

University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

**A Thesis Submitted for the Degree of PhD at the University of Warwick**

<http://go.warwick.ac.uk/wrap/70000>

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it. Our policy information is available from the repository home page.

**Why did my baby die?**

**An evaluation of parental and professional experiences of joint agency investigations following sudden unexpected death in infancy.**

**Dr Joanna Jane Garstang**

**MBChB MSc MRCPCH**

**A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Health Sciences**

**Warwick Medical School**

**University of Warwick**

**December 2014**

## Table of Contents

Abstract.....	11
List of abbreviations and specialist terms .....	12
Introduction .....	16
Chapter one Background .....	22
Section 1.1 Definitions.....	22
Section 1.2 Current understanding of SIDS .....	23
Section 1.3 The Joint Agency Approach (JAA) to investigating unexpected infant deaths .....	29
Chapter two Literature Review – what do bereaved parents want from professionals after the sudden death of their child?.....	40
Section 2.1 Introduction .....	40
Section 2.2 Methods.....	41
Section 2.3 Description of results .....	51
Section 2.4 Results of Critical Appraisal Studies .....	64
Section 2.5 Narrative Synthesis of Results.....	66
Section 2.5 Discussion.....	83
Section 2.6 Conclusions .....	84
Chapter three Literature review of the evidence for effective investigation of SUDI.....	85
Section 3.1 Introduction .....	85
Section 3.2 Methods .....	86
Section 3.3 Compliance with best practice in SUDI investigation .....	88
Section 3.4 Results of literature searches .....	91
Section 3.5 Results - different models of investigating SUDI .....	96
Section 3.6 Detailed consideration of different models of SUDI investigation .....	100
Section 3.7 Key enablers and barriers common to all models .....	114
Section 3.8 Key factors for effective SUDI investigation .....	116
Section 3.9 Discussion.....	118
Chapter Four Aims, methodology and methods .....	121
Section 4.1 Aims and research questions.....	121
Section 4.2 Theoretical perspectives .....	122
Section 4.3 Methodology - Evaluation of the JAA .....	127
Section 4.4 Methodology - Mixed methods .....	130

Section 4.5 Methods – Objectives, case definition and study area .....	135
Section 4.6 Study design .....	137
Section 4.7 Methods of data collection .....	140
Section 4.8 Methods of data analysis .....	148
Section 4.9 Results of analysis .....	151
Section 4.10 Summary .....	158
Chapter five Introduction to results. ....	159
Section 5.1 Recruitment of cases.....	159
Section 5.3 Details of participation.....	164
Section 5.4 Description of participating families and cases .....	165
Section 5.5 Description of participating professionals .....	167
Section 5.6 Parental Wellbeing.....	168
Section 5.7 Summary of introduction to results.....	180
Chapter six Bereaved parents’ and professionals’ experiences of the JAA.....	182
Section 6.1 Introduction .....	182
Section 6.2 Parents’ and professionals’ experiences of the visible elements of the JAA .....	184
Section 6.3 Pre- hospital care .....	184
Section 6.4 Hospital .....	190
Section 6.5 The joint home visit (JHV) .....	196
Section 6.6 Follow-up .....	207
Section 6.7 Bereavement support .....	215
Section 6.8 Social Care .....	223
Section 6.9 Coroners’ Enquiries .....	225
Section 6.10 Professionals’ experiences of JAA elements not visible to parents.....	227
Section 6.11 Multi-agency meetings .....	228
Section 6.12 Joint agency working.....	234
Section 6.13 Discussion.....	241
Chapter seven Parents’ understanding of the cause of death .....	245
Section 7.1 Introduction .....	245
Section 7.2 Results- Official causes of death .....	247
Section 7.3 Results - Modifiable factors contributing to deaths .....	251
Section 7.4 How important is finding a cause of death for the parents?.....	252
Section 7.5 Do parents understand the cause of death? .....	256

Section 7.6 Parents' understanding of modifiable factors .....	259
Section 7.7 Blame and modifiable risk factors .....	264
Section 7.8 Discussion.....	278
Chapter eight The West Midlands Child Death Overview Panel SUDI Study .....	282
Section 8.1 Introduction .....	282
Section 8.2 Methods.....	284
Section 8.3 Results.....	288
Section 8.4 Causes of death.....	289
Section 8.5 Risk Factors .....	290
Section 8.6 Discussion.....	295
Chapter nine Discussion.....	301
Section 9.1 Summary of findings of literature reviews and studies .....	301
Section 9.2 Synthesis of the results of the studies and literature reviews.....	303
Section 9.3 How robust is the JAA as an investigative process? .....	303
Section 9.4 The challenges of determining the complete cause of death .....	305
Section 9.5 Understanding the cause of death and the role of blame.....	311
Section 9.6 Addressing the families' needs .....	313
Section 9.7 Agencies working together to investigate SUDI .....	315
Section 9.8 Strengths and limitations of the studies .....	317
Section 9.9 Conclusion.....	321
Section 9.10 Further Research.....	322
Chapter 10 Improvements to the Joint Agency Approach .....	324
Section 10.1 JAA Investigations to be led by specialist SUDI clinicians. ....	325
Section 10.2 Reconsidering the role of uniformed non-specialist police .....	328
Section 10.3 Engaging with mothers and other care givers .....	329
Section 10.4 Joint home visits must remain mandatory .....	329
Section 10.5 Better recognition of poor parenting and dangerous infant sleep practices.....	330
Section 10.7 Improving the classification of cause of death .....	332
Section 10.8 Clarifying the process for final case discussions .....	336
Section 10.9 Better working together .....	337
Section 10.9 Summary of recommended improvements to the JAA .....	339
References .....	342
Appendix 1 .....	351

Appendix 2 Critical appraisal of quantitative studies .....	368
Appendix 3 Critical appraisal of qualitative studies.....	378
Appendix 4 In-depth interview schedules for parents’ and professionals’ interviews. .	387
Appendix 5 Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) .....	392
Appendix 6 Parental structured interview or self-completion questionnaire.....	394
Appendix 7 Health, police and social care data extraction proformas.....	408
Appendix 8 CDOP Form C .....	414
Appendix 9 Ethical Approvals .....	423

## Table of tables

Table 1 Professionals involved in the JAA.....	35
Table 2 Search terms used for literature searches .....	43
Table 3 Inclusion criteria.....	47
Table 4 Exclusion criteria .....	47
Table 5 Critical appraisal questions for surveys.....	49
Table 6 Critical appraisal questions for qualitative research.....	49
Table 7 Numerical results of literature searches.....	51
Table 8 Details of quantitative studies .....	53
Table 9 Details of qualitative studies.....	58
Table 10 Details of studies with both qualitative and quantitative data .....	63
Table 11 Details of websites searched.....	86
Table 12 Search terms used for SUDI models literature review.....	87
Table 13 Details of included papers, research reports and conference presentations....	92
Table 14 Basic models of SUDI investigation .....	98
Table 15 Assessment of Coroner or ME led models .....	107
Table 16 Assessment of healthcare-led model.....	109
Table 17 Assessment of JAA .....	114
Table 18 Gold standard JAA template .....	154
Table 19 Gold standard JAA template continued .....	155
Table 20 Example of framework matrix for JAA experiences.....	157
Table 21 Reasons for non-recruitment of cases .....	162
Table 22 Social deprivation IDACI scores of SUDI cases .....	164
Table 23 Social deprivation IDACI ranks of SUDI cases.....	164
Table 24 Distribution of quotes from cases illustration parental wellbeing .....	169
Table 25 Distribution of quotes from cases illustrating experiences of the JAA .....	183
Table 26 Distribution of quotes from cases illustrating understanding causes of death .....	247
Table 27 Causes and risk factors for deaths .....	248
Table 28 Evidence base for risk factors for SIDS.....	286
Table 29 Classification of cause of death.....	289
Table 30 Risk factors and preventability of death .....	292
Table 31 Classification of SUDI as per Randall et al (2012).....	334
Table 32 Suggested new classification for SUDI cases.....	335
Table 33 Critical Appraisal of quantitative studies .....	368
Table 34 Critical Appraisal of qualitative studies.....	378

## Table of figures

Figure 1 Flow chart of JAA process .....	34
Figure 2 Map of West Midlands region .....	37
Figure 3 Map of counties of West Midlands region .....	37
Figure 4 Flow chart for selection of studies.....	52
Figure 5 Quantitative codes, qualitative codes and themes .....	67
Figure 6 Proportion of eligible cases referred and recruited to study .....	160
Figure 7 Recruitment from different areas.....	162
Figure 8 Experience of professionals managing SUDI cases .....	168
Figure 9 Box plot of parental HADS scores .....	170
Figure 10 Maternal HADS and time since death.....	171
Figure 11 Maternal alcohol consumption.....	172
Figure 12 Paternal alcohol consumption .....	173
Figure 13 Maternal smoking habits .....	174
Figure 14 Paternal smoking habits.....	175
Figure 15 Social care involvement in SUDI cases .....	224
Figure 16 Frequency of risk factors in unexplained deaths .....	251
Figure 17 Mothers understanding of cause of death .....	257
Figure 18 Maternal anxiety and self-blame .....	269
Figure 19 Maternal depression and self-blame .....	269
Figure 20 Distribution of modifiable factors and category of death .....	291
Figure 21 Total number of family and environmental risk factors and categories of death .....	293



## **Dedication**

To Jim, who was awarded his PhD in 1971, but did not live to see me complete mine.

To Stella Foxglove, whose story inspired me to improve how we care for bereaved parents.

## **Acknowledgements**

I would like to acknowledge the bereaved parents who told me their stories; without them this work would not have been possible. I would also like to thank the many paediatricians, pathologists, police officers, social workers, nurses and CDOP coordinators for referring families to the study, forwarding data or participating themselves in the project.

I am very grateful to my supervisors Dr Peter Sidebotham and Professor Frances Griffiths for their support, guidance and patience throughout this project.

I could not have written this thesis without the love and support of my husband Simon and my sons Thomas, Nicholas and Daniel. Special thanks go to my parents Carol and Clive and my parents-in-law Kathie and Jim for their help with the boys; by taking over our house during term times so that I could go to conferences and having them to stay during the school holidays. I feel tremendously sad that Jim never saw this work finished as he became ill and died as I was preparing this thesis for submission.

## **Declarations**

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree, apart from the background material in chapter four relating to the choice of study methods, which was previously submitted for my MSc in Child Health in 2008.

The work presented (including data generated and data analysis) was carried out by the author except in the cases outlined below:

Chapter two: quality control of papers for inclusion for systematic review by Dr Peter Sidebotham and Professor Frances Griffiths.

Chapter three: independent critical appraisal of papers for systematic review and contribution towards analysis of key policy factors for investigation of SUDI by Dr Peter Sidebotham and Ms Catherine Ellis.

Chapter five: determination of IDACI scores and ranks for non- recruited cases by Ms Deborah Foster

Chapter eight: independent analysis of risk factors on CDOP Form C by Ms Catherine Ellis.

The systematic review in chapter two has been published by the author. The details of the publication are shown below and the published version is at appendix 1.

What do bereaved parents want from professionals after the sudden death of their child? A systematic review of the literature

Authors: Garstang Joanna, Griffiths Frances, Sidebotham Peter,

Journal: BMC Pediatrics.2014, 14:269

DOI: 10.1186/1471-2431-14-269

URL: <http://www.biomedcentral.com/1471-2431/14/269>

Ethical approval was obtained from NHS Research Ethics Committees or the University of Warwick Biomedical and Scientific Research Ethics Committee.

## **Abstract**

### **Aims**

Since 2008, in England, all sudden unexpected deaths in infancy (SUDI) must be investigated jointly by police, health and social care. This thesis aims to learn of parents' and professionals' experiences of this joint agency approach (JAA) and use this knowledge to improve these investigations.

### **Methods**

1. Systematic literature review of bereaved parents' experiences.
2. Systematic literature review of different models of SUDI investigation.
3. A mixed methods study of JAA investigation of SUDI cases; involving case note analysis, questionnaires and in-depth interviews with parents and professionals.
4. A descriptive study of outcomes of JAA SUDI investigation using Child Death Overview Panel (CDOP) data.

### **Results**

In the mixed methods study, 23/111 families were recruited giving theoretical saturation; the median time between death and parental study participation was 33 weeks. Parents felt that the JAA provided information about the death but offered minimal emotional support; they were often distressed by non-specialist police attending their home as part of the investigation. The joint home visit by police and paediatrician was shown to be a key investigative process. Social care were only involved in 13/23 JAA investigations. Some coroners were reluctant to share information with paediatricians preventing effective JAA investigations.

In the CDOP study were obtained for 93% SUDI cases. Final case discussions were used to discuss risk factors but not to determine the cause of death; in nearly all cases the final cause of death relied on post-mortem examination alone and ignored death scene examination findings. Many deaths were labelled as unascertained despite fulfilling diagnostic criteria for SIDS.

### **Conclusion**

Ideally, SUDI investigations should be carried out only by specialist clinicians who do this work frequently and the JAA should be fully integrated with social care and coroners' investigations. There needs to be a clearer system for classifying unexplained SUDI. Police should reconsider their immediate response to SUDI; parents would like more follow-up and bereavement support from professionals.

## **List of abbreviations and specialist terms**

### **CAIU    Child abuse investigation unit.**

The specialist police unit responsible for investigating child abuse as well as all unexpected child deaths, regardless of cause.

### **CONI    Care of Next Infant**

An enhanced care and support package, provided by health visitors and paediatricians, for infants born in families who have previously lost infants to SIDS.

### **CDR    Child death review**

The process of reviewing all child deaths at a local or regional level, with the aim of learning lessons to prevent deaths in the future.

### **CDOP    Child death overview panel**

The local child death review teams in England and Wales.

### **CDOP Form C**

The standard template used by child death review team in England and Wales

### **DDUD    Designated doctor for unexpected deaths**

The paediatrician with responsibility for ensuring the appropriate investigation of child deaths in their local area.

### **Death scene analysis**

A professional examination of the scene of death; but not necessarily jointly by police and paediatrician as in the joint home visit.

### **DI        Detective inspector**

Senior police officer usually leading the police element of unexpected infant death investigations.

**ED      Emergency Department**

The hospital department that receives emergency cases without prior appointment or referral.

**FCD      Final case discussion**

The multi-agency meeting at the conclusion of the unexpected infant death investigation which analyses in detail all information relevant to the death.

**FSID      Foundation for the study of infant deaths**

This has now become the Lullaby Trust

**GP      General Practitioner**

**HADS      Hospital anxiety and depression score**

This is a validated self-completion screening tool for anxiety and depression (Zigmond and Snaith, 1983).

**HV      Health visitor**

**ICD 10      International classification of diseases version 10**

This is the classification by the World Health Organisation containing codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.

**JAA      Joint agency approach**

The multi-agency investigation by police, health and social care into sudden child deaths as detailed in chapter five of Working Together to Safeguard Children (HM Government, 2013).

**JHV      Joint home visit**

The joint visit by the paediatrician and police officer to view the family home and see the setting in which the infant died; this takes place shortly after the infant death.

### **Kennedy Report**

The report led by Baroness Kennedy into the management of SUDI that led to the creation of the joint agency approach (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004).

### **LSCB    Local safeguarding children board**

The multi-agency group of professionals from each local government area with responsibility for ensuring that agencies work together to safeguard and promote the welfare of children.

### **Lullaby Trust (formerly FSID)**

This is a UK charitable organisation which provides support to parents bereaved by unexpected infant deaths. It also funds research into SUDI, promotes safe-sleeping campaigns and provides training to professionals.

### **Preventable deaths**

Those death in which modifiable factors may have contributed to the death(HM Government, 2013).

### **Strategy meeting**

A formal meeting chaired by social care, for the investigation of child protection concerns; the meeting is also sometimes referred to as a **section 47 Strategy meeting**.

### **SIDS    Sudden infant death syndrome**

The sudden and unexpected death of an infant, occurring during sleep, that remains unexplained after a complete autopsy, medical history and review of the circumstances of death (Krous et al., 2004).

### **SIO    Senior investigating officer**

The police officer leading any investigation.

**SOCO   Scenes of crime officer**

A civilian forensic scientist who may assist police with crime scene investigations.

**SUDI   Sudden unexpected death in infancy**

The sudden and unexpected death of an infant that could not have been predicted as a possibility 24 hours before the death (Fleming et al., 2000)

**SUDI Paediatrician**

The paediatrician leading the investigation of unexpected infant deaths; this may be, but is usually not the same paediatrician as the designated doctor for unexpected deaths.

**WM   West Midlands region**

The area comprising of the counties of Herefordshire, Shropshire, Staffordshire, Warwickshire, West Midlands and Worcestershire



## Introduction

*“You can stop resuscitating; leave the notes on my desk.”*

This was the standard advice that I received as a junior paediatric registrar, in the early 2000s, from consultants when I was managing a case of ‘cot death’. Typically, a baby would be brought in dead to the Emergency Department (ED) early in the morning; we would attempt resuscitation for a few minutes while I telephoned the consultant on-call for permission to stop resuscitation as this was clearly futile. On most occasions the consultant did not attend the ED as these cases were considered appropriate for registrars to manage alone. Parents were asked few questions by the medical team although they were interviewed by uniformed police officers who also visited the home and frequently removed items of bedding and clothing. Usually the consultant would write to the parents and offer them an outpatient appointment a few weeks later; these were often not accepted as the parents had never met the consultant. The hospital team rarely saw the post-mortem examination report and in the few cases that I did the results did not seem to fit with the little information that had been obtained in the ED. I felt that families were receiving a very poor service.

In 2006, I was involved in setting up a training course to teach paediatricians, police officers and social workers the new joint agency approach (JAA) to investigating unexpected child deaths (Garstang and Sidebotham, 2008). As part of this course I heard the moving account of a bereaved mother whose daughter died of Sudden Infant Death Syndrome (SIDS); she explained that having left her baby daughter’s body at the hospital she never heard again from any medical professional about why her daughter had died. The mother felt utterly unsupported and went on to develop post-traumatic

stress disorder. This account convinced me that as professionals we had to improve how we investigated such deaths and treated the bereaved families.

The JAA is fully described in the next chapter but I will briefly outline it here. The aim of the JAA is to establish the full cause of death and address the families' needs; the JAA became statutory in 2008 (HM Government, 2013). When parents discover that their baby has died they typically telephone 999 and an ambulance is dispatched. The baby and parents should then be taken to the ED at a local hospital and once any resuscitation has finished the parents should be allowed to hold their baby to say goodbye. Ambulance control notifies the police of all sudden child deaths and a specialist police team should go to the ED; if the police need to secure the home this should be done in a sensitive manner. A consultant paediatrician is expected to attend the ED; this could be the on-call hospital paediatric consultant or another paediatrician tasked specifically with managing SUDI cases (the SUDI paediatrician). At the ED a consultant paediatrician and specialist police should take a detailed history together from the parents and a joint home visit to see the scene of death is arranged by the specialist police and SUDI paediatrician. All SUDI cases require post-mortem examinations. There is an initial multi-agency information meeting, a few days after the death attended by the SUDI paediatrician, specialist police, GP, health visitor and social care to share all relevant information, plan further investigations and arrange support for the family. Once all investigations are complete, some months later, a final multi-agency case discussion is held and the cause of death is discussed and follow-up planned for the family. Prior to the introduction of the JAA, most SUDI cases were investigated by uniformed police and a post-mortem examination alone with minimal involvement by paediatricians.

The JAA was introduced in Birmingham in 2008; I was a senior community paediatric registrar and immediately took part in the on-call rota for consultants to be SUDI paediatricians. I was 'acting-up' as a consultant in recognition that my limited experience from the training course meant that I already had greater expertise in managing SUDI according to the JAA than most established consultants. Despite all agencies agreeing a local protocol (West Midlands Police, 2009) there were significant difficulties in implementing the new procedures as well as resistance from some professionals in all agencies to the new practices. However, I felt that we were investigating deaths much more thoroughly and offering a better service to the bereaved families. I did have concerns though about whether the JAA was too intrusive for some parents and also how one could explain the complex issue of the role of modifiable risk factors, such as co-sleeping and smoking, to parents without leading them to blame themselves.

During this period I was working towards my MSc in Child Health and beginning to question the evidence-base behind many community paediatric practices. I realised that the JAA was based upon the consensus of expert opinion alone (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004); it had mainly been used in research projects and not in routine clinical practice, in addition it had never been formally evaluated. I also realised during this time that I really wanted to take time away from clinical practice to allow me to focus on research.

Community paediatrics involves caring for children with multiple medical and frequently social problems within a multi-agency environment. Improvements in outcome for these children and their families are likely to come from complex interventions involving many professionals rather than from medical treatment alone. As a community paediatrician, I wanted a research project that would reflect this multi-agency family-

focused perspective as this would then be relevant for both my clinical practice as well as my academic training. Evaluating the JAA was therefore an obvious choice of research project for me as it allowed me to combine my interest in research, the JAA and my community paediatric experience.

I used the dissertation element of my MSc to start planning for my PhD (Garstang, 2009); subsequently in 2010 I was successful in obtaining a NIHR Doctoral Research Fellowship which enabled me to undertake this research.

### **Aims, research questions and objectives**

The overall aim of this research is to improve the wellbeing of parents whose infants have died suddenly and unexpectedly. The research questions were:

1. What are the experiences of families whose unexpected infant deaths were investigated by the joint agency approach?
2. What are the experiences of professionals investigating unexpected infant deaths using a joint agency approach?
3. How effective is the joint agency approach at determining cause of death and contributory risk factors?

In order to answer all these research questions two different studies were needed.

The West Midlands SUDI study was a mixed methods study of parental and professional experiences of the JAA; this informed the first two research questions. The West Midlands Child Death Overview Panel (CDOP) SUDI study was a descriptive outcome study using routinely collected anonymised data on SUDI cases from CDOPs and this informed the third research question.

The objectives for this thesis were:

1. To systematically review the literature concerning bereaved parents' experiences following sudden child death.
2. To systematically review the literature concerning the methods and outcomes for different models of SUDI investigation.
3. To recruit the families of eligible SUDI cases in the study area and to recruit the professionals investigating these cases.
4. To collect data from health, police and social care records for all recruited cases.
5. To survey study parents experiences of the JAA using structured interviews or self-completion questionnaires.
6. To interview a sample of parents and professionals in-depth to obtain a greater understanding of their experiences of the JAA.
7. To analyse the data from the case note analysis, structured parental interviews and in-depth parental and professional interviews.
8. To obtain routinely collected anonymised data on all SUDI cases in the region from Child Death Overview Panels (CDOP).
9. To analyse CDOP data concerning cause of death, presence of modifiable risk factors for death and preventability of death.
10. To synthesize the findings from both literature reviews and research studies and then review the implications for clinical practice.

### **Outline of thesis**

Chapter one consists of a detailed explanation of the background to this thesis; the current understanding of the causes of SUDI and SIDS including the role of asphyxia and the process of the JAA is described in full. Chapter two is a systematic review concerning what bereaved parents want from professionals after a sudden child death. Chapter three is a systematic review of the evidence for different models of SUDI investigation.

The West Midlands SUDI study is covered in chapters four to seven. The aims, methodology and methods are discussed in chapter four, and in chapter five there is an introduction to the results of the study describing the cases, families and professionals recruited. Chapter six gives details of the parents' and professionals' experiences of each element of the JAA. In chapter seven the parents' understanding of why their baby died is considered; this includes their understanding of risk factors as well as the final cause of death and how their understanding of these relates to issues of blame. The West Midlands CDOP SUDI study is covered in chapter eight. The findings of both studies and both literature reviews are discussed in chapter nine and potential improvements to the JAA are detailed in chapter ten.

## **Chapter one Background**

This chapter introduces the concepts of sudden unexpected death in infancy (SUDI) and Sudden Infant Death Syndrome (SIDS); it considers the current understanding of pathological mechanisms and risk factors for SIDS and the role of accidental asphyxia in some SUDI. The joint agency approach (JAA) to investigating SUDI is explained in some detail; the key events that occur and the different tasks for professionals.

Each year, in England and Wales around 3-400 infants die suddenly and unexpectedly, having been previously healthy; some of these infants may have a cause found subsequently for their death but the majority remain unexplained (Office for National Statistics, 2013).

### **Section 1.1 Definitions**

Sudden unexpected death in infancy (SUDI) is defined as the death of an infant which was not anticipated as a significant possibility 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to death (Fleming et al., 2000). SUDI is therefore a presentation of death and not a diagnostic cause of death; deaths presenting as SUDI may have a cause identified subsequently during investigations such as a previously unrecognised infection or congenital malformation. The majority of SUDI remain unexplained and are labelled as unascertained deaths or Sudden Infant Death Syndrome (SIDS).

The term SUDI is not always used according to the definition above; frequently publications use the terms SIDS and SUDI interchangeably and do not consider unexpected deaths that subsequently have a cause of death determined to be SUDI. In this thesis I will be using Fleming's definition of SUDI as a presentation of death and

those deaths that remain unexplained after investigation will be referred to as SIDS, unexplained or unascertained deaths.

The most recent definition of SIDS (the San Diego definition) is that of the sudden and unexpected death of an infant less than 1 year of age, with the onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and a review of the circumstances of death and the clinical history (Krous et al., 2004). SIDS can be diagnosed up to two years of age but these cases are extremely rare, SIDS in over one year olds will be discussed subsequently. Earlier definitions of SIDS only required the death to be unexpected by clinical history and a post-mortem examination to fail to establish the cause of death (Beckwith, 1970); there was no requirement for further investigations. However, using the San Diego definition, SIDS cannot be diagnosed unless the death scene has been examined (death scene analysis) and a detailed medical history obtained from the parents. In addition, an international consensus group agreed that no individual professional should make a diagnosis of SIDS alone but that there should be a multi-professional case review to assess all relevant information before any diagnosis is reached (Bajanowski et al., 2007a).

## **Section 1.2 Current understanding of SIDS**

### **Risk factors for SIDS**

SIDS remains a poorly understood phenomenon. Current understanding suggests there is probably no single underlying cause, but rather a range of causes operating through a final common pathway. Many epidemiological studies in the 1980s and 1990s showed risk factors associated with SIDS. These factors can be intrinsic to the infant such as pre-term delivery before 37 weeks gestation (Blair et al., 2009), multiple births (Carpenter et



al., 2004), congenital anomaly that does not directly cause death (Leach et al., 1999), and the presence of minor illness such as respiratory tract infection or otitis media that in itself is insufficient to cause death (Gilbert et al., 1990). SIDS occurs disproportionately in male infants; 60% of SIDS victims are male and this has remained the case following the decline in SIDS since the 1990s possibly reflecting the inherent genetic vulnerability of male infants (Mage and Donner, 2009).

Many risk factors for SIDS relate to unsafe sleep environments including: infants sleeping prone (Fleming et al., 1990) or side sleeping (Carpenter et al., 2004), co-sleeping with an adult or another child (Blair et al., 2009, Carpenter et al., 2013), overheating (Gilbert et al., 1992), wearing a head covering (Blair et al., 2008) or the use of soft sleeping surfaces such as sleeping on duvets or pillows (Blair et al., 2009). Infants sleeping on sofas are at increased risk and the risk of death increases substantially if they are co-sleeping on a sofa with a parent who has consumed alcohol (Blair et al., 2006). Parental smoking also increases the risk of SIDS; particularly maternal smoking antenatally, but also parental smoking postnatally (Blair et al., 2009).

Several risk factors relate to the domestic environment of the infants. SIDS occurs more frequently if the mother or primary care giver has symptomatic depression at the time of the death (Mitchell et al., 1992). Alcohol consumption by the primary carer of more than 2 units in the 24 hours pre-death increases the risk of SIDS (Blair et al., 2009, Carpenter et al., 2013); similarly so with parental substance misuse (Blair et al., 2009, Carpenter et al., 2013). SIDS occurs more frequently in over-crowded households (Leach et al., 1999) and in socially deprived families (Spencer and Logan, 2004). The association with social deprivation has become more marked following the overall decline in SIDS since the 1990s. In the Avon region of South-West England, during 1984-8 23% of SIDS occurred in the 10% most deprived communities whereas by 1999-2003 this had risen

to 48% of SIDS cases (Blair et al., 2006). Data from the CESDI SUDI study, from 1993-6, were that 25% of SIDS occurred in families of social class V or who were unemployed (Fleming et al., 2000). Given the association with social deprivation and the risk factors described above it is not surprising that child protection concerns occur frequently in SIDS cases; however these relate to neglect or poor parenting and are not necessarily a direct cause of death such as non-accidental head injury (Stanton, 2003). Estimates for non-accidental death presenting as SUDI range from 5-10% (Bajanowski et al., 2005, Levene and Bacon, 2004).

A previous unexplained infant death in the family increases the risk for subsequent infants (Bacon et al., 2008, Carpenter et al., 2005); this may reflect similar genetic inherent vulnerabilities, similar exposure to exogenous risk factors or child protection issues. An analysis of SUDI in families where an infant had already died of SIDS showed that 13% of the second deaths were due to unnatural causes but also that unnatural causes could not be excluded in a further 43% (Bacon et al., 2008).

### **Pathological Mechanisms for SIDS**

The current pathological understanding of SIDS is described by the Triple Risk Hypothesis (Filiano and Kinney, 1994); this proposes that SIDS occurs when an inherently vulnerable infant enters a critical period of homeostatic control and is then exposed to an exogenous stressor. All three factors need to be present for a death to occur; the inherent vulnerability may relate to genetic factors, or biological factors such as previous prematurity or defects in cardio-respiratory control as detailed later. The critical period is an important concept; the majority of SIDS type deaths occur under the age of four months, with only 6% occurring between the ages of one and two years (The Lullaby Trust, 2012), in 2010 there were 139 registrations of deaths due to SIDS in infants under one year and 8 registrations of children aged one to four years old (Office

for National Statistics, 2011) The median age of SIDS cases has fallen in recent years from thirteen weeks in the CESDI SUDI studies during 1993-6 (Fleming et al., 2000) to nine weeks in 2003-6 (Blair et al., 2009) The inherent vulnerability of potential SIDS victims therefore stops being an issue after the critical period as after the age of two years sudden unexplained death is extremely rare. The exogenous stressors are the risk factors for SIDS, such as prone sleeping, over-heating or minor infections.

One physiological explanation for SIDS is that it can be viewed as a failure of the respiratory regulatory pathways especially the control of auto-resuscitation. This is explained in some detail in Garcia et al. (2013) and is outlined here. SIDS infants typically do not have difficulties with respiratory control noted during their life. This is because there are many neural networks based within the ventral respiratory column in the brainstem which are responsible for respiratory control during breathing in normal conditions. Any inherent error or loss of one of these networks is unlikely to result in changes to respiratory patterns due to compensation by other networks. During hypoxia, unlike in normal breathing, only one neural network remains active, probably in order to conserve energy. This network, in the pre-Botzinger complex, is responsible for auto-resuscitation and is thus very vulnerable to any failures in its pathway. The auto-resuscitation network is highly dependent on serotonin and abnormalities of serotonin have been associated with SIDS in many studies. In addition many other genetic polymorphisms affecting the pre-Botzinger complex have been found in SIDS victims including tumour necrosis factor alpha, aquaporin 4 and interleukins.

If an infant lies face down in the mattress during sleep, as may occur when an infant is placed prone, there is a limitation to air flow or possible airway obstruction and the infant becomes progressively more hypercapnic and hypoxic. This should result in activation of the auto-resuscitation neural networks in the pre-Botzinger complex and

the infant should arouse and turn their head to the side to alleviate the air flow limitation or airway obstruction. The hypercarbia and hypoxia are corrected by a series of sighs and gasps leading to the restoration of normal breathing. In SIDS infants, there is a failure of this auto-resuscitation mechanism and the infant will become progressively more hypercapnic and hypoxic resulting eventually in bradycardia and death (Garcia et al., 2013).

There are other suggested pathological mechanisms for SIDS including altered immune responses or infection; these could be a trigger for the failure of respiratory control pathway previously described, or work independently of it. SIDS victims have been shown to have higher levels of interleukin 6 (IL 6) in the cerebro-spinal fluid than infants dying suddenly from trauma; IL 6 can cause respiratory depression (Vege et al., 1995). Similarly, specific interleukin genotypes for IL8 are associated with SIDS compared to infant deaths from infection (Ferrante et al., 2010); both these findings suggest that overstimulation of the immune system possibly in response to a minor infection may lead to SIDS.

Infection may have a directly causal role for some SIDS cases; this is separate to detectable clinical infection such as pneumonia or septicaemia as these would be explained causes of deaths so therefore not SIDS. Toxigenic bacteria, such as staphylococcus aureus, that frequently colonise the body with no ill effect, may release toxins which diffuse across mucus membranes into the blood. These toxins can rapidly cause circulatory collapse, leading to death and this has been shown in animal studies (Blackwell and Weir, 1999). Toxigenic bacteria are found more commonly in the nasopharynx of SIDS victims than control infants, bacterial concentrations are increased in infants who sleep prone and in those exposed to cigarette smoke, nasal temperature is

higher in infants sleeping prone and this facilitates toxin production and release (Morris, 1999).

### **Deaths due to accidental asphyxia**

Some SUDI cases are due to accidental asphyxia as opposed to a failure of auto-resuscitation as in SIDS. In an accidental asphyxia death any infant exposed to that particular set of circumstances is highly likely to die, unlike in SIDS where it is the combination of a vulnerable infant and exogenous stressor. Asphyxial deaths may occur in co-sleeping situations for example where a parent accidentally overlays an infant in bed or where an infant becomes trapped between the parent and the back of a sofa. It is very difficult to determine an asphyxial death; in the majority of cases with a clear history such as those detailed above, the post-mortem examination is entirely normal. There are no histopathological findings considered to be diagnostic of asphyxia (Mitchell et al., 2002); pulmonary haemorrhage can occur in asphyxial deaths but may also occur as a terminal event in SIDS particularly in younger infants (Becroft et al., 2001). In many unsafe sleep environments therefore it is impossible to be certain whether an infant accidentally asphyxiated or died of SIDS. The diagnosis of SIDS can still be used if there is a possibility of accidental suffocation; this is specifically included in the San Diego definition of SIDS for category II SIDS deaths (Krous et al., 2004). However, current practice in the UK is that pathologists rarely use the diagnostic term of SIDS for deaths where there is any possibility of accidental asphyxia, preferring to label these deaths as unascertained (Gould et al., 2010). Data on UK death registrations reveal that during 2002-10, approximately 1/3 of unexplained SUDI are certified as unascertained and 2/3 as SIDS but very few cases are recorded as accidental suffocation or strangulation (Office for National Statistics, 2012). In the USA, a much greater proportion of SUDI are classified as accidental suffocation (Kim et al., 2012).

## **Section 1.3 The Joint Agency Approach (JAA) to investigating unexpected infant deaths**

### **The Kennedy Report**

*“It is every family’s right to have their baby’s death investigated thoroughly”* Baroness Helena Kennedy QC

In the early 2000s, two mothers, Sally Clark and Angela Cannings, who had been convicted of murdering their infants were subsequently released on appeal. Sally Clark’s conviction was considered unsafe due to the failure of the pathologist conducting the post-mortem examination to disclose microbiology results; these results may or may not have been relevant to the death (R v Clark, 2003). Angela Cannings’ conviction was unsafe due to a genuine disagreement between expert witnesses, therefore guilt could not be proved beyond all reasonable doubt (R v Cannings, 2004). The incidence of SIDS had fallen dramatically in the 1990s following the recognition of the risks of prone sleeping and the ‘Reduce the Risks’ public health campaign; as a result SUDI was much rarer and child protection issues occurred in a greater proportion of cases (Blair et al., 2006). Paediatricians had begun to feel ill-equipped to manage SUDI cases and there were concerns about the overall low standards of investigation that had led to the acquittals. As a result a Working Group was established, chaired by Baroness Helena Kennedy QC, to determine new standards for investigating unexpected infant deaths; this Working Group consisted of paediatricians, pathologists, coroners, police officers and parent support groups. The Kennedy Report detailed a joint agency protocol for the management of SUDI (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004). This protocol was based upon evidence from the CESDI SUDI study (Fleming et al., 2000) and the investigative practices for SUDI that had

been used in Avon for many years. However the recommendation for a history to be taken from the parents jointly by police and a paediatrician and a joint visit to the death scene were not based on published research but on expert opinion.

### **The Joint Agency Approach**

In 2008 joint agency investigation of all unexpected child deaths following the Kennedy protocol became a legal requirement in England and Wales. Each local authority area was required to establish a Joint Agency Approach (JAA) protocol for responding rapidly to unexpected child deaths as well as a Child Death Overview Panel (CDOP) to review all child deaths in the locality. The Local Safeguarding Children Board (LSCB) is responsible for ensuring that these procedures take place. The Designated Paediatrician for Unexpected Deaths in Childhood is required to ensure that relevant professionals are notified of unexpected child deaths, to co-ordinate the JAA investigation and convene multi-agency discussions. (HM Government, 2013). (The term Designated Paediatrician for Unexpected Deaths in Childhood is used in Working Together and the West Midlands, but other terms may be used elsewhere in England).

The aim of the JAA is to establish the complete cause of death, including any relevant risk factors and address the needs of the family; this includes the need for safeguarding procedures. The JAA tries to balance the conflicting need for forensic and medical investigation of deaths as well as supporting families (HM Government, 2013).

In Working Together (HM Government, 2013) the JAA is referred to as 'the rapid response' and this is the term used by many SUDI professionals. I have chosen not to use this term as it is the joint nature of the investigation that distinguishes the JAA from other investigative approaches and whilst the investigation is a thorough process it is rarely rapid.

### ***The JAA process***

The JAA is best understood in terms of the events taking place after an infant is found to have died unexpectedly at home, this description is based on practices in the West Midlands which mirror those recommended in the Kennedy Report and Working Together to Safeguard Children. This approach is outlined in the West Midlands Protocol (West Midlands Police, 2009); the specifics of implementation may vary from place to place, both within and beyond the West Midlands. Typically when a parent telephones 999, an ambulance is dispatched and the infant along with their family should be taken to the nearest emergency department with paediatric facilities. Rarely, there may be clearly suspicious circumstances suggesting that the death was unnatural; in this event the infant may be left at the scene of death pending forensic investigation. If the infant has clearly been dead for some hours transport to the ED may be by funeral director instead of by ambulance.

The police are notified of the death either by ambulance control or by the hospital and attend immediately. At the ED, once any resuscitation has stopped, parents should be encouraged to hold and spend time with their child under the supervision of hospital or police staff.

A consultant paediatrician is expected to attend the ED and take a detailed medical history from the parents and examine the infant's body; these activities are done jointly with a police officer from the Child Abuse Investigation Unit (CAIU). These police are specialist officers who are used to working with families and children and should have further training in managing SUDI; they also investigate cases of child abuse hence the name. Their involvement is a matter of routine and does not imply that there is anything suspicious about the death. The consultant paediatrician may be the acute general paediatrician who is on-call or a community paediatrician who attends the hospital



specifically to manage unexpected deaths; the tasks may be shared by hospital and community paediatricians. In some locations a specialist nurse may fulfil some or all of these roles. The term 'SUDI paediatrician' is used for the paediatrician or specialist nurse managing the death regardless of their background.

There needs to be an examination of the environment where the death occurred, by the CAIU police and SUDI paediatrician; this is done as a joint home visit (JHV) with the parents showing the exact sleeping arrangements. These include detailing the position the baby was put to bed in and found in; the type of bedding and clothing and how the bedding was found in relation to the baby. The position of any co-sleeping adults or other children is also recorded. Some police forces use Scenes of Crime Officers (SOCO) to take video recordings or photographs of the death scene. In the UK, dolls are typically not used to reconstruct sleep scenes although this is common practice in other countries. The JHV is also a chance for any further history to be clarified, particularly if there has been a handover of the case between paediatricians, and for the home circumstances to be assessed. Ideally, the JHV is done as soon as the parents leave the hospital but this may not be possible if the SUDI paediatrician has other clinical commitments. If there is any delay the CAIU police need to ensure that the parents can access their home or collect any possessions they need in the interim. The JHV should be completed within 48 hours of the death.

The infant will require a post-mortem examination; this is usually done by a paediatric pathologist following the detailed protocol in the Kennedy Report. The pathologist will be sent copies of the SUDI paediatrician's history and examination as well as the report from the JHV. If there are any criminal concerns the post-mortem will be conducted jointly by a forensic and paediatric pathologist.

There is an initial multi-agency discussion about the case; for uncomplicated deaths this may be done by telephone alone but more often it is a formal meeting. The meeting is usually chaired by the SUDI paediatrician and attended by CAIU police, a social worker, the family's General Practitioner (GP) and the health visitor (HV). All relevant background information on the family is shared and plans are made about which further actions are needed and who should do these; this includes identifying who is best placed to support the family. If significant safeguarding concerns arise at this stage the meeting may become a formal child safeguarding Section 47 Strategy Meeting; chaired by social care as described in chapter one of Working Together (HM Government, 2013).

Once all investigations are complete the final case discussion is held; this is usually at least 4 months after the death due to the time required for histological examination of post-mortem specimens. The case discussion often takes place at the GP surgery but may be held elsewhere, and is chaired by the SUDI paediatrician. It should be attended by the same key personnel as at the initial case discussion. Ideally, the pathologist should be present but if this is not possible the SUDI paediatrician should clarify any issues regarding the post-mortem examination report with the pathologist before the review meeting. The case discussion should determine as far as possible the cause of death; considering whether the investigations have determined a cause of death or the death remains unexplained. All potential risk factors should be discussed including any child safeguarding concerns. A follow-up plan for the family is made, usually the SUDI paediatrician visits the parents at home to discuss the cause of death and any other matters arising from the case discussion but for some families the GP or another paediatrician may do this instead. A written summary of the meeting is sent to the parents and a copy should be given to the parents' GP to ensure that there is a permanent notification of the infant's death in the parents' health records.

The process of the JAA is summarised in figure 1 and the key personnel in table 1.

Figure 1 Flow chart of JAA process

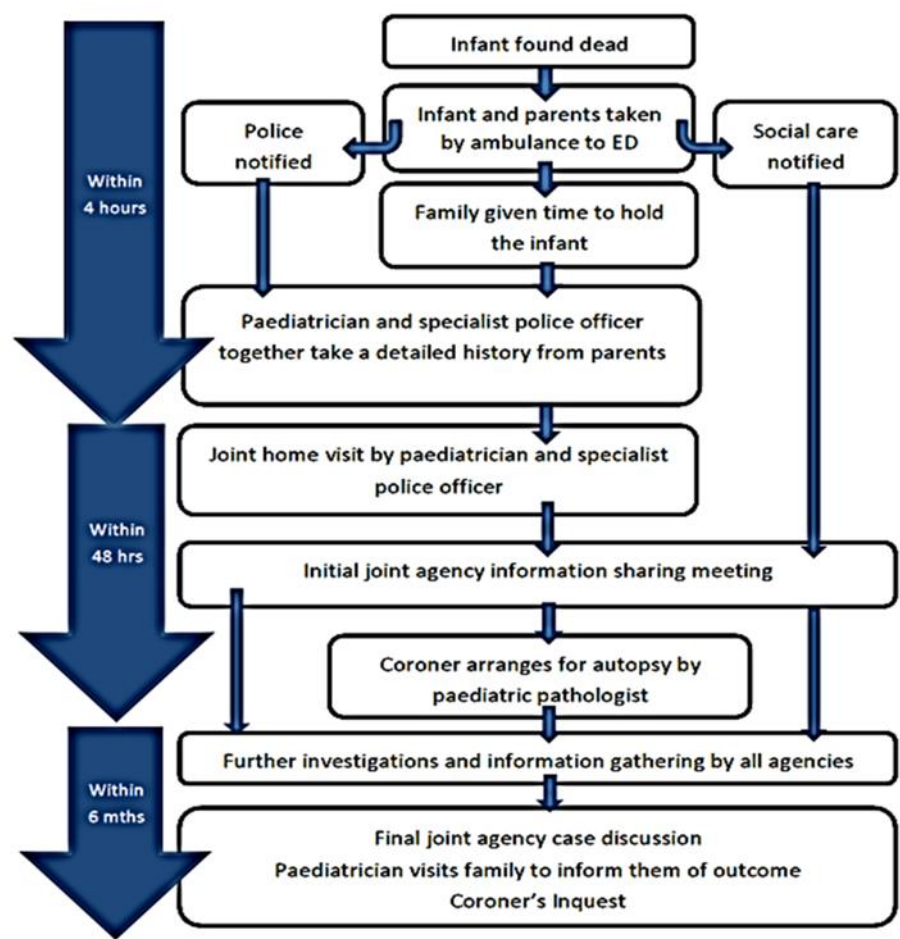


Table 1 Professionals involved in the JAA

Professional	Agency	Role
<b>Designated Doctor for Unexpected Deaths in Childhood</b>	Health	Consultant paediatrician with responsibility to co-ordinate the multi-agency team of professionals required to investigate unexpected child deaths. May carry out the role of SUDI paediatrician for some cases.
<b>SUDI paediatrician</b>	Health	Consultant paediatrician who attends ED in the event of a SUDI, takes a complete history with the police from the parents, visits the home to see the scene of death with the police, and chairs the initial and final case discussion. This role may be taken by a hospital paediatrician or community paediatrician or shared.
<b>SUDI specialist nurse</b>	Health	To support the Designated Doctor or SUDI paediatrician; in some locations may carry out the role of SUDI paediatrician
<b>Senior Investigating Officer</b>	Police	Officer of at least Detective Inspector rank from specialist Child Abuse Investigation Unit takes a complete history with the SUDI paediatrician from the parents, visits the home to see the scene of death with the SUDI paediatrician, attends initial and final case discussions.
<b>Social Worker</b>	Social Care	Attend initial and final case discussions; address any child protection concerns
<b>Child Death Co-ordinator</b>	Variable	Organise case discussions; minute meetings, collect autopsy reports and other relevant information.

If at any point in the JAA there are suspicions that the death may not be due to natural causes the police take the lead in the investigation and the JAA may stop; this is to ensure that any enquires do not prejudice any potential criminal proceedings.

### ***The Coroner***

The JAA is a separate process from coroners' enquiries; the coroner is required to investigate any unexpected death. The hospital and police notify the coroner of any unexpected infant death and the coroner will request the post-mortem examination.

The police investigation is on the behalf of the coroner unless it becomes clear that a crime is being investigated. It is expected that the coroner and JAA professionals share information with each other to assist in the investigation into unexpected child deaths (HM Government, 2013) and in some areas coroner's officers attend final case

discussions. Some coroners require police to take formal statements from parents for all

SUDI cases even if there are no suspicious features while others are content with the reports from the SUDI paediatrician and CAIU police officers. At the time of the study all SUDI cases had inquests although with the implementation of more recent coroners' rules this is no longer necessary (HM Government, 2009).

### ***The Child Death Overview Panel***

Child Death Overview Panels (CDOP) were established in 2008 along with the introduction of the JAA, CDOPs review all child deaths from birth to a child's eighteenth birthday regardless of whether the death was unexpected or not. CDOPs consist of a multi-agency group of professionals who review all child deaths in their local area to learn lessons about child deaths with the aim of being able to prevent similar deaths in the future, this is achieved by categorising deaths and identifying relevant modifiable factors. The CDOP process does not seek to establish the cause of death, this is the role of the coroner assisted by information from the JAA. CDOP is a statutory process overseen by the LSCB; cases are reviewed in an anonymised form, usually several months after the death. CDOP review all child deaths in a locality, SUDI cases only account for a small proportion of their caseload.

CDOP is therefore a relatively new process in England although child death review has been practised for many years in New Zealand, Australia and the USA (Fraser et al., 2014). A confidential enquiry into child deaths, in 2006, prior to the introduction of the CDOP process showed that the majority of child deaths were preventable or potentially preventable, this was also true for half of death that were not unexpected. Lack of recognition of serious illness, failure to follow-up patients and poor coordination of care were common short-comings (Pearson, 2008).

## The West Midlands JAA

The research study took place in the greater West Midlands region; covering the counties of Herefordshire, Shropshire, Staffordshire, Warwickshire, West Midlands, Worcestershire. These are shown in figures 2 and 3.

**Figure 2 Map of West Midlands region**



**Figure 3 Map of counties of West Midlands region**



The West Midlands has a population of 5.6 million people, and covers 13,000 square km. There are some densely populated cities with areas of marked social deprivation as well as rural areas. It has 11 local authorities, 14 hospitals with one specialist children's hospital, seven coroners, three police forces, and ten Child Death Overview Panels. The

infant mortality rate is 5.3 per 1000 live births which is the highest in England (Office for National Statistics, 2014a).

The West Midlands has one JAA SUDI protocol (West Midlands Police, 2009) although its implementation varies in each location. The role of the SUDI paediatrician may be carried out entirely by acute hospital paediatricians, by community paediatricians, or the tasks may be shared between them. Not all areas had specialist nurses; their role varies from working alongside SUDI paediatricians to performing all the roles of the SUDI paediatrician.

All the police forces have specialist CAIU teams; although these worked mainly in office hours there were always senior officers on-call and available for unexpected child deaths out of hours.

### **Evidence for the use of the Joint Agency Approach**

As discussed previously, the JAA is based on the Kennedy report which was a consensus of expert opinions, representing the many professionals involved in SUDI as well as bereaved parents. There has been little research evaluating the use of the JAA in terms of its effectiveness in determining cause of death, risk factors or supporting parents. A case-control study of SIDS in the south-west of England used a JAA to investigate SUDI; this showed good compliance with procedures. However there was a dedicated research team to investigate cases and support local health care professionals (Sidebotham et al., 2010). Of the 157 SUDI cases in the study, 67 (43%) had a causal explanation found and 90 (57%) remained unexplained and were classified as SIDS (Blair et al., 2009). In comparison, the CESDI study, ten years earlier had diagnostic rates of 20% (Fleming et al., 2000) relying on post-mortem examination, death scene analysis by non-specialist police and variable amounts of clinical history. Some of the variation in

diagnostic rates relates to changes in post-mortem examinations and ancillary investigations rather than the overall investigative process. An audit of the JAA in Birmingham, West Midlands, showed good compliance with procedures; in this situation however the JAA was performed by local NHS clinicians rather than an expert team (Garstang et al., 2013). There is no published evidence of parental experiences of the JAA.

This chapter has explained the process of the JAA investigations following SUDI and outlined the key events and actions that professionals need to undertake. The next chapter considers the viewpoint of bereaved parents and what they actually want from professionals after the sudden death of a child.



## **Chapter two Literature Review – what do bereaved parents want from professionals after the sudden death of their child?**

### **Section 2.1 Introduction**

The previous chapter outlined current understanding of SIDS and SUDI as well as detailing the JAA. In this chapter the experiences of bereaved parents following sudden child death are examined in order to inform the understanding of how parents may perceive the JAA, this being a much more comprehensive thus possibly intrusive investigation than traditional investigative approaches. This literature review has already been published in BMC paediatrics, the published version is shown at appendix 1.

The focus of this literature review is the effects on bereaved parents of interactions with professionals after the death of their child; in other words, how what we say or do, as professionals, affects the bereaved parents. This subject was chosen as it fits well with the aims of the research project - improving the well-being of bereaved parents by learning of their experiences of the joint agency approach to investigating infant deaths.

### **Literature review research question**

The original research question was: 'What are the effects on bereaved parents of interactions with professionals following the death of their child?' For the review an investigation can be a clinical investigation such as autopsy, a clinical consultation with parents about the death (but not purely bereavement counselling), police or social service investigations regarding the death.

As I began to study the literature it was clear that parents were speaking out about what they wanted from professionals after their children's deaths. The original research question puts the parents in a passive position that is not justified by the literature and

risks losing the bereaved parents voices. Following further refinements of the research question I reformatted it as: 'What do bereaved parents want from professionals after the unexpected death of their children?'

### **Methodology**

The literature review is a mixed studies review, including both qualitative and quantitative data, reflecting the mixed-methods nature of the research project and to ensure valuable research evidence is not missed.

The qualitative and quantitative data were initially analysed separately using a thematic analysis as described by Braun and Clarke (2006). The results were then combined using a narrative synthesis process (Mays et al., 2005). In this process, the qualitative and quantitative data are initially analysed separately, then looked at as a whole to see if the results complement each other and can be assimilated; or if they oppose each other at how this may be explained. I am aiming for a rich description of the whole data set rather than detailed nuances of individual themes as I am not attempting to re-analyse the primary data.

I will not attempt a meta-analysis of the quantitative studies as they are nearly all measuring different elements of the parental experience so it would not be useful.

## **Section 2.2 Methods**

### **Search Strategy**

A PICO format has been used:

Population – parents bereaved following the death of a child aged 0-18 yrs.

Intervention – medical follow-up, autopsy, police or social service investigation.

Comparator – no specific control or comparator groups were specified, any appropriate control group would be considered in included in studies.

Outcome – parents’ experiences, mental health or wellbeing.

### **Databases**

The following databases were searched: Assia (IBSS, CSA sociological abstracts, CSA social services abstracts, psychinfo, psycharticles), Ovid and CINHAHL. Web of Science was not formally searched as initial searches showed only very few references, none of which had not been found already. Google Scholar was also used as a backup, but limited to the first ten screens of results only.

All initial searches were carried out in November and December 2010, with the exception of Google scholar which was searched in May 2011. Searches were updated in May 2014.

Snowball searching of all included articles was carried out with another six articles found for inclusion.

The search terms used are shown in Table 2

Table 2 Search terms used for literature searches

Database	Search terms
<b>Assia</b>	1 Child* and death or autopsy and parent* or bereavement
	2 Child* and death and police or social work
	3 Child* and murder and parent*
	4 Child* and death or autopsy and parent* or bereavement and social worker or police or physician
<b>Ovid</b>	1 Grief or self-help group or prof- family relations or bereaved parent as keyword (k.w)And SIDS or child mortality or infant mortality or cause of death
	2 Death (expl- explode) – limit to <18yrs And Bereavement expl/grief expl/parent# bereavement (k.w) And Autopsy expl
	3 Death expl – limit to <18yrs And Bereavement expl/grief expl/parent# bereavement (k.w)/parent# expl And Forensic pathology expl/ forensic science expl/ forensic# (k.w)/forensic medicine expl
	4 1. Death expl – limit to <18yrs And Bereavement expl/grief expl/parent# bereavement (k.w)/ parent#expl And P?ediatrician (k.w) or physicians role expl or physician practice pattern exp or attitude of health personnel expl or physician expl or health visitor (k.w.) or community health nursing expl
	5 Death expl – limit to <18yrs And Bereavement expl/grief expl/parent# bereavement (k.w) And Social worker (kw) or social work expl or police expl or police (kw)
	6 Death expl – limit to <18yrs And coroner expl or medical examiner expl or coroner k.w.
<b>Cinhahl</b>	Search using 'child death' as word in abstract
<b>Google Scholar</b>	1 'bereaved parent doctor'
	2 'bereaved parent social work'
	3 'bereaved parent police'

## **Grey Literature**

I have attempted to access as much unpublished material, as possible, that is relevant to the literature review. This has involved contacting many of the research bodies for infant death and bereaved families. The Lullaby Trust has an archive of unpublished research; unfortunately this was not accessible. (The archive was recently moved to the Wellcome Library but has not yet been catalogued). I approached The Child Bereavement Trust, Sids and Kids (Australia) and the International Society for the Study and Prevention of Infant Death (ISPID) about unpublished studies but none had details of any. I also checked the websites of the following bereavement associations and professional bodies: British Association for the Study and Prevention of Child Abuse and Neglect (BASCPAN), Stillbirth and Neonatal Death Society (SANDS), Bereavement Care UK (Cruse) and Compassionate Friends UK. There were no relevant reports on any of these websites. I did not contact these latter organisations directly as my contacts to date with the other organisations were entirely unproductive.

I have also contacted colleagues from the police, who were members of the Association of Chief Police Officers, and social care for suggestions of how to access unpublished material as well as for unpublished research. I have been given an unpublished research report (Serry and Bathgate, 2011) by a colleague at an ISPID conferences for inclusion in the review.

## **Inclusion and Exclusion Criteria**

The literature review concerns the parents' perspective so only data on parents' experiences were included; data of professionals describing their actions towards parents were excluded. Papers had to be original research (either qualitative or quantitative) or a systematic review of research. Case reports were excluded as these are likely to be unrepresentative of wider parental experiences. Similarly the Redfern

Report (2001) into the organ retention scandal at Alder Hey Children's Hospital was excluded; whilst this contained much data on parents' experiences these were considered to not be representative of normal medical practice.

Papers had to include data on post-death interactions with professionals although this did not have to be the main focus providing there were some data concerning post-death events. Studies where the only interaction was bereavement counselling were excluded because this is the role of a trained counsellor or therapist and not of the professionals such as paediatricians, police officers or social workers following the JAA.

In order to maximise data on parental experiences papers were included as long as there were some data on children aged from birth to 18 years at death. A few papers therefore include data on adult deaths, with the experiences of parents of adult children or other relatives detailed. It is not possible to separate the adult and child data from these papers, all the data are included so that child data are not lost.

Studies purely focusing on pregnancy loss and stillbirth have been excluded. While there are similarities between parents' experiences of pregnancy loss, stillbirth and those with live born children who subsequently die, parents' experiences of pregnancy losses and stillbirth are likely to be different to those of later bereaved parents; as the mother is a patient herself and the loss is managed by maternity services rather than the emergency department. However, there are studies with data on infant deaths that include stillbirth and miscarriage; these studies have been included to ensure that no data are missed on post-natal infant death.

Only papers published since January 1990 have been included. This is to reflect the decline in sudden infant deaths after 1990 following the 'Back to Sleep' campaign, and also that, prior to the mid-1980s, the management of child deaths was very different to

current practice, and parental experiences may differ significantly. For example, although most children, on being discovered to have died at home, would have been taken to the Emergency Department rather than directly to the mortuary, the family would have had little contact with paediatricians as such deaths would have been managed by junior emergency doctors (Walker, 1985). Similarly papers containing data relating to deaths that occurred prior to 1980 have been excluded.

Initially papers on all child deaths, regardless of cause were included. However there were several papers purely focussing on deaths of terminally ill children. The circumstances of these children's deaths were quite different to the unexpected deaths so I decided to exclude studies where all the deaths were expected; the JAA should not be followed for expected deaths. A few studies detail experiences of both sudden and expected deaths, these have been included to ensure no data on sudden deaths are missed.

There were a few papers only studying parents' experiences after their child had been murdered. These papers were excluded as the parents' experiences, particularly with the police, were very different to those of other bereaved parents. In addition if the death is clearly a homicide from the outset, these deaths are investigated by police alone and not following the JAA. Where papers of sudden deaths in children include homicide deaths as well as other sudden deaths, these have been included.

Each culture deals with death differently, and the subjective experience of parents following child death relates to the parents' cultural background. To ensure similarity of experiences only studies from Europe, North America and Australasia are included; this also fits with my British cultural background and understanding.

The inclusion and exclusion criteria are summarised in Tables 3 and 4.

**Table 3 Inclusion criteria**

<b>Inclusion Criteria</b>	
<b>1.</b>	Paper must be original research or systematic review of research
<b>2.</b>	Paper must include data on parental experiences of interactions with professionals after child death.
<b>3.</b>	Paper must include data on children aged 0 -18 years at death.
<b>4.</b>	Paper published since January 1990
<b>5.</b>	Research carried out in Europe, North America or Australasia

**Table 4 Exclusion criteria**

<b>Exclusion Criteria</b>	
<b>1.</b>	Papers detailing bereavement counselling as the sole interaction
<b>2.</b>	Papers concerning stillbirth or pregnancy losses alone with no data on deaths of live born children
<b>3.</b>	Papers only containing data relating to children dying prior to 1980
<b>4.</b>	Papers only concerning deaths of terminally ill children
<b>5.</b>	Papers only concerning children dying due to homicide

### **Selection process of studies**

The titles, abstracts and full text articles were studied twice (one month apart) by me for thoroughness. A consecutive sample of 100 titles and abstracts each was reviewed by FG and PS for quality control.

There were some foreign language papers. The French papers were read by me, I was able to establish that they were not original research but editorial articles so they were excluded. A Spanish paper (Krauel Vidal et al., 1992) was read by a colleague, AS, who determined that it was relevant and a formal translation has been made. The Scandinavian articles were read by colleagues at an international conference and a formal translation has been obtained for one Danish paper (Teklay et al., 2005).



## **Critical Appraisal**

All included articles were critically appraised. Many papers had both qualitative and quantitative data in them; they were appraised according to the overall nature of the paper. For example; Covington (1993) is a qualitative analysis of a national survey, this was appraised as a qualitative paper although it also contains some descriptive statistics which are included in the quantitative results section. One quantitative study was a randomised controlled trial of a bereavement intervention (Dent 2000); this has been appraised as a cross-sectional survey as the data of interest are the survey responses of parents not the outcome of the trial.

Most of the quantitative papers were cross-sectional surveys and there are few critical appraisal tools available for these. Questionnaire-based surveys cannot prove cause and effect; this can only be done by experimental studies. Ethical constraints make trials of care for bereaved parents unfeasible, so retrospective surveys and qualitative research are the mainstays of evidence in this field.

The main difficulty with retrospective questionnaire-based surveys is recall bias, especially as the information is gathered from the participants only once, usually months or years after the event in question (Elwood, 2007pg 44-5). External validity is key in addressing the merits of a questionnaire-based survey. It is vital to ensure that the sample of bereaved parents surveyed represents the wider population of bereaved parents; if not the results are likely to be biased and cannot be generalised outside of the study (Elwood, 2007 pg 81) .

I selected the critical appraisal tool for cross-sectional surveys from 'Making sense of Critical Appraisal' by Olajide Ajetunmobi (2002 chapter 4), as it includes reference to development of the survey tools such as piloting and validation as well as sampling of

the population. The relevant critical appraisal questions are summarised in table 5 below.

**Table 5 Critical appraisal questions for surveys**

<b>1</b>	<b>Is there a clear statement of aims and clear description of the target population?</b>
<b>2</b>	Is the chosen type of survey appropriate?
<b>3</b>	How were the survey questions generated?
<b>4</b>	Were survey questions validated?
<b>5</b>	Was the survey instrument piloted?
<b>6</b>	Is the sampling frame justified?
<b>7</b>	Was the chosen sampling design justified?
<b>8</b>	What was the response rate?
<b>9</b>	Were efforts made to ensure a better response?

I used the Critical Appraisal Skills Programme checklist (CASP, 2010) to appraise the qualitative papers as this contains all the key elements yet is not too unwieldy. This appraisal tool focuses on the appropriateness of the selected research methods, how participants were recruited, the relationship between the researcher and participants and methods of analyses. Other appraisal tools such as Tong et al (2007) cover the same categories but in much greater detail; many papers are unable to publish at such length so this level of appraisal is not helpful. The relevant critical appraisal questions are summarised in table 6 below.

**Table 6 Critical appraisal questions for qualitative research**

<b>1</b>	<b>Was there a clear statement of the aims of the research?</b>
<b>2</b>	Was the research design appropriate to address the aims?
<b>3</b>	Was the recruitment strategy appropriate to the aims?
<b>4</b>	Were the data collected in a way that addressed the research issue?
<b>5</b>	Has the relationship between the researcher and the participants been adequately considered?
<b>6</b>	Have ethical issues been taken into consideration?
<b>7</b>	Was the data analysis sufficiently rigorous?

## **Data extraction, analysis and synthesis**

I extracted the data and coded data separately for quantitative and qualitative papers but used the same process. Firstly, I read the papers in their entirety then re-read them extracting relevant data. During extraction I developed and refined codes based on the data. All data was coded. Coded data was reviewed and codes from both qualitative and quantitative papers combined into themes.

However, the themes included data from studies that recruited bereaved parents whatever the cause of death and data from studies that recruited bereaved parents where the cause of death was of a distinct type such as neonatal death or SIDS. Many of the studies focused only on one aspect of the parent's experience of child death. It was important to ensure that the synthesis took account of this heterogeneity of studies.

I selected the data from two papers (Finlay and Dallimore, 1991, Dent et al., 1996) to create a reference framework against which data from the other studies could be compared. These data were chosen as together the papers from which they were extracted, reported studies that recruited parents experiencing all types of child death. Finlay and Dallimore included any child death from any cause; Dent et al only included sudden deaths in children aged between 1 week and 12 years. They also studied all aspects of the experience including experiences at the time of the death in the Emergency Department, contact with the police and follow-up with General Practitioners and paediatricians. The process of synthesis involved comparison within each theme of the data from all other papers with the reference framework.

For each theme the reference framework findings are presented first and then the synthesis of data from other studies.

## Section 2.3 Description of results

### Search Results

The numbers of references found on the databases are shown in table 7.

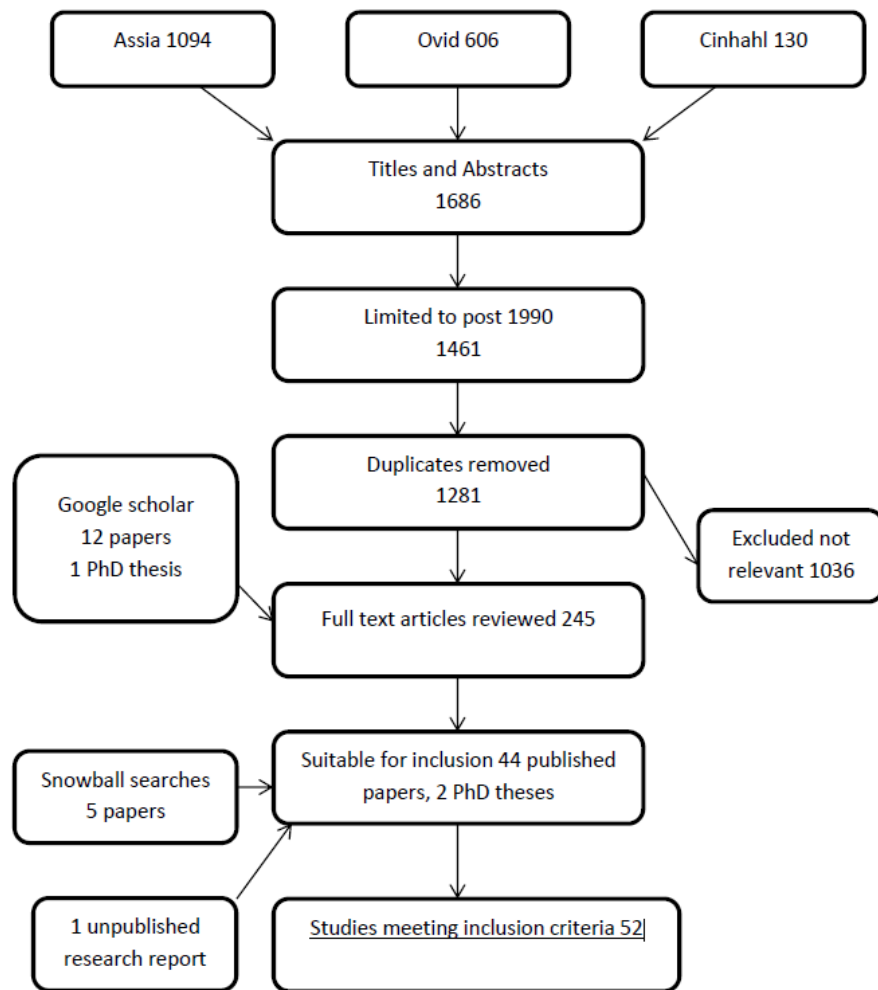
Table 7 Numerical results of literature searches

<i>Process</i>	<i>Number of references</i>	<i>Total</i>
Search of Assia	1094	
Search of Ovid	606	
Search of Cinahl	130	
		1686
Results Limited to 1990 and later		1461
Duplicates removed		1281

1281 titles and abstracts (where given) were reviewed for possible inclusion. In total 245 full text articles were read and eventually 46 selected for inclusion in the literature review.

The subsequent search of Google Scholar produced 12 new papers and 1 unpublished PhD thesis none of which were included. Snowball searching produced an additional 5 studies for inclusion and 1 unpublished research report was obtained giving a total of 52 studies. This process is illustrated in figure 4.

Figure 4 Flow chart for selection of studies



Of the 52 included studies, 25 were quantitative studies, 20 were qualitative studies and 7 had both types of data in the same study. More than 4000 bereaved parents participated in the original studies included in the review.

### Description of Quantitative Studies

19/25 quantitative studies were questionnaire surveys, 16 of these were sent by post, one distributed by a support group and two were telephone surveys. 5/25 quantitative studies were structured interviews and one was a case note review. Ten studies were from North America, five from the UK, two from Australia the remainder were all European.

Many of the studies had only minimal data relevant for the review; a simple count of included items from each study has been undertaken to allow for comparison. 14/25 studies had between one and four items for inclusion, 7/25 had between five and nine items and 4/25 had ten or more. The total relevance of papers varied, eight had all their results included, six had more than half included and 11 had less than half with six of these studies having only one or two facts of relevance. Sample sizes varied with the smallest number of participants was 22 and largest 892.

Details of each quantitative study included are given in table 8.

**Table 8 Details of quantitative studies**

<b>Authors and Year of Publication</b>	<b>Name of Study</b>	<b>Population and Country</b>	<b>Study Type</b>	<b>Number of relevant data items</b>	<b>Proportion of study results included</b>
<b>Ahrens et al. (1997)</b>	Pediatric death: managing the aftermath in the emergency department	SIDS parents N=37 USA	Postal questionnaire survey	>10	100%
<b>Dent et al. (1996)</b>	A study of bereavement care after a sudden and unexpected death.	Parents of children dying suddenly N=42 United Kingdom	Postal questionnaire survey	>10	50%
<b>DiMarco et al. (2001)</b>	Evaluating a support group for perinatal loss	Parents of infants dying perinatally N=121 USA	Postal questionnaire survey	1	Minimal data

<b>Finlay and Dallimore (1991)</b>	Your child is dead	Parents of children dying of any cause at any age N=120 United Kingdom	Postal questionnaire survey	>10	100%
<b>Harper and Wisian (1994)</b>	Care of bereaved parents. A study of patient satisfaction	Parents of infants dying perinatally and in infancy N=28 USA	Postal questionnaire survey or questionnaire distributed at support group	5	66%
<b>Hazzard et al. (1992)</b>	After a child's death: factors related to parental bereavement	Parents of children dying of any cause at any age N=45 USA	Structured interview	1	Minimal data
<b>Krauel Vidal et al. (1992) (translated from Spanish)</b>	Attitude towards parents after the death of their newborn infant in a neonatal unit	Parents of infants dying on neonatal units N=49 Spain	Postal questionnaire survey	5	100%
<b>Laakso and Paunonen-Ilmonen (2002)</b>	Mothers' experience of social support following the death of a child	Mothers of children dying under age 7 years. N= 91 Finland	Questionnaire and structured interview	3	50%
<b>Livesey (2005)</b>	A multiagency protocol for responding to sudden unexpected death in infancy: descriptive study	Parents of infants dying suddenly and unexpectedly N=29 United Kingdom	Postal questionnaire survey as part of audit of practice	1	Minimal data

<b>Macnab et al. (2003)</b>	Death and bereavement in a paediatric intensive care unit: Parental perceptions of staff support	Parents of children dying on intensive care unit N=24 Canada	Questionnaire and structured interview	7	100%
<b>McDonnell et al. (1999)</b>	A national model of care service for professionals dealing with sudden infant death	Parents of infants dying of SIDS N=131 Republic of Ireland	Structured interview	5	50%
<b>Meyer et al. (2002)</b>	Parental perspectives on end-of-life care in the pediatric intensive care unit	Parents of children dying on paediatric intensive care units N=56 USA	Postal questionnaire survey	6	33%
<b>Neidig and Dalgas-Pelish (1991)</b>	Parental grieving and perceptions regarding health care professionals' interventions	Parents of children dying of any cause at any age. N=22 USA	Postal questionnaire survey	3	25%
<b>Oliver et al. (2001)</b>	Beneficial effects of a hospital bereavement intervention program after traumatic childhood death	Parents of children dying from trauma N=54 USA	Structured interview	3	Minimal data
<b>Ostfeld et al. (1993)</b>	Maternal grief after sudden infant death syndrome	Parents of infants dying of SIDS N=38 USA	Postal questionnaire survey	3	Minimal data



<b>Powell (1991)</b>	Sudden infant death syndrome: a crisis for parents and health professionals	Parents of infants dying of SIDS N=40 Republic of Ireland	Structured interview	7	25%
<b>Rahman and Khong (1995)</b>	Perinatal and infant postmortem examination. Survey of women's reactions to perinatal necropsy.	Mothers of infants dying perinatally N=29 Australia	Telephone questionnaire survey	4	100% (published as letter only)
<b>Rankin et al. (2002)</b>	Cross sectional survey of parents' experience and views of the postmortem examination	Mothers of infants dying perinatally or in infancy N=148 United Kingdom	Postal questionnaire survey	4	100%
<b>Royal College of Pathologists and Royal College of Paediatrics and Child Health (2004)</b>	Sudden Unexpected Death in Infancy ; A multi-agency protocol for care and investigation	Parents of infants dying of SIDS N=892 United Kingdom	Postal questionnaire survey and comments made to support group by other parents	7	100%
<b>Sexton and Stephen (1991)</b>	Postpartum mothers' perceptions of nursing interventions for perinatal grief.	Mothers of infants dying perinatally N=30 USA	Telephone questionnaire survey	4	50%

<b>Spooren et al. (2000)</b>	Survey description of stress of parents bereaved from a child killed in a traffic accident. A retrospective study of a victim support group	Parents of children dying in road traffic accidents N=85 Belgium	Postal questionnaire survey	4	25%
<b>Sullivan and Monagle (2011)</b>	Bereaved parents' perceptions of the autopsy examination of their child	Parents of children undergoing autopsy N=53 Australia	Postal questionnaire survey	>10	50%
<b>Teklay et al. (2005)</b>	Contact with relatives after forensic autopsies	Relatives of patients having forensic autopsy N=360 Denmark	Case record review by pathology department	2	100%
<b>Thuen (1997)</b>	Social Support after the Loss of an Infant Child: A Long-Term Perspective.	Parents of infants dying of SIDS N=251 Norway	Postal questionnaire survey	2	Minimal data
<b>Vennemann et al. (2006)</b>	Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families.	Parents of infants dying of SIDS N=141 Germany	Postal questionnaire survey	4	100%

### Description of Qualitative Studies

17 / 20 qualitative studies involved in-depth interviews with bereaved parents, three studies analysed data from open-ended questions in surveys or structured interviews. Nine papers were from North America, five from the UK, two from Australia and the remainder were all European.

Many of the studies had only small amounts of relevant data; a simple count of included items from each study has been undertaken to allow for comparison. 10/20 studies had between one and four items for inclusion, 4/20 had between five and nine items and 6/20 had ten or more. The total relevance of papers varied, four had all their results included, two had more than half included, 14 had less than half included with nine of these having less than a quarter of the data included. The sample size ranged from 6 to 137.

Details of each qualitative study included are given in table 9.

