

Classification of sleep-related sudden unexpected death in infancy

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TITLE

Classification of sleep-related sudden unexpected death in infancy: a national survey.

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Sudden Unexpected Death in Infancy

Accidental Asphyxia

Cause of Death

Child death review

ABSTRACT

Aims

To identify how British Child Death Overview Panels (CDOP) and paediatric pathologists classify cause of death for sleep-related Sudden Unexpected Death in Infancy (SUDI).

To determine compliance with national requirements for SUDI investigation.

Methods

Electronic survey of CDOPs and pathologists using three vignettes of SUDI cases illustrating: accidental asphyxia, typical Sudden Infant Death Syndrome (SIDS) and SIDS with co-sleeping.

Results

38(41%) of 92 CDOPs returned questionnaires, 32 were complete. 13(14%) of 90 pathologists returned complete questionnaires. 31(97%) CDOPs and 7(53%) pathologists agreed with the cause of death in the accidental asphyxia case; 24(75%) CDOPs and 9(69%) pathologists in the typical SIDS case; and 11(34%) CDOPs and 1(8%) pathologist in the co-sleeping SIDS case. Pathologists used the terms SUDI or unascertained as the cause of death for the accidental asphyxia case (46%) and the co-sleeping SIDS case (77%). These terms were used by CDOPs for the typical SIDS case (25%) and the co-sleeping SIDS case (41%). 17(46%) CDOPs reported compliance with guidelines for investigation in more than 75% of cases.

Conclusion

There is wide variation in classification of deaths, with only limited agreement between CDOPs and pathologists. The terms SIDS and accidental asphyxia are underused, even in typical cases. (199 words)

Abbreviations

CDOP Child Death Overview Panels

SIDS Sudden Infant Death Syndrome

SUDI Sudden Unexpected Death in Infancy

Key Notes

Child Death Overview Panels and paediatric pathologists differ widely in their classification of causes of death in Sudden Unexpected Death in Infancy.

Child Death Overview Panels are more likely to classify deaths as due to accidental asphyxia than paediatric pathologists.

Less than half of Child Death Overview Panels reported that local investigation of unexpected infant deaths was compliant with national guidance.

INTRODUCTION

There are around 200 unexpected and unexplained infant deaths each year in England and Wales (1). Many different terms are used to describe these deaths. Sudden Unexpected Death in Infancy (SUDI) is used for death of an infant that was not predicted as a possibility in the 48 hours prior to the death or to the collapse that led to death (2). SUDI is not a diagnosis and the term is used in the UK to identify deaths requiring multi-agency investigation, its use and meaning varies internationally. SUDI may be due to acute medical conditions or external causes (accidents and injuries), but the majority remain unexplained. Unexplained SUDI can be labelled as Sudden Infant Death Syndrome (SIDS, International Classification of Diseases version 10 (ICD-10) R95), which is defined as the death of an infant aged less than 1 year, associated with sleep that remains unexplained by detailed post-mortem examination, medical history or circumstances of death (3). Many unexplained SUDI are certified instead as 'unascertained' (ICD-10 R99) and this category accounts for up to 40% of such deaths in England and Wales (1). After death certification, an algorithm determines the ICD code, but this may not always reflect the certifier's intention (4); these ICD codes are used for national statistics.

All SUDI in England should have detailed multi-agency investigation following national guidelines (5). This includes a detailed medical history, a joint home visit by police and paediatrician or specialist nurse to examine the scene of death, a post-mortem examination by a paediatric pathologist, and final multi-professional case discussion to review all information and provisionally determine the cause of death. The conclusion of the case discussion should be shared with the coroner who certifies the official cause of death. Despite a copy of the multi-agency case discussion being shared with the coroner, evidence suggests that coroners frequently rely solely on pathologists' findings rather than drawing on the full multi-professional investigation (6). Once all investigations are complete, SUDI are also reviewed by local Child Death Overview Panels (CDOP) to classify deaths,

and to identify potentially modifiable factors and learning (7). Anonymised data are collated by the recently established National Child Mortality Database to enable detailed analysis and learning.

Infant deaths from unintentional asphyxia often have similar non-specific post-mortem findings to SIDS (8) and no findings are diagnostic (9). Differentiating between SIDS and unintentional asphyxia relies on good parental accounts and scene examination. There is wide variation in classification of sleep-related SUDI internationally; with England and Wales reporting less than 4% of such deaths due to accidental suffocation or strangulation in bed (ICD-10 W75) in 2002-10, compared to 27% in the USA and 34% in New Zealand (10). In Sweden, 1% of unexpected infant deaths are registered as due to accidental asphyxia (11). The numbers of infant deaths in England and Wales recorded as due to accidental suffocation or strangulation in bed have not increased despite the requirement for detailed SUDI investigation (12), and there is some evidence that even with detailed investigation professionals may not be recognising unintentional asphyxia deaths (6).

The difficulty of identifying unintentional asphyxia deaths is increasingly recognised: In New Zealand 20% of such deaths were originally misattributed to SIDS (13), and a recent reanalysis of SUDI in New South Wales resulted in the proportion of deaths due to unintentional asphyxia increasing from 4% to 19% (14). Research from the USA has shown a wider variation in professional practice in classifying the cause of death for SUDI (15). In the UK, pathologists tend to avoid the diagnostic term SIDS if the infant was co-sleeping at death preferring the term 'unascertained' for co-sleeping deaths where parents have consumed alcohol or drugs (16).

Given these difficulties and discrepancies in classification, we decided to ascertain current practice among CDOPs and paediatric pathologists for classifying cause of death in sleep-related SUDI, and to determine compliance with recommended SUDI investigations.

The research questions were:

Research questions

How do Child Death Overview Panels (CDOP) and paediatric pathologists classify cause of death for sleep-related SUDI?

To what extent do local areas comply with national requirements for the investigation of SUDI?

METHODS

This was an electronic survey of CDOP and paediatric pathologists practices for classifying SUDI.

Study materials

We created three vignettes of sleep-related SUDI cases shown in Table 1. The post-mortem examinations for all three cases were inconclusive with no cause of death given. We gave background family and social histories reflecting social deprivation often associated with SUDI. The full case information is in appendix S1.

The cases were reviewed by an international group of SIDS experts at the Pediatric Forensic Medicine and Clinical Forensic Medicine meeting held in Oslo in May 2017 to ensure that they fitted with the proposed diagnoses.

Table 1 Summary of SUDI cases

We developed a questionnaire for CDOPs to complete based on the information provided in the three case histories. For each case, CDOPs were asked to state what they considered the cause of death to be. The options for cause of death were: SIDS, SUDI, unascertained, accidental asphyxia or other. CDOPs were asked how often they reviewed SUDI cases and about the process of SUDI investigations in their local area. The questionnaire is in appendix S2.

We developed a web-based survey for UK paediatric pathologists to complete, using these 3 cases with full but inconclusive post-mortem examination results. For each case pathologists were asked to state their opinion on the correct cause of death from a choice of: SIDS, SUDI, unascertained, accidental asphyxia or other. The questionnaire and post-mortem reports are in appendix S3.

Data Collection

In September 2017 we emailed the managers of all 92 CDOPs in England informing them of the study and inviting participation. One follow-up reminder email was sent to non-responders after 3 months. On receipt of signed consent, we sent the three case vignettes and questionnaire. We asked CDOPs to review the cases at a panel meeting in their normal way, and to complete the questionnaire based on their case review. CDOPs were asked to state what they would normally record as the cause of death for such cases, and what they considered the correct cause of death for each case. All questionnaires were returned by 30 April 2018.

