Sheffield Teaching Hospitals NHS Foundation Trust Participant in Research Experience Survey report (22-23)

Background:

The Participant in Research Experience Survey gives participants in research an opportunity to share their experience of taking part. By using this feedback, research teams can identify the factors that impact on a participant's experience of research participation, and then use them to design and deliver research that will be more appropriate, accessible and meaningful for participants.

This report covers the results of the 2022/2023 adult PRES at Sheffield Teaching Hospitals. Reports from previous years can be found on the Clinical Research & Innovation Office website here.

Summary of results:

A total of 428 respondents from 24 studies completed the Participant in Research Experience Survey across Sheffield Teaching Hospitals NHS Foundation Trust in 2022-2023. This placed us 4th in Yorkshire and Humber, and we exceeded our target set by the CRN for the 3rd year in a row (target of 307). We received ~100 more responses than we had in 2021-2022, from double the number of studies. We are grateful to all the research participants and the study delivery teams for their valuable contribution to this.

The increase in the number of individual studies we are receiving responses for is particularly positive, as it highlights we are giving more participants the opportunity to inform how we can improve delivery of the study for other participants, as well as more generally for other studies across the Trust in the future. In previous years we have highlighted the importance of increasing engagement with Directorate teams to raise awareness of the importance of PRES; the increase in the number of studies that PRES has been received for from across Directorates could be related to this, but may also be related to the initiation of a Clinical Trials Assistant team who are involved in research delivery across many Directorates across the Trust and who understand the value and importance of offering PRES, and have the time with participants to enable this.

As with previous years, the option of completing the PRES online or via paper gives flexibility to both study teams and participants. Approximately 300 participants completed the survey via paper. There are clear benefits to the paper survey in that teams can ensure the correct site/trial information is included (unlike the online survey where participants must correctly enter this information themselves), and participants can complete and return the survey to a member of the trial team at a study visit. However, where visits are carried out remotely, or where teams couldn't provide a hard copy of the survey, the benefits of being able to offer participants the chance to complete the survey digitally are clear. Although digital surveys require participants to enter some site/trial information themselves, teams have effective processes in place to ensure this information is provided clearly. This limits the likelihood the information won't be entered correctly and ensures responses can be attributed to the correct site and study, and thus feedback shared with the relevant team to act on.

Overview of STH responses 22/23 (Quantitative questions)

The information that I received before taking part prepared me for my experience on the study

- 95% strongly agreed or agreed (3% more than 21/22)

I feel I have been kept updated about the research

- 85% strongly agreed or agreed (15% more than 21/22), however 8% neither agreed or disagreed and just 4% disagreed or strongly disagreed

I know how I will receive the results of this research study

- 27% agreed they know how they will receive the results (2% more than 21/22)
- 42% felt they knew to some extent
- 30% did not know how they will receive the results (4% more than 21/22)

I know how to contact someone from the research team if I have any questions or concerns

- 92% strongly agreed or agreed (1% more than 21/22)
- 4% disagreed or strongly disagreed (same as 21/22)

The researchers have valued my taking part in the research

- 94% strongly agreed or agreed (1% less than 21/22)

Research staff have always treated me with courtesy and respect

- 98% strongly agreed or agreed (same as 21/22)

For 69% of respondents it was the first study they had taken part in (6% less than 21/22), and 93% of all respondents would consider taking part in research again (2% more than 21/22)

Free text responses

Participants have the opportunity to give further feedback in their own words and there was plenty of positive feedback based on their own experiences. The reasons people get involved are varied but many people who have been involved in studies during and in the time after the COVID-19 pandemic, report feeling like they are making a valued contribution to medical research that will make a difference to many others.

The comments given can be assigned to various themes:

- *Making a difference to future healthcare*
- *Care and friendliness of research team*
- *Feeling valued and supported*
- *Communication*
- *Practicalities of participation*
- *Reassurance with health monitoring*

Highlights from these positive aspects are detailed below:

"Feeling that I was contributing and that contribution was welcomed and valued. Everything was well explained and all aspects thoroughly professional."

"Everyone involved from admin to clinical staff were welcoming, friendly, informative and professional."

"Excellent staff, so friendly and made me feel appreciated for taking the time"

"I believe the information I received from the beginning of the trial was helpful and informed all my decisions."

As well as giving feedback about positive aspects of their experience, participants were also asked about what would have made their experience better. A large number did state that "nothing" could have been better, but there were more themes that did emerge (including those that also fell into what was positive about their experience). The themes were:

- *Communication*
- *Practicalities of participation*
- *Trial procedures*

Example responses from the above themes included:

Communication – a reminder of how to contact the research team, better explanations as to how the equipment functions, quicker replies to queries, reminder texts for follow ups would be helpful, more feedback about the results of the study, clarity on who to contact for checking appointments or general queries.

Practicalities – keeping visits shorter and less waiting time, being offered refreshments for visits that were longer than stated, better compensation, easier parking and access to the facility, appointments outside of the working day.

Trial procedures – better working of the app which regularly didn't work, having a professional phlebotomist take blood, if the heart monitor stayed on better.

<u>Overall recommendations</u>

Broadly, the findings from 22/23 are very positive and show some improvements on the previous year. Areas for improvement and opportunities for addressing this feedback are:

1) Communication

Study teams will be encouraged to make improvements and will be supported to do so by sharing of best practice, ensuring participant information complies with the new HRA Quality Standards, and encouraging continued involvement of the public in research who can advise on appropriate and timely dissemination of study results.

2) Practicalities of participation

Teams can act on feedback and ensure length of visits are accurately representative of the expected time for study visits (This has already been demonstrated by changes implemented in the Sheffield CRF 2022/2023 Participant Feedback (nihr.ac.uk)). Wider discussions around improving access and enabling parking should take place involving relevant colleagues.

3) Trial procedures

Teams will be encouraged to check software is accessible where possible and be encouraged to feed comments back to Sponsors where improvements could be made (as demonstrated by Sheffield CRF), and will be encouraged to involvement relevant patients and the public in study design to ensure suitability for prospective participants.

Further reading

A bulletin from the NIHR about PRES 22/23 can be found here Participant in Research Experience Survey (PRES) | NIHR with the 22/23 PRES Executive Summary available here 2022/23 PRES Executive Summary | NIHR.

The PRES report for Y&H Clinical Research Network can be found here - 2022/23 Patient Research Experience Survey results: A year of positive feedback from research participants | NIHR