



**WELCOME to the 10th Expanded Newborn Screening newsletter. The main focus of this newsletter is an update on which activities are still ongoing. Although the period on which the evaluation is based has now finished, babies are still being screened at our sites, the communication study is about to begin, filming is underway, and we're still collecting and analysing data for our final report to the Newborn Screening Committee. We've also included a summary of the feedback we received from you all on how the ENBS pilot has run. As always, thank you for your ongoing commitment to this project, and we hope you enjoy the newsletter!**

## What are the results so far from the ENBS pilot?

The average number of days between birth and referral was 11 day

The average number of days between referral and diagnosis was 4 days (range 0-14 days)

218 parents declined screening – just 0.05% of the 437,187 babies were not screened as part of the pilot

During the ENBS pilot we identified 30 screen positives, including 12 true positives

Approx 6000 visitors to our website during the 12 months

## What are we doing now?

As 19 July 2013 was the final date for babies to be included in the data collection for the cost-effectiveness study we're now starting to pull together the final reports around the Expanded Newborn Screening programme. A preliminary report (which doesn't include cost effectiveness data) has already been submitted to the Fetal, Maternal and Child Health subcommittee of the Newborn Screening Committee (NSC) for their consideration at the end of October. An update to the systematic review conducted by the PhG foundation is imminent, and will be included in the report we submit to the NSC in November.

Whilst screening for inclusion in the study has now finished, screening is ongoing at the study sites until 31 March 2014. We've requested that midwives and health visitors continue to distribute the Expanded Screening leaflet to new parents. If you have any queries about this please contact [jason.sowter@sch.nhs.uk](mailto:jason.sowter@sch.nhs.uk) or your regional co-ordinator.

We'll provide an update on the number of births, declines, and screen positives in November.



We want your feedback and comments! We want this newsletter to be useful and interesting to you. Please provide feedback and any information that you would like including in the newsletter by contacting [k.jeays-ward@sheffield.ac.uk](mailto:k.jeays-ward@sheffield.ac.uk).

## Which activities are underway?

### Cost effectiveness study

Although the screening evaluation period ended on 19 July 2013 we are following up each true positive case for 21 weeks, which means that data collection will be ongoing until late November. Our health economists are currently building their models, and will include their first thoughts on the cost effectiveness of ENBS in the report to the NSC.

### Films

We've already worked with Optical Jukebox to produce short films introducing rare diseases and screening, and each of the five conditions. We're now producing some extra films looking at the use of emergency regimens, and what it is like for families living with recently diagnosed children.

### Communication study

Louise Moody and her team at Coventry University are about to begin the Communication Study, which will help ensure that information given to parents of screen positive children is provided at the most appropriate and least anxiety-inducing times. Louise and her team will be in touch with the clinical leads at each site shortly.

### Contact details

Dr Clare Gibson has now left the ENBS project. Dr Kathy Jeays-Ward has taken over the role of Project Manager, and can be contacted by email ([k.jeays-ward@sheffield.ac.uk](mailto:k.jeays-ward@sheffield.ac.uk)) or phone (0779 3592622).

## What did you think about the ENBS pilot?

Questionnaires were made available to midwives, clinicians and laboratory staff who had been involved in the ENBS pilot. The questionnaires were tailored to each group, and over the coming months we hope to follow up some of the feedback received. Whilst most of the feedback indicates that the project has and is running well there are clearly aspects of the project that might benefit from reflection, discussion and further development.

Thank you for your feedback...now is an excellent time to be looking at how expanded screening could be improved!

81% thought the ENBS project has proceeded without issue  
19% would do something about the project differently with hindsight  
100% thought the clinical, dietetic, and screening protocols, and the GP letters were clear, though many would like the chance to improve them  
83% thought the diagnostic protocols were clear, though many would like the chance to improve them  
100% thought the information sheet for parents is appropriate, but only 13% used the written translations, and 33% didn't know that written translations were available. 0% used the audio translations  
50% of clinicians used resources that weren't provided by ENBS whilst treating cases

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