

## **Involving Children, Young People and Families: OPRU's Public and Patient Involvement and Engagement (PPIE) Strategy**

### **Why is participation important for OPRU?**

There are several reasons why we think it's important to involve young people and families in our research:

- It ensures OPRU's research is informed by the views of children and young people and their families
- It increases the quality of our research by making it more relevant
- It improves recruitment and retention rates within our studies
- It ensures our research tools are appropriate
- It increases the impact of our findings and dissemination

### **Who facilitates the participation of children, young people and families for OPRU?**

Our participation activities are facilitated by the [National Children's Bureau](#) (NCB). NCB promotes the wellbeing of children and young people, challenges inequalities and promotes their active participation in the research, services and policies that affect them. There are two NCB participation groups involved in OPRU's research: the Young Research Advisors (YRAs) and the Families Research Advisory Group (FRAG).

NCB staff liaise with Research Leads at OPRU to ensure that participation is embedded in all studies, and respecting the fact that the nature of participation will vary from project to project. NCB work with Research Leads to decide which aspects of their research could benefit from input from the YRAs and FRAG and set up a timeline for participation activities.

### **Who are the YRAs and FRAG?**

The NCB YRA group plays a key role in ensuring the quality, relevance and impact of OPRU's research studies. Established in 2011, the YRAs are a diverse group of children and young people aged 7-18, recruited from across England. In addition, a number of children and young people with additional needs aged up to 25 play an active role in the group.

The NCB FRAG is made up of parents and carers who meet regularly to consult on research projects. This is a diverse group of parents and carers of children aged 2-17 years and up to 25 if their child has an additional need, recruited from across England.

Members of both the YRA and FRAG receive ongoing training in research methods, ethics and key policy issues to ensure they can meaningfully contribute to the development of OPRU's research projects.

## **How the YRAs and FRAG are consulted**

There are several ways in which the groups contribute to participation activities within OPRU, including:

- Setting research priorities by contributing to OPRU's work plan
- Commenting on research tools such as topic guides and questionnaires to be disseminated to children, young people, parents and carers
- Providing advice and ideas about recruitment of participants for research studies
- Commenting on project findings
- Advising on dissemination strategies

## **Resources for Participation**

- 2 x half-day meetings with both YRA and FRAG are held each year
- 1 x virtual consultation with both YRA and FRAG are available for OPRU researchers each year, e.g. for piloting a survey or to provide consultation on a short report
- There is flexibility about when the meetings are scheduled to ensure they happen at a time most appropriate for the research team
- In addition to these meetings, there is a full-day YRA meeting in Years 1 and 3 to help with the work planning of the OPRU

NCB's staff are experienced at making the sessions with the YRAs and FRAG interactive. NCB staff ensure that all materials used in sessions are of an appropriate level to promote engagement and enable participation of group members.

Lead researchers from OPRU also attend the YRA and FRAG meetings when discussing their projects. This ensures that the sessions are meaningful for both sides. Having the Lead Researchers present allows the YRA and FRAG members to have their questions answered and also ensures that the discussion is relevant and useful for the researcher. Using this model also encourages researchers to think more actively about participation as they understand the benefits of involving and engaging with the YRA and FRAG.

## **Monitoring**

NCB contact the OPRU Lead Researcher to ask for feedback after YRA/FRAG meetings. Questions to the researchers include:

- What difference did PPIE make to the research?
- Did you get everything from the session that you hoped to achieve?
- What suggestions were you not able to act upon / use?
- When will you provide feedback about what difference their input made?

- Could anything have been improved about the meeting?

Responses from the OPRU researchers are collated and fed back to OPRU management team. This feedback is used by NCB to further improve their engagement with the YRA and FRAG group members, and to ensure that NCB are meeting the needs of OPRU researchers.