

Determining when in the research process to involve consumers and to what extent

Transcript

Slide 1	This module is designed to help you understand when in the research process to involve consumers and the scope and extent of consumer involvement in research.
Slide 2	<p>After completing this module, you will have a better understanding of how to identify the aims and objectives of partnering with consumers, ideas as to when consumers can assist throughout the research process and the degree to which consumers can be involved in research.</p> <p>For more general information about partnering with consumers please review module 1. If you would like to know more information about how to select consumers for your research study or on the partnering process such as communication with consumers and evaluation of consumer partnering please review the other modules for health professionals.</p>
Slide 3	<p>When partnering with consumers in research it is important to identify the aims and objectives of consumer involvement. You need to consider</p> <ul style="list-style-type: none"> - The problem you are trying to solve - How consumer insights can help you solve this problem and - What questions you need to ask the consumer to gather their thoughts and experiences to gain the insights you are looking for.
Slide 4 Video	<p>Bernadette Tanner: We are perhaps changing some thought processes. One example I could give you is we were talking on the subject of quality assurance. And I asked you know what did they mean by that and we've ended up saying, talking about quality improvement rather than quality assurance.</p> <p>And then I offer my thoughts. And then we have a discussion and sometimes we come up with a different plan. It's more a different perspective that we bring.</p> <p>Tim McCallum: So I was able to have a lot of influence in the actual research project itself and the type of data that we wanted to collect. And through my own lived experience, I was able to draw on my own health benefits of being a singer and what that meant to me in terms of my independence and my health out in the community.</p> <p>Jessica Taylor: Researchers work in their own world and by bringing in external community representative, we help to expand their vision and expand some of their ideas. So my involvement has helped to bring about new ideas, new avenues for support, new funding opportunities and also bring new ideas from my experience as a consumer.</p> <p>Natasha Taufatofua: Yeah, so I guess there are a lot of. Things that the consumers head along the way that you know a little light bulb moments. To me, that made me think about the direction that we should go in in terms of my research, so nothing was set in stone at the very beginning, so they highlighted some things about.</p> <p>You know how they connected with health care professionals and how their views about diabetes and medications weren't necessarily the same as what some of our health care professionals provide in terms of their education. And so then that kind of led me to thinking</p>

	there, which you're probably interviewed healthcare professionals, to get their views and see how that lines up with what our consumers were saying as well.
Slide 5	<p>Where and when to involve consumers in your research will depend on the aims and objectives of consumer involvement for your research.</p> <p>Ideally though, it is good practice to partner with consumers as early as possible in the research process. However, if you have already started a research project consumer involvement is still possible.</p> <p>Consumers can be involved throughout the research process. This may include</p> <ul style="list-style-type: none"> - Developing the research question/s - Funding or grant application preparation - Developing the methods - Conducting the research for example collecting data - Analysing and interpreting the data and - Disseminating and implementing the results of the research
Slide 6	<p>Consumers can assist to develop and prioritise your research questions.</p> <p>This may be in the form of individual patient interviews or a one-off focus group to understand the priorities of consumers and where there are unmet needs. Patient groups or consumer groups may also be able to assist you to clarify and prioritise your research questions.</p>
Slide 7	<p>Consumers can assist in applying for and completing grant applications. Some grant and funding bodies necessitate consumer involvement. While this is not the case for all funding, it does demonstrate that the research is more likely to be relevant to the people that the research will impact. Consumers may also write a letter of support for funding and ethics applications.</p> <p>Consumers may even be listed as grant applicants depending on the extent of their involvement in the research process, however early and careful planning is required to make this successful. It is also important to realise that true consumer involvement must be authentic and meaningful, not just a tick box on a grant application.</p>
Slide 8	<p>The development of research methods can involve the consumer. Consumers may assist to develop the methods, [click] review or refine the study protocol which may in turn improve the feasibility and acceptability of the research being conducted.</p>
Slide 9	<p>Consumers can play an integral part when conducting the research. This may include:</p> <p>Review of patient-facing material such as patient information and consent forms or education material.</p> <p>Assist in recruitment and retention of participants by promoting trust between the research team and the participant and</p> <p>Conducting interviews and focus groups alongside researchers.</p>
Slide 10	<p>Consumers may assist in data analysis as well as identification and contextualisation of important findings.</p> <p>Consumers may offer new or interesting insights when analysing qualitative research and support researchers to develop meaningful themes. Consumer involvement in qualitative data analysis may also assist researchers to manage bias.</p> <p>When analysing data, consumers may be able to select the findings that are more relevant to the public or specific consumer groups.</p>
Slide 11	<p>Consumers can play an important role in the dissemination of results by</p> <p>Providing advice on the most appropriate and creative way of communicating the results to the wider community</p> <p>Assist with, or write a plain language summary of results so information is more easily understood by the public</p> <p>Consumers can share results with their networks; for example on social media or through newsletters with patient or community groups</p>

