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Research for All

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Practice case study

A community-based approach to public involvement in research

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Peer review

This article has been peer-reviewed through the journal's standard double-anonymous peer-review, where both the reviewers and authors are anonymised during review.

Abstract

Our practice case study focuses on involving members of the public in research, including those with little interest in the topic being researched. We begin by describing standard guidance on public involvement, noting that it often takes place when people move out of the places and relationships in which they spend most of their time. Public involvement guidance often talks about establishing 'a formal patient or public panel' and using 'patient support groups'. Our case study describes a different model: public involvement that happens in the settings and groups where people meet in their everyday lives. We call this 'community-based public involvement'. The main part of our paper describes this approach and reasons why the research team chose it. We also discuss how they went about it. Those involved then give their feedback: the members of the communities, the public involvement lead and the wider research team. We conclude by encouraging wider use of a community-based model of public involvement.

Keywords public health; climate change; public involvement and engagement; survey design

Key messages

- Public health research requires innovative public involvement approaches.
- Public involvement in everyday settings – where people work or meet socially – creates opportunities to reach different parts of the population, including people who are not interested in the research topic.
- Public involvement in such settings can be a mutually beneficial activity.

Introduction: why a different approach to public involvement?

Our practice case study focuses on public involvement in research. The principle of public involvement is widely accepted by researchers, research funders and policy makers. It has its origins in a recognition that service users should be actively involved in decisions about the services they receive (Boote et al., 2002; Fitzgibbon et al., 2014). As the UK's 2005 research governance framework put it, research needs to be conducted with 'the active involvement of service users' (Department of Health, 2005). There are strong ethical arguments for such involvement – it is important in its own right, particularly for publicly funded research, and there is evidence that it can enhance the quality of research (Gradinger et al., 2015).

In the UK, the term 'patient involvement' has given way to 'patient and public involvement'. However, although the concept of 'involvement' has been widened to include the public, the orientation to service users remains. For example, the UK's major health research funding body notes that 'when using the term "public" we include 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' (NIHR, 2021). The guidance continues with advice on 'inclusive locations', with universities and hospitals as the first-mentioned settings. Other guidance on public involvement has a similar bias towards models developed for involving patients in research. For example, advice on 'how to involve people in your research' includes 'via patient support groups', 'running a survey or interview in a setting where your target audience may be found e.g. clinic waiting rooms' and establishing 'a formal patient or public panel' (Imperial College Public Experience Research Centre, 2024).

As others have noted, there are problems with these standard models of public involvement (Bunton, 2008). While the guidance does not exclude public involvement being integrated into people's everyday lives, the suggestions for 'how to involve people' tend to rely on engaging people when they move outside the settings and relationships in which they spend most of their time. Rather than researchers going to the places where people live and work, contact is made with members of the public when they move into formal and/or patient-related settings ('clinic waiting rooms', 'a formal panel', 'patient support groups').

This approach may work for research involving some groups of patients. However, it does not fit well when research is focused on the general population. When such research does not concentrate on a particular health condition or patient group, there are no obvious (groups of) people for the researcher to approach. Moreover, such research may seek to understand the views of people who are not particularly interested in the research topic, or research in general, and who are therefore unlikely to volunteer to take part in, for instance, a survey or public involvement panel. Therefore, there are no obvious ways for the researcher to get in contact with suitable public contributors.

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A different approach to public involvement

This research is concerned with how the public thinks about climate change and health, including those who may not have thought much about climate change (NIHR Public Health Policy Research Unit, 2024). There were two surveys of UK adults: exploring people's concerns about climate change (Survey 1) and people's views on policies to tackle climate change (Survey 2). The research team wanted to involve members of the public to help design the two surveys. The team aimed to involve people in the everyday settings in which they live and work.

Public involvement aims

This community-based approach to public involvement (PI) – rather than, for example, a more conventional PI focus group – was chosen because it was better suited to the project's public involvement aims. These were:

1) Gathering information from people without their needing to leave the places and groups of which they were a part.
2) Involving people who may not usually be involved in research and may not have a particular interest in climate change.
3) Speaking with people from different ages, genders and social backgrounds in both urban and (semi-)rural areas.
4) Asking open and closed questions in quick (approx. five-minute) one-to-one conversations.

Finding community groups

To achieve their aims, the team wanted to approach community groups: groups of people who meet regularly around work or a common interest. Before the research team approached community groups, the research team's public involvement lead (PI lead) sought advice from a climate emergency officer at a local authority. This person had used a similar approach for a public consultation on a climate strategy. They confirmed that they had found it an effective way to reach people who are usually not involved in consultations.

