



# Sudden unexpected death in infancy

A multi-agency protocol for care and investigation

The report of a working group convened  
by The Royal College of Pathologists and  
The Royal College of Paediatrics and  
Child Health

Chair: The Baroness Helena Kennedy QC

*This document received input from many stakeholders (see Appendices V and VI) and was discussed and approved by the Councils of both The Royal College of Pathologists and The Royal College of Paediatrics and Child Health. In accordance with the publications policy of The Royal College of Pathologists, the document was placed on the Fellows and Members Area of their website from 25 June to 16 July 2004 for consultation. To date, 15 detailed replies were received and forwarded to the members of the Working Group, who found them very helpful in preparing this final report. Inevitably, given the nature and sensitivity of the subject, some contentious issues remain. The Working Group expects that the protocol will be further refined in future and welcomes feedback from those who use it. Comments should be sent to [publications@rcpath.org](mailto:publications@rcpath.org) with 'SUDI' in the subject line.*

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# CONTENTS

**Preface** by Professor James Underwood and Professor Sir Alan Craft v

**Introduction** by The Baroness Helena Kennedy QC 1

## **A Executive summary of the recommended protocol**

0.1 Abstract 17

0.2 Key elements of the recommended procedures 18

0.3 Summary of tasks of individual agencies and professionals 21

## **B The protocol and rationale for its introduction**

1 Introduction 29

2 Initial assessment of the infant presenting unexpectedly dead or moribund 30

3 Care of the parents 32

4 Initial multi-agency communication 35

5 Initial home visit 37

6 Further multi-agency discussion 38

7 Post-mortem examination 38

8 Local case discussion meeting 41

9 The role of the coroner 43

10 Multi-agency training and audit 44

**Figure 1** The Avon multi-agency approach to sudden unexpected deaths in infancy and childhood 46

**Table 1** Routine samples to be taken immediately after sudden unexpected deaths in infancy 47

**Table 2** The Avon clinicopathological classification of sudden unexpected deaths in infancy 49

**References** 51

## **Appendices**

**Appendix I** Parents' perspective on the investigation of sudden unexpected deaths in infancy 53

**Appendix II** Information to be collected by the paediatrician at the first interview and the home visit 57

**Appendix III** Autopsy protocol for sudden unexpected deaths in infancy 62

**Appendix IV** The police response to infant death 66

**Appendix V** Membership of the Working Group 71

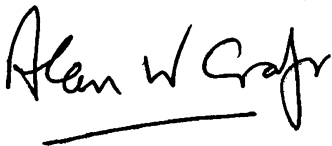
**Appendix VI** List of stakeholders 72



# PREFACE

The death of any baby is a tragedy. Every parent has a right to have such an event properly investigated. After the acquittal of Sally Clark in January 2003, The Royal College of Pathologists and The Royal College of Paediatrics and Child Health established an intercollegiate Working Group to review how sudden deaths in infancy should be investigated. These tragic events have occasionally led to the unwarranted incrimination of parents. Infants and children also need protection where there is evidence, from a previous death, that they may be at risk. We also need more research to illuminate our understanding of why some infants die suddenly and unexpectedly.

The issues are complex and challenging, and they are of great public and professional interest. Therefore, we were pleased that Baroness Helena Kennedy QC accepted our invitation to chair the intercollegiate Working Group. We are deeply grateful to her and to all those who contributed to this report.

A handwritten signature in black ink that reads "Alan W Craft". The signature is written in a cursive style with a horizontal line underneath the name.

**Professor Sir Alan Craft**

President, The Royal College of Paediatrics and Child Health

A handwritten signature in black ink that reads "James Underwood". The signature is written in a cursive style.

**Professor James Underwood**

President, The Royal College of Pathologists



# INTRODUCTION

In 2003, three high profile criminal cases involving the prosecution of mothers for causing the deaths of their babies created public consternation.

The common feature in their cases was that here were mothers who had suffered the loss of more than one infant. The repetition of sudden deaths without explanation raised suspicion amongst professionals and, in the absence of any eye-witness evidence of harmful conduct, the police investigations relied upon medical expertise, particularly that of paediatricians and pathologists. That evidence, when placed under careful scrutiny, raised serious concerns about the role of the expert witness in the courts, about the standard of proof and the quality of evidence, and about the procedures adopted for the investigation of sudden unexpected deaths of children. The Presidents of The Royal College of Pathologists and The Royal College of Paediatrics and Child Health recognised the seriousness of the events that were unfolding and, even before the hearing of Angela Cannings' successful appeal, established a Working Group to consider the implications of these cases for the medical profession. The overriding concern was that steps should be taken to prevent miscarriages of justice while protecting the interests and safety of children.

An important starting point is the acknowledgement that in the vast majority of cases where babies suddenly die, nothing unlawful has taken place. Children are four times as likely to die in the first year of life from both natural and unnatural causes than at any other time.

Parents suffering a terrible tragedy need sensitive support to help deal with their loss. It is every family's right to have their baby's death properly investigated. Families desperately want to know what happened, how the event could have occurred, what the cause of death was and whether it could have been prevented. This is important in terms of grieving, but is also relevant to a family's high anxiety about future pregnancies and may identify some hidden underlying cause, such as a genetic problem. And if there happens to be another sudden infant death in the family, carefully conducted investigations of an earlier death also help prevent miscarriages of justice.

The Working Group has included not only a number of paediatricians and pathologists, it has also had the benefit of experience from a number of Government departments, a Director of Social Services, a coroner, two very senior police officers and a member of the Foundation for the Study of Infant Deaths. It was very clear to the Working Group from the outset that our own processes should be open and transparent. One of the crucial ways of securing trust and maintaining confidence in the integrity of the medical profession is to shed some of the traditional mystique and engage openly in debate about how

systems and procedures might be improved. To that end, we chose to involve as many interested parties as possible in the creation of the report, inviting comment and views from other doctors, the judiciary, the legal profession, families, social workers, The Coroners' Society, coroners' officers and others (see Appendix VI).

The report is based upon the legal system in England and Wales and it is recognised that there are different organisational issues in Scotland. However, we would hope that the underlying principles could be shared across jurisdictions.

There is still great variance around the country as to how a sudden infant death is handled by doctors and the police. There are 43 police forces in England and Wales, each with their own procedures, and there are 28 Strategic Health Authorities. There are also many social service departments. The geographical remits of these different agencies do not coincide with each other and they have different operational methods. The coroners who sit within these areas can also have quite distinct ways of working. This diversity creates a very complicated patchwork in which good practice can often be found, but stories of insensitivity and failure are still sadly and angrily being told: parents being treated with inappropriate suspicion, numbers of policemen in uniform arriving shortly after an emergency call, babies being taken straight to mortuaries and parents being given too little information or information that is communicated with little sensitivity.

The need for a compulsory national protocol for the investigation of a sudden unexpected death in infancy is now vital. It should be as uncomplicated as possible, available on websites and in handbooks for all professionals involved, *and it cannot be optional*. The creation of national principles and procedures is at the heart of this report and underpins the framework for a compassionate, professional investigation of such deaths.

Clearly there should be sufficient flexibility for minor modifications, for example, in relationship to the specific professional roles. However, the home visit is the best way of identifying or eliminating areas of concern early on. We would expect the role to be filled by a paediatrician but what is crucial is that there is a dedicated, specially trained and experienced health professional fulfilling the function and it has to be someone who will have the confidence of the family and authority with the police. Where no such professional currently exists in an area or lack of training prevents adoption of the protocol, such training should be given as a matter of high priority.

Where no suitable paediatrician can be identified, consideration may be given to the home visit being conducted by an experienced and appropriately trained general practitioner or health visitor.

## THE NATIONAL INVESTIGATION PROTOCOL

In about a third of the country, local professionals have already agreed to a multi-agency protocol; however, about 600 babies die suddenly every year in the UK and the creation of a high quality investigation should be a national requirement. The intention is that the family should be at the centre of procedures and every process should be sensitive to the family's needs.

A number of excellent protocols for the investigation of infant deaths already exists but we decided to draw on the experience of one of our own members, Professor Peter Fleming, who devised the Avon and Somerset protocol, adjusting it where we felt it was necessary. The protocol calls for a paediatrician working with a specially trained senior police officer to visit a bereaved family at home within 24 hours of a death to take a complete history and offer initial support. This provides an opportunity for the family to explain events in the setting where they took place and the sleeping arrangements can be seen *in situ*. Unlike the situation in most adult deaths, parents usually lift the child and attempt all manner of resuscitation when a small child or baby dies. They clean away sputum and vomit from the airways. They apply damp cloths; blow into the mouth. Those descriptions flood back to parents as they relive events back at their home and they can explain the absence or presence of different features. It is important that a doctor is at the heart of this investigation of the scene as someone who understands the normal care of babies and who can talk the family through the events in a sensitive way. This home visit conducted by medical and police professionals is at the heart of the protocol and is not a negotiable element. The medical royal colleges should develop multi-professional training packages as soon as possible.

The protocol also requires that the post-mortem examination is conducted by a paediatric pathologist who has access to the information gathered at the home visit. On a number of occasions, the pathologist engaged in these cases has had extensive experience of adult deaths but is inexperienced in dealing with babies. It is for this reason that we recommend the use of paediatric pathologists or of a forensic pathologist with some training in paediatric pathology, who is properly accredited to do this work. It should be noted, however, that there is currently a severe shortage of both forensic pathologists and paediatric pathologists, a problem that will have to be addressed with some urgency, as our subsequent recommendations indicate.

The protocol also requires all the professionals to meet after full information about the family and the death is available, to agree what factors might have contributed to the death, provide a multidiscipline report for the coroner and plan further support for the family.



In addition, the Working Group felt that it was essential to set out the standardised protocols for pathologists involved with sudden unexpected deaths in infancy so that all the proper examinations are conducted, records of all interventions are made available (including information as to efforts at resuscitation), a skeletal survey organised, tissue samples taken (including frozen liver sections) and clear records kept for any future need. This is another of the crucial elements of these recommendations. Similar protocols with regard to record keeping should be a requirement for the clinicians and paediatricians who are involved at accident and emergency departments or at any other stage of the process. There needs to be clear guidance for all doctors in these cases on the collection of non-biological data and instructions for history taking, with a minimum dataset. This is so that parents can access this information at any future date should genetic information be forthcoming or scientific advances take place that will provide explanations for the loss of their baby. It also means that an expert engaged at a later stage, for whatever reason, has a solid basis upon which he or she can base an opinion.

### ***Recommendations***

- ◆ The creation of a compulsory national investigation protocol.
- ◆ The reinforcement of the standardised protocol for pathology with additional requirements in the cases of sudden unexpected infant death.
- ◆ The creation of a protocol for doctors such as paediatricians dealing with the central components of history taking, examination and investigation, which must include family structure, relevant family history and psychosocial factors.

## **THE ROLE OF THE EXPERT WITNESS**

Those who give medical evidence to courts have a duty to ensure that the foundation of that evidence is sound. Unfortunately, doctors are occasionally drawn into error because they base their testimony on medical belief rather than scientific evidence. There is also the temptation, particularly in the very adversarial arena of the criminal courts, to be pushed into certainties where there are none. Barristers for the Crown hate the words “I don’t know”, whereas the defence lawyer loves them. In criminal cases where guilt must be based on the high standard of proof “beyond reasonable doubt”, an expert’s reservation may be the rock upon which a prosecution founders. However, the expert witness should constantly remind himself or herself that they are independent and not there to win for a side. This can be very difficult because just as lawyers and judges can experience case hardening, so can doctors. Those regularly involved with child abuse can find it hard to be dispassionate and indeed sometimes become hawkish. A doctor can be convinced, based on his or her experience, that a defendant is guilty but unless there is compelling evidence supported scientifically, he or she should not express that view in criminal proceedings.

Doctors sometimes fail to appreciate that there is a difference between the role and expectations of professional and expert witnesses. Sometimes doctors may appear in their professional capacity describing their treatment of a patient. At other times, they will be expected to attend as experts, able to express an opinion but founding their views on a scientific base. Unfortunately, there is insufficient training emphasis on the necessity of a scientific foundation for expert testimony. Nor are doctors sufficiently trained in the differences between the courts. The evidence the practitioner gives in the family courts is subject to a different standard of proof and is given subject to an injunction about protecting the paramount interests of the child. The situation in the criminal courts is quite different because liberty is at stake and the preferred truth must be that the person on trial is not guilty. This is the presumption of innocence. However, doctors who spend most of their time giving expert testimony in family courts may not be conscious of the need to make a transition. Unfortunately, textbooks, professional journals, specialist training syllabuses and other material often provide insufficient guidance on these points.

It is our view that paediatricians involved in the acute management of patients should not be expected to give expert testimony in cases involving those patients. It is a *sine qua non* that doctors treating patients must develop partnerships with them and with the immediate family to ensure the best medical outcome. This will inevitably result in a degree of intimacy and therefore subjectivity when evaluating the case as a whole. This is the opposite of what is required of the expert witness, who should be objective, impartial and detached.

In addition, a paediatrician dealing with a stressful, difficult situation may make decisions on the spot, which he or she may feel obliged to justify later; again this may interfere with the appropriateness of the doctor who was on duty being called as an expert witness. He or she may be called to give evidence about the management of the case as a witness of fact describing the medical care provided, but they should not be propelled into the role of expert.

It is also important to recognise that a paediatrician whose expertise is child abuse will have a very different perspective from one whose expertise is in sudden infant deaths, the majority of which are a result of natural causes. The view a professional takes is inevitably affected by the nature of his or her experience and this should be an important consideration in the choice of experts and in the self-awareness experts should have.

It is also important that the courtroom is not a place used by doctors to fly their personal kites or push a theory from the far end of the medical spectrum. The expert should have recent clinical experience, peer reviewed research and should not roam outside of his or her area of expertise. Lawyers often try to

press the professional expert to expand their testimony into areas where they have no expertise and he or she can end up expressing a hunch with alarming certainty. Doctors should be willing to say "I don't know" without shame or inhibition.

## DISCLOSURE

It is the duty of an expert instructed by the Prosecution to act in the cause of justice. It follows that if an expert has carried out a test that casts doubt on his opinion, or if such a test has been carried out in his laboratory and is known to him, he is under a duty to disclose it to the Defence. It does not matter that he or she thinks it is irrelevant. It is when experts start to make such judgements that serious miscarriages of justice can take place. This duty exists irrespective of any request by the Defence. It is also not confined to the documentation on which the opinion or findings of the expert are based; it extends to anything that might arguably assist the Defence.

### *Recommendations*

- ◆ The Royal Colleges or specialty associations should accredit experts.
- ◆ Doctors should have special instruction on the role of the expert witness before holding themselves out as court experts.
- ◆ Such instruction should be renewed at least every five years.

## JUDGES

Whether a witness is competent to give evidence as an expert is for the judge to determine. He or she first has to decide whether the subject matter of the opinion falls within the class of subjects upon which expert testimony is permissible. The second question is whether the witness has acquired by study or experience sufficient knowledge of the subject to make his or her opinion of value in resolving the issues before the court. In cases that will largely turn on an evaluation of expert opinion, a judge should satisfy himself or herself that new or unfamiliar technology, techniques or theories have sufficient scientific basis. As Lord Steyn has said in one of the leading cases on expert testimony, "It would be entirely wrong to deny to the law of evidence the advantages to be gained from new techniques and ... advances in science". Our knowledge and understanding of the human condition is advancing constantly and it would be unjust to close out evidence because it is new and challenges old certainties. However, the courts should ascertain that new developments are grounded in science and a proper body of research.

### **Recommendations**

- ◆ Before an expert gives evidence, the trial judge should establish the credentials of the expert.
- ◆ What is the expert's area of practice?
- ◆ Is he/she still in practice?
- ◆ What is his/her area of expertise?
- ◆ To what extent is the witness an expert in the subject to which he/she testifies?
- ◆ When did he/she last see a case in his/her own clinical practice?
- ◆ Is he/she in good standing with their medical royal college?
- ◆ Is he/she up to date with continuing professional development?
- ◆ Has she received training in the role of the expert witness in the last five years?
- ◆ To what extent is his/her view widely held?

