



## **Surrey Child Death Review Partnership**

### **Neurodisability and Infant and Child Deaths in Surrey.**

### **A Thematic Review of Deaths That Occurred Between 2016- 2020**

"If we can get it right for this group of children we should be able to improve health and child protection for all children".

(SSCB, 2018)

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## Foreword

Being a parent is one of the most rewarding jobs but amongst the joy, there is often worry and fear, and an even bigger fear of those worries not being taken seriously or of them being dismissed by professionals. The diagnosis of a complex disease or life limiting illness is one of the most devastating blows that a parent can receive as on receiving this news, the hopes and dreams that they had for their child may often taken from them.

In 2013 the Royal College of Paediatrics and Child Health published their 'Overview of Child Deaths in the Four UK Countries' report. This highlighted a number of key issues, one of which was that two thirds of children who died had a chronic condition, most frequently neurological, reflecting the shift in survival combined with more effective prevention of perinatal deaths.

In addition, the National Confidential Enquiry into Patient Outcome and Death. Each and Every Need. 2018 stated that "All children and young people with a neurodisability should have the right to receive the same high quality healthcare as anyone else. This should include close attention to detail to ensure their wider needs are appropriately understood and described at every opportunity, including health conditions, family reported issues, technology dependencies and need (or not) for care 24/7".

The Surrey transforming care plan, 2017 identified 5700 children with Learning Disabilities living in Surrey and 2,700 with autism each with their own identified needs. As a system, we need to work together to understand the modifiable factors that lead to a child being born with a disability and to learn of and act upon the opportunities to prevent or minimise their effect. According to Unicef, the first 1,000 days of life – the time spanning roughly between conception and a child's second birthday – is a unique period of opportunity when the foundations of peak health, growth, and the brain's development of pathways that influence performance or function such as intellectual functioning, reading ability, social skills, memory, attention or focus skills are established for life. Surrey Heartlands Health and Care Partnership has chosen to make the first 1,000 days of life a focus of its work, taking greater account of what are known as the Wider Determinants of Health – a diverse range of social, economic and environmental factors which impact on people's health.

The thematic review of Neurodisability and infant and child deaths that occurred in Surrey between 2016 and 2020 identified a number of factors that were present and affected the children and young people who died within this time. These factors included, income deprivation, ethnicity and prematurity. For example, the data suggested that the pattern of deaths of the children that were reviewed does not match the ethnic distribution within the live population in Surrey with 22% of the babies included in the review being Asian within a general population in Surrey where only 6.3% of people are Asian/Asian British. In addition, the children who were Asian were more likely to be living in the areas within the lowest third in terms of income deprivation in Surrey. This echoes the experience in Birmingham where the Pakistani, black African and Afro-Caribbean populations have been identified as being overrepresented in child deaths, and analysis from the city's Child Death Overview Panel highlighted Pakistani families as being particularly affected and where councillors have recently voted in favour of establishing a new multi-agency taskforce with the goal of reducing infant mortality in the city by at least 50% by 2025, and working with community groups and faith leaders to help minimise risk factors.

The authors identify a number of opportunities "not to be missed" within this report. Surrey Heartlands Integrated Care System has a unique opportunity to work as a system to tackle some of the risk factors that have been identified in this thematic review and that of previous

reviews undertaken by the Child Death Review Partnership. In addition, work already carried out in Surrey within the LeDeR programme and refreshed “Learning from lives and Deaths - people with a Learning Disability and Autistic people - LeDeR Policy, March 2021” gives further opportunities to learn, share good practice and make improvements to commissioning decisions and service delivery that will support and improve both the life expectancy and experience of vulnerable groups by reducing or eliminating the health inequalities that are currently in existence.

As a system, we need to work together, as identified in this review and in the National Confidential Enquiry into Patient Outcome and Death. Each and Every Need. (2018) to “achieve exceptional communication between service providers .... Using robust networks to ensure that each and every need is met.” We also need to support and listen to parents as the people who know their child the best when they express concerns and look to practitioners for help.

Eileen Clark, RN, MBA, Deputy Director for Quality and Nursing  
NHS Surrey Heartlands Clinical Commissioning Group

## A Parents Journey

Being a parent is one of the most rewarding jobs, but it can also be one of the most difficult. Sleep deprivation can lead to worries that may make parents feel paranoid that something is wrong. Sometimes, when a parent has these worries, they may feel that professionals are not taking them seriously. This was the sad experience for one of our Surrey families. Names have been changed for anonymity.

When Kerry found out she was pregnant with her second baby she was overjoyed. Three weeks after her baby Olivia was born, she started to scream and was struggling to feed, she seemed very different from Kerry's first baby. She was screaming all the time and clearly in discomfort. Kerry was struggling to help Olivia even though she had tried interventions she had used with her previous baby.

Kerry attended the GP and Health Visitor repeatedly but felt that they were dismissive of her worries. The GP and Health Visitor reassured Kerry that it was reflux or colic. They kept asking her about postnatal depression and her Mental Health history.

Kerry felt that Olivia seemed to be constantly in pain. The GP prescribed a different reflux medication and a laxative but the medication did not seem to make any improvement, nor did the various specialist milks.

When Olivia was 14 weeks old, the GP asked Kerry "what do you think is wrong with her?" Kerry could tell they were implying that it was she who had the problem. The Health Visitor was also asking about Kerry's Mental Health. Kerry felt anxious but this was only because no-one seemed to be taking her concerns seriously.

Olivia was not meeting her milestones. Kerry knew her development was delayed. She was still having to be held like a new-born even though she was now 14 weeks old. The Health Visitor visited Kerry, Kerry asked about the possibility that Olivia was having seizures when she went stiff and the Health Visitor explained them to be symptoms of reflux, colic and Kerry's mental health. Kerry then asked the GP about the chances of Cerebral Palsy as Olivia was still not holding her head up but Kerry felt her concerns were dismissed immediately. Kerry knew something was wrong but she felt she was making it all up and became increasingly nervous when seeking help.

At 6 months old, a new Health Visitor came to review Olivia, her first review since she was 14 weeks old. The Health Visitor raised concerns about delayed development, Kerry felt relieved someone else could see it too. A paediatrician referral was made and after a six week wait Olivia was seen. He listened to Kerry and sent Olivia for blood tests, a brain scan, urine test, ophthalmology and nutritionist. Kerry felt that this was the first time someone really listened to the whole story and took her concerns seriously.

One night Olivia had a seizure that eventually lasted over 24 hours, Kerry received the diagnosis that Olivia had a neurological condition that would result in lifelong disability. Sadly Olivia passed away soon after the diagnosis was made.

## 1 Introduction

This report presents the findings of a thematic review undertaken by Surrey Child Death Review Partnership of children who had been diagnosed with a neurodisability and died aged between 28 days to 18 years during the period 1<sup>st</sup> April 2016 - 31<sup>st</sup> March 2020.

For the purposes of this review we will be defining neurodisability as an umbrella term for conditions associated with impairment involving the nervous system (brain and/or spinal cord) and including those caused by disease or injury, encompassing conditions such as cerebral palsy, autism and learning disability. They can be static or progressive in nature, however many children with neurodisability have complex and continuing needs and are frequent users of Children's services, education and health services at all levels; community, primary care, inpatient and outpatient settings. The term complex neurodisability is often used to describe those children with accompanying comorbidities. This includes motor impairments as well as medical diagnoses.

As with our previous thematic review, the aim of this thematic review is to identify patterns and themes in child deaths in Surrey and to look at how we can work more effectively together to prevent further deaths. Every child'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 deaths.

## 2 Background

In a review of child deaths that occurred between 2001-2010, the Royal College of Paediatrics and Child Health found that two-thirds of children who died in England, Scotland or Wales had a chronic condition and between 30% to 40% of the children who died were affected by a neurological/sensory condition, more than any other group of conditions<sup>1</sup>.

NICE guidance in 2017 emphasised the need for improvements in care that can and should be made for patients with a cerebral palsy up to the age of 25 years.<sup>2</sup>

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<sup>1</sup> [CHRUK\\_Module%20A%20low%20res%20\(2\).pdf \(rcpch.ac.uk\)](https://www.rcpch.ac.uk/chruk/module%20A%20low%20res%20(2).pdf)

<sup>2</sup> National Institute for Health and Care Excellence (NICE) Clinical guidelines [NG62]: Cerebral palsy in under 25s: assessment and management. Published January 2017

Following on from this in March 2018 the National Confidential Enquiry into Patient Outcome and Death published a report on the quality of care provided to children and young people with chronic disabling conditions, focusing in particular on cerebral palsy. The report took a critical look at areas where the care of patients might have been improved. This report "Chronic Neurodisability: Each and Every Need"<sup>3</sup> highlighted the need for 'multidisciplinary care which is proactive and supported by exceptional communication with the patient at the centre, the report highlighted that this leads to improved outcomes when compared to passive monitoring of the natural history of the disabling health condition.'

The report highlighted that all children and young people with a neurodisability should have the right to receive the same high quality healthcare as anyone else. This should include close attention to detail to ensure their wider needs are appropriately understood and described at every opportunity, including health conditions, family reported issues, technology dependencies and need (or not) for care 24/7. When needs are adequately recognised they are more likely to be dealt with effectively as part of the overarching care plan. To achieve this goal, exceptional communication between service providers is required using robust networks to ensure that each and every need is met.

