

Scottish Government submission of 13 December 2023

PE2067/A: Improve data on young people affected by conditions causing Sudden Cardiac Death

We are grateful to be able to respond to this petition on the important issue of young sudden cardiac death. This is a matter that the Scottish Government takes very seriously. Many of us in this parliament will have known David Hill and my thoughts are with his colleagues and family for the loss they have experienced.

This petition raises an important issue, namely that the epidemiology of sudden cardiac death in Scotland remains uncertain and there is potential to improve this matter. We acknowledge that investigation into the cause of sudden unexpected death can go on for several years and molecular autopsy, or genetic investigation, can support in the recording of a more precise cause of death.

To this end, we have recently provided funding to the West of Scotland Inherited Cardiac Conditions Service and the Network for Inherited Cardiac Conditions (NICCS) to deliver a sudden cardiac death project, which will include a focus on improving clinical pathways for families, alongside enhancing data quality and regional and national audit.

The petition particularly calls for the commissioning of research into this matter. I should outline that within the Scottish Government, the Chief Scientist Office (CSO) has policy responsibility for health research. CSO provides funding opportunities through a response mode scheme.

Further information about the CSO funding schemes, the application process, and upcoming deadlines can be found at [Response Mode Funding Schemes – Chief Scientist Office \(scot.nhs.uk\)](https://www.scot.nhs.uk/response-mode). 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.

The petition requests the setting up of a pilot study to establish if voluntary screening can reduce deaths. While decisions on research

funding are the purview of the CSO, I think it would be helpful to the Committee for me to address the matter of screening for cardiac conditions associated with sudden cardiac death in the young more broadly in this response.

In Scotland, NICCS guidance following a cardiac arrest or sudden cardiac death includes consideration of first-degree relatives, noting that appropriate family screening can be coordinated through the Inherited Cardiac Conditions service.

With regard to population level screening, the Scottish Government, along with the rest of the United Kingdom, relies on advice about screening programmes from the UK National Screening Committee (NSC), an independent expert advisory group.

The NSC does not currently recommend population screening for cardiac conditions associated with sudden cardiac death in the young. In response to recent queries on this matter, I have written to the NSC to ask whether there are plans to review this recommendation either as a) part of a regular review cycle or b) in light of the expansion of the NSC's remit to include targeted and stratified screening. I am particularly interested to understand the NSC's position on screening amateur athletes for cardiac conditions associated with sudden cardiac death in the young.

I would reiterate that the Scottish Government takes the issue of sudden cardiac death very seriously, and so we have been considering our strategy to ensure that we address this matter in Scotland as best we can.

Our strategic priorities are:

- a) To raise awareness of cardiac arrest, sudden cardiac death and inherited cardiac conditions, among medical professionals and the public.
- b) To take steps to prevent sudden cardiac death through the provision of education, symptoms awareness and CPR training to young people.

- c) To ensure that people and their families affected by cardiac arrest or sudden cardiac death can access the right support, including bereavement support where this is necessary.
- d) To support work to improve national data standardisation relating to sudden cardiac death, sudden unexpected death, and inherited cardiac conditions.

We are already taking steps to deliver on these strategic priorities. This includes funding NICCS and the West of Scotland ICC service to deliver a sudden cardiac death project, and funding a bystander cardiac arrest support line for those who have witnessed a cardiac arrest (details can be found here - [Provided CPR - Chest Heart & Stroke Scotland \(chss.org.uk\)](https://www.chss.org.uk))

We will continue to deliver on these priorities by working closely with our National Heart Disease Task Force and NICCS, to support existing programmes of work, and specifically, to deliver the sudden cardiac death project.

Alongside this, we will continue delivery of the Out of Hospital Cardiac Arrest Strategy, which has particular relevance to the strategic priorities above. Save a Life for Scotland continue to raise awareness of cardiac arrest, CPR and defibrillation, with an overall objective of increasing survival.

We will continue to consider how updates on this strategic work on sudden cardiac death could best be brought together so that those with an interest in this important issue can see the progress we are making and any further actions needed are identified.

To conclude, I would like to express my gratitude to the petitioner for raising this important issue. I trust that my response has outlined the importance with which the Scottish Government regards the issue of young sudden cardiac death, including a recognition that there is potential to improve data standardisation relating to sudden cardiac death in Scotland.

We will continue to work alongside our Heart Disease Task Force, NICCS, and Save a Life for Scotland to deliver our strategic priorities for addressing sudden cardiac death in Scotland, including the delivery of a sudden cardiac death project, a bystander support line, and continued delivery of our Out of Hospital Cardiac Arrest Strategy. Finally, we will take into consideration the advice from the UK NSC in response to our

letter regarding screening for cardiac conditions associated with sudden cardiac death in the young and will consider how this can be brought together in order that those with an interest can be updated on progress and any further actions needed are identified.

Kind regards,

**JENNI MINTO MSP
MINISTER FOR PUBLIC HEALTH AND WOMEN'S HEALTH**