



## Surrey Child Death Review Partnership

### Neonatal deaths

### a thematic review of deaths that occurred between 2016- 2021

*“Sadly, the death of a baby is not a rare tragedy. Every day in the UK around 14 babies die before, during or soon after birth. That means that nearly every two hours a family is faced with the devastation of the death of their baby.”*

SANDS<sup>1</sup>

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<sup>1</sup> [Help save babies' lives | Sands - Stillbirth and neonatal death charity](#)

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## Foreword

The death of a child is a tragedy and the impact of that death on the lives of the immediate and wider family, those close to them, the community and professionals cannot be underestimated. The effect on the lives of families and those close to them is profound and permanent affecting both their physical and mental health.

This report presents the findings of a thematic review undertaken by Surrey Child Death Review Partnership of neonatal deaths that occurred over a five-year period. Central to this report are the voices of parents who have experienced the death of their baby. The pain and devastation are so evident. This is why it is important that we do all we can to learn from the deaths of children and do all that we can to prevent future deaths.

Article 6 of the United Nations Convention on the Rights of the Child states that government should:

“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’.

Since 2000 the rate of deaths in the neonatal period has been decreasing in most Organisation for Economic Co-operation and Development (OECD) countries, however the UK has a relatively high rate of neonatal mortality compared to other countries such as Japan, Finland and Sweden who have the lowest rates. We must do better.

By counting the number of neonatal deaths within Surrey, gathering information on where and why these deaths occurred and by trying to understand the underlying contributing causes and avoidable factors, health-care providers, their partners and policy makers can help to prevent future deaths and improve the quality of care provided throughout the health system. This report presents a number of recommendations and opportunities not to be missed. These provide an opportunity for learning and to develop practice together to ensure we do all we can to reduce to the number of neonatal deaths in Surrey.

Amanda Boodhoo

Chair of Surrey Child Death Overview Panel

## Parental Voice

Our babies were born prematurely in November 2019. One of our little boys died the following day, and our other little one lived for four and a half months before he died in April 2020.

I have been a primary school teacher for ten years. I had to leave my classroom suddenly one morning in November 2019 when I noticed some bleeding. My teaching assistant covered the class while I went to get checked at the hospital. I never managed to finish teaching that lesson as my boys arrived ten days later.

My maternity leave plans got blown out of the window and in November my leave began, earlier than expected. We spent 18 weeks in NICU. At the time I felt cheated – I was spending my maternity leave in an intensive care unit with one baby gone, and one struggling to survive. In April, when our second little one died, we felt empty. How would we ever come to terms with what had happened to our family over the last five months? How would we go on without our children?

Five weeks later I needed to discuss my return to work with school. My part time request would not be able to be accepted and I would need to go back full time if I wanted to return. I eventually agreed to return full time and to just take a day at a time.

I recently returned, just over nine months since I had to leave my class that day in November to get a check-up. These first few weeks have been more challenging than I ever could have imagined. Going back to ten hour working days leaves me with little time to rest or to continue to process what has happened.

Grief is overwhelming and exhausting. It's now six months since we lost our second little one and although I am now mostly able to function and put one foot in front of the other, my brain is still foggy, and I continue to feel a deep sorrow which is like a very heavy black rucksack that I'm having to carry around with me.

I sometimes glaze over in class and my mind goes blank. Last week this happened while I was teaching a maths lesson and I froze, began to shake and had to leave the room as my mind had taken me back to the moment when one of our boys was taken away from us. I managed to get to the school office where I broke down and felt real panic. It was a scary experience.

Much of the motivation I used to have for my job has disappeared because, since our boys, nothing seems of any importance. I am conscientious so I still work hard but the 'spark' I used to sometimes get from teaching definitely isn't there at the moment. How can I be happy teaching other people's children when I can't go home to my own babies each day?

I cry a lot at work. Before the children come in, at break time, at lunchtime and after school. There are days when I manage to hold all my tears in only for them to explode out of me when I get home. Other days I'm not so strong and I sob at my desk wondering how I'll get through the next ten minutes.

Two boys in my class have the same name as one of my babies. I have to say that name tens of times each day, and it feels like a little dagger piercing me each time I do. While I was setting up the classroom in the summer holidays, I found it unbearable sticking fresh new name labels onto the children's trays knowing my boys would never have a tray. These are just some of the examples of how everything I do, especially at work, brings me back to my boys.

My teaching assistant and some of the other teachers I work with are very supportive and kind, which is a real help. Another help is the bereavement leave I plan to use to break up the coming months. However, despite these things, I am wondering whether full time classroom teaching is going to be manageable for me long term now.

If I'm really honest (which I recently promised myself I would be), is it what I want? I know life isn't as easy just doing what makes you happy - after all, we have bills to pay – but knowing, loving and losing my boys has changed my perception on life dramatically. I now know what is important and after everything I've been through, both physically and mentally, over the last nine months, I'm starting to realise that maybe I deserve a break. Maybe I need to ask myself: *What will help me right now? What will bring me a little bit of happiness? What can I do that will help me to keep my boy's memory alive while helping other families in similar positions?*

Maybe the answer is finding a part time role or working in another field of education. Maybe it's a complete change I need, a new direction? Or maybe I need to give myself time and permission to *not be ok* and to take however long I need to work things out.

Nothing is certain - everything feels complicated. But what calms me is just taking a moment to sit quietly, connect with my boys and feel the love we share. I know they're saying, "It's OK Mummy, you're doing a great job. Be kind to yourself – we will always love you."

No one can take that away from me – it's what keeps me going.

***Anonymous<sup>2</sup>***

Written October 2020 and reproduced with kind permission of the author.

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<sup>2</sup> [Returning to work after a loss \(twintrust.org\)](https://www.twintrust.org)

## 1 Introduction

This report presents the findings of a thematic review undertaken by Surrey Child Death Review Partnership of neonatal deaths that occurred between 1 April 2016 – 31<sup>st</sup> March 2021.

For the purposes of this review, we will be defining neonatal deaths as; babies whose normal residence is Surrey, who die within 28 days of birth or those born after 22+6 weeks who show signs of life as defined in the MBRRACE national clinical guidance<sup>3</sup> or post neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital following birth. Stillbirths and terminations were not included in the review.

As with our previous thematic reviews, 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 neonatal deaths, as defined above, that occurred over a five-year period.

## 2 Background

The neonatal mortality rate has been decreasing in most Organisation for Economic Co-operation and Development (OECD) countries since 2000. As with the infant mortality rate, the UK has a relatively high rate of neonatal mortality compared to other countries. In 2019, there were 2.9 neonatal deaths per 1,000 live births in the UK. The United States consistently has one of the highest neonatal mortality rates while Japan, Finland and Sweden have the lowest rates.

One of the United Nations Sustainable Development Goals includes a target to reduce neonatal mortality to at least as low as 12 deaths per 1,000 live births by 2030. The UK has already met this global target, however, the NHS Long Term Plan recently reiterated the government's ambition to achieve a 50% reduction in stillbirth and neonatal mortality by 2025.<sup>4</sup>

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<sup>3</sup> [signs-of-life-guidance-document.pdf \(rcm.org.uk\)](https://www.rcm.org.uk/signs-of-life-guidance-document.pdf)

<sup>4</sup> [Stillbirths and neonatal and infant mortality | The Nuffield Trust](#)

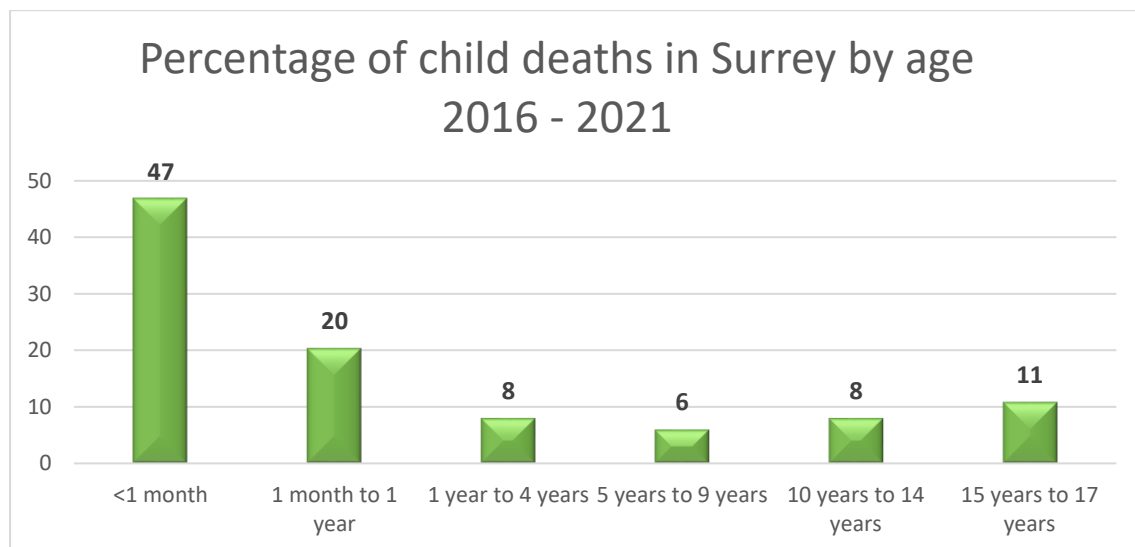
NHS England Saving Babies' Lives Care Bundle vs2 2019<sup>5</sup>, reports that an evaluation of maternity units over a 2 year period preceding 2017, where version one of the care bundle had been implemented, still births fell by a fifth. Saving Babies' Lives is designed to tackle stillbirth and early neonatal death and is a significant driver to deliver the ambition to reduce the number of still births bringing four elements of care together:

- Reducing smoking in pregnancy
- Risk assessment and surveillance for foetal growth restriction
- Raising awareness of reduced foetal movement
- Effective foetal monitoring during labour
- Reducing preterm birth

The number of live births in England and Wales occurring with a gestational age of under 24 weeks has [continued to increase despite the overall decrease in total live births](#). In 2019, live births where gestational age was under 24 weeks increased to 0.15% compared with 0.13% in 2018 and 0.10% in 2010. These increases may contribute to recent variations in the neonatal mortality rate and is something ONS continue to monitor. (ONS 2019)

## 2.1 Current epidemiology in Surrey

**Graph 1: Percentage of child deaths in Surrey by age**



<sup>5</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/07/saving-babies-lives-care-bundle-version-two-v5.pdf>

Chart 1: High Impact Areas in Early Years



## Early Years - High Impact Areas Surrey

Key to trend icons

	Decreasing and getting better		Decreasing and getting worse		Increasing and getting better		Increasing and getting worse		No significant change
	Cannot be calculated (missing data)		Not available (no method)		Not applicable		Too early to say (new indicator)		Too early to say (new method)

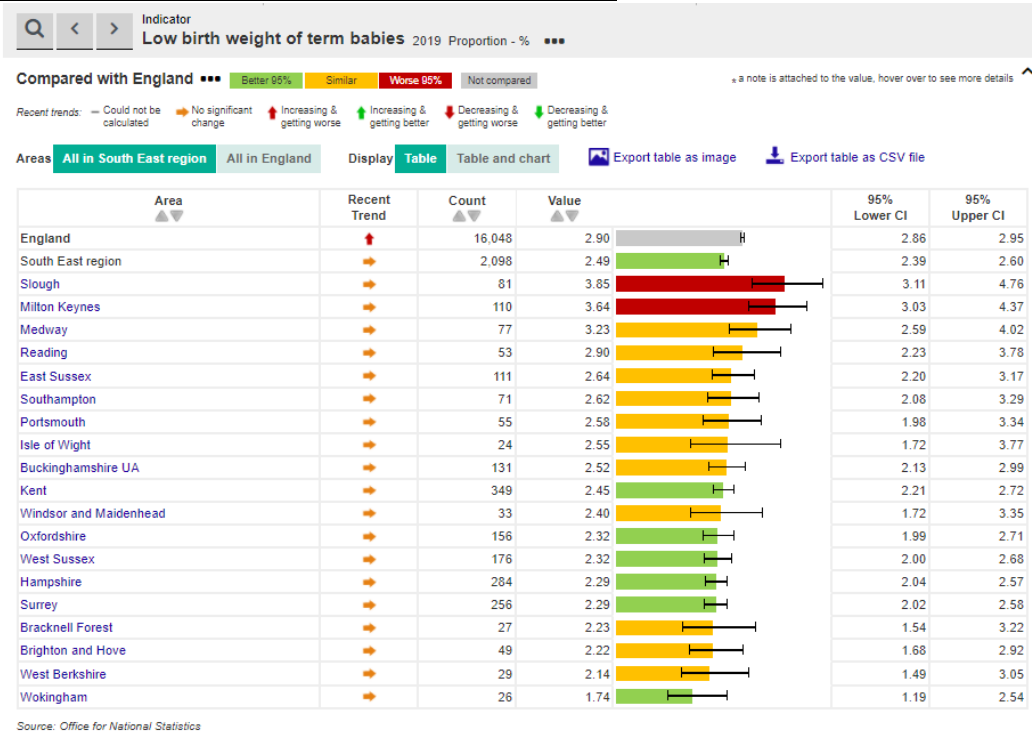
Hover over a trend icon for further details

Hover over current performance for further details about missing data

High impact area	Key performance indicator	Current performance	Current trend
Transition to parenthood and the early weeks	Teenage pregnancy, 15 - 17 years	8.5 per 1,000 (2019)	Decreasing and getting better
	Smoking at time of delivery	6.0% (2020/21)	No significant change
	Smoking at booking	7.3% (2018/19)	Too early to say (new indicator)
	Maternal obesity at booking	16.9% (2018/19)	Too early to say (new indicator)
	Low birth weight of term babies	2.3% (2019)	No significant change
	Infant mortality rate	3.6 per 1,000 (2018 - 20)	No significant trend

