

Report on Involving Children and Young People in Research

Summary

This report presents the findings from both a mapping exercise and survey regarding the process of involving children and young people in research as advisers as opposed to research participants. Both these activities were undertaken by INVOLVE Coordinating Centre staff with guidance and advice from the Children and Young People's Working Group which consists of young people, public involvement leads and researchers.

The mapping exercise demonstrated that there is a diverse range of active Children and Young People's groups across England, and several parent groups. Key findings from the survey reveal some fundamental barriers that make meaningful involvement difficult: time, money and gatekeepers.

This report additionally outlines the benefits of involvement. It is apparent that there is a need for more education and training regarding involving children and young people in research, especially in relation to ethical issues and involving those who are vulnerable. INVOLVE will use this report as a catalyst for future work.

Introduction

“Going the Extra Mile” (2015) <https://www.nihr.ac.uk/patients-and-public/documents/Going-the-Extra-Mile.pdf> provided the blueprint for the future of public involvement and sets out ambitious but essential challenges to both the public and those who work in this field.

One of the recommendations states that: “A diverse and inclusive public involvement community is essential if research is relevant to population needs and provides better health outcomes for all.”

It is important to address gaps in the representation of children and young people, and the confidence of the system in involving them.

Building on this recommendation INVOLVE formed a working group to focus on involving children and young people in research as advisers.

While the Working Group knew of various initiatives involving children and young people in research across England, there is no central repository or understanding of what groups exist, and where, and for what function. It was decided to undertake a national mapping exercise and survey to address this.

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Acknowledgements

The authors would like to thank the children and young people working group members for their time and input into this project: Sophie Ainsworth; Megan Barlow-Pay; Mike Bell; Katrina Brooks; Sam Goold; Sagar Jilka; Deidre Leyden; Jenny Preston; Simon Stones.

When referencing this document please use the following:

Sonpal, K., Walker, E., Swallow, V., Brady, L-M., Stones, S. (2019) Report on involving children and young people in research. Southampton: INVOLVE

1. Mapping Exercise

The starting point of this work was to map the children and young people's groups which were involved in a consultative, collaborative, or co-production function (or mix of all three), in a research context, that currently exist in England. It was acknowledged by the working group that it would likely be impossible to capture all the groups, especially as many are only active for the duration of a study. However, it was felt that it was important to undertake this exercise given that it has not been attempted before in the UK.

Anecdotal experience of people included in the working group was that involvement of children and young people as research advisers is on the increase, and this was an identified priority of the Going the Extra Mile report.

Method

The mapping exercise began with an email, which was sent out by individual members of the working group, to contacts they had working in patient and public involvement of children and young people in research. As the working group consisted of a mix of those both in and outside of the NIHR, including young people, it was anticipated that this would ensure that the questions were widely circulated.

The following questions were asked:

- What is the name of the group?
- Where is the group based?
- Who is the main point of contact?
- Is the group general or condition specific?

Respondents were also invited to supply any other relevant information including group websites.

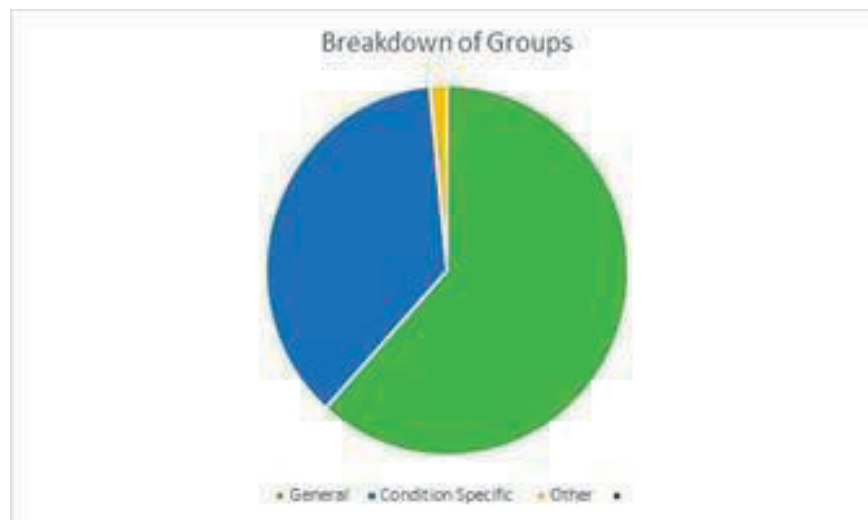
Following this initial email push the mapping exercise was also promoted via Twitter.




