



*Translating Research into Better Health Outcomes*

# Engaging Consumers in Health Research: Report of Initial Consultations

June 2017





Patient and public  
benefit is at the core  
of what we do



## EXECUTIVE SUMMARY

Sydney Health Partners is one of the first four Advanced Health Research and Translation Centres in Australia, recognised by the National Health and Medical Research Council in 2015 for being a world leader in translating research into better health outcomes for our community. Our Partnership includes the Sydney, Northern Sydney and Western Sydney Local Health Districts; the Sydney Children's Hospitals Network (Westmead); the University of Sydney; and nine affiliated independent medical research institutes.

Patient and public benefit is at the core of what we do. In 2016, SHP conducted an initial project to better understand how health care consumers wished to influence and engage with health research. This report summarises the findings from initial consultations held with 20 consumer representatives who were drawn from SHP's partner health services. The following key messages emerged from consumers in response to two key questions:

*How can researchers better engage patients and other health care consumers in the development of research questions that address priority issues from a patient/consumer perspective?*

- Help us understand more about research
- Listen to us and respect what we say
- Be totally honest with us
- Make it easy for us to get involved

*How can researchers best communicate with patients and other health care consumers the importance of participating in research? What information do patients and health care consumers need to have?*

- You've got to sell it! Tell us why research is important
- Go where people are
- Tell the whole story
- Make it a positive experience
- One size doesn't fit all

From these findings, four key recommendations are made to strengthen consumer engagement in SHP's research and translation activities. Importantly, these recommendations are consistent with initiatives undertaken by other organisations seeking to promote consumer engagement in health research.

## Recommendations

1. That SHP develops and issues a statement of principles and values for consumer engagement in health research, to be endorsed and promoted by all partners.
2. That SHP makes available promotional and educational materials targeted at the community about the value of health research and research participation.
3. That SHP provides training and resources for health care providers and researchers about engaging consumers in health research.
4. That SHP includes measures of consumer engagement activities in its performance metrics, which are made publicly available.

A number of additional options are offered for further consideration and discussion among SHP and its members (page 12).



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## BACKGROUND

Sydney Health Partners (SHP) aims to improve health services to better meet peoples' health needs by using existing research to drive high quality care; and by conducting new research that directly addresses important challenges faced by our community and health care providers.<sup>1</sup> Clearly, 'people' are central to the aspirations and success of SHP.

There have been widespread calls for broader engagement of health care consumers and the wider general public in health research, including defining the research questions that matter most to them.<sup>2,3</sup> There are many potential benefits associated with greater consumer engagement in research including improved relevance, accountability, quality and outcomes; decreased costs; more effective research translation; and improved public confidence in research. At the same time, many barriers can exist both for researchers (e.g., extra time and cost), and consumers (e.g., tokenism; power imbalances and use of disempowering language; poor role descriptions; lack of training, supervision and support; lack of access to resources; and consumers being brought into a project too late).<sup>4,5</sup>

Several approaches have been used in an effort to strengthen consumer engagement in health research. For example, the James Lind Alliance (JLA), established in the UK in 2004, uses a highly structured process to bring patients, carers and clinicians together to identify and prioritise research questions specifically about treatment (<http://www.jla.nihr.ac.uk/>). In the US, the Patient-Centered Outcomes Research Institute (PCORI) focuses on comparative clinical effectiveness research and topics, questions and outcomes most important to patients and those who care for them (<http://www.pcori.org/>). Since 2012, PCORI has awarded over \$1.2 billion to patient-centred research that compares two or more healthcare options. A condition of funding is that patients are engaged as partners who help determine what is studied and how.

More recently, the Canadian Institutes of Health Research introduced a national strategy for patient-oriented research that includes a patient engagement framework.<sup>3</sup> In Australia, the Code for the Responsible Conduct of Research (2007), the primary guide for institutions and researchers in responsible research practices issued by the National Health and Medical Research Council (NHMRC), advocates for appropriate consumer involvement in research.<sup>6</sup> The NHMRC has also released an updated Statement on Consumer and Community Involvement in Health and Medical Research,<sup>7</sup> replacing the first statement issued in 2002.<sup>8</sup>

