

# Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective

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An outcome of the workshop held on 31 Oct. 2016 by  
Health Consumers NSW and Research4Me

February 2017

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## ACKNOWLEDGEMENTS

A number of people contributed to this workshop and report. Thanks to all the participants (listed in Appendix 2) and to the consumer organisations of which they are members. Thanks also for your interest, knowledge and passion for consumer engagement, active and generous sharing of experiences in the workshop, and reviewing the draft report. Thanks also to Serena Joyner for feedback on the workshop agenda and to Julia Brockhausen and Kay Powell for assistance in preparing the report for printing. Special thanks are given to Jenn Kidd for logistical support for the workshop.

### **Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective**

*An outcome of the workshop held on 31 Oct 2016 by Health Consumers NSW and Research4Me*

This report was written by Dr Janelle Bowden and Dr Anthony Brown based on the discussions and outcomes of the *Co-designing Research with Health Consumers* workshop held on 31 October 2016.

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## DEDICATION



### **Sally Crossing AM 1946-2016**

Sally Crossing's advocacy helped found Health Consumers NSW and she served as its first Co-Chair with Betty Johnson AO.

Sally was also involved in founding the Breast Cancer Action Group and Cancer Voices. She was a passionate advocate for engaging health consumers in research and helped formulate Cancer Australia's guidelines for consumer involvement.

In 2012 Sally was appointed to the NHMRC Working Committee that reviewed the 2002 Statement on Consumer and Community Participation in Health and Medical Research. An updated Statement was released in September 2016.

In 2014 she received an honorary doctorate from the University of Sydney for her "extraordinary leadership and contributions to supporting those with cancer from diagnosis, through treatment, care support and survivorship, in both advocacy and research".

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## EXECUTIVE SUMMARY

On 31 October 2016, Health Consumers NSW and Research4Me held a joint workshop with 13 health consumers/health consumer organisation representatives with experience in health and medical research to explore consumer involvement in the co-design of research and clinical trials. This report outlines the background, objectives, discussion and ideas raised at that workshop.

It was clear that the consumers involved in the workshop had a very sophisticated understanding of the value of health and medical research. There was a vast range of experiences with people from different experiences of illness and involved in many different types of research. It was clear that people give up their time to help design research projects because they believe that engaging consumers leads to better research outcomes that are more relevant to consumers and the community.

In summary, the following themes were identified to be impacting on the level of involvement of consumers in research:

- Types of research;
- Consumer availability and experience;
- Funding consumer involvement;
- Finding the 'right' consumer;
- Consumer training and support;
- Researcher beliefs and culture;
- Researcher training;
- Clarity about roles and responsibilities;
- Language.

Key enablers identified which would help support increased consumer involvement in research included:

- Appropriate selection processes and training for consumer representatives;
- Flexibility in working with consumers and respecting the value of their contribution;
- Training of researchers to better partner with consumers;
- Increased/better use of plain language by researchers;
- Funding consumer involvement in research;
- Support materials and structures for both consumers and researchers.

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With respect to clinical trials specifically, there was hearty discussion about whether or not there was a need for greater community awareness of clinical trials. Beyond that, the group identified the following as ways consumers could add value to trials:

- Improving health literacy and educating the community about trials;
- Promoting trial opportunities;
- Participating in clinical trial steering committees;
- Providing peer support before and during trials, to improve recruitment and retention;
- Training and supporting consumer reps to partner more effectively with researchers.

There was consensus amongst the workshop attendees on most issues identified, however there were a few contentious issues that will require further exploration. These include:

- Whether or not there should be payment to consumer reps (beyond reimbursement of out-of-pocket expenses);
- Whether there should be recruitment payments or incentives for completion of high-risk procedures in clinical trials for clinical trial participants;
- What information is appropriate to share with researchers about potential consumer representatives, and how should that information be handled/protected;
- Whether or not there is a need for community education about clinical trials;
- Whether there should be any type of accreditation for consumer representatives.

As a result of this workshop, Health Consumers NSW will explore the idea of developing a guiding set of principles around what is important to consumers about being involved in research, and facilitate further discussion of the issues raised. Research4Me will continue exploring the needs of clinical trial stakeholder groups to facilitate increased consumer involvement in clinical trials.

Thanks are offered to the attendees of the workshop for their open discussion and valuable contribution to our understanding of the issues surrounding consumer involvement in research.

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## ABBREVIATIONS

HCNSW	Health Consumers NSW - peak body for health consumers in NSW.
HREC	Human Research Ethics Committee
NHMRC	The National Health and Medical Research Council (Australia). The main government body that funds health and medical research in Australia.