Judges should also be alert to the risks that can arise when a cosiness develops in the courtroom because the same witnesses appear time and time again.

## **LAWYERS**

While ultimate responsibility to determine the competence of an expert lies with the judge, lawyers also have responsibilities. If the Prosecution are permitted to call a witness of tenuous qualification as an expert in the given field, the burden of proof might shift imperceptibly and a burden be cast on the defendant to rebut a case that should never have been before the jury at all. If the Defence are able to call a 'quack', inappropriately qualified doctor or enthusiastic amateur and present their evidence as having equal value to that of a well established authority on a subject, another kind of injustice can be perpetrated.

The "positive duty to disclose", in the context of scientific evidence, obliges the prosecution lawyer to make full and proper inquiries from medical and scientific experts to ascertain whether there is material that should be disclosed.

When a lawyer is defending an accused person, he or she should present the client's case without fear or favour. It would be wrong to expect lawyers to pull their punches or present a case in a diluted form when the outcome might lead to the loss of a person's liberty and possibly the destruction of their family life. Every effort should be made to find an explanation for what occurred and a counter view to that being pressed by the Prosecution. However, it is unprofessional to present as experts those who are not or who do not have the expertise in the required area, or pressing medical or other witnesses to express opinions beyond their experience. Lawyers for the prosecution and the defence should have this firmly in mind as they conduct cases and call expert witnesses.

After discussions with the Bar and the Judiciary, the Working Group recommends that the criminal courts should adopt a procedure similar to that in civil proceedings as part of good case management. Before there is a criminal trial, there is a preliminary hearing called a Pleas and Directions Hearing, at which the judge sets out a timetable and makes orders for the conduct of the case. It is our recommendation that in cases that essentially turn on expert testimony, the judge should order that the experts meet and clarify areas of conflict and report back to the court. This will help to clarify the issues of contest and enable the court to evaluate whether the case should be proceeding.

Following the Court of Appeal judgement in *R v Cannings* 2003, if there are two views and both are equally valid, it would be unwise to proceed with a trial against an accused, as the outcome may well be unjust. However, in civil cases where the central issue is child protection and proof is on the lesser standard – the balance of probabilities – a court may prefer the testimony of one expert and base its judgement on that preference in the interests of the child.

Widening the pool of experts is imperative and the Working Group was concerned that the National Health Service should recognise the importance of testimony in courts and should be willing to release doctors to give evidence.

### ***Recommendations***

- ◆ Trial judges in the criminal courts in cases where expert testimony is central should order a pre-trial meeting of experts to establish areas of conflict and set them out in writing for the court.
- ◆ Judges should be proactive in exercising their duty to establish the expertise of witnesses appearing before them and should ensure that courts are not used to push a theory with an insufficient scientific base. Judges should also ensure that experts have recent clinical experience. The expertise of witnesses coming from outside of the jurisdiction should be tested with the same rigour as that of British experts. Establishing the expertise of witnesses should be included in judicial training.
- ◆ The Crown Prosecution Service should exercise restraint about proceeding in cases based on medical evidence where valid opinions exist on both sides.
- ◆ The pool of experts from which the Crown draws should be as wide as possible to prevent the development of divisions into prosecution experts and defence experts and also to avoid the cosiness that comes with over-familiarity.

## **HUMAN RESOURCES**

There is only one paediatric forensic pathologist in the country. Throughout the whole of England and Wales there are just 40 paediatric pathologists, which

means they are thin on the ground and often unavailable at the crucial time. There should be a drive to increase those numbers but it has been recognised that negative media coverage is reducing the pool of paediatricians who will testify in court and particularly the number of trainees willing to enter paediatric pathology. The Working Group came to the view that in order to make best use of human and other resources, these aspects of pathology services should be regionalised. In each group of Strategic Health Authority areas, there should be at least two pathologists who are certified as being appropriately qualified to carry out a post mortem for sudden unexpected death in infancy (SUDI). They would either be paediatric pathologists or forensic pathologists adequately trained in working to a paediatric protocol.

It is therefore imperative that opportunity is made available to expand the skills of current forensic pathologists and paediatric pathologists with training opportunities to acquire the appropriate skills. We strongly advocate the creation of a specific qualification in forensic paediatric pathology.

### ***Recommendations***

- ◆ Expand the numbers of paediatric pathologists experienced in infant autopsies.
- ◆ Establish a specific qualification in forensic paediatric pathology to cover deaths in infancy.

## **CORONERS**

Coroners play a vital role in cases of sudden unexpected infant death. The coroner is informed and orders that a post mortem is conducted by a pathologist. It is our recommendation that the coroner orders that such a post mortem is conducted where possible by a paediatric pathologist or forensic pathologist with a specific qualification to cover deaths in infancy. Clearly this is unnecessary where a baby has been killed in a car accident or has been stabbed, but in the cases of sudden unexplained death, where very careful judgements and an intimate understanding of an infant's metabolism is concerned, pathologists with experience of small children and the newborn should be instructed.

The post mortem on an infant will commonly require transfer to a specialist centre that may be some distance away, but this can normally be done relatively quickly. Section 22 of Coroners' Act 1988 does not, in our view, preclude such a transfer. Ancillary investigations including radiology, microbiology, metabolic studies and sometimes detailed neuropathology are required, and advice from specialists other than the pathologist performing the post mortem are needed. This increases the cost of these autopsies compared with routine coroners' post mortems. Whilst the coroner will ultimately be responsible for these costs, the extra revenue and resource required will have to be addressed.

The coroner has the power to make orders that may assist in resolving questions as to the cause of death. For this reason, the coroner should automatically order that blocks and slides containing the tissue samples of the baby are retained in perpetuity or until further order. Legislation is currently in train to reform the Coroners' Courts and this should be an ideal moment for the creation of greater coherency nationwide.

An issue of concern to parents is the way in which *cause of death* is entered in the death certificate of a baby who has died unexpectedly. Different coroners have different practices. In some places, "unascertained" has now come to have a stigma attached to it, suggesting the death was suspicious, but this is largely because other coroners enter "SUDI" (sudden unexpected death in infancy) or "SIDS" (sudden infant death syndrome), which provides a parent with a label to communicate in shorthand what happened.

The first point at which this can be an issue is when the coroner is asked to issue a certificate of the fact of death so that a funeral can proceed. It is our view that the coroner should, at this point, enter a note on the certificate saying that death has occurred, is being investigated and further information will be available to the Registrar of Births and Deaths in due course. There is no need to say more.

After an inquest, if the police intend no further investigation, the coroner should enter the death as "SIDS" where the death meets the international criteria for SIDS, and in all other cases he or she should enter the death as "SUDI" It is unfair to families that on the register of deaths there should be an entry of "unascertained", which could mean that future generations will misinterpret its meaning as inferring something suspicious.

The issue of inquests is another area of controversy. Inquests are not always ordered and there has developed amongst families a feeling of resentment and stigma if they are subject to an inquest while others in apparently similar circumstances are not. It is our view that different practices breed feelings of injustice. Providing satisfactory guidelines as to when or whether there should be an inquest has led us to the view that inquests should be ordered in all but exceptional cases where the cause of death is very clearly natural.

### **Recommendations**

- ◆ Coroners should instruct paediatric or forensic pathologists with appropriate expertise, and other specialists where necessary, working to a paediatric protocol.
- ◆ Coroners should order the retention of all tissue blocks (including frozen specimens) and microscope slides in perpetuity or until further court order and such retention falls within the coroners' exemption in the legislation regarding the retention of human tissue.

- ◆ Certificates of the fact of death, releasing the baby's body for a funeral, should say nothing other than that death has occurred or that further information will be forthcoming to the Registrar of Births and Deaths in due course.
- ◆ Inquests should be ordered in *all* cases of sudden unexpected death in infancy, save where there are immediately recognisable natural causes, e.g. a heart defect or overwhelming infection where coroners' 'Pink forms' will be issued. The inquest should not take place until after the multi-professional meeting.
- ◆ We recommend that such an inquest is held *in private* should the family so wish, save in the exceptional circumstances where the coroner feels an open process is in the public interest, e.g. where there has been a failure of equipment such as a mattress or a travel cot.
- ◆ Coroners should enter the cause of death in the Registrar of Births and Deaths as "SIDS" in those cases that meet the international definition of SIDS, and in other cases where there will be no further investigation as "SUDI".
- ◆ The examination of an infant found suddenly and unexpectedly dead has to be conducted even more thoroughly and carefully perhaps than any other type of post mortem. The cost of paediatric post mortems must be met by the coroner and adequate resources should be made available. A full range of tests, including neuropathology, microbiology, biochemistry, toxicology, as well as investigations for genetic metabolic disorders, will all add to the expense of these post mortems and the cost must be met.

## TISSUE RETENTION

Parents who have experienced the sudden loss of a baby want to understand what has happened. Evidence from the Foundation for the Study of Infant Deaths confirmed that if parents are taken into the confidence of professionals and have procedures explained, they understand the need for the compulsory retention of small quantities of tissue for blocks and microscope slides.

Brain retention, however, is a very difficult and sensitive issue. A huge amount of information is lost if brains are not retained and properly examined. Detailed examination of the central nervous system can be crucial. The information is extremely valuable, firstly so that families can be fully informed about the reasons for their baby's death, but also for our better understanding generally of the causes of sudden death in infancy. The altruism of parents who have lost babies should not be underestimated. When purposes are properly explained, parents are very willing to do what they can to further medical understanding of these tragic occurrences.



The taking of initial samples from the brain may take up to two or three weeks and we would like to see this expedited. Many pathologists say this can be done within a week to ten days and thereafter the brain can be returned for burial. However, most neuropathologists advocate retention of the brain until microscopic diagnosis is complete, which can take up to three or four months. This enables much more complete analysis than initial sampling and may, in the long run, provide an answer to the parents' quest for an explanation.

Few families would wish to wait so long before holding a funeral; some families wish to bury a body as intact as possible for religious and personal reasons, and this should be respected. The Alder Hey Inquiry has exposed the raw feelings there are about tissue retention. However, with careful and sensitive communication, many parents will agree to donation of the brain when the reasons are explained. In the view of the Working Group, brain retention should only take place with explicit consent from parents. Where there is a homicide investigation, the coroner will almost invariably order the retention of the brain.

### ***Recommendations***

- ◆ Parents should be informed that blocks and slides will be retained by compulsory coroner's order. Brain retention, beyond that ordered by the coroner, should only take place with the specific consent of the parents. However, they should be asked if they are prepared to consent to the donation of the brain because of the much greater possibilities of gaining personal information about the baby at a later stage and of the benefit that could accrue to future generations from research.

## **IMPROVEMENT OF PROFESSIONAL SKILLS**

Appropriate training was a recurring theme in our work – for police officers, for doctors, for nurses, for social workers and for coroners' officers. Good communication between professionals and between professionals and parents is vital, but professionals should also be sensitised to emotions being experienced by parents. Sometimes this comes instinctively but much of it can also be learned. Simple, practical training is important.

One coroner's officer told the Working Group that training for coroners' officers was "lamentable" but that the University of Teesside is now running a two-week course. We would like to see such a course include specific training to deal with SUDI and we would like to see it become compulsory and certificated.

For some professionals, specialised training is more complex. After the miscarriages of justice in the 1980s and early 1990s, which raised concern about the evidence of forensic scientists, the Council for the Registration of Forensic Practitioners was established. The Royal College of Paediatrics and Child Health has been working with the Council over the last year to try to

develop a registration system for forensic paediatrics. We strongly endorse this development. The Royal College of Pathologists should establish a supplementary programme of training in forensic paediatric pathology for pathologists with training in paediatric pathology.

### ***Recommendations***

- ◆ Certificated training for the handling of sudden unexpected death in infancy should be made available to police, social workers, ambulance crews, paramedics and coroners' officers.
- ◆ Registration systems should be created for forensic paediatrics and forensic paediatric pathology.
- ◆ The medical royal colleges, in collaboration with other professional bodies, should create a multidisciplinary training package.

## **POLICE**

The involvement of the police at an early stage often alarms parents who have just lost a baby. If the police do not make it clear, and with sensitivity, that they always attend when an unexpected sudden death takes place and that this is simply part of their overall duties, parents can be very distressed. Not so very long ago, stories were told of police arriving and cordoning premises off as though they were dealing with a murder scene and removing the cot and every item connected with the baby. It is therefore essential that police start from the position that the vast majority of babies' deaths are from natural causes. However, for the police this is hard to reconcile with modern training for criminal investigations, which emphasises the importance of 'the golden hour' – the first hour of evidence gathering that produces crucial evidence before it can be lost or contaminated. The point that has to be emphasised in police training is the statistical one that few of these cases should be cause for suspicion. Suspicion should arise only if there is material evidence of something irregular, such as medical evidence of injury or evidence of concern from social services or police Child Protection Unit records.

Accepting that uniformed officers will respond to matters of emergency involving life or death, police should, whenever possible, be out of uniform and specially trained for the investigation of such an event. Experience already shows that close working relationships with medical professionals usually means that the assigned police officers quickly develop the skills and sensitivity required for the handling of these cases. The Association of Chief Police Officers has already improved police practice considerably by producing an impressive set of guidelines for the handling of sudden infant death (ACPO Crime Committee, 2000). These recommend that the police officer attending a sudden infant death should be a detective of at least inspector rank who has been specially trained for these cases. The guidelines emphasise the importance of good liaison between police and paediatricians. Although the police guidelines recommend

that police take a history from the carers of the baby before anyone else, this is not incompatible with the home visit, where the police officer and doctor attend the family home and have events recounted there. The police would welcome a national protocol to create coherence across the country.

## THE CROWN PROSECUTION SERVICE

The Crown Prosecution Service (CPS) has special caseworkers dealing with such sensitive issues as infant deaths and they work closely with the police once an investigation has begun. These lawyers should also have special training in the protocol as closer liaison will create a much more thoughtful decision-making process when it comes to charging. It is essential that account should be taken of the multi-professional review before there is any decision to prosecute.

### *Recommendations for police and CPS*

- ◆ Police officers and CPS lawyers who will handle infant deaths should receive special training.
- ◆ No decision to prosecute should be made without reference to the multi-professional review.

## QUESTIONS THAT HAVE BEEN RAISED

1. Should the protocol for sudden unexpected death in infancy be extended to include the sudden deaths of older children up to the age of 16?

The structure and approach of the protocol could be used for the deaths of older children with modifications. Clearly the questions asked of parents and some professionals may be different and the investigation would be broader, because the older a child is, the less dependent he or she is on adults.

2. How would the protocol interface with Child Death Review Teams, which will be created in every local authority under new Government plans?
3. The existence of a national protocol should enhance the work of the Review Teams in providing clearer avenues of contact and establishment of responsibilities. As well as providing oversight of individual deaths, the Review Teams will also be looking at the bigger picture of what the causes of infant and child deaths are in their locality. Improved investigations of SUDI will be a basis for better research and epidemiological study.

New children's legislation will create Local Safeguarding Children Boards, which will have responsibility for the welfare of children in their areas. In our view, these boards should have responsibility for the overview of the implementation of this report's recommendations and should audit its application. Nothing we have proposed should interfere with the introduction of the new Children's

Trusts as a means of delivering integrated services for children. It should be one of the fundamental functions of every Director of Social Services to see the implementation of this protocol in his or her area.

4. Is it not too much to expect paediatricians around the country to take part in a home visit in the company of the police within the first 24 hours after a baby has died? Will the police not prefer to do their own home visit? Would the taking of a good case history by the paediatrician not provide the required information? Could this not be a recommended but non-essential part of the protocol?