Table 9 Details of qualitative studies

Authors and Year of Publication	Name of Study	Population and Country	Study Type	Number of relevant data items	Proportion of study results included
Ashby et al. (1991)	An enquiry into death and dying at the Adelaide Children's Hospital: a useful model?	Parents of children dying in hospital N=6 Australia	Interviews with staff and parents, written submissions	4	Minimal data
Bellali et al. (2007)	Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation.	Parents who were asked to donate their children's organs N=22 Greece	In-depth interviews with parents	4	Minimal data

<b>Bright et al. (2009)</b>	A broken heart-- the physician's role: bereaved parents' perceptions of interactions with physicians."	Bereaved parents, children dying of any age, including adulthood, of any cause N=137 USA	Postal survey with open-ended question	10	100%
<b>Kuhn (2008)</b>	The process of parental bereavement following the violent death of a child. PhD Thesis	Parents of children (including young adults) dying in violent deaths N=11 USA	In –depth interviews with parents	15	Not applicable PhD Thesis
<b>Lemmer (1991)</b>	Parental perceptions of caring following perinatal bereavement	Parents of infants dying in the neonatal period N=28 USA	In –depth interviews with parents	4	25%
<b>Macdonald et al. (2005)</b>	Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death	Parents of children dying on paediatric intensive care units (PICU) N=12 Canada	Field ethnography	5	50%
<b>McHaffie et al. (2001b)</b>	Follow up care of bereaved parents after treatment withdrawal from newborns	Parents of infants dying on neonatal intensive care (NICU) N=108 United Kingdom	In –depth interviews with parents	4	100%

<b>Meert et al. (2007)</b>	Parents' perspectives regarding a physician-parent conference after their child's death in the paediatric intensive care unit	Parents of children dying on paediatric intensive care units (PICU) N=56 USA	In –depth interviews with parents (2007)	11	100%
<b>Meert et al. (2008b)</b>	Parents' perspectives on physician-parent communication near the time of a child's death in the paediatric intensive care unit	Secondary analysis of data from Meert, Eggly et al. (2007)		3	Minimal Data
<b>Meert et al. (2009)</b>	Examining the needs of bereaved parents in the paediatric intensive care unit: a qualitative study.	Parents of children dying on paediatric intensive care units (PICU) N=46 USA	In –depth interviews and focus groups with parents	15	75%
<b>Meyer et al. (2006)</b>	Improving the quality of end-of-life care in the paediatric intensive care unit: parents' priorities and recommendations	Parents of children dying on paediatric intensive care units (PICU) N=56 USA	Open-ended postal questionnaire	6	Minimal Data
<b>Nordby and Nohr (2009)</b>	Interactive emergency communication involving persons in crisis	Parents of SIDS infants N=11 Norway	Semi-structured interviews with parents	3	Minimal Data

<b>Pector (2004)</b>	How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased, and attachment to survivors.	Parents of multiple birth infants who die neonatally N=70 USA	Narrative email survey	11	25%
<b>Reilly et al. (2008)</b>	'When your child dies you don't belong in that world anymore.' - Experiences of mothers whose child with an intellectual disability has died	Bereaved mothers of children who had an intellectual disability (ID) N=9 United Kingdom	In-depth interviews with parents	5	25%
<b>Schaap et al. (1997)</b>	Long-term impact of perinatal bereavement. Comparison of grief reactions after intrauterine versus neonatal death	Parents of infants dying perinatally N=38 The Netherlands	In-depth interviews with parents	3	Minimal Data
<b>Skene (1998)</b>	Individualised bereavement care	Parents of infants dying neonatally N=9 United Kingdom	Semi-structured interviews with bereaved mothers	2	Minimal Data
<b>Snowdon et al. (2004)</b>	Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents	Parents of infants dying on neonatal intensive care (NICU) N=18 United Kingdom	Semi-structured interviews with bereaved mothers	2	Minimal Data

<b>Swanson et al. (2002)</b>	Panel discussion. Grief and bereavement with the loss of a twin	Mothers of multiple birth children dying at any time (including adulthood) N=66 Australia	Semi-structured interviews with bereaved mothers	6	Minimal Data
<b>Todd (2007)</b>	Silenced grief: living with the death of a child with intellectual disabilities	Bereaved parents of children who had an intellectual disability (ID) N=13 United Kingdom	In-depth interviews with parents	1	Minimal Data
<b>Wisten and Zingmark (2007)</b>	Supportive needs of parents confronted with sudden cardiac death--a qualitative study	Parents of sudden cardiac death victims (including adults) N=28 Sweden	In-depth interviews with parents	21	100%

### Description of Studies containing both qualitative and quantitative data

4/7 mixed data studies were questionnaire studies, 2 were interview studies and one was a combination. Three studies were from the UK, two from the USA and the other two were European.

2/7 studies four or less items of relevance for inclusion, 3/7 had between five and nine items, 2/7 studies had more than ten. The total relevance of the papers varied, two had less than a quarter of their data included and the remainder had half or more.

Details of each study with both qualitative and quantitative data are given in table 10.

**Table 10 Details of studies with both qualitative and quantitative data**

<b>Authors and Year of Publication</b>	<b>Name of Study</b>	<b>Population and Country</b>	<b>Study Type</b>	<b>Number of relevant data items</b>	<b>Proportion of study results included</b>
<b>Calhoun (1994)</b>	Parents' perceptions of nursing support following neonatal loss	Parents of infants dying in neonatal units N=23 USA	Questionnaire distributed by support group	8	100%
<b>Covington and Theut (1993)</b>	Reactions to perinatal loss: a qualitative analysis of the National Maternal and Infant Health Survey	Mothers of infants dying perinatally N=413 USA	Postal questionnaire survey	11	75%
<b>Dent (2000)</b>	Support for families whose child dies suddenly from accident or illness. PhD Thesis	Parents of children dying suddenly N=72 United Kingdom	Postal questionnaire survey	4	Not applicable – PhD thesis
<b>Dyregrov (2002)</b>	Assistance from local authorities versus survivors' needs for support after suicide	Parents of children who committed suicide N= 128 Norway	Postal questionnaire survey with in-depth interviews for a sample of participants	7	50%



<b>McHaffie et al. (2001a)</b>	Consent to autopsy for neonates	Parents of infants dying on neonatal units N=108 United Kingdom	In-depth interviews with parents	8	75%
<b>Merlevede et al. (2004)</b>	Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death	Relatives of people dying suddenly N=74 Belgium	Structured interview and analysis of clinical records	3	25%
<b>Sterry and Bathgate (2011)</b>	Scottish Cot Death Trust Project Report	Parents of infants dying of SIDS N=109 United Kingdom	Internet or postal questionnaire survey	>10	75%

## Section 2.4 Results of Critical Appraisal Studies

23 papers were critically appraised as qualitative studies and 29 papers were critically appraised as quantitative studies. Potential recruitment bias was an issue as frequently studies recruited directly from bereavement support groups which parents had to actively choose to join; 12/29 quantitative studies and 6/20 qualitative studies used bereavement groups for recruitment. The quantitative studies had low recruitment rates; only 12/29 studies had more than 50% recruitment and in 7 studies the

recruitment rate could not be calculated as it was unclear how many eligible families had been contacted.

Many studies gave no socio-economic data on participants so it is difficult to judge whether the participants reflect the general population of bereaved families; only 12/23 qualitative and 16/29 quantitative studies gave socio-economic data on participants. Where the studies do give this data in the majority of cases participating parents are white, married, have completed some higher education and earn higher than average incomes. This may affect the generalizability of the results as most child deaths occur in socially deprived families.

There were issues with the method of data collection for some quantitative studies and data analysis for some qualitative studies which could affect the validity of these results. 28 /29 quantitative studies used bespoke questionnaires or structured interview schedules; details of how these were developed and piloted were only given in 9 cases. Even when validated tools had been used (for example Di Marco (2001)), the only element of the results that was relevant was the open ended, non-validated question at the end of survey. 5/23 qualitative studies gave little or no details of the method of qualitative analysis undertaken.

Some of the papers with the most relevant data for the review had more difficulties identified on critical appraisal, such as the parental survey by FSID (Royal College of Pathologists 2004) which used a non-validated questionnaire and additional comments made by bereaved parents to the organisation. Despite many studies having deficiencies highlighted by the critical appraisal process none have been excluded; this is to ensure no parental experiences are lost. Where necessary, individual study findings are discussed with reference to their critical appraisal results.

The results of quantitative studies' critical appraisal are shown in appendix 2 and qualitative studies in appendix 3.

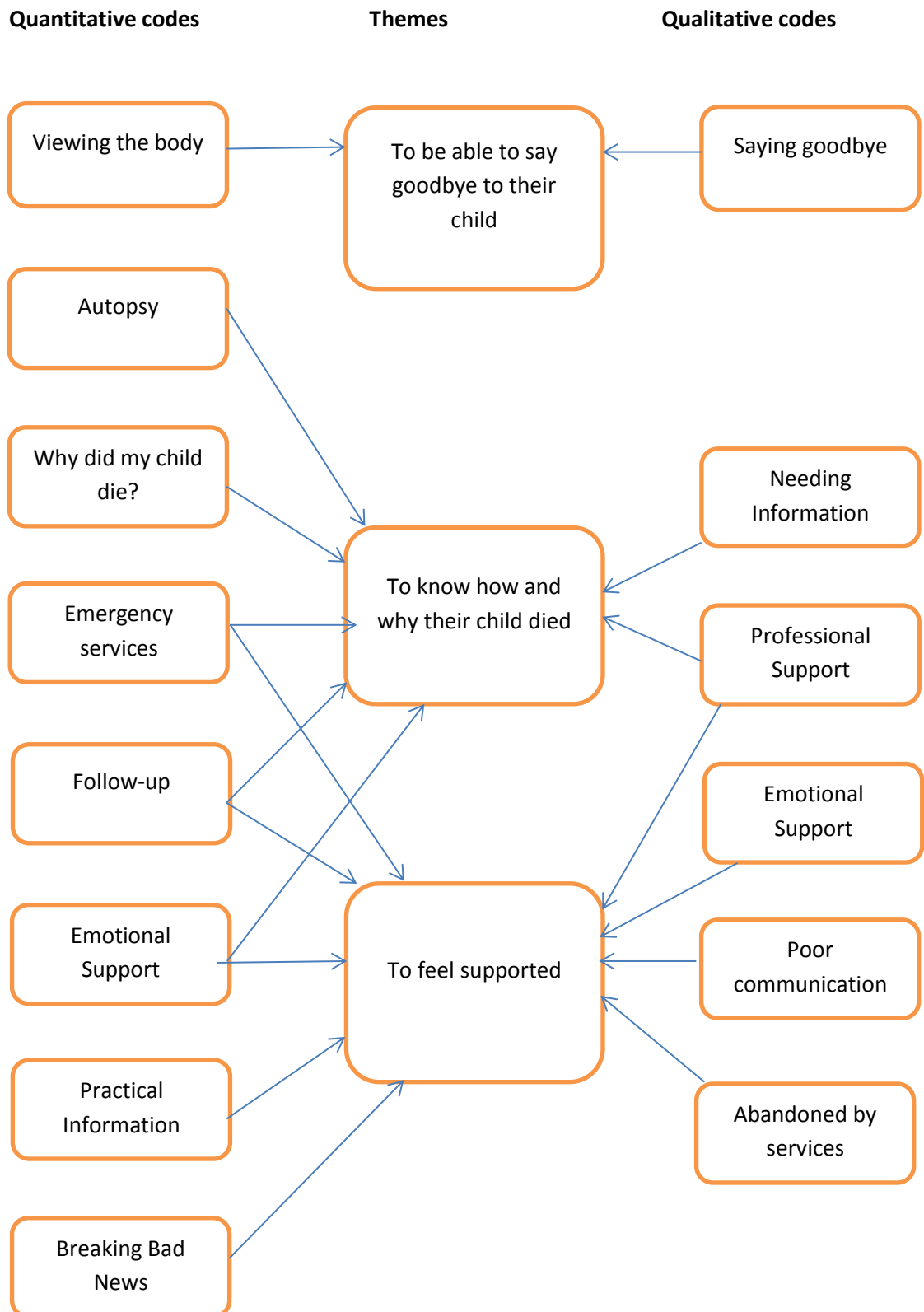
## **Section 2.5 Narrative Synthesis of Results**

### **Coding and Themes**

Three core themes emerged from the review on what bereaved parents want from professionals after the death of their child: to be able to say goodbye, to understand why and how their child died, and to feel supported by professionals.

The codes from the quantitative and qualitative data and the main themes that emerged from them are shown in figure 5.

Figure 5 Quantitative codes, qualitative codes and themes



## **Narrative Synthesis of Literature**

### ***Parents want to be able to say goodbye to their child.***

I just sat there, and that was good (Wisten and Zingmark, 2007)

In the reference framework parents wanted time to hold or be with their children after death to say goodbye, even if the body was mutilated; parents deeply regretted this if they were unable to do so (Finlay and Dallimore, 1991, Dent et al., 1996). These were consistent findings across many studies of all types of child death; with qualitative studies detailing parents' desire for privacy, a peaceful space and adequate time to be able to say farewell (Ashby et al., 1991, Lemmer, 1991, Reilly et al., 2008, Meyer et al., 2006, Wisten and Zingmark, 2007, Merlevede et al., 2004, Meert et al., 2009, Calhoun, 1994, Schaap et al., 1997). When the time comes for the child's body to be removed to the mortuary, parents want this done in a dignified manner, showing respect for the child (Ashby et al., 1991) and allowing parents to accompany them (Dent et al., 1996).

In interview studies, parents have described seeing or holding their infant or child's body as helpful and that not being able to do so increased their grief (Swanson et al., 2002, Bellali et al., 2007, Macnab et al., 2003, Wisten and Zingmark, 2007) In Bellali et al. (2007), after allowing their children's organs to be donated, parents were not able to see their children again and this greatly increased their distress in the months afterwards. In Merlevede et al. (2004), relatives who left the scene of the resuscitation, were described as feeling 'torn apart' by their decision as they could not be with their dying family member. Mothers of babies dying early in infancy have described not being allowed to hold them to say goodbye, have mementoes or any say in the funeral arrangements, and they felt this made it more difficult for them to resolve their grief (Swanson et al., 2002).

However survey findings of the benefit of seeing a child's body are less certain. In one study after perinatal death 30/30 mothers found seeing the baby helpful (Sexton and Stephen, 1991) whereas only 6/21 parents found this helpful in a study of a wider range of child deaths (Neidig and Dalgas-Pelish, 1991). Parents may choose not to see their child after death, but one-third of parents in a large qualitative study (n=38) expressed regret that they decided not to see their baby after a perinatal death (Schaap et al., 1997). However, even when warned of potential regret, a minority of neonatally bereaved parents still felt strongly that they did not want to see their baby (Skene, 1998). None of the survey studies specifically reported on parents' experiences of holding their child.

Qualitative studies have reported that parents may still wish to see their child after a traumatic death although others may prefer to remember them unhurt (Kuhn, 2008). When parents do not see their child they often imagine the injuries to be worse than they really are (Merlevede et al., 2004).

***Parents want to know how and why their child died.***

I still don't know what happened to my boys. No one would or could tell me what happened...(Covington and Theut, 1993)

Many different studies of all types of child death confirmed the parental need for information about their children's deaths identified in the reference framework (Bellali et al., 2007, Covington and Theut, 1993, McHaffie et al., 2001b, Pector, 2004, Merlevede et al., 2004, Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004, Sullivan and Monagle, 2011, Oliver et al., 2001, Dent et al., 1996, Finlay and Dallimore, 1991). Conversely, a case record review showed that only 28% of relatives sought results of forensic autopsy examination despite these not being

available from any other source; families may not though have been aware that they could seek these results (Teklay et al., 2005).

Both surveys and interview studies have reported that information after any type of child death may help parents make sense of the death and help with their grief (Kuhn, 2008, Wisten and Zingmark, 2007, Sterry and Bathgate, 2011, Spooren et al., 2000, Thuen, 1997, Covington and Theut, 1993). Interview studies reveal that information about the death reassures parents that children did not suffer and everything possible was done to save them. (McHaffie et al., 2001b, Merlevede et al., 2004, Wisten and Zingmark, 2007). Similarly, detailed information reassures parents that their actions were appropriate, helping to diminish some of their feelings of guilt (Meyer et al., 2006, Merlevede et al., 2004, Meert et al., 2007, Sterry and Bathgate, 2011). Conversely, other mothers have reported that detailed knowledge whilst helpful does not ameliorate all their anxiety (Covington and Theut, 1993).

In a study of parents bereaved following road traffic accidents (Spooren et al., 2000), parents completed the Inventory of Complicated Grief (ICG) (Prigerson et al 1997 in (Spooren et al., 2000)), which is a validated tool for assessing traumatic grief, as well as rating their satisfaction with services. 41/78 parents were dissatisfied with the information received and dissatisfaction was significantly associated with a higher score for traumatic grief ( $p=0.03$ ) measured by the ICG. However, dissatisfaction with the practical help provided by the emergency services at the time of death was more strongly associated with traumatic grief ( $p=0.008$ ).

Parents want to know the cause of death especially for sudden unexpected deaths; the lack of explanation for SIDS or sudden cardiac deaths may result in further parental distress (Dent et al., 1996, Wisten and Zingmark, 2007). Consistent with this a survey of 892 SIDS parents found that finding the cause for death was of the greatest importance

for parents (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) and a survey of 413 perinatally bereaved mothers showed that 21% were struggling to understand why their baby died with 51% wanting further information (Covington and Theut, 1993).

A consistent finding of studies of all types of child death is that parents have requested follow-up appointments with professionals to ask for further information as at the time of the death they were too distressed to comprehend detailed answers (Wisten and Zingmark, 2007, Merlevede et al., 2004, Covington and Theut, 1993, Bright et al., 2009, Meert et al., 2007). However, parents have commented in interview studies that returning to the hospital may cause distress from traumatic memories (Macdonald et al., 2005, McHaffie et al., 2001b), and that following a neonatal death there may be an additional burden of appointments in several different departments (McHaffie et al., 2001b). Families have suggested that written information should be available as memory difficulties are common in acute grief situations (Dyregrov, 2002).

Bereaved parents have described, in interviews, their increased distress with long waits for information about why or how their child died (Wisten and Zingmark, 2007, Kuhn, 2008) and how the lack of information has led them to assume that it is being deliberately withheld (Covington and Theut, 1993, Finlay and Dallimore, 1991) or that litigation may be their only option to obtain the answers (Finlay and Dallimore, 1991). Following violent deaths, parents spoke of their determination to obtain information from the authorities (Kuhn, 2008).

### ***Autopsy***

Autopsy is included in the theme of 'understanding why and how their child died' as it is a means by which the cause of death may be found and then shared with the parents. Autopsy is a legal requirement in many countries following unexpected death, although



parents may also consent to an autopsy for more information when it is not mandatory. Autopsy may reveal a complete cause of death, and be a source of good information, if well explained to the parents; but the death may remain unexplained after autopsy such as in SIDS cases. It is an invasive procedure that has a poor public image after scandals such as the organ retention issue at Alder Hey Hospital.

An interview study of neonatal deaths found that autopsy results may be a powerful tool in helping parents reach a sense of closure (McHaffie et al., 2001a); similar results were shown in a survey of SIDS parents where 66% (93/141) believed that mandatory autopsy had helped resolve their grief, even for the 17% (24/141) parents who had not wanted the autopsy initially (Vennemann et al., 2006). Conversely with autopsy of older children, a survey showed only 40% of parents found the results useful and 38% thought the results helped with their grief; however this survey had a low response rates so these results may not be generalizable (Sullivan and Monagle, 2011).

Interview studies and surveys have detailed parents' reasons for consenting to autopsies: to obtain further information about neonatal deaths and future pregnancies in particular was the reason given by 'the majority of parents' (McHaffie et al., 2001a) and by 50% of parents in another neonatal study (Rankin et al., 2002). Bereaved parents following all types of child death wanted information from their child's autopsy to help other families in the future (McHaffie et al., 2001a, Snowdon et al., 2004, Sullivan and Monagle, 2011). Around half of parents who declined neonatal autopsy in 2 studies did so because they had no unanswered questions and half because they do not want their baby's body traumatised further (McHaffie et al., 2001a, Rankin et al., 2002). Parents may find the discussions around consenting to autopsy useful. This was the case for 14/16 parents after a perinatal death (Rahman and Khong 1995) but only useful for 46% of parents of older children (Sullivan and Monagle 2011).

Surveys and interview studies have shown that a small minority of parents, after consenting to child autopsy subsequently regret it, this ranges from 6-8% (Sullivan and Monagle, 2011, Rankin et al., 2002, Rahman and Khong, 1995); but after refusing a neonatal autopsy some parents regret the loss of potential information, this ranges from 7% (Rankin et al., 2002) of those declining autopsy to 30% (Rahman and Khong, 1995). Thorough explanations of the autopsy process are needed, particularly if parents are going to view their children again afterwards, sanitising explanations prior to autopsy may result in more distress later (Snowdon et al., 2004).

In Dent et al, some parents struggled to understand the autopsy results despite explanations from professionals (Dent et al., 1996). Consistent with this finding other studies have shown parents not receiving autopsy results despite giving consent to the procedure; this happened in 4/13 intensive care deaths (Macnab et al., 2003). After sudden cardiac death some parents received autopsy results by post so lacked the opportunity to discuss the results with a clinician (Wisten and Zingmark, 2007) and a study of paediatric autopsy reported that only 42/52 parents had results explained to them (Sullivan and Monagle, 2011). Parents have reported not understanding explanations of results and thus feeling that their questions remained unanswered (Covington and Theut, 1993, Sterry and Bathgate, 2011); this was the case for 8/16 mothers following neonatal autopsy (Rahman and Khong, 1995) but in a much larger survey of neonatal autopsy 101/120 parents thought the results were explained appropriately and only 16/120 parents wanted further explanation (Rankin et al., 2002).

Discussing the autopsy result may be of benefit to parents: of 23 parents who still had unresolved anger or guilt nearly 3 years after a SIDS death, 17 of these had received no results from the autopsy (Powell, 1991). 46% of SIDS parents found seeing a pathologist helpful and reassured them that they were blameless for the death; of the 18% of

parents who found the pathologist unhelpful the reasons stated were not actually being able to meet the pathologist, lack of information given or feeling blamed (Serry and Bathgate, 2011).

***Parents want to feel supported by professionals***

*Supporting the parents*

I spoke with the coroner because she said if there was anything that I wanted to know that she would try and find out for me .... I wanted to know about my son's last seconds and what they did.... She went to the hospital and found out who was on duty that night and talked with them. .... She said he was alive when he got to the hospital and he had a strong heartbeat but he was brain dead and there was no way he could survive. Even though it was hard to hear these things, I really needed to know. She said there had been a nurse with my son and that she had recognised him.(Kuhn, 2008)

The quote above shows an example of good professional support for a bereaved mother: the emotional support of being available to listen to her concerns and the professional actions of finding out the information required by the parent and sharing it with her in a sensitive way such that it helped the mother in her grief.

Supporting parents involves professionals helping parents in their search to understand the death as well as giving emotional support. Often these roles are intertwined (as in the quote from Kuhn) and it is difficult to determine precisely what type of support is being given. Support at the time of death is largely emotional support but also includes providing information; later support includes both emotional support and professional actions such as maintaining contact.

### *Emotional Support*

I just remember the nurses all standing around the bed with tears in their eyes.

It was a tear that I knew that they were parents and they were coming to me as a parent (Kuhn, 2008)

Parents felt supported by professionals who showed they were upset when breaking bad news; conversely they were offended if professionals were cold and unemotional. Many parents felt uncared for by the hospital immediately after their child's death often being left to arrange their own way home (Finlay and Dallimore, 1991).

Consistent with the reference framework, other studies of all child deaths report that parents appreciate staff members showing emotion (Kuhn, 2008, Calhoun, 1994, Meert et al., 2008b, Meyer et al., 2006, Pector, 2004, Dent, 2000, DiMarco et al., 2001) and mothers interviewed after a neonatal death interpreted staff who lacked emotion as being uncaring (Lemmer, 1991). Similarly other surveys reported on a lack of care shown to parents; 20% (83/413) of perinatally bereaved parents commented on a lack of sensitivity and care by their caregivers (Covington and Theut, 1993) and 37/70 parents were dissatisfied with hospital staff after road traffic accident deaths (Spooren et al., 2000).

Other studies have given further details of parents' experiences of emotional support; doctors are valued as guiding parents through the crisis of their children's deaths (Bright et al., 2009, Meert et al., 2009), social workers and chaplains have been important to parents after intensive care deaths (Macnab et al., 2003), police officers have been supportive with sudden deaths but their presence can be upsetting for some due to the implication that a crime may have occurred (Sterry and Bathgate, 2011, Wisten and Zingmark, 2007). Parents may clearly remember interactions with professionals at the

time of their children's deaths; later these memories may bring comfort or distress for both hospital (Meert et al., 2009) and community deaths (Nordby and Nohr, 2009).

Nurses often provide more emotional support to families than other health care professionals; this is particularly so after perinatal loss but also after other child deaths. In Sexton and Stephen (1991) 26/30 perinatally bereaved mothers valued a nurse talking through their feelings with them; similarly in Calhoun (1994) 12/23 mothers said they had emotional support from nurses which was very helpful however 5/23 mothers commented on a lack of openness or honesty from the nurses. Following death on paediatric intensive care all 13 families in one study reported nurses as very supportive (Macnab et al., 2003). However, following perinatal deaths some nursing staff have avoided bereaved parents which has caused offence (Pector, 2004).

Most parents wanted mementoes of their child but these were offered to less than half of families following sudden child death (Dent et al., 1996). Photographs were valued by 28/29 mothers after perinatal loss and the baby's clothes by 26/27 (Sexton and Stephen, 1991). Similarly following SIDS, 34/37 parents wanted a memento but 15 of these parents would have preferred to receive this 2-3 weeks after the death rather than immediately (Ahrens et al., 1997). After paediatric intensive care deaths all 13 mothers in one study rated mementoes as very helpful (Macnab et al., 2003). Parents of older children usually want all their possessions back (Oliver et al., 2001) but the process of having to sign for their child's belongings may cause offence if not handled sensitively (Finlay and Dallimore, 1991).

### ***Emergency Services***

The police were respectful enough but having to deal with the questioning, taking pictures, raiding the bins ...and emptying you of all your Child's possessions just hours after her death was awful...(Sterry and Bathgate, 2011)

In the reference framework there were mixed findings with some but not all parents praising the police for their support (Finlay and Dallimore, 1991). In Dent et al., most parents were happy with the emergency services although 28% of parents thought the police unsympathetic and one-third of parents were not allowed to accompany their child in the ambulance.

Only four studies, all of SIDS, detailed parents' views of the police; these were similarly mixed. In one study 48% of 109 parents thought the police were kind and helpful, but 30% felt they were unhelpful and treated parents as guilty and assumed that a crime had been committed (Sterry and Bathgate, 2011); another study commented on disproportionate police involvement (Livesey, 2005). Conversely, in Ireland, satisfaction with police services following SIDS was high with 86/100 parents finding police helpful (McDonnell et al., 1999) and 75% of 69 parents stating that police carried out the process of identification sensitively (Powell, 1991). These results are surprising given that there is a similar level of involvement by UK and Irish police in SIDS cases.

Only two other studies reported parents' views on ambulance services. 50% of 109 SIDS parents thought ambulance staff were helpful but 21% criticised ambulance staff for seeming to panic and being ill-equipped to deal with infants (Sterry and Bathgate, 2011). 41/80 parents were dissatisfied with ambulance services following road traffic accident deaths and this was associated with increased traumatic grief reactions using the Inventory of Complicated Grief (Spooren et al., 2000).

### **Professional Support**

I have been very lucky this time. My health visitor has been a gift from the gods. She has made herself available at any time. Previously I had a stillbirth and no-one came near me. (Dent, 2000)

In Finlay and Dallimore, the most helpful support for parents was on-going contact with a professional present at the time of death. In Dent et al., parents wanted more practical information about dealing with the bereavement and for professionals to remain in contact with them. As in the reference framework, bereaved parents in other studies wanted continuing contact with medical teams both after sudden deaths and those in hospital (Dent, 2000, Meert et al., 2009, Meert et al., 2007, Sterry and Bathgate, 2011). This is particularly important after sudden deaths and suicides, as grief-stricken parents may feel unable to contact professionals themselves, suggesting contact should be offered routinely and continued for some months (Dent, 2000, Dyregrov, 2002, Wisten and Zingmark, 2007). In interview studies parents have explained that they want professionals to show that they care about them and their family after the death (Bright et al., 2009, McHaffie et al., 2001b, Meert et al., 2007), sharing memories of the child is an important part of this (McHaffie et al., 2001b, Bright et al., 2009) as is attending funerals or offering formal condolences (Meert et al., 2009, Macdonald et al., 2005, Pector, 2004, Bright et al., 2009, Sterry and Bathgate, 2011).

### ***Abandonment***

It seems like they care so much while it's going on and as soon as it's done they forget about you. You build a pretty good trust with these people for a couple of months of your life and all of a sudden they aren't there. I would have liked my doctor to have at least called me. (Meert et al., 2007)

Parents in interview studies described feeling abandoned by professionals when contact stops after a child death having grown close to staff during prolonged hospital stays (Meert et al., 2007, Ashby et al., 1991, Meert et al., 2009) or with the abrupt cessation of support services after deaths of children with intellectual disability (Reilly et al., 2008, Todd, 2007). Similar feelings of abandonment by professionals are also felt by parents

after sudden cardiac death (Wisten and Zingmark, 2007) or SIDS (Sterry and Bathgate, 2011) despite their families not being known to services prior to the death.

Parents have expressed their anger at hospital services lack of concern for them as bereaved parents (Bellali et al., 2007). This lack of interest in the parents once they leave the hospital has led to mothers questioning whether the compassion displayed at the time of death was actually genuine (Schaap et al., 1997).

### ***Follow-up of bereaved parents by physicians or other health professionals***

In Finlay and Dallimore, only 16/120 families had any hospital follow-up. In Dent et al., more than half of parents had no follow-up with a hospital paediatrician; of those who did 88% found it helpful. Very few families had formal follow-up with the GP or health visitor but all of these found this helpful.

Rates of hospital follow-up for bereaved parents are very variable from low levels: 6/37 (16%) of SIDS deaths in the USA (Ahrens et al., 1997), to much higher levels, 77% of 31 parents after SIDS deaths in Ireland (McDonnell et al., 1999). In a Scottish study of SIDS parents, 36/93 (39%) had no contact at all with a paediatrician, whilst 44/96 (46%) saw a pathologist for a discussion of autopsy results (Sterry and Bathgate, 2011); however these results may not actually reflect current practice as some cases recruited were of infants dying up to 20 years previously. In a more recent US study, 68% of 56 parents had follow-up with community paediatricians and 77% with intensive care paediatricians after a death in paediatric intensive care (Meyer et al., 2002) and in Scotland 54/59 (92 %) of neonatally bereaved parents had follow-up appointments within 1 year of the death but only 22% of these were within 6 weeks (McHaffie et al., 2001b). It is clear therefore that there are no set patterns to hospital or specialist follow-up after child death.



Similar to the reference papers, in 13 studies parents stated that they would like more medical follow-up after all child deaths (Ahrens et al., 1997, Harper and Wisian, 1994, Ostfeld et al., 1993, Dent, 2000, Kuhn, 2008, McHaffie et al., 2001b, Meert et al., 2007, Meert et al., 2009, Merlevede et al., 2004, Reilly et al., 2008, Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004, Krauel Vidal et al., 1992, Hazzard et al., 1992) and no study reported parents wanting less contact with professionals.

Although Dent et al reported high rates of parental satisfaction with paediatric follow-up lower rates were found in other studies: 56% and 63% for SIDS (Sterry and Bathgate, 2011, Ostfeld et al., 1993), 33% for perinatal deaths (Neidig and Dalgas-Pelish, 1991) and paediatric intensive care deaths 62% (Meyer et al., 2002). Again, unlike in Dent et al., in one study only half of parents were satisfied with GP or health visitor follow-up after SIDS (Sterry and Bathgate, 2011) although other parents have commented that they found comfort by talking to their health visitor as she had known the child in life (Dent, 2000). Surveys of bereaved parents showed that parents appreciated follow-up appointments where paediatricians have explained the cause for infant deaths (Harper and Wisian, 1994, Ostfeld et al., 1993) and some parents also want their doctors to offer emotional support in the longer term (Laakso and Paunonen-Ilmonen, 2002, Harper and Wisian, 1994). For Norwegian SIDS parents, such emotional support from professionals is associated with increased positive affect up to 5 years after the death (Thuen, 1997), but a British study of bereavement support for parents by health visitors failed to show any benefit (Dent, 2000). However, not all parents will want emotional support, 4 to 7 years after SIDS, 46% of 141 parents did not want psychological support from professionals and 55% did not want to join self- help groups (Vennemann et al., 2006).

In the Scottish SIDS study, parents described the characteristics of professionals that they found helpful or unhelpful. Long-term support from paediatricians, General Practitioners and health visitors, particularly with the subsequent pregnancy was rated as helpful. Parents appreciated professionals visiting them at home, being compassionate, given information and medication if requested. Parents disliked it if professionals were uncomfortable around them as bereaved parents or if the professionals seemed inexperienced or made tactless comments (Sterry and Bathgate, 2011).

Given all the evidence of bereaved parents wanting personal, supportive and longer-term follow-up after child death it is surprising that one study (Krauel Vidal et al., 1992) seemingly has results to counter this. In this paper of bereaved parents' satisfaction with neonatal intensive care, the parents received autopsy reports and a summary of the medical treatment by post and 73% of parents were satisfied with this system. This result may have been in part due to the low response rate of the postal survey (22%), other similar studies have response rates around 50%. 95% of the parents did request more psychological or social work support to be available to them and the authors have reported that since the survey they have changed their practice and offer all parents a follow-up appointment a few weeks after the death. This implies that the authors felt that parents needed more face to face follow-up care.

### **Good Communication**

your son has received irreversible damage from blunt force trauma (Bright et al., 2009)

In Finlay and Dallimore, twice as many parents said that the bad news had been broken in a sympathetic manner compared to those who did not. In Dent et al, all parents reported that they had been told sensitively about their child's death. Other surveys

show varying rates of satisfaction with breaking bad news, from 46% following sudden deaths at any age to 62% following child deaths in road traffic accidents (Spooren et al., 2000) and 87% after neonatal deaths (Krauel Vidal et al., 1992). Dissatisfaction after any sudden death in children or adults was mainly associated with a lack of information (Merlevede et al., 2004).

Other qualitative studies give further details from a wide range of child deaths. When breaking bad news professionals' language should be appropriate for the parents to understand, not give false hope but not be so factual as to give offence; parents should be given time to assimilate information prior to addressing other issues (Bright et al., 2009, Meert et al., 2008b). The informant should have a caring and understanding attitude (Macnab et al., 2003). Parents want to feel listened to at the time of the death (Covington and Theut, 1993, Reilly et al., 2008) and subsequently (Swanson et al., 2002, Kuhn, 2008). Parents have reported that sometimes professionals lack compassion (Bright et al., 2009), dismiss their feelings (Kuhn, 2008), avoid parents (Pector, 2004), or show them outright hostility (Kuhn, 2008) and openly judge their lifestyles or parenting choices as their children lie dying (Meert et al., 2009). Parents have described a lack of confidence by medical staff in managing child deaths; this has occurred in the Emergency Department (Wisten and Zingmark, 2007) as well as by community health services (Sterry and Bathgate, 2011). Parents have also described actions by professionals that are inappropriate and insensitive: handing bereaved mothers routine well-baby information (Lemmer, 1991), suggesting infant deaths are 'God's Will' or that mothers can have another baby; and suggesting that parents should be satisfied as they have surviving infants in deaths following multiple pregnancies (Pector, 2004, Swanson et al., 2002).

## **Section 2.5 Discussion**

This review includes the experiences of over 4000 bereaved parents whose children died unexpectedly at any age. The review has highlighted considerable consistency in what parents report as their needs following an unexpected child death. The findings group under three key themes. Parents need to say goodbye to their child; the family should be welcomed into the hospital and allowed as much time and space as they need. Parents usually want to be able to see and hold their child even if their injuries are severe and may subsequently regret not seeing their child if persuaded not to by well-intentioned staff. Parents need to know exactly why and how their child died; they often will agree to autopsy to obtain this knowledge. They often struggle to remember the information given at the time of death and value follow-up appointments with health care professionals to be able to ask further questions about their child. Parents want professionals to support them in their quest to understand why their child died and to offer them emotional support; this includes acknowledging the depth of the parents' loss at the time of death and remaining in contact with them subsequently.

There was a significant overlap in findings in many studies and theoretical saturation was reached before all papers were coded; thus it is unlikely that any significant themes have been missed. The review is however limited by the lack of papers published on interactions with police or other agencies so while it may be clear what parents want from health care professionals it is less certain what parents may want from other services. Most of the studies recruited mainly from white families with above average incomes; this may reduce the generalizability of the results as child deaths occur more commonly with social deprivation.

This literature review includes data on child deaths of all ages; the only comparable similar reviews are of parents' experiences of perinatal deaths. These results are similar

in that parents found holding their baby after death to be beneficial and wanted more information on why their baby died (Gold, 2007).

## **Section 2.6 Conclusions**

It is clear from this literature review that parents would like to be offered more support from professionals after child death; the support should not finish when parents leave the hospital without their child. Hospital staff should be trained to support parents at the time of child death and policies put in place to ensure families are able to say goodbye to their child in a dignified way. Clinical staff should ensure that contact is maintained with bereaved parents and they are invited back for follow-up appointments to discuss their child's death as a matter of routine; no parent should be left with unanswered questions about their child's death.

### **Implications of this literature review for the JAA**

As the JAA is an elaborate process there remains the potential for this to become intrusive for the parents; although parents may obtain more information as to the cause of death, the enquiry process may increase their distress. It is essential that the JAA is delivered in a way that is supportive to parents, to help them to understand the reasons why their child died, and enable them to say goodbye to their child in an appropriate and supported way.

This literature review detailed what bereaved parents want from professionals; the next chapter reviews the literature concerning different models for investigation of SUDI that have been used in the developed world and the evidence supporting their use.

## **Chapter three Literature review of the evidence for effective investigation of SUDI**

### **Section 3.1 Introduction**

The previous chapter considered the evidence of what bereaved parents want from professionals following a sudden child death whereas this chapter looks at the evidence for different ways of investigating SUDI. In May 2014 I was commissioned by the Sax Institute in New South Wales, Australia, to write a review of the evidence concerning different ways of investigating SUDI to help them revise their local SUDI policy, that literature review forms the basis of this chapter. The JAA is a uniquely British approach to investigating SUDI but in this chapter I consider the different models of investigation in use in other countries as well as variations in the provisions of the JAA in England. I review the evidence for each of these models in effective investigation of SUDI compared with perceived best practice; and look at enablers and barriers to effective investigation. Using the evidence from all different investigative models, I then discuss evidence-based key elements of effective SUDI investigation.

#### **Research questions**

The research questions for this review were led by the requirements of the Sax Institute.

They are:

What are the current models of practice for investigating SUDI?

What is the evidence to support these investigative models?

## Section 3.2 Methods

### Method of searching and selecting models of SUDI investigation

I carried out a structured review of the literature as detailed in the next section. I also directly contacted the National MCH Center, ISPID and SIDS and Kids for publications and searched the websites of several other child death review programmes internationally and of SIDS bereavement support organisations for relevant papers; these organisations and their websites are shown in table 11. The funder also provided some policy documents relating to Australia and other countries; I was already familiar with UK investigative models. I contacted professionals in the field of SUDI research either by email or at the annual ISPID (International Society for the Study and Prevention of Perinatal and Infant Death) scientific workshop held in June 2014 for details of their local policies and practices. Most of the evidence describing models of SUDI investigation came from the grey literature.

Table 11 Details of websites searched

Organisation	Country	Website
Lullaby Trust	UK	<a href="http://www.lullabytrust.org">www.lullabytrust.org</a>
NHS Wales	Wales (UK)	<a href="http://www2.nphs.wales.nhs.uk">www2.nphs.wales.nhs.uk</a>
The National MCH Center for Child Death Review	USA	<a href="http://www.childdeathreview.org">www.childdeathreview.org</a>
International Society for the Study and Prevention of Perinatal and Infant Death		<a href="http://www.ispid.org">www.ispid.org</a>
Sids and Kids	Australia	<a href="http://www.sidsandkids.org">www.sidsandkids.org</a>
Northwest Infant Survival and SIDS alliance	USA	<a href="http://www.nwsids.org">www.nwsids.org</a>
Canadian Foundation for the Study of Infant Deaths	Canada	<a href="http://www.sidscanada.org">www.sidscanada.org</a>

### Method of searching and selecting evidence to support these investigative models

I accessed published research, grey literature and conference presentations to ensure that I found all relevant evidence for the review. I searched Ovid (Medline) and CINAHL

databases from 01.01.2003 to 26.05.14. The search terms are shown in table 12. I hand-searched two key journals: Forensic Science International and Child Abuse Review. I also checked the websites described previously and shown in table 11.

**Table 12 Search terms used for SUDI models literature review**

Database	Search Terms	
<b>Ovid</b>	1	SIDS and investigation\$
	2	SIDS and (interprofessional relations or interdisciplinary communication or patient care team or interprofessional working)
	3	SIDS and child death review
	4	SUDI
<b>CINAHL</b>	1	SIDS and investigation\$
	2	SIDS and interprofessional relations
	3	Child death review and infant death
	4	SUDI

I included papers that were of original research or systematic reviews of research from Europe, North America or Australasia to ensure similarity of context. All articles had to be published in English due to lack of time and finance to permit translations. Only papers published after 2003 were included to ensure that only current evidence was used; this was a requirement of the funder. I selected for inclusion papers that had data on outcomes of SUDI investigations in terms of diagnosis, determination of risk factors, or the evaluation of SUDI processes; there were no studies with parent-reported outcomes.

### **Critical appraisal of papers**

I critically appraised all papers. Since there are few tools designed for descriptive studies and audits, I based my critical appraisal on whether the study methods were appropriate, the method addressed potential areas of bias, the study sample was clearly defined, and that a representative sample had been achieved. No paper was excluded



due to deficiencies in critical appraisal; strength of evidence was based upon the following bespoke criteria:

1. Good evidence: Independent review of data – for example Child Death Review team analysis of data collected by death scene examiners or prospective research study
2. Moderate evidence: Audit against pre-determined standards
3. Weak evidence: Self-reported outcomes – for example questionnaires or the same team collecting and analysing data

### **Section 3.3 Compliance with best practice in SUDI investigation**

In order to assess the evidence to support the use of the different models of SUDI investigation I needed to compare these models with the accepted standards for best practice. However, there is no internationally accepted standard for best practice in SUDI management although the minimum standard should enable a diagnosis of SIDS to be made correctly. This relies on a detailed medical history, complete post-mortem examination and a review of the circumstances of death (Krous et al., 2004).

Bajanowski et al. (2007a) published an international consensus of medical experts on investigation and diagnosis of SIDS; this paper mainly details pathological tests but includes the need for a thorough scene examination by forensic medicine experts or police officers who have had specialist training in SUDI death scene evaluation. They also state that a multi-professional meeting is required to classify the death and that no individual professional should be making a diagnosis of SIDS by themselves.

The most comprehensive review of best practice in SUDI management is detailed in the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004); this is based on the consensus of a multi-professional working group including paediatricians, pathologists, coroners, police officers, social services and

bereaved parents. Some of recommendations arose from the findings of the CESDI SUDI studies (Fleming et al., 2000) but others were not based on published evidence. The stated aim of the Kennedy protocol is to 'establish as far as is possible the cause of death'. The key elements of this multi-agency management are:

Police and paediatrician take a joint history and account of events from the parents

Police and paediatrician jointly examine the scene of death with the parents

A complete autopsy by a pathologist trained in paediatric autopsies.

An initial multi-agency case discussion within days of the death and a multi-agency case review once all investigations are complete.

The joint medical history taken by police and paediatrician and the joint death scene examination are expected practice in SUDI investigation in England and detailed as such in the national guidance in Working Together (HM Government, 2013), these practices are also recommended by the Association of Chief Police Officers (Marshall, 2012 pg 50). However, the Kennedy Report recommendation for these practices was based solely on expert opinion rather than published research. In many areas in England these joint practices take place but other areas do not; the police in these areas have concerns about potential contamination of evidence if it subsequently transpires that a crime has been committed.

### **What do bereaved parents want?**

The standards described above do not detail what support and information should be provided to the bereaved parents although parents did contribute to the Kennedy Report. Drawing on these parental perspectives, the report suggested that 'it is every family's right to have their baby's death properly investigated.' It highlights that families want to 'know what happened, how the event could have occurred, what the cause of

death was and whether it could have been prevented.’ The report recognises that there are statutory requirements that must be fulfilled following an unexpected death, and a need to ensure justice is done: for the child, the family, and the wider society. These needs must be balanced against the wishes of the family and this underpins a compassionate, professional investigation of these deaths.

### **Core objectives for investigation of SUDI**

The following core objectives of an appropriate response to SUDI were developed by myself with Dr Peter Sidebotham for the purposes of the Sax commissioned SUDI review, combining the parental perspectives with the aims of investigation outlined in the Kennedy report, the requirements of justice, and a public health approach to reducing infant deaths. These objectives are:

- To identify, as far as is possible, any recognisable cause of death; within that, to identify, as accurately as possible:
  - any medical cause of death
  - any non-intentional external cause of death (including non-intentional asphyxiation/overlaying)
  - any suspicious death (overt or covert homicide)
  - sudden infant death syndrome, where the criteria for diagnosis have been met and other causes excluded;
- To identify any factors contributing to the death, including factors in the physical or social environment, parental care, and service provision or need;
- To support the family through a sensitive, respectful approach that allows them to grieve and recognises their need for information;
- To learn lessons for the prevention of future child deaths;

- To ensure that all statutory requirements in relation to the death are fulfilled and that the public interest is served through the appropriate administration of justice and protection of children.

### **Section 3.4 Results of literature searches**

#### **Models of SUDI investigation**

I accessed ten policy documents or investigative protocols from eight different countries and obtained detailed explanations but without supportive documents for two further countries. All models identified were included in the review.

#### **Evidence to support investigative models**

Out of 269 titles and abstracts found by database searches, 11 were suitable for inclusion. These were supplemented by two relevant publications already known to me and by one conference presentation.

In total 12 published papers, one conference presentation and one abstract of a poster presentation were included in the review; these are shown in table 13. Six of these were evaluations of SUDI investigations and the remainder were studies of the findings of SUDI investigations which gave information on the effectiveness of the investigative processes. Outcomes of the studies were:

Compliance with investigative processes

Proportion of cases where a cause of death was determined

Proportion of cases where risk factors for death were determined

Proportion of cases with missing data

**Table 13** Details of included papers, research reports and conference presentations

Study	Model of Investigation	Setting	Aim of study	Study design	Sample size	Findings	Quality of evidence*	Implications
<b>Boylestadt (2014)</b>	Health-led investigation. Death scene analysis by medical forensic investigators only with parents' consent. Multi-disciplinary case review	Norway	To establish trends in sudden death in infants and small children	Retrospective case review	109 SUDI (up to 4 years old) during 2011-3	42/109 (39%) cases had death scene investigation 30/63 (48%) cases from Oslo had death scene investigation 14/42 (33%) cases with death scene investigation had cause for death determined	3	Non-mandatory investigation results in low-uptake by parents. Centres with more cases perform more complete investigations
<b>Brixey et al. (2011)</b>	Medical Examiner-led investigation. Death scene examination using national standard form.	Wisconsin, USA	To illustrate the use of Child Death Review data when examining risk factors for SIDS and accidental suffocation deaths	Retrospective CDR data analysis	51 in 2 year period	Sleep location recorded in 100% Position put to sleep missing in 6/51 (12%), position found in missing in 4/51 (8%), usual sleep location unknown in 7/51 (14%)	1	Despite national templates for death scene examination key information can still be missed
<b>Camperlengo et al. (2012)</b>	Coroner or Medical Examiner-led investigation	Whole USA	To examine the characteristics and policies of coroners or ME offices managing SUDI	Questionnaire sent to all coroner or ME offices in USA	1717 of 1998 (86%) offices responded	In 2004, 50% of offices had no SUDI cases, 31% had less than 5 SUDI. 66% of offices with at least 1 death had policies for autopsy and death scene examination	3	Coroner or ME led investigations in the USA may be diverse in nature and frequently conducted by offices with little experience of SUDI.
<b>Garstang et al. (2013)</b>	Locally provided JAA	Large city Birmingham UK	To assess compliance with JAA procedures	Prospective audit of SUDI cases	47 in 42 months	94% had detailed medical history taken, 100% had death scene analysis, 64% offered follow-up with paediatrician. Previously unrecognised child protection issues discovered.	2	JAA can be used effectively. Child protection issues may not be identified without multi-agency investigation

<b>Hutchison et al. (2011)</b>	Coroner-led investigation. Police death scene examination by non-specialist police. No case reviews	Auckland region of New Zealand	To assess details on autopsy and police reports of unexplained SUDI or accidental suffocation cases	Retrospective case notes review	221 SUDI during 2000-9	Medical history data missing in > 50% of cases, parental smoking missing in 89% Location of sleep known in 84-88% of cases but 42% sleep position only known in 58%.	1	Detailed medical histories are required. Non-specialist police are not effective at death scene examination.
<b>Kerbl et al. (2003)</b>	Health-led investigation. Detailed medical history and death scene examination by medical researcher. Multi-disciplinary case review	Styria region of Austria	To assess the usefulness of the European SIDS classification	Prospective study of SUDI cases	56 SUDI during 1993-2002	39/56 (70%) cases recruited for detailed scene examination and medical history. 11/56 (20%) cases had cause of death determined Risk factors of parental smoking or unsafe sleep environment found in 28/39 SIDS cases	1	Non-mandatory SUDI investigation results in many parents choosing not to have adequate investigations
<b>Landi et al. (2005)</b>	Medical Examiner-led investigation. No protocols in place	King County (KC) Washington State, New York City (NYC), Uruguay**	To compare investigative process and final cause of death for SUDI cases in the USA and Uruguay	Comparative study of SUDI management in 2 US centres and Uruguay	56 SUDI King County 258 SUDI New York	In KC 95% had detailed medical history and 85% death scene examination 4/56 (7%) had cause of death determined In NYC 50% had detailed medical history and 30% death scene examination. 52/258 (20%) had cause of death determined.	1	Clear protocols are needed to ensure adequate investigation of SUDI
<b>Li et al. (2005b)</b>	Medical Examiner-led investigation. Detailed medical and social history. Death scene examination using national standard form. No case reviews	Maryland, USA	To review epidemiological characteristics and scene findings of SUDI cases	Retrospective case review using ME records	1619 SUDI during 1990-2000	723/1619 (45%) had cause of death determined Detailed death scene information for 98% of cases. In 33 co-sleeping deaths parents unable to provide clear information about the death scene.	1	Limited experience of the death scene examiners may have resulted in the lack of information available.

<b>Livesey (2005)</b>	Locally provided JAA but non- statutory	Sussex, UK	To assess how a JAA protocol works in practice	Retrospective case note review	29 SUDI during 2000-2	11/29 (38%) had cause of death determined. Major difficulties in implementing the JAA. Most cases had only a few elements of JAA investigation none had complete investigation.	2	It is difficult to Implement non-statutory SUDI investigations
<b>Meersman and Schaberg (2010)</b>	Medical Examiner-led investigation. Death scene examination. No case reviews.	Rhode Island, USA	To review demographic characteristics, death scene and clinical information for SUDI cases	Retrospective case note review	22 SUDI during 2008-9	Information on parental drug, alcohol and smoking largely incomplete. Missing sleep scene information in 5/22 (23%) cases.	1	Limited experience of the death scene examiners may have resulted in the lack of information available.
<b>Nagaruru Venkata and Ashtekar (2014)</b>	Locally provided JAA	Wales, UK	To assess compliance with new JAA investigative process	Prospective audit	15 SUDI during 2012-3	JAA was used correctly in all eligible cases	2	Good compliance to mandatory protocols can be achieved within a short period of starting.
<b>Pasquale-Styles et al. (2007)</b>	Medical Examiner-led investigation. Detailed medical history and scene examination by specialist nurse. No case reviews.	Michigan, USA	To review information from death scene examination of SUDI cases	Retrospective case note review	209 SUDI during 2001-4	49/209 (23%) cases had cause of death determined. In 12% of cases the information obtained from the nurse visit was significantly different to that obtained in the initial police visit, and further risk factors were identified by the nurse in 44%	1	Medical histories and death scene examination are performed better by specialist professionals than by non-specialist police officers.

<b>Sidebotham et al. (2010) and Blair et al. (2009)</b>	Flying squad version of JAA	South-west England.	To evaluate the implementation of procedures for investigating sudden child death.	Case control study and process evaluation	157 SUDI cases during 2003-6	94% had early multi-agency case discussions, 95% had joint death scene examination by police and paediatrician, 88% had final case review, 93% of parents had formal feedback from case review 67/157 (43%) had a cause for death determined	1	A flying squad version of the JAA produces thorough investigations; local health services also contributed to case discussions and in some cases were confident to perform joint death scene analysis with police.
---	-----------------------------	---------------------	--	---	------------------------------	---	---	--

\*Quality of evidence 1= Good; independent review of data or prospective research study. 2= Moderate; audit against predetermined standards. 3= Weak; self-reported outcomes.

\*\* This study compares US investigative procedures with Uruguay; data from Uruguay have not been included due to the different context



## **Section 3.5 Results - different models of investigating SUDI**

There were four basic types of SUDI investigative models identified in the literature although there were different sub-types in different locations. Some of these models are in use for SUDI research projects and not in routine practice.

### **1. Coroner or Medical Examiner-led investigation**

This system is used throughout the USA although its implementation varies widely as most states have several coroners' or Medical Examiners' offices. Some areas have multi-agency case review to determine complete cause of death whereas others have Child Death Review (CDR) as an overview process at state level (Camperlengo et al., 2012). In New Zealand there is currently a national research project into SUDI using a Coroner-led system of investigation with dedicated SUDI liaison workers conducting scene analysis and taking medical histories. There are no multi-agency case reviews (Communio, 2013).

### **2. Healthcare-led investigation**

A healthcare-led model of investigation is currently used in Ireland (ISIDA) although unexpected deaths are still reported to the coroner. The police will visit the home on behalf of the coroner but formal death scene examination does not take place. The local SIDS organisation is available 24 hours to advise professionals and support families. In Norway, the departments of forensic medicine lead the investigation performing death scene examination when parents give consent; police involvement is minimal (Boylestadt, 2014).

### **3. Police-led investigation**

In Australia, police-led investigations are used in the states of Victoria and South Australia. Police will visit the scene of death possibly with forensic investigators; no

medical history is routinely taken. Case review only occurs following deaths in children who were known to child protection services.

#### **4. Joint agency approach model (JAA)**

This approach is used in England and Wales (HM Government, 2013); the entire investigative process is multi-agency in nature with detailed case discussion to determine the full cause of death and risk factors for each case.

The different models are summarised in table 14.

Table 14 Basic models of SUDI investigation

Model name	Lead Agency	Initial history from parents	Death scene examination	Autopsy	Prospective individual case reviews	Countries using this model
<b>Coroner or Medical Examiner-led investigation</b>	Coroner or Medical Examiner	Taken by police, death scene examiner or Medical Examiner	Death scene examiner	Variable	Variable	USA New Zealand (research project)
<b>Healthcare-led investigation</b>	Health	Taken by doctor	Doctor and police but independently	Variable	Multi-disciplinary case review within health	Ireland Norway Austria (research project)
<b>Police-led investigation</b>	Police	Police	Police and forensic team	Variable	none	Australia Denmark
<b>Joint Agency Approach model</b>	Health and police jointly	Taken by paediatrician and police	Jointly by police and paediatrician	Mandatory	Multi-agency case review	England Wales

## **Compliance with best practice in SUDI management**

There is no internationally accepted standard for best practice in SUDI management although the minimum standard should enable a diagnosis of SIDS to be made correctly. This relies on a detailed medical history, complete post-mortem examination and a review of the circumstances of death (Krous et al., 2004). All models of investigation except the police-led model comply with this standard.

Bajanowski et al. (2007a) published an international consensus of medical experts on investigation and diagnosis of SIDS; this paper mainly details pathological tests but includes the need for a thorough scene examination by forensic medicine experts or police officers who have had specialist training in SUDI death scene evaluation. They also state that a multi-professional meeting is required to classify the death and that no individual professional should be making a diagnosis of SIDS by themselves. The JAA, Coroner or Medical Examiner-led, and Healthcare-led approaches also meet this standard of best practice providing there is death scene analysis by specially trained examiners, an autopsy and multi-professional case review to determine the cause of death.

The most comprehensive review of best practice in SUDI management is detailed in the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004); this is based on the consensus of a multi-professional working group including paediatricians, pathologists, coroners, police officers, social services and bereaved parents although not all recommendations were based on published evidence, some were based on opinion alone. The stated aim of the Kennedy protocol is to

‘establish as far as is possible the cause of death’. The key elements of this multi-agency management are:

Police and paediatrician take a joint history and account of events from the parents

Police and paediatrician jointly examine the scene of death with the parents

A complete autopsy by a pathologist trained in paediatric autopsies

An initial multi-agency case discussion within days of the death and a multi-agency case review once all investigations are complete.

If the Kennedy Report is accepted as best practice then the Joint Agency Approach clearly complies with this and other models do not.

The models described above do not detail what support and information should be provided to the bereaved parents although parents did contribute to the Kennedy Report. Drawing on these parental perspectives, the report suggested that ‘it is every family’s right to have their baby’s death properly investigated.’ It highlights that families want to ‘know what happened, how the event could have occurred, what the cause of death was and whether it could have been prevented.’ The report recognises that there are statutory requirements that must be fulfilled following an unexpected death, and a need to ensure justice is done: for the child, the family, and the wider society. These needs must be balanced against the wishes of the family and this underpins a compassionate, professional investigation of these deaths.

### **Section 3.6 Detailed consideration of different models of SUDI investigation**

There is limited evidence published to support any model for investigating SUDI; most models do not state their desired outcomes therefore evaluating against outcomes is

difficult. The implicit outcome of all models is to determine the cause and relevant risk factors for death; however comparison between models is challenging as different countries have widely differing diagnostic labelling for causes of death. For example, an infant found dead in a co-sleeping environment may be labelled as SIDS, unascertained death, or accidental asphyxia. SUDI can also be divided into unexplained SUDI, consisting of SIDS and unascertained deaths and explained SUDI, deaths with a diagnosis of whatever cause whether this is medical, accidental or criminal. Thus the deceased co-sleeping infant if diagnosed as an accidental asphyxia is an explained SUDI death but if labelled as SIDS it becomes unexplained SUDI. Comparing rates of unexplained versus explained SUDI can therefore be misleading. There are classification systems for SUDI, such as the Avon Classification (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) which help to separate risk factors from cause of death; however these cannot be applied to aggregate data only to individual cases. It is not possible therefore to use the Avon Classification with the published studies to try to get conformity of diagnoses and outcomes.

### **1. Coroner or Medical Examiner-led models of SUDI investigation**

In the USA there are nearly 2000 local coroner and Medical Examiner offices and each have their own methods of investigating SUDI. Half of offices had no SUDI cases at all in 2004 and 31% had between 1 and 4 SUDI cases; of offices having at least one SUDI, 66% had a protocol concerning death scene investigation and autopsy. There are now however standard national templates for assessing death scenes and national training for scene examiners (Camperlengo et al., 2012).

***Process and outcome evaluation of Coroner or Medical Examiner-led models of SUDI investigation***

Landi et al. (2005) compared SUDI investigations in two US centres, King County, Washington State, and New York City; both had Medical Examiner-led investigations and although were protocols in place for managing SUDI, these were not mandatory and were much less detailed than SUDI protocols currently. During 1998-2001 there were 56 cases in King County and 258 in New York City. In King County, the Medical Examiner took a detailed history from 95% of parents and there were death scene examinations for 85%. In New York City, 50% of parents had a detailed history taken by Medical Examiners and only 30% had a death scene examination. The diagnostic rate was 7% for King County and 20% for New York; the lower rate for King County was because the autopsy did not include histology or metabolic tests. These tests were performed in New York and are now considered part of routine SUDI investigations internationally. The authors commented on the difficulties faced by individual Medical Examiner offices trying to investigate SUDI without statutory protocols.

In Maryland, USA, the Chief Medical Examiner's Office leads all SUDI investigations, taking a detailed medical history from parents, examining the death scene, collecting background information on the parents including social service contacts, and conducting an autopsy. Multi-agency case reviews do not take place. There were no details given of the personnel conducting these investigations, in particular whether they had any specialist training in SUDI although national SUDI forensic investigative templates were used. 802/1619 (49.5%) of SUDI were classified as SIDS and 45% of deaths had a cause identified; this included deaths that were due to drowning, smoke inhalation and overt homicide resulting in a high diagnostic rate. Death scene locations were recorded for all SIDS cases and sleep locations were recorded for 98%. 372 infant deaths occurred in co-

sleeping environments; but in 33 of these, despite death scene examinations and parental interviews, the location of the baby, the parents and other items as well as parental alcohol or drug use was unclear, making it difficult to determine the cause of death (Li et al., 2005a).

In Milwaukee County, Wisconsin, USA, there is a Medical Examiner-led system with dedicated child death scene examiners using national SUDI forensic investigative templates but no multi-agency case reviews. Analysis of all 52 deaths of infants due to SIDS or unintentional asphyxia in the years 2007-8 showed there were highly detailed data on sleep scenes: location of last sleep, co-sleeping, availability of cots, presence of objects presenting a potential asphyxiation risk, the position the baby was put down to sleep in, and position the baby was found in. However, information on the position of the baby when put to sleep was missing in 6 cases, position when found in 4 cases and the usual place of sleep in 7 cases (Brixey et al., 2011).

The Wayne County Medical Examiners' Office in Detroit, Michigan, USA, has one public health nurse who investigates all SUDI cases taking a detailed medical and social history from the parents at home and performing death scene reconstruction with the use of a doll. Police may also do scene examinations and interview parents prior to this. During 2001-4, 214 SUDI cases were investigated by the public health nurse; 23% had a cause of death identified. Potential risk factors for asphyxia were identified in 85% of cases and conclusive evidence of asphyxia (confirmed overlay, strangulation or entrapment) in 13%. The information obtained by the public health nurse concerning the sleep position was completely different from that obtained from initial police reports in 12% of cases and she found potential risk factors that were not disclosed to the police in 44% of cases (Pasquale-Styles et al., 2007). The differences in interviewing between police and public health could be interpreted in two ways: either separate interviewing is preferable as



parents may be more honest with a nurse than police. Alternatively, the police not being trained in SUDI investigation did not ask the appropriate questions so therefore missed important information. In the latter scenario, joint interviewing may therefore have facilitated accurate information gathering. In Rhode Island, USA, the Office of the State Medical Examiner leads SUDI investigations using death scene investigators and scene reconstructions with dolls. During 2008-9 there were 22 unexplained infant deaths (including those classified as SIDS). In 3 cases the sleep position was unknown and in 5 cases it was unknown if a crib or bassinette was available. Information on drugs, alcohol and cigarettes were largely incomplete (Meersman and Schaberg, 2010).

Currently in New Zealand, there is a nationwide SUDI research study in progress under the jurisdiction of the coroner. There are 4 SUDI liaison workers covering the country; these workers come from nursing or psychology backgrounds. Local police visit families, take statements and perform death scene analysis. If there are no suspicions of potential non-accidental injury the family are referred to the SUDI research study and a SUDI liaison worker contacts the parents after the funeral and arranges to visit the family; this may be several days after the death. The liaison worker takes a full medical history and account of events from the extended family and performs detailed death scene analysis with doll reconstruction. Despite the non-statutory role of the liaison worker parents are usually honest and open about unsafe sleep environments; often different, more detailed information about sleep environments and the family is obtained compared to initial police reports. The delay can be helpful as it allows the family to overcome the initial shock of the situation and reflect more accurately on events; however this detailed information is not available to the pathologist. Although formal follow-up of families is not done by the SUDI liaison workers they notify GPs and Well Child health providers and can refer families to Community Paediatricians if

necessary; multi-agency case reviews are not held for individual cases. As this is a project still in process there are no results available currently (McLardy, 2014).

Prior to the current research project in New Zealand the police performed death scene examination alone. Analysis of all 236 SUDI cases during 2000-9 showed that there were large amounts of missing data on the forensic pathology reports; data were missing for the majority of cases concerning birth weight, gestation, breast feeding, maternal smoking, drug and alcohol use. Sleep position was only known for 58% of cases although sleep environment (for example cot or sofa) was known for 84-88%. The authors commented on the need for a consistent SUDI death scene investigative protocol (Hutchison et al., 2011).

#### ***Key enablers and barriers to Coroner or Medical Examiner led models of SUDI investigation***

The most effective model of Medical Examiner-led SUDI investigation appears to be that in Wayne County, Michigan (Pasquale-Styles et al., 2007); where all death scene investigations and interviews are done by one expert public health nurse allowing her to gain considerable expertise compared to smaller offices that rarely deal with SUDI cases. The current New Zealand system is also likely to be highly effective for the same reasons. The other studies gave few details on the personnel performing death scene examinations or their experience but given the much smaller numbers involved their experience is likely to be much less. The other studies all had varying amounts of data missing from death scene examination although in Pasquale-Styles et al. (2007) 5 families refused death scene examination and interview by the public health nurse. In Brixey et al. (2011) the authors commented that prospective case review was likely to enhance the investigative process despite an already good availability of information from their existing death scene examination.

Using a health care professional to investigate deaths is likely to be less traumatic for parents than police investigations; the presence of police frequently inadvertently conveys a message that criminal investigations are underway. Health care professionals are also used to working with grieving families and have considerable communication skills.

***Summary Assessment of Coroner or Medical Examiner led models of SUDI investigation***

The Coroner or Medical Examiner led model complies with the diagnostic standards for SIDS according to Krous et al. (2004) and Bajanowski et al. (2007b) but does not reach the standard of the Kennedy Report. It has the potential to fulfil 4/5 core objectives for SUDI investigations; there is no evidence available regarding support for parents. The diagnostic rate in these studies varies widely due to different definitions of SUDI, different standards of post-mortem examination and different criteria for deemed deaths to be due to accidental asphyxia. Table 15 shows the assessment of Coroner or Medical Examiner-led models against the 5 core objectives.

Table 15 Assessment of Coroner or ME led models

Objective	Objective achieved	Details
To identify as far as possible any identifiable cause for death	Yes	Diagnostic rates for SUDI from 7 to 45%
To identify any factors contributing to the death	Yes	Many studies reported missing information on risk factors. Most accurate recording of death scene information from more experienced investigators.
To support the family and recognise their need for information	No	No evidence available.
To learn lessons for the prevention of future child deaths	Yes	In conjunction with Child Death Review programmes
To ensure that all statutory requirements in relation to the death are met including any criminal, civil or child protection matters	Yes	Inherent in this model of investigation

## 2. Healthcare-led models of investigating SUDI

### *Process and outcome evaluation of health led models of SUDI investigation*

In Norway, forensic pathologists from five regional centres lead the investigation of SUDI; autopsy is mandatory for unexpected deaths. There is no national protocol in place yet although one is being considered. In cities, SUDI cases are taken to hospital where paediatricians will take a medical history from the family; in rural areas SUDI cases go directly to the mortuary. Police briefly interview parents but do not do death scene analysis; this is done following the autopsy by the forensic pathologist or medical forensic investigators providing families give consent and there is no criminal suspicion. There is a multi-disciplinary case review but this is confined to health, and GPs rarely

attend. Autopsy results are shared with parents by the GP or local hospital paediatrician. Families are supported by the national SIDS support group. During 2010-13, there were 109 sudden unexpected deaths in children aged less than four years with 65 of these managed by the forensic institute in Oslo. 42 cases had death scene investigations of which 30 were from Oslo. 30/42 (71.4%) cases remained unexplained after complete investigation. 15/30 SIDS cases were sleeping prone and 8/30 were co-sleeping of which 5/8 were co-sleeping with parents who were smokers (Boylestad, 2014).

A healthcare-led model of investigating SUDI was used for an Austrian research project. At the time of death there was an initial police interview and scene visit; but 39/56 parents of SUDI cases consented to detailed scene analysis and interview by a researcher between one and ten weeks after the death. There was a multi-disciplinary case review consisting of health professionals and representatives from SIDS parents' organisations to consider all information from the research visit as well as the autopsy results. 22 deaths were classified as classic SIDS, 19 as 'borderline' SIDS (minor pathological findings insufficient to explain death), 11 cases (19.6%) had a complete explanation for death and in four cases parents declined autopsy. Risk factors of parental smoking and an unsafe sleep environment were present in 28/39 SIDS cases (Kerbl et al., 2003).

### ***Key enablers and barriers to healthcare-led models of SUDI investigation***

A healthcare-led model has the disadvantage that full investigation of SUDI relies on parents' consent allowing them to opt out of giving medical histories or death scene examination. When full investigation is non-mandatory it can discourage professionals from providing the service as it may be viewed as an optional extra rather than as best

practice. There needs to be clear leadership and commitment to make complete investigations standard as in Oslo, compared with other forensic centres in Norway.

### ***Summary Assessment of Healthcare-led models of SUDI investigation***

The healthcare-led model complies with the diagnostic standards for SIDS according to Krous et al. (2004) and Bajanowski et al. (2007b) but does not reach the standard of the Kennedy Report. It has the potential to fulfil 3/5 core objectives for SUDI investigation; the main shortfall is the lack of mandatory investigation. The diagnostic rate for SUDI ranges from 20-30%. Table 16 shows the assessment of healthcare-led models against the 5 core objectives.

**Table 16 Assessment of healthcare-led model**

<b>Objective</b>	<b>Objective achieved</b>	<b>Details</b>
<b>To identify as far as possible any identifiable cause for death</b>	Yes	Diagnostic rates for SUDI from 20-30%
<b>To identify any factors contributing to the death</b>	Yes	Death scene analysis by experienced scene investigators
<b>To support the family and recognise their need for information</b>	Yes	Medical follow-up for parents is part of these programmes
<b>To learn lessons for the prevention of future child deaths</b>	No	Not stated currently but would be met if there are Child Death Review programmes in place
<b>To ensure that all statutory requirements in relation to the death are met including any criminal, civil or child protection matters</b>	No	A voluntary model allows parents to decline appropriate investigations

### **3. Police-led models of investigating SUDI**

There are no publications evaluating any police-led SUDI investigations. The police-led model does not reach any accepted standard for the diagnosis of SIDS or investigation of SUDI.

#### **4. Joint Agency Approach**

This is the mandatory model of SUDI investigation currently used in England and Wales based on the Kennedy Report. The process of the JAA has been described in some detail in chapter one. Most regions in England use a locally-based provision of the JAA with investigation led by local clinicians; this is the case in the West Midlands. A 'flying squad' model of the JAA has been used for SUDI research projects previously and is current clinical practice in Greater Manchester. The key outcomes of the JAA are the identification of the full cause of death including any risk factors, and that the needs of the family are addressed; this includes the need to address any child protection concerns.

##### ***Process and outcome evaluation of the JAA***

###### ***Locally provided JAA***

In the city of Birmingham, there is an on-call rota for consultant community paediatricians to be available 24 hours as a SUDI paediatrician although initially cases are managed by hospital consultants. In 2010-11, there were 19 SUDI cases. The SUDI paediatrician was notified within two hours of all SUDI cases; a JAA also took place prior to withdrawal of life support on PICU for two infants. 17/19 (94%) of cases had a detailed medical history taken, 100% had a joint home visit by specialist Child Abuse Investigation Unit (CAIU) police and SUDI paediatrician and 100% had early multi-agency information sharing meetings. 11/17 (64%) families had a follow-up meeting with the SUDI paediatrician to discuss the final case review findings; previously unrecognised safeguarding concerns were detected in four cases. There were some difficulties with obtaining post-mortem examination reports in a timely manner from the coroner. Police and health services worked well together but involving social care professionals was more problematic (Garstang et al., 2013).

### *'Flying Squad' JAA*

A model similar to a flying squad version of the JAA was used for a large research project based in the south-west of England. A research team of paediatricians and specialist health visitors led joint home visits, initial multi-agency information sharing meetings and final case reviews, with contributions from local paediatricians. Local services provided the specialist CAIU police and social care response. The research protocol was agreed with all local coroners prior to any recruitment. The research team were notified of 155/157 deaths (99%) with a median time to notification of two hours. There were initial multi-agency discussions in 94% of cases. A joint home visit took place for 95% of eligible cases; these took place within 24 hours for 76% of families. Final case discussions were held for 88% of cases with a median time to discussion of five months. 93% of families received formal feedback from the case discussion (Sidebotham et al., 2010). Of the 157 SUDI cases in the south-west of England study, 67 (43%) had a causal explanation found and 90 (57%) remained unexplained and were classified as SIDS (Blair et al., 2009).

A 'flying squad' version of the JAA is used in Greater Manchester area of north-west England for all sudden unexpected deaths in childhood (SUDIC). It is a densely populated, socially deprived area with higher than average infant mortality; with between 70-100 SUDIC each year. There are 12 local hospitals and one specialist children's hospital covering ten separate local government boroughs. A team of ten local SUDIC paediatricians take part in a weekly rota for all unexpected child deaths up to the age of 18 years; the paediatricians are on-call for one week at a time for sudden deaths and have no other clinical commitments during this period. All SUDIC, unless clearly homicide, are taken to the local hospital ED; the SUDIC paediatrician is notified of the death and attends the ED usually arriving within two hours of the death. The SUDIC paediatrician along with a Detective Inspector jointly take a history from the parents,



fully examine the child and then visit the home to do the death scene examination. All these findings are shared with the paediatric pathologists although frequently the SUDIC paediatrician attends the post-mortem examination. All Detective Inspectors in the Greater Manchester police have specialist SUDIC training. There are initial multi-agency information sharing meetings, final case reviews and follow-up appointments with parents as in the locally provided JAA. There are four coroners covering Greater Manchester and the differing procedures required for each coroner has caused some difficulties. (Dierckx, 2014)

### ***Key enablers and barriers to the JAA***

The mandatory requirement to use the JAA is a powerful enabler. In the south of England a multi-agency protocol for SUDI was used in 2000-2 prior to this being a mandatory process; there was poor compliance with the process with only 1/28 cases having a joint home visit although all cases had multi-agency discussions (Livesey, 2005). In comparison, in Wales the JAA only started in 2011, an audit of one Welsh region for 2012-3 showed compliance with JAA procedures in 35/45 (78%) of unexpected child deaths (Nagaruru Venkata and Ashtekar, 2014).

At the start of the JAA, many paediatricians expressed their unease about joint home visits as examining death scenes was a completely novel task. However, following a short training course most felt confident in their ability to do this jointly with the police (Garstang and Sidebotham, 2008). Another barrier to the JAA frequently commented on by paediatricians is the time required to investigate SUDI and the difficulties of fitting joint home visits at short notice around other clinical commitments. It was estimated during the south-west England study that the mean time required by paediatricians for each SUDI case was 12 hours excluding travelling time. By having a dedicated research team this could bypass the need for a local paediatrician to be available at short notice;

however during the project local paediatricians' confidence in managing SUDI increased markedly and in the latter years of the study they frequently led investigations and carried out joint home visits without the research team (Sidebotham et al., 2010).

Despite the lack of research evidence behind the Kennedy Report's recommendation for a joint medical and police history and a joint home visit there were no difficulties with these practices identified by the JAA audit in Birmingham, the south-west England study or in Manchester (Garstang et al., 2013, Sidebotham et al., 2010, Dierckx, 2014) Good working relationships between health professionals, the coroner and local CAIU specialist police are vital to success in all types of JAA provision.

### ***Summary Assessment of JAA model of SUDI investigation***

The JAA model complies with the diagnostic standards for SIDS according to Krous et al. (2004) and Bajanowski et al. (2007b) and the recommendations of the Kennedy Report. It has the potential to fulfil all core objectives for SUDI investigations; this is shown in table 17.

Table 17 Assessment of JAA

Objective	Objective achieved	Details
To identify as far as possible any identifiable cause for death	Yes	Diagnostic rates for SUDI from 21-43%
To identify any factors contributing to the death	Yes	Complete information available for majority of cases
To support the family and recognise their need for information	Yes	Medical follow-up for parents is part of these programmes
To learn lessons for the prevention of future child deaths	Yes	As part of established Child Death Review programmes
To ensure that all statutory requirements in relation to the death are met including any criminal, civil or child protection matters	Yes	Mandatory investigation

### Section 3.7 Key enablers and barriers common to all models

There are several key enablers and barriers common to all models leading to successful SUDI investigations.

#### ***1. Close working with the Coronial System***

The strength of Coroner or Medical Examiner-led models are that there is one investigative process unlike the JAA or healthcare-led investigations where coroners' Enquiries run in parallel. In many cases there are excellent working relationships between JAA professionals and the coroner but this is not always the case resulting in difficulties in sharing vital information. In order for any model of SUDI investigation to be successful it either needs to be embedded in the Coronial system or for there to be clear protocols for information sharing and accountability between the coroner and SUDI professionals. The coroner has to accept the validity and need for thorough SUDI investigations above and beyond standard coronial procedures. In most jurisdictions the

coroner will have a specific and limited remit in inquiring into the cause and circumstances of an unexpected death. This typically does not include wider public health perspectives, nor elements of care for the bereaved family. Any system of investigation, if it is to address the key objectives detailed previously, needs to include or be embedded within the coronial system, but extend beyond the strict legal remit of the coroner.

## ***2. Clear leadership by SUDI professionals***

The most effective models had clear local champions ensuring that investigative protocols are followed and other professionals were supported in their roles. In the locally-provided JAA these were the Designated Doctors for Unexpected Deaths and the Detective Inspectors in the CAIU; research teams provided this leadership for the ‘flying squad’ model. Leadership was provided by coroners or Medical Examiners in these models or by committed clinicians in the healthcare-led models.

## ***3. Specialist provision of investigative services***

SUDI is a rare event; the most effective investigators in assessing death scenes and taking detailed medical histories were those professionals dealing with the greatest number of cases. Frequently the investigators dealing with the highest volume of cases were specialist nurses for whom SUDI was the majority of their workload, unlike paediatricians who (outside of a flying squad model) encounter SUDI only rarely. Further training is required for any professional doing SUDI investigation; most paediatricians will not feel comfortable examining a death scene and police scene examiners may be focussed on excluding crime rather than finding an explanation for death. Although paediatricians are experienced in taking medical histories from parents they may need further training on the precise details needed in a SUDI history.

#### ***4. Professionals need to see the value of the process***

Thorough investigation of SUDI is time consuming; if professionals see little benefit from this investigation either to parents or society they will be reluctant to participate fully and may even become a barrier to effective working by others. It is the role of the lead SUDI professionals in each area to enthuse and support their colleagues in this new way of working.

