SAD Cases in the Coroners’ Courts

REPORT OF A CONFERENCE AT THE UNIVERSITY OF OXFORD
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The Foundation for Law, Justice and Society

Courts and the Making of Public Policy

In the last fifty years, courts have emerged as key participants in the public policymaking process, exercising discretion to make decisions which have far-reaching consequences in terms of the distribution of benefits and burdens within society.

This programme provides a critical assessment of the role of courts in the public policymaking process, assessing their level of influence and scrutinizing the efficacy and legitimacy of their involvement.

The programme considers a range of issues within this context, including:
- the relationship between courts, legislatures, and executives
- how judicial policymaking fits within a democratic society
- what training and qualifications judges have for policy decisions
- how suitable the judicial forum is for handling policy choices.

SAD Cases in the Coroners’ Courts

This is a report of a conference organized by the Centre for Socio-Legal Studies, University of Oxford, in association with the Foundation for Law, Justice and Society, to explore legal and medical aspects of coroners’ inquests into sudden adult deaths. The conference was funded by grants from the Foundation for Law, Justice and Society, The British Heart Foundation, and the University of Oxford’s Law Faculty. Professor Hugh Watkins chaired the conference. The Guest Lecturer was Michael Burgess OBE, HM Coroner of the Royal Household and Legal Secretary of the Coroners’ Society of England & Wales.
Foreword
Michael Burgess OBE, HM Coroner of the Royal Household and Legal Secretary of the Coroners’ Society of England and Wales

The conference was a worthwhile exercise: it gave medical practitioners of various disciplines opportunities to contribute to a worthwhile debate. It may not have settled anything very much (or at all) but cross-discipline debates such as this are critical if there is to be mutual understanding and respect and if ‘lessons’ are to be learnt.

Acronyms are often a problem, as was well demonstrated at the conference. They develop for very good reasons and with an initial set of criteria, but all too often the underlying basis is overlooked and the definition extended.

There is a general problem with categorizing a death where there is no identified medical cause of death. The problem was acute with infants and, as we now know, gave rise to the sudden infant death syndrome (SIDS) or sudden unexpected deaths in infants (SUDI) where, despite exhaustive tests, no cause of death could be found. As there was no evidence of any unnatural element to the death, the presumption (not, I suggest, an unreasonable one) was that it should be classified as ‘natural’. The alternative would have been an inquest with an ‘open’ verdict (i.e., that in which the evidence does not show how the cause of death arose).

Applying this same principle to other deaths, i.e., that in the absence of any evidence of an unnatural element to the death, even if there is no certain medical cause of death demonstrated at post-mortem, on the balance of probabilities it follows that it may not be unreasonable to classify it as a natural death of unknown cause. The generally accepted view is that these are often sudden deaths with a cardiac origin, hence the focus that, over the years, we have given to post-mortem analysis of the cardiac system.

This conference took place whilst Inquests and Coroners were regulated by the Coroners Act 1988 and Coroners Rules 1984. Since the conference and before this report was published, on 25 July 2013 the Coroners and Justice Act 2009 was brought into force, establishing a new coroner system. Whilst the basis for referral to coroners remains as before, the coroner does now have the means of running an ‘investigation’ with full post-mortem and associated analysis without the need to open and then conduct an inquest. It is my view that this could be a rather better way to examine these cases individually, provided the resources are made available to undertake the necessary examinations.

The Coroners and Justice Act 2009 (s.46) also abolished the office of Coroner of The Queen’s Household — thereby consigning me, and that ancient office, to history!
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Executive Summary

The Centre for Socio-Legal Studies, University of Oxford, in association with the Foundation for Law, Justice and Society, hosted a conference entitled ‘SAD Cases in the Coroners’ Courts’ on 10 January 2013. The aims of the conference were to bring together medical and legal experts to discuss some of the complex evidential issues arising at inquests into sudden adult deaths, in which an inherited genetic abnormality might be one of the possible causes of death requiring investigation. This Executive Summary highlights key issues discussed at the conference, which are explained in more detail in the main body of the report below.

Definitions and Terminology

1. The first session explored definitions and terminology concerning ‘SAD’ or sudden adult deaths, from legal, medical, and pathology perspectives. Speaker presentations in this session revealed a significant lack of clarity in definitions across and between disciplines. The variation in understanding is matched by apparently variable practices and protocols in coroners’ investigations, post-mortems, especially genetic testing, and the final verdicts on cause of death. Absence of evidence of pathology or clinical cause of death does not necessarily justify a coroners’ finding predicated solely on inference or opinion that an inherited cardiomyopathy was the most probable cause of death. Variable understandings of SAD and investigative practices means that there are likely misdiagnoses of cause of death, with adverse consequences for improved understanding and identification, and potentially inappropriate resource allocation.

1.1. ‘SAD’ is likely to be understood differently by different experts. It has no settled medical and legal definition. It is a fluid and descriptive acronym, which is not uniformly understood to indicate a specific abnormality or disease. Some may understand SAD to infer a genetic cardiac abnormality, but to others, it could suggest a genuinely unexplained death, or a range of identified or unidentified, possibly (but not necessarily) cardiac, conditions associated with sudden death.

1.2. ‘Sudden death’ to a coroner usually means that an inquest might be needed when the cause of death is unexplained. Sudden unexplained death triggers the need for a coroner to investigate the cause of death; a sudden death to the coroner thus means that, pending investigation, cause of death remains an open question.

1.3. To medics and pathologists, ‘SAD’ could be an abbreviation of ‘sudden adult’ or ‘sudden arrhythmic’ death, to which various meanings can be attributed. Sometimes the ‘SAD’ acronym is understood to be a description of a genuinely unexplained death (‘sudden adult death’). In other contexts the SAD acronym can be understood to reference a range of potential underlying causes of death. Many non-cardiac, non-genetic medical conditions are associated with sudden death, and it may be inferred by some that ‘SAD’ is intended to encapsulate this category of possible causes of death, although circumstantial and medical evidence may require or justify a more specific verdict reflecting an underlying condition associated with sudden death (epilepsy, obesity, alcohol misuse, diabetes), which may not be evident from histology. At the other end of this uncertainty spectrum the SAD or SADS acronym may be understood to justify an inference of a genetic disorder causing potentially fatal cardiac arrhythmias (Sudden Arrhythmic Death syndrome), and having profound implications for relatives.
1.4. Some such cardiac abnormalities might be identified through post-mortem genetic testing. Protocols and practices between pathologists and coroners in different areas are thought to vary widely. Pathology opinions expressed at the conference strongly advocated taking appropriate tissue samples for freezing and later gene testing, and urged that families should be contacted and counselled regarding possible risks of inherited cardiomyopathies. By contrast, the legal perspectives emphasized that the coroner’s power to order post-mortem testing, including gene testing, is restricted to the sole purpose of determining cause of death.

1.5. Despite the uncertainties, some pathologists might recommend that SADS (sudden adult/arrhythmic death syndrome) be recorded as a cause of death. However, the legal justification for such a finding, particularly if predicated on an absence of evidence, is questionable. SAD or SADS is not a legally recognized verdict. The question is whether it falls legitimately within ‘natural causes’, in which case it must impute evidence of disease or injury. It is doubtful whether the balance of probabilities test could be satisfied if there is no evidence at all of any abnormalities associated with sudden death.

1.6. Coroners should investigate pathology, but ought also to investigate medical history and the facts/circumstances of the death. From the coroner’s perspective, SIDS (sudden infant death syndrome), ‘SAD’ (sudden adult death) and SUDEP (sudden unexplained death in epilepsy) implies a precise cause is unexplained, but in the latter that there is evidence of epilepsy which is associated with sudden death. Evidence of clinical cause of death (such as Long QT) should exclude a description or verdict of SAD being the cause of death.

