Citizen Participation and Public Petitions Committee

5th Meeting, 2024 (Session 6), Wednesday 20 March 2024

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

Petitioner	Sharon Duncan
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to commission research to establish how many people aged 14-35 are affected by conditions that cause Young Sudden Cardiac Death; clarify the number of people who die annually in Scotland from these conditions; and set up a pilot study to establish if voluntary screening can reduce deaths.
Webpage	https://petitions.parliament.scot/petitions/PE2067

Introduction

1. This is a new petition that was lodged on 14 November 2023.

2. A full summary of this petition and its aims can be found at **Annexe A**.

3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B.**

4. Every petition can collect signatures while it remains under consideration. At the time of writing, 2,035 signatures have been received on this petition.

5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. Two responses have been received from the Minister for Public Health and Women's Health and are included at **Annexe C** of this paper.

6. A submission has been provided by the petitioner. This is included at **Annexe D**.

Action

The Committee is invited to consider what action it wishes to take on this petition.

Clerks to the Committee

Annexe A

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

Petitioner

Sharon Duncan

Date lodged

14 November 2023

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to commission research to establish how many people aged 14-35 are affected by conditions that cause Young Sudden Cardiac Death; clarify the number of people who die annually in Scotland from these conditions; and set up a pilot study to establish if voluntary screening can reduce deaths.

Previous action

I have written to, and met with, my MSP, Oliver Mundell, regarding the lack of clarity in data currently available.

I have also introduced an MSP Pledge urging MSP's to support a national strategy to prevent Young Sudden Cardiac Death and help save the lives of at least 12 healthy young people who die every week. Along with other bereaved parents, I have raised money to provide screening and publicised this issue in national press and television.

Background information

On 19 March 2022, my son, David Hill, died while playing for the Parliament's rugby team in Dublin. Almost a year after his death we found that he had died from an undiagnosed genetic condition which stopped his heart.

There is no screening programme for young people with these conditions and current estimates are that there are at least 12 preventable deaths each week in the UK.

Cardiac Risk in the Young (CRY) support and fund research as well as providing screening, which is mostly funded by bereaved families. Through this, CRY believes the incidence of young people identified with a potentially fatal cardiac condition (if untreated) to be 1:300, with another 1:100 to be found with a condition that could cause serious issues later in life if not monitored. The National Screening Committee (NSC) believe the incidence to be approx. 1 or 2:100,000. This discrepancy makes it difficult to establish the benefit of funding a national strategy. With accurate data from Scotland, the NSC could revisit their decision.

Screening costs £65 per person, and initially consists of an ECG, with follow-up by cardiologists.

Annexe B

Briefing for the Citizen Participation and Public Petitions Committee on petition PE2067: Calling on the Scottish Parliament to urge the Scottish Government to commission research to establish how many people aged 14-35 are affected by conditions that cause Young Sudden Cardiac Death; clarify the number of people who die annually in Scotland from these conditions; and set up a pilot study to establish if voluntary screening can reduce deaths

Introduction - brief overview of issues raised by the petition

The petitioner is seeking three things:

- Research to establish how many young people between the ages of 14 and 35 are affected by sudden cardiac death
- How many people in that age bracket die annually in Scotland Sudden Cardiac Death
- A pilot study to find out if screening for certain heart conditions could reduce sudden cardiac deaths in this age group

Agreement on the number of young people affected by sudden cardiac death is difficult. This is because of the way deaths are classified, and particularly with this age group, because of the range of underlying conditions which could lead to sudden cardiac death. Another challenge is that much of the research has been done with athletes whose physiology and hearts are physically different from the general population.

The UK National Screening Committee, based on all the evidence and research it reviewed up to 2019, did not recommend population-wide screening for conditions leading to sudden cardiac death. Population wide screening is always a balance. As this UK Government blog, 'Why saying no to screening can be a good thing' explains:

> "Implementing a screening programme which isn't supported by the evidence would waste public money that would be better spent in other ways – for instance in providing better treatment services, researching more accurate tests or helping GPs to make earlier diagnoses. They could also hurt significant numbers of people by providing unnecessary anxiety, false reassurance or encouraging them to get treatments they don't need. Sometimes these treatments can have unpleasant or dangerous side effects."

What is sudden cardiac death in the young (< age 39) and what causes it?

According to the UK National Screening Committee:

> "Sudden Cardiac Death (SCD) is the sudden and unexpected death of a person caused by a problem with their heart. The causes in people under the age of 39 are often a thickening of the heart muscle or an electrical problem with the heart. In older people, SCD is more likely to be caused by a narrowing of the blood vessels that supply the heart."

