

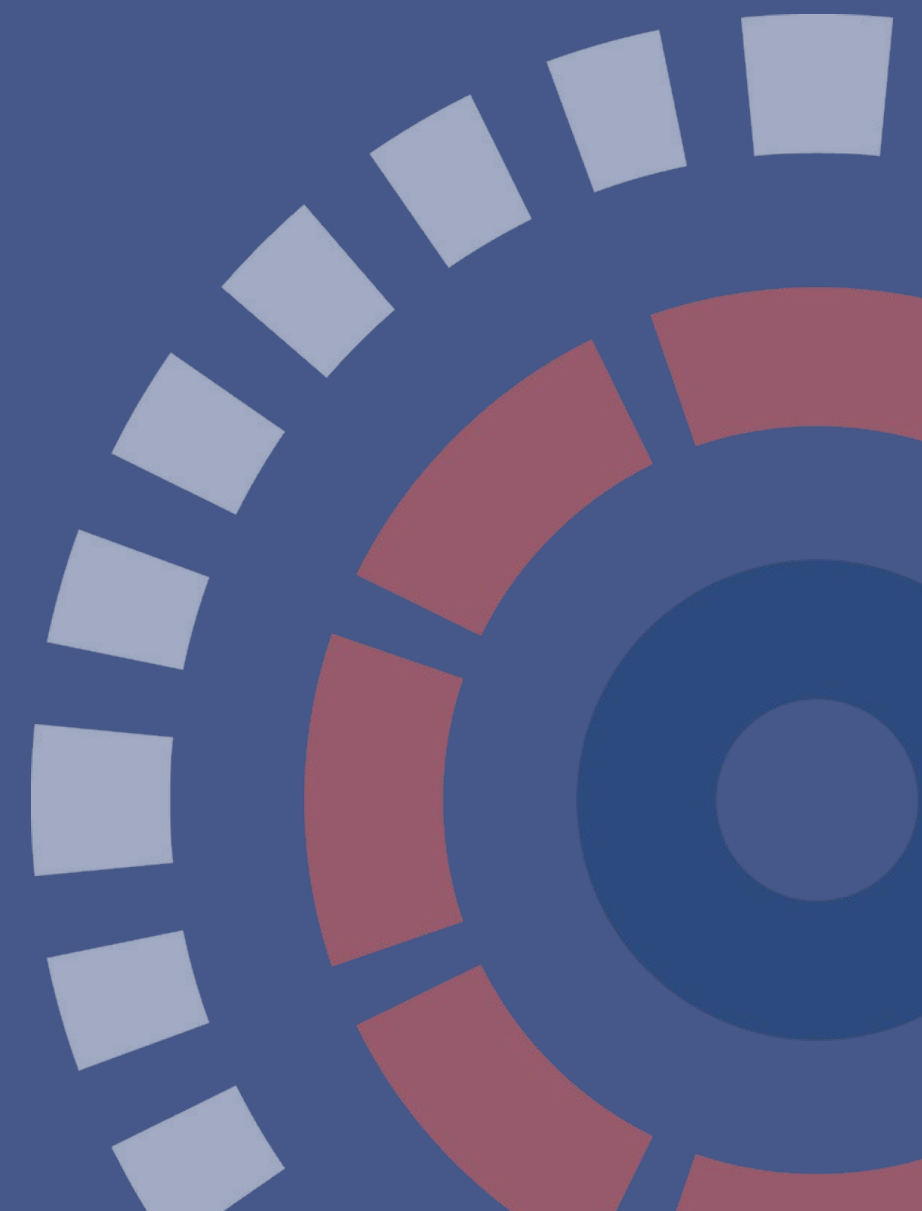


Participant in Research Experience Survey

2023/24

FINAL
REPORT

NIHR | Clinical Research Network Wessex



Summary

The Participant in Research Experience Survey provides research participants the opportunity to anonymously feedback about their experience.

This takes about five minutes and can be via a paper survey or an online form - in Wessex, 2023/24 saw nearly three-quarters of surveys delivered via paper. It also saw the highest ever number of responses to the survey but a lower number from participants who were children/young people compared to last year. The number of responses increased each quarter of the financial year.

Satisfaction was overwhelmingly positive and had increased for adults in 2023/24 compared to 2022/23, reversing the trend seen in previous years, and in some cases equalling/improving from pandemic levels in 2020/21. The highest number of responses was from participants in infection, cancer, and cardiovascular disease studies and the majority of respondents were taking part in their first research study.





Summary continued

With regards to demographics, there was a roughly equal split of male/female respondents, most were aged 60-69 and 70-79 years, and white. This age distribution reflected the research participants across Wessex.

Six themes were identified from the open-ended responses - staff attitudes, communication, motivation (to take part in research), practicalities, recognition, and learning.

A number of improvement projects were implemented to address the findings from 2022/23 which included letters to Chief Investigators of two commercial studies feeding back about the study design/data collection, cascading how study findings would be shared, and more frequent contact with participants in the case of one particular study. Looking forward to 2024/25, there will be an increased focus on obtaining feedback from children/young people and taking a 'digital first' approach to move away from survey completion by paper.