1.7. An absence of positive cause of death evidence ought not to lead to an unsupported pathology opinion of SAD as cause of death (inferring an unidentified genetic disorder, or arrhythmia). Subject to legal jurisdiction and remit of the inquest, all circumstances must be investigated if there is no pathological explanation for cause of death. An open verdict (sudden death = cause unascertained) may be appropriate.

1.8. Although there has not, apparently, been any systematic data collection and analysis, it is believed that, across the 100 or so coroners’ areas, approaches to SAD definitions, investigations, and verdicts are inconsistent. The lack of consistency and coherence has potentially adverse implications for understanding prevalence and identification of causes of death, and may result in misallocation of resources.

Identification and Prevalence, Genes and Statistics

2. During this session, diagnosis through screening, genetic testing, and statistics was discussed. Genetic testing of the deceased and family can make a very important, although not necessarily conclusive, contribution to a more accurate understanding of cause of death in individual cases, and secondly, can enable targeting of screening and treatment to protect families from similar future deaths. Statistical data on prevalence, using screening data and/or death certificate data, could be used in inquests to inform opinions about probable cause of death. However, despite these very important aspects of genetic and other health screening, there is a lack of coordinated and reliable data collection and analysis nationally, and a lack of systematic integration across coroners’ areas and into the NHS, earlier attempts at a national system having been abandoned.

2.1. Post-mortem genetic testing (molecular autopsy) and family screening are important to (a) contribute to understanding cause of death and (b) to preventing similar fatalities in the same family. Both molecular autopsy and family screening can contribute to inquest investigations. Screening of family of sudden death patients in some studies has revealed a high prevalence of channelopathy gene mutations. Whilst potentially equivocal regarding cause of death, molecular autopsy and family history
can contribute to the inquest process. The family should be targeted for screening and testing.

2.2. Data on prevalence in the general population could contribute to better investigation and understanding of causes of death in SAD cases. Assessing prevalence through statistics, especially if predicated on death certificate data, is likely compromised due to inaccuracies and variables in definitions, inquest and pathology practices, and verdicts on death certificates. This could be resolved by ensuring standardization of definitions and terminology associated with sudden adult deaths, evolving uniform practices and protocols for coroners and pathologists, and ensuring a robust data collection system.

2.3. The 2005 NHS Framework included an entire chapter on sudden cardiac death, with plans for systemic integration between coroners’ courts and medical services, aimed at improving the screening and treatment of relatives of victims. However, ensuring effective targeting of problems and existing deficiencies would have required a greater understanding of national trends and practices. The UK Cardiac Pathologists Network set up a system for data collection in 2006, in part aimed at supporting implementation of the NHS Framework objects relating to sudden cardiac deaths. However, the data collection was essentially voluntary, leading to patchy capture across the country. Only one audit report was produced in 2010. Funding has subsequently been withdrawn. Thus, there remains a lack of understanding of the nature and extent of problems with appropriate care pathway referrals between coroners’ courts and medical services.

SAD Inquests: Ambit, Evidence, and Proof

3. Speakers considered the procedural and investigative scope that a coroner may or should pursue during an inquest into a sudden death, and, with respect to suspected inherited cardiac abnormalities, the probative value of statistical and genetic evidence.

3.1. From a legal perspective, the inquest’s scope should be directed to establishing ‘how’ a person dies, which is generally interpreted as the means by which a person died (i.e., immediate clinical cause), so the coroner will not usually look beyond the immediate facts and circumstances pertaining to the cause of death. But sometimes, the investigative scope of an inquest may extend to wider facts and circumstances of how the deceased came by their death, especially if the death might have involved a breach of the legal right to life.

3.2. In SAD cases, many of the conference speakers had noted that post-mortem evidence might well be inconclusive; there may be little or no positive evidence pointing to cause of death. Typically, the person would have been largely asymptomatic, and would not have had a diagnosis during life of an inherited cardiomyopathy. If there is evidence that a diagnosis and/or appropriate treatment was missed, due to systemic failing in the health care system, then that may require the wider facts and circumstances to be investigated.

3.3. If there is no positive evidence suggesting cause of death, the coroner may seek expert opinion evidence from a specialist, possibly someone specializing in inherited cardiomyopathies. However, expert evidence can also be misleading; the probative value of expert opinions should not be overstated. Studies show that expert evidence can be flawed, through human error, instrumental or technical errors, and fundamental errors in methodology.

3.4. In the absence of positive evidence on cause of death it is important for coroners to consider how expert evidence should be used in decision-making. Studies of jury responses to evidence show that the expert’s credentials are influential and can affect the value placed on, and interpretation of, complex evidence; other studies show that lawyers have difficulty in recognizing scientifically or methodologically flawed research data.
3.5. At inquests the coroner is likely to call one expert only; the process lacks a basic safeguard of adversarial testing of opposing expert opinions. Doctors and pathologists appearing at inquests to give an expert opinion on cause of death, which needs to satisfy the balance of probabilities standard of proof, are therefore in a position of great responsibility.

3.6. Expert evidence could well include prevalence statistics and a probability element. Studies have shown poor reasoning and flawed responses of juries to complex data and statistical evidence processed and presented as probabilities. There should be national guidance to standardize the ways in which expert evidence is used and presented at inquests to prevent flawed reasoning and errors in assessment of probable cause of death based on expert and statistical evidence.

Protecting Relatives: Medical and Legal Issues

4. Medical and legal experts discussed implications for relatives that can arise in the SAD inquests. How should those rights and interests be protected?

4.1. First, appropriate experts in inherited cardiomyopathies should be involved in investigating family medical history that could reveal important information about possible propensity to similar sudden deaths, which might point the inquest investigation towards an inherited cause of death.

4.2. If a suspected cause of death was a dangerous genetic cardiac abnormality, medical experts considered it vital that there should be an effective system for referral, advice, screening, and treatment of surviving relatives whose lives are potentially at risk from the same inherited condition. There is no systematic process for ensuring that relatives receive appropriate advice and referral to medical experts.

4.3. Referral depends on individual pathologists’ and coroners’ practices and levels of awareness.

4.4. Legally, however, coroners’ powers are restricted and should only be used for the narrow purpose of identifying the cause of death. It was proposed that the state’s legal obligation to protect the right to life of relatives imposed a positive obligation to put in place effective systems to ensure that relatives at risk are able to access information, advice, screening, and treatment, in order to mitigate the risk of similar future deaths.

4.5. In any event, there remain significant questions about the privacy and dignity of the deceased, and whether or not genetic information revealed in the post-mortem process should be shared with and between relatives. Furthermore, there are ethical considerations: it is not always in the best interests of relatives to be told that they have a fatal genetic defect.

4.6. There is scope, and an apparent need, for a more sophisticated and balanced approach to competing medical, legal, and ethical rights of relatives to life, health protection, privacy, choice, autonomy, and dignity.

Conclusions and Recommendations

5. The conference revealed the need for further research and collaborative work across disciplines in many areas relevant to SAD inquests. There is scope for improved consistency in the approach taken to investigating cause of death by pathologists and coroners, which could be achieved through national guidelines and protocols on SAD inquests, and, in particular, on genetic evidence. Some of the most critical points are summarized here.

5.1. There is clear need for experts to collaborate, leading to the development of national training and guidance for coroners and pathologists, on legal definitions and medical/scientific terminology relevant to SAD inquests. Currently there is endemic confusion and lack of clarity over the legal and medical meanings of ‘SAD’ and associated acronyms and terminology, as well as its use at inquests and cause of death findings.
5.2. In the absence of any positive post-mortem evidence, it should be for the coroner, not the pathologist, to weigh up that evidence, together with all other relevant factual evidence, before deciding on the inquest findings.

