



Norfolk Safeguarding  
Children Board

**NHS**

Norfolk and Waveney  
Integrated Care Board

# NORFOLK & SUFFOLK CHILD DEATH OVERVIEW PANEL (CDOP)

Annual Report 2022 - 2023



Suffolk  
Safeguarding  
Partnership

**NHS**

Suffolk and North East Essex  
Integrated Care Board (ICB)

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# INTRODUCTION

The two local Child Death Overview Panels (CDOP), one for Norfolk and one for Suffolk, review the death of every resident child aged under 18 years in Norfolk and Suffolk. They report in respectively to Norfolk and Suffolk Safeguarding Children Partnerships.

In October 2018, the Department of Health and Social Care (DHSC) assumed national leadership of the child death review process and published guidance; *Child Death Review: Statutory and Operational Guidance (England)*<sup>1</sup> for reviewing the deaths of all children<sup>1</sup> regardless of the cause of death. This guidance aims to put bereaved families at the heart of the review process.

It also aims to standardise practice and outputs to enable thematic learning.

The data collected is uploaded to the National Child Mortality Database (NCMD) via the use of E-CDOP software which captures data from CDOPs across England in one place. This makes it possible to draw out a greater level of background information regarding children who die and the factors that may contribute to their deaths, enables a more systematic approach to reducing child death where possible and assists learning about how best to support bereaved families<sup>1</sup>. NCMD produces annual monitoring and occasional thematic reports into specific areas of practice.

The Child Death Overview Panel (CDOP) annual report is a summary of the activity carried out by the panels in line with the national guidance which include child mortality trends, causes of death, modifiable factors, actions taken, and any lessons learnt – all of these are considered by each CDOP for every child death. The aim is to seek to improve outcomes for children across Norfolk and Suffolk.

This report summarises the work of both CDOPs and the cases that have been reviewed in the period from April 2022 to the end of March 2023.

Each county has established a specific Child Death Review Team (CDRT) Suffolk since 2019 with Norfolk following from April 2021. These have both proved instrumental in improving the quality and effectiveness of practice.

The CDOP process is important, can be challenging and is rewarding. Thanks are due to all those who have taken part and contributed to this process in Norfolk and Suffolk.

<sup>1</sup>[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf)

<sup>2</sup> before their 18<sup>th</sup> birthday

<sup>3</sup>[https://www.ncmd.info/wp-content/uploads/2021/06/NCMD\\_2nd\\_Annual\\_Report\\_June-2021\\_web-FINAL.pdf](https://www.ncmd.info/wp-content/uploads/2021/06/NCMD_2nd_Annual_Report_June-2021_web-FINAL.pdf)

# Executive Summary

During 2022/23, Norfolk and Suffolk CDOPs met on **15** occasions (8 in Suffolk; 7 in Norfolk). There were **88** deaths of Norfolk and Suffolk resident children aged under 18 years old notified to CDOP during this period, compared to 84 in 2021/22, 60 in 2020/21, 79 in 2019/20 and 50 in 2018/19. The pattern of age groups notified reflected that in England as a whole. Although the majority were neonates, 0-27 days (34%) this was a lower proportion than the England average of 41%. The percentage of infants aged 28-364 days was the same (18%) as for England. The distribution for the other age groups was like England (11-13%).

In 2022/23 the two CDOPs reviewed **89** deaths between April 2022 and March 2023, of which **46** reviews were in Norfolk and **43** in Suffolk. This was an increase from 2021/22 when 63 cases were reviewed. The numbers of reviews fluctuate year-on-year but show the work of the child death overview panel. The pattern of cases reviewed varies. It is hard to make much of this due to small numbers. Norfolk and Suffolk have been able to compare their figures with other counties in the Eastern region which helps to identify any significant outliers.

## Key findings were:

Of the **89** deaths reviewed over **59.5% were under 1 year of age. 39 (43%) were neonates (0-27 days), and 14 were infants aged between 28 and 364 days.**

The main categories of death across all the age groups were **'perinatal/neonatal event', 'chromosomal, genetic, and congenital anomalies', 'malignancy', 'sudden unexpected unexplained death', 'infection', 'suicide or deliberate self-inflicted harm' and 'trauma and other external factors, including medical/surgical'.**

The proportion of modifiable factors identified (Figure 10) was greatest in children aged 15 – 17 years old, where 5 out of 9 cases (56%) were considered to have modifiable factors, followed by 10 – 14 years where 3 of the 8 cases (38%) had modifiable factors identified. Most modifiable factors (n=14) were identified in neonates (n=39). Modifiable factors were identified in a range of categories of death.

Nationally, modifiable factors were identified most frequently in deaths (Figure 11) that were classed as SUDI and those where children died due to 'deliberately inflicted injury, abuse or neglect' (2021 NCMD data for England).

Norfolk and Suffolk took a median of **226** days between the child's death and CDOP meeting. This is not significantly different from last year's average of 223 days and is significantly faster than the England average of 335 days (Figure 3).

## Principal areas of learning:

We continue to see recurring themes.

The themes relate to:

**Communication:** everyone must be aware of the importance of clear communication especially ensuring that what has been said has been understood by the recipient.

**Information sharing:** This is linked to communication. It is a common theme in all areas of care and challenges arise due to lack of shared records, and anxieties and unwillingness to share important information.

**Record Keeping:** This is vital as it is the way that information is shared between clinicians. If information is not recorded; it cannot be evidenced to have happened.

**Assessments:** it is important that assessments are thoroughly completed, whether this is a clinical or social assessment. Professional curiosity and talking to others are vital to ensure we are as rigorous as possible.

**Parental factors:** There are several cases in which parental behaviours affecting health such as smoking, recreational drug and alcohol use, obesity and neglect of their children's care affect a child's well-being. Services can only try to encourage adults to change their behaviours and ensure that where they exist suitable interventions are persistently offered even after any initial refusal to accept. It is important that professionals consider the potential impact of parental behaviours on their children's health and wellbeing.

**Safe sleeping environment:** This is a recurrent theme in cases of unexpected infant and early childhood deaths. A safe sleep area can reduce the risk for sudden infant death syndrome (SIDs) and other sleep related deaths. The importance of repeating the message about safe sleeping environments cannot be overemphasised.

**Training:** All organisations must encourage training and identify deficiencies where additional input could improve the situation. This can be a challenge as there are increasing amounts of required training mandated, and staff may become overloaded with 'opportunities to learn and improve'. Consideration should be given to which opportunities are key and would make the most difference for staff in their area of work.

**Listening to parents:** Parents feeling that they have not been fully listened to or understood is a common theme. Of course, it is very hard to make comparisons with all cases where children survive however, we need to be very cautious that we do not dismiss a parent's concerns without full consideration and a thorough assessment.



The guidance requires that Child Death Review Meetings (CDRM) are held to support the gathering of information and liaison between professionals involved in the case. This is not only to provide information but also to ensure the family and those involved in the child's life are supported.

## E-CDOP

E CDOP is thoroughly embedded now, and we have been using this system to collect data for five years. Notification of a child death can be made 24 hours a day via this link <https://www.ecdop.co.uk/NorfolkSuffolk/Live/Public> and will automatically be sent to the relevant CDOP Manager/Administrator and Child death review team. Notifications should be made as soon as possible. More than one notification may be sent. It is more important to make a notification than to wait for all the information to complete the form.

All the data is automatically uploaded to the NCMD at the point of notification and updated when cases are completed. If there is a safety alert this can be raised at the time of notification and will be sent to all CDOPs to be raised nationally.

NCMD not only produces national annual and individual reports but has started to produce a regional report using the data submitted from all the cases reviewed by CDOP panels.

# Unexpected Deaths

The commonest category of unexpected death in the cases reviewed was Sudden Unexpected Deaths in infancy/childhood (SUDI/SUDC), followed by infection, suicide/self-inflicted harm, and trauma.

There is a robust system to ensure multi-agency meetings are held after each unexpected death. Initial multi-agency/SUDIC meetings were chaired by Children's Services in both Norfolk and Suffolk during 2022/23. There were 21 joint agency responses in 2022-2023 although 2 were stepped down. Suffolk held 10 SUDIC meetings and Norfolk 9.

Serious Incident investigations are carried out within Hospital Trusts when a child dies unexpectedly during a hospital admission or there are concerns within an individual agency. Six Serious Incident Investigations were carried out in Suffolk between 01st April 2022 and 31st March 2023 and five in Norfolk.

All acute trusts hold Morbidity and Mortality meetings (M&M). They are held either via Microsoft Teams or face to face. Holding them via Microsoft Team has enabled staff from different organisations to be invited regardless of where the child has died. For children who die in tertiary hospitals out of area the review will be held in that hospital although sometimes the local hospital may also hold a review.

The final Child Death Review meetings is ideally held about 2 months after the death but will often be delayed due to waiting for a serious incident report, forensic post-mortem results, a criminal investigation an inquest or a safeguarding practice review. It should provide the best forum to discuss all the care and treatment provided and the opportunity for frank discussions about clinical care. However, this must be done constructively and with the aim of encouraging learning to try to prevent future deaths. It is a chance to consider questions from the child's family. It is also a chance to highlight good practice. The CDR meeting can also be helpful for staff who need support or want to talk about their experience after a child has died.

It is important that all partners work together to reduce delay as it can be challenging for families and staff and delays the dissemination of learning. It should be beneficial for all those who were involved in the care of the child to help understand what other professionals' roles are and provides a holistic review of the child and support to other professions who will have been affected by the child's death. It is important to include schools, voluntary organisations, and other non-clinical staff. It can be challenging for clinicians to discuss complex medical decision making with non-clinical professionals.

