

# How can consumers become involved in research?

## Transcript

Slide 1	Welcome to module 5 of the 'partnering with consumers and the community in Metro South' online learning package
Slide 2	This module is designed to provide consumers with information regarding how to become involved in research. We anticipate that after viewing this module you will have a better understanding of the different ways you can be involved in research, what roles you might undertake and where you can find out more information about becoming involved in research.
Slide 3	<p>Your involvement may depend on how much time you have, what your preferences are and the various skills that you bring. Many consumers have a wealth of skills, additional to their lived experience, that they may choose to contribute to research. Your involvement in the research cycle might also change over time as you develop new capabilities.</p> <p>Some examples include:</p> <ul style="list-style-type: none"> <li>Providing your opinion, perspectives and previous health care experiences as a member of a group of advisory committee.</li> <li>Giving feedback, commenting on, or contributing to written material for the research study you are involved in</li> <li>Collecting information or data by being involved in participant interviews or focus groups</li> <li>Assisting in analysis of the research study results, or giving a consumer perspective on understanding or interpreting the results, or</li> <li>You could also be involved in writing up the results or sharing them in the community through presentations or newsletter articles or social media posts.</li> </ul>
Slide 4	<p>Irrespective of the research activities you choose to be involved in, it is important to remember that you do not need to be an expert in the research topic or in the research process. Your value is that you have lived experience of the health service or health topic being researched, or you have provided care to someone with lived experience. You offer a unique perspective that is valuable to researchers because of your experience of living with an illness, or disability, or involvement in using a particular health service. You do not need to represent everybody's opinions. Your experience and perspective is what is important.</p> <p>It is important for you to think carefully about your past experiences with healthcare and your emotional reactions to these. If your past experiences are upsetting or make you very angry then you need to make sure that you are able to work in a positive manner with the research team rather than to focus on your negative experiences so that you can all move forward in a positive way. If this is a challenge for you for a particular research topic then discuss it with a trusted person who can help you to decide whether being involved in that research is the right thing for you.</p>
Slide 5 Video	<p>Bernadette Tanner: I had a lived experience of the Metro South Health system and I have been in this community for over 30 years and I have had because of my involvement, particularly with the aged population, my aged family, particularly because of that. I feel I've got a lot to offer and wanting to put forward my opinion and improve the health system.</p> <p>Tim McCallum: Because I have lived with a spinal cord injury for over 20 years and have also been a singer during that time, I noticed the impact of what singing has had on my health, both physical and emotional. And so I think by being a co-investigator in this project, bringing my lived experience and the fact that I have a bit of skin in the game.</p> <p>I would highly encourage any consumer out there that wants to be involved in any investigation or research projects. After all, we're the ones that it impacts the most.</p>

	<p>We're the ones with the lived experience, where the ones with the skin in the game, really. So we're the best people to actually be involved in any type of research, so I just encouraged anyone out there who has a passion to improve quality of lives of people living with all kinds of disabilities or medical issues to get involved in in research. Be the leaders in that area don't just be participants. Be co-investigators be lead researchers, the challenge is out there, so take it. Elizabeth Miller: Bite the bullet and do it. If you've got a passion for something that needs improving, or if there's a research topic that really interests you. I think it's worth finding out how you can contribute, how you can be a part of that. Even if you're afraid to start, you know it's good to start somewhere, and I think it takes commitment on the part of consumers as well. You've got to be willing to be accountable, be reliable, read stuff when you have to be for meeting. Do what you asked to do.</p> <p>Jessica Taylor: Becoming a consumer in research is really powerful and quite special, so if you're considering joining as a consumer, be yourself and bring your own experience. People will appreciate you for who you are and don't be shy.</p> <p>You can expect them to hold meetings with you prior to a session, or to debrief. You can expect to be involved and it advisory level, so helping the committee make decisions, or you can expect to be apart of focus groups or interviews.</p> <p>Bernadette Tanner: Expect a few challenges in the way of finding the time. So the reading you have to do, the new terminology. All of those sorts of things, but far outweigh by the value that you gain from being part of the team. I would advise to speak up to speak up when you don't understand. Speak up when you want to ask a question or if you feel uncomfortable doing something. I have found our team has been extremely cooperative, extremely helpful, and it's a very relaxed, friendly environment. It's worth becoming very engaged in the process.</p> <p>Satrio Nindyo Istiko: There is support out there beyond then, just that committee that you're involved with, so it's really important to engage with other how consumers as well and have that kind of informal mentoring, or even just sharing about your experiences, and also listen to their experiences as well.</p>
Slide 6	<p>When you begin your involvement in a research study, you should expect that the research team will provide you with support. This will include -</p> <ul style="list-style-type: none"> <li>- Providing you with clear information about your role and what your responsibilities will be, and their expectations of you during the research study.</li> <li>- Expecting to be treated as an equal member of the team where people communicate openly, with mutual trust and respect for you and your knowledge and experiences.</li> <li>- Providing you with regular feedback about how your input has made a difference.</li> <li>- Ensuring you have opportunities for a range of training and support. This may include having a mentor or buddy.</li> <li>- Payment of expenses incurred as part of your involvement in the research study such as parking, and clear information about how to claim these expenses.</li> <li>- Having a single contact person who can provide you with information or support and</li> <li>- Encouraging your involvement in evaluation of the impact you have had, what has worked well and what could be improved.</li> </ul>
Slide 7	<p>Initially, there are two areas researchers will likely seek your input. This information provides some advice to help you for your first time.</p> <p>You will likely be sent material to read prior to the meeting, and if possible try to read this information before the meeting. Ask questions both for your own understanding but also to offer insights to researchers. Sometimes it's the simple or obvious questions that may be important. Speak freely, researchers are interested in what you have to say as you may address topics that have not been considered. You will also most likely identify aspects of the research which are not clear which will help the researchers address these gaps.</p>

