

Sudden Unexpected Death in Infancy – Stakeholder Report

Audit 2015-2018

March 2023

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Published March 2023

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Introduction

Background

A sudden unexpected death in infancy (SUDI) is deemed to have occurred where there is no known pre-existing condition which would make the death predictable. All infant deaths which happen suddenly, and for which there is no apparent reason, are unexpected. From the outset, all such causes are unknown (or unascertained), and therefore defined as SUDIs until more information is available.

SUDIs account for the largest number of infant deaths in those aged 2-6 months. There is a reduction in incidence beyond 12 months, with only a few cases per year in Scotland between 12 and 24 months.

This report covers SUDIs that occurred during 2015-2018. Due to the small number of SUDI each year, we collate the data from 3-4 years, analyse it and summarise the data into one report to ensure it is not patient identifiable. Because of the length of time it takes to complete the SUDI review process we were unable to begin analysis of the data until 2021 and some information was still outstanding in 2022.

SUDI programme

The SUDI programme has been running since 2009 and aims to share learning from SUDI and improve the processes with relevant professionals, and care for bereaved families across Scotland. Those affected by SUDI are deemed to be the family, those close to the deceased infant and all professionals involved in the case and its subsequent review. This includes all relevant NHS professionals, Scottish Ambulance Service (SAS), procurators fiscal, police, social workers and appropriate voluntary sector organisations across Scotland.

Initially, the Scottish Government asked NHS Quality Improvement Scotland (now Healthcare Improvement Scotland (HIS)) to facilitate the development of the following:

- A web based toolkit providing resources to all professionals involved in the investigation of a SUDI.
- SUDI review multidisciplinary meetings to be co-ordinated timeously after each SUDI.
- The collection of national data to identify any trends and risk factors, which may influence future practice.
- The evaluation of the SUDI review process and the toolkit.

From April 2014, NHS boards have co-ordinated the SUDI review process locally. HIS continues to make early contact with all professionals involved and collate completed SUDI review reports to ensure that learning is shared.

Some professionals will be involved in each SUDI which occurs in their area, for example, the paediatric pathologist. For others such as GPs, health visitors or police officers, they may only be involved with one SUDI in their career and without a toolkit or guidance may find the identified roles for professionals ambiguous. Without clear guidance, professionals may not provide the best support for bereaved families, and may not know how to access support for colleagues or themselves.

For each SUDI notification received from National Records of Scotland (NRS), HIS contacts the general practice involved to raise awareness of the SUDI review process and signpost them to the SUDI toolkit. This will assist professionals to improve the care provided to the family following the death of an infant by being better informed about what will happen and how long the process may take.

The purpose of a SUDI review is to discuss all aspects of the death, including possible causes or contributing factors to discover what lessons can be learned and to plan support for the family, particularly in identifying support needs for any future pregnancies. HIS regularly contacts the pathologists and the Scottish Fatalities Investigation Unit (SFIU) to find out when the review can proceed.

Any learning from SUDIs is collated and shared with health professionals and any other relevant professionals through audit findings. Analysing the data from each SUDI may allow us to identify contributing factors, for example, demographic and socioeconomic factors. This could allow NHSScotland and other partner organisations to change their processes and procedures where necessary to improve the pathways for bereaved patients.

[National Hub for Reviewing and Learning from the Deaths of Children and Young People](#)

Scotland has a higher mortality rate for under 18s than most other Western European countries, with over 300 children and young people dying every year. Around a quarter of those deaths could be prevented.

With no national system to support consistent reviewing and learning from deaths of all children and young people in Scotland, the Scottish Government commissioned Healthcare Improvement Scotland and the Care Inspectorate to set up the [National Hub for Reviewing and Learning from the Deaths of Children and Young People](#).

The National Hub aims to:

- Ensure that the death of every child in Scotland is subject to a quality review
- Develop methodology/documentation to ensure all deaths of children and young people that are not subject to any other review, are reviewed through a high quality and consistent review process
- Improve the quality and consistency of existing reviews.
- Improve the experience and engagement with families and carers, and
- Channel learning from current review processes across Scotland that could direct action to help reduce preventable deaths.

