

# Participant in Research Experience Survey (PRES) 2023/24

Annual Report



## Participant in Research Experience Survey

The Participant in Research Experience Survey (PRES) aims to offer as many research participants as possible the chance to contribute their experiences of taking part in research. The research participant experience is an essential part of delivering a world-class research delivery network with participant feedback providing research delivery teams, study sponsors and the National Institute for Health and Care Research (NIHR) with actionable data to improve accessibility of health and care studies and increase recruitment rates and retention of participants.

The NIHR has undertaken the Participant in Research Experience Survey (PRES) on an annual basis since 2015/16. The NIHR Research Delivery Network (RDN) Coordinating Centre provides national oversight and coordination of PRES content and design, with the PRES Advisory Group providing strategic advice for future development. The survey is administered by fifteen Local Clinical Research Networks (LCRNs) and their affiliated organisations throughout England.

## Acknowledgements

The NIHR would like to thank all participants of health and care research studies and the respondents of PRES, without whom world-leading health and social care research would not be possible.

Moreover, we would like to thank the 15 Local Clinical Research Networks and their Delivery Organisations for their tireless efforts in managing the dissemination of the surveys, and to the PRES Advisory Group members and PRES Public Partners for their advice, expertise and valued contributions.

## About the PRES Advisory Group

The PRES Advisory Group provides expert guidance and decision-making to the NIHR RDN Coordinating Centre in relation to the future development and implementation of PRES. The group meets quarterly and membership consists of representatives from the NIHR, LCRNs, their Delivery Organisations and the public.<sup>1</sup>

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<sup>1</sup> The NIHR Research Delivery Network replaced the Clinical Research Network on 1 October 2024. 12 Regional Research Delivery Networks (RRDNs) will replace the current 15 Local Clinical Research Networks (LCRNs) on 1 October 2024 and working with the Research Delivery Network Coordinating Centre (RDNCC), make up the NIHR Research Delivery Network.

# Executive Summary

The Participant in Research Experience Survey (PRES) is now in its ninth year. Through the use of PRES, research teams and delivery organisations can gain insight into the experience they provide to research participants and receive recommendations for enhancing accessibility, inclusion, participant recruitment and retention. PRES feedback is also important in identifying ways to support participants' well-being and encourages a willingness to take part in research in the future.

- In 2023/24, a total of 35,519 research participants completed and returned the PRES. This is almost double the annual ambition of 18,000 and is the highest annual response to date.
- 33,601 responses to the adult participant PRES were received, a 10% increase from 2022/23 (30,705 responses were received in 2022/23).
- The number of responses to the children and young persons survey (CYP), completed by those under the age of 16, remains similar to 2022/23 (1,860 in 2023/24 and 1,898 in 2022/23).

The survey showed positive feedback from research participants for:

- Being given clear information at the start of the research study (93% of adults and 95% of CYP respondents agreed with this statement).
- Being treated with kindness/ courtesy and respect by the research team (94% of CYP and 95% of adults said they 'agreed' or 'strongly agreed').

Participants reported a less positive experience for:

- Knowing how they would find out the results of the research study (77% of adults and 82% of CYP respondents agreed with this statement).
- Being kept updated about the research study (72% of adults and 75% of CYP respondents agreed with this statement).
- Knowing how to contact someone from the research team should they have any questions (84% of adults and 86% of CYP participants agreed with this statement).

In addition to study experience data, participant demographic data was collected alongside question responses in the adult PRES. The highest percentage of total adult respondents were aged between 65 to 70 years (16%) with 86% of adult respondents reporting their ethnicity as 'White ethnic group'.

# Table of Contents

Participant in Research Experience Survey	2
Acknowledgements	2
About the PRES Advisory Group	2
Executive Summary	3
Findings & Recommendations	5
What we have learnt through PRES	5
PRES data 2023/24 in comparison to previous years	5
What we have achieved to date with PRES	7
Standardisation of the question set	7
Pilot of PRES Centralised Processing	7
Development of the National PRES Dashboard	7
Co-creation of alternative versions of PRES	8
Limitations to the current format and process of PRES	8
National recommendations and actions	10
Methods & Survey Administration	14
Survey delivery	14
Data management	15
Data Analysis	15
Quantitative data	15
Qualitative/Free text data	15
Adult Survey Results	16
Respondent profile	16
Quantitative findings: Adults	20
Qualitative findings: Adults	26
Children and Young People Survey Results	29
Respondent profile	29
Quantitative findings: Children and Young People	33
Qualitative findings – Children and Young People	38
Easy Read Survey Results	40
Summary of findings	40
Case Studies	42
Glossary	45
Appendix	47
Further Information	51



# Findings & Recommendations

## What we have learnt through PRES

A total of 142,801 research participants have shared their experience of research through PRES, since the question set was standardised in April 2018. This has provided NIHR with a rich data set, helping to identify what key factors create a positive research experience for participants. When PRES data are compared across 2018-2024, the following have been identified as significant contributing factors to a positive research experience:

- Research studies and trial activities that are accessible for all participants regardless of access needs or background;
- Research teams providing clear information about study requirements such as attendance at appointments and adherence to treatment protocols, and agreeing communication preferences at the outset of the study;
- Person-centred care and building of supportive relationships between staff and study participants;
- Practicalities of participation: the practical elements of taking part in research that create a positive experience e.g. the availability of refreshments, car parking, clear signage, study and site information in advance of an appointment;
- Technical elements of research (where applicable) e.g. easy access to online apps;
- Provision of regular updates on overall trial progress: receiving results/conclusions of trial; regular updates on test results, recruitment rates.

Participants also would like to know about negative trial outcomes or ‘null hypothesis’ results, not just positive results;

- Greater frequency and consistency of information and communication to improve study recruitment and retention

Through PRES data, research teams and researchers have received timely feedback that has been used to mitigate the issues that might negatively affect recruitment and retention in a trial. Study sponsors and LCRNs have used PRES data to help improve the design and delivery of health and care research to make research more accessible and inclusive for all potential participants, and facilitate ongoing study retention and future recruitment.

However, despite PRES data demonstrating a relatively positive overall experience for research participants; in some regional areas or particular trials, we see feedback relating to elements of a service that can still be improved.

## **PRES data 2023/24 in comparison to previous years**

When compared to PRES data analysed from 2021/22 and 2022/23, there are noticeable declines in participant experience for several experience categories. The decline in participant experience is reflective of previous recommendations from the 2022/23 PRES report around a need to improve trial communication and engagement throughout the life cycle of the research study.

The largest decline year on year is reflected in the question “I feel I have been kept updated about this research study”:

- Responses that “agree” with this statement have declined from 82% of adult respondents in 2021/22, to 77% in 2022/23 and 72% in 2023/24.
- Likewise, CYP responses have shown a decline from 92% in 2021/22, to 87% in 2022/23 and 75% in 2023/24 in those participants selecting the option “strongly agree” or “agree”.

Similarly, when asked “I know how to contact someone from the research team if I have any questions or concerns” demonstrated a downward trend in positive responses:

- 90% of adult respondents responded positively in 2021/22, compared to 85% in 2022/23, and 84% in 2023/24.
- 93% of CYP responded positively in 2021/22, versus 90% in 2022/23, and 86% in 2023/24 were in agreement with the statement.

When participants were asked if they would take part in research again, a 9% decline in positive responses were noted for CYP participants:

- 98% of CYP selected “agree” in 2021/22, versus 92% in 2022/23 and 89% in 2023/24.

93% (2021/22), 91% (2022/23) and 91% (2023/24) of adult respondents agreed that they would take part in research again demonstrating an overall consistent response year-on-year.

This suggests that further exploration around the reasons for not wanting to take part in research again would be of benefit to researchers and study teams, particularly with the CYP age groups, to evaluate room for improvement and identify factors affecting this measure.

This decline may relate to a change in participants’ expectations around how they will be looked after and communicated with, rather than a change to the level of service provided by research. With increasing numbers of respondents over time, it may also reflect the views of a larger, more representative population of research participants.

Finally, when participants were asked if they agreed with the statement “I know how I will receive the results of this research”:

- An increase in positive scores was observed in adult respondents with 74% selecting “strongly agree” or “agree” in 2022/23 in comparison to 77% in 2023/24
- This upward trend was not observed in CYP respondents however, who reported a decline in satisfaction between 2021/22 and 2023/24 with 87% and 82% respectively.

## **What we have achieved to date with PRES**

### **Standardisation of the question set**

In 2020/21 PRES moved from using non-standardised versions of PRES participant surveys that varied by region, to one standard, nationally approved question set for PRES. This has allowed study teams to compare data across sites and regions, as well as gaining a national picture of participants' experience of research.

### **Pilot of PRES Centralised Processing**

From 1 April 2022 to 31 March 2023, nine LCRNs piloted the use of a centralised approach to printing and processing paper copy responses to PRES. The process involved national level printing and distribution of a new standard format of PRES returned to a Freepost address and processed by an external data processing company. The anticipated benefits of a centralised approach to processing were to:

- Decrease the time staff spent on data entry, instead focusing on data quality assurance which would speed up reporting processes
- Increase data quality through the use of specialists trained in data entry and CRN quality assurance processes for PRES
- Offer overall cost benefits for PRES by offering an 'at scale approach,' i.e. the more LCRNs involved in central processing, the more cost-effective printing and distribution to sites could be
- Reduce issues around timely sharing of feedback with LCRNs and delivery teams as they are received
- Improve the design of the survey making it more attractive for research participants to complete and more accessible for a wider population.

In April 2023, a centralised process for processing paper versions of PRES was rolled out nationally. This is a standard process for the collection of participant data from paper versions of PRES (excluding Large Print and Easy Read). This decision allowed a more frequent data exchange between the processing company and research sites and led to a reduction in administrative responsibilities for the LCRN regions.

## **Development of the National PRES Dashboard**

In March 2024 the PRES National Dashboard was launched to LCRNs, research teams and researchers across the NIHR. The dashboard allows users to view and filter PRES results from across England. Registered users can filter responses to the PRES multiple choice questions including by study name and site / NHS trust and can compare experiences with demographic data of age, gender and ethnicity. The dashboard allows research teams to access participant experience data across their study sites and to take steps to improve the study participant experience.