The UK National Screening Committee (UK NSC)

The UK National Screening Committee (UK NSC) advises ministers and the NHS in the 4 UK countries about all aspects of screening and supports implementation of screening programmes.

UK NSC is part of the Department of Health and Social Care, the Welsh Government, The Scottish Government, and the Department of Health (Northern Ireland).

In the NSC's evidence review on SCD, incidence is discussed, and it is acknowledged that there is uncertainty. However, it included 11 studies where incidence in the general population was reported, in which the incidence ranged from 1.01 to 2.89 per 100,000 person-years. (see pages 26 – 30).

Much of the evidence and research into sudden cardiac death in the young is focused on young elite athletes which, the UKNSC argues, doesn't translate well to the general population. This limitation was raised a number of times throughout the report:

> "This review has 3 key limitations. Firstly, in line with UK NSC standard practice, a rapid review methodology was used to review evidence published since 2014. This approach may increase the risk that key publications are missed during the evidence selection process. Secondly, risk of bias in included studies means that there continues to be uncertainty as to the true incidence of SCD and test accuracy of screening tests. In particular, the assessment of question 2 on test accuracy was significantly limited by incomplete follow-up of screen-negative patients in studies. Thirdly, studies often focussed Page 11 on athletes, rather than the general population, leading to concerns regarding the applicability and generalisability of the evidence." (see pp10-11 of NSC evidence review)

> "Furthermore, studies were typically undertaken in athletes, thereby limiting their applicability to the general population. No relevant studies were identified that assessed the effectiveness of screening to prevent SCD compared to no screening" (p 45 of NSC evidence review).

People have sought to understand the data better and below are two examples of FOI responses. What the UK NSC makes clear, and what makes knowing incidence difficult, is the number of conditions of the heart that might lead to sudden cardiac death. Working from deaths data is not necessarily a good indicator of those who have died suddenly from a range of heart conditions, as it will not separate out those who had their condition diagnosed. Put another way, not all underlying heart conditions will lead to sudden death in the young.

A Freedom of Information (FOI) request was submitted to the Office of National Statistics (ONS) in June 2023. The ONS provided the information on data for deaths due to ‘acute myocardial infarction’ – sudden cardiac arrest for 2022. Out of 20,557 such deaths, in England and Wales, 19 were registered for the 0-29 age group. ONS also provided comparable data for the years 2013 – 2021. The number of deaths registered in that age group over those years in England and Wales ranged between 10 in 2014 to 21 in 2013.

Another FOI request was submitted in February 2023, asking about the number of deaths resulting from Sudden Adult Death Syndrome between 2018 and 2022. In their response, the ONS looked at data from different codes from ‘acute myocardial infarction’ (as used in the above request) as they are found on death certificates.

> “All of the conditions mentioned on the death certificate are coded using the International Classification of Diseases, Tenth Revision (ICD-10). From all these causes, an underlying cause of death is selected using ICD-10 coding rules. The underlying cause of death is defined by World Health Organisation (WHO) as:
>
> a) the disease or injury that initiated the train of events directly leading to death, or
>
> b) the circumstances of the accident or violence that produced the fatal injury” (ONS)

The ICD-10 codes examined were for Sudden Adult Death Syndrome (ICD-10 code R96) Cardiac Arrhythmia and Sudden Cardiac Death. The response includes a link to a spreadsheet giving the data across 5 year age bands from under 1 year to over 90 years old for England and Wales only and for each year from 2018 – 2021 inclusive.

What data is there and why is it difficult to assess incidence of SCD?

The petitioner highlights that there is not a consensus on the incidence of SCD in the UK, with estimates ranging from 12 per week in the UK, to 1.3 cases per 100,000 people aged 1 – 35 years old. The petitioner states that the UK National Screening Committee (UKNSC) believe the incidence to be 1 or 2 in 100,000.

