

Welcome Pack for New CUH Patient and Public Involvement (PPI) Panel Members

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Research and Development Department**
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Dear new panel member,

Thank you for your interest in the Cambridge University Hospitals (CUH) Patient and Public Involvement (PPI) Panel. Our panel members assist researchers to improve research and make sure it is relevant to participants, benefitting patients now and in the future.

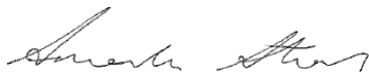
Joining the CUH PPI Panel

The Cambridge University Hospitals (CUH) Patient and Public Involvement (PPI) panel is a group of around 60 people from Cambridge and the surrounding areas who are interested in research. The panel is open to anyone living in the **East of England** (or with a connection to CUH through their lived experience) **who are not currently working in health research, the pharmaceuticals industry, or the media.**

Panel members provide their thoughts and opinions on research projects submitted by local researchers via email. We also run online meetings with researchers to discuss their projects and there are occasionally opportunities to get involved with specific research through joining advisory committees or steering groups.

In case this might be of interest, I have attached our “Welcome Pack” for new members. **If you would like to join the panel, please complete the joining and confidentiality form** on the last page of the pack and return it to me, and we will organise a time for you to meet with us to answer any questions and learn a bit more about you.

I look forward to hearing from you soon.



Amanda Stranks
Patient and Public Involvement Lead

Enclosed in this pack: An introduction to our organisations, overview of CUH PPI panel, information on providing feedback to researchers, expenses and the joining form with confidentiality agreement.



Who are the Cambridge BRC PPI team?



Amanda Stranks
Patient and Public
Involvement (PPI) Lead

Dr Amanda Stranks is the Strategy Lead for Patient and Public Involvement and Engagement (PPI/E) and Communications at the Cambridge BRC. Amanda directs the overall strategy of our PPI team, working with researchers and the community to make the research that goes on at CUH accessible to everyone.

Before moving into PPI, Amanda worked as a scientific researcher, having gained a doctorate in Immunology from the University of Oxford and a master's degree in Public Health from the University of Cambridge. She is passionate about scientific communication and involving patients and the general public in all stages of research.

Gail Holloway is the PPI Coordinator for the CUH PPI Panel. Gail is the main point of contact for CUH panel members and acts as a go-between for panel members and researchers. She also works closely with Amanda to help researchers design PPI plans for their research.

Gail previously worked for the Ophthalmology department, as a theatre coordinator. Prior to this, she was responsible for rebuilding both the paediatric Sleep Study and Long-Term Ventilation services for children with respiratory disorders. Gail is currently studying a BA (hons) degree in English Literature and Creative Writing in her spare time.



Gail Holloway
PPI Coordinator
(CUH PPI Panel)



Georgina Norris
PPI Coordinator (NIHR
BioResource, Cambridge)

Georgina Norris is the PPI Coordinator for the NIHR Cambridge BRC, helping researchers with PPI training and advice, and facilitating focus groups. Georgina is experienced in running a variety of advisory groups at local and national level, including public, lived experience, young people and rare disease panels.

Georgina also organises activities and events for NIHR Cambridge BRC including rare disease national events. She has previously worked for NHS Blood and Transplant as a Marketing Coordinator and has a background in media and event planning.

How does PPI help research?

Volunteers on the CUH PPI Panel bring fresh perspectives from outside the research community (scientists, doctors/healthcare staff and support staff) and help researchers in Cambridge to make sure their research meets the needs of patients.

Panel members share their thoughts on research projects through activities like discussion groups, commenting on documents and completing surveys, to help make sure that scientists and clinicians do research that serves the needs of patients and the public.

You don't need any prior experience or knowledge to contribute, just a willingness to share your opinions and questions to make research better for everyone. All opinions are equally important!

We welcome new members from all backgrounds aged 16 or over.

People join us so they can:

- Work with researchers to improve health research
- Improve patients' experience of taking part in research
- Discover more about the world-renowned research at the Cambridge BRC
- Learn more about health care research
- Develop new skills

This booklet will summarise the work we do at CUH and the NIHR Cambridge BRC, but if you are interested, the NIHR has lots of online resources to help members of the public get involved in research across the country. See the [NIHR website](#) for more information.



