

Practical considerations for partnering with consumers in research

Transcript

Slide 1	This module is designed to address the practical considerations when partnering with consumers in research.
Slide 2	<p>After completing this module, you will have a better understanding of the practicalities of partnering with consumers with respect to partnering processes, communication and evaluation strategies.</p> <p>If you would like further information on the objectives of consumer partnering, how to partner with consumers during different aspects of the research process or how to select consumers for your research study please review the other modules for health professionals.</p>
Slide 3	<p>Key points to consider in the partnering process include:</p> <ul style="list-style-type: none"> • Obtaining support, • Organising funding for reimbursement, • Clearly articulating the role of the consumer • Providing training and support, and • Considering ethical approval • Resolving conflict • Evaluating consumer partnering in research <p>We will talk about each of these in more detail in the following slides.</p>
Slide 4	<p>Firstly, it is important to [click] liaise with relevant personnel and stakeholders to obtain support to partner with consumers for your research project. This will ensure that you have the necessary support and are aware of local arrangements for involving consumers– such as any financial or human resource issues that may arise from the proposed arrangement. Depending on where the research will be conducted, the type of research you are undertaking, and how you intend to partner with consumers you might need to:</p> <ul style="list-style-type: none"> • Gain support and approval from your team leader or director, associate researchers and/or other sites, • Liaise with finance and/or human resources departments, or • Attend training or receive support from a researcher who is experienced in partnering with consumers in research
Slide 5	<p>You need to consider if you will need to seek funding to provide reimbursement to consumers. At a minimum, consumer out of pocket expenses such as car parking and mileage should be reimbursed. Funding consumer engagement is considered international best practice because it:</p> <ul style="list-style-type: none"> • Is a material way of acknowledging the value of consumer involvement, • Enables a broader range of people to partner in research by removing potential barriers that may prevent some consumers from being able to be involved in research, and

	<ul style="list-style-type: none"> • May increase the sense of equity within the group or committee if both researchers and staff are being paid for their time <p>Other costs may include refreshments and room hire, for example, if you were hosting a focus group. It is therefore recommended that you include the costs reimbursement and partnering activities when developing budgets and/or submitting research funding applications.</p>
Slide 6	<p>When consumers are invited to partner in research, it is important that there is a clear and shared understanding of what they are being invited to do. To achieve this, an Expression of Interest should be developed to:</p> <ul style="list-style-type: none"> • explain why you are asking consumers to be involved, • be clear about the anticipated time commitment, • let them know what they can expect from you, in terms of accessibility, mentoring, training, support or payment, • and discuss your expectations for the project and listen to and discuss their expectations <p>For formal roles, a role description should also be developed.</p>
Slide 7	<p>It is important to provide consumers with appropriate training and support. Research suggests that consumer partnering is more likely to have a positive impact if consumers receive adequate training for their role. The exact type of training and support consumers might need will vary depending on the partnering activities and the consumers' previous experience. It is important to [click] discuss any training needs with consumers at the beginning of their involvement.</p> <p>Some examples of different types of training may be:</p> <ul style="list-style-type: none"> • Orientation to the Queensland Health Code of Conduct • Providing background reading materials before meetings so they have appropriate information about the research topic, • Delivering an in-person training session or course about the research topic, or • Providing 'on the job' training about their role and responsibilities, and being clear about your expectations of them.
Slide 8	<p>Ethical approval is not required for most consumer involvement activities, because consumers are not acting as research participants, but instead acting in a research advisory, consultative or collaborative role. However, it is important to decide if consumers should be listed as study investigators on the project's ethics application. There are two questions to ask when identifying whether a consumer should be listed as a study investigator.</p> <ul style="list-style-type: none"> • Will the consumer/s be involved in a significant portion of the research process? • Are the consumer/s key members of the research team? <p>If you answered yes to either of these questions, you should list the consumer/s as project investigator/s. You do not need to list consumers as investigators if their involvement is likely to be once-off or sporadic (such as providing feedback on a document). As with all research projects, you may need to register any changes to study investigators with the Human Research Ethics Committee. For example if a consumer becomes involved as a project co-investigator at a later stage in the project.</p> <p>It is also important to remember that any consumer listed as a study investigator cannot be a participant in the research study, as this would be a conflict of interest.</p>

