

Dear Mr Sinclair,

The UK National Screening Committee (UK NSC) has received the request from Assistant Coroner Valarie Charbit, to comment on the investigation and inquest concerning the death of Adam Ankers. The UK NSC has read the coroner's report. The Committee would firstly like to extend its deepest sympathies to Adam Ankers' family.

The UK NSC has provided a response to the sections in which it has been named. The responses provided have been shared with the Chair of the Committee and is sent from the UK NSC Secretariat.

We have endeavoured to address the specific points raised.

Section 5: Coroner's Concerns

Point C: That there is a need for better understanding of the use of defibrillators particularly by lay persons and trained first aid persons

UK NSC reply: The UK NSC is an independent scientific advisory committee that provides evidence-based recommendations to UK ministers and the NHS regarding population and targeted screening programmes. The use of defibrillators and the need to better inform the public on their use is outside of the UK NSC's remit to comment on. As is the case with screening information published for the public, the UK NSC champions the need for clear informative information to enable a lay person to understand the relevant subject matter.

Point D: That cardiac screening in those aged 14 and upwards reduces the risk of sudden cardiac death and this is not available to all young people or young football players

UK NSC reply: The UK NSC last examined the evidence for conditions that convey a risk of sudden cardiac death (SCD) in people under the age of 39 in 2019. Following a public consultation, the UK NSC recommended that a population screening programme for risk of SCD should not be introduced. The committee recognised that this was an important health problem, however it did not have the evidence to be assured that harms of screening would be outweighed by the benefits.

Firstly, there is no suitable population screening test. A poorly predictive test may a) lead to large numbers of people receiving a positive test result but who may not have a condition that can cause SCD and b) risks falsely reassuring those who might benefit from treatment.

In addition to test suitability, the UK NSC must examine whether there is an effective treatment for people identified as having the condition found by screening. Many heart conditions put an individual at risk of SCD. The 2019 review did not find any research on treatments or interventions to prevent SCD in people found by screening. The review

did, however, summarise guidelines developed for people at high risk. The guidelines provided advice on how to manage some of the relevant heart conditions.

Unfortunately, this advice was not based on good evidence, and there was no advice in the guidelines for other heart conditions that may also be found by screening. Further information on the UK NSC's 2019 review can be found on the [UK NSC recommendation page for sudden cardiac death](#).

As per the UK NSC's [evidence review process](#), the UK NSC is re-examining the evidence for SCD to see whether there has been a change in the literature base from the last review. The UK NSC will open a public consultation on SCD based on an updated evidence map which is expected in the Spring.

Point E: That cascade communication of genetic or hereditary diseases is imperfect and does not reach more than half of those in families that need to know about it.

UK NSC reply: The UK NSC seeks to recommend systematic, evidence-based population and targeted screening programmes that start with identifying everyone at risk, through to diagnosis and treatment. The pathway includes identification of the eligible population, invitation to attend screening, testing, diagnosis and treatment, and ensuring quality assurance. The UK NSC recommends screening where the benefits of screening outweigh the harms. The UK NSC cannot comment on the current provision of cascade testing at present as this is currently the responsibility of the NHS.

High risk patients with family members with hypertrophic cardiomyopathy or arrhythmogenic right ventricular cardiomyopathy should be routinely identified and cared for by the NHS Inherited Cardiac Condition (ICC) clinics. There is a project that is developing an integrated pathway which enables all families affected with SCD to access genomic testing on stored tissues and DNA when SCD is suspected. Identifying a family where an inherited cardiac condition has led to SCD means they can be tested and monitored if necessary, so their condition is managed - with the potential to save their lives.

If you have any queries regarding our response, do please get in touch.

Kind regards,

UK NSC secretariat

The UK National Screening Committee is hosted by:
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UK
National
Screening
Committee



Department
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Social Care