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## **Original Paper**

### **Title: An evidence-based guide to the investigation of sudden unexpected death in infancy**

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#### **Contributors**

The study was designed by JG, CE and PS. JG performed the literature searches, selected articles for inclusion, extracted data and wrote the initial report. CE selected articles for inclusion and contributed to the report. PS advised on study progress, data analysis and contributed to the report. All authors commented on and approved the final version of the manuscript, have a copy of the manuscript and share responsibility for the results.

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#### **Competing interests**

This study forms part of JG's doctoral thesis funded by The National Institute of Health Research (NIHR) as a NIHR Doctoral Fellowship (DRF – 2010-03-045). NIHR had no involvement in the study design, data collection, analysis or interpretation of the data or in the decision to submit the paper for publication. The views expressed in this publication are those of the authors and not necessarily those of NIHR.

CE, PS, none declared

## **Original Paper**

# **An evidence-based guide to the investigation of sudden unexpected death in infancy**

## **Abstract**

### **Purpose**

Many countries now have detailed investigations following Sudden Unexpected Death in Infancy (SUDI) but there is no clear evidence as to the most effective way to investigate SUDI. This systematic literature review addresses the following questions: What are the current models of practice for investigating SUDI? What is the evidence to support these investigative models? What are the key factors for effective SUDI investigation?

### **Methods**

This was a systematic review of papers from Europe, North America and Australasia, detailing models of SUDI investigation or the outcomes of SUDI investigations.

### **Results**

The review includes data detailing four different models of investigation: police-led, coroner or medical examiner-led, healthcare-led or joint agency approach models.

There were 18 different publications providing evidence of effectiveness of these models. All models, with the exception of police-led models have the potential to reach best practice standards for SUDI investigation. Key factors identified for effective SUDI investigation include the need for mandatory investigation, strong leadership, integration with coronial services and for investigations to be provided by specialist professionals.

## **Conclusion**

Detailed SUDI investigation should lead to greater understanding of why infants die and should help prevent future deaths. The challenge is now to ensure that local SUDI investigative practices are as effective as possible. (208 words)

## **Keywords**

Sudden Unexpected Death in Infancy

Sudden Infant Death Syndrome

Death scene investigation

Cause of death

Evidence-based practice

## **Key points**

Detailed SUDI investigations should be mandatory and are most effective when integrated with coronial services

Death scene examinations for SUDI should be undertaken only by specialists who perform these regularly

Support and follow-up for families should be an integral part of the SUDI investigation process

## **Introduction**

Sudden Unexpected Infant Death (SUDI) is a major contributor to post-neonatal mortality in the developing world. SUDI can be defined as the death of a child 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 the death[1]. Given appropriate investigation, SUDI cases may have the cause of death determined; deaths can be due to medical causes, accident or non-accidental injury. However even with thorough investigation no cause of death is found in at least half of SUDI cases [2] and these cases may be diagnosed as Sudden Infant Death Syndrome (SIDS) [3] or labelled as unascertained deaths.

Knowing the cause of death is of the utmost importance for families to help them come to terms with the death [4]. It is also essential in the small proportion where a crime may have been committed, to ensure that such cases are appropriately detected and justice administered. There is a further wider value for society in general as the learning generated from untimely deaths may be used to help prevent future deaths. The investigation of SUDI varies widely between different countries but frequently involves the police or coroner as well as health services, and detailed examination of the scene of death is becoming more commonplace. Many countries now have child death review processes and in some this includes immediate prospective investigation of SUDI cases as well as an overview of child deaths at population level [5].

There is little clarity about the best way of investigating SUDI in terms of finding a cause of death, supporting families and preventing future deaths. We therefore undertook this literature review to inform best practice in investigating SUDI. We describe the different models of investigation for SUDI in use internationally; we review the evidence of effective investigation for each of these models compared with perceived best

practice; and use this evidence to determine key factors for effective investigation. The research questions for this review are:

What are the current models of practice for investigating SUDI?

What is the evidence to support these investigative models?

What are the key factors for effective SUDI investigation?

## **Methods**

### **Search strategy and selection of papers**

We searched Ovid (Medline) and CINAHL databases from 01.01.1995 to 31.12.14. The search terms are shown in table 1. We hand-searched four key journals: Forensic Science International; Forensic Science, Medicine and Pathology; Child Abuse and Neglect; and Child Abuse Review.