Making connections with the kind of groups that would – collectively – fit with the project's aims and would be interested and available to talk with the PI lead was the biggest challenge. The research team already had a connection with a community hub. For other connections, the team relied on the PI lead's personal and professional networks. The research team learned that the search for community groups required:

- Thinking carefully about (hidden) opportunities in existing networks – who can help connect with whom?
- Building on existing strong connections – i.e. personal and close ones. They provided a shortcut to many communities and enabled the PI lead to ask for introductions through her network.
- Helping contacts to pass on information effectively while minimising the burden on them. For example, the PI lead provided a written document about the research, public involvement and questions in order to help people and groups to discuss the request.
- Researchers' flexibility: the PI lead was prepared to be flexible and meet with people in communities when it suited them best, for example on Sundays or at short notice.
- Time – not every lead materialised.
- Going with the flow – the PI lead did not quite know a group's make-up and the setting until arrival for the first meeting.

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Three community groups became involved in the research, along with some members from the PI lead's personal network. The community groups were:

- Members of a church congregation in a village (during tea and biscuits after their church service).
- Staff at a community nursery in a town (during work).
- Members of a knitting group in a community cafe in a city (during their meeting).

Meeting with community groups

The PI lead had three rounds of meetings with the groups.

- Round 1 (March 2023): to find out what people think about when they think about climate change. Thus, the community-based input provided starting points for developing Survey 1 about how the public thinks about climate change and health.
- Round 2 (July 2023): to check how the main worries that were to be covered in Survey 1 resonated with people, and how they thought about them in terms of space and time.
- Round 3 (February 2024): to develop Survey 2, which focused on shaping climate change policies. People were asked what topics the policies should focus on, whether to formulate policies as threats or opportunities, and how policies should be paid for. During Round 3, the PI lead also asked for feedback on the public involvement approach.

All visits were arranged with the community leader (i.e. the vicar, the nursery manager and the chief executive of the development trust) who conveyed information to the community members. In each round of meetings, around 35 people were involved. Before each meeting, the team prepared:

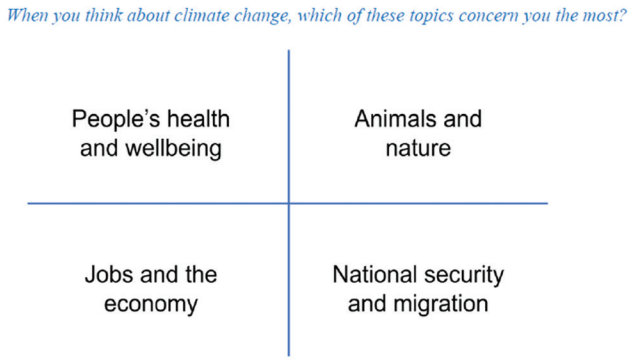
- A very brief plain English narrative about the (progress of the) research, the reason for asking the questions as well as any impact PI had had on the research so far.
- A set of open and closed PI questions that could be covered in a five-minute conversation. The same questions were asked across each group (see Figure 1).
- Any documents that would aid the conversation, such as a project summary and an overview of the topics respondents were asked to rank (see Figure 2). These were laminated or held together in a folder because conversations were conducted in many different ways. For example, while drinking tea, while standing up, or while sitting on a tiny chair among playing toddlers.

Figure 1. Questions asked during meetings with members of the communities (Round 1, March 2023)

Questions for public contributors

- *Do you ever think about climate change? And if so, how often?*
- *When you hear the words 'climate change', what is the first thing you think of?*
- *When you think about climate change, what do you think or worry about the most? And why?*
- *What inspires or spurs you on the most to take steps to help slow down climate change?*
- *Is it important to you to know what you can do to help slow down climate change?*
- *Where do you find information?*

Figure 2. Overview of topics community members were asked to rank, starting with the topic that concerned them the most in the context of climate change



To make authentic, open conversations possible, the PI lead focused on building further trust and rapport with each community (NIHR, n.d.) This included:

- Bringing biscuits as a token of appreciation.
- Showing interest in the work or activity (for example, attending the church services).
- Wearing a work badge.
- Stressing that the conversations were not mandatory.
- Trying to put people at ease.
- Respecting their views.

The PI lead took notes during the conversations and recorded them in a PI log afterwards. She also wrote down reflections after some of the meetings to process learning experiences. The PI lead created presentations to report on PI during the monthly team meetings. She also ensured community groups received financial reimbursement for their involvement.

