



Glossary: common terminology used in Consumer and Community Involvement in Research

- **Advocacy Organisation:** A group or organisation that works to influence public policy and resource allocation decisions within political, economic, and social systems and institutions. These organisations aim to represent and advance the interests of their members or a specific cause.
- **Carer:** A person who provides unpaid care and support to a family member or friend who has a disability, chronic illness, mental health condition, or is elderly and frail.
- **Community:** A group of people who share a common interest or identity. This may include:
 - Cultural background
 - Geographic location
 - Shared health issue
 - Shared demographics
- **Consumer (Health Consumer):** A person who uses or has used health services or is a carer for someone who uses health services. Through having lived experience of the health care system, consumers provide valuable perspectives.
- **Consumer Network (Consumer Group, Consumer Collective):** A group of consumers who work together to share information, support each other, and collaborate on advocacy and research interests.
- **Consumer Advocate (Consumer Representative, Consumer Champion):** A consumer who actively promotes and supports the interests and rights of other consumers, particularly in healthcare and research settings.
- **Consumer and Community Involvement in Research (CCIR):** Consumer and community involvement in research refers to the active partnership between researchers, health professionals and those affected by or who may benefit from the research or healthcare improvement. Consumer and community involvement is about projects being carried out with or by consumers and community members rather than to, about or for them.
- **Consumer involvement, participation, and engagement:** The terms involvement, participation and engagement are three distinct terms with different meanings.
 - Involvement is consumers and community working alongside health professionals and researchers, in partnership, to shape what research or project is undertaken, how it is carried out and how results are shared and applied in practice.
 - Participation is where patients and consumers are participants in a project and data is being actively collected from them.
 - Engagement involves the sharing of the findings and outcomes of a project.
- **Lived experience:** Firsthand experience and knowledge gained by having personally dealt with a particular health condition, disability or social issue. Lived experience can provide valuable and unique insights into the realities and challenges faced by consumers and carers.
- **Patient:** An individual who receives or has received medical care or treatment. Patients, like health consumers, provide valuable insights based on their personal healthcare experiences.