



**CHILD DEATH REVIEW PROGRAMME
AND ALL WALES PERINATAL SURVEY**

**Sudden Unexpected
Death in Infancy -
A Collaborative Thematic
Review 2010-2012**

January 2015



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Foreword

The death of every child is a tragedy for their family, community and wider society. When the child is an infant who dies suddenly and unexpectedly their parents are left reeling with shock and their pain affects all those around them. That is why we must strive to do all we can to prevent as many of these deaths as possible.

Article 6 of the United Nations Convention on the Rights of the Child states that 'States Parties recognise that every child has the inherent right to life' and 'shall ensure to the maximum extent possible the survival and development of the child'.

The number of unexplained sudden infant deaths (uSID) in Wales has fallen significantly over the past 25 years but is still higher than the rate in some other developed countries. We must do better.

This thematic review identifies modifiable factors that have contributed to uSID in Wales, and opportunities for prevention, and makes recommendations to reduce the risk of future uSID.

The review was carried out by a cross sectoral panel. Each member brought their own skills, knowledge and experiences to this important work.

It was clear that many factors contribute to the risk of uSID and that future efforts to prevent these tragic deaths must be a collective effort.

Together, we must do all we can to reduce to an absolute minimum the number of these deaths in Wales.

A handwritten signature in black ink, appearing to read 'Gaynor Richards'.

Gaynor Richards MBE
Independent Chair



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Glossary

All Wales Perinatal Survey (AWPS)

The All Wales Perinatal Survey began in 1993 as a continuous surveillance of perinatal and infant mortality in the Principality and is funded by the Welsh Government.

Apparently life threatening event 'ALTE'.

An event in an infant or child that appears life-threatening to the parent. This may involve changes in responsiveness, breathing, colour, or muscle tone. Most are not truly life threatening but they appear so to the parent and in a minority of cases can be an indicator of serious illness. Severe ALTE are sometimes referred to as 'near-miss' sudden infant death.

Bed sharing Planned sharing of a sleep surface (usually a bed) as an all-night preferred sleeping arrangement for infant and parent or parents.

Child Death Review Programme (CDR)

A programme run by Public Health Wales which aims to identify and describe patterns and causes of child death, including any trends, and to recommend actions to reduce the risk of avoidable contributory factors.

Co-sleeping Any occasion when parent and infant are asleep together on a shared sleep surface.

Cot Death A lay term used for any sudden death of an infant during sleep, usually but not always in a cot. Analogous to Sudden Unexpected Death in Infancy (SUDI).

Infant deaths Deaths at ages under one year (>0 and <8,760 hours old at death).

MBRRACE-UK

In 2012 MBRRACE-UK (<https://www.npeu.ox.ac.uk/mbrpace-uk>) was appointed by the Healthcare Quality Improvement Partnership (HQIP) to continue the national programme of work investigating stillbirths and infant deaths. MBRRACE-UK began web based collection of perinatal data for the whole of the UK in January 2013. All Wales Perinatal Survey receive regular downloads of data from MBRRACE-UK thus reversing the data flow that previously existed in Wales. All Wales Perinatal Survey will ensure full ascertainment and quality of Welsh data, and produce an annual report from these data.

Neonatal deaths Deaths in the first 27 completed days of life (>0 and <672 hours old at death).

Overlaying The term overlaying is used to describe the death of an infant attributed to airway occlusion caused by the parent accidentally lying on the baby during sleep.

Parent We have chosen to use the term 'parent' or 'parents' throughout this document, whilst recognising that living arrangements are far more complex than this and some infants may have died in the care of another caregiver.

Perinatal deaths Stillbirths, and deaths in the first six days of life (>0 and <168 hours old at death).

Post neonatal infant deaths Deaths at ages 28 days and over but under one year (from 672 to <8,760 hours old at death).

Post perinatal infant deaths Deaths at ages seven days and over but under one year (from 168 to <8,760 hours old at death).

PRUDiC Procedural Response to Unexpected Death in Childhood. The 'PRUDiC' process has been in place in Wales since 2010 and introduced a framework for the multiagency investigation of all unexpected deaths of children from birth to <18 years. It succeeded the 2004 SUDI Protocol. The PRUDiC meeting collates detailed information about the death that is then provided to the coroner and pathologist to assist in the investigation of the cause of death. PRUDiC may also identify important lessons that may be learned from individual deaths that are addressed locally through Regional Safeguarding Children Boards, using the Child Practice Review process if appropriate. Information is also routinely provided to the CDR Programme Team using standard forms (Notification of Child Death and Record of Child Death) completed by the Head of Safeguarding for the relevant Health Board, and this enables any important messages to be shared nationally and to inform Public Health policy.

Registrable deaths Babies who are still born (from 24 weeks gestation) or who are live born and subsequently die.

Sudden infant death syndrome 'SIDS'.

The death of an infant that is sudden and unexpected and remains unexplained after a full investigation. Full investigation implies a full paediatric history, autopsy, examination of the scene of death and review of background including social factors.

Sudden unexpected death in infancy 'SUDI' or 'SUID'.

The death of an infant that occurs suddenly (without warning) and unexpectedly (the child does not have a condition known to be associated with SUDI). SUDI may remain unexplained after full investigation (in which case the death is termed SIDS, unascertained, or in this review SIDS/unascertained are grouped together as uSID), or a cause of death may be identified (explained SUDI).

The Lullaby Trust (TLT) The Lullaby Trust is the major UK charity in the field of sudden infant death. TLT provides specialist support for bereaved families, promotes expert advice on safer baby sleep and raises awareness on sudden infant death.

Unascertained death A term used by pathologists for a sudden unexpected death in infancy that remains unexplained after full investigation, but where there are features that appear to preclude the use of the term 'Sudden Infant Death Syndrome'.

Unexplained death Any death, whether sudden or not, that remains unexplained after full investigation.

Unexplained sudden infant death 'uSID', the term used in this review to group all SIDS and unascertained deaths. Analogous to the Office for National Statistics term 'unexplained infant deaths' but that term has the disadvantage that it is not explicit that the death was sudden.

UNICEF-BFI The UK Baby Friendly Initiative is based on a global accreditation programme of UNICEF and the World Health Organization. It is designed to support breastfeeding and parent infant relationships by working with public services to improve standards of care.

Abbreviations:

ADDE	Annual District Deaths Extract
ALTE	Apparently Life Threatening Event
AWPS	All Wales Perinatal Survey
BFI	Baby Friendly Initiative
BME	Black and Minority Ethnic
CDR	Child Death Review Programme
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy
MYE	Mid Year Estimates
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
ONS	Office for National Statistics
PRUDiC	Procedural Response to Unexpected Death in Childhood
SID	Sudden Infant Death
SIDS	Sudden Infant Death Syndrome
SUDI	Sudden Unexpected Death in Infancy (analogous with SUID)
SUID	Sudden Unexpected Infant Death (analogous with SUDI)
uSID	Unexplained Sudden Infant Death
WIMD	Welsh Index of Multiple Deprivation



Summary

This was the first collaborative review of Sudden Unexpected Deaths in Infancy in Wales. It was a joint initiative between Child Death Review Programme (CDR) and All Wales Perinatal Survey (AWPS). The review included a brief overview of all sudden deaths under the age of two, but the main focus was upon those which were unexplained sudden infant deaths (termed uSID for the purposes of this review).

Welsh uSID rates have typically been similar to, or marginally higher than those in England or other comparable European countries. Despite the reduction in uSID rates over the past 25 years it is clear that too many babies are dying and that the prevalence of known risk factors associated with these deaths suggests that many more could be prevented.

This review looks in detail at the 45 uSID that happened in the three year period 2010-2012 in Wales. It describes the demographics of these infants and highlights the level of modifiable risk factors that may have contributed to many of the deaths.

The evidence gathered from the deaths themselves was supplemented by a review of the recent literature evidence in this area, and detailed discussion within the panel over the course of two days, that drew upon the expertise of a large number of professionals from a wide range of backgrounds. The panel debated themes that appeared to emerge from the discussion of individual cases, and this discussion contributed to the recommendations

contained in the review.

The review of the 45 uSID cases showed an association with younger age of the infants (more than half being under 12 weeks of age), low birth weight and prematurity, deaths in winter months, younger mothers and residence in lower deprivation quintile areas.

The rate of smoking in parents of infants dying as a uSID was alarmingly high and from the information obtained it appeared that the breast feeding rate was disappointingly low.

There was a particular emphasis on the current debate around co-sleeping and its inter-relationship with known risk factors that are associated with higher risk of uSID.

In a significant minority of cases there were concerns about various more subjective issues such as social, environmental and lifestyle that, whilst difficult to confirm as causal factors, generated much debate about how these factors might link to uSID and how to achieve a high standard of infant care at all times. The challenge of promoting safe infant care and reducing these deaths further was discussed at length and some areas were highlighted for further debate and exploration in future. Various recommendations were made that we hope will lead to concerted action and will ultimately result in fewer babies dying and fewer families having to suffer the unbearable tragedy of losing a much-loved infant in this way.



Key recommendations

- **The Welsh Government, Public Health Wales, health boards and primary care providers should continue to provide advice based on “Reduce the risk of cot death” (Welsh Government, 2014) to all families with new babies. The panel agreed that the Welsh Government should not adopt a position of blanket discouragement of co-sleeping, but need to emphasise that co-sleeping in association with other risk factors carries a very high risk of uSID.**
- **Welsh government, Public Health Wales and healthcare providers should continue the universal provision of advice to all families with new babies, recognising the particularly important roles of midwives, health visitors and GPs.**
- **The panel recommends that Welsh Government should consider mechanisms to deliver the existing health promotion messages more effectively. These could include:**
 - **facilitating debate about effective prevention strategies,**
 - **consideration of a national campaign,**
 - **exploring innovative approaches including modern media,**
 - **developing mechanisms of reaching the most vulnerable families,**
 - **evaluating impact.**
- **Health boards, Public Health Wales and Welsh Government should strengthen their efforts to reduce smoking, especially in young women and parents during pregnancy and in the first year after child birth.**

- **Front line professionals should receive regular training so that they understand the key messages on the prevention of uSID, including research evidence on the interaction between co-sleeping and other risk factors such as smoking, low birth weight, very young infants and alcohol consumption, and are able to deliver these messages to parents.**
- **The Welsh Government and local authorities should review their policies and provision of social housing to ensure conditions are appropriate for families with young, vulnerable babies and that urgent action is taken in response to professionals concerns or recommendations.**
- **The Welsh Government should work with partners to promote debate and encourage research into concrete measures to reduce population rates of uSID, and unsafe co-sleeping in particular.**
- **The Welsh Government should inform all Safeguarding Children Board partners of its expectation that there will be unimpeded information sharing with the CDR programme when any child dies.**
- **The CDR programme should continue to monitor trends in unexpected infant death rates as part of its routine activity. This review should be repeated at an appropriate interval if there are concerns about the rate of progress in reducing these deaths.**



Introduction

Following the successful pilot, the Child Death Review Programme (CDR) was established in 2012 and became part of core activity for Public Health Wales in April 2014. The aim of the programme is to identify and describe patterns and causes of child death, including any trends, and to recommend actions to reduce the risk of avoidable contributory factors (Child Death Review Programme, 2012). The steering group advises the programme on themes to be reviewed. It is informed by the data and emerging themes identified through the CDR database, topical issues, issues of concern raised by stakeholders and the potential for prevention.

In January 2014, the steering group agreed that the programme should review the sudden and unexpected deaths of infants associated with sleep. It was agreed that the review should be performed in collaboration with colleagues from the All Wales Perinatal Survey (AWPS) who collect information on perinatal and infant mortality in Wales.

The AWPS is funded by the Welsh Government through Public Health Wales and is well established as providing accurate and complete surveillance of perinatal and infant mortality in Wales. The survey aims to improve the understanding of the ways in which the risk of death in late fetal life and infancy may be reduced. It includes babies who die from 20 weeks gestation to one year of age, born to mothers who are usually resident in Wales, or whose baby dies in Wales.



Background

In 2013, the child poverty strategy progress report by the Children's Commissioner for Wales identified that child poverty is on the increase and now affects one in three children living in Wales. There is a strong association between deprivation and the risk of death. The death rate among children living in the most deprived fifth of Wales is 70% higher than those living in the least deprived areas (Children's Commissioner for Wales, 2013).

Most child deaths occur in infancy and the most common causes of these deaths are conditions relating to the perinatal period and congenital anomalies. In Wales, 13% of deaths in infancy are unexplained, including five percent attributed to sudden infant death syndrome (Humphreys, et al., 2014).

The current thematic review aims to identify effective interventions and produce focused recommendations to prevent sudden and unexpected deaths in infants and young children in Wales.



Methods

3.1 Case definition

3.1.1 Criteria

The collaborative thematic review considered all sudden and unexpected infant deaths relating to a sleep environment who died within Wales, or who were normally resident in Wales but died elsewhere. In addition, details of deaths of children over one year of age but under two years of age were included in the initial data gathered and have been referred to briefly in the report, though they were not the main focus of the review and were not analysed in detail.

