Pan-Lancashire Thematic Review of Sudden Unexpected Deaths of Infants in the pan-Lancashire region from 2012-2015

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Introduction

The Pan-Lancashire Child Death Overview Panel (CDOP) was formed in April 2008 and from its earliest days realised that information about safer sleeping was required for local families and to support additional information and training provided for health care professionals.

The Give Me Room to Breathe Campaign (GMRTB) was initiated in 2008/09, as an extension of a police initiative previously run solely in East Lancashire. As these messages were relevant to all parents and carers, GMRTB was rolled out across the rest of pan-Lancashire.

The GMRTB campaign gained national recognition but in 2011/12 it was identified that there were inconsistencies within local services (e.g. breastfeeding peer support workers and children's centre staff) around the advice given regarding infants sleeping with their mothers. On further investigation it was highlighted that all agencies across pan-Lancashire were providing slightly different information, using different materials and the professionals themselves were unclear on what they should be advising families.

As a result, the Pan-Lancashire multi-agency safer sleep guidance was reviewed and developed to underpin the Campaign with the aim of preventing inconsistent messages, and reducing the incidence of child deaths with risk factors associated with unsafe sleeping practices.

We launched the new Safer Sleep For Baby (SSFB) campaign in 2012/13, which saw the development of family friendly materials provided by different agencies, to reinforce the messages at key points in a child's development. Recently, other Local Safeguarding Children Boards (LSCBs) within the North West Region have also started using our materials. This is the first step in trying to improve consistency of messages at a regional level.

The publication of the NICE Postnatal Care Guidance on Safer Sleep in 2014 prompted a need to review the Lancashire Safer Sleep Guidance to reflect the new recommendations, but also feedback and comments from frontline practitioners. In December 2015, the team decided that a useful tool would be gained with the systematic review of local data and an analysis of themes, in sudden and unexpected deaths of infants, which seemed to be associated with sleep.

It was agreed that the review should include representation from the three local authority areas, and the following agencies: CDOP, SUDC Service, Public Health, Early Years, and health visiting.

Background

887 child deaths have been reviewed (960 notifications) of pan-Lancashire residents from April 2008 – March 2015. 211 of these deaths were deemed to have modifiable factors; 1 fifth of these were due to sudden unexpected, unexplained deaths with the majority of risk factors associated with unsafe sleeping. The current thematic review aims to identify trends, inform future SUDI thematic reviews, identify focused recommendations to inform our Safer Sleep Campaign, improve data collection and ultimately reduce sudden and unexpected deaths in infants within the pan-Lancashire area.

Context

UK child death rates are higher than those of several other developed countries in key areas (Viner, et al., 2014). Children die of many causes but infants make up a large proportion and have been highlighted as an area where further action is needed.

Until the rate fell in the early 1990s after the identification of the risk of prone sleeping, and the successful 'Back to Sleep' campaign, unexplained sudden infant death was the commonest single cause of post-neonatal infant mortality; even today it constitutes a significant proportion of all deaths. Unexplained sudden infant death therefore remains an important and potentially preventable cause of infant mortality, and the number of such deaths per 1,000 live births is an important comparator with other parts of the UK and other countries. It is widely seen as a marker for the development of healthy, baby-friendly communities that prioritise infant welfare and, as such, a low death rate is an important goal.

NICE guidance has recently been released providing recommendations on co- sleeping and reducing the risk of sudden unexplained infant death, covering the first year of an infant's life (National Institute for Health and Clinical Excellence, 2014).

There were 249 unexplained infant deaths in England and Wales in 2013, a rate of 0.36 deaths per 1,000 live births. This is the first rise in unexplained infant deaths since 2008. Before 2013, the rate had fallen steadily from 0.41 in 2008 to 0.32 in 2012

Almost two thirds (65%) of these deaths were recorded as sudden infant deaths, and 35% were recorded as unascertained (where no other cause of death is recorded)

Unexplained infant deaths accounted for 9% of all infant deaths occurring in 2013

Just over half (55%) of all unexplained infant deaths were boys in 2013 (138 deaths) compared with 64% in 2012 (150 deaths)

The largest monthly rise in unexplained infant deaths was in February 2013. This coincided with a colder than average mean monthly temperature and is a consistent finding across previous years.

The rate of infant deaths rose from 0.92 to 1.27 for mothers aged under 20. Although numbers are very small, this was four times greater than the combined categories of babies born to mothers aged 20 and over (0.32)

Figure 1: Most recent data from ONS

The SUDC Prevention Group provides Pan-Lancashire Safer Sleep Guidance and a Safer Sleep for Baby Campaign across Lancashire, and the unitary authorities of Blackburn with Darwen and Blackpool.

The rate of sudden unexplained deaths of an infant in the Pan-Lancashire area appears to be marginally higher than the rate in England as a whole, and is significantly higher than the rate in the more affluent regions of South-East England.

The Netherlands, for example, has a much lower rate (0.074 in every 1,000 in 2012: Stichting Wiegedood). It is clear that there is some way to go in reducing the risk and that many lives could be saved if more of the current widely accepted recommendations for reducing the risk were universally followed.

It could be argued that the outstanding success of work on SUDC prevention in the UK has not received the recognition it deserves, possibly as the surviving infants, who might otherwise have died of SUDC but did not, cannot be identified. These individuals will never know who they are and what fate might have befallen them had there not been a positive health promotion message that led to a reduction in deaths. In this respect, the success rate of SUDC reduction campaigns is somewhat 'hidden' compared, for example, with patients whose lives have been saved by a pioneering new technique in surgery for example, and their families, who are able to publicly express their emotions at having their lives saved.