The National Hub has been tasked with ensuring reviews are conducted on all deaths of live born children up to the date of their 18th birthday, or 26th birthday for care leavers who are in receipt of continuing care or aftercare at the time of their death. This includes SUDIs. This was implemented nationally on 1 October 2021.

Audit Aims

The purpose of this audit was to collate the SUDI data from 2015-2018 and identify any trends, as well as highlighting known risk factors. We also aimed to share relevant research on SUDI linked with known risk factors.

This information will be used to share learning with stakeholders and help shape future work for the SUDI programme.

Method

Audit development

The Data, Measurement and Business Intelligence (DMBI) team within HIS was asked to create a workbook based on questions from the previous audit of 2011-2014 data, as the original intention was that the two sets of information could be compared.

Completion of the workbook involved collecting demographic data from each of the cases along with data associated with risk factors involved in SUDI. The sources of data used to complete the workbook were NRS notifications, post mortem reports, SUDI History and Examination (H&E) forms (where available), and SUDI review reports.

The data was entered into the workbook by several members of the SUDI team, with one person then checking the information for continuity and to mitigate, as far as possible, for interpretation of this information.

The core analyses focused on deaths that remain unexplained after investigation (generally final cause of death R95, R99, W75 and T71) in children aged up to 12 months. This group included both Sudden Infant Death Syndrome (SIDS) and 'unascertained deaths' and these were considered together. This matched the previous audit of 2011-2014 data, which aligned with the approach taken by [a thematic review of SUDI undertaken by Public Health Wales](#). It is recognised that this approach excluded the deaths of babies that had a known underlying condition.

The DMBI team analysed the completed workbook and produced a data report to highlight the occurrence of SUDI relating to knowing risk factors (such as co-sleeping) and to raise awareness of key themes from the data.

Limitations

There were several limitations in using this approach, not least of all being the availability of data. Several of the questions asked were in keeping with the data collected in the H&E forms, which used to be completed in emergency departments following a suspected SUDI and returned to HIS. This was a lengthy form, which was considered onerous to complete and was not usually fully completed or returned. It also contained identifiable information about the parents and family of the infant. Therefore, in May 2018, NHS boards were advised by the Scottish Government to stop completing and sending H&E forms to HIS, and instead hold data locally. Any data that had been sent to HIS between 2014 and 2017 was also returned to NHS boards. For the purpose of this audit, it meant that if H&E data was not available for a case, there were large gaps in the available information and "not known" was recorded in response to several questions as it was not available from other sources.

HIS is notified of all SUDIs via a weekly NRS report. However, some of these cases are later removed from the SUDI database as post mortem reports reveal the cause of death to be something other than SUDI.

Evidence Review

In addition to the workbook, we requested an evidence review, which was conducted by the Evidence Directorate within HIS (Appendix 1). This was done to assist with understanding the difference in the occurrence of SUDI events elsewhere in the world to potentially highlight what is being done differently and what could be adopted in Scotland, as well as the similarities to emphasise these factors in SUDI events.

We believe that including current research in our report will provide stakeholders with an understanding of key factors in SUDI events as well as a comparison of how Scotland's figures relate to both UK and international statistics.

2015-2018 SUDI overview

Number of Confirmed SUDI Cases by Year in Scotland 2015 – 2018

In total, for the period of 2015-2018, HIS was informed of 166 SUDI cases by NRS. However, 74 of these were later re-classified as non-SUDIs and were removed from our database. A further eight cases were removed as the infants were over 12 months old, leaving 84 cases to be considered for the audit, with between 17 and 24 reported a year.

The variation in the SUDI numbers was not mirrored in NRS estimates for the number of children aged under one. A chi-square test was not significant at the 5% level, suggesting there has been no change in the occurrence of SUDI between 2015 and 2018.

