Surrey Child Death Review Partnership

Sudden Unexpected Death in Infancy, a thematic review 2014- 2020

"The sudden and unexpected death of an infant is one of the most devastating tragedies that could happen to any family. In spite of substantial reductions in the incidence of sudden unexpected death in infancy (SUDI) in the 1990s, at least 300 infants die suddenly and unexpectedly each year in England and Wales." NHS Digital (2019). [1]

[1] Child Death Reviews: year ending 31 March 2019. https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content)

Contents

Foreword

The death of a child, of any age, brings heartbreak and devastation. Bereavement can influence every aspect of well-being, from physical and mental health to feelings of connectedness and the ability to function day to day. Learning to live with the loss of a child is one of the most painful experiences we can encounter.

Despite being very rare, SUDI is the most common cause of death for infants between 1 and 12 months old. In December 1991 the Back to Sleep campaign was launched, Sudden Unexpected death in Infancy [SUDI] deaths in the UK fell instantly by round 85%, and with astonishing speed. Ultimately the Back to sleep campaign was a huge success and helped to stimulate a change in practice which resulted in an abrupt decline in the number rate of SUDI. Whilst it is extremely good news that SUDI has gone down in England and Wales, at least 300 infants still die suddenly and unexpectedly each year; evidence has shown that many more babies' lives could be saved if all families had access to and followed safer sleep advice. Babies and young children are reliant on their caregivers to make decisions which keep them safe. Across the country many infants sleep in environments and in circumstances which are not safest for them. A baby is reliant on their care givers to keep them safe during sleep times.

Between 2011 and 2012, there were 6 Sudden Unexplained Deaths in Infancy (SUDI) within Surrey which were reviewed by CDOP and modifiable factors were identified. As a result, a county wide Safe Sleep campaign was undertaken to raise awareness amongst professionals and parents of the risk factors that have been identified that increase the risk of infant deaths. The final action of this campaign was completed in November 2014 with the inclusion in the Child Health record (Red book) of easily accessible Safe Sleep information for parents and a Midwife assessment to be completed with parents as soon as possible after birth but by the latest, five days old. These pages were developed with the input and agreement of the Maternity services, 0-19 community services, Safeguarding Children and Public Health. Surrey Heartlands CCG continues to fund these pages in all Red books across Surrey.

Since 2015, Surrey CDR team have been highlighting a continued increase in the number of SUDIs across the county. In response, we committed to lead and undertake a systematic thematic review of SUDI's over the time frame 2014-2020. This thematic review aims to provide a comprehensive picture and understanding of child deaths in Surrey to identify learning and action needed to facilitate a whole systems approach to reduce SUDIs in Surrey. Defeating SUDI is a battle on two fronts – research to identify causes and build greater understanding of why it occurs, and by educating and promoting ways to reduce the factors that create increased risk. Our aim is to minimise the numbers of SUDI in our County because every baby and young child's life matters. We want all unsafe sleep related deaths in babies to be a thing of the past. We want the pain and suffering that families experience when

their child dies suddenly and unexpectedly to stop. We believe that if every baby slept in the safest way possible, we would reduce these tragic deaths by at least 50 %.

Out of routine: A review of sudden unexpected death in infancy (SUDI) in families where the children are considered at risk of significant harm (2020) highlighted SUDI prevention has all the hallmarks of other safeguarding work and should be understood as such. A whole system approach is essential. All practitioners working with children and families are in a unique position to educate parents about safer sleep advice so need to ensure that they understand and can explain information on safer sleep advice. It is very important that we work together to ensure safer sleep messages consistently reach all families to reduce risks before and after the baby is born and ensure each sleep time is a safe one. It is only by consistently and regularly discussing safer sleep at each contact with parents before and after the baby is born that we can empower women, their partners or the main carers of babies to change behaviour and adopt safe sleep practices for the future in order to protect other children and prevent future deaths.

This thematic review identifies modifiable factors that have contributed to SUDI in Surrey, opportunities for prevention, and makes recommendations to reduce the risk of future SUDI. Together, we play a vital part and must do all we can to reduce the risks of SUDI. It is right and desirable that we do everything in our power to prevent such terrible suffering for families.

Noreen Gurner-Smith

Safeguarding Manager with Lead for Chid Death Review Services, Surrey Heartlands CCG

Parental Voice

A few years ago we lost our baby boy. It was a pain so strong that I have never felt before and I hope I never feel again. Following a post mortem, we were told our baby died from Sudden Unexpected Death in Infancy (SUDI). This was really hard as it meant there were no answers. Nothing to explain why our baby had died. I asked myself every night what I did wrong. Did he have too many layers? Was he on his back enough when sleeping? Should I have given him more of his bottle? Should I have given him less of his bottle? I never found any answers to any of my questions and I don't think I ever will.

Soon after he died, I met the nurse from the CDR Team. She was kind and listened to me talk about our baby. She reassured me that they way I felt was normal and that I wasn't going mad. She visited, called and text to see that I was ok, and helped explain what was happening. She had to explain everything many times as I couldn't remember conversations for long, I just kept forgetting everything. Her help was invaluable and kept me and my partner together at a time where everything was just falling apart. It was comforting to know I was never alone and I could call her whenever I needed support.

It was reassuring to know that everyone did everything they could to find out why our little boy died. An outcome of SUDI did not really feel like an answer. I guess there is still so much for science to learn and reviews like this one will help to find answers for parents like us, we both thank you for all that you are doing to try to help uncover the mysteries of why babies die from SUDI.

1 Introduction

This report presents the findings of a thematic review undertaken by Surrey Child Death Review Partnership in response to a number of unexpected deaths in infancy in Surrey during the period 1 April 2014 – 31st March 2020.

For the purposes of this review we will be looking at both;

1. Babies under the age of one whose deaths are categorised as either 'Sudden unexpected death in infancy' (SUDI) or 'Sudden Infant Death' which is used to describe the sudden and unexpected death of a baby or toddler that is initially unexplained and
2. 'Sudden Infant death Syndrome' (SIDS) which is the term reserved for deaths that remain unexplained after the post mortem and thorough investigation. Sometimes other terms such as SUDI or 'unascertained' may be used, also in babies under the age of one.

As with our previous thematic review, the aim of this thematic review is to identify patterns and themes in unexpected deaths in infancy in Surrey and to look at how we can work more effectively together to prevent further deaths. Every baby's death is a tragedy and we need to work in partnership to look at the evidence surrounding each of these deaths and work together to implement system wide improvements based on best practice to prevent future deaths.

This piece of work has been supported by the detailed information held by the Surrey Child Death Overview Panel (CDOP); a multi-agency panel with responsibility for comprehensively reviewing all child deaths in Surrey, in order to better understand how and why children die, identify modifiable factors and learning that could prevent a similar death in the future. Whilst each child death is reviewed individually by the panel, this thematic review provides the opportunity to look across all the sudden unexpected deaths in babies aged under 1 year that occurred over a six-year period.

2 Background

There were 200 unexplained infant deaths in the UK in 2017, of these 26 were in the South East region.[2]' Of the 200 deaths, 183 occurred in England and Wales a rate of 0.27 deaths per 1,000 live births: a statistically significant decrease from 0.32 deaths per 1,000 live births in 2016. Just over half (55.2%) of all unexplained infant deaths were boys in 2017 (0.29 deaths per 1,000 live births). This is a slight increase from 51.3% in 2016. All mother's age groups have seen a decrease in SIDs rates since 2004 with mothers aged under 20 having the lowest decline in SIDS rates of 11.3%.

[2] *Office of National Statistics, National Records of Scotland and Northern Ireland Statistics and Research Agency 2019*

2.1 Current epidemiology in Surrey

Chart 1: Low Birth Weight of Term babies

Low birth weight of term babies 2018 — Proportion - %

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	→	16,224	2.86	2.82	2.91
South East region	→	2,091	2.40	2.30	2.50
Slough	→	82	3.71	3.00	4.59
Milton Keynes	→	105	3.35	2.77	4.04
Buckinghamshire	→	168	3.10	2.67	3.59
Reading	→	52	2.80	2.15	3.66
Southampton	→	78	2.74	2.20	3.41
Portsmouth	→	60	2.74	2.13	3.51
East Sussex	→	118	2.66	2.23	3.18
Isle of Wight	→	26	2.64	1.81	3.84
Windsor and Maidenhead	→	38	2.64	1.93	3.60
Medway	→	61	2.41	1.88	3.08
Kent	→	354	2.37	2.14	2.63
Oxfordshire	→	151	2.23	1.91	2.61
West Sussex	→	171	2.18	1.88	2.53
Hampshire	→	269	2.17	1.92	2.44
Surrey	→	249	2.15	1.90	2.43
Wokingham	→	30	1.97	1.39	2.80
Bracknell Forest	→	21	1.67	1.10	2.55
Brighton and Hove	↓	37	1.58	1.14	2.16
West Berkshire	→	21	1.52	1.00	2.32

Source: Office for National Statistics

Surrey has fewer low birth weight, term babies than England and the South East regional average.

Chart 2: Smoking Status at time of delivery

Smoking status at time of delivery 2018/19 — Proportion - %

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↓	61,399	10.6	10.5	10.7
South East region	↓	8,744	9.7*	9.5	9.9
Medway	→	564	15.9	14.7	17.1
Isle of Wight	→	168	15.6	13.6	17.9
Kent	↑	2,173	13.8	13.3	14.3
Milton Keynes	↑	365	13.3*	12.0	14.6
Portsmouth	→	297	13.0	11.7	14.4
Southampton	→	384	12.3	11.2	13.5
East Sussex	↓	574	11.7	10.8	12.6
West Sussex	→	724	9.1	8.5	9.7
Hampshire	↓	1,113	8.7	8.3	9.2
Oxfordshire	→	484	7.5	6.9	8.2
Buckinghamshire	→	388	7.5*	6.8	8.2
Windsor and Maidenhead	→	105	7.4	6.1	8.9
Slough	→	163	7.4	6.4	8.6
Bracknell Forest	→	93	7.4	6.1	9.0
Surrey	→	701	6.1*	5.7	6.5
Brighton and Hove	→	146	5.8	5.0	6.8
Wokingham	→	94	5.6	4.6	6.8
West Berkshire	↓	87	5.6	4.5	6.8
Reading	↓	120	5.6	4.7	6.6

Source: Calculated by PHE from the NHS Digital return on Smoking Status At Time of delivery (SATOD)

Surrey has fewer mothers smoking at time of delivery than the England and South East region, although there were still 701 women smoking at time of delivery in Surrey in 2018 – 19.