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Background

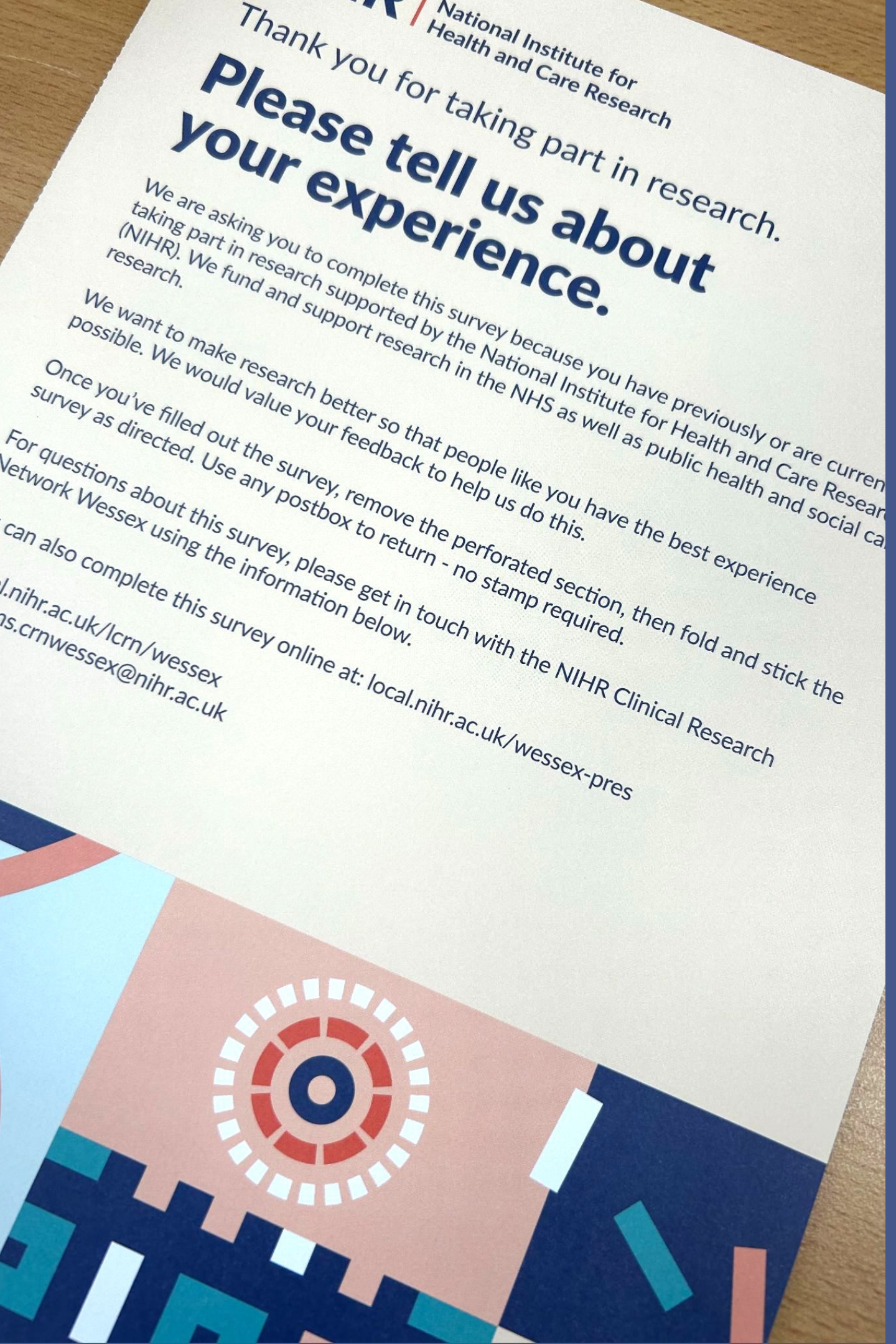


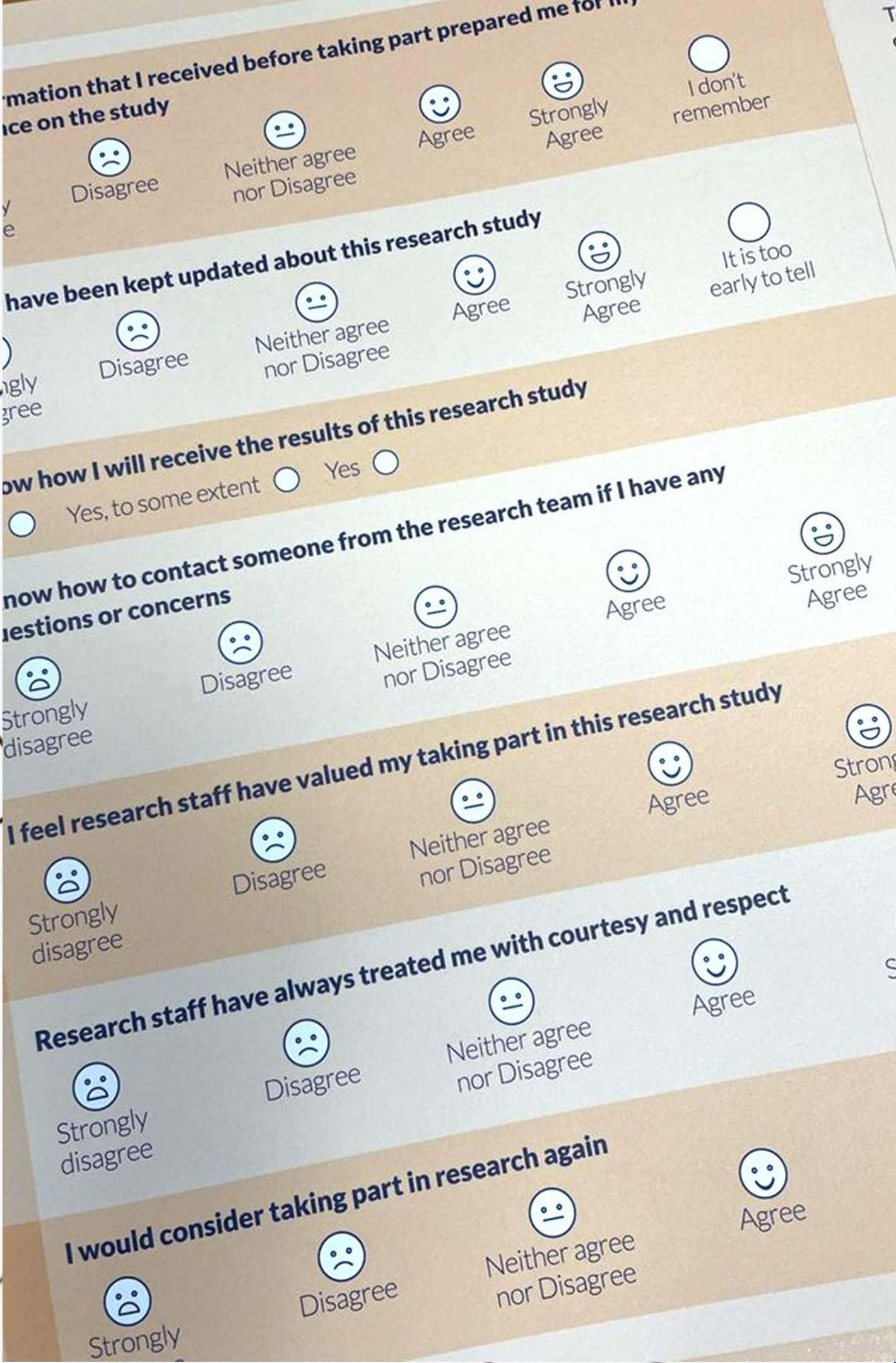
Background

The Participant in Research Experience Survey provides an opportunity for research participants to anonymously feedback their experience of taking part in research.

Feedback is requested towards the end of a participant's research journey for each study and takes around five minutes.

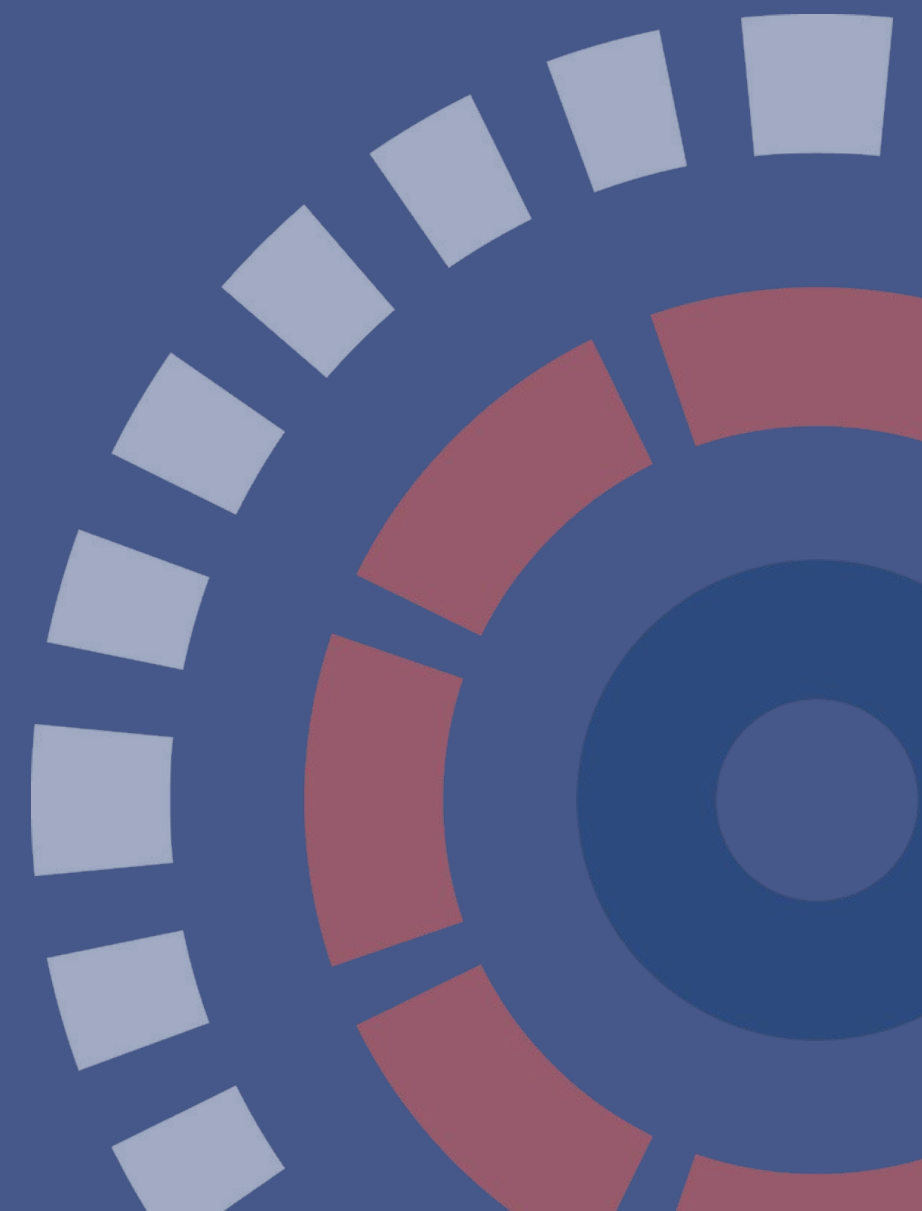
The responses inform improvement projects to both increase the reach and responses to the survey itself but also importantly to improve the experience for research participants.





