Following a review of the evidence against strict criteria, the UK NSC does not currently recommend universal screening for congenital adrenal hyperplasia (CAH) in newborns.

CAH is a rare condition caused by altered genes from both the mother and father. The severity of symptoms and the age at which they develop varies. In some cases symptoms never develop at all. It can cause serious illness in babies shortly after birth and as they get older. A child with CAH may lack the steroid hormones (a type of chemical produced naturally) that manage the amount of water and salt in the body. The infant may also have too much of a particular hormone (androgen) that can affect sexual development.

Newborn screening has been suggested as it might find babies with these disorders before they become ill. The aim of early treatment would be to improve its health and the experience of the family.

Key findings supporting the UK NSC recommendation

- UK study data suggests around 40 babies are born each year with CAH in the UK. Some evidence suggests CAH is more common in people of an Asian background. More studies are needed to better understand which groups of people would be included in any future screening programme.
- Studies suggest the current screening test (using 17-OHP immunoassay) incorrectly identifies a large number of babies as having CAH.
- Studies also suggest the accuracy of this test was much poorer in babies born early and newborn babies with a low birth weight. This means that affected babies may be missed through screening.
- There was evidence that screening might not reduce the deaths related to CAH and takes place too late to benefit people with some types of CAH.

The UK NSC regularly reviews its recommendations on screening for different conditions in the light of new research evidence becoming available.

To find out more about the UK NSC’s congenital adrenal hyperplasia recommendation, please visit:

legacy.screening.nhs.uk/congenitaladrenalhyperplasia

The UK National Screening Committee (UK NSC) advises ministers and the NHS in the 4 UK countries about all aspects of screening and supports implementation of screening programmes.

Find out more about the UK National Screening Committee at www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc. The UK NSC evidence review process is described at www.gov.uk/government/publications/uk-nsc-evidence-review-process and a list of all UK NSC recommendations can be found at legacy.screening.nhs.uk/recommendations.

The UK NSC secretariat is hosted by Public Health England (www.gov.uk/phe).