

POSTER PRESENTATION

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Evaluation of population newborn screening practices for rare disorders in member states of the European Union

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As a result of a tender launched by the European Commission, an activity has started with the aims of identifying and evaluating all aspects deemed relevant to the implementation of a public health action in newborn screening (NBS), taking into consideration the views of professionals, patients and health authorities. As a result, newborn screening practices and policies will be mapped in the whole European Union and analysed on the basis of current expert methodologies and stakeholders' views. Within the perspective that NBS is implemented as a public health initiative, a range of aspects will be considered, which ensure the feasibility and sustainability of the screening programme and its efficacy in improving population health, as well as patient care and quality of life. Moreover, challenges and opportunities resulting from NBS implementation will be identified and solutions proposed, accompanied with the information necessary to let national authorities make their own free but informed choices. Finally, the feasibility of supporting actions at the Community level will be explored in order to identify the strategies which the European Commission can adopt to promote the establishment and improvement of NBS programmes in the EU.

The expected deliverables are:

- 1) Report on the practices of NBS for rare disorders implemented in all the Member States
- 2) Expert opinion, including a decision-making matrix, on the development of European policies in the field of newborn screening for rare diseases.

- 3) A European Union Network of Experts on Newborn Screening (EUNENBS)
- 4) European Experts Consensus Workshop on Newborn Screening

At the European Conference on Rare Diseases, the questionnaire set up to collect information on NBS in the EU and the criteria for inclusion of experts in EUNENBS will be presented.

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