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Bliss
for babies born too soon, too small, too sick

Involving parents in research

Every year about 80,000 infants are born requiring support in a neonatal unit. This difficult start to life can have far reaching, life-long consequences, making it critically important that these babies are given the best possible care in the moments, days and weeks following birth. Bliss believes that having a strong evidence base is integral for developing better treatments, improving outcomes and helping babies reach their full potential.

Earlier this year, Bliss conducted a survey of 590 parents of premature and sick infants. The survey revealed that most parents are willing and open to consider taking part in medical research. Some said that if they had known it was an option they would have asked for more information, thereby identifying a need to share research opportunities with parents. The most common reason for parents wanting to take part was identified as a desire to help future premature or sick babies.

By working with families and researchers, Bliss can ensure that the experiences of families are listened to and learnt from. INVOLVE, a national advisory group funded by the National Institute of Health Research (NIHR), aims to empower the public to become involved in research.[1] It defines public involvement as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

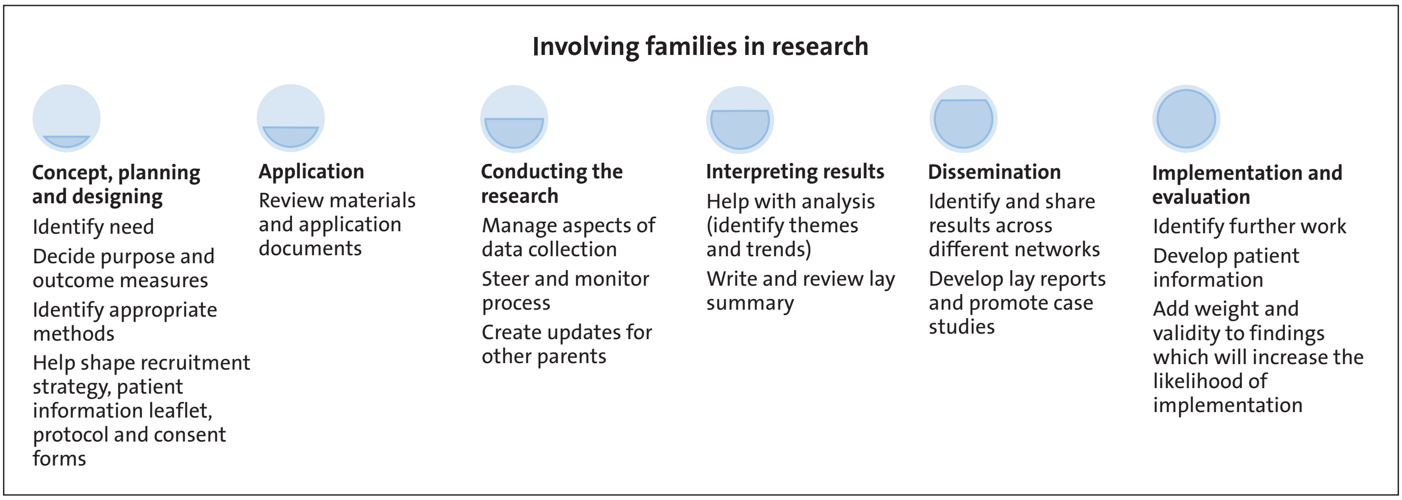
Bliss wants to make certain that research is addressing the issues that families feel are important, and encourage involvement by designing projects that families can understand and support. In this way the quality of research will improve as parents and other family members offer unique insights, ensuring the project is accessible to other members of the public and increasing the likelihood of participation.

Some funding bodies, such as NIHR, ask how patients and user groups have influenced the planning and design stages of a project, as well as any plans for further participation. Involving the public will ensure that a project is people-friendly and centred on those who are most likely to benefit from it. A number of websites can offer guidance to healthcare professionals about patient and public involvement in the research process.[2,3] Bliss believes it is best to have input from families right at the start of a project, however it is never too late for them to participate. **FIGURE 1** demonstrates how neonatal healthcare professionals can involve families at many stages of their research projects.