## **Co-creation of alternative versions of PRES**

There are currently a number of alternative versions of PRES which have been co-created with relevant groups of public partners. These include:

- Large Print PRES: this has the same question set as the standard adult version of PRES, but presented in a larger print/ high contrast format
- Easy Read PRES: developed in partnership with people with learning disabilities to provide a version of PRES which has language and format adaptations to make the survey easier to read and understood by a greater number of participants
- Children's PRES 0-6: designed to be completed by the parent of the child who is participating research

- Children and Young People's PRES 7-11: uses adapted language suitable for this age group
- Children and Young People's PRES 12-15: uses adapted language suitable for this age group.

## **Limitations to the current format and process of PRES**

Despite considerable improvements in the standardisation and accessibility of PRES, there are still several limitations in its scope and use, which are mentioned below:

- There is inconsistency in how PRES is delivered online locally with various online platforms and data collection approaches used across regions.
- PRES is not completed by those who drop out of research at an earlier stage of their research journey, and therefore does not capture their views and experiences. This omits vital insights from those who may have a different experience of taking part in research.
- Study sponsors and LCRNs have limitations in what they can improve at a site level as participants' experience often reflects things outside of their immediate control. E.g. transport options, car parking and access to refreshments.
- Currently, there is a lower uptake of alternative versions of PRES including Large Print and Easy Read. We need to understand if there is a need for these versions in the long-term or if there are issues in offering them at a site level or awareness of their availability.
- We have three versions of CYP PRES and consistently receive fewer responses to these surveys compared to the adult PRES. We have observed that CYP PRES is more likely to be completed by parents and carers across all age groups, therefore is there a need for three versions in the future?
- Despite recommendations since 2018 around the need to improve the way study teams communicate progress and results throughout the study cycle with participants, this measure continues to be rated less positively than others across adult and CYP respondents. We need to develop more targeted initiatives to improve this measure across all regions.
- PRES has a low uptake in research studies delivered in settings outside of secondary care (NHS hospitals). We need to scope potential barriers to delivering PRES in wider settings such as GP surgeries, community centres, social care and hospices.

## National recommendations and actions

	<b>Recommendations</b>	<b>Suggested actions</b>	<b>Who is responsible</b>
1	Improve communication with participants at key time points in the study to promote participant retention and engagement.	Identify key time points in the study life cycle where participants want - and would benefit from - communication about the study, for example, recruitment rates, preliminary findings and final results.	Study teams/ Chief Investigators
2	Make it easier for participants to contact study teams and have more accessible options for doing so.	Ensure participants are provided with - and have access to - a variety of methods to contact study teams with queries or questions once they have consented. This information may need to be shared more than once throughout the lifecycle of the study. Consider introducing check-ins to ensure that participants have all the information they need and that they understand it and know who to direct questions to.	Study Teams/ Chief Investigators
3	Explore participant data around not wanting to take part in research again.	Identify possible factors that may affect participants' decision to take part in research again and consider improvement initiatives. Consider using a variety of methods to capture this feedback, that does not burden the participant but which makes it easy, quick and accessible for them to share their insights (e.g. further research and development of the 'Ok to say No' survey).	PRES Advisory Group/Study teams

4	Consider accessible and inclusive ways for participants to access the results of research studies they take part in, if they choose to do so.	Leverage local innovations and digital solutions to make it easier for all participants to access study findings. Consider local examples of best practice and consider if a standardised approach to the delivery of this information is feasible for the RDN.	PRES Advisory Group/RRDNs/Study teams
5	Explore preferred methods for communication and engagement specific to children and young people and review current CYP PRES surveys.	Identify the unique information needs of children and young people throughout the research participation process. Use this information to test new approaches and improve CYP engagement throughout the study life cycle to help improve their experience of participating in research. Work with CYP patients and community groups to review the current three CYP surveys. Identify questions which are meaningful and clear and develop a new version of the survey(s) if necessary or beneficial to improve response rates.	RRDNs/RDNCC
6	Embed a digital-first approach to PRES delivery	Collaborate with RRDNs and research delivery teams to embed a 'digital first' approach to the delivery of PRES. This will reduce the cost and environmental impact of PRES and allow research teams quicker access to participant feedback via local and national dashboards. Consider the accessibility of the 'digital first' approach to ensure that PRES continues to reach communities with access needs. The needs of non-digital users will still need to be met, therefore a scalable and cost effective option for paper versions of PRES will also need to be created.	PRES Advisory Group/RRDNs with support from RDNCC and study teams

7	Review the PRES question set to reflect the needs of wider settings	Increase the capacity and capability of PRES across the wider research system and settings to ensure participant experience feedback can be gathered from people accessing research outside of non-hospital settings (e.g. GP surgeries, community pharmacies etc.). Review PRES questions and national dataset to respond to user needs and study team feedback to improve data comparison and actionable improvements.	RRDNs/RDNCC/Study teams/Chief Investigators
8	Ensure study teams have access to PRES data in a timely manner to enable improvements to participant experience whilst a study is still ongoing	Work towards monthly PRES data submissions for all Regional Research Delivery Networks to ensure that the National Dashboard has 'near live' participant experience data (within a month of PRES responses being received).	RRDNs/RDNCC
9	Encourage wider stakeholders to engage with PRES data to expand the impact of participant experience feedback	Encourage and support wider stakeholders to access PRES data through the national PRES Dashboard. Develop an understanding of the data needs of non-research delivery workforce stakeholders for instance DHSC, study sponsors, NIHR Coordinating Centre, and NHSE.	RDNCC
10	Offer PRES at different time points throughout the research study lifecycle to capture a wider variety of feedback	Consider the timing of PRES to ensure participant experience data is gathered both at an earlier stage of their research journey and throughout longitudinal studies that may run over a number of years. This will ensure that feedback is received from participants that may leave the study early and would allow for research teams to address site level issues immediately, with the aim of improving other study participant's experiences as the study progresses.	PRES Advisory Group/Chief Investigators/Study teams

# Methods & Survey Administration

## Survey delivery

PRES content and design are coordinated nationally by the NIHR RDNCC. The PRES Advisory Group provides guidance and expert advice, used for decision-making and the survey's ongoing development. Every year, the results of the annual survey are analysed, and the results are released as an annual report. LCRNs also produce a regional-level report of PRES results on an annual basis.

During 2023/24 PRES delivery was coordinated by 15 LCRNs and delivered by their delivery organisations. The 15 LCRNs support clinical research delivery and supports the research infrastructure throughout England<sup>2</sup>.

## Survey administration

For the financial year 2023/24 PRES was distributed to research delivery site teams by 15 LCRNs. Responses to the 2023/24 survey were collected from participants who took part in studies between 1st April 2023 and 31st March 2024. Participants were offered the choice of completing the survey on paper or online, with accessible versions of PRES (Easy Read and Large Print) available if required.

Respondents of the adult survey were aged 16 years or older and included people who were recently consented into a study, people who had completed taking part in a study, and people who had been taking part in a study for some time. Feedback was collected from people participating in research studies across a range of clinical health conditions, of which the most common were Public Health, Cancer, Primary Care and Cardiovascular Diseases.

Respondents of the CYP survey were aged between 0 to 15 years. CYP respondents had the option to complete the survey themselves, with help from their parents or carers, or have their parents or carers complete the survey on their behalf. Although data comparison between the adult and CYP surveys was possible, the CYP survey's question set was not identical to the adult PRES survey, as the question set language was tailored to be more understandable to the relevant CYP age groups. The text used for both adult and CYP surveys is provided in the appendix.

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<sup>2</sup> The Research Delivery Network replaced the Clinical Research Network on October 1, 2024. 12 Regional Research Delivery Networks (RRDNs) will replace the current 15 Local Clinical Research Networks (LCRNs) on October 1, 2024.

## **Data management**

During 2023/24, adult and CYP PRES survey data were submitted to NIHR CRN CC by each of the 15 LCRNs. Data were collated, cleaned and analysed for any missing or incorrect entries by the NIHR CRN CC team.

# **Data Analysis**

## **Quantitative data**

Results are shown in this report from the adult survey and the CYP survey by age grouping (dependent upon the version of the survey which was completed). Gender and ethnicity data were not collected in the CYP survey. Findings from the adult survey include additional commentary where relevant, highlighting any differences in participant experience by age, gender or ethnic group.

Positive percentages were calculated using the top two positive responses for each question i.e. a positive response was classified as “Easy/Somewhat Easy, Strongly Agree/ Agree, and Yes/ Yes, to some extent” depending on the survey question taken into consideration.

Invalid responses like ‘I don’t remember’, ‘It is too early to tell’, ‘Not sure’ and ‘No response’ were excluded from the analysis.

## **Qualitative/Free text data**

Topic Modelling was performed to discover the topics / themes that run through the feedback received and to organise, understand and summarise the textual information. Topic Modelling helps to discover hidden topical patterns that are present across data.

Prior to the analysis, data were cleaned and transformed according to topic modelling requirements. Some special characters and white spaces were removed from responses, which did not affect the analysis. After data cleaning, Latent Dirichlet Allocation was performed to uncover topics based on word frequency. The identified topics are usually based on a small number of words.



# Adult Survey Results

## Respondent profile

Overall, the 2023/24 adult PRES survey received 33,601 responses. This figure was 9% higher than in 2022/23 (n=30,705). 51% of adult surveys were completed online and 49% on paper.

67% of adult respondents in 2023/24 took part in research for the first time. Almost two-thirds of total adult respondents (63%) in 2023/24 were aged over 55 years old.

Please note that some surveys were excluded from the analysis owing to poor data quality and duplication of response. Therefore, the total number of respondents throughout this report will be slightly lower than those presented in Tables 2 and 4.

**Table 2.** Number and percentage of adult surveys completed , by age (Year)

Respondent age	No. of surveys completed	% of surveys completed
16 - 24 Years	664	2%
25 - 34 Years	4,039	12%
35 - 44 Years	2,541	8%
45 - 54 Years	3,446	10%
55 - 64 Years	7,768	23%
65 - 74 Years	7,852	23%
75 Years and above	5,373	16%
Not Stated	1,918	6%
<b>Total</b>	<b>33,601</b>	<b>100%</b>

When exploring responses by sex registered at birth, more than half of respondents were female (55%), 42% were male, and < 1% preferred not to say.

For Q. 15, overall, 96% reported that their gender was the same as their sex registered at birth, with <1% opting not to disclose this information.