The Working Group feels strongly that the home visit is one of the recommendations at the heart of the protocol and that a paediatrician would make him or herself available if a child was critically ill and SUDI should be treated with the similar seriousness and priority by the hospitals. These visits will rarely take place in the middle of the night. Such visits should be appropriately remunerated. It does require some flexibility to be built into the system, e.g. it could be a senior nurse practitioner that fulfils the role, but the medical professional should be an identified SUDI expert. The person should be referred to as the 'SUDI specialist' or 'SUDI paediatrician'.

## CONCLUSION

For innocent parents to have a child taken from them, or to be prosecuted and convicted of killing a child who actually died of natural causes, is the stuff of nightmares. It is right and desirable that there should be public indignation at the failures that lead to such terrible suffering. When we no longer feel rage at injustice, we will have lost our humanity and our claims at living in a civilised society. However, we must also acknowledge that in a small percentage of the cases where a baby dies, something unlawful will have taken place. Despite our unwillingness to accept the possibility, we have learned conclusively in the last 30 years that some mothers, fathers and other carers do induce illnesses in their children and sometimes fatally harm them. Child protection is a responsibility all of us must bear because of the special vulnerability of the youngest among us, who have no voice.

Creating rules and procedures that square the circle of maintaining high standards in the interest of justice for parents, while also safeguarding the young and ensuring their wellbeing, is an almighty challenge. We hope our recommendations can effect positive change within the system and go some way to guard the best interests of all concerned.

**The Baroness Helena Kennedy QC**  
**September 2004**



# A EXECUTIVE SUMMARY OF THE RECOMMENDED PROTOCOL

## 0.1 Abstract

- 0.1.1 We describe a protocol for the investigation and care of families after the sudden unexpected death of an infant or young child. The aim of the investigation is to establish as far as is possible the cause of death and, in order to do this, it is important that the medical processes are similar to those of a child with a rare condition requiring special investigation in a tertiary centre. The investigation is to be carried out by specially trained individuals, with an emphasis on multi-agency working, involving close collaboration and the sharing of information between hospital- and community-based clinical staff, the pathologist, the police, social services and the coroner's service. The investigation will concentrate not just on the child, but will consider family history, past events and the circumstances in which the child lived. Research has shown that these factors can be a rich source of information in determining why a child died. All parts of the process should be conducted with sensitivity, discretion and respect for the family and the child who has died.
- 0.1.2 A key aspect of the protocol is that all staff involved should retain an open mind, knowing that some deaths will be a consequence of neglect or abuse, but recognising that the majority are natural tragedies. All agencies have a duty of care to parents as well as to the child who has died and other surviving children.
- 0.1.3 All NHS Trusts (including Hospital Trusts, Primary Care Trusts and Ambulance Trusts), police services, social services departments and coroners' services throughout England and Wales are recommended to implement this protocol in full, on a mandatory basis as soon as appropriate training of all relevant local staff has been completed. This training should be organised and commenced as soon as possible, with a view to full implementation of the protocol with a minimum of delay. Precise local arrangements will depend upon close collaboration between the agencies in developing service specifications and in implementation.
- 0.1.4 The local establishment of the protocol, as well as the monitoring of its implementation and audit of its effects, must be the joint responsibility of senior designated professionals in each agency.
- 0.1.5 Appropriate multi-professional training will be required before implementation of this protocol. Senior designated professionals in each agency must be given the responsibility for organising and maintaining such training programmes.

## 0.2 Key elements of the recommended procedures

- 0.2.1 Once a baby has been declared dead, the coroner has jurisdiction over the body and all that pertains to it. *Coroners must therefore be consulted over the development of procedures locally and should be asked to give general approval for the measures agreed, so as to avoid the need to obtain specific approval on each occasion.*
- 0.2.2 The majority of sudden unexpected deaths in infancy are natural tragedies, but a minority are a consequence of ignorance, neglect or abuse. The investigation should keep an appropriate balance between medical and forensic requirements and should take account of possible risks to other children in the household.
- 0.2.3 Professionals should approach the investigation with an open mind and families should be treated with sensitivity, discretion and respect.
- 0.2.4 There should be a multi-agency approach involving collaboration among: accident and emergency (A&E) department staff, ambulance staff, child protection coordinators, coroners, coroners' officers, general practitioners (GPs), health visitors, midwives, paediatricians, pathologists, police and social workers.
- 0.2.5 Each Trust should identify and ensure access to a named paediatrician with special responsibility for sudden unexpected deaths in infancy (SUDI paediatrician), who will sometimes be the same as the paediatrician designated for child protection.
- 0.2.6 In each agency, a senior person with suitable training and experience should be identified as having responsibility for implementation of the national procedure, including continuing training for all relevant staff.
- 0.2.7 Babies found dead at home should always be taken into the A&E department, not to the mortuary, and resuscitation should always be initiated unless clearly inappropriate.
- 0.2.8 The parents should be allocated a member of staff to care for them and should normally be given the opportunity to hold and spend time with their baby at some point while at the A&E department. They should also be offered mementoes, e.g. a lock of hair or a photo.
- 0.2.9 As soon as possible after arrival, the baby should be examined by a consultant in paediatrics and a careful history should be taken from the parents.
- 0.2.10 A standard set of investigative samples should be taken immediately upon arrival and after death is confirmed.

- 0.2.11 As soon as death has been confirmed, notification should be given to the coroner, the police, the paediatrician designated to deal with sudden unexpected deaths in infancy (the 'SUDI paediatrician') and the primary care team. The paediatric pathologist should also be informed as soon as possible.
- 0.2.12 When the baby is pronounced dead, the paediatrician should break the news to the parents, and explain police and coroner involvement and the need for a post-mortem examination, including that tissue blocks and slides will be taken and retained permanently as part of the pathology medical record. The paediatrician should also give the parents the opportunity to donate tissues or organs for research.
- 0.2.13 An initial strategy discussion should be held between the lead professionals who will be involved in the investigation – the supervising police officer and the designated paediatrician – to agree their approach and to ensure continuing close collaboration as frequently as necessary, often by telephone. The on-call paediatrician or the SUDI paediatrician should talk urgently to the social service department to review any relevant social services or child protection information on the infant, other close family members and members of the household.
- 0.2.14 If significant concerns are raised at any stage about the possibility of abuse or neglect, a decision may be taken for the police to become the 'lead agency'. The police should be informed immediately that significant suspicion arises so as to ensure any further interviews with the family accord with the requirements of the Police and Criminal Evidence Act 1984.
- 0.2.15 Preferably within 24 hours of the death, the police officer and the SUDI paediatrician should visit the home to talk with the parents and examine the place where the baby died (which may not be at the home). They may make this visit together, or they may visit separately and then confer.
- 0.2.16 The SUDI paediatrician should compile a report for the coroner and the pathologist, based upon the clinical circumstances of the death, the history obtained at the home visit and a review of all relevant medical and social records.
- 0.2.17 The coroner will order a post-mortem examination to be carried out as soon as possible, preferably within 48 hours, by the most appropriate pathologist. In most cases, this should be a paediatric pathologist, following a recommended protocol, but if significant concerns have been raised about the possibility of abuse or neglect, a forensic pathologist should take the lead, assisted by a paediatric pathologist. If the post-mortem examination reveals no sufficient identifiable cause of death, whether or not any concerns have been raised during the post-mortem examination or previously about the possibility of abuse or neglect, the pathologist should categorise the death as "unexplained pending further investigations" and the coroner should in every case hold an inquest.



## Sudden unexpected death in infancy

- 0.2.18 The results of the post-mortem examination should be discussed with the parents at the earliest opportunity. This is usually part of the SUDI paediatrician's role.
- 0.2.19 A case discussion meeting should be held, usually in the GP's surgery, as soon as the results of the main post-mortem tests are available, approximately 8–12 weeks after the death. This meeting should involve the GP, health visitor, midwife (if appropriate), SUDI paediatrician, other paediatrician if involved, pathologist(s), senior investigating police officer, possibly coroner and, where appropriate, social worker. All relevant information concerning the circumstances of the death, the infant's history, family history and subsequent investigations should be reviewed. The main purpose is to share information, agree the cause of death and plan future care for the family. There must be an explicit discussion of the possibility of abuse or neglect and, if no evidence is identified to suggest maltreatment, this should be documented as part of the report of the meeting. The report should be sent to the coroner, who should take the case discussion information into consideration in the conduct of the inquest and in the cause of death notified to the Registrar of Births and Deaths. Where significant concerns are raised about the possibility of abuse or neglect, the social services department will take the lead in any further investigation, and may convene a child protection strategy meeting or case conference.
- 0.2.20 The paediatrician should write a detailed letter to the parents, giving information concerning the cause of the infant's death and make arrangements to meet them to explain the contents of the letter, answer questions and offer future care and support.
- 0.2.21 Appropriate multi-professional training will be necessary prior to implementation of this protocol. Priority must be given to the organisation and maintenance of such training programmes.
- 0.2.22 A robust process (preferably utilising a standardised assessment tool) should be put in place to audit the operation of the national procedure after each case.

## 0.3 Summary of tasks of individual agencies and professionals

### 0.3.1 *Accident and emergency staff*

- ◆ Ensure that your Trust has access at all times to a consultant paediatrician with special responsibility for SUDI (the 'SUDI paediatrician'); this will almost always involve an on-call rota of a number of such paediatricians, usually across more than one Trust.
- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Attempt resuscitation until it is clear that it cannot be successful.
- ◆ Call the on-call paediatrician and/or the SUDI paediatrician (according to the agreed local arrangement).
- ◆ Keep careful records, including the history given by the parents and notes on the initial physical examination, plus detailed records of all interventions and procedures carried out in the A&E department, including the sites of attempted venous and arterial access.
- ◆ As soon as death has been confirmed, inform the coroner (or coroner's officer) and ensure that any further action has the coroner's approval.
- ◆ Look after the parents sensitively, offer mementos and keep them informed.

### 0.3.2 *Ambulance staff*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Attempt resuscitation unless it is clear that the baby has been dead for some time.
- ◆ Keep the parents informed.
- ◆ Take the baby to the most suitable A&E department (not to the mortuary).

### 0.3.3 *Chief Executive of NHS Trusts (including Primary Care Trusts in England and Local Health Boards in Wales)*

- ◆ Ensure there is a local agreement, in line with the recommendations of this report, between the coroner, police and your NHS Trust on the principles of how unexpected deaths in infancy should be handled.
- ◆ Ensure that your Trust has agreed access at all times to a consultant paediatrician with special responsibility for SUDI, and that this responsibility is included in the job description. This will involve two or more such paediatricians arranging an 'on-call' rota for this purpose, usually covering more than one NHS Trust.
- ◆ Ensure appropriate multi-professional training is provided and funded for all relevant professionals within your Trust.

## Sudden unexpected death in infancy

- ◆ Ensure that pathology investigations in SUDI post-mortem examinations on infants dying in your Trust can be carried out at the request of a coroner (either within your Trust or, with agreement, within another Trust that has appropriate facilities).
- ◆ If you have a department of paediatric pathology, and after appropriate discussion, agree that it should accept referrals from elsewhere for SUDI post-mortems.
- ◆ Encourage your medical and nursing staff to give high priority to attendance at SUDI case discussions.

### 0.3.4 *Coroner*

- ◆ Ensure that the investigation of unexpected infant deaths has a proper balance between medical and forensic requirements.
- ◆ Agree standard procedures in advance, in line with the recommendations of this report, with the relevant local NHS Trusts and the police so that specific approval on each occasion is not needed.
- ◆ Ask to be provided with a full history as obtained at the home visit.
- ◆ Ensure that the post mortem is carried out by a pathologist with appropriate and recent paediatric training and expertise, (working with a forensic pathologist when maltreatment is suspected), if necessary ensuring the infant is transported to an appropriate specialist centre for that purpose.
- ◆ Make a copy of the post-mortem report available to the SUDI paediatrician and (if there are no suspicious circumstances) give permission for him or her to discuss it with the parents.
- ◆ Authorise, and ensure that parents are informed, that tissue blocks and slides are to be taken at post-mortem examination (see Appendix III) and retained indefinitely as part of the pathology record.
- ◆ Ensure that parents are informed about any further bodily material that has been retained after the initial post-mortem examination, for how long it is likely to be required and the purpose of this retention.
- ◆ Within the scope of the Coroners Rules, stipulate and authorise the period for which such further bodily material should be retained.
- ◆ Ensure the body is released for burial or cremation as soon as possible.
- ◆ Save those where there are clear natural causes immediately recognisable at post mortem (and a certificate of the cause of death can therefore be issued immediately), hold an inquest following every sudden unexpected infant death and schedule the inquest as expeditiously as possible.
- ◆ At inquest, take account of the report of the multi-agency case discussion meeting; summon all the relevant local professionals to attend the inquest if no multi-agency meeting has taken place.
- ◆ Avoid the term “unascertained” as the final registered cause of death; if the death meets the international criteria for sudden infant death syndrome (SIDS)<sup>1,20</sup> that is the term that should be the registered cause of death.

- ◆ Hold the inquest in private if this is possible and not against the public interest.

0.3.5 *Coroner's officer*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Visit the family as necessary, treating them with sensitivity, and keeping them fully informed about all the procedures that are taking place, and helping them with the practical arrangements.
- ◆ Explain to the parents what takes place in an inquest and let them know that they can take a friend, and ask questions at the inquest.

0.3.6 *General practitioner (GP)*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ If called to the scene of death, send the baby to the A&E department rather than to the mortuary.
- ◆ Visit the parents at home as soon as convenient.
- ◆ If necessary, advise on suppression of lactation.
- ◆ Make the GP notes available to the SUDI paediatrician and attend the case discussion meeting.
- ◆ With the health visitor, ensure that the family receives adequate support, both now and for a future pregnancy.

0.3.7 *Health visitor*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Visit the family at home as soon as convenient.
- ◆ Facilitate the visit by the SUDI paediatrician.
- ◆ Make the health visiting notes available to the SUDI paediatrician and attend the case discussion.
- ◆ With the GP, ensure that the family receives adequate support, both now and for a future pregnancy.

0.3.8 *Midwife (if still involved with the mother and baby)*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Visit the family at home as soon as convenient.
- ◆ If necessary, advise on suppression of lactation.
- ◆ Make the midwifery notes available to the SUDI paediatrician, and attend the case conference.

## Sudden unexpected death in infancy

- ◆ Ensure that a prominent note is made in the mother's obstetric records to alert staff dealing with a future pregnancy.

### 0.3.9 *On-call consultant paediatrician*

- ◆ Ensure that your Trust has access at all times to a consultant paediatrician with special responsibility for SUDI; this will almost always involve an on-call rota of a number of such paediatricians, usually across more than one Trust.
- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Agree in advance the division of responsibility between the on-call paediatrician and the SUDI paediatrician in the event of an unexpected infant death.
- ◆ Whenever possible, be available yourself or ensure that the SUDI paediatrician is available to go to the A&E department soon after a baby has been brought in unexpectedly dead when you are on call.
- ◆ Consult with the supervising police officer on the approach to the investigation.
- ◆ Ensure the SUDI paediatrician has the opportunity to visit the family's home, or do so yourself, preferably within 24 hours of the death, to talk with parents and examine the environment in which the baby died.
- ◆ Collate all relevant medical and social records for the SUDI paediatrician.
- ◆ Prepare a report for the pathologist prior to the post-mortem, including information on the details of resuscitation procedures.
- ◆ Facilitate the arrangement of a case discussion meeting by the SUDI paediatrician (to be convened as soon as results of post-mortem tests are available) and if appropriate help the SUDI paediatrician prepare a report of the meeting for the coroner. This meeting should usually be chaired by the SUDI paediatrician.
- ◆ Maintain good communication with the police or the SUDI paediatrician at every stage.
- ◆ Offer to talk with the parents again whenever they wish, or ensure that the SUDI paediatrician does so.