Nonetheless SUDC prevention has a large effect on our society: from the late 1980s when close to 1600 infants (ONS) were dying every year in England & Wales, the number has dropped to 249 deaths in 2013 (ONS). This means that in the 20-25 years since the UK Government-sponsored 'Back to Sleep' campaign, perhaps 20,000 infants have not died, and have gone on to be able to fully contribute to society; their parents and extended families have been spared the most tragic bereavement imaginable, and have avoided the consequent impact on their emotional health and productivity., and health and other services have been saved from the resulting pressures upon their resources. This is a compelling argument for health promotion activity in this area. The majority of SUDCs are still associated with well-known and modifiable risk factors and are almost certainly preventable, as shown by some other countries which have much lower rates than the UK.

This still has important potential for reduction in deaths that is achievable, possibly with very modest financial outlay in comparison with the obvious benefits. The Pan-Lancashire area absolutely has the potential to lead other parts of England and other developed countries in this field, if there is the will.

Terminology used in the review

The terminology used in this area can be confusing. The term Sudden Infant Death Syndrome ('SIDS') was introduced in the 1970s to describe sudden and unexpected infant deaths that remained unexplained after a full autopsy, detailed paediatric history, social enquiry and examination of the scene of death.

'SIDS' is generally regarded by coroners as a natural cause of death and enables this verdict to be given at inquest, which is seen as helpful and kinder to families, although technically it is misleading as the cause of death is unknown.

Since the early 1990s the term 'unascertained' has increasingly been used by pathologists to distinguish those deaths that are unexplained but where there appear to be features that would preclude the use of the term 'SIDS'. This tends to be linked with coroners giving an 'open' verdict at inquest, which is less satisfactory from the parents' point of view and may be regarded as carrying an implication of blame or guilt. It has been suggested that this distinction is unhelpful and that the criteria for calling a death 'unascertained' as opposed to 'SIDS' are very unclear and used inconsistently (Limerick & Bacon, 2004).

The Office of National Statistics (ONS) refers to 'SIDS' deaths as 'sudden infant deaths' which invites confusion with 'Sudden Unexpected Death in Infancy' or the synonymous "Sudden Unexpected Death of an Infant' or 'Sudden Unexpected Infant Death' (SUDI/SUID). These terms include all sudden and unexpected infant deaths whether they are explained or not, so can be further divided into 'explained SUDI' and 'unexplained SUDI'.

ONS uses another term 'Unexplained infant deaths' to include SIDS and unascertained together. However, this does not emphasize the 'sudden' nature of the deaths under consideration and arguably could lead to confusion with the deaths of ill children whose cause of death is not clearly defined.

For the purposes of this review we have used Sudden Unexpected Death of a Child (SUDC) as a blanket term which includes all unexpected deaths in childhood, synonymously.

Modifiable Factors

CDOP categorise the 'preventability' of each death, using the term 'modifiable factors', the definition of which is taken from the UK Government's 2015 document 'Working Together to Safeguard Children'.

Modifiable factors identified	The panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths
No Modifiable factors identified	The panel have not identified any potentially modifiable factors in relation to this death

Figure 2: Modifiable factors category taken from the CDOP Form C Analysis Proforma

Methods

Case definition: Criteria

This collaborative systematic and thematic review considered all sudden and unexpected infant deaths relating to a sleep environment who died within Lancashire, including the unitary authorities of Blackburn and Blackpool. We included deaths of infants aged 0 weeks to 18 months, whose deaths were recorded and fully reviewed by the CDOP.

The intention at the outset was to be inclusive and to include deaths classified as sudden infant death, unascertained death and also any deaths that may have been subjectively attributed to a specific cause, where this related to factors associated with infant care or the infant sleeping environment, because these may be equally important in generating health promotion messages which could reduce the number of infant deaths in Lancashire and perhaps further afield.

There were 86 child deaths which were identified from cases reviewed by CDOP between April 2008 and December 2015 using the following criteria: children under 18 months of age **and** the case has been reviewed by CDOP **and** had a category of 1, 3, 8, 9 or 10 **and/ or** the child suffered a sudden collapse, where the child was found unresponsive, or there were safer sleep concerns identified within the CDOP review.

A further exclusion criteria was also developed: children above 18 months of age, children with a clear cause of death due to trauma/ external factor e.g. RTC, fire, drowning, deaths due to infection as a result of an underlying condition, deaths due to withdrawal of treatment/ palliative care, children with infection who die in hospital, cases not completed by CDOP, deaths classified as 2, 4, 5, 6, or 7.

Category	Name & description of category
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.
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.
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 inflected injury, abuse or neglect. (category 1).
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.
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.
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.
7	**Chromosomal, genetic and congenital anomalies** Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease,cystic fibrosis, and other congenital anomalies including cardiac.
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).
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.
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).

Figure 3: CDOP categories 1-10

The Panel decided to complete an in-depth review of the cases completed by CDOP within the last 3 reporting years (2013/14, 2014/15 and 2015/16), as from this time period forward the quality of the information collated was consistent and robust: this gave 24 child deaths with dates of death between July 2013 and August 2015.

It was acknowledged that only using the last 3 years' worth of data wouldn't allow for robust statistical analysis to be conducted as the numbers would be too small;

however, it does allow current trends in sudden infant deaths within pan-Lancashire to be identified.

Similarly, deaths which occurred suddenly and unexpectedly, and were explained after full investigation, were included in the initial data gathered but these were also excluded from the detailed analysis. Explained SUDC may also share some of the known risk associations with unexplained sudden infant death, but they are a very varied group and are not the main focus for the review**.**

As these deaths were 'explained' they were excluded from the detailed analysis but they remain important for the purposes of the review as they may impact upon health promotion messages to some extent.

Review panel

A review panel was convened, this consisted of a core team which was established from members of the SUDC Prevention Group (including public health representative, CDOP Coordinator, Infant Feeding Specialist, Children's Centre manager, SUDC Nurses, integrated health manager) a sub group of the CDOP, together with a representative from the health visiting service.

