

THANK YOU!

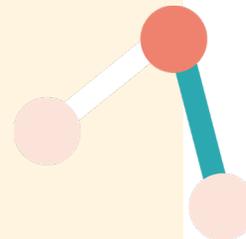


Participant in Research Experience Survey 2020-21 Report

Summary

The Participant in Research Experience Survey (PRES) is a confidential evaluation of the experience of taking part in research studies supported by the National Institute for Health Research (NIHR) Clinical Research Network (CRN). In the West of England, the survey is distributed to participants by study teams and administered by the Clinical Research Network West of England (CRN WE).

Last year, the survey ran from August 2020 until March 2021 and was the CRN WE's most successful year for PRES responses. 1,126 people took the time to complete a survey, almost double the 621 responses received during the previous year.





Background

The COVID-19 pandemic presented the NIHR with an unprecedented challenge. As COVID-19 case numbers increased across the UK in early 2020, it was necessary to pause many non-COVID-19 studies as both research and NHS services responded to the pandemic and to ensure patient safety. The NIHR has been at the forefront of research into COVID-19, by coordinating research activity across England through prioritised Urgent Public Health (UPH) studies.

In 2020/21, clinical research in the West of England saw a 73% increase in recruitment, with **74,537 participants** taking part in research compared to 43,198 the previous year (2019/20). Participants in the region were recruited into a total of **401 studies** across **248 sites**. 34,192 participants volunteered in 35 UPH studies.

Qualitative responses

What was positive about your research experience?

945 (84%) respondents left a comment explaining what made their research experience positive. The majority of these comments, which take up over 25 A4 pages, mention the friendliness and professionalism of research staff.

“The dedication and organised manner of staff especially given the whole process. Was so impressive given the scale and time limits of running the study. Both admin, communication and clinical aspects were fantastic.”

“The staff were always extremely positive, friendly and helpful and made me feel extremely at ease.”

“Slick, well organised team so visits were as short as possible. Feels good to be part of a study which may be of national and international benefit.”

Other positive comments from participants mentioned that they felt they were contributing and helping the community.

“Feel like I’m helping in some small way in pandemic.”

“Being actively involved in helping to find a vaccine. Helping the community”

“Proud to be trying to help find a solution to COVID.”

“I felt like I have been contributing to my community and globally.”

Vaccine related studies: What would have made your research experience better?

391 respondents (65%) did not give an answer to this question. 22 respondents answered there was 'nothing that could improve' the research; their experience was 'perfect' and 'very positive'.

Across the remaining 194 respondents (32%), these themes became apparent:

Parking and travel: Ten respondents mentioned parking difficulties. Three people mentioned appointments closer to home would be better, three thought it would have been easier if the appointment had always been in the same place.

Expenses: 12 respondents expressed a desire for parking expenses or general expenses to compensate for missed work, including comments relating to how this affects equality and diversity.

Refreshments: Eight people asked for refreshments.

Priority post boxes: Five people expressed annoyance at having to use or difficulty finding priority post boxes, or difficulty getting there before the last collection.

Technical: There were 20 comments about technical issues, such as website design. five people asked for less paperwork. Three people would have preferred text reminders rather than emails. One person highlighted how, when experiencing technical issues, there was no way to get help.

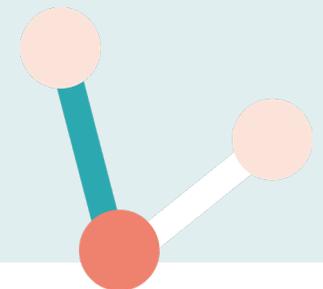
Questionnaire clarity: Three people found the questionnaires too long, difficult to fill in or unclear.

Communication about the study: 22 respondents expressed interest in more information and more regular communications. There were comments that expressed the desire for more details about the study, more regular updates about the study and how it works, and generally asking to be kept up to date with developments.

Communication about appointments: 12 people expressed that overall study communications could have been improved, highlighting the need for clearer communication over specifics of study changes. 12 people suggested more appointment availability, especially for out-of-hours times or weekends.

Mixed messaging: 17 people mentioned difficulties with appointment emails, getting hold of the appointment team or discrepancies in messaging.

Swabbing: 12 people mentioned the swabbing - calls for less swabbing, and/or to be informed about the amount of swabbing prior to signing up.



