

Online survey insight report: Involving children, young people, and families in our research

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Date of activity: August – September 2021

Report originally published: 20 October 2021

Updated: 01 February 2022

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SUGGESTED CITATION:

Halle Johnson, Aubrey Cunnington, Maria Piggan. Online Survey Insight Report: Involving children, young people, and families in our research. NIHR Imperial Biomedical Research Centre (20-10-2021), doi: [10.25561/94137](https://doi.org/10.25561/94137)



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Background

The National Institute for Health Research (NIHR) currently funds 20 Biomedical Research Centres (BRCs) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College, London and Imperial College Healthcare NHS Trust and is currently funded until 2022. It has 12 research themes, 4 of which are cross cutting.

As part of the reapplication for the BRC competition run by the NIHR, a public involvement online survey was conducted to inform research relating to children, young people and family research was conducted. The survey was facilitated by the Patient Experience Research Centre (PERC), a core facility of the current Imperial BRC and aimed to explore parent and family caregiver views on child health research in North West London.

Approach and purpose

Public involvement was considered a crucial component of the development of this proposed theme's programme of research. Through the online survey we particularly wanted to understand the views of parents and family caregivers in the North West London community on child health and paediatric research, including views on how this research should be approached and the areas of research of greatest importance to them. The survey particularly targeted parents and caregivers of children aged 12 or under as this was the age group most relevant to the research being proposed in the BRC reapplication.

Efforts were made to disseminate the survey to those who had not previously taken part in public involvement in research activities at Imperial College, London, or at all. The importance of capturing these views was to increase the representativeness of those individuals whose voices are not usually heard in public involvement in research which is a continuing area of focus.

Survey format

The survey was hosted on Qualtrics, an online survey platform. The survey included 10 questions, which asked respondents to provide their views on research priorities for this area of research as well as sharing their views on children's participation in research. The survey also captured the relevant experience of respondents and demographics (age, gender, ethnicity, area of residence).

Survey dissemination

The survey was disseminated online between August – September 2021 through the following routes:

- By the North West London Clinical Commissioning Group (CCG) Engagement Manager posting it on the online "Nextdoor" platform
- Through Imperial College Healthcare NHS Trust (through clinical colleagues and Connecting Care for Children)
- To existing North West London and PERC networks ("Voice" NW London group, recent PERC mailing list signups, through the PERC team)
- To HealthWatch CWL – including Young HealthWatch
- Through the North West London Care Information Exchange Homepage
- By asking members of the Imperial BRC Public Advisory Panel to disseminate it to relevant individuals across their wider community
- Through Twitter

Key Insight Summary

The responses to the survey represented 74 children from 51 respondents. Respondents were asked to share their views on child health and paediatric research by ranking research areas which were perceived to be most important for research to pursue as well as their opinions on possible research methods and their own child/children being invited to take part in research.

In regard to overall research priorities, respondents ranked both **the most common illnesses which cause children to need to go to repeated GP appointments or hospital outpatient appointments over long periods of time** and **rare illnesses which cause a sudden life-threatening problem or cause children to need many hospitalisations** as the most important areas for research to pursue.

When asked about childhood infections, respondents ranked **better ways to find the cause when a child has a suspected infection** as the highest priority, followed by **more research into developing new vaccines to prevent common childhood infections**. For research aiming to develop new tests to identify suspected infection within children, respondents felt that an **accurate test (that will almost always be right) which may take longer**, was more important than a **quick test with less accuracy**.

Responding to the Child Health & Paediatric theme's proposed research areas, respondents deemed that any **research into early brain injury or brain damage** should prioritise **developing new, better treatments for brain injury, to reduce the possibility for later disability** and that research into **developing new tests for childhood wheeze** should be prioritise **identifying the cause of the problem and finding the best treatment**.

