



University
of Glasgow

Research Shaped Together: Code of Practice



Practice Guidelines and Expectations

The following Code of Practice outlines the behaviours, approaches, and standards expected when undertaking patient and public involvement and co-production activities with the community. It aligns with the Six Guiding Principles in the Research Shaped Together: A Scottish Approach to Health Research. While it is recognised that approaches will vary depending on the nature and context of the activity, researchers should be able to demonstrate how they have considered and applied these principles.

These expectations should be understood as a shared commitment between researchers, facilitators, organisations, and community members. The principles and expectations within this Code are intended to guide how we work together, while remaining responsive to community feedback, learning, and ongoing development. They are not intended to be static standards but a shared framework that supports continuous learning, reflection, and improvement.

This Code of Practice has been co-designed with community members, researchers, staff and partners through a series of collaborative workshops and engagement activities. The expectations within this document reflect the experiences, priorities, and recommendations shared by those involved and will continue to evolve through ongoing feedback and review.

1. Safety and Safeguarding

Why this matters:

Everyone involved in Public and Patient Involvement and Engagement (PPIE) should feel safe, respected, and supported. Creating a psychologically, emotionally, and physically safe environment enables people to contribute openly and confidently.

We recognise that discussions may involve personal experiences or sensitive topics, and we are committed to responding with compassion, professionalism, and care.

Community members told us that feeling welcomed, listened to, and respected is essential to building trust and encouraging meaningful participation.

Researchers are expected to:

- Act respectfully, professionally and compassionately at all times
- Recognise signs of distress, discomfort or fatigue and respond sensitively
- Avoid placing pressure on individuals to share personal experiences or opinions
- Understand their safeguarding responsibilities and know how to report or escalate concerns
- Seek advice or support when safeguarding or wellbeing concerns arise
- Maintain appropriate professional boundaries while building positive and trusting relationships
- Be aware of power imbalances and take steps to create equitable opportunities for participation
- Respect confidentiality while explaining any limits to confidentiality where safeguarding concerns require information to be shared
- Continually reflect on their own practice and seek opportunities to improve inclusive and safe engagement

In practice we will:
Create welcoming environments that promote emotional, psychological, and physical safety.
Provide clear information about safeguarding, confidentiality, and available sources of support.
Explain what participants can expect before activities begin, including how information will be used.
Recognise that participation may involve sensitive or emotional discussions and provide opportunities for breaks or additional support where appropriate.
Respect personal boundaries, lived experiences, and individual choices about what participants wish to share.
Ensure everyone can pause, step away, or withdraw from an activity at any time without pressure or negative consequences.
Respond promptly and appropriately to safeguarding concerns or disclosures.
Adopt trauma-informed approaches wherever appropriate, recognising that past experiences may influence how individuals engage.
Regularly check understanding and ensure participants feel comfortable throughout engagement activities.

Safeguarding is everyone's responsibility.

A concern does not need to be a confirmed safeguarding issue before someone seeks advice or support.

If a community member becomes distressed, discloses a concern, or appears to require additional support, the first response should be calm, respectful and non-judgemental.

Where appropriate, researchers should:

- Listen and give the person time and space to explain what they need
- Avoid making assumptions about their circumstances or support needs
- Ask the person what would feel helpful or supportive to them
- Respect their choices about who they would like to involve in supporting them, where this can be done safely
- Consider whether they would like to contact a trusted family member, friend, community representative or another responsible adult
- Provide appropriate information or signposting to health, community or specialist services
- Seek advice or escalate the concern where it is beyond their role, knowledge or training

Researchers should not attempt to provide counselling, clinical advice or specialist intervention unless this forms part of their professional role.

Sources of support

Where appropriate, community members may be supported or signposted to:

- **NHS Inform** for reliable information about health, mental health and available support
- **NHS 24 – 111** where urgent health advice or assessment is required but the situation is not an immediate emergency
- Relevant local community, voluntary or specialist services
- A trusted family member, friend, community representative or other responsible adult
- An appropriate health or social care professional
- **999** where there is an immediate risk to life or a medical emergency

Samaritans can also provide emotional support on **116 123**, free of charge, day or night, 365 days a year. https://www.samaritans.org/scotland/how-we-can-help/contact-samaritan/?utm_source=chatgpt.com

Where possible, we should ask the community member what sources of support are important to them rather than automatically assuming that formal services are the most appropriate option.

