Norfolk Safeguarding Children Partnership

Suffolk Safeguarding Partnership

Norfolk & Suffolk Child Death Overview Panel (CDOP)

Annual Report 2020-2021

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Introduction

The local Child Death Overview Panels (CDOP) review the death of every resident child aged under 18 in Norfolk and Suffolk. The child death review process is overseen by the Designated Doctor for Child Deaths in conjunction with the CDOP Manager or Administrator and the Chair of the CDOP.

In October 2018 the Department of Health and Social Care assumed national leadership of the child death review process and published guidance; *Child Death Review: Statutory and Operational Guidance (England)*[1] for reviewing the deaths of all children[2] regardless of the cause of death. This 'Guidance' aims to put bereaved families at the heart of the review process. It also sought 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[3].

The 'Guidance' advised that CDOPs reviewing less than 60 deaths should combine with another CDOP. Norfolk and Suffolk both meet this criterion and share Waveney, which sits within Suffolk as a local authority, but health services are commissioned by Norfolk. A shared report meets both counties' requirements and was first produced in 2019 - 20.

The Child Death Overview Panel (CDOP) annual report is a summary of the activity carried out by the panel. Production of an annual report on local patterns and trends in child deaths, any lessons learnt, and actions taken and the effectiveness of the wider child death review process is recommended in the national 'Guidance'. The aim is to seek to improve outcomes for children across Norfolk and Suffolk.

This report summarises the work of both CDOP panels and the cases that have been reviewed in the period from April 2020 to the end of March 2021. Of course, as we are all too well aware, this time frame coincided with the global pandemic created by responses to the COVID-19 virus. This led to a number of necessary practice changes perhaps the most significant of which was a move to virtual meetings using the collaborative communication platform; Microsoft TEAMs.

Suffolk developed a new Child Death Review Team (CDRT) in September 2019 and Norfolk followed suit from April 2021.

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.

[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf

[2] before their 18th birthday

[3] See https://www.ncmd.info/wp-content/uploads/2021/06/NCMD_2nd_Annual_Report_June-2021_web-FINAL.pdf

Executive Summary

During 2020/21, Norfolk and Suffolk met on 6 occasions each.

There were 60 deaths of Norfolk and Suffolk resident children aged under 18 years old notified to CDOP in 2020-2021 compared to 78 in 2019/20 and 50 in 2018/19. This variation is likely to be due to the relatively small numbers involved.

In 2020/21 Norfolk and Suffolk reviewed 79 cases which had occurred between 2017/18 and 2020/21, 42 reviews for Norfolk and 37 for Suffolk. This was an increase from 2019/20 when 53 deaths, which had occurred between 2016 and 2020 were reviewed. This was partly due to the introduction of the themed neonatal panel in Suffolk; as cases had been held back for the first panel in June 2020.

A few outstanding complex cases caused significant delays in completing the Child Death Review (CDR) process in 2020/21. There were two cases from 2017/18 and three from 2018/19 where there were criminal investigations which took a considerable time to complete followed by the inquest and completion of a local Safeguarding Children Practice Review which were undertaken sequentially.

Information sharing has improved significantly this year to enable the early completion of E-CDOP[4] forms. However, waiting for the outcome of forensic post-mortem results, serious incident investigations in hospitals, the coroner's inquest, Safeguarding Children Practice Reviews or criminal investigations will delay cases coming to CDOP.

Of the 79 deaths reviewed, 48 were of an infant under a year of age. 35 babies died in the neonatal period (0-27 days). 13 babies died between 28 - 364 days after birth.

Key findings were:

The predominant categories of death for neonates were extreme prematurity followed by congenital/chromosomal/genetic conditions. Thirteen babies were 24 weeks or less gestation.

In children the main categories of death were 'chromosomal, genetic and congenital anomalies', sudden unexpected death infancy and childhood (SUDIC), suicide and malignancy.

Modifiable factors in children were found more commonly (figure 8) in children aged 1-4 years (83%) followed by adolescents aged 15 – 17 years (55%). Nationally, modifiable factors were identified most frequently in deaths that were classed as SUDI and those where children died due to trauma or self-harm.

Principal areas of learning were:

- Communication: This was a common theme that included communication between agencies, between clinicians and with families and listening to parents.
- Smoking and safer sleeping: effects on a pregnancy or SUDIC, also associated with co-sleeping and the use of drugs and alcohol.
- Adequate monitoring, staff ratios, senior review
- Uncertainty of how COVID-19 might present in babies and children
- Low threshold to consider severe infection and illness and start treatment.

[4] Electronic Child Death Overview Panel

The Child Death Overview Panel (CDOP) Panel

The statutory responsibility of CDOP is set out in the Children Act 2004 and Working Together 2018. CDOP's primary function is to undertake an anonymised secondary review of each child death where the identifying details of the child and treating professionals are redacted.