### 0.3.10 *SUDI paediatrician*

- ◆ Advise the Strategic Health Authority on the commissioning of services relevant to care and investigation after SUDI.
- ◆ Ensure that a paediatrician with special responsibility for SUDI (and appropriate training and experience) is available at all times within your Trust. This will involve establishing an on-call rota with several paediatricians, usually in more than one Trust. Such responsibilities should be recognised in job descriptions.

- ◆ Ensure the development and implementation of a local agreement (in line with the recommendations of this report) between the coroners, police and NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Agree in advance the division of responsibility between the on-call paediatrician and the SUDI paediatrician in the event of an unexpected infant death.
- ◆ Respond to notifications of SUDI when you are on call by promptly attending whenever possible and providing immediate telephone advice and information to healthcare staff, police and other staff directly involved.
- ◆ Take the medical lead:
  - in the instigation and running of the multi-agency protocol for care and investigation after SUDI
  - in communication with other healthcare professionals
  - in the communication with other agencies, notably the police, the coroner's office and the social services department.
- ◆ Ensure all necessary multi-agency strategy discussions take place.
- ◆ Arrange to visit the family at home (preferably with a member of the police child protection team and a member of the primary healthcare team) as soon as possible after the death to talk with the family, and to examine the environment in which the infant collapsed or died (which may not be in the family home).
- ◆ Collate all relevant medical records (in collaboration with the local on-call consultant paediatrician).
- ◆ Provide a report for the pathologist prior to the post mortem.
- ◆ Ensure the family are fully informed and given appropriate support at all stages.
- ◆ Coordinate, organise and chair the local case discussion meeting as soon as the full results of the post-mortem investigations are available, usually 2–3 months after the death, and usually held in the primary care setting.
- ◆ Prepare a written summary of the local case discussion meeting and ensure it is distributed to all relevant professionals, including the coroner.
- ◆ Offer to meet the family to explain the outcome of the local case discussion meeting, including the cause of the infant's death, and send the family a full written report, in accessible language.
- ◆ Liaise with the coroner whenever necessary in the organisation and conduct of the inquest.

#### 0.3.11 *Pathologist*

- ◆ Only undertake post-mortem examinations on SUDI cases if you have appropriate and recent expertise and training in this field.
- ◆ If you are instructed as a forensic pathologist, but without appropriate expertise in paediatric pathology, ensure that a pathologist with appropriate and recent paediatric training and expertise is also involved.

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Ensure that an adequate history (preferably including a detailed account of the precise circumstances of the death from a home visit) is available before starting the post-mortem.
- ◆ Ensure that a full skeletal survey is carried out before starting the post-mortem examination. This should be reported by a radiologist with recent experience and training in paediatric radiology (preferably before the post-mortem examination is conducted).
- ◆ Follow the recommended protocol for SUDI post-mortems (see Appendix III).
- ◆ The phrase “unexplained pending further investigation” should be used initially unless a clear and sufficient natural or unnatural cause for the death has been identified.
- ◆ Inform the coroner (and ensure the family is informed) about what bodily material has been retained.
- ◆ Inform the coroner (and ensure the family is informed) if retention of whole organs is necessary for further investigation, and whether the organ (e.g. the brain) can be returned to the body in a week or so after fixation and sampling.
- ◆ When criminal proceedings are likely, ensure that retention of adequate tissue or organ samples (e.g. the whole brain) is discussed with the coroner and that, if such retention is considered necessary, the sample is made an exhibit so that its retention is covered by The Criminal Justice Act 2003.
- ◆ Agree to the release of the body for funeral as soon as possible, consistent with conducting an appropriate and thorough examination.
- ◆ Ensure that your findings are explained to the parents (with the coroner's permission), usually by the SUDI paediatrician.
- ◆ Attend the local case discussion meeting.

#### 0.3.12 *Police*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Investigate the possibility that the death may have been unnatural, but keep in mind that most SUDI arise from natural causes.
- ◆ Avoid the attendance of uniformed officers at the home if possible.
- ◆ Ensure that any officer involved has specialist training and experience (officers from child protection team or with family liaison unit training may be appropriate).
- ◆ Liaise with the paediatrician and other agencies from the outset and confer about possible causes of death.
- ◆ Always treat the family with sensitivity.

0.3.13 *Social services*

- ◆ Familiarise yourself with the local agreement between the coroner, police and local NHS Trusts on the principles of how unexpected deaths in infancy should be handled.
- ◆ Review the child protection register and any other records relating to the baby who has died and to other members of the family and the household.
- ◆ Provide a family and social history and make any relevant records available for the strategy discussions and the local case discussion meeting.
- ◆ Attend the case discussion meeting (if social services are involved with family).
- ◆ Take appropriate action if causes for concern are raised in the strategy discussions or case discussion meeting.
- ◆ Carry out a risk assessment whenever appropriate for any surviving or subsequent children.





# B THE PROTOCOL AND THE RATIONALE FOR ITS INTRODUCTION

## 1 Introduction

- 1.1 The majority of unexpected infant deaths are natural tragedies and a priority for all involved in the investigation of such deaths must be the appropriate care of the bereaved family, even in those instances in which the infant's death has occurred as a consequence of neglect or abuse. There is nothing to be gained by insensitive behaviour by the professionals involved.
- 1.2 This protocol is derived from various multi-agency protocols currently operating in different areas and aims to provide a generally applicable framework suitable for use in all parts of the UK.

In the absence of any prospective controlled studies on optimal care and investigation after the sudden death of an infant, the protocol in this report has been developed after a systematic review of the various protocols operating in the UK and several other countries, the evidence upon which they are based and the reported outcomes for families and involved agencies.<sup>1-6</sup>

The aim is to provide a framework for the investigation and care of families after all unexpected deaths in infants and children up to the age of two years. With minor changes in emphasis, the same protocol is suitable for unexpected childhood deaths up to the age of 16, though this falls outside the remit of the present Working Group. The procedures for young people over the age of 16 will need modification, as many will be living outside the family home.

- 1.3 The emphasis of this approach is to try, if possible, to find the cause of the infant's death, incorporating both medical and forensic investigation. Over the years, detailed study of sudden infant deaths has led to the recognition of factors that are of importance in understanding and preventing such tragedies (e.g. the infant's sleeping position, parental smoking, inappropriate sleeping environments).<sup>7-10</sup> It is therefore important that this investigative approach is emphasised in all dealings with the bereaved family. Our increasing ability to identify metabolic and other medical causes of sudden death in infancy and the mounting (and reasonable) expectation of parents that such conditions should be identified requires a wide and up-to-date knowledge of and familiarity with the literature in this field, together with considerable experience in the recognition of particular patterns of presentation of different conditions. Sudden unexpected deaths in infancy (SUDI) are now far less common than in the past, thus referral to a specialist paediatrician and a pathologist with special expertise should, as for any child with an unusual or complex condition, be

routine practice. This represents a recognition that whilst cases of SUDI are rare, they may be due to natural conditions that are unusual and difficult to detect, and require very special techniques for diagnosis.<sup>11-13</sup>

## 2 Initial assessment of the infant presenting unexpectedly dead or moribund

- 2.1 The great majority of infants found collapsed or dead will be brought immediately to an A&E department, where resuscitation will be instituted or continued. Nothing in this protocol should interfere with the absolute priority of effective resuscitation if this is possible. Resuscitation, once commenced, should be continued according to the *Advanced Paediatric Life Support Protocol*,<sup>14</sup> until an experienced doctor (usually the consultant paediatrician on call) has made a decision that it is appropriate to stop further efforts.
- 2.2 On occasions, it is apparent to the attending doctor or ambulance staff that an infant found collapsed out of hospital has been dead for some time and attempted resuscitation is inappropriate. On such occasions, a forensic medical examiner or GP may certify the fact of death at home. In such circumstances, the family will almost invariably have picked the child up and may have attempted resuscitation, thus the original condition in which the child was found will already have been changed. In these circumstances, there is no value in insisting that the family and child remain where they are but there are significant benefits to the family (and to the further investigation of the scene of the death) if the family and child are immediately taken to a hospital's A&E department, with resident paediatric staff on site. This will also ensure that the family receive appropriate medical and social support, and the protocol for investigation of the cause of the child's death is implemented immediately. While religious and cultural practices must be respected, it is important that the possibility of abuse or neglect is not missed as a consequence of inadequate initial examination of the child. Since the Department of Health's 1991 'Back to Sleep' campaign to reduce the risk of sudden infant death syndrome (SIDS), there have been marked changes in the socio-economic distribution of SUDI, with proportionately far more deaths occurring in the most deprived families, many of which consist of single mothers without immediate adult support.<sup>7,16</sup> For such isolated parents, immediate skilled professional support is likely to be of particular value.<sup>17</sup> A further consequence of the fall in numbers of SUDI is that progressively fewer primary healthcare professionals will have personal experience of dealing with the needs of families and the need to collect relevant information in such circumstances.
- 2.3 In the A&E department, the care of the family and the investigation of the cause of the death should follow a similar course, whether or not resuscitation has been attempted.

- 2.4 If resuscitation has been attempted, the intravenous and intra-arterial lines inserted for this purpose should be removed (subject to coroner's consent, after carefully documenting for the pathologist all such sites of access). Other sites of attempted vascular access should also be carefully recorded. If an intravascular cannula has been inserted and it is thought that it may have contributed to failed resuscitation (e.g. by causing a pneumothorax), then it should not be removed. If an endotracheal tube has been inserted, this should also be removed after its correct placement in the trachea has been confirmed by direct laryngoscopy (preferably by someone other than the person who inserted it). Endotracheal tubes or intravenous lines left *in situ* are distressing to parents who almost always wish to see and hold their child. An endotracheal tube left *in situ* in such circumstances may become dislodged during handling of the child by staff before the post mortem, so the only way to be certain that the tube has been correctly placed is by direct inspection immediately after resuscitation is discontinued.
- 2.5 The infant should be carefully and thoroughly examined by a consultant in paediatrics or A&E medicine immediately after resuscitation has ceased. A particular note should be made of any marks, abrasions, skin rashes, evidence of dehydration or identifiable injuries at this time. The presence of hepatomegaly should also be sought and noted. The presence of any discolouration of the skin, particularly dependent livido, should be carefully and accurately documented. Skin livido and pallor from local pressure (e.g. on the nose in a child who has been face down) will usually fade over a few hours and may not be present when a pathologist sees the baby. Consideration should be given to asking for a police photographer to photograph any such skin discolouration as soon as possible, as it may help in estimating the time of death, as well as the position in which the child was lying. Frothy fluid, commonly bloodstained, is often present around the nose and or mouth and its presence should be documented, though it will usually be wiped away as part of the resuscitation process. The presence of such fluid, whether or not it is bloodstained, does not signify the cause or the mode of death.
- 2.6 Any stool or urine passed by the infant, together with any gastric or nasopharyngeal aspirate obtained, should be carefully labelled and frozen after samples have been sent for bacterial culture and for virology. If the nappy is wet or soiled, it should be removed, labelled and frozen also.
- 2.7 During the process of resuscitation, various investigations will be initiated, including blood samples for blood gases, urea and electrolytes, full blood count, blood sugar and blood culture. Blood and, if possible, urine samples should also be taken at this time for metabolic investigations (see Table 1). If resuscitation is not instituted, then in most cases such investigations should be taken as soon as possible after the arrival of the infant. A lumbar puncture should also be performed and a sample of cerebrospinal fluid (CSF) sent for microscopy and

culture. If possible, a further sample of CSF should also be frozen for future metabolic investigation.

*It is important to note that once life has been declared to be extinct by the attending doctor, no samples may be taken without the consent of the coroner (see below).*

- 2.8 *Once death has been confirmed by the attending doctor (usually the consultant paediatrician), the coroner assumes immediate responsibility for the body and no further samples for investigation may be taken without the coroner's permission.* In many parts of the country, there is a clear understanding with the coroner that certain samples may be taken immediately after the end of resuscitation in order to facilitate appropriate investigation and, in particular, to identify the presence of metabolic conditions, which are increasingly being recognised as causes of unexpected death in infancy.
- 2.9 It is the recommendation of this Working Group that, with the sole exception of those very rare instances where taking the samples will confuse or prevent full investigation of injuries contributing to the infant's death, coroners should routinely give permission for such samples to be taken in the A&E or paediatric departments. As part of the local implementation process for this protocol, each coroner should be asked to approve a standard set of investigative samples to be taken in these circumstances without the need for hospital staff to seek prior approval from the coroner's officer in each case.
- 2.10 Details of the recommended samples to be taken and the purposes for which they are intended are given in Table 1. It is important to note that it may be very difficult to obtain blood samples from an infant after death, and generally samples should not be taken by cardiac puncture because of the risk of causing damage to intrathoracic structures and confusing the interpretation of findings at post mortem. If the post mortem is to be conducted within 24 hours of the death, most of the blood samples may be more appropriately taken by the pathologist at the beginning of the procedure (see Appendix III).

### **3 Care of the parents**

- 3.1 Immediately upon their arrival at the hospital, the parents should be allocated a member of staff to care for them, explain what is happening and provide them with facilities to contact friends, other family members and cultural or religious support. The member of staff allocated to the family should ensure that they are kept fully informed during the course of the resuscitation and, subject to the approval of the medical staff involved, the parents should be given the option to be present during the resuscitation. The allocated member of staff should stay with the parents throughout this period to explain what is going on, particularly

the procedures that may look alarming, such as cutting off clothing or attempts at vascular access, including the use of intraosseous needles or intubation.

Staff will need to make an assessment of the capacity of the parents to engage in the processes unfolding around them. For some, the shock of the situation will impede their understanding; for others, there may be issues of language, health or mental capacity that need to be taken into account. If there is a possibility that the family may become witnesses or defendants in criminal proceedings, the police will need to make an early judgement about whether they should be seen as 'vulnerable witnesses' and information from the perception of the allocated member of staff will be of benefit in this decision.

Immediate responsibility for providing information and coordinating appropriate care and support to the family should rest with the on-call paediatric team (almost always led by the consultant paediatrician on call). Whilst senior staff from the disciplines of emergency medicine and/or intensive care may have been involved in the resuscitation, it is generally more appropriate for continuing pastoral care of the family and liaison with the primary care team or other agencies to be the responsibility of the consultant paediatrician on call, or the paediatrician with special responsibility for SUDI (see below).

- 3.2 The consultant paediatrician on call should, as part of the initial assessment, take a detailed and careful history of events leading up to and following the discovery of the infant's collapse. A check-list of the relevant information is attached shown in Appendix II. It is important that, as far as possible, the parents' or carers' account of events should be recorded *verbatim*. At an early stage of the process, the on-call paediatrician should make contact with the paediatrician with special responsibility for SUDI (the 'SUDI paediatrician') and agree precise arrangements and timing for the SUDI paediatrician to meet the family. Whenever possible, this should be before the family leave the A&E Department.
- 3.3 The parents and other close relatives should normally be given the opportunity to hold and spend time with their baby. Professional presence during such times should be discreet. Such quiet time is very important for families.
- 3.4 Many parents value photographs of their baby taken at this time, along with handprints or footprints and a lock of hair. Again, only in very exceptional circumstances should such mementos not be taken. Each coroner should be asked to approve this as part of the local implementation process.
- 3.5 When the baby has been pronounced dead, the on-call consultant paediatrician or the SUDI paediatrician should break the news to the parents, having first reviewed all the available information. This interview should be in the privacy

of an appropriate room. The member of staff allocated to care for the family should also be present at this time.