#### ***5. The investigation needs to be a mandatory process***

Mandatory investigation ensures that all cases are fully investigated and that parents cannot opt out of detailed investigations. Death scene analysis, a complete medical history and a multi-agency case review should be viewed as necessary as autopsy. If parents are able to opt out then only minimal information from police initial reports and visits to the scene are available, limiting the chances of determining the cause of death, risk factors and potential learning. Similarly, a mandatory process ensures that all SUDI professionals accept the requirement to investigate SUDI thoroughly according to local protocols. In the JAA, the police elements of the investigation and the autopsy are done on behalf of the coroner so do not require consent; parents can decline paediatric involvement but in practice this is exceptionally rare. Integration of detailed SUDI investigations with coronial investigations should enable these detailed investigations to take place in every case.

### **Section 3.8 Key factors for effective SUDI investigation**

The key factors for effective SUDI investigation include both policy factors relating to SUDI investigation as a whole as well as optimising the performance of individual elements. As shown in the literature review in chapter 2, most parents want to know

and understand why their child died. Increasing the effectiveness of SUDI investigations, providing this is done in a sensitive manner, should also improve care for the families.

## **Key policy factors**

### **1. Mandatory detailed SUDI investigation**

Ideally, detailed SUDI investigation according to a structured protocol should be mandatory; if not, many parents will decline them limiting the learning from individual cases and for whole populations. SUDI occurs disproportionately in socially deprived families (Blair et al., 2006) who may be less likely to consent to detailed scrutiny by health, police and social services. Mandatory SUDI investigation results in higher rates of completed investigation and without such requirements, professionals may be reluctant to spend their time on services considered non-essential. *Based on strong evidence- (Boylestad, 2014, Garstang, 2009, Livesey, 2005, Kerbl et al., 2003)*

High rates of participation have been obtained in SUDI research studies that require parental consent; however these have relied on the leadership and commitment by researchers to recruit families (Sidebotham et al., 2010) and this is unlikely to be translated into routine practice.

### **2. Integration of SUDI investigations with Coronial Services**

When the coroner is not integral to the SUDI process this can be a barrier. SUDI investigations should be fully integrated with those conducted by the coroner or led by the coroner as this leads to a smoother investigative service, less duplication of investigation and better sharing of information. *Based on strong evidence - (Li et al., 2005b, Pasquale-Styles et al., 2007, Brixey et al., 2011, Garstang et al., 2013)*

### **3. Strong leadership by a SUDI policy champion**

Effective SUDI investigation needs clear leadership at a local and regional level to ensure that policies are transformed into routine practice; without this SUDI investigation is

likely to flounder. SUDI models that have strong leadership have higher rates of completed investigation. *Based on strong evidence* -(Li et al., 2005b, Pasquale-Styles et al., 2007, Sidebotham et al., 2010, Brixey et al., 2011)

## **Key elements of SUDI investigation**

### **4. Medical history and account of events**

The medical history should be taken by an experienced health care professional such as a paediatrician or specialist child health nurse. Forensic investigators, police officers or SUDI liaison workers from non-health backgrounds will not have this expertise. *This is based on weak evidence* (Pasquale-Styles et al., 2007, Hutchison et al., 2011)

### **5. Death scene examination**

Death scene examination is most effective at determining risk factors and possible causes for death when done by experienced professionals who have had specialist training and perform these examinations regularly rather than by local police officers. This is based on strong evidence. (Camperlengo et al., 2012, Pasquale-Styles et al., 2007, Brixey et al., 2011, Hutchison et al., 2011)

### **6. Multi-agency case conference**

There is international consensus that SIDS should not be diagnosed by any individual alone (Bajanowski et al., 2007a) but few investigative approaches do so. Multi-agency conferences allow consideration of wider factors in SUDI such as child protection issues or poor parenting that might otherwise be missed. This is based on weak evidence - (Garstang et al., 2013)

## **Section 3.9 Discussion**

The literature review identified four distinct models for investigating SUDI: Coroner or Medical Examiner-led models, healthcare-led models, police-led models and the JAA.

All these investigative models except for the police-led model have the potential to meet the minimum standard of investigation required for SIDS death according to an international consensus (Bajanowski et al., 2007a). The key evidence-based factors for maximising effectiveness of SUDI investigation are that detailed investigation needs to be a mandatory requirement and integrated within the coronial system. SUDI investigations should be performed by specialist professionals who undertake these duties on a regular basis.

This literature review has encompassed a comprehensive review of recent published and grey literature on SUDI investigations from many developed nations with similar contexts to the UK. Although the funders required a tight time-scale for the review it is unlikely that any significant evidence was missed. There were however relatively few publications available for inclusion and many of these were not direct evaluations of SUDI investigations but reports of the findings of these investigations. It was difficult to compare outcomes of SUDI investigations between studies due to differences in use of diagnostic terms; for example, some studies much more readily labelled deaths as due to accidental asphyxia than others.

While there have been many research projects studying causes and risk factors for SUDI; there have been very few projects evaluating how best to investigate individual SUDI cases. As yet, there have not been attempts to identify research evidence supporting best practice in SUDI investigation; all previous publications have been based on a consensus opinion of experts. The findings of this review are similar to the recommendations of the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) and Bajanowski et al. (2007a) but go further by suggesting policy factors needed and the key practitioner components needed for effective investigations.



This review has implications for the JAA. Most areas use a locally-provided model with individual clinicians managing SUDI cases only rarely. This may mean that investigations are less accurate and less effective at determining causes and risk factors for death. Coroners' enquiries run in parallel with the JAA and this has potential to cause duplication of investigation which may confuse and distress families. In addition there is some evidence that individual coroners can be a barrier to smooth functioning of the JAA itself. These issues will be considered in much more detail in the West Midlands SUDI Study.

The first three chapters have outlined the background to this thesis, what bereaved parents want from professionals and the evidence to support the different models of SUDI investigation. The next chapter moves onto the main research project, the West Midlands SUDI study and details the aims, methodology and methods.

## **Chapter Four Aims, methodology and methods**

The previous chapter considered the evidence to support different methods of investigating SUDI; in this chapter I move on to describe the aims, methodology and methods of the West Midlands SUDI project.

My overall motivation for this project is to improve how professionals investigate unexpected infant death; this includes ensuring investigations are as thorough as possible so that parents can know why their child died and that the bereaved family are adequately supported. The research project has been designed with this intention.

### **Section 4.1 Aims and research questions**

The overall aim of the West Midlands SUDI project is to improve the well-being of parents whose infants have died suddenly and unexpectedly. The research aim is to formally scrutinise the new national joint agency investigation undertaken following a sudden unexpected death in infancy; assessing the outcomes of the investigation, the family's experience and well-being.

The research questions for the project are:

1. What are the experiences of families whose unexpected infant deaths were investigated by the joint agency approach?
2. What are the experiences of professionals investigating unexpected infant deaths using a joint agency approach?
3. How effective is the joint agency approach at determining cause of death and contributory risk factors?

## **Section 4.2 Theoretical perspectives**

The WMSUDI project fits within a pragmatic perspective in that the choice of research design was selected principally in that it would answer the research questions rather than selecting a design to fit with a pre-determined method or paradigm (Andrew and Halcomb, 2009 pg 21). There are many different features of pragmatism, these have been described in some detail by Burke Johnson and Onwuegbuzie (2004). The key elements that relate to the WMSUDI project are:

- There is a high regard for the reality of the inner world of human experience in action, this means the experiences of the parents and professionals of the JAA are considered as valuable as the more 'concrete' data such as the case records detailing the events that occurred.
- Knowledge is viewed as being both constructed and based on the reality of the world, this refers to the parental and professional experiences being related to both the events that took place as well as their feelings about these events.
- It views truth, meaning and knowledge as changing over time; this accepts that parents' and professionals' views of the JAA may change, particularly as the JAA is an evolving process.
- It endorses practical theory, this fits well with the overall aim of the project, using the knowledge gained to improve parental wellbeing.
- It endorses a strong practical empiricism as a path to determine what works, this ties well with the project as the methods have largely been designed to maximise recruitment, knowing that this will be the major difficulty with the study.

Fundamental to pragmatism is the belief that the research question should be the impetus for choosing research design, rather than a method or a paradigm (Andrew and

Halcomb, 2009 pg 21). This is entirely what happened with the project, in that the methods were planned to allow the research question to be answered, bearing in mind the difficulties of recruiting bereaved parents and following them over time.

A pilot study for the WMSUDI project took place in 2008, with the aim of trying out the research methods for a larger project. The intention was to recruit bereaved parents at least four years after their infants' deaths. This had been informed by discussion with bereaved parents who felt that a significant time period was needed to allow their grief to subside so that they could reflect on the events of the JAA. Parents were approached by letter about the study; but the approach was completely unsuccessful in recruiting any parents at all; as a result the literature was extensively reviewed for guidance in how to recruit bereaved families into research. The data collection methods have been designed taking into account the evidence for this literature review. The pilot study and literature review were the topic of my MSc Dissertation (Garstang, 2009).

Although the overall theoretical perspective is pragmatism; this approach is best viewed as a mosaic of several different underlying theoretical perspectives and assumptions, these are discussed below.

### **Generalizability of parental experiences**

The experience of participating parents may not reflect all other parents' experiences but these experiences are not unique and are considered generalizable otherwise it would not be possible to generate wider learning from the research project.

Referral to the study relied on local paediatricians explaining to parents about the project during follow-up appointments some months after the death. In instances where the JAA does not function well parents are often lost to follow-up so were not informed about the study. Local paediatricians also had considerable power in deciding

whether to refer families to the study or not and may have withheld study information from parents if they considered that the management had been sub-optimal. As a result; most cases, but not all, were those where the JAA had functioned well; particularly in regard to follow-up. However, many cases had elements in which the JAA did not work as intended and parents frequently reported negative experiences. Theoretical saturation of data was reached so it seems unlikely that significant parental experiences were missed; increasing the generalizability of the results.

### **Subjectivism, Materialism and Idealism**

During the research interview parents told their story of what happened with the investigation into their child's death. Each parent's experience is highly individual and has a meaning unique to them, so is highly subjective. There may be many realities, with different meanings, to different individuals involved in the same case of infant death. Some of these meanings may only be generated with social interaction, such as in a research interview. Similarly, some professionals may have strong opinions about the JAA and this might affect what they choose to say during the interview. These different meanings relate to the underlying theory of subjectivism as described by Dyson and Brown (2006 pg 12).

The data generated from the parental interviews and questionnaires relate to two different underlying concepts. Firstly, materialism, the study of 'hard' facts, for example, attendance at the scene of a child's death by uniformed police officers, which could be corroborated by studying case records in addition to the parents' recall. Secondly, idealism, the study of more abstract issues such as the parents' views on the JAA, and their perception that certain professionals may have been very caring (Dyson and Brown, 2006 pg 33).

## **Scientific realism**

The West Midlands SUDI project is studying the process and experience of users of the JAA; this will be used to inform better practice and so improve the well-being of the bereaved parents. This fits well with Scientific Realism (Dyson and Brown, 2006 chapter 3) which combines both people's intentional actions (agency) and the parameters within which people live and work (structure). Scientific realism aims to make wider generalisations from research findings including how people may want services to function if they could decide completely afresh, disregarding what is there already. Bereaved parents are unlikely to know how the JAA should proceed. Their perceptions will be based on what actually happened, and parents may for example, be satisfied with services that I know should function better. Scientific Realism permits knowledge of unobservable structures whether the people involved are aware of them or not, allowing the researcher to 'know better' than the research subjects.

## **Professional autonomy**

The professionals are agreeing to take time away from work to be interviewed putting them in a position of power by consenting (or not) to help with the research project. They can tell or withhold information as they wish, unlike other professional investigations with which they may be compelled to assist. Conversely, professionals may be feeling that the JAA renders them powerless as they no longer have the autonomy to decide how to investigate each child's death and they may feel inadequately trained or supported for their new role.

## **Maternal guilt**

Mothers often blame themselves for their child's death; viewing it as a failure of their parenting that they could not keep the child alive; self-blame however is a normal part of grieving (Murray-Parkes, 1996).

The JAA should result in parents having more knowledge about their child's death than previously. Parents may now be more aware of their actions which related to the death of their child, such as their own consumption of alcohol or co-sleeping with their infant with the potential to increase maternal self-blame. The role of self-blame in the parents' experiences will be studied as part of the data analysis.

## **Critical Realism**

The effectiveness of the JAA in establishing the cause of death and relevant risk factors will be determined mainly by a separate research study due to the difficulties in recruiting families for the WMSUDI project. However the case note analysis and detailed case studies will contribute towards this by detailing the process of the JAA. The implementation of the JAA varies between families and regions having a significant impact on its effectiveness, so it is vital that what is actually happening in the JAA in each case is determined. There will be different elements, for each family, that help determine why their child died, and different parts that the parents may find supportive or unsupportive. This ties in well with Critical Realism (Pawson and Tilley, 1997). In brief this states that the aim of evaluation research should be to answer the question of why a programme works, for whom and in what circumstances. Research focuses on the mechanisms of programmes - what it is about a programme that makes it work; as well as the social context in which programmes operate. In short the causal outcomes of a programme (results) follow from mechanisms acting in contexts.

There are therefore many different theoretical perspectives that relate to this project. These perspectives can be viewed as fitting within the overall perspective of pragmatism. The use of pragmatism as a theoretical perspective has come about with the rise of mixed methods research and the need for finding a unifying solution to the 'paradigm wars' between qualitative and quantitative research.

### **Section 4.3 Methodology - Evaluation of the JAA**

The aim of the JAA, as stated in Chapter 5 of Working Together (HM Government, 2013) is to understand the reasons for a child's death and to address the possible needs of other children and family members. All enquiries towards this aim are expected to balance the forensic and medical examination requirements with the need to support the family. Professionals are expected to be open-minded and treat families with sensitivity and discretion. The WMSUDI project is therefore an evaluation of the JAA encompassing parental and professional experiences as well as the effectiveness of the JAA.

*Evaluation can be defined as:* 'the critical assessment, on as objective basis as possible, of the degree to which entire services or component parts fulfil stated goals' (St Leger et al., 1997 pg 1). This involves examining the structure, process and outcomes of a service and using this to judge the service's value. Research differs from evaluation in that research can be used purely for generating knowledge but evaluation should result in people being able to make more informed decisions about services as it also involves value judgements (Ovretveit, 1998 pg 13). Given that the aim of the project is to improve the well-being of bereaved parents, this involves making judgements about practices in the JAA which may be upsetting to parents or of limited investigative value.



A key part of evaluation is assessing the effectiveness of the evaluated service. Effectiveness is determined by the efficacy (whether a procedure works or is of benefit) of individual procedures, the correct targeting of services, acceptability of those services, structure of service and ease of access. The efficiency of service is also part of the overall effectiveness, i.e. is it managed in the best way to make use of its resources? (St Leger et al., 1997 pg 23). Evaluation of a policy can also include an assessment of how the policy was developed, whether the policy is based on good evidence or not. In this project the effectiveness of the JAA includes both the effectiveness of the JAA in determining cause and risk factors for death, and the parental and professional experiences of how the JAA works in reality. The project is not attempting to assess cost-effectiveness or the evidence base behind the JAA, which resulted from the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004).

There are many different ways that health services can be evaluated. Ovreteit (1998) describes six basic designs: a descriptive study, that aims to describe what is happening in a service, as well as those using it; an audit where a service's performance is compared with a pre-determined standard; an outcome evaluation where people are compared before and after receiving a service; a randomised controlled trial; and an intervention to a service study where different groups of patients or staff are compared before and after the change to service. All these designs are very simple in that they only evaluate one aspect of a health service and none of them include the users' or providers' perspectives.

The WMSUDI project incorporates elements of descriptive study, outcome evaluation, and intervention to service study in its mixed method design. It aims to detail how, in each case the JAA takes place. The WMSUDI project looks at outcomes in terms of

parental well-being, determination of risk factors, child protection concerns, and causes of death; these will then be compared with other published data. Additionally, it seeks to learn of professionals' and parents' experiences and satisfaction with the process.

Describing the process of the JAA is a significant part of the WMSUDI project. This is because although the JAA is a national policy the way it is implemented varies significantly in each locality, with differing practices of paediatricians, police and social services. It is vital to be able to understand what is happening with the JAA before making any inferences about its effectiveness.

The complex mixed methods used in the WMSUDI project are similar to that of other NHS evaluations. The NIHR Service Delivery and Organisation website details ten research reports concerning evaluation of models of service delivery, published since March 2007 (NIHR, 2012). All the evaluations involve the use of several different methods and studying service provision in more than one location. In nine, a significant part of the evaluation process is a detailed description of the service provision in question by examination of routine documents, direct observation of the service or interviews with service providers. Nearly all involve either patient or carer interviews or questionnaires for satisfaction with services. Only one evaluation involves an RCT in its methodology, although others use control groups for comparisons. It is clear from this that in practice, policy evaluation is highly complex and varies greatly between projects, but also that the WMSUDI project, as a service evaluation, has a methodology that is similar to other nationally-commissioned projects.

One of the weaknesses of the WMSUDI project is the lack of direct comparison between the JAA and previous approaches to investigating infant death. It had been planned originally to compare families where a JAA approach had taken place following an infant death with those families where a JAA did not take place (usually limited police and

health investigation). This would have required recruiting families retrospectively, where babies had died before 2008 when the JAA was introduced. The method was piloted, unsuccessfully, by writing to bereaved families and inviting them to take part in the study (Garstang, 2009). The WMSUDI project has been designed to maximise recruitment by approaching the families soon after the infants' deaths. As a result, it is not possible to have a control group within the study as all families should have a JAA investigation. Comparison with other approaches to investigating SUDI have had to be made using other published data.

There are difficulties inherent to evaluations. The boundaries of what is being evaluated (in the case of WMSUDI project the JAA) need to be clearly defined. As this is not a controlled experiment the service being evaluated may change during the evaluation making it difficult to assess the cause of any changes in outcome. The knowledge that an evaluation is occurring may alter professional practice reducing the reliability of the outcomes. Evaluation is rarely a neutral process and can create hostility; professionals may feel threatened by potential changes to services resulting from the evaluation (Ovretveit, 1998 chapt 10).

#### **Section 4.4 Methodology - Mixed methods**

This is a mixed methods research project as the research questions relate both to parent and professional experiences and effectiveness of the joint agency approach. Mixed methods can be defined as research which combines both qualitative and quantitative data in one study and integrates the data during the research process (Andrew and Halcomb, 2009 pg 10). There are many different methodologies that can be used within mixed methods and I discuss some of the relevant options available here.

## **Multiple case study**

The methodology for the WMSUDI study bears many similarities to multiple case study methodology as described by Yin (2014). Case study is suited well to evaluations, the depth of data can capture the complexities of situations and both qualitative and quantitative data and multiple perspectives can be included. Case study involves investigating cases in depth within the real world context; conclusions are drawn across cases, with the aim of being able to make analytical generalisations from the results. Case study should have a rigorous design with a systematic collection of data from multiple sources of evidence which are then triangulated, fitting well with mixed methods. Cases are analysed as a whole prior to conclusions being drawn across cases but results from multiple case study can be presented entirely as cross-case analysis with no requirement to report details of individual cases. Yin describes a method for cross-case synthesis using tables for comparing characteristics of interest between cases. This is similar to the matrices of Framework Analysis, the methodology I have selected for my data analysis, which will be discussed later.

## **Qualitative Comparative Analysis**

Another method for comparing across multiple case studies is Qualitative Comparative Analysis (QCA) as described by Ragin (2009). This method is designed to systematically compare cases using formal tools whilst still treating each case as a whole. It accepts that there can be multiple pathways and multiple combinations of factors leading to the same final outcome. QCA was specifically aimed at studies with between 10 and 100 cases so would fit with the WMSUDI project well. However, the starting point of QCA is the outcome of interest and the research should be designed to address all the relevant

conditions that may lead to this outcome. Relating this to the WMSUDI project would be saying, for example, that the outcome is parental wellbeing and the research focus would be on which factors in the parental experience lead to or prevent wellbeing. As the research questions are much wider, concerning parental and professional experiences of the JAA with no clear outcome of interest this methodology clearly would not work for the WMSUDI project.

### **Critical Incident Review**

The detailed case analysis with the intention of improving professional practice ties in well with Critical Incident Review (CIR) this is a method for improving patient safety following serious adverse events in health care (Mahajan, 2010). It relies on detailed reports from professionals rather than highly structured questionnaires to ensure that what actually happened is made clear and acknowledges that in most cases there is a complex series of events rather than a single error leading to the adverse outcome. CIR requires whole systems to be analysed from senior management downwards rather than focussing on isolated events. There are two types of failure: active failure refers to errors or omissions by frontline staff and latent failure refers to senior management decisions that created the conditions for poor practice.

In order to obtain the level of information needed for CIR-type analysis professionals had in-depth interviews, conducted by telephone allowing me to probe for further details of the investigative process and to challenge their decision making. This level of detail would not have been possible in a questionnaire or purely from the case note analysis. The professional interviews therefore focused on why they took certain decisions (for example not to do a joint home visit), more general difficulties with implementation of the JAA as well as what happened with the JAA in each case. Unlike CIR however; professionals were also interviewed about what was working well in the

JAA, seeking to highlight good practice and the mechanisms leading to this rather than purely focussing on failures.

### **In-depth interviews**

The experiences of the bereaved parents are central to the research project and in-depth interviewing offers the best way to be able to learn of these in detail. I have used the theory of in-depth interviewing as described by Kvale (2007) as the rationale for this choice. In short, qualitative research interviews attempt to understand the world from the participants' perspective; to explore the participants' lived experiences. This knowledge is constructed in the interaction between the interviewer and participant, with the interviewer probing the participant for more information and clarification of answers as well as noting when nothing is said on a subject of relevance. The interpretation of in-depth interviews is at both the factual level – understanding what events occurred, as well as the meaning level – what the events actually meant for the participant. The interviewer should be open to unexpected answers and interpretations and not have pre-determined categories for expected responses. There may be ambiguity of individual responses in that participants may have ambiguous views on their experiences.

Conducting research with bereaved parents is a very sensitive area; however previous research has shown that bereaved parents view in-depth research interviews and even questionnaires about their experiences positively (Dyregrov, 2004). Bereaved parents may find it therapeutic to talk through the events of their child's death as a way of making sense of events to themselves, or appreciate being able to talk about the events of the death which they may be unable to do with family or friends. It is clear therefore, that despite the sensitivities of the issues in question that conducting in-depth interviews with bereaved parents is an appropriate methodology.

## **Framework Analysis**

Framework analysis has been selected as the most suitable methodology for analysing the data; this was developed for policy evaluations and its characteristics suit the project well. Framework analysis is grounded in the original accounts of the subjects of the research; allowing comprehensive review of all relevant material and easy retrieval of original data. It is a systematic process yet allows for change if needed during the analysis. It allows for within- and between-case analyses. There is a clear process with explicit methodology enabling the results and interpretation of them to be accessible to the reader (Ritchie and Spencer, chapter 9 in Bryman and Burgess, 1994).

## **Final composite choice of methodology**

I selected a design similar to multiple case study, with data collected from case records and from in-depth parental and professional interviews. I then synthesised data from the different sources. This was vital to the analysis as parental recall of stressful events may not be entirely accurate. Synthesis of the data sources allows parental descriptions to be compared to other descriptions of events allowing a deeper analysis of why parents had such a recall of events. For example, in one case in this study, why did parents think no doctor spoke to them in the Emergency Department when the case records clearly record that a doctor had? Similarly, assessing parental understanding of the cause for their infant's death can only be undertaken if the documented cause of death is available for comparison. The professional interviews focussed on all aspects of the JAA rather than just failings as in CIR.

Framework analysis was selected as the most suitable methodology for analysing the data. There was a significant risk that the huge amounts of data generated would become unmanageable and this method mitigated against this. It allowed the parents'

and professionals' experiences to be at the forefront of the analysis; reflecting the research questions and the overall aim of improving bereaved parents' wellbeing. This approach enabled comparison between data sources within cases as well as between the cases themselves.

#### **Section 4.5 Methods – Objectives, case definition and study area**

Drawing on the established aims and research questions the objectives for this study were set as:

1. To identify SUDI cases in the study area, who died between September 2010 and August 2013.
2. To recruit eligible SUDI cases in the study area, who died between September 2010 and August 2013
3. To advertise the study directly to bereaved families, in order to maximise recruitment.
4. To recruit professionals involved in the SUDI process.
5. To collect data from the health, police, coroners' and social service case records for each recruited case and from the parents' GP records.
6. To survey study parents using a self-completed questionnaire or structured interview in order to obtain their perceptions of: the cause of death, the care received following the death and psychological well-being.
7. To interview a sample of parents in depth to obtain a greater understanding of the effects of SUDI investigation on the family.
8. To interview a sample of professionals in depth to obtain their perceptions of the joint agency approach.
9. To analyse the data from the case note analysis and structured parental interviews.



10. To analyse the data from the in-depth parental and professional interviews.
11. To triangulate the data and review implications for clinical practice

### **Project Steering Group**

A project steering group was established consisting of a SUDI paediatrician, SUDI specialist nurse, bereaved parent, experienced child protection social worker, experienced senior child protection police officer, and a representative from the Lullaby Trust (the national charity for SUDI research and parent support). The members were appointed directly by me; the majority were already known to me or my supervisor from our previous work with SUDI and were mainly based locally for practical reasons. The group helped with the overall design of the project; they also reviewed and revised parent literature, interview schedules and questionnaires. They advised on alternative strategies to assist with recruitment such as advertising directly to parents. The group reviewed the analysis of results; by recoding a selection of transcripts at the meeting and the whole group discussing the findings together.

### **Definition of cases**

Each case or unit of analysis is a single SUDI JAA investigation; the death itself is a marker for the case. Consent was required from parents to access case data so therefore bereaved families were recruited to the study. The West Midlands joint agency protocol was implemented throughout the region during 2006-8 so all SUDI would have had a joint agency investigation.

### **Study Area**

The study was based in the former West Midlands NHS Strategic Health Authority Area covering the counties of Herefordshire, Shropshire, Staffordshire, Warwickshire, West Midlands and Worcestershire. This region was chosen for several reasons; it was a

distinct region with a large and diverse population; moderately high rates of SUDI in comparison to other regions (0.39 per 1000 live births compared to 0.21-0.67 (Statistics, 2012)); was easily accessible from Warwick Medical School; and there were established links with local practitioners, thus facilitating positive engagement with the study.

## **Section 4.6 Study design**

The original study methods included a cross sectional survey of JAA investigation of SUDI cases in the West Midlands region of England involving case note analysis and structured interviews. In addition in-depth interviews were planned with a purposive sample of bereaved parents and the relevant professionals.

### **Selection and exclusion criteria**

JAA cases were eligible for the study if the infant had lived in the study area and had died between the age of one week and one year and the death was considered initially as a SUDI case. Cases were still eligible for recruitment if a medical cause for the death was subsequently found provided that at the time of death, the death was considered sudden and unexplained. Only deaths occurring between 01 September 2010 and 31 August 2012 were initially included; this was then extended for a further year to 31 August 2013 due to low recruitment.

Only SUDI cases under one year old were eligible for inclusion because those cases over one year only rarely present as SUDI and may have post-mortem examinations outside of the West Midlands . This would have made case ascertainment very difficult and it is probable that many cases would have been missed.

Cases were excluded if the baby had never left hospital since birth or if the family had moved out of the study area since the death. Families could be recruited prior to the conclusion of the coroner's inquest as in some cases these were delayed for nearly two

years after the death. Cases were excluded if there were ongoing criminal investigations. Parents had to be over the age of 16 at recruitment.

### **Population size**

Calculating the number of cases of SUDI in a region is not straightforward as SUDI is a presentation and not a diagnosis; therefore there is no ICD10 code for SUDI on death certificates. The number of SUDI cases can only be roughly estimated by studying the ICD 10 codes for death registration. It is relatively easy to determine the number of SUDIs that remain unexplained after investigation as these are coded with specific ICD 10 codes for SIDS or unascertained deaths; however it is much more difficult to determine the number of explained deaths presenting as SUDI. These deaths will be coded as the underlying illness such infection or congenital malformation but there is no way of knowing what proportion of the deaths were sudden and unexpected rather than occurring after a period of illness.

The original population size calculation was based on 2006 data in which there were 113 deaths of infants aged between four weeks and one year, in the West Midlands, from all causes. Based on the assumption that any cause of death except those due to perinatal problems (ICD 10 P0-P96) or congenital malformations, deformations or chromosomal abnormalities (ICD10 Q0-Q99) could present as SUDI; 623 of a total of 996 post neonatal infant deaths were potential SUDI (Office for National Statistics, 2008). Given this SUDI rate of 63%, there would be 70 SUDI in infants aged four weeks to one year in the West Midlands per year. In addition there were a further 310 deaths of infants aged between one and four weeks, of which a smaller but indeterminate amount would have presented as SUDI (Office for National Statistics, 2008). I therefore estimated that there were 100 cases of SUDI per year in the study area giving potentially 200 families in the initial 24 month study period.

These data were re-examined in view of the fact that in the first nine months of the project there had only been 45 SUDI cases in the study area. Data from 2007 were used as these were the most up to date available; there were 106 post neonatal deaths in the West Midlands. Re-analysis of these data suggested that the original estimation of the proportion of deaths presenting as SUDI had been overestimated. A new estimation was made based on the assumption that deaths coded as infectious diseases (ICD 10 A00-B99), diseases of the nervous system (ICD 10 G00-99), diseases of the respiratory system (ICD 10 J0-99), symptoms not elsewhere classified (ICD R0-99) and external causes (ICD 10 U509, V01-Y89) were all potential SUDI; this accounted for 476 of a total of 1016 post neonatal infant deaths (Office for National Statistics, 2009). This more conservative estimate was that 43% of deaths between four weeks and one year of age present as SUDI. Due to the huge variety of conditions causing neonatal deaths I did not attempt to estimate the SUDI rate for this age group as it would be too inaccurate. The revised prediction for the number of SUDI cases was therefore around 60 per year (10 between 1 and 4 weeks, 50 over 4 weeks), giving potentially 180 cases in the study period which had been increased to 3 years due to the recruitment difficulties. This seemed realistic at the time as there had been 45 SUDI in the first 9 months although in retrospect it was still an overestimate. At the start of this study, there was no reliable way to estimate the number of SUDI cases in the region; the pathology department at Birmingham Women's Hospital perform post-mortem examinations for many categories of infant death from a large area of England and do not have easy access to data pertinent to just the West Midlands. Reliable estimates can now be obtained from Child Death Overview Panels but these were only just being established in 2009 when this project was being planned.

The intention was to recruit as many as possible of the eligible families. Similar studies have achieved participation rates of approximately 50% (Hynson et al., 2006, Dyregrov, 2004) but these have involved participants of higher socio-economic status than the

local SUDI population. However as we were using clinicians well known to the families to facilitate recruitment, we hoped to recruit 50% giving a sample size of 90.

## **Section 4.7 Methods of data collection**

### **Identification and recruitment of SUDI cases**

The vast majority of SUDI cases in the study area have post-mortem examinations at the Department of Perinatal Pathology at Birmingham Womens' Hospital; two or three SUDI cases a year have post-mortem examinations at Birmingham Children's Hospital. Both these pathology departments were telephoned for details of SUDI cases on a bi-monthly basis. To preserve confidentiality the pathology department only disclosed for each case the dates of birth and death, the referring hospital and the name of the local SUDI paediatrician.

SUDI paediatricians were emailed or telephoned about the relevant cases from their area; although cases were only identified by dates of birth and death as these were rare events the paediatricians were easily able to recall the names of the infants so access the families' contact details. The SUDI paediatricians were asked to outline the study to the parents at a follow-up meeting after the final case discussion; this is typically 4 to 6 months following the death but for some cases was over a year after the death. The SUDI paediatrician gave the parents an introductory study letter and pre-paid reply form to be completed if parents wanted to participate. Parents were also given another pre-paid reply form to return if they subsequently wanted to withdraw from the study; there was also a 24 hour answer phone number for this purpose. A set of study paperwork for each case was sent to the SUDI paediatrician to be kept in the clinical notes as a reminder; paediatricians were also reminded about recruitment by child death administrative staff. In some areas the role of the SUDI paediatrician is carried out

by a specialist nurse. In these cases the specialist nurse was asked to approach the family in the same way as the SUDI paediatrician.

I telephoned parents approximately 2 weeks after the reply form was received; this allowed them time to change their minds prior to the telephone call. During the call, I outlined the 3 options for the study : a home visit with an in-depth interview with case note analysis, a self-completion questionnaire to be returned by post with case note analysis, or case note analysis alone. Telephone contact was chosen as bereaved families have valued this approach previously and if telephone contact is not made parents of lower literacy levels may not respond (Meert et al., 2008a, Hynson et al., 2006)

For parents who opted for an interview, an appointment was to be made to visit them, usually at their home. At the visit the study was explained fully and informed consent to participate obtained. For parents who chose to complete a questionnaire or partake in the case note analysis alone consent forms and questionnaires were sent by post with a prepaid reply envelope included.

A website was set up to try and increase recruitment knowing that significant numbers of parents were not being told about the study by their local paediatricians. This website was advertised by The Lullaby Trust, the national charity for SUDI research and parent support, using their website, Facebook page and Twitter feeds. There were no enquiries received from parents via the website.

This was a complex way of contacting parents but it was an ethical requirement. Clinical researchers are not able to access identifiable patient details for research projects unless they are part of the patient's clinical team; which I was not. I therefore had to rely on SUDI paediatricians to help in recruitment although I was well aware that in

previous similar studies local clinicians have limited researcher's access to bereaved families (Dent et al., 1996).

### **In-depth interviews and questionnaires**

The original plan had been for all parents to complete an initial structured interview at around six months after the death; the structured interview would then guide the purposive sampling for in-depth interviews at approximately one year after the death. This method was revised to offer parents a choice of in-depth interview with case note analysis, self-completion questionnaire with case note analysis, or case note analysis alone. Recruitment had been very slow with many parents not recruited until at least a year after the death; after the first few structured interviews it became clear that most parents wanted to tell their stories in some detail and not be constrained by the questionnaire used in the structured interview. In addition, some parents had declined the study but fed back to their SUDI paediatrician that had they had the option of completing a questionnaire without having to talk to a stranger about events they would have felt able to participate. The structured interview questions were identical in content to the self-completion questionnaire.

When planning the project bereaved parents advised that at least four years were needed after the death before parents could make sense of the events due to their grief. With this in mind follow-up in-depth interviews were planned for parents recruited in the first two years of the study, these interviews took place between 22 and 28 months after the death. These were only possible for cases where infants had died between 1 September 2010 and 31 August 2012 in order to be able to complete the whole project on time.

The in-depth interview and questionnaire covered the following topics:

The original investigation, whether there was a home visit and by whom?

How did the parents feel about the investigation?

What support they received following the death and from whom?

Parental knowledge of the cause of death of their baby.

Parental physical and mental health since the death

Parental employment and time off work after the death.

Parental smoking, alcohol and drug use.

The parental in-depth interview schedules are shown in appendix 4 and structured interview or self-completion questionnaires in appendix 6. Bereaved parents gave advice on the development of the interview schedule and questionnaire.

Prior to the interview I had received no information about the case; the first account of events and cause for death that I heard was from the parents. During my visit, but after the interview, parents were asked to complete the questionnaire.

In-depth interviews were audio recorded and field notes written. In depth interviews lasted between one and five hours; the median time was 2.5 hours. All interviews were conducted in English as this was preferred language of all participating parents. A professional transcriber did the in-depth interview transcription.

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) was completed by all parents having interviews or completing questionnaires and repeated for those who had follow-up interviews. The Hospital Anxiety and Depression Scale is shown at appendix 5.



## **Case note analysis**

The rationale for collecting the case note data was to allow an assessment of the process and outcomes of the JAA, to help further understand parental experiences and allow triangulation of data. The outcomes of the JAA relate to its aims: establishing the cause and risk factors for death and addressing the needs of the family. The process was assessed using details of JAA events recorded in police and health records to ascertain exactly what happened and these were compared with the JAA as described in the West Midlands protocol (West Midlands Police, 2009). This could then be triangulated with the parents' and professionals' views on JAA events. The outcomes were assessed from information on cause of death and risk factors from health and coroners' records as well as details of any social care involvement with the family after the death. Data on causes and risk factors for death were also triangulated with parental understanding of the cause of death; I could not assess their understanding without being able to compare with the documented cause. I used background information on families from police and social care records to help understand parental experiences.

The case notes from health, police, and social care were studied for all cases. I attended a meeting of the senior police officers for Child Protection for each force in the study area (West Midlands, West Mercia, Staffordshire and Warwickshire); following this I was allowed unrestricted access to police case records for all cases. In contrast, access to social care records was often extremely difficult, this was compounded by the fact that each local authority (cases came from ten different local authorities) had different research access procedures. Frequently, I contacted the Child Death Overview Panel administrator prior to contacting social care as they routinely obtain social care information about every child who dies. If the family had not been known to social care I did not contact social care to seek further access to their records. Health records were

accessed without issue as research and ethical approval had been granted by every relevant NHS trust in the region. The ethical approvals are shown at appendix 9.

The case notes from health included infant hospital records, SUDI case records from the SUDI paediatrician, minutes from initial and final case reviews and post-mortem examination reports. I developed a standard proforma for data extraction based on my clinical practice in managing SUDI cases; this was trialled on the first two cases then revised. The health records proforma is shown at appendix 7.

I studied health records for events of the JAA; hospital records for details of events in the Emergency Department, SUDI case records for joint home visits, follow-up appointments and other contacts with parents and case review minutes for details of who attended and when meetings were held. Outcomes from health records included the final cause of death and risk factors identified according to case review minutes and post-mortem examination reports.

I extracted data from police records using a standard proforma; this was developed with a police officer experienced in managing SUDI cases. I studied records for background information on families such as prior parental convictions or domestic violence and events of the JAA such as police actions at the time of the death, forensic investigations at the scene and property taken (for example baby clothes and feeding bottles). The police records proforma is shown at appendix 7.

I requested a copy of the coroner's inquisition (inquest verdict) for each case directly from the coroner's office.

I extracted data from social care records using a standard proforma; this was developed with a social work manager who was experienced in working in child protection. I studied records for background information on involvement with the family prior to

death and outcomes such as details of any investigations after the death or child protection involvement subsequent to death for surviving siblings. The social care records proforma is shown at appendix 7.

In most cases I saw the whole case file and extracted the data myself, in a few cases photocopies of case files were sent by post. In two social care cases social workers completed the proforma themselves and I did not see the case files. I entered data from the completed proforma into an excel workbook.

### **General Practice Records**

The GP records were relevant as they contained information about parental wellbeing; bereaved families are likely to seek information about the death or emotional support from GPs after sudden deaths (Merlevede et al., 2004).

I requested a computer summary printout for all parents for all consultations in the year following the death. This was readily available for most cases although some families were not registered with GPs resulting in no records being available. I recorded the number of consultations during the year, excluding any for maternity services. I coded consultations as to whether they were for bereavement support, acute illness or chronic (pre-SUDI) illness.

### **Interviews with Professionals**

Interviews with professionals took place for the cases where parents had opted to have in-depth interviews. The professionals were SUDI paediatricians, SUDI specialist nurses, police officers and social workers; I attempted to interview all of these professionals for each case although only a minority of families had social workers. The paediatricians and nurses were identified as part of the process of recruiting the families; they usually had contact details for the police officers if not I was able to obtain these via other

police contacts. Social workers' contact details were obtained from the social care case records. In a few cases, professionals could not be identified or had moved posts so could not be contacted.

Professionals were either interviewed in person, after I had viewed the case records or by telephone at a later date. Professionals were asked about the details of the JAA investigation, their involvement with the family, how the multi-agency working had proceeded, and their views on the JAA in general. In some cases professionals were asked to clarify events from the case records or were asked about the rationale for certain decisions such as the reasoning for using police tape to seal off houses.

Interviews were audio recorded and transcribed; they lasted between 10 and 45 minutes.

### **Ethical Issues**

All elements of the WMSUDI study were approved by the Solihull NHS Research Ethics Committee without issue.

Research with bereaved parents is a sensitive area and there were safeguards in place to protect families. The bereaved parents were contacted in the first instance by their local SUDI paediatrician about the research study; in several cases the paediatricians did not feel it was appropriate to ask the parents due to mental health concerns, fragile parental relationships or domestic violence. Once parents had agreed to be contacted about the research project there was a two week delay prior to them being telephoned about the study to allow them further time to change their minds. Similarly, interview dates were always arranged at least two weeks ahead so not rushing parents into decisions about participation. At the start of each research interview parents were told in detail about the study and reminded that they could stop the interview or withdraw

from the study at any point during the interview or subsequently. Often parents needed to stop the interview when upset but in all cases, having recovered their composure, parents wanted to continue. At the end of the interview, parents were given an information sheet with details of the Lullaby Trust so they could access these services if needed. I attempted to telephone all parents a few days after the interview to check that they had recovered from the interview. No one reported any further problems but I was not able to contact some families.

In some instances, it was clear that parents had significant mental health issues either from their in-depth interview discussions or completion of the HADS questionnaire. I discussed these with the parents at the time of the interview and suggested that they contact their GP or the Lullaby Trust for further help. In some cases I offered to contact the GP on their behalf.

As part of the informed consent process, parents were told that if they disclosed information that could lead to concerns that any child (living or dead) may be at risk of abuse or may have been previously, further action would need to be taken. This would involve discussing the case with PS (who is a Designated Doctor for Child Protection) and possibly referring the matter to police and social care. I did have to make a child protection referral for one family, where the mother had significant mental health issues that were impairing her ability to care for her remaining children.

## **Section 4.8 Methods of data analysis**

### **Data Management**

I entered data from the closed questions in the questionnaires and structured interviews into SPSS databases for further statistical analysis. Answers from open-ended

questions and comments made by parents during structured interviews were analysed with the in-depth interview data.

I entered data from the case note proformas into Excel spreadsheets; with separate tables for records from health care, police, social care and the parents' GP. I created an additional cause of death table showing the cause of death as identified by the post-mortem examination, coroner and final case discussion.

I analysed qualitative data using a Framework Approach (Ritchie and Spencer, chapter 9 in Bryman and Burgess, 1994) with NVIVO software. I checked transcripts for accuracy with the audio-recording prior to coding. The codes were not determined in advanced but developed as transcripts were coded.

### **Initial analysis**

After I had coded ten parental interviews I summarised the codes; the supervision team read the scripts, we discussed the codes and refined where needed. Following this the remaining parental interview transcripts were coded, field notes and comments from questionnaires and structured interviews were coded in the same way. The professional interviews were coded using the same coding structure although this required the development of some additional codes.

I coded and analysed the few parental follow-up interviews in exactly the same way as the initial interviews. Firstly, this was because the content was similar to the original interviews and only one new code of 'Changes' was required to code these completely. In addition, the time scale of follow-up interviews was not very different to some initial interviews; follow-up interviews took place between 22 and 28 months after the death and some initial interviews did not take place until nearly two years after the death. One topic that had been planned for follow-up interviews was how parents found caring for

subsequent-born infants but this was addressed in the initial interview for five families as they had either already had another baby or had surviving multiples.

In some cases I used the case notes directly to corroborate or refute events described by parents during their interviews; such as police not allowing parents to go with their baby to hospital. In this case the time the police arrived at the house is clearly documented as is the time the parents were driven to hospital by police nearly 30 minutes later. In another case, the mother said that no doctor spoke to her at the Emergency Department but there is a medical history completed by a Consultant Paediatrician.

I held a project steering group meeting where the coding structure was discussed; this allowed for a variety of perspectives from other professionals and bereaved parents to consider the early results of the data analysis. Whilst there were some useful insights for analysis gained no-one felt that any changes were needed to the coding structure.

### ***Case boundaries***

Considerable amounts of data were collected for each case but not all of these were included in the analysis; only data directly relevant to the JAA were. For example, in some cases, babies were successfully resuscitated in the ED only for the baby to die subsequently in the intensive care unit. In such cases events on the intensive care unit have been excluded as these do not form part of the JAA.

The coronial system runs in parallel with the JAA but is a separate process. Despite this, I have included the data on coroners as interactions with the coroner have a significant impact on the functioning of the JAA and this then can impact on the parents' experiences.

Social care is intended to be an integral part of the JAA but in practice social care investigations often are a separate process. Where cases have had social care investigations these data have been included even if the investigation was entirely separate from the JAA; this is to allow analysis of joint working practices and look for ways that these could be improved.

## **Section 4.9 Results of analysis**

### **Codes**

I developed the following codes initially for the parental interviews and then also used them for the professional interviews:

- Pre-hospital – Any event prior to the infant dying and events at the scene of death prior to transfer to hospital. This code also included events taking place at the home address while the parents were still at the hospital with their baby for example interactions between police and other family members.
- Hospital – Events in the hospital at the time of death including return visits to see the baby again prior to post-mortem examination.
- Joint Home Visit/ Return from hospital – Events when parents returned home from the hospital including any joint home visit (JHV) by police officers and the SUDI paediatrician or specialist nurse.
- Follow-up – Any contacts after the JHV between the parents and SUDI paediatrician or specialist nurse, police officers, coroners' officers or social worker.
- Coroner – Any interactions with the coroner or coroner's officers including the Inquest
- Social care – Any interactions with social workers.



- Police - Any interactions with police officers.
- Paediatrician – Any interactions with the SUDI paediatrician or specialist nurse.
- Primary care – Any interactions with any member of the primary care team.
- Multi-agency meetings – Any experiences relating to the initial or final case discussion.
- Blame – Any mention of blame whether it was self-blame, feeling blamed, blaming others, not feeling any blame and professionals trying not to avoid blame.
- Cause of death – description of cause of death whether accurate or not.
- Understanding risk factors – description of risk factors relevant to the infant death.
- Needing answers – parents wanting answers as to why their baby died and if the death could have been avoided.
- Wellbeing – descriptions of parental physical and mental health after the death and attempts parents made to improve their wellbeing such as attending counselling services.
- Work – description of returning to work after the death and interactions with employers and colleagues.
- Changes – changes parents have made to their lifestyle or ways in which they have changed as people as a result of the death.
- New baby – experiences for a subsequent sibling or surviving multiple birth sibling.
- Fathers – experiences fathers feel are different for them as compared with their partners’.
- Negatives – any event described as a negative experience for whatever reason by parents or professionals.

- Positives – any event described as a positive experience for whatever reason by parents or professionals.

The following codes were developed specifically for the professional interviews.

- Balance of caring vs criminal – any mention of trying to balance the need of professionals to investigate the death fully yet be supportive to the family
- Working together – experiences of multi-agency working
- Professional views – views on the JAA in general rather than relating to the specific case that was the subject of the interview

### **Timelines**

A timeline of events was created for each case. This started with any significant events in the infant's life which could have been related to the death; it included all the events of the JAA, any follow-up visits and concluded with the Inquest and the return of any property taken by the police. The timeline included data from in-depth interviews with the parents, case notes and professional interviews. The timeline only had a summary of the event with a reference to the relevant interview rather than verbatim quotes. In addition to the details of events, there were columns for significant positive and negative experiences of both parents and professionals. Timelines were also created for cases without parental interviews although these contained far fewer data. The timelines enabled triangulation of data between parental and professional recall and events documented in the case notes. It also allowed for easy comparison of experiences and views within each case.

### **Comparison with Gold Standard JAA**

A gold standard JAA was developed with reference to the local multi-agency protocol for investigating SUDI and Working Together to Safeguard Children. This was discussed and

refined with PS, who is an expert in this field. Using the timeline, each case was compared with the gold standard to detail any deficiencies or highlight good practice in the JAA. The gold standard JAA is outlined in tables 18 and 19.

**Table 18 Gold standard JAA template**

Phase	Time	Event	Achieved yes/no/partially Details if needed
<b>Pre-hospital</b>	Immediately after death or baby found collapsed	Ambulance arrives promptly and transfers parents and baby to hospital even if baby declared dead by paramedic. Parents not to be separated from their baby.	
		If police arrive at home they sensitively secure the scene whilst awaiting specialist child protection police officers.	
<b>Hospital</b>	Next few hours	On arrival at ED if resuscitation attempted parents allowed to watch and kept updated of events by staff.	
		Once baby declared dead the family is allowed to spend as much time as they wish with their baby, whilst being supervised by police or medical staff.	
		Consultant paediatrician to examine the body and immediate post-mortem samples to be taken.	
		Consultant paediatrician and specialist child protection police officer to take medical history and history of events from parents. They should explain procedures to parents (need for JHV, autopsy etc.)	
		ED staff to ensure parents are supported and cared for whilst in the department	
		Liaison between police, social care and health about the family	
<b>Joint Home Visit (JHV)</b>	Within 24 hours	JHV by SUDI paediatrician (or specialist nurse) and specialist child protection police officer. If this is to be delayed arrangement should be made for parents to gain access to their home if needed.	
<b>Multi-agency meetings</b>	Within 2 working days	Early multi-agency information sharing meeting by telephone or in person to be held within 2 working days of death. GP, HV, specialist child protection police, SUDI paediatrician or specialist nurse and social care to attend.	
<b>Post-mortem examination</b>	Within 5 working days	Post-mortem examination by paediatric trained pathologist following protocol as per Kennedy report	

Table 19 Gold standard JAA template continued

Phase	Time	Event	Achieved yes/no/partially Details if needed
Follow-up	2 to 4 weeks later	2 to 4 weeks later follow-up visit (possibly telephone call) by SUDI paediatrician or specialist nurse (Specialist child protection police too if needed) to give interim pm results and offer further information.	
	1 to 6 months	Parents kept up to date with progress of investigations during next 6 months by SUDI paediatrician or specialist nurse or specialist child protection police.	
	Within 6 months	Post-mortem report completed and sent to coroner and SUDI paediatrician	
	Within 6 months	Final Case Discussion attended by SUDI paediatrician, specialist nurse, specialist child protection police, social care, HV and GP	
	After final case discussion	Follow-up meeting between SUDI paediatrician or specialist nurse (possibly specialist child protection police too) and parents to explain cause of death, answer further questions and prepare them for the inquest.	
	After Inquest	Specialist child protection police to contact parents about returning any property and to arrange for this to be done in a sensitive manner	

## Framework Matrices

I studied the qualitative dataset as a whole and re-read the content of several individual codes to try and determine how the codes were related to each other. There was a huge amount of information and without being able to subdivide it further it would be difficult to generate any precise meaning from it. Eventually I arranged the codes into three broad themes: experiences of the JAA, understanding the cause of death, and parental wellbeing. A framework matrix was developed for each theme and included data for each case from parental and professional interviews and parental questionnaires. The matrices allowed for comparison of experiences within cases between parents and professionals as well as comparison between cases. The matrices were used as a way of summarising data; quotes were not put in them but line

references to the relevant transcripts. An example of the matrix for experiences of the JAA is shown in table 20.

Table 20 Example of framework matrix for JAA experiences

	Pre-hospital	Hospital	Joint Home Visit	Follow-up	Coroner	Social care	Multi-agency meetings	Working Together	Positive experiences	Negative experiences
Parent interview										
SUDI paediatrician interview										
Social worker interview										
Police interview										

## **Section 4.10 Summary**

The West Midlands SUDI study is an evaluation of the JAA from both parents' and professionals' perspectives with the aim of improving the wellbeing of bereaved parents. It is a mixed methods research project, using structured questionnaires, case note analysis and in-depth interviews. The overall theoretical perspective is that of pragmatism; the choice of research design was selected principally in that it would answer the research questions rather than selecting a design to fit with a pre-determined method or paradigm.

I was notified of all SUDI cases during the study by the pathologists performing the post-mortem examinations; I then asked the local SUDI paediatrician for each case to outline the study to the parents at the end of the JAA investigation, this was typically six to twelve months after the death. Participating parents could choose to complete structured questionnaires, have in-depth interviews or allow access to case records alone. I also conducted in-depth interviews with police, SUDI paediatricians and social workers who were involved in the JAA investigations for each case. I used a Framework approach to analysis; this enabled comparison of experiences between parents, professionals and case records both within the same case and between different cases. In addition, by comparing cases with a 'gold standard' JAA investigation, I was able to identify both good and poor professional practices.

The next chapter describes the results of recruitment, the participating families and professionals.

## **Chapter five Introduction to results.**

In the previous chapter the aims, methodology and methods of the West Midlands SUDI study were explained in full. This chapter describes the recruitment of SUDI cases, the difficulties of recruitment and compares the recruited cases with those not recruited. The chapter includes description of the recruited families, their participation in the study and their wellbeing as well as a description of the recruited professionals.

### **Section 5.1 Recruitment of cases**

I obtained the dates of birth, dates of death, referring hospital and SUDI paediatrician for all SUDI cases in the region from the pathologists who performed the post-mortem examinations. I then asked the SUDI paediatrician for each case to inform the parents about the study during a follow-up consultation at the conclusion of the JAA, a few months after the death. If the parents were interested in the study they completed a study referral form with their contact details which were sent to me; however not all cases referred to the study by SUDI paediatricians were subsequently recruited as some parents then declined to participate. This system maintained the confidentiality of SUDI cases until the parents consented to participate in the study whilst enabling me to track cases to ascertain which had been recruited. Some SUDI paediatricians also contacted me to explain why they had been unable to refer cases.

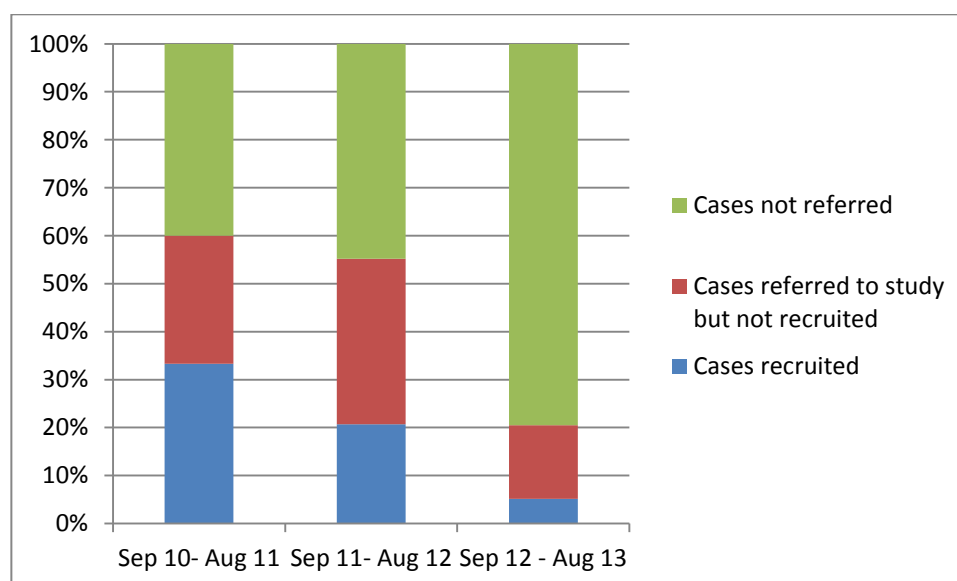
There were 109 eligible SUDI cases having post-mortem examinations at Birmingham Women's Hospital (BWH) and four further cases from Birmingham Children's Hospital. 23 SUDI cases were recruited, all from BWH giving a recruitment rate of 20%.

Cases were recruited between April 2011 and September 2013. Cases were referred to the study by SUDI paediatricians; these referrals slowed significantly in the last year of the study. In the first year of the study 60% of cases were referred, in the second year



this was similar at 55% but for the final year it was 21%. The proportion of referred cases that were finally recruited into the study also fell from 56% in the first year to 38% in the second year and 25% in the final year. The proportion of cases recruited over time is illustrated in figure 6.

**Figure 6 Proportion of eligible cases referred and recruited to study**



A major reason for this was that there was a new coroner appointed for one part of the study area, where the majority of SUDI cases occurred. The new coroner refused to release post-mortem examination reports or allow final case discussions prior to the Inquest which were not taking place until several months' after the death. SUDI paediatricians were not permitted to contact families in the interim. These actions resulted in delays in completing JAA investigations and as cases could only be recruited once the JAA investigation was complete this prevented timely recruitment from this area; additionally more families were lost to follow-up due to the delays. Prior to the change in coroner 76% of cases from the area had been referred to the study (although not necessarily recruited), after the change the referral rate was 20%. In many other areas SUDI paediatricians failed to ask families about the study; the reasons for this are unclear. In some the SUDI paediatricians explained that they did not ask the parents

about the study as they thought they would be too distressed, in others the SUDI paediatricians initially would agree to approach the family about the study but then never responded to my requests for further information regarding whether the family had been informed of the study and what the outcome was. In many cases SUDI paediatricians did not respond to any communication from me about the study.

Recruitment finished in March 2014. I had been analysing data concurrent with interviewing parents and professionals and it was becoming increasingly clear that no new themes were emerging as parents and professionals were describing the same issues with the JAA. My initial analysis suggested that there were specific difficulties with the initial police response and that while the JAA led to a greater understanding of why infants died, parents did not feel supported by professionals. As I continued analysing transcripts there were little new data emerging that were relevant to this theory; therefore the concept of theoretical saturation had been reached (Holloway, 2013 p178) so I stopped recruiting cases.

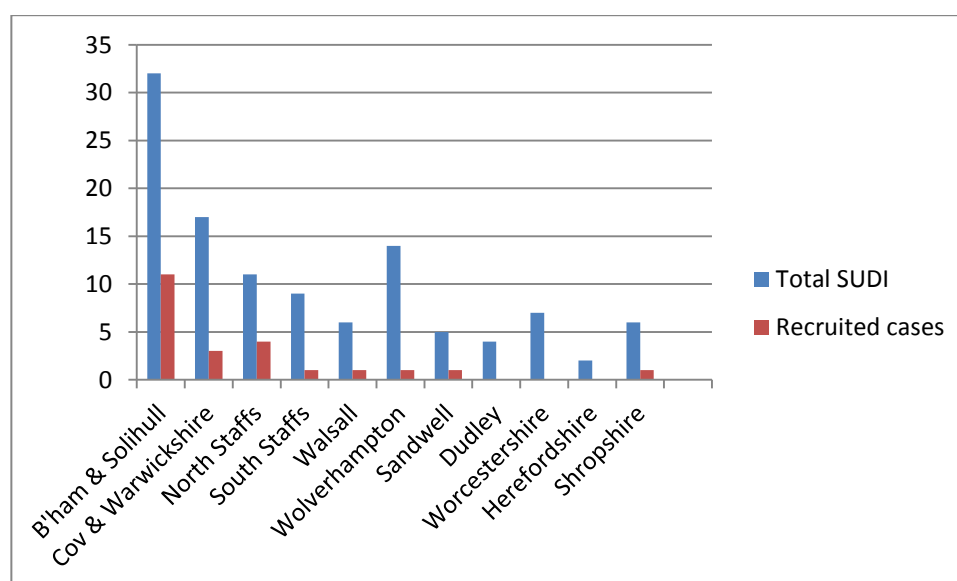
The reasons for non-recruitment of cases are shown in table 21. Only about half of the parents of eligible cases were informed about the study by their SUDI paediatrician and of these around half of parents consented to take part.

Table 21 Reasons for non-recruitment of cases

Reason for non-recruitment	Number of cases (%)
JAA not complete at study closure	4 (4.4)
Case not suitable due to child protection investigations and Serious Case Review	5 (5.5)
Parents not offered follow-up by SUDI paediatrician after FCD	6 (6.6)
Parents declined or did not attend or lost to follow-up by SUDI paediatrician after FCD	14 (15.5)
Parents not asked by SUDI paediatrician	32 (35.5)
Parents declined to participate in study when asked by SUDI paediatrician	21 (23.3)
Parents initially agreed to study then subsequently declined to participate	8 (8.8)
<b>Total number of non-recruited cases</b>	<b>90</b>

The recruitment rate varied widely by area, the highest recruitment was in Birmingham and Solihull where 34% of eligible cases were recruited. Three areas recruited no cases. The contribution of cases from different areas is shown in figure 7.

Figure 7 Recruitment from different areas



## **Section 5.2 Comparison between recruited and non-recruited cases**

### **Social deprivation**

I compared the social deprivation of recruited SUDI cases with non-recruited cases using the Income Deprivation Affecting Children Index (IDACI)(Department for Education, 2014). I selected this rather than the more general measure of the Index of Multiple Deprivation as IDACI relates specifically to children and families. The IDACI score gives the proportion of children in the area who are living in income deprivation based on households receiving social security benefits or tax credits with an income (excluding housing benefits and costs) below 60% of the national median. The lower the IDACI rank the greater the deprivation of the area. The score and rank relate to a fixed geographical area with a population of approximately 1000. The IDACI is based on postcodes and I obtained the scores and ranks for the recruited cases. In order to preserve the confidentiality of the non-recruited families the IDACI their scores and ranks were obtained for me by the pathology department at Birmingham Women's Hospital; these were not available for two non-recruited SUDI cases so the analysis is based on 111/113 SUDI cases .

The mean scores and ranks for recruited and non-recruited cases were not significantly different; these are shown in tables 22 and 23. Therefore social deprivation of the locality that recruited families and non-recruited families lived in did not therefore differ significantly; this however is a broad picture and individual families may be considerably more or less socially deprived than the score or rank implies.

**Table 22 Social deprivation IDACI scores of SUDI cases**

	Mean IDACI score	95% CI limits of mean IDACI score	Independent t test
Recruited cases	0.314	0.232-0.395	t (109) = - 1.21 p=0.229
Non recruited cases	0.367	0.328-0.406	

**Table 23 Social deprivation IDACI ranks of SUDI cases**

	Median IDACI rank	Mean IDACI rank	95% CI limits of mean IDACI rank	Independent t test
Recruited cases	6702	9206	5617-12796	t (109) = 0.654 p=0.514
Non recruited cases	5134	8012	6419-9605	

## Age

There was no difference between the ages of recruited and non-recruited cases. The mean age of recruited cases was 100 days (95% CI 69-131 days). The mean age of non-recruited cases was 105 days (95% CI 88 -123 days).

I was unable to compare the maternal age between recruited and non-recruited cases as maternal age was only available for recruited cases.

## Section 5.3 Details of participation

### Interviews

14 families chose to have in-depth interviews, six families had structured interviews, two families allowed case note access alone and one family completed a postal questionnaire. Six of the families having initial structured or in-depth interviews had in-depth follow-up interviews.

Structured interviews took place with a mean time of 27 weeks after the death (range 20 – 44 weeks); in-depth interviews took place with a mean time of 50 weeks after the death (range 36-80 weeks). Follow-up interviews took place with a mean time of 2 years and 2 months after the death (range 2 years 0 months to 2 years 4 months).

In-depth interviews with professionals working with the cases were held in 12/14 cases that had in-depth interviews; the relevant professionals could not be contacted in two cases due to retirements and personnel changes. Seven cases had CAIU police officers and SUDI paediatricians interviewed, one case had a CAIU police officer and a SUDI specialist nurse, two cases had CAIU police officers, SUDI paediatricians and SUDI specialist nurses, and two cases had CAIU police officers, SUDI paediatricians and social workers.

### **Case records**

SUDI paediatrician records were obtained for all 23 cases and police records for 22/23 cases. Coroners' inquisitions and post-mortem examination reports were obtained for all cases, social care records were obtained for 18 cases. In two cases CDOP administrators established that there had been no involvement by Social Care with the families so I did not seek further access to the records. In three cases there were no social care records held on families.

GP records were obtained for 22/23 mothers and 10/13 fathers; the missing records relate to parents not being currently registered with a GP.

## **Section 5.4 Description of participating families and cases**

The cases are not described individually in order to preserve confidentiality. The mean age of cases was 100 days (14 weeks 2 days); 16 cases were male infants and 7 female. 16 cases remained unexplained after a full JAA investigation and 7 deaths were found to

be due to medical causes. In 13 cases both parents took part in the study, completing interviews or questionnaires and ten mothers took part alone; two of these mothers agreed to case note access alone. Lone mothers were supported during interviews by friends or their own mothers. In two cases, grandmothers contributed to the interview as they had been present during the JAA investigation.

In 16 cases, the parents were married or in a stable relationship with each other although not all couples lived together. There were seven single mothers; four of these had split from the father before the death and three after the death.

Seven SUDI cases were the mothers' first born child, four were second born children and twelve had two or more older siblings. Two SUDI cases were from multiple pregnancies leaving surviving infants. Twelve families did not have a further pregnancy during their time in the study, four families had new babies at the time of the initial interview and three mothers were pregnant. At follow-up interview, two further families had new babies and two other mothers were pregnant.

The mean maternal age at interview was 31 years with a range of 18 to 43 years. The mean paternal age at interview was 35 years with a range of 21 to 44 years.

Employment data were available for all 13 fathers and 21/23 mothers. 11/13 fathers were in employment and two were unemployed both at the time of death and at interview. 7/21 mothers had returned to work at the time of interview; the remainder were on maternity leave or were stay at home parents. 3/21 mothers were working at the time of death.

The highest educational achievement for ten mothers was completion of secondary school to age 16 years, eight mothers completed some further education after the age of 16 and four mothers were university graduates. Four fathers were university

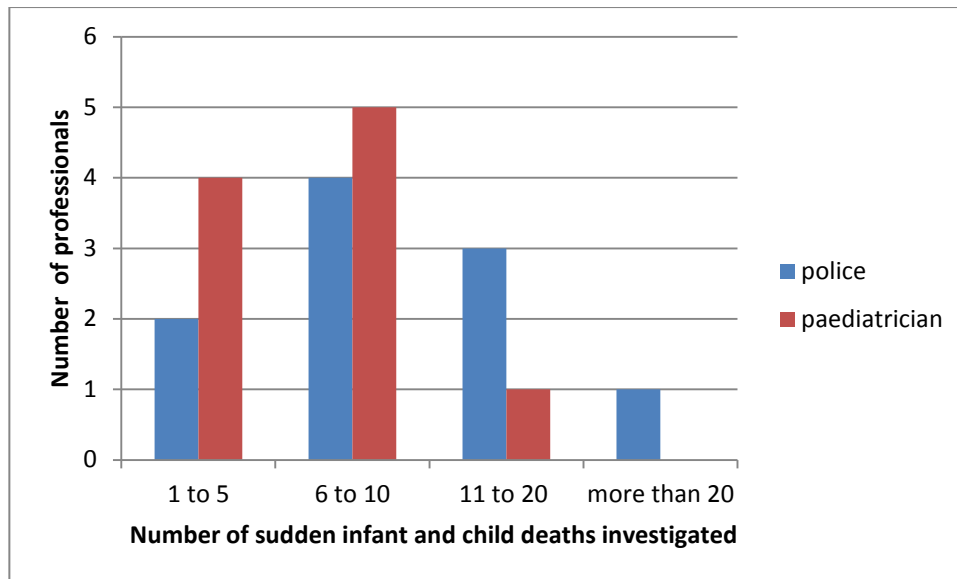
graduates, six had completed some further education and three were educated to secondary school level only.

## **Section 5.5 Description of participating professionals**

There were 12 cases which had in-depth professional interviews; these involved ten paediatricians, two of whom were interviewed twice about two different cases. There were 11 police officers interviewed, one of whom was interviewed twice about two different cases. The experience of these professionals in using the JAA to investigate sudden infant or child deaths is shown in figure 8. Three of the paediatricians were particularly experienced being regional designated doctors for unexpected death. In general, police officers had greater experience of using the JAA than paediatricians as there are many less police officers investigating sudden infant and child deaths than paediatricians. For example, in the West Midlands police force (which covers the entire West Midlands County) there are seven CAIU police teams each led by a Detective Inspector (DI). The DI typically leads the police element of the JAA, attending the hospital, JHV and case discussions. In comparison there are ten SUDI paediatricians for Birmingham alone and many more in other parts of the West Midlands.



**Figure 8 Experience of professionals managing SUDI cases**



## **Section 5.6 Parental Wellbeing**

This section mainly includes data from structured questionnaires although some interview data are presented to create a description of the families and their wellbeing after the death. All quotations used have been anonymised as far as possible to avoid possible identification of cases; therefore case reference numbers have not been used. Quotes were selected from cases to help illustrate findings. Some cases had more quotes selected than others; this was due to either a longer interview resulting in a larger number of quotes to select from or cases that highlighted particular issues. The distribution of the selection of quotes from the 17 cases having in-depth interviews is shown in table 24 below.

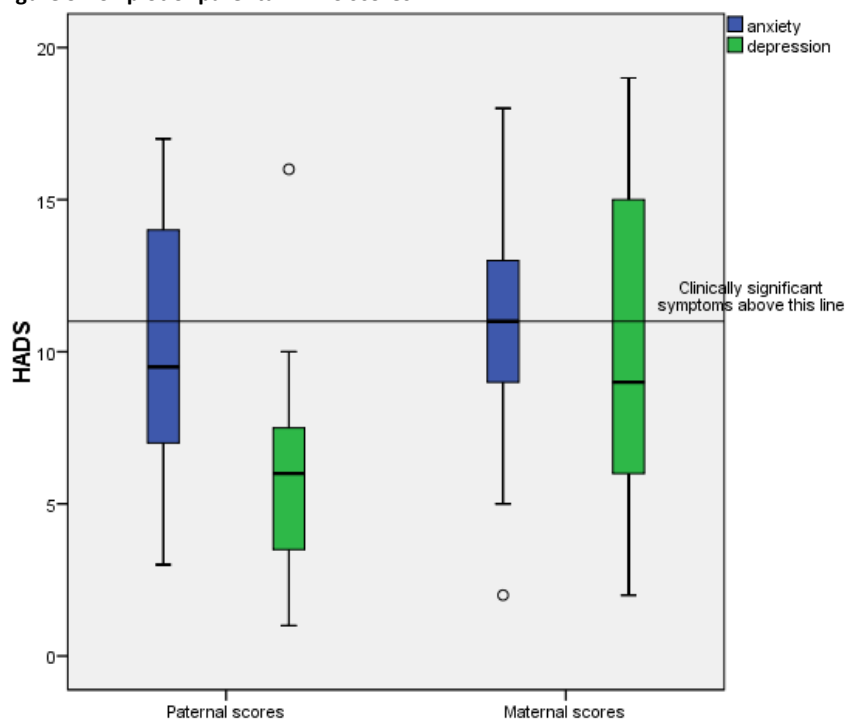
**Table 24 Distribution of quotes from cases illustration parental wellbeing**

<b>Case code</b>	<b>Number of parental quotes used</b>
A	2
B	3
C	2
D	1
E	1
F	2
G	0
H	1
I	1
J	0
K	3
L	1
M	0
N	1
O	2
P	2
Q	2

### **Anxiety and Depression**

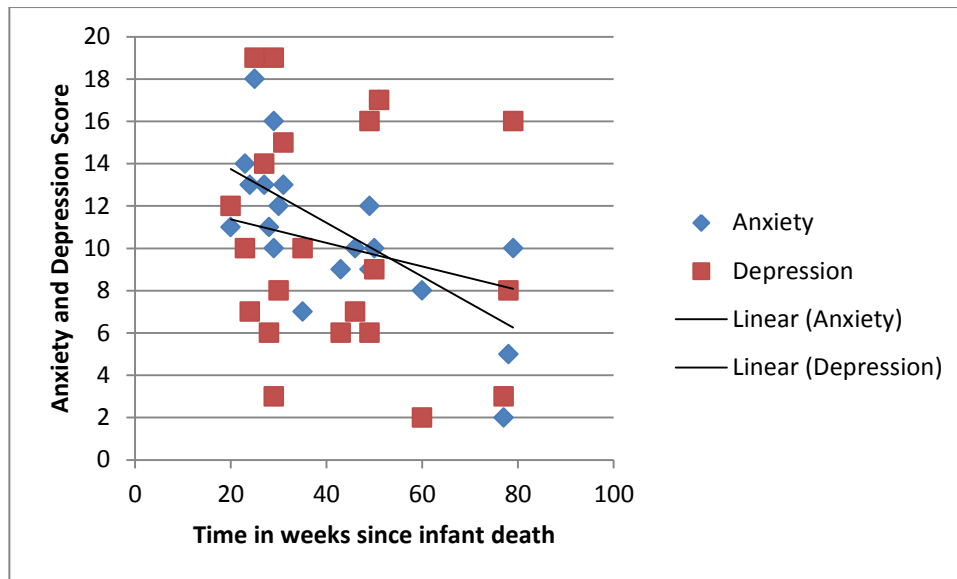
21 Mothers completed the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983); this has a maximum score of 21 with a clinically significant score being 11 or more. 11/21 mothers had anxiety scores of 11 or greater and 8/21 had depression scores of 11 or greater. The mean anxiety score was 11.0 (95%CI 9.2-12.7) and mean depression score was 10.1 (95% CI 7.7-12.6). 13 fathers completed HADS. 5/13 had anxiety scores of 11 or greater and one father had a depression score greater than 11. The mean anxiety score was 9.9 (95% CI 7.2-12.7), the mean depression score was 6.4 (95% CI 4.0-8.8). Therefore nearly half of the mothers had clinically significant anxiety and depression at the time of interview but these issues were less common in the bereaved fathers. The maternal and paternal HADS scores are illustrated in figure 9.

**Figure 9 Box plot of parental HADS scores**



Mothers completing HADS sooner after the death had higher scores for anxiety than those doing so later but depression scores were less related to the time passed since the death. These are shown in figure 10. Parental HADS scores did not relate to the time since death.

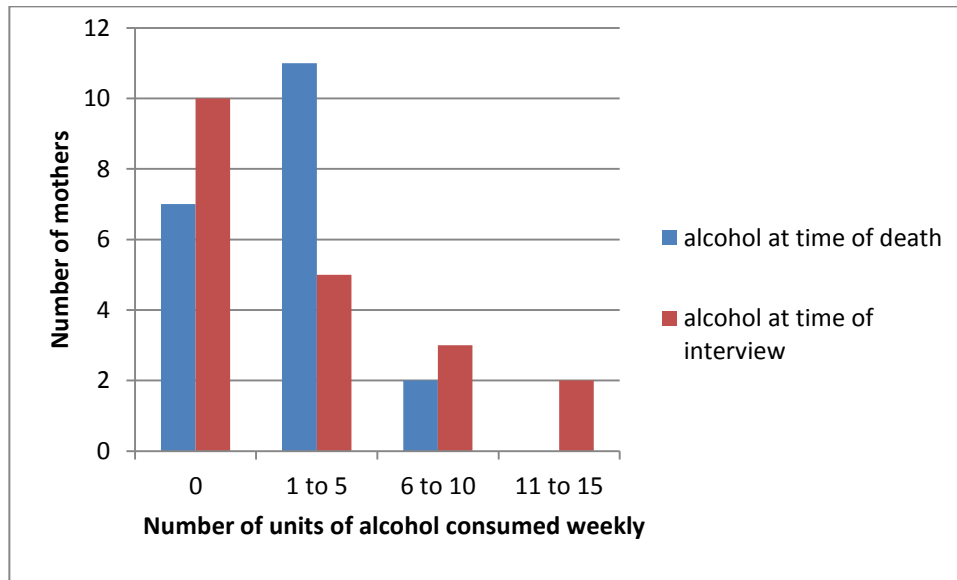
Figure 10 Maternal HADS and time since death



## Alcohol

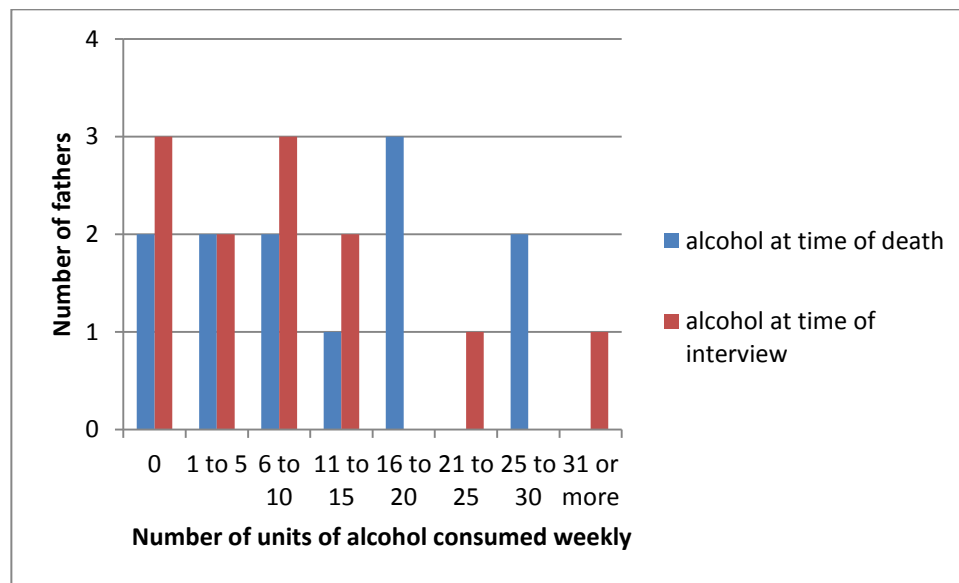
Data on alcohol consumption were available for 21/23 mothers. One mother had a significant alcohol problem, drinking 54 units per week at the time of death increasing to 84 units by the time of interview. This case has been excluded from the analysis of median alcohol consumption. Alcohol consumption remained similar with mothers consuming a median of 1.5 units weekly at the time of the death and 1.0 unit weekly at the time of the interview. Seven mothers increased their alcohol intake after the death, five decreased it and seven remained the same. Maternal alcohol consumption is shown in figure 11.