When a concern needs to be escalated

Concerns may include, but are not limited to:

- Significant emotional distress
- Concerns about self-harm or thoughts of suicide
- Concerns about abuse, exploitation or neglect
- Concerns about a person's immediate safety
- A person disclosing that they or someone else may be at risk
- Any situation where a member of staff, researcher or facilitator is concerned that someone may not be safe

Where there is an immediate risk of serious harm or a medical emergency, appropriate emergency services (**999**) should be contacted.

Where a concern is not an immediate emergency but there is significant concern about someone's safety or wellbeing, appropriate professional advice should be sought rather than attempting to manage the situation alone.

Confidentiality and information sharing

Community members should be treated with respect and their information handled sensitively.

Researchers should explain, wherever possible, how information shared with them will be used and who may need to know.

Confidentiality cannot always be guaranteed where there is a serious concern about someone's safety, the safety of another person, or where there is a legal or organisational requirement to share information.

Only information that is necessary and appropriate should be shared, and this should be done with the appropriate person or service.

Community Engagement Officer

The Community Engagement Officer can provide an important first point of contact for community members involved in PPIE.

The Community Engagement Officer has relevant training in suicide intervention, self-harm intervention and Scottish Mental Health First Aid, and can provide appropriate initial support, recognise potential concerns and help community members access relevant sources of support.

This role does not replace clinical, emergency, safeguarding or specialist services. The Community Engagement Officer will seek appropriate advice or escalate a concern where it falls outside their role, knowledge or training.

If the concern involves a member of the research team

Community members can raise a concern about any individual involved in the PPIE activity, including researchers, staff, students, facilitators, community members or any other member of the research team.

No individual should be responsible for managing a concern where they are directly involved in the matter being raised.

Community Voice

“Availability of a safe space”

“Familiar faces so invite someone we know”

“Have approachable safeguards.”

Statement:

“Safety is not just about procedures; it’s about how people are treated,”

2. Respectful Communication

Why this Matters:

Effective communication is at the heart of meaningful Public and Patient Involvement and Engagement (PPIE). Respectful communication helps to build trust, strengthen relationships, and ensure everyone feels informed, valued, and able to contribute. We recognise that people come with different experiences, backgrounds, cultures, languages, and levels of confidence, and communication should always be inclusive, accessible, and responsive to individual needs.

Community members consistently told us that they want information to be easy to understand, opportunities to ask questions without judgement, and regular updates throughout the research process.

Researchers are expected to:

- Listen actively, respectfully, and without judgement
- Recognise and value lived experience as an important form of knowledge alongside professional and academic expertise
- Communicate with empathy, kindness, and professionalism
- Avoid language or behaviours that may be discriminatory, dismissive, stigmatising, or intimidating
- Check understanding rather than assuming information has been understood
- Acknowledge questions and contributions meaningfully, ensuring participants know they have been heard
- Welcome constructive challenge, different perspectives, and opportunities for learning and reflection

In practice we will:
Use clear, inclusive, and accessible language, avoiding unnecessary jargon, acronyms, or technical terminology
Explain research concepts, processes, and expectations in plain English, checking understanding throughout engagement activities
Communicate openly about roles, responsibilities, timelines, decision-making processes, and any changes that may affect participants
Provide opportunities for people to ask questions, seek clarification, and share their views in ways that suit them
Be honest and transparent about what can and cannot be influenced through involvement activities
Provide regular updates and feedback so participants understand how their contributions have informed research, policy, or decision-making
Respect confidentiality, privacy, and agreed boundaries during discussions
Adapt communication methods where possible to meet individual accessibility, language, or communication needs
Communicate honestly when plans change, explaining the reasons and any impact on participants

Community Voice

“Feeling listened to matters just as much as being asked.”

“Check understanding.” “Regular updates and feedback.”

“Acknowledge contributions.”

“No Jargon.”

Statement:

“Respectful communication is fundamental to building trusted relationships and creating research that is inclusive, transparent, and shaped by the communities it serves.”