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Methods



Survey versions

In Wessex, the 2023/24 survey was administered via a paper survey that was completed before 'folding and sticking' it together in order to send it freepost to the central processing facility for data entry. Alternatively the survey could be completed online.

Four different versions of the survey were delivered during 2023/24 for:

1. Adult participants.
2. Participants aged 0-6 years old (to be completed by a parent or carer).
3. Participants aged 7-11 years old.
4. Participants aged 12-15 years old.

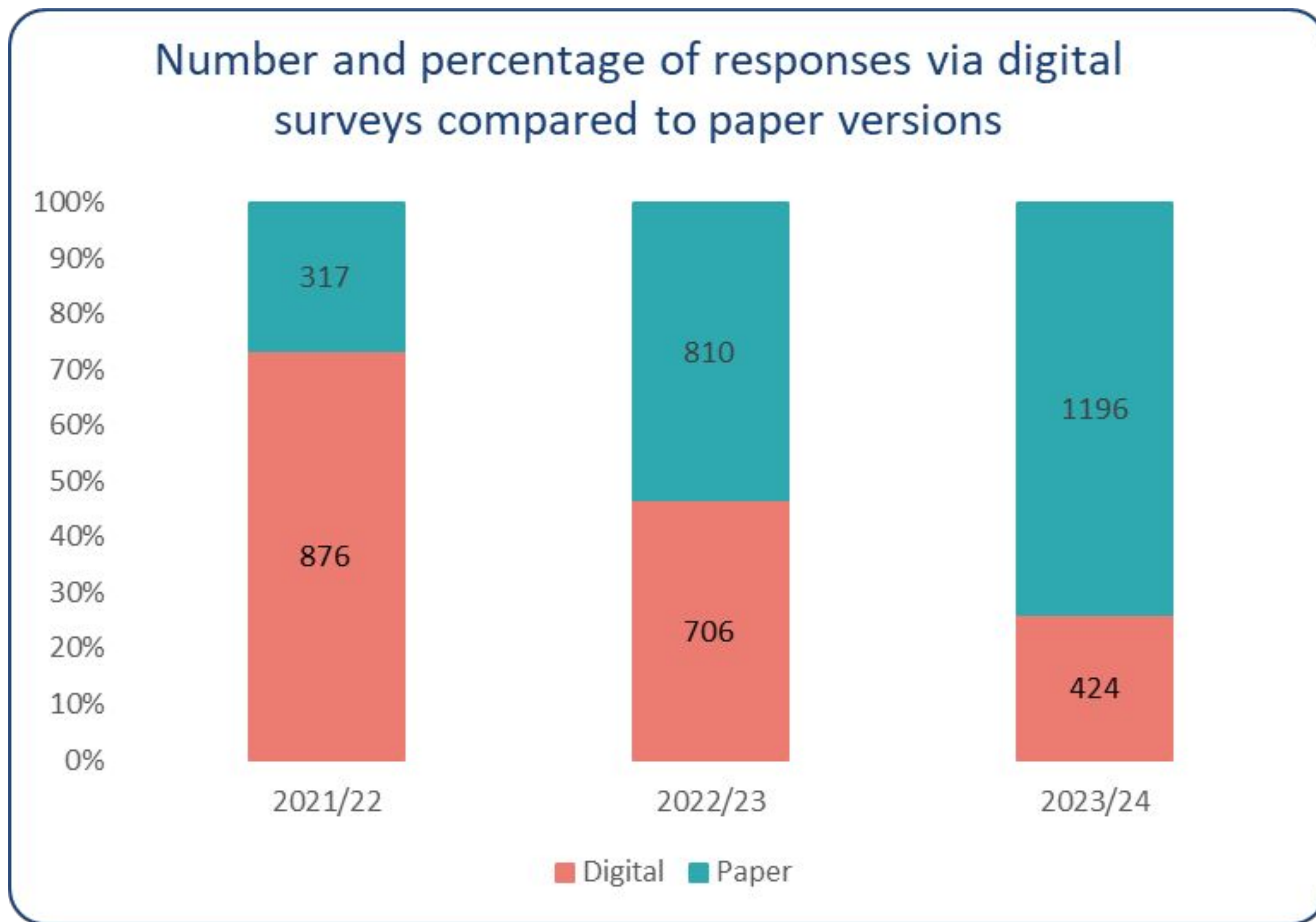
In contrast to 2022/23, the survey versions for children/young people were also available in paper format during 2023/24.

Data from the paper and online versions of the survey were collated. Tables and graphs were produced of the numbers and percentages for the numeric data and themes were drawn out from the open-ended responses.



There has been an increase in paper surveys used each year, contrary to the desire to move paperless. The online version may have been encouraged in 2021/22 given the need to (and lack of capacity to) enter the data for the paper version, particularly during the pandemic. Similarly, paper versions for children/young people were not available in 2022/23. The desire to use paper versions may be due to the incorporation of the survey into 'business as usual' and the inclusion in participant 'packs'. However, there will need to be a move to a 'digital first' approach going forward due to the expense of the paper surveys (pointed out by some participants in the survey feedback) as well as for environmental sustainability reasons.

