

Involving children and young people as advisors in research

Top tips and essential key issues for researchers

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What is involvement in research?

Patient and public involvement in research is often defined as doing research 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Introduction

This is a short overview of the key issues on involving children and young people in NHS, public health and social care research in response to requests from researchers for practical information on what they need to consider when involving children and young people in research. The original 13 Top Tips, developed in 2016, have been reviewed and then updated by several Young People's Advisory Groups (YPAG), and the members of the INVOLVE Children and Young People's working group which includes young people.

As with the involvement of adults, involvement of children and young people in research may take many forms, but it should ideally follow an established method, agreed in collaboration with children and young people. The process should be more than a tickbox gesture - not just involvement for the sake of involvement. Involving children and young people should be meaningful to all involved.

Involving children and young people requires different considerations to the involvement of adults, covered in many other resources. The purpose of this document is to highlight:

- top tips for researchers
- practical and essential information on how to plan the involvement of children and young people in research
- where to go for more detailed guidance and other resources

Top tips for involving children and young people in research

"Never overlook comments from young people - they are unlikely to continue to contribute if you ignore their points" Young person

Here are 17 top tips for researchers.

The most important message that we received from the young people who we consulted was that they want researchers to talk and listen to them, and this principle informs all the tips below:

1. show respect for our contribution - make us feel included and like an equal part of the team
2. don't make assumptions about what we're interested in or what we're capable of - talk to us
3. our involvement needs to benefit us too - such as by learning new skills, receiving vouchers/payment, taking part in engaging activities, meals out, certificates of attendance, references or CVs
4. provide training and support so we can get fully involved - don't just throw us in at the deep end
5. give us feedback on what happens after our involvement - show us what difference we're making, so we know our involvement is worthwhile
6. use realistic and understandable language that is age appropriate
7. ensure that there is plenty of time for introductions at initial meetings
8. present the information in an interesting and accessible manner - format text appropriately and present in an engaging and interactive way, don't just use Powerpoint!
9. involve us in as many parts of the research as possible, from as early as possible and throughout the process
10. where possible, empower and support us to develop our own research ideas
11. always provide decent refreshments - ask about any dietary requirements and preferences
12. find ways to ensure we can all contribute as much as we want to, whatever our age, needs or abilities
13. make sure that the meeting is interesting for us
14. we each have our own different circumstances - interests and availability might change so reassure us if we have to miss a session and fill us in afterward and try to be flexible
15. organise meetings at times and places that are easy for us to get to and where we feel comfortable
16. if there is a gap between meetings, keep in touch and give us updates - even if nothing has happened
17. communicate with us in different ways such as online, text, social media, phone or 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 depending on the type of 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, being co-applicants and contributing to the co-production of the proposal

- **literature reviewing:** suggesting search terms, commenting on editing information, commenting on whether the literature reflects their thoughts/experiences
- **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, and helping to advertise on social media
- **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, designing infographics and videos, writing blog posts, giving presentations at conferences and communicating with other young people

Children and young people can also take a user led approach and involve researchers and health care professionals in their research. For example, working with them to think of relevant research questions/topics; finding researchers with proposal writing skills to support with funding opportunities.

How can researchers involve children and young people in research?

Several models of involvement have emerged in the last two decades including: Consultation, Collaboration, User-led research and Co-production. 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
- as co-researchers working alongside adult researchers, sharing power and responsibility from the start to the end of the project
- by doing their own research, supported by or alongside adult researchers
- working with researchers to [co-produce research](#)
- as commissioners coming up with ideas for research

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 are the commitments going to be, including time?
- what difference will involving children and young people make to the research?
- what difference will the involvement make to children and young people and their peers?
- 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. Discuss how researchers and the research project will benefit from their involvement.

Who to involve

It is important to realise that children and young people are not a standardised group any more than adults are. Children and young people are differentiated by gender, ethnicity, disability, social class, etc. This needs to be taken into consideration when deciding who to involve to ensure that their involvement is not tokenistic and adds value.

As much as children and young people have a right to be involved researchers must also be aware that they also have a right not to be involved. Those who are under particular stress may not be able to see the personal benefit of being involved, and ultimately whether to be involved or not is a personal decision whatever the circumstances. It is important to respect this and consider that no matter how interesting your research topic is, or how much you want to involve diverse or 'less frequently heard' children and young people, those you wish to involve may have other priorities.

All children and young people are potentially vulnerable, but the literature shows that those who are considered particularly vulnerable such as users of mental health services (Mawn et al, 2015), looked after children (Powell and Smith, 2009) and young people with experience of substance misuse services (Brady et al, 2018) are often absent from publications on the involvement of children and young people in research. It is important to consider how to involve these children and young people, and realise that "traditional" models of involvement may not work. A more flexible approach may be needed (Brady et al, 2018). It should also not

be assumed that all children and young people have internet use, access to a smart phone, social media or a permanent address. Discussion with them about the most suitable way to make contact and involve them is crucial in order to maintain continued involvement.

