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

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Record Status
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Authors' objectives
To collate all possible modes of prescreening communication and consent for newborn (neonatal) screening (NBS); examine midwives', screening professionals' and users' views about the feasibility, efficiency and impact on understanding of each; measure midwives' and parents' preferences for information provision; and identify key drivers of cost-effectiveness for alternative modes of information provision.

Authors' conclusions
This project highlighted the importance of focusing on information receipt and identified key communication barriers. Health professionals strongly preferred informed consent, which parents endorsed if they were made aware of sample storage. Uniform models of information provision were perceived as ineffective. A choice of information provision was supported by health professionals and parents, which both enhances cost-effectiveness and improves engagement, understanding and the validity of consent. Remaining uncertainties suggest that more research is needed before new communication modes are introduced into practice. Future research should measure the impact of the suggested practice changes (informing in third trimester, information toolkits, changed role of midwife).

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