- 3.6 The family must also be informed at this time that the coroner will need to be informed because the baby has died suddenly and unexpectedly and that, as a matter of routine practice, the police also have to investigate the death. The paediatrician must explain that possible medical causes of the infant's death will also be very carefully and thoroughly sought. *For families with an established contact with a particular social worker, it will be important to inform and involve this known social worker at an early stage.*
- 3.7 Unless the cause of death is immediately apparent to the paediatrician (e.g. the typical rash of meningococcal septicaemia), it is important to explain to the parents that the cause of the death is not yet known and that the aim of the investigation is to establish the cause of death. The parents must be informed that the coroner will order a post-mortem examination and that this will be carried out by a pathologist with special expertise in diseases of children (a paediatric pathologist), just as if the child had a rare or serious disease and was being referred to a specialist in life. This may require transport of the child some distance from home, but arrangements will be made by the coroner's service for the child to be returned to the local hospital or funeral director as soon as possible. The nature and purpose of the post mortem should be explained to the parents in understandable terms and they should be given a copy of the NHS leaflet on the post-mortem examination ordered by the coroner.<sup>18</sup> It is important that the family know where the post mortem will be carried out, what the approximate timescale will be and when they will be able to see the child again.

Parents have the right to be represented at the post-mortem examination by a medical practitioner of their choice, provided they have notified the coroner of their wishes (Coroners Rules, 1984).

- 3.8 Before the family leave the A&E department, the consultant paediatrician on call should see them, if possible together with the senior detective designated to lead the investigation of the death (see below). Whenever possible, the SUDI paediatrician should also be present for this initial joint interview with the parents.

Part of the role of the paediatrician at this stage is to give the family help, information and support in their bereavement. This may be helped by the use of leaflets such as those published by the Foundation for the Study of Infant Deaths.

## 4 Initial multi-agency communication

- 4.1 As soon as possible after the arrival of the child in the A&E department, the police should be contacted and arrangements made for the senior detective designated to lead the investigation of the death to attend and talk to the parents as soon as possible (preferably with the consultant paediatrician on call or the SUDI paediatrician). Whenever possible, this officer should be experienced in child protection work, preferably a member of the police child protection team. The social services department should also be contacted and asked to check immediately their records relating to the child, the immediate family members, other members of the household and others with whom the child has lived. Any relevant information identified by the social services department should be promptly shared with the police and paediatrician.
- 4.2 In each Trust, there should at all times be access to a paediatrician with special responsibility for investigation of unexpected deaths in infancy and childhood (the 'SUDI paediatrician'), who will sometimes be the same as the designated lead for child protection. This role will usually be shared by two or more paediatricians, commonly in neighbouring Trusts, to provide an on-call arrangement. As noted above, this paediatrician should be contacted as soon as possible after any unexpected infant death so that he/she can, if possible, attend at the A&E department to meet the family and explain their role.
- 4.3 On some occasions, particularly if concerns have been raised about neglect, non-accidental harm or unusual circumstances of the death, the police may appoint a family liaison officer to maintain close and continued contact with the family over the few days after the death. If a family liaison officer is appointed, the family must be given clear and accurate information on his/her role.
- 4.4 The sequence of procedures is set out in Figure 1, The Avon multi-agency approach to sudden unexpected deaths in infancy and childhood.
- 4.5 At the earliest opportunity, the consultant paediatrician on call or the SUDI paediatrician should talk to the duty social worker to review any relevant social services or child protection information on the infant, close family members, other members of the household, or others who have been involved in the infant's care. The on-call paediatrician should introduce the senior investigating police officer and, if possible, the SUDI paediatrician to the parents, and take a full and careful history from the parents on the events preceding the child's death and events after discovery of the death. The parents should, if they wish, be given the opportunity for the police to interview them separately from the paediatrician, but in virtually all instances they are likely to prefer to talk to both together. This joint interview will be conducted with care and sensitivity but must include a thorough exploration of the circumstances of the death, relevant events and previous history (see Appendix II). The paediatrician should



emphasise the importance of this detailed history for trying to understand possible medical causes of the child's death and explain that this is of equal importance to the collection of relevant information by the police.

- 4.6 It is important that the parents are told that the police will be involved, and that social services' records will be checked after all unexpected deaths in childhood, regardless of cause or family circumstances.

Under the Police and Criminal Evidence Act 1984, if the paediatrician or the police officer has significant suspicions that the death may be unnatural, the law demands that the suspect's rights are protected and certain legal restrictions apply in terms of how they can be spoken to, and by whom.

- 4.7 Before the family leave the A&E department, the paediatrician on call and the investigating police officer (together with the designated paediatrician for unexpected childhood deaths if possible) should briefly review the history and circumstances of the death, consider any issues that raise questions of abuse or neglect, and review any relevant social services' information on the telephone with the emergency social worker. Any child protection concerns for other children in the household should also be discussed. If significant concerns emerge about child protection issues, this discussion will become the initial multi-agency strategy discussion .
- 4.8 At this stage, arrangements should be made for a home visit as soon as possible by the SUDI paediatrician and the investigating police officer. Parents must be informed that such a visit is routine but that the police have to thoroughly investigate the circumstances of all unexpected deaths of children. At this visit, the paediatrician's role is to help identify understand and investigate factors that may have contributed to a natural or accidental cause of the death, and ensure that the pathologist is fully informed before starting the post-mortem examination (see Appendix II). Arrangements should be made to ensure that the scene of the baby's collapse and/or death is left undisturbed until this visit takes place.
- 4.9 The police, SUDI paediatrician and social services should ensure that all relevant medical, forensic or social information is shared and discussed at this stage, as part of the continuing multi-agency cooperation. The SUDI paediatrician should make contact with the family's GP and health visitor as soon as possible to ensure they are fully informed and to obtain any additional relevant medical social or family information.

If significant concerns are raised at these initial discussions about the possibility of neglect or abuse as a cause for the child's death, a decision may be taken for the police to become the 'lead agency' and to immediately initiate a formal crime scene investigation at the site of the infant's collapse or death.

In these circumstances, multi-agency child protection procedures should follow the guidance of *Working Together*.<sup>19</sup>

## 5 Initial home visit

- 5.1 As soon as possible after the infant's death, the SUDI paediatrician and senior investigating police officer, accompanied by the family's GP or health visitor if possible, should visit the family at home or at the site of the infant's collapse or death (which may not have occurred in the family home), to talk through in great detail the events leading up to the infant's death and to carry out a very careful and systematic examination of the site of the infant's death. They should again emphasise the routine nature of the visit and the purpose of the investigation as trying to find out the cause of the death.

Provided effective arrangements have been made for the scene of the child's death or collapse to be undisturbed, this joint home visit should not usually take place in the middle of the night. Many families will prefer to return initially to the home of a friend or relative rather than their own home on leaving the A&E department. At the discretion of the senior investigating officer, the police may visit the home immediately in the absence of the family, to investigate the scene of the death, but it is important that the police minimise any disturbance of the scene before the on-site discussion with the parents. If a home visit by the SUDI paediatrician cannot be organised to take place within the necessary time frame, the police may need to attend without the paediatrician.

Social services and/or childcare services may be involved in helping to facilitate this initial visit, for example by providing care for other children with immediate care needs.

- 5.2 In some cases, the initial investigation will include a police video with or without still photography of the scene of the infant's death, collected either at the time of the joint interview with the parents or at a prior visit (see above), together with any additional forensic investigations deemed necessary by the senior investigating officer. It is very rarely necessary or valuable for bedding to be removed from the home, and removal of bedding before the home visit will make the detailed review of the circumstances of the death by the SUDI paediatrician and investigating police officer more difficult and potentially less valuable.
- 5.3 As part of this home visit, the SUDI paediatrician, together with the GP or health visitor, will provide information, care and support to the family and make arrangements for further contact and communication with them. In certain circumstances, it may be appropriate for another paediatrician to be involved in this process, for instance if the latter had prior knowledge of the child or family. The involvement of the GP or health visitor in this initial visit is of great

importance in ensuring that the primary health team are fully informed of what has happened and are therefore in a position to provide the best and most appropriate bereavement support and care to the family over the course of the next few days and weeks.<sup>17</sup>

- 5.4 The SUDI paediatrician will also, at this stage, make appropriate arrangements to see the family again with the initial results of the post-mortem examination, which should usually be available within a few days. The investigating police officer may also wish to attend this subsequent meeting to inform the family about police and coroner's procedures.

## **6 Further multi-agency discussion**

- 6.1 After the home visit and 'death scene' investigation, the senior investigating police officer, the SUDI paediatrician, the GP and the health visitor should, in all cases, further review any significant concerns that may have arisen about the possibility of neglect or abuse having contributed to the infant's death. If significant concerns have been raised, the police may institute a 'crime scene' investigation at this stage, but this is rarely necessary or appropriate.

## **7 Post-mortem examination**

- 7.1 The post-mortem examination will be ordered by the coroner, and should be carried out (within 48 hours of the infant's death whenever possible) by a pathologist with recent expertise and training in paediatric pathology. If significant concerns have been raised about the possibility of neglect or abuse having contributed to the infant's death, the paediatric pathologist should be accompanied by a forensic pathologist and a joint post-mortem protocol should be followed (see Appendix III). If at any stage during a post-mortem in the absence of a forensic pathologist the paediatric pathologist becomes concerned that the death may be a consequence of abuse, the procedure must be stopped. The examination should recommence as a joint procedure by a forensic pathologist together with the paediatric pathologist, in the presence of the senior investigating police officer or other designated police representative.
- 7.2 Prior to commencing the post-mortem examination, the pathologist should be fully briefed on the history and physical findings at presentation, and the findings of the death scene investigation by the SUDI paediatrician and investigating police officer. In those areas where a video recording at the death scene has been made, it is very helpful for the pathologist to have the opportunity to view the video and discuss it with the paediatrician(s) and police officer prior to commencing the post-mortem examination. Other photographs of the child

that may have been taken at presentation or in the A&E department should also be made available.

The post-mortem procedure should routinely include a full radiological skeletal survey, reported on by a radiologist with paediatric training and experience.

- 7.3 The preliminary results of the post-mortem examination should be discussed by the SUDI paediatrician and pathologist, together with the senior investigating police officer, as soon as possible (usually within 48 hours of the initial post-mortem examination) and the coroner should be immediately informed of the initial results. If the initial post-mortem findings suggest evidence of neglect or abuse as a cause of the infant's death, the police child protection team and social services department should immediately be informed and further investigations set in process. If the initial post-mortem findings do not identify grounds for suspicion of an unnatural death, then no further police or social services investigation is likely to be necessary at this stage and the SUDI paediatrician will assume the role of lead professional in communicating information to the primary care team and the family. This will almost always involve a further meeting with the family and GP a few days after the post mortem to pass on this preliminary information. It is helpful for the investigating police officer to also attend this meeting, to ensure that he or she is fully informed and to answer any relevant questions from the family.
- 7.4 In all cases, there should be a further multi-agency discussion (usually on the telephone) involving the pathologist, social services, police and SUDI paediatrician plus any other relevant healthcare professionals very shortly after the initial post-mortem results are available, to ensure no additional information has come to light to raise additional concerns about child protection issues.
- 7.5 At the post-mortem examination, tissue blocks, other specimens and frozen samples will be taken according to a standard protocol (see Appendix III) and other samples will be taken as deemed necessary by the pathologist in order to ascertain the cause of death. Whole organs will not routinely be retained, but when this is deemed necessary by the pathologist, the coroner and the family must be informed, and the family given the opportunity in due course for return of such samples to the body if appropriate. This applies particularly to the brain (see Appendix III). If parents have requested that tissues or organs be donated for therapeutic or research purposes then, with the consent of the coroner, such additional tissues or organs may be retained by the pathologist. As part of the explanation about the post-mortem examination given to the parents (see Chapter 3 above, paragraph 3.7), the paediatrician must explain that tissue blocks including frozen samples and slides will be taken and will be retained permanently as part of the pathology records, but that other larger tissue samples

or whole organs will not ordinarily be retained. At this time, the paediatrician should also give the parents the opportunity to donate tissues or organs for therapeutic or research purposes, as set out in the NHS information booklet on post-mortem examinations ordered by the coroner.

The impact on post-mortem procedures of the the Human Tissue Bill (currently before Parliament) has not yet been fully defined, though retention of tissue samples required for the purpose of diagnosis in cases referred to the coroner will still be permitted. The information and consent procedures for retention or donation of other tissue or organ samples for therapeutic or research purposes will need to be reviewed in the light of this new legislation.

#### 7.6 *Terminology*

There has been considerable variation between pathologists in the terminology used to report the initial findings from the post-mortem examination. Some pathologists have taken the view that, since at this stage the full results of histology, microbiology, toxicology and multi-professional review are not available, it is not appropriate to use the term “sudden infant death syndrome” (SIDS). Some pathologists have therefore used the term “unascertained” as an honest statement of their ignorance of a cause of death at this stage, with a view to giving a more precise cause later if possible. Others have used the term “sudden unexpected death in infancy” (SUDI) – a tautology – in order to signify that, whilst no cause has yet been identified and the definition of SIDS cannot yet be met, they have no cause for suspicion and the funeral can therefore proceed, with the death being initially registered as “SUDI”, with a more precise diagnosis (which may be “SIDS”) following the full results of investigations. Yet other pathologists reserve the term “unascertained” for those cases in which they have serious concerns about the possibility of unnatural causes or where they feel that further investigation is needed to rule out this possibility.<sup>21</sup>

The Working Group formed the opinion that it is essential that the interpretation of these terms and their use must be standardised between pathologists and between coroners.

The recommendation of the Working Group is that the following procedure be followed.

- a) If after the initial post-mortem examination a complete and sufficient cause of death (e.g. a lethal congenital heart abnormality) is found, then this must be given as the cause of death at this stage. However, the further review of the circumstances of the death as noted elsewhere in this report should still be followed, as factors affecting the quality of care may be identified and lead to improvements in subsequent care, or other underlying contributory medical conditions (e.g. immunodeficiency) may be identified with potential genetic implications for the family.

- b) If in the light of initial findings (including the circumstances of the death) the pathologist feels that there is no clear or sufficient cause of death – *whether or not there are some concerns about the possibility that abuse or neglect might have contributed* – he/she should give the initial 'cause' of death to the coroner as "unexplained pending further investigation". Clearly, in these circumstances the continued close cooperation of all agencies will be of great importance, and the nature and content of any further investigations by the police or social services department will be determined by the strategy discussion immediately after the initial post-mortem results are available.

In these circumstances (which will include the great majority of sudden unexpected deaths in infancy), the Working Group recommends that the coroner should open and adjourn an inquest and, providing there are no valid objections, issue a coroner's interim certificate of the fact of death to allow the funeral to proceed. Opening an inquest will thus have no attached stigma and the use of the holding term, "unexplained pending further investigations", by the pathologist will avoid connotations of suspicion.

Information given to the Foundation for the Study of Infant Deaths by bereaved families suggests that this approach will be acceptable to the great majority of bereaved families, who are willing to wait for confirmation of the precise cause of death, provided they are kept informed, and are meanwhile able to proceed with the funeral arrangements.

- c) Finally, if during the initial post-mortem findings emerge that clearly identify neglect or abuse as the most likely explanation for the death, the police will become the lead investigating agency and the provisions of normal criminal investigations should be set in motion, including the requirements of the Police and Criminal Evidence Act 1984. Further contact by any of the professionals (social services, police, paediatrician) with any individual being treated as a suspect in such a criminal investigation would then be subject to the restrictions required by this Act.

## 8 Local case discussion meeting

- 8.1 As soon as possible, usually 8–12 weeks after the infant's death (once the results of all relevant investigations have been obtained), a case discussion meeting is to be held, usually in the health centre or GP's surgery and chaired by the SUDI paediatrician. This meeting should involve the GP, health visitor, paediatrician(s), pathologist, senior investigating police officer and, where appropriate, a social worker. At this case discussion meeting, all relevant information concerning the circumstances of the death, the infant's history, family history and subsequent investigations should be reviewed. The main purpose of the meeting is for sharing

information and for future care planning for the family. At this meeting, a formal classification of the cause of the infant's death should be agreed. The Avon clinicopathological classification of sudden unexpected infant deaths is a helpful structure in which to consider all of the potentially contributory factors that may be relevant (see Table 2).<sup>1</sup> In some cases, the coroner or coroner's officer will wish to attend these meetings; in others, the police will attend both as the investigating agency and as the coroner's representative.

