

Top PPI and engagement tips for improving EDI in research design

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CAPC researchers Jo Burgin and Yvette Pyne discuss menopause research with local community members in Barton Hill

Introduction: Why share these tips from PPI&E contributors?

Health research funders are increasingly requiring evidence that researchers address health inequalities through improving equality, diversity and inclusivity (EDI) in research. Below are tips gained from Patient/Public Involvement and engagement (PPI&E) at CAPC, which may help you with planning your next project. See also the [NIHR INCLUDE Ethnicity Framework](#) – guidance for *‘Improving inclusion of under-served groups in health and care research’*.

These PPI&E tips from the Centre of Academic Primary Care (CAPC), University of Bristol, may highlight what you should plan and cost for in your grant application, to improve diversity in your research. It is challenging for researchers to do extensive pre-grant PPI, given tight deadlines and lack of funding for engagement work. This is why these tips – already gathered through extensive PPI&E work at CAPC – may help you on your way.

NB: these tips are not intended to be a substitute for doing PPI&E – your grant applications will require you to describe the specific pre-grant PPI&E work you have done and how this has influenced your plans. But they can be a prompt for your discussions and can help shape your plans for study design and budgeting, including participant recruitment and intervention design, so that you make sure these are relevant to everyone who could benefit.

These tips are drawn from PPI and engagement activities with people who are diverse in:

- Ethnic heritage
- Post-code across the Bristol region and beyond
- Gender
- Religion
- Age (range from early 20s to 70s/80s)
- Sexuality
- Digital literacy and IT access

- Education
- Employment
- Health care experiences - in relation to acute and long-term physical and mental health conditions (as patients, family members/carers, support group leads). Conditions include anxiety, depression, autism spectrum, eczema, shingles, thyroid disease, rheumatoid arthritis, chronic pain, fibromyalgia, irritable bowel syndrome, food allergies and intolerance, sickle cell anaemia, stroke, heart disease, heart failure, kidney disease, multiple sclerosis, type 2 diabetes, dementia, domestic violence and abuse.
- While there are many individual features to consider, it is also important to think of the multiple compounding effects of intersectionality on people's health risks and experiences.

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Tips from PPI&E contributors on how to build diversity in your study

Advertising images: When designing your materials for study recruitment, use images that represent a range of people, especially in relation to the populations that you are speaking to, or hope to recruit for your study. Can you show people of different ethnic heritage, age, gender and other protected characteristics? It makes a difference for audiences to **‘see people like me’** represented.

Media and local advertising campaigns: To reach your target populations, try raising awareness of your study through TV and local radio. This may help, for example, to encourage patients to contact their GP, or at least to be better informed if invited by their GP (if their GP is a recruitment site), if the study is about diagnosis or treatment and especially if access to treatment is time sensitive. PPI suggestions pre-COVID-19 included showing videos in GP waiting rooms or placing links to videos and information on the GP practice website and on Facebook. PPI have also suggested placing posters in locations close to your study populations, including public toilets, supermarkets, local libraries, motorway services, playgrounds, blocks of flats and other places with community noticeboards, distributing at health information events and community group meetings, or sharing electronic pdf versions via neighbourhood Facebook groups or WhatsApp. Don't forget that translation into other languages may make these more likely to be read by communities whose first language is not English. And better still, put time into local community engagement – visiting groups most likely to have people you are trying to reach – for face-to-face conversations. These can help reinforce messages that people may have seen or heard about through other routes.

Identify GP practices in parts of Bristol with diverse populations – e.g., Central and East Bristol – if involving GP-based recruitment. One PPI member told us, “If you start with a diverse population, you have more chance of a diverse population coming forwards. But this is not a guarantee.” You may be able to connect with a GP-based research network, such as GPs at the Deep End Network (<https://deependgps.bristol.ac.uk>).

Take a community-based approach: Wider family members, grandmothers, friends, can have a strong influence on health seeking behaviour and decisions. One PPI contributor told us, “When women talk to each other they question more than they question the health professionals, and whether they encourage or discourage, it could go either way.” Researchers may need to do

community engagement to support PPI and participant recruitment, for example, by speaking at workshops, coffee mornings, and other community gatherings. One contributor said, “If women share experiences as mothers – they can influence change.”

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Building trust. Consult and work face-to-face with local communities in order to build confidence in research and allay fears of exploitation. PPI tell us that some people may feel suspicious about the motives of university researchers. One PPI contributor of Caribbean heritage told us. “Especially with covid people are even less trusting now.”

Taking part in community group meetings can be a vital way to help build trusting relationships. One Barton Hill community group leader told us:

“We don’t want researchers to come and collect data and go. We have a lot to contribute to the research, to contribute ideas. With Jo and Yvette [see image above], it showed how the community are resourceful and really can contribute something [for example, menopause information leaflets]. It’s also an opportunity to do capacity building for the local community. This is where the universities and the institutions have a role to play to give opportunities to the people who can also become an active partner.”

Trust is particularly an issue if researchers do not clearly explain what research is – the concept of research itself may be new. Explain your reasons for doing the research and for targeting a particular community – and who will benefit and when. One PPI contributor said about the idea of invitation letters, “I have letters all the time from the NHS – it’s just a piece of paper – I don’t see any human connection on there – that helps a lot – if I hear it from the person that’s doing the research that makes a connection.”

