

# Preterm birth and parent communication preferences

## What We Found

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*Parents of preterm children want to hear about the long-term challenges associated with prematurity within the first year of their child's life. Parents feel that health visitors and educational professionals are not well informed about the consequences of prematurity for development and learning<sup>1</sup>.*

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We found that parents of children who were born preterm want to receive information about the potential consequences of prematurity for development and learning when their child is still a baby. However, not all parents want this so flexibility should be offered to individual families.

As well as wanting to be well informed themselves, parents said that they would feel better supported if health care and educational professionals involved in their child's care were more knowledgeable about prematurity.

Parents feel that it is important to highlight the potential for positive progress and the benefits of early intervention and support when discussing challenges that their child might face.

They said that research into long-term outcomes related to prematurity should focus on identifying strengths and developing new interventions rather than focusing on deficits.

Parents who had previously taken part in research with their child reported positive experiences but noted the importance of sharing research findings and individualised feedback with participants.

## What We Suggest

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*Opportunities for conversations between parents and doctors should be offered early on and in a flexible way. Training about prematurity should be offered to health visitors, early years educators, and teachers.*

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Based on these findings we make the following recommendations for research and practice:

- Training about prematurity and its consequences should be provided to key stakeholders in the preterm children's care including health visitors, early years educators, special educational needs assistants and teachers
- Doctors should work with parents to offer flexibility in the timing and format of delivery of information about long-term outcomes
- Research should focus on identifying protective factors and on developing interventions designed to improve outcomes
- Research findings should be communicated to participants

# Preterm birth and parent communication preferences

## What We Did

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*Parents of children born preterm were asked to complete a survey about their attitudes and preferences around research and communication.*

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## Why We Did It

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*Children who are born preterm are more likely to experience challenges with learning and development during childhood. We wanted to ask parents when and how they wanted to be communicated with about this so that practices can be aligned to their needs and wants.*

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## Thank you

*This research could not have happened without the generosity of all the families who took part.*

We invited parents of preterm children to take part in an online survey.

The survey asked questions about:

- parent and child demographic information including whether the child experiences any challenges or has any diagnoses
- parent priorities for research and past research experiences
- parent preferences for communication
- invited parents to share or raise any other issues not covered by the specific survey questions

148 parents of children between the ages of 0 and 12 years from around the UK responded to the survey.

Children who are born preterm are more likely to experience developmental challenges. These can include things like delays in learning to speak, trouble focusing their attention, or issues with physical skills like learning to write. Although challenges like these are more common, each child will experience these challenges differently and many children will not face any long-term challenges associated with their prematurity. For this reason, it is hard for doctors to know if and when they should share information about long-term challenges with parents especially at what can be an already distressing time.

Research into the types of challenges that children born preterm can face is important for predicting which children might need extra support, what their needs might be and the best way to support them. Parent priorities for research may differ from those of researchers and clinicians and so it is important to take their priorities and opinions into consideration when designing studies.

We wanted to ask parents directly about these issues which affect themselves and their family so that research, clinical and educational practices can be aligned with their needs and priorities.

These findings are important as they help doctors to make decisions about when and how to communicate with parents. They indicate how researchers can improve the experience of participating families and highlight how the quality and breadth of support parents and children can access could be improved through training for key professionals.

1. Ginnell L, Boardman JP, Reynolds RM and Fletcher-Watson S. Parent priorities for research and communication concerning childhood outcomes following preterm birth. *Wellcome Open Res* 2021, 6:151 (<https://doi.org/10.12688/wellcomeopenres.16863.1>).

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