## DEFINITIONS

For the purposes of this workshop, the following definitions were used:

**Consumers:** People who use, have used, or are potential users, of health services including their family and carers.<sup>1</sup>

**Community:** Groups of people or organisations with a common local or regional interest in health.<sup>1</sup>

**Engagement:** Activities that involve people who use health services (consumers or communities) in decision-making, policy development, service delivery, evaluation and research.

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## BACKGROUND

### Consumer Engagement In Research

The 1999 Health and Medical Research Review (The Wills Report)<sup>2</sup> recommended consumers have the opportunity to participate in decisions about priorities for research, that consumers whom participate in research should be told about the outcomes of that research, and that researchers should involve the community in the research processes.

In 2002, The Consumers Health Forum of Australia Inc (CHF) and the National Health and Medical Research Council (NHMRC) worked in partnership with consumers and researchers to develop the first Australian Statement on Consumer and Community Participation in Health and Medical Research<sup>3</sup>, which was updated in November 2016. The Statement outlines the benefits of consumer involvement in medical research as below.

**Benefits to the public of consumer and community involvement include<sup>3</sup>:**

- Research being conducted that is relevant to community needs;
- Public awareness of, and support for, science and research, and;
- More effective translation of research to deliver improved health outcomes.

**Benefits to research and research institutions include<sup>3</sup>:**

- Increased community relevance, through improved research priorities and projects informed by consumer and community perspectives and lived experiences;
- Public confidence in research through improved openness and transparency in the conduct of research;
- Public confidence in research through improved accountability and openness over the use of public money;
- Communities being better informed and having a greater understanding of research, and;
- Increased opportunities to continuously improve the quality of research.

There have been numerous reviews of medical research in Australia since 1999, each acknowledging the value of the consumer in research. Most recently, the Medical Research Future Fund Research and Innovation Strategy 2016-2021<sup>4</sup> included as one of its objectives 'maximise opportunities for research translation by engaging with consumers'.

Other drivers for increased consumer engagement in research include:

- Funders of research (for example, the NHMRC<sup>5</sup> and Cancer Institute NSW<sup>6</sup>) that are requiring researchers to outline how consumers are involved in research projects.
- Journals like The British Medical Journal who advocate for increased consumer participation, for example in conferences<sup>7</sup> and review of medical literature<sup>8</sup>.



- Consumers and consumer organisations who through the use of technology can now communicate with each other, identify challenges, drive research questions and priorities, and advocate for research funding. Examples of consumer driven groups driving the research agenda include: PatientsLikeMe<sup>9</sup> and The Michael J. Fox Foundation (MJFF) for Parkinson's Research<sup>10</sup>; Researchers themselves.
- Standards, such as those for Australian healthcare organisations against which they are accredited<sup>11</sup>.

In 2005 a Model Framework and Resource Pack to support researchers to involve consumers in research was released.<sup>12</sup> The Consumer and Community Health Research Network at The University of Western Australia's School of Population Health and the Telethon Kids Institute releases The Green Book in 2008 (revised 2012<sup>13</sup>), The Purple Book in 2014<sup>14</sup>, and Fact Sheets in 2011<sup>15</sup> as resources to assist and inspire researchers to involve consumers in research. However, analysis in 2010<sup>16</sup> suggests that consumer engagement in research is still in its infancy in Australia. A qualitative study of the barriers perceived by researchers to increasing consumer involvement is outlined in a 2016 report<sup>17</sup> and below.

**Key Findings about barriers from a researcher perspective** to consumer and community involvement could be characterised into the following categories<sup>15</sup>:

- Time and effort;
- Funding;
- Finding the 'right' people;
- Sensitivity and confidentiality;
- Organisational and policy barriers;
- Personal Barriers;
- Research fatigue;
- Group dynamics.

We could only identify one organisation in Australia that provides resources and education to consumers and researchers on working together in research. Involving People in Research<sup>18</sup> is based in Western Australia and facilitates opportunities for consumer involvement in research there. A number of state-based cancer and health consumer groups provide training directed to consumers in getting involved in or reviewing research funding applications, and/or consumer matching services for researchers.

Health Consumers NSW and Research4Me co-hosted this workshop with a view to exploring the involvement of NSW consumers and consumer-driven NGOs in research, and to identify possible barriers and enablers for increasing consumer involvement in research.

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## Patient Centricity in Clinical Trials

Clinical Trials are essential part of the process for gathering the evidence for healthcare practitioners and patients to know which treatments may work and be safe for a given health condition, and the best way to use those treatments.

