PRIMARY CARE RESEARCH CENTRE

University of Southampton

Welcome to Patient and Public Involvement with the Primary Care Research Centre

We depend on each other, and we all have something to give

Thank you for thinking about becoming a **public contributor** and reading this **Welcome Pack!** Without you, we are not able to do research which results in **services that meet everyone's needs.**

As a public contributor, your opinion and your experience really matter.

Your views could **guide** research, **influence** future treatments and **improve** services for patients and the public.

What is a Public Contributor?

(Jean, public contributor) *…"from my perspective, it can be best described as a privilege. I have contributed to and influenced outcomes, including research processes, from start to finish, enabling me to give something back to society….you get to meet a variety of people from all walks of life with the same aims and goals."*

Public Contributors are members of the public who:

- Share their personal experience of an illness or health condition that they or someone they have cared for may have experienced, or a service they have used …
- Tell us how they and the different communities they belong to understand and feel about a health issue
- Provide a listening ear – listen to researchers and share ideas about solutions to their research problems

(Bethan, PhD student) *"Public contributors are important because they highlighted the importance of open conversations from the beginning, on aspects of the work they were interested in such as, access needs i.e. dyslexia, sensory impairment/s, expenses and what their time commitment was."*

You **do not need qualifications** to be involved, your life experiences are the only qualifications needed. We want to hear from **EVERYONE**, regardless of age, ability, orientation, culture, religion!

What is the Southampton Primary Care Research Centre?

The research centre is a place which does research about improving health and keeping people healthy.

We are doing research on:

- Helping people with **long-term health conditions** take care of themselves and keep well. This is called 'managing a long-term condition'
- Helping people to take the right **medication** in the right way e.g., using antibiotics
- Developing relationships and talking with people about keeping healthy. This is called **'healthcare communication'**

We need to hear from all sorts of people to make sure that the research is relevant to the people that the research is for.

(Bethan, PhD student) *"I'm grateful for the guidance and support received from public contributors right through my PhD"*
(Jean, public contributor) *"being involved gives opportunity to add to the knowledge/skill base and brings benefits to improve health and social care outcomes for patients and the public."*

How can I help, how can I get involved?

(Margaret, public contributor) " *I have worked on many topics which include nursing care, depression, English and Chinese flower herbal remedies for Upper and Lower Respiratory Tract Infections"*

There are lots of different roles you might be interested in:

- **Specific Research Projects** - e.g., a study on self-assessing sore throats
- **General Committees** - e.g., planning the work of the research centre
- **Focus Groups** - e.g., looking at specific issues like acne, children's insomnia, antibiotic prescribing

All projects have different needs, and all public contributors have different experiences or health conditions. **All are welcome!** You can choose which project and which parts of a project you want to do. It's all up to you.

The Centre's PPIE Officers regularly sends out details about research projects which need help from public contributors. If you think the project looks interesting and you think you are a "good fit" you should:

1. Contact the researcher who is running the project (Project PPIE Lead)
2. Email the Centre's PPIE Officers to let them know that you have made contact with the researcher

The Project PPIE Lead will then contact you and together you can agree your level of involvement and the support you need to take part.

Researchers need to hear your views and will send you information about their project plan and the activities they plan before any meetings. You will usually need to spend some time reading and thinking about their ideas and approach. If you need help to understand some of the paperwork the PPIE Project Lead will help you.

They will ask you what you think about their ideas and plans. **Your responses are really valuable** because researchers may not have thought about those ideas before. So please be confident that **your contribution is important**. If you feel you need help to speak up in a meeting please let the Project PPIE Lead know.

It may not always be possible for the research team to act on your recommendation or immediately to address an issue you consider important – that may have to wait for a later project. But what you have said will be recorded and is important. In return, the research team **will trust you** to be **considerate, prepared,** and **confidential** about the work being discussed.

In other words, you can expect each other to act as good colleagues and, in the research world that is the ideal!

How will you be supported?

There will always be a member of the team (Project PPIE Lead) allocated to support you. The support you are given will be based on what kind of project you are helping with and what type of support you need. Some people might need help to feel confident and others might need large print documents.

Most meetings are held virtually, please let us know if you require support to access online meetings. On occasion, a meeting might be held face to face, in which case, if public transport is not accessible, please let us know. If you are required to attend a meeting in person and you need the meeting rooms to have an Induction Loop or if you need a British Sign Language Interpreter (BSL), please let us know so that we can remove any barriers to taking part.

Example: Amaya is going to be a public contributor on a research project and is provided with the following:

- The Project PPIE Lead name and contact details and opportunity to have an informal meeting to talk about any support needs
- Information on their role in the research (their time commitment)
- When and where meetings will happen
- If the project pays fees (vouchers or money) for involvement
- How to claim expenses for printing or the cost of bus fares

Reimbursement or covering your costs:

Each project will reimburse your time, including any reasonable out-of-pocket expenses such as bus fares or parking tickets. You will need to provide the receipt.

It's a really good idea to fill in the claim form as soon as possible after the meeting. It is also a good idea to keep a record of all expenses, date of claim, and date payment received. If you are unclear about how much you will be remunerated or if you need help filling in the form or keeping records, please ask either the Project PPIE Lead or the Centre's PPIE Officers.

How are Public Contributors helping?

Public contributors are important from the very start to the end. They help to **identify, design** and **shape** the project, and make sure results are widely spread.

Your involvement may well have helped get the project funded, you will have made sure that many more relevant voices are heard, and you will know more about how research works.

Planning in research is **really important** if we want to make sure we have the **right resources** to **reach different groups of people**.

When public contributors ask questions like:

- *'have you thought about this?'*
- *'don't you think we should tell...?'*

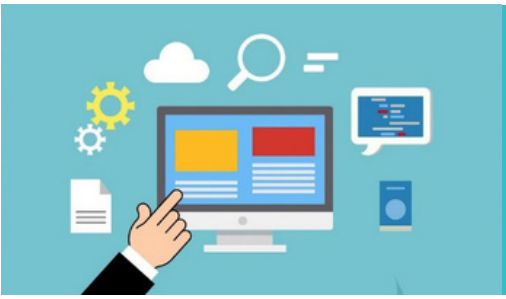
or share information like:

- *More people will come if you are located...*
- *More people will look at the information if...*

they help shape the research for the better. Sometimes the public contributors ask the difficult questions that really help researchers to work in a way that really tackles health inequality.

Want to get involved?

By now you will be wondering how you can help as a public contributor. If you want to know more and find out about how we can support you to take part please contact the Centre's PPIE Officers: PrimaryCarePPIE@soton.ac.uk.



Resources

NIHR UK Standards for Public Involvement – a framework for what good public involvement in research looks like (to see the NIHR UK Standards for Public Involvement linked to the Primary Care Research Centre, a copy can be requested from the PPIE Officers)

NIHR Learning for Involvement – An interactive course for new and experienced reviewers of health and social care research, which has been produced by a team of public reviewers and patient and public involvement professionals with the NIHR

NIHR SPCR – Resources for public contributors

NIHR Centre for Engagement & Dissemination – scroll halfway down the page for payment rates

Wessex PIN – a regional collaboration of staff and public contributors working within NIHR organisations across the Wessex area to develop and deliver best PPI practice

NIHR INVOLVE Jargon Buster and Downloadable PDF Version - definitions of some of the terms commonly used in public involvement in research

People in Research – a platform for researchers to find public contributors and public contributors to find opportunities to get involved in research

Healthtalk – a collection of people's lived experiences of health conditions and their involvement in research

NIHR - Learning for Involvement Training - patient engagement training, peer research training, improving inclusivity in research, inclusive research

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