**Figure 11 Maternal alcohol consumption**



Data on alcohol consumption were available for 13/13 fathers. One father had a significant alcohol problem drinking 84 units per week at the time of death increasing to 108 units by the time of interview. This case has been excluded from the analysis of median alcohol consumption. Alcohol use declined slightly with fathers consuming a median of 12.5 units weekly at the time of the death and 8.0 units weekly at the time of the interview. Three fathers increased their alcohol intake after the death, three decreased it and six remained the same. Paternal alcohol consumption is shown in figure 12.

Figure 12 Paternal alcohol consumption



Parents were asked about their use of alcohol during interviews; several spoke of using alcohol as a coping strategy with four parents realising that their drinking was problematic.

...more binge drinking, I weren't an alcoholic, I didn't need to have a drink ...I

was just a bit stupid with it ...it was like it was something to do...it was just

"what can I do tonight, just might as well get drunk" (mother)

I just didn't want to think about nothing, I just was drinking....sometimes a

couple of bottles of whisky a day... And because I was having nightmares I didn't

want to remember them ... so I would just black out and then hopefully didn't

remember nothing when I woke up. (father)

Other parents however avoided alcohol recognising the detrimental effect it could have on them.

I could very much see alcohol was going to steer me into a depression, more of a depression, so I made the conscious decision that actually I wasn't going to drink because I could quite easily see myself sat in a corner with wine around and me a blubbering mess. (mother)

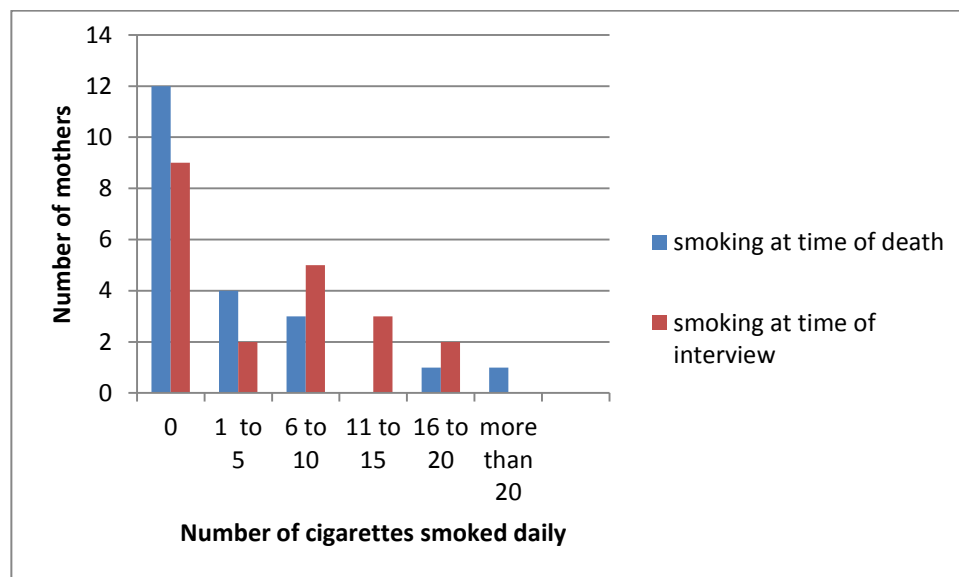
## Smoking

Data on smoking were available for 21/23 mothers; 12/23 were smokers at the time of interview and 9/21 smoked at the time of the death. Cigarette consumption increased from a median of none at the time of death to 5 cigarettes daily at interview. One mother described how she smoked more as a way of coping after the death.

I found myself when I lost her..."oh it's her nappy time now, what will I do, I'll have a fag. She's meant to be having her bottle now; I'll go and have a fag".  
(mother)

Mothers' cigarette use is shown in figure 13.

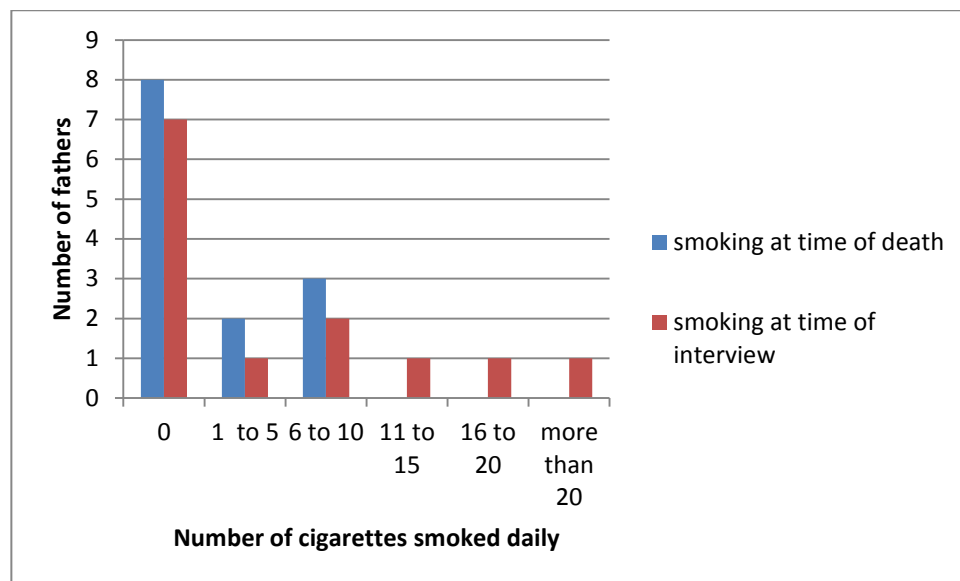
Figure 13 Maternal smoking habits



Data on smoking were available for 13/13 fathers; 6/13 were smokers at the time of interview and 5/13 smoked at the time of the death. Although cigarette consumption appeared to remain static with a mean of zero cigarettes smoked at both time points, 4/6 smoking fathers increased their consumption between the death and interview.

Fathers' cigarette use is shown in figure 14.

**Figure 14 Paternal smoking habits**



## **Coping with the death**

### ***Recovery***

During the interviews parents spoke about how they had coped following the death of their baby. A common sentiment was that they would never be the same as before the death, the magnitude of the loss did not diminish with time although the pain did lessen.

I don't think I'll ever be the same, I never can .... There is something that actually breaks in you that you cannot repair... (mother)



It's not something I would ever forget ... but it is getting a lot easier than it was.

(mother)

Parents described struggling to recover:

I can go a few weeks and feel.... and then something will happen and I'll be back in the hole again. But it's been like that for the last 6 months. I feel like I am moving on and then I just hit a.....I just go back down again. (father)

I still don't sleep now, I have nightmares all the time.....it was just...there was nothing we could do. (father)

For some parents, they found frequent reminders of their baby too painful to deal with and avoided seeing other babies or returning to places they had visited together.

I very rarely leave the house because I don't want to see people with babies... (mother)

There is just an army and multitude of places that we can't go... It's just...it's everything, it gets into everything, every aspect of your life. You've really got nothing normal left. (mother)

The memories were so painful for one family that they never returned to live in their house again and moved away.

Well you couldn't get me back in that house for love nor money ..... We needed a fresh start. (mother)

However, other families took comfort from happy memories of their baby in their home.

I loved it here and I still do, that's why I'm not ready to move just yet... I feel like she's still here ... and she left me here...it makes me feel a lot more at ease and everything. (mother)

Parents also explained how they had managed to cope with the death and begin to make a recovery. Some refused to let grief consume them and tried to focus on the positives of their life rather than their loss.

I think you are always going to carry grief with you and...but you can choose how you carry it, so it's not that you try and block it off but you can use it to try to help you grow as a person. (mother)

Fundraising for medical charities played an important role in some parents' recovery:

...And then she died and two days afterwards, I went out for a run and I said to my wife I'm going to do things in her memory and since then I've ran I think 5 half marathons... all in her memory and all for FSID. (father)

### ***Families***

Parents discussed their relationships; some felt that they had become stronger while others had come under pressure or broken down.

I just think it's drawn us closer together... ...I actually think I find myself being a lot more protective of her now than I ever have done previously (father)

Like he's got a second job now just to not come home ... We don't communicate like we used to do before ...it's like he hates me and I hate him but we can't say .... (mother)

Many families had older children and frequently parents spoke of how this forced them to try and stay positive and not become overwhelmed with grief although this was not always possible.

You just have to carry on cos you've got other kids and that. Sort of like smiling and putting a brave face on it. (mother)

Sometimes I feel like I literally can't get out of bed, I don't want to get out of bed, there is nothing to get out of bed for. And I know that's wrong because I've got the other children... (mother)

Similarly, another pregnancy or a new baby gave parents a new focus.

I've had to be alright because of being pregnant. (mother)

I am so glad that I got pregnant soon after because that gave me a focus to...I just felt like everything had been taken away from me, I was on maternity leave without my baby, I just didn't know where I was going with anything, nothing really mattered as much. (mother)

However, for the families with surviving multiple birth infants it was not so straightforward. Parents found it difficult to grieve for their loss at the same time as caring for survivors.

I don't think I could have accepted it because if I accepted it and dealt with it I didn't know how much I would break down and I needed to be there for [survivor] because I still had a tiny baby that needed me constantly. (mother)

I was still dealing with a baby and there have been times when that has been very difficult. (mother)

## **Returning to work**

Many parents found returning to work helpful; it gave them something to focus on other than their loss and provided a structure to their lives. Three fathers and two mothers returned to work within two weeks of the death

For me when I went back to work, it takes my mind off it and is my sort of..... It's my escape from it. (father)

It was hard but it was quite a supportive environment and that was actually quite helpful in bringing that structure to your life because after two weeks, you are sort of wondering around without any sort of structure and it's very hard.  
(father)

Part of my concern was if I go away, back to work, how will my wife be and how will she cope... (father)

Employers were frequently very supportive to bereaved parents; allowing them paid time off work in the weeks after the death and to attend follow-up meetings. Some employers arranged bereavement counselling. All mothers who returned to work thought their employers were helpful as did 7/9 fathers; none thought them unhelpful.

Two mothers found returning to work too painful and subsequently left their jobs; one was working in a day nursery and struggled to care for the young children in her charge. Another found she was unable to concentrate on office work.

Self-employed parents typically had to return to work much sooner than other parents or they would lose income and suffer longer-term damage to their businesses. One mother and two fathers had to return to work within a week of the death because of this; all found this very challenging.

Fathers often worried about leaving their partners at home alone when they returned to work.

## **Section 5.7 Summary of introduction to results**

There were significant difficulties in recruiting cases for the study, the greatest being that only half of parents were informed of the study by their SUDI paediatrician. 23 cases were recruited, 21 of these giving detailed interview or questionnaire data; these involved 21 mothers and 13 fathers. Theoretical saturation of data was obtained. Cases came from a wide range of social backgrounds and family composition but they reflected the whole SUDI population in the region in terms of social deprivation scores and age.

Half of mothers had clinically significant anxiety and depression symptoms; one-third of fathers had clinically significant symptoms of anxiety but only one father for depression. Whilst parental alcohol use overall did not differ significantly before and after the death, some parents became reliant on alcohol as a way of coping and began to drink excessively. Similarly, parents smoked more cigarettes following the death.

Parents' lives were indelibly changed by the death but by the time of the interview most parents felt that they had moved on from the intense pain of their initial grief. Some parents' lives became quite restricted as they avoided places and people that might trigger painful memories.

Some parents' relationships broke down following the death, but others felt the death drew them closer together. The need to care for older children in the family helped parents to stay positive and recover. Similarly, further pregnancies and new babies gave parents a new focus to their lives again, although those with multiple births found caring for survivors while grieving very difficult.

Returning to work also played a role in parents' recovery but this could be challenging for self-employed parents who had to return soon after the death for financial reasons.

In the next chapter the experiences of these families of the JAA investigation into their infants' death and the experiences of professionals working with them will be considered in some detail.

## **Chapter six Bereaved parents' and professionals' experiences of the JAA**

### **Section 6.1 Introduction**

The previous chapter outlined the recruitment of cases to the study and described the participating parents' family composition and their wellbeing as well as the experience of professionals in managing SUDI cases. This chapter considers the parents' and professionals' experiences of the JAA.

The parents' and professionals' experiences are largely based on the qualitative interview data although to a lesser extent questionnaire and case note data are also included. JAA experiences are discussed to two main sections: the 'visible' elements of the JAA that are seen by all and the 'hidden' elements that involve only professionals and the family may not be aware of. Parents' experiences are therefore only relevant to the visible elements but the professionals' experiences relate to all parts of the JAA.

The expectation in Working Together (HM Government, 2013) is that social care are fully integrated into the JAA; however in practice they work separately. Social care data are therefore considered as a distinct element of the JAA. Coroners' enquiries are an entirely separate process from the JAA; although Working Together expects that professionals from the JAA and the coroner share information. Experiences of the coroners' enquiries are therefore only considered where they relate directly to the JAA as the project is evaluating the JAA and not coronial services.

One aim of the JAA is to support families; this support is often provided by primary care teams or independent bereavement or counselling services. Parents' experiences of such bereavement support are therefore included as part of the JAA.

### Selection and use of quotations

All quotations used have been anonymised as far as possible to avoid possible

identification of cases; therefore case reference numbers have not been used.

Professionals' quotes are attributed to the professional group only; for example

paediatrician or police officer. Quotes were selected from cases to help illustrate

findings. Some cases had more quotes selected than others; this was due to either a

longer interview resulting in a larger number of quotes to select from or cases that

highlighted particular issues. The distribution of the selection of quotes from the 17

cases having in-depth interviews is shown in table 24 below.

**Table 25 Distribution of quotes from cases illustrating experiences of the JAA**

Case code	Number of parental quotes used	Number of professional quotes used
A	5	9
B	7	6
C	7	Not interviewed
D	5	4
E	7	10
F	4	Not interviewed
G	8	7
H	3	7
I	8	9
J	8	5
K	3	3
L	3	2
M	4	3
N	6	6
O	2	Not interviewed
P	3	Not interviewed
Q	1	Not interviewed

There are more quotes from mothers than fathers as more mothers were interviewed.

The majority of professional interviews were with police officers or paediatricians so

these form most of the professionals' quotes.



## **Section 6.2 Parents' and professionals' experiences of the visible elements of the JAA**

The parents' and professionals' experiences of the visible elements of the JAA are divided into 7 key stages:

1. Pre-hospital care - interactions with professionals after discovering the baby until arriving at the Emergency Department
2. Hospital – experiences in the Emergency Department on the day of the death
3. Joint Home Visit (JHV) by police and paediatrician or specialist nurse
4. Follow-up contacts with professionals, from after the JHV until after the final case discussion
5. Bereavement support
6. Social Care
7. Coroner's enquiries

The aims of the JAA are to establish the complete cause of death and to address the need of the family; addressing these needs also includes the need for safeguarding children as well as emotional support. These aims seem to conflict; conducting a full investigation into the death can be seen as highly intrusive when parents are recently bereaved and need support. These difficulties will be considered for each stage of the JAA.

## **Section 6.3 Pre- hospital care**

### *Ideal pre-hospital care*

*The baby and parents should be taken as soon as possible to the ED; this may be by emergency ambulance or by a funeral director. If uniformed police arrive at the home,*

*they should sensitively secure it whilst the family are at hospital and then wait for specialist police from the Child Abuse Investigation Unit.*

### **Parents' experiences of pre-hospital care - difficulties with uniformed police**

Parents' accounts of events prior to arrival at the hospital were predominantly negative; this is hardly surprising considering the horror of the overall situation. For some parents, their experiences were made significantly worse by the actions of uniformed non-specialist police. In parts of the study area, uniformed police are automatically notified of an out of hospital paediatric cardiac arrest by ambulance control. They attend the house immediately, possibly even before the ambulance. These uniformed police officers are not part of specialist Child Abuse Investigation Units (CAIU) so have no specialist training in managing child deaths. In other locations without this immediate police response parents did not report such issues.

The difficulties faced by parents reflected the uniformed police's inexperience in managing sudden child deaths; there seemed to be an automatic assumption that a crime must have occurred so the home was treated as a crime scene. Investigating the death as a crime was the priority rather than supporting the parents; as a result, police often refused parents access to collect vital possessions such as keys or telephones and families were required to leave their homes immediately.

My wife went in the ambulance with the baby and my phone was upstairs in the bedroom and I needed my shoes as well; there was a police lady stood at the top of the stairs and she wouldn't let me go upstairs....(father)

We'd all got to leave the house; no-one was to go upstairs. I suppose in a way it's like a murder scene. At the time that's how you feel. (grandparent)

I was angry .....if it had just been me and my husband, it wouldn't have bothered me but I'd got young children that had seen everything and then I suppose for them they are in their pyjamas, to be told that they've got to come out of the home at that time of night. (mother)

This assumption that a crime had occurred was even more evident for one family where the ambulance declined to transfer the baby to hospital as she had been dead for some hours. Whilst this transfer was arranged several uniformed police waited in the house, which was a very small property, causing much distress to the family.

But then my other son was in the kitchen and he was washing up and I suppose keeping busy, and there was an officer in there with him and there was an officer in here with us, there was an officer in the hallway, there was an officer at the front door, and there was officers upstairs. (mother)

What really was upsetting is that I felt like we were kept apart...as if to see if somebody would say something different to what had happened or.... and we wasn't allowed to shut the door.....if we shut it, they opened it and they would make a point of standing in the doorway so we couldn't shut the door... A uniformed officer would open the door and would stand there with his arms folded staring at us... (mother)

Families commented on a lack of empathy and support from the uniformed police. This may be due to the police's inexperience in dealing with such situations; considering that expressing sympathy to the parents may be inappropriate if the parents are suspects. Alternatively, the police may just be overcome with the horror of the parents' situation and not know what to say to them. Parents talked of police officers standing watching them 'like statues' and of silent police car rides to hospital.

I was sat in the back of the [police] car and no-one spoke to me, I always remember the silence, it was awful, the silence was so bad....You just wanted someone to turn around and go 'are you okay?' Not that they were judging me or anything, just that I wanted someone to hold hands with me... (mother)

Uniformed police even refused to allow the parents of one baby to accompany her to hospital; only driving the parents to the ED when directed to do so by the hospital. This probably again relates to a lack of empathy and the police having no idea as to what the correct procedure was.

The ambulance just took her, and then we come back in here and the next thing the police were everywhere.... We said can we go and see her and they said no, we had to wait.....but they just wouldn't let us go and the next minute she got something through her radio and said 'come on'. (mother)

In other cases the uniformed police decisions seemed illogical. In one family with many children, the baby had been found collapsed late in the evening and was being resuscitated in the ED. Uniformed police attended the home and according to the CAIU, the senior officer soon decided that this was a non-suspicious event; but despite this still appeared to treat the family as witnesses to a crime:

My brother phoned and said 'there is 3 policeman here, they won't let the children go to sleep upstairs and it's 4am now' ..... So when he asked them if he could take them to his house, they wouldn't let them go to his house.... Yes, so they had to sleep on the floor.... (mother)

Other families however, did comment positively on the practical support provided by the uniformed police such as securing their homes and offering lifts to hospital:

I'd gone in the police car so we were actually pleased they had arrived because I wouldn't have been able to go in the ambulance. (mother)

### **Specialist police opinions of difficulties with uniformed police**

I asked CAIU police officers during their interviews to explain the reasons for the actions of the uniformed police that so distressed families. Frequently deaths occurred whilst CAIU teams were off duty; however there is always a CAIU senior officer available on-call for SUDIs. Despite this, often the on-call CAIU officer was not contacted and uniformed police acted without their advice until the CAIU team came on duty and the case was handed over.

And there lies the difficulty because the way we respond is we send untrained uniformed staff first of all and sometime it can be an hour, hour and half before I get a phone call. (police officer)

My uniformed colleagues ... they were called at 06:18 in the morning., ambulance control contacted Police and unfortunately we never start until 8 o'clock ... although they obviously have an out of hours SIO [senior officer] who they could have contacted....But they didn't contact them..." (police officer)

Uniformed police do not typically have experience of SUDIs or knowledge of the multi-agency SUDI protocol that is in use throughout the study region.

And I wasn't sure whether the people that we were speaking to [the uniformed police] had had any experience of SUDIs or the SUDI protocol .... (police officer)

So initially there was a duty inspector who had gone straight down the crime scene really ..... it was almost like locked down as a potential crime scene. So I had to de-escalate that so that was something where the protocol wasn't followed at the very early stage. (police officer)

Uniformed police often do not contact the CAIU on-call officer out of hours unless they have concerns; however given their lack of experience of SUDI cases one wonders how they could correctly identify a suspicious case. In addition this shows that uniformed police do not consider that they need advice or support in managing a non-suspicious case, despite their lack of experience.

If there was anything...I think if there was anything suspicious in the matter then they would obviously have contacted the SIO, anything that was causing them any concern. (police officer)

In some cases, the CAIU were not aware of the difficulties that the families had faced with the uniformed police until I raised these during the interview; the CAIU officers were highly critical of the actions of their colleagues. However, as I was raising these problems several months after the death it makes providing feedback to the uniformed officers much more challenging.

I didn't pick up that from this one but to not allow parents to go to hospital, it's... what powers are we using to keep them in their own home, to prevent them going to hospital...but I think sometimes we are paralysed by a lack of knowledge, aren't we? ..... But I don't know why that was done...poor decision I would say. (police officer)

### **Difficulties with the Ambulance Service**

Whilst there is a clear regional protocol that all SUDI cases, even if obviously dead, must be transferred urgently to the ED by ambulance or funeral director; in 2 cases there were significant delays. In both cases, the paramedic removed the baby from the parents placing them alone in a bedroom; this separation was then continued by the uniformed police who waited with the families causing huge distress.

...they didn't say to me 'oh do you want to go upstairs and hold her' or 'do you want us to bring her down here', she was just upstairs for hours on her own.

(mother)

In one case, the local EDs also initially refused to accept the baby resulting in more confusion and distress for the mother:

And was it twice or three times...which hospital we was going to, we drove all around the city [in a police car]... and they kept changing... 'We're going to the one hospital'... 'No, we're going back, we're going to another hospital'. And it was just a big sham of what we were doing, we were driving round the city for god knows how long. (mother)

Ambulance personnel were not interviewed for the research study; but it seems that there is a lack of knowledge of the protocols regarding transport to the ED and allowing parents to hold their baby.

## **Section 6.4 Hospital**

### **Ideal Hospital Care**

*Parents are allowed to watch any resuscitation; after death parents are encouraged to hold their baby for as long as they wish, supervised by a member of staff. The consultant paediatrician and CAIU police officer should take jointly a detailed medical history and account of events from the parents; they must also explain the process of the JAA. The ED staff need to ensure that the parents are supported, cared for and kept informed throughout their time in the department.*

### **Parents' Experiences of Hospital Care – overall positive experiences**

Almost all parents rated their experiences of care in the ED very highly, most of the negative issues reported related to isolated incidents in an otherwise overall good

experience. This is likely to reflect that whilst in hospital there are professionals, usually nurses, dedicated to caring for the parents, whilst other professionals are busy with other tasks of investigating the death.

Parents praised nurses for their support; this was even the case for the family who had a poor experience in hospital who still described the nurses as “exemplary”. Parents appreciated nurses caring for them by ensuring that they had food and drink, welcoming the extended family and arranging for religious services.

All hospital staff were very respectful of our wishes and explained everything well that they needed to do. We were given plenty of time and privacy with all our family after the baby died. (mother)

For some families, specialist bereavement teams cared for them even though their baby had been brought in dead to the ED; their help was highly valued.

She went to the bereavement suite ...an absolutely fantastic lady, nothing was too much trouble...she even said you can bring her own toys, anything you want with her, just bring them up, which I did, and she was absolutely lovely.  
(mother)

Parents appreciated staff crying with them for their babies, as in the literature review in chapter two, this showed to them that the staff understood the magnitude of their loss.

The nurse that was on duty that morning, she was just amazing. She even sat and cried with us ... even the policeman broke down. So you know, they were lovely, but they helped us so much ... they were fantastic. (mother)

Parents also described being supported by police officers in the ED both emotionally as in the quote above and practically by providing transport to the hospital. These were



uniformed and CAIU officers; clearly one would expect CAIU officers to be able to support parents but this also shows that empathy and kindness are not unique to the CAIU.

Despite the caring role of the hospital; the JAA investigation needs to start with a detailed account taken from the parents by police and the hospital or SUDI paediatrician. Parents rarely mentioned this at interview and when they did it was generally described in neutral terms so not considered as a negative or neutral event:

The paediatrician came in and explained the process .... I think I had to go through what had happened the day before.... leading up to the point where I found her. (mother)

However, nurses were still able to support parents even when other professionals were focussed on investigating the death:

Well, at first the paediatrician kept questioning me to find out what had gone on and what had happened, and then another nurse interrupted her and said 'let her go and see her baby' and then we were allowed to go into the room and hold her. (mother)

### ***Poor experiences of hospital care***

With one notable exception, parents' poor experiences of care were isolated incidents in otherwise overall good care. A frequent complaint was that the room provided for the family was small and cramped "like a broom cupboard". In some instances poor communication was at the root of the negative experience; parents had been told or assumed that their baby was dead and then were confused by mixed messages that the baby was being resuscitated or to hurry to the hospital.

... because I had already told myself that she had gone and then you're telling me.....not telling me but kind of giving me a false hope that you are trying to revive her ... I felt quite angry because I thought you've built my hopes up.....(mother)

But I was like 'but she's dead' and she wouldn't answer that question and so you have that moment of thinking 'well maybe she's not dead'. It was really horrible, absolutely awful. (mother)

These quotes would suggest that staff are trying to be kind breaking by bad news gently; but in reality the parents clearly know that their baby is dead and the false hope created makes the situation more painful. Similarly, in the quote below, staff were trying to be kind but actually leaving the parents alone in the relatives' room was not helpful for them.

...then there was the sort of charade of ...people coming in and going out and coming and going out and saying ... 'we need to ask you some questions but we'll leave you for the time being' ..... I got to the point where I sort of said 'can someone actually ask us some questions'. (mother)

Another parental account reflects poor communication and a lack of empathy by medical staff without any suggestion as to why the doctor presented herself in such a way.

The doctor who worked on the baby did not explain anything and was very harsh with her words, I was made to feel like I had done wrong and she was very unsympathetic, not a nice lady. (mother)

Parents also highlighted poor communication between staff; one mother had to repeat her account of events several times, whilst in the ED, to different professionals. In

another case the baby had collapsed and died in the ED and the hospital staff while alerting the coroner had not thought to inform the police or commence a JAA investigation. The parents were shocked to be telephoned by the ED consultant later at home to be told "Against our better judgement the police are now involved".

One family rated their time in the ED very negatively; however, this mother arrived at the ED distraught as her baby had been declared dead at home by a paramedic and then taken from her; she desperately wanted to see her baby again but this was still not arranged until two hours after her arrival. Both poor communication and a lack of care and support were issues for this family which is in direct contrast to that perceived by all the others.

My sister had to go and ask just to get me some paracetamol just because my head was banging and no-one had come to say 'are you okay?'... (mother)

...no-one had been applied to me sort of, to my care as such and we just didn't know what was going on at any time... (mother)

Similarly, but to a lesser extent, another mother described the lack of care taken in obtaining hand and foot prints and dressing her baby. There were not appropriate paints or clothes in the ED but no attempt seems to have been made to find alternatives; this lack of attention to detail spoilt some of the mother's last memories of her baby.

Although she's a girl they did her prints in blue.....so now when I look at them I think well that's not her, she wasn't a boy. (mother)

While some families described police supporting them in the ED (as detailed previously) others found their presence and actions distressing in that they showed a lack of understanding or sympathy for the parents; again focussing on the need to investigate

the death. One mother told of uniformed police insisting that she leave her baby, during resuscitation, for questioning.

Suddenly, these two policewomen came and said 'can we have a word with you?' And I said to them 'can I sit down here because my son?' and they said 'no, would you come here'. (mother)

Another mother commented on the lack of sensitivity shown by the police when taking her baby's clothes:

I'm just standing there looking at this stranger holding my baby's clothes because they were just in a clear bag... and to her it's just a parcel that she'd got to hold,... that's their job but a little bit of common sense... you don't want to see those things.(mother)

The mother who felt that the hospital showed her little care also considered that the CAIU police were insensitive; however there were serious concerns about the circumstances of the death and as such mother did need formal questioning. This mother felt blamed by the police and this may be why she perceived them so negatively.

The policeman in the relatives' room .... I just felt like he was constantly staring at me and making me feel really aware of how I was acting, what I was doing... and then from that point I didn't want him anywhere near me ...I wouldn't go in the room in the end, I was just outside the hospital smoking. (mother)

### **Professionals' experiences of hospital care**

Professionals made few comments about parents' experiences in the ED; these were a split between supporting the parents and investigating the death. One CAIU police

officer was horrified that the bereaved mother was placed in a tiny room in the ED near to other babies who could clearly be heard crying.

...but I felt that the worst place that the mother would want to be was in a room off a corridor where there are lots of other screaming babies basically. And I have to say I felt very uncomfortable. (police officer)

Some professionals commented on good practices in the ED. They complemented full medical histories taken by hospital paediatricians and joint examination of babies by police and paediatricians. They also criticised poor working practices in hospital. Frequently hospital paediatricians took a detailed medical history from the parents without waiting for CAIU police to arrive so preventing a joint history being taken. As a result often parents had to retell their story; although in other cases the written account was good enough that this was not needed. No police officers commented that joint history taking had resulted in contamination of evidence or that it was preferable for police to interview parents separately from the paediatrician.

## **Section 6.5 The joint home visit (JHV)**

The aim of the JHV is for police and the SUDI paediatrician to jointly examine the scene of death, ask parents further questions and offer support to the parents. The SUDI process should be explained and parents can be signposted to bereavement services.

### **Ideal Joint Home Visit**

*The JHV should be conducted by a CAIU police officer with the SUDI paediatrician or specialist nurse within 48 hours of the death; but ideally much sooner. Police should enable parents to access their home and collect possessions prior to the JHV if there is any delay.*

17/23 cases had a joint home visit by a SUDI paediatrician or specialist nurse and CAIU police officer; 14/17 took place within 24 hours of the death. Two visits were delayed by a few days, in one case this was due to the mother's distress; the CAIU police were unconcerned by the delay as they had already seen and photographed the house while the mother was at the hospital. In the other case the infant died out of home and the JHV was used to explain the initial post-mortem examination results to the parents and offer support. One JHV took place prior to death when an infant was in PICU but withdrawal of life support was anticipated.

### **Parents' experiences of the JHV – predominantly but not entirely positive**

The JHV was a positive experience for most parents, some were neutral about it but for a few mothers it was a significantly negative experience. Many parents said that the JHV did not make their situation any worse; they accepted the need for it and were content just to get it done and have some private family time.

There were many different factors in JHVs that parents rated positively; these related to providing information, support returning to the scene of death and showing compassion. Some described the JHV as helping them to understand why the baby may have died even when there was little explanation available at the time. Families also valued the information given to them about the process of the JAA; often they were given information leaflets in hospital but found the explanations very helpful. Parents appreciated professionals who were non-judgemental; often parents blamed themselves for the death at this time.

Yeah, I never felt once like they were judging me or anything (mother)

..I think they handled it very well because particularly at that stage we thought she had suffocated and because it was something that I'd done.... (mother)

Similarly, parents also praised the compassion shown to them by professionals.

Frequently, there was a delay before the SUDI paediatrician was available for the JHV.

Police would drive the parents' home and wait with them or allow them some time to themselves while waiting.

The paediatrician...he was a very, very lovely gentleman. (father)

I always felt I should go back and say thank you to the police who attended.

(mother)

Returning to the place where they found their baby is difficult for some parents.

However, being forced to see the death scene again, accompanied by professionals could be a therapeutic process and doing this soon after the death prevented the return from becoming more daunting. Similarly, other parents wanted to tell their story to the police before their memories of events began to fade.

I think the practicalities as well of everything that comes after a death in the family, that them being able to do it so quickly afterwards is really good because then it was done, if I'm honest. (mother)

### ***Negative experiences of the JHV***

Whilst most parents' overall experiences of the JHV were positive or neutral there were often elements within these that parents found distressing. In many instances these difficulties related to actions by uniformed police officers rather than the CAIU; as with pre-hospital events there seemed to be an assumption that a crime had been committed and this required investigation. Parents returned from hospital to find uniformed police at their home preventing them from going in; this lack of access even extended to neighbours not being able to go home as one mother had taken her baby to the neighbour's flat when she found him lifeless.

Well really we weren't allowed in the house .... I left home with no shoes on my feet, I was wearing my neighbour's shoes so when I come back I wanted my own shoes on and the police said 'well you're not allowed out there'. (mother)

.... But they wouldn't allow my neighbour back in her house for hours and she's got six kids... (mother)

One family commented that they felt intimidated by the sheer number of police at their home;

The police weren't that bad but it was just the fact you couldn't go to the toilet, you couldn't do nothing. They were just standing there so it was a bit intimidating like, watching everything you did. (mother)

These police then suddenly left which confused the parents further:

The family was here and the policeman was just standing in the hall... Writing everyone who came in, yes and then all of a sudden he had gone, he didn't even say bye, he had just gone. We didn't even know he went. He had just gone. (mother)

Parents often stated that the police presence made them look and sometimes feel guilty even when they knew they were blameless:

We came home from hospital accompanied by the policeman and doctor to be met by uniformed officers outside our door, I was very unhappy about this, I was made to look and feel guilty of doing something wrong which isn't the case. (mother)

Another criticism was of poor communication with all professionals; parents complained of having to repeat their story again at the JHV having already done so several times



already. In contrast other parents found the JHV helpful in that they only had to give their account once. Some parents found the CAIU police questioning uncomfortable.

Well it felt uncomfortable because I felt...they kept just asking questions but you're just upset and you don't want to speak but they keep pushing and pushing. (mother)

Poor communication was also an issue for some SUDI paediatricians; some families remained unclear as to the purpose behind the JHV and found no support in the process:

I couldn't understand why the doctors were here ... why would they want to come and look at her bedroom? ...The paediatrician was slightly...not rude but to the point ... 'did you have the heating on?' ... 'I don't know what day it is at the moment and no, the heating wasn't on'. (mother)

The JHV itself was hugely difficult for a small minority of mothers. These mothers were so distraught at the death of their baby that they could not bear to talk to professionals at all; in addition returning to the scene of the death was intensely painful and they did not feel ready to face this. In some of these families, the fathers alone or other relatives attended the JHV and liaised with all the professionals while the mother stayed with away; unfortunately for single mothers the situation was more problematic.

One mother had a very poor perception of the JAA process following a delayed transfer to hospital and felt unsupported once there. She felt very negatively towards a JHV particularly as she was asked repeatedly about it by the CAIU police. Due to her reluctance the JHV was arranged for 3 days later but the mother still found this really difficult although she did understand the need for it.

All throughout the day I remember the police officer constantly 'We need to have a meeting back at your house, we need to have a meeting back at your house'. To which I said, 'No,... it's the last thing on my mind right now, I don't want it'. (mother)

I didn't want to be there so...I walked out; I left my boyfriend in the house with the police and doctor... (mother)

I didn't like it but I understood the reason why I had to show the doctor that [the sleep scene] and I did see the reasoning behind it. (mother)

### **Professionals' Experiences of JHV**

The professionals who took part in JHVs were overwhelmingly in favour of them; a frequent comment was that they were the most useful part of the JAA. Professionals found seeing the sleep scene and general home environment invaluable. Police described how helpful they found it for the SUDI paediatrician to take the lead in asking questions; they felt this reduced the parents' anxieties about the police involvement.

...So I think that works well ...I wanted it to look like it's a medical professional taking the lead here and we were there and supporting. I think the home visit is very good. Because you've got that...two different lenses really you know."  
(police officer)

Yes because with this particular home visit, the sleeping arrangements of Mum and baby were obviously very important and I don't think she was able to verbalise those enough to give us an idea of what had happened, whereas at the home address, she showed us exactly where they had been sleeping, exactly what positions they had been in... (police officer)

Paediatricians thought the JHV was helpful for parents; it gave them a chance to ask further questions and to discuss complex issues that perhaps they would not have felt able to in hospital.

Mum had lots and lots of questions about how and why this had happened ....

So she voiced a lot of that even at that first visit. (paediatrician)

I felt it went quite well...I would say that the police handled it very sensitively...

But Mum was able to sort of demonstrate to us on the double bed exactly

where the baby was, what position Mum was in, what position Dad was in...I

think they found it helpful to do that, although distressing, as it is for all parents.

(specialist nurse)

Professionals also spoke of the difficulties in some JHVs although these did not outweigh the benefits of doing them; they were aware of the sensitivities of doing the JHV soon after the death.

...These home visits initially are always quite stressful because obviously the acute grief of the family.... (paediatrician)

At times, the parents were upset due to the actions of the uniformed police; both CAIU police and paediatricians then had to address these issues and rebuild the parents' trust before moving on. In one case, the actions of the uniformed police actually hindered the sleep scene analysis.

One of the things was that..., when they found that she was dead they sort of panicked a bit and they ran next door ... the next door flat was ticker taped off and there was a policeman in there... So we had to sort all that lot out so that...I wouldn't say hampered things but it coloured what we were trying to do.

(paediatrician)

... So the police had gone in with great big Size 10 boots and caused a lot of distress to the family, ahead of us getting there so ... we had to recoup all of that...then it went quite well but we clearly could not look at properly the place where the baby had been sleeping and so on because the police had torn a great hole in the mattress and so all the bedding and so on was not how it had been. (paediatrician)

The wife was very upset and part of her main concern was that other officers, earlier in the day had attended and they had cut out the top part of the mattress ...I mean, they had ruined it effectively and I have to say it was something that I didn't agree with... (police officer)

In one case, due to the mother's distress, the JHV was delayed. Despite this, it was difficult for all concerned although the professionals did manage to obtain all the information that they needed.

Mum was still very, very distressed ... even trying to talk to her in a sort of comforting kind of way was actually quite difficult because she just wanted the process to be over and done with....she did give us quite a lot of information.... We managed to do an examination of the scene .... that was really helpful ....and it was still helpful just to see the state of the home. I think Mum found it incredibly stressful, it felt uncomfortable putting her through that in a sense ...I wanted to talk to her about things like the process and what would happen next... but Mum really just got to the point where she just wanted us to leave.... (paediatrician)

The paediatrician considered alternatives to the JHV for cases such as this where the parents are distraught and not ready to return home.

She was really devastated and in my mind, the reason that she didn't want the home visit was because she didn't want to go back to where it had happened, not...I didn't get the impression that she was trying to hide anything... (police officer)

...Because there were no other sort of concerns, we felt it was worth waiting [for the JHV] but perhaps it would have been better to try and do it even if Mum hadn't been there, ... and think whether we might ....just look at the scene and then maybe speak to parents at another date... (paediatrician)

No police officers raised concerns about the JHV potentially preventing thorough forensic analysis or jeopardising criminal prosecutions.

### **Parents and Professionals experiences in cases without a JHV**

Six cases did not have JHV; one infant collapsed whilst travelling and died a few days later on PICU so there was no scene to visit. The remaining five cases were from two different areas which do not do JHVs routinely. In four cases, the CAIU police alone examined the death scenes shortly after the infants died; the SUDI paediatricians met the families a variable time after the death ranging from the next day to one month later. In the remaining case, the SUDI paediatrician met the parents at the hospital and took a detailed history there; meanwhile the CAIU police visited the home.

The later timing of the paediatrician's visit can enable them to share the initial post-mortem examination results with the parents; both families and paediatricians felt that this was useful.

so when my husband came back and he said you know 'They've said that there's no signs of him being...of his airways blocked or anything like that' and things like that...so that did put my mind at rest... (mother)

... And if the preliminary PM is done quickly enough, we can actually feedback the results of that at the same time, so I think an early visit done at sort of 3 or 4 days is often more meaningful, more useful. (paediatrician)

However, in some cases without a JHV there are issues of information not being collected. In one case, the SUDI paediatrician first visited the family a month after the death. As a result the only medical history obtained was that taken in the ED; this was a complex case with pre-existing medical problems and the death remained unexplained, a fuller history may have been useful. In another case the police visited the home without the parents; who never showed anyone exactly how the baby was sleeping when she died. These are clearly sub-optimal practices; the parents commented that the police statement was inaccurate and the SUDI specialist nurse felt that information was missed.

I mean we have been out [to the home] since then but yes, probably we did [miss details], we did on the sort of precise sleeping arrangements. Yes, I'm sure we did. (specialist nurse)

...because I remember reading the report and thinking 'well that's not really right', there were certain things that were slightly wrong... (father)

In another case, information was missed about feeding difficulties in a breast-fed baby as the SUDI paediatrician met with the father rather than the mother as she was very distressed.

My husband just decided that he wanted to take charge and I was just not in any...as far as I was concerned...I'd lost my son; nothing could change that so I wasn't really bothered about any of the ins and outs of things. I was just quite happy not to have to go through things. (mother)

Mum wasn't there, which may be why that information didn't get picked up.

She's one of...of all the cases.... where the mums have sort of almost withdrawn and been so...such nervous wrecks for want of a better word that it's been difficult to communicate with them. (paediatrician)

In one case, a baby died the day after sustaining a minor accidental injury at home.

There was no JHV and the police examined the house thoroughly prior to taking a detailed account of events from the parents or discussing the case with the SUDI paediatrician.

There was no-one at our house the next day, it was just taped off.... I rang me Dad...he said 'I can't get in to get you any clothes because they wouldn't let me through the door.' So there were police here, there and everywhere, all over the place. See I can't understand, how did they get in the house? How did they get in the house cos I locked the door when I left the house? (father)

The police later took detailed formal statements separately from both parents with the father required to show exactly where and how the injury occurred. However, this was several days after the death when the post-mortem examination had clearly shown that the injury was trivial and unrelated to the death. This process caused distress to both parents and could have been avoided if there had been better communication between the SUDI paediatrician and police.

It felt like he was just checking everything in the house...you're on pins by this stage anyway, your life is shit, it can't get any worse than this and then you've got someone peering about your house like you're a murderer. (father)

At interview, the professionals involved in these cases were asked about whether they could see any benefits in JHVs. Unlike the professionals who have done JHVs, these professionals often saw little added value from a JHV.

We are also not entirely convinced about the value of doing it necessarily that early, and with the Police. I think sometimes it may be helpful but sometimes what we are finding is that the most important bit is the inter agency communication and that actually going to see the family is important but giving them a little bit of time to get over the initial shock. (paediatrician)

From the ones [home visits] I've been I don't see how it could help. We take photographs of the scene and sometimes we seize bedding if there's blood on it, 'em...if there is nothing suspicious I don't know how that would help the paediatrician... I don't know how it would. (police officer)

## **Section 6.6 Follow-up**

The aim of follow-up within the JAA is supportive; helping parents to understand why their child died and addressing other needs for support within the family. The investigative process of the JAA is complete.

### **Ideal Follow-up**

*The SUDI paediatrician should inform the parents of the initial post-mortem examination results even if these are inconclusive; this can be done by telephone. After the final case discussion the SUDI paediatrician should arrange to visit the family at home to explain in detail the complete cause for the death, meanwhile parents should be able to contact the SUDI paediatrician or specialist nurse for information and support. Police should arrange for any items taken for the investigation to be returned to the family in a sensitive manner.*



## **Parents' Experiences of Follow-up**

The parents' experiences of follow-up were mixed with good and poor experiences common within the same cases. In twelve cases there was only one follow-up visit from the SUDI paediatrician after the JHV with no contact in-between; therefore these families will often have been waiting more than six months for any information about why their infant died. Ten cases had additional telephone conversations or up to three follow-up visits from the SUDI paediatrician or specialist nurse.

There were different issues with follow-up from police and paediatricians, so these will be considered separately.

### **Follow-up with SUDI paediatrician**

Most of the positive experiences about follow-up related to parents being able to get answers to their questions about the baby's death. Parents appreciated follow-up visits from the SUDI paediatrician: being told the cause of death before the Inquest, having a chance to ask for more information and have the death explained in lay terms. When needed, paediatricians arranged medical follow-up for surviving siblings, helping to reassure parents.

The paediatrician tried to put it into a way that we would understand it rather than medical terms but he left us with a report of it.... So he did explain pretty much right through it. (father)

The paediatrician was really good at this, how she read it to me; she was very clear and thorough. That I liked .... Them coming to your home and speaking to you before coroner's court, I would absolutely agree with that... (mother)

A common complaint of parents was of the long wait for final results from the post-mortem examination and final case discussion; the median time for cases to be closed

was 23 weeks. Infant post mortem examinations rely on histology to determine the cause of death; this takes around six to eight weeks for completion but longer for complex cases. The body is usually released to the funeral directors a few days after the initial examination and this can cause confusion to parents as they assume that final results will be available shortly afterwards.

So the autopsy is dealt with in that first week so it's a bit like, the findings are there, you are not telling me they don't write them up for months and months and months, and I think to take that long to release them....for me, in the whole part of the process, the length of time for the release of the autopsy and for the inquest, I think are the two things that I think are really bad. (mother)

Parents frequently felt that they had to do the chasing to get results; they often were telephoning the SUDI paediatrician or specialist nurse to be updated on the progress.

I do think the care you get when you are actually there, to the care you get afterwards.....which I think it's afterwards when you want to be informed. You don't want to have to keep ringing round because every time you ring, you have to go through it all again.... (mother)

...like they were supposed to keep in touch with me ... just even if they never had any news... I don't like the way it were done about that. I had to keep phoning and pestering them to know if there was anything.... (mother)

Some parents felt that they did not get enough follow-up. This was very evident for one family who had no contact with any JAA professionals after the JHV and subsequently heard the cause for their baby's death at the Inquest; they had been expecting to be told the death was due to SIDS but were shocked when this was not the case. The

parents described that because of this, the Inquest was the worst day of their lives that they had experienced since the day the baby actually died.

I went back and sat in a kind of bubble thing, it was just I could not believe it, I'd told myself it was cot death ....and then when the pathologist was explaining it, I just could not believe it... And then all afternoon it was like I couldn't hear what was going on around me, I was just in this little space world of my own, it was so surreal and strange. (mother)

Another family said that, despite having a lot of contact with the specialist nurse, they wished they could have seen a doctor to explain about why their baby died. The parents had been sent a follow- up appointment to see a paediatrician at the local hospital but did not attend; it may have been because it was with the paediatrician that they met acutely in the ED, they thought she was insensitive.

Many parents commented that while they received information from SUDI paediatrician or specialist nurse there was little emotional support provided and they were left to arrange this for themselves.

...It's hard enough, I mean if the school hadn't have sorted out that counselling, I don't know how I would.....because it's not something I probably would have thought to do myself. (mother)

I mean we went over it before...in hindsight, how pleased we were with the clinical side of things but disappointed with the mental health support. (father)

### ***Follow up with police***

Only a minority of parents had any follow-up with the police. One family felt very let down as the police had been very supportive following a previous infant death but not after the subsequent death.

The other one used to come every day to see if we were okay and to bring us information.... but it was completely different this time, we didn't see the policeman ever. I phoned him, didn't I but I never seen him.....they never got back to me, I never heard off them again. (mother)

Other families did have follow-up contact with the police but found this intrusive and insensitive. One mother still felt that she was under surveillance concerning her other children when police made an unexpected visit even though the officer was very pleasant. Another family was telephoned repeatedly by the police asking for further information.

..but yet the police still aren't prepared to say 'well, okay, we understand that it's cot death so we are going to leave you alone now rather than coming back '...and every few months contacting you and just sort of saying 'have you had an update, can we come and interview you again just in case anything's changed?' ...well, nothing has changed...it's the one thing with the baby that I found the coldest, with the police involvement probably. (father)

Parents also commented on the police returning any items that had been taken as part of the investigation. For some families this was done in a very sensitive way which they really appreciated:

My husband said the bloke [police officer] was lovely. He took my husband in a room, they'd even put her clothes in a gift box and tissue paper inside, and they had even put a nappy in. I mean my husband said he couldn't fault them in that way at all, and the police officer even gave my husband his number and said 'if at any time you need to know anything, just ring me.'(mother)

However, for others this was a traumatic experience. One mother was sent to the main police station where items were handed back in evidence bags straight from the freezer.

[The police could have] handed the clothes dry for a start.....instead of handing them frozen. That was just uncalled for and leaving milk in his bottle. Not even washing it out or anything, it was just solid so I couldn't even keep his bottle.... I didn't appreciate how they just left his nappy in with his clothes. That's disgusting. You would think they would put that in a separate bag from his clothes...it's revolting... (mother)

In the cases where families perceived the police negatively it seems as if the police lacked sensitivity or basic courtesy; all these deaths were due to natural causes and there were no child protection concerns. It is not difficult to return telephone calls or to telephone a family prior to visiting them. The police could consider asking other professionals such as the coroner's officer or SUDI paediatrician first for updated information rather than always contacting the family.

### **SUDI Professionals experiences of Follow-up**

SUDI paediatricians and nurses talked of their role in following-up families but police officers did not. Follow-up was described as essentially a task of supporting the family; the investigation as such was now complete. Paediatricians explained how it was important that families felt comfortable with follow-up visits; parents were offered a choice of meeting at their home or elsewhere. When necessary, health visitors were invited along to help support the parents.

I think the most useful part was that I was sort of able, with the health visitor, to offer some support following the death. I mean they knew their health visitor quite well and we kept in touch. (specialist nurse)

...I think it was useful, and we met them in their home...so we gave them the option of coming here, not necessarily to where we cared for the baby but coming to the hospital or coming to the home and they preferred for us to go to them so it was in their setting. (paediatrician)

I always went with the health visitor so there was a familiar face and she always spoke to the health visitor, that's where her relationship was, that was who she obviously trusted. She wanted to speak to the doctor but no question was ever asked of me. (paediatrician)

Paediatricians and nurses had detailed discussions with parents about the causes for the death; they also frequently wrote afterwards to the parents so they had something to refer back to.

....So we went home again .... so I went through it [the post-mortem report] word for word for 3 hours with Mum explaining all of the second opinions ... (paediatrician)

Paediatricians also arranged medical follow-up for surviving siblings and access to the Care of the Next Infant (CONI) scheme for subsequently born infants. Some parents had concerns about their babies' medical care and SUDI paediatricians and nurses assisted by accompanying parents to meetings with the relevant clinicians or by writing statements for complaints procedures.

...she pretty much wanted her thoughts and feelings to be presented so I was there for a while. So I managed to get down what she had said ...I think she was still trying to pull information for herself to use for other purposes [a complaint] regarding her daughter's death. ....then I typed it up and gave it back to her

and she thought that was really useful and it would help her in the future...

(specialist nurse)

Mum still had concerns about the episode in neonates.....So we did suggest that she see one of the neonatal consultants to talk that through so they did ask if either the paediatrician or I would go with them for that... (specialist nurse)

The other thing that I felt was very positive was that, because Mum had got some concerns about who had seen the baby in Baby Clinic,...our Head of health visiting was quite happy to go out and see Mum at home and discuss those concerns with her. (specialist nurse)

SUDI paediatricians and nurses did also talk of some of the difficulties concerning follow-up and the negative impact of these on the parents. They spoke of the long waits for the post mortem examination reports:

....but there were certainly long delays. I mean I am not sure that that helps necessarily because you explain things at the beginning, mind you most of the parents won't take it in but you find yourself going over old ground again. (paediatrician)

...I think we all kind of learn as we go along from experiences of what happens...the stony silence following our initial flurry of visits... (paediatrician)

Like parents, SUDI paediatricians commented on the lack of emotional support that the JAA process provides and that this could be a role for the SUDI nurse.

I feel a nurse would add something to the process because I think they have got the time to make more calls and do additional visits... everything goes quiet for several months until you get the final PM. I feel that sometimes some on-going

contact and support would be helpful and I think that is probably something we are not very good at offering and I suppose not a priority in our already over-stretched work plans. (paediatrician)

However, another SUDI paediatrician still felt that families were not offered enough support despite the involvement of a SUDI nurse and that there should be more specialist bereavement services readily available.

I don't think it worked very well for the family...we've got a bereavement midwife for neonates but we are very poorly set up in terms of ongoing support I think. (paediatrician)

## **Section 6.7 Bereavement support**

Ideal bereavement support

*There are no standards for how bereaved parents should be supported; however The Lullaby Trust recommends that GPs or health visitors should make contact with families to express their sympathies and offer support.*

### **Primary Care**

22/23 mothers were registered with a GP so consultation data were available. In the year after the death mothers had a mean of 11.5 (95% CI 7.6 – 15.5) GP consultations; this excluded consultations concerning routine antenatal care for any subsequent pregnancy. Mothers had a mean of 5.6 (95% CI 3.0-8.3) consultations where the focus was on bereavement care and 5.7 (95% CI 2.5-8.9) regarding acute illness. One mother had 15 consultations all for the management of a chronic medical condition that predated the SUDI; there was no mention of the infant death in her GP case summary.

10/13 fathers were registered with a GP so consultation data were available. In the year after the death fathers had a mean of 6.6 (95% CI 1-8.2) consultations; with a mean of



3.3 (95% CI 0.2-6.8) for bereavement care and 1.7 (95% CI 0.0-3.4) for acute illness. Two fathers did not consult their GP at all during the year after the death and four GP case summaries made no reference to the infant death.

The majority of parents, but not all, felt that their GP had been supportive after the death; GPs were frequently praised for their care.

Our doctors have been fantastic throughout all of it ... (father)

On the day of the death parents were pleased when GPs prescribed lactation suppressant medication and offered them sleeping tablets. Some fathers needed GP sick notes to be able to have paid time away from work. In the weeks after the death, some parents saw their GP regularly to talk about events and were allocated longer appointment slots.

I mean I'd been talking quite regularly with my doctor, it was like we went from a weekly basis to a fortnightly basis to a monthly basis ...and I felt comfortable sort of with her. (mother)

I went to my GP.....I'm not so great on talking so they have sort of supported me because I haven't actually been back to work or anything as such yet ...  
(mother)

GPs helped parents access bereavement support services and where necessary mental health services. GPs also assisted parents with the post-mortem report; after one medically explained death, the coroner refused to release this to the SUDI paediatrician however it was released to the GP following their direct request on the behalf of the parents. Another mother received the post-mortem report in the post and immediately took it to her GP for help in understanding it.

A minority of parents felt that their GP had not been supportive; there was little contact with the GP apart from offers of sedative medication and telephone condolence calls from reception staff.

I saw my GP for about five minutes when I asked for my sleeping pills and he prescribed them to me .....but I never heard anything off him again. I haven't been back to the GP since that day. I mean my children are under the same one and they have never even asked about them. (mother)

In two cases GPs refused to prescribe lactation suppression medication furthering mothers' distress.

... probably the most negative thing that happened to me was.....I went in to see my GP to get some hormone drugs that stop my milk supply and he basically said that they are not very good for you .... And that's the worst decision my GP has ever made because it think it shows that there is actually a lack of comprehension about how painful it is. (mother)

In three cases parents said that their GP had offered to arrange bereavement support for them and they felt let down when this did not materialise.

The GP was supposed to put me forward for counselling but that was six weeks ago and nothing's come for me ... (mother )

One mother, who overall felt supported by her GP, was very distressed when she attended an appointment while a routine well-baby clinic was taking place.

I remember one time I went to go to the Doctors and it was on a Tuesday afternoon, which I know now is baby clinic day...Talk about walking into your worst nightmare! ... Babies everywhere...and that can knock me back... (mother)

Some parents were angry with their GP blaming them for failing to diagnose illness possibly preventing the death. These families did not feel supported by their GP.

I took her to the Doctors, and he said “no, everything’s fine, everything’s fine” and then obviously she passed away, he came round to like...he wasn’t really asking much, he was like “it was nothing to do with that that she died” (mother)

Many parents had continuing contact with Health Visitors or midwives and most found them supportive particularly if they had known the baby in life. Some went to extraordinary lengths to help parents; one bereaved mother with no surviving children was visited regularly by her sister’s Health Visitor. One community midwife despite changing her work base continued to provide care for a bereaved mother.

But then I got in touch with my sister’s health visitor, she’s been far more help ... and really it was nothing to do with her because I’d moved to the area. She wasn’t my health visitor and I hadn’t got a baby anymore but she comes about every two weeks.... But she’s lovely. (mother)

It was nice to see my midwife, because she’s lovely and she’s been so lovely. She’s actually changed surgeries now but she took me over to her new surgery so I still continued with her throughout... (mother)

Some families had surviving multiple birth infants, they were immediately offered the Care of the Next Infant (CONI) scheme which provided enhanced Health Visiting services and apnoea monitors which were greatly valued by parents.

It was a wonderful programme to be part of because I never would have left the house again if it wasn’t for the fact that they gave us these portable monitors and we were obviously given quick access to hospitals and doctors if we needed it and they were marvellous, absolutely brilliant. (mother)

There were two other families with pre-school children where the SUDI had raised child protection concerns. Health visitors attended these families regularly, providing support that was valued by the mothers.

The HV she was an angel, absolute angel. (mother)

A few mothers felt unsupported by their health visitors; this often occurred when there was minimal contact after the death. Some parents were sent letters offering for the health visitor to call but did not respond to these.

No, the health visitor sent me a card.... She acknowledged it as such but no, she didn't come and see me, no. (mother)

One mother had very little support from primary care; she scored very highly for both anxiety and depression at the initial interview and at follow-up 2 years after the death. She was struggling to parent her new baby due to being overwhelmed with fear that this baby may die. As the death was due to a medical condition the new baby was not on the CONI scheme so the mother had very little contact with Health Visitors. The mother had asked her GP for a referral to counselling services but nothing had materialised. Social care had become involved briefly after the local police were concerned about mother's mental state. There was no mention of the infant death in the mother's primary care consultation record although she had numerous appointments for the management of a chronic medical condition.

Health visitor...I hardly see her and if I see her she going to think I'm a right nutcase. (mother)

I told my GP and he said he would write a letter [for counselling]. I haven't heard so I've just left it. (mother)

## **Counselling and bereavement support**

Half of parents either had used or wanted to use counselling or psychological support services. These parents felt that they did not want to burden family or friends with their grief and some fathers felt that they could not talk to their friends about the death at all.

Yes, it was something I wanted to do [attend counselling]; it was something I felt I needed help with. I definitely couldn't deal with it myself and I didn't necessarily think it was fair on friends or family perhaps to support me maybe as much as I needed. (mother)

I mean none of my male friends, they're all completely disappointing ...none of them are able to really... to know how to support... It's like "if you want to go and get drunk"...so it's like "well, that's quite nice but it's not really the point". (father)

Other parents were clear that they did not need counselling, preferring to talk to family members about the death.

I know I can talk to any of my family and a word will never go any further so why should I talk to a stranger when I've got so many people that I can trust and that seen what I went through, they saw and they helped me. I don't thinking talking to a stranger will benefit me in any way. (mother)

It would be hard to just come out and start speaking to somebody that you don't really know. (mother)

Some parents felt that they did not need counselling as they were able to manage their grief themselves; however some viewed counselling as a failure to cope and did not want to seek support despite significant symptoms.

... every time I'm on a low I can't just go off and drink myself into oblivion... but I feel like I've failed if I've got to see a counsellor, I just want to try and get through it my way, if that's possible. (father)

Parents often found it hard to access counselling services. Many charitable organisations provide bereavement support but they expect clients to self-refer and do not accept referrals from health care professionals. Parents found it difficult to make these arrangements:

The school had already sorted out the counselling for me and the kids .....I mean, if it weren't for them, that was something else we had to do ourselves... I would have had to have rung round and found counselling for my kids. (mother)

The SUDI specialist nurse gave me the numbers to phone on SIDS and things and I said to the lady, you know crying and whatever, "I'm not having no counselling, you're just given some numbers to phone" (mother)

... because I'm with this drink and drug counselling, they do bereavement counselling in there so I've done it myself, I've got it all set up ... only by doing it myself. (mother)

GPs also tried to access counselling or mental health services for parents but were often unsuccessful or there were long waits for parents to be assessed. Many parents did however use the GP for support instead of or as well as counselling services; this was discussed in the primary care section.

Many parents found talking to other bereaved parents very helpful; this was usually an informal process. Some parents tried to access local support groups but while there are support groups for stillbirth and neonatal deaths there are few suitable local groups for SUDI due to its rarity. Similarly, parents with surviving infants struggled to find support

from people who appreciated the difficulties of grieving for a baby whilst caring for a survivor.

I've got a very good friend who actually had a baby girl who died at just under a month old and that would now have been 10 years ago so they were kind of that bit further ahead ...I spent quite a lot of time with my friend, she was just a really good person, in terms of also just understanding... (mother)

...it was nice then to talk to somebody else who had had almost exactly the same sort of thing. (father)

I'm on TAMBA, there is a bereavement site there, there are more women who have had twins who have lost one....I didn't feel I belonged with SANDS and that would have been the one that we both would have gone to because ... we just wanted to go to a group and maybe just listen to other people but they made me feel not welcome... (mother)

Overall, several parents commented that the JAA provided them with very little emotional support which they really needed.

But the support services for the sort of mental health side were really lacking. (father)

I think that would be my main point actually, I think that I specifically thought ...counselling would be part of that strategy and it wasn't. (father)

## Section 6.8 Social Care

Ideal social care

*Social care should be involved in the JAA particularly attending initial multi-agency discussions, deciding whether further social care assessments are necessary and if so arranging this and keeping SUDI professionals updated.*

### **Social care involvement in cases**

In nine cases, there was full social care involvement; with attendance at both initial and final multi-agency meetings and assessment of whether further social care involvement was necessary. However, in one case this was not recorded in the social care records only in the multi-agency meeting minutes. A social worker attended the home following one SUDI with CAIU police due to their concerns about the poor home circumstances and possible child neglect.

In two cases, families were referred to social care following concerns by the SUDI paediatrician and CAIU police. In these cases social care investigations were entirely separate from the JAA with social workers not attending multi-agency meetings.

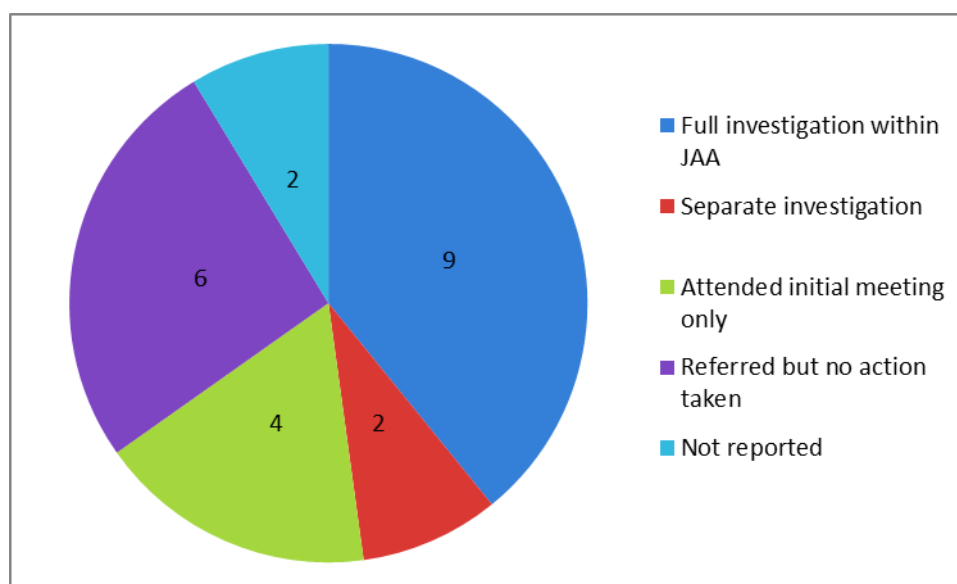
In four cases, social workers attended the initial multi-agency meeting but decided no further action was required and did not attend final meetings. In six cases, following routine social care referral for SUDI, the case was closed with no further action and social workers did not attend any multi-agency meetings. In two of these cases there were parenting issues; in one there were pre-existing concerns raised by professionals with poor school attendance by older siblings. The other case involved a co-sleeping death where the mother was intoxicated with alcohol and drugs.

In two cases deaths were not reported to social care; one of these families had a CAF in place prior to the birth due to concerns about the mother's ability to parent.



Social care involvement is shown in figure 15.

**Figure 15 Social care involvement in SUDI cases**



### **Parents' Experiences of Social Care**

Only five families described involvement with social care; the other families had no face to face contact with them. Two families, both of professional backgrounds, had a single visit from a social worker. These parents thought highly of the social care involvement; they recognised the need for child protection enquiries after a sudden death but appreciated the bereavement support offered to them particularly for their surviving children.

Well, yes we automatically triggered a visit ... I think it was probably a bit of everything because there was obviously a large part that was actually checking that we were safe as parents, primarily... He was very keen to follow up on how they [the siblings] would deal with the baby's death as well, did they need referring for any counselling, emotional or psychological support and then a bit on us... (mother)

The other families had all been known to social care prior to their babies' deaths although none had been on child protection plans. All had initial assessments; one family had a Common Assessment Framework put in place, one a Child in Need plan and one a Child Protection Plan. These families viewed social care involvement more negatively as unnecessary intrusion although they did comply with all recommendations. Two families felt that social care were not open with them during their initial visits; the parents thought the social workers were there to offer support to them when actually they were assessing the surviving siblings.

Social Services were on about me getting a new dog not suitable for the house but he was golden. (father)

We got rid of the dog, we listened to them and we got rid of it. (mother)

To me that [the death] was just an excuse for the social workers to get involved, they wanted to be fully on me because there's been domestic violence between me and the Dad. (mother)

It's disgusting and I don't even know she was doing it. I'd understand if the social worker had come in and said 'right, we have got to do this assessment on [name] and also talk about the baby'. (mother)

## **Section 6.9 Coroners' Enquiries**

Coroners' enquiries are an independent process and not part of the JAA; parents' and professionals' experiences with the coroner are only considered when they have a direct bearing on the JAA.

## The role of the coroner

*All unexpected deaths have to be referred to the coroner for further investigation. It is the role of the coroner to determine the cause of death. The coroner will make arrangements for the post-mortem examination and the results of this belong to the coroner. The body remains under the control of the coroner until all relevant examinations are complete, then it is released to the family's funeral director. Working Together (HM Government, 2013) directs that coroners should share information with other professionals as part of the JAA; likewise any professional involved in an unexpected death may be required to provide information for the coroner.*

## Parents' experiences of coroners' enquiries

Most parents' interactions were with coroners' officers rather than the coroner himself. Coroners' officers telephoned parents often in the days immediately after the death and usually informed them of the interim post-mortem examination results. Parents generally viewed these contacts as positive and informative although some commented on long waits for information to be available.

The coroner's officer hasn't phoned us up out of anything other than necessity but she always has asked how we are as people, it hasn't just been like 'by the way, the results are in, can you come here now?' (mother)

Parents' complaints about coroners' officers mainly focused on poor communication; parents were not always updated with results and felt they had to chase them for answers, parents were upset by misspelt names on documents and some thought coroners' officers were unsympathetic.

I had to keep phoning the coroners' officer saying 'have you heard anything yet?' and they kept telling me two weeks, they would phone us back in two

weeks and they never phoned, so I had to keep phoning them to find out.

(mother)

I felt like the coroner's officers had forgotten us because I was chasing them

....which upset me because I felt like suddenly she wasn't... she was just a

number... (mother)

Some coroners insist that formal statements are obtained from parents for all SUDI cases regardless of the circumstances of the death although most coroners are content with the reports from the SUDI paediatrician and CAIU police. These statements have to be taken by the CAIU police soon after the death and parents generally found the process distressing even if they felt the police were supportive of them.

After he had questioned me about anything, he did turn around and apologise.

He said "I am sorry about the questions that I have asked you but I have had to, it's my job, it's procedure. We have to do it with everyone". (mother)

The coroner's officer, rather than the SUDI paediatrician or specialist nurse, explained the results of the post-mortem examination to two families. Both these families commented that this left them with many unanswered questions and they would have preferred for this to be done by a medical professional. One further family only heard the cause of death for the first time at the Inquest and found this hugely distressing, their baby died of a rare medical cause but prior to the Inquest they had assumed the cause of death was SIDS. Their anxieties were only settled after a later discussion with the SUDI paediatrician.

### **Section 6.10 Professionals' experiences of JAA elements not visible to parents**

These elements of the JAA concern interprofessional working which is going on 'behind the scenes' so is not visible to parents. There are two main themes: multi-agency

meetings and joint agency working which includes experiences of social care and coroners' enquiries.

## **Section 6.11 Multi-agency meetings**

### **Ideal multi-agency meetings**

*There should be an early information sharing meeting about the SUDI case within 2 working days; attended by the SUDI paediatrician or specialist nurse; CAIU police, primary care and social care. If significant child protection issues come to light this becomes a formal strategy meeting. The Final Case Discussion (FCD) is held a few months' after the death when the final post-mortem examination results and all other information are available; full multi-agency attendance is again expected. The FCD considers the full cause and risk factors for the death as well as support and follow-up for the family.*

### **Details of multi-agency meetings**

Initial multi-agency meetings were held in 22/23 cases; the one case without a meeting the death occurred on the PICU following withdrawal of life-support. CAIU police were involved and discussion took place with PICU medical staff but not as part of SUDI procedures. 20/22 initial meetings were face to face meetings and two were telephone discussions only. These meetings were chaired by the SUDI paediatrician in 19 cases, the specialist nurse in one case and the Operations Manager for Safeguarding children in two cases. The Health Visitor attended these meetings in 21/22 cases and the GP in 7/23.

Final multi-agency case discussions were held in 21/23 cases. In one case the SUDI paediatrician decided it was not necessary as there was a fully explained medical cause for death with no social or parenting concerns raised. However, one part of the study

area final case discussions are not held due to difficult working relationships with local paediatricians; as a result one SIDS case did not have a case discussion.

Final case discussions were attended by Health Visitors in 11 cases and GPs in 14; all but three cases included either a Health Visitor or a GP and many were held at the GP practice. In one case, the family was not registered with a GP so neither a GP nor Health Visitor attended. In two other cases, both from the same locations it was not clear if primary care were invited to the case discussion and these were held at the child death co-ordinator's office. Paediatric pathologists attended two case discussions.

The mean time to final case discussion was 23 weeks; this cannot be held until the post-mortem examination results are available. Post-mortem reports were completed a mean of 16 weeks after the death but there was then a further mean delay of seven weeks before final case discussions were held. Some of these delays were due to difficulties accessing the post-mortem report from coroners and some due to problems organising the case discussion at a time convenient for all involved professionals.

In two cases the final case discussion took place over a year after the death; in both of these post-mortem samples were sent overseas for second opinions resulting in a lengthy delay for the post-mortem report to be available.

The coroner's inquest took place after the final case discussion in 13/21 cases, before in 3/21 and the timing was unclear in 5/21 cases.

### **Successful multi-agency meetings**

Professionals were very positive about multi-agency meetings, describing them as "helping to put the pieces together" and as a major conduit for effective communication. Successful meetings are reliant on full attendance by professionals;

who then share relevant information leading to a complete understanding of the cause of death and support plans for the family.

***Full attendance at multi-agency meetings***

Several professionals commented on the value of sharing information and being able to see other agencies' perspective on cases. At the initial meeting this information allowed professionals to clarify events, be reassured about potential safeguarding issues and allocate tasks appropriately between agencies.

I thought the initial multi-agency meeting was very good... So just to get that real understanding of each agencies knowledge of the family and then it was a little bit of a tasking meeting really with people going away with their various tasks to do. (police officer)

There were a few sort of low grade issues that Social Services had just commented on ...but actually when you looked back and you worked it all out there was nothing worrying at all. So actually from that point-of-view, the information sharing was very useful. (paediatrician)

The early meeting is best with everyone from all agencies involved with the families. It is a chance for me to see if there are any concerns that I don't already know and need to take action about. (police officer)

Similarly, information sharing was a key element of the FCD with further background information on families often provided by school representatives who attended to be able to support older siblings.

The family had been known by the school for 8 years so as final meetings go, there wasn't much that around the table we didn't have. (paediatrician)

The paediatric pathologists attended some FCDs; when they did this greatly aided discussions particularly in complex cases.

I think we probably had everybody that we needed there except for the pathologist and that was .....slightly difficult in the end because I did have the post mortem report but I hadn't got the expertise of the pathologist to explain why the findings were as they were. (paediatrician)

It's most useful when a pathologist turns up and can translate their findings. This is much better than when the paediatrician is there alone - the pathologist joins in the discussion and is often asked questions by the paediatrician too. (police officer)

Professionals not attending multi-agency meetings were a problem in some cases; frequently social care were absent even when there were safeguarding issues; limiting the information available about the family.

Getting social care to engage was pretty awful; I don't think they came to either multi-agency meeting. They did send a report though. (paediatrician)

I think Social Services hadn't actually fed back to anybody in particular their ongoing assessments and involvements... I think it was the Police that had the Social Care information at the last meeting. (paediatrician)

Police sometimes did not attend FCDs if they had no new information to impart viewing it as a box ticking exercise; whilst this was not always a problem it could reduce the amount of new information and learning available to them.

I think it's useful because it reviews not only the sort of cause and precipitating factors or risk factors but it can review the process and what has happened and



sometimes we've had feedback of bits of information and we've not had police or social services there to take it away and respond to it. (paediatrician)

### ***Understanding the cause of death and identifying risk factors***

Professionals described challenging discussions at FCD as they sought to understand complex pathology; this was easier if the pathologist was present at the meeting.

I thought it did work because in this case there was a very unusual issue... I'd not come across that before but it was very useful to sit amongst qualified people and hear them discussing what they thought that could mean and if there were any conclusions to come from that. (police officer)

The meetings I thought were really good and particularly the final one, where we had the pathologist there, that was really helpful and we debated in some detail and I think the conclusions we came to were pretty sound... It was a concerning case. (police officer)

Professionals were keen to identify relevant risk factors so be able to make recommendations and prevent future similar deaths.

No, she probably died from this infection... and there was an issue around her missing immunisation. We made recommendations... a follow up system for non-attendance at immunisations... (paediatrician)

I find it very helpful because the whole idea of the process is ...to see what we can learn from the death which we are looking at ... If we as a team can prevent another death from happening again in the future, that is what it's all about and that's what our aim is. (police officer)

We did have discussions about whether abuse or neglect were a factor and we felt that they weren't but there were clear contributory factors... she was co-sleeping but also that mother had been drinking was obviously a concern and we were quite keen to make sure that that would be followed up if Mum got pregnant again... (paediatrician)

### ***Planning support for families***

Several professionals identified one role of the multi-agency meetings being to plan who would support the parents. Early meetings focused on providing immediate support for parents; however the mother of the SUDI case in the second quote felt very strongly that the JAA had provided no bereavement support for her at all, she was required to access this herself.

I do remember the distress of the mother and sometimes that helps with the rapid response meeting,... sometimes you think 'hang on, there's some potential here for things to go even more horribly wrong if someone doesn't get the support that she needs'. (police officer)

Everybody shared appropriate information and it was all about trying to provide proper support for the family and making sure all the procedures were carried out to see what we could learn from the death. (police officer)

The FCD also considered support needs of parents but also longer term issues such as the next pregnancy and ensuring that if parents moved GPs their new practice was aware of the situation.

We had everybody there [at the FCD], including the GP and I think we found that the father wasn't accessing .....help that perhaps he required and the GP was going to deal with that. (paediatrician)

At the final meeting you're looking at how to support the family in the future. Mum wanted to get pregnant again and there were discussions around how the family could be supported and because she'd moved they were making sure that records had been forwarded on and a follow up phone call was made [to the new GP] to make sure that they were fully au fait with the circumstances, and I think that's a really, really good thing. (police officer)

### **Section 6.12 Joint agency working**

Professionals described their experiences of joint agency working very positively overall with some suggesting that there should be similar protocols in place to cover joint investigations in other areas. There were some difficulties with the process however and with the coroner and social care in particular; these specific issues will be considered separately.

#### **Positive attributes of joint agency working**

Police and paediatricians described their roles as complementing each other: allowing a dual perspective on the situation, being able to provide a balance between the need to investigate a potential crime whilst being sensitive to the needs of the family. There were no comments by police officers that joint history taking or the JHV had potentially jeopardised criminal investigations.