Of the cases reviewed in 2022 –2023 there were 3 safeguarding practise reviews in Suffolk and 1 in Norfolk. These reviews will delay the case being presented to CDOP. In addition, inquests will also delay a case coming to CDOP panel. Suffolk held 7 inquests and Norfolk held 12.

# Expected Deaths

For infants under a year of age, the main cause of death continues to be chromosomal, genetic, and congenital anomalies and perinatal deaths, most of which occur in the first 27 days of life in extremely premature infants.

For children over a year of age, deaths from chromosomal, genetic, and congenital anomalies are spread across all age groups. Deaths from malignancy (11/89) also occur within all age groups.

There were 2 deaths in children with a chronic medical condition. It is important that we do not misclassify this group. If a child has cerebral palsy as a consequence of a perinatal/neonatal event the category of death should be perinatal/neonatal even if the child dies aged 17. The NCMD report on *The Contribution of Newborn Health to Child Mortality across England* provides good evidence of the impact of how illness around the time of birth affects the health of children at any age and draws out learning and recommendations for service providers and policymakers.

The palliative care teams have regular multi-agency meetings in place for children expected to die with malignancy. In general, the teams who are well known to the families will act as key workers for the families and take the lead in providing support for them. These children are often well known to the local hospice team.

It is important that The Child Death Review Teams work with the haematology /oncology teams and palliative care teams to embed the statutory process of child death reviews and collation of information about the cases. It is important to reduce any duplication of work from internal debriefs and mortality review meetings. The teams aim to gather information about management of malignancy and other palliative care cases for the National Child Mortality Database.

It is important that the hospital that the child presents to is involved in review meetings to ensure any learning is shared with staff. If the child died out of area, then the hospital where they died usually hold the final meeting.

## Perinatal Mortality Review Tool

The Perinatal Mortality Review Tool (PMRT) is a standardised national tool which was developed to support high-quality standardised perinatal reviews. It was developed through a collaboration led by MBRRACE-UK<sup>4</sup> and was released in January 2018.

There is an expectation that all neonatal units use the PMRT to review all deaths of babies born after 22 weeks, who die within 28 days, or after 28 days if they were receiving neonatal care. It has taken time to implement this tool locally due to staffing levels and provision of sufficient support to enable the administrative processes.

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<sup>4</sup> MBRRACE is a report which is led by the National Perinatal Epidemiology Unit, at the University of Oxford, this report is an analysis and investigation into the cause of maternal death, stillbirths, and infant death.

The PMRT focuses on clinical care. CDOP processes have a wider, more holistic approach. Thus, they overlap but do not duplicate. The review of babies who die in hospital is very important and consideration should be given to involving the coroner for any deaths that were unexpected, either due to the circumstances at the time of delivery or subsequently on the neonatal unit.

## Integrated MBACE/eCDOP

In 2022 Norfolk and Suffolk joined a pilot project from NCMD to develop a single notification system whereby midwifery staff would notify MBACE, and it would automatically notify E-CDOP. It has taken some time to iron out the issues that have arisen during the pilot regarding information pulled from one system into another. The plan is to roll out to all CDOPs over the next year in 2023 to 2024.

# Child Death Review Teams (CDRTs)

**Suffolk:** The team is made up of 3 nurses (2 FTE) and an administrator (0.8 FTE). The team have had changes of staff over the last year. Two of the nurses have been in post since the creation of the team in 2019, with the third joining the team in August 2022. The team administrator left her post in March 2023 and a new administrator appointed May 2023.

**Norfolk:** The team is made up of 3 nurses (2.2 FTE) and a part time administrator 0.5 WTE has now been in place for two years.

The purpose of the CDRT's is to:

- co-ordinate the health response for Norfolk and Waveney and Suffolk following all child deaths, including co-ordination of Child Review Meetings, information gathering and sharing.
- share information with the Child Death Overview Panel.
- support the Designated Doctor for Child Deaths.
- act as a key worker for the family where appropriate.
- ensure that all families and professionals are fully supported throughout the child death review process.
- provide training and development on the Child Death Review Process and learning from child deaths across the health economy to ensure the process is conducted as effectively as possible and that learning is shared to prevent future child deaths.
- work with the LeDeR teams to complete a LeDeR review.
- work closely with relevant professionals to promote best practice around palliative care.

# CDOP Panel Activity Data

## 2022 – 2023

### Notifications of deaths

There were **88** deaths between 1<sup>st</sup> April 2022 – 31<sup>st</sup> March 2023, of which **45** were in Norfolk and **43** in Suffolk. Over the last three years the number of notifications has varied. There were 84 deaths in 2021/22 during the second year of the COVID-19 pandemic (**45** in Norfolk; **39** in Suffolk), 60 deaths in 2020/21 during the first year of the pandemic (33 in Norfolk; 27 in Suffolk) and 78 in 2019/20 (42 in Norfolk; 37 in Suffolk).

To contextualise the **88** deaths relative to the population, Table 1 shows mid 2021 population estimates for 0 – 18 years old (the most updated population estimates published by ONS), the number of deaths, and the rate per 100,000 people aged between 0 – 18 years old for Norfolk and Suffolk. The table shows that there were 27 deaths per 100,000 children and adolescents in Suffolk and in Norfolk, 25 deaths per 100,000.

Table 1

	Population estimate 0 – 18 years old	Number of deaths	Rate per 100,000
Norfolk	176,700	45	25
Suffolk	155,100	43	27

Neonatal deaths remain the highest proportion of notifications, followed by infants aged 28 - 364 days. This has been consistent over the last three years. For infants aged less than 364 days, there were 46 death notifications in the 2022/23 period. Of those 30 deaths (34%) were neo-nates compared with 35 in 2021/22.

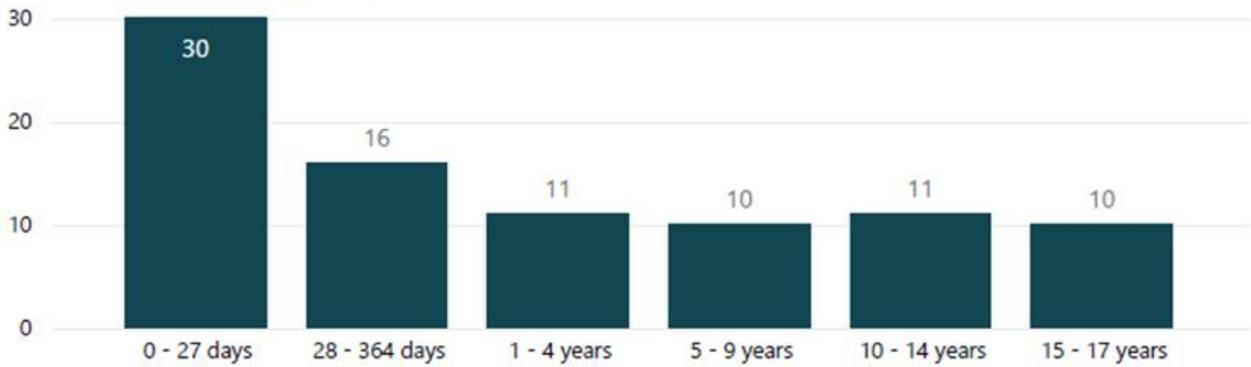
Of the neonatal death notifications in the 2022/23 period, 17 babies (56%) were 23 weeks or less gestation at death. There were 8 babies born between 24 weeks and 36 weeks and 5 babies born greater than 37 weeks.

Over the last three years across the eastern region there has been an increase in notifications of babies born at 23 weeks or less who subsequently die.

When death notifications were examined according to month, the numbers varied from 11 in February 2023 to 4 in June 2022. When compared to previous years, no significant trend was observed.

Figure 2

Death notifications by age group



% of death notifications by age group - CDOP



% of death notifications by age group - National (England)



# CDOP Cases Reviewed 2022-2023

## Number of Reviews

In 2022/23 Norfolk and Suffolk CDOP panels reviewed a total of **89** deaths (**46** Norfolk and **43** Suffolk). This was 41% higher than 2021/22 when 63 cases were reviewed. A significant increase in workload for the two CDOPs.