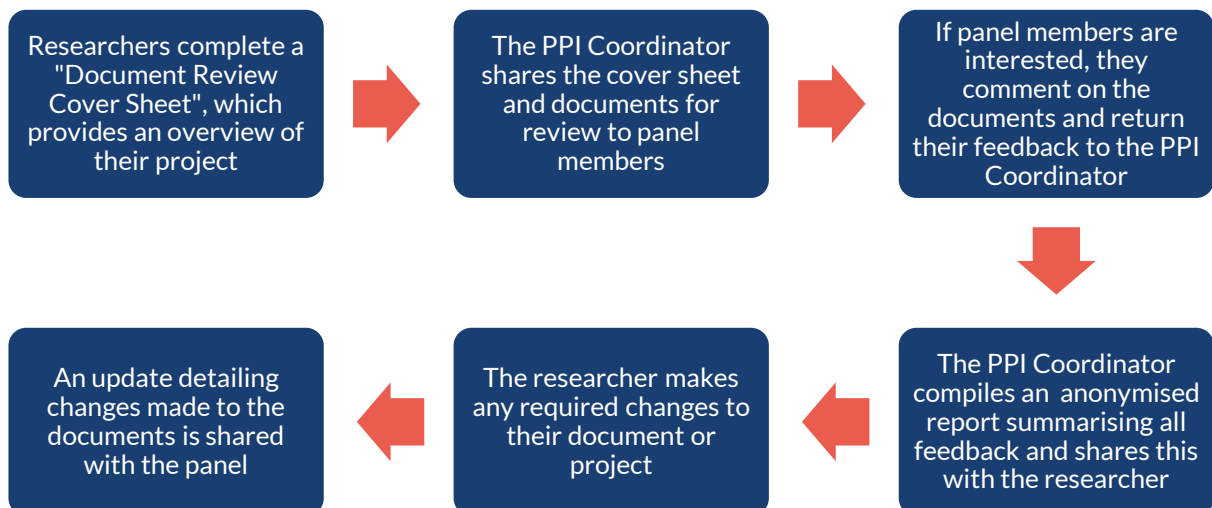
What do panel members do?

Document reviews

Panel members are invited to share their opinions on research documents and proposals (ideas for research). This provides researchers with valuable perspectives (those of patients and the public) from outside of their experience that are relevant to their research. Researchers can improve their study proposal/design or revise the wording of their documents as a result. We often see the following types of documents, but we welcome anything and everything!

- **Lay summaries:** short pieces (usually under 500 words) summarising a research project in a way that is easy to understand for non-specialists.
- **Patient/participant information sheets:** a description of what taking part in a research study would mean for somebody, in an accessible and easy-to-read way (e.g. how long a study is, what you will do as a participant, what the research is aiming to find out etc.).
- **Consent forms:** forms that people sign before agreeing to take part in a study, share their personal information etc. These should be clear, easy to understand and consistent with information sheets.
- **Invite letters:** letters sent to people to invite them to be part of a research project.

First, researchers talk to the PPI coordinator about their research project and request PPI input from the CUH panel. The following process then takes place:



There are two types of document reviews that panel members can choose to be involved with, if they are interested and have time:

1. **Academic research.** This is the bulk of the research we look at. Academic researchers are people who conduct research while employed by a university, hospital, or research institute using public (e.g., from the department of health or NIHR) funds, but sometimes using charity money. Many of our academic

researchers come from CUH and other local NHS services such as GP surgeries and the Royal Papworth Hospital. We also work with academics from the University of Cambridge and Anglia Ruskin University, and scientists working on the Addenbrooke's site at institutes like the Medical Research Council and Cancer Research UK.

- 2. Industry research.** Occasionally, we support private companies to incorporate PPI into their research, for example if a pharmaceutical company (such as AstraZeneca or Pfizer) would like input on documents that they are using as part of a clinical trial. In these cases, the company is charged a fee for service. You are welcome to opt out of industry reviews if you feel they are not of interest. If you currently work in the pharmaceutical industry, you will not be permitted to conduct industry document reviews.

Panel members are welcome to choose how they comment on the documents. Some panel members like to share their views as an email and others like to “track changes” within documents. More detail on how to give feedback can be found later in this pack, in the section ‘Is there a “right” kind of feedback?’.

To limit the number of emails panel members receive and maintain the number of responses at a meaningful level, projects are shared out equally across the panel – this means that you may not receive an invitation to every project.