We contacted the British and Irish Paediatric Pathologists Association (BRIPPA), who sent an email invitation with a link to the survey to all members in November 2018. Two reminder emails were sent. The survey was closed on 31 January 2019.

Statistical Analysis

We entered the information from questionnaires into an SPSS database. We used descriptive statistics for analysis although the numbers were too small for meaningful comparison.

Ethical Approval

The study received ethical approval from the University of Warwick Biomedical and Scientific Research Ethics Sub-committee reference REGO-2018-2228.

RESULTS

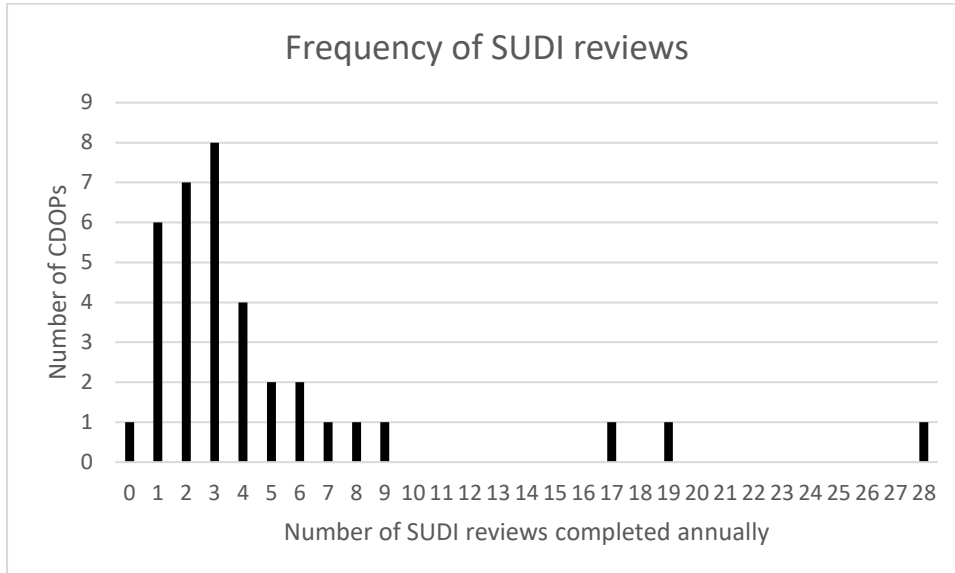
We invited all 92 English CDOP to participate, 48 (52%) responded, and 38 (41%) returned completed questionnaires. Three of 38 participating CDOPs did not consider the cases and gave information on local SUDI investigative practices only. One CDOP did not detail local SUDI practices.

The pathologists' survey was sent to all 90 members on the email list of BRIPPA, 30 (33%) pathologists accessed the survey and 13 (14%) completed it.

Frequency of SUDI reviews

The number of SUDI reviewed by each CDOP annually ranged from 0-28 with a median of 3; 75% of CDOPs reviewed 5 or less cases per year. The frequency of SUDI reviews is shown in figure 1.

Figure 1 Frequency of SUDI reviews



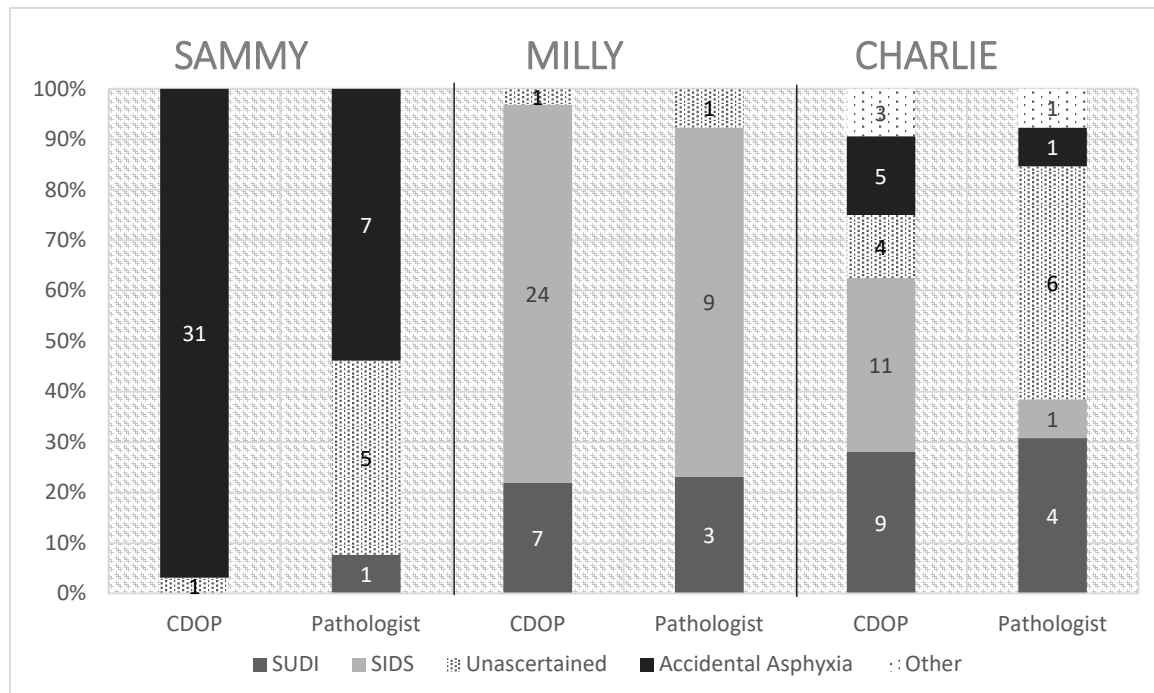
Causes of death

In response to the question ‘What cause of death would your CDOP normally record for a case such as this?’ 35 CDOPs responded, they most frequently stated they would record whatever the conclusion of the post-mortem examination was. 16 of 35 (46%) CDOPs responded this way for CHARLIE’s case, 13 (37%) for MILLY and 15 (43%) for SAMMY. Some CDOPs further commented that it was not their remit to consider the cause of death as they always accepted the post-mortem conclusion; and three CDOPs did not answer further questions on the cause of death.

32 CDOPs gave answers to the question ‘What do you actually think is the correct cause of death?’ All but one CDOP gave the cause of death for SAMMY as accidental asphyxia, however nearly half of pathologists recorded unascertained or SUDI. CDOPs and pathologists had very similar responses for MILLY with the most frequent cause of death given as SIDS followed by SUDI in both groups. There was considerable variation in the cause of death given by both CDOPs and pathologists for CHARLIE with no majority for any cause. The most common cause stated by CDOPs was SIDS (11 (34%) of 32)

or SUDI (9 (28%) of 32) whereas the most common cause stated by pathologists was unascertained (6 (46%) of 13). Three CDOPs gave other causes for CHARLIE, these were: ‘multifactorial – illness, small and overheating’, ‘illness and suffocation’ and ‘anything but SIDS’, one pathologist gave another cause ‘unexplained SUDI’. The comparison of causes of death is shown in figure 2.