Overall, 85% of respondents stated their ethnicity as White (Table 3). A further 7% of respondents were Asian or Asian British, 2% Black, Black British, Caribbean or African, 1% Mixed or Multiple ethnic groups, and <1% belonged to other ethnic groups. 4% of respondents did not state their ethnicity.

This is broadly consistent with the England wide 2021 census where 81.0% of residents in England identified themselves as belonging to the 'White' ethnic group, 9.6% identified as being Asian or Asian British, 4.2% as Black, Black British, Caribbean or African, 3.0% as Mixed or Multiple ethnic groups and 2.2% as belonging to Other ethnic groups.

**Table 3.** Number and percentage of responses, by ethnic group (Q. 16)

Respondent ethnic group	No. of respondents	% of respondents
White	26,846	85%
Asian	2,213	7%
Black	481	2%
Mixed	386	1%
Other	155	< 1%
Not Stated	1,394	4%
<b>Total</b>	<b>31,475</b>	<b>100%</b>

**Table 4.** Number and proportion of all adult surveys returned by LCRN during 2023/24.

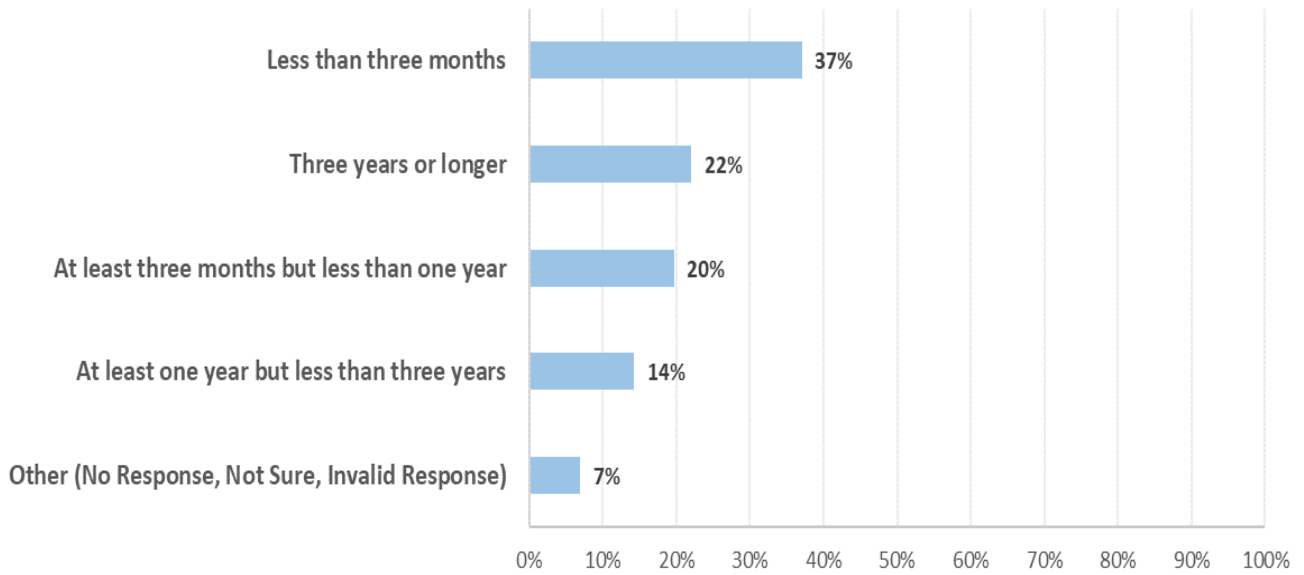
LCRN	No. of surveys	% of surveys
West of England	5,673	17%
East of England	3,340	10%
Yorkshire & Humber	2,895	9%
North East & North Cumbria	2,827	8%
East Midlands	2,291	7%
Kent, Surrey & Sussex	2,281	7%
North Thames	2,233	7%
West Midlands	1,933	6%

Greater Manchester	1,874	6%
South London	1,593	5%
Wessex	1,582	5%
North West London	1,440	4%
South West Peninsula	1,312	4%
North West Coast	1,188	4%
Thames Valley & South Midlands	1,139	3%
<b>Total</b>	<b>33,601</b>	<b>100%</b>

Adult survey responses were distributed by all 15 LCRNs and respondents to the adult survey were asked to confirm who completed the survey. The majority (89%) stated that they had completed it on their own, with 4% saying someone else filled it in with them, and a further 3% of survey respondents indicating that someone else other than the research participant had helped them complete the survey.

Participants of the adult survey were asked to confirm the length of time they had been involved in a research study, with data displayed in Figure 1.

**Figure 1.** Length of time survey respondents had been a participant of a research study (Q. 10).



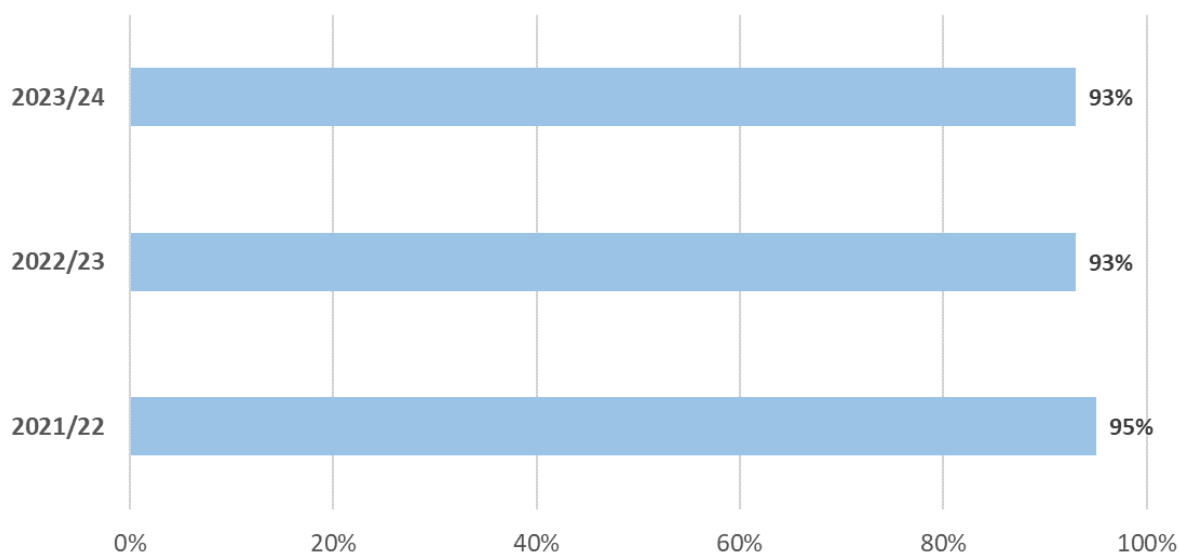
## Quantitative findings: Adults

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

In 2023/24, 93% of adult respondents responded positively (selected 'strongly agree' or 'agree') that the information they received prior to taking part in the study prepared them for their experience. This is stagnant at 93% from last year, with a decrease noted from 95% in 2021/22. (See Figure 2. below).

Similar to previous years, 25-34 year old respondents were the most likely to strongly agree or agree with this statement (95%) compared to other age groups, while the least likely (92%) were those aged over 75. On average, 93% of participants from all ethnic backgrounds were likely to 'strongly agree' or 'agree' with the statement (Asian/Asian British: 92%, Black/African/Caribbean/Black British: 93%, Mixed/Multiple Ethnic groups: 92%, White: 93%).

**Figure 2.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether the information that they received before taking part prepared them for their experience on the study (Q. 1), by survey year

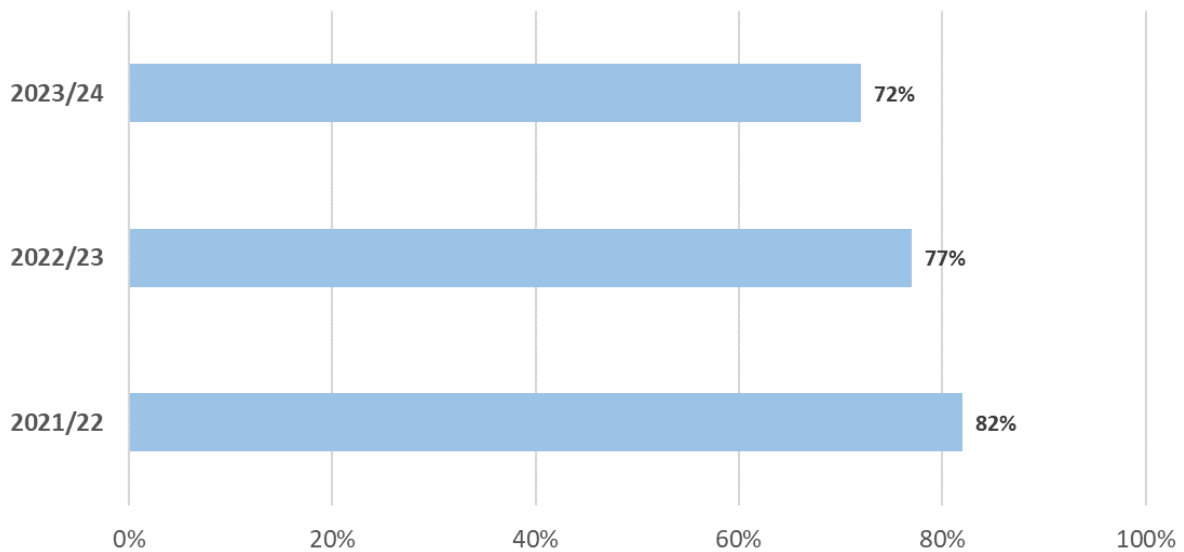


## Q2. I feel I have been kept updated about this research study

There was a decline in the proportion of positive responses to this statement in 2023/24 with 72% selecting 'strongly agree' or 'agree' that they "have been kept updated about the research study" they have been involved in compared with 82% in 2021/22 and 77% in 2022/23 (Figure 3 below).

Data analysis of this question revealed that the least likely to 'strongly agree' or 'agree' with this statement were respondents aged 75 years or over (67%) followed by respondents from the age group 35-44 years (70%). This is in contrast to 77% of 25-34 year old respondents. People of Asian ethnicity were most likely (78%) to 'strongly agree' or 'agree' that they felt they were kept updated about the study compared to all the other groups that were on average 74% in agreement with the statement.

