



NUFFIELD DEPARTMENT OF  
**PRIMARY CARE**  
HEALTH SCIENCES

**Patient and Public Involvement  
(PPI) welcome guide**

**Let's get  
started**

**“PPI can be eye-opening when it’s done right.”**

**– Angela, research operations manager.**

**T**hank you for your interest in getting involved in research at the Nuffield Department of Primary Care Health Sciences, often called the Primary Care Department for short. We are very pleased to welcome you.

Input from patients and the public, people like you, helps to guide and shape our research. Your opinions and experience really matter and can make a difference. We use the term ‘patient and public involvement (PPI) contributor’ to describe the people who help research in this way.

## **About the Primary Care Department**

The department carries out research into the way that healthcare is offered in general practice (GP) and the community.

The main focus is on improving health and healthcare, and includes the prevention, early diagnosis and management of conditions. It covers a wide range of areas and brings together experts from many different backgrounds.

Some examples of research topics are:

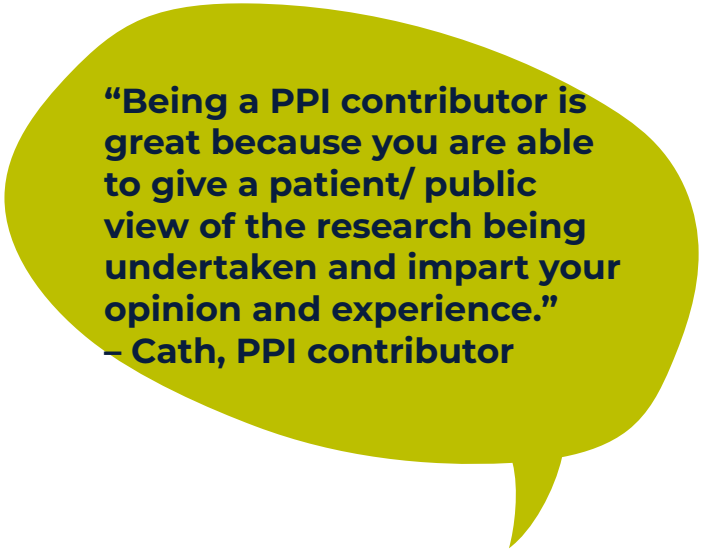
- Ways to help people stop smoking
- How the use of antibiotics can be reduced
- Whether text reminders can help people manage their diabetes
- Collecting people’s experiences of living with mental health conditions

# Your role as a PPI contributor

There are lots of ways that you can get involved as a PPI contributor.

These include:

- Using your personal experience to suggest ideas for areas of research, important outcomes or ideas for improving services
- Helping researchers write about their research in a way that is clear and understandable
- Telling us how you and the different communities you belong to understand and feel about a health issue
- Listen to researchers and help them with solutions to their research problems, such as how to tell people about their work and how to use it to make changes.



**“Being a PPI contributor is great because you are able to give a patient/ public view of the research being undertaken and impart your opinion and experience.”**  
– Cath, PPI contributor