Discussion groups

Some research projects are more easily discussed in person. This usually happens when research is still at the very early stages and researchers would like to hear your thoughts on their initial ideas for the study design. Panel members can be invited to participate in focus or discussion groups, where panel members meet directly with a research team and the PPI Coordinator (sometimes via video call). Members decide whether they would like to be invited to these groups, and can choose which discussions to attend, depending on their interests and availability.

Further involvement opportunities

Panel members can also be invited to get further involved in research projects - for example, by joining an advisory committee or steering group for that project. External opportunities are usually shared with the panel in a Weekly Round-Up every Thursday.

Supporting researcher training sessions

The PPI Team provide PPI training for researchers and talks for members of the public interested in PPI. A key part of these trainings is hearing from a PPI contributor about their experiences i.e., how they got involved in PPI, what they like to see (and don't like so much!) and why they enjoy their role. This is usually a short 5-minute talk followed by a Q&A session. All panel members are welcome to come and speak, regardless of how long they have been involved for.





What are the benefits of joining?

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

- You don't need to travel (unless you choose to attend in-person events).
- You choose which pieces of research to get involved with, depending on your time and personal interests; you are under no obligation to review any particular study or number of studies; our only requirement is that you get involved in a minimum of one activity (like a document review) per calendar year.
- You will receive feedback from researchers, so you know that your input has made a difference.
- You can withdraw from the panel at any time.

You will be supported by the CUH PPI Team

The CUH PPI Team will be in regular communication with you about any involvement opportunities you have expressed an interest in. In addition to this, we provide the following (optional) activities:

- Bi-annual panel meetings to meet the PPI team and other panel members. At these meetings we discuss our work and the future direction of the panel.
- Quarterly researcher talks: an exclusive opportunity for CUH panel members to interact directly with local researchers, who give a short presentation on their work, followed by a Q&A session.
- Several research information events open to public contributors in the East of England covering big questions submitted by panel members
- Learning opportunities for those who wish to develop their skills and share knowledge and expertise with staff and volunteers.
- A quarterly newsletter to keep everyone up to date, including a feedback report from our researchers and a calendar of other events and talks.

The PPI team are always available to help you and make your experience as a volunteer the best it can be. You are welcome to reach out via email at any time!

Your comments directly impact research

'This fresh unbiased perspective is so helpful to us as clinicians and innovators who can easily become wrapped up in what we are trying to achieve. Constructive criticism helps us to define more clearly what we are trying to achieve and communicate this better!'

Dr Kathryn Beardsall
Consultant Neonatologist

'We were very grateful to receive your comments which were thoughtful, considered and constructive. Where edits or additional information were suggested, we have incorporated these as far as possible and the result has been a much improved lay summary'

Dr Frances Early
Applied Health Research Lead, Respiratory Medicine

Is there a “right” kind of feedback?

Sometimes new (or experienced) panel members are unsure of what feedback researchers are looking for and worry that they are doing it ‘wrong’.

The right feedback for you

Whatever your impressions of the project were, that is the right feedback from you. This is still true (and especially important) if you found the research so difficult to understand or engage with that you didn’t make it to the end of what you were reviewing! If that is true for you, then it likely holds true for many others and could ultimately prevent them participating in the research. Please feel free to provide feedback, even if that feedback is ‘I wasn’t interested in this project’ or ‘I couldn’t understand anything, so couldn’t comment’. Questions and suggestions are very useful too.

What AND why

Any and all responses to a research project are useful to the researcher – it is helpful to know if you found a proposed project interesting, inspiring, concerning, ambiguous, obvious, alarming or anything else. What is even more useful, if you can, is the why. Helping the researcher understand *why* you have had a particular response is more likely to help them improve their research – what concerned you? What could they change to make it clear? Which bit is most alarming?

Spelling and grammar

It is up to you whether you choose to correct misspelled words and/or poor grammar. Suggestions about ways to improve the wording can be very helpful for researchers trying to make their research clear and engaging.

Feedback delivery

There is no wrong feedback, but delivery is important – please remember there is a person on the other end of the feedback! Negative feedback can be very useful to researchers but needs to be targeted at the specifics of the project, and not at the researcher themselves. For example, ‘this is the worst research I have ever seen’ would be much better delivered as ‘I feel strongly that this project needs significant changes to be successful, for example...’.



Thinking tools

If (and only if!) you want some inspiration, here are some things you could think about. These are only thinking tools and are not more 'right' than any other feedback that you have given!

Would I participate in the study if eligible? Would I recommend it to a close friend or family member with this condition? Why or why not?