Data Sources

The core team reviewed all of the information on each of the 24 cases identified and considered the following documents per case:

- CDOP AB form containing multi-agency information as minimum – health acute and community information, police, children's social care and mental health information
- CDOP Form C (statutory form to be completed for every child death
- Coroner's inquisitions and post mortem reports (where available)
- Sudden Unexpected Death in Childhood (SUDC) Service End of Case Discussion reports (where available)

The core team met over two half-day meetings; the first was on the 22nd January 2016. The session included a presentation of the different forms and documents to be considered to familiarise the team with the documents. The CDOP coordinator presented the information for 12 cases and utilised the in-depth review grid to facilitate the discussion, recording details that informed the review report.

The second meeting was held on the 5th February 2016, during which it was agreed to exclude 2 of the cases as they didn't meet the criteria; therefore 22 cases were included in the in-depth review. A detailed quantitative review of all the remaining deaths (10) was undertaken similar to that of the meeting on the 22nd January 2016.

The two main authors drafted the first report, to which the thematic panel provided comment. The draft report was also shared with the CDOP for consideration with a particular view to assessing the clarity of conclusions and recommendations, and their potential to lead to action and achievable outcomes. Following a review by the authors of the comments from the thematic panel and CDOP, the final report was reissued before being presented to the Local Safeguarding Children Boards (LSCB), shared with partners and published on the three LSCB websites.

Findings

Infants and children included in this review:

Demographics of SUDC cases

Looking in more detail at the cases in our review, the following demographic details emerge:

Gender

There were 14 boys (64%) and 8 girls (36%) in this review. For comparison, the SUDC rate in 2013 in England and Wales was 55:45 boy to girl, and the previous year it had been 64:36 boy to girl. Most studies have shown an excess of male infants in SUDC statistics.

Parity of the infant

<5 of the 22 children included in our thematic review were the first child of both mother and father; <5 others were firstborn for the mother, however in <5 of those cases was the mother the carer when the infant died. So we can deduce that 'inexperienced parenting' was not a theme.

Deaths by month of the year

Breaking this data into year quartiles, the figures are:

Jan-Mar 5 = 21%
Apr-Jun 4 = 17%
Jul-Sep 9 = 37%
Oct-Dec 6 = 25%

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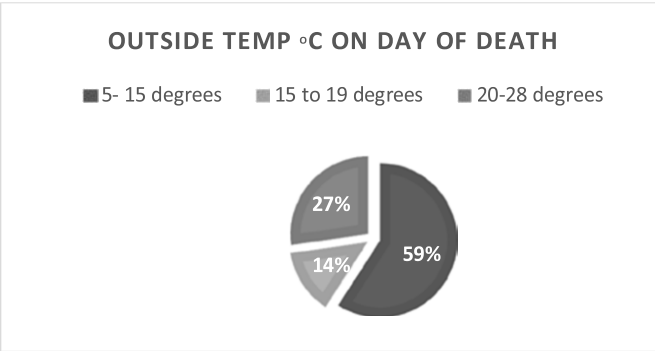
Figure 4, deaths by month of the year

There does not seem to be any theme here, so the group then considered the temperature of the day when the baby died, to see if any theme could be found.

Deaths by outside temperature



These average temperatures were gathered from Blackpool Airport records so will vary across the patch slightly of course.

High temperatures obviously increase the risk of baby overheating, and low outside temperatures increase the likelihood that carers will have central heating or fires on in the baby's rooms, increasing the risk of overheating.

Deaths by day of the week

Clearly as these were sleeping related, and sometimes at night, the 'sleep episode' may have begun the day before, which may explain the high number of deaths on Sundays. The data on the period between infant last being seen apparently well, and them being found responsive, is not routinely collected or available, but may present some interesting findings for a subsequent review.

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Figure 5, deaths by day of the week

Deaths by area

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Figure 6, unexpected deaths April 13-December 16 BwD

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Figure 7, unexpected deaths April 13-December 16 Blackpool

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Figure 8, unexpected deaths April 13-December 16 E Lancs

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Figure 9, unexpected deaths April 13-December 16 N.Lancs

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Figure 10, unexpected deaths April 13-December 16 Central Lancashire

What is clear is that these deaths are occurring in the populations in the lowest socio-economic areas (Blackpool, parts of East Lancs, and Blackburn-with-Darwen), and that (see map) they are also located in a 'corridor' in East Lancs, which transects Blackburn-with-Darwen.

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Figure 11 and 12, SUDC's by area of live births

Deprivation Overall figures for Lancashire (2013-15) in the most deprived areas – within our review, 11 of the 22 cases (50%) were decile 1; in the normal population 26% might be decile 1 (all births). 20 out of 22 were quintile 1 (91%). The preponderance of areas with higher levels of deprivation is consistent with most studies of SIDS. Within the panel meetings there was discussion on the ways in which high levels of deprivation could impact upon the rate of SUDC, via modifiable and other factors. This has an effect on infant care practices through creating many competing pressures on parents and distracting from the important focus on the needs of the young infant. In addition, there are challenges in targeting health promotion advice at the populations most at risk, when they are often the most difficult to reach.

Age of infant at death

According to the most recent (2013) ONS review on SUDC, most (70%) infant deaths are likely to occur in the first four weeks after birth (neonatal period) but unexplained infant deaths are more likely to happen after the first four weeks. In 2013, 82.3% of unexplained infant deaths occurred in the post-neonatal period (at least 28 days but less than 1 year after birth). In figure 13 the age of the infants at the time of death is shown: the oldest included in our review was 18 months and the youngest was 6 weeks.

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Figure 13, Number of SUDCs by age of infant and time of death

ONS data over recent years suggests that SUDI is occurring at a younger age than was historically seen. The peak incidence in the 1990s was at three to four months (Leach, et al., 1999), but ONS 2012 data showed that 37 of 221 deaths (16.7%) were in the first month of life and almost half (48%) of unexplained infant deaths in the post-neonatal period occurred after 28 completed days but before two completed months.