Results

As a result of this exercise we learned of 35 groups from around England of which:
20 were generic groups (including 2 parent and carer groups);
12 were condition specific; and
3 fell under the category of 'other'.

Within this category were:
1 group that focused on social care;
1 on public health
the remaining was a participatory action research group.



Graph showing the different types of CYP groups in England.



These involvement groups covered many different conditions from cardiovascular disease to Cystic Fibrosis, as well as several mental health groups.

Table showing breakdown of condition specific groups that responded to survey

Condition
Mental Health (including depression and anxiety)
Cardiovascular Disease
Cystic Fibrosis
Rheumatic Conditions
Attention Deficit Hyperactivity Disorder
Epilepsy
Asthma

There is a wide geographical spread of groups across England, and some areas such as Southampton and Birmingham have more than one group. Perhaps not surprisingly, there are most groups based in areas where there are big teaching hospitals and/or Universities.

As expected London had the largest number of children and young people's groups.



Location of CYP groups in England according to survey

Location	Number of Groups
London	6
Birmingham	4
Southampton	3
Lancashire	3
Sheffield	3
Brighton	2
Cambridge	2
Bristol	2
Newcastle	2
Cardiff	1
Liverpool	1
Edinburgh	1
Manchester	1
Nottingham	1
Bradford	1
Cumbria	1
Reading	1

Map of YPAGs





Limitations

This exercise has its limitations, and not all groups which members of the working group are aware of have responded to the mapping exercise. Although there is a range of condition-specific groups, those that involve other groups of vulnerable children such as, for example, those with a disability, refugees and children and young people living in local authority care (or Looked After Children) are not represented.

It is essential that these children and young people are given a chance to shape and comment on research, and involving people in social care research is a current priority for the Department of Health and Social Care.

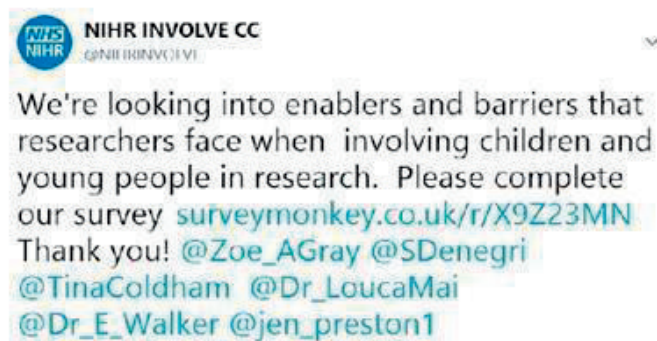
However, this may be another reminder that researchers are not listening to these young people. This could be because they are unsure about how to access them, or do not know how to involve them, so guidance on involving particularly vulnerable children and young people may be helpful in ensuring that their voices are heard.

2. Survey

Alongside the mapping exercise, the working group devised a survey to send to researchers looking at barriers and enablers to involving children and young people in research.

Method

This survey was advertised, similarly to the mapping exercise, by the working group using their local contacts. It was also posted on Twitter and the INVOLVE website during the summer of 2018.



134 people responded. However, some respondents reported on examples of children and young people participating in research, not in an involvement capacity.

77% of respondents were actively involving children and young people in research with the majority involving eight or more children and young people. The ages of those involved was wide ranging although most were between 12 - 24 years old. There was a variety of type of involvement occurring in a number of different settings such as in clinical settings, schools and voluntary sector organisations.