Since 2013 Bliss has supported over 30 projects that, in a variety of ways, have considered the views of parents and given them the opportunity to contribute. For example, Bliss took part in the preterm birth priority setting partnership with healthcare professionals and families, in which a consensus of 15 research priorities for preterm birth was decided upon.[4,5] Bliss has also contributed to various reports such as the recently launched perinatal mortality surveillance report published by MBRRACE-UK, which looked at infant mortality across the UK.[6] Bliss is part of the Neonatal Data Analysis Unit (NDAU)[7] and the National Neonatal Audit Programme (NNAP);[8] groups that look at information collected for quality improvement and audit purposes. Bliss works alongside health professionals and parents, utilising its expertise to provide a representative parent perspective.

There are several ways in which Bliss can help support neonatal healthcare professionals to conduct their research.[9] For example, Bliss can:

- provide letters of support to funders stating why there is a vital case for a project



Involving families in research

Concept, planning and designing
Identify need
Decide purpose and outcome measures
Identify appropriate methods
Help shape recruitment strategy, patient information leaflet, protocol and consent forms

Application
Review materials and application documents

Conducting the research
Manage aspects of data collection
Steer and monitor process
Create updates for other parents

Interpreting results
Help with analysis (identify themes and trends)
Write and review lay summary

Dissemination
Identify and share results across different networks
Develop lay reports and promote case studies

Implementation and evaluation
Identify further work
Develop patient information
Add weight and validity to findings which will increase the likelihood of implementation

FIGURE 1 Ways in which neonatal healthcare professionals can involve families in their research projects.

- help to organise and run steering/focus groups
- disseminate findings through its social media network, newsletter for health professionals and by a ‘Bliss briefing’
- use its extensive network of parents to find people who can participate in steering groups, be co-applicants and review material.

Bliss will continue to support parents and researchers to work together. With effective research the lives of infants can be improved and including parents in this process can make research more considerate of the difficulties parents face when they have a premature or sick baby on a neonatal unit.

For more information, visit www.bliss.org.uk/research.

References

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Case study

Helen gave birth to premature twins born at 26 weeks’ gestation. Helen and her infants participated in three trials: I2S2 (iodine supplementation in preterm infants), Hop-On (Helping Our Premature infants ON to better motor skills) and Panda (Preterm AND After). Helen said that making decisions about research made her feel more like a mum:

“As a parent on the neonatal unit I often felt marginalised; that everything was out of my control. Nurses were caring for my children when I should have been. I wasn’t the first person to touch or hold my children, I wasn’t the first person to feed them or change their nappies. The medical team was making important decisions about my children and I often felt totally powerless despite their best efforts to keep me informed and explain things. I wanted to be fully involved in my children’s care.

“It is vital that parents are involved in the planning and execution of neonatal research and in many cases it could be a great opportunity to get parents more involved in their child’s care. Having a premature baby is such an emotionally difficult time, the stress and anxieties can be overwhelming. The feelings, fears and concerns of parents need to be considered when putting together medical trials. How would doctors know if they are even asking the right questions if they haven’t asked the opinion of parents? Also parents won’t give consent if they don’t understand the research so it’s really important that the patient leaflets are well written.”

Later Helen used her experience as a parent on a neonatal intensive care unit to give feedback on the WHEAT (WithHolding Enteral feeds Around packed red cell Transfusion in preterm neonates) trial, led by Dr Chris Gale. Dr Gale tells us why he thinks the parent voice is important and the difference having a parent like Helen has had to his project:

Helen and her premature twins participated in three clinical trials.

“It seems simple common sense that parents should be involved in neonatal research right from the start. This ensures that research is relevant and important to parents and ultimately to the babies themselves. It is not surprising therefore that such involvement has more tangible benefits: research with high levels of patient involvement is over four times more likely to recruit to target than research without such involvement.

“Parental involvement has changed the trial in many ways, from how recruitment is planned to how twins are randomised, and has ensured that parent information sheets are easy to read and address concerns that might not be obvious to clinicians (such as hunger in a baby who is receiving intravenous fluid) but are to parents.”