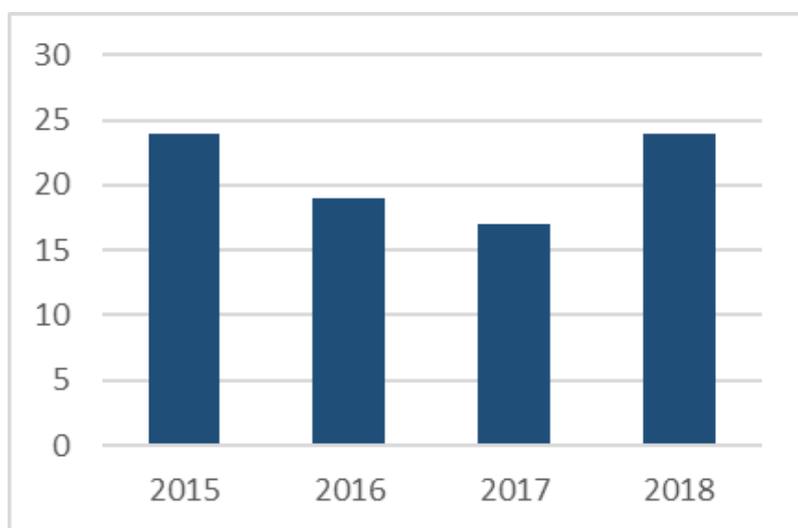


Figure 1: Total number of SUDI cases per year.

Risk factors

From the data collected, the following risk factors can be highlighted:

- infant demographics
- infant birth status
- sleep environment, and
- deprivation status.

Infant demographics

Number of Infants by Age Group in Weeks at Time of Death, 2015 – 2018

The highest number of SUDI (39) occurred in the youngest age group (0-9 weeks) and reduced in number as age increased.

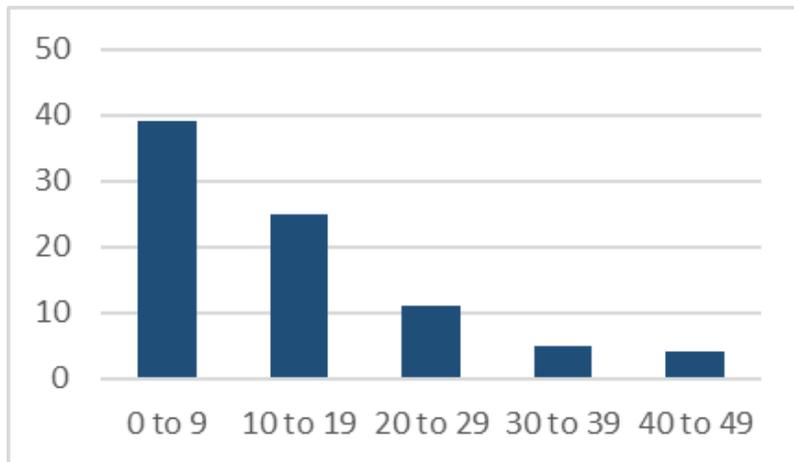


Figure 2: Infants by age group (in weeks) at time of death.

Number of Infants by Gender, 2015 – 2018

There were almost twice as many SUDI for males compared to females. National Record for Scotland estimates deaths under one to be 51% male to 49% female in the same period. A chi-square test of association between gender and SUDI was not significant at the 5% level for this audit.

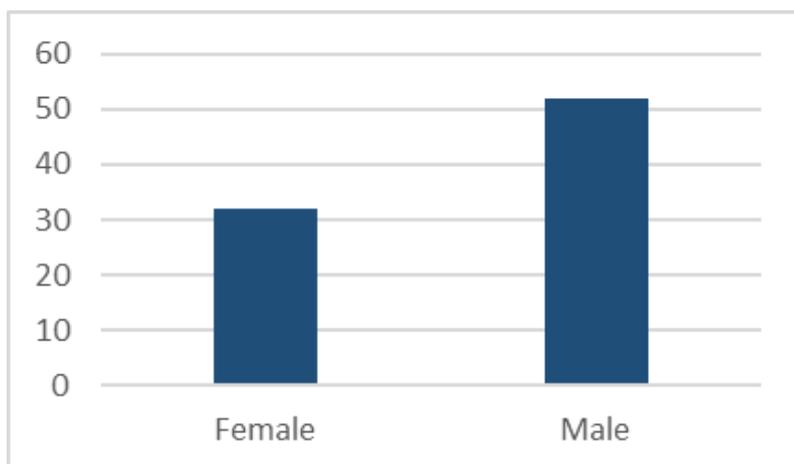


Figure 3: Total number of infants by gender.