Chart 3: Under 18s conception rate per 1000

Under 18s conception rate / 1,000 2018 — Crude rate - per 1000

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↓	14,736	16.7	16.4	17.0
South East region	↓	1,990	13.5	12.9	14.1
Medway	↓	110	23.2	19.1	28.0
Reading	→	48	20.2	14.9	26.7
Portsmouth	→	56	18.9	14.2	24.5
Milton Keynes	→	84	18.4	14.7	22.8
Isle of Wight	→	36	17.9	12.5	24.8
Southampton	↓	57	17.4	13.1	22.5
Kent	↓	448	17.2	15.6	18.9
East Sussex	→	135	15.6	13.1	18.5
West Sussex	↓	168	12.9	11.0	15.0
Brighton and Hove	↓	51	12.6	9.4	16.6
Hampshire	↓	274	12.4	11.0	14.0
Slough	→	33	12.3	8.5	17.3
Surrey	↓	210	10.5	9.1	12.0
West Berkshire	→	30	10.2	6.9	14.5
Oxfordshire	↓	110	10.1	8.3	12.2
Bracknell Forest	→	21	9.8	6.0	14.9
Buckinghamshire	→	81	8.5	6.8	10.6
Wokingham	→	23	7.5	4.8	11.3
Windsor and Maidenhead	→	15	5.5	3.1	9.1

Source: Office for National Statistics (ONS)

The rate of conceptions in Surrey in under 18s is lower than both the South East Region and the England average.

Chart 4: Infant mortality rate 2016 -2018

Infant mortality rate 2016 - 18 — Crude rate - per 1000

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	7,608	3.9	3.8	4.0
South East region	–	1,086	3.6	3.4	3.9
Slough	–	43	5.7	4.1	7.6
Milton Keynes	–	55	5.2	3.9	6.8
Southampton	–	42	4.5	3.2	6.1
Buckinghamshire	–	73	4.1	3.2	5.1
Hampshire	–	169	4.1	3.5	4.7
Isle of Wight	–	14	4.1	2.2	6.8
Kent	–	206	4.0	3.4	4.5
West Berkshire	–	19	3.8	2.3	5.9
Medway	–	39	3.6	2.6	5.0
Windsor and Maidenhead	–	18	3.6	2.1	5.7
Reading	–	25	3.5	2.3	5.2
Portsmouth	–	26	3.5	2.3	5.2
Wokingham	–	18	3.4	2.0	5.4
Brighton and Hove	–	27	3.3	2.2	4.9
East Sussex	–	50	3.3	2.5	4.4
Surrey	–	116	3.0	2.5	3.6
West Sussex	–	77	3.0	2.3	3.7
Bracknell Forest	–	12	2.8	1.5	5.0
Oxfordshire	–	57	2.5	1.9	3.3

Source: Office for National Statistics (ONS)

The infant mortality rate in Surrey is lower than the England average and the South East region.

Chart 5: Proportion of new birth visits completed within 14 days 2018-2019

Proportion of New Birth Visits (NBVs) completed within 14 days 2018/19 — Proportion - %

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Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	540,610	88.8*	88.7	88.9
South East region	–	80,697	87.5*	87.3	87.7
Isle of Wight	–	1,051	95.5*	94.1	96.6
Buckinghamshire	–	5,518	95.4	94.8	95.9
Wokingham	–	1,610	94.2	93.0	95.2
West Berkshire	–	1,452	93.7	92.4	94.8
Reading	–	1,997	93.3	92.1	94.3
Oxfordshire	–	6,644	92.7	92.1	93.3
Kent	–	15,379	91.5	91.0	91.9
Hampshire	–	11,959	90.0	89.5	90.5
Bracknell Forest	–	1,200	88.8	87.0	90.3
Brighton and Hove	–	2,163	88.0	86.7	89.3
West Sussex	–	7,486	87.3	86.6	88.0
Milton Keynes	–	2,859	86.1	84.9	87.3
Southampton	–	2,468	85.4	84.1	86.6
Slough	–	2,065	84.8	83.4	86.2
Medway	–	2,914	84.6	83.4	85.8
Surrey	–	10,571	83.8	83.2	84.4
East Sussex	–	3,986	81.5	80.4	82.5
Windsor and Maidenhead	–	1,277	79.0	76.9	80.9
Portsmouth	–	957	40.1	38.2	42.1

Source: PHE's interim reporting of health visiting metrics: https://www.gov.uk/government/collections/child-and-maternal-health-statistics#health-visitor-service-delivery-metrics

Chart 6: Proportion of infants receiving a 6 – 8 week review 2018 - 2019

Proportion of infants receiving a 6 to 8 week review 2018/19 — Proportion - %

Export table as image Export table as CSV file

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	529,715	85.4*	85.3	85.5
South East region	–	81,427	86.4*	86.2	86.6
Isle of Wight	–	1,051	96.1*	94.8	97.1
Oxfordshire	–	7,018	95.6	95.1	96.0
Buckinghamshire	–	6,279	94.5	93.9	95.0
Brighton and Hove	–	2,255	92.2	91.1	93.2
Milton Keynes	–	3,038	91.3	90.3	92.2
Reading	–	2,110	89.4	88.1	90.5
East Sussex	–	4,349	89.0	88.1	89.9
West Berkshire	–	1,548	88.5	86.9	89.9
Bracknell Forest	–	1,360	88.5	86.8	90.0
Medway	–	3,081	88.0	86.9	89.0
Kent	–	14,785	87.9	87.4	88.4
Hampshire	–	11,603	87.0	86.5	87.6
West Sussex	–	7,117	82.8	81.9	83.5
Surrey	–	10,265	81.1	80.4	81.8
Slough	–	1,922	80.7	79.1	82.2
Southampton	–	2,368	80.0	78.5	81.4
Wokingham	–	1,505	78.9	77.0	80.7
Windsor and Maidenhead	–	1,281	77.5	75.4	79.4
Portsmouth	–	1,530	65.0	63.1	66.9

Source: PHE's interim reporting of health visiting metrics: https://www.gov.uk/government/collections/child-and-maternal-health-statistics#health-visitor-service-delivery-metrics

Charts 5 and 6 show that Surrey was performing statistically worse than the rest of the South East Region for New Birth Visits and 6-8 week reviews in 2018 - 2019. These are critical contacts with parents to assess and discuss safer sleep practices.

Vaccination coverage

The European Region of the WHO has set a 95% uptake rate for childhood immunisations. Currently, Surrey falls below this and the national (England) benchmark in relation to cover rates for most childhood immunisations.

The DTaP/IPV/Hib or '5-in-1' vaccine provides protection against five serious childhood diseases. In Surrey during 2015-16, an average of 82.4% of children received their initial DTap/IPV/Hib by their first birthday, compared to 93.5% in England.

The PCV vaccine protects against certain types of pneumococcal infection. During 2015-16, an average of 84.5% of children in Surrey received their initial PCV by their first birthday, compared to 93.5% in England.

In Surrey and Sussex, average Men B vaccination uptake for the first six months of 2016 for dose 1 was 94.9%, and 88.3% for the second dose.

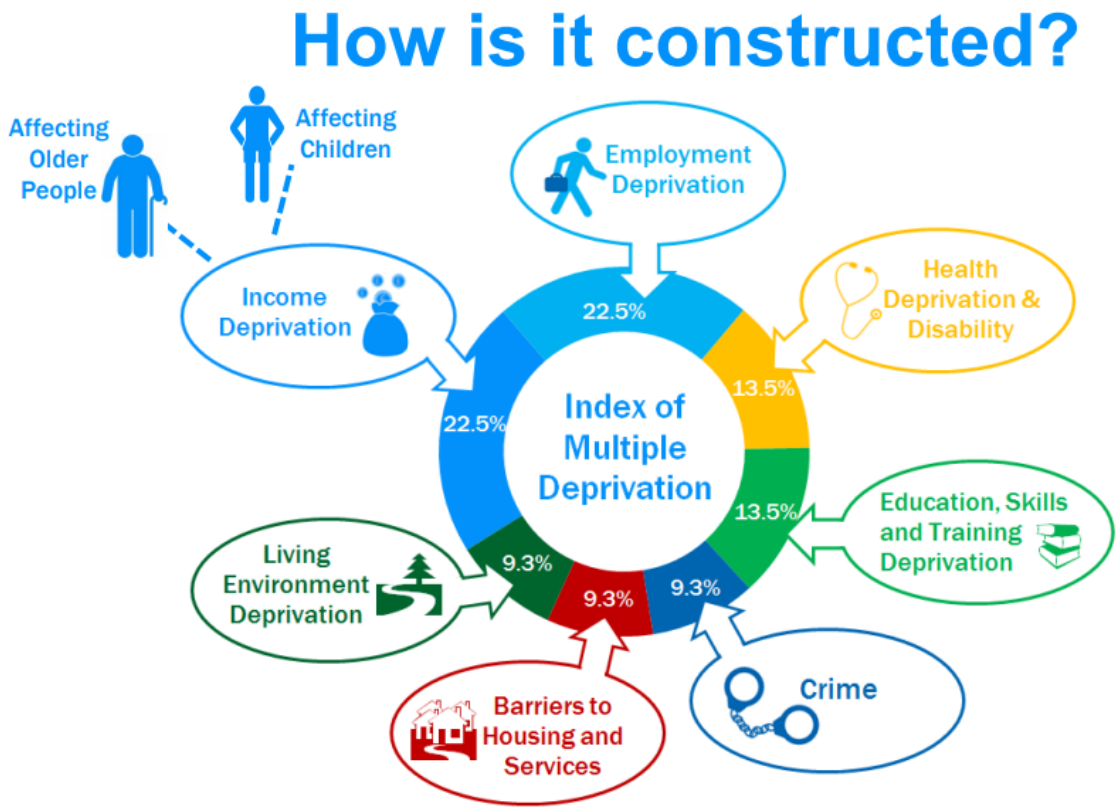
An oral vaccine against rotavirus infection, a common cause of diarrhea and sickness, is given as two doses for babies aged 8 and 12 weeks, alongside their other routine childhood vaccinations. Data across Surrey CCGs demonstrates a high level of uptake for the first dose, with average uptake ranging between 93% in Surrey Downs CCG and 97% in Guildford and Waverley CCG. However, uptake rates do appear to decrease for the second dose, with figures ranging from 87% in Surrey Downs CCG to 92.8% in East Surrey CCG.[3]

Deprivation:

The Indices of Deprivation are a unique measure of relative deprivation at a small local area level (Lower-layer Super Output Areas) across England and have been produced by the Ministry of Housing Communities and Local Government and its predecessors in similar way since 2000. The Indices of Deprivation 2019 (IoD2019) is the most recent release. The Index of Multiple Deprivation is the official measure of relative deprivation for small areas (Lower Super Output Areas) in England. It ranks every LSOA in England from 1 (most deprived area) to 32,844 (least deprived area).

