

Guiding Principles for Public Involvement in SHARE health research



Introduction

The involvement of the public and of community partners in our research is a core component of the SHARE ethos and practice. This document, based on a desk-based literature review and group discussion, aims to:

1. Establish guiding principles for the SHARE collaborative
2. Identify various roles of public involvement in research
3. Explore how the public is remunerated when involved in research
4. Support grant preparation with ideas for budgets, terms of references etc

Our Guiding Principles

- To aim for the maximum degree of public involvement and power sharing possible in all our research
- To provide appropriate emotional support for community partners in our research
- To provide appropriate cultural support for community partners in our research
- To provide appropriate instrumental support for community partners in our research
- To build capacity, sustainability, and accreditation with community research partners (educational support)
- To increase representation and diversity in our research teams
- To set out equitable recognition in knowledge co-production (e.g., co-authoring, co-presenting)
- To proceed transparently and equitably with clear communication using appropriate channels through all phases of involvement (e.g., payments and contracts)

SOME KEY DEFINITIONS

The definitions below are suggestions of how different authors have understood some of the common terms we use in research. They are not exhaustive or final. We have included them here to give an idea of the variety and nuances of approaches in this field, and to guide our writing and thinking.

Co-author

Any person that significantly contributes to writing a book, report, article, or research publication. This is a proxy measure of research collaboration¹ and key recognition of contribution to knowledge production.

Co-investigator

A researcher who has similar responsibilities and works alongside the research **Principal Investigator** (who is ultimately responsible for the conduct of a research project).²

Collaboration

Working together with another person or group with the aim of achieving a specific objective. Collaborative research, therefore, can be defined as research involving coordination between the researchers, institutions, organizations, and/or communities. This cooperation can bring distinct expertise to a project. Collaboration involves an ongoing partnership between you and the members of the public you are working with, where decisions about the research are shared³.

Community-based participatory research (CBPR)

A collaborative approach to research, which equitably involves all partners in the research process and recognises the unique strengths that each brings. CBPR begins with a research topic of importance to the

¹ Ponomariov, Branco, and Craig Boardman. "What is co-authorship?" *Scientometrics* 109, no. 3 (2016): 1939-1963.

² <https://www.washington.edu/research/faq/whats-difference-pipd-multiple-pi-co-pi-co-investigator-application-pi/>

³ Bansal, Seema, Saniya Mahendiratta, Subodh Kumar, Phulen Sarma, Ajay Prakash, and Bikash Medhi. "Collaborative research in modern era: Need and challenges." *Indian journal of pharmacology* 51, no. 3 (2019): 137.

community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities⁴.

Co-production

Co-producing a research project is an approach in which researchers, practitioners, and members of the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance. Key principles include: sharing of power; including all perspectives and skills; respecting and valuing the knowledge of all those working together on the research; reciprocity; and building and maintaining relationships⁵.

Public consultation

This exercise in research refers to a process by which the public's input is sought on the research that will affect them with aim of improving efficiency, transparency, and public involvement. You ask members of the public for their views and use these views to inform your decision making. ⁶

Participatory research

An umbrella term for a school of approaches that share a core philosophy of inclusivity and of recognizing the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users, and stakeholders of the research. The aim is to systematically inquire/conduct research with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change⁷.

Peer research and Peer researcher

Peer research is a participatory research method in which people with lived experience of the issues being studied take part in directing and conducting the research.

Peer researchers (also referred to as 'community researchers') use their lived experience and contextual understanding of a social or geographical community to help generate information about their peers for research purposes. Peer researchers may be involved in assisting with research design, developing research tools, collecting, and analysing data or writing up and disseminating findings⁸.

Public engagement

When information and knowledge about research is provided and disseminated to the public such as through science festivals open to the public with debates and discussions, awareness of research through media⁹.

Public involvement (Patient and Public Involvement (PPI))

Public involvement in research is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on, and developing research

⁴ Wallerstein, Nina B., and Bonnie Duran. "Using community-based participatory research to address health disparities." *Health promotion practice* 7, no. 3 (2006): 312-323.

⁵ Coldham, Tina, and I. A. Group. "Guidance on co-producing a research project." (2018).

⁶ Fishkin, James S., Robert C. Luskin, and Roger Jowell. "Deliberative polling and public consultation." *Parliamentary affairs* 53, no. 4 (2000): 657-666.

⁷ Cargo, Margaret, and Shawna L. Mercer. "The value and challenges of participatory research: strengthening its practice." *Annu. Rev. Public Health* 29 (2008): 325-350.

⁸ Lushey, Clare. *Peer research methodology: Challenges and solutions*. SAGE Publications Ltd, 2017; Edwards, Rosalind, and Claire Alexander. "Researching with peer/community researchers—ambivalences and tensions." *The SAGE handbook of innovation in social research methods* (2011): 269-292.

⁹ <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

materials and undertaking interviews with research participants. It is an active partnership between members of the public with researchers that influences and shapes research¹⁰.

Public research participation

When people take part in a research study such as being recruited to a clinical trial, completing a questionnaire, or participating in a focus group discussion¹¹.

Important notes for SHARE-specific work

The term 'public' includes patients, potential patients, carers, and people who use health and social care services as well as people from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Public consultation, collaboration, and co-production denote broad approaches to involving people in research, associated with progressively increasing levels of power and influence.