According to a 2012 Australian Government survey, the Australian community is familiar with the term clinical trial (82%), and around two-thirds say they are willing to participate in trials<sup>19</sup>. Despite this, some 90% of Australian trials face delays due to a lack of people to participate<sup>20</sup>, resulting in delays in when patients will get access to treatments that may improve or cure their conditions.

It can be difficult to find people willing to participate and able to meet the requirements of the clinical trial, whether that be from a medical or practical point of view. The poor recruitment can *in part* be explained by a lack of awareness in the community as well as clinical trial design flaws.

A 2015 Australian government report into the conduct of clinical trials in Australia<sup>21</sup> noted in the summary that one barrier to Australian clinical trials was a lack of awareness and support for clinical research:

*"...Difficulties with patient recruitment arose in many cases due to a lack of referrals from GPs, and a lack of awareness about relevant clinical trials in the general community. It was felt that clinical research was seen by the broader community and also the medical community as secondary to clinical care..."*

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*Other contributing factors to poor patient accrual reported during consultations and in the published literature relate to protocol design rather than operational factors. These included patient eligibility criteria not reflecting current medical practice or being too restrictive, a perceived lack of value of the study question or product, and/or protocol requirements being too complicated."*

The report outlined the implications for Australia of being unable to recruit to clinical trials:

*"Not meeting recruitment targets will put investment in clinical research in Australia by this organisation on the chopping block." – Case Study 4*

*"Short and longer term impacts of delayed start up combined with poor patient accrual include: patients potentially miss out on early access to new medications; ...and international corporations consider this performance (cost, timeliness of startup and capacity to reach recruitment targets) when making decisions regarding future investment in clinical trial activity in Australia." – Case Study 7.*

In order for Australian to continue to benefit from the advantages clinical trials bring to our healthcare system, which include more engaged practitioners, exposure to the latest medical advances early, a culture of continuous improvement and better patient outcomes, then addressing the issues that contribute to poor clinical trial recruitment are essential.

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One approach to addressing recruitment issues that is gaining momentum internationally is the movement to make clinical trials more patient-centric. Yet an understanding by the community of the role they can play in improving and promoting clinical trials and, the knowledge and pathways to connect patients and researchers to be able to work together are underdeveloped. Research conducted in 2015<sup>22</sup> amongst research, industry and patient groups found similarities in approach to engagement by the three stakeholder groups, but key differences in the perceived barriers and benefits to partnering with patient groups. It concluded that there was a need for the development of best practices for patient-centred clinical trial design and execution.

However, given the very specific role of clinical trials in translating research into practice, the increasing requirement by funders for consumers to be involved in the clinical trials they fund, and government efforts to improve the clinical trials environment in Australia for its economic and social benefits, more focussed education and support to enhance consumer involvement in clinical trials is specifically needed.

Research4Me and Health Consumers NSW co-hosted this workshop with a view to exploring the involvement of NSW consumers and consumer-driven NGOs in clinical trials specifically, to assess their interest in increasing that involvement as partners in the clinical trial process, and identify any specific barriers and enablers relating to consumer involvement in clinical trials.

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## THE WORKSHOP

### Planning and Objectives

Research4Me and Health Consumers NSW came together to host a workshop to explore their joint interest in consumer involvement in the design of health and medical research generally, and more specifically clinical trials.

Invitations were distributed by email a month prior to the workshop to research-active consumers, research contacts for consumer health NGO groups based in NSW, and Government agency representatives with an interest in supporting clinical trials infrastructure that were known to each organisation.

A pre-workshop survey was distributed via SurveyMonkey® to collect background information on the research-related activities of those invited. Five surveys were returned prior to the workshop and the feedback received is presented in Appendix 1. Not all survey respondents attended the workshop.

The objective of the workshop was to discuss the following, which would help Health Consumers NSW and Research4Me to identify the next steps each organisation might pursue in their support of consumer involvement in research:

1. To understand how consumers and organisations are currently involved in co-design of research, discuss the challenges of and examples of success of that involvement with a view to identifying the barriers, and brainstorming enablers, for increased involvement.
2. Discuss the challenges of clinical trials, why there is a growing interest in greater patient-centricity and partnership with consumers, and what interest and capacity attendees may have in being more actively involved in and contributing to the success of clinical trials.

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## The Workshop

The 3-hour workshop was held as a roundtable discussion with introductory presentations by HCNSW and Research4Me to lead the discussion. Small groups were given time to brainstorm challenges and then the group as a whole discussed ideas raised, categorised them and shared thoughts on possible solutions.