# Things you can do

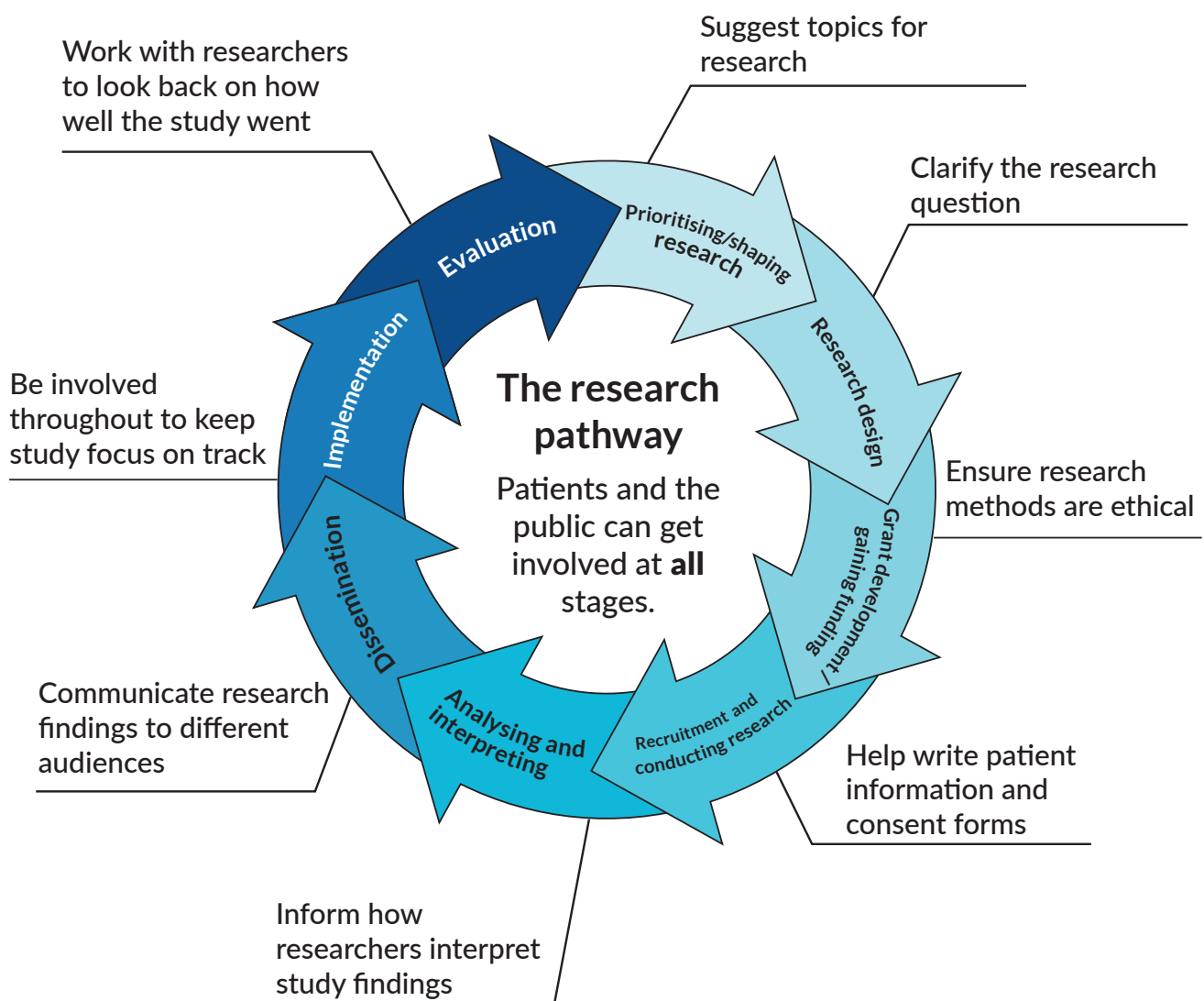
There are lots of different ways to get involved, and you don't need any special skills or qualifications, or to know about research or be a medical expert. The research team and PPI Manager will be there to support you and explain anything that isn't clear, and to offer training if it's needed.

What's important is your own life experience – this might be as someone with a condition or illness, or as a carer for someone, or of using a treatment or health service. We want to hear from everyone, regardless of age, ability, orientation, culture or religion.

The diagram below shows some of the things that you might help with. You might do this by taking part in a discussion group about a topic, having a one-to-one phone call with a researcher or joining an advisory group that meets regularly. It's up to you what you choose to do and how you want to do it.

**“Working with patients and members of the public has really helped me ensure that findings I produce in the research have practical implications for service users.”**

**– Georgette, DPhil candidate**



## Jargon buster

The research world uses lots of words and phrases that you may not be familiar with.

Here are links to two jargon busters where you can find definitions of some of the most common.

If you aren't sure about what something means, please ask the researcher you're working with or the PPI Manager who will be happy to explain.



- [www.nihr.ac.uk/glossary](http://www.nihr.ac.uk/glossary)
- [clahrc-peninsula.nihr.ac.uk/uploads/attachments/PPI/Jargon%20Buster.pdf](http://clahrc-peninsula.nihr.ac.uk/uploads/attachments/PPI/Jargon%20Buster.pdf)

## Reimbursement and expenses

Researchers should always reimburse any expenses, such as travel or care costs, that you have from getting involved in a project. You will probably need to fill in a claim form and it's a good idea to do this as soon as possible, as well as keeping a record of all activities and payments with dates.

Wherever possible, researchers will also pay you for your time – this will sometimes be in vouchers. This will usually be in line with national guidance – you can find more details online at [bit.ly/NIHRPPIpayment](http://bit.ly/NIHRPPIpayment).

It's important to be aware of your responsibility to ensure any tax and/or National Insurance due on payments is paid, and that you inform the Job Centre if you're receiving benefits.

See 'The implications of being paid for involvement' section in the NIHR PPPI payment guidance for more information: [bit.ly/PPIandbenefits](http://bit.ly/PPIandbenefits). You don't have to accept any payment you are offered.

**Thank you very much for your interest – we look forward to working with you!**

## Keeping in touch

If you signed up through the website ([www.phc.ox.ac.uk/ppisignup](http://www.phc.ox.ac.uk/ppisignup)) you will receive emails from the Patient and Public Involvement (PPI) Manager about opportunities to get involved with research. These will provide contact details (usually of a researcher working on the project) so you can find out more.

You can also contact the PPI Manager if you have any concerns or queries ([ppi@phc.ox.ac.uk](mailto:ppi@phc.ox.ac.uk)).

If you decide you no longer wish to receive these emails, please contact [ppi@phc.ox.ac.uk](mailto:ppi@phc.ox.ac.uk) and you will be removed from the mailing list.

## Acknowledgements

With thanks to Sonia Newman and colleagues at the Southampton Primary Care Research Centre for allowing us to use their 'Welcome Pack' as a starting point. Also to Lynne Maddocks who created the original version on which both Southampton's and this updated guide are based.

Thanks also to Sharon Dixon, Angela Martin and our PPI contributors for their helpful feedback.