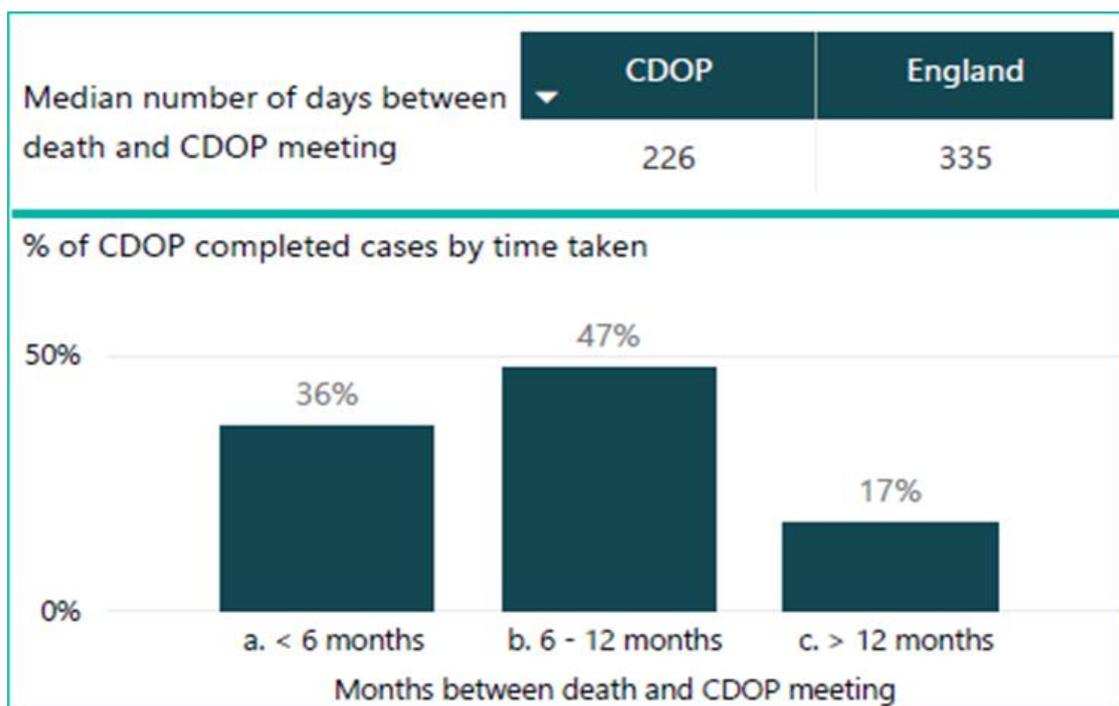
Table 2<sup>5</sup>

	Neonatal deaths reviewed (0-27 days)	Total deaths reviewed
2019/20	13	53
2020/21	35	79
2021/22	25	63
2022/23	39	89

## Duration of Review

Of the **89** reviewed cases across Norfolk and Suffolk, **83%** of cases were completed within 12 months of the child's death, with **36%** of cases completed within 6 months of the date of death. Norfolk and Suffolk took a median of **226** days between the child's death and the CDOP meeting. This is similar to last year's average across both counties (223 in 2021) and substantially (33%) better than the national picture (Figure 3).

Figure 3



<sup>5</sup> Table 2 shows there were fewer neonatal reviews in the previous year due to cases being held back.

The time taken to complete reviews reflects the individual circumstances and the complexity of cases, including necessary investigations from hospitals, coroner's inquests (which were further delayed by the COVID-19 pandemic), criminal investigations, and Child Safeguarding Practice Reviews.

There were 21 joint agency responses of which 12 were in Suffolk although 2 of these were subsequently stood down as the cause of death became clear. There were 9 in Norfolk.

Criminal investigations can take well over a year before concluding. In 2022/23, there were **2** cases in Norfolk (one due to non-accidental injury which went to court and the other a road traffic incident where no criminal action was pursued) and **2** cases in Suffolk, where no further action was taken.

Suffolk hospitals undertook '6 Serious Untoward Incident' investigations and Norfolk undertook 5.

There were 7 inquests in Suffolk and 12 in Norfolk, one was a Waveney child.

There were 3 Safeguarding Children Practice Review in Suffolk and 1 in Norfolk.

There is an option to alert NCMD if there is a risk of serious harm identified. No alerts were made from Suffolk in this recording year. Norfolk alerted about the risk of strangulation from unsecured wires to baby monitors/video equipment in babies' rooms.

### Record of attendance at Norfolk CDOP 2022/23

<b>CDOP Attendance 2022-2023</b>			
<b>26-May-22</b>	<b>28-July-22</b>	<b>15-Dec-22</b>	<b>26-Jan-23</b>
22 Attended	22 Attended	23 Attended	22 Attended
2 Apologies	3 Apologies	4 Apologies	6 Apologies

<b>CDOP Neonatal Attendance 2022-2023</b>		
<b>23-Jun-22</b>	<b>22-Sep-22</b>	<b>23-Mar-23</b>
19 Attended	24 Attended	21 Attended
11 Apologies	10 Apologies	10 Apologies

### Record of attendance at Suffolk CDOP 2022/23

<b>CDOP Attendance 2022-2023</b>				
<b>11-May-22</b>	<b>13-Jul-22</b>	<b>07-Sep-22</b>	<b>09-Nov-22</b>	<b>08-Feb-23</b>
23 Attended	19 Attended	23 Attended	22 Attended	18 Attended
18 Apologies	22 Apologies	18 Apologies	19 Apologies	23 Apologies

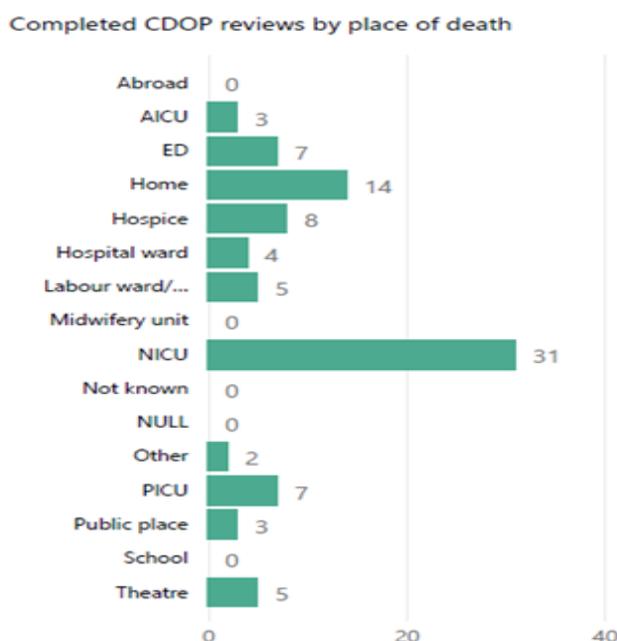
<b>CDOP Neonatal Attendance 2022-2023</b>		
<b>13-Apr-22</b>	<b>12-Oct-22</b>	<b>08-Mar-23</b>
Not Recorded	18 Attended	15 Attended
Not Recorded	37 Apologies	40 Apologies

# Summary of reviewed cases in 2022/23

## Location of Death

Norfolk and Suffolk CDOP reviewed **89** deaths in 2022/23 which occurred in the following settings: **14** at home, **7** in the emergency department of a hospital, **8** in a hospice, **3** in a public place, and the rest (**47**) in a hospital; **the majority in a neonatal unit** (Figure 4). This mirrors the national pattern.

Figure 4

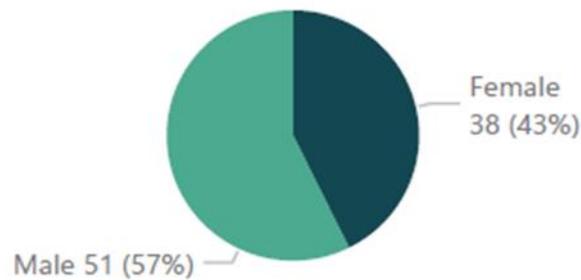


## Gender

Nationally the mortality rate is slightly higher for males than females (**males 56%; females 44%** for 2020/21 England child death notifications). Of the deaths reviewed across Norfolk and Suffolk, in 2022/23 **57% (44/63)** of deaths occurred in males and **43% (19/63)** (Figure 5).

Figure 5

Completed CDOP reviews by gender

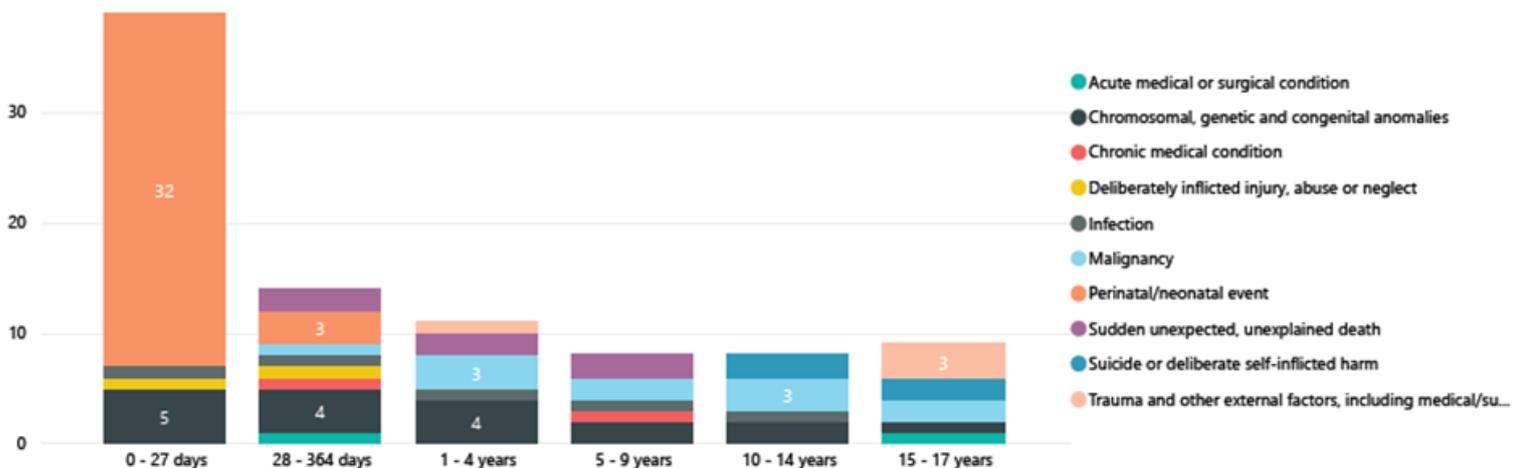


### Age

59.5% (53) of the 89 cases were of children under the age of one. There were 39 neonatal (0 - 27 days) and 14 infant (27 days – 364 days) deaths reviewed in Norfolk and Suffolk. The lowest number of deaths reviewed was in children aged 5 – 9 years and 10 – 14 years (8.9%, 8.9%, 8/89 and 8/89 cases respectively). (Figure 6).