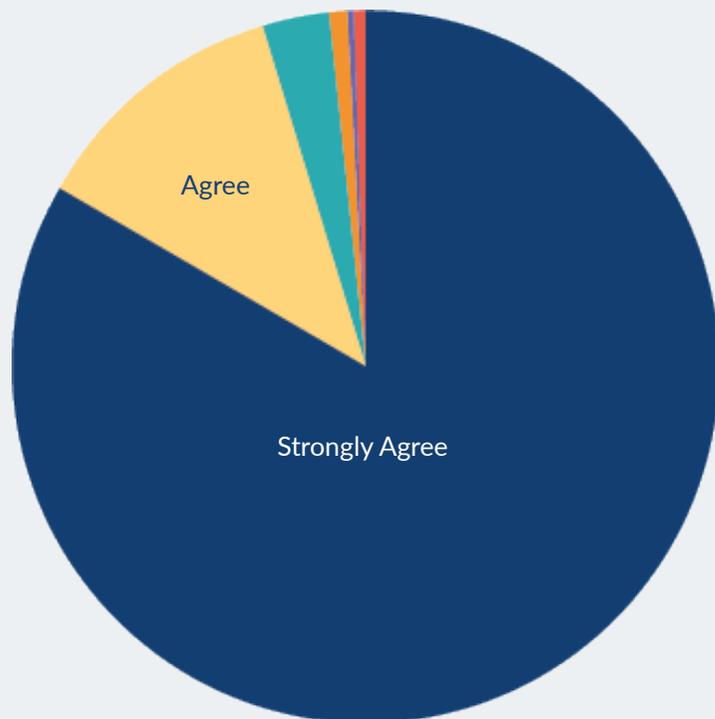
Non-vaccine related studies: What would have made your research experience better?

357 PRES were identified as being completed by a non-vaccine study participant.

79 (22%) of the respondents in a non-vaccine study (of those PRES returned with identifiable studies) offered further commentary to the free text question, 'What would have made your research experience better?'

The main theme of the comments is around requests for better communications - more communication throughout and for outcomes to be communicated, either results of the personal tests undertaken or the overall outcome of the research in general.

Quantitative responses



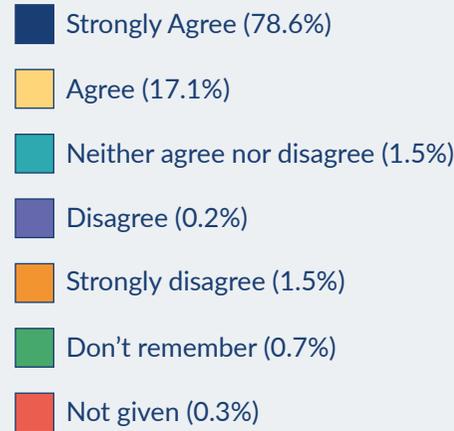
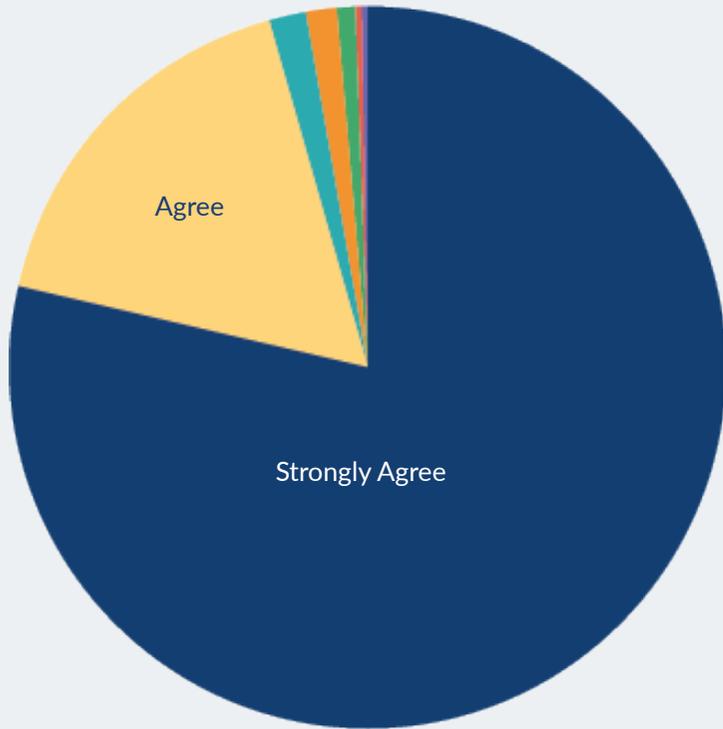
I would consider taking part in research again

95.4% of respondents either strongly agreed or agreed with this important statement. This highlights that taking part in research is an overwhelmingly positive experience for participants in the West of England.