### **Gray literature**

We searched the websites of several child death review programmes internationally and of SIDS bereavement support organisations for relevant papers; these websites are shown in table 2. We were already familiar with UK and Australian investigative models; we contacted professionals in the field of SUDI via ISPID (International Society for the Study and Prevention of Perinatal and Infant Death) for details of their local policies and practices.

### **Selection criteria for papers on models of investigation**

As we were attempting to describe current models of investigation in use internationally we included all papers describing investigative models.

## **Selection criteria for papers concerning evidence to support models of SUDI investigation**

We 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; however scrutinising the English abstracts of other language publications revealed we were not missing any original research papers. Only papers published since 1995 were included to ensure that evidence was current and that no relevant research after the introduction of safe sleep campaigns was missed. We 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.

JG and CE read the titles, abstracts and full text articles. We critically appraised all papers basing this 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

## **Assessment of compliance with best practice in SUDI investigation**

There is no internationally accepted standard for best practice in SUDI management; we based our assessment of the following criteria: the minimum acceptable standard was

that which allowed a diagnosis of SIDS to be made according to the San Diego definition [3]. A more stringent standard is that investigations conformed to the international consensus of Bajanowski and colleagues [6] and the highest standard is that investigations were compliant with the key principles of the Kennedy Report [7]. These standards are shown in table 3.

We created the following core objectives of an appropriate response to SUDI based upon the need to thoroughly investigate deaths, support parents, 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; including accidental asphyxia, suspicious deaths, medical deaths and SIDS where diagnostic criteria have been met;
- 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.

## **Results**

### **Search results**

We accessed twelve policy documents or investigative protocols detailing models of SUDI investigation from eight different countries. All models identified were included in the review. These papers are shown in table 4.

Out of 432 titles and abstracts found by database searches, 62 full text articles were read and 15 were suitable for inclusion. These were supplemented by two relevant publications already known to us and by one conference presentation. No suitable articles were found by hand searching.

In total 15 published papers, one government report, one conference presentation and one abstract of a poster presentation were included in the review; these are shown in table 5. Seven 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

## **Different models of investigating SUDI**

There were four types of SUDI investigative models identified in the literature; coroner or medical examiner-led models, healthcare-led models, police-led models and the Joint Agency Approach (JAA) model. These models are summarised in table 6.

## **Evidence to support 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.

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

In the multicenter analysis by Landi and colleagues, thorough death investigations were hampered by lack of statutory protocols and differing practices by local Medical Examiner offices [8]. In the USA there are standard national templates for assessing death scenes and national training for scene examiners but these are not mandatory and SUDI cases are often managed by coroner or medical examiner offices that deal with SUDI only rarely [9].

The most effective death scene investigations were reported where one public health nurse conducted all SUDI death scene investigations for the region [10]; this resulted in considerably more complete information than the use of the US national templates by multiple death scene examiners [11, 12] or when there was no information concerning or variable use of templates [13-15]. Trained death scene examiners did obtain detailed information concerning the scene but frequently missed relevant information on other risk factors such as parental smoking [16]. Similarly, in New Zealand, large amounts of information concerning death scenes and parental drug and alcohol use were unavailable when death scene examination was conducted by non-specialist police without standard protocols [17].

### **Healthcare-led models of investigating SUDI**

In a healthcare-led model of investigating SUDI, as long as minimum statutory requirements are met parents can decline further investigation such as death scene analysis or even autopsy. As a result, SUDI investigation may be less thorough. In Norway, after sudden death of children less than four years old, parents consented to death scene examination by a forensic pathologist or medical forensic investigator in 42/109 cases nationally, with higher rates achieved of 30/65 cases in Oslo which is a centre for SUDI research [18]. Similarly, using a healthcare-led model within an Austrian

research project 39/56 parents consented to detailed scene analysis and some parents declined autopsy [19].

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

New South Wales has previously used a police-led model of investigation; analysis of this by their Child Death Review Team showed significant difficulties with police taking complete medical and social histories from families and lack of detailed death scene analysis. Similarly, lack of information meant that the role of neglect or non-accidental injury could not be determined in 50/186 cases [20].