The Index of Multiple Deprivation 2019 combines information from seven domains of deprivation to produce an overall relative measure of deprivation. The domains are combined according to their respective weights are shown in the chart below. In addition, the seven domain-level indices are published along with two supplementary indices: the Income Deprivation Affecting Children Index and the Income Deprivation Affecting Older People Index

[3] https://www.surreyi.gov.uk/jsna/screening-and-immunisations/



IMD is presented as a score, a rank and a decile for each Lower Super Output Area (LSOA). There are 32,844 LSOAs in England, those ranked 1 to 3,284 are in Decile 1, those ranked 3,285 to 6,569 are in Decile 2, etc. The IMD score itself has little meaning. Rank and Decile are most often used to describe the area. The deciles are calculated by ranking the 32,844 LSOAs in England from most deprived to least deprived and dividing them into 10 equal groups. LSOAs in decile 1 fall within the most deprived 10% of LSOAs nationally and LSOAs in decile 10 fall within the least deprived 10% of LSOAs nationally.

How does Surrey rank? There are 709 LSOAs in Surrey. In the overall IMD, none are in decile 1, but there are 4 in decile 2. More than half are in deciles 9 and 10, the least deprived. See chart below.

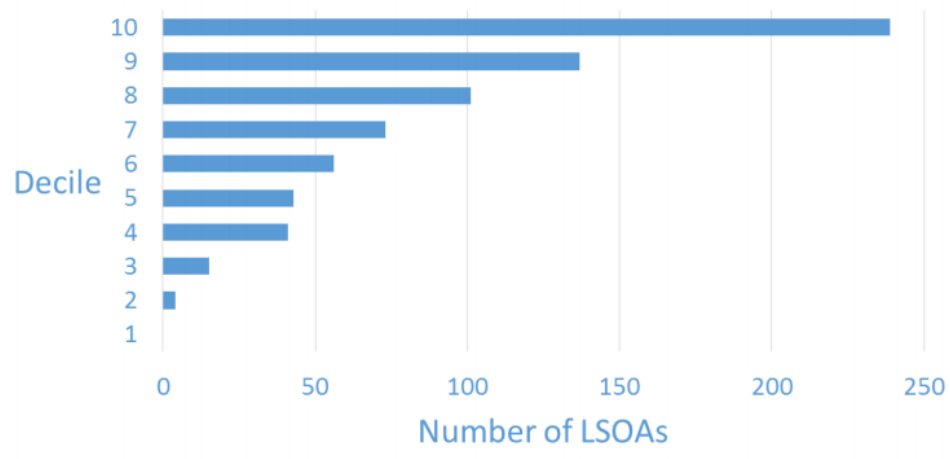
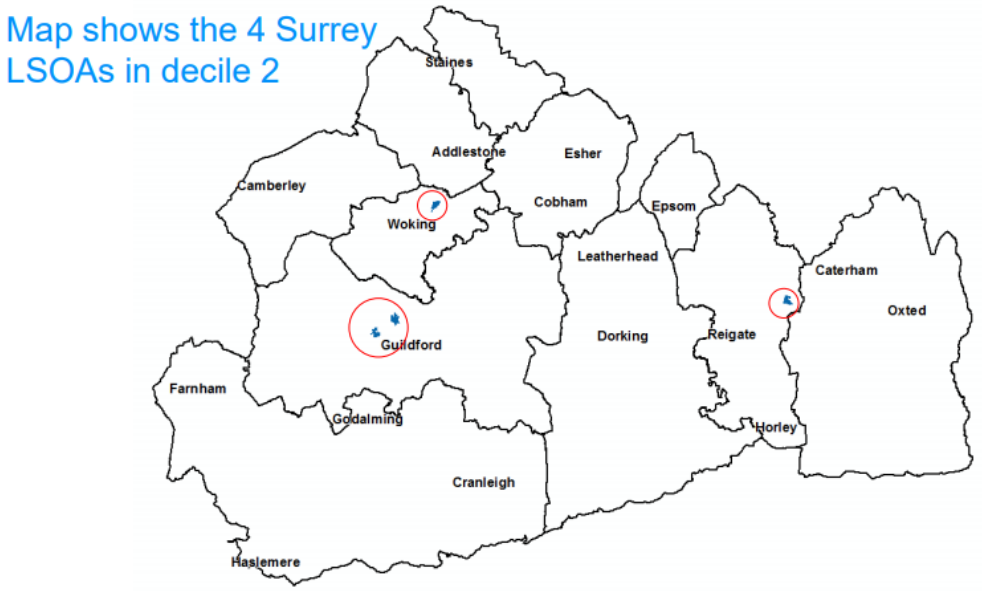


Chart 7: Number of LSOAs in England

Chart 8: LSOA in decile 2 in Surrey

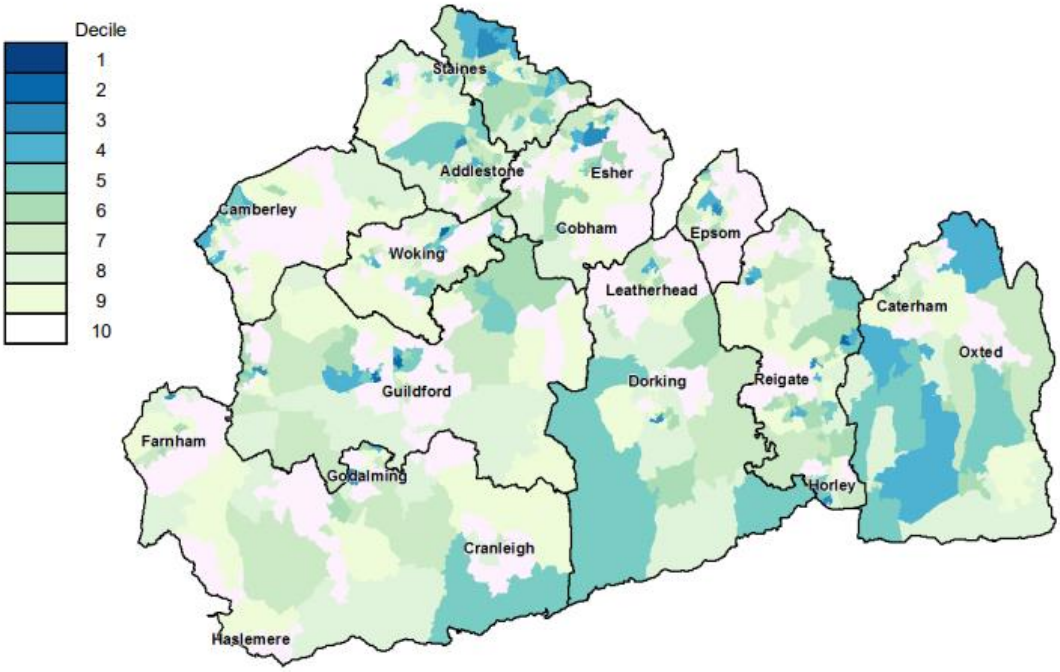
Where are the most deprived areas in Surrey?



These are: Part of Hooley, Merstham & Netherne ward in Reigate & Banstead Borough
Part of Canalside ward in Woking Borough
Parts of Westborough and Stoke wards in Guildford Borough

Chart 9: LSOAs in Surrey

How does Surrey look overall?



2.2 Current Policy context

Surrey Health and Care Partnership and Surrey County Council, in line with National government policy are focusing on the first 1000 days of a child's life.

Public Health England's *Best Start in Life*[5] outlines why the first 1000 days of a child's life is critical to focus on for the health and wellbeing of current and future generations:

Chart 10: Key priorities identified in PHE 'Best Start in Life'

Approximately **80%** of brain development takes place by the age of 3

Up to **20%** of women develop mental ill-health during pregnancy or within a year of giving birth. This can lead to disordered attachment with long term consequences for the mother and baby

Key adverse health outcomes would be reduced by **18-59%** if all children were as healthy as the most socially advantaged

In areas of social disadvantage, **50%** of children have significant language delays

7% of children around five years of age have speech, language and communication needs

£23bn per year: the cost of failure to deal adequately with perinatal mental health problems and child maltreatment

The Surrey Health and Wellbeing Strategy clearly identifies *'starting well'* as a priority.

The outcomes to be delivered by the first 1000 days programme are essential to the delivery of the broader Health and Wellbeing Strategy ambitions as outlined below.

Priority 1

Helping people live healthy lives

- Improved healthy life expectancy for children being born now, focusing in particular on tackling existing health inequalities in Surrey by focusing on prevention and the wider determinants of health

Priority 2

Supporting the mental health and emotional wellbeing of people

- Supporting the emotional wellbeing of mothers and families throughout and after their pregnancy
- Preventing isolation and enabling support for those who do feel isolated

Priority 3

Supporting people to fulfill their potential

- Improved school readiness rates for children with free school meal status

Additionally, the first 1000 days is designated as a Surrey Heartlands Health and Care Partnership priority.

Download the Health and Wellbeing Strategy at
www.healthysurrey.org.uk/about/strategy

[5] Giving every child the best start in life. LGA Early Years Conference, 29 March 2017, Presentation (PDF): https://www.local.gov.uk/sites/default/files/documents/W3%20Giving%20every%20child%20the%20best%20start%20-%20Alison%20Burton%20and%20Lucy%20Pylypiw%2C%20PHE.pdf

3. Methods

3.1 Case definition

Baby and infant deaths for this review were defined as probable SUDI/ SIDS aged 0 - 1 year normally resident in Surrey, between 1 April 2014 and 31 March 2020.

3.2 Data sources

Information on the babies and infants was obtained from the Child Death Overview Panel database.