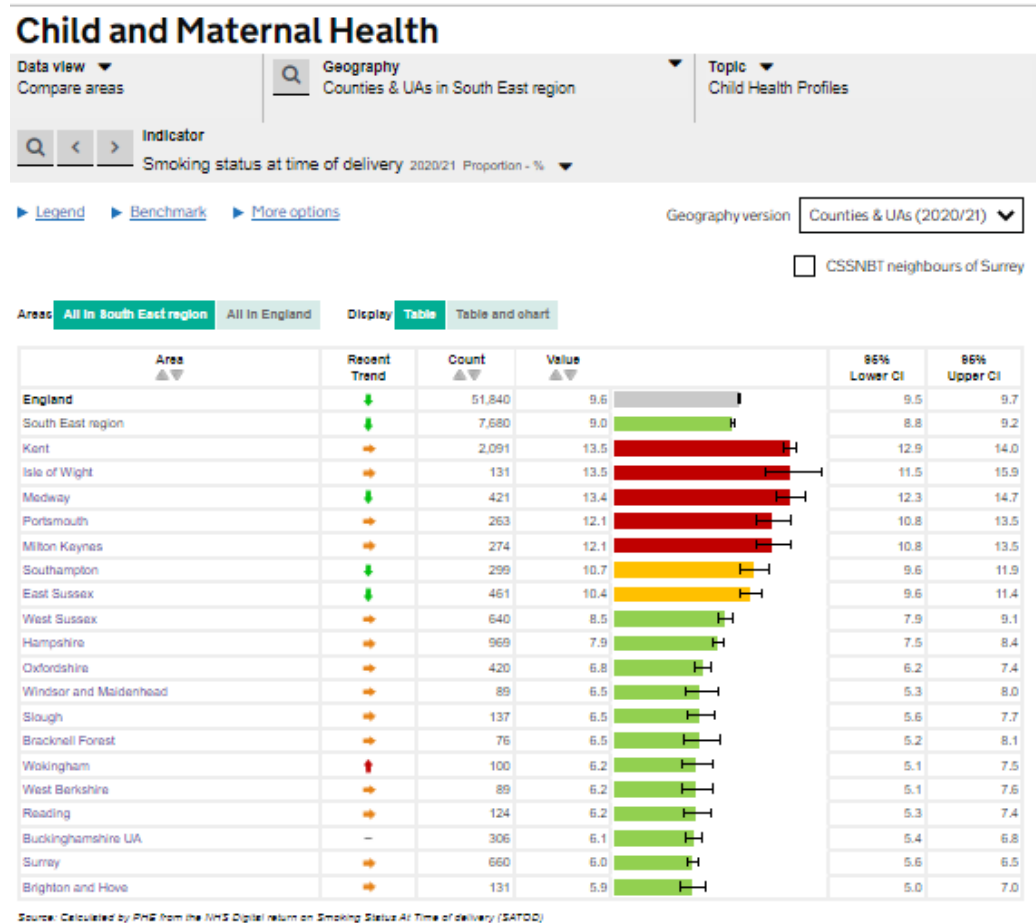


## Chart 2: Low Birth Weight of Term babies



Surrey has fewer low birth weight, term babies than England and the South East regional average. Low birth weight is caused by intrauterine growth restriction, prematurity or both. It contributes to a range of poor health outcomes; for example, it is closely associated with foetal and neonatal mortality and morbidity, inhibited growth and cognitive development, and noncommunicable diseases later in life. Low birth weight infants are about 20 times more likely to die than heavier infants.

### Chart 3: Smoking Status at time of delivery



Surrey has fewer mothers smoking at time of delivery than the England and South East region, although there were still 660 women smoking at time of delivery in Surrey in 2020 - 21.

Smoking during pregnancy is the leading modifiable risk factor for poor birth outcomes, including stillbirth, miscarriage, and pre-term birth. Smoking during pregnancy also increases the risk of children developing several respiratory conditions, attention and hyperactivity difficulties, learning difficulties, problems of the ear, nose and throat, obesity, and diabetes.

In England as of 2020/21, 9.5% of women were smoking at the time of delivery, which equates to around 51,000 babies born to pregnant smokers in England each year. Rates of smoking in pregnancy have a strong social and age gradient with poorer and younger women much more likely to smoke in pregnancy.

In the 2017 Tobacco Control Plan for England, the Government set a target of reducing the prevalence of smoking during pregnancy to less than 6% by 2022, measured as smoking at the time of delivery (SATOD). However, to achieve this ambition smoking in pregnancy rates would need to decline by 3.5 percentage points by 2022, almost as much as the total decline over the last decade.

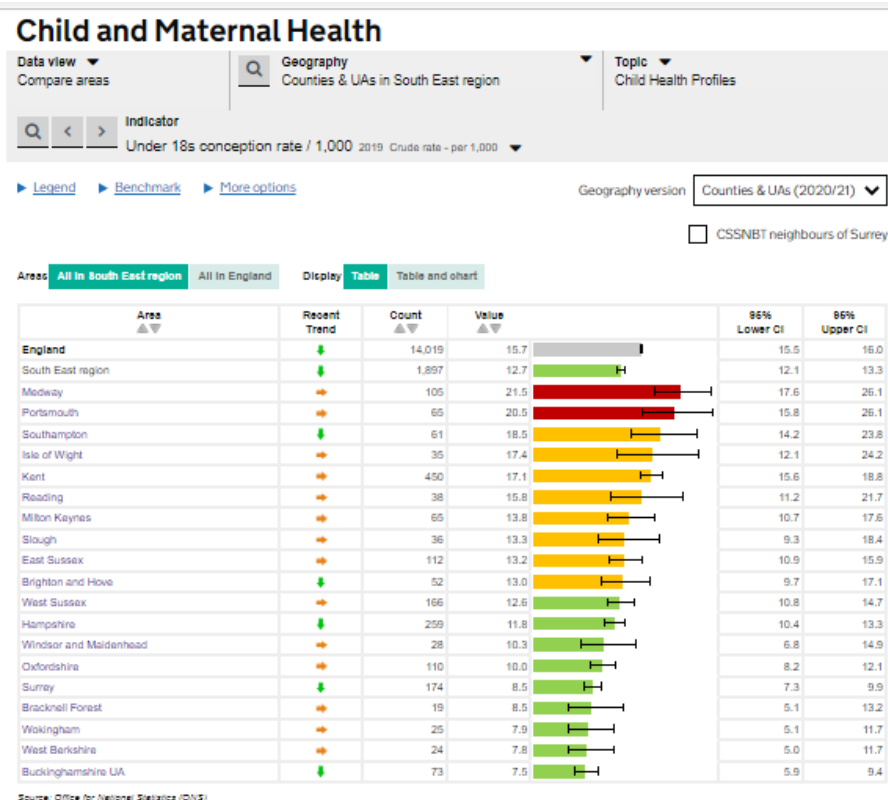
The risks of miscarriage, perinatal mortality (stillbirth and neonatal death) and preterm birth are all linked to smoking during pregnancy<sup>6</sup>

### Chart 4: Impact of smoking on pregnancy

	Maternal smoking	Second-hand smoke exposure
<b>Low birth weight</b>	Average 250g lighter	Average 30-40g lighter
<b>Stillbirth</b>	Double the likelihood	Increased risk
<b>Miscarriage</b>	24-32% more likely	Possible risk
<b>Preterm birth</b>	27% more likely	Increased risk
<b>Heart defects</b>	50% more likely	Increased risk
<b>Sudden infant death</b>	3 times more likely	45% more likely

**Source:** Action on Smoking and Health. Smoking in pregnancy challenge group. Review of the Challenge 2018. July 2018.

### Chart 5: Under 18s conception rate per 1000 2019

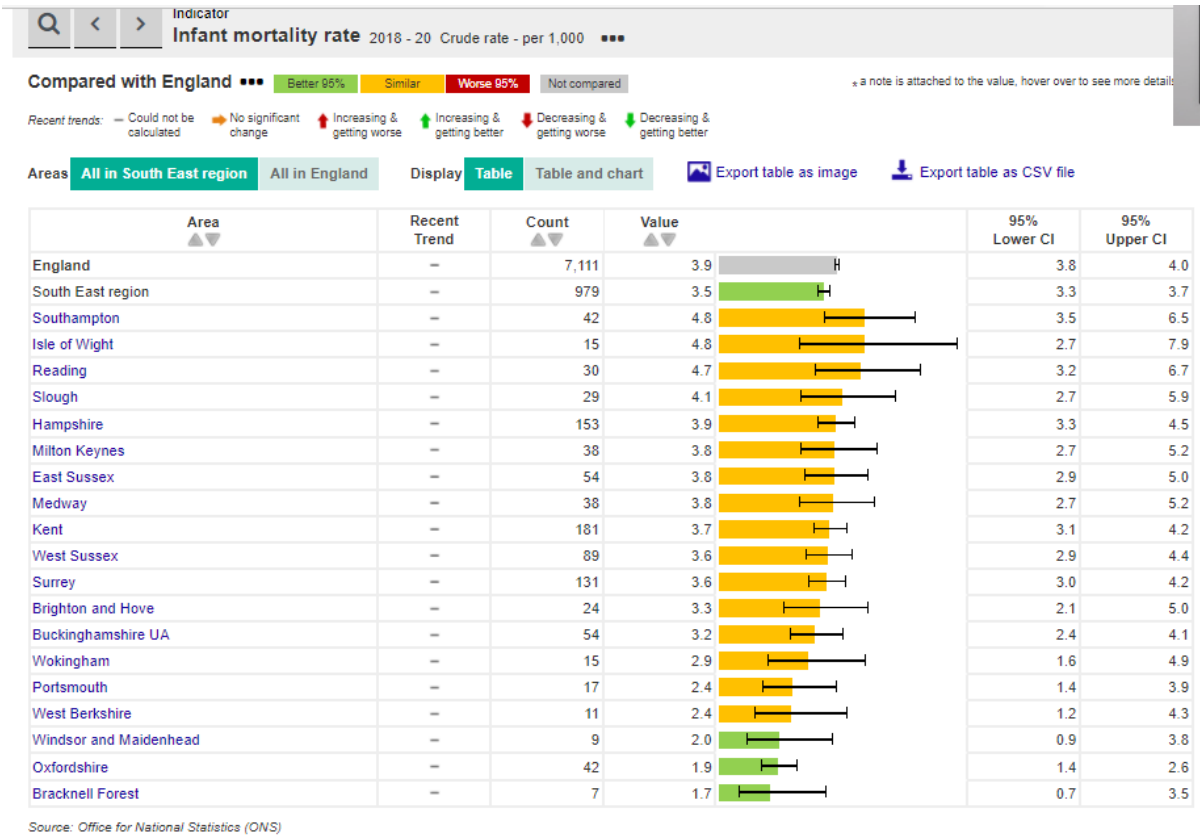


The rate of conceptions in Surrey in under 18s is lower than both the South East Region and the England average. We know in Surrey that we have an older population of mothers, the percentage of mothers aged above 35 in UK is 23% compared to 31.3% in Surrey. The evidence highlights a risk to the baby of stillbirth,

<sup>6</sup> ASH. Smoking, pregnancy and fertility December 2021

miscarriage, chromosomal abnormalities, low birth weight, large for gestational age, preterm delivery for babies born to older mothers.<sup>7</sup>

### Chart 6: Infant mortality rate 2016 -2018



Surrey has an infant mortality rate of 3.6 per 1000 live births (2018-20) whilst this shows no significant change Surrey’s rates are higher than the majority of our statistical neighbours: West Berkshire 2.4 per 1000 live births, Oxfordshire 1.9 per 1000 live births and Windsor and Maidenhead 2.0 per 1000 live births, Hampshire 3.9%.

### Chart 7: Proportion of new birth visits completed within 14 days 2018-2019

<sup>7</sup> [patient-information-leaflet-raised-maternal-age-in-pregnancy-rde-19-089-001.pdf](http://patient-information-leaflet-raised-maternal-age-in-pregnancy-rde-19-089-001.pdf) (rdehospital.nhs.uk)

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

Proportion - %

[Export table as image](#) [Export table as CSV file](#)

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
<b>England</b>	–	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 8: 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
<b>England</b>	–	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 7 and 8 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 practices.

## **Vaccination coverage in mothers**

Vaccines against Flu, Pertussis and COVID-19 are safe and recommended for pregnant individuals. Preventing these serious illnesses and their complications by vaccination has been shown to protect babies from becoming severely unwell in the first few months of life.

Monthly pertussis vaccination coverage (%) in pregnant women by STP: England, July to September 2021 for Frimley Health and Care ICS was 62.2%, 59.1% and 62.1% for each of the months and for Surrey Heartlands Health and Care Partnership was 74.5% 72.7% and 73.5% compared to the England average of 65.4% 64.9% and 64.5%.

## **Antenatal Screening:**

NICE Guidance on antenatal care<sup>8</sup> states that at the first antenatal (booking) appointment the following screening programmes should be offered:

- NHS infectious diseases in pregnancy screening programme (HIV, syphilis and hepatitis B)
- NHS sickle cell and thalassaemia screening programme
- NHS foetal anomaly screening programme.

The recent Antenatal Screening Standards Report<sup>9</sup> identifies that some Surrey Acute Trusts haven't met the thresholds in some areas of antenatal screening. Including the timely communication of positive results for hepatitis B, the timely communication of results for syphilis, the timely reporting of prenatal diagnosis (PND) results to parents for sickle cell and thalassaemia and the turnaround time for sickle cell testing.

By meeting thresholds necessary interventions can be discussed and parents have maximised time to make an informed choice, by providing information about living with and supporting a child with sickle cell disease or thalassaemia and termination of pregnancy as early as possible.

