
Prepared by
White Coats Foundation

November 2021

REFLECTIONS PAPER

De- Mystifying Consumer and Community Involvement in Research (CCI)

Webinar Series
15th & 22nd September,
2021





01 - 03

ABOUT WHITE COATS

04 - 07

PANELISTS & PRESENTERS

08 - 10

WEBINAR 1 - INTRODUCTION & POLL

11 - 15

TOPIC 1: WHAT IS CONSUMER AND COMMUNITY INVOLVEMENT(CCI) IN RESEARCH?

16 - 21

TOPIC 2: HOW CAN CONSUMERS BECOME INVOLVED IN RESEARCH?

22 - 25

TOPIC 3: HOW CAN CONSUMERS PREPARE TO BECOME INVOLVED IN RESEARCH?

26

WEBINAR 2- THE DISCUSSION & INTRODUCTION

27 - 30

TOPIC 1- HOW DO CONSUMERS ACCESS OPPORTUNITIES TO BE INVOLVED IN RESEARCH?

31 - 33

TOPIC 2. WHAT ARE THE BARRIERS TO CONSUMER AND COMMUNITY INVOLVEMENT IN RESEARCH?

34 - 40

TOPIC 3- HOW DO WE ENSURE THAT CCI IN RESEARCH IS VALUE ADDING AND NOT TOKENISTIC?

41 - 42

SUMMARY & RECOMMENDATIONS

42 - 44

RESOURCES

About White Coats Foundation

White Coats Foundation (WCF) is a NFP DGR registered charity established in recognition of the need to raise awareness about the role of clinical trials in advancing medical science and healthcare.

Why

Clinical trials have the potential to benefit people's health and can provide options in circumstances where treatment choices are limited or there are none.

How

WCF is delivering on this mission through a variety of initiatives that encourage listening, learning, collaborating, networking and sharing.

WCF initiatives involve the general public, health care professionals, patients and carers because there are knowledge deficits that exist within each of these communities.

All WCF initiatives align with its charitable purpose and fit into one of the 5 core arms of the foundation.

- **Education and Resources**

Access to credible resources and information to help guide peoples journey in understanding clinical trials. WCF employs creative strategies to enhance education and learning. "Behind the White Coat" is one example of our educational activities which is a video series that goes behind the scenes of drug discovery. The series gets up close and personal with those that assist in making new therapeutics possible. Other activities include education webinars and website content with links to key resources.



- **Research**

The research arm of the foundation is dedicated to exploring knowledge deficiencies and other barriers in relation to research and clinical trials awareness. WCF is currently developing a national benchmarking survey aimed at investigating Australian clinician's perception, experience and value of clinical trials. Future projects include investigating the gap between reported public willingness to participate in clinical trials, and the under recruitment experienced by researchers. The project will also seek to gain a qualitative understanding of the level of awareness and knowledge of clinical trials within the Australian community through a series of focused interviews.

- **Merchandise**

Symbolism aids awareness. Through the WCF merchandise arm we create branded products that can be used as awareness tools in the community. The "Keep Cup" is the first idea in our range of "useable" products designed as a tool to help patients lead an awareness movement. One cup equals one conversation. We have an evolving product line with merchandise that can extend to health care professionals and general sales at conferences and events.

- **Fundraising**

The WCF is dedicated to raising funds to support early research and initiatives that facilitate the discovery of better health. The WCF launched its first fundraising campaign in 2020- 'The Power of One'. The inaugural campaign was run as an online event which highlighted the power 'one' has to influence change. One disease can change lives but so can one new discovery. The recipient of the Power of One 2020 Grant was The University of Newcastle for their research project- 'Brain Cancer and Cognitive decline: The acceptability of Cognitive Screening for Aboriginal people in New South Wales (NSW)'.

- **Events**

White Coats Foundation events have a focus on connecting the clinical trial community and patients to share feedback and experience on clinical trials. As humans we connect through sharing of stories. Our events allow people to learn from one another. It is these stories that also have the power to positively impact practice, and how people relate to clinical trials. White Coats Foundation launched its inaugural event, the "Thank- You" session in 2019. The Thank-You sessions are a unique opportunity for health care professionals and Industry members to acknowledge and thank patients directly for their contribution to the discovery process.

The vision of the 'Statement on Consumer and Community Involvement in health and medical research', co-authored by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF), aspires

“ to see consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.”

There is a growing movement and need to incorporate the voice of consumers in research. However, as part of WCF interactions with the sector on a consumer and Industry level it has become apparent that there is some confusion as to what consumer and community involvement in research means.

Who are consumers? How can consumers use their knowledge, experience and insights to improve research, clinical care and outcomes for patients?

Consumer participation in health and medical research has for a long time primarily been associated with participation as a 'subject' or 'clinical trial participant' in a research trial. However, consumer and community involvement in research (CCI) does not include clinical trial participation. The scope for consumer involvement is much broader than this but how are consumers being involved in the broader range of research roles and opportunities available to them?

WCF aimed to address these issues through a 2 part webinar series creating an opportunity for stakeholders with an interest in or focus on consumer and community involvement in research to ask questions, share experiences, listen and learn from others who are effectively involving consumers in research.

In bringing key stakeholders together WCF aimed to raise awareness; foster improved understanding; help reduce duplication of effort, encourage collaboration, and identify any gaps in progress on current efforts to involve consumers in research.

The webinar series had a total of 241 unique registrations and 260 attendees over the two sessions.

This paper is a reflection of the discussion that took place over the series. It incorporates the views of the speakers, panelists and attendees. Each discussion topic includes a summary of salient points as 'key takeaways'. Areas raised during the webinar that were not addressed in this series have been captured for consideration as 'future discussion' topics. These items will be reviewed and prioritised for the WCF educational webinar agenda in 2022.

Acknowledgement of Country

White Coats Foundation acknowledges the Aboriginal and Torres Strait Islander nations of Australia as the traditional owners of our country. We pay respects to ancestors and elders past, present and emerging.

Presenters and Panelists

White Coats Foundation would like to acknowledge and thank the presenters and panellists for their generous time and contribution to this webinar series.

Ms Leanne Weekes- Programme Director CT:IQ, Program Manager Bellberry Limited



Leanne has over 12 years of diverse bio-pharma research and development experience, including managing clinical trials and programmes of trials for pharma's and CROs across Australia, New Zealand, the UK and Europe.

Leanne is now the Programme Director of Clinical Trials: Impact & Quality (CT:IQ), an MTPConnect funded initiative bringing the clinical trial sector together to develop and implement recommendations that will improve the impact, quality and efficiency of clinical trials.

Sarah Lukeman - Community Engagement Coordinator, Hunter Cancer Research Alliance

Sarah joined a clinical trial in 2006 when she developed a rare form of acute leukaemia, and is alive today because of that.

Sarah has been a trained consumer involved with cancer research since 2016, partnering with a number of basic-science researchers and sitting on funding panels. She helps Hunter Cancer Research Alliance (HCRA) researchers involve consumers in their research and connects them to the Consumer Advisory Panel she mentors and supports.



Ms Lee Hunt- Cancer Consumer Advocate



Lee has been involved as a cancer consumer and advocate since undergoing Consumers Involved in Research training in 2014 at Cancer Council NSW. She is an Executive Member of Cancer Voices and sits on the Faculty of Radiation Oncology Council.

Lee is a member of several cancer research projects, clinical trials, and cancer committees and has made presentations at both national and international conferences.

Presenters and Panelists

Ms Jill Yates- Consumer Advocate



After careers in teaching and law, Jill retired around 10 years ago following a breast cancer diagnosis. Since that time, Jill has been involved in a wide range of consumer roles which she has found very rewarding.

Mr Zy Phillips- Consumer Advocate

Zy is a father of two special children with high needs. Together with his wife Brita, they are making it work one day at a time.



Ms Lisa Carstairs- Consumer Advocate



Lisa is a proud Aboriginal woman who has extensive first-hand experience across the cancer consumer spectrum; first having been diagnosed with advanced breast cancer in 2008, undergoing lengthy multi-chemotherapy treatment variants, radiation therapy and subsequent cancer diagnoses.

As a Cancer Voices consumer representative, she relishes the opportunity to work with cancer research teams. Lisa has seen first-hand how feedback, through her cancer journey, can make a significant difference for people undergoing cancer treatments in the future. Additionally, she has extensive experience working in the federal health sector and Royal Australian and New Zealand College of Radiologists (RANZCR), specialising in improving Aboriginal health outcomes.

