

Participant in Research Experience Survey (PRES)



NIHR Clinical Research Network
Coordinating Centre (NIHR CRN CC)

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What obstacles or opportunities do you see for delivering PRES?



PRES questions

FOR STAFF USE:

Study name/acronym: _____

Research site (Hospital/GP Practice): _____

Study IRAS/CPMS Number: _____

Optional:

- ages - 0-6; 7-11; 12-15
- demographics
- contact information

Please rate how strongly you disagree or agree with the following statements about your research experience by ticking the face or circle that matches your answer best.

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

Strongly disagree Strongly agree I don't remember

I feel I have been kept updated about the research

Strongly disagree Strongly agree It is too early to tell

I know how I will receive the results of the research

Yes Yes, to some extent No

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

Strongly disagree Strongly agree

The researchers have valued my taking part in the research

Strongly disagree Strongly agree

Research staff have always treated me with courtesy and respect

Strongly disagree Strongly agree

I would consider taking part in research again

Strongly disagree Strongly agree

2

Please use the boxes below to explain your answers to the above questions or provide any other feedback on your experience in research.

The comments that you write will be read in full by your healthcare provider and NIHR. We may use your comments in reports about research and for promotional activities, but we will remove any information that could identify you before publishing any of your feedback.

The NIHR Privacy Statement can be found here:
www.nihr.ac.uk/documents/nihr-privacy-policy/12242

What was positive about your research experience?

What would have made your research experience better?

How long have you been taking part in this research study?

Less than three months
At least three months but less than one year
At least one year but less than three years
Three years or longer
Not sure

Is this the first research study you have taken part in?

Yes No

Who completed the survey?

The person taking part in the research
The person taking part in the research with someone else
Someone else on behalf of the person taking part in the research

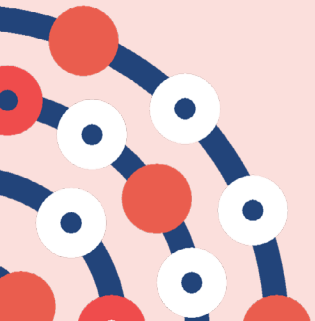
3

PRES methodology

- Regionally adapted and coordinated
- Delivery teams distribute
- Paper or online
- 5-mins to complete
- Given at final or the same stage of engagement
- Complete it alone
- Once per person per study
- Doesn't need HRA REC approval



How might you use the PRES results?