Figure 6

Completed CDOP reviews by age group



### Ethnicity

In 2022/2023, ethnicity data was recorded in 97.7% (87/89) of cases (Figure 7). It was unknown in 2 cases (both neonatal cases). This is an improvement from last year when 9 cases did not have ethnicity recorded. Ethnicity was not known or not stated in 7.3% of cases from the 2021 England data.

Figure 7

Completed CDOP reviews by ethnic group and age group

Ethnic Group	0 - 27 days	28 - 364 days	1 - 4 years	5 - 9 years	10 - 14 years	15 - 17 years	Total
White	30	10	11	6	7	8	72
Unknown	2	0	0	0	0	0	2
Other	0	1	0	0	1	0	2
Mixed	4	1	0	2	0	0	7
Black or Black British	1	2	0	0	0	1	4
Asian or Asian British	2	0	0	0	0	0	2
<b>Total</b>	<b>39</b>	<b>14</b>	<b>11</b>	<b>8</b>	<b>8</b>	<b>9</b>	<b>89</b>

### Category of Death

Categories of child death are identified nationally and were provided to CDOPs by the Department for Education. Of the Norfolk and Suffolk child deaths, **35 (39.3%)** were due to perinatal/neonatal events, **18 (20.2%)** were due to chromosomal, genetic, or congenital anomalies, and **11 (12.3%)** due to malignancy). (Figure 8). There appears to be a rise in the number of deaths categorised as due to infection (5/89). Of the deaths reviewed in 2021-2022 and 2020-2021 there was just one case in each year categorised as infection.

Figure 8

Completed CDOP reviews by primary category of death

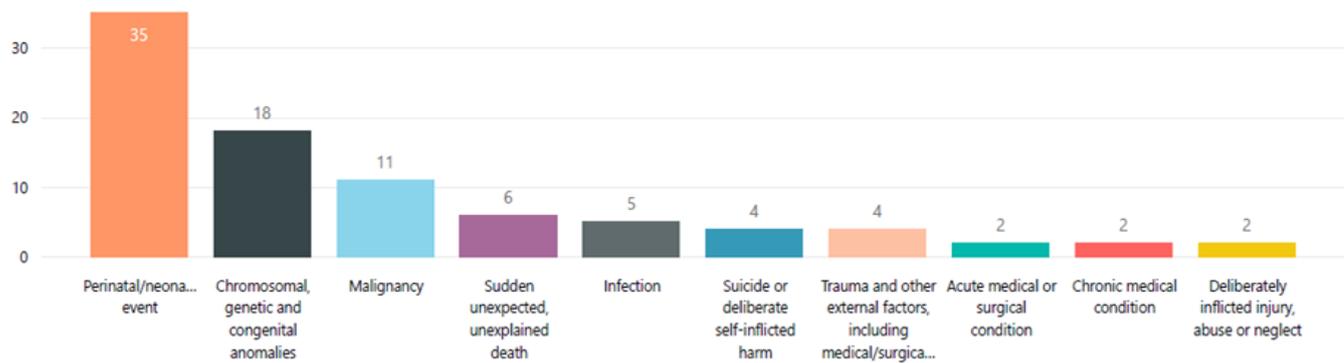
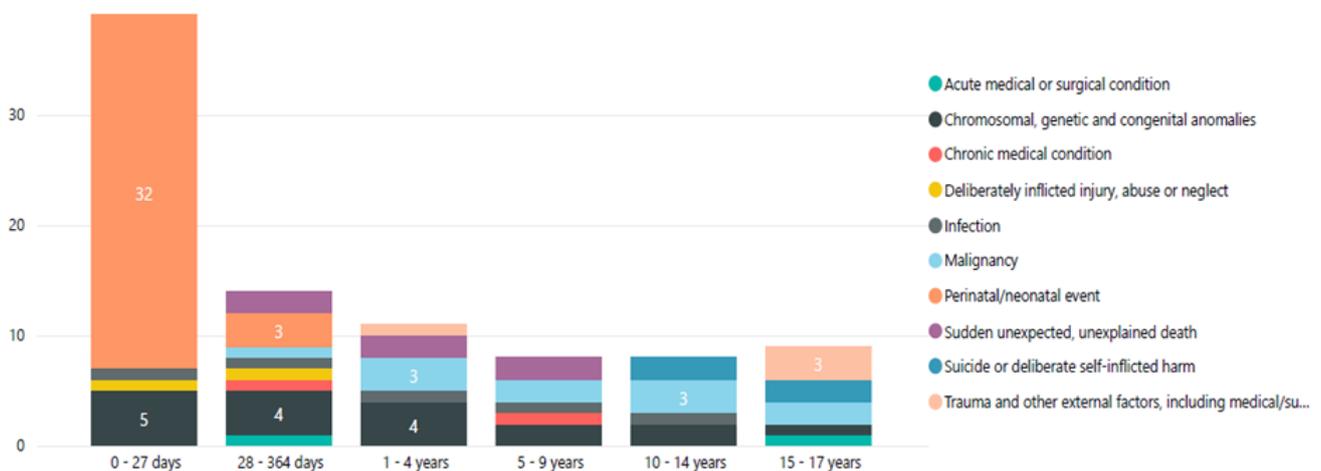


Figure 9 details the breakdown of category of death by age group. Deaths due to chromosomal, genetic, or congenital anomalies were seen across the age range. Peak ages for sudden, unexpected unexplained death are 28 - 364 days (2/14 cases), 1 - 4 years (2/11 cases) and 5 - 9 years (2/8 cases).

Figure 9

Completed CDOP reviews by age group



# Modifiable Risk Factors

Of the **89** child deaths reviewed by the panels in 2022/23, **34% (30)** of the cases identified modifiable factors that may have contributed to the child's death. The 2022 national average for England was **39%**. There is wide variation between regions. Norfolk was at the upper end of the range in 2021/22. Fewer cases were identified as having a modifiable factor in 2022/23.

Norfolk and Suffolk panels have done work to consider whether a factor is modifiable, and this has encouraged robust discussion both in the child death review meetings and in panels. NCMD introduced a discussion video on modifiability in CDOP reviews aimed at improving national consistency. This is available at: <https://uclpartners.com/ncmd-webinars/>. This was shown to panel members. The current advice from NCMD is that unless the panel have considered a possible intervention then a factor may be contributory but should not be recorded as modifiable. If an intervention has been available and offered but the parent has not followed the advice, then the factor is not modifiable. This is open to debate, and it is important that CDOP panels consider how an identified factor may be modified.

Children aged 15-17 years continue to have the highest proportion of deaths recorded as having modifiable factors (56% 5/9 cases). The next highest proportion of cases with modifiable factors identified this year were in those aged 10-14 year (38% 3/8). Babies aged 0-27 days (36%; 14/39 cases) and 1-4-year-olds (36%; 4/11 cases) had a similar number identified.

Figure 10

% of cases where modifiable factors were identified by age group

Age group	Completed Reviews	Cases where modifiable factors identified	Modifiable Factors Identified (%)
0 - 27 days	39	14	36%
28 - 364 days	14	4	29%
1 - 4 years	11	4	36%
5 - 9 years	8	0	0%
10 - 14 years	8	3	38%
15 - 17 years	9	5	56%
<b>Total</b>	<b>89</b>	<b>30</b>	<b>34%</b>

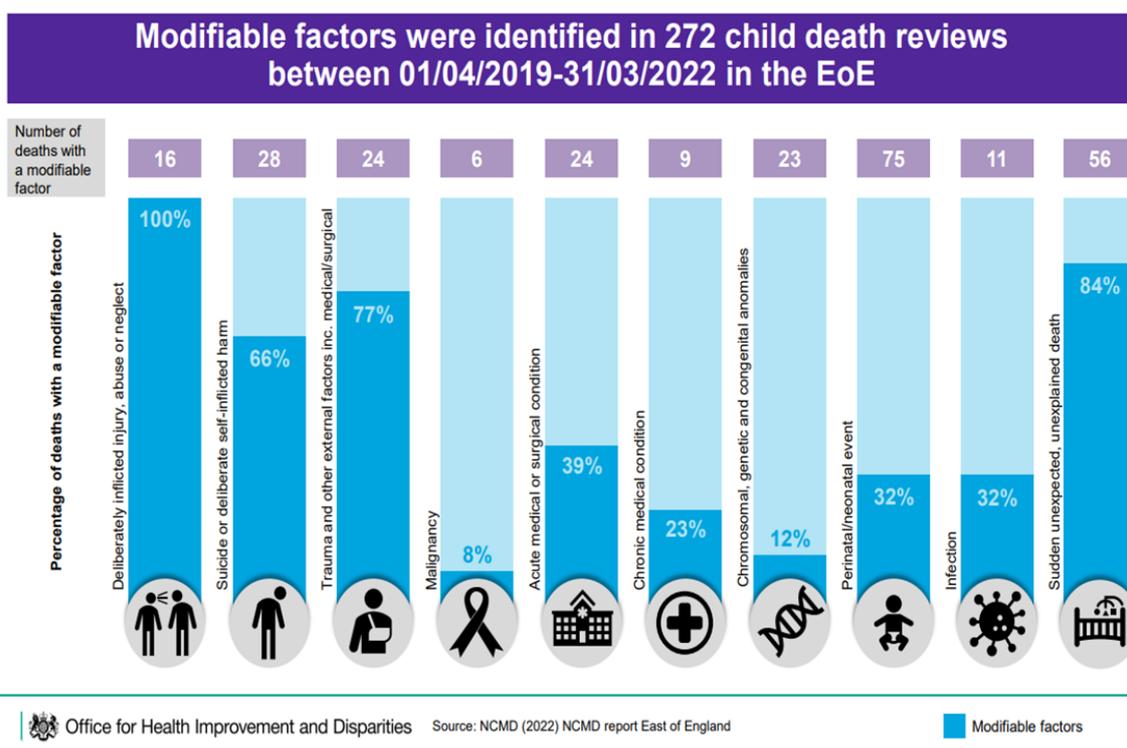
When we consider the category of death; potentially modifiable factors were identified in all the cases classed as 'trauma and other external factors, including medical/surgical complications/error' (4/4) and 'deliberately inflicted injury, abuse or neglect' (2/2) (Figure 11). 40% (14/35 cases) of deaths due to perinatal/neonatal events were considered to have modifiable factors.