Is the explanation clear enough that I could explain this research to a friend?

Would the intervention / medicine / treatment be what you wanted if you had this condition? Would you use it?

What might stop me being able to take part, even if I wanted to?

What information would I want to know before I agreed to take part? Who would I want to hear this information from?

Were there any terms I needed to look up or passages I needed to re-read in order to understand what was happening?

Is there anything that caused me to have a particularly strong response (positive or negative)? Which bit? Can I explain why?



Member expectations

Panel membership

No specific experience is required for you to be involved in research, and all previous and lived experience is valuable – the strength of our panel for researchers is the wide variety of backgrounds and experiences of our members. We particularly need the views and experiences of people who have little or no experience of research at all – like most people! CUH PPI panel membership is open to anyone who:

- Lives in the East of England (or has a personal connection to CUH)
- Is aged over 16
- Can receive PPI opportunities via email

AND:

- Is not currently employed in health research (including commercial research), the pharmaceutical industry or the media

In order to help our researchers ensure that our research is relevant to our local population and meets their needs, we think it is important that members of the CUH PPI panel are based in the East of England or that they have a personal link to CUH or our research through other means (usually through treatment at our specialist services).

Similarly, researchers need the views, perspectives and experiences of people from outside of the research sphere, so panel membership is not routinely available to researchers or people working in research, who have other means through which they can influence and improve research.

Finally, panel members have access to information and materials that may contain confidential information about research that is not yet in the public domain, or that may provide a material advantage if it were accessible to competitors – as such, members of the media, commercial research organisations or academic researchers are not typically able to join.

However, we do recognise that some health researchers and people working in these industries have specific lived experience that they can bring to research – if you currently work in one of these occupations but have lived experience of a health condition, we will discuss with you the best way for you to be involved in our research.

Panel membership

Panel members can choose what types of activity they they would like to hear about (see the 'What do panel members do?' section for more information) by selecting from the options on the joining form.

You are free to choose which projects to respond to – we have some members who respond to nearly all of the opportunities sent to them, and others who choose to respond to just one or two projects per year as their time and interests allow. Your contribution is valuable however much time you can give!

Membership of the CUH PPI panel is completely voluntary and members can leave the panel at any time, without having to give a reason. If you would like to resign your membership, please let the PPI coordinator know via email. It is also possible to 'pause' membership (stop being sent opportunities for involvement) for up to a year and to change the type of activities you wish to be contacted about at any time, by letting the PPI coordinator know.

Membership expectations

We hope that you will find membership of the CUH PPI panel a flexible and easy way to be involved in research, and we do not place many requirements on our panel members.

In order to maintain your membership, panel members are expected to:

- Contribute to at least one document review per year (if you have opted to receive document reviews)

OR:

- Contribute to at least one discussion group per year (if you have opted to participate in discussion groups) – this may be through follow up comments if you are unable to attend any of the groups offered.

Panel members who have opted to receive both document reviews and discussion group invitations only need respond to one project from either category to retain their membership. Those who have not contributed to any projects will receive a reminder in October of each year that they need to contribute to at least one project for their membership to remain active. Those whose active membership has lapsed will not be sent more projects until they actively opt back in through discussion with the PPI coordinator or PPI lead.

We also expect that panel members will contribute constructively, honestly and sincerely, and that they will respect the views of others even where they do not agree. Negative feedback about any research project is welcome and warmly encouraged as it is essential to improving research.

However, feedback that is personally directed (at the researcher, patients or other public contributors) or that is derogatory or disrespectful may not be passed on, or may be edited beforehand.

When you complete the joining form you will be asked to acknowledge that you understand these requirements.



Payment and expenses for taking part in PPI activities

We recognise and appreciate the time that panel members take to support research and the expertise that they bring. CUH PPI Panel members volunteer their time and **most activities do not result in payment**. This enables us to involve as many people as possible and allows us to make involvement opportunities through the panel flexible to your needs and circumstances. Panel members can undertake as few or as many activities as their interest and circumstances allow.

Reimbursement policy

However, no-one should be out-of-pocket to be involved in our research. We will reimburse the following expenses related to in-person activities, with prior agreement from the PPI team:

- Travel and/or parking
- Food
- Stationery and equipment necessary to carry out in-person activities

Please use the most economic and practicable forms of transport for meeting your individual needs. Private vehicle travel expenses will be paid at 45p/mile. Please use the most direct route available, wherever possible. The cost of parking at the hospital site will be covered, and parking arrangements will be made clear for other venues. You will be supported to complete any reimbursement requests when they arise.