Slide 9	<p>When partnering with consumers in research you need to ensure your practice is inclusive and reflects the diversity of the people and cultures you are planning to partner with. To achieve this you should:</p> <ul style="list-style-type: none"> • Use clear and simple language, avoiding jargon when communicating in both oral and written forms, • Ask people (such as speakers of languages other than English or people with visual impairment) how you can best meet their specific needs – they will be able to tell you what works best for them to help their understanding, • Ensure reimbursements are paid promptly, so that people are not left ‘out-of-pocket’ for long, • Think about where you are going to hold meetings, and whether this will be accessible to everyone (e.g. consider factors such as transport, parking, disability requirements, stair accessibility) • Do not assume that everyone has easy access to a computer, has internet data for videoconferencing or that they can print out long documents. You should instead offer to post printed copies of information if needed, and • You should allow adequate time for people to read information and documents.
Slide 10	<p>It’s important to be aware that there may occasionally be times that things might not go well when involving consumers. Resolving conflict as early as you are aware of it is crucial. Many issues can be quickly resolved with good communication but can become significant problems if not addressed quickly. Depending on what the issue is, we suggest you consider some of the following strategies:</p> <ul style="list-style-type: none"> • Acknowledge that there is a problem • Ask the consumer to describe their experience and concerns, • Listen to what they tell you and openly discuss their concerns, as well any concerns that you might have, • Allow space and time for all involved to reflect, • Refer back to the Queensland Health Code of Conduct or any relevant documents that you developed at the start of the project, such as Terms of Reference or Confidentiality Agreement, • Set a timeframe and action list for agreed changes to happen, • Let people know about any actions, changes or decisions, • Ensure support is available if necessary. <p>If you are unable to resolve issues using the above strategies or if either you or the consumer feel a more independent review of the situation is required, then a more formal approach should be considered. It is helpful to outline the procedure for complaints and resolving differences before you start the project, so that the information and processes are clear from the beginning.</p>
Slide 11	<p>To improve the quality of consumer partnering, it is important to evaluate the process. Process evaluation should be a continuous activity and the research team should periodically reflect on [click] what is working well, what the challenges are and what could be improved. Engaging in such processes will:</p> <ul style="list-style-type: none"> • improve your understanding of what aspects of involvement work best for you and for the consumers, • confirm whether inclusive materials and processes met the needs of participants,

	<ul style="list-style-type: none"> understand whether clear expectations and roles have enabled successful working relationships.
Slide 12	<p>It is important to think about how you will evaluate consumer partnering even before you begin your research project. One example is surveying consumers at the start of a project to see what their expectations are, and then again at the end to see if they were met. Remember, though, that you cannot publish or disseminate these results unless you have ethics approval.</p>
Slide 13	<p>Lastly, funding organisations are increasingly asking researchers to report on the impact of their research, so it's important to think about how you will assess the impact that involving consumers has had on your research. This may involve recording [click] how consumers have been involved throughout your project as [click] well as what difference it has made to the research and if relevant, what impact the research has had on patient outcomes.</p>
Video	<p>Delena Amsters: When evaluating consumer or end user engagement in research my biggest concern is to make sure that the consumers themselves are having a good experience. What I've done in the past is simply asked the consumers or the service users about their experience. Sometimes it's good to get a third party who's not involved in the research to ask those questions so that the consumers that you're working with don't feel that they're obliged to give you a positive answer to all your questions.</p> <p>Ruth Cox: The other thing that's really useful is there are checklists around. So, for example, the Group 2 checklist is really quite simple, the shortfall, and it gets you to think about things like what influence did the consumers have on the research. What were the benefits? But also, what were the challenges of consumers working as part of the research team? And I think that it's important that we all are aware that there are going to be challenges. Like with anything that's worthwhile, there's always tricky stuff, so I've kept a reflexive diary. So thinking about things that have come up when I've been working with consumers and how they might have influenced myself or the research, or what impact the research might have had on them.</p> <p>What insights have you gained from evaluating consumer engagement</p> <p>Ruth Cox: Some of the insights I've gained from doing evaluation of the involvement of consumers of research have been things like it's not easy. It takes commitment. It takes time, but then research is amazing. The other sorts of things I've learned is that you need to be really flexible to be able to accommodate people's needs and preferences, you know these people are giving a lot of their time and their energy and their expertise and so it's important that you accommodate their needs where you can, particularly if you don't have funding as well, which is often the case. If you don't have funding, then it's important that you try and recognize and reward people as well as you can outside the money side of things so it's around being welcoming and being appreciative, saying thank you, having nice food, that kind of thing.</p> <p>Delena Amsters: I've gained a lot of insights from going back and talking to people about their engagement and the number one thing that I've learned is that I have to put aside my preconceived ideas about what it is that people will enjoy or not enjoy in an engagement process. I also have to put aside my biased about the best way to communicate through engagement process.</p>
Slide 14	<p>This concludes this module. You are now on your way to understanding the process, communication and evaluation considerations that are required when involving consumers in your research.</p> <p>For further information on consumer partnering in research please see the useful links documents accompanying these modules.</p>

