

The Listening Series: including everyone in public engagement with research

Guidance for researchers

The untold wealth
of untold stories
from unheard people
in unregarded places...

Ian McMillan, 2020. @IMcMillan

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Introduction

The fundamental purpose of engaging and involving the public and patients with research is to help ensure that our work is both widely understood by non-academic audiences, and importantly, underpinned by real-life experiences so it is relevant to society. In addition, people who are affected by the outcomes of research and who may be funding it through taxation, have the right to a say in it. Indeed, organisations that fund research increasingly require detailed plans for public engagement and involvement.

However, there are numerous barriers - structural, social, economic and practical - that can prevent people from engaging. This can mean, for example, that those affected by social and economic deprivation, people from ethnic minority groups, and those living with disabilities, are less likely to take part in conversations about research, attend research-related events, join advisory groups or enrol as research participants.

As researchers and PPI representatives from the NIHR Policy Research Unit in Maternal and Neonatal Health and Care (NIHR PRU-MNHC) based in the National Perinatal Epidemiology Unit (NPEU), we wanted to find out how to increase the engagement of people who are currently under-represented in Oxford Population Health research. We invited 20 people to take part in five online discussions. The discussions were centred on research carried out at the NPEU.

What is public engagement and involvement?

In line with all Oxford Population Health's public engagement and involvement work we followed the University of Oxford's broad definition of Public Engagement with Research (PER). This describes public engagement as the exchange of information, knowledge and ideas, between research communities and the public around the design, conduct and dissemination of research. The purpose is to inform and inspire lay audiences about research, consult and listen to public views about research and collaborate with them to do research. We are also guided by the National Institute for Health Research (NIHR) definitions of involvement, where 'research is carried out "with" or "by" ... the public rather than "to", "about" or "for" them', and participation, 'where people take part in a research study'. Engagement and involvement can happen in numerous ways – for instance, through events, media content, advisory groups, discussion groups and one-to-one.

The participants were individuals and representatives of:

- community groups working with parents of Black and South Asian ethnicity
- teenagers
- fathers
- parents living with physical or learning disabilities
- those affected by social and economic deprivation.

Although the discussion focused on the NPEU's work, the main messages we identified are generalisable across population health research. We have summarised these messages as 'themes' in this guidance and the accompanying [Listening Series video](#). We have also included some suggestions about how to put these into practice.

Themes

We identified five themes from the Listening Series discussion groups. Some of these are relevant to individual research projects, while others may be more relevant at a strategic level. All relate to public engagement in its broadest sense. Some may help you when thinking about how to find the right people to get involved with your project, for example as public and patient representatives (PPI representatives). Some may also help with thinking about how to increase diversity and equity in actual participation with a research project, although this is not the primary focus of this guidance.

Theme 1 - Build trust

Relationships are at the heart of all good public involvement. This is even more important for people who may mistrust anything they perceive as part of the establishment, who may not see the relevance of research to their lives, or who are simply not interested in research. Building these relationships takes time, but ultimately can be very rewarding for everyone. Here are some ideas to get you started:

- Begin by asking your research group lead, colleagues or your department's public engagement lead about any relevant **established networks or relationships** they have with organisations or individuals. They may be able to introduce you to people they have worked with before so you can 'inherit' a level of trust. They can also give you guidance about what the group or individual is likely to need so they are able to engage meaningfully.
- Write a **short informal piece about yourself and your work** on a relevant blog site. For example the [PRU-MNHC blog](#) or your department's blog site, or social media platform, such as Facebook. You can then share this with new contacts. You could also prepare and forward this in an email or print out to give to people. Many members of the public know very little about health research and what a researcher does. They may need to know more about you and what you do, in simple language, before they commit to anything.
- Identify and work with **trusted intermediaries**, such as people running social support, or peer support programmes for people at risk of poor health outcomes or those who feel isolated. These intermediaries are 'experts' in their areas. They have the trust of the people they represent.

'People in these "hard to reach" communities, at the end of these policies, want change more than anyone else, and you've got the researchers who want to do the research. We really need to get that middle bit right, because that's what's causing the bridge and the divide.'

Agnes Agyepong, Maternity Voices Partnership, Guys and St Thomas'