### **Joint Agency Approach**

This model of SUDI investigation based on the Kennedy Report [7], is currently mandatory in England and Wales [21]. Typically the JAA is provided by local clinicians but it has also been used by specialist research teams. The mandatory requirement to use the JAA is a powerful enabler; prior to this attempts to establish joint agency SUDI investigations in the south of England were unsuccessful [22]. In comparison, in Wales the JAA commenced in 2011, and an audit of one region for 2012-3 showed compliance with JAA procedures in 35/45 (78%) of unexpected child deaths [23]. Similarly, another audit of the JAA in the city of Birmingham showed that it had been successfully implemented with all cases having joint death scene examination by police and paediatrician within 48 hours, all having early multi-agency discussions and 11/17 families having follow-up meetings with paediatricians. Child protection concerns were identified in four cases that may have otherwise been missed. There were some difficulties with obtaining post-mortem examination reports in a timely manner from the coroner and difficulties involving social care professionals [24]. When a specialist research team used the JAA similar results were obtained but more families had follow-up with 93% receiving formal feedback after the process [25]. Of the 157 SUDI cases in

this study, 67 (43%) had a causal explanation found and 90 (57%) remained unexplained and were classified as SIDS [2].

### **Compliance of different models of SUDI investigation against best practice standards.**

The police-led model does not comply with any best practice standard so is not considered further. The other models all comply with the standards of Krous et al. [3]; the healthcare-led model and the JAA comply with Bajanowski et al. [6], the coroner or medical examiner-led model only does so when there are prospective case reviews to determine cause of death. The JAA alone achieves the standard of the Kennedy Report [7].

The assessment of the healthcare-led, coroner or medical examiner-led and JAA models against the core principles for SUDI investigation is shown in table 7. The diagnostic rate for SUDI varies widely due to different diagnostic thresholds and definitions. The JAA fulfils all five core objectives for SUDI investigations, coroner or medical examiner-led models fulfil only four due to lack of evidence of support for families, although if this were in place it would fulfil all five. The healthcare-led model fulfils three core objectives with the potential to fulfil four if child death review programmes are in place. The main shortfall of this model is the lack of requirement for mandatory investigation.

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

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

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. 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- [19, 22, 18, 24]*

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

When the coroner is not integral to the SUDI process this can be a barrier to effective multi-agency working. 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 -[16, 11, 12, 10, 15, 14, 24]*

## **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 –[12, 11, 10, 25]*

## **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. *Based on moderate evidence [10, 17, 20]*

## **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. *Based on strong evidence - [9-11, 17, 20, 15, 16]*

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

Multi-agency conferences allow consideration of wider factors in SUDI such as child protection issues or poor parenting that might otherwise be missed. *Based on weak evidence* -[24]

## **Discussion**

The literature review identified four distinct models for investigating SUDI: coroner or medical examiner-led models, healthcare-led models, police-led models and a joint agency approach. 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 [6]. We could only obtain one publication concerning the police-led model; it is possible that if medical professionals were able to support the police investigation by taking a detailed medical history and sharing this with the pathologist that this model could meet minimum standards. 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 gray literature on SUDI investigations from many developed nations with similar contexts to the UK and 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 [7] and the international consensus paper [6], but go further by suggesting policy factors needed and the key practitioner components needed for effective investigations.

This review has implications for SUDI investigation internationally. In many countries, SUDI investigations are performed by individuals who do so only infrequently; this may mean that these investigations are less accurate and less effective at determining causes and risk factors for death. Where coroners' enquiries are a separate process to other more detailed SUDI investigations, there is the potential to cause duplication of processes which may confuse and distress families. There can also be difficulties with appropriate sharing of relevant information between the two investigative processes.

Our clinical experience as professionals using the joint agency approach has suggested that most parents are willing to accept detailed SUDI investigations and value the information that the process provides. We need to ensure that parental views are not lost as we strive for more effective investigation. In addition, effective SUDI investigation is expensive at a time when healthcare and coronial budgets are limited. The challenge is to convince policy makers of the need for effective investigation of SUDI so that we can have a greater understanding of why infants die and use this to reduce infant deaths in the future.