Presenters and Panelists

Ms Anne McKenzie (AM)- Consumer Advocate, Telethon Kids Institute



Anne McKenzie AM has held professional and voluntary roles as a consumer advocate for the past three decades. Since 2004, Anne has worked in research organisations to increase the community voice in research and has developed organisational frameworks for engagement, training and resources

Mr George Kiosoglou- Consumer Representative, Walter Eliza Hall Institute (WEHI), Melbourne Academic Centre for Health (MACH), and Australian Health Research Alliance (AHRA) CCI Initiative (Vic)

George spent 41 years working in the IT industry before retiring in 2016. In April 2013 he was diagnosed with Acute Myeloid Leukaemia and underwent chemotherapy followed by an Allogenic Stem Cell transplant in the same year. He is on various grant review boards, committees, including, Melbourne Health Ethics Committee, a Consumer Representative for WEHI and MACH and the AHRA CCI initiative.



Ms Angela Todd- Research Director, Sydney Health Partners



Angela has worked across health and research sectors in Australia and Canada. In her current work with Sydney Health Partners she leads various research improvement strategies including promoting consumer and community involvement in health research.

Presenters and Panelists

Dr Jane Hobson- Senior Advisor, Research Management Cancer Council NSW



Jane heads Cancer Council NSW's \$10 million annual research grant funding program and has previously held senior positions at Australian universities creating and implementing strategies for research and researcher development.

Ms Cathy Florek- Director, Head of Engagement Strategy, Bristol Myers Squibb

Cathy has been with Bristol Myers Squibb, based in Princeton, New Jersey for over 30 years, spending the majority of her time in R&D. In her current role as Head of Clinical Trial Engagement Strategy within Global Development Operations, she oversees a team of Engagement Strategy Leads who focus on bringing the voice of patients, caregivers and sites into trial designs and implementation, with a goal to drive meaningful change, improved experience, and generate greater patient diversity in our clinical trials.



A/Prof Christine Chaffer- Head Cancer Cell Plasticity Laboratory, Garvan Institute of Medical Research Sydney.



Christine's research focuses on developing new therapies for cancer patients to prevent the development of metastasis and chemotherapy-resistant disease. She obtained her PhD from The University of Melbourne, and completed her post-doctoral studies at MIT, Boston, USA.

Webinar 1: The Presentations

Webinar 1 included presentations from key leaders on consumer and community involvement in research on three key topics with an opportunity for attendee interaction and discussion. The aim was to clarify what consumer and community involvement in research means and to look at the different ways in which consumers can be involved.

Reference to real life examples of consumer participation in research were provided. Training options available to support consumer involvement in research and the benefits and value of training programs were also reviewed.

Key questions addressed :

1. What is consumer and community involvement (CCI) in research?
2. Who are consumers and communities?
3. What roles exist for consumer involvement in research?
4. What training options are available to support consumers interested in being involved in research?



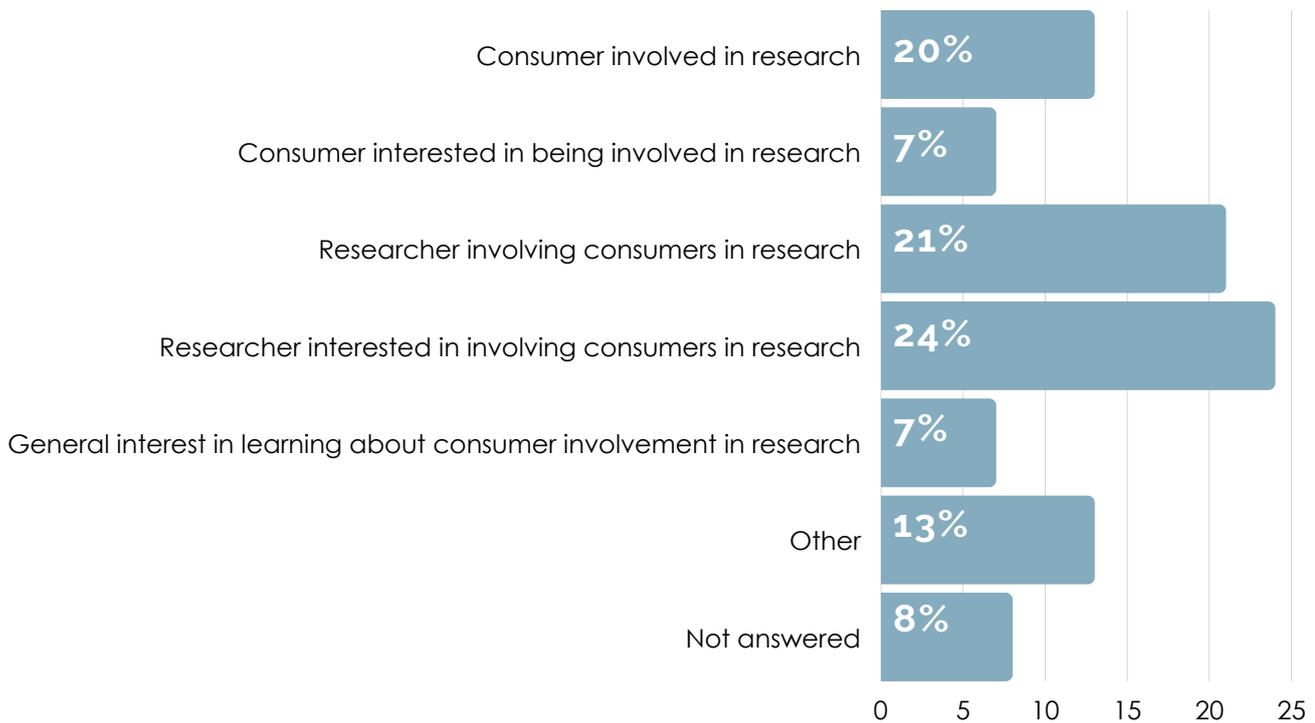
The Poll

Prior to the commencement of the session, a live poll was conducted to gain a better understanding of attendees. 114 attendees participated in the Poll. We asked three key questions.

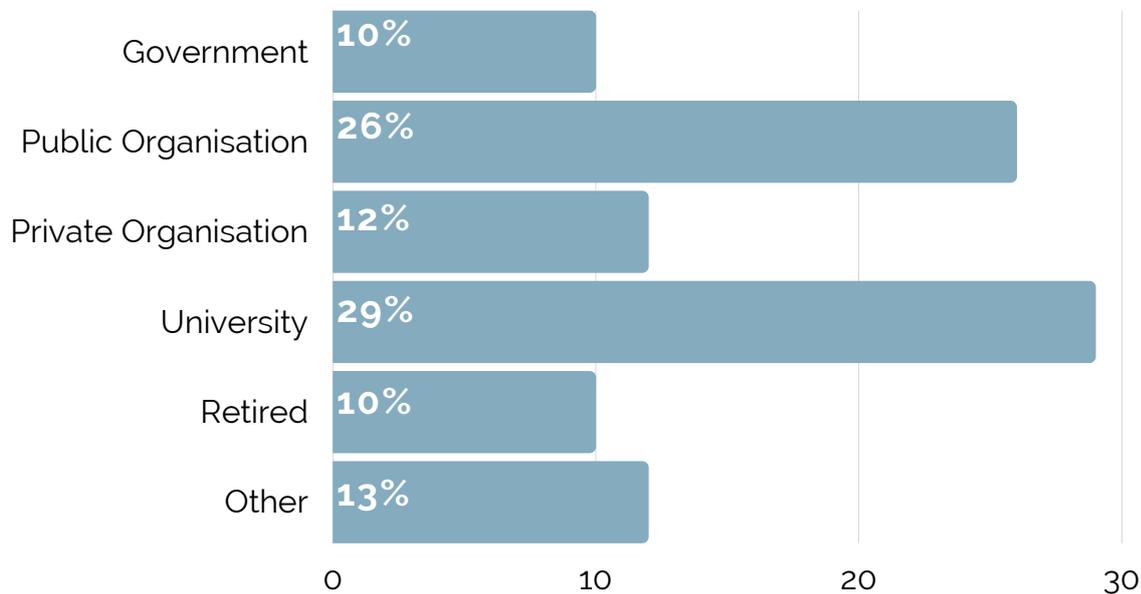
Poll Questions

Are you a:

