Following a review of the evidence against strict criteria, the UK NSC does not currently recommend universal screening for Fragile X syndrome in pregnancy.

Fragile X syndrome results in a spectrum of intellectual disabilities ranging from mild to severe. However, the more severe learning disabilities are thought to be rare. It is more common in boys.

People affected by Fragile X can get on easily with others. But the condition can also result in social and behavioural problems such as an inability to concentrate for long periods, overactivity, and anxiety in unfamiliar social situations. The development of speech and language skills can be delayed and can continue into adulthood.

Key findings supporting the UK NSC recommendation

- Problems with the accuracy of the pre-natal genetic test, which would not give enough information about whether the baby would go on to develop Fragile X symptoms or not.

- The test is labour intensive and therefore unsuitable for a screening programme. There are alternatives, including specially designed kits, but the evidence for these is very limited.

- There is no good evidence that screening during pregnancy would mean that treating or managing the condition in the infant would improve compared to a diagnosis in childhood.

- There are no curative or preventative treatments that could be offered to those identified through screening.

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 Fragile X syndrome recommendation, please visit:

www.screening.nhs.uk/fragilex