Research Investigator Guidelines

This guideline is to help researchers clearly communicate with parents who have shown an interest in being involved in their research. A parent role description should be used alongside more detailed background information on the research study in lay terms, a terms of reference for the specific group/panel/committee, and data protection information. Please note this is not a template for parent *participation* in research. Please see our Research Support Policy for guidance on additional information to include for parent participation resources.

Parent Involvement Role Description Template

**What is the study?**

* Lay summary using jargon-free language
* Research aims
* Project timeline

**What would my role be in this study?**

* Why you need parents to be involved in your research
* Purpose and aims of PPI group/panel/steering committee that you are recruiting parents for
* Scope for parents to influence some of the important research decisions
* Other members of the group/committee

**What would be expected of me?**

‘Your experience of your time on a neonatal unit will help us understand how we can make our study parent and baby friendly’, e.g.

* comment on research design
* comment on parent information documents
* identify important research outcomes
* discuss how to support parents participating in the study

**What experience do I need?**

For example experience of having a baby admitted to a neonatal unit/having a premature baby (specific gestation)/having a baby that required a certain treatment.

**How often will I need to go to the meetings?**

* Number of meetings/contact per year, long-term timeline
* Option of teleconference/online meetings when face-to-face is not possible

**Will I need to do anything before the meetings?**

* Amount of time required to prepare for meetings should be kept to a minimum
* Any documentation that needs to be looked over before a meeting will be sent well in advance

**Can I tell my family/friends about my role on the research project?**

* Confidentiality of content that will be discussed / other parent’s personal experiences

**What is a conflict of interest?**

* Ask to be told if a parent is involved with any other research group or funding body, related to the study. May also want to be told if family or friends are currently in NNUs as parents/staff

**How will I be supported?**

* Give a variety of options for support: researchers/external charities/local support groups
* Give the option for parents to leave the study whenever they wish, without having to give a reason

**Will you cover my expenses?**

* Details of procedures of claiming payments
* All travel expenses to meetings should be covered – provide details about what can be claimed
* Additional expenses should be considered: overnight accommodation, subsistence, childcare, training courses etc.
* You may like to include incentives for public involvement e.g. vouchers, lunch provided etc.

(INVOLVE have produced an ‘Involvement calculator’. Please click [here](http://www.invo.org.uk/resource-centre/involvement-cost-calculator/) to calculate the costs of involving parents in your project and tips to help you budget for effective involvement.)

**Who can I contact?**

Provide contact details for internal research team and external organisations such as Bliss (hello@bliss.org.uk).

Useful resources

NIHR Patient and Public Involvement

<http://www.rdslondon.co.uk/RDSLondon/media/RDSContent/files/PDFs/RDS_PPI-Handbook_web_1.pdf>

NIHR Public Co-Applicants in Research

<http://www.invo.org.uk/wp-content/uploads/2019/01/Guidance_on_public_co-applicants_Jan_2019.pdf>

INVOLVE website

<http://www.invo.org.uk/>