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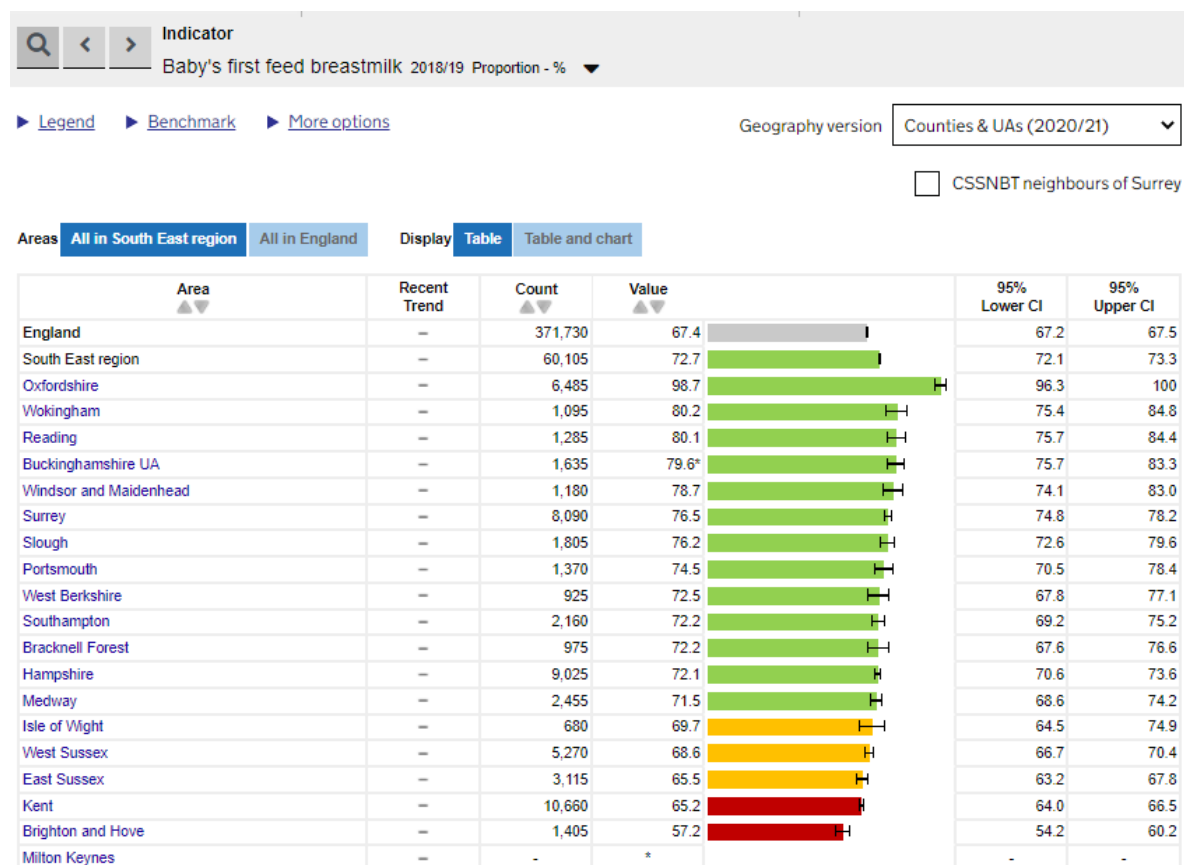
<sup>8</sup> <https://www.nice.org.uk/guidance/ng201/chapter/Recommendations#organisation-and-delivery-of-antenatal-care>

<sup>9</sup> [Antenatal screening standards: data report 1 April 2019 to 31 March 2020 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/87444/antenatal-screening-standards-data-report-1-april-2019-to-31-march-2020.pdf)

## Breastfeeding:

There is extensive published evidence on the benefits of breastfeeding on improving outcomes for both babies and mothers.<sup>10</sup> Unicef Baby Friendly's work to support breastfeeding improves health and cuts costs in every country worldwide. Exclusive breastfeeding is recommended by the WHO for babies until six months' old and thereafter with other foods for two years and beyond. Harvesting of colostrum may also be appropriate in some cases.

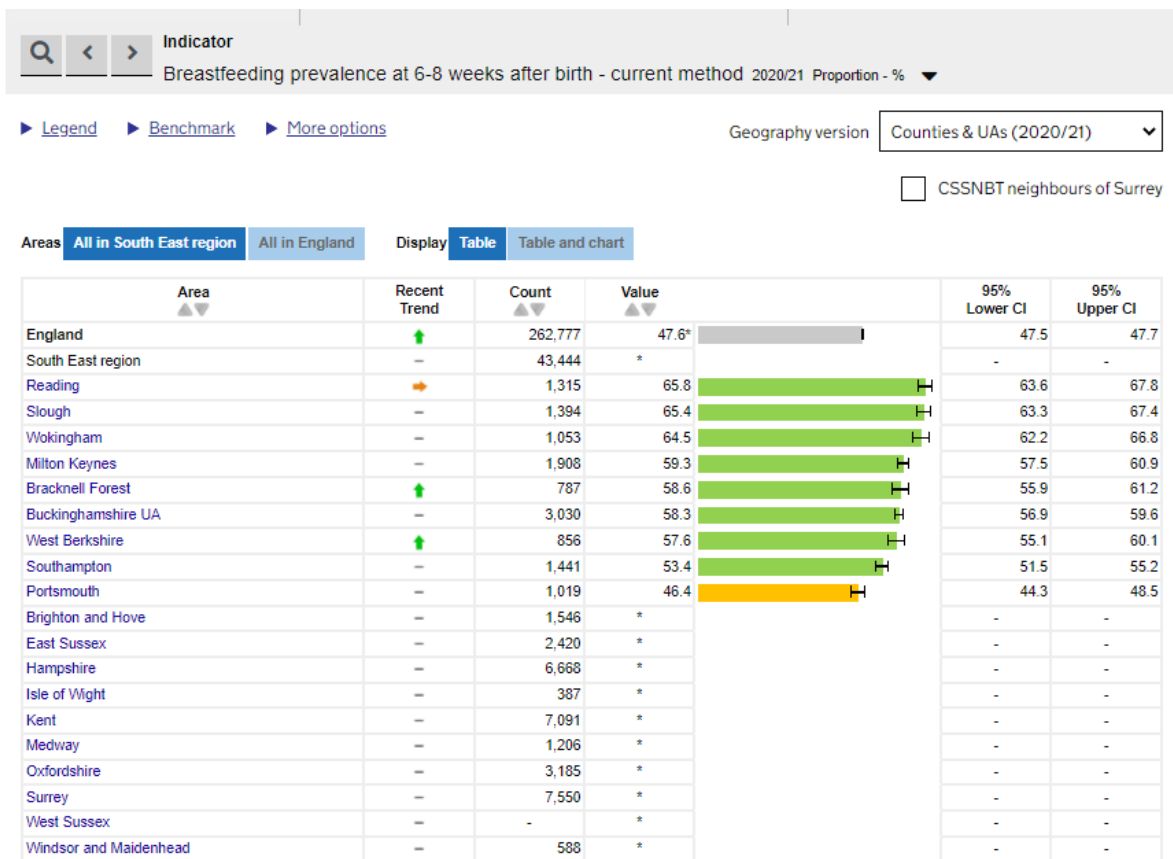
### Chart 9 – Percentage Baby's first feed breastmilk 2018-19



Surrey is performing better than the England and South East Region for percentage first feed breastmilk.

<sup>10</sup> [Breastfeeding resources - Baby Friendly Initiative \(unicef.org.uk\)](https://www.unicef.org/uk/breastfeeding-resources)

## Chart 10 – Breastfeeding prevalence at 6-8 weeks after birth 2020-21



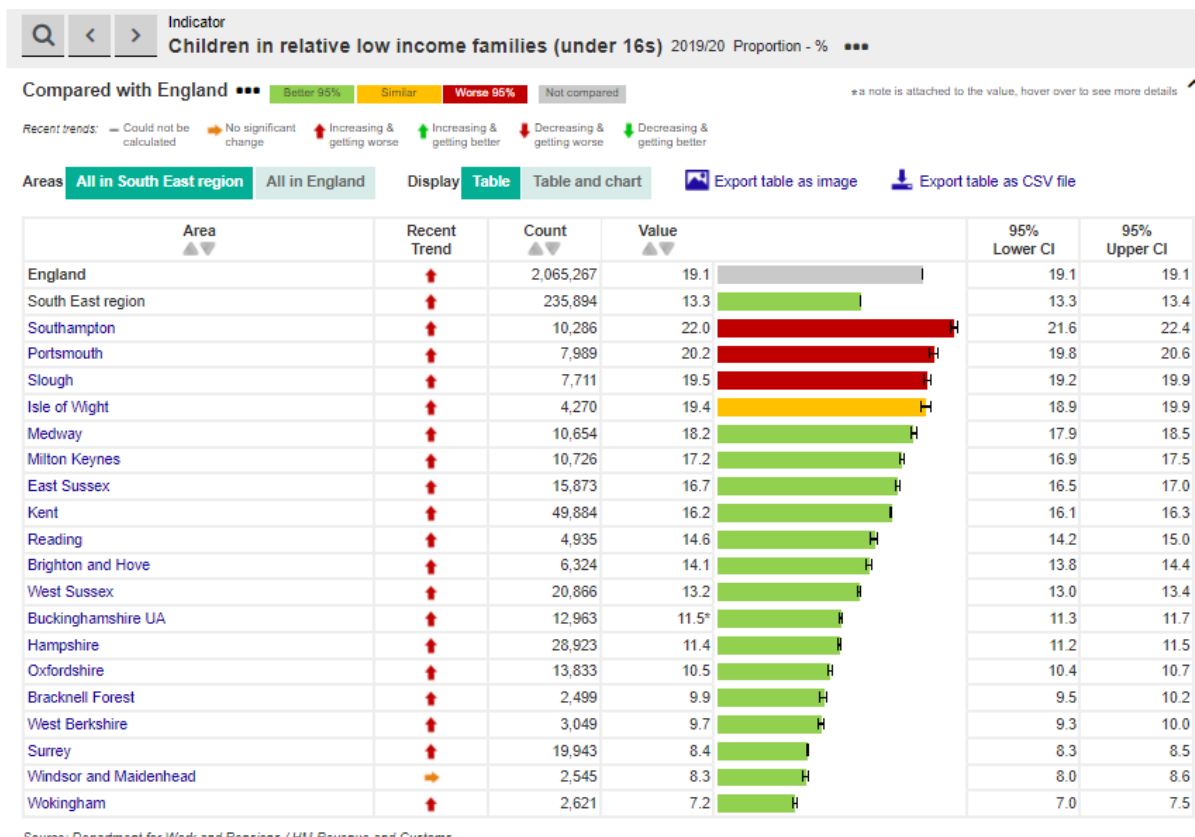
Source: PHE's interim reporting of health visiting metrics

Breastfeeding prevalence at 6-8 weeks after birth is not available for Surrey, this data collection and reporting issue has been on-going for a number of years and in order to better understand the picture locally it is important that this data is published.



## Deprivation:

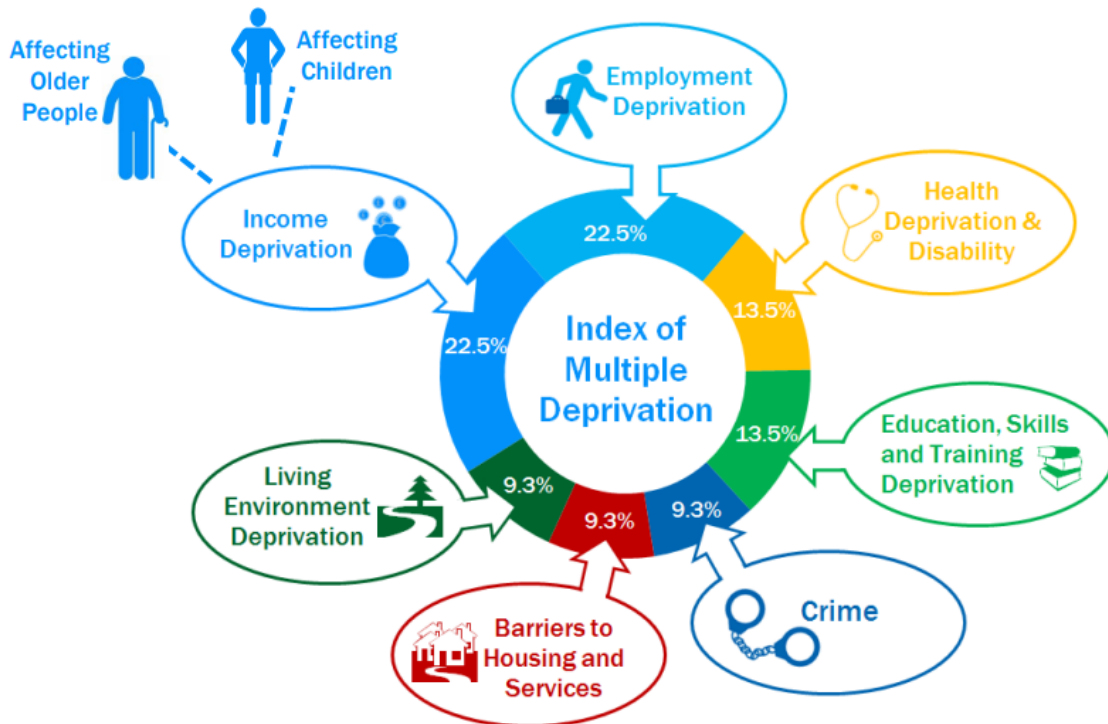
### Chart 11 – Children in relative low income families (under 16s) 2019-20



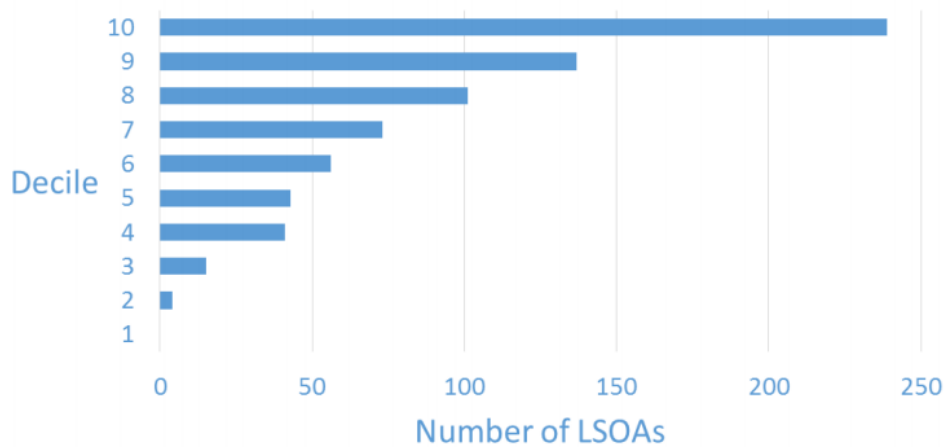
The Indices of Deprivation are a unique measure of relative deprivation at a small local area level (Lower-layer Super Output Areas) across England and have been produced by the Ministry of Housing Communities and Local Government and its predecessors in a similar way since 2000. The Indices of Deprivation 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). Each LSOA is grouped into a decile(1-10) depending its rank, the lowest 10% of ranked LSOAs will be grouped in decile1, being the most deprived and LSOAs in decile 10 fall within the least deprived 10% of LSOAs nationally.

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

# How is it constructed?



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.

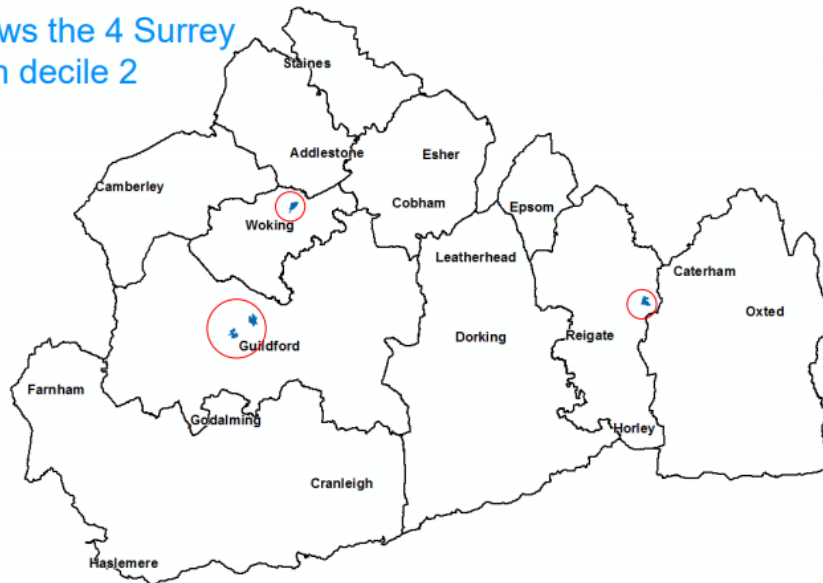


**Chart 12: LSOAs by IMD Decile in Surrey**

### Chart 13: LSOA in decile 2 in Surrey

Where are the most deprived areas in Surrey?

