Patient Experience in Research Survey (PRES) Guidance for Barts Health

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Patient Experience in Research Survey (PRES) Guidance for Barts Health

This guidance has been adopted and localised for staff at Barts Health NHS Trust. The original version was produced by Christine Menzies, Patient and Public Involvement and Engagement Manager for CRN North Thames.

1. Why do we deliver PRES?

Through PRES we aim to put research participant experience at the centre of research delivery so that we can:

- Demonstrate to research participants that their contribution is valued
- Positively impact recruitment to and retention within research studies

PRES delivers these aims through:

- Providing an opportunity for as many research participants as possible to share their experience of taking part in research
- Promoting collaboration between research teams and research participants to co-produce solutions to research experience challenges
- Increasing research workforce understanding of factors contributing to a positive research experience for participants
- Increasing awareness of factors likely to impact participant recruitment and retention during the design of new studies

2. How was PRES developed?

PRES began as a pilot within a small cohort of the 15 Local Clinical Research Networks (LCRNs) and their Partner Organisations. Between 2015/16 to 2018/19 the survey became part of the CRNs core business - as reflected by it becoming an HLO. PRES continues to be delivered by all 15 LCRNs and increasing numbers of their Partner Organisations.

In 2019, the CRN, in conversation with stakeholders across the Network and beyond, made the decision to nationally standardise the survey questions and methodology.

The aims of this change were to:

- Support the long term ambition of every participant in an NIHR supported study has the opportunity to feedback about their experience
- Increase the usefulness of the data collected by PRES
- Increase capacity for local CRNs and partner organisations to disseminate and act on the results of PRES by reducing local capacity needed to deliver the survey

The CRN Coordinating Centre worked with the LCRNs to analyse previous surveys and then commissioned the Picker Institute, a charity with globally recognised expertise in patient experience measurement, to further analyse the surveys and methodologies. This led to developing a new national set of questions for adults and children, as well as new delivery guidance.

The new national approach for PRES came into effect from April 2020.

3. What are the benefits of using PRES in our organisation?

3.1 Demonstrating we are promoting a research-active culture

Promoting a research-active culture in our organisation is a requirement of both the NHS Long Term Plan and the Care Quality Commission (CQC) Well-Led Framework. To fulfill the expectations of both, our organisation must demonstrate that we:

- Enable staff to deliver research
- Promote research participation to patients and carers
- Involve patients and carers in your research initiatives

PRES can support us in evidencing that we are involving patients and carers in our research initiatives.

The CQC recognises that a research-active culture is a key indicator of high-quality leadership in health and social care organisations. It assesses the extent to which research is promoted through two mechanisms:

- The Well-Led Framework, introduced in 2019, and
- The annual Inpatient Survey.

The Well-Led Framework (NHS Trusts) expects that there are: 'robust systems and processes for learning, continuous improvement and innovation within health and social care NHS Trusts. This will be assessed as part of inspections through review of the extent to which staff are participating in the delivery of research and the extent to which patients and carers are aware of opportunities to engage in health and care research.

In addition, the CQC Inpatient Survey asks respondents 'During this hospital stay, did anyone discuss with you whether you would like to take part in a research study?' This Inpatient Survey will only capture a certain segment of your patients though. PRES is a way to reach your wider research participants and demonstrate you are actively engaging them in research.

3.2 Celebrating successes and improving research delivery in our organisation

Feedback from research participants can help us understand both what we are doing well, and where there are opportunities to make changes to improve the experience of participants taking part in research at our organisation.

Both the 2018/19 and 2019/20 PRES results were highly positive with the vast majority of respondents reporting a positive experience of taking part in research. These results can be affirming and motivating for research staff, especially the free text responses where research participants are able to share what they particularly valued about taking part.

Where participants report a negative experience, this is also really helpful for research teams. LCRNs and partner organisations across the country have been able to use feedback about what didn't go well to inform improvement projects. This has led to the introduction of many new initiatives in research delivery teams aimed at improving the experience of participants in research.