The research on the protection of disabled children indicates that they are more at risk of being abused than non-disabled children. However, they are less likely than other children in need to become the subject of child protection plans. Disabled children are usually involved with a wide range of professionals (Ofsted, 2012).<sup>4</sup>

The Care Quality Commission's 'state of health care and adult social care in England 2018/19':

- described as a 'common picture' the situation where 'people with a learning disability or autism had not had access to the help they needed as children from health, social care and education services [and when] they encountered a crisis in their lives, there was nothing available locally to avoid going into hospital'.
- noted that 'organisations that represent people who use services have told us about the barriers that people are coming up against when trying to get diagnoses and assessments, particularly for dementia, autism, mental health conditions and social care. These include long waiting times, the need to be persistent, eligibility for assessments and the timing of assessments'.

There was a statutory requirement that all child deaths to be reviewed since 2008 but most neurodisability deaths were identified as expected deaths so were reviewed at Child Death Overview Panel (CDOP) only and did not meet the criteria for the more in-depth process of a Child Death Review Meeting (CDRM) prior to discussion at CDOP. A CDRM is a multi-professional meeting where all matters relating to an

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<sup>3</sup> [NCEPOD - Chronic Neurodisability: Each and Every Need \(2018\)](#)

<sup>4</sup> [Ofsted publication \(publishing.service.gov.uk\)](#)

individual child's death are discussed by the professionals directly involved in the care of that child during life and their investigation after death. This may help to explain why the data was limited or missing in some cases.

From 2008, CDR processes were made mandatory for Local safeguarding Children Boards in England for all child deaths up to the age of 18 years. Following a review of CDR processes, two documents published in 2018 (*Working Together to Safeguard Children* and *Child Death Review Statutory and Operational Guidance*) detail the processes that must be followed when a child dies. Since September 2019, in line with the new guidance, all child deaths must now have a Child Death Review Meeting (CDRM) which is a multi-professional meeting where all matters relating to an individual child's death are discussed by the professionals directly involved in the care of that child during life and their investigation after death.

The aims of the CDRM are:

- to review the background history, treatment, and outcomes of investigations, to determine, as far as is possible, the likely cause of death;
- to ascertain contributory and modifiable factors across domains specific to the child, the social and physical environment, and service delivery;
- to describe any learning arising from the death and, where appropriate, to identify any actions that should be taken by any of the organisations involved to improve the safety or welfare of children or the child death review process;
- to review the support provided to the family and to ensure that the family are provided with the outcomes of any investigation into their child's death

A standardised report is completed at the CDRM detailing modifiable factors, identified learning and action taken that may prevent future child deaths. This report is shared with CDOP. The review by the CDR partners at CDOP is intended to be the final, independent scrutiny of a child's death by professionals with no responsibility for the child during their life. The purpose of a review is to ensure we are able to learn from deaths, that learning is widely shared and that actions are taken, locally and nationally, to reduce preventable child deaths in the future. Analysis of deaths and data from all CDR reviews across England are uploaded onto the National Child Mortality Database system (NCMD) to identify themes and enable national learning.

The Child Death Review Statutory and Operational Guidance sets out key features of what a good child death review process should look like and should be followed by all organisations involved with the process of child death reviews in England in order to standardise practice nationally and enable thematic learning to prevent future deaths. Chapter 5 of this guidance, as far as it relates to the functions conferred on CDR partners by sections 16M to 16P of the Children Act 2004, is statutory guidance issued under section 16Q of that Act and CDR partners must have regard to it. It builds on the statutory requirements for child death review set out in Chapter 5 of *Working Together*.

NICE guidance (2017)<sup>5</sup> for end of life care for infants, children and young people states that advanced care plans can help people with a life-limiting condition plan for and receive care at the end of their life that is in line with their wishes. Talking with the child or young person, and their parents or carers, at appropriate stages allows them to influence the care that they receive and improves their experience of care. This includes involving parents and carers when a potentially life-limiting condition is diagnosed in a baby during pregnancy. Advance care plans should be appropriate to the circumstances and continuously updated throughout the delivery of care and support.

**Table 1. Numbers of 14 to 17 year olds on learning disability registers and numbers having checks in England**

<b>Age 14 to 17</b>	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>
On learning disability register	14,211	15,335	16,513
Had a check	3,588	5,016	6,098
Coverage	25%	33%	37%

Table 1 shows numbers on the learning disability register and numbers having checks in England aged 14-17 years old. Young people aged 14 to 17 are not as well covered as people aged 18 and older, although the numbers of checks rose much faster for the younger age group.<sup>6</sup>

<sup>5</sup> [Quality statement 1: Advance care plan | End of life care for infants, children and young people | Quality standards | NICE](#)

<sup>6</sup> [Chapter 7: health checks 2017 to 2018 - GOV.UK \(www.gov.uk\)](#)

**Table 2. Below obtained from PHE (2018) People with Learning Disabilities in England; Education and children's social care update.**

The number of children with a Statement of SEN or an EHC Plan and a primary SEN associated with learning disabilities in state funded primary and secondary schools and state funded and non-maintained special schools in England, 2010 to 2018									
	2010	2011	2012	2013	2014	2015	2016	2017	2018
MLD	41,030	36,645	34,715	33,455	32,410	31,115	29,650	28,564	28,241
SLD	25,230	26,045	26,880	27,540	28,330	28,940	29,001	29,120	29,492
PMLD	8,680	9,100	9,460	9,715	9,810	10,010	9,955	10,010	10,032
Total	74,940	71,790	71,055	70,710	70,550	70,065	68,606	67,694	67,765

Data presented in: Special Educational Needs in England, January 2018

## 2.1 Current epidemiology in Surrey

In Surrey there are: 5,700 children with learning disabilities and 2,700 with autism, of whom 647 are 16-17 year olds with learning disabilities and 98 with autism (Surrey transforming care plan, 2017).

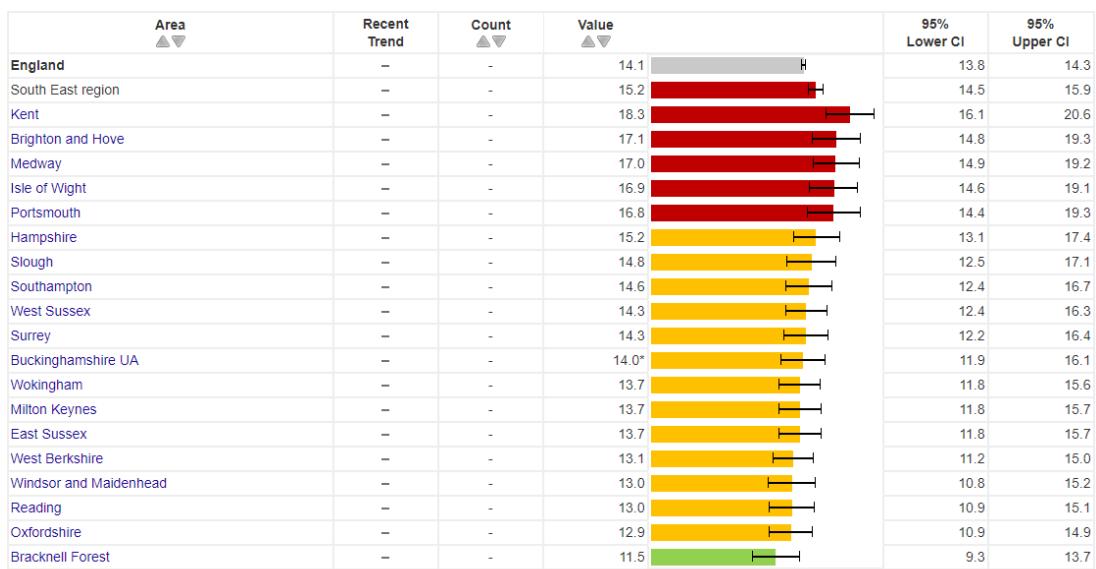
In January 2019, there were 196,697 pupils in Surrey's maintained schools, academies and independent schools. 23,000 of these children are receiving special educational needs (SEN) support.<sup>7</sup>

As of July 2019 there are 386 maintained schools and academies in Surrey of which 24 are special schools.<sup>8</sup>

<sup>7</sup> <https://www.surreyi.gov.uk/jsna/children-with-send/>

<sup>8</sup> <https://www.surreycc.gov.uk/schools-and-learning/teachers-and-education-staff/school-management/statistics/numbers-of-maintained-and-academy-schools-in-surrey#:~:text=Numbers%20of%20maintained%20and%20academy%20schools%20in%20Surrey,%20%2013%20%207%20more%20rows%20>

**Chart 1: Percentage of children with a long-term illness, disability or medical condition diagnosed by a doctor at age 15.**



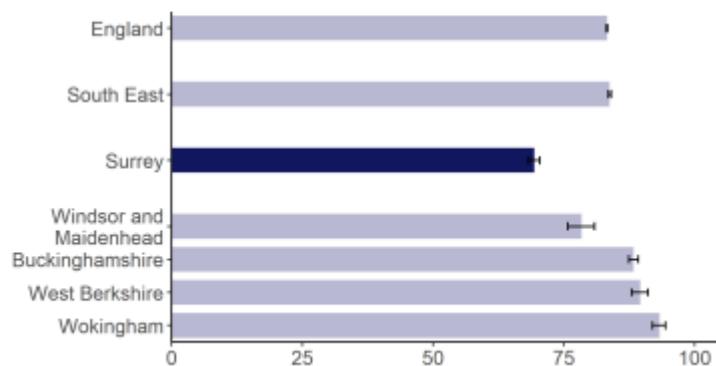
Source: What About YOUTH (WAY) survey, 2014/15

69.3% of children aged 2-2½ years were at or above the expected level of development in all five areas of development (communication, gross motor, fine motor, problem-solving and personal-social skills) in 2019/20. This is worse than the England average. 72.4% of children were at or above the expected level of development for communication skills and 73.7% for personal-social skills which is worse when compared with England average of 88.9% for communication and 92.9% for personal-social skills.

