

# Getting involved in research: A guide for the public

Cambridge University Hospitals' Patient and Public Involvement Panel

## Who are our Public Contributors and what do they do?

Volunteers on our public panel review research documents, share their thoughts and provide feedback about research projects taking place in Cambridge.

No special experience or knowledge is needed, just a willingness to share your opinions and questions to make our research better for everyone.

We welcome new members from all backgrounds over 16 years of age.

### People join us so they can:

- Work with researchers to improve health research
- Improve patients' experience of taking part in future research
- Discover more about the world-renowned research conducted on the Cambridge Biomedical Campus
- Contribute to innovative research projects
- Learn and develop new skills



## How does it work?

Readers receive research documents to review via email from the panel coordinator. Each project includes:

- A brief introduction to the study with information detailing what is required accompanies each request. This usually takes the form of questions from the researchers together with a time within which to respond (usually two weeks)
- Panel members choose which document(s) to read/comment on depending on individual interest and available time.

## Confidentiality

Your contact details will not be passed on to researchers without your express permission. When you join, you will be asked to sign an agreement to keep the research ideas confidential. You will not under any circumstances, be sent any personal information relating to patients or study participants.

## It's a very flexible, worthwhile way to volunteer your time

- You don't need to travel
- You select which pieces of research to comment on, depending on your time and individual interests
- You will receive regular feedback from researchers so you know your input is worthwhile
- You can withdraw from the panel at any time and you are under no obligation to review any particular study or number of studies

**"Don't be intimidated by the fact that you are helping very brilliant medical researchers. You have a value to them, and the reason you exist in this role is because you have insights and skills that they don't have."** *Panel member*

### Readers may be asked to comment on:

- **Plain English summaries** – a brief summary written for members of the public rather than specialists. It should be written clearly and simply without jargon and with an explanation of any technical terms
- **Patient information sheets** – these are given to potential participants in a study to provide information and help them decide if they wish to take part
- **Patient consent forms** – for potential participants to complete once they've decided to take part in a research study
- Patient & Public Involvement (PPI) sections of **funding applications** – a description of how the research project plans to involve people
- **Study protocols** – a full description of the research study, setting out what participants will do and how the results will be determined

## **What impact does our Panel have?**

'I went through all the suggestions one by one and systematically applied changes to the documents. The documents read a lot better after the edits.'

*Dr Gaby Captur Clinical Lecturer and NIHR Rare Diseases Translational Research Fellow*

'Your comments have been incredibly useful – in particular pointing out parts of the summary that are confusing. I have now extensively revised this based on your advice, and the advice of other groups. Many thanks to all of you.'

*Mr Stephen Price Consultant Neurosurgeon*

**The National Institute for Health Research (NIHR) has lots of online resources to help members of the public taking part in all sorts of ways in research. See [bit.ly/NIHR-learn-zone](http://bit.ly/NIHR-learn-zone) for more.**

## **How we support and communicate with our members**

**We provide:**

- Regular (optional) meetings, enabling members to hear the latest news from researchers as their studies progress
- Learning opportunities for those who wish to develop their skills and share knowledge and expertise with staff and volunteers
- A short monthly e-newsletter to keep everyone up to date, including a feedback report from our researchers, and a calendar of other events and talks

Cambridge University Hospitals' Patient and Public Involvement Panel coordinators are here to help. Please get in touch if you would like more information.

**Contact: Amanda Stranks, PPI/E and Communications Strategy Lead**  
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**"Try and imagine the practicalities of the research study. Imagine the people who will be participants. If it were you, or someone for whom you cared, what would be your thoughts? What would you want to happen to agree to participate?"** *Panel member*

## CUH Patient and Public Involvement

Research Member Ros with her dog Penny

**"I enjoy the flexibility of being able to work in my own time, with no pressure, and without having to attend meetings. The feedback from researchers proves how valuable the work of panel members is. Give it a go. You will definitely enjoy it. There is always help/advice should you need it."**



Ros

Research Member Jeremy

**"I find the work stimulating engaging and highly enjoyable. I commend Public and Patient Involvement to all who have the time and desire to make a positive contribution to those whose wish it is to make the experience of being a patient a better one."**



Jeremy

Professor John Bradley

Director of the NIHR Biomedical Research Centre

**"If you involve people, and you involve them early, you will reap the benefits as a research programme evolves."**



John Bradley

For more information call 01223 254620 or email [ppi@addenbrookes.nhs.uk](mailto:ppi@addenbrookes.nhs.uk)



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