

**UK National Screening Committee
Public Consultation
Newborn Screening Severe Combined Immune Deficiency (SCID)**

Purpose

This document provides information on the UK NSC's public consultation on newborn screening for SCID.

Background

This is the second time that the UK NSC has consulted on newborn screening for SCID. The previous review concluded that SCID was a promising candidate for a screening programme but further information on the following was needed:

- the epidemiology of condition in the UK
- the performance of the screening test in the UK
- the management and outcomes of babies who are detected by screening but do not have SCID
- the clinical and cost effectiveness of screening compared to current practice

Two new review documents go together with this note. These are:

- a systematic review of the evidence relating to three areas identified by the previous review
- the results of a modelling exercise and cost effectiveness evaluation

The modelling exercise suggests that early detection through screening is likely to improve pre and post transplant survival in those babies who are affected by SCID but who are not currently detected early as a result of a family history of SCID. The cost effectiveness evaluation suggests that screening is likely to be cost effective.

However, both documents draw attention to the limited information on screening for SCID in the UK.

Consultation

The UK NSC is proposing that a practical evaluation of newborn screening for SCID should be undertaken in the NHS. The aim of this would be to generate sufficient information on key issues to inform a recommendation on whether SCID should be added to the newborn screening panel.

These might include, but not be confined to:

- the number of healthy babies found to have low numbers of white cells (that is, a 'false positive' result) is not known
- what care and treatment is best for babies who are found to have low numbers of white cells for reasons other than SCID
- what proportion of babies are found by screening rather than as siblings
- detailed costings of the screening pathway

Details

Stakeholders are invited to comment on the consultation documents and on the UK NSC's proposal. This provides stakeholders with an opportunity to:

- make an overall statement of their views on screening for the condition being reviewed and on the standard of the review
- draw attention to disagreements with the review's recommendations or with particular aspects of a review
- highlight potential inconsistencies in the interpretation of the evidence which has been included in the review
- alert the Committee to questions or evidence which may have been omitted by a review and which may contribute to the recommendation
- suggest amendments to important errors in the wording of the review document

Public consultation for these purposes helps ensure that the Committee is informed about the views of stakeholders as it develops its recommendations.

The consultation response form can be accessed by clicking the 'feedback form' link found at <https://legacyscreening.phe.org.uk/scid>.

Deadline

The consultation will be open between 4th August 2017 and 4th November 2017.