

Study title: Providing information about newborn screening antenatally

Pre-interview information

Before the interview, we would like you to give some thought to how much information you think people should receive about newborn screening and how much of a choice parents should have. To help you do this we have enclosed two cards. One is called “how much choice?” the other is “how much information?” On each card we outline different options for offering services to parents. On the back of each card you will find some points to think about related to this issue. We will discuss your preferences in the interview, but it would be useful if you could let me know which options you prefer when I call you the day before the interview.

Please do not hesitate to telephone me if you have any questions or if you would like to discuss any of the information before the interview.

How much information should we give parents?

Options:

- d.) Parents receive information about how the heel prick test will be carried out, when they will receive the results of the test AND information about each of the conditions their baby is being screened for.
- e.) Parents receive information about how the heel prick test will be carried out, when they will receive the results of the test and information which lists the names of the conditions screened for. Parents will be told where they can get further information about each condition their baby is being screened for, should they want it.
- f.) Parents are only told that screening will take place and when they will get the results.

Points to consider

- Many of the conditions are rare
- In England we currently screen babies for 5 conditions.
- In the next few years it is likely that we will screen for more conditions (possibly around 10 different conditions). Some countries screen for many more than this and we may keep increasing the number of conditions in England.
- Much of the information about newborn screening is given during pregnancy
- How much information would you like to have about newborn screening for your baby?
- How much time would you like midwives to take to discuss screening with you?
- What should be the cost of providing information to parents about newborn screening?

How much choice

- e.) Parents can choose if their baby will be screened or not
- f.) Parents can choose if their baby will be screened or not AND if they say yes, they can choose which conditions they would like their baby to be screened for
- g.) Health care professionals will assume parents want their baby to be screened. If parents do not want their baby screened, they will have to explain the reason why to a healthcare professional
- h.) Parents do not have any choice about screening as screening is compulsory for all babies

Points to consider

- For some conditions being screened, treatment may not yet be available.
- In some cases, the information you might get from screening may not have an impact of your baby's health.
- Some conditions, if not picked up early, may require more treatment and can possibly result in worse outcomes for that child.
- How much control would you like to have over whether your baby is screened or not?
- How involved would you like healthcare professionals to be making a choice about newborn screening?
- How comfortable would you feel making a decision about screening for your baby in each of the scenarios listed above?