Participant in Research Experience Survey (PRES) 2022/23

Annual Report

Participant in Research Experience Survey

The Participant in Research Experience Survey (PRES) has been conducted annually by the National Institute for Health and Care Research (NIHR) Clinical Research Network (CRN) Coordinating Centre (CC) since 2015/16. Through PRES, NIHR CRN CC aims to make research participant experience central to research delivery by providing an opportunity for as many research participants as possible to share their experience.

PRES also promotes collaboration between research teams and participants to co-produce solutions to challenges in the design and delivery of research studies that are identified through participant feedback.

PRES content and design is coordinated nationally by NIHR CRN Coordinating Centre, with continual development guided by the PRES Advisory Group. Delivery of the survey is coordinated by 15 Local Clinical Research Networks (LCRNs) across England, and their partner organisations. Analysis of survey results is undertaken by Picker[1].

Acknowledgements

Huge thanks are given to all the participants in health and care research, and to the respondents of the Participant in Research Experience Survey, without whom world-leading health and social care research would not be possible.

We thank the 15 Local Clinical Research Networks and their Partner Organisations for their work in coordinating the distribution of the surveys and to the PRES Advisory Group members and Public Partners for their expertise and valued contributions.

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[1] www.picker.org

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Executive Summary

The Participant in Research Experience Survey (PRES) is now in its eighth year. PRES enables study teams and sites to understand the experience they are offering their research participants, providing intelligence on what improvements need to be made to help improve participant recruitment and retention. PRES feedback is also important to help support participants' wellbeing and encourage willingness to take part in research again in the future.

In 2022/23, a total of 32,603 participants from over 2,400 research studies completed the PRES, an increase of 27% on the previous year:

- 30,705 responses to the adult participant PRES were received, a 21% increase from 2021/22 (n=30,705 vs 25,459).
- The number of responses to the Children and Young People Survey ('CYP' - defined as those under the age of 16) increased by 653% from the survey's first iteration in 2021/22 (n=1,898 vs 252).

The survey received positive feedback for:

- Being given clear information at the start of the research study (86% of CYP participants agreed that study information was 'easy' to understand).
- Being treated with kindness/ courtesy and respect by the research team (70% of CYP and 72% of adults said they 'strongly agreed').

Participants' reported a less positive experience for:

- Knowing how they would find out the results of the research study (only 40% of adults said 'yes').
- Being kept updated about the research study (only 46% of CYP and 43% of adults said 'strongly agree').
- Knowing how to contact someone from the research team should they have any questions (only 47% of adults said 'strongly agree').

In 2022/23, alternative Easy Read and Large Print versions of the adult survey have been introduced to enhance accessibility and inclusion.

In 2023/24, the NIHR CRN CC should continue to facilitate the sharing of best practice examples across LCRNs so that participant information and communication is clear, timely and responsive. Efforts to boost the number of adult and CYP surveys should continue across all LCRNs to ensure a representative data set for 2023/24.

32,603 participants from over 2,400 research studies gave their feedback in 2022/23

Image created by Stan Podoba/Adrien Coquet from the Noun Project

Introduction

About PRES

The adult version of the Participant in Research Experience Survey (PRES) has been conducted annually by the National Institute for Health and Care Research's (NIHR) Clinical Research Network (CRN) Coordinating Centre (CC) since 2015/16. The survey was extended to capture the experiences of children and young people for the first time in 2021.

Participant feedback helps the NIHR CRN CC understand the factors that impact upon people's experiences of research and their willingness to put themselves forward for studies. This enables research teams and participants to shape future trial design and delivery. The survey has also been made a

Higher-Level Objective by the Department of Health and Social Care (DHSC) meaning that the importance of listening to research participant feedback is recognised by both DHSC and NIHR CRN CC[2].

The survey intends to highlight the importance of participant engagement in clinical research and to provide information to support improvements in participant recruitment and retention.

Over time, NIHR CRN CC is committed to ensuring that every research participant has the opportunity to provide feedback. As such, the development of PRES is ongoing to respond to the changing needs of the patient population. To date, this has been done by introducing an online version of the survey and by developing separate versions for children and young people. More recently, the survey's readability has been enhanced with the development of Large Print versions that meet the minimum recommended requirements for people with low vision, and an Easy Read version for people who find it easier to navigate a survey with pictures and fewer words. These were piloted and launched in April 2023.

This report presents findings from both the 2022/23 adult and Children & Young People (CYP) surveys.

About the NIHR Clinical Research Network

NIHR's Clinical Research Network (CRN) CC supports patients, the public and health and care organisations across England to participate in high-quality research, thereby advancing knowledge and improving care. The CRN comprises 15 Local Clinical Research Networks (LCRNs) and 31 clinical specialties (e.g. cancer, pain management, neurological disorders) who oversee the delivery of high-quality research by region and therapy area. National leadership is provided through the NIHR CRN CC.

The NIHR CRN CC supports the delivery of high-quality health and care research in England by providing funding for staff, facilities, equipment, and support services, ensuring that research is not subsidised with funding that has been earmarked for health and care treatments and services. The NIHR CRN CC also provides a vast range of national and local resources and activities - such as specialist workforce training, management of information systems that support research, patient and public involvement opportunities and communications resources - with the aim of supporting health and care organisations, staff, patients, and service users to be active in health and care research.

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[2] https://www.nihr.ac.uk/documents/research-participant-experience-survey-report-2018-19/12109#Delivery

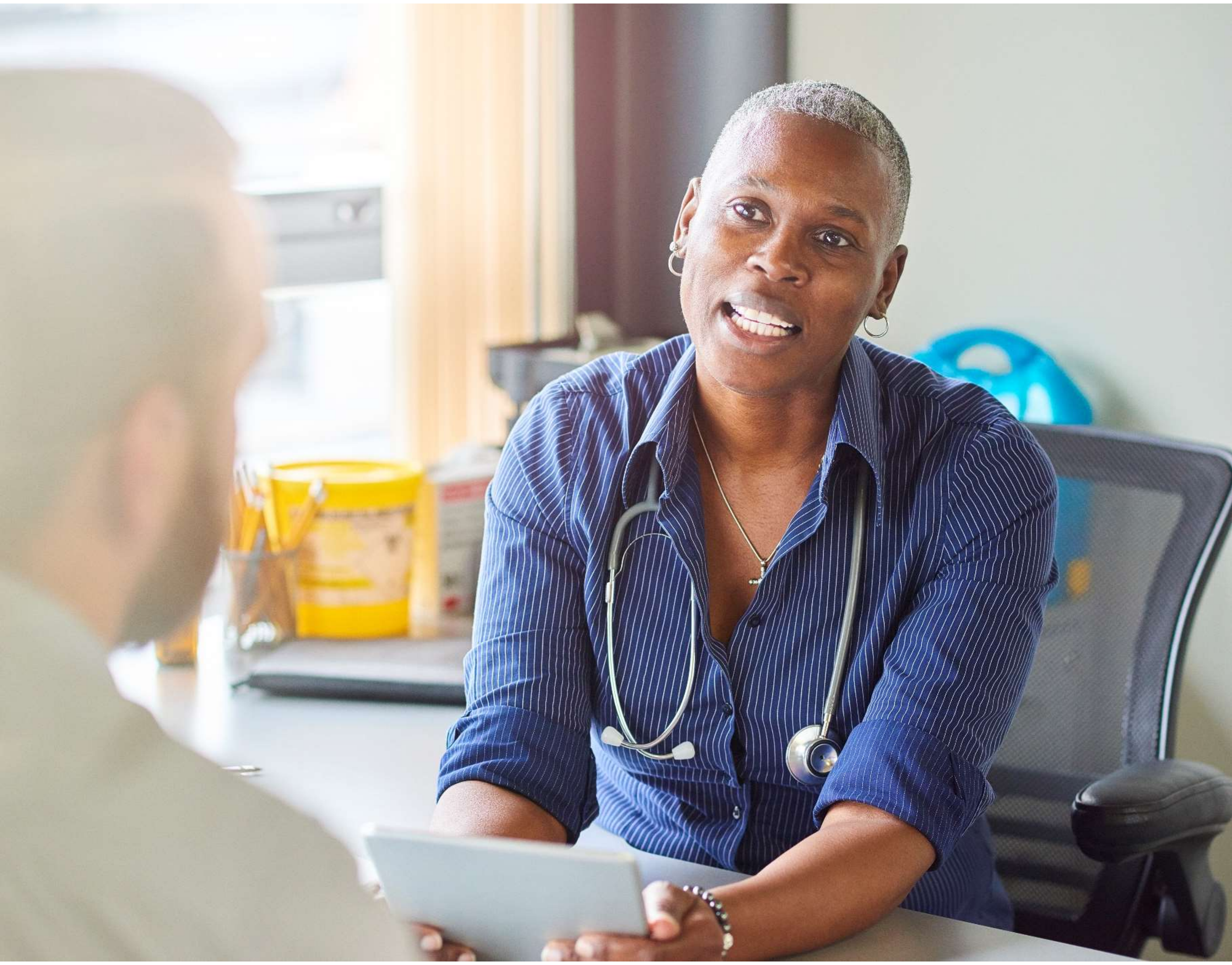
About Picker

Picker is a leading international health and social care charity. Picker carries out research to understand individuals' needs and their experiences of care. Picker:

- Influences policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspires the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empowers those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

About the PRES Advisory Group

The PRES Advisory Group provides expert guidance and decision making to the NIHR CRN CC in relation to the future development and implementation of PRES. The Group is made up of representatives from the NIHR, LCRNs, their partner organisations, public members, research design specialists, and accessibility and inclusion experts.



Impact of PRES recommendations 21/22 report and progress in 22/23

1. **Continue to promote and prioritise positive relationships between research site staff and study participants;** *Ensure staff have time allocated to build relationships with participants and respond to concerns and queries in a timely way. This may be particularly important to do with those for whom it is their first research experience.*

The LCRNs have worked to improve communications with Partner

Organisations in all regions to raise awareness of PRES and encourage study teams to have conversations with research participants about taking part. This is demonstrated in a rise in responses overall for both adult and CYP PRES. East of England LCRN developed an online PRES module to be delivered to research sites to explain what PRES is and why it is an important tool to improving relationships between study teams and participants. This online module was adopted at the national level for the use of anybody who is delivering PRES across Partner Organisations. Patient and Public Involvement and Engagement (PPIE) Leads have used various methods to encourage conversations about participant experiences during a study and acting swiftly on site-level data (e.g. offering water in a waiting room or better signage to the research area).

2. **Consider how recruitment and retention strategies could take into account the specific motivations of potential participants and respond to these;** *Emphasise the altruistic benefits of volunteering for research and explain the difference participating will make. The benefits of taking part should be made clear in patient information including helping participants learn about their condition and about research.*

Study teams have reported (via PPIE Leads at national meetings) and via the national impact framework, that staff feel confident in having open and transparent conversations with participants about what taking part in research means for them. Be Part of Research and Join Dementia Research participation platforms have formed part of conversations at a site level, to signpost participants of a trial who might be interested in taking part in other research studies or opportunities for their family/friends.

3. **Positive feedback relating to research staff should be disseminated to staff to recognise the role they play in ensuring participants' experience is positive;** *Local and national findings from PRES could be shared with delivery teams to celebrate these successes, and could be used to help emphasise the importance of relationship building when training new research staff.*

National level PRES findings are shared with national, regional and local research delivery teams via email, monthly LCRN PPIE meetings, National Research Operational meetings, PRES Advisory Group meetings and disseminated to our community groups, research champions, the wider public and key stakeholders. Data is shared monthly, quarterly and annually by the NIHR CRN CC team, with regional and local partners feeding back more often. The mechanisms that PRES uses (centralised processing for paper versions, digital PRES dashboards and local LCRN data cleansing) ensures that any direct study site feedback is fed back in 7 days from the receipt of participant data. This allows for immediate escalation of any issues that may affect participant experience or trial delivery.

4. **(a) Communication to research participants, specifically regarding information provision, study results, and dissemination of contact details, should be improved for both adult and CYP studies;** *Information needs to be provided to participants at the right time and in the right format.*

   The results from PRES show that some participants are not always clear on what will be involved in a study when they consent. Information should be co-designed with public partners who are representative of the intended participants to ensure relevance and accessibility. It is vital that participants are kept updated as far as possible on both their own progress but also of the trial overall. Participants should be made aware of when and how they will hear about interim and final results. Participants should be kept informed of ways of reaching out to study teams with questions, and who their primary contact is.

   4. **(b) Let participants know as early as possible in their research journey how they will receive the study results;** *Research teams should tell participants as early as possible how they are likely to receive the study results, and when. This information should ideally be provided when the participant joins the study.*

The Easy-Read and Large Print accessible versions of PRES were launched, following a process of co-design and pilot testing. LCRNs have responded to this recommendation with the creation of participant feedback and contact postcards that include information about what happens in, during and after a trial and who to contact with any questions. LCRNs have worked with their partner organisations and communications teams to redesign Trust intranet pages to include a "research results" section. This has helped to make the results of research more accessible and improve the transparency of research. Also, the Research Design Service has engaged with the NIHR CRN CC team to discuss how to improve sharing of trial results with public partners that have contributed to the development of a research study from the concept/feasibility stage.

5. **Ensure research activities are as easy and un-burdensome as possible for participants and that realistic expectations are set from the start;** *Involve public partners early on in the co-design of the research. Walk-through the participant's journey with them to get a better sense of the barriers such as travel, appointment scheduling, waiting times, comfort and other improvements to the research location that might be needed. Involve participants in discussions about tests and procedures that you want to undertake.*

Patients and the public continue to be actively involved in the co-design of research trial documents and research prioritisation groups via steering committees, funding panels, site-level PPIE groups and by accessing wider NIHR CRN CC centre opportunities (e.g. People in Research). LCRNs have aimed to address potential barriers for participants using methods that have included adapting appointment times to suit people with additional physical or access needs. Research Champions have been involved in local initiatives aimed at 'road testing' the end to end participant journey before opening a trial, which has led to an improved participant experience in the PRES data for 22/23. The national impact framework data for PPIE revealed that Research Champions have been actively involved in discussions at a site and regional level, working together with research teams to explore how to best explain tests and procedures in a clear and concise way.

6. **Increase the links between LCRNs to promote networking and to share examples of challenges and solutions, thereby encouraging the sharing of good practice;** *The experience of participants in research varies across England, and it is therefore up to the CRN as a whole to come together to improve by sharing knowledge and best practice.*

The CRNCC co-hosts and co-facilitates a monthly LCRN PPIE meeting with an agenda that focuses on regional and national issues of importance for research delivery and participant experience. The CRNCC have implemented monthly PRES drop-in sessions for network staff responsible for delivering and collecting PRES data. This provides a platform for troubleshooting and sharing of best practice between regions. The PPIE impact framework is completed twice annually by LCRN Leads and provides the CRNCC team with examples of innovation, regional issues that need to be addressed and oversight over the network as a whole. The CRNCC team feeds back findings directly to regional leads and via the national monthly meetings to encourage shared decision making, peer support and to celebrate initiatives that help to increase knowledge and delivery of research. The PRES Advisory Group has expanded to include representation from all LCRN regions, four public representatives and several partner organisations to provide a consultative and decision making resource for PRES and research participant experiences across England. There is a dedicated page on the PRES microsite to share local examples and best practices across LCRNs and partner organisations to support the local delivery of PRES.

7. **Take steps to increase the response rate to the adult PRES and ensure we are reaching diverse and under-represented groups;** *CRN should work to increase national coordination of PRES dissemination and collection to increase local capacity to engage with wider groups. CRN should start monitoring the diversity of those taking part in PRES to increase understanding of barriers and gaps in knowledge and improve participant experience for all. Continue to monitor the accessibility of PRES and develop new formats that allow the widest possible audience the opportunity to feedback on their experiences.*

The response rate for adult and CYP PRES has increased dramatically for 22/23 with 32,603 responses overall. Diversity monitoring of participants continues for adult versions of PRES with 87.6% of participants selecting 'white' as their background. LCRNs have worked to increase responses from study participants from wider ethnic and under-served groups by collaborating with the Research Ready Community Champions and study teams at a site level. Responses from non-white participants are consistent with data from the United Kingdom Census (2021) with 8.8% respondents from an Asian/Asian British population. Asian/Asian British responses increased in Q4 2022/23 compared to Q1 (9.7% vs. 5.8%), which reflects the ongoing work by LCRNs and study teams to make PRES data more representative of the wider population. Additionally, Easy-Read and Large Print versions of PRES were introduced.

8. **Take steps to increase the response rate to the CYP PRES to allow for more meaningful analysis by LCRN, and to increase the volume of qualitative feedback relating to the experience of participants aged 0 to 15;** *Children and young people are an under-served group in research, so we have a lot to learn regarding how the experience can be improved to help encourage others to participate. Almost one third of LCRNs did not collect any responses to the CYP survey. Measures should be taken to widen the distribution of the CYP PRES across the country. The CYP surveys have not undergone the same level of user-input into their design and wording as the adult survey. This could be revisited, consulting with children and conducting user testing with the relevant age cohorts, to increase data quality, engagement and independent response.*

Responses received from CYP groups increased by 653% in 2022/23 when compared with 2021/22. A centralised processed version of the paper PRES has been introduced and positively received across all LCRNs and by parents, children and young people. User testing and refinement of the CYP surveys is still required and planned for in 2023/24.

The PRES Advisory Group identified several priorities for PRES delivery and development in 21/22. These were:

- ***Design and user testing of alternative versions of PRES to widen and improve accessibility***

Easy-Read and Large Print versions of PRES available nationally. These were tested and piloted with groups that identified themselves as having relevant lived experience in this area.

- ***Start the standardised collection of demographic data around age, sex, gender and ethnicity to begin to understand if there are specific differences in people's experience among these groups***

Data collection for these metrics are now standardised for the adult PRES survey. Deeper analysis is now required to understand differences and barriers. CYP surveys also require collection of this data and assessment of appropriateness for this population.

- ***Development of additional guidance for staff and the public on why they should participate in PRES***

A national PRES learning module has been designed/developed and disseminated for all LCRNs and partner organisation staff in collaboration with East of England LCRN.