5.3. ‘SAD’, SADS, or similar ought not to be used as a formal verdict if it is not clearly defined and understood, and if there is no positive evidence to support such a finding.

5.4. There is a need for systematic national data collection and analysis on coroners’ and pathologists’ practices and procedures, to enable better understanding of SAD inquests and verdicts, and to improve the understanding of national prevalence and trends.

5.5. National guidance and protocols for coroners and pathologists should be developed to ensure that all SAD cases are investigated appropriately and consistently.

5.6. There is an urgent need for clarification of appropriate practices and procedures concerning genetic evidence in inquests generally, and at SAD inquests in particular. This should address post-mortem practices and procedures, as well as consideration of the probative value of genetic test results, as well as legal and ethical considerations.

5.7. There is a need for national practices and protocols to be developed to ensure that relatives are able to access potentially life-saving advice, screening, and treatment. This will require systematic integration of the inquest and health care systems. Arguably, human rights laws oblige the state to take positive steps to implement such potentially life-saving systems.

5.8. However, there is also a need for careful consideration of how best the inquest and health care systems should protect the legal and ethical rights of relatives, taking into account not only the right to life, but also rights to privacy, confidentiality, dignity, choice, and autonomy.
Introduction

On 10 January 2013, the Centre for Socio-Legal Studies in association with the Foundation for Law, Justice and Society hosted a multi-disciplinary conference at the Examination Schools, Oxford University, on ‘SAD Cases in the Coroners’ Courts’. ‘SAD’ can mean sudden adult death, or sudden arrhythmic death; other acronyms are used to describe these types of death. It usually signifies sudden collapse and sudden death without any prior warning of a young, ostensibly fit and healthy adult. Due to the sudden unexplained nature of the death, the coroner should be notified, and an inquest opened, in order to investigate the cause of death.

SAD inquests, to establish cause of death, raise a range of complex investigative, evidential, ethical, and legal issues. Diagnosis of cause of death is exclusionary: besides post-mortem investigations for evidence of disease and other disorders, a coroner will be interested to establish the toxicology and other forensic evidence. Amongst other factors, a range of genetic disorders could potentially be a cause of death: SAD cases may raise suspicion that a previously undiagnosed, possibly inherited heart defect or cardiomyopathy was the cause. Consequently, establishing cause of death is also important for living relatives. There has been much attention focused on the medical side of genetically inherited cardiac disorders, through the important work of organizations such as Cardiac Risk in the Young (CRY). A recent Royal Society of Medicine initiative sought to develop national standards for certain aspects of SAD inquests.

Inquests are a legal process and this conference aimed to open the debate into a cross-disciplinary forum. What is SAD? What are the possible medical and other causes of death? What legal and evidential issues arise for coroners when investigating cause of death in these complex cases? Should coroners ensure that post-mortem genetic testing is done? What are the legal and ethical implications of testing the deceased for genetic defects as part of the post-mortem? How should relatives’ health, privacy, and dignity be protected? What, if any, general and specific legal obligations do coroners’ and other public agencies have regarding the health, privacy, and dignity of surviving relatives? If the post-mortem reveals no positive evidence on cause of death, what other evidence ought the coroner to seek? How do medical terms relate to legal verdicts? Is SAD, or the other acronyms used in respect of these types of death, appropriate for use as a formal cause of death finding?

The main aim of the conference was to explore some of these complex issues. We brought together medical and legal academics and practitioners to explore definitions, practices, and procedures, and some of the ethical and legal implications of using genetic evidence at inquests.

The conference was chaired by Professor Hugh Watkins, expert in molecular genetics and molecular biology of heart muscle disease/molecular genetics of complex cardiovascular phenotypes. The distinguished guest lecturer was Michael Burgess OBE, Her Majesty’s Coroner of the Royal Household, Legal Secretary of the Coroners’ Society of England and Wales and formerly HM Coroner for Surrey. The conference was funded through grants from the Foundation for Law, Justice and Society, the British Heart Foundation (BHF), and Oxford University’s Law Faculty. It was organized by Dr Rebecca Money-Kyrle (lawyer) and Dr Sonia Macleod (a lawyer and geneticist), both postdoctoral researchers at Oxford’s Centre for Socio-Legal Studies, in association with the Foundation for Law, Justice and Society, together with cardiologist Dr Andrew Money-Kyrle (Buckinghamshire NHS Trust and the John Radcliffe Hospital, Oxford). Conference speakers included cardiologists Professor William McKenna, Professor Perry Elliot, Dr Elijah Behr, and Dr Andrew Money-Kyrle; specialist pathologists Dr Patrick Gallagher and
Dr Richard Colling; HM Deputy Coroner for Westminster Dr Adela Williams; legal experts Professor Jonathan Herring, Dr Charles Foster, and Dr Rebecca Money-Kyrle; and law and genetics expert Dr Sonia Macleod.6

In his introductory remarks, Professor Watkins welcomed the delegates, who had come from all over the country to attend the conference. The audience included coroners, pathologists, medics, solicitors, barristers, and academics. He noted that in his field, knowledge of genetic abnormalities of the heart associated with sudden death was evolving very rapidly. The conference would provide an opportunity for exchange of ideas and knowledge across disciplines in this rapidly evolving area.
Sudden death, or sudden adult death, or any of the similar acronyms, are not a distinct category of legally recognized verdict. Instead, cause of death verdicts in SAD cases would fall into these legally recognized categories:

- natural causes, industrial diseases, dependency on drugs or non-dependent abuse of drugs, want of attention at birth, lack of care or self-neglect;
- suicide, attempted or self-induced abortion, accident or misadventure, death sentence, lawful killing, and open verdict;
- murder, manslaughter, or infanticide;
- still-birth (obviously irrelevant in adult cases, but potentially relevant in sudden infant deaths).

A natural causes verdict indicates proof (balance of probabilities) of ‘injury or disease causing death,’ reflecting immediate cause of death and any associated morbid conditions. In non-violent sudden death cases where there is no suspicion of criminality or other alternative cause, a verdict of death by natural causes, either specifying cause (disease or injury) or ‘unascertained,’ or, if the evidence does not support a natural causes ruling, an open verdict, are the most likely alternatives. An open verdict signifies that ‘the evidence did not fully or further disclose the means whereby cause of death arose.’ This presents challenges for coroners if experts in inherited cardiomyopathies give opinion evidence that the death has the hallmarks of a genetic abnormality yet to be identified, and/or if there is no evidence revealed in the post-mortem process to support that opinion. If SAD or SADs is recommended as a specific natural cause without any supporting evidence, does that fall into the legal category of a disease that can be ascribed as the cause of death on the balance of probabilities? Or would an open verdict be appropriate? It is possible, but arguably not always desirable, that a narrative verdict may be used.
This presentation concluded that the terms ‘sudden death’, sudden adult death, or sudden unexplained death, do not justify any presumption as to possible cause of death, but instead should be regarded as the starting point for a factual investigation to answer the ‘who, how, when and where’ questions. Sudden death means that all possible causes of death should at least initially be open questions. Until evidence is available to satisfy the civil standard of proof on cause of death, the death will remain ‘unexplained’.