3. Inclusion and Accessibility

Why this matters:

Meaningful Public and Patient Involvement and Engagement (PPIE) can only happen when people have fair and equitable opportunities to take part. We recognise that barriers to participation are not the same for everyone and may include physical, sensory, communication, cultural, financial, digital, language, or personal circumstances. By considering accessibility and inclusion from the outset, we can create opportunities for a broader range of people to contribute their knowledge, experiences, and perspectives.

Community members told us that inclusion means more than being invited, it means feeling welcomed, understood, supported, and able to participate in ways that work for them.

Researchers are expected to:

- Discuss access and communication needs respectfully and without making assumptions
- Adapt engagement approaches wherever possible to meet the needs of participants
- Recognise that people communicate, process information, and participate in different ways
- Create supportive opportunities for quieter, less confident, or seldom-heard voices to contribute
- Use inclusive, respectful, and culturally sensitive language. See Appendix C- Language Use in Community Engaged Research.
- Avoid practices that may unintentionally exclude, disadvantage, or marginalise individuals or groups
- Reflect regularly on whose voices may be missing from discussions and consider how these perspectives can be included
- Recognise that inclusion is an ongoing commitment requiring continuous learning, reflection, and improvement

In practice we will:
Consider accessibility and inclusion from the earliest stages of planning, rather than as an afterthought
Identify, discuss, and reduce barriers to participation wherever reasonably possible
Offer flexible and varied opportunities for people to participate, recognising that one approach will not suit everyone
Provide accessible materials, formats, and communication methods wherever possible, using plain English and alternative formats where needed
Discuss individual access requirements respectfully and make reasonable adjustments wherever practicable
Consider practical barriers such as transport, childcare, caring responsibilities, timing, digital access, and financial costs when planning engagement activities
Recognise and respect cultural, social, economic, and individual differences that may influence participation
Actively seek to involve communities and individuals whose voices are often underrepresented in research
Regularly review engagement approaches to ensure they remain inclusive and responsive to community needs

Community Voice

“Make it easier to understand.”

“Meet people where they are.”

“Offer different languages, styles, fonts, apps and digital technologies”

Statement:

“There is no single ‘right’ way for people to participate.”

4. Researcher Conduct and Competencies

Why this matters:

Meaningful Public and Patient Involvement and Engagement (PPIE) relies on trust, relationships, and mutual respect. The attitudes, behaviours, and competencies of researchers, staff, students, and facilitators play a significant role in shaping people's experiences of involvement. We recognise that lived experience and community knowledge are forms of expertise, and meaningful collaboration requires openness, reflection, accountability, and a willingness to learn.

Community members told us that genuine involvement is built through honesty, consistency, and respectful relationships. They also highlighted that trust can be lost when people feel their involvement is tokenistic or when researchers fail to follow through on commitments.

Researchers are expected to:

- Act with integrity, honesty, transparency, and professionalism
- Recognise lived experience as expertise and value community knowledge equally and respectfully
- Build trust through consistent, respectful, and reliable engagement
- Communicate honestly about what can and cannot be influenced within a project or decision-making process
- Avoid over-promising or creating unrealistic expectations
- Be open to feedback, challenge, and reflective practice, recognising that learning is an ongoing process
- Acknowledge mistakes, respond constructively, and take responsibility where improvements are needed
- Undertake relevant training and development where appropriate, including safeguarding, inclusion, accessibility, trauma-informed practice, and culturally responsive engagement
- Recognise that meaningful involvement requires time, preparation, and sustained commitment
- Respect the time, knowledge, and contributions of community members and acknowledge these appropriately

In practice we will:
Promote ethical, reflective, and community-informed approaches to involvement, engagement, and co-production
Recognise and actively address potential power imbalances within research relationships
Value lived experience and community knowledge alongside academic, clinical, and professional expertise
Support ongoing learning, training, and development for researchers, staff, students, and facilitators
Recognise relationship-building as an essential part of meaningful involvement and co-production rather than an additional task
Encourage openness, honesty, accountability, and shared decision-making wherever possible
Create opportunities for reflection, feedback, and continuous improvement throughout projects
Promote a culture where community members feel respected, valued, and able to challenge or question decisions safely

Community Voice

“Relationships come before research.”