### Figure 11

% of cases where modifiable factors were identified by category of death

Primary category of death (CDOP)	Completed Reviews	Cases where modifiable factors identified	Modifiable Factors Identified (%)
Trauma and other external factors, including medical/surgical complications/error	4	4	100%
Suicide or deliberate self-inflicted harm	4	3	75%
Sudden unexpected, unexplained death	6	2	33%
Perinatal/neonatal event	35	14	40%
Malignancy	11	0	0%
Infection	5	2	40%
Deliberately inflicted injury, abuse or neglect	2	2	100%
Chronic medical condition	2	1	50%
Chromosomal, genetic and congenital anomalies	18	1	6%
Acute medical or surgical condition	2	1	50%
<b>Total</b>	<b>89</b>	<b>30</b>	<b>34%</b>

Norfolk and Suffolk CDR teams are aiming to ensure that contributory factors (factors which contributed to the death but were not modifiable), and modifiable factors (factors which if an intervention was introduced/offered may have affected the outcome) are identified and differentiated. In cases where modifiable factors are identified, ideas are sought as to how they can be addressed. Of the 31 cases reviewed in 2022/23 as having a modifiable factor, these were further reviewed and split into contributory and modifiable factors (Table 3). The NCMD produced regional figures for the East of England about modifiable factors. These were incorporated into the following graphic. This helps to compare us with our neighbours.



## Table 3: Contributory and modifiable factors

### The Suffolk and Norfolk Child Death Overview Panel identified modifiable factors in 58 cases reviewed between 1<sup>st</sup> April 2022 to 31<sup>st</sup> March 2023.

Category of death	Domains	Contributory Factors	Modifiable Factors	How can this be addressed
<b>Deliberately inflicted injury, abuse or neglect</b>	Factors intrinsic to the child		- Multiple injuries as a result of concealed birth and where was placed to die	- Public Health promotion for pregnancy services and options in all circumstances. Norfolk Concealed Pregnancy Group to review case and feedback to Suffolk.
	Social Environment	- Chaotic household- social factors- red flags that weren't acted upon		
	Physical Environment	- Concealed pregnancy - Unknown if injures caused by machinery or by someone.		
	Service Provision		- Safeguarding concerns needed to prompt further investigations. - Investigation for bruising of non-mobile baby not undertaken.	- The Norfolk pathway for Professionals "Injuries to a non-mobile infant protocol"- updated. - Safeguarding protocols highlighted and retraining- especially for consultants.
<b>Suicide or deliberate self-inflicted harm</b>	Factors intrinsic to the child	- Parents did not share suicidal history with professionals. - Previous self-harm/suicidal ideation, - Previous suicide attempts - Undiagnosed long Covid.		
	Social Environment	- Poor maternal mental health - Poor physical and mental health of main care giver. - Feelings of failing academically. - Recent end to same sex relationship	- Social/community isolation (moved from another country/culture).	- See service provision
	Physical Environment		- Access to medication which had previously been identified as a risk.	- NFST and Acute trust to review access to medications as part of care plans/discharge
	Service Provision	- Referrals were made to primary care services; lack of co-ordination meant the young person received no input. - No key professional in place. - No support given after previous suicide attempt.	- Lack of oversight from Mental Health Services - Mental health history and current mental needs not assessed. - Lack of professional awareness of refugee families in area. - Poor multiagency working and poor sharing of information. - Adult focused, not child focused. - Family wrongly identified as Universal – should have been Universal Plus. - Lack of escalation regarding support for child. - Poor record keeping. - Lack of professional curiosity - Professionals failed to identify child as a Young Carer and risk assess this. - Health failed to put an effective safety plan in place regarding access to medication for a further overdose.	- New referral system SPOC hosted by CCS -introduced- April 2023 - Correct representations needed on Community Refugee Panel. - Health Visiting/School Nurse Service to review and update transfer in policy and to review identification of family needs. - Suffolk CYP Suicide Prevention Plan 2022-2027- public health to continue to update CDOP panel on progress. - Schools – to look further to see if there needs to be some strengthening of the self-assessment for risk of suicide, and how learning could be properly targeted to reach school communities in a way that makes a difference. - Friends – find ways to let young people know what to do if a friend is showing signs of suicide ideation (where to get help). - SSP to present learning from suicide cases together in a podcast/webinar. Need for a wider look at suicide rather than focus on one specific case. Broadening discussions about the work in suicide prevention and what support is available. - As part SSP review all agencies to reflect on learning and evidence changes in: - ➤ documentation and record keeping. ➤ Weaknesses in information sharing and communication within and between agencies which would have helped to build a picture of what life was like for the child. ➤ The need for a whole family approach. ➤ The need to consider how adult mental health concerns in a family impact on children and young people in the family. ➤ Understanding the role of a young carer – professionals working with children and young people need training and support in understanding the impact of being a young carer. ➤ The need for young people who are struggling with their mental health and showing signs of suicide ideation, to have access to a named GP or Practice Nurse.

				<ul style="list-style-type: none"> <li>➤ Regular 'reaching out' by health services to children and young people who are struggling with their mental health and showing signs of suicide ideation.</li> <li>- Genogram training for Health Visitors.</li> </ul>
<b>Trauma and other external factors</b>	Factors intrinsic to the child	<ul style="list-style-type: none"> <li>- Nitrous oxide</li> <li>- Alcohol &amp; Cannabis use</li> </ul>	<ul style="list-style-type: none"> <li>- Use of recreational drugs while driving</li> </ul>	<ul style="list-style-type: none"> <li>- Public health to take further, with an awareness campaign</li> </ul>
	Social Environment	<ul style="list-style-type: none"> <li>- Impact of Covid -lockdown</li> </ul>		<ul style="list-style-type: none"> <li>- Police liaison provided teaching at the college</li> </ul>
	Physical Environment	<ul style="list-style-type: none"> <li>- Driving an unfamiliar vehicle at speed</li> <li>- No cycling helmet worn and wearing ear buds</li> <li>- Video wires for child monitor not fixed securely to wall.</li> </ul>	<ul style="list-style-type: none"> <li>- Stairgate safety</li> <li>- Seatbelt safety</li> <li>- Motorcycle (not) British Standard helmet</li> <li>- Bridle way had no barrier to ensure the cyclist dismount.</li> <li>- Monitor wire- manufacturers guidelines not followed, and wire not secured to wall.</li> </ul>	<ul style="list-style-type: none"> <li>- Public health safety awareness campaigns.</li> <li>- Locally: put on the Just One Norfolk Parenting website.</li> <li>- Health promotion for new parents Grow egg.</li> <li>- CDOP raised an Alert re danger of loose, accessible monitor wires.</li> <li>- Coroner issued Regulation 28 to the Suffolk Highways Agency</li> <li>- Sign added to this bridleway to advise cyclist to dismount.</li> <li>- Work with local football club to education children cycling on these roads and bridleways.</li> </ul>
	Service Provision	<ul style="list-style-type: none"> <li>- Lack of professional curiosity</li> </ul>		<ul style="list-style-type: none"> <li>- Additional training for professionals</li> </ul>
<b>Acute medical or surgical condition</b>	Factors intrinsic to the child		<ul style="list-style-type: none"> <li>- Child was not receiving adequate nutrition through PEG as PEG was not functioning.</li> </ul>	<ul style="list-style-type: none"> <li>- See service provision</li> </ul>
	Social Environment	<ul style="list-style-type: none"> <li>- History of maternal alcohol abuse.</li> <li>- Mother was a smoker.</li> <li>- Poor Maternal mental health.</li> <li>- Mother and Child socially isolated which was exacerbated by both their learning needs.</li> <li>- Multiple safeguarding concerns made.</li> </ul>	<ul style="list-style-type: none"> <li>- Child neglect - not taken for emergency treatment. Professional advice not followed.</li> </ul>	<ul style="list-style-type: none"> <li>- See service provision</li> </ul>
	Physical Environment	<ul style="list-style-type: none"> <li>- Poor home environment (Social housing).</li> </ul>		
	Service Provision		<ul style="list-style-type: none"> <li>- Professionals aware of issues with PEG tube but not replaced.</li> <li>- Health Professionals failed to see child in the weeks leading up to their death when illness was identified.</li> <li>- Poor communication between agencies.</li> <li>- No lead professional.</li> <li>- No advocate for child.</li> </ul>	<ul style="list-style-type: none"> <li>- Professionals to ensure they have an alternative contact number or person that they can speak to about the child in an emergency.</li> <li><b>Serious case review:</b></li> <li>- Senior Health Leaders need to satisfy themselves that the process for referring, triaging and assessing requests for PEG tube replacements and treatment ensure that where a PEG tube condition is potentially life-threatening, that immediate action is taken.</li> <li>- Capacity of parent's ability to manage PEG feeds needs to be regular reviewed and escalation to MASH if needed.</li> <li>- Multi-Agency Professional Curiosity e-learning package offered by Suffolk County Council's Workforce Development to include learning around families who are not contactable and curiosity around this (with specific reference to child with disabilities).</li> <li>- Children with vulnerabilities to have a named lead professional.</li> <li>- SSP to collaborate with SEND leads in Suffolk to ensure EHCPs are holistic and include an assessment of risk of vulnerabilities.</li> <li>- MASH to undertake an audit and review of thresholds concerning referrals of children with special needs and a disability.</li> <li>- Safeguarding Partnership should review local safeguarding guidance to ensure that guidance includes advice on seeing the physical conditions of the property when visiting families.</li> <li>- All services to review transition arrangements.</li> <li>- Local agency emergency planning arrangements need to ensure that any if there are any future pandemic, vulnerable children continue to be seen and home visits made.</li> <li>- SSP to review training across all services to ensure practitioners have the skills and tools for: - communicating with children with disabilities, cultural competence and social isolation.</li> </ul>