**Medical Definitions**

**Dr Andrew Money-Kyrle** explained various medical acronyms associated with sudden adult deaths. SAD is an exclusionary diagnosis. Many of the terms associated with SAD cases are only relevant if no evidence of a specific disease or cause is found on post-mortem. The terms used include: SCD (sudden cardiac death); SUDs (Sudden Unexpected Death Syndrome); SADS (Sudden Adult or Arrhythmic Death Syndrome), and SIDS or Sudden Infant Death Syndrome. These are all variations on a simple theme: they suggest that at post-mortem no (other) specific disease, injury, or cause has been established. Dr Money-Kyrle went on to consider why these terms came into usage in the context of SAD inquests. Professor M. J. Davies first described ‘SUDs’ in 1992, recommending that if a person dies and the post-mortem shows a morphologically normal heart, then SUDS should be recorded as a cause of death in preference to ‘natural death — cause unascertained’. In contrast, there are other specific conditions known to be potentially fatal, such as ‘Long QT Syndrome’ and Brugada Syndrome. Both are inherited and both may be diagnosed through genetic testing.

‘SADS’ is also used to abbreviate a similar phrase, with different implied meaning: Sudden Arrhythmic Death Syndrome, as used by Behr et al.12 That article reported on a survey of sudden deaths. First-degree relatives were studied to look for genetic cardiac abnormalities; 22% of families showed genetic cardiac disease. Investigation of those families is important, but AMK noted that in 78% of families no abnormality was found, so SADS terminology here is apparently driven by a lack of alternative hypotheses.

From the medic’s perspective, verdicts in ‘SAD’ inquests could include: natural death — cause unascertained; Sudden Cardiac Death; Sudden Unexpected Death; Sudden Adult Death; Sudden Arrhythmic Death; Sudden Infant Death, or specific diagnoses of disorders including, for example, Brugada syndrome; Long QT syndrome; Hypertrophic Cardiomyopathy; Catecholaminergic Polymorphic Ventricular Tachycardia; and Wolff–Parkinson–White syndrome. There ought to be precise diagnosis wherever possible, but uncertainty should also be noted. Depending on the evidence at inquest, a cause of death could (or should?) be recorded as ‘unknown’ because (a) the mechanism is not yet known to medical science (for example, new mutations); or (b) deficient investigation or lack of evidence has led to the cause being missed. Family rights are important; relatives can be screened and treated if required. Data collection on coroners’ practices, samples for genetic testing, and corroborative information on family history, ECGs, symptoms and so on, is needed.

**The Pathology of Unexplained Cardiac Deaths**

In this presentation, Dr Richard Colling and Dr Patrick Gallagher considered SAD cases from the pathologist’s perspective. Sudden death cases referred to the pathologist will prompt consideration of a range of possible causes of death, which the pathology investigations will be directed to excluding.

Richard Colling explained that the pathologist interprets evidence of cardiac failure according to recognized ‘grades of certainty’. Cardiac failure can be difficult to diagnose on autopsy; circumstantial evidence is important. Cardiomyopathies can cause sudden death.

Unexplained cardiac deaths are thought to account for up to 4% of sudden natural cardiac deaths, but some have no associated pathology. Unexplained deaths with no cardiac pathology can be associated with epilepsy (Sudden Unexplained Death linked to epilepsy; or SUDEP); SUDEP is an accepted diagnosis of cause of death. Prior diagnosis of severe epilepsy is important; post-mortem histology may not reveal abnormalities. Neuropathology tests can be done.
and spleen samples could be frozen to allow later genetic testing. Alcoholism is also associated with sudden death (Sudden Unexplained Death in Alcohol Misuse, or SUDAM), as is diabetes, typified with the person found dead in bed. Hypoglycaemia causing QT abnormalities is thought to be a possible cause; genetic testing has suggested links to changes in the SCN5A gene.

Besides these associations with underlying non-cardiac conditions, sudden death is clearly associated with inherited cardiac disease. Colling referred to the M. J. Davies paper on ‘SAD’, which Colling explained as ‘sudden arrhythmic death’ syndrome rather than sudden adult death syndrome (as it was described earlier in the day). Pathologically, these cases would not reveal macro- or microscopic changes in the heart, nor, in most cases, conduction system abnormalities. There is a European protocol for autopsies and DNA extraction in these cases. Practice standards, protocols on DNA testing, and awareness of conditions associated with unexplained cardiac death across pathology is variable. Some pathologists have experienced coroners/coroners officers actively discouraging storage of samples for gene testing. Storage facilities and protocols might be locally deficient.

Patrick Gallagher discussed pathology investigations that would be necessary in sudden death cases. Sometimes, obvious evidence deems histology unnecessary (e.g., ruptured aortic aneurysm, primary intracerebral haemorrhage, massive pulmonary embolism, carcinomatosis with positive biopsy in life, ruptured myocardial infarction, upper GI tract lesions, or diverticulitis causing GI haemorrhage). Otherwise, histology is required, and essential if there are lung lesions, especially in decomposed patients (tuberculosis) or asbestos-related patients; in post-operative (particularly cardiothoracic) deaths; if sudden death associated with ‘SADS’, SUDEP, SUDAM, diabetics, or obesity is suspected; and to investigate previously unsuspected tumours.

The collection of tissue samples (frozen) for genetic testing, with advice to the family on screening, should be initiated in cases where there are structurally normal hearts, and if autopsy reveals evidence of conditions including Hypertrophic Obstructive Cardiomyopathy, Idiopathic left ventricular hypertrophy ± fibrosis, Arrhythmogenic cardiomyopathy, Idiopathic (dilated) cardiomyopathy, especially in younger patients with heavy hearts, right ventricular, or atrial myocarditis.

**Coroner Verdicts and Definitions of SAD**

Adela Williams sits as HM Deputy Coroner for Westminster, and in this presentation she addressed how coroners investigate SAD inquests. The coroner has jurisdiction to investigate where cause of death is unknown, usually by inquest, including potentially time-consuming post-mortem/genetic testing. Sudden death of young people prompts family concerns. Within the legitimate remit of the inquest and coroners’ jurisdiction, in the absence of pathological diagnosis of cause of death, all circumstances should be considered.

Sudden unexplained death inquests include ‘SIDS’ (sudden infant death syndrome, i.e., that occurring in children under one year old); SUDEP (unexplained death where there is a history of epilepsy); and ‘others’, including SAD (sudden adult death), which category included unexplained deaths thought to be cardiac (sudden arrhythmic death). SAD is an exclusionary diagnosis. A death should not be described as SAD if a clinical cause is identified (e.g., Long QT).

Absence of positive pathology evidence should not justify a pathology opinion on cause of death. The pathologist’s role is to provide facts and evidence from the post-mortem to the coroner, not to prejudge the coroner’s verdict. Pathologists do not have access to all the relevant evidence. The coroner assesses the pathology evidence, and all other factual and circumstantial evidence, weighing up all that evidence when judging the probable cause of death. Without positive post-mortem or other factual evidence of probable cause, a coroner’s finding of cause ‘unascertained’ could be the most justifiable and appropriate, otherwise there is a significant risk that the coroner and/or pathologist would ascribe a false cause of death.

There are also concerns about inconsistent post-mortems and inquest findings, the same pathological presentation being ascribed ‘SAD’ in...
younger adults but as 'ischaemic heart disease' or similar in other older people. Pathology (post-mortem, and possibly referral to cardiac pathologist), medical history, and the circumstances of death (witness statements) should be investigated. Potentially relevant medical facts associated with sudden death include history of diabetes, epilepsy, alcoholism, medication, asthma, and diet (for example, anorexia).