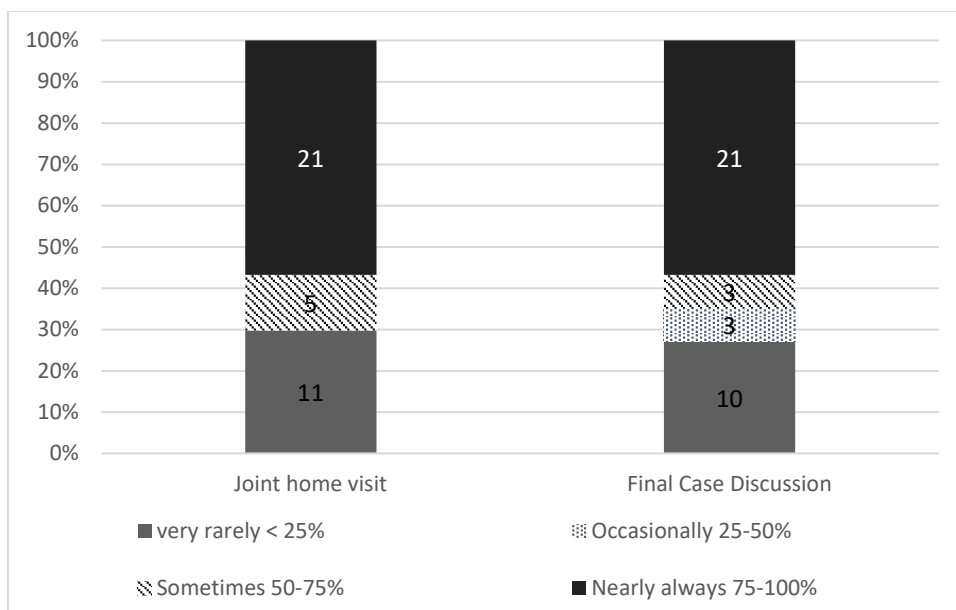
Figure 2 Comparison of causes of death



Compliance with national standards for SUDI investigations

21 (57%) of 37 CDOPs reported that joint home visits by police and healthcare professionals take place for between 75 to 100% of SUDI cases, but 11 (30%) stated that these rarely occurred, happening in less than 25% of cases. 21 (55%) of CDOPs also reported that final case discussions took place for between 75-100% of SUDI cases, but 10 (27%) stated that these rarely occurred, happening in less than 25% of cases. 17 (46%) CDOPs reported both joint home visits and final case discussions taking place more than 75% of the time, and 8 (22%) of 37 reported that both these happened less than 25% of the time. These are shown in figure 3.

Figure 3 Compliance with national standards for SUDI investigation



DISCUSSION

There is considerable variation in the classification of sleep-related SUDI cases from both CDOPs and paediatric pathologists. The cases of *CHARLIE* and *MILLY* were written based on internationally agreed diagnostic criteria for SIDS (3). For *CHARLIE*, more than 5 different causes of death were given; only 11 (34%) CDOPs and 1 (8%) pathologist stated SIDS as the cause of death. This case involved a vulnerable infant in a hazardous co-sleeping environment (17), with features that could be consistent with accidental asphyxia, but no clear evidence of this; nevertheless, 5 CDOPs gave accidental asphyxia as the cause of death. There was greater agreement with the case of *MILLY*, who died in a safe-sleep environment where 24 (75%) CDOPs and 9 (69%) pathologists gave SIDS as a diagnosis, with the remainder stating unascertained or SUDI as the cause. For *SAMMY*, who died co-sleeping on a sofa with an intoxicated parent, 31 (94%) CDOPs stated the cause of death was accidental asphyxia but only 7 (54%) pathologists did so, with the remainder stating unascertained or SUDI. Despite the divergence of opinion, almost half of CDOPs stated that they normally did not consider the cause of death, but accepted the cause of death as given by the pathologist.

CDOPs have been reviewing all child deaths in England since 1st April 2008, so are familiar with cases such as these; this study therefore reflects normal CDOP practices. The cases were reviewed and refined by international SIDS experts for clarity of diagnosis, and were designed as typical SUDI cases

presenting in clinical practice, strengthening the generalisability of the findings. Our findings are unique, in that identical cases were sent to both professional groups but were limited by the low response rate in particular from paediatric pathologists. It would be informative to repeat the study with coroners.

Our findings of a wide variation in practice in SUDI classification was also reported in a much larger survey of US Medical Examiners and Coroners (15). We found that CDOPs much more readily classified deaths as due to accidental asphyxia than pathologists; a recent review of SUDI cases in Australia also showed that pathologists consistently under-diagnosed accidental asphyxia (14). Similarly, a review of infant suffocation deaths in New Zealand reported that only 75% were initially categorised as such (13). The tendency among both CDOPs and pathologists to give SUDI as the cause of death for some cases is concerning, since this is not a diagnostic term, and was always meant to be used as a descriptive term for sudden and unexpected infant deaths requiring further investigation. A recent international consensus on SUDI classification has suggested that deaths certified as unexplained SUDI are coded as SIDS, using the proposed new ICD 11 codes (4), which would provide greater consistency.

This study provides further evidence that the classification of SUDI in England is confused. Cases that could be diagnosed as SIDS are labelled unascertained, denying parents of a diagnostic label that has brought comfort to many, while cases of accidental asphyxia are not recognised as such, potentially limiting learning and preventative strategies. Some of this ambiguity could be avoided by rigorous adherence to the national standards for SUDI investigation. By pulling together the full multi-agency findings, including the history, scene examination and autopsy findings, the final case discussion is ideally placed to provisionally determine the cause of death and to share these conclusions with the coroner in order to inform their decision. Similarly in Sweden, the lack of home visits and death scene investigations contributes to the low diagnostic rate for accidental asphyxia (11). We found that compliance with national standards for SUDI investigation was low: just under half of CDOPs

reported both joint home visits and final case discussions taking place more than 75% of the time. This lack of implementation of multi-agency SUDI investigation was also found in a retrospective analysis of English SUDI cases between 2008-17 (18), our findings show this is an ongoing significant concern given that this is a statutory requirement. Poor coordination between coronial and multi-agency investigation may also be contributing to the difficulties (19).

To improve this situation there needs to be a concerted effort to ensure that full multi-agency SUDI investigation becomes embedded in routine clinical practice, and that failure to implement national statutory guidance is not an option. Currently there is no national SUDI multi-agency training, to ensure that professionals have the skill and understanding to contribute to investigations and discussions around the cause of death and that reports share the same standards; this needs addressing as a matter of urgency. The 2016 Kennedy Guidelines(5), gave clear directions as to the terminology to be used for infant deaths; these are summarised in Box 1. These recommendations are consistent with a new international consensus on the classification of SUDI (4), and the Kennedy guidelines in their entirety are endorsed by the Royal College of Pathologists, Royal College of Paediatrics and Child Health and the Chief Coroner. We should seek to follow these accepted best practices for investigation and classification of SUDI so that we can appropriately diagnose SIDS, recognise accidental asphyxial deaths, increasing our learning and helping to prevent future infant deaths.

Box 1 Summary on recommended terminology for infant deaths from 2016 Kennedy Guidelines(5)

ACKNOWLEDGEMENTS

Competing Interests

JG has received research grants from the National Institute of Health Research (DRF 2010-0345) and is an executive committee member of the National Network of Child Death Overview Panels.

PS is a trustee of the Lullaby Trust and the Association of Child Protection Professionals. He is a member of the National Panel for Child Safeguarding Practice Reviews. PS contributed to the development of national guidelines for both SUDI investigation and child death review.

All other authors declare no competing interests.

