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**Research Support Policy**

Bliss exists to give every baby born premature or sick in the UK the best chance of survival and quality of life. We champion their right to receive the best care by supporting families, campaigning for change, supporting healthcare professionals, and enabling life-changing research.

In line with Bliss’ mission we are committed to supporting research that can tangibly improve outcomes for babies born premature or sick. Bliss needs to be certain that research projects are of good quality and will deliver genuine benefits to babies, parents and families. Therefore, before agreeing to support a research project, we carefully assess each proposal to check it meets our required assessment criteria. When the research relates to prematurity, we particularly welcome those proposals that fall within the top 15 uncertainties of preterm birth research identified through the [James Lind Alliance Priority Setting Partnership 2013-14](https://www.bliss.org.uk/research-campaigns/research/how-we-support-research/setting-research-priorities). We are also interested in supporting those studies that clearly demonstrate a commitment to involving parents in the research process.

**Bliss can support your research by:**

* Reviewing application materials and parent information leaflets.
* Writing a letter of support.
* Supporting parent advisory groups/PPI groups.
* Participating in the project’s steering group.
* Taking on the role as a co-applicant in appropriate cases.
* Helping to communicate around the project, and assist with dissemination of results
* Sourcing parents to assist in the design of research questions.
* Sourcing parents to sit on a steering group
* Sourcing parents to be co-applicants on a project (see guidance on [public co-applicants in research](http://www.invo.org.uk/wp-content/uploads/2019/01/Guidance_on_public_co-applicants_Jan_2019.pdf)).
* Sourcing parents to participate in the research itself

**Involving parents or ex-neonatal patients in research design / oversight**

Bliss promotes patient and public involvement and engagement (PPIE) in all stages of a research project, from the early design stages, through to the dissemination of results. 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.

Due to issues of data protection, we are unable to release the contact details of parents directly to a third party. This means that Bliss can circulate, on the researcher’s behalf, details of the research opportunity via our social media and e-publications, for researchers then to recruit parents directly.

If participating in a research project is likely to involve costs to the individual, it is important to consider these costs in advance and to be able to provide details to participants of how expenses will be reimbursed. INVOLVE’s [budgeting for involvement guidance](http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/) as well as their [Involvement Cost Calculator](http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/) may be helpful.

Parents who agree to be involved in a research project should be provided with the following information:

* **Before the project begins:**
* An easy-to-read summary of the research project in clear, jargon-free language that explains why parent involvement is important. This should include information about research aims and proposed timescales.
* A terms of reference for groups and committees.
* A ‘Parent Role Description’, which answers questions such as: ‘what is involved?’, ‘how much time will it take?’, ‘will I be paid or reimbursed for my time and any expenses such as travel?’, ‘will I be required to prepare for meetings?’ and ‘who can I contact for help and support?’ Please download our Parent Role Description template.
* Confidentiality, data protection information and the right to withdraw without having to give a reason, should be respected at all times.
* **During the project:**
* The name and contact details for a research representative should be given to parents in case they have comments or concerns at any time while being involved in the project.
* Adequate support options for those who may become distressed during meetings due to reflecting on potentially stressful experiences.
* Updates and progress of the project.
* **After the project has taken place:**
* A summary of the research results in easy-to-read, jargon-free language.
* Feedback opportunities about their involvement experience. Please share these views with Bliss.

**Parent participation in research**

Parent involvement is different to parent participation. Involvement is using members of the public to help guide and oversee a research project, whereas parent participation is where parents are contributing to the research itself i.e. recruited to a clinical trial, completing a questionnaire or participating in a focus group. The information guidance set out above for involvement is also important for parent participation. Additional things to consider in *Participation Information Leaflets* include:

* A brief summary of the potential benefits of participating in the research project for the individual and more broadly for sick/premature babies and their families.
* Any risks involved in the research.
* Data protection policies.
* External organisations that can provide support for people who may become distressed while participating in the research e.g. Bliss.
* A summary of the research results in easy-to-read, jargon-free language, regardless of whether the results are positive or negative, or whether the child involved in the study passed away at any time after recruitment/participation.

**Bliss’ expectations when supporting research**

All researchers who receive support from Bliss are asked to:

* Let us know the outcome of the funding decision (if applicable).
* Acknowledge the contributions to the research from participants (parents) and Bliss staff in any relevant research publications.
* Provide Bliss with regular updates on the progress of your research.
* Supply a short lay summary of the overall findings for possible inclusion in our publications and website.
* Supply us with copies of any articles or presentations arising from the research.
* Provide advance notice of any related media releases or publications arising from the research.

Furthermore, as a co-applicant we would expect to:

* Receive a request for our involvement at least 6 weeks in advance of the submission deadline.
* Be involved in the early stages of the development of the research project.
* Sit on the steering group of the project.

**Charges**

We may charge a fee for our services, dependant on the level of involvement you request. As a minimum, we will seek to recover any actual costs incurred by us fulfilling your request for support.

**Our promise to you**

We will:

* Undertake a full and thorough review of the request for support against our strategy and assessment criteria.
* Respond to requests for support within 2 weeks.
* Provide feedback on requests for support which are rejected by Bliss.
* Seek permission before using any partner name or logo.

**Terms and conditions for providing support**

The researchers and their host institution:

* Will complete a Bliss’ support in research request form.
* Will acknowledge the support of Bliss in any publications or reports from this project.
* Understand that by supporting this project, Bliss is not taking any responsibilities for the research and is therefore not liable for any claims of negligence, harm or oversight that might arise during the course of this research.
* Are responsible for ensuring adherence to all relevant research governance requirements including regulatory requirements.
* Understand that the use of the Bliss’ name or logo must have prior written agreement.
* Undertake to provide a lay summary of the results of this research to the research participants (parents) and to Bliss.