Delivery methods





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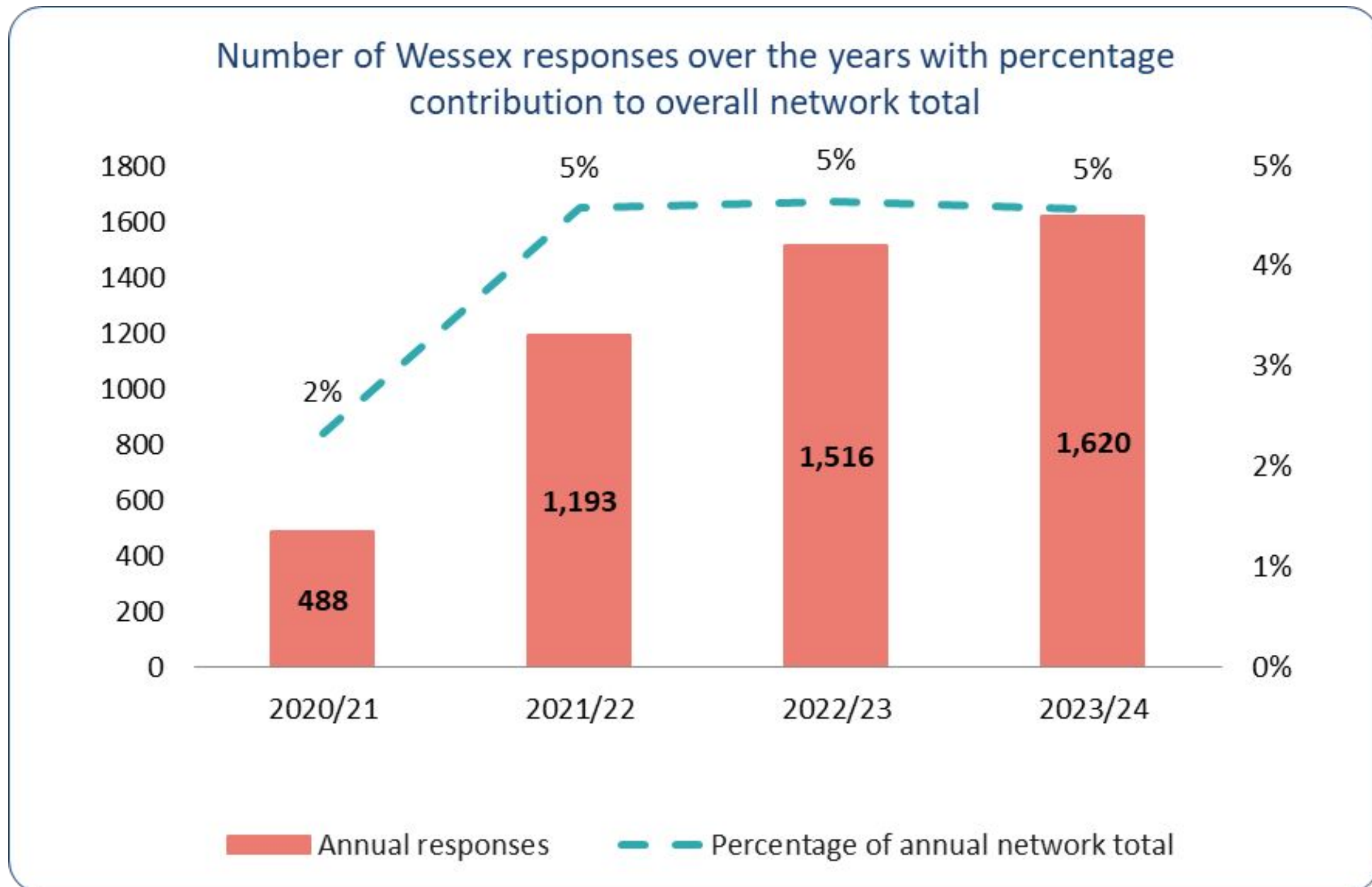
Results



Performance in relation to overall network

The Wessex region has increased its responses to the survey year on year, with 1,620 responses in 2023/24 - exceeding its target of 1,237 responses and being well over three times as many as in 2020/21.

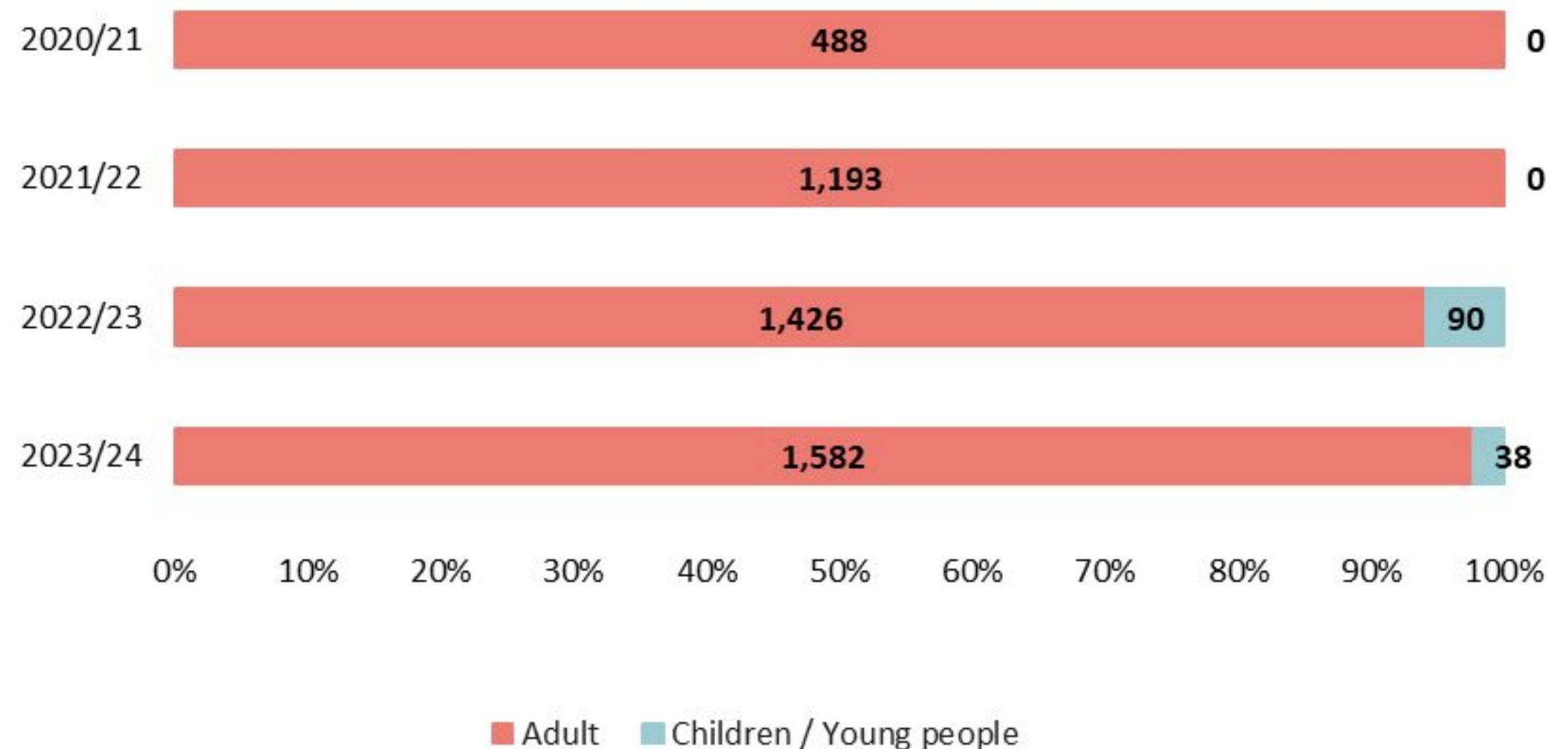
This is likely a result of the move to the survey being delivered throughout the financial year and incorporation into 'business as usual'. However, Wessex's contribution to the overall network's responses has remained stable at 5% for the last three financial years but increased from 2% in 2020/21, likely for the same reason (please see hatched line).