- ***Pilot the feasibility of a centralised processing of PRES responses to improve data collection and processing***

Centralised processing for the paper version of PRES is now standardised across all LCRNs both for adult and children versions. Only authorised versions of PRES are accepted for data inclusion outside of this.

- ***Devise a step-wise approach to introducing a shift towards digital PRES***

A national digital version of PRES is planned for development in 2023/24 alongside an evaluation of the sustainability of PRES.

- ***Create a national, publicly accessible dashboard that will enable the reporting of national and local level PRES data***

A national dashboard for PRES is currently in development, planned completion in 2023.

- ***Scale-up the use of the CYP PRES nationally***

All LCRNs and partner organisations are now expected to deliver CYP versions of PRES.

Summary of 2022/23 findings & recommendations

This report presents the findings from the 2022/23 survey, detailing the experiences of over 1,800 children and young people, and over 30,000 adults who participated in research studies . Note that the findings represent the views of a sample of research participants and may not be representative of those people who do not wish to take part in studies or who are unwilling to provide feedback.

Children and young people quantitative results summary

The 2022/23 survey of children and young people (CYP) received a total of 1,898 responses, a marked increase on 252 responses in the 2021/22 survey. A large number of the responses came from one LCRN, North East & North Cumbria (NENC).

Of all CYP responses, 82% of participants answered the 0-6 survey, 6% answered the 7-11 version, and 12% filled in the version for 12-15 year olds.

The majority of CYP surveys (85%) were completed by the parent or carer of the child/young person, with 97% of responses to the 0-6 survey being completed by the parent or carer and 49% of the 7-11 survey. The 12-15 survey was most likely to be answered by the child/young person (48%). Therefore a recommendation for future CYP PRES developments should look for ways to improve completion by CYP.

For 90% of children/young people, it was the first research study they had taken part in. Three-quarters (75%) had been taking part in the research study for less than three months.

Respondents gave particularly positive scores for the following:

- Being given information at the start of the research study that was easy to understand (86% said that study information was 'easy' to understand).
- Always being treated with kindness and respect by the research team (70% said 'strongly agree').

The least positive scores were around communication, as follows:

- Being kept updated about the research study (only 46% said 'strongly agree').
- Knowing how to contact someone from the research team if they had any questions or concerns (only 46% 'strongly agree').

Feedback was more positive this year compared to 2021/22 in relation to:

- The information received at the start of the research being 'easy' to understand (86% vs. 64%).
- Participants knowing how they would find out the results of the research (up from 41% to 56%) – albeit the score on this question still requires improvement.

Table 15 in the Appendix summarises the changes in scores compared to 2021/22.

Analysis by LCRN showed considerable variation in scores for each question, offering learning opportunities to be shared. There was variation between LCRNs and within: an individual network might have scored highly on one question but low on another.

Children and young people free text results summary

The survey included two free text boxes, which invited respondents to give additional feedback both about the positive aspects of their experience of participating in research, and what could have made their experience better.

In total, 500 CYP comments were reviewed and sorted into themes and subthemes. Sentiment was also assigned to each comment and was assigned as either positive, neutral or negative.

Seven subthemes were highlighted within the data regarding positive aspects of participation:

- Research staff/team.
- Information and communication.
- Practicalities of taking part.
- Procedure (comments about ease of tests being carried out/ receiving medication).
- Motivation to participate.
- Treatment outcome.
- Other.

A second free text question asked whether there was anything that would have made their research experience better. Nine subthemes emerged from the data including:

- Practicalities of taking part.
- Information and communication.
- Nothing to improve.
- Other.
- General experience of research participation.
- Feedback about results/progress.
- Research staff/team.
- Survey (comments on length/ relevance/ question type where a survey was part of the research).
- Procedure (comments about timeliness/ ability to carry out procedures such as blood tests).

Adult quantitative results summary

The 2022/23 adult survey received 30,705 responses, a 21% increase on the 25,459 responses in 2021/22.

Seventy-six per cent of adult respondents said it was the first research study they had taken part in. Fifty-nine per cent reported being in the research study for less than a year (37% for less than three months). As a general rule, older participants were more likely to have been involved in the study for a longer period.

The majority of adult research participants (93%) completed the survey themselves, however 13% of those aged over 75 had the help of another person or another person completed it on their behalf.

Scores for six of the seven questions have unfortunately dropped incrementally across the three-year survey period. Of particular note was Q4 'I know how to contact someone from the research team if I have any questions or concerns': the percentage who said 'strongly agree' has decreased from 73% (2020/21) to 68% (2021/22) to 47% (2022/23). When combining the 'strongly agree' proportion with 'agree', there is still a year-on-year decrease, although not as marked.

The only question in the adult survey that has not seen any decline is Q3 'I know how I will receive the results of the research' – though notably, this is the lowest scoring question each year in terms of the proportion saying they 'strongly agree' (41% in both earlier survey years and 40% in 2022/23). Table 16 in the Appendix shows the changes in scores compared to 2021/22. It shows that whilst there have been moderate decreases in scores of the combined top two responses (e.g. 'strongly agree' + 'agree'), far greater decreases are evident when looking at the top response only (e.g. 'strongly agree'). One possible explanation is that post-Covid, many healthcare appointments have moved online, and for convenience reasons this is what people now prefer. Further investigation would therefore be recommended.

Adult respondents gave the most positive scores in relation to:

- Always being treated with courtesy and respect by research staff (72% said 'strongly agree').
- Receiving information before they took part in the research study that helped prepare them for their experience (62% 'strongly agree').
- Reporting that they would consider taking part in research again (60% 'strongly agree').

The 2022/23 survey highlighted some action points around the topic of communication with participants:

- Participants knowing how they would receive results of the research study (only 40% said ‘yes’).

- Being kept updated about the research study (only 43% ‘strongly agree’).
- Knowing how to contact someone from the research team if they had any questions or concerns (only 47% ‘strongly agree’).

Of note, participants aged over 75 reported less positive experiences than other age groups across all scores. It is possible that this is partly due to other people filling in the survey on behalf of the participant, since proxy responses can sometimes be more negative. Regardless, it is crucial that participants are given all the information they need, in an understandable and accessible way.

Differences in reported experience were also observed across ethnic groupings with Asian or Black participants often reporting less positive experiences, e.g. 50% said that they felt their participation in the research was valued compared to 60% of White participants.

By age, 25-34 year olds gave the most positive scores across all questions.

Positivity of experience tended to be fairly consistent across questions at LCRN level: Greater Manchester, West of England, Wessex and Yorkshire & Humber frequently achieved the highest scores, while Kent, Surrey & Sussex and North West London had some of the least positive scores.

Adult free text feedback summary

As with the children and young people's survey, the adult version asked respondents to provide additional feedback, in their own words, about their experience of being a research participant.

Firstly, they were asked to feed back any positive aspects of their experience. Nine subthemes were identified, including:

- Research staff/team.
- Information and communication.
- Motivation to participate.
- Practicalities of taking part.
- Procedure (ease of tests being carried out/ receiving medication).
- Treatment outcome.
- Feedback about results/progress.
- Other.
- Survey (length/ relevance/ question type where a survey was part of the research).

When adult participants were asked what would have made their experience better, 13 subthemes were identified including:

- Practicalities of taking part.
- Information and communication.
- General experience of research participation.
- Feedback about results/progress.
- Research staff/team.
- Nothing to improve.
- Procedure (not having all tests as outlined/ ability of staff to carry out procedures such as blood tests).
- Survey (length/ relevance/ question type where a survey was part of the research).
- Incentives/expenses.
- Side effects.
- Treatment outcome.
- Vaccine approval.
- Other.

Overall findings & recommendations

Table 1. Summary of recommendations and suggested actions

Recommendation		Suggested action
1	Establish how LCRNs can increase respondent numbers further for the next survey wave.	Work with LCRNs that have seen large increases e.g. North East & North Cumbria in the CYP survey, to establish what mechanisms were used to facilitate increases in respondent numbers. Communicate successes and strategies back to LCRNs ahead of the next survey.
2	Continue to improve survey accessibility, opening it up to as many participants as possible.	Ensure that different modes e.g. online or paper are available. Online also has the advantage of being cheaper than paper-based surveys so this option should be in place and promoted across all LCRNs. Ensure alternative versions of the survey are made available to suit participants' individual needs e.g. the Easy Read and Large Print versions that have been developed, and also the recently updated adult survey, redesigned with the aim of increasing engagement and accessibility. Ensure that an identifier is added to each alternative survey version that can be inputted at data entry. This will enable NIHR CRN CC to log numbers completing the accessible versions.
3	Ensure that all research participants receive the information that they need, in a timely and accessible manner.	Sometimes participants felt forgotten about once they were recruited into the research study. For others, the information or communication did not suit their needs – participants aged 75+, and Asian and Black participants often reported a worse participant experience. Tailor communications to people's individual needs and check that they have all the information they need and understand it.
4	Check that any software used in research studies is accessible if participants report that they are having difficulties.	The free text comments often mentioned an app that is used – was this suitable for everyone, how could this be improved? Several comments point to the app not working properly or not being user friendly. If people experience frustrations with the software, then it is possible they will drop out and/or not volunteer for future studies.

5	Explore how some LCRNs achieve better scores than others on individual measures and effectively facilitate sharing of best practice examples.	Conduct a review amongst LCRNs to establish baseline current practices and pinpoint differences across the networks. For example, in terms of study information being given out, is there a set template that certain LCRNs follow, or is it developed on an ad hoc basis?
6	Investigate the potential impact that data from North East & North Cumbria has had on the overall CYP results.	Conduct an analysis of the CYP results with and without this data. Consider how the potential impact of individual networks can be lessened in future years by applying a representative weight to the data.
7	Examine CYP free text comments under the themes of 'information and communication' and 'practicalities of taking part' to pinpoint what separates a good from a not so good experience.	Ensure that as part of the qualitative analysis theme generation 'Information and communication' and 'practicalities of taking part' are explored separately in the CYP survey data to identify what was good about participants' experience and what could be improved.

Methods

Survey delivery

PRES content and design is coordinated nationally by the NIHR CRN CC. Continual development of the survey and decision making are guided by the PRES Advisory Group. Analysis of the annual survey results is conducted annually by Picker.

PRES survey delivery is coordinated by 15 Local Clinical Research Networks (LCRNs) and delivered by their partner organisations, which together cover England.

PRES comparisons

This report details the findings from the 2022/23 PRES survey, collected via responses to the adult version of the survey and three age-specific versions for children and young people (CYP); 0-6 years, 7-11 years and 12-15 years. All questions across the three CYP surveys are comparable to one another. Comparisons between data from the adult survey and the CYP surveys are not possible in all instances. For the purposes of this report, the findings from the adult and CYP surveys are reported separately.

In 2020/21 for the first time, the adult survey questions were nationally standardised, meaning all LCRNs asked participants the same questions. This has allowed for the identification of national level themes and recommendations.

Historical data comparisons are possible across adult survey data, allowing for analysis of 2022/23 data against responses from the 2021/22 and 2020/21 survey. The 2022/23 CYP survey results can be compared against 2021/22, the year the survey was introduced.

Analysis

This report focuses on the most positive level of agreement to a statement or question (e.g. ‘strongly agree’). Five out of the seven questions in the CYP survey and four out of seven in the adult survey had over 90% of people giving a positive response (e.g. ‘strongly agree’ + ‘agree’), hence reporting the survey results in this way reveals participants’ strength of agreement and hence offers more actionable insight. A full breakdown of responses by question and across survey years are available separately on request.

When looking at any differences in scores across LCRNs, please be mindful that scores are not always representative of the entire LCRN population.

Terms used in this report

The abbreviation ‘n=’ means the number of people or responses. For example, n=100 means that 100 people answered the question.

The term ‘participants’ refers to people who took part in a health and care research study, or to people who filled in the PRES survey, giving feedback about their experience of taking part in an NIHR CRN CC supported research study.

Survey administration

The survey was administered by 15 LCRNs to participants in studies between April 2022 and March 2023. Participants were offered the choice of completing the survey on paper or online, to suit their preference and needs.

For the adult survey, respondents were aged 16 years or older. Respondents include people who had just started to take part in a study, people who had completed taking part in their study, and people who had been taking part for some time. Feedback came from participants from a range of study designs, including Covid research and observational studies.

For the CYP survey, participants were aged between 0 to 15 years. Respondents had the option to complete the survey themselves, with help from their parents or carers, or have their parent or carer complete the survey on their behalf.

Question text by CYP survey version was not standardised across the three versions, however data comparison was possible. The full question text for the survey is provided at Table 6.

Data management

Adult survey data was submitted to NIHR CRN CC by each of the 15 LCRNs. CYP survey data was submitted by each of the 13 LCRNs that offered PRES for their CYP research trials. NIHR CRN CC collated the data and provided it to Picker in two files, one containing adult data and one containing CYP data.

Picker reviewed the files to ensure that all fields were present and contained only valid and in-range responses. Picker found out-of-range responses to seven questions in the adult data, and to three questions in the CYP data. Out-of-range responses were resolved directly with consultation of NIHR CRN CC by removing the question responses from the dataset. This had no impact on the total number of responses, as it was only the out-of-range responses to individual questions that were removed, rather than the entire data from a given respondent.

For both adult and CYP data, duplicate records were identified from responses within each LCRN due to identical data contained in their closed question and free text responses (and additionally in their year of birth for adult data). Deduplication was performed on the following criteria:

- Maintain the response that is most complete.
- In cases where both records are equally complete, maintain the response from the earliest quarter.

Six CYP responses from one LCRN in Quarter 2 were reported as missing from the data upon receipt. These responses were not located and are thus not included in the data.

The final data set (after removal of invalid entries, out of range responses, and duplicates) that was used for analysis had entries less than 32,603:

- The total number of adult respondents after data cleaning was 30,586.

The total number of CYP respondents was 1,884.

Analysis

Quantitative data

Results are shown overall and by CYP age grouping, relating to the survey version which was completed. We did not collect gender or ethnicity information in the CYP survey. In addition, results are shown split by LCRN to help direct improvement initiatives.

As above, charts are shown at an overall level and by breaking down results at LCRN level. Commentary is provided in the findings from the adult survey highlighting any differences in participant experience by age, gender or ethnic group.

To protect the identity of respondents, suppression rules have been applied to the data. If the total number of responses to a question is fewer than 11, data for that question are suppressed. For the CYP survey, two LCRNs had fewer than 11 responses, therefore, this has been supressed throughout the CYP section. For individual questions and for sub-group data, there may be cases where the base size per question is fewer than 11. In this case, the data will be suppressed.

Free text data

Drawing the sample

Overall, there were 44,888 free text responses across the adult and CYP surveys. However, many respondents had ineligible responses for Q8 and Q9 (e.g., too short). Following data cleaning of free-text responses (which included the removal of non-informative responses i.e., “nil” “n/a” and removing response with less than five characters), 18,312 comments remained for Q8 (What was positive about your research experience?) and 9,046 comments remained for Q9 (What would have made your research experience better?).

For the adult survey, 1,500 comments were sampled for analysis, with 750 comments allocated to each free-text question (Q8 and Q9). To draw the sample, responses were classified according to whether a respondent answered positively or negatively to Q7 which asked respondents whether they would consider taking part in research again.

For Q8, the sample was drawn by proportionally selecting responses from each LCRN using an “equal proportions stratification”. This approach was taken to ensure views from around England were included and that the number of comments coded is proportional to the number of responses from each LCRN. For Q9, all responses from those who answered negatively to Q7 (n=286) were included and the remaining 464 were selected using the same method as for Q8.

For the CYP surveys, 500 free text comments of more than five characters long were sampled and coded: 250 for Q8 and 250 for Q9. The adult coding framework was utilised for the CYP coding, although some subthemes were not needed.

The same sampling method was used for the CYP free text. For Q9, there were just 3 responses with a negative answer to Q7. The remaining 247 were selected in the same way as the adult sample.

Coding the data

The comments in the sample were removed from most of the accompanying quantitative data responses, so that reviewer’s interpretation of a comment was not influenced by the respondent’s answers to other questions. The only question to remain in the data for coding was the response to Q7, asking whether respondents would consider taking part in research again.

The coding framework developed for the 2019/20 analysis and used in the previous two years’ analysis was utilised for this survey iteration and updated to include one new code. The comments were coded using Microsoft Excel. Sentiment was assigned to each comment, to identify positive, negative, or neutral comments. Comments coded as neutral were either simply neither positive or negative or contained a mix of positive and negative comments. If a comment just included a suggestion of improvement, with no obvious negativity, this was also assigned as neutral

Children and Young People Data

Children and Young People data were analysed and presented in the same format as the adult survey data, with frequency and percentage of responses to each response option provided for each closed question per survey version.

During data cleaning of the adult survey data, cases recorded under ‘children’ speciality were identified. These cases were queried with the CRN, which led to the reallocation of 36 cases into the CYP data set.

Children and Young People Survey Results

Respondent profile

Respondent details for the Children and Young People (CYP) survey are indicated in Table 2. Overall, there were 1,898 responses to the CYP survey showing a considerable increase compared to 2021/22 when 252 responses were received.

Participants were offered the choice of completing the survey online or on paper:

- 79% of CYP surveys were completed online; 21% on paper.

10% of children/young people had taken part in previous research studies.

Amongst all CYP responses, most completed the 0-6 survey version (82%), with 6% completing the 7-11 survey, and 12% the 12-15 version.

Table 2. Response numbers and percentages, by survey version

Survey version	No. of respondents	% of respondents
0-6 Years	1,551	82%
7-11 Years	115	6%
12-15 Years	232	12%
Total	**1,898**	**100%**

Please note that some surveys were excluded from the analysis owing to poor data quality and due to duplication. Therefore, the total number of respondents throughout the remainder of this report will be slightly lower than those presented in Table 2.

For the majority of respondents (90%) the research study they were taking part in was their first one. Not surprisingly, the younger the respondent, the more likely it was that this was their first research study: 0-6 (95%); 7-11 (76%), and 12-15 (65%).

Overall, the majority of respondents (75%) had been taking part in the study for less than three months. This was the case for most 0-6 survey respondents (83%), though respondents aged 7-15 were more likely to have been involved in the research study for a longer period. Around two-fifths of those answering the 7-11 or 12-15 version had been in the study for at least a year, compared to a much smaller proportion of those completing the 0-6 survey. Further details are indicated in Table 3 below.

