



Bliss Content Review Panel

Member information pack

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Background

1. Why does Bliss exist?

Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment it needed to safely care for premature and sick babies.

Determined to do something, these volunteers formed a charity to give vulnerable babies the care they deserve. Almost 40 years later Bliss has grown into the leading UK charity for the 90,000 babies born needing neonatal care every year.

Our vision

Bliss' vision is that every baby born premature or sick in the UK has the best chance of survival and quality of life.

Our mission

Bliss champions the right for every baby born premature or sick to receive the best care. We achieve this by [empowering families, influencing policy and practice, and enabling life-changing research](#)

Our values

Trusted

We are entrusted to give voice to all babies born premature or sick. We believe that trust is earned and our actions must always be based on what is best for babies.

Supportive

We believe that developing supportive relationships is at the heart of what we do, and only by supporting others are we able to achieve our goals.

Ambitious

We always go the extra mile to deliver excellence and seek improvement in all we do.

2. What do Bliss' information and resources do?

[Bliss provides](#) specialist information for parents of babies born premature or sick. This information covers a range of topics, from being in the neonatal unit, watching and understanding your baby, feeding, and common illnesses. It is designed to empower parents with the information they need when their baby is in hospital and shortly after they have gone home, and to give them the confidence to be more involved in the care of their baby.

As well as information for families, Bliss produces campaign reports aimed at health professionals and policy makers, and non-advice products like fundraising guides.

Many of these are currently available to order free of charge as a printed copy from our [shop](#), but some are available online only. Some of the information guides can also be found in languages other than English.

3. Why do we need a Content Review Panel?

Bliss is accredited by the Information Standard, which identifies producers of reliable health and social care information. This includes print publications, online information and resources, and any posters or leaflets which might provide health information.



A big part of this accreditation is getting feedback and comments from both the public and health care professionals, to make sure that what we provide is accurate and up to date, and continues to meet our users' needs.

The Bliss Content Review Panel will help us to review and update our information as part of the Information Standard process, as well as helping us create and review content which falls out of scope of this process (e.g. information specifically created for health care professionals).

General questions

1. Who are Content Review Panel members?

The Content Review Panel will be made up of public and health care professionals who provide feedback and comments on content and information that is due for review. Members can also input on proposals for new information or resources. If relevant, you can use your experiences of neonatal care to provide insight and guidance to ensure that the information we provide is up to date and accurate, and that it meets the needs of our users. There may also be public members of the panel who do not have specific experience of neonatal care.

2. Who can be a member?

We need to receive public and expert professional feedback for all of our content and information and resources. This is part of our accreditation for the Information Standard, and is important to ensure that we have feedback from people with relevant expertise on the topic, as well as the people who will be using our resources.

Therefore we're looking for members of the public, and health professionals who have worked within neonatal care within the last 5 years, and within in the UK.

We're looking for a range feedback from both groups.

For the public members, we're looking for:

- Parents with experience of having a premature or sick baby in the UK in the last 5 years **OR**
- Parents who have had their children within the last 5 years **OR**
- Individuals who are the age of our target audience (between 18-50)

For the health professional members, we're looking for a range of skills and expertise:

It's really important that we maintain a range of professional feedback as part of our panel. This includes:

- Consultant Clinicians – experts in the various fields of neonatal care and up to date with current research
- Doctors – medical doctors taking part in neonatal care in units
- Neonatal Nurses – experienced nursing staff who are directly involved in the regular care of neonates
- Breastfeeding Nurses – nursing staff based in neonatal units who support mothers and families with breastfeeding and expressing breast milk
- Family Support Nurses – nurses who regularly focus on family-centred care in units
- Community Midwives – midwives who regularly visit new mothers in the community, once they've been discharged.
- Relevant allied health professionals

3. As a member, what will I be expected to do?

If you join the panel as a health care professional member, we need your experience and expertise to ensure that our information remains accurate and up to date. We also need to make sure we use your expertise in the creation of new information, so that we can

continue to provide the most useful and needed information, based on robust medical and social care evidence sources and research.

If you join the panel as a public member, we'd like to hear your feedback and comments on existing content and information as we conduct regular reviews of the resources we provide. If relevant, we'd like you to bring your experiences of having a child in neonatal care within the last 5 years to Bliss, so that we can make sure our content is as relevant for our users as possible. We also want to include members of the public in our focus groups for developing new information, to hear what would be useful and to make sure we're improving parental confidence in caring for their baby.

4. Can I discuss my role with friends, family and/or colleagues?

You can tell friends, family and/or colleagues that you are a member of the panel. We may also publicise your relationship with Bliss as a thank you for your contributions – for example in print versions of our information or on our website. However, we ask that you remember that we might talk about sensitive or confidential issues during the panel meetings, and in these cases, you are bound to treat these in the strictest of confidence.

For all members of the panel, we ask you to be continually aware of potential conflicts of interests, and to declare these in full both when you join the panel, and throughout your time as a panel member. We ask you to do this through completing the conflicts of interest declaration form.