The data identified for this review show a rather different pattern, with none of the 22 deaths occurring before six weeks of age, and 9 of the 22 (41%) between 6 and 9 weeks of age, with 82% taking place between 6 weeks and 7 months of age. There were no deaths in this review which took place between 6 and 14 months of age, but <5 between 14 and 18 months of age: these <5 children had all been unwell in the previous week, and <5 was attributed to myocarditis on the pathology report. It is not clear why this review should have such different findings from other reviews, but the numbers are small and these may not be significant differences.

What is clear and consistent between various studies is that unexplained SUDC is rare after six months of age and that prevention strategies must focus on very young babies.

Age of mother

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Figure 14, age of mother at time of infant death

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Figure 15, age of mother at time of infant birth

Younger maternal age has previously been associated with a higher risk of unexplained sudden infant death (ONS, 2011). However in our review, <5 of the 21 of the mothers of babies who died as a SUDC were under 21 years old. This is far less than would be expected purely from population demographics. In this review the median age of the infant's mother at the time of birth was 29.5 years (with a mean of 28.95 years) and the percentage of mothers in our review who were under 30 years at the time of their infant's death was 45%. The percentage of mothers under 30 at the time of their infant's birth in the Pan Lancashire region in 2014 was, by comparison, a much higher 56%.

Other reviews and studies of this type have suggested that further attention should be paid to ensuring young mothers receive the safer sleep information, but in this review, records for <5 of the mothers under 21 years of age contained documentary evidence that they received safer sleep information.

As a significant number of the infants in this review were not being cared for younger mothers on the day of their death, we continue to believe that making an effort to publicise the Safer Sleep for Babies information to all age groups is essential.

Unexplained sudden infant death and birth weight

Research evidence has shown that low birth weight (LBW) is associated with a higher risk of SUDC and the review data supports this.

Low birthweight (under 2.5kg) can be caused by a number of factors. For example, smoking has been identified as a major risk factor contributing to low birthweight. Babies born to women who smoke weigh, on average, 200g less than babies born to non-smokers (source: ONS 'Birth Characteristics in England and Wales' 2014).

7.4% of live births in England and Wales were low or very low birthweight (VLBW) in (under 2.5Kg) in 2014 (ONS). In the Pan Lancashire area this figure is around 8.4% which is higher than the population average. However, by comparison, in this review, 5 of the babies aged under 6 months at time of death, weighed under 2.5kg at birth (23%).

These 5 infants were all in the same room as their carer had been sleeping in, when they were found unresponsive, and none of them had been sharing a sleeping surface with their carer, although <5 of these infants was a twin, and had been sharing a sleeping surface with their twin. <5 of the households was smoke free – <5 out of the five mothers were smokers.

<5 of these cases the infant habitually slept in a bouncy chair, which is where they were found unresponsive, in <5 cases the infant was found on its side / front in its moses basket, in <5 cases the twins were sleeping together. None of these are appropriate sleeping scenarios for infants. In <5 of the cases, the room in which the infant(s) were found was noted to be very warm, by the first responder.

Previous evidence reviews (for example the Welsh Thematic Review on Infant Death) have showed that VLBW and LBW babies were around five times more likely to suffer SUDC than babies of average birth weight. In <5 out of five cases in this review, it is not observable from documentation whether the parents had received information about safer sleep, particularly smoking, temperature and safe sleeping positions and environments for babies, which should be given in the immediate neonatal period by the discharging midwife or neonatal staff member, and re-iterated by health visitor and children's centre staff in the following weeks. This data was not recorded.

At the same time, this review data show that the vast majority of babies who died had had a normal birth weight, so prevention strategies cannot be targeted too narrowly and must include babies of all weights.

Unexplained sudden infant deaths and prematurity

A total of six babies (27%) in our review were premature ie born before 37 weeks. Of these, none were born before 32 weeks. None of the babies in our review were born later than term + 11, ie 41 weeks 4 days' gestation, which is within a normal range.

As expected, babies born early are over-represented in this sample of infants suffering an SUDC, but still account for a small minority of all cases. This is consistent with the literature in this area.

Looking at all infant deaths (of any cause), the link with prematurity is very clear with 67% being born prematurely, reflecting that a large proportion of all infant deaths occur in the neonatal period due to complications of prematurity: perhaps some of the complications of prematurity present an associated risk for SUDC that we cannot predict as we do not yet understand. <5 of the infants in our review who were born before 37 weeks, were not also LBW ie less than 2.5kg at birth, and in <5 cases the infant had been experiencing cyanotic episodes in the previous days, in <5 cases the baby had been prop fed and then found unresponsive in an adult bed with a pillow, and in another case, while the infant was breastfed, and was found lying on its back in a Moses basket in the parents' room (though the father smoked), the infant had been born 3 months early, and recorded as being 'snuffly' and having thrush in the week before it died. See further on in this review for more on illness prior to SUDC.

Location of death

All apart from <5 of the deaths included in our review occurred in the usual residence for the child. <5 was with the father who did not live with the mother, and <5 died in the grandparent's home being cared for by the grandparents. Without an appropriate comparison group, it is impossible to say whether this is more than expected. There has been anecdotal reporting of infants sleeping in temporary or unusual settings as a risk factor for SUDC but there is no strong evidence base for this and it accounts for a minority of cases.

Ethnicity

Fourteen of the families were known to be White British, <5 were South Asian and six of a mixed ethnic background. However, population data identifies 83.9% white, 13% South Asian and 2.5% mixed ethnic background, within the <18 year age group in Lancashire.

The proportion of deaths within the 'mixed ethnic background' is clearly much higher than the general population suggests would be expected, but as this sample is small perhaps this figure is not significant. It is worth continuing to watch this area to see if there is a true theme.

