

A toolkit for collaboration between healthcare consumers and researchers



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The Collaboration toolkit

Welcome to the collaboration toolkit designed by, and for, healthcare consumers and researchers. It is a collection of materials to help consumers and researchers to understand each other and work well together.

Whether you are a consumer with lived experience of a health condition, or a person researching a health condition, the toolkit is designed to help you understand the perspectives of your collaborators, to work together effectively.

Some of the reasons you may find it useful to work with the toolkit are:

A consumer

- You have been invited to join or are currently a member of a research governance board or reference group
- You have been invited to join or are currently a member of a research team in your capacity as an expert about a health condition
- You have been invited to participate in, or currently are, a participant in a research study
- You plan to attend an information session or research related event about findings from a research project

A researcher

- You are in the early stages of planning a research project about a health condition and/or people living with the health condition
- You are currently conducting a research project about a health condition and/or people living with the health condition
- You want to share your findings with the community

The toolkit provides a set of materials that you can use as a researcher or as a consumer to enhance collaboration.

It seems obvious that it is a good idea for people studying a health condition and people with experience of that health condition (consumers) to talk to each other.

Why collaborate?

When researchers talk to people who live with a health condition (consumers), they may have a clearer understanding of their priorities, and their struggles living with the condition. Similarly, when people with lived experience of a condition (consumers) talk to researchers, they may have a clearer understanding of how researchers focus on particular elements of the condition and attempt to puzzle out a solution. When they talk together, they may be able to come to useful, informed ways of prioritising, structuring and refining research questions and developing effective ways to develop research solutions.

Types of collaboration

Collaborative research tree



Consumers can engage in research in a range of ways depending on their inclination and capacity. There is no “better” or more important mode of engaging in research, as everyone participates in the way that suits them and their life circumstances best.

Receivers of knowledge are consumers who are keen to be informed and updated on emerging research. They may attend seminars or receive regular updates through newsletters from sites they subscribe to. All active researchers (co-researchers and advisors) are also receivers of knowledge.

Participants engage in research by entering into clinical trials, or trials of devices, or focus groups or interviews. It is an ethical requirement that

participants are able to access the findings of research that they have been part of.

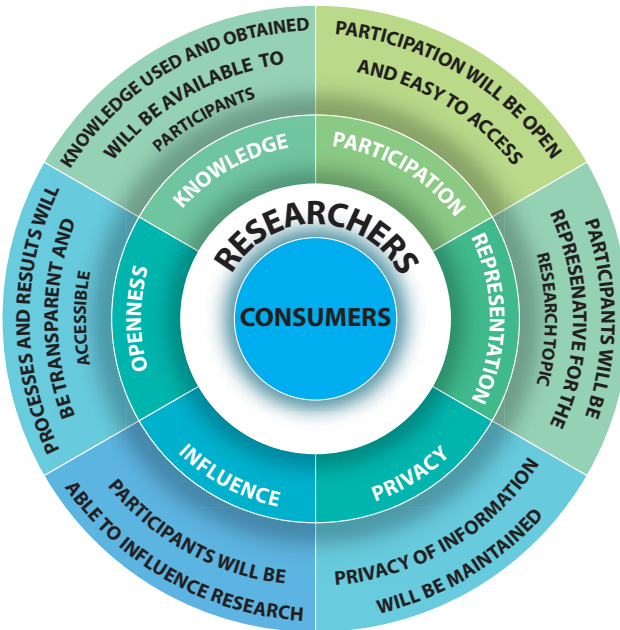
Co-researchers engage as members of research teams. They may be involved at the beginning of the research developing the methods, and collaborating with applications for funding. They may also enter later in the research cycle, helping to collect, and analyse data. It is important where possible that higher degree by research opportunities be available for consumers interested in research in this area.

Advisors hold more directive roles. For example, they may sit on Advisory Boards to determine research priorities or assess research outcomes, or on grant assessment panels.

Principles of engagement

When consumers become involved in research, they can feel as though they are entering a foreign land. Even people who are familiar with research, or who have been science or health care leaders, can find that the world of research is built by and for researchers studying a health condition rather than people living with the condition (consumers).

It's useful to lay down some ground rules about what consumers should expect from research.



The wheel sets out the six key principles of collaboration: knowledge, privacy, influence, openness, participation, and representation.

Knowledge: The underlying hypotheses and research methods are often complex and require higher order scientific literacy. To work effectively as co-

researchers or advisors, consumers must have a working mental model of the research question and the scientific thinking behind it. Researchers should be prepared to engage in developing the scientific literacy of researchers or advisors who do not have this background.

Privacy: Many people may have kept their illness private from their workmates, or peers. This may impact upon how they wish to, or are able to, engage in research. This should be respected by research administrators and researchers. As a standing ethical principle, consumers should not be identifiable without their express consent throughout the processes of research, and information should not be diverted for other purposes.

Influence: Consumers who are co-researchers and advisors should, where relevant, be able to exert influence over the research. Failure to do this runs the risk of tokenism.

Openness: Processes of research should be clear to participants, and the results should be made available to them in ways that are accessible. Placing a summary on a dedicated website is of little use if the person does not have access to the internet or is not able to read or digest the research results. A number of different feedback mechanisms may be necessary.

Participation: Engaging in research as a participant, co-researcher and advisor can be logistically demanding. Researchers should be aware that transport and mobility limitations can impact on consumers' ability to engage in research. Other barriers may include fatigue, and flare-up of illness symptoms.

