

What are the different ways in which a member of the public can participate in (Health and Social Care) research?

Members of the public can get involved in health and social care research in a variety of meaningful ways—ranging from helping shape what research gets done, to participating in studies, to helping share findings. These roles generally fall into two broad categories: **public involvement** and **participation**.

Public Involvement (active collaboration in the research process)

Here, the public is **actively involved in research**, rather than just being the subject of it. This can include:

1. **Co-designing research studies**
 - Helping identify relevant research questions
 - Contributing to study design, ensuring it's acceptable and accessible
 - Advising on methods and language used
2. **Being a member of advisory or steering groups**
 - Giving feedback during different stages of the research
 - Ensuring the research stays relevant to the needs of patients and the public
3. **Helping develop recruitment materials**
 - Ensuring language is understandable and inclusive
 - Helping with outreach strategies to improve diversity in research participation
4. **Helping to interpret findings**
 - Bringing a real-world perspective to make sense of data
 - Providing context that researchers might miss
5. **Disseminating research results**
 - Co-authoring publications or blogs
 - Speaking at events or helping to share findings with communities
6. **Advocating for research**
 - Raising awareness about the importance of research in communities
 - Acting as ambassadors to increase engagement and trust

Public Participation (taking part as a subject of research)

This is more traditional and still crucial. It involves:

1. **Taking part in clinical trials or observational studies**
 - Volunteering to test new treatments, therapies, or interventions
2. **Completing surveys or interviews**
 - Sharing experiences or perspectives as part of data collection
3. **Donating samples or data**
 - Contributing biological samples (e.g. blood, saliva)
 - Sharing health data (e.g. medical records, app data) under ethical conditions

Other Forms of Engagement

1. **Citizen Science**

- Helping collect or analyse data (e.g. using apps or online platforms)
- 2. **Crowdsourcing ideas or solutions**
 - Offering insights via public challenges or innovation platforms
- 3. **Taking part in public consultations**
 - Giving opinions on research priorities or ethical issues

Why It Matters

Involving the public improves **relevance**, **quality**, and **impact** of research. It ensures studies are grounded in real-world concerns and helps build **trust** and **transparency** in the research process.

NIHR INVOLVE (now part of the **NIHR Centre for Engagement and Dissemination**, as INVOLVE was integrated into it in 2020) makes a **clear distinction** between:

- **Involvement**
- **Engagement**
- **Participation**

Here's how **NIHR** defines “research participation”:

Research Participation (according to NIHR INVOLVE)

“Participation” refers to people taking part in a research study. For example, people being recruited to take part in a clinical trial or other research study, and being the subject of the research.”

— **NIHR INVOLVE**

So in short:

- It means being **the subject** of the research.
- It's **not** the same as being actively involved in shaping or designing the research.
- Participants may fill in questionnaires, be interviewed, give biological samples, or test new treatments.

Comparison with Other Terms (NIHR's Definitions)

Term	Description
Involvement	Research is done <i>with</i> or <i>by</i> members of the public (e.g., co-designing studies, advising on methods).
Participation	Research is done <i>to</i> or <i>on</i> people (e.g., taking part in a study).
Engagement	Providing information about research to the public (e.g., events, media, public lectures).

Here's a concise table outlining the distinctions between **Involvement**, **Engagement**, and **Participation** in health and social care research, as defined by the National Institute for Health and Care Research (NIHR):

NIHR Definitions: Involvement, Engagement, and Participation

Term	Definition	Example Activities
Involvement	Research carried out <i>with</i> or <i>by</i> members of the public, rather than <i>to</i> , <i>about</i> , or <i>for</i> them.	<ul style="list-style-type: none"> • Collaborating on study design - Serving on advisory panels - Co-authoring research publications
Engagement	Providing information and knowledge about research to the public.	<ul style="list-style-type: none"> • Hosting public lectures - Sharing research findings through media - Participating in science festivals
Participation	People taking part in a research study as subjects.	<ul style="list-style-type: none"> • Enrolling in clinical trials - Completing research surveys - Donating biological samples for research

For a more detailed explanation, you can refer to the NIHR's official guidance on public involvement in research:

- **NIHR Briefing Notes for Researchers:** [NIHR](#)

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