The three-year period 2010-2012 was chosen in order to gather sufficient numbers for a meaningful thematic review, whilst at the same time being recent data that would reflect current trends in sudden unexpected deaths in infancy in Wales. It was clear that the numbers were still likely to be too small for any formal statistical analysis and that was not our intention. The sample was intended to give a 'snapshot' of the current situation in Wales in relation to sudden unexpected death in infancy that would form the basis for extended debate within the panel meetings.

The intention at the outset was to be inclusive and to include deaths classified

as sudden infant death, unascertained deaths and also 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 that could reduce the number of infant deaths in Wales.

Sudden and unexpected deaths of children dying between one and two years of age were included in the initial information gathered. The number of deaths is far smaller than in the first year of life, but ONS reported 11 one to two year old deaths in England and Wales in 2011 that remained unexplained and are analogous to unexplained sudden infant death (uSID). These deaths serve to remind us that children, and even adults, may suffer a sudden, unexpected and unexplained death at any age and that the choice of the first birthday is for statistical convenience. However, in order to be comparable with the majority of published studies, the main part of the review focused on sudden and unexpected infant deaths (i.e. under one year) that remained unexplained after full investigation.

Similarly, deaths that occurred suddenly and unexpectedly that were explained after full investigation were included in the initial data gathered and were described briefly in the review but these were also excluded from the detailed analysis. Explained SUDI 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.

The review specifically excludes deaths that were identified as expected and explained through a specific medical condition including prematurity or congenital anomaly.

Deaths due to accidents and external causes were excluded apart from those directly related to infant care practices. 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.

Data were gathered on infants dying from birth onwards but in order to be comparable with data from other sources, data of infants dying in the first month were separated where appropriate to show the post-neonatal (deaths after the first month) unexplained sudden infant death rate.

3.1.2 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

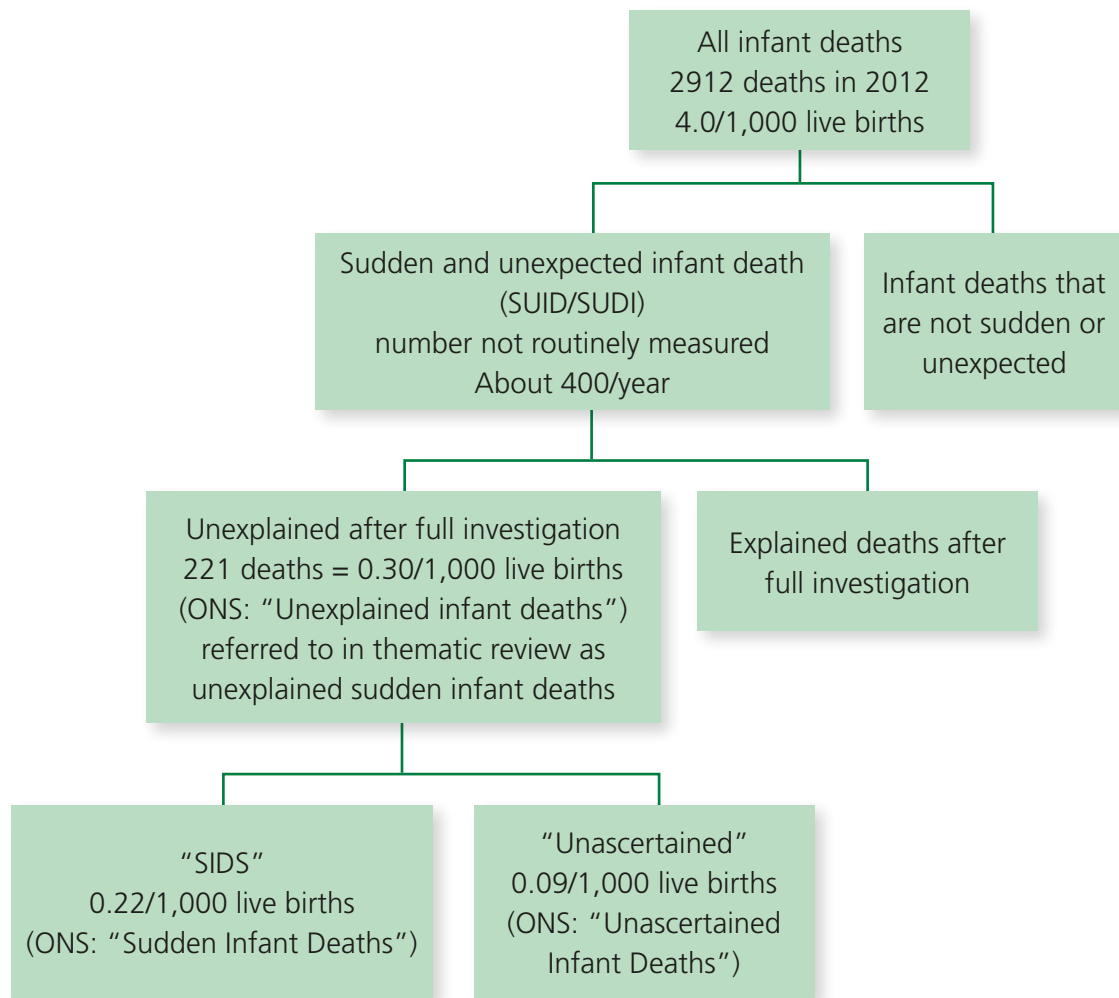
this verdict to be given at inquest, which is seen as helpful and kinder to families, although technically it is misleading as the cause of death is unknown.

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 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 therefore used the term 'unexplained sudden infant death' (uSID) synonymously with the ONS term 'unexplained infant death':

Figure 1 All infant deaths - England & Wales (2012)



Produced using data from Office for National Statistics

3.2 Data sources

Data were collected from a number of sources to improve completeness and depth. These sources were:

- All Wales Perinatal Survey database
- Child Death Review Programme database
- Procedural Response to Unexpected Deaths in Childhood (PRUDiC) review meeting minutes
- Police incident investigation reports
- Coroner's and Post Mortem reports
- External unofficial sources including media and internet reports

3.3 Core team

A core team was established from members of the CDR programme and the AWPS together with the Professional Lead for the purposes of this review. The core team reviewed all of the information on the cases identified in the review and updated the database held by the CDR programme. Core team members presented the evidence from the cases and the evidence review at the panel meetings and facilitated the discussion, recording details that informed the review report.

3.4 Thematic panel

A thematic panel was convened, with members drawn from academia, nursing, public health, police, third sector, primary care, emergency medicine, pathology, neonatology, paediatrics, health visiting, midwifery, social care and ambulance service (see page 1 for further details).

Two all-day meetings were held. The first was on the 5 September 2014. The morning session included a presentation of the risk factor review and an in-depth narrative discussion of selected infant deaths, chosen for the quality and range of information available. This enabled discussion of a broad range of themes. The afternoon focused on the identification of key themes from these deaths and additional data needed to support further understanding of the risks involved and how they might be mitigated.

The second meeting was held on 16 October 2014. During the morning, the panel was presented with a more detailed quantitative overview of all the deaths of infants (under one year) that were medically unexplained

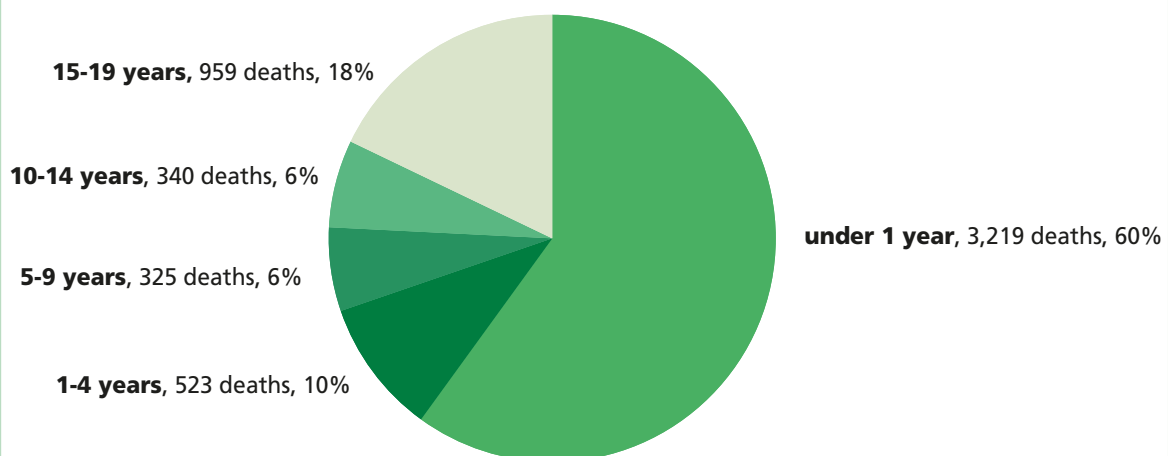
and identified key messages and conclusions. The panel then considered the evidence review of effectiveness of interventions and developed draft recommendations.

The professional lead, in partnership with members from the CDR team and AWPS, drafted the first report to which the panel provided comment. The draft report was also shared with the Child Death Review Steering Group for consideration with a particular view to assessing the clarity of conclusions and recommendations, and their potential to lead to action and achievable outcomes. The Core team considered all the comments made by the panel and Steering group and reissued the final report to the panel members before submitting it to Welsh Government via the Director of Health Intelligence at Public Health Wales.

3.5 Policy 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 (figure 2) and have been highlighted as an area where further action is needed:

Figure 2 UK Deaths in infants, children and young people in 2012



Source: Office for National Statistics. Vital Statistics: Population and Health Reference Tables. 2012.
www.ons.gov.uk/ons/rel/vsob1/vital-statistics-population-and-health-reference-tables/index.html

Similarly, in Wales the same pattern is seen with the majority of child deaths occurring in the first year of life (table 1):

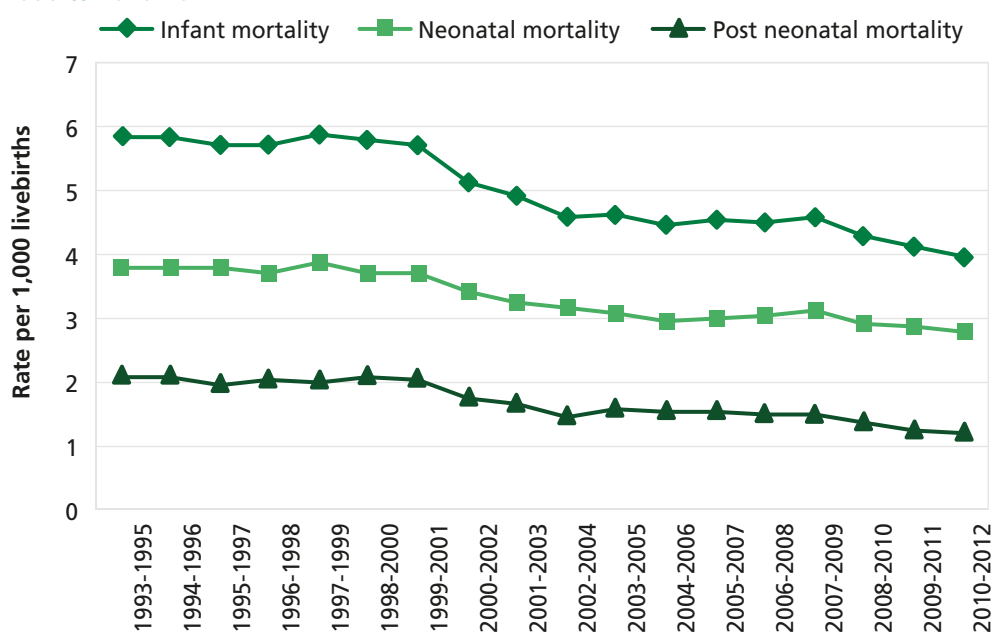
Table 1 Child deaths by age group, Wales, 2010-2012

	Average annual number	Proportion of child deaths*	Rate per 100,000	(95% confidence interval)
<1 year	143	64%	400.6	(363.6 to 440.3)
1-4 years	21	10%	15.0	(11.6 to 19.2)
5-11 years	20	9%	8.5	(6.5 to 10.9)
12-17 years	39	18%	17.7	(14.6 to 21.2)

Produced by the Public Health Wales Observatory, using ADDE & MYE (ONS). Rates should be interpreted with caution where there are a small number of events. *Percentages may not add up to 100 due to rounding

Infant mortality has been declining in Wales for many years, as it has in other developed countries (figure 3).