Families will not ordinarily be invited to these meetings, as the large number of professionals present and the very technical and detailed nature of some of the discussion (including detailed discussion of the interpretation to be placed upon the gross, histological and laboratory findings of the post mortem) will make the meeting inappropriate for bereaved parents, many of whom are likely to find such a meeting intimidating and distressing. This meeting will thus be the equivalent within this protocol of a strategy meeting in the *Working Together* framework, to which parents are also not invited. The parents must, however, be fully informed of the outcome of the meeting at a separate meeting with the SUDI paediatrician and GP or health visitor (see below).

- 8.2 During the course of this case discussion meeting, it is important that there is an explicit discussion of the possibility of neglect or abuse as a contributory factor to the infant's death. If no evidence is identified to suggest neglect or abuse as contributory factors, this should be documented as part of the report of this meeting. The quality of medical and social care that was given to the child and family should also be discussed at this meeting, identifying any shortcomings and appropriate measures to improve future care. For these reasons, holding such a meeting even in those instances in which a complete and sufficient medical (natural) explanation has been found for the death may be of value.
- 8.3 After the local case discussion meeting, the SUDI paediatrician, in close consultation with the pathologist, should write a detailed report on the available information concerning the cause of the infant's death as a letter to the parents, and arrangements should be made for the SUDI paediatrician and the GP or health visitor to jointly see the parents to explain the content of this report, to answer any further questions and to make plans for any future additional care and support that may be appropriate, including the question of further investigation of family members or subsequent children for metabolic or other familial disorders. A copy of the report of the meeting should be sent to each of the agencies involved. This may be of great importance in assessing the possibility of risk (particularly from metabolic or other familial conditions) to surviving and future children in the family.
- 8.4 Finally, the results of the local case discussion meeting should be communicated to the coroner. The information available from this meeting will potentially be

of great value to the coroner in the organisation and conduct of the inquest, and will ensure that correct information is included in the final registration of the cause of death notified to the Registrar of Births and Deaths.

As noted below, for those deaths that meet the agreed international definition of sudden infant death syndrome,<sup>20</sup> this should be the registered cause of death after the inquest.

## **9 The role of the coroner**

- 9.1 The coroner must be informed after any unnatural or sudden death of unknown cause, and will order an investigation into the circumstances and cause of that death. This investigation will, in almost all cases, include a full post-mortem examination of the body by a pathologist instructed by the coroner. Procedures and practices adopted by coroners, and the involvement of the coroner's service in the various multi-agency protocols for the investigation of unexpected childhood deaths currently operating in different parts of England and Wales, vary widely.
- 9.2 The protocol set out in this document, based upon a systematic review of the various approaches adopted in the UK and internationally, considerable practical experience and wide consultation, is compatible with the current role of the coroner and should be seen as a broadly based professional procedure in which the coroner's service can be fully integrated, without compromise or loss of the essential independence and judicial role of the coroner.
- 9.3 The coroner and/or the coroner's officer should be fully informed and involved in all stages of the protocol. As the legal authority charged with the investigation and certification of all unexpected deaths, the coroner must be kept informed of all significant information obtained from the multi-professional communications and interviews with parents.
- 9.4 The report from the multi-agency local case discussion meeting should in all cases be sent to the coroner, and in some instances the coroner or coroner's officer will choose to be present at this meeting. This report will ensure that, where the cause of death has been certified by the coroner without an inquest, any new or more accurate information is appropriately notified to the Registrar of Births and Deaths for onward transmission to the Office for National Statistics. For those instances (which we suggest should be the great majority of sudden unexpected deaths in infancy) in which the coroner has ordered an inquest, the information from the local case discussion meeting will inform and assist the conduct of the inquest.



- 9.5 The Working Group recommends that, in order to protect the bereaved family, the inquest should be held in private rather than in public wherever possible. Information given to the Foundation for the Study of Infant Deaths from bereaved parents shows that, while parents support the recommendation that inquests be held in every case in order to achieve the most thorough possible investigation of the death, they favour this procedure only if inquests can be held in private, without the press present. Holding inquests in private would require a modification of the Coroners Rules.
- 9.6 Where the information available to the inquest shows that the death meets the international definition of sudden infant death syndrome (SIDS) – i.e. the death is unexpected, and remains unexplained after a careful review of the history, examination of the circumstances of death and the conduct of a full post-mortem examination to an agreed protocol<sup>20</sup> – then the death should in all cases be registered as being due to SIDS.
- 9.7 Where no sufficient cause of death has been established but there are gaps in the documentation, or for other reasons the death, whilst not shown to be due to abuse or neglect, does not meet the definition of SIDS, a designation as “unascertained” may be unavoidable.
- 9.8 The use of this approach, in which the inquest is informed by the outcome of the multi-professional case discussion meeting, including the clinical history, examination of the circumstances of death, thorough post-mortem examination and multi-professional review, will mean that only in exceptional circumstances should the term “unascertained” be given as the cause of death by the coroner after the inquest.

*It is the view of the Working Group that the use of the term “unascertained”, which carries implications that the death may have been the result of neglect or abuse, should generally be avoided.*

## **10 Multi-agency training and audit**

- 10.1 Experience of implementation and continuation of locally run multi-agency arrangements for care and investigation after unexpected deaths in childhood has shown the importance of initial and continuing joint training of the staff in all of the agencies involved. Differences in the normal ‘culture’ of operation between different agencies can lead to misinterpretation of information, failure to recognise the role or expertise of the other agencies, and potentially to important information not being shared. In the field of child protection, such lessons have been painfully learned, and must be applied to the development of well functioning multi-agency arrangements after unexpected childhood deaths.

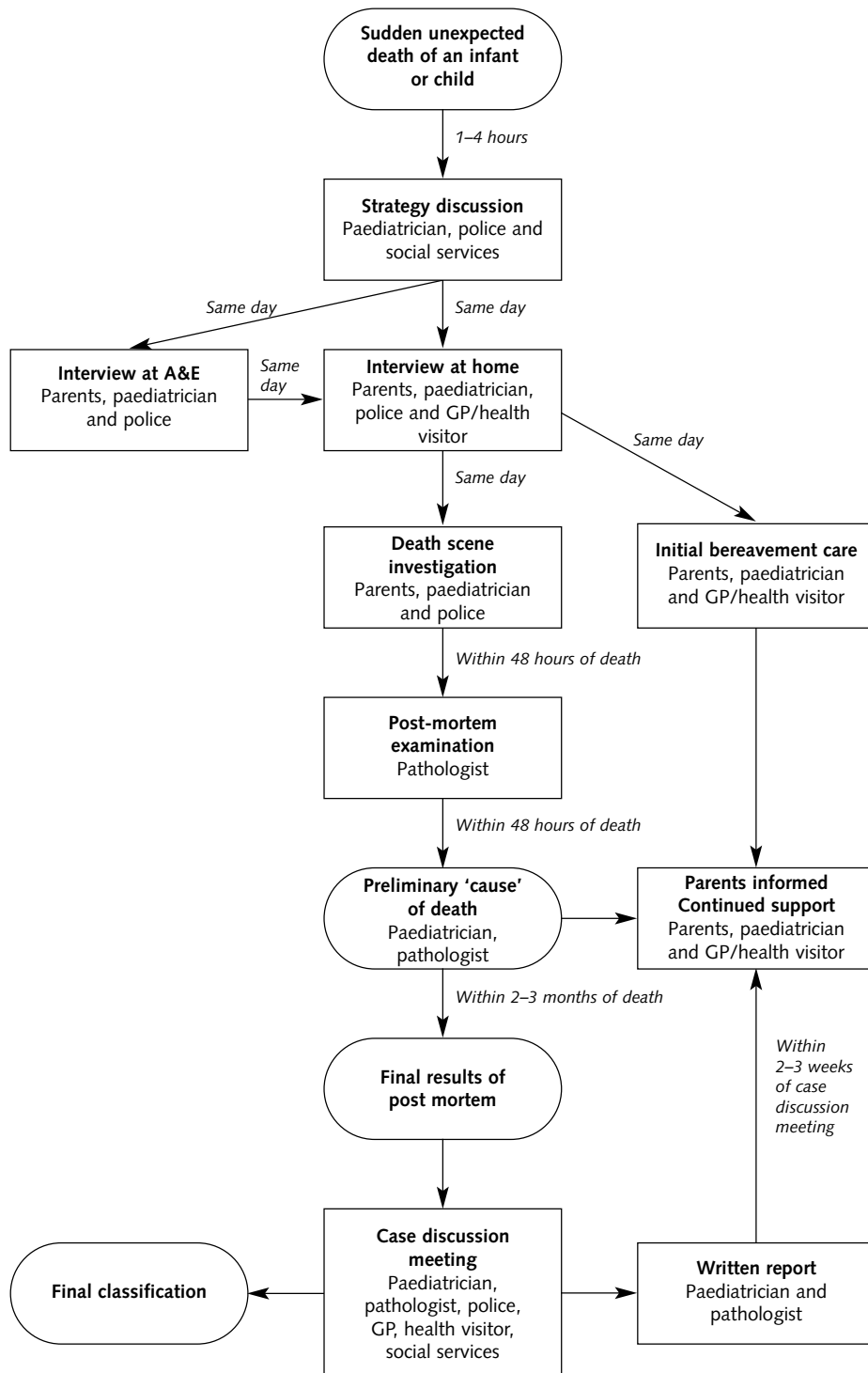
*Responsibility for oversight of audit and monitoring of the operation of the multi-agency protocol should rest with Local Safeguarding Children Boards.*

- 10.2 In addition to training and education of all professionals involved, it is essential that a robust process be put in place to audit the operation of the protocol after each case, to ensure communications are effective and staff respond appropriately, and to promptly identify potential resource and staffing difficulties. Responsibility for the conduct of such audit and for reporting its outcome on a regular basis should be placed jointly with identified senior managers in each of the agencies involved. As noted above, overall responsibility for the implementation and audit of the protocol should rest with the Local Safeguarding Children Boards.

There also should be a responsibility placed on those doing the audit to collate the information and share it regionally and nationally. The development of a standardised tool will facilitate this process.

- 10.3 Prior to implementation of this protocol, there will be a need for the training and education of professionals in all of the agencies involved. Appropriate training may best be offered as part of multi-agency training programmes, under the supervision of the medical royal colleges and other professional organisations. Such a training programme must be established as a matter of priority, in order to ensure that, within as short a period as possible, in each district there is a core of appropriately trained professionals within each agency. In particular, the The Royal College of Paediatrics and Child Health should develop a programme for the training and accreditation of paediatricians with special responsibility for sudden unexpected deaths in infancy ('SUDI paediatrician').

**Figure 1** The Avon multi-agency approach to sudden unexpected deaths in infancy and childhood<sup>1</sup>



### **Table 1** Routine samples to be taken immediately after sudden unexpected deaths in infancy

Blood samples should be taken from a venous or arterial site (e.g. femoral vein). Cardiac puncture should be avoided as this may cause damage to intrathoracic structures and make post-mortem findings difficult to interpret.

If the post mortem is to be conducted within 24 hours of the death, it may be best for the samples to be taken by the pathologist.

<b>Sample</b>	<b>Send to</b>	<b>Handling</b>	<b>Test</b>
<b>Blood</b> (serum) 1–2 ml	Clinical chemistry	Spin, store serum at –20°C	Toxicology
<b>Blood</b> cultures – aerobic and anaerobic 1 ml	Microbiology	If insufficient blood, aerobic only	Culture and sensitivity
<b>Blood</b> from Guthrie card	Clinical chemistry	Normal (fill in card; do not put into plastic bag)	Inherited metabolic diseases
<b>Blood</b> (Lithium heparin) 1–2 ml	Cytogenetics	Normal – keep unseparated	Chromosomes (if dysmorphic)
<b>Cerebrospinal fluid</b> (CSF) (a few drops)	Microbiology	Normal	Microscopy, culture and sensitivity
<b>Nasopharyngeal aspirate</b>	Virology	Normal	Viral cultures, immuno-fluorescence and DNA amplification techniques*
<b>Nasopharyngeal aspirate</b>	Microbiology	Normal	Culture and sensitivity
<b>Swabs</b> from any identifiable lesions	Microbiology	Normal	Culture and sensitivity
<b>Urine</b> (if available)	Clinical chemistry	Spin, store supernatant at –20°C	Toxicology, inherited metabolic diseases

\* Samples must be sent to an appropriate virological laboratory.

**NB Optimal microbiological and virological investigation after SUDI is currently the subject of a review by the Health Protection Agency, which will aim to produce definitive, evidence-based recommendations within the near future. The current recommendations should be seen as an interim *minimum* standard.**

**1a Additional samples to be considered after discussion with consultant paediatrician**

1. Skin biopsy for fibroblast culture.
2. Muscle biopsy if history suggestive is of mitochondrial disorder.

**1b Forensic considerations**

- ◆ Ensure you have the permission of the coroner to take samples.
- ◆ Document all samples taken, label and ensure an unbroken 'chain of evidence'.
- ◆ This may mean handing samples to a police office directly, or having the laboratory technician sign on receiving them in the laboratory.
- ◆ Samples given to police or coroner's officer must be signed for.
- ◆ Record the site from which all samples were taken.

**Table 2** The Avon clinicopathological classification of sudden unexpected deaths in infancy<sup>1</sup>

This grid is completed at the multidisciplinary case discussion meeting (see Figure 1).

An entry must be made on the line of each heading line, and a score (0 to III) accorded to each line as agreed by all professionals present.

The overall score is generally equal to the highest score within the grid.

A score of III equates to a complete and sufficient cause of death.

Scores of I to II B meet the definition of SIDS.

Classification	0	I A	I B	II A	II B	III
Contributory or potentially 'causal' factors	Information not collected	Information collected, but no factors identified	Factor present, but not likely to have contributed to ill health or to death	Factor present, and may have contributed to ill health or possibly to death	Factor present, and certainly contributed to ill health and probably contributed to death	Factor present, and provides a complete and sufficient cause of death
History (note 1)						
Death-scene examination (note 2)						
Pathology (note 3)						
Other (specify)						
Other evidence of neglect or abuse?						
Overall classification (note 4)						

**Notes**

(1) To include a detailed history of events leading up to the death, together with medical, social and family history, plus an explicit review of any evidence suggesting past neglect or abuse of this child or other children in the family.

(2) Results of a detailed review of the scene of death by the paediatrician and police child protection officer, in the light of the history given by parents or carers.

(3) Pathological investigations to a standardised protocol, including gross pathology, histology, microbiology, toxicology, radiology, clinical chemistry and any relevant metabolic investigations, including frozen section of liver stained for fat.

(4) This will generally equal the highest individual classification listed above.

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# Appendix I

## Parents' perspective on the investigation of sudden unexpected death in infancy

*This appendix was submitted to the Working Group by The Foundation for the Study of Infant Deaths (FSID).*

FSID is a voluntary organisation set up in 1971 with the aims of promoting research into the causes of infant death, supporting families and disseminating information about infant death and infant health. Through its national network and its helpline, FSID is in touch with the majority of parents whose baby has died suddenly and unexpectedly for no obvious reason, and receives comments about the way infant deaths are investigated. In addition, in 2001, as part of its current campaign to improve the investigation of sudden unexpected death in infancy (SUDI), FSID conducted a postal survey of bereaved families to get their views on proposals to improve the investigation of deaths through comprehensive multi-agency protocols. FSID is therefore uniquely well placed to describe the perspective of parents on the investigation of sudden unexpected deaths in infancy.

### **Dissatisfaction with present system**

In the 12-month period ending 30 June 2003, FSID was contacted by 1046 bereaved families. Many parents expressed dissatisfaction with various aspects of the way that SUDI are currently investigated, particularly the following:

- ◆ inconsistency, insensitivity and unjustified suspicion on the part of judicial and health professionals
- ◆ lack of informed support from judicial and health professionals
- ◆ inadequate investigation of possible natural causes of death
- ◆ inadequate explanation of the results of the post-mortem examination
- ◆ delays in the release of the body for burial or cremation
- ◆ with regard to inquests: the implication (to parents) of suspicion, the delay and lack of information, the intimidating nature of the proceedings and the attendant media publicity.