<b>Chronic medical condition</b>	Factors intrinsic to the child	- Chronic lung disease due to prematurity.		
	Service Provision		- Mother smoked in pregnancy. Offered smoking cessation but didn't engage. (Not asked again in pregnancy and no further attempts to engage mother with smoking cessation).	- Smoke free pregnancy being rolled out in Suffolk - Mothers are now followed up by a midwife with a telephone call to offer stop smoking support
<b>Chromosomal, genetic or congenital anomaly</b>	Factors intrinsic to the child	- Presentation of minor illness throughout infancy and acute/sudden onset illnesses which needed GP/A&E care. - Wrong diagnoses.		
	Service Provision	- Communication challenging across multiple boundaries of care provision.  - Child nursed by a student nurse with limited face to face oversight from registered nurse.	- Delay in diagnoses and appropriate treatment. - Issue with availability of information - full health history from GP not utilised by secondary care. Health history may have helped with diagnoses. - Failure to recognise deteriorating child. Parents views that child was seriously unwell were not fully considered.	- Awareness on diagnosing rare conditions. Named Consultant to do a case study raising awareness across UK. - GP surgeries and hospitals to review how they record significant events on records and share with other agencies caring for child. - Consideration for secondary care requesting chronology from primary care when there are difficulties in finding a diagnoses. - Designated Nurse for Safeguarding Children to raise the issues of information sharing between primary and tertiary providers with the Integrated Care Board. - Local hospitals to remind colleagues of the importance of having visual checks of a child and not just relying on recorded observations. - Professionals to raise awareness of the importance of listening to parents - parents know their children best.
<b>Perinatal/neonatal event</b>	Factors intrinsic to the child	- Denied/ concealed pregnancy. - Congenital pneumonia. - Extreme Prematurity - High risk of preterm delivery due to previous treatment for cervical surgery - Poor maternal mental health. - Complications in pregnancy - Smoking/vaping in pregnancy. - Maternal sepsis. - Acute/sudden onset illness. - Gestational diabetes.	- Smoking cessation not offered – missed opportunity.  - Mother did not access care perinatally or antenatally. - High maternal BMI. - Baby had Covid-19. - Known smoker at time of booking but declined referral to smoking cessation, no further intervention. - Maternal infection -baby had Congenital Syphilis. Effective treatment/management for Syphilis was not given in pregnancy.	- LMNS – ongoing- specialist team at JPUH - Norfolk Safeguarding partnership have worked on producing a report to reduce the harm from concealed pregnancy. - Campaign and emphasis on maternal obesity and the risks for premature labour. - More emphasis on weight management programmes perinatally needed. Weight management programmes to be promoted across Suffolk. - Smoke free pregnancy to continue to be promoted throughout Suffolk to improve engagement with smoking cessation
	Social Environment	- Poor maternal health. - Mother exposed to second hand smoke antenatally. - Deprivation - Mother did not call 999 once baby born.	- Maternal smoking. - Maternal drug use. - Paternal smoking/drug use. - Refusal of Covid 19 vaccine - mother and baby contracted Covid.	- Promote Covid-19 vaccine and risk to mothers and unborn babies. - Raise awareness that parents with mental health issues may need additional support and time processing bad news. - Smoke free pregnancy to continue to be promoted throughout Suffolk to improve engagement with smoking cessation.
	Service Provision	- Communication between clinicians and decision-making regarding managing delivery - Carbon monoxide screening service suspended during covid 19 pandemic, since reinstating inconsistent testing/recording. - Smoking cessation not offered due to error in system. - Delays in treatment. - Suboptimal Temperature regulation in theatre/neonatal unit - Blood gas recording not optimal. - Poor maternal record keeping of key results/observation.	- Communication: importance of clear/ unambiguous language. - Communication: systems used to contact midwifery had inherent delays - Missed opportunity to offer service and therefore treatment. - Clinical assessment of mother interventions in babies' interests. - Recognising need for senior involvement assessment/decision making i.e., training - Issue with treatment, including delays - missed opportunity to provide effective treatment for Syphilis in pregnancy.	- Coroner issued regulation 28- for the midwifery unit across the region to review urgency categories for C-Sections - Training in preterm prevention for all staff in antenatal clinics - Ensure risk assessment is repeated at each contact antenatally to increase likelihood of an error being rectified. - Antenatal clinic patient numbers have been reviewed and minimum of 4 'decision maker' staff (ST3 and above) to be present in each clinic to facilitate a comprehensive review of each patient (already actioned). - Training obstetric staff to ensure they know how to access patient records. - Training for medical staff re advice given to women calling with symptoms which require urgent face to face review - Trigger Alert poster to be displayed in clinical areas and sent to all staff about the importance of returning referral calls as urgent in cases of abdominal pain, vaginal bleeding and reduced foetal movements.

				<ul style="list-style-type: none"> <li>- For all women whose first language is not English, face to face review to eliminate any misinterpretation of symptoms described.</li> <li>- Standard operating procedures for preterm neonates in the theatre environment to be created.</li> <li>- Raising awareness across materiality services of carbon monoxide monitoring in pregnancy.</li> <li>- If not already in use, hospitals to consider using electronic blood gas records so that Consultants can review patient's blood gas remotely and contribute to care decisions - making it more accessible.</li> <li>- Change in process for iCASH – <ul style="list-style-type: none"> <li>➢ Clinical Assessment process and templates have been reviewed to require a second professional to peer review all cases and management plan where a pregnant woman presents with Syphilis; all initial appointments in this case will be face to face.</li> <li>➢ The recall process across all clinics has been reviewed and a safety net process implemented in all localities.</li> <li>➢ Yearly audits.</li> </ul> </li> <li>- Learning from PMRT reviews to shared across maternity services including neonatal operation delivery group.</li> </ul>
<b>Infection</b>	Factors intrinsic to the child	- Had Chicken Pox at time of death.		
	Social Environment	- Previous neglect.	<ul style="list-style-type: none"> <li>- Child on Child in Need Plan at time of death and was awaiting home visit from Social Worker after moving into current house.</li> <li>- Parents were not appropriately caring/responding to an unwell child (left overnight without review).</li> </ul>	- Safeguarding Partnerships in Cambridgeshire and Suffolk to review learning around transferring care between counties
	Physical Environment		<ul style="list-style-type: none"> <li>- Unsafe sleeping arrangements - Room was cluttered and small, travel cot was extremely small, hot with window shut tight and duvet and blankets in the cot.</li> <li>- Concerns around overheating.</li> </ul>	<ul style="list-style-type: none"> <li>- 0-19 Service to review checklists to ensure 'Check Sleeping Environment' is on there.</li> <li>- Sleeping environment of older children to be considered as part of the safer sleep task and finish group.</li> </ul>
	Service Provision	- Autistic and LD	<ul style="list-style-type: none"> <li>- Missed recognition of sepsis</li> <li>- Staff not aware that patients with autism and LD may not exhibit the typical behaviours when in pain or unwell.</li> <li>- Poor communication/information sharing between agencies - Cambridge failed to transfer CIN case to Suffolk, therefore Suffolk Social Care had not been to the home.</li> <li>- No referral/assessment/review undertaken - no Health Visitor 'moving in' check completed - sleeping area not viewed.</li> </ul>	<ul style="list-style-type: none"> <li>- NHS England working with partners to improve identification- sepsis 6 tools.</li> <li>- To involve lead LD nurse to support staff in managing children with Autism and LD when they are unwell and to consider the use of sedation or anaesthesia to ensure their care is not disadvantaged.</li> <li>- Training of staff in recognition of the sick child and training in paediatric life support</li> <li>- Safeguarding Partnerships in Cambridgeshire and Suffolk to review learning around transferring care between counties.</li> <li>- 0-19 Service to review transfer in policy's and make amendments.</li> </ul>
<b>Sudden Unexpected Unexplained death</b>	Social Environment		<ul style="list-style-type: none"> <li>- Adult caring for child not recognising signs of illness and seeking medical attention.</li> <li>- Smoking cannabis, smoking cigarettes</li> <li>- Exposure to cigarette smoke.</li> </ul>	<ul style="list-style-type: none"> <li>- CCS- health professionals promoting access to information websites to help parents identify red flags.</li> <li>- Public health to take further with an awareness campaign</li> </ul>

# Learning and Recommendations from 2022/23 Child Death Reviews

The aggregated learning from CDOP and the Neonatal CDOP for all child deaths should inform local strategic planning on how to best safeguard and promote the welfare of children across Norfolk and Suffolk.