## Chart 2: Child development at 2-2.5 years compared to Statistical neighbours, the South East and England average.

### Child development at 2-2½ years

**Children at or above expected level of development  
in all five areas at 2-2½ years, 2019/20 (percentage of  
children reviewed)**



We know that being born with a low birth weight (under 2500 grams) is associated with an increased risk of infant mortality, developmental issues in childhood and poorer health in later life. Surrey has lower rates of low birth weight babies than other areas in the South East Region. There are a number of risk factors for having a low birth weight baby and these are discussed below.

## Chart 3: Low Birth Weight of term babies 2019<sup>9</sup>

Area ▲▼	Recent Trend	Count ▲▼	Value ▲▼	95% Lower CI	95% Upper CI
England	↑	16,048	2.90	2.86	2.95
South East region	►	2,098	2.49	2.39	2.60
Slough	►	81	3.85	3.11	4.76
Milton Keynes	►	110	3.64	3.03	4.37
Medway	►	77	3.23	2.59	4.02
Reading	►	53	2.90	2.23	3.78
East Sussex	►	111	2.64	2.20	3.17
Southampton	►	71	2.62	2.08	3.29
Portsmouth	►	55	2.58	1.98	3.34
Isle of Wight	►	24	2.55	1.72	3.77
Buckinghamshire UA	►	131	2.52	2.13	2.99
Kent	►	349	2.45	2.21	2.72
Windsor and Maidenhead	►	33	2.40	1.72	3.35
Oxfordshire	►	156	2.32	1.99	2.71
West Sussex	►	176	2.32	2.00	2.68
Hampshire	►	284	2.29	2.04	2.57
Surrey	►	256	2.29	2.02	2.58
Bracknell Forest	►	27	2.23	1.54	3.22
Brighton and Hove	►	49	2.22	1.68	2.92
West Berkshire	►	29	2.14	1.49	3.05
Wokingham	►	26	1.74	1.19	2.54

Source: Office for National Statistics

<sup>9</sup> [Child and Maternal Health - PHE](#)

The greatest modifiable risk factor for low birth weight is exposure to tobacco smoke. Exposure to tobacco smoke includes both maternal smoking and exposure to environmental tobacco smoke in the home.

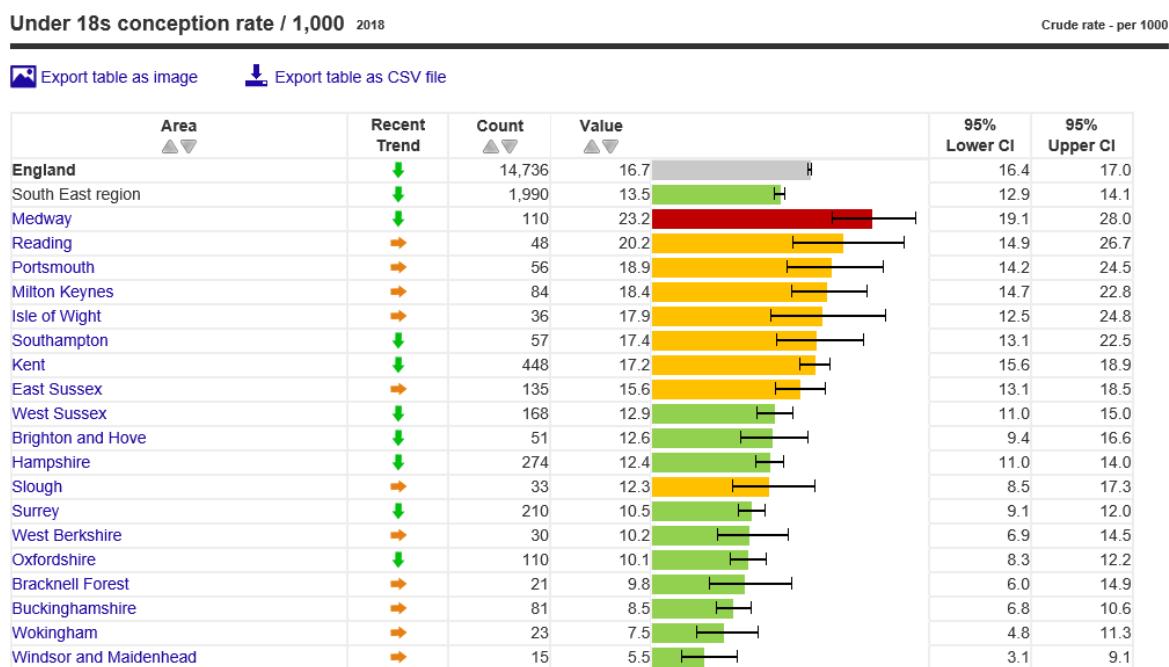
#### Chart 4: Smoking status at time of delivery 2019 -2020



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 798 women smoking at time of delivery in Surrey in 2019 - 2020.

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



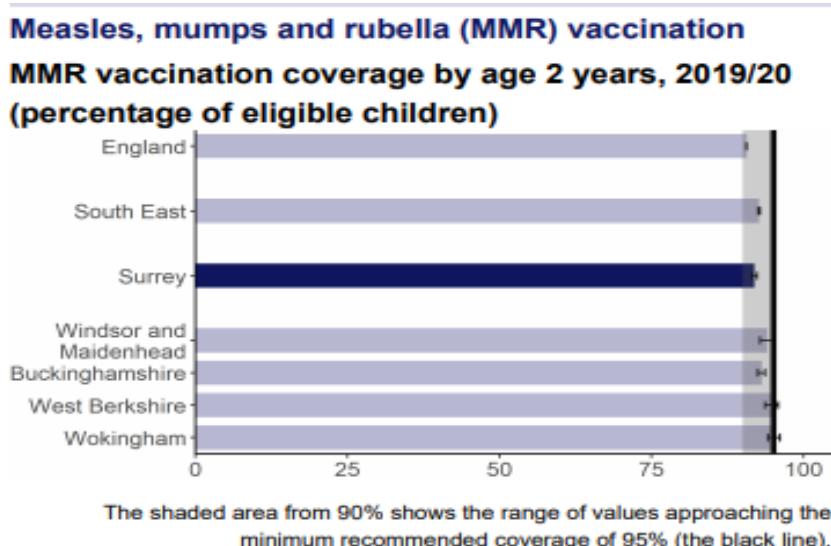
Source: Office for National Statistics (ONS)

In 2018 in Surrey, approximately 11 girls in every 1000 aged under 18 conceived. This is lower than the regional average and lower than the England average. Mother's age is associated with having a low birth weight baby.

We know that vaccinations protect babies and children against contracting communicable diseases the long term effects of which can potentially lead to neurological damage. 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.

In 2019 -2020 slightly less than 95% (the minimum recommended coverage level) of children have received their first dose of MMR immunisation by the age of two in this area (92.0%). By the age of five, only 83.3% of children have received their second dose of MMR immunisation in Surrey.

#### **Chart 6: MMR vaccination coverage by age 2 years 2019/20**



#### **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.

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.

Public Health England's *Best Start in Life* 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.

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

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<sup>10</sup> [NHS England » Best Start in Life](#)

The Surrey SEND Systems Partnership has a vision that partners work together to enable all children with Special Educational Needs and Disabilities (SEND) in Surrey to thrive and achieve their full potential. This is part of the Surrey SEND strategy 2019-2022.<sup>11</sup>



## Our principles of transformation

### Our five key principles

1. Children with special educational needs are identified earlier and supported in a timely and effective way in order to improve their outcomes and wellbeing.
2. There is an increased focus on earlier intervention and prevention to offer help and meet needs at the earliest opportunity, reducing the demand on high cost, high need interventions.
3. Children and young people are helped to become resilient and independent so that they can lead independent and fulfilling lives in their own communities.
4. The voices of our children, young people and families are heard so they can shape and inform how we work together to get the best results
5. Surrey's early years settings, schools, colleges and other providers are able to support children to live, learn and grow up locally and achieve their full potential



## The Learning Disability Mortality Review (LeDeR) programme;

The LeDeR programme based at the University of Bristol was established in response to the recommendations made in the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (2013). Its aim is to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and make service improvements in response to the identified learning. LeDeR should be embedded as part of quality assurance/mortality/safeguarding work, primary care development/ownership, commissioning intentions, contract delivery to ensure service change is written into contracts. This is because people with learning disability die around 20 years younger than other people.

The child death review process is the primary review process for children with learning disabilities hence it is not necessary for the LeDeR programme to review each case separately. However when notified of the death of a child or young person aged 4-17 years who has learning disabilities, or is very likely to have learning disabilities but not yet had a formal assessment for this, the CDOP co-ordinator should report that death to the LeDeR programme. Furthermore the LeDeR contact

<sup>11</sup> [Surrey SEND Partnership strategy 2019-22 \(openobjects.com\)](http://openobjects.com)

is invited if appropriate to ensure collection of additional LeDeR specific information. Learning from Surrey CDOP is fed into the LeDeR governance processes and there are close working relationships between the two teams in Surrey, with LeDeR representatives invited where appropriate to CDOP meetings to ensure effective reviews of the children.

This gives an awareness into the crucial work undertaken by LeDeR for both children and adults with learning disability with the aim identifying learning which will lead to making service improvements and then improving the lives of people with learning disability.