’SAD’ cases have no alternative pathology. There are misdiagnoses of cause of death. Coroners’ approaches to definitions of SAD, and to cause of death verdicts in SAD inquests, are inconsistent. It is not clear to what extent coroners are using narrative verdicts in SAD cases. If there is insufficient evidence to support a natural causes verdict, then an open verdict ought to be given.
Session 2: Identification and Prevalence, Genes and Statistics

Genetic Evidence in Sudden Death Inquests

In this session, **Dr Elijah Behr** discussed some of the studies of SAD deaths, focusing on genetic aspects. Between 5% and 40% of UK sudden cardiac deaths are classified as SADS deaths, in which the heart was morphologically normal. In this cohort, family screening and genetic testing of the deceased had enabled identification of high prevalence of genetic variants associated with potentially fatal channelopathies (e.g., Long QT, Arrhythmogenic Right Ventricular Cardiomyopathy [ARVC], Brugada syndromes [BrS] and Catecholaminergic Polymorphic Ventricular Tachycardia [CPVT]). Channelopathies have been identified in relatives in 22–50% of instances of SADS deaths.

Dr Behr referred to case histories to illustrate how family screening and molecular autopsy could contribute to the inquest process. In one case, in screening taking place after the inquest, siblings and children of the deceased were found to have a novel Long QT mutation; the inquest was reopened and the cause of death changed to Long QT. Post-mortem identification of a mutation can indicate the need/opportunity for screening and treatment of relatives, although the risk factors from very rare mutations is unknown, and a negative result does not exclude potentially fatal mutations. The equivocal aspect of molecular autopsy and screening needs to be factored into evaluation of evidence.

Differential Definitions, Statistics, and Evidential Veracity of Statistical Evidence

In this presentation **Dr Sonia Macleod** considered how inconsistent definitions and verdicts impact on understanding of prevalence. SAD diagnoses are exclusionary. If a death is classified as SAD, whether ‘sudden arrhythmic’ or ‘sudden adult’ death, relevant factors include medical records, symptoms when alive, family history suggesting predisposition, and post-mortem tests (especially genetic) (although negative results are not conclusive).

Death certificate and/or autopsy data indicating prevalence could be relevant. However, accurate and useful statistics depend on high-quality data. Autopsy studies show highly variable prevalence information. For example, studies of the US military found thirteen SAD deaths per 100,000 recorded deaths each year, whereas a similar study of US athletes shows 0.5 per 100,000 per year. This could be due to inconsistent methods, including variation in underlying definitions. A death certificate study is another way of assessing prevalence, but again, variations in definitions and processes can undermine data accuracy. A UK study based on death certificates suggests 1.8 per 100,000 deaths or eight deaths per week are attributed to SAD. This data was extracted from Office for National Statistics data of coded causes of death taken from death certificates. But coroners’ practices vary widely. The Ministry of Justice data show that in 2010, 64% of deaths were sent for autopsy in Gloucestershire, Powys, and Northumberland, but the figure was only 26% for Nottinghamshire. Thus, relying on prevalence data to assist evaluation of inquest evidence is unreliable, and could contribute to amplification of data inaccuracy through a circular feedback process. Solutions include clarifying and standardizing definitions and inquest/pathology procedures across regions. The UK Cardiac Pathologists Network could play an important role.

UK Cardiac Pathologists Network SAD Database: Definitions and Remit

**Perry Elliot** explained that the UK Cardiac Pathologists Network was established following the inclusion in the 2005 Coronary Heart Disease National Service Framework (NSF) of a chapter to
underpin UK-wide best practice regarding arrhythmias and Sudden Cardiac Death. It anticipated the creation of NHS systems to identify, screen, and treat relatives following sudden cardiac death, which in practice would need to involve coroners and family doctors. Referral pathways would be complex, involving pathologists, coroners, GPs, and specialist cardiologists, along with other sub-specialties (electro-physiologists, cardiovascular imaging specialists, interventional cardiologists, and cardiac surgeons). There was a lack of data on the extent to which relatives were being adequately referred. In 2006 a National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report identified core failings on coroners and autopsy practices.15

These factors led to cardiac pathologists setting up the UK Cardiac Pathology Network (UKCPN) in 2006. Its aims included to establish a national specialist network; to implement protocols; to provide specialist pathology training; to advise pathologists, coroners, and families; to set up regular case review meetings; and to identify areas for future research. A database was set up for cardiac pathologists to record cases of deaths possibly caused by inheritable disorders. The purpose of the database included allowing prevalence to be identified, and to support National Service Framework (NSF) implementation. An audit report was produced in 2010; by 2011, with only thirty-two further deaths recorded on the database, it became apparent that data collection and accuracy was undermined by lack of consistent engagement and participation across different regions. Funding was withdrawn and the UKCPN database initiative is no longer functioning.

In the absence of a nationally coordinated system linking the coroners’ courts to the NHS for referrals and counselling, other organizations provide expertise and are proactive in offering these types of services. These include Cardiac Risk in the Young (CRY), and the Genetic Information Service run by the British Heart Foundation (BHF).16 The BHF had part-funded the conference. The Genetic Information Service provides advice, counselling, and screening to individuals and families who have been diagnosed with a genetic abnormality, and relatives of individuals who have died when the cause of death is suspected to be an inherited cardiac abnormality.
Session 3: SAD Inquests: Ambit, Evidence, Proof

The Ambit of Inquests

As had been noted by other conference speakers, there may be little or no conclusive post-mortem evidence defining the cause of death. Charles Foster considered what the law required in terms of the scope of a coroner’s investigation into the wider facts and circumstances of the death in order to satisfy the obligation to determine how a person died. Usually, ‘how’ a person dies is interpreted to mean ‘by what means’, but in some cases, as the court ruled in the case of Middleton, ‘how’ should be given a wider interpretation, to mean ‘how the deceased came by his death’.17

Genetic Evidence, Statistics, and the Burden of Proof

In this presentation, Dr Sonia Macleod looked at the potential problems caused by use of genetic and statistical evidence at SAD inquests. Studies have looked at how juries and lawyers respond to statistical evidence and expert evidence. These studies concerned criminal proceedings, which can be distinguished in some respects from inquests. Most notably the criminal process is adversarial but the inquest is inquisitorial, so in the case of the latter, evidence is not challenged and tested in the same manner. Dr Macleod also noted that a verdict depends on a ‘beyond reasonable doubt’ standard of proof, whereas the civil balance of probabilities standard applies to most coroners’ cases.21

The coroner may call an expert to give evidence on issues such as the probability that a sudden death was caused by cardiac genetic abnormality. That evidence could be presented in various forms, including statistical and probabilistic calculations on prevalence. However, studies show that expert evidence can be flawed as a result of human error, instrumental or technical error, and/or methodological factors (Dror and Charlton 2006). Dr Macleod cited the example of Roy Meadows’ expert evidence on SIDS, for the prosecution case against Sally Clark for murdering two of her children. Meadows’ evidence for the prosecution on the statistical probability of two SIDS deaths occurring in one family (1 in 73 million) was fundamentally flawed for methodological reasons. Clark was convicted of murder.20

As SADS cases can be decided in the absence of conclusive evidence, it is essential to examine how expert evidence is used in decision-making. Dr Macleod used a case study to illustrate that different pieces of evidence will not be considered equally probative. Probative value will depend upon the type of evidence and the way in which it is presented. The more complex the evidence is, the more jurors rely on the expert’s credentials.21 Even lawyers have difficulty recognizing scientifically/methodologically flawed research,22 so jurors are likely to as well. Doctors are perceived as particularly credible.23 Simply the presence of an opposing expert itself impacts positively on juror reasoning about scientific evidence,24 a safeguard that in the vast majority of inquests is not present in the inquisitorial coronial process. The fact that doctors give unopposed, complex scientific evidence, which only has to satisfy the balance of probabilities threshold, puts them in a position of great responsibility.