At the University of Western Australia, Anne McKenzie introduced a Consumer and Community Involvement Program in 1998 to support data linkage research. In 2002, it became a joint initiative of the University and the Telethon Kids Institute, and now provides a wide range of infrastructure and resources to support consumer involvement across health research, including a network of consumer and community volunteers, researcher and consumer training programs, and various templates to facilitate engagement processes (Consumer and Community Health Research Network, WA, <http://www.involvingpeopleinresearch.org.au/>). A recent evaluation of the Program's training workshops for researchers suggested significant shifts in attitudes and behaviours towards consumer engagement, although the results were based on participant self-report.<sup>9</sup>

More limited programs that provide training for consumers to specifically participate in the review of research funding applications and/or to participate in ethics review committees are offered by a number of state-based cancer and health consumer groups.<sup>10</sup>

Locally, Associate Professor Allison Tong and Professor Jonathan Craig, at The Children's Hospital at Westmead/The University of Sydney, have led an Australian initiative to identify research priorities in chronic kidney disease (see Box 1). Initial work has focused on adult patients<sup>11</sup> but more recently has also given attention to children with chronic illness. Professor Susan Kurrle, University of Sydney, leads the NHMRC Cognitive Decline Partnership Centre which aims to improve the lives of people living with dementia. She and her team are at the forefront of engaging consumers in dementia care research, including the involvement of consumers throughout the centre's organisational structures and research activities (see Box 2).

While these various initiatives have focused on strengthening consumer engagement in research and identifying research priorities from the consumer perspective, the responsibility for conducting the research generally remains with researchers. Models of consumer-led research are also emerging, where research is planned, directed and executed by consumers. Clinicians and researchers may still be involved, however the balance of power lies with the consumer.<sup>4</sup>

**BOX 1:** At the Centre for Kidney Research, The Children's Hospital at Westmead, Associate Professor Allison Tong and Professor Jonathan Craig have led a program of engaging patients with chronic kidney disease and their carers in discussions about research priorities. Combined consultations with patients, carers, clinicians, allied health professionals and researchers have been conducted, using processes somewhat modelled on the James Lind Alliance approach, but conducted over a shorter timeframe and not limited to questions about treatment. At a national workshop involving 30 consumers and carer representatives and 28 health professionals 83 potential research questions were identified. After several rounds of discussion and ranking, the top-ranked questions that emerged focused on prevention, lifestyle, quality of life, and long-term impacts, providing guidance for future research projects in chronic kidney disease that will be relevant to all key stakeholders.

Jonathan and Allison also co-founded and are on the Executive Committee of the global Standardised Outcomes in Nephrology (SONG) Initiative, which aims to establish consensus-based core outcomes across the spectrum of chronic kidney disease ([www.songinitiative.org](http://www.songinitiative.org)). To date, SONG has involved ~2500 stakeholders (including ~800 patients/caregivers) from around 100 countries in various focus groups and consensus workshops (see the SONG Handbook for details <http://songinitiative.org/reports-and-publications/>).

**BOX 2:** The NHMRC Cognitive Decline Partnership Centre (CDPC, <http://sydney.edu.au/medicine/cdpc/research/>), led by Professor Susan Kurrle, University of Sydney, aims to improve the lives of people living with dementia as well as their families and carers by supporting research about best practice in dementia care. The CDPC partnership includes: government (NHMRC); 3 residential aged care industry partners (HammondCare NSW, Brightwater Care Group WA, Helping Hand Aged Care SA); researchers; and consumers (through Alzheimer's Australia).

Consumers are embedded throughout the CDPC's operational structures. The CDPC's Governance Authority and Executive Team each include consumer representation. The Scientific sub-committee, which reviews all funding applications, nominates panels of 3, including 1 consumer member, for each review. Each funded research activity is encouraged to involve at least 1 consumer member throughout the research lifecycle. To date, approximately 25 consumers have variously contributed to high-level priority setting and funding decisions, as well as steering and advisory committees and project teams. Critically, they have advised on the most effective communication tools for consumers as stakeholders and have been integral in dissemination of results.

Despite these efforts, the recently released Australian Medical Research and Innovation Strategy, 2016-2021, which will guide the Medical Research Future Fund (MRFF), notes the generally limited degree of consumer engagement in research.<sup>12</sup> Among the first priorities under the strategy is a commitment to establishing a consumer-driven health and medical research agenda.<sup>13</sup>

In September 2016, Sydney Health Partners initiated a series of consultations to better understand how health care consumers wished to influence and engage with the development and conduct of research across our member organisations.