## **LeDeR policy 2021**

The new LeDeR policy<sup>12</sup> aims to set out for the first time for the NHS the core aims and values of the LeDeR programme and the expectations placed on different parts of the health and social care system in delivering the programme from June 2021. It will serve as a guide to professionals working in all parts of the health and social care system on their roles in delivering LeDeR.

This policy outlines a number of changes to existing LeDeR processes. Some of these changes, such as the new review process, will need to be implemented by local systems in line with the changes to the web-based platform which will go-live on 1 June 2021. Other changes, such as staffing models and local governance arrangements will need to change in line with the development of integrated care systems and relevant human resources processes. By 1 April 2022 all changes within this policy must be implemented by integrated care systems.

The policy has been co-produced with bereaved family members, people with a learning disability, health and social care professionals and people from across the LeDeR workforce.

## **3 Methods**

### **3.1 Case definition**

Children and young people's deaths for this review were defined as children aged between 28 days and 18 years, who were resident in Surrey, who died between 1<sup>st</sup> April 2016 and 31<sup>st</sup> March 2020 and had a diagnosis of a neurodisability.

For the purposes of the review we defined neurodisability as an umbrella term for conditions associated with impairment involving the nervous system (brain and/or spinal cord) and included those caused by disease or injury, encompassing conditions such as cerebral palsy, autism and learning disability. Neurodisabilities can be static or progressive in nature, however many children with neurodisability have complex and continuing needs and are frequent users of Children's services, education and health services at all levels; community, primary care inpatient and

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<sup>12</sup> [NHS England » Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#)

outpatient settings. The term complex neurodisability is often used to describe those children with accompanying comorbidities. This includes motor impairments as well as medical diagnoses.

For the purposes of this review we will use the term neurodisability to cover all of the children within the review.

### 3.2 Data sources

Information on the children and young people 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 neurodisability as an umbrella term for conditions associated with impairment involving the nervous system (brain and/or spinal cord) and includes those caused by disease or injury, encompassing conditions such as cerebral palsy, autism and learning disability, 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 neurodisability.
- Evidence of effective interventions to support the prevention of neurodisability.

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, Up-to-date 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 going back to 7 years. 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 26 NICE Guidelines, Systematic reviews and original research articles were collated thematically.

The London, Kent, Surrey and Sussex Regional Searching Guidance (Jan 2020)<sup>13</sup> document informed the search process and approach taken.

### 3.4 Thematic review group

A thematic review group was convened. Members were drawn from LeDeR, CCG quality directorate, consultant paediatrician, safeguarding, public health, child death review team, psychologist, and specialist community children's nursing services.

## 4 Findings

### 4.1 Babies and Children included in this review

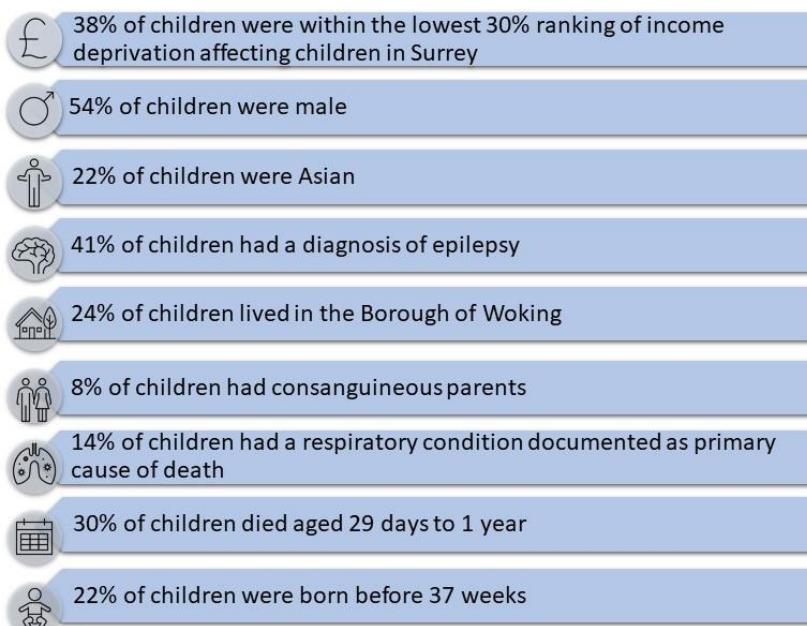
Between 1st April 2016 and 31st March 2020, 37 babies and children met the case definition for the thematic review of having a neurodisability.

### 4.2 Summary of babies/children

**Chart 7: Overview of results of the finding of the Neurodisability Thematic Review**

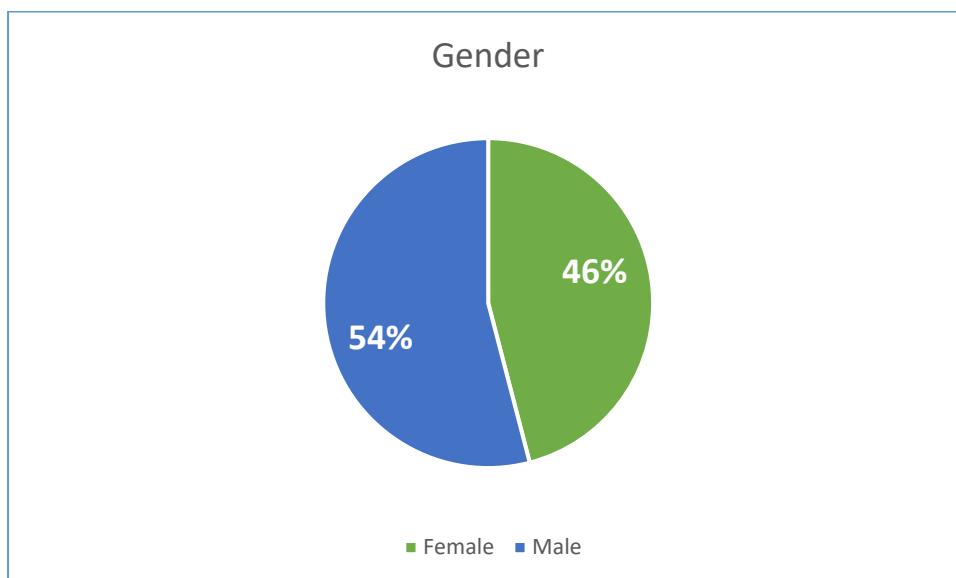
## Neurodisability Thematic Review Findings 2016-2020

Analysis of  
37 Cases

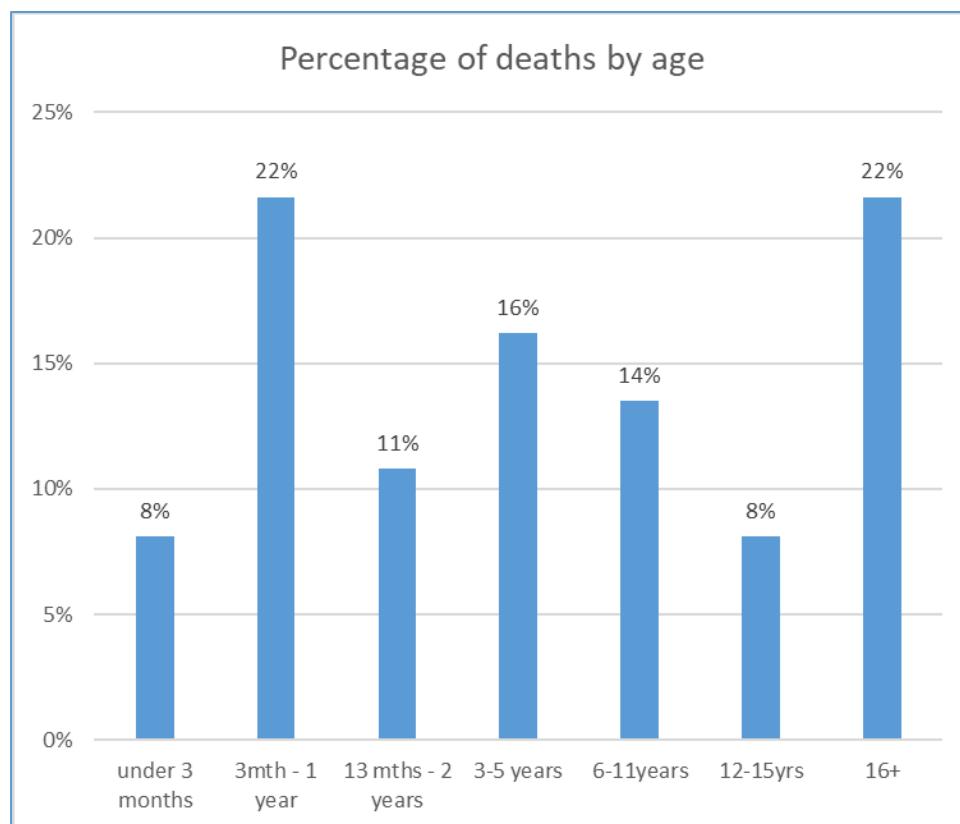


<sup>13</sup> The London, Kent, Surrey and Sussex Regional Searching Guidance (Jan 2020) Regional Searching Protocol Working Group.