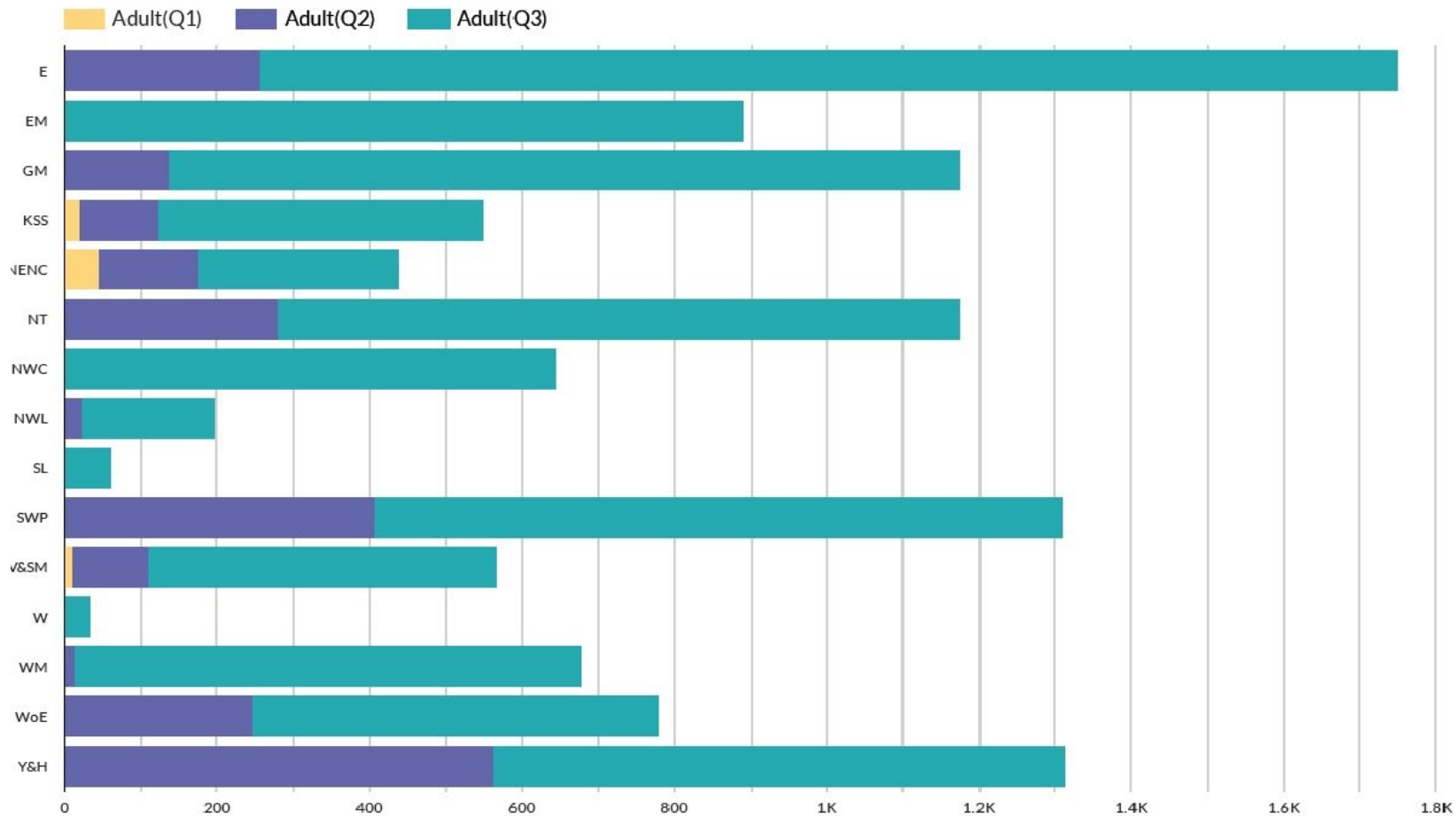


Q3 2020/21

- 11,562 adult responses
- 456 studies
- 178/357 Trusts & CCGs

- 75% of responses for UPH
 - 43% of which vaccines
- 49% digital responses

Highest responding studies (<i>vaccine</i>)	<i>n</i>
SIREN	3109
Novavax (<i>v</i>)	2839
Oxford/AstraZeneca (<i>v</i>)	1905
ENSEMBLE 2 (<i>v</i>)	414
Clinical Characterisation Protocol for Severe Emerging Infection	293



Example themes from PRES 20/21

COVID Vaccines

Fears about site safety is arising as a minor but present issue. One participant reported receiving no information about how the hospital was being made COVID safe

Participants are not arriving with realistic expectations about visit lengths and waiting times- wait times can then feel disorganised when participants don't know what is going on

Use of apps and journals is confusing some participants and they are not clear where to get support from with this.

Many participants are receiving less communication than they expected about the study progress and what's expected from them eg reminders about their next visit

Participants want greater clarity about how the roll out of approved vaccines will affect the study they are part of and also updates when there are issues in the news such as trials stopping due to safety

Example themes from PRES 19/20

Insights	Recommendations
<p>Regular communication, throughout the research process, was highlighted as being important to a lot of people.</p>	<p>Keeping people informed about research changes and procedures at all stages of the project may help keep people's motivation to continue</p>
<p>People participate in studies for a range of individual reasons both personal and altruistic.</p>	<p>Understanding a person's motivation for participating can help you to understand how to make them feel more fully engaged.</p>
<p>The relationship with the research team impacts on whether participants have a positive research experience.</p>	<p>Experiences with the research team could be made even better through improved scheduling and preparedness and ensuring the research team are available to answer questions and address arising concerns.</p>

Filter Results By:

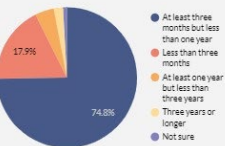
Partner Organisation Study Name Study ID Speciality

Paper or Electronic? Commercial or Non-Commercial Age Group

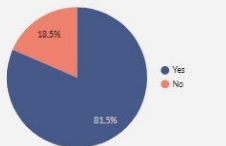
Year

Total surveys completed: **1,125**

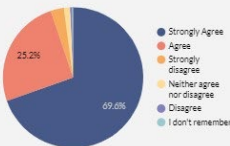
How long have you been taking part in this study?



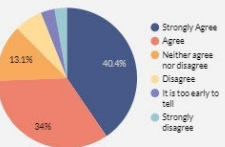
Is this the first study you have taken part in?



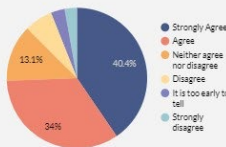
The information that I received before taking part prepared me for my experience on the study.



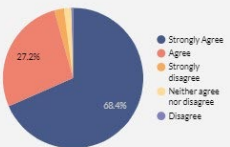
I feel I have been kept updated about the research.



I know how I will receive the results of the research.



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



Search...



Research Participant Experience Survey Report 2018-19

Published: 20/05/2019 | Read Time: 32 minutes | Version: 4 | Print this document

Contents

What is this Report about?