Figure 3 Infant, post neonatal and neonatal mortality, three year rolling average rates in Wales 1993-1995 to 2010-2012



Produced by All Wales Perinatal Survey (using All Wales Perinatal Survey data)

Unexplained sudden infant death, up until the rate fell in the early 1990s, was the commonest single cause of post-neonatal infant mortality and still contributes a significant proportion of all deaths. Unexplained sudden infant death therefore remain an important

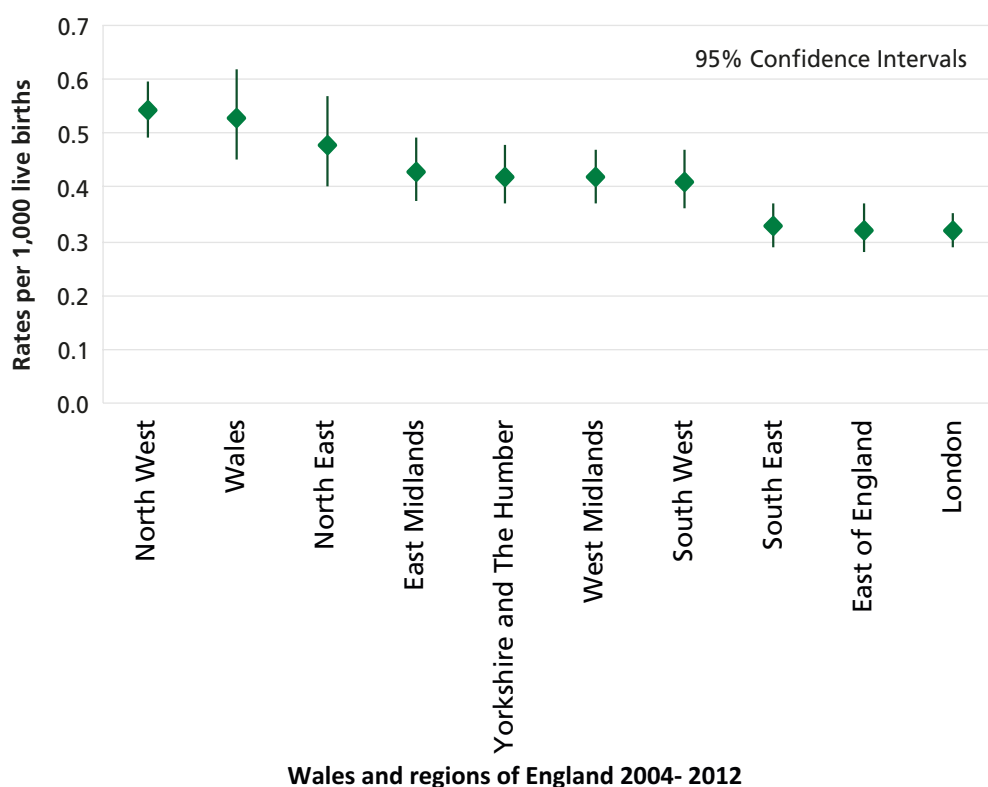
and potentially preventable cause of infant mortality, and the number of such deaths per 1,000 live births is an important comparator with other parts of the UK and other countries. It is widely seen as a marker for the development of healthy, baby-friendly

communities that prioritise infant welfare and, as such, a low death rate is an important goal.

The Welsh Government produces guidance on the prevention of sudden infant deaths, last updated in January (Welsh Government, 2014). Public Health Wales NHS Trust has also published guidance in the 2014 publication 'Bump, Baby and Beyond' (Public Health Wales, 2014). NICE guidance has recently been released providing recommendations on co-sleeping and sudden infant death syndrome covering the first year of an infant's life (National Institute for Health and Clinical Excellence, 2014).

The rate of unexplained sudden infant deaths in Wales 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. From 2004-12 the Welsh rate of 0.53 deaths per 1,000 live births appears to be the second highest rate for the different regions of England & Wales (figure 4) (ONS data).

Figure 4 Unexplained infant death rates, with 95% confidence intervals, 2004-2012



Source: the Office of National Statistics

The most recent ONS figures available show that in 2012 the uSID rate for England and Wales was 0.3 in every 1,000 live births and for Wales alone was 0.37 in every 1,000 live births. England and Wales overall has a rate of uSID comparable with most developed nations but some way behind the best. The Netherlands, for example, has a much lower rate (0.074 in every 1,000 in 2012 (Stichting Wiegedood, n.d.)). It is clear that there is some way to go in reducing the risk and that many lives could be saved if the current widely-accepted advice for Reducing the Risk was universally followed.

It could be argued that the outstanding success of uSID prevention in the UK has not received the recognition it deserves, possibly as the surviving children, who might otherwise have died of uSID 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 uSID reduction campaigns is somewhat 'hidden' compared, for example, with patients cured of a cancer and their families who are able to publicly express their emotions at having their lives saved.

Nonetheless uSID prevention has a large effect on society. From late 1980s when close to 1600 infants (ONS) were dying every year in England & Wales, the number has dropped to 221 deaths in 2012 (ONS). This means that in the 20 years since the UK Government-sponsored 'Back to Sleep' campaign in 1991-2, of the order of 25,000 infants have not died and continue to fully contribute to society. Their parents and extended families have been spared the most tragic bereavement imaginable

and the consequent impact on their emotional health and productivity. Health and other services have been spared the resulting pressures upon their resources. This is a compelling argument for health promotion activity in this area. The majority of uSID are still associated with well-known and modifiable risk factors and are almost certainly preventable, as shown by some other countries that appear to demonstrate much lower rates. This still has important potential for reduction in deaths that is achievable, possibly with very modest financial outlay in comparison with the obvious benefits. Wales has outstanding potential to lead other parts of the UK and other developed countries in this field if there is the political will.



Findings

4.1 Research evidence review

4.1.1 Summary

A high level review of literature was undertaken by the Public Health Wales Observatory Evidence Service.

The evidence review addressed three main questions:

- What are the main risk and protective factors for sudden unexplained infant death during sleep, in children under two years old?
- What interventions might be effective in addressing risk factors, increasing protective factors and reducing sudden unexplained infant death during sleep?
- Is existing Welsh Government guidance on reducing the risk of 'cot death' deaths supported by the current evidence base?

The evidence review concluded that sleep position, co-sleeping, unsupervised sleep, pre and post-natal maternal smoking and being small at birth are risk factors for Sudden Infant Death (Price, et al. 2014). Whether or not co-sleeping in the absence of parental smoking or other factors was a risk factor remained unresolved. The research evidence review found that the evidence that head covering

is a risk factor and that breast feeding and dummy use as protective factors are inconclusive. Current guidance from Welsh Government was broadly in line with this evidence base.

The evidence review that was undertaken included sources published in the last 10 years. Full details of the methodology used together with the findings of the evidence review are in the evidence review report which is available as a separate publication here: www.publichealthwales.org/childdeathreview

4.2 Infants and children included in this review: demographics

4.2.1 Number and category of deaths

Between 2010-2012, a total of 108,067 live births were recorded in Wales (55,255 male (51.1%), 52,809 female (48.9%), three unknown). The total number of deaths during these years amongst children under one year of age after a live birth was 447 (AWPS). There were a further 29 deaths between one and two years of age (CDR). Of these, AWPS/CDR data identified 125 that were possible sudden and unexpected deaths under two years of age.

Fifty were excluded as they did not meet the inclusion criteria, i.e. did not occur during sleep, were not sudden (e.g. the child had been ill and deteriorating prior to death) or were not unexpected (e.g. they had a medical condition that would be expected to cause sudden death at some time).

This left 75 children who were included in the review, 63 under one year of age and 12 who died in the second year of life.

Of the 63 infants under one year, 45 were unexplained after full investigation and in 14 a cause for death was identified (in four of the deaths, there was insufficient information available and they could not be included in the review).

For the 12 one to two year old children seven deaths were explained and five unexplained.

It is possible that the review has underestimated the number of explained sudden deaths due to the ways that data on child deaths are collected, that is if the cause of death was confirmed that cause will become the classification of death for that child regardless of whether their death was sudden and unexpected or not.

The 45 infants identified as having an uSID in Wales during this period is broadly comparable with ONS data for Wales that identified 19 'unexplained infant deaths' in 2010, 11 in 2011 and 13 in 2012 (43 in total). The figures are not identical, presumably because ONS uses date of registration of death whereas the review used date of death and also the different approach used in this review, where cases were looked at in detail using information from various sources, providing more data to accurately classify the deaths.

The uSID rate identified during this review, of 0.42 in every 1,000 live births over this three-year period, is broadly comparable with ONS data for that period.

The five children aged between one and two who suffered an unexplained sudden death were considered by the Core team and no obvious themes emerged from the initial reading of the cases. Due to the small numbers and the fact that most published literature considers infants and not one year olds, a decision was made to exclude these children from further analysis.

4.2.2 Explained sudden deaths

Of 14 explained SUDI under one year of age, the identified causes of death included infection, congenital anomaly, cardiomyopathy, chronic illness, complications of birth or prematurity, or external causes.

For the infants over one year of age but under two years, seven were identified as having a defined cause of death including infection, congenital anomaly and volvulus; and a further five remained unexplained.

These cases were all reviewed by the thematic review core team. The deaths were all very different with no clear themes emerging from these cases and the numbers were very small. They were noted but were then excluded from the more detailed analysis which involved uSID under one year of age. The remainder of the report considers under one year old children whose death remained unexplained after full investigation.

4.3 Demographics of uSID cases

Looking in more detail at the group of uSID under one year of age, the following demographic details emerge:

4.3.1 Sex

There were 24 boys (53%) and 21 girls (47%). The uSID rate per 1,000 live births was 0.43 for boys and 0.40 for girls, a male: female ratio of 1.09.

Most studies have shown an excess of male infants in SIDS statistics.

The numbers for Wales show a slightly lower male preponderance than expected from ONS England & Wales data which showed a male:female ratio of 1.65 in 2012. Given the small numbers the panel felt that this could still be within normal variation and that no conclusions could be drawn from this.

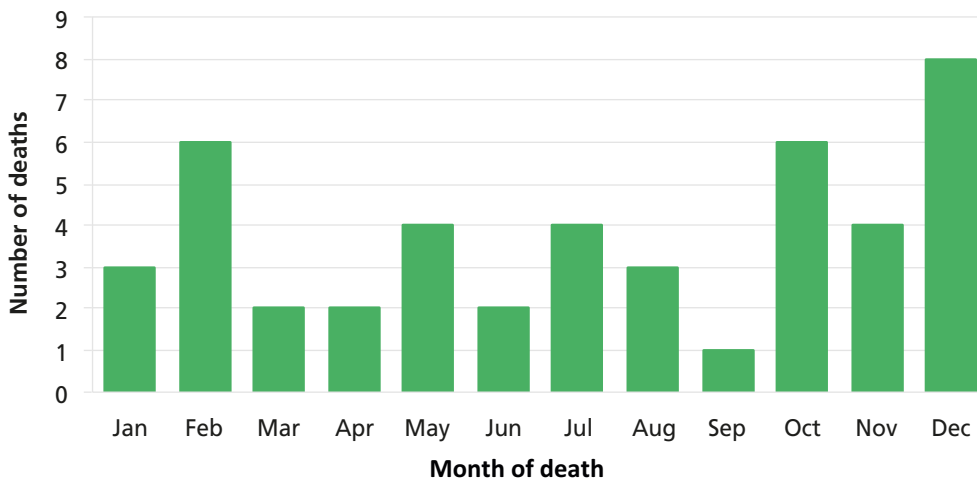
4.3.2 Deaths by month of the year

Breaking this into year quartiles the figures are:

Jan-Mar	11	24%
Apr-Jun	8	18%
Jul-Sep	8	18%
Oct-Dec	18	40%

The slight preponderance of deaths in the winter months shown in figure 5 is unsurprising, as there has always been a recognized seasonal variation in SIDS rates. However, recent ONS data of deaths occurring in 2012 has suggested a flattening of the seasonal variation with no particular winter peak. It is not clear why the seasonal variation should have become less in the years since the rate of SIDS has declined.