3.3 Research evidence review

A series of evidence searches were undertaken to review the literature around SUDI and babies under 1 year, with reference to issues identified by the working group, who supported the thematic review. In particular, the evidence review sought to identify:

- Evidence of the risk factors for SUDI..
- Evidence of effective interventions to support the prevention of SUDI

Following a series of scoping searches, a thorough review of the evidence was undertaken with a focus on high level evidence sources including NICE Guidelines, the Cochrane Database of Systematic Reviews and point of care tools (BMJ Best Practice, UpToDate and Clinical Key). This was followed by searching original research (primarily PsycINFO via Healthcare Databases Advanced Search, HDAS and the PsycARTICLES database).

Search results from HDAS were filtered based on their title and abstract. Articles that included results of systematic reviews, RCTs and larger studies were given more prominence.

Limits were applied and the search results were limited to studies of Sudden Unexpected Death in Infancy or SIDS. The results were also limited to include English language articles only and research and reviews from the last 10 years.

Following the filtering process the search results were reviewed, prioritised and collated into themes. In total NICE Guidelines, Systematic reviews and original research articles where collated thematically.

The London, Kent, Surrey and Sussex Regional Searching Guidance (Jan 2020)[4] document informed the search process and approach taken.

[4] The London, Kent, Surrey and Sussex Regional Searching Guidance (Jan 2020) Regional Searching Protocol Working Group.

3.4 Thematic review group

A thematic review group was convened. Members were drawn from academia, safeguarding, public health, child death review team, 0-19 team, police, trading standards and members were approached from maternity services for input, but they did not attend the meetings.

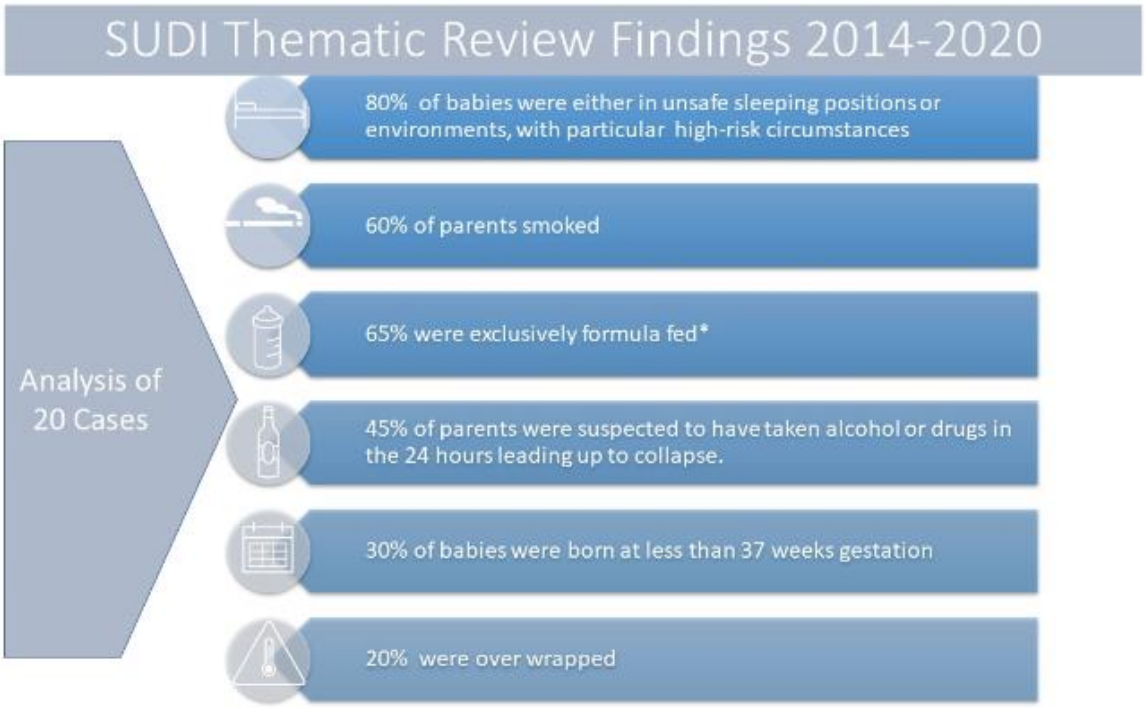
4 Findings

4.1 Babies included in this review

Between 1st April 2014 and 31st March 2020, 20 babies met the case definition for the thematic review of probable SUDI. 12 of the babies were female (60%) and 8 male (40%).

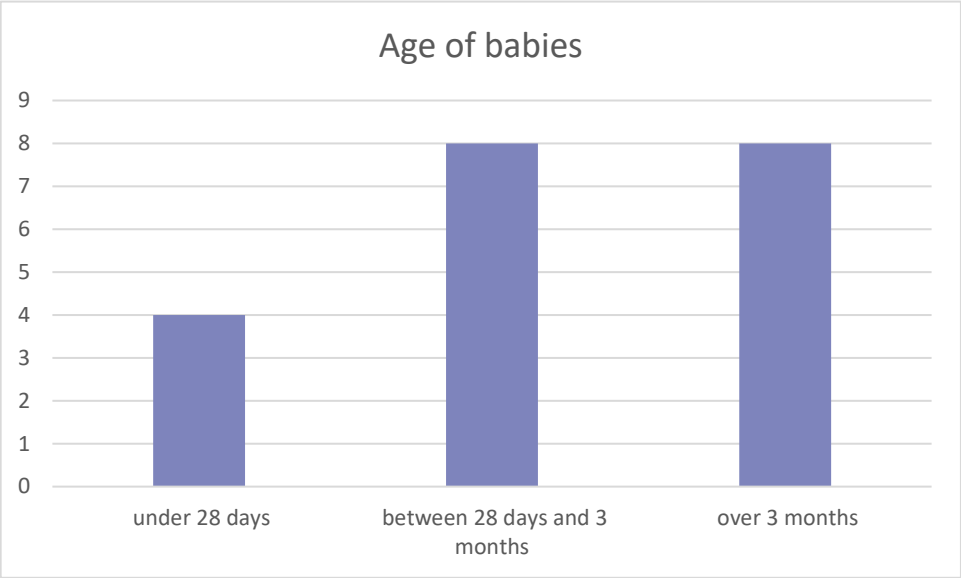
4.2 Summary of babies

Chart 11: SUDI Thematic Review Main Findings



* whilst breastfeeding has well evidenced protective factors for reducing risks of SUDI, this figure should be viewed in light of the number of breastfed babies at the same age. The numbers of babies are too small to make direct comparisons with the local breastfeeding prevalence data.

Chart 12 and 13: Age and number of babies included in the review



age	number of babies	%
under 28 days	4	22%
between 28 days and 3 months	8	44%
over 3 months	8	44%

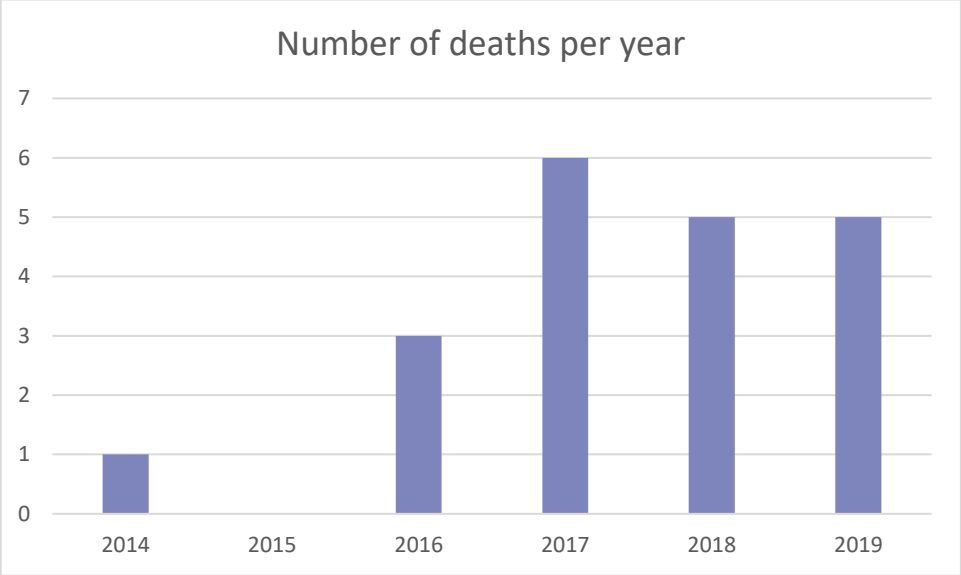
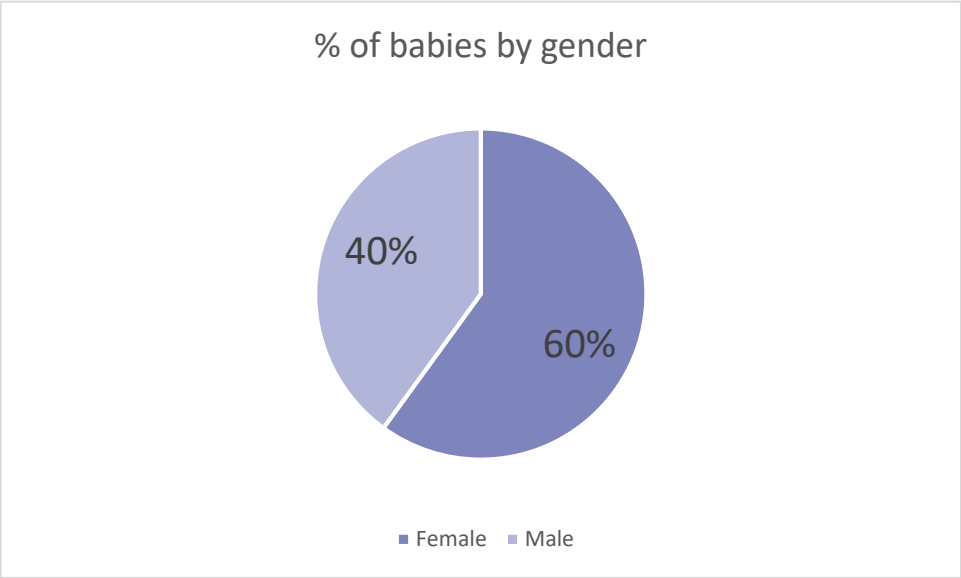


Chart 14: Percentage age and gender of children involved in the review



Gender	%	number of babies
Female	60%	12
Male	40%	8

Prematurity

Prematurity in weeks	number of babies	%
less than 37 weeks	7	35%
37+ weeks	13	65%