This report shares results of the Research Participant Experience Survey 2018-19. The survey is about the experience of participants in health research. Individuals were surveyed between April 2018 and March 2019. The survey has been conducted annually by the National Institute of Health Research since 2015-16. It is carried out to help continually improve the experience of taking part in health research. It gives participants a chance to feedback on what went well and what could be improved and this report is produced and shared with a wide range of stakeholders in the health research community. This year the title of the report has changed from 'Patient Research Experience Survey' to 'Research Participant Experience Survey'. This is because individuals that take part in research are typically referred to as 'participants' and may not necessarily be patients.

A note on the terms used in the report

Where the expression 'n%' is used it means the number of people who answered that question. For example, 'n=807' means 807 answered the question.

Participants: an individual who took part in a health research study

Respondents: individuals who filled in this survey to feedback on their experience of participating in health research

1. What is this Report about?
 1. A note on the terms used in the report
 2. Acknowledgements
 3. Introduction
 3. Executive Summary
2. Delivery
 1. Design
 2. Research Intervention:
 2. Research Staff:
 3. Study Information:
 4. Study organisation and environment:
3. Recommendations
 1. Recommendation
 1. Insight from Survey
 2. Recommendation
 1. Insight from Survey
 3. Recommendation
 1. Insight from Survey

Search...



Patient Research Experience Survey results 2019/20 - CRN Greater Manchester

Published: 07/09/2020 | Read Time: 3 minutes | Version: 1 | Print this document

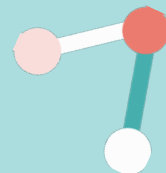
Contents

Greater Manchester patient responses - data overview

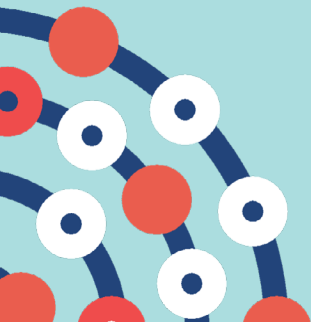
Which health area was the study in?

- Meningitis - 908**
- Cardiovascular - 119
 - Diabetes - 94
 - Lung - 64
 - Cancer - 103
 - Breast cancer - 45
 - Renal - 37
 - Urology - 40
 - Prostate cancer - 38
 - Neurology - 21

1. Greater Manchester patient responses - data overview
 1. Which health area was the study in?
 2. I was given all the information I needed in relation to the study.
 3. How old are you?
 4. How did you find out about this study?
 5. It is important to me to know the overall results of the research study. (rated on a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree)
 6. I had / am having a good experience taking part in research. (rated on a scale of 1 to 5, where 1 is



Examples from PRES



Lift No.11

RESEARCH TODAY
SAVES LIVES
TOMORROW!

Did you know...

that Broomfield Hospital encourages patients to take part in research?

Research is for everyone and can be anything from letting us analyse your health records, to trying out a different or new treatment to improve your health.

Please ask your healthcare professional and GP about research today.

@MEHTresearch

“I WAS WELL
INFORMED
& LOOKED
AFTER”

“THE STUDY
PROVED
BENEFICIAL
& HELPFUL”

NHS
Mid and
South Essex
NHS Foundation Trust



NIHR CRN East Midlands

@NIHRCRNEastMids

It's fantastic to see that so many people who have taken part in #COVID19 research are interested in being involved in more research studies in the future!

#ResearchVsCovid

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East Midlands



of people who took part in COVID-19 research in the East Midlands said that they would consider taking part in research again

Figure from the Participant in Research Experience (PRE) followed by NIHR CRN East Midlands and regional partners.

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Network Eastern

Recruitment Enhancement Tool for Research Delivery Teams:
Learning from the experience of people who have taken part in research

This document is a recruitment enhancement tool, designed for use by clinical research teams delivering research studies. The information contained in this document is based on feedback from over 7,000 research participants between 2015 and 2020 via the Participant in Research Experience Survey. The survey is produced by the NIHR Clinical Research Network Eastern and delivered annually by research teams across the Eastern region. The information in this document comes directly from people who have taken part in a research study, their words, their experiences and their ideas for improvement.

The aim of the document is to give research staff a better understanding of what is important to the participant during the delivery of the research, so that they can make improvements in the service they provide and enhance participant experience where possible. Improving participant experience will help to ensure recruitment and retention to the study is successful.

Your voice is important too!

Research delivery staff can be influencers. You may feel that you cannot control what national study teams provide, however you are the patient's advocate. Feeding back comments and suggestions from patients on how to improve study delivery may not result in changes to the current study protocol but it could influence future study design.

NIHR | Clinical Research Network
Thames Valley and
South Midlands

CRN TVSM staff:
could public
volunteers help you
explain your study
better to patients?





crncc.ppie@leeds.ac.uk

Additional links:

- [NIHR website](#)
- [NIHR CRN](#)
- [NIHR CRN Portfolio](#)
- [PRES](#)

