NIHR | Applied Research Collaboration
North East and North Cumbria

Ethical Practice Guidelines

for Public Involvement and Community Engagement

Introduction

Working in partnership with public contributors, patients, service users, experts by experience and with communities is an integral part of conducting health and social care research. Ensuring that there are opportunities for the voices of the most marginalised and excluded/unheard communities to be at the heart of research is a social justice issue. And, creating opportunities that support ethical practice in research, requires attention to the values and principles that underpin reciprocal, meaningful and sustainable relationships with people and communities.

These guidelines will help to support researchers, public contributors, practitioners and anyone interested in health and care research to work towards ethically sound research practice specifically for the Public Patient Involvement/ Engagement (PPI/PPIE) element of the work. They do not replace the need for formal ethical approval for a research study (for example through NHS or University ethics processes). The guidelines are intended for use by people working in or contributing to health and social care research including public contributors, VCSE organisations as well as researchers.

A small working group of public contributors, researchers and Public Involvement and Community Engagement (PICE) leads have developed these guidelines which we hope will encourage the development of ethical literacy (a better understanding of ethical issues) in relation to PICE amongst the research community. This is not intended to be an exhaustive list, but indicative of some of the key aspects that people might want to consider before undertaking PICE activity.

The document contains the following:

- An overview of key aspects to consider and discuss when undertaking PICE activity (page 2).
- A more detailed outline of these aspects with links to further guidance and resources (pages 3-7).
- A glossary of key terms (page 8).
- An overview of the research cycle (page 9)
- A checklist you can use as your progress through your project (page 10-11)

These guidelines are underpinned by the UK Standards for Public Involvement UK Standards for Public Involvement and uses the NIHR definition of public involvement to mean *'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research'* (Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR).

Involvement should take place at all stages throughout the Research Cycle *.

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Key aspects to consider throughout the research cycle

Safeguarding	• Be aware of policies and what to do if an incident occurs. • Consider where to meet people and safety considerations. • Establish whether you need a risk assessment.
Access, inclusion and equity	• Offer everyone an opportunity to contribute and ensure that research processes do not exclude people and communities.
Working in challenging and sensitive areas of research	• Think about whether topics might be triggering or difficult for public members / researchers. • Ensure that you have time built in for breaks/ reflection as appropriate. • Make available lists of contacts for support during and after sessions.
Confidentiality/ consent/assent	• Set clear guidelines about sharing personal experiences, what will be shared and how it will be used. • Ensure that the activity is GDPR compliant. • Make sure that everyone knows whether and under what circumstances confidentiality could be breached. • Ensure all team members have appropriate training in data protection.
Agreeing boundaries from the outset	• Develop a set of working agreements/terms of reference or ground rules that include expectations about language and behaviour of all people involved.
Communication	• Ensure there is ongoing two-way communication throughout. • Consider whether you need translators / interpeters and book these in advance.
Training and support	• Discuss with public contributors what training might be needed for them to take part. • Consider what specialist training the research team might need for the groups they will be working with.
Developing sustainable reciprocal relationships	• Be clear about the expectations of the relationship with public contributors. • Give details on the duration of the work and what might happen after the work finishes. • Consider the impact on public contributors and communities.
Managing conflict	• Have a plan in place for any potential conflict that might arise and how you will manage this.
Valuing public contributors	• Let people know how their input influenced the work. • Give consideration to involving people as co-authors/ co-applicants. • Make sure there are fair and flexible remuneration policies in place in line with national guidelines.

Issue to address	Possible areas to think about	Other information/resources
Safeguarding	- Training opportunities / induction to clarify safeguarding roles / responsibilities? - DBS (see definitions) Clearance for PPI leads and public contributors - Lone worker (see definitions) policies for research institution - Travel policies (including giving lifts, business insurance etc.) - Meeting spaces (people's own homes, public buildings etc.) - Process for reporting safeguarding concerns using your own institutions Safeguarding Policy and wherever possible with the full knowledge and consent of the individual/s concerned. - Making sure everyone aware of the process for reporting safeguarding incidents, how they will be investigated, by whom and in what timeframe - Supporting people who are sharing lived experiences in a way that may make them less safe or may exacerbate existing difficulties and challenges - Anticipate and take steps to address and/or be prepared for any physical risk e.g. when doing outdoor/physical activities. Is first aid training needed? Is a Risk Assessment required? - Discuss physical risk and safety according to individuals' own health prior to activity - Knowledge of protocols and reporting procedures should an adverse event occur - Think about any additional needs/medical needs that any individual might have. Do you need information about medical needs, emergency contact details etc. - Consider issues around Duty of Care (see definitions)	NIHR Safeguarding Guidance | NIHR Lone workers: how employers should protect them - Overview - HSE Ofsted safeguarding policy - GOV.UK (www.gov.uk) A BARE RADICAL TOOLKIT: Trauma informed Youth Engagement (usrfiles.com)
Access, inclusion and equity	- Ensure that research processes (recruitment, support and training, remuneration etc.) do not further exclude people and communities that are already marginalised - Consider issues such as gender, ethnicity, faith, culture, socio-economic status and neurodiversity when creating opportunities for involvement - Articulate and address power imbalances	https://ayph.org.uk/engaging-young-people-in-health-services-research-and-service-design/ Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles,-