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Figure 16 and 17– ethnic profiles

Social concerns

There was some previous social concern noted in many of the 22 cases. Any mention of social concern prior to the death was included. This included where the infant or any family member were known to agencies, including the Police, prior to the death. In 15 of the 22 cases there was explicit mention of the absence of social concerns and in 7 of the 22 there was no mention of social concerns.

As all of these cases had been discussed previously at CDOP meetings, any significant ongoing social concerns should have been addressed.

We did not as a review group have comparison data on what percentage of the general population may have, for example, a criminal record or be known to the police, or to have reports of domestic abuse.

It is also possible that there was some retrospective reporting bias in identifying social concern, as this may have been an area that people investigating cases of SUDC felt was important to look for and document after a death has occurred.

Associated factors and themes

Co-sleeping and infant sleeping environments

We are using the term 'co-sleeping' for the purposes of the review, to refer to a child who dies whilst sharing a sleep surface with another person. 'Co-sleeping' encompasses habitual 'bed-sharing' as a planned all-night sleeping arrangement, and also unintended or irregular co-sleeping whether in a bed or on another less safe sleep surface e.g. sofa. These sorts of child deaths have been reported frequently in other parts of the country, and although there are deaths of this in our review of these 22 cases, they are not 'parent on sofa with child'-type situations and so not typical of the type reported elsewhere: <5 infants were co-sleeping.

Co-sleeping has been the subject of much recent debate, and is the reason that Lancashire's Safer Sleeping Guidance and GMRTB campaign were revised into the SSFB campaign we run today.

It is important to emphasise that the reason that co-sleeping has been linked with an increase in sudden infant deaths in many studies is not known: it is too simplistic and potentially very distressing for the parents, to attribute these deaths to overlaying. In addition to unintended airway compromise, other hypotheses such as overheating or exposure to infection or cigarette smoke are viable. It's also possible that babies are taken into their parent or carer's bed when they are unwell, either because the infant is more fretful or because they want to keep a closer eye on them, and this would then present an associated risk for the death.

In a few cases there may be objective evidence of overlaying but for the majority the cause remains unknown. The proportion of unexplained sudden infant deaths occurring whilst the infant was sharing a sleep surface with another person apparently rose significantly as the death rate fell in the 1990s (Fleming, et al., 2000; Tappin, et al., 2002; Blair, et al., 2014). In other words, the health promotion advice and

Modification of infant care practices that has led to the reduction in overall SIDS rate appears to have been less effective for the co-sleeping infants than for those sleeping in cots or other sleep surfaces. It is not clear whether the overall co-sleeping rate for all babies has changed during this period. Many infants who co-sleep may do so for only part of the night or for some nights and not others, so there are significant challenges for researchers in establishing appropriate control data.

In the absence of reliable comparison data, it is difficult to know whether the high rate of co-sleeping deaths is disproportionate but most published case-control series suggest that it is (Blair, et al., 2014). A number of additional factors have been identified in research that appear to combine with co-sleeping to increase the risk of unexplained sudden infant death. These include co-sleeping on a sofa or armchair, where either or both parents are smokers or where the parent has consumed alcohol or drugs.

Some authors have extended this to include parents who are 'impaired' in other ways including excessive tiredness, obesity or illness. In this review a similar pattern is seen. Additionally we know that not being a breastfed baby is an associated risk for co-sleeping, and for SUDI in general, which is why the recommendation to breastfeed forms one of our 'six steps for safer sleep' in the Pan-Lancashire campaign.

Of nineteen unexplained sudden infant deaths in the under 12 month olds in our review, six were found in an adult bed (five of these were smoking families), <5 were on the sofa, <5 on unsuitable sleeping surfaces, and <5 in a bouncy chair which was routinely used for his or her sleep episodes.

Nine of the nineteen infants were found in a cot or Moses basket, though <5 of these were not found sleeping on their back: again we know that not sleeping on their back is an associated risk for SUDC.

Some other similar reports are able to report on the mental state of the parents in the weeks and months before the infant's death, but this information is not systematically recorded and so it's difficult to reach any conclusions in the review. We did see that a larger-than-expected proportion of the parents had extensive criminal records and there was a substantial amount of domestic abuse, so together with the smoking status of the parents of these infants, this would seem to fit with the overall picture found in other reviews that the level of mental ill-health is higher in this group, but given the small populations sizes, we cannot say that this is statistically significant or suggest it might be a causative factor.

Smoking

In 2014/15, the data available to this review panel (from ONS) stated that 16.88% of women living in the pan-Lancashire smoke throughout pregnancy, as judged by the 'smoking at the time of delivery' (SATOD) rate. This is one of the highest rates in the UK, which has a smoking at the time of delivery although the rate has been falling since 2005. SATOD prevalence in the whole of England was 11.4%, which is lower than 2013/14 (12.0 per cent) and continues the steady year-on-year decline in the percentage of women smoking at the time of delivery from 15.1% in 2006/07. The smoking prevalence varied amongst Clinical Commissioning Groups from 2.1% in

NHS Central London (Westminster) to 27.2% in NHS Blackpool – which obviously increases our average in the pan-Lancashire area.

15 of 22 infants in our review were known to have died in smoking households (68%). The smokers were predominantly the carer themselves, but in <5 cases the mother was the main carer but the resident father smoked, and in at least <5 of these cases the father smoked cannabis. In <5 cases the parents did not smoke but the grandparents who were caring for the infant when they died, did smoke heavily.

Figure(s) removed to maintain confidentiality

Figure 18, smoking status of households

This suggests an excess of smoking families in the review families which would be consistent with what is known about risk factors for SUDC.