Chart 15: Percentage of babies by age when born:

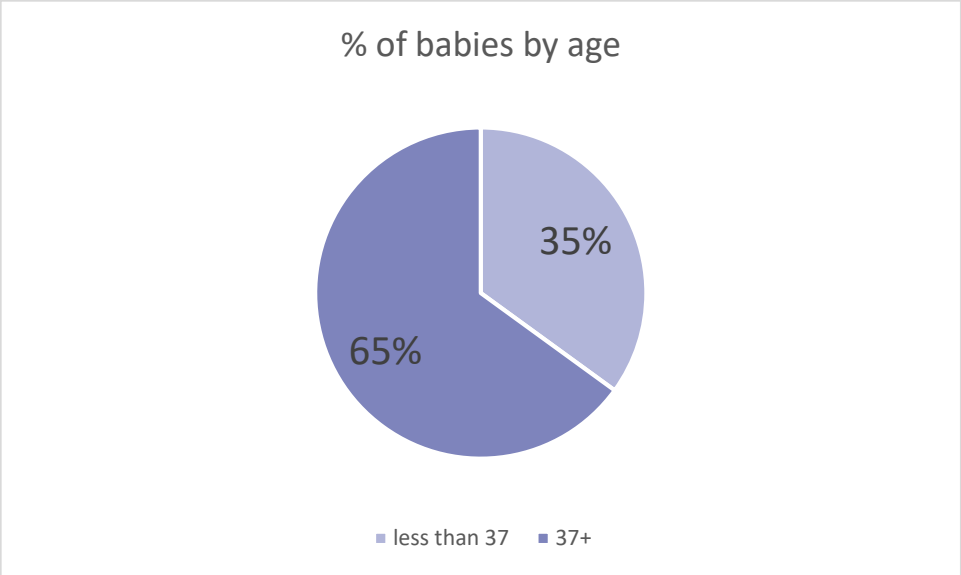
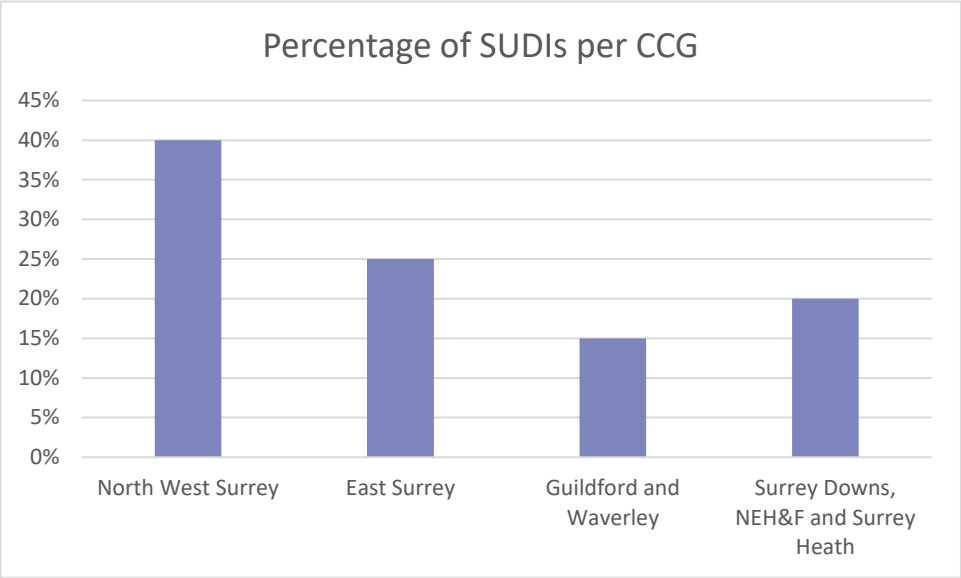


Chart 16: Percentage of SUDIs by CCG:



CCG	North West Surrey	East Surrey	Guildford and Waverley	Surrey Downs, NEH&F and Surrey Heath
Number of babies	8	5	3	4
Percentage of babies	40%	25%	15%	20%

Chart 17: Percentage of Maternal Age

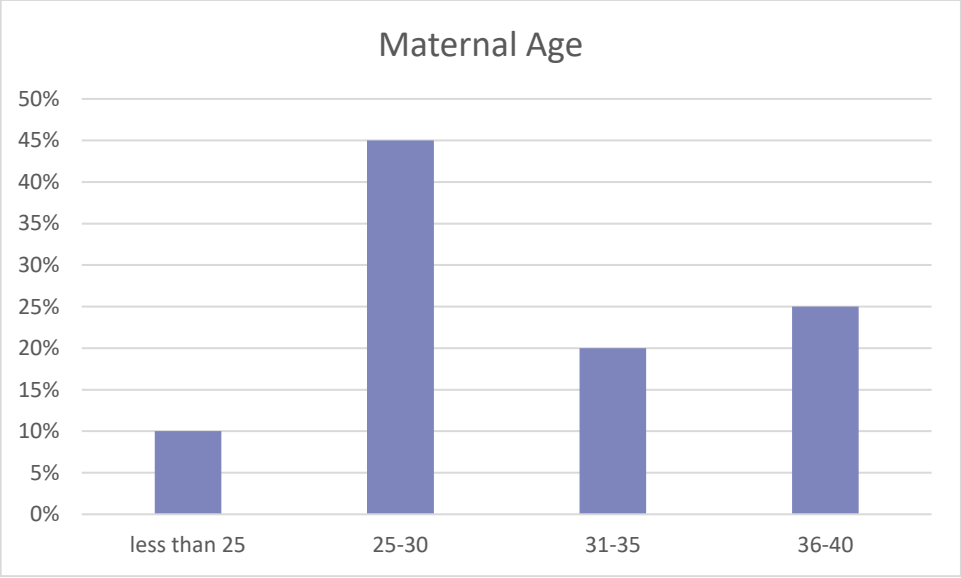
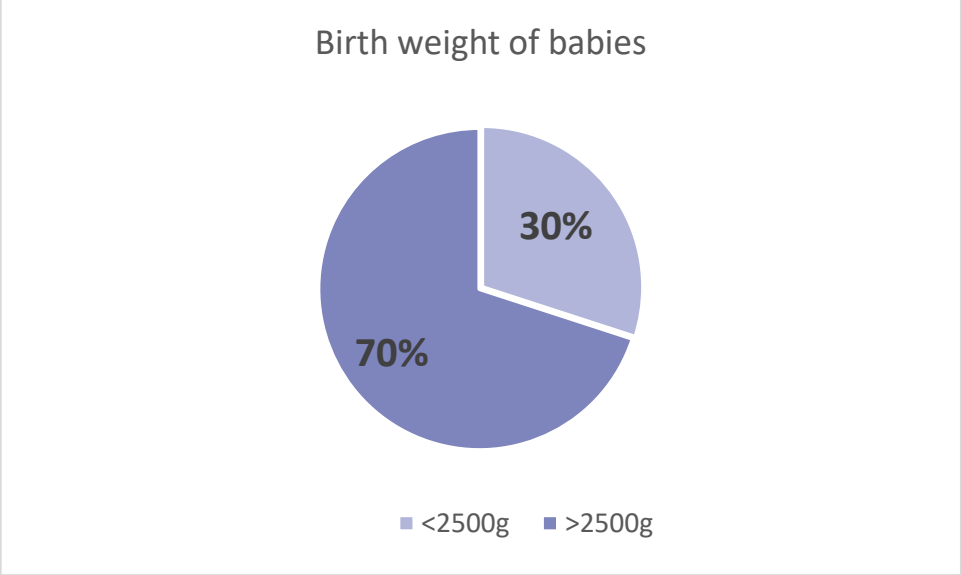


Chart 18: Percentage of birth weight of babies



birth weight	number of babies	%
<2500g	6	30%
>2500g	14	70%

5 Strengths and limitations

A major strength of this report was the multiagency involvement and joint working through the thematic review group. In addition to this, the involvement of the Surrey Child Death Review (CDR) Team and the information held by the Surrey Child Death Overview Panel (CDOP) allowed for an in-depth study of the common themes. In July 2018, a revised version of *Working Together to Safeguard Children* was published and an additional document for the child death review process entitled *"Child Death Review Statutory and Operational Guidance"* was published in October 2018. These two statutory documents lay out in detail the processes that must be followed when a child dies. The statutory guidance states that families should be involved in child death review processes and that parents should be assured that any information concerning their child's death which they believe might inform the meeting would be welcome. The high engagement of families in the CDR process in Surrey meant that the review had access to in-depth information including valuable parental input.

Whilst every death from SUDI is a tragedy, the small numbers for this review mean that it will not be possible to have statistically robust data on the themes identified. Although we do know that a number of the themes are backed up with supporting published evidence and mirror the national picture.

6. Issues identified in this review

There is no advice that guarantees prevention of SUDI but it is possible to reduce the risk. There are a number of well documented risk factors such as sleep position, smoking and alcohol use by parents and carers.

6.1 Unsafe sleep environment

The Lullaby Trust highlights the factors that evidence associates with an *increased* risk of SIDS. These are:

- Unsafe sleeping positions
- Unsafe sleeping environments, **with particular high-risk circumstances highlighted** :
    - Co-sleeping where household smoking or recent drug or alcohol use are present
    - Temperature and overwrapping
    - Bedding and mattresses

Of the babies included in the review 80% fitted into the above circumstances.

6.1.1 Sleep position

"In the 1970s and 1980s, several studies showed an apparently increasing number of sudden deaths in infancy, and epidemiological studies in Europe and New Zealand showed an apparent association with the (relatively recently introduced) practice of putting infants down to sleep in a prone position. The dramatic reduction in the numbers of such deaths that followed attempts to dissuade parents from using the prone sleeping position for babies led to a reduction in SUDI cases in Avon and in New Zealand and subsequently led to widespread adoption of 'Back to Sleep' campaigns in many countries in the early 1990s. Almost all of which were followed by substantial falls in the numbers of unexpected infant deaths, which was reflected in a marked fall in the overall infant mortality rate and the post neonatal mortality rate"[5]

Along with greater risk associated with placing a baby on the front or side to sleep, there is also a greater risk to babies who are in a room alone. International advice to parents across the world advises that babies should be put on their backs to sleep and sleep in the same room as their parent(s) for the first six months of their lives. https://www.ispid.org/infantdeath/id-prevention/id-leaflets/

According to BASIS, which is run by the Durham Infancy and Sleep Centre as an online resource for to up-to-date research based evidence about infant sleep, we 'still do not know what it is about prone sleep that increases a baby's chances of dying suddenly and unexpectedly. Various explanations such as toxic mattress

[5] Sudden unexpected death in infancy: aetiology, pathophysiology, epidemiology and prevention in 2015 Peter J Fleming, Peter S Blair, Anna Pease

gases and rebreathing exhaled carbon dioxide have been investigated and debunked. One potential finding relates to sleep patterns -- babies experience more deep sleep and fewer spontaneous arousals in the prone position: it may be that babies some babies' brains are not well enough developed to arouse themselves from particularly deep sleep when confronted with a physiological stressor, such as head covering.'[6]

Of the eight babies in the review placed on their backs a small number were found prone, these babies were over five months old, at which stage we would expect them to be able to roll by themselves.