The following sections collate and summarise the content of those discussions.

## Themes Identified to Impact Consumer Involvement

### 1. Types of Research

It was identified that some types of research are more conducive to consumer involvement than others, some disciplines are more open to involving consumers than others, and different research projects may have different needs. It was felt that medical and health research could learn from qualitative and social science research methodologies. One example, not mentioned in the workshop, is participatory action research that involves people in all stages of the research process<sup>23</sup>.

It was raised that funding bodies categorise research in different ways and it can be difficult to fund research that does not fall neatly into an existing category. This makes it difficult to do research that uses new or innovative methodologies, and which could also benefit from consumer involvement.

### 2. Consumer Availability

Consumers have lives outside of their health condition/experience. Taking considerable time out from family or work responsibilities to contribute (usually voluntarily) is often difficult. To help consumers to more actively contribute, respecting their 'day job' and being flexible to the needs of different consumers is important. For example, holding meetings outside of standard work hours of 9-5pm, providing sufficient time to review documents, enabling virtual working, or provision of hard-copies of document in ample time for them to read and reviewed, may all help consumers be more involved.

### 3. Funding consumer involvement

There was some discussion about the issue of volunteerism versus funding consumer involvement. Time and finding can be an issue for both researchers and consumers, though not all researchers respect and consider this for consumers. All agreed that consumers should be reimbursed at a minimum for actual expenses they incur. However, there was not agreement as to whether consumers should be paid for their time, or what an appropriate payment might be. This may need to be explored on a case-by-case basis.

Whenever possible, it was suggested researchers apply at a minimum for reimbursement of consumer expenses as a line item in their research funding budgets.

There was some discussion about the difficulties of resourcing consumer engagement within the existing system of research funding. This was due, in part, to there not being a clear pathway for funding consumer involvement in research. Most applications for research funding do not include a budget for consumer engagement and it is not clear how funding bodies would react to such an expense.

### 4. Finding the 'Right' Consumer

It was recognised that some consumers have difficulty balancing their personal experiences and agendas with the broader common experiences and agendas of representing a community of people with a particular health condition. Adequate training, clear and fair recruitment process, and clear mutually understood statements of roles and responsibilities may go some way to alleviating this.

Likewise, not all consumers want or are able to be involved in co-design processes.



One example of the spectrum (or ladder) of engagement was discussed (Figure 1), as a reminder that the level of engagement appropriate may depend on the project, researcher needs and consumer abilities/interest. The group felt it was important that there were selection processes and training available to ensure the 'right' consumer was appointed for the 'right' role. To facilitate the appointment of the right person, researchers should also consider in advance what they expect of their consumers, and communicate those expectations (See later theme 'Clarity about roles and expectations') and what their consumers can expect of them.

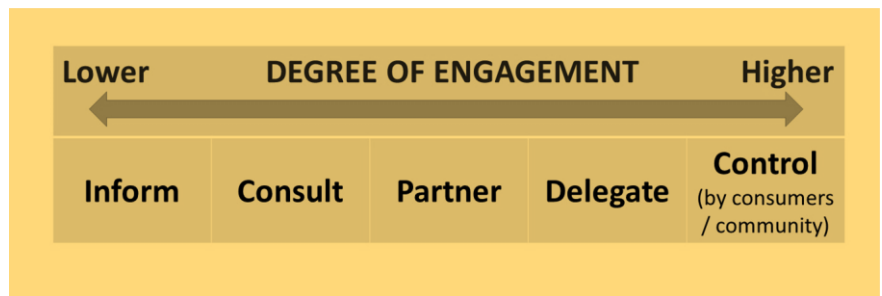


Figure 1: Spectrum of Engagement<sup>24</sup>

An unexpected point of contention amongst attendees was what personal information should be provided by a consumer/consumer organisation to a research team about a person in order to assess their suitability as a consumer representative for a project. Some expressed concerns about keeping the confidentiality of consumer representatives' personal details, diagnoses, and experience, especially given the sensitive nature of some health conditions (such as having a mental health diagnosis or being HIV positive). For noting, one organisation present which matches consumers with researchers does not disclose information about the person. They use information provided by the researchers about the consumer they are seeking to find a match based on what they know about consumers on their database. They then refer the consumer to the researchers, but leave it up to the consumer to disclose what they feel is appropriate to share with the researchers.

## 5. Consumer Training & Support

Work needs to be done to determine what basic skills or research knowledge consumer representatives should have, with different projects perhaps needing different levels of skill.