Figure 5 Month of death (2010-2012)

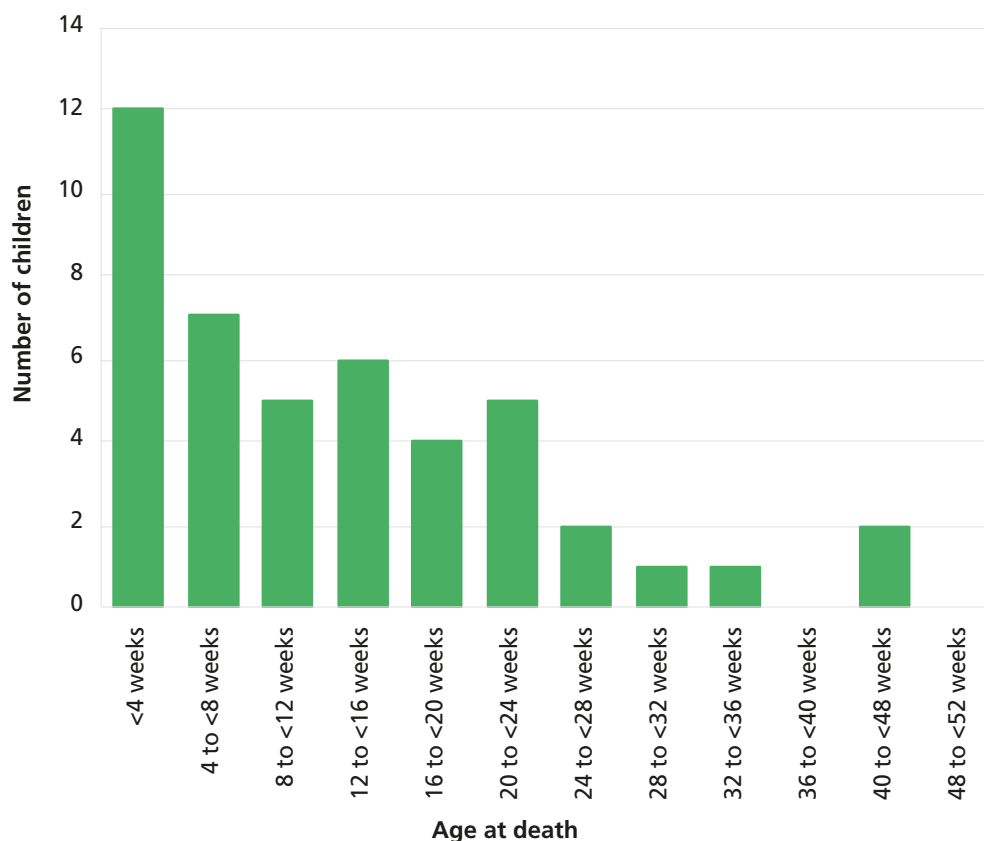


Produced using data from Child Death Review Programme

4.3.3 Age of infant at death

In figure 6 the age of the infants at the time of death is shown.

Figure 6 Age of infant at death in weeks (2010-2012)



Produced using data from All Wales Perinatal Survey and Child Death Review Programme

Twelve of the 45 infants (27%) were under four weeks of age (two of these were under one week of age), 12 of the 45 (27%) were between four and 12 weeks; 15 of the 45 (33%) were between 12 weeks and 24 weeks; and six of the 45 (13%) were over 24 weeks.

ONS data over recent years suggests that uSID 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 Welsh data identified for this review show a rather different pattern, with 12 of the 45 deaths (27%) occurring before the first four weeks, and seven of the 45 (15%) between 4 and 8 weeks of age. It is not clear why this should be the case but the numbers are small and this may not be a significant difference.

What is clear and consistent between various studies is that uSID is rare after six months of age and that prevention strategies must focus on very young babies, including the neonatal period (first month of life).

4.3.4 Age of parent

Younger maternal age is associated with a higher risk of unexplained sudden infant death (ONS, 2011). In the review the median age of the infant's mother at the time of birth was 23 years (with a mean of 25 years). This is slightly younger than the average age of all mothers giving birth in Wales in 2012, where the mean age of mothers is 28 years (AWPS). In our review 13 of the 45 mothers were under 21 years of whom seven were under 20. Eight of the 45 mother's were >30 years of age.

4.3.5 Unexplained sudden infant death and birth weight

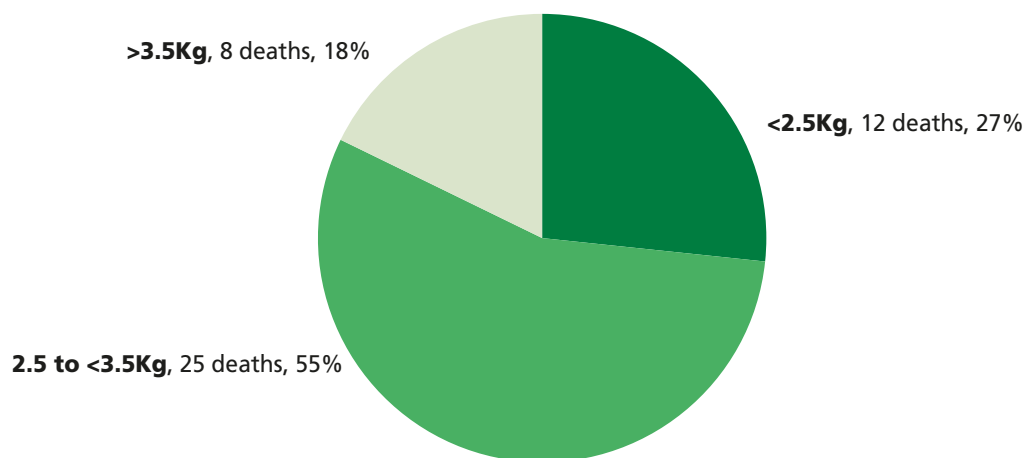
The breakdown of uSID cases by birth weight is illustrated in figure 7.

The evidence review commissioned for the review showed that low birth weight babies were around five times more likely to suffer an uSID than babies of average birth weight.

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

For comparison, of all infant deaths (due to any cause) in the review period, 31% were below 2.5Kg at birth, reflecting that a large proportion of all infant deaths relate to prematurity and neonatal complications.

Figure 7 Birth weight of infants (2010-2012)



Produced using data from All Wales Perinatal Survey and Child Death Review Programme

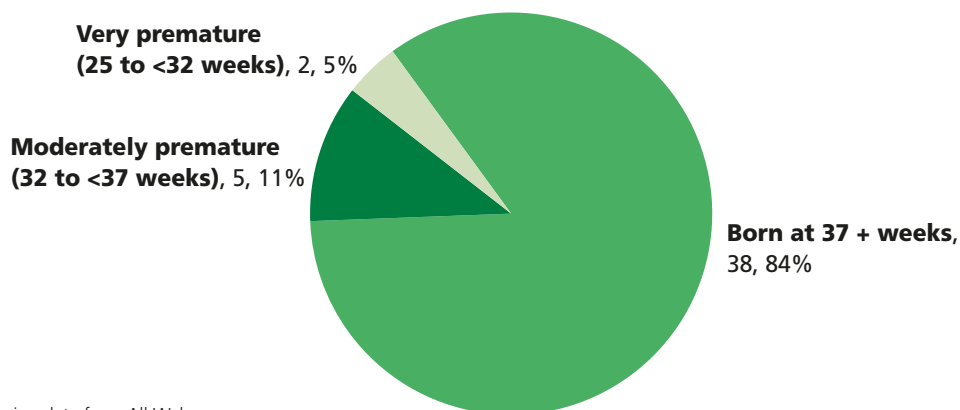
Research evidence has shown that low birth weight is associated with a higher risk of uSID and the thematic review data support this. Twelve (27%) of all the babies who suffered a uSID were below 2.5Kg at birth. For comparison, AWPS data indicates that 8.4% of all Welsh babies are born with low or very low birth weight (under 2.5Kg).

4.3.6 Unexplained sudden infant deaths and prematurity

A breakdown of all uSID cases examined in the review by gestation is illustrated in figure 8.

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 (AWPS).

Figure 8 Gestational age at death (2010-2012)



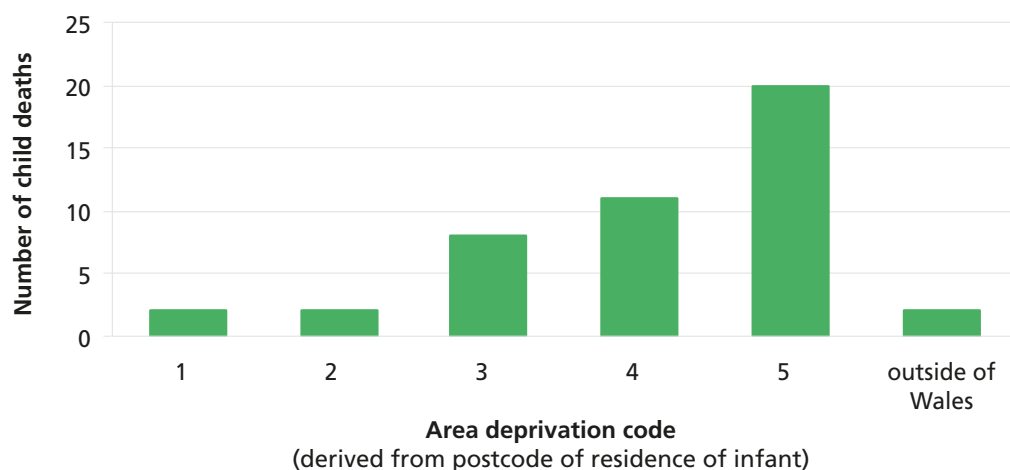
Produced using data from All Wales Perinatal Survey and Child Death Review Programme

A total of seven babies (15%) were premature. For comparison, AWPS data indicates that 7.1% of Welsh babies were born prematurely during the review period. As expected, premature babies are over-represented in this sample of infants suffering an uSID, but still account for a small minority of all cases. This is consistent with the literature in this area.

4.3.7 Deprivation

The Welsh Government uses the Welsh Index of Multiple Deprivation (WIMD) as the official measure of relative deprivation for small areas in Wales (Welsh Government, 2011). Figure 9 illustrates the number of deaths within each WIMD code derived from postcode of residence of infant.

Figure 9 Welsh index of deprivation quintile (2011)



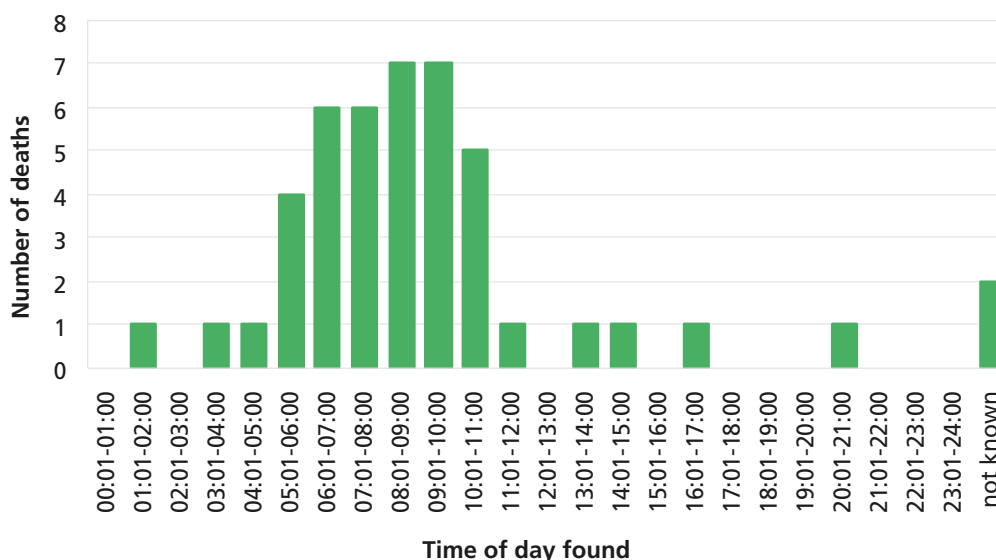
Produced by the Public Health Wales Observatory, using National Statistics Postcode Lookup, Office for National Statistics Welsh Index of Multiple Deprivation (WIMD) 2011, Welsh Government

Two cases could not be classified as the family was not resident in Wales (so WIMD cannot be assigned). Overall figures for Wales (2010-12) in the most deprived areas - quintile 5 is 26% (all births); and 28% (infant deaths) (AWPS). The preponderance of areas with higher levels of deprivation is consistent with most studies of SIDS. Within the panel meetings there was much discussion on the ways in which high levels of deprivation could impact upon the rate of SIDS. 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.

4.3.8 Time of day when the infant was found dead

Again, data in figure 10 are consistent with most published studies, in that most deaths occur during the night. Infants are found when their parent wakes in the morning, having been last seen alive the previous night or in the early hours of the morning (Leach, et al., 1999). Of the infants found dead during the daytime, some of them had been seen shortly before being found dead, but others had been put to sleep a long time before they died, the previous night or in the early hours of the morning and had not been seen in the intervening period.

Figure 10 Time infant found at death/deceased (2010-2012)



Produced using data from Child Death Review Programme

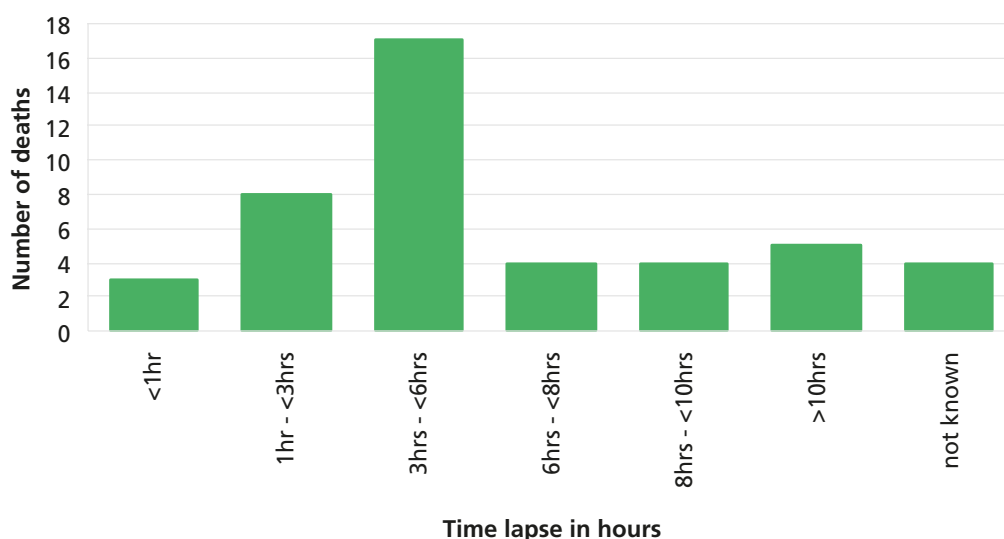
This led to discussion amongst the panel members about the importance of supervising young babies closely and keeping a close eye on them, and avoiding long periods without feeds.