I always find it of great assistance to have the paediatrician there with you and you can actually share what both your viewpoints are; it's more a case of two professionals trying to work out exactly what has happened and at the same time trying to cause as little distress to the parents as possible. (police officer)

The role relationship was such that paediatrician took the lead but I made sure that I ticked all the police potential criminal investigation boxes along the way.  
(police officer)

I mean obviously prior to the JAA coming in, I think it was very much a police-led process, and I can remember being a health visitor at that time and parents being quite distressed by the way that cases had been handled by the police, in perhaps not too sensitive a way. (specialist nurse)

These observations still held true for more complex SUDI cases where there were initial suspicions that non-accidental injury may have been the cause of death.

I'm really positive about the JAA ...even when there are concerns from our perspective that there may have been a crime ... it doesn't compromise our investigation and I think it adds to the information that we get, and forensically it doesn't create a problem for the police investigation... (police officer)

There was this history before she died, suddenly and unexpectedly, of her having knocked her head, and so liaison between Police, Social Services and myself...the GP and so on, was really extremely helpful to try and understand the significance of that – or the lack of importance of it – and to be able to maybe diffuse a little bit the concerns around that and reassure the parents.  
(paediatrician)

The professionals frequently described that good working relationships between agencies was a key part of effective multi-agency working; the same professionals often worked with each other and this helped to provide an efficient service. Experienced professionals were able to support less experienced professionals regardless of the

agency; Child Death Overview Panel administrators provided effective case management support to all agencies.

I think because I had a few of the people from the different agencies before, it was just a bit slicker so with this case, it happened fairly smoothly from my point of view. (paediatrician)

I find that the Designated Doctors in this area are really approachable, very easy. (police officer)

Only two social workers were interviewed; they had been very involved in their SUDI cases, attending JHVs, interviewing parents with the police and attending multi-agency meetings. They were very positive about the JAA and multi-agency working.

I thought that the joint working there was quite good because the police had spoken to me about the children's father and explained that he was a risky adult and they were concerned about him... And then they arranged to meet him at the police station because obviously they had to interview him and they invited me along to that one which I thought was much more helpful because it was the same sort of questions really... (social worker)

It was quite a smooth process from our point of view, I know the police officer that I went out with [to do the JHV] ... and I felt comfortable doing that visit with him because I knew him, because we'd worked together for a long time. And it was a very quick process with the meeting when all the agencies were there, we engaged well with the Health Visitors and I thought the information sharing was fine. (social worker)

## **Difficulties with joint agency working**

In many cases although overall the JAA went well it had a poor start with lack of co-ordination between agencies and little joint working. The actions of the uniformed police at the home were often disproportionate and forensic investigators removed items from the home that prevented any meaningful examination of the scene of death by paediatricians. Occasionally there were delays in notifying the SUDI paediatrician; particularly when deaths occurred out of hours or if there were uncertainty as to whether the SUDI protocol should be followed. Hospital paediatricians were often took medical histories from families without waiting for CAIU police and as a result police had to re-ask some questions.

It wasn't truly joined up, that the police did do their own thing... No, I think they'd already done it [visited the home] ... they were off and sorting it before... we became involved as a community team... (paediatrician)

I wasn't present when the first part of the history was taken, which means that I miss out on some of the story and I end up asking questions at a later point, which they've already been taken through. So I think the hospitals do tend to fly solo on that one, they've got a pro forma to fill in and they think it's their job so they carry on and do it. (police officer)

Despite a regional multi-agency protocol for SUDI investigation each locality had a different way of implementing this resulting in some confusion for agencies that crossed boundaries. In some areas, the hospital paediatricians would carry out all the roles of the SUDI paediatrician doing the JHV and all follow-up whilst in other areas hospital paediatricians would hand the case over to a designated SUDI paediatrician; this could cause a lack of continuity and delays.

The area is made up of ten policing areas and we've got seven local authorities, one of which is a city which we divide into four.... They've got different health authorities and we all do things slightly differently in ten different ways. (police officer)

The lack of continuity with paediatricians is a problem. Sometimes the SUDI Paediatrician does come to A&E but not always.... The difficulty with suspicious deaths is when the story changes with different doctors - they might not realise. The new doctor might not know that the story changed; this can cause a problem. The main problem of getting a SUDI paediatrician is in office hours, at weekends or at night it is easier as they are not in clinic. (police officer)

In a few cases there was evidence of paediatricians actively blocking joint agency working; declining to liaise with the police seeing SUDI as a purely medical event.

I think there are some paediatricians who are particularly difficult...she wouldn't speak to me ... she decides that there is not going to be any sort of JAA [following an unexpected older child death] .... (police officer)

He [the acute paediatrician] didn't come to our initial meetings ...they are invited but they don't tend to come to the meetings, and he often doesn't like us to conclude without him...you know, he likes to do his own conclusion so I think that's partly why we all...the staff [SUDI professionals] didn't meet....There was a role there for the acute paediatrician ...he is more powerful and he normally does it... (paediatrician)

Yeah, we back off it, that's right because traditionally ...as a team we don't work necessarily that well with them [acute paediatricians], so they actually do often

feel that that's their role [managing SUDI] and their responsibility and don't want us to tread on their toes, very much so. (paediatrician)

### ***The Coroner***

The role of the coroner is to assign the cause of death and as such the result of the post-mortem examination is the property of the coroner. During the study period all SUDI cases were required to have an Inquest; however in September 2013 the coroners' rules changed and whilst all SUDIs are investigated by the coroner, Inquests are only held for deaths deemed to be from unnatural causes. There are seven coroners' districts in the study area and each coroner has a slightly different way of managing cases; some require formal police statements to be completed by the parents but others were willing instead for police and paediatricians alone to send statements based on the SUDI case records.

In some locations professionals were highly critical of the coroner seeing him as a barrier to effective investigation and wanting better liaison. There were particular difficulties in obtaining post-mortem examination reports despite frequent requests from SUDI paediatricians; often they were sent to the families' GP and even directly to parents.

Clearly we have problems with the coronial system ....but in general terms I think we could get better liaison with the coroner, not trying to usurp the coronial process but let's try to work in harmony, instead of him feeling that we are almost acting illegally at times by having a multi-agency meeting before the inquest. (paediatrician)

It is a big issue and even when we ring the coroner's officer, they still will not send us any copy. And sometimes the GPs have it so the specialist SUDI nurse



ends up randomly ringing GPs who go “oh I’ve had that age” and we haven’t known about it and we’ve been waiting for it. The pathologist will send it ....but otherwise sometimes it can be really, really hard.... (paediatrician)

The coroner in can be a barrier – I understand that he thinks the JAA is doing his role. (police)

However, in other locations professionals had good working relationships with the coroner, readily sharing information and coroners specifically requested that SUDI paediatricians visit families to explain the post-mortem examination results.

The coroner actually phoned me after they had done the post mortem and asked me to meet the parents. So I actually met them before the final case discussion, which is not the usual case but because the coroner was happy and asked me to, I did. (paediatrician)

The new coroner’s rules also make clear that post-mortem examination results should be disclosed upon request to interested parties such as the SUDI paediatrician (HM Government, 2009). All the cases in the study died prior to the new rules coming into force; however some SUDI paediatricians have commented that despite these new rules they still have difficulties obtaining the post-mortem examination reports.

### ***Social Care***

Other professionals comments on social care were mixed; negative views related to the lack of social care involvement with the JAA but when social care were involved they were rated highly. There were varying practices depending on the location; in some areas senior social work managers attended and at times chaired the initial multi-agency meeting and could then make an informed decision as to whether further social care assessment was warranted. At times, social workers visited families jointly with

other professionals either as part of the actual JHV or for follow-up. In other areas social care were rarely involved even with deaths involving parental drug and alcohol misuse and when families were subject to social care assessment there was little feedback available to the FCD.

The meetings I have been to are often run by a social worker or there is a social worker there.... (paediatrician)

Generally, yes.... they have Senior Managers who oversee it, so if there are issues like we can't get hold of someone, we just go straight to the people at the top and they sort it. So yes, they [social care] do contribute and they are involved and if we haven't contacted them, they will contact us. So it does work. (paediatrician)

...Getting them [social care] to engage was pretty awful, I don't think they came to either multi-agency meetings. They did send a report though. (paediatrician)

### **Section 6.13 Discussion**

The parents' and professionals' experiences of the JAA and case note data have been considered according to each stage of the process and good practices and difficulties have been highlighted. The factors contributing to good or poor experiences occur throughout the process and are not unique to any stage alone. Parents tended to describe more negative experiences than positive or neutral ones; this probably relates to the overall horror of the situation of the sudden death of a baby. Good practices by professionals may not be recognised as such by the parents in such a sad situation and they may only recall the elements of their care that went wrong; however the professionals have highlighted areas of good practice in many cases. As only approximately 20% of eligible cases were recruited it is quite possible that those parents

taking part are not representative of the majority and may have chosen to do so because their experiences of the JAA were particularly poor or good; however theoretical saturation of data was reached so it is unlikely that any significant themes were missed. By necessity I focus more on negative experiences as it is by analysing what is going wrong with the JAA that I can seek to improve it.

Good practices related to caring for parents; acknowledging their loss, showing compassion and being non-judgemental. These attributes could be shown by all professionals at any stage of the process: hospital nurses, uniformed or CAIU police, SUDI paediatricians, specialist nurses and primary care. Caring for parents included practical support: uniformed police driving families to hospital, nurses providing food and drink, police returning baby clothes sensitively or a SUDI nurse helping a mother compose a letter of complaint. A key element of good practice by SUDI paediatricians was explaining the cause of death to parents and helping them to understand this; parents found this much more helpful than coroners' officers attempting to explain post-mortem examination findings. SUDI paediatricians further supported parents by arranging and even attending with them follow-up with other specialists.

Poor experiences related to professionals, from all agencies not knowing or following the relevant SUDI protocols. When ambulance staff were reluctant to transfer infants declared dead at home to hospital, police went to some lengths to persuade them to do so; when in fact the protocol states that a funeral director should be used. Uniformed police have little knowledge of the SUDI protocol and frequently failed to notify the CAIU of SUDIs when these occurred out of hours. This lack of knowledge led to uniformed police treating SUDIs as potentially suspicious deaths and managing them as a crime causing huge amounts of distress to families. In some locations Working Together is not followed in that JHVs do not occur routinely.

Poor communication was an issue in some negative experiences. Hospital staff created false hope for parents who knew that their babies were dead. Parents had to repeat their account of events several times to different professionals. Some parents did not understand why a JHV was needed so felt unsupported by the process. At times there was a lack of consideration shown to the parents in hospital; seating them in inadequate small rooms in the ED with crying babies nearby and failing to find suitable clothes for their babies to wear. Similarly, police did not always take care to return items to parents handing them over directly from the evidence store deep freeze. Part of poor communication is the long wait for post-mortem examination results and final case discussions.

SUDI paediatricians and parents commented on the lack of emotional support provided by the JAA; many parents struggled to access appropriate counselling or bereavement services for themselves and their surviving children. In a few cases mothers are so overcome with grief that they cannot engage with professionals making the JHV very problematic. Whilst some primary care teams offered high levels of support to bereaved families, other teams did not contact parents; often the infant death was not recorded in the father's medical record.

Professionals were very positive about joint agency working seeing it as a real strength of the SUDI investigation. There are barriers to effective working such as coroners and a worrying lack of engagement by some social care departments. However it should be possible to overcome these obstacles with negotiations by experienced SUDI professionals.

Whilst there is an inherent conflict in the aims of the JAA in identifying the complete cause of death and meeting the needs of the family the issues highlighted are not insurmountable. It is not that these aims are incompatible but that at times

professionals fail to follow accepted protocols, communicate poorly with families and offer little emotional support.

The next chapter looks at parents' understanding of the cause of death: understanding what an unexplained death or SIDS is and the role of risk factors in these deaths. It also considers the role of blame and whether this is related to the cause of death or parental understanding.

## **Chapter seven Parents' understanding of the cause of death**

### **Section 7.1 Introduction**

The previous chapter examined parents' and professionals' experiences of JAA investigations; this chapter looks in more detail at the parents' understanding of why their baby died. It compares the causes of death as given by final case discussions, coroners and pathologists with the parents' explanations. Parents' understanding of the role of modifiable risk factors is considered along with the theme of blame.

#### **Methods**

The coroner's inquisition, post mortem examination report, final case discussion (FCD) notes and CDOP Form C were studied for each case. These documents all detail cause of death and relevant risk factors; this information was extracted separately from each of the documents for each case.

Parents were asked in the questionnaire if they understood why their baby had died and to explain the cause of death. During the in-depth interviews parents talked in some detail about the reasons for the death. As I was not aware of the cause and risk factors for death prior to interviewing parents I was unable to probe them about this but relied upon parents telling me what they thought relevant. However, a few families had a second follow-up interview and during these interviews I was able to ask about risk factors when the parents had not spoken about these before. Professionals working with these families were also interviewed and asked about discussing relevant risk factors with the families after the death.

Interviews were transcribed and analysed using a Framework approach. Themes were developed inductively; there were four relating to understanding the cause of death: needing answers, cause of death, understanding risk factors and blame. A framework matrix was used combining these themes from the interview data with the causes and

risk factors for death from the case notes. The parents' descriptions of the cause of death were compared with the official causes of death stated for each case to assess how accurate their understanding was; this was then compared with the parents' assessment of their own level of understanding (quite clear, some idea, no idea) according to the questionnaire. Parents' descriptions of risk factors were compared with those obtained from the FCD notes, Form C and any professional interviews. The cases were split into two different groups: one for medically explained deaths and the other for SIDS or unascertained deaths. These groups allowed for comparison between cases as well as between the groups themselves.

### **Selection and use of quotations**

All quotations used have been anonymised as far as possible to avoid possible identification of cases; therefore case reference numbers have not been used.

Professionals' quotes are attributed to the professional group only; for example paediatrician or police officer. Quotes were selected from cases to help illustrate findings. Some cases had more quotes selected than others; this was due to either a longer interview resulting in a larger number of quotes to select from or cases that highlighted particular issues. The distribution of the selection of quotes from the 18 cases having in-depth interviews or completing written questionnaires is shown in table 26 below.

**Table 26 Distribution of quotes from cases illustrating understanding causes of death**

Case code	Number of parental quotes used	Number of professional quotes used
A	2	0
B	7	0
C	1	Not interviewed
D	4	1
E	3	1
F	1	Not interviewed
G	1	1
H	2	1
I	3	1
J	2	3
K	7	0
L	3	0
M	2	0
N	0	1
O	3	Not interviewed
P	3	Not interviewed
Q	5	Not interviewed
R	2	Not interviewed

There are more quotes from mothers than fathers as more mothers were interviewed.

The majority of professional interviews were with police officers or paediatricians so these form most of the professionals' quotes.

## **Section 7.2 Results- Official causes of death**

Separate causes of death were given for each case by the pathologist, coroner and by a consensus of all professionals at the final case discussion (FCD). The causes of deaths were in three broad categories: SIDS, unascertained deaths and deaths due to fully explained medical causes. Six deaths were classified as SIDS, ten deaths as unascertained and seven from medical conditions. In order to preserve anonymity the causes of death and relevant risk factors are not shown for individual cases but only in aggregate and details of rare medical conditions have been removed. The causes of death given by the pathologist, coroner, FCD and the relevant risk factors are shown in table 27.



Table 27 Causes and risk factors for deaths

Category of death	Number of cases	Cause of death from post-mortem examination	Cause of death from Coroner's Inquisition	Cause of death from Final Case Discussion	Relevant risk factors from Final Case Discussion or JAA investigation
SIDS	3	SIDS	SIDS Natural causes	SIDS (no FCD in 1 case)	Co-sleeping in parents' bed Preterm infant (2 cases) Co-sleeping on sofa Using adult duvet (2 cases) Multiple birth (2 cases) Side/prone sleeping (2 cases) Maternal smoking in pregnancy and postnatally (2 cases) Death in car seat
	1	SIDS	SIDS Natural causes	Unascertained SIDS	
	1	SIDS with some symptoms of viral infection	SIDS with some symptoms of viral infection Natural causes	SIDS with some symptoms of viral infection	
	1	Hypoxic- ischaemic brain damage due to cardiorespiratory arrest	Hypoxic- ischaemic brain damage due to cardiorespiratory arrest Natural causes	Hypoxic- ischaemic brain damage due to cardiorespiratory arrest (SIDS equivalent)	
Unascertained	5	Unascertained	Not ascertained Open verdict	Unascertained	Minor lung pathology Potential asphyxiation hazards close to infant Side/prone sleeping (3 cases) Using adult duvet and pillows Co-sleeping in parents' bed (5 cases, 1 with possible overlaying) Preterm infant Maternal excess alcohol consumption on night of death (2 cases)
	2	Unascertained	Not ascertained Natural causes	Unascertained Natural causes	
	1	Unascertained	Not ascertained Open verdict	Unascertained SIDS	
	1	Unascertained	Not ascertained Natural causes	Unascertained but with evidence of minor infection insufficient to cause death	

	1	Sudden Unexpected Death in Infancy	Sudden Unexpected Death in Infancy Natural causes	Sudden Unexpected Unexplained Death	Maternal smoking in pregnancy and postnatally (4 cases) Maternal drug use (2 cases) Co-sleeping on sofa Congenital malformation Multiple birth Vulnerable family due to social concerns
Medical causes of death	3	Rare cardiac cause	Rare cardiac cause Natural causes	Rare cardiac cause (FCD not held in 1 case)	None identified
	1	Cardiorespiratory arrest due to rare medical cause	Cardiorespiratory arrest due to rare medical cause Natural causes	Cardiorespiratory arrest due to rare medical cause	
	1	Hypoxic- ischaemic brain injury due to cardiorespiratory arrest due to rare medical cause	Hypoxic- ischaemic brain injury due to cardiorespiratory arrest due to rare medical cause Natural causes	Hypoxic- ischaemic brain injury due to cardiorespiratory arrest due to rare medical cause	
	1	Cardiac abnormality arising from rare metabolic condition	Cardiac abnormality arising from rare metabolic condition Natural causes	Cardiac abnormality arising from rare metabolic condition	
	1	Infection	Infection Natural causes	Infection (vaccine preventable)	Parental smoking Missed vaccinations Poor housing

On the coroner's inquisition, in all cases the injuries or illnesses causing death were identical to the pathologists' stated cause of death. The coroners' conclusions as to whether the deaths were due to natural causes or an open verdict varied; in most cases where the infant's final sleep was clearly hazardous open verdicts were given.

The FCD reached similar conclusions to the coroner's inquest; however FCD highlighted relevant risk factors for each death. This gave a much broader understanding as to why each child died and how the deaths may have been prevented compared to the much narrower focus of the coroner and pathologist. In four cases there were differences of opinion between the coroner, pathologist and FCD; this related to differences in interpreting the information on the cause of death rather than further information being available to the FCD.

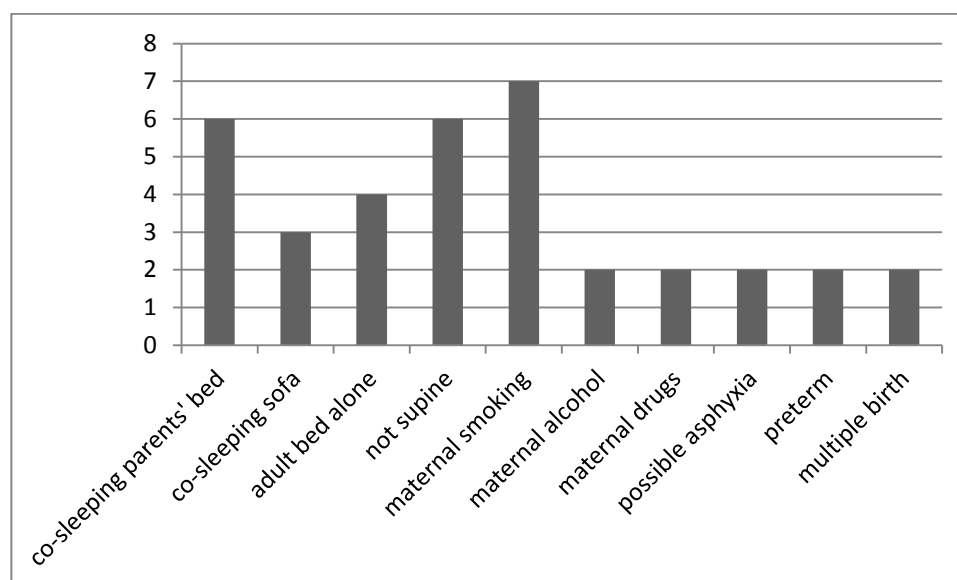
In two cases, the FCD felt that the deaths should be classified as SIDS rather than unascertained. In another the FCD wished to label an unascertained death as SIDS, the SUDI paediatrician discussed this with the pathologist who felt this was not appropriate as the baby had been asleep for only a short period before death so this case remained categorised as unascertained despite fulfilling diagnostic criteria for SIDS (Krous et al., 2004) In one case classified as SIDS, the pathologist commented that there was nothing to suggest airway obstruction in the history; the pathologist had not viewed the sleep scene unlike the SUDI paediatrician and police officer who disagreed with this statement. This death was labelled as SIDS due to natural causes whereas other co-sleeping deaths in similarly unsafe environments were generally labelled as unascertained with open verdicts.

### Section 7.3 Results - Modifiable factors contributing to deaths

Only one death from a medical cause had any relevant modifiable factors; this infant died of an infection, but had missed immunisations which may have protected her. She also lived in very poor housing and both parents smoked, increasing her vulnerability.

The SIDS and unascertained deaths were similar in that most had multiple potentially modifiable factors present; these will be considered as one entity and referred to as unexplained deaths from now on. Only one unexplained death had no modifiable factors but this was in an intrinsically vulnerable infant. In 14 cases the infants were sleeping in unsafe environments, co-sleeping with parents on sofas or in beds, or sleeping alone on adult beds with pillows and duvets. Only two deaths occurred when the infants were sleeping in their own cots or cribs but in both these cases the mothers smoked during pregnancy and after the birth. The frequency of modifiable factors in unexplained deaths is shown in figure 16.

**Figure 16 Frequency of modifiable factors in unexplained deaths**



## **Section 7.4 How important is finding a cause of death for the parents?**

The parents' need to understand why their baby died came across very strongly in most interviews although parents were not specifically asked about how important it was for them to know the cause of death:

Yes, I suppose I felt it was quite important really to hear what the findings were really because it was unexpected, he was such a healthy boy and it was such a shock. ....I really wanted to know and that was all really I guess. (father)

In most cases, the cause of death is not immediately apparent on post-mortem examination and detailed histological and metabolic tests are required; as a result it is usually at least four months before the final results are available. During this time parents often became increasingly anxious about the cause of death; one common worry was that the baby had suffocated either by rolling prone or when co-sleeping. In this situation parents were greatly reassured by explanations of SIDS and post-mortem examination reports (although asphyxia cannot be ruled out by post-mortem examination). During this wait one mother, even began to question her own actions and create theories for the death:

That's what you...you turn it on yourself when you don't hear anything, then you make things up in your head. 'It must have been this, it must have been this, it must have been this'...because you don't know anything.....Which leaves me to sit there wondering what it was and thinking 'we don't know anything about the toxicology' and I'm thinking 'how could you possibly have poisoned...how have you poisoned him?' Well you don't know, until that comes back, you don't know, and that was weeks. (mother)

For some families, knowing the cause of death was of the greatest importance. In one case, post-mortem samples were sent overseas for further opinion and the coroner offered the mother a verdict of natural causes to conclude the Inquest or to wait until the full results were available several months later. The mother was outraged to even be offered this choice:

So at that point literally last year they said to me 'you can have a death certificate now and we will go ahead and go to coroner's court, or you can wait until the test results come back...', and I said 'I'll wait because I've got nothing else better' ...there's nothing else to do and I want to know everything, you can't give me a death certificate if you haven't done all your [investigations]....  
(mother)

This mother felt she had to fight to get the answers about her infant's condition; obtaining this information helped her to still feel as if she was a mother and that she had a role to fill:

So that just shows the strength that I have to be still sat here so I need to know what's going on with her, it gives me a sense of feeling I'm still her  
Mum.(mother)

Eventually, a cause of death was found; this was explained to the mother by the SUDI paediatrician and specialist nurse. For the mother this was a relief as an answer had finally been found, the specialist nurse saw her again a few days later and was amazed in the change in her:

.....for me that was amazing, seeing her the week after because she was just a totally different woman. This was a woman that didn't go outside, never smiled and she was up, she was dressed, she was, you know, smiling...a totally, totally

different woman from when we first saw her, it was just amazing, just the results of that just changed her completely. (nurse)

Other families had similarly long waits for results but no cause of death could be established and the deaths remained unexplained. For these parents, the lack of explanation was a severe blow, offering no relief to them. In one case, the baby had a congenital malformation and was unwell at the time of death; the mother fully expected the cause of death to be related to these but was shocked that the death remained unexplained.

She was upset ... because she never got an answer, you know, cos we had boiled it down to it was that cyst. (grandmother)

Similarly, another family had suffered two sudden infant deaths, the first was explained by a previously undetected congenital anomaly but the second remained unexplained.

It's different...that's what really got us, how could they do the same tests but why have they found nothing for this baby? (father)

It's just, not having an answer; I don't think it's fair like...why? (mother)

Likewise, for two other families where the deaths remained unexplained, the parents really struggled with the lack of reason for the deaths. These parents understood the concept of SIDS but this offered no comfort.

I have days when I have really been beyond sad and I'm angry ...because you can't understand a healthy baby dying. You can understand a poorly baby dying but you can't understand a healthy baby dying. (mother)

I know now they are saying natural causes but what's natural about a healthy person dying? (mother)

A minority of families did not talk about the importance of finding the cause of death; this may have been that they were being interviewed after they had had final follow-up meetings with their SUDI paediatrician and had the cause of death (or lack of cause of death) explained to them so the topic has lost its pertinence. However often police officers spoke of parents at the initial home visit desperately wanting to know why their infants died; these families had not spoken about this during their interviews.

The husband in all fairness was very good and supportive and said 'I understand why you're doing this, and I want you to try and find out why my son is in hospital, why has he stopped breathing, you know, help me understand'. (police officer)

Dad was very helpful and he said he understood we were there to do a job and he just wanted to find out himself what had happened. (police officer)

Even when parents at interview did not talk about their need to know why their baby died; several families illustrated their desire for knowledge by asking questions about the death. These parents had already received an explanation for the death from their SUDI paediatrician but still had 'What if?' type questions.

I think I'm always gonna 'what if?'...I'm always gonna like, of the thing with her lungs with the Health Visitor, I think what if I'd have followed that up and said 'right, I want a second opinion' or 'I want to go to the hospital' (mother)

What if we'd not done...what if we had done everything by the letter...had we done everything that we should do, completely 100%, would that have changed things? (father)

One mother said that knowing the cause of death was of little importance to her as it changed nothing; she was the only parent to voice this opinion. However this mother



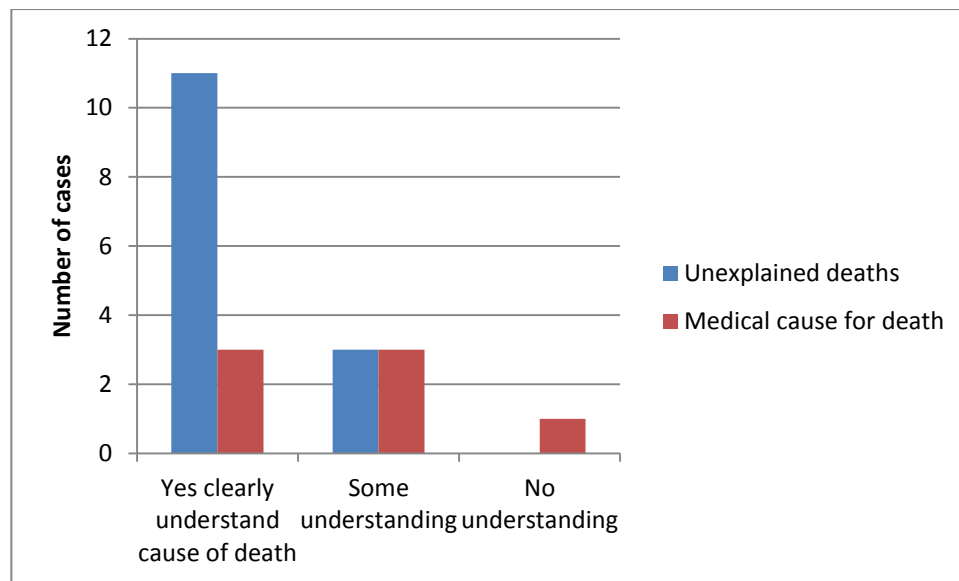
also complained of the long wait until the post-mortem examination results were available; clearly she did want this information but what she was saying was that in reality it made little difference to her. This may have been because the death remained unexplained, had a full cause for the death been determined this may have altered her perception.

I very much felt it [knowing the cause of death] doesn't change anything, and even though the findings were... it was an unascertained death... but it doesn't change the reality of what happened. (mother)

### **Section 7.5 Do parents understand the cause of death?**

In the questionnaire, parents were asked: 'Do you know why your baby died?' and given three possible answers: "yes, quite clearly", "I have some idea but I am not quite sure" or "no, I have little idea". Parents were then asked to give the cause of death. 34 parents of 21 infants responded, 23 felt they fully understood the cause of death, 10 said they had some idea and one parent had no idea why their child died. In all but one case both parents gave the same answer, in this case an unexplained death, father thought he clearly understood but mother was not quite sure. Mothers' understanding of cause of death is shown in figure 17.

**Figure 17 Mothers understanding of cause of death**



### **Understanding the cause of death for medical deaths.**

Of the seven families with a medical cause for death six gave accurate descriptions of the cause of death which closely matched the terms used by the professionals. Four of these families stated on the questionnaire that they fully understood the cause of death and two families stated they had some idea but were not quite sure. This uncertainty reflected that whilst the final cause for the death was clear the underlying reason for the infant developing the condition remained unknown.

...when we saw the geneticists ... one of the questions we raised at the time – was if we did have more children, could this happen again, to which they couldn't really answer because they still haven't determined whether it was genetic or anything as such like that. (mother)

Three families understood the cause of death but had significant unanswered questions relating to it; these were mainly about whether the condition should have been detected before the death.

Our baby died of ... an undiagnosed condition that nobody found even though all the signs were there. I still have doubts about the results, something doesn't make sense... (father)

One mother did not understand the cause of death at all; indicating such on the questionnaire and being unable to explain the diagnosis at interview at all. The SUDI paediatrician had tried to explain the diagnosis to the mother at a follow-up visit. Part of the mother's difficulty was that the baby had been completely well until his collapse and she could not understand how the baby's condition was not detected before.

But I don't believe what they are saying because I took him to all his needles, I took him to all his check-ups, somewhere down the line the doctor could have known. (mother)

### **Understanding the cause of death for unexplained deaths.**

Understanding the cause of death in unexplained deaths is an oxymoron; however what I meant by this phrase is that the parents appreciate that despite a full investigation no complete explanation for the death has been found. Eight families could explain the meaning of SIDS or an unascertained verdict at interview; six of these stated that they clearly knew why their baby died and two that they had some idea only.

As much as an unascertained death can be, and I think that's the thing isn't it ...so it's very clear apart from the fact that nobody knows what it is. (mother)

...that was one of the things I asked the paediatrician, I said 'what is it' and she said 'that's the whole point, we don't know'. (mother)

...something in his brain...he'd stopped breathing and his brain wasn't developed enough to sort of say... 'Baby, you're not breathing, breathe son'.  
(father)

Two families stated they only had some idea why their baby died; in one this referred to the fact that whilst some significant pathology had been found at post mortem this was not enough to explain why the baby died so the cause of death remained unexplained.

The paediatrician said that the baby had had some bleeding and not just at the time of death, ...she'd had previous bleeding that had resolved itself ....And yet he said the people who did the autopsy couldn't see how that would have caused her to die. (mother)

In four cases, the parents said they were quite clear why the baby died or had some idea according to the questionnaire, but on further analysis of the text it became clear that the parents' descriptions of the cause of death did not match those from the official documents. In one, the mother stated that she understood clearly and the baby had died of a medical cause, bronchitis. In reality this death was labelled as SIDS by the FCD with risk factors of lung pathology that was not significant enough to cause death by itself and unsafe sleeping. The other three cases overlap significantly with understanding modifiable factors for death so these will be discussed in that section.

## **Section 7.6 Parents' understanding of modifiable factors**

Parental understanding of modifiable factors was relevant for 15 unexplained deaths and one medically explained death with modifiable factors.

### **Parents who understand modifiable factors**

Five families appeared to fully understand the relevant modifiable factors for their infants' deaths and discussed them during the interview; one additional family did not mention modifiable factors during my interview but had made it clear to their specialist nurse that they understood. These were cases where infants had been in unsafe sleep environments or where parents were smokers.

Some parents talked openly about their actions and it was clear that they had understood the risks their babies had been exposed to:

If they say that nine out of ten cot deaths are in families where family members smoke, whether you do it around the baby or not... But I was thinking to myself 'I can't see how that makes any difference' and I mean, I fell asleep with him by accident that night when it happened but the amount of times I'd put him in bed with me...(mother)

For other parents, it was clear that the original discussion of modifiable risk factors with the SUDI paediatrician had been difficult and it was similarly difficult for parents to discuss these with me during the interview. By acknowledging modifiable risk factors for the death, parents are acknowledging that the death itself was potentially avoidable.

Yes because my wife sort of listened to it [the SUDI paediatrician talking about risk factors] and thought 'well he was in our bed at the time when he died and should I have put him in there...had I put him in his cot, would things have turned out differently?' (father)

I just wanted her to be comfortable and warm and... I've sort of come to terms with that I didn't do anything wrong..... So if all I'm guilty of is loving her a bit too much, then so be it. (mother)

One mother did not mention during the interview that her baby died while co-sleeping; however she had talked this through with the SUDI specialist nurse so it was clear that she did understand the relevance of this:

She clearly understands and I mean she did say to me when she was pregnant with the [next] baby..., she said 'I'm going to be really, really, really clear this

time, that this baby will be sleeping in their own crib and that as much as I might be tempted, I will not be co-sleeping'. (nurse)

### **Parents who do not understand modifiable factors**

In seven families there were modifiable factors present but it is not clear that the parents understood the significance of these; however in three of these there was no evidence of any discussion of modifiable factors between the parents and SUDI paediatrician. In one case, the sole modifiable factor was maternal smoking; this was documented on the CDOP Form C but neither identified as such by the SUDI paediatrician nor mentioned by the mother at interview even though we paused for her to have a cigarette.

Well we didn't [discuss any risk factors] that time because I don't think there was any identified in the whole process with her. (Paediatrician)

In another case, where a baby died after being placed to sleep on her side, on soft bedding, the SUDI paediatrician deliberately avoided discussing this with the parents, not wanting to blame them.

...So once the death has happened, we don't...I don't think we dwell on the risk factors because I think, that's right, we're not trying...we don't want to apportion blame to parents. (Paediatrician)

In three families there was no mention of relevant modifiable risk factors despite evidence of detailed discussions between the SUDI paediatricians and the parents concerning these. In these cases the parents may be glossing over the significance of the modifiable risk factors possibly even completely denying them to protect themselves from the reality of the knowledge. It could also be that the parents simply did not understand despite the explanations.

One baby died co-sleeping on a sofa, under a duvet. The mother described the death as 'cot death' and did not elaborate further; similarly, this mother also played down her involvement with social care when there was extensive social care involvement. However, whilst this mother may have been minimising the modifiable factors, this death was actually classified as SIDS by the pathologist and coroner despite other similar deaths generally being labelled as unascertained.

One baby died of an infection having missed the relevant protective immunisations; the parents were able to describe the infection which caused his death but did not mention vaccination at all. The parents spoke only of the GP who did not refer the baby to hospital, which at the time of the assessment was not clinically necessary. The parents may have been downplaying the lack of immunisations but I am not sure that they really understood the issues.

Another baby was co-sleeping in bed with his mother, who had consumed a large amount of alcohol and illicit drugs. The mother did not mention any of this during the interview and said that as no cause of death had been found she thought the death would be classified as SIDS.

It confused me a little bit because I don't know, they [the paediatrician and police officer] just basically came to my house and said 'we've done all the tests, everything that we've done and we can't find any reason for it, for the death' so I've made the assumption then that... at the inquest when that's all brought together, then it will be put down to SIDS ...because that's what SIDS is, isn't it? It's when there's no explanation? (mother)

From the mother's description it seems as if she really did not understand the role that the alcohol, drugs and co-sleeping may have played in the baby's death. However, this

was discussed with her by the SUDI paediatrician and police officer who did a joint follow-up visit; mother apparently did not disagree with their findings but made little comment.

Yeah, I said that the post mortem hadn't found - hadn't been able to ascertain a cause for the baby's death, and then the police officer fed back the toxicology results and said that her blood alcohol levels were twice the drink-drive limit at the time she found him, and that there were also drugs. Mum said she wasn't surprised about the alcohol because she'd had a drink but she did seem surprised about the drugs but she didn't discuss it any further. (paediatrician)

I thought the mother wasn't the most communicative of people. I think she was...well, was she ashamed about what had come out about the alcohol and the drugs? I'm not sure. It may have been that but she didn't tell us how she felt about it. (police officer)

Given the detailed conversation between the SUDI paediatrician, police officer and mother it does seem surprising that she really did not understand the issues; I think it is more likely that she was denying the reality of what happened as this was too painful.

One baby died co-sleeping on a sofa; his mother did talk about the sofa during the interview; in fact she sat on the same sofa whilst we talked. I think the mother did understand the issue of co-sleeping but downplayed this somewhat as the baby was not right next to her:

In a way it's made me open my eyes a lot more as well because you don't realise what it could do like with co-sleeping but I weren't actually right next to him like I usually was but in another way it makes you feel bad cos you like to



get your little loving in your own time kind of thing. But I can understand what they are saying about it. (mother)

I think this case illustrates well the difficulties for parents of understanding modifiable risk factors; in that by acknowledging these, parents are accepting that had they made different choices their baby might not have died. In the quote below this mother is clearly trying to protect herself from the reality of the risk of co-sleeping on the sofa; if the baby's death was inevitable (as he knew he was going to die) the choice of sleep location becomes irrelevant.

So normally the two of us would cuddle up on the sofa there together...Yeah and that one night he said to me like 'nah Mum, you sleep down that end'...obviously he didn't want me to wake up next to him, he knew. That's how I've got to look at it. (mother)

## **Section 7.7 Blame and modifiable risk factors**

As discussed already, some SUDI paediatricians are concerned that by explaining the role of potentially modifiable risk factors to parents this may lead to them blaming themselves for the death and at times SUDI paediatricians have avoided these conversations altogether. Parents were not asked specifically about blame during interviews but this topic came up spontaneously for many families when talking about the cause of the death. There were four different categories of blame relating to parents: those who blamed themselves, those who blamed others, those who felt blamed and those who blamed no-one. Parents could show more than one category of blame, such as blaming themselves and others for the death. There was a mix of cases within each category from those cases where families understood modifiable risk factors, those where they did not understand risk factors and those where there were no potentially modifiable risk factors.

## **Blaming themselves**

Six mothers and one father (relating to six cases) blamed themselves to some extent for the death; some seemed to blame themselves completely for the death and others less so. In three cases there were no modifiable risk factors and the deaths could not have been prevented; in the remaining three cases there were modifiable risk factors present that were understood by all the parents.

All six mothers described feeling guilty because their baby had died; they had failed in their role as a mother; these feelings of guilt did not relate to the cause of death and were expressed by mothers where deaths were unpreventable as well as those with potentially modifiable risk factors.

At this point I didn't have any idea how long I'd been asleep and then feeling this overwhelming guilt....I've slept for hours and she's just died. (mother)

There's nothing anybody could do to stop you feeling guilty, no matter how much you did or you didn't do wrong because you are ultimately responsible for that child. (mother)

I think there is a part of her that she still blames herself, and that's never ever going to go away... (father)

Three mothers blamed themselves completely for the death; these cases were all different in terms of potentially modifiable risk factors, cause of death and maternal understanding of the cause.

One baby died suddenly of a medical cause whilst with a child carer; the mother fully understood the cause of death and that it could not have been prevented. Despite this she blamed herself for being at work yet also made clear that she did not want any blame put on the child carer. However, when the mother was re-interviewed, two years

later, she no longer blamed herself and accepted that the death was unpreventable and blamed no-one for the death.

...I mean when everything was still very raw, a lot of the conversations we had at the time were from your [the mother's] point of view, when you were talking to me...it was almost like a blame thing, you know. 'I blame myself, if I hadn't have gone back to work, he'd be fine'. (father)

Another baby died of a rare medical cause that could not have been prevented. The mother never understood or accepted the diagnosis and instead she blamed her every action; this was still the case at follow-up two years later.

I blame myself in one way because I had so much stress, right, I am thinking was it really me because I had so much stress that I couldn't even.....I was unwell myself. (mother)

And then.....I don't believe them, like I said I don't believe what's just been said because it doesn't click because I don't know, maybe there is something missing because I do blame myself since... but what I don't get, that if he got sick, why didn't the monitor [baby alarm] pick it up? (mother)

I'm thinking why was I making them sandwiches then? I always make them, why did I suddenly have to do that? If I found him sooner he would be here?  
(mother)

For this mother, her extreme self-blame seems linked to her lack of understanding of the cause for her baby's death; however several professionals had tried to explain the cause of death to the mother.

One baby died co-sleeping on a sofa with his mother, she was a smoker and had had some wine to drink that evening. Both parents blamed themselves completely for the death and their self-blame became the focus of the interview.

I mean, I fell asleep with him by accident that night when it happened but the amount of times I'd put him in bed with me...because I slept with my eldest son, ...so I couldn't see anything wrong with that. I'd done it and I'd got away with it and I'd smoked all the time I was having him ...and the amount of times that I think to myself, 'you shouldn't have fell asleep'...but I hadn't done it on purpose, had I? (mother)

You see, I kick myself, why didn't I wake you both up and say 'go to bed'? You just looked dead comfy and I knew my wife hadn't had much sleep and the baby hadn't had much sleep that day and I thought 'oh, I'll just let them have a sleep'. (father)

But when something dreadful has happened and the baby's gone you think about everything, like I think, well that night, you know, I'd had a couple of glasses of wine... they say that's alright and I think but it's not alright when you're tired....I really shouldn't have had any at all. You're always tired. ....And I'm thinking, 'well it won't make it any difference because it's not like you're drunk and you couldn't get up with the baby' ...no, but you're far more likely to fall asleep or not be... you're not fully compos mentis, are you, when you've had any? And I'm thinking well if I'd have had none, I wouldn't have fallen asleep and if he'd have none he probably wouldn't have left me there. (mother)

These four parents had similar extreme feelings of guilt although the circumstances of death were very different. Notably all these parents scored highly for both anxiety and

depression on HADS with all scores in the clinically significant range. In either domain a score of 8-10 is of borderline significance and a score of more than 11 is considered clinically significant; the maximum score is 21 (Zigmond and Snaith, 1983). The mean anxiety score for the three mothers who blamed themselves completely for the death was 17.0 (95% CI 14.5 – 19.5) with a median score of 17 compared to 9.9 (95% CI 8.4- 11.5) with a median score of 10 for all other mothers. The mean depression score for the three mothers who blamed themselves completely was 18.3 (95% CI 15.5 – 21.2) with a median score of 19 compared to 8.8 (95% CI 6.6- 11.0) with a median score of 8.

These scores are shown in figures 18 and 19. An independent t test was used to determine if the mean scores were significantly different

The independent t test for anxiety was:

$$t(19) = -3.91, p < 0.001$$

The independent t test for depression was:

$$t(19) = -3.68, p < 0.002$$

Therefore the HADS scores were significantly different between the self-blaming mothers and mothers who did not self-blame.

HADS were not significantly associated with whether parents understood the cause of death or with whether the death was due to a medical cause or was unexplained.

Figure 18 Maternal anxiety and self-blame

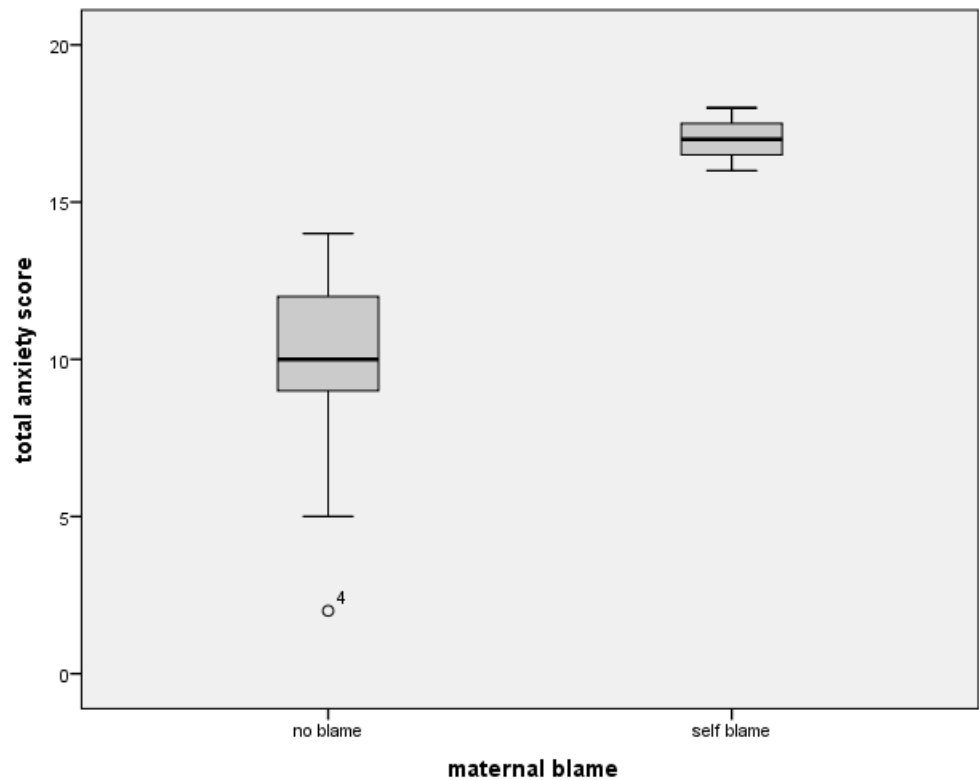
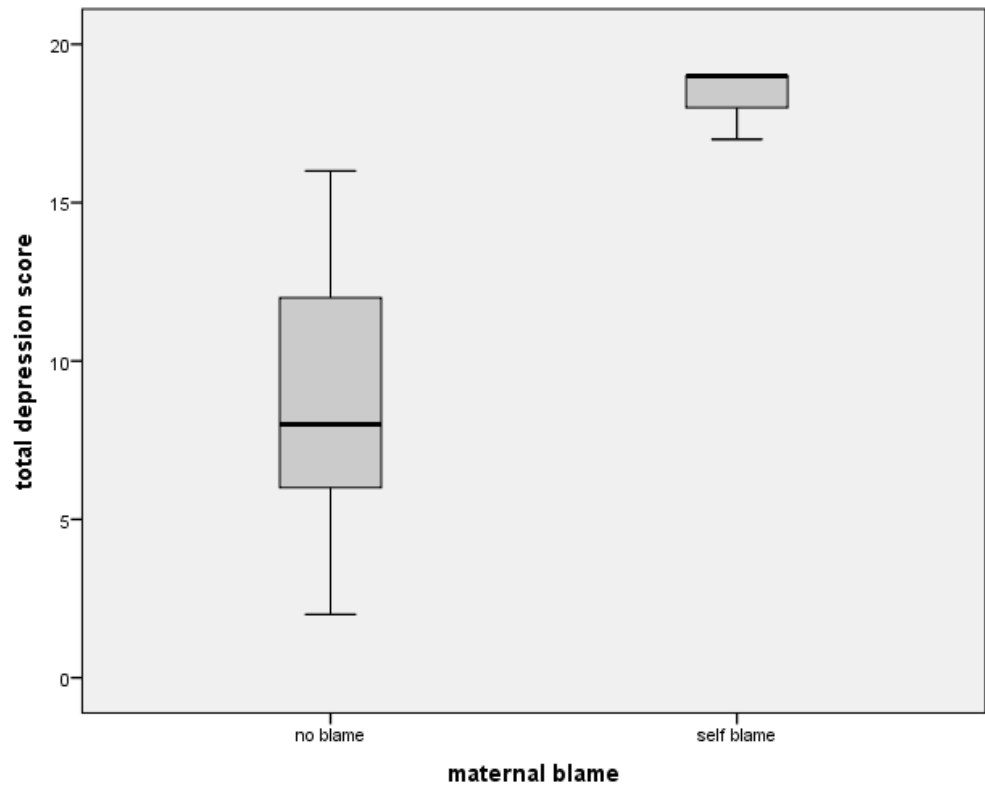


Figure 19 Maternal depression and self-blame



At follow-up one mother was no longer blaming herself and had a HADS score in the normal range; another had a score which remained very high and she continued to self-blame. The remaining mother was not followed up.

There were two other cases somewhat similar to the one just discussed (co-sleeping on a sofa, alcohol consumption and parental self-blame). These deaths were also unexplained with potentially modifiable risk factors which the parents understood.

These mothers also regretted their choice of actions telling of 'what if I had done something different?' They still blamed themselves somewhat for the death although these feelings were much less extreme than those of the parents in the previous case; neither mother had clinically significant scores on HADS.

....even now, I still think...I don't blame myself as much but I do think 'what if...what if that night had been different and I'd not got him out to feed him and he'd been in his Moses basket, would it have happened?' (mother)

Yes because my wife sort of listened to it [the SUDI paediatrician talking about risk factors] and thought 'well he was in our bed at the time when he died and should I have put him in there...had I put him in his cot, would things have turned out differently?' (father)

### **Feeling Blamed**

In three cases the parents felt blamed by the professionals for the death; two were unexplained with modifiable risk factors and one was an explained medical death.

In one unexplained case, the mother initially felt very blamed by the SUDI paediatrician when he spoke about the risk factors for SIDS; the baby had been sleeping on the mother's bed using a pillow and adult duvet as she was worried about keeping the baby

warm. However at a follow-up interview two years after the death she no longer felt blamed and could only just recall her animosity towards the SUDI paediatrician.

The parents of the baby dying of a medical cause, felt blamed by the doctors in the emergency department although the death could not have been predicted; the experience suggests poor communication was the cause for this mother feeling at fault.

The doctor who worked on the baby did not explain anything and was very harsh with her words; I was made to feel like I had done wrong. (mother)

In the remaining case, the mother felt blamed by the police. The baby had died in a co-sleeping situation where the mother had consumed excessive alcohol and used illicit drugs.

...he [the police officer] really made me feel like I'd done something wrong, which really is a big observation to make, if you don't know nothing sort of thing, and everybody else [the family] agreed with me, that that was how he was... (mother)

As discussed earlier this mother really did not seem to appreciate the risk to the baby from her actions and she genuinely appeared to believe that she had done nothing wrong; alternatively she was just denying this to herself as the knowledge was too painful to consider. The police were concerned about the mother's alcohol consumption and arranged for a police surgeon to attend the hospital to take a blood sample from her for toxicology analysis.

...although I didn't have an alcohol level for some time because the samples take some while to come back, with the bed sharing ...I was concerned that we might have criminal offences here. (police)



In this situation the police may have transmitted their feelings that this death could have been avoided to the mother, who being convinced that she was not at fault interpreted this as being blamed. However, several families have said that just seeing the police in hospital made them feel guilty even when the police showed great sensitivity to them.

### **Blaming others**

In five cases, the parents blamed other people for their infant's deaths; in some of these cases blaming others may have been a deflection from not acknowledging their own actions. In other cases, the blame by parents seems justified to some extent.

One baby died of infection having missed immunisations. He was unwell for a few days before his death and had been taken to the GP the day before he died. The parents accepted the GP's reassurances and did not take action when the baby deteriorated. The GP records showed that the baby did not need hospital admission at the time but the parents refused to accept this blaming the GP for not recognising the severity of the illness. The parents did not question their own inaction when the baby's condition got worse.

Well I just really think it was down to the Doctor because they should have done something....I kept telling them there was something wrong. (father)

Because the night before he died, we had family come over ...and my cousin said 'he looks like he's going to die' ...she actually said that. I said well the doctor said to give him Calpol so there was nothing else we could do. (father)

In this case it seems probable that by blaming the GP for failing to diagnose the baby; the parents are absolving themselves of responsibility for the lack of immunisations and their failure to seek further medical advice.

One family had had a previous infant death so apnoea monitors were recommended for all subsequently born infants. The parents were advised to stop using the apnoea monitor by a health care worker; a few days later the baby died co-sleeping with both parents. Despite the parents understanding the risks of co-sleeping (as described earlier) they did not refer to this during the interview but instead expressed their anger at the health care worker.

And like, the question is, why did they tell us to turn the monitor off but nothing's happened, nothing, not a question or nothing, they've got away with it. But in your mind, you're thinking 'why, why, why, why at that age? What would have happened if we'd had it on?' But nothing's happened, that's it, case is closed now, that's it, they can't do nothing. (father)

Other parents questioned why the rare condition that caused the infant's death had not been detected earlier. However, the health records detailed that the Health Visitor had been concerned about the infant's feeding difficulties and recommended that the parents see the GP but they did not follow this advice.

In all these cases it seems that by blaming others for the death the parents have avoided responsibility for their actions such as not seeking appropriate medical advice or co-sleeping.

One baby was born prematurely and growth restricted, spending many weeks on the neonatal intensive unit but no diagnosis was found for her condition until after her death. She died a few days after she was discharged home; mother had requested an apnoea monitor from the hospital as the baby had had a respiratory arrest two weeks prior to discharge but this was declined. The mother blamed the neonatal unit for not listening to her concerns.

...She wasn't well enough, you [medical staff at the neonatal unit] didn't know what was wrong with her so how could you send her home knowing she was well enough to come home without an apnoea monitor, and how in God's name did you know she was well enough to come home because you still to this day don't know what was wrong with her. So, you know, it's all wrong. (mother)

In this case, it might seem that the mother has some reason for being angry with the neonatal unit; this was clearly a very vulnerable infant. Although apnoea monitors have not been shown to prevent SIDS, it may have offered some reassurance to the mother given the previous respiratory arrest. Even had the baby died on the apnoea monitor the mother may have felt comforted that everything possible had been done.

One baby had complex medical problems and was unwell intermittently for weeks before his death; the death was unexplained. The mother was convinced that had the baby been reviewed in hospital he may not have died:

...But I think it was my own GP's fault, over here for not taking notice of what I was saying. I do actually think it's that GP cos maybe if he would have sent him to the hospital and had routine check-ups then maybe he would have been here today, we'll never know.(mother)

This was a very complex case and the JAA investigation was sub-optimal; as a result it remains unknown whether an urgent hospital referral was warranted or would have been helpful. It is difficult therefore to comment on the mother blaming the GP, whether there was any justification for this or not. This was a co-sleeping death, the mother did not mention this at interview and it is not certain whether this issue was discussed with her by the SUDI paediatrician.

Conversely, in another case, the parents did not seek to blame others when one could understand them doing so. The mother had been struggling to breast feed a pre-term baby. She had been given some inappropriate breast feeding advice from a peer support group; that it was alright to co-sleep and not ever to consider topping-up with formula. The mother was exhausted and fell asleep breastfeeding in bed, the death was unexplained. The parents were critical of the service but did not hold them accountable for what happened.

We're not trying to put fault on anybody, it could be anything still but they should have clear guidelines, shouldn't they? (father)

### **No blame**

In six families there was no mention of blame at all and in six other families they explained that they blamed no-one for the death. In eight cases there were potentially modifiable risk factors present, in three of these, the parents fully understood this. In three cases the parents did not understand and in two cases the parents were not told of the risk factors. In four cases, there were no potentially modifiable risk factors for the death.

In one case, the father had always accepted that the death was unavoidable so that there could be no blame; the mother however blamed herself for the death initially but subsequently moved away from this.

...I mean when everything was still very raw, a lot of the conversations we had at the time were from your [the mother's] point of view, when you were talking to me...it was almost like a blame thing, you know. 'I blame myself, if I hadn't have gone back to work, he'd be fine' ..... I was on the other side of the coin

saying 'look, nobody could have predicted this; it was one of those horrific freaks of nature'. (father)

In one case, the parents had expected the death to be classified as SIDS but they subsequently found out she had died of a rare medical cause. They felt this exonerated them from any blame.

I was expecting it was sudden death and that was it really. And then we'd beat ourselves up for the rest of ourselves up for the rest of our lives thinking what if we'd have done this and maybe if we'd done that.....even though we've got three healthy children. (mother)

It may be that these parents, understanding that nothing could have done to prevent the death are able to avoid blaming themselves or others. However, for some mothers as described previously, it takes time to overcome the maternal guilt due to the death to be able to reach this acceptance.

For some families with modifiable risk factors present, they accepted responsibility for their choice of actions but did not feel they should take blame for them. In one unexplained death where the baby was sleeping on the mother's bed, covered with a duvet to ensure she stayed warm in a cold house; the mother initially felt blamed by the SUDI paediatrician. However, at follow-up two years later, the mother accepted that her actions whilst contrary to safe sleeping advice had been done with the best of intentions and no longer felt any blame.

So if all I'm guilty of is loving her a bit too much, then so be it. (mother)

Similarly, another baby died sleeping on a plastic changing mat. The parents fully appreciated that their actions may have contributed to the death but they were very

clear that they did not intend to blame themselves perceiving that as a negative action, but instead taking responsibility for their choices.

And I could choose to let myself feel very guilty and that in a sense would kill your spirit... I'm happy to accept that I have some responsibility in his death and that's a different thing to being guilty. (mother)

...you understand that you behaved in a certain way in good faith ....it's not that you have a crystal ball and you can foresee ...and if you beat yourself up by looking backwards, you'll never get on with life...you'll always be twisted up inside ..And that doesn't help you then go on and live your life .... ...enjoy your family and cherish what you've got. (father)

For some parents, a lack of blame may be part of a self-protection mechanism and almost be a denial of the issues surrounding the death. This is different to accepting responsibility as in the previous cases as these parents are suggesting that the deaths could not have been prevented or that their actions did not have a bearing on the death.

In one case, an unexplained death with modifiable risk factors, whilst the parents understood these, they interpreted the label of SIDS as an absolution so that there could be no blame attributed.

We've both always said we were quite glad when it came back that it was Sudden Infant Death ....because it's been Sudden Infant Death, we sort of go 'well we couldn't have done anything, if it was going to happen, it was going to happen... (father)

Another baby died co-sleeping on a sofa. The mother seemed to understand the risk factors but downplayed them; suggesting that her actions had no relation to the death.

She spoke of conversations through a medium with her dead baby, absolving her of blame:

I've had like spirit readings and that.... And he comes through straight away, so that was a real big help to know I hadn't done nothing wrong... (mother)

## **Section 7.8 Discussion**

Being able to understand the cause of death is of the greatest importance for bereaved parents; this came across strongly from the parental interviews and concurs with the findings of the literature review. Not knowing why their baby died causes further distress to the parents, whether this is due to long waits for the results of post-mortem examinations or because these results cannot give a reason for the death and it remains unexplained. A death that remains unexplained by its nature is an unpredictable event rendering the parents powerless to prevent future tragedies, thus increasing the anxiety and grief (Murray-Parkes, 1996); parents therefore need to have as much information as possible on the cause of death. Having understood these, parents may be in a better position to emotionally accept and make sense of their child's death.

Parents need to understand the relevant modifiable risk factors for unexplained deaths; they cannot really understand the death if these facts are omitted. Prior to the 1990s, SIDS was viewed as similar to a lightning strike: it could neither be prevented nor predicted and this was the explanation and reassurance given to parents; professionals were encouraged to emphasize the unpreventable nature of SIDS to parents (Kotsubo, 1983). As our knowledge of SIDS has moved on this is no longer true; as reflected in the study data all but one unexplained death had modifiable risk factors for SIDS and many had multiple risk factors. Parents deserve to be told all the facts surrounding their babies' deaths as this knowledge may help the parents come to terms with the death.

Bereaved parents are capable of fully understanding modifiable risk factors for SUDI but by understanding these factors the parents are acknowledging that had they taken a different course of action perhaps their baby may not have died; this is clearly a very difficult issue to accept. Parents' acceptance and understanding appears to vary even within the same the interview; parents described the unsafe sleep environment and how it may have contributed to the death but subsequently spoke of the death as inevitable. This oscillation between acceptance of risk factors and viewing the death as unpreventable is similar to the oscillation in grieving in the dual process model (Stroebe and Schut, 2010); this describes two modes of coping during grieving: loss-orientated and restoration-orientated coping. During loss-orientated coping a bereaved person focuses on the pain of the loss, the events of the death and altering their emotional bonds with the deceased. In restoration-orientated coping the focus is on making life changes and being distracted from the grief; this provides a respite from the exhaustion and pain of loss-orientated coping. Individuals typically oscillate between these two modes.

Decades ago, doctors frequently withheld upsetting diagnoses (such as a cancer diagnosis) from patients with the paternalistic view that they were protecting patients from distress; similarly information was routinely withheld from parents of infants on neonatal intensive care units for the same reasons. The basis of this paternalism was that doctors had a duty of care to patients; the information would harm them by causing distress so potentially upsetting information should be kept from patients. However, Buchanan (1978) argued that this would only be valid if one could show that providing information would be more harmful than not providing the information and one could only do so with a detailed knowledge of the individuals concerned. It seems now that some SUDI paediatricians are being similarly paternalistic in withholding potentially upsetting information about risk factors from parents; however this poses a



much greater risk to the parents as many will search the internet and other sources for information about SIDS or SUDI; surely it is preferable for a SUDI paediatrician to sensitively discuss the relevant risk factors with the parents than to leave them to learn about this alone and unsupported. Similarly, some parents used the term SIDS to describe deaths as inevitable thus unpreventable. Again it may be that some SUDI paediatricians are hiding behind SIDS as a diagnostic term to avoid having to discuss modifiable risk factors; again this is a disservice to parents. If parents are not given information about risk factors they will not be able to make informed decisions for their subsequently born children; the possibility of another SIDS case within the same family due to lack of information is a much greater harm than that of parental distress from discussing modifiable risk factors.

One reason that some SUDI paediatricians are reluctant to talk about modifiable risk factors with parents is that they do not want them to blame themselves for the death. Some professionals have advocated that knowledge of these risk factors will lead to parents being blamed and that professionals should focus on wider health promotion strategies instead (Powell, 1996). However, self-blame is a normal part of grieving, by blaming oneself for the death it stops being a random unexplained event and but can be controlled giving a sense of order; this situation is easier to live with (Murray-Parkes, 1996). Many mothers did blame themselves even for deaths with no modifiable risk factors; however much of this self-blame related to them failing as mothers because their child had died. Some identified that whatever the cause for the death they would feel guilty. The few parents for who self-blame were a major feature all had significant issues of anxiety and depression according to HADS whereas only a minority of other parents had significant scores on HADS. As self-blame is part of depression it may be that the depression itself was at the root of the self-blame rather than the circumstances or parental understanding of the cause of death. Other studies have

shown that self-blame is common in mothers after stillbirth and associated with greater anxiety and depressive symptoms (Cacciatore et al., 2013); similarly self-blame was associated with greater grief in both parents following infant or child death (Hazzard et al., 1992). An alternative explanation could be that both self-blame and depression or anxiety were related to pre-existing personality traits. However, this possibility is not something that we were able to explore with the data available.

These findings should reassure SUDI paediatricians that explaining modifiable risk factors to parents after a SUDI does not lead to self-blame as self-blame is likely to be part of the grieving process or, when severe, a depressive illness.

Some parents may feel blamed by professionals for the death; this may relate to parents denying to themselves the role of modifiable factors in the death. Similarly they may blame others, especially health care professionals, for perceived poor care. Whilst in some cases there may be some justification for this, often by blaming others parents can avoid recognition of their own responsibility. However, anger following a death is common and it may be that the anger directed at health care professionals is merely re-directed anger at the death itself (Rowe in Stanford, 2011). Parents are able to move on from these feelings of blame and acknowledge that their actions may have played a role in the death; although it may take some time for parents to reach this acceptance.

The next chapter looks at the West Midlands Child Death Overview Panel SUDI study; this is a descriptive study of the outcomes of the JAA. It describes the causes of death and presence of risk factors for a large set of SUDI cases from the West Midlands.

## **Chapter eight The West Midlands Child Death Overview Panel SUDI Study**

### **Section 8.1 Introduction**

The WM SUDI study is an evaluation of the Joint Agency Approach to investigating SUDI; the aim of the JAA is to determine the complete cause of death as well as to address the needs of the family. The previous chapters have studied the parents' and professionals experiences of the JAA and the parents' understanding of the cause of death, risk factors for death and the role of blame. This chapter evaluates how effective the JAA is in establishing causes of and risk factors for death by means of a second research study utilising Child Death Overview Panels (CDOP) data.

The cause of death is ascertained primarily by the post-mortem examination but this is assisted by a detailed medical history obtained from the parents; risk factors are determined by this history and by a thorough examination of the death scene at the joint home visit by the police and a paediatrician. However, some SUDI are caused by asphyxia, such as those deaths due to accidental overlaying by a parent in a co-sleeping situation. The cause of death in these cases relies heavily on the parents' accounts of events and thorough scene examination because post-mortem examination findings are often insignificant (Mitchell et al., 2002) and there are no pathological findings that can be considered diagnostic of asphyxia (Becroft et al., 2001). Despite investigations, most SUDI remain unexplained with only 20-40% having a cause of death established (Fleming et al., 2000, Blair et al., 2009).

One original WM SUDI study research question was: 'How effective is the joint agency approach at determining cause of death and contributory risk factors?' My intention had been to use data from the WM SUDI study to answer this question; however as the

difficulties with recruitment became apparent it was clear that this would not result in a representative sample so an alternative approach was needed. I therefore decided to use data from local Child Death Overview Panels.

It is a statutory requirement that all child deaths are reviewed by local CDOP; the aim of this is to learn lessons about child deaths to improve the welfare and safety of all children in the locality (HM Government, 2013). The CDOP does not determine the cause of death this is done prior to cases being reviewed. It is the duty of coroners to determine the cause of death but their determination of this should be informed by evidence from the final case discussion (FCD) as well as the post-mortem examination. The CDOP membership consists of representatives from Public Health, police, paediatrics, neonatology, midwifery, children's services, local government and education. After FCD for SUDI cases, all the case documents are sent to the CDOP; these documents include minutes of all meetings, post-mortem examination reports, hospital and JHV reports. This should result in CDOPs obtaining complete case information on the JAA investigation for every SUDI case; these records are then anonymised.

All CDOP members review the case summaries and discuss them during meetings, agree on risk factors that were present and complete the CDOP Form C which is a standard template and shown at appendix 8. Risk factors include those intrinsic to the child, in the family and environment, parenting capacity and service provision. Each risk factor can be marked on the Form C as yes/no for relevance to the death as well as graded 0 – no information available, 1 - present but not relevant to the death, 2 -relevant to the death, 3 - complete explanation for the death; risk factors can also be described in the free text sections. Panel members also consider whether the death is potentially preventable or not according to the definition given in Working Together. Preventable deaths are those deaths in which modifiable factors may have contributed towards the

death (HM Government, 2013). The Form C thus contains detailed outcomes on the JAA investigation.

I therefore chose to use data from CDOP Form Cs in the West Midlands; this became the West Midlands SUDI CDOP study, a descriptive study of CDOP outcomes for SUDI cases. Having obtained an initial sample of Form Cs it was clear that this was a much richer data set than anticipated and the scope of this study was widened. The research questions for the WM SUDI CDOP study are:

1. What is the effectiveness of the JAA and CDOP in determining the cause of death and risk factors for SUDI?
2. What is the profile of causes and risk factors for SUDI in the West Midlands?

## **Section 8.2 Methods**

I obtained the dates of birth and death of all SUDI cases in the study region aged between one week and one year, dying between 1 September 2010 and 31 August 2012, from the pathology departments at Birmingham Women's Hospital and Birmingham Children's Hospital. These two centres conduct all infant post-mortem examinations for the locality. The study period is 12 months shorter than that of the WM SUDI study which recruited SUDI deaths occurring from September 2010 to August 2013; this is because there is often a delay of several months after the FCD before cases are reviewed at CDOP and thus Form Cs would not be available for several of the cases in the final year of the study.

The study region consisted of the counties of Warwickshire, West Midlands, Worcestershire, Staffordshire, Shropshire and Herefordshire. I contacted the Chairs of all ten local CDOPs and asked for copies of the CDOP Form C for all relevant SUDI cases. These were received between September 2013 and January 2014.

There was considerable variation in how they were completed by individual CDOPs leading to difficulties comparing forms. The grading of risk factors using the 0-3 scale was inconsistent; risk factors were frequently only mentioned in the narratives but the relevance of these was not always recognised leading to erroneous conclusions on the preventability of deaths. Therefore all forms were re-analysed independently with a colleague (CE) who is also an experienced CDOP member. We independently completed the risk factor yes/no and 0-3 grade fields and considered the preventability of each death. We then compared results and discussed and resolved any differences. To assist coding, we created a reference list of risk factors for SUDI based on the Avon Clinico-Pathological Classification (Sidebotham and Fleming, 2007); these risk factors are shown in table 28.

**Table 28 Evidence base for risk factors for SIDS**

Category	Risk Factor	Reference
Intrinsic to the child	Acute illness (e.g. URTI /otitis media) with symptoms present at time of death but not actual cause of death	Gilbert et al. (1990)
	Preterm birth before 37 weeks gestation	Blair et al. (2009)
	Congenital anomaly not causing death	Leach et al. (1999)
	Multiple birth	Carpenter et al. (2004)
	Previous unexplained infant death	Carpenter et al. (2005), Bacon et al. (2008)
Family and Environment	Symptomatic depression in mother or primary carer at time of death	Mitchell et al. (1992)
	Alcohol use by mother > 2 units in last 24 hours	Carpenter et al. (2013), Blair et al. (2009)
	Substance misuse by parent	(Blair, Sidebotham et al. 2009; Carpenter, McGarvey et al. 2013)
	Smoking by mother in pregnancy or postnatally	Blair et al. (2009)
	Poor housing or overcrowding	Spencer and Logan (2004), Leach et al. (1999)
	Domestic violence	Spencer and Logan (2004)
	Co-sleeping	(Blair, Sidebotham et al. 2009; Carpenter, McGarvey et al. 2013)
	Sleeping on pillow or other soft surface e.g. adult duvet	Blair et al. (2009)
	Sleeping prone or side sleeping	Carpenter et al. (2004)

There is no published guidance on how to score risk factors for parenting capacity or service provision; CE and I considered poor parenting based on our professional experience and graded this present at level 2 if poor parenting had contributed in any way, including one-off isolated decisions, to the death. Using this rationale, we considered co-sleeping deaths where parents had consumed more than 2 units of

alcohol as a poor parenting decision and graded this at level 2. Risk factors for service provision were parents being unable to access appropriate health services or failures by service providers; this did not include parents choosing not to engage with services as this was considered to be a parenting risk factor.

I entered the following data items for each case into a SPSS database: age at death, narrative description of cause of death (SIDS, unascertained death, medical cause and external cause), presence of significant risk factors at level 2 or greater and preventability of death. Within the family and environment domain I further detailed significant risk factors of any unsafe sleeping environment (such as the use of soft bedding, sleeping on a sofa or co-sleeping with an adult), parental alcohol consumption of greater than two units or illicit drug use the night before death, current parental mental health problems, housing issues, domestic violence and parental smoking. I then totalled the family and environmental risk factor scores for each case; the maximum score possible was 6.

We considered the possibility of accidental asphyxia for all unexplained deaths according to the circumstances of the death scene. Asphyxia was considered probable if the infant was found under a parent, at the bottom of the parents' bed under bedding or if there were significant suffocation hazards present such as plastic bags. Infants found face down were not considered to have asphyxiated as this is a common SIDS finding, possibly representing a failure of arousal mechanisms (Garcia et al., 2013).

Deficiencies in service provision could only be judged on the information on the Form C although these often referred to the findings of clinical governance reports which provided clarification. For forms with no reference to further reports the decision was purely based on CE's and my professional judgement. Again, these were graded as present at level 2 if service provision had any impact on the death.



I used 3-way chi-squared test for determining significant associations between risk factors and categories of death or 2-way between acute illness, SIDS and unascertained deaths alone, with  $p < 0.05$  considered statistically significant.

Ethical approval was granted from the University of Warwick Biomedical and Scientific Research Ethics Committee, this is shown at appendix 9.

### **Section 8.3 Results**

There were some difficulties obtaining data from CDOPs due to the requirement for approval from all the agencies represented. However, all ten CDOPs did eventually release relevant Form Cs although this took up to 18 months from the initial request.

There were 70 SUDI cases having post-mortem examinations at the two pathology departments during the two year study period and Form Cs were available for 65 cases (93%). As the Form Cs were all anonymised it was not possible to match cases with the pathology department notifications to ascertain which the missing cases were or to enquire why they were not available. Form Cs were complete in 53/65 (82%) cases and in 10/12 cases missing information related to a single item, such as domestic violence or parenting capacity. Two cases, from different CDOPs, were missing several items of information regarding the family and environment and in one of these it was not possible to determine the preventability of the death.

In 52/65 (80%) cases there was complete agreement between CE and myself on recoding of Form Cs; there was some discussion but eventual agreement on the remaining forms. In 30/65 (46%) cases reanalysis of Form Cs only involved standardising the format of information but in 35/65 (54%) cases reanalysis included reinterpreting the information according to our reference list, leading to reclassification of risk factors and potentially the preventability of death.

The median age at death was 2.3 months for all deaths, 3.1 months for medically explained deaths, 2.0 months for SIDS and 2.1 months for unascertained deaths. 48/65 (74%) of deaths were of male infants.

## Section 8.4 Causes of death

Causes of death are shown in table 29. Most deaths 45/65 (69%) remained unexplained after a JAA investigation. 21/65 (32%) were classified as SIDS, 24/65 (37%) were labelled as 'unascertained'; 20/65 (31%) of deaths were due to a medical cause with 12/20 (60%) of these due to infection and 6/20 from cardiac disease. In 63/65 (97%) cases the cause of death given by the final case discussion was identical to that given by the coroner and pathologist in the post-mortem examination report. In two cases deaths which were categorised as 'unascertained' by coroners and pathologists were subsequently classified as SIDS at final case discussion.

**Table 29 Classification of cause of death**

Cause of death		Pathologist/Coroner classification	FCD classification	Research study classification
Medical Cause		20 (31%)	20 (31%)	20 (31%)
Asphyxia		0 (0%)	0 (0%)	9 (14%)
Unexplained, of which:		45 (69%)	45 (69%)	36(55%)
	SIDS	19 (29%)	21 (32%)	36(55%)
	'Unascertained'	26 (40%)	24 (37%)	0 (0%)

## Deaths due to asphyxia

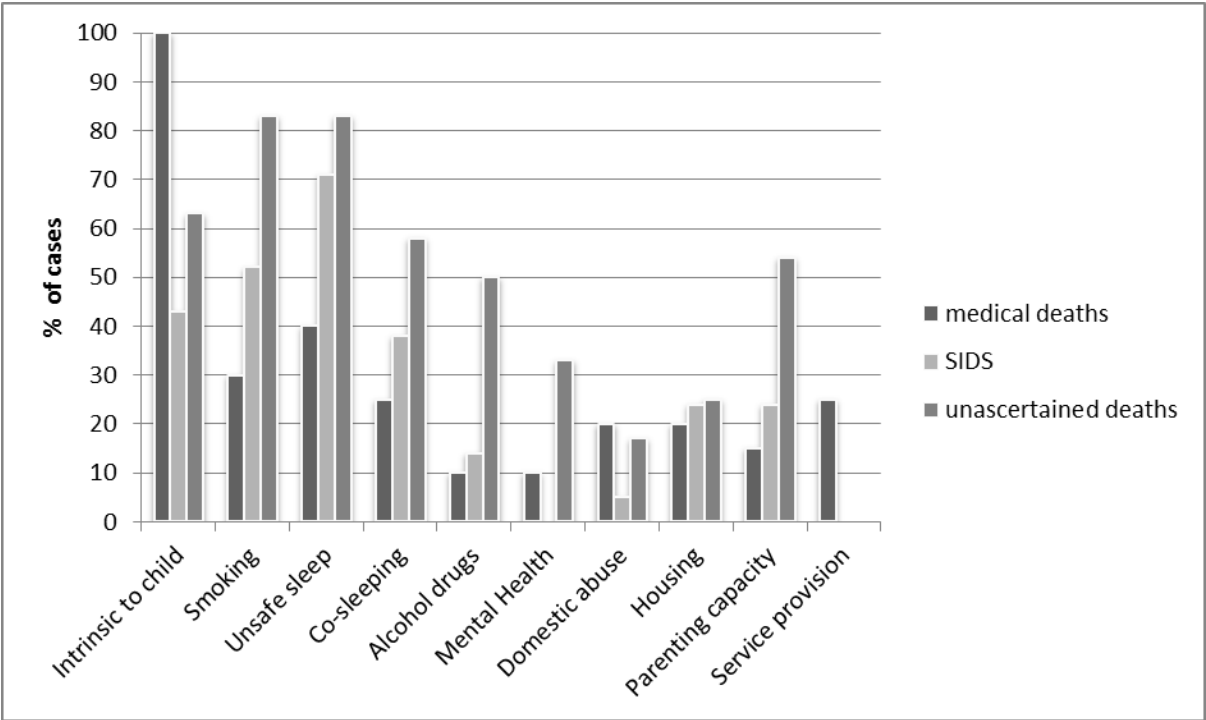
No deaths were identified as being due to accidental asphyxia on the Form Cs as received; however after reanalysis 2/21 SIDS deaths and 7/24 unascertained deaths were probably due to accidental asphyxia. In two of these cases the Form C

documented significant post-mortem examination findings consistent with asphyxia. In one case the Form C detailed no specific findings at post-mortem examination, in the remainder the Form C gave no information on post-mortem examinations other than the conclusion of SIDS or 'unascertained death'. Five infants were found at the bottom of their parents' beds, face down and entirely covered with bedding, three of these were infants who were too young to be able to have moved themselves into the position in which they were found. Two infants were found directly under their parents. Eight probable asphyxia cases involved parents consuming more than two units of alcohol before co-sleeping and in six of these cases the parents were most likely intoxicated at the time of retiring to bed. The remaining 18 'unascertained deaths' met criteria for a diagnosis of SIDS (Krous et al., 2004) and were reclassified as SIDS.