4. Why use PRES with, or instead of, other research experience surveys?

4.1 To give research participants the greatest influence

By completing PRES, research participants are given the opportunity to use their own experience of taking part in research to help shape research far beyond the study they have taken part in, or the healthcare service they have used. PRES results are published nationally and shared with stakeholders across the research system, including in research funding and design.

Many of the negative issues that participants raise about their experience simply can't be dealt with by the research delivery teams alone - they are often issues that have arisen from the research design, or even funding requirements. By completing PRES, participants are able to ensure their experiences are shared back with the bodies that influence the whole research system.

4.2 To shape and improve an influential participant experience measure

In joining the PRES community, research teams are offered a unique opportunity to contribute, learn and discuss the patient experience in the context of its measurement, and its impact. PRES is the largest survey of its kind in the country, and by having a larger volume of valid data from a wide range of study designs, we generate knowledge to share with research funders and research design teams. In turn, these data can help to support them in providing better health and social care research in the future.

4.3 PRES can work alongside other surveys

Many studies or trusts may have their own surveys of research participants or about patient's care and PRES has been purposefully designed to complement this by keeping the question set short and focused.

5. Ethical guidance on PRES

Following consultation by Clinical Research Network Coordinating Centre (CRNCC) with the NHS Health Research Authority (HRA) in 2019, it has been confirmed that PRES is not research and does NOT require NHS approval before being conducted within health and social care settings. The HRA advises that the results obtained from their online decision-making tools can be taken as authoritative. These are:

- Is my study research?
- Do I need NHS Research Ethics Committee (REC) approval?

The results of the HRA online decision tools for PRES are available for download.

These results are in line with the harmonised UK-wide edition of the Governance Arrangements for Research Ethics Committees (GAfREC) 2018; the UK Policy Framework for Health and Social Care Research (2017) and the National Research Ethics Service (NRES) Defining Research table and algorithm 'Does my project require review by a Research Ethics Committee?'

6. Inclusion of studies and participants

- PRES can be delivered on **studies that are supported by the National Institute for Health Research Clinical Research Network (NIHR CRN)**.
- You can collect PRES responses from participants on other studies that are not on the NIHR portfolio but you will not be able to submit those responses to the Local Clinical Research Network (LCRN) against their High Level Objective target.
- **PRES may not be suitable for some studies or participants**. Studies that are exempt include those where there are concerns over the capacity of the participant to take part in PRES, where studies are a bi-product of a procedure (tissue sampling) or in situations where it is not appropriate to approach a participant e.g. trauma or grief.
- Any participant on a PRES eligible study should be offered the opportunity to complete PRES.
- A participant should only complete PRES **once per study**.
- If a participant is taking part in more than one study eligible for PRES, they may complete PRES **once for each individual study**.
- In the case of studies where participants would have to attend multiple different sites as part of the study protocol (e.g. both a GP surgery and a secondary care clinic), to avoid double-counting, only one of the sites will be able to conduct PRES for that particular study.
- Some participant groups may need accessible or otherwise adapted versions of PRES. Contact the Research Engagement team should you require alternate versions.

7. Distribution of PRES

- PRES should ideally be distributed in a way that **allows participants to complete it alone, not in the presence of the researcher** or another member of staff. This is to reduce bias and enable them to give the most honest and useful feedback.
- PRES is designed with the assumption that it will be distributed **during a participant's final engagement with a study**. Therefore, as your default, you should distribute it at this point.
- Even if you are not able to distribute PRES during a participant's final engagement with a study, you may be able to distribute it at another stage in the study. The key principle is to try, as far as possible, to give it to participants **at the same stage of the study** so the survey measures a consistent length of experience.
- PRES can also be administered by **Patient Research Champions (PRCs)**, independent of the research team. To find out more about how working with PRCs can add value to your team, contact the Research Engagement team.