Respondents' rankings identified that following a period of serious illness for a child which required a long hospital stay, research should be focused on **preventing it from happening again**, followed by **understanding why it happened**. Genetic testing to identify a possible genetic cause of a serious illness was considered appropriate with the majority of respondents wanting to know any **relevant results from genetic testing related to the child's illness as well as any other results which may be significant (e.g. to other family members')**

Respondents were also invited to share their views on the use of routine data for child health research. When data was de-identified, respondents felt an opt-out process **for people to be able to say if they don't want their data to be used in this way for research** was most important, in comparison to data where individual children may be identified, in which an opt-in process with **people specifically being asked to agree for their data to be used in this way for each research project** was preferred. Additionally, respondents were less in favour of **'data being easily available for research' when** there was a chance that individual children may be identified.

Lastly, respondents were asked to provide their views on whether they would be happy for their child to hear about opportunities to take part in research from a relevant health professional while at hospital. Overall, respondents were happy for this to happen, but i would like **to know more details about the research**.

How the insights were used

The insight report summarising the key findings from the online survey was made available to relevant researchers and the BRC Executive in order to shape the BRC application. A full report on all public involvement activities undertaken in preparation for the BRC application can be found [here](#).

Those who completed the survey were also given the opportunity to sign up for future public involvement, engagement, and participation opportunities.

We would like to thank all those members of the public who gave their time and thoughtful insights through these activities, and the researchers who engaged enthusiastically in the process.

Survey findings

Summary of respondents

A total of 50 responses to the survey were received (see Appendix 1 for demographics of respondents), the majority of which (80.4%) identified as parents of a child/children, and 17.6% identified as a caregiver (e.g., grandparent) see Table 1.

Table 1. Respondent’s experience

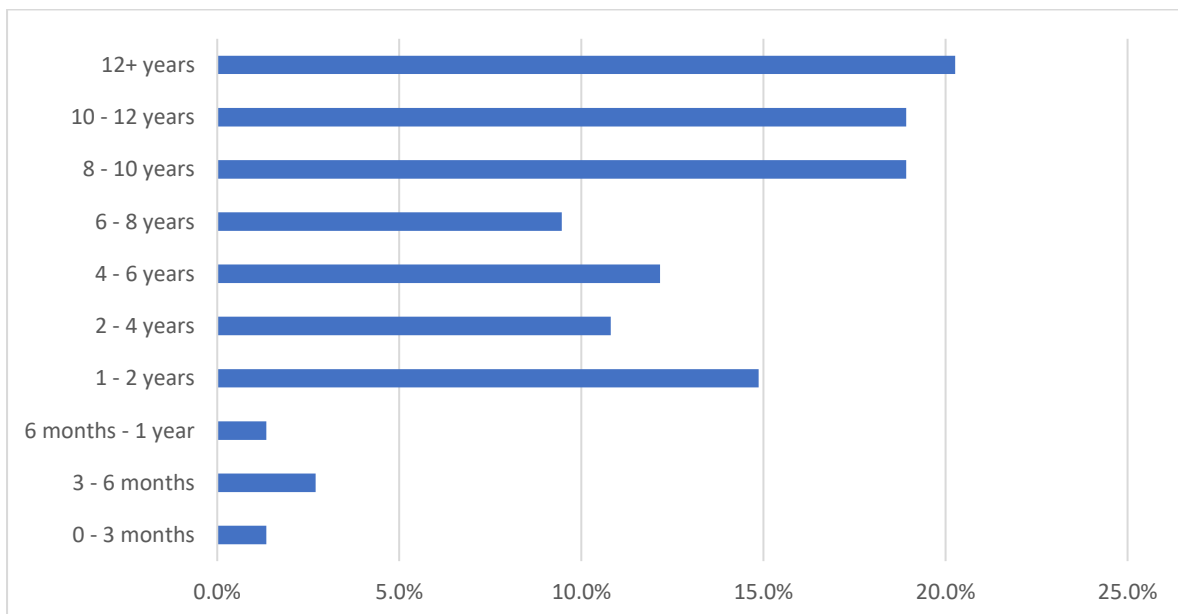
Experience	N	%
I am a parent of a child/children,	41	80.4%
I am a caregiver (e.g., grand parent, aunt/uncle etc.),	9	17.6%
I am a member of the public interested in child health research	2	3.9%
Other	1	2.0%
Prefer not to say	0	0.0%

*Note, some respondents indicated that they represented multiple experience categories

As part of the survey, respondents were also asked to indicate the age of the child/children in which they were responding on behalf of, which is outlined in Figure 1.

