
Involving children and young people in research: top tips and essential key issues for researchers

“Never overlook comments from young people – they are unlikely to continue to contribute if you ignore their points” (young person)

Introduction

This is a short overview of the key issues on involving children and young people in NHS, public health and social care research. These have been developed by INVOLVE in response to requests from researchers for practical information on what they need to consider when involving children and young people in research.

What is involvement in research? INVOLVE defines ‘involvement’ as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them. This might include involving people in setting research priorities, design, carrying out the research, analysis, reporting and dissemination, rather than participating in research or in research education.

The purpose of this document is to highlight:

- top tips for researchers ranked by children and young people
- practical and essential information on how to plan to involve children and young people in research
- where to go for more detailed guidance and other resources.

The information was developed by reviewing existing information and guidance on involving children and young people in research. It is not intended as a comprehensive handbook or manual.

The top tips were developed by selecting those that focused on the practicalities and asking children and people involved in research to identify which ones they thought were most important and if anything was missing.

Top tips for involving children and young people in research

Here are 13 top tips for researchers, ranked in order of importance by children and young people.

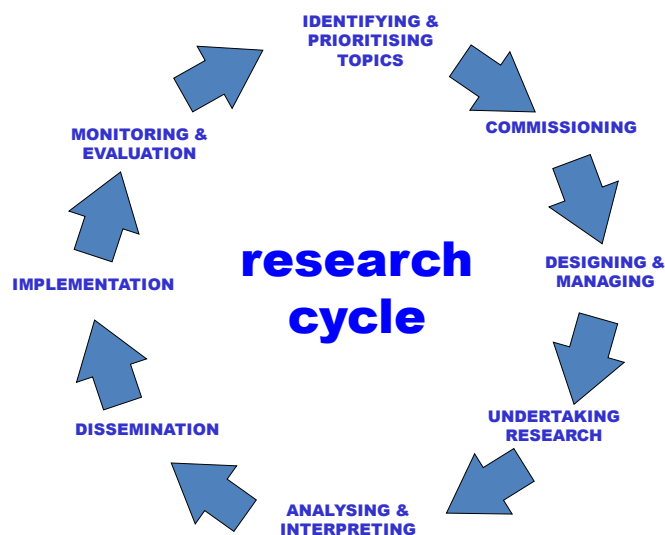
The most important message that we received from the young people that we consulted was **talk to us** and this principle informs all of the tips below:

1. **Don't make assumptions** about what we're interested in or what we're capable of – ask us.
2. Our involvement needs to **benefit us** too – such as by learning new skills, vouchers, payment, activities, meals out, references or having fun.
3. Provide **training and support** so we can get fully involved – don't just throw us in at the deep end.
4. Give us **feedback** on what happens after our involvement – show us what difference we're making, so we know our involvement is worthwhile.
5. Use **words** that we can **understand**, but without trying to sound young and cool!
6. **Involve us** in as many parts of the research as possible, from as early as possible and throughout the process.
7. Always provide decent **refreshments** – not just sandwiches, pizza too!
8. Show **respect** for our contribution – make us feel included and like an equal part of the team.
9. Find ways to ensure we can **all contribute** as much as we want to, whatever our age, needs or abilities.
10. **We have busy lives** and our circumstances, interests and availability might change. Reassure us if we have to miss a session and fill us in afterwards.
11. **Organise meetings** at times and places that are easy for us to get to and where we feel comfortable.
12. If there is a gap between meetings, **keep in touch** and give us updates.
13. **Communicate** with us in **different ways** such as online, text, social media, phone and post – ask us what we prefer as we don't all use social media or email.

Key issues for researchers

This section provides information on the key aspects of involving children and young people in research, from the planning stages through to evaluation.

What aspects of research can children and young people get involved in?



Involvement should start as early as possible in the [research process](#). It may vary from a few stages to the whole process depending on the research and the interests and availability of the children and young people involved. Take into consideration whether there are any aspects of the research that may be too challenging, sensitive or inappropriate for children and young people.