It was identified that some consumers are reluctant to talk about their experience, or may not have the confidence to do so. They also need some coaching in how to be careful with their own story before they begin to connect with researchers. Constantly reliving an experience can be stressful, and there is the potential to change over time in the re-telling. There is also a lack of general knowledge about research and research processes by consumers. These are elements that would be useful to cover in any consumer training.

A number of cancer organisations currently provide training to consumers to assist them to become consumer representatives. As useful as this training was to one attendee, they identified that once they become part of a research team, the knowledge they felt the research team assumed and expected was vastly different.

As such, it was identified that both generalist training to potential consumer representatives, as well as ongoing support to consumer representatives involved in research (for example, connecting more experienced consumer representatives with new consumer representatives) would be of value.

Where possible, the group advocated that there should always be more than 1 consumer representative on a project. This will reduce the possibility of less representative views, but more importantly, will ensure consumers have a peer in the group that they can gain confidence and support from.

There was significant discussion and difference of opinion about whether there should be some type of accreditation scheme for consumer representatives, with a national database of accredited consumers. Some felt this would create an additional barrier and access issues for some consumers to get involved, while others thought it might create a level of comfort for researchers in the basic skills and knowledge of the consumers they were recruiting.

## 6. Researcher Beliefs & Culture

It was generally felt that the culture of research (the beliefs and practices of most researchers) is the most significant barrier to effective and meaningful engagement with consumers. Most people had positive stories about individual researchers who understand the value consumers bring to research and were empathetic in their communication with consumers but they were seen as exceptions.

There was widespread agreement that many researchers that have contact with patients believe that they are therefore able to speak on behalf of patients, and hence do not think patients need be directly involved in their research. Getting researchers to understand that their experience treating patients is not the same as the patient experience is an important first step in helping them appreciate the value including consumers in their research team might bring.

There was also the perception that some researchers just include consumers in order to 'tick a box', but that they don't actually believe in or see real value from consumer involvement. Tokenism, often as a result of considering the involvement of consumers too late, is common.

Researchers can be patronising toward consumers - 'what do they know?'. This can lead to consumers/consumer groups getting frustrated, mistrusting and disengaging from researchers. Appropriate training may help address these attitudes and behaviours.

Some attendees expressed the view that younger researchers are more adaptable and hence more likely to involve consumers as just something that you do. It was felt that older researchers find it more difficult to change how they have always done things. However, others had experienced exactly the opposite with more experienced researchers seeing the increased value of consumer involvement. This demonstrates that it is not a matter of age or research experience, but likely willingness to engage, which will define who involves consumers in their research.

Ensuring those more experienced with involving consumers lead and mentor others to include consumers will help change the culture of research.

## 7. Researcher Training

Just as consumers need support to work with researchers, researchers are also lacking the basic skills and knowledge to work with consumers.

The group identified the following as useful for researchers to be trained on in order to work effectively with consumers:

- A. Understanding how consumers can add value to their research, and the levels of engagement that consumers can have, from consultation to control. See suggestions for further work required to support this training in the boxed example.

### Adding Value

The group identified it can be hard to demonstrate the added value consumers bring. It was felt there is a need to quantify success and for the evaluation of what consumer engagement brings to research. The following ideas were suggested for the types of information that should be collated to improve the evidence base for the value of including consumers in research:

- Calculate the retrospective monetary value add on specific projects, for example, value of reduced research waste, saved time/resources, better/relevant research outcomes, recruitment/retention spend, speed of dissemination/implementation of research.
- Showcase successful projects that have involved consumers (e.g. funding success, % involvement, types of involvement)
- Showcase projects where consumer voice influenced outcomes of research/ translation of findings.

- B. Learning how to effectively listen to consumers, without getting defensive or dismissive about the contribution. Consumers have different backgrounds, knowledge and experiences, and that will shape what, and how effectively, they might communicate their ideas and experience. (Equally, consumers need to be willing and confident to engage, listen to and ask questions of researchers, to make the partnership effective).
- C. Defining the level and type of engagement they are seeking, as well as the role they would like the consumer to take, prior to engaging consumers.
- D. Learning who to approach, and how, as well as how to select the right people.
- E. Being empathetic to the consumer's health journey (see boxed example).
- F. Practicing using plain language to explain research concepts or their project simply to a lay audience.