The term peer researcher is contested. It carries an implication, in some instances, that the *academic* researcher might determine what 'peer' means in a given study. This which might prioritise one identity category (e.g., HIV status) over others (e.g., gender or ethnicity).

The term 'peer researcher' has further implications for immediate disclosure of the peer researcher's characteristics (for example, whether they are living with HIV) with little or control over such information (for example during dissemination of findings)¹².

It is therefore advisable to engage in early conversations with community partners as to the best definition for the 'peer researcher' role and to ensure peer researchers are aware and happy to be defined as such. The term 'community researcher' can be used where appropriate to resolve some of these issues.

Other considerations

The terminologies defined so far are largely affected by context and subjectively chosen by the users. There are a range of other linked terms to consider:

- Participatory learning and action
- Participatory action research
- Community-partnered participatory research
- Cooperative inquiry
- Dialectical inquiry
- Decolonizing methodologies
- Participatory or democratic evaluation
- Social reconnaissance
- Emancipatory research
- Citizen science

The terms used in every research project should be carefully chosen, explained, and communicated to all stakeholders involved for mutual understanding from the initial stages of engagement and throughout involvement.

¹⁰ Hayes, H., S. Buckland, and M. Tarpey. "Briefing notes for researchers: public involvement in NHS, public health and social care research." Eastleigh: INVOLVE (2012).

¹¹ <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

¹² Ibáñez-Carrasco, F., Watson, J.R. & Tavares, J. Supporting peer researchers: recommendations from our lived experience/expertise in community-based research in Canada. *Harm Reduct J* **16**, 55 (2019). <https://doi.org/10.1186/s12954-019-0322-6>

Remuneration of public participation and involvement in research

The public can either participate in research as participants (as primary sources of data) or be involved as active research team members such as peer or community researcher. In both circumstances, remuneration must consider their level of involvement in the research project and, where appropriate specific skills are required.

There is no harmonised approach of public remuneration in research, however, it is best to have a clear payment and recognition policy in place so that the public is aware of what is being offered prior to participation so that they can make an informed decision on whether to participate. Principles of remuneration are transparency and communication.

Lynch *et al* (2021) developed a framework¹³ to consider when remunerating public participation or involvement in research by distinguishing reimbursement, compensation, and incentive in the table below:

Reimbursement	Compensation	Incentive
Goal		
Full coverage of reasonable expenses	Fair payment for time and burden	To encourage enrolment and retention in important and ethical research of participants for whom reimbursement and compensation are insufficient motivations
Variability		
Amounts will vary per participant depending on expenses incurred	Rates should be uniform across participants	Aim for uniformity across participants and offer after completion.
Coverage		
May include transport to and from visits, meals, accommodation	Amount of time spent in the research activity	Amount needed to motivate participants
Factors to consider		
Pre-payment (vouchers) or refund of out-of-pocket expenses	Duration, impact of research activity	Study importance and urgency of recruitment, study budget, type of participants sought.
Relevant benchmarks		
Reimbursement rates and incurred costs with receipts	Payment in comparable research	Incentives offered in other similar research, institutional requirements, uniformity within acceptable range across various research projects

The NIHR developed the [Payment guidance for research and professionals](#)¹⁴ that highlights rates for honorarium payments to public involvement in research depending on the task and time spent:

Task	Estimated time spent to complete task	Rate
Reading and commenting on an abstract	<30 minutes	£12.50
Activity requiring little or no preparation such as participating in a focus group discussion	≤1 hour	£25.00
Activity likely to require some preparation such as the need to read papers or review a few short documents	Approx 2 hours	£50.00
Activity likely to require some preparation such training delivery	Approx half a day's work	£75.00

¹³ Lynch, Holly Fernandez, et al. "Promoting ethical payment in human infection challenge studies." *The American Journal of Bioethics* 21.3 (2021): 11-31.

¹⁴ <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

Involvement in all-day meeting such as attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel.	All-day	£150. 00
For involvement in meetings that require substantial preparation such as chairing or co-chairing a meeting	All-day	£300.00

This guidance can be adapted depending on the institution and context and **the role (and rate of pay) of the public** or community partners.

Below is a SHARE example of time allocated to collaborative tasks in the one of our studies

TASK	ESTIMATED TIME	TOTAL TIME (hours)
Read documents for ethics submission	3 hours	3
Ethics committee attendance and preparation	2 hours	2
Reviewing study materials	1 day (8 hours)	8
Advisory group meetings attendance and preparation – 2x/year	3 hours/meeting = 6 hours/year for 3 years	18
Attending peer researcher training	1 day (8 hours)	8
Supervising peer researchers	3 hours every month for 1 year	36
Results workshop x 2 and preparation	Each workshop + preparation is 4 hours	8
Results dissemination – assistance with writing lay reports	1 day (8 hours)	8
Reviewing academic papers/ conference presentations	2 days (8 x 2 hours)	16

NOTE: We will strive for equity and transparency with all our collaborators. These payment guidelines are our ‘ballpark’ standards; will consider the circumstances of each individual or organisation and the adequate amount of time spent on the given task, based on skill and expertise where appropriate.