Table 3. Length of time taken part in research study, by survey version

	Total	0-6 years old	7-11 years old	12-15 years old
Less than three months	**75%**	83%	42%	32%
At least three months but less than one year	**11%**	9%	15%	20%
At least one year but less than three years	**5%**	3%	29%	14%
Three years or longer	**5%**	1%	12%	29%
Not sure	**4%**	4%	2%	5%

The three CYP survey versions each asked who had filled in the survey, the child/young person, the parent or carer, or both (Table 4). As expected, parents/carers were most likely to be the person completing the survey for participants aged 0-6 (97%); parents/carers were most likely to complete the survey for 7-11 year olds (49%), whilst it was most likely for 12-15 year olds that they would complete the survey themselves (48%).

There is evidence suggesting that so-called ‘proxy’ responses - where the survey is filled in by someone on behalf of the research participant – result in less positive responses[3]. This should be considered when viewing the results of the CYP survey: since 97% of the 0-6 surveys were completed by the parent or carer. Therefore, we might reasonably expect a positivity of response to be lower for this survey version than for the 7-11 and 12-15 versions.

Note: a few responses were excluded from the analysis for this and other questions in the CYP survey owing to poor data quality. This is accurate not only in terms of the de-duplication but also in terms of the free text questions' responses, which were eliminated from the study owing to their length and others, such as "Invalid responses," "I don't remember," and more.

---

[3] Graham C. 2016. Incidence and impact of proxy response in measuring patient experience: secondary analysis of a large postal survey using propensity score matching. *International Journal for Quality in Health Care* 28(2): 246–252, https://doi.org/10.1093/intqhc/mzw009

Table 4. Who completed the survey, by version

	Total	**0-6 years old**	**7-11 years old**	**12-15 years old**
The child/ The young person	**9%**	2%	21%	48%
The parent or carer	**85%**	97%	49%	31%
Both the child/ young person and the parent or carer together	**6%**	2%	30%	21%

CYP surveys were distributed across 13 LCRNs. Though we do not know how many were distributed, the number of returned surveys by LCRN were logged and a proportion of the total returned surveys were reported – see Table 5.

North East & North Cumbria LCRN received the most returned surveys of all the LCRNs, accounting for 40% of all respondents in this year's survey (Table 4). Yorkshire & Humber and North Thames comprise 14% and 13% of all responses respectively, with all other LCRNs accounting for between 1% and 6%.

Due to the high proportion of the total responses that are from North East & North Cumbria, some caution should be taken when interpreting national CYP data, as it is likely to disproportionately reflect experiences from participants in this region rather than be representative of experiences across England.

Table 5 displays the number and proportion of CYP responses by LCRN region for 2022/23, and the percentage split for 2021/2022 as a comparison.

Table 5. Number and proportion of all CYP surveys returned in 2022/23, compared to 2021/22, by LCRN

LCRN	No. of surveys returned 2022/23	% of total surveys returned 2022/23	% of total surveys returned 2021/22
North East & North Cumbria	768	40%	4%
Yorkshire & Humber	269	14%	14%
North Thames	248	13%	17%
North West Coast	112	6%	1%
Greater Manchester	96	5%	-
Wessex	89	5%	-
West of England	80	4%	20%
Thames Valley & South Midlands	79	4%	15%
South London	70	4%	<1%
East of England	68	4%	22%
North West London	15	1%	1%
West Midlands	3	<1%	5%
Kent, Surrey & Sussex	1	<1%	-
Total	**1,898**	**100%**	**100%**

Survey questions

The three CYP surveys asked the same questions, though the wording was tailored to the age of the participant (Table 6).

Table 6. Question text by CYP survey version

Q	0-6 survey version	7-11 survey version	12-15 survey version
Q1	The information that I received about the research when my child was invited to take part was easy for me to understand	Was it easy or hard to understand the information you got at the start of the research?	The information I got at the start of the research was easy to understand
Q2	I feel I have been kept updated about this research study	I knew what was happening during this research study	I always knew what was happening during this research study
Q3	I know how I will receive the results of this research study	I know how I will get the results of this research study	I know how I will get the results of this research study
Q4	I know how to contact someone from the research team if I have any questions or concerns	I know who I need to talk to if I have any questions about this research study	I know who to talk to from the research team if I have any questions
Q5	I feel the research staff have valued my child taking part in this research study	The research team made me feel valued	The research team made me feel valued
Q6	Research staff always treated my child with courtesy and respect	The research team were always nice to me	The research team always treated me with kindness and respect
Q7	I would consider my child taking part in research again	I would take part in research again	I would take part in research again
Q8	What was positive about your child's research experience?	What did we do well?	What did we do well?
Q9	What would have made your child's research experience better?	What could we do better?	What could we do better?
Q10	How long has your child been taking part in this research study?	How long have you been taking part in this research study?	How long have you been taking part in this research study?
Q11	Is this the first research study your child has taken part in?	Is this the first research study you have taken part in?	Is this the first research study you have taken part in?
Q12	Who answered these questions?	Who answered these questions?	Who completed this survey?

Quantitative findings: Children and Young People

Q1. The information received at the start of the research was easy to understand.

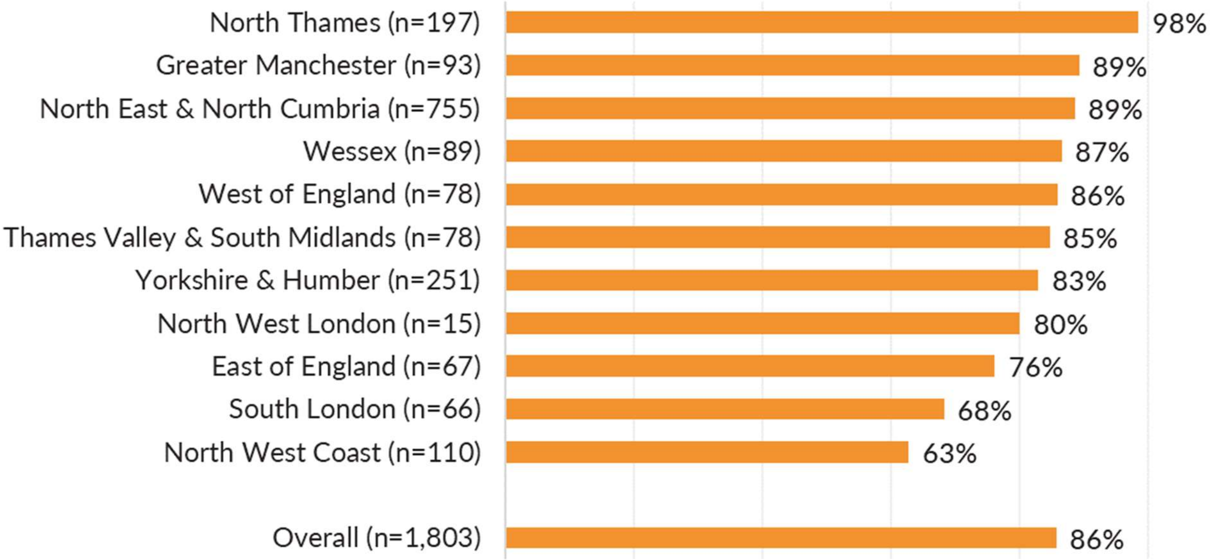
Overall, in 2022/23, 86% of respondents agreed that the information they received prior to the research starting was 'easy' to understand. This was an improvement of 22% since the previous survey wave in 2021/22.

Across the survey versions, those completing the 0-6 survey were most likely to state that the information was 'easy' to understand (87%), compared to those completing the 12-15 or 7-11 versions (81% and 71% respectively) – See Figure 1.

By LCRN, there was a difference of 35% between the top and bottom scores, with almost all participants at North Thames – 98% - who said that the information given to them was 'easy' to understand. See Figure 2 for further insights.

Figure 1. Percentage of respondents selecting 'easy' when asked whether the information they received at the start of the research was easy to understand (Q1) by CYP survey version

Figure 2. Percentage of respondents selecting ‘easy’ when asked whether the information they received at the start of the research was easy to understand (Q1), by LCRN



In the open-ended survey questions, several respondents commented positively about the information provided prior to the study starting:

“We were approached nicely, and the communication was clear.”

“I was asked if I had any questions on several occasions and felt fully informed at all times.”

However, some felt it could be more concise.

“Maybe a little more condensed explanation.”

Q2. I feel I have been kept updated about this research study.

In 2022/23, 46% of respondents ‘strongly agreed’ that they had been kept up to date about the research, a decline of 10% since the previous survey year.

Those completing the 0-6 version were least likely to feel that they had been kept up to date (43% who said ‘strongly agree’), compared to those answering the 12-15 (52%) or 7-11 version (59%; Figure 3).

The scores by LCRN ranged from 63% for the West of England, down to 24% for Wessex (Figure 4).

Figure 3. Percentage of respondents selecting ‘strongly agree’ when asked whether they had been kept updated about the research study (Q2) by CYP survey version

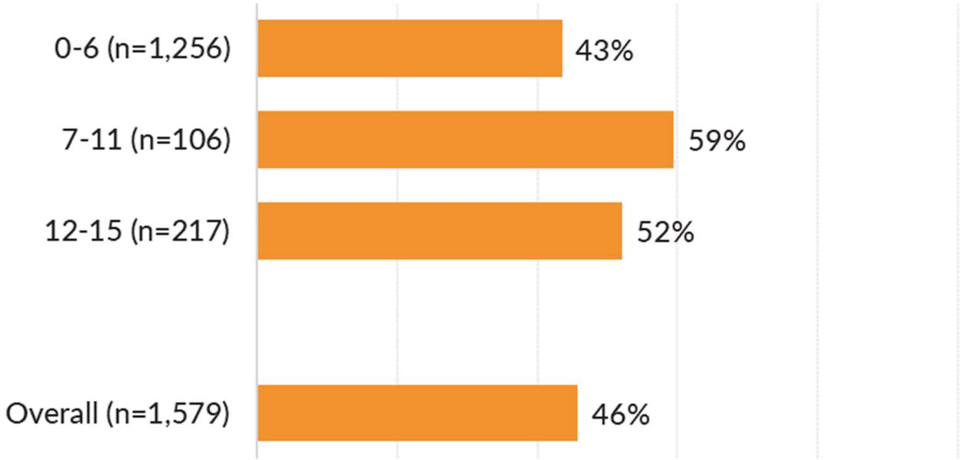
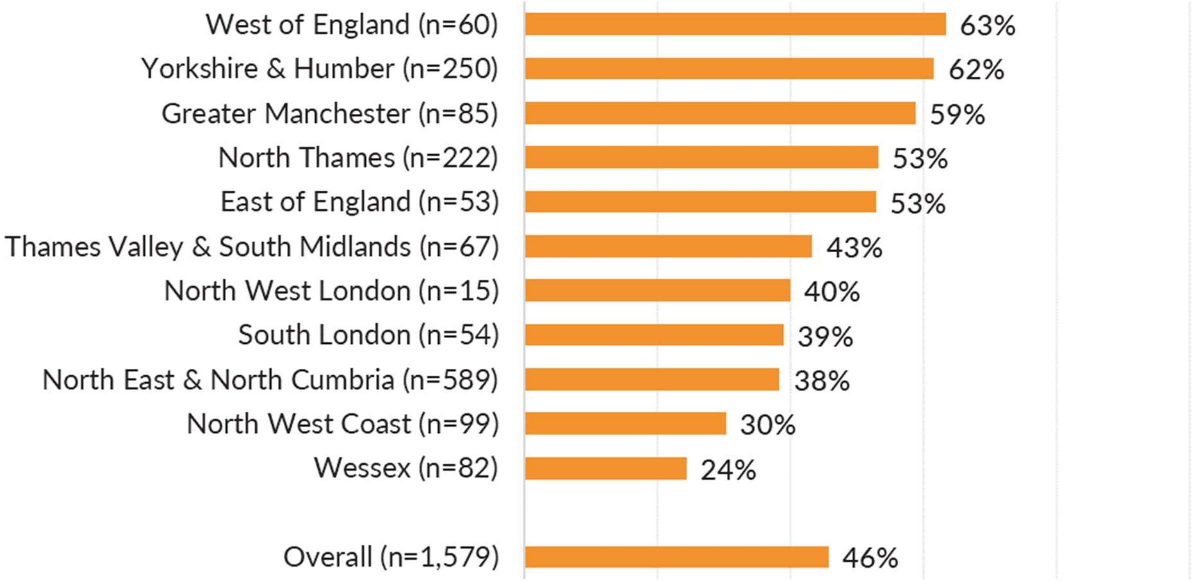


Figure 4. Percentage of respondents selecting ‘strongly agree’ when asked whether they had been kept updated about the research study (Q2), by LCRN



In the open-ended survey questions, some respondents reported being kept updated and informed throughout the study.

> “We have been informed straight from the beginning about this study and the purpose of it. Information was very clear and easy to be understood by my child taking part in the study. The researcher was very professional and kept me informed all the time, answering all my questions promptly and efficiently.”
>
> “Put us at ease, treated us well, kept us informed and put us first.”

However, some commented that they would like to be kept informed, implying this was not the case for all.

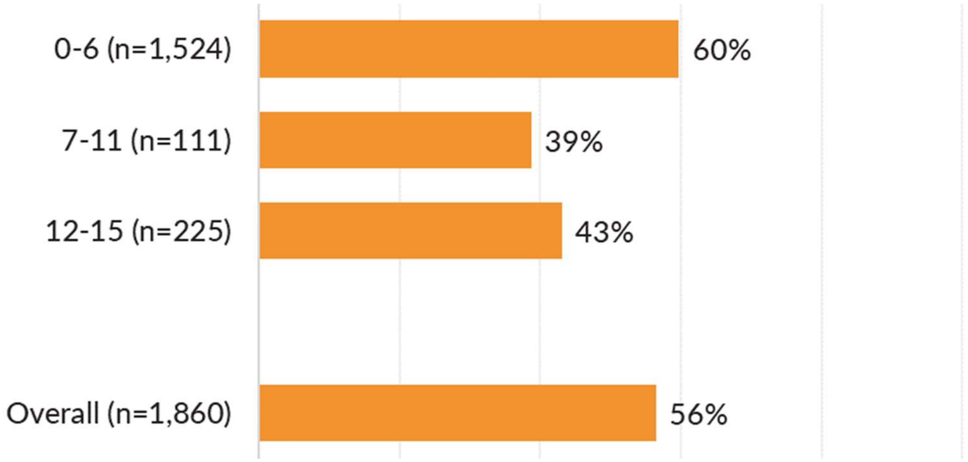
> “More information and kept updated with surveys and outcomes.”
>
> “It would be great if the clinical trial research team sent updates on the wider research programme e.g. any data/papers published.”

Q3. I know how I will receive the results of this research study.

Overall, 56% of people responding to the CYP survey selected ‘yes’, they knew how they would find out the results of the research, an encouraging improvement of 15% since 2021/22 (where 41% strongly agreed).

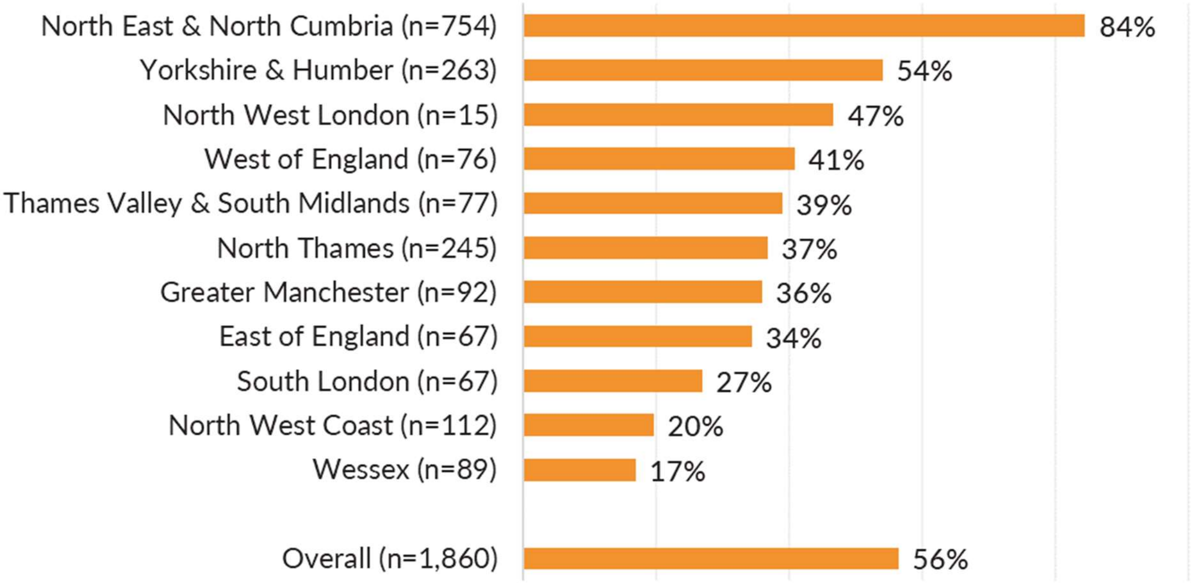
By survey version, those responding to the 0-6 survey were most likely to ‘strongly agree’ (60%), compared to those completing the other versions (43% for 12-15 and 39% for 7-11) See Figure 5.

Figure 5. Percentage of respondents selecting ‘yes’ when asked whether they knew how they would receive the results of the research study (Q3), by CYP survey version.



There was considerable variation in responses to Q3 by LCRN (Figure 6). The top score was for North East & North Cumbria with 84% of respondents ‘strongly agreeing’, 30% ahead of the next highest scoring LCRN, Yorkshire & Humber (54%). A considerably lower proportion of respondents at Wessex (17%), North West Coast (20%) and South London (27%) LCRNs ‘strongly agreed’ that they knew how they would find out the results of the research.

Figure 6. Percentage of respondents selecting 'yes' when asked whether they knew how they would receive the results of the research study (Q3), by LCRN



Some survey participants reported in the free text that they were unsure whether they were given an indication of when/how they would receive such information.