## CONSULTATION PROCESS

SHP liaised with patient engagement staff in each of the three Local Health Districts (Sydney, Western Sydney and Northern Sydney) and the Children's Hospital Network (Westmead) to access existing networks of patient and carer representatives (Appendix 1). Between December 2016 and April 2017, three focus groups (n=16 participants) and four one-on-one interviews were conducted with volunteer patients, carers and other health consumer representatives (Appendix 2). The volunteers comprised a diversity of people in terms of gender, age, socio-economic and cultural backgrounds, and health care conditions and experiences.

Discussions with consumers focused on two questions:

- How can we better engage patients and other health care consumers in the development of research questions that address priority issues from a patient/consumer perspective?
- How can we best communicate with patients and other health care consumers the importance of participating in research? What information do patients and health care consumers need to have?

Consultations were also held with selected health and research personnel with experiences in engaging consumers in health research (Appendix 3).



## RESULTS

Most, but not all, health consumers who were consulted had had direct experience as a research participant. They commented on the value of health research as a social good and recognised the contribution it could make to better health care and improved health outcomes. A small number reported negative experiences, for example, feeling like a 'guinea pig' or 'lab rat', or undergoing a procedure that was unexpectedly painful. However, the majority reported positive experiences and were pleased to have participated.

The health consumers' responses to the two guiding questions are summarised below.

### How can we better engage with health consumers about their research priorities?

#### 1. Help us understand more about research

Consumers suggested that many among the general public have little awareness of, or experience with health and medical research and how it can be relevant to them or their families. Marketing and education efforts are needed to explain the role of research in health care, how people can recognise "good quality" research, and the kind of information they should know to feel well-informed. There is also a need to tackle stereotypes about 'bad research' (people's knowledge of past well-publicised unethical practices), and beliefs that people have been 'used' or have things done to them without their consent. Participants with complex or rare health conditions spoke of feeling especially vulnerable to being used or experimented with by the health sector, both clinically and in research.

Several consumers also wanted to better understand the balance between doing more research versus using the research results we already have, and the balance between research focused on treating the sick versus research about staying healthy.

*There's an education piece about different types of research; it's not just 'big pharma'*

*... The worst thing about looking up stuff online is you don't know if you are looking at rubbish or you're looking at something authoritative or whatever, so people get terribly muddled...*

## 2. Listen to us and respect what we say

Consumers said that if researchers wanted to engage with them, then they needed to be confident that they would be respected and their voices heard. This would likely involve researchers investing time into building relationships, trust and credibility with individual consumers and consumer groups, particularly if a longer term partnership was intended. Consumers wanted researchers and clinicians to recognise that they were the experts of their own health conditions and care needs; they often knew more about their health conditions than health professionals. They were the persons with the lived experiences and should be believed (including if they are children or young adults). It was also important to recognise that people have multiple health conditions and issues, and it is not 'real' for them when researchers or clinicians focus on one 'bit' (e.g., their diabetes, or their heart condition). Too many participants spoke of experiences of not being listened to or believed by health care professionals. There was a common view that clinicians and researchers might need some kind of training in how to better listen to and speak with consumers. They should also recognise that, if they ask consumers for their views, they need to be prepared to have their ideas and plans challenged, changed or even totally turned around.

*You've got to start with lived experience. If research is going to be about people and the outcomes are going to be about people, you've got to start with lived experience. And you've got to intentionally listen to the lived experience.*

*Respecting and listening to the person with the lived experience – it's true for a child too*

*There's a lot of research about ill health... what if we were researching what does being well look like in 50 years' time?*

## 3. Be totally honest with us

Consumers advocated strongly for the importance of transparency in research, its proposed purpose, risks and benefits, and how consumer input would be used. They also argued strongly for information about how research results would be fed back and used, and what changes might be made as a result of the research. They wanted communications to reflect language styles and concepts that were culturally and socially relevant to the target audience (including translated materials where appropriate).

*Being transparent, knowing what the intent is of the research and then how the application is going to happen. ... 'Cause otherwise it's just research for research sake and it goes nowhere ... If people can see that there are changes being made, then people are willing to come on the journey.*

## 4. Make it easy for us to get involved

Consumers suggested various ideas to help facilitate consumer involvement in research. For example, a pool or register of interested consumers could be established who might be approached periodically about engaging in upcoming research. It was noted, however, that 'consumer representatives' tend to be highly motivated volunteers, and not necessarily reflective of the wider community. Attention therefore would need to be given to ensuring diversity in such a pool. Community-based forums could be held, and email or other online services established where people could make suggestions about health and medical research questions. At the same time, it was important to recognise that consumers are not scientists: they bring their perspectives of living with specific health conditions and/or using health services, and the questions they might formulate may be quite different from those posed by researchers.