Seven of the babies in the review had either been placed in a prone position or on their sides, in several cases this was following advice from family members or friends.

Chart 19: Positions babies were placed in to sleep

Number of babies	position placed in
4	side
8	back
3	prone
5	not known

6.1.2 Unsafe sleeping environments

According to Unicef evidence shows that sleeping in close contact helps babies to settle and supports breastfeeding, which in turn protects babies from Sudden Infant Death Syndrome (SIDS).[7] On any night, 22% of babies will bed-share, so in the UK 149,000 babies will be in bed with their parent tonight.[8]

Evidence shows that rather than co-sleeping alone, it is co-sleeping when a particular high risk circumstance is present which is the concern and increases the risk to the baby.

[6] www.basisonline.org.uk/about-us/

[7] https://www.unicef.org.uk/babyfriendly/wp-content/uploads/sites/2/2016/07/Co-sleeping-and-SIDS-A-Guide-for-Health-Professionals.pdf

[8] Blair, PS & Ball, HL (2004), "The prevalence and characteristics associated with parent-infant bed-sharing in England." Archives of Disease in Childhood, 89(12):1106-10. doi:10.1136/adc.2003.038067

9

Of the babies in the review, ten were co-sleeping. Of these six of the babies were in a household where parents had consumed drugs or alcohol in the previous 24 hour period and eight were in a household with parental smoking.

For reasons that remain unclear, the risk of SIDS is particularly high for infants who sleep with parents on a sofa (Blair et al. 1999). Infants who sleep in a separate room from their parents are at increased risk compared to infants who sleep in the same bedroom (Blair et al. 1999).

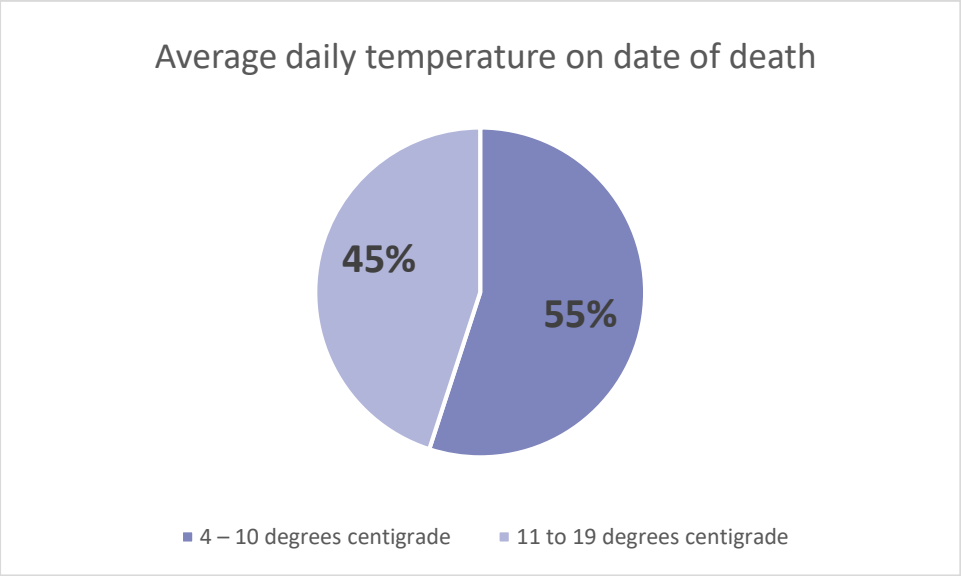
A number of babies were found in either baby nests or homemade versions of these, the evidence is clear that the safest place for babies to sleep is in a clear cot. "There is evidence to suggest that babies are at higher risk of SIDS if they have their heads covered and some items added to a cot may increase the risk of head-covering. Unnecessary items in a baby's cot can also increase the risk of accidents."[10]

[9] Blair, PS, Sidebotham, P, Pease, A & Fleming, P (2014), "Bed-Sharing in the Absence of Hazardous Circumstances: Is There a Risk of Sudden Infant Death Syndrome? An Analysis from Two Case-Control Studies Conducted in the UK." PLOS One. http://dx.doi.org/10.1371/journal.pone.0107799

[10] A clear cot is a safer cot - The Lullaby Trust

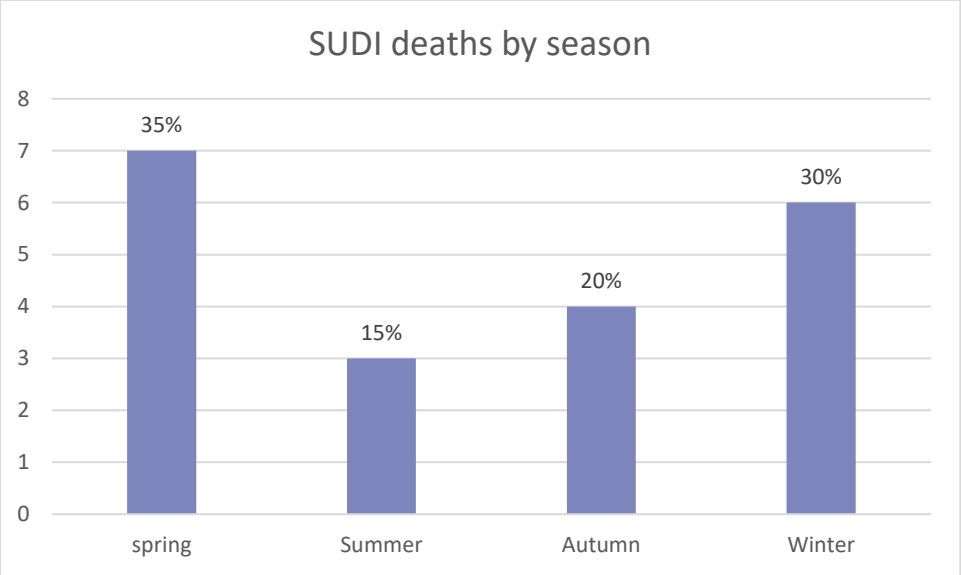
6.2 Temperature

Chart 20: Average daily temperature on date of death:



Winter months are associated with a higher SIDS rate. Possibly due to overheating and over-bedding which are both more likely in winter due to an increased use of central heating at night and the extra use of bedding and clothing, regardless of the indoor temperature. This is the reasoning given by ONS behind the rise in unexplained infant deaths in February 2013, when the monthly temperature was below average (ONS: 2015). In 2015 28% of unexplained infant deaths occurred in the winter, as opposed to 22% in summer. This figure is replicated in the Surrey data with 30% of deaths occurring in the winter and 20% in the summer.
When sleeping in bedding up to 85% of an infant's heat loss is through the head (Fleming et al. 1992). If covered by bedding this heightens the risk of hyperthermia, as well as hypoxia due to rebreathing of air and lack of oxygen. Studies (Ponsonby et al., 1991; Williams et al., 1996) have found infants who died were more heavily wrapped infants and households with heating on all night, in comparison to control infants with matched variables.

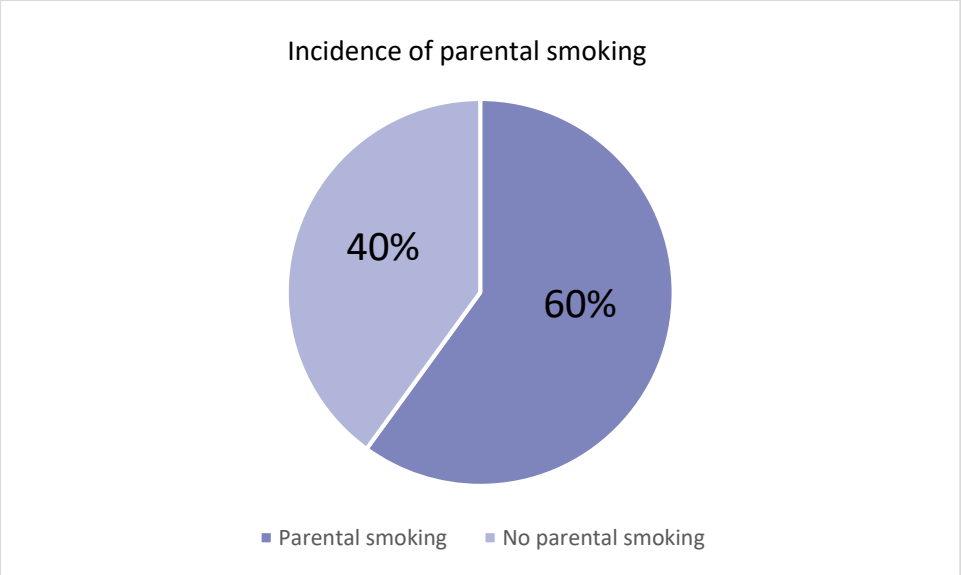
Chart 21: SUDI deaths by season:



6.3 Parental Smoking

Smoking is still the single biggest identifiable risk factor for poor birth outcomes. Babies are at greater risk of SUDI when a mother smokes during pregnancy or if there is smoking in the home. An estimated one-third of SUDI deaths could be prevented if mothers did not smoke in pregnancy[11]. Of the babies in the review 60% lived in households with a smoker.

Chart 22: Incidence of parental smoking



11 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/431396/London_sudden_deaths_in_infancy_update_factsheet.pdf

6.4 Parental drug and alcohol use

In the National Review 'Out of Routine'. A review of Sudden Unexpected Death in Infancy (SUDI) in families where the children are considered at risk of significant harm'[12] Almost all of these tragic incidents involved parents co-sleeping in unsafe sleep environments with infants, often when the parents had consumed alcohol or drugs. In addition, there were wider safeguarding concerns – often involving cumulative neglect, domestic abuse, parental mental health concerns and substance misuse.

