



Patient Research Experience Survey 22/23 Results





Background

The National Institute of Health Research Clinical Research Network (NIHR CRN) established the Patient Research Experience Survey (PRES) nationally to better understand the patient experience of taking part in research across the region.



Through PRES we aim to put research participant experience at the centre of research delivery so that we can:

- Demonstrate to research participants that their contribution is valued
- Positively impact recruitment to and retention within research studies



PRES delivers these aims through:

- Providing an opportunity for as many research participants as possible to share their experience of taking part in research
- Promoting collaboration between research teams and research participants to co-produce solutions to improve research experience
- Increasing research workforce understanding of factors contributing to a positive research experience for participants
- Increasing awareness of factors likely to impact participant recruitment and retention during the design of new studies



NIHR PRES at Barts Health



2018/19

9 research teams/ units
15 medical specialties

Target: 150

Results: 202 adult, 40 children

Total: 242



2019/20

19 research teams/ units
17 medical specialties

Target: 450

Results: 595 adult, 232 children

Total: 831



2020/21

7 research teams/ units
8 medical specialties

No local target

Results: 290 adult, 22 children

Total: 312



2021/22

9 research teams/ units
12 medical specialties

No local target

Results: 123 adult, 36 children

Total: 159



2022/23

12 teams/ units

15 medical specialties

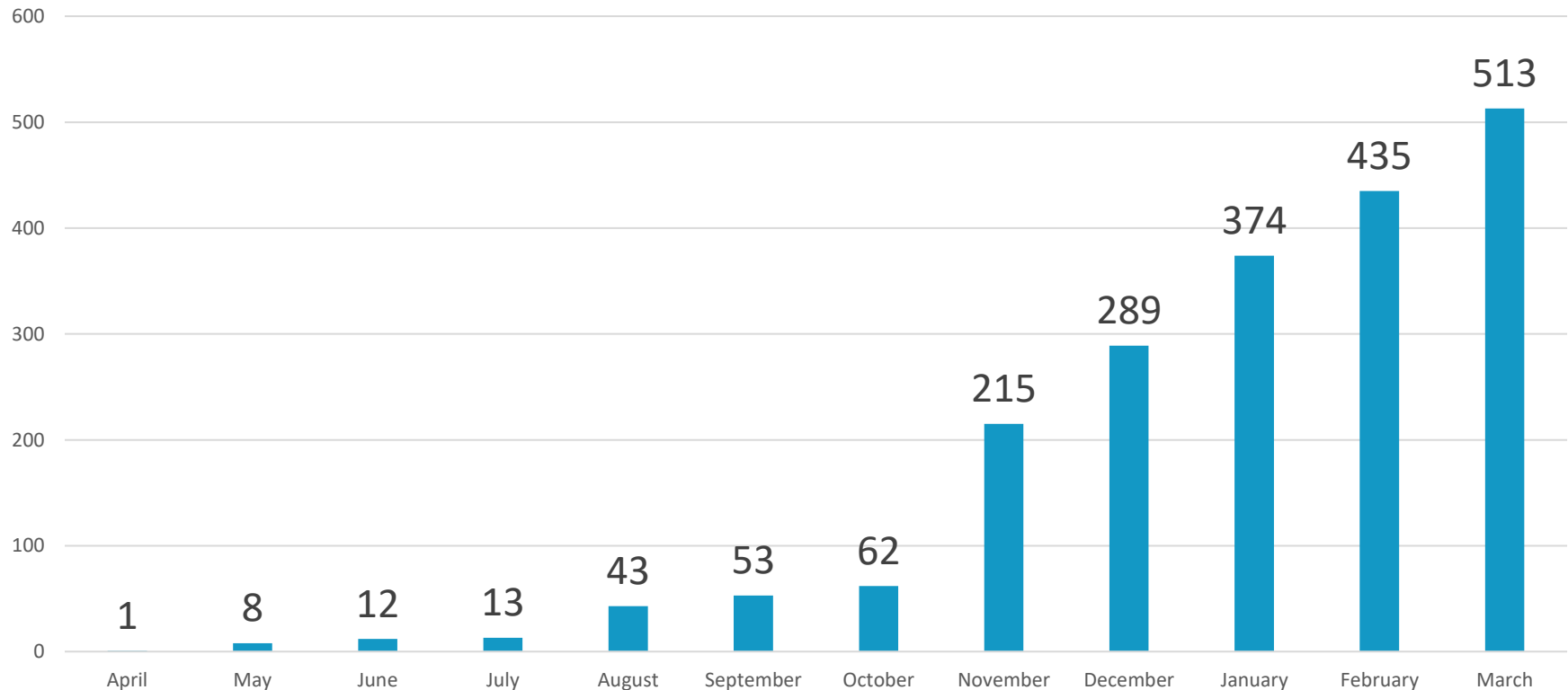
Target: 455

Results: 424 adult, 89 children

Total: 513



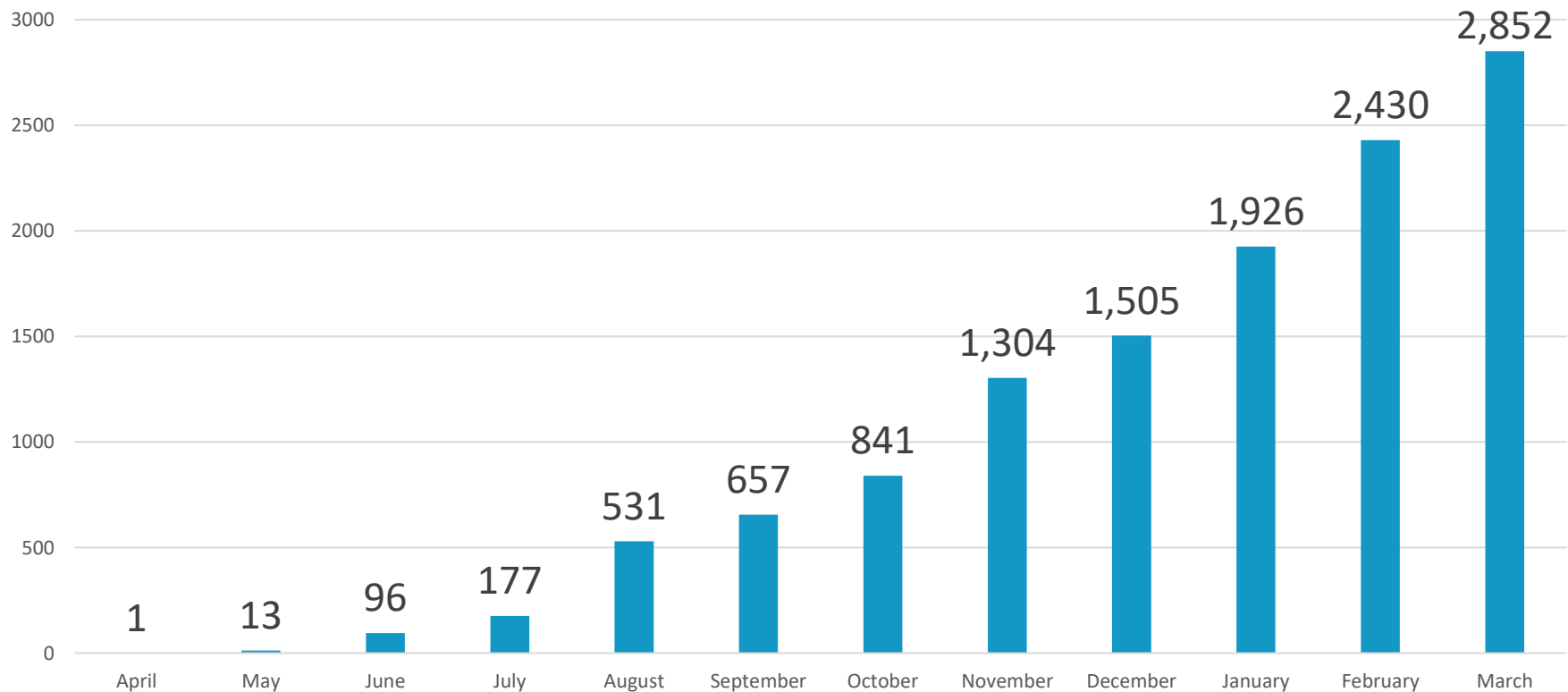
NIHR PRES at Barts Health: 22/23 month-by-month



