

Bliss' framework for research support: information for neonatal researchers

1. Introduction

At Bliss, achieving the best outcomes for babies born premature or sick – now and in the future – is at the heart of everything we do, and one of our strategic objectives is for babies born premature or sick to benefit from neonatal research that can lead to practical improvements in their care. We believe that by supporting research, we are investing in babies' futures through the continuous improvement of their care.

We are committed to working with researchers to deliver innovations in research and practice that can save vulnerable babies' lives, improve their long-term quality of life and raise standards of care. We are particularly focused on ensuring that parents, relatives and ex-neonatal patients can be involved in research from the early design stages through to the final stages of the project, so that their perspectives and views are sufficiently taken into account in all aspects of a research project.

However, as a charity our capacity to provide research support is limited, therefore we have developed the framework below to guide researchers in their applications to us, in sharing our broad priorities which inform where we are most likely to be able to agree to a research support request.

2. Overview

When we have been able to fund research, our [research strategy](#) has set out clearly the imperative that we will support research which will *tangibly improve outcomes for babies born premature or sick*, and we retain this as an overarching aspiration for our research support more broadly.

We set out below the various factors that we will take into consideration when reviewing requests for research support; these cover, in order of priority:

- Primary focus of the research
- At what point on the perinatal journey the research study / intervention is taking place
- Evidence of need for the research
- Previous support for the same project
- Role of lead researcher / research team

Given our limited capacity we will also take into account the level of support requested (see section 5 below); requests for ongoing support and/or more active involvement are more likely to be successful if they align clearly with our highest priority criteria.

3. Decision-making framework for research support

Factor	Not accepted	Low priority	Mid priority	High priority
<i>Primary focus of research</i>	<ul style="list-style-type: none"> Parents' health outcomes Parental mental health (outside of neonatal stay duration) Neonatal workforce School age children 	<ul style="list-style-type: none"> Preventing premature birth / reducing complications through antenatal interventions Specific medical products / drugs / clinical interventions 	<ul style="list-style-type: none"> Longer-term outcomes for babies born premature or sick End-of-life / bereavement care Immediate post-discharge support to improve babies' outcomes (first 6 months after discharge) 	<ul style="list-style-type: none"> Family centred care / parental involvement in care Developmental care, including impact on neurodevelopmental outcomes The most effective ways of judging whether a premature or sick baby is feeling pain Emotional and other practical support to improve attachment and bonding of premature or sick babies and their families Experience of full-term babies and their families
<i>When taking place on perinatal pathway</i>	<ul style="list-style-type: none"> More than two years after neonatal discharge (unless relates to longitudinal study) 	<ul style="list-style-type: none"> More than 6 months after neonatal discharge 	<ul style="list-style-type: none"> Antenatal period, labour and birth Up to 6 months post-discharge from neonatal care More than two years: for longitudinal outcomes only 	<ul style="list-style-type: none"> During admission on neonatal unit
<i>Evidence of need for the research / Bliss' involvement in the research</i>		<ul style="list-style-type: none"> Extensive existing evidence on the subject Other organisation is better-placed to input [see section 4 below] 	<ul style="list-style-type: none"> Some existing evidence on the subject 	<ul style="list-style-type: none"> Identified evidence gap Recommendation in national report that research needed to improve outcomes for babies Research intended to build evidence of / reduce health inequalities
<i>Previous support for project</i>			<ul style="list-style-type: none"> Involved in earlier phase of related research 	<ul style="list-style-type: none"> Included in funding application for same project
<i>Lead researcher</i>	<ul style="list-style-type: none"> Undergraduate 	<ul style="list-style-type: none"> Masters student 	<ul style="list-style-type: none"> PhD student 	<ul style="list-style-type: none"> Practising neonatal clinician Neonatal academic

4. Signposting to other charities in the sector

Bliss works closely and collaboratively with a range of other charities in the pregnancy and baby sector – including through our membership of the [Pregnancy & Baby Charities Network](#) – and we recognise that, in some cases, research requests directed at Bliss may be better supported through working with one of our partner charities; where this is the case, we will refer researchers on to our charity partners who we believe are better-placed to respond to the research request.

5. Requests for research support: process

We have two different processes through which to request research support, based on the level of support required:

- Requests for one-off, limited support should fill out [this request form](#); this covers:
 - Request for research involvement opportunities to be advertised / shared via Bliss' social media channels, with all contact going directly to the researcher
 - Letter of support from Bliss
- Requests for ongoing support and/or more active involvement should fill out [this request form](#); this covers:
 - Reviewing application materials / parent information leaflets or similar
 - Supporting parent advisory groups / PPI groups
 - Participating in the project's steering group
 - Being a co-applicant on the project
 - Actively supporting parent/patient involvement, e.g. through recruiting and facilitating focus groups
 - **Please note that as Bliss is a charity which relies on voluntary donations to fund our work, we can only provide research support of this kind where funding is made available for Bliss and/or included in the research funding application.**

In order to manage our workload and capacity effectively, relevant staff at Bliss meet monthly – typically on the second Monday of the month – to review requests received; **please therefore ensure that you submit your request a minimum of 4 weeks before you need a response, by emailing a completed copy of the relevant form to research@bliss.org.uk.**

In exceptional cases, where requests are particularly time-critical and/or relate to specific emerging issues, please email research@bliss.org.uk with an explicit request for early consideration.