The review did not elicit any information about e-cigarettes. At the time of writing there is some debate about e-cigarettes in relation to SUDC. In the absence of any compelling evidence from research, the pragmatic view that is emerging in the UK is that e-cigarette users should follow the SUDC prevention guidance as for tobacco smokers, including avoiding co-sleeping. A recommendation of this review would be that data about use of e-cigarettes should be gathered

Parental alcohol consumption or drug use

Data were limited for many families. 13 out of 22 families (59%) were known to have used drugs or alcohol in the 24 hours prior to the child's death, 5 of whom were known to have been co-sleeping with a parent at the time of their death: all 5 co-sleeping infants included in this review had slept with parents who had had alcohol in the previous 24 hours. There may have been some reporting bias in that alcohol history may have been sought or documented more carefully after a co-sleeping death because of the known implications. In 8 out of the 22 families (14 unknown) there was a prior history of drug use, mainly cannabis, of whom <5 were co- sleeping deaths. Data was limited, however together with the high level of smoking households, this did raise concern amongst the panel that a significant proportion of deaths were occurring in families with clear contra-indications to co-sleeping.

Recommendation: CDOP to ask other sources about associated risk of cannabis in sleeping infant deaths, and cascade this to frontline staff for onward dissemination to families.

No meaningful data were available for prescribed drug use and this was flagged as an area for improvement in future data gathering.

Sleeping position for cot-sleeping babies

Of the 8 infants under 12 months (42%) who were known to have died in a cot, crib, Moses basket or other purpose designed infant sleep surface, there were very limited data on their sleeping position: the position in which the infant was reported to have been found is recorded but of course we cannot know the position in which they were left: <5 were reportedly found not on their backs. <5 of the babies found in their cots were noted to be in the 'feet to foot' position: this highlighted a lack of communication or understanding in this important area that was, of course, a major factor in the 'Back to Sleep' campaign in the early 1990s.

Solitary sleeping

Of the 17 babies under six months, 5 were not sleeping in the room where their carer was, at the time of their death. In 7 of the 17 cases, the room in which the infant was found unresponsive was noted by the responders to feel warm. Average daily temperature for the days of the infants' deaths is discussed elsewhere, but it is worth reminding frontline staff to reiterate the temperature message to all families, as well as the recommendation to have babies sleep in the same room as their carer. It is worth noting that in the five infants who were born LBW (under 2.5kg) and who would have therefore spent some time in one of the area's neonatal unit, the infant's documentation in <5 cases showed that the safer sleep for babies information had been shared with the parents.

Head covering

In a number of the cases there was a specific reference to the infant possibly having their head or face covered by or buried in bedding when found: <5 of the under 12 month old infants in the review were sleeping with a pillow which is not recommended as appropriate for a child under 12 months. Of course we do not know how many of the infants were sleeping with bedding covering their faces, or how it came to be there.

Overheating / temperature

6 of the 19 babies under 12 months when they died (32%), were noted to have inappropriate (eg adult duvet) or multi-layered bedding which may have contributed to overheating, which is known as an associated risk for SUDC.

Illness preceding death

18 of the 22 (82%) infants had been unwell in the week before death, many of whom had seen a healthcare professional eg doctor or health visitor, in this time. One had been hospitalised in the previous week. These included <5 cases of fever (<5 had had immunisations), <5 mentions of babies being sweaty, seven mentions of babies being 'snuffly', <5 babies who were on or had had antibiotics in the previous week (<5 had also been seen for thrush, the other had not), <5 who was still under observation as they had been born small for gestational age (SGA) after an inter-uterine growth retardation (IUGR), <5 under observation for faltering growth, a previous cyanotic episode, and an investigation for an elongated head shape.

Seven of the unwell had had thrush (candida albicans) noted in the previous week; 15 were not noted to have had thrush, but of course they were not noted NOT to have

had thrush either, so we do not know. <5 of the babies with thrush was breastfed; thrush in breastfed babies may be passed from mother to baby via milk, and so may indicate antibiotic use or general low immunity in the mother, whereas thrush in the bottle fed infant can indicate poor hygiene of bottles or poor sterilisation technique – and this was actually noted in <5 of the cases. We had at the time of conducting the review, not been aware of any existing findings of thrush being an associated risk factor for infants in SUDC cases, but having consulted with experts in the field have been made aware of literature in which this phenomena is mentioned.

Infant Feeding Method

One modifiable factor already included in the Pan Lancs Guidance on Safer Sleep for Babies, and the SSFB campaign targeted to reduce SUDCs, is the encouragement for mothers to breastfeed. However there are other modifiable infant feeding-related variables which we know may impact on SUDC outcomes, including overfeeding, prop feeding, early introduction of solids and flat feeding. These are discussed below, but one recommendation of this review might be that we do more work on educating health professionals around the risks involved in these feeding practices as part of the safer sleep messages as well as part of the infant feeding messages.

Not Breastfeeding

<5 of the 22 infants was breastfed at the time of death, although it was noted that <5 other babies had been breastfed earlier in their lives. Records for the others are not clear. Evidence is clear on the risks of artificial and bottle feeding for infants in the short and long term.

Because of the varying ages of the infants in this review, relevant comparable population breastfeeding rates for Pan-Lancs cannot easily be deduced although we do have some statistics: initiation was 68.7% in 2013 for example in the pan Lancashire area, whereas for context national initiation was 73.9% so we are quite a lot lower than the national average. The national 6-8 week prevalence of exclusive breastfeeding in 2013 was 32.3% and 'any breastfeeding' was 47.2%. From this we may surmise that the breastfeeding rate in the pan-Lancashire population may be lower than the national average, but we may also assume that the breastfeeding rate in the population of our review was much lower than that in the general population, although this is a very small study and so it's not possible to say whether this is statistically significant.

Large milk feeds before sleeping

Large bottles and overfeeding was noted in 6 cases: inappropriate feeds in <5 cases (milky tea / baby rice added to bottle); prop feeding or flat feeding was noted in <5 cases for the baby's last feed before being found unresponsive – <5 of those was also a large feed.