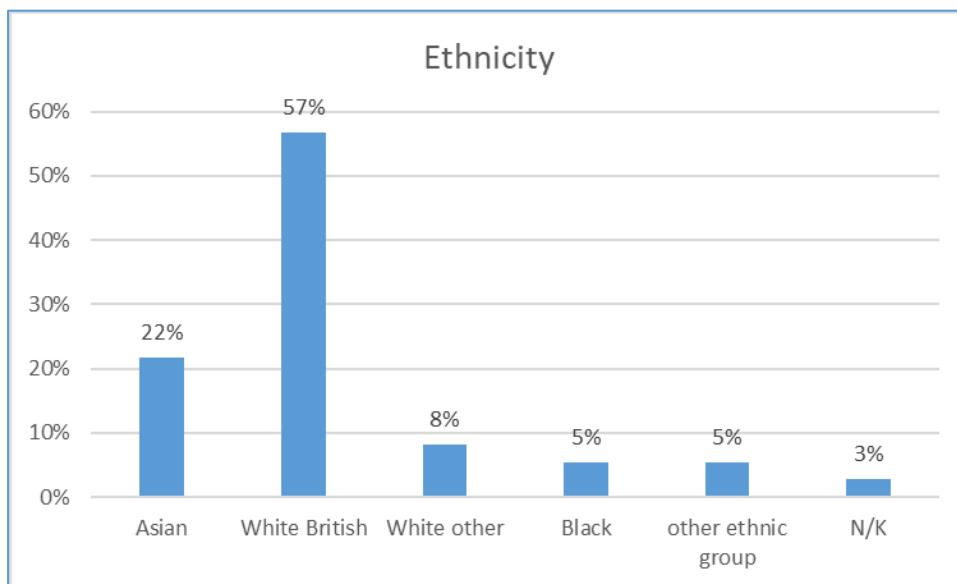
**Chart 8: Gender of the babies and children in the review.**



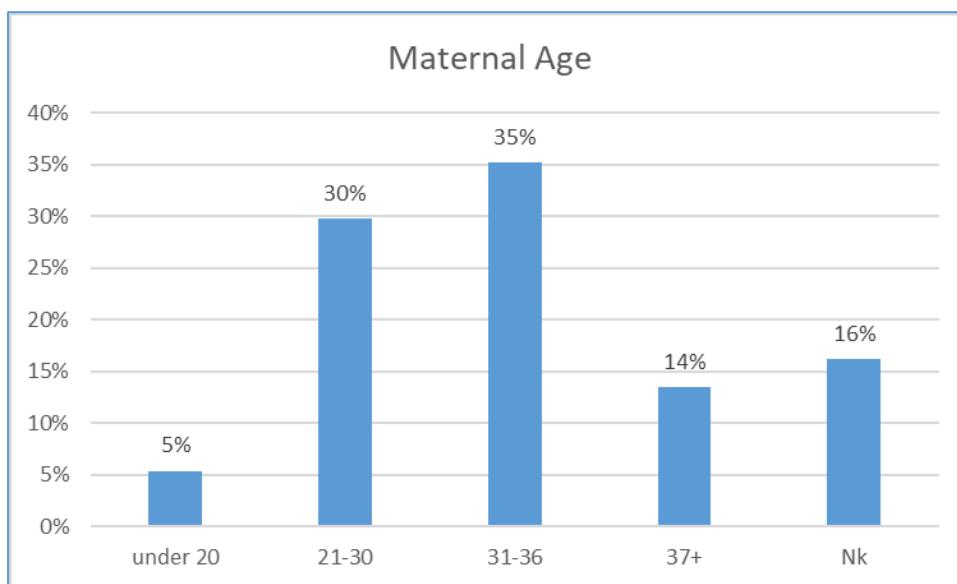
**Chart 9: Percentage of deaths by age for children included in the review**



**Chart 10: Ethnicity of children included in the review**

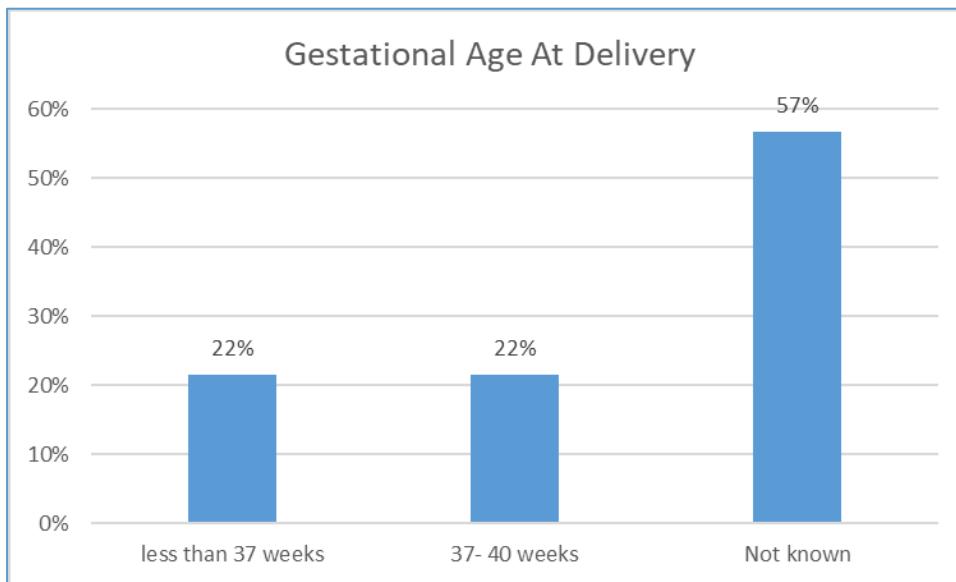


**Chart 11: Maternal age when child was born.**

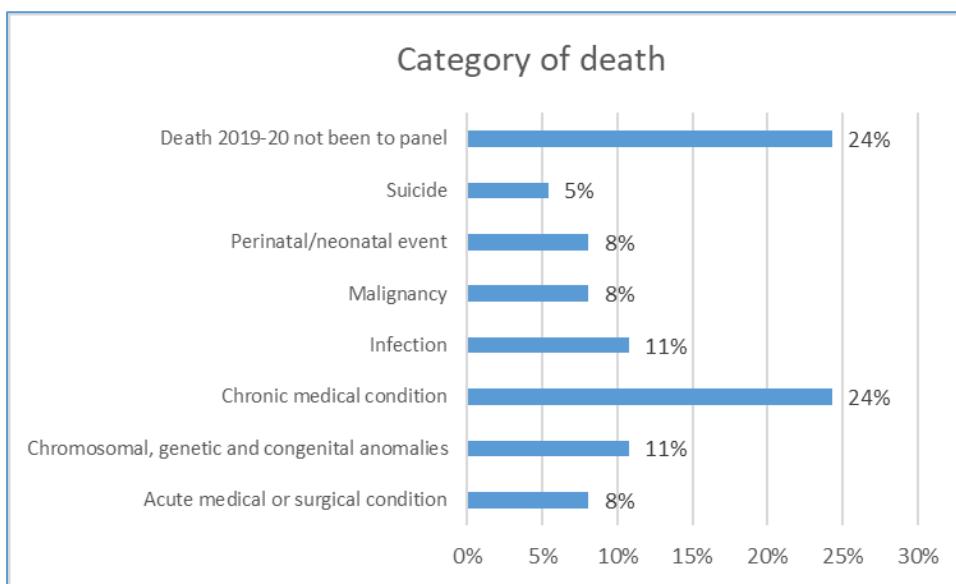


The average maternal age within Surrey between 2010-17 was 30-34 years (ONS 2019).

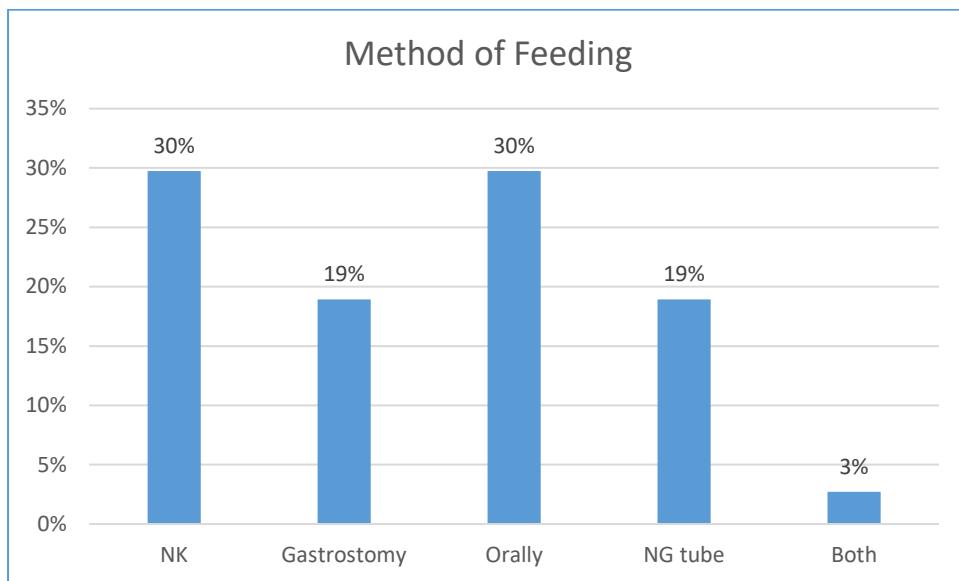
**Chart 12: Gestational age at Delivery**



