

**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.

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

Class	ICD-10 code
	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 I30 and I51, 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 I00 – I99, 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 \(nrscotland.gov.uk\)](https://nrs.scot.nhs.uk/vital-events-reference-tables/)

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
F	746	884	874	875	1017	938	998	893	921	971	1028	1137	

Source: [Vital Events Reference Tables | National Records of Scotland](https://nrs.scot.nhs.uk/vital-events-reference-tables/)  
([nrs.scotland.gov.uk](https://nrs.scotland.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

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at [spice@parliament.scot](mailto:spice@parliament.scot) Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP