicians and researchers. It was anticipated the two projects would inform planning for future work.

The projects attracted a high level of interest, with over 160 consumers, researchers and clinicians providing input into the environmental scan, and 63 people attending three initial training sessions. The environmental scan highlighted excellent examples of consumer involvement in health research, largely driven by individual champions. Evaluation of the training by participants was very positive and showed that the learning objectives were met. Further details about both projects are provided in this report.

The two projects provided new opportunities for consumers and researchers to connect with each other across traditional institution and discipline boundaries and uncovered excellent existing consumer-researcher partnerships. Sydney Health Partners is well placed to continue fostering these connections to build a network of consumer and researcher champions to guide the development of infrastructure and resources that support wider consumer involvement in health research.

Recommendations

1. Promote the use of clear and consistent language about consumer involvement in health research.
2. Develop a Consumer and Community Involvement in Health Research Strategy for SHP, including key actions for the next 2-5 years.
3. Develop and promote existing guidelines and practical resources to support consumer involvement in health research (including guidance on remuneration and recognition of input).
4. Showcase local examples of consumer involvement in health research, for example through
   - Consumer and researcher interviews and stories (videos or podcasts), reflecting different research approaches and health areas, illustrating principles of good practice
   - An annual forum for researchers and consumers to network and hear about partnerships in research across various disciplines

- An annual SHP Consumer Involvement in Health Research Award.

5. Provide further joint introductory training for consumers and researchers (online and face-to-face if possible).
6. Develop further modular-based training sessions aimed at consumers, clinicians and researchers.
7. Explore opportunities to include consumer involvement in health research in undergraduate and higher degree research education.
8. Identify local consumer involvement champions and develop a buddying and mentoring program for consumers and researchers.

Acknowledgements

Sydney Health Partners and Health Consumers NSW gratefully acknowledge and thank the following people for their significant contributions:

- the two project leaders, Carrie Hayter (environmental scan, project management) and Dr Ilse Blignault (training)
- the Steering Committee, comprising Ms Mary Potter, Professor Yun-Hee Jeon, Professor Kathryn Refshauge, and Professor Allison Tong
- Emma Collins and Serena Joyner (Health Consumers NSW) who provided valuable assistance in the training sessions
- Linda Komarek (Sydney Health Partners) who provided overall project and secretariat support.

Note on language

There are inconsistencies in the language used when referring to the involvement of consumers in health research. The term ***involvement*** is used in this report to define an active partnership between health consumers and researchers and/or research organisations, where consumers are actively involved in the research process. This may include being a consumer representative on a research committee, being a co-researcher in undertaking research, co-writing research reports or presenting at conferences and seminars. The role of consumers as research participants (or subjects) is not included in the term involvement. The acronym CCI is sometimes used for 'consumer and community involvement'.

Suggested citation

Sydney Health Partners & Health Consumers NSW, (2021). Strengthening Consumer Involvement in Health Research across Sydney Health Partners. Summary report of Stage 1 work: environmental scan and introductory training.



Environmental Scan

Purpose

The environmental scan was undertaken to help identify:

- existing consumer networks and areas of good practice
- existing consumer involvement, infrastructure and resources and any gaps
- barriers to consumer and community involvement.

It was undertaken alongside the development of the introductory training, and information was used to help guide the training content and session format.

Data Gathering

Information was gathered through an online survey, interviews and a stakeholder workshop. The views of consumers, clinicians, researchers, and consumer and community engagement managers (within SHP's health service partner organisations) were captured.

In total, 168 respondents across Sydney Health Partners completed the survey. Respondents identified as a researcher (n=98), clinician (n=73) or health consumer (n=54).

Themes emerging from the survey data were further explored in interviews with 24 stakeholders, including 16 from SHP (6 consumers, 7 researchers and/or clinicians, and 3 consumer engagement managers).

Finally, an online workshop (World Café) was attended by 28 champions of consumer involvement (including 12 consumers, 3 consumer researchers, 10 researchers and/or clinicians). Participants discussed what they would like consumer involvement in SHP to look like in 5 years' time, and what would be needed to achieve this vision.

Findings

The gathered information was structured into four domains, drawing on the Consumer and Community Engagement Framework developed by the South Australian Health and Medical Research Institute (SAHMRI)[2]: Leadership and Culture, Governance, Capacity Building, and Infrastructure.

Leadership and Culture

Feedback from stakeholders identified the importance of leadership and creating a culture where consumer involvement is valued within organisations. This is particularly important for organisations that fund health and medical research, as highlighted by one participant:

> *"Until we get organisations who fund research (such as the NHMRC) formally committing to CCI, it's going to just limp along. We will continue to have a situation where there will be pockets of brilliant work, and then there'll be inconsistency."*

Another participant (researcher) described the value of involving consumers in research:

> *"There is power in partnerships. It allows the exchange of knowledge*

and experiences in a meaningful and constructive manner. Involving consumers in research requires a lot of time, investment and commitment – but it is fundamental. It is about building trust and relationships."

Although there are examples of consumer involvement in health research across SHP, there is no overarching framework or strategy. There are opportunities for leadership in this area, for example in the development of consumer involvement criteria for research projects directly funded by Sydney Health Partners, policy and practice guidelines and resources that provide practical suggestions on how to support consumer involvement in research (see Recommendations 2 and 3).

Governance

Many stakeholders identified governance structures or processes within their organisations that support consumer involvement. These included dedicated staff, policies, training opportunities and the inclusion of consumers on boards and committees. An innovative example is the Research Co-Design Committee at Western Sydney Local Health District (WSLHD), created in recognition of the drive to include consumers in research, with a link to the WSLHD Consumer Council.

Some researchers and clinicians also described creating their own engagement structures by working with consumers, consumer advocacy groups, non-government organisations and Aboriginal community organisations.

However, it was also noted that many of the policies and processes that exist across (and sometimes within) partner organisations are inconsistent. The reimbursement of consumers for their time and expertise is the most obvious example of this, with consumer reimbursements rates and processes varying across projects. This issue was raised by both consumers and researchers during interviews and at the stakeholder workshop (see Recommendation 3).

Capacity Building

The need for training was identified by consumers, researchers and clinicians. The survey results indicated that a higher percentage of consumers had accessed training and support (60%) than researchers and clinicians (40%). This included seminars/ conferences, practical on-the-job training and mentoring.

Consumers raised the importance of buddying and mentoring programs, such as those run by Cancer Voices NSW and the Walter Eliza Hall Institute of Medical Research. Training courses that were commonly mentioned included those offered by Health Consumers NSW, the Cancer Council NSW and Cancer Voices NSW. The topics of most interest to consumers for future training included the research process from start to finish (including how to get involved at the different research stages), the roles and expectations of all parties (including how to work most effectively together) and the ethics process.

Researchers and clinicians reported attending training through their university or local health district, the Cancer Council NSW, the Patient-Centred Research (PACER) Network, and the Australian Clinical Trials Alliance. Topics of interest for future training included navigating ethics processes, and how to attract and engage consumers in health research. The inclusion of consumer involvement theory and practice

in undergraduate and higher degree research degrees was suggested as another way to build capacity. The importance of bringing researchers, consumers, and clinicians together to learn from each other was also emphasised (see Recommendations 5, 6, 7, 8).

Infrastructure

Most stakeholders were aware of national resources, tools, and guidance documents such as the National Health and Medical Research Council's Statement on Consumer and Community Involvement in Health and Medical Research[3], Ethical Conduct in Research with Aboriginal and Torres Islander People and Communities[4], and the National Framework for Consumer Involvement in Cancer Control[5], however there was low awareness of local resources.

Many stakeholders mentioned the need for practical mechanisms to connect researchers, clinicians and consumers interested in working together (see Recommendations 3, 4). There are some existing models and systems that could be promoted, for example:

- Step Up for Dementia Research program (the University of Sydney)
- Join Us Register, connecting researchers and potential study participants (the George Institute for Global Health).
- Poche Centre, where researchers work alongside Aboriginal and Torres Islander peoples and communities to improve the health of Indigenous people (the University of Sydney).

