

# **PE2067/E: Improve data on young people affected by conditions causing Sudden Cardiac Death**

## **Minister for Public Health and Women's Health written submission, 19 April 2024**

Thank you for your consideration of our previous response and your further correspondence asking for clarification on the Scottish Government's role in informing the work of the UK National Screening Committee (UK NSC), specifically whether the Scottish Government can make recommendations to the UK NSC. I hope the information provided below is helpful.

As you know, the UK NSC does not currently recommend systematic population screening of people under the age of 39 for cardiac conditions associated with sudden cardiac death (SCD). This recommendation was last reviewed in December 2019, and details regarding the reasons they did not recommend screening can be found on their website: [Sudden cardiac death - UK National Screening Committee \(UK NSC\) - GOV.UK \(view-health-screening-recommendations.service.gov.uk\)](https://www.gov.uk/view-health-screening-recommendations.service.gov.uk)

However, the UK NSC will review this recommendation in due course, and will take account of any new evidence available to them at that time. Should they recommend a screening programme following this review, then the organisations with responsibility for screening in Scotland will advise Scottish Ministers on how to take that recommendation forward.

The UK NSC is an independent, expert advisory group which advises all four UK nations on aspects of screening. It is sponsored by the Department of Health and Social Care on behalf of the other UK countries, and is accountable to the four Chief Medical Officers of the UK, who also agree the workplan for the UK NSC and have visibility on any decisions made.

Designated representatives, including those from the Scottish Government, develop, support and deliver the UK NSC strategic plan to enable and ensure national policy alignment across the UK. Representatives from Scotland attend all UK NSC meetings and clinicians and policy officials remain in close contact to discuss any emerging issues. However, officials cannot vote on committee decisions and at all times must respect and uphold the independence of the committee in formulating its advice. For the same reason, the Scottish Government and the other governments of the UK cannot tell the UK NSC which issues it should consider or review.

The UK NSC formulates its advice and recommendations based on the best and most up to date evidence available. The process involves a robust, transparent, and comprehensive appraisal of the evidence available. Reviews provide an overview of the best quality and informative studies relevant to the internationally agreed criteria for assessing the viability, effectiveness and appropriateness of a screening programme.

Guidance on how the UK NSC assesses the evidence base against its criteria can be found here - [UK NSC evidence review process - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

Kind Regards,

**Jenni Minto MSP**

**Minister for Public Health and Women's Health**