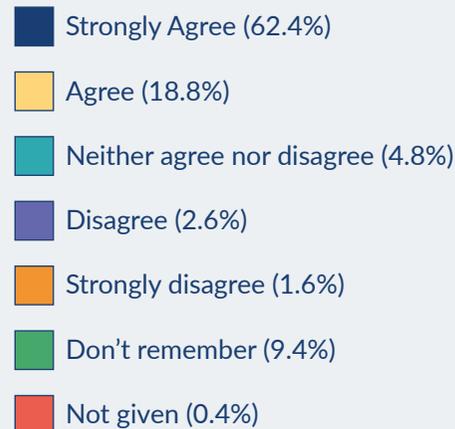
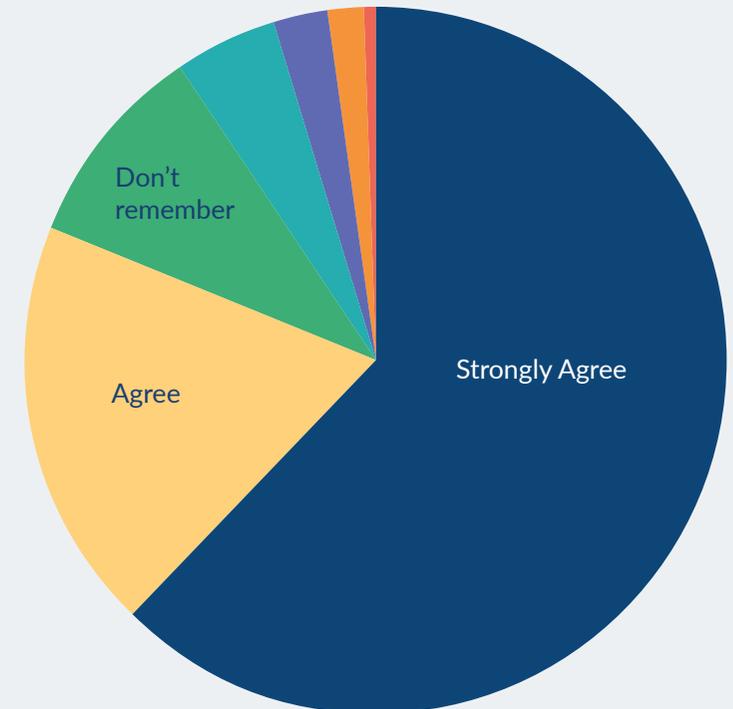
The information that I received before taking part prepared me for my experience on the study

It's positive that 95.7% of people either strongly agreed or agreed that the information they received before taking part prepared them for their experience on the study.



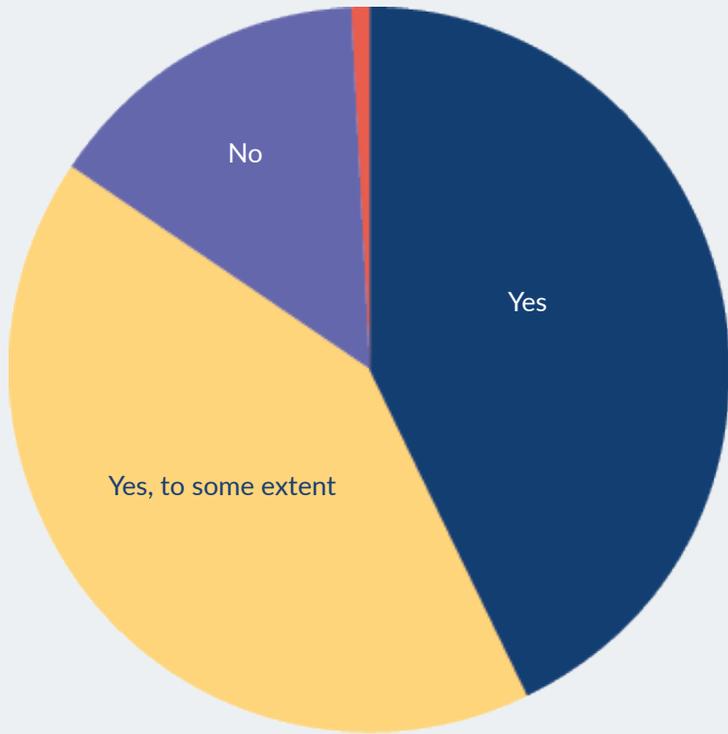
I feel I have been kept updated about the research