## **Section 8.5 Risk Factors**

The distribution of risk factors is shown in figure 20. Risk factors and preventability of death are shown in table 30.

Figure 20 Distribution of risk factors and category of death



**Table 30 Risk factors and preventability of death**

	CDOP Classification			
Risk Factor	Medical cause of death (n=20*)	SIDS (n=21**)	'Unascertained' (n=24)	Chi-Square (p-value)
<b>Factors intrinsic to the child</b>				
Any intrinsic risk factor	Not Applicable	9 (43%)	15/24 (63%)	ns
Acute illness	Not Applicable	4(19%)	9/24 (38%)	ns
Prematurity	8/20 (40%)	5 (24%)	3/24 (13%)	ns
Congenital anomaly	6/20 (30%)	2 (10%)	4/24 (17%)	ns
<b>Factors in the family and environment</b>				
Any unsafe sleep environment	8 (40%)	15 (71%)	20 (83%)	8.431 (0.015)
Co-sleeping with a parent	5 (25%)	8 (38%)	14 (58%)	ns
Parental alcohol or illicit drug use	2 (10%)	3 (14%)	12 (50%)	10.981 (0.004)
Maternal smoking	6 (30%)	11 (52%)	20 (83%)	10.246 (0.006)
Current parental mental health issues	2 (10%)	0 (0%)	8 (33%)	9.432 (0.009)
Housing Issues	4 (20%)	5 (24%)	6 (25%)	ns
Domestic violence	4 (20%)	1 (5%)	4 (17%)	ns
<b>Factors in parenting capacity</b>				
Parenting capacity	3/20 (15%)	5 (24%)	13 (54%)	8.276 (0.016)
<b>Preventability of death</b>				
Death preventable	9 (47%)	19 (90%)	23 (96%)	19.574 (0.001)

\*In 1 medical death lack of information meant that preventability of death could not be assessed

\*\* In 1 SIDS case information on factors intrinsic to the child was missing

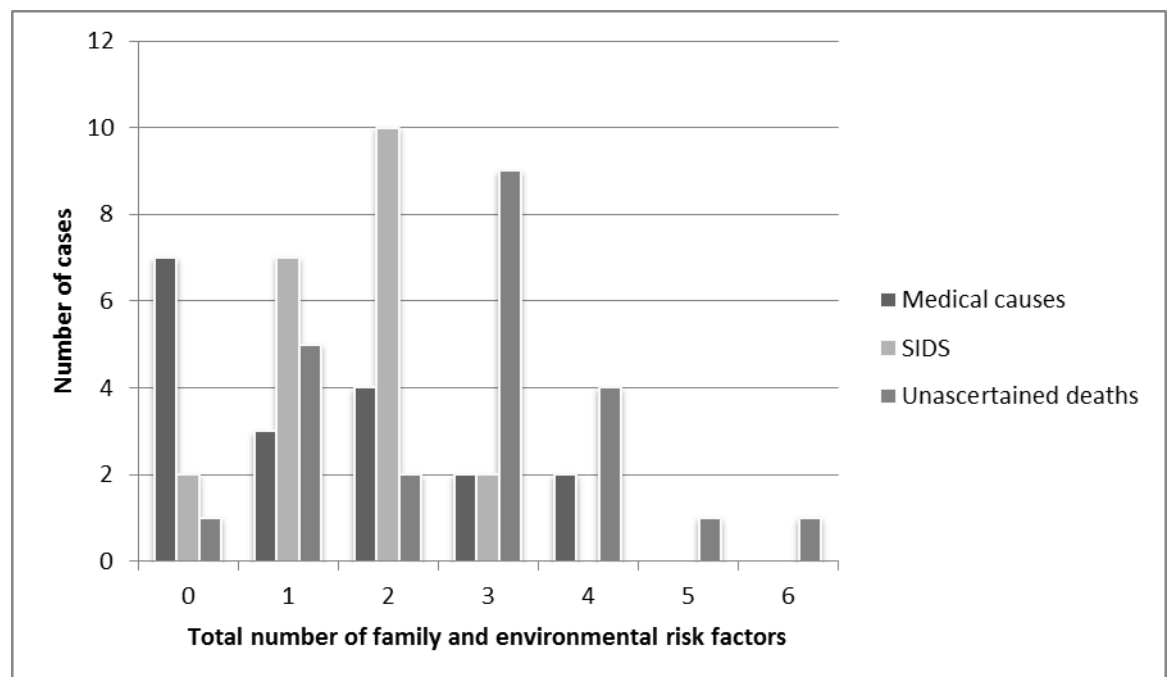
### Risk Factors Intrinsic to the Child

Acute illness can be both a cause of death and a risk factor on Form C so all medical deaths had acute illness listed as a risk factor. This was the only intrinsic risk factor in 9/20 medical deaths. There were no significant differences between category of death and previous prematurity or congenital anomalies; this probably reflects that infants with congenital anomalies or previous prematurity have increased vulnerability so are more likely to die of any cause than other infants.

### Risk Factors in the Family and Environment

The total number of family and environmental risk factors and cause of death are shown in figure 21.

**Figure 21** Total number of family and environmental risk factors and categories of death



‘Unascertained deaths’ had significantly higher total family and environmental risk factor scores with a mean of 2.6 (95% CI 2.0– 3.3) compared to 1.6 (95% CI 1.2-1.9) for SIDS and 1.1 (95% CI 0.8-1.3) for medical causes. SIDS and ‘unascertained deaths’ were significantly more likely to be in an unsafe sleep environment compared to medically

explained deaths ( $p=0.015$ ) and occur in families where there was maternal smoking in pregnancy or postnatally ( $p=0.006$ ). The parents of 'unascertained death' cases were significantly more likely than SIDS or medically explained deaths to have consumed more than two units of alcohol or taken illicit drugs the night before death ( $p=0.003$ ) or have current mental health problems ( $p=0.02$ ). The combination of alcohol and co-sleeping was a common finding but in three cases (one 'unascertained', two SIDS) co-sleeping occurred without parental alcohol consumption or smoking. Two of these infants had been premature and growth retarded, one had not yet reached term and the other had a corrected age of two weeks post term. Only one infant therefore died in a co-sleeping environment in the absence of other risk factors.

Only three cases of SIDS or 'unascertained deaths' had no risk factors in the family and environment; however all of these infants were intrinsically vulnerable infants due to previous prematurity, multiple births or congenital abnormalities.

### **Risk Factors for Parenting Capacity**

Risk factors for parenting capacity were present in 3/20 (15%) cases with a medical cause for death, 5/21 (24%) SIDS and 13/24 (54%) 'unascertained deaths'; this was a statistically significant difference ( $p=0.016$ ). Parenting risk factors for 'unascertained deaths' and SIDS were similar; the most common was the combination of alcohol consumption with co-sleeping occurring in 2/8 co-sleeping SIDS and 6/14 co-sleeping 'unascertained deaths'. Some families were already well known to social care due to drug addiction or having had previous parenting assessments. Parenting risk factors for medical deaths involved young mothers with chaotic lifestyles failing to recognise illness in their infants or not engaging with services. Poor parenting was only identified as a risk factor by the local CDOP in 9/21 cases; the role of poor parenting was recognised on reanalysis by CE and me in the remaining 12/21 cases. The parenting risk factors were

very similar in both groups of cases; those where the CDOP had recognised poor parenting and those where the CDOP had not.

### **Risk Factors for Service Provision**

There were five medically explained deaths but no SIDS or 'unascertained deaths' in which issues with service provision may have contributed. In two cases infants missed immunisations and died of vaccine preventable diseases; primary care services had not attempted to engage with the parents about this. In two cases parents may not have received appropriate advice from primary care about the final illness and in one case there were difficulties with community midwifery services.

### **Effectiveness of the JAA in determining risk factors**

Risk factors were identified in one or more domains in every case although in one case the only risk factor was the acute illness that led directly to the death. 54/65 (83%) cases had complete information on the Form C, however the accuracy of the information on Form Cs is unknown. As there is no gold standard to compare these data with, one cannot actually state the effectiveness merely describe what has been observed.

### **Preventability of deaths**

Deaths were considered to be preventable in 9/20 medical cases, 19/21 SIDS and 23/24 unascertained deaths; this was a statistically significant difference ( $p=0.001$ ).

## **Section 8.6 Discussion**

Thorough investigation of SUDI cases, using a JAA resulted in 31% of deaths having a medical cause for death determined. Risk factors were found in all cases; most SUDI were avoidable, 83% had potentially modifiable risk factors and 79% were considered preventable. Nearly all SIDS and 'unascertained deaths' occurred in risky environments,



with a majority in unsafe sleep situations and exposed to maternal smoking; the few that occurred in the absence of environmental risk factors were in inherently vulnerable infants. One-third of 'unascertained deaths' along with a small number of SIDS cases were potentially caused by accidental asphyxia; in these cases excessive alcohol consumption by parents who co-slept with their infants was a common finding. A minority of medically explained deaths may have been preventable had different actions been taken by health care providers.

This is the first study to combine data from several regional CDOPs enabling a large set of similar deaths to be studied; one strength is that it includes data from nearly all SUDI cases in the West Midlands in a two year period; 93% of eligible cases were included and 83% had complete data. Detailed information on risk factors was available for all SUDI cases regardless of final cause of death as all SUDI cases had a JAA investigation. A limitation of the study is that the quality of the data was entirely dependent on individual CDOPs; there were significant disparities on the amount of detail recorded on Form Cs from different CDOPs. Potentially, some information on risk factors collected for medically explained deaths was subsequently not recorded on Form Cs no longer being deemed relevant; however this seems unlikely as most Form Cs, regardless of cause of death were very detailed. Our interpretation of the relevance of risk factors was different to that of the CDOPs in more than half of cases; we used an evidence-based guide to assist our interpretation and developed strict parenting criteria as there is no evidence base for these. However, it may be that our interpretation of some cases was wrong and that CDOPs having fuller information had reached an appropriate conclusion. During the two-year study period there were 70 SUDI cases in the West Midlands region, but the local CDOPs reviewed 1073 child deaths in total, SUDI therefore account for less than 1% of their caseload (Coventry Solihull and Warwickshire Child Death Overview Panels, 2013).

The study relied on routinely collected anonymised data; it was therefore not possible to have any control population and comparing risk factors between SIDS and unascertained deaths with medically explained deaths may be misleading as these are clearly not 'normal' infants, however the CESDI SUDI study showed that risk factors were similar between infants dying of SIDS and those whose unexpected deaths were subsequently explained (Platt et al., 2000).

This is the first study to evaluate the JAA in routine clinical practice. Only one other study has used a similar multi-agency approaches to investigating SUDI but clinicians were assisted by dedicated research teams (Sidebotham et al., 2010); despite this similar proportions of deaths in each study had medical explanations: 31% in this study and 43% in the South- West of England and similar rates of maternal smoking and hazardous sleeping environments were also found (Blair et al., 2009). Death scene examination now takes place in many countries following SUDI but despite this studies report inadequate recording of information such as sleep scene details or parental alcohol and smoking habits (Hutchison et al., 2011, Li et al., 2005b, Meersman and Schaberg, 2010). In comparison the JAA is a more robust investigation with only minimal amounts of information missing from cases.

This study highlights the difficulties in correctly classifying causes of infant deaths. In the UK, deaths are only classified as due to asphyxia if in addition to the history and scene examination there are supportive pathological findings such as extensive pulmonary haemorrhage; therefore accidental asphyxia as a very rare cause of death in the UK (Office for National Statistics, 2012). This is different to the USA where many deaths are diagnosed as accidental asphyxia based on death scene analysis alone (Pasquale-Styles et al., 2007) and up to 12% of otherwise unexplained SUDI attributed to accidental asphyxia (Kim et al., 2012). In this study nine deaths that were labelled as SIDS or

‘unascertained’ were probably due to accidental asphyxia and two of these had supportive pathological findings. Clinicians risk confusing parents by labelling such deaths as ‘unascertained’ as this may prevent them from understanding why their baby died and increase the risk to their future infants.

The definition of SIDS is the death of an infant, under 1 year of age, occurring during sleep that cannot be explained despite a complete investigation including a post-mortem examination, full medical history and death scene analysis (Krous et al., 2004). In this study only around half of unexplained deaths were categorised as SIDS with the remainder, especially those with more risk factors, labelled as ‘unascertained’. All the ‘unascertained deaths’, with the exception of those probably due to asphyxia, could be correctly categorised as SIDS. This reluctance to use SIDS as a diagnosis reflects the reported practices of most paediatric pathologists in the UK who will not classify a death as SIDS if there is any possibility of a non-natural cause such as co-sleeping deaths when parents have consumed alcohol (Gould et al., 2010). Increasing numbers of infant deaths are now registered as unascertained rather than from SIDS (Office for National Statistics, 2013). International consensus is also that a diagnosis of SIDS should not rest with one individual alone but be made following a multi-professionals discussion (Bajanowski et al., 2007b); however this was not the practice in this study. In nearly all cases the final cause of death was that given by the pathologist alone; it was only rarely altered at final case discussion despite the availability of further information.

This study shows that deaths labelled as ‘unascertained’ include those that are highly likely to be from accidental asphyxia as well as deaths that meet accepted international diagnostic criteria for SIDS. These are two very different types of death; the ‘triple risk hypothesis’ (Filiano and Kinney, 1994) describes SIDS as occurring when inherently vulnerable infants die in response to a stressor which normal infants would not

succumb to. In an accidental asphyxia death; all infants exposed to that situation would be likely to die; these two groups of infants are clearly different. The sudden unexplained death of a growth retarded infant, sleeping in the same bed as his parents, is a very different situation to the death of a normally grown infant found underneath an intoxicated parent despite both types of death being labelled 'unascertained'. These deaths are likely to have different mechanisms and certainly different modifiable risk factors, by combining deaths such as these into the same category of 'unascertained' this will impede further analysis of causes of death thus limiting possible learning and potential strategies to prevent future deaths.

This study has highlighted the ability of CDR to make direct changes to local services to help prevent future child deaths. The JAA identified shortcomings in health service provision that may have contributed to some deaths; leading directly to local service reviews or more formal investigations. As a result, clinical practices have been strengthened, for example with more robust methods for recalling infants missing immunisations and ensuring appropriate triage of infants by out of hours medical services.

There have been numerous public health campaigns to promote safe sleeping environments for infants and their success may be reflected in the decline in the rate of unexplained death in infancy in England and Wales from 0.5 deaths per 1000 live births in 2004 to 0.34 in 2011 (Office for National Statistics, 2013). However, these results show that nearly all SIDS and unascertained deaths occurred in hazardous sleep environments and that maternal smoking was an additional risk factor for the majority; many of these deaths should be preventable. Clearly there are difficulties with health education messages either not reaching these families or parents not understanding the information or choosing not to follow advice. Many of the 'unascertained deaths'

occurred in families with mental illness, drug or alcohol misuse and chaotic lifestyles; reaching such families with health education messages is challenging. As health professionals, we need to find ways to better support these families in making the right choices to enable their children to grow up healthily.

The results of both research studies and both systematic literature reviews have now been presented. The next chapter synthesises the results of these and discusses the strengths and limitations of the findings.

## **Chapter nine Discussion**

The overall aim for this research project is to improve the wellbeing of bereaved parents whose infants die suddenly and unexpectedly; this has required a detailed analysis of the Joint Agency Approach (JAA) to investigating SUDI involving two separate studies. It also involved two literature reviews, one concerning bereaved parents' experiences after sudden child death, and one comparing different methods of investigating SUDI. This chapter will synthesise the findings of the research projects and literature reviews, and consider their strengths and weaknesses. Potential improvements to the JAA will be considered in the next chapter.

### **Section 9.1 Summary of findings of literature reviews and studies**

#### **Literature review of what bereaved parents want from professionals after sudden child death**

This review identified that:

- Parents wish to be able to say goodbye to their child at hospital.
- Parents need to know the full details about why and how their child died.
- Parents want follow-up appointments from health care professionals after the death; to enable them to obtain further information about the death and for the emotional support provided by the continuing contact.

#### **Literature review of different methods for investigating SUDI**

This review identified key policy factors for effective SUDI investigation:

- Detailed SUDI investigations should be closely aligned with coronial investigative processes.
- Strong leadership is required from all agencies involved.

- SUDI investigations are most effective when carried out by specialist teams who perform these regularly.

### **Summary of findings of The West Midlands SUDI study (the SUDI study)**

The SUDI study evaluated parents' and professionals' experiences of the JAA as well as comparing the actual practice of JAA investigations with best practice as outlined in Working Together (HM Government, 2013) and the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004). The findings were that:

- Parents overall had positive views on the JAA although typically they felt that whilst the investigations may have given them information about their child's death, the process offered them little emotional support or follow-up.
- The presence of uniformed police at their home, commencing a crime scene investigation caused significant additional distress to many parents.
- Nearly all parents were able to understand the cause of their child's death; some were able to understand the role of modifiable risk factors.
- Some SUDI paediatricians were reluctant to explain the role of risk factors to parents for fear of them self-blaming; however self-blame although common in mothers was strongly related to anxiety or depression rather than to the cause of death.
- All professionals valued the multi-agency nature of the JAA.
- In some areas, joint home visits were not routinely carried out; in these cases relevant information was often missed.
- Despite social care being an integral element of the JAA, often their involvement was minimal even in cases with child protection concerns.

## **Summary of findings of The West Midlands SUDI CDOP study (the CDOP study)**

The CDOP study was a descriptive study of the outcomes of the JAA, the findings were:

- 69% of SUDI cases remained unexplained after JAA investigation and were categorised as SIDS or 'unascertained deaths'
- In nearly all cases the cause of death given at final case discussion was identical to that determined at post-mortem examination.
- There were nine cases where infants had probably died of accidental asphyxia but the JAA did not identify these and labelled them as 'unascertained deaths' or SIDS.
- Nearly all unexplained deaths had multiple modifiable risk factors with poor parenting a significant risk.

## **Section 9.2 Synthesis of the results of the studies and literature reviews**

All the findings of the literature reviews and studies were listed and compared with each other. They were then combined into groups or themes of similar findings. Frequently themes had results from both studies, or a combination of study and literature review findings. The synthesis of results is presented according to these themes.

## **Section 9.3 How robust is the JAA as an investigative process?**

The literature review of different methods of SUDI investigation demonstrated that the JAA is one of the most thorough investigative models for SUDI; as unlike other investigative models it fulfils all the key objectives for SUDI investigation. These objectives are: to identify, as far as possible, any recognisable cause of death; to identify any relevant risk factors for the death; to support the family; to learn lessons to prevent future deaths and to ensure that all statutory requirements in relation to the death are fulfilled. Other investigative models for SUDI (Medical Examiner or coroner-led,



healthcare-led and police-led) do not meet these objectives due to lack of mandatory investigations and lack of support for families. If the JAA is used as detailed in *Working Together* (HM Government, 2013), England and Wales should have one of the best systems in the world for investigating unexpected infant deaths.

The JAA is set apart from the other investigative models for two main reasons: firstly that the investigation is both conducted and led by professionals from different agencies and secondly that support for families is a key part of the process. However, while the JAA gives details of the investigative elements of the JAA it gives little information on how families are to be supported. The literature review of what bereaved parents want identified that parents want both information about the death as well as emotional support from professionals. There is however an inherent difficulty for professionals trying to fulfil both tasks; an effective investigator may have to ask challenging questions of the parents and this could conflict with the need to provide emotional support. Parents have reported that once child protection issues have been raised by professionals that they are treated less courteously than before (Komulainen S., 2009) and of feeling judged, by doctors while their children were dying on intensive care units, due to their lifestyles (Meert et al., 2009).

The robustness of the JAA relies on the professionals adhering to the statutory guidance and principles described in *Working Together* (HM Government, 2013) and not only selecting certain elements of the JAA to follow. The principles of the JAA are that each child death is a tragedy and enquiries must balance both forensic and medical requirements as well as the need to support the family. These enquiries should seek to understand the complete reasons for each child's death and address the needs of the rest of the family; this includes the need to safeguard any current or future siblings. It is

implicit in these principles that agencies work together in a co-ordinated manner and share information to help achieve a thorough investigation.

#### **Section 9.4 The challenges of determining the complete cause of death**

In both studies there was a wealth of information on risk factors for most cases creating a very detailed understanding of the home situation and the events directly leading to the death. Therefore, the JAA appears to be effective at determining the full reasons for deaths. However, some cases from the SUDI study had incomplete JAA investigations and this directly impacted on the quality and quantity of information available.

Occasionally, when mothers were extremely distressed, professionals communicated with other family members instead and did not take medical histories from or view the sleep scene with the mother. Although this practice was done with the best of intentions to try to ease the mother's burden, the result was that key information was missed. Mothers (or primary carers) must therefore be at the forefront of the investigation.

In some locations in the SUDI study, joint home visits by police and SUDI paediatrician to view the scene of death were not standard practice. Professionals from these areas frequently did not accept the need for these joint visits. Similarly, a few cases from the CDOP study lacked large amounts of information concerning risk factors but the details of the JAA investigative process were not known. The literature review concerning investigating SUDI found that when death scene visits are not mandatory they take place much less frequently as they become seen as an optional extra and not a core part of the investigation. Given the value of the joint home visit and the reluctance by some professionals to provide this it is important that this remains a mandatory part of the JAA.

The only similar evaluation of the JAA to investigating SUDI was the south-west of England sleep scene study (the SWISS study); however this was part of research project into SUDI rather than as routine clinical practice. The SWISS study involved 155 SUDI cases in 4 years, 43% of these had an explanation for the death and 57% were unexplained and categorised as SIDS, none were labelled as unascertained (Blair et al., 2009). Whilst this is broadly similar to the results of the CDOP study which had 31% explained deaths and 69% unascertained or SIDS, it suggests that the SWISS study may have been more effective at determining causes of death than current practice in the West Midlands. In the SWISS study, local clinicians were involved in the SUDI investigations but the research team provided support and leadership. For the first two years of the study the research team attended joint home visits with local SUDI paediatricians; it was only after this time that the local paediatricians were confident to manage these alone (Sidebotham et al., 2010).

In contrast in the West Midlands, although there are some very experienced SUDI paediatricians, most managed only one or two SUDI cases each year and few had ready access to experts in infant death for further advice or support. In the West Midlands SUDI study there were 16 different SUDI paediatricians managing the 23 cases and this pattern of large numbers of paediatricians managing small numbers of cases is likely to be replicated in the CDOP study although there are no data concerning this. In part these practices are due to the requirement to have a paediatrician available to carry out joint home visits within 24 hours. As a result, individual SUDI paediatricians lack experience so may not recognise the significance of some findings at death scenes, may not interpret these findings correctly, and may lack confidence in explaining the relevance of these to other professionals at the case discussion.

Similarly, the literature review concerning different methods of investigating SUDI showed that the most effective SUDI investigations were those carried out by specialist teams performing such investigations frequently. In Pasquale-Styles et al. (2007), one public health nurse carried out all 204 infant death scene examinations for the city in a four year period. The scene examination involved the use of a life-size doll which the mother was asked to place in the exact position covered by bedding as she put the infant to sleep in; the mother was then asked to position the doll exactly in the same position as the infant was found in. Current JAA practice is to ask very detailed questions of the parents about the sleep position and possibly ask them to demonstrate using a toy as the life-size dolls are considered likely to distress the parents (Sidebotham and Fleming, 2007 p117). If the questioning is done thoroughly it should result in information equivalent to the detailed doll re-enactment. Given the relative inexperience of many SUDI paediatricians this seems improbable.

However, despite detailed information on the circumstances of death being available to professionals following the JAA, this was not reflected in the final case discussions' eventual determination of the cause of death. In nearly all cases from both studies, the conclusion of the final case discussion was identical to the cause of death as stated on the post-mortem examination report. The post-mortem examination conclusions are based upon the examination findings and not on the wider information from the death scene and medical history, although these may be used in the interpretation of these findings. It seems that the final case discussion is used to discuss the relevance of risk factors for deaths and plan support and follow-up for the family but frequently it does not come to any conclusion about the actual cause of death.

Working Together does not detail the format that the final case discussion should take but states that it is to share information about the cause and risk factors for death and

plan future care for families; a record of the discussion should be sent to the coroner to inform the inquest (HM Government, 2013). The Kennedy Report recommended that the Avon Clinico-Pathological Classification should be used; this is a detailed form which allows the relevance of every finding to be classified (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004). Having completed the classification the user then can determine whether the death is fully explained from whatever cause or remains unexplained so should be classified as SIDS. However, in my experience, this form is rarely used in the West Midlands as many professionals find it too complicated. In the SWISS study the research team attended nearly all final case discussions throughout the project being able to directly advise proceedings (Sidebotham et al., 2010); but in the SUDI study final case discussions were often chaired by inexperienced paediatricians. As a result there was little debate on the cause of death and a reliance on the pathologist's conclusion alone; discussions were restricted only to the consideration of risk factors.

There is a lack of clarity concerning the use of SIDS as a diagnostic term; as more risk factors for SIDS are recognised professionals become less confident in labelling unexplained infant deaths as SIDS (Li et al., 2009, Shapiro-Mendoza et al., 2009). In both the SUDI and CDOP studies, the terms SIDS and unascertained deaths were used almost interchangeably by pathologists; although there was a tendency to label unexplained deaths with more environmental risk factors as unascertained deaths rather than SIDS. This is similar to the findings of a Delphi study of UK pathologists, where SIDS type deaths associated with alcohol or co-sleeping were usually labelled as unascertained (Gould et al., 2010). However, a SIDS diagnosis does not exclude deaths where asphyxia cannot be ruled out (Krous et al., 2004) so it would still be correct to label these deaths as SIDS; labelling such deaths as unascertained does not reflect the complex interplay of environmental risk factors and inherent vulnerability that is found in SIDS (Krous, 2013).

The ultimate responsibility for determining the cause of death rests with coroners; they issue the death certificate so their conclusions are recorded in national statistics. One aim of the JAA is however to establish the complete cause of death and this is determined at the final case discussion. The report from this discussion is sent to the coroner to assist him or her at the Inquest; however in all cases from both studies, the conclusion of the coroner was identical to that given by the pathologist in the post-mortem examination report, appearing not to take into account the further information that was available from the final case discussion. Given that it is considered best practice internationally that a diagnosis of SIDS only be given following a multi-professional discussion and not by any single professional working in isolation (Bajanowski et al., 2007b) it seems reasonable to suggest that coroners should make use of the information available from final case discussions and not rely on the pathologists' findings alone.

Given the lack of clarity of the final case discussion process, there being no clear consensus on which deaths should be diagnosed as SIDS and which as unascertained, and the primacy given by coroners to the post-mortem report conclusion there seems little purpose to SUDI paediatricians trying to lead final case discussions to determine the cause of death. There needs to be some diagnostic criteria for SIDS and unascertained deaths that reflect the complex interplay of intrinsic and external risk factors which are acceptable to pathologists, paediatricians and coroners. Once these are in place there will be value in final case discussions considering the cause of death. It is important to try and reach a diagnostic consensus for many reasons although in England and Wales the Office of National Statistics has always included infant deaths categorised as unascertained as well as SIDS when calculating SIDS rates (Office for National Statistics, 2013); while this allows for accurate population level statistics it does not help understand individual cases. The Kennedy Report advised against using the

term 'unascertained' as this can be perceived as implying the death may be suspicious and deliberately inflicted by the parents. Unclear terminology can be confusing for parents, an 'unascertained' death can be viewed as entirely unexplained so therefore unpreventable but this is rarely the case. The mechanisms and risk factors for SIDS and asphyxia deaths are likely to be very different such as with the sudden unexplained death of a growth retarded infant, sleeping in the same bed as his parents compared to the death of a normally grown infant found underneath an intoxicated parent. By labelling both these very different deaths as 'unascertained' this will impede further analysis of causes of death thus limiting possible learning and potential strategies to prevent future deaths. These concerns are currently widespread within the SIDS research community and there are calls for a new diagnostic consensus to be reached (Blair, 2015, Hunt et al., 2015). The CDOP study highlighted that there were several cases of probable accidental asphyxia that had not been identified as such and instead were labelled as unascertained deaths or SIDS; this finding reflects the situation in the UK where very there are apparently very few such deaths (Office for National Statistics, 2014b) unlike in the USA and New Zealand where these are much more common (Shapiro-Mendoza et al., 2009, Hayman et al., 2014). Infant deaths due to asphyxia are difficult to diagnose as these rely heavily on parental history and detailed scene examination because post-mortem examination findings are only rarely supportive (Krous et al., 2007). Given the relative weakness in death scene analysis in the JAA compared to the USA, and the primacy given to post-mortem examination findings it is therefore not surprising that accidental asphyxia is rarely diagnosed in the UK.

Paediatricians may also be reluctant to diagnose accidental asphyxia due to the fact that it is very difficult to distinguish between accidental asphyxia and deliberate suffocation at post-mortem examination (Byard, 2004 p136). In addition, under English law it is a criminal offence for an intoxicated adult to overlay an infant leading to their death

although in practice this is very rarely prosecuted (HM Government, 1933).

Professionals are therefore likely to avoid diagnosing asphyxia and this avoidance is actually recommended by one leading UK paediatric pathologist due to the harm this diagnosis might cause to parents (Cox, P in Sidebotham and Fleming, 2007 chapter 9).

The CDOP study showed that there was a failure of professionals from all agencies to recognise the role of sub-optimal parenting in some deaths; this was only recognised by local CDOPs in 9/21 cases with parenting concerns. If deaths associated with poor parenting are not recognised it is more difficult to protect infants in the future. This is true not only for subsequently born infants in these families who may need additional support from social care, but also for children in the wider population. By recognising the role of poor parenting in child deaths, professionals working with vulnerable families can be better informed and target appropriate information and resources to support them, potentially preventing further child deaths.

### **Section 9.5 Understanding the cause of death and the role of blame**

In the SUDI study, some SUDI paediatricians spoke of their reluctance to discuss the role of modifiable risk factors with bereaved parents as they did not want parents to blame themselves or feel they are being blamed for the death. Given this, although there were no diagnosed cases of accidental asphyxia in the SUDI study it is likely that SUDI paediatricians would have been similarly reticent about discussing these deaths with families. It seems that there is a fear by professionals of being seen to blame parents, or increasing their self-blame following a child death.

Sudden infant death has occurred throughout history and until the early 20<sup>th</sup> century was largely assumed to be due to overlaying; after this time infants were increasingly likely to die in their own cribs ruling out overlaying so instead they were attributed to a variety of medical causes; however parents were still widely blamed for the deaths



(Russell-Jones, 1985). The term Sudden Infant Death Syndrome was first defined in 1970, recognising that although these deaths were unexplained they had striking similarities (Beckwith, 1970). Professionals embraced the use of the diagnosis of SIDS particularly because it shifted blame away from the parents as these deaths were now viewed as being due to an unknown medical cause (Limerick and Downham, 1978).

With the improved investigation of SIDS cases there is a much greater understanding of the role of modifiable risk factors and asphyxia in particular which can be a risk factor for some deaths and directly causal for others (Shapiro-Mendoza et al., 2009, Li et al., 2009); in some SUDI cases parents therefore bear some responsibility for the death no matter what the intention was behind their actions. In the SUDI study professionals did not want to blame parents worrying that this will increase their grief. If a death is attributed to accidental asphyxia it clearly is fully avoidable therefore the responsibility most likely lies with the caregivers; however if the death remains unexplained as no-one knows what caused the death no-one could be blamed for it. Professionals may increasingly recognise the role of accidental asphyxia in many deaths; and also that these deaths are unlikely to be SIDS, hence the decline in the use of SIDS as a diagnosis. However, professionals may be hiding behind the term unascertained, rather than using the term accidental asphyxia to avoid issues of blame.

Similarly, in the CDOP study, professionals did not recognise the role that parental actions played in many deaths. Again, failure to identify the issues meant that the professionals did not have to confront parents about their actions. This limits any learning from SUDI cases at a population level and leaves subsequently-born infants exposed to similar risks.

All parents in the SUDI study spoke of how important it was for them to understand the full reasons why their baby died. Parents could understand the role of modifiable risk

factors and their own actions in relation to the death; this understanding would enable them to minimise the risk to future children. Reassuringly, the study showed that parental self-blame is not associated with their understanding of the cause of death or the presence of modifiable risk factors. Some mothers did completely blame themselves for the death but this was strongly associated with clinically significant anxiety and depression as measured by HADS rather than the cause of death itself; the greatest self-blame was seen in depressed mothers of infants dying of unpreventable medical causes.

It is of course wrong for professionals to blame parents when, with the obvious exception of homicide cases, the parents had not intended to harm their children. However the professionals' fear of blame has led to an unjustified reluctance to identify asphyxia deaths or poor parenting and to share full information with parents. The SUDI study showed that such difficult information can be shared sensitively with parents and this should be standard practice rather than the exception.

### **Section 9.6 Addressing the families' needs**

The SUDI study showed that the main focus of professionals was to investigate the death; supporting families was a lesser priority. Part of supporting families should be that the investigations cause the minimum amount of added distress to the families considering the substantial pain of their loss. In the SUDI study many parents commented on the anguish caused by the actions of the non-specialist uniformed police who often attended the home along with the ambulance. The police officers assumed they were investigating a crime so prevented parents from collecting vital possessions such as shoes, key and telephones, and insisted that other family members leave the house as soon as possible. In a few cases, a paramedic declared the infant dead at home; then removed the infant from their parents while transport to hospital was arranged. These actions, which were contrary to the local protocol, caused a huge amount of grief to parents. The difficulties with police and ambulance staff were similar

to those reported in the literature review of bereaved parents' interactions with professionals, showing that they were not unique experiences.

One element of supporting families is helping them to understand why their child died; this was very important for families in the SUDI study and also shown in the literature review; lack of information increases the parents' distress. Although the JAA was effective in determining complete information about the cause of death there were often long delays before this was shared with parents. In particular, parents were rarely told the initial post-mortem examination results and as discussed previously, paediatricians often withheld information about the role of modifiable risk factors to try to prevent parents self-blaming or feeling blamed. A key role for professionals in supporting families is therefore providing this information for parents in a timely manner and helping them to understand it. The new coroner's rules require that coroner's enquiries must be finished within six months unless there are exceptional circumstances (HM Government, 2009) and this should speed up the process of obtaining the post-mortem examination report. However, in the West Midlands part of the delay has been due to the workload in the pathology department and so the new rules have had little effect on this. In any case, six months is still a long time for parents to wait for the post-mortem examination findings.

The JAA provided little emotional support to families in the SUDI study and many felt let down that it did not do so. The purpose of follow-up visits from SUDI paediatricians was to share information about the cause of death rather than to address parents' emotional needs; parents often struggled to access bereavement support services on their own. Parents frequently felt isolated from professionals; there were usually waits of several months with no contact from the SUDI paediatrician following the initial joint home visit. This finding was echoed by the literature review which detailed that parents

want medical follow-up to include emotional support as well as information about the death.

Given that many deaths are associated with poor parenting, professionals may feel uncomfortable about providing emotional support to parents whose actions could have contributed towards the death. However it is only in situations where criminal proceedings are pending that the SUDI paediatrician must avoid contacting the family. Health visitors should be routinely maintaining contact with parents if there are other pre-school age children in the household. In the SUDI study many families in which there were parenting issues felt that their health visitors were highly supportive without being judgemental. Only three mothers had regular contact with social workers due to parenting concerns; these mothers did feel supported by the social workers although they found the assessment process somewhat intrusive. It is therefore possible for professionals to continue to support families even if poor parenting played a part in the death.

### **Section 9.7 Agencies working together to investigate SUDI**

The SUDI study showed that a major strength of the JAA is the close co-operation between the different agencies and between the SUDI paediatrician and CAIU police officers in particular. All relevant information is shared between the agencies and duplication of investigation can be avoided. In many cases the SUDI paediatrician and CAIU police officer jointly take the detailed medical history obtained from the mother; this fulfils the both medical and police requirements and minimises the trauma for the parents. However, there are some barriers to effective joint working, in particular the lack of engagement by social care and the reluctance of some coroners to share information with other professionals.

The SUDI study showed that in 8/23 cases social care were not involved in the JAA; in two of these cases there were parenting concerns prior to the death. In two other cases social care ran separate investigations without sharing information with JAA professionals. In the CDOP study poor parenting was a factor in 21/65 cases; although in 13/21 cases this poor parenting was not identified by the JAA or CDOP process. There is a need for social care to be fully involved with the JAA to help in the identification and assessment of poor parenting that is prevalent in so many SUDI families.

In the SUDI study, many SUDI paediatricians commented on the huge difficulties they faced in obtaining post-mortem examination reports from the coroner; without these reports the JAA stalls as a final case discussion cannot be held. Similarly, the literature review of investigative models for SUDI identified that close working with the coronial system was vital for effective SUDI investigation and that coroners had to accept the need for detailed SUDI investigation that went beyond the usual remit of identifying the cause of death. This expanded remit includes identifying risk factors for deaths, supporting parents, initiating child protection enquiries and learning lessons from deaths to prevent future deaths.

Working Together states that whilst the post-mortem examination report is the property of the coroner it should normally be shared with the SUDI paediatrician as soon as possible (HM Government, 2013). Rule 13 of the 2013 Coroner's Rules clearly states that relevant documents, such as the post-mortem examination report should be disclosed without delay to any 'interested persons' such as the family, GP or SUDI paediatrician. The disclosure can be at any time and does not need to wait until the Inquest is completed. These points are re-iterated in the Chief Coroner's Guide to the Coroners and Justice Act 2009 (Chief Coroner, 2013 sections 117-26). Coroners who withhold or delay the release of post-mortem examination reports are therefore acting

contrary to national statutory guidance and the law but despite this some still continue to do so even after the 2013 changes. Effective ways of working with all coroners need to be established as when post-mortem examination reports are delayed this slows the JAA investigation and increases the parents' distress unnecessarily.

## **Section 9.8 Strengths and limitations of the studies**

### **Strengths**

The SUDI study allowed for a very detailed understanding of cases due to the triangulation of data within each case from parental interviews, professional interviews and case records from every agency. This allowed for confirmation of parents' accounts that on first hearing seemed questionable; such as the parents who spoke of uniformed police not allowing them to accompany their child to hospital, this was corroborated by the police log. It also allowed for parental understanding of risk factors to be assessed; this would have been impossible without the case records detailing the discussions between the SUDI paediatrician and parents concerning these. The comparison of parental and professional perspectives within each case allowed for the balance between forensic and medical investigation as well as supporting families to be assessed.

The Framework Approach allowed for comparison of findings between cases as well as within cases. SUDI cases were recruited over a large geographical area and each locality had its own interpretation of the JAA despite the existence of the local protocol (West Midlands Police, 2009). This meant that I could compare cases where the JAA had been carried out differently; in particular cases with and without a joint home visit by police and SUDI paediatrician. Similarly, it allowed for comparison of professional experiences with differing investigative methods.

A wide diversity of parent and professional experiences has been captured; including both good and bad experiences. Theoretical saturation of data was reached. The recruited cases were from socially diverse backgrounds, covering all social classes. The sample of recruited cases reflected the social diversity of SUDI cases in the region as a whole, and the proportion of cases with medically explained deaths compared to unexplained deaths was similar in both studies. These suggest that the sample of cases are representative of the wider population of SUDI. Given the diversity of experiences and theoretical saturation of data, the findings of the study should be generalizable outside of the West Midlands.

One potential criticism of the study could be that the JAA process may have been significantly different for recruited cases compared to the SUDI population in general. However, as a separate project linked to my clinical work, I audited the JAA in Birmingham. During 2010-11 I obtained data on 18/19 (90%) of SUDI cases having a JAA investigation. All cases had a joint home visit by a SUDI paediatrician and police officer within 24 hours of the death, the mean time between the death and final case discussion was six months, and 11/18 (64%) families were offered follow-up visits by the SUDI paediatrician (Garstang et al., 2013). These results are similar to those in the SUDI study, with 17/23 (74%) cases having joint home visits and a median time to final case discussion of 23 weeks; however all cases had follow-up visits as this was part of the recruitment process. It is likely therefore that the recruited cases had similar JAA investigations to those who were not recruited.

The key findings from parents in the SUDI study were that they really needed to know why their baby died, they were distressed by long waits for information and that they wanted more support from professionals. These findings are identical to those in the literature review concerning what bereaved parents wanted from professionals after

sudden child death; this increases their validity and suggests that the parents participating in the study had similar views and experiences to bereaved parents in general.

The CDOP study had nearly complete data concerning all SUDI cases in the West Midlands in a two year period; as a result the findings are likely to be generalizable to the wider population of SUDI cases in the UK. The CDOP study complemented the SUDI study in that it allowed a much wider set of cases to be analysed as one of the limitations of the SUDI study was the very low recruitment rate in some areas of the West Midlands. The CDOP data from the areas with low recruitment in the SUDI study were similar to those from areas with higher recruitment; therefore it is likely that the cases were similar regardless of whether they were recruited or not. Some findings from the different studies were complimentary to each other, strengthening their validity. The SUDI study highlighted the poor engagement by social care in the JAA and the CDOP study revealed the failure of the JAA to identify poor parenting practices.

### **Limitations**

A significant limitation of the SUDI study was the low recruitment; often eligible families were not given information about the study by their SUDI paediatrician. Low recruitment occurred commonly when there were long delays in the JAA process and many of these families were lost to follow-up by the time the JAA investigation concluded. The audit of JAA processes also showed that only 64% of families were offered follow-up after SUDI (Garstang et al., 2014). This lack of follow-up and long delays in the JAA that were common in non-recruited cases may mean that these non-recruited families have had significantly worse experiences than those who took part. However, these poor experiences are likely to be similar to the negative features of the



JAA described by participating parents such as the distress of long waits for information and the lack of support provided by the process.

Some areas, despite having many SUDI, recruited almost no cases. It is possible that the experiences of parents from these areas could be very different from other areas of the West Midlands; however all areas followed the same multi-agency protocol and the same specialist police Child Abuse Investigation Unit covered the areas with lowest recruitment as that with the highest. Despite the low recruitment I think it is therefore likely that no significant parental or professional experiences of the JAA have been missed and the experiences detailed in the SUDI study are representative and generalizable.

Relatively few cases with child protection concerns were recruited; five cases were not recruited due to on-going child protection investigations although there were three families in the study who had social care interventions, one of whom had a child protection plan. As a result the knowledge generated of experiences of child protection investigations following SUDI is limited although there was much more knowledge concerning social care involvement in SUDI cases in general.

The literature review of what bereaved parents want from professionals was deliberately limited to literature from Europe, Australasia and North America to ensure similarity of cultural context; therefore the findings are only likely to relate to these populations. Likewise the findings of the SUDI and CDOP studies are only applicable to areas with similar cultures. The participating families in the literature review were typically middle class, higher income earners which is not reflective of the fact that SUDI occurs more commonly in socially deprived families. This could have limited the generalizability of the findings but the parents in the SUDI study were socially deprived and reported similar needs to those in the literature review.

## **Strengths and limitations compared to other studies**

The SUDI study is directly relevant to any professional involved in the JAA for many reasons. The SUDI study includes data on parents' and professionals' experiences in addition to the investigative process, which makes it unique; there are currently no other publications on these despite the JAA being a mandatory process. The CDOP study is the first study to combine data from several different CDOPs giving detailed information on the outcomes of the JAA; it is difficult to compare this with other studies as there are very few publications on the outcomes of SUDI investigations, as detailed in chapter three. The CDOP study had complete information on risk factors for nearly all cases; most other similar studies that used Child Death Review data were missing significant amounts of information on risk factors (Meersman and Schaberg, 2010, Brixey et al., 2011, Hutchison et al., 2011). The only other evaluation of the JAA was undertaken with the JAA being used as a research tool (Sidebotham et al., 2010) rather than in routine clinical practice as in the SUDI study. The SUDI study findings are therefore of greater relevance for professionals investigating SUDI clinically.

## **Section 9.9 Conclusion**

The findings of SUDI study were robust; there was a wide diversity of professional and parents' experiences. The social demographics, diagnoses and risk factors, and the format of the JAA investigations were similar between the recruited cases and the wider population of SUDI implying that a representative sample had been recruited. The CDOP study included nearly complete data on all SUDI cases in the region in a two year period. There were several findings in common between the studies and literature reviews. All these suggest that the results of the studies are valid and can be generalised to a wider population of bereaved parents.

The aims of the JAA are to identify the complete cause for deaths and to support families; these aims are currently not fully realised. The JAA is effective at identifying complete information concerning SUDI cases but rarely uses this to establish a final cause of death; this is most likely due to the lack of experience of the professionals leading investigations, lack of perceived value for the final case discussion process, and uncertainty surrounding the diagnosis of SIDS. The JAA provides very limited support to families; many wanted it to provide more, frequently struggling to access bereavement support. Most parents had to wait several months for information about the cause of death with minimal contact from professionals meanwhile.

### **Section 9.10 Further Research**

Some parents, but not all, want more support as part of the JAA. In reality it is difficult for SUDI paediatricians or specialist nurses to provide a high level of emotional support due to workload pressures and that they are healthcare professionals not bereavement counsellors. Health visitors officially only work with families if they have pre-school age children, so following a SUDI families may have no further contact with Health Visitors. It is unclear therefore who should be providing support to bereaved parents. There could be a role for a specialist bereavement health visitor, working with families who have had a SUDI, supporting them through their bereavement and possibly as part of the Care of Next Infant (CONI) scheme. Further research could focus on evaluating a bereavement health visitor model, to establish whether this is beneficial to parents and the cost implications of this enhanced service. Many families had very high consultation rates with primary care services following the SUDI and a bereavement Health Visitor may reduce these.

It was clear from the CDOP study that there is little uniformity of practice among CDOPs in determining when parenting practices constitute a risk and could be considered as

poor parenting; there is also little published evidence concerning this. A focus for research could be in creating an evidence base to help decision making in CDOPs; this could be done possibly as a Delphi process with CDOP members. There needs to be a more uniform approach to CDOP as otherwise analysing data at a national level will be very difficult and could be meaningless.

The results of the CDOP study showed that infants are continuing to die in unsafe sleep environments despite many years of safe sleep information campaigns. Parents are therefore not receiving, not understanding or choosing not to act on the information available to them. We need further research to obtain a greater understanding of why parents ignore safe sleep advice so that we can tailor safe sleep messages appropriately to the families where these are most needed.

This chapter has shown that the JAA needs improving; to be better at determining and classifying causes of death as well as offering more support to bereaved families. This should lead to not only enhancing the wellbeing of bereaved parents as in the original aim of the research, but also to a greater understanding of why infants die; potentially reducing infant deaths in the future. The final chapter of this thesis considers the improvements needed to the JAA to enable these to happen.

## **Chapter 10 Improvements to the Joint Agency Approach**

In this chapter I suggest improvements to the JAA; these are based on the findings from both research studies and both literature reviews. These concern improving individual investigative elements of the JAA, providing more support for families, improving diagnosis and classifications of death, and more effective joint working. I have only evaluated the JAA in the West Midlands region so to some extent these recommendations may be specific to the West Midlands alone. However, the requirement for JAA investigation applies to all of England and Wales although each area has its own unique implementation of the JAA. Across the West Midlands there were many different ways in which the JAA was implemented: in some areas police and paediatricians jointly interviewed parents, in others this was done separately. Similarly, not all areas carried out joint home visits, and where these did take place the paediatric input was provided by hospital paediatricians, designated doctors for unexpected child death or specialist nurses. Given the diversity of approaches within the JAA most of the findings should be generalizable outside of the West Midlands so many of the recommendations will therefore apply nationally.

If implemented, these recommendations could result in more effective investigation of deaths and a better understanding of why infants die. This would help prevent infant deaths in the future as well as improve the wellbeing of bereaved parents, which was the original aim of this thesis.

“It is every family’s right to have their baby’s death properly investigated”

Baroness Helena Kennedy, QC.

The JAA is based upon the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) and while there is little doubt that the

overall standard of investigation following SUDI has improved since its introduction; the JAA it is not functioning in the way that the Kennedy Report intended. The JAA therefore needs revising in order to ensure that SUDI cases are investigated effectively yet in a manner that is sensitive to families.

The aims of the JAA are to establish the complete cause for death, including any relevant risk factors as well as addressing the needs of the family. This includes the need for information about the death, the need for emotional support and potentially the need to safeguard any other children in the family. As discussed in the previous chapter, the JAA only partially meets these aims. In particular, although very detailed information about the death is collected this does not result in consistent or accurate diagnosis of the cause of death. Families frequently felt that the JAA offered them little emotional support and they struggled to access bereavement support services themselves. Child safeguarding issues were often overlooked by all professionals and social care was similarly uninvolved in many cases.

### **Section 10.1 JAA Investigations to be led by specialist SUDI clinicians.**

The Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) recommended that there should be dedicated, specially trained health care professionals to lead the medical investigation of SUDI and chair the case discussions. This would most likely be a paediatrician, hence the term SUDI paediatrician, but could also be a specialist trained nurse. It was expected that a SUDI paediatrician be appointed for each health care trust and that in order to allow a 24 hour service there would need to be a SUDI paediatrician rota established across trusts.

Currently, most SUDI paediatricians in the West Midlands only manage two to three cases a year; many trusts have several SUDI paediatricians and SUDI rotas have been established within trusts rather than across them (Garstang et al., 2013). This is a very

different practice from that recommended by the Kennedy Report and from the original research study using the JAA (Sidebotham et al., 2010) where an expert research team directly provided investigations and were able to advise and support local clinicians. It is difficult for paediatricians who manage SUDI cases only rarely to develop sufficient expertise and confidence, as shown in both the SUDI and CDOP studies; this is particularly pertinent for detailed medical histories and the death scene examination at the joint home visit. There is strong evidence from overseas that death scene analysis is best performed by experts, from a health care background, who do this regularly otherwise important information on sleep scenes is often missed (Camperlengo et al., 2012, Pasquale-Styles et al., 2007, Brixey et al., 2011, Hutchison et al., 2011) and that medical histories are best obtained by experienced health care professionals (Pasquale-Styles et al., 2007, Hutchison et al., 2011). This evidence, combined with the findings of our studies, suggests that significant improvements could be achieved if the response to SUDI was led by specialist SUDI clinicians as detailed below.

The paediatric input to the JAA should be only from paediatricians or specialist nurses with specialist expertise in investigating SUDI; the numbers of clinicians involved should be limited to allow individuals to maintain a sufficient case load to maintain their skills. SUDI investigation is a specialised service and should be commissioned as such, similar to the provision of paediatric post-mortem examinations. It is not appropriate that such specialised investigations are allocated to any paediatrician as is currently the situation in much of the West Midlands. This may require networks of specialist paediatricians or nurses covering a child death rota and working across boundaries as in the north-west of England (Dierckx, 2014) or limiting SUDI investigations to designated doctors for unexpected deaths only.

Currently, there is a requirement from the police for the joint home visit to take place within 48 hours but ideally sooner; it could be challenging to provide such timely home visits with fewer specialist clinicians available. However, it may be better for the joint home visit to take place somewhat later with an expert paediatrician or nurse rather than immediately with a non-expert as in the current situation. One solution may be for the Child Abuse Investigation Unit (CAIU) police, to do an initial scene visit with the parents soon after the death, taking photographs and videos as needed. Assuming this visit raises no concerns that the death may be suspicious the family can return to their home. The joint home visit is then conducted at a later date, with the specialist SUDI paediatrician or nurse and the CAIU police; it would be important that the CAIU police re-attend the home for this visit as the joint nature of the scene examination brings different perspectives and understandings that may be more difficult to share otherwise. The delayed joint home visit may be of particular benefit for mothers who are extremely distressed at the time of the death and finding it difficult to engage with the JAA investigation.

As detailed above, having an expert SUDI paediatrician or specialist nurse may improve the standard of medical histories obtained from families and the quality of death scene analysis at the joint home visit. The process of final case discussions could also be enhanced by being chaired by an experienced specialist; this will be discussed later.

This recommendation for a specialist SUDI clinician is based on the results of the SUDI and CDOP studies as well as the literature review; the findings therefore are applicable outside of the West Midlands. Some areas may however already be using a specialist model.



## **Section 10.2 Reconsidering the role of uniformed non-specialist police**

Frequently, uniformed non-specialist police arrived at the home shortly after the initial 999 telephone call was made; there was often a considerable delay before the specialist police from the CAIU were informed. The actions of uniformed police who assumed they were investigating a crime caused great distress to most parents.

The requirements of the initial police response to SUDI are detailed by Marshall (2012); police have to secure the location that the death took place as the cause of death is unknown. Uniformed police may have to do this immediately after the death but their presence should be kept to a minimum and this role should be taken over by specialist officers as soon as possible. Although these actions are a necessary part of police investigations Marshall explains that they should be done as discreetly and sensitively as possible. Similarly, the police response to SUDI as detailed in the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) suggests that uniformed police attendance be kept to a minimum to avoid causing unnecessary distress to families.

Uniformed police have little training in managing child deaths yet in the SUDI study, in some locations they were routinely sent to these incidents. There needs to be consideration within the police forces nationally about how best they can provide an immediate response to SUDI that fulfils the need to preserve the scene of death whilst not traumatising families.

One solution may be that ambulance control could notify the on-call CAIU police officer directly; this officer can then lead the investigation immediately and advise uniformed police on proportionate actions. Additionally, SUDI training for uniformed officers could be arranged; highlighting that SUDI is very rarely a criminal matter; the parents are

innocent victims and should be treated as such. Uniformed police should be encouraged to contact the on-call CAIU officer rapidly and not wait until office hours.

### **Section 10.3 Engaging with mothers and other care givers**

Mothers are usually the primary care givers so have the most knowledge of an infant's medical history. It is therefore vital that professionals try as far as possible to engage with the mother even if she is very distressed and not rely on histories or joint home visits with other relatives. In the rare cases when communication with the mother is too difficult at the time of death, professionals could take an introductory history from other family members and conduct an initial scene visit. However, it would then be wise to visit the mother subsequently to obtain a detailed medical history and view the sleep scene even if this is several days later.

Mothers may not always place the baby for their final sleep; this may have been done by the father or another care-giver. In these situations it is extremely important that they take part in the joint home visit and medical history or vital information may be lost.

### **Section 10.4 Joint home visits must remain mandatory**

Working Together states that a joint home visit should take place in all SUDI investigations (HM Government, 2013) and this was considered a 'non-negotiable' part of the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004). However, there was concern that this recommendation was not based on published research and that it could lead to contamination of evidence and in some areas of the West Midlands joint home visits are not standard practice. The SUDI study however provided strong evidence of the benefit of joint home visits: important information was missed from death scenes where these were examined by police alone, police officers and paediatricians taking part in joint home visits found these to be

extremely useful and there were no difficulties reported with contamination of evidence.

As discussed already, there is strong evidence for death scene examination by specialist clinicians; it should remain standard national practice that joint home visits take place for all SUDI unless there are exceptional reasons not to, such as a high level of concern that the death may be a criminal matter. Greater involvement of specialist clinicians should ensure that this occurs.

### **Section 10.5 Better recognition of poor parenting and dangerous infant sleep practices**

In the CDOP study, there were several deaths associated with the combination of excessive alcohol consumption and co-sleeping but this was not recognised by professionals, from all agencies, as a parenting risk factor. These parents may have been good parents in other respects but showed poor decision making in terms of the choice of infant sleep location which contributed towards the death. The failure to acknowledge these infant sleep situations as dangerous prevents learning from deaths at a population level and exposes subsequently born infants potentially to the same risks.

Similarly, CDOPs did not identify other factors such as parental drug misuse, poor school attendance by siblings, pre-existing parenting concerns or lack of engagement with services as parenting issues. Again the failure to appropriately recognise the concerns underlying these issues may result in harm to other children in these families. Ideally, all SUDI professionals need to be able to recognise the role that parenting practices or poor parental decision making may play in some deaths; this is not to blame parents but to help prevent deaths in the future. Even with detailed information about safe sleeping some parents will choose not to follow this advice, due to competing demands of parenthood or other reasons, and there will continue to be unsafe sleep deaths.

Despite this professionals should still seek to recognise these practices to help parents make informed decisions.

This recommendation is based purely on data from the West Midlands and other CDOPs elsewhere may function differently; however the risks of co-sleeping and parental alcohol consumption have been widely reported (Carpenter et al., 2013). It seems reasonable to suggest that nationally we should aim for better recognition of poor parenting and unsafe sleep practices.

## **Section 10.6 Increasing the support for families**

Many families in the SUDI study felt let down by the JAA, in that although they obtained information about the death they were offered very little emotional support.

After the joint home visit, many families waited several months before they had further contact with JAA professionals and this increased their anxiety and distress. There clearly needs to be more attention paid to supporting families alongside investigating the cause of death. This does not require SUDI clinicians to become bereavement counsellors but instead SUDI clinicians could ensure that full information is shared with parents more promptly, and assist parents in accessing bereavement support if they want this. SUDI clinicians should ideally visit parents at home with the interim post-mortem examination results even if these are inconclusive, as is often the case. This visit is likely to be a few days after the death and allows the opportunity to review the information given initially, which distressed parents may have not remembered. Parents can be reminded that the final results will not be available for several months but they can be encouraged to contact the SUDI paediatrician or specialist nurse in the interim. For those parents who want bereavement support services; the SUDI clinician could have the contact details available for local providers. As many bereavement services

only accept clients who self-refer, the SUDI clinician could consider telephoning the service with the parents to help them establish this contact.

In some instances, SUDI paediatricians were reluctant to discuss relevant modifiable risk factors with families worrying, unnecessarily, that this would increase their self-blame. This risks leaving subsequently-born children exposed to the same risk factors, or that parents find this information out for themselves which is likely to be much more distressing. To some extent this could be mitigated by support from the Care of Next Infant (CONI) scheme but despite this infants still die in unsafe sleep environments on the CONI scheme (Waite et al., 2015) as was the case for one baby in the SUDI study. SUDI clinicians should aim to be honest with parents and share all relevant information about the death with them.

### **Section 10.7 Improving the classification of cause of death**

The stated aim of the JAA is to establish the complete cause of death including identifying risk factors as well as addressing family's needs (HM Government, 2013), although legally it is only the coroner who can actually determine the cause of death. The process of determining the cause of death is however made more difficult by the lack of consensus amongst professionals about which diagnostic terms to use for unexplained infant deaths. These diagnostic difficulties are not unique to the UK and are the subject of much international debate (Byard, 2013, Sidebotham, 2010). The San Diego definition of SIDS permits a diagnosis of SIDS to be made even if asphyxia cannot be excluded; a SIDS category II death is one where "mechanical asphyxia or suffocation caused by overlaying is not determined with certainty" (Krous et al., 2004); however in clinical practice (as opposed to research projects) the different categories of SIDS are rarely used. Deaths due to asphyxia are difficult to diagnose as there is no conclusive pathology (Mitchell et al., 2002). Pulmonary haemorrhages are associated with

asphyxial deaths (Krous et al., 2007) and also with co-sleeping deaths suggesting that these may have an asphyxial mechanism (Weber et al., 2012). However, they are not uniformly found in either situation, and may be found without any other evidence of asphyxia, and in non-co-sleeping deaths.

As investigation of SUDI has improved in many countries there is an increasing recognition of the role that asphyxia plays in some SUDI; however this has led to an increased reluctance to use the diagnostic label of SIDS and more deaths are categorised as unascertained (Gould et al., 2010). The Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004) recommended that the term unascertained is avoided as this may unfairly imply that the death is suspicious. The difficulty lies in differentiating genuine accidental asphyxial deaths where the asphyxia would be lethal to any infant (such as a plastic bag over the face or entrapment) from situations where there is sub-lethal asphyxia in inherently vulnerable infants, which may be the case in SIDS deaths. There clearly are major issues concerning which deaths should be diagnosed as due to asphyxia, which should be labelled SIDS, and whether any should remain undetermined and if so, how these should be labelled.

In the UK, asphyxia deaths are usually only diagnosed in the few cases where there are supportive pathological findings (Cox, P in Sidebotham and Fleming, 2007 chapter 9). In England and Wales in 2013, there were only 7 deaths recorded as accidental asphyxia or strangulation in bed (ICD 10 code W75); this accounted for 3.3% of all unexplained infant deaths (Office for National Statistics, 2014b). However, in the USA, death due to asphyxia can be diagnosed on history and scene findings alone. Detailed death scene examination now takes place in most states following SUDI and the rates of accidental asphyxia deaths has increased from 1.8% of all unexplained infant deaths in 1984 to 13.5% in 2004 (Shapiro-Mendoza et al., 2009).

These diagnostic dilemmas contribute to the inability of final case discussions to accurately determine causes of death. There have been newer practical classification schemes suggested to help consistent diagnosis of SUDI cases (Randall et al., 2012, Blair et al., 2012) and UK professionals could consider using these or other similar systems. The classification by Randall et al (as shown in table 31) removes deaths with significant risks for asphyxia from the SIDS category, whereas Blair et al.'s classification keeps all unexplained deaths within a SIDS diagnosis. Randall et al.'s classification is likely to be more acceptable to UK professionals as it reflects the current thinking that many deaths with significant asphyxial risk factors are not a natural phenomenon, whereas SIDS is considered a natural, if not fully understood, phenomenon.

**Table 31 Classification of SUDI as per Randall et al (2012)**

Category	Diagnosis	Description
A	SIDS	SIDS as per San Diego diagnosis, this includes some minor elements of asphyxia such as an infant lying face down on a firm mattress.
B	Unclassified – possibly asphyxia related	Scene suggests life-threatening asphyxial challenge; this includes all situations of unsafe sleeping such as co-sleeping on sofas or co-sleeping with an intoxicated adult. It excludes situations that are clearly lethal such as overlaying or entrapment between furniture
C	Unclassified – non-asphyxia	Cases with potentially life threatening non-asphyxial processes such as extremes of temperature, disease processes which are not of lethal extent
D	Unclassified - other	Cases with two or more potentially lethal processes simultaneously or where the cause of death is unclear such as potential unproven homicides
E	Unclassified	Cases with inadequate investigation
F	Known cause of death	Death due to fully explained natural or unnatural causes; this includes medical causes, trauma, definitive asphyxia

Randall's classification is however quite complex so it may not be acceptable to UK clinicians. I suggest that a new SUDI classification is used that can be linked to ICD10 codes; this is shown in table 32. The new classification system recognises asphyxial risks

and allows deaths to be classified as accidental asphyxia if there is highly supportive evidence from the death scene visit without supportive post-mortem examination findings. It has two categories for deaths in which asphyxia may be relevant: unexplained deaths with possible asphyxia, and deaths probably due to asphyxia. The latter category recognises that one cannot be entirely certain that deaths are due to asphyxia only that this is the most likely cause. Any death that is unexplained, unless it is possibly due to asphyxia should be classified as SIDS.

**Table 32 Suggested new classification for SUDI cases**

Category	Diagnosis	ICD10 code	Description
A	SIDS	R95	SIDS as per San Diego diagnosis, this includes some minor elements of asphyxia such as an infant lying face down on a firm mattress, minor infections or pathological findings that are insufficient to explain the death.
B	Unexplained with possible asphyxia	R99	Infant co-sleeping with intoxicated parent Infant co-sleeping on sofa or other recognised hazardous sleep environment
C	Probable accidental asphyxia	W75	Infant found underneath parent Infant found trapped under bedding in co-sleeping environment Infant found entrapped between bed and wall or between other items of furniture Infant found with other impediment to breathing e.g. pillow occluding nose and mouth Co-sleeping deaths where infant has significant pulmonary haemorrhage or extensive facial petechiae
D	Homicide	X85-Y09	Deaths due to non-accidental injuries or clear evidence of homicide
E	Medical causes of death	As per underlying cause	Deaths due to any underlying medical cause
F	Unexplained	R99	Cases with inadequate investigation



The earlier recommendation that SUDI investigations be performed only by specialist paediatricians would help facilitate the use of this new classification. This could improve the robustness of the death scene examinations and as a result there should be more accurate information available to enable the cause of death to be determined.

### **Section 10.8 Clarifying the process for final case discussions**

Both the SUDI and CDOP studies showed that at final case discussions professionals discuss the circumstances of deaths in detail but the cause of death is taken from post-mortem examination reports. There needs to be clear guidance as to what the expected outcomes of final case discussions are. In the West Midlands, the Avon Classification is rarely used at final case discussions, this classification allows for all relevant factors to be considered before assigning a final cause of death. Frequently the CDOP Form C (shown at appendix 8) is used instead; this was designed for use with all child deaths of any cause. The disadvantage of the Form C is that at the beginning of the form is a box for 'cause of death as presently understood' in which the post-mortem examination conclusion is written. The Form C then details all risk factors for the death and finishes with a broad categorisation of type of death; there is no further prompt to reconsider the cause of death in light of the other information available from the final case discussion. It is very easy therefore when using a Form C to consign the final case discussion to a consideration of risk factors alone and not the actual cause of death. If Form Cs are to be used in final case discussions the meeting needs to ensure that a conclusion as to the cause of death is reached after all relevant risk factors have been discussed. This conclusion could be based upon the new classification for SUDI shown in table 32.

The earlier recommendation of the involvement of specialist SUDI paediatricians or nurses will enhance final case discussions as they will be chaired by a clinician who is highly experienced in the process so familiar with both the procedures and the required outcomes. This recommendation is based solely upon evidence from the West Midlands however it could apply to other regions if required.

## **Section 10.9 Better working together**

It is implicit in the JAA detailed in Working Together to Safeguard Children (HM Government, 2013) that agencies jointly investigate deaths and share all relevant information as they are working for a common purpose. As shown in the SUDI study although police and health services work well together there are difficulties working with social care and coroners.

### **Engagement with social care**

One aim of the JAA is to address the needs of the family; this includes the need to safeguard any other children in family including those yet to be born. An assessment of the family by social care should therefore be an integral part of the JAA and a minimum standard of involvement is suggested here. An experienced social worker should attend the initial information sharing meeting so that an informed decision can be reached as to whether any further assessment of the family is needed. It cannot be acceptable that social care close SUDI cases without further discussion with the other professionals involved; this discussion can only be achieved at the initial multi-agency meeting where all relevant information is shared. If further assessment of the family by social care is necessary, the family's social worker should attend the final case discussion; this should be considered similar in importance to a social worker attending a child protection conference. The social worker will then have a much greater understanding of the cause for the death so will be better placed to support the family. Other professionals will also then be aware of the social care input the family are receiving and this will also help

them to support the family. Ideally, social care should also attend the final case discussion even if they have not had involvement with the family in the interim as it is possible that the investigation reveals new information of relevance for social care. Other agencies should be aware of the requirements for social care involvement and should feel empowered to take action via the LSCB if this does not happen.

This recommendation is based only on data from the West Midlands where there are well publicised difficulties with children's social care. It may be that in other regions there are no such issues and there is therefore no need for these recommendations.

### **Working with Coroners**

In the SUDI study Coroners were frequently a barrier to effective JAA investigations due to their reluctance to release post-mortem examination reports to SUDI paediatricians.

This is contrary to both guidance from the Chief Coroner (Chief Coroner, 2013) , Working Together (HM Government, 2013) and the recommendations of the Kennedy Report (Royal College of Pathologists and Royal College of Paediatrics and Child Health, 2004). The guidance from the Chief Coroner is clear; section 117 states that "a coroner must normally disclose copies of relevant documents to an interested person, on request, at any stage of the investigation process." The post-mortem report is defined as a relevant document in section 120; the only relevant reason for withholding the post-mortem report would be if criminal charges were likely, this is not the case for the vast majority of SUDI. The situation with coroners should now be improving as most of the SUDI cases in the study died prior to the new coroners' rules coming into force.

Additionally, it would appear that Coroners rarely used information from the final case discussion to inform their ruling on the cause of death usually relying on the post-mortem examination report alone; this again is contrary to the Kennedy Report.

Coroners need to accept the validity and need for the JAA. The remit of the coroner's investigation is to consider the cause of death; unlike the JAA, it does not extend to considering risk factors, safeguarding issues or public health implications. Coroners must therefore be expected to follow the guidance of the Chief Coroner; to share post-mortem examination reports and other relevant information as a matter of routine with JAA professionals.

The conclusions of final case discussions are likely to be much more robust if the recommendations for improving the classification of the cause of death as well as the process of final case discussions are implemented. These robust conclusions are likely to be of benefit to Coroners as they have the potential to simplify Coroners' Enquiries. Using a standard classification scheme such as the one in table 32 should result in more deaths being correctly classified as SIDS. As these are considered due to natural causes there is no requirement to hold an Inquest. Although Inquests will still be required for undetermined deaths, asphyxial deaths, as well as deaths with clear evidence of an external cause; the detailed information from the final case discussion will assist the proceedings and possibly Inquests could be held without witnesses. This would save considerable time and money as well as minimising the distress of parents who often find the Inquest a very painful event which offers them little benefit.

### **Section 10.9 Summary of recommended improvements to the JAA**

1. The role of SUDI paediatrician should be limited to fewer paediatricians or nurses with further specialist training in investigating SUDI; these specialist clinicians will be able to build considerable expertise by managing larger numbers of cases.

2. The specialist Child Abuse Investigation Unit police should be notified promptly of any SUDI case in order to minimise the involvement of uniformed police officers.
3. Mothers must be included in the JAA process. Initial histories and scene visits may take place with other family members if the mother is very distressed but a detailed history will be needed subsequently. The scene examination should be done with whoever placed the infant for their final sleep present.
4. The joint home visit by police and SUDI paediatrician or specialist nurse should remain mandatory unless there are exceptional circumstances.
5. All SUDI professionals should be confident in recognising the role that poor parenting and dangerous sleep environments may play in some deaths.
6. The SUDI paediatrician or specialist nurse should visit parents at home with the interim post-mortem examination results.
7. The SUDI paediatrician or specialist nurse should keep parents up to date with the progress of investigations and encourage the parents to contact them if needed whilst waiting for the results.
8. The SUDI paediatrician or specialist nurse should help parents to access bereavement counselling services if they require this support.
9. The SUDI paediatrician or specialist nurse should share all relevant information about the death with the parents; this includes the role of modifiable risk factors.
10. UK SUDI professionals need to consider using a consistent classification scheme for SUDI; this scheme should then be used to classify the cause of death at the conclusion of the JAA, for all SUDI cases.

11. Deaths should be classified as accidental asphyxia where there is highly suggestive evidence from scene examination and history even if there are no supportive findings on post-mortem examination.
12. There needs to be a clearer process for final case discussions; the classification of the cause of death using a standard scheme should be part of this process.
13. A social worker should attend the initial multi-agency case discussion for all SUDI cases.
14. If social care have any further involvement with the family, a social worker must attend the final case discussion; however it is highly desirable that a social worker attends for all SUDI cases.
15. Coroners should release post-mortem examination reports promptly to SUDI paediatricians.
16. The Coroner should use the complete information available from final case discussions to inform the Inquest.
17. The Coroners' conclusion as to the cause of death should reflect the cause of death agreed on at the final case discussion using the standard classification scheme for SUDI.

## References

- AHRENS, W., HART, R. & MARUYAMA, N. 1997. Pediatric death: managing the aftermath in the emergency department. *Journal of Emergency Medicine*, 15, 601-3.
- AJETUNMOBI, O. 2002. *Making Sense of Critical Appraisal*, London, Hodder Arnold.
- ANDREW, S. & HALCOMB, E. J. (eds.) 2009. *Mixed methods research for nursing and the health sciences*, Oxford, UK: Wiley-Blackwell.
- ASHBY, M. A., KOSKY, R. J., LAVER, H. T. & SIMS, E. B. 1991. An enquiry into death and dying at the Adelaide Children's Hospital: a useful model? *Medical Journal of Australia*, 154, 165-70.
- BACON, C. J., HALL, D. B., STEPHENSON, T. J. & CAMPBELL, M. J. 2008. How common is repeat sudden infant death syndrome? *Arch Dis Child*, 93, 323-6.
- BAJANOWSKI, T., VEGE, A., BYARD, R. W., KROUS, H. F., ARNESTAD, M., BACHS, L., BANNER, J., BLAIR, P. S., BORTHNE, A., DETTMAYER, R., FLEMING, P., GAUSTAD, P., GREGERSEN, M., GROGAARD, J., HOLTER, E., ISAKSEN, C. V., JORGENSEN, J. V., DE LANGE, C., MADEA, B., MOORE, I., MORLAND, J., OPDAL, S. H., RASTEN-ALMQVIST, P., SCHLAUD, M., SIDEBOTHAM, P., SKULLERUD, K., STOLTENBURG-DIDINGER, G., STRAY-PEDERSEN, A., SVEUM, L. & ROGNUM, T. O. 2007b. Sudden infant death syndrome (SIDS)--standardised investigations and classification: recommendations. *Forensic Science International*, 165, 129-43.
- BAJANOWSKI, T., VENNEMANN, M., BOHNERT, M., RAUCH, E., BRINKMANN, B., MITCHELL, E. A. & GE, S. I. D. G. 2005. Unnatural causes of sudden unexpected deaths initially thought to be sudden infant death syndrome. *International Journal of Legal Medicine*, 119, 213-6.
- BECKWITH, J. B. 1970. Discussion of Terminology and Definition of the Sudden Infant Death Syndrome. In: BERGMAN, A. B., BECKWITH, J. B. & RAY, C. G. (eds.) *Sudden Infant Death Syndrome. Proceedings of the Second International Conference of the Causes of Sudden Death in Infants*. Seattle: University of Washington Press.
- BECROFT, D. M. O., THOMPSON, J. M. D. & MITCHELL, E. A. 2001. Nasal and intrapulmonary haemorrhage in sudden infant death syndrome. *Archives of Disease in Childhood*, 85, 116-120.
- BELLALI, T., PAPAZOGLU, I. & PAPADATOU, D. 2007. Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive & Critical Care Nursing*, 23, 216-25.
- BLACKWELL, C. C. & WEIR, D. M. 1999. The role of infection in sudden infant death syndrome. *FEMS Immunology & Medical Microbiology*, 25, 1-6.
- BLAIR, P. S., BYARD, R. W. & FLEMING, P. J. 2012. Sudden unexpected death in infancy (SUDI): suggested classification and applications to facilitate research activity. *Forensic Science, Medicine & Pathology*, 8, 312-5.
- BLAIR, P. S., MITCHELL, E. A., HECKSTALL-SMITH, E. M. & FLEMING, P. J. 2008. Head covering - a major modifiable risk factor for sudden infant death syndrome: a systematic review. *Arch Dis Child*, 93, 778-83.
- BLAIR, P. S., SIDEBOTHAM, P., BERRY, P. J., EVANS, M. & FLEMING, P. J. 2006. Major epidemiological changes in sudden infant death syndrome: a 20-year population-based study in the UK. *Lancet*, 367, 314-9.
- BLAIR, P. S., SIDEBOTHAM, P., EVASON-COOMBE, C., EDMONDS, M., HECKSTALL-SMITH, E. M. & FLEMING, P. 2009. Hazardous co-sleeping environments and risk factors amenable to change: case-control study of SIDS in south west England. *BMJ*, 339, b3666.