**Chart 13: Category of death as assigned by Surrey Child Death Overview Panel**

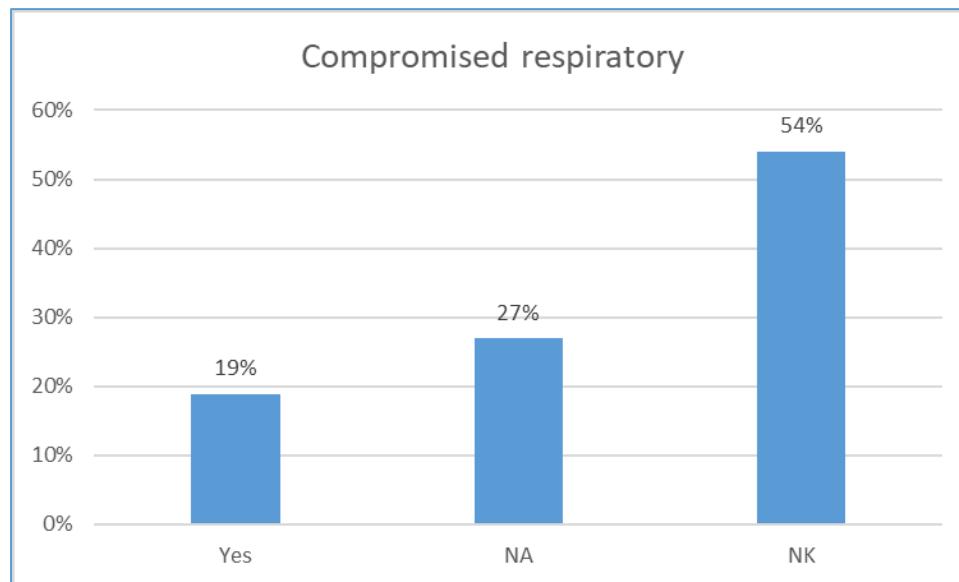


### **Chart 14: Method of feeding**



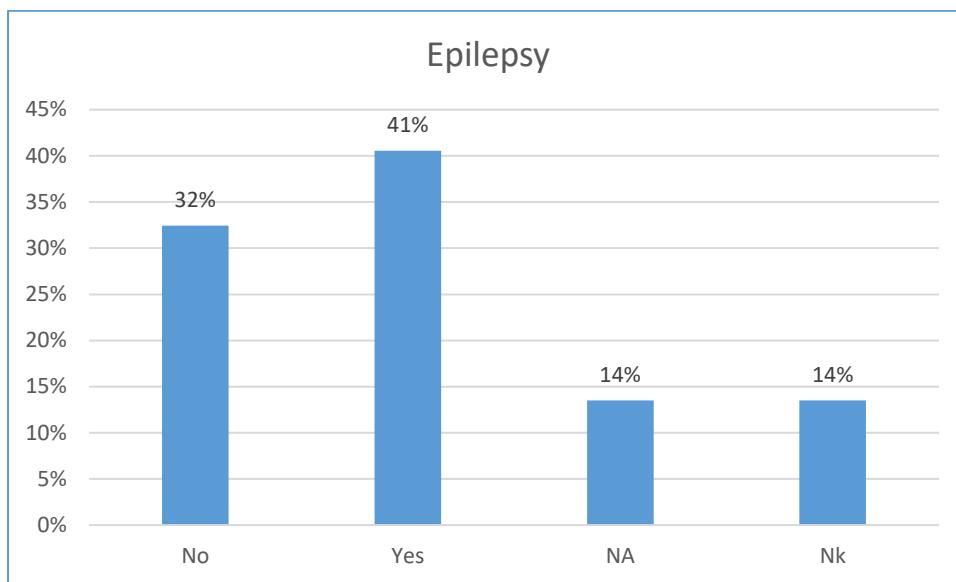
There are known increased risks of aspiration and dysphagia with some non-oral feed methods. The graph illustrates a gap in our data collection in this area, this something we are working to improve in the future. Currently it presents a complex picture that requires further investigation.

### **Chart 15: Percentage of babies and children with compromised respiratory function.**

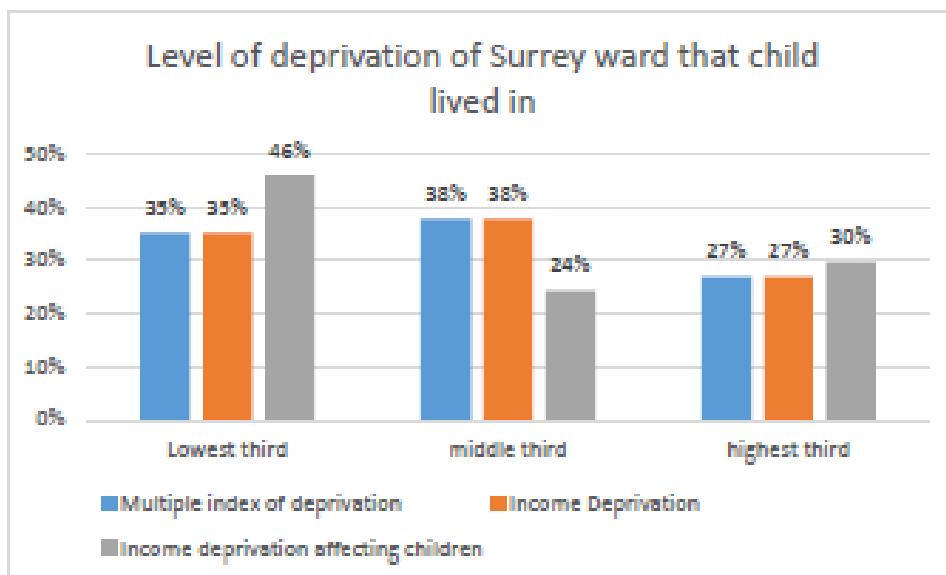


This graph also highlights a gap in our data collection and we are working to improve collection of this data.

**Chart 16: Percentage of babies and children with a diagnosis of Epilepsy**



**Chart 17: Level of deprivation by Surrey ward that child was resident in**

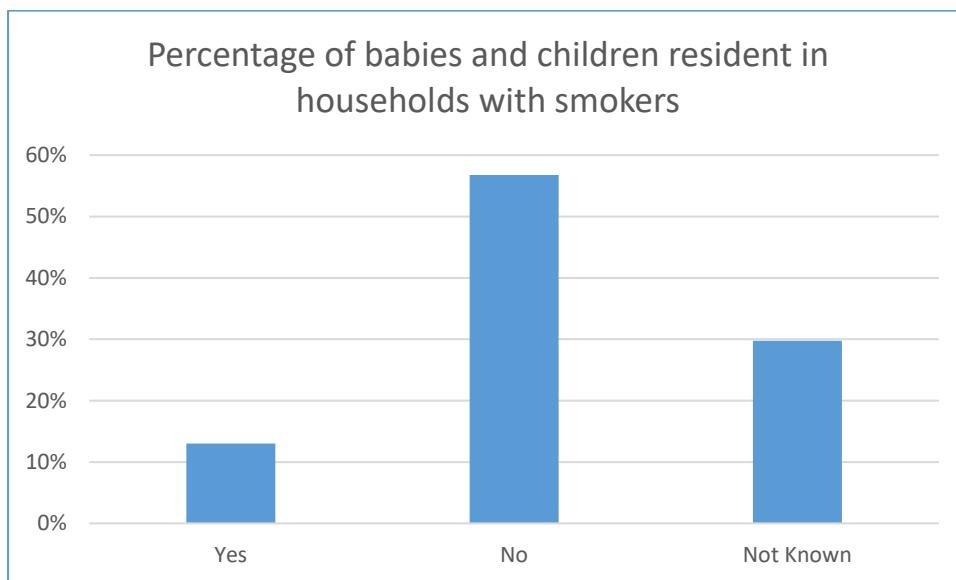


**Table 3: Income effecting children in Surrey, comparison of all cases with neurodisability cases.**

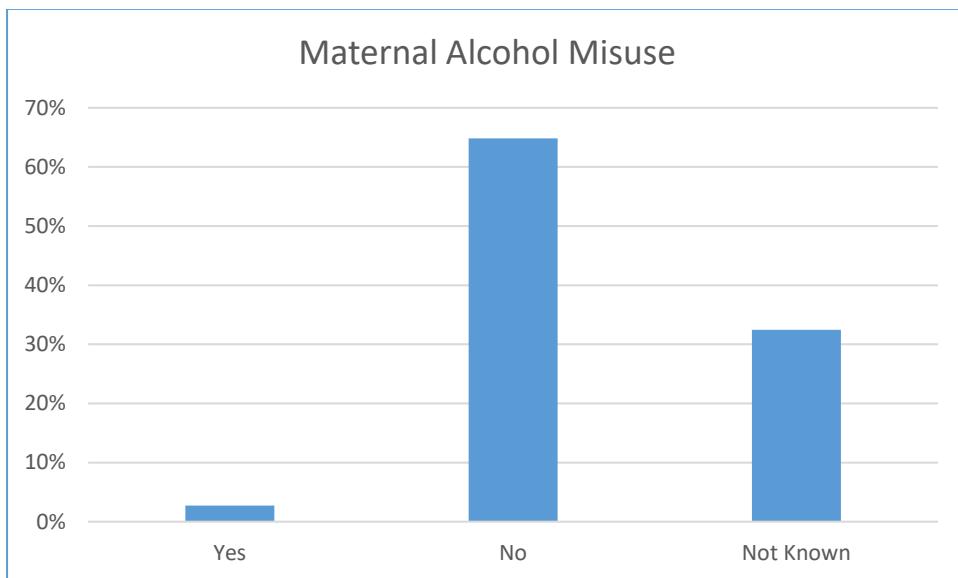
Income affecting children in Surrey	Neurodisability cases (37)	All cases (233)
Lowest third	46%	41%
Middle Third	24%	37%
Highest third	30%	22%

For the lowest and top third of income affecting children the percentage of children dying with a neurodisability is higher than the percentage for all children.