The majority of respondents (81.2%) felt they had been kept up to date about the research. For the 9.4% of respondents who said it was too early to tell, this may be related to the time it takes for research results to be published.



I know how I will receive the results of the research

Whilst the majority of respondents knew how they would receive the results of the research, the uncertainty from a number of respondents shows there is room for improvement. Although publication of results may be some time in the future, it is important to put systems in place to share these results and communicate to participants how and when this will be done.

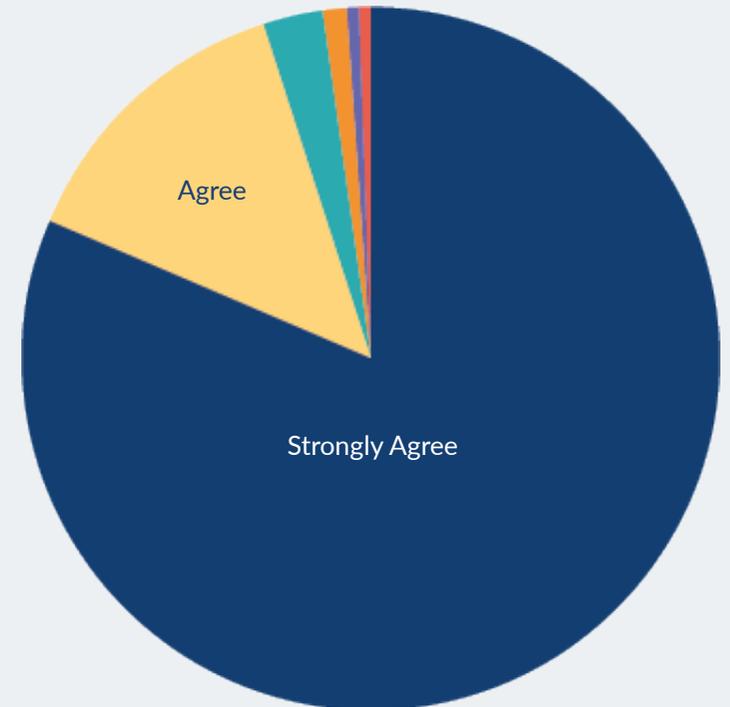


- Yes (42.9%)
- Yes, to some extent (41.6%)
- No (14.7%)
- Not given (0.7%)

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

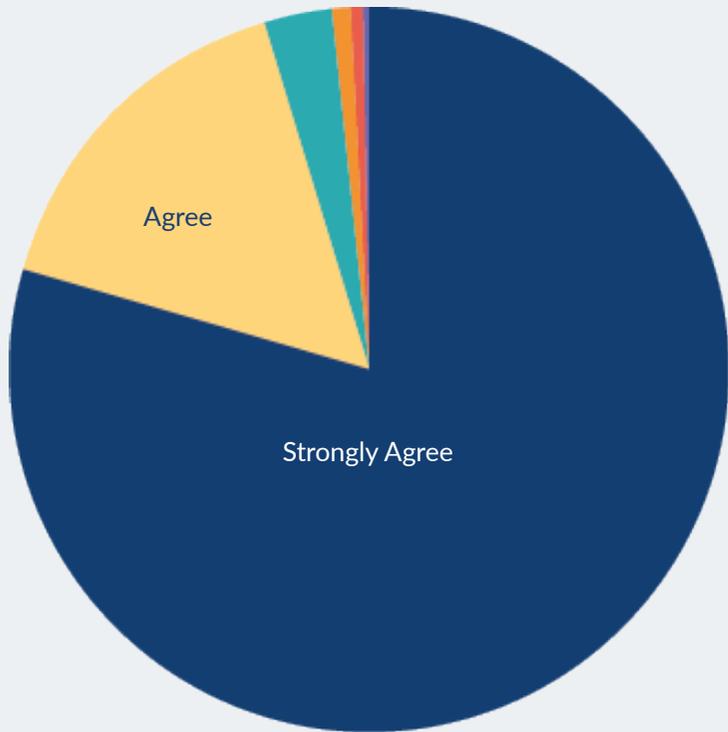
It's encouraging that the majority of respondents know how to contact the research team if they have any questions.