Feedback from the community groups

During the third and final round of public involvement, the PI lead asked the community leaders and members for feedback on the public involvement approach. This feedback was positive and indicated that there were mutual benefits.

Community leaders said they had agreed to being involved because they saw it as a learning opportunity for their community and because they felt grassroots involvement is important. All were happy to be involved in future research. Their comments included:

> Like lots of churches, we try to be more environmentally aware and friendly. It was an opportunity for us to learn and get us thinking.

> It's important for our staff to be aware, because they're expected to teach children about basic values such as recycling and picking up litter.

> The community voice is often overlooked.

What the community members said confirmed that their involvement had indeed been a learning opportunity for them. Some were not sure what climate change meant and others said it helped them see the bigger picture of climate change. For example, one person said:

> I enjoyed the conversation. It helps me understand more about climate change.

Some people mentioned that it was important to talk to 'people on the street'. They felt community visits were an effective way to encourage public involvement and that the format was helpful too. They said, for example:

> If you had put on a meeting, we wouldn't have come. If you were on the telly, I would have turned you over. I would have thought: I've heard it all before. But you got us here, and we can't get away! I enjoyed it. It got me thinking.
>
> During the conversations, I could see that people were smiling and their body language looked comfortable. It's what we need: gentle conversations. And then you came back and told us how the research was progressing. So then we felt part of a process.
>
> It's nice to have a conversation without it being an argument.

Impact of the approach on the research team and research project

The PI lead felt privileged and honoured to meet and speak with people in the places where they work, worship and spend their leisure time. At the same time, the relative unfamiliarity with the groups, and therefore unpredictable nature of the conversations, combined with a sense of responsibility for the interpersonal dynamics, pushed the PI lead out of her comfort zone.

The conversations had a range of important impacts on the design of the research. It enabled the research team:

- To gain a feel for what climate change means to people of different ages, genders, places and backgrounds in the UK. This helped determine the content of the two project surveys.
- To test different formats for the multiple-choice questions about climate change concerns and policy options. It confirmed the importance of including options such as 'not sure' and 'no opinion'.
- To check how response options resonated with people. For example, one question asking about people's concerns about climate change included 'National security and migration' (see Figure 1). People felt it was vague and/or politically laden. The category was therefore split into: 'Migration (people having to move)', 'Social unrest or social tension', and 'Vital resources (such as water, food, energy)'. These evoked much stronger responses among public involvement contributors and were incorporated into the surveys.
- To appreciate that people often mentioned current headlines when talking about climate change. As a result, the project was extended to include a study of coverage of climate change and health on social media. The surveys also asked what, if any, social media the survey participants used (e.g. Facebook, TikTok, Twitter etc).
- To realise that some of the survey questions were unclear. The wording of the surveys was changed to improve readability.
- To build connections with community groups that could benefit future research projects.

Studies have found that, through discussion, people can engage their friends and family in a positive feedback loop that encourages deeper engagement with the issue of climate change (Stevenson et al., 2019; Valdez et al., 2018). Feedback from one community group confirmed that the PI lead's community visits had sparked further engagement:

> It opened up a lot of discussions among the staff team about what climate change actually means, and also what little things we as an educational setting can do to promote and help from a young age.

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Conclusion

By working together and writing this practice case study, it became clear that the research team had achieved its public involvement aims, with the two surveys informed and guided by members of the public. The model of community-based public involvement illustrated that it is possible to involve people who may not necessarily be interested in a research topic. It is possible to engage in brief conversations that minimise the burden on these contributors. And it is possible to elicit meaningful input from members of the public in this way. Moreover, the study's authors demonstrated that a community-based and conversation-based approach was valued by community members as well as the research team.

Our practice case study provides what the research community calls 'proof of concept' and 'proof of principle': a small-scale model that demonstrates the feasibility and value of an approach. The research team and the community leaders are keen to continue the model in further projects.

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Declarations and conflicts of interest

Research ethics statement

This practice case study describes an approach to public involvement. Public involvement does not require ethical approval but does have Standards for Public Involvement. These Standards were taken in consideration in the development of the approach. The PI input informed the design of a PH-PRU study that had received ethical approval.

Consent for publication statement

Not applicable to this article.

Conflicts of interest statement

The authors declare no conflicts of interest with this work.

Declaration of generative AI use

We used AI to suggest edits to the questions to improve readability, which helped us improve our approach.

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