

Top tips for involving children and young people in research

- 1** **Involve us early on** in as many parts of the research as possible, so that we can truly get involved in shaping the project.
- 2** **Show respect for our contribution** – please help to make us feel included and like an equal part of the team.
- 3** **Find ways to ensure we can all contribute** as much as we want to; whatever our age, needs or abilities.
- 4** **Provide training and support opportunities** so that we are better equipped to get fully involved in research.
- 5** **Use words and phrases that we can understand**, but without trying to sound young and cool!
- 6** **Make sure our involvement benefits us too**, such as by learning new skills, receiving vouchers, payment, meals out, references or simply by having fun!
- 7** **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.
- 8** **Organise meetings at times and places** that are easy for us to get to and where we feel comfortable.
- 9** **Communicate with us in different ways** such as online, text, social media, phone and post. Ask us what we prefer as we do not all use social media or email.
- 10** If there is a gap between meetings, **keep in touch and give us updates**, even if it's such a simple 'hello, here's what has been happening...'
- 11** **Give us feedback on what happens after our involvement** – show us what difference we are making, so we know our involvement is worthwhile.
- 12** **Try not to make assumptions** about what we are interested in or what we are capable of – please ask us.
- 13** **If you're able to, please provide decent refreshments** for events and meetings we attend – it can sometimes be the deciding factor as to whether we attend, or not!

*“Patient and public involvement with children and young people is a self-evident benefit that fair and equal partnerships in research require. **Everyone with a legitimate interest in research should be able to contribute to its design, review, conduct and dissemination**, otherwise our venture with children and young people in the driving seat will fail to thrive.”*

Summary publication date: April 2019. Prepared by Simon R Stones.

This is a summary of the article 'Framework to help design and review research involving children', published by Jennifer Preston, Simon R Stones, Hugh T Davies and Bob Phillips in Archives of Disease in Childhood in 2019. Top tips adapted from: NIHR INVOLVE - Involving children and young people in research: top tips for researchers, published in 2016.

