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Launch of the Sudden Cardiac Death pathology database

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 (cardiomyopathy) 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. Chapter 8 of the Department of Health's National Service Framework for CHD, launched in 2005 and covering arrhythmias and sudden cardiac death, emphasises the importance of family assessment when a sudden cardiac death occurs in a young person.

One of the first steps in establishing a diagnosis is expert review of the sudden death victim's heart. The recently established UK Cardiac Pathology Network (UKCPN) aims to develop a network of pathologists to provide local coroners with an expert cardiac pathology service, and promote best pathological practice in sudden death cases.

A national database allowing UKCPN pathologists to record information on cases referred to them is being formally launched today. Establishment of the database has been funded by the Department of Health. It will provide epidemiological data on the frequency of sudden cardiac death as well as important demographic information. The database will also provide information on geographic variation in the uptake of specialist cardiac pathology services. In the long-term, it is hoped that the database can be linked to other clinical databases to facilitate assessment of the families of young sudden death victims.

The database has been developed by the NHS Information Centre so the IT infrastructure is NHS-based and secure.

Patrick Gallagher, Co-chair of the UKCPN says: “This is a most welcome development. Pathologists obtain important information from careful post mortem examination of young sudden death victims. This database will ensure that this information is recorded and retained centrally. It is important that details of the post mortem examination are available to cardiologists and geneticists who will be investigating relatives of sudden death victims”.

Perry Elliott, a specialist cardiologist at the Heart Hospital in London, and a driving force behind the establishment of the database and Co-chair of the UKCPN Steering Group, says: “The establishment of a national database for young sudden death victims represents a major step-forward in the development of clinical services dedicated to the management of inherited cardiovascular disease. For the first time, we will be able to map sudden death cases across the UK and to monitor implementation of national guidelines on pathological examination. The database will also provide cardiologists and geneticists with a vital resource that will assist in the management of families affected by inherited cardiovascular conditions”.

Professor Peter Furness, President-Elect of the Royal College of Pathologists, said: The College welcomes this initiative and would emphasise the importance of high-quality, standardised post mortem examinations that help identify genetic cardiac disorders that may cause sudden unexpected deaths in young people. We hope that the data leads to a better understanding of these disorders and, ultimately, better outcomes for families, especially for those who have suffered the loss of a loved one.

Dr John Clark, Secretary of the British Association in Forensic Medicine says: “The British Association in Forensic Medicine is pleased to support the development of the SCD Pathology Database. We see it as an important part of the work of the UK Cardiac Pathology Network in developing protocols to assist coroners, pathologists and, importantly, families in the appropriate investigation of these tragic deaths”.

Michael Burgess, a coroner who has been instrumental in the development of sudden cardiac death services generally, says on behalf of the Coroners’ Society: “The Coroners’ Society of England and Wales welcomes the establishment of this database as being as being an invaluable source of the best information relating to sudden cardiac death and, potentially, a tool in the recognition (and subsequent diagnosis and treatment among surviving family members) of congenital cardiac conditions. The Society believes that, in time, it could prove to have wider research capabilities and even prove to be a model for use in other health related areas”.

John Coopey, on behalf of the Coroners’ Officers Association says: “The Coroners’ Officers’ Association is pleased to be associated with the development of this database. We see the information it will collect being of great benefit to pathologists and the coroners service, but most importantly to families by giving them clear information on cause of sudden cardiac death and so help reduce the number of such deaths.

Professor Roger Boyle, National Director for Heart Disease and Stroke at the Department of Health says: “I congratulate Patrick, Perry and all of their colleagues on the work they have done in getting this database up and running. It will make an enormous difference immediately following one of these tragic instances when investigating the causes of a sudden death is so crucial. The establishment of the UKCPN, the launch of this database and the upcoming launch of the British Heart Foundation’s Genetic Information Service in February, represent key major milestones in the development of sudden cardiac death services and will lead to more families getting the expert information, advice, treatment and support they need”.