UK NSC recommendation on Hereditary Haemochromatosis

Following a review of the evidence, the UK NSC does not recommend a national population based screening programme for Hereditary Haemochromatosis (HH).

HH is an inherited condition where a fault in the HFE gene can cause iron to slowly build up in the body. Over time the extra iron is deposited around the body and organs.

Excessive iron levels can cause a number of symptoms such as fatigue, joint pain and stiffness. It can also cause more serious damage to organs such as the liver, pancreas and the heart.

It has been suggested that offering screening, by looking for the fault in the HFE gene, will help identify individuals who are at a higher risk of developing the condition. The purpose of this would be to monitor iron levels and reduce them if they get too high.

Key findings supporting the UK NSC recommendation

- Although a faulty HFE gene is known to cause iron to build up this doesn’t happen to everyone. Many people with the faulty gene do not experience any ill health.
- The UK NSC review did not find any evidence that helped improve our understanding of this. Screening would find people who would never have a problem and this may cause unnecessary worry and anxiety.
- No evidence was found which provided information on the effectiveness of a screening programme.

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 HH recommendation, please visit:

[legacyscreening.phe.org.uk/haemochromatosis](http://legacyscreening.phe.org.uk/haemochromatosis)

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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/uknsc](http://www.gov.uk/uknsc), including the UK NSC’s detailed evidence review process.

A list of all UK NSC recommendations can be found at [legacyscreening.phe.org.uk/recommendations](http://legacyscreening.phe.org.uk/recommendations)

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