Number of Infants by Percentile Weight at Time of Death, 2015 – 2018

The weight at death decile for each case was derived from the World Health Organisation weight for age standards, by accounting for the age and gender of infants at death. In a standard population, 10% of children would be in each decile. In the SUDI population, 37% were the first decile. A chi-square test was significant at the 5% level, suggesting a relationship between weight and the prevalence of SUDI, where lower weight children are more likely to have a sudden or unexpected death.

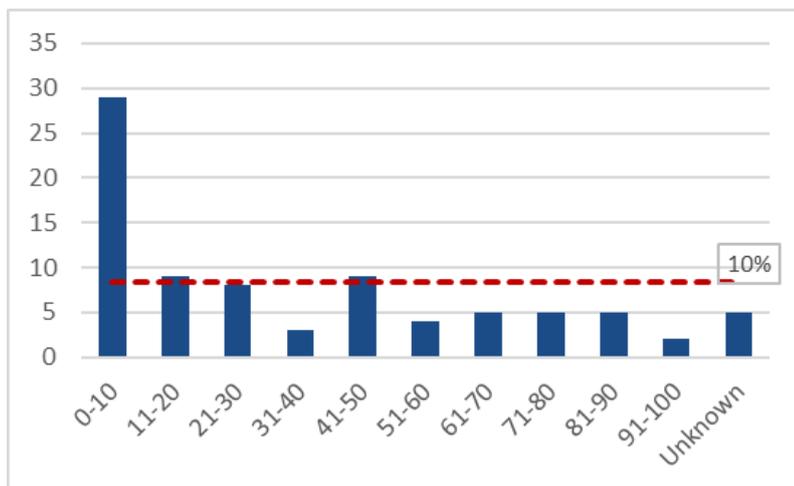


Figure 4: Infants by percentile weight at time of death.

Infant birth status

Number of Infants by Singleton and Multiple Birth, 2015 – 2018

Infants from multiple births account for 7% of SUDIs. In the Scottish population, 3% of births are from multiple births. A chi-square test was significant at the 5% level, indicating children from multiple births are more likely to die suddenly or unexpectedly.

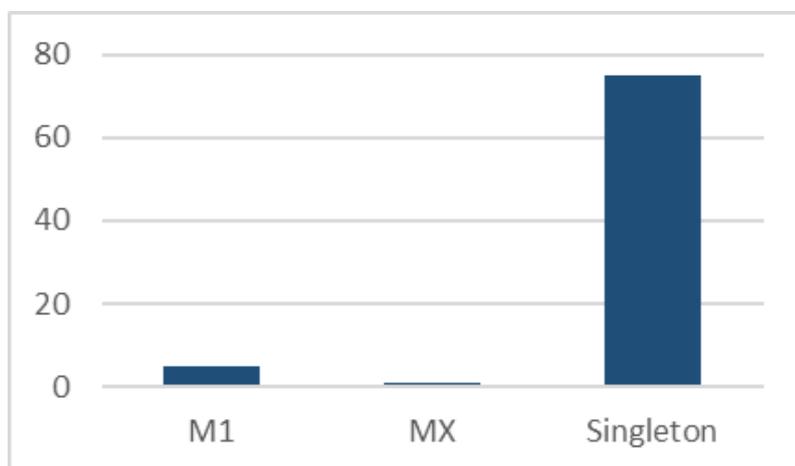


Figure 5: Total number of infants by birth status (M1 – twins, MX – multiple).

Number of Infants by Pre-Term and Term Births, 2015 – 2018

Of the 60 cases that had gestation at birth recorded, 28% of these were pre-term. Public Health Scotland data shows that 6% of births in Scottish hospitals were pre-term. A chi-square test of association was significant at the 5% level, indicating that children who were born pre-term are more likely to have a sudden or unexpected death, although the high number of SUDI where gestation is not known potentially makes this test inconclusive.