- Strongly Agree (81.6%)
- Agree (13.4%)
- Neither agree nor disagree (2.8%)
- Disagree (0.7%)
- Strongly disagree (1.1%)
- Not given (0.4%)



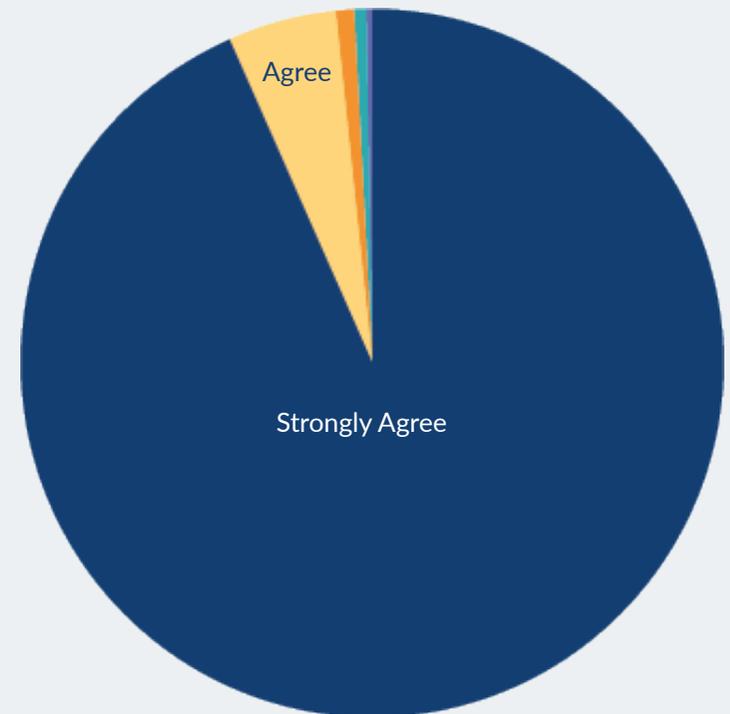
The researchers have valued my taking part in the research

It's positive that 95.4% of people either strongly agreed or agreed that researchers valued them taking part in research. Participants are at the heart of clinical research; without them, many of the discoveries and advances we make would simply not be possible.



Research staff have always treated me with courtesy and respect

98.3% of respondents felt the research staff always treated them with courtesy and respect, this mirrors the comments received in the qualitative question which highlighted the friendliness and professionalism of research staff.



Recommendations

The responses received from the PRES overwhelmingly demonstrate that the majority of participants in the West of England have a positive experience of taking part in research.

With this in mind, the CRN West of England is always looking to highlight areas of learning and identify any opportunities to improve the experience of taking part in research.

The CRN WE will work with research staff in the region to implement the following recommendations:

- Participants should be kept up-to-date about the research - 15% of respondents stated they did not know how they would receive the results of the research.
- The CRN WE will work with researchers and partner organisations to evaluate and improve the representativeness of our PRES responses.
- Participants should be offered diverse clinic times, including out-of-hours and weekends.
- Study specific issues, which have been fed back to study teams, should be considered in future study designs.
- Researchers and research teams should work to reduce waiting times where possible - although it should be noted that some waiting time is unavoidable in vaccine clinics which require post-vaccine observation.
- Participants should be provided with sufficient information up-front about time commitment, number of visits, requirement for regularity of swabbing. This is something that can be developed at both the pre-screening and consent stages.
- Explore the possibility for refreshments and/or communicate with participants in advance to let them know that refreshments may not be available.

Next steps

The recommendations listed above will be used to develop an action plan to address the themes identified from the PRES responses.

Responses from the ongoing survey are regularly shared with study teams to enable real-time analysis and improvements to practice. This will ensure participants' experiences play a role in shaping how studies are delivered.