CDOP is attended by senior representatives across health, social care, police, education and other agencies. Consultant paediatricians attend to provide clinical expertise from the acute hospitals. CDOP reviews information on all child deaths to inform local strategic planning, identify any modifiable/ contributing factors and consider any lessons to be learned. CDOP is a core body within the respective local Safeguarding Partnerships for Norfolk and Suffolk respectively.

The 2018 'Guidance'[5] encourages learning from deaths and uses the term modifiable factors to mean 'factors that might by means of locally or nationally achievable intervention be modified to reduce the risk of future child deaths'. There is some variability in what might be classed as 'modifiable' thus deaths may now be assessed as having 'modifiable' factors. It is still proving a challenge to agree consistent factors that are amenable to intervention. The National Child Mortality Database (NCMD) and the Eastern Region group are both considering how to improve consistency between panels.

In 2020/21 the Norfolk CDOP was chaired by the Designated Doctor for Child Death as an interim arrangement pending the appointment of a new chair. A new, independent Chair has since been appointed and took up the position from late June 2021. In Suffolk the Independent Chair of the Suffolk Safeguarding Partnership continued as chair of Suffolk CDOP.

Panels have been held consistently every two months, with a total of 12 meetings taking place between 1 April 2020 and 31 March 2021 across Norfolk and Suffolk. 79 cases were reviewed.

Themed neonatal panels were held every 6 months in Norfolk and Suffolk with representation from the acute trusts. This has proved a successful approach to reviewing neonatal deaths. The panel has encouraged representation from governance leads of antenatal services (Midwifery and Obstetrics) as well as Post-natal services. The panel takes place once a Perinatal Mortality review (PMRT) has been completed (if relevant). The PMRT has taken some time to become embedded in all the units across both counties.

Neonatal deaths remain the most common category of death thus a thorough understanding of the contribution of antenatal factors to neonatal deaths is crucial and complements the work of MBRRACE-UK[6]. CDOPs continue to identify potentially modifiable factors during pregnancy which may lead to premature delivery such as smoking, obesity, alcohol misuse and domestic abuse.

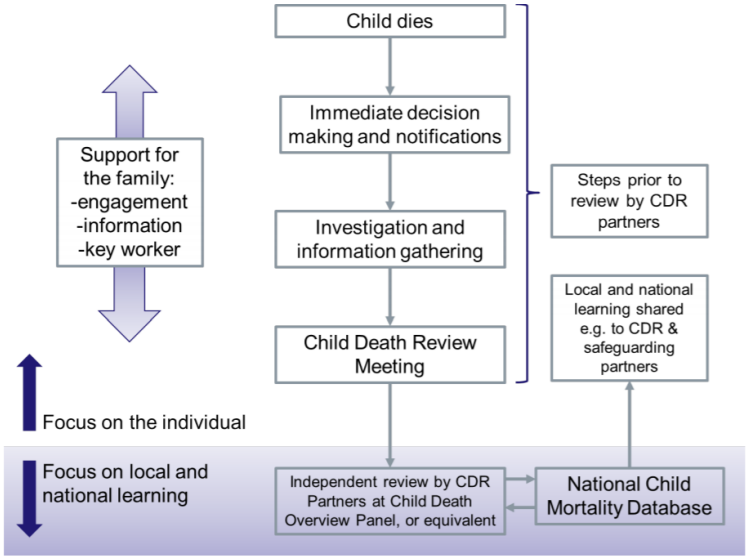
[5] Op cit

[6] MBRRACE-UK is **a national audit programme** and is commissioned by all UK governments to collect information about all late foetal losses, stillbirths, neonatal deaths and maternal deaths across the UK. The programme tracks information about where and why babies and mothers die every year.

The Child Death Review (CDR) Process

All CDRs follow systems and processes recommended in “Working Together to Safeguard Children, 2018” (Figure 1).

Figure 1



The guidance requires that Child Death Review Meetings (CDRM) are held in order 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 are supported and to support those involved in the case.

Electronic CDOP (E-CDOP)

This is the second complete year that Norfolk and Suffolk have used the E-CDOP forms to collect and collate information. Notification of a child death can now be done at any time of day or night and will automatically be sent to the CDOP Manager/Administrator and CDRT. Notifications must be made within 48 hours of the child’s death and include whether the child was positive for COVID-19 or not. It is vital that understanding of the notification process is widespread.

All the data is automatically uploaded to the National Child Mortality Database (NCMD) at the point of notification and when cases are completed. The NCMD have produced two full annual reports on national data collected in 2019/20 and 2020/21. NCMD provide each local CDOP with a breakdown of their activity. This Norfolk and Suffolk annual report is based on the data we provided to NCMD.