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TABLES AND FIGURES

Table 2 Summary of SUDI cases

Case	Summary of circumstances of final sleep	Proposed Diagnostic Category
SAMMY	Male infant, minor viral symptoms, 11 weeks old, slept on sofa with father who consumed 4 cans of strong lager. Found between father and back of sofa with face wedged against sofa cushions.	Accidental Asphyxia
MILLY	Female infant, minor viral symptoms, 10 weeks, placed to sleep on her back in a Moses basket, found in same position.	SIDS ³ using the internationally agreed San Diego Diagnosis
CHARLIE	Male infant, minor viral symptoms, 9 weeks old, placed to sleep in between parents in double bed, mother consumed 1 can of cider, father 2 cans of lager. Found lying on his back, on top of the duvet, one blanket folded double loosely covering his face.	SIDS ³ using the internationally agreed San Diego Diagnosis with some features that could be consistent with but not conclusive of asphyxia

Box 1 Summary on recommended terminology for infant deaths from 2016 Kennedy Guidelines (5)

“It is our recommendation that:

- professionals working together in responding to unexpected child deaths use the terms ‘SUDI/SUDC’ at the point of presentation to include all unexpected infant/child deaths
- those deaths for which a clear medical or external cause is found should be referred to as such as soon as the cause is identified
- those infant deaths under 12 months of age that meet the criteria for a diagnosis of SIDS are labelled as such
- all other unexplained deaths are referred to as ‘SUDI, unexplained’, ‘SUDC, unexplained’ or ‘Unascertained’ until such time that the coroner issues a legal cause of death following an inquest that has taken full account of information from the rapid response multi-agency investigation and the local case review meeting (5).”

Appendix S1

Case Summary for SUDI case Sammy, male infant aged 11 weeks

Summary of Case and Circumstances leading to death:

Sammy was the fourth child to both parents. He was found unresponsive on the sofa where he had spent the night with his father. A 999 call was made at 0930 on 28 Feb 17, paramedics attended the home within 6 minutes. Sammy was stiff and cold; he was declared dead at the scene by paramedics and subsequently taken to the Emergency Department with his parents.

A joint agency investigation was commenced according to local guidelines.

The day before his death he had seemed slightly unwell with loose stools and decreased feeding. Mother did not seek medical advice as she was not concerned about him and the older children had recently had stomach upsets.

In the evening, Sammy seemed happy and fed well taking approximately 200 mls of formula at 8pm. He was sleeping on the sofa next to his father who was watching TV. Mother went to sleep in the bedroom at around midnight, having put the other children to bed at 10pm. Sammy woke at around 1 am and Father gave him approximately 100mls of formula. Father lay Sammy in the crook of his arm while he continued watching TV. Sammy often slept on the sofa with Father as Mother slept in the double bed with two of the older children (Katie age 18 months, Harry age 3).

Father drank 4 cans of strong lager between 8pm and midnight, he did this on most nights.

At 0930 Mother entered the sitting room and saw Father was still asleep; initially she could not see Sammy so woke Father to ask where he was. As Father got up they both realised Sammy had fallen between Father and the back of the sofa. His face was wedged against the sofa cushions.

Background Medical History

Gestation 41 weeks Birth weight 4500gm

Last recorded weight (8 weeks) 5900gm

Received 1 dose infant immunisations age 8 weeks

White British ethnicity, no stated religion

No known disability

Sammy was born induced at 41 weeks gestation due to post maturity. He was bottle fed, and grew along the 75 centile. Mother first attended antenatal clinic at 24 weeks gestation, she missed several midwife appointments subsequently. Neither Mother nor Sammy had attended the 6 week postnatal appointment although he was brought for immunisation at 8 weeks.

Family details

Mother aged 24, full time carer

Father aged 28, unemployed

Three siblings, Katy 18mths, Harry 3 yrs, Bruce 6 yrs

Father is known to police for theft and driving while banned.

Mother smoked 10 cigarettes per day and continued throughout pregnancy. Father smokes 20 cigarettes daily and occasional cannabis. The house smelled strongly of smoke during the joint home visit.

The health visitor had provided safe-sleep advice and completed the safe sleep risk assessment as part of the primary visit when Sammy was 10 days old.

Sammy was not known to social care. The family had been referred to social care 3 years previously following an unexplained injury to Bruce, initially they were supported with a child in need plan but this was closed 2 years ago.

Bruce often attends school late and his attendance is 85%. Harry is not registered for nursery although he is eligible for a place.

Case Summary for SUDI case Milly, female infant aged 10 weeks

Summary of Case and Circumstances leading to death:

Milly was the third child born to both parents. She was found unresponsive, on her back, in her moses basket at 0030 on 28 Feb 17, aged 10 weeks. Paramedics attended the home within 7 minutes of the 999 call, Milly was transferred to the Emergency Department but declared dead at 0130 following prolonged attempts at resuscitation. A joint agency investigation was commenced according to local guidelines.

The day before her death she had seemed not quite herself, being more sleepy, slightly irritable and feeding less. Mother assumed that she was teething so took no further action.

In the evening, Milly seemed happier and fed better taking approximately 150 mls of formula at 1900 and a further 100mls when she woke at 2300. She was put down to sleep in her moses basket, on her back, in her parents bedroom at 2330. She was wearing a sleep suit, vest and cardigan, and was covered by one blanket folded double.

At 0030, her mother went upstairs to go to bed. When she put the light on she noticed Milly looked very white. Milly was lying on her back in the exact same position she had been left in. The blanket was pulled up to chest height; it was not over her face. Mother lifted Milly out of the moses basket and realised she was not breathing. Milly was still warm. Parents commenced CPR and contacted emergency services.

Background Medical History

Gestation 38 weeks Birth weight 2400gm

Last recorded weight (8 weeks) 3900gm

Received 1 dose infant immunisations age 8 weeks
White British ethnicity, Church of England religion
No known disability

Milly was born spontaneously at 38 weeks gestation, she was discharged from hospital aged 14 hours. She was bottle fed from birth. She was born on the second centile and had followed this since birth. Mother had attended all health appointments antenatally and postnatally. Milly was known to universal health services. She saw the GP for her 8 week check and no concerns were noted.

Family details

Mother aged 27, stay at home mother

Father aged 34, works as truck driver

Jake (brother) aged 3 years, Lisa (sister) aged 2 years. Jake had been diagnosed with asthma, glue ear and speech delay.

Parents are not known to police.

Mother had suffered from post-natal depression with Jake and Lisa but had not reported any symptoms with Milly. The family were seen regularly by the Health Visitor.

Mother smoked 5 cigarettes per day, she had smoked until 8 weeks pregnant when she managed to stop altogether. Mother restarted smoking when Milly was 10 days old. Father smokes 20 cigarettes daily. Both parents smoke outside the house.

At the joint home visit, the house did not smell of smoke. The temperature in a bedroom drawer was 21°C.

Neither parent consumed any alcohol on the night Milly died. The parents consume alcohol only occasionally when socialising with friends.

Paternal grandparents lived locally and grandmother came to visit once a week.

The health visitor had provided safe-sleep advice and completed the safe sleep risk assessment as part of the primary visit when Milly was 10 days old.

Milly was not known to social care.

Jake attends nursery class at the local primary school; his attendance is 90%. School have no concerns about the family.

Case Summary for SUDI case Charlie, male infant aged 9 weeks

Summary of Case and Circumstances leading to death:

Charlie was the first child to both parents. He was found unresponsive in bed between both his parents at 0800 on 28 Feb 17, aged 9 weeks. Paramedics attended the home within 10 minutes of the 999 call, Charlie was transferred to the Emergency Department but declared dead at 0825. A joint agency investigation was commenced according to local guidelines.