**Figure 3.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether they feel they have been kept updated about the research study (Q. 2), by survey year



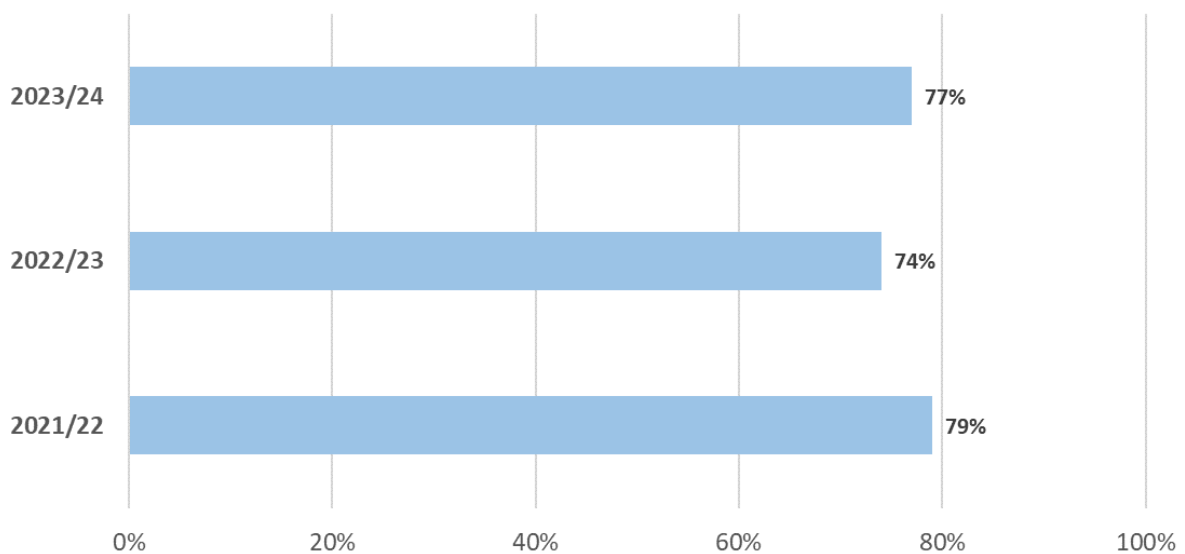
### Q3. I know how I will receive the results of this research study

Participants were asked whether they knew how they would receive the results of the research. There was an increase in positive responses to this question with 77% of respondents saying that they were aware of how they would receive the results of the research study, versus 74% in 2022/23.

When analysed by age group, 25-34 year olds and 55-64 year olds were most likely to report positive responses to this question (81% for both) when compared to 70% of respondents over 75 years old.

In addition, Asian participants were most likely to select a positive response to this question with 89% saying 'yes' or 'yes to some extent' when compared to White respondents (76%).

**Figure 4.** Percentage of respondents selecting 'yes' or 'yes to some extent' when asked whether they know how they will receive the results of the research study (Q. 3), by survey year.

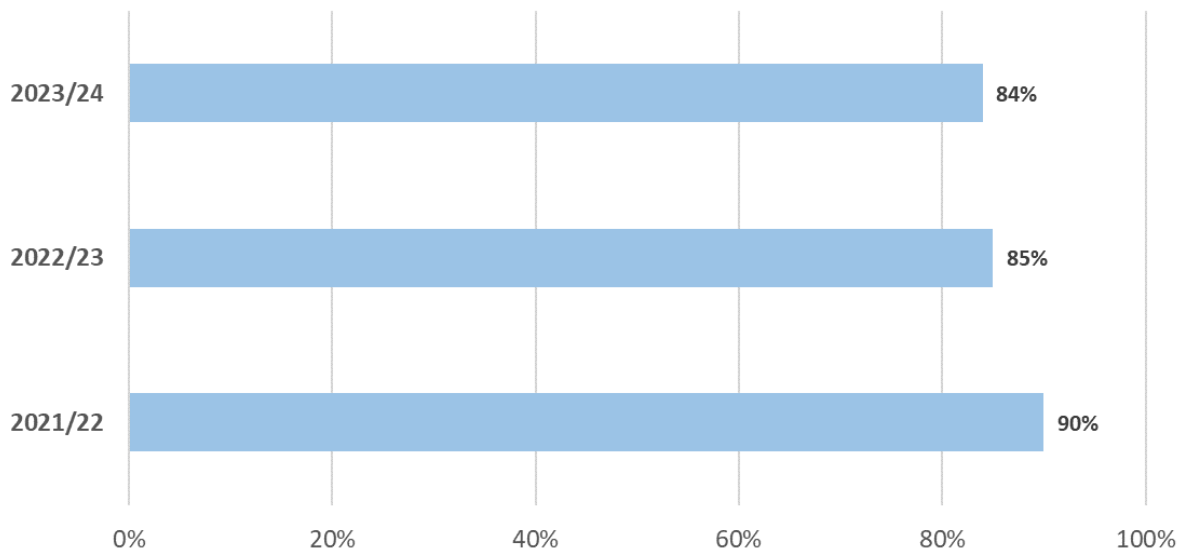


### Q4. I know how to contact someone from the research team if I have any questions or concerns

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 lower than previous years with 84% of respondents selecting 'agree' or 'strongly agree' with this statement in 2023/24 versus 90% in 2021/22 (Figure 5).

When analysed by age and ethnic group, data showed that all respondents were likely to report knowing how to contact someone from the research team by selecting 'agree' or 'strongly agree' (on average 85% by age and 84% by ethnicity selected these options).

**Figure 5.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether they know how to contact someone from the research team if they have any questions or concerns (Q. 4), by survey year.

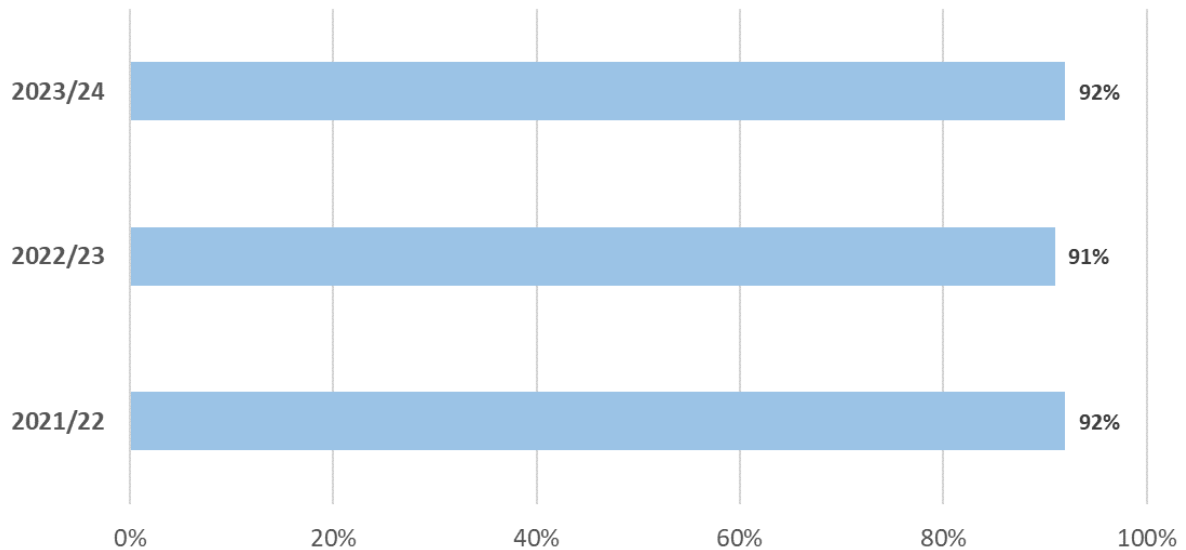


### **Q5. I feel research staff have valued my taking part in this research study**

The proportion of respondents who 'strongly agreed' or 'agreed' that they felt their contribution was valued by the researchers has remained stable between 2021/22, 2022/23 and 2023/24 (92%, 91% and 92%, respectively) (Figure 6).

When analysed by ethnic group, respondent data showed participants of Black ethnicity were most likely to say they felt their participation was valued (94% 'strongly agree' or 'agree').

**Figure 6.** Percentage of respondents selecting ‘strongly agree’ or ‘agree’ when asked whether they feel research staff valued their taking part in the research study (Q. 5), by survey year

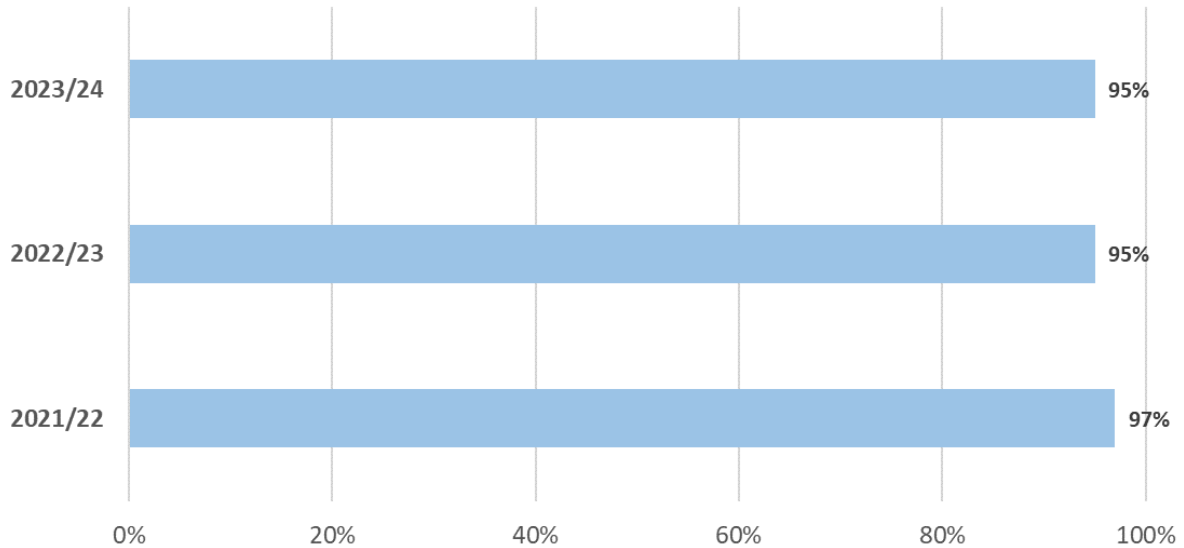


### **Q6. Research staff have always treated me with courtesy and respect**

In 2023/24 respondents were equally as likely to select ‘strongly agree’ or ‘agree’ to the question “they were treated with courtesy and respect by research staff” as they had been in 2022/23 (95%). However, this figure has decreased by 2% since 2021/22 (97%) (See Figure 7).