Involvement can take place at many different stages of research, for example:

- Thinking of research questions: coming up with ideas that are relevant and important to them
- Proposal writing: contributing to research design, advising on methods and strategies for recruiting young research participants
- Literature reviewing: suggesting search terms, commenting on existing information
- Developing research tools: devising interview/focus group/survey questions, advising on questionnaire design and helping to test out the tools
- Recruitment of research participants: advising on the approach, commenting on recruitment materials, talking to friends and advising on reaching specific groups
- Data collection: undertaking research as interviewers/facilitators, with training and support

- Data analysis and interpretation: helping with data entry, commenting on statistical analysis and qualitative data coding, commenting on emerging findings
 - Reporting on research findings: co-writing report sections, contributing to report layout and design, helping to formulate recommendations
 - Dissemination: identifying potential audiences, writing summaries and media releases, giving presentations at conferences and to other young people.
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How can researchers involve children and young people in research?

Children and young people can be involved in research in a number of different ways:

- Going to one-off discussion groups or consultation meetings about particular elements of the research
 - As members of a young people's advisory group, which may meet face-to-face, online or in other ways
 - As members of an advisory group with adults
 - By doing their own research, supported by or alongside adult researchers
 - As commissioners coming up with ideas for research.
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What do researchers need to plan for before involving children and young people?

Clarity on the roles and purpose

- What is the purpose of involving children and young people?
- What will the involvement look like and what will it not include?
- What difference will involving children and young people make to the research?
- How would children and young people like to be involved in this research?

Benefits: Explain how the children and young people will benefit from being involved. This might range from the chance to have their say and improve services that affect them, through to the development of skills, formal recognition or reward

Who to involve: Children and young people are not all the same. Think about how to:

- Manage the needs, abilities and preferences of children and young people of different ages and maturity
- Define the nature of the group, whether generic or made up of individuals with specific experiences of particular conditions or services
- Be as inclusive and diverse as possible, for example supporting the involvement of disabled children and young people as well as those from minority ethnic communities and potentially excluded groups

- Work with ‘gatekeepers’, including schools, services and parents and carers, both to recruit children and young people to be involved, and to support their ongoing involvement if required
- Involve parents and carers in the research, in addition to and separately from their role in supporting their child’s involvement, for example running parallel meetings.

Legal requirements: There are legal and ethical implications to consider when involving children and young people in research. Put policies, procedures and record keeping in place to ensure the safeguarding and protection of everyone involved.

- **Personal details:** information on each person should be collected and stored securely in accordance with the Data Protection Act. This could include date of birth, emergency contact, special needs, access needs, dietary requirements, medical information (allergies and medication), NHS number and GP contact details^{1 2}.
- **Choice:** young people and parents or carers need to make an informed choice to get involved. Parental consent is normally required for under 16-year-olds and may also be necessary for young people aged 16 to 18. Any information provided should be accessible, clear and interesting, so involving children and young people in developing this can be helpful.
- **Child protection:** to recruit children and young people from schools or health and social care settings, and when working alone with children and young people, members of the research team may need clearance from the Disclosure and Barring Service (DBS) to show that they are safe to work with vulnerable people³.
- **Confidentiality:** protect the identity of children and young people who have been involved, including when reporting on the research. Check if they wish to be named on reports or other outputs and seek consent for their preferred use of full or first name, initials, pseudonym or full anonymity. Be prepared for a combination of choices. This should be discussed with them and/or their parents or carers⁴ at different stages of the project.
- **Payment:** work out the levels and methods of any payments to children and young people, including reimbursement of their expenses and those of parents and carers. Decide which elements of the involvement, such as preparation and travel time, are or are not covered⁵.
- **Employment legislation:** if offering payment, be aware of legal restrictions on the times and amount of hours that young people aged under 16 can undertake as a paid activity.
- **Benefits legislation:** young people aged 16 and over, and parents and carers, may be in receipt of benefits. Seek guidance on how this might be impacted by a payment for involvement.

¹ Guidelines for Research with Children and Young People (NCB Research Centre, 2011)

² Hear us out! (VIPER, 2014)

³ Involving Children and Young People in Policy, Practice and Research (NCB, 2015)

⁴ Involving Children and Young People in Policy, Practice and Research (NCB, 2015)

⁵ How to remunerate and reward children and young people’s involvement (Participation Works, 2009)

Resources needed: Involving children and young people requires time, money and planning.