Performance by survey type

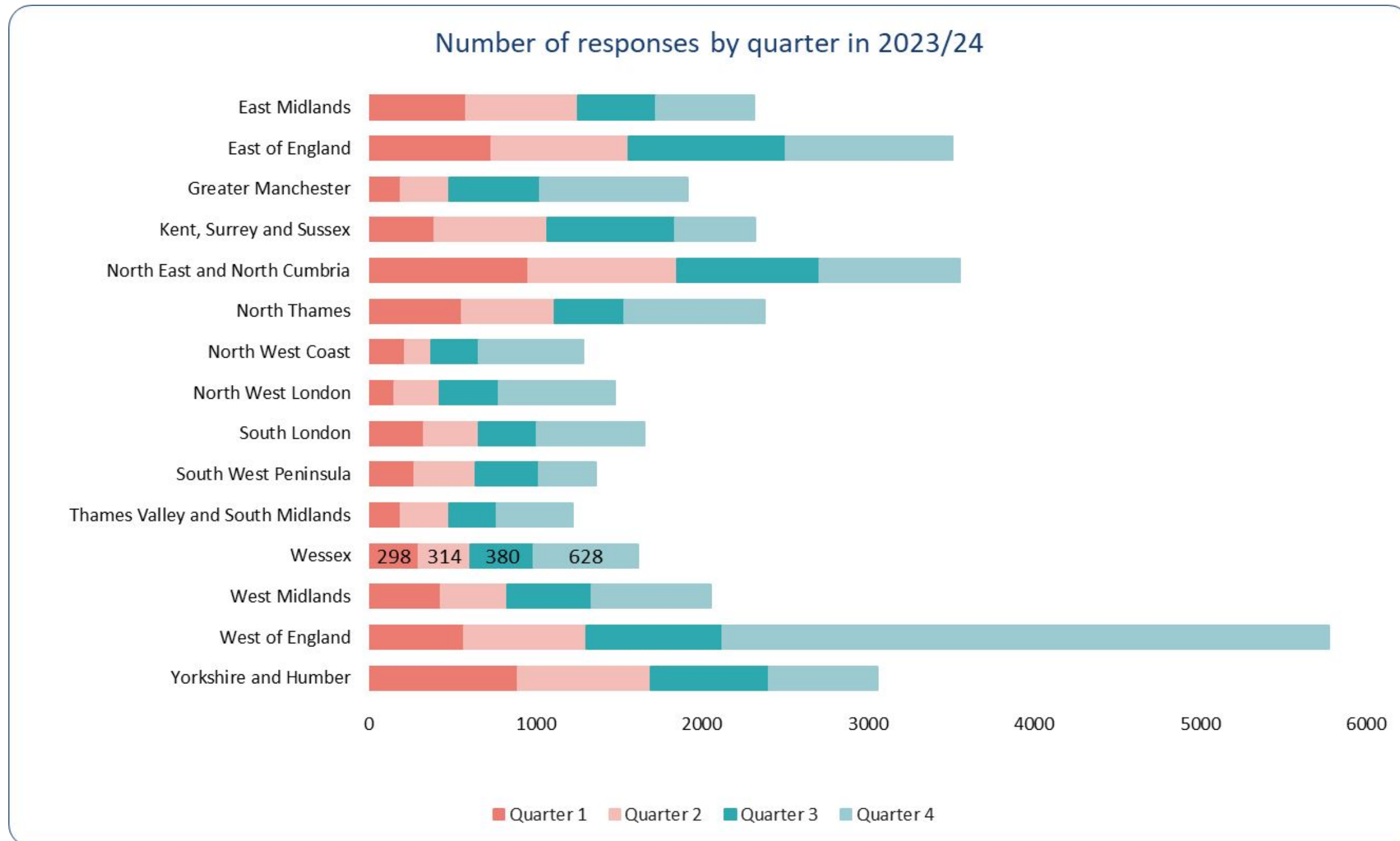
The version of the survey for children/young people was administered in 2022/23 for the first time. The number/percentage of responses from children/young people was higher in 2022/23 than in 2023/24. This was due to the vast majority of responses in 2022/23 being for the HARMONIE study (n=87) - a Wessex led study helping to protect babies from respiratory infections.

Number and percentage of responses from adult participants versus children/young people over the years



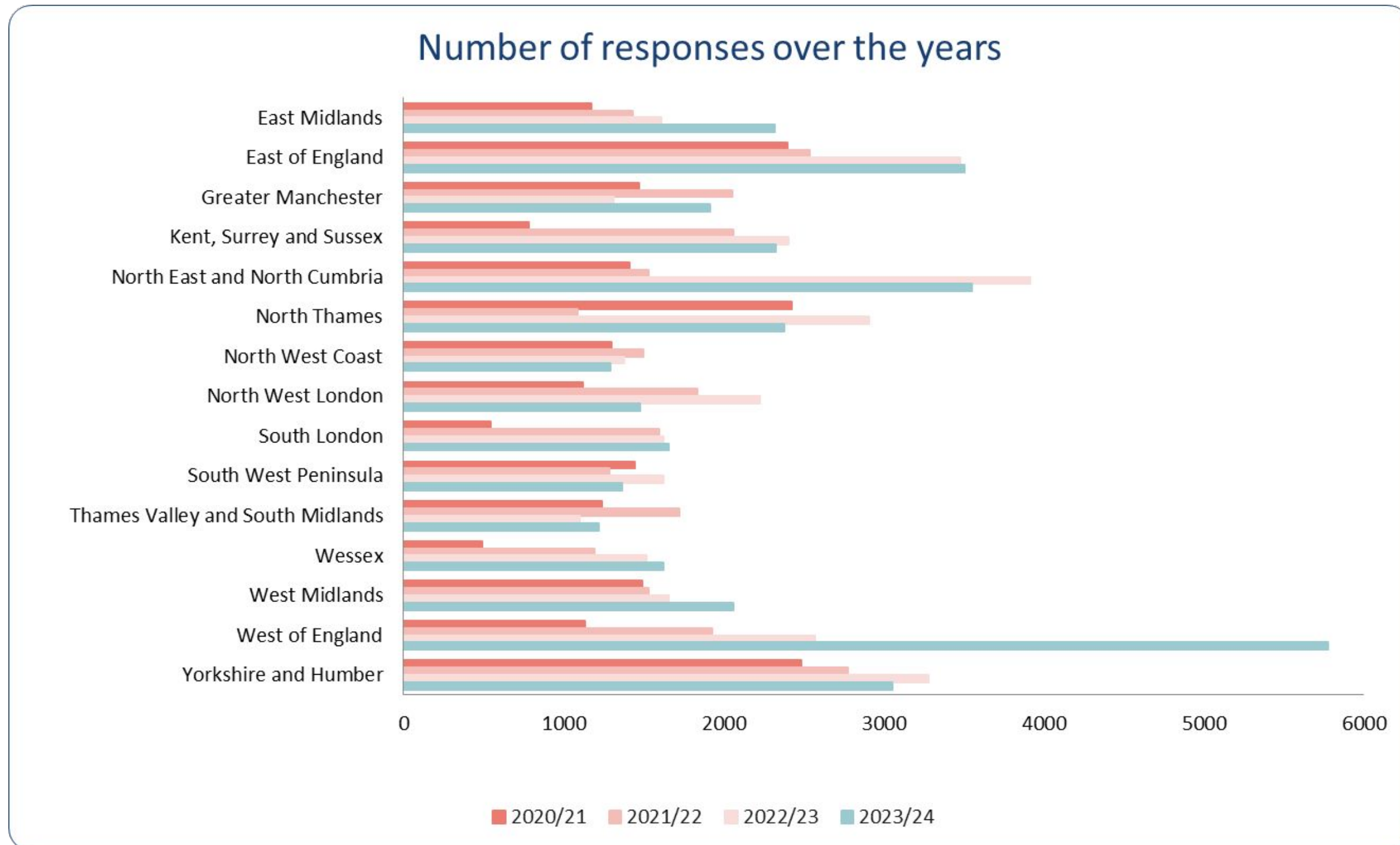
Performance by quarter compared to other networks

Wessex increased its responses to the survey each quarter of the 2023/24 financial year - from 298 between April and June, 314 July to September, 380 October to December, and 628 January to March. This trend by quarter was seen in several other regions. This trend has also been experienced historically and is likely a result of the survey previously having been administered in the last quarter of the financial year. However in 2023/24, the survey became embedded within usual practice/ 'business as usual' so there was a 'slow and steady' approach as desired over a rush to meet target towards the end of the financial year.