Evidence of SAD is likely to affect prevalence rates, which contain a probability component. Dr Macleod proceeded to outline how studies have shown that laypeople are poor at reasoning with probability and can be influenced by presentational format and framing.25 She detailed her own research, which indicates that, by providing accessible information and amending presentational formats (for example, by contextualizing them), probability reasoning can be improved. Recommendations to standardize the way in which prevalence rates are presented across coronial jurisdictions were made.
Session 4: Protecting Relatives: Medical and Legal Issues

Medical Issues for Relatives: Case Studies

Professor William McKenna explained some of the ways in which clinicians specializing in inherited cardiac disease can assist inquests in determining more precisely the cause of death in SADS cases. Clinical expertise is essential for the protection of relatives from the potential risk of similar sudden death. He illustrated his talk with a number of case histories, which showed that, by taking an extended family history from relatives of the deceased, patterns of sudden death or collapses in family members could be revealed. This type of investigation of family history is specialized work, requiring an appreciation of the ways in which genetic abnormalities can be traced through extended family networks. For many personal and cultural reasons, relatives do not always spontaneously volunteer relevant information, owing to its sensitive nature. Some families involve complex step-relationships or adoptions, and exploring the genetic relationships requires great sensitivity. Information is not always shared between family members.

In other illustrative examples, detailed questioning of relatives about the past medical history of the deceased and family, focusing on palpitations, dizzy spells, faints, and collapses, may bring out evidence of an inherited cardiac condition. This line of questioning is not typically undertaken within the inquest process unless an expert cardiologist specializing in inherited disorders is involved. Non-specialists are unlikely to have the requisite knowledge and expertise.

In cases in which an extensive family history has uncovered premature death(s) amongst relatives, genetic testing of either the deceased or relatives can result in the identification of specific genes known to cause channelopathies or cardiomyopathies. In a number of inquests this has led to a far more precise determination of the cause of death than might otherwise have been available to the coroner. In addition, it has allowed an opportunity to invite relatives, should they wish, to be screened for the relevant inherited disorder. This can result in appropriate counselling, medication, and, in some cases, treatment with devices such as Implantable Cardiac Defibrillators (ICDs) for relatives who remain at risk of sudden death. Some high-risk families need continued monitoring.

The protection of family members and the prevention of further similar deaths was an extremely important outcome of the inquest process. However, there is a lack of protocols and systems within the NHS and in the coroners' courts for dealing with such cases. This lack of a structured approach and dialogue can result in opportunities to protect families being missed. Professor McKenna cited, with permission, a family in which the sudden death of one son did not trigger, through the inquest process, the appropriate involvement and investigations by a cardiologist of other family members. It was only after the subsequent collapse and death of a brother that the danger was appreciated and steps were taken to protect the wider family. A more structured approach to SADS cases at inquests could prevent similar deaths.

The Right to Life and the Rights of Others

As had already been remarked on by many of the other speakers, there is no national framework integrating the inquest process and health care systems. This means that the protection of relatives who are potentially at risk of inheriting cardiac abnormalities that are suspected as a cause of death at SAD inquests is far from certain. Dr Rebecca Money-Kyrle’s presentation considered what legal rights and obligations exist towards relatives in the context of a SAD inquest. What rights do relatives have during the inquest proceedings? Are there any legal obligations that ought to ensure better...
systematic management of risks to surviving relatives, when a person’s death may have been caused by an inherited cardiac disorder? What privacy rights do relatives have regarding medical information and genetic data?

Relatives have limited procedural rights at inquests. The coroner must notify them of the inquest if contact details are known.26 They have a right to be notified of post-mortem, and to attend or be represented.27 Relatives, as ‘interested persons’, may examine witnesses at an inquest hearing.28 Disclosure of evidence and reports is discretionary,29 but in practice most coroners will not withhold post-mortem reports from the family.

Relatives have no legal right to require any genetic tests to be done on the deceased, either as part of the inquest investigation, or to find out about potentially inheritable health risks for their own interests. Coroners have discretion, but no obligation, to do genetic testing when investigating cause of death. Coroners’ discretionary power to order genetic investigations can only be exercised for the purpose of investigating cause of death; protection of relatives may be a collateral outcome of such genetic testing, but cannot be the primary purpose of the exercise of coroners’ discretion. It would be ‘ultra vires’ the coroner’s legal powers to order genetic tests solely for an ulterior purpose of protecting the health of surviving relatives.

Regarding substantive risks, there have been efforts to develop a more systematic approach to the referral of relatives. An expert forum convened by the Royal Society of Medicine in 2011 recommended guidelines for coroners and pathologists to work together to ensure young adults at risk of sudden cardiac death are identified and offered screening (Sheppard, Burgess and others30). The guidelines have no legal force. Dr Money-Kyrle proposed that it was at least arguable that the state has a legal duty to establish adequate systems and protocols for appropriate referral of relatives for counselling and medical care, in order to protect relatives from similar deaths. Article 2 of the ECHR included positive obligation on the state to protect the right to life, which in narrow circumstances can extend to protective health care measures. It is this legal obligation that Dr Money-Kyrle proposed could be invoked to insist on development of a national, integrated system for screening and referral from coroners’ courts into the health system. Under Article 2, the state should maintain a general system of laws and procedures to protect life, including provision of an adequate health care system,31 and effective operations and systems within individual hospitals and health care institutions.32

Some narrowly defined circumstances can trigger ‘operational duties’ for the state to mitigate threats to individuals’ lives, originally restricted to criminal threats to life. The operational duty arises if the authorities knew or ought to have known of the existence of a real and immediate risk to the life of an identified individual or individuals. There could be a breach of Article 2 if the authorities failed to take measures within the scope of their powers which, judged reasonably, might have been expected to avoid that risk (Osman v UK).33 Recent case law extended the operational duty to some health care settings.34 There are no reported legal cases on the operational duty being triggered by investigation of genetic disorders at inquests, but relevant principles can be drawn from other cases on both the general protective duty and the operational duty, regarding health vulnerabilities. For example, the European Court has held that the state’s general positive obligations to protect the right to life can require health monitoring of the descendants of service personnel exposed to nuclear tests, to prevent life from being avoidably put at risk.35 In mental health and detention contexts, the recognized higher risk of self-harm and suicide amongst compulsorily detained populations in prisons and mental health institutions36 requires the state to maintain systems and procedures to mitigate that risk (for example, ‘suicide’ watch, removal of ligature points and implements potentially used to self-harm, etc.). Recent case law suggests there is a specific requirement to mitigate health risks when relocating elderly patients from one residential care setting to another.37

Regarding life-threatening medical conditions, the most closely analogous legal cases concern HIV risks. The state’s general duty in respect of infectious diseases is to ensure that systems and procedures are in place, to mitigate known risks to the public. If properly implemented, arguments about
operational duties in individual cases ought rarely to arise. One could assert similar legal arguments regarding inherited genetic abnormalities revealed during an inquest.

There are counter-arguments to be considered. First, as noted, there is no case law 'on point'. Article 2 does not impose an operational obligation on the state to all persons at real and immediate risk of death. The courts have reiterated that the positive obligation should not impose a disproportionate burden on the state.

A number of points were summarized briefly regarding the private and family rights of relatives under Article 8 ECHR. Article 8 could bolster relatives' pursuit of disclosure of post-mortem genetic information because Article 8 also implies a right of access to personal records and information that will allow a person to make sense of his life. Article 8 also raises questions about protecting the privacy of relatives in the inquest forum. An inquest is a public hearing with limited legal grounds to exclude press and public. Should coroners' authority be extended to allow exclusion of evidence related to inherited cardiac abnormalities (for example, family medical history, genetic test results), to protect the private and family rights of the relatives of the deceased? These privacy issues required careful consideration in SAD cases, and ought to be factored in to any national guidelines on SAD inquests.