Even allowing for the inherent difficulties of a SUDI investigation and for the inevitable distress to the family, the substance and consistency of the complaints suggest that they are often justified.

Other parents, however, commented favourably on how the death of their baby was investigated and how they were treated. This suggests that it is possible to carry out an investigation in a thorough yet sensitive manner, but that this depends on the system that operates in a particular area and on the attitudes and skills of the professionals involved.

### **Survey of parents' opinions**

In the 2001 opinion survey, FSID wrote to the 3200 bereaved parents on its database to seek their views on specific points relating to the FSID campaign for improved investigation. 893 replied. The main points to emerge were as follows.

Most parents (89.6%) were in favour of the proposal that a paediatrician should visit the home to ask questions and talk with parents soon after the baby's death. This dispels previous notions that such visits are inappropriate or should be deferred until later. A large majority of parents (92.9%) supported the proposal that the paediatrician and the police should work together and share information. This suggests that most parents are prepared to forego strict medical confidentiality in the interests of a more thorough and efficient investigation. A similarly large proportion of parents (95.0%) thought it a good idea that professionals should meet to discuss the cause of the death and to plan support for the family.

For most parents who have been unexpectedly bereaved, the single most important issue is to find out why their baby died. A thorough post-mortem examination, including comprehensive laboratory tests, is an essential element of the investigation, but it can take up to eight weeks for results to become available. The survey therefore explored parental attitude to delay. Most parents in the survey (72.5%) would be prepared to accept a delay of six to eight weeks in the issuing of the death certificate if the extra information that then became available might enable the death to be more accurately certificated, so long as there was no concomitant delay in release of the body. However, only a minority of parents (22.3%) would accept a delay in the issue of the death certificate if it entailed a similar delay in the release of the body. Thus it appears that parents would favour a system whereby the body is released for burial or cremation at an early stage, but thorough investigation into the cause of death, using retained tissues, continues over a longer period.

There has been an increase in recent years in the proportion of SUDI for which an inquest is held. In 1995, inquests were held in 18% of cases of SUDI, while today they are held in over half. An inquest provides a means to consider all relevant information prior to the issue of the death certificate, but is a cause of great parental anxiety. Nonetheless, most parents in the survey (74.1%) said they would accept an inquest being held after every SUDI if this was the only way that all information could be properly considered before the death certificate was issued. However, acceptance was dependent upon the inquest being held in private, not public, in order to avoid media attention. From the parents' point of view, what is required is a method of investigation that would provide the same thoroughness as an inquest, but without the suspicion, fear, delay, lack of support and media presence that inquests may now entail.

A smaller supplementary survey was undertaken in 2002 to find out what parents thought about the retention of tissues following SUDI post-mortems. The majority (85%) of the 200 respondents agreed with FSID's position that certain key tissue samples should be routinely retained for an indefinite period for diagnostic purposes without the need for parental consent (though consent would be essential for any use of tissues for research).

### **Police investigation**

From FSID's experience of speaking to parents throughout the country, it would appear that most are aware that a small proportion of SUDI arise from some form of maltreatment and acknowledge that it is appropriate for the police to take an interest in all cases. Innocent parents will accept the need for a police investigation so long as it is managed sensitively and ensures a proper balance between medical and forensic elements. Indeed, some parents have told us that they are reassured by the police investigation because when they have come through it they feel they have been formally exonerated of any suspicion of wrongdoing, so that no stigma can remain.

However, the grief of bereaved parents can be cruelly compounded if police, and other judicial and forensic authorities, behave in a way that suggests they are suspected, unjustly, of having killed their child. Examples of such behaviour include frequent visits to the house by uniformed officers in marked police cars, repeated and unsympathetic questioning, seizure of bedding and other items without explanation, refusal to allow parents to hold their baby to say goodbye, imprisonment while the post-mortem examination is being conducted and tactless comments such as reference to the baby's room as a 'scene of crime'. It is very important, from the parents' perspective, that those investigating SUDI should have adequate training in the complexities and sensitivities of death in infancy.

### **Conclusions**

When parents are unexpectedly bereaved, their overwhelming need is to find out why their baby has died, and they would like the investigation to be as thorough as possible. They support the compilation of a detailed and comprehensive history; a meticulous post-mortem examination, with all appropriate ancillary tests, and careful discussion between the professionals involved. They understand that all this may take some time and they will accept, in the interest of greater accuracy, a delay before the issue of the death certificate. Contrary to views expressed in the media, most bereaved parents would accept the routine retention of tissues following post-mortem for possible later diagnostic review. Parents recognise the need for the police to be involved in the investigation of SUDI, but many complain that at present this is carried out in an inappropriate and insensitive manner. Families find it difficult if they have to wait for a long time before they can hold a funeral for their baby, and hurtful if the circumstances of their baby's death are exposed to public scrutiny. At all

## Sudden unexpected death in infancy

stages, parents need to be told what is happening, what has been found so far and what will happen next. It is also important that families should be given proper support in their bereavement.

FSID believes that if parents are treated with sympathy and respect, and are kept fully informed throughout, they will accept a rigorous investigation and be able to cope with it more readily than has often been supposed.

# Appendix II

## Information to be collected by the paediatrician at the first interview and the home visit

### Introduction

The importance of the history being taken by an experienced paediatrician, with knowledge and understanding of the care of infants and sensitivity to the needs of the family, cannot be over-emphasised.

This list is meant as a guide. It cannot be comprehensive, as additional specific questions may arise as a consequence of information given by the parents.

Encouraging the parents to talk spontaneously, with prompts about specific information, is likely to be better than trying to collect a structured history in the more usual way. In recording parents' accounts of events, it is important to use their own words as far as possible. (Ideally, information should be recorded *verbatim*.)

Much of the information is very sensitive. Parents may feel very vulnerable when asked about their sleeping arrangements, alcohol intake or drug use, so great skill is needed in asking the questions in a non-threatening way, with no implication of value judgment or criticism. Parents may ask directly if their alcohol intake has contributed to the baby's death; it is very important that the interviewer does not jump to conclusions about such questions, whilst not being dishonest when asked direct questions.

### The baby

- ◆ First name and family name (plus any other names by which the baby may be known).
- ◆ If possible, obtain the NHS number as this may facilitate access to other records.
- ◆ Date of birth and place of birth.

### Mother

- ◆ Full name (plus any other names by which the mother may be known).
- ◆ Full address, including post code.
- ◆ NHS number if possible.
- ◆ Date of birth.
- ◆ Phone number (home number and mobile number) and phone number of any available close relative or friend (to facilitate making contact again).

## Sudden unexpected death in infancy

- ◆ Address to which mother will be returning when she leaves the hospital, plus phone number there and the name of the person with whom mother will be staying.

### **Mother's partner and/or father of baby**

- ◆ Full name (including any other names by which he may be known).
- ◆ Full address, including post code.
- ◆ Date of birth.
- ◆ Phone number (home number and mobile number) and phone number of any available close relative or friend (to facilitate making contact again).
- ◆ Address to which father/partner will be returning when he leaves the hospital, plus phone number there and the name of the person with whom he will be staying.

### **Other members of the household (present and in the recent past)**

- ◆ Names.
- ◆ Dates of birth.
- ◆ Relationship to baby who has died.

### **Family medical history**

- ◆ A detailed account of past medical and social history of all members of immediate family and household.
- ◆ Particular note and detailed information (name, date of birth, place of birth) of any previous children.
- ◆ Also detailed information on any deaths in infancy or childhood of any offspring, siblings or other close relatives of any member of the current household (to include as much information as possible concerning date of birth, age at death, place of death, cause of death and any other known information).

### **Social and family history**

- ◆ A detailed account of the social structure of the family and of the household, including detailed information on alcohol, tobacco and other drug use, together with information on any prescription or non-prescription medications that may have been present or in use in the household.
- ◆ Information on recent changes in composition of the household (e.g. who has come and who has gone, and for what reasons).

### **Detailed medical history of mother**

- ◆ Details of past medical and social history of the mother, including any significant past illnesses or injuries.
- ◆ Detailed past obstetric history, including detailed information on the pregnancy leading to the birth of the baby who has died.

### **Detailed medical and developmental history of the baby who has died**

To include:

- ◆ gestation
- ◆ birth weight
- ◆ perinatal or neonatal problems
- ◆ type of feeding (and date and reason for changing type of feeding)
- ◆ growth, development and past assessments (e.g. health visitor or GP routine, well-baby checks)
- ◆ immunisations
- ◆ any known contact with infection
- ◆ medication (either prescribed or over the counter)
- ◆ if possible, obtain the parent-held child health record to copy (return this to the parents after copying it); plot the weight record onto a centile chart.

### **A detailed narrative account of the baby's feeding, sleeping, activity and health over the two-week period prior to the death**

This should include information on:

- ◆ changes in feeding or sleeping patterns
- ◆ changes in place of sleep
- ◆ changes in individuals responsible for providing care to the baby
- ◆ any social, family or health related changes in routine practices over the past two weeks
- ◆ any illness, accident or other major event affecting other family members in the past two weeks.

### **A detailed (hour-by-hour) narrative account of events within the 48 hours prior to the infant being found dead**

A detailed description of:

- ◆ precisely where the baby was placed for sleep
- ◆ duration of sleeping period
- ◆ position at the end of the sleeping periods
- ◆ any changes in routine care or routine activity levels
- ◆ any disruptions to normal patterns.
- ◆ information on the activity and location of all significant members of the household
- ◆ information on alcohol intake and recreational drug use by members of the household during this period.

### **The final sleep**

A very careful description of when and where the baby was placed to sleep, including:

- ◆ the nature of the surface
- ◆ clothing
- ◆ bedding



## Sudden unexpected death in infancy

- ◆ arrangement of bedding
- ◆ precise sleeping position
- ◆ who was sharing the surface on which baby was sleeping (e.g. bed or sofa)
- ◆ how often the baby was checked
- ◆ when he or she was seen or heard
- ◆ the times at which the baby awoke for feeds
- ◆ whether feeds were given
- ◆ whether they were taken well
- ◆ who else was in the room at each stage
- ◆ what were the activities of others in the room
- ◆ were they awake
- ◆ where, when and by whom was the baby found
- ◆ what was the appearance of the baby when found
- ◆ what was the position of the baby when found
- ◆ where was the bedding
- ◆ were there any covers over the baby
- ◆ had the covers and the position of the covers moved
- ◆ were there other objects in the cot or bed adjacent or close to the baby (e.g. teddies, dolls, pillows)
- ◆ was the heating on
- ◆ what type of heating was there
- ◆ were the windows and/or doors open?

### **Action after baby was found**

A detailed narrative account of events that followed the discovery of the baby collapsed or apparently dead, to include details of:

- ◆ when, how and by whom the emergency services were called
- ◆ who was with the baby at each stage
- ◆ was resuscitation attempted and if so by whom
- ◆ were any responses obtained from the baby
- ◆ how long did it take for the emergency services to arrive?

### **Further specific questions**

In addition to the information outlined above, information should be collected on the parents' perception of:

- ◆ whether the baby was feeding as well as, or less well than, usual in the past 24–48 hours
- ◆ any vomiting
- ◆ any respiratory difficulty, noisy breathing, in-drawing of the ribs, wheezing or stridor
- ◆ excessive sweating
- ◆ unusual activity
- ◆ unusual behaviour
- ◆ level of alertness

- ◆ difficulty sleeping
- ◆ difficulty waking the baby
- ◆ passage of stool and urine (how often and how much)
- ◆ were any healthcare professionals consulted within the past two weeks, the past 48 hours or the past 24 hours
- ◆ if so, who was contacted, what was the problem described to the healthcare professionals and what advice was given
- ◆ was the baby seen and assessed by any healthcare professional during the past two weeks?

**Whilst most of the medical and social history will be obtained during the initial discussion with the parents in the A&E department, a very careful and detailed account of the final 24–48 hours will almost always be considerably supplemented by information collected at the time of the initial home visit and close examination of the circumstances of death.**

The home interview and visit to the place where the baby died can be very difficult, but may also be of great value in understanding the sequence of events leading to the death. Parents commonly find this home interview, whilst stressful and sometimes painful, very helpful – the fact that the paediatrician is willing to spend this time with them, helping to understand what has happened to their baby may in itself be very important to the family and many questions commonly arise out of this visit (in particularly in relation to the factors that may have contributed to the death).

At the end of the interview, it is essential that the paediatrician spends some time with the family ensuring they know what will happen next, when they will next be contacted by the paediatrician, when and where the post mortem will take place, and how they will be informed of the preliminary results.

Time will also be needed for the paediatrician to help the parents deal with the very powerful emotions that are commonly brought out by this discussion. If conducted sensitively and with awareness of the parents' needs, this interview can have a therapeutic 'debriefing' value for the family – commonly allowing them to talk about some of their feelings for the first time. Parents have commonly reported that this home visit has been an extremely important and very positive aspect of their care.

# Appendix III

## Autopsy protocol for sudden unexpected deaths in infancy

### The role of the autopsy

To establish the cause of death and to address the issues related to the circumstances of death:

- ◆ whether the death is attributable to a natural disease process
- ◆ to consider the possibility of accidental death (trauma, poisoning, scalding, drowning)
- ◆ to consider the possibility of asphyxia/airway obstruction
- ◆ to consider the possibility of non-accidental injury
- ◆ to document the presence/absence of pathological processes and to contribute to the multidisciplinary clinicopathological evaluation of the death.

### Clinical information relevant to the autopsy

The pathologist should have available a comprehensive history and report on the circumstances of death prior to starting the post-mortem examination.

Ideally, available information should include:

- ◆ detailed history, including details of pregnancy, delivery, post-natal history, ante-mortem history and precise circumstances of death including family history (previous sibling deaths, consanguinity, drug use, sleeping arrangements)
- ◆ event-scene investigation report from paediatrician and/or police officers if available
- ◆ report of the coroner's officer
- ◆ GP records
- ◆ reference to the child protection register
- ◆ reference to resuscitation procedures
- ◆ results of examination by a consultant paediatrician
- ◆ results of septic screen, if done in an A&E department
- ◆ details of any other investigations sent from the A&E department, and any results available so far. All results from such investigations should be reviewed by the pathologist as well as by the SUDI paediatrician.

### The autopsy procedure

- ◆ If there is any suspicion of abuse contributing to the death, consider requesting a joint post-mortem examination with a forensic pathologist.
- ◆ Consider close adherence to the rules of evidence from the outset of involvement (e.g. identification and corroboration of evidence).

- ◆ Full autopsy (external and internal examination), with attention to: weights, measurements, presence/absence of secretions or blood around nose and mouth and petechial haemorrhages on face, conjunctivae or oral mucosa (consider photography for documentation of dysmorphism and/or evidential purposes).
- ◆ Any evidence of injury (a full skeletal survey reported by a paediatric radiologist is mandatory in such cases).
- ◆ Weights of all major organs.
- ◆ If suspicious of intracranial injury, no needles should be placed within the skull or the eye until the scalp, skull and intracranial contents have been examined and injury excluded.

### **Specific significant organ systems**

All organs to be systematically examined.

### **Organ retention**

- ◆ If trauma to the brain/spinal cord is suspected, consider retaining these organs; also consider retaining the eye for specialist neuropathological referral.
- ◆ In general, if the clinical history and pathological findings require any particular organ to be retained for further assessment, this should be discussed with the coroner's office.
- ◆ If the family has given consent for organs or tissues to be retained for research purposes these should be retained (with the agreement of the coroner).