Elliot et al (2020) found that Infants prenatally exposed to both alcohol and cigarettes continuing beyond the first trimester have a substantially higher risk for SIDS compared to those unexposed, exposed to alcohol or cigarettes alone, or when mother reported quitting early in pregnancy. Given that prenatal drinking and smoking are modifiable risk factors, these results address a major global public health problem. [13]

Five of the babies had parents who were known to drug and alcohol services. Nine of the babies were in households where the parents has consumed drugs or alcohol in the 24 hour period prior to the child's death.

6.5 Parental mental health

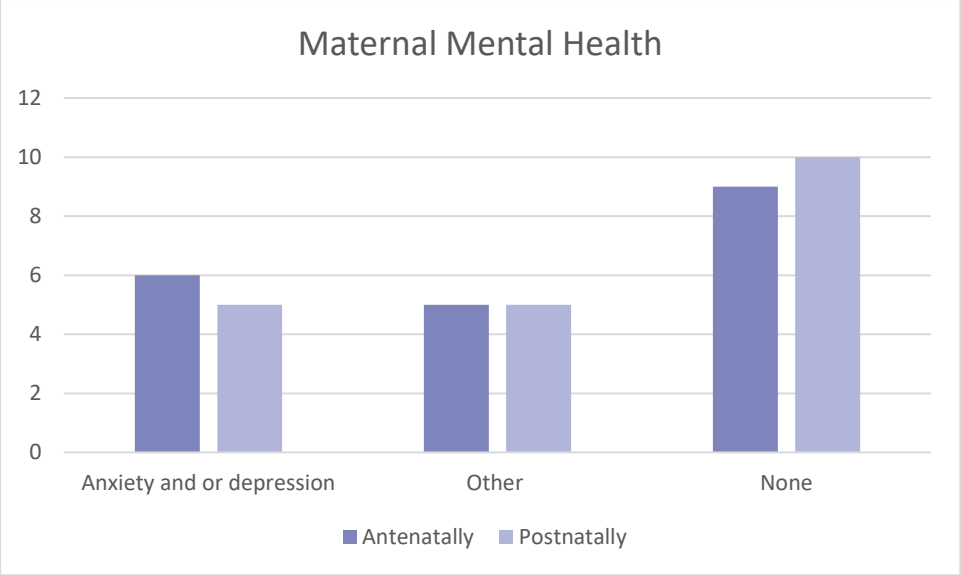
Although parental mental health concerns are common, the Child Death Review Programme in Wales in their thematic review of SUDIs 2010 – 2012 asked 'whether babies being cared for by a parent with a mental health problem may have additional vulnerabilities or a potential for an increased risk of unexplained sudden infant death. 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.' They concluded that 'In the absence of more robust data no conclusion can be drawn from the review cases.' [14]

Chart 23: Maternal Mental Health

[12] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/901091/DfE_Death_in_infancy_review.pdf

[13] https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(19)30256-1/fulltext

[14] Sudden Unexpected Deaths in Infancy - English.pdf (wales.nhs.uk)



	Anxiety and or depression	Other	None
Antenatally	6	5	9
Postnatally	5	5	10

6.6 Neglect and deprivation

The Index of Multiple Deprivation (IMD) is an overall measure of deprivation based on factors such as income, employment, health and education within an area. There are different measurements for England and Wales, which are not comparable.
In 2017, the infant mortality rates were higher in the most deprived areas than in the least deprived areas in England. The rate was 5.2 deaths per 1,000 live births in the most deprived areas compared with 2.7 deaths per 1,000 live births in the least deprived.[15] For the babies in the review in regards to IMD decile, there is a higher odds of experiencing a SUDI in deciles 3-6 after which the risk decreases becoming almost negligible in the highest deciles. Due to the small numbers these findings should be used as an indication only.

6.7 Method of infant feeding

There is extensive data to show that breastfeeding has a protective factor in reducing SUDIs. One meta-analysis of breastfeeding & SIDS: 'Breastfed' babies had about 'half the risk' of SIDS than those who were not breastfed. The authors

[15] Child and infant mortality in England and Wales - Office for National Statistics (ons.gov.uk)

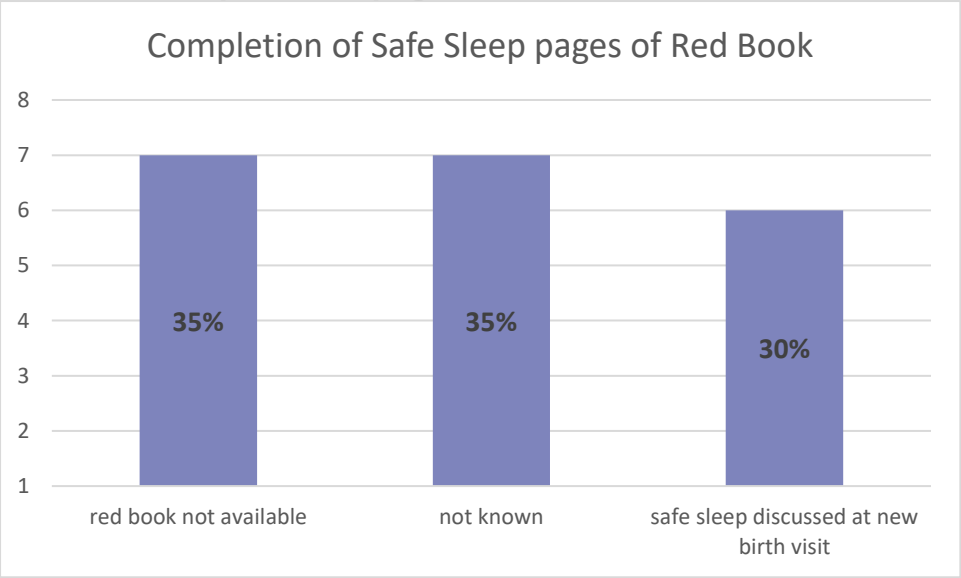
concluded that the effect was stronger when breastfeeding was exclusive.[16] Of the babies in the review 35% of them were breastfed.

6.8 Professional advice and conversations with parents

Out of Routine: A review of SUDI in families where children are considered at risk of significant harm'[17] concluded that 'it is clear that families with children at risk of significant harm through child abuse or neglect also face a range of wider risks stemming from their background contexts and circumstances. Situational risks and out of routine circumstances act together to increase the risks of SUDI and may mean that families find it difficult or impossible to engage with standard safer sleep messages.' In 2016 a 15% cut to the budget for the commissioning of Health Visiting services by Surrey County Council coincided with an increase in SUDI deaths.[18] Data in this report also shows that the proportion of new birth visits and 6-8 weeks checks completed in 2018 – 2019 were significantly worse than the England average. Whilst the numbers of SUDIs are too small to draw robust conclusions, this policy change and change in practice should be considered.

In November 2014 there was the inclusion in the Child Health Record (red book) easily accessible safe sleep information for parents and a midwife assessment to be completed with the parents as soon as possible after birth but by the latest, five days old. These pages were developed with the input and agreement of the Maternity services, 0-19 services, Safeguarding Children and Public Health. NHS Guildford and Waverley CCG provided the funding for these pages in all red books across Surrey. Of the babies in the review there was evidence that just under a third of them had their safer sleep assessment completed in their red book although not all of the books were available to be seen as the police had removed them for evidence.

Chart 24: Completion of pages in red book



[16] Hauck, F. R., Thompson, J. M. D., Tanabe, K. O., Moon, R. Y., & Vennemann, M. M. (2011). Breastfeeding and Reduced Risk of Sudden Infant Death Syndrome: A Meta-analysis. Pediatrics, 128(1), 103–110. doi:10.1542/peds.2010-3000

[17] Out of routine: A review of sudden unexpected death in infancy (SUDI) in families where the children are considered at risk of significant harm (publishing.service.gov.uk)

[18] SURREY COUNTY COUNCIL (surreycc.gov.uk)

6.9 Triple Risk Model

[19]

The Triple Risk Model

On their website BASIS present the theory for the triple risk model, 'the more that is discovered about SIDS risk the more it is recognised that causation cannot be reduced to a single factor. The triple-risk model (or triple risk hypothesis) is the best current consensus explanation for SIDS encompassing three key factors:

- a vulnerable infant (e.g. they may have a physiological abnormality of some kind)
- a critical developmental period (e.g. the first six months of life, when SIDS is more common);
- an external stressor. (infant is placed prone to sleep, their breathing is compromised by soft bedding, etc.).

Research has identified different risk factors for physiological or developmental vulnerability as well as external factors, and is ongoing into how these factors combine to cause SIDS. This document outlines the identifiable intrinsic factors (e.g. prematurity and low birthweight) that are associated with increased SIDS-risk, and the external, or modifiable, risk factors for SIDS.

Each factor is outlined with a few examples below.

Age:
The critical developmental period for most infants appears to be 2-4 months of age. This is when most SIDS deaths occur. Infants who are born prematurely are likely to have a delayed critical period compared to term babies.

Vulnerability:

[19] https://www.basisonline.org.uk/hcp-the-triple-risk-model/

e.g. Asphyxia and brainstem abnormalities - Prematurity Smoke exposure during gestation. There are some intrinsic factors of infants (characteristics they are born with) that may make them more vulnerable than others to SIDS, such as brain-stem abnormalities. Studies are increasingly homing in on the relationship between breathing regulation and neurochemical abnormalities in the brainstem that can impair protective responses. Prematurity is likely to be associated with SIDS due to an inability of some of these infants to mount a normal arousal response in the face of a physiological challenge. Smoke exposure in utero has a similar explanation in blunting an infant's normal arousal response.

Environment:

Sleeping position - Head covering - Overheating - Post-natal smoke exposure - Formula feeding - Sleeping in a room alone - Soft bedding - Bed-sharing - Soft toys etc.

Subsequent studies identified further key risks: parental smoking-, head-covering, overwrapping, and infant illness also were associated with increased risk (Fleming et al. 2003; Fleming et al. 1996) along with soft bedding, soft sleep surfaces, overheating (Flick et al. 2001; Moon, et al 2007), breastfeeding for less than two weeks, and 'co-sleeping' (Vennemann et al. 2009).