Source: NIHR ODP



NIHR Clinical Research Network: North Thames PRES 22-23 month-by-month

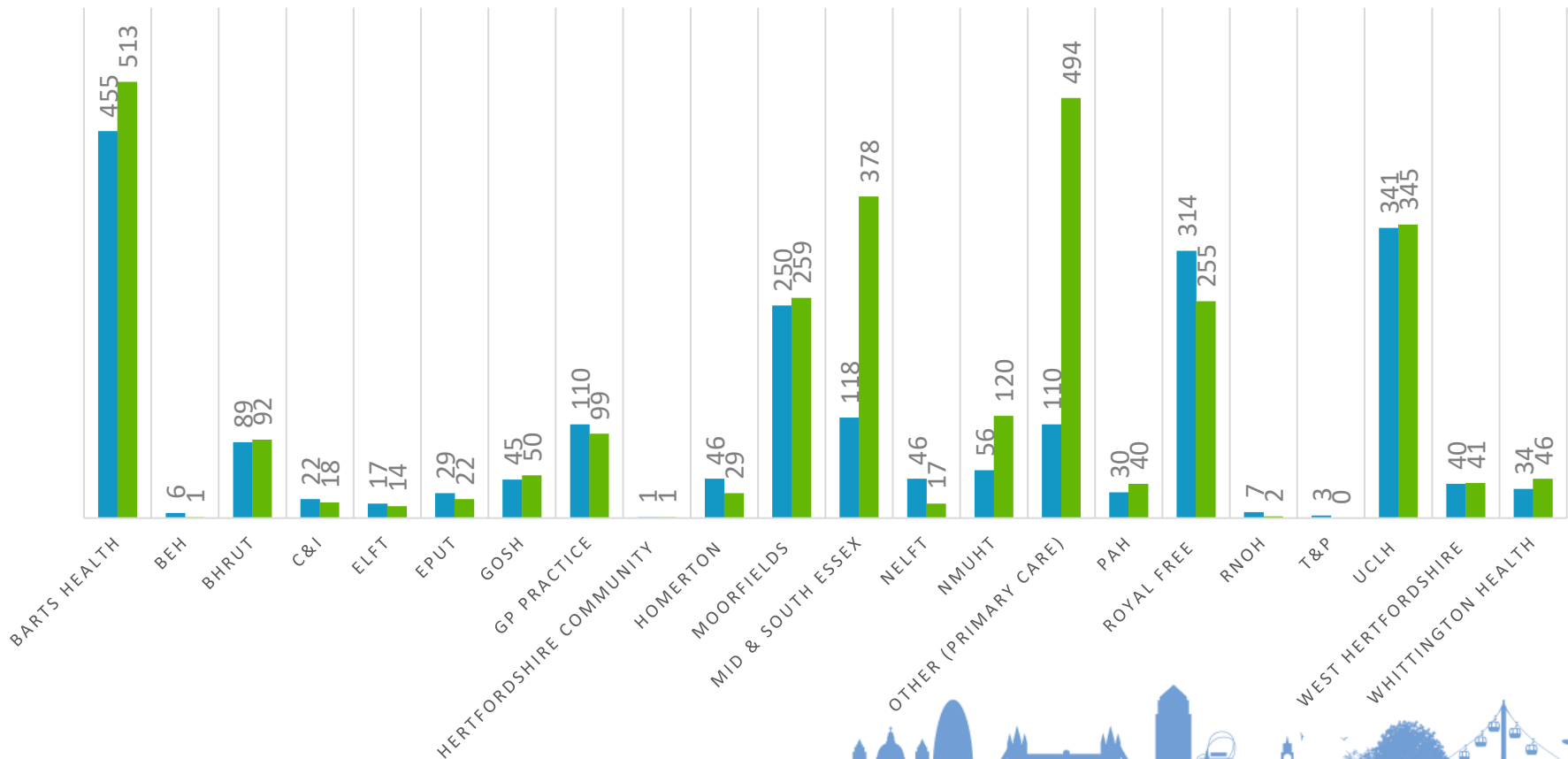


Source: NIHR ODP

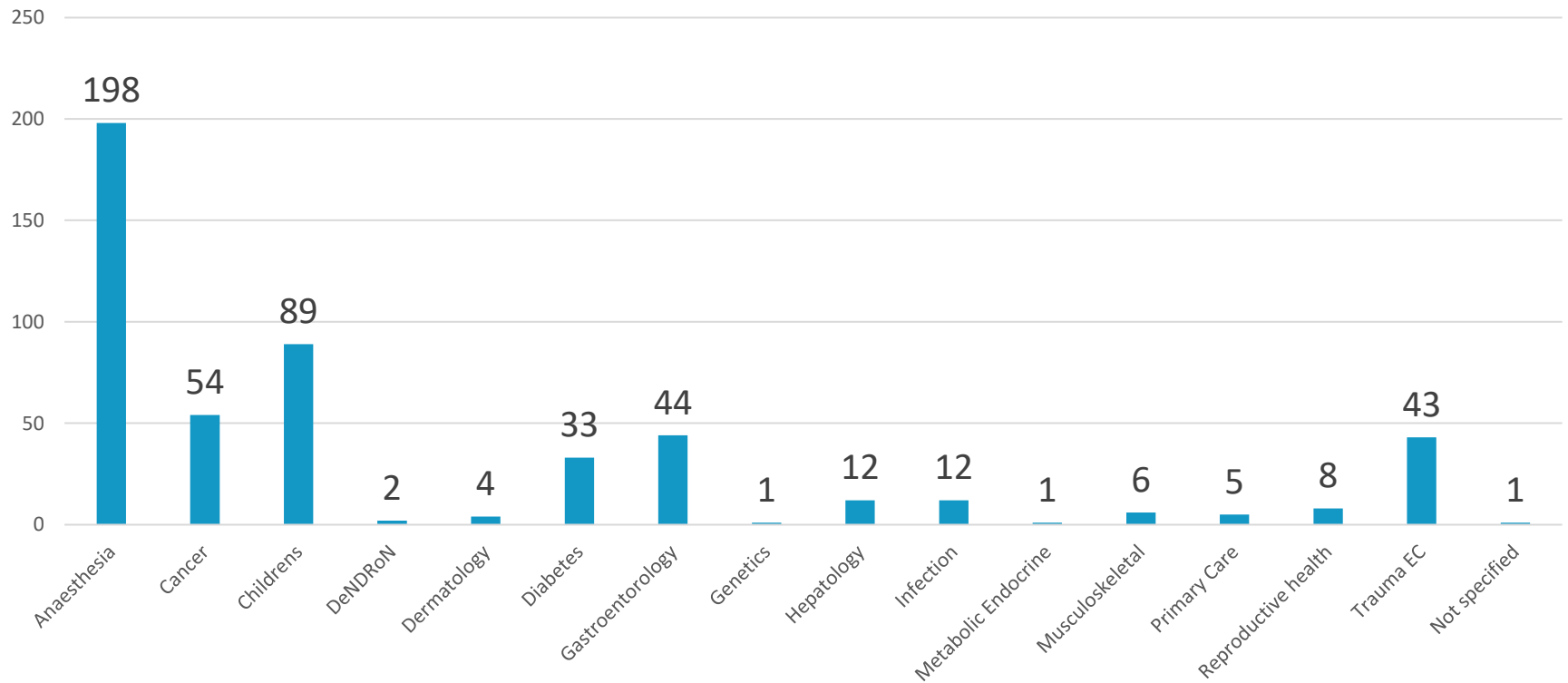


CRN:NT PRES 22-23 returns against targets

■ PRES target 22/23 (3% of 21/22 accrual) ■ End of Year Responses



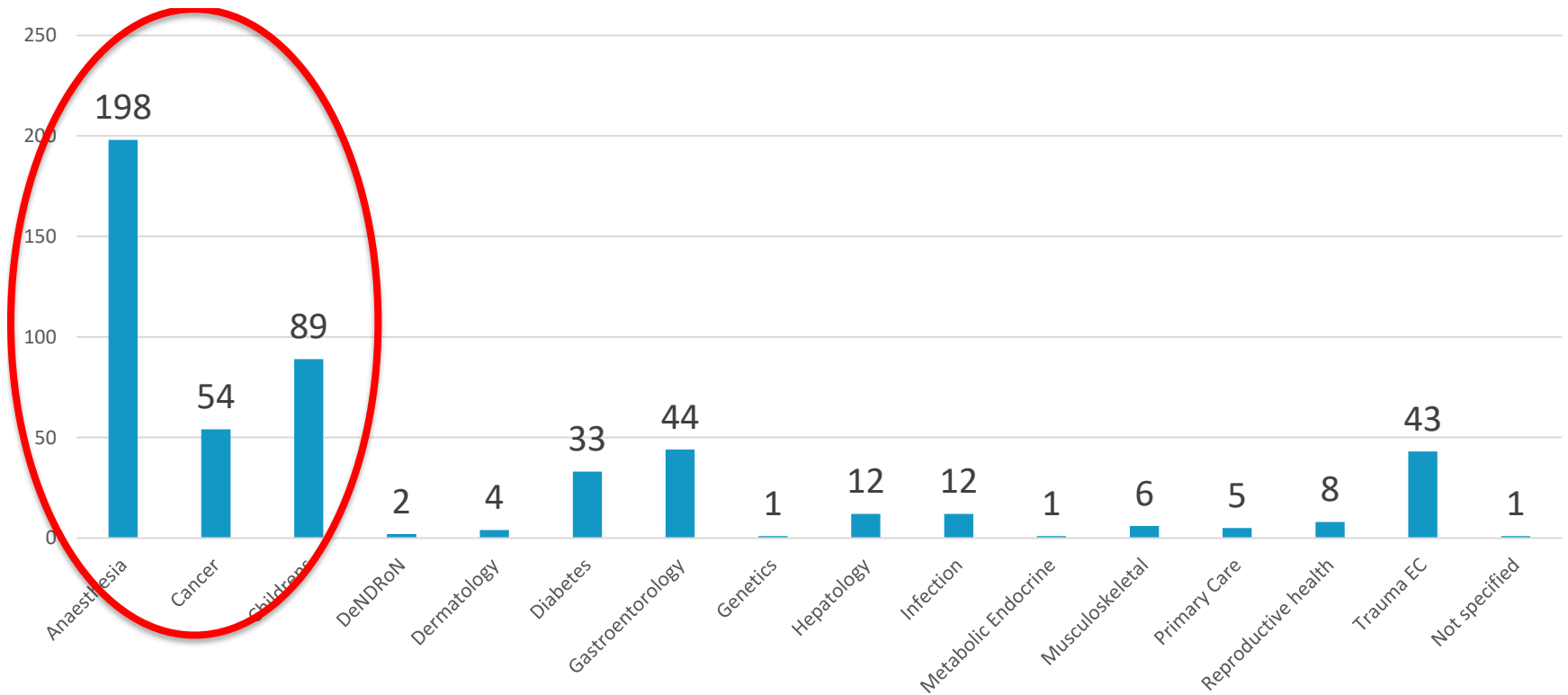
Barts Health PRES 22-23 by Specialty



Source: NIHR ODP



The top 3 performing clinical specialties were each rewarded with Amazon gift vouchers.



Source: NIHR ODP



PRES 22/23: responses grouped by ethnicity

Ethnic Group PRES 2022/23	(%)
White British	47
Not stated (child survey)	19
Indian	5.8
Any other White background	5.7
African	3.5
Bangladeshi	2.9
Caribbean	2.9
Irish	2.7
Other	2.7
Any other Asian background	2.5
Prefer not to say	1.2
No response	1.2
Pakistani	0.8
Any other Mixed/Multiple ethnic backgrounds	0.8
White and Asian	0.4
Chinese	0.4
Any other Black background	0.4
Gypsy or Irish Traveller	0.2
Arab	0.2
White and Black African	0.2

Ethnic Group PRES 21/22	(%)
White British	43.8
Not Stated (Child's Survey)	19
Not Stated	7.3
Any other White Background	5.8
Asian/Asian British: Indian	4.4
White Irish	4.4
Any other Asian/British Background	2.9
Prefer Not to Say	2.9
Any other Mixed Background	2.2
Black/Black British: African	1.5
Black/Black British: Caribbean	1.5
Mixed: White and Black Caribbean	1.5
Other	1.5
Asian/Asian British: Bangladeshi	0.7
Asian/Asian British: Pakistani	0.7
Mixed: White and Asian	0
Mixed: White and Black African	0

Source: NIHR ODP
(n = 513)