Unexpected Deaths

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

There is a robust system to ensure multi-agency meetings are held after each unexpected death. The initial multi-agency meetings were chaired by Children's Services in both Norfolk and Suffolk during 2020/21. If the information shared suggested that the death was related to safeguarding, then the meeting becomes a section 47 or complex strategy meeting, and social care will take responsibility for subsequent meetings. This is uncommon. If, however it is primarily health related then Health should take the lead for arranging subsequent meetings.

In Norfolk the acute trusts hold regular mortality meetings (M&M) to review unexpected deaths. The organisation of these meetings has improved significantly. They are now being held via Microsoft Teams and people from different organisations can be invited.

If there are safeguarding concerns and multi-agency involvement a Safeguarding Children Practice Review may be triggered (if related to safeguarding practice). Three deaths reviewed in this report underwent this process as well as a Coroner's Inquest. If there are concerns within an individual agency this would result in a serious incident investigation within the Trust(s) involved. Serious incident investigations are carried out more frequently. Cases of grave concern often become subject to a full local Safeguarding Children Practice Review.

If required a subsequent early meeting takes place to consolidate information gathered and review all the information obtained since the child's death and any new information which may be available from the initial post-mortem findings. This is an opportunity to complete a reporting Form B for E-CDOP although both the meetings and completing forms is still not yet embedded.

A date for the final CDRM should ideally be agreed at an initial meeting although this is not always practical and most commonly done in Suffolk through Suffolk County Council. It is held about 2 months after the death but may be delayed if the post-mortem results are not available or if there are additional serious incident reports in which case the meeting should be held once these have been completed to maximise learning. There has been significant delay for cases where there has been a serious incident investigation and it is important that CDR partners work together to reduce this delay because it is very challenging for families and delays the dissemination of learning. Reviews should now be considered alongside investigations, not in a sequence, even though a continuing investigation may limit the scope of a large-scale review. Reviewing in general is now becoming more often than not thematic and issue based.

The final CDRM should be a multi-professional meeting where all matters relating to the child's death are discussed by the professionals involved in the child's care. This may be a hospital mortality review meeting or held by the CDR team. The junior staff produce excellent presentations which provide a good summary of events and learning. Professionals from outside the organisation have not been routinely invited to hospital mortality meetings. However, with the new guidance, the acute hospitals have been encouraged to invite other professionals for a holistic review of the child.

It is important that the learning from a serious incident (SI) report is discussed in this meeting. The advent of COVID has meant that meetings now take place by Microsoft Team's video link. This has been a positive introduction. It is now possible to invite a wide range of people including those from tertiary hospitals, primary care, hospices and schools who previously would not have been able to join a face-to-face meeting due to distance to travel or time away from the day job.

If the child had no links to the hospital the meeting would have been hosted by the Designated Safeguarding team (Norfolk) or Child Death Review Team (Suffolk). In cases where it was important to have multi-agency attendance there may be an additional meeting held by the designated team.

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.

For children over a year of age, these are mostly due to malignancy and chronic medical conditions. The palliative care teams have regular multi-agency meetings in place prior to and after the death. The debrief meetings already consider learning which should be reported through to CDOP.

The main challenge is to avoid duplication of reports; however, it is important to get details of the child's treatment and death into the E-CDOP forms. These forms should be completed by clinicians known to the child.

When children die in tertiary hospitals it had been difficult to access meetings held to review deaths however as more teams have developed their child death review processes and with the use of 'Microsoft Teams meetings' local clinicians are now invited to join the tertiary hospital mortality meeting.

Child Death Review Teams (CDRTs)

Suffolk

In Suffolk the CDRT of 3 nurses overseen by the Designated Nurse for Safeguarding have thrived and made a huge difference to the response and support that families receive after a child has died. The dedicated service to support families and professionals for all deaths, both expected and unexpected, including neonatal deaths, has identified many unmet needs. They coordinate the CDR process and offer follow up for families and clinicians throughout the process. There is a separate report for Suffolk CDR team's work.

Norfolk

During 2020/21 a business case was developed for a new CDRT of 3 nurses and an administrator. During the period of development, the Rapid Response Team, employed by the Norfolk and Norwich University NHS Trust, continued to provide a dedicated on-call service for unexpected deaths and provide immediate support and information gathering in the first 24 hours. However, the team handed in their notice and were due to stop working from January 2021.There was an interim period before the new team were appointed and started work. The NNUH Rapid Response senior nurses continued to provide cover until the new team started in April 2021 and the acute hospitals agreed that if necessary, clinicians would do home visits which was greatly appreciated.