	Consumers can present the findings at conferences or at community forums
Slide 12 Video	<p>Satrio Nindyo Istiko: So I've been very lucky that the type of research that I've been involved with, the researchers and other stakeholders decide to engage with consumers from the beginning. So what that means is that we actually get to sit down together and look at the research questions and the problems that lead to be solved for this particular research questions and what is the consumers input and perspective on that particular issues. Particularly, I think trying to understand how to support research in terms of participant recruitment, informed consent process, withdrawal process, secondary data use and then also about translating and disseminating research outcomes.</p> <p>Tim McCallum: So as a co-investigator, my role in our research project was actually conducting the singing therapy side of things, and as a professional singer myself, I was actually teaching the consumers how to sing, what to sing, different techniques and helping set up for the collection of the research data.</p> <p>Ruth Cox: When I was developing a research protocol really early on in my journey, I worked with about four different consumers about various aspects. So, for example, participant information sheets, getting them to read them and tell me, does this make sense or not? Or is this enticing to you, is it interesting that kind of thing also just even pitching my research idea and seeing consumers think that it was interesting and something that they personally want to be involved in was really useful? Also worked with consumers on literature reviews, looking at search terms. Even the research question. I've worked with consumers on qualitative content analysis and also thematic analysis and the consumers named the themes and that was great because it actually brought their voice to a publication that we were looking at that was about consumer engagement. So to have those consumers actually name the themes was really powerful and I think it made it more real to them people who are reading it.</p>
Slide 13	<p>There are many levels of involvement of consumer engagement in research with greater time and knowledge required of consumers with increasing involvement, and impact on decision making. This slide is based on the International Association Public Participation, or IAP2 spectrum. There is no right or wrong way to engage consumers in research. It depends on the goals of the engagement process.</p> <p>Consumer engagement in research commences when you are providing information to the public about research. It is important to provide objective and balanced information to consumers.</p> <p>You may consult with consumers to seek advice on different aspects of your research. When you consult with consumers, it is more of a one-way process where you are seeking feedback. When partnering with consumers it is important to acknowledge the feedback and input of consumers and how this has influenced the research study.</p> <p>When you involve consumers in your research it moves to a two way process where you are seeking their support throughout the research study by consumers attending working groups or being members of advisory panels.</p> <p>You may choose to collaborate with consumers for your research study which encompasses a shared partnership with equal footing in all aspects of the research study. Consumers may be co-investigators or members of the steering committee.</p> <p>Consumers may lead the research with researchers acting in a supporting role. Consumers make the final decisions and researchers will assist to implement these decisions.</p>

Slide 14

In summary, when considering partnering with consumers in your research it is important to understand the aims and objectives for involving consumers in your research as this will impact how you engage with consumers.

Consumers are able to participate in all aspects of the research process and it is encouraged to partner with consumers at the beginning.

There is a spectrum of consumer involvement in research. Consumers will require more time and research knowledge as they become more involved in the research process and more influential in the decision making.

Consumers can make a positive difference to your research study and understanding when and to what extent to involve consumers will support you as you move through the research process.

If you would like further information about partnering with consumers in research please review the useful links document that accompanies these modules.