

# Introduction: Partnering with consumers and the community in Metro South Health

## Transcript

Slide 1	Welcome to module 1 of the 'partnering with consumers and the community in Metro South' online learning package.
Slide 2	This module aims to provide you with introductory information about partnering with consumers for research. After completing this learning package, we want you to feel confident in understanding what consumer involvement is, why consumer engagement in research is important and common benefits and challenges of involving consumers in research.
Slide 3	To start with, it's important that we define who we are referring to when we use the term 'consumers and the community'. This term is used to refer to a wide range of people who may be involved in partnering to improve research including patients, their carers, family members, friends and consumer organisations such as the Cancer Council or Carers QLD.  For the duration of this module, we will use the term 'consumer' to refer to these parties.
Slide 4	Now we know who consumers are, but what does partnering with consumers in research actually mean? Well, consumer partnering is when researchers and clinicians work together with members of the community to conduct research.  This approach represents a shift away from viewing consumers as 'passive' participants in research where the research is done 'to', 'about' or 'for' them to including them as 'active' participants in the research process where research is conducted 'with' or 'by' consumers.
Slide 5	Consumers can become engaged in the research process in a variety of ways. They can partner with clinicians and researchers to make decisions about research priorities, practice and policy.  Some examples of how consumers can be engaged in research <b>priorities</b> include contributing to topic selection and ensuring that research questions being asked are important to people. When looking at research <b>practice</b> , they can assist in identifying how the research should be undertaken, what measures should be used and how to disseminate the results. And in terms of <b>research policy</b> , consumers can help organisations improve the support for researchers and healthcare providers to partner with the community.  If you would like further information about the diverse ways consumers can be involved in research, this link to the Cancer Council website provides further ideas for consumer involvement in a variety of health related research.
Slide 6	Now, you might wonder 'why do consumers become involved in research'? Well, these reasons can be broadly classified into two categories.  Some consumers may be motivated by personal reasons, such as their own experience of the healthcare service or a desire to bring a change to the care provided to themselves or others a similar condition.