*Patients have great research ideas. What do they do with them? Where do they take them?*



## How can we best communicate with health consumers about participating in research?

### 1. You've got to sell it!

Consumers argued that participating in research is most often an individual choice. People need to be convinced why research is relevant and important to them, and why they should participate, especially if they are among the 'harder-to-reach' (e.g., young people, healthy people, ethnic and cultural groups). Many people also think that research is 'beyond' them; they think they don't know enough or can't contribute enough and therefore don't participate.

To increase participation, consumers commented on the need for various communication and marketing strategies including using multiple education and promotion options about health research in general, as well as targeted messages to potential participants for specific research projects. The importance of being clear about the target audience was emphasised, because this had implications for what was communicated, the language used, how it was communicated, etc. Consumers emphasised the importance of using plain English and culturally appropriate concepts (not legalese, medicalese or bureaucratese), and some commented on the stigma of specific words like 'research' or 'trial' for some groups. It was also noted that messages targeting carers and other family members may sometimes be different from those used with patients. Consumers suggested using multiple formats, e.g., posters, pamphlets, letters, internet, apps, registries, media (TV, radio, newspapers), but also cautioned against emails ('everyone is overloaded') and 'cold-calling' by telephone. It was also suggested that providing examples of where research has made a significant contribution to improving health would increase motivation to participate by demonstrating that research was worthwhile. Finally, consumers suggested using GPs or peer representatives as research advocates who might bring credibility and trust.

*It's a communication strategy... you need to identify who your audience is that you're wanting to engage with, and whether it's internet, or whether it's email, whether it's newsletters, community radio, local print. There are many different ways that you can engage with people.*

*In that community (specified cultural group), mental health as a concept doesn't really exist. You've got to completely turn the message and the language around and say it's when people are unwell but it's not for physical reasons. You can't use the term mental health – it's irrelevant... Cultural backgrounds will dictate the communication.*

### 2. Go where people are

With clarity around the target audience of any research project, there are many avenues for reaching the 'right' people. Health settings offer numerous locations where people are sitting and waiting for extended periods - Emergency Departments, transit lounges, hospital wards, hospital clinics, and GP and other doctors' rooms. Caution was raised about engaging with sick patients about research, as they are often vulnerable (and sometimes desperate), and may be taken advantage of.

More broadly, consumers suggested using community networks and settings where people gather, e.g., sporting clubs, cultural and other community centres, schools (parents, grandparents), public libraries, churches, volunteer groups (e.g., Lions and Rotary Clubs), etc.

### 3. Tell the whole story

To encourage research participation, consumers again advocated the importance of being fully transparent about a research project, including its purpose, risks and benefits, time commitments, use of the results, etc. Consumers also emphasised the importance of study participants receiving feedback about a project, even if some years later. People need to see that their contribution means something. Participants should be asked whether, and how they would like to receive such results; most consumers who had been research participants had never received feedback about the research in which they had participated.

### 4. Make it a positive experience

Consumers suggested that researchers should ensure that people who participate in research have a positive experience including communications, administrative processes, reimbursement of expenses, etc., to encourage them to participate in future studies and to promote research participation to their family and friends. Every effort should be made to ensure participants do not feel they are being used as a guinea pig or lab rat.

*I think people don't like that feeling of being a guinea pig. And often even the word 'study' instead of 'research' gets them along. 'I'm doing a study on...' sounds better than 'I'm doing research into...'. You know what I mean. We don't want to feel like lab rats.*

### 5. One size doesn't fit all

There are some population groups that may require different and/or additional efforts to engage in research. For example, some cultural and community groups are either averse to participating in health research (because of negative stereotypes and/or adverse past experiences), or are unfamiliar with research as a legitimate activity within health care. There are also specific sensitivities and considerations when involving children and teenagers in health research, for whom clinicians and family often act as gatekeepers – sometimes without consulting the individuals involved. Children with chronic and/or rare health conditions have extensive experience with the health system, but they also mature and change at different rates over time. While recognising the role of parental oversight, consideration should be given to direct engagement with children and the role of child consent for research participation.