- The whole research team should be aware of what the children and young people will be doing and how they will be supported.
- Staffing levels and expertise should be appropriately planned, especially when involving disabled children and young people and those with special needs.
- Other costs might include transport, carer expenses, translation, production of resources, postage, room hire, catering, equipment, accommodation, accreditation, reward and staff time

Where do you find children and young people to get involved?

There are different ways to identify children and young people to get involved.

One option is to access an established young people's research advisory group (YPAG). This could save time and the young people will have a good understanding of research. However involvement may be limited by location and available time in scheduled meetings, and input may be more generic. Setting up a new group ensures targeted recruitment of children and young people with specific experiences, but takes time, planning and resource. Gatekeepers are key^{6 7 8}. These include:

- Parents and carers
- Youth groups and libraries
- Schools and teachers
- Doctors and social workers
- Other services used by young people.

Realistically, for longer-term involvement of a year or more, researchers should be prepared for some children and young people to drop out as their circumstances and interests change. Plan to recruit additional people at later stages if required.

What are the practicalities to keep in mind?

Plan for the practicalities of involving children and young people, and seek regular feedback from them on their experiences.

- **Availability:** children and young people may have existing educational, family and social commitments. If they are still in full-time education they will not be available during the day in term time and exam time can also be busy. Religious holidays may impact on their availability. Be flexible about meeting times, which may need to be held in the evenings, at weekends or during school holidays
- **Frequency:** the longer the gap between activities, the harder it may be to maintain recall and interest. More frequent may be a burden. Plan with the

⁶ Young People in Research: How to involve us, Guidance for researchers from the PEAR young people's public health group (PEAR, NCB Research Centre, 2010)

⁷ Involving Children and Young People in Policy, Practice and Research (NCB, 2015)

⁸ YPAG start up tool <http://ypag.grip-network.org/> [accessed 09/11/15]

children and young people and their parents or carers to see what will work best for them

- **Size:** if a group is too small, the people involved may not be confident making decisions. A large group may be overwhelming. Any group needs to be effectively managed and moderated
- **Flexibility:** consider the best model for the children and young people and what will work best for them. For example one-off consultations or one-to-one meetings might be helpful as well as or instead of a fixed-location group with ongoing involvement.
- **Communication:** keep it varied. In between face-to-face contact, social media (Facebook, YouTube, Twitter), texting, smartphone apps, newsletters and posting information online may be helpful. However be aware that not all children and young people use these platforms, or are comfortable doing so with adults with whom they are working.
- **Location:** choose venues that are safe and easy to find. Consider neutral venues that are not associated with a particular treatment or condition.
- **Travel:** if children and young people are required to travel to any meetings, plan in advance how bookings will be made, if younger people will need to be accompanied, whether they will need to be collected and whether overnight accommodation will be required.
- **Fun:** make sure that the activities are fun, varied and interesting. Keep meetings relaxed, interactive and informal. Use warm-up and energiser activities to keep things interesting and have frequent breaks. Develop innovative and creative approaches such as virtual discussion forums or simple methods for young children such as play and drawing. Seek to create an atmosphere in which everyone feels comfortable and be flexible about taking breaks.

How do you support children and young people's involvement in research?

Supporting children and young people's involvement in research requires time, expertise and money. Researchers should reflect on this when planning their process and budget.

- Ensure the **staff team** includes those with experience and skills in working with children and young people, who are non-judgemental, friendly, welcoming and approachable. Consider staff training needs in this area and have a named contact with whom the children, young people and their parents or carers can keep in touch.
- **Find out** what the children and young people already know, and what they need to know to do the tasks required of them.

- Provide individualised age and developmentally appropriate **training** that is relevant, interesting and stimulating, not too far in advance of the task. Plan for an induction and be prepared for ongoing and unanticipated training needs.
- Always agree **ground rules** with the children and young people, such as tolerance to others, manners and taking turns.
- Be **sensitive**: provide information in advance about content that individuals may find challenging or triggering, and put those items at the end of a meeting so people can choose to leave early. Follow up with a call to ensure people are ok. Not everyone wants to speak in meetings, so enable people to have their say afterwards, for example via email, if they want to.
- Where **parents and carers** need to be involved, think about how this can support rather than limit the opportunity for each child or young person to have their voice heard in their own right, for example by creating different activities for them or by providing a difference space for the parents and carers to wait in.
- Plan an **exit strategy** to support those involved as the research ends. This might include the identification of other opportunities or securing further support through another agency.