The modifiable factor themes and the associated learning, to emerge in 2022/23 are:



## Communication:

This is a common theme and often threads through many cases. Examples include how organisations communicate with each other and between each other to ensure continuity of patient care. Language barriers can pose a challenge and increase the chance of miscommunication. Young people with a learning disability may also pose a challenge but training of staff and development of posts dedicated to support patients and carers with a learning disability are important for organisations. It is important to ensure that the person 'you' are intending to communicate with has understood what you intended to say.

## Information sharing:

This is particularly evident in cases linked to poor mental health and communication.

## Assessments

One of the themes that came out of the CDOP reviews was that if a case was not assessed thoroughly opportunities to intervene were missed. Whether this was a clinical assessment of how sick a child was, or whether an intervention was required to deliver a baby urgently or a social care assessment. Staff must always be professionally curious but may also be under pressure due to insufficient staff and time and may miss important information that would alter their practice at that time. Good training is vital and recognition that children may present in unexpected ways particularly if they have a learning disability.

## Training

Clinical staff: There have been cases reviewed where training to support staff making better decisions is important. There has been a lot of work to develop tools to help recognise sepsis such as Sepsis 6. Non mobile babies are extremely vulnerable, and it is important to recognise that what appear to be minor injuries always need thorough assessment and discussion because they may be a sign of significant non accidental injury. Management of pregnancy needs well trained teams to manage and recognise that a timely intervention may prevent a premature birth and subsequent tragic events. This is not just the staff in hospitals but also staff who may be contacted for advice to recognise a history that suggests urgent intervention is required.

Parents are not expected to be trained but they do need to recognise when their child is unwell and when to seek advice. There have been many developments using websites and both Cambridge community services and Suffolk Community services and the ICB have a wide range of information to access and support parents' decision making.

Young people: There are many campaigns developed to help young people recognise risks that they might put themselves at. In the cases reviewed there were public health campaigns regarding road safety, driving under influence of drugs and alcohol, use of seat belts and wearing helmets on bikes and motorbikes. The police have educational programmes in schools as well.

## Neonatal

Concealed pregnancies are associated with increased risks to babies and as a result of the concerns there has been a working group to develop a policy to try to reduce the incidence of concealed pregnancies: <https://norfolkscp.org.uk/about/policies-procedures/children-in-specific-circumstances/527-concealed-denied-pregnancy> . This remains a challenging area.

Smoking continues to be linked to prematurity and smoking cessation programmes are important to develop to maximise impact. These are being further developed to offer support throughout the pregnancy and not to take no for an answer.

Increasing body mass index is associated with adverse outcomes. This remains a challenge and really needs a wider social policy to tackle this. However, all clinical contacts need to consider how to support mothers who present overweight.

## Parental factors

Recreational drugs, smoking. Parents able to recognise when their child is unwell and also parents being listened to when they know their child is unwell. We have also seen cases where parents have not always been listened to when they know their child is unwell. We must remember that for most parents they know their child best and can often identify when the child is deteriorating before clinical signs are shown.

## Safe sleeping

This remains an area where the messages regarding where your baby sleeps need to be regularly reinforced and by multiple professionals at every opportunity particularly where there is an identified vulnerability in the family and any safeguarding concerns. Parents and carers need to be aware of the risks and what the outcome may be from not following advice. The Lullaby Trust <https://www.lullabytrust.org.uk/> has very helpful information as well as local public health websites <https://www.justonenorfolk.nhs.uk/> and <https://onelifesuffolk.co.uk/> .

## Health and safety

There have been cases which were clearly preventable due to unsafe installation of equipment bought as a safety device. In one case baby monitor wires were not correctly installed. In a second case a stairgate was put on top of another and in both cases a child died from strangulation. The first case was referred to the NCMD via E-CDOP as containing important national learning and discussed by the NCMD with the Royal Society for the Prevention of Accidents (RoSPA) who subsequently updated the information on their 'Kid Safety Hub'. NCMD also ensured that the learning from this case was fed into RoSPA's National Home Safety Committee.

There were deaths due to unsafe approach to road junctions and there have been both public health campaigns and local community groups. The importance of cycle helmets and being fully aware of surroundings by not having ear pods when cycling.

## Other learning

It is important to recognise how often families express thanks to those involved in the care of their child and recognise that the treatment, support, and management has all contributed to their child making the most of their life. The hospices and teams treating children with malignancy or complex needs are often thanked by families for all that they have done in very difficult circumstances. Enabling children to live the best life they can and to die peacefully is a great achievement.

# Child Death Review Achievements and Deliverables

This is the fourth joint annual report for Norfolk and Suffolk CDOP. In the third joint annual report which covered the period April 2021 – March 2022, the following objectives were set for 2022 - 2023:

- **Norfolk and Suffolk CDOP teams aim to reduce the administrative load for midwives and neonatologist involved in completing the Perinatal Mortality Review Meetings and the E-CDOP forms.**



Norfolk and Suffolk e-CDOP have been a pilot sites for the roll-out of the integrated system for notification of deaths and collection of data for: MBRRACE-UK, Perinatal Mortality Review Tool (PMRT), Child Death Review Process (including Child Death Overview Panels and the National Child Mortality Database). Although this is in progress a complete cycle using MBRRACE has not been completed. There have been some ‘teething’ problems relating to the amount of information that is feeding through into E-CDOP through the new system. This is being addressed by NCMD.

- **The Norfolk CDR team had planned to lead on the Paediatric Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) agenda.**



This has been taken on as a pilot project by consultant paediatricians at NCHC in Norwich who are offering families an appointment at the Nook.

- **CDOP was aware of the variability in modifiable factors identified. The NCMD training video has been shown to panel members. NCMD also changed the C analysis forms, introducing factor-specific dropdown lists. This change aimed to improve the consistency of reporting across CDOPs and streamline the process for recording contributory factors.**



There has been a reduction in cases identified as having a modifiable factor in this year’s report. The proportion is similar to that nationally. It is more important that we show evidence of change. This is a challenge but is the aim of CDOP.

- **Suicide awareness and advice to professionals on prevention needs to continue.**



There were 4 cases of suicide reviewed in 2022-23. These remain devastating particularly for the families and for all organisations. Public health continues to promote suicide awareness and there are programmes of promotion within schools. Helping friends to speak to their friends and know who to go to when they are worried is a message that we must continue to promote. Many cases are unexpected but often there have been subtle clues.

- **Continue to be active participants in the East of England CDOP professionals' network to share learning and system-led improvement.**
- **The national professional body, the Association of Child Death Review Professionals has run a successful and well attended conference and will run a second on in November 2023. The group are working on job descriptions for designated doctors, working with the RCPCH to develop further training for paediatricians and working on developing and supporting training for all professionals associated with child death review. In addition are working on guidelines for anaphylaxis deaths, deaths associated with consanguinity, children who die abroad and most importantly updating the Kennedy Guidelines which are out of date to bring them into line with current practice.**
- **Continue to audit CDR processes across Norfolk and Suffolk to review compliance with statutory guidelines and identify areas of weakness. This highlights that some of the reports from serious incidents take longer than the recommended 60 days both in Norfolk and Suffolk. PMRTs continue to be a challenge due to the constraints on the time of staff available to complete these. Whilst there has been an increase in the bereavement midwifery service there has been limited staff time made available from the obstetric team.**
- **Norfolk and Suffolk are now adding deprivation index data to the CDOP data, so that future annual reports can include analysis of child death and deprivation. The NCMD Report: Child Mortality and Social Deprivation 2021<sup>1</sup> found a clear association between the risk of child death and the level of deprivation. This year we have an NCMD report for Norfolk and Waveney from 2019-2023 which also highlights the link between deprivation index and child mortality.**
- **Norfolk and Suffolk now collate additional learning identified during the CDR process and produce action plans after each CDOP.**
- **To continuously improve data completeness, ensuring that we are capturing 100% of the data required. Improving this data will enable us to understand trends locally but also for the NCMD to link with other data sets, leading to more comprehensive analysis in future.**
- **Ensure delegate attendance at CDOP is robustly documented.**

Most organisations have good attendance at CDOP. It is important to ensure that governance leads are invited in order to promote learning an effect change within their organisations.

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<sup>1</sup> The report can be found here: [Child Mortality and Social Deprivation | National Child Mortality Database \(ncmd.info\)](https://ncmd.info)

## Norfolk and Suffolk CDR team achievements

- Training for frontline practitioners has continued to be delivered throughout 2022/2023 to raise awareness of CDR processes and the role of the keyworker and lead professionals. This has included extending our training sessions to our local university so that the training could be delivered to student nurses and student midwives. We have also held specific trainings sessions disseminating learning, this has included 2 separate sessions delivered to primary care practitioners on promoting the signs of sepsis and gastrostomy care.
- Improvements to the notification process – CDR team now ensure that all professionals across the MDT team are made aware of a child death in Suffolk within 24 hours of receiving eCDOP notification.
- Task and finish group for SIDS established with multiagency representation to review safe sleep advice and identify what improvements needed in Suffolk to reduce SIDs.
  - Worked in partnership with the Suffolk Safeguarding Partnership to create and deliver a Safer sleep pod cast aimed at families.
  - Supported the development of a multiagency risk assessment tool for SIDS.
- Delivered a free face to face learning from Child Deaths study day (attended by 120 attendees).
- Driving forward improvement of recording of CO and BMI monitoring in pregnancy
- Introduced the Greater Manchester Health and Social Care Policy for the support of children and young people in crisis to Suffolk.
- Improved relationship with governance teams and Patient safety teams within the West Suffolk Hospital
- This year saw an increased case load and demand for training and support for professionals. The team kept everything going and successfully delivered the same level of service and support to professionals and families.
- Embedded liaison links with Hospice services
- Allocated a Domestic Abuse champion in CDR team to improve awareness and recording of DA in Child Death Reviews along with improving actions from learning.
- Ensured that every family had the opportunity to participate in the Child Death Review of their child and bringing their voice into the review and sharing at CDOP.
- Attendance to Safeguarding Conference at James Paget University Hospital in order to share the work of the CDR Team and the need for all professionals to be aware of the statutory process.
- Identified an equal need for Fathers and seeking support groups specifically for this group of often overlooked individuals.
- Specifically identifying lack of education within the GP trainee group and rolling out a supported education platform with the Designated GP for safeguarding in Norfolk & Waveney.
- Evolution to develop more transparency for tertiary units and outside agencies ensuring greater information sharing.
- Audit tool expanded for improving the collation and capturing of data relevant to the CDR process.
- Audit tool developed for family feedback to ensure our service delivery is of the standard required and needed for families.

