



Engaging young people in health services research and service design: a new look at ethical issues

Briefing Paper, March 2022

*“ There’s no point in
talking to young people
if you don’t listen to
what they say. ”*

Young person interview

Key messages – issues and contradictions

Wide range of ways of involving young people

There is a wide range of different ways of involving young people in health services research and development. The National Institute for Health (NIHR) has set these out in a ‘research cycle’ including identifying and prioritising topics, commissioning and funding projects, designing and managing the work, disseminating and implementing the findings. People may be actively involved in the research process itself, or they may be participants or subjects of the research. Some of these activities are traditional research activities, but others are classified as “patient and public involvement”.² The public may also get involved in advising about new services, without any research element. Understanding exactly what it is we are asking young people to do is critical to understanding the ethical considerations.

Some of the themes from existing research that our scoping review identified included:

- **The importance of ensuring informed consent and protecting confidentiality** and the challenge of balancing protection and participation
- **An acknowledgement that official procedures may be necessary but lacking** in terms of real world issues and successful communication with young people. They may also be prohibitively demanding in terms of time and resources
- **There is not enough focus on young people’s competence, agency and rights**, with more attention paid to risk management
- **There has been a lack of attention given to the ethics and demands of non-research forms of engagement**, co-production and co-design, with a lack of consistency about whether ethical approval is needed or not

Knowledge gaps and unanswered questions

As a result of our scoping exercise, consultation with young people and discussions with stakeholders we identified a range of issues and contradictions affecting how we think about the ethical frameworks around young people’s engagement in health research and service development. These included:

- **There is a divided literature**, with one body of work looking just at research ethics, and a different literature on principles behind engaging people in service development. But are there any ethical ‘universals’ for involving young people? What might stand in the way of this?

“ ... you get loads of...oh you’re doing great...after a while if you’ve heard that so much... it’s like: but what’s actually happening? We want to see results, or you just feel like your time has been wasted. ”

Young person interview

- **Do we over-scrutinise some things and under-scrutinise others?** The issue of proportionality in ethical scrutiny across the engagement spectrum has not been addressed systematically to date. It may be unethical to allow some activities to go ahead without any scrutiny, but over zealous, rigid procedures not designed with young people in mind might discourage researchers from involving young people, which is also potentially unethical.
- **How can we ensure engagement is meaningful?** To the young people we spoke to, this was a critical ethical issue, yet it does not feature in existing ethics frameworks for research, for example.
- **How can ethical scrutiny respond to the more fluid, dynamic kinds of engagement** that are becoming more common? Where does the process start and end? How can we move beyond ‘tick box’ exercises that result in a limited ‘ethics done’ kind of approach?

“ You need to fight to be able to hear the voices of people who struggle to be heard. They’re the ones who need to be heard most. ”

Young person interview

- **How can ethics help to ensure broader representation of young people in research and service development?** This includes ensuring diversity among young people who participate, but the young people we spoke to also stressed that they felt it was unethical to be asked to represent whole sections of their community.
- **How should ethics reflect the involvement of young people in the transition to adulthood?** To what extent are there ethics specific to children and how do these relate to young adults, for example, 19 and 20 year olds?
- **What do young people think?** In the scoping review we undertook for this project we included a small number of papers that have included young people’s perspectives on ethics of engagement, but these are in the minority. In the next section we summarise the main messages from the interviews undertaken by Common Room for this project.

“ I get asked quite a lot to be involved in different groups and one of the things I’m trying to work on is removing this....not laziness, but the immediacy of going to the one person who’s on every single group. Because I think I’m starting to fill that role in my area...it’s not good for the patient involvement if I’m the only person on the group. ”

Young person interview



Adapted from NIHR (2021)

² NIHR (2021) Briefing notes for researchers – public involvement in NHS, health and social care research

What young people say: How to get it right

The young people we spoke to reflected a rather different view of the ethics of youth engagement from the majority of the papers we reviewed.

Their starting point was what was 'fair', and the extent to which they were properly heard, rather than how to manage risk. They worked together to produce 10 'top tips' for involving young people:

1. **Don't just rely on the same usual suspects.**

Go the extra mile and take the time to ensure there is diversity among your participants

2. **Consider the impact of involvement on the young people.** Think what you can do to support them throughout

3. **Involve enough young people and the most appropriate young people** to truly represent your project

4. **Acknowledge and respect young people's involvement.** To work alongside them as partners will require thought, planning and investment

5. **Share the outcomes with young people.** Be clear and transparent about the impact of their work

6. **Show young people that you value their time and expertise.** Make sure expenses and incentives are given and their contributions are always acknowledged

7. **Have a clear authentic purpose for involving young people.** Avoid tokenism by making sure projects are meaningful and involve young people from day one

8. **Promote involvement opportunities in a way that reaches the right young people.** Use their platforms, language and networks

9. **Understand the young people you want to work with.** Consider their experiences, needs and personal barriers they may face

10. **Give young people choice.** Where possible adapt to make the experience more comfortable for them.

“ Be transparent, honest. Really try to engage. ”

Young person interview

“ ...you don't really want to say no because they're doing things to benefit you, and I feel like a lot of people understand they've helped you out, and you're not going to say no due to you being grateful for things... ”

Young person interview

“ They just expect us to be happy to share our story and they don't understand the psychological trauma from that... ”

Young person interview

Conclusions and next steps

At the moment the way in which we approach ethics in relation to young people's participation varies hugely depending on what kind of activity they are engaged in.

On one hand, the ethical frameworks employed often have their historical roots in academic medical trials where harm might be quite likely. This has led to a framing of ethics as being mainly about risk rather than rights and opportunities. On the other hand, there are some outstanding gaps in how we apply ethical principles to some other kinds of participation over and above traditional research. Where guidelines do exist – for co-designing services with young people, for example – there is little meeting point between these and traditional research ethics. But to young people this may all be literally rather academic. They are simply helping us with our work.

In addition, it is critical to move beyond viewing ethics approval as something that researchers have to 'get through' before projects can start. We need ethics that can be extended and developed to handle more iterative and dynamic ways of involving young people in research and service development.

The next steps in this work includes working with partners to establish whether there are 'universal ethics' that apply across the whole spectrum of youth engagement, and what those might be. We also need to establish whether there are issues specific to health related research and service delivery, or whether the issues are universal across all kinds of engagement. It is also critical that young people's voices become part of the process of working out what is 'fair' in terms of our reliance on them to inform our work.

With many thanks to the young people who took part in the interviews, to our partners at **Common Room**, particularly Liz Neill, to Safya Benniche who helped with the scoping review, to the stakeholder who took part in a webinar to discuss the issues.

COMMON ROOM

The project has been funded by the **Nuffield Foundation**, but the views expressed are those of the authors and not necessarily the Foundation. Visit www.nuffieldfoundation.org.





More information

This briefing paper was written by Ann Hagell, Association for Young People's Health. For more information about the project and the analyses summarised here, email info@youngpeopleshealth.org.uk

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