On average, 96% of respondents from all age groups and 95% from all ethnic groups were likely to select ‘strongly agree’ or ‘agree’ when asked if they felt they were respected by research staff.

**Figure 7.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether research staff have always treated them with courtesy and respect (Q. 6), by survey year



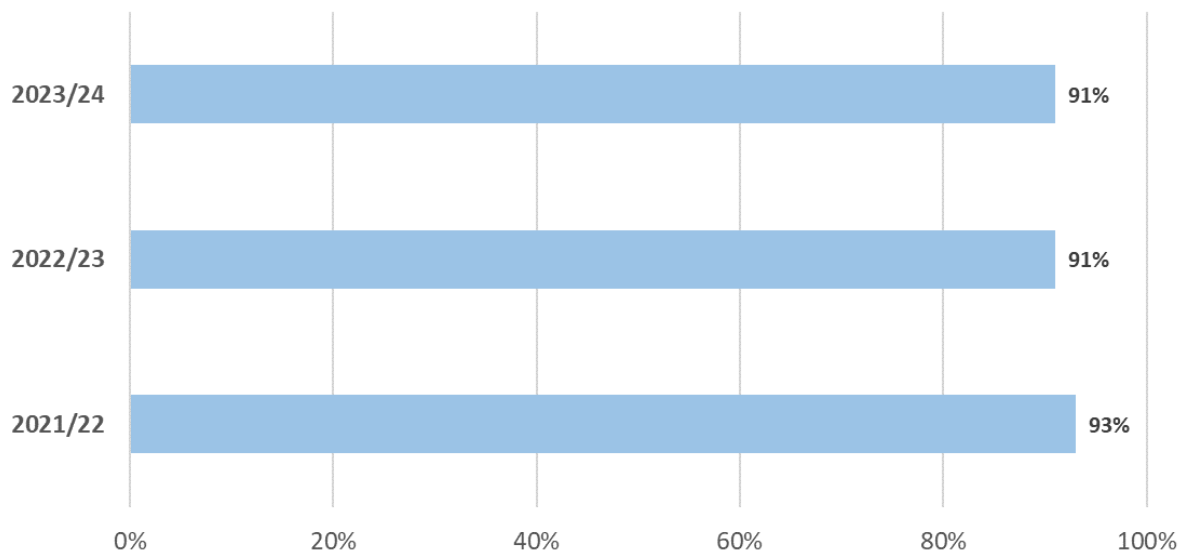
### **Q7. I would consider taking part in research again**

In 2023/24, 91% of respondents 'strongly agreed' or 'agreed' with this statement, a figure replicated in 2022/23, but with a noted decrease from 93% in 2021/22. Whether participants would likely take part in research again might be dependent upon other factors linked to their overall participant experience and thus be captured across other measures in the survey (see Figure 8).

Approximately 95% of 25-34 year olds suggested they would consider participating in future research studies (indicated by a response of 'strongly agree' or 'agree'). The least likely age group to respond positively to this question were participants over 75 years old (with 85% selecting 'strongly agree' or 'agree').

People of White or Mixed ethnicity were most likely to select 'agree' or 'strongly agree' to this statement with 92% White and 93% Mixed ethnicity when compared to 86% of participants of a Black ethnic group.

**Figure 8.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether they would consider taking part in research again (Q. 7), by survey year.



## Qualitative findings: Adults

### Q8. What was positive about your research experience?

Question 8 of the adult survey asked about the positive aspects of participants' research experience with free text responses. Upon analysis, the topics and sub-topics that were identified as prominent from participant data are outlined below.

#### Staff attitudes

Participants reported that research staff were helpful / friendly / approachable / professional / welcoming; they treated the participants with respect and made them feel valued. Research staff were reported as efficient and knowledgeable and were not hurried in their approach to patient care. Great care was taken of participants in situations where there were side effects from trial treatments.

#### Clear communication and information sharing

Participants provided feedback that research staff were clear with trial instructions and that the researchers took their time to explain everything to them. Participants also reported that they experienced efficient and flexible ways to book appointments as part of their study. In addition, participants felt they were being kept up to date with the

progress of the trial and there were clear lines of communication between them and the research team. Regular email updates were shared and there were examples of having an option to contact the research team via telephone for those who did not have the facility of an internet connection.

## **Motivation to take part**

Participants reported that they were happy to contribute to a research study and felt honoured to be able to contribute their part in society (i.e. altruistic motivations for taking part). Participants felt like they were making a difference for future generations and some participants mentioned that the treatment they received through the trial helped them to feel better and improved their health condition.

## **Q9. What would have made your research experience better?**

When asked this question, participants identified areas where there was room for improvement, which have been summarised below:

### **Practicalities of taking part**

Participants reported long waiting times in general at their appointments. There was also evidence of considerable wait times at the pharmacy for trial medications and when waiting for test results. Participants suggested that providing more flexibility in selecting appointment times would be appreciated. Allowing an appointment to be booked at a location closer to their home would be beneficial as this would shorten travel times. Another suggestion by participants highlighted that using a message or online booking service for appointments would be helpful to them.

Regular reminders for upcoming appointments with a reminder of the appointment location and time would be welcomed by participants. Additionally, making participants aware of the entire schedule of appointments for the lifetime of the study when they consent would be really helpful to them to help plan travel or sharing of caring responsibilities in advance.

### **Trial related surveys**

Participants reported that as part of the research study, they were often asked to complete surveys and that the questions in those surveys were not relevant, repetitive and at times the survey was too long. This feedback did not relate to completion of the PRES survey.

## **Trial results and communication**

Participants in some studies reported that they were not kept informed about the progress of the study, trial results and that there was no communication after the study ended. They reported that they would appreciate receiving insights on the progress of the research study during and after the study had been completed using information that is easy to understand and in layman's terms.

They also reported that clear communication and guidance on where to find research staff upon arriving for the appointment would make their study experience better. Regular and more interaction with the researchers leading the study would also be a positive addition to the research experience.

## **Treatments**

Participants reported experiencing side effects when taking part in a study that resulted in them feeling poorly. A common theme was the need for more information upfront about medication and possible side effects, with some participants feeling unprepared for certain reactions.

Several respondents wanted better communication and more flexibility regarding medication dosage, especially after observing side effects.

Clearer instructions on medication protocols and handling side effects were requested, along with easier access to information on self-management.

Psychological support for dealing with the uncertainty of side effects and treatment responses was noted as a gap by a few respondents.



# Children and Young People Survey Results

## Respondent profile

Respondent details for the Children and Young People (CYP) survey are indicated in Table 5. Overall, there were 1,860 responses to the CYP survey showing a similar number of survey responses to 2022/23 (1,898).

Participants were offered the choice of completing the survey online or on paper. 84% of CYP surveys were completed online and 16% on paper.

86% of CYP respondents were taking part in a research study for the first time. Not surprisingly, the younger the respondent, the more likely it was that this was their first research study. For 0-6 year olds, this finding was 88%, for 7-11 year olds it was 81%, and for 12-15 year olds, 77%.

Amongst all CYP responses, most participants completed the 0-6 survey version (74%), with 13% of the total respondents completing the 7-11 and 13% completing the 12-15 version.

**Table 5.** Response numbers and percentages, by survey version

Survey version	No. of respondents	% of respondents
0-6 Years	1,383	74%
7-11 Years	243	13%
12-15 Years	234	13%
<b>Total</b>	<b>1,860</b>	<b>100%</b>

Please note that some survey responses were excluded from the analysis owing to poor data quality and response duplication. Therefore, the total number of respondents throughout this part of the report will be slightly lower than those presented in Table 5.

Overall, the majority of CYP respondents had been taking part in the study for less than three months. This was reflected most in responses to the 0-6 year old survey (60%), with 52% of 7-11 year olds and 39% of 12-15 year olds reporting to have been a part of a research study for less than three months.

**Table 6.** 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	<b>56%</b>	60%	52%	39%
At least three months but less than one year	<b>21%</b>	19%	21%	33%
At least one year but less than three years	<b>12%</b>	11%	14%	15%
Three years or longer	<b>2%</b>	1%	5%	5%
Not sure	<b>6%</b>	6%	5%	4%

The three CYP survey versions each asked participants to indicate who had filled in the survey with the following options: “the child or young person”, “the parent or carer”, or “both”. Parents or carers were most likely to be the person completing the survey for participants aged 0-6 (88%). 48% of parents/carers completed the survey for 7-11 year olds, whilst 43% of 12-15 year olds completed the survey themselves. Overall 75% of the total CYP surveys were completed by the parent/carers in 2023/24.

During 2023/24 CYP surveys were distributed across 15 LCRNs. The number of returned surveys per LCRN are reported in Table 7 with North East & North Cumbria LCRN accounting for 39% of all CYP responses for the entire 2023/24 period.

Due to the high proportion of total CYP responses from North East & North Cumbria LCRN, 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 LCRN regions in England.

Table 7 displays the number and proportion of CYP responses by LCRN region for 2023/24, and the percentage.