- To connect with people who may not reach out to organisations or support programmes is a challenge. Having a chronic health condition, being the parent of a small child, and living on a low income can all contribute to people being isolated and effectively 'hidden'. You may be able to **enlist the help of healthcare professionals**, such as GPs, nurses and those treating chronic conditions who have a long-term relationship with their patients.
- **Personalise invitations and adverts** for specific groups. People who feel excluded or on the margins of society often assume their input isn't wanted. Even if your research concerns the whole population, you might need targeted invitations for people with disabilities or chronic health conditions, for example. The same applies when presenting results to the general public; be clear about who the results apply to and how they could be of use to people from different backgrounds.
- **Be prepared to listen and respond appropriately** to people's personal experiences. People who already feel marginalised can easily feel dismissed or disregarded, so you need to have the skills to reassure them that their story is important. You need to allow time to hear those stories, as many people will have a deep need to share them before they can contribute more generally on a topic. As part of a long-term plan, look into getting some training in active listening skills.
- **Keep in regular contact (every month or two)** with people involved in your research, depending on the project. Make it clear those are your timelines for updates. Even if there hasn't been much (or any) progress on a project, let people know. You are giving them an insight into how the research process works and will ensure they don't feel you have forgotten or lost interest in them.
- **Plan what you are going to do when your project comes to an end.** One of the specific issues mentioned was that individuals and groups often felt 'dropped' by researchers once they had got the input they needed. If these are new contacts, are they happy to be added to a department database or have their details passed to your colleagues? How will you communicate your findings and appreciation of their input? Ask them how they would feel if you got in touch at a later date about different work.
- **Volunteering for a group or organisation** linked to your primary research interest is a longer term strategy that could lead to new contacts and unexpected insights. Be prepared to need to demonstrate your commitment before gaining people's trust to prevent them from feeling 'used'.



Theme 2 - Include us from the beginning

Involving people from the start of a project is important to demonstrate that their input is valued. People in the Listening Series told us they sometimes felt 'exploited', that they were only being 'brought out' when it was convenient to the researchers. People who get involved want to be partners in the research process, so including them in early discussions and meetings is an important foundation for building trust.

Early input also helps to gather perspectives and insights that will make your research more reflective of people's lived experiences. Ideally, involvement should start at the grant application stage. Indeed, some funders now require this. But if this isn't possible, then try to involve people in the first official project meeting. Keep notes of suggestions from your stakeholders, along with details about why they can, or cannot be acted upon, and share these with them. To help you get started early:

- If your department runs a **public advisory group, or patient panel**, get in touch with the panel coordinator to find out if this panel, or some of its members, might be useful for your research.
- Go to your **trusted intermediaries at relevant organisations** to help put you in touch with people who might want to get involved with your research. This could be through their social media channels. They will have suggestions about what information, and in what format, their members and followers are likely to respond to. They can help to share information throughout the life cycle of a project.
- You could host some **online information sharing events** for specific groups that you want to engage and involve. Again, tap into relevant external organisations, intermediaries and contacts to help you build an audience for your events.



Theme 3 - Show us impact

People may not have much time, but they do want change. Showing them how your work has made a difference is critical to catching their interest. Impact can be felt in a variety of ways, from comments which shape the research design, participant recruitment materials and surveys, to the impact the research results have in helping change policies and health care. There's also the individual impact that being engaged and involved has on people's personal or professional lives - whether they are members of the public or researchers.

'There's a feeling that you're giving information and it goes into a rather large pit and you never hear anything more. So illustrating something simple like: "You said, we did", something that shows what you said was important, we listened and we were able to act on it.'

Sue Pettigrew, St Michael's Fellowship

- **Prepare examples** of how your work has previously fed into, or could feed into, a larger programme and how that could result, in changes to policy and guidance or treatment. Choose examples that are likely to interest your audience. For example, when we talked to a group of fathers, they wanted to see references to the importance of including them in maternity care. Other groups and individuals might be more interested in work that's specific to their location, or that could bring positive change for their friends, family and community.
- Involve public contributors when you **think about the impact** of your work. Discuss your research questions with the individuals and groups who are likely to be affected by it and ask for their ideas when sharing the eventual results. They know what people like them are likely to respond to and this, in turn, may lead to you expanding your questions or producing more popular resources.
- When working directly with PPI representatives, at the end of each meeting or consultation **summarise the key points and write a brief response** to each one. Even if you can't implement a suggestion, explain why not and perhaps suggest other avenues. This is also a useful record to have when writing up your research for publication. Some journals now request details of PPI input on a project using specific formats, such as the guidance for reporting public and patient involvement tool - [GRIPP2-LF or SE](#).
- Reporting the outcome of work using formats such as ["You Said, We Did"](#) displays, either online or in reality, are popular for work, including health services, that has been co-produced between organisations and the public. Discuss with your colleagues and manager what you could do as a group to describe how your research feeds into service change? Does your department have a website or another online platform where you could publish something similar?



Theme 4 - Use communication that is clear and appropriate for each audience

What you think is plain language probably isn't. Some part of your audience might have a low reading age, or English may not be their first language. In addition some of your audience may be visually impaired, or have hearing or learning difficulties. Your work needs to be accessible.

- **Keep sentences and words short and simple and use lots of images.** Of course, make sure that if you use pictures of people, they are appropriate and represent the diversity of the population. If you are asking organisations to share something on social media, supply your message in an image as a JPEG file. Keep your message short and simple and include a clickable link to a website where people can find more information.