We do not routinely reimburse any digital costs (e.g., Internet or data use) associated with involvement. If the use of digital communications is a barrier to you, please let us know and we will explore the best way to move forwards.

Payment policy

There are currently no payments associated with any PPI activities arranged and managed by the CUH PPI Team for the panel. However, we are currently in the process of revising this policy so this may change in the future. Once the updated policy is available, it will be shared with all panel members.



Privacy and Confidentiality Statement

Anonymity for panel members

Anonymity for panel members is absolutely vital to ensure that everyone feels able to give honest feedback to researchers. Your contact details will not be passed on to researchers or anyone else without your permission. The feedback that you provide on different research projects is confidential and completely anonymous; researchers cannot tell who comments have come from. It is very important that your anonymity is preserved, so please do not contact any researchers using information you have gained through being a panel member (e.g. information about a specific research project) unless they have first invited you to do so. This applies even when you know the researcher in a personal or professional capacity; you must not inform that researcher that you have seen and/or commented on their documents.

Preserving the anonymity of panel members is also important to optimise the PPI experience for researchers. Building and maintaining trust with researchers is very important for the PPI Team. Researchers enter into an understanding with us that they will not be directly contacted by panel members unless otherwise requested, which is one of the reasons why an anonymous report is compiled by the PPI Coordinator. Receiving only this anonymous report (and not individual emails from multiple panel members revealing their identity) is beneficial for researchers for a number of reasons:

1. Researchers are not affected by unconscious bias and view feedback from all panel members equally. Researchers may perceive or interpret feedback differently if they become aware that it has been sent by an ex-colleague, a patient, a friend, or someone with specific qualifications.
2. Researchers view all feedback as a whole, so they cannot stop at the first response they read, or weight responses differently depending on the avenue used to return feedback.
3. Researchers are very busy and often juggling multiple projects and responsibilities, including clinical duties. Only receiving one report with all feedback protects their inbox from becoming overwhelmed by dozens of emails, that would be difficult to sort through and likely get lost.
4. Combining all feedback (positive and negative) through a single point of contact enables the PPI Team to work through all feedback with the researcher and work out next steps. This is especially important if there is lots of negative feedback that needs to be carefully considered. It is highly likely that if a researcher received multiple emails with negative feedback from several panel members directly to their inbox, they may choose not to engage in PPI again, which is something we want to avoid!

If you choose to leave the panel, all your personal information will be deleted from our records.

Confidentiality for researchers

All members of the CUH PPI Panel are asked to sign a confidentiality agreement when they join, stating that they will not discuss the research projects they are sent with anyone outside the panel. As a member of the panel, you will be considered a trusted member of the extended research team and this is the reason that you are privy to information that would otherwise be confidential. Therefore, you must not pass on any materials that are shared with you or discuss the details of research projects with anyone, even in passing. This applies to friends, colleagues, or people with lived experience of a condition that relates to research you are involved with through the CUH PPI Panel.

The fields of biomedical and health research are competitive, with many different research groups investigating similar subject areas. Researchers therefore have an expectation that their ideas will not be shared outside of the research team. The early-stage research that the panel views may later be associated with intellectual property (IP).

If you choose to download documents shared with you as part of a research project, it is best practice to delete these documents once the project is completed and we request that you do so. If you choose to leave the panel, please delete all documents that relate to your time as a CUH PPI Panel member.

You will not under any circumstances be sent any personal information relating to patients or study participants.

If you think you know somebody from outside the panel who would be interested in getting involved, please invite them to get in touch or let the PPI team know.



Privacy Policy

The information we collect

The type of personal information we collect will vary according to the interactions you are having with the NIHR Cambridge BRC. Different interactions and information collected are outlined below:

- We will collect personal data such as your name, email address, registered postal address and current occupation. This is to confirm your eligibility for participation in the research projects we may ask you to take part in, and also for suitable training opportunities that may arise.
- We will also ask for and collect additional data such as date of birth, current and past associations with health research and best phone number on which to contact you.
- We may ask you what is known as special category data, for example on ethnicity and gender. This is for equality and diversity monitoring and is stored separately and encrypted to maintain anonymity. You are not obliged to supply this information.
- We may ask for your bank details if we need to reimburse or pay you for any expenses incurred or work carried out in your capacity as a PPI panel member.