Think about how to:

- manage the needs, abilities and preferences of children and young people of different ages, developmental stages and backgrounds
- 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 children and young people with experience of additional health needs (for example, acute and chronic health conditions, disabilities and other needs) as well as those from minority ethnic communities and potentially excluded and/or seldom heard groups
- work with 'gatekeepers', including schools, services and parents and carers, both to recruit the children and young people to be involved, and to support their ongoing involvement if required
- involve parents and carers if the research is appropriate, in addition to and separately from their role in supporting their child's involvement, for example running parallel meetings

Legal requirements and ethical legislation

There are legal and ethical implications to consider when involving children and young people in research. Ensure appropriate policies and procedures are 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 2018 General Data Protection Regulations. 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. This information must be destroyed once children and young people are no longer involved in the research.

Choice

Children and young people and parents or carers need to make an informed choice to get involved. Parental or legal guardian consent is normally required for under 16-year-olds and may also be necessary for young people aged 16 to 18, especially if they are considered particularly vulnerable. Any information provided should be accessible, clear and interesting, so involving children and young people in developing this can be useful. Permission (in the form of assent) should generally also be captured for all children under 16 years of age, ensuring that children and young people are equally happy to take part. All these forms must be stored securely. However, it can sometimes be the case that children and young people are estranged

from their family so consent can't be obtained, or the research is focusing on a sensitive topic and parents are unaware of the child's knowledge and/or experience in this area. In these circumstances the National Children's Bureau Guidelines state that parental consent can be waived if it "would potentially breach the child's right to confidentiality" (Swan et al, 2011, p.30). If this does happen it is imperative that the child or young person is supported by a specific project worker and the study management group (Brady and Graham, 2019). The child or young person should also be reassured that they can leave the project at any time.

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 will need up to date clearance from the Disclosure and Barring Service (DBS) to demonstrate that they are safe to work with vulnerable people. Ensure that researchers/professionals working with children and young people have received appropriate safeguarding/child protection training.

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 or initials. However, be aware that journals do not allow submissions that include anonymous contributors or pseudonyms as article authors. Therefore, authorship should be discussed with the children and young people and/or their parents or carers at different stages of the project. Only in exceptional circumstances can an author be anonymous in a journal, for example to avoid a breach of patient confidentiality or harm to a patient. However, this would need to be discussed with the journal editor. For further information on this please refer to the FAQ section in the [Public Co-Applicants in Research guidance](#). Other options for authorship can include a project group, for example, 'Study young people's advisory group'.

Payment

Work out the levels and methods of any payment to children and young people, including reimbursement of their expenses and those of parents and carers. They should never be out of pocket when it comes to travel expenses. Decide which elements of the involvement, such as preparation and travel time, are or are not covered. This should be made clear before children and young people decide to get involved. You can find out more in the National Institute for Health Research (NIHR) [Payment Guidance for Researchers and Professionals](#).

Employment legislation

If offering payment, be [aware of legal restrictions](#) on the times and numbers of hours that young people under the age of 18 can undertake as a paid activity.

Benefits legislation

Children and young people up to the age of 16 years will not be in receipt of benefits in their own right that can be affected by payments. Their parents or carers who may be in receipt of state benefits will not have these affected by payments to a child or young person under the age of 16 years.

Young people aged 16 or over, may be in receipt of benefits or may be living at home supported by their parents or carers as they are in continued education.

Young care leavers aged 16 and 17 years may be funded by the local authority for their costs of living and housing, or be in receipt of benefits. Care leavers 18yrs to 25 yrs may have continuing advice and support from the local authority. The local authority has discretion to charge for their costs. The young person must be left with the same level of income as they would have been entitled to from benefits.

Where young people are to be paid for their help in research and they are in receipt of state benefits they are subject to strict benefit conditions. If they inadvertently breach conditions on earnings or other issues they can have their benefits sanctioned (reduced) or stopped entirely.

It is therefore essential to provide young people with reliable independent guidance on benefit conditions before they agree to accepting payments. Jobcentre staff are not trained to give this advice. You can find more about welfare benefits and payment in the [NIHR Payment Guidance for members of the public](#), and the [NIHR Payment Guidance for researchers and professionals](#).

Expenses

Where children and their families are living on a low income they may not be able to afford upfront costs such as for travel. Therefore, as a simple and easy way around this would be to ensure that travel is booked and paid for in advance by the research team.

Where people are in receipt of benefits and are reimbursed the exact cost of expenses for involvement in research this will not affect their benefits. Where parents or carers assist the young person to travel and are reimbursed the travel costs, if they receive benefits the reimbursement is for 'service user involvement'. The Jobcentre must be told that the reimbursement is for 'service user and carer involvement'.