Limitations

The environmental scan aimed to identify champions of consumer involvement and examples of innovative practice within Sydney Health Partners. It was not possible to do a 'deep dive' into every partner organisation. It is very likely that there are many exemplary people and projects that the project team did not identify. It was also beyond the scope of the project to investigate the needs and experiences of each individual SHP partner organisation. Further exploration of consumer involvement activities within SHP's medical research institute partners is needed.



Introductory Training for Consumers and Researchers

Purpose

The training course was intended as an introduction to consumer involvement in health research. The objectives were to:

- increase awareness of the scope of consumer involvement in health research and the associated public benefits and opportunities for consumers and researchers
- enhance understanding among consumers and researchers of effective and satisfying ways of working together
- jointly explore strategies for overcoming common barriers to consumer involvement in health research.

Method

The original plan was to deliver separate training for consumers and researchers at venues across Sydney Health Partners. In response to the findings of the environmental scan, this was replaced by a joint introductory training program designed to bring the different stakeholder groups together. Further, due to the COVID-19 pandemic and associated restrictions, plans for face-to-face training had to be replaced by a 2-hour online workshop delivered via zoom. Participants were also asked to allocate approximately 30 minutes to review preparatory material, and 30 minutes to review follow-up material and complete an evaluation survey.

Three online sessions were delivered in December 2020 with a focus, in turn, on Sydney, Northern Sydney and Western Sydney Local Health Districts.

The training covered the 'why', 'what' and 'how' of consumer involvement in health research, providing local examples and an overview of the range of approaches and models used. Interviews were included to share the experiences and insights of consumers and researchers, along with a Question & Answer session. Participants broke into small groups to discuss ways to overcome barriers, boost enablers and reflect on diversity/ inclusive practice. The discussion was fed back to the wider group at the end.

The training was evaluated through analysis of registration and participant survey data and facilitator debriefing sessions.

Findings

Of the 63 participants who attended training, 40% recorded their role as 'Health consumer', 48% as 'Researcher', 5% as 'Clinician' and 14% as 'Other'. The online survey was completed by 38 participants, a response rate of 60%, and feedback was overwhelmingly positive. Respondents reported several changes in knowledge and awareness:

- 89% reported an increased awareness of the scope of consumer involvement in health research
- 86% reported greater awareness of the benefits of consumer involvement in health research
- 89% reported an enhanced understanding of how health consumers and researchers can work together effectively
- 89% reported an enhanced understanding of the barriers to involving consumers in health research

- 73% reported an enhanced understanding of ways to overcome these barriers.

The following quotes from survey respondents illustrate the key messages taken away from the training:

> *"I hadn't realised that there are many opportunities for consumers to participate in research."* (Consumer)

> *"Consumer engagement in research is vital but consumers need to be qualified, prepared and willing to spend the time."* (Consumer)

> *"'Nothing about us without us'. Importance of consumer and community involvement in research. And the earlier they participate in the research cycle, the better."* (Researcher)

> *"Involve consumers as early in the research process as possible. For it to be a successful involvement and not tokenistic, consumers and researchers need to be equal partners – equally respected for their input and ideas."* (Researcher)

The training evaluation highlighted the need to keep building the capacity of researchers to work productively with consumers, and to support training for consumers so they can be effectively involved in health research.

References

1. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. BMC Health Serv Res 2014; 14(1): 89.

2. South Australian Health and Medical Research Institute (SAHMRI) and Health Consumers Alliance of South Australia Inc. *A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute* (2014, Issue June). https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf

3. National Health and Medical Research Council. *Statement on Consumer and Community Involvement in Health and Medical Research,* 2016. Canberra: NHMRC. Available from: www.nhmrc.gov.au/_files_nhmrc/file/publications/16298_nhmrc_-_statement_on_consumer_and_community_involvement_in_health_and_medical_research-accessible.pdf

4. National Health and Medical Research Council. *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for researchers and stakeholders,* 2018. Commonwealth of Australia: Canberra. Available from: https://www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities

5. Cancer Australia and Cancer Voices Australia. *National Framework for Consumer Involvement in Cancer Control*, 2011. Cancer Australia, Canberra, ACT. Available from: https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf