**Informing parents about newborn screening**

Pre-screening information provided to parents plays an important part in newborn screening (NBS) programmes. It can both support informed choice and, evidence suggests, can decrease distress when a positive newborn screening result is reported. From an analysis of the information provided by 26 European countries we summarize topics covered and the considerations taken into account by professionals when developing or updating information for parents.

**Presentation of NBS information**

It is important when providing NBS information for parents to ensure that both the content and layout are appropriate. It is advisable to not to overload parents with information and, where possible, to make use of images and pictograms to illustrate the information provided. The route by which the information is delivered should also be considered carefully taking into account that most people in their twenties and thirties will preferentially access information on mobile devices such as a tablet or mobile phone. Printed material, such as an information sheet, a leaflet or a booklet (Box 1) can also be valuable as a documentary record and access in both forms upon request may be the best option. The information, in whatever form, will need to be available in the languages commonly used in our increasingly ethnically diverse countries.

**Box 1. Three types of printed information material.**

*Information sheet*: the information about NBS is presented to fit on one A4, single or double sided.

*Leaflet*: a product that folds into three, resulting in six panels for information.

*Booklet*: consists of multiple pages with information.

It is important to remember that there are varying degrees of literacy across Europe and offering short videos can be a valuable alternative for those who would find it difficult to read the information. An example using English is shown: <https://www.youtube.com/watch?v=_afr5olIpTM> but YouTube can support a number of languages across Europe and could be used in antenatal clinics etc.

If a family has neither a PC nor smartphone and is relatively illiterate, verbal explanation by a health professional or a podcast played by the health visitor can be considered.

**Positive and negative results:**

These words can be confusing for parents and interpreted differently from their use in the screening laboratory. As the words are so widely used they may be difficult to avoid it can be helpful to provide a description to accompany the test results e.g. “positive” – indicates that the condition is suspected , “negative” means that the condition is not suspected.

**Interested in this study?**

Read it here: [Informing Parents about Newborn Screening – A European Comparison Study](https://www.mdpi.com/1013206)

Read more about the information aspects in the accompanying infographic: Information aspects for NBS information