Press release: Screening committee recommends trial of testing babies for SCID

Following a review of the evidence, the independent expert screening committee recommends that screening for severe combined immunodeficiency (SCID) should be tried for a period of time in the NHS.

SCID refers to a number of rare inherited conditions which affect the development of a baby's white blood cells – these are an important part of the immune system and make it difficult for babies to fight infections. Around 15 to 25 babies are born with the condition every year in the UK. The treatment is a bone marrow transplant, which can repair the damaged immune system.

The trial period will allow the committee to gather information about the practicalities and likely effect of screening before a final recommendation is made on whether to include SCID in the NHS newborn bloodspot screening programme.

Screening, as part of the newborn blood spot screening programme, would look for babies with low numbers of white blood cells as a sign that they may have SCID, but the independent committee found that more evidence is required on whether screening for the condition would do more good than harm, as it is not clear:

- how many babies may be diagnosed with having the condition when they do not (false positives)
- what care and treatment to offer babies with other conditions that cause low numbers of white blood cells

Professor Anne Mackie, Director of Programmes for the UK National Screening Committee (UK NSC), said:

> There is still uncertainty whether screening for SCID would lead to babies who are well being diagnosed with the condition and receiving unnecessary treatment. It's also unclear what would be the best care and treatment to offer babies who don't have SCID, but are found to have other immune deficiency conditions.
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> We need to find out if screening for SCID would provide overall benefits or do more harm by falsely diagnosing those without the condition. That is why the committee has recommended screening over a trial-period which will help them decide whether NHS screening for SCID should be recommended.

After careful consideration of the evidence, the UK NSC did not recommend

introducing screening programmes for the following conditions:

Newborn screening for Cytomegalovirus (CMV)

Cytomegalovirus is a common viral infection found in children and adults which doesn't always have symptoms nor need to be treated. If it is passed from mother to baby during pregnancy this is called congenital CMV infection. Screening was not currently recommended as it is not possible to know which babies are going to develop long-term health problems. So more research is needed to distinguish between babies that will suffer from the infection and babies that will not.

Human T-cell lymphotropic virus (HTLV) in pregnancy

Human T-cell lymphotropic virus (HTLV) can be passed from person to person through blood transfusion or unprotected sexual contact. HTLV infection can also be passed from mother to child. This is usually through breastfeeding for longer than 6 months. Screening was not recommended as the risk of a mother passing HTLV to their child through breastfeeding is low unless breastfeeding is continued beyond 6 months.

Newborn screening for biliary atresia

This is a rare condition that causes the bile ducts to become blocked or inflamed. Bile is a digestive fluid necessary to digest fatty acids and vitamins. If it cannot drain away from the liver, bile can build up and cause serious liver damage in the early years. Screening was not recommended as there is no reliable test which could be used to find babies with biliary atresia in the first week of life.

Iron deficiency anaemia (IDA) in children under 5 years

IDA is the most common form of anaemia and occurs when iron levels are too low to support the production of red blood cells, usually because of a lack of iron in the diet. Children aged under-5 are especially at risk. It is possible that IDA may affect a child's development, but this is not known for certain. Screening was not recommended as it is not known how many children in the UK are affected. It is uncertain whether IDA in children under the age of 5 causes adverse developmental outcomes and whether it gets better without treatment. Also a suitable test is not yet available.

The UK NSC will review all these recommendations again in 3 years as part of its regular evidence review process or earlier if significant new evidence becomes available.

The latest screening recommendations were made at the UK NSC meeting on 25 October 2017, the minutes of which are published today (6 December 2017).

Background

1. The UK National Screening Committee is independent of, but supported by, Public Health England.
2. View the detailed summaries of the recommendations for all of the conditions mentioned.
3. Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.