# Feedback from Families & Professionals (2022-2023)

*"The CDR nurse has been an inspiring nurse to work with. She has shown absolute dedication and enthusiasm for her job. She uses skills learnt elsewhere to inform her work and shares this with colleagues"* Professional feedback about CDR nurse.

*Mum very grateful for CDR nurse listening to her concerns and including them in the CDR process, she was pleased to hear that learning has taken place and that changes have been made. Contact with bereaved parent with update from CDOP.*

*"I want to thank you for everything you have done for me and my family. Personally, I couldn't have got through the last 10.5 months without you."*  
Bereaved grandmother

*"It has been a huge improvement to know exactly who the central contact is to liaise with the bereaved family to enable our services to respond sensitively to the wishes of the family. The CDR nurses' knowledge of procedure and processes is an amazing resource. I have also been impressed with the level of support they have been able to provide families following the loss of their child"*  
Professional feedback about CDR nurse.

*"Thank you so much, I couldn't have got through this and done this without your help. It really helped you laying it on thick to me and telling me what I needed to do because that's what I needed, and I am so proud of myself"* – Bereaved parent.

*Parents were very thankful for the CDR team working together with the coroner and the paediatrician to enable their wishes to be heard with not wanting a PM. Parents shared they were not sure how they would have coped if their wishes had not been listened too.* Bereaved parent

*"I just wanted to say a big thank you for the support you've shown us and our family in the last 12 months +. We could never have prepared ourselves for what we've faced in the last year and most recently, but you've made it that little bit easier to get through when a lot of things have felt quite overwhelming, and I imagine will continue to in waves going forward"* Bereaved parent.

*"Thank you for all your help at this difficult time, I really appreciate all the memory making you did. Thank you for everything from your team, you are great ladies".* Bereaved parent

*"She has developed this post extremely well and despite coming up against barriers at times has calmly and persistently helped other clinicians understand the role and the importance of making the end of a child's life and the period afterwards less painful for parents and their families"* Professional feedback about CDR nurse.

*Conversation with mum who said she was so pleased to be able to talk to someone about her daughter, she said she felt able to off load and felt so much calmer after the call which she was very thankful for. Initial contact to parents newly bereaved by CDR nurse.*

*"Just a quick email to thank you so much for attending and delivering such a great session to the students on Thursday. They all really enjoyed it and found it very interesting".* CDR team  
Training delivered at University of Suffolk

*Thank you for attending the inquest in our absence and for everything the CDR team have done for our family. We couldn't have got through this without you.* Bereaved parent

*"I don't have enough words for your kindness and support you have offered. Thank you so much for all your support. Ever so much appreciated".* Bereaved parent

*"The CDR nurse has provided an excellent service to the staff and more importantly, the families when children tragically die. She demonstrates autonomy but is also able to reflect with staff to ensure quality and consistency."* Professional feedback about CDR nurse

# Forward Plan for 2023-2024

The child death review teams have been a very successful and important development. It is important that they continue to be supported themselves to enable them to continue to do the jobs that they do. It is important that all organisations are aware of their statutory duty to support the child death review process and to contribute both their time and information. The child death review meeting is an important opportunity to ensure that families concerns have been considered and that staff are able to have an open and frank discussion regarding the care that each child receives. It is as important to highlight the excellent care that families receive whilst also trying to improve care when it has not been optimal.

Ensure that the roles of child death review teams and child death overview panels are clear. The CDR teams are mainly responsible for supporting the child death review process as well as families where there is no other key worker. The role of the child death overview panel is to identify actions where possible to reduce those factors identified as modifiable. Whilst some may be local actions others may require a national steer and changes of policy. CDOP can use a variety of organisations to promote changes that may ultimately reduce child deaths. This more national issues relate to smoking, diet, and deprivation.

## Suffolk CDR team

- Task and finish group for SIDS to deliver safe sleep webinar and to create a multiagency risk assessment tool.
- To develop and set up a peer support group for bereaved parents and carers in Suffolk.
- To continue to deliver CDR training with MDT professionals ensuring new staff and teams are aware of the CDR process.
- To have more interaction and communication with senior colleagues within the ICB to improve the sharing and implementation of learning.
- To support colleagues within NHS trusts to be able to initiate the CDR process out of hours when our team are not at work. (To continue to embed the SUDIC webpage into practice to support practitioners out of hours).
- To raise awareness of domestic abuse in Child Death Reviews.
- To improve the recording of CDOP actions using the SMART model.

## Norfolk CDR team.

- Continue to improve communication with the tertiary units with both the expected and unexpected child deaths.
- Continue to deliver training to all partner agencies involved with the children and their families.
- Develop strategies to raise awareness of the importance of face-to-face meetings between families and medical teams involved with the care of the child who died. Interim meetings to answer families' questions prior to feedback of results can alleviate mistrust and anger.
- We strive to maintain a standard which gives best outcomes for families with the family audit feedback tool and will aim to extend this to professionals in 23/24 to ensure we identify future training needs.
- Due to retirements in the next year, there will be changes to the staffing of the CDR nursing team and a recruitment process.

# Appendices

## 1. Definitions

- **Stillbirth rate:** The number of babies born after the 24th week of pregnancy who do not show any signs of life per 1000 total births (live and still births).
- **Perinatal mortality rate:** The number of stillbirths plus the number of babies dying within the first week of life per 1000 total births (live and still births).
- **Low birth weight rate:** The number of babies born weighing less than 2500g expressed as a percentage of total births (live and still births).
- **Infant mortality rate:** The number of deaths of children aged under one year per 1000 live births.
- **Neonatal mortality rate:** The number of neonatal deaths (those occurring during the first 28 days of life).
- **Post-neonatal mortality rate:** The number of infants who die between 28 days and less than one year.
- **Child mortality:** the number of child deaths for every 100,000 people alive in the population aged from 1-17.
- **Unexpected death of a child:** defined by the Department for Education as the death of an infant or child, which was not anticipated as a significant possibility 24 hours before the death, or where there was similarly unexpected collapse or incident leading to or precipitating the events that led to the death.
- **Modifiable child deaths:** those in which modifiable risk factors may have contributed to death. These factors are defined as those which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths.

## 2. Child Death Review Panel legislation and principles

### Regulations relating to child death reviews.

Regulation 6 of the Local Safeguarding Children Boards Regulations 2006 made under section 14 of the Children's Act 2004 sets out the board's and now the Partnership's responsibilities in relation to the child death review process. It states that the Partnerships are responsible for:

- a. Collecting and analysing information about each death with a view to identifying –
  - i. Any case giving rise to the need for a review as mentioned in regulation 5(1)(e).
  - ii. Any matters of concern affecting the safety and welfare of children in the area of the authority; and
  - iii. Any wider public health or safety concerns arising from a particular death or from a pattern of deaths in that area.
- b. Putting in place procedures for ensuring that there is a coordinated response by the authority, their agency partners, and other relevant persons to an unexpected death.

- c. The responsibility for determining the cause of death rests with the coroner or the doctor who signs the medical certificate of the cause of death (and therefore is not the responsibility of the Child Death Overview Panel (CDOP))
- d. In reviewing the death of each child, the CDOP should consider modifiable factors, for example, in the family environment, parenting capacity or service provision, and consider what action could be taken locally and what action could be taken at a regional or national level as a result of a set of circumstances.

### 3. The Principles

Four underlying principles guide the overview of all child deaths:

- Every child's death is a tragedy.
- Learning lessons
- Joint Agency Working
- Positive action to safeguard and promote the welfare of children.

The function of CDOP is achieved by:

- Reviewing the available information on all deaths of children up to 18 years (including deaths of infants aged less than 28 days) to determine whether there were any modifiable risk factors which may have contributed to the child's death.
- Collecting, collating, and reporting to an agreed national data set – the National Child Mortality Database (NCMD) - for each child who has died.
- Meeting regularly to review and evaluate the routinely collected data for the deaths of all children, and thereby identifying lessons to be learnt or issues of concern.
- Monitoring the response of professionals to an unexpected death of a child
- Referring to the Chair of the Local Safeguarding Children Partnership any deaths where the panel considers there may be grounds to consider a child safeguarding practice review.
- Monitoring the support services offered to bereaved families.
- Identifying any lessons or improvements and considering how best to address these and their implications for the provision of both services and training.

### 4. Norfolk and Suffolk CDOP – Joint Terms of Reference

- Available from panel administrators if you would like to review.

# ACKNOWLEDGEMENTS

This annual report has been co-produced between, Suffolk, Norfolk and Waveney CDOP and CDR Teams.

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*We thank you for your continued support in contributing towards the Child Death Review/CDOP Process*

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