

Insight and Involvement Group

Welcome to our growing community!

Thank you for completing our survey. You are a member of a group of parents, carers, family members, and people who were sick or premature babies themselves. This group has been created to help ensure that **the lived experience** of people affected by neonatal care is central to Bliss' work. It is there to make sure the voices and experiences of those closest to neonatal care are listened to, learnt from, and inform all our plans, services and activities.

As part of this group, you will be given opportunities to be involved in work right across the charity, and in research and other work which shares our vision – to give babies born premature or sick the best chance of survival and quality of life.

Thank you for your time, your efforts, and your contribution. Your voice and your experience will help babies born premature or sick.

If you have any questions about the group or want to talk to someone at Bliss about your involvement, you can email involvement@bliss.org.uk.

What work can I be involved in?

As a member of the group, you will be invited be involved in work right across the charity. You will also be asked to contribute to research projects led by others, which work towards the same aims as Bliss.

For example, you might be asked to be involved in work to:

- Help ensure our communications are focused on parents, and families and other service users.
- Help make sure research projects are informed by lived experience.
- Help shape the strategic direction of Bliss' fundraising, for example reviewing possible new fundraising initiatives.
- Help determine which research projects Bliss will support.
- Develop new information resources covering aspects of neonatal care.

During the next year we anticipate that the group will play an important role in some key projects:

- Helping to design new peer and remote services to improve our reach and the effectiveness of our support for families.

- Setting-up and supporting the development of a project to understand the 'barriers' parents face to being involved in their baby's care on the unit.
- Reviewing and evaluating our information for families.
- The development of Bliss next three-year strategy.

How can I be involved?

You will be offered different types of opportunity to be involved. Some will be designed to be quick and easy to complete, and some will ask you to invest more time. In some cases, you may be asked to meet with an individual or group more than once.

Opportunities to be involved in research carried out by others will usually involve being asked to review materials used to engage with families and others with lived experience, being asked to be interviewed or be part of a focus group to help researchers learn more about a particular topic.

We will send opportunities to be involved in Bliss work which will be one of these:

Short surveys

These will ask a small number of specific questions, for example about a communications campaign or a fundraising product.

Long surveys

These will ask more extensive questions about your experience, for example to help us develop new information resources.

Interviews and conversations

We may invite you to speak to one of our team, to talk through an aspect of your experience, for example the type of support you felt you needed at different stages in your journey and why.

Focus groups

These are small groups of 4-6 people, meeting once or twice to discuss a particular piece of work or theme.

Project involvement groups

These are small groups of 4-6 people overseeing the progress of a project over a sustained period (e.g. 3-6 months).

Consultation groups

Small to medium-sized ongoing groups of 4-20 people, with an interest or experience in a particular topic, e.g., full term and sick babies or family centered care.

How will I be contacted?

We will contact you every three months by an email newsletter, which will contain opportunities to be involved as well as updates on what we have been doing.

In between these newsletters, we will also get in touch with you directly to ask you to be involved in specific pieces of work. We will use the information you have given us in the survey to help us share opportunities that might most interest you.

How long will I be in the group for?

We expect that most people will be with the group for 12 to 24 months. We will ask annually in May whether you would like to stay with the group, and to update your preferences. If you no longer wish to be part of the group, you can let us know by emailing involvement@bliss.org.uk.

Is there anything else I need to be aware of?

While we will make sure that individual experiences are not shared with the group, some of the work you will be asked to help with may involve information being shared which is sensitive in nature or which should be treated as confidential. We will ask you to agree to manage this information appropriately at the start of any involvement where this is relevant.

We appreciate the support that you will be able to provide. **Understanding your experience is crucial to Bliss' work.** We understand that sharing your experience, and hearing about the experience of others, may be difficult. You will never be expected to share anything you do not want to share or be involved in anything which makes you feel uncomfortable. We will make sure that at the start of any involvement you are aware of the support that is available to you should you need it.

How do I ask questions if I want to know more?

You can always speak to us if you need to discuss anything, share your thoughts, ideas or concerns. The best way to make contact initially is via emailing involvement@bliss.org.uk.