

# Content of Newborn Screening (NBS) information



In order to provide parents with relevant information about NBS, several topics deserve attention. Based on a comparison of European information products, the following topics should be considered or evaluated for inclusion in your NBS information.

- **The purpose of screening**  
Describing the aim and importance of participation in NBS.
- **Medical implications of screening**  
Describing conditions in the programme, giving information about the conditions, and describing possible treatment options.  
Providing links for sources of additional information.
- **The likelihood of positive and negative findings**  
Describing the possible results of NBS and/or explaining the probability of positive and negative findings.
- **The possibility of false positive and false negative findings**  
Explaining that false positive and false negative results may be obtained.
- **The uncertainties and risks attached to the screening process**  
Describing the uncertainties and risks of the screening test to indicate the reliability, such as an inconclusive result of NBS and that a 'normal' screening result does not guarantee that the baby is healthy.
- **Social implications of screening**  
Describing how to deal with possible included (hereditary) conditions and mention that there are certain risk groups for some conditions.
- **Financial implications of screening**  
Describing possible costs for parents to participate in the NBS programme based on the initial screening test, not on follow-up testing and/or treatment.
- **Follow-up plans including the availability of counselling and support services**  
Describing when and how parents will be notified if the screening results are 'normal' and the next steps if the parents receive a positive NBS result.
- **Storage NBS material**  
Describing general information on storage of NBS material and/or why NBS material is stored, such as for quality control and test development or research purposes. How long the samples are stored and how access is regulated.
- **Consent parents**  
Describing if parental consent is needed to participate in NBS, and/or describing which system is used for acquiring consent and whether this consent can be for individual conditions or for screening as a whole.
- **Privacy and confidentiality**  
Describing the importance of privacy and confidentiality regarding the NBS process.
- **Performing the blood collection**  
Describing the way in which the screening test is performed.
- **Stakeholders**  
Describing stakeholders that are involved in the NBS process, and/or describing where they are involved.