The day before his death he had seemed slightly unwell with an upper respiratory tract infection, having a cough, runny nose and reduced feeds. Mother took him to the Walk in Centre in the morning where he was reviewed by a GP, all observations were within normal parameters, mother was reassured and sent home.

In the evening, Charlie seemed happier and fed better taking approximately 150 mls of formula at 8pm. He was put down to sleep in his cot in the parents bedroom at 8.30pm, he awoke again at 0200

and had a 100ml formula feed. He seemed slightly unsettled so Mother put him in bed between her and Father, this was their usual practice if Charlie awoke in the early hours.

Mother drank 1 can of cider around 9pm, Father had 2 cans of lager during the evening.

At 0800 Father woke and realised that Charlie was not breathing and looked blue. Charlie was lying on top of the duvet on his back between his parents. He was wearing a vest, baby grow and cardigan. He was covered by one blanket folded double, this was loosely covering his face.

Background medical history

Gestation 37 weeks Birth weight 2100gm Last recorded weight (8 weeks) 3900gm

Received 1 dose infant immunisations age 8 weeks

White British ethnicity, Roman Catholic religion

Charlie was born spontaneously at 37 weeks gestation, he remained in hospital for 3 days due to difficulties establishing feeds. He was bottle fed. He was born on the second centile and had followed this since birth. He remained a difficult baby to feed taking a long time to complete feeds and was often unsettled during feeding - mother had discussed this with the health visitor. This had improved by the time of his first immunisations.

Family details

Mother aged 21, worked in call centre

Father aged 24, works as labourer

No siblings

Parents are known to police due to 2 reports of domestic violence during the pregnancy.

Mother had seen the GP to talk about post-natal depression having been referred by the Health Visitor. The GP had suggested medication but mother was not keen. Mother had attended all health appointments antenatally and postnatally. Mother seemed to have a good bond with Charlie.

Mother smoked 10 cigarettes per day, she had smoked until 20 weeks pregnancy when she managed to stop altogether. Mother restarted smoking when Charlie was 3 weeks old. Father smokes 15 cigarettes daily. Both parents smoke outside the house.

Father had been in foster care as a teenager following a family breakdown. The parents had started their relationship only shortly before Mother became pregnant. Maternal grandparents lived locally and grandmother came to visit several times a week.

The health visitor had provided safe-sleep advice and completed the safe sleep risk assessment as part of the primary visit when Charlie was 10 days old.

Charlie was not known to social care.

Appendix S2

Survey of CDOP classification of infant sleep deaths

Instructions for CDOPs

1. Please distribute the case summaries (Form B) for the infants Charlie, Milly and Sammy as you would normally for your CDOP meeting. If your usual practice is to send out Form Bs prior to panel for members to read beforehand please do send the case summaries too.
2. As part of your CDOP meeting please discuss the three cases and complete questions 1-6 for CHARLIE (CO-SLEEPING DEATH), questions 7-12 for SAMMY (SOFA DEATH) and 13-18 for MILLY

(MOSES BASKET DEATH). Take care not to confuse CHARLIE, SAMMY and MILLY. There is no need to complete a CDOP form C for these cases.

3. The questions 19 -22 are about local practices in investigating SUDI; these should be completed by the CDOP manager.

4. Once complete please email the questionnaire back to Joanna.garstang@nhs.net or send via post to: Dr J. Garstang, Room B028, Warwick Medical School, Gibbet Hill Road, Coventry CV4 7AL.

Many thanks for your time and help with this project.

Date of panel meeting

Questions about CHARLIE (CO-SLEEPING BED)

1. What cause of death would your CDOP normally record for a case such as Charlie?
.....

2. Which of these words best describes this cause of death: please tick ONE box only

- Unascertained
- SIDS (Sudden Infant Death Syndrome)
- SUDI (Sudden Unexpected Death in Infancy)
- Accidental Asphyxia
- Other

3. What do you actually think is the correct cause of death for Charlie?
.....

4. Which of these words best describes this cause of death: please tick ONE box only

- Unascertained
- SIDS (Sudden Infant Death Syndrome)
- SUDI (Sudden Unexpected Death in Infancy)
- Accidental Asphyxia
- Other

5. Please list any relevant risk factors identified from the case history

6. Please categorise CHARLIE (CO-SLEEP) death based on the answer given in question 3 using the following scheme.

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	Deliberately inflicted injury, abuse or neglect 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	Suicide or deliberate self-inflicted harm 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	Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect. (category 1).	<input type="checkbox"/>
4	Malignancy 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	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	<input type="checkbox"/>
6	Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.	<input type="checkbox"/>
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	<input type="checkbox"/>
8	Perinatal/neonatal event 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 includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).	<input type="checkbox"/>
9	Infection 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	Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).	<input type="checkbox"/>

Questions about SAMMY (SOFA)

7. What cause of death would your CDOP normally record for a case such as Sammy?

.....

8. Which of these words best describes this cause of death: please tick ONE box only

Unascertained

SIDS (Sudden Infant Death Syndrome)

SUDI (Sudden Unexpected Death in Infancy)

Accidental Asphyxia

Other

9. What do you actually think is the correct cause of death for Sammy?

.....

10. Which of these words best describes this cause of death: please tick ONE box only

Unascertained

SIDS (Sudden Infant Death Syndrome)

SUDI (Sudden Unexpected Death in Infancy)

Accidental Asphyxia

Other

11. Please list any relevant risk factors identified from the case history

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.....

12. Please categorise SAMMY (SOFA) death based on the answer given in question 9 using the following scheme.

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	Deliberately inflicted injury, abuse or neglect 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	Suicide or deliberate self-inflicted harm 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	Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect. (category 1).	<input type="checkbox"/>
4	Malignancy 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	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	<input type="checkbox"/>
6	Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.	<input type="checkbox"/>
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	<input type="checkbox"/>
8	Perinatal/neonatal event 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 includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).	<input type="checkbox"/>
9	Infection 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	Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).	<input type="checkbox"/>

Questions about MILLY (MOSES BASKET)

13. What cause of death would your CDOP normally record for a case such as Milly?
.....

14. Which of these words best describes this cause of death: please tick ONE box only

- Unascertained
- SIDS (Sudden Infant Death Syndrome)
- SUDI (Sudden Unexpected Death in Infancy)
- Accidental Asphyxia
- Other

15. What do you actually think is the correct cause of death for Milly?
.....

16. Which of these words best describes this cause of death: please tick ONE box only

- Unascertained
- SIDS (Sudden Infant Death Syndrome)
- SUDI (Sudden Unexpected Death in Infancy)
- Accidental Asphyxia
- Other

17. Please list any relevant risk factors identified from the case history

.....
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.....

18. Please categorise MILLY (MOSES BASKET) death based on the answer given in question 15 using the following scheme.

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	<p>Deliberately inflicted injury, abuse or neglect 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.</p>	<input type="checkbox"/>
2	<p>Suicide or deliberate self-inflicted harm 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.</p>	<input type="checkbox"/>
3	<p>Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect. (category 1).</p>	<input type="checkbox"/>
4	<p>Malignancy Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.</p>	<input type="checkbox"/>
5	<p>Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.</p>	<input type="checkbox"/>
6	<p>Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.</p>	<input type="checkbox"/>
7	<p>Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.</p>	<input type="checkbox"/>
8	<p>Perinatal/neonatal event 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 includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).</p>	<input type="checkbox"/>
9	<p>Infection 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.</p>	<input type="checkbox"/>
10	<p>Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).</p>	<input type="checkbox"/>

Questions about local SUDI investigations

13. How many SUDI cases (unexpected infant deaths of any cause) did your CDOP review in 2016?

.....