Conflicts of interests may not necessarily prevent you from taking part in the panel, in fact in many cases it won't, but it's important that we're aware of them and have documented them to ensure we have a transparent content production process.

Conflicts of Interests include, but are not limited to:

- Financial conflicts:
 - Paid or consultancy work from a particular body which could influence your decision making around health care or social care policies, for example pharmaceuticals, healthcare, or biotech firms
 - Receiving funding from a particular body which could influence your decision making around health care or social care policies, for example pharmaceuticals, healthcare, or biotech firms
 - Investing personally in pharmaceuticals, healthcare, biotech or related areas which could influence your decision making around health care or social care policies
 - Donating to or holding strong affiliations with organisations or charities which could influence your decision making around health care or social care policies

- Non- financial conflicts:
 - A close personal affiliation with individuals within organisations which might influence Bliss’ production of materials. For example, affiliations with the Information Standard, NHS England, the Department of Health, other charities etc.
 - Having previously worked for or been affiliated with organisations which might influence Bliss’ production of materials. For example, affiliations with the Information Standard, NHS England, the Department of Health, other charities etc.
 - Being a board or panel member with organisations which might influence Bliss’ production of materials. For example, affiliations with the Information Standard, NHS England, the Department of Health, other charities etc.

5. How can I handle difficult topics being discussed?

Most parents will have had very difficult and sad times while their baby was in the neonatal unit. As a public panel member, you will be expected to read and comment on papers which cover issues such as survival rates for preterm babies, or serious incidents that have occurred in hospitals affecting preterm mortality (death) rates for units.

It is important to think about how this may affect you, and whether you are able to deal with upsetting issues without causing yourself undue or unbearable distress. If you have had experience of neonatal care, thinking about your baby’s stay on the neonatal unit may always be emotional, but it may still be too early for you to take part in these discussions. This is why we recommend that parents who have had personal experience of neonatal care to wait at least a year before becoming directly involved with helping Bliss with neonatal resources development, or volunteering.

Practical Questions

1. Who might contact me?

You will mostly be contacted by the Senior Information and Content Officer, but may be contacted by other members of the Information and Support Team at Bliss. By signing up to be a member of the panel, you’re also allowing Bliss to be able to contact you with news of other Bliss updates and opportunities, such as fundraising or events.

2. How will I provide feedback?

We will mostly ask for your feedback in one of two ways:

- Written feedback:
 - Email responses to specific questions or feedback forms
 - Completing online surveys
- Focus groups:
 - Regular meetings (mostly based in London but could be held elsewhere in the UK if relevant)
 - A teleconference option will be available for people unable to attend in person
 - May be just public members, health care professionals or both

3. How much of my time will it take?

We will contact you regularly with a request for written feedback, but will of course do our utmost to combine relevant requests to save you time. We will not expect to contact you any more regularly than twice a month. We will aim to have several focus groups throughout the year, and we require panel members to join at least one of these sessions, either in person or by teleconferencing. Focus groups will last around 2 hours.

4. Where will meetings be held?

Meetings will be generally held either in Bliss' head office (Crucifix Lane, London, SE1 3JW) or at a central London location. Meeting dates and times will be organised with the group's availability, and reasonable travel costs will be reimbursed. Lunch will also be provided if the meeting is held over this time of day.

5. Do I have to prepare before meetings?

Panel members will need to have read the information/resources being discussed before the meeting begins. We will send you details of the publication/resource as well as a list of questions to think about whilst reading them. You can either jot your ideas down, or just come with your ideas.

6. What if I can't attend a meeting?

We do not expect all of our panel members to be able to attend every meeting, although we will do our best to plan around a specific health care professional's availability if it's needed for a particular information/resource (e.g. a breast feeding nurse when reviewing our information on feeding).

We do ask panel members to attend at least one focus group a year.

If you've confirmed attendance but then cannot make the meeting, please provide us with as much notice as possible. If travel has already been booked but you are then unable to attend the meeting, we ask that you try to get a refund.

7. How can I resign from the panel?

Once you have joined the panel, your term is for 1 year, with the ability to continue in the role beyond this. However, you can of course resign at any time by giving us written notice. We may ask you for the reason you're resigning, so that we can keep this on record.

We will always look to replace someone who has resigned from the panel, so that we can make sure we always have enough representatives. If a health care professional panel member resigns, we will need to make sure their specific expertise is replaced too.

8. What are the terms of reference?

- The Content Review Panel will be made up of both members of the public and/or families with neonatal experience, and a range of health care professionals.
 - Feedback may be sought from these groups individually or as a joint group, where appropriate
- Both of these two groups that make up the Content Review Panel will be a minimum of 8.
- This is a voluntary role, and so panel members will not be reimbursed for their time. However, reasonable reimbursement will be made for travel to focus groups.
- Focus group meeting times and agendas will be decided ahead of the meetings, taking into account group availability.
- Meeting notes and minutes will be provided to the group within 4 weeks.