



CEG Guide: SCID screening and childhood immunisations

What is SCID?

SCID (Severe Combined Immunodeficiency) is a group of rare, usually recessively inherited conditions that cause major immune system problems. About 1 in 40,000 babies born in England have SCID (approximately 16 babies per year). Infections that are not serious for most babies can be life-threatening for those with SCID.

About the SCID screening programme

A pilot three-year screening programme started on 1st September 2021. This large-scale trial will test two thirds of England's new-born babies for SCID as part of the new-born blood spot test, carried out routinely at five days old. The possible results are:

- SCID suspected
- SCID not suspected
- Test declined
- Test not offered

If SCID is suspected, a sample is sent to Great Ormond Street Hospital for further testing. The results may be:

- SCID positive/confirmed
- SCID ruled out/definitely negative

Results are sent to the Child Health Information Service (CHIS), BCG vaccination providers, and to the parents. If SCID is suspected or confirmed the GP will receive a direct communication from the hospital. CHIS emails a weekly file with all blood spot test results to the practice's generic email address.

Where to find test results for your patients

- Red Book entry
- Child Health Information Service (CHIS)
- Parents' new-born bloodspot screening outcome letter
- Entry in the GP record (once practice staff have coded it from the CHIS file, or hospital letter)



What practices need to do

It is important that live vaccines are avoided in infants with SCID; these include rotavirus and BCG.

Code SCID screening results as soon as you receive them.

Remind parents to bring the Red Book and the letter with the outcome of the new-born bloodspot screening when they are invited for their routine 8-week immunisation appointment.

Rotavirus

You should make reasonable efforts to ascertain the SCID screening outcome before administering rotavirus vaccine. This would involve checking for a record in the Red Book, the GP record, screening outcome information sent by CHIS, or with the parent/caregiver. In the absence of an abnormal SCID screening result, or if no result can be found, rotavirus vaccination can go ahead.

BCG

The BCG vaccine is now given to eligible babies at 28 days of age to allow time for their SCID result to be available. The neonatal BCG vaccine is administered by approved providers, eg NELFT/Vaccination UK. The role of the GP is only to refer any eligible babies (before their 1st birthday) who have missed the offer. For children over 12 months old who are eligible and seeking BCG vaccination, GP practices should refer them onto their local ICB commissioned TB service.

Useful resources

- A handy, printable [NHS flowchart on how to check for SCID outcomes \(on page 2\)](#)
- UK Health Security Agency (formerly PHE): [Rotavirus vaccine and SCID: information for GPs and practice nurses](#); [SCID screening: information for parents and carers](#)
- UK Health Security Agency (formerly PHE): [Changing the timing of the neonatal BCG immunisation programme to a 28 day immunisation programme](#); [BCG vaccination patient flowchart](#); [BCG vaccination data flowchart](#)
- Letter from NHS England: [Changing the timing of the neonatal BCG immunisation programme to a 28-day immunisation programme](#) – includes further links to educational and training materials.
- Great Ormond Street Hospital: [Severe Combined Immunodeficiency](#)

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