14. How often do joint home visits take place as part of SUDI investigations in your area? (A joint home visit is where the police, paediatrician or specialist nurse visit the home together with the parents to see where the infant died).

Please tick one box

Very rarely – in up to 25% of SUDI cases

Occasionally – between 25-50% of SUDI cases

Sometimes – between 50-75% of SUDI cases

Nearly always – more than 75% of SUDI cases

15. How often is a final case discussion held at the end of SUDI investigations in your area? (A final case discussion is a multi-agency meeting held by the professionals involved in the SUDI investigations to review the findings, discuss causes and risk factors for death, and plan follow-up for the family)

Please tick one box

Very rarely – in up to 25% of SUDI cases

Occasionally – between 25-50% of SUDI cases

Sometimes – between 50-75% of SUDI cases

Nearly always – more than 75% of SUDI cases

16. If you have any other comments please feel free to write them here

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.....

Many thanks for your time and help in completing this questionnaire.

The infant has fair coloured skin. He appears well nourished and well cared-for. There is anterior hypostasis, with paleness around the mouth, nostrils and forehead. There are petechiae related to the lividity on the left part of the thorax and shoulder. The face appears normal with normally sited ears, patent choanae and normal closure of the lip and palate. There are no tears of the frenula of the mouth or tongue. The eyes are normal. The pupils are equal and central. There are no conjunctival petechiae. The anterior fontanelle is closed. The back, thorax, abdomen and limbs appear normally formed. The hands and feet are normally formed with five digits on each extremity and normal palmar creases. The external genitalia are of normal male type and the anus is normal. There is no nappy rash.

No evidence of bruises or injury seen.

INTERNAL EXAMINATION:

Cardiovascular system:

PERICARDIUM: Normal.

HEART: The heart is of a normal size and its position is situs solitus. There are no epicardial petechiae. The systemic and pulmonary venous return is normal. The atrio-ventricular and ventriculo-arterial connections are concordant. The chambers are normal with patent valves. There is no defect of the atrial or ventricular septum and the ventricular myocardium is normal. The foramen ovale and ductus arteriosus are closed. The coronary ostia are normally sited and patent. The great vessels are normally arranged and there are two umbilical arteries.

Respiratory system:

LARYNX, TRACHEA AND MAJOR BRONCHI: Appear normally formed.

DIAPHRAGM: Appears normal.

PLEURAL CAVITIES: Normal and contain minimal fluid.

LUNGS: The lungs are of normal size and show normal lobation. The parenchyma is congested. The pleural surfaces of the lungs show few petechiae. There are no pneumothoraces.

Gastrointestinal system:

MOUTH, MAJOR SALIVARY GLANDS, TONGUE and OESOPHAGUS: Appear normally formed.

PERITONEAL CAVITY: Normal and contains minimal fluid.

STOMACH: Normal and contains 16mls of milk curd.

INTESTINES: Are normally fixed and rotated. No evidence of ischaemia or haemorrhage is seen.

LIVER: The liver appears normally formed with normal external and cut surface.

GALL BLADDER and PANCREAS: Normal.

Reticuloendothelial system:

SPLEEN: The spleen appears normal with a granular cut surface.

MESENTERIC LYMPH NODES: Enlarged.

THYMUS: Normal.

Surface petechiae are seen.

Endocrine system:

THYROID: Appears normal.

ADRENALS: Normal.

PITUITARY: Appears normal.

Genitourinary System:

KIDNEYS: The kidneys are normally sited and are of normal size. They show normal lobulation. No abnormality of the external or cut surfaces is identified and the pelvicalyceal system is not dilated.

URETERS: There is a single ureter of normal calibre on each side.

BLADDER: Is normal and empty.

INTERNAL GENITALIA: The testes are normal and are fully descended.

Musculoskeletal system and skin:

The skin is pale.

The subcutaneous fat thickness is 1cm.

The muscle bulk appears normal and no abnormality of the bones and joints is identified. On examination of the internal aspect of the thoracic cage, no rib fractures are identified. The spine appears normal.

Skull and central nervous system:

SCALP: Appears normal.

SKULL: Normal cranial bones, anterior fontanelles, dural folds and venous sinuses.

MENINGES: Normal.

CEREBROSPINAL FLUID: There is a small amount of clear cerebrospinal fluid.

BRAIN: Neuropathology was performed on 03.05.17

Cerebral Hemispheres: Gyral development is consistent with the age. There are two symmetrical cerebral hemispheres with normal olfactory and optic nerves. The corpus callosum is present.

The ventricles, cerebellum, mesencephalon, pons and medulla oblongata are normal

The falx and tentorium show no haemorrhage.

MIDDLE EARS: Clear.

SPINAL CORD: Not examined.

MORPHOMETRIC INDICES AND ORGAN WEIGHTS:

	Observed	Expected at 11 weeks of age
Body weight (Kg)	6850	75 th centile
Foot length - Left (cm)	9.4	
Crown-rump length (cm)	62	75 th centile
Crown-heel length (cm)	44	57±3.7
Chest circumference (cm)	42	
Abdominal circumference (cm)	41	
Head circumference (cm)	41	75 th centile
Brain (g)	747	674 (542 – 768)
Thymus (g)	38.88	37.9 (16.7 – 72.9)
Heart (g)	31	33.5 (16.0 – 50.0)
Lungs (g)	111	140 (103 – 204)
Liver (g)	266	235 (186 – 304)
Spleen (g)	44	25.9 (12.5 – 41.5)
Pancreas (g)	5.06	5.19 (0.30 – 10.2)
Kidneys (g)	89.10	46.7 (27.3 – 77.2)
Adrenals (g)	6.10	4.69 (2.90 – 9.38)

Brain: The sections show normally developed cortex. The white matter is congested. The ventricles appear normal with no evidence of intra or periventricular haemorrhage. Both hippocampi are normal. The deep grey matter is normal. Mid brain structures with pons medulla oblongata and mesencephalon are normally developed.

Spinal cord: Normal.

Cerebellum: Normal folia and normal nuclei.

Falx: There is minimal haemorrhage in the posterior falx.

Pituitary: Normal.

Thymus: Normal.

Cortex and medulla: Occasional petechiae.

Thyroid: Normal.

Trachea: Normal.

Lungs: Section taken from each lobe of both lung shows evidence of patchy intraalveolar oedema and intraalveolar fresh bleeding. There is no evidence of any infectious process.

Heart: Normal. No excess of lipid deposition with Oil-red-O stains.

Diaphragm: Normal.

Muscle: Normal.

Liver: Normal portal tracts and cords of hepatocytes. No excess of lipid deposition is seen with Oil-red-O stains.

Oesophagus: Normal

Stomach: Normal.

Intestines: Normal.

Mesenteric lymph node: Normal.

Spleen: Congested red pulp with presence of patchy haemorrhage.

Pancreas: Normal endocrine and exocrine components.

Adrenals: Normal.

Kidneys: Normal glomeruli and tubules. There is no excess of lipids identified with Oil-red-O stains.

Bladder: Normal.

Ribs: Normal haematopoietic cell elements. Normal chondrocostal junction.

ANCILLARY INVESTIGATIONS

Fluid Cyto, reported by Department of Paediatric Haematology, No unequivocal NRBCs seen on blood film.

Blood, VITDB2, reported by Clinical Chemistry Department

<u>Vitamin D</u>	Total 25-OH Vitamin D	88.3 nmol/L
	25-Hydroxy Vitamin D2	<6.0 nmol/L
	25-Hydroxy Vitamin D3	88.3 nmol/L

Blood culture, reported by Department of Microbiology, Enrichment Aerobic bottle negative. Single bottle only FINAL REPORT.