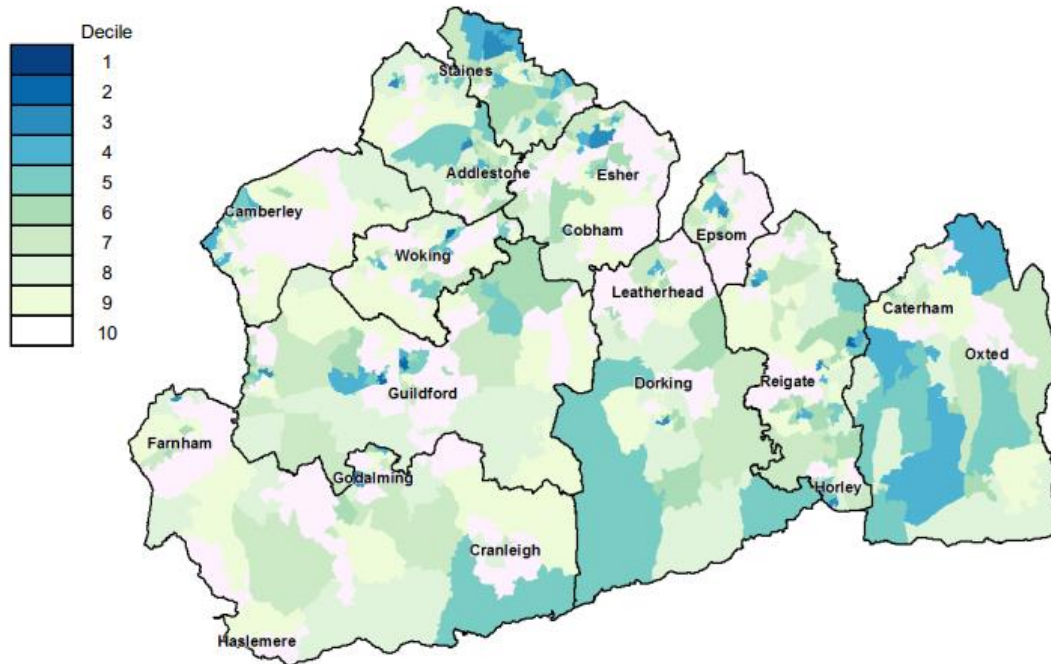
Map shows the 4 Surrey LSOAs in decile 2



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 14: LSOAs in Surrey

How does Surrey look overall?



Income Deprivation Affecting Children Index (IDACI) rankings for Surrey wards, calculated by averaging the LSOA scores in each larger area after they have been population weighted, enable a comparable local picture of deprivation impacting children. The table below shows the percentage of each CCG's wards (pre 2020) that are in the lowest 20% of IDACI.

**Table 1 - Percentage of each CCG's wards (pre 2020) that are in the lowest 20% of IDACI.**

CCG Pre 2020	% Wards rankings Lowest 20% of IDACI
North West Surrey	27%
East Surrey	27%
Surrey Downs	13%
Guildford and Waverley	11%
Surrey Heath	20%
North East Hants and Farnham	20%

## Pollution

There are areas in Surrey that have a high level of air pollution, which is higher than the governments recommended level for certain pollutants. We know this because local authorities, like Surrey County Council and the District and Borough Councils, have a duty to monitor the air quality and to check if it within the governments recommended limit. The pollutants that are monitored are large particulate matter (PM10) and nitrogen dioxide. The source of both these pollutants in Surrey is road traffic.

The areas that do exceed this level are known as an [Air Quality Management Area \(AQMA\)](#) - there are 26 AQMAs in Surrey. Once an AQMA is declared, an Air Quality Action Plan has to be produced. The plan is produced in consultation with Surrey County Council and the highways authority, and will identify steps which can be implemented to try and improve the Air Quality within the AQMA.<sup>11</sup>

A number of research projects have investigated the links between maternal exposure to particulate matter (PM) and foetal growth, resulting in adverse birth

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<sup>11</sup> [Air Quality - Healthy Surrey](#)

outcomes, including infant death, stillbirth, preterm birth (PTB), term low birth weight (TLBW) and small for gestational age (SGA). This is of public health importance as adverse birth outcomes have been consistently associated with increased risk of chronic conditions in later adulthood such as obesity, diabetes, and cardiovascular diseases (CVDs).

Emerging evidence suggest that there is a link between poor outcomes for babies and pollution. “Ambient and household PM<sub>2.5</sub> were associated with reduced birth weight and gestational age, which are, in turn, associated with neonatal and infant mortality, particularly in low- and middle-income countries.”<sup>12</sup> It was not possible to map outcomes for neonates against pollution in Surrey, but this piece of work should take place when data is available in order to understand the impact of pollution locally on outcomes for babies and children.

Implementation of air quality management and other approaches to reduce PM exposure may lead to large reductions in the global incidence of TLBW and PTB infants and the associated disease burden. Mitigation measures even in low-exposure regions, such as the UK, will likely manifest in significant improvement in these outcomes because the increase in risk is steeper at lower than in higher exposures.<sup>13</sup>

## 2.2 Current Policy and safety 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. With the publication of ‘The First 1000 Days Strategic Plan for Surrey 2020 – 2025’<sup>14</sup>

Public Health England’s *Best Start in Life*<sup>5</sup> 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:

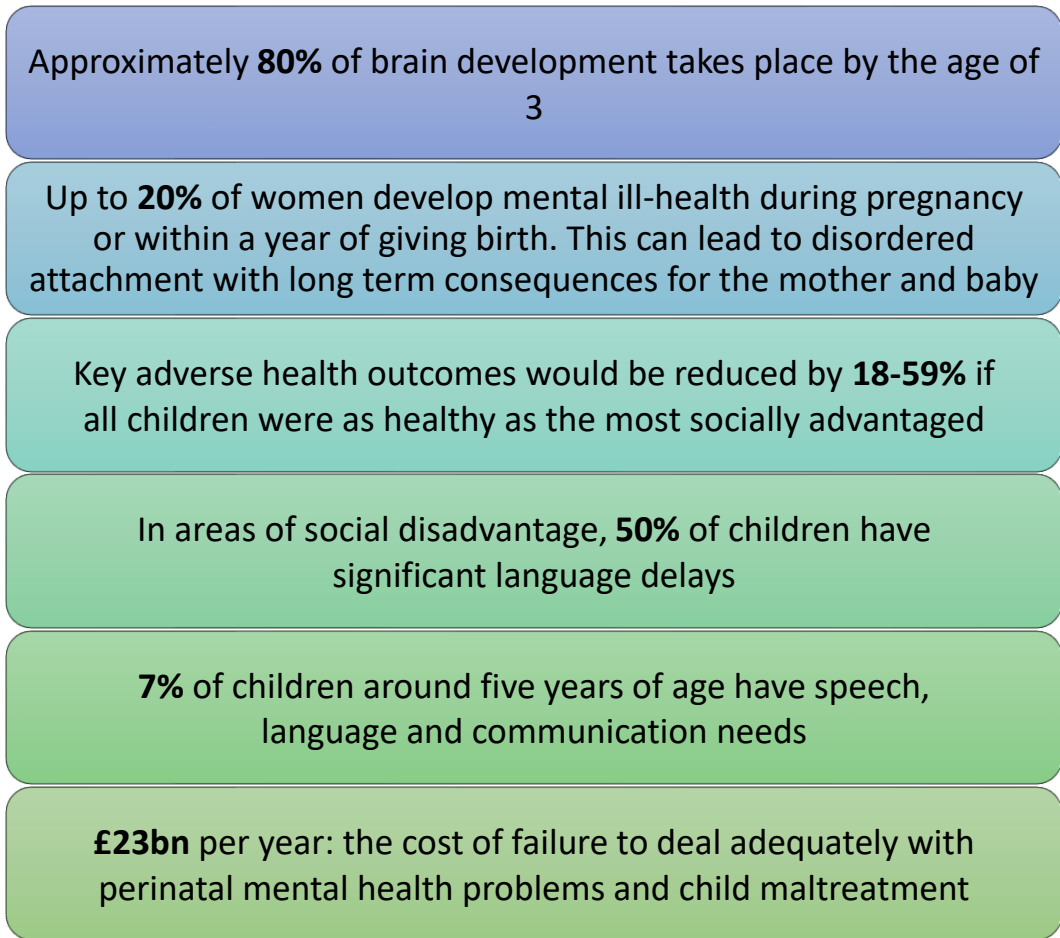
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<sup>12</sup> [Ambient and household PM2.5 pollution and adverse perinatal outcomes: A meta-regression and analysis of attributable global burden for 204 countries and territories \(plos.org\)](#)

<sup>13</sup> [Ambient and household PM2.5 pollution and adverse perinatal outcomes: A meta-regression and analysis of attributable global burden for 204 countries and territories \(plos.org\)](#)

<sup>14</sup> [210423-First\\_1000\\_Days\\_Strategy\\_v2\\_0\\_SyHeartlandsICS.pdf \(surreyheartlands.uk\)](#)

**Chart 15: Key priorities identified in PHE 'Best Start in Life'**



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](http://www.healthysurrey.org.uk/about/strategy)

The Maternity Transformation Programme<sup>15</sup> is also supporting the roll out of continuity of carer so that by 2021 most women will be offered the opportunity to have the same midwife caring for them throughout their pregnancy birth and postnatally. Evidence shows that the continuity models improve safety and outcomes; women who receive continuity of care are 16% less likely to lose their baby, 19% less likely to lose their baby before 24 weeks and 24% less likely to experience pre term birth.

Prevention of preterm birth is now a national priority. National guidance is in place to enable prevention strategies focusing on importance of good communication between professionals and parents, strategies to ensure high quality active and or palliative care as appropriate and interventions to optimise outcomes for babies born too soon.

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<sup>15</sup> <https://www.england.nhs.uk/mat-transformation/>

In addition to this early separation affects mother-baby bonding, reduces the mother's affective response and has a negative impact on maternal behaviour. Studies demonstrate that mothers who were separated from their babies in the early postnatal period, show lower affective responses and less maternal behaviour in response to babies' cues, which can be seen from as early as 4 days to up to the age of 1 year, when compared to mothers who were never separated from their babies.

A post mortem examination is the single most useful investigation in providing information about cause of death, but research shows that a significant number of health professionals underestimate the value of a post mortem and others find it difficult to broach with parents.

One important way to increase post mortem rates is to improve the quality of the consent process. The Sands Post Mortem Consent Package<sup>16</sup> improves the consent process for both bereaved parents and professionals.

The package contains:

- A parent friendly consent form, endorsed by the Human Tissue Authority and supported by the relevant professional organisations
  - Guidance for health professionals who discuss post mortem consent with parents
  - A booklet to be given to parents whose baby has died when the option of a post mortem is first mentioned
  - Guidance for hospital, trust or health board managers who are deciding whether to adopt the Sands post mortem consent form
- 
- Learning outcomes for training health professionals who will seek consent.

All these documents can be downloaded from the [Human Tissue Authority website](#).

Patient harm due to unsafe care is a large and growing global public health challenge and is one of the leading causes of death and disability worldwide. Most of this patient harm is avoidable. As countries strive to achieve universal health coverage and the Sustainable Development Goals, the beneficial effects of improved access to health services can be undermined by unsafe care. Patient safety incidents can cause death and disability, and suffering for victims and their families. The financial and economic costs of safety lapses are high.

There is often reduced public confidence and trust in local health systems when such incidents are publicised. Health workers involved in serious incidents involving death or serious harm to a patient can also suffer lasting psychological harm and deep-seated feelings of guilt and self-criticism.

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<sup>16</sup> <https://www.sands.org.uk/professionals/sands-post-mortem-consent-package#:~:text=The%20Sands%20Post%20Mortem%20Consent,by%20the%20relevant%20professional%20organisations>



In England the NHS Patient Safety Strategy (2019)<sup>17</sup> tackles patient harm defining how the NHS will continuously improve patient safety, building on the foundations of a safer culture and safer systems. It includes the Patient Safety Incident Response Framework (PSIRF), the latest version will be introduced in 2022 outlining how providers should respond to patient safety incidents and how and when a patient safety investigation should be conducted.

The MBRRACE-UK programme of work involves continuing the national Confidential Enquiry into Maternal Deaths (CEMD) and national surveillance of late foetal losses, stillbirths and infant deaths.<sup>18</sup> In addition the programme includes a series of themed topic-based confidential clinical reviews of serious maternal and infant morbidity, and stillbirths. As near-miss events and cases of serious morbidity are more numerous than deaths, lessons can be learned quickly and improvements in care can be instituted more rapidly following their investigation.

Multiple pregnancy is associated with an increased risk of maternal and perinatal morbidity and mortality. The MBRRACE-UK perinatal surveillance report 2020<sup>19</sup> highlighted that the increased risk of mortality associated with twins compared to singletons is almost double for stillbirths and over threefold for neonatal deaths and that over the period 2013-17 rates of both stillbirth and neonatal mortality for twins had reduced

Three important factors are likely to have had a significant influence in reducing perinatal loss for twin pregnancies:

- (i) invasive interventions for pre-morbid monochorionic complications;
- (ii) advancements in neonatal care; and
- (iii) improved antenatal care pathways.

Several professional bodies and guidelines have made important contributions to the latter, including the first National Institute for Health and Care Excellence (NICE) recommendations for antenatal care for twin and triplet pregnancies<sup>20</sup> and in 2013 the publication of eight quality standards for the clinical care for multiple pregnancies<sup>21</sup>.

The Recent Ockenden Report<sup>22</sup> reviewing maternity services at Shrewsbury and Telford Hospital NHS Trust identified the need for improvements to patient safety recommending that neighbouring trusts and their maternity services work together to ensure that local investigations into all serious incidents declared within their maternity services are subject to external oversight by trusts working together, to ensure effective learning using a system wide approach. As well as ensuring that maternity services listen to the women and their families, and that their voices heard.