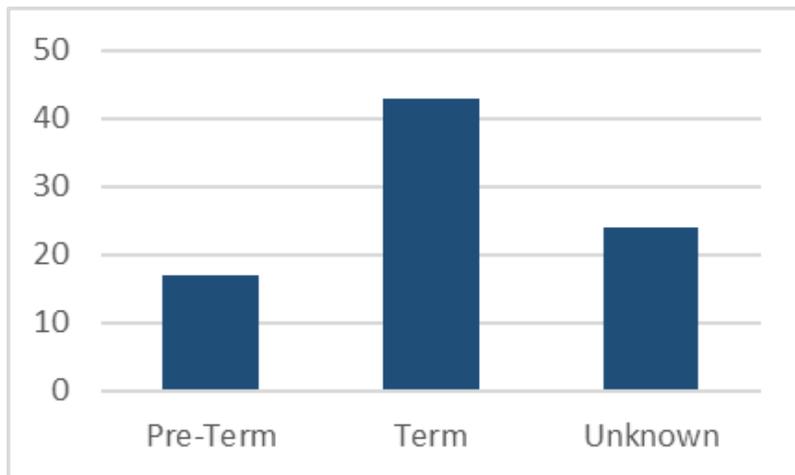


Figure 6: Total number of infants by gestation at birth.

Sleep environment

Number of Infants by Surface Last Put Down to Sleep On, 2015 – 2018

It was most common for infants to have been in an adult bed for their last sleep, followed by a cot then Moses basket.

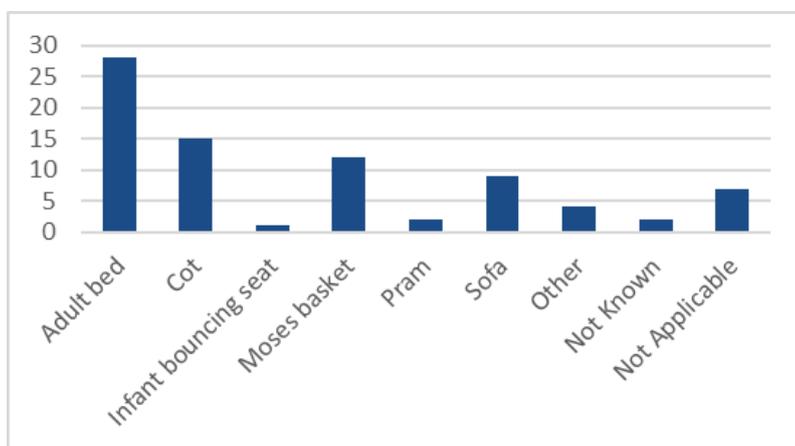


Figure 7: Number of infants by surface last put down to sleep on.

Number of Infant Sharing Sleep Surface during Last Sleep, 2015 – 2018

Where known and applicable, marginally more infants had been sharing a sleep surface during their last sleep, than not.

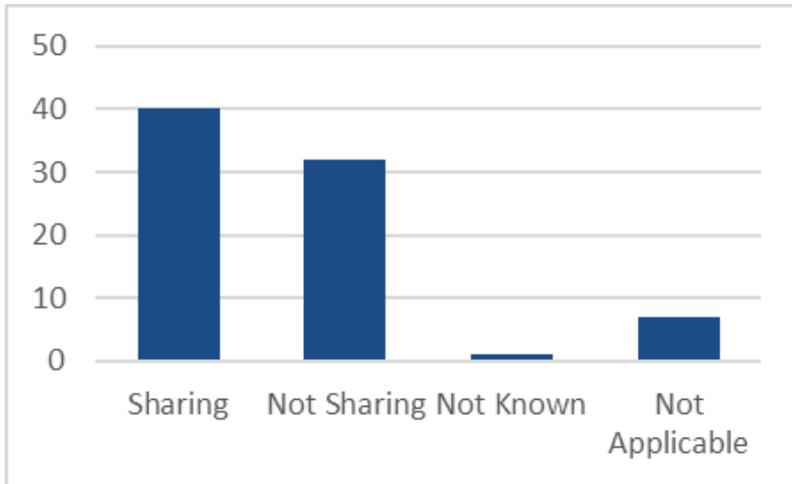


Figure 8: Total number of infants that were sharing a sleep surface during last sleep (e.g. bed/sofa).

Number of Infants by Time in Hour of Day Discovered Dead, 2015 - 2018

It was more common for the death of an infant to be discovered in the morning, particularly around the hours of 5.00-5.59 am and 7.00-7.59 am.