Cerebrospinal fluid, reported by Department of Microbiology: Volume Number of bottles 1. Total volume (mls) 2. Appearance Pink turbid fluid. Gram film Organisms NOT seen. Routine culture No growth obtained. Further requests (referred) CSF viral studies to follow.

Faeces, reported by Department of Microbiology, Rotavirus EIA Rotavirus DETECTED. Cryptosporidium stain Cryptosporidium oocysts NOT seen. Faecal culture Salmonella sp. NOT isolated. Shigella spp. NOT isolated. Escherichia coli 0157 NOT isolated. Campylobacter culture Campylobacter NOT isolated.

Bronchial swab, reported by Department of Microbiology, Fungal culture Fungi NOT isolated. Mycoplasma culture Mycoplasma hominis/Ureaplasma NOT isolated. Routine culture Yielded commensals only.

Lung Swab, reported by Department of Microbiology,: Fungal culture Fungi NOT isolated. Mycoplasma culture Mycoplasma hominis/Ureaplasma NOT isolated. Routine culture Yielded commensals only.

Nasal swab, reported by Department of Microbiology, Routine culture Moderate growth of Streptococcus pneumoniae. Sensitive: Penicillin. Neisseria culture Neisseria meningitidis Not isolated.

Tissue Culture & Enzyme Assay, reported by Dr X, Consultant Clinical Scientist, Children's Hospital:

We have measured fatty oxidation flux with the following results:-

Tritium Release Assay of β -oxidation of Fatty Acids

FIBROBLASTS: Screening tests for defects in mitochondrial β -oxidation using [9,10³H]myristate and [9,10³H]palmitate and [9,10³H]oleate. Results are expressed as percentage of simultaneous controls.

Assay	Myristate	Palmitate	Oleate
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Date	(% of simultaneous controls)	(% of simultaneous controls)	(% of simultaneous controls)
01/03/17	93	92	102
01/03/17	97	100	107

Each result is the duplicate mean determination

These results are essentially **NORMAL** and exclude nearly all primary defects of long and medium chain fatty acid oxidation.

Dried Blood Spot, reported by Clinical Chemistry Department, Children's NHS Foundation Trust,

PM Acyl carnitine

Post mortem dried blood spot acylcarnitine profile. No significant abnormality detected.

(Post-mortem dried blood spots typically have high C3, C4, hydroxy –C4 and C6 acylcarnitines). Post mortem sample.

Tissue Lung, reported by Department of Microbiology,

Respiratory PCR

Result from reference lab:

Test referred to: HPA laboratory, Leeds

Test result:

No respiratory viruses detected by PCR.

Cerebrospinal Fluid, Virology, reported by Microbiology Dept,

Adenovirus PCR

Adenovirus PCR Inhibitory

Herpes Group Viruses

Herpes Simplex PCR Inhibitory

Varicella Zoster PCR Inhibitory

Enterovirus PCR

Enterovirus PCR Inhibitory

Nose Swab, reported by Department of Microbiology, Respiratory virus PCRs

RHINOVIRUS DETECTED

- The external examination was unremarkable.
- The internal examination showed a few petechiae on the lungs and thymus.
- The histology was unremarkable. The ancillary investigations identified the presence of adenovirus in the faeces; rhinovirus, parainfluenza 4 and enterovirus were cultured from the nose swab.
- Milly had been slightly unsettled the previous night. Her mum put her to sleep on her back in her Moses basket as usual.
- The only risk factors identified in this case was parental smoking

MACROSCOPIC FINDINGS

EXTERNAL EXAMINATION:

The body is that of a normally formed female infant identified by hospital name bands present on left ankle.

The following marks of resuscitation are noted:

- Intraosseous needle mark on left shin.

The infant has fair coloured skin. She appears well nourished and well cared-for. There is posterior hypostasis, with paleness around the buttocks. There are petechiae related to the lividity over the upper back and shoulders. The face appears normal with normally sited ears, patent choanae and normal closure of the lip and palate. There are no tears of the frenula of the mouth or tongue. The eyes are normal. The pupils are equal and central. There are no conjunctival petechiae. The anterior fontanelle is patent. The back, thorax, abdomen and limbs appear normally formed. The hands and feet are normally formed with five digits on each extremity and normal palmar creases. The external genitalia are of normal female type and the anus is normal. There is no nappy rash.

No evidence of bruises or injury seen.

INTERNAL EXAMINATION:

Cardiovascular system:

PERICARDIUM: Normal.

HEART: The heart is of a normal size and its position is situs solitus. There are no epicardial petechiae. The systemic and pulmonary venous return is normal. The atrio-ventricular and ventriculo-arterial connections are concordant. The chambers are normal with patent valves. There is no defect of the atrial or ventricular septum and the ventricular myocardium is normal. The foramen ovale and ductus arteriosus are closed. The coronary ostia are normally sited and patent. The great vessels are normally arranged and there are two umbilical arteries.

Respiratory system:

LARYNX, TRACHEA AND MAJOR BRONCHI: Appear normally formed.

DIAPHRAGM: Appears normal.

PLEURAL CAVITIES: Normal and contain minimal fluid.

LUNGS: The lungs are of normal size and show normal lobation. The pleural surfaces of the lungs show few petechiae. There are no pneumothoraces.

Gastrointestinal system:

MOUTH, MAJOR SALIVARY GLANDS, TONGUE and OESOPHAGUS: Appear normally formed.

PERITONEAL CAVITY: Normal and contains minimal fluid.

STOMACH: Normal and contains 16mls of milk curd.

INTESTINES: Are normally fixed and rotated. No evidence of ischaemia or haemorrhage is seen.

LIVER: The liver appears normally formed with normal external and cut surface.

GALL BLADDER and PANCREAS: Normal.

Reticuloendothelial system:

SPLEEN: The spleen appears normal with a granular cut surface.

MESENTERIC LYMPH NODES: Enlarged.

THYMUS: Normal.

A few surface petechiae are seen.

Endocrine system:

THYROID: Appears normal.

ADRENALS: Normal.

PITUITARY: Appears normal.

Genitourinary System:

KIDNEYS: The kidneys are normally sited and are of normal size. They show normal lobulation. No abnormality of the external or cut surfaces is identified and the pelvicalyceal system is not dilated.

URETERS: There is a single ureter of normal calibre on each side.

BLADDER: Is normal and empty.

INTERNAL GENITALIA: The ovaries and uterus are normal.

Musculoskeletal system and skin:

The skin is pale.

The subcutaneous fat thickness is 1cm.

The muscle bulk appears normal and no abnormality of the bones and joints is identified. On

examination of the internal aspect of the thoracic cage, no rib fractures are identified. The spine

appears normal.

Skull and central nervous system:

SCALP: Appears normal.

SKULL: Normal cranial bones, anterior fontanelles, dural folds and venous sinuses.

MENINGES: Normal.

CEREBROSPINAL FLUID: There is a small amount of clear cerebrospinal fluid.

BRAIN: Neuropathology was performed on 03.05.17

Cerebral Hemispheres: Gyral development is consistent with the age. There are two symmetrical cerebral hemispheres with normal olfactory and optic nerves. The corpus callosum is present.

The ventricles, cerebellum, mesencephalon, pons and medulla oblongata are normal

The falx and tentorium show no haemorrhage.

MIDDLE EARS: Clear.