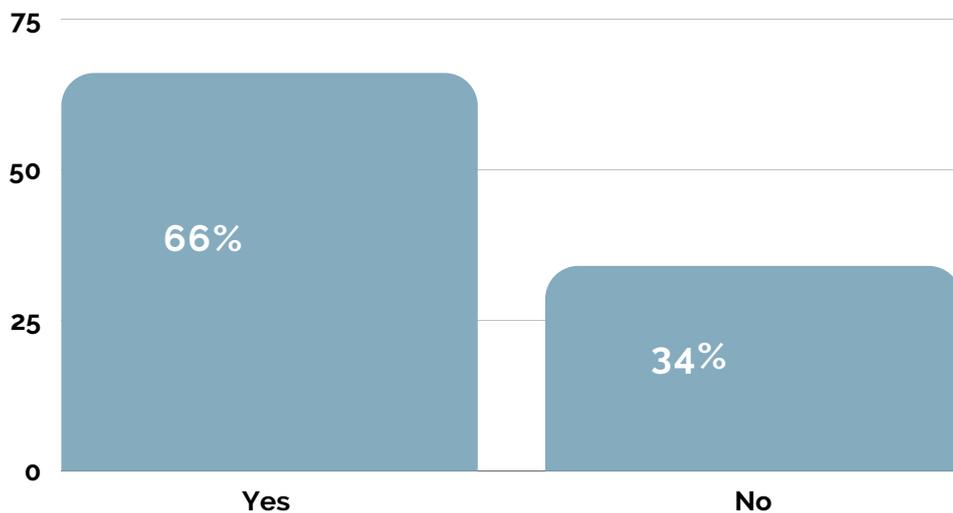
Audience %



Area of Employment %



Does consumer and community involvement in research include clinical trial participation?



It was encouraging to see that the majority of researchers in attendance were interested in involving consumers in research (24%) and that 21% of researchers were already involving consumers.

66% of attendees polled thought that CCI in research included clinical trial participation, which is incorrect. This result is, however, consistent with WCF experience on feedback from the sector.

Topic 1: What is Consumer and Community Involvement in Research?



Ms Leanne Weekes (Program Director, CT:IQ and Program Manager Bellberry) provided key definitions on consumer and community involvement which were drawn directly from the Australian Clinical Trials Alliance (ACTA) and Clinical Trials Impact Quality (CT:IQ) Consumer Involvement and Engagement Tool Kit.

The Consumer Involvement and Engagement Toolkit provides practical advice for researchers and research organisations wishing to conduct patient-centred clinical trials and provides guidance and tools to help plan, deliver, evaluate and report consumer and community involvement and engagement activities.

Ms Weekes advised that the contents of the Tool kit aligns with NHMRC language and definitions and has been NHMRC checked and approved. The content was also ratified by a working group of end-users (researchers, research organisation representatives, and consumers) who endorsed definitions and content throughout.

The primary audience of the tool kit is aimed at researchers and research organisations wishing to conduct more patient centric clinical trials, however, the guidance is relevant to all types of research.

Ms Weekes advised that it is not a 'static' document. The content is updated as required.

Definitions

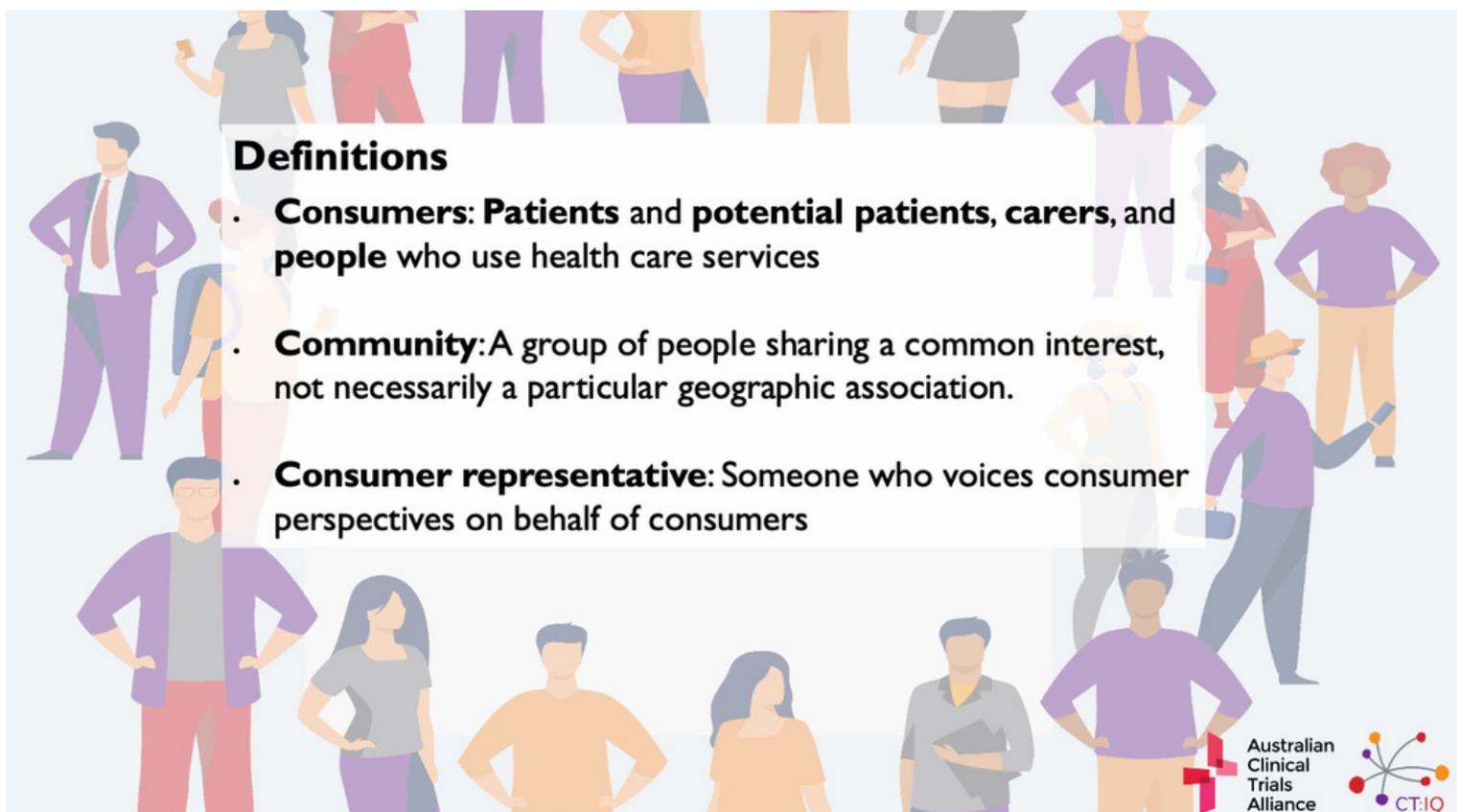
'**Consumers** are defined as patients and potential patients, carers and people who use health care services. Consumers can also be people who represent the views and interests of a consumer organisation, a community or a wider constituency.'

'**Consumer and Community Involvement** is where consumers and the community actively work with researchers or research organisations to help shape decisions about health research priorities, policy and practice'

'The active partnership is important to ensure decision making is '**with**' or '**by**' consumers rather than '**to**,'**about**' or '**for**' consumers.'

It was established that 'Consumer Involvement' is not the same as taking part in research.

'**Consumer Representatives**- voice perspectives on behalf of consumers (organisation or a community)'.
'



Definitions

- **Consumers:** Patients and potential patients, carers, and people who use health care services
- **Community:** A group of people sharing a common interest, not necessarily a particular geographic association.
- **Consumer representative:** Someone who voices consumer perspectives on behalf of consumers

Australian Clinical Trials Alliance 

'Consumer Engagement'- is where information and knowledge about research is shared with consumers and the community so they are better informed on why, how, where and by whom research is conducted'.

One attendee commented that the definition of engagement is narrower than definitions seen elsewhere, such as the UK. They felt that *'confining it to sharing of knowledge and information is relatively 'low level'*. More information and examples of broader definitions were requested from the attendee but no further information was provided. In relation to consumer and community involvement, Ms Sarah Lukeman noted that the UK, USA and Canada generally use the term 'Patient and Public Involvement (PPI) in research. Ms Lukeman referred to the PIE acronym (introduced by Anne McKenzie, AM) as an easy way to think about the different levels of consumers in research.

