**Research Investigator guidelines:**

**Parent involvement in research**

Bliss encourages the involvement of parents in all stages of neonatal research. In order to effectively involve parents it is important that both you, as a researcher, and the people you involve have a shared and clear understanding of what they are being invited to do.

INVOLVE defines public involvement in research as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.

In order to ensure a positive relationship between parents and the research team we strongly advise you and your team to carefully follow and adhere to the guidelines below:

**Why them?**

* Explain why do you need these parents and their babies?
* Make your expectations clear and engage in open and honest conversations about it
* Create a role description so expectations are clear from the beginning INVOLVE have developed a [role description template](http://www.invo.org.uk/be-clear-with-the-people-you-want-to-involve/template-two/) you may find useful.
* Discuss and agree the aims of your research and how what you have agreed will be implemented.
* Provide parents with the scope to influence some of the important decisions from the very start

**Clear communications**

* Set up a terms of reference from steering, advisory and committee groups
* Avoid jargons and acronyms if parents don’t understand what you want from them or are trying to achieve they are unlikely to take part.
* Parents involved in research should receive updates on the progress and outcomes of the research they have been involved in. Even let parents know when the project is delayed or will not be progressing
  + Develop a timeline for those involved so they know when to expect feedback.
  + Bliss’ role is to help you source suitable parents to be involved in your research. In order to log how we have assisted you with your parent involvement please inform us of who has been recruited to be involved in your project and what their methods of involvement have been.
* Please provide each parent involved with the opportunity to provide feedback about their involvement experience. Please share these views with Bliss.
  + A good way of encouraging this is to ask parents to keep a research log (as little or as long as they like) this can include any questions they have, observations or feelings towards the study. This type of information may be useful to you as well. Please remember that different parents will want to engage to differing amounts, this may be due to other commitments.
* Confidentiality, data protection and the right to withdraw should be respected at all times.
  + Parents have a right to expect that their personal details will be kept securely and kept in confidence. Please do not pass on parent’s personal information to other users without their permission.
* Please always be courteous to our parents and their babies they have experienced a very traumatic event so be sure to bear this in mind and always thank them for sharing their time effort and experiences.

**Support**

**Travel and childcare costs**

All out of pocket expenses should be covered. The procedures for claiming payments, including cut-off dates for organisational systems and dates payment will be received should be made known to those involved.

Travel expenses should be covered and details should be provided about what can be claimed (e.g. public transport, taxi fares, car mileage etc.)

Additionally the following expenses should also be considered:

* overnight accommodation if applicable
* subsistence (food and refreshment whilst on ‘business’ or bought due to having to be at a certain place at a certain time)
* childcare or replacement carer/person providing support
* telephone, internet access, fax costs, stationery and other equipment
* conference fees
* Attendance of training courses or sessions.

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.

Sometimes, depending on the type of participation/engagement you would like from parents, you may like to use incentives to encourage involvement. Ideas include:

* Free prize draws for surveys returned
* Group trips
* Provide a lunch / refreshments
* Offer a crèche
* £10 - £15 shopping vouchers for attendance at an event. Vouchers can be ordered online from [http://www.vouchers4charity.org.uk](http://www.vouchers4charity.org.uk/)

**Training**

* Where necessary provide training, briefing and debriefing for parents and other appropriate parties, consult with parents as to how this takes place (could be face to place or internet based exercises).
* You could also provide statistical training for the parents involved and perhaps provide them with a certificate as this will not only give them a skill they have directly benefitted from and could perhaps add onto their cv but also help them to understand discussions around statists providing a higher level of engagement and understanding.

**Respect**

* Be flexible about meeting times. Work / study commitments this means some people may only be able to meet in the evenings, others will need to avoid school run times. When contacting people initially to find out if they want to get involved, ask what times are best for them.

**Useful resources**

**RDS London handbook**

[**http://www.rdslondon.co.uk/RDSLondon/media/RDSContent/files/PDFs/RDS\_PPI-Handbook\_web\_1.pdf**](http://www.rdslondon.co.uk/RDSLondon/media/RDSContent/files/PDFs/RDS_PPI-Handbook_web_1.pdf)

**INVOLVE website**

[**http://www.invo.org.uk/**](http://www.invo.org.uk/)