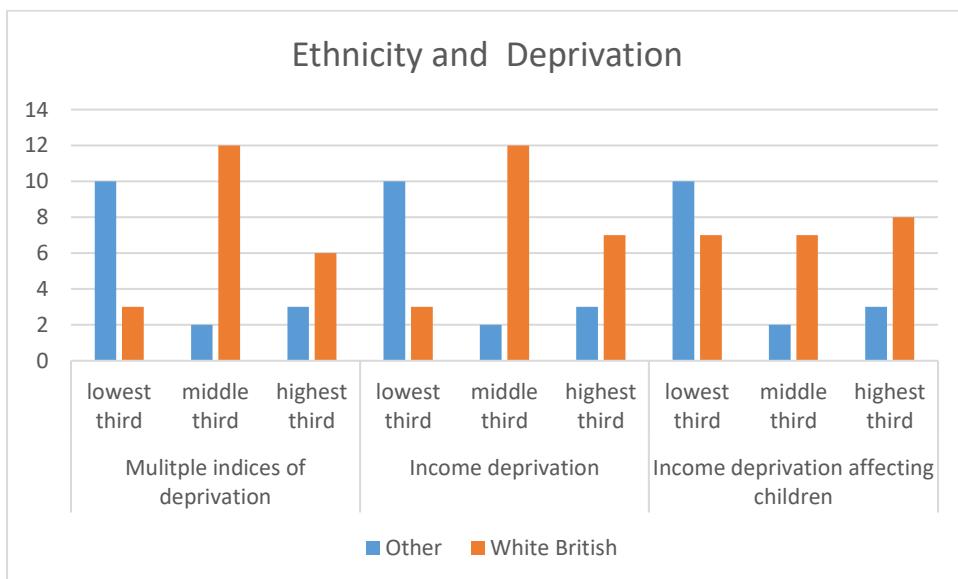
**Chart 18: Percentage of babies and children resident in households with smokers**



**Chart 19: Percentage of babies and children resident in households where maternal alcohol misuse has been identified.**

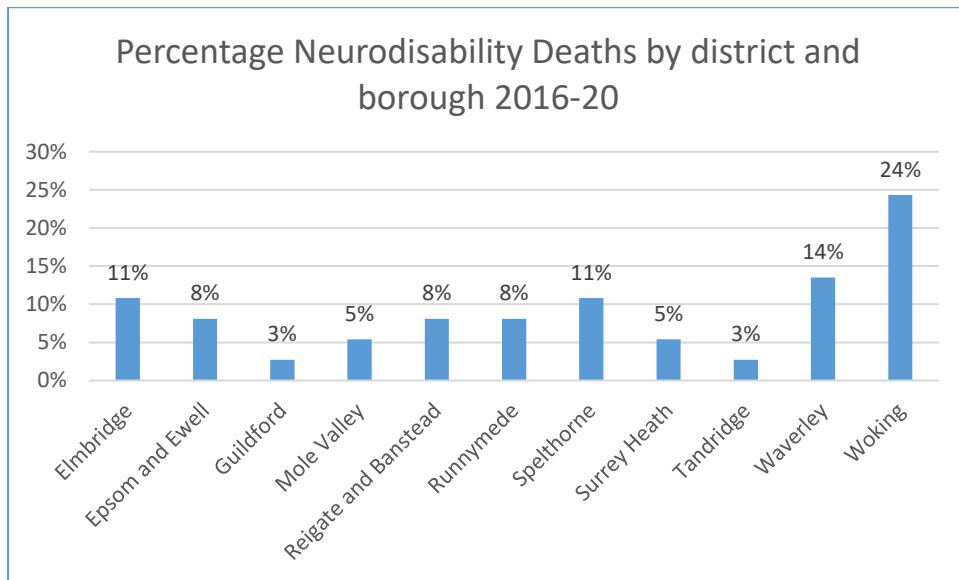


**Chart 20: Breakdown of Ethnicity in relation to poverty**

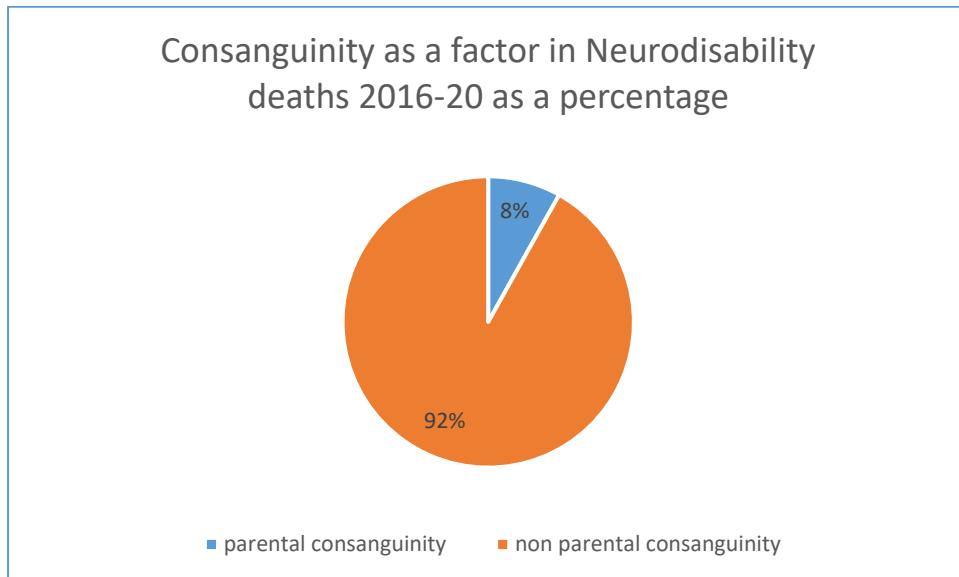


Whilst the numbers are too small (less than 3) to show the breakdown of deaths by ethnicity other than White British, the majority of the children whose ethnicity is Asian were in the lowest third for each of the above areas of deprivation.

**Chart 21: Percentage of neurodisability deaths by district and borough**



**Chart 22: Neurodisability deaths where consanguinity was a factor as a percentage**



## **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 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**

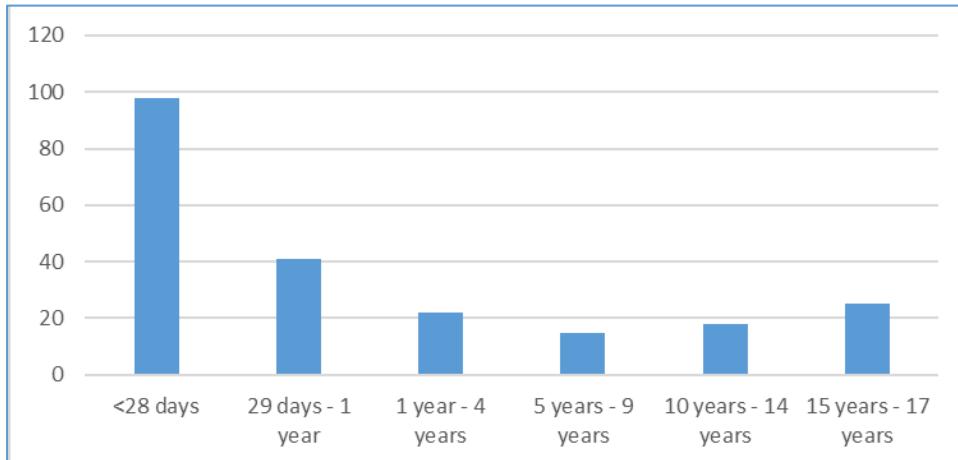
Whilst there is no advice that completely guarantees prevention of neurodisabilities it is possible to reduce some risk factors and also to improve gaps in care which then enhances standards of care and quality of life. There are a number of well documented issues and risk factors which have been highlighted in this review process.

### **6.1 Lack of Advanced Care planning and training for professionals.**

During this review there were discussions around the planning prior to death with the families of children with life-limiting conditions. Children with life-limiting conditions sometimes die following prolonged illnesses. In these situations, the best time to start supporting the family is while their child is still alive; 'parallel planning' is the term used to describe plans made for end of life while active treatment is still being pursued. It often involves a palliative care team. In parallel planning, consideration should be given to identifying a 'team around the family', writing an advance care plan, and giving thought to cultural and religious requirements. A child or family may choose to be cared for at home or in a hospice at the end of life. Parallel planning allows the clinical team to plan how best to move the child from the hospital (if appropriate) and to ensure that there are staff in place with the right skills to provide the appropriate level of care. Planning for death also allows discussions relating to organ and tissue donation to occur.

## 6.2 Age at death

**Chart 23: Age at death of all Surrey children notified to CDOP April 2014 – March 2018**



Deaths of the children with neurodisabilities were not representative of ages of child death in the general Surrey population. The above chart show that the age distribution of deaths in children in Surrey which follows an expected pattern linked to national trends with most deaths being seen in children in the first month of life and ¾ of child deaths occurring before the age of five.