	• Don't make assumptions about what people can/can't do or what they might want/not want to be involved in as people. • Consider issues around gatekeeping i.e. allow young people, learning disabled people, care home residents etc. to choose what they want to be involved in, and how rather than creating opportunities for them to only be involved in issues that you/other adults think they might be interested in • Be careful to avoid representation/misrepresentation. Do community leaders represent their communities? How has this mandate been acquired? Consider issues around participatory democracy as opposed to representative democracy as this may encourage greater equity	2nd-edition-(2022)-.pdf (durham.ac.uk) Equality, diversity and inclusion | NIHR
Confidentiality/consent/assent	• Ensure that there is clarity and transparency about the purposes of the activity, what the information will be used for, and whether contact will be one-off or ongoing (e.g. coming back to people later on for more discussion or to share outcomes of funding applications that they have fed into etc.) • Some groups by their very nature may be hard to keep people anonymous e.g. rare disease – need to inform people of this so appropriate informed actions can be taken. • Ensure any issues about GDPR (see definitions) and confidentiality are agreed from the outset • exercise caution in the use of AI - what does it store, where does it store it, who has access to the notes, are people happy there is an AI note taker being used? • Links to online meetings only shared with agreed group and entry to meeting monitored • Where people are taking up roles as co-researchers/peer researchers and are sharing lived experience make sure that there are clear guidelines about who shares what, and with whom, and need to be open about the content and nature of discussions	Glossary | NIHR

	• Need to ensure we have appropriate permissions before sharing research-related documents with public members. • Consider use of social media, personal accounts, WhatsApp groups etc. What is it OK to share and what not to share? • Permission gained for use of images/anonymous artwork/quotations etc. in media, presentations, publications etc. • Create the understanding that people can withdraw consent/pull out of PICE activity or group at any point • Agree what will happen if confidentiality/GDPR is breached	
Working in challenging/sensitive areas of research	• Be aware of potentially triggering topics for researchers and public contributors. Be aware of potentially sensitive or triggering topics and be prepared to respond carefully if someone becomes distressed (for example, don't overcrowd agendas so there is time and space within meetings, consider having additional space for people to take a break, build in time to speak to people informally after meetings end etc.). • Consider that topics we may not consider as 'sensitive' may be viewed as sensitive/distressing by the person involved. • Consider protocols for if someone is ill/dies during public involvement activity • Consider issues of emotional risk • Support services both within the institution i.e. staff welfare/counselling as well as external helplines and organisations i.e. MIND, Samaritans, NCDV and Refuge etc. (identified at the outset shared with all contributors and researchers). • Opportunities for preparation and de-briefing before and after sessions • Ensuring there are sufficient numbers of researchers/facilitators to support people during sessions, and they feel confident in how to support someone	Researching sensitive topics in healthcare | Evidence-Based Nursing (bmj.com) Emotion in public involvement: A conceptual review - Liabo - 2024 - Health Expectations - Wiley Online Library Survivors-Charter-v2.pdf (survivorsvoices.org) Contact NCDV · Domestic Abuse and Violence Support Home - Mind PPI-trauma-informed-guidance-2024-(1).pdf (imperial.ac.uk)
Agreeing boundaries from the outset	• Agreeing working definitions from the outset – to avoid confusion and misunderstandings • Agreeing these together with all members involved	All about Ethics | Co-Production Collective (coproductioncollective.co.uk)