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<sup>17</sup> <https://www.england.nhs.uk/patient-safety/the-nhs-patient-safety-strategy/>

<sup>18</sup> [Reports | NPEU > MBRRACE-UK \(ox.ac.uk\)](#)

<sup>19</sup> [https://www.npeu.ox.ac.uk/assets/downloads/mbrpace-uk/reports/perinatal-report-2020-twins/MBRRACE-UK\\_Twin\\_Pregnancies\\_Confidential\\_Enquiry.pdf](https://www.npeu.ox.ac.uk/assets/downloads/mbrpace-uk/reports/perinatal-report-2020-twins/MBRRACE-UK_Twin_Pregnancies_Confidential_Enquiry.pdf)

<sup>20</sup> <https://www.nice.org.uk/guidance/ng137>

<sup>21</sup> <https://www.nice.org.uk/guidance/qs46/chapter/quality-statement-8-preparation-for-birth>

<sup>22</sup> [OCKENDEN REPORT - FINAL \(ockendenmaternityreview.org.uk\)](#)

The Healthcare Safety Investigation Branch (HSIB) Maternity Programme year in review 2020<sup>23</sup> identified the most frequently recurring themes, which were

- effective escalation of safety concerns about mothers and babies
- clinical oversight
- clinical assessment and monitoring. In addition, investigations highlighted:
- how the use of clinical guidelines influence the care provided
- the impact of pathways of care crossing healthcare boundaries on the care provided to mothers and babies.

In Surrey in the past 5 years there have been 7 HSIB reports.

Surrey has in place a joint Maternity & Neonatal Serious Incident Review and Closure Panel which operates and acts as a formal single mechanism for assuring that Serious Incidents (SIs) are properly investigated, recommendations and actions are achievable, measurable and implemented in a timely manner and the likelihood of repeated SIs is minimised by ensuring that lessons learnt are disseminated and acted upon throughout Surrey Heartlands and to partner agencies where relevant.

Many potentially modifiable risk factors which influence pregnancy outcomes are present before conception. This means that prenatal care is often given too late to change the outcome of the pregnancy. The UK Health Security Agency paper relating to making the case for preconception care<sup>24</sup> sets out the need for a whole system approach to preconception care before a first pregnancy. The NHS Long Term Plan (2019)<sup>25</sup> sets out a number of targets with regard to pregnant women and their partners who smoke, these include:

- Supporting people in contact with NHS services to quit based on a proven model implemented in Canada and Manchester. By 2023/24, all people admitted to hospital who smoke will be offered NHS-funded tobacco treatment services.
- The model will also be adapted for expectant mothers, and their partners, with a new smoke-free pregnancy pathway including focused sessions and treatments.

## **NHS Charging for Maternity Care**

Pregnant women who are not ordinarily resident in the UK are sometimes billed for NHS maternity care. This can provide a financial barrier to accessing treatment which may ultimately impact on the health of mother and child.

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<sup>23</sup> [https://hsib-kqcco125-media.s3.amazonaws.com/assets/documents/HSIB\\_Maternity\\_programme\\_year\\_in\\_review\\_2020-21\\_Report\\_V29.pdf](https://hsib-kqcco125-media.s3.amazonaws.com/assets/documents/HSIB_Maternity_programme_year_in_review_2020-21_Report_V29.pdf)

<sup>24</sup> [Making the case for preconception care \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/82444/making-the-case-for-preconception-care.pdf)

<sup>25</sup> [NHS Long Term Plan » Overview and summary](https://www.nhs.uk/longtermplan/overview-and-summary/)

National data shows that neonatal deaths represent the largest proportion of child deaths in England and removing barriers to maternity care might help save and improve lives in the future.

<sup>5</sup> 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>

## **Cuddle Cots**

The benefits to bereaved parents being able to take their child home and care for them, make lasting memories and express their love to their baby in the tangible ways that parents do naturally, such as examining their body, admiring adorable features, noticing family resemblances, bathing, dressing their little one, as they would have expected to do, are enormous and include:

- Increased memory making and bonding experience of parents
- Reduced Postnatal Depression and Post Traumatic Stress
- Reduced need for early counselling
- Allowing friends and family to meet the baby, which may help the grieving process and reduce social isolation and surround themselves with support

However when at home in a warm room a baby's condition can deteriorate quickly, so keeping the baby cool is essential and can be achieved with the use of a cuddle cot. This is a cooling pad, which can be inserted into a Moses basket, connected to a specially insulated hose and is quietly cooled by a cooling unit. It is small, light and quiet, making it easily portable and is simple to use with minimal instruction. The Cuddle Cot cools to a suitable temperature, keeping baby cool and slowing down the natural changes, without feeling too cold to touch.

Parents will be supported to set up and use the Cuddle Cot at home for a 24 hr period and supported with last goodbyes such as bathing /washing, nappy change, dressing and photographs or simply just staying close and holding their little one. Families are able to take their baby out of the cot for cuddles, keeping them close as they shower them with love and create those special memories they can cherish forever. It may also be an opportunity for other family members, such as older siblings or grandparents, to spend time together too.

## **3. Methods**

### **3.1 Case definition**

Infant deaths were included as cases in the study if they met all of the following criteria:

- Death of an infant > 22+6 weeks gestation
- Normal residence Surrey
- Post neonatal deaths where the baby dies in a neonatal unit after 28 days but has never left hospital following birth

- Pregnancies which involved terminations of pregnancy (including foetal reductions) and stillbirths were excluded.

Of our 141 cases in Surrey there have been 36 neonatal deaths where the gestation has been less than 22+6 weeks. This represents 26% of our neonatal deaths. Hence a decision has been made to include a high-level data set relating to these cases to identify key themes that can added to the overall learning from this thematic review. See section 4.3 for graphs on these babies.

### 3.2 Data sources

Information on the babies 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 neonatal deaths, 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 neonatal mortality
- Evidence of effective interventions to support the prevention of neonatal mortality

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 for original research via Healthcare Databases Advanced Search using the CINAHL, Medline, EMBASE and EMCARE databases.

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 neonatal mortality. 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)<sup>26</sup> document informed the search process and approach taken.

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<sup>26</sup> 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, acute hospitals, public health, child death review team, 0-19 team.

## 4 Findings

### Data limitations:















Over the past 2 years the SCDR Team have developed a comprehensive database to ensure that known risk factors, over and above those captured on the National Child Mortality Database (NCMD), are captured. The high percentages of 'not known/stated' in the presented data can largely be attributed to data pre 2020.

### 4.1 Babies included in this review

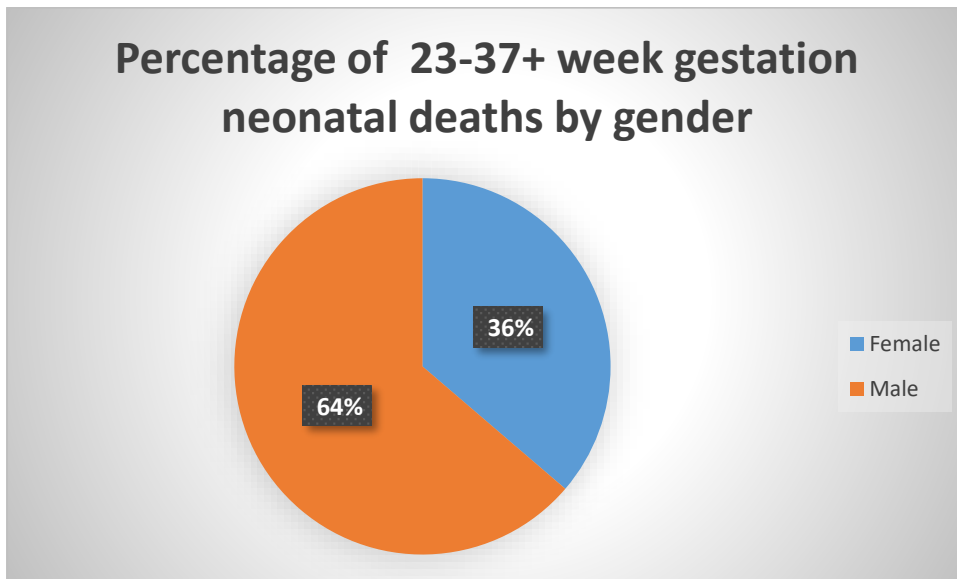
Between 1st April 2016 and 31st March 2021, 105 babies met the case definition for the thematic review of neonatal mortality.

## 4.2 Summary of babies

### Key Findings of Surrey Neonatal Mortality Review 1<sup>st</sup> April 2016- 31<sup>st</sup> March 2021, where data was known

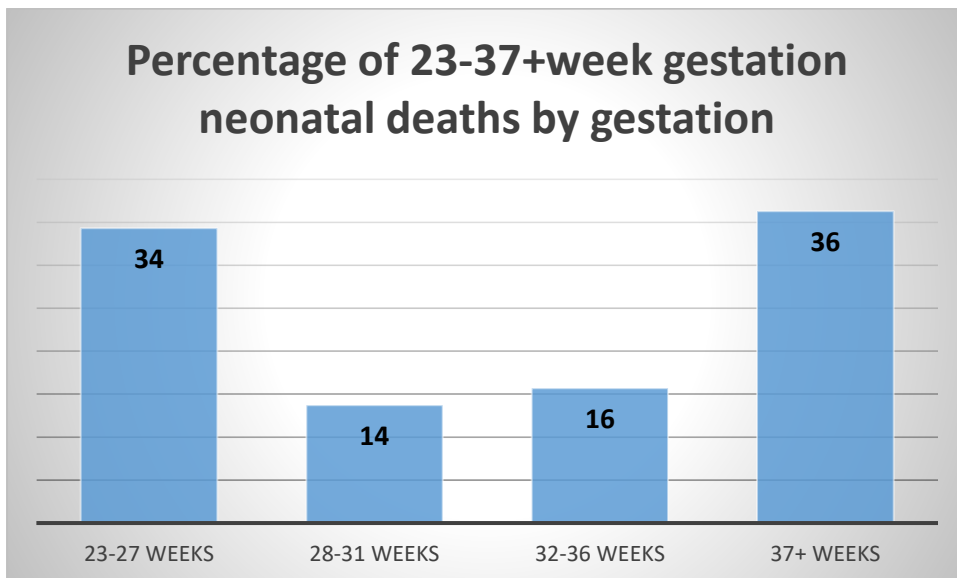
Key Findings of 141 Neonatal Mortality cases	Findings 23-37+ Weeks Gestation	Findings pre 22+6 Weeks Gestation
 Male gender	<b>63%</b>	<b>50%</b>
 Placental Histology	<b>67%</b>	<b>37%</b>
 BMI (overweight/obese/severely obese)	<b>53%</b>	<b>82%</b>
 Post-mortem	<b>49%</b>	<b>28%</b>
 Maternal age 35+	<b>40%</b>	<b>40%</b>
 Resident in poorest third of Surrey Wards	<b>34%</b>	<b>42%</b>
 Maternal mental health issues at time of booking or previously	<b>29%</b>	<b>30%</b>
 Smoking in household and or antenatally	<b>28%</b>	<b>12%</b>
 Multiple pregnancies	<b>20%</b>	<b>27%</b>
 Previously experienced domestic abuse or disclosed at booking	<b>20%</b>	<b>21%</b>
 Transfer ex utero	<b>18%</b>	<b>N/A</b>
 Ethnicity Black or Asian	<b>8%</b>	<b>20%</b> *Asian
 Ethnicity white other	<b>6%</b>	<b>20%</b>
 Alcohol misuse maternally or in household	<b>7%</b>	<b>11%</b>

**Chart 16: Percentage of 23-37+ week gestation neonatal deaths by gender**



Infant mortality is higher in boys than girls in most parts of the world this data is replicated in Surrey.

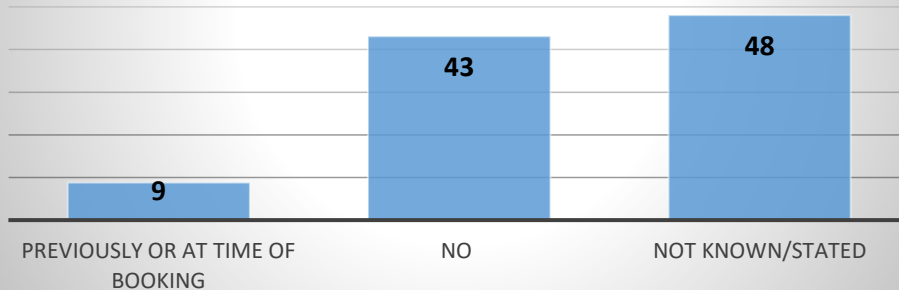
**Chart 17 – Percentage of 23-37+ week gestation neonatal deaths by gestation**



63% (22/35) of the 23-27 week deaths were between 23+0-24+6 gestation

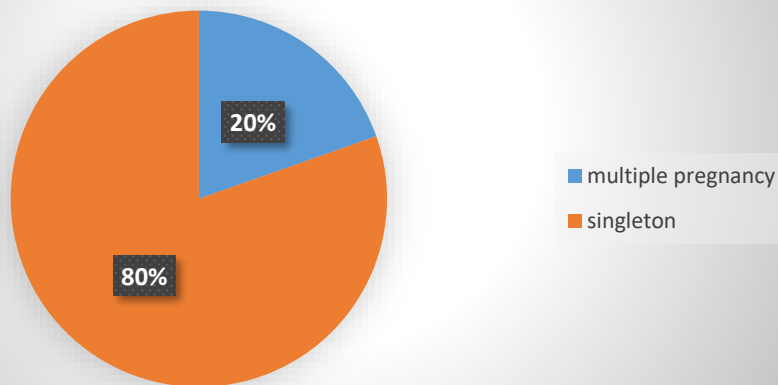
**Chart 18 – Percentage of 23-37+ week gestation neonatal deaths where domestic abuse was a risk factor**

### Percentage of 23-37+week gestation neonatal deaths where domestic abuse was a risk factor



**Chart 19 - Percentage of 23-37+ week gestation neonatal deaths by pregnancy type**

### Percentage of 23-37+week gestation neonatal deaths by pregnancy type

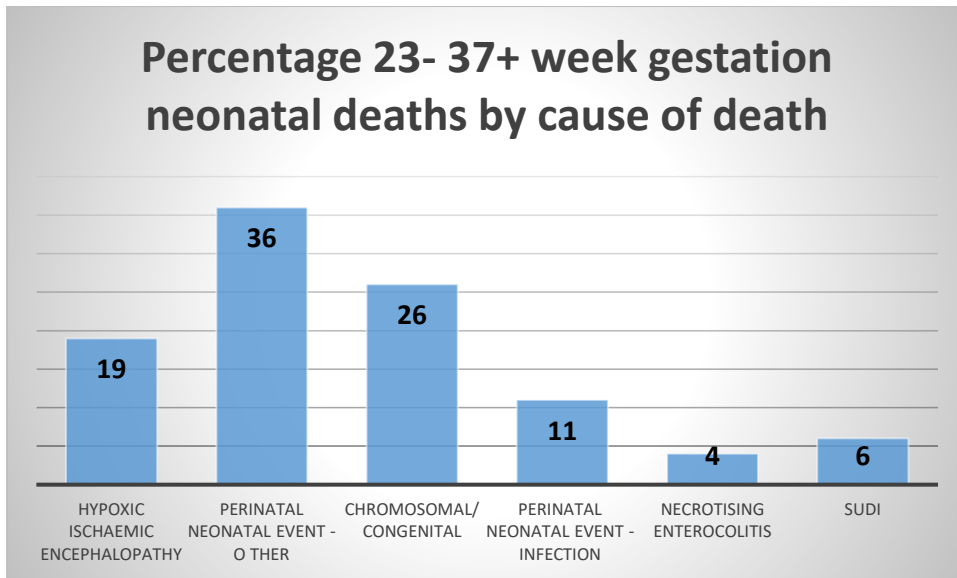


Multiple pregnancies are, compared to singletons, twice as likely to be stillborn and are 4.3 times more likely to result in neonatal death compared with singleton pregnancies. Twins and triplets have a higher risk of being born prematurely (before 37 weeks) and having a low birthweight of under 2.5kg (5.5lb). Most twins and triplets are born prematurely. Multiple pregnancies represent 1.56% of the total number of births, so our data mirrors national data, where babies born as a result of a multiple pregnancy are over-represented in this review at 20% of all deaths.

