

Provision of information about newborn screening antenatally: a sequential exploratory mixed-methods project

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Plain English summary

Antenatal newborn screening information

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Plain English summary

We looked at how to tell parents about newborn bloodspot screening in their baby. We considered whether parents should choose if screening happens or whether it could be carried out routinely in all babies without asking. Using published research we created a list of all of the ways that parents can be given information about screening. Through interviews and surveys we looked at parents' and midwives' preferences and opinions. We also considered the costs of giving information in different ways. We found that:

- Parents and health professionals both thought that parents should be fully informed before bloodspot screening is carried out.
- Both groups thought that this was not currently happening. Published research supports this opinion.
- Changes to increase parents' understanding and ability to make a real choice could be achieved without increasing midwife workload. Group appointments were supported as a way to enable midwives to spend longer explaining about screening without adding to their overall workload.
- To be useful, information must be provided before the baby is born, in the final 3 months of pregnancy.
- Both groups rejected the idea that everyone should receive information in the same way. Both groups wanted parents to be able to select from a range of materials and levels of information.
- Parents especially need to know that screening is optional and that samples are stored.
- Asking parents to indicate their preferences during late pregnancy was popular with parents and midwives.

These suggestions appear to be more cost-effective than current practice. We suggest that future research should measure the impact of putting these changes into practice.

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