



Evaluation of the Linked Antenatal and Newborn Screening Programme

Newborn outcomes

Information for midwives and healthcare professionals offering newborn blood spot screening

The project began 1st September 2010 and aims to assess the outcomes of the linked antenatal and newborn screening programme. For babies with sickle cell or thalassaemia the following will be assessed:

- outcomes of newborn screening in terms of mortality and morbidity of children affected by sickle cell or thalassaemia up to age 5;
- timely entry of affected babies or children in to care
- a look back at the mothers antenatal screening history

The screening programme has approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent. (<http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/>) so you do not need to obtain consent from parents for this data to be provided.

However, it is important not to override dissent. To address this issue a section has been added to the 2014 version of the NHS "Screening tests for you and your baby" which tells parents how to contact the screening programme if they do not want their baby's identifiable data to be used to evaluate the screening programme. This information is reprinted in appendix one.

What do you need to do now:

- Read page 47 of "Screening tests for you and your baby" 2014 version.



- If the leaflet "[Screening tests for you and your baby](#)" is not available use the text given in Appendix One
- Read [Guidelines for newborn blood spot sampling, 2012](#) and [Newborn Blood spot health professional handbook](#), 2012 section 4
- Contact the Project Administrator if you want additional information about this work, email scts.evaluation@nhs.net or call 0207 848 6627
- Full details of the project and data collection forms can be obtained on the NHS Sickle Cell and Thalassaemia Screening Programme website <http://sct.screening.nhs.uk/evaluation>
- Remember you do not need to seek consent from parents for the data to be provided

Appendix one

It is also important to know that identifiable data on babies affected with sickle cell disease or thalassaemia may be used to evaluate and improve screening. If you do not wish your baby's screening data to be used in this way, email scts.evaluation@nhs.net or call 0207 848 6627. More information at: sct.screening.nhs.uk/newborn.

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