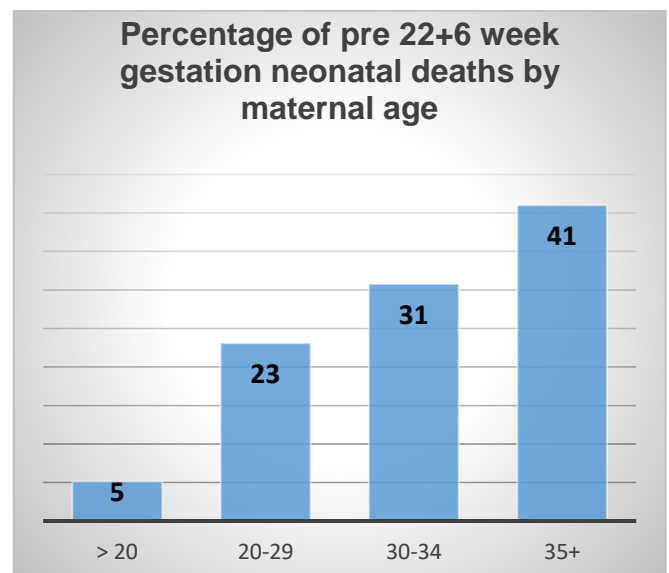
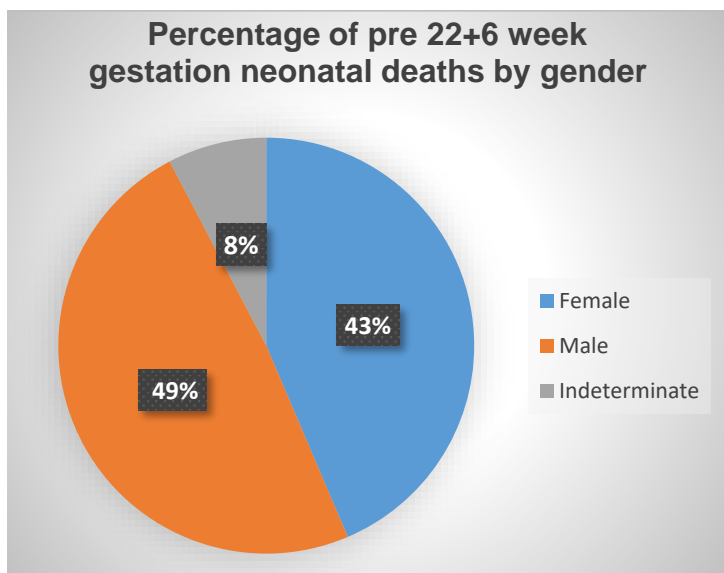


Around 6 in 10 twins are born before 37 weeks. Almost 8 in 10 triplets are born before 35 weeks.

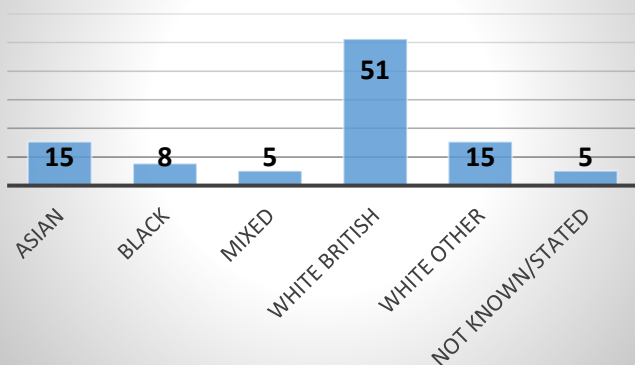
**Chart 20 - Percentage 23 – 37+ week gestation neonatal deaths by cause of death**



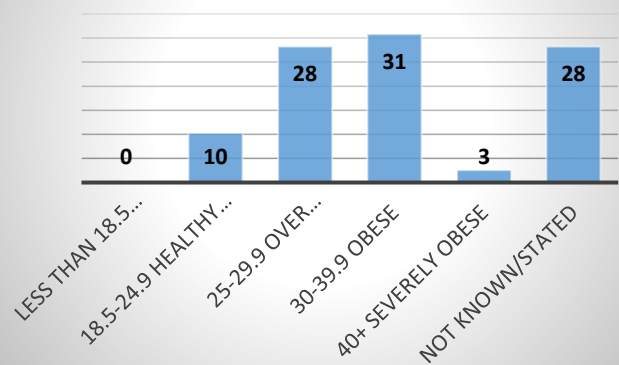
**4.3 Graphs to show findings Pre 22+6 week gestation:**



**Percentage of pre 22+6 week gestation neonatal deaths by ethnicity**

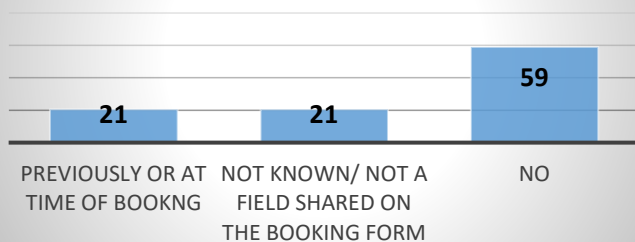


**Percentage of pre 22+6 week gestation neonatal deaths by maternal BMI**

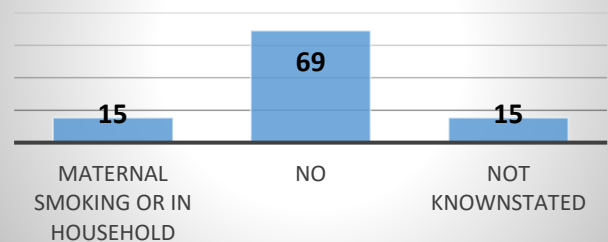


86% (24/28) of mothers whose BMI was known were in a category of overweight or higher. This is significantly higher than cases with a gestation of 23-37+ weeks. It should be noted that the impact of the cases where BMI was not known/ stated may reduce this percentage.

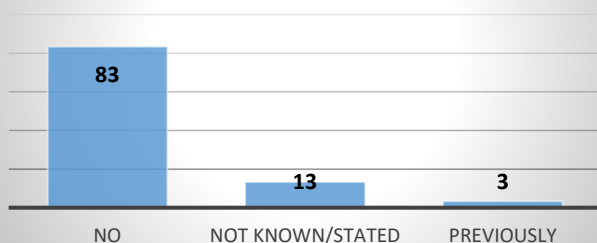
**Percentage of pre 22+6 week gestation neonatal deaths where domestic abuse was a risk factor**



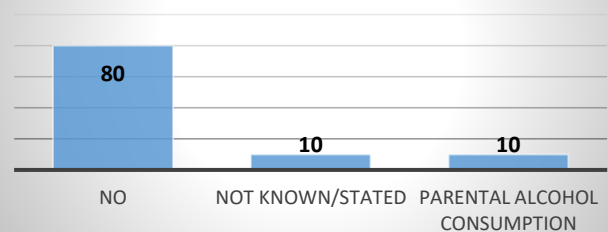
**Percentage of pre 22+6 week gestation neonatal deaths where smoking was a risk factor**



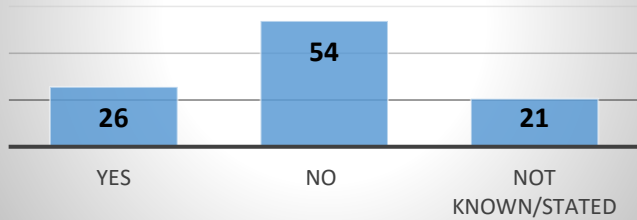
**Percentage of pre 22+6 week gestation neonatal deaths where drug misuse was a risk factor**



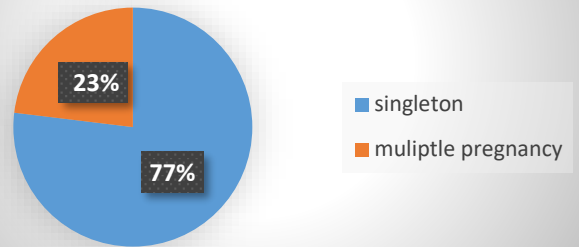
**Percentage of pre 22+6 week gestation neonatal deaths where alcohol misuse was a risk factor**



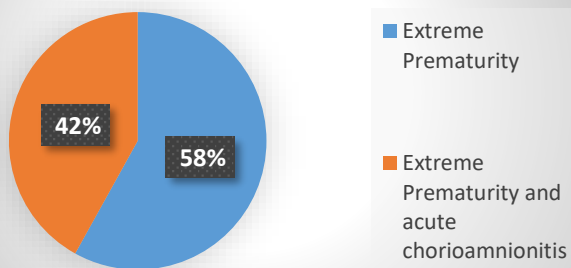
**Percentage of pre 22+6 week gestation neonatal deaths where maternal mental health was a risk factor**



**Percentage of pre 22+6 week gestation neonatal deaths by pregnancy type**



**Percentage of pre 22+6 week neonatal deaths by Cause of Death**



This data is taken from the Child Death Overview Panel final analysis form and is populated by a medical certificate of cause of death (MCCD) or post mortem findings.

## 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.

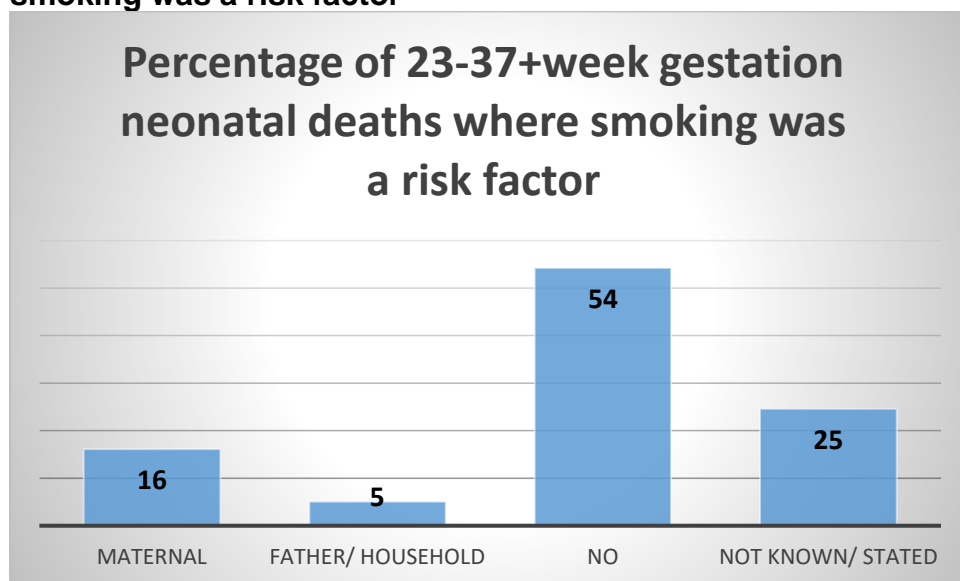
Whilst every death from neonatal death is a tragedy, the small numbers for this review mean that it will not be possible to have statistically robust data on the themes identified. Although we do know that a number of the themes are backed up with supporting published evidence and mirror the national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

## 6. Issues identified in this review

### 6.1 Parental Smoking

Smoking is still the single biggest identifiable risk factor for poor birth outcomes. Of the babies in the review % parental smoking.

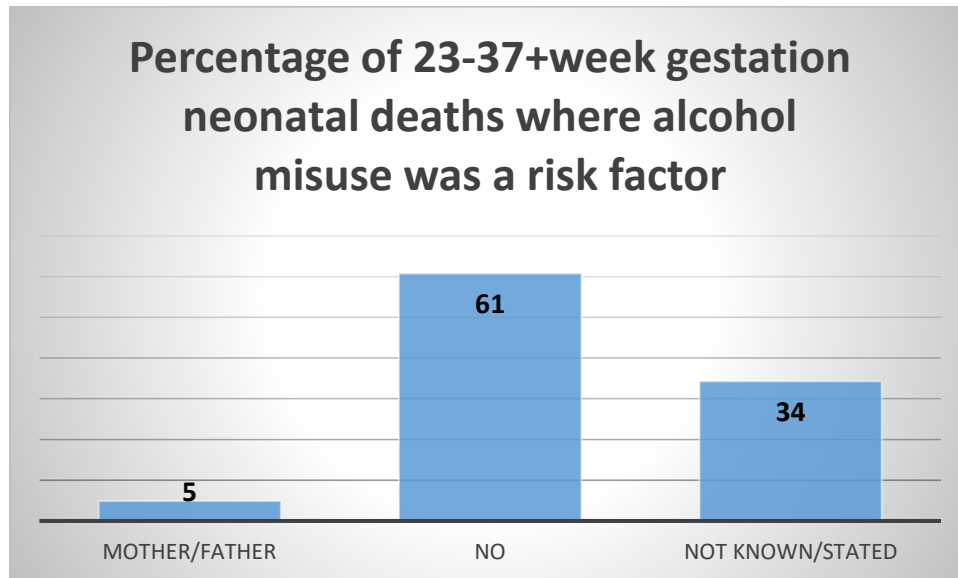
**Chart 21 – Percentage of 23 – 37+ week gestation neonatal deaths where smoking was a risk factor**



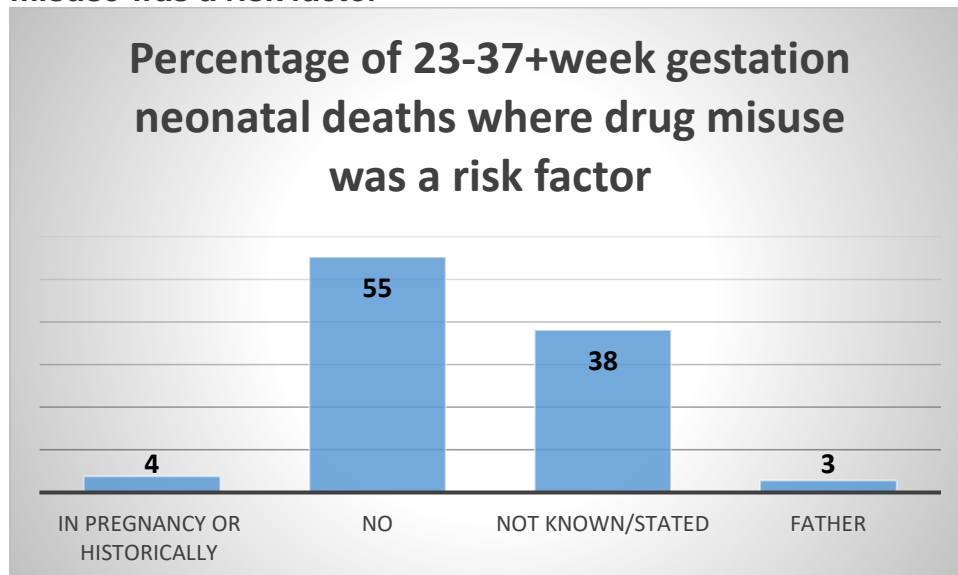
Whilst there are still data gaps for a quarter of the babies included in the review, 28% (25/89) of cases where smoking status was known had either maternal smoking or smoking in the household.