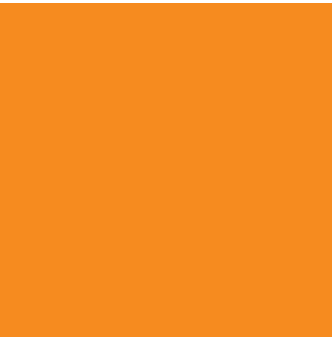
The levels of involvement mentioned spanned the spectrum of consultation, collaboration, co-production, and through to user-led.

"Will be collaborative through workshops. We are looking at how to involve children at earlier stages of the research project design and dissemination of results."

"Co-production, particularly using creative arts."

"Disabled Young- person led research project."

Unfortunately, misunderstanding as to what involvement actually is continues to exist.



Respondents reported a need for education around involvement, along with basic awareness-raising of children and young people’s capacities for being involved in research, and not simply participating in research.

Barriers to involvement of children and young people

Several key barriers to involvement also emerged.

Time

Lack of time was cited by many respondents as a barrier to involving children and young people:

“The funding, time and staff capacity. Youth involvement deserves to be well thought out and structured but current resources limit that. Establishing and building relationships with young people and gatekeepers can be a difficult task.”

As well as lack of time for research staff to involve children and young people, the issue of children and young people not having enough time to be involved was raised several times, for example:


“Engagement issues around school holidays and children’s multiple activities after school.”

However, this may be because it is preferable for some researchers to involve children and young people during core work hours, when most children and young people are in school, instead of at evenings and weekends when children and young people could be available for involvement activities. In fact, it is the practice of several members of the working group to almost exclusively involve children and young people at weekends and during school holidays.

Money

Another major barrier to involving children and young people was funding:

“Constantly having to find funds.”
“Money has an impact on the number of children we can involve.”
“It’s opportunity, funding and focus.”



This is not an uncommon problem in public involvement. While the NIHR Research Design Service offers a small amount of money to potential NIHR-funded and charity-funded research for public involvement activities at the prefunding stage <https://www.rds-sc.nihr.ac.uk/information-for-researchers/> this is the only scheme, to the knowledge of the working group, to consistently offer funding for public involvement.

This allows for the public (at whatever age) to be involved in the research at its inception and to advise on the research design from the user perspective. Children and young people and parents or carers can also be involved at this stage to help with identifying the costs that will be incurred by children, young people and parents/carers if they participate in a proposed research project thus helping to ensure that there is sufficient money allocated to public involvement within each research grant application.

Gatekeepers

A significant barrier to public involvement was also gatekeeping, and the main gatekeepers identified were parents and schools.

“Lack of opportunity to talk to young people about research in a non-clinical setting, ie when they are attending for treatment. Parents tend to want to protect their children from anything that is not strictly necessary as part of their treatment.”

“Require openness from services and not acting as gatekeepers.”

“...lack of schools' recognition of the value of their research work sometimes acts as a barrier to them attending events which involve travel in school hours.”

““Getting consent from disengaged parents.”

These findings indicate that there is more work to be done in order to promote the importance of public involvement to parents, schools and colleges. The difference between involvement and participation needs to be made clear, with sufficient information given to gatekeepers to allow them to make an informed decision. This taps into a wider issue of the lack of awareness on research generally, and possibly negative preconceived ideas surrounding it. However, it is important to recognise that there are many parents who value the importance of public involvement and fully support their child's role within it.



Benefits and impact of involving children and young people

The main benefits to involving children in research respondents identified were:

- ensuring that the research is relevant
- helping develop materials that were appropriate
- improving tools and data analysis
- increasing the self-esteem of those involved

“The main benefits for the research have been improved data analysis/ interpretation and dissemination. There have been significant wider benefits for the researchers and young people.”

“The questionnaire was more user friendly, confidence from the researchers that young people understood the questions.”

“Kept the research young person centred. Provided insight and ideas into the research design, data collection, analysis and dissemination.”

“Involved both current and recent service users who were rarely heard, they were able to provide insight and co-produce materials, contribute to analysis and write up.”

“They are able to represent the younger persons perspective of their condition and how it impacts their life, enabling treatments to evolve that are more personalised to their needs.”

“Motivating for me as the researcher.”

“Their work has informed reporting to the UN Committee on the rights of the child as well as local practice and occasionally national guidance.”

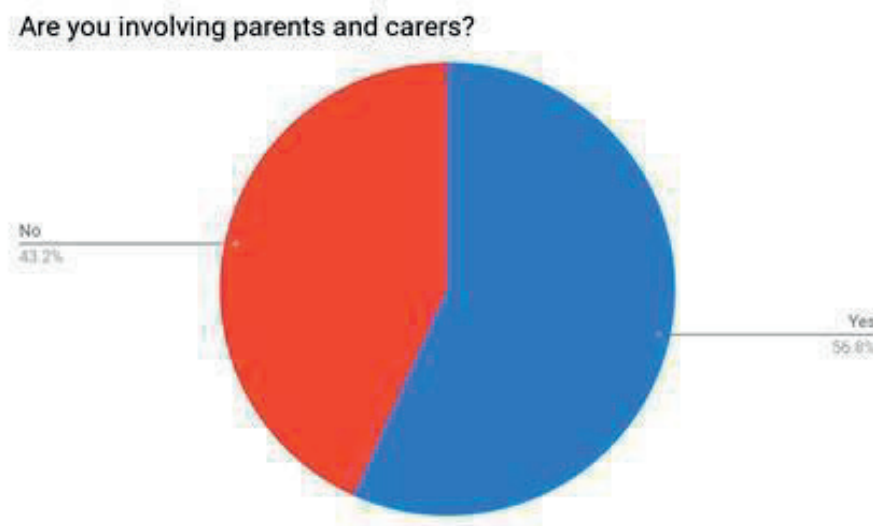


“Their creativity also ensured the reporting of findings was interesting and informative for other young people e.g. blog posts and infographics.”

These benefits are wide ranging and illustrate that the involvement of children and young people can aid the children and young people themselves, the research and the researcher. Continuing to promote these benefits is essential if children and young people are to be heard.

Parents and Carers

The survey also asked about whether people were involving parents and carers in their work. Just over half of those who responded to the survey involved parents and carers.



Proportion of respondents that include parents and carers in their work

Some parents were involved in research that involved very young children; others sat in on joint groups with children; and there were groups that were completely separate. Whilst there are benefits to having parents and carers and children at the same meeting, such as having someone familiar there which may encourage discourse, researchers should be mindful that children conversely may not be as forthcoming in their opinions when their own parents or carers are present, especially when discussing sensitive issues. However, this may ignite a lively debate that can provide the researcher with rich information.

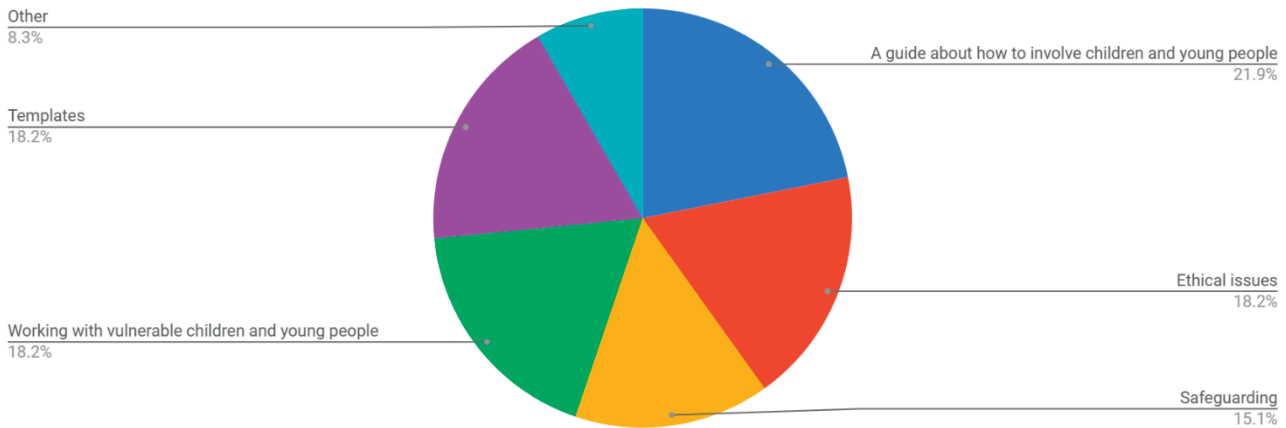
It is the practice of some members of the working group, where it is relevant to a study, to involve both children and young people, and parents; both groups will come together at the beginning of a face-to-face meeting, and split up in two groups for the involvement activities, then brought together at the end. It is especially important that parents and