It is not clear where CRY’s data, claiming 12 young people die each week from undiagnosed cardiac conditions has come from. A figure of 8 deaths per week in young people is addressed in an evidence report following a consultation exercise as part of review from the UKNSC in 2019:

> The characterisation of the incidence of SCD as 'low' was considered to be incorrect. In particular, some stakeholders refer to the paper by Papadakis et al (2009), which reported an incidence of 1.8 deaths per 100,000 people per year in the UK, and they state that this equates with 12 young sudden cardiac deaths per week, more than 600 young sudden cardiac deaths per year in the UK
>
> **Response**: Based on the evidence evaluated in this document, the review concluded that there remains some uncertainty as to the true incidence of SCD, although most studies in the general population reported an incidence of between 1 and 2 cases per 100,000 person-years. Limited data precluded the reviewers from drawing conclusions regarding incidence of sudden cardiac arrest (SCA) or effect of race on incidence. The paper by Papadakis et al (2009) was considered as part of this review. This paper examines deaths across the English and Welsh population and concludes that "the incidence of cardiac death in the young in England and Wales is 1.8 per 100,000 per year, which corresponds to eight young lives per week." This estimate is based on death certificate data. As noted in the review on page 26, use of death certificates to estimate SCD incidence is likely to lead to over-estimation

Incidence of an event or condition is the rate of cases over a specified period for the population at risk of that event or condition; those cases that have been newly identified. Person-years is another way of expressing incidence: it is the number of occurrences, divided by the number of people in the population included in the study in a given year.

For example: There might be 600 new cases of diabetes in a group of 100,000 people being studied over a year.

- 600 new cases divided by (100,000 x 1 year)
- 600 new cases divided by 100,000 person-years
- This would be expressed in research as 0.006 cases of diabetes per 100,000 person-years

The 12 young people per week in England and Wales referred to as dying from 'sudden cardiac death' includes a wide range of causes, including ‘*possible* cardiac deaths’ since a proportion of these deaths may represent misclassifications of cardiac deaths and in particular Sudden Adult Death Syndrome as epilepsy or drowning. The classifications used in the academic paper are shown in the table below. Office for National Statistics data was used (England and Wales), looking at the years 2002 – 2005 inclusive. In its introduction, the paper describes the variability of data in various studies.

Examples of the most frequent International Classification of Diseases-10 codes included in each class (presented in order of frequency) in the study of deaths of individuals aged 1 – 34 years.

Class	ICD-10 code
Class A1	R96: other sudden death, cause unknown
	I49.9: cardiac arrhythmia, unspecified
	I46.1: sudden cardiac death, so described
	I45.6: pre-excitation syndrome (WPW)
Class A2	I21.9: acute myocardial infarction, unspecified
	I25.1: atherosclerotic heart disease
	I42.0: dilated cardiomyopathy
	I42.9: cardiomyopathy, unspecified
Class A3	I50.9: heart failure, unspecified
	I51.9: heart disease, unspecified
	I50.1: left ventricular failure
	I50.0: congestive heart failure

Class	ICD-10 code
Class B	G40.9: epilepsy, unspecified
	G41.9: status epileptics, unspecified
	W69: drowning and submersion while in natural water
	J46: status asthmatics

Data for Scotland

National Records for Scotland collate all the data on deaths in Scotland. It is possible to see the number of deaths allocated to the various ICD-10 codes from a number of years. For the purposes of this SPICe briefing, the codes between 130 and 151, relating to deaths associated with some problems of the heart were used. However, from the other examples, it can be seen that other codings have been included or excluded. For context, there are 100 separate classifications for diseases of the circulatory system (codes 100 – 199, which will also have sub codes)

SCD occurs when no underlying heart condition has been previously diagnosed, hence the call for screening by the petitioner.

In 2022, under these codings between I30 and I51 there were 13 deaths of males between the ages of 15 and 35 and 5 women between the ages of 15 and 35. There were 5 deaths of children below the age of 15.

There were 2 deaths of males between ages 15 and 35 due to the single coding for ‘cardiac arrest’(code I46) (heart attack), and 1 female in 2022.

The table below gives the numbers of deaths from ‘other forms of heart disease’, including cardiac arrest, for males and females between the ages of 15 and 34 for each of the last 6 years in Scotland. The numbers of cardiac arrest alone will be much lower, but because sudden cardiac death can arise from a number of conditions, a broader number of classifications was selected.

Table 1 (from NRS data table 6.04: Deaths, by sex, age and with cause of death one of "I30-I51 IX. Other forms of heart disease", Scotland 2017-2022

Year	Male	Female	Total
2017	**15**	**6**	**21**
2018	**7**	**5**	**12**
2019	**10**	**11**	**21**
2020	**16**	**6**	**22**
2021	**16**	**7**	**23**
2022	**13**	**5**	**18**

Source: Vital Events Reference Tables | National Records of Scotland (nrscotland.gov.uk)

Looking at the data table 6.01, which provides the data on deaths by cause and sex between 2011 and 2022, and using the same range of codes I30 - I51 – 'Other heart diseases'. The total numbers are given in the table below. It is important to note that these are deaths from a wider range of heart conditions than sudden cardiac death, and across the whole lifespan (under age 1 to over 90 years).