Early introduction of solid foods

Early introduction of solid foods was noted in 5 of the 8 babies who died aged over 3 months and under 5 months. Mentions were made in some cases of rice in bottles and laid back feeding of purees to young infants: both of which are against current guidance.

Night time feeding advice

An area of discussion that followed on from the co-sleeping debate was whether any advice could be given about where babies should be given their night feeds. There does not appear to be any clear evidence from research on this particular topic and we know that it is a question that is frequently asked by mothers

.

For breast fed babies, the evidence base which informs the UNICEF UK Baby Friendly Initiative message endorses feeding with mother and baby lying together in the parental bed in the 'C' position and the panel saw no reason to contradict this (UNICEF UK - The Baby Friendly Initiative, 2010), (Blair & Inch, 2010) It was accepted that it was inevitable that the feeding mother would fall asleep at times and would be inadvertently co-sleeping, whether this was their intention or not, and the evidence seems not to find this an associated risk for the baby.

Alternative feeding strategies, for either breast or bottle fed babies, might include the parent sitting up in bed propped on pillows and feeding the baby, or getting out of bed and sitting on an upright chair to feed (as opposed to an armchair or sofa). The former position involves some risk that the parent may flop forward onto the baby if they fell asleep; whereas feeding on a chair might lead to the baby falling to the floor if the parent fell asleep, and so both are problematic if parent is very tired.

There was a consensus that parents should be discouraged from feeding their baby on a sofa or armchair at night or at other times of excessive tiredness because of the likelihood of inadvertent co-sleeping on the sofa, which is associated with a high risk of infant death.

There has been no evidence in this review of babies dying as a direct result of night time feeding, but as many of these babies been found unresponsive during the night, where they were fed immediately before a sleep episode, and there does appear to be a theme of inappropriate feeding in terms of quantities and delivery of milk, and of early introduction of non-milk foods (though we have no comparator of this behaviour in the general population) it seemed appropriate to consider this theme here.

Dummy use

There has been some report that regular sleep-time dummy use may reduce the risk of SUDC, but the association in the evidence review (which appears to have been funded by a dummy manufacturer) is weak and seems to relate to an increased associated risk for an infant who habitually goes to sleep with a dummy but goes to sleep without a dummy on the sleep episode where they are later found unresponsive. A paper published after the evidence review was conducted suggests that the protective effect only in any case applies to co-sleeping infants (Blair et al 2014).

Data on dummy use was not available for the purposes of this review, as it was not systematically collected by those investigating the deaths: only one case had a note of dummy use or otherwise.

A recommendation of this review is that in future cases, information on prior dummy use with the deceased infant is systematically requested, and also that guidance from frontline health professionals does not suggest dummies as a preventative measure against SUDC.

Risk factors table

Figure removed to maintain confidentiality

Table 1 illustrates the risk factors known to be present in the deaths reviewed.

This review is likely to underestimate the association with some risk factors. Parents may understandably not volunteer information about alcohol and drugs, and other data are not routinely gathered currently and may not be mentioned in the material available to the review (e.g tiredness, prescription drugs, even mother's smoking status in pregnancy which WOULD have been gathered in the perinatal period, but may not be recorded in the evidence after the child's death).

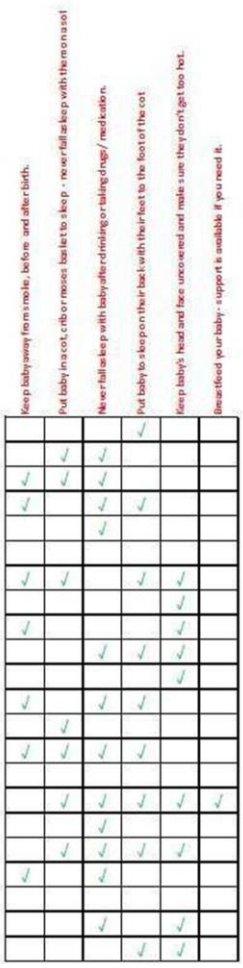

Figure 19 and 20, safer sleep messages

Discussion of Safer Sleep Messages

In 14 of the 22 families, safer sleep discussion had been documented previously in the child's notes. In <5 of the cases it is thought the staff member may have had some communication issues with the parents as English was not their first language. In <5 cases the information was given to and understood by the parents, but the child sadly died at the grandparents' house whilst in their care. In <5 cases it was noted that information had been given and reinforced multiple times. In 8 of the 22 cases it is not known from the records we have had access to in this review whether this information was given. **We recommend that this message is reinforced to frontline staff.**

Strengths and Limitations

A major strength of this review was the multi sectoral nature of the panel. This allowed for a truly representative discussion of the deaths that extended beyond health to consider multifactorial issues.

There were a number of areas on which the panel's discussions were limited by a lack of information. To try to address this situation for future reviews, the panel would like to make some **recommendations for the development of new data collection**

templates to be going forwards. The process for prospective collection of data on notification of a sudden and unexpected infant death was also discussed during this review, and will hopefully be improved and made more robust as a result.

Limitations of the review include the time constraints and availability of a larger, more multi-disciplinary, and consistent group across the two half days, and access to the group while writing up the report, which was done quite quickly and by two main authors

Missing or inconsistent information

Other similar thematic reviews have been able to report upon for example the time of day when the infant was found, and the number of hours between last contact and the time that the infant was found. However this data has not been recorded in our review, and in many cases is not recorded in the original documents we had access to. **A recommendation to record information more systematically so that this area can be looked at in the future,** seems prudent.