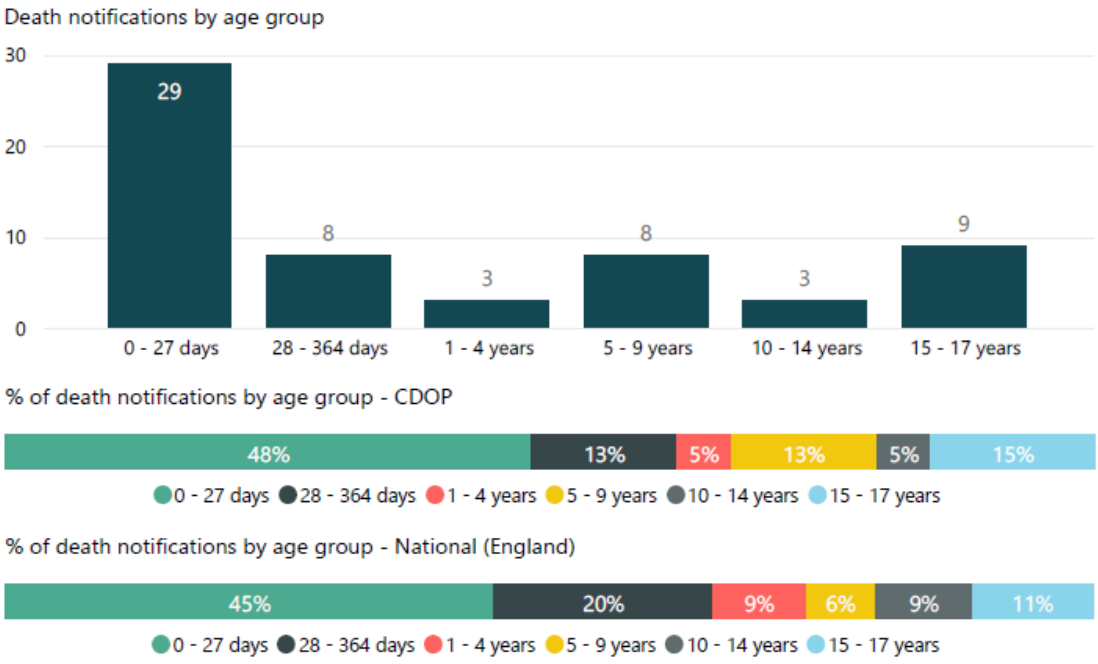
CDOP Panel Activity Data 2020 - 2021

Death Notifications

60 death notifications were reported during the year April 2020 - March 2021, of which 33 were in Norfolk and 27 in Suffolk. Over the last three years the number of notifications has varied, with 50 in 2018/19 and 78 in 2019/20.

Although similar numbers to last year, there were more notifications of babies dying in the first month of life, than notifications of infants dying aged 28 - 364 days. This older group reduced in number from 21 in 2019/20 to 8 in 2020/21. For other ages the numbers are similar. Notifications of neonates remains the highest proportion of notifications. Due to the relatively small numbers, it is hard to see a statistical difference over a one-year period.

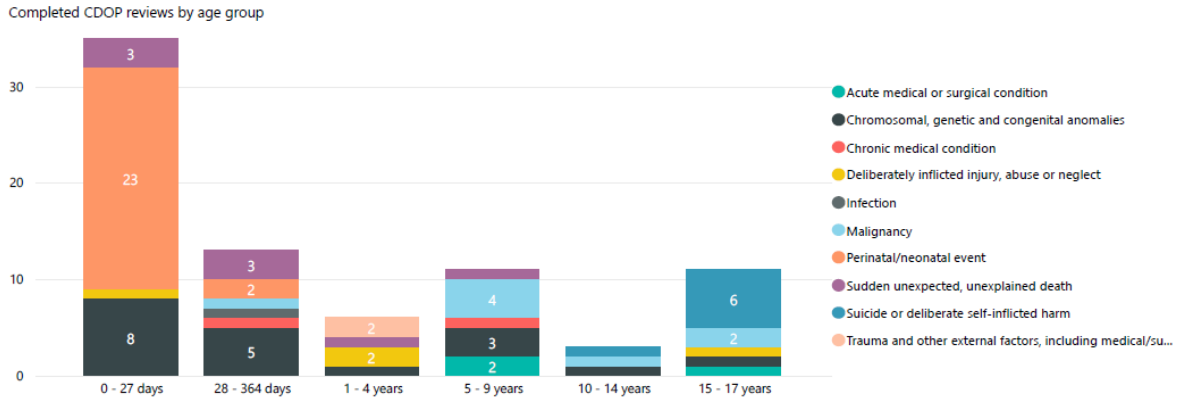
Figure 2



Number of Reviews

In 2020/21 Norfolk and Suffolk CDOP panels reviewed a total of 79 deaths (42 Norfolk and 37 Suffolk), (Figure 3). This was more than the previous 2 years (2018/19: 65 cases, and 2019/20: 53 cases). The higher number was due to delaying the review of neonatal cases in Suffolk until the neonatal panel started in June 2020. Due to the proportion of neonatal deaths this had a larger effect on the overall numbers.