As some respondents had multiple children, the survey responses represent a total of 74 children, aged from 0 to over 12 years. The largest age group was the 12+ years of age (20.3%) with the smallest represented age groups being the ‘6 – months to 1 year’ and ‘0 – 3 months’ (1.4%).

Figure 1. Age distribution of children on which survey responses were made on behalf of



Research priorities

The following section outlines the frequency of rankings of the first seven questions within the survey, which focused on understanding the research priorities of parents and caregivers within

child health. For each of the questions respondents were asked to rank responses from 1 = the most important to 4 = least important for research to address.

What is the most important area for us to research?

Across respondents, **‘the most common illnesses which cause children to need to go to repeated GP appointments or hospital outpatient appointments over long periods of time’** and **‘rare illnesses which cause a sudden life-threatening problem or cause children to need many hospitalisations’** were equally prioritised as the most important area for research to pursue (see Table 2).

Table 2. Frequency of rankings of ‘What is the most important area for us to research?’

Frequency of scores:	The most common illnesses which cause children to be brought to hospital Emergency Departments	The most common illnesses which cause children to need to go to repeated GP appointments or hospital outpatient appointments over long periods of time	Rare illnesses which cause a sudden life-threatening problem or cause children to need many hospital admissions.	Rare illnesses which cause children to need extra care or support at home or school over a long period of time
1 (most important)	11	17	17	6
2	12	10	9	17
3	12	8	15	13
4	16	15	10	14
No response	0	0	0	1

Research into childhood infection

Two questions asked respondents to share their views on research priorities relating to childhood infections. 22 respondents felt that **‘better ways to find the cause when we think a child has an infection’** was the highest priority area for research to pursue followed by 15 respondents choosing **‘developing new vaccines to prevent common childhood infections’** (see Table 3).

When asked about developing new tests to identify suspected infection within children, respondents (n=23) felt that an **‘accurate test (that will almost always be right), even if it takes 24 hours to get the results’** would be the most important (see Table 4) .

Table 3. Rankings of ‘What are the most important things we should be researching to tackle infections in children?’

Frequency of scores:	Better ways to find the cause when we think a child has an infection	Finding out which children will benefit most from the treatments we already have (like antibiotics)	Discovering new treatments for infections	Developing new vaccines to prevent common childhood infections
1 (most important)	22	5	10	15
2	12	11	21	5
3	7	19	13	10
4	10	16	7	21
No response	0	0	0	0

Table 4. Rankings of 'If we were developing a new test for children with a suspected infection, what would be most important for you?'

Frequency of scores:	An accurate test. Even if it takes 24 hours to get the results, it will almost always be right	A quick test. Even if it is a little less accurate, the result could be available in under 1 hour	A simple test. A single test that might work on saliva or a drop of blood from a child's finger	A 'prediction' test which tells the doctor whether a child's illness will get better or worse
1 (most important)	23	11	11	6
2	11	8	22	11
3	13	14	11	13
4	4	18	7	21
No response	0	0	0	0

Research into early brain injury

Sometimes babies are not very well when they are born. One cause of this can be brain injury (sometimes called "brain damage") at birth. Respondents were asked to provide their views on what sort of research into this problem would be the most important to pursue. The majority of respondents (n=29) considered, '**developing new, better treatments for brain injury, to reduce the possibility of later disability**' to be most important (see Table 5).

Table 5. Rankings of 'What sort of research into early brain damage or injury do you think is most important to you?'

Frequency of scores:	Developing tests to find the reason for the brain injury	Developing new, better treatments for brain injury, to reduce the possibility of later disability	Developing better ways to predict which babies will have a disability after a brain injury.
1 (most important)	12	29	9
2	19	13	16
3	18	6	24
No response	1	2	1

Research into childhood wheeze

Respondents were asked to consider what would be most important for them if a new test for young children (0-5 years old) who had "wheeze" (a continuous whistling sound in their airways) or breathing difficulties was developed. Respondents ranked a test which can tell the '**cause of the problem**' and '**the best treatment**' as most important for this area (see Table 6).