### Being Empathetic

One attendee described working with researchers on a project researching a new treatment for the serious health condition she was being treated for. She described being given a something to read that was justifying the need for the research to a funding body. That justification included the statistics on poor success rates for current treatments of that condition and survival indications. As they put it, *'My treating physician had not (and probably would never have) given me that information. It was very confronting.'*

Researchers need to consider the personal journey consumers who may be living (or have lived) with the condition they may be studying are on. Researchers should be mindful of what a consumer might know about their condition/treatments and the impact 'the facts' may have on them when considering what and how disease specific information is discussed.

The group felt it was important that researchers experienced in working with consumers mentor and encourage other researchers with less experience.

## 8. Clarity About Roles and Expectations

In the experience of the group, the intent of consumer involvement can be unclear. The value a consumer can add to a project may be limited if the research team have not properly defined the role of the consumer, and outlined their expectations to the consumer. People said there were times when they were unsure of how to contribute, or what they were supposed to contribute, as a result their contribution felt less meaningful (see boxed example below). When a consumer understands what is expected from them, it makes it easier to deliver on that and understand their role.

### Expectations

An attendee shared one of their experiences as the consumer representative in a research team on a highly technical research project. They were asked to review and sign off on the lay summary for a funding application. They were unclear on exactly what they were being asked to do. For example, were they supposed to review the science of the project, the context of the project, the meaning and impact of the project to the consumer, or the lay language used to describe the project. They didn't have any idea of the context or validity of the science (given that was not their primary occupation), and they didn't understand some of the language used in the lay summary. They didn't have the confidence to seek clarity from the research team and didn't want to be seen as blocking the research, so just signed off on it.

So while the researchers had sought consumer input, the lack of clarity regarding the consumer role meant the consumer input received was possibly less valuable than it could otherwise have been.

If consumers have expectations about what they want to (or can) contribute to a project, then they should also discuss these with the research team up front, or as their expectations change. It is critical for both sides to have a common understanding of the expectations, for the partnership to succeed.

## 9. Language

Much of the terminology used in research is not familiar or accessible for consumers. This was identified as an enormous barrier to consumer involvement. Greater use of plain language by researchers would help address this concern.

## GENERAL DISCUSSION

### What roles can consumers/consumer organisations have in clinical trials?

An outline of the clinical trial process and different ways consumers might be involved in that process was discussed.

Attendees agreed that consumer involvement in clinical trials was important. When asked how they felt consumers/consumer groups could contribute, the following ideas were specifically raised:

- Including consumers on trial steering committees, right from the start;
- Advocating for consumer involvement in trials;
- Training consumers to contribute to trials;
- Educating the community: “Are there clinical trials I can be part of?” and building a database of potential participants. (See boxed example below for some ideas discussed);
- Promoting trials and increased health literacy for consumers;
- Peer support at start and during trial, to support recruitment and retention of participants

#### Educating the community

Some of the ideas raised for increasing community awareness of trials included:

- Providing written information on trials upon admission to hospital
- A basic training module creating basic awareness of trials, something like the Surf Life Saving CPR training.
- Approach schools to educate Year 12 students about the possibility that they might one day become a health consumer, and as part of the journey may be approached (or actively wish) to contribute to clinical trials.



The following were raised by different attendees as important for consumers involved in trials:

- Acknowledging the risk to trial participants;
- Providing appropriate payment or other incentives for recruitment and/or high risk procedures. (There was however some contention within the group about the appropriateness of payments to consumers, and as such, this idea needs further exploration);
- Providing feedback to consumers/consumer groups at the end of the trial;
- A sense of shared responsibility between the researchers and consumers for the trial, and outcomes of the trial
- Consistent, long-term partnership by research organisations with consumers along every step of the process. That will increase consumer propensity to want to engage with research, build trust and develop the relationship to be more meaningful.

### **What role can consumers play to drive behavioural change in researchers?**

The following ideas were raised as possibilities to encourage greater consumer involvement by researchers:

- Creation of a consumer involvement tick or logo. It was felt that making it easy to identify research that had consumer involvement would also help build trust with people being asked to participate in the research. Through the discussion, attendees were made aware of the global #PatientsIncluded initiative creating charters for conference, patient information, trials, and other aspects of healthcare (<https://patientsincluded.org/>)<sup>25</sup>;

- Greater involvement in ethical review of projects. As an example, one organisation supports people to write complaint letters to the chairs of HRECs when they have issues with a research project;
- Better understanding the consumer experience of clinical trials. There was value seen in eliciting participant feedback via surveys at recruitment, and at the end clinical trials to learn more about the participant experience;
- Creating standing consumer panels that could serve as a starting point for advice;
- Developing a guiding set of principles around what is important to consumers about being involved in research, which the group proposed Health Consumers NSW should establish.

