# SCID screening: crib sheet for blood spot takers

This information is to support conversations with parents and carers about screening for severe combined immunodeficiency (SCID). It is available digitally on [GOV.UK](http://www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications) (search for ‘Newborn blood spot screening programme supporting publications’). Please refer to the SCID parent information during discussions (also on [GOV.UK](http://www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications)). The SCID e-learning module is at [www.e-lfh.org.uk/](http://www.e-lfh.org.uk/) (search for ‘SCID’).

## SCID screening evaluation

Parents and carers can decide if their baby will have screening for SCID. Screening for SCID uses the same blood taken from the heel prick newborn blood spot screening test. It does not require any additional blood spots.

Most babies will get a ‘SCID not suspected’ result which means it is very unlikely they have SCID. A ‘SCID suspected’result means it is more likely, but not certain, that the baby will have the condition.

## SCID suspected results

The newborn screening laboratory will contact the specialist immunology team if the blood spot shows ‘SCID suspected’. This will be within about a week of taking the initial blood spot. The specialist immunology team will contact the parents or carers and invite them and their baby to attend an appointment within 2 working days.

At the appointment, an immunology specialist will examine the baby and offer the parents or carers a blood test (flow cytometry) for their baby. Most flow cytometry results will be available the same day. The flow cytometry test will confirm if the baby:

* has SCID (needs further tests)
* has another condition affecting the immune system (needs further tests)
* does not have SCID or another condition (baby discharged)

## Babies born before 37 weeks

A small proportion of babies born at less than 37 weeks who have been screened for SCID and are still in hospital will need a second sample at 37 weeks corrected gestation or on discharge, whichever is sooner.

The laboratory will request a second sample, if one is needed.

Where a repeat congenital hypothyroidism (CHT) sample is needed on discharge, the same blood spot sample can be used for this and the second SCID sample.

There is no need for a second SCID screening sample if the initial sample was taken in the community, regardless of the gestation at birth.

## Areas offering BCG

BCG is a selective neonatal programme. Eligible babies are immunised, in line with the policy outlined in chapter 32 of the Green Book on [GOV.UK](http://www.GOV.UK) (search for ‘Green Book’).

From 1 September 2021, there will be a change to the age at which parents or carers are offered the BCG vaccination for their baby. This is necessary because the BCG is a live vaccine and can make the treatment for SCID more complicated.

BCG should only be given to babies who have a ‘SCID not suspected’ or ‘SCID not offered’ result. Babies who have a ‘SCID suspected result’ should only be given BCG on the advice of a specialist.

The BCG provider is responsible for checking the SCID screening result before giving the vaccine.

The BCG vaccine should be given at about 28 days of age – by which time SCID results will be available.

## SCID screening: movers in and movers out

Most scenarios in which families move after a baby is born are straightforward. The following scenarios are to help blood spot sample takers.

**Scenario 1:** Parents or carers initially lived in a SCID screening area and had SCID information before their baby was born. However, they move to a non-SCID screening area before their baby has blood spot screening.

**Action:** Do not offer parents or carers SCID screening as part of the blood spot sample. Send blood spot card to the newborn screening laboratory following the usual process.

**Scenario 2:** First blood spot sample taken in a non-SCID screening area. Baby needs a repeat sample, by which time the parents or carers have moved to a SCID screening area.

**Action:** Do not offer the parents or carers SCID screening as part of the repeat blood spot sample and do not provide information about SCID. Midwives should tick the ‘repeat’ box on the card and send the blood spot card to the newborn screening laboratory following the usual process.

**Scenario 3:** First blood spot sample taken in a SCID screening area. Baby needs a repeat sample, by which time the parents or carers have moved into a non-SCID screening area.

**Action:** Offer parents or carers SCID screening as part of a repeat blood spot sample. Midwives should tick the ‘repeat’ box on the card and send the blood spot card to the newborn screening laboratory following the usual process.

## SCID screening: research into parents’ views and experiences

As part of newborn blood spot screening, parents should be asked if they are happy to be contacted by researchers to take part in a research project. Any such project is approved by a research ethics committee. The consent to research contact, applies to any research contact, not just to research for SCID.

Midwives are not seeking parents’ consent to be part of research. Parents are being asked to consent to be contacted by the researchers, who will explain what is involved and ask whether the parents wish to take part.

Separate consent for research contact is not required in relation to SCID. If the parents do not want to be contacted by researchers, write ‘decline research contact’ on the blood spot card.

If a parent declines research contact, their baby can still be screened for SCID and the other conditions. It is very important that this wording is used, so that it is clear that research contact is being declined and not the screening test.