PRES 2022/23: responses grouped by age

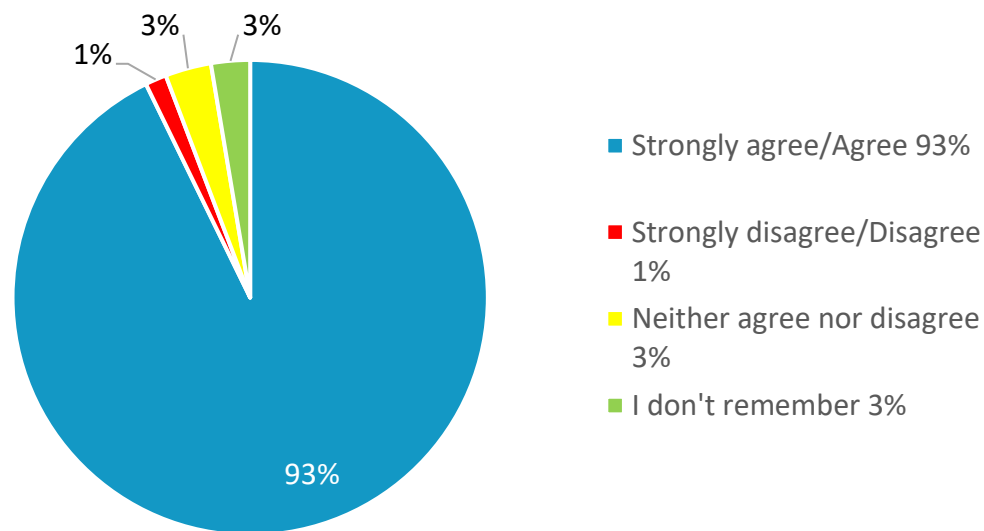
Respondents Age 22/23	(%)
65-74	22.6
55-64	21.1
Not stated	15.8
12-15	12.7
45-54	7.2
7-11	6.4
35-44	4.7
75-84	3.1
25-34	2.1
85+	1.9
16-24	1.4
0-6	1.0

Respondents Age 21/22	(%)
65-74	24.8
55-64	15.3
Not stated	14.6
12-15	11.7
45-54	9.5
7-11	7.3
35-44	6.6
75-84	3.6
25-34	2.9
85+	2.9
16-24	0.7
0-6	0.0

Source: NIHR ODP
(n = 513)



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

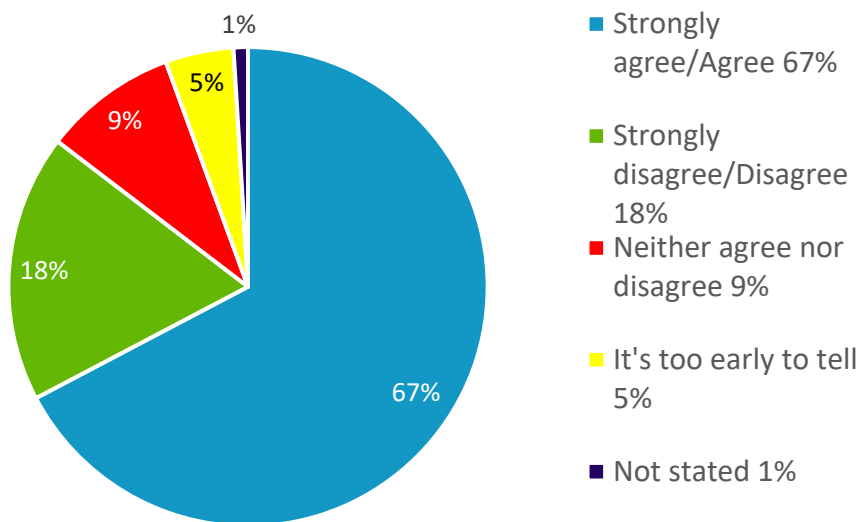


21-22 Results	
Strongly agree/Agree	93%
Strongly disagree/Disagree	2%
Neither agree nor disagree	3%
I don't remember/no response	2%

Source: NIHR ODP
(n = 424)



I feel I have been kept updated about the research

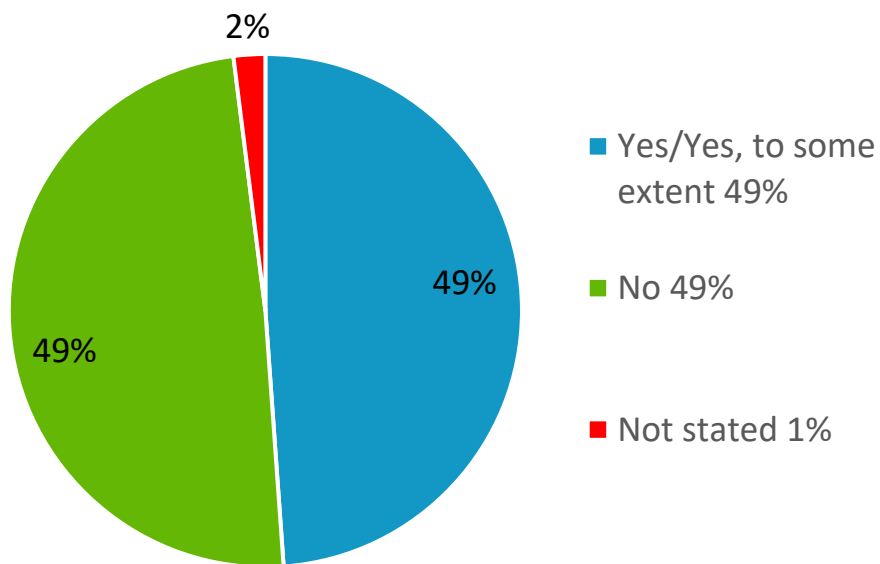


21/22 Results	
Strongly agree/Agree	72%
Strongly disagree/Disagree	5%
Neither agree nor disagree	13 %
It's too early to say/tell	10%
Not stated	0%