4.3.9 Number of hours until found

A few babies had been left for long periods without their parent checking on them (figure 11). This may have been their normal style of parenting (which was a cause for concern within the panel) or it may have been that they usually relied on the infant to wake them for a feed 'on demand' and had slept longer than usual because the baby did not wake them.

this is more than expected. There has been anecdotal interest in infants sleeping in temporary or unusual settings as a risk factor for uSID but there is no strong evidence base for this and it accounts for a minority of cases. We did not encounter any deaths during this period in childcare settings, though that has been reported as an issue in some countries (De Jonge, et al., 2004).

Figure 11 Time lapse from when the infant was last seen alive/checked and found dead (2010-2012)



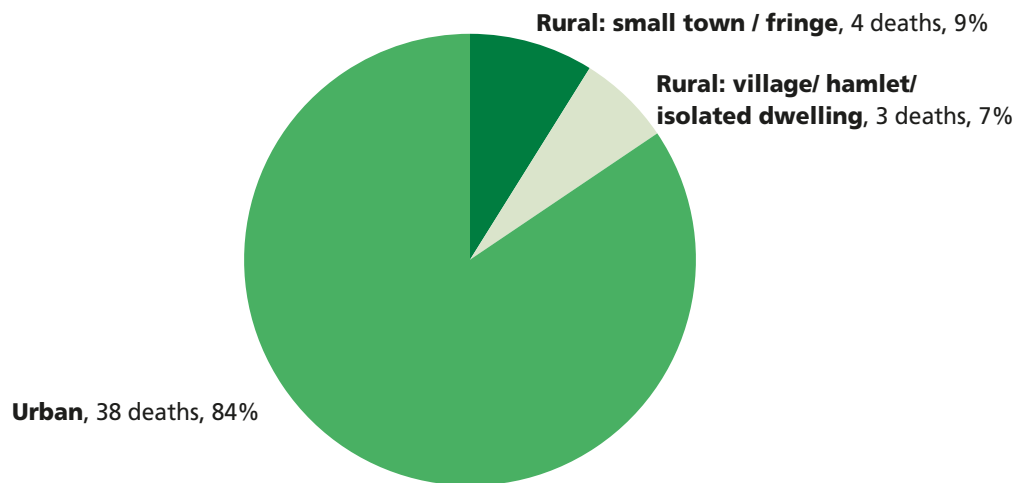
Produced using data from the Child Death Review Programme

4.3.10 Location of death

All apart from six of the deaths occurred in the usual residence for the child. These six occurred at another location, mainly in temporary accommodation including visiting relatives homes or on holiday. This means that about 13% of deaths happened when the child was not in their usual residence. Without an appropriate comparison group, it is impossible to say whether

4.3.11 Urban and rural deaths

Figure 12 Urban/Rural classification (2010-2012)



Produced by Public Health Wales Observatory, using National Statistics Postcode Lookup, Office for National Statistics (ONS) Urban/rural classification, ONS

Figure 12 illustrates the numbers of deaths occurring in urban areas. Thirty eight of the 45 deaths (84%) were in urban areas, whereas only 67% of the population of Wales live in urban areas (ONS, 2011).

4.3.12 Ethnicity

Fourteen of the 45 families were known to be White British, 28 unknown and three of an ethnic minority or mixed background. Population data identifies 6% from a BME background within the <25 year age group in Wales.

4.4 Associated factors and themes

4.4.1 Co-sleeping

We have chosen 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 sleep surface e.g. sofa.

This has been the subject of much recent debate. The evidence review highlighted the known risks identified from research in this area. Further publications are emerging regularly and one additional retrospective analysis of UK data was published after the evidence review was completed and was considered by the panel in the second meeting (Blair, et al., 2014).

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 would be simplistic, and inappropriately distressing for the parents, to attribute these deaths to overlaying. As well as unintended airway compromise, other hypotheses such as overheating or exposure to infection or cigarette smoke are viable. 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. Of 45 unexplained sudden infant deaths, 26 were sharing a sleep surface with another person at the time of death. Twenty of these were sharing an adult bed (one was a sofa-bed) and six were sofa-sharing, which is known to be a very high risk sleep arrangement.

Of the remaining 19, 16 were not co-sleeping at the time of death. The sleeping location of three babies was unknown. Thirteen infants were found in a cot/ Moses basket. One of the 13 infants was in a cot in a separate room from the parent but the remainder were in the parental sleeping room. Three died in other locations.

For six of the 26 co-sleeping deaths, co-sleeping in an adult bed was the usual sleeping arrangement for the child and parent. For one child who died whilst co-sleeping, the usual sleeping arrangement was on a sofa. For the remainder, co-sleeping was not their usual sleeping arrangement and the parent had chosen to co-sleep for a specific reason, usually that the infant was unsettled.

The co-sleeping deaths in the parental bed were often linked with other known or suspected risk factors that are believed to combine with co-sleeping to increase the risk of death. For example:

- In 18 of 26 cases one or other parent were known to be smokers and, in only one case, they were known to be non-smokers (data were missing for seven cases).
- The parent was known to have consumed alcohol in the 24 hours prior to the co-sleeping death in eight of the 26 deaths. In 12 cases it was not known whether alcohol was involved or not and six were specifically stated not to have had alcohol, though of course this information may not always be reliable.
- Eight of the 26 parents had a past history of illicit drug use. This data was not known in 15 of the 26 deaths.

Co-sleeping was associated with illness in the infant prior to death in 10 of 26 cases. This is relevant as it has been suggested that parents may be more likely to bring their baby into bed with them when they are ill, either because the infant is more fretful or because they want to keep a closer eye on them. This is a possible explanation for some of the excess death rate in co-sleeping infants but it seems unlikely to account for the majority.

Eleven of the 26 co-sleeping fatalities were associated with recorded parental mental health concerns, of whom seven mothers were reported to have been depressed prior to the death. One parent did not have mental health concerns and 14 were unknown. As discussed elsewhere in this document, there is no evidence that these concerns were causally related to the child's death or that maternal mental health concerns are over represented in this sample.

Six of the 26 were single parent families, nine lived with both parents and four were in shared accommodation with relatives (seven unknown).

In 17 of 26 families suffering a co-sleeping death there was a background of recorded social concern. In three there were no social concerns, and in six cases there was no mention of social concerns in the data available.

Twelve of the 26 (46%) were from WIMD area 5 areas (high deprivation index) compared with 20 out of 45 (44%) of all the uSID deaths.

Table 2 illustrates some of the confirmed or possible risk factors that were identified and whether these were in association with co-sleeping or not. Table 3 illustrates the minimum number of risk factors known to be present in the deaths reviewed.

- Sofa sharing
- Smoking in either or both carers
- Carer alcohol consumption in the 24 hours prior to death
- Carer history of illicit drug use
- Carer depressive illness
- Low birth weight
- Prematurity

Table 2 Risk factors (2010-2012)

Risk factor	Incidence in co-sleeping uSID cases (n=26)	Incidence in non-co-sleeping uSID cases (n=16)	Incidence where information missing (n=3)	Incidence in total uSID cases (n=45)
Sofa sleeping	6 (23%) (1 unknown)	0	1 (2 unknown)	7 (16%) (3 unknown)
Smoking	18 (69%) (7 unknown)	7 (44%) (6 unknown)	(3 unknown)	25 (56%) (16 unknown)
Alcohol at time of death or past history of concern	11 (42%) (10 unknown)	2 (13%) (7 unknown)	(3 unknown)	13 (29%) (20 unknown)
Any history of drug use in either parent	8 (31%) (10 unknown)	3 (19%) (7 unknown)	(3 unknown)	11 (24%) (20 unknown)
Illness of child in week prior to death	10 (38%) (2 unknown)	9 (56%) (3 unknown)	1 (2 unknown)	20 (44%) (7 unknown)

Table 3 Multiple risk factors (2010-2012)

	Incidence in co-sleeping uSID cases (n=26)	Incidence in non-co-sleeping uSID cases (n=16)	Incidence where information missing (n=3)	Incidence in total uSID cases (n=45)
one identified risk factor*	1	6	0	7
two identified risk factors*	5	2	0	7
three identified risk factors*	8	5	0	13
four identified risk factors*	9	0	1	10
five identified risk factors*	2	1	0	3
six identified risk factors*	0	0	0	0
seven identified risk factors*	1	0	0	1

*NB: Some cases have missing data so these numbers represent minimum incidence of risk factors.

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 and may not be mentioned in the material available to the review (e.g. parental obesity, tiredness, prescription drugs).

4.4.2 Co-sleeping comparison with previous welsh study

SUDI deaths in Wales for the three years 1999-2001 have previously been reviewed and reported in the AWPS/CESDI annual report for 2001 (Davis, 2001). The findings at that time were:

There were 88 recorded SUDI deaths in Wales between 1999 and 2001¹.

Data was incomplete in some cases due to difficulty in obtaining post-mortem reports, therefore for 22 cases the sleeping arrangement was unknown.

- In total 43 of the 66 children for whom information was available were co-sleeping
- In 31 cases the infant was sleeping in bed with one or both parents
- In 10 cases the infant was asleep on a sofa with an adult
- One child was recorded as being asleep on the parent but it is not recorded where they were.
- One child was in a cot with a sibling
- Only 15 infants were alone in their own cot, crib, moses basket or bed.
(This may be an overestimate as, where it was recorded that the child was 'in bed' it was assumed to be the child's own bed or cot, not an adult bed). In six cases it is specifically mentioned that the face was covered. In four cases the infant was recorded as being prone when found, and in two cases bedding placed over the side of the cot had fallen into the cot. These figures are probably underestimates as this information was not always available.
- Two infants were sleeping alone on a sofa or chair and two were in a pram or pushchair.
- One child each was on a beanbag, adult bed alone, moses basket, on a pillow on the floor with a duvet over, and in a car seat next to a sofa.

All Wales Perinatal Survey/Confidential Enquiry into Stillbirths and Deaths in Infancy annual report for 2001

¹ AWPS 'Sudden Infant Death' numbers. These numbers may not be strictly comparable as the current Review explored the cases and their classification in more detail using various sources of data. A few of the 88, had they been examined in more detail, might have been attributed to a cause other than uSID but we believe the numbers are broadly comparable.

Comparing the 1999-2001 analysis with the 2010-2012 data used for this review the following similarities are noted:

Table 4 Location of death (2010-2012)

	1999-2001	2010-2012
Total unexplained SID	88	45
Location of death unknown	22 (25%)	2 (4%)
Location of death known	66 (75%)	43 (96%)
Co-sleeping	43/66 (65%)	26/43 (60%)
Co-sleeping in adult bed	31/66 (47%)	20/43 (46%)
Sofa-sharing	10/66 (15%)	6/43 (14%)
Died alone in cot/ Moses basket or other infant-specific sleep surface	15/66 (23%)	13/43 (30%)

Source: Confidential Enquiry into Stillbirths and Deaths in Infancy (1999-2001) and Child Death Review Programme (2010-2012)

Apart from the total numbers having fallen significantly in the interim, the figures are remarkably similar.

It is notable that the proportion of deaths occurring whilst co-sleeping apparently rose in the early 1990s (prior to the 1999-2001 study) but has remained stable subsequently despite a continued reduction in total uSID numbers. The reasons for this are not clear.

4.4.3 Smoking

Twenty five of 45 infants were known to have died in smoking households (55%), four out of 45 in non-smoking families and in 16 out of 45 of the deaths data was unknown.

Eighteen of the 26 co-sleeping deaths (69%) involved smoking parents, seven of the 26 unknown and one of the 26 not smoking.

Of the 13 babies that were in a cot or other intended infant sleep product,

six of 13 (46%) were smoking families, three of 13 non-smoking and four of 13 unknown.

In Wales, the 2012 Tobacco and Health report from the Public Health Wales Observatory stated that around one in six females living in Wales smoke throughout pregnancy. This is the highest rate of the UK nations, although the rate has fallen since 2005. Smoking prevalence amongst women aged 16 to 34 was 27%, and the rate is higher again in more deprived areas. In 2010, results from the Welsh Health Survey showed that 39 per cent of children lived in households where at least one adult was a current smoker, and 17 per cent of children lived in households where at least one adult had smoked in their home in the past seven days. Again, this rate was higher in families with lower socio-economic classification (Public Health Wales Observatory, 2012).