> "App doesn't work. Not sure how/if I'll be told final outcome of trial."
>
> "I know that this research will help other babies to be treated in the future. Would be great if results will be shared with parents."

Others explained that they knew how to find such information if they didn't have it already.

> "I'm not 100% sure on what happens thought-out the long-term study or how to get the results but it's probably in the information we have and if not, the research team will help."

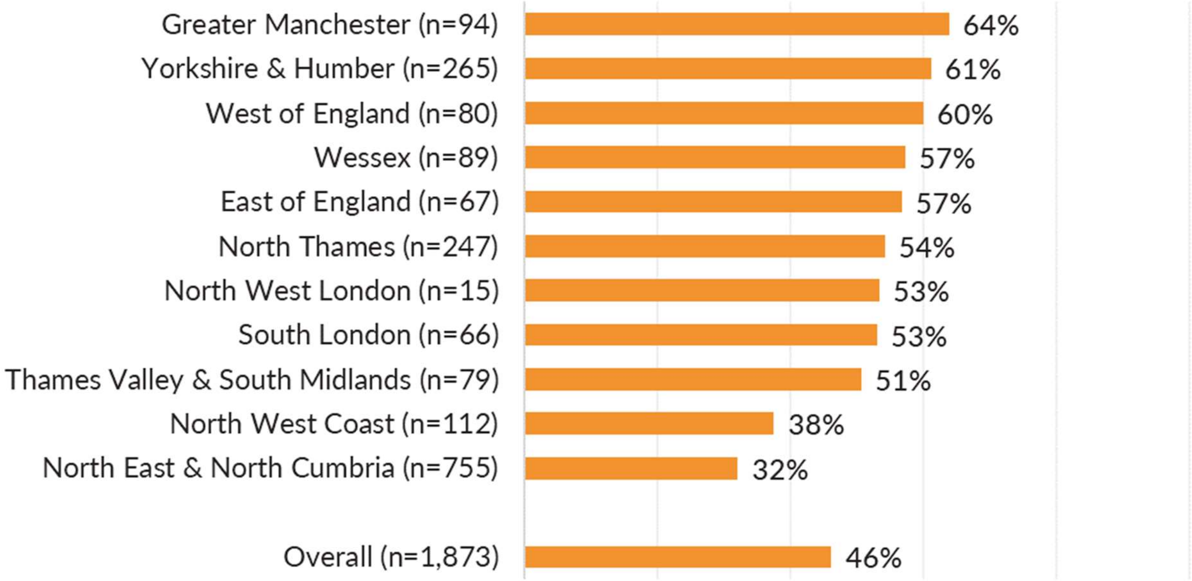
Q4. I know how to contact someone from the research team if I have any questions or concerns.

Overall, in 2022/23, 46% of respondents 'strongly agreed' that they knew how to contact someone from the research team should they have any questions or concerns. This is a decrease from 67% in 2021/22.

Those answering the 7-11 survey were most likely to report that they knew how to contact someone (56% 'strongly agreed') compared to those completing the 0-6 (46%) or 12-15 (45%) versions.

At LCRN level, North East & North Cumbria (32%) and North West Coast (38%) received the lowest proportions of people saying they 'strongly agreed' to Q4 when compared to other networks, namely Greater Manchester (64%), Yorkshire & Humber (61%) and West of England (60%) – Figure 7.

Figure 7. Percentage of respondents selecting 'strongly agree' when asked whether they knew who/how to contact someone from the research team if they had any questions or concerns (Q4) by LCRN



Some survey participants mentioned in the free text that the research team had open lines of communication and were easy to contact if they had any queries.

> "Child has been provided with excellent care throughout the study. The team are easily contactable and are helpful and friendly."
>
> "Very friendly & welcoming. following up with email and phone calls. Explaining the process, the diaries etc. Kept us both well informed during the visits."

This unfortunately wasn't the case for all, as some noted receiving no response:

> "The app used to collect data did not work for me; I had contacted the team for a solution but never heard back from them."
>
> "More information and a direct number for people to call to get answers."

Q5. I feel research staff have valued my/my child taking part in this research study.

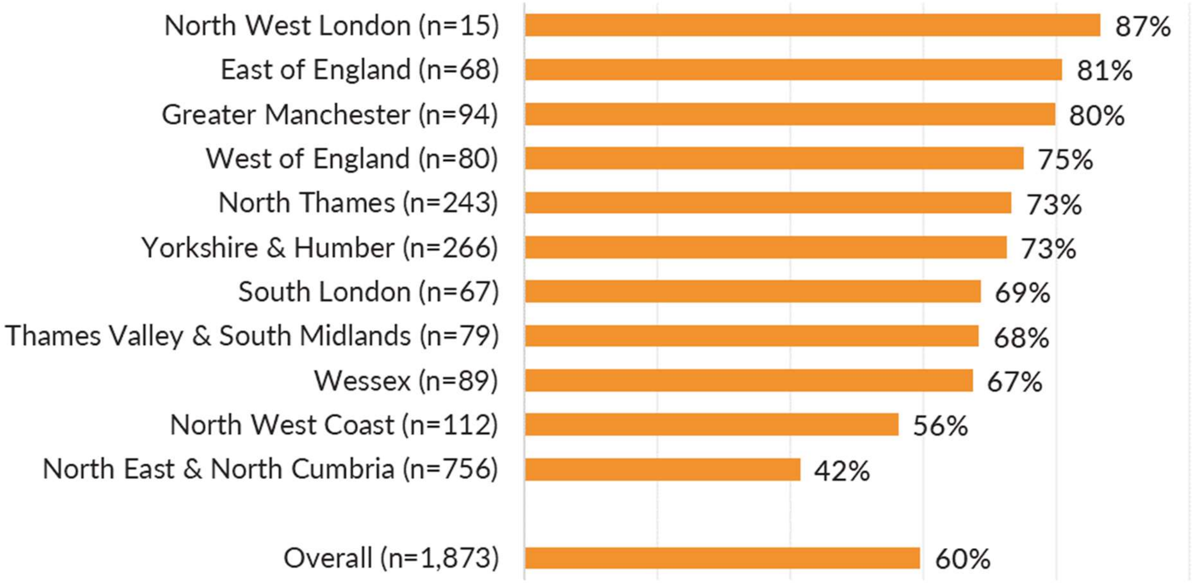
In 2022/23, 60% of respondents ‘strongly agreed’, when asked whether they felt valued by staff for their taking part in the research study. This has declined from 76% in the previous survey wave in 2021/22 (Figure 8).

Of all survey versions, those responding to the 7-11 survey were slightly more likely (65%) than those answering the 12-15 (60%) or 0-6 (59%) versions to ‘strongly agree’ at Q5.

Figure 8. Percentage of respondents selecting ‘strongly agree’ when asked whether they felt research staff valued them/ their child taking part in the research (Q5), by survey year.

Similar to other questions, there was considerable variation in scores by LCRN. North West London LCRN had the highest proportion of respondents saying they ‘strongly agreed’ that they felt valued (87%), followed by East of England and Greater Manchester (81% and 80% respectively). North East & North Cumbria (42%), and North West Coast (56%) generated the lowest proportions of people ‘agreeing strongly’ that they felt their participation was valued. See Figure 9 for a breakdown of scores to Q5 by LCRN.

Figure 9. Percentage of respondents selecting 'strongly agree' when asked whether they felt research staff valued them/ their child taking part in the research (Q5), by LCRN



Some respondents noted in the open-ended survey questions how they felt they/their child were valued as participants.

> "Very friendly team, everything was explained clearly and easy to understand. I felt my child was highly valued as a participant."
>
> "Staff were all very nice and explained the process well, so we always felt informed and valued as participants."

There were no comments in the CYP sample that specifically implied they did not feel valued.

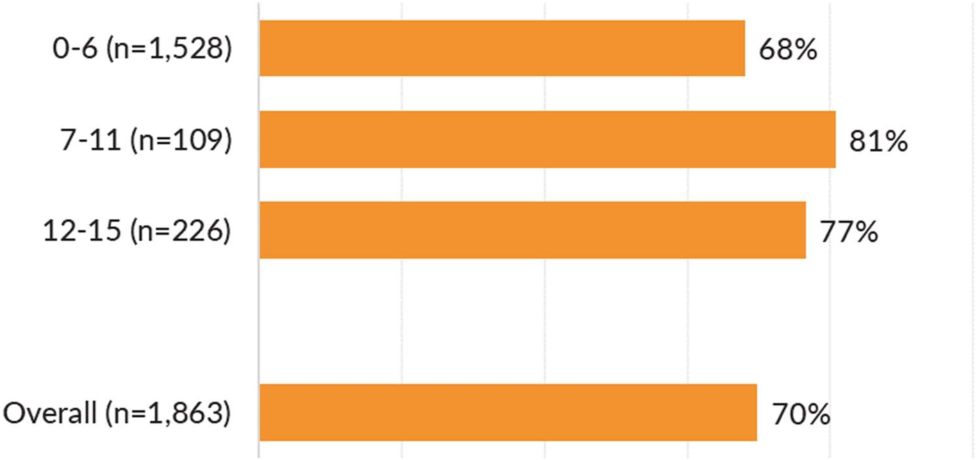
Q6. Research staff have always treated (the child or young person) with kindness and respect.

Whilst 70% of CYP respondents or parents/carers in 2022/23 ‘strongly agreed’ that they or their child had been treated with respect, this had decreased from 90% in the previous survey wave in 2021/22 (90%) – Figure 10.

Respondents completing the 7-11 (81%) or 12-15 (77%) survey versions were more likely than those returning the 0-6 version (68%) to ‘strongly agree’ to Q6 – Figure 11.

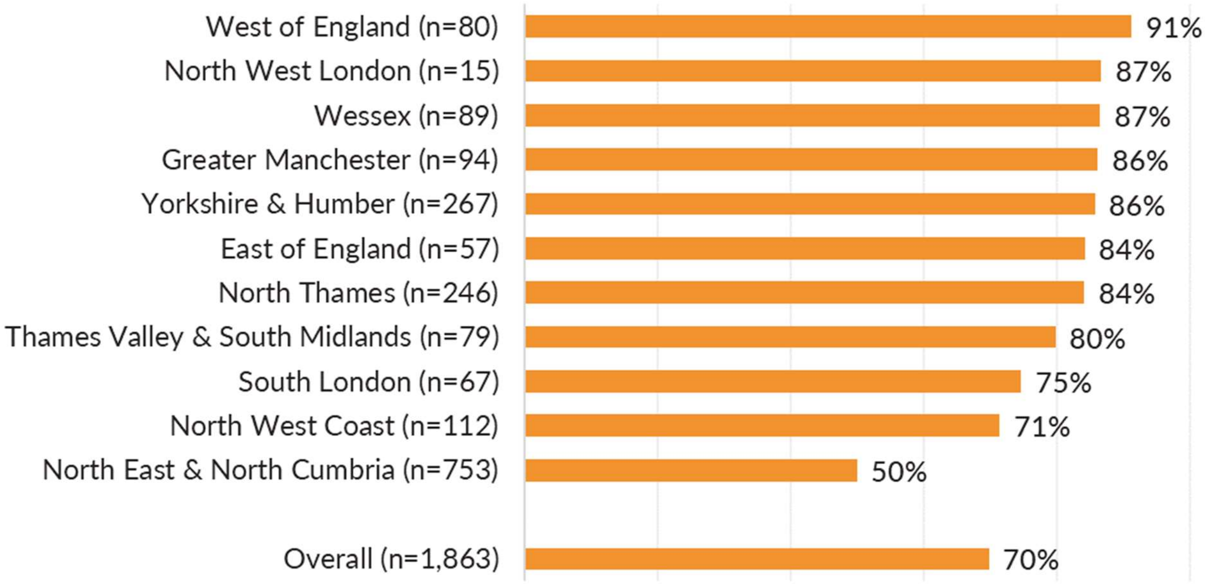
Figure 10. Percentage of respondents selecting ‘strongly agree’ when asked whether research staff have always treated the child or young person with kindness and respect (Q6), by survey year.

Figure 11. Percentage of respondents selecting ‘strongly agree’ when asked whether research staff have always treated the child or young person with kindness and respect (Q6), by CYP survey version



The majority of LCRNs generated high percentages of respondents who ‘strongly agreed’ that the child/young person was treated with kindness and respect by research staff. Figure 12 displays the percentage of respondents strongly agreeing to Q6 by LCRN and indicates a 41% range in scores across the LCRN regions.

Figure 12. Percentage of respondents selecting ‘strongly agree’ when asked whether research staff have always treated the child or young person with kindness and respect (Q6) by LCRN



In the open-ended question responses, several respondents noted how they felt respected by the staff and that the staff treated them with dignity.

> “Respected me and treated me with dignity.”
>
> “Everything. The staff looked after us beautifully. They were friendly, professional, caring, and respectful. The room had plenty of toys to entertain her. Fantastic. Everything was explained very clearly.”

Again, there were no comments that specifically implied anything negative about the research staff in the sample of CYP comments coded.

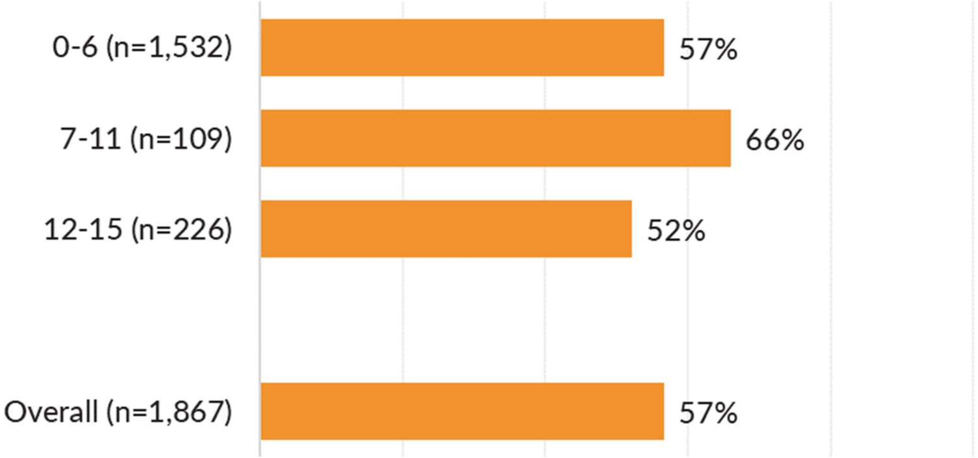
Q7. Would consider taking part in research again.

Last year, in the 2021/22 survey, over three-quarters of respondents (77%) 'strongly agreed' that they (the child or young person) would consider taking part in research again, or parents/carers would consider their child taking part again. This figure has unfortunately worsened to 57% this survey year (Figure 13).

Figure 13. Percentage of respondents selecting 'strongly agree' when asked whether they would consider taking part in research again (Q7), by survey year

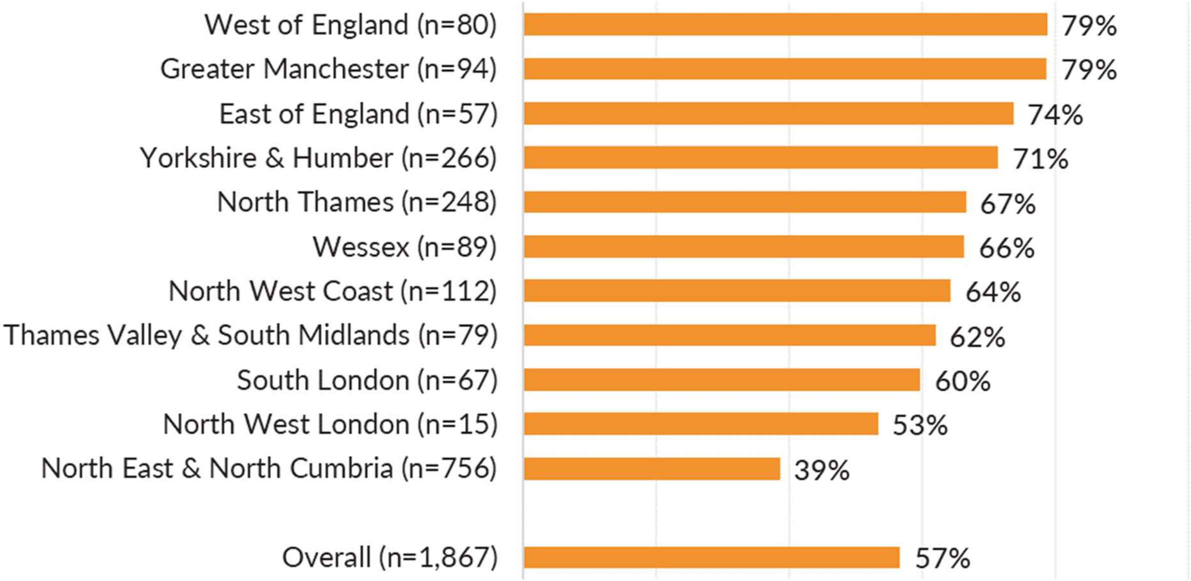
Respondents that completed the 7-11 survey version were more likely to 'strongly agree' that they would consider taking part in future research studies (66%) than other survey version respondents: 0-6 (57%) and 12-15 (52%) – see Figure 14.

Figure 14. Percentage of respondents selecting 'strongly agree' when asked whether they would consider taking part in research again (Q7), by CYP survey version



As with other survey questions, there was considerable variation in responses to Q7 (the proportion of respondents reporting that they 'strongly agreed' that they would consider taking part in future research studies) by LCRN (Figure 15). West of England and Greater Manchester both scored the highest, with 79% of respondents 'strongly agreeing' that they would consider taking part in a research study again. This contrasts with 39% at North East & North Cumbria and 53% for North West London.

Figure 15. Percentage of respondents selecting 'strongly agree' when asked whether they would consider (their child) taking part in research again (Q7), by LCRN



Qualitative findings – Children and Young People

Q8. What was positive about your child’s research experience?/What did we do well?

Overall, 38% (730/1884) of eligible respondents provided a response of five or more characters in length to Q8, which asked about positive aspects of participant’s research experience.