### Research Funding

Unprompted and unexpectedly, the consumer group raised their frustration with research funding systems, the poor success rates, and the time that applying for funding takes away from the conduct of research. The discussion demonstrated that consumers are genuinely supportive of research and empathetic to the administrative burden and funding challenges faced by researchers.

Via the discussion, the group were advised of the 2016 NHMRC review of grant funding and provided with the links<sup>26</sup> to information about that review subsequent to the workshop.

## CONCLUDING REMARKS

Given the limited time (3 hours), the depth of discussion and consensus in themes raised by the group was surprising, and consistent with other literature about barriers to consumer involvement in research. There were a number of areas where agreement was not reached and it is clear that further discussion and exploration is warranted. There is, however, a clear mandate from the group to develop a guiding set of principles around what is important to consumers about being involved in research.

The common theme in comments about the workshop was that there needed to be more time for discussion. Health Consumers NSW and Research4Me will look at next steps to continue that discussion and build momentum and support for greater inclusion of consumers in research, and clinical trials specifically.

## OTHER INFORMATION

### Additional Resources

1. Consumer Involvement in Research - Does it work? An Evaluation of the Cancer Voices NSW Consumers in Research Programme. July 2016. [Available by contacting [info@cancervoices.org.au](mailto:info@cancervoices.org.au)]
2. [Cancer Australia](#) Consumer Learning – Consumer Involvement in Cancer Cooperative Trial Groups – Information to help consumers understand how they can play a role in research
3. [New medicines, faster | Joseph Kim | TEDxPhoenixville](#) (YouTube, 15mins). This inspiring TEDx Talk by Joseph Kim talks about the value of clinical trials, and the question of how to get people to care about taking part in clinical trials.
4. [Patient-Centricity in Clinical Trials- Nancy Santanello, MD, MS, Former Merck VP of Epidemiology](#) (YouTube, 2min). This video provides a quick snapshot to patient-centricity in the pharmaceutical industry.
5. [How to implement patient centricity from Lode Dewulf at UCB pharma](#) (YouTube, 11min) This video uses a real patient story to demonstrate the difference between learning about a condition, treating a condition, and the lived experience of a condition, and hence the value of seeking out the patient perspective.

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## About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policy-makers. Our mission: Consumers shaping health in NSW. We promote the best quality, appropriate health outcomes for consumers of health care services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of health care in NSW.

### Contact Details:

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## About Research4Me

Research4Me (a trading name under AccessCR Pty Ltd) is a for-purpose enterprise that is reimagining how the community engages with clinical trials, and those that run clinical trials.

By working with and bringing members of the public, research and healthcare providers, government and industry together, Research4Me aims to improve public awareness, participation, experience and partnership in clinical trials.

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## APPENDIX 1: SUMMARISED PRE-WORKSHOP SURVEY FEEDBACK

The following presents the summarised feedback from five individuals/organisations that completed the pre-workshop survey sent to all workshop invitees.

### Which health area/s are you/your organisation interested in?

- Stem cells, regenerative medicine
- Dementia and aged care
- People living with HIV
- Diabetes
- Multiple sclerosis/autoimmune disease

### Research related activities individuals/organisation are currently involved in:

	RESPONSES
Funding research projects	2
Setting research priorities/agendas	3
Research Consumer Advisory Committees/Panels	4
Design/Co-design of research projects	4
Helping researchers find participants for their projects	4
Finding consumers to work with researchers on design of research	1
Promoting the value of research to the general public	4
Advocacy about research to government	4
Not very involved in research	0

**Types of Research involved in:**

	The only type of research we are involved in	The main type of research we are involved in	We are sometimes involved in this	We occasionally are involved in this	We are never involved in this	Response Count
Clinical Trials	0	1	2	1	1	5
Other types of research	0	3	1	0	1	5
If Other, what types of research are you involved in?						3
Answers:						
	<ul style="list-style-type: none"> <li>• Cohorts, bench research, registries</li> <li>• Social research with universities and program development with unis and other NGOs</li> <li>• Basic research, clinical research, social and applied research</li> </ul>					

**How would you describe the experience of being involved in co-design of research?**

	Responses
Mostly positive	2
No direct experience	3

**Can you give an example of how your consumer involvement improved a research project?**

- Strategy development, input towards areas of research priorities, selection of research projects, advocacy, policy development.
- It gives the researchers first hand knowledge and the consumer has their voice heard
- We were able to add to the lived experience and also ask questions that the researchers had not thought of.

