



The following definitions have been adapted from Telethon Kids¹ and Australian Clinical Trials Alliance. The language has been simplified with the assistance of open-source AI.

Consumer led research: People with lived experience:

1. Choose what to study
2. Plan how to do it
3. Do the research themselves or ask others to do it

Examples include

- Research project where the lead investigator is someone with lived experience
- Steering groups that are led by people with lived experience.

Research partnership: Researchers work with people with lived experience to plan, do, and share (disseminate) research.

Examples include

- People with lived experience join research teams and attend planning and operational meetings.

Involvement means people with lived experience and community members work with researchers to help decide what research to do, how best to do it and how to use the results.

Examples include

- defining research questions (choose what to study)
- identifying outcomes of interest (decide what to measure)
- helping design and deliver the research projects (plan and do the research)
- improving the content and readability of participant information (make information easier to read)
- making trials more attractive to potential participants (help more people join studies as participants)
- analysing research findings (look at the results)

- ensuring a balanced assessment of research findings (make sure everyone understand all the findings)
- helping design and deliver further involvement/engagement activities (plan ways to involve more people)

Consultation is when researchers tell people with lived experience and community members about a study plan and

- Ask what they think
- May use some of their ideas
- Let them know what was done with their comments

Examples (ways to ask for ideas) include:

- community talks
- group discussions
- questions for people to answer
- meetings with groups of people with lived experience or community members
- ‘pitch fest’ activities

Engagement: Researchers share and talk about studies with people with lived experience and the community to help them understand research, know about studies they can join, and see how being in studies can be part of their care.

- Why we do research
- How we do it
- Where it happens
- Who does it

Examples include:

- sharing research findings (telling people what we learned)
- teaching about how studies are planned (‘research 101’)
- research open days (days when people can visit and learn about research)
- giving talks to the public
- using websites, social media and/or newsletters to share information about studies

<p>Telethon Kids https://www.telethonkids.org.au/globalassets/media/images/pagesections/research/help-shape-our-research/purple_planning_book_271015.pdf</p>	<p>ACTA</p>
<p>Lead the research: consumers and community members identify the research needed and set the appropriate research agenda. they then undertake the research</p>	

<p>themselves, or commission researchers to do this on their behalf.</p> <p>Examples</p> <ul style="list-style-type: none"> • Consumer or community researchers • Community-led steering groups 	
<p>Research partnership: researchers work in partnership with consumers and community members to plan, undertake and/or disseminate the results of research</p> <p>Examples:</p> <ul style="list-style-type: none"> • Consumer or community researchers • Membership of steering group 	<p>Involvement is where consumers and community representatives actively work with researchers and research organisations to help shape decisions about health research priorities, policy and practice. Some examples of consumer involvement include:</p> <ul style="list-style-type: none"> • defining research questions • identifying outcomes of interest • helping design and deliver the research projects • improving the content and readability of participant information • making trials more attractive to potential participants • analysing research findings • ensuring a balanced assessment of research findings • helping design and deliver further involvement/engagement activities
<p>Advise: researchers seek the advice of consumers or community members e.g. about how to recruit participants or how to disseminate results</p> <p>Examples</p> <ul style="list-style-type: none"> • Asking consumers or community members to comment on documents • Community forums or conversations • Reference groups • Research buddies • Meetings with community or consumer groups 	
<p>Consult: researchers offer information about a research study or plan to consumers and community members and seek their views about it. they do not necessarily take these views on board, but they will usually offer feedback about what they have done in response to comments</p> <p>Examples</p> <ul style="list-style-type: none"> • community conversations • focus groups • surveys • meetings with consumer or community groups 	
<p>Informed: researchers make information about the research available to consumers or community members, they do not seek views on the research.</p> <p>Methods often used:</p> <ul style="list-style-type: none"> • Websites • Talks • Newsletters 	<p>Engagement is where information and knowledge about research is shared with consumers and the community so that they are better informed on why, how, where and by whom research is conducted.</p> <p>Engagement is about creating a dialogue with consumers and the community to improve research literacy and increase trial awareness to encourage trial participation as a routine care option.</p>

	<p>Some examples of consumer engagement include:</p> <ul style="list-style-type: none">• sharing research findings• consumer training on product or protocol development• research open days• sharing information through public talks and lectures• using social media to highlight trials/trial topics
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¹ McKenzie, A & Hanley, B. Planning for Consumer and Community participation in Health and Medical Research. A practical guide for health and medical researchers. Telethon Kids Institute. (2014).

² Australian Clinical Trials Alliance & CT:IQ. Consumer Involvement and Engagement Toolkit. <https://involvementtoolkit.clinicaltrialsalliance.org.au/>. 2019