



UK NSC recommendation on screening for cardiac conditions associated with sudden cardiac death (SCD) in the young

Following a review of the evidence against strict criteria, the UK NSC does not currently recommend systematic population screening for cardiac conditions associated with SCD in the young.

SCD is the sudden and unexpected death of a person caused by a problem with their heart. The causes in people under the age of 39 are often a thickening of the heart muscle or an electrical problem with the heart. In older people, SCD is more likely to be caused by a narrowing of the blood vessels that supply the heart.

Screening might help by identifying heart conditions at an early stage before they cause symptoms. This in turn would allow treatment to start earlier.

Key findings supporting the UK NSC recommendation

The effects of SCD can have a devastating impact on the affected individual and beyond. Our public consultation received many responses from the families and friends of people who lost their lives to SCD. They also drew attention to its even wider impact on the communities in which the families and friends live and work.

The UK NSC has very carefully considered the recommendation on screening to prevent SCD. The result of the committee's consideration was that a screening programme in all young people under the age of 39 should not be offered in the UK for the following important reasons identified by this review.

The test

A screening test must reliably identify people at risk of the condition, or outcome, the screening programme aims to prevent. This is because incorrect test results can cause harm. People with the condition who are missed by screening can be given false reassurance. People without the condition who receive positive test results can be given unnecessary tests and treatments. In these ways, screening can cause unintended harm.

The review found that most of the research on the different tests for SCD is in professional athletes whose hearts have different characteristics from non-athletes/the general population. Research like this is important, but tests can work in different ways in different groups of people. So the research we have on the tests might not provide a good indication of what they would find if all young people under the age of 39 were tested.

The review also found that the research on the tests did not report good accuracy. A high percentage of those receiving positive tests did not have a condition that may cause SCD. The reliability of the test also depends on the number of people with the condition who would be missed by the screening test. The way the research was done means that it is not possible to estimate the percentage of people who would have conditions missed by the test.

Treatment

A screening programme must be able to offer a way of treating, preventing or managing a condition when it is identified, and this treatment should be based on good evidence. This is one of the requirements for establishing any new population screening programme.

Many heart conditions put an individual at risk of SCD. The review did not find any research on treatments or interventions to prevent conditions related to SCD found by screening. The review looked at guidelines developed for people at high risk of SCD. The guidelines provided advice on how to manage some of the heart conditions. Unfortunately this advice was not based on good evidence. There was no advice in the guidelines for other heart conditions related to SCD that may be found by screening.

The review did not find any examples to show the effectiveness of screening programmes in young people for the prevention of SCD. Previous UK NSC reviews have found examples of screening programmes, but these have mainly been for professional athletes. It is not known whether systematic population screening would work to reduce deaths.

Finally, the review was concerned about the effect of receiving an incorrect positive test on people that go for screening. We know very little about this, but there are concerns that people may stop engaging in physical activities if they receive an incorrect positive result.

Screening benefits and harms

Because of these findings, it was not possible for the review to estimate the balance of benefit and harm that may come from screening all young people under the age of 39. At the moment there is guidance on testing family members of people at risk of SCD. Effective implementation of this guidance may help prevent SCD in some groups of people who are at high risk. Effective implementation of this guidance through a targeted screening programme may help prevent SCD in some groups of people who are at high risk.

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 recommendation on screening for cardiac conditions associated with sudden cardiac death (SCD) in the young, please visit:

legacyscreening.phe.org.uk/suddencardiacdeath

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. 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)