**Table 7.** Number and proportion of all CYP surveys returned in 2023/24, by survey type, by LCRN

LCRN	0-6 Years	7-11 Years	12-15 Years	No. of surveys returned 2023/24	% of total surveys returned 2023/24
North East and North Cumbria	687	11	27	725	39%
East of England	99	37	29	165	9%
North Thames	79	37	32	148	8%
West Midlands	66	49	10	125	7%
Yorkshire and Humber	59	22	26	107	6%
West of England	66	14	25	105	6%
North West Coast	82	5	14	101	5%
Thames Valley and South Midlands	75	3	4	82	4%
South London	28	13	24	65	3%

South West Peninsula	47	4	0	51	3%
Kent, Surrey and Sussex	32	9	2	43	2%
Greater Manchester	21	11	9	41	2%
Wessex	28	5	5	38	2%
North West London	10	12	12	34	2%
East Midlands	2	10	14	26	1%
North West London	2	1	1	4	< 1%
<b>Total</b>	<b>1,383</b>	<b>243</b>	<b>234</b>	<b>1,860</b>	<b>100%</b>

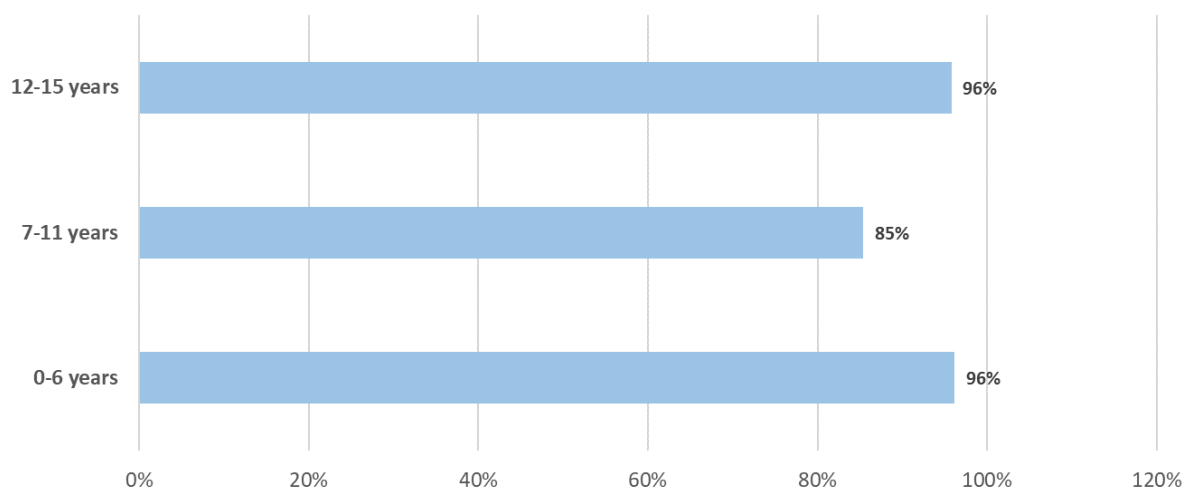
## Quantitative findings: Children and Young People

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

Overall, in 2023/24, 95% of CYP respondents agreed that the information they received prior to the research starting was 'easy' or 'somewhat easy' to understand.

Across the three CYP survey versions, those completing the 0-6 years and 12-15 years surveys were most likely to state that the information was 'easy' or 'somewhat easy' to understand (96%), compared to those completing the 7-11 version (85%).

**Figure 9.** Percentage of respondents selecting 'easy' or 'somewhat easy' when asked whether the information they received at the start of the research was easy to understand (Q. 1) by CYP survey version for 2023/24

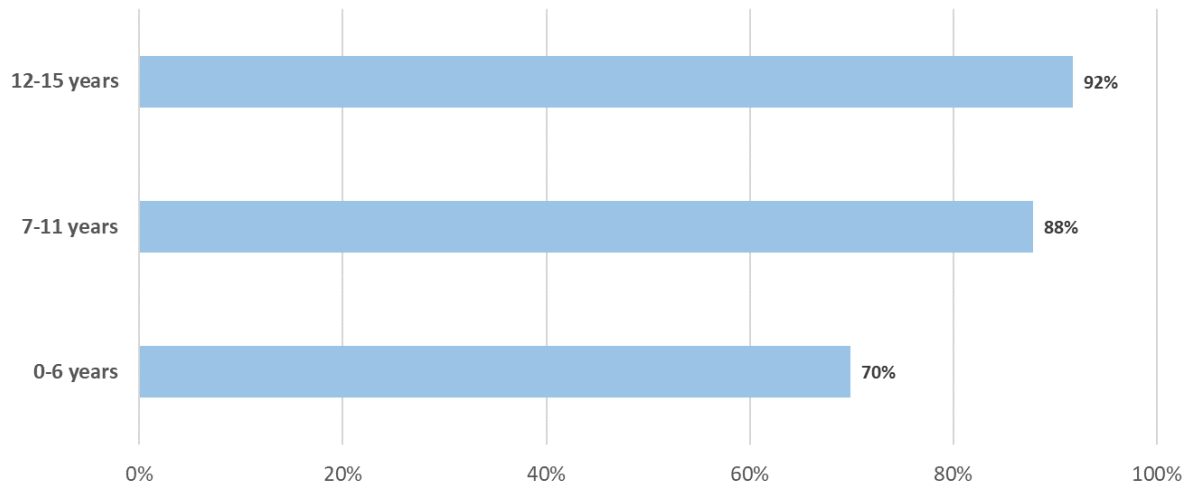


### Q2. I feel I have been kept updated about this research study.

In 2023/24, 75% of respondents 'strongly agreed' or 'agreed' that they had been kept up to date about the research, a decline of more than 10% since the previous year (87% in 2022/23).

Respondents completing the 0-6 years CYP version were least likely to feel that they had been kept up to date about the research study with 70% selecting 'strongly agree' or 'agree'. This is in contrast to those answering the 12-15 years (92%) or 7-11 years version (88%). See Figure 10.

**Figure 10.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether they had been kept updated about the research study (Q. 2) by CYP survey version.

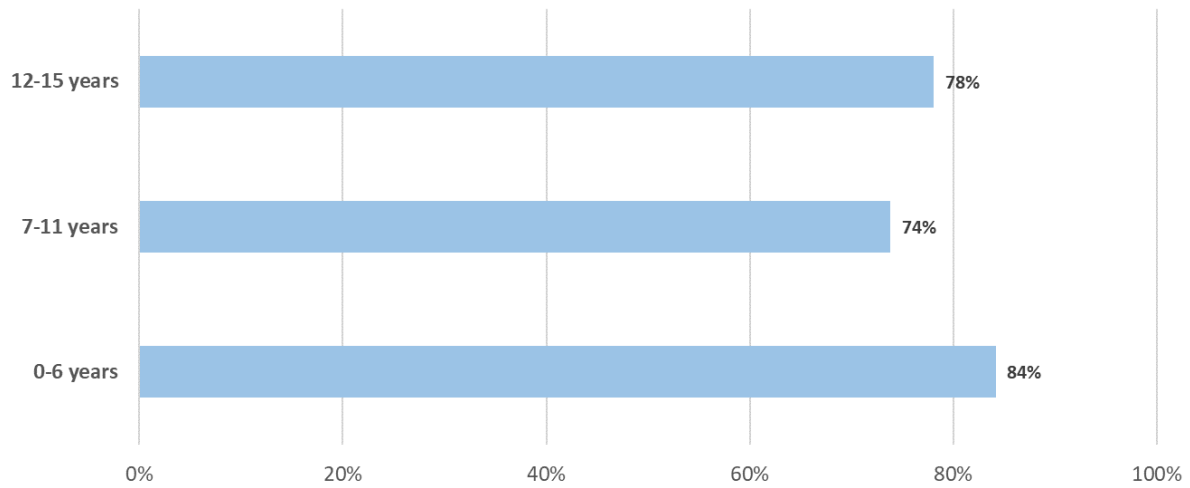


### Q3. I know how I will receive the results of this research study

Overall, 82% of people responding to all versions of the CYP survey said they knew how they would receive the results of the research, an encouraging improvement of 7% since 2021/22, where only 75% 'strongly agreed'.

By survey version, those responding to the 0-6 years survey were most likely to select 'yes' or 'yes, to some extent' to this question (84%), when compared to those completing the other age versions (78% for the 12-15 years survey and 74% for 7-11 years survey). See Figure 11.

**Figure 11.** Percentage of respondents selecting ‘yes’ or ‘yes, to some extent’ when asked whether they knew how they would receive the results of the research study (Q. 3), by CYP survey version.

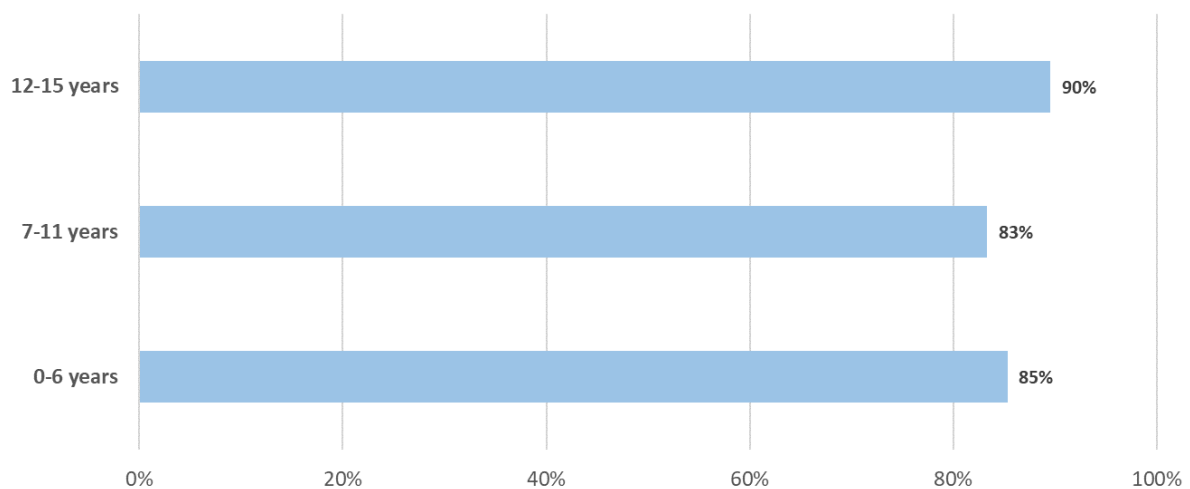


#### **Q4. I know how to contact someone from the research team if I have any questions or concerns**

Overall in 2023/24, 86% of CYP respondents ‘strongly agreed’ or ‘agreed’ that they knew how to contact someone from the research team should they have any questions or concerns. This is a decrease from 90% demonstrated in 2022/23.

Those answering the 12-15 years survey were most likely to report that they knew how to contact someone (90%) compared to those completing the 0-6 version (85%) or the 7-11 version (83%). See Figure 12.