*Younger people have less contact with the health system... they're not going to take time off work to do research*

*There are appropriate pathways for different communities, and where and how they gather. Sometimes you need to invest more time to get the right cross-section.*

*You get fatigued... having a rare disease attracts everyone.*

“ There are specific sensitivities and considerations when involving children and teenagers in health research



## RECOMMENDATIONS

Sydney Health Partners (SHP) is committed to broader engagement with health care consumers and the wider general public to facilitate research that answers questions that matter most to them. This is the right thing to do: if we seek to support a health system that is patient-centred, our research activities should be too.

While there are individuals within Sydney Health Partners who have embraced this approach in their research activities, there are opportunities for SHP to provide leadership in promoting and facilitating consumer engagement across our partner activities. Four key recommendations are made to strengthen consumer engagement in SHP's research and translation activities. Importantly, these recommendations are consistent with those made by other organisations seeking to promote consumer engagement in health research (Consumer and Community Health Research Network, WA; Health Consumers NSW<sup>10</sup>).

Recommendations	Collaborators
1. That SHP develops and issues a statement of principles and values for consumer engagement in health research, to be endorsed and promoted by all partners.	SHP partner organisations, Health Consumers NSW
2. That SHP makes available promotional and educational materials targeted at the community about the value of health research and research participation (see Consumers Health Forum of Australia).	SHP partner organisations, Clinical Trials and Education Thematic Streams, LHD patient engagement networks, Health Consumers NSW
3. That SHP provides training and resources for health care providers and researchers about engaging consumers in health research (see Consumers Health Forum of Australia and Consumer and Community Involvement Program (WA)).	SHP partners, Education Thematic Stream, Primary Health Networks, Health Consumers NSW
4. That SHP includes measures of consumer engagement activities in its performance metrics, which are made publicly available.	SHP partners, LHD patient engagement networks, Health Consumers NSW

In addition, the following options are offered for further consideration and discussion:

### Options for future consumer engagement:

- That SHP considers hosting training for members of the community about health research and research translation (possibly drawing on existing resources such as those provided by Consumer and Community Involvement Program (WA), NSW Cancer Institute, and Health Consumers NSW).
- That SHP explores the feasibility and utility of establishing an online registry for members of the community interested in contributing to health research (to advise on the design/conduct of research and/or to be a research participant; see Macquarie University's Cognitive Science Register as an example).
- That, in due course, SHP might evaluate satisfaction with its consumer engagement activities among both participating consumers and researchers, to ensure their respective needs are being met.

### Options for future organisational support:

- That SHP considers the establishment of a Community Engagement sub-committee, potentially reporting to the Governing Council, to provide consumers perspectives on SHP's work at a strategic level as well as advising on, and overseeing consumer-engagement related activities.
- That SHP considers allocating resources (human and financial) towards consumer engagement activities across the partnership.

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## APPENDIX 1

Health personnel who facilitated recruitment of health consumer representatives

Organisation	Contact persons
Northern Sydney Local Health District	Marissa Dodds, Anthony Marsh
Western Sydney Local Health District	Coralie Wales, Tara Lee
Sydney Local Health District	Timothy Morcombe, Nicholas Bates
The Children's Hospital Network (Westmead)	Laura Griffin, Kelly Bowler, Bianca Pratt

## APPENDIX 2

Health consumer volunteers who participated in discussions

Affiliated health organisation	Name
Northern Sydney Local Health District (14 Dec 2016)	Adam Johnston Barbara Lewis Katherine Gill Louise Brown Marjorie James Peter Heggie Shirin Kanji Susan Moylan-Coombs Tessa Milne
Western Sydney Local Health District (27 Feb 2017)	Judith Lababedi Kathie Collins Sue Ramsay
Sydney Local Health District (6 Mar 2017)	Alan McPhail Ann-Mason Furmage Jan McDonnell Sue Norman
The Children's Hospital Network (Westmead)	Jessie Gavin (21 Apr 2017) Katie Viviers (6 Apr 2017) Lisa Ainsworth (11 Apr 2017) Tiffany Watts (5 Apr 2017)

## APPENDIX 3

Health personnel with experience engaging consumers in health research who participated in discussions

Organisation	Contact persons
Centre for Kidney Research, The Children's Hospital Westmead, University of Sydney	Associate Professor Allison Tong, Professor Jonathan Craig
NHMRC Cognitive Decline Partnership Centre, Sydney Medical School, Northern, University of Sydney	Jennifer Thompson, Professor Susan Kurrle
NSW Cancer Institute	Alisha McInerney, Dr Danielle Herbert

