



NIHR's partnership with Picker ensures its continued quality research

The National Institute for Health and Care Research (NIHR)
fund health and care research



NIHR's mission is to improve the health and wealth of the nation through research. Its Clinical Research Network (CRN) coordinate and support the delivery of high-quality research in the NHS and across wider health and social care settings. The CRNs National Coordinating Centre (NCC) oversees 15 Local Clinical Research Networks (LCRNs) across England. LCRNs help increase the opportunities for participants to participate in clinical research, ensure that studies are carried out efficiently, and support the [Government's Strategy for UK Life Sciences](#) by improving the environment for commercial contract clinical research.

In 2021/22, the NIHR CRN helped 1,289,937 participants take part in over 4,600 trials in England. Participant experience is an important element in maintaining this level of engagement, as positive experiences may encourage participation in future studies.

The Participant in Research Experience Survey

Since 2015/16, the NIHR CRN has conducted the Participant in Research Experience Survey (PRES) annually. Its purpose is twofold; to signal the importance of participant engagement in health and care research; and to provide information to support improvements in participant recruitment, retention, and communication locally. Picker have partnered with NIHR to deliver the data cleaning, analysis and reporting of PRES since the 2019/20 iteration. The 2021/22 PRES survey collected 25,459 responses.

NHS trusts, such as [South Tyneside and Sunderland NHS Foundation Trust](#), believe it is vital to listen to the experiences of research participants and so have embraced PRES as a way to invite participants to share their research experience, with the feedback shared across their teams and wider Trusts.

Examples of PRES data being used to optimise participant experience nationally include the adaptation of appointment times to suit people with additional needs, using Public Research Champions to 'road test' the end-to-end participant journey before opening, and the creation of participant feedback postcards to address a reported lack of knowledge about what happens in/during/after a trial.

Working with the NIHR to continually improve PRES

The NIHR CRN approached Picker in 2019 to conduct a review of PRES to evaluate if the programme was continually meeting its objectives. Following the review, Picker provided recommendations for improving the survey methodology and questionnaire. This included:

- Proposing cognitive testing to assess how people understand, interpret, and respond to questions.
- Suggesting LCRN's retain flexibility in determining methods of administration but recording the response method.
- Providing advice around data collection methods to maximise data quality.

Further to the review, Picker have partnered with NIHR to deliver the data cleaning, analysis and reporting of PRES since the 2019/20 iteration.

Over time, Picker and the NIHR CRN have developed a strong collaborative relationship to implement a range of improvements to PRES. Our partnership actively seeks opportunities to achieve greater impact by encouraging ideas and knowledge to be shared freely. Some examples of recent improvements are summarised in the next section.

Adapting PRES for Children & Young People

In its original form, PRES was designed for adult participants. While some LCRNs independently developed and implemented separate surveys for children and young people (CYP), the format, design, and content varied. Picker, boasting a wealth of experience in developing tools to measure the experiences of CYP across various healthcare settings, was approached by NIHR CRN in 2020 to perform a review of the content of existing LCRN CYP surveys. As a result, Picker made several recommendations for a standardised, national version which have since been adopted, including:

- Using three versions of the CYP surveys for different age ranges.
- Ensuring direct and unambiguous question wording.
- Incorporating the same question areas covered in the adult PRES.

Accessibility review of PRES

As part of a wider accessibility review at CRN and following the NIHR adopting Picker's recommendations for the CYP PRES surveys, Picker advised how to approach delivering PRES to participants living with cognitive or visual impairments. Picker recommended that two adapted versions of the adult PRES questionnaire be developed: one for participants with a cognitive difficulty and another for people with a visual impairment.

Engaging stakeholders on PRES reporting

In March 2023, Picker engaged various stakeholders across LCRNs via a remote workshop to understand views on PRES reports and how they might be improved. Stakeholders provided valuable insight into the barriers they face transitioning PRES data into actionable improvement plans. This insight informed a set of recommendations for NIHR CRN to consider going forward, including the creation of LCRN-specific reporting and data tables.

Future partnership between Picker and NIHR

The success of Picker's previous analysis of PRES has led to their appointment of delivering and reporting PRES 2022/23. Picker have supported the CRN to create automated validation of PRES data submissions by coding script into data entry spreadsheets which serves to cross-check data against validated lists. Consequently, the process for data checking has become more efficient and seamless, maximising both data quality and reducing burden on the CRN and on individual LCRNs.

Speaking about the collaboration with Picker, Dr. Angela Polanco, National Head of Public Engagement for NIHR CRN, said:

"Picker has been transformative in helping the NIHR turn PRES into a standardised national-level tool that captures the participant experience in a way that is accessible, easy to use and scalable to our 15 Local Clinical Research Networks. Picker has consistently provided high-level and professional consultation to explore elements of the survey, which has led to direct improvements for national and local level reporting and data analysis".



About Picker

We are a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care.

We work with NHS trusts, government bodies, charities, academic institutions, and commercial organisations, and are an approved contractor for the CQC.

Our eight Principles of Person Centred Care provide an internationally renowned quality improvement framework.

The Picker Principles



Fast access to reliable health advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement and support for family and carers



Clear information, communication and support for self-care



Involvement in decisions and respect for preferences



Emotional support, empathy and respect



Attention to physical and environmental needs

About NIHR

The National Institute for Health and Care Research fund, enable, and deliver world-leading health and social care research that improves people's health and wellbeing, and promotes economic growth.

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