

National Audit of Sudden Arrhythmic Death 2010



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The U.K. Cardiac Pathology Network (UK CPN) is a network of cardiac pathologists throughout England and Wales established to provide local coroners with an expert cardiac pathology service, and for the promotion of best pathological practice in sudden cardiac death cases.

National Audit of Sudden Arrhythmic Death 2010

First annual report: Key findings
from the National Audit of
Sudden Arrhythmic Death.

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Summary

In most middle-aged and older adults, sudden cardiac death is caused by coronary artery disease. In contrast, sudden cardiac death in individuals aged less than 35 years is frequently caused by inherited disorders of cardiac muscle (cardiomyopathies) and cardiac rhythm (ion channelopathies). The genetic nature of many of these diseases means that the relatives of young sudden cardiac death victims are at risk of similar events. In 2004, chapter 8 of the Department of Health's National Service Framework for coronary heart disease recommended family assessment when a sudden cardiac death occurs in a young person. In response to this challenge, The UK Cardiac Pathology Network (UK CPN) was formed in order to provide local coroners with an expert cardiac pathology service and to promote best pathological practice in sudden death cases. A national database allowing UK CPN pathologists to record information on cases referred to them was launched in November 2008 in partnership with the NHS Information Centre for health and social care (NHS IC) and the Department of Health. This first report describes the data collected up to October 2010.

Introduction

The UK Cardiac Pathology Network

In 2004 the Department of Health (DH) issued a consultation document on a National Service Framework (NSF) chapter dedicated to "Screening and Sudden Cardiac Death (SCD)" in the under 35 year age group. The consultation was the outcome of parliamentary lobbying over many years by support groups for families of victims of sudden cardiac death, with the added impetus of recent high-profile sudden deaths in athletes reported in the media. The document was relatively short with a brief reference to the role of pathologists in establishing the cause of death in these cases. There was no reference to the need for accurate pathological diagnosis as a pre-requisite to accurate death certification or to involvement of HM Coroner and pathologists, including referral to expert pathologists, in achieving this commendable aim. The document was brought to the attention of the Royal College of Pathologists' Histopathology Subspecialties Advisory Committee in late 2004. Responses were submitted from the College and its Autopsy Working Group and from the British Association of Cardiovascular Pathologists—a group established in 2003 by Dr. Patrick Gallagher (Southampton). The definitive NSF chapter 8, published in 2005, included among its many attachments two documents located in the Sudden Death section – the College Autopsy Scenario 1 on investigating sudden deaths of probable cardiac origin and a brief document "Information for Coroners". A year after publication, a core group met at the Heart Hospital under the chairmanship of Dr. Perry Elliott, a consultant cardiologist with a special interest in inherited heart muscle diseases. Proposals for a cardiac pathology network were drawn up together with plans to establish a national sudden arrhythmic death syndrome (SADS) pathology database to register all cases and to facilitate collaborative audit, case review and research. In the September 2006 issue of the e-newsletter of the Royal College of Pathologists an advertisement was placed asking for expressions of interest in setting up a UK-wide regionally based cardiac pathology network. Just before Christmas 2006, the College facilitated a meeting, chaired by Professor Peter Furness, to which all who expressed an interest were invited. This meeting brought together about 20 pathologists who had expressed an interest in joining a Cardiac Pathology Network with the twin aims of improving the standard of the cardiac post mortem and increasing detection of conditions leading to SCD. This informal network is now a formally constituted unaffiliated organisation, the UK Cardiac Pathology Network (UK CPN). The aims of the organisation are to develop a network of pathologists throughout England and Wales that provides local coroners with an expert cardiac pathology service and to promotion of best pathological practice in sudden death cases. To date there are 46 pathologists in the network: 28 from District General Hospital backgrounds with a high coronial workload, 8 from Forensic Pathology institutions and 10 with a declared interest in cardiac pathology (4 from teaching hospitals and 6 from specialist units, including 1 from Great Ormond Street Hospital).

Sudden Arrhythmic Death Syndrome (SADS) Database

From early 2007 the Core Group worked to develop the dataset in consultation with the NHS IC. The database was designed and β -tested in 6 pathology departments around the U.K. for a period of 3 months. Once feedback had been obtained, the database was launched in November 2008.

The database is supported by a web-based system. To register, all users must complete a Data User Certificate (Further information about registration is provided on this certificate). Access levels allows the user to create new records, edit existing records for their own hospital code, upload images and files for each record and export own data for local analysis. More detailed instructions on how to participate in the audit, and a copy of the SADS dataset, can be accessed from The NHS IC website <http://www.ic.nhs.uk/our-services/improving-patient-care/heart-disease> and by following the SADS/User information link.

Throughout 2009, feedback from pathologists using the database was collated and used to develop a second version of the database. This version went live in March 2009. The data presented in this report represents the total number of patients entered up to and including 1 October 2010.

Data Summary

The analysis in this report is derived from data up to and including 1 October 2010. 8 centres were registered with the NHS IC. All registered centres entered data during the audit period (table 1). Data on 283 cases of sudden cardiac death were available. Of these, 166 (59 per cent) were from a single centre (Royal Brompton Hospital, London). Only data submitted to the audit is included in the report. Numbers shown may not represent all cases seen in centres.

Gender and age distribution

Gender was recorded in 99 per cent of patients. The majority (64 per cent) of patients entered were male (figure 1).

The date of birth and death of patients were entered in 232 (82 per cent) of patients. Data in the remaining 51 were either missing or incorrectly recorded.

Table 1
Numbers of patients by centre

Hospital	n	%
Gloucestershire Royal Hospital	12	4.24
Great Ormond Street Hospital for Children	23	8.13
Harefield Hospital	33	11.66
Royal Brompton Hospital	166	58.66
Southampton General Hospital	44	15.55
St Thomas Hospital	3	1.06
Whiston Hospital	1	0.35
Arrowe Park Hospital	1	0.35
Total	283	100.0

Figure 1
Gender distribution

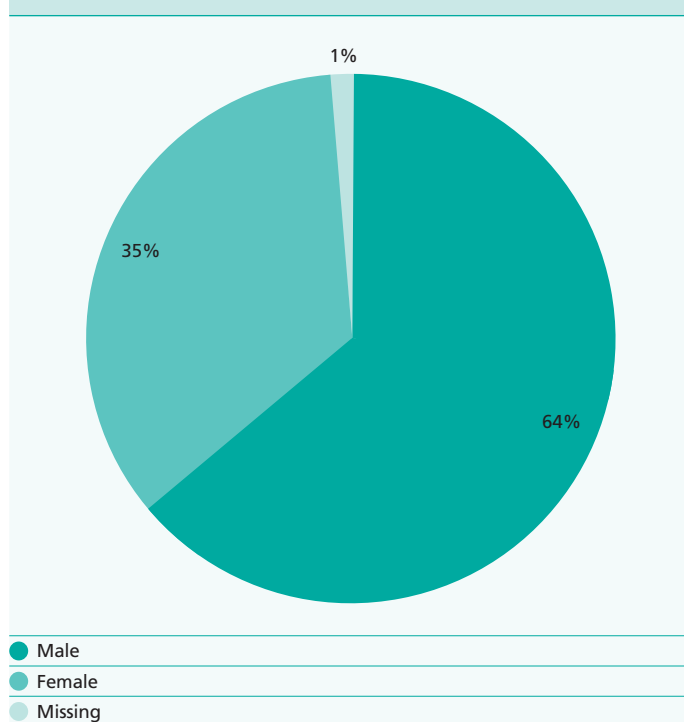
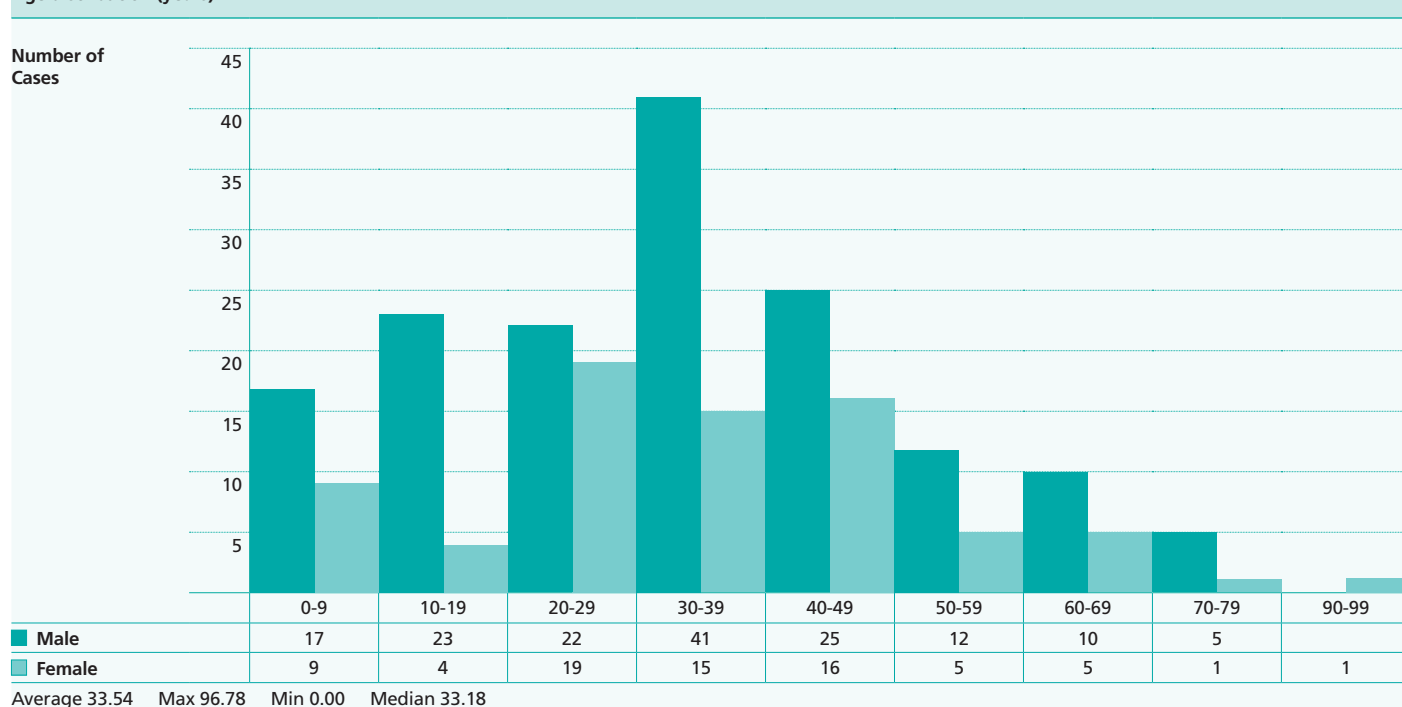


Table 2
Age distribution (years)



Ethnicity

Ethnicity was recorded in 59 per cent of records. The majority of those with available data were described as white British/other.

Circumstances of Death

The circumstances (level of activity) at the time of death were recorded in 268 (95per cent) patients.

Toxicology screen

Data on whether a toxicology screen had been performed were recorded in 262 patients. Unknown was recorded in 6 patients. Data were missing in 15 patients. A toxicology screen was performed in 166 individuals.

Ethnicity	n	%
White British/other	96	33.92
Black African/Caribbean	7	2.47
Mixed	1	0.35
Indian	1	0.35
Pakistani	3	1.06
Other ethnic	2	0.71
Unknown	6	2.12
Missing	167	59.01
Total	283	100

Circumstance	n	%
Died in bed	59	20.85
Died in sleep	11	3.89
Died at rest	100	35.34
Died during exertion	11	3.89
Died during mild exertion	11	3.89
Died during moderate exertion	15	5.30
Died immediately after exertion	4	1.41
Died during severe exertion	9	3.18
Died circumstances other	9	3.18
Died during emotional state	5	1.77
Died circumstances unknown	34	12.01
Missing 15	15	5.30
Total	283	100.00

Retention of tissue

Table 5 lists the samples that were retained following post-mortem.

Family History

Responses to the presence of a relevant family history are shown in table 6. The majority (220; 78per cent) of data were unknown or missing.

Diagnoses and comorbidities

Pathologists were asked to record their final diagnoses using the ICD coding system. Two hundred and twenty two diagnoses were entered (78 per cent of total cohort). The commonest diagnostic code was sudden cardiac death – so described (86); sixty four patients had a cardiomyopathy.

Spleen
No 80
Yes 16
Heart retained
No 204
Yes 64
Missing data 15
Tissue blocks
No 101
Yes 170
11 missing
1 unknown

Response	n
Yes < 35	2
Yes 35-60	4
Cardiomyopathy	2
Arrhythmia	1
Yes > 60	1
Premature sudden death	12
Diabetes	1
Other	11
None	29
Unknown	177
Missing	43
Total	283

Table 6
Final diagnosis

ICD10 codes	n
I011. Acute rheumatic endocarditis	1
I058. Other mitral valve diseases;I080. Disorders of both mitral and aortic valves;I350. Aortic (valve) steno-sis;I390. Mitral valve disorders in diseases classified elsewhere	1
I078. Other tricuspid valve diseases	1
I083. Combined disorders of mitral- aortic and tricuspid valves	1
I11. Hypertensive heart disease	1
I110. Hypertensive heart disease with (congestive) heart failure	1
I219. Acute myocardial infarction- unspecified	2
I24. Other acute ischemic heart diseases	1
I249. Acute ischaemic heart disease- unspecified	2
I27. Other pulmonary heart diseases	1
I270. Primary pulmonary hypertension	1
I279. Pulmonary heart disease- unspecified	1
I312. Haemopericardium- not elsewhere classified	1
I328. Pericarditis in other diseases classified elsewhere;I426. Alcoholic cardiomyopathy	1
I340. Mitral (valve) insufficiency	1
I341. Mitral (valve) prolapse	1
I342. Nonrheumatic mitral (valve) stenosis;I350. Aortic (valve) stenosis	1
I348. Other nonrheumatic mitral valve disorders;I37. Pulmonary valve disorders	1
I350. Aortic (valve) stenosis	1
I370. Pulmonary valve stenosis	1
I371. Pulmonary valve insufficiency	1
I372. Pulmonary valve stenosis with insufficiency	1
I40. Acute myocarditis	1
I400. Infective myocarditis	1
I401. Isolated myocarditis	2
I418. Myocarditis in other diseases classified elsewhere	1
I42. Cardiomyopathy	6
I420. Dilated cardiomyopathy	15
I421. Obstructive hypertrophic cardiomyopathy	11
I422. Other hypertrophic cardiomyopathy;I498. Other specified cardiac arrhythmias	1
I424. Endocardial fibroelastosis	1
I426. Alcoholic cardiomyopathy	4
I428. Other cardiomyopathies	11
I429. Cardiomyopathy- unspecified	11
I431. Cardiomyopathy in metabolic diseases	1
I432. Cardiomyopathy in nutritional diseases	2
I438. Cardiomyopathy in other diseases classified elsewhere	1
I447. Left bundle-branch block- unspecified;I45. Other conduction disorders	1
I456. Pre-excitation syndrome	1
I458. Other specified conduction disorders	1
I461. Sudden cardiac death- so described	86
I469. Cardiac arrest- unspecified	1
I490. Ventricular fibrillation and flutter	1
I50. Heart failure	1
I509. Heart failure- unspecified	1
I514. Myocarditis- unspecified	5
I516. Cardiovascular disease- unspecified	6
I517. Cardiomegaly	14
I519. Heart disease- unspecified	1
I71. Aortic aneurysm and dissection	1
I710. Dissection of aorta [any part]	6
I711. Thoracic aortic aneurysm- ruptured	1
I740. Embolism and thrombosis of abdominal aorta	1
I99. Other and unspecified disorders of circulatory system	1
Missing	61
Total	283

Key Findings

The SADS database is designed to collect data that can be used to determine the epidemiology of SADS in the population and to audit pathological practice. The data presented in this report represent a unique snapshot of the current procedures for recording sudden death cases in the United Kingdom. The data collected so far provide important information on the aetiology of SADS and the demographics of SADS victims.

Participating centres

A striking finding in the database is that a single centre, The Royal Brompton Hospital, accounts for the overall majority of the data collected. This reflects the particular interest of the cardiac pathologists at The Royal Brompton, as well as the membership and structure of the UK Cardiac Pathology Network (UK CPN). A major focus for the next 12 months for the UK CPN is to increase the participation by other pathologists and centres that are examining sudden death cases. In order to achieve this goal UK CPN will be working with the Department of Health, Royal College of Pathologists and the Coroners Society.

Data collection

The basic demographics on patients were well recorded in over 95 per cent of patients. Similarly data on the circumstances at the time of death were reasonably complete. However a substantial proportion of entry points were missing for the final diagnosis code. The feedback from participating pathologists has indicated that the current international classification of disease coding system is inadequate for describing the file pathological diagnosis. Based on this feedback, a second version of the database now includes a tailor made diagnosis field to complement the ICD coding system.

Tissue retention

The major goal of the National Service Framework for Coronary Disease (Chapter 8) and Guidelines from the Royal College of Physicians is to increase the number of samples that are retained for subsequent diagnostic purposes from sudden death victims. The splenic tissue which is essential for the subsequent genetic analysis of samples was retained in only 16 individuals. Interestingly, whole hearts were retained in 64 individuals and tissue blocks in 170 individuals. These data indicate that considerably more work needs to be done to provide coroner services and examining pathologists with the infrastructure to facilitate the retention of tissues in accordance with current Human Tissue Act Authority Rules.

Family history

The prime motives behind collection of data on sudden death is that inheritable diseases account for a significant proportion of deaths, at least in individuals aged less than 35. Data collection for this particular field was poor. This reflects the extreme difficulty that pathologists and coroner services have when trying to determine family history soon after the demise of a young sudden death victim. In order to improve data on the problems of familial disease it would be necessary to link the SADS database to the data in individuals subsequently screened clinically by cardiological and genetic services. This is the subject of ongoing discussions within the UK CPN steering group.

Conclusions

SADS in younger people is often caused by inherited cardiac disease. A Coroner's post-mortem is vital to determine the cause of death and provides the opportunity to assess the potential risk to the family. The SADS database provides pathologists with a system for recording key characteristics of SADS victims and for auditing pathological practice. To date, the database has provided epidemiological data on the frequency of sudden cardiac death as well as important demographic information. It also provides a tool that can monitor implementation of national guidelines on pathological examination. In the long-term, the database will provide information on geographic variation in the uptake of specialist cardiac pathology services and may be linked to other clinical databases to facilitate assessment of the families of young sudden death victims. A formal data committee will be constituted with representation from UK CPN, DH and Coroner's Society. The role of the committee will be to draw up rules pertaining to data analysis. In the long-term, it is hoped that the database will link to other national clinical databases to facilitate assessment of the families of young sudden death victims. One of the core principles of the database was the development of rolling reports for UK CPN and users of the audit.

The Future

The SADS audit is the culmination of a considerable effort by individuals and organisations which play an essential role in the evaluation of sudden death victims and their families. Over the next year, data from the audit will be used to develop standards and measurements of good clinical practice as it pertains to the evaluation of sudden cardiac deaths. The results will also be disseminated to Coroners and Coroners Officers in order to improve and extend co-operation with healthcare services. In parallel with this activity, the UK CPN are developing an audit of coronial autopsies for SCD scenarios. That will be rolled out 2011/12. In the medium-term, The UK CPN steering group will examine other key areas of cardiac pathology with the aim of developing quality criteria analogous to those used elsewhere in general pathology practice.

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