Confidentiality and Genetic Information: To Know or Not to Know?

Professor Jonathan Herring discussed some of the legal and ethical concerns about privacy, confidentiality, and dignity that genetic evidence in SAD inquests raise. He explained that, in some respects, these matters conflict with points made by some of the other speakers regarding genetic testing of the deceased and presumptions about the sharing of information with living relatives. He questioned the presumption that it is always in the best interests of relatives to be informed of inherited risks. Do relatives also have a right not to know?


Information about the deceased's health and medical condition may still be regarded as confidential, so it should not necessarily be presumed that disclosure to family members is lawful and ethical. The duty of confidentiality survives death, but the General Medical Council (GMC) states:

- Whether and what personal information may be disclosed after a patient's death will depend on the circumstances. If the patient had asked for information to remain confidential, you should usually respect their wishes.
- If you are unaware of any instructions from the patient, when you are considering requests for information you should take into account:
  - (a) whether the disclosure of information is likely to cause distress to, or be of benefit to, the patient's partner or family;
  - (b) whether the disclosure will also disclose information about the patient's family or anyone else;
  - (c) whether the information is already public knowledge or can be anonymised or coded; and
  - (d) the purpose of the disclosure.

Regarding genetic information, the traditional view on confidentiality has been challenged. The challenge is justified on the basis that genetic information is not personal or individual; public policy arguments have also been asserted.

Alternative approaches maintain the traditional approach to confidentiality, but suggest that genetic information is an exception to the rule. The GMC approach to genetic information and confidentiality follows this approach:

Confidentiality:
- If a patient refuses consent to disclosure, you will need to balance your duty to make the care of your patient your first concern against your duty to help protect the other person from serious harm. If practicable, you should not disclose the patient's identity in contacting and advising others of the risks they face.
An alternative approach regarding confidentiality rights and the right to know frames rights as shared by the group with genetic links to the deceased. Lucassen and Parker’s model uses the analogy of a ‘joint account’, proposing that, since genetic information is shared by more than one person, the conventional model of confidentiality should be reconsidered. The genetic information should be available to all ‘account holders’ (family members) unless there are good reasons to do otherwise.43 Roy Gilbar adopts a similar approach, which, with reference to genetic information, reconceives confidentiality and privacy from the perspective of the family unit. Gilbar has proposed a relational interpretation of autonomy; the impact of genetic information engages familial dynamics and responsibilities in the right to know.44

These approaches leave important unresolved issues. Should there be a right to know or permissibility to be informed? Who does the disclosure? Is disclosure of the source required or permissible? Is there a right not to know? Professor Herring questioned whether there is a right not to know, which should be weighed into the equation when considering how to manage information emerging during a SAD inquest about potentially fatal genetic conditions.

The right not to know has been recognized by international organizations and in international law. Article 5(c) of the UNESCO Universal Declaration on the Human Genome and Human Rights states that:

The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.

In a similar vein, the World Health Organization states that:

the wish of individuals and families not to know genetic information, including test results, should be respected, except in testing of newborn babies or children for treatable conditions.45

Article 10.2 of the European Convention on Human Rights and Biomedicine states:

Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.

The right not to know is also recognized by the GMC:

If, after discussion, a patient still does not want to know in detail about their condition or the treatment, you should respect their wishes, as far as possible. But you must still give them the information they need in order to give their consent to a proposed investigation or treatment...46

The right to know can be justified on grounds of autonomy and the protection of choice, but does information about genetic disorders also have the potential to undermine autonomy? Autonomy could be undermined by information overload, fear, and irrational prejudice that could be precipitated by disclosure of genetic information about potentially life-threatening conditions.

Professor Herring proposed justifications for the right not to know. There is the argument of autonomy that concerns the adverse effect of harmful information; autonomy could be best served with the comfort of ignorance. The right not to know can also be justified on grounds of privacy and the value of intimate space, as expressed by Graeme Laurie: ‘individuals enjoy, and are entitled to enjoy, a measure of psychological privacy which can be invaded by unwarranted disclosures of information’.47

Others have criticized the notion of a right not to know. For example, John Harris and Kirsty Keywood argue that ignorance is inimical to the exercise of autonomy. You cannot make a choice to not know something you don’t know. Non-disclosure has the propensity to cause harm to others.

Balancing competing claims, Roy Gilbar has proposed that the following should be considered:

1. the availability of cures or preventive measures;
2. the severity of the disease and likelihood of onset;
3. the nature of the disorder;
4. the availability of genetic testing and its accuracy in assessing the risk;
5. the relative's likely emotional reaction when given the information;

6. the effect any decision (to disclose or not to disclose) will have on the familial relationship and on the dynamics of the particular family.
This is a summary of the closing lecture given by Michael Burgess, Coroner of the Queen’s Household, who has extensive experience of working on policy and practice concerning SAD deaths.

Mr Burgess opened his remarks by providing some perspective on his experience of the prevalence of SAD cases, saying that, during his time as the Surrey Coroner, around twenty to twenty-five deaths per year were SAD cases, out of a total of 4,500.

He went on to describe his work with many of the cardiologists specializing in the field, and brought attention to his collaboration with McKenna, Elliot, and others on the National Service Framework (NSF) Chapter 8, which could have solved many of the issues raised at the conference, had it not been for the abandonment of the project due to withdrawal of funding in 2004-5.

Addressing the issue of confidentiality, Mr Burgess made clear that documents and evidence can only be used for the purpose of the inquest, and that some medical records disclosed to coroners contain confidential and sensitive medical information irrelevant to the cause of death, which probably ought not to be disclosed.

If a post-mortem does not establish a natural cause of death, the coroner must hold an inquest. Under the Coroners and Justice Act 2009 implemented in July 2013 there will be an investigation process before a formal inquest. How this will work in practice will not be known until the new rules and guidelines have been finalized.

Every so often, coroners receive reports of cases discussed at the conference: young people in excellent health being struck down. This prompts intrusive and possibly hurtful questions: whether the deceased was a drug addict, or consumed excessive alcohol, engaged in risky activities and so on. Premature deaths may be associated with these activities. Otherwise, the coroners’ investigation is similar to the process applied to other deaths, such as seeking witness evidence, questioning doctors, establishing information about habits and lifestyle, and the factual circumstances of the death. The family is asked questions, especially parents and siblings. The NSF Chapter 8 protocol that was abandoned in 2004-5 had envisaged trained counsellors to ask these sensitive questions to compile information for the inquest, and to counsel family members.

Pathologists are given all relevant information obtained from family, doctors, and witnesses. If a pathologist does not receive adequate or sufficient information he or she should seek more information from the coroner. Mr Burgess said he provided detailed instructions to pathologists, expected them only to work to the level of their competence, to seek further instructions from him at any time, and, if an underlying cardiac condition was suspected, to contact a centre of excellence and agree on how to proceed, including whether the whole heart should be made available for detailed examination elsewhere. He had frequently worked with Dr Mary Sheppard at the Royal Brompton Cardiac Pathology Unit, who was able to provide a detailed examination of tissue samples or the whole heart within about ten days, enabling the relatively prompt release of the body to the family for the funeral. Mr Burgess’s practice was to try to keep the family informed, and, if further detailed examinations were necessary, to refine a cause of death, before family would be consulted and counselled about tissue retention and other implications for the family. Family members could receive medical tests and that evidence could be fed back into the inquest process. General toxicology screening to eliminate a drug- or substance-related cause is normally undertaken. An inquest may still be necessary, which prolongs the process of
establishing cause of death, but allows a more thorough examination of all the evidence. The family should know what evidence they will hear before going into court.