How should children and young people be recognised and rewarded for being involved?

Children and young people should be recognised and rewarded for their involvement. The level of reward may depend on age and the activity and on their benefits or employment status. If possible, choices and options should be presented in advance. There are formal and informal ways to show that young people and children's contributions are valued.

- **Remuneration**: this might include payment of money or vouchers.
- **Accreditation**: this can be done through the Award Scheme Development and Accreditation Network (www.asdan.org.uk) or with the National Open College Network (www.nocn.org.uk)¹⁰.
- **Certification**: personalised acknowledgement of involvement, including any training undertaken, for educational portfolios.
- **References**: for college, universities and employers.
- **Formal acknowledgement**: being named on a report or nominated for an award.
- **Training**: the opportunity to learn new skills, such as website design, video production or copywriting.
- **Social activities**: meals out, outings or group leisure activities.

The importance of saying thank you and noting the difference a child or young person's involvement has made to the research should not be underestimated.

How do you evaluate children and young people's involvement?

Involve children and young people in an evaluation, to understand the impact and learn from their experiences.

⁹ How to involve children and young people in research (Participation Works, 2009)

¹⁰ How to involve children and young people in research (Participation Works, 2009)

- Try and evaluate young people’s experience of involvement at the end of each meeting or at regular intervals, so that their feedback can inform and improve future involvement
- An end-of-project review could include informal critical reflection with the children and young people.
- Those involved could also help to develop a more formal evaluation, to ensure it captures the aspects that have been important to them.
- Share the learning with other researchers to improve the evidence and good practice for involvement, for example in published papers or at conferences. Involve the children and young people in reporting on their experiences.

Further reading and resources:

A full list of resources and references on involving children and young people in research is available on the [INVOLVE website](#)

These key issues have been drawn from the following resources:

Reward, recognition, employment and benefits

- DRAFT Good practice for payment and recognition of children and young people involved in research – things to consider (INVOLVE, 2016) – to be published shortly
- [How to remunerate and reward children and young people’s involvement](#) (Participation Works, 2009)

Ethics

- [Children and clinical research: ethical issues](#) (Nuffield Council on Bioethics, 2015)
- [Involving Children and Young People in Policy, Practice and Research](#) (NCB, 2015)

Communication

- [Guidance on the use of social media to actively involve people in research](#) (INVOLVE, 2014)

Tools, exercises, games and training materials

- [GenerationR, Resources](#)
- [YPAG start up tool](#)
- [VIPER](#)
- [Young People as Researchers](#) (Save the Children, 2000)
- [Children and Clinical Research - Global Health Training Centre](#)

Other useful guidance

- [Evaluation of Consumer Involvement in the NIHR Clinical Research Network: Children 2013-2014](#) (NCB Research Centre, 2014)
- [Hear us out!](#) (VIPER, Council for Disabled Children, 2014)

- [Guidelines for Research with Children and Young People](#) (NCB Research Centre, 2011)
 - [Involving children and young people in health services](#) (RCPCH, 2011)
 - [Young People in Research: How to involve us, Guidance for researchers from the PEAR young people's public health group](#) (PEAR, NCB Research Centre, 2010)
 - [How to involve children and young people in research](#) (Participation Works, 2009)
 - [A Guide to Actively Involving Young People in Research: For researchers, research commissioners, and managers](#) (INVOLVE, 2004)
 - References on the INVOLVE website <http://www.invo.org.uk/find-out-more/involving-children-and-young-people/references-on-involving-children-and-young-people-in-research/>
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- **Alpha Young People's Research Advisory Group**
<http://decipher.uk.net/public-involvement/young-people/>
- **National Young People's Mental Health Advisory Group**
<http://www.invo.org.uk/find-out-more/how-to-involve-people/involving-children-and-young-people/the-national-young-peoples-mental-health-advisory-group/>
- **Young Person's Advisory Group Liverpool**
<http://generationr.org.uk/liverpool/>
- **Young Person's Advisory Group London**
<http://generationr.org.uk/london/>
- **Young Healthwatch Bristol**
<http://healthwatchbristol.co.uk/about-us/young-healthwatch/>
- **Y-SBNT young advisors**

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