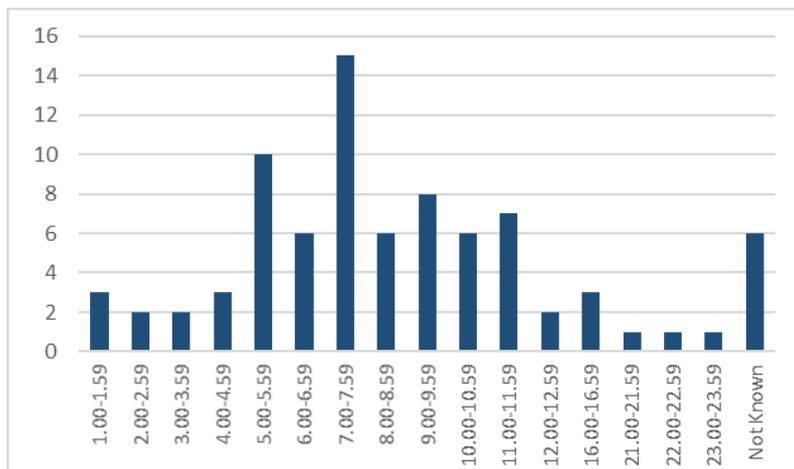


Figure 9: Infants by the time of discovery of death

Deprivation status

Number of Infants by Deprivation Status Decile, 2015 – 2018

The most deprived areas of Scotland had the highest numbers of SUDI, and the numbers generally decreased as deprivation reduced. To illustrate, there were 25 SUDI from the most deprived areas and 1 from the least deprived areas. National population estimates from National Records for Scotland for those aged under one by Scottish Index of Multiple Deprivation (SIMD) decile in 2020 were used to determine if the high number of SUDI from more deprived areas followed the national spread. A chi-square test was significant at the 5% level, suggesting there were more SUDI than expected from more deprived areas.

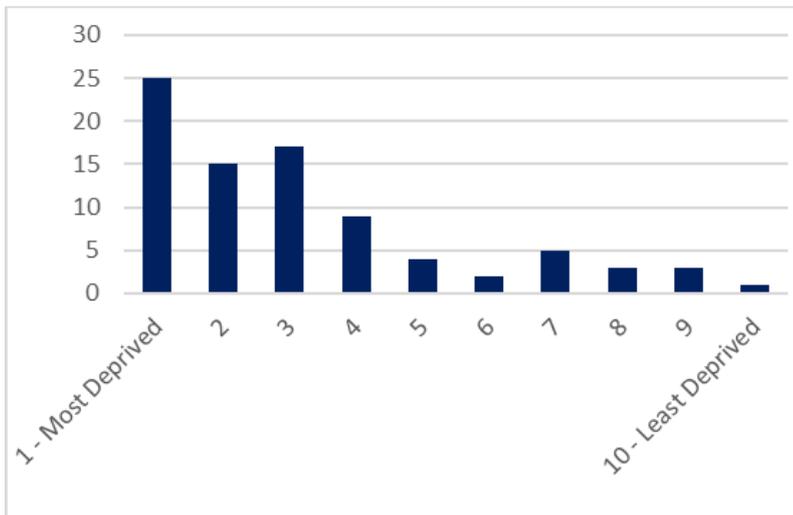


Figure 10: Infants by deprivation status decile

Summary of analysis

Infant demographics

These results show that the majority of SUDI events happen in the youngest age group (0-9 weeks) with a higher number of male SUDIs than females. Although an increased number of male infants died, statistics for this audit period indicated that males were no more likely to suffer a SUDI event than females.

With age and gender accounted for, it can be seen that there was a higher proportion of deaths in the lower weight decile.

Infant birth status

The results in this section reflect the known risks of SUDI associated with prematurity or multiple births. Pregnancies involving multiple infants are also known to be a risk for premature births in itself.

Gestation has an effect on health and infants born pre-term can have multiple difficulties following birth. Public Health Scotland published [a report](#) detailing that prematurity is the main reason infants are admitted into neonatal care and is the single biggest cause of death in infancy. The more premature the infant is, the higher the risk.