From the CYP survey, 250 comments for Q8 were analysed. The same coding framework was used in both CYP and adult survey versions, however, the CYP section of the free text did not always require all subthemes. For Q8, seven subthemes were used for CYP, one fewer than in 2021/22. Comments were coded into multiple subthemes if they mentioned multiple aspects of the research participation. See table 7 below for a summary of each of the subthemes that emerged from the data.

The three most common subthemes within the free text sample analysed were: research staff/team (n=185), information and communication (n=125) and practicalities of participating (n=60).

Table 7. Summary of CYP feedback on positive aspects of their participation.

Theme

Theme	Subtheme	Description/examples
Experience of research	Procedures (20 mentions; 18 positive; 2 neutral)	Procedure was simple; quick/ easy process; did not hurt
	Research staff/ team (185 mentions; 181 positive; 4 neutral)	Staff were friendly/ kind/ helpful/ supportive/ put us at ease; excellent staff; staff involved child; nothing was too much trouble
	Practicalities of taking part (60 mentions; 56 positive; 4 neutral)	Excellent organisation; good/clean facilities; appointments on time; convenient home visits; no need for extra samples/interference
	Motivation to participate (21 mentions; all positive)	To find out whether child is at risk; research improves medical care; knowing we could help others in the future
Results and communication	Treatment outcome (12 mentions; all positive)	Changed my child’s life; after treatment, child is striving; study achieving what we wanted

	Information and communication (125 mentions; 124 positive; 1 neutral)	Communication was clear; well explained; answered questions
Other	Other (8 mentions; 5 positive; 3 neutral)	Comments coded here if they could not be assigned to any of the above codes and were not enough comments to create a new code

Research staff/ team

Research staff were mentioned frequently in comments made by children and young people (CYP) and their parents/carers (n=185). These were vastly positive, with only four comments assigned a neutral sentiment. CYP and their parents shared how the staff were friendly, organised, approachable and contributed to their positive experience.

> "Staff have always been kind, supportive and informative."
>
> "Yes, the staff are really friendly and approachable. There have been really helpful."
>
> "The study team are lovely - very easy to work with, very kind and very informative without being overwhelming."
>
> "We have been made to feel very welcome, given all the information and advice needed during the study and feel we have been well supported."
>
> "Being honest and forthcoming. being friendly and caring."

Information and communication

Information and communication was the second largest subtheme (n=125), with many positive experiences reported. Respondents noted how they received enough information or that it was easy to understand. Additionally, participants shared that they were kept well informed and received follow ups in the form of emails and calls. Staff communication has been noted positively throughout. More specifically, that information was explained well or with age-appropriate explanations.

“We have been informed straight from the beginning about this study and the purpose of it. Information was very clear and easy to be understood by my child taking part in the study. The researcher was very professional and kept me informed all the time, answering all my questions promptly and efficiently.”

“Every detail was explained in great depth. We felt very included in all information and part of a team.”

“Very friendly & welcoming. Following up with email and phone calls. Explaining the process, the diaries etc. Kept us both well informed during the visits.”

“Age-appropriate information. No pressure felt it was my choice whether I took part. Very friendly.”

“Staff were warm and engaging, great at communicating, kind and compassionate, very organised and thoughtful.”

“Took the time to explain about eczema and how to best apply the cream. In all the time we've been having treatment no one has made me feel so listened to.”

Practicalities of taking part

Practicalities of participating, the third main subtheme (n=60), had 56 positive comments, the remaining, neutral. Respondents spoke of the organisation of the research, as well as the safety of the environment. Some noted the ease of taking part due to vaccinations being carried out at home. Whereas others reported that the rooms were well equipped, for treatment and activities for the children.

“Everything. The staff looked after us beautifully. They were friendly, professional, caring, and respectful. The room had plenty of toys to entertain her. Fantastic. Everything was explained very clearly.”

“…rooms are brill and well equipped for treatment…”

“My child’s participation has been valued right from the first initial enquiries. He (and us as parents) have been treated respectfully. Facilities were clean, bright, and modern and we wanted nothing during our visit.”

“Friendly, safe environment, interesting, helping my child, excellent staff.”

“She was able to have the vaccines in the comfort of home, the vaccines were administered swiftly.”

Motivation to participate

All comments relating to motivation to participate in research (n=21) were positive in sentiment. Respondents generally noted how they would hope that the research is going to positively impact others in the future. Some people wanted to know whether their child is at risk and others felt that they would find out more information by taking part.

“Staff was friendly and knowing it will help other children in future.”

“Research nurses always lovely + kind. It's nice to feel like you're helping a child by contributing to the study, at a time when you're feeling most helpless.”

“Knowing I can find out if my baby is at risk.”

Procedures

There were 20 comments in the ‘procedures’ subtheme. Comments under this subtheme were mostly about the practical side of the research; vaccinations and taking blood.

“Took my blood easily without it hurting, they talk me through every part.”

“You welcomed me and my sister with kind words and smiles! You tried to get things done as fast as possible with fun things to do when we wait. Nurses make us feel at ease when doing blood and make it quick and painless.”

“It didn’t hurt that much when you put the needle in, and they were very kind to me.”

Treatment outcome

The 12 comments coded under ‘treatment outcome’ were all positive. Parents and children wrote how the treatment has improved conditions, prevented illness and infection and improved children’s lives in general.

> “This has really changed my daughter’s life, her sleep, motor skills have improved, we are very happy.”
>
> “Well looked after throughout. the study appears to be achieving what we wanted. excellent organisation and knowledge from research staff.”

Other

Comments coded under this theme (n=8) were varied and included a few comments about feedback and results. Other comments included those relating to finding the research enjoyable and interesting.

> “Great project, we really enjoyed it and was beneficial.”
>
> “Everything about the content of this research.”
>
> “Just something new, never knew it existed.”

Q9. What would have made your child's research experience better?/ What could we do better?

Overall, 16% (301/1884) of eligible respondents provided a response of five or more characters in length to Q9, which asked what would have made the research participants' experience better.

As with Q8, 250 CYP comments were analysed for Q9. Similarly, the same coding framework was used in both survey versions, however, CYP did not always require all subthemes. For Q9, nine subthemes were used. See Table 8 below for a summary of each of the subthemes that emerged from the data.

The three most common subthemes that emerged from the data were practicalities of participating (n=105), information and communication (n=63) and comments stating that they felt nothing needed to be done (n=44).

Table 8. Summary of CYP participant feedback on what could have made their research experience better.

Theme	Subtheme	Description/examples
Experience of research	General experience of research participation (35 mentions; 31 positive; 4 neutral)	Everything simple and straightforward; very positive/pleasant experience; process is as expected
	Procedures (5 mentions; 3 neutral; 2 negative)	Procedure late; suggestions of a nurse/ phlebotomist to do blood tests; less bloods to be taken; taking bloods was distressing
	Survey (12 mentions; all neutral)	Questions could be clearer/easier; response options not suitable; daily diary quite complicated
	Research staff/team (13 mentions; 9 positive; 3 neutral; 1 negative)	Staff have been kind/professional/helpful/ funny
	Practicalities of taking part (105 mentions; 3 positive; 94 neutral; 7 negative)	Locations to be closer; better signage/ directions; challenges with app/app to be more user friendly; quiet room for children; facilities for new mothers (breastfeeding etc);
Results and communication	Feedback about results/progress (17 mentions; 1 positive; 14 neutral; 2 negative)	To get results of trial sooner; long time to find out whether on the treatment/ placebo; unsure how/when results will be shared;

		would be great to get updates on progress of trial
	Information and communication (63 mentions; 2 positive; 60 neutral; 1 negative)	Some information rushed; more reminders; explain reason(s) for blood tests; recap of information; interactive video of information; direct number in case of questions
Other	Nothing (44 mentions; 36 positive; 8 neutral)	Nothing- can't fault; nothing- care has been amazing; at this stage- nothing
	Other (38 mentions; 37 neutral; 1 negative)	Comments coded here if they could not be assigned to any of the above codes and were not enough comments to create a new code

Practicalities of taking part

This was the most common subtheme (n=105) for this question. Similarly, to 2021/22, suggestions for practical improvements were varied. Respondents asked for flexibility in appointment times; particularly important for those in school. Others suggested offering a wider range of venues to minimise travelling and others felt directions and signage could have been better, as well as parking. Many mentioned that the app was temperamental, which was off-putting for some.

> "Appointment times could be after school hours. Nothing else, very good."
>
> "The app is terrible, never works. Would really put me off participating again and may not actually be possible to complete this study."
>
> "Parking at hospital could be better."
>
> "Allocated parking spaces as very hard to manage with car seats etc in the narrow spaces."
>
> "Better signage on arrival for appointment."

Information and communication

Information and communication was the second most common subtheme (n=63). Most of the comments in this subtheme were assigned a neutral sentiment (n=58). The only negative comment within this subtheme was regarding being given the wrong information due to being assigned to the wrong group (see first comment below). Suggestions for improvement related to being informed of the timescales and receiving more information once the research study had started. Some suggested receiving written information following meetings would be beneficial while others felt research information could have been given earlier.

> “At one of the vaccinations they got the group wrong for my child so gave me the wrong information, so it was only because I questioned it that they checked. however, the vaccines they had brought were correct.”
>
> “Finding out about the project prior to giving birth instead of day of discharge - mums aren’t always thinking clearly at that point.”
>
> “To have had follow up information sent in the post as you don't always remember what's going on whilst in hospital.”
>
> “Reminders for diary completion only being sent if not completed. We were still receiving reminders for completion each month even if the diary had already been completed.”

Nothing and General experience of research participation

Comments under these subthemes were generally positive. Respondents reported that nothing could have been improved (n=44) and for most, added general commentary on their research participant experience (n=35), hence being coded in both subthemes.

> “Nothing. Can’t fault my experience at all.”
>
> “Nothing, it has been straight forward, pleasant and informative.”
>
> “I couldn't fault anything; it’s been an extremely positive experience.”
>
> “Nothing, just more of this approach as it was interesting to learn.”

Other

Comments coded under this theme (n=38) were varied; some of these were not actionable such as knowing whether they received placebo or not; being given the treatment rather than placebo. A couple were requests to inform of further opportunities while others felt unable to comment as it was early on in their research experience.

> “Let us know about other opportunities to take part e.g. 'Age of Wonder'.”
>
> “If another family was going through the same study, just so we had someone else to talk to.”
>
> “That I could have taken part in more!”
>
> “Too early to tell as he hasn’t taken part just yet.”

Feedback about results/ progress

There were 17 comments about feedback about results/ progress. Most (n=14) of these comments were assigned a neutral sentiment. Many comments related to uncertainty about finding out the results of the research.

> “It may be that I've forgotten but I'm not sure how I’ll receive the results of the study.”
>
> “Hope discussions with the doctors about updates of the research study and the future plan for my child.”
>
> “It has been smooth and straight forward so far. I would be interested to know of any findings in the future but don't know if this is possible.”

Research staff/team

The subtheme ‘Research staff/team’ had 13 comments, the majority of which were positive (n=9) with only 4 comments assigned a neutral sentiment.

> “Nothing as the two ladies (name) and (name) that looked after my child were brilliant.”
>
> “I cannot think of anything, everyone had been incredibly kind. I had to cancel an appointment due to illness and the team were understanding and were able to rearrange our appointment.”
>
> “Lovely lady couldn't have done anything more to explain or help out.”

Survey and Procedures

Some respondents noted aspects about the survey (n=11) such as the survey questions were difficult, irrelevant, or not detailed enough and some would appreciate being able to leave more free text. The comments about procedures (n=5) related to the more practical side of the research; blood samples and having trained staff undertaking the procedure.

> “A bit more from the app, like more reminders and more things to fill in. The questions don’t really ask much, and I wanted to explain more.”
>
> “The format of the surveys/questions. Some questions didn't have answers that fit our experience, so it was hard to know how to answer.”
>
> “The centre and staff were/are excellent. I only wish the phlebotomy dept could have been used more as cannulation/bloods were by far the most distressing/traumatic part of the research. At times this was almost unbearable.”

Adult Survey Results

Respondent profile

Overall, 30,705 people responded to the adult survey. This was higher than the previous survey waves in 2021/22 (n=25,459) and 2020/21 (n=20,749).

52% of adult surveys were completed online and 48% on paper.

Nearly a quarter of adults (24%) had taken part in previous research studies. Almost two-thirds of adult respondents

(63%) in 2022/23 were aged over 55 (Table 9).

Please note that some surveys were excluded from the analysis owing to poor data quality and due to duplication. Therefore, the total number of respondents throughout the remainder of this report will be slightly lower than those presented in Table 9.

Table 9. Respondent numbers and percentages, by age (Q13)

Respondent age	No. of respondents	% of respondents
16-24	509	2%
25-34	2,411	8%
35-44	2,714	9%
45-54	3,401	11%
55-64	6,477	21%
65-74	7,311	24%
75+	5,572	18%
Not stated	2,191	7%
Total	**30,586**	**100%**

When exploring responses by sex registered at birth, half or respondents were female (50%), 39% were male, 1% preferred not to say 10% did not respond to the sex question (Table 10).

For Q15, overall, 99% reported that their gender was the same as their sex registered at birth, with 1% opting not to disclose this information. Younger respondents were less likely than older survey participants to state that their birth sex and their gender were the same, with 96% saying that they were the same, 1% that they were not and 3% opting not to state this.

Table 10. Respondent numbers and percentages, by sex registered at birth (Q14)

Sex registered at birth	No. of respondents	% of respondents
Female	15,391	50%
Male	11,822	39%
Prefer not to say	243	1%
Not stated	3,130	10%
Total	**30,586**	**100%**

Overall, 83% of respondents stated their ethnicity as White (Table 11). A further 8% of respondents were Asian, 2% Black, 1% Mixed, and 1% another ethnic group. Five per cent of respondents did not state their ethnicity.

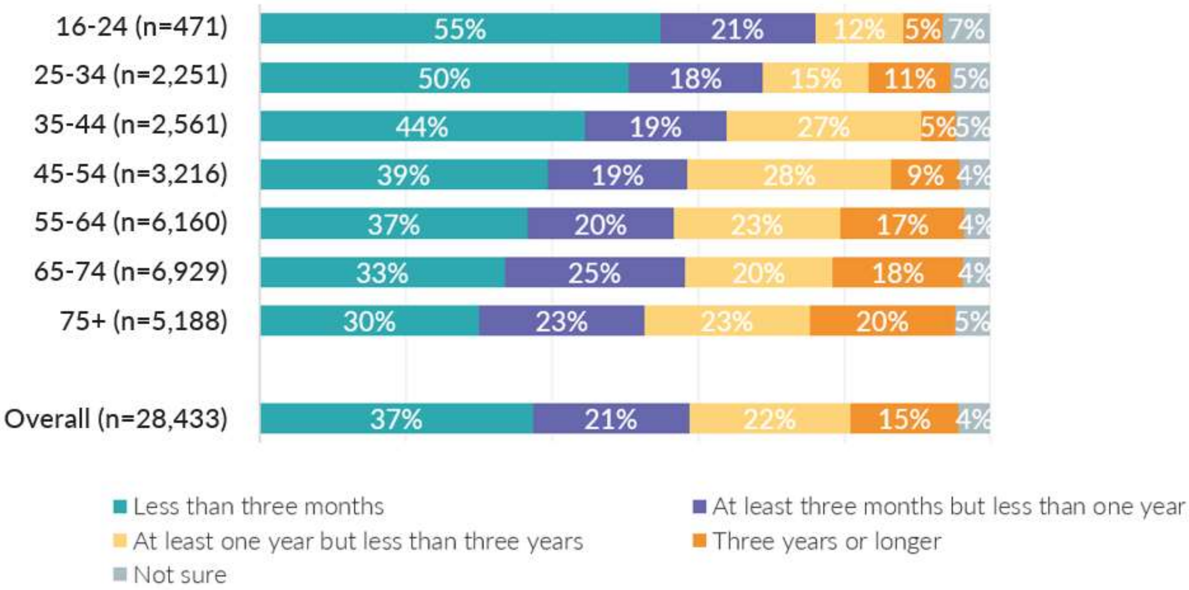
Table 11. Respondent numbers and percentages, by ethnic group (Q16)

Respondent ethnic group	No. of respondents	% of respondents
White	25,511	83%
Asian	2,571	8%
Black	439	2%
Mixed	334	1%
Other	272	1%
Not stated	1,459	5%
Total	**30,586**	**100%**

For around three-quarters of respondents (76%), the research study was the first they had participated in. The proportion who stated it was their first research study did not differ greatly by age group for those aged 25+, with this figure ranging only from 74-77% across all age bands. Those aged 16-24 were most likely to state that it was their first research study with 87% reporting this.

The length of time a respondent had been involved in a research study did differ with age, however (Figure 16). The younger the respondent, the more likely it was that they had been participating for less than three months. Generally, older respondents tended to have been involved in a research study for longer.

Figure 16. Length of time taken part in research study (Q10), by age.



Respondents were asked who completed the survey. The majority – 93% - stated that they had completed it on their own. A further 4% said someone else filled it in with them, and 3% of surveys indicated that someone else other than the research participant had filled them in. These figures were similar across all age bands (the proportion stating they completed the survey on their own ranged from 91-96%), except for participants aged 75+. For this age group, 87% reported having completed it themselves, 8% with the help of another person, and 4% were recorded as someone else having completed it on their behalf.

Adult survey responses were distributed by 15 LCRNs. Proportionally, survey returns were more evenly split across the LCRNs (Table 12) in 2022/23 when compared to the CYP survey (Table 3). East of England, North East & North Cumbria and Yorkshire & Humber each accounted for 10-11% of all adult survey respondents, with all other LCRNs contributing between 3 and 9% of the total.

North East & North Cumbria increased its share this survey year, accounting for 10% of all adult returns, up from 5% in 2021/22. North Thames has shown a similar increase, going from 4% to 9% of adult respondents. Greater Manchester (4% from 8% previously) and Thames Valley & South Midlands (3% from 7%) reduced their share of returns this survey year.

Table 12. Number and proportion of all surveys returned in the adult 2022/23 survey year compared to 2021/22, by LCRN.