## 6.2 Parental drug and alcohol use

**Chart 22 – Percentage of 23-37+ week gestation neonatal deaths where alcohol misuse was a risk factor.**



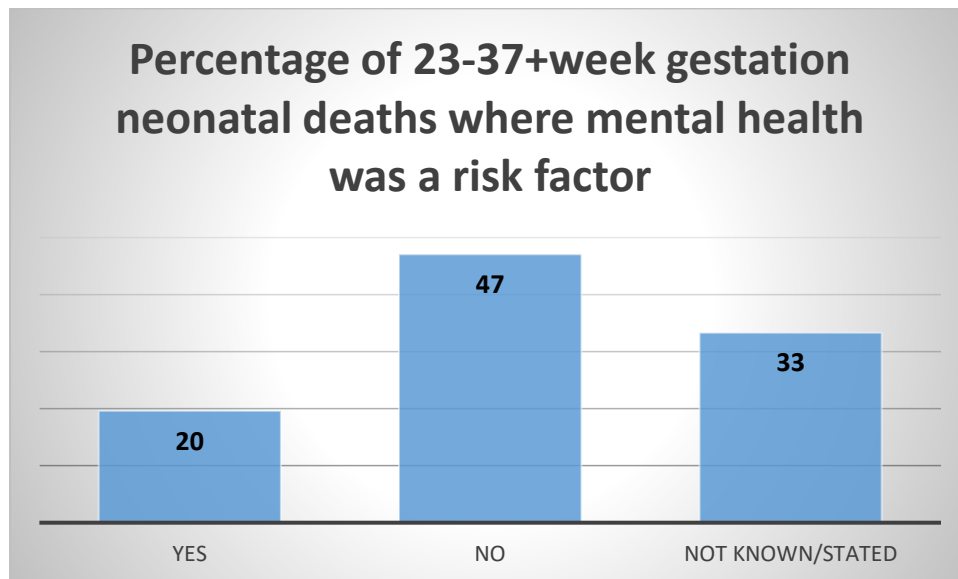
**Chart 23 – Percentage of 23 – 37+ week gestation neonatal deaths where drug misuse was a risk factor**



Given that prenatal drinking and smoking are modifiable risk factors, these results address a major global public health problem.<sup>27</sup>

### 6.3 Parental mental health

**Chart 24 – percentage of 23-37+ week gestation neonatal deaths where mental health was a risk factor**

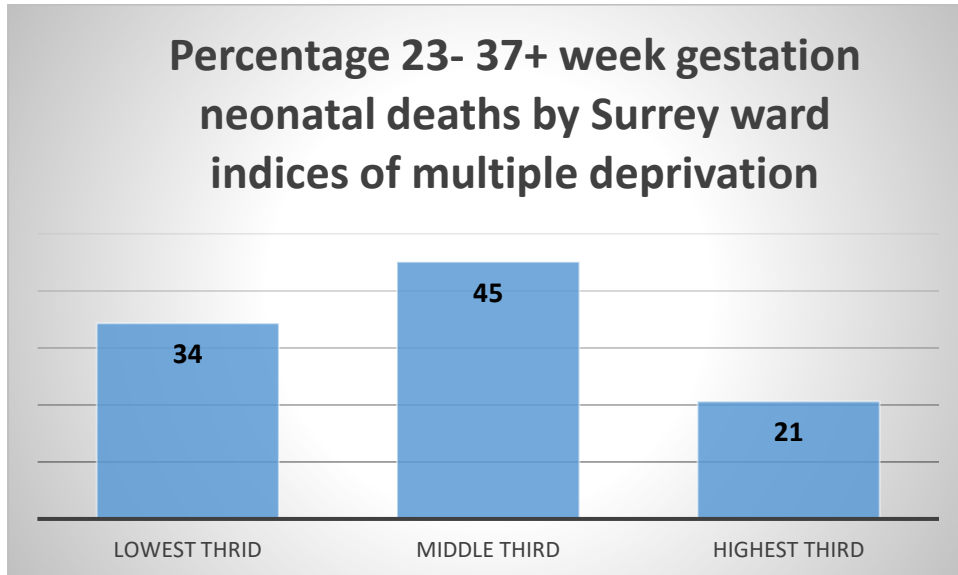


Although parental mental health concerns are common and the data set is small, we do know that it is important to ensure these parents are supported after a loss of a baby to ensure they have effective mental health support in place.

<sup>27</sup> [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(19\)30256-1/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(19)30256-1/fulltext)

## 6.4 Neglect and deprivation

**Chart 25 – Percentage 23 – 37+ week gestation neonatal deaths by Surrey ward indices of multiple deprivation**



More detailed analysis of the data and findings showed that 50% (8/16) of cases in 2020-21 were in lowest third, which is higher than all previous years within the scope of this review.

In Surrey there are 56 wards, 20 of the wards with the highest levels of deprivation are in North West Surrey, 6 in Guildford and Waverley, 14 in East Surrey, 6 in Surrey Downs, 6 in Surrey Heath and 2 in North East Hampshire and Farnham.

Below is a summary of our cases living in third poorest wards in Surrey:

55% lived in North West Surrey (26/47)

9% lived in Guildford & Waverley (4/47)

6% lived in Surrey Heath (3/47)

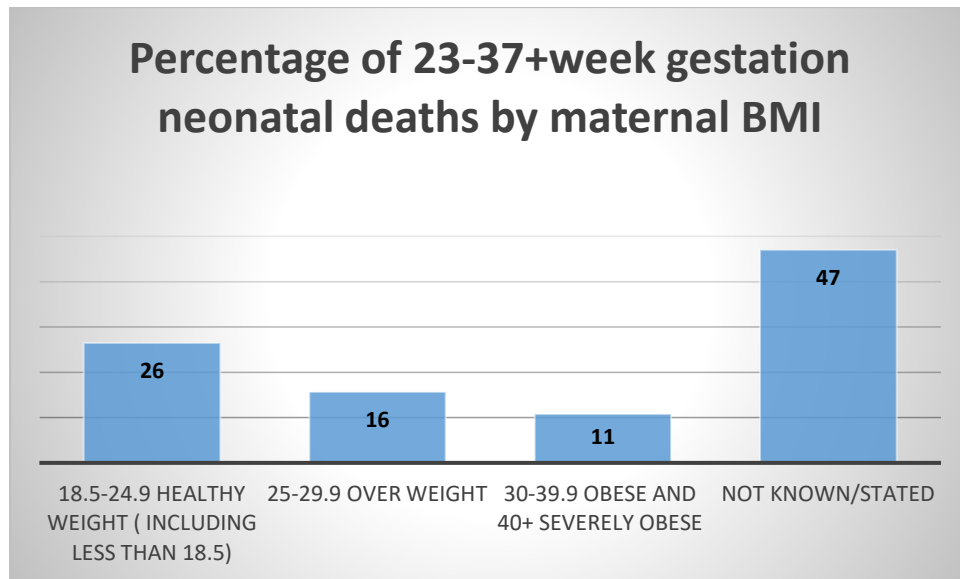
19% lived in East Surrey (9/47)

11% lived in Surrey Downs (5/47)

Overall 47 cases had parents living in most deprived third of wards.

## 6.5 Maternal Obesity

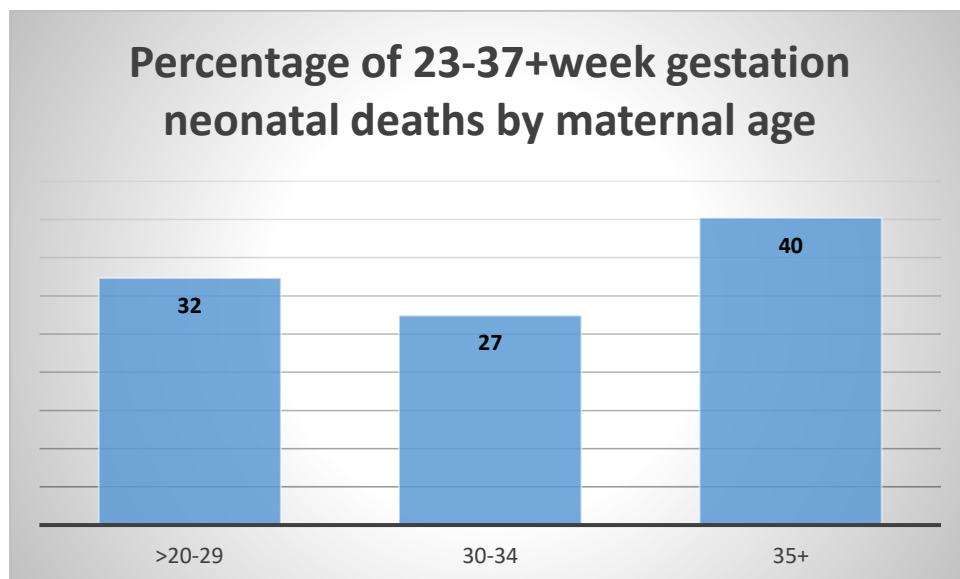
**Chart 26 – Percentage of 23-37+ week gestation neonatal deaths by maternal BMI**



Of the cases where maternal BMI is known 52% had a BMI of underweight/ overweight/ obese/ severely obese, so only 48% of the women had a healthy weight. In Surrey 16.9% of women were identified as obese in early pregnancy in 2018-19.

## 6.6 Maternal Age

**Chart 27: Percentage of 23-37+ week gestation neonatal deaths by maternal age**

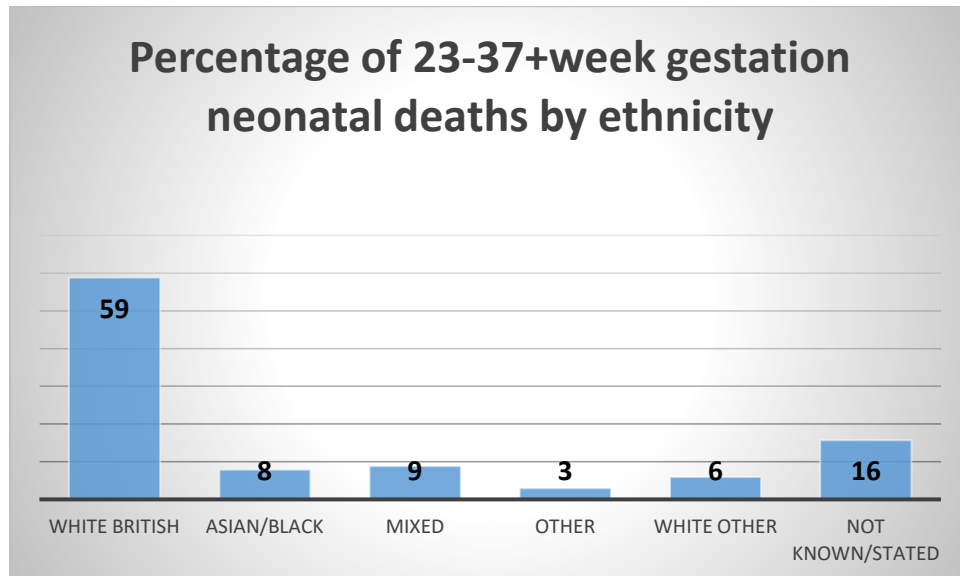


We know that in Surrey we have an older maternal age than other areas of the UK, 31.3% of mothers are aged over 35 years compared to 23% in the rest of the UK.



## 6.7 Ethnicity

Chart 28 – Percentage of 23-37+ week gestation neonatal deaths of ethnicity



We know that at 83.5% of the Surrey population are White British, so we know that neonatal deaths are not tracking the ethnic population of Surrey and children of Asian and mixed heritage are disproportionately represented amongst babies who have died.

### 6.7 In Utero Transfer

20% (20/105) of babies transferred ex utero to NICU. An in utero transfer is indicated when there is an increased risk of delivery within the next seven days for one or more of the following reasons.

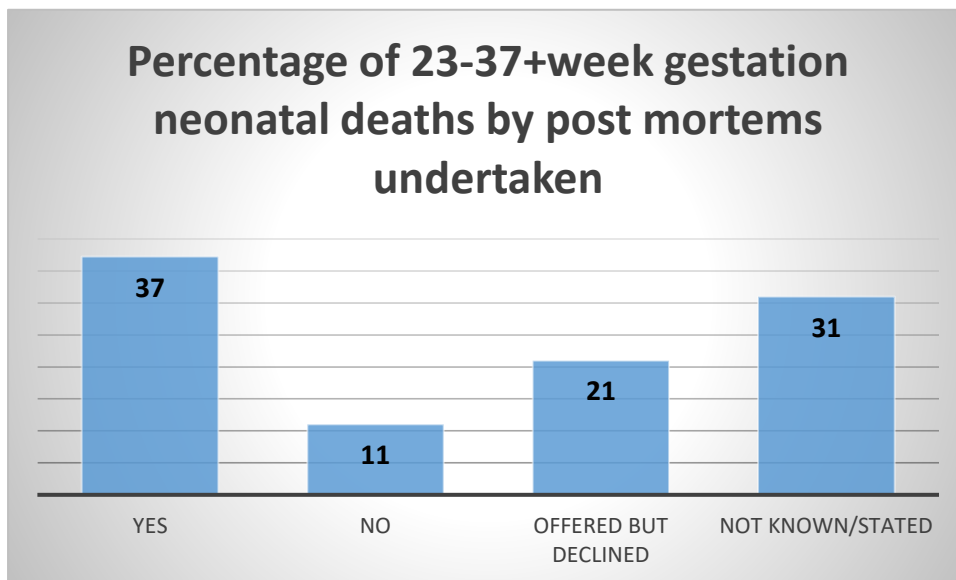
- Maternal medical or surgical condition needing tertiary level input.
- Foetal medical or surgical condition needing iatrogenic delivery at tertiary centre with facilities and capacity for neonatal management, including for any diagnosed subspecialty condition (cardiac).
- High risk of spontaneous or iatrogenic birth in a unit without facility or capacity to manage the newborn (usually due to prematurity) as per national service specification.