SPINAL CORD: Not examined.

MORPHOMETRIC INDICES AND ORGAN WEIGHTS:

	Observed	Expected
Body weight (Kg)	4585	
Foot length - Left (cm)	8.4	
Crown-rump length (cm)	40	
Crown-heel length (cm)	59	
Chest circumference (cm)	45	
Abdominal circumference (cm)	39	
Head circumference (cm)	37	
Brain (g)	620	607 (556 – 679)
Thymus (g)	30	27.7 (10.7 – 48.8)
Heart (g)	32	29.0 (21.5 – 35.5)
Lung left and right (g)	130	121 (99.6 – 142)
Liver (g)	190	177 (130.0 – 234)
Spleen (g)	20	17.3 (11.2 – 29.3)
Pancreas (g)	8	5.26 (2.86 – 11.2)
Kidney left and right (g)	50	48.0 (25.8 – 61.5)
Adrenals (g)	3.5	4.35 (2.95 – 5.98)

HISTOLOGY

Brain: The sections show normally developed cortex. The white matter is congested. The ventricles appear normal with no evidence of intra or periventricular haemorrhage. Both hippocampi are normal. The deep grey matter is normal. Mid brain structures with pons medulla oblongata and mesencephalon are normally developed.

Spinal cord: Normal.

Cerebellum: Normal folia and normal nuclei.

Falx: There is minimal haemorrhage in the posterior falx.

Pituitary: Normal.

Thymus: Normal.

Cortex and medulla: Occasional petechiae.

Thyroid: Normal.

Trachea: Normal.

Lungs: Normal.

Heart: Normal. No excess of lipid deposition with Oil-red-O stains.

Diaphragm: Normal.

Muscle: Normal.

Liver: Normal portal tracts and cords of hepatocytes. No excess of lipid deposition is seen with Oil-red-O stains.

Oesophagus: Normal

Stomach: Normal.
Intestines: Normal.
Mesenteric lymph node: Normal.
Spleen: Congested red pulp with presence of patchy haemorrhage.
Pancreas: Normal endocrine and exocrine components.
Adrenals: Normal.
Kidneys: Normal glomeruli and tubules. There is no excess of lipids identified with Oil-red-O stains.
Bladder: Normal.
Ribs: Normal haematopoietic cell elements. Normal chondrocostal junction.

ANCILLARY INVESTIGATIONS

Fluid Cyto, reported by Department of Paediatric Haematology, No unequivocal NRBCs seen on blood film.

Blood, VITDB2, reported by Clinical Chemistry Department

<u>Vitamin D</u>	Total 25-OH Vitamin D	68.3 nmol/L
	25-Hydroxy Vitamin D2	<6.0 nmol/L
	25-Hydroxy Vitamin D3	68.3 nmol/L

Blood culture, reported by Department of Microbiology, Enrichment Aerobic bottle negative. Single bottle only FINAL REPORT.

Cerebrospinal fluid, reported by Department of Microbiology: Volume Number of bottles 1. Total volume (mls) 2. Appearance Pink turbid fluid. Gram film Organisms NOT seen. Routine culture No growth obtained. Further requests (referred) CSF viral studies to follow.

Faeces, reported by Department of Microbiology, Enterovirus EIA Enterovirus DETECTED. Cryptosporidium stain Cryptosporidium oocysts NOT seen. Faecal culture Salmonella sp. NOT isolated. Shigella spp. NOT isolated. Escherichia coli 0157 NOT isolated. Campylobacter culture Campylobacter NOT isolated.

Bronchial swab, reported by Department of Microbiology, Fungal culture Fungi NOT isolated. Mycoplasma culture Mycoplasma hominis/Ureaplasma NOT isolated. Routine culture Yielded commensals only.

Lung Swab, reported by Department of Microbiology, Fungal culture Fungi NOT isolated. Mycoplasma culture Mycoplasma hominis/Ureaplasma NOT isolated. Routine culture Yielded commensals only.

Nasal swab, reported by Department of Microbiology, Routine culture no growth. Neisseria culture Neisseria meningitidis Not isolated. Parainfluenza 4 EIA Parainfluenza detected. Rhinovirus EIA rhinovirus detected. Enterovirus EIA enterovirus detected.

Tissue Culture & Enzyme Assay, reported by Dr X, Consultant Clinical Scientist, Children's Hospital:
 We have measured fatty oxidation flux with the following results:-

Tritium Release Assay of β -oxidation of Fatty Acids

FIBROBLASTS: Screening tests for defects in mitochondrial β -oxidation using [9,10³H]myristate and [9,10³H]palmitate and [9,10³H]oleate. Results are expressed as percentage of simultaneous controls.

Assay	Myristate	Palmitate	Oleate
Date	(% of simultaneous controls)	(% of simultaneous controls)	(% of simultaneous controls) 01/03/17
	93	92	102

Each result is the duplicate mean determination

These results are essentially **NORMAL** and exclude nearly all primary defects of long and medium chain fatty acid oxidation.

**Dried Blood Spot, reported by Clinical Chemistry Department, Children's NHS Foundation Trust,
PM Acyl carnitine**

Post mortem dried blood spot acylcarnitine profile. No significant abnormality detected.

(Post-mortem dried blood spots typically have high C3, C4, hydroxy –C4 and C6 acylcarnitines). Post mortem sample.

**Tissue Lung, reported by Department of Microbiology,
Respiratory PCR**

Result from reference lab:

Test referred to: HPA laboratory, Leeds

Test result:

No respiratory viruses detected by PCR.

Cerebrospinal Fluid, Virology, reported by Microbiology Dept,

Adenovirus PCR

Adenovirus PCR Inhibitory

Herpes Group Viruses

Herpes Simplex PCR Inhibitory

Varicella Zoster PCR Inhibitory

Enterovirus PCR

Enterovirus PCR Inhibitory

Nose Swab, reported by Department of Microbiology, Respiratory virus PCRs

RHINOVIRUS, PARAINFLUENZA 4 AND ENTEROVIRUS DETECTED

Viruses tested: Influenza A/B, RSV, Parainfluenza 1-4, human metapneumo, rhino, corona & adeno viruses.

Toxicology reported by Dr X, Department of Clinical Chemistry, Royal Hallamshire Hospital,

	Blood Plain	Blood Preserved	Gastric Contents
Ethanol	-	Not detected	-
Paracetamol	Not detected*	-	-
Salicylate	Not detected	-	-
Opiates	Not detected**	-	-
Benzodiazepines	Not detected	-	-
Barbiturates	Not detected	-	-
Cannabinoids	Not detected	-	-
Methadone	Not detected	-	-
Cocaine metabolites	Not detected	-	-
Phenethylamine group	Not detected	-	-

	Vitreous Plain
Sodium	142mmol/L

Potassium	13.0mmol/L
Urea	6.1mmol/L
Creatinine	<15µmol/L
Glucose	0.2mmol/L

* **Limit of quantitation (Paracetamol) =10mg/L blood, 500mg/L gastric contents.**

** **Limit of detection (Opiates) = 50µg/L Specific gas chromatography-mass spectrometry screen.**

There were no additional toxicological findings in blood or gastric contents by gas chromatography-mass spectrometry.

Comments: A negative toxicological screen.

The Urea concentration is slightly higher than usually observed.

The Glucose concentration is likely to be due to post-mortem degradation.

Skeletal Survey, reported by Dr XR, Department of Radiology, Children's NHS Foundation Trust,
Postmortem (*sic*) skeletal survey. . Normal bone density. No fractures have been identified.