LCRN	No. of surveys returned 2022/23	% of surveys returned 2022/23	% of surveys returned 2021/22
East of England	3,412	11%	10%
North East & North Cumbria	3,149	10%	5%
Yorkshire & Humber	3,009	10%	11%
North Thames	2,657	9%	4%
West of England	2,490	8%	7%
Kent, Surrey & Sussex	2,402	8%	8%
North West London	2,208	7%	7%
West Midlands	1,655	5%	6%
South West Peninsula	1,625	5%	5%
East Midlands	1,608	5%	5%
South London	1,556	5%	6%
Wessex	1,427	5%	5%
North West Coast	1,269	4%	6%
Greater Manchester	1,215	4%	8%
Thames Valley & South Midlands	1,023	3%	7%
Total	**30,705**	**100%**	**100%**

In terms of survey mode, 52% of respondents completed the survey online and 48% on paper.

Quantitative findings: Adults

Q1. The information that I received before taking part prepared me for my experience on the study.

In 2022/23, 62% of adult respondents 'strongly agreed' that the information they received prior to taking part in the study prepared them for their experience. Whilst this is a moderately high percentage of participants, it is somewhat lower than the previous two survey years (2021/22, 73% and 2020/21, 75%) - see Figure 17.

By age, 25-34 year olds were most likely to 'strongly agree' with this statement (70%), while just 53% of respondents aged over 75 said the same.

People of Black or Asian ethnicity were least likely to 'strongly agree' that the information was easy to understand (both 54%).

At LCRN level, scores for Q1 ranged from 68% 'strongly agreeing' in Wessex, Greater Manchester and West of England, to lower scores of 51% (Kent, Surrey & Sussex), 56% (North West London) and 57% (North Thames)

Figure 17. Percentage of respondents selecting 'strongly agree' when asked whether the information that they received before taking part, prepared them for their experience on the study (Q1), by survey year

In the free text, several respondents commented positively about the information they were given at the start of the research.

> “(Name) was very friendly and explained everything very well. She ensured that I had read through everything well and didn’t rush me to agree to anything. Thank you.”
>
> “Information given at time of agreeing to participate in research.”
>
> “Although I am in the early stages of the trial, I was made very aware of the purpose of the trial. Everything relating to the trial was explained to me very clearly and all queries I had were dealt with.”

However, others seemed less positive that they had received all the information they needed.

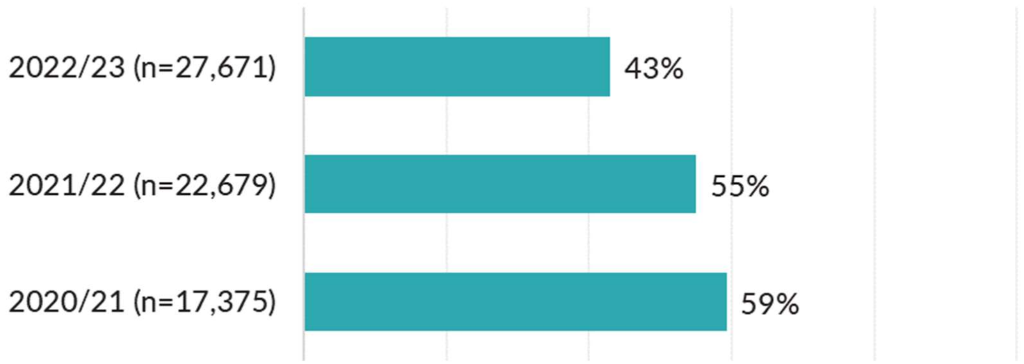
> “Knowing the exact details of what you're going to be signing up for. I would not have taken part. none of this helped my surgery.”
>
> “If I was given more of an explanation about what I could opt in and out from before the day of my surgery as I was already feeling quite anxious.”

Q2. I feel I have been kept updated about this research study

As with Q1, there was a decline in the proportion of respondents saying they ‘strongly agree’ that they have been kept updated about the research study they have been involved in. The proportion stating this in 2022/23 was 43%, down from 55% in the previous survey year and 59% in the year before that – see Figure 18.

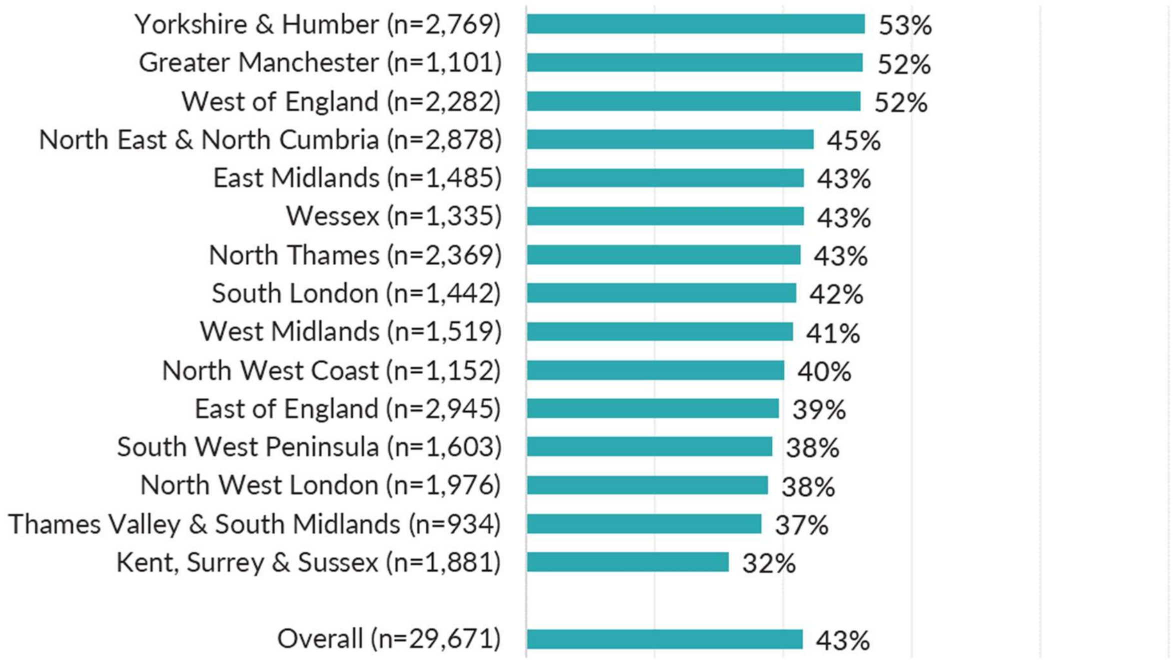
Least likely to ‘strongly agree’ that they had been kept up to date were the youngest and oldest respondents: 42% of 16-24s, 40% of those aged 65-74 and 36% of over 75s reported this, compared to 49% of those aged 25-34, and 47% of 35-44s, 45-54s, and 55-64s.

Figure 18. Percentage of respondents selecting ‘strongly agree’ when asked whether they feel they have been kept updated about the research study (Q2), by survey year



Analysis by LCRN (Figure 19) showed variation between the top and bottom scoring networks, with Yorkshire & Humber, Greater Manchester and West of England achieving the highest scores (52-53%), and Kent, Surrey & Sussex showing the lowest score with 32% ‘strongly agreeing’ that they had been kept updated about the research.

Figure 19. Percentage of respondents selecting 'strongly agree' when asked whether they feel they have been kept updated about the research study (Q2), by LCRN



Feedback from respondents to the open-ended questions suggested that some people were pleased with how they were kept updated overall and throughout the research study.

"Being kept updated and treated respectfully at all times."

"Interesting taking part, as results of tests explained, often receive emails with updates of research."

"Comprehensive materials. Friendly staff/researchers. Updates on studies and results throughout."

Others were unsure of the progress of the study and commented that receiving updates would improve their experience or participating.

"Updates on outcome report. Receiving the report would be a bonus."

"Maybe some updates on how the trial is going so far - even if it is only interim findings. I found some information on the pharmaceutical company's website but not via the research team."

Q3. I know how I will receive the results of this research study.

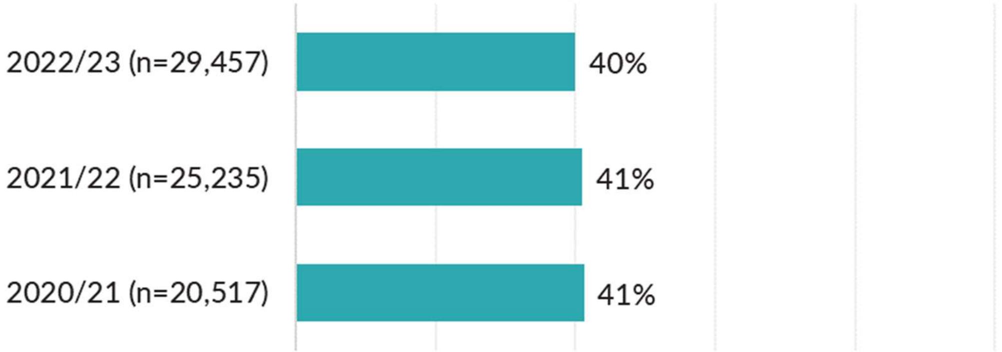
Participants were asked whether they knew how they would receive the results of the research (Figure 19).

There was very little change compared to previous years - 2022/23, 40% and 2021/22 & 2020/21 both 41% - though the proportion who said they knew is perhaps quite low.

25-34 year olds were most likely to report that they knew how they would find out the results of the research (47%), while older respondents were far less likely to agree: 65-74s (37%), 75+ (35%).

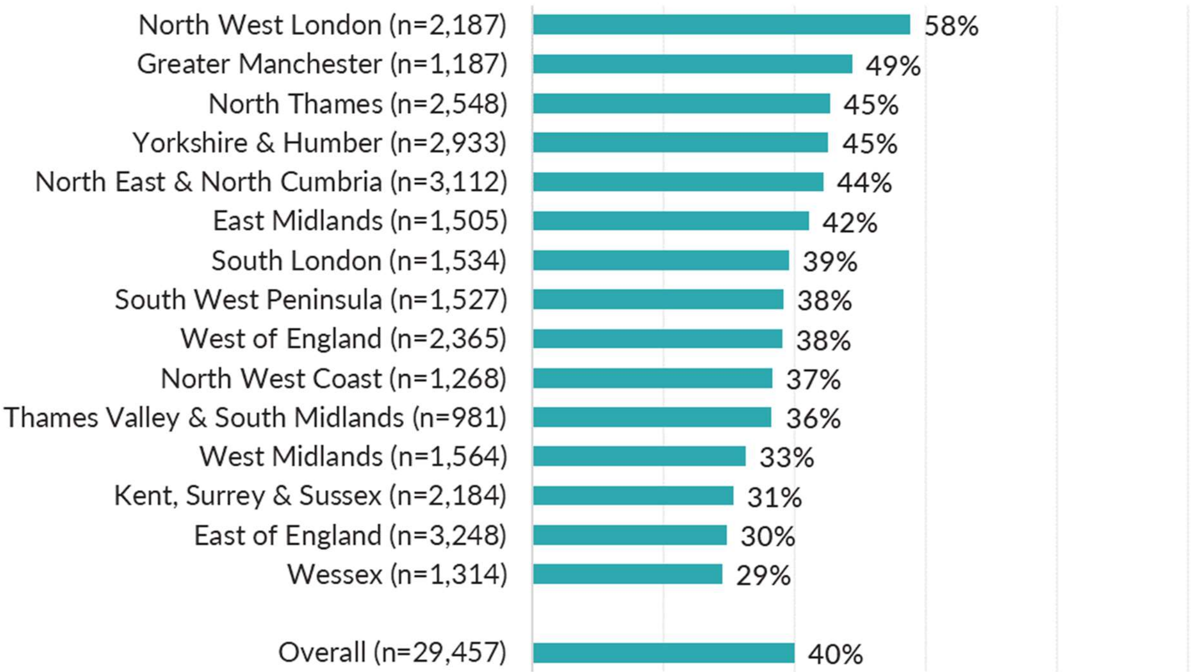
Asian participants were most likely to indicate that they knew how they would find out results of the research (64% said 'yes'), and White respondents, least likely (37%).

Figure 19. Percentage of respondents selecting 'yes' when asked whether they know how they will receive the results of the research study (Q3), by survey year



Analysis by LCRN showed North West London ahead of other LCRNs with 58% of respondents agreeing that they did know how they would find out the results of the research. This was also true for almost half (49%) of respondents in Greater Manchester LCRN. Wessex (29%), East of England (30%) and Kent, Surrey & Sussex (31%) received the lowest scores on this question- See Figure 20.

Figure 20. Percentage of respondents selecting 'yes' when asked whether they know how they will receive the results of the research study (Q3), by LCRN



One participant explained in the free text section of the survey that they had been informed about how results will be shared.

> "Clear concise explanation of research, reason for research, what to do to take part, how I would receive results, when I would receive results and given contact numbers in case I had queries."

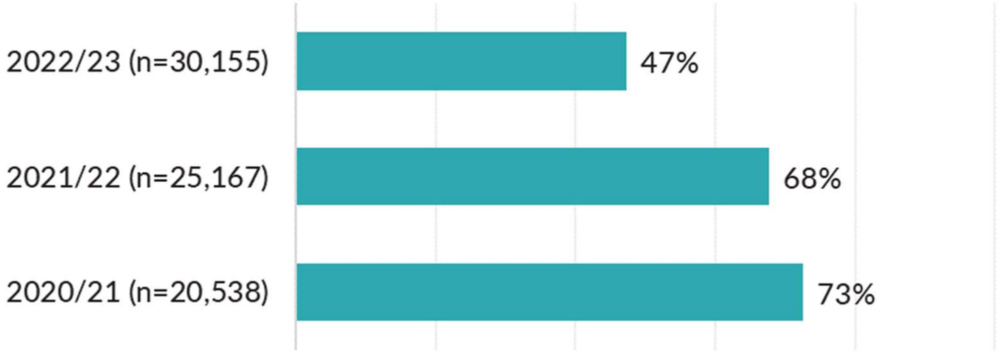
Others reported that they were unsure whether they were given an indication of when or how they would receive such information.

> "I am not sure if I was told if I would get to hear the results of my trial or not, but it would be nice to hear about them and know when/if my participant voucher was on its way."

Q4. I know how to contact someone from the research team if I have any questions or concerns

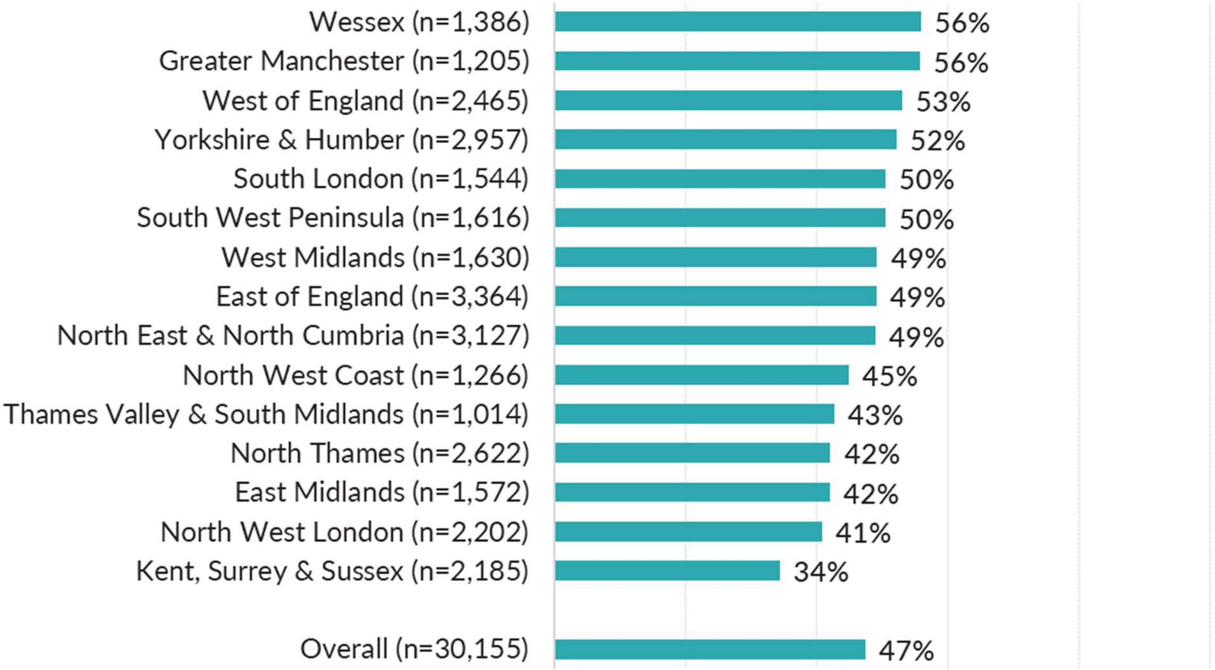
The percentage of respondents who answered that they knew how to contact someone from the research team if they had any questions or concerns was notably lower in the most recent survey year, with 47% saying they ‘strongly agreed’, compared to 68% in last year’s survey and 73% in 2020/21 -Figure 21. By age, over 75s were least likely to report knowing how to contact someone (41%); most likely were 25-34s, 35-44s, and 45-54s (ranging from 51-53%). 45% of 16-24s, 50% of 55-64s and 47% of 65-74s said they knew how to contact someone. Respondents of Asian, Black or ‘other’ ethnicity were less likely to say that they knew how to contact someone (35%, 40% and 40%) than people of White (49%) or Mixed ethnic background (47%).

Figure 21. Percentage of respondents selecting ‘strongly agree’ when asked whether they know how to contact someone from the research team if they have any questions or concerns (Q4), by survey year



At local network level (Figure 22), Kent, Surrey & Sussex scored the lowest for Q4 with just 34% who said ‘strongly agree’ when asked if they knew how to contact someone from the research team. This is in contrast to Wessex and Greater Manchester, both of which had 56% of respondents stating this.

Figure 22. Percentage of respondents selecting 'strongly agree' when asked whether they know how to contact someone from the research team if they have any questions or concerns (Q4), by LCRN



Many respondents mentioned in their free text comments that the research team were easy to contact if they had any queries. Others specifically mentioned that the staff were responsive and had open lines of communication.