- BOYLESTADT, L. 2014. Trends in sudden death in infants and small children in Norway. *ISPID annual scientific meeting*. Soria Moria, Oslo.
- BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- BRIGHT, K. L., HUFF, M. B. & HOLLON, K. 2009. A broken heart--the physician's role: bereaved parents' perceptions of interactions with physicians. *Clinical Pediatrics*, 48, 376-82.
- BRIXEY, S. N., KOPP, B. C., SCHLOTTHAUER, A. E., COLLIER, A. & CORDEN, T. E. 2011. Use of child death review to inform sudden unexplained infant deaths occurring in a large urban setting. *Injury Prevention*, 17 Suppl 1, i23-7.
- BRYMAN, A. & BURGESS, R. G. (eds.) 1994. *Analyzing Qualitative Data*, London: Routledge.
- BUCHANAN, A. 1978. Medical Paternalism. *Philosophy & Public Affairs*, 7, 370-390.
- BURKE JOHNSON, R. & ONWUEGBUZIE, A. J. 2004. Mixed methods research: a research paradigm whose time has come. *Educational Researcher*, 33, 14-26.
- BYARD, R. W. 2004. *Sudden death in infancy childhood and adolescence*, Cambridge, Cambridge university press.
- BYARD, R. W. 2013. Changing infant death rates: diagnostic shift, success story, or both? *Forensic Science, Medicine & Pathology*, 9, 1-2.
- CACCIATORE, J., FRØEN, J. F. & KILLIAN, M. 2013. Condemning self, condemning other: Blame and mental health in women suffering stillbirth. *Journal of Mental Health Counseling*, 35, 342-359.
- CALHOUN, L. K. 1994. Parents' perceptions of nursing support following neonatal loss. *Journal of Perinatal & Neonatal Nursing*, 8, 57-66.
- CAMPERLENGO, L. T., SHAPIRO-MENDOZA, C. K. & KIM, S. Y. 2012. Sudden infant death syndrome: diagnostic practices and investigative policies, 2004. *American Journal of Forensic Medicine & Pathology*, 33, 197-201.
- CARPENTER, R., MCGARVEY, C., MITCHELL, E. A., TAPPIN, D. M., VENNEMANN, M. M., SMUK, M. & CARPENTER, J. R. 2013. Bed sharing when parents do not smoke: is there a risk of SIDS? An individual level analysis of five major case-control studies. *BMJ Open*, 3.
- CARPENTER, R. G., IRGENS, L. M., BLAIR, P. S., ENGLAND, P. D., FLEMING, P., HUBER, J., JORCH, G. & SCHREUDER, P. 2004. Sudden unexplained infant death in 20 regions in Europe: case control study. *Lancet*, 363, 185-91.
- CARPENTER, R. G., WAITE, A., COOMBS, R. C., DAMAN-WILLEMS, C., MCKENZIE, A., HUBER, J. & EMERY, J. L. 2005. Repeat sudden unexpected and unexplained infant deaths: natural or unnatural? *Lancet*, 365, 29-35.
- CASP. 2010. Critical Appraisal Skills Programme Qualitative Research Checklist. Available: [www.casp-uk.net](http://www.casp-uk.net) [Accessed March 2013].
- CHIEF CORONER 2013. The Chief Coroner's Guide to the Coroners and Justice Act 2009.
- COMMUNIO 2013. SUDI Nationwide Study; increasing understanding of SUDI. In: COMMUNIO (ed.). Auckland.
- COVINGTON, S. N. & THEUT, S. K. 1993. Reactions to perinatal loss: a qualitative analysis of the National Maternal and Infant Health Survey. *American Journal of Orthopsychiatry*, 63, 215-22.
- DENT, A. 2000. *Support for families whose child dies suddenly from accident or illness*. PhD Thesis, University of Bristol.
- DENT, A., CONDON, L., BLAIR, P. & FLEMING, P. 1996. A study of bereavement care after a sudden and unexpected death. *Archives of Disease in Childhood*, 74, 522-6.
- DEPARTMENT FOR EDUCATION 2014. Education and skills in your area.
- DIERCKX, E. 2014. *RE: Personal Communication*. Type to GARSTANG, J.



- DIMARCO, M. A., MENKE, E. M. & MCNAMARA, T. 2001. Evaluating a support group for perinatal loss. *MCN, American Journal of Maternal Child Nursing*, 26, 135-40.
- DYREGROV, K. 2002. Assistance from local authorities versus survivors' needs for support after suicide. *Death Studies*, 26, 647-68.
- DYREGROV, K. 2004. Bereaved parents' experience of research participation. *Social Science & Medicine*, 58, 391-400.
- DYSON, S. & BROWN, B. 2006. *Social Theory and Applied Health Research* Maidenhead, McGraw - Hill, Open University Press.
- ELWOOD, J. M. 2007. *Critical Appraisal of Epidemiological Studies and Clinical Trials*, Oxford, Oxford University Press.
- FERRANTE, L., OPDAL, S. H., VEGE, Å. & ROGNUM, T. O. 2010. Cytokine gene polymorphisms and sudden infant death syndrome. *Acta Pædiatrica*, 99, 384-388.
- FILIANO, J. J. & KINNEY, H. C. 1994. A perspective on neuropathologic findings in victims of the sudden infant death syndrome: the triple-risk model. *Biol Neonate*, 65, 194-7.
- FINLAY, I. & DALLIMORE, D. 1991. Your child is dead. *BMJ*, 302, 1524-5.
- FLEMING, P., BLAIR, P., BACON, C. J. & BERRY, P. 2000. Sudden Unexpected Deaths in Infancy: The CESDI SUDI Studies 1993-1996. London: The Stationery Office.
- FLEMING, P. J., GILBERT, R., AZAZ, Y., BERRY, P. J., RUDD, P. T., STEWART, A. & HALL, E. 1990. Interaction between bedding and sleeping position in the sudden infant death syndrome: a population based case-control study. *BMJ*, 301, 85-9.
- GARCIA, A. J., 3RD, KOSCHNITZKY, J. E. & RAMIREZ, J. M. 2013. The physiological determinants of sudden infant death syndrome. *Respir Physiol Neurobiol*, 189, 288-300.
- GARSTANG, J. 2009. Planning a project to evaluate a new approach to investigating unexpected infant death and learning from a pilot study that failed to recruit any bereaved families. Warwick University.
- GARSTANG, J., DEBELLE, G. & AUKETT, A. 2013. Investigating Unexpected Child Deaths: An Audit of the New Joint Agency Approach. *Child Abuse Review*, n/a-n/a.
- GARSTANG, J., GRIFFITHS, F. & SIDEBOTHAM, P. 2014. What do bereaved parents want from professionals after the sudden death of their child? A structured narrative review of the literature.
- GARSTANG, J. & SIDEBOTHAM, P. 2008. Interagency training: establishing a course in the management of unexpected childhood death. *Child Abuse Review*, 17, 352-361.
- GILBERT, R., RUDD, P., BERRY, P. J., FLEMING, P. J., HALL, E., WHITE, D. G., OREFFO, V. O., JAMES, P. & EVANS, J. A. 1992. Combined effect of infection and heavy wrapping on the risk of sudden unexpected infant death. *Arch Dis Child*, 67, 171-7.
- GILBERT, R. E., FLEMING, P. J., AZAZ, Y. & RUDD, P. T. 1990. Signs of illness preceding sudden unexpected death in infants. *BMJ*, 300, 1237-9.
- GOLD, K. J. 2007. Navigating care after a baby dies: a systematic review of parent experiences with health providers. *J Perinatol*, 27, 230-7.
- GOULD, S. J., WEBER, M. A. & SEBIRE, N. J. 2010. Variation and uncertainties in the classification of sudden unexpected infant deaths among paediatric pathologists in the UK: findings of a National Delphi Study. *J Clin Pathol*, 63, 796-9.
- HARPER, M. B. & WISIAN, N. B. 1994. Care of bereaved parents. A study of patient satisfaction. *Journal of Reproductive Medicine*, 39, 80-6.
- HAZZARD, A., WESTON, J. & GUTTERRES, C. 1992. After a child's death: factors related to parental bereavement. *J Dev Behav Pediatr*, 13, 24-30.

- HM GOVERNMENT 1933. Children and Young Persons Act.
- HM GOVERNMENT 2009. Coroners and Justice Act.
- HM GOVERNMENT 2013. WorkingTogether to Safeguard Children. London: DfES.
- HOLLOWAY, I. 2013. Qualitative Research in Nursing and Healthcare. 3rd edition ed.: Chichester: Wiley.
- HUTCHISON, B. L., REA, C., STEWART, A. W., KOELMEYER, T. D., TIPENE-LEACH, D. C. & MITCHELL, E. A. 2011. Sudden unexpected infant death in Auckland: a retrospective case review. *Acta Paediatrica*, 100, 1108-12.
- HYNISON, J., ARONI, R., BAULD, C. & SAWYER, S. M. 2006. Research with bereaved parents: a question of how not why. *Palliative Medicine*, 20, 805-811.
- ISIDA Sudden Death in Infancy. SIDS model of care for Professionals.
- KERBL, R., ZOTTER, H., EINSPIELER, C., ROLL, P., RATSCHKE, M., KOSTL, G., STRENGER, V., HOFFMANN, E., PERROGON, A., ZOTSCH, W., SCHOBEL, P., GRANZ, A., SAUSENG, W., BACHLER, I., KENNER, T., IPSIROGLU, O., KURZ, R. & STYRIAN SUDDEN INFANT DEATH STUDY, G. 2003. Classification of sudden infant death (SID) cases in a multidisciplinary setting. Ten years experience in Styria (Austria). *Wiener Klinische Wochenschrift*, 115, 887-93.
- KIM, S. Y., SHAPIRO-MENDOZA, C. K., CHU, S. Y., CAMPERLENGO, L. T. & ANDERSON, R. N. 2012. Differentiating cause-of-death terminology for deaths coded as sudden infant death syndrome, accidental suffocation, and unknown cause: an investigation using US death certificates, 2003-2004. *Journal of Forensic Sciences*, 57, 364-9.
- KOMULAINEN S., H. L. 2009. Understanding parents information needs and experiences where professional concerns regarding non-accidental injury were not substantiated. London: Royal College of Paediatrics and Child Health.
- KOTSUBO, C. Z. 1983. Helping families survive S.I.D.S. *Nursing*, 13, 94-6.
- KRAUEL VIDAL, J., SILVA VAZQUEZ, M., IBANEZ FANES, M., FLORENSA PALAU, R. & MORENO HERNANDO, J. 1992. [Attitude towards parents after the death of their newborn infant in a neonatal unit]. *Anales Espanoles de Pediatria*, 36, 419-22.
- KROUS, H. F. 2013. A commentary on changing infant death rates and a plea to use sudden infant death syndrome as a cause of death. *Forensic Science, Medicine & Pathology*, 9, 91-3.
- KROUS, H. F., BECKWITH, J. B., BYARD, R. W., ROGNUM, T. O., BAJANOWSKI, T., COREY, T., CUTZ, E., HANZLICK, R., KEENS, T. G. & MITCHELL, E. A. 2004. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics*, 114, 234-8.
- KROUS, H. F., CHADWICK, A. E., HAAS, E. A. & STANLEY, C. 2007. Pulmonary intra-alveolar hemorrhage in SIDS and suffocation. *Journal of Forensic & Legal Medicine*, 14, 461-70.
- KUHN, S. K. 2008. *The process of parental bereavement following the violent death of a child*. Ph.D. Thesis, Duquesne University.
- KVALE, S. 2007. *Doing Interviews*, Los Angeles, SAGE.
- LAAKSO, H. & PAUNONEN-ILMONEN, M. 2002. Mothers' experience of social support following the death of a child. *Journal of Clinical Nursing*, 11, 176-85.
- LANDI, K., GUTIERREZ, C., SAMPSON, B., HARRUFF, R., RUBIO, I., BALBELA, B. & GRECO, M. A. 2005. Investigation of the sudden death of infants: a multicenter analysis. *Pediatric & Developmental Pathology*, 8, 630-8.
- LEACH, C. E., BLAIR, P. S., FLEMING, P. J., SMITH, I. J., PLATT, M. W., BERRY, P. J. & GOLDING, J. 1999. Epidemiology of SIDS and explained sudden infant deaths. CESDI SUDI Research Group. *Pediatrics*, 104, e43.

- LEMMER, C. M. 1991. Parental perceptions of caring following perinatal bereavement. *Western Journal of Nursing Research*, 13, 475-89; discussion 489-93.
- LEVENE, S. & BACON, C. J. 2004. Sudden unexpected death and covert homicide in infancy. *Arch Dis Child*, 89, 443-7.
- LI, L., FOWLER, D., LIU, L., RIPPLE, M. G., LAMBROS, Z. & SMIALEK, J. E. 2005b. Investigation of sudden infant deaths in the State of Maryland (1990–2000). *Forensic Science International*, 148, 85-92.
- LI, L., ZHANG, Y., ZIELKE, R. H., PING, Y. & FOWLER, D. R. 2009. Observations on increased accidental asphyxia deaths in infancy while cosleeping in the state of Maryland. *American Journal of Forensic Medicine & Pathology*, 30, 318-21.
- LIMERICK & DOWNHAM, M. A. 1978. Support for families bereaved by cot death: joint voluntary and professional view. 1, 1527-1529.
- LIVESEY, A. 2005. A multiagency protocol for responding to sudden unexpected death in infancy: descriptive study. *BMJ*, 330, 227-8.
- MACDONALD, M. E., LIBEN, S., CARNEVALE, F. A., RENNICK, J. E., WOLF, S. L., MELOCHE, D. & COHEN, S. R. 2005. Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death. *Pediatrics*, 116, 884-90.
- MACNAB, A. J., NORTHWAY, T., RYALL, K., SCOTT, D. & STRAW, G. 2003. Death and bereavement in a paediatric intensive care unit: Parental perceptions of staff support. *Paediatr Child Health*, 8, 357-62.
- MAGE, D. T. & DONNER, M. 2009. A Unifying Theory for SIDS. *Int J Pediatr*, 2009, 368270.
- MAHAJAN, R. P. 2010. Critical incident reporting and learning. *British Journal of Anaesthesia*, 105, 69-75.
- MARSHALL, D. 2012. *Effective investigation of child homicides and suspicious deaths*, Oxford, Oxford University Press.
- MAYS, N., POPAY, J. & POPE, C. 2005. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research & Policy*, 10, 6-20.
- MCDONNELL, M., CULLEN, A., KIBERD, B., MEHANNI, M. & MATTHEWS, T. 1999. A national model of care service for professionals dealing with sudden infant death. *Irish Journal of Medical Science*, 168, 237-41.
- MCHAFFIE, H. E., FOWLIE, P. W., HUME, R., LAING, I. A., LLOYD, D. J. & LYON, A. J. 2001a. Consent to autopsy for neonates. *Archives of Disease in Childhood Fetal & Neonatal Edition*, 85, F4-7.
- MCHAFFIE, H. E., LAING, I. A. & LLOYD, D. J. 2001b. Follow up care of bereaved parents after treatment withdrawal from newborns. *Archives of disease in childhood. Fetal and neonatal edition*, 84, F125-8.
- MCLARDY, E. June 2014 2014. *RE: personal communication regarding NZ SUDI Study*. Type to GARSTANG, J.
- MEERSMAN, S. C. & SCHABERG, M. J. 2010. Rhode Island Child Death Review: sudden infant death and sudden unexpected infant deaths, 2008-2009. *Medicine & Health, Rhode Island*, 93, 219-21.
- MEERT, K. L., BRILLER, S. H., SCHIM, S. M., THURSTON, C. & KABEL, A. 2009. Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. *Death Studies*, 33, 712-40.
- MEERT, K. L., EGGLEY, S., DEAN, J. M., POLLACK, M., ZIMMERMAN, J., ANAND, K. J., NEWTH, C. J., WILLSON, D. F. & NICHOLSON, C. 2008a. Ethical and logistical considerations of multicenter parental bereavement research. *J Palliat Med*, 11, 444-50.

- MEERT, K. L., EGGLEY, S., POLLACK, M., ANAND, K. J. S., ZIMMERMAN, J., CARCILLO, J., NEWTH, C. J. L., DEAN, J. M., WILLSON, D. F. & NICHOLSON, C. 2007. Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit. *Journal of Pediatrics*, 151, 50-5.
- MEERT, K. L., EGGLEY, S., POLLACK, M., ANAND, K. J. S., ZIMMERMAN, J., CARCILLO, J., NEWTH, C. J. L., DEAN, J. M., WILLSON, D. F. & NICHOLSON, C. 2008b. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, 9, 2-7.
- MERLEVEDE, E., SPOOREN, D., HENDERICK, H., PORTZKY, G., BUYLAERT, W., JANNES, C., CALLE, P., VAN STAHEY, M., DE ROCK, C., SMEESTERS, L., MICHEM, N. & VAN HEERINGEN, K. 2004. Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death. *Resuscitation*, 61, 341-8.
- MEYER, E. C., BURNS, J. P., GRIFFITH, J. L. & TRUOG, R. D. 2002. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 30, 226-31.
- MEYER, E. C., RITHOLZ, M. D., BURNS, J. P. & TRUOG, R. D. 2006. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*, 117, 649-57.
- MITCHELL, E., KROUS, H. F. & BYARD, R. W. 2002. Pathological findings in overlaying. *J Clin Forensic Med*, 9, 133-5.
- MITCHELL, E. A., THOMPSON, J. M., STEWART, A. W., WEBSTER, M. L., TAYLOR, B. J., HASSALL, I. B., FORD, R. P., ALLEN, E. M., SCRAGG, R. & BECROFT, D. M. 1992. Postnatal depression and SIDS: a prospective study. *J Paediatr Child Health*, 28 Suppl 1, S13-6.
- MORRIS, J. A. 1999. The common bacterial toxins hypothesis of sudden infant death syndrome. *FEMS Immunology & Medical Microbiology*, 25, 11-17.
- MURRAY-PARKES, C. 1996. *Bereavement: studies of grief in adult life*, London, Routledge.
- NAGARURU VENKATA, R. & ASHTEKAR, S. 2014. G151(P) PRUDiC – 2 year review of paediatric deaths. *Archives of Disease in Childhood*, 99, A67.
- NEIDIG, J. R. & DALGAS-PELISH, P. 1991. Parental grieving and perceptions regarding health care professionals' interventions. *Issues in Comprehensive Pediatric Nursing*, 14, 179-91.
- NIHR. 2012. *NIHR Service delivery and organisation programme. Evaluating models of service delivery*. [Online]. Available: <http://www.sdo.nihr.ac.uk/rsummevaluate.html> [Accessed 17 January 2012 2012].
- NORDBY, H. & NOHR, O. 2009. Interactive emergency communication involving persons in crisis. *Journal of Telemedicine & Telecare*, 15, 351-5.
- OFFICE FOR NATIONAL STATISTICS 2008. Mortality Statistics, childhood, infant and perinatal 2006. *Series DH3*.
- OFFICE FOR NATIONAL STATISTICS 2009. Mortality Statistics, childhood, infant and perinatal, 2007. *DH3*. National Statistics.
- OFFICE FOR NATIONAL STATISTICS 2012. Infant deaths mentioning selected causes 2002-10.
- OFFICE FOR NATIONAL STATISTICS 2013. *Unexpected Death in Infancy, 2011*. Lond: HMSO.
- OFFICE FOR NATIONAL STATISTICS 2014a. *Child Mortality Statistics: Childhood, Infant and Perinatal, 2012*. London.
- OFFICE FOR NATIONAL STATISTICS 2014b. *Mortality Statistics: Deaths registered in 2013 (Series DR) Table 5. Series DR*.

- OLIVER, R. C., STURTEVANT, J. P., SCHEETZ, J. P. & FALLAT, M. E. 2001. Beneficial effects of a hospital bereavement intervention program after traumatic childhood death. *J Trauma*, 50, 440-6; discussion 447-8.
- OSTFELD, B. M., RYAN, T., HIATT, M. & HEGYI, T. 1993. Maternal grief after sudden infant death syndrome. *Journal of Developmental & Behavioral Pediatrics*, 14, 156-62.
- OVRETVEIT, J. 1998. *Evaluating Health Interventions*, Maidenhead, Mc Graw Hill, Open University Press.
- PASQUALE-STYLES, M. A., TACKITT, P. L. & SCHMIDT, C. J. 2007. Infant death scene investigation and the assessment of potential risk factors for asphyxia: a review of 209 sudden unexpected infant deaths. *Journal of Forensic Sciences*, 52, 924-9.
- PAWSON, R. & TILLEY, N. 1997. *Realistic Evaluation*, Thousand Oaks, CA, Sage Publications Ltd.
- PECTOR, E. A. 2004. How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased, and attachment to survivors. *Journal of Perinatology*, 24, 714-22.
- POWELL, C. 1996. Sudden infant death: who's to blame? *British Journal of Nursing*, 5, 1099.
- POWELL, M. 1991. Sudden infant death syndrome: a crisis for parents and health professionals. *Irish Journal of Medical Science*, 160, 282-5.
- RAGIN, C. C. 2009. *Configurational Comparative Methods: Qualitative Comparative Analysis (QCA) and Related Techniques*, Los Angeles, SAGE.
- RAHMAN, H. A. & KHONG, T. Y. 1995. Perinatal and infant postmortem examination. Survey of women's reactions to perinatal necropsy. *BMJ*, 310, 870-1.
- RANDALL, B., DONELAN, K., KOPONEN, M., SENS, M. A. & KROUS, H. F. 2012. Application of a classification system focusing on potential asphyxia for cases of sudden unexpected infant death. *Forensic Science, Medicine & Pathology*, 8, 34-9.
- RANKIN, J., WRIGHT, C. & LIND, T. 2002. Cross sectional survey of parents' experience and views of the postmortem examination. *BMJ*, 324, 816-8.
- REDFERN, M., KEELING, J. W., POWELL, E. 2001. The Royal Liverpool Children's Inquiry Report London: HMSO.
- REILLY, D. E., HUWS, J. C., HASTINGS, R. P. & VAUGHAN, F. L. 2008. 'When your child dies you don't belong in that world anymore.' - Experiences of mothers whose child with an intellectual disability has died. *Journal of Applied Research in Intellectual Disabilities*, 21, 546-60.
- ROYAL COLLEGE OF PATHOLOGISTS & ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH 2004. Sudden Unexpected Death in Infancy ; A multi-agency protocol for care and investigation. Royal College of Pathologists, Royal College of Paediatrics and Child Health
- RUSSELL-JONES, D. L. 1985. Sudden infant death in history and literature. *Arch Dis Child*, 60, 278-81.
- SCHAAP, A. H., WOLF, H., BRUINSE, H. W., BARKHOF-VAN DE LANDE, S. & TREFFERS, P. E. 1997. Long-term impact of perinatal bereavement. Comparison of grief reactions after intrauterine versus neonatal death. *European Journal of Obstetrics, Gynecology, & Reproductive Biology*, 75, 161-7.
- SEXTON, P. R. & STEPHEN, S. B. 1991. Postpartum mothers' perceptions of nursing interventions for perinatal grief. *Neonatal Netw*, 9, 47-51.
- SHAPIRO-MENDOZA, C. K., KIMBALL, M., TOMASHEK, K. M., ANDERSON, R. N. & BLANDING, S. 2009. US infant mortality trends attributable to accidental suffocation and strangulation in bed from 1984 through 2004: are rates increasing? *Pediatrics*, 123, 533-9.

- SIDEBOTHAM, P. 2010. Do we Need a New Definition for SIDS? Commentary on 'Sudden Unexpected Death in Infancy and the Dilemma of Defining the Sudden Infant Death Syndrome' by Henry Krous *Current pediatric reviews* 6, 13-4.
- SIDEBOTHAM, P., BLAIR, P. S., EVASON-COOMBE, C., EDMOND, M., HECKSTALL-SMITH, E. & FLEMING, P. 2010. Responding to unexpected infant deaths: experience in one English region. *Arch Dis Child*, 95, 291-5.
- SIDEBOTHAM, P. & FLEMING, P. 2007. *Unexpected Death in Childhood: A handbook for practitioners*, Chichester, John Wiley & Sons Ltd.
- SKENE, C. 1998. Individualised bereavement care. *Paediatric Nursing*, 10, 13-6.
- SNOWDON, C., ELBOURNE, D. R. & GARCIA, J. 2004. Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents. *Archives of Disease in Childhood Fetal & Neonatal Edition*, 89, F208-11.
- SPENCER, N. & LOGAN, S. 2004. Sudden unexpected death in infancy and socioeconomic status: a systematic review. *J Epidemiol Community Health*, 58, 366-73.
- SPOOREN, D. J., HENDERICK, H. & JANNES, C. 2000. Survey description of stress of parents bereaved from a child killed in a traffic accident. A retrospective study of a victim support group. *Omega: Journal of Death and Dying*, 42, 2000-2001.
- ST LEGER, A. S., SCHNIEDEN, H. & WALSWORTH - BELL, J. P. 1997. *Evaluating Health Services' Effectiveness*, Milton Keynes, Open University Press.
- STANFORD, P. (ed.) 2011. *The Death of a Child*, London: Continuum Books.
- STANTON, A. N. 2003. Sudden unexpected death in infancy associated with maltreatment: evidence from long term follow up of siblings. *Arch Dis Child*, 88, 699-701.
- STATISTICS, O. F. N. 2012. *Unexplained Death in Infancy - England and Wales, 2010* [Online]. London. Available: [www.statistics.gov.uk](http://www.statistics.gov.uk).
- STERRY, L. & BATHGATE, L. 2011. Scottish Cot Death Trust Project Report Scottish Cot Death Trust.
- STROEBE, M. & SCHUT, H. 2010. The dual process model of coping with bereavement: a decade on. *Omega (Westport)*, 61, 273-89.
- SULLIVAN, J. & MONAGLE, P. 2011. Bereaved parents' perceptions of the autopsy examination of their child. *Pediatrics*, 127, e1013-20.
- SWANSON, P., BROCKBANK, J., HOUGHTON, J., MOUNTBATTEN, P., READ, B., ROSS, A. & WOODWARD, J. 2002. Panel discussion. Grief and bereavement with the loss of a twin. *Twin Research*, 5, 150-2.
- TEKLAY, B., WIWE, L. B. & THOMSEN, J. L. 2005. [Contact with relatives after forensic autopsies]. *Ugeskrift for Læger*, 167, 289-93.
- THE LULLABY TRUST 2012. Cot Deaths facts and figures. In: THE LULLABY TRUST (ed.).
- THUEN, F. 1997. Social Support after the Loss of an Infant Child: A Long-Term Perspective. *Scandinavian Journal of Psychology*, 38, 103-110.
- TODD, S. 2007. Silenced grief: living with the death of a child with intellectual disabilities. *Journal of Intellectual Disability Research*, 51, 637-648.
- TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349-357.
- VEGE, Å., ROGNUM, T. O., SCOTT, H., AASEN, A. O. & SAUGSTAD, O. D. 1995. S cases have increased levels of interleukin-6 in cerebrospinal fluid. *Acta Pædiatrica*, 84, 193-196.
- VENNEMANN, M. M. T., RENTSCH, C., BAJANOWSKI, T. & ZIMMER, G. 2006. Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families. *International Journal of Legal Medicine*, 120, 352-4.

- WALKER, R. 1985. Cot deaths: the aftermath. *Journal of the Royal College of General Practitioners*, 35, 194-6.
- WEBER, M. A., RISDON, R. A., ASHWORTH, M. T., MALONE, M. & SEBIRE, N. J. 2012. Autopsy findings of co-sleeping-associated sudden unexpected deaths in infancy: relationship between pathological features and asphyxial mode of death. *Journal of Paediatrics & Child Health*, 48, 335-41.
- WEST MIDLANDS POLICE. 2009. *West Midlands Best Practice Multi-Agency Protocol for the Investigation of Sudden Unexpected Death in Infants and Children under 18 years of age* [Online]. Available: [http://solihullscb.proceduresonline.com/chapters/contents.html#anchor\\_p9](http://solihullscb.proceduresonline.com/chapters/contents.html#anchor_p9).
- WISTEN, A. & ZINGMARK, K. 2007. Supportive needs of parents confronted with sudden cardiac death--a qualitative study. *Resuscitation*, 74, 68-74.
- YIN, R. K. 2014. *Case Study Research: Design and Methods*, Los Angeles, SAGE.
- ZIGMOND, A. S. & SNAITH, R. P. 1983. The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67, 361-70.

## Appendix 1

Garstang et al. *BMC Pediatrics* 2014, **14**:269  
<http://www.biomedcentral.com/1471-2431/14/269>



### RESEARCH ARTICLE

### Open Access

# What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature

Joanna Garstang<sup>1\*</sup>, Frances Griffiths<sup>2</sup> and Peter Sidebotham<sup>1</sup>

## Abstract

**Background:** The death of a child is a devastating event for parents. In many high income countries, following an unexpected death, there are formal investigations to find the cause of death as part of wider integrated child death review processes. These processes have a clear aim of establishing the cause of death but it is less clear how bereaved families are supported. In order to inform better practice, a literature review was undertaken to identify what is known about what bereaved parents want from professionals following an unexpected child death.

**Methods:** This was a mixed studies systematic review with a thematic analysis to synthesize findings. The review included papers from Europe, North America or Australasia; papers had to detail parents' experiences rather than professional practices.

**Results:** The review includes data from 52 papers, concerning 4000 bereaved parents. After a child has died, parents wish to be able to say goodbye to them at the hospital or Emergency Department, they would like time and privacy to see and hold their child; parents may bitterly regret not being able to do so. Parents need to know the full details about their child's death and may feel that they are being deliberately evaded when not given this information. Parents often struggle to obtain and understand the autopsy results even in the cases where they consented for the procedure. Parents would like follow-up appointments from health care professionals after the death; this is to enable them to obtain further information as they may have been too distraught at the time of the death to ask appropriate questions or comprehend the answers. Parents also value the emotional support provided by continuing contact with health-care professionals.

**Conclusion:** All professionals involved with child deaths should ensure that procedures are in place to support parents; to allow them to say goodbye to their child, to be able to understand why their child died and to offer the parents follow-up appointments with appropriate health-care professionals.

**Keywords:** Child death, Bereavement, Parent, Sudden infant death syndrome, Child death review, Multi-professional working, Physician interactions

## Background

The death of a child can be considered one of the most devastating life events for parents. It is an upset to the natural order of events; most parents rightly expect their children to outlive them. Several years after their child has died, bereaved parents may continue to feel the impact of the death on a daily basis [1].

The investigation following an unexpected child death varies in different countries, but in many cases involves the police or Coroner as well as health services, with many now having integrated Child Death Review (CDR) processes [2]. CDR typically includes overview of child deaths at a population level with the intention of learning lessons and preventing future deaths; a process that rarely involves parents. However, in many countries CDR also involves detailed investigation of individual child deaths, requiring full medical and social histories

\* Correspondence: [Joanna.J.Garstang@warwick.ac.uk](mailto:Joanna.J.Garstang@warwick.ac.uk)

<sup>1</sup>Division of Mental Health and Wellbeing, Warwick Medical School, Coventry CV4 7AL, UK

Full list of author information is available at the end of the article



© 2014 Garstang et al.; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.



from parents, death scene analysis and autopsy [3,4]. This detailed CDR process has a clear focus on determining the cause of death but does not necessarily address the needs of the family; this is particularly pertinent as detailed CDR could be considered intrusive for the recently bereaved parents.

We undertook this literature review to inform best practice in supporting parents after sudden child death given the potential for intrusion of the new detailed CDR processes. We therefore reviewed the literature on bereaved parents' interactions with professionals such as physicians, nurses, police officers and social workers after the death of their child. This review details bereaved parents' experiences with such professionals and how the parents wished that they had been treated by professionals rather than professional opinions of what best care for bereaved parents may be. The question for our review is 'What do bereaved parents want from professionals after the unexpected death of their children?'

## Methods

We used thematic analysis [5] and a narrative synthesis process [6].

The project did not require ethical approval as it only involved reviewing literature.

## Search strategy

### Databases

We searched ASSIA, Ovid (MEDLINE) and CINAHL databases from 1.1.90 to 31.8.13. Google scholar was also used but limited to the first 10 screens of results only. We snowball searched all included articles. The search terms used are shown in Table 1.

### Grey literature

We contacted or checked the websites of several bereavement associations and professional bodies for details of any unpublished research reports. These organisations were known to us from our practice or prior attendance at international conferences; they included The Lullaby Trust (UK), SIDS and Kids (Australia), International Society for the Study and Prevention of Infant Death (ISPID), the Child Bereavement Charity (UK), British Association for the Study and Prevention of Child Abuse and Neglect (BASCPAN, UK), Stillbirth and Neonatal Death Society (SANDS), Bereavement Care UK (Cruse) and Compassionate Friends UK.

### Inclusion and exclusion criteria

We included original research and systematic reviews of research concerning bereaved parents interactions with health professionals, police or social workers. Included papers were from Europe, North America or Australasia

**Table 1 Search terms used for literature searches**

Database	Search terms
Assia	1 Child* and death or autopsy and parent* or bereavement and social worker or police or physician
	2 Child* and death and police or social work
	3 Child* and murder and parent*
Ovid	1 Grief or self-help group or prof- family relations or bereaved parent as keyword (kw) And SIDS or child mortality or infant mortality or cause of death
	2 Death (expl- explode) – limit to <18 yrs And Bereavement expl/grief expl/parent# bereavement (kw) And Autopsy expl
	3 Death expl – limit to <18 yrs And Bereavement expl/grief expl/parent# bereavement (kw)/parent# expl And Forensic pathology expl/ forensic science expl/forensic# (kw)/forensic medicine expl
	4 1. Death expl – limit to <18 yrs And Bereavement expl/grief expl/parent# bereavement (kw)/ parent#expl And P?ediatrician (kw) or physicians role expl or physician practice pattern exp or attitude of health personnel expl or physician expl or health visitor (kw.) or community health nursing expl
	5 Death expl – limit to <18 yrs And Bereavement expl/grief expl/parent# bereavement (kw) And Social worker (kw) or social work expl or police expl or police (kw)
	6 Death expl – limit to <18 yrs And coroner expl or medical examiner expl or coroner k.w.
Cinahl	Search using 'child death' as word in abstract
Google scholar	1 'bereaved parent doctor'
	2 'bereaved parent social work'
	3 'bereaved parent police'



and published from January 1990 to May 2014. Papers were included if they contained even minimal data on bereaved parents' interactions with professionals even if this was not the main focus of the paper. We defined child death as death occurring from birth to 18 years. There was no limitation on language of publication.

We excluded papers concerning bereavement counselling as the sole interaction, papers with no data on live-born children, papers containing data solely relating to children dying prior to 1980 and papers only concerning deaths by homicide or of terminally ill children.

#### Selection process of studies and critical appraisal

JG read the titles, abstracts and full text articles twice (one month apart) for thoroughness. FG and PS reviewed a consecutive sample of 100 titles and abstracts for independent comparison. Formal translations were obtained for two non-English publications.

All included articles were critically appraised according to the overall nature (predominantly quantitative or qualitative) of the paper. We selected the critical appraisal tool for cross-sectional surveys [7] as it includes reference to development of the survey tools such as piloting and validation as well as sampling of the population. We used the critical appraisal tool for qualitative research [8] as it focuses on the key requirements available in most publications: appropriateness of the selected research methods; how participants were recruited; the relationship between the researcher and participants and methods of analyses.

#### Data extraction, analysis and synthesis

We undertook data extraction and coding separately for quantitative and qualitative papers but used the same process. Firstly, we read the papers in their entirety then re-read them extracting relevant data. During extraction we developed and refined codes based on the data. All data was coded. Coded data was reviewed and codes from both qualitative and quantitative papers combined into themes.

However, the themes included data from studies that recruited bereaved parents whatever the cause of death and data from studies that recruited bereaved parents where the cause of death was of a distinct type such as neonatal death or SIDS. Many of the studies focused only on one aspect of the parent's experience of child death. For our synthesis it was important to ensure we took account of this heterogeneity of studies.

We selected the data from two papers [9,10] to create a reference framework against which data from the other studies could be compared. These data were chosen as together the papers from which they were extracted, reported studies that recruited parents experiencing all types of child death. Finlay and Dallimore [9] included

any child death from any cause; Dent et al. [10] only included sudden deaths in children aged between 1 week and 12 years. They also studied all aspects of the experience including experiences at the time of the death in the Emergency Department, contact with the police and follow-up with General Practitioners and paediatricians. The process of synthesis involved comparison within each theme of the data from all other papers with the reference framework.

For each theme we present first the reference framework findings, and then we present our synthesis of data from other studies.

## Results

### Search results

Out of 1294 titles and abstracts found by database searches 46 were suitable for inclusion. Snowball searching produced an additional 5 studies and we obtained 1 unpublished research report giving a total of 52 included studies, of which 25 were quantitative, 20 qualitative and 7 mixed. This is shown in Figure 1. More than 4000 bereaved parents participated in the original studies included in the review.

22 studies were from North America, 12 from the UK, 14 from other European countries and 4 from Australia. 19/25 quantitative studies were questionnaire surveys, 5 were interview surveys and one was a case series. 17/20 qualitative studies involved in-depth interviews with bereaved parents, 3 studies analysed data from open-ended questions in surveys. 4/7 mixed data studies were questionnaire studies, 2 were interview studies and 1 was a combination.

13 studies included child deaths from any cause, 16 studies were of perinatal deaths, 10 studies of SIDS, 7 studies were of deaths on paediatric intensive care units, 3 studies of deaths from trauma, 2 studies of deaths of children with intellectual disability and 1 of suicides. Most studies focused on bereaved parents experiences and perceptions of care and support or interaction with professionals; some purely focussed on views on autopsy.

Details of the included studies are given in Tables 2, 3 and 4.

### Results of critical appraisal

18 studies recruited directly from bereavement support groups which parents had to actively choose to join; thus these parents' experiences may be different from those choosing not to join. The quantitative studies recruitment rate varied from 22 to 100%; in 7 studies the recruitment rate could not be calculated as it was unclear how many eligible families had been contacted.

Death in childhood is associated with lower socio-economic status [11] and this should be reflected in the socio-economic status of participating parents; however

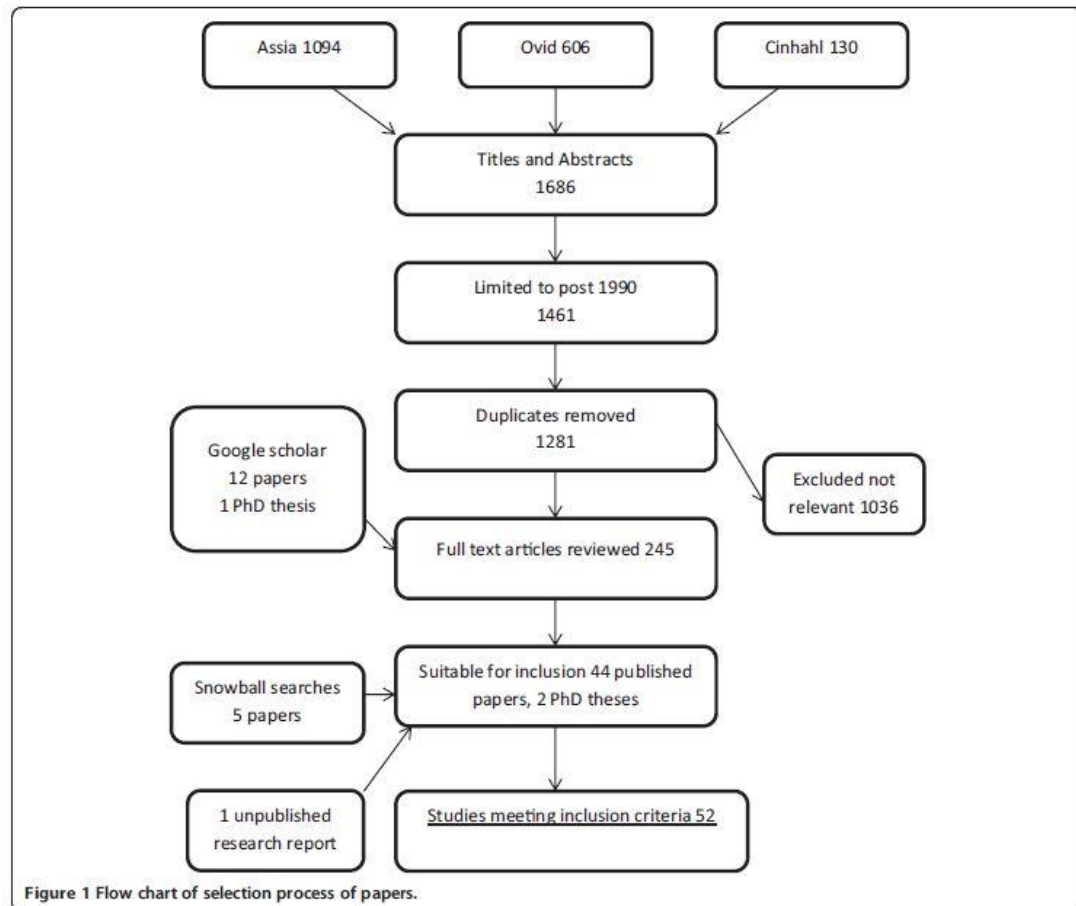


Figure 1 Flow chart of selection process of papers.

only 28 studies provided these data. Reporting studies only gave brief details describing 'most' participating parents as white (75-100%), married (70-100%), completing some higher education (50% university, mean of 13-14 years in education) and earning higher than average incomes.

It was difficult to judge the reliability of results in 10 studies due to limited details of data collection, development of questionnaires or interview schedules and methods of qualitative analysis. Despite these deficiencies no studies were excluded; this was to ensure no parental experiences are lost but where necessary these issues are highlighted along with the results of these studies.

The results of the critical appraisal process are given in Additional files 1 and 2.

#### Narrative synthesis of results

Three themes emerged from the review on what bereaved parents want from professionals after the death

of their child: to be able to say goodbye, to understand why and how their child died, and to feel supported by professionals.

The themes are shown in Figure 2. A summary chart for health care professionals is shown in Figure 3.

#### Parents want to be able to say goodbye to their child

In the reference framework parents wanted time to hold or be with their children after death, to say goodbye even if the body was mutilated; parents deeply regretted this if they were unable to do so [9,10]. These were consistent findings across many studies of all types of child death; with qualitative studies detailing parents' desire for privacy, a peaceful space and adequate time to be able to say farewell [12-20].

In interview studies, parents have described seeing or holding their infant or child's body as helpful and that not being able to do so increased their grief [16,21-23]; however survey findings of this are less certain. In one



**Table 2 Details of included quantitative studies**

Authors and year of publication	Name of study	Population and country	Study type	Proportion of study results included
W Ahrens, R Hart and N Maruyama [50] 1997	Pediatric death: managing the aftermath in the emergency department	SIDS parents N = 37 USA	Postal questionnaire survey	100%
A Dent, L Condon, P Blair and P Fleming [10] 1996	A study of bereavement care after a sudden and unexpected death.	Parents of children dying suddenly N = 42 United Kingdom	Postal questionnaire survey	50%
MA DiMarco, EM Menke and T McNamara [48] 2001	Evaluating a support group for perinatal loss	Parents of infants dying perinatally N = 121 USA	Postal questionnaire survey	Minimal data
I Finlay and D Dallimore [9] 1991	Your child is dead	Parents of children dying of any cause at any age N = 120 United Kingdom	Postal questionnaire survey	100%
MB Harper and NB Wisian [57] 1994	Care of bereaved parents. A study of patient satisfaction	Parents of infants dying perinatally and in infancy N = 28 USA	Postal questionnaire survey or questionnaire distributed at support group	66%
A Hazzard, J Weston and C Gutterres [60] 1992	After a child's death: factors related to parental bereavement	Parents of children dying of any cause at any age N = 45 USA	Structured interview	Minimal data
J Krauel Vidal, M Silva Vazquez, M Ibanez Fanes, R Florensa Palau and J Moreno Hernando [59] (translated from Spanish) 1992	Attitude towards parents after the death of their newborn infant in a neonatal unit	Parents of infants dying on neonatal units N = 49 Spain	Postal questionnaire survey	100%
H Laakso and M Paunonen-Ilmonen [59] 2002	Mothers' experience of social support following the death of a child	Mothers of children dying under age 7 years. N = 91 Finland	Questionnaire and structured interview	50%
A Livesey [51] 2005	A multiagency protocol for responding to sudden unexpected death in infancy: descriptive study	Parents of infants dying suddenly and unexpectedly N = 29 United Kingdom	Postal questionnaire survey as part of audit of practice	Minimal data

**Table 2 Details of included quantitative studies (Continued)**

AJ Macnab, T Northway, K Ryall, D Scott and G Straw [23] 2003	Death and bereavement in a paediatric intensive care unit: Parental perceptions of staff support	Parents of children dying on intensive care unit N = 24 Canada	Questionnaire and structured interview	100%
M McDonnell, A Cullen, B Kiberd, M Mehanni and T Matthews [52] 1999	A national model of care service for professionals dealing with sudden infant death	Parents of infants dying of SIDS N = 131 Republic of Ireland	Structured interview	50%
EC Meyer, JP Burns, JL Griffith and RD Truog [56] 2002	Parental perspectives on end-of-life care in the pediatric intensive care unit	Parents of children dying on paediatric intensive care units N = 56 USA	Postal questionnaire survey	33%
JR Neidig and P Dalgas-Pelish [25] 1991	Parental grieving and perceptions regarding health care professionals' interventions	Parents of children dying of any cause at any age. N = 22 USA	Postal questionnaire survey	25%
RC Oliver, JP Sturtevant, JP Scheetz and ME Fallat [33] 2001	Beneficial effects of a hospital bereavement intervention program after traumatic childhood death	Parents of children dying from trauma N = 54 USA	Structured interview	Minimal data
BM Ostfeld, T Ryan, M Hiatt and T Hegyi [58] 1993	Maternal grief after sudden infant death syndrome	Parents of infants dying of SIDS N = 38 USA	Postal questionnaire survey	Minimal data
M Powell [53] 1991	Sudden infant death syndrome: a crisis for parents and health professionals	Parents of infants dying of SIDS N = 40 Republic of Ireland	Structured interview	25%
HA Rahman and TY Khong [45] 1995	Perinatal and infant postmortem examination. Survey of women's reactions to perinatal necropsy.	Mothers of infants dying perinatally N = 29 Australia	Telephone questionnaire survey	100% (published as letter only)
J Rankin, C Wright and T Lind [43] 2002	Cross sectional survey of parents' experience and views of the postmortem examination	Mothers of infants dying perinatally or in infancy N = 148 United Kingdom	Postal questionnaire survey	100%
Royal College of Pathologists and Royal College of Paediatrics and Child Health [31] 2004	Sudden Unexpected Death in Infancy; A multi-agency protocol for care and investigation	Parents of infants dying of SIDS N = 892 United Kingdom	Postal questionnaire survey and comments made to support group by other parents	100%

**Table 2 Details of included quantitative studies (Continued)**

PR Sexton and SB Stephen [24] 1991	Postpartum mothers' perceptions of nursing interventions for perinatal grief.	Mothers of infants dying perinatally N = 30 USA	Telephone questionnaire survey	50%
DJ Spooren, H Henderick and C Jannes [36] 2000	Survey description of stress of parents bereaved from a child killed in a traffic accident. A retrospective study of a victim support group	Parents of children dying in road traffic accidents N = 85 Belgium	Postal questionnaire survey	25%
J Sullivan and P Monagle [32] 2011	Bereaved parents' perceptions of the autopsy examination of their child	Parents of children undergoing autopsy N = 53 Australia	Postal questionnaire survey	50%
B Teklay, LB Wiwe and JL Thomsen [34] 2005	Contact with relatives after forensic autopsies	Relatives of patients having forensic autopsy N = 360 Denmark	Case record review by pathology department	100%
F Thuen [37] 1997	Social Support after the Loss of an Infant Child: A Long-Term Perspective.	Parents of infants dying of SIDS N = 251 Norway	Postal questionnaire survey	Minimal data
MMT Vennemann, C Rentsch, T Bajanowski and G Zimmer [42] 2006	Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families.	Parents of infants dying of SIDS N = 141 Germany	Postal questionnaire survey	100%

**Table 3 Details of included qualitative studies**

Authors and year of publication	Name of study	Population and country	Study type	Proportion of study results included
MA Ashby, RJ Kosky, HT Laver and EB Sims [12] 1991	An enquiry into death and dying at the Adelaide Children's Hospital: a useful model?	Parents of children dying in hospital N = 6 Australia	Interviews with staff and parents, written submissions	Minimal data
T Bellali, I Papazoglou and D Papadatou [22] 2007	Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation.	Parents who were asked to donate their children's organs N = 22 Greece	In-depth interviews with parents	Minimal data
KL Bright, MB Huff and K Hollon [39] 2009	A broken heart—the physician's role: bereaved parents' perceptions of interactions with physicians.	Bereaved parents, children dying of any age, including adulthood, of any cause N = 137 USA	Postal survey with open-ended question	100%
SK Kuhn [27] 2008	The process of parental bereavement following the violent death of a child. PhD Thesis	Parents of children (including young adults) dying in violent deaths N = 11 USA	In –depth interviews with parents	Not applicable PhD Thesis
CM Lemmer [13] 1991	Parental perceptions of caring following perinatal bereavement	Parents of infants dying in the neonatal period N = 28 USA	In –depth interviews with parents	25%
ME Macdonald, S Liben, FA Carnevale, JE Rennick, SL Wolf, D Meloche and SR Cohen [40] 2005	Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death	Parents of children dying on paediatric intensive care units (PICU) N = 12 Canada	Field ethnography	50%
HE McHaffie, IA Laing and DJ Lloyd [29] 2001	Follow up care of bereaved parents after treatment withdrawal from newborns	Parents of infants dying on neonatal intensive care (NICU) N = 108 United Kingdom	In –depth interviews with parents	100%
KL Meert, S Eggly, M Pollack, KJS Anand, J Zimmerman, J Carcillo, CJL Newth, JM Dean, DF Willson and C Nicholson [38] 2007	Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit	Parents of children dying on paediatric intensive care units (PICU) N = 56 USA	In –depth interviews with parents (2007)	100%
KL Meert, S Eggly, M Pollack, KJS Anand, J Zimmerman, J Carcillo, CJL Newth, JM Dean, DF Willson and C Nicholson [46] 2008	Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit	Secondary analysis of data from Meert, Eggly et al. [38]		Minimal Data
KL Meert, SH Briller, SM Schim, C Thurston and A Kabel [18] 2009	Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study.	Parents of children dying on paediatric intensive care units (PICU) N = 46 USA	In –depth interviews and focus groups with parents	75%

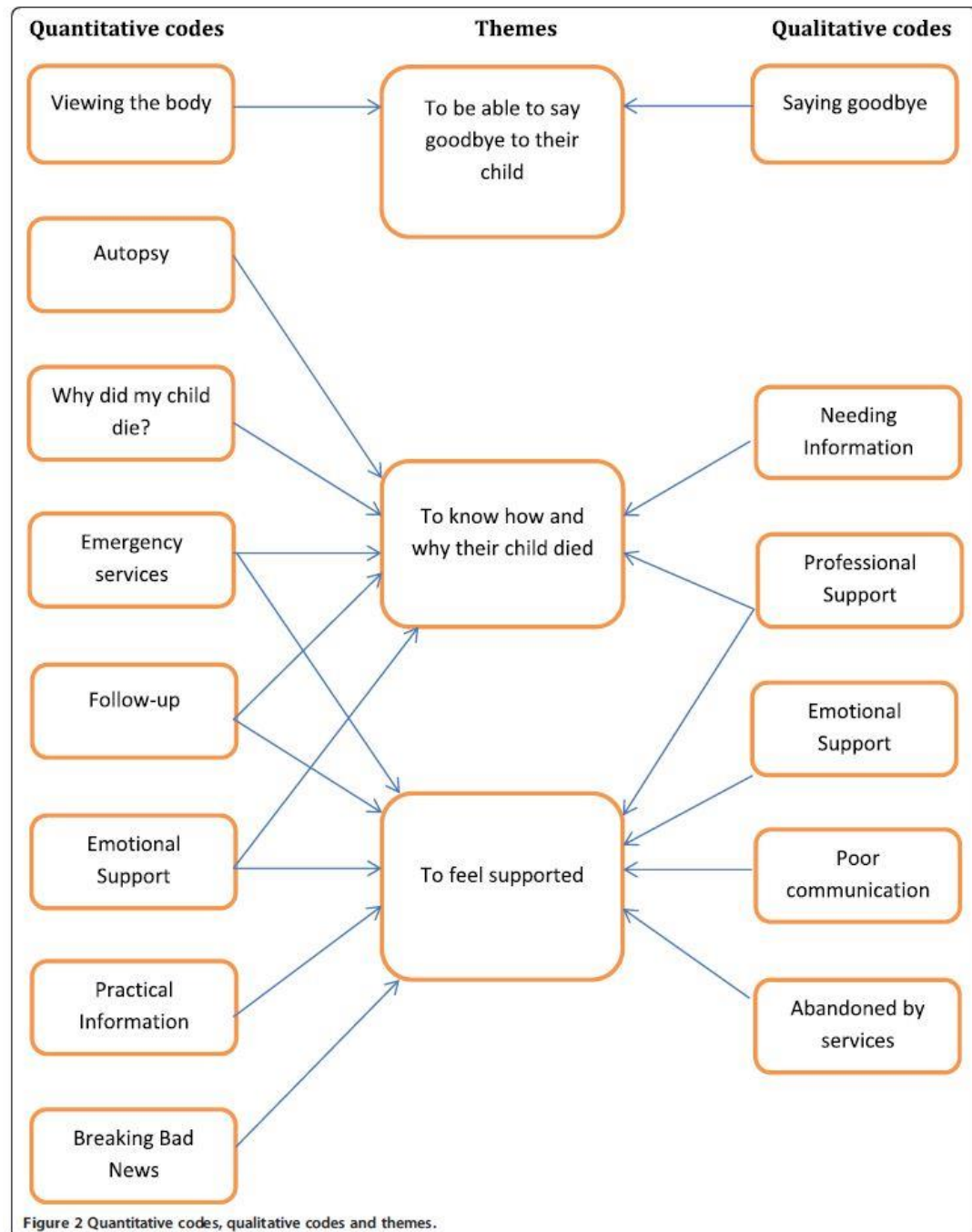
**Table 3 Details of included qualitative studies (Continued)**

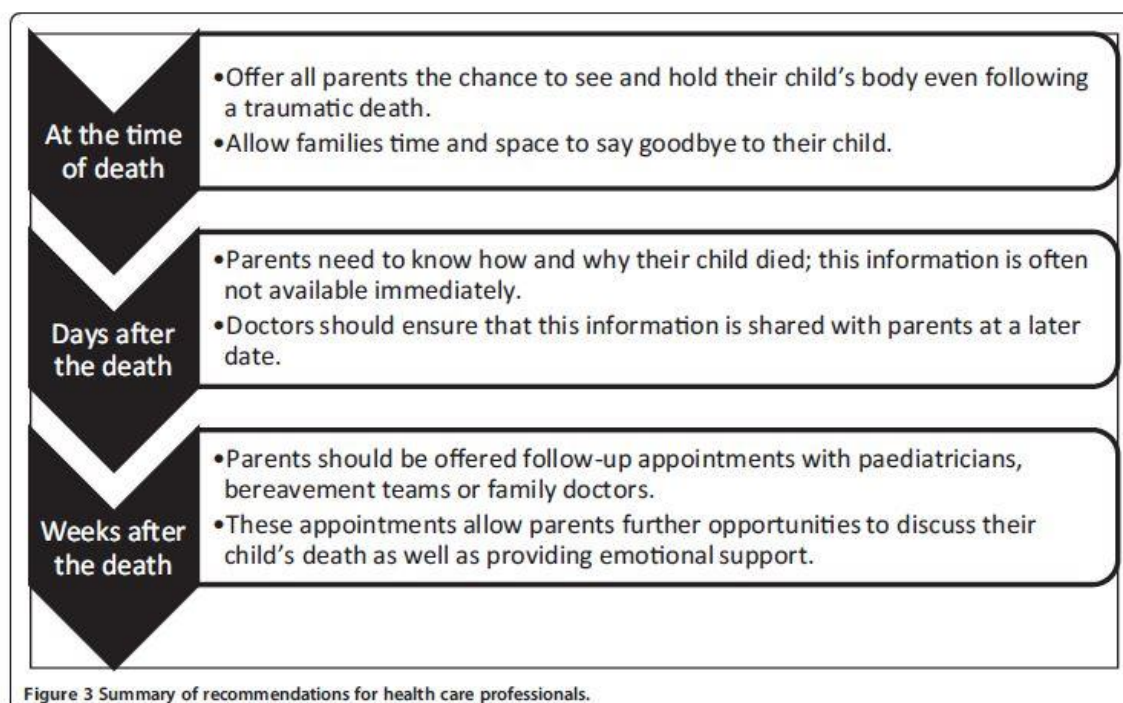
EC Meyer, MD Ritholz, JP Burns and RD Truog [15] 2006	Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations	Parents of children dying on paediatric intensive care units (PICU) N = 56 USA	Open-ended postal questionnaire	Minimal Data
H Nordby and O Nohr [49] 2009	Interactive emergency communication involving persons in crisis	Parents of SIDS infants N = 11 Norway	Semi-structured interviews with parents	Minimal Data
EA Pector [30] 2004	How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased, and attachment to survivors.	Parents of multiple birth infants who die neonatally N = 70 USA	Narrative email survey	25%
DE Reilly, JC Huws, RP Hastings and FL Vaughan [14] 2008	'When your child dies you don't belong in that world anymore.' - Experiences of mothers whose child with an intellectual disability has died	Bereaved mothers of children who had an intellectual disability (ID) N = 9 United Kingdom	In-depth interviews with parents	25%
AH Schaap, H Wolf, HW Bruinse, S Barkhof-van de Lande and PE Treffers [20] 1997	Long-term impact of perinatal bereavement. Comparison of grief reactions after intrauterine versus neonatal death	Parents of infants dying perinatally N = 38 The Netherlands	In-depth interviews with parents	Minimal Data
C Skene [26] 1998	Individualised bereavement care	Parents of infants dying neonatally N = 9 United Kingdom	Semi-structured interviews with bereaved mothers	Minimal Data
C Snowdon, DR Elbourne and J Garcia [44] 2004	Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents	Parents of infants dying on neonatal intensive care (NICU) N = 18 United Kingdom	Semi-structured interviews with bereaved mothers	Minimal Data
P Swanson, J Brockbank, J Houghton, P Mountbatten, B Read, A Ross and J Woodward [21] 2002	Panel discussion. Grief and bereavement with the loss of a twin	Mothers of multiple birth children dying at any time (including adulthood) N = 66 Australia	Semi-structured interviews with bereaved mothers	Minimal Data
S Todd [55] 2007	Silenced grief: living with the death of a child with intellectual disabilities	Bereaved parents of children who had an intellectual disability (ID) N = 13 United Kingdom	In-depth interviews with parents	Minimal Data
A Wisten and K Zingmark [16] 2007	Supportive needs of parents confronted with sudden cardiac death—a qualitative study	Parents of children suffering a sudden cardiac death (including adult deaths) N = 28 Sweden	In-depth interviews with parents	100%



**Table 4 Details of included mixed data studies**

Authors and year of publication	Name of study	Population and country	Study type	Proportion of study results included
LK Calhoun [19] 1994	Parents' perceptions of nursing support following neonatal loss	Parents of infants dying in neonatal units N = 23 USA	Questionnaire distributed by support group	100%
SN Covington and SK Theut [28] 1993	Reactions to perinatal loss: a qualitative analysis of the National Maternal and Infant Health Survey	Mothers of infants dying perinatally N = 413 USA	Postal questionnaire survey	75%
A Dent [47] 2000	Support for families whose child dies suddenly from accident or illness. PhD Thesis	Parents of children dying suddenly N = 72 United Kingdom	Postal questionnaire survey	Not applicable – PhD thesis
K Dyregrov [54] 2002	Assistance from local authorities versus survivors' needs for support after suicide	Parents of children who committed suicide N = 128 Norway	Postal questionnaire survey with in-depth interviews for a sample of participants	50%
HE McHaffie, PW Fowlie, R Hume, IA Laing, DJ Lloyd and AJ Lyon [41] 2001	Consent to autopsy for neonates	Parents of infants dying on neonatal units N = 108 United Kingdom	In-depth interviews with parents	75%
E Merlevede, D Spooren, H Henderick, G Portzky, W Buylaert, C Jannes, P Calle, M Van Staey, C De Rock, L Smeesters, et al. [17] 2004	Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death	Relatives of people dying suddenly N = 74 Belgium	Structured interview and analysis of clinical records	25%
L Stery and L Bathgate [35] 2011	Scottish Cot Death Trust Project Report	Parents of infants dying of SIDS N = 109 United Kingdom	Internet or postal questionnaire survey	75%





study after perinatal death 30/30 mothers found seeing the baby helpful [24] whereas only 6/21 parents found this helpful in a study of a wider range of child deaths [25]. Parents may choose not to see their child after death, but one-third of parents in a large qualitative study ( $n = 38$ ) expressed regret that they decided not to see their baby after a perinatal death [20]. However, even when warned of potential regret, a minority of neonatally bereaved parents still felt strongly that they did not want to see their baby [26].

Qualitative studies have reported that parents may still wish to see their child after a traumatic death although others may prefer to remember them unhurt [27]. When parents do not see their child they often imagine the injuries to be worse than they really are [17].

#### **Parents want to know how and why their child died**

Many different studies of all types of child death confirmed the parental need for information about their children's deaths identified in the reference framework [17,22,28-33]. Conversely, a case record review showed that only 28% of relatives sought results of forensic autopsy examination despite these not being available from any other source; families may not though have been aware that they could seek these results [34].

Both surveys and interview studies have reported that information after any type of child death may help parents make sense of the death and help with their grief

[16,27,28,35-37]. Interview studies reveal that information about the death reassures parents that children did not suffer and everything possible was done to save them [16,17,29]. Similarly, detailed information reassures parents that their actions were appropriate, helping to diminish some of their feelings of guilt [15,17,35,38].

Parents want to know the cause of death especially for sudden unexpected deaths; the lack of explanation for SIDS may result in further parental distress [10]. Consistent with this a survey of 892 SIDS parents found that finding the cause for death was of the greatest importance for parents [31] and a survey of 413 perinatally bereaved mothers showed that 21% were struggling to understand why their baby died with 51% wanting further information [28].

A consistent finding of studies of all types of child death is that parents have requested follow-up appointments with professionals to ask for further information as at the time of the death they were too distressed to comprehend detailed answers [16,17,28,38,39]. However, parents have commented in interview studies that returning to the hospital may cause distress from traumatic memories [29,40], and that following a neonatal death there may be an additional burden of appointments in several different departments [29].

Bereaved parents have described, in interviews, how the lack of information has led them to assume that it is being deliberately withheld [9,28] and following violent



deaths their determination to obtain information from the authorities [27].

**Autopsy** An interview study of neonatal deaths found that autopsy results may be a powerful tool in helping parents reach a sense of closure [41]; similar results were shown in a survey of SIDS parents where 66% (93/141) believed that mandatory autopsy had helped resolve their grief, even for the 17% (24/141) parents who had not wanted the autopsy initially [42]. Conversely with autopsy of older children, a survey showed only 40% of parents found the results useful and 38% thought the results helped with their grief; however this survey had a low response rates so these results may not be generalizable [32].

Interview studies and surveys have detailed parents' reasons for consenting to autopsies: to obtain further information about neonatal deaths and future pregnancies in particular was the reason given by 'the majority of parents' [41] and by 50% of parents in another neonatal study [43]. Bereaved parents following all types of child death wanted information from their child's autopsy to help other families in the future [32,41,44]. Around half of parents who declined neonatal autopsy in two studies did so because they had no unanswered questions and half because they do not want their baby's body traumatised further [41,43].

Surveys and interview studies have shown that a small minority of parents, after consenting to child autopsy subsequently regret it, this ranges from 6-8% [32,43,45]; but after refusing a neonatal autopsy some parents regret the loss of potential information, this ranges from 7% [43] of those declining autopsy to 30% [45]. Thorough explanations of the autopsy process are needed, particularly if parents are going to view their children again afterwards, sanitising explanations prior to autopsy may result in more distress later [44].

In Dent et al., some parents struggled to understand the autopsy results despite explanations from professionals [10]. Consistent with this finding other studies have shown parents not receiving autopsy results despite giving consent to the procedure; this happened in 4/13 intensive care deaths [23]. After sudden cardiac death some parents received autopsy results by post so lacked the opportunity to discuss the results with a clinician [16] and a study of paediatric autopsy reported that only 42/52 parents had results explained to them [32]. Parents have reported not understanding explanations of results and thus feeling that their questions remained unanswered [28,35]; this was the case for 8/16 mothers following neonatal autopsy [45] but in a much larger survey of neonatal autopsy 101/120 parents thought the results were explained appropriately and only 16/120 parents wanted further explanation [43].

#### **Parents want to feel supported by professionals**

**Emotional support** Parents felt supported by professionals who showed they were upset when breaking bad news; conversely they were offended if professionals were cold and unemotional. Many parents felt uncared for by the hospital immediately after their child's death often being left to arrange their own way home [9].

Consistent with the reference framework, other studies of all child deaths report that parents appreciate staff members showing emotion [15,19,27,30,46-48] and mothers interviewed after a neonatal death interpreted staff who lacked emotion as being uncaring [13]. Similarly other surveys reported on a lack of care shown to parents; 20% (83/413) of perinatally bereaved parents commented on a lack of sensitivity and care by their caregivers [28] and 37/70 parents were dissatisfied with hospital staff after road traffic accident deaths [36].

Other studies have given further details of parents' experiences of emotional support; doctors are valued as guiding parents through the crisis of their children's deaths [18,39], social workers and chaplains have been important to parents after intensive care deaths [23], police officers have been supportive with sudden deaths but their presence can be upsetting for some due to the implication that a crime may have occurred [16,35]. Parents may clearly remember interactions with professionals at the time of their children's deaths; later these memories may bring comfort or distress for both hospital [18] and community deaths [49].

Most parents wanted mementoes of their child but these were offered to less than half of families [10]. Other studies confirm the significance of these mementoes or returning a child's clothing and possessions after sudden deaths [33,50] or those on intensive care [23]; photographs may be particularly valued after a perinatal death [24].

**Emergency services** In the reference framework there were mixed findings with some but not all parents praising the police for their support [9]. In Dent et al., most parents were happy with the emergency services although 28% of parents thought the police unsympathetic and one-third of parents were not allowed to accompany their child in the ambulance [10].

Only 4 studies, all of SIDS, detailed parents' views of the police; these were similarly mixed. In one study 48% of parents thought the police were kind and helpful, but 30% felt they were unhelpful and treated parents as guilty and assumed that a crime had been committed [35]; another study commented on disproportionate police involvement [51]. Conversely, in Ireland, satisfaction with police services following SIDS is high with 86/100 parents finding police helpful [52] and 75% of 69 parents stating that police carried out the process of



identification sensitively [53]. These results are surprising given that there is a similar level of involvement by UK and Irish police in SIDS cases.

Only two other studies reported parents' views on ambulance services. 50% of 109 SIDS parents thought ambulance staff were helpful but 21% criticised ambulance staff for seeming to panic and being ill-equipped to deal with infants [35]. 41/80 parents were dissatisfied with ambulance services following road traffic accident deaths [36].

**Professional support** In Finlay and Dallimore, the most helpful support for parents was on-going contact with a professional present at the time of death [9]. In Dent et al., parents wanted more practical information about dealing with the bereavement and for professionals to remain in contact with them [10]. As in the reference framework, bereaved parents in other studies wanted continuing contact with medical teams both after sudden deaths and those in hospital [18,35,38,47]. This is particularly important after sudden deaths and suicides, as grief-stricken parents may feel unable to contact professionals themselves, suggesting contact should be offered routinely and continued for some months [16,47,54]. In interview studies parents have explained that they want professionals to show that they care about them and their family after the death [29,38,39], sharing memories of the child is an important part of this [29,39] as is attending funerals or offering formal condolences [18,30,35,39,40].

Parents in interview studies described feeling abandoned by professionals when contact stops after a child death having grown close to staff during prolonged hospital stays [12,18,38] or with the abrupt cessation of support services after deaths of children with intellectual disability [14,55]. Similar feelings of abandonment by professionals are also felt by parents after sudden cardiac death [16] or SIDS [35] despite their families not being known to services prior to the death.

**Follow-up of bereaved parents by physicians or other health professionals** In Finlay and Dallimore, only 16/120 families had any hospital follow-up [9]. In Dent et al., more than half of parents had no follow-up with a hospital paediatrician; of those who did 88% found it helpful. Very few families had formal follow-up with the GP or health visitor but all of these found this helpful [10].

Rates of hospital follow-up for bereaved parents were very variable ranging from 16% to 77% for SIDS [50,52], 77% for deaths on paediatric intensive care [56] and 92% for neonatal deaths [29]. Similar to the reference papers, in 13 studies parents stated that they would like more medical follow-up after all child deaths [14,17,18,27,29,31,38,47,50,57-60] and no study reported parents wanting less contact with professionals.

Although Dent et al. reported high rates of parental satisfaction with paediatric follow-up [10] lower rates were found in other studies: 56% and 63% for SIDS [35,58], 33% for perinatal deaths [25] and 62% for paediatric intensive care deaths [56]. Again, unlike in Dent et al., in one study only half of parents were satisfied with GP or health visitor follow-up after SIDS [35] although other parents have commented that they found comfort by talking to their health visitor as she had known the child in life [47]. Surveys of bereaved parents showed that parents appreciated follow-up appointments where paediatricians have explained the cause for infant deaths [57,58] and offered emotional support in the longer term [57,61]. For SIDS parents, such emotional support from professionals is associated with increased positive affect up to 5 years after the death [37]; however, not all parents will want emotional support [42].

**Good communication** In Finlay and Dallimore, twice as many parents said that the bad news had been broken in a sympathetic manner compared to those who did not [9]. In Dent et al., all parents reported that they had been told sensitively about their child's death [10].

Other surveys show varying rates of satisfaction with breaking bad news, from 46% following sudden deaths at any age to 62% following child deaths in road traffic accidents [36] and 87% after neonatal deaths [59]. Dissatisfaction after any sudden death in children or adults was mainly associated with a lack of information [17].

Other qualitative studies give further details from a wide range of child deaths. When breaking bad news professionals' language should be appropriate for the parents' to understand, not give false hope but not be so factual as to give offence; parents should be given time to assimilate information prior to addressing other issues [39,46]. Parents want to feel listened to at the time of the death [14,28] and subsequently [21,27]. Parents have reported that sometimes professionals lack compassion [39], dismiss their feelings [27], avoid parents [30], or show them outright hostility [27] and openly judge their lifestyles or parenting choices as their children lie dying [18]. Parents have also described actions by professionals that are inappropriate and insensitive: handing bereaved mothers routine well-baby information [13], suggesting infant deaths are 'God's Will' or that mothers can have another baby; and suggesting that parents should be satisfied as they have surviving infants in deaths following multiple pregnancies [21,30].

## Discussion

Our review found that parents wish to be able to say goodbye to their child at the hospital; staff need to ensure that families are welcomed and that they are given time and privacy to say their farewells. Receiving timely



and appropriate information about their child's death is an important part of the grieving process for parents. Parents value emotional support from professionals at the time of death and in the subsequent weeks and months. Parents appreciate follow-up appointments with professionals both to help them understand why their child died and as a way of offering continuing support to the family. These findings can be used by any professional supporting bereaved parents within health care, police or social services.

This review includes the experiences of over 4000 bereaved parents whose children died unexpectedly at any age. The review has highlighted considerable consistency in what parents report as their needs following an unexpected child death, despite differing ages of children and causes for deaths. There was a significant overlap in findings in many studies and theoretical saturation was reached before all papers were coded; thus it is unlikely that any significant themes have been missed. The review is however limited by the lack of papers published on interactions with police or other agencies so the findings may have limited applicability outside of health care. Most of the studies recruited mainly from white families with above average incomes; this may reduce the generalizability of the results as child deaths occur more commonly with social deprivation.

This literature review includes data on child deaths of all ages; the only comparable similar systematic reviews are of parents' experiences of perinatal deaths. These results are similar in that parents found holding their baby after death to be beneficial and wanted more information on why their baby died [62].

## Conclusions

It is clear from this literature review that parents would like to be offered more support from professionals after child death; the support should not finish when parents leave the hospital without their child. Hospital staff should be trained to support parents at the time of child death and policies put in place to ensure families are able to say goodbye to their child in a dignified way. Clinical staff should ensure that contact is maintained with bereaved parents and they are invited back for follow-up appointments to discuss their child's death as a matter of routine; no parent should be left with unanswered questions about their child's death.

As child death review (CDR) processes become more elaborate there remains the potential for this to become an intrusive process for the parents; although parents may obtain more information as to the cause of death, the enquiry process may increase their distress. CDR is now undertaken in many countries so the potential for parental distress is great. It is essential that all such processes are developed and delivered in ways that are

supportive to parents, help them to understand the reasons why their child died, and enable them to say goodbye to their child in an appropriate and supported way.

## Additional files

**Additional file 1: Table S1.** Critical Appraisal of quantitative studies.

**Additional file 2: Table S2.** Critical Appraisal of qualitative studies.

## Abbreviations

SIDS: Sudden infant death syndrome; CDR: Child death review.

## Competing interests

The authors declare that they have no competing financial interests in the manuscript. JG is funded as a Doctoral Research Fellow by the National Institute of Health Research (NIHR) to evaluate multi-agency working following Sudden Unexpected Death in Infancy; this funding has covered the costs of preparing this manuscript. PS is a Designated Doctor for unexpected child deaths and has published extensively on the investigation of unexpected child deaths and SIDS.

## Authors' contributions

JG performed the literature searches, selected articles for inclusion, critically appraised studies, extracted the data, performed the thematic analysis and prepared drafts of the manuscript. FE and PS conceived the idea, performed quality control, advised on the thematic analysis and amended earlier drafts of the manuscript. All authors read and approved the final draft of the manuscript.

## Authors information

JG is currently evaluating multi-agency working following Sudden Unexpected Death in Infancy. PS is a Designated Doctor for unexpected child deaths and has published extensively on the investigation of unexpected child deaths and SIDS.

## Acknowledgements

JG is funded as a Doctoral Research Fellow by the National Institute of Health Research (NIHR) to evaluate multi-agency working following Sudden Unexpected Death in Infancy; this funding has covered the costs of preparing this manuscript. NIHR have not had any other input into this manuscript. The views expressed in this publication are those of the authors and not necessarily those of NIHR.

## Author details

<sup>1</sup>Division of Mental Health and Wellbeing, Warwick Medical School, Coventry CV4 7AL, UK. <sup>2</sup>Division of Health Sciences, Warwick Medical School, Coventry CV4 7AL, UK.

Received: 13 May 2014 Accepted: 3 October 2014  
Published: 15 October 2014

## References

1. Dyregrov A, Dyregrov K: Long-term impact of sudden infant death: a 12- to 15-year follow-up. *Death Stud* 1999, **23**(7):635-661.
2. Vincent S: Child Death Review Processes: A Six-Country Comparison. *Child Abuse Rev* 2014, **23**(2):116-129.
3. Government HM: *Working Together to Safeguard Children*. London: DfES; 2013.
4. Sidebotham P, Pearson G: Responding to and learning from childhood deaths. *BMJ* 2009, **338**:b531.
5. Braun V, Clarke V: Using thematic analysis in psychology. *Qual Res Psychol* 2006, **3**(2):77-101.
6. Mays N, Popay J, Pope C: Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *J Health Serv Res Policy* 2005, **10**(1):6-20.
7. Ajetunmbi O: *Making Sense of Critical Appraisal*. London: Hodder Arnold; 2002.
8. CASP: *Critical Appraisal Skills Programme Qualitative Research Checklist*. In 14 October 2010 edn. 2010.