8. Information Governance and Data Privacy

- While the surveys do not request personal data, respondents may input identifiable and sensitive data on either paper or digital versions of PRES (there are written instructions on the survey advising participants that they must not share personal data.) Therefore, PRES data should be handled with the assumption that it could include sensitive and identifiable data.
- When data is shared with the national CRNCC team for reporting, it has been pre-anonymised by the LCRN and so the CRNCC will never hold identifiable or sensitive data about any research participant in the organisation. For any information held by the CRNCC the data controller is the Department of Health and Social Care.
- PRES results are also reported annually within Barts Health to the Joint Clinical Research Board and via the WeImprove LifeQI platform.

9. Survey versions

There is one adult survey and three children's versions (0-6 years, 7-11 years, 12-15 years). Surveys can be completed online or on paper.

Below are the links to the 4 surveys:

Online survey for ADULTS and over 16s

Online survey for children 0-6 years old

Online survey for children 7-11 years old

Online survey for children 12-15 years old

Three questions which must be answered by staff

There are three questions on the survey, which are to be filled in by staff **BEFORE** handing them to each patient to complete. It is important that staff complete this section to ensure responses are correctly coded. Likewise, if patients are completing the surveys online, staff should make sure participants know the study name and study number (IRAS or CPMS number) of the respective study they are feeding back on. To help with this, research staff must add this information to the URL slips before handing them to the participants.

Questions to be completed by a member of staff.

Full site name, or the site code_____

Study name/acronym:_____

Study number (IRAS or CPMS):_____

10. Site codes

The unique site ID codes should be added to the paper-based versions of the survey or URL slips before being given to the participant to complete. Please make sure all staff members supporting the delivery of PRES are made aware of the site code they are to use. If in doubt, Barts Health NHS Trust can be used. The name must be written in full rather than abbreviated. **Please note: the online survey does not allow site ID codes to be inputted, instead participants are required to select Barts Health NHS Trust from the drop down menu.**

Site Code	Site Name	Trust Name
R1H	BARTS HEALTH NHS TRUST	(To be used for cross-site studies)
R1H12	THE ROYAL LONDON HOSPITAL	
R1H13	MILE END HOSPITAL	
R1HNH	NEWHAM GENERAL HOSPITAL	
R1HKH	WHIPPS CROSS UNIVERSITY HOSPITAL	
R1HM0	ST BARTHOLOMEW'S HOSPITAL	

11. How will the survey be delivered?

Each CRN:NT partner organisation has a nominated PRES lead(s) responsible for the delivery of PRES within their organisation or team. The Research Engagement team (Neeta Patel and James Marshall) are PRES leads for Barts Health, supporting a network of 'PRES Delivery Leads' across our five hospitals. Local PRES Delivery Leads are responsible for the day-to-day delivery of PRES to research participants.

Patients should be given the choice of completing the survey using the paper copy of the survey or the electronic version via the link to Google forms. The electronic versions can be completed using a mobile phone, PC, iPad or other electronic device or alternatively participants can also complete the survey at home if they are given the link for the respective survey along with the answers for the three staff questions (study name/acronym, site ID code or full hospital name, study IRAS or COMS number). To help with this there are URL slips available which list the weblink for the survey as well as the QR code and the three questions, which must be completed by a member of staff before handing the slip to the patient. For paper copies, a local member of the team or a PRC must input results online.

This year CRN: North Thames along with eight other LCRNs are piloting a new centralised postage paid, stick and seal survey. These will include the same questions as the online version but in the format of one handy sheet, which patients can conveniently complete, seal and post in their own time. PRES delivery leads may also benefit from having a collection box or something similar in clinic to put completed surveys in once received, which can be easily sent on to the central processing unit by staff. At the end of each week, the company

uploading the data from this new centralised survey, emails Christine Menzies with details of surveys received from their region, this data is then added to the CRN: North Thames PRES dashboard, along with the online survey data. See below for instructions for accessing the dashboard.

If you would like to receive URL slips and/ or copies of the new centralised survey, please inform christine.menzies@nihr.ac.uk, stating the survey (ie, adult, 0-6yrs, 7-11yrs, 12-15yrs) and the quantity required, along with your full delivery address.