'Using innovative ways, like an animation, is a fantastic way of communicating key messages. Presenting the findings in an academic abstract doesn't convey messages to the public in the same way.'

Celia Suppiah, Parents1st UK

- Explore using **infographics, videos, podcasts and storytelling**, especially for the dissemination of results. Make sure you have budgeted for this.
- Remember that **to be accurate you may have to be more descriptive**. For example, in maternity research literature some writers use the word 'parents' rather than 'mothers and fathers' or 'women and men' as they feel it is more inclusive. But the fathers we spoke to disliked the use of 'parents' as they perceived it as applying to mothers, rather than themselves. They wanted researchers to make specific mention of dads. Using communication that's potentially sensitive means consulting the group you're trying to reach about what they perceive as appropriate.

'If you want to reach fathers, use images of fathers. They will see it as relevant, if they can see themselves depicted.'

Katherine Jones, Fatherhood Institute

- **Identify the social media** platforms most likely to be used by the people you want to engage in your work. Running a social media feed for a research project can be complicated and time-consuming, so look at what charities, organisations and influencers are doing on your preferred platform. And ask yourself if there is anything you could offer those organisations in exchange for them sharing your messages?



Theme 5 - Imagine life in our shoes

People are busy, with very different priorities to yours. If someone is trying to find a home, a job or look after a young family, your research will not be one of their priorities, particularly if it doesn't feel relevant to their daily life. Do everything you can to make their engagement and involvement as easy as possible. This also applies to participation in research.

- Have a mindset of **doing things *with* people and families**, not “to” them.
- Think about the people you want to speak to, and how and where they spend their time. **Reach and go out to them** rather than expecting them to come to you in a university building or place far from where they live. Think about places of worship, public transport, schools, community hubs, local peer support groups and GP surgeries.
- **Budget for payment and expenses** to acknowledge the time people are giving up. It is common practice to compensate PPI representatives. Follow your department's PPI payment policy, or guidance from the National Institute of Health Research ([NIHR](#)) if your department doesn't have its own policy.
- **Make every effort to ensure payment systems work smoothly** for people involved in your research. Double your efforts when you are involving people who are more likely to be struggling financially. They may need some payment in advance, for example, if they have a pay as you go smartphone which they use to join online meetings.
- Be mindful of people's access to technology – **many people rely on a smartphone** for home access to the internet. This means they will be looking at a small screen and won't have access to a printer. You might need to post out documents or PowerPoint presentations ahead of meetings. Find out which video conferencing software your contributors prefer.
- When you are communicating with people, do you have to use email for everything? **Ask people how they would prefer to be contacted**; they might prefer text, WhatsApp or Facebook Messenger for example.
- **Be flexible** when planning involvement. Sticking to office hours may work for people who are attached to an organisation you are working with, or who are retired, or not in paid employment, but not for many others. People may be working, looking after children or have other caring responsibilities that all need taking into account.
- **Emphasise the opportunities available to people** through research involvement and engagement, such as learning new things, developing interests and gaining skills.

'There are young parents that are dealing with social services and their priorities are not filling out a survey that they don't know what's going to come out of it. Their priority is making sure their child is not going to be removed by social services.'

Harriet Williams, independent advocate for young parents

Final thoughts

We've covered a lot of ground in this guidance. And you may be feeling overwhelmed by the additional work, which reaching out to people, currently under-represented in population health research, might bring. But you don't have to do everything listed and not all at the same time. Draw on the support resources available to you, such as your research group lead, or public engagement and involvement colleagues.

Good engagement and involvement requires planning, sufficient resources and time. It may make sense to have a dedicated person to lead your public involvement.

Do remember that if you want to reach groups and individuals who are marginalised and under-represented you will have to go above and beyond. But at the end of the day your research will only be better as a result.

And above all, remember that you owe it to the patients, the public, groups and individuals, who have shaped your research and contributed to your career, to acknowledge their impact.

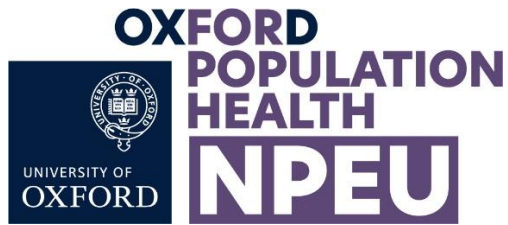
Additional resources

University of Oxford website on Public Engagement with Research
<https://www.ox.ac.uk/research/public-engagement/how-engage>

Nuffield Department of Primary Care Health Sciences, University of Oxford, **Guide for researchers working with Patient and Public Involvement (PPI) Contributors**

Available as a PDF from <https://www.phc.ox.ac.uk/ppi/information-for-researchers>

Medical Sciences Division, University of Oxford, About Public Engagement with Research
<https://www.medsci.ox.ac.uk/divisional-services/support-services-1/public-engagement>



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