"It's easy as PIE "



Ms Lukeman noted that whilst she has come to accept the CCI terminology, the term consumer has a connotation of choice but people do not choose their illness and they do not choose to be a consumer of the health system, ie 'I did not choose to get Leukaemia', so 'consumer' can be misleading. This view was shared by another attendee who also expressed- 'I didn't choose to catch COVID, I am not a consumer'.

Ms Lukeman shared her preference for the term 'Health Citizen'. There was some shared preference for the adoption of this term amongst webinar attendees, which was noted as a term being used in other countries around the world. However, one attendee expressed that the focus should be on ensuring consumers include people who can speak to personal lived experience rather than people with personal experience managing consumers as part of employment. Clarification on the term "lived experience" was also requested by one attendee.

Other alternate terms for 'consumer' presented in the chat and Q&A from attendees included:

'Personal Health Advocates'

'Citizen Scientists'

"I prefer public involvement generally but then specifically say who you mean. In dementia it will be 'people with dementia' or dementia carers etc"

There was also some dissatisfaction with the term 'patient' still being assigned to people who receive health interventions. Ms Lukeman suggested that language is important and being referred to 'as a person who has cancer' as opposed to a 'cancer patient' helps recognise the whole person, not just their disease.

What do we mean by research?

Ms Weekes clarified that consumer involvement can occur across the research discovery timeline as depicted in the slide below.

What do we mean by research?



Key Takeaways:

- Consumer involvement in research requires an active partnership
- Consumer involvement in research does **not** include clinical trial participation
- Different levels of consumers in research can be thought of as 3 pieces of PIE - participation, involvement and engagement which are complimentary but different ways to work with consumers.

Future Discussion Topics:

- Review current definition of consumer and community involvement in research:
 - The term consumer has a connotation of choice and being a 'consumer' of disease
 - Involvement versus participation: What's the difference?

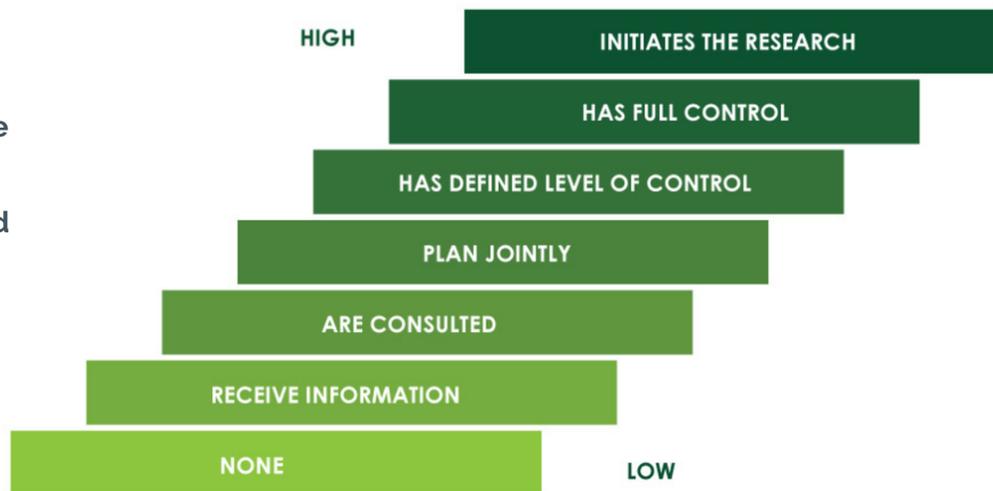
Topic 2: How Can Consumers Become Involved?



After establishing currently used terminology and definitions for consumer and community involvement, Ms Sarah Lukeman, Community Engagement Coordinator Hunter Cancer Research Alliance, talked about the different ways in which consumers can be involved in research. She noted that involvement can range from consultation through to consumers initiating research.

The ladder of consumer participation

It was noted that this should not be viewed hierarchically and that each role hold its own importance.



Adapted from Brager & Specht (1973) In Consumer Focus Collaboration (2000)
Improving Health Services through Consumer Participation: A Resource Guide for Organisations



What can a consumer do?

Ms Lukeman stated, “Consumers are invested in the outcome of your research. Consumers want your research to succeed. They are like a cheer squad. A professional consumer will provide the same level of expertise in their area as other members of your research team. Good consumer involvement is about establishing and building good relationships”.

Contribution at a basic research level as opposed to clinical research or public health research will have different requirements, and Ms Lukeman noted that “just like every research is different every consumer is different. There is no one-size fits all”.

Consumer Roles

(This list is only an example of some of the roles consumers can undertake).

Disease Expertise	Research Prioritisation, Design and Methodology	Grants	Media, Conferences, Publicity, Events
<ul style="list-style-type: none"> • Contribute lived experience • Share personal journey/story and impact of living with disease 	<ul style="list-style-type: none"> • Assist researchers to define or refine research topics • Input on research design or methods • Assist with plain language summaries and presentations • Review draft questionnaires, consent forms, patient information sheets • Pilot questionnaires 	<ul style="list-style-type: none"> • Team member on grant applications • Review grant applications • Panel member for research grants, PhD selection etc • Assist with fundraising/new grant opportunities 	<ul style="list-style-type: none"> • Media interviews and public presentations • Attend workshops, forums and conferences as a consumer representative • Visit labs and meet research teams • Assist with dissemination of findings and information through networks or wider community • Co-author (publications)

Consumers can be involved in specific research projects or contribute to research areas more broadly. They may also be members of steering groups, advisory boards (for research departments or program specific councils) boards and conference organising committees. Relationships can be long or short-term.

At the higher end of the ladder of participation consumers may also be associate/co-Investigators as well as initiate and lead research projects. One attendee was keen to understand the panels view on “consumer-led research” and a relevant definition for this type of work. Ms Lukeman felt that 'consumer-led' research includes research that is planned and led by consumers (patients and carers) with lived experience of a disease. The balance of power would lie with the consumer in the process. This was flagged as an area requiring further discussion.

There was interest expressed from some attendees in hearing from consumers who had initiated their own trials and received funding as well as discussion around the problems faced by consumers involved in trials.

Interaction and Forming Relationships with Consumers

Researchers can interact with consumers via Zoom, email, phone or face to face. Working with consumers to determine the best form of communication is important. Attendance at regular team meetings can be a good way to form an inclusive and effective partnership.

It was noted that consumers hold other roles in society that can bring multifaceted perspectives to research. They are more than their lived experience of a disease. Diversity of consumer voice is important and multiple voices is desirable.

Ms Lukeman stated, *“As a consumer I always try to remember those that are not in the room with me”*.

Recognising and rewarding consumers is also important and it doesn't have to be monetary. Inclusion at conferences, or the opportunity for consumers to give a presentation can be acceptable forms of recognition and reward.

There was general agreement on the examples of consumer roles presented, but it was suggested that in reality the consumer experience is not so ideal or well supported. Mental health services and Dementia Research were identified as areas that could learn from exemplary public involvement in cancer research.

This webinar series was focused on researcher and consumer relationships and roles, however, one attendee felt that there needs to be more focus on the relationship between consumer representatives and the consumers they represent.

More detail on how consumer advocates consult with communities to represent their needs, and how they facilitate the inclusion of patients from under-served communities was requested.

Ms Jill Yates, Consumer Advocate, shared her experience as a consumer involved in research following a diagnosis of Breast Cancer in her life. She highlighted a number of roles that presented different rewards for the consumer and the researcher. Ms Yates stated that consumer involvement in research is often linked with clinical trials. However, she noted, *'clinical trials are the end game of a long series of steps in research'*. She pointed out that it's important for consumers who may participate in a clinical trial to derive benefit over and above just being a participant. Consumer input can help ensure that clinical trials are designed to maximise benefit to patients.

Ms Yates roles as a consumer include the following:

- **Assessing research applications-** (consumer involvement almost always required for funding)- this can involve making amendments, having input on research topics, assisting with dissemination of results, and ensuring research is presented in such a way that it is understandable to the wider community.
- **Consumer Representative, Radiation Oncology Alliance-** Ms Yates stated that this committee has a focus on safety and consumers. The committee is comprised of representatives across a range of specialties involved with the delivery of radiation therapy. As a recipient of radiation therapy, Ms Yates noted that this qualified her with specialty knowledge, and consumers can often underestimate the value of their own lived experience.
- **Member of a Consumer Advisory Panel for National Breast Cancer Foundation-** this role involves assessment of research applications. Ms Yates noted that consumers can play a significant role in determining funding by marking applications against specific criteria.