Source: NIHR ODP
(n = 424)



I know how I will receive the results of the research

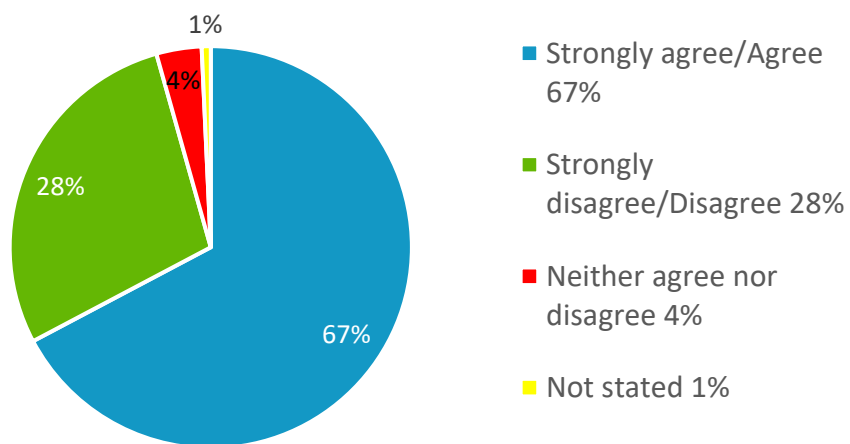


21/22 Results	
Yes/Yes, to some extent	77%
No	22%
No response	1%

Source: NIHR ODP
(n = 424)



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

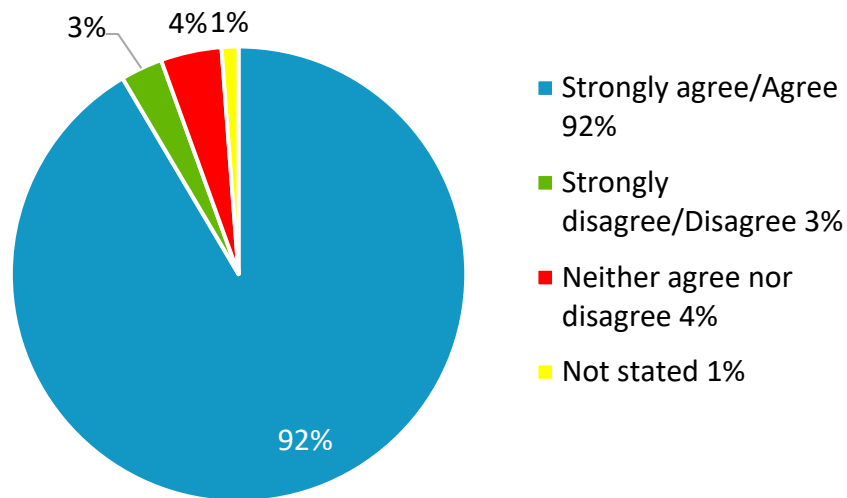


21/22 Results	
Strongly agree/Agree	89%
Strongly disagree/Disagree	4%
Neither agree nor disagree	6%
No response	1%

Source: NIHR ODP
(n = 424)



The researchers valued my taking part in research

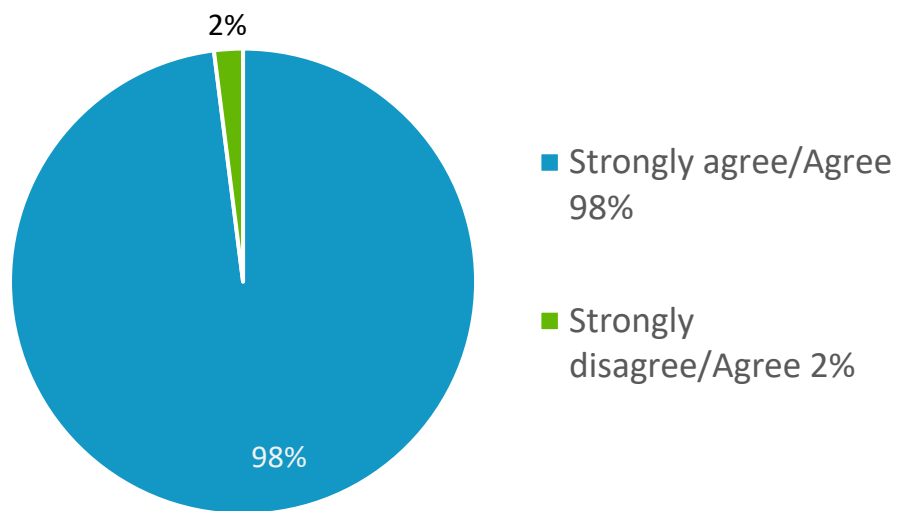


21/22 Results	
Strongly agree/Agree	91%
Strongly disagree/Disagree	2%
Neither agree nor disagree	6%
No response	1%

