

Co-designed strategies for delivery of positive newborn bloodspot screening results to parents: the ReSPoND mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Plain English summary

The ReSPoND mixed-methods study

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Plain English summary

We worked with parents and health-care professionals to design strategies to promote effective communication of positive newborn bloodspot ('heel-prick') screening results. A positive screening result indicates that a child might be affected by one of nine life-changing conditions that are screened for.

First, we asked health-care professionals how they communicate positive newborn bloodspot screening results to each other and to families. We then asked health-care professionals about their experiences of giving and parents about their experiences of receiving positive screening results, and about their priorities for improving communication practices. Next, we asked parents and health-care professionals to work together to develop strategies (interventions) to address these priorities. Finally, we tried out three strategies in practice and asked health-care professionals and parents what they thought of them.

We found that health-care professionals are aware of the importance of clearly communicating positive screening results. Difficulties existed when positive screening results were communicated from laboratories to clinical teams, particularly in the case of congenital hypothyroidism. Although health-care professionals were committed to making sure that communication was carried out well, the way in which this was done varied for many reasons, including variation in the resources available and a lack of clear guidance. When our new strategies were tried out in practice, most health-care professionals and parents who were interviewed thought that they helped to improve the communication of positive screening results. However, we identified several barriers, including organisational and contextual factors, that made these strategies difficult to use in practice. The new strategies would not cost the NHS more and could be cost neutral when delivered by teleconsultations.

In summary, variation continues to exist and changing practice is difficult, but our newly developed strategies show potential to improve communication. More work is needed to test these at a larger scale.

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