The NIHR can provide members of the public with access to a Benefits Advice line run by the Bedford Citizens Advice Bureau. For more information please contact ced@nihr.ac.uk

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 as part of the research team and how they will be supported to do this. Staffing levels and expertise should be appropriately planned, especially when involving disabled children and young people and

those who are considered vulnerable who may need extra support. Other costs may include transport, carer expenses, translation or interpretation, production of resources, postage, room hire, catering, equipment, accommodation, accreditation such as a certificate, 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 Advisory Group (YPAG). There are several that can be accessed through the [Generation R website](#), but this is not an exhaustive list. Using YPAGs 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. These may include:

- parents and carers
- youth groups and libraries
- schools and teachers
- doctors and social workers
- third sector/charitable organisations
- other services used by young people

It is important that gatekeepers are aware of the importance of public involvement and the essential role that children and young people can have in prioritising, designing, implementing and disseminating research so that they are able to make an informed decision. However, as well as being a barrier to involving children and young people gatekeepers can also enable involvement.

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 or as their health needs vary. Children and young people should be made aware that it is their right to stop being involved if they so wish and it will not affect any current or subsequent care. Plan to recruit additional people at later stages if required.

What are the practicalities to keep in mind?

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 their availability. Be flexible about meeting times, which may need to be held in the evenings, at weekends or during the 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 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 in taking part in discussions or making decisions. A large group may be overwhelming. Any group needs to be effectively managed and moderated. A facilitator may be helpful.

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, and again letting children and young people decide between face-to-face contact, social media (eg. Snapchat, Instagram, Facebook, Youtube, Twitter), text messages, instant messaging apps (eg. Whatsapp, Messenger), networking apps (eg. Slack), 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. You'll need to pay particular consideration for those with extra physical and mental health needs to ensure that venues are accessible. Consider neutral venues that are not associated with a specific treatment or condition; though others may prefer a location near to a place they are familiar visiting, such as the hospital, to

reduce anxiety when travelling to new places. Don't assume that everything has to be out of the 'clinical environment'. Ask what would be best for them.

Travel

If children and young people are required to travel to any meetings, plan in advance how the 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. Travel should ideally be booked for children and young people in advance to avoid them (and/or their parents or carers) being out of pocket.

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 working with children and young people, who are non-judgemental, friendly, welcoming and approachable - consider staff training needs in this area
- 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 - the [Generation R website](#) has a number of resources including videos and games that can be used for training
- always agree on shared ways of working with the children and young people, such as tolerance to others, listening and taking turns
- be sensitive: provide information in advance about any meeting 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
- 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 different 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
- the above point also applies to children and young people who move away or reach a particular age which means they no longer fall within the Terms of Reference for the group

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. You can find more about payment in the NIHR's Payment Guidance documents [for members of the public](#) and [for researchers/professionals](#)
- accreditation: this can be done through the [Award Scheme Development and Accreditation Network](#) or with the [National Open College Network](#)
- 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.

Ending of involvement

At the end of their involvement children and young people should be given copies of the main project outputs, be informed of what will happen next and be debriefed. An end of project celebration event may be appropriate and appreciated (Brady and Graham, 2019).

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.

- try and evaluate 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 of good practice for involvement, for example in published papers or at conferences
- involve the children and young people in reporting on their experiences if they wish to be involved

It is also important for researchers to reflect on the involvement process and their own role within it.

References and other useful guidance

eYPAGnet (2020): [Toolkit for involving young people in research](#)

[Children and clinical research: ethical issues](#) (Nuffield Council on Bioethics, 2015)

[Involving Children and Young People n Policy, Practice and Research](#) (NCB, 2015)

[Evaluating the extent and impact of young people's involvement in National Institute for Health Research \(NIHR\) studies: an assessment of feasibility](#) (Brady and Preston, 2017)

[Hear us out!](#) (VIPER, Council for Disabled Children, 2014)

[Involving children and young people in research](#), National Children's Bureau

[Guidelines for Research with Children and Young People](#) (NCB Research Centre, 2011)

[Research into Young People's Participation in Local Decisions](#) (VIPER)

[Children and Clinical Research - Global Health Training Centre](#)

You can search for more involvement resources and references on public involvement on [Learning for Involvement](#)

References

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- [Alpha Young People's Research Advisory Group](#)
- [Young Persons Mental Health Advisory Group](#)
- Adolescent Mental Health Advisory Group
- [Generation R Young Person's Advisory Group London](#)
- [Generation R Young Person's Advisory Group Liverpool](#)
- [Young Healthwatch Bristol](#)
- Y-SBNT young advisors
- Young Adults Patient and Public Involvement (YAPPI) Group
- Southampton NIHR Clinical Research Facility and Biomedical Research Centre's Children's PPI Group.