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**Table 1 Search terms used for the 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  |

Table 2 Details of websites searched

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

**Table 3 Best practice standards for SUDI investigation**

| <b>Publication</b>           | <b>Method of consensus</b>   | <b>Standards</b>  |
|------------------------------|--|---|
| <b>Krous, Beckwith [3]</b>   | Expert panel of paediatric pathologists, forensic pathologist and paediatricians   | In order for SIDS to be diagnosed there must be: <ol style="list-style-type: none"> <li>1) A detailed medical history</li> <li>2) A complete post-mortem examination</li> <li>3) A review of the circumstances of death.</li> </ol>   |
| <b>Bajanowski et al. [6]</b> | Expert panel of paediatric pathologists, forensic pathologist and paediatricians   | As per Krous et al., 2004 but with further recommendations that: <ol style="list-style-type: none"> <li>4) The death scene examination should be performed by specialist police or forensic medicine experts with training in SUDI</li> <li>5) The diagnosis of SIDS should not be made by any individual working alone but following a multi-professional consensus</li> </ol>   |
| <b>Kennedy Report [7]</b>    | Working group of paediatricians, pathologists, forensic pathologists, police, coroners, bereaved parents and SIDS support groups | As per Krous et al., 2004 but with further recommendations that:<br>SUDI investigations should consist of <ol style="list-style-type: none"> <li>1) A medical history taken jointly by police and paediatrician</li> <li>2) A joint examination of the death scene by police and paediatrician</li> <li>3) Initial multi-agency case discussion within days of death</li> <li>4) Final case discussion once all investigations complete</li> </ol> <p>These investigations must be balanced with the need to support the bereaved family.</p> |

**Table 4 Policy documents and research papers detailing models of SUDI investigation**

| <b>Country</b>     | <b>Publication details</b>  |
|--------------------|---|
| <b>Australia</b>   | Policy Directive Death- Management of SUDI in New South Wales [26]<br>Tackling SIDS, a community responsibility [27]<br>Sudden Unexpected Death in Infancy, The New South Wales Experience [20] |
| <b>Austria</b>     | Classification of SID in a multi-disciplinary setting [19]  |
| <b>England</b>     | Working together to safeguard children [21]   |
| <b>Ireland</b>     | Sudden death in infancy, SIDS model of care for professionals [28]  |
| <b>New Zealand</b> | SUDI nationwide study, increasing understanding of SUDI [29]  |
| <b>Norway</b>      | Trends in sudden death in infants and small children in Norway [18]   |
| <b>USA</b>         | SIDS diagnostic practices and investigative policies [9]<br>Responding to a sudden unexpected infant death: the professional's role[30]<br>Sudden unexplained infant death investigation [31]   |
| <b>Wales</b>       | Procedural response to unexpected death in childhood [32]   |

**Table 5** 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>Boylestad [18]<br/>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<br>30/63 (48%) cases from Oslo had death scene investigation<br>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. [11]<br/>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%<br>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. [9]<br/>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. [24]<br/>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.   | 2                    | JAA can be used effectively. Child protection issues may not be identified without   |

|                                   |  |                                      |   |                                       |   |  |   |  |
|-----------------------------------|--|--------------------------------------|---|---------------------------------------|---|--|---|--|
|                                   |  |                                      |   |                                       |   | Previously unrecognised child protection issues discovered.  |   | multi-agency investigation   |
| <b>Gessner et al. [14]</b>        | Medical Examiner-led investigation<br>Death scene examination by state police without standard template.<br>Occasional interview by public health nurses           | Alaska<br>USA                        | To determine the contribution of different risk factors to SIDS   | Retrospective<br>CDR data<br>analysis | 130 SIDS cases in 5 year period<br>1992-7 | Public health nurse interviews rarely occurred.<br>Information on sleep location unknown in 16/130 (12%), co-sleeping status unknown in 20/130 (15%)   | 1 | Death scene analysis by non-specialist police without standard templates may result in loss of important information                       |
| <b>Hutchison et al. [17] 2011</b> | Coroner-led investigation.<br>Police death scene examination by non-specialist police.<br>No case reviews  | Auckland<br>region of<br>New Zealand | To assess details on autopsy and police reports of unexplained SUDI or accidental suffocation cases       | Retrospective<br>case notes<br>review | 221 SUDI during<br>2000-9                 | Medical history data missing in > 50% of cases, parental smoking missing in 89%<br>Location of sleep known in 84-88% of cases but sleep position only known in 58%.  | 1 | Detailed medical histories are required.<br>Non-specialist police are not effective at death scene examination.                            |
| <b>Kemp et al. [16]</b>           | Medical Examiner-led investigation.<br>Death scene examination by trained investigator using standard template and doll reconstruction.<br>Prospective case review | St Louis,<br>Missouri,<br>USA        | To describe the prevalence of risk factors related to sleep among infants dying suddenly and unexpectedly | Retrospective<br>case notes<br>review | 119 SUDI during<br>1993-7                 | Details of parents smoking habits not recorded in >50% of cases. Information on sleep position missing in 12/119 (10%) cases, sleep location missing in 8/119 (7%). Detailed narratives available for accidental suffocation cases | 1 | Thorough scene information can be obtained by experienced scene examiners but information on other risk factors (eg smoking) may be missed |
| <b>Kerbl et al. [19] 2003</b>     | Health-led investigation.<br>Detailed medical history and death scene examination by medical   | Styria region<br>of Austria          | To assess the usefulness of the European SIDS classification  | Prospective<br>study of SUDI<br>cases | 56 SUDI during<br>1993-2002               | 39/56 (70%) cases recruited for detailed scene examination and medical history.<br>11/56 (20%) cases had cause of death determined   | 1 | Non-mandatory SUDI investigation results in many parents choosing not to have adequate   |