> "The attentiveness and genuine care received from Dr. (anonymised) & the team. I was well informed & felt looked after. I was able to make contact at any time if I needed to & felt comfortable to ask questions."
>
> "Grateful to take part. Very thorough triage and monitoring throughout. Open access for any questions or concerns supportive. Clear how research will benefit others."

This unfortunately wasn't the experience of all participants though:

> "Not easy to contact research team. Can't ring them back plus they relocated so had to find new location."

Q5. I feel research staff have valued my taking part in this research study.

The proportion of respondents saying they ‘strongly agreed’ that their contribution was valued by the researchers has fallen compared to the previous two years: in 2022/23, 58% stated this, compared to 70% in 2021/22 and 71% in 2020/21 – Figure 23.

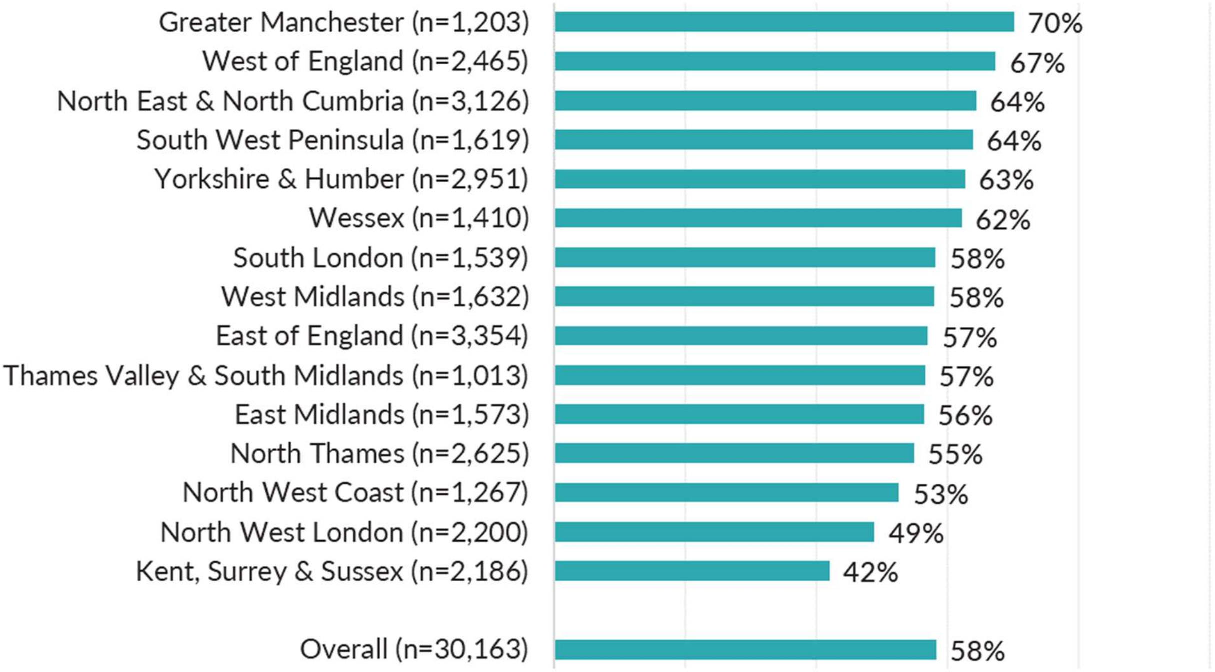
Participants aged 25-34 were most likely to report feeling that their contribution had been valued (66% saying ‘strongly agree’). Older people were the least likely to report this: 57% of 65-74s and 51% of those aged over 75.

Respondents of White ethnicity were most likely to say they felt their participation was valued (60% ‘strongly agree’) – contrasted against 50% of Asian or Black participants.

Figure 23. Percentage of respondents selecting ‘strongly agree’ when asked whether they feel research staff valued their taking part in the research study (Q5), by survey year

Analysis of scores for Q5 by LCRN (Figure 24) showed considerable variation in people’s experience, with 70% of respondents in Greater Manchester stating that they ‘strongly agreed’ that researchers had valued their taking part, against just 42% in Kent, Surrey & Sussex.

Figure 24. Percentage of respondents selecting 'strongly agree' when asked whether they feel research staff valued their taking part in the research study (Q5), by LCRN



Several respondents noted how they felt they were valued as participants:

> "Each time I've participated by giving blood, I've been warmly thanked, and appreciation was given. I've never been rushed."
>
> "I feel valued as a participant, and it was explained of all the pros and cons of the trial. the team were polite, knowledgeable, and showed empathy and compassion towards me."

Another shared how they did not always feel valued during the research.

> "Communication better. Reimbursements within a much shorter time. I don't think I have been paid fully for the online questions. Don't really feel valued when things go wrong."

Q6. Research staff have always treated me with courtesy and respect.

Compared to the two previous years, respondents in 2022/23 were less likely to ‘strongly agree’ that they were treated with courtesy and respect by research staff. Though almost three-quarters of respondents (72%) did ‘strongly agree’ with this statement, this is a decrease from 85% stating this in 2021/22, and 87% in 2020/21- See Figure 25.

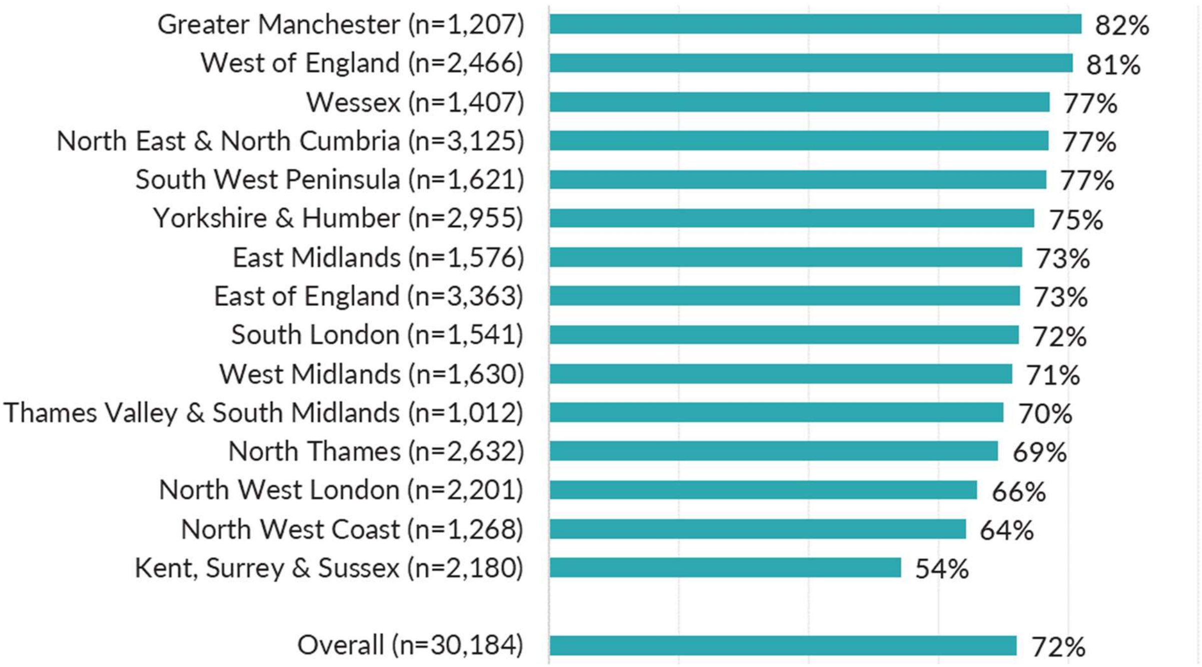
Those aged 25-34 were most likely to ‘strongly agree’ with this statement (79%) and over 75s, the least likely (65%).

Participants of Mixed or White ethnicity were most likely to report feeling they were respected by research staff (74% and 73% respectively ‘strongly agree’). In contrast, 65% of Asian or Black participants reported this.

Figure 25. Percentage of respondents selecting ‘strongly agree’ when asked whether research staff have always treated them with courtesy and respect (Q6), by survey year

There were some stark differences between the top and bottom LCRN scores for Q6, with 82% and 81% of respondents at Greater Manchester and West of England respectively ‘strongly agreeing’ that they were treated with courtesy and respect, contrasted with 54% at Kent, Surrey & Sussex (Figure 26).

Figure 26. Percentage of respondents selecting ‘strongly agree’ when asked whether research staff have always treated them with courtesy and respect (Q6), by LCRN



Several respondent free text comments mentioned the staff/team and in most cases, these were very positive.

> “The staff have been amazing. Made to feel like more than a patient.”
>
> “The staff have treated me with the most respect and I feel at ease with them.”
>
> “Everything. The staff looked after us beautifully. they were friendly, professional, caring, and respectful. The room had plenty of toys to entertain her. Fantastic. everything was explained very clearly.”

However, not all participants had such a positive experience.

> “Staff were rude. Poor bedside manner. Not properly greeted on arrival. Just directed instructions as soon as I arrived without any please/thank you or introduction. They just wanted to get me out quickly so they could finish early. Only got further info on how to reclaim travel expenses when I asked. Did not offer any refreshments after the checkup. Was treated like a lab rat without any courtesy. Very poor experience indeed.”

Q7. I would consider taking part in research again.

Whether participants would likely take part in research again might be linked to their experience across other measures. Considering the decline in reported experience across most other measures in the survey it is perhaps not surprising that the proportion of respondents this survey year 'strongly agreeing' that they would take part in research again has reduced to 60%, from 74% in 2021/22 and 77% in 2020/21 – see Figure 27.

Over two-thirds of 25-34 year olds suggested they would consider participating in future studies (69% 'strongly agree'). Least likely were 16-24s and 65-74s (both 59%) and over 75s (47%).

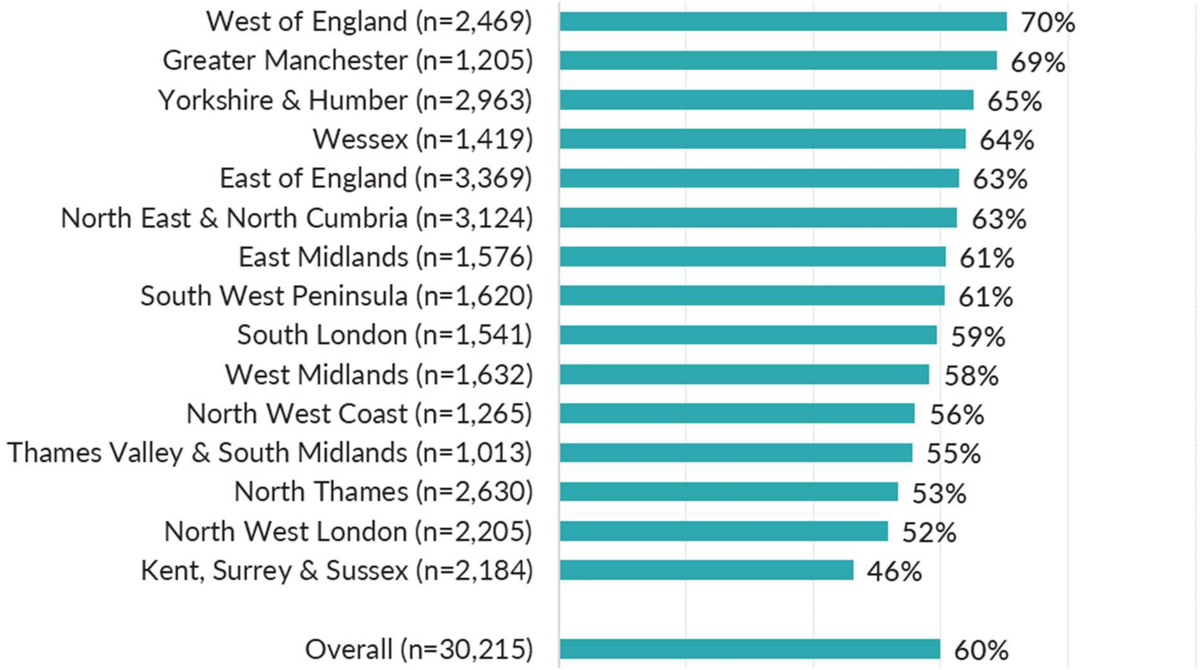
People of White or Mixed ethnicity were most likely to say that they would consider partaking in future research (61% and 59% who said 'strongly agree', respectively). Comparatively, only 46% of Black, Asian (51%) or 'Other' ethnic groups (52%) said the same.

Figure 27. Percentage of respondents selecting 'strongly agree' when asked whether they would consider taking part in research again (Q7), by survey year

Reassuringly, 70% of participants in West of England LCRN and 69% of those in Greater Manchester answered 'strongly agree' when asked whether they would take part in research in future. In contrast, just under half (46%) of participants in Kent, Surrey & Sussex said the same- see Figure 28

.

Figure 28. Percentage of respondents selecting ‘strongly agree’ when asked whether they would consider taking part in research again (Q7), by LCRN



When filtering by respondents who gave a negative response at Q7 (disagree or strongly disagree that they would consider taking part in research again), some of the free text comments shed light on why people would be discouraged from taking part in future research:

> “Would have been good if the app worked better from the start. Can’t imagine the data is that accurate based on app functionality. Would have been good that helpline was better staffed when I had difficulties in receiving first dose at start of trial. Was quite stressful. “

Qualitative findings: Adults

Q8. What was positive about your research experience?

Overall, 57% (17582/30586) of eligible respondents provided a response of five or more characters in length to Q8, which asked about positive aspects of participants' research experience.

A sample of 750 comments for Q8 were analysed to understand the positive aspects of participating in research that respondents shared. The same coding framework was used for adults and children. Nine subthemes were utilised, which is one fewer than 2021/22.

Comments were coded into multiple subthemes if they mentioned multiple aspects of research participation.

There were three prominent subthemes within the sample of free text comments analysed; research staff/team (n=356), information and communication (n=263) and motivation to take part (n=209). Table 13 shows a summary of the positive feedback given by participants, organised by subtheme.

Table 13. Summary of adult feedback on positive aspects of research participation.

Theme	Subtheme	Description/examples
Experience of research	Procedures (85 mentions; 79 positive; 5 neutral; 1 negative)	Reassuring to be seen regularly; tests were simple and easy; being able to take part/receive medication/ having access to medication they otherwise would not
	Survey (10 mentions; 9 positive; 1 neutral)	Easy/quick to answer survey; questions were interesting; survey easy to follow
	Research staff/ team (356 mentions; 347 positive; 7 neutral; 2 negative)	Staff were friendly/ professional/ helpful/ knowledgeable/ kind/ welcoming; staff treated me with respect; staff made me feel valued; provided quality care; comments on staff interactions
	Practicalities of taking part (116 mentions; 108 positive; 7 neutral; 1 negative)	Well organised; efficient; arranging appointments with ease; appointment times were kept; safe environment; straightforward; ran smoothly; convenient; easy to participate
	Motivation to participate (209 mentions; 205 positive; 4 neutral)	Happy to contribute to research; felt like I was helping people; wanted to be part of the wider picture

Results, feedback and communication	Treatment outcome (55 mentions; 51 positive; 2 neutral; 2 negative)	Reassurance; knowledge from participation e.g., antibody status/ learning about health; gave more confidence; the treatment has improved my condition/ quality of life e.g., eyesight improved; improvement to my physical health
	Feedback about results/progress (24 mentions; 21 positive;1 neutral; 2 negative)	Receiving updates/ feedback about their personal results; being kept up to date with the progress of the trial
	Information and communication (263 mentions; 253 positive; 8 neutral 2 negative)	Clear explanations/ instructions; kept updated throughout; received enough information; clear lines of communication; regular emails; my questions were answered; information was detailed; felt listened to
Other	Other (43 mentions; 19 positive; 21 neutral; 3 negative)	Comments coded here if they could not be assigned to any of the above codes and were not enough comments to create a new code

Research staff/ team

Out of all comments in the research staff/team subtheme (n=356), there were only two negative and seven neutral comments. The rest shared positivity relating to the staff, regarding their professionalism, kindness and how they interacted with the participants.

"The research staff were polite and friendly and did everything they could to make sure I was happy and understood all aspects of the research. They made the whole experience pleasant and enjoyable. They obviously valued the contribution of the participants. Great sense of humour! The research staff could not have made the experience any better."

"The friendly approach of the study team and their friendly reassuring manner put me at ease straight away. The whole experience seems well organised and seamless. I have been guided through by nurses and been provided with medication to reduce side effects to an absolute minimum."

"Very proactive team. Quick to answer any questions. Very polite team."

"The staff conducting all the tests have always been very professional, friendly and courteous."

"The researchers are always courteous and friendly. They make it easy to discuss private or potentially embarrassing subjects."

.

Information and communication

There were 263 comments under this subtheme. The majority of comments coded under this subtheme were positive (n=253). Respondents share that they received clear explanations, with the ability to ask questions and have them answered in a clear and timely manner. Comments were coded under this subtheme if they mentioned having contact details of researchers, should they have any questions throughout.

"The staff were helpful, answered any questions I brought with me, I felt valued, if I phoned somebody was always there."

"It is early on in the process however all of my communication so far has been very clear and helpful, and I feel I am able to find some positivity from my recent diagnosis to be able to participate in this project."

"The level of information and the high level of care from the nurses especially when I was worried about some side effects I experienced."

"The staff were very welcoming and informative. The tests were explained fully beforehand. I took part in a survey with the doctor but was able to ask questions and was given more information about my condition. The venue/area felt very safe and spacious."

"Caring, kind understanding nurse, it's nice to know they are at the end of the phone if you need them, and their support helped a lot. I found the app very helpful too."

Motivation to participate

Comments coded under this subtheme reflect on reasons why people wanted to take part in research (n=205); with the vast majority wanting to help others and improve medical research.

“A positive feeling that I was contributing to medical research.”

“Knowing that it could possibly help someone else in the future.”

“If positive or negative - results either way give information to medical science.”

“Made to feel that every contribution I made was valuable to the team. It was good to be part of a research trial that has made a positive difference and saved lives.”