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

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 uSID. 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 uSID prevention guidance as for tobacco smokers, including avoiding co-sleeping.

4.4.4 Parental alcohol consumption or drug use

Data were limited for many families. Eight parents were known to have used alcohol in the 24 hours prior to the child's death (24 unknown), all of whom were known to have been co-sleeping. 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 11 families (21 unknown) there was a prior history of illicit drug use, of whom eight were co-sleeping deaths. Data was limited, this did raise concern amongst the panel that a significant proportion of deaths were occurring in families with clear contra-indications to co-sleeping.

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

4.4.5 Solitary sleeping

Only one baby was known to be sleeping in a cot in their own room, separate from the parent. For two babies the sleeping location was unknown.

4.4.6 Sleeping position for cot-sleeping babies

Of the 13 infants 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 of only three babies was known, one each on back, front and side (10 unknown). This highlighted a lack of data in this important area that was, of course, a major factor in the 'Back to Sleep' campaign in the early 1990s.

4.4.7 Head covering/entanglement

In two cases there was a specific reference to the infant having their head or face covered by bedding when found.

4.4.8 Breast feeding

Only eight of the 45 infants were known to have ever been breast fed (data missing in nine, 28 not breast fed). Of the eight who were breast fed, five were co-sleeping babies (all sleeping in adult beds) and three were not co-sleeping.

For the five babies who were breast fed and co-sleeping, bed-sharing in an adult bed was their usual sleeping arrangement in three cases, all very young babies, all of whom were in smoking families. The usual sleeping arrangement for one was unknown and one usually slept in a crib next to the parental bed.

Six of the eight breast fed babies who died were known to have a parent who smoked (including four of the five co-sleeping deaths) and one was unknown. The significance of this was that the breast fed babies who died almost all had other risk factors and there was no evidence that planned co-sleeping in conjunction with breast

feeding, in families with no other risk factors, was implicated in these deaths.

4.4.9 Illness preceding death

Twenty of the 45 (44%) infants had been unwell in the week before death, 18 had not and data were missing for seven. Of the 20 children who had been unwell, most had respiratory symptoms ranging from runny nose and cough to bronchiolitis or recovering from pneumonia. None of these illnesses was considered adequate to explain death.

Of the 20 infants who had been unwell, 10 were co-sleeping at the time of death. For three of these infants co-sleeping was their usual sleeping arrangement, and four were unknown. This does not particularly lend weight to the suggestion that infants are more likely to be taken into a co-sleeping arrangement when they are ill, but the numbers are very small.

4.4.10 Long interval between infant last being seen alive and found dead

There were 13 of 45 cases where the infant had not been seen for over six hours, and nine of the 45 had not been seen for eight or more hours before being found dead. In many of these cases there were some pre-existing overt social concern or a history of drug or alcohol concerns. Panel members expressed significant concern that babies should not be left for long periods without feeds or supervision. There was discussion about the circumstances that could lead to this situation and existing health promotion projects that could endorse this view.

4.4.11 Dummy use

There is some research evidence that regular dummy use may reduce the risk of uSID but the association is fairly

weak and a recent paper published after the evidence review was conducted suggests that the protective effect only applies to co-sleeping infants (Blair et al 2014). Data on dummy use were scant in this review. In nine of the 45 cases there was specific mention that the baby used a dummy, one of whom was breast fed. In no cases was there a specific mention that the baby did not use a dummy but for the other cases (36 of 45) data were absent. The panel could draw no conclusions from this.

4.4.12 Social concerns

There was some previous social concern in 30 of the 45 cases. Any mention of social concern prior to the death was included. This ranged from relatively minor subjective concerns to active involvement of Children's Social Services prior to the death. In four of the 45 cases there was explicit mention of the absence of social concerns and in 11 of the 45 data were missing. Some of the cases reviewed raised concerns about neglect and the panel discussed whether they should have been referred to Social Services at some time prior to the child's death. The information available to the panel was too limited to form a definite view on this.

As all of these cases had been discussed as part of SUDI protocol or the PRUDiC procedure, any significant ongoing social concerns should have been addressed.

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 uSID felt was important to look for and document after a death has occurred.

Social concerns identified included:

- Parental history of child abuse or neglect
- Parental substance misuse
- Parental alcohol abuse
- Parental mental health concerns
- Domestic Abuse
- Poverty
- Debt
- Poor attendance at health appointments
- Concerns about infant care practices in relation to sleep environment and feeding
- Families in receipt of services e.g. 'Team Around the Child'²

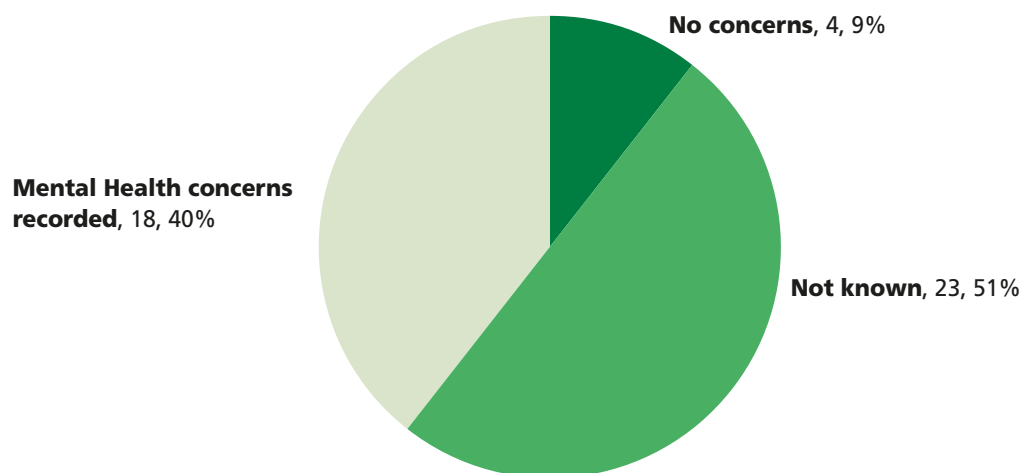
4.4.13 Domestic abuse

Any mention of domestic abuse in the material supplied was included for these purposes. A past history of domestic abuse was specifically mentioned in 10 of the 45 cases and excluded in six of the 45 cases but data were absent for 29 of the 45 cases. The 10 cases with mention of a history of domestic abuse also demonstrated various other social concerns. There was no suggestion that any of these infants had been abused.

4.4.14 Maternal mental health

A maternal mental health concern was explicitly stated in 18 of the 45 cases but data were absent in 23 cases; and there were no mental health concerns in four cases. Any mention of mental health concern in the material available to the review was included, so this was a low threshold and did not necessarily correspond to a formal medical diagnosis.

Figure 13 Mental health concerns in parent (2010-2012)



Produced using data from Child Death Review Programme

² Team Around the Child or Team Around the Family are examples of services that support vulnerable families at a level below the threshold for safeguarding intervention.

The most frequent concerns reported were depression and self harm. Given the nature of the PRUDiC/CDR processes and the breadth of information shared it is likely that most significant mental health problems will have been noted. It is questionable whether this was an excess compared to population norms and the data were too limited to form any firm conclusions.

There were very limited data about mental health problems in the male parent, these being mentioned in only two cases.

Although parental mental health concerns are probably very common, and there was no desire to stigmatise parents, the panel discussed whether babies being cared for by a parent with a mental health problem may have additional vulnerabilities or a potential for an increased risk of unexplained sudden infant death. There was discussion about whether a depressed parent could be as responsive to their baby's needs as they might wish to be had they not been depressed. There was also discussion around the risks of parenting if affected by prescribed medication, and particularly the perceived risks of co-sleeping in this situation. In the absence of more robust data no conclusion can be drawn from the review cases.

4.4.15 Housing and living conditions

The review identified a number of concerns about the home environment common to several of the households where babies died:

- Families living with extended family members and sharing their accommodation
- Overcrowded accommodation

- Inadequate accommodation
e.g. no cooking facilities
- Damp accommodation
- Accommodation in a poor state of repair and decoration or inadequately furnished
- Accommodation cluttered, untidy, dirty or unhygienic

The impression gained by the panel was of a preponderance of families living in areas with higher levels of deprivation, and the cases gave some insight into the poor state of housing that is prevalent in some parts of Wales. Whilst the information is highly subjective, there were concerns that many infants are living and dying in housing situations that most people would view as sub-standard. The panel were also concerned that poverty and poor housing could inadvertently lead to more risky infant sleeping arrangements.

The panel discussed schemes such as 'The Baby Box Co' (The Baby Box Co, 2014) and 'Pepi-Pod' (Pepi-pod, 2014) that are intended to enable a safe sleeping environment for new-born babies with minimal outlay and that can be used easily even in crowded or space-restricted surroundings. These are not strictly evidence-based as a means of reducing the risk of uSID but for the more vulnerable families may have significant advantages. The panel supported the potential for research in this area.

4.4.16 Household structure and family lifestyle

The review identified a number of factors common to several of the families of babies who died:

- Single mothers
- Families where mother's partner was not the biological father of all of her children
- Families where three generations were living together
- Families where there were difficult interpersonal or intergenerational relationships

The panel did not have any relevant control data or any other means of determining how usual or unusual these family circumstances are in Wales. The panel gained an impression of some families living in a temporary or somewhat disorganised situation but did not feel any firm conclusions could be drawn from this.

4.4.17 Young mothers

Thirteen of the 45 of the mothers of babies who died as a uSID were under 21 years old (seven under 20 and six aged 20 but under 21 years). This is more than would be expected purely from population demographics. Looking at this group in more detail:

- Eight of 13 (62%) were co-sleeping (two unknown).
- Two of 13 were known to have been sofa-sleeping at the time (one with an adult, one it is not known if they were on the sofa alone or with another individual).
- Five of the 13 were low birth weight babies.

- Three of the 13 were breast fed (two unknown).
- Ten of the 13 infants had smoking parents (three unknown).
- Three of the 13 had a known history of domestic abuse (eight unknown).
- Four of the 13 had any mention of parental mental health concerns (eight unknown).
- Eight of the 13 were from a WIMD deprivation area 5 (high index of deprivation), two from area 4, two from area 3, one from area 2.
- Ten of the 13 mentioned some social concerns in the material reviewed (two not known).

4.4.18 Deprivation

As highlighted in the section 4.3.7, there is a preponderance towards higher deprivation level areas of residence. There was discussion as to whether absolute poverty contributed to the deaths through non-availability of important items, such as a cot or crib. This was possibly the case in one of the deaths reviewed. The focus of the panel's discussion was more in terms of how deprivation and poverty can impact on infant care practices through creating many competing pressures on parents and distracting from the important focus on the needs of the young infant. The panel recognised that this is a complex area that poses great challenges for health promotion.



5 Strengths & limitations

A major strength of this review was the multi sectoral nature of the panel. There was representation from health (primary, secondary, tertiary and public health, across different specialties), social services, ambulance service, police, academia and the third sector. This allowed for a truly representative discussion of the deaths that extended beyond health to consider multifactorial issues.

This Welsh national review covered a three year period, retrospectively collecting information from a wide range of sources allowing opportunities to identify themes and potentially modifiable contributory factors to sudden and unexpected infant deaths in Wales.

The information on deaths of young children included in this review is akin to a case series; it allows associated factors to be identified, but does not provide evidence for causation and cannot contribute new information on the effectiveness of health promotion interventions. For this reason, the review is supported by a review of international evidence which has informed the recommendations.

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 CDR programme data collection templates were further developed during the course of this review and will be used in this revised form going forwards. The process for prospective collection of data on notification of a sudden and unexpected infant death was also reviewed during this review, and will be improved and made more robust as a result.

The panel recognised that the views of families who have experienced the loss of an infant or young child in this way are extremely important; however contact was not made directly with individuals for the purposes of this review. This would have been logistically challenging and would have altered the nature of the panel meetings considerably. It was helpful that the panel members were able to engage in robust debate during this review, which might have been rather different had the panel included more parent representatives, but for future reviews this is something we would wish to address. Some of the panel members had experienced a child bereavement and were able to draw upon that experience, but they were not chosen for that reason. We did, however, include representation from several key third sector organisations who advocate for families in these circumstances.



6 Conclusions

6.1 Sudden infant deaths where a cause of death was identified

These deaths were included at the initial stage of the review in order to avoid missing relevant cases and have a 'first look' at the cases and numbers. There are no comparator data for England & Wales as a whole, though some research has highlighted similarities in the epidemiology of explained SID compared with uSID (Leach, et al., 1999), (Platt, et al., 2000). We identified that as SUDI is a 'mode' of death rather than a specific cause then the current data collection is likely to miss some cases.

The number of explained SUDI identified was quite small and the causes of the deaths reflected the prevalence of potentially fatal conditions in Welsh children. No generalisable messages emerged from this part of the review and these deaths will not be discussed in detail.

One infant's death had been attributed to 'overlying' and therefore was not included in the final analysis of unexplained SUDI cases. We acknowledge that there can be a degree of subjectivity about whether a co-sleeping SUDI is attributed to

overlying or not. We gained the impression during the review that the threshold for attributing such deaths to overlying was high and was dependent upon there being other evidence that the death was explained in this way.