	• Discuss and agree expectations and values • Develop a set of working agreements/terms of reference or ground rules that include expectations about language and behaviour of all people involved (addressing issues about oppressive and discriminatory language and behaviour) • Consideration for when a public member is going to be in touch with research participants – could this be when PPI crosses into more 'peer research' - do we need to seek further ethical guidance?	Research ethics review and members of the public who are actively involved in research
Communication	• Ensuring language is inclusive, accessible and intelligible • Ensuring there is ongoing two-way communication throughout • Ensure any translation/interpreters (foreign language and BSL) are booked in advance, and that there is sufficient money in the budget to cover costs • Consideration for people's ability to use/access technology • Communication of impact/dissemination/outcomes, including feedback on smaller outcomes and impacts of PPI activities as the project progresses	Training guides: How to work effectively with interpreters and translators - ARC (nihr.ac.uk)
Training and support	• Make sure there are opportunities for skills building, skills sharing and for developing capacity • What training is available/needed? • Ongoing support needs should be clarified and agreed from the outset and reviewed over time	Homepage - Learning for Involvement Ethics in Patient and Public Involvement (PPI): A collaborative workshop for ARC East of England researchers and PPI members | ARC East of England (nihr.ac.uk)
Developing sustainable reciprocal relationships	• Consider carefully your relationships with public contributors and colleagues. Are they co-researchers, colleagues, volunteers, and friends? Be clear about the difference to avoid misunderstandings. • What happens at the end of the research? • Work is ongoing through the Creating Connections Network and Research Engagement Post at VONNE to develop	Community Engagement Toolkit (rdsresources.org.uk) Ethics Guidance for Developing Partnerships with Patients and Researchers - CIHR (cihr-irsc.gc.ca)

	VCSE research capacity and co-produce resources.	North East and North Cumbria VCSE Research Partnerships Programme (vonne.org.uk)
Conflict resolution	• What to do when things go wrong • How is, for example, bullying managed? • Where do public contributors go for external advice/support when they are unhappy with how they are being involved/treated • Ensure there are clear guidelines about access to PPI leads, line managers within institutions or HR advice/conflict resolution	
Valuing public involvement	• Ensure that there are numerous ways that public contributors time, expertise and knowledge are recognised and rewarded e.g. payment and vouchers, expenses covered, treated with respect, told how their contribution has influenced the work, or involved as a co-author/ co-applicant on occasions where possible/ suitable. • Ensure remuneration processes are efficient, avoid bureaucracy, adhere to NIHR/HRA guidance and do not penalise people who are for example welfare benefits claimants etc. • Offer letters for DWP / work coach if requested to clarify PICE / service user involvement should not affect benefit entitlement or eligibility. • Be clear that no individual should be out of pocket as a result of their involvement • Consider giving back to communities, VCSE organisations e.g. by providing training, advice/support for impact evaluation, volunteering etc. • Be prepared to write references, letters of support and provide certificates as/when this is helpful	Payment guidance for researchers and professionals | NIHR https://www.nihr.ac.uk/documents/welfare-benefits-jobcentre-letter/27407.

Glossary

Ethical Approval: For the purposes of this document we are using ‘ethical approval’ to refer to formal processes for obtaining ethical approval to undertake research.

DBS: Disclosure and Barring Service Disclosure and Barring Service - GOV.UK (www.gov.uk)

Duty of care: a duty of care is a legal obligation that is imposed on an individual, requiring adherence to a standard of reasonable care to avoid careless acts that could foreseeably harm others, and lead to claim in negligence.