11.1 Conducting the survey over the phone

A member of staff independent from the research staff or a **Patient Research Champion (PRC)**, can contact a patient to ask if they would be happy to complete the survey over the phone to gather an insight into their experience of being a recent study. PRCs are Trust registered volunteers who support research staff by carrying out approved activities, including administering PRES. Patients may feel more comfortable in answering the survey with a PRC over the phone, away from the research site and staff. The Research Engagement team oversee the PRC programme and find placements with research teams across the Trust. If you would like to find out more information, please get in touch with Neeta and James.

If patients are participating in more than one study for different clinical conditions, they are permitted to complete a separate questionnaire for each one, should they wish to do so.

11.2 Targets

Our target for PRES 2022/23 is 455 survey responses. This is based on 3% of the 15,170 participants we recruited to portfolio studies during 2021/22.

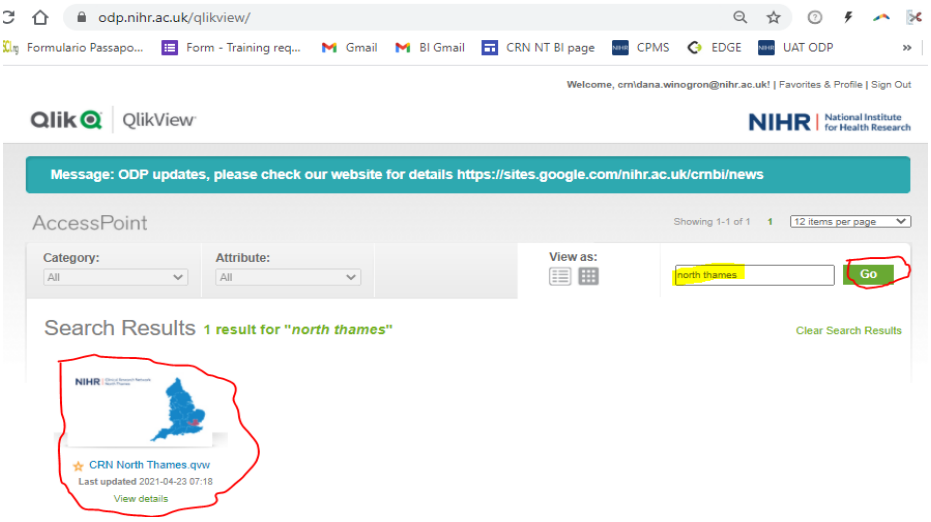
11.3 How to view live data

Sites raw data along with pie charts of their results can be viewed using the PRES dashboard located on the NIHR Open Data Platform (ODP), see link below.

https://odp.nihr.ac.uk/QvAJAXZfc/opendoc.htm?document=crncc_users%5Ccrn%20north%20thames.qvw&lang=en-US&host=QVS%40crn-prod-odp

Please note, you need an ODP account to access the platform. If you do not have one, go to https://portal.nihr.ac.uk/register?app=ODP. You can use your NHS trust or academic email to register.

Once you are logged into ODP, search for “North Thames” in the Search bar



You then need to scroll along the header, to find the PRES dashboard which is the last item listed.

1. Click on Barts, from the 22 partner organisations listed.
2. Click on the survey you want to view the data for, i.e. adult or childrens
3. You can then view pie charts for all the quantitative results. To download the pie charts, simply right click on them, press print, then press ''Save as''.
4. Click on the demographic data to view pie charts for the data by age and also by ethnicity.
5. Further along click on raw data to view all the responses. Right click and then press 'Send to excel' and enable data.
6. You can filter raw data sheet by specialty, IRAS number, study name etc to identify PRES results for your local studies.

The data for PRES 2022/23 can now be viewed on the dashboard. Due to issues with North Thames constructing a new Google survey for PRES 2022/23, it has not been possible to include the data for PRES 2021/22 on the dashboard. In future years, colleagues from Business Intelligence should be able to include data from previous years surveys. However, if you do wish to see data from 2021/22, this can be provided. Please get in contact with James and Neeta to request this information.

12. Questions

Any questions should be directed to Neeta and James, Research Engagement, at patientsinresearch.bartshealth@nhs.net