Source: NIHR ODP
 (n = 424)



Research staff have always treated me with courtesy and respect

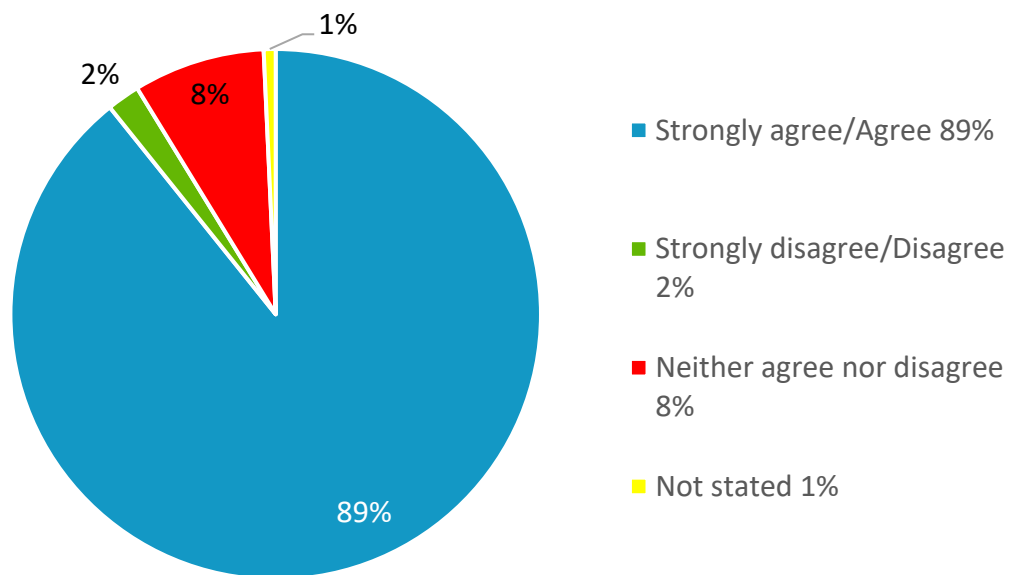


21/22 Results	
Strongly agree/Agree	95%
Strongly disagree/Disagree	2%
Neither agree nor disagree	1%
No response	2%

Source: NIHR ODP
(n = 424)



I would consider taking part in research again

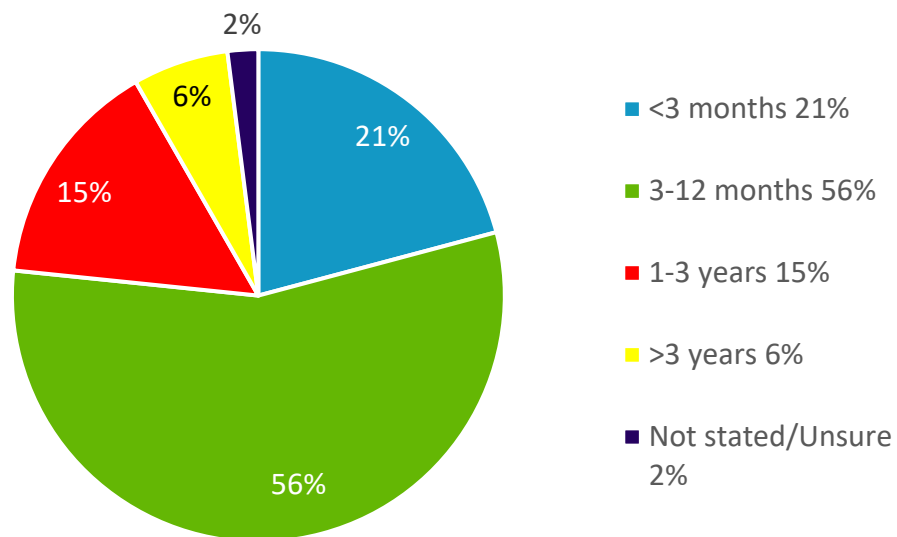


21/22 Results	
Strongly agree/Agree	72%
Strongly disagree/Disagree	5%
Neither agree nor disagree	13%
It's too early to tell	10%

Source: NIHR ODP
(n = 424)



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

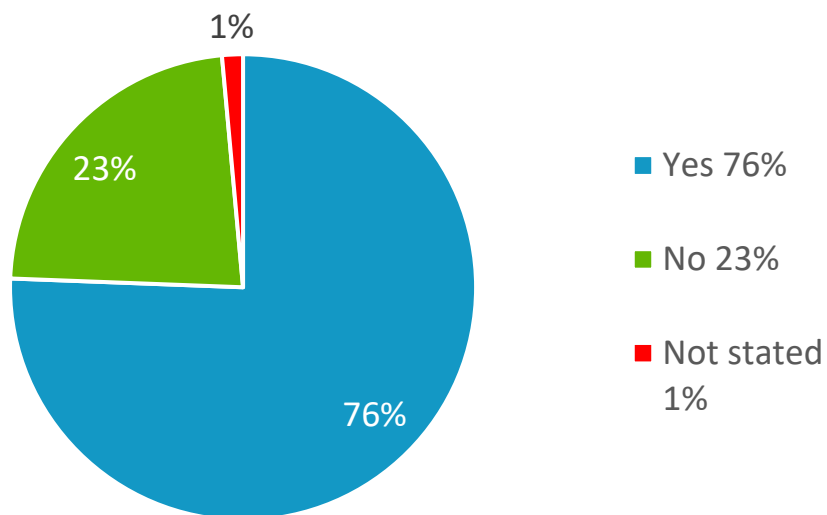


21/22 Results	
Less than 3 months	22%
3-12 months	28%
1-3 years	37%
>3 years or longer	6%
Not sure/Unsure	8%