Table 6. Rankings of 'If we were developing a new test for young children who had "wheeze" or breathing difficulties, what would be most important to you?'

Frequency of scores:	A test that can tell us the cause of the problem	A test that can tell us which is the best treatment	A test that can tell us whether the child's illness will get better or worse	A test that can tell whether the problem is likely to occur again
1 (most important)	28	24	1	0
2	14	20	12	5
3	5	3	22	18
4	4	4	16	28
No response	0	0	0	0

Research into serious illness

Respondents were asked to consider the scenario of their child/children recovering after a serious illness which required a long hospital stay and to share what research would be most important to them following such an incident. Respondents ranked **'preventing it from happening again, even if we don't know why it happened'** as the most important priority (see Table 7).

Respondents were also asked to consider whether following serious illness they would consider genetic testing to find a possible genetic cause for the illness. All respondents felt that the results of genetic testing would be important, and the majority of respondents (74.5%) highlighted that they would want to know as much information as possible including **'relevant results related to the child's illness as well as any other results which may be significant (e.g. to other family members'** (see Table 8).

Table 7. Rankings of 'If your child had been in hospital for a long time with a severe illness, but has now recovered, which of the things listed below would be most important to you?'

Frequency of scores:	Prevent it from happening again, even if we don't know why it happened.	Understand why it happened, even if that required the child taking part in research studies	Find out if other members of the family are at risk of similar illness	Getting back to normal life and putting the illness out of your mind
1 (most important)	27	15	5	3
2	11	19	19	2
3	10	11	18	9
4	2	6	9	37
No response	1	0	0	0

Table 8. Responses to ‘If your child had been in hospital for a long time with a severe illness and was offered genetic testing (to find changes in genes that can cause health problems) to understand if there is a genetic cause for the illness, would you :’

	n	%
Want to know relevant results related to your child's illness as well as any other results which might be significant (e.g. to other family members)	38	74.5%
Want to know the results even if they won't change your child's treatment	10	19.6%
Want to know the results only if they change your child's treatment	2	3.9%
Not want to know the results of the genetic testing	0	0.0%
No response	1	2.0%

Views on child health research

The following three questions asked respondents to share their views on how child health and paediatric research should be conducted, including their views on use of routine data (e.g. GP or hospital records) for research and their views on their child/children participating in health research.

Use of routine data

When asked if researchers should be allowed to use anonymised/de-identified data (i.e., data in which it would be impossible to identify individual children) from large numbers of children which is collected when children attend a GP or hospital appointment, the majority of respondents felt this should be allowed. However, 39.2% respondents felt that **‘people should be able to say if they don't want their data to be used in this way for research’**, and 23.5% felt that **‘people should be asked to agree for their data to be used in this way for each research project’**. 29.4% of respondents were happy for such data to be **‘easily available’** for researchers. In contrast, 3.9% of respondents felt that this ‘data was not collected for the purpose of research, and therefore should not be made available to researchers’ (see Table 9).

Respondents were also asked to consider a further scenario in which the use of routinely collected data (e.g., electronic health record data) could lead to individual children being identified, with the caveat that it would only be done if essential for the research and would be kept confidential by the research team. Again, most respondents felt that this type of data should be made available for research purposes, however nearly half of respondents (49.0%) felt that people **‘should be specifically asked to agree for their data to be used in this way for each research project’** and 25.5% felt that people **‘should be able to say if they don't want their data to be used in this way for research’**. 13.7% of respondents felt that this data should be **‘easily available’** for researchers, whereas 7.8% felt that this data **‘should not be made available to researchers’** at all (see Table 10).