9. Finlay I, Dallimore D: Your child is dead. *BMJ* 1991, **302**(6791):1524-1525.
10. Dent A, Condon L, Blair P, Fleming P: A study of bereavement care after a sudden and unexpected death. *Arch Dis Child* 1996, **74**(6):522-526.
11. Petrou S, Kupek E, Hockley C, Goldacre M: Social class inequalities in childhood mortality and morbidity in an English population. *Paediatr Perinat Epidemiol* 2006, **20**(1):14-23.
12. Ashby MA, Kosky RJ, Laver HT, Sims EB: An enquiry into death and dying at the Adelaide Children's Hospital: a useful model? *Med J Aust* 1991, **154**(3):165-170.
13. Lemmer CM: Parental perceptions of caring following perinatal bereavement. *West J Nurs Res* 1991, **13**(4):475-489. discussion 489-493.
14. Reilly DE, Huws JC, Hastings RP, Vaughan FL: 'When your child dies you don't belong in that world anymore'. - Experiences of mothers whose child with an intellectual disability has died. *J Appl Res Intellect Disabil* 2008, **21**:546-560.
15. Meyer EC, Ritholz MD, Burns JP, Truog RD: Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics* 2006, **117**(3):649-657.
16. Wisten A, Zingmark K: Supportive needs of parents confronted with sudden cardiac death—a qualitative study. *Resuscitation* 2007, **74**(1):68-74.
17. Merlevede E, Sporeen D, Henderick H, Portzky G, Buylaert W, Jannes C, Calle P, Van Staey M, De Rock C, Smeesters L, Michem N, Van Heeringen K: Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death. *Resuscitation* 2004, **61**(3):341-348.
18. Meert KL, Briller SH, Schim SM, Thurston C, Kabel A: Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. *Death Stud* 2009, **33**(8):712-740.
19. Calhoun LK: Parents' perceptions of nursing support following neonatal loss. *J Perinat Neonatal Nurs* 1994, **8**(2):57-66.
20. Schaap AH, Wolf H, Bruinse HW, Barkhof-van de Lande S, Treffers PE: Long-term impact of perinatal bereavement. Comparison of grief reactions after intrauterine versus neonatal death. *Eur J Obstet Gynecol Reprod Biol* 1997, **75**(2):161-167.
21. Swanson P, Brockbank J, Houghton J, Mountbatten P, Read B, Ross A, Woodward J: Panel discussion. Grief and bereavement with the loss of a twin. *Twin Res* 2002, **5**(3):150-152.
22. Bellali T, Papazoglou I, Papadatou D: Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive Crit Care Nurs* 2007, **23**(4):216-225.
23. Macnab AJ, Northway T, Ryall K, Scott D, Straw G: Death and bereavement in a paediatric intensive care unit: Parental perceptions of staff support. *Paediatr Child Health* 2003, **8**(6):357-362.
24. Sexton PR, Stephen SB: Postpartum mothers' perceptions of nursing interventions for perinatal grief. *Neonatal New* 1991, **9**(5):47-51.
25. Neldig JR, Daigas-Pelish P: Parental grieving and perceptions regarding health care professionals' interventions. *Issues Compr Pediatr Nurs* 1991, **14**(3):179-191.
26. Skene C: Individualised bereavement care. *Paediatr Nurs* 1998, **10**(10):13-16.
27. Kuhn SK: The process of parental bereavement following the violent death of a child. PhD Thesis. Duquesne University; 2008.
28. Covington SN, Theut SK: Reactions to perinatal loss: a qualitative analysis of the National Maternal and Infant Health Survey. *Am J Orthopsychiatry* 1993, **63**(2):215-222.
29. McHaffie HE, Laing IA, Lloyd DJ: Follow up care of bereaved parents after treatment withdrawal from newborns. *Arch Dis Child Fetal Neonatal Ed* 2001, **84**(2):F125-F128.
30. Pector EA: How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased, and attachment to survivors. *J Perinatol* 2004, **24**(11):714-722.
31. Royal College of Pathologists, Royal College of Paediatrics and Child Health: Sudden Unexpected Death in Infancy: A multi-agency protocol for care and investigation. In *Royal College of Pathologists, Royal College of Paediatrics and Child Health*. 2004.
32. Sullivan J, Monagle P: Bereaved parents' perceptions of the autopsy examination of their child. *Pediatrics* 2011, **127**(4):e1013-e1020.
33. Oliver RC, Sturtevant JP, Scheetz JP, Fallat ME: Beneficial effects of a hospital bereavement intervention program after traumatic childhood death. *J Trauma* 2001, **50**(3):440-446. discussion 447-448.
34. Teklay B, Wive LB, Thomsen JL: Contact with relatives after forensic autopsies. *Ugeskr Læger* 2005, **167**(3):289-293.
35. Sterry L, Bathgate L: *Scottish Cot Death Trust Project Report*. Scottish Cot Death Trust; 2011.
36. Sporeen DJ, Henderick H, Jannes C: Survey description of stress of parents bereaved from a child killed in a traffic accident. A retrospective study of a victim support group. *Omega: J Death Dying* 2000, **42**(2):2000-2001.
37. Thuen F: Social Support after the Loss of an Infant Child: A Long-Term Perspective. *Scand J Psychol* 1997, **38**(2):103-110.
38. Meert KL, Eggly S, Pollack M, Anand KS, Zimmerman J, Cardillo J, Newth CIL, Dean JM, Willson DF, Nicholson C, National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network: Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit. *J Pediatr* 2007, **151**(1):50-55.
39. Bright KL, Huff MB, Hollon K: A broken heart—the physician's role: bereaved parents' perceptions of interactions with physicians. *Clin Pediatr (Phila)* 2009, **48**(4):376-382.
40. Macdonald ME, Liben S, Carnevale FA, Rennick JE, Wolf SL, Meloche D, Cohen SR: Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death. *Pediatrics* 2005, **116**(4):884-890.
41. McHaffie HE, Fowle PW, Hume R, Laing IA, Lloyd DJ, Lyon AJ: Consent to autopsy for neonates. *Arch Dis Childhood Fetal Neonatal Ed* 2001, **85**(1):F4-F7.
42. Vennemann MMT, Rentsch C, Bajonowski T, Zimmer G: Are autopsies of help to the parents of SIDS victims? A follow-up on SIDS families. *Int J Leg Med* 2006, **120**(6):352-354.
43. Rankin J, Wright C, Lind T: Cross sectional survey of parents' experience and views of the postmortem examination. *BMJ* 2002, **324**(7341):816-818.
44. Snowden C, Elbourne DR, Gaida J: Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents. *Arch Dis Childhood Fetal Neonatal Ed* 2004, **89**(3):F208-F211.
45. Rahman HA, Khong TY: Perinatal and infant postmortem examination. Survey of women's reactions to perinatal necropsy. *BMJ* 1995, **310**(6983):870-871.
46. Meert KL, Eggly S, Pollack M, Anand KS, Zimmerman J, Cardillo J, Newth CIL, Dean JM, Willson DF, Nicholson C: Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med* 2008, **9**(1):2-7.
47. Dent A: Support for families whose child dies suddenly from accident or illness. PhD Thesis. University of Bristol; 2000.
48. DiMarco MA, Menke EM, McNamara T: Evaluating a support group for perinatal loss. *MCN Am J Matern Child Nurs* 2001, **26**(3):135-140.
49. Nordby H, Nohr O: Interactive emergency communication involving persons in crisis. *J Telemed Telecare* 2009, **15**(7):351-355.
50. Ahrens W, Hart R, Maruyama N: Pediatric death: managing the aftermath in the emergency department. *J Emerg Med* 1997, **15**(5):601-603.
51. Livesey A: A multiagency protocol for responding to sudden unexpected death in infancy: descriptive study. *BMJ* 2005, **330**(7485):227-228.
52. McDonnell M, Cullen A, Kiberd B, Mehanini M, Matthews T: A national model of care service for professionals dealing with sudden infant death. *Irish Journal of Medical Science* 1999, **168**(4):237-241.
53. Powell M: Sudden infant death syndrome: a crisis for parents and health professionals. *Irish Journal of Medical Science* 1991, **160**(9):282-285.
54. Dyregrov K: Assistance from local authorities versus survivors' needs for support after suicide. *Death Studies* 2002, **26**(8):647-668.
55. Todd S: Silenced grief: living with the death of a child with intellectual disabilities. *Journal of Intellectual Disability Research* 2007, **51**(8):637-648.
56. Meyer EC, Burns JP, Griffith JL, Truog RD: Parental perspectives on end-of-life care in the pediatric intensive care unit. *Crit Care Med* 2002, **30**(1):226-231.
57. Harper MB, Wislan NB: Care of bereaved parents. A study of patient satisfaction. *J Reprod Med* 1994, **39**(2):80-86.
58. Ostfeld BM, Ryan T, Hlatt M, Hegyi T: Maternal grief after sudden infant death syndrome. *Journal of Developmental & Behavioral Pediatrics* 1993, **14**(3):156-162.
59. Krauel Vidal J, Silva Vazquez M, Ibanez Fanes M, Florensa Palau R, Moreno Hernandez J: [Attitude towards parents after the death of their newborn infant in a neonatal unit]. *Anales Espanoles de Pediatría* 1992, **36**(6):419-422.

<http://dx.doi.org/10.1186/1471-2431-14-269>

60. Hazzard A, Weston J, Gutierrez C: After a child's death: factors related to parental bereavement. *J Dev Behav Pediatr* 1992, **13**(1):24-30.
61. Laakso H, Paunonen-Himonen M: Mothers' experience of social support following the death of a child. *J Clin Nurs* 2002, **11**(2):176-185.
62. Gold KI: Navigating care after a baby dies: a systematic review of parent experiences with health providers. *J Perinatol* 2007, **27**(4):230-237.

doi:10.1186/1471-2431-14-269

**Cite this article as:** Garstang et al: What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature. *BMC Pediatrics* 2014 **14**:269.

**Submit your next manuscript to BioMed Central  
and take full advantage of:**

- Convenient online submission
- Thorough peer review
- No space constraints or color figure charges
- Immediate publication on acceptance
- Inclusion in PubMed, CAS, Scopus and Google Scholar
- Research which is freely available for redistribution

Submit your manuscript at  
[www.biomedcentral.com/submit](http://www.biomedcentral.com/submit)





## Appendix 2 Critical appraisal of quantitative studies

Table 33 Critical Appraisal of quantitative studies

Study	Statement of aims	Survey type	Development of survey questions	Piloting and Validation of survey	Sampling Frame and Design	Response rate	Efforts to improve response	Details of Socio-economic status of participants
<b>Ahrens et al. (1997)</b>	To identify healthcare provider actions that will facilitate bereaved families recovery	Postal questionnaire survey	Unknown method	Questionnaire reviewed by SIDS parents support group	Parents contacted from SIDS support group mailing list - risk of inherent bias, deaths up to 16 years prior to survey	62% 37/60 parents completed survey	no	None given
<b>Calhoun (1994)</b>	To confirm appropriateness of nursing interventions after death of infant	Questionnaire distributed by support group	Guided by previous research study	Questionnaire reviewed by expert panel and piloted with bereaved parents	Parents attending a parental loss support groups, risk of inherent bias as participants selected by support group co-ordinator	55% 23 complete surveys and 42 partially complete surveys included	no	Mean age 31 years, all parents married
<b>Dent et al. (1996)</b>	To establish parents views on care received after the sudden death of	Postal questionnaire survey	Advised by bereaved parents	Pilot study completed	Parents of any child dying suddenly in study area, risk of bias as GP needed to agree to family to be	58% GP agreed access to 72/185 eligible	no	None given

	their child				contacted, access denied in several cases	families, 42/72 families completed survey		
<b>Dent (2000)</b>	To see if a bereavement assessment tool helps HV to work with bereaved parents	Postal questionnaire survey	Advised by bereaved parents and experience Health Visitors	Pilot study completed	Parents of any child dying suddenly in study area notified by emergency departments or ambulance control.	59% 72/122 completed survey	1 reminder letter sent	Most parents married, all white british ethnicity
<b>DiMarco et al. (2001)</b>	To determine if attending a support group helps after perinatal loss	Postal questionnaire survey	Standardised tool used	Previously validated	Parents on mailing list of perinatal loss newsletter, some of whom attended support groups (not clear if parents had to opt in for newsletter)	32% 128/400 parents completed survey	2 reminder letters sent	Most participants white and married
<b>(Dyregrov, 2002)</b>	To describe what help suicide survivors want and receive	Postal questionnaire survey with interviews for a sample of participants	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire  Previously validated tool Kvale method for interviews and analysis	Parents of all suicide cases in 18 month period details obtained from police records	77% 128/166 parents completed survey	No	Participants similar to non-participants but no further details.

<b>Finlay and Dallimore (1991)</b>	To determine parents views on how the death of their child should have been handled	Postal questionnaire survey	Unknown method	Unknown	Parents who were members of bereavement support organisation, risk of inherent bias as only support group members participating	80% 120/150 families completed survey	no	None given
<b>Harper and Wisian (1994)</b>	To determine which physician behaviours are helpful to bereaved parents	Postal questionnaire survey or questionnaire distributed at support group	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	Parents referred to perinatal loss support group by hospital regardless of whether they were attendees or not	Unknown 37 families completed survey from unknown total	no	Mean age 30. Middle-lower income
<b>Hazzard et al. (1992)</b>	To determine which experiences of bereaved parents affect grief	Structured interview	Bespoke questionnaire similar to one published previously. Standardised tool also used	Unknown for bespoke questionnaire Previously validated tool	Parents of children dying in hospital in study period and from bereavement support group. Risk of bias as permission needed from doctors to contact parents only given in 88% of cases, and support group recruitment. Analysis showed non-responders similar to responders	Unknown 18/59 families from hospital and additional 16 parents from support group completed survey	Bereavement support group used to increase recruitment	51% parents >35 years, 65% earned > \$30K per annum
<b>Krauel Vidal</b>	To examine the	Postal	Unknown	Unknown	Parents of babies	27%	no	None given

<b>et al. (1992)</b>	care of parents when a baby dies on NNU	questionnaire survey	method		dying on NNU – no further details given	49/180 families completed survey		
<b>Laakso and Paunonen-Ilmonen (2002)</b>	To find tools to help healthcare workers support bereaved mothers	Questionnaire and structured interview	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	Parents of children dying in 4 year time period – no further details given	54% 91/169 parents completed survey	no	None given
<b>Livesey (2005)</b>	To see how a multi -agency SUDI protocol works in practice	Postal questionnaire survey as part of audit of practice	Unknown method	Unknown	Parents of all SUDI cases in study area in set time period	Unknown	no	None given
<b>Macnab et al. (2003)</b>	To determine which staff behaviours are helpful to parents of children dying on PICU	Questionnaire and structured interview	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	Parents of all local children dying on PICU in set time period, risk of bias as non-local families and coroners cases excluded	100% 13/13 families completed survey	Not needed	All approached participated but more than 50% had completed higher education
<b>McDonnell et al. (1999)</b>	To evaluate parents' experiences of services by professionals	Structured interview	Unknown method	Unknown	All parents from a national SIDS register	70% 131/188 families completed survey	no	None given

	after SIDS							
<b>Merlevede et al. (2004)</b>	To identify the needs of suddenly bereaved relatives	Structured interview and analysis of clinical records	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire  Previously validated tool	Relatives of all sudden death cases approached identified by hospital records. Non responders were relatives of older adult dead patients	48% 53/110 relatives completed interview	1 telephone call reminder	None given
<b>Meyer et al. (2002)</b>	To examine priorities of parents at time of child death on PICU	Postal questionnaire survey	Bespoke questionnaire based on clinical experience and literature review	Questionnaire reviewed by professionals and piloted with bereaved parents	Parents of all children dying on a PICU in 2 year time period	58% 56/96 families completed survey	no	Mean age 42, 75% married 91% Caucasian
<b>Neidig and Dalgas-Pelish (1991)</b>	To collect information from bereaved parents regarding health professionals' interventions	Postal questionnaire survey	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire  Previously validated tool	Convenience sample of parents from bereavement support group, risk of bias due to this, wide time frame of bereavement from months to many years	Unknown 22 parents completed survey from unknown total	no	All white, all completed high school, 57% completed higher education
<b>Oliver et al. (2001)</b>	To determine which initiatives helped bereaved parents	Structured interview	Unknown method	Unknown	All parents completing a hospital bereavement program, risk of bias dropouts not recruited	70% 54/77 families completed survey	No	None given

<b>Ostfeld et al. (1993)</b>	To better understand characteristics and resources that effect the grieving process after SIDS	Postal questionnaire survey	Questionnaire based on similar SIDS one used by authors previously	Questionnaire based on similar SIDS one used by authors previously	Parents from a statewide SIDS support group, whose baby died in set time period, risk of bias from support group recruitment	44% 38/86 families completed survey	no	Responders older than non responders
<b>Powell (1991)</b>	To assess if the presence or absence of social support influences outcome for SIDS parents	Structured interview	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	Parents of all SIDS cases in one region, data from national register.	66% 40/61 families completed survey	no	None given
<b>Rahman and Khong (1995)</b>	To learn of bereaved parents views on perinatal autopsy	Telephone questionnaire survey	Unknown method	Unknown	Mothers of infants dying in perinatal period; details from a hospital list.	Unknown 29 mothers completed survey	no	None given
<b>Rankin et al. (2002)</b>	To describe bereaved mothers experience and views of infant autopsy	Postal questionnaire survey	Unknown method	Unknown	Mothers attending a hospital bereavement service – inherent risk of bias	63% 166/258 mothers completed survey	2 reminders sent	Mean age 32
<b>Royal College of</b>	To seek parents views on SIDS	Postal questionnaire	Unknown method	Unknown	Parents on mailing list of support group and	28% 893/3200	no	None given

<b>Pathologists and Royal College of Paediatrics and Child Health (2004)</b>	national support group campaign for improved SUDI investigation	survey and comments made to support group by other parents			all comments made to national support group by parents in one year. Inherent risk of bias but huge survey	families completed survey and further 1046 other contacts from parents		
<b>Sexton and Stephen (1991)</b>	To determine maternal perceptions of nursing interventions for bereavement support	Telephone questionnaire survey	Questionnaire development guided by literature review	Unknown	Mothers attending perinatal bereavement support programme– inherent risk of bias	54% 30/56 mothers completed survey	no	23% of mothers 23 years or younger
<b>Spooren et al. (2000)</b>	To assess parents views on support received at time of child's death from RTA	Postal questionnaire survey	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	All parents on mailing list of national support group for families of children killed in RTA. Risk of bias from mailing list recruitment. Deaths of adult children included.	41% 55/133 families completed survey	no	None given
<b>Sullivan and Monagle (2011)</b>	To explore bereaved parents' views on autopsy	Postal questionnaire survey	Questionnaire development guided by literature review and	Bespoke questionnaire reviewed by bereaved parents.	Parents on mailing list of bereavement support newsletter who then requested to receive the	Unknown 53 families completed survey. 831 families	no	None given

			clinical practice, also standardised tool	Previously validated tool	questionnaire about experience of autopsy. Risk of bias from mailing list recruitment.	on mailing list		
<b>Sterry and Bathgate (2011)</b>	To report bereaved families experiences following SUDI	Internet or postal questionnaire survey	Unknown method	Unknown	All parents on mailing list of national support group for SIDS – inherent risk of bias. Wide time frame of bereavement from months to many years	22% 109/487 families Completed survey	no	None given
<b>Teklay et al. (2005)</b>	To see how often relatives seek the results of forensic autopsy	Case record review by pathology department	Not applicable	Not applicable	All forensic autopsy cases in one year in department. Includes adult deaths.	All 380 cases included	Not applicable	Not applicable
<b>Thuen (1997)</b>	To assess the relationship between support and long-term psychological adaption of bereaved SIDS parents	Postal questionnaire survey	Unknown method for bespoke questionnaire, also standardised tool	Unknown for bespoke questionnaire Previously validated tool	Parents on mailing list of national SIDS support group. Risk of bias from mailing list recruitment. Wide time frame of bereavement from months to many years	27% 169/630 families competed survey	no	86% of parent still married, mean education duration 13 years



<b>Vennemann et al. (2006)</b>	To assess bereaved parents views about autopsy following SIDS	Postal questionnaire survey	Unknown method	Unknown	Parents recruited from those taking part in previous national SIDS study.	38% 141/373 families completed survey	1 reminder sent	Participants were of higher SES than non-participants, but otherwise similar
--------------------------------	---	-----------------------------	----------------	---------	---	---------------------------------------	-----------------	--



## Appendix 3 Critical appraisal of qualitative studies

Table 34 Critical Appraisal of qualitative studies

Study	Statement of research aims	Appropriate research design	Recruitment strategy appropriate	Does data collection address research issue	Relationship between researcher and participants	Ethical Issues	Rigorous data analysis	Details of Socio-economic status of participants
<b>Ashby et al. (1991)</b>	To enquire into the management of children who are dying and their families	Interviews with staff and parents, written submissions	Not stated how families recruited	No details given	Not stated who carried out interviews	Not stated	No qualitative analysis undertaken, results purely descriptive	None given
<b>Bellali et al. (2007)</b>	To identify needs and expectations of parents from health care professionals around the time of child organ donations	In-depth interviews with parents	Families identified through medical records of children dying as potential organ donors	In-depth interviews at parental home, recorded and transcribed	Interviews piloted No description of interviewer	Mental health follow-up arranged for parents if needed, ethical guidelines followed	Detailed description given, analysis by 3 researchers	None given
<b>Bright et al. (2009)</b>	To enhance understanding of	Open ended questions at	All bereaved parents on	Not stated	No face to face contact	Ethical approval	Nvivo software used no further	45% of parents were college

	how bereaved parents feel about interactions with physicians at the time of child death	end of postal survey	statewide mailing list approached			obtained for study	details given	grads, 97% were white
<b>Covington and Theut (1993)</b>	To analyse the answers of bereaved mothers to an open-ended question	Open-ended question on national & infant health survey	Survey sent to >8000 bereaved mothers, 400 answered open-ended question	Not stated but very wide question used	No face to face contact	Not stated	2 authors analysed data, no further details given	None given
<b>Kuhn (2008)</b>	What is bereavement process of parents following violent death of a child?	In-depth interview with parents	Parents contacted via victims crime unit office	In depth interviews at parental home or location of their choice. Interviews recorded and transcribed. Data saturation reached	Discussed – little detail given	Ethical approval obtained for study. Counsellor available for participants if needed	Grounded theory used, solo analysis (PhD thesis)	7/11 parents completed high school, all were white
<b>Lemmer (1991)</b>	What do perinatally bereaved parents perceive as care-giving from nurses or	In –depth interviews with parents	Parents contacted via hospital or bereavement support groups	In depth interviews at parental home or location of their choice. Interviews recorded and	Interviews piloted No description of interviewer	Ethical approval obtained for study.	Grounded theory used, 2 authors analysed data, full details of analysis given	Parents had higher than average income, mean of 14 years education for mothers, 15

	physicians?			transcribed				years for fathers
<b>Macdonald et al. (2005)</b>	To understand experiences of parents whose children die on PICU	Field ethnography method	Parents contacted via hospital list of deaths	In depth interviews at parents' home or location of their choice. Interviews recorded and transcribed, extensive field notes used	Details of interviewers given, relationship not further discussed	Ethical approval obtained for study	Whole team worked on analysis, full details given	Multicultural sample of parents
<b>McHaffie et al. (2001a)</b>	To determine parents views on autopsy after withdrawal of treatment on NNU	In –depth interviews with parents	Parents recruited from neonatal follow-up interview	Location of interview not stated. Interviews recorded and transcribed	Not stated	Ethical approval obtained for study	Sample of data coding checked for consistency with other authors. No further details of analysis	More teenagers and unemployment in non - participants than participants but still reflective of neonatal unit population
<b>McHaffie et al. (2001b)</b>	To explore parents perceptions of bereavement care following a death on NNU	Secondary analysis of data from McHaffie, Fowlie et al. (2001						
<b>Meert et al. (2007)</b>	To investigate parents perceptions of	In-depth interviews with parents	All parents of children dying on	Telephone interview, recorded and	Research assistants conducted	Ethical approval obtained for	Analysed by 2 authors, doctor and behavioural	75% of parents were white, 52% were

	desirability of a conference with the physician after child death on PICU		PICU in preceding 12 months approached	transcribed. Interview guide led by literature review, piloted. Data saturation reached	interviews, quality control by authors	study	scientist independently, 3 <sup>rd</sup> person checked sample for consistency. Bereaved parents reviewed analysis. Software used, thematic analysis, Full details given.	college graduates, 70% were married, employed or homemaker
<b>Meert et al. (2008b)</b>	To describe parents perspectives on physician communication at time of child death on PICU	Secondary analysis of data from Meert, Eggly et al. (2007)						
<b>Meert et al. (2009)</b>	To gain a greater understanding of parents needs around the time of child death on PICU	In-depth interviews with parents, focus groups with bereaved parents	All parents of children dying on PICU in 6 month period approached	Interview guide based on previous research and literature. Interviews and focus groups in hospital, videotaped and transcribed	Interview by PICU physician and chaplain jointly, focus group lead by medical anthropologist	Ethical approval obtained for study	Thematic analysis, full research team involved in process, full details given.	Individual parents 55:45 white: black, focus group 85:15 white: black

<b>Meyer et al. (2006)</b>	To identify parents priorities for end of life care	Open ended questionnaire sent to bereaved parents	All parents on children dying on PICU in 2 year period	Questionnaire based on clinical experience and literature review. Piloted	No face to face contact	Ethical approval obtained for study	No analysis of open –ended answers quotes given verbatim in report	75% were married, 91% were white
<b>Nordby and Nohr (2009)</b>	To understand how parents experience communication, care and empathy with emergency telephone operators	Semi-structured interviews	Bereaved parents recruited via national SIDS support group – random selection but 6 urban 5 rural	Discussion of methodology and theoretical perspectives but no further detail given	Not stated	Not stated	Not stated	Mix of urban and rural cases
<b>Pector (2004)</b>	To elicit bereaved multiple birth parents perceptions regarding support	Narrative email survey	Bereaved parents recruited via support groups and websites	No details of how survey developed	No face to face contact.	Ethical approval not required for internet survey.	Eaves grounded theory approach used. Transcription checked with participants. Single author analysis	Most parents were married
<b>Reilly et al. (2008)</b>	To learn of the experiences of bereaved parents whose child had an intellectual	In-depth interviews	Bereaved parents recruited from support groups,	Interview schedule developed from published questionnaire,	Interviewer was research student with experience of ID,	Ethical approval obtained for study	Interpretive Phenomenological Analysis used, 2 researchers	None given

	disability (ID)		charities and hospices. Homogenous sample from bigger study	piloted	discussed in detail		analysed results	
<b>Schaap et al. (1997)</b>	To describe long term effects after perinatal death	In-depth interviews with parents	Bereaved parents who had taken part in previous perinatal study contacted via GP	No details of how interview schedule developed, interview recorded and transcribed	Not stated	Ethical approval obtained for study	No details given	None given
<b>Skene (1998)</b>	To hear individual stories of bereaved mothers	Semi-structured interviews with bereaved mothers	Bereaved mothers from one regional neonatal unit	Interview schedule guided by literature review, piloted. Interviews recorded and transcribed	Role of interviewer discussed	Ethical approval obtained for study	Coded and themes described by single author. No further details given.	None given
<b>Snowdon et al. (2004)</b>	To report attitudes of neonatally bereaved mothers to autopsy	Semi-structured interviews with bereaved mothers	Bereaved parents of neonates who had been part of medical trial. Access to parents via	Interview schedule guided by literature review. Interviews recorded and transcribed	Not stated	Ethical approval obtained for study	Analysed by identifying and grouping themes by research team, computer software used. No further	None given



			neo- natologists (with some difficulties)				details given	
<b>Swanson et al. (2002)</b>	To study nature of bereavement in mothers of dead multiple birth child	Semi- structured interviews with bereaved mothers	Mothers recruited via multiple birth child health study and bereavement groups	Interview schedule developed from literature and refined after first 10 interviews. Interviews recorded and transcribed. Location not given.	Not stated	Ethical approval obtained for study	No details of qualitative analysis given. Results checked with bereaved mothers in focus groups	All parents were white and English speaking with wide range of socioeconomic status
<b>Todd (2007)</b>	To examine the bereavement experiences of parents of children with intellectual disabilities (ID)	In-depth interviews with bereaved parents of children with ID	Recruited via newsletter and personal contacts (support groups for ID unsuccessful)	Not stated how interview schedule developed. Interview in parents' home Interviews recorded and transcribed.	Role of interviewer discussed	Ethical approval obtained for study	Grounded theory used. Analysis and interviewing con-current. Full details given	None given
<b>Wisten and Zingmark (2007)</b>	To elucidate perceived support and understand parents needs	In –depth interviews with bereaved parents	Purposive sample of parents from study on sudden	Not stated how interview schedule developed. Interview in	Not stated	Ethical approval obtained for study, ethical issues	Content analysis method used, 2 authors analysed data.	None given

after sudden cardiac death	cardiac death	parents' home Interviews recorded and transcribed.	discussed.
-------------------------------	------------------	---	------------



## Appendix 4 In-depth interview schedules for parents' and professionals' interviews.

### WM SUDI study qualitative parental interview questions

Infant study reference number.....

Name of Baby	
Other names baby was known by	
Date of Birth	
Date of Death	
Age at Death	
Time between death and interview	

Location of Interview	
Date of Interview	
Start time of interview	
Finish time of interview	

Names of those present at interview	Relationship to baby	Age

**Introductory questions:**

1. Tell me about your pregnancy with *name*?
2. How was the birth, when did you go home?
3. What was *name* like as a baby?

**Events at the time of death:**

4. What happened when *name* died?
5. What happened at the hospital?

**Home visit:**

6. Who came to see where *name* died? Was it the police? Was a doctor with them?
7. What did they do in your home?
8. How did you feel about it at the time?
9. How do you feel about it now?
10. If there was anything different that the police or doctor could have done what would it be?
11. Is there anything else you want to tell me about the police and doctor's visit?

**Follow-up:**

12. Did the children's doctor or other professional come and see you at home to discuss why *name* died?
13. Were you offered a hospital appointment to discuss this instead?
14. Would you have liked an appointment?
15. How did you feel about the follow-up visit or appointment?

**Knowledge of cause of death:**

16. Can you explain to me what you understand of why *name* died?
17. Who explained about *name*'s death to you and when?

**Parental health following the death:**

18. How would you describe your health after *name*'s death?
19. How is your health now?

**Fathers' experiences:**

20. How did you react to *name*'s death? Was this different to your partner's reaction?
21. How did other people treat you? Was it different to your partner?

## WM SUDI Study follow-up qualitative parental interview schedule

Infant study reference number.....

Name of Baby	
Other names baby was known by	
Date of Birth	
Date of Death	
Age at Death	
Time between death and interview	
Date of original WMSUDI interview	

Location of Interview	
Date of Interview	
Start time of interview	
Finish time of interview	

Names of those present at interview	Relationship to baby	Age

## **Interview Guide**

### ***Introductory Questions***

1. How have things been since we last met? How are you now?

### ***Changes in Childcare Practice (For families with new babies:)***

2. How have you found caring for *new name*?
3. Are you doing anything differently to before?

### ***Parental Wellbeing***

4. How has your physical and emotional health been since we last met?
5. Have you made any changes to your lifestyle or family life that you might not have made if *name* was still alive?
6. Do you think you have changed as a person as a result of *name's* death? How much of this change do you think is due to *name's* death?

### ***Views on events of the Joint Agency Approach***

7. Have your thoughts on what happened with the police, doctors, social workers or anyone else involved after s/he died changed?
8. Has the way you think about police, doctors or social workers changed as a result of *name's* death?
9. What is your understanding of why *name* died?

### ***Use of support services***

10. Have you been to any counselling or bereavement services? Did you find this helpful?

### ***CDOP Process***

11. Did you have any involvement with the Child Death Overview Panel? How did you find this process?

### ***Alcohol and Tobacco***

12. Can you tell me how much alcohol (if any) you drink each week at present?
13. Can you tell me how many cigarettes (if any) you smoke each week at present?

## West Midlands SUDI Study Professional interview schedule

Name of Professional	
Agency	
Work base	
Date of Interview	
Reference number of infant case	

### Professional Background

1. How long have you worked with SUDI cases for?
2. How many cases have you managed according to the joint agency approach?

*All the following questions refer to the case of baby reference number ..... Please try to answer the questions without disclosing confidential case information.*

### Police and Paediatricians only

3. Did you take part in a joint home visit? If not why not?
4. Did you find this joint home visit useful? If not why not?

### All Agencies

5. Was there a final case discussion? Were you able to attend? If not why not?
6. Did you find the case discussion useful? If not why not?

### Paediatricians only

7. Did you inform the family of the results of the case discussion? How? If not how were they informed?
8. How did you find this process?
9. Have you arranged further follow-up for the family?

### All Agencies

10. How did you feel that the multi-agency process worked in this case?
11. What do you think were the most useful elements (if any) of the joint agency approach in investigating this case?
12. What do you think were the least useful elements (if any) of the joint agency approach in investigating this case?
13. Were there any particular difficulties with the joint agency approach in this case?
14. Is there anything that you would have wanted to have done differently in this case? Why?
15. Do you have any further views on the joint agency approach that you would like to share?



## Appendix 5 Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)

---

Please read each item below and circle the number next to the reply that comes closest to how you have been feeling **in the past week**. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

---

I feel tense or wound-up

1. **Most of the time**
2. **A lot of the time**
3. **From time to time, occasionally**
4. **Not at all**

I feel as if I am slowed down

1. **Nearly all the time**
2. **Very often**
3. **Sometimes**
4. **Not at all**

I still enjoy the things I used to enjoy

1. **Definitely as much**
2. **Not quite so much**
3. **Only a little**
4. **Hardly at all**

I get a sort of frightened feeling like 'butterflies' in the stomach

1. **Not at all**
2. **Occasionally**
3. **Quite often**
4. **Very often**

I get a sort of frightened feeling as if something awful is about to happen

1. **Yes, definitely and quite badly**
2. **Yes, but not too badly as I should**
3. **A little, but it doesn't worry me much care**
4. **Not at all as ever**

I have lost interest in my appearance

1. **Definitely**
2. **I don't take as much care**
3. **I may not take quite as**
4. **I take just as much care**

I can laugh and see the funny side of things

1. **As much as I always could**
2. **Not quite as much now**
3. **Definitely not so much now**
4. **Not at all**

I feel restless as if I have to be on the move

1. **Very much indeed**
2. **Quite a lot**
3. **Not very much**
4. **Not at all**

Worrying thoughts go through my mind

- 1. A great deal of the time**
- 2. A lot of the time**
- 3. Not too often**
- 4. Very little**

I look forward with  
enjoyment to things

- 1. As much as I ever did**
- 2. Rather less than I used to**
- 3. Definitely less than I used to**
- 4. Hardly at all**

I feel very cheerful

- 1. Never**
- 2. Not often**
- 3. Sometimes**
- 4. Most of the time**

I get sudden feelings of panic

- 1. Very often indeed**
- 2. Quite often**
- 3. Not very often**
- 4. Not at all**

I can sit at ease and feel relaxed

- 1. Definitely**
- 2. Usually**
- 3. Not often**
- 4. Not at all**

I can enjoy a good book or radio or TV  
programme

- 1. Often**
- 2. Sometimes**
- 3. Not often**
- 4. Very seldom**

Please check that you have answered ALL the questions. Thank you

ZIGMOND, A. S. & SNAITH, R. P. 1983. The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67, 361-70.

## Appendix 6 Parental structured interview or self-completion questionnaire

Version 4 dated 10/11/11

Name of baby	
Date of Birth	

Name of parent		
Age of parent		
Date questionnaire completed		
Questionnaire completed by - please circle correct answer	mother	father

**Please complete the questionnaire by yourself. There is one copy of the questionnaire for each parent.**

**This questionnaire is about how you thought and felt about the professionals ( for example police, doctors, nurses, social workers) at the hospital and who might have visited you at home after your baby died.**

**1a** Was your baby taken to hospital? Yes/No *please circle correct answer*

If no - where was your baby taken to?

.....

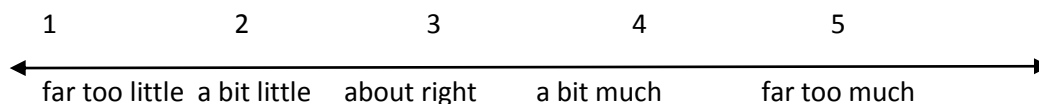
*If your baby was not taken to hospital after they had died please go straight to question 2a.*

**1b** Which hospital was your baby taken to? .....

**1c** Did the ambulance or hospital staff try to resuscitate (do CPR/ heart massage) your baby? Yes/No/Not sure *please circle correct answer*

**1d** Did you have the opportunity to hold your baby after treatment had been stopped at the hospital? Yes/No/Not sure *please circle correct answer*

**1e** Using a scale of 1 -5 with 1 being far too little time, 3 being about right and 5 being far too much time, how much time would you have liked to have had to hold your baby after treatment had been stopped?



**1f** Is there anything else you want to say about holding your baby in hospital after treatment had been stopped? Please write it in the space below (you can continue on another piece of paper if needed)

.....  
.....  
.....

**1g** Did a children's doctor (paediatrician) talk to you after your baby died?

Yes/No/Not sure *please circle correct answer*

**Other children at home?** Yes/No/Not sure *please circle correct answer*

.....

What would happen next, for example the police and doctor visiting you at home

.....

1 2 3 4 5

very uncaring a bit uncaring neutral a bit caring very caring

11. Using a scale of 1 to 5, with 1 being very uncaring, 3 being neutral (neither caring or uncaring) and 5 being very caring:

How caring do you think the police at the hospital were towards you when your baby died? (There is another question later about the police who visited you at home)  
*please circle the number to show how helpful you think they were*

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
←				→
very uncaring	a bit uncaring	neutral	a bit caring	very caring

**1m** If there is anything else you want to say about your time in hospital please write it in the space below.

.....

.....

**2a** Did the police come and visit you at home and see where your baby died?

Yes/No/Not sure *please circle correct answer*

**2b** Did a specialist children's doctor (paediatrician) or nurse visit you at home and see where your baby died?

Yes/No/Not sure *please circle correct answer*

**2c** Did the specialist children's doctor (or nurse) visit you with the police?  
*please circle correct answer*

Yes with police / Yes but not with the police / No /Not sure

**2d** Did anyone else visit you with the police?

Yes/No/Not sure *please circle correct answer*

If yes was it the: *please circle correct answer*

Midwife/ Health Visitor/ Family Doctor/Someone else - please write below who

.....

**2e** How long after your baby's death did the police visit? *please circle correct answer*

same day / next day/did not visit/ later - please write below how many days

.....

**2f** How long after your baby's death did the specialist children's doctor (or nurse) visit?

*please circle correct answer*

Same day/ next day / did not visit/later -please write below how many days

.....

**2g Did any other professional visit you at home about your baby's death?**  
*please circle correct answer*  
**Midwife / Health Visitor/ Family Doctor / Coroner's Officer / other person/ no**  
**one**

**If other person please write who .....**

**2h How long after your baby's death did the other professional visit?**  
*please circle correct answer*  
**Same day/ next day / did not visit/ later -please write below how many days**  
.....

*Question 3a-d are about the specialist children's doctor or nurse visiting you at home after your baby's death. If the specialist children's doctor or nurse did not visit you please go to question 4 a*

*These questions are about your experience at the time of the visit and now looking back.*

**3a. Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

How helpful did you find it, at the time, to have a specialist children's doctor (paediatrician) or nurse visit you at home to talk about your baby's death?  
*please circle the number to show how helpful you think they were*

**1    2    3    4    5**  
←-----→  
very unhelpful      a bit unhelpful      neutral      a bit helpful      very helpful

**3b Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

How intrusive did you find it, at the time, to have a specialist children's doctor (paediatrician) or nurse visit you at home to talk about your baby's death?  
*please circle the number to show how intrusive you think they were*

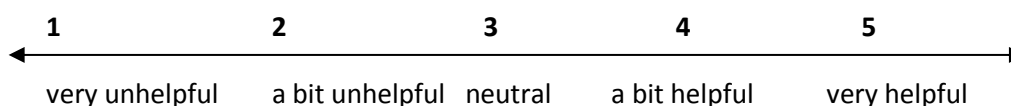
**1    2    3    4**  
←-----→  
very intrusive      quite intrusive      a very little intrusive      not intrusive at all

**3c. This question is about how your feelings about the professionals visiting you at home may have changed over time.**

**Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

Thinking about the specialist children's doctor (paediatrician) or nurse visit now, how helpful did you find the visit?

*please circle the number to show how helpful you think they were*

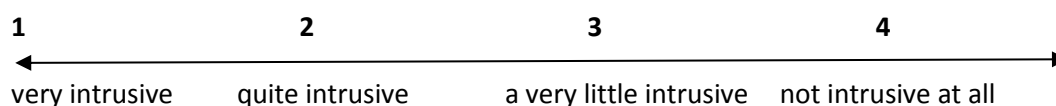


**3d** This question is about how your feelings about the professionals visiting you at home may have changed over time.

**Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

Thinking about the specialist children's doctor (paediatrician) or nurse visit now, how intrusive did you find the visit?

*please circle the number to show how intrusive you think they were*

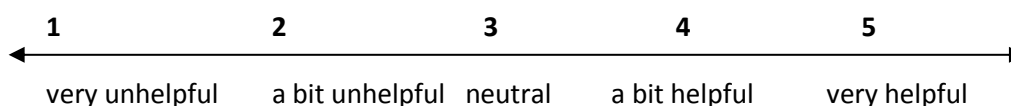


*Question 4a - b are about what you might have felt if a specialist children's doctor or nurse did not visit you at home after your baby's death. If a specialist children's doctor or nurse did visit you at home after your baby's death please go to question 5a.*

**4a** Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:

How helpful do you think it would be to have a specialist children's doctor (paediatrician) or nurse visit you at home, after your baby's death?

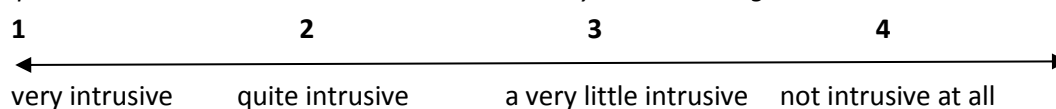
*please circle the number to show how helpful you think it might be*



**4b** Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:

How intrusive do you think it might be to have a specialist children's doctor (paediatrician) or nurse visit you at home, after your baby's death?

*please circle the number to show how intrusive you think it might be*





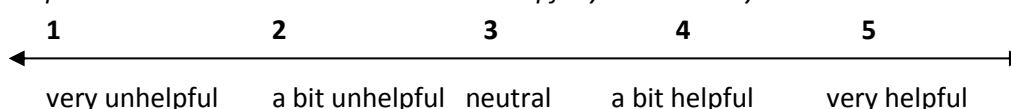
Questions 5a-d are about the police visiting you at home about your baby's death. If the police did not visit you at home after your baby's death please go straight to question 6a.

These questions are about your experience at the time of the visit and now looking back.

**5a. Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

How helpful did you find it, at the time, to have the police visit you at home to talk about your baby's death?

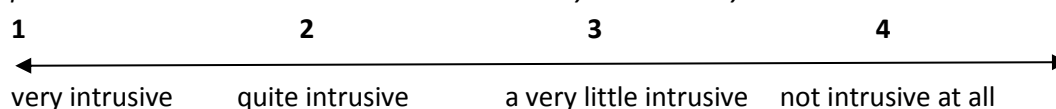
*please circle the number to show how helpful you think they were*



**5b Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

How intrusive did you find it, at the time, to have the police visit you at home to talk about your baby's death?

*please circle the number to show how intrusive you think they were*

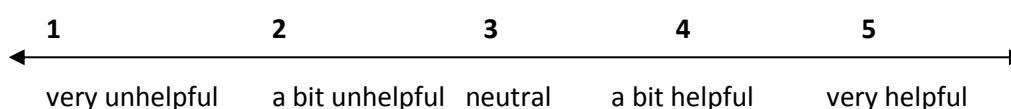


**5c.** This question is about how your feelings about the professionals visiting you at home may have changed over time.

**Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

Thinking about the police visit now, how helpful did you find the police visit?

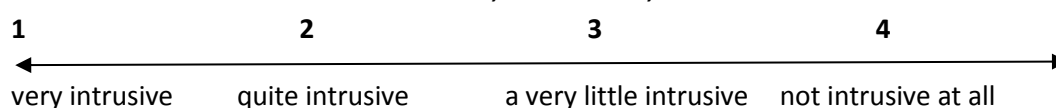
*please circle the number to show how helpful you think they were*



**5d** This question is about how your feelings about the professionals visiting you at home may have changed over time.

**Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

Thinking about the police visit now, how intrusive did you find the police visit? *please circle the number to show how intrusive you think they were*



**6a** Have any other professionals, for example the Coroner's Officer, Health Visitor, family doctor or midwife, visited you some days or weeks later to talk about your baby's death?

*please write down which professionals visited you*

.....

.....

*If no other professionals visited you please go on to question 7a*

**For each professional (apart from police and specialist children's doctor or nurse) please say how helpful or intrusive you found them.**

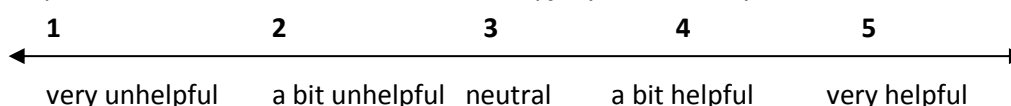
**6b** Type of professional (midwife, coroner's officer etc)

.....

**Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

How helpful did you find the professional's visit?

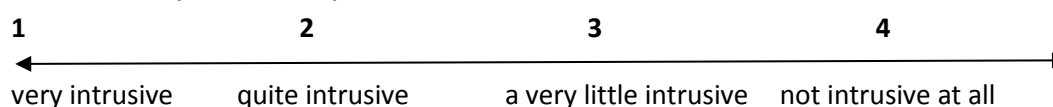
*please circle the number to show how helpful you think they were*



**Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

How intrusive did you find the professional's visit? *please circle the number to show*

*how intrusive you think they were*



***If no other professionals visited you please go on to question 7a***

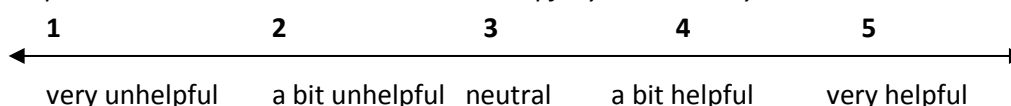
**6c** Type of professional (midwife, coroner's officer etc)

.....

**Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:**

How helpful did you find the professional's visit?

*please circle the number to show how helpful you think they were*



**Using a scale of 1 to 4, with 1 being very intrusive and 4 being not intrusive at all:**

How intrusive did you find the professional's visit? *please circle the number to show*

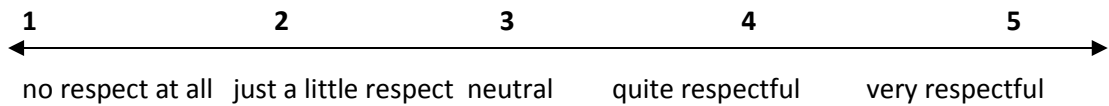
*how intrusive you think they were*



**7c** For any other professional who visited you about your baby's death. Please write down the type of professional (for example midwife)

.....

**Using a scale of 1 to 5 with 1 being no respect at all, 3 being neutral (neither lack of respect or respectful) and 5 being very respectful:**

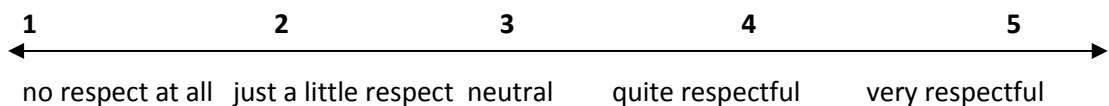


**If no more professionals visited please go to question 8a.**

**7d** For any other professional who visited you about your baby's death. Please write down the type of professional (for example midwife)

.....

**Using a scale of 1 to 5 with 1 being no respect at all, 3 being neutral (neither lack of respect or respectful) and 5 being very respectful:**

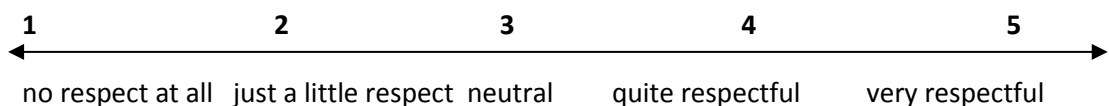


**If no more professionals visited please go to question 8a.**

**7e** For any other professional who visited you about your baby's death. Please write down the type of professional (for example midwife)

.....

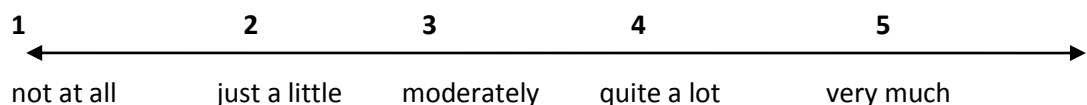
**Using a scale of 1 to 5 with 1 being no respect at all, 3 being neutral (neither lack of respect or respectful) and 5 being very respectful:**



Questions 8a -e are about how much the professionals listened to what you had to say when they came to visit you after your baby's death. Please answer for each professional who visited you.

**8a Using a scale of 1 to 5 with 1 being not at all and 5 being very much:**

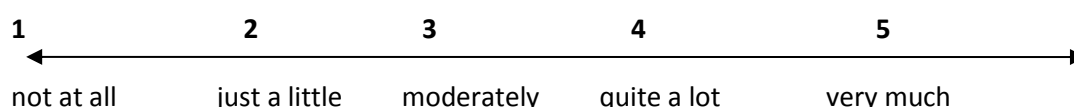
How much did the police listen to you when they visited?



**If no more professionals visited please go to question 9a.**

**8b Using a scale of 1 to 5 with 1 being not at all and 5 being very much:**

How much did the specialist children's doctor (or nurse) listen to you when they visited?



**If no more professionals visited please go to question 9a.**

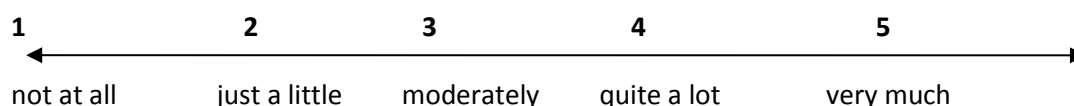
**8c** For any other professional who visited you about your baby's death.

Please write down the type of professional (for example midwife)

.....

**Using a scale of 1 to 5 with 1 being not at all and 5 being very much:**

How much did the professional listen to you when they visited?



**If no more professionals visited please go to question 9a.**

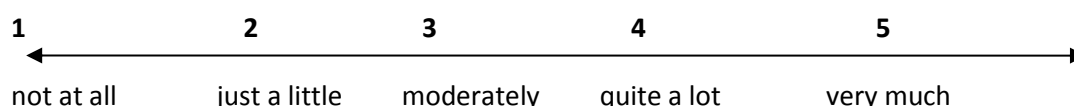
**8d** For any other professional who visited you about your baby's death.

Please write down the type of professional (for example midwife)

.....

**Using a scale of 1 to 5 with 1 being not at all and 5 being very much:**

How much did the professional listen to you when they visited?



**If no more professionals visited please go to question 9**

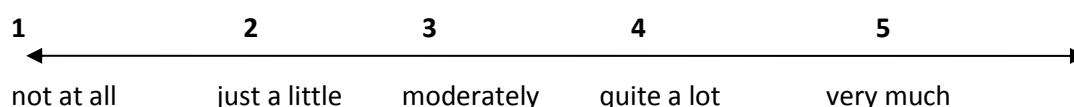
**8e** For any other professional who visited you about your baby's death.

Please write down the type of professional (for example midwife)

.....

**Using a scale of 1 to 5 with 1 being not at all and 5 being very much:**

How much did the professional listen to you when they visited?



9 If you have any other views about professionals visiting you at home to talk about your baby's death please write them down here (please continue on another piece of paper if you would like)

.....

.....

.....

**Questions 10a-c are about how much you understand of why your baby died.**

**10a Do you know why your baby died?**

*please circle answer*

Yes, quite clearly / I have some idea but I am not quite sure/ No, I have little idea

**10b** Please write down what you understand of why your baby died, for example, she died of a heart problem that had not been known about before.

.....

.....

.....

**10c Who explained to you what your baby died of?**

*please circle answer*

**Specialist children's doctor or nurse/ Family Doctor / Police / Coroner's Officer  
/Someone else / No one did**

If someone else explained why your baby died please write down who this was

.....

Questions 11a- d are about the Coroner's inquest into your baby's death.

**11a Was there an inquest into your baby's death? Yes/No/Not sure**

*please circle answer*

**11b Did you attend the inquest? Yes/No**

*please circle answer*

**11c Do you know the outcome of the inquest? Yes/No/Not sure**

*please circle answer*

**11d** If you know the outcome of the inquest please write it down

.....

**11e** If there is anything else you want to say about the Coroner's inquest please write it down in the space below

.....

.....

Questions 12 a -c are about your health after your baby's death

**12a** Have you had any health problems yourself, after your baby's death? Health problems include mental health difficulties such as anxiety, panic attacks or depression, as well as physical health problems such as asthma and back pain.

**Yes/No**

*please circle answer*

**12b** Compared to your health before your baby died, is your health the same, better or worse?

**Same/Worse/Better**

*please circle answer*

**12c** Please complete the table below with details of the health problems you have had since your baby's death. Some examples have been put in the table already to show you how to fill it in. (If you have had no health problems please go on to the next question)

Health problem	How long after your baby's death the health problem started	How long did health problem last	Any other comments
Anxiety attacks	Straight away	Still a problem	Seeing counsellor
Back pain	1 month	3 months	Had painkillers
Chest infection	3 months	2 weeks	Had antibiotics

Questions 13a -d are about your employment

**13a** When your baby died were you:

*please circle answer*

**in employment/ maternity leave/stay at home parent/ at college/ unemployed**

**13b** Please write down the last job you had or if you were at college please write down your college course.

.....

**13c** Have you returned to work or college since your baby's death?

**Yes/No**

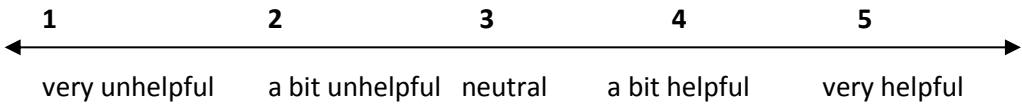
*please circle answer*

**13d** If you returned to work or college, please write down when you returned.

.....

**13e** Using a scale of 1 to 5, with 1 being very unhelpful, 3 being neutral (neither helpful or unhelpful) and 5 being very helpful:

How helpful did you find your employer or college after your baby's death?  
*please circle the number to show how helpful you think they were*



Questions 14a - are about smoking, alcohol and drug use

**14a** Please write down how many cigarettes (if any) you smoke each day now

.....

**14b** Please write down how many cigarettes (if any) you were smoking each day at the time your baby died

.....

**14c** Please write down how many units of alcohol you drink each week now. (One unit of alcohol is a small glass of wine, half a pint of beer or lager or one measure of spirits.)

.....

**14d** Please write down how many units of alcohol you were drinking each week at the time your baby died.

.....

**14 e** Please give details of any illicit drugs that you use now.(Illicit drugs are street drugs such as cannabis, heroin and cocaine.)

.....

**14f** Please give details of any illicit drugs that you were using when your baby died.

.....

Please complete the following questions about how you are feeling now.



## Appendix 7 Health, police and social care data extraction proformas

### Health records data extraction proforma

**SUDI study no.....**

1. Date of death .....

2. Was there a joint home visit? Y/N

When did the joint home visit take  
place?.....

3. list important findings from the home visit

.....  
.....  
.....  
.....

4. Was there an early multiagency meeting? Y/N

list who attended

.....  
.....  
.....  
.....

When was early meeting held?

.....

5. Was there a final multiagency meeting? Y/N

list who attended

.....  
.....  
.....  
.....

When was final meeting held?

.....

6. What follow-up was arranged for the family?

.....  
.....  
.....  
.....

When was this?

.....  
.....

7. What modifiable(risk) factors for SUDI were determined?

.....  
.....  
.....  
.....

8. What was the LCD final cause for death/ modifiable factors

.....  
.....  
.....  
.....

## Police data extraction proforma

**Case number of infant.....**

Date of data extraction.....

### Parental Background

1a. Are there any previous parental convictions Yes/No

1b. If yes how many .....

1c. For what?.....

2a. Are there any records of drug or alcohol misuse by the parents? Yes/No

2b. If yes brief  
details.....

3a. Are the family known for domestic violence? Yes/No

3b. If yes how many incidents on  
record.....

3c. Were incidents male to female aggression/ female to male aggression/ both partners  
fighting/ other/

### Investigation

4a. Was a joint home visit carried out with a paediatrician or specialist nurse? Yes/no

4b If not, why not.....

5. What was the state of the house during the home visit?..  
.....  
.....

6a. Were any items (eg clothing/bedding) taken from the house or baby? Yes/No

6b. If yes give  
details.....

6c. Were any of these items shown to be of value to the investigation later? Yes/No

6d. If yes give  
details.....

7a. Were any house to house enquiries carried out? Yes/No

7b. If yes was any relevant information gained Yes/no

7c. If yes give  
details.....

8a. Were any concerns voiced by the wider family about the baby's death Yes/No

8b.If yes give  
details.....

8c. Were any reassurances voiced by the wider family about the baby's death Yes/No

8d. If yes give  
details.....

9a. Were any child protection concerns raised by the police? Yes/No

9b. If yes give  
details.....

### **Police Statements**

10a. Were there any major discrepancies between the police statements, medical notes and parental interview?

10b. If yes give  
details.....

## Social care data extraction proforma

**Infant Case number**.....

**Date of Data Extraction**.....

### Involvement of Social Care prior to death

1a. Was the baby or family known to social care prior to the death? Yes/No

1b. If yes for what reason were they known?

.....  
.....  
.....

2a. Were there child protection concerns prior to the death? Yes/No

2b. If yes outline concerns

.....  
.....  
.....

2c. Had there been a formal strategy meeting? Yes/No When.....

2d. Was there a child protection plan in place? Yes/no/previously - expired by time of death

2e. Outline details of child protection plan.

.....  
.....  
.....

3a. Were other LA childrens services involved for the baby? Yes/no

3b. If yes give details

.....  
.....  
.....

4a. Was any particular support in place for a teenage mother? Yes/no/not teenage mother

4b. If yes give details

.....  
.....  
.....

5a. Was there a CAF in place? Yes/no

5b. If yes give details

.....

.....  
.....

**Involvement of Social Care after the death**

6a. Were any child protection concerns found after the death? Yes/No

6b. If yes outline details

.....  
.....  
.....

7a. Was there a formal strategy meeting Yes/No when.....

8a. Was there a child protection plan put in place for siblings Yes/no

8b. If yes give details.

.....  
.....  
.....

9a. If there were not any child protection concerns what role did social care take following the death eg supporting family? Give details

.....  
.....  
.....

9b. Was any particular bereavement support put in place for the family by social care? Yes/No

9c If yes give details

.....  
.....  
.....

## Appendix 8 CDOP Form C

### Analysis Proforma

*This proforma is used by the Child Death Overview Panel (CDOP) to:*

- *evaluate information about the child's death;*
- *identify lessons to be learnt; and*
- *to inform an understanding of all child deaths at a national level.*

*Where prior to the CDOP meeting, a local case discussion is held, the local team may complete a draft Form C to be forwarded to the CDOP to inform their deliberations.*

Agencies represented at the meeting:	
<b>Primary Health Care</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Paediatrics</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Hospital Services</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Mental Health Services</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Ambulance Services</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Police</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Children's Social Care Services</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Schools</b>	<b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/>
<b>Other (Specify)</b>	

**List of documents available for discussion**

Cause of death as presently understood

#### Case Summary

**A few paragraphs at most: a summary of the background and a factual description of events leading up to death. This should be as short as possible.**

**The CDOP should analyse any relevant environmental, extrinsic, medical or personal factors that may have contributed to the child's death under the following headings.**

For each of the four domains below, determine different levels of influence (0-3) for any identified factors:

- 0 - Information not available**
- 1 - No factors identified or factors identified but are unlikely to have contributed to the death**
- 2 - Factors identified that may have contributed to vulnerability, ill-health or death**
- 3 - Factors identified that provide a complete and sufficient explanation for the death**

**This information should inform the learning of lessons at a local level.**

#### Domain - Child's needs

Factors intrinsic to the child

**Include any known health needs; factors influencing health; development/ educational issues; behavioural issues; social relationships; identity and independence; abuse of drugs or alcohol; note strengths and difficulties**

Please enter relevant information



<p><b>Please tick the following boxes if these factors were present or may have contributed to the death</b></p> <p><b>Condition:</b></p>		<p><b>Relevance</b></p> <p><b>(0-3)</b></p>
<p>Acute / Sudden onset illness</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p><b>Chronic long term illness</b></p>		
<p>Asthma</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Epilepsy</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Diabetes</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Other chronic illness</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p><b>Disability or impairment</b></p>		
<p>Learning disabilities</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Motor impairment</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Sensory impairment</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Other disability or impairment</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	
<p>Emotional / behavioural / mental health condition in the child</p> <p>Specify:</p>	<p><b>Yes / No / NK</b></p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	

Allergies	Yes / No / NK	
Specify:	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Alcohol/substance misuse by the child	<b>Yes / No / NK</b>	
Specify:	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Domain - family and environment		
Factors in the family and environment <b>Include family structure and functioning; including parental abuse of drugs or alcohol; wider family relationships; housing; employment and income; social integration and support; community resources; note strengths and difficulties</b>		
Please enter relevant information		
<b>Please tick the following boxes if these factors were present or may have contributed to the death</b>  <b>Condition:</b>		<b>Relevance</b> <b>(0-3)</b>
Emotional/behavioural/mental health condition in a parent or carer Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Alcohol/substance misuse by a parent/carers Specify	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Smoking by the parent/carers in household or during pregnancy Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Housing Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Domestic violence Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Co-sleeping Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Bullying Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Gang/knife crime Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Pets/animal assault Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Domain - parenting capacity		
Factors in the parenting capacity <b>Include issues around provision of basic care; health care (including antenatal care where relevant); safety; emotional warmth; stimulation; guidance and boundaries; stability; note strengths and difficulties</b>		
Please enter relevant information		
<b>Please tick the following boxes if these factors were present or may have contributed to the death</b>		<b>Relevance (0-3)</b>
<b>Condition:</b>		
Poor parenting/supervision Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Child abuse/neglect Specify:	Yes / No / NK <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

Domain - service provision		
Factors in relation to service provision <b>Include any identified services (either required or provided); any gaps between child's or family member's needs and service provision; any issues in relation to service provision or uptake</b>		
Please enter relevant information		
<b>Please tick the following boxes if these factors were present or may have contributed to the death</b>  <b>Condition:</b>		<b>Relevance</b>  <b>(0-3)</b>
Access to health care  Specify:	Yes / No / NK  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Prior medical intervention  Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
Prior surgical intervention  Specify:	<b>Yes / No / NK</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	

The CDOP should categorise the likely/cause of death using the following schema.

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

Category	Name & description of category	Tick box below
1	<b>Deliberately inflicted injury, abuse or neglect</b> This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.	<input type="checkbox"/>
2	<b>Suicide or deliberate self-inflicted harm</b> This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	<input type="checkbox"/>
3	<b>Trauma and other external factors</b> This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. <b>Excludes</b> Deliberately inflicted injury, abuse or neglect. (category 1).	<input type="checkbox"/>
4	<b>Malignancy</b> Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	<input type="checkbox"/>
5	<b>Acute medical or surgical condition</b> For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	<input type="checkbox"/>
6	<b>Chronic medical condition</b> For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. <b>Includes</b> cerebral palsy with clear post-perinatal cause.	<input type="checkbox"/>
7	<b>Chromosomal, genetic and congenital anomalies</b> Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	<input type="checkbox"/>
8	<b>Perinatal/neonatal event</b> Death ultimately related to perinatal events, eg sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It <b>includes</b> cerebral palsy without evidence of cause, and <b>includes</b> congenital or early-onset bacterial infection (onset in the first postnatal week).	<input type="checkbox"/>
9	<b>Infection</b> Any primary infection (ie, not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.	<input type="checkbox"/>

10	<b>Sudden unexpected, unexplained death</b> Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. <b>Excludes</b> Sudden Unexpected Death in Epilepsy (category 5).	<input type="checkbox"/>
----	--	--------------------------

**The panel should categorise the 'preventability' of the death – tick one box.**

Preventable child deaths are defined in paragraphs 7.23 and 7.24 of *Working Together to Safeguard Children*

<b>Modifiable factors identified</b>	The panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths	<input type="checkbox"/>
<b>No Modifiable factors identified</b>	The panel have not identified any potentially modifiable factors in relation to this death	<input type="checkbox"/>
	Inadequate information upon which to make a judgement.  <i>NB this category should be used very rarely indeed.</i>	<input type="checkbox"/>

#### Issues identified in the review

**List the issues identified by the review group. This list may include the absence of certain key persons from the discussion or the lack of key documents.**

#### Learning Points

**List the learning points that emerge. These may well overlap with the issues and with recommendations.**

Recommendations

List any recommendations, even if already picked up as learning points or ‘issues’

**Specific agency**

**LSCB**

**Regional**

**National**

Follow up plans for the family, where relevant

Possible Actions

**Should this death be referred to another agency or Authority (e.g. Police, Coroner, Health and Safety Executive, Serious Case Review panel) for further investigation or enquiry? If so, please state**

☐ Yes                      ☐ No                      ☐ Already done

**If yes please specify;**

Appendix 9 Ethical approvals

## Appendix 9 Ethical Approvals



National Research Ethics Service

**Birmingham, East, North and Solihull Research Ethics Committee**

REC Offices

Osprey House  
Albert Street

Redditch

B97 4DE

Telephone: 01527 587528  
Facsimile: 01527 587501

17 June 2010

Dr Joanna Garstang

18 Barcheston Road

Knowle  
Solihull  
B93 9JS

Dear Dr Garstang

**Study Title:** **Sudden Unexpected Death in Infancy in the West  
Midlands: an Evaluation of the Joint Agency Approach  
to Investigating Unexpected Infant Deaths. (The West  
Midlands SUDI Project).**

**REC reference number:** **10/H1206/30**

Thank you for your letter of 26 May 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to



management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application		18 March 2010
Protocol	1	02 February 2010
Investigator CV		
Interview Schedules/Topic Guides	Structured Parentla 1	02 February 2010
CV Peter Sidebotham		
CV Frances Ellen Griffiths		
Hospital Anxiety and Depression Scale	1	02 February 2010
Qualitative parental interview questions	1	02 February 2010
Qualitative Professional interview Questions	1	02 February 2010
Participant Consent Form: Consent to access infant hospital records	1	02 February 2010
Consent to access GP records	1	02 February 2010
Consent to access Police Records	1	02 February 2010
Consent to access Social Services records	1	02 February 2010
GP/Consultant Information Sheets	1	02 February 2010
Consent to access Coroners Reports	1	02 February 2010
Consent for audio-recording	1	02 February 2010
Covering Letter		26 May 2010
Participant Information Sheet: Family	2	24 May 2010
Participant Consent Form: Parent	2	24 May 2010
Parent Introduction Sheet	2	24 May 2010
Introduction Sheet Contact Details	2	24 May 2010
Response to Request for Further Information		26 May 2010

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

## After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review — guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroutonres.rmsa.nhs.uk](mailto:referencegroutonres.rmsa.nhs.uk).

<b>10/H1206/30</b>
--------------------

<b>Please quote this number on all correspondence</b>
---

Yours sincerely



**Dr Rex J Poison Chair**

[Email: Karen.Green@westmidlands.nhs.uk](mailto:Karen.Green@westmidlands.nhs.uk)

L./

*Enclosures:* "After ethical review — guidance for researchers"

Copy to: Peter Hedges, Director, Research Support Services  
University of Warwick, Coventry CV4 8UW  
R&D Birmingham Women's Hospital

---

## National Research Ethics Service

### NRES Committee West Midlands - Solihull

REC Offices  
Prospect House  
Fishing Line  
Road Enfield  
Redditch B97  
6EW

Tel: 01527 582534  
Fax: 01527 582540

30 August 2011

Dr Joanna Garstang

18 Barcheston Road

Knowle  
Solihull  
B93 9JS

Dear Dr Garstang

**Study title:** **Sudden Unexpected Death in Infancy in the West  
Midlands: an Evaluation of the Joint Agency Approach to  
Investigating Unexpected Infant Deaths. (The West  
Midlands SUDI Project).**

**REC reference:** **101H1206130**

**Amendment number:** **AMO2 (our ref)**

**Amendment date:** **10 August 2011**

The above amendment was reviewed on 26 August 2011 by the Sub-Committee in correspondence.

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	3.1	10 August 2011
Covering Letter		10 August 2011

Protocol	3.0	01 June 2011
Questionnaire: Parental Questionnaire Appendix 1	3	01 June 2011
Questionnaire: Qualitative parental interview questions Appendix 2	3	01 June 2011
Questionnaire: Qualitative professional interview questions Appendix 3	3	01 June 2011
Participant Information Sheet: Parents Introduction Sheet Appendix 4	3	01 June 2011
Participant Information Sheet: Family Information Leaflet Appendix 5	3	01 June 2011
Participant Consent Form: Parent Consent Forms	3	01 June 2011

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in

England

## National Research Ethics Service

GP/Consultant Information Sheets	3	01 June 2011
Investigator CV	3	01 June 2011
Appendix 8 cv	3	01 June 2011
Appendix 8 cv	3	01 June 2011
Advertisement	3	01 June 2011

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**10/H1206/30:**

**Please quote this number on all correspondence**

Yours sincerely

**Dr Rex J Poison**  
**Chair**

E-mail: [Karen.Greenwestmidlands.nhs.uk](mailto:Karen.Greenwestmidlands.nhs.uk)

*Enclosures:*                      *List of names and professions of members who took part in the review*

*Copy to:*                      *Peter Hedges, Director, Research Support Services, University of Warwick Ms Ceri Jones, R&D Manager, University Hospitals Coventry and Warwickshire NHS Trust*

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in  
England

---

## National Research Ethics Service

### **NRES Committee West Midlands - Solihull By**

#### **Correspondence**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Rex J Poison - Chair	Consultant Physician	Expert
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management	Expert

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the Research Ethics Committees in  
England



## National Research Ethics Service

### NRES Committee West Midlands - Solihull

REC Offices  
Prospect House  
Fishing Line  
Road Enfield  
Redditch B97  
6EW

Tel: 01527 582534  
Fax: 01527 582540

16 November 2011

Dr Joanna Garstang  
NIHR Doctoral Research Fellow  
Room B022  
Health Science Research Institute  
University of Warwick  
Coventry  
CV4 7AL

Dear Dr Garstang

**Study title:** Sudden Unexpected Death in Infancy in the West  
Midlands: an Evaluation of the Joint Agency  
Approach to Investigating Unexpected Infant Deaths.  
(The West Midlands SUDI Project).

**REC reference:** 101H1206130

**Amendment number:** AM03

**Amendment date:** 10 November 2011

Thank you for your email of 10 November, notifying the Committee of the above amendment.

The amendment has been considered by the Chair.



The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented

immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

#### **Documents received**

The documents received were as follows:

Document	Version	Date
Protocol	4	10 November 2011

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

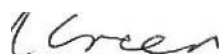
---

10/H1206/30:

Please quote this number on all correspondence

---

Yours sincerely



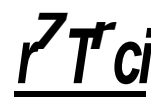
**Mrs Karen Green**

***Committee Co-ordinator***

[E-mail: Karen.Green@westmidlands.nhs.uk](mailto:Karen.Green@westmidlands.nhs.uk)

*Copy to: Peter Hedges, Director, Research Support Services, University of Warwick*

*Ms Ceri Jones, R&D Manager, University Hospitals Coventry  
and Warwickshire NHS Trust*



## **Health Research Authority**

---

**NRES Committee West Midlands - Solihull**

---

East Midlands  
REC Centre The  
Old Chapel  
Royal Standard  
Place  
Nottingham NG1  
6FS

Telephone: 0115  
8839390 Facsimile:  
0115 8839294

20 August 2012

Dr Joanna Garstang  
N1HR Doctoral Fellow  
Warwick Medical School  
Room B022  
Division of Mental Health and Wellbeing  
Medical School Building  
CV4 7AL

Dear Dr Garstang

**Study title:** **Sudden Unexpected Death in Infancy in the West  
Midlands: an Evaluation of the Joint Agency  
Approach to Investigating Unexpected Infant  
Deaths, the Follow-Up Study**

**REC reference:** **12/WM/0211**

**IRAS Project Reference:** **109156**

The Research Ethics Committee reviewed the above application at the meeting held on 08 August 2012. Thank you for attending to discuss the study.

The Committee informed you that they acknowledge that there is potential for upset/distress and that a mechanism is in place to deal with this. You stated that you already know the parents; sometimes during interviews they are stopped, have a drink etc. but parents always wish to continue. Some other parents do not wish to take part.

The Committee asked for clarification over the reference to 'Nurses' in the application and asked whether this should refer to 'Midwives'. You stated that this refers to the original study and not to this one. However, you confirmed that it was correct in that it refers to 'Nurses' and not 'Midwives'.

You were asked if the external review of the study identified any areas to address. You confirmed that the main issue was regarding recruitment. You confirmed that you already have some families interested in participating. Another issue was regarding being able to cope with the amount of data, and you confirmed that this was feasible.

---

The Committee informed you that they had noted in the application that data collected will be given to the parent for verification. However, this is not mentioned in the Participant Information Sheet. You stated that this would not be the case; it refers to the results being given to a user/advisory group, which includes some professionals, to see if they agree with the results.

11. You were asked how you will ensure that there is no bias in the study. You stated that you are aware of this possibility; and so the Academic Supervisors (of which there are two) will be Looking at the transcripts and there will be 3-way discussion on analysis.

The Committee further discussed the potential for bias in the study after you left the room. They agreed that it was satisfactory that the Academic Supervisors will ensure that there is no bias.

## **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

## **Ethical review of research sites**

### **NHS Sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites {"participant identification centre"}, guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document.. Version</i>	<i>,</i>	<i>Date</i>
Covering Letter		29 June 2012

GP/Consultant Information Sheets	1	01 June 2012
Interview Schedules/Topic Guides	1	01 June 2012
Investigator CV	Dr Peter Sidebottom	25 June 2012
Investigator CV	Dr Joanna Garstang	26 June 2012
Investigator CV	Frances Ellen Griffiths	
Letter of invitation to participant	1	01 June 2012
Other: appendix 1 in-depth interviews	1	01 June 2012
Other: Email from Sponsor confirming sponsorship		26 July 2012____
Participant Consent Form: Appendix 5	1	01 June 2012
Participant Information Sheet: Appendix 4	1	01 June 2012
Protocol	1	01 June 2012
Questionnaire: Appendix 2 Hospital Anxiety and Depression Score	1	01 June 2012
REC application	109156/337951/1/918	03 July 2012
REC application	Non-NHS SSI	25 June 2012

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Mr Richard Mupanemunda declared that he had worked in the past with the Chief Investigator of this study. However, this was some time ago, and he no longer works with her and has no involvement in this piece of research. The Committee did not deem this to be a conflict of

interest and agreed that Mr Mupandmunda stay in the meeting and participate in the review and decision of this study.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

#### Reporting requirements

The attached document "After ethical review — guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/WM/0211**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

**t A L ) „**

**Dr Rex J Poison**  
**Chair**

[Email: trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review— guidance for researchers"*

*Copy to:*

*Dr Peter Sidebottom — Academic Supervisor*

*Professor Frances Griffiths — Academic Supervisor*



**NRES Committee West Midlands - Solihull**  
**Attendance at Committee meeting on 08 August 2012**

**Committee Members:**

AI0076	.Proession'!		Y
Mrs Lynne Gray.	Senior Biomedical Scientist	Yes	
Mrs Rosemary Harris	Solicitor (non-practising)	No	
Mrs Theresa Hyde	Retired Head Teacher	No	
Dr Jennifer Lim	Social Scientist	Yes	
Mrs Irene Linder	Assistant Manager, Local Authority - Retired	Yes	
Ms Veronica Morgan	Midwife	Yes	
Dr Richard Mupanemunda	Consultant Paediatrician	Yes	
Dr David O'Brien	GP	Yes	
Dr Rex J Poison	Consultant Physician - Chair	Yes	Chairing
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management - Vice Chair	Yes	
Mr Rajeshwar Singh	Chartered Engineer - Retired	Yes	
Ms Gill Tomlinson	Head of Radiology, Solihull Hospital	Yes	

**Also in attendance:**

"Nan. O.liPaiti6n!6;y:."	
Mrs Lisa Gregory	Committee Coordinator
Ms Trish Wheat	Committee Coordinator

28 September 2012

# Warwick

## Medical School

PRIVATE

Dr Joanna Garstang  
Clinical research Fellow  
Warwick Medical School  
University of Warwick  
Coventry, CV4 7AL

Dear Jo,

---

Study Title and BSREC Reference: *Sudden Unexpected Death in Infancy (SUDI) in the West Midlands: an evaluation of the joint agency approach to investigating unexpected infant deaths, Child re overview panel study (The WM SUDI COOP study)- 245-10-2012*

Thank you for submitting the above-named project to the University of Warwick Biomedical and Scientific Research Ethics Sub-Committee for Chair's approval.

I am pleased to confirm that your application meets the required standard which means that full approval is granted and your study may commence.

I take this opportunity to wish you success with the study and to remind you any substantial amendments require approval from the committee before they can be made. Please keep a copy of the original signed version of this letter with your study documentation. The

committee also requires you to complete an End of Study Declaration Form when you reach the end of your study: this form has been e-mailed to you.

Yours sincerely,

Professor Jane Barlow  
Chair

Biomedical and Scientific

Research Ethics Sub-Committee

Copy:

File

Dr Peter Sidebotham

**Biomedical and Scientific  
Research Ethics Subcommittee**

Enquiries: Clair Henrywood B032  
Medical School Building Warwick  
Medical School, Coventry, CV4  
TAL.

Tel: 02476-528207

Email: [bsrec@warwick.ac.uk](mailto:bsrec@warwick.ac.uk)

THE UNIVERSITY OF

WARWICK