A Barton Hill community member told us about the importance of having open conversations to explain what research involves and the risks: “A lot of people are reluctant to take part in research... For historical reasons people say ‘I don’t want to be a guinea pig – I have thrown the information in the bin.’”

Employ community workers as PPI co-applicants and as co-researchers: PPI contributors have recommended, “training people within the community - they can help out and work alongside researchers in a more accessible way” to build trust and break down communication barriers.

The word ‘bugs’, which was meant to indicate virus or bacteria, was translated to ‘insects’ in Gujarati!

Take care to avoid cultural assumptions and translation errors. Check with local communities about the correct language and cultural references when advertising a study. For example, there may be cultural differences in how people describe signs and symptoms such as memory loss, pain or changes in mood. The wording of adverts, consent forms and questionnaires is especially important.

Do 'back-translation' checks with community members if you have used a translation service or other individuals to translate patient-facing documents and video scripts, to make sure that these make sense to your target audience. On one occasion, the word 'bugs', which was meant to indicate virus or bacteria, was translated to 'insects' in Gujarati!

Work with local religious leaders to raise awareness: Leaders at a local mosque, gurdwara, synagogue or church, may encourage their faith community to find out more and take part in a study or survey. Many faith communities run play groups for children where you can meet parents, and support and activity groups for people of all ages.

Raising awareness with Somali and other community members, Barton Hill. Members of the Somali community in Barton Hill tell us that Somali language TV and radio are important sources of information for many older Somali people. Younger adults and families are more likely to get information via WhatsApp rather than Facebook. Community members also find it useful to have information distributed with primary school newsletters (to reach parents and wider family), or printed and placed on local notice boards, for example in play areas and foyers of blocks of flats (ask the local caretaker).

Be aware of difficulties that some patients may have in getting to see a GP or pharmacist: Especially relevant for primary care research and recruitment through general practice, Barton Hill residents (Somali and South Asian) tell us anecdotally about repeatedly trying to call their GP practice only to be told that there are no appointments available: "Sometimes we're ringing all day and don't get an appointment". One spoke of giving up and going to hospital A&E instead. And there may or may not be a pharmacy within easy reach in some neighbourhoods, all of which influence research participant recruitment in some areas.

"Sometimes we're ringing all day and don't get an appointment."

You may want to consider overcoming these logistical barriers by opening a special research clinic in the community you wish to recruit from, or create special invitation letters for interested community members to take to their GP, to speed up referral to a hospital research clinic. All of which is possible with research ethics approval and with sufficient planning and effort.

Accessibility – languages. Depending on the population you wish to recruit, you may need to cost for translation and interpreting. One person told us, "As a black person, from an ethnic minority, I have fear that if I talk people will not understand me – fear of not being taken seriously." Bristol has people speaking more than 91 languages, and these may be clustered around certain GP practices. See local council census information for the most spoken languages in your study recruitment area. Even if family members can do informal interpreting during a consenting process or interview, PPI have recommended that it is better to plan and cost for a professional interpreter so that there is less pressure on family members (see also Trial Forge 3 practical guidance on [how to recruit and retain individuals from ethnic minority groups](#)).

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Accessibility - learning difficulties and cognitive impairment. Plan and cost for easy-read versions of your study recruitment materials. There are approx. 1 million people in the UK with learning disabilities, whose voices are under-represented in health research, and more than 4 in 10 adults [struggle to understand health information written for the public](#). In the Bristol region, there are estimated to be more than 500,000 people with dementia, whose voices are under-represented in health research. Translation of easy read versions will be a way to make recruitment materials more accessible for people with low literacy in English.

You could consider working with people with learning difficulties to co-produce these documents to ensure that terminologies used are not insensitive.

We are also getting feedback that most prospective study participants prefer easy-read versions anyway, regardless of which languages they speak, and levels of literacy or cognitive ability.

You may find it useful to look at the following guidance:

- Learning Disability Wales course about making information easier to understand: <https://www.ldw.org.uk/training-events/>
- NHS E-guide to making information accessible for people with a learning disability: <https://www.england.nhs.uk/publication/guide-to-making-information-accessible-for-people-with-a-learning-disability/>
- Accessible Information Standard: <https://www.england.nhs.uk/ourwork/accessibleinfo/>
- Trial Forge 3 guidance on 'How to decide which ethnic groups your trial needs': <https://www.trialforge.org/trial-forge-centre/how-to-decide-which-ethnic-groups-your-trial-needs/>

Accessibility – sensory impairment. For people who may be partially sighted, use large-font text in printed materials or consider a verbal consenting process. For people who are deaf and hard of hearing (more than 100,000 in the Bristol area), plan presentations and meetings in venues with a closed loop amplification system and/or with a British Sign Language Interpreter. You can get more advice on this from the [Centre for Deaf and Hard of Hearing People](#), Fishponds.

Quoting from this PPI&E guidance in your grant applications

You are welcome to refer to the points made in this document in your grant applications by making it clear that this is 'previous PPI work at CAPC' and then following up with your own bespoke PPI work around your project. We welcome your feedback and additional tips that can be shared more widely.

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