

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

Chest Heart and Stroke Scotland (CHSS) written submission, 26 April 2024

Chest Heart & Stroke Scotland (CHSS) would like to thank the Citizen Participation and Public Petitions Committee for the opportunity to respond to PE2067: Improve data on young people affected by conditions causing Sudden Cardiac Death.

Firstly, we send our sincere condolences to Sharon Duncan and all of David Hill's family for their tragic loss. We welcome Sharon's work to draw parliamentary attention to this important issue.

Chest Heart & Stroke Scotland is Scotland's largest organisation supporting people with chest, heart, and stroke conditions, including Long Covid. We ensure that people across Scotland get the support they need to live full lives, including through community-based prevention and early detection services.

As part of our prevention work, we have recently introduced the use of portable ECG monitors which can identify Atrial Fibrillation. Our Health Defence team based in Maryhill, Glasgow have also worked on community detection of other conditions, such as hypertension, supporting hundreds of people to understand health risks and to be referred on for further support where required. We also deliver an Out of Hospital Cardiac Arrest (OCHA) Aftercare project to support those who witness or provide CPR to someone who experiences cardiac arrest at home or in the community.

Early detection of heart conditions saves lives and allows for the greatest chance to access successful treatment that reduces disability. As such, CHSS wants to ensure that Scotland's approach to heart condition detection and prevention reaches as many people as possible. This approach must be both comprehensive and informed by the best available evidence.

While the most recent UK National Screening Committee review does not currently recommend systematic population screening of people under the age of 39 for cardiac conditions associated with sudden cardiac death (SCD), it is important to note that this review did also conclude that 'further research is necessary to understand whether screening is effective'.

As addressed in the Petition, the SPICe briefing provided to the Committee, and in the NSC review of the evidence, the true incidence of Sudden Cardiac Death in the young is uncertain and there is a clear need to establish stronger data on this.

Since much of the available research on focuses on young athletes, there is also a clear need to understand the appropriateness of screening at a general population level, consider ways to mitigate potential unintended negative consequences of screening such as false positives, and ascertain the most effective form of screening programme. For example, while resting electrocardiograms (ECGs) may improve

diagnostic yield, research in young athletes found 25% of people affected by a disease that may lead to sudden cardiac death would still remain undetected.

CHSS believes Scottish Government commissioned research, including a pilot study on voluntary screening, could provide crucial insight and offer a valuable contribution to the current evidence base. In particular, any research undertaken should address:

- Reliability and accuracy of testing.
- Effectiveness of screening to the general population.
- Condition treatment and management when identified at screening.
- Potential unintended consequences of screening (including false positives).

Ultimately, Chest Heart & Stroke Scotland supports the petition's calls for further research, including a pilot study on voluntary screening. It is crucial that we build a robust evidence base on the impact of screening. We are very happy to engage further with the Committee on this important issue and discuss in greater detail.