Researchers should test the accessibility of meeting rooms and have work-arounds such as remote conferencing for those who are fatigued or physically unable to attend.

Representation: Researchers should attempt to engage with groups of people who are often under-represented in research: young people, elders, people with young children, those who have invisible disabilities and may still be in the workforce, and those suffering from disabilities that limit their physical attendance.

Using the wheel

For consumers: Reflecting on this wheel, how does the research you are engaged in meet these principles? If there are gaps in how they approach engagement, discuss with the researchers where improvements can be made to enhance engagement.

For researchers: Use the Table in Appendix A to assess your own project's inclusiveness for people living with a health condition.

Getting to know one another

Desktop exercises enable participants (consumers) to take on different roles and consider the components of the principles for engagement and how they might apply in practice. The scenarios for three exercises are included here. They are designed to be role playing exercises with participants playing the roles of Advisor, on a governance board, or Co-researcher or Participant. We have included a detailed example of the responses raised by one of the scenarios.

Case study 1: Test a new wearable sensor patch to measure fatigue through sweat

A new wearable sensor patch is developed to measure fatigue through chemicals in sweat. This has been used in the military and is good at detecting early signs of fatigue before the person detects it. It is proposed that this may be relevant for people living with rheumatoid arthritis (RA) and other conditions where fatigue is a key symptom. Should this study be pursued? What would be needed for participation?

Things to consider about the proposed study as an advisor

While a person living with rheumatoid arthritis (RA) is an expert about their own experience of RA, being a member of a governance board may need some scientific knowledge to understand the research being proposed and/or undertaken. A useful exercise, and one that could build relationships with researchers, is to ask them to present their research proposal to the governance board in a format suitable for non-scientific experts and answer any questions about their work.

When assessing a project such as this, board members need to consider whether the research is of benefit: do people living with RA need such information about fatigue to manage their health? Is

a form of early warning about the onset of fatigue useful or of benefit? Might it cause harm and what risks, if any, will it mitigate?

Are there any competing research ideas?

If so, why might this project be better and how can the Board choose between them? How can the Board rank and prioritise symptoms and determine which is more worthy of investigation? The Board will have to agree on a way to do this.

It is also important to find out about any costs associated with participating and assessing the burden it may place on participants especially as fatigue is a common symptom.

A key concern is about the degree of influence a Board member has. What is in place to ensure a member has a voice within the Board and will be listened to; are they the only person living with RA on the Board? How will consensus be reached?

Things to consider as a co-researcher

A researcher may focus more on the co-design aspect. Are people living with RA involved in designing the study? They may also be interested in the source study and its methods and outcomes. Has this work already been done in this area? What are the real life benefits, effectiveness of the previous work?

Things to consider as a participant

Participants will be interested in knowing what the purpose of the study is, and what is required to participate. If they are personally invested in the project –perhaps because they have a high level of fatigue–they would need to understand if the project carried risks for them in terms of exacerbating fatigue; or if the researchers have included consideration of access barriers to research because of fatigue. Are they doing some outreach into people's homes or work if that is suitable and easier? Participants will also wish to know how they can be informed of the results of the study, and when.

The diagram below outlines the types of infrastructure support needed to maximise involvement of consumers in research.



The same process of undertaking different role plays can be used for these two hypotheticals:

Case study 2: High levels of Human Herpes Virus 6 (HHV 6) antibodies may indicate imminent relapse for people with an autoimmune disorder. Study to monitor people with multiple sclerosis (MS) for HHV 6 and check against symptoms

In one study of people with MS, HHV 6 antibodies are high before a relapse occurs. No one knows if this is a causation, or occurs for another reason. It is proposed to monitor people with MS for HHV 6 antibodies, checking against their symptoms. Should the study be pursued? What would be needed for participation?

Case study 3: Work with people living with disabilities to develop a model for disability-friendly workplaces including retraining if needed

People living with disabilities often have to adapt their health condition to the workplace rather than having the workplace adapt to them. The proposed study will develop with people with disabilities a model that ensures that people with disabilities are able to optimally work in their workplace. The model also includes a policy for retraining for people who can no longer work in their former workplace. Should the study be pursued? What would be needed for participation?

Self-assessment questions for researchers

Appendix A. Self-assessment table for researchers: Principles of engagement

This self-assessment tool is for researchers to review their own practice, against a series of indicators.

	Self-questions	Evidence
Participation	Have we ensured that participants can physically access meeting rooms?	
	Do we enable remote teleconferencing?	
	Are research facilities environmentally stable – not too hot or cold?	
	Do we enable consumers who have full time jobs to engage in research?	
Privacy	Do we have a policy known to our research administrative staff about maintaining privacy when contacting members?	
	Do we have a clear confidentiality policy available for consumers?	
Knowledge	Have we articulated a process for enhancing scientific literacy of participants, advisors and co-researchers?	
	What are the appropriate ways we disseminate research learnings to community?	

	Self-questions	Evidence
Representation	Have we undertaken a review of representativeness of our samples?	
	Are there any systematically unsampled, and potentially relevant, subpopulations?	
	How do we enhance their representation, when necessary?	
Influence	Do we create conditions to ensure participants' ideas and opinions will be valued and considered?	
	How can we ensure varied opinions are managed and dissenting voices heard?	
Openness	Do we assess whether or not participants understand the research project they are in?	
	Have we ensured that results are made available to participants in a timely and accessible fashion?	

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