Strategy for children, young people, parents, and public involvement in the Policy Research Unit Children and Families

Introduction

Public involvement in research is the active partnership and proactive involvement of children, young people, parents, and the public. We actively seek their views to inform and shape our research and working practices.

What do we want to do:

Our overall **aim** is to conduct high-quality research to improve the health and well-being of children and families, including helping parents/carers to be well* and to care for their children. Our research is shown to the government to help them make decisions about policy relating to children and young people's health, health, and well-being of siblings in a family, or health and well-being of parents/carers. We also develop methods and data resources to improve the quality and timeliness of evidence that can be used by the local or national government

Public Involvement:

We are committed to ensuring that children, young people, parents/carers, and the public are involved in the work of the **NIHR Policy Research Unit for Children and Families**, where and when it is appropriate. This includes the views and experiences of siblings and of parents/carers, including on their own health and wellbeing. The goal is to have a family view in all our work, from the ideas stage, through the methods and analysis to the end results and communication of findings.

Involvement is integral to our research, but the model of involvement, and individuals involved, will depend on each project.

Our research will investigate the social and environmental factors that affect the health and well-being of children, young people, and families as well as looking at what health care services can do to help children, young people, and their parents/carers to be as well and healthy as possible. We have a strong focus on the health inequalities, by which we mean systematic differences in health, well-being, and life opportunities among those who have higher and lower incomes, those who live in different parts of the country, those from different ethnic groups, and those living with a disability or chronic conditions in one or more family members.

*When we talk about being well, we mean mentally and physically well. You feel able and want to get up and get on with your day.

We make the results of our research accessible to the public through easy-to-read summaries, blogs, podcasts, and infographics. We also publish policy briefings and academic journal articles which can be found on our website here.

Finally, we pledge honesty and transparency to our children, young people, and parents/carers and promise to not involve them for the sake of involvement.

How the public help in our research:

To see how we are engaging the public in our research you can view our current research projects here.

Within this strategy when we refer to public involvement we mean:

- Involving the public in decisions that affect them.
- Public involvement should be meaningful, accessible, and inclusive
- Public involvement should be from the beginning of the research not as an afterthought or undertaken in a tokenistic manner
- We will clearly set out at the start of a research project what the public can and cannot influence. We will share knowledge, and information so that their input is on an equal footing
- As the research progresses, we will share updates with our lay contributors

How the public is involved in our work:

In our programme of work, the public have contributed to our research in lots of different ways. Below are some examples of how the public have been involved in our work, but depending on the project, the time you have available and your experience these could be different. We will always support you to get involved.

- Helping to develop and review research proposals
- Attending a meeting to share your views and ideas or to take part in a consultation
- Taking part in collaborative research
- Acting as a peer researcher to interview each other or facilitating focus groups
- Taking part in focus groups, one-to-one interviews, or surveys to share their views
- Supporting the analysis or interpretation of research results
- Sharing your views and ideas to help create reports and how we can best present the findings.
- Supporting us to make our events, research materials, and outputs accessible and inclusive

Benefits of involving the public in our work:

- Involving members of the public, ensures we keep a family view, with a tight focus on how the research being undertaken will benefit parents/carers, children, and young people.
- The public provides us with a unique perspective, for example drawing from their lived experience of health and well-being or use of health and other services
- When we listen to public views, our research improves, and we become sensitive to the needs, perspectives, and circumstances of the Families in England; this makes our research more relevant. We also have a greater insight into the needs of local communities, which can help improve and shape services.

Resources

The Policy Research Unit Children and Families has a dedicated lead for Patient and Public Involvement who works with and directly reports to Dr Jenny Woodman (j.woodman@ucl.ac.uk) co-director for public health. We invest in Public Involvement because we believe public involvement enhances the way we work and the quality of each of the research projects we do.

We will involve children, young people, and parents/carers across the entire research programme and in all stages of projects, from the ideas phase of projects to project design, data collection, and analysis to the dissemination of findings. We will seek inclusive contributions, from multiple groups and individuals from across England, including less-heard voices (survivors of domestic violence and abuse, with mental health problems or chronic conditions, those who are care experienced or have had contact with children's social care, and those from minority ethnic groups.).