“Don’t just ask us—work with us.”

Statement:

“People can tell when involvement is genuine and when it is tokenistic.”

5. Accountability and Feedback

Why this matters:

Meaningful Public and Patient Involvement and Engagement (PPIE) depends on trust, transparency, and accountability. Community members have a right to know how their time, experiences, and contributions have influenced research, decisions, and outcomes. Providing regular feedback demonstrates respect, strengthens relationships, and helps build confidence that involvement has made a difference.

We recognise that not every suggestion can be implemented. However, we are committed to being open and honest about decision-making, explaining the reasons behind decisions, and ensuring participants understand how their voices have been considered.

Community members consistently told us that closing the feedback loop is one of the most important aspects of meaningful involvement.

Researchers are expected to:

- Follow through on agreed actions and commitments wherever possible
- Communicate updates in a timely, honest, and transparent manner
- Acknowledge mistakes, learn from them, and take appropriate action to improve future practice
- Respond constructively, respectfully, and professionally to feedback, concerns, or complaints
- Recognise that accountability includes explaining decisions as well as celebrating successes
- Ensure participants know how to raise concerns and where to access support if required
- Contribute to a culture of continuous learning, reflection, and improvement across involvement and engagement activities
- Recognise that meaningful feedback is an ongoing conversation, not a single update at the end of a project

In practice we will:
Provide opportunities for ongoing feedback, reflection, and shared learning throughout involvement activities
Explain how community contributions have informed research, policies, services, or decision-making wherever possible
Communicate openly when suggestions cannot be implemented, providing clear explanations for decisions
Provide regular updates throughout projects so participants understand progress and next steps
Recognise and celebrate the contributions made by community members and partners
Review involvement practices regularly to identify opportunities for learning and continuous improvement

Ensure concerns, complaints, or compliments can be shared safely, respectfully, and without fear of negative consequences

Use feedback from community members to improve future involvement and engagement activities

Community Voice

“What do you do with our feedback and the results?”

“Regular updates and feedback.”

“Show the Journey over 6 months, a year, with regular updates and evaluations – did it make a difference?”

Statement:

“People want to know what changed because of their involvement.”

6. Community Partnership

Why this matters:

Meaningful Public and Patient Involvement and Engagement (PPIE) is built on genuine partnerships between researchers, communities, and organisations. Partnership working is more than consultation, it is about sharing knowledge, influence, responsibility, and decision-making wherever possible. By working together from the earliest stages of research, we can develop more relevant, inclusive, and impactful research that reflects the priorities, experiences, and expertise of the communities it aims to benefit.

Community members told us that meaningful partnership is based on trust, mutual respect, shared ownership, and long-term relationships rather than one-off engagement activities.

Researchers are expected to:

- Work collaboratively, respectfully, and equitably with community members and partner organisations
- Recognise and actively address power imbalances within co-production and decision-making processes
- Support shared decision-making wherever appropriate, recognising that different projects may involve different levels of participation
- Value lived experience as expertise and recognise the unique knowledge that communities bring to research
- Remain flexible and responsive to community priorities, feedback, and changing circumstances
- Avoid tokenistic, extractive, or transactional approaches to involvement and engagement
- Invest time in developing trusted relationships before, during, and after research activities
- Recognise that successful co-production requires openness, humility, mutual learning, and shared responsibility

In practice we will:
Involve communities as early as possible in project planning, design, delivery, evaluation, and decision-making
Support collaborative and shared approaches throughout the research journey wherever possible
Recognise community members as equal partners whose lived experience and local knowledge are valued alongside academic, clinical, and professional expertise
Acknowledge, recognise, and value contributions fairly, meaningfully, and in line with agreed payment and recognition guidance
Promote long-term relationship-building rather than one-off consultation or engagement activities
Create opportunities for shared learning, mutual benefit, and capacity building for both researchers and communities
Work openly and transparently to develop shared goals, expectations, and responsibilities
Ensure community perspectives continue to shape projects throughout their lifecycle, not only at the beginning

Community Voice

“Work with us, not for us.”

“Build relationships before you build research.”

Statement:

“Co-production means sharing power, not simply sharing opinions.”