Lone worker: Lone workers: how employers should protect them - Overview - HSE

GDPR (General Data Protection Regulations): UK GDPR guidance and resources | ICO

VCSE: Voluntary Community and Social Enterprise

PPI/PPIE/PICE: Patient and Public Involvement, Community Engagement

HRA: Health Research Authority

NIHR: National Institute for Health and Care Research

HR: Human Resources

DWP: Department for Work and Pensions

*The Research Cycle

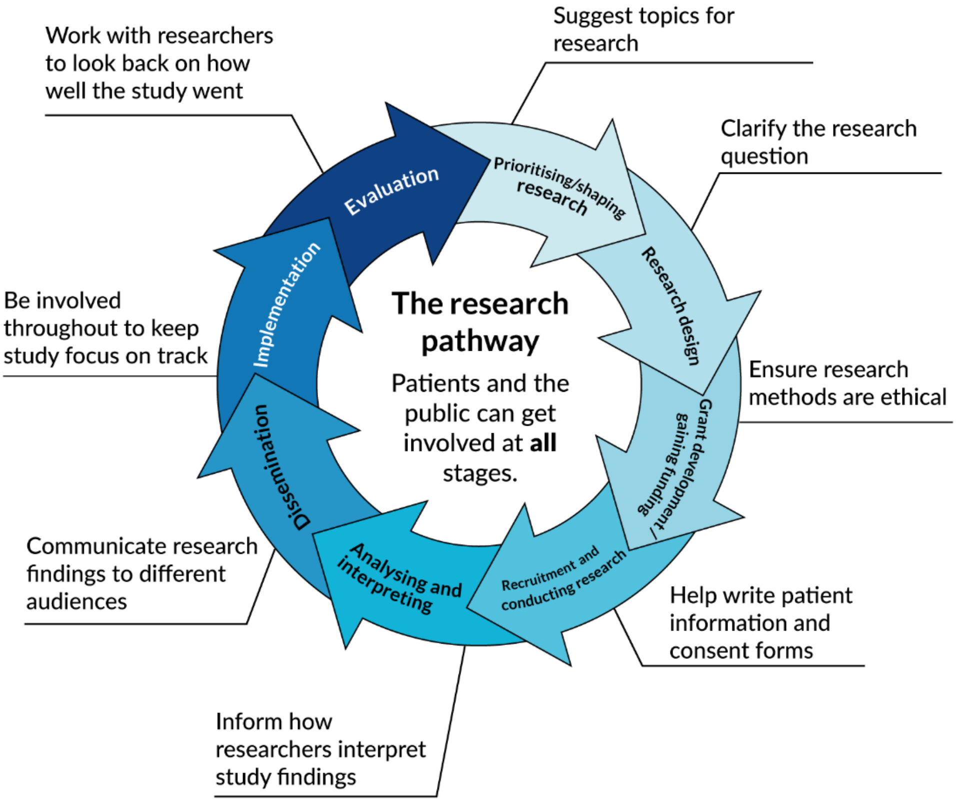

Figure 1 -https://www.medsci.ox.ac.uk/research/patient-and-public-involvement/section-3-ppi-and-the-research-pathway

Checklist for working with public contributors

The following checklist can be used as a guide throughout the research cycle and it's likely you will need to refer back to the checklist as you progress through your research.

It is designed to support both researchers and public contributors, though it is expected that researchers will lead on the completion of the checklist.

The checklist is separated into ten sections, and you may also choose to add your own categories specific to your research area.

Safeguarding

- ☐ I am aware of the policies, have completed the required training, and know what to do if an incident occurs.
- ☐ I have considered where to meet people and the safety considerations.
- ☐ I have told a colleague / supervisor where I am and logged this (where required).
- ☐ I have checked if a risk assessment is required.
  - ☐ If yes, risk assessment checked and signed off by supervisor.

Access, inclusion and equity

- ☐ Have you offered a wider group of people the opportunity to contribute, to ensure that research processes do not exclude people and communities?
  - ☐ If not, note why this is and communicate this. ***For example, you are targeting a particular group.***
- ☐ I have checked everyone is able to access the venue (if in person)
- ☐ I have considered options for in-person, online participation, or via the telephone.

Working in challenging and sensitive areas of research

- ☐ I have considered whether topics might be triggering or difficult for public members / researchers.
- ☐ I have time built in for breaks/ reflection as appropriate.
- ☐ I have made a list of contacts available for support before, during and after sessions.

Confidentiality/ consent/ assent

- ☐ I have set clear guidelines about sharing personal experiences, what will be shared and how it will be used.
- ☐ I have ensured that activities are compliant with the Data Protection Act (2018) / GDPR.
- ☐ I have made sure that everyone knows whether and under what circumstances confidentiality could be breached.
- ☐ I have checked that all team members have appropriate training in data protection.

Agreeing boundaries from the outset

☐ I / we have developed a set of working agreements/terms of reference or ground rules that include expectations about language and behaviour of all people involved.

Communication

☐ I have a plan for ongoing two-way communication throughout.
☐ I have checked whether I need translators / interpreters.
☐ I have booked these in advance.
☐ I have checked that my information is easy to read and accessible.
* ***you can use online tools and guidance to help you or ask for feedback.***

Training and support

☐ I have talked to public members about what training might be needed so they can take part.
☐ I have checked if specialist training is needed for research and the groups they will be working with.

Developing sustainable two-way relationships

☐ I have been clear about the expectations of the relationship with public contributors.
☐ I have given details on the duration of the work and what might happen after the work finishes.
☐ I have considered the impact (positive /negative) on public contributors and communities.

Managing conflict

☐ I have a plan in place for any potential conflict that might arise and how I will manage this.

Valuing public contributors

☐ I have a plan to let people know how their input influenced the work.
☐ Considered and discussed involving people as co-authors/ co-applicants.
☐ There are fair and flexible remuneration policies in place in line with national guidelines.

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