	<p>While other people may choose to engage in research for social reasons, such as having their own voice, influencing the process that impacts other people's lives or the opportunity to give back.</p>
Slide 7	<p>Elizabeth Miller: I think that I must be born with a curiosity gene, if there is such a thing because for as long as I can remember, I've always asked lots and lots of questions. Things like, well, why is it like that? Or what does that mean? How can it be done better? I think I've always found pleasure in learning new things and expanding my knowledge, and I guess that's a form of research, even in it's most primitive state.</p> <p>I happen to come across a flyer last year that was advertising 1/2 day workshop designed for allied health staff who wanted to improve their understanding of how to involve consumers in both research and innovative projects, so of course, this piqued my curiosity gene, didn't it? And I asked another question, whether I, as a consumer might be able to attend as well.</p> <p>Thankfully the answer was yes, and I suppose I really just wanted to find out what people felt about involving service users in research projects, what their challenges were? How they plan to go about it and what opportunities might be available for me to participate or contribute from my own personal experience of health care, my background training and my previous exposure to other research projects in the past. Taking that simple test has opened the door to some interesting developments as I have started to build relationships with healthcare staff who are undertaking research projects and have been brave enough to enter into a world in involving consumers in authentic ways across each of those stages across the research process.</p>
Slide 8	<p>Now that we know who consumers are, what consumer partnership is and why consumers become involved in research, it is important to talk about why clinicians and researchers should partner with consumers.</p> <p>Whilst there are numerous benefits to engaging with consumers, it is a core democratic principle that people who are affected by research have a right in expressing what and how publicly funded research is undertaken. As such, it is an expectation both nationally and internationally that consumers are involved in all stages of the research cycle.</p> <p>In Australia, there are standards and policies that promote consumer and community involvement in research. Key national standards and policies include the:</p> <ul style="list-style-type: none"> <li>•National Safety and Quality Health Service Standards, which require that consumers be involved in the organisational and strategic processes that guide the planning, design and evaluation of health services in Australia.</li> <li>•The Australian Code for the Responsible Conduct of Research which states that appropriate public involvement in research should be encouraged and facilitated by research institutions and researchers.</li> <li>•The National Health and Medical Research Council's Statement on Consumer and Community Involvement in Health and Medical Research (2016) which states that consumers add value to health and medical research and they have a right and responsibility to be actively involved in it.</li> </ul> <p>And locally, the Metro South Research Strategy acknowledges the importance of consumer and community opportunities to participate and be involved in research, viewing it is an integral part of person-centered care.</p> <p>To access these key standards and policies please click on the links. These agencies acknowledge that effectively partnering with consumers in research adds research value to research, and has many benefits for stake holders.</p>
Slide 9	<p>So, what are some of the benefits of clinicians and researchers partnering with consumers? Well, we might see:</p> <ul style="list-style-type: none"> <li>• Improvements in recruitment by: <ul style="list-style-type: none"> <li>• making the research more appropriate and acceptable to potential participants,</li> <li>• improving the information provided so that people can make informed choices, and</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• helping to include seldom heard groups.</li> <li>• Increased participant retention by: <ul style="list-style-type: none"> <li>• helping to ensure that the methods proposed for the study are acceptable and sensitive to the situations of potential research participants</li> </ul> </li> <li>• Better quality data and data interpretation by: <ul style="list-style-type: none"> <li>• Brining their own personal knowledge and experience of your research topic or being able to provide a more general perspective.</li> </ul> </li> <li>• Enabling wider and more effective dissemination of findings, which in turn leads to greater uptake of research findings and clinical practice change.</li> </ul> <p>Also, it is now common for funding bodies to require some form of community engagement to be considered eligible for competitive research grants, and scientific journals, such as the British Medical Journal, now have guidelines around the reporting of patient and public involvement in research.</p>
Slide 10	<p>Ruth Cox: So one of the main reasons I think it's really important to partner with consumers in research is because the research is about them, and so I think it's the right thing to do,</p> <p>Elizabeth Miller: adding my voice to the knowledge base of what true genuine consumer involvement looks like and hopefully helping to confirm that engaging with consumers really does lead to improved quality and outcomes in health.</p> <p>Ruth Cox: I think another benefit is that the research is better because you get information from people who are similar to the people that you want to participate, and they help you to design your research so that it's more appropriate.</p> <p>Elizabeth Miller: So a big benefit to me is that it's good to be able to keep on using my mind and being well occupied through learning new things.</p> <p>Ruth Cox: Yeah, so for me personally also, partnering with consumers have been fun like that's one of the main things I've gotten out of it is we've actually enjoyed learning together and.</p> <p>Elizabeth Miller: I sort of benefits for health professionals by partnering with consumers. Well, I might not have all of the training needed to do the work of a fully fledged academic researcher, but what I can bring to the table is that I'm creative and innovative. I can challenge preconceived assumptions.</p> <p>I can help to improve the relevance of research to what consumers really need. Because I see things through a different lens, perhaps? I can bring an additional perspective. Partnering in research from first hand experiences. I think it's important to learn all you can about best practice consumer engagement and principles.</p>
Slide 11	<p>Whilst there are many benefits to partnering with consumers in research, it is also important for clinicians and researchers to be aware of potential challenges they may encounter.</p> <p>Some common challenges that may impact consumer willingness to partner in research may be that they</p> <ul style="list-style-type: none"> <li>• Don't value or recognize their own expertise and the value that it brings, or</li> <li>• They may not trust researchers</li> </ul>
Slide 12	<p>Potential challenges impacting clinicians and researchers may be</p> <ul style="list-style-type: none"> <li>• A fear that consumers will be bring a biased view,</li> <li>• Reluctance to share their power and knowledge, and/or</li> <li>• Lack of training and confidence about how to partner with consumers.</li> </ul>
Slide 13	<p>There are also factors that impact both consumers and researchers. These may include:</p> <ul style="list-style-type: none"> <li>• The absence of a shared language,</li> <li>• A lack of respect for different viewpoints,</li> <li>• Stereotypes or stigma,</li> <li>• Different agendas between groups, and/or</li> <li>• And lack of time and money to include consumers.</li> </ul>

Slide 14	<p>Whilst there can be challenges with partnering with consumers, there are a number of things you can do to minimize any potential issues. Firstly, you should aim to establish the partnership as early in the research process as you can. It's also important to:</p> <ul style="list-style-type: none"> <li>• Be inclusive and reach out to people from diverse backgrounds</li> <li>• Maintain integrity and treat everyone with respect</li> <li>• Keep people informed and involved at all stages throughout the research</li> <li>• Use language that can be understood by everyone</li> <li>• Know that one size doesn't fit all – keep an open mind and work with people to figure out how you can best work together.</li> </ul>
Slide 15	<p>Ruth Cox: So just give it a go try something small and build on that. It doesn't have to be really complicated, it can be starting with something like consumers having a look at your participant information sheet and giving you feedback about whether it's readable, whether they understand it. I think you need to choose the right consumers for the types of project you're going to do. Make it clear about the role and expectations, really think about engaging consumers early if you can. They really have some valuable input into protocol development and things like recruitment processes.</p> <p>Elizabeth Miller: Find out if there's a need or education or training that would help them to contribute well, because well informed consumers actually are able to contribute.</p>
Slide 16	<p>That concludes module 1. Hopefully, you are now on your way to being able to answer the following questions:</p> <ul style="list-style-type: none"> <li>-What is the value of including consumers in your research?</li> <li>-How might consumers shape your research?</li> <li>-What barriers may you encounter when it comes to partnering with consumers and how may you combat these?</li> </ul>