	<p>When commenting on written material make sure you understand what input the research team would like from you. Typically, you might comment on whether the information is useful, the material is clear and easily understood - with limited jargon, and the format is easy to read with appropriate space and font size.</p>
Slide 8 Video	<p>Ruth Cox: I think the important thing for us was to do training as we needed, as we went along. So rather than do a big formal workshop or training at the beginning, it's important to be able to provide support, it's not always training, learning, development as people are going rather than thinking you can just do it at the beginning and then it's all done. And the other thing with training, and I've always been really surprised with Liz and with the other consumer is I don't always know what they want to know and so I will try and anticipate it and then they'll ask me questions. And then I'm there as a resource. So it's not just about me it's not about a one way thing, it's about us interacting and working out what's needed.</p> <p>Elizabeth Miller: Yeah, it usually comes up in our meetings. You know that, hey, we'd like to know more about that, or what does this mean? Or what is this paper about, we don't understand it. So yes, it has it. But there has been other opportunities for learning like you know, the webinars and the Metro South Health workshops that happened. The CHF Forum, Consumers Health Forum and you know there's, I think if you really want to learn there's plenty of opportunities to learn.</p>
Slide 9	<p>The training and support opportunities offered to you will vary depending on your level of knowledge and experience, and the amount of involvement you will have in the research study. You might receive training about what it means to be a consumer partner in a research study when you start. You can also direct what learning and support you think you might need to expand your knowledge.</p> <p>There is a wide variety of learning and support which can be tailored to your specific needs. This may include –</p> <ul style="list-style-type: none"> <li>- information about what it means to be a consumer partner and orientation to the organisation.</li> <li>- online modules such as these, which can provide technical information about the research topic or more general information about research processes.</li> <li>- one-on-one sessions with a researcher to explain the research in plain language</li> <li>- A mentor or buddy who can assist you throughout the research study.</li> </ul> <p>It is also important that you are provided with training about general topics such as confidentiality and the ethical conduct of research.</p>
Slide 10	<p>This could be a consumer and researcher talking together. Ruth and Lis or Ruth and Theresa – discussing qual research.</p>
Slide 11	<p>You may even have your own research idea or topic based on your experiences with healthcare delivery. If you would like to share this idea there are a number of ways you could do this.</p> <ul style="list-style-type: none"> <li>- You could contact a community group or organisation that shares your interest in a particular disease, condition or disability.</li> <li>- You could speak with research or consumer partnering staff at your local hospital and health service or</li> <li>- You could discuss your research idea with your healthcare team.</li> <li>- Contact a university or a research organisation such as the Brisbane Diamantina Health Partners or the Victorian Comprehensive Cancer Centre</li> </ul> <p>Contacting these people might help you to link directly with research groups who would be interested in your research idea.</p>
Slide 12	<p>If you would like to find more information about involvement in research, there is a 'Partnering with Consumers' useful links document that accompanies these modules.</p> <p>You could also contact the Metro South Consumer Partnering team to find out more information about how you might be involved in research within Metro South Health.</p>

Slide 13	<p>In summary, there are many different ways you can be involved in research depending on your preferences and experience. Your involvement in research will be valued, and you do not need to be an expert. There are many learning opportunities and supports available to you so you can feel comfortable and maximise your input.</p> <p>Thank you for taking the time to view this module, if you haven't already viewed the introduction to partnering with consumers and introduction to research modules these may be helpful in providing you with more information.</p> <p>There is also additional information in the useful links document that accompanies these modules.</p>
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