Mr Burgess recommended reference to the Royal Society of Medicine (RSM) 2011 seminar and the article in the Royal College of Pathologists’ Bulletin in 2012. There should be periodical review of investigative techniques similar to the RSM initiative. All medical certificates of cause of death, signed by doctors or pathologists after a post-mortem, give an opinion on cause of death; if they are to be accepted as evidence at an inquest they must be credible and made by someone with the requisite expertise, which, as had been said previously, is not always the case.

In SAD cases, verdicts may be natural causes, an open verdict (less likely), or a narrative verdict. In referring to the relationship between SADS and SIDS, Mr Burgess emphasized the difficulty for families of an open verdict in sudden infant death cases, owing to the fact that it is a diagnosis of exclusion. Similarly, SUDEP is often now accepted in many areas, further to Ledbetter’s 1990s campaign. Mr Burgess posed an open question: in the absence of evidence of violence or unnaturalness, should there be a presumption of natural cause of death?

There have been many lost opportunities over the past ten years in developing and improving the coroners and pathology services. Things may change under the new rules and regulations to be introduced soon. The informal inquiry process will be better recognized. The Chief Coroner will be able to issue guidance. However, parts of the 2009 Act have been, and other parts could be, repealed.

Mr Burgess was of the opinion that the scope of coroners’ powers was already sufficient to carry out a comprehensive investigation, without the need to rely on Article 2, ECHR. The loss of a loved one suddenly and prematurely because of an inherited heart condition traumatizes families; Mr Burgess said that coroners must ‘go the extra mile’ so that lessons can be learnt in order to prevent a second trauma of another unexpected death in the same family. Lives can be saved by working together. As Professor McKenna had pointed out, sudden cardiac death (SCD) is preventable.
Speaker Profiles

**Elijah Behr** is a Senior Lecturer at St George's, University of London and an Honorary consultant cardiologist at St George's Hospital, specializing in cardiac electrophysiology.

**Michael Burgess** OBE is HM Coroner of the Royal Household, Legal Secretary of the Coroner’s Society of England and Wales, and, formerly, HM Coroner for Surrey.

**Richard Colling** is a trainee in histopathology in the Severn Deanery in Bristol. He is a graduate of the Peninsula Medical School (2009) and holds an additional degree in biosciences.

**Perry Elliot** is Clinical Director of the Inherited Cardiovascular Disease Unit, University College London; Reader in Inherited Cardiac Disease (2005) and Professor (2012); Fellow of the European Society of Cardiology (2005); Vice-President of the Cardiomyopathy Association; and Deputy Editor of *The Heart Journal* (2009).

**Charles Foster** MA, Vet MB, MRCVS, St. John’s College, Cambridge is a barrister at the Outer Temple Chambers. He is also Research Associate, HeLEX Centre for Health, Law and Emerging Technologies, Oxford; Fellow of Green Templeton College, University of Oxford; and has published widely on a wide range of subjects, including medical law and ethics.

**Patrick Gallagher** is a cardiac pathologist at the University of Bristol.

**Jonathan Herring** is Professor of Law at the University of Oxford; Fellow and Tutor in Law, Exeter College; and Research Associate, HeLEX Centre for Health, Law and Emerging Technologies, Oxford. He is also an Editorial Board member, *Family Court Reports* and Editor of *Child and Family Law Quarterly*. Jonathan has published extensively on criminal, family and medical law, sexual offences, crimes against corpses, parental failure to protect children from death, on the law’s treatment of older people, and legal issues surrounding dementia.

**Sonia Macleod** BA Oxon, PhD Cantab, is a non-practising barrister and Visiting Fellow in Law and Genetics, Centre for Socio-Legal Studies, Oxford. She holds various research interests in Medical Law, with a recent ESRC-funded project on how jurors reason about genetic evidence.

**William McKenna** is Professor of Cardiology, UCL.

**Andrew Money-Kyrle** MA Oxon, MD London, FRCP is a consultant cardiologist at Buckinghamshire Healthcare Trust and Oxford University Hospitals Trust.

**Rebecca Money-Kyrle** MA Cantab, MSt Oxon, DPhil, Oxon, is a solicitor (England & Wales) (currently non-practising) and post-doctoral researcher, Civil Justice Project, Centre for Socio-Legal Studies, University of Oxford.

**Hugh Watkins** MD, PhD, FRCP, FMed Sci is Field Marshal Alexander Professor of Cardiovascular Medicine, Honorary Consultant in Cardiology and General Medicine, Head of Radcliffe Department of Medicine, and Director of the British Heart Foundation Centre of Research Excellence at the University of Oxford. He is also Fellow of the Academy of Medical Sciences, Fellow of the American Heart Association, and Associate Editor of *Circulation Research*. His expertise lies in the fields of Molecular Genetics and Molecular Biology of the Heart Muscle Disease/Molecular Genetics of Complex Cardiovascular Phenotypes.

**Adela Williams** is HM Deputy Coroner for Westminster, a solicitor (partner) at Arnold & Porter, and registered medical practitioner. She advises on medicinal products and devices regulation, and represents clients before the Appeal Board of the Prescription Medicines Code of Practice Authority. She also advises on technology appraisals by the National Institute for Health and Clinical Excellence (NICE), Scottish Medicines Consortium, and the All Wales Medicines Strategy Group.
Notes

1. The conference was funded by grants from the Foundation for Law, Justice and Society, the British Heart Foundation, and Oxford University’s Law Faculty Research Support Fund.

2. For further information see <www.csls.ox.ac.uk>.

3. Cardiac Risk in the Young. For further information see <www.crt-y.org.uk>.


5. Speakers’ biographical details are set out at the end of this report.


10. The initial purpose of narrative verdicts was to satisfy the requirements of right to life investigations under Article 2, ECHR. Whilst Article 2 cases are relatively rare, statistical data indicates that coroners may be giving narrative verdicts in a much wider category of cases, with one in seven verdicts returned during 2010 being a narrative verdict, compared with a 1% figure in 2001: Coroners Statistics 2010 England & Wales. Ministry of Justice Statistics Bulletin, p. 8. Available at <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/217480/coroners-bulletin-2010.pdf>.


12. A point of discussion raised by Jonathan Henning’s presentation was whether this is legally and ethically correct in light of confidentiality and DNA retention laws.


23. R 7 ibid.

24. R 57 ibid.


29. Savage v South Essex Partnership NHS Foundation Trust.

30. LCB v United Kingdom (1999) 27 EHRR 212 at para 36 (in that case, it was held that there had been no violation of Article 6).

31. Edwards v United Kingdom at paras 54–56; R (Amin (Imtiaz)) v Secretary of State for the Home Department at para 30; Savage v South Essex Partnership NHS Foundation Trust.

32. Watts v UK (2010) 51 E.H.R.R. 555. The applicant claimed the care home move would reduce her life expectancy by 25%. The claim failed on the facts because of lack of particularized evidence of specific medical risk and because Council had undertaken consultation and risk assessment. The principle stands that, had the facts and evidence stood up to scrutiny, a claim on these grounds could be made out.


34. Robane v Penneke Care NHS Foundation Trust.

35. Gaskin v United Kingdom (1990) 12 EHRR 36; Gurr v Italy (1998) 26 D R R R 362; Powell v UK.


37. Ibid, paragraph 69.


45. The Bulletin of the Royal College of Pathologists, 160 (October 2012), 216.
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Rebecca Money-Kyrle MA Cantab, MSt Oxon, DPhil, Oxon, is a solicitor (England & Wales) (currently non-practising) and post-doctoral researcher, Civil Justice Project, Centre for Socio-Legal Studies, University of Oxford.

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