Performance benchmarked to other networks by year

Despite increasing its performance year on year, Wessex has not performed as well as other regions e.g. West of England with a similar population size and geography. Whilst regions are not in competition but collaboration, West of England's exceptional number of responses in 2023/24 was due to high recruitment from the [Avon Longitudinal Study of Parents And Children](#), a large-scale birth cohort study.



Adult participants who responded to the survey were overwhelmingly positive about their experience. Whilst this had decreased year on year for most questions from 2020/21 to 2022/23, satisfaction had increased in 2023/24 for all questions compared to 2022/23 and in some cases had even equalled or improved from pandemic levels in 2020/21 (highlighted in green). These positive findings could be because delivery organisations are seeing the importance of the survey and enacting improvement projects as a result. In all but one case (highlighted in yellow), satisfaction was higher for Wessex compared to the network average .

Adult satisfaction by year and compared to overall average for network

Question	Year				Network average for 23/24
	20/21	21/22	22/23	23/24	
1. The information that I received before taking part prepared me for my experience on the study	96%	94%	93%	96%	93%
2. I feel I have been kept updated about this research	92%	80%	75%	82%	72%
3. I know how I will receive the results of this research	93%	78%	68%	76%	77%
4. I know how to contact someone from the research team if I have any questions or concerns	94%	93%	90%	91%	84%
5. I feel research staff have valued my taking part in this research study	94%	91%	91%	96%	92%
6. Research staff have always treated me with courtesy and respect	98%	97%	94%	98%	95%
7. I would consider taking part in research again	97%	89%	92%	94%	91%

Again, satisfaction was overwhelmingly positive on the whole for participants who were children/young people. 2022/23 was the first year that the surveys for children/young people were administered so it is only possible to compare two financial years. Satisfaction had dropped in 2023/24 for all but two questions (highlighted in green). This may be due to the fewer number of responses (n=38). However again, satisfaction was the same or higher than the network average apart from for two questions (questions 2 and 4).

Satisfaction by year and compared to overall average for network for children and young people

Question	Year				Network average for 23/24
	20/21	21/22	22/23	23/24	
1. The information that I received before taking part prepared me for my experience on the study	N/A	N/A	100%	97%	95%
2. I feel I have been kept updated about this research	N/A	N/A	60%	74%	75%
3. I know how I will receive the results of this research	N/A	N/A	69%	82%	82%
4. I know how to contact someone from the research team if I have any questions or concerns	N/A	N/A	96%	84%	86%
5. I feel research staff have valued my taking part in this research study	N/A	N/A	98%	95%	91%
6. Research staff have always treated me with courtesy and respect	N/A	N/A	100%	97%	94%
7. I would consider taking part in research again	N/A	N/A	96%	92%	89%

For conciseness, specialty data are presented rather than study and site data. The highest number (n) of responses were from participants taking part in infection, cancer, and cardiovascular studies. This differs somewhat from research recruitment where the highest recruitment was in cancer, children, and cardiovascular disease. This may be explained by the 'research hubs' continuing to administer the survey for infection studies. However, survey responses were much lower for the children specialty.

Specialties with over 20 responses

Specialties	n
Infection	472
Cancer	333
Cardiovascular disease	103
Mental health	90
Anaesthesia, perioperative medicine, and pain management	79
Respiratory disorders	74
Gastroenterology	62
Hepatology	48

Specialties	n
Dementias and neurodegeneration	46
Reproductive health and childbirth	37
Primary care	35
Children	33
Diabetes	30
Renal disorders	29
Surgery	27
Musculoskeletal disorders	26

Research experience of respondents

The highest percentage of adult participants responding to the survey were in the study for less than three months. This was also the case for children/young people. However, the majority were taking part in their first research study - for both adults and children/young people.

Note: percentages do not all add up to 100% due to rounding.

Question	Adult valid %	Children/ young people valid %
How long have you (has your child) been taking part in this research study?	valid n=1,531	valid n=36
Less than three months	43%	56%
At least three months but less than one year	22%	28%
At least one year but less than three years	21%	14%
Three years or longer	14%	3%
Is this the first research study you have (your child has) taken part in?	valid n=1,563	valid n=37
No	27%	5%
Yes	73%	95%

Characteristics of respondents

The majority of adult respondents to the survey were the person taking part in the research. However, the parent/carer responded to the survey in the majority of cases for children/young people. This was because the majority of children/young people were aged 0-6 years old.

Question	Adult valid %	Children/ young people valid %
Who completed this survey?	valid n=1,547	valid n=37
The person taking part in the research	95%	-
The person taking part in the research with help from someone else	3%	-
Someone else on behalf of the person taking part in the research	2%	-
The child/young person	-	16%
The parent or carer	-	76%
Both the child/young person and the parent or carer together	-	8%

Sex and gender of respondents

There was a roughly equal split of respondents by the sex they were registered with at birth. Only six respondents reported as not having the same gender they were registered with at birth (0.4%).

Note: children/young people were not asked this.

Question	Adult valid %
What sex were you registered at birth?	valid n=1,561
Female	53.3%
Male	46.7%
Is your gender the same as you were registered at birth?	valid n=1,546
No	00.4%
Yes	99.6%

Age of respondents

The most common age categories for respondents were 60-69 years (25.6%) and 70-79 years (25.4%).

These were also the largest age groups of research participants in Wessex.

Note: children/young people were not asked this but this can be inferred from the survey version completed. Percentages do not add up to 100% due to rounding.

Age group/survey version	Valid % (valid n=1,593)	Age group/survey version	Valid % (valid n=1,593)
0-6 year survey	1.6%	50-59 years	15.4%
7-11 year survey	0.4%	60-69 years	25.6%
12-15 year survey	0.3%	70-79 years	25.4%
16-19 years	0.3%	80-89 years	9.0%
20-29 years	5.9%	90-99 years	0.4%
30-39 years	7.2%	100-109 years	0.1%
40-49 years	8.2%		

Ethnicity of respondents

The vast majority of respondents were white. However, it is likely that this lack of diversity reflects the research participants rather than the population, although these data are not collected to verify.

Note: children/young people were not asked this.

Ethnic group	Adult valid % (valid n=1,553)
Asian/Asian British	1.5%
Black/African/Caribbean/Black British	0.4%
Mixed/multiple ethnic groups	0.8%
White	97.0%
Other ethnic groups	0.3%

Themes from open ended responses

Six themes were identified from the open-ended responses to the survey:

Staff attitudes

Communication

Motivation

Practicalities

Recognition

Learning



Staff attitudes theme

Staff attitudes was the largest theme. Positive feedback about staff was received almost universally. Participants reported that staff treated them with respect and made them feel valued. However, this was likely prompted by the survey design having earlier questions on these topics.