|                                  |   |   |  |  |   |   |   |   |
|----------------------------------|---|---|--|--|---|---|---|---|
|                                  | researcher.<br>Multi-disciplinary case<br>review  |   |  |  |   | Risk factors of parental smoking or<br>unsafe sleep environment found in<br>28/39 SIDS cases  |   | investigations  |
| <b>Landi et al. [8]<br/>2005</b> | Medical Examiner-led<br>investigation.<br>No protocols in place   | King County<br>(KC)<br>Washington<br>State,<br>New York<br>City (NYC),<br>Uruguay** | To compare<br>investigative process<br>and final cause of<br>death for SUDI cases<br>in the USA and<br>Uruguay | Comparative<br>study of SUDI<br>management in<br>2 US centres<br>and Uruguay | 56 SUDI<br>King<br>County<br>258 SUDI<br>New York | In KC 95% had detailed medical history<br>and 85% death scene examination 4/56<br>(7%) had cause of death determined<br>In NYC 50% had detailed medical<br>history and 30% death scene<br>examination. 52/258 (20%) had cause<br>of death determined. | 1 | Clear protocols are needed<br>to ensure adequate<br>investigation of SUDI   |
| <b>Li et al. [12]<br/>2005</b>   | Medical Examiner-led<br>investigation.<br>Detailed medical and social<br>history.<br>Death scene examination<br>using national standard<br>form.<br>No case reviews | Maryland,<br>USA  | To review<br>epidemiological<br>characteristics and<br>scene findings of SUDI<br>cases                         | Retrospective<br>case review<br>using ME<br>records                          | 1619 SUDI<br>during<br>1990-2000                  | 723/1619 (45%) had cause of death<br>determined<br>Detailed death scene information for<br>98% of cases.<br>In 33 co-sleeping deaths parents unable<br>to provide clear information about the<br>death scene.   | 1 | Limited experience of the<br>death scene examiners<br>may have resulted in the<br>lack of information<br>available. |
| <b>Livesey [22]<br/>2005</b>     | Locally provided JAA but<br>non- statutory  | Sussex, UK  | To assess how a JAA<br>protocol works in<br>practice   | Retrospective<br>case note<br>review   | 29 SUDI<br>during<br>2000-2                       | 11/29 (38%) had cause of death<br>determined. Major difficulties in<br>implementing the JAA. Most cases had<br>only a few elements of JAA<br>investigation none had complete<br>investigation.  | 2 | It is difficult to Implement<br>non-statutory SUDI<br>investigations  |
| <b>New South<br/>Wales Child</b> | Police-led Investigation<br>Medical history and death   | New South<br>Wales,   | To describe current<br>SUDI investigative  | Retrospective<br>case note   | Random<br>sample of                               | 39/186 (21%) Proportion of cases with<br>risk factors determined or missing cases   | 1 | Investigations led by non-<br>specialist police result in   |

|   |   |                     |  |                                    |                           |  |   |  |
|---|---|---------------------|--|------------------------------------|---------------------------|--|---|--|
| <b>Death Review Team [20] 2005</b>          | scene examination by non-specialist police.<br>No case reviews  | Australia           | practice   | review using standard SUDI records | 81/186 SUDI during 2000-2 | not stated however psychosocial and clinical history were missing from majority of cases. Lack of information in 50/186 (27%) meant that safeguarding issues could not be determined   |   | significant loss of relevant information.  |
| <b>Meersman and Schaberg [13] 2010</b>      | Medical Examiner-led investigation.<br>Death scene examination – (no details of examiners’ experience or use of standard templates)<br>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.<br>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, Ashtekar [23] 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. [10] 2007</b>     | Medical Examiner-led investigation.<br>Detailed medical history and scene examination by specialist nurse.<br>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. [25] 2010</b>          | Flying squad version of JAA   | South-west England. | To evaluate the implementation of procedures for   | Case control study and process     | 157 SUDI cases during     | 94% had early multi-agency case discussions, 95% had joint death scene examination by police and   | 1 | A flying squad version of the JAA produces thorough investigations; local health   |