Figure 3

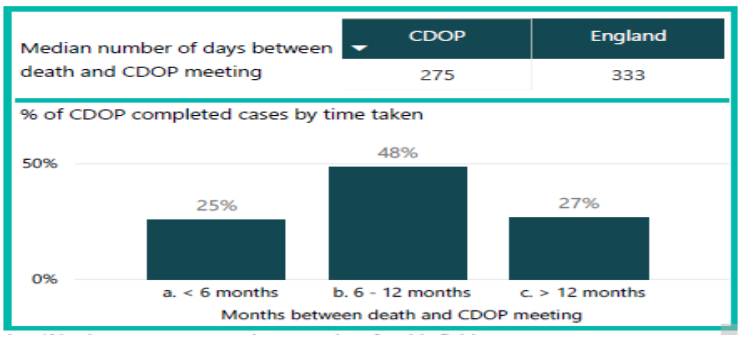


The number of child deaths reported to both Norfolk and Suffolk CDOP and case reviews completed have varied over the last 5 years and there does not appear to be a trend in either direction. This is likely to be due to normal variation found where there are relatively small numbers.

Duration of Reviews

Of the 79 reviewed cases across Norfolk and Suffolk, 73% were completed within 12 months of the child's death. Norfolk and Suffolk took an average 275 days between the child's death and CDOP meeting compared to 333 days for England (Figure 4).

Figure 4



The time taken to complete reviews reflects the individual circumstances and complexity of cases, including necessary investigations from hospital, coroner's inquests (also delayed by covid), criminal investigations, and Child Safeguarding Practice Reviews. Criminal investigations can take well over a year before coming to a conclusion. However, these cases will subsequently be discussed in CDRMs so that any learning can be actioned. There is an option to alert NCMD if there is a risk of serious harm identified. There were two[7] cases where a child died from asphyxia due to stairgates being put on top of one another.

Previously delays were due to challenges in accessing enough information to complete the review. This is no longer the case and the quality of information has improved significantly.

Summary of reviewed cases in 2020/21

Location of Death

Norfolk and Suffolk CDOP reviewed 79 deaths in 2020/21 which occurred in the following settings: 21 at home, 1 abroad, 6 in a hospice and the rest in a hospital (the majority in a neonatal unit or labour ward). This mirrors the national pattern.

Gender

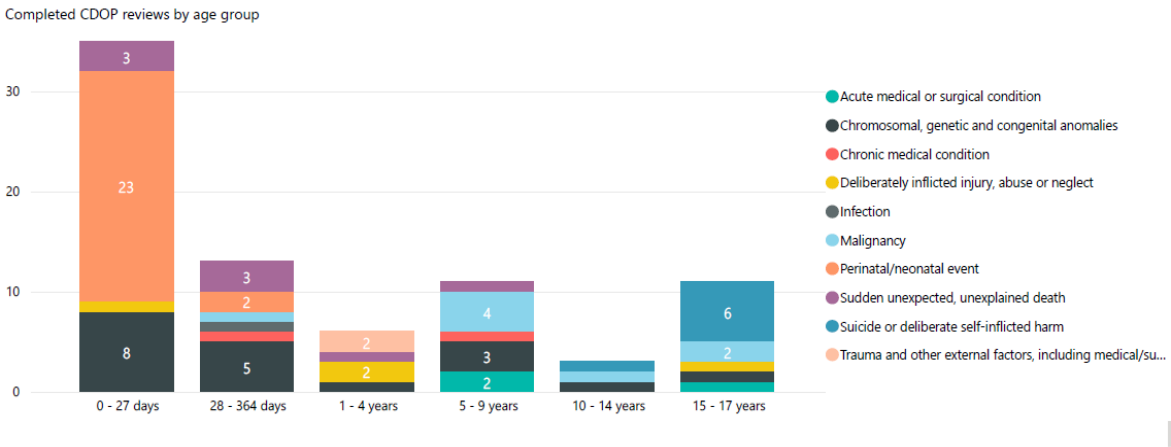
Nationally the mortality rate for males is slightly higher than for females however of the deaths reviewed 43% of deaths occurred in males and 53% in females, 2 indeterminate and one unknown in 2020-2021 across Norfolk and Suffolk. It is important that we gather this data on all the deaths.

[7] To date, only one of these has been reviewed whilst the other remains outstanding

Age

60% (48) of the 79 reviewed deaths were of children who died under the age of one (Figure 7). This is comparable to the national figure of 63%. Neonatal deaths accounted for 44% of all reviewed cases (nationally 42%). The lowest numbers of deaths were in children aged 10 - 14yrs (3%).