Sleep environment

Co-sleeping is a well-documented risk in SUDI when in combination with other risk factors such as parental alcohol intake, drug use and smoking. Although data on additional factors have not been included in this analysis, the results show that the adult bed was the most common place for last sleep. This aligns with findings from the [Patterns and trends of child deaths in Wales, 2011-2020 published in April 2022](#).

It was noted when analysing the data that although parents often put their infant to sleep in the child's sleeping environment, they often moved the infant into the adult bed to comfort or soothe the child and accidentally sleep with the infant in the bed. In these instances, safer sleeping guidelines were not generally followed.

Deprivation status

Our results are consistent with research on the relationship between deprivation status and SUDI events. The majority of SUDI events occur in deprived families, demonstrating the growing gap in health inequality. It has been recognised that in deprived groups, there may be a decreased understanding in the advice given by health care professionals as well as being sceptical of the information provided. This can result in deprived families adopting unsafe practices and being more susceptible to misinformation.

SUDI Reviews

Learning from SUDI Review Reports

A SUDI review is held for each SUDI case, with the SUDI review report and opportunities for learning documentation being returned to HIS. This enables us to identify any trends or any learning that may inform the SUDI programme.

All SUDI review reports from 2015-2018 were analysed and the following themes were identified:

- lack of knowledge of the SUDI process
- multiagency working
- family involvement and engagement, and
- delays.

Lack of knowledge of SUDI process

As SUDI is relatively uncommon, some professionals may not be aware of the process that needs to be followed when one of these deaths occurs. This applies not only to health professionals, but also to partner organisations.

Below are extracts taken from two SUDI review reports:

“DS [XXXX] described the distress for both the family in this case but also for the police involved... It can be distressing for all parties involved and as it is not common and may be the first time the personnel have experienced such an event. If all cases attend ED it allows us to provide a debrief for other agencies involved and an opportunity to discuss their experiences or concerns”.

“There were issues surrounding the transfer of [infant] to hospital with disagreement between police and ambulance control as to where he should be taken (Hospital X or Hospital Y)”.

Multiagency working

Not only do several organisations need to work together whilst dealing with a SUDI event, but also during the review process and taking forward any learning. In addition, agencies should be working together in order to provide the bereaved family with assistance and support.

Here are two instances where this issue was raised in SUDI review reports:

“GP know family well and was not approached for IRD nor SUDI police review, which he felt was significant given that there was a history of a child protection review within the family home”.

“Mum’s past history of drug misuse was documented in her primary care records but does not appear to have been noted in the pregnancy file regarding the infant, nor in the infant’s neonatal record. The midwifery and neonatal governance teams will look and see if there was a missed opportunity here to identify what would appear to have been an ongoing issue of drug misuse in mum”.

Family involvement and engagement

Families often feel that the SUDI process is not explained to them fully, and that they are not kept informed about what is happening:

“Particularly, the family were upset at their inability to meet the normal cultural practices of their religious faith that the infant or child would be buried within 24 hours of death.....the family expressed their particular upset about the nature of the post mortem and the fact that they had not been fully advised about what this would entail. In particular, they were distressed at the decision requiring a thorough post mortem examination and therefore the appearance of the infant when they received his body home.”

“The family have expressed their own view that they have not been fully informed of the SUDI Review process and it is believed by the SUDI Paediatrician that the family have felt slightly unsupported by our NHS services.”

Delays

There are often significant delays between the different stages in the SUDI process, often up to a year or more, and understandably this can be traumatic for bereaved families, so may feel that they are being left without any answers:

“I have recently spoken with mum because she was quite distressed about receiving a letter informing her of the SUDI review process. She was concerned that it had taken so long after the death of [infant] for which I apologised”.

Conclusions and further work

The findings from the 2015-2018 SUDI data are consistent with the risk factors highlighted in our evidence review (Appendix 1) and in publications from [England](#) and [Wales](#).

Safer sleeping practices are recognised as a key risk reduction measure and in June 2022 new Scottish Government and NHS Safer Sleep for Babies [resources](#) were published in partnership with the Lullaby Trust, UNICEF Baby Friendly Initiative and BASIS the Baby Sleep Information Source based at Durham University. Further updates to these resources are currently underway to ensure clarity for families and professionals who use them.

