

How can we help to ensure that young people remain at the heart of CPRU research?

INVOLVING YOUNG PEOPLE TO MAKE RESEARCH MORE MEANINGFUL

- Participation of children and families provides important perspectives on the research carried out by the CPRU
- Young research advisors serve as 'critical friends' to offer constructive input to help shape projects
- In return, participants receive training and experience that will enhance their CVs and future prospects

A photograph of three young people standing in front of a large, textured tree trunk. On the left is a young boy with light brown hair, wearing a grey hoodie and blue jeans. In the center is a young man with dark hair, wearing a blue denim jacket with a white fur collar over a black t-shirt and black pants. On the right is a young woman with long dark hair, wearing a black jacket over a teal top and black pants. They are all looking towards the camera. The background is slightly blurred, showing green foliage and a fence.

It is part of the UK Government's vision that patients and the public should be involved in decisions about their care. Shared decision-making is high on the health agenda.

Public involvement at the research stage, before guidelines or policies are created, is not well-established. But the CPRU, with support from National Children's Bureau, is helping to ensure that the public has a say early on in the research process.

With its networks across the UK, National Children's Bureau (NCB) is ideally placed to provide the expertise required for the CPRU's patient and public involvement cross-cutting theme.

NCB, a leading children's charity, has been improving the lives of vulnerable children and young people for over 50 years. Cathy Street was Director of NCB's Research Centre from 2012 to 2016, and explained the role of the organisation for CPRU. "Right

from the outset, NCB has provided a commentary from the perspectives of young people and parents and carers on the different CPRU projects."

Not just 'nice to have'

Cathy explained why participation from children and families is so important: "Service user involvement is very much a theme for the NHS, and for good reason.

"There are important grounds for making sure that we include patients. First, because it improves service quality: it definitely helps to boost engagement if people feel that they have had a voice.

"Second, there have been cases in the past when a lack of patient and public consultation has had serious consequences, as highlighted by the inquiries into children's care at Alder Hey and Bristol Children's Hospitals. These examples illustrate why we really must have a lay perspective on, for example, how health services collect and share data to improve service provision."



Critical friends

Participation of children and families helps CPRU researchers target their projects towards the people set to benefit. As Cathy explained: “Our patient and public advisors are there very much as a ‘critical friend’ – to provide constructive commentary about what the research needs to focus on, and to ensure it is relevant to the concerns and issues that might be affecting children and young people.

“Participants might work with us at any stage of a project, to look at the research questions or information sheets, or to view early findings and offer their perspectives – they might tell us, ‘That’s really interesting,’ or, ‘We don’t think that’s a true reflection of what worries young people.’

“It lets us look at our work from another angle.”

How does participation work?

Cathy described the participation process: “We use the NCB network to recruit young research advisors. We aim to have around 16 young people and about 10-12 parents or carers. We offer them a one-year partnership and try to refresh the groups on a regular basis.

“Most advisors will join a workshop every two months or so, depending on the needs of the different CPRU projects. But the level of involvement

can vary – some teenagers love the social element of meetings, others prefer to review documents or research tools at home.

“Over the last three years, we’ve diversified into more creative ways of ensuring young people are actively involved early on, when research questions are being considered. We’ve used social media to develop more interactive ways of sharing information and recruited smaller themed subgroups.”

A two-way street

Signing up to support the involvement programme can be extremely rewarding for participants too. NCB delivers training to its young research advisor group and the process equips them with transferable skills such as public speaking, writing for the web and putting together briefing papers. Their experience provides a positive addition to their CVs, potentially boosting their employment outlook.

However, NCB needs to take care not to over-train. As Cathy explained: “We don’t want to turn young people into professionals by the back door,

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because then they lose the young person’s perspective. It’s a balance between providing skills, and opportunities to use them, but not to the extent that they are no longer representative of the general young person population. That way, we can be sure to include views that will help keep research as meaningful as possible.”





Animated engagement: an example of excellent participation

When they turn 18, children with long term-health conditions must transition from child to adult health services. It can be a difficult time, as CPRU research by Linda Wijlaars (research associate in statistics) has shown. This research is clearly of importance to both children making the move and their families, but how can we communicate the complex issues in an engaging way? The answer – animation!

Linda explained: “Our research showed that children with long-term health problems such as asthma or diabetes are more likely to be admitted to hospital during the transition from child to adult health services than those without long-term conditions. This is obviously a challenging time. We needed to find an effective way to get this research across to the people it matters to: young people and their families. We hit upon an animation as a nice, digestible format.”

Participation was absolutely key to the success of the animation. Linda said: “We got young people aged 10 to 24 years involved in putting it together – they’re much better than us at telling the story behind our data in a way that makes sense to young people.”

“They helped to select the bits of my research that are most interesting and relevant to them. They also worked with the animator and scriptwriter to come up with a short story that would highlight the key findings of the study. So really, the story in the animation is mostly them.”

The young people involved highly valued the opportunity to have their say. One commented: “Young people working on projects like this is important because it gives a different perspective. If you are working for young people, you need to get a child or teenager’s ideas. It helps to make it better.”

Additionally, working with the young research advisors is a chance for CPRU researchers to get away from the computer and talk to the people who they’re doing research for and on. Linda added: “It’s very motivating to be able to engage with teenagers who care about what you’re doing as it’s their daily lives.” The animation was produced in conjunction with a CPRU conference, *Drawing on data to transform lives: improving services for vulnerable adolescents*.

More information

Abstract:

Wijlaars L., Hardelid P, et al. (2015). Emergency admissions across the transition from paediatric to adult care: cross-sectional analysis of English hospital data. *Lancet*. 386 (9988), p.77.

National Children’s Bureau
www.ncb.org.uk

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Our aim is to provide evidence for policy and practice for the health and well-being of children, young people and families.

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