“The research nurses and my consultant were absolutely fantastic. They treated me with such respect and it didn't matter how many times I contacted them to ask a question or if I was at all worried about anything they put me totally at ease. It was an honour to take part in the trial, I couldn't of got through my medical condition without them. 100% praise for them.”

“The team! Honestly felt so valued, welcomed and appreciated. I personally wasn't scared but completely can see that if someone was scared, the team would have put their mind at rest and helped them relax. I felt that I could raise any questions or concerns and not be thought of negatively. In all honesty, the team have made this whole experience fantastic and even enjoyable.”

Communication theme



“More information about the context of the research. I've had nothing about results and I don't know whether it is too early or whether I will receive information.”

“It would be really good to know more about the research study process, timings and - ultimately - plan for sharing outcomes + findings”



As in 2022/23, communication was another large theme. Whilst participants generally felt informed at the beginning, they would have liked to have received details of the findings in particular.

Motivation theme

Participants reported the reasons they took part in research. These motivations were mainly around helping others and giving back to the NHS but also included receiving better care for themselves etc.



“More targeted treatment for my risk level; feeling that I am under greater care (than I would be under standard NHS treatment); feeling that I'm contributing to improve treatment for other patients in future; excellent level of overall care.”

“Knowing I'm helping others and hopefully saving NHS time and money, maybe even lives.”



Practicalities theme

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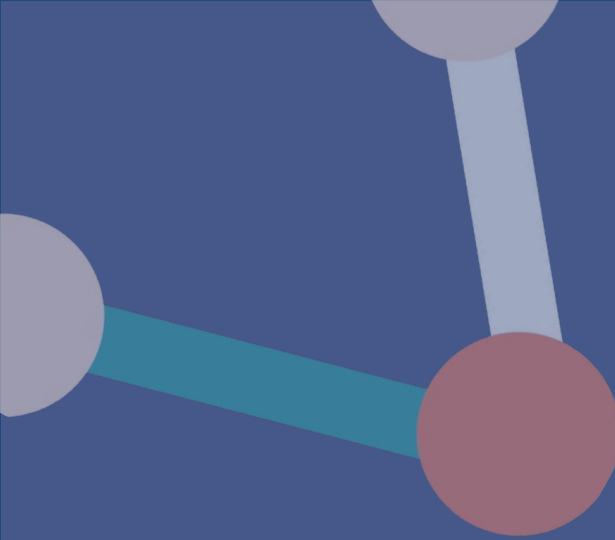
“Maybe better signposting so I am not late because I got a bit confused about where to go.”

“When taking bloods, it took a couple of attempts so was quite uncomfortable. It seemed to be due to the inexperience of the staff members.”

”

Participants would have preferred closer venues and better parking/signposting. There also seemed to be several cases where blood taking was problematic.

Recognition theme



Whilst a smaller theme, some participants acknowledged that they would have appreciated expenses/payment (and quicker payment if paid). A simple offer of refreshments would also have made a difference to participant experience.

“It would have been good to have some compensation for the time taken to complete the survey. Cash/voucher!!”

“Having travelled 22 miles to take part a cup of tea would have been very welcome.”

Note: delivery organisations aim to reimburse participants in line with the study protocol and reimbursement schedule and have listened to feedback and highlighted to participants that refreshments were available to them.

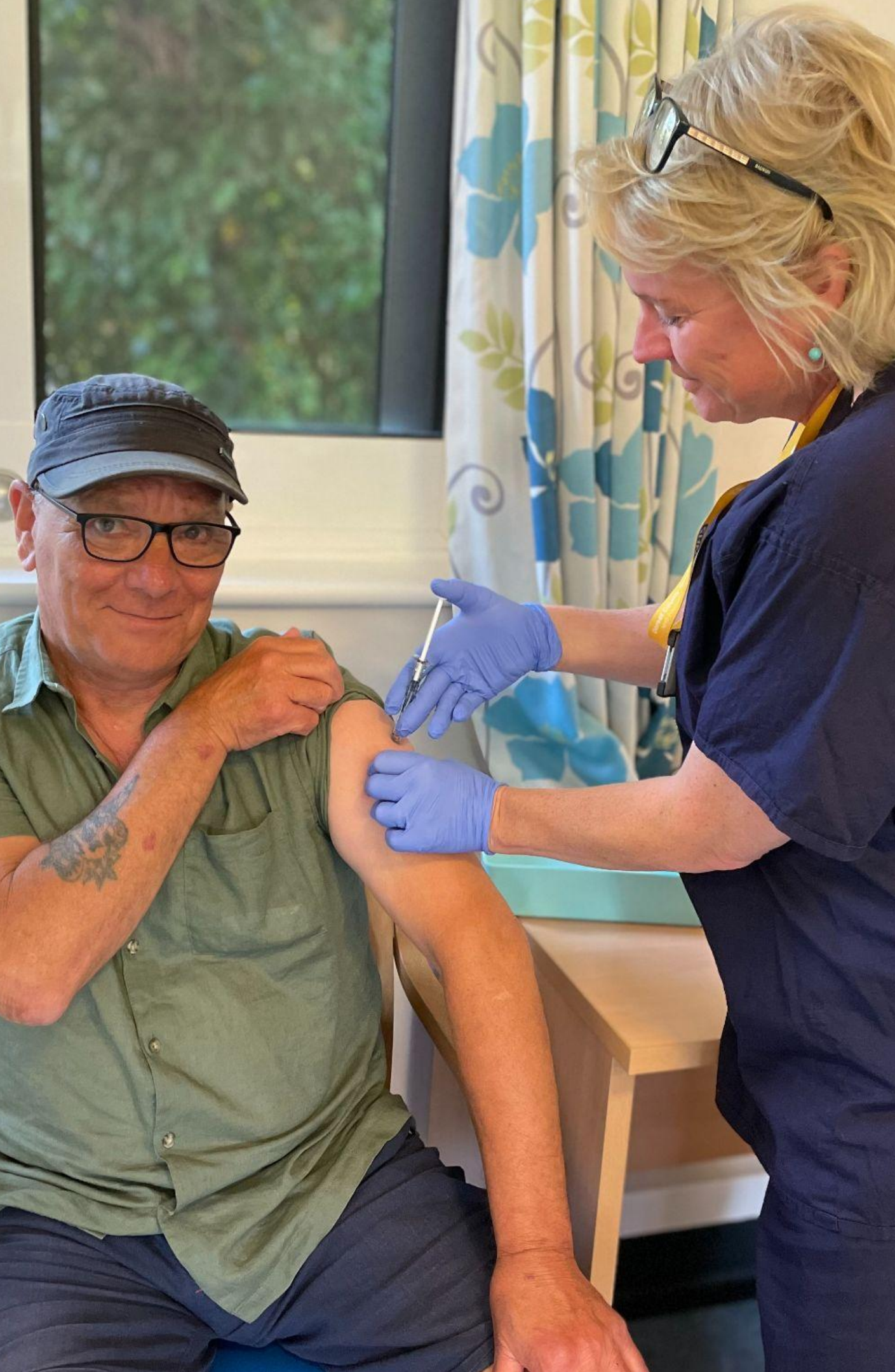
Learning theme

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"Good to know some information that I was not aware of previously"

Albeit the smallest theme, participants found taking part in research an important learning experience.

"The fact that not only was the research engaging and insightful but it probed my mental capabilities and made me think about how I can cope with my condition and enhance my productivity in my mental diagnosis."



4

Improvements implemented



Participant experience

A number of initiatives were implemented to address the 2022/23 findings:

1. Letters with a collation of non-identifiable open-ended responses from the 2022/23 findings were sent to the Chief Investigators of two commercial studies given they received feedback specific to the study design/data collection. This was to ensure they were aware of the challenges experienced so that they could be addressed and learnings taken forward in future study designs in order to improve the experience for participants.
2. Delivery staff were asking at site initiation visits how participants would receive the study results so this could be cascaded to participants to address an ongoing finding from the survey.
3. Related, delivery staff implemented an email template in September 2023 for the Determining the Effectiveness of a Feno-guided asthma INtervEntion in primary care study when the first participants reached their twelve month follow-up - it reminded participants how they would find out about study results/their future clinical care but also highlighted the survey.
4. A particular good news story is that the survey findings resulted in more frequent contact with participants e.g. the Treat to Target in Gout study has moved from annual contacts to bimonthly contact as a result of feedback.

However, as data were provided quarterly in 2023/24 to delivery organisations, there was the opportunity to enact timely change in response to feedback.



Reach and response

A number of **additional** strategies were also implemented during 2023/24 in order to increase the reach of the survey and hence the number of responses which resulted in the highest number of responses to date e.g.:

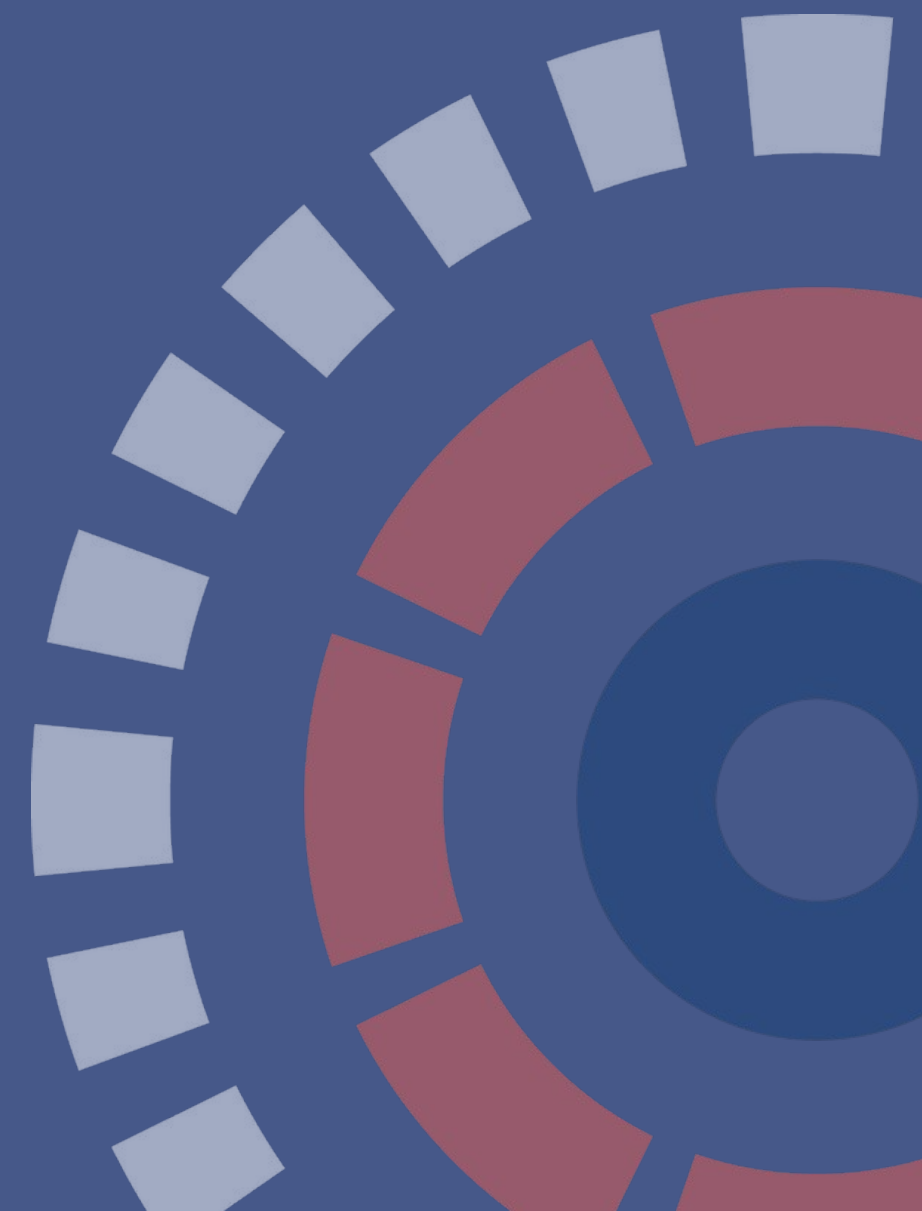
1. An animation was rolled out to increase engagement with the survey which was reportedly often played on clinic days etc:
<https://www.youtube.com/watch?v=GpUP6FjX6Qk>
 2. Primary care was targeted as having untapped potential e.g. through emails, continued provision of text message/email templates, and an agenda item at virtual practice visits.
 3. The survey was embedded into usual practice/‘business as usual’ e.g. incorporated into standard operating procedures, discussed during study set-up and tracked on the local portfolio management system, Working Groups were created to embed the survey, and new starters were trained up in delivery organisations to bring about culture change.
 4. A new local dashboard was created based on North East and North Cumbria’s version and it was clear that delivery organisations were accessing for real-time feedback.
 5. Related to technology, some delivery organisations were having success with the use of electronic tablets with cleaning systems in place whilst others experienced challenges due to internet connectivity etc. Laptops and mobiles were often used for this reason to encourage completion of the survey ‘there and then’.
 6. Practice and learnings continued to be shared via the Working Group which was often rolled-out wider e.g. ‘you said, we did’ notice boards and Quick Response codes in waiting rooms and on laminated cards for lanyards to act as a handy aid memoire etc.
- Nationally, Wessex would like to see the survey included in schedules of events and included in the criteria to add to the national portfolio of studies etc.





5

Looking forward



Looking forward

A culture of continuous improvement means there will be ongoing initiatives to increase both the reach/response of the survey as well as participant experience e.g.:

1. An increased focus on obtaining feedback from children/young people, perhaps introducing a target in line with research recruitment.
2. A 'digital first' approach will be taken i.e. encouraging online completion in the first instance due to the cost of the paper option and for environmental sustainability reasons. However, it is important that a paper option is still offered in order to not digitally exclude.
3. Related, it is hoped that South Central Regional Research Delivery Network will be an early adopter of any national digital platform solution.
4. Wessex has been piloting uploading data monthly as opposed to quarterly so it is hoped that the national dashboard will also be updated monthly and become more user-friendly potentially negating the need for the local dashboard and thereby providing national consistency.

However, anticipate there may be some upcoming logistical challenges to work through given the change of geography associated with the transition to Regional Research Delivery Networks and the complexity around merging networks for the South Central Regional Research Delivery Network. Of importance, is learning from all across the new geography (and nationally) to improve participant experience.



Thank you

Thank you to all the Participant in Research Experience Survey respondents for taking the time to complete the survey to help improve the experience of research participants in the future. Thank you also to all the delivery organisations and those who have inputted into this report, particularly Alexandra Babbage, Jazz Bartholomew, and Carolyn Chance.