This was the only sudden infant death in this review that was attributed to an accident within the sleeping environment. There has been interest in accidental deaths relating to the sleep environment in other countries, but our review would suggest that these deaths form a very small proportion of the total (Moon, et al., 2011).

One infant death that initially presented as a sudden and unexpected death had subsequently been attributed to physical child abuse. It is well recognised that infants may present with an 'apparently life threatening event' after abusive head trauma in particular (Adamsbaum, et al., 2010). No infant deaths presenting as SUDI were subsequently attributed to deliberate smothering during the period under review, probably reflecting that this form of child abuse is rare and the threshold for diagnosing it is very high.

The four infection-related sudden infant deaths raise pertinent issues about potential prevention strategies.

There has been some debate about the prevention of deaths due to perinatally acquired 'Group B Streptococcus' in particular, although we are unaware of any plans to implement any new initiatives in Wales and evidence of the effectiveness of screening is lacking (UK National Screening Committee, 2012).

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).

The remainder of the explained deaths related to chronic or severe underlying illnesses that are unlikely to be amenable to a prevention approach. The panel discussed how parents' awareness of severe or evolving illness in their child might be improved and whether early recognition of illness might prevent some deaths, but the review itself could provide no evidence to support this. Pragmatically we felt that it was helpful for parents to be well educated about the early warning signs of severe illness and we understood that this is usual practice for parents of infants with chronic conditions. The panel commended the early warning scoring system 'Babycheck' (The Lullaby Trust, 2014) and the important role played by Health Visitors in supporting new parents in this way.

6.2 Sudden unexpected deaths in the second year of life

These deaths form a small but well-recognised group that share some of the characteristics of deaths in the first

year of life. The 12 deaths identified included five that remained unexplained after full investigation. That is broadly in line with the number that might be expected from ONS data. The panel did not feel that any conclusions could be drawn from this data so they were not analysed in any more detail.

6.3 Unexplained sudden infant deaths

This was the main focus of the review and occupied most of the panel discussion and the evidence review.

6.3.1 Incidence and demographics

The figures identified in the review closely matched AWPS and ONS statistics for uSID for the period in question. Any minor variances between the cases identified by CDR/AWPS and those counted by ONS may be due to differences in data reporting and the detailed analysis of cases adopted for the review that might lead to more accurate classification of some cases.

Whilst the numbers of uSID identified in the review were too small to be amenable to detailed statistical analysis, the rate of uSID in Wales is comparable with the remainder of the UK and other developed countries. Historically, the Welsh rate has been slightly higher than that for England as a whole and certainly higher than the more affluent English regions. It is possible that this slightly higher rate may be attributable to population demographic factors such as inequality, deprivation levels, smoking, low birth weight or pregnancy rates in younger women, but detailed analysis of these associations was outside the remit of the current review.

As noted earlier in this report, some other countries have achieved significantly lower rates of unexplained sudden infant deaths and this must be an aspiration for Wales. The majority of deaths should still be viewed as preventable, although the rates are fortunately much lower than in the 1980s and early 1990s. The panel endorsed the view that complacency was not an option and further efforts must be put into reducing the rate further.

The demographic data for Welsh deaths in this review were compatible with what is known about uSID generally and did not throw up any major surprises. The association with areas of higher levels of deprivation (WIMD 4 and 5) enables a degree of targeting of extra effort in prevention and health promotion, but deaths have occurred in all areas and no infant can be said to be immune to uSID, so the implication is that prevention strategies must be delivered universally.

The babies considered in the review possibly included more deaths than might be expected from ONS England and Wales data in respect of girls, deaths in the first month of life, and deaths during winter months, but the numbers were small, certainly too small for statistical significance. We did not feel that any firm conclusions could be drawn from this.

The low birth weight and prematurity data are compatible with ONS data for England & Wales. Low birth weight babies are confirmed as a vulnerable group who should be targeted for additional health promotion advice, but they still make up the minority of all deaths.

6.3.2 Social, lifestyle and infant care factors

Some cases presented in the review highlighted an apparent lack of attention and responsiveness to the infant's needs, or where the infant appeared not to be been receiving the level of care and attention that most babies should receive. Examples included several cases where there was a long period between the baby being last seen to be alive and subsequently being found dead, or situations where it appeared that the parent's focus on their infant may have been distracted by other events.

The data are largely subjective and anecdotal and there is not good comparator data for the population as a whole. It is difficult to draw firm conclusions from this without appearing critical or judgmental of parents who may be living with many different pressures, but it was a cause for concern amongst panel members and generated lengthy debate.

This is discussed further in Section 7 'Key Recommendations'.

6.3.3 Housing

There were anecdotal accounts of babies dying in housing situations that were subjectively very sub-standard. Whilst no firm conclusions could be drawn in terms of causation, the panel felt that babies should not be living in circumstances that appeared to reasonable professionals to be below the minimum standard required. We felt that families with young babies should be a priority for adequate housing. We discussed whether over-crowded housing could be a factor in increasing the probability of high-risk infant care practices such as unsafe bedsharing, and whether poverty could be a factor

i.e. the economic non-availability of important equipment impacting upon infant care. The reviewed cases did not lend weight to the latter discussion, i.e. we did not identify many babies where the lack of physical equipment appeared to be a factor in the child's death, but there were anecdotal cases where overcrowding could have been a factor.

6.3.4 Smoking

The review supports what is already known about uSID, that many cases are associated with tobacco smoking. This has been known for many years and is already targeted in Health Promotion activities. The panel members were concerned that smoking in pregnancy and in households with young babies was still prevalent in the cases studied despite the known risks and the publicity around this risk factor.

We would endorse established smoking prevention activities and encourage further research. For example on the problem of smoking in young people (who will be the parents of tomorrow's infants), young women in particular, smoking in pregnancy and in the year after childbirth.

6.3.5 Solitary sleeping

The evidence from the review suggests that this known risk factor does not account for a significant proportion of uSID in Wales and is unlikely to be a fruitful area for future health promotion activity. It seems that the existing Health Promotion message about keeping babies in the same room as the parent until at least six months has been effective and that very few deaths are now occurring with the infant alone in a separate room from the parent. That is good news and this advice should remain part of the Welsh Reducing the Risks message.

6.3.6 Breast feeding

A small but significant proportion of deaths occurred in breast fed babies. Without control data for the review babies, it is not possible to say whether breast fed babies were over- or under-represented in uSID numbers. The deaths that did occur were associated with the presence of other risk factors. The proportion of breast fed babies that died whilst co-sleeping was similar to the rate for all of the babies included in the review, though the numbers were very small.

6.3.7 Illness preceding death

As with other published studies, quite a high proportion of infants had been unwell in the week prior to death (Leach, et al., 1999). Respiratory symptoms in particular were associated with unexplained sudden infant death in around a third of uSID cases. Again, without control data it is not possible to say that this is in excess of the expected rate. The respiratory illness was not the given cause of death, and in the absence of compelling pathological findings it is unclear how respiratory infection contributes to uSID. Given how common these illnesses are in the child population this does not lend itself to any targeted health promotion activity. In the panel meeting there was discussion about targeting children who present for medical attention with respiratory infection, encouraging their parents to strive to reduce risk factors for SUDI during the period of illness. However, as virtually all infants will catch a cold at some time, this is information that should be delivered to the whole population.

6.3.8 Dummy use

The panel noted the evidence review findings in this area. There was remarkable little information on dummy use in the thematic review babies and this has been flagged as an area for improved data gathering going forwards. No firm conclusions could be drawn on this.

6.3.9 Co-sleeping

A large part of the debate in panel meetings centred upon this area. Opinion is, of course, the enemy of science and it was apparent from some of the literature reviewed in the course of the thematic review that disparate 'camps' are emerging where co-sleeping is concerned, and that this may cloud the issue somewhat. Impressively, the panel members managed to steer a path through this minefield and achieved a common view on how we should proceed.

It is important to try to capture this debate at this point. On a wider national and international level the debate is far from being concluded, but we hoped to be able to assist policy-makers in forming a pragmatic plan based on current evidence.

Some issues are widely agreed, such as:

- The proportion of babies that suffer an unexplained sudden infant death who are co-sleeping at the time appears to have increased at the same time as the overall uSID rate decreased in the early 1990s.
- The total number of co-sleeping related uSID appears to have declined but not by as much as cot-sleeping uSID. In other words, the health promotion activity and modified infant care practices that were so successful in preventing cot-sleeping

deaths have been less successful in preventing co-sleeping deaths.

- Although up to date population data for co-sleeping are limited, the rate of co-sleeping uSID is probably in excess of what would be expected for the population at large simply due to chance.
- The risks associated with co-sleeping seem to diminish with rising age of the infant.
- Co-sleeping appears to combine with certain other risk factors to create very high risk sleeping environments for uSID. These factors include sofa-sharing, parents who have consumed alcohol or drugs, are excessively tired (recent discussions in the literature extend this to parents who are 'impaired' in a more general sense e.g. through illness or obesity but this is perhaps less well studied), are smokers, or infants who were born prematurely or of low birth weight. There is general agreement that parents should be made aware of these risks and co-sleeping actively discouraged where they apply.
- Low-risk families where no other known risk factors are present, whether they co-sleep or not, comprise a very small proportion of all uSID cases, so strategies aimed at modifying their infant care practices will not have a large impact on the rate of uSID for the whole population. In other words, a very small risk, even if it is multiplied, remains a very small risk. In Public Health terms this is therefore a less fruitful area for Health Promotion activity.

Other areas are subject to more debate, for example:

- Different observers may vary in their view of the 'population-attributable risk' of unsafe co-sleeping. For example, one large retrospective statistical analysis of multiple studies concluded that "our models predict that 88% of the deaths that occurred while bed sharing would probably not have occurred had the baby been placed on its back in a cot by the parents' bed" (Carpenter, et al., 2013).
- For low-risk families where all other risk factors are absent the relevance of discouraging co-sleeping is a subject of debate and there is no general consensus. Published studies suggest that the risk of co-sleeping may be increased for very young babies even in the lowest risk families but the difference is often not statistically significant (Carpenter, et al., 2013), (Vennemann, et al., 2012). The risk for older babies appears to decline and co-sleeping with older babies in the absence of other risk factors appears to be protective, i.e. the risk of uSID is reduced, though as very few deaths occur after six months the impact of this as a strategy for reducing overall uSID numbers would be very limited (c.f. evidence review).
- The potential 'unintended consequences' of discouraging bed sharing as a planned practice in low-risk families have been highlighted, such as the potential for parents to choose a less safe environment (e.g. sofa) for night-time feeds, or the potential impact upon the success and duration of breast feeding. This is an area that would require further research (Bartick & Smith, 2014).

The governments of some countries have chosen to amend their national policy in recent years to a position of generally discouraging bed sharing or other unplanned co-sleeping. Most notably the United States Government has endorsed the recommendations of the American Academy of Pediatrics in 2011, and the Government of the Netherlands has also adopted this position.

A counter argument to this, and a view expressed within the panel discussions, is that for any government to issue guidance of this type whilst the debate is still very active is likely to lead to confusion on the part of the public that may undermine other more widely agreed messages.

6.3.10 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 the night feeds. There does not appear to be any clear evidence from research on this particular topic and the clinicians on the panel confirmed that it is a question that is frequently asked by mothers. The data gathered during the course of the review did not shed any light on this.

For breast fed babies, UNICEF UK Baby Friendly Initiative 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.

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. In the absence of research evidence the panel was unable to make a clear recommendation on this.

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 sofa-sharing which is associated with a high risk of infant death.

The panel discussed an 'ideal world' situation involving the non-feeding parent remaining awake to supervise the feed, support the feeding parent and then ensure that the infant is put back in the cot next to the parent's bed. This was thought to be an ideal situation but it was felt that this was unlikely to be achievable in many families in the real world and would of course depend on there being two parents in the household. The panel felt that it would be reasonable to discuss this option with parents, particularly if the risk of uSID was thought to be heightened by unavoidable risk factors, but this approach would be heavily dependent upon the motivation of the non-feeding parent.



