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## **SUMMARY OF A RECOMMENDATION BY COHERE FINLAND SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCY (SCID) USING A HEEL PRICK TEST FOR NEWBORN BABIES**

At its meeting on 25 September 2020, the Council for Choices in Health Care in Finland (COHERE Finland) adopted a recommendation on screening for severe combined immunodeficiency (SCID) using a heel prick test for newborn babies.

Newborns with severe combined immunodeficiency (SCID) do not survive past early childhood without treatment. The sooner the treatment, or stem cell transplantation, is started, the more likely it is that the child will avoid infections causing permanent damage to their body and the disorder can be cured. The timely presymptomatic diagnosis of SCID through screening improves the prognosis.

It is possible to introduce SCID screening for newborns by adding it to the existing newborn blood spot screening programme. For this reason, COHERE Finland has evaluated blood spot screening and the possibility of adding SCID to the programme by using the programme's 14 evaluation criteria that were approved by the screening work group of the Ministry of Social Affairs and Health in 2005. Based on a separate study on the quality of newborn blood spot screening,<sup>1</sup> there are quality problems with the implementation of blood spot screening; there is large regional variation and a need to improve consistent communication and information materials, the training of healthcare personnel and the ways of collecting information. The positive predictive value of SCID screening is currently too low. Once SCID screening for newborns is introduced, the BCG vaccine can no longer be given at maternity hospitals but during a separate hospital visit. Measures are needed to guarantee the vaccination coverage.

If blood spot screening was implemented to a high standard and the price of the SCID test was about EUR 4, the cost per life year gained with screening would be approximately EUR 14,800. The price of the screening test has the biggest impact on cost-effectiveness. If the incidence of SCID was only 1 in 80,000 live births, the cost per life year would rise to EUR 23,300. Giving those at risk of tuberculosis the BCG vaccine also has an impact on the cost-effectiveness of SCID screening. The vaccine cannot be administered until the results of a SCID screening test are known, and it will be given during a separate hospital visit when the baby is about two weeks old. In addition, a rise in the incidence of tuberculosis due to a possible decline in the vaccination coverage has an impact on cost-effectiveness. Cost estimates do not take account of measures that are necessary to ensure the quality of blood spot screening.

COHERE Finland considers that SCID can be added to the existing newborn blood spot screening programme as a new disease, providing that:

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<sup>1</sup> Matti Salo: [Vastasyntyneiden aineenvaihduntasairauksien seulonnan nykytilanteen selvitys](#) (Study on the current state of neonatal screening for metabolic diseases). REPORTS AND MEMORANDUMS OF THE MINISTRY OF SOCIAL AFFAIRS AND HEALTH 2020:18



1. Under the decree on concentrating specialised medical care, university hospitals assume joint responsibility for rectifying the quality problems with the newborn blood spot screening process and weaknesses in data collection as regards the activities of healthcare professionals (training, provision of information to parents and recording of such information).
2. It is possible to ensure at the national level that those who at risk of tuberculosis get the BCG vaccine at the age of about two weeks during a separate hospital visit. This can be done in a way that does not result in a decline in the vaccination coverage. The Finnish Institute for Health and Welfare has issued national guidelines on the administration of the BCG vaccine.
3. The national diagnostic threshold for SCID screening will be lowered so that the positive predictive value will exceed 10%. The possibility of further reducing the recall and retest rates must be examined.

This is a summary of a recommendation adopted by the Council for Choices in Health Care in Finland (COHERE Finland). The actual recommendation and the related background material are available in Finnish on the [website of COHERE Finland](#).

The summary of the recommendation is also available in [Finnish](#) and [Swedish](#) on the website.

The Council for Choices in Health Care in Finland (COHERE Finland) works in conjunction with the Ministry of Social Affairs and Health, and its task is to issue recommendations on services that should be included in the range of public health services. Further information about service choices in health care is available on [the COHERE Finland website](#).