### **Minimum blocks for histological examination**

- ◆ Five lobes of lung (H&E, and Perls' method for iron).
- ◆ Heart (free wall of left and right ventricle, interventricular septum).
- ◆ Thymus.
- ◆ Pancreas.
- ◆ Liver.
- ◆ Spleen.
- ◆ Lymph node.
- ◆ Adrenal glands.
- ◆ Kidneys.
- ◆ Costo-chondral junction of a rib to include bone marrow sample.
- ◆ Muscle.
- ◆ Blocks of any lesion, including fractured ribs.
- ◆ Brain: four to six blocks including cerebral hemisphere, brainstem, cerebellum, meninges and spinal cord; dura if there is haemorrhage.

(In cases with no clinical evidence or macroscopic autopsy findings explaining death, it is strongly recommended that the brain is examined only after adequate fixation, for one to two weeks).

If any organ is to be retained for fixation and more extensive sampling, this must be discussed with the coroner and the appropriate authority obtained. This may necessitate a delay in the funeral arrangements to allow return of the organ(s) to the body after fixation and sampling.

**Other samples required (if not already taken in the A&E department)**

- ◆ Bacteriology (blood, cerebrospinal fluid, respiratory tract, any infective lesion).
- ◆ Virology (post-nasal swabs or nasopharyngeal aspirate, lung, cerebrospinal fluid and faeces if indicated).
- ◆ Consider agreeing protocols with local medical microbiology departments to use modern DNA amplification techniques for organism recognition.
- ◆ Biochemistry (urine, if present, for metabolic investigations or toxicology; blood and bile spots on Guthrie card for acylcarnitines by mass spectrometry if metabolic disease suspected or if fat stains on frozen sections are positive).
- ◆ Frozen section – stained with Oil Red O for fat on liver and kidney, skeletal and cardiac muscle (mandatory in all unexplained unexpected infant deaths).
- ◆ Consider toxicology (peripheral blood, whole unpreserved in fluoride bottle, urine, sample of liver, stomach content; request an illicit drug/ alcohol screen, specify other drugs as indicated from the history).
- ◆ Skin sample for fibroblast culture.

**Clinicopathological summary and report to the coroner**

- ◆ Summarise the clinical history and main pathological findings.
- ◆ Consider whether the pathology satisfactorily explains the clinical circumstances of the death.
- ◆ Consider whether there are features indicating a familial/genetic disease requiring screening and counselling of the family.
- ◆ Consider whether there are features sufficient to suggest non-accidental injury or neglect.
- ◆ If a complete and sufficient natural explanation of the death is identifiable at the initial post-mortem examination, the coroner must be informed of this and usually no inquest will be required.
- ◆ If, during the initial post mortem, findings emerge that clearly identify neglect or abuse as the most likely explanation for the death, the coroner must be immediately informed and the police will become the lead investigating agency. The provisions of normal criminal investigations will be set in motion, including the requirements of the Police and Criminal Evidence Act 1984.
- ◆ If, in the light of initial post-mortem findings (including careful consideration of the circumstances of the death), there is no clear or sufficient natural cause of death – *whether or not there are some*

*concerns about the possibility that abuse or neglect might have contributed* – the initial 'cause' of death should be given to the coroner as "unexplained pending further investigation". In these circumstances, the continued close cooperation of all agencies will be of great importance, and the nature and content of any further investigations by the police or social services department will be determined by the strategy discussion immediately after the initial post-mortem results are available.

- ◆ *The use of the term "unascertained", which carries implications that the death may have been the result of neglect or abuse, should generally be avoided.*
- ◆ The report must include details of any samples taken or kept and instructions for their further retention or disposal, as authorised by the coroner.
- ◆ A full report, including the results of all further investigations undertaken (e.g. histology, microbiology, toxicology, radiology, virology, histochemistry, biochemistry or metabolic screening of blood or other samples), should be prepared and made available to the coroner and to the multi-professional local case discussion meeting, usually held 8–12 weeks after the death and chaired by the SUDI paediatrician.
- ◆ The pathologist should, if possible, attend and take part in the multi-professional local case discussion meeting.

# Appendix IV

## The police response to infant death

*This appendix is an abbreviated version of the confidential Association of Chief Police Officers' Infant Death Guidelines (2002) and the full guidelines must be referred to during any investigation.*

### 1 Introduction

- 1.1 Child and baby deaths upset the normal sequence of events within the human race. Healthy children are not meant to die, and when they do the trauma caused to parents and family is great. Despite a huge reduction in infant deaths in recent years (largely brought about by education campaigns for new parents), every year in England and Wales, several hundred children will die before they reach one year of age. The vast majority of these deaths occur as a result of natural causes, such as disease, physical defects or accident. A small proportion of so-called 'cot deaths' are, however, caused deliberately by violence, by maliciously administered substances or by the careless use of drugs. Investigating officers must be aware that as the number of genuine unexplained deaths decreases, the proportion of all infant deaths which could be attributed to homicide is likely to increase; education campaigns will not stop people killing children. A person is more likely to die by homicide in the first year of life than at any subsequent age. Apart from actual violence, an infant is not only vulnerable to prescription and controlled drugs but also to household materials such as salt, and even excess feeding of water. Unlike adults, children are unlikely to question or even notice such administration.
- 1.2 Every child who dies deserves the right to have their **sudden and unexplained death** fully investigated in order that a cause of death can be identified, and homicide excluded. Apart from anything else, this will help to support the grieving parents and relatives of the child. It is also important to enable medical services to understand the cause of death and, if necessary, create interventions to prevent future deaths in children. The police have a key role in the investigation of infant and child deaths, and their prime responsibility is to the child, as well as siblings and any future children who may be born into the family concerned.
- 1.3 Sometimes a child is found unexpectedly very ill at home and dies unnaturally soon afterwards in hospital. Such cases should be investigated using these guidelines.

- 1.4 A determined cause of death cannot always be established. Pathologists or coroners tend to classify such cases as cot deaths; Sudden Infant Death Syndrome (SIDS); unascertained or undetermined. All these categories mean the same thing that **no cause of death has been found**.
- 1.5 There are a number of guiding principles that must underpin the work of all relevant professionals dealing with a sudden unexplained child death. These are listed below.
  - ◆ To maintain a sympathetic and sensitive approach to the family, regardless of cause of the child's death. Police action needs to be a careful balance between consideration for the bereaved family and recognising the potential of a crime having been committed.
  - ◆ A coordinated and timely inter-agency response, particularly in respect of information sharing.
  - ◆ To keep an open mind.
  - ◆ To share information.
- 1.6 It is recommended that the principles of this chapter are adhered to for all child deaths but it needs to be recognised that the older the child, the more likely it will be that the death is suspicious because the probability of death by unascertained natural causes decreases with age.

## 2 Who should attend a sudden infant death?

- 2.1 If the police are the first professionals to attend the scene then urgent medical assistance should be requested as the first priority. Police attendance should be kept to the minimum. Several police officers arriving at the house can be distressing especially if they are uniformed officers in marked police cars.
- 2.2 A detective officer of at least Inspector rank must immediately attend the scene and take charge of the investigation, in all cases of sudden unexplained infant deaths, whether or not there are any obvious suspicious circumstances. This is the case if the child is still at the scene **or** if the child has been removed to hospital.
- 2.3 As with all sudden deaths, when the body has not been removed from the scene, a doctor must attend to certify death. When the circumstances are obviously suspicious this must be a police surgeon. If at hospital, then the resident doctor will certify death.
- 2.4 Good cooperation and liaison between police and paediatricians is very important. The detection of child abuse is part of the standard training of paediatricians, which should equip them to carry out a quasi-forensic external examination and to arrange the relevant investigations such as a skeletal survey



and tests for abnormal bruising. Assistance can be provided in the form of early examination of the body, collating relevant information from medical records, preparing reports for pathologists and convening a meeting among all medical professionals involved with the family. It is recommended that the carers are spoken to in the first instance by police, but it is likely that a paediatrician may want to take a medical history at some stage.

- 2.5 The coroner's officer must be notified as soon as possible. As well as the usual functions they perform, their experience in dealing with sudden deaths and bereaved families will be invaluable in explaining to the parent/carer what will happen to their child's body and why. If the coroner's officer asks to attend the scene then this should be allowed without the necessity of further consultation. They will also be able to liaise directly with the coroner. The investigating officer and the coroner's officer should continue to liaise closely throughout the investigation.
- 2.6 The senior detective attending will be responsible for deciding whether to request the attendance of a scene-of-crime officer (SOCO). Certainly if items are to be removed or photographs or a video are to be taken (see 5.5) their attendance will be essential.
- 2.7 In some forces it may be considered appropriate for a family liaison officer (FLO) to attend to assist the investigating officers. The role of the FLO is dealt with elsewhere in the Murder Investigation Manual.

## **6 Further and subsequent action by police**

- 6.1 If it is considered necessary to remove items from the house, do so with consideration for the parents. Explain that it may help to find out the cause of their child's death. Before returning the items, the parents must be asked if they actually want them back.
- 6.2 If articles have been kept for a while, try to ensure they are presentable and that any official labels or wrappings are removed before return. Return any items as soon as possible after the coroner's verdict or the conclusion of the investigation. The term investigation will include any possible trial or appeal process.
- 6.3 Consideration must be given to evidencing any factors of neglect which may be apparent.
- 6.4 Details of death must be notified to the coroner. It may be appropriate for an officer who has already built a rapport with the parent/carer to obtain details on the appropriate form.

- 6.5 Often the first notification to the police occurs when the child is already at hospital. In such cases consideration should be given to designating scenes, both at the hospital and at the location where the child was first discovered to be unwell.
- 6.6 Often medical staff interview parents before the police arrive at hospital in an effort to establish the circumstances surrounding the child's collapse.
- 6.7 If police are aware of the case before the child has been taken to a hospital, then the child's body must be accompanied to the hospital for the purpose of continuity of identification. It is recommended that the body should be taken to a hospital casualty department rather than a mortuary, firstly to enable any chance of resuscitation and secondly to make it easier to get an early expert physical examination by a paediatrician. This should be done appropriately and sensitively.
- 6.8 A physical external examination recorded by way of photographs should be undertaken by medical staff and police at the earliest possible stage in order to record any suspicious or unidentifiable marks.
- 6.9 It is entirely natural for a parent/carer to want to hold or touch the dead child. Providing this is done with a professional (such as a police officer, nurse or social worker), present, it should be allowed in most cases, as it is highly unlikely that forensic evidence will be lost. If however, the death has by this time been considered suspicious, the SIO should, where possible, be consulted before a parent/carer is allowed to hold the child.
- 6.10 If the parents/carers wish to accompany their child to the mortuary, then this should normally be facilitated, ensuring that they are accompanied by a police officer, family liaison officer, child protection officer or coroner's officer as appropriate.
- 6.11 Hospitals often wish to supply bereaved parents with a lock of hair, or foot or handprints. Police should only refuse these considerations if there is good reason to believe it would jeopardise the investigation, and it is highly unlikely that this would be the case.

## Sudden unexpected death in infancy

- 6.12 If there is any lack of agreement between medical staff and police about the handling of the body then the coroner's officer must be informed at once in order that the coroner can decide on the appropriate course of action.
- 6.13 In all cases, the police should request a paediatric pathologist or a pathologist with some paediatric expertise carries out a post mortem. A full skeletal survey should be requested and this should be carried out and interpreted by a paediatric radiologist, or radiologist with paediatric expertise, to ensure the best possible result. It is important that the skeletal survey includes the whole body. The investigating officer must give a full briefing to the pathologist(s), including showing of the video and photographs of the scene, and to sharing of all information gathered thus far.
- 6.14 Whether or not the post mortem reveals physical signs of injury it is important that extensive toxicological tests are carried out.
- 6.15 In any case where the death is suspicious, a forensic post mortem must take place and if the Home Office pathologist does not have paediatric experience, they should be encouraged to work alongside a paediatric pathologist or pathologist with paediatric experience to maximise the opportunity for the recovery and interpretation of evidence.
- 6.16 It is good practice for the SIO to call upon the services of the National Crime Faculty (NCF), who can provide an up to date list of experts as well as knowledge of the latest investigative techniques.

## 8 Conclusion

- 8.1 Whilst it is felt the investigation of infant deaths is of such a specialised nature as to warrant the inclusion of a separate chapter in the Murder Investigation Manual, in every case where the death is felt to be suspicious, the same thought processes, vigour, expertise and professionalism, which are always applied to adult homicides must also be employed. Children are citizens who have the same rights as any other people to the protection offered by the criminal law as well as the expert services of the police.

*This appendix is an abbreviated version of the CONFIDENTIAL ACPO Guidelines. It is essential that investigators refer to the entire guidance when they encounter a case involving infant death.*

# Appendix V

## Membership of the Working Group

### The Baroness Helena Kennedy QC Chair

Ms Joyce Epstein	Director, Foundation for the Study of Infant Deaths
Professor Peter Fleming	The Royal College of Paediatrics and Child Health
Mr John Fox	Detective Superintendent, Hampshire Constabulary
Dr Isabella Moore	The Royal College of Pathologists
Mr John Pollard	HM Coroner, Manchester South
Professor R Anthony Risdon	The Royal College of Pathologists
Dr Darren Shickle	Observer, Department of Health
Dr John Sills	The Royal College of Paediatrics and Child Health
Mr Jon Stoddart	Deputy Chief Constable, Durham Constabulary
Mr Andrew Webb	Director of Social Services, Stockport Borough Council
Ms Charlotte Balazs	Working Group administrator

# Appendix VI

## List of stakeholders

The following organisations accepted an invitation to send a representative to attend the Stakeholder Meeting on 7 April 2004 at The Royal College of Pathologists, 2 Carlton House Terrace, London.

Also in attendance were the Presidents and other representatives of The Royal College of Pathologists and The Royal College of Paediatrics and Child Health and all members of the Working Group.

British Association for Community Child Health  
British Paediatric Pathology Association  
Child Protection, Metropolitan Police  
Child Protection Nurse, South Wiltshire  
Child Protection Unit, Department for Education and Skills (England)  
Consultant Community Paediatrician  
Coroners' Officers Association  
Crown Court Procedures Section, Criminal Procedure and Evidence Unit,  
Crown Prosecution Service  
Family Law Bar Association  
Foundation for the Study of Infant Deaths  
HM Coroner Cheshire  
HM Coroner Manchester South  
HM Coroner Peterborough  
National Society for the Prevention of Cruelty to Children  
North Wales Health Authority paediatrician  
Paediatric Accident and Emergency Department, Alder Hey Hospital  
Paediatrics and Child Health, Department of Health (England)  
Policy Advisory Board for Forensic Pathology, Home Office  
Policy Officer, Child Health, Department of Health (England)  
Science Policy Unit, Home Office  
Scientific Development and Bioethics Division, Department of Health  
(England)  
Scottish Cot Death Trust  
The Royal College of Pathologists' Lay Advisory Committee  
Vulnerable Children's Unit, Department for Education and Skills (England)

## **The Royal College of Paediatrics and Child Health**

The Royal College of Paediatrics and Child Health is the body charged with the education and training of paediatricians in the UK. Founded in 1996 as the successor organisation to the British Paediatric Association (BPA), it has 8000 members across the world.

The College runs MRCPCH, the standard UK examination for entry to the paediatric register, convenes working parties and standing committees to provide the best available advice on clinical issues, and works to improve standards of child health in the UK and overseas.

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## **The Royal College of Pathologists**

The Royal College of Pathologists is a professional membership organisation with charitable status, concerned with all matters relating to the science and practice of pathology. The College was founded in 1962 and received its Royal Charter in 1970. Its total membership is almost 8000, of which over 5700 are from the United Kingdom. Its members work mostly in hospitals, universities and industry.

The main specialties of pathology that the College represents are clinical biochemistry, cytopathology, forensic pathology, genetics, haematology, histocompatibility and immunogenetics, histopathology, immunology, microbiology, neuropathology, paediatric pathology, toxicology, transfusion medicine, veterinary pathology and virology.

The objectives of the College are to advance the science and practice of pathology, further public education in the field of pathology, promote research in pathology and disseminate the results.

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