This may include assessment of the following:

- Magnitude of the problem identified and extent of benefit
- The pathway for realising the benefit of the research
- Translation into further clinical research and or clinical benefits
- Equity- with particular emphasis on underrepresented or under-served groups with a high disease burden
- Consumer Involvement- establishing meaningful consumer involvement in all stages of the research

Ms Yates noted, *'the consumer role personalises the research and keeps the consumer in focus'*.

She felt that whatever skills and experience consumers have, there is a suitable and valuable role in research for them.

Mr Zy Phillips, Consumer Advocate, was accompanied by his son Ari Phillips, and also spoke about his experience as a consumer involved in research. Mr Phillips noted that his involvement as a consumer in research was inspired by his son, (who has a rare form of Muscular Dystrophy), and that he was motivated by making a change for future generations.

Mr Phillips stated, *"I'm not a medical professional, I am a Dad. When we received Ari's diagnosis at a very young age we didn't know what to do. Part of our response was to sit in a corner and cry but then we realised we can be the poor me's or can we do something better and we decided to become involved where we possibly can"*.

Mr Phillips journey started out with an enquiry to Muscular Dystrophy WA and eventually led to his involvement with the Telethon kids Institute (Children's Respiratory Research) as a consumer on a panel.

Mr Phillips shared an example of how his involvement in the design process for a sleep study saw the trial move from being conducted in the hospital to the home.

Mr Phillips said, *"We were looking at how it will impact not just Ari as a participant but the consumer- as a father and other kinds of roles. Sleep studies are very important for people like Ari, but they are done in a clinical setting, you get woken at night by all manner of things. Ari's uncomfortable, results may not necessarily be great but that's what you've got"*. Mr Phillips noted that bringing the research into the home made Ari and the family more comfortable, but the results were also better for the researchers.

"Researchers have to think about and understand how their research affects people as well as the results they are getting. The better they treat people, and the more comfortable they are, the better the results", said Mr Phillips.

Mr Phillips acknowledged that he is motivated by his son but he implored everyone to think about research. He stated, *"You just need to find the motivation to do your part. It may not be for this generation but future generations are really going to feel the difference. If one person gets benefit from what we have done as a group and what Ari's been through, then job done for us"*.

Key Takeaways:

- Consumer involvement in research can range from consultation through to consumers initiating research.
- A consumer can provide the same level of expertise in their area of experience as other members of a research team.
- Consumers can be involved in specific research projects or contribute to research areas more broadly.
- Diversity of consumer voice is important and multiple voices are desirable.
- Recognising and rewarding consumers is important but it doesn't always have to be monetary.
- Whatever skills, knowledge or experience consumers have, there is a role in research for them.

Future Discussion Topics:

- Explore the relationship between consumer representatives and consumers. How is the voice of the community captured and incorporated into research?
- What is consumer-led research? Examples of consumer-led research and pathways for funding.
- Explore the challenges and the reality of the consumer experience in research and trials.
- Consumer involvement in research in therapeutic areas besides cancer, which is currently better represented.

Topic 3: How Can Consumers Prepare to Become Involved?



This topic aimed to explore the training options available to support consumers interested in being involved in research. Ms Anne McKenzie, AM, Consumer Advocate, Telethon Kids Institute initiated the discussion with a presentation on the Telethon Kids Institute formal involvement program aimed at supporting researchers, clinicians and consumers working together.

Ms McKenzie noted that the biggest success factor in the involvement of consumers in research has been their training program. It was first developed in 2007 in collaboration with UK expert Ms Bec Hanley, at the University of WA and Telethon Kids Institute.

The program covers topics such as:

- Funding
- Understanding linked data
- Being effective on a research team
- Payment (issues around this)

The program has been important to helping consumers understand how to work with researchers in making decisions about research policy and practice and to advocate for translation of research results to improve practice. The training transitioned from being face to face to an online module in 2021.

Ms McKenzie noted that Telethon Kids Institute also launched a workshop for researchers in 2009, stating, *"You could train a thousand consumers but it's never going to happen unless researchers are on board. The workshops for researchers looks at the foundations of involvement and things like writing in plain language"*.

The programs for both consumers and researchers can be accessed here:

<https://training.telethonkids.org.au/>

Researcher training is a fee for service and consumer training is free.

Dr Jane Hobson, Senior Advisor, Research Management Cancer Council NSW (CCNSW) also spoke about consumer training. Cancer Council NSW provides two forms of training. There is an online 'Consumers In Research' course - which is an initiative between National Breast Cancer Foundation, Cancer Voices and Cancer Council NSW. There are 4 short modules designed to inform and prepare community members to be involved in health and medical research. The course is available from Cancer Council Australia website. <https://www.cancer.org.au/online-resources/elearning/consumers-in-research-training>

Dr Hobson suggested that it is important for consumers to be linked back to an organisation so they can represent the community and not just themselves. CCNSW is funded by donations, it doesn't receive any government funding. Therefore, consumers are also brought into the funding decision making process. Dr Hobson stated that it is essential to fund research that is of scientific merit and equally of value to the community they serve and represent.

Consumers are not expected to evaluate the science, even though many are highly knowledgeable. Each project receives an NHMRC score and a consumer review panel score. Both equally contribute to create a ranked list.

Many of the webinar attendees were pleased to learn about the training options to support consumers, however, one attendee felt that much of the current training is still "introductory". There was interest to learn more about programs for consumers that have been involved in research for a longer period of time and that could accommodate advanced learning and skill development in areas such as study protocol writing.

Lee Hunt, Cancer Consumer Advocate spoke to her experience as someone who had completed the CCNSW CIR training program. Her view was that it is important for consumers to undergo training.

Ms Hunt stated, *"Before I did the training I wouldn't have had the confidence to be involved in research. I realised I had a lot of knowledge, training, skills and experiences that could actually really help research evolve, and make sure researchers were doing research that's actually going to benefit cancer patients"*.

Another important aspect of the training that Ms Hunt highlighted was how it empowers consumers to understand how they can add value. Ms Hunt stated, *"Without the training you wouldn't have the concepts and knowledge on how to become involved"*.

Understanding what life is like for a researcher and the battles they face to stay in research was another enlightening facet of the course. Ms Hunt felt that she developed a new appreciation for the role of a researcher and the challenges they face to stay in research.

Ms Hunt described her role as a consumer involved in research as being a *"very powerful experience. If patients and the community want the best research possible to improve health outcomes they must be involved"*.

Ms McKenzie noted that the keys to successful consumer involvement in research require the following:

*Positive Culture

- Support from the top level of an organisation
- Champions throughout an organisation
- Processes, resources and training to support meaningful involvement and engagement
- Extensive networks and links to consumer organisations
- Committed and passionate community members
- Staying on message, that consumers add value to research is essential.

Proactive Planning

- Having a planned budgeted strategy for consumer involvement is also important.
- Considering the aim of involvement
- The level and stages of involvement
- How consumers and community members will be found
- What resources are required
- Training needs or other potential barriers that may hinder effective involvement

*organisational and community

A variety of resources aimed at supporting effective consumer involvement in research can be accessed from the Telethon Kids Institute website- <https://www.telethonkids.org.au/be-involved/help-shape-our-research/>

Key Takeaways:

- Telethon Kids Institute offers free Online training for consumers interested in being involved in research. They also run programs for researchers which are a fee for service. www.telethonkids.org.au
- Cancer Council NSW (CCNSW) offers a free online 'Consumer Involvement in Research' course that can be accessed from the Cancer Council Australia website. It has a "Cancer" Focus. <https://www.cancer.org.au/online-resources/elearning/consumers-in-research-training>
- Training is important to helping consumers understand how to work with researchers and preparing them for roles that will enable them to participate in making decisions about research policy and practice and to advocate for translation of research results to improve practice.
- Training empowers consumers to understand how they can add value.
- Positive community, organisational culture, and proactive planning are essential to successful CCI in research.

Future Discussion Topics:

- Advanced training options and support to upskill experienced consumers i.e protocol writing

Webinar 2: The Discussion

This webinar was a facilitated discussion with an expert panel and attendee participation.

This webinar was held a week after the first session and a video copy of the first webinar was made available for viewing a few days before the second 'Discussion webinar'. The recording is accessible on the White Coats Foundation website and Youtube channel.

Three key topics were selected for interactive discussion:

1. How do consumers learn about and access opportunities to be involved in research?
2. What are the barriers to consumer involvement?
3. How do we ensure consumer involvement in research is value adding and not a tokenistic exercise?