Practicalities of taking part

This subtheme covered comments relating to all practical aspects of participating in research (n=116), safety of the environment, appointment times and efficiency and locality of research sites.

“Staff were courteous & efficient ensuring there were no undue delays.”

“Well organised with clear information, good administration and efficient processing of research activities on the day.”

“Quick taking bloods, nice to have urine hatch!”

“Ability to have appointments booked around work so no extra travel, staff friendly and informative.”

“I was reassured by taking part in this important research in the safe, professional environment of (name) hospital.”

“The staff in the unit are lovely and the surroundings and experience are great.”

“The location is not far from my home, I was able to go with my daughter, the staff were helpful and friendly, tea/coffee/water and biscuits offered after tests as people had to fast.”

“Parking was convenient if expensive. I was never kept waiting long, if at all, when attending appointments. It was easy to rearrange appointments by phone. Staff were friendly. I was pleased to have the extra covid vaccination.”

Procedures and Survey

Although these subthemes were coded separately, they both relate to the elements of the research that participants took part in. For some, there were more practical elements (procedures; n=85), while others were involved in written tasks (survey; n=10). Comments coded under ‘procedures’ mentioned not only physical procedures, but also the reassurance participants felt by taking part in research. Comments relating to surveys tend to explain how quick, easy and relevant the questions in the surveys and daily diaries were.

“Met a lovely lady who explained everything, it was pleasant and non-invasive.”

“It was a quick blood test.”

“Having to take pills daily the prospect of a monthly injection is a good idea, also I get regular check-ups with this team.”

“I was reassuring to be seen/examined regularly, especially immediately after finishing treatment. also, feels good to be able to contribute to 'cancer research'.”

“On time, nurse was so lovely, explained everything. no problem at all. Didn't hurt. was so easy.”

“The questionnaires were very interesting and the response from the team were very fast and had enough information.”

“The research team were friendly, and the questionnaire was easy to follow and complete.”

“Easy to use daily diary and the reminders they sent.”

Treatment outcome

A smaller proportion of the comments mentioned the outcome of the research on their condition (n=55) and how their knowledge of the condition or symptoms experienced had improved.

> "The antiviral worked very well and helped me have very mild symptoms. prior to taking the medication, I was beginning to feel quite unwell..."
>
> "Helped me to understand symptoms of dementia and the relevance of physical fitness."
>
> "I have found out a lot about my condition due to the research. It is very daunting finding out you have a condition like this at a younger age. All areas of the team I came into contact with were very professional, informative and made me feel at ease."

Feedback about results/ progress

Fewer comments mentioned the results or progress of the research (n=24), but those that did generally commented on how they received positive or regular feedback.

> "Clear instructions. No long-time commitment. Real time results delivered."
>
> "Being kept informed and shown results month by month. Department all very polite and welcoming."
>
> "Comprehensive materials. friendly staff/researchers. Updates on studies and results throughout."

.

Other

Comments coded in ‘other’ (n=43) did not relate to any of the aforementioned subthemes and did not have sufficient detail to create a new subtheme. Some comments in ‘other’ were also not actionable.

> “There was nothing negative, so it was all positive.”
>
> “First time I have taken the survey.”
>
> “Sharing ideas with participants from different trusts.”
>
> “Seeing people who cared about my husband’s condition. Going to the hospital once a fortnight during lockdown was our only social event!”

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Q9. What would have made your research experience better?

Overall, 29% (8745/30586) of eligible respondents provided a response of five or more characters in length to Q9, which asked what could have improved the research participants' experience.

As with Q8, 750 comments were analysed for Q9. Similarly, the same coding framework was used in both survey versions. For Q9, 13 subthemes were used, which is three more than 2021/22. Table 14 shows a summary of respondents' feedback on what could have made their research experience better, organised by subtheme.

Practicalities of participating (n=199), information and communication (n= 192) and general experience of research participation (n=136) were the three most common subthemes.

Table 14. Summary of adult participant feedback on what could have made their research experience better.

Theme	Subtheme	Description/examples
Experience of research	General experience of research participation (136 mentions; 110 positive; 11 neutral; 15 negative)	Experience was great; I had a good experience; satisfied; positive experience; everything was okay/ fine
	Procedures (53 mentions; 1 positive; 23 neutral; 29 negative)	Multiple/ painful attempts to carry out blood tests; carry out all tests expected, rather than just some; equipment not working
	Survey (46 mentions; 1 positive; 27 neutral; 18 negative)	Survey questions difficult/ strange/ not relevant/ too long/ repetitive; reduce volume of survey; a desire to add a free text comment to explain answers in more detail
	Research staff/team (83 mentions; 27 positive; 17 neutral; 39 negative)	Wanting more contact with staff; a desire for more skilled/ knowledgeable staff; staff to be more friendly/ welcoming
	Practicalities of taking part (199 mentions; 5 positive; 134 neutral; 39 negative)	Free/easier parking; more local facilities; ability to have blood taken locally; ensuring appointments are on time; app was temperamental; absence of drinks/ snacks; a desire for

		shorter appointments; more flexible appointment times
	Side effects (13 mentions; 3 neutral; 10 negative)	Undesirable aftereffects: treatment made them poorly; impacts on body/life
	Incentives/expenses (17 mentions; 7 neutral; 10 negative)	A desire for funding/ reimbursement for travel/ parking; payment/ incentives for time; to be exempt from parking charges rather than reimbursed
	Vaccine approval (7 mentions; 1 neutral; 6 negative)	Issues with travel/ receiving boosters due to communications/ decisions around the Covid-19 vaccine approval
Results and communication	Treatment outcome (8 mentions; 4 positive; 4 negative)	Didn't benefit me; not feeling better; condition did not improve; if the result had been positive/ was quick enough to help
	Feedback about results/progress (97 mentions; 2 positive; 74 neutral; 21 negative)	A desire for: regular updates on overall trial progress; to receive results/ conclusions of trial; regular updates on test results; to receive results/ feedback sooner; formal copy of results via email
	Information and communication (192 mentions; 15 positive; 100 neutral; 77 negative)	A need for more information, clearer instructions, clearer information, and provision of contact details/ phone numbers; not easy to contact research team; emails not responded to; reminder emails/ texts sent unnecessarily
Other	Nothing (69 mentions; 54 positive; 15 neutral)	Nothing- can't fault; nothing- care has been amazing; at this stage- nothing
	Other (67 mentions; 5 positive; 55 neutral; 7 negative)	Comments coded here if they could not be assigned to any of the above codes and were not enough comments to create a new code

Practicalities of taking part

Practical aspects of taking part in research (n=199) were cited most when respondents were asked whether anything could be improved. Respondents noted that directions/signage could be improved, as well as locality of the site, booking systems, shorter appointments, and minimal waiting times. Others noted that the app was not always working.

"The app actually working so I could login when asked."

"1. Quicker appointment system. 2. Email updates e.g., re how recruitment is going etc."

"Wish hospital is nearer to my house!"

"Slightly more time to read and understand leaflet."

"Having this in a closer hospital for transport. However, the hospital is wonderful, and they make you feel so safe and cared for."

"Less waiting time when arriving to site."

"There were a lot of changes to timings and conflicting information for appointment times and location."

Information and communication

There were many comments relating to information and communication (n=192). These mentioned having clear or consistent information. Some would have liked more information, while others felt there was too much. Several respondents mentioned receiving reminder emails to complete surveys, despite having already done so. Others would have liked an opportunity to complete the research face to face.

"Giving me more information about study although I received the emails beforehand."

"Not getting emails repeatedly asking me to do the survey since completing it."

"Maybe a bit more in-person delivery, but not a lot I can think of."

"I have read the information, but it would have been better from the staff there explaining how to be contacted and how our survey would be used and more."

"Understanding more about what each session was looking for would have helped me feel more involved."

"Maybe a bit more contact very much me going with questions or queries and little check-ins so far."

"Email communication could have been better, after the ward changed, and I think the previous ward-based email address stopped being replied to."

General experience of research participation

There were 136 general comments relating to participants experience of research. Comments in this subtheme were generally positive, noting that it was a 'good experience'. There were 15 negative comments and 11 neutral. Some of the negative comments referenced reasons for why respondents would not participate in future research.

"…someone experienced to take blood as took several attempts of inserting needles for blood tests. Would not participate again as treated like a commodity/experimental guinea pig."

"I feel I was forgotten and in fact went for more than two years before being reinstated onto cancer pathway."

"The nurse that took my samples and walked me through the study was so horribly rude to me. I almost left in the middle of it as she was yelling at me and talking to me as if I was stupid. It was a terrible experience, and I would not recommend that anyone does the study at the location I was at in case they also have the same nurse [detail omitted]."

"…I think I would have preferred to have known what exactly I was taking, and I won't be taking part in future research connected with fertility as I felt that this lack of control had a negative impact on me."

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Feedback about results/progress

Ninety seven respondents commented in response to Q9 on how they would like feedback on either their personal results or the progress on the research in general. Others would have also liked some feedback on how to improve their health.

> “To be given feedback and regular contact with research nurse. I feel this has all been a complete waste of my time.”
>
> “Far more information, proper testing of the blood test if you are taking five tubes, heart tests, exercise monitor, blood pressure test over a period and give us feedback how to improve the health.”
>
> “Getting the report I was promised would be forthcoming within 6 weeks as thanks for taking part in the research (which I have not received yet).”
>
> “Kept me up to date. Try to remember when they have made an appointment for me and not left me sitting in the waiting room for 2 hours. I am no longer taking part in the survey. Also did not let me know results from 1st visit were useless.”
>
> “Having received my results - it has been over 5 weeks since I had assessment and am yet to hear anything back - is there something shady happening with my blood sample, I fear?”
>
> “When the results have been finalised, I would like to be informed of its outcomes and to what these results will mean going forward.”

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Research staff/team

There were 83 comments coded under the research staff/team subtheme. Almost half of these were negative in sentiment (n=39), with 17 neutral. Respondents commented on the friendliness of staff, as well as how knowledgeable and professional they appeared.

"If the nurse who did my check-up wasn't so rude and condescending. It gave me severe anxiety and a panic attack once the study was finished."

"The health care and staff appeared unprofessional and untrained which was undermining the confidence."

"If the people there were a bit friendlier and chattier. I got the feeling they were all a bit jaded with testing people - which they probably were."

"I was not impressed by the staff when I visited the cardiac unit at (name). I was a voluntary impatient and could have been treated with more respect."

"On reception I encountered two surly ladies who were doubtful I had an appointment and generally throughout the process made me feel unwelcome and uncomfortable."

Nothing to improve

There were 69 respondents in the sample who had suggested that there was nothing that could have made their experience better.

"Nothing to date, the researcher who visited me was very helpful."

"I have nothing to give, as I was totally happy throughout the 2-year experience."

"Nothing, I was happy with all that was given and how kind the staff were. Thank you."

Procedures

Of the 53 comments coded under the subtheme ‘procedures’, more than half were negative in sentiment (n=29). Some respondents were disappointed that not all tests that were stated, were carried out whereas others commented on the pain caused by their procedure(s).

> “Certain people hurt more than others when taking blood.”
>
> “Stated medical tests are to be conducted. only data and blood collected. no diabetics test, no ecg, no urine test, no stool exams. Website says conducting all tests.”
>
> “The procedure and aftereffects were just too much”.
>
> “Doing the tests, I was told would be done - no ecg, no retina check, no lung function check - the hall looked very dirty and not cleaned - hardly a clinical environment.”
>
> “This site should have been offered all the tests which were informed on the website. The test site I have attended offered very basic tests, so I was disappointed.”
>
> “Courtesy from the staff of her introduction in who she was. She worked like a robot. She was unable to take blood and left me with a painful hand.”

Survey

Forty-six participants commented on aspects of the survey, where these were part of the research. Several participants who took part in a survey-based research activity commented on the length, difficulty, and relevancy of parts or all of the survey or questions. Others felt there could be some clarity around certain questions to aid accurate answers.

"I felt the questions asked were rather pointless or no real benefit or help to anyone considering this research."

"A lot of the question do not take age into consideration. For example difficulty running for a bus. Old age or heart failure? Fatigue or heart failure."

"Some questions are (probably necessarily) a little narrow. Daily experience of problems varies, so it's difficult to give a specific answer - when it could be quite different on another day."

"The questionnaire I was asked to complete was poorly designed, done by someone with no training in questionnaire writing. Hence many of the questions will not elicit accurate or meaningful answers."

"The daily diary was so poorly designed, and I was really resentful having to deal with that every day."

Incentives/ expenses

There were 17 comments that noted that being paid for time spent, or reimbursements for travel expenses would have made their research experience better. These comments were all negative or neutral in sentiment.

"I was unable to travel due to this study, I have not been paid correctly, emails not responded too."

"Since there were extra hospital appointments involved free parking would have helped."

"If the travel reimbursement was adequate. As two for a journey that required taking two buses one way made me feel like never enjoying with the NHS research. not the money but the ridicule of it."

"Getting paid for my time. I don't mind doing research for free, but I did give up my time so some payment would be nice."

Side effects

A small number of respondents in the sample noted the undesirable side effects (n=13) they experienced.

"More research about how I am feeling. what side effects I am having. How I feel generally."

"Not having had such awful side effects and reactions to the treatment."

"Knowing all the facts about the effects on my joints and muscles through the injection in my stomach and the radiotherapy."

"I was very poorly on aza, begged to come off it and it was trebled!! Please listen to patients as they know their bodies."

Treatment outcome

Of the 8 comments that mentioned treatment outcome, half were positive and noted the treatment had improved participants' condition. However, there were four that were negative that showed disappointment in the outcome of the treatment.

"Some type of treatment of my symptoms."

"If I have had a positive response from overall medications and research benefits, it would have been better. But it didn't benefit me."

"If research was quick enough to help me."

"If the result had been positive."

Vaccine approval

Similar to previous years, some participants had difficulties with travel or gaining access to further treatment as a result of taking part in the research (n=7).

"I was unable to travel due to this study, I have not been paid correctly, emails not responded too."

"The problem with the NHS uploading status of Novavax vaccines has been frustrating in terms of planning overseas travel. I do appreciate how the study reacted and gave good support."

Other

As with Q8, comments coded into the ‘other’ subtheme (n=67) did not fit into other subthemes and/or there were not sufficient comments to create a new subtheme. Several comments in this theme were not actionable either.

> “No previous experience, so difficult to compare.”
>
> “No improvements I can think of. But I think my future involvement in research would only be of limited use due to advancing age! (Counter-intuitive to research a cure for old age! There isn't one!).”
>
> “Due to circumstances I have had to temporarily stop the research.”

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Glossary

CRN	‘Clinical Research Network’ Supports patients, the public and healthcare organisations across England to participate in research
CYP	Specifically, the ‘Children and Young People Survey’, or generally, ‘Children and Young People’
DHSC	‘Department of Health and Social Care’ Supports ministers in leading the nation’s health and social care to help people live more independent, healthier lives for longer.
LCRN	‘Local Clinical Research Network’ Across England, these coordinate delivery of PRES
NIHR	‘National Institute for Health and Care Research’ Working in partnership with the NHS, universities, local government, other research funders, patients and the public, NIHR funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth.
PRES	‘Participant in Research Experience Survey’ An annual survey conducted by NIHR to record the experiences of research participants.

Appendix

Table 15 shows the percentage change in scores in brackets, versus the previous year. The strength of positive response has decreased compared to 2021/22: combined figures have decreased only slightly but there is a much larger decrease in the percentage of participants selecting the top response at Q2 and Q4-7.

Table 15. Percentage of CYP respondents choosing top response/top 2 response by survey year*

Q	2022/23 % of respondents choosing top 2 responses (n=1,884)	2022/23 % of respondents choosing top response (n=1,884)	2021/22 % of respondents choosing top 2 responses (n=252)	2021/22 % of respondents choosing top response (n=252)
Q1	97% (+9%)	86% (+12%)	78%	64%
Q2	87% (-5%)	46% (-10%)	92%	56%
Q3	87% (+12%)	56% (+15%)	75%	41%
Q4	90% (-3%)	46% (-21%)	93%	67%
Q5	95% (-5%)	60% (-16%)	100%	76%
Q6	96% (-4%)	70% (-20%)	100%	90%
Q7	92% (-6%)	57% (-20%)	98%	77%

*Percentages based on valid responses i.e. excludes ‘I don’t remember’ at Q1 and ‘It is too early to tell’ at Q2.

Q1 ‘Easy’/‘Somewhat easy’
Q2, Q4-Q7 ‘Strongly agree’/’Agree’
Q3 ‘Yes’/’Yes, to some extent’

Table 16 shows the percentage change in scores in brackets, versus the previous year. Moderate decrease in combined scores of up to 5%, but more considerable decreases when analysing by the top response (with exception of Q3).

Table 16. Percentage of adult respondents choosing top response/top 2 response by survey year*

Q	2022/23 % of respondents choosing top 2 responses (n=30,586)	2022/23 % of respondents choosing top response (n=30,586)	2021/22 % of respondents choosing top 2 responses (n=25,459)	2021/22 % of respondents choosing top response (n=25,459)	2020/21 % of respondents choosing top 2 responses (n=20,749)	2020/21 % of respondents choosing top response (n=20,749)
Q1	93% (-2%)	62% (-11%)	95%	73%	96%	75%
Q2	77% (-5%)	43% (-12%)	82%	55%	89%	59%
Q3	74% (-5%)	40% (-1%)	79%	41%	81%	41%
Q4	85% (-5%)	47% (-21%)	90%	68%	93%	73%
Q5	91% (-1%)	58% (-12%)	92%	70%	93%	71%
Q6	95% (-2%)	72% (-13%)	97%	85%	98%	87%
Q7	91% (-2%)	60% (-14%)	93%	74%	94%	77%

*Percentages based on valid responses i.e. excludes ‘I don’t remember’ at Q1 and ‘It is too early to tell/Not sure’ at Q2.

Q1-Q2, Q4-Q7 ‘Strongly agree’/’Agree’
Q3 ‘Yes’/’Yes, to some extent’

Further Information

For further information about the 2022/23 PRES results, using PRES to help you with your study or any other aspect of PRES, please contact the NIHR Clinical Research Network Patient and Public Involvement and Engagement team: crn.ppie@leeds.ac.uk