Source: NIHR ODP
(n = 424)



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

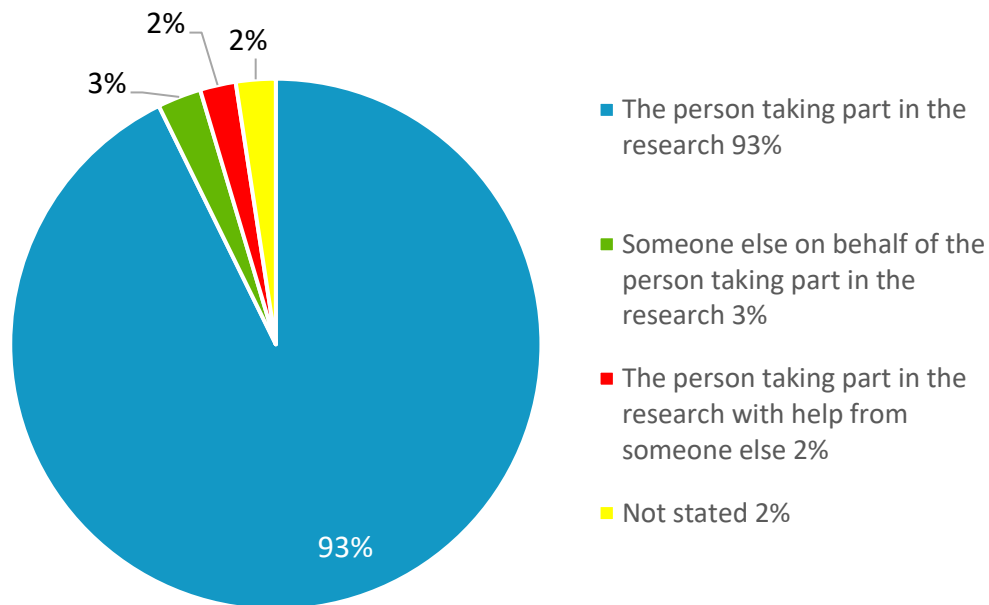


21/22 Results	
Yes	61%
No	35%
Not stated	2%

Source: NIHR ODP
(n = 424)



Who completed the survey?



21/22 Results	
The person taking part in the research	89%
Someone else on behalf of the person taking part in the research	2%
The person taking part in the research with someone else	5%
Not stated	4%

Source: NIHR ODP
(n = 424)



What we do well

“Huge amounts of support and expert knowledge from the team running the trial”. Diabetes study patient

“Research team are great, value the monthly check in discussions. Also, would be keen to participate in future studies if possible”. Infection study patient

“Everyone I have interacted with has been fantastic. Someone has been at hand whenever I needed help or treatment. I have been given full visibility of what the trial will require/offer. I have a good idea of the next 2 years on the study which is reassuring”. Gastroenterology study patient

“The kindness and care shown by the staff and the care they took in explaining the study”. Hepatology study patient



Where can we improve?

“Whilst informed about my own treatment, I have not been informed how the research is progressing generally”. Cancer study patient

“I don't know if I will be informed about the outcome of the research”.
Reproductive health and childbirth patient

“I don't know how long this research will take”. Trauma & EC patient

“Provide a little more information about the research itself and how it is going to be used in the future”. Cancer study patient



Here are some of the changes we've made locally in response to PRES

- Offering virtual follow-ups for patients who travel further, where possible
- Sharing information before and during research
- Feeding back trial results and impacts
- Contacting patients by phone/in clinics and giving them the option to receive study information via their preferred mode of conversation



Operational Updates for 23/24

- Minor changes to online surveys – these have already been made
 - If you need access to the links, they can be found on the PRES section of the [CRN North Thames webpage](#)
- The centralised stick and seal surveys will be the only paper versions of PRES accepted (excluding easy-read and visually impaired versions)
 - To order stick and seals and/or QR code slips, complete the form https://bit.ly/PRES_requestform and send to ppie.crnnorththames@nihr.ac.uk
- Further information including our localised guidance can be found on the [JRMO webpage](#)





NHS Trust

Take part in Research

Clinical research plays a significant role to help improve our patients' healthcare and the services we provide.

Barts Health NHS Trust is currently taking part in over 1000 clinical trials and other research studies.

Over 20,000 patients participated in research last year.

Many doctors and nurses working in this hospital play a key part in research and so do our patients. Our patients' participation in research is vital to help improve future treatments and services.

There are many ways to get involved. Want to find out more?

Ask your healthcare advisor about research which may be suitable for you.

Alternatively, please visit:
www.bartshealth.nhs.uk/research/takepart
or email: patientsinresearch@bartshealth.nhs.uk

Barts Health: Changing Lives

Thank you!

For more information on PRES, please visit
www.bartshealth.nhs.uk/takepart (patients and the public)
www.jrmo.org.uk (healthcare professionals, researchers)
or contact Neeta Patel or James Marshall at
Patientsinresearch.bartshealth@nhs.net