Helenius et al highlight the value of having extremely premature births in tertiary neonatal units and suggest an association of increased mortality and severe brain injury among those extremely preterm (EP) infants born in non-tertiary centres or transferred out within 48 hours after birth. Through a propensity analysis to match the retrospective cohorts from National Neonatal Research Database (NNRD) of UK,

the authors rightly suggested the promotion of births of EP infants in tertiary perinatal facilities.<sup>28</sup>

### 6.8 Post-mortem and placental histology

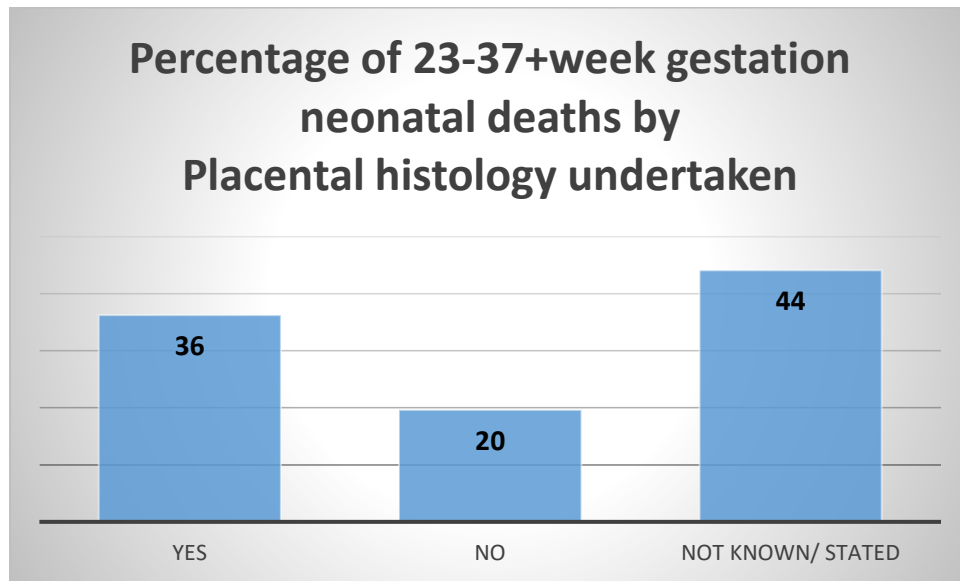
**Chart 29 - Percentage of 23-37+ week gestation neonatal deaths by post-mortems undertaken**



Of the 37% of post-mortems undertaken 50% (19/39) were coronial post mortems

<sup>28</sup> Helenius K, Longford N, Lehtonen L, Modi N, Gale C. Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants; observational cohort study with propensity score matching. *BMJ* 2019;367:15678.

**Chart 30 - Percentage of 23 – 37+ week gestation neonatal deaths by placental histology undertaken.**



In order to better understand why babies have died and to prevent future deaths within families the evidence suggests that placental histology should be offered, we know from anecdotal evidence at CDOP meetings that disposal of placentas before histology has been offered is an on-going issue that is backed up by the evidence in this Chart.

### **6.9 In Vitro fertilisation (IVF)**

The National Institute for Health and Care Excellence (NICE) fertility guidelines<sup>29</sup> make recommendations about who should have access to IVF treatment on the NHS in England and Wales.

But individual NHS clinical commissioning groups (CCGs) make the final decision about who can have NHS-funded IVF in their local area, and their criteria may be stricter than those recommended by NICE. In Surrey Patients registered with a GP practice fall under a policy established by NHS Surrey.

The referral must be made before the patient's 40th birthday.

Treatment must begin within six months of the patient's 40th birthday.

Two IVF cycles are funded, meaning:

- Two fresh cycles, and;
- Two subsequent frozen cycles, using stored embryos, if the fresh cycles fail.

Anecdotal evidence suggests that more research is needed to establish the impact of being born as a result of IVF and also the local policy which may lead to more

<sup>29</sup> [Overview | Fertility problems: assessment and treatment | Guidance | NICE](#)

mothers seeking IVF either privately funded or abroad where the same safeguards may not be in place as those found within the NHS.

## **6.10 Family engagement**

Themes identified from parents feedback during the thematic review:

### **Excellent care received on the neonatal units**

- Nearly every family that commented on the care received said they were very happy with the care given on the Neonatal units, staff were kind and caring and did everything they could for their baby.
- Parents were given as much time as they needed with their deceased baby and supported to make memories with them.
- Parents were grateful for the support given by the bereavement midwives.

**Overall, parents were satisfied with the care they received during the antenatal, delivery and post delivery period. However there were reports of the following:**

- Impact of Covid-19 on hospital visiting policies
- No sense of urgency by midwives although mothers were clearly distressed.
- A lack of pain relief or belief in the level of pain mothers were experiencing whilst in labour.
- Bereaved mothers left within earshot of crying babies and other mothers in labour.
- Lack of contact or inappropriate contact by Community Midwife or Health visitor following discharge.

## 7 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 neonatal deaths.

### 7.1 Overarching issues:

- **There should be full implementation of the NICE Quality Standard Promoting health and preventing premature mortality in Black, Asian and other minority ethnic groups.**

There should be full implementation of the NICE Quality Standard Promoting health and preventing premature mortality in black, Asian and other minority ethnic groups, to address the health inequalities experienced by this population. There should be appropriate access to an interpreter.

### 7.2 Early prevention and pre-conception care:

- **Full implementation of the NICE antenatal care guideline NG201.**
- **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<sup>30</sup>. 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.

Referrals should include everyone in the household and may include expanding the maternity support workers role to support smoking cessation in order to address the expectation of smoking cessation offer as detailed in the NHS Long Term Plan.

- **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

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<sup>30</sup> <https://www.nice.org.uk/Guidance/pH26>

referral to specialist alcohol services and are able to access specialist alcohol treatment.

➤ **Weight management**

Full implementation of the NICE guideline on weight management before, during and after pregnancy.

Data on BMI of mother should be routinely collected as part of the CDR process.

➤ **Air Quality Management Systems**

When data is available AQMS should be used to map against neonatal and child mortality in order to further understand the impact of pollution in Surrey on outcomes for babies and children.

➤ **IVF**

There was insufficient data on the impact of IVF on babies born in Surrey. Anecdotal evidence has highlighted this as a risk and identifying this data and the available evidence to evaluate if this is an issue for Surrey babies should be completed.

### **7.3 During Pregnancy:**

➤ **Improvements to data collection and information sharing.**

Effective data collection should be completed to ensure that record keeping is consistent across Surrey, where information is not known it would be more appropriate to use terms such as 'not asked', this will improve the ability to analyse data. Improvements should be made to collecting data, for instance ethnicity data is currently incomplete on records used for this review and this should be improved for future analysis. Information sharing protocols and systems should be used so that mothers do not 'slip through the net' and safeguarding concerns are shared so mothers can be supported from within the system. This is both across providers and also within departments in acute trusts. There should be developments in Surrey in line with 'what the best looks like' across the Country.

➤ **Full implementation of the MBBRACE recommendations on twin pregnancy care.**

Fully implement national guidance and resources.

➤ **Full implementation of the CQC recommendations on pregnancy care.**

The recommendations highlighted three main areas of governance, leadership and risk management which if implemented effectively can improve outcomes for babies.

- **Implementation of the 'Tommy's App' in each acute hospital in Surrey**

This clinical decision tool for the NHS and for women is an app which is shared between healthcare professionals and women, to help ensure every woman receives the right care at the right time and ultimately, save more babies' lives. It is supported by the Royal College of Obstetricians and Gynaecologists, NHS Digital and the Royal College of Medicine. Ashford St Peters Hospital are an early adopter site for this app and when appropriate, it should be rolled out and implemented in all maternity hospitals in Surrey.

#### **7.4 Delivery:**

There were a number of issues in relation to delivery that should be implemented.

- **Full implementation of the NICE Guidance on Preterm Labour and Birth NG25**

This guideline covers the care of women at increased risk of, or with symptoms and signs of, preterm labour (before 37 weeks), and women having a planned preterm birth. It aims to reduce the risks of preterm birth for the baby and describes treatments to prevent or delay early labour and birth.

- **Development of appropriate local guidance and systems on in utero transfers.**

A unit guideline on maternal transfer identifying different degrees of urgency is adhered to by all healthcare professionals. Training on the indications and contraindications for maternal transfer is attended by all responsible healthcare professionals with clear guidance on standardised pathways for referrals.

- **Standardised approach to thermoregulation across Surrey**

This will be supported through the South East Optimisation of the Preterm project, Surrey Heartlands LMNS are part of this work alongside KSS Neonatal ODN, SE AHSN & SE Maternity Transformation team.

- **NHS charging for maternity care.**

The CDOP chair should share the maternity rights charity Maternity Action email template, which they have developed to help CDOP chairs take action. This email template clearly sets out the rules around maternal charging and requests that the trust review its processes.

#### **7.5 Post-delivery:**

- **Transfer of baby and mother to tertiary units:**

When babies are transferred to tertiary units their mothers should also be transferred with them. All appropriate staff should complete the 'Avoiding Term Admissions into Neonatal Units' module on the e-learning for Health Care Platform. [HEE elfh Hub \(e-elfh.org.uk\)](http://HEE.elfh.org.uk) which includes a module on the importance of avoiding mother and baby separations.

➤ **Placenta Histology:**

In line with Royal College of Pathologists guideline for 'Tissue pathway for histopathological examination of the placenta' the decision regarding the indications for referral of a placenta for histopathology should be agreed with local obstetricians and neonatologists and implemented across all Surrey hospitals<sup>31</sup>.

➤ **Post-mortems**

All appropriate staff in maternity and neonatal units to undertake the e-learning module on Perinatal post-mortem consent.<sup>32</sup>

All maternity units to implement the Sands post-mortem consent package or similar.

➤ **National Bereavement Care Pathway**

All hospital trusts in Surrey should sign up to and work towards the [NBCP Standards | National Bereavement Care Pathway \(NBCP\) \(nbcpathway.org.uk\)](http://nbcpathway.org.uk)

There should be access to appropriate rooms to have bereavement meetings. It is not appropriate for mothers who have lost a baby to be on the ward with live births and also when going back for meetings in the maternity unit.

Organ donation and care pathways and conversations should take place. One important way to increase post-mortem rates is to improve the quality of the consent process. The Sands Post-mortem Consent Package<sup>33</sup> improves the consent process for both bereaved parents and professionals. Please note that parents should be offered printed copies (not downloads) of the booklet [Deciding about a post mortem examination](#).

➤ **Maternity Voices Partnership**

There should be support for maternal voice and the role of the MVP in each of the acute trusts.

➤ **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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<sup>31</sup> [Microsoft Word - G108\\_TPplacenta\\_LW.doc \(rcpath.org\)](#)

<sup>32</sup> [Perinatal Post-mortem Consent - elearning for healthcare \(e-lfh.org.uk\)](http://e-learning-for-healthcare.org.uk)

<sup>33</sup> <https://www.sands.org.uk/professionals/sands-post-mortem-consent-package#:~:text=The%20Sands%20Post%20Mortem%20Consent,by%20the%20relevant%20professional%20organisations>



There should be a standardised approach across Surrey to supporting mothers to express colostrum prior to a caesarean section.

There should be full reporting of 6-8 week breastfeeding data in Surrey so this can be published. UNICEF neonatal assessment are expecting all neonatal units to provide detailed feeding information on their IT systems, this should be collated and shared with partners in order to inform service delivery and commissioning.

➤ **The Child Death Review Partnership should ensure that there is effective information gathering and recording of data**

Discharge summary from booking and if applicable final hospital should be routinely made available to CDR for purposes of the CDOP processes. This should include capturing of whether the parents have learning disabilities.

➤ **Cuddle Cots**

Parents should be given the opportunity to access the Child Death Review cuddle cot at home service for families living in Surrey, offering recently bereaved parents of a neonate or stillborn baby support while using a Cuddle Cot in their own home. Unless the death has been referred to the coroner, there is no legal reason why parents should not be able to take their baby home from the hospital and make their own arrangements.<sup>34</sup> It is important that all bereaved parents are made aware of this option.

There is no obligation to use a cuddle cot. It is just an available option, which allows parents to take their baby home for a short time if they so wish.

➤ **Support for staff**

The emotional impact of palliative/end of life care on neonatal staff can lead to acute or chronic secondary stress. Secondary stress is 'the stress caused by the pressures placed on professionals who care for others in need' (Wicks, 2006). The impact of this emotional burden can be confounded by repeated deaths, a particularly challenging death or a current personal experience of palliative/end of life care.

Experience of traumatic events and vicarious trauma are occupational challenges for people working within healthcare. The need to support staff following traumatic events at work is essential to avoid poor mental health outcomes.

Some providers in Surrey have introduced Trauma Risk Management (TRiM), an evidence based approach of peer delivered psychological support. It is a mechanism to detect early signs of traumatic stress problems, facilitate early informal support and to encourage formal help-seeking for those that need it. The TRiM model bases itself on keeping employees functioning after traumatic events by providing support and education to those who require it. TRiM aims to identify those who are not

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<sup>34</sup> [Neonatal Death Full Guidance Jan 2020 0.pdf \(nbcpathway.org.uk\)](#)

coping after potentially traumatising events and ensure they are signposted to professional sources of help.

With the development of Integrated Care Systems (ICS), work is in progress to facilitate the extension of the TRiM model to all staff working within the ICS.

➤ **Standardisation of Perinatal Mortality Review Tool across Surrey**

Whilst the aim of the national PMRT programme is introduce the PMRT to support standardised perinatal mortality reviews across NHS maternity and neonatal units in England, Scotland and Wales. There should be an opportunity for learning on completing the tool to take place across the County to ensure consistency across the County.

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Thanks to the members of our Thematic Review Steering Group, who supported discussions around the evidence and aided the direction of the review. We are extremely grateful to them for sharing their expertise on this area.

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