## 6.3 Consanguinity

Consanguineous marriage is a union between couples related as second cousins or closer. Globally, 10.4% of the population are married to a biological relative or a progeny of such a relationship. It is also preferred among some families and communities in the UK. There are potential social, economic, and genetic advantages to consanguineous marriages but since blood relatives are more likely to carry the same gene variants than unrelated people, a higher incidence of autosomal recessive genetic disorders ensues. This manifests as higher population rates of congenital abnormality, infant and child mortality. Congenital abnormalities occur in 2-3% of pregnancies however this risk is doubled in consanguineous couples to around 6% (Sheridan et al., 2013)<sup>14</sup>. In their 2020 annual report the National Child Mortality Database stated that “the elevated risk is often exaggerated and the great majority of births to cousins are not affected by autosomal recessive genetic conditions. Risk clusters in families, and research shows that access to genetic information, counselling and testing is often poor for people in families where deleterious gene mutations exist. CDOPs reported the presence of consanguinity as

<sup>14</sup> [Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study - PubMed \(nih.gov\)](#)

a ‘modifiable’ factor in 33 deaths reviewed this year. The majority of these were categorised as deaths due to chromosomal, congenital, or genetic anomalies. Unlike other child deaths, most deaths caused by autosomal recessive genetic conditions are not avoidable through medical treatment or better care of the pregnant woman or child. Instead, reducing these deaths implies reducing conceptions and/or reducing the number of affected babies being born (i.e. termination of pregnancy). Clearly, both the decision to become pregnant and to terminate a pregnancy are personal choices with significant moral and religious considerations. Further work is therefore needed to clarify whether deaths of babies to consanguineous couples were anticipated, that is, whether it was the couple’s choice to proceed, and whether couples are receiving access to the information and support they need to make such difficult decisions in an informed manner. The labelling of consanguinity in-and-of-itself as a modifiable risk factor should be refined in future CDOP reporting, since the key focus must be on the presence of genetic mutations that present risk”.<sup>15</sup>

The percentage of consanguineous deaths of children and babies included in the review is 8%, there is no clear data on the percentage of consanguineous births in Surrey, but we do that in the general population in England they account for 8% of births. Further investigation of this is required. A number of areas in the UK where there is a high prevalence of consanguinity have implemented interventions to respond to the increased genetic risk associated with consanguineous marriage and further work needs to be undertaken to consider if such an approach should be undertaken in Surrey.

#### 6.4 Ethnicity

22% of the babies included in the review were Asian. In Surrey 86.7% of the population aged 0-17 are White (81.7% White British), 5.0% are mixed, 6.3% are Asian/Asian British and 1.1% Black/Black British. The relatively low numbers of the children included in the review mean it is not possible to be statistically significant however current data does suggest that the pattern of deaths does not match the ethnic distribution within the live population.<sup>16</sup> We do know from national data that babies of mothers who were themselves born in India, Bangladesh and East Africa have an increased risk of death, and babies of mothers born in the Caribbean, the rest of Africa and Pakistan have double the risk compared with babies of mothers born in the UK (ONS data). We also know from national data that infant mortality in the Gypsy Roma Traveller community is three times higher than in the rest of the population.

In Surrey the percentage of deliveries to mothers from black and minority ethnic (BME) groups in 2015/16 was 10.2% in Guildford and Waverley CCG, 23.5% in North West, 27.9% in Surrey Downs, this compares with a national rate of 29.8% and a local rate in the South East of 20.2%.

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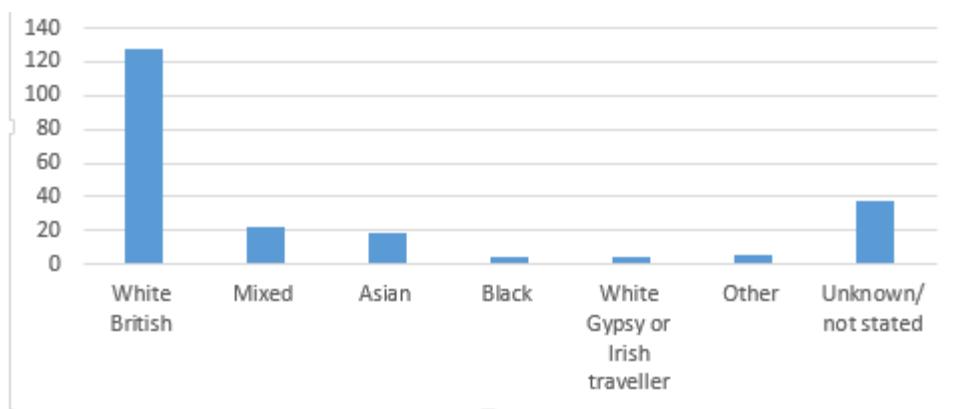
<sup>15</sup> [NEW: NCMD second annual report published | National Child Mortality Database](#)

<sup>16</sup> Office for National Statistics Census 2011 data from table (DC2101EW: Ethnic group by sex by age)

Nationally for babies born in 2015 with a known gestation, the lowest infant mortality rate was to babies in the white other ethnic group at 2.2 deaths per 1,000 live births.

We know from our four year CDOP report that the pattern of deaths of infants and children from BAME backgrounds does not match the pattern in the general Surrey population either.

**Chart 24: Ethnicity of all Surrey children who died and their death was reviewed by CDOP between April 2014 and March 2018**



## 6.5 Prematurity

22% of the babies and children included in the review were born before 37 weeks, this compares with around 8% of births in the UK which are preterm.<sup>17</sup>

## 6.6 Parental smoking

Smoking prevalence in adults in surrey in 2019 was 10% and smoking at time of delivery was 7.3%, whilst probably not statistically significantly higher at 13% in the households in which the babies and children included in the review lived, we do know that reducing exposure to second hand smoke both in households and in-utero would reduce the potential harm to these babies and children.

## 6.7 Neglect and Deprivation

A number of the children in the review were known to children's social care and had social services involvement it was not often clear which child had a disability social worker or not. 14% were known to social care, some of these families were referred

<sup>17</sup> [Premature birth statistics | Tommy's \(tommys.org\)](https://www.tommys.org/pregnancy-and-birth/birth-statistics/premature-birth-statistics)

for issues around neglect, this may highlight the added stress on families supporting their child with disabilities.

Of the children included in the review they were a higher percentage living in areas where income deprivation affects households with children and when this was broken down by ethnicity children who were Asian were more likely to be living in the areas within the lowest third in terms of income deprivation in Surrey.

## 6.8 Family engagement

Themes identified from parents and carers during this thematic review included:

- Parental concerns around delays in diagnosis and management of care for example “some parents felt that their concerns about their child were not taken into account e.g. if the doctor felt that our child did not have hypermobility, why were there no further investigations? Why did SALT discharge the child for not meeting targets? Should the targets not be changed to increase support? Furthermore a lack of information sharing between two hospitals which resulted in test results not being shared and the care pathway offered was questioned by parents”.
- Breakdown in communication between carers and professionals for instance mother reported “ poor care on the children’s ward and felt the doctor in charge was not listening to her concerns regarding her child’s deterioration which resulted in heated conversations. This then led to the child being transferred to a different hospital which mother was happy about’.
- Lack of advanced care planning; “written communication in relation to the advanced care plan was meant to have been completed however documentation was not made available to the local team. In addition the family attended a hospital about 10-12 times using the open access protocol however communication regarding the management of care was reported to remain poor which resulted in delayed treatment for the child”.

## 7 Opportunities not be missed

**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 improve gaps in care of children with a neurodisability.

- There should be full implementation of NICE guidance (2017) on end of life care for infants, children and young people. There should be clarity around advanced care plans for end of life care and there is a need to train professionals around implementation of advanced care plans. Professionals should also receive training on having difficult conversations with parents in

relation to thresholds for intubation and decisions around giving life support or not following local and national guidance/policies.

- All parents/carers should be offered an opportunity to have a conversation with their paediatric team following the death of their child.
- There should be improved access and co-ordination of services/appointments for children seen by the multidisciplinary team.
- In line with recommendations in the LeDeR annual report, services should link together within systems to improve information sharing and communication between professionals, this would allow for understanding and support around missed appointments, discharge summaries or change of circumstances, amongst other issues. General Practitioners should be aware of the potential multifaceted needs of this group of patients and access published care pathways as required.
- There should be better support for parents and carers with children with a neurodisability offering better person and family centred care including respite care with a more coordinated approach and multidisciplinary team working which is key for this group of complex patients.
- There should be further investigation and identification of the prevalence of consanguinity amongst the population of babies and children with a neurodisability in Surrey. It may be appropriate for genetic counselling to be offered to these parents before conception.
- Surrey Safeguarding Children’s Partnership SSCP) Neglect Strategy 2021-2023 should be implemented across the system.
- The Oliver McGowan Mandatory Training in Learning Disabilities and Autism should be completed by all staff working in health and social care so they receive learning disability and autism training, at the right level for their role. They will have a better understanding of people’s needs, resulting in better services and improved health and wellbeing outcomes<sup>18</sup>
- The Child Death Review Partnership should ensure that there is effective information gathering of data around;
  - modifiable factors in the neonatal period from the respective hospitals.
  - oral feeds, gastrostomy feeds and the management of these.
  - CAMHS involvement and parent’s mental health.
  - birth information including apgar scores.
  - factors relating to poverty including receipt of benefits and housing conditions.
  - recording if an end of life plan existed.
  - the types of social care involvement.

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<sup>18</sup> [The Oliver McGowan Mandatory Training in Learning Disability and Autism. | Health Education England \(hee.nhs.uk\)](https://www.hee.nhs.uk/oliver-mcgowan-mandatory-training-learning-disability-and-autism)

- There should be full implementation of the NICE Quality Standard on Ante-Natal care to reduce the risks to the unborn child that may potentially lead to a neurodisability.<sup>19</sup>
- 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<sup>20</sup>.

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<sup>19</sup> [Overview | Antenatal care | Quality standards | NICE](#)

<sup>20</sup> [Overview | Promoting health and preventing premature mortality in black, Asian and other minority ethnic groups | Quality standards | NICE](#)

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