

# Research Engagement Newsletter

## July 2023

### International Clinical Trials Day 2023 Review

Thank you to everyone who joined us in May for our ICTD23 event “Inclusive Healthcare Research: The Conversation Continues. Our programme this year featured examples of best practice in community and public engagement, with excellent presentations from a variety of projects striving to make our research practice more inclusive. These covered topics such as the NIHR’s Research Ready Community Champions Programme, and reflections of public involvement and co-production to support inclusive health research from the Applied Research Collaboration (ARC) North Thames. Hearing the unique stories and experiences from public contributors of these projects was a highlight of the event, as many attendees included in their feedback. The post-event reception also provided an excellent networking opportunity, bringing together a diverse group of people, comprised of staff and members of the public from a variety of backgrounds. Overall, we’re really pleased with how it went and are thankful for those who came and have left us with feedback.



If you were unable to attend the event, you can watch the recording on the Trust’s [YouTube channel](#).

### NIHR Patient Research Experience Survey 22/23 Results

*“I received huge amounts of support and expert knowledge from the team running the trial”.*  
Diabetes study patient

*“The research team are great, value the monthly check in discussions. Also, would be keen to participate in future studies if possible”.* Infection study patient

*“Everyone I have interacted with has been fantastic. Someone has been at hand whenever I needed help or treatment. I have been given full visibility of what the trial will require/offer. I have a good idea of the next 2 years on the study which is reassuring”.* Gastroenterology study patient

These are some of the comments we received from patients as part of PRES 22/23. We are pleased to announce that Barts Health once again recorded the most survey responses to the PRES survey in the CRN North Thames region in 2022/23, surpassing our target of 455 with a total of 513. Of these responses, 424 were completed by adults and 89 by children.

Generally, most feedback was positive; for instance, 98% of people said the research staff treated them with courtesy and respect, up from 95% in 2021/22. We also received a similar score from patients who said they felt researchers valued their taking part in the research, this up to 92% from 91% last year. Based on this experience, 89% of people would consider taking part in research again, marking a significant improvement on the previous year where we received a score of 72%.

There were, however, some areas where we are under-performing compared to 2021/22. For example, only 67% of respondents said they know who to contact if they have any questions or



concerns about the research, a markedly lower proportion than 89% from the previous campaign. We also received a lower score for patients being kept updated on the research (67% compared to 71% in 21/22). Similarly, less than half (49%) of patients said they knew how they will receive the results of the research, whereas 77% of people said they knew in last year's results. Between August and October, the research engagement team will meet with local PRES delivery teams to identify and implement improvements locally in response to feedback they have received.

Please click [here](#) for more information about NIHR PRES 22/23 at Barts Health.

### NIHR PRES 2023/24

We previously shared some important changes made to NIHR PRES for the current year. As we have received a few questions from researchers regarding these, we wanted to share them again:

- There are some slight tweaks on this year's survey, which have already been made to the standard online surveys from last year. As such, please continue to use the same links as before, which are available on the PRES section of the CRN North Thames webpage. I have also attached a resources sheet which includes a link to our full localised guidance for administering PRES on our JRMO webpage and the new links.
- You will no longer be able to offer participants the self-printed copies of PRES (i.e., the PDF versions we've previously circulated). The survey can only be offered online or by using the centralised stick and seal survey for both adults and children. If you would like to receive some stick and seal surveys, updated QR code/ URL slips, please complete the attached form, and return it to [ppie.crnorththames@nihr.ac.uk](mailto:ppie.crnorththames@nihr.ac.uk).
- There is an easy-read survey and a survey for those people who are visually impaired, as attached. Both versions can be printed locally.
- From April 23 onwards, PRES eligibility expanded to include all NIHR-supported portfolio studies with the only exclusions being non-consenting studies and those deemed ineligible by CI/PI/CRNCC.

If you are a researcher delivering an NIHR-supported portfolio study, we encourage you to offer PRES to your study participants. For more information, and to discuss how we can support you, please contact Neeta and James at [patientsinresearch.bartshealth@nhs.net](mailto:patientsinresearch.bartshealth@nhs.net)

### NHS England Guidance on working in partnership with people and communities

The [statutory guidance](#) has been released by NHS England to help work effectively with people and communities. It sets out the main legal duties, reasons for working with people and communities, and the leadership needed to realise these benefits. It also provides 10 principles to follow to build effective partnerships with people and communities, to meet public involvement legal duties and the new 'triple aim' of better health and wellbeing, improved quality of services and the sustainable use of resources.

### Why research inclusion leads to better outcomes: an Asian woman's perspective

One year on from the publication of the Race Equality Framework was published, public contributors Kalsum Akhtar, Syeda Islam and Yesmin Begum have written a blog post for NIHR, reflecting on why this work matters to them as Asian women, and why it would matter to organisations. Click [here](#) to read the full blog post.



## **PPIE Resources**

### **UCL Ethics Guidance for PPIE and Co-production**

As a joint project between UCL Engagement and Co-Production Collective, this report offers guidance for ethical processes when working with public contributors and co-producers. It represents the outcome of over 50 conversations with internal and external experts, including public contributors, lay editors, public engagement/involvement managers, and researchers. You can see the full report [here](#).

### **How do I champion equality, diversity and inclusion in public engagement?**

Developed by Imperial College London, this [resource](#) breaks down some of the terminology around this topic, also providing practical tips and guidance to ensure good practice when planning engagement activities.

### **Managing Difficult Situations in Public Involvement Workshop Report**

How can we manage difficult situations in patient and public involvement? Nuffield Department of Primary Care Health Sciences and NIHR Applied Research Collaboration Oxford and Thames Valley held a workshop, finding that training, systems and processes and culture and expectations are key to support researchers when delivering PPI activities. Read more in the [full report](#).

## **PPIE Opportunities for patients and the public**

### **Opportunity to Join the Lived Experience Network**

UCLPartners are looking for more people to join their Lived Experience Network. This is a diverse community of patients, carers and public contributors who are given opportunities to share their views and knowledge, and work with projects from across our area to make sure that we are tackling the biggest health challenges and developing solutions that work. Please share this with patients who may be interested in joining the Lived Experience Network. [Find out more about our Lived Experience Network](#).