Figure 5



There were 35 neonatal (0 - 27 days) and 13 infant deaths reviewed in Norfolk and Suffolk and both counties have introduced biannual neonatal panels.

Ethnicity

Ethnicity data was reported for most cases reviewed with 61 classified as 'White' (77%), 5 'mixed', 2 'Black or Black British' and 1 Asian or Asian British (Figure 8).

It is important that we record ethnicity in all child deaths; and this was not recorded in 9 cases.

Figure 6

Completed CDOP reviews by ethnic group and age group

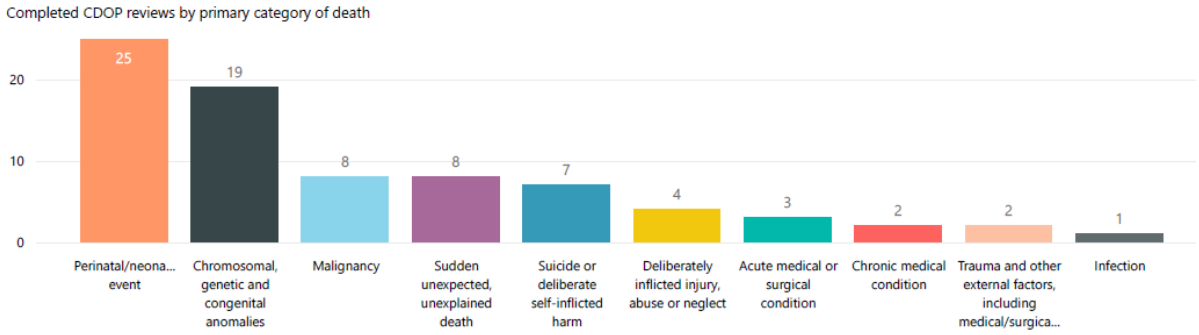
Ethnic Group	0 - 27 days	28 - 364 days	1 - 4 years	5 - 9 years	10 - 14 years	15 - 17 years	Total
White	27	9	4	7	3	11	61
Unknown	6	2	0	1	0	0	9
Other	0	0	0	1	0	0	1
Mixed	2	2	1	0	0	0	5
Black or Black British	0	0	0	2	0	0	2
Asian or Asian British	0	0	1	0	0	0	1
Total	**35**	**13**	**6**	**11**	**3**	**11**	**79**

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, 25 were due to perinatal/neonatal events (31 %), 19 were chromosomal genetic and congenital anomalies (24 %); 8 due to malignancy (10%) and 8 due to SUDI, 7 from suicide or self-inflicted harm and 4 deliberate harm (4%). Acute medical or surgical, chronic medical conditions, trauma and infection accounted for 8 cases (10 %).

Figure 7 details the breakdown of category of death by age group.

Figure 7



Modifiable Risk Factors

Of the 79 child deaths reviewed by the panels in 2020/21, 41% (32) of the cases identified modifiable factors that may have contributed to the child's death. The national average for England was 34% but there is wide variation between regions. It is not clear why there is so much variability but may be due to different information received by CDOP panels and how it is interpreted. It may also suggest a lack of consistency across panels in deciding whether something is possible to modify or not.

Last year (2019/20) Infants aged 28 - 364 days had the highest proportion of deaths assessed as having modifiable factors (73%), followed by those aged 10 – 14 years (43%) however this year it was children aged 1- 4 years (83%), although the absolute numbers were small (5/6) and teenagers aged 15-17 years (55%) (6/11) were the highest. (Figure 8).

When we consider the category of death; modifiable factors were felt to have contributed in all the cases classed as acute medical and surgical (3/3) and infection (1/1). The modifiable factors related to; recognition of the deteriorating child and communication both listening to parents and between clinicians. In both the cases where death was due to trauma (2/2) modifiable factors were identified.

Figure 8

% 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	35	12	34%
28 - 364 days	13	6	46%
1 - 4 years	6	5	83%
5 - 9 years	11	3	27%
10 - 14 years	3	0	0%
15 - 17 years	11	6	55%
Total	**79**	**32**	**41%**

In 75% (6/8) of the cases where the deaths were categorised as SUDI modifiable factors were identified which included safer sleeping, out of routine, smoking and improved communication.

In addition, smoking has also been identified as a possible contributory factor in deaths from premature delivery. Conveying this message to pregnant women and their partners remains challenging.

Learning and Recommendations from 2020/21 Child Deaths 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 learning to emerge in 2020/21 are:

1: Communication

The importance of good communication skills cannot be over emphasised, and miscommunication or misunderstanding can have wide reaching consequences when we fail to communicate information effectively. The ability to communicate is one of our most powerful tools however we underestimate how often we can miscommunicate and not listen actively to families.