Topic 1- How do Consumers Access Opportunities to be Involved?

In the first webinar of the series it was made clear that the need and demand for the patient voice is growing. There is increasing need and interest from researchers and consumers to work together to create more meaningful and impactful research. The roles for consumers and training options to support interested consumers were addressed in the first webinar but the opportunities for connecting and learning about available opportunities was an area that required further attention.

The avenues collectively highlighted by the panel as pathways for consumers to learn about opportunities to become involved in research included:

- **Consumer based organisations-** Ms Todd, Research Director, Sydney Health Partners, highlighted that consumer based organisations are key to promoting opportunities for consumer involvement in research.
- **Disease specific groups/awareness organisations** (diabetes, cardiovascular etc) were also noted to be making efforts to advise on disease specific research opportunities.
- **Consumer Health Forum**-newsletter communicating opportunities for consumers.
- **Health Consumers NSW (HCNSW)**- promote opportunities to their consumer base on opportunities for being involved in research.
- **Cancer Council NSW**- newsletter.
- **Cancer Voices (CV)**- provide a consumer matching service. Researchers can contact CV via their website and request a consumer. Details are collected to facilitate a match.
- **Consumer and Community Involvement Program (WA)**
- **Health Issues Centre (Victoria)**
- **Victorian Comprehensive Cancer Centre (VCCC)**
- **Social Media**-Twitter, FB etc. Reaching out to disease specific groups or advocates.
- **Clinicians**-making personal requests
- **Networking events**

Additional resources noted by attendees included:

- **Local Health Districts (NSW)**- consumer managers and research directorates work together to facilitate communication of opportunities.
- **Hospitals**- Consumer Engagement Managers.
- **Peter MacCallum Cancer Centre** has a consumer advocate department, who put out requests for involvement in different research/trials.

Ms Hunt noted that her pathway to learning about consumer involvement in research had a natural progression which started with seeing an advertisement in the Cancer Council NSW newsletter. However, she noted that it's not always as straight forward and can be 'hit or miss', especially in areas outside of cancer.

Ms Hunt went through the system at Cancer Voices which is well established, however, she feels that the matching process is still time intensive. Researchers can contact Cancer Voices via the website and request a consumer and details are put down to make a match.

"..... as research is becoming more specific with targeted therapies, the matching is getting harder to do".

Ms Hunt stated that last year there were 82 requests for consumers through Cancer Voices. The Cancer Voices NSW matching process is currently undertaken by a volunteer. She added, *"It takes lot of time and energy"*.

Ms McKenzie agreed that the consumer matching process is time consuming, but manageable. In her previous role at the University of Western Australia (UWA) and Western Australia Health Translation Network (WAHTN), Ms McKenzie was part of setting up a consumer matching service- 'Consumer and Community Health Research Network' (now known as the 'Consumer and Community Involvement Program'). It was 'loosely' based on the Cancer Council NSW model. In 2019, there were over 3000 people in the network. The program is currently used by the Telethon Kids Institute. Ms McKenzie noted that one of the most important factors to consumer involvement is in successful matching. She advised that there needs to be alignment between researchers and consumers and that there should be a clear understanding about what both parties want to get out of the activities of involvement.

Mr Kiossoglou, Consumer Representative- WEHI, MACH and AHRA, agreed stating, *"Communication is huge... getting to know each other is important. It's a journey that develops along the way. If you don't get a match it can kill everyone's experience"*.

These points highlighted that a process beyond just learning about opportunities to become involved in research, is necessary to ensure successful partnerships are formed.

Ms Todd stated that many researchers she has worked with don't know how to reach out to consumers. She stated, *"We often hear from researchers saying I'm looking for a consumer with experience in X do you know someone who could do it?"*

Ms Todd urged that researchers need to view building relationships with consumers in the same way they build and develop collaborative partnerships with other researchers. There has to be a genuine commitment.

This idea was supported by panelists and one attendee commented,

"Building a relationship between a researcher and a consumer takes time. It won't happen overnight, and may take some years for it to reach its optimal level of operation and success".

Whilst services to communicate consumer involvement opportunities in research were identified it was noted that they are fragmented, often state based, disease specific, and less established in areas outside of cancer. The idea of a centralised resource was put forward as a suggestion to the panel.

Ms Lukeman felt that a centralised resource was not realistic because all consumers are different. Her advice was to not just think about the disease but to also consider relevant language and cultural groups when looking for consumers- eg Aboriginal health organisations. She stated, *"You don't need to keep to a disease, anybody can be a consumer".*

Ms Hunt agreed and felt that researchers should look to employ a range of methods which might include Twitter, Facebook, personal requests to clinicians and networking events. Ms Hunt felt that training for consumers and researchers was also important to building successful partnerships and that consumers interested in being involved in research should consider training programs.

Ms Di Vito-Smith, (WCF Series facilitator), questioned the panel about whether there was an expectation on consumers looking to be involved in research, to have a basic understanding of science.

Ms Hunt responded, *"You don't have to have a science background you are there to provide a lived experience. It's the job of the researcher to explain it and if they can't do that then they need to try again"*

Mr Kiosoglou added, *“At Walter and Eliza Hall Institute (WEHI) we tell consumers you don’t need to know about science. It influences researchers to get out of their bubble. It forces them to talk a different language and explain things differently”.*

Ms McKenzie also stated, *“I still don’t understand all the terminology, I’m not a researcher I’m not a scientist. If you want extra training that’s fine but I don’t want to know about meta-analysis and systematic reviews. There are experts for that. The expertise I bring is as a consumer member of a team”.*

Ms McKenzie urged that the science should not be a barrier to consumers interested in being involved in research. In her experience she has come across parents with children that have a disease and they dismiss their ability to contribute to research because they think they are ‘just a mum’ or ‘just a dad’. However, she noted, *“their knowledge is massive”.*

Ms Todd also agreed and stated- *“Consumer perspectives are valuable because they are not researchers, and that a team is stronger for multiple perspectives”.*

Key Takeaways:

- Pathways to learn about consumer involvement exist, however they are fragmented, often state based, disease specific, and less established in areas outside of cancer.
- Consumer involvement in research goes beyond learning about opportunities. There is a process required to facilitate matching of consumers and researchers to maximise successful partnership outcomes.
- Training (researchers and consumers) can be helpful to successful involvement in research.
- Scientific knowledge is not a pre-requisite for successful consumer involvement in research.

Future Discussion Topics:

- Access to consumer involvement in research opportunities- how can we improve equity of access to opportunities and diversify the pool of available consumers?
- Culturally and Linguistically Diverse (CALD) consumer involvement in research: How do we improve access to consumer involvement opportunities in CALD communities?

Topic 2. What are the Barriers to Consumer and Community Involvement in Research?



Key barriers identified by the panel and attendees to CCI in research include the following:

Access

Researcher

- Not knowing where to find consumers

Consumers

- Not knowing where to go to find out about CCI opportunities

Value

Researchers

- Researchers not understanding the value that consumers can bring to research. They do it as a tick box exercise because the granting body says you need a consumer. Mr Kiosoglou suggested integrating the value of consumer involvement into the academic curriculum. He had the opportunity to speak with students as part of the VCCC Master of Science program and felt this presented an opportunity for early and effective engagement and messaging.
- Research organisations not seeing the value of consumer input as much as the research itself.



There was agreement amongst some attendees and panelists that when the National Clinical Trials Governance framework becomes part of accreditation for clinical trial service providers that it will place a greater level of importance on engaging and involving consumers in research.

Language and Culture

- Language- most materials are presented in English.
- Cross-cultural barriers- this includes language barriers (body language and gestures) but may also include cultural values and beliefs which can present barriers to communication.
- Medical jargon- Ms Todd noted that researchers don't appreciate how foreign their language can be. She stated, *"We use so many acronyms like 'NHMRC' or 'HREC' that's part of our world and we forget that those terms are not necessarily part of the consumers world. As professionals we have to be conscious of talking in terms that everybody understands"*. One attendee commented that consumer 'buddies' can be helpful to negotiating the research system and related jargon.
- Cost- the cost of outreach to culturally and linguistically diverse communities (CALD) is not taken into consideration and these groups are often not consulted and 'miss out'.

Technology

- Technology Proficiency- Mr Kiossoglou noted that if consumers are required to interact using computer-based technologies and other associated technologies it can be preclusive to involvement or diminish the experience of involvement if the consumer's abilities are inadequate.
- Competing demands on technology in the home due to more people working from home or home schooling as a consequence of the pandemic.
- Technology may present barriers for people geographically particularly those living in regional, rural and remote areas.

