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

## British Heart Foundation (BHF) Scotland written submission, 22 April 2024

Thank you for your invitation for British Heart Foundation Scotland to give views in response to PE2067: Improve data on young people affected by conditions causing Sudden Cardiac Death.

I would like to first share BHF Scotland's condolences to the family of David Hill. We applaud their work to raise awareness of sudden cardiac death and have welcomed the opportunity to hear from them at the Cross-Party Group on Heart and Circulatory Diseases, to which BHF provides the secretariat.

We note the briefing from the Scottish Parliament's Information Centre (SPICe) which highlights the uncertainty around the incidence of Sudden Cardiac Death in those aged under 35.

BHF Scotland supports the position of the Scottish Government to follow the recommendation of the UK National Screening Committee on population screening for cardiac conditions. We note that the current recommendation is against a population level screening programme, with the reasons laid out in both briefing from SPICe and the response from the Minister for Public Health and Women's Health.

Research is vital to improving our understanding of both the prevalence of the conditions that cause sudden death and how to best identify those at risk.

BHF Scotland would be supportive of any high-quality research studies into both the prevalence of conditions that cause sudden cardiac death in those under 35, as well as pilot projects that could provide further evidence around the effectiveness of screening at a whole population level.

BHF Scotland is involved in funding research into the causes of sudden cardiac death and screening for related conditions. Research funded by the BHF, alongside Cardiac Risk in the Young (CRY) has improved the interpretation of ECG tests in the screening of young athletes and demonstrated significant reductions in false positives<sup>1</sup>, and influenced protocols around testing for cardiac conditions following a sudden cardiac death<sup>2</sup>.

However, we recognise that despite this progress the methods of screening currently developed are not evidenced to be precise enough to be accurate at a population level.

<sup>&</sup>lt;sup>1</sup> Sharma et al. 2017. <u>International Recommendations for Electrocardiographic Interpretation in Athletes.</u>

<sup>&</sup>lt;sup>2</sup> Anastasakis et al. 2016. <u>Sudden unexplained death in the young: epidemiology, aetiology and value of the clinically guided genetic screening PE</u>

In addition to efforts to identify and prevent sudden cardiac events, BHF Scotland also believes that action is critical to improve survival from sudden cardiac arrest. Currently, only 1 in 10 people in Scotland survive a cardiac arrest. Whilst this figure is double the level in 2015, there are more actions to be taken and evidence shows that CPR and timely defibrillation can more than double the chances of survival.

RevivR is a new online CPR training course developed by the BHF that allows people to learn CPR in just 15 minutes without any specialist equipment – all you need is a smartphone and a cushion. To specifically support CPR skills in young people we have developed Classroom RevivR, a tool designed to teach CPR skills to 11 to 16-year-olds and is free to all educational settings.

Additionally, The Circuit is a first-of-its-kind national defibrillator network developed by the BHF and its partners that connects all defibrillators in the UK to a single network. Registering defibrillators on The Circuit allows ambulance services to quickly direct people to their nearest defibrillator. As of February 2024, there were more than 7,600 defibrillators registered on the circuit in Scotland.

BHF Scotland is committed to reducing the impact of sudden cardiac death in Scotland through research, encouraging CPR training and registering defibrillators.

BHF Scotland supports the UK National Screening Committee in their recommendation not to implement population level screening based on the most up to date available evidence. We would, however, support the funding of further research to better understand the prevalence of these conditions and how best to effectively screen for them on a whole population basis.

We would be happy to provide further details or evidence if the Committee would find this useful and look forward to any opportunities to further explore this important and urgent topic.