

Working with PEDRI Community Connect organisations

A guide for researchers

PEDRI Community Connect helps researchers connect with community organisations that may be interested in supporting patient and public involvement and engagement (PIE) in data research.

Community organisations have existing relationships with the people and communities they support. These relationships are built on trust and often over many years. When approaching an organisation through Community Connect, researchers should respect this relationship and aim to build meaningful, mutually beneficial involvement.

This guide explains what to consider **before making contact, when approaching an organisation, and throughout your work together.**

1. Check that the organisation is a good fit

Before contacting an organisation, **read its Community Connect information carefully.**

Consider:

- Does your research align with the communities the organisation works with?
- Does it align with the organisation's interests and priorities?
- Is the type of involvement you are looking for something the organisation has said it can support?
- Are there particular accessibility, communication or practical needs you should consider?

Please do not send the same general request to multiple organisations without considering whether your project is relevant to each one.

Community organisations often have limited capacity. A targeted and thoughtful approach helps organisations decide whether an opportunity is right for them and their community.

2. Involve communities as early as possible

Where possible, involve people **before important decisions have already been made.**

Community involvement can help researchers:

- develop or refine research questions
- identify priorities that matter to communities
- design accessible and inclusive research

- review research materials
- identify potential barriers to participation
- interpret findings
- decide how findings should be communicated and shared.

Think about where you are in your research and where community involvement can still have a meaningful influence.

PIE should not simply be added to a project after the main decisions have been made.

For example, if you are working within data research [this guide from the NIHR Imperial Biomedical Research Centre suggests](#) outlines different ways public members could have influence on each stage of the research cycle.

3. Be clear about what you are asking for

Before approaching an organisation, decide what kind of involvement you are looking for.

For example:

Co-creation or co-production

Working with community members across several stages of the research.

A one-off PIE session

For example, discussing a research question, reviewing materials or providing feedback on an aspect of the project.

A Public Advisory Group

Establishing a group that contributes to the research over a longer period.

Consultation or feedback

Asking people to comment on a particular question, resource, finding or decision.

Be realistic about what community members can influence. Clearly explain where decisions are still open to change and where they are not.

4. Plan for the resources involvement requires

Meaningful community involvement takes time and resources.

Before making contact, consider:

- What funding is available for PIE?
- Can community members be paid or reimbursed for their time?

- Are there costs for travel, accessibility, interpretation or other support?
- Does the community organisation require funding for staff time or coordination?
- How much time will people need to participate?
- Have you allowed enough time for the organisation to plan and recruit people?

Where appropriate, researchers should offer **payment, reimbursement or other appropriate recognition** for people's contributions.

Community organisations may be busy or have limited staff and resources. **Contact organisations with as much notice as possible.**

5. Make your first approach clear and simple

Your first email does not need to explain every detail of your research.

Community organisations have told us that **too much information can make an opportunity harder to understand and consider.**

Start with a short, accessible overview.

Your first email should include:

☐ **Who you are**

Your name, organisation and role.

☐ **How you found them**

Explain that you found the organisation through **PEDRI Community Connect.**

☐ **A short description of your research**

Explain what you are researching and why in plain language.

☐ **Where you are in the research process**

For example: developing a funding application, designing the research, recruiting, analysing data or sharing findings.

☐ **What kind of PIE you are looking for**

For example: co-production, a one-off session, reviewing materials or establishing a Public Advisory Group.

☐ **Why you are approaching this organisation**

Explain why their community's experience or perspective is relevant to your project.

☐ **What you would like them to do**

Be specific about the involvement you are asking for.

☐ **The expected time commitment**

Include the number and approximate length of meetings or activities where possible.

☐ **Your timescales**

Explain when you would like involvement to happen and whether there are any deadlines.

☐ **Payment and resources**

Explain what funding, payment or reimbursement is available.

6. Make involvement accessible

There is no single approach that will work for every community.

Ask the organisation and community members what they need to participate. Do not assume.

Depending on the community, this might include:

- Easy Read information
- plain English and avoiding technical language
- translated materials or interpretation
- accessible venues
- online, face-to-face or hybrid options
- additional time to read information and make decisions
- breaks during meetings
- different ways to contribute
- support from a trusted person
- meeting people in familiar community settings.

For example, some people with learning disabilities may need Easy Read materials, additional time and support from someone they know well. Some people may also experience digital exclusion, meaning online involvement is not always accessible.

Where possible, **adapt the research process to the community rather than expecting the community to adapt to the research.**

7. Work through trusted relationships

Community organisations often have established, trusted relationships with the people they support.

Listen to their advice about the best way to approach and involve their communities.

Where appropriate, this may mean:

- working through existing community groups
- holding activities in familiar community spaces
- asking trusted staff to introduce researchers
- adapting your engagement approach based on the organisation's experience.

Researchers should avoid assuming that access to an organisation automatically means access to its community.

Trust needs to be respected and maintained.

8. Make involvement meaningful

People should understand **why you are asking for their involvement and what will happen because of it.**

Throughout the project:

Explain → Listen → Act → Feedback

Explain what you are asking and why.

Listen to what people tell you.

Act on their contributions where possible.

Feedback what changed—or explain why something could not be changed.

PIE should be an ongoing relationship rather than a one-off transaction.

9. Close the feedback loop

Do not let communication stop once an involvement activity has finished.

Tell community members:

- what you heard from them
- what you changed as a result
- what you could not change and why
- what happened next in the research
- what the research eventually found.

Think about how findings can be returned to the community in an **accessible and useful format**, rather than only through academic publications.

Remember

Community Connect is about building meaningful connections, not simply recruiting people to research.

Approach organisations early, be clear about what you are asking, respect their expertise and existing relationships, and make sure that people's contributions have a meaningful opportunity to influence your work.

Before you contact a Community Connect organisation

Use this quick check:

- ☐ I have read the organisation's Community Connect information.
- ☐ My research is relevant to the organisation and the communities it supports.
- ☐ I know what stage my research is at.
- ☐ I can explain my research briefly and without technical language.
- ☐ I know what type of PIE I am asking for.
- ☐ I can explain why I am approaching this particular organisation.
- ☐ I have identified what community members will genuinely be able to influence.
- ☐ I have considered the time and resources the involvement will require.
- ☐ I can explain what payment, reimbursement or funding is available.
- ☐ I have allowed sufficient time for the organisation to consider the request.
- ☐ I am prepared to adapt my approach to make involvement accessible.
- ☐ I have a plan for feeding back what happens as a result of people's contributions.