**Figure 12.** Percentage of respondents selecting ‘strongly agree’ or ‘agree’ when asked whether they knew how to contact someone from the research team if they had any questions or concerns (Q. 4) by survey version.

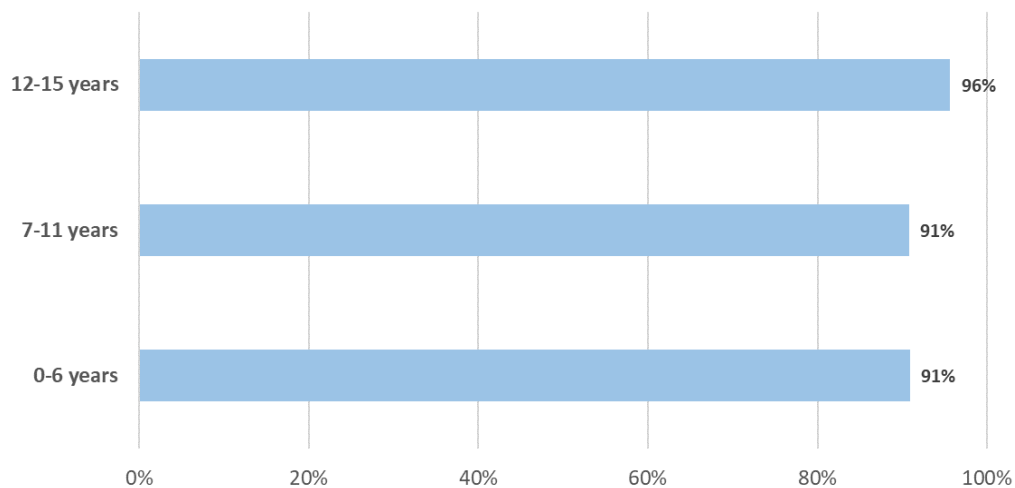


## Q5. I feel research staff have valued my/my child taking part in this research study

In 2023/24, 91% of CYP respondents 'strongly agreed' or 'agreed', when asked whether they felt valued by staff for taking part in a research study. This showed a decline from 95% as seen in 2022/23.

Of all CYP survey versions, those responding to the 12-15 survey were slightly more likely to select 'strongly agree' or 'agree' to this question (96%) than those answering the 0-6 or 7-11 versions (both 91%).

**Figure 13.** Percentage of respondents selecting 'strongly agree' or 'agree' when asked whether they felt research staff valued them / their child taking part in the research (Q. 5), by survey version.

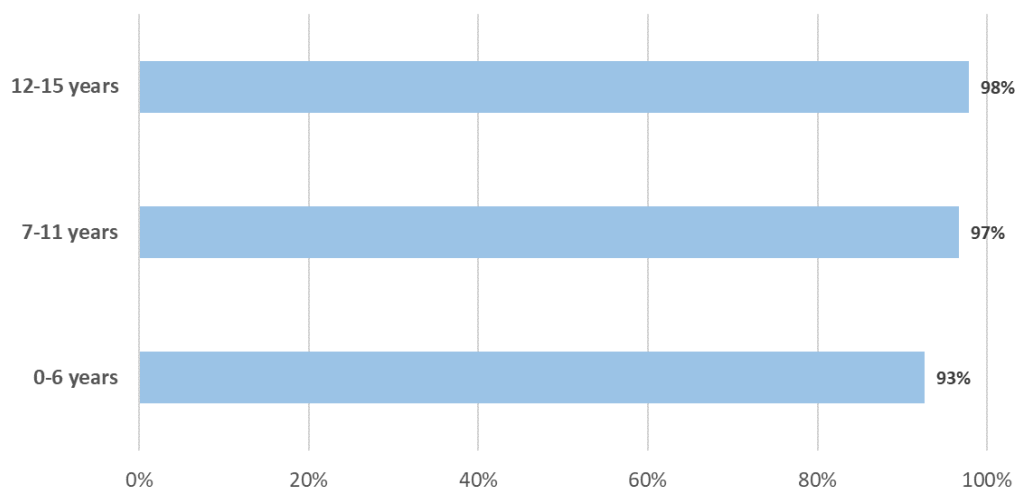


## Q6. Research staff have always treated (the child or young person) with kindness and respect

Whilst 94% of the total CYP respondents (or parents/carers) in 2023/24 'strongly agreed' or 'agreed' that they or their child had been treated with respect, this showed a decrease from 96% in 2022/23.

Respondents completing the 12-15 (98%) or 7-11 (97%) CYP survey versions were more likely than those completing the 0-6 version (93%) to 'strongly agree' or 'agree' with the statement in this question (see Figure 14)

**Figure 14.** Percentage of respondents selecting ‘strongly agree’ or ‘agree’ when asked whether research staff have always treated the child or young person with kindness and respect (Q. 6), by CYP survey version.

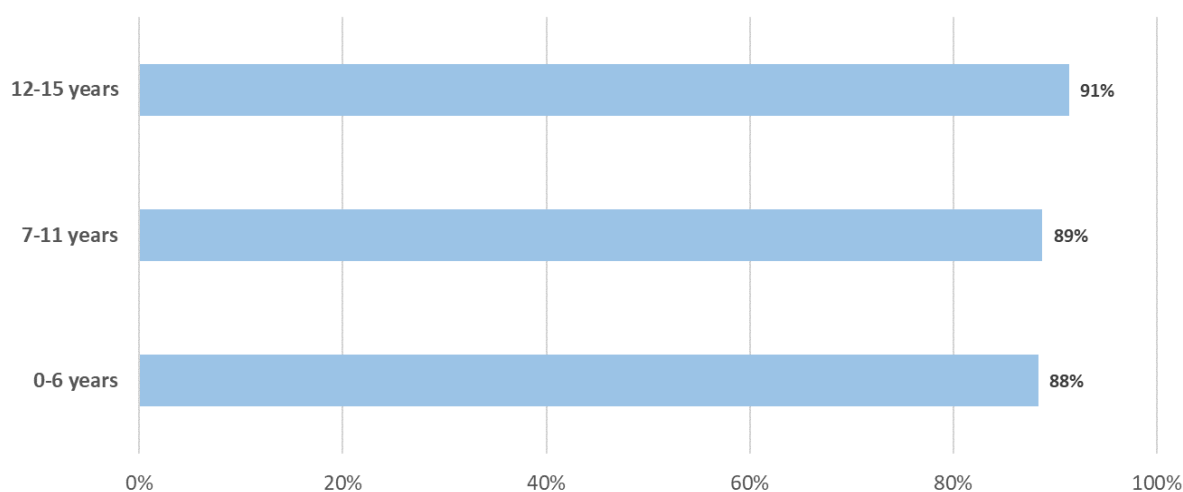


### Q7. Would consider taking part in research again

In 2023/24, 89% of CYP respondents ‘strongly agreed’ or ‘agreed’ that they (the child or young person) would consider taking part in research again, or that parents/carers would consider consenting on behalf of their child to take part in research again. This figure demonstrated a small decrease from 90% in 2022/23.

Respondents who completed the 12-15 survey version were more likely to be in agreement with this statement (91%) and said they would consider taking part in future research studies. See Figure 15.

**Figure 15.** Percentage of respondents selecting ‘strongly agree’ or ‘agree’ when asked whether they would consider taking part in research again (Q. 7), by CYP survey version.



## Qualitative findings – Children and Young People

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

For Question 8, three main topic themes were identified in the dataset.

#### **Staff attitudes**

Participants appreciated research staff for their helpful and friendly attitudes and reported that they were easy to approach and patient with them. Staff were reported to be welcoming and were positively engaged with the child participant. The research staff were reported as being responsive and available by email.

#### **Communication and information sharing**

Respondents shared that study instructions were well explained and that all their questions were answered adequately. Participants felt they were kept well informed during the study and staff communication with patients was noted to be positive throughout. All trial related information shared was reported to be in simple layman's terms and easy to understand for participants of all ages.

#### **Motivation to participate**

Respondents generally noted that they felt that the research they took part in was helpful to them and they felt good about their participation as it would help people in the future. They also reflected that they felt the research they took part in will positively impact others in their position. They appreciated the opportunity to participate in research and reacted positively to the choices available to them around their level of participation.

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

#### **Technical problems**

Participants reported that some applications used as part of a study were problematic to use, which resulted in discontentment and frustration. Improved usability for apps used in studies or improved technology would be appreciated by CYP participants.

#### **Information Sharing**

Participants reported wanting more information on the research study and the meaning of the study results for them and the wider population. Some respondents mentioned

that they did not hear anything about the study once they had consented or outcomes from their test results. Similar to adult survey respondents, it was also recommended that study teams provide more detailed information about the activities of the research study in advance, so that they knew what to expect. This would improve their experience of taking part in research.

## **Other**

CYP respondents reported that a thank you note would be greatly appreciated from study teams for their participation. Participants also mentioned that some studies were difficult for the child due to the number of blood tests involved. They reported that this was not ideal, but they appreciated that the research staff did all they could to make sure the child had a smooth and positive experience despite this.

# Easy Read Survey Results

## Summary of findings

58 responses were received throughout 2023/24 across 3 LCRNs, namely CRN Yorkshire & Humber (n=55, 95%), CRN East of England (n=2, 3%) and CRN Thames Valley & South Midlands (n=1, 2%). The majority of respondents to this version of the survey were taking part in Primary Care specialty studies (86%). Respondents were primarily aged between 25-34 years old and were of an Asian/Asian British ethnic group (85%).

Table 8. shows the percentage of respondents that responded positively (selected 'Yes') to each of the questions found in the Easy-Read PRES survey.