carers are involved in research when their child might not be able to express their opinions, for example due to illness or young age.

Education and Training

The survey also asked about education and training regarding involving children and young people in research. 65.2% of those who responded stated that they had the knowledge, skills and leadership to support the involvement of children and young people. However, this contrasts with the 74.2% who would like more guidance and support in involving them and the 60% who indicated that they would like further training. Workshops and online training were the most requested methods of training. When asked what guidance and support they would find helpful the results were as follows:

Guidance and Support



Breakdown of what type of guidance and support respondents would like

As a result of these findings the children and young people’s working group initially plans to update the Top Tips document <http://www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-January2016.pdf> and the INVOLVE website, and potentially hold a showcase event for researchers, and children and young people. Future work may involve collaborating with other organisations, including those in the charity sector, and schools and colleges who are considered key gatekeepers for many researchers.

Out of the 31 respondents who were not currently working with children and young people, or hadn't done over the last two years, 90% indicated that they were keen to do so. It may be speculated that more training would increase their knowledge and confidence on how to involve children and young people in a way that adds value to their research.

Conclusion

The mapping exercise and survey have provided a wealth of information on the spread of children and young people's advisory groups across England as well as providing an insight into the issues surrounding involving children and young people in health, social care and public health research.

Children and young people of all ages are being involved in a variety of ways across the country. This is seen as having benefit for the children and young people themselves, the researchers and the research. However, there are still significant barriers in place that prevent involvement or make it more challenging. Overcoming these barriers is not an easy process, but this report has identified some points that may make involvement easier.

Firstly, is it worth repeating that the NIHR Research Design Service can offer some money for public involvement at the pre-funding stage for NIHR and charity research. This does not cover ongoing involvement costs, but it is anticipated that these would be fully incorporated into the research budget while it is devised for a research application for funding.

We also recommend that schools and colleges are provided with more education regarding research. This may ensure that research myths are dispelled amongst both staff and students, therefore helping to remove the barrier of accessing children and young people for research involvement. However, this is a long-term piece of work which would involve collaboration with local educational establishments, researchers and research organisations. Nonetheless, these ambitious plans could be transformational in removing this barrier.

Time was the final main barrier cited. Many researchers reported that a significant amount of time is required to involve children and young people in a way that is meaningful. Involvement needs to be tailored to individual groups as a one size fits all approach will not add value. Increased resources and support may help researchers find the time for involvement. Involvement should be treated as an equally important part of research as other components and it may be argued that true involvement might save time, ensuring, for example, that the research question is relevant and the correct research methods and design are being employed.


Numerous benefits to involving children and young people in research were mentioned ranging from ensuring the research is relevant to improving research tools. It is imperative that children and young people are given the opportunity to showcase the impact that they can have on research. The voices of young people are incredibly powerful and it is important that they are given opportunities to express themselves to a wide audience.

One thing that came out strongly from the survey is that there is a need for more guidance and training on involving children and young people in research. Ethical issues and working with those who are classed as vulnerable were key topics that arose. INVOLVE is able to take on some of these requests, but education regarding the involvement of children and young people in the research community more widely would be greatly beneficial.



This mapping exercise and survey have helped provide a clear direction for future work in reference to involving children and young people in health, social care and public health research. There is much that researchers can learn from their colleagues who work in different sectors, but it is clear that there is more work to be undertaken.

Children and young people deserve to be involved in research in a meaningful, suitable manner and it is crucial to knock down barriers and provide them with this opportunity.



INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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