Petitioner submission of 7 March 2024

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

In its introduction, the SPICe briefing is slightly inaccurate in what I seek. The first bullet point should read "*Research to ... are affected by* ***conditions that cause*** *Sudden Cardiac Death*." This is an important difference as some conditions may cause an increase in morbidity in affected individuals, having an impact on health and well-being as well as the social and economic impact of these conditions on the individual, their employers and the NHS.

I believe that understanding of the incidence of these conditions, not only of the deaths caused, is essential when developing treatment pathways, which this government has supported through NICCS (Network for Inherited Cardiac Conditions Service), National Heart Disease Task Force, and OHCA (Out of Hospital Cardiac Arrest) strategy. However, the OHCA strategy looks at Cardiac Arrests (CA) in people of all ages without considering if CA was avoidable. Figure 6 of the Scottish Ambulance Service OHCA report 2019-2022 shows the OHCA worked, and from age 10-39, it shows **218** young people suffering a Cardiac Arrest in one year – 2021-2022. Although some individuals in the age scale are outwith the scope of my petition, this remains a significant number of young people.

The causes of CA can often be identified and include diagnosis of conditions that lead to a cardiac event, however for many young people affected by Sudden Cardiac Death there are no diagnosed conditions, no warning symptoms and they simply die in their sleep. It is also challenging, as a bereaved mother, that the improved clinical pathways for families are only of benefit for most people **after** the sudden loss of a family member.

As acknowledged, there is uncertainty regarding the incidence. The National Screening Committee "*stands ready to … support any high-quality research into improving the identification and management of people at risk of Sudden Cardiac Death*", providing an opportunity to commission new research, with NSC input to clarify expectations, in terms that are not open to misinterpretation. I am not a statistician and find the different ways of reporting – 2 cases /100,000 person years versus 1:300 – confusing. Much existing research has been based on

figures from England and Wales. It is represented by the figure 1.8 per 100,000 per year or 8 per week, and based on ONS data using the International Classification of Diseases (10 codes which identify possible cardiac deaths) using Class A1, A2, and A3. When considering the deaths in Class B from drowning and seizures, over 90% of these had underlying conditions associated with cardiac deaths, so 8 deaths per week is likely an understatement of the incidence of SCD. Note, these figures have not included any deaths from Scotland (or Northern Ireland), and the existing research is greatly based on incidence in athletes, which doesn't represent the incidence in the general population.

I also seek clarification of the number of young people who die from conditions associated with YSCD. This data would improve information available of the impact of YSCD on the Scottish population, and could be clarified using the ICD-10 coding, but takes no account of the deaths registered as natural causes, one of whom was my son. Post-mortem data was only available 6 months after he died, with a recommendation for genetic follow-up. It took nearly a year before we knew he had died from an undiagnosed genetic cardiac condition, and his cause of death hasn't been changed. To accurately clarify the number of young people who die requires more than a data search. This is particularly pertinent as 80% of young people who die from YSCD are fit and healthy without underlying conditions, meaning any cardiac irregularities have not been picked up and cannot be diagnosed post mortem. This leads to an outcome of natural causes, which is inaccurate but also devastating for families like mine.

Lastly, I am asking for a pilot study to establish if voluntary screening could reduce deaths in young people from the conditions leading to YSCD. I believe this could be pursued alongside the work done to establish the incidence of these conditions.

Research already exists regarding the "Diagnostic yield and financial implications of a nationwide ECG screening programme to detect cardiac disease in the young", concluding that inclusion of ECG in screening, alongside a questionnaire, gave a 5-fold increase in detection, showing this is a safe strategy to investigate incidence in the population. It is already used by athletic organisations around the world and the military of several countries as a trusted clinical tool to screen for cardiac conditions.

This government has worked to improve support and treatment pathways for families after the death and diagnosis of a loved one, and these could be modified to incorporate individuals at risk and intervention offered when the incidence is recognized. The uptake could be monitored as part of the same research, and evaluated after a set period of time.

Although the study and intervention in Italy was only with athletes, the introduction of mandatory screening in organised sport resulted in a reduction of 89% of deaths. Work has been completed here by CRY Chief Executive, Dr Steve Cox, around anxiety and detriment to well-being associated with the screening process, which showed that while the process did provoke anxiety, there was no lasting impact in the views of the participants, and the knowledge gained by individuals was sufficiently reassuring to make the process worth doing.

To compare, the NSC has recently introduced newborn screening for a condition called tyrosinaemia. Accurate incidence in the UK is unknown, and data discrepancies from Europe, US and Australia estimate between less than 1 per 944,000 births to more than 1 per 31,000 births. The screening programme reported 100% sensitivity, but the PPV (positive predictive value) varied from 40% to 100%. There was no identification of randomized controlled trials. In their report, the NSC clarify that tyrosinaemia is a rare disease that shows symptoms either before 6 months old or in later life, but can be fatal. Other forms cause significant morbidity. It is a genetic condition with an expected incidence in the UK of 1.8 per 100,000 births, screened without any UK based studies, but with clearer treatment pathways.

When comparing to SCD, it is possible to see correlation – a rare disease with fatal outcomes, potential long-term impact on individuals' health, discrepancies in the incidence, and of genetic origin.

However, this petition is not an attempt to change NSC policy today. I wish to firstly see a reduction of young people who die every year in Scotland from preventable cardiac conditions, but also to provide clear evidence to support a policy review by NSC regarding the introduction of screening in young people for SCD, and removing the need for our bereaved families to fundraise to provide this screening.

Therefore, I urge the Committee to fully support my petition. Some of what I seek may be outwith the purview of the Committee, but I believe

these strategies are possible with the backing and support from the Scottish Government. The NSC “stands ready to support high quality research” and this provides an opportunity for this Government to provide accurate data to facilitate a NSC review, but more importantly, to save the lives of young people in Scotland.