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- We have recently completed an MS research priorities survey in which the MS community (patients, friends, family, and those with a professional connection to MS) responded to questions about different areas of MS research. This will help inform our research strategy going forward.

**What training and/or resources (if any) do you currently use to upskill yourself/your consumers to be involved in co-design of research?**

- None in co-design of research.
- A designated worker is available for assistance before during and after the research project
- Masters degree, attend conferences and read current up to date literature
- None.

**What do you see as the 3 main barriers to increasing you/your organisation's involvement in research?**

- Money, limited time a person with dementia can participate, not considered "scientific" enough to participate
- Time, funding, relevant research projects
- We have no barrier in involvement in research, but we have more work to do in involving consumers in more aspects of what we do

**What else would you like to tell us about consumer involvement in co-design of research/clinical trials?**

- Consumer involvement is essential to ensure rigor of any project. Consumers of the potential outcome of trials must be involved from the get go.



## APPENDIX 2: WORKSHOP ATTENDEES

	<b>Role, organisation, area of interest</b>
Melinda Cruz	CEO, Miracle Babies
Shirley Baxter	Consumer Rep, Cancer
Susan Taylor	Consumer Rep, Cancer
Tarra van Amerongen	Consumer Rep, Cancer
Grainne Mullen	Consumer Rep, Cancer
Jill Yates	Consumer Rep, Cancer
Craig Lawn	Consumer Rep, Melanoma
Lee Hunt	Consumer Rep, Cancer; Cancer Voices NSW
Cecilia Gray	Consumer Rep, Cancer
Dianne McGirr	Consumer Rep, Cancer
Lisa Melton	Research Director, MS Research Australia
Craig Cooper	CEO, Positive Life NSW
Elaine Todd	Consumer Rep, Dementia
Anthony Brown	CEO, Health Consumers NSW
Janelle Bowden	Executive Officer, Research 4 Me

## APPENDIX 3: WORKSHOP EVALUATION

I was listened to and my experiences contributed to the discussion in todays workshop

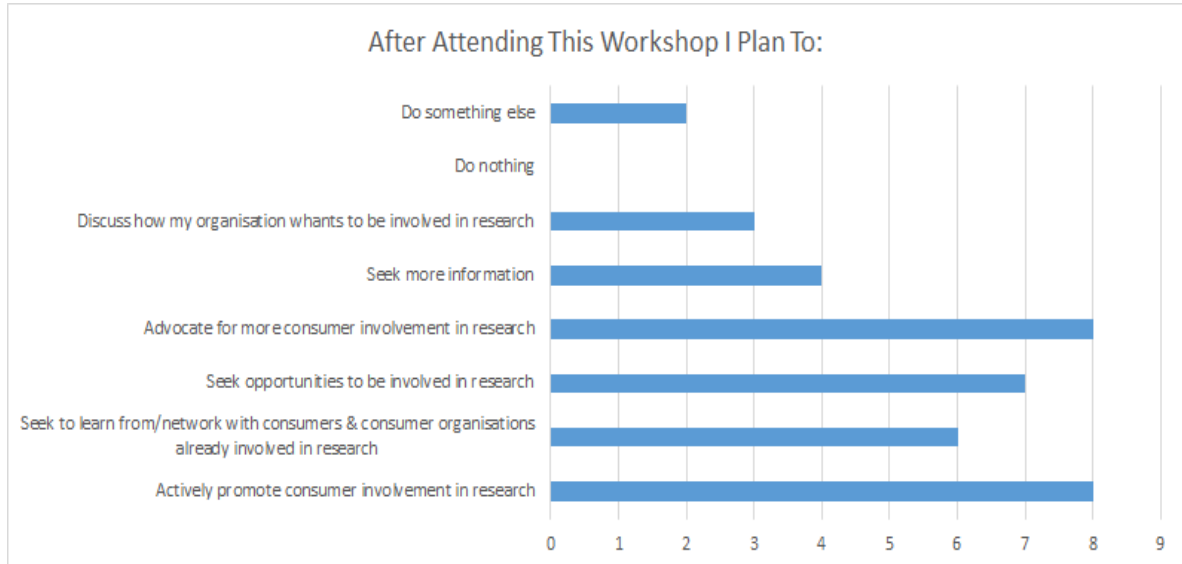


I was listened to and my experiences contributed to the discussion in todays workshop



This workshop increased my understanding of clinical trials





For noting: Something else responses:

- I would like to work with Janelle to do a pro bono project on clinical trial design from a patient-centric perspective
- I already do these.



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