|                                  |   |                          |  |                                |                         |  |   |   |
|----------------------------------|---|--------------------------|--|--------------------------------|-------------------------|--|---|---|
| <b>and Blair et al. [2] 2009</b> |   |                          | investigating sudden child death.  | evaluation                     | 2003-6                  | paediatrician, 88% had final case review, 93% of parents had formal feedback from case review<br>67/157 (43%) had a cause for death determined     |   | services also contributed to case discussions and in some cases were confident to perform joint death scene analysis with police. |
| <b>Thogmartin et al. [15]</b>    | Medical Examiner-led investigation. Death scene examination by police or medical examiner personnel. (no details of examiners' experience or use of standard templates) | Palm Beach, Florida, USA | To determine the effect of various risk factors on the incidence of SUDI and the frequency of autopsy findings | Retrospective case note review | 217 SUDI during 1986-99 | 48/217 (22%) cases sleep position or co-sleeping status unknown<br>Cases from 1990 onwards had more detailed and quicker death scene examinations. | 1 | More SUDI had cause of death determined with detailed scene examination after 1990 than before then.                              |

\*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

Table 6 Different Models of SUDI Investigation

| <b>Model name</b>                                    | <b>Lead Agency</b>          | <b>Initial history from parents</b>                       | <b>Death scene examination</b>      | <b>Autopsy</b> | <b>Prospective individual case reviews</b>   | <b>Countries using this model</b> |
|--|-----------------------------|---|-------------------------------------|----------------|--|-----------------------------------|
| <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<br>New Zealand                |
| <b>Healthcare-led investigation</b>                  | Health                      | Taken by doctor   | Doctor and police but independently | Variable       | Multi-disciplinary case review within health | Ireland<br>Norway<br>Austria      |
| <b>Police-led investigation</b>                      | Police                      | Police  | Police and forensic team            | Variable       | none   | Australia                         |

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|                     |            |               |               |       |              |         |
|---------------------|------------|---------------|---------------|-------|--------------|---------|
| <b>Joint Agency</b> | Health and | Taken by      | Jointly by    | Mand- | Multi-agency | England |
| <b>Approach</b>     | police     | paediatrician | police and    | atory | case review  | Wales   |
| <b>model</b>        | jointly    | and police    | paediatrician |       |              |         |

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**Table 7 The fulfilment of core objectives by different models of SUDI investigation**

| <b>Objectives</b>                             |   |   |  |  |  |
|---|---|---|--|--|--|
| <b>Model of SUDI investigation</b>            | To identify as far as possible any identifiable cause for death | To identify any factors contributing to the death   | To support the family and recognise 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 met including any criminal, civil or child protection matters |
| <b>Coroner or Medical Examiner-led models</b> | Achieved  | Achieved  | Not achieved   | Achieved   | Achieved   |
|   | Diagnostic rates for SUDI from 7 to 45%                         | Many studies reported missing information on risk factors. Most accurate recording of death scene | No evidence available  | In conjunction with Child Death Review programmes          | Inherent in this model of investigation  |

|                              |  |   |  |  |  |
|------------------------------|--|---|--|--|--|
|                              | information from more experienced investigators. |   |  |  |  |
| <b>Healthcare-led models</b> | Achieved   | Achieved  | Achieved   | Not achieved   | Not achieved   |
|                              | Diagnostic rates for SUDI from 20-30%            | Death scene analysis by experienced scene investigators | Medical follow-up for parents is an integral part of this model    | No evidence available but would be met if there are Child Death Review programmes in place | A voluntary model allows parents to decline appropriate investigations |
| <b>Joint Agency Approach</b> | Achieved   | Achieved  | Achieved   | Achieved   | Achieved   |
|                              | Diagnostic rates for SUDI from 21-43%            | Complete information available for majority of cases    | Medical follow-up for parents is an integral part of this approach | In conjunction with Child Death Review programmes  | Mandatory investigation of all SUDI                                    |