

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

## **Cabinet Secretary for Health and Social Care written submission, 1 April 2025**

Thank you for writing to me on the important issue of young sudden cardiac death and for highlighting the evidence that the Committee has received so far.

Firstly, the Committee has requested an update on discussions that have been had with the Chief Scientist Office (CSO) about commissioning or supporting research into the impact of diseases leading to sudden cardiac death in Scotland. I can confirm that, following a meeting on 18 April 2024 with Sharon and Gordon Duncan, I asked officials to explore with the CSO any opportunities to support research into sudden cardiac death in the young.

My officials sought further advice from CSO and, consistent with previous responses provided to this Committee by the Minister for Public Health and Women's Health, it was confirmed that the CSO is a response mode funder and does not commission research on specific topics. It was reiterated that applications on sudden cardiac death are welcomed and would go through CSO's standard independent expert review process to allow funding decisions to be made. [Further information about the CSO funding schemes, the application process, and upcoming deadlines can be found at https://www.cso.scot.nhs.uk/grant-funding/.](https://www.cso.scot.nhs.uk/grant-funding/)

Scottish researchers are also able to apply to the National Institute of Health Research (NIHR) schemes that CSO buys into. Information about these opportunities is available on the CSO website. Beyond these routes, there are other large scale funders of cardiovascular research in the UK, including the British Heart Foundation – information on applications for grant funding from BHF can be found here - [What we fund - Cardiovascular Research Grants - BHF](#).

CSO also reached out to the Cardiovascular Research Network to encourage any academics in Scotland with an interest in this topic, to make a research application on sudden cardiac death via any of these routes.

With regard to the Committee's second question, asking what consideration the Scottish Government has given to commissioning a pilot study on voluntary screening. I would highlight the information provided above – that within the Scottish Government, the CSO has policy responsibility for health research and that funding opportunities are provided through a response mode scheme.

Further, the Committee has also asked what engagement the Scottish Government has had with the British Heart Foundation, Cardiac Risk in the Young (CRY) or Chest, Heart & Stroke Scotland on the commissioning of a pilot study on voluntary screening. The decision to provide funding for such a research project, or indeed to apply themselves for research funding to deliver a project on this topic, would be the individual responsibility of those organisations and therefore the Scottish Government has not engaged with the three organisations on this particular ask of the petition.

You have also drawn my attention to the written evidence provided by CRY about the misunderstanding of the incidence of Young Sudden Cardiac Deaths, and asked whether Scottish Government officials have raised this matter during its engagement with the UK National Screening Committee (NSC).

I should reiterate for the Committee that the UK NSC is an independent, expert advisory group which advises all four UK nations on aspects of screening. While representatives from Scotland attend UK NSC meetings and remain in close contact to discuss any emerging issues, they must, at all times, respect and uphold the independence of the committee in formulating its advice, which is based on the best and most up to date evidence available.

As outlined in the UK NSC response to the Committee, dated 9<sup>th</sup> May 2024, the UK NSC does not make decisions regarding which conditions to screen for based on how rare a condition is or is not. Rather, it assesses evidence against a set of internationally recognised criteria covering the condition, the test, the treatment options, and the effectiveness and acceptability of the screening programme. The details of the criteria considered by the UK NSC with regard to screening those aged under 30 for cardiac conditions associated with sudden cardiac death can be found in the evidence summary provided here (summarised on pages 8-11); [Sudden cardiac death - UK National Screening Committee \(UK NSC\) - GOV.UK](#)

In summary, challenges included;

- A lack of a sufficiently predictive test for risk of sudden cardiac death
- Often low quality evidence supporting guideline statements relating to the treatment of individuals without symptoms.

The UK NSC plans to review the evidence relating to population screening for SCD within the next three years, in line with their current work plan. The evidence review process involves consultation and engagement with stakeholders and opportunities for internal and external stakeholders, such as CRY, to draw the UK NSC's attention to developments. This is set out more fully in the [UK NSC stakeholder engagement strategy](#).

The CRY response reiterates the important issue raised by the original petition, which is that the epidemiology of sudden cardiac death remains uncertain and there is potential to improve this matter. To this end, we are working closely with the West of Scotland Inherited Cardiac Conditions Service, the Network for Inherited Cardiac Conditions (NICCS), genetics and pathology services, and the Scottish Cardiac Audit Programme, to enhance data quality and develop a robust national audit process in order that we might improve the understanding of sudden cardiac death incidence in Scotland.

Yours sincerely

**NEIL GRAY**