Table 2 – Deaths in all age groups (NRS data table 6.01 deaths by cause and sex - ICD 10 codes I30 – I51 'other forms of heart disease'

Other heart diseases – ICD10 codes 130 - 151		**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**	**2018**	**2019**	**2020**	**2021**	**2022**
	M	553	645	705	759	775	810	799	804	804	883	908	1008
	F	746	884	874	875	1017	938	998	893	921	971	1028	1137

Source: Vital Events Reference Tables | National Records of Scotland (nrscotland.gov.uk)

Screening for risk of sudden cardiac death in people under age 39

The UK National Screening Committee does not currently recommend screening for this condition. This was last reviewed in December 2019. The Committee provides comprehensive explanation of the factors considered in making their recommendations. The next review is expected to be completed in 2024.

After a review, the Committee publishes an evidence review. This document provides the evidence on which the current UK NSC recommendation is based. In the background to this review it states:

> "The intention of screening for SCD is to detect an underlying cardiac condition, which, through the initiation of early treatment, reduces the likelihood of sudden cardiac death. Potential treatment options include lifestyle changes, drug therapy, and insertion of an implantable cardioverter defibrillator. Standard strategies for screening include a physical assessment and medical history, which may be supplemented by an electrocardiogram (ECG)."

The Committee states that for a screening test to be useful, there needs to be an effective way of treating, managing or preventing a condition, based on good evidence, for people found to have a condition through population screening (that is, the screening of healthy people). Many heart conditions put an individual at risk of SCD, and the review found no research on treatment or interventions to prevent SCD in people found by screening.

Conditions affecting the structure of the heart:

Coronary Artery Disease

Dilated Cardiomyopathy

Hypertrophic cardiomyopathy

Marfan Syndrome

Arrhythmogenic cardiomyopathy

Myocarditis

Aortic dissection

Conditions affecting the electrical conduction pathway:

Brugada syndrome

Catecholaminergic Polymorphic

Ventricular Tachycardia

Short QT syndrome

Long QT Syndrome

Wolff-Parkinson-White Syndrome (WPW)

Other reasons that screening was not recommended:

- Most research is on professional athletes, whose hearts have different characteristics, so the evidence is not useful in screening all people under age 39
- The review also found that the research on the screening tests did not report good accuracy, meaning that a high percentage of those having a positive test will not have a condition that may cause SCD. The research could also not estimate the proportion of people who would be affected but missed by the test.
- Because of the inadequate evidence from existing research there were also concerns about someone receiving an incorrect positive test, which could have a damaging and long-term effect on someone who wrongly believed they were at risk.
- They do say “At the moment, there is guidance on testing family members of people at risk of SCD. Effective implementation of this guidance through a targeted screening programme may help prevent SCD in some groups of people who are at high risk.”

The petitioner asks that a pilot study be carried out to screen for certain heart conditions. It is not clear what further evidence this might provide to the sum of research, given the issues raised by the UKNSC on the range of conditions that might or might not lead to sudden cardiac death in the young. A test has to be robust enough to provide clear and reliable positive and negative results. Also, clear treatment pathways need to be developed. Sometimes, screening can lead to over treatment or unnecessary treatment for conditions which might not manifest in a serious or life-threatening way. Overdiagnosis, false positives and overtreatment of suspected breast cancer is an example, leading to around 1 in 5 women identified through screening being unnecessarily treated for cancer that would not develop or be life threatening. According to the UK Government, around 4,000 women are offered treatment for breast cancer in the UK each year that they do not need.

Anne Jepson
Senior Researcher
17 January 2024

Annexe C

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). 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)](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

Minister for Public Health and Women's Health submission of 8 February 2024

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

I am writing to provide an update to my response to Petition PE2067, *improve data on young people affected by conditions causing Sudden Cardiac Death*, dated 13 December 2023.

I noted in that original response that the UK National Screening Committee (NSC) does not currently recommend population screening for cardiac conditions associated with sudden cardiac death in the young, and that I had written to ask whether the NSC had plans to review this recommendation.

The NSC provided a response on 27 December 2023, in which they advised that no new peer-reviewed published evidence has been provided to change the NSC's position since its most recent review, in 2019. However, the committee stands ready to review any update to the evidence base and would support any high-quality research into improving the identification and management of people at risk of sudden cardiac death.

The UK NSC will review the evidence again for screening for sudden cardiac death in due course. A date for the start of that review has not yet been finalised.

I hope this further information is helpful.

Yours sincerely,

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

Annexe D
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.