Payments, incentives, and rewards:

We have a payment, incentives, and reward policy that sets out how we recognise and reward your valuable and expert contributions.

Continuous improvement

Across our work, we are committed to reflecting on and improving the involvement of the public. Within our work, we will ask for feedback from all researchers, partners and children, young people, and the public. This helps us to share learning and identify areas for improvement. We document all public involvement activities as they take place and reflect on activities, areas for improvement, and what went well.

Co-production

Our work is guided by the NIHR guidance on co-producing research projects (2021). Our research offers a great opportunity to work together.

The co-lead Lucy Read has extensive experience in stakeholder involvement. Through this work, they have co-produced research that has seen participants facilitate research, undertake analysis of findings, and co-producing content. Young people access social media and information online, in ways that adults do not, and given our commitment to getting the findings of our research into the hands of children and young people. We aim to co-produce outputs in creative ways that resonate with the end audience. This is about real-world implementation and impact, and children, young people, and parents/ carers can help advise us on the best modes of dissemination.

UK Standards for Public Involvement

The UK Standards for Public Involvement in November 2019 and guidance on putting the standards into practice is central to our practice. These standards reflect our values around, and general ethos towards, children, young people, parents/carers, and public involvement. Each standard is applicable to the research undertaken in the Policy Research Unit Children and Families.

Diversity and inclusion

- Children and young people themselves constitute a demographic that is often not involved in health and social care research. A large part of our work is involving children and young people, as well as parents/carers and members of the public where relevant.
- Development of a broad network of public involvement groups to engage those with protected characteristics to have, those with lived experience (survivors of domestic violence and abuse), children and young people with multiple long-term conditions and carers of children with complex care needs.
- We believe very strongly in including all young people and parents/carers who wish to be involved in our research, and make efforts, through a flexible, blended approach of public involvement, to involve them (i.e., we do not expect all interested children and young people, parents and the public can attend face-to-face meetings).

Training, support, and accessibility

- We are mindful of ensuring that those involved in our research have sufficient support and learning as they need to be able to be involved in our work. As part of our work, we will deliver training and support sessions that aid those involved in our public involvement and our research to meaningfully engage (A guide to training and support for public involvement).
- Through our public involvement, we will make sure participants have all the support that they need to meaningfully take part. We will provide childcare, interpreter, and palantypist support if these are needed for those taking part.

Communications

We make concerted efforts to discuss our research in plain English and will involve children, young people, parents and patients in producing infographics, posters, podcasts and other material they advise is appropriate

Working together

- Our ethos is to work in partnership with organisations that work directly with children and young people. We have found that working in partnership with others has meant reaching children, young people, and parents/carers that otherwise might not be involved in sharing their views, ideas, and voice. We follow the organisation's policies and procedures for engagement and their remuneration policies which are always consistent with that of INVOLVE, to show appreciation for the involvement of their engagement.

  We treat children, young people, and parents/carers as experts by experience, and therefore, have the same power in the involvement process as the Policy Research Unit Children and Families research staff. We are always careful to manage the expectations of children, young people, and parents/carers in our public involvement and engagement and are thoughtful of different access needs so that we can minimise any barriers to involvement as possible.

Partnerships:

Partnership and working together are central to our work. We proactively work with others to make sure we are reaching those who need to be involved in and influence our research. We are connected to many relevant Public Involvement groups. These are:

- ADIRA – A survivor's mental heal and well-being organisation
- Anna Freud Centre
- The Social Care Institute of Excellence
- Biomedical Research Centre
- National Children's Bureau
- RCPCH & Us
- Great Ormond Street Hospital Young Persons' Advisory Group
- Great Ormond Street BRC Parent and Carers Research Group
- PenARC PenPIG and PenCRU - Understanding Patient Data
- Voices – A survivor-led domestic abuse charity
- Voices from care – organisation for care experienced young people

Through our research, we have access to rich sources of data which we share with partners to improve the health and wellbeing of children, young people, and their families.