<5 of the 22 was reported as a category 1 (neglect), and <5 were category 9 (infection) <5 of these (75%) - all term babies - had modifiable factors: mums and dads smoked in <5 cases, there was confirmed cannabis use in <5 of those cases, and <5 were inappropriate sleeping environments, <5 had large milk feeds noted, and <5 had had early introduction of solid foods noted: <5 were 2 months and <5 were 15 months old so early introduction of solids was not happening / not noted or potentially even relevant, respectively.

The remaining 17 were listed as category 10: sudden unexplained death – <5 of the 17 listed no modifiable factors although **one might argue that not breastfeeding could be listed as a modifiable factor in cases <6 months.**

Also recommend greater consistency in reporting of deaths as SIDS

Conclusions

Sudden infant deaths where a cause of death was identified

We identified that as SUDC is a 'mode' of death rather than a specific cause, and that the current data collection is likely to miss some cases. The number of explained sleep-related sudden infant deaths identified – i.e. with a cause of death recorded on the coroner's certificate, but included in our review, was quite small. No generalisable messages emerged from this part of the review and these deaths will not be discussed in detail, however the <5 infection-related sudden infant deaths (i.e. those where the coroner's report listed a cause of death), together with the high rate of illness and infection in the week prior to death amongst the other 21 cases included in our review, raise pertinent issues about potential prevention strategies.

The prevention of deaths due to respiratory infection is a potential area for development. In particular, the possibility of active immunisation against respiratory syncytial virus (the common cause of winter chest infections in babies) infection is an area of debate. Currently passive immunisation is offered to high risk babies (Gov.uk, 2013).

82% of the babies included in this review had been ill in the previous week, but interestingly this review found that 7 out of 22 of the babies had been recognised as having thrush (candid albicans) in the week or so before their deaths.

The panel considered how parents' awareness of illness in their child might be improved and whether early recognition of illness might prevent some deaths, but of course the review itself could provide no evidence to support this. Clearly it is helpful for parents to be well educated about the early warning signs of illness, and when to seek support, and we understood that this is usual practice for parents of infants with chronic conditions – but not perhaps for parents of 'normal healthy' infants.

Identification of Modifiable Factors

Our Pan-Lancashire 'Six Steps to Safer Sleep' campaign outlines the modifiable factors of avoiding smoking, appropriate sleep placement, drug and alcohol use of parent / carer, feet to foot / back to sleep, avoiding overheating / overwrapping, and breastfeeding.

Within our review, none of the babies had no modifiable risk factors for SUDC (see table 1). <5 of the babies had had just one negative modifiable risk factor - paternal smoking - however this baby/babies had other known associated (and obviously non-modifiable) risks of prematurity and low birth weight. Many of the infants in our review had a great many of the modifiable associated risks, and so their individual risk was many times greater than a baby without those risks. <5 of the infants had all 6 modifiable risk factors recorded.

Key messages & Recommendations

Recommendations on reducing the risk

It would seem that the 6 steps are still valid and cover the 6 modifiable factors, however it is not certain that.

Recommendation on content of advice for parents

One recommendation of this review might be that we do more work on educating health professionals around the risks involved in these feeding practices as part of the safer sleep messages as well as part of the infant feeding messages.

Recommendations for disseminating the message

It is worth reminding frontline staff to reiterate the room temperature message to all families, as well as the recommendation to have babies sleep in the same room as their carer for ALL sleeps.

Frontline staff must give parents clear consistent messages in a non-judgemental way, as it is clear that a one-size-fits-all ante-natal programme around reducing risks, fails for example to acknowledge the cultural and personal importance of safe infant feeding. While there is a lot of general information which may be appropriate to all, this individualised care may mean that for some parents, this information could be tailored to their specific circumstances

We have some concerns about comprehension of the messages in families where English is not the first language, or where reading skill may not be up to understanding all of the text in the existing campaign products, and recommend that pictorial versions are developed and made available for each frontline health care professional to use.

It is unclear from some of the records we have reviewed, whether the established pan-Lancashire safer sleep messages have been discussed according to local guidance, as the discussions were not recollected by the families or recorded in the baby's notes. We recommend that this message is reinforced to frontline staff.

Research and related recommendations

Recommend that the panel ascertains whether large milk feeds or unsuitable feeds could be a contributory factor or associated risk for SUDC. We would be particularly interested in knowing whether other areas / large studies found the same? We would also like to know whether early weaning was an associated risk.

Recommendations on data collection, monitoring, & future reviews

Recommendation about more systematically identifying deaths has having had modifiable factors according to our list – currently of 6 - but which may need to be added to with large feeds, prop feeding

The panel recommend that in future information about the child's health in the week before death is systematically asked for and recorded, because if there is found to be an association, then this may become a modifiable factor and thus something which can be altered to reduce the risk of SUDC.

Recommend we ask other sources about associated risk of cannabis in sleeping infant deaths, and cascade this to frontline staff for onward dissemination to families.

No meaningful data were available for prescribed drug use and this was flagged as an area for improvement in future data gathering.

Possibly recommend that infant feeding status at birth and 6-8 weeks is obtained from the child's records in future to form part of case history for CDOP, to improve analysis going forward.

A recommendation of this review is that in future cases, information on prior dummy use with the deceased infant is systematically requested, and also that guidance from frontline health professionals does not suggest dummies as a preventative measure against SUDC.

The panel would like to make some recommendations for the development of new data collection templates to be going forwards. The process for prospective collection of data on notification of a sudden and unexpected infant death was also discussed during this review, and will hopefully be improved and made more robust as a result.

Other similar thematic reviews have been able to report upon for example the time of day when the infant was found, and the number of hours between last contact and the time that the infant was found. However this data has not been recorded in our review, and in many cases is not recorded in the original documents we had access to. A recommendation to record information more systematically so that this area can be looked at in the future, seems prudent.

Also recommend greater consistency in reporting of deaths as SIDS – should this be used where the death had no obvious cause regardless of whether there were modifiable risk factors, or only where there were no known risk factors?

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