Interpersonal Skills

- Skills and ability to communicate with diverse groups.
- Fear- some researchers are not sure how to approach consumers. Ms Lukeman noted that some researchers are worried about upsetting a patient by asking them questions. She reassured that consumers are people who have chosen to be involved and to share their story with researchers. They have usually finished active treatment or are on long term treatment. Ms Lukeman advised that her CCI journey did not commence until 10 years after her illness. 'Accidental Counsellor Training' (or other similar courses) were suggested as a way of building up interpersonal skills and the ability to more comfortably manage potentially difficult conversations. It was acknowledged that researchers might need to step out of their comfort zone to contact someone they don't know. Also, clinicians and clinician researchers are unlike lab based researchers, because they are seeing people all the time, however, Ms Lukeman advised *"...talking with patients in clinical trials or in a practice setting is different to the conversation you would be having with them as a consumer in research"*.

Ms DiVito-Smith suggested that perhaps relationships between researchers and consumers need to be thought of in a less transactional manner, *"We are all humans at the end of the day. It's an important element of establishing a partnership"*

Ethics

One of the attendees asked if there was an ethics process for involving consumers in research if they are not participants.

The panel agreed that there was no ethics requirement and Ms Lukeman felt that it would be unethical not to include consumers. *"These are the people the research is being done for, so there is an ethical requirement to involve them"*.

Ms Di Vito- Smith asked the panel if involving consumers in research could be included as a question in an ethics application template. This would help ethics committees determine if consumers had been consulted in the review of the research and had a voice.

Ms McKenzie noted that she has sat on the National Health Medical Research Councils (NHMRC) Consumer and Community Advisory group and this is an issue that has been repeatedly presented for consideration. It is currently not part of an ethics submission template.

One attendee advised that this is already a necessary element in Aboriginal and Torres Strait Islander research. There was general support from attendees that this become a compulsory element of future ethics templates.

Key Takeaways:

- Barriers to consumer involvement exist for both researchers and consumers. Key barriers include- access issues; value of the process of involvement; language and cultural barriers; technology proficiency and interpersonal skills.
- Involving consumers in research is not part of the ethics review and approval process.

Future Discussion Topics:

- Should ethics applications include a question to determine if researchers have involved consumers in their research.



Topic 3- How do we ensure that CCI in Research is Value Adding and not Tokenistic?

A/Prof Christine Chaffer, Head Cancer Cell Plasticity Laboratory Garvan Institute of Medical Research and Ms Lisa Carstairs, Consumer Advocate, were invited to talk to their relationship as an example of a meaningful researcher-consumer partnership. Their insights on elements that contribute to successful relationships were captured around three key themes:

- Introductions
- Relationships
- Value

Researcher Perspective

A/Prof Christine Chaffer

A/Prof Chaffer stated that whilst consumer involvement in research started out as a 'tick in the box' exercise for her, the experience with consumers helped her see the value they can bring to research. *"There is so much to be gained from building strong relationships with our consumers that can really add value to our research"*.

A/Prof Chaffer noted that taking the initial step to engage with consumers can be daunting. She said that researchers may be 'hesitant to approach consumers', 'concerned about saying the wrong thing', or 'struggle with conveying their science clearly'.

In her experience A/Prof Chaffer acknowledged that her involvement with consumers has been 'transformative'. Hearing consumers' experience is a reminder that research is not just a 'lab bench experience' it's actually going to make a difference to people's lives.

Key elements of a successful relationship:

Introductions

Initially contact might be over email and then phone. It's important to determine if there is a connection between both parties. A/Prof Chaffer noted, *"I found that connecting with consumers really enhances the information exchange and how much we learn from each other"*.

Relationships:

Once you have established contact you have to think about building a relationship. This takes time and might involve having 'coffees' together. You need to take time to get comfortable. It's important that consumers feel they are able to say things like, 'I don't understand'. Investing time into the relationship will mean better communication and better outcomes for the aims of involvement.

Building a relationship might also include introducing consumers to other key members of the research team, so consumers can see where the research takes place. A/Prof Chaffer stated that once a relationship has been established with consumers bringing them into the lab can be mutually beneficial, *"...it is really transformative for my lab to actually hear their (consumer) stories. We are really focused on our scientific career and goals and the desire to discover new biology, but those goals really take on another dimension when you appreciate the human element"*. A/Prof Chaffer noted that there are some researchers who are very connected to their work and driven by first-hand experience but others need to see and hear patient stories to make that connection, and to appreciate what they are doing as scientists. She stated, *"Lisa's story was so impactful for all the scientists in my lab"*.

Value

A/Prof Chaffer also noted that consumer involvement puts a sharper lens on the objectives of the research and can lead to changes in practice.

"We do experiments, we can use many different types of chemotherapy, but hearing stories from consumers like Lisa saying, 'that chemotherapy was terrible, I don't want that', helps us to think differently and ask if there is an alternative way we could do some of our experiments. Hearing Lisa's story helped us to think about the long-term impact the treatments we are developing and studying can have on patients, and how we could consider that to help create a different experience".

Consumer Perspective

Ms Carstairs - Consumer Advocate stated, "I love the process of being a consumer in research. I get so much out of it. I don't mind talking about my cancer journey. It's kind of complex and all over the place but I love talking about it".

She attributed the following factors to successful involvement:

Key elements of a successful relationship:

Introductions

Ms Carstairs felt that the initial contact should include setting clear objectives. Ms Cairstairs stated that the first conversation she had with A/Prof Chaffer involved clearly articulating the goals of the relationship and her role in the research. She also felt that understanding the objectives of the research and what the expectations of the research team were of her, was helpful.

Ms Carstairs noted that there is a misconception that it takes a lot of time to be involved as a consumer in research. She advised that it is important to be clear about your personal availability from the outset. Establishing expectations around commitment can avoid problems for both parties down the track.

Relationships

Ms Carstairs attributes the success of her relationship to having a good rapport with A/Prof Chaffer but also in meeting other members of the research team which provides a more holistic experience.

Positive interactions between A/Prof Chaffer and the broader research team were viewed as key elements to her successful involvement.

Value

Ms Carstairs stated, "*Making a difference for future generations so others don't have to go through the hideousness I went through*", is a key driver for her involvement. Also, seeing the difference she is making as a consumer in research is a key motivating factor for her.

One attendee asked if the relationship between A/Prof Chaffer and Ms Carstairs was exclusive, however, A/Prof Chaffer noted that she works with multiple consumers and advised "the more voices we hear the more we can strive to meet the needs of those patients".

Measuring Impact

Observing the elements of effective consumer-researcher relationships can be a simple way for other researchers to emulate success in their own practice. However, the question of measuring impact was raised with the panel. Ms Todd noted that many consumers seek “proof” that their contributions are making a difference, and researchers want to have ‘objective evidence’, but ‘how’ consumers are involved will influence the ‘way’ impact is measured.

Ms Todd provided the following examples:

Example 1

Involvement Activity- Consumers helping identify a research question

Impact Measure- the impact might be that the researcher changed the nature of the question because of consumer input, and it’s now a question that matters to consumers and not just researchers.

Example 2

Involvement Activity- Involving consumers in designing a survey for consumers with a lived experience of dialysis.

Impact Measure- consumer impact might be that consumer input has influenced the development of meaningful questions that participants respond to.



The type of involvement will affect the impacts you look for.

It was noted that there are tools to assist with measuring impact but that they should be applied with discretion. There is no one size fits all tool. Researchers should adopt a flexible and tailored approach.

Remuneration

The question of remuneration for consumers was raised in the context of the 'value' of consumer involvement. It was agreed that this required a separate discussion but there was general agreement that this expectation would vary amongst consumers and these preferences were views to be respected.

Ms McKenzie noted that if a consumer is the only person in a team not being paid then it might be considered de-valuing that person's expertise and experience. She suggested that it comes down to making "an offer".

Ms Lukeman agreed that socioeconomic factors need to be taken into consideration, "*I think it's important for diversity, that you don't only have consumers that can afford not to be paid*".

It was suggested that payment could introduce the risk of being implicated with influencing consumer input, however, it was noted that financial reimbursement was not the only way of valuing a relationship.

Mr Kiosoglou stated, "*A lot of consumers are not looking for money. They are looking to make a difference. So don't use the financial side of it as a barrier to being able to get consumers involved*".