6.10 Family engagement

Losing a baby to Sudden Infant Death Syndrome (SIDS) triggers a severe loss reaction. The severity of the loss may be attributed to the baby's age, the lack of satisfactory explanation for the death, and a lack of social recognition. A study aimed at examining the loss experienced by Israeli parents (N=12) who lost a baby to SIDS through the theoretical lens of ambiguous loss. A deductive and inductive thematic analysis revealed that, for these bereaved parents, entities of the baby-physical and psychological-are unclear. Thus, the parents' loss is likewise unclear and ambiguous.[20]

Any bereavement can be immense, but with the sudden death of an infant, families can often feel the profound effect of shock and trauma. It is often the parents that have found their child unresponsive and begin the distressing process of resuscitation or witnessing medics resuscitating. As a consequence the grieving process may therefore be more complex, intense and longer, although the actual experiences of grief may be similar to other bereavements.

After a sudden infant death, it can be more difficult to come to terms with why it happened because there is no clear cause. Families can often struggle with not having a significant finding at post mortem and the infant was well in the days leading up to their death. Parents often struggle with guilt for long periods also. A sudden infant death commonly occurs at night and parents feel that they let their child down because they were fast asleep whilst their child was dying. The feeling of guilt maybe further intensified for parents if an unsafe sleep environment is noted.

20

Neither here nor there and a little bit of both: The ambiguous loss experience of parents who lost a baby to sudden infant death syndrome, Mahat-Shamir, M (2020). Death Studies: Aug 2020 p 1-10

Thinking can become circular, endlessly trying to find answers to 'what if?' questions, searching to make sense of what has happened in a way that feels bearable. There can be specific challenges for the whole family, and for children and young people when grieving after a sudden infant death. Managing sibling's safe sleep going forward can become a source of great anxiety. The need to watch your child sleep may be overwhelming. All of these elements can be completely overwhelming and parents can feel lost and isolated. Many parents experience aching arms and can hear their child crying. The baby belongings and equipment serving as a constant reminder and some parent feel a strong need to continue with routine childcare tasks. This can be especially traumatic if the mother is still lactating. All of these anxieties may also be renewed if the parents have another baby in the future. Being given the opportunity to talk about your grief is an important part of getting through a bereavement. Surrey CDR Team proactively contact all families via the named nurse/child death review nurse to offer them bereavement support, the opportunity to contribute to the CDR process and allow their voice and the voice of their child to be heard, the following are themes that were identified by parents in the review:

Infant had symptoms of a cold or snuffle in the days prior to death

- *Families report that their child has symptoms of a cold or mild congestion in the days leading up to the event.*
- *Any contacts with a health professional had always resulted in reassurance that this is normal or dismissed completely.*
- *Parents felt that concerns regarding cold symptoms should have been more thoroughly investigated by health professionals.*

Overwhelming support and praise for ambulance service response and intervention

- *Every family noted that the first responders were kind, caring and considerate.*
- *Ambulance crews often stayed with the family after arrival at hospital to offer continued support and explain what was happening.*
- *Parents felt that their child received treatment promptly by the ambulance service and that multiple paramedics attended.*
- *Parents also felt that everything was done that could have been done.*

Police involvement caused distress and further trauma

- *Every family noted that they were shock or confused by police involvement.*
- *Parents reported that the police investigations increased their distress at a time when they were in shock.*
- *The police investigation was often described as traumatic and disturbing.*
- *All families understood the need for a Police investigation after it was explained to them the reasons why.*
- *The police were respectful but needed many questions answered.*

Blame

- *In all cases, the mother has initially blamed herself and felt responsible for the child death.*
- *In all cases the mother reported she felt guilty that she had not protected her child.*
- *Some parents struggled with not knowing when their child actually died and how long they had been dead for.*

7 Opportunities for prevention

7.1 Existing activities which contribute to the prevention of SUDI

Our review of current best practices both national and international highlighted the following as key to SUDI reduction.

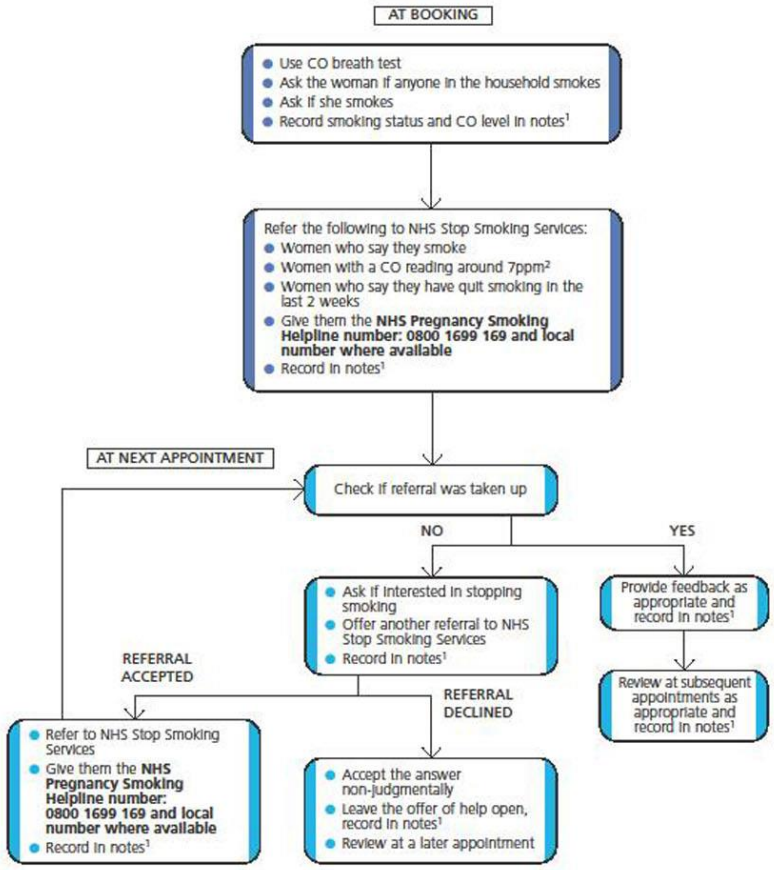
Unicef BFI accreditation:

Surrey NHS trusts and community providers have various levels of Unicef Baby Friendly Initiative Accreditation, Unicef BFI have included more detailed questions about safe sleeping in their revised mother audits for the Health visiting service which were introduced in August 2019.

Stop smoking provision for pregnant women and their partners:

Recommendation 1: Referral pathway from maternity services to NHS Stop Smoking Services

Provide all women with information (for example, a leaflet) about the risks of smoking to her and the unborn child, including smoking by partners or family members. Address any concerns she, her partner or family may have about stopping smoking. Tell partners and family members about NHS Stop Smoking Services.



[1] Preferably the patient handheld record.
[2] Lower level (e.g. 3 ppm) may apply for light/infrequent smokers. Note: higher level might apply if prior exposure to other sources of pollution, e.g. traffic fumes, leaky gas appliances.

8 Recommendations

Recommendations and opportunities not to be missed are summarised below. These were selected as there is a real chance that development of these opportunities could inform action to prevent deaths of babies from SUDI.

- **Better knowledge and awareness for parents on safer sleep:**

In line with 'Out of Routine. A review of Sudden Unexpected Death in Infancy (SUDI) in families where the children are considered at risk of significant harm'[21]

21 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/901091/DfE_Death_in_infancy_review.pdf

recommendations, Surrey Safeguarding Children Partnership (SSCP) should ensure partners adopt a practice model that encompasses reducing the risk of SUDI within wider strategies for promoting infant health, safety and wellbeing. Partners should use the questions in the review in relation to the knowledge, understanding and skills of their workforce – in particular, practitioners' understanding of the views of parents about safer sleeping, local multi-agency systems and processes for risk assessment and management, managing workforce capacity, and quality assurance.

Unicef Baby Friendly Initiative have included more detailed questions about safe sleeping in their revised mother audits for the Health visiting service which should be used to monitor conversations that are taking place with parents.

The previous audit on safer sleep conversations initiated by the Child Death Review Nurse was completed in 2017. A further audit should be carried out by the Surrey Child Death Review Partnership and a planned re-audit completed the following year to monitor progress.

Where appropriate Surrey Trading Standards should support work around safety of baby nests and the messaging around clear cots should be included in conversations with parents.

In line with NICE Quality Standard QS37 women, their partner or the main carer should be given information on the association between co-sleeping and sudden infant death syndrome (SIDS) at each postnatal contact. Commissioners should ensure that they commission services that provide information about the association between co-sleeping and SIDS, and that train healthcare professionals to understand and explain this information and give it to women, their partners or the main carers of babies at every postnatal contact.

When published in April 2021 partners should fully implement NICE Guidance on Postnatal Care.[22]

- **Support for parents from smoking cessation services:**

Full implementation of NICE guidance - Smoking: stopping in pregnancy and after childbirth. "Helping pregnant women who smoke to quit involves communicating in a sensitive, client-centred manner, particularly as some pregnant women find it difficult to say that they smoke. Such an approach is important to reduce the likelihood that some of them may miss out on the opportunity to get help" NICE 2020[23]. In line with NICE guidance systems should be in place to enable these women and their partners to be clearly identified and referred into services appropriately so sensitive conversations can take place and support to quit smoking can be accessed.

[22] https://www.nice.org.uk/guidance/GID-NG10070/documents/short-version-of-draft-guideline-2
[23] https://www.nice.org.uk/Guidance/pH26

- **Reduction in alcohol and substance misuse in parents:**

In line with NICE Quality Standard QS11 evidence of local arrangements to ensure that alcohol awareness training that promotes respectful, non-judgmental care is delivered to all health and social care staff who potentially work with patients or service users who misuse alcohol. Health and social care staff opportunistically carry out screening and brief interventions for hazardous (increasing risk) and harmful (high-risk) drinking as an integral part of practice and people who may benefit from specialist assessment or treatment for alcohol misuse are offered referral to specialist alcohol services and are able to access specialist alcohol treatment. Parents should also be routinely reminded of the risks of co-sleeping even after any alcohol has been consumed as evidence shows that alcohol can reduce responsiveness in caregivers.

- **Increased support for breastfeeding**

In line with NICE Quality Standard QS37 evidence of local arrangements for breastfeeding support should be provided through a service that uses an evaluated, structured programme. In Surrey all neo-natal units, maternity units, community providers and family centres to work towards achieving Unicef BFI accreditation. GP training on supporting breastfeeding to be rolled out across the County.

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