This includes communication between agencies, between clinicians, communicating risk to families about their behaviour (in pregnancy), missed opportunities to communicate due to an unrecognised condition in a patient, language barriers and people communicating concerns regarding possible suicidal ideation in friends or family members. Translation services are important to ensure families have understood clinical staff.

Hearing parents' concerns and remembering children can deteriorate fast is important. A parent may be more able to pick up those subtle signs that their child 'is not right' (see below). Professionals should never assume they know a child better than her or his parent(s).

There have been individual cases where it was recognised that communication between health professionals both within hospitals and between hospitals could have been improved. This is a theme both in preventing deaths but also afterwards when sharing information and supporting families.

2: Safer sleeping

Safer sleeping continues to emerge as a recurrent theme in CDOP reviews locally, regionally, and nationally. Co-sleeping, especially combined with additional factors including substance misuse, alcohol and smoking (indoors and outdoors) and a change of routine were identified as contributory factors to SUDI and SUDIC particularly if the baby was premature or suffered a recent viral illness.

There was less face-to-face work from health visiting and social care due to COVID-19 restrictions. The lack of Personal Protective Equipment (PPE) affected the frequency of home visits in some cases. This also had some impact on the quality of information gathered to inform the assessment. It is important to know where the baby is sleeping and to show professional curiosity. The importance of communication and translation services and being aware of increased vulnerability (ex prem, respiratory tract infections, complex needs) is another reason to be cautious about how much risk can be assessed virtually.

It is important that the issue of safer sleeping is raised with parent(s)/carer(s), at every opportunity by both health and social care professionals who should also make themselves aware of sleeping arrangements for any baby under their professional supervision.

In addition, it is recognised it is important to meet fathers and to ensure that both parents are aware of messages regarding safer sleeping.

3: Recognition and management of sick children

Last year's recommendation that recognition of the sick child continues to be a challenge remains and highlights the importance of:

- Listening to parents' concerns
- Examination and recording of vital signs
- Using recommended guidance

Children can deteriorate very quickly. In all cases the relevant cases reviewed the parent (s) had been particularly concerned. Any abnormal results should be acted on. Guidelines can help but should not be stuck to rigidly for instance borderline tachycardia or a low blood pressure needs to be responded to. A low temperature is as concerning as a high temperature.

In this report although the figures suggest there was just one death from infection, some of the deaths from infection were classified under 'acute medical/surgical' or 'chronic medical' as their primary cause of death however these conditions increased their vulnerability to sepsis. Early consideration and treatment of possible viral causes should be given when there is an unwell child.

The emergence of COVID-19 has also caused some challenges and uncertainty in the early months regarding impacts on both children and seeing children.

Signs of sepsis may be misinterpreted in children with complex needs.

Norfolk and Waveney Clinical Commissioning Group (CCG) led an awareness raising event about this with ambulance services and primary care.

4: Neonatal deaths:

Many of the neonatal deaths are analysed using the Perinatal Mortality Review Tool (PMRT) which requires input from the antenatal and postnatal teams. Themes that emerged included:

- Antenatal: smoking in pregnancy, obesity, concealing pregnancy, working with high-risk fathers.
- Delivery: Monitoring, awareness of risk factors requiring senior review, adequate staffing in high-risk deliveries.
- It remains challenging for staff to communicate with parents to ensure parents understand how unwell their child is and the chances of survival when they may not want to hear the message.

Additional learning:

- Raising awareness of suicide and the importance of talking to young people about suicide. Talk to others if concerned about possible suicidal ideas.
- Think Aorta: recognition of conditions predisposing to aortic dissection.
- Think Heart: recognising signs of congenital heart disease in babies.
- Public health message regarding identifying a designated driver/non-drinker to look out for their friends. Ensure school have access to regular drug awareness briefings. School nursing service can offer support to all young people up to 18 years.
- Risks from concealed pregnancy: a working group has been developed across Norfolk and Suffolk and the Suffolk policy adapted in both counties
- Joint Murder/Suicides [of parent and child(ren)] subject to a local safeguarding review and joint action plan 'Andy and Arin'. Importance of recognition of mental health problems in mothers, role of fathers and ensuring that fathers are included in assessment, and the importance of professional curiosity, and of assessing cultural and other diversity factors when parents move from another country with unfamiliar cultural beliefs
- Children and young people with complex needs: when to escalate concerns when health is affected by safeguarding concerns
- Safety related and unintentional causes of death

    - Water safety (securing pools and ponds in family homes) professionals to be curious and offer safety guidance – there is no legislation in UK regarding pool/pond safety
    - Stair gates (never put one on top of another)
    - Bouncy Castles not registered with ADIPS (Amusement Parks Standards for Inspection) or PIPA; an Inflatable Play Inspection scheme

Additional learning for bereaved families, organisations and staff after a child's death included:

- Considering organ donation and raising awareness through neonatal units' paediatric wards and intensive care.
- Supporting the use of the PMRT since its introduction across Norfolk and Suffolk in 2018
- Improving communication between the Coroner's Service and Paediatrics to ensure that post-mortem results are available as soon as possible to be fed back to families
- Problems with Kennedy sampling[8], clinicians knowing what samples to take and when and how to do skin fibroblasts
- Children with complex needs:
    - Importance of developing and discussing end of life (use of ReSPECT paperwork)
    - Use of mental capacity act and identifying an advocate now rolled out in Suffolk
    - Access to home adaptations rapidly when child has palliative care needs to be identified
    - Involve CDR team with palliative patients so that families are aware of their role
- Challenge for families from press intrusion when an inquest is held, and family details are made available to the public. As inquest may be delayed which is particularly distressing for families.

[8] Kennedy Sampling is routine sampling taken immediately after a sudden unexpected death in infancy.

- Bereavement services commissioned for children whose parents die unexpectedly, or where a child dies suddenly. St Elisabeth Hospice in East Suffolk and Nicky's Way in West Suffolk are already available.
- Parental rights when a child dies: when parents separated both have equal rights to be made aware of the death and to see the child after death
- CDRT to provide training for trusts and organisations.

Groups and networks

The East of England Regional CDOP Professionals Network has continued to meet regularly in 2020/21 to share learning and support system-led improvement across the region. This provides a forum to support developments. The group have provided an important source of peer review to those working in child death.

Child Death Review Achievements

This is the second joint annual report for Norfolk and Suffolk CDOP.

We will continue to develop a joint local analysis of trends and focus on areas for further action such as safer sleeping.

Suffolk's Child Death Review Team have continued to develop their role with families and organisations including the acute trusts in Suffolk to support their role in reviewing child deaths. Cross boundary working has improved. The Suffolk team supported the Waveney area until the appointment of the Norfolk Child Death Review team.

Both panels continue to implement the E-CDOP software to ensure the most effective collection of data.

The completion of forms online has improved in general but there continues to be some difficulties in getting completion of reporting forms. When these are completed well the information gathered is rich and will improve our understanding nationally into circumstances that increase the risk of child death.

As a result of the data collected the National Child Mortality Database produced a report that has shown that nationally child death is linked to deprivation. Interestingly, an analysis of the three-year data for Norfolk did not show any clear link

Neonatal themed panels have taken place in both Norfolk and Suffolk and have proved a much more effective way of reviewing these deaths. There has been better attendance from antenatal services, which is crucial to consider how to prevent premature delivery which accounts for the most significant number of child deaths.

COVID-19 has had a huge impact to everyone's lives however it does not appear to have had a similar impact on child deaths.

As a result of COVID-19, panels have taken place virtually and there has been no interruption to the CDOP panels. This has proved an opportunity to improve attendance at CDOP.

A highly successful 'Learning from Child Death' event took place in October 2020 coordinated by Cindie Dunkling on behalf of the Eastern CDOP group. There were ten talks given over a 5-day period, attended by 986 people.

The Suffolk CDR team produce a newsletter with learning in a format for easy reference

Suicide awareness and advice to professionals on prevention was shared widely.

The Perinatal Mortality Review Meetings are becoming embedded, but the acute teams are not well resourced to carry these out in a timely way. This is an area that continues to need development.

Forward Plan for 2021 - 2022

- Norfolk's new CDR team to support all partners and families to facilitate the CDR process.

- Suffolk's CDRT continue to implement and refine the new child death pathway, including raising awareness with key stakeholders regarding their roles and responsibilities. There continue to be some challenges and as a new team and working with such a challenging subject there have been some barriers to cross however the team is enthusiastic and their role supporting families cannot be underestimated.

- Improve the process of capturing learning in a format for easy reference (data system/dashboard) and ensure sharing across the system on a regular basis.

- Continue to be active participants in the East of England CDOP professionals' network to share learning and system-led improvement. This group will feed into a new national group the Association of Child Death Review partners.

- Norfolk and Suffolk panels to develop and agree a joint Terms of Reference.

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:

1) Every child's death is a tragedy
2) Learning lessons
3) Joint Agency Working
4) 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. Learning from Child Deaths Event - October 2020

Talks were given from a variety of national and local speakers on the following topics:

- SIDS—Where is baby sleeping?
- Neonatal Deaths
- Information sharing
- The Post-Mortem
- Bereavement
- Rare Condition's
- Advanced Care Planning
- Impact of Covid 19
- Professional Curiosity
- NCMD

The links to these talks can be found on the Suffolk safeguarding Partnership web page below:

Child Death Overview Panel (CDOP) » Suffolk Safeguarding Partnership (suffolksp.org.uk)