**Table 8. Percentage of respondents who selected 'yes' per Easy-read question during 2023/24**

Question	% of participants that responded positively
You were given information before taking part in the research study. Did this information help you to prepare?	88%
Were you kept up to date about the study?	86%
Do you know how you will get the results of the research study?	84%
Did you know how to contact someone from the research team if you had any questions or worries?	90%
Do you know if the research staff were thankful that you took part in the research study?	88%
Were the research staff polite and did they treat you with respect?	98%
Do you think you will want to take part in research again?	74%

Similar to the Adult and CYP PRES surveys, the Easy-Read survey collected responses to free-text questions, which asked participants to identify what they felt was a positive factor to their research experience and what could have been done to make their experience better. The responses to the free-text questions in the Easy-Read survey mirrored responses from other versions of the survey and related to experiencing

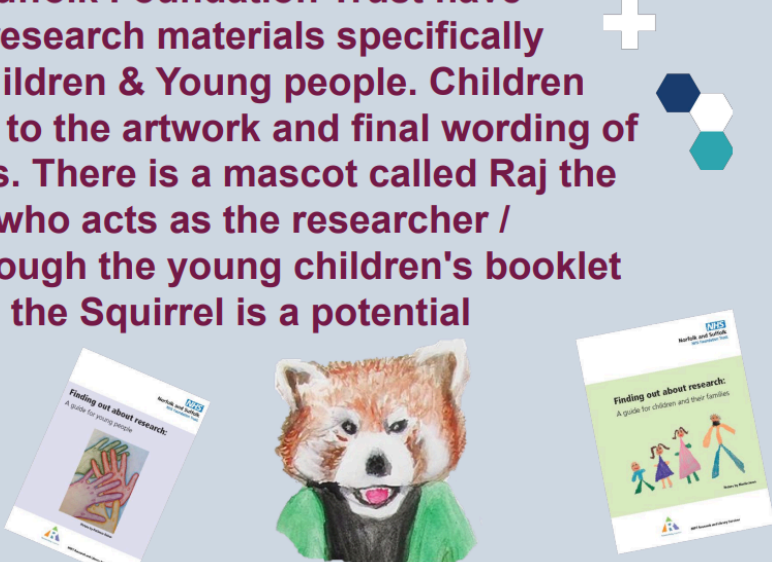
positive research staff attitudes with improvements recommended in the sharing of study results both during and after the study had been completed. Participants also reflected that they would like to have the option of choosing study appointments in locations that are more convenient for the participants.

# Case Studies

Below are a few case studies that demonstrate impact from PRES participant feedback. The following examples demonstrate how different research teams and linked NHS Trusts have worked to make improvements to their research studies based on PRES feedback.


## Case study 1: Norfolk and Suffolk NHS Trust (East of England LCRN)

**Norfolk & Suffolk Foundation Trust have developed research materials specifically aimed at Children & Young people. Children contributed to the artwork and final wording of the booklets. There is a mascot called Raj the Red Panda who acts as the researcher / narrator through the young children's booklet and Sammy the Squirrel is a potential participant.**



The image shows two research booklets and a Red Panda mascot. The mascot is a plush toy with orange fur, black ears, and a green shirt. The booklets are titled 'Finding out about research: A guide for young people' and 'Finding out about research: A guide for children and their families'. The booklets feature colorful illustrations of children and a family. The mascot is positioned between the two booklets.

## Case study 2: Improvements and actions implemented from 2019/20 PRES Report (East of England LCRN)



The image shows a collection of research materials, including a 'Finding out about your research' booklet, a 'Moving ahead with your research' questionnaire, and a 'Research Completion Pack' certificate. The certificate is titled 'This is to certify that (insert name) is an Official Researcher Junior Researcher' and is signed by Dr. John Wilson, Director of Research. The materials are laid out on a wooden surface.

**A Research Completion Pack** was designed by the research team at the Norfolk and Suffolk NHS Foundation Trust (pictured left).

The pack is given to outgoing participants and provides information about where to find out the results of the research they took part in. The pack includes:

- 1) Finding Your Results Leaflet (developed in partnership with their Trust Library Services)
- 2) Moving Ahead Questionnaire (so the participant can decide if they want to be involved again in the future and give a snapshot experience rating)
- 3) A certificate and/or letter of thank you depending on the participant's age
- 4) Further reading leaflets about mental health as provided by the Library.

- **Improving consent:** participant feedback on their experiences of the consent process are being used when training research staff.
- **Using technology:** we listened to participant feedback around the use of technology and offered the option of both online and paper surveys.
- **Flexible appointments:** each year the number of participants who are able to choose an alternative date for their appointment has increased in parallel with the number of participants who are happy with their appointment time and date.
- **Parking:** in response to the feedback around parking for research appointments, many trusts in Eastern offer free, subsidised or reserved parking for research participants.
- **Finding out the results:** we understand how important it is for many participants to find out the results of the research they took part in. Work is ongoing to improve the way we tell participants how to find out the results of the research they took part in.
  - The importance of telling participants how to find out the results is included in all appropriate training programmes locally and CRN wide.
  - 1,594 participant's have been sent a copy of this survey results report, along with a thank you letter and information on how to be involved again.
  - Feedback and thank you events were held at a number of Trusts.

### Case study 3: Newcastle Patient Recruitment Centre (NENC LCRN)

The research team at PRC: Newcastle, together with the sponsor (Enteromed Ltd) remains dedicated to prioritising patients by not only providing the results in a timely manner, but by doing so in an easily accessible webinar. The patient-friendly webinar took place to maximise access for working participants. The Chief Investigator and the sponsor, EnteroMed presented the provisional results to participants followed by an interactive question and answer session. This approach again raises the bar in patient-centric research delivery by enabling direct dialogue and bucks the usual trend of post-trial communicating being given via a letter.

EnteroMed Ltd, in partnership with NIHR Patient Recruitment Centre: Newcastle, hosted a live webinar to share the initial findings of the RELIEVE IBS-D trial with all its participants and research delivery staff. The trial investigated the efficacy and safety of a treatment for Irritable Bowel Syndrome with Diarrhoea.

## Case study 4: Improvements and 'You said, We did' examples (North West London LCRN)

You said

We did

How your feedback has made a difference

We value feedback from research participants. It helps us to understand what went well, and what could have gone better. The Participant in Research Experience Survey has already made a difference.

“ A cup of tea would have made the experience better. ”

Tea and coffee has been introduced in waiting areas.

London North West University  
Healthcare NHS Foundation Trust



“ The visits take a long time and are quite onerous. ”

If the visit is expected to last more than an hour, we now offer to split the appointment over multiple visits.

DREAMS & PATHfinder studies



# Glossary

<b>CRN</b>	<p>‘Clinical Research Network’</p> <p>Supports patients, the public and healthcare organisations across England to participate in research</p>
<b>CYP</b>	<p>‘Children and Young People’</p>
<b>DHSC</b>	<p>‘Department of Health and Social Care’</p> <p>Supports ministers in leading the nation’s health and social care to help people live more independent, healthier lives for longer.</p>
<b>DOs</b>	<p>Delivery Organisations</p> <p>Previously known as Partner Organisations, relates to research delivery sites that offer PRES to participants.</p>
<b>LCRN</b>	<p>‘Local Clinical Research Network’</p> <p>Across England in 2023/24, 15 LCRNs coordinated the delivery of PRES.</p>
<b>NIHR</b>	<p>‘National Institute for Health and Care Research’</p> <p>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.</p>
<b>PRES</b>	<p>‘Participant in Research Experience Survey’</p> <p>An annual survey conducted by NIHR to record the experiences of research participants.</p>
<b>RDN</b>	<p>‘Research Delivery Network’</p> <p>Previously known as Clinical Research Network, came into force on October 1st 2024.</p>

**RDNCC** 'Research Delivery Network Coordinating Centre'

Previously known as Clinical Research Network Coordinating Centre, came into effect on April 1st 2024.

**RRDNs** 'Regional Research Delivery Networks'

Previously known as Local Clinical Research Networks. Came into effect on October 1st 2024.

# Appendix

**Table 9.** Percentage of Adults who responded ‘positively’ to their participant experience in 2023/24

	2021/22	2022/23	2023/24
The information that I received before taking part prepared me for my experience on the study	95%	93%	93%
I feel I have been kept updated about this research study	82%	77%	72%
I know how I will receive the results of this research study	79%	74%	77%
I know how to contact someone from the research team if I have any questions or concerns	90%	85%	84%
I feel research staff have valued my taking part in this research study	92%	91%	92%
Research staff have always treated me with courtesy and respect	97%	95%	95%
I would consider taking part in research again	93%	91%	91%

‘Positively’ is defined as ‘strongly agree’ or ‘agree’ to the survey question.

**Table 10.** Percentage of Children & Young Persons who responded ‘positively’ to their participant experience in 2023/24

	2021/22	2022/23	2023/24
The information received before taking part prepared me/my child and was easy to understand	78%	97%	95%
I feel I have been kept updated about this research/I knew what was happening	92%	87%	75%
I know how I will receive the results of this research	75%	87%	82%

I know how to contact someone from the research team if I have any questions or concerns	93%	90%	86%
I feel research staff have valued the child taking part in this research study	100%	95%	91%
Research staff have always treated the child with courtesy and respect	100%	96%	94%
I would consider my child taking part in research again/I would take part again	98%	92%	89%

'Positively' is defined as a 'strongly agree' or 'agree' to the survey question.

## PRES Survey Questions

The adult survey asked the below questions on participant experience and respondent demographics (Table 10).

**Table 11.** Question text for the adult survey

Questions	Adult survey
Q1	The information that I received before taking part prepared me for my experience on the study
Q2	I feel I have been kept updated about this research study
Q3	I know how I will receive the results of this research study
Q4	I know how to contact someone from the research team if I have any questions or concerns
Q5	I feel research staff have valued my taking part in this research study
Q6	Research staff have always treated me with courtesy and respect
Q7	I would consider taking part in research again
Q8	What was positive about your research experience?
Q9	What would have made your research experience better?
Q10	How long have you been taking part in this research study?
Q11	Is this the first research study you have taken part in?
Q12	Who completed this survey?
Q13	What is your year of birth?

Q14	What sex were you registered at birth?
Q15	Is your gender the same as the sex you were registered at birth?
Q16	What is your ethnic group?

The three CYP surveys asked the same questions, though the wording was tailored to the age of the participant (Table 11).

**Table 12.** Question text by CYP survey version

Questions	0-6 Years old survey	7-11 Years old survey	12-15 Years old survey
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	What did we do well?	What did we do well?

	research experience?		
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?

# Further Information

For further information about:

- 2023/24 PRES results;
- how you can use PRES to help improve participant experience in your study
- case study information, or
- for information on any other aspect of PRES.

Please contact the NIHR Research Delivery Network Coordinating Centre Public Partnership team at: [rdncc.ppt@leeds.ac.uk](mailto:rdncc.ppt@leeds.ac.uk)