Depending on your interactions with us, we may at times ask for other data from you, in which case we will supply a separate privacy notice at the point of that collection. This will cover data processing, use, disclosure, and retention period.

How and why we use your personal information

We may use your information for a variety of purposes:

- Marketing communications to highlight the activities of the NIHR Cambridge BRC and opportunities for engagement. We will seek your explicit consent to contact you for marketing purposes and will NEVER use ANY of your information including images without your prior consent.
- Equality and diversity data is collected for equality monitoring purposes. This will only be used in an anonymised form to monitor our compliance with equality and diversity objectives, and to allow us to identify, and plan initiatives to address, areas where there may be underrepresentation or inequality in our systems, processes or procedures.

How we protect your personal data

Accuracy

We are committed to maintaining accurate records. The most efficient way of verifying or amending your personal information is to contact one of the PPI team at Cambridge BRC.

Security

We are committed to ensuring that your information is secure. CUH uses leading technologies and encryption software to safeguard your data and maintain strict security standards to prevent any unauthorised access to it. We make every effort to reduce the risks associated with data in transit over the internet by using appropriate technology, including (but not limited to) SSL for any of our websites or applications which collect data from you. However, we cannot guarantee the security of your data in the parts of its journey which are not under our direct control.

Confidentiality

We will not sell your personal information. We will not disclose your personal information to third parties outside of the NIHR Cambridge BRC, unless we have your consent, or are required by law to do so.

Storage of your personal information

We will keep your data for varying amounts of time depending on the nature of the interaction with our services:

- We only store data that is necessary for a specific purpose.
- We will not store your data for longer than is necessary for the purpose for which it was collected unless we are legally obligated to do so by contract or other legal requirement as a public body.
- Your data will be securely deleted when no longer needed for the purpose(s) for which it was collected.

Your rights over your personal data

As a data subject, you may have the following rights under the Data Protection Laws:

- the right of access to personal data relating to you
- the right to correct any mistakes in your information
- the right to ask us to stop contacting you with direct marketing
- rights in relation to automated decision making
- the right to restrict or prevent your personal data being processed
- the right to withdraw consent

We will respond in a timely manner to any rights that you wish to exercise, within a month of receiving your request. If you choose to leave the panel, all your personal information will be deleted from our records.

Contacting the Regulator

If after reading this privacy notice, you do not think the NIHR Cambridge BRC has processed your data in accordance with this notice, you should let us know as soon as possible. Similarly, you have the right to lodge a complaint with the Information Commissioner's Office if you think there is a problem with the way we are handling your personal identifiable information. Their website is: <https://ico.org.uk/>



CUH PPI Panel Joining Form

Please complete, sign and return this form via email or post.

Title: _____

Name: _____

Address: _____

Post code: _____

Email: _____

Telephone (optional): _____

Which activities are you most interested in getting involved in? *(Please tick relevant boxes)*

- Document review (academic research)
- Document review (industry)
- Discussion groups
- Further involvement opportunities
- Researcher training sessions
- Preventative healthcare

Confidentiality agreement: I hereby agree and acknowledge that except where such matters come into, or are already properly in the public domain, I will keep secret and confidential all matters relating to the research or affairs of the Trust and will not disclose any such matters to any person unless otherwise agreed in writing by the Trust, or unless I am ordered to do so by a court of competent jurisdiction. If I breach this agreement, I accept all repercussions myself and do not hold CUH responsible for any consequences.

Conflict of interest: I will declare any conflicts of interest prior to the review of any relevant applications or agenda activity. If there is a conflict, NIHR Cambridge BRC reserves the right to ask me not to take part in any activities pertaining to the topic in question. Examples of conflict could include employment with an organisation applying for BRC support or playing an active role in patient or public involvement and engagement on a research study being submitted for review by the NIHR Cambridge BRC

Signed: _____

Print name: _____ Date: _____

If you have any questions please contact Amanda Stranks, PPI Lead at a.stranks@nhs.net or Gail Holloway, PPI Research Coordinator at gail.holloway@nhs.net. Your information will be stored securely in a location that can only be accessed by the CUH PPI Panel Coordinator and the PPI Strategic Lead. Your data will not be shared with any other organisation or department within CUH NHS Foundation Trust without your prior consent. You may choose to leave the panel at any time, for any reason, at which point all your details will be deleted. Details of panel members who have been continuously inactive for longer than one calendar year will be deleted unless otherwise requested. Thank you.