Attendees generally agreed that "*value is more than just money*". Training, conference opportunities, expense reimbursement for things like parking or co-authorship of papers and adding names of consumers to papers as associate investigators, is validation of input and all are acceptable forms of recognition and reward.

Ms Florek added that in the US they are obligated to pay patients (consumers) for their time.

Pharmaceutical Perspective

Ms Cathy Florek

Ms Florek is the Director of Patient Engagement at Bristol Myers Squibb (BMS) in the USA. She clarified that the term “patients” is generally used in place of consumers in the US.

Ms Florek highlighted that BMS has several programs for patient involvement in research. Her team the ‘Patient Voice’ is endorsed by senior leadership, to be involved in protocol review committee meetings to bring patient insights forward.

She noted that it has taken time for the clinical research teams to get on board with the value that patients can bring and to understand that there might be some additional time involved in gathering insights from patients prior to clinical development, but that it can save time in the long run. They recognise that it can help with a more successful enrolment process into studies because they are communicating with patient advisors to understand the patient journey, their needs, experience and priorities. Ms Florek stated, *“We are looking at their own unique disease perspective to understand how we can develop our protocols and lessen the burden on them”*. Ms Florek noted that patients bring a perspective that cannot be seen through the *‘scientific lens of a clinical scientist’*.

Ms Florek’s team engage with a variety of patients (with and without clinical trials experience). She noted that bringing in different perspectives to understand unique experience is important.

Avenues of outreach include:

- Patient advocacy organisations
- Working through advisory boards
- Site investigators (can help identify patients that may want to have a role in the development of future protocols). Interested patients are contacted and they go through a screening process.

Ms Florek stated that her team primarily work with “lay” patients, and they have a group within BMS (Patient Advocacy) that drives the Patient Expert Engagement Resources (PEER) program. The PEER program works with expert patient advocates who may not necessarily be patients themselves. They advocate for patients and have clinical trials expertise.

Ms Florek advised that working with patients has led to protocol changes in areas such as visit schedules and procedure requirements, but that not all requests for change are possible. Occasionally requests might affect vital endpoints and when this happens Ms Florek advised that every effort is made to ensure patients are provided with feedback and reasons why a change can not be implemented.

Study teams are beginning to request patient feedback and she is noticing that patient involvement is something that's enthusiastically being adopted at BMS and by many other Industry partners.

In terms of measuring impact Ms Florek noted that metrics are still new to them. They are exploring how to capture metrics related to impact of engagement. A more prominent focus for her team is on how to effectively close the loop with patients so that they are aware of the value they bring to research through their involvement.

Ms Lukeman questioned Ms Florek about how consumer input is being captured from countries outside the USA that might be involved in running a study. Ms Lukeman noted Australia as an example and highlighted that although there is a shared language with the US, there are differences.

Ms Florek acknowledged that there are different perspectives to be gained from patients outside the US but that her teams focus has been on ensuring they are a 'well-oiled machine' in the US first and to then look at local country leads to help identify organisations that can help find patients in other geographies. Ms Florek advised that they are not familiar with the relevant local organisations in other countries and they don't have any relationships with local advocacy groups that can assist. It is something they will look at on a country basis for expanding their patient voice work

Key Takeaways:

- Investing time in building relationships with consumers is important to facilitating better outcomes for both researchers and consumers.
- Providing consumers with feedback on the impact of their involvement can positively reinforce the relationship and create improved value for both parties.
- The way consumer impact is measured will depend on how consumers are involved.
- Acknowledgment of consumer value is important and should be negotiated according to consumer preference. Recognition and reward does not have to be financial.

Future Discussion Topics:

- Recognition of consumer value: financial and non-financial options
- Measuring Impact: A closer look at the tools that can be used to assess outcomes and value of involvement.

Summary:

This webinar series intended to clarify some of the basic definitions of CCI in research and the types of roles and training available to support consumers interested in being involved.

Additionally, the series aimed to explore the barriers to involvement from a consumer and researcher perspective and how to ensure consumer involvement is a value adding process.

It was expected that the sessions would highlight voices and issues that are being overlooked or that require further discussion.

Some of the key issues included:

- There is some confusion around the current definition of consumer and community involvement in research. The term consumer has a connotation of choice and being a 'consumer of disease. There is also a misconception that consumer involvement includes clinical trial participation.
- Training options for consumer involvement in research are mostly introductory. There is a growing need for advanced training support for experienced consumers.
- This series focused on the researcher-consumer relationship, however, there was a request for improved understanding of the consumer representative-consumer relationship, and how consumer representatives are incorporating the views of those they represent.
- There is no clear pathway for researchers to connect with consumers or for consumers to connect to involvement opportunities. The issue is more prevalent in areas outside of cancer. This presents a barrier to involvement and can affect the pool of available consumers. CALD community involvement was also noted as a group that is still marginalised.

Recommendations:

Based on the outcomes of the discussion in the webinar series White Coats Foundation proposes to do the following:

- Prioritise future discussion topics for follow up in the 2022 White Coats Foundation webinar agenda.
- Work collaboratively with all relevant stakeholders in the sector to address areas requiring reform.
- Work collaboratively with stakeholders to continue to raise awareness of available resources and maintain a central repository on the White Coats Foundation website of information that can support consumer involvement in research.

Resources:

Following is a summary of resources shared by speakers, panellists and attendees during the course of the webinar series.

Researcher Training

Health Consumers NSW- (training for health researchers and for research consumers).

Training does not have a disease specific focus.

Website: www.hcnsw.org.au

Telethon Kids Institute

Website: <https://training.telethonkids.org.au/>

Resources (cont):

Consumer Training

Health Consumers NSW

Website: www.hcnsw.org.au

Health Issues Centre (Vic)

Website: <https://hic.org.au/>

Cancer Council NSW (CCNSW) offer a free online 'Consumer Involvement in Research' course that can be accessed from the Cancer Council Australia website. It has a "Cancer" Focus. www.cancer.org.au/online-resources/elearning/consumers-in-research-training

Breast Cancer Network Australia

Website: <https://www.bcna.org.au/get-involved/volunteer-for-bcna/seat-at-the-table-bcna-consumer-representative-program/>

Telethon Kids Institute:

Website: <https://training.telethonkids.org.au/>

Union for Cancer Control (UCC)-

Patient Advocate Course

Website: <https://www.uicc.org/>

Consumer Matching

Cancer Voices NSW

Website is: www.cancervoices.org.au

Consumer and Community Involvement Program (WA)

Website: www.cciprogram.org/

Access CR-Janelle Bowden moderates a Facebook group where researchers can post opportunities for consumers.

<https://www.facebook.com/groups/Research4MeGameChangers>

Consumer Buddy Programs

Cancer Voices NSW is setting up a buddy system for new consumers with an experienced consumer to support them as they set off on their journey.

WEHI Consumer Buddy Program

Website: <https://hic.org.au/.../walter-and-eliza-hall-institute.../>

Resources (cont):

Other

Australian Clinical Trials Alliance and CT:IQ Consumer and Community Engagement Tool Kit- Website: <https://involvementtoolkit.clinicaltrialsalliance.org.au/>

Telethon Kids Institute- Planning for Consumer and Community Participation in health and medical research

Website:

https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf

The National mental Health Commission published 'The Mental Health Safety and Quality Engagement Guide' which focuses on participation by consumers and carers at a governance level. This is where people with a lived experience can have influence on strategic decision-making and in promoting systemic changes in all aspects of mental health services. Website: www.mentalhealthcommission.gov.au/mental-health-reform/consumer-and-carer-engagement/safety-and-quality-engagement-guidelines

The NHMRC toolkit for researchers.

Website: www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement

Federation of Ethnic Communities Council Australia (FECCA)

Website: www.fecca.org.au/about/what-we-do/

(Promoting diverse consumer involvement)

South Australia Health Medical Research Institute (SAHMRI)- has a consumer involvement platform: Website: www.sahmri.org/consumer-community-engagement/

Journal Article: The Universal Patient Language: A set of resources and tools to design patient communications that support better health literacy

Website: www.content.iospress.com/articles/information-services-and-use/isu180031

This webinar series was produced by



Christine Zahren - Series Producer
Fiona Cameron - Series Producer
Michelle De Vito Smith - Series Facilitator
Deepti Pandey - Series Co-ordinator

for more on our team go to
https://whitecoatsfoundation.org/about/our_team/

thank you

whitecoatsfoundation.org