As noted previously in this report, there were limitations in the information available to us to answer the audit questions. Where there was no data available from H&E forms, we were reliant on information provided in post mortem reports and review reports, which varied in the level of detail they contained.

The SUDI team has worked with stakeholders to develop a revised H&E form for clinicians to use for their own review and learning from SUDIs. However, as this form contains identifiable information about the parents and family of the infant, it cannot be returned to HIS.

The implementation of the National Hub in October 2021 means that for the first time in Scotland, a consistent set of national data is being collected for all deaths of children and young people. This core review data set does not contain all the information we would wish to collect specifically for SUDIs. Therefore, we propose to develop a specific SUDI sub form in 2023 as part of the work of the National Hub.

Family engagement

The themes identified from the SUDI review reports highlight the impact on bereaved families, particularly the length of the SUDI process and the potential lack of knowledge by professionals who provide support to them.

In 2020-21, we developed 7 minute briefings for GPs, police and procurators fiscal which summarised the process following a SUDI.

One of the key objectives of the National Hub is to improve the experiences and engagement with bereaved families and carers. In partnership with third sector colleagues, The National Hub developed a survey to better understand the experience of families and carers following the death of their child. The feedback from families was reflected in [When a child dies: Learning from the experiences of bereaved families and carers report](#) published in June 2022, which highlighted that:

- Families and carers experiences of care and support following the loss of their child varied considerably. While some families spoke very positively about the compassionate care and practical and emotional support they received from a range of services and organisations, others faced more difficulties in accessing the help they needed.

- Access to professionals who knew their child was at times, difficult, particularly when a considerable period of time had passed since the child's death.
- Families and carers did not always understand the review process or how they could contribute to it, and not all felt they were kept informed about the progress of the review. The identification of a key contact person was highlighted as being crucial in preventing families and carers having to repeat their story to different professionals, clarifying expectations and helping guide them through the review process.
- Importantly, families talked about the significant emotional impact of their loss, and the need for professionals to recognise that their capacity to process information or ask questions at the time of the death was considerably affected.

A learning point arising from the survey was that an information leaflet would be helpful, particularly as families told us they experienced difficulties retaining new information. The National Hub is currently working with third sector partners and consulting with bereaved parents on the development of a national leaflet.

Appendices

Appendix 1

The Evidence Directorate within HIS produced this [evidence synthesis](#).

Appendix 2

A range of audit questions were used to gather data and where we did not have enough data, these were not used in the analysis. The questions were as follows:

Demographics

- gender,
- date of birth,
- date of death,
- age in days,
- age in weeks,
- month of death,
- NRS cause of death code,
- post code,
- urban/rural status and,
- deprivation status.

Parental characteristics

- Maternal age,
- Maternal smoking during pregnancy,
- Was any adult resident in the household current smoker at time of infant's death?
- Had either parent/carer consumed alcohol within the 24 hours prior to the infant's death?
- Was either parent/carer a habitual user of illegal drugs or methadone at the time of infant's death?
- Was the infant under the care of social work at the time of death? and,
- Had the infant been on the child protection register at any point?

Infant characteristics

- Singleton/Multiple,
- Gestation at birth in completed weeks,
- Birthweight,
- Birthweight centile,
- Weight at death,
- Weight centile at death,
- Had the infant ever received any breastfeeding? and,
- Was the infant receiving any breastfeeding at the time of death?

Circumstances of death

- Was infant found in their usual home?
- Location found if not usual home,
- Time infant last seen/known to be alive,
- Time infant was discovered unresponsive,
- Time between infant last seen and discovered unresponsive,
- Position infant was usually put down to sleep,
- Position infant was put down for last sleep,
- Position of infant when found,
- Surface infant was usually put down to sleep on,
- Surface infant was put down to sleep on for last sleep,
- Did infant habitually sleep in a room on their own?
- Had infant been sleeping in a room on their own during their last sleep?
- Did infant habitually share a sleep surface?
- Was infant sharing a sleep surface during last sleep? and,
- Final Cause of death (1a, 1b, 1c).

Published March 2023

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Healthcare Improvement Scotland

Edinburgh Office
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

Glasgow Office
Delta House
50 West Nile Street
Glasgow
G1 2NP

0131 623 4300

0141 225 6999

www.healthcareimprovementscotland.org