

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

Many researchers understand the value of involving children and young people in NHS, public health and social care research, but are unsure how to go about it.

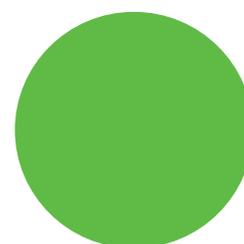
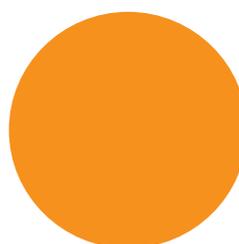
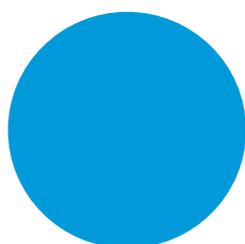
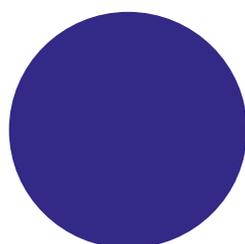
What is involvement in research?

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 tips were developed by:

- reviewing existing information and guidance on involving children and young people in research
- selecting those that were relevant to ‘how’ you involve children and young people
- asking children and young people involved in research to identify which ones they thought were most important and if anything was missing.

More detailed practical guidance including **essential** requirements for good practice such as safeguarding, legal and ethical requirements, alongside further reading and resources can be found in a related document **Involving children and young people in research: top tips and essential key issues for researchers 2016** www.invo.org.uk/wp-content/uploads/2016/12/involvingcyp-tips-keyissues-January2016.pdf



Top tips for involving children and young people in research

Top tips for researchers ranked in order of importance by children and young people with some of their comments in quotes. The most important message that we received from the children and young people was **talk to us** and this principle informs all the tips below:

- 1. Don't make assumptions** about what we're interested in or what we're capable of – ask us.
Children and young people's interests and abilities vary. Talk to them about how they want to be involved and what they feel they can contribute. Give them options.
“We are very interested in what you do, that's why we're there helping you. It would be good to hear about prior successful research, or even just what you do as part of your job.”
- 2. Our involvement needs to benefit us** too – such as by learning new skills, vouchers, payment, activities, meals out, references or having fun.
What's in it for them? It might be the chance to have their say about something that affects them or to improve services or treatment for other young people. An enhanced CV, new references and an opportunity to extend their networks and make new friends may also be motivating factors to getting involved.
“Do fun stuff – social activities and outings – not just staying in a room all day.”
- 3. Provide training and support** so we can get fully involved.
Find out what people know and what they need to know in order to fulfil their role. Provide individualised age and developmentally appropriate training that is relevant, interesting and stimulating, but not too far in advance of the task. Plan for an induction and be prepared for ongoing and unanticipated training needs.
“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.
Let children and young people know that their contributions are important and what difference they have made. Also keep them informed of the wider progress of the research to retain their engagement.
“I would love to know, after I have taken part in the research, if or how I have been a help to anyone!”
- 5. Use words** that we can **understand**, but without trying to sound young and cool!
Use age-appropriate language and terminology. Actively encourage people to ask questions and to say if they don't understand something.
“Avoid acronyms and jargon – they can be confusing.”

6. **Involve us** early on in as many parts of the research as possible.

There are ways to involve children and young people in most aspects of research. This could include thinking of research questions, proposal writing, literature reviewing, developing research tools, recruitment, data collection and analysis, reporting and dissemination.

“Involve us at all stages.”

7. Always provide decent **refreshments** – not just sandwiches, pizza too!

Children and young people get hungry and hunger can be distracting. Make sure they're well catered for with food and snacks that they enjoy, and be flexible about taking breaks.

“Providing snacks isn't necessarily crucial in the research itself, but it's useful in motivating people to come in the first place!”

8. Show **respect** for our contribution – make us feel included and like an equal part of the team.

Respect is important for a child or young person to feel like a genuinely valued member of the team. A good chair or facilitator can help to include them. It is also essential that the whole research team is actively supportive of their involvement.

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

“Our facilitators always check in with us individually if there's something that's difficult (follow up email /phone call) which shows they care and that we are valued as people.”

9. Find ways to ensure we can **all contribute** as much as we want to, whatever our age, needs or abilities.

Not everyone will want to or be able to make the same contribution. The important thing is to find out what each individual needs to contribute in the way that they want to.

“Some younger children may feel intimidated by the older children. This should not become a barrier which stops them from contributing.”

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.

Children and young people may have existing educational, family, social and religious commitments. Be flexible about meeting times, which may need to be held in the evenings, at weekends or during school holidays.

“A lot of young people worry if they can't make a meeting or research and that if they miss out for a while that they can't come back. Let us know it's ok, don't be annoyed if we can't make a session, fill us in afterwards and reassure us it's okay to get back involved when we can again.”

11. **Organise meetings** at times and places that are easy for us to get to and where we feel comfortable.

Choose venues that are safe and easy to find. Consider neutral venues that are not associated with a particular treatment or condition if this could be uncomfortable or upsetting for anyone.

“Meetings don't have to be close by (sometimes we like to have a chance to travel to new places) but they should not be too hard for us to get to.”

“We do not want to be lost or walking around in the dark.”

12. If there is a gap between meetings, **keep in touch** and give us updates.

The longer the gap between activities, the harder it may be to maintain recall and interest. Keep in contact with the children and young people so they stay updated and understand the progress of the research and the impact of their involvement.

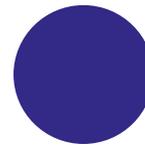
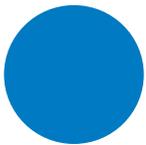
“[[t’s] important for us to have lots of updates on what is happening in the project.”

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.

Keep the communication varied. In between face-to-face contact, social media (Facebook, YouTube, Twitter), texting, smartphone apps, newsletters and posting information online may be helpful. Talk to the children and young people about how they want to be communicated with.

“Remember not all young people use social media or email, but adults often assume that they do!”

“Don’t be offended if I cannot reply.”



Acknowledgements:

Thank you to all the young people who ranked, provided feedback and made suggestions for the top tips for researchers, either online or during their group meetings.

Detailed information on how the top tips were developed and who was involved is available in the related document **Involving children and young people in research: top tips and essential key issues for researchers 2016** www.invo.org.uk/wp-content/uploads/2016/12/involvingcyp-tips-keyissues-January2016.pdf

Date: January 2016

Reference: INVOLVE (2016) Involving children and young people in research: top tips for researchers, INVOLVE, Eastleigh

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Further information and resources on involving children and young people are available on our website: **www.involve.nihr.ac.uk**

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