Key messages

- 7.1.1 Sudden and unexpected death in infancy and the second year of life affects Welsh children with an incidence rate similar to most other developed countries and English regions, where comparable data exist.
- 7.1.2 uSID is a significant cause of death in the first year of life and an important contributor to infant mortality statistics.
- 7.1.3 The rate of 'unexplained infant death' (uSID) recorded by ONS from 2004-2012 is slightly higher in Wales than some English regions but is reducing.
- 7.1.4 AWPS data show a significant fall in the number of 'SID' deaths in Wales in the past 10-15 years, of the order of a 50% reduction. This is on the back of a very significant reduction in uSID in the UK that began in the very late 1980s (from a peak in 1987-1988) and accelerated in the early 1990s at the time of the then 'Back to Sleep' campaign.
- 7.1.5 Some countries appear to show significantly lower rates, suggesting that this is an achievable goal and that there should be further initiatives to reduce the current rate. Data quoted from other countries may not be directly comparable with the data in this review (e.g. the review quotes deaths from birth to 365 days of age and other quoted statistics may state post-perinatal (deaths after the first week) or post-neonatal rates (deaths after the first month)). Notwithstanding this, Welsh rates are concerning and further reductions are almost certainly achievable. There may be societal reasons why some countries have lower rates e.g. reduced levels of inequality, lower levels of absolute poverty, more nurturing styles of parenting, greater levels of conformity with government advice in some societies etc. Some of these influences may be difficult to address, at least in the short term, but Wales should aspire to the lowest rates seen in some European countries and should strive for this goal.
- 7.1.6 The characteristics of the 'explained SUDI' and second-year deaths did not reveal any particular unexpected findings or local challenges that need to be addressed in Wales. They are a disparate group comprising infants and one to two year old children who have died of a wide range of different conditions. No formal recommendations were made about this small group of children.

- 7.1.7 Although not studied directly in this review, it is generally agreed that uSID has a significant impact on the health of parents, extended family members and wider society, and creates pressures on medical and other services.
- 7.1.8 The infant deaths studied in detail in this review had a high prevalence of known risk factors for uSID, with many infants being exposed to multiple risk factors. This is despite all new parents being routinely offered prevention advice by midwives, health visitors and GPs.
- 7.1.9 Although higher risk groups have been clearly identified in this review, such as smokers, young mothers, families living in socio-economically disadvantaged areas, low birth weight babies, most of these risk factors only affect a minority of cases. The implication is that although additional effort should be put into preventing uSID in the families that appear to be more vulnerable, a universal approach to risk reduction is still required.
- 7.1.10 The Welsh deaths reviewed showed a high proportion of uSID deaths in the first month of life. Whilst the numbers are small and may not be statistically significant this does appear different to the overall situation in England & Wales and is an area that would justify further scrutiny.
- 7.1.11 Very few deaths occurred in older infants over six months of age or in 'low-risk' infants who were not known to have been exposed to any of the recognised risk factor associations with uSID.
- 7.1.12 As expected there was an apparent excess of premature and low birth weight infants in the cases studied, although they still form a minority of all cases.
- 7.1.13 Younger mothers were also apparently over-represented in the cases studied, in keeping with the findings of other studies, but still accounted for a minority of cases. Younger parents may need more modern approaches to health promotion and optimisation of infant care practices, and may be less receptive to traditional risk reduction advice. Imaginative initiatives along the lines of The Lullaby Trust 'Bubbalicious' programme and the use of social media may have a greater impact for these families and should be explored further in future.
- 7.1.14 There appears to be a preponderance of deaths in areas of higher deprivation, although uSID can happen to any infant and no family can be considered immune from this problem. The reason why uSID is associated with areas of higher deprivation was not explored in detail in this review but is likely to be multifactorial and other variables such as smoking, the sleep environment, social or environmental factors that distract from safe infant care, low birth weight, prematurity, young maternal age etc. are all likely to be contributing factors.
- 7.1.15 The overall rate of co-sleeping at the time of a uSID was high, consistent with other studies of UK uSID deaths. The review identified a particular issue around unsafe co-sleeping, i.e. where other known risk factors are present and co-sleeping appears to be a major aggravating factor. This health promotion message has been clearly identified since the 1990s and it is concerning that the message has not been more effective at reducing these deaths.

- 7.1.16 In the majority of uSID cases involving co-sleeping, this was not the preferred or intended sleeping arrangement for the infant. Whilst data were limited, the impression gained was that co-sleeping was often chosen as a pragmatic solution for an infant who was unsettled on the night in question, or was unintended co-sleeping.
- 7.1.17 The merits and risks of planned co-sleeping in 'low risk' families who do not have any other identifiable risk factors has been a subject of some debate in recent years. The research evidence suggests some increase in risk for very young babies, though most studies have not shown this to be statistically significant. There is a suggestion of reduced risk for older infants (i.e. co-sleeping for these babies appears to protect against uSID). These 'low risk' infants account for a very small proportion of all uSID deaths and targeting this population for health promotion advice would not affect the overall uSID rate greatly. In this review, all of the co-sleeping babies suffering a uSID, for whom information was available, had other risk factors.
- 7.1.18 The rate of smoking in parents of infants dying as a uSID was very high. This is an area where further action is still needed.
- 7.1.19 The cases reviewed showed a high prevalence of comments about social concern, housing concern or other adversity, the use of illicit substances or domestic abuse. How these factors relate to the incidence of uSID is not clear. This suggests that many of the families in whom uSID occurs are likely to be harder to reach with health promotion messages, despite the existence of targeted programmes for vulnerable groups.
- 7.1.20 Mental health concerns in either parent raised concerns about an increased vulnerability of the infant to uSID, although hard evidence of this is lacking. There is some evidence that a history of inpatient care for mental health problems or maternal depression is associated with a higher rate of uSID (Royal College of Psychiatrists, 2011). The panel felt that where mental health concerns were identified there should be additional support for the parent(s), including an emphasis on reducing the risk of uSID.
- 7.1.21 Appropriate sleeping environments are an essential part of uSID prevention. Midwives, health visitors and social workers can play an important role before and after birth, including asking to see the baby's normal sleep environment and offering advice and support on managing this environment to minimise the risk of uSID.
- 7.1.22 Some of the deaths occurred in families that appeared either to be somewhat disorganised (a few bordering on chaotic), were in temporary living situations, where the infant had not been observed by an adult for a long time before being found dead, or where either parent was known to be impaired by alcohol or substances at the time the child died. Whilst the mechanisms linking these factors with sudden death in the infant were unclear and many confounding variables are possible, there was a strong feeling within the panel that these were situations where the infant's needs may not have been prioritised or there may have been other distractions that tended to reduce the important focus on the infant. The panel considered whether a consensus statement could be developed, with an emphasis on

having structure and routine to the day, keeping the baby close to the parent, regular observation of the baby and highly attentive parenting. This would need further debate about how to promote safer parenting styles without stigmatising parents in disadvantaged situations.

7.1.23 Poor housing conditions were mentioned in a number of the case reports. Although there was no reason to believe that poor housing was causally linked with uSID, some of the conditions described were concerning to the panel and there was a consensus that young vulnerable infants should not be living in conditions that most reasonable people would regard as unacceptable.

7.1.24 Overall breast feeding rates were low in the cases under review. The evidence review suggests that the overall protective effect of breast feeding in relation to uSID is fairly small but this is still an achievable and desirable outcome.

7.1.25 Solitary sleeping, i.e. the infant sleeping in another room from the parent, was not a major factor in the cases studied.

7.1.26 A sizeable minority of the infants studied had been mildly unwell in the few days before death. This generated debate about whether parents should be given additional warnings about preventing the exposure of the infant to additional risk factors for uSID at these times.

7.1.27 The review elicited very little information about dummies, and the evidence review highlighted the limitations of evidence in this area. On balance the panel did not feel that encouragement of dummy use

was likely to be an effective means of preventing uSID, though the evidence base should be disseminated to enable parents to make an informed choice.

7.1.28 Although the numbers of uSID identified in the review did not include many babies dying in less common, unusual or unintended sleep places, there are a number of reports in the literature describing infants dying whilst sleeping in places or equipment that were not intended for that purpose. The panel re-emphasised that the safest place for a baby to sleep is in a cot, crib or Moses basket that should be in the same room as the parent during the night. Other baby equipment should always be used in line with the manufacturer's recommendations and infants should be very closely observed if sleeping in another location.

7.1.29 There is a notable lack of evidence-based or 'best practice' recommendations for parents on where best to feed their infant during the night, whether they are breast or bottle feeding. Unicef BFI has produced some consensus advice on this for breast feeding mothers that the panel broadly endorsed but this seems to be an area where there is a need for greater clarity. The role of the non-feeding parent (if present) was also discussed and it would be helpful for there to be a wider debate about recommendations in this area.

- 7.1.30 This review was the first time CDR data had been used for this purpose and highlighted some difficulties with data gathering. Difficulties were experienced in obtaining some of the data required, and in some instances the data were not shared. For example, data on infant sleeping position at the time of death were often lacking and even the location of the baby was not identifiable in all cases. This needs to be addressed to enable future reviews to be conducted more easily. Resolving these issues will make it easier to conduct similar reviews in the future.
- 7.1.31 Welsh Government should consider mechanisms to promote safer infant care practices in response to the concerns that arose during this review about infants being left unsupervised and without feeds for long periods of time.
- 7.1.32 The panel identified that some parents believe that by smoking outdoors or in another room the child was not being exposed to second hand smoke. Professionals should advise parents that any smoking during pregnancy or in the first year of the child's life increases the risk of uSID. Whilst there is no firm research evidence yet concerning e-cigarettes we would endorse the pragmatic view taken by The Lullaby Trust that e-cigarette users should follow the uSID prevention guidance as for tobacco smokers, including avoiding co-sleeping (The Lullaby Trust, 2014).



8 Recommendations

Recommendations were put forward by the panel, based on the review of information on the infant deaths, the evidence review and the expertise of panel members who contributed to a very thorough discussion of the issues during the two panel days. The recommendations included are those that had a high degree of consensus. Recommendations highlighted in bold were considered by the panel to be strongly recommended.

8.1 Recommendation on content of advice for parents

1. **The Welsh Government, Public Health Wales, health boards and primary care providers should continue to provide advice based on “Reduce the risk of cot death” (Welsh Government, 2014) to all families with new babies. The panel agreed that the Welsh Government should not adopt a position of blanket discouragement of co-sleeping, but need to emphasise that co-sleeping in association with other risk factors carries a very high risk of uSID.**

8.2 Recommendations for disseminating the message

2. **Welsh government, Public Health Wales and healthcare providers should continue the universal provision of advice to all families with new babies, recognising the particularly important roles of midwives, health visitors and GPs.**

3. The vast majority of cases identified in the review were infants who had been exposed to known risk factors that are addressed within current guidance. **The panel recommends that Welsh Government should consider mechanisms to deliver the existing health promotion messages more effectively. These could include:**

- facilitating debate about effective prevention strategies,
- consideration of a national campaign,
- exploring innovative approaches including modern media,
- developing mechanisms of reaching the most vulnerable families,
- evaluating impact.

4. Welsh Government and Health Boards should particularly consider new and imaginative approaches for reducing risk for babies with very young parents.

5. Health boards and primary care providers should ensure that uSID prevention messages are emphasised at times when young babies are especially vulnerable, e.g. when presenting for medical attention with respiratory illness.

8.3 Reducing the risk

6. **Health boards, Public Health Wales and Welsh Government should strengthen their efforts to reduce smoking, especially in young women, parents during pregnancy and in the first year after child birth.**

7. Welsh Government and health and social care providers should ensure that the existing evidence base on co-sleeping is disseminated to professionals at the 'front line' dealing with new born babies. **Front line professionals should receive regular training so that they understand the key messages on the prevention of uSID, including research evidence on the interaction between co-sleeping and other risk factors such as smoking, low birth weight, very young infants and alcohol consumption, and are able to deliver these messages to parents.**

8. Welsh Government, health boards and primary care providers should seek to reduce rates of prematurity and low birth weight by promoting pre-conceptual care and providing advice for potential parents as identified by the "baby SAFER!" campaign.

9. Welsh Government and health boards should continue to promote breast feeding.

8.4 Recommendation on social housing provision

10. **Welsh Government and local authorities should review their policies and provision of social housing to ensure conditions are appropriate for families with young, vulnerable babies and that urgent action is taken in response to professionals concerns or recommendations.**

8.5 Research and related recommendations

11. **Welsh Government should work with partners to promote debate and encourage research into concrete measures to reduce population rates of uSID, and unsafe co-sleeping in particular.** This could include research into Baby Box provision and other innovations.

12. In the absence of a strong evidence base, Welsh Government should develop an initiative to try to achieve consensus on the advice that should be given to parents about the safest place to feed their babies during the night.

8.6 Data collection, monitoring and future reviews

13. **The Welsh Government should inform all Safeguarding Children Board partners of its expectation that there will be unimpeded information sharing with the CDR programme when any child dies.**

14. The CDR programme should continue to work with others to increase the multiagency 'ownership' of the CDR process and re-emphasise the need for unimpeded data sharing.

15. The CDR programme should further refine its data collection for uSID following this review, including ensuring complete and timely identification of all cases.

16. The Safeguarding Children Service, Public Health Wales should consult with multi agency partners and consider introducing standardised templates to complement the PRUDiC process. This should include one for taking the initial paediatric history/first account in unexpected deaths to ensure that it is comprehensive to make the data available to future reviews more robust.

17. The CDR programme, AWPS and MBRRACE-UK should continue to work together including sharing information to allow regular monitoring and analysis of infant deaths in Wales, in particular uSID.

18. The CDR programme should continue to monitor trends in unexpected infant death rates as part of its routine activity. This review should be repeated at an appropriate interval if there are concerns about the rate of progress in reducing these deaths.



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