Table 9. Responses to ‘Do you think researchers should be allowed to use data from large numbers of children which is collected when children attend a GP or hospital appointment?’

	n	%
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Yes, this data should be made easily available for research to improve the health of children, but people should be able to say if they don't want their data to be used in this way for research	20	39.2%
Yes, this data should be made easily available for research to improve the health of children	15	29.4%
Yes, but people should be specifically asked to agree for their data to be used in this way for each research project	12	23.5%
No, this data was not collected for the purpose of research and should not be made available to researchers	2	3.9%
Other	2	3.9%
No response	0	0.0%
Other free text:		
Every participant should be asked to opt in or out.		

Table 10. Responses to 'Do you think researchers should be allowed to use routinely collected Electronic Health Record data in which individual children may be able to be identified?'

	n	%
Yes, but people should be specifically asked to agree for their data to be used in this way for each research project	25	49.0%
Yes, this data should be made easily available for research to improve the health of children, but people should be able to say if they don't want their data to be used in this way for research	13	25.5%
Yes, this data should be made easily available for research to improve the health of children	7	13.7%
No, this data was not collected for the purpose of research and should not be made available to researchers	4	7.8%
Other	1	2.0%
No response	0	0.0%
Other free text:		
Yes but only if the data can be kept absolutely for the eyes of the researchers and relevant medical personnel and the patient/parent		

Participating in research

Lastly, respondents were asked to provide their views on whether they would be happy for their child to hear about opportunities to take part in research from a relevant health professional while at hospital. 56.9% of respondents were '**OK with this but would want to know more details**' and 13.7% were '**OK with this but would probably not want their child/children to take part**'. 25.5% of respondents were 'happy and keen for their child/children to participate, because research is important to help other children', whereas 3.9% noted that they would be '**unhappy if asked about this whilst at hospital/during the hospital visit**'.

Table 11. Responses to ‘If you brought your child to hospital, how would you feel if when you were talking to a healthcare professional whilst you were there and you were asked “Would you like to hear about opportunities for your child to take part in research?”’

	n	%
I would be OK with this, but would want to know more details	29	56.9%
I would be happy and keen for my child to participate, because research is important to help other children	13	25.5%
I would be OK with this, but would probably not want my child to take part	7	13.7%
I would be unhappy if I was asked this whilst at hospital/during the hospital visit	2	3.9%
Other	0	0.0%
No response	0	0.0%

Appendix 1: Demographics of Respondents

Age (in years)		
Mean (range)	45 (30 - 66)	
Age groups (in years)		
18 – 30	1	2.0%
31 – 40	14	27.5%
41 – 50	18	35.3%
51 – 60	8	15.7%
61 – 70	3	5.9%
70+	0	0.0%
Prefer not to say	3	5.9%
Not provided	4	7.8%
Gender		
Female	45	88.2%
Male	4	7.8%
Gender variant/non-binary	0	0.0%
Other	0	0.0%
Prefer not to say	1	2.0%
Not provided	1	2.0%
Ethnic group		
White		
English/Welsh/Scottish/Northern Irish/British	18	35.3%
Irish	0	0.0%
Gypsy or Irish Traveller	0	0.0%
Other White background	10	19.6%
Mixed/Multiple Ethnicity		
White and Black African	0	0.0%
White and Black Caribbean	0	0.0%
White and Asian	1	2.0%
Other Mixed/Multiple background	3	5.9%
Asian/Asian British		
Indian	1	2.0%
Pakistani	1	2.0%
Bangladeshi	0	0.0%
Chinese	1	2.0%
Other Asian background	1	2.0%
Black/African/Caribbean/Black British		
African	1	2.0%
Caribbean	3	5.9%
Other Black/African/Caribbean background	1	2.0%
Other ethnic group		
Arab	1	2.0%
Any other ethnic group	3	5.9%
Prefer not to say	4	7.8%
Not provided	1	2.0%

Location		
Harrow	5	9.8%
North West London (<i>postcode includes Golders Green, Willesden, The Hyde, St John's Wood, Kilburn, Kentish Town, Hendon, Hampstead, Cricklewood</i>)	6	11.8%
Twickenham	3	5.9%
West London (postcode includes Shepherds Bush, West Ealing, West Kensington, Hammersmith and Fulham